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DOCTOR OF PHILOSOPHY

Moving on together: what makes a successful transition into adulthood for young disabled people (14-25 years of age)?

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MOVING ON TOGETHER:

WHAT MAKES A SUCCESSFUL TRANSITION INTO ADULTHOOD FOR YOUNG DISABLED PEOPLE (14-25 YEARS OF AGE)?

Thesis submitted in fulfilment of the requirements for the Degree of Doctor of Philosophy in Bangor University (13/4/16)

Sally Rees

Bangor University

School of Social Sciences

DECLARATION

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This work has not been previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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Date: 13/04/16

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CONTENTS

INDEX OF FIGURES…… 16

INDEX OF TABLES…….. 18

ACKNOWLEDGEMENTS…… 20

DEDICATION……..... 21

SUMMARY…… 22

CHAPTER ONE: INTRODUCTION……... 24

1. Introduction…….... 24

1.1 Overarching Aims and Objectives……. 26

1.2 Outline of Chapter One……..... 26

1.3 My 'Insider' perspective…… 27

1.3.1 Parental context…… 28

1.3.2 Professional context……..... 28

1.4 Background to Transition and Key Working in Wales…….. 28

1.4.1 Characteristics of a successful transition……. 32

1.5 Definitions…….. 33

1.5.1 What is Key Working…… 33

1.5.2 Single point of contact……. 34

1.5.3 Defining a Key Worker…… 35

1.5.3.1 Designated Key Worker…….. 35

1.5.3.2 Non-Designated Key Worker…….. 35

1.5.3.3 Defining the intervention of a Transition Key Worker……... 36

1.5.4 Defining a person-centred approach……..... 37

1.5.5 Defining the target population of young people and their parents/carers…… 38

1.5.5.1 Age range……..... 39

1.5.6 Prevalence rates…… 39

1.6 Introducing the initial conceptual framework……..... 40

1.7 Structure of the Thesis……... 42

1.7.1 Chapter Two: Realist Synthesis Methods…… 42

1.7.2 Chapter Three: The Realist Review Findings……..... 43

1.7.3 Chapter Four: Transition Key Worker Stakeholder Evaluation Methodology……... 43

1.7.4 Chapter Five: Parent Interviews……... 43

1.7.5 Chapter Six: Interviews with Young People…… 43

1.7.6 Chapter Seven: Transition Key Worker Interviews……..... 44

1.7.7 Chapter Eight: Interviews with Site Leads……... 44

1.7.8 Chapter Nine: Synthesis of Findings across the Stakeholders……. 44

1.7.9 Chapter Ten: Overall synthesis across the Realist Review and Stakeholder Evaluation……... 44

1.7.10 Chapter Eleven: Critical Analysis and Discussion……..... 45

1.7.11 Chapter Twelve: Conclusion…….. 45

CHAPTER TWO: REALIST SYNTHESIS METHODS…… 46

2. Introduction…… 46

2.1 Locating Realism……... 47

2.1.1 Core principles and suppositions of Realist Synthesis (Review): the Context, Mechanism and Outcomes (CMO) configuration…… 48
2.1.2 Unravelling complexity created by multiple individual and organisational involvement……..... 50
2.2.3 Rationale for adopting a Realist Review (Synthesis) approach…….. 50

2.2.4 Developing the theory of enquiry: the programme and mid-range theory areas…… 51
.
2.2.5 Review structure: scoping the literature…….. 53

2.2.5.1 Changes in the review process……..... 55

2.3 Searching Process……... 55

2.3.1 Selecting Transition Protocols/Pathways……..... 57

2.3.2 Inclusion criteria……... 58

2.3.3 Exclusion criteria……. 59

2.3.4 Data extraction……..... 59

2.4 Analysis, reporting and synthesis processes…….. 59

2.5 Conclusion…….. 60

CHAPTER THREE: REALIST REVIEW FINDINGS……. 61

3. Introduction…… 61

3.1 Aims and Objectives of the Review……...…… 62

3.2 How the Review will be presented……...……. 62

3.3 Main Findings: Phase One (Policy/consultation and Transition and Key Working documentation…….
63

3.3.1 Data extraction…….…… 63

3.3.2 Stakeholder Workshop (10 March 2011)...…….. 65

3.3.3 Review of policy and consultation documentation…….. 66

3.3.4 Mid-range theory area development…… 69

3.3.5 Review of Transition and Key Working related literature……... 70

3.3.5.1 The contextual findings……... 70

3.3.5.2 Key Finding 1: Having a structure (protocols/pathways) as an intervention promotes an understanding of transition planning processes (Theory Area 1)……. 71

3.3.5.3 Key Finding 2: The concept of continuity plays an important part in achieving a successful transition (Theory Area 4)..... 72

3.3.5.4 Key Finding 3: Pro-active support is a crucial to accomplish successful transitions (Theory Areas 2 and 5)……... 73

3.3.5.5 Key Finding 4: A person-centred approach to planning is a key enabler to promote decision-making (Theory Area 3)…….. 75

3.4 Main Findings: Phase Two (Transition Protocols and Pathways)……..…….. 76

3.4.1 The 26 Transition Protocols/Pathways……..... 76

3.4.2 The 11 Transitions Protocols/Pathways: the focused review……... 79

3.4.2.1 Key Finding 1: It is the intention of a protocol/pathway to achieve continuity from children to adult services (Theory Areas 1 and 4)….. 79

3.4.2.2 Key Finding 2: There is variability in person-centredness practice (Theory Area 3)……..... 80

3.4.2.3 Key Finding 3: A hierarchy of decision-making exists (Theory Area 3)……..... 81

3.4.2.4 Key Finding 4: Planning well, in detail with young people and their parents, is absent from protocols/pathways (Theory Areas 2 and 5).... 81

3.4.2.5 Further theory development……... 82

3.4.2.6 Key Finding 5: Transition processes requires governance and an accountability trail (linked to Theory Area 1)……. 83

3.5 Synthesis across the two review phases……. 83

3.5.1 Theory Area 1: Having a structure provides the basis to ensure good transitions for young people…….. 85

3.5.2 Theory Area 2: Proactive support arrangements foster early planning with young people..... 86
3.5.3 Theory Area 3: Active decision-making is a critical aspect to enable young people be control of the choices they make…….. 86
3.5.4 Theory Area 4: Continuity of provision is the intention of the transition process……... 87
3.5.5 Theory Area 5: Planning well is crucial to achieve successful transitions into adulthood……... 88
3.5.6 Theory Area 6: The transition process requires governance and an accountability trail……..... 88
3.6 Conclusion…….. 89

CHAPTER FOUR: THE TRANSITION KEY WORKER STAKEHOLDER EVALUATION METHODOLOGY…….. 91

4. Introduction…… 91

4.1 Aims and Objectives…….. 91

4.2 Adopting Thematic Analysis approach……..…… 92

4.3 Phases of Thematic Analysis……. 93

4.3.1 Familiarisation with the data: Transcription (Phase 1)…… 94

4.3.2 Generating the initial codes (Phase 2)…… 94

4.3.3 Searching for themes (Phase 3)……..... 95

4.3.4 Reviewing and refining themes (Phase 4)……..... 95

4.3.5 Theme reduction (Phase 5)…….. 96

4.3.6 Reporting (Phase 6)…….. 96

4.4 Use of Reflection and Reflexivity……..... 96

4.5 The Semi-Structured Interviews……..... 97

4.5.1 The Sites…… 97

4.5.2 Semi-Structured Interview Schedules……... 98

4.5.2 1 Semi-Structured Interview timeframe…….. 99

4.5.3 Recruitment of participants……... 99

4.5.3.1 Inclusion criteria…….. 99

4.5.3.2 Exclusion criteria……. 99

4.5.4 Invitation to participants……... 100

4.5.4.1 Information to participants…….. 100

4.5.4.2 Choice of location of interviews…….. 100

4.5.5 Digital voice recording……... 101

4.6 The Interviews…… 101

4.6.1 Potential distress to participants……... 101

4.6.2 Data storage, confidentiality and data protection…… 102

4.6.3 How consent was obtained…….. 102

4.6.3.1 The consent process……..... 103

4.6.3.2 Assessing competence……..... 103

4.6.4 Disclosure during interview…… 105

4.6.5 Payment to participants……... 106

4.7 Synthesis of findings across the Review and Evaluation……... 106

4.8 Critical Analysis process…… 106

4.9 Conclusion…….. 106

TRANSITION KEY WORKER STAKEHOLDER EVALUATION
CHAPTER FIVE: PARENT INTERVIEWS……... 108
5. Introduction…… 108

5.1 Parent Interviews…… 109

5.1.1 Characteristics of parent participants…….. 109

5.1.2 Transcript analysis…….. 110

5.1.3 Key Findings and Descriptive Themes…… 111

5.2 Main Findings…… 113

5.2.1 Key Finding 1: The past influenced how parents think, discuss and plan for change and prepare for their son/daughter's future adult life…….. 113
5.2.2 Key Finding 2: A hierarchy of pace setting exists which shaped how parents managed the progress of transition……..... 119
5.2.2.1 Second Level: Local organisation of services and support (including reference to the First Level: Legislation and policy related to transition)……..... 120

5.2.2.2 Third Level: Parents (e.g. poor experiences, difficult managing change)……..... 124
5.2.2.3 Fourth Level: Young people (lack of involvement e.g. at reviews) ….. 126

5.2.3 Key Finding 3: The perceived vulnerability of young people by their parents, together with a parent's own susceptibilities hinders a young person's progress towards independence…… 128
5.2.4 Key Finding 4: Parents felt fortunate to have and be in a position to provide support, but that the intervention of a Transition Key Worker is only privileged by the few…….. 133
5.2.5 Parental Transition trajectory: their experiences……..... 135

5.3 My personal analytical perspectives…….. 140

5.4 Summary…… 142

CHAPTER SIX: INTERVIEWS WITH YOUNG PEOPLE…… 144

6. Introduction…… 144

6.1 The Interviews…… 145

6.1.1 Characteristics of participant young people……..... 145

6.2 Main Findings…… 146

6.2.1 Key Finding 1: Young people were not overtly concerned about and are ready to think about their own future…… 148
6.2.2 Key Finding 2: Young people had a clear idea about what was important to them as they progressed towards adulthood……... 151
6.2.3 Key Finding 3: Young people want to have support to manage their transition into early adult life…….. 155
6.2.4 Comparing young people's and parental experiences of the transition process……..... 157
6.3 Summary…… 162

CHAPTER SEVEN: TRANSITION KEY WORKER INTERVIEWS…… 164

7. Introduction…… 164

7.1 The Interviews…… 165

7.1.1 Transition Key Worker characteristics……..... 165

7. 2 Main Findings……... 166

7.2.1 Key Finding 1: Time played a crucial factor in involving, supporting and planning with young people and their parents…… 168
7.2.2 Key Finding 2: Local structures and systems are not conducive to delivering a transparent and understandable transition process……... 171
7.2.3 Key Finding 3: Transition Key Workers need to understand the *'whole picture'* (TKW2)……. 176
7.2.4 Key Finding 4: Preciousness and non-acceptance hindered joint working, local co-operation and planning with young people and their parents……... 181
7.2.5 The 'Insider' analytical perspective: the professional experience……... 184

7.3 Summary…… 187

CHAPTER EIGHT: INTERVIEWS WITH SITE LEADS…… 189

8. Introduction……..... 189

8.1 The Interviews…… 190

8.1.1 Characteristics of the Site Leads…….. 190

8.2 Main Findings…… 191

8.2.1 Key Finding 1: A clear strategic steers was required to support the management of change to deliver a workable transition process……... 192
8.2.2 Key Finding 2: Continuity of provision remained elusive…….. 197

8.2.3 Key Finding 3: Working together challenged professionals and organisations…….. 198
8.2.4 Key Finding 4: The implementation of person-centred practice tailored to an individual's transition challenged a prevailing service-led mindset…….. 201
8.2.5 Key Finding 5: Achieving sustainability was problematical…….. 205

8.2.6 The 'Insider' analytical reflective perspective: Joint project lead……..... 209

8.3 Summary…… 213

CHAPTER NINE: SYNTHESIS OF FINDINGS ACROSS THE STAKEHOLDER GROUPS……..... 216

9. Introduction…… 216

9.1 Main Findings……..... 217

9.1.1 Key Finding 1: Time played an important role during the transition process……..... 221
9.1.2 Key Finding 2: Transition Key Workers and Site Leads were unaware of the impact of parental past experiences which had impeded their positive thinking about the future……. 222
9.1.3 Key Finding 3: The future was indeterminate for stakeholders and managing change difficult for all…… 224
9.1.4 Key Finding 4: A Past/Time/Future continuum was present, which may determine whether a successful transition is achieved……..... 227
9.2 Conclusion…….. 229

CHAPTER TEN: OVERALL SYNTHESIS ACROSS THE REALIST REVIEW AND EVALUATION…… 230

10. Introduction…… 230

10.1 Main Findings…….. 231

10.1.1 Key Finding 1: The transfer from children to adult services is depicted a linear. However, the stakeholder experience is somewhat different…….... 234
10.1.2 Key Finding 2: The transition process remains complex with or without transitional support……... 236
10.1.3 Key Finding 3: All stakeholders needed to be ready for change (Mid-Range Theory area 7)……... 240
10.2 Conclusion: The overall mapping of the CMO configurations…… 247

CHAPTER ELEVEN: CRITICAL ANALYSIS AND DISCUSSION……... 249

11. Introduction……..... 249

11.1 Structure of the Chapter……... 249

11.1.1The Critical Analysis…….. 249

11.1.2 The Discussion…….. 250

11.2 Section One: The Realist Review……..... 250

11.2.1 Quality Standard 1: The Research Problem…….. 251

11.2.1.1 Criterion 1: The research topic is appropriate for a realist approach.... 252

11.2.1.2 Criterion 2: The research question is constructed in such a way as to be suitable for realist synthesis…….. 252

11.2.2 Quality Standard 2: Understanding applying the underpinning principles of realist reviews……... 253

11.2.3 Quality Standard 3: Focussing the review……..... 255

11.2.4 Quality Standard 4: Constructing and refining the realist programme theory……..... 255

11.2.5 Quality Standard 5: Developing a search strategy……..... 256

11.2.6 Quality Standard 6: Selection and appraisal of documents……... 257

11.2.6.1 Legislation, policy and consultation documentation tool……..... 257

11.2.6.2 Transition and Key Working individual extraction tool……... 258

11.2.6.3 Included studies data extraction tool…… 258

11.2.6.4 Transition Protocol/Pathway criterion tool……... 258

11.2.6.5 Individual Transition Protocol/Pathway tool…… 258

11.2.7 Quality Standard 7: Data extraction……. 258

11.2.8 Quality Standard 8: Reporting……... 259

11.3 Section Two: Thematic Analysis of qualitative interviews – The Stakeholder Evaluation……..... 261

11.3.1 Question 1: Was there a clear statement of the aims of the research?..... 262

11.3.2 Question 2: Is the qualitative methodology appropriate?..... 263

11.3.3 Question 3: Was the research design appropriate to address the aims of the research?..... 263
11.3.4 Question 4: Was the recruitment strategy appropriate to the aims of the research?..... 266
11.3.5 Question 5: Was the data collected in a way that addressed the research issues?..... 267
11.3.6 Question 6: Has the relationship between the researcher and participants been adequately addressed?..... 269
11.3.7 Question 7: Have ethical issues been taken into account?..... 269

11.3.8 Question 8: Were the data analysis sufficiently rigorous?..... 271

11.3.9 Question 9: Is there a clear statement of findings?..... 273

11.3.10 Question 10: How valuable is the research?..... 274

11.4 Section Three: Reflective assessment of my multiple perspectives……..... 275

11.4.1 Question 1: What is the paradigmatic approach within which the research is situated?..... 276
11.4.2 Question 2: What have been the participants past experiences with research and researchers profession?..... 277
11.4.3 Question 3: What kind of boundaries should be established between the researcher and the participants?..... 277
11.4.4 Question 4: How should the researcher present his/her role to a participant?..... 278
11.4.5 Question 5: Should a researcher offer practical advice during an interview?..... 279
11.4.6 Question 6: What impact did the intervention have on the nature of the relationship?..... 280
11.5 Section Four: The Discussion…….. 280

11.5.1 The Realist Review……... 280

11.5.2 The Realist Evaluation…….. 286

11.6 Conclusion…… 291

CHAPTER TWELVE: CONCLUSION……... 293

12. Introduction……..... 293

12.1 Contribution to new knowledge……... 293

12.1.1 Viability of Key Working provision…….. 296

12.1.2 The revised integrated programme theory……..... 297

12.1.3 The 'Insider' perspective……... 302

12.2 Implications for future research……... 302

12.3 Recommendations for policy and transition-related practice……... 304

12.4 Conclusion…… 306

REFERENCES…… 308

APPENDICES…… 325

Appendix One: Social and Medical Model of Disability in the context of young people…… 326
Appendix Two: Definition of Disability related to young people…….. 328
Appendix Three: Data Extraction Tool 1: Policy and consultation documentation tool…….. 331
Appendix Four: Data Extraction Tool 2: Transition and Key Working documentation tool……... 343
Appendix Five: Data Extraction Tool 3: Included Studies Data Extraction Tool… 345
Appendix Six: Data Extraction Tool 4: Transition Protocol/pathways extraction of 26 examples……... 368
Appendix Seven: Data Extraction Tool 5: Transition Protocol/Pathway individual extraction tool……. 369
Appendix Eight: Rameses Publication Standards for Realist Synthesis……... 370

Appendix Nine: Young Person's Interview Schedule…….. 372

Appendix Ten: Parent Interview Schedule……... 373

Appendix Eleven: Transition Key Worker Interview Schedule……... 376

Appendix Twelve: Site Leads Interview Schedule……... 379

Appendix Thirteen: Invitation Letter - Young People…….. 382

Appendix Fourteen: Invitation Letter - Parents…… 384

Appendix Fifteen: Invitation Letter - Transition Key Workers…… 386

Appendix Sixteen: Invitation Letter - Site Leads……. 388

Appendix Seventeen: Information Booklet - Young Person…… 391

Appendix Eighteen: Information Booklet - Parent……... 398

Appendix Nineteen: Information Booklet - Transition Key Worker…… 404

Appendix Twenty: Information Booklet - Site Leads…….. 409

Appendix Twenty-One: Young Person's Consent Form…….. 416

Appendix Twenty-Two: Parent Consent Form……. 418

Appendix Twenty-Three: Transition Key Worker Consent Form…… 420

Appendix Twenty-Four: Site Leads Consent Form…….. 422

Appendix Twenty-Five: Assent Form……... 425

Appendix Twenty-Six: Thematic Mapping - Parents……... 428

Appendix Twenty-Seven: Thematic Map - Young People……... 429

Appendix Twenty-Eight: Thematic Map - Transition Key Worker…….. 430

Appendix Twenty-Nine: Thematic Map - Site Leads…….. 431

Appendix Thirty: Stages of Theory Development…… 432

Appendix Thirty-One: Cares Conference Abstract…….. 433

INDEX OF FIGURES

Figure 1:	**The 4 P's: Steady State Model……..**	**41**
Figure 2:	**The underlying core elements of the 4 P's……**	**42**
Figure 3:	**The Positivist. Realist and Constructivist paradigms……..**	**47**
Figure 4:	**Context/Emergence Cycle……..**	**48**
Figure 5:	**Example of generative causation (CMO configuration)…….**	**49**
Figure 6:	**Diagrammatic representation of the realist review cycle……**	**53**
Figure 7:	**Flow diagram: Search process and article disposition……**	**64**
Figure 8:	**Theory Development 1……**	**66**
Figure 9:	**Theory Development 2……**	**69**
Figure 10:	**External mechanisms/internal components of a protocol/pathway…..**	**79**
Figure 11:	**Theory Development 3……**	**83**
Figure 12:	**Flow diagram: Consent/Assent processes…….**	**105**
Figure 13:	**Parents: Key Findings and Descriptive Themes……..**	**112**
Figure 14:	**Hierarchy of pace setting……**	**120**
Figure 15:	**Diagrammatic representation: Parental transition experience……..**	**137**
Figure 16:	**Young People: Key Findings and Descriptive Themes……**	**147**
Figure 17:	**Diagrammatic representation P9 and YP3……..**	**159**
Figure 18:	**Diagrammatic representation P5 and YP1……..**	**161**
Figure 19:	**Transition Key Worker: Key Findings and Descriptive Themes……..**	**166**

Figure 20: **Service-led versus Needs-Led Transition Process…… 213**

Figure 21: **Diagrammatic visualisation of the Past/Time/Future continuum……. 226**

Figure 22: **Diagrammatic representation of a standard transition pathway…….. 232**

Figure 23: **Diagrammatic representation of a transition pathway experienced by Stakeholders……. 233**

Figure 24: **Diagrammatic 'close up' of the pathway experience……... 235**

Figure 25: **Overall mapping: The revised programme theory with the CMO configurations…….. 246**

Figure 26: **An alternative interpretation of CMOc…… 298**

Figure 27: **Revised programme theory…… 301**

INDEX OF TABLES

Table 1:	**Transition Key Worker Intervention…….....**	**37**
Table 2:	**Realist Review Framework……**	**54**
Table 3:	**Search Strategy……**	**57**
Table 4:	**Transition Protocol/Pathway Types……...**	**58**
Table 5:	**Realist Review structure……..**	**63**
Table 6:	**Diagrammatic representation of the CMO configurations……..**	**84**
Table 7:	**15-point Checklist of Criteria for Good Thematic Analysis……....**	**94**
Table 8:	**Example of Coding Framework (parent)……..**	**95**
Table 9:	**Transition Key Worker Sites……**	**97**
Table 10:	**Recruitment numbers……..**	**100**
Table 11:	**Parent characteristics……**	**106**
Table 12:	**Young people's characteristics……...**	**146**
Table 13:	**Transition Key Worker characteristics……**	**166**
Table 14:	**Site Leads characteristics……**	**191**
Table 15:	**Site Leads: Key findings and descriptive themes……..**	**192**
Table 16:	**Synthesis matrix across the participant stakeholders……..**	**218**
Table 17:	**Mapping the seventh and final mid-range theory area……**	**245**
Table 18:	**Quality Standards for realist synthesis for researchers and peer reviews……...**	**251**

Table 19: CASP tool for qualitative research (2013)……. 262

Table 20: Advantages and Limitations of Thematic Analysis…….. 265

Table 21: Reflection and Conflict questioning (Jack, 2008)…….. 276

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DEDICATION

I would like to dedicate this thesis to all those who took part and generously shared their experiences. Furthermore, I dedicate this work to all those young people who freely talked about plans for the future, you were inspirational and I hope your wishes and aspirations have come true for you all. To parents, I know it's hard, but we do need to let go and give our children autonomy or put our trust in others to support them as we would wish.

SUMMARY

Background: A good transition from child to adult services remains a challenge for young disabled people (14-25) due to multiple organisations and professionals involved. Delineating what should happen is described in transition protocols/pathways, yet there is little evidence of their effectiveness, especially for young people for whom such protocols/pathways are intended to support.

Aims and objectives: The aim was to understand the transition process, the contextual relationships, and the external and internal mechanisms facilitated by the intervention of a Transition Key Worker and how they may help create opportunities to achieve good outcomes for young people moving into adulthood.

Methods: A Realist framework, as advocated by Pawson and Tilley, utilised an underpinning programme theory to unpick how protocols/pathways work to better manage the transition process and to evaluate how 14 sites implemented transition key working. A stakeholder workshop commenced the realist process to develop the mid-range theory and to identify what works, how it works and in what circumstances for young people. Thematic analysis was used to analyse 61 stakeholder interviews. I drew upon my 'insider' perspectives and reflexivity, which was a novel feature.

Main Findings: Parents' poor experiences of 'pre-transitional' support hindered preparation for their child's future and determined their ability to think positively and let go of the past, which was not found in the literature or identified by Transition Key Workers. However, young people were not majorly concerned about the future. The mid-range theory areas of structuring the transition process, having support, planning well to make active decisions, with parents being ready for change within a robust governance and accountability framework were key indicators which determined what makes a successful transition. Transition Key Workers were regarded as an essential facilitator of the process. How to plan effectively and in detail with young people from was absent.

Conclusion: The findings contribute by providing major insights into understanding what stakeholders considered to be the key elements of achieving successful transition. Determining a successful transition is individual and young people should not be coerced to fit into imposed systems, which limit their aspirations. The linear description of the transition process in current protocols/pathways does not fully represent the complexities where multiple organisations are involved. There is a need to set out in guidance how to plan with young people. The development of a new mid-range theory provides a significant contribution to inform practice in supporting young people to plan well for their futures.

CHAPTER ONE
INTRODUCTION

1. INTRODUCTION

This Thesis presents an in-depth Realist review and qualitative Realist evaluation of the experiences of young people in transition to adulthood with disabilities, as well as the processes and outcomes for young people[1] with a disability aged 14 to 25 and their parents[2] from the intervention of a Transition Key Worker supporting transition into adulthood. The geographical focus of this study is on Wales. The empirical work undertaken was located within the context of a pilot project funded by the Welsh Government to develop Transition Key Working across 5 local authority sites (£1.5m), and subsequent matched European Social Fund: Reaching the Heights - First Footholds grant programme funding (£1.5m) across a further 7 Welsh counties. The pilot and additional sites were jointly managed by the Welsh Government and the Care Co-ordination Network UK (known latterly as CCN Cymru)[3]. CCN Cymru was additionally funded to support the project management. As Director of CCN Cymru[4], I was the responsible joint lead for taking forward the development of key working through the transitional years into adulthood on behalf of the Welsh Government.

A *'Cost and Benefit of Transition Key Working: an analysis of five pilot projects'* (2013), funded by the Welsh Government was undertaken. However, it was carried out during the early the development with a small sample. I considered it too early to ascertain the impact and effectiveness of the intervention. Few young people had transitioned into adult services and many were at the beginning of the transition process.

---

[1] Young people with a disability will be referred to as young people and in the singular young person.
[2] Parent/carers will be referred to as parents
[3] CCNUK, known as CCN Cymru was the leading Third Sector organisation promoting key working as the best practice model in supporting disabled children and young people (0-25 years of age) and their families.
[4] Post ended 30 April 2014

Therefore, an accurate and feasible evaluation of the net benefits and impacts against the net costs of the Transition Key Worker role was identified as problematical since no such comparison could be undertaken without the availability of reliable longitudinal data. Furthermore, the cost benefit analysis did not provide new or additional insight or evidence to the Welsh Government. The work reported in this thesis was designed to supplement and goes beyond the cost benefit analysis to better understand the transition process. My interest in understanding the key element to achieve as successful transition for all young people became my motivation. However, establishing baselines, to evaluate was absent, as were thoughts about how to evaluate overall the Transition Key Working sites. At that point, my interest to ensure evidence could be presented, led to my doctoral studies.

The development of Transition Key Working should also be cited with the context of health, social care (children and adult) and education, with each sector representing a crucial part of the transition process, alongside young people and their parents, as the service beneficiaries. Transition Key Working supports and co-ordinates the multi-faceted journey into early adult life for those young people who require a continuum of support and services aided through the provision of a Transition Key Worker. It is proactive, focusing on positive outcomes by identifying the needs of young people to prepare them for the future. The Transition Key Worker offers emotional and practical support, with the aim to empower young people to act independently, make choices and manage their changing status from child to adult. A definition of key working and the key worker role is outlined in section 1.5 within this chapter.

It can be deduced that the transition into adulthood for disabled young people and their parents continues to be a protracted and daunting experience for many. It is a process which sees many individuals and families in conflict with local and national processes, complex funding arrangements, varying eligibility criteria between child and adult services and a lack of choice and insufficient local services to meet their needs. As a result, inadequate planning at an early stage has led to inconsistencies and unpredictability and become the typical experience. This is my personal and professional experience, having an ‘insider’ view as a beneficiary (outlined under point

1.3 in this chapter), but also having professional expertise both at a strategic and 'grassroots' level.

1.1 OVERARCHING AIMS AND OBJECTIVES

The overarching aim was to answer the thesis research question *'What makes a successful transition for disabled young people (14-25 years of age)?'* The principal objectives were firstly to understand what young people, their parents and those working with them considered to be the key elements of achieving successful transition into adulthood and commenced with a Stakeholder Workshop in March 2011 of 170 participants (young people (n=48), parents and professionals), which I facilitated in my role as Director of CCN Cymru. I embraced a Realist approach (outlined in Chapter Two) advocated by Pawson and Tilley (1997) and McCormack *et al*. (2007) to involve recipients (e.g. patients) and/or deliverers (e.g. professionals) of services in research, which was the initiation point of this research.

Secondly, to identify and understand through three types of evidence (policy and consultation documentation, broad transition and Key Working-related literature and Transition Protocol/Pathway examples) the role Transition Protocol/Pathways plays in achieving better outcomes for young people, by determining what worked for whom, how it works and in what particular circumstances related to the process of transition into adulthood and establishing the context, the mechanisms and anticipated outcomes (Pawson and Tilley, 1997).

I drew upon the experiences of young people, their parents and professionals working in the field of transition into adulthood and explored the role of a Key Worker as an intervention, supplemented throughout by my own experiential perspectives both personally and professionally over 22 years. Reflection and reflexivity is an embedded feature of this thesis (see point 1.3).

1.2 OUTLINE OF CHAPTER ONE

This chapter commences with transparency of my social position as an 'insider' from the outset; my parental and professional background and experiences and what that 'insider' perspective represents in terms of the research is explored. The chapter continues outlining the contextual aspects of transition into adulthood, with reference to

transition and key working-related literature and legislation, policy and consultation documentation relevant across child and adult services. This chapter also sets out the theoretical context by defining the concept of Transition, a person-centred approach and Key Working; what it is and the different models of delivery.

This Chapter concludes with a description of the development of a prospective 'candidate' programme theory (the conceptual framework) in my management role for CCN Cymru, a summary of what the reader can expect in subsequent chapters commencing with a Realist Review to formally appraise transitional-related literature and the key issues, including Transition Protocols and Pathways[5] as the foundation context, and in an sequential approach a thematic analysis of interviews with the key stakeholders (Young People, Parents, Transition Key Workers and Site Leads).The latter chapters will, firstly present a synthesis across the stakeholders, and secondly an overall synthesis across the Realist Review and Stakeholder evidence.

1.3 MY 'INSIDER' PERSPECTIVE

My own experiences, both parental and professional, have been the catalyst to explore the complex process of transition of young people with complex needs into adulthood. As a receiver of specialist health, social and education services for a son with complex learning and medical needs from an early age and subsequently experiencing the transition process into adulthood, I have lived through all that it entails from the inside. Furthermore, from an 'insider' standpoint, as a professional lead on transition and Key Working in Wales, an additional professional perspective is privileged. My emic position is an important consideration as I have existed and been defined within in a particular social group (a parent of a disabled child) for over twenty years, as I have within a specific professional role. Additionally, an emic 'insider' position is of key consideration as the joint Project Lead for the Welsh Government, having observed the development of Transition Key Working within this professional role. I consider my emic experiences to have provided a unique and richer interpretation of Transition Key Worker role and function in practice, as well as having acquired the ability to reflect to

[5] Transition Protocols and Pathways will be described throughout as Transition Protocols/Pathways

inform my etic 'outsider' position as a researcher keen to understand what makes a successful transition for young people.

1.3.1 Parental Context

I am parent of two young adults with an Autistic Spectrum Condition. My eldest son was diagnosed at the age of 5 with Infantile Autism and at the commencement of my doctoral studies was 16 years old. Preliminary discussions related to my eldest son's next steps along the transition pathway were in the early stages. My youngest son had recently been diagnosed with Asperger's Syndrome and thoughts about his future, as with my eldest son were uncertain. Planning for both their futures was central to my existence as their parent.

1.3.2 Professional Context

As the Director of a charity promoting Key Working for children and young people with a disability (0-25) and their families, raising awareness of having a named point of contact; a Key Worker through the transition age range was my primary function. Supporting local authorities and their co-terminus health boards[6] was a key focus of my role and responsibilities. Having been a previous recipient of key worker support in the early years of my eldest son's life, and then as a promoter of the need to have a Key Worker through the transitional years, I understood the importance of having named support. Whilst the issues have been felt personally, and what might need to happen to improve transition processes considered professionally, my personal perspective continued to resonate across all aspects of my parental and professional life. This will bring a unique contribution to this research.

1.4 BACKGROUND TO TRANSITION INTO ADULTHOOD AND KEY WORKING FOR YOUNG PEOPLE

McGinty and Fish (1992) described 'Transition' as a *'phase or period of time between the teens and twenties which is broken up educationally and administratively. During*

[6] At the commencement of the research 22 Local Health Boards existed. In 2009 the 22 health boards merged to form 7 new health boards in Wales.

the phase there are changes of responsibility from child to adult services, from school to further and higher education and from childhood dependence to adult responsibility' (p.6), although other transition points occur during childhood, for example the transition from primary into secondary education. McGinty and Fish's description remains pertinent and the term 'Transition' is widely used within the vocabulary of a formal process that will happen for young people, their parents and those working with them from the age of 14 until they reach adulthood. The transition into adult services is usually depicted as being either 18 or 19 years of age depending upon when a young person leaves a specialist school or when they move from receiving services from children's into adult social care or from paediatrics into adult health care provision. The process can nominally continue to the age of 25 (NSF, 2005, 2006). However, the timing of the transfer will be variable depending upon the individual young person, their circumstances and which services they transit into post transition, for example adult healthcare provision.

The transition into adulthood for disabled young people age 14 to 25 has been acknowledged as a complex process (Beresford, 2004; Department for Children, Schools and Families, 2007), which can be testing for all those involved. Maudsley (2000) highlighted that the term 'transition' has become principally associated with young people who require additional support in accessing services into adulthood and that to facilitate and manage those transitional changes, transition planning is a necessity. Carnaby *et al*. (2002), in a case study of young people with learning disabilities, also concluded that there is a need to apportion *'significant energy and planning'* (p.187) and that young people's and parental involvement in transition review meetings and improved co-ordination between schools and adult services would advance service planning between agencies and, in turn, provide effective service provision to young people.

The participation of young people in planning for their future is crucial and central to achieving successful transitions. However, the transition experience can be intangible and leads young people and their families on a complicated journey through a myriad of barriers and challenges which they need to overcome to ensure that there is a supportive structure in place to create a transitional experience that is concrete, straightforward and

seamless between children's services into adult service provision (Carnaby *et al*., 2002); Beresford, 2004). Young people's participation in their own transition is inconsistent, depending upon local transition processes. Whilst, both the general and more specific focused transitional literature gives some insight into the key aspect of achieving a successful transfer for young people, there is no accepted or a fully replicable model. The presence of and involvement of differing local structures, funding agreements and organisations makes for a potentially troublesome and fractious process from both the standpoints of young people and their families and that of professionals and multi-agency service providers throughout transition (Sloper *et al*., 2010). It is important to know what will be needed or what needs to be understood and appreciated to achieve successful outcomes for young people and their parents; their experiences and requirements.

Key aspects of what makes a successful transition are apparent in the literature and tacit experiential knowledge. Dee *et al*. (2002) advocated that *'choice, feelings, relationships, change and respect'* (p.6) are core requirements to ensure that quality of life is optimised and that through the transitional phase robust planning is fundamental to the change process. Nonetheless, families have expressed their experiences as a continuous battle to understand how services operate and what is available to support them through the transitional phase (Sloper *et al*, 2006). This battle is exacerbated during the transitional phase when conflicting eligibility criteria between services acts as an obstruction to active discussions and effective early planning. Officialdom, numerous contact points, the varying eligibility criteria, and deferment of decision-making provide a level of frustration and disappointment for many which needs to be assuaged and requires further investigation.

It has been acknowledged that transition into adulthood, within the Welsh context, has been and still remains a challenging experience for many disabled young people and this has been well established through self-disclosures of direct experience and through careful consultative processes. The Welsh Assembly Government responded to reports of poor transition practices by undertaking two key reviews in an attempt to remediate concerns expressed by young people, parents and those providing transitional support. The former Education and Lifelong Learning (ELLS) Committee Policy Review of

Special Educational Needs, Part 3: Transition (2006) identified 47 recommendations; items 8 and 9 are of significance. Firstly, recommendation 8 specifically identified that *'key workers are appointed to support all children and young people with additional needs, their parents and carers, throughout their education'* (p.19) Secondly, recommendation 9 highlights the need for the development of a *'framework of guidance, professional responsibility and appropriate training within which key workers should be appointed and operate'* (p.19). The Equality of Opportunity Committee's Review of Services for Disabled Young People: 'Why are disabled young people left until last?' (2007) carried out a rights-based consultation and identified 40 recommendations. The review acknowledged that disabled young people required a proactive and co-ordinated approach to planning for the future, including the provision of a Transition Key Worker, to enable their transition into adulthood be a rewarding and positive experience.

The Welsh National Service Framework (NSF) for Children, Young People and Maternity Services (2006) is of relevance to transition with a specific section within Chapter 5. Key action 5.33 is explicit to Key Working: '*A key transition worker is to be appointed to all disabled young people at age 14. It is their responsibility to ensure that the young people, their families and all relevant agencies are appropriately involved in the planning process. The key transition worker co-ordinates the planning and delivery of services before, during and after the process of transition and will continue to monitor and have contact with the young person until the age of 25 years'* (p. 54).

The Autistic Spectrum Disorder Strategy for Wales (2009) makes reference to and recommends the need to provide a Transition Key Worker for young persons with Autism. The Enterprise and Learning Committee report (2010) on specialist provision for young people with Autism in further education, which specifically highlighted two recommendations that there should be senior level transition workers for all young people in Wales with Autism from the age of 14 (recommendation 3), and that the report recommends *'given the success of the pilot approach in Wales, all areas of the country should be served in future by multi-agency forums, including Transition Key Workers'* (recommendation 6, p.5). In response to the two policy reviews, and the key actions

related to transition in Chapter 5 of the NSF (i.e. key action 5.33), and more latterly the Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales (2007), the Welsh Assembly Government established a Transition External Strategic Reference Group, with a sub group structure, which included a Transition Planning Process and Transition Key Working sub groups. These groups aimed to inform the transition policy agenda and developed action plans and work streams to improve the transitional experience of young people with a disability by working in partnership with key agencies to deliver a smooth transition into adulthood. As a result Jane Hutt AM, the former Minister for Children, Education and Lifelong Learning and Skills, announced in December 2007 a grant funding stream (£.1.5m) to the develop transition key working in Wales as previously mentioned at the opening of this Chapter. In June 2008, local authorities (Children and Young People's Framework Partnerships amongst others) were invited to apply to become a Transition Key Worker pilot site. Further matched funding was secured from the European Social Fund: Reaching the Heights – First Footholds grant programme and subsequently 7 further sites (Objective 1 local authority areas) were funded. The attention the Welsh Assembly Government gave to understanding how young people and their families were experiencing transition, from a professional perspective across multi-agency partnerships (education, health and social care), was keenly welcomed.

1.4.1 Characteristics of a successful transition

The key characteristics which define a successful transition depend upon the perspective of the individual. A young person's perspective is likely to differ from their parents. Likewise, a parent's viewpoint is unlikely to be the same as professionals and organisations providing support and services through the transitional years into adulthood. However, early researchers (Mitchell, 1999; Carnaby *et al*., 2002, Dee *et al*., 2002; Forbes *et al*., 2002; Heslop *et al*., 2002; Beresford, 2004) in the late 1990's and early 2000's identified a number of critical success factors which were likely to achieve good transitional experiences for young people and their parents:

- A workable and understandable transition planning process, including a holistic Transition Plan for young people encompassing their health, social care and educational needs, work, training and daily activities, money/benefits, friends and relationships to support a young person's passage towards independence.

- Proactive engagement (young person and parent) with professionals across multi-agency partnerships (e.g. social care, health, education, housing, leisure and community services), with the provision of a key worker.

- Continuity of provision between child and adult services, with co-ordination the key feature.

- Young people involved in the decision-making; making their own choices.

- Focus on individuality and the strengths young people have to support their transition into adulthood.

- Communication and information sharing between the stakeholders (young people, parents and professionals across multi-agency partnerships).

From a parent perspective, other aspects are important markers to measure whether a transition has been successful, such as the young person is happy, liked, supported, safe, is able to engage in meaningful activities to develop their social development and interaction with others, including their peers, but is seen and treated as an individual.

1.5 DEFINITIONS

1.5.1 <u>What is Key Working?</u>

Key Working can be defined as a co-ordinated approach across the statutory and Third Sector (e.g. health, social care, education, housing and leisure services) to support disabled children and young people and their families (CCN Cymru, 2012). There are two main Key Working models; designated or non-designated (contributing as part of their substantive post), both of which encompass the *'individual tailoring of support and services based on the assessment of need, inter-agency collaboration at a strategic and practice level and a key worker for the child or young person and their family'* (https://www.ccncymru.org.uk, 2012) and are the strengths of Key Working models. Key working, as a conceptual way of working and in response to and in line with Children Act (1989), has seen key worker services established in a number of local authority areas across Wales since the early 1990s (e.g. Ceredigion, Carmarthenshire, Pembrokeshire,

Wrexham). Over time young people and their families have expressed the view that a single point of contact (a named person, the Key Worker), who acts as the co-ordinator and supporter through the period known as transition into adulthood would be beneficial and important in ensuring a successful early adult life, with the co-ordinator focusing on outcomes. Although, Key Working is not a novel concept, I was a recipient of non-designated Key Worker support nearly eighteen years ago; the support through the transitional years in Wales was a relatively unknown phenomenon.

1.5.2 Single point of contact

Previous research has identified that parents of disabled children and young people value the access to a single contact point (Sloper *et al*., 2006; Greco *et al*., 2005) to co-ordinate services and support to their child and family as parents have found it difficult to navigate and understand what provision is available and when. This single contact type of support has been acknowledged and recommended, and dates as far back as 1976 (Court Report) to provide for adequately trained and experienced staff for those caring for those children with special needs. The Warnock Report (1978) also highlighted the need for a single point of contact to support families of disabled children. Existing research (Liabo *et al*., 2001; Greco *et al*., 2005; Sloper *et al*., 2006) suggests that the Key Worker provides an effective role in ensuring that there is a collaborative approach between the professionals involved with a family and that the family has the means to access co-ordinated services delivered by a multitude of services providers.

Importantly, no Randomised Controlled Trails have been carried out to assess the effectiveness of Key Working. Therefore, the evidence on effect is limited to the experiences of the provider and receiver of Key Worker support and no outcome measures exists beyond the Key Working Standards offered by CCN Cymru (2013). However, Greco *et al*. (2005) highlighted that despite existing evidence less than one third of those families caring for a severely disabled child had access to a Key Worker in the UK. It has not increased exponentially since that time, despite early research (Glendinning, 1986) indicating that when comparing those families in receipt of a Key Worker service, as opposed to those who did not, families where there was Key Worker involvement were more satisfied (Liabo *et al*., 2001), less restricted and that the well-being, particularly of mothers, was improved and they were less likely to feel isolated.

Two small scale studies (Prestler, 1998, Tait & Dejnega, 2001) identified that many key workers reported greater job satisfaction and contentment, and that their role as the co-ordinator identifying and addressing needs, as well as providing essential emotional support fostered fulfilment and confidence (Greco *et al*., 2005).

1.5.3 Defining a Key Worker

The role of the Key Worker is diverse. The Key Worker is the co-ordinator of care in broad terms, and provides support, connects services, arranges appointments, acts as an information point, can advocate, and ensures that an assessment of need is undertaken and reviewed as appropriate. The Key Worker is the supporter, of both the child or young person and their family. A Key Worker can either be in a designated role (single nominated function) or one that is non-designated (those who key work with a small number of families as part of their professional role, but also carry on working in that main role).

1.5.3.1 Designated Key Worker

A designated Key Worker is a person who undertakes that sole function. They are multi-tasked individuals and may be working with between 15-30 families with children across the age range. In some instances, depending upon the makeup of the Key Working service, they could be key working for up to 60 families over a number of years. CCN Cymru (2012), as good practice, recommended that, ideally a designated Key Worker should work with no more than 30 families, and if supporting a young person through transition, between 15-20 cases at any one time. A designated Key Worker could be employed by a statutory agency or by a Third Sector organisation and are seen by parents to be more independent and could potentially find themselves in conflict with their employers when seeking services and support on behalf of the child or young person and their families (Greco *et al*., 2005) when managers have a differing view to provision sought.

1.5.3.2 Non-Designated Key Worker

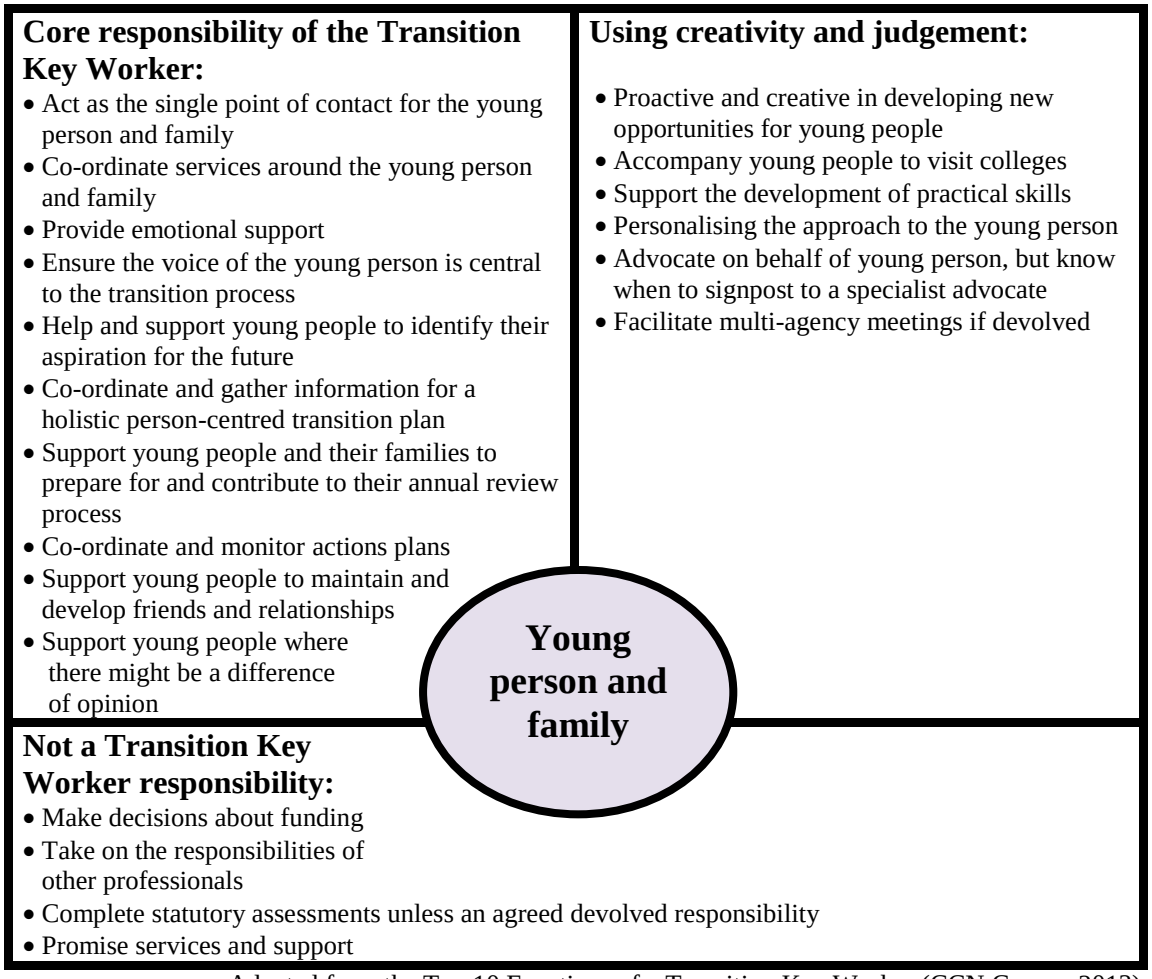
A Non-Designated Key Worker, otherwise known as a contributing Key Worker within certain Key Worker services, is someone who provides some of their time as part of

their substantive post (e.g. a Social Worker, Health Visitor or other health professional, but less likely to be a teacher). A Non-Designated Key Worker will, in as with the Designated Key Worker responsible for co-ordinating and key working for a smaller number of families; 1-2 families, giving for example one day per week of their time. The Non-Designated Key Worker may already know the child or young person and their family; therefore a relationship may possibly have been built giving the non-designated individual a platform to undertake the role in a more immediate way. There is a prevailing trend that the key worker role is being subsumed into a key working function of other professional roles (non-designated), rather than maintaining the specific role of a Key Worker (Department for Education and Department of Health, 2915; Together for Short Lives, 2015).

1.5.3.3 Defining the intervention of a Transition Key Worker

The Transition Key Worker intervention aims to provide a single point of contact for a young person and family through transition into adulthood. Table 1 identifies the core responsibilities, where a Transition Key Worker can use creativity and judgment and the responsibilities which are those of others.

Table 1 Transition Key Worker intervention



Adapted from the Top 10 Functions of a Transition Key Worker (CCN Cymru, 2013)

1.5.4 Defining a person-centred approach

The creation of person-centred approaches emerged from Essential Lifestyle Planning (Smull & Harrision, 1992) in the United States during the 1990's as a means to work with people with learning disabilities; understanding what is important to people and how best to support them within their community. The approach consisting of person-centred thinking, planning and practice has at its heart the individual; continuously *'listening and learning, focusing on what is important to someone now and in the future and acting upon this in alliance with their family and friends'* (https://www.helensandersonassociates.co.uk, 2014) to enable them to achieve the best possible life outcomes with appropriate support networks. The approach embraces the principles of the Social Model of Disability (Appendix One), which focuses on the

holistic needs of a person; challenging and changing society's attitude so as to positively embrace our human differences. The Social Model promotes integration and inclusion, removing imposed societal barriers, whereby disabled people were solely defined by their impairment or condition; the locus of the 'cure or fix' focused Medical Model, which relies, unreflectively so on the socially constructed premise that 'normality' is fundamental. Person-centredness like the Social Model enables opportunity; children, young people and adults reaching their full potential by focusing on what the individual can do rather than on what they are not able to do, unpicking complex situations by considering what is working and what may not be working and using what is working to support what might be working in a person's life.

Key Working through the transitional years places the young person at the centre, working with them to consider what is important to them; breaking down the steps towards adulthood and is sited within the Social Model. While, a person-centred approach focuses on the needs of the individual, its implementation in practice is affected by arrangements in terms of care funding, the type of care provided and by those responsible and accountable for the operational delivery of this care; key areas of concern during the transition process.

1.5.5 Defining the target population of young people and their parents

There is no single clear or agreed definition (Appendix Two) of disability. Whilst, the definition of disability originates from the Disability Discrimination Act (1995) by defining a disabled person as someone who has a physical or mental impairment, which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities there remain varying interpretations of this definition within policy and at a local level. The definition underpinning this study is The Children Act (1989) which defines disabled children and young people (aged 0-18) by these terms; *'if he/she is blind, deaf or dumb or suffers from a mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed'* (p.41). However, the definition of Special Educational Needs (SEN) is cited within the Education Act (1996) and contributes to the variability given the definitional overlap between children/young people who have SEN and those with a more traditionally 'defined' disability. The definition of SEN may include a

variety of difficulties, but may not include all children and young people defined as disabled; those with physical disabilities who have an 'average IQ' for example. A young person who does not meet the criteria as being regarded disabled could still be eligible for assessment as a child in need under Section 17 paragraph 10 (a) or (b), which further contributes the variability, making it problematic to identify which young people are eligible for transitional support. Local eligibility criteria between child and adult services to access specialist provision also varies according to where a young person lives, which can preclude many vulnerable disabled young people who are at significant risk from receiving transitional support.

1.5.5.1 Age range

The National Service Framework for Children and Young People and Maternity Services (2006) adopts the Children Act (1989) definition of disability. However, in terms of age range the NSF extends its remit to include young people aged up to 25. This is in contrast with the Children Act (1989) where the upper age range is 18 years of age. These age range differentiations add to the variability of exit from children services and entry into adult services. I applied the NSF age range to capture the experiences of young people across the 14-25 age range to capture young people post their transfer to adult service provision.

1.5.6 Prevalence rates

Prevalence rates, as a result of varying definitions, are also unreliable. It was estimated that between 7-18% of the national population of young people are disabled (General Household Survey, 2009). In Wales per head of population, this is marginally higher. The statistical prevalence of disability in Wales between 2007 and 2010 (Statistics for Wales, 2011) is based on a small sample data set of young people aged 16-24 suggests that there approximately 10.3% of that population of young people live with a disability. However the focus is on health-related conditions with no data related to young people with a learning disability or to the numbers of young people between 14-16 years of age.

In Wales it has calculated (based on figures provided by local authorities seeking European Social Fund Objective 1 Reaching the Heights: First Footholds grant funding) that there are estimated to be 2,350 young people representing a wide spectrum of conditions who are likely to be experiencing transitional arrangements into adult services and the assessments associated with determining access to various types of adult service provision over the next 3-5 years across 15 local authority areas (covering the period of this research). This data should be approached with some caution however due to varying data collection methods across each local authority area, thereby limiting comparability. The young people who would benefit from Key Worker support and receive 2 or more non-universal services are likely to have complex learning and medical needs, including an Autistic Spectrum Condition, specific syndromes or rare-genetic conditions.

1.6 INTRODUCING THE INITIAL CONCEPTUAL FRAMEWORK

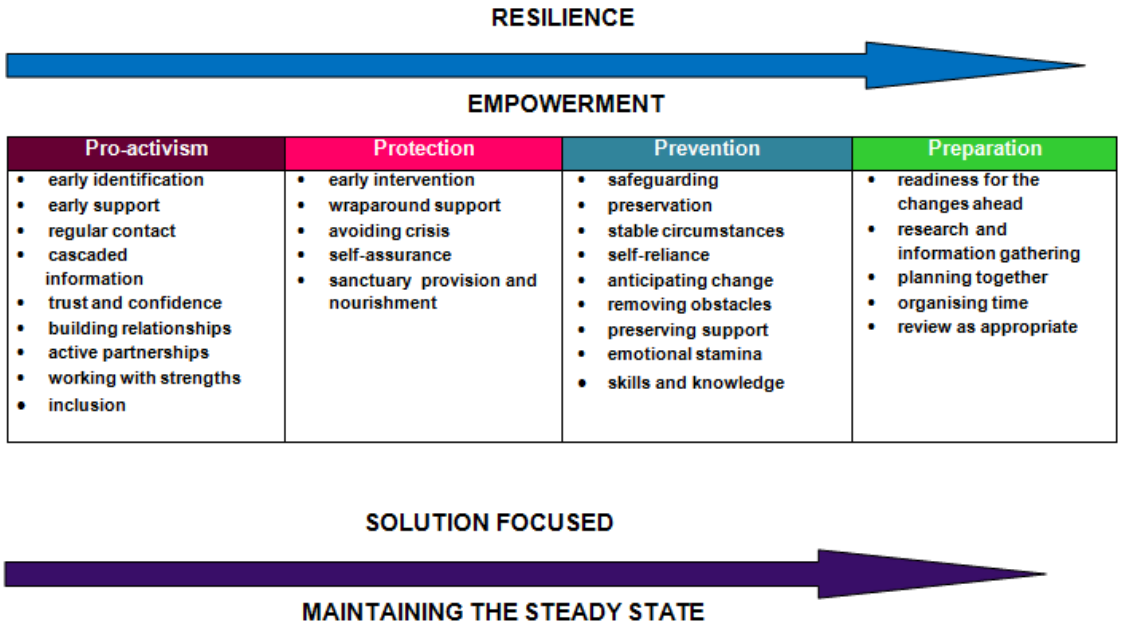
The 4 P's: Steady State Model was developed and was widely consulted on as part of my professional role as the Director of CCN Cymru in developing Key Worker services and to provide a conceptual explanation of the Key Working role. The model sets out inherent elements to maintain children and young people and their families in stable circumstances to avoid the often reported last minute crisis management interventions such as hastily arranged multi-agency panel meetings, particularly during the transition into adulthood phase. The **'4 P's - Steady State'** (Figure 1) paradigm (Rees, 2010) connects four critical concepts of **P**revention, **P**rotection, **P**ro-activism and **P**reparation to maintain an equilibrium in the lives of children and young people and their families and how key workers should work and support them.

The 4 P's were coined in consequence of close working with multi-disciplinary expertise across health, social care (children and adults) and education sectors, as well as from young people and their parents to determine the underlying core linking concepts which underpin the provision of stable transitional support. These became delineable as the 4 P's (Figure 2); key concomitants to achieve a 'Steady State'. The 4 interlocking conceptual components of transitional support promote resilience and empowerment, reflecting young people and their parents' solution focused psychology and readiness confront the challenges ahead of them during the transitional years. The 4

P's was used as an initial conceptual model to underpin the implementation of the Key Worker role in the initial Transition Key Working pilot sites and used as the initial theoretical candidate model in the Realist Review and Evaluation in Chapters Three and Chapters Five through to the concluding chapter.

Figure 1. The 4 P's: the Steady State Model

Figure 2. Underlying core element of the 4 P's



1.7 STRUCTURE OF THE THESIS

This Thesis is structured in three reporting phases. Qualitative Realist research methods are applied to answer the emergent research question of *'What makes a successful transition for disabled young people?'* derived from the Stakeholder Workshop and subsequently clarified during the Realist Review of the literature (Phase One). Phase Two reports the findings from the Realist Evaluation across four stakeholders groups (Young People, Parents, Transition Key Workers and Site Leads). The third phase provides a synthesis of evidence across the stakeholder groups and, in turn, across the first two phases. Each chapter builds upon the previous using the initial 4 P's as the basis of the thesis. The empirical work of the thesis is used to further develop 4 P's conceptual framework and a refinement of the theory is reported in the concluding chapter. The next section provides an outline of the succeeding chapters.

1.7.1 Chapter Two: Realist Synthesis Methods

This Chapter outlines the rationale and methods for utilising a Realist approach to review transition and Key Working-related literature, including policy and consultation documentation.

1.7.2 Chapter Three: Realist Review Findings

This Chapter comprises two parts with coverage on the findings of a Stakeholder Workshop, including setting out how the initial researcher question was developed. Utilising a Realist methodology I ascertain the context, the mechanisms involved in the transition process, who is involved and how they are involved across three types of evidence; legislation, policy and consultation documentation, Transition-related literature (first phase) and a review of local, regional and national Transition Protocols/Pathways (second phase). This Chapter concludes with a synthesis of the findings across the two phases.

1.7.3 Chapter Four: Transition Key Worker Stakeholder Evaluation Methodology

Chapter Four outlines the rationale of using a thematic analytical framework to identify, analyse and report patterns or themes within interviews across the four groups of participant stakeholders. The Stakeholder Evaluation processes are described, the recruitment of participants and consent procedures.

1.7.4 Chapter Five: Parent Interviews

This Chapter draws upon the findings of the Realist Review and details the findings from a series of in-depth interviews with 30 parents of young people aged between the ages of 14-23. The main and underlying themes are explored to ascertain their experiences both positive and negative of the transition process and the intervention of a Transition Key Worker. The Chapter concludes by mapping the experiences of two parents alongside my own experiences of the transition pathway process and my personal parental analytical reflective perspective of the transition process.

1.7.5 Chapter Six: Interviews with Young People

This Chapter reports the findings of 14 interviews undertaken with young people who are or who have received the intervention of a Transition Key Worker. This chapter considers whether their experiences mirror those of their parents through the transition process by mapping the experiences of two parents and their children.

1.7.6 Chapter Seven: Transition Key Worker interviews

Following on from Chapters Five and Six, this Chapter explores the experiences of 14 Transition Key Workers and what they consider, as elicited through detailed interviewing to be a good transitional process. This Chapter considers what is important to and for Transition Key Workers from their experiences of working directly with young people. This chapter concludes with an 'insider' analytical reflective perspective drawing upon my professional experience and knowledge of transition processes.

1.7.7 Chapter Eight: Interviews with Site Leads

This chapter focuses on a series of 7 interviews with Site Leads, including an interview with a local authority area not currently funded to develop transition key working. I conclude this chapter with my experiences as a project lead by offering a reflective perspective highlighting the issues Site Leads faced in providing a needs-led as opposed to a service-led provision of transitional support. I present an assistor and inhibitor matrix as a significant finding.

1.7.8 Chapter Nine: Synthesis of findings across the stakeholders groups

Chapter Nine focuses on a synthesis matrix of three key findings across the participant stakeholders by mapping their experiences against the mid-range theory areas and the initial conceptual model. This chapter concludes with a fourth finding and presents a diagrammatic visualisation of a Past/Time/Future configuration to explain the factors which contribute to both a difficult and successful transition.

1.7.9 Chapter Ten: Overall synthesis across the Realist Review and Stakeholder Evaluation

Building upon the previous chapter I present an overall synthesis of findings across the Realist Review and the Realist Evaluation. I will offer a new interpretation of the transition pathway process illustrated utilising a Context, Mechanism and Outcome (CMO) framework of the transition process, which may or may not achieve successful transitions for young people, their parents and those supporting them.

1.7.10 Chapter Eleven: Critical Analysis and Discussion

The critical analysis is reported in three sections. Firstly, using the RAMESES (Quality Standards for Realist Synthesis for researchers and peer reviewers (Wong *et al*., 2014) I look critically at the Realist Review; the methodology and reporting. Secondly, using the CASP (Critical Appraisal Skills Programme) Tool (2013) a critical appraisal of the thematic analysis of the stakeholder interviews is offered. Thirdly, this section provides a reflection from my multiple perspectives and reflexivity, building upon those reported in Chapters Five, Seven and Eight by presenting a more detailed account using a framework (Jack, 2008) originally designed for clinical practitioners that has been adapted for my specific circumstances (i.e. professional manager and parent researcher). This penultimate chapter also provides a comprehensive discussion across the Realist Review and the stakeholder evaluation within the context of the wider literature.

1.7.11 Chapter Twelve: Conclusion

To conclude, this Chapter summarises the contribution of this thesis to developing new knowledge and a better understanding of the transition process, the implications for future research and sets out a series of recommendations to inform policy and transition-related practice. This final chapter concludes by presenting the original 4 P's model as a further developed integrated theoretical framework to help explain what the Key Worker needs to address and bring about to make a good transition for young people and their parents.

The next chapter outlines the Realist methodological framework to review transition-related literature, including policy and consultation documentation and Transition Protocols/Pathways.

CHAPTER TWO
REALIST SYNTHESIS METHODS

2. INTRODUCTION

This chapter provides the rationale and a description of the methodology used to conduct a realist review of evidence related to the transition into adulthood, key working through the transition process and the role a Transition Protocol/Pathway plays in understanding the experiences, processes and outcomes for young people receiving the support of a Transition Key Worker. As outlined in Chapter One the transition process is a complex social/health/education programme made up diverse organisations with their own differing internal structures and systems made up of multiple professionals with varying responsibilities and expertise in delivering support to young people with varying individual needs. A realist theory-driven approach looks to unpack causation; what happens for whom and when and in what circumstances when receiving a complex intervention. There has been an emergent use of Realist Synthesis (Review)[7], as opposed to a more traditional systematic review approach to explain complex social and/or health programmes (McCormack *et al*., 2006; Rycroft-Malone *et al*., 2010; Best *et al*., 2012; Greenhalgh *et al*., 2012). More recently, given discussion regarding the use and value of realist methodology (Greenhalgh *et al*., 2012), the RAMESES (Realist and Meta-review Evidence Synthesis: Evolving Standards) Project (2013) developed publication standards for Realist Synthesis/Reviews, as with other review methodology, for example, PRISMA for Cochrane-style systematic reviews, to aid researchers in their design; thus, enabling researchers to evaluate the *'quality and rigour of research outputs'* (RAMESES Project, 2013). I adopted the RAMESES standards to maintain rigour and transparency in answering the overarching research question *'What makes a successful transition into adulthood for disabled young people?'* In this next section I

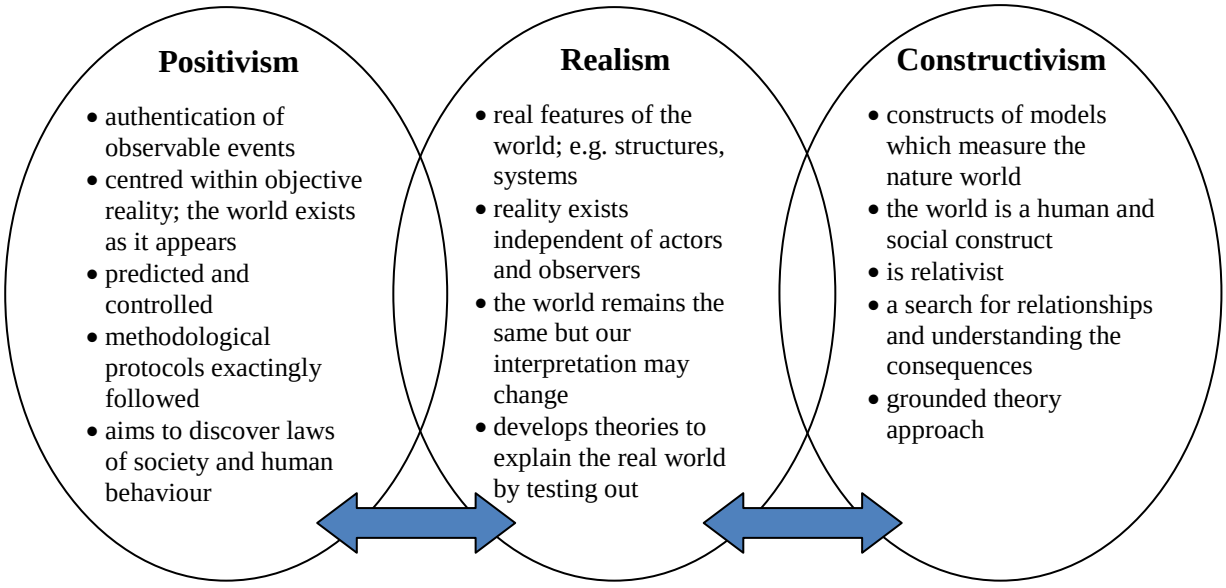
[7] Throughout this thesis I will use the term Realist Review rather than Synthesis, although they are interchangeable

locate Realism and explain the core principles and suppositions of Realist Synthesis (Review) and the rationale for adopting realist methodology.

2.1 LOCATING REALISM

Realism is located within the philosophy of science and exists as paradigm, which considers that reality is processed, indirectly, for example through language and retrospective real-life experiences and is not therefore directly measurable (RAMESES Project, 2013). Realism, is situated between and combines elements and the principles of Positivism (centres on a real world we can understand through observing directly) and Constructivism (an interpretation), thus creating overlaps. Figure 3 represents the connections between the three concepts. A realistic paradigm provides an alternative way by drawing upon what is known in the world (reliable knowledge) and scientific systematic advancement focusing on *'that theories refer to real features of the world* and that *'Reality' here refers to whatever it is in the universe (i.e., forces, structures, and so on) that causes the phenomena we perceive with our senses'* (Schwandt, 1997, p. 133).

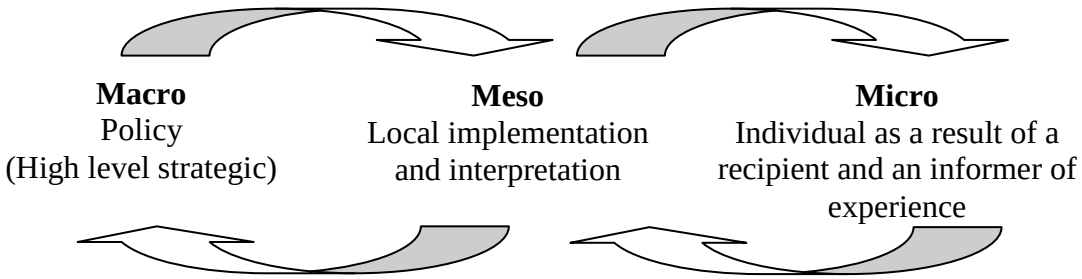
Figure 3. The positivist, realist and constructivist paradigms



A distinguishing feature of Realism is construing causation. Notwithstanding, variant forms of Realism, such a Bhaskar's (1975) critical purist realist approach, more widely cited within the realm of Realism, the work of Pawson and Tilley (1997) is seminal in

describing a realist methodological approach to disentangle complex social and/or health programmes. Pawson and Tilley searched for Context, Mechanism and Outcome chains of reasoning to explore causal relationships and how emergence (change in context), for example in policy (macro) is likely to change what happens for an individual (micro) and change their own context within the meso (a change at an implementation level) (Figure 4). Changes practice or the way an intervention is delivered for example is likely to be identifiable through adoption of such a model. Therefore, an intervention is not mis-perceived as static, but evolving, thus adding to the complexity of and the cyclical nature of a context and emergence model.

Figure 4. Context/Emergence Cycle

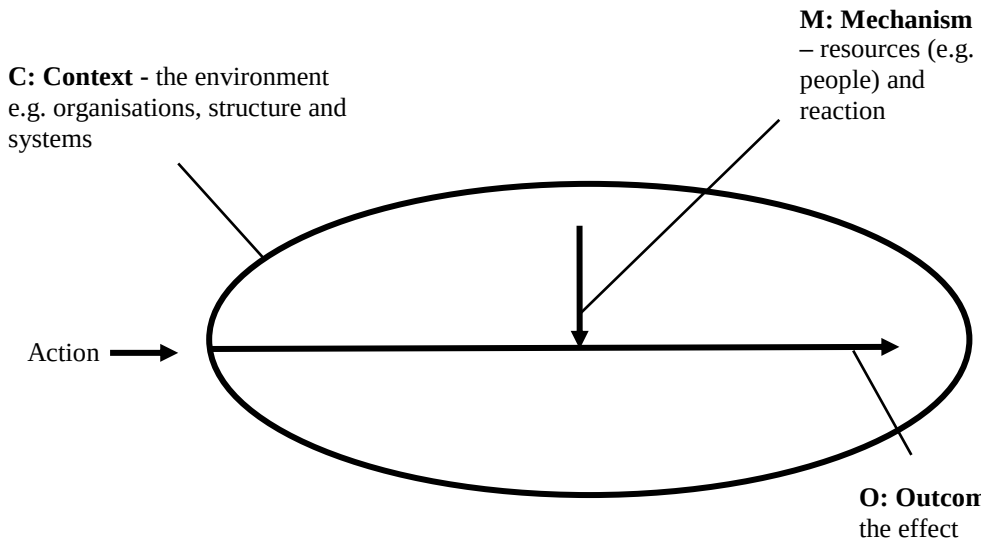


2.1.1 Core principles and suppositions of Realist Synthesis (Review): the Context, Mechanism and Outcome (CMO) configuration

Realist inquiry pursues causation by unpacking and seeking an understanding of the configurational relationship between context and outcome and the role of mechanism(s), described by Astbury and Leeuw (2010) as *'underlying entities, processes, or structures which operate in context to generate outcomes of interest* (p.368). Pawson and Tilley (1997) set out the principles of realistic research by exploring the approach within the context of crime prevention as a means to explain generative causation; that an outcome is generated by the action of individual or groups of interacting mechanisms in particular contexts. Pawson (2002) first described Realist Synthesis (Review) as a means to undertake a synthesis of findings from primary studies, both qualitative and quantitative to produce and, in turn, test out a programme theory to understand what works, how it works and for whom and in what circumstances; a key tenet of realist methodology. Robson (2002) offers an explanatory

illustration to understand what is meant by a Context, Mechanism Outcome configuration (Figure 5), by using the analogy of gunpowder. Gunpowder will ignite; the spark (mechanism) and cause an explosion (outcome) as a result of the flame or firing if certain ideal conditions (the context) are present such as the compound of the gunpowder contains the required chemical elements, is dry and oxygen is present to ignite a fuse of the right type. Therefore, an explosion is caused when a mechanism is triggered when it is acting in a particular context(s).

Figure 5. Example of generative causation (CMO configuration)



(Pawson and Tilley, 1997)

Furthermore, as Astbury and Leeuw (2010) noted that, firstly, there is a need to open up the *'black boxes'* (p.363) to identify *'families of mechanisms'* (p.371) and their kinships, which they described as having three main characteristics; that mechanisms are underlying and can be *'hidden'* (p.368). Mechanisms could also be expressed as being dormant. However, the aim is to make them visible and generating demi-regularities (a semi-predictable pattern) to trigger them to achieve an outcome. Mechanisms are *'sensitive to variation'* (p.368) due to the delivery or change in context. Therefore, the mechanism needs a specific environment to be effective.

2.1.2 Unravelling complexity created by multiple individual and organisational involvement

Realist approaches can be located within the family of process evaluation (Moore *et al*., 2014) which aim to understand the functioning of a complex intervention such as a social and/or health intervention where multiple organisations and individuals are involved in implementation and delivery. Pawson and Tilley (1997) used, as the basis of realist methodology, a number of broad principles, which include, that if a service is delivered in a certain way, a patient for example, should have improved outcomes or at least attempt to achieve the middle ground. However, to improve outcomes, for example, in the context of disabled young people achieving a successful transition into adulthood, it is dependent upon the context and how a mechanism is activated, which as Astbury and Leeuw (2010) ascribe can be variable and sensitive to a change in context, causing further complexities. Therefore, it is important to understand the Context, the Mechanisms and the Outcome of a particular intervention such as a Transition Protocol/Pathway, and test out to unravel the complexity by developing an explanatory programme theory.

Pawson (2006) considered the importance of exploring why an intervention (the key worker mediated transition process) works, but also how. However, McCormack *et al*., (2006) highlighted that *'when it comes to the delivery of complex programmes and services, the "same" intervention never gets implemented in an identical manner'* (p.14. Likewise, transitional policies, protocols and the key worker support associated with disabled young people moving through the process of transition into adulthood are unlikely to be implemented in the same way when being implemented at a local level, and the consequent service provision is not likely to be the same for each individual. Therefore, the individual receiving a transitional intervention is likely to be different to that of his/her peers.

2.2.3 Rationale for adopting a Realist Review (Synthesis) approach

Unlike a traditional systematic review to examine the relevant literature, a Realist approach provides the opportunity to which follow *a* diverse and iterative process (Pawson *et al*., 2004). It is method which is considered to be less prescriptive and

inflexible, but nonetheless methodical and as thorough as a systematic review process where its use is considered more appropriate in unravelling the research question. In applying the principles of Realist Synthesis methodology (Pawson and Tilley, 1997; Pawson, 2006) realist synthesis provides a framework for drawing together existing and relevant published research documentation to explicate the key contextual components and mechanisms which help understand how outcome patterns (demi-regularities) are achieved. Through using this approach a variety of resources can be reviewed to explore complicated and problematic circumstances such as the transition from childhood into adulthood.

Whilst, employing flexible reasoning (Pawson, 2006), it could be considered a limitation in that it is not a standardised formulaic process, and may be problematical in replication. Rycroft-Malone *et al*. (2010) suggest that the customised nature of a Realist Review approach does not mean that the theories developed could not be tested out by using different methodology but that *'the demands on a realist synthesiser are different'* (p.319) and that to assure the quality of the research is *'dependent on the reviewers' explicitness and reflectivity'* (p.319). Therefore, to maintain research integrity the appraisal of the literature must be of a high quality and well considered following the development of a well thought out realist methodological framework. Consequently, a series of data extraction tools were developed for this study to appraise the evidence and a framework constructed which could be replicated for use in future research work.

2.2.4 Developing the theory of enquiry: the programme theory and mid-range theory areas

A central constituent of good practice (Forbes *et al*., 2002; Heslop *et al*., 2002, Beresford, 2004) is to involve the key stakeholders in planning services and to participate in directing commissioners to make arrangements to meet the needs of those who require the support of public sector organisations. Likewise, the foundation of realist methodology (Pawson and Tilley, 1997) is to engage with and involve those who are currently or who are likely requires services. The tenet of person-centred practice is co-production, which is *'about individuals, communities and organisations having skills, knowledge and ability to work together, create opportunities and solve problems'* (Helen Sanderson Associates, 2014, www.helenesandersonassociates.co.uk) and also

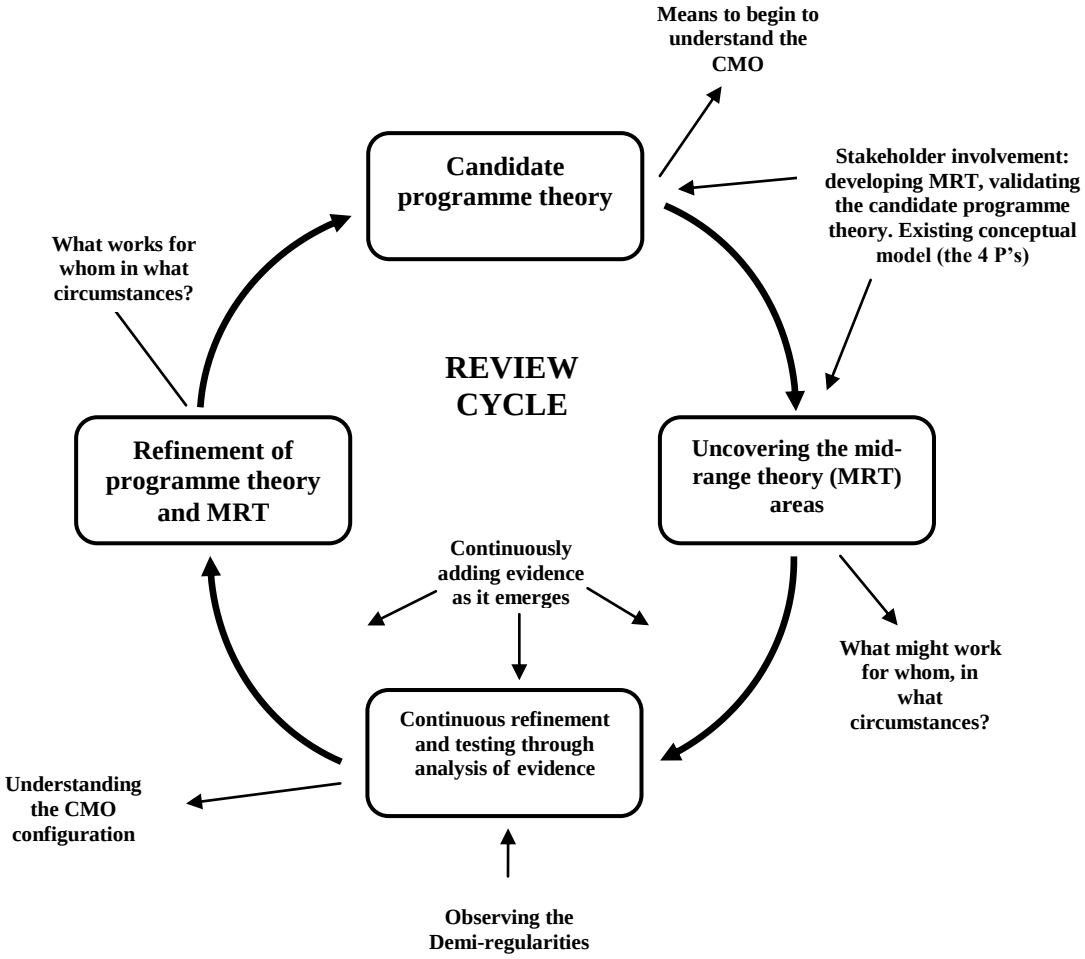
advocates bringing all key stakeholders together to develop services. Realist methodology recognises the importance of stakeholder involvement and participation in unpicking the how and intervention works or indeed how it does not work.

The Review drew upon this principle as the key starting point by hosting a Stakeholder Workshop, which involved young people, parents and professionals (e.g. strategic managers and practitioners), to consider the key components of a successful transition for young disabled people. The initial research question for the Realist Review was derived from the findings of the workshop. Participants were asked to consider, from their perspective, what were the key components and elements of providing a successful transition into adulthood and, in consultation, validate the candidate programme theory (conceptual framework) outlined in the introductory chapter.

Uncovering the mid-range theory or theories is the aim of a Realist Review to understand causation and build an explanation by identifying re-occurring patterns or demi-regularities in extrapolated evidence. *'Middle-theory involves abstraction, of course, but they are close enough to observed data to be incorporated in propositions that permit empirical testing'* (Merton, 1967, p.448); guesstimates that can be generalised. Identifying mid-range theory areas can evolve from a variety of means and sources including from literature. The objective being to test and refine, by repeated questioning of the data, to validate or refute the candidate and mid-range theory area suppositions and seek out alternatives and report any deviation or suggest a new theoretical paradigm.

Figure 6 represents diagrammatically the Realist Review cycle to be adopted, commencing with stakeholder involvement in mid-range theory development. For the purposes of this Review a candidate programme theory (conceptual framework) existed and formed the basis for initial scoping of the evidence.

Figure 6. Diagrammatic representation of the Realist Review cycle



after Pawson and Tilley, 1997, p.85

2.2.5 Review Structure: scoping the literature

McCormack *et al*. (2006) established a staged process to form a framework for undertaking a realist review based on the methodology advocated by Pawson *et al*. (2004). A number of steps were required over 2 main phases (Table 2), which instigated purposeful search of the literature. However, throughout the review process searches were ongoing. The first phase drew out the mid-range theory areas from the evidence; referred to as concept mining (Pawson *et al*. 2004) to extract the evidence and was the first action. Secondly, the theory formulation is central and provided the opportunity to explore a broad range of literature (legislation/policy, transition and transition protocol/pathway-related material). The second phase was formed in two parts; the

'finding' and the analysis, and culminated in a synthesis of the evidence. The final phase enabled the construction of the narrative to report the main findings.

Table 2 Realist Review Framework

Phase 1		
Phase 1a	**Step 1**	**Step 2**
Ongoing search of literature related to transition into adulthood	• stakeholder workshop to validate candidate programme theory and identify emerging mid-range theory areas • initial review question shaped to enable an initial search - data extraction form developed for the review of the broad literature • search of the legislation, policy, guidance and consultation documentation: - data extraction tool developed • initial search broad transitional literature	• search for and test mid-range theory areas in the legislation and policy documentation
Phase 1b	**Step 3**	**Step 4**
On-going search of literature related to transition into adulthood and specific to Transition Protocols/ Pathways	• complete the initial data extraction from the broad transitional and key working literature (mapped to the CMO, 4 P's and mid-range theory areas • initial analysis • ongoing searches	• refine the mid-range theories related to the main theory • identification coded system established to provide anonymity (Transition Protocols/Pathways
Phase 2		
Phase 2a	**Step 5**	**Step 6**
Transition Protocols/ Pathways	• data extraction tools developed to examine Protocols in detail: - broad range selection - selection	• synthesise findings
Phase 2b	**Step 7**	**Step 8**
	• develop format for the narrative specific construction	• report findings • discussion • conclusion

The first phase commenced with a Stakeholder Workshop (Phase 1a, Step 1) which explored from the outset the transitional issues and identified what makes a successful transition into adulthood from participant stakeholder perspectives. The identified outcomes of the workshop informed the initial review question to enable a search of the

broad transition literature, the literature related to transition protocols and pathways to commence. A search of the legislation, policy, guidance and consultation documentation related the process of transition was undertaken to consider the context and what they say about the transition process. Step 2 commenced with a search for the mid-range theory areas followed, in sequence, with a search for evidence related to the programme theory based upon the initial review question to form potential the mid-range theory areas. The last action within Step 2 established a sampling strategy.

The second part of the first phase (1b, Step 3) the broad literature was extracted and an initial analysis undertaken. Step 4 included refining the initial conceptual model and mid-range theories. An identification coding system was developed to ensure the anonymity of the Transition Protocols and or Pathways selected (Welsh and English examples). The second phase (2a, Step 5) commenced with the development of a further data extraction template to examine in detail the broad range selection of 26 Transition Protocols and Pathways, followed by the development of an extraction form to capture the more defined selection of 11 examples. An exploration and synthesis of the findings is concluded in Step 6. The final phase (2b, Step 7) the format for the narrative is constructed and the global findings reported (Step 8). Further details of the data extraction forms developed are outlined under point 2.3.4 (p.56).

2.2.5.1 Changes in the Review process

Any changes to the review process were explained throughout the reporting of findings, including theory building or theory revision.

2.3 SEARCHING PROCESS

A Search Strategy (Table 3) was implemented and included searches of electronic databases, manual searches of reports and other relevant publications. The search was conducted in two parts to reflect the phased approach encapsulated in the methodology. However, an on-going process to capture new evidence as it emerged ensued to the completion of the thesis. A search of past and current policy documentation was instigated which directly or indirectly related to the transition process and key working through an exploration of government, European Court of Human Rights and the United Nations websites, using search terms *'transition disabled young people', 'transition into*

adulthood', *'key working'*. The search of legislative and policy evidence spanned the period from 1970 when two crucial ground-breaking Acts came into force related to accessing social care provision (Social Services Act) and giving rights to disabled people to welfare support (Chronically Sick and Disabled Person's Act) to 2015 to take into account emerging reforms to social care and special education needs.

The broad literature, using the search terms; *'transition planning for young disabled people'* was specific so as to omit evidence related to other young people, for example those with a mental health condition. The term *'key working disabled children'* was used to draw out evidence related to the key working model (CINAHL, MEDLINE, Social Services Abstracts, local authority websites, Google Scholar and hand held items). Title and abstract or summary was initially interrogated to avoid duplication and level of importance. Source material held by me was hand searched. The last stage examples of *'transition protocols and pathways disabled young people'* as the overarching search term were extracted.

Table 3 Search strategy

<table>
<tr><th>Phase 1</th><th>Phase 2</th></tr>
<tr><td><u>Legislation , policy & consultation literature</u>
Search terms:
• Legislation related to children and young people
• Policy guidance related to children and young people

Search period:
from 1970 to 2015 (emerging new legislation)
Search engines:
Google, www.legislation.gov.uk, www.wales.gov.uk, www.un.org, www.echr.coe.int</td><td rowspan="2"><u>Transition Protocols/Pathways</u>
Broad search : Welsh and English examples (Table X Types)
• Search of local authority websites: search term Transition Protocol/Pathways for disabled young people
• Hand held Welsh items (through role a Director of CCN Cymru and project lead for developing transition key working)
• Google: search term Transition Protocol/Pathways for disabled young people

Search period: 2005 to end 2013
Search engines:
Local authority websites (Wales and England)</td></tr>
<tr><td><u>Literature related to transition into adulthood for disabled young people</u>
Search terms:
• Transition into adulthood for young disabled people*
• Transition Protocol/Pathways
*specific to avoid literature related to other young people (i.e. those with mental health diagnoses)

Search period:
earliest to 2014 (time of writing)

Search engines:
CINAHL, MEDLINE, Wiley Online Library, Google Scholar, PsycINFO, Social Services Abstracts, Social Policy Research Unit (University of York, specific organisation websites)</td></tr>
<tr><td><u>Exclusions:</u>
No material to be excluded during the first phase unless related to disabled children and or young people.</td><td><u>Duplication or Emergence:</u>
Duplicated material excluded across both phases
Emergence of new legislation or policy superseding previous policy included.</td></tr>
</table>

2.3.1 <u>Selecting Transition Protocols/Pathways</u>

25 Transition Protocols/Pathways were extracted from hand-held items (Welsh examples), local authority and health-related websites and formed the basis of an initial scoping to explore the overall content and intention of each example. 10 examples meeting a range of protocol/s/pathways outlined in Table 4 were subsequently extracted from the original 25 for an in-depth exploration. A newly published protocol (regional example not previously extracted) was added to increase the original 25 to 26 examples. The 11 protocols identified for detailed analysis where selected on the basis that they were either Welsh or English local authority partnership examples, protocols/pathways

considered national models and those which were single agency or condition-specific types. The selection of the 11 protocols/pathways were also extracted based upon a set of principles advocated by the Transition Information Network (2009)[8] and key headings common to existing protocols/pathways. All extracted examples were coded to preserve anonymity.

Table 4 Transition Protocol/Pathway types

Type of Transition Protocol/Pathway
Local authority: Welsh
Local authority: England
'National' models
Condition specific or health organisation specific
Joint county/co-terminus county examples
Regional collaborative examples (a latter inclusion)

2.3.2 Inclusion criteria

In the spirit of realist inquiry, date of publication did not exclude material from initial searches unless of course the material found was not directly related to the transitional experience of disabled young people. Recent publications, within the time span of writing this realist review, were included. Transition Protocols/Pathways examined included those developed from 2005 up to and including those recently published. Legislative and policy documentation included items from 1970 to present. Other relevant 'grey' material (e.g. factsheets, newsletters, PowerPoint presentations, website postings) were included. A more focused search of local authority websites, to included examples from 2005 to current or newly developed examples of Transition Protocols/Pathways. Unpublished relevant documentation pertaining to transition were included to inform the literature review. To ensure rigour, publications only from

[8] TransMap 5 principles: comprehensive multi-agency engagement, the full participation of young people and families, the provision of high quality information, effective transition planning and an array of opportunities for living life.

trustworthy sources were included. I adopted the use of AACODS Checklist (Tyndall, 2010) to augment the bespoke extraction tools developed to appraise the grey literature and journal based evidence.

2.3.3 Exclusion criteria

Journal publications and reports were excluded where only an abstract and not the full text were available. Publications which did not include young people in the transitional age range 14-25 were also excluded. Documentation which did not contribute to theory building was similarly excluded.

2.3.4 Data extraction

To ensure rigour, five bespoke data extraction tools (DET) were developed for appraisal and relevance. Each tool was designed for the purposes of extracting specific types of evidence across the two phases of the search process to contribute to theory building. The evidence was firstly read and hand annotated, and subsequently re-read as the tools were populated. The search strategy was followed to ensure that the evidence was gathered and extracted in an ordered and observable way. Modifications to the tools were made as mid-range theory areas emerged to continue the refinement and further testing of the conceptual model:

Appendix 3 DET 1: Policy and consultation documentation.
Appendix 4 DET 2: Transition or Key Working related documentation (individual analysis).
Appendix 5 DET 3: Included studies (mapping to the CMO, 4 P's and mid-range theory areas.
Appendix 6 DET 4: Transition Protocols/Pathways (the extraction of 26 examples).
Appendix 7 DET 5: Transition Protocols/Pathways (individual tool).

2.4 ANALYSIS REPORTING AND SYNTHESIS PROCESS

Data analysis and synthesis, utilising the findings from the data extraction process is described in three sections in recognition of the 3 types of data extracted and reported sequentially; theory building intrinsically throughout the reporting as follows:

1. Policy and consultation documentation

2. Broad transitional related and specific to Transition Protocol/Pathways
3. Transition Protocols/Pathways

A synthesis across the three streams was undertaken to draw together the evidence. The RAMESES publication standards for Realist Synthesis (Wong et al., 2014) were used as the basis for structuring the reporting of the Review and are set out in Appendix 8. Changes in the initial conceptual theory are reported and further testing was undertaken through the evaluation of interviews across the 4 participant stakeholder groups set out in the introductory chapter.

2.5 CONCLUSION

In conclusion, this chapter explained and explored the rationale for using a Realist approach to appraise a range of evidence across transition into adulthood and key working and the role of a Transition Protocol/Pathway. The design, to ensure rigour and transparency, followed an iterative process founded in observing the realist review cycle and a realist review framework by Pawson and Tilley (1997) by developing bespoke data extraction methods to explore and understand the CMO configuration. By adopting a realist review approach the aim was to understand how the outcomes for disabled young people and their parents were produced (the mechanisms) and in what context(s) and the impact and change in both the process and transitional practice in the future. The Review is reported using the standards set out by the RAMESES Project (2013).

The next chapter will report the findings from the realist review to determine the CMO configuration, test out the candidate programme theory and identify the mid-range theory areas.

CHAPTER THREE
REALIST REVIEW FINDINGS

3. INTRODUCTION

Moving from childhood for young disabled people[9] is defined within the parameters of a structured programme into adulthood (Special Educational Needs Code of Practice, 2001 (England), 2002 (Wales); draft new Code of Practice (England), 2014); known as the transition process. The process has been described as complex, with multiple individuals and organisations involved across child and adult services (Hirst and Baldwin, 1994; Morris, 1999 and 2002; Forbes *et al*., 2002; Beresford, 2004; Abbott and Heslop, 2009). Delineating what should happen, for whom and in what circumstances is transmuted through, at a local level, the implementation of a Protocol/Pathway[10], which is a tangible manifestation of the process. Protocols/pathways are seen as the means to set out across agencies (Health, Social Care, Education and the Third and Community Sector) the course of action and the responsibilities of those involved in supporting young people to deal with a succession of adjustments occurring during a specific life stage into adulthood.

Achieving a successful transition remains a challenge for many young people and those supporting them. The process, as a paradigm, has become nebulous as to how it is applied and what it achieves for the individual. There is relatively sparse evidence of the effectiveness of a protocol/pathway, as an intervention, especially relating to the benefits for young people as intended beneficiaries. The evidence relating to what works well is relatively unclear across all aspects of a young person's journey into adulthood, therefore making difficult the solution to answering the question; what is the

[9] Disabled young people (14-25) will be referred to throughout this Chapter as young people.
[10] The term protocol/pathway will be used to encompass examples described as a procedure, policy or guideline. The term Pathway will be used when specifically exploring examples contained with a Protocol

best way to deliver a successful transition? (Sloper *et al*., 2010). There is a clear need to understand how a protocol/pathway for transition can help/or indeed not as may be the case, in achieving successful transitions for young people, as defined by them.

3.1 AIMS AND OBJECTIVES OF THE REVIEW

The previous chapter described the methodological approach and rationale for undertaking a Realist synthesis to provide an explanatory account as to what works for young people, contextual influences; the environment in which the transition process is dependent upon and the mechanisms; activators of change to generate outcome(s) of interest. The Review aimed to answer the key research focus of this study: *'What makes a successful transition into adulthood for disabled young people? And; Do Transition Protocols/Pathways help to achieve successful outcomes?'* as well as to further refine the programme theory so as to 'test' out throughout the primary study (Realist Evaluation). The objective was to understand how the transition process functions and the role of a protocol/pathway as an intervention and identify the circumstances within which the complex process of transition, the contextual relationships and the external and internal mechanisms facilitated by a protocol/pathway help create opportunities to achieve good outcomes for disabled young people entering early adult life.

3.2 HOW THE REVIEW WILL BE PRESENTED

This chapter is presented in two main sections to reflect the phased extraction of data (Table 5). Phase 1 (Part 1) reports the findings of a Stakeholder Workshop to establish, from a participant perspective what they considered to be the rudiments of a good transition and the research question. Part 2 focused on what the policy and consultation documentation revealed and secondly, the literature related to the transition of young people and key working to inform the second phase of the Review. The second phase explored transition protocols/pathways. This phase will be reported in three parts centring on the key findings of the focused review of transition protocols/pathways. The chapter will conclude with a synthesis of the findings presented.

Table 5 Review structure

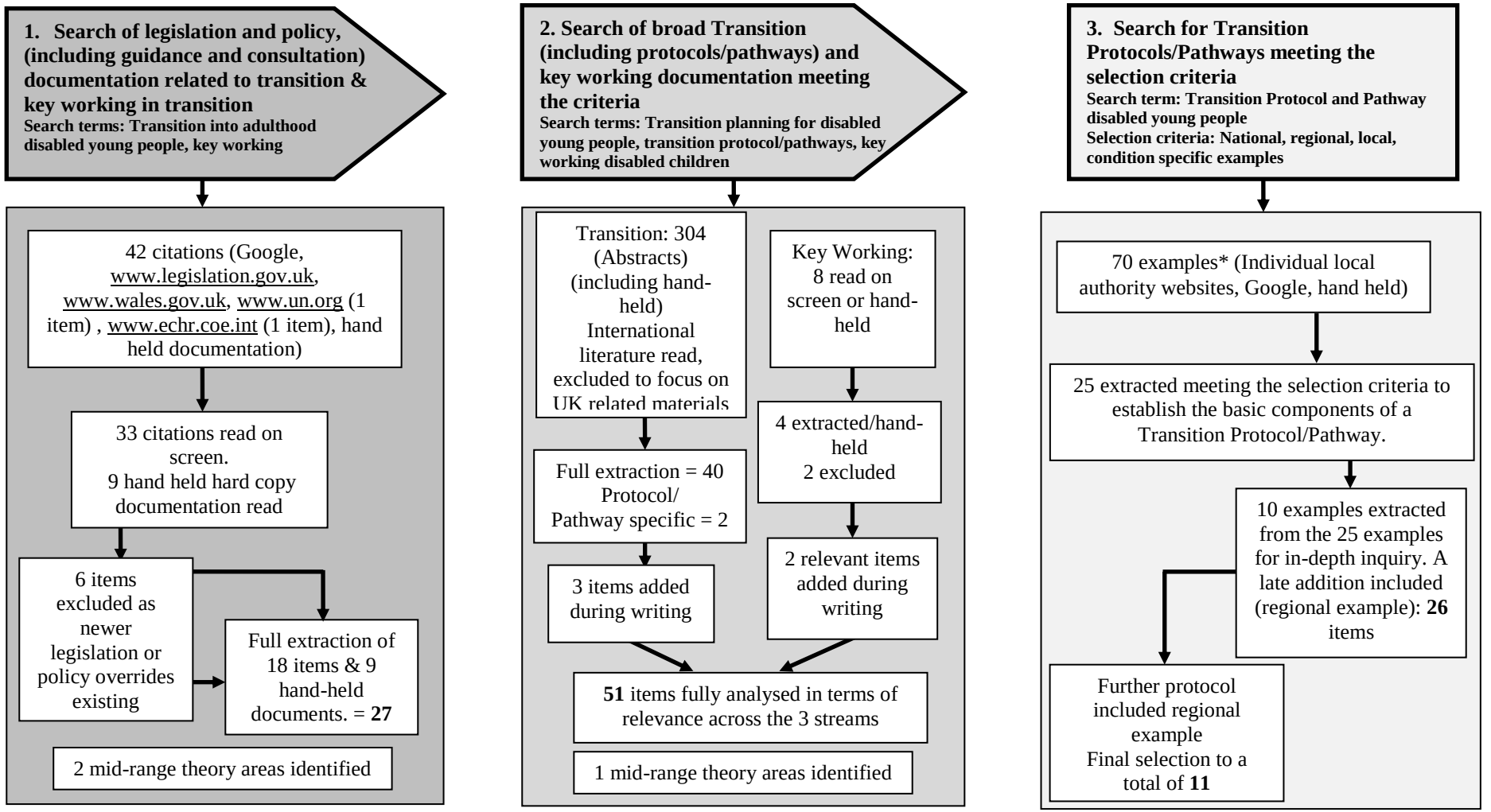
Phases	Action	Intention
Phase 1	**Part 1:Stakeholder Workshop**	• **Establish the elements of a good transition** • **Establish the overarching research question Affirm via consultation the programme theory** • **Identify mid-range theory areas to test the evidence**
	Part 2: Review of legislation, policy, guidance and consultative related to Transition and Key Working	• **Establish the intention** • **Establish the basis of Key Working in transition Confirm or refine candidate programme theory** • **Identify additional the mid-range theory areas; testing them out**
	Review of the broad transition and key working literature	• **Identify the key elements of transition** • **Continuation of testing**
Phase 2	**Part 1: Review of a selection (26) of Transition Protocols and/or Pathways (selected based upon type (Table 3)**	• **To contextualise the overarching features** • **Identify the Context, Mechanism and Outcome (CMO) configuration** • **To develop a framework to analyse random and focused selection**
	Part 2: Focused selection (11) of Transition Protocols and/or Pathways (selected from the original 26 across type of example)	• **Establish the CMO configuration**
	Part 3: Synthesis across the 2 phases	• **Reconfirm and present the overall CMO**

3.3 MAIN FINDINGS: PHASE ONE (POLICY/CONSULTATION AND TRANISTION AND KEY WORKING DOCUMENTATION)

3.3.1 Data Extraction

The literature search was iterative and purposeful and the three-streamed search approach (Figure 7) elicited a broad range of literature directly or indirectly related to the transition process and Key Working. Figure 7 outlines the outcome of the searches and the three tables set out the included evidence used in this Realist Review.

Figure 7. Flow diagram: Search process and article disposition (a three-pronged searching process)★



*Search ceased at 70 identifiable examples meeting the selection criteria due to likely data saturation and in consultation with supervisor to come to consensus and constituted the representative sample to select the original intended 25 specimens

✦Incorporating reference to protocols/pathways

★Search period: October 2009 (from Ethics Submission) to November 2104

3.3.2 Stakeholder Workshop (10 March 2011)

The 4 P's as the initial conceptual model[11] (candidate programme theory) was presented in Chapter One which explained the core elements of key working across the 0-25 age range, which were considered pertinent and synergist to the transition process during a consultative process. Drawing upon the principles of stakeholder involvement, a workshop was organised in my role as Director of CCN Cymru. The participants indicated that there was need for a structure to enable the other elements of the transition process (e.g. access to support) to happen. The professional participants described a protocol/pathway as the main vehicle for outlining the key arrangements which underpin a successful transition. Young people were less interested in how the process was instigated, but spoke more generally about having a transition plan which was their own and which allowed them to have key involvement in directing their own transition, with the presence of a proactive supporter (a key worker) to support them, as required to make important decisions along their journey towards adulthood.

Three mid-range theory areas evolved from the findings of the workshop, which were likely to underpin the candidate programme theory (Figure 8) with supportive arrangements and active decision-making as probable central mechanisms:

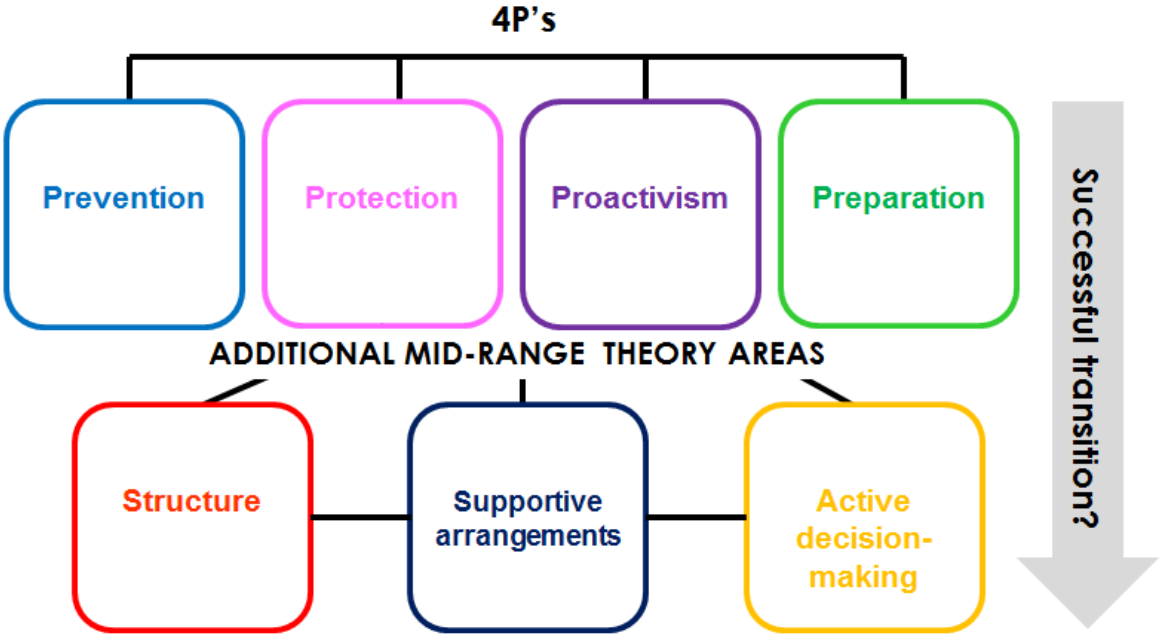
Theory Area 1: Having an understandable structure provides the basis to ensure good transitions for young people.
Theory Area 2: Proactive support arrangements foster early planning with young people.
Theory Area 3: Active decision-making enables young people to be control of the choices they make.

An overarching research question *'What makes a successful transition into adulthood for disabled young people?' Do transition protocols/pathways assist and achieve successful outcomes?*' was shaped, using stakeholder perspectives, to ensure that the

[11] I will use the term candidate programme theory throughout this chapter, in line with Realist terminology

global elements of the transition process could be pursued in the literature. The stakeholder participant re-validated the candidate programme theory.

Figure 8. Theory Development 1



3.3.3 Review of policy and consultation documentation

Abbott and Heslop (2008) considered that there was not a lack of policy, yet it was *'not at all clear whether or not these policies are leading to better outcomes'* (p.53) or whether the multiple issues that have become associated with the transition process could be addressed. The contextual environment, set within policy (Children Act, 1989, 2004; Education Act, 1996; Learning and Skills Act, 2000; Code of Practice (COP) of Special Educational Needs (SEN), 2002, 2001 (Wales and England versions); National Service Framework (NSF) for Children and Young People and Maternity Services, 2004 [England], 2005 [Wales]) suggests that the process requires a structural framework to achieve successful transitions for young people as an overarching outcome.

The Children Act (2004) enabled local authorities to develop transitional procedures to improve service delivery and co-ordination to vulnerable groups of young people by

promoting multi-agency partnerships and engagement and continuity between agencies. The development of multi-agency protocols/pathways was the inferred main vehicle for driving effectual working partnerships. Yet, the need to develop an agreed protocol/pathway was considered a notion of good practice (Kaenhe, 2010), rather than as a statutory obligation. Nonetheless, the 2004 Act (Section 25) placed a duty on local authorities to make arrangements to co-operate with partner organisations, such as health boards and made this a general principle. However, the detail of how an accountable transitional structure arises from a multi-agency perspective is less clear, particularly for adult providers.

In Wales, and similarly in England, there was an appeal for the rationalisation of transition-related policy (Education, Lifelong Learning and Skills Committee (ELLS), Welsh Assembly Government, 2007, Equality of Opportunities Committee (EOC), Welsh Assembly Government, 2007, DOH, 2008). There was the intention, paralleling the Stakeholder's views, that having an understandable process should be the central drive to enable young people to plan, with support (key worker) to make active decisions and plan well for their own futures. The Court Report (1976) highlighted that a supportive response to provide continuity was valued by parents in particular, with the Warnock Report (1978) suggesting the need for a single point of contact (a key worker) to support early dialogue with young people. However, no duty on the part of service providers to uphold this policy intention applies, with a lack of specificity across policy and guidelines with regard to the supportive arrangements which should be made available through transition and how support should be delivered in operational terms.

Contextually, the requirements associated with transition planning for young people with Special Educational Needs (SEN) were located within the Education Act (1996). A Code of Practice (COP) for SEN (2002) was issued giving local authorities the terms to carry out specific functions, but the emphasis is set within the domain of education and depicted as a linear phenomenon. Local authorities were given the responsibility to begin developing a formalised transition for a young person from 14 years of age (Year 9). The Act (1996) stated that a local authority must include the need to develop a Transition Plan for a young person; a tangible outcome of the transition process from an operational standpoint, but that discussion about a young person's future should be an

ongoing dialogue to plan effectively. The COP shaped a young person's involvement and that professionals should *'adhere to the principles that underpin the nature of transition and transition planning and the requirements of the young people and their parents….transition planning should address the comprehensive needs of the child'* (Part IV, 9:52). In consideration, there was little within the policy which set out how to shape a Transition Plan; what it should contain and how young people were to be supported to develop their own plan. Supporting young people to plan well, highlighted as a crucial element (DCSF, 2006); what they needed to think about across all aspects of their lives, was largely absent.

Wood and Trickey (1996) reviewed the impact of the COP on the process and concluded that whilst a transition plan and the review of the plan gives parents and those working with young people the occasion to work together there was still the need give *'serious consideration to….balancing the elements of the process and to deciding how services can be networked in order to assist the young person to achieve a successful transition to adult life'* (p.124). Furthermore, Wood and Trickey pointed out that if this does not transpire then it may result in a *'paper exercise which benefits no-one'* (p.124). Nonetheless, the development of a Transition Plan is seen as fundamental in encapsulating the voice and needs of a young person to inform the decision-making (Children Act, 1989; UNCRC, 1989; Education Act, 1996; Learning and Skills Act, 2000; Mental Capacity Act, 2005).

To conclude, the 3 mid-range theory areas identified by the workshop participants were represented within the policy, yet their significance is somewhat understated, with a focus on process itself. Whilst, promoting a structural response within consultative initiatives (Education, Lifelong Learning and Skills Committee, Welsh Assembly Government, 2007, Equality of Opportunities Committee, Welsh Assembly Government, 2007) to improve the transition process it has not reduced the lack of clarity and complexities brought forth by the numerous organisations and professionals involved. It has not clarified or endorsed the ownership of the process or prevented the complexity irrespective of the existence of a protocol/pathway.

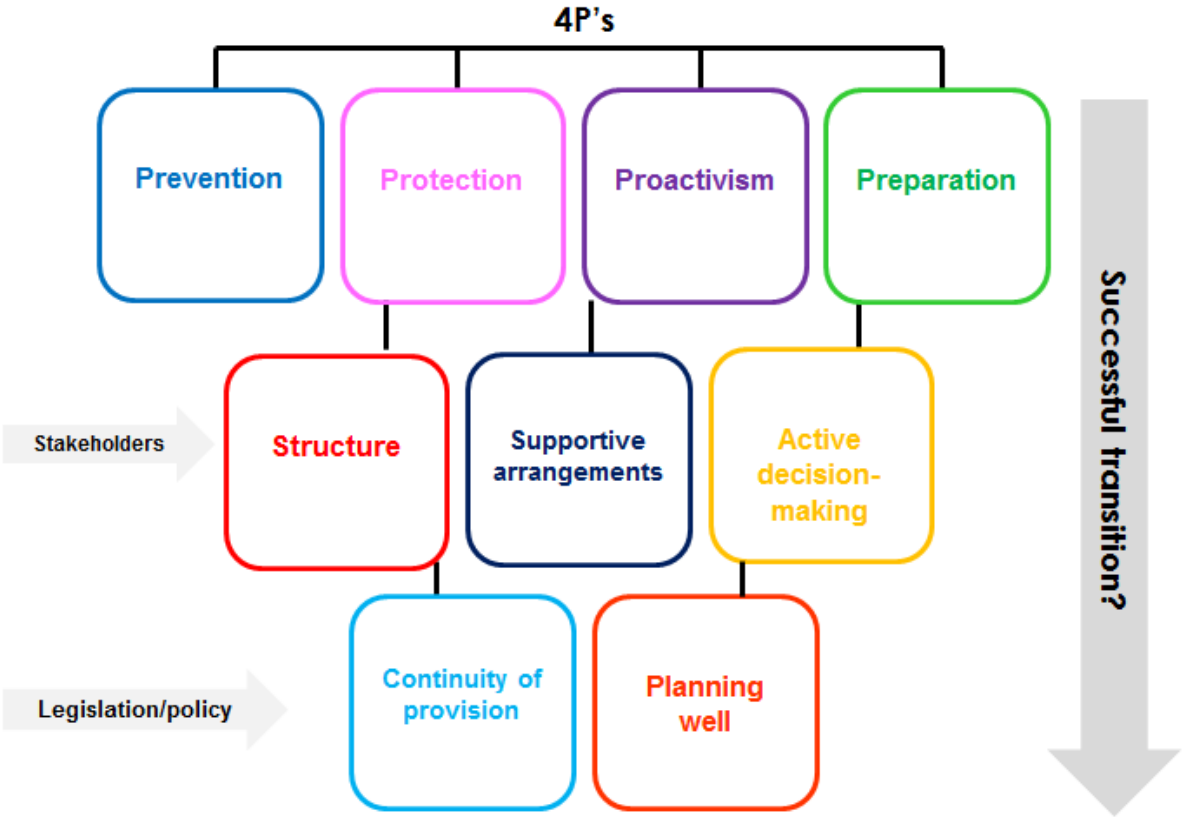
3.3.4 Mid-Range Theory Area development (Figure 9)

The policy suggests that continuity and planning well are also considered important mechanisms, but continuity of provision is contingent on specific legislative directives and planning well on young people being supported to do so.

Theory Area 4: Continuity of provision is the intention of the transition process.

Theory Area 5: Planning well is crucial to achieve successful transitions into adulthood.

Figure 9. Theory Development 2



3.3.5 Review of Transition and Key Working related literature

The Included Studies Tool (Appendix Five) was developed which identified within the narratives their specific relevance to the CMO, programme theory and mid-range theory areas and enabled the focused reporting outlined in the next section.

3.3.5.1 The contextual findings

There has been some focus on what could make a successful transition (Mitchell, 1999; Forbes *et al*., 2002; Heslop *et al*., 2002; Ward *et al*., 2003; Dee, 2006; Department of Health (DOH) and Department for Children, Schools and Families (DCSF), 2007; DOH, 2008; Sloper *et al*., 2010). Tisdall (1994) suggested that there was no clear agreement as to what constitutes as good transition for young people. Moreover, Mitchell (1999) concluded that *'within the literature it is clear that theorising the transition from childhood remains the focus of conceptual ambiguity and debate'* (p.756). The process was seen as unpredictable due to the variability of multi-agency responses to how it is implemented (Heslop *et al*., 2002; Sloper *et al*., 2010; Watson *et al*., 2011).

Beresford (2004) highlighted the prevalence of *'grey literature'* exploring the experiences of and the journey taken by disabled young people; what happens and when it happens and the consequences, which was more often than not depicted as difficult rather than deemed successful. The transition process was conceptualised as being convoluted (Hirst and Baldwin, 1994; Morris, 1999; Morris, 2000; Forbes *et al*., 2002; Beresford, 2004) for young people as they confront adolescence and manage the transition into adult life, rather than on prevention and focus on the strengths and spirit they bring to tackle the obstacles they need to overcome. Those barriers are often higher and wider for young disabled people than their non-disabled peers. *'Fixed pathways'* that *'take young people from school to college and then on and on into further education'* (Abbott and Heslop, 2009, p.53) have no due regard to exploring other options for young people (Carnaby *et al*., 2003).

3.3.5.2 Key Finding 1: Having a structure (protocol/pathway), as an intervention, promotes an understanding of transition planning processes (Theory Area 1)

The evidence suggests (Dee *et al*., 2002; DCSF, 2007; Council for Disabled Children, 2009; Sloper *et al*., 2010), informed by the findings of the workshop, that there is a need for an overarching structure as the lynchpin to operationalise the transition process. A protocol/pathway is seen as important to the process; fashioned collaboratively to promote understanding (Commission of Social Care Inspection, 2007; Everitt, 2007; Kaehne and Beyer, 2009; Kaehne, 2010). Having structure to construct how the transitional process is managed is perceived to be the main means to encourage an understanding of the importance of promoting a continuum between child and adult services. At least theoretically speaking, a partnership protocol/pathway is considered to be the central instrument in realising this aim (Forbes *et al*., 2002; Heslop *et al*., 2002; Beresford, 2004; DCSF, 2007; DOH, 2008; Kaehne, 2010). Nonetheless, the process is continually seen as challenging despite the presence of protocols/pathways.

The Commission for Social Care Inspection (2007) found that protocols were *'weak on quality assurance* (p.42), aimed at a professionals and would be *'difficult for parents and young people to access'* (p.42). Barnes (2008) considered that *'no specific set of protocols'* (p.1) were available to formalise a local framework, but that *'there was general agreement that a multi-agency teamwork approach….was an effective way forward'* (p.1) to promote understanding. 'TransMap: *How to develop a transition protocol'* (2009) provides a yardstick for multi-agency partnerships to aspire to; what needs to happen, what a protocol might contain and why the content recommended is important. Yet, the provision of information to guide practitioners, young people and their parents on how to plan well is largely absent. Moreover, Mitchell (1999), reasoned that there needs to be a *'more flexible perception of transition'* (p.766) and recognised that the transitional process is one which is multifaceted and *'must incorporate and be able to appreciate lengthy transition processes* (p.767). A protocol/pathway, at a local strategic level (DCSF, 2007) sets a standard expectation on agencies; that a pathway is in place for a young person from the age of 14 and outlines supportive needs over either a 6 year period to the age of 19 or over 11 years to 25, depending of course upon local policy.

Good practice was reported (Tan and Klimack, 2004; Sloper *et al*., 2010; Watson *et al*., 2011; Beresford *et al*., 2013), such as multi-agency co-ordination and commitment to operationalise an overall transitional framework. Kaehne (2010), to some extent Knapp et al's (2008) work considered the role of a protocol/pathway, but not beyond that of developing partnerships. Kaehne acknowledged that it *'worked with the assumption that transition protocols may foster good partnerships'* (p.187). However, a protocol/pathway was seen as only one of many factors which helped promote good transition planning and that in fact *'protocols may be only a minor component'* (p.187), albeit important for establishing communication channels between all stakeholders involved in the process of supporting a young person's transition through children's and into adult services. Without a local protocol/pathway in place, agencies would find it difficult to communicate to young people and their parents the administrative and organisational procedures underlying the process of transitioning a young person to adult services.

3.3.5.3 Key Finding 2: The concept of continuity plays an important part in achieving a successful transition (Theory Area 4).

At present, the trigger to bring together children and adult service providers under one multi-agency strategic transitional statement is encapsulated within the context of legislation and policy (Education Act, 1996; Children Act, 2004; DOH, 2006; DCSF, 2007; DOH, 2008). The promotion of continuity appears to be a key factor (Council for Disabled Children, 2009); that having a continuous framework supports practitioners to achieve a faultless transfer for young people. Forbes *et al*. (2002) also identified *'six dimensions of continuity'* (p.13)[12], which they used as their conceptual framework to analyse their evidence which was a useful in defining continuity. However, a linear description of the transition process is far from the reality many young people experienced.

[12] Six dimensions of Continuity: Experienced, Information, Flexible, Cross boundary/team,, longitudinal, and relational/personal.

Forbes *et al*. (2002) identified four models to understand the role continuity plays. Those models, directional, sequential and developmental are helpful; a professional model (the fourth model) allows for professionals involved in supporting young people to move between both child and adult services; encouraging seamlessness. Though, varying structures and multi-professional involvement will be different for each young person a pre-set or standardised pathway may not elicit the wished-for outcomes of the individual (Abbott and Heslop, 2008), unless a protocol takes account and incorporates an amalgam of four models advocated by Forbes *et al*. (2002). Each model has a shortcoming in that they are not person-centred and are reactive rather than preventative and proactive in intent. However, Forbes *et al*. (2002) reported a long-lasting continuous ideal between services *'is a difficult concept to define and has different emphasises within different care settings'* (p.13). An uninterrupted ideal is not clear across organisations. Sub interventions, for example, the provision of transition workers (Sloper *et al*., 2010) and outcome processes, which include measuring progress and quality were seen as part of providing continuity into early adulthood.

3.3.5.4 Key Finding 3: Pro-active support is a crucial to accomplish successful transitions (Theory Areas 2 and 5)

Setting out individual and agency responsibilities (Forbes *et al*., 2002; DCSF, 2007; Knapp *et al*., 2008; Kaehne, 2010) was an intention of protocols/pathways. Providing support was articulated as being at different levels, times or stages; be individual to the end receiver. A practitioner providing support was variously described as a key worker or transition worker, with the supporter needing to be dependable (Beresford *et al*., 2013) and that actions were carried out as agreed.

The relationships developed between the young person, their family and professionals working with them were identified as important. Dee (2006) noted, however that *'fragile networks (they) rely on relationships between individuals rather than on robust strategic planning and operational frameworks'* (p.104). Dee (2006) suggested that parents were often discontented by the dearth of support they received and were *'despite being determined to be proactive and problem-solving parents feel unable to challenge authority'* (p.67). A negative view of professionals was held by parents

(Smart, 2004). Beresford *et al*. (2013) considered that when a young person had unhelpful contact with professionals that they *'felt that better to "trust" more informal sources of help and support'* (p.79). This support often came from parents whom they trusted. Staff turnover or a sudden departure and shortfalls in staff supporting young people were reported, amplifying the levels of apprehension both for the young person, family and those working with them (Dee, 2006). Such issues were not formally addressed in protocols/pathways.

Fiorentino *et al*. (1997) maintained that *'young people and carers need all the support they can get to make it easier for them to handle the necessary changes taking place in their lives'* (p.269) and plan well with support. Forbes *et al*. (2002) supplemented this by suggesting that parents also need support to manage the changing nature of their relationship with their child as they become adults. This point was further advocated by Beresford (2004); that parents play an important role in supporting the *'adjustment to changed relationships with young people'* (p.584). Cowen *et al*. (2010) suggests that a key component of a personalised transition is the need for expert and tailored support; that *'professional support is important, but it must be co-ordinated, simplified and appropriate to the needs of the young person and their family'* (p.3).

The supporter of young people with more complex needs was likely to be a key worker (Cavet, 2007; DCSF, 2007) co-ordinating and joining up support and services. Recent research (Welsh Government, 2013) concluded that a Transition Key Worker *'offers important benefits for the majority of families with the Transition Key Worker offering emotional and practical support* (p.65) during a key moment in the lives of young people. However, more recent policy direction (Welsh Government, 2014) appears to veer away from of using the term 'key worker', with a suggestion that *'local authorities should adopt a key working approach…with a single point of contact to help ensure the holistic provision and co-ordination of services and support'* (DOH/DOE, 2015, p.37); but duty to provide a contact point is not provided. Many young people continue to lack the co-ordinating presence of key worker (Every Disabled Child Matters, 2012).

3.3.5.5 Key Finding 4: A person-centred approach to planning is a key enabler to promote decision-making (Theory Area 3).

Since the early 2000's the prevailing policy direction (Community Care Act, 1990; Fulfilling the Promises (Wales), 2001; Valuing People, 2001; Equality Act, 2010) has led to some local authorities adopting person-centred planning. Centring the young person at the core of planning for their own future has been seen to facilitate decision-making in a person-centred way (DOH, 2011; Welsh Government, 2014; DOH/DOE, 2015) giving them their voice, heard equally alongside their parents, practitioners and decision-makers. Making choices were often not straightforward (Small *et al*., 2003), with changing ideas and quandaries about what might happen for young people, and this has made the process of decision-making protracted; young people and parents sensing a loss of control. Moreover, Smart (2004) suggested that *'young people themselves were found to be marginalised in the planning process, with very few being involved in any decision making'* (p128) Decisions were made by default by parents, with professionals colluding, by not listening to what the young person wanted (Dee, 2006).

Beresford (2004) highlighted that *'planning for transition needs to be person centred'* and with *'young people's preferences, goals, aspirations taking centre stage'* (p.885). Beresford further concluded that young people and their parents have a central role in the transition planning process and also in decision-making, but that *'careful planning'* (O'Brien, 2006, p.195) is essential. Sloper *et al*. (2010) found that, although Government endorsed a person-centred approach, it was not always adopted. Further to this, maintaining key worker provision was not always in place; making it difficult to build relationships with young people to understand what is important now and in the future and adapting as young people grow, try new things and change their minds by stimulating person-centred conversations. Sloper *et al*. (2010) found that young people did not have contact with a worker until 16 years of age, or over, and so were not captured at an early point in transition sufficient to explore options in a timely and person-centred way.

The complexities of making informed decisions about the level of support needed for a young person in transition could be seen as being generated by having many agencies involved and the structural differences, both strategically and operationally between

such agencies appear not to be addressed by the presence of protocol/pathway. Dee (2006) identified that decision-making processes ranged from a consensus decision to where choices, overtime, are explored to achieve agreement. Decision-making at the right time in planned way, so that young people have thought about the future and what support was required was identified as a preventative approach. But, as Knapp *et al*. (2008) established, the consequences of an unplanned *'unsuccessful transition are substantial'* (p.512). The end results are extensive and the cost of not delivering support to young people impacts on the State, when crisis management is required to remediate. Ultimately decisions will be made, tracking the end destinations of young people was reported as difficult (Caton and Kagan, 2006) due to young people disengaging and disappearing from view. No measures to monitor endpoints (Commission for Social Care Inspection, 2007) were present, therefore ascertaining whether a decision made leads to a successful transition.

3.4 MAIN FINDINGS: PHASE 2 (TRANSITION PROTOCOLS AND PATHWAYS)

3.4.1 The 26 Transition Protocols/Pathways

A selection of 26 protocols/pathways (Part 1) established the overarching high level content and internal interventions to provide the context to review a smaller focused sample (Part 2), which are reported in this main section. A bespoke tool (Appendix Four) was developed based upon the TransMap (2009) principles of effective transition processes outlined in footnote 5 (p.42) and compromised of 18 criteria, identified through the initial reading, to appraise the local, regional, condition specific and national protocol/pathway examples.

The scoping of the 26 protocols/pathways suggested that they were seen as the main means for organisations to set out their strategic and operational tasks. All follow a similar blueprint, whether a local authority partnership or a national development example. The centre of attention is on the legislative parameters (C13). Most examples, the statutory requirements, shape the structure and the content (19:26), of which 5 made little reference to key legislation, which required observance. The first criterion (C1) aimed to identify that a protocol/pathway was developed by a multi-agency partnership.

Thirteen of the protocols purported to be multi-agency, with a further 9 partly fulfilling the requirement, but the detail of which agencies were involved; their commitment, engagement and responsibilities and to what level was inexact or variable. 2 protocols from their opening premise seemed to set out to be multi-agency, but were more multi-disciplinary within a single organisation and were predominately health-related, despite promoting a holistic pattern of practice. The intent of most of the protocols/pathways were to ensure that *'the needs of disabled young people becoming adults are effectively addressed across boundaries between services in a seamless manner by an agreed multi-agency transition protocol'* (TP01), with a focus on early intervention, integrated working and smarter commissioning. A preventative and protective function of a protocol/pathway was less prominent.

An internal intervention primarily employed, within a protocol, was the inclusion of a diagrammatic pathway setting out when a certain action is required and by whom this action should be undertaken, and occasionally an example of Transition Plan template. The pathways were based upon the requirements of education to meet their obligations to hold an annual review and commence transition planning. All structurally follow the standard staged process based upon age or school year, setting out the process in most cases from the age of 14; focusing largely on one key step, that being the move from school into further education. The role of other organisations appeared unclear, supporting the findings reported earlier in this chapter.

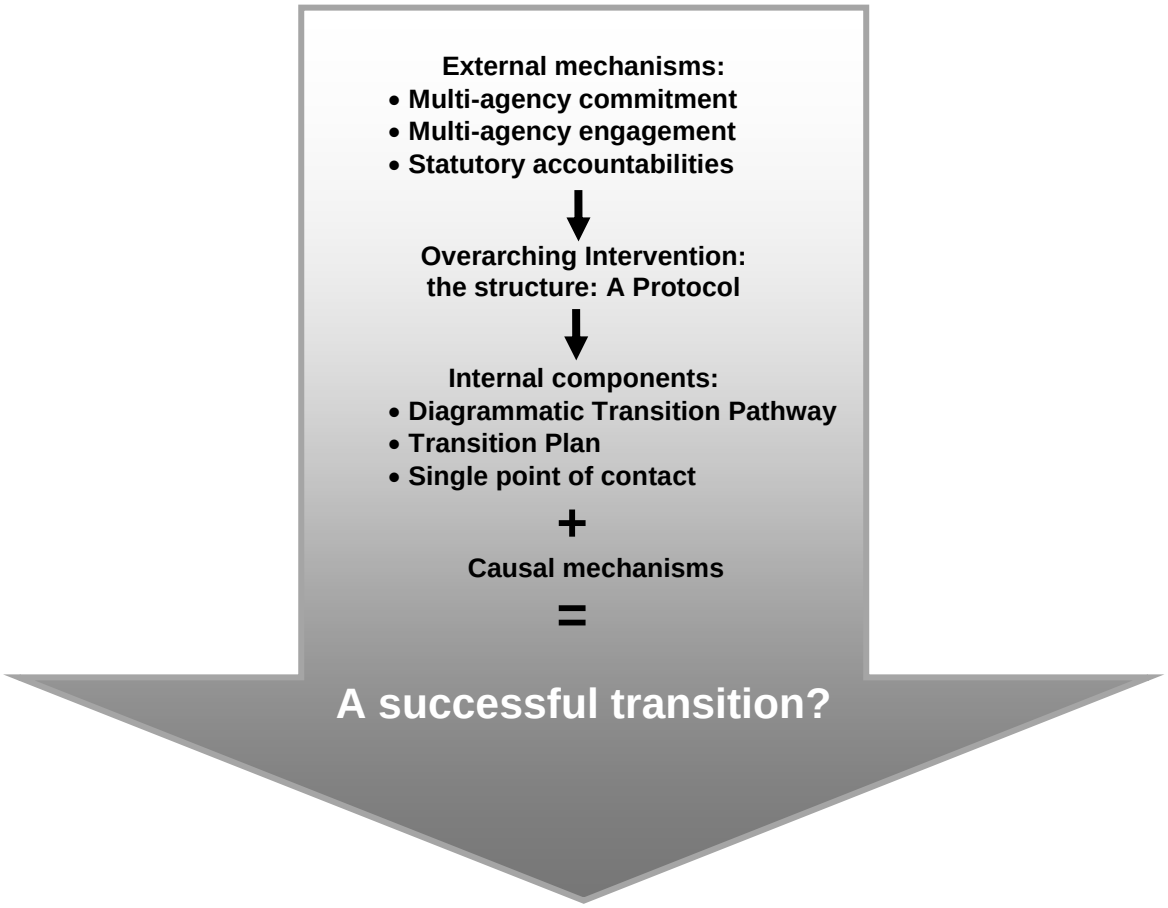
Overall, many protocols/pathways were unable to fully define who the protocol/pathway was for or identify a single point of contact. The 26 protocols largely set out the principles of transition planning. Nonetheless, 38% of the protocols did not set out or only partially made reference to what constitutes good planning. Those protocols/pathways which did not fully explore good planning processes also gave limited information about what would be expected of practitioners to support a young people to develop their transition plan. Interestingly, although a person-centred approach was advocated within policy, only 19% of the protocols/pathways made reference to person-centredness; one making an attempt to communicate the process of

person-centred thinking[13] and the tools those working with young people might use to gather information. Furthermore, 42% of the protocols/pathways did not outline how decisions were made about what support and services young people required or how young people are supported to make choices.

The overriding premise of most of the protocols/pathways was the need to promote a *'smooth and effective transition for disabled young people'* and *'jointly implemented across agencies collaboratively to bring together the responsibilities of key agencies'* (TP14). Only one protocol clearly stated that a pathway within a protocol should initiate change *'in order to improve life chance outcomes'* (TP07). Eleven of the 26 protocols did not set out how they monitored, reviewed or evaluated the successes or not of a protocol/pathway or state what were the intended outcomes for young people. High level outcomes were predominant. There appeared to be some confusion within protocols/pathways as to what the actual outcomes were, what they meant; the mechanisms to achieve an outcome(s). However, the external mechanisms to trigger protocol/pathway development were present and internal components emerged (Figure 10) as contributing factors.

[13] A set of values, skills and tools which can be used, for example, by those supporting people in a social care, education or health setting. www.helensandersonassociates.co.uk

Figure 10. External mechanisms and internal components of a protocol/pathway



3.4.2 <u>The 11 Transition Protocols/Pathways: the focused review</u>

A further specific tool (Appendix Five) was developed to appraise the 11 protocol/pathways and focused on their relevance to the theory areas. The tool was useful in identifying a sixth theory area which is reported at the end of this section.

3.4.2.1 Key Finding 1: It is the intention of a protocol/pathway to achieve continuity from children to adult services (Theory Areas 1 and 4)

Continuity is expressed in protocols/pathways as delivering services in a seamless manner, across boundaries, with a single point of contact as the active intercession; providing the supportive components to foster a continuum into adulthood. Yet, the responsibility of supporting young people to plan is variously described; only one giving a role descriptor. Where the presence of a key worker appeared they were seen to

enhance the transition process; acting as the conduit for sharing, communicating and co-ordinating across the professional input from partner agencies; highlighted as key mechanisms. Pinpointing, with any depth, as to how young people and their parents should be supported was not widely detailed. The literature suggests that a key worker is essential when using protocol/pathway, but many young people lacked a key worker to provide continuity between child and adult services.

3.4.2.2 Key Finding 2: There is variability in person-centredness practice (Theory Area 3)

The similarities, in terms of context, were based upon the need to improve the process by involving young people and parents. Centring the young person at the heart of their own transition was less apparent in emphasis. Taking a person-centred approach (TP05, TP06, TP07), to a lesser extent 5 other examples (TP01, TP02, TP04, TP09,TP10) appeared to be the notable distinction between the 11 protocols, although no example fully set out how a person-centred approach would be implemented. Examples where more detail was included highlight the value of person-centred planning in supporting decision-making and promoting independence and were threaded throughout two examples (TP05 and TP07). TP07 and TP10 explored person-centred planning, but not the detail as to what person-centred tools were useful and when. TP10 pathway approach acknowledged that person-centred transition planning when widely employed is recognised as being an important aspect of good practice in transition. TP05 does acknowledge the importance to taking a person-centred approach, but is not followed through in terms of mapping through the pathway.

In terms of person-centred support and interaction young people and their parents were articulated as one homogenous entity, rather than seeing the young person and their parents requiring their own person-centred support and engagement; that it might be different in managing the changes in their lives. Further to this a personalised approach (TP07) for each young person, focusing on at what is important to move them forward was promoted, but was less evident as to how this might be achieved in the protocol/pathway examples.

3.4.2.3 Key Finding 3: A hierarchy of decision-making exists (Theory Area 3)

Contextually, decision-making happens at various levels and at different times beginning with agreeing the implementation of a protocol/pathway and subsequently the monitoring and reviewing its execution, usually by a multi-agency Transition Group/Board (TP01, TP04 and TP06). A Transition Group/Board was likely to oversee the policy and procedural development at a local level to ensure that transition planning and assessment takes place and consequently the commissioning of suitable services is undertaken. There was an emphasis on acting as early as possible to ensure that decisions about future support provision into adulthood were timely. However, access to support a decision needed to be made about who is eligible and from commencement of the process access to provision is noted in a number of protocols. Identifying and gaining entrance usually via a Transition Panel or Transition Planning Group (TP02, TP05) appeared to be the norm. A number of the protocols/pathways identified that decision-making needed to be wide-ranging and responsive; letting young people and parents know how to expedite a smooth transfer to adult provision and what individual decisions needed to be made. This was essentially omitted on how young people were encouraged to make their own decisions.

3.4.2.4 Key Finding 4: Planning well, in detail with young people and their parents, is absent from protocols/pathways (Theory Areas 2 and 5)

How to plan in detail, based upon an individual's needs, was mostly missing in protocols/pathways. The planning process is expressed as being personalised and visible, with those working with young people; listening and responding to them to stimulate further discussion about the future, yet how that materialises for young people is less evident. Variability exists, as Sloper *et al*. (2010) identified in the structure of pathways and for whom they are intended; therefore not all young people would be eligible and planning well less likely. For those young people, typically identified as those with Asperger's Syndrome, would be unlikely to receive support to plan their transition with limit entitlement due to an assessment based upon their IQ as the benchmark. Similarly, where eligible, there was no guarantee that services will be provided. Therefore, planning in detail is likely to support active decision-making to achieve entitlement based upon the identifiable individual need and a successful

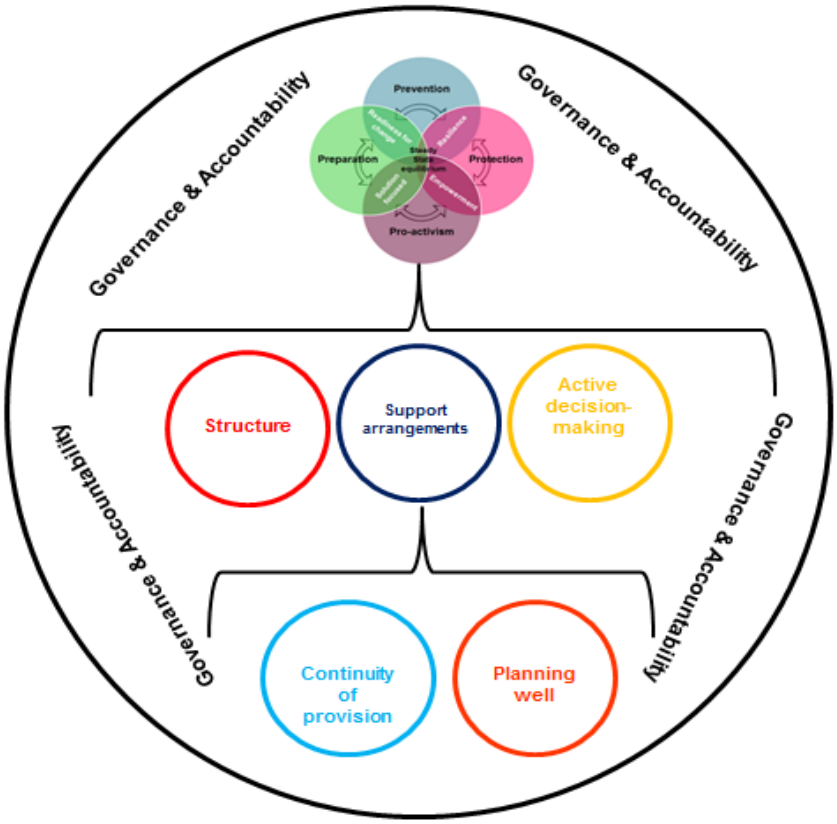
transition. However, defining who as eligible was also somewhat indistinct and inconsistent due to local interpretation and variation of acceptance and recognition. Planning well and preparing young people; how to support them was not fully explored or present across the 11 examples. Governance and accountability arrangements to formalise planning processes were indistinct and largely education-focused.

3.4.2.5 Further Theory Development

During the latter stage of the review having good governance and an accountability trail was identified as an important consideration to ensure that the transition process is managed effectively and a crucial mid-range theory area which could be explored across the protocol/pathway examples.

Theory Area 6: The transition process requires governance and an accountability trail.

Figure 11. Theory Development 3



3.4.2.6 Key Finding 5: Transition processes requires governance and an accountability trail (linked to Theory Area 1)

It was established during the first phase of the Review that a range of legislation and policy, directly or indirectly sets the context and direction of the transition process; providing functional information to support the development of protocols/pathways. It was the intention of protocols/pathways to provide a good governance framework for the process, setting out responsibility chains across organisations to influence what happens for young people. An accountability trail is less evident. Transition Panels/Meetings where operating as the identifiers of eligible young people to ascertain the levels of support required, but not all protocols/pathways set out how decisions would be reached about what types of support and services would be available to a range of young people.

3.5 SYNTHESIS ACROSS THE TWO REVIEW PHASES

The mid-range theory areas identified during the workshop, built upon during the first and second phases, can be observed across the evidence and within a context, mechanism and outcome (CMO) configuration (Table 6). The importance of the mechanisms were somewhat concealed within the vernacular of a protocol/pathway; the protocol/pathway itself seeming to take precedence over the practicalities of setting out how to plan with young people using a person-centred approach. However, repeated patterns appeared across the evidence, 'stitched together' to form familial enclaves across the mid-range theory areas. Collectively, as causal mechanisms emerged, they appeared preventative as a product and the means to protect; preparing young people for change; key components of the candidate programme theory. Nonetheless, the internal mechanisms within protocols/pathways were not joined up in an integrated manner, were sporadically present and unrecognised as to their facilitative influences; mere statements in the narrative, but would by their presence be likely to have created opportunities to achieve good transitional outcomes for young people. The final section of findings is outlined under the six theory areas.

Table 6 Representation of the CMO configuration

OVERAL CONTEXT: a process with multiple individuals and organisations involved happens over a numbers of years		MID RANGE THEORY AREAS	CONTEXT	MECHANISMS	INTENDED/UNINTENTED OUTCOMES	SUCCESSFUL TRANSITION? A SEVICE OUTCOME
	THE INTERVENTION: Protocol/Pathway	**1. HAVING A STRUCTURE**	• Plethora of legislation and policy • Complex construct across education, health & social care • Described as linear • Depicted as unpredictable • Varied interpretation and application • Promotes continuousness across child and adult services	🡻 Multi-agency commitment and engagement 🡻 Discharging statutory accountabilities 🡻 Co-operation 🡻 Understanding of the process 🡻 Rationalisation 🡻 Activating the process	• Boundary issues addressed • Seamless provision in place • Process understood by all **But** • Emphasis on one transition point • Rarely linear • Divide between child and adult services	
	OVERARCHING MECHANISMS ACROSS TEE MID-REANGE THEORY AREAS	**2. CONTINUITY OF PROVISION**	• Intention to move from children to adult services • Varying eligibility criteria • Numerous exit points	🡻 Continuous delivery 🡻 Co-ordinated response by working together 🡻 Sharing 🡻 Communicating	• Stability through the process • Co-ordinated response centred on the young person **But** • Divide between children & adult services: differing eligibility	
		3. SUPPORT ARRANGEMENTS (activated by a Key Worker)	• Single point of contact variously represented • Co-ordination of professionals involved	🡻 Engaging young people and their parents 🡻 Planning together 🡻 Personalised 🡻 Receptive atmosphere	• Relationships built, able to consider the future • All involved understand the needs and wishes of the young person **But** • Lack of presence of a key worker	
		4. ACTIVE DECISION-MAKING	• Hierarchy of decision-making • Lack of separation between young person and parent • Regulated at 16 by the Mental Capacity Act	🡻 Options presented 🡻 Planning well 🡻 Responding to needs & wishes 🡻 Pre-emptive action	• Young people involved in making their own decisions • Young people at the centre of their own transition **But** • Lack of detail of how decisions are made: made by parents	
		5. PLANNING WELL (activated by a person-centred Transition Plan)	• Differing expectations • Varying roles and responsibilities • Proactive support	🡻 Person-centred approach 🡻 Preparing young people and parents for change	• Young people prepared for the future **But** • The how to plan in detail is missing • Lack of evidence of use of person-centred approaches within protocols/pathways	
		6. GOVERNANCE AND ACCOUNTABILITY	• Plethora of legislation and policy • Not clarified process or reduced complexity • New legislation emerging changing the context	🡻 Influence 🡻 Responsibility 🡻 Authority to act 🡻 Transparency 🡻 Probity	• A transparent process for all involved • Understanding who is responsible for ensuring young people transit smoothly into early adult life	

3.5.1 Theory Area 1: Having a structure provides the basis to ensure good transitions for young people.

The transition process, described as a complex construct may be better understood and conceptualised through a framework which draws together the widely recognised constituent parts of a young person's transitional journey into adulthood. A protocol/pathway was considered to be the central intermediation (NSF, 2006, 2007; DSCF, 2007; DOH, 2008; Kaehne, 2010) to encourage multi-agency commitment and engagement. A protocol/pathway, developed with the mutual co-operation and a shared vision across agencies (Everitt, 2007), was seen as the ideal; removing barriers between organisations (Forbes *et al*., 2002; Sloper *et al*., 2010; DSCF, 2007; DOH, 2008), but this was contingent on being translated into practice. There was the expectation that a protocol/pathway was accessible to all; providing the basis to achieve a successful transitional experience for young people.

The structure of the process is envisioned linearly. Protocols/pathways present it as such, but the process is seldom a straightforward experience and unlikely due to the varied interpretations and application (Mitchell, 1999). A pathway depicted visually contributed to conveying the complexities of the process rather than making it easier to understand. Young people experience an undulating transition experience moving up, down and sideways towards adulthood, which is contrary to the intention. Structurally, the concentration is on one transition point; from school to college (COP, 2002), with passing reference to moving from the family home into supported living.

The unpredictable reality of transition planning, cited by the workshop participants and reflected within the broader literature, such as differing eligibility criteria, made it difficult to overcome some of the bureaucratically originated difficulties emergent during the 'in between' phase from children's to adult's services such as the age a young person is likely to transfer to an adult provision. Whilst it was the intention of a protocol/pathway to bridge this service divide, marked differences between the way children and adults services are configured were reported by young people, their parents and practitioners (Hirst and Baldwin, 1994; Forbes *et al*., 2002; Beresford, 2004; Sloper *et al*., 2010) creating a chasm, one which had not been entirely closed by the presence of a protocol/pathway.

3.5.2 Theory area 2: Proactive support arrangements foster early planning with young people.

Across the key working related literature, a single point of contact, as an active personalised intervention was highlighted as important; providing the supportive activities of the process to nurture timely planning and the likely activators of the mechanisms. The role was variously described, more commonly the term key worker was cited, but many young people had no access to a key worker (Liabo *et al*., 2001; Greco *et al*., 2005, Sloper *et al*., 2010). Parents, in the absence of a practitioner or a trusting relationship (Dee, 2006) relied on informal support networks (Beresford *et al*., 2013) to support early planning in transition. Young people and parents were often seen as one unit and supported as such, rather than their individual needs and support requirements being accounted for and responded to on a personalised basis. Reference within policy to the provision of a contact person is acknowledged. Yet, whilst the current policy direction (DOH/DOE, 2013; Welsh Government, 2014; DOH/DOE, 2015) makes reference to accessing key worker support, no statutory duty is specified to direct such expectation of multi-agency partners.

3.5.3 Theory Area 3: Active decision-making is a critical aspect to enable young people be control of the choices they make

Decision-making processes are complex with multiple decision-makers involved following their own organisational protocol/pathway to assess the level(s) of support required for young people and provide such support accordingly. Whilst young people are preparing and making decisions to secure their own place in the community as a contributing adult they have the same expectations as other young people (Ward *et al*., 2003; DOH, 2011). However, unlike their non-disabled peers are 'assessed' in order to determine their capacity to be able to attain this perfectly natural ambition. They are not solely in control of decisions made albeit about their own lives. These are the privilege of a Transition Panel; the challenge is that such a panel, well intentioned as it may be, may not know the young person concerned as an individual.

Planning for change needs to happen directly with young people. Maintaining steady progression, individually commensurate, to ensure that they have time to express their wishes and thoughts about the future was less obvious in protocols/pathways. For young

people, preparation is key and the need to plan (Dee, 2006) a requisite. The complexities of multi-agency input, together with the levels of need, planning well using a person-centred approach was seen as necessary to be able to have *'meaningful discussions'* (Carnaby *et al*., 2003, p.187)) as they plan their future. Dee (2006) concluded that taking a person-centred approach to planning should be *'based on the premise that the outcomes of the process is the life that the person wants'* (p.24). Therefore, capturing young people's wishes in a person-centred way promotes person-centred decision-making. Those working with young people need to deeply root their ideology in positioning the young person at the heart of the transition process (DCSF, 2007); that they are in control of the choices and decisions they make. However, how decisions are arrived at was not clearly represented within protocols/pathways.

3.5.4 Theory Area 4: Continuity of provision is the intention of the transition process.

The Children Act (2004) and recent legislative instruction (Care Act, 2014; Social Services and Well-being (Wales) Act. 2014; DOH/DOE, 2015) places a responsibility on organisations to co-operate and make transitional arrangements for young people between child and adult services. Continuity is expressed in protocols/pathways as delivering services in a seamless manner, across boundaries, correspondingly described in policy (NSF, 2004 [England], 2005 [Wales]; DCSF, 2007; DOH, 2008). Workshop participants highlighted that within a recognised transitional structure continuity of provision was more likely where there was multi-agency commitment and partnership working. However, protocols/pathways were varied in their intentions, with some commonalties outlining the steps to achieve continuity into adulthood; their resolve was to create a smooth transition from children to adult service providers, but the focus was from an educational perspective, rather than a young person's holistic transition across a *'wide range of domains'* (O'Brien, 2007, p.195). Abbott and Heslop (2008) suggested that *'transition is not a singular static experience'* (p.53), therefore continuity across all aspects of a young person's life was considered a critical factor. Young people valued this (DOH, 2008), lessening the impact of change and minimising the adjustments they need to assimilate as they approach early adulthood.

3.5.5 Theory Area 5: Planning well is crucial to achieve successful transitions into adulthood.

There were few instances where *'a stage not an age'* (TP10) related process was argued as an alternative. Setting specific age or time limits can be unhelpful and not person-centred to the individual. Establishing an understandable process was the objective of policy (Education, Lifelong Learning and Skills Committee (ELLS), Welsh Assembly Government, 2007, Equality of Opportunities Committee (EOC), Welsh Assembly Government, 2007, DOH, 2008; DOC/DOH, 2015); planning well a key factor. Yet, protocols/pathways set the timeline, which did not reflect cognitive age, therefore, were not walking at a pace to suit young people individually to plan in a judicious manner. There were a small number of Transition Plans templates within protocols/pathways, which were basic information depositories; lacking the opportunity to develop detail. There was perfunctory mention of using a person-centred approach in protocols/pathways. However, practitioners may well be using person-centred thinking tools to work with young people to gather what is important to and how best to support them, but is not apparent in the evidence. Most of the protocols/pathways did not fully centre the young person at the heart of the process, despite textual protestations. The young person is lost amongst the main properties of a protocol/pathway; planning thoroughly was more of an aspiration with protocols/pathway rather than an overall directive set out for organisations to adhere to.

3.5.6 Theory Area 6: The transition process requires governance and an accountability trail.

The difficulties with transition processes have been widely reported (Mitchell, 1999; Morris, 1999 and 2002; Dee *et al*., 2002; Beresford, 2004; Commission for Social Care Inspection, 2007) and consulted upon over many years. The untimeliness of the process, together with the variances in the age of transfer has contributed to the transition process being described as complex (Beresford, 2004; Everitt, 2007; Dee, 2006). Young people, their parents and those supporting them require a process that is transparent so they are able to understand who is responsible for setting the process in action to ensure that young people transit smoothly into early adult life. Yet, the probity of the process

remains obscured by a lack of how a structural intervention should be sustained and how ownership is stimulated within policy.

Differing expectations, inadequate interagency working, lack of opportunities and specific adults services, which replicate those received in childhood have been described (Hirst and Baldwin, 1994; Fiorentino *et al*., 1998; Morris, 1999, Heslop *et al*., 2002; Abbott and Heslop, 2008; Abbott and Heslop, 2009; Dee, 2009; Sloper *et al*., 2010), which appear not to be succinctly addressed by the presence of a structure to actuate and understand the process. The stories of challenge, frustration and concerns remained unchanged (Hirst and Baldwin, 1994; Morris, 1999, 2002; Beresford, 2004, Forbes *et al*., 2004; Sloper *et al*, 2010; Beresford *et al*., 2013). Governance and accountability arrangements need to be clear and upheld to ensure that young people achieve good outcomes into early adulthood.

3.6 CONCLUSION

The two-phased approach identified the importance of structuring the transition process; developing a framework through into early adulthood. This review highlighted that, although a structure existed, presented in the form of a protocol/pathway, such documentation does not appear to make the transition process for young people, their parents and those supporting them, including key workers, less complex or create the opportunities to achieve features of what constituted a good transition. A protocol/pathway is a multifaceted programme intervention, with internal interventions, such as a key worker, acting as the agents operationalising the transition process. A protocol appears to contribute to the complexities rather than simplify it, with the continuity between child and adult services remaining a pinch point.

Recognising the challenge; the need to improve the transition into adulthood process is well documented. Young people and their parents have, are currently and will experience further contextual change as new legislation is enacted and implemented locally. In Wales and England, replacing the Statement of SEN with a single multi-agency plan, as well as considering how social care will be delivered in the future is potentially unsettling for young people and their parents creating the potential for further testing times. Nonetheless, it is also an opportunity to focus the spotlight on the use and content of protocols/pathways to improve and firmly establish the key

mechanisms of transitional services; directing commissioners and practitioners. It was surprising that consideration was not given within current protocols/pathways as to ways to guide practitioners on how to plan well with young people and their parents; the key mechanism and giving them workable documentation to do so. Crucial to a successful transition is addressing the missing element of 'the how' in realist methodological thinking; tailoring transition to the individual.

The 4 P's conceptual framework explains, in part, the constituent parts of the transition process in terms of preventing young people being bounced from one person to another by having a proactive point of contact to protect them through the process and be able to holistically prepare for the future. However, the focus was frequently not solely on the young person as the intended receiver of transitional support. More commonly, young people and parents are seen as one, rather than separating out their individual support needs. The transition process epitomises the tendency for establishing complex social, or in this case, a multi-agency programmes for people who require an understandable process, which alleviates rather than compounds psychological distress. Presently transitional care arrangements can be far too bureaucratically layered, geographically variable and financially driven. For young people and parents, their main interests were in accessing the support of a single point of contact (a key worker) and services, with the *'need to able to enjoy adolescence and not worry about the future'* (Rees, 2011, p.5). Not all young people had access to a key worker or a person designated as the single point of contact to other services. The findings from the Review highlighted that multiple stakeholders need to develop a simplified transition process, that it should not be seen as linear, but serpentine and acknowledged as such.

The next chapter outlines the rationale of using a thematic analytical framework to identify, analyse and report patterns or themes within interviews across the four groups of participant stakeholders.

CHAPTER FOUR: TRANSITION KEY WORKER STAKEHOLDER EVALUATION METHODOLOGY

4. INTRODUCTION

This chapter outlines the methodological approach to collecting and analysing 61 semi-structured interviews from multiple stakeholder perspectives. I drew upon the key principles of Realist methodology I used to review the literature in Chapter Three; that of establishing the context, identifying causal mechanisms and outcomes (Pawson and Tilley, 1997) and established a thematic analysis framework to identify reoccurring themes (patterns) and the meaning across the datasets of four participant stakeholder groups (young people, parents, Transition Key Workers and Site Leads) to:

- Answer the overarching research question ***'What makes a successful transition for disabled young people?'*** and,

- to continue to test out the candidate programme theory (conceptual framework) and mid-range theory areas. The next section will set out the aim and objectives and rationale for adopting a thematic analysis approach to analyse the stakeholder interviews.

4.1 AIMS AND OBJECTIVES

The primary objective of the stakeholder evaluation was to explore the experiences of young people, parents, Transition Key Workers and Site Leads of the transition process and the key worker model through transition into adulthood. The aim, set in Chapter One, was to understand and draw upon the experiences of young people, their parents and those working and what they considered to be the key elements of achieving a successful transition into adulthood. Furthermore, the aim was to explore the role of the Transition Key Worker as the main intervention to determine what works for whom, how it works and in what particular circumstances related to the process of transition

into adulthood to establish the context, the mechanisms and anticipated outcomes (Pawson and Tilley, 1997). I reflect on my personal and professional experiences in the context of the stakeholder evaluation. Consequently, reflection played an important role throughout this thesis.

4.2 ADOPTING A THEMATIC ANALYSIS APPROACH

Through discussions with my supervisors, and in consultation with Dr Gemma Griffith (Bangor University) experienced in use of thematic qualitative data analysis I adopted a thematic analysis approach to analyse the semi-structured interview transcripts. The flexibility of this approach to evaluating qualitative data so as to identify and report recurrent and important themes was a crucial consideration. This analytic approach facilitated the recognition of the patterns within individual data sets and data corpus across stakeholder participant interview transcripts and provided a framework for describing the experience of negotiating services during the transition into adulthood; a social phenomenon of considerable complexity. In adopting a thematic analysis framework the opportunity was afforded to delve ontologically into the lives, experiences, relationships and behaviours of those involved in the transition process and to do so within the social model of disability and resonated with a realist approach that *'interventions are always embedded in a range of attitudinal, individual, intuitional, and social processes, and thus program outcomes are generated by a range of macro and micro social forces'* (Pawson and Tilley, 1997, p216). The use of thematic analysis enabled me to develop the *'ability to see'* (Boyatzis, 1998, p.7) patterns in the data and explore underneath the surface and subsequent layers of the observed data. I considered that thematic analysis could be applied within a realist construct and, therefore, was a well-matched process to describe patterns found in the data corpus. I was eager that the research design for the evaluation continued the theory-driven flexible realistic approach I employed for the Review; searching for the demi-regularities (patterns in the data) to understand the CMO configuration(s) of the transition process.

Thematic Analysis, whilst previously argued, unlike grounded theory, that there was no clear agreement on how to conduct this from of analysis (Braun and Clarke, 2006). The methodology had previously been criticised for its lack of depth in interrogating the data but, nonetheless, become an extensively adopted method to appraise primary qualitative data such as from interviews (Attride-Sterling, 2001). Braun and Clarke

(2006) argued that *'thematic analysis should be considered a method in its own right'* (p.4) rather than being located with other analytic forms such as grounded theory. However, Attride-Sterling (2001) ascribed that *'the value of qualitative research lies in its exploratory and explanatory power, prospects that are unachievable without methodological rigour at all stages of the research process'* (p.403). Therefore, Braun and Clarke (2006), in the footsteps of Ritchie and Spencer (1994) and Attride-Sterling (2001) provided clarity and a valid six-phased 15 point checklist (Table 7, p.94) for thematic analysis which was the adopted framework for this evaluation; a framework which ensured and demonstrated both rigour and transparency throughout the thematic analysis process. In order to ensure that there was internal quality assurance I maintained a reflective journal and kept detailed supervision notes to document decision-making trails, the interpreting of the data and noted my personal responses to each interview I undertook (Reynolds *et al*., 2011).

Semi-structured interviews are likely to produce wide-ranging and complex quantities of data. Therefore, using a thematic approach, the aim was to encapsulate and summarise the meaning within a potentially significant dataset by robust coding (Boyatzis, 1998), by assigning a word or passage of text, which represented a segment of data. Thematic Analysis can be inductive; that themes have a relationship with the dataset, as assumptions are driven by the data rather than within an existing framework or a deductive theoretically driven means to analyse data. I took an inductive approach, incorporating inductive thinking and data processing from familiarisation with the data, the initial coding through to the collapsing of a manageable set of themes across each stakeholder group.

4. 3 PHASES OF THEMATIC ANALYSIS (TABLE 7)

The six phases of good thematic analysis involved developing techniques to sense or discover themes and doing it reliably and developing the codes by building a hierarchy of themes following Boyatiz (1998) and Ryan and Bernard (2003) in constructing the coding framework outlined under point 4.3.2. I interpreted the information and themes within the context of the 4 P's (the initial conceptual model) and the mid-range theory areas. This next section sets out the phases promoted by Clarke and Braun (2006).

4.3.1 Familiarisation with the data: Transcription (Phase 1)

All semi-structured interviews were voice recorded with the agreement and informed consent of participants. The recordings were transcribed verbatim; exceptions were made in cases of repeated use of linguistic fillers such as 'ums', 'you know' or 'aha', other than in those cases where these contextualised the point being made. Likewise, non-verbal exclamations or silences were be noted where appropriate and in context, including interruptions during interview. Initial patterns in the data were noted in a reflective journal. Journals were kept throughout the process. The transcribed interviews were re-read alongside the audio recording to ensure accuracy. Line-by-line familiarisation and coding was the prescient aspect of the first phase.

Table 7 15-Point Checklist of Criteria for Good Thematic Analysis

PHASES		THE PROCESS
1.	**Familiarisation: getting to know the data, incorporating inductive thinking**	1.Data transcribed to an appropriate level of detail and checked for accuracy from the audio recording • Reading/re-reading transcripts • Early identification of areas of interest or preliminary codes: developing a 'codebook' within a reflective journal
2.	**Generating the initial codes**	• Coding initial areas interest across the 4 participant groups data • Reflect on the conceptual model and the mid-range theory areas to inform the development of the coding framework • Develop coding framework (hand approach): individual data coding tool for the participant groups • Collate data relevant to each code identified
3.	**Searching for the themes**	Per participant group: • Gather codes into themes • Gathering data to each theme represented • Generate master tool per participant group
4.	**Reviewing and refining the themes**	• Generate thematic maps across the 4 participant groups
5.	**Theme reduction: defining and naming themes**	• Collapse themes into high level themes, define and name across the 4 participant data sets and report per chapter • Test out the candidate programme theory and mid-range theory areas identified through the Realist Review
6.	**Reporting**	• Final analysis and checkpoint prior to reporting • Report finding across the 4 participant groups semi-structured interviews • Synthesise across stakeholder groups

(after Braun and Clarke, 2006)

4.3.2 Generating the initial the codes (Phase 2)

Phase 2 commenced with identifying codes per participant group; going through the process one group at a time, by hand, rather than using a software programme such as

Atlas ti. A crucial element of this phase was to reflect the conceptual model, the theory development and the mid-range theory areas to inform the development of the coding framework to capture an interpretation of the phenomenon (Boyatiz, 1998, vii) of the transition process. As an early researcher, developing a coding framework, systematically analysing interview transcripts maintained familiarisation with data and crucially enabled fluent sensing of emergent and recurrent themes. The data was returned to in what might be describe as a cyclical fashion to ensure that as many codes as feasible were collated from the data corpus. Each transcript was coded and then represented within an individual coding framework tool (Table 8) to ensure internal validity by applying the appropriate word(s) or segments of text to particular and easily traceable codes.

Table 8 Example of the coding framework (parent example)

Code (theme) & sub codes	ID/page/ line no.	Quote demonstrating code (theme)
Managing change: • worried about the future beyond caring	P14/5:174-175	I've been out of employment all those years. Now X is 20 what support is there out there for parents like me? There is going to be a significant change in my circumstances, both financially and emotionally. That is what I'm worried about.
Continuity of provision: • change of staff	P14/5:159-161	The one thing that has been quite difficult though is the difficulty is with staff changing. It's really disruptive for him.

4.3.3 Searching for themes (Phase 3)

The third phase focused on extracting the *'candidate themes'* (Braun and Clarke, 2006) across the four stakeholder groups and master tool per participant group was developed under the same headings outlined in Table 8 above.

3.3.4 Reviewing and refining themes (Phase 4)

Phase 4 offered the opportunity to review and refine the themes across the datasets to begin to proffer a comprehensible credible account. Initial wide-ranging thematic maps were developed to ensure that the identified themes are fittingly represented across the body of participant data (Appendices Twenty-Six to Twenty-Nine).

4.3.5 Theme reduction (Phase 5)

This phase was crucial and focused on defining, naming and collapsing into high level themes across the participant stakeholder datasets which aided reporting in a succinct and concentrated manner.

4.3.6 Reporting (Phase 6)

The sixth and final phase was checkpoint and provided opportunity to re-check the data corpus to ensure that within the reporting there was accurate representation. The findings of the participant stakeholder groups are reported in separate chapters followed by a synthesis across the entire data corpus.

4.4 USE OF REFLECTION AND REFLEXIVITY

Reflection played an important role; taking account of the multiple perspectives I was able to draw upon outlined in the introductory chapter. Maintaining a reflective journal was crucial, not only to note codes, but also to capture an account of my thoughts, ideas and post interview reactions to ensure that my role as a researcher was both active and considered, rather than provide a impassive account. Capturing my thoughts and ideas; the *'conceptual baggage'* (p.) coined by Kirby and McKenna (1989), both the *'intellectual thinking and emotional comments……being cognisant of the relationship between the thinking and the emotional part'* (p.50-52) provided an instinctive, prior knowledge and unique dimensional blend. Reporting and acknowledging my personal experiences aimed to avoid bias and making assumptions.

As a frequent presenter over many years, both as a parent and professional sharing my experiences, my personal circumstances may well be known to participants, particularly the Transition Key Workers and Site Leads. However, parent and young people, through contact with the sites, may have been involved in consultation and evaluation days I organised in my former role as Director of CCN Cymru. It was important, as the researcher, to minimise discussion related to my multiple roles, but also for me to be aware of my potential reaction to a participants personal experiences.

THE SEMI-STRUCTURED INTERVIEWS

4.5.1 The Sites

Table 9 sets out the sites to which the pool of participants were drawn. It was not expected that there would be full coverage across the 22 local authorities areas in Wales, but that participants from across at least two non-funded sites would be asked to take part. Participants were drawn from 12 funded sites (15 local authority areas) and from two non-funded sites.

Table 9 Transition Key Worker Sites (including non-funded sites)[14]

Welsh Assembly Government funded sites (3 year funding ending 31/03/11)	ESF sites funded to 2013 commencing c. September 2010	Non funded local authority areas
Anglesey*	Bridgend	Cardiff
Ceredigion*	Caerphilly	Flintshire
Gwynedd*	Carmarthenshire	Newport
Monmouthshire	Conwy	Powys
Pembrokeshire*	Denbighshire	Vale of Glamorgan
	Torfaen	Wrexham
	Neath Port Talbot	
	Rhondda Cynon Taff	
	Swansea	
	Blaenau Gwent	
	Merthyr Tydfil	

Key:

- Designated Transition Key Worker provision
- Non Designated Transition Key Worker provision
- Mixed designated and non-designated
- Some activity but not formalised

*Continuation through ESF funding

[14] The names of the sites were in the public domain and were the non-funded counties and all Site Leads interviewed gave consent.

4.5.2 Semi-Structured Interview Schedules

Four semi-structured interview schedules were developed (young person, parent, Transition Key Worker and Site Leads). The content of the schedules were determined from the findings of the Review. The young person's interview schedule (Appendix Nine) covers 5 topic areas. The schedule, under 5 sections sought their experiences in preparing for entering adult life, their involvement and participation in transition planning, the role of the Transition Key Worker and the future thinking. The parent interview schedule (Appendix Ten), with 5 sections, corresponded to the young person's schedule, seeking their experience in preparing their child for adult life, and their involvement and participation in transition planning. The Transition Key Worker schedule (Appendix Eleven) covered 7 sections and sought to discuss the following key areas across the 7 respective sections:

1. General matters (e.g. the length of time they have been supporting a young person to and their conceptual understanding of key working).
2. Recruitment
3. Interview process
4. Training and supervision
5. Their involvement in the transition planning processes
6. Their role
7. Working with others
8. Their own well-being as well as some questions around considerations for the future.

An interview schedule (Appendix Twelve) was developed to use with Site Leads and mirrored the Transition Key Worker schedule, but with a focus on developing transition key working/standard transition service and local multi-agency structures.

4.5.2.1 Semi-Structured interview timeframe

The interviews were held within a 12-month specified timeframe from December 2012 until the end of November 2013 taking into account the availability and circumstances of the participant cohort. The interviews, particularly with young people, remained focused and guided by the pre-designed semi structured interview topic guide.

4.5.3 Recruitment of participants

Participants were identified as requiring or receiving the support of a Transition Key Worker. They were identified, having completed a questionnaire (not included in this evaluation) and a consent form which indicated their agreement to be contacted to take part in a research interview. Participants, primarily young people and parents were also identified by Transition Key Workers and invited to take part. Other professionals were invited, where applicable. Table 10 outlines the minimum recruitment per participant group.

4.5.3.1 Inclusion criteria

Young people, both male and female between the ages 14-25 with significant and complex additional learning or medical needs and/or a co-morbidity of conditions were eligible to take part. Parents of those receiving the support of a Transition Key Worker or a named professional providing transition support were also eligible. A young person's participation was not dependent upon parental participation. Likewise, a parental agreement to participate was not dependent upon their son's/daughter's involvement. All Site Leads were asked to ensure that Transition Key Workers were invited and encouraged to take part in the evaluation. Site Leads, as part of their commitment to develop transition key working and non-funded sites, through their contact with CCN Cymru were also invited to take part.

4.5.3.2 Exclusion criteria

Participants were excluded where a consent form was not or only partially completed. A reminder was issued to achieve consent where there was an indication of participation. Young people who were under the age of 13 or over the age of 25 were excluded. A young person who did not have capacity to consent was excluded. Young people under

the age of 16, where the assent of a parent was absent, were also excluded from the evaluation.

Table 10 Recruitment numbers

Participant groups	Minimum Sample Size	No. of interviews
Young people	10	13
Parents	14	26 (n:30 taking part)
Transition Key Workers	12	14
Site Leads	6	7 (n:15 taking part
Total	42	61 (n:72 taking part

4.5.4 Invitation to participate

Participants were contacted to take part by invitation using their preferred method indicated on their consent form (by telephone, email or letter). Where indicated by letter or email, invitation letters (Appendices Thirteen to Sixteen) were distributed to take part. A follow up telephone call was made or email sent to arrange the date, time and place. Participants were informed that they would be able to contact me for further information about the evaluation and the interviews.

4.5.4.1 Information to participants

All participants received information about the purpose of the evaluation. The information identified how participants would be involved, what form it would take and what participants may expect during an interview. All information was provided bilingually to participants (Appendices Seventeen to Twenty). Easy read information was provided to young people.

4.5.4.2 Choice of location of interviews

The interviews took take place in a venue, which was safe and confidential and known to the participants, including the family home or other location as requested such as a school or college. Where appropriate and agreed, a young person could request that a suitable supporter attend the interview, for example, a parent or their Transition Key

Worker, prior to it taking place. As an interviewer, I was mindful of the participant's time and family situation and or commitments on the day of the interview.

4.5.5 Digital voice recording

Interviews were recorded using a digital voice recorder. The recordings were transcribed onto a pre-designed template so as to structure later data coding. Once transcribed and re-checked with the audio file, the recordings were deleted to protect confidentiality, as outlined in participant information sheets and again, this reassurance was re-emphasised upon concluding an interview. It was not anticipated that there would be refusal to be recorded; a condition of the consent process. In the unlikelihood, upon interview, that an interviewee did not want to be recorded, detailed notes would be taken to ensure their experiences were captured and shared at the end of the interview to agree an accurate account.

4.6 THE INTERVIEWS

The interviews were, particularly with young people kept succinct and adapted upon meeting the young person as the interview commenced. It was expected that the interviews would last between 60-90 minutes depending upon participant availability and their responses to questions posed. Interviews with Site Leads included others invited individuals involved in developing transition key working locally, therefore the interviews could last longer. However, it was anticipated that some interviews may conclude earlier or last longer and an allowance was made to account for longer lasting interviews by not scheduling back-to-back interviews, where overrun was likely.

4.6.1 Potential distress to participants

The risk of causing distress to those participating was extremely low. However, it was recognised that participants, particularly young people may have found, given the complex nature of moving into adulthood, that they had endured a particularly difficult experience and as such have found it difficult to express themselves. Likewise, parents may also have had difficult and stressful times leading to an emotive recounting of these experiences. . It was important to provide:

- A safe environment

- Reinforcement of the confidential nature of the evaluation and that anonymity would be preserved.
- A family member could be present not only for the young person, but also for parents, where appropriate and agreed prior to interview.
- A young person may wish the presence of their Transition Key Worker to support them through the interview.
- All participants were made aware that they can withdraw from taking part in the interview at any point.
- A risk assessment of a venue, if required, would be initiated, but it was expected that interviews would take place in the family home (young people and parents) and the office base (Transition Key Workers and Site Leads).

4.6.2 Data storage, confidentiality and data protection

All data collected was anonymised. All participants were assigned an identification code and this was stored securely. Details of age, gender and address were entered onto a database which was protected by a password. Electronic interview transcripts were password protected on a computer. The computer was protected with a password. All paperwork related to those taking part were locked in a filing cabinet. Each Site Lead was issued with an ID code to ensure anonymity. I had sole access to the information collected. All personal data is kept in line with the Data Protection Act 1998 and will be destroyed in accordance, after 5 years of receiving the data. Participants were informed of their right to seek permission to access any record kept in their name under the Freedom of Information Act 2000. Access was not provided to another individual.

4.6.3 How consent was obtained

A participant information booklet (Appendices Seventeen to Twenty) was provided to each participating group. This booklet explained the nature of and how as a participant they will be involved. Transition Key Workers assigned to young people were asked to communicate the process and what was involved and distributed the young person's and parent information pack (introduction letter, participant information and consent form).

4.6.3.1 The consent process

It was essential that young people were given a voice and that it was their right to participate (UNCRC Article 12). Therefore, it was important to receive consent so they were able to share their experiences and views. The evaluation took into account the requirements set out under the Mental Capacity Act (2005) when seeking the participation of disabled young people over the age of 16 and to ensure that:

- The model of consent worked on the premise that it was the young person's right to participate, and that parents were likely to act as *'gatekeepers'* (Macnab et al, 2007), therefore seeking parental and Transition Key Worker support would be crucial to enable young people to take part.
- That young people felt safe to express their views and experiences, and
- as part of their participation it may help to improve services for themselves, their peers and for other young people in the future.

The consent forms (Appendices Twenty-One to Twenty-Four) were written in a language and format to enable as many of the participants to take part in the evaluation. An assent form was also developed (Appendix Twenty-Five). Any young person under the age of 16 their assent form was required to be countersigned by proxy by a parent or an official guardian. The consent process outlined in Figure 12 was explained in the information provided. Two copies of the consent form were provided, which contained an ID code. One signed copy (self-addressed envelope provided) to be returned to the researcher and the second held by the participant.

4.6.3.2 Assessing competence

An essential part of the consent process was the need to assess the potential participant's capacity to autonomously give their informed consent. For the purposes of this evaluation the young person's named Transition Key Worker was best placed to assess the ability of the young person to provide their consent. A parent, likewise, was also in a position to assess.

It was important that it should not be assumed that because a young person has a learning disability/additional learning need that they could not consent to the process and that for the purposes of this evaluation a competent young person:

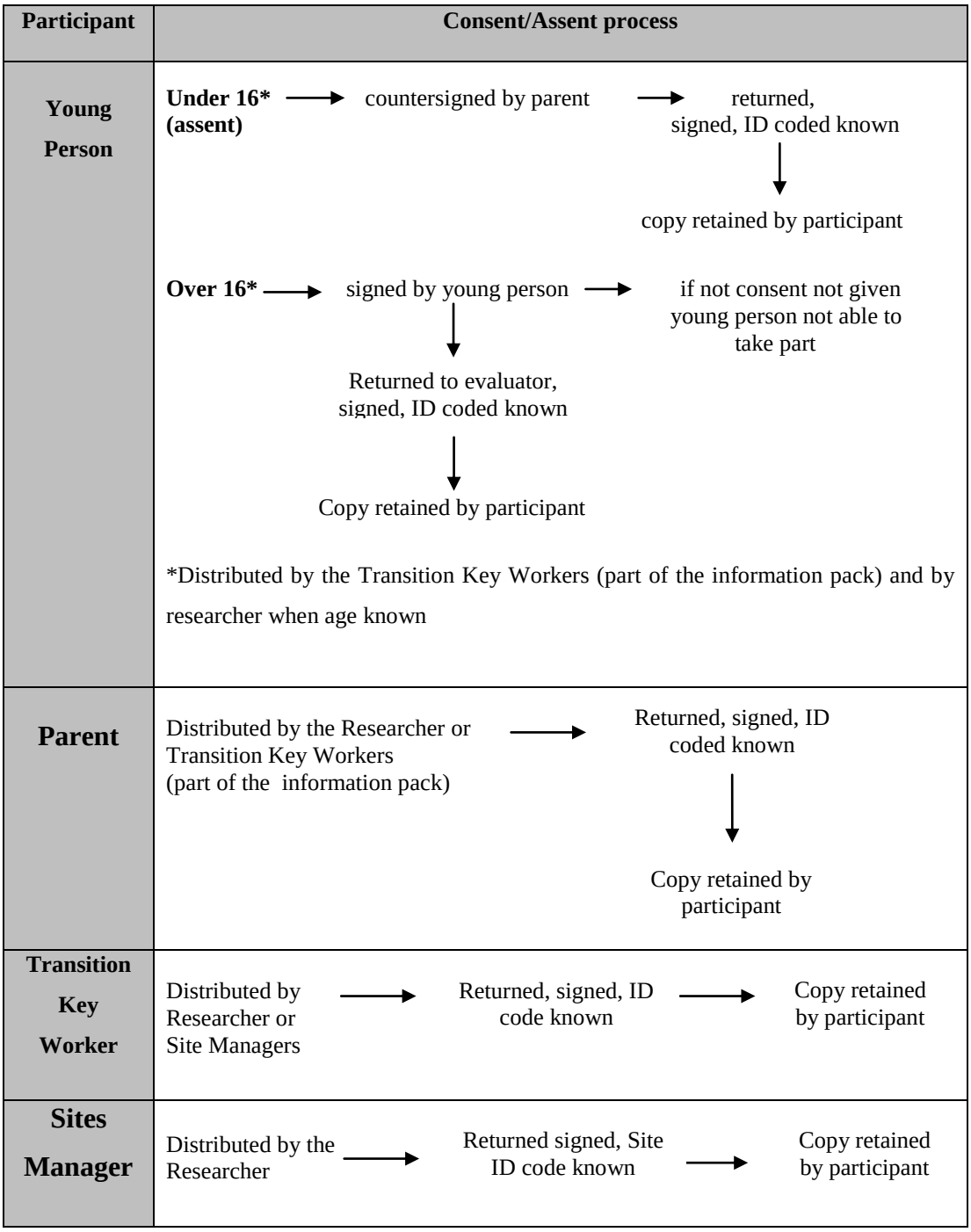
- Would be able to understand information provided about the evaluation and that it was a low risk procedure,
- that the information was accessible, taking account of an individual's communication needs, including information about the evaluation in Welsh,
- that they would be able to use the information to decide whether they would like to share their experience, and
- that they would be able communicate their views and wishes using their own style of communication.

The legal framework (Mental Capacity Act (MCA), 2005) concerning the ability of a young person to provide consent differs, depending on whether they are aged under or over the age of 16.

For the purposes of this evaluation:

- Young people under 16 years would not be deemed automatically legally competent to give consent. To ascertain assent from young people under 16 years, proxy consent would be obtained from someone with parental responsibility.
- MCA, 2005 applies to people aged 16 and over. Once they have reached the age of 16, they are presumed, in law, to be competent unless there is evidence to the contrary.
- Young people over 18 years are adults and, as such, once a person has reached the age of 18 only they can give consent and no other person is able to do this on their behalf.
- If a young person over 18 is deemed not competent (MCA, 2005), they would not be included in the evaluation.

Figure 12. Flow diagram: Consent/Assent Process



4.6.4 <u>Disclosure during interview</u>

All information collected as part of this evaluation was kept strictly confidential, unless anything discussed or observed raised serious concerns about the safety (physical and emotional well-being of a child, young person, family member or professional).

Information would only be disclosed for the purpose of protecting a child or young person, family member or individual and standard safeguarding procedures were followed. As a researcher, interviewing young people and vulnerable adults, a Disclosure and Barring Service Check was held by me as the primary interviewer. The information provided to participants included a statement regarding safeguarding and disclosure.

4.6.5 Payment to participants

Any costs incurred were be met by me, as the researcher (e.g. hiring venues, refreshments, travel). However, apart from the travel expenses incurred by myself it was not expected that venues would need to be hired for the purposes of conducting the interviews Payments would not be made directly to participants.

4.7 SYNTHESIS OF FINDINGS ACROSS THE REVIEW AND EVALUATION

A synthesis of findings across the Review and Evaluation is presented in Chapter Nine. The overall mapping of the refined programme theory with the CMO configurations of the transition process is displayed in tabular format to provide a structure concluded the overall synthesised findings of this study.

4.8 CRITICAL ANALYSIS PROCESS

For the purposes of thinking critically about the methodological and reporting quality of the qualitative study that I had undertaken (Chapter Eleven) I applied the CASP (Critical Appraisal Skills Programme) Tool for appraising qualitative research (2013) to the report of my qualitative empirical study.

4.9 CONCLUSION

The Thematic Analysis framework used was located within an ontological paradigm of the reality of stakeholders' experiences which established a chain of data-driven evidence. Undertaking the interviews I gained insight through an active rather than a passive role to analysing the data corpus by drawing upon my personal and professional experiences of the transition process. Thematic Analysis provided a flexible framework within which to apply Realist principles of analysis driven by my theoretical

assumptions set out in the introductory chapter. The ability to sense, in the first instance, and then observe the patterns in the words of those experiencing the transition process was compatible with the theory-driven realist approach to understand and present the CMO configuration(s) of the transition process.

TRANSITION KEY WORKER STAKEHOLDER EVALUATION

CHAPTER FIVE: PARENT INTERVIEWS

5. INTRODUCTION

This chapter reports the qualitative findings from interviews with parents of young disabled people (14-23 years of age at time of interview); one of four stakeholder interview groups, which are reported in subsequent chapters to provide a rounded perspective of the transition process and the role of Transition Key Workers. As reported in Chapter Three, in a policy context, the transition process, is set within a special education-based system, which defines young people were eligible from the age of 14 and what and when support and services would be provided. However, findings from the review reinforced that achieving a successful transition for many young people remained a conundrum for the receivers and deliverers of transition support (Hirst and Baldwin, 1994; Pownceby *et al.*, 1997; Fiorentino *et al.*, 1998; Morris, 1999, 2002; Forbes *et al.*, 2002; Heslop *et al*, 2002*;* Dean, 2003; Beresford, 2004; Townsley, 2004; Sloper *et al.*, 2010; Watson *et al.*, 2011; Beresford *et al.*, 2013).

The parental and professional findings from the Stakeholder Workshop and throughout the review process of transition-related literature highlighted that the challenges of providing a seamless transition persist. The need for a consistent structure, continuous support (a Key Worker) and to plan well and enabling young people to make decisions about their own futures were identified during the Stakeholder Workshop as important features of achieving a successful transition and were evident in the general and grey transition-related literature. Nevertheless, thinking about the future; the changes that will happen, what the future might look like and how parents realise their son/daughter's hopes and expectations remained prime posers. This chapter reports 4 key findings that build upon the themes which emerged, first from the Stakeholder

Workshop, and secondly from the Review to seek further clarity on *'What makes a successful transition into adulthood for disabled young people?'*

To illustrate the individual impact on parents overtime the experiences of a parent of a young person with ASC age 17 at time of interview followed by a parent of a young man age 20 with Down Syndrome are mapped, as a comparator, of my own parent experience by providing my personal perspective of key points during my son's transition into adulthood and why my transitional experience was somewhat different from other parents, but equally stressful and problematic.

5.1 PARENT INTERVIEWS

The majority of interviews were held in the family home by prior arrangement. Three parents chose to be interviewed in their child's school. The age of the children of the parent participants range from 14, just at the start of the transition process through to the eldest aged 23, now settled into his own supported living tenancy. The interviews were audio recorded, where parents had indicated agreement. 3 parents indicated at arrival that they did not want to be audio recorded lengthy hand written notes were taken and verified as accurate by those parents. The length of interview varied depending upon the time parents were able to give and ranged from 15 minutes to over 2 hours. 10 counties were represented through parent participation, but are not noted in Table 8 to avoid unintentional breach of confidentiality.

5.1.1 Characteristics of parent participants

26 interviews were conducted over a period of 10 months (from December 2012 to October 2013), with 30 parents taking part (Table 11). The participants were contacted to take part either by letter, email or by telephone, responding to their preference of communication.

Table 11 Parent characteristics

ID	Gender of Parent(s)	Gender of young person	Age of young person✦	Main Condition/difficulty of young person	Type of professional involved	Length of input of TKW*
P1	F	F	18	Dual sensory/CP	Designated TKW	Uncertain★
P2	F	F	17	Asperger's Syndrome	Designated TKW	18 mths
P3	M/F	M	22	Awaiting diagnosis	Transition Support Worker	6 mths
P4	F	F	20	CP/Learning Disability	Transition Support Worker	6 mths
P5	M/F	M	19	ASC	Designated TKW	1 year
P6	F	M	17	Asperger's Syndrome	Designated TKW	6 mths
P7	F	F	18	Down's Syndrome	Non-Designated TKW	> 1 year
P8	M	F	20	Sensory Impairments	Transition Support Worker	1 year
P9	F	M	20	Down's Syndrome	Transition Worker	< 1 year
P10	M/F	M	17	Asperger's Syndrome	Designated TKW	> 1 year
P11	M/F	M	18	Asperger's Syndrome	Designated TKW	> 1 year
P12	F	F	18	ASC	Non-Designated	18 mths
P13	F	F	14	Angelman Syndrome	Designated TKW	> 1 year
P14	F	M	20	Ataxia	Non-Designated TKW	> 1 year
P15	F	M	17	Down Syndrome	Transition Support Worker	> 1 year
P16	F	M	14	ASC	Designated TKW	> 1 year
P17	F	F	14	Angelman Syndrome	Designated TKW	> 1 year
P18	F	M	16	ASC	Non-Designated TKW	> 1 year
P19	F	M	21	Down Syndrome	Transition Support Worker	Uncertain
P20	F	M	23	Epilepsy (rare form)	Adult Social Worker	Uncertain
P21	M	M	17	Down Syndrome	Social Worker/No TKW	Uncertain
P22	M	M	15	Tuberous Sclerosis	Designated TKW	< 1 year
P23	F	F	22	Down's Syndrome	Designated TKW	3 years
P24	M	M	16	ASC	Designated TKW	2 years
P25	F	F	21	Down's Syndrome	Designated TKW	3 years
P26	F	M	14	Learning Difficulties	Designated TKW	4 mths

* at time of interview
✦ Young person's age at time of interview
★ Parents unable to quantify length of involvement

Key:

F	Female
M	Male
TKW	Transition Key Worker
CP	Cerebral Palsy
ASC	Autistic Spectrum Condition

5.1.2 Transcript analysis

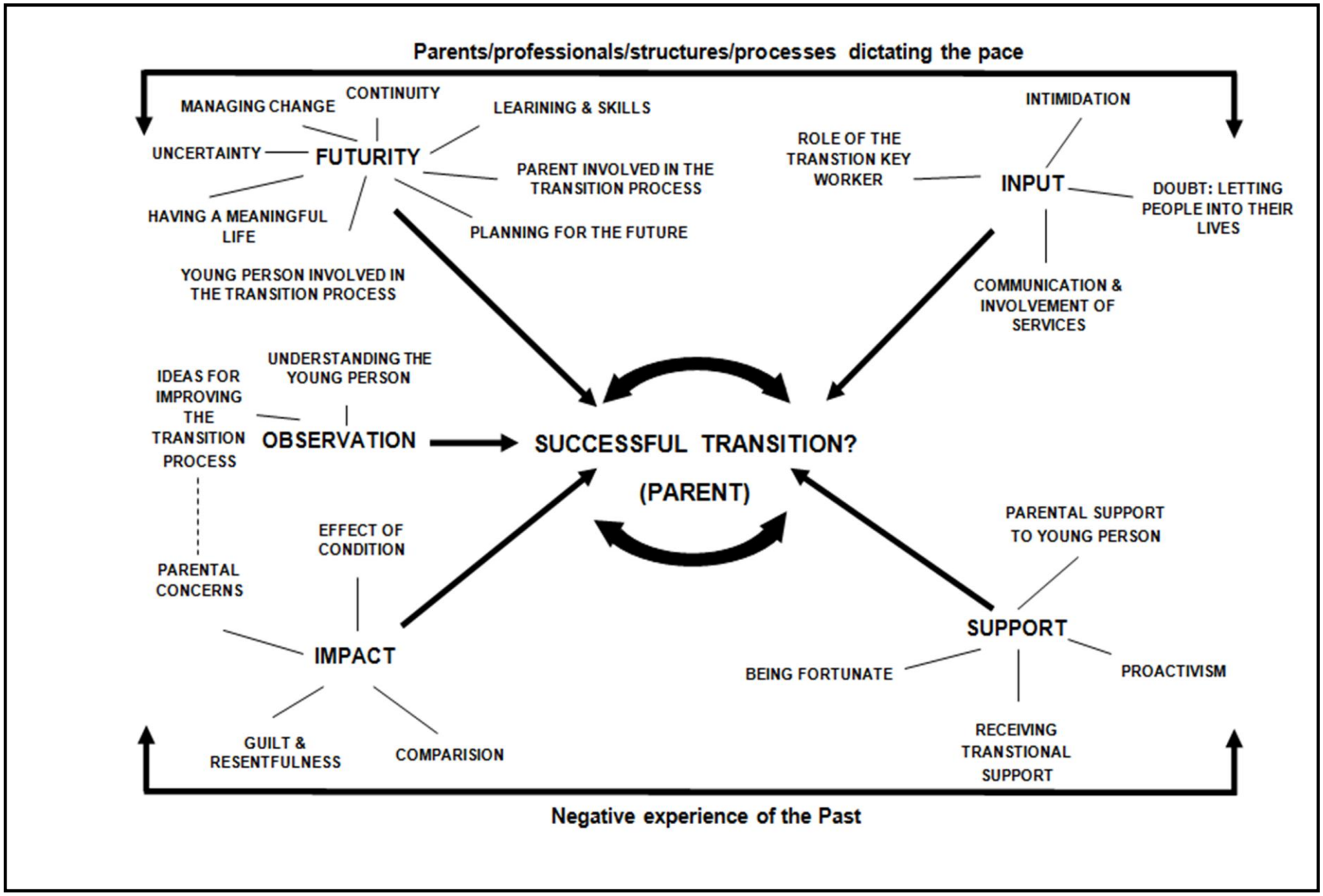
Initial thoughts, post each interview, were recorded in a reflective journal and maintained throughout and subsequently added to as the audio recordings were transcribed to begin to tease out the initial themes. A 'hand' analysis framework template was developed and employed to uncover the multi-varied personal experiences

of parents encountering a similar phenomenon. Repeated codes materialised during the in-depth analysis of the first 2 interviews transcripts and formed basis of the development of the coding and was added to as the analysis continued of the 24 remaining transcripts.

5.1.3 Key findings and descriptive themes

Figure 13 is a diagrammatic representation of the key finding and descriptive themes which were derived from the coding framework represented in a thematic map presented in Appendix Twenty-Six. The next section presents 4 key findings.

Figure 13. Key findings and descriptive themes



5.2 MAIN FINDINGS

5.2.1 Key Finding 1: The past influenced how parents think, discuss and plan for change and prepare for their son/daughter's future adult life

Parents past experiences had a tangible presence in their lives. The extent to which the past dictated the future was an unexpected novel finding not previously privileged and was not conceptually represented in the initial or the developing programme theory of the intervention (4 P's). Past experiences reverberated in the background, but repeatedly came to the forefront as the central plank of segments of conversation. The past appeared to be acting as the contextual noise, growing louder at times of crisis, only being temporarily modulated when a trauma was forestalled. The spectre of the past correlated to certain fixed points in time or when certain difficult situations arose pre-transition. Those fixed points often commenced upon a parents initial contact with a professional, for example, receiving a diagnosis in a child's first few hours of life when *you've got this baby joy for 7 hours and then somebody says hang on a minute this kids not right and I thought what do you mean and he was our first as well....we've got this child we didn't expect...my husband said it was like we had this alien'* (P9) to incremental contact incidences such as *'we started with the initial assessment.....because I think that day you (reference to the Transition Key Worker)….we were at breaking point.....my husband walked in and he…..just walked straight out the door' (response to professionals again being in the house and went to sit in the garden shed)* (P2), so built episode upon episode upon their difficult contact points with services.

First contact during the early years contributed shaping a parent's view of professionals and services they subsequently came into contact with during the transition process. The first, early and subsequent positive contact was crucial, but many parents reported that preliminary contact had been problematical and intermittent. Their whole notion of planning and preparing for future was framed within the context of the level of contact with support services from birth or diagnosis onwards; predominantly centring on negative encounters they described. Parents were unable to assuage, forget or cease retelling their stories. This left them feeling wounded without those wounds being fully

healed as their child entered adolescence. A Pandora box of negative thoughts and feelings transpired, set against a repetitive backdrop of downbeat words, which peppered their responses; *'struggled', 'worried', 'scared', 'doubt', 'intimidated', 'guilt', 'powerlessness'* and *'loss'*, which were all related to the past or more recent experiences of caring and supporting their children to the present day.

Although, we are all made up from facets of the past, some are happy, others less so and we lock those unhappy memories away, others that stay with us in the here and now and we find it difficult to dispel, parents of disabled young people are no different. It defines who we are and how we act. Yet, their focus on the past filtered consistently through to the present. Some parents were able to focus their attention to consider what they were pleased about or what had worked well to reflect positive aspects of the transition process and centre on the future. However, the negative experiences parents shared seemed to stop them celebrating the encouraging aspects which were also described. One such example includes that of a child being able to return to school after months of behavioural reclusion and now independently negotiating use of public transport to a nearby village. They appreciated that these were significant, but swiftly passed over the constructive impact such milestones had on both the young person and themselves, quickly returning to *'we walk 50 metres behind him….he can't be out on his own in case….'* (P6). Such narrations reveal something of the hesitancy of some parents to embrace positive experiences and progressive steps in consequence of a fear of further 'barriers' emerging which threaten to disrupt the sustainability of moving forward seamlessly into a supported adulthood. Lack of support and associated negative experiences have long lasting impact, irrespective of subsequent 'positive' experiences.

The future is a difficult concept; thinking about what is to come can be difficult to perceive not only for young people, but also their parents. Sometimes we just do not know as thinking about the future is not a concrete notion during the early days of transition. Parents were nervous about many aspects of transition, which slowed down their thoughts their child's futurity; their sense of being in the future. Their anxieties and uncertainties were firmly based within a continuous cycle of autobiographical accounts, closely associated with seeing their child as vulnerable and the distress that brought forth, as well as asking for support which did not materialising. It clouded their views about the future, the input and support they were currently or could receive and

the impact on themselves. Where parents felt more fortunate in terms of the support they had received; usually from children services, they were confined by the pace of transition, which is reported later in this chapter. They were bound by structural differences, the diversity of delivery across agencies and access to professional support to help them deal with past events.

Parents wanted to strive for what they coined *'a different life'* (P4) making numerous comparisons, mostly based upon past circumstances contrasting their lives to other families with non-disabled children, reinforcing how unalike they felt. They sought '*to be able to just be like everybody else, do you know what I mean by that, I know it sounds ridiculous'* (P9) and not have to think about dealing with the transition process. Many parents felt different, but did not want to be seen as different. Their norm was described as wanting a similar life to their neighbours; to the families with children in the same street, to other working mothers:

> ***'I'd have a different life if X (son) didn't have Down's Syndrome; it's been so disruptive'.***
>
> P9

Not having a life they had expected was a focus of their grief and deep-rooted unhappiness and measuring the life other families of non-disabled children reinforced their attention to past circumstances; what if my son or daughter had not been disabled? By comparing, it vied with their innermost thoughts; that they should not equate their lives and circumstances with others, but should accept their personal situation. The resentfulness they articulated seeped further into their here and now, hindering their thinking about the next steps for them and their children.

Many of the parents compared, their now adolescent children, to when they were younger. The comparison was largely associated with the support they had received in the early years as opposed to more latterly during adolescence and found that *'I think….you get all this input and help and then boom they hit 18 or 19 and it's all gone. It needs to carry on.....They need it from 16 onwards. They need a life'* (P4). This parent suggested that, although they accepted that they had needed support in the early years and had a good experience, she felt that her child was *'easier to manage; easier to*

take out, everything was easier, and I just wish I could freeze time' (P4). She balanced it against when her child became a teenager and then young adult when short break provision ceased at 19 and other activities terminated for example and were not replicated in young adulthood. More positively, where there had been the early input of a key worker through transition, parents were less likely to dwell on their past experiences, however there were few were this was the case.

Parental scepticism grew from early childhood onwards as to the role other people (professionals) would play in supporting them. Likewise, not being believed or accepting parental concerns and, as a result, been ignored, so their distrust increased exponentially with each and every lack of response or dismissal; *'at the beginning other people (reference to professionals) did not accept there was anything wrong with X (young person named). I had no one to talk to, had no support'* (P17). One parent, with her son already living in supported housing with 2:1 support after a protracted transition, was concerned about a reduction in support due to the current economic situation and local authority cutbacks. She reported that she would need to fight on as she had always done and this would become another past marker of distress:

> ***'When I saw his most recent assessment that said my son, who has no language, my son has complex Epilepsy, with severe learning difficulties, but according to the assessment he was able to go to the shops on his own and manage his finances. He can't even talk, so you know when you see things like that it really makes you wonder what the agenda is there so we are determined to fight for X (son named)'.***
>
> P20

This parental comment typified a continual underlying concern about what the future held for young people and themselves even if they had managed to work their way through the transition process; the uncertainties made it a trying time for many who were aware of the economic situation facing local authorities, and any thoughts about managing the changes ahead were amplified as the result of past instances of disappointment, current misgivings and of indeterminate times ahead.

Parents appreciated, upon reflection, the need to start the thinking from the age of 14. There were a few examples where parents felt that to start discussing the future at 14 was too soon. However, there was a polar opposite view that in one case a parent considered that starting even earlier was preferable. The intervention of the Transition Key Worker appeared, for some, to be the catalyst for starting to think about their son or daughter's prospects, but in some instances the young person was on the cusp of entering young adulthood before any thoughts of the future was discussed:

> ***'It was only when the social worker, you know, from adult learning disability team, who sent us X (Transition Key Worker named) that we talked about the transition thing'.***
>
> P5: Parent of a young man with Autism who was 18 when a Transition Key Worker was introduced

Translating the transition process for parents, at the beginning, appeared problematical; understanding what needed to be thought about, let alone for a young person. As one parent expressed that *'it's hard holding a balance really, as X (name of son) concepts of time and future and planning are limited, so as parents we feel we have to do quite a lot of the thinking for him'* (P21). Moving on from thinking, parents wanted to have the opportunity to talk, but it was varied as to the level of discussion they wished to have with professional contacts, including the Transition Key Worker. Reticence surfaced, and they concluded that they were not *'expecting great things'* (P5), largely due to past contact with individual professionals. Significantly, they felt that professionals were waiting for a crisis to emerge before there was more proactive contact and that it reinforced negative experiences that they had had in the early years to more recent recall of less than accommodating contact.

In preparing for changes ahead, parents exhibited some difference of opinion. Some judged that they were planning and preparing well and in a timely way. However, in describing their certainty, they were not sure of what support was available to help them plan and prepare, even with the input of a Transition Key Worker. The idea of starting early; preparing ahead did feel comfortable for some, so small changes could occur; taking an incremental approach to planning:

'Starting the transition process early is good as well, but doing his likes and dislikes made such a difference and starting projects on things he likes and changing some of the small things, which before would make him upset all week'.

P16

In terms of preparation, one parent voiced, who was not alone in their observation, that they perceived that professionals they were dealing with *'weren't thinking about what was best for X (name of young person) and they didn't come up with reasonable other options; we tried talking about what was reasonable'* (P14) and when they did it was a last minute reaction and rush to resolve; reinforcing parental focus on the inadequacies of response and perpetuating the negative impact and introducing poor contact experience.

To summarise, many parents found it difficult to conceptualise their son/daughter's future as an adult. The presence of the past made it difficult for them to accept and celebrate the progress their children were making towards adulthood. Their focus was on their own responses; their own transition, whilst endeavouring to balance this by working their way through a transition process they did not fully understand. Parents were experiencing their own transition; dealing with the emotional impact built up through caring. Parents framed the transition process within their own uncertainties and worries. It appeared that young people were subordinate to how they were coping with the impending adjustments; small or large small. Managing the changes that would happen increased their return to the past and brought forth their internal and external anxieties. However, they welcomed support and could see that life might have been different; more difficult without the intervention of a Transition Key Worker and that it was *'nice to have someone at the end of a phone you can actually speak to that is going to say don't worry how we'll sort it out, rather than "oh well I'll get back to you" because that is what they all say and they don't (P13)* and that *'she (reference to the Transition Key Worker) worked things through with X (son) as he opened up to her. He is less anxious and before he was frustrated at what was happening'* (P5) to counter dwelling on the past, move forward and embrace change and plan for the future within the current transition process.

5.2.2 Key Finding 2: A hierarchy of pace setting exists which shaped how parents managed the progress of transition.

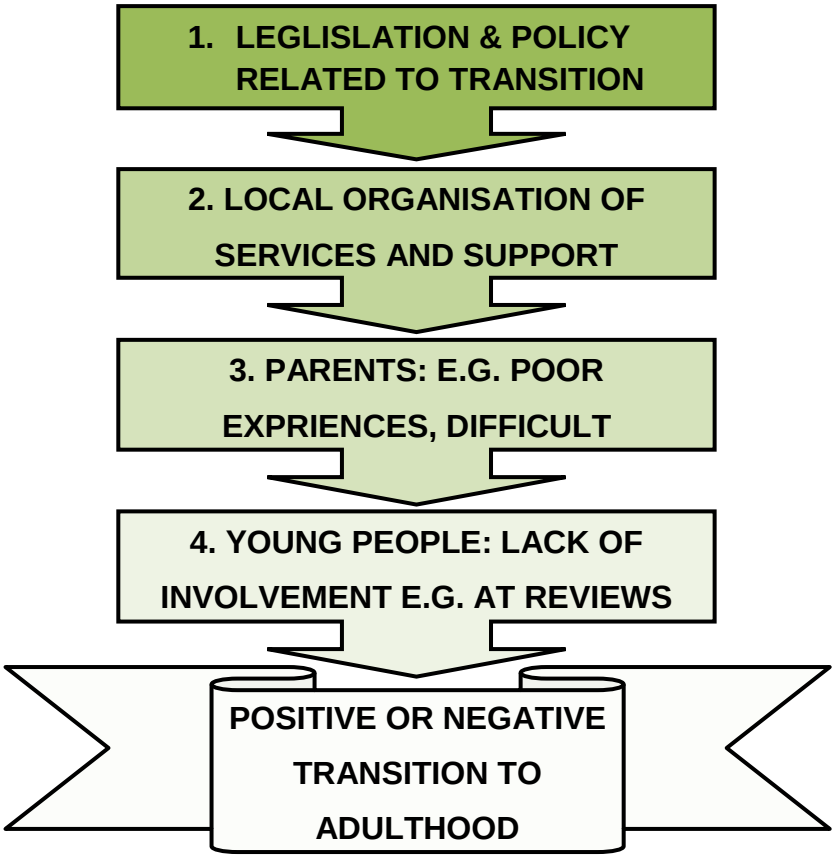
Four levels of pace setting (Figure 14), during the transitional years, transpired as a novel finding and not anticipated as a critical element of transition process or the initial conceptual model (4 P's). The whole notion of pace setting was a consideration from a structural perspective from the top down, with legislation and policy (1st Level) establishing the evolvement of the transition process laying down the way in which local organisational arrangements (2nd Level) responded to the precepts of transition (e.g. local Transition Protocols and Pathways and Annual Review processes) described in Chapter Three. Parents perceived there to be, within local provisions, two particular gateways into transitional and adult support services (2nd Level):

a) The eligibility criteria services used to open up access, particularly adult social care and,

b) the lack of professional responses to requests for support and services to help them to manage the changes that parents conceded would inevitably occur as their child matured.

Parents themselves were also acting as a third level through their engagement in the transition process and their ability to think about their child moving into early adult life whilst carrying the baggage of the past explored in Key Finding 1. Young people were also involved in pacing their own transition (4th Level) by parental proxy reports of their non-attendance or brief presence at their Annual Reviews.

Figure 14. Hierarchy of pace setting



5.2.2.1 *Second Level: Local organisation of services and support (including reference to the First Level: Legislation and policy related to transition)*

Parents were, whether consciously or unconsciously, following a transition process set out in local Transition Protocols and Pathways. One parent indicated that they felt the transition process was burdensome and that they *'were just going through the usual formalities and it did feel we were being asked too early to think about what X (young person named) wanted to do….it felt a little onerous on me'* (P15). Parents had to contend with local transitional structures and systems which had been created by local authorities and their partners in complying with legislation and policy (UK and Wales). Parents who were more aware of how the transition process was ordered; prescribed

within the top stratum (SEN Code of Practice, Wales, 2002[15]; England, 2001[16]) level for example, understood the term 'Transition', that it meant change in the context of their child moving on into adulthood, understanding that they knew they needed to plan, therefore, needed to be involved. They did not however, fully understand that discussions about their child's future post the age of 14 would take place, on the whole, within a school's Annual Review framework (local authority 2nd Level).

Many parents could not remember discussions taking place despite attendance at reviews and where they could remember that *'I attend and the girls and there was some discussion about the future……I must say, that really the older the girls get the more pathetic the annual reviews are. People don't turn up so what's the point?'* further hindering parental opportunity to discuss the next steps towards transition without their understanding being clarified. More than one parent could not remember whether an Annual Review when their son/daughter was 14 actually took place as *'we've had so many (meetings)'* (P10). There was a lack of awareness as to the purpose of the Transition Annual Review. Parents felt unprepared as to what to expect, could not pinpoint the beginning of the process and were unsure when it would end. They could not see beyond their immediate situation and preferred not to be an active participant to move forward. In nearly all cases no Transition Plan appeared to be in place or in development, contrary to the procedures set out in the SEN Code of Practice. There were examples of a One Page Profile[17] being perceived to be a Transition Plan. No parent was able to show what they supposed to be a Transition Plan, apart from paperwork which related to assessments or reports from school for example. Parents

[15] The Welsh Government issued a White Paper in May 2014 on their legislative proposals for additional learning needs for consultation. It is the intention to replace the Statement of Special Educational Needs with an Individual Development Plan (IDP) for children and young people (0-25) and issue a new Code of Practice.

[16] A Draft SEN Code of Practice (2014) was issued by the Department for Education in England in October 2013 for children and young people from birth to 25 years of age. Consultation on the proposal to replace Statements of Special Educational Needs with a 0 to 25 Education, Health and Care (EHC) plan closed in December 2013. There is the intention that the new Code of Practice will come into force from 1 September 2014.

[17] A One Page Profile captures what is important to a person and how best to support them. The profile can also include what people like and admire about a person.

were not aware of the importance of having a Plan, recording actions, and who was responsible.

Mostly, parents conceded that they needed to know what to do, but were unsure as to what they should be asking for, and combined with some ambiguity as to whether an active Transition Plan was in place, made planning difficult and a slow process. Parents described meetings that have taken place to discuss their child overtime, but very few were happy that the professional cohort supporting them were working in *'different directions'* (P6) from what the family or young person wanted. Parents considered that they were running to a timetable which they were not in control of, with others regulating the transition process. One parent described that they had *'to go from week to week and I think of the future constantly, I can only really cope now in small chunks. There is no certainty about anything is there?'* (P18). Positively, where a young person was clear about the future; what they would like to occur, for example, '*wants to be a rock star or a hairdresser….because I would like him to be able to follow his dream, but we just don't know how much of that is going to be able to achieve'* (P26) parents were unsure how to progress beyond an idea to focus on a realistic aspiration or how it could be achieved.

A number of parents could not recall actions being set or where there was recollection they did not know who responsible for making sure actions were being taken forward and planning was happening. A small group of parents, particularly those who had benefited from a new style of review, had professional support (school-based key worker), so felt more prepared to move forward. A comprehensive school in one area had activated a more person-centred approach to holding reviews. Those parents had got used to a 'standard' review approach, but now felt more involved with the new style and were able to feel comfortable to engage and think more proactively and act confidently about the future:

> ***'Previously, I really felt that up until the last review X (school named) was setting unrealistic goals, which was frustrating. I felt isolated by that that and not listened to and X (child named) was not being fully included. Since then, more recently, with the new reviews it has been better. X (child named) was there going through what was important to her and what people liked about her. It was so different'.***
>
> **P13**

detrimental one; dismissing, blocking and discounting parental desires or requests. In the case of one parent she felt that they were talking about another young person, so coloured her experience of subsequent Annual Reviews and resistance to taking part and discuss further planning for the future as *'They've been difficult. I felt I was being bullied and that I needed to take someone to the meetings. My Dad came. When I showed that I was upset their attitudes changed.....I felt bullied on my own, no one was pro-active.....I have nothing to compare, but I wouldn't do it again (go on her own to a review)'* (P16). Parents also felt blocked if they brought their own ideas or research to the table and that their views were not being listened too and their opinions were not valued. This added to their vexations and further to their time bank of poor past experiences of contact and continuing their tussle to move onwards in a positive manner.

Becoming more knowledgeable gave some parents leverage to gain support and if they could *'quote the law so we felt able to challenge and think they might respect us more.....we felt listened to for once to what we had to say'* (P15). However, the young person in this case was still awaiting a diagnosis of Autism at the age of 21 and the support (key worker support) they had received in early childhood was absent in early adulthood making it difficult for the parent to move forward to negotiate a route into adult social care:

> ***'The route for us was frustrating and annoying and unfortunately you could say things which weren't recognised and the only way to get something was to put in down in a letter or write an email. It was very frustrating and wouldn't want anybody to be in that situation, but unfortunately more families are going to be in that situation. It just doesn't give you any faith in a system where you've got to keep plugging. You are getting the answers you want to hear, but nothing actually happens'.***
>
> **P24**

Professionals (2nd Level pace setter) were also seen as influencing and shaping the progress of transition, by their contact time with young people and their families. Parents valued the time professionals gave to support them and their children and were

more likely to be open or in a position to start the discussions as they began to build a relationship with for example a Transition Key Worker. However, for those parents who had experienced limited contact, many wanted to start talking about planning, but felt unable to because of the restricted time or lack of presence of named transition specialist. The predominant view was that social worker (2nd Level) input acted as the main mechanism to open the gate to support, particularly from adult social care, but this was absent. Overtime, the resentment had built where access was seemingly obstructed, whether by eligibility criteria to trigger the assessment process or through a general lack of adult social care response. However, parents continued to find it difficult to make contact with named professionals to gain their input during the childhood years; not knowing whether there was a Social Worker involved, and if contact was made only to find out that their son/daughters' case had been closed and were not informed; placing another barrier in the way of progressing transition and another past happening to add to the memory bank.

5.2.2.2 Third Level: Parents (e.g. poor experiences, difficult managing change)

Parental past experiences were often dictating what happened and when it happened for their son/daughter as they entered adolescence. Doubt continued to reign amongst parents about letting professionals into their personal lives; being privy to private thoughts and feelings about managing their complex family dynamics. They wanted to be self-determining, to remain independent and allowing a professional over the threshold and trusting them was a dilemma for some parents; *'you get all these social workers who try to rule your lives I think and have felt this and have disagreed with them'* (P8). Accounts of being fearful of social service input was still prevalent amongst the group of parents, with the perception that if social services were contacted that the thought of being seen as a *'bad parent.....they're going to take her away'* (P2) was still keenly felt. This feeling of being seen as a *'bad parent'* (P2) in this case began to be ameliorated when demystified by the developing relationship with a empathic professional; the Transition Key Worker and the parent began to become more comfortable to opening the door to other professionals becoming involved. This parent then began to enable her daughter to think about her own transition rather than the parent obstructing contact or the rate of her daughter's progress towards dealing with her issues.

Further reported was that when professionals made appointments there was a tendency for them not to turn up, with the parent waiting at home all day all exacerbated their frustrations and additional items to top up their list of inferior encounters. Therefore, parents were less likely to maintain their engagement with professionals who they believed were not interested in their circumstances:

> ***'Sometimes you're very lucky, but most of it doesn't work because they haven't been there, they haven't lived it, they haven't done it…. most of the time people don't want to hear what parents have to say because it's messy, if you like. It's not what they want to hear, it's not somebody sitting there saying everything is wonderful and everything you know is successful!'***
>
> **P13**

The opening of the door to professionals for some parents had become onerous based upon numerous exchanges across education, health and social care from birth or diagnosis onwards. Achieving the balance between autonomy and dependence for some had been exhausting particularly in the early days with the multiple contacts that came with having a son/daughter with a disability. The uncertainty as to who would turn up at their door and who would not, that some of the parents became less willing to engage during the transition phase:

> ***'I don't know what it's like now for the youngsters today (referring to parents of young disabled children), but every week somebody was coming to the house, 9 o'clock, 2 o'clock, 4 o'clock, Monday, Tuesday, Thursday and I found that I didn't know what I was doing because there was that many people'.***
>
> **P9**

Parents who had had previous experience of being let down expected to be let down again and this was reinforced by their contact with other parents of older young people who shared their stories of disappointment and unwillingness to participate in the transition process. One parent stated that *'if they're going to save these babies they need to make provisions into adulthood'* (P4) and many felt that from the age 17 they expected their contact with services to become more difficult and protracted despite the

earnest intervention of a Transition Key Worker, but that planning the support provision early, knowing that their child existed and would become an adult, would help.

5.2.2.3 Fourth Level: Young people (lack of involvement e.g. at reviews)

Parents variously self-reported examples of their son/daughter's involvement in their own transition by attending their school Annual Reviews. When young people did attend parents understood the significance; that young people could manage to pace their own transition. Where the involvement of young people worked well parents indicated it was where a Transition Key Worker took a person-centred stance in working with the young person to ask what was important to them and was more likely to capture their participation. In one case a young person upturned their original decision, wanting to remain locally, rather than attend a residential college some distance away by taking charge of what would happen:

> ***X (young person) knows what she wants and visiting the local college as an alternative it surprised me totally she'd wanted to go there after X (Transition Key Worker) suggested it.....it completely threw me to begin with. I was so surprised. But I'm happy with X (young person named) making her own choice.....I think it's interesting as we thought we know what X wanted and we talked about it. X does know her own mind, she made her own decisions, she worked with X (Transition Key Worker) like I said he talked to her about what she wanted'.***
>
> **P7**

For those young people attending their reviews, parents suggested that there were increased levels of confidence, especially where the transition process had been explained in a way that was understood. Conversely, where it was not made clear or there was resistance to involving them in the planning for their own future, confidence levels were lower and less likely to accept becoming an adult:

> ***'X (young person) has no understanding at all. He doesn't understand; it's non-existent in his world, he's not ready to accept'.***
>
> **P10**

A young person developing their Transition Plan was seen as important. Parents could see that by providing visual evidence of involvement, young people would have a self-belief that their contribution would be valued. For parents the involvement of the young person signalled discussions around living independently and the certainty from the young person's point of view that it would happen for them and that they would have a home of their own. Parent perceptions of what young people wanted changed with hearing about their hopes and dreams and '*their lives, their futures, their hopes and what they wanted from everything and it was really moving. They told us what they wanted; they knew what they wanted, which was really surprising to me. They knew exactly what they wanted to do and what they could achieve and that they were going to achieve'* (P13). Crucial to this was that parents believed that, due to professionals getting to know the young person that working closely with them had given them a confident voice and that they could actively contribute to their own transition to plan for next steps.

For young people to deal with the changes, continuous input from practitioners and services was seen as valuable to adjust to new circumstances, but parents considered it was problematical due to a number of issues. Firstly, of having uninterrupted worker involvement; but reports of *'gone through a few social workers and transition workers'* (P15) and that secondly, *continuity was a big issue and there has been a turnover of staff in the team, which doesn't help me or X (son named)'* (P18). Parental frustration proliferated with them seemingly moving from one social worker to another and not having the contact time they wished for *'the last one I only saw just the once and then that's it'* (P12). Proxy reported by parents, was that young people needed the consistency of input from one person (Transition Key Worker) and where that was missing it caused issues for the young person in establishing a new relationship with another worker. Parents also were challenged by having a change in worker, having also built up a rapport only to have to start again, re-tell their story which slowed down the tempo of the transition process.

To summarise, four levels dictated the pace of a young person's transition into adulthood. Parents appeared to be unaware, due to their anxieties, brought about by their apparent preceding inferior contact experiences, that they were party to determining the rate of progression through transition by not wanting to think, discuss,

plan and prepare even with the support of a named professional. It espied, that their disinclination to begin to think and find the right moment to discuss what they wished for the future for their child was as a result of their difficulty coping with a whole host of adjustments that would take place as their child became 16, for example, when they (young person) would be able to, under the Mental Capacity Act (2005), to make their own decisions in their own right.

Although nearly all the parents understood that there was a need to start thinking about the future and that time passes quickly. Parents of those, particularly at the younger end of the transition age range, albeit not exclusively, felt it was too soon. Why the need, their child was still a child and that there was still time to think about the future and plan. Parents wanted to take small steps to change *'some of the small things'* (P16), rather than begin to fully discuss the future on a wider scale, but experiencing a new style of Annual Reviews enabled them to begin to work their way through the transition process and visualise their child's future in early adulthood. The hands-on approach a Transition Key Worker, who was consistently involved helped parents manage change and deal with adjustment. This encouraged parents to have a more active voice and presence at reviews to discuss further provision and how that would be accomplished where previously there had been *little support and communication….but it has now improved because of X (Transition Key Worker)….it really helped with that'* (P17) and they could begin to contemplate their child as an independent adult making their own decisions and stand back.

5.2.3 Key Finding 3: The perceived vulnerability of young people by their parents, together with a parent's own susceptibilities hinders a young person's progress towards independence

There was a conflict between parents wanting transition to take place and their child becoming independent of them, yet resisting at the same time. Their struggle to manage the idea of their child becoming autonomous was based on the perception that their child was vulnerable. It was exacerbated by hurtful events and the actions of other people. They were apprehensive about their child's exposure to the wider world and the response of others to them with the thinking that *'I didn't think she would be safe to walk or go anywhere on her own, I just wanted to wrap her in a blanket and keep her*

safe because she was so vulnerable….it's just upsetting when people don't understand her and we live in a small valley and still the boys will shout nasty things to her' (P2) being a source of concern to stifle their child's self-governance.

Their child being intimidated and picked on and how that affected the young person *'she wouldn't go anywhere in the car.....she wouldn't wash, she was sleeping up in the attic and I couldn't get her down from there, it was like a complete breakdown'* (P2) were key concerns. Parents wanted to keep them safe, but did want to let go to provide a level of free will to their son/daughter, but it was being suppressed by their anxieties about their child being defenceless. One parent she thought it would be like *'letting go of a six foot four inch toddler, we've got lots of issues to face….all we want is to keep him safe, so it's really a balance isn't it between independence on the one hand and on the other to protect him as he is totally vulnerable'* (P18).

Other people's reactions concerned parents and they were reluctant to enable their son/daughter to be fully independent despite a Transition Key Worker providing travel training, for example, to give them more freedom. Parents preferred to work on the basis of time-limited independence. As a consequence parents imposed the speed of their child became autonomous to keep them protected. Where young people were supported to become independent their self-confidence grew and procuring of a bus pass was seen as a *'golden ticket'* (P14). Nonetheless, there was a fear that a young person would not be able to leave the house without support based upon previous failed attempts despite a Transition Key Worker taking time to prepare them successfully and parents seeing the evidence. When parents conceded that the young person was capable of going out on their own there was wariness just in case they got lost or ran out into the road. Parents were reluctant to rejoice in some of the successes the young people had achieved in promoting their own independence. They continued to focus on aspects of their lives that had not gone well and kept their child close and dependent and not ready *'to start a little snips of the apron strings*' (P4).

On a positive note some parents wanted their children to live on own home, but wanted to prepare gradually. Parents did report a degree of non-acceptance of their child not wanting to grow up and not wanting circumstances to change, which made it difficult to plan with their reluctance to move on. Parents who were financially secure talked of

converting of the family home; *'the house is a good size….X could have a space of his own in the house....we could convert it'* (P11). Other parents less economically protected expressed a wish for their child to be living close to the family home and as a result were also limiting their child's independence proposing such options.

The constant qualms about the future and parental capacity to care in the long term weighed heavily for many parents if they could not prolong the support that they currently provided. They felt that they would need to fight stronger and harder to gain more support. The impact of needing to fight endlessly, especially where decisions had not been fully communicated by the decision-making of multi-agency local panels, as well as by the Welsh Government related to funding for specialist residential colleges, for example, left them exhausted and feeling exposed.

Being an older parent or getting older was of the greatest concern and increased the likelihood of them feeling powerless as they sensed both their own physical and emotional strength deteriorate. They felt that they would be less in control to dictate what might happen for their child and that they would become more vulnerable and not safeguarded. The biggest fear was that their child would be left on their own and not supported. A number of parents recognised that their own health was waning and they tried to think about the future and plan. These parents felt it was *'a concern of course as we are older parents, so it's important that we see X (daughter named) settled for the future….I feel that this is the point where it's the most difficult….she has elderly parents....she's the youngest and we are not going to be around'* (P23).

Single parents had similar fears, many of whom had been caring for over twenty years, but were concerned about who would support them as parents when their circumstances changed not only financially, but emotionally changed when their child left home. There were two parents, with similar feelings of what the future held, given the corollary of their lives thus far, with decreasing coping mechanisms, the persistent worries they faced around where they child would be living and the fear of whether they would still be living at home. They were alarmed about the impact that would have not only for the young person, but also for them as parents. It appeared to be more of concern to mothers than fathers, with mothers reporting that they carried most of the responsibilities for making plans for the future and making decisions:

'My main worry is if they don't leave, move out what will happen. It feels like it is all on my shoulders. My husband takes very little responsibility. But what will happen to X (daughter)?'

P12

'Will he be living at home, can't see that being any different and we are afraid of him living at home.....it's a constant worry'.

P10 (Mum)

Parents did have their own individual ways of coping and continued to cope as they felt that there was no alternative and increased their own susceptibility to stress. Coping with the daily complexities single-handedly had isolated some of the parents and more than one parent felt that they were leading a *'lonely life'* (P4, P9, P12) as their caring responsibilities had lost them friends along the way to a point one parent felt that she had no friends and was socially isolated:

It's ridiculous…..they need to stop picking on people who are the most vulnerable and need that extra bit of help or stop letting the babies survive. You know, stop battling, ploughing hundreds and thousands of pounds into keeping these children alive when there's nothing for them once they reach adulthood.....(parent asked whether she coped because she had become more resilient over the year's).....I am, well I used to be, but I'm crumbling fast'.

P4

The impact of years of coping with unpredictable outbursts or obsessive behaviour had got to a point for some parents where they felt that they had little left to give to seek solutions or manage on a daily basis, never mind thinking about the future. They wanted to hand over their caring responsibilities describing how it *'wasn't planned, it was just dropped on us….I never expected it'* (P9). The feeling of not knowing what was next troubled many parents. Again, this feeling was linked to how they perceived they had been treated previously; by professionals, services and life in general. Where decisions had been agreed about the future it did not feel a relief that their child was going away to a residential college. Parents understood the opportunities this would bring, but

equated it to it a sense of being a *'massive loss'* (P13) and were not looking forward to this change.

The continual pressing for support, had led to high incident self-reporting of anxiety, frustration or irritation, low self-esteem and disclosure of breakdown and needing therapy or counselling, with one parent *'my own mental health has being affected, it's all upsetting and distressing…it's not been taken away….I've really struggled and have got quite depressed at times with it that I now have counselling; how awful is that?'* (P15). This particular parent went further to reveal that she had recently sought further help even though she did not really want to talk to anyone about how she felt she thought that it was *'like I'm going into the unknown'.* Parents also highlighted that their own anxieties mirrored those experienced by their child and the combination made for a potential explosive family situation:

> ***'He (reference to older son) is taking out his frustrations on me and because of my own health issues it's hard to prepare for anything really and I don't feel supported'.***
>
> ***P11 (Mum)***

Money was a concern; their own and their child's financial situation and how they would manage financially once they left home, without having the benefit of their child's entitlement's. Worrying about paying bills and losing their home or being re-housed were aligned with their diminishing funds, especially in single parent situations. However, the need to maintain their child at home was not necessarily linked to receiving benefits, but was also associated with parental concerns related to their child living on their own rather than relying on their benefits as part of the family income. They were worried about benefit changes looming and how they would continue to support their child once they became adults; making them both financially vulnerable.

To conclude, though accepting that planning for the future needed to start parents were worried about their children leaving home and them being on their own *'but to where, we don't know, it needs to be a safe environment?'* (P10) was a constant question (P2, P3, P5, P7, P9 and P14). Parents were consumed with worry about their child being independent; being scared of their child's safety a key feature. The years of caring,

poor contact time with services and professionals, together with the lack of support led parents into a cycle of fretting with little cessation to them move forward. Parents were concerned that, although they could see that there might be opportunity to secure *'a good future, but I'm still petrified even some of the little things, like getting a bus.....but being able to talk about my worries does help though'* (P17). However, this parent also thought that taking a *'going with the flow'* approach would suffice. This parent was reluctant to engage further in discussions about planning for her daughter's future as her anxieties had besieged her to a point where she was unable to embrace the positive outcomes, which she had previously inferred. This parent however, did recognise that she had high anxiety levels, and was concerned about the impact her negative stance may have on her daughter for her to embrace an independent life after being supported by a Transition Key Worker.

5.2.4 Key Finding 4: Parents felt fortunate to have and be in a position to provide support, but that the intervention of a Transition Key Worker is only privileged by the few.

Apposite to the influencing features of the past, was the feeling of being fortunate. Being lucky manifested itself on a number of levels. Parents sought to remove the burden of traversing the transition process and they would have struggled to survive the transitional years without the involvement of a Transition Key Worker as *'it took the pressure off us (having a Transition Key Worker) as it was all getting too much'* (P11 [D]). Another parent had found the transition process challenging and judged that, *'we've had so much support we've hardly had to fight for anything (but)….I think it probably makes a difference who your Transition Key Worker is, but ours is really good'* (P23) and felt lucky to have had such support. Being fortunate was also conceived as being *'privileged'* (P3) to have received Transition Key Worker support and how effective it had been even in the short to medium term. There was a wish that it *'could be stretched a bit more'* (P3) so that other young people and families could benefit as they understood the value of the role and what the person undertaking it had achieved for their child.

Luck was also associated with accessing good social care support, predominantly from children services, but also from a special school or resourced specialist provision. It was

balanced with other parents expressing being less fortunate due not having received a good level of support from their perspective and although Transition Key Worker support was offered they were reluctant to accept based upon previous contact with social care specifically; *'I don't feel as, when X was a youngster, I got support really you know as a Mum'* (P9). There was a feeling amongst some parents that there were not on *'the priority list'* (P11) or the support was *'long armed'* (P12) so became more reluctant to engage during discussions about the future. Being fortunate, for some parents was framed within their do-it-yourself attitude and their ability to so was out of necessity rather than by deliberate design. They considered that it had been imposed upon them.

Significantly, despite a small number of protestations of poor engagement with a Transition Key Worker, more often than not associated with contact time, the support received by such a professional was highly prized above other professional contributions during transition. Uppermost, the Transition Key Worker was seen as the key information provider *'knowing what is out there'* (P17), *'helped with the relationship we have with others'* (P11) and that and that young people were *'more self-confident'* (P10) to try new activities, leave the family home without being anxious or return to school or college whereas before they had been refusing to do so:

> ***'He has recently gone back to school.....It's something I could have never dreamed of. He is getting a lot of support'.***
>
> **P6**

Parents discussed the subject of support in an in-depth manner describing the type received currently, but also from the early years onwards, both good and inferior. There was a mixed response to the support provided by a Social Worker, and where parents expected to access a Social Worker it was not forthcoming and they felt luckless. Where the support was perceived to have been *'generally good'* (P5) or for some to be excellent it was within the context of the support they had received from a Disabled Children's Team previously, rather than from a Transition Team or more specifically an Adult Social Care Team. One parent considered that *'there are lots of things they say are offered, but when you actually get there they are not. So, up until recently we've*

had nobody to talk to' (P13) since their child moved past the age of 14. Those who received support in early childhood, who were already known, appeared to be an indicator as to whether they were likely to get adult social care support post the age of 18/19, including the input of the Transition Key Worker:

> ***'I think that has been made better because we have had that support from social workers (from a Disabled Children's Team) just to make sure that things are in place and knowing we are allowed to contact them any time (reference to a Transition Key Worker). You know if we've got any worries or concerns'.***
>
> **P18**

Other parents signalled the importance of being lucky to have extended family support, particularly to just have a break from their caring role, but this was as a result of not being able to access local authority short break provision. They were happy that they could call upon family members to give them some time away from caring. They did, however, consider that they had not been fairly treated by not having the full engagement of a professional to gain some breathing space from their caring responsibility. This added to their list of disappointments over the years.

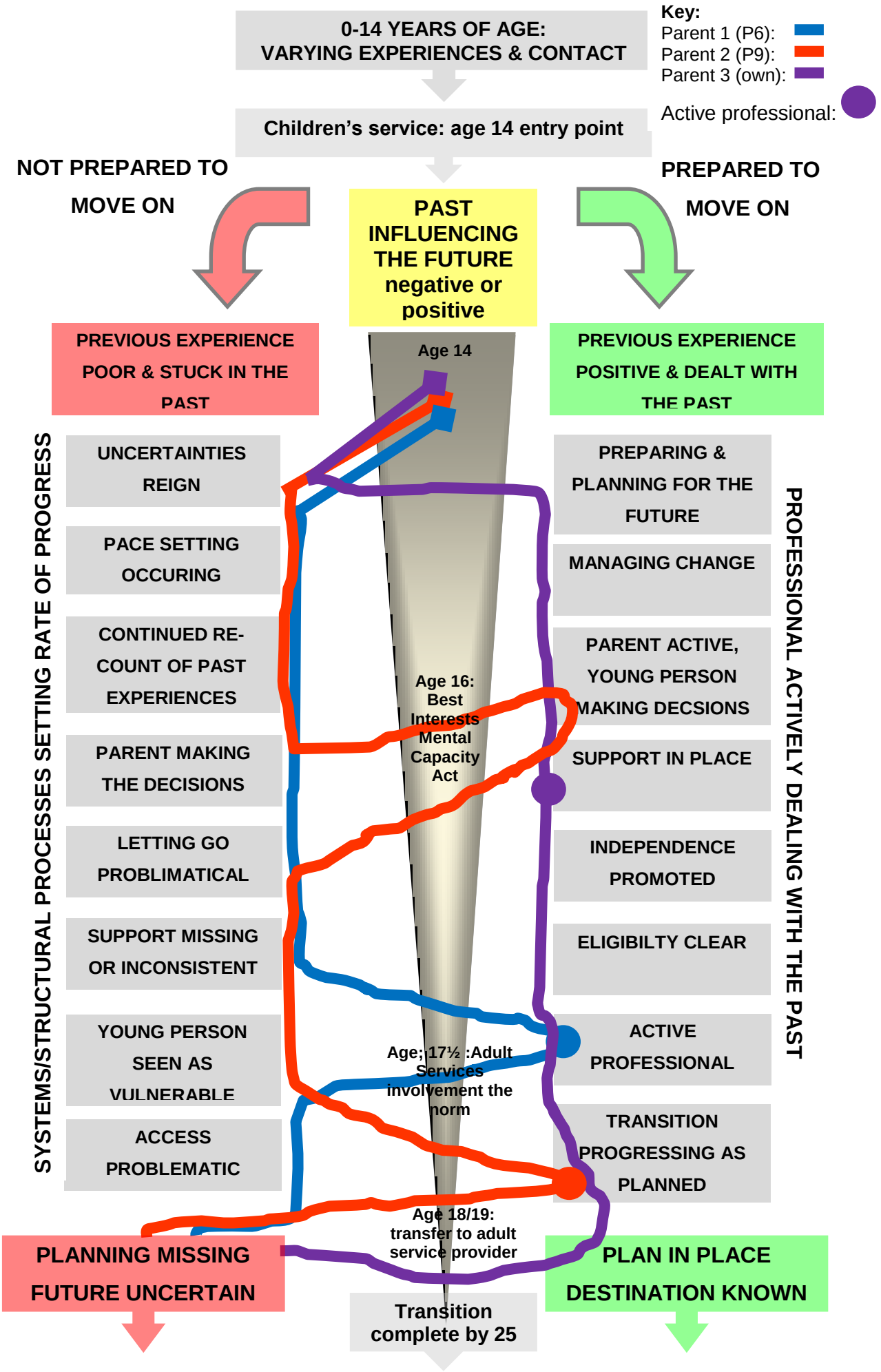
In conclusion, parents cherished the contribution of a Transition Key Worker. They considered themselves to be fortunate to have had the opportunity to have direct contact with one professional who would support them and their child. Parents were aware that other parents had not accessed a Transition Key Worker and felt privileged, but concerned that other parents should have the right to the same support. However, even with support parents felt that they were not a priority, but still felt it had been a fortunate event in being introduced to a Transition Key Worker.

5.2.5 Parental Transition Trajectory: their experiences

This section is set within the context of the parental key findings and presents the impact overtime of a parent's unique and personal experiences of the transition process. To illustrate this individual impact I present a diagrammatic representation accompanied by pen pictures of two parents mapped against my personal experiences Figure 15 explains the key episodes in a parent's trajectory towards their child's

transition to adult life and services. Their experiences typified all the parents interviewed, irrespective at which point a Transition Key Worker was introduced and were parents who remained firmly stuck in the past due to prior experiences; mostly poor and found it difficult to think, discuss, plan and prepare for their child's future and their own. Both parents struggled to let go of the past and were unclear about what the future would look like for them and their children in adulthood, but wanting to secure a level of independence for their children. At the time of interview both parents were uncertain about the future and the detailed planning for it was absent. I too was unsure, despite planning well what would happen next in my son's life. Boxes 1, 2 and 3 provide a brief contextual narrative to the diagrams which expressed the parental transitional journey and that of my own.

Figure 15. Diagrammatic representation of parental transition experience



The diagram and the narratives show no appreciable difference in the experience of the both parents, who did not have intervention of a Transition Key Worker in the early stages of the transition process. Both parent's previous poor experiences far outweighed any positivism and their ability to deal with past events and move on. Their past encounters and their child's vulnerability made them anxious, and despite Parent P9 being happy to see her son move into his own home the likelihood was somewhat remote with less than a year before her son returned from residential college.

Box 1 Parent Pen Picture 1 (P6): Parent of a young person age 16 with Asperger's Syndrome

PREVIOUS EXPERIENCE POOR & STUCK IN THE PAST

Semi-knowledgeable parent, pre-transition experience mixed; difficult in the early years. Young person seen as vulnerable. Parent anxious about the future based upon more recent events.

Uncertainties reign: Unsure of how the process works yet had experience; Attended 14+ Transition Review; uncertain of attendance at subsequent reviews; irregular attendance of young person. Non-attendance of Adult Services. Parent uncertain when Adult Service get involved.

Pace setting occurring: No Transition Plan development, uncertain about what will happen next. Feeling the weight of the process and getting son to a local university.

Continued re-count of past experiences: Continued return to experiences pre-transition, but acknowledges that there was a good level of support from another county. Impact of behaviour affecting parent; reports of continued lack of sleep causing memory problems

Parent making the decisions: Parent made decisions; yet young person has capacity. Options seen to be 'sold' by school post 16.

Support missing or inconsistent: Classroom support was variable; too closely followed around school

Letting go problematical: Parent not letting go. Young person still being followed around a retail outlet. Feeling lucky; wanting to convert house to build self-contained flat for son to stay at home. Wanting to set up son in his own business.

Young person seen as vulnerable: Parent unhappy to let son go out on his own.

Access problematic: Parent concerned son will not reached the eligibility criteria post 18 for adult social care support.

PREVIOUS EXPERIENCE POSITIVE & DEALT WITH THE PAST

Positive experience of social care and key worker support pre-transition. Son managed in the mainstream school setting with classroom support.

Parent active, young person making decisions: Parent actively sought information and researched options.

Support in place: Transition Key Worker introduced at 16. Support given to aid independence (e.g. travel training). Parent appreciation of key worker.

Box 2 Parent Pen Picture 2 (P9): Parent of a young person age 20 with Down's Syndrome

PREV IOUS EXPERIENCE POOR & STUCK IN THE PAST

Traumatic birth, multiple professional input, parent not wanting people constantly on the door step. Dad felt he'd been given an 'alien'. Parent feeling different to other mothers; felt had a different life to one expected and wanted a life other parents of non-disabled children. Parent angry with life, professionals and services.

Uncertainties reign: Parent worried; physical health compromised. Wants to do the right thing for son, but feels a failure.

Pace setting occurring: Parent wanting to move on, wants peace of mind No recollection of having attended the 14+ Transition Review; no Transition Plan in place

Continued re-count of past experiences: Continual recollection of past events; especially in early childhood; wanting to have a different life. Moved from 1 job to another wanting to be like other working mum's of non-disabled children

Support missing or inconsistent: Transition Support Worker intermittedly in contact. Considers professionals and services were unreliable. Parent feels supported lessened as son got older, yet needs the same

Access problematic: Application for housing stalled (lack of social housing); parent and Transition Support Worker demoralised. Parent anxious as it is uncertain what will happen post residential college.

PREVIOUS EXPERIENCE POSITIVE & DEALT WITH THE PAST

High anxiety pre-transition continue into the transition year's but tries to remain hopeful that her son will be able to live independently. Son doing well at residential college.

Parent active, young person making decisions: Son wants home of his own and made his intentions clear. Parent respects son's hopes and wishes, but still concerned about his vulnerability.

Transition progressing as planned: Transition Support Worker involved at 19. Son happy and doing well at residential school. Supported housing application submitted.

My own experiences were somewhat different during the early stages, but led to more protracted discussions about my son's future. I made an early decision to pursue a supported living placement, but planning in detail for this significant move was absent from the professionals involved. Whilst, I pro-actively engaged, knew in detail the transition process, knew who to contact and when, my experiences were nevertheless stressful, protracted and difficult as it had been pre, throughout and post transition into adult services, largely without key worker involvement, but with a reasonably active Transition Social Worker from adult services. My journey began to mirror the other two parents as the transfer to adult services loomed.

Box 3 Parent Pen Picture 3: Researcher's experience. Son age 21 at time of writing

PREVIOUS EXPERIENCE POOR & STUCK IN THE PAST

Traumatic birth and early years. Mixed experience of professional input, but Key Worker involvement pre-transition years. Became problematic post primary in dispute with local authority. Not seen as a parent but a professional, perceived as being treated differently. Anxiety levels high; lacking sleep causing difficulties in daily functioning

Uncertainties reign: Return to previous point in the transition process at 19: stressful period leading up to transfer to adult service; housing placement not suitable. Continually reminding county that their transition practice is poor. My experiences when my son was 11 a continual reminder that I too was being influenced by previous poor encounters with services

PREVIOUS EXPERIENCE POSITIVE & DEALT WITH THE PAST

Preparing and Planning for the future: Knowledge and expertise useful. 14+ Annual Review non-attendance of Adult Services. Transition Social Worker in place and active. Early decision made to pursue supported living option. No evidence of anyone developing son's Transition Plan. Knowledge to develop plan myself using person-centred thinking. Plan in place and agreed at 16.

Managed change: Son previously in residential specialist school, managed change earlier at 12 and began to let go overtime towards transition and through into early adulthood.

Parent active, young person making the decisions: Active in driving son's transition, drawing in key people to have a rounded view of son's future and supported independence. 2 'Plan A' options proposed by parent. Determined to act in son's best interests

Transition progressing as planned: Last minute change of mind and preferred 'Plan A' option to be considered. Best Interests meeting takes place. Preferred option agreed. Extension accepted to stay in school beyond Year 13 to manage transition to supported living. Settled in supported living 18 months later.

Return to uncertainty with current supported living placement in doubt due to change of status of house by provider. Son to move uncertain how he will cope with a big change in his life. My anxieties return, I felt like I was back to square one.

5.3 MY PERSONAL ANALYTICAL PERSPECTIVES

I have multiple perspectives from which to interpret the findings as a parent, a former Director of a charity promoting Transition Key Working, a former Non-Executive Director of a Health Board (lead for children and young people and disability), a project lead for the Welsh Government and also as a researcher. This brought both a rich, varied and rounded knowledge and understanding of the transition process, but also a tension between what I may advocate, voice and action as a parent, which may be

contrary to what I may be able to express as an opinion professionally. It can become blurred, with the need and appreciation to ensure that my own parental views did not cloud or impose unless relevant and delivered in an appropriate manner. During the course of my studies, at the forefront personally, was the frustrations and sometimes the irritation I felt at not being listened to, despite being a knowledgeable parent and having the professional specialism in the field of transition. I understood the plates I had to keep spinning until such time I felt that decisions, usually made by people who do not know your child; I could accept so that I could stop spinning the plates and relax. You hope you can endeavour to feel comfortable at that moment in time with the pronouncements made about your child's future adulthood, but I soon realised that I could not relax and needed to keep a strong hold on the situation.

I understood the need to start thinking and planning early as other parents indicated. I knew that it would not be straightforward due to the very complexities my son presented, but also from the intricacies posed by the transition process itself; planning in detail would be crucial, Therefore, I took what I knew, used it and created a Transition Plan for him; drawing in varied opinion and expertise. I had not expected to do this, but out necessity and lack of local authority pro-activity. Therefore, from a parent standpoint I was not surprised that most interviewed parents could not provide a copy of their child's Transition Plan since one did not exist. However, from a project lead stance somewhat surprised given the drive to support transition plan development across first the Transition Key Working pilot and then European Social Fund: Reaching the Heights funded sites.

I tend not to dwell on past events or poor experiences on the surface, despite having had a difficult time coping with parenting two children with an Autistic Spectrum Condition (ASC). Those past experiences however, do remain as a legacy and have affected my decision-making both positively and negatively. It was somewhat unforeseen that parents found it difficult to think about their child's future post adolescence. It was uppermost in my thinking pre-transition as my son was already residing at a specialist ASC residential school. Perhaps I had let go earlier and, therefore could think about my son becoming supported to lead a 'semi-independent' life. Furthermore, I was surprised parents were bringing their past experiences into the here and now, that they were stuck in the past, were ruminating and were unable to fully move on. Upon reflection, should

I have been more aware of this I also had experienced difficult times from my son's birth onwards. The impact of the past, the pace setting and the perceived parental vulnerability of their child had a significant impact on the parent experience of the transition process.

5.4 SUMMARY

To conclude, the overwhelming presence of past negative experiences in lives of parents (Key Finding 1) shaped and influenced their feelings, thinking and actions to deal with the transition process in the moment and in their thoughts about preparing for their child's future adulthood. Parental views, as a consequence of their perceived poor treatment, and in turn their engagement, were dictated by a hierarchy of pace setting (Key Finding 2) from the top down as prescribed in policy, but also included parents themselves by focusing on their pre-transition experiences which hindered planning. A cycle of negativity became embedded, whereby parents expected and often experienced a lack of contact and support through the transition process.

Unproductive aspects, such as focusing on their child's perceived vulnerability (Key Finding 3) and their promotion of time-limited independence, acted as persistent thread throughout. The input of a named professional (Transition Key Worker) to ameliorate and plan to achieve a successful transition and independence for their child in early adulthood had only realised brief periods of semi-autonomy by giving them opportunities to, for example travel on a bus on their own. Parents were able to briefly celebrate their child's self-determining successes, but retreated to the past as the focus of their attention.

Parents did understand that they should think, discuss, plan and prepare for their son or daughter's future and confront and manage change (Key Finding 4). Yet, they found it difficult to manage the likely changes as many where finding the transition process distressing or an obstructive experience, which stifled parents moving forward (Key Finding 2). Nonetheless, parents were able to identify what they considered would bring about a successful transition, which was observed within the context of the role of the Transition Key Worker and the regular contact and building good relationships with them. The intervention of the Transition Key Worker in Wales added a new aspect to

the transitional process. Those in receipt of their support related a more encouraging experience and felt privileged to have been in receipt (Key Finding 4).

The parental findings brought a novel dimension, previously unreported. The encumbering factor of the past determined whether a parent experienced a good transition themselves or not. The past dominated and it filtered through the other findings and influenced the progress of their son/daughter's transition into adulthood.

The next chapter explores the experiences of young people; their own perceptions of their own transition and what it meant to them and how they think their lives will be like as they enter adulthood.

CHAPTER SIX
INTERVIEWS WITH YOUNG PEOPLE

6. INTRODUCTION

This chapter reports the qualitative findings of interviews with young people (age 16-21 at time of interview) with a disability. This chapter follows on from the findings of reported in the previous chapter, which described parental experiences of the transition process. Parents depicted their current circumstances, but also recounted past accounts of contact and access to services, which they disclosed as challenging, particularly their child gaining entry and then receiving adult social care support post 18/19 years. Previous encounters had left parents exasperated and weary, and despite receiving support through their child's adolescence were not able to envisage, embrace and celebrate their child's impending adulthood. Parents struggled to manage the changes that would happen as their child proceeded towards adulthood. They shared their experiences pre-transition; how they felt unsupported through intermittent contact with a named professional. Parents found it difficult to dispel past events, which had been traumatic in their lives caring for their child and found it difficult to focus on thinking about and helping support their child to plan for the future.

Young people who took part in the Stakeholder Workshop described that they appreciated the need to plan for their future, yet needed to be supported to do so. They were not necessarily interested in how the transition process worked, but wanted to attend their Annual Reviews and to have some sense of what came next by having what they termed a 'pathway' to follow. They did want to become independent, have their parents stand back so that they could make their own decisions and for their parents to *'try not to be too over protective'* (young person, 10 March 2011). Young people wanted to start having conversations about the future and they were seen as fundamental in securing a firm foundation to build towards a positive young adulthood. Early involvement of a Transition Key Worker, many of whom were receiving the intervention, was seen as pivotal to achieving a successful supported transition into

adult life. They felt that *'transition should be something we enjoy and for this to happen we need the right people in our lives to help us'* (young person, 10 March 2011), but that their parents needed support to move on as they became independent. Building on the earlier work on what makes a successful transition from the perspective of young people this chapter will explore how young people felt and dealt with their own transition and their experiences of preparing for adulthood by reporting three key findings and concludes with a comparison of a parent/child experience of the transition process overtime.

6.1 THE INTERVIEWS

The young people were contacted to take part either by letter, email or by telephone and responded to their preference of communication as previously reported in Chapter Four. The interviews were held in the family home, with the agreement of parents. In some instances a parent(s) and or Transition Key Worker was present at the request of the young person. The interviews were recorded apart from three where the young person indicated at the start of the interview that they did not want to have their own voice recorded. Substantial hand written notes were taken and the content validated by them. The length of interview varied depending upon the individual circumstances of the young person, their style of communication and the modification of the semi-structured interview to adapt to the young person. The interviews were timed between 12 to 56 minutes.

6.1.1 Characteristics of participants young people

The 13 interviews with young people (Table 12) were conducted over a period of 10 months (from December 2012 to October 2013). 7 female and 6 male participants took part. 6 having an Autistic Spectrum Condition, 3 with a learning disability, 2 young people with Down Syndrome, 1 having a visual and hearing impairment and 1 with Ataxia. The age range of the young people covered the transitional age pathway into adulthood. The youngest taking part was 16 having recently started a local college and the eldest at 21 who has returned home after 3 years at specialist residential college. Some of the young people, like those who took part in the Stakeholder workshop, had dedicated Transition Key Worker support at the time of interview. Seven counties were represented, but are not named to protect identity.

Table 12 Characteristics of young people

ID	Gender	Age at interview	Difficulty/Condition	Type of Key Worker or Professional involved
YP1	M	19	ASC	Designated TKW
YP2	F	20	Visual/Hearing Impairment	Transition Support Worker
YP3	M	20	Downs Syndrome	Transition Social Worker
YP4	M	17	ASC/Bi-polar	Designated TKW
YP5	F	19	Learning Disability	Designated TKW
YP6	M	20	Ataxia	Non-Designated TKW
YP7	F	17	Specific Learning Disability	Transition Support Worker
YP8	F	21	Down Syndrome	Designated TKW
YP9	F	22	Learning Disability	Designated TKW
YP10	M	19	ASC	Designated TKW
YP11	M	16	ASC	Transition Support Worker
YP12	F	17	ASC	Designated TKW
YP13	F	16	ASC	Designated TKW

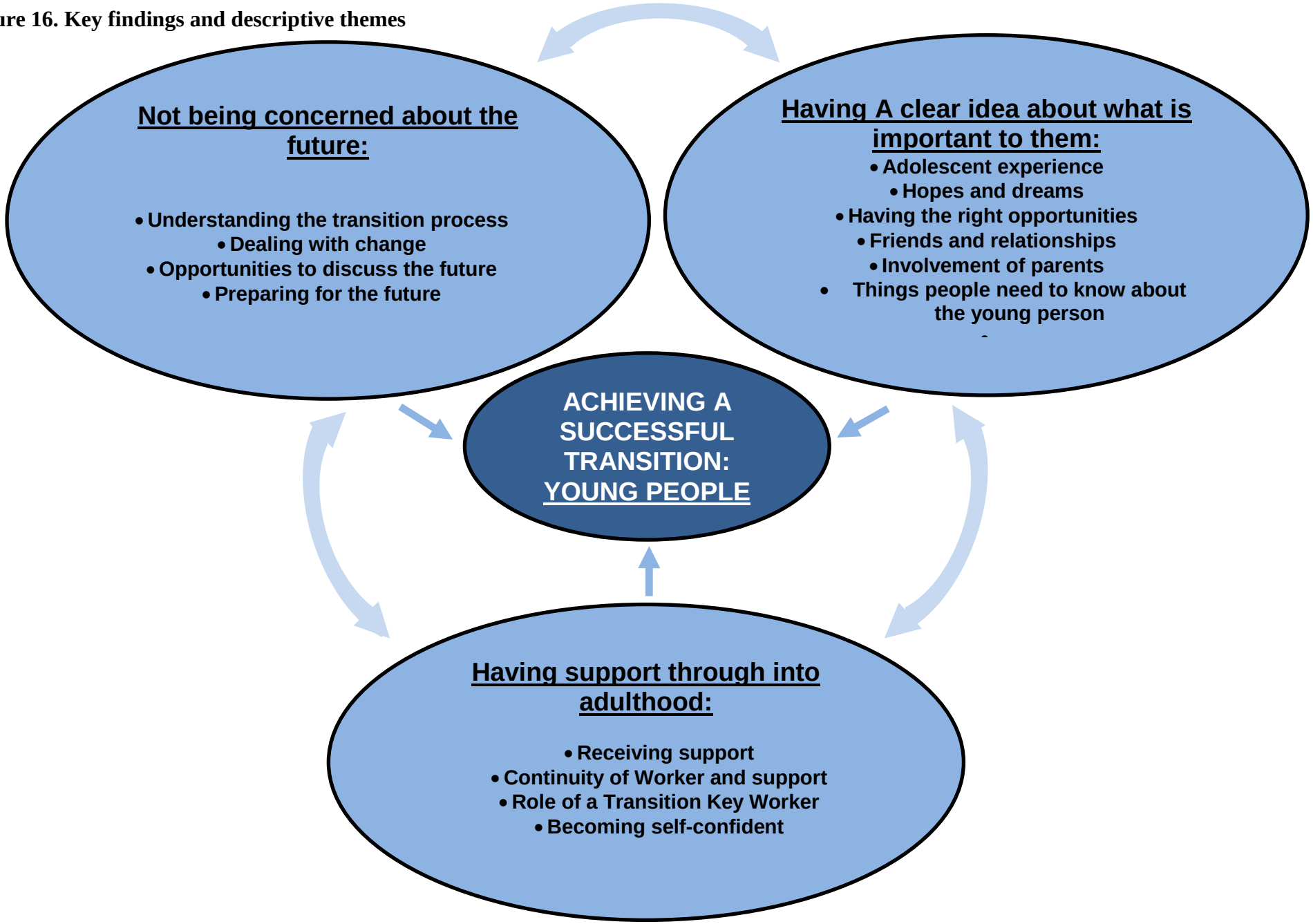
Key:

F	Female
M	Male
TKW	Transition Key Worker
ASC	Autistic Spectrum Condition

6.2 MAIN FINDINGS

Figure 16 describes, graphically, three key findings and their associated themes that young people considered were important as they progressed through transition and contributed to a successful transition. A detailed map of the thematic structure is shown in the appendices to this thesis (Appendix Twenty-Seven).

Figure 16. Key findings and descriptive themes



6.2.1 Key Finding 1: Young people were not overtly concerned about and are ready to think about their own future

Young people, unlike their parents, were not noticeably anxious about their own future, but had clear ideas about what it would look like as they became young adults. They tried *'not to worry, try to get on with my life the best I can'* (YP1) and to enjoy going to college, which signalled that they felt *'grown up now, now I'm in college* (YP12) and independent. Young people felt ready for change and that it was *'going well, from school to college, like I was ready for change....but it went well and it was local to me'* (YP6). Young people understood they would need to adjust to different situations beyond school and that school was different from a college environment. Moving away from home after college was also an indicator that they had matured and were ready for the adult world.

Young people equated the concept of transition to be the move between one setting to another. One young person felt that transition meant that she had to go *'through changes, but like it was hard, but I've come through it and left school, moved to college and things like that'* (YP5). Young people valued the opportunities presented to them to prepare them for college, which included trying out new activities or experiencing the college canteen, which many were concerned about ahead of full-time college. Most young people had a clear picture of what their life would look like beyond school/college and described it both at meetings and with their parents by telling *'mum what I want and I need to have a job in sports….when I have a house it will be just watching sport (like) football'* (P3) and in thinking about the future had a plan:

> ***'Yes, childcare course. We are working on this for next year for us to do work experience at a primary school nearby and then to see about courses. I've just looked at the hairdressing so far'.***
>
> **YP7**

Many of the young people felt that they had had the opportunity to discuss their ideas about their future and that being able to attend their Annual Reviews. They were able to tell people about themselves and the important areas of their lives. A number (n:3) of young people had experienced a person-centred Annual Review and were, with the

support of a Transition Key Worker, prepared and confident to take part, whereas previously they were not attending:

> ***'When I was in school we had an annual review presentation and talked in front of people as I was confident to talk about routines, and families and things. At my review we talked about going to a big or small college, so I wanted a small one really. When I went to X college to look it was huge and I was like I'm not coming here, it was absolutely huge and there were loads of people…. so X was the best college ever (reference to the smaller college)'.***
>
> **YP12**

However, whilst attending their reviews had been a positive experience, young people were not able to say whether they had a Transition Plan with *'no I don't think I have a Transition Plan. X (Transition Key Worker)….we looked at the future and put it down….(Was it called a One-Page Profile?) Yes, that's it.....we looked at the future'* (YP1). The lack of evidence of a Transition Plan had also been observed by parents. Those young people who had developed a One-Page Profile described it as a good experience, being able to see visually a pen portrait, despite not having developed their plan. They could use their One-Page Profile, sometimes through use of audio visual aids such as a PowerPoint™ presentation, at their Annual Reviews to discuss options; communicating vital personal information about their likes, hopes, ambitions and care preferences for teachers and allied professionals. Discussing options for the future triggered, for some young people, a distinct move towards independence by accessing travel training for example, so that they could travel on their own to a local college like other young people, whereas previously they had been apprehensive.

There were some exceptions where young people were not thinking about the future and *'just think about the present sometimes'* (YP2) and struggled to voice how they felt about what their life would be like beyond adolescence and were happy to be able to *'step out of the house'* (YP2) without feeling anxious. Where young people felt unprepared they felt *'no one wanted to help to get me onto a college course; it's a struggle, if affects my mental health and things get out of control'* (YP4). In this case the Transition Key Worker intervened and worked towards the young person returning to school and planning for college. Young people divulged that they were *'swayed by*

others ideas and not what I'm saying myself' (YP6), but the Transition Key Worker helped them take control of decision-making. One young person felt that they would not have accepted the need to move on *'I wouldn't get this far if I wouldn't have had a Transition Key Worker'* (YP6) and think about a work placement.

Young people did wrestle with change in one specific area. They found it difficult to accept the loss and cope when the Transition Key Worker was no longer involved *'I've been missing her….so that is hard'* (YP8) and losing their Transition Key Worker at the age of 19 concerned those young people who had transferred to adult services. Young people wanted their Transition Key Worker to continue for longer and were worried they were going to feel *'worse when taken away, back to where I was before, worried about not going out again'* (YP4). So, while the Transition Key Worker was involved to help with their concerns they were aware that they might not meet the criteria for adult social care support and:

> ***'You don't know what life will throw at you. It would be helped if I was still to have X (TKW), but I know that is not what is going to happen as I'm 19 now' (reference to not knowing about accessing adult social care).***
>
> **YP1**
>
> ***'But it is worrying us about X (TKW), not having her anymore….I've been happy with X (TKW), Mum says were coping, but I'm unsure about what will happen for me next'.***
>
> **YP5**

Although young people were not evidently concerned about their own future they were about their parents. Three young people had parents who had serious health issues so *'sometimes I worry about my parents'* (YP4). One young man knew that the Transition Key Worker was short-term, so was anxious *'about the future, I worry about getting a job, doing things on my own. I worry about Mum's health, generally worried. I'm surrounded by bad news stories',* but he did *'want to be my own person'* (YP4) and not to have to worry about his mother's health. Nevertheless, he was resolute that he wanted to live on his own; he wanted *'to be settled somewhere'*. One young person had, in recent times, lost her mother after a long illness and had returned home from residential

school and despite a place at a specialist college away from home did not want to leave her family and activities she liked taking part in locally. Her father tried to persuade her to go to college, but she saw her future at home with her family close to her and made her own choices would be:

> ***'missing out on all the family activities if I was away at residential college and missing all the activities I like doing. I just want to be with family….I'm happy to stay where I am with family to be honest'.***
>
> **YP2**

Young people overall wanted to work towards independence. They felt confident and were expecting or were already attending a local or a residential college. They researched options; they could discuss what those options were and how they would go about achieving an independent life. They saw that going to college was their gateway to future employment and that visiting and experiencing the college environment dispelled their anxieties about managing the change from school. Young people worked out what they needed to study and that they would be able and ready for the workplace and with the wherewithal in adult life to be independent, for example:

> ***'What do you want to do when you leave college, do you want to work with animals****? No I would like to work in a school after I leave college. I would like to work with animals as well.* ***What sort of work would you like to do with animals?*** *I like to become a police dog handler with X police force.* ***And how do you think you will do that?*** *I would have to do a full training course in dog walking which is one the animal care thing and then I'd have to go through then the X police to get the training I need'.*
>
> **YP10**

6.2.2 Key Finding 2: Young people had a clear idea about what was important to them as they progressed towards adulthood

Young people had well-defined opinions of what was important to them, both general and more specific to individual's hopes and dreams. The essentials, as they saw them, were that they wanted to have positive experiences, try out new things, be challenged,

but alongside this they wanted to have the right opportunities rather than *'having to accept what is available…..they only work on what's available and not what I want to do'* (YP6). They felt that the options proposed were not always based upon having a choice or sourcing options that were grounded within their wishes. They felt that having limited choices narrowed what they were able to access and what was offered was not what they wanted to do *'well it's been the only thing (reference to an IT course) that has been suitable to my needs really….modules of the same thing each time! I didn't get much help with making choices'* (YP2). Where choice or trying out new activities were more apparent the young person framed it within their experiences of attending a local special school or a residential specialist college rather than from other sources. Young people could list what they felt was a wider selection, such a gorge walking. Young people, in a post college state, were less able to describe their week apart from activities they could access from local authority day centre facilities or work opportunities and occasionally from a Third Sector organisation. They felt they were not suitable for them or challenged them by learning new skills.

Having the right opportunities were linked to employment or accessing a work opportunities placement. The young people in the upper age range were concerned, where they had been able to access a work placement or paid work; that it did not always work out for them:

> ***'You see X (disability employer) didn't work out; I think they didn't understand me or what was OK important for me really. I didn't like it there. It's been really hard about employment. The X (disability employer) didn't understand my needs or my situation. I didn't feel comfortable I just went along with it but it wasn't what I wanted. I think they need proper training I told X (TKW)'.***
>
> **YP1**

Young people were clear about what they wanted related to employment:

- ***'To find the right job, find the right career and we are looking at my options'.*** **(YP1)**

- ***'Work, things like work when I'm older in a nursing home. I had a work experience'*. (YP5)**

- ***'I want to drive a bus or work at the bus station'*. (YP6)**

- ***'My dream job would be running a hair salon; my own business and I'm hoping I will be calling my shop 'X' salon'*. (YP9)**

They were not limiting their prospects despite highlighting limited choice. They were actively informing both their parents and professionals supporting them what they wanted and they were able to illustrate how they would achieve their employment goals. They knew what they needed to study at college and obtained work experience to aid them in their endeavours:

> ***So tell me what you would like to do when you leave college, what job would you like?*** *I would like to work with elderly people because I care for them.*
> ***If you want with elderly people what do you think you will have to do to be able to do, have to study?*** *Well I went there for my work experience.*
> ***What did you do in the Day Centre to help?*** *Washed the dishes, washed the dishes for them. Cleaned the tables up a bit….*
> ***So that is what you would like to do when you leave?*** *Yes.*
>
> **YP12**

Having friends and maintaining the friendships made at school were important to young people. Some young people struggled to maintain those made at college once they had left and did not *'have a massive social life outside the family'* (YP2). Making friends at college was associated with them gaining confidence with socialisation, but incidents of bullying had taken place both in special and mainstream college environments and had caused upset as young people wanted to be happy and settled, making new and maintaining long standing friendships:

> ***'When I was young I was in X (residential college) and it makes me happy. But, my first year I got bullied so cos, so I got bullied my first, second and third year. So I was, but not me, but I'm used to that now so I'm actually OK with it. Well my Mum knows everything about it so I took it to my Mum what happened at the college'.***
>
> **YP8**

Keeping in touch with friends, where the young person had or was being supported by a Transition Key Worker was more likely to happen and was encouraged. One Transition Key Worker set up a social club so young people could get together with their friends. It also acted as a catalyst to prompt sleepovers and going shopping together after receiving travel training. The older range young people who were now living in their own home largely wanted to live with other young people so that they could *'when inside the house I love to cook for everybody'* (YP9) and spend time together.

Young people wanted the choice to live independently, and in one case the young person saw that, by going to residential college, he could be in his own home sharing *'a bungalow, 3 people and me in a house; they are my friends. Help is next door. I have lots of friends now in college'* (YP3). All but one young person wanted to be able to have their own home with support and live in a place they liked, but not too far from family and friends '*Well I live in X (seaside town named) and it's by X (mountain named) and it's really peaceful where am and I live with X, X (friends named) and my supportive staff team'* (YP9) or *'I would like to live by my mother because I don't want to live far away because I really home sick…….I'm going to do so……..so I'm going to live near to my mother'* (YP12).

Parents were encouraged by the Transition Key Worker to participate and become involved in their child's transition and that young people wanted their parents to '*trust X (reference to the Transition Key Worker) completely and I'm safe, she has given them confidence and (they) don't worry so much and she checks out if I'm OK with them'* (YP4). Where young people felt that they lacked the confidence to be independent and living in their own home, yet wanting to be autonomous was associated, as reported under Key Finding 1, with the health of their parents or not being able to access support from adult social care to move into their own home and saw it as an unlikely outcome:

> ***My Mam and Dad have been very involved with me, we are close. Mam's been poorly so we look after each other. We've talked about me having my own home and I'm OK about living on my own. I think it will be difficult so I'm not confident about that. It will have to be somewhere local, but you know adults (reference to adult social care) are not involved and that makes me a bit down and I don't understand that'.***
>
> **YP1**

To summarise, Young people were clear about their ideas, what was important to them and were working it out, with support to achieve their hopes and dreams. They were certain that they wanted their parents involved, but wanted the Transition Key Worker to work with their parents and that were trusted by them. Most of the young people wanted a home of their own; to be independent, have a job, maintain established friendships or make new friends. Foremost, they wished that those supporting them fully understood them, for example, the importance of their specific routines or having the right environment to people that were significant and that professionals were working with their individual qualities and strengths to bring about a successful transition in all areas of their lives.

6.2.3 Key Finding 3: Young people want to have support to manage their transition into early adult life

Important to young people were that those supporting them understood them, how they felt and how they would like to be supported to manage their transition into adulthood. They described their experiences of being supported, which were varied pre and during transition. Some of the young people found it difficult to distinguish between professionals who they came into contact with, whether they were a Transition Key Worker, Support Worker or Social Worker. Whilst, they did not have concerns about their own future they did about not having support and that they *'hardly had anybody, we sometimes had a Social Worker'* (YP2). Some young people had not had continuity of contact since leaving children's services. One young person felt that she did not *'see anybody, they seem to come and go social workers, we get a new one and then they aren't around, then another, they've left and we don't seem to have anybody* (YP2)*'.*

Young people cited their parents as their main supporters, irrespective whether they had contact with or fully understood the Transition Key Worker role or that of other professionals who were involved. Those who did understand the Transition Key Worker role would make contact with their Transition Key Worker *'knowing someone is there to talk to when I'm angry or upset…..show me around unfamiliar places like when I was going to college, someone helping with a task I don't understand'* (YP13). There was a counter view, which was directed at other professionals, that they did not understand what was important to them. Where there had been some support they felt constrained

by not being allowed to be self-sufficient and that *'staff (college) worried about me getting about, college not letting me go, worried about me being on the bus; it's OK, but they are not listening to me'* (YP6). One young person who was receiving Transition Key Worker support felt that what he wanted was not respected by others supporting him:

> ***'It's helpful to understand how I feel, this is important to me….I didn't feel valued people….X & X (other professionals) were condescending and patronising. I felt that teachers had a different spin on what I was like and not what I felt or was like. But I have grown in confidence'.***
>
> **YP4**

The main focus of attention was the support they received from their Transition Key Worker, seeing that person as a *'massive help in my life'* (YP1). This young person was able to feel at ease, able to express his wishes and supported to do so. The Transition Key Worker helped him to deal with aspects of his life he found challenging and that the Transition Key Worker knew who to contact to help him manage his transition into early adulthood:

> ***'We talked about independence and helped to look at the future, she (reference to a TKW) told me what she could do and she helped to bring other people to see me; helping me find the right career. She talked a lot at meetings as well. It was what you say a turning point and she is an absolute treasure'.***
>
> **YP1**

Young people gave other examples of the support they had received from their Transition Key Worker, particularly the support they had to deal with the practicalities of life; going out into the community, helping to complete forms; *'helping with small things…….sorted out things like I was second sitting for dinners and by the time mothing for me to eat in the café, I went on first sitting then; the Transition Key Worker took the pressure off'* (YP4).

Young people equated their contact time with a Transition Key Worker to increased levels of confidence in managing change and that they could *'go out and have a talk*

and like get a drink and talk about anything' (YP8) whereas previously their self-confidence had been lower. Young people felt that they could trust the Transition Key Worker and they would not let them down as other professionals sometimes had in the past. They appreciated that the Transition Key Worker would visit them at home, but also visited them at school or local or residential college and helped them manage the change between settings. Finally, knowing the Transition Key Worker would be there to help them was a principal requirement for many and that the *'Transition Key Worker is there, a friend, I'm confident I can talk to X (Transition Key Worker) when I have something I need to talk about'* (YP4). Young people valued the input of the Transition Key Worker and the benefit of their intervention to support them through the transition process.

6.2.4 Comparing a young people's and parental experiences of the transition process

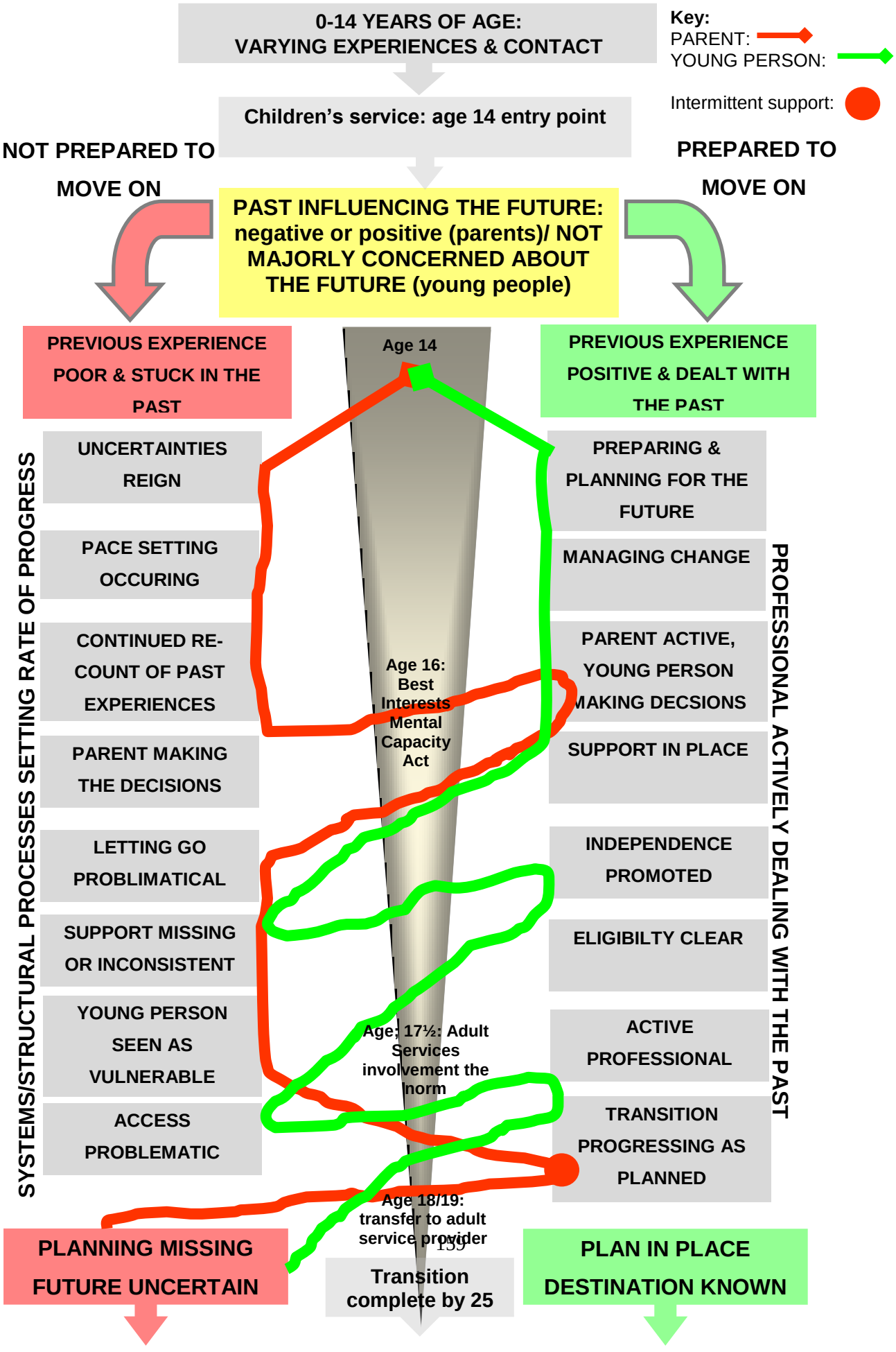
In this next section I compare the experience of two parent/child combinations overtime of the transition process. In Chapter Five parental experiences of the transition processes where problematical. Box 4 introduces YP3, a young man with Down Syndrome. His mother (P9), was represented in the parental mapping (Figure 15) reported in the previous chapter, who had high anxiety levels and recounted poor experiences of contact with professionals and services, and despite a successful transfer of her son from special school to a residential specialist college, his future beyond college; where he was going to live, what his week would look like, was uncertain. YP3's experiences were mapped alongside his mother's (Figure 17) Box 5 introduces YP1, a young man with Asperger's Syndrome and P5 are similarly mapped (Figure 18). Boxes 4 and 5 provide a brief description of each young person to provide the context.

Box 4 Pen Picture YP3 (Box 2: P9)

X is an outgoing young man aged 20 who was clear about what he wanted to happen in the future. He was attending a residential specialist college. He felt that he had a good experience of school and when he was of nursery school age had attended local mainstream school, but much to his mother's dismay it had been decided that he would transfer to one of the counties special schools, without consultation. X remained a learner in a special school until he was 18 and dealt well with the move to a new school site in the last few years of school. He had made many friends and making friends continued to be important to him. He was not worried about the future. His Mum, who was present, felt that because what was said would happen over the years would continue into adulthood. X understood that as he became an adult that things would change for him. He had taken part in Annual Reviews at school and the plan to go to a residential college was explored and agreed. X had a strong view that he should be able to be independent and have a home of his own which he did not want to share with anyone else. He expected that to happen as soon as he left college. He wanted to live near Manchester United Football Ground. Football was his passion and he wanted to have a job that was sports related.

He received most of his support from his parents and extended family, and from time to time had access to a Support Worker who did not always turn up to take him out. A Transition Support Worker was involved but contact with her was intermittent and her attempts to liaise with housing had been frustrating and an application for supported living accommodation had stalled due to a lack of suitable housing stock and placement availability. X was adamant that he would be living in his own home, perhaps working in a leisure centre and would be keeping in touch and seeing his friends made at college. Mum was supporting his wishes and wanted him to live independently. Mum continued to be anxious about his future and her own and how she and her husband would cope if he came home to live.

Figure 17. Diagrammatic representation of YP3 and P9 (young person age 20)



Box 5 Pen Picture: YP1 and P5

YP1:

X, an articulate young man, who had attended both a special school and a well-known combined specialist mainstream college, was living at home at the time of interview. He had a philosophical outlook and was not overly concerned about his own future. He was with the help of his TKW been researching options. However, he had been unhappy about one of his work opportunity placements, which had not gone well and he felt that they, specialist disability employers needed to be able to understand him and that they did not. He had also volunteered in local charity shops, but would have preferred to work in a library.

X understood the transition process and had attended his Annual Reviews. He did want to live independently in his own home, not far from his parents but was not sure whether he would be possible or when it would happen. His main concern was his parents, looking into the future, particularly his Mum who was in poor health. He had built a good relationship with his TKW and now at 19 was upset about losing her input, which he valued. X was actively making his own decisions, but checked out with both his parents and the TKW. X had not had a Transition Plan, but the TKW had, with X, developed his One-Page Profile.

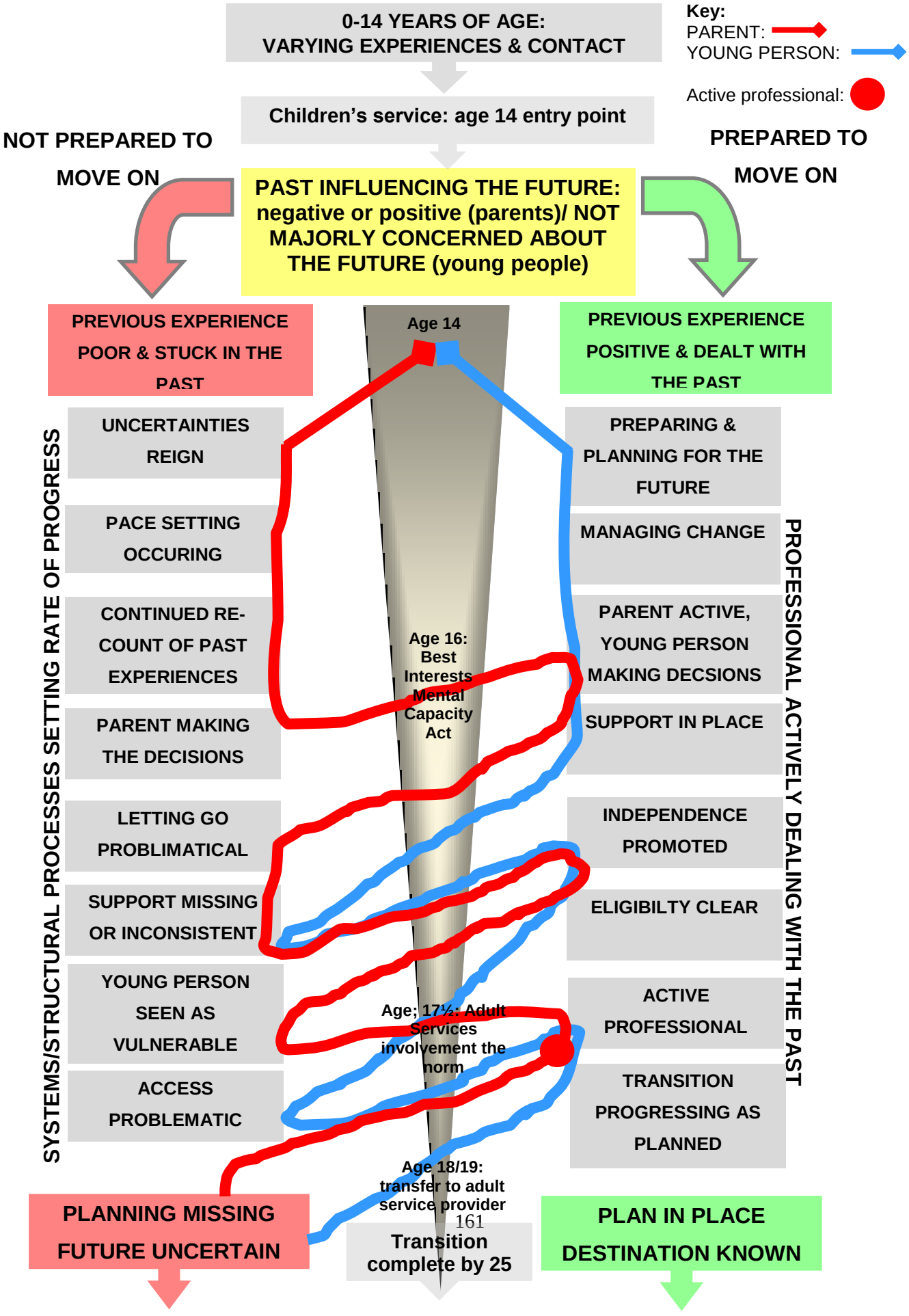
P5:

Both parents were very concerned about what the future would hold for their son, particularly Mum who had serious health problems. They had had a relatively good experience of services pre-transition, but it had been sporadic and access to a link worker and short break provision had ceased. They confirmed that they had, before being introduced to the TKW, had had no support, and felt that they needed help as their son reached adulthood.

Since the input of the TKW they felt more positive and wanted their son to be able to lead an independent life, but his poor work experiences had left them wondering what type of work he would be able to access. They expressed that they tried to be realistic and *'coped I suppose, we had ways of coping, but we never really felt we were listened to about what was going to be best for X to meet his needs'*

They had some understanding of the transition process and confirmed that their son had never had a Transition Plan, but were aware of the existence of his One-Page Profile. They felt that since they had got to know and trust the TKW that their son was able to open up to her and had gained confidence. Both parents appreciated what the TKW had achieved, but were also worried about losing her input, knowing that their son would not meet the criteria for adult social care and therefore his future was uncertain.

Figure 18. Diagrammatic representation of P5 and YP1 (young person age 19)



Both examples show that parents had difficult times during the transitional years and found it hard to think about the future, let go and were unclear as to what were their son's prospects. The young people were relatively happy at the commencement of the transition process and not generally concerned about the future, were managing change and understood that transition meant moving and becoming an adult. As they approached the transition into early adult life they became less sure and more concerned about what their future held and began to mirror their parents' concerns. The parents were promoting independence, but at the same time were concerned about their child's vulnerability. Both examples presented had received a mixed level of support, but only one young person's had access to a Transition Key Worker and, through their involvement working towards their independence had progressed. There was the concern that losing that input would be detrimental in achieving independence. Appreciably, there appeared to be little difference with or without Transition Key Worker support of the transition process. However, YP1/P5 felt that their confidence and trust in the Transition Key Worker was a significant factor in considering the options moving forward. Nonetheless, in both cases it became less clear what the future would hold and the uncertainties the parents felt at the beginning of the transition process returned as their child entered early adulthood.

6.3 SUMMARY

In summary young people were generally happy. They were mostly content, thus far, with what had happened through transition and felt it was a good transition, unlike parents who were anxious and resisted thinking and planning for their child's future. Young people had a clear visualisation of what their future might look like. They were not majorly concerned about their own futures, unlike parents, but were about their own parents, especially where a young person reported their concerns about the health of a family member, which worried them above other aspects moving forward into adulthood. However, they were anxious about losing the support of their Transition Key Worker who they felt had contributed towards a successful transition by supporting them practically as well as discussing options post school. A number of young people had not reached the age to transit into adult services, and where, therefore nervous about what would happen and once they lost Transition Key Worker support.

Young people were clear about what was important to them and wished to discuss and share those aspects and were able to in certain cases at an Annual Review. They understood that there would be change and that the transition process meant change, but that change was mainly associated with the move from school to college. They did want independence; to have their own home. Most wished to live near their families and friends, but some felt confined by professionals not allowing them the freedom to travel independently; that it was not safe. Above all young people valued the support they had received particularly from a Transition Key Worker, which paralleled parents views reported in the previous chapter and how they had facilitated additional support as a consequence of their intervention. A further discussion related to the experiences of young people and parents are set out in Chapter Ten.

The next chapter builds upon this and the previous chapter reports the experiences of Transition Key Workers and their role in supporting young people and parents through the transition process.

CHAPTER SEVEN
TRANSITION KEY WORKER INTERVIEWS

7. INTRODUCTION

This chapter builds upon the parent and young people's findings described in the previous two chapters by exploring the experiences of Transition Key Workers in delivering support to young people and their parents. Parents shared their varied experiences of Transition Key Worker support, but also their experience of pre-transition contact with professionals and services, which had challenged and frustrated them. They focused mainly on the negative aspects of past exchanges and the lack of service responses, which many considered to be poor or inadequate. They were able to articulate the positive benefits of receiving Transition Key Worker support, identifying increased levels of confidence amongst young people for example. However, they were worried about the future; their son/daughters and their own and what it would mean, but many were reluctant to begin planning. Conversely, young people were less worried about the future, were upbeat with many having a clear idea of what they wanted and where they would like to be in the future. Parents called for a reliable, continuous and understandable transitional structure. They felt they had to contend with a local framework that was difficult to circumnavigate, which heightened their unease about engaging with the transition process. Contrariwise, young people were not explicitly concerned about the structural aspects; how it worked, what it would mean to them individually, but were happy to have the support of a Transition Key Worker to achieve a successful transition.

In the context of Stakeholder Workshop, outlined in Chapter Three, the professional participants, including Transition Key Workers described that they wished for a transparent multi-agency transition, one which was standardised with comprehensible guidelines. They considered that by having guidance and a coherent structure young people and parents and themselves would know what to expect and would have a defined understanding of roles and responsibilities through the process. They indicated that there was a need to plan early with young people and that the early involvement of

a Transition Key Worker was a critical factor in initiating prompt discussions with young people and their parents and commence planning to achieve successful transitions. This chapter explores the contribution and experiences of the Transition Key Worker in preparing young people for adulthood; how they supported both young people and their parents and sought to further understand *'What makes a successful transition into adulthood for disabled young people?'* from the perspective of Transition Key Workers. This chapter presents four key findings, concluding with an 'insider' perspective in which I draw upon my experiences and knowledge by offering an additional view and an adjunct to my parental views reported in Chapter Four.

7.1 INTERVIEWS

Fourteen designated (solely carrying out the Transition Key Worker function) and non-designated (undertaking the function of a Transition Key Worker alongside a substantive post e.g. Social Worker) Transition Key Workers were interviewed over a period of 12 months commencing in October 2012. Thirteen interviews were conducted, as agreed, in their place of work. One Transition Key Worker chose to be interviewed by telephone. Two Transition Key Workers chose to be interviewed together and separate transcriptions were made of their contributions. All were audio recorded, with the exception of 1 interview where the participant did not want to be recorded and extensive hand written notes were taken and validated by the Transition Key Worker. Interview times varied from 27 minutes to an upper range of 1 hour 21 minutes. 8 counties are represented.

7.1.1 Transition Key Worker characteristics

14 interviews were conducted with designated (solely carrying out the role) and non-designated (key working for a small number of young people alongside a substantive post). Table 13 represents the type of professional interviewed, their designation and previous professional role, numbers of young people supported at the time of interview, period in post and the range of young people they were working with. The aim was to ensure that there was, depending upon responses, equal coverage and variety of grant funded and non-granted funded Transition Key Workers.

Table 13 Characteristics of Transition Key Workers (TKW) (Red text denotes Transition Key Workers funded through the Welsh Government/ESF: Reaching the Heights grant)

ID	Type of TKW or professional providing transitional support	Professional role prior to post	Caseload at time of interview	Time in post	Type of young person supported
TKW1	Designated TKW	Social Worker	12	18 mths	ASC* including Asperger's Syndrome
TKW2	Designated TKW	Teacher	17	6 mths	Pan disability (complex needs)
TKW3	Designated TKW	Worked with vulnerable adults	15	2 yrs	Pan disability (complex needs)
TKW4	Designated TKW✦	Assistant Psychologist	10	< 2 yrs	Pan disability (complex needs)
TKW5	Non-Designated TKW✦	Support Worker	3	2 yrs	Physical & Severe Learning Disability
TKW6	Non-Designated TKW	Transition Specialist	30	18 mths	Pan disability (complex needs)
TKW7	Designated TKW	Social Worker	24	> 3 yrs	Pan disability (complex needs)
TKW8	Designated TKW	Support Assistant	66♦	>1 yr	Moderate to Severe Learning Disability
TKW9	Designated TKW✦	Social Worker	5	< 6 mths	Learning Disability
TKW10	Designated TKW/ Social Worker★	Social Worker	32	18 mths	Learning Disability & ASC
TKW11	Designated TKW	Worked with younger children	32	>1yr	Asperger's Syndrome
TKW12	Designated TKW✦	Social Worker	60	4 yrs	Pan disability (complex needs)
TKW13	Designated TKW✦	Transition Officer	3	2 mths	Pan disability (complex needs)
TKW14	Designated TKW✦	Social Worker	13	5 mths	Pan disability (complex needs)

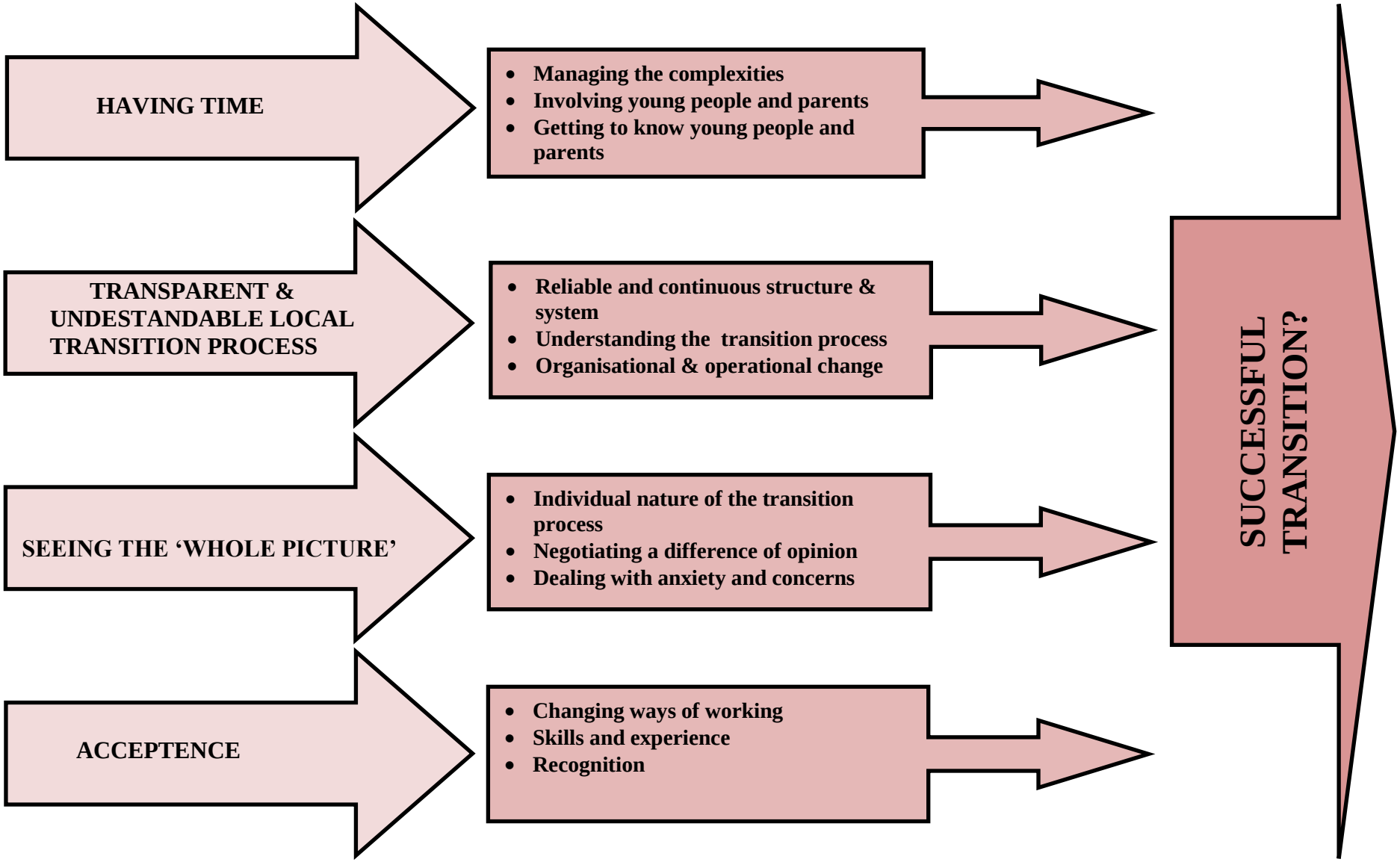
Key:
ASC Autistic Spectrum Condition
TKW Transition Key Worker

✦ Part-time
♦ Can work with a young person from Year 7 (age 11), but predominately from the age of 14
★ 50% under 18

7.2 MAIN FINDINGS

Figure 19 provides a diagrammatic representation of 4 high level findings and the descriptive themes. A detailed thematic map is presented in the Appendices to this thesis (Appendix Twenty-Eight).

Figure 19. Transition Key Worker: Diagrammatic representation of the high level findings and main descriptive themes



7.2.1 Key Finding 1: Time played a crucial factor in involving, supporting and planning with young people and their parents

Transition Key Workers worked within a specific timeframe and age-range articulated in policy, but were aware that their tenure in post was potentially time-limited. They felt that time was against them in involving and preparing young people they were supporting who had complex needs and family dynamics. Planning in a well-timed manner was frequently absent. Transition Key Workers were conscious of high caseload demands where the *'higher your caseload gets the more impossible it gets to do that (reference to planning with young people) because you've obviously got cases which are more complex and take up a lot more of your time'* (TKW2). Further to this *'one young person's circumstances sometimes demand a lot of attention and even though it could be said the caseloads are smaller (than social workers) it's irrelevant at times when you are focused on one individual who takes up all your time'* (TKW6). Transition Key Workers considered that building relationships was also time-consuming. Providing equal or sufficient periods with young people especially where caseloads where higher (>20) led to inconsistency of time available for Transition Key Workers who were traversing child and adult services. They prioritised those aged 18 and Transition Key Workers who worked across into adult services found that they were unable to work and plan with young people 14-17 in the same way. The rush to complete the Unified Assessment was the priority, rather than encouraging involvement to develop cohesive transition plans.

Time spent with young people and their parents listening, hearing and responding was seen as a fundamental dynamic aspect of proactive transition planning, which fostered a trusting relationship and friendship. Transition Key Workers saw themselves as a *'friend'* (TKW5) and valued the time they spent with young people getting to know them, identifying areas which they could actively support the young person to manage their changing circumstances. Having *'hands-on'* (TKW1) time garnered insight into the personal situations of the individual and was regarded as a predominant function of their role that *'a lot could be done quite easily really by just spending a bit of time with young people'* (TKW7). However, non-designated Transition Key Workers did not always have the flexibility to respond promptly due to competing responsibilities or pressures of their substantive professional role (e.g. Social Worker).

There was a view that some parents were *'a little bit reluctant to let outsiders in….. I think that is where it is difficult because a lot of parents don't see it and they hold you at a distance, but a lot of families I think they are quite private and they want you know don't want people coming in'* (TKW7). This lengthened the time it took to get to know the young person, family and plan with them. Transition Key Workers considered that parents did not always see the positives of involving their child in transition planning. Transition Key Workers considered that a fear still persisted of the stigma of social service input as parents worried about involving social workers through previous contact. There was a notably appreciation, from the Transition Key Worker perspective, that giving their time alleviated some of their suspicions, which had not been assuaged by previous contact experiences and opened the door to them taking part in their child's transition:

> ***'I've found that being a TKW..... (we) aren't feared by the family, so getting to know them is easier and we can build up the knowledge about them'.***
>
> ***TKW13***

Transition Key Workers understood the need to keep parents involved; they put in time, but that sometimes they worked *'on the basis that they will use their initiative'* (TKW6) to make contact, rather than themselves maintaining a proactive response. Transition Key Workers perceived parental defensivity and that it was *'the biggest stumbling block, they have their own agenda in a way, thoughts and feelings as well, which is understandable as a parent'* (TKW2). Transition Key Workers understood that their engagement with parents was individual and varied due to their circumstances where *'you've got one or two families who are literally on the phone to us for an hour a day. That way it's hard to take caseloads because you don't know how each family will be and how they will engage'* (TKW3) making it difficult to plan Transition Key Worker time. Transition Key Workers felt that most parents did understand the transition process and the need to plan early, once it had been explained to them, but as reported in Chapter 4 many parents were unsure of what the transition process entailed, particularly once their child was at a residential college and were less likely to plan for their return to their home locality:

> ***'Three years flies by so quickly….they often start to panic rather than having that clear plan in their head and the goals that when that young adult comes home this is what is going to happen'.***
>
> **TKW2**

The means to engage young people in their own transition had been a challenge, particularly with those young people with Asperger's Syndrome at the beginning of developing a new service and it took time to encourage their involvement. These young people did not *'want to be seen as having a disability and don't want to be associated with it so don't want to go to groups and groups for the over 18's there is nothing much for them for their age range so it's what else I can help them with'* (TKW11). Other Transition Key Workers found young people had difficulty accepting support and failed to *connect with (them)…. you have also got to judge things a bit carefully and sensitively and you don't want to let people down either…..sometimes you have to take a step backwards'* (TKW7) and take the time to reconnect them.

Transition Key Workers indicated that time was a factor not only for themselves, but also for social workers. They felt that social workers had less time to spend with young people and families, so as long as they (Transition Key Workers) were not *'swamped by parents'* (TKW6) they could invest as much time as possible to support young people. It was believed that social workers relied *'predominantly on the parents' views, especially if you've got someone who has difficulties with communicating, they haven't got the time to spend to get to know that young person and how they actually feel about things* (TKW4) as Transition Key Workers could. A number of Transition Key Workers appreciated that it was *'quite hard because some of them (social workers) feel overstretched then they haven't found it very easy in accepting suggestions'* (TKW7) from a Transition Key Worker:

> ***'I don't think that social workers….have the time to do any of this hands on work because it is time consuming or even if pieces of work are short they are still time consuming'.***
>
> **TKW1**

There was a view that there should be an extended time-period and contribution of children's services where *'a children's social worker needs to be involved a bit longer…. so many see that there is a shut door as well to services…. everything seems new to them again'* (TKW10). A newly involved professional (an adult social worker) was seen to be time-limited, which made relationship building difficult with the young

person as the Transition Key Worker had achieved in the same way. Transition Key Workers were more able to apportion periods of time to individual young people.

To conclude, Transition Key Workers indicated that what worked well was having protected time to connect with young people and their families to understand their needs and wishes and plan with them to work towards good outcomes. Transition Key Workers felt that *'what's worked really well….is having the time to go to families…. identify what is needed with child and the family…. it doesn't matter how long it takes to do an activity….. I'm not restricted to time so nothing is rushed, you've got time to explain, to do it with them, draw from it, consolidate it'.* (TKW1). There was an underestimation of the time it took to nurture a trusting relationship with a young person and their parents before any discussions and planning could take place. Transition Key Workers highlighted that some parents were resistance to becoming involved, avoided contact and did not want *'outsider'* support. Transition Key Workers needed to encourage parental involvement, without causing parents to feel unsettled about future planning. Transition Key Workers felt that time spent on an equitable basis enabled them to deal with individual circumstances and encouraged the participation of young people in their own transition planning.

7.2.2 Key Finding 2: Local structures and systems are not conducive to delivering a transparent and understandable transition process

Transition Key Workers were obliged to work within the same local transition structures and systems as young people and parents. While, they became '*so passionate then….because you do tend to get frustrated with the system like a parent….because you're facing the same difficulties' (*TKW3) which made it time-consuming to encourage the growth in local transition planning. There was varied awareness of the transition process. Many thought that young people moving from children's into adult social care services was relatively straightforward and that services were connected. They realised that they '*didn't really understand the complexity of it'* and that they *'didn't really understand… I thought it would be set in stone….I thought that people always….go to Day Service, they just go along, they always visit them, they're all connected. I was quite naïve until I started working within' (*TKW3). The anticipation that the transition process ran smoothly was expressed by the newly appointed worker

and that the relationship between child and adult services would be positive. As they became more conversant with the relationships between key agencies the *'the culture wasn't there'* (TKW2), and that *'transition is a minefield and the complexities of it all, people don't realise'* (TKW10), which had made it unviable to facilitate a smooth transfer for many young people. Where there were the beginnings of cultural change in delivering support across child and adult services, Transition Teams had been established. These teams were all sited within adult social care, with children's services actively engaged.

Most Transition Key Workers were aware that a local Transition Protocol existed setting out the process. Those who accessed the protocol found it a useful tool at the beginning of their tenure, especially those less familiar with supporting young people. However, many found that their local protocol failed to provide sufficient information about how to plan with young people:

> ***It (a Transition Protocol) didn't give me a sense of how to plan and I needed to know how to plan with young people as that was part of my role and that would have helped, but wasn't there in the protocol'.***
>
> **(TKW11)**

Transition Key Workers felt that their local protocol was service-orientated and did not always set out the role young people and their parents would play in the transition process. Transition Key Workers considered that the process was less than transparent, not consistent and was confusing not only to them, but to those they were working with. These views reflected a key finding explored in Chapter Three, where many local protocols lacked the detail of how to plan with young people, but also what would be expected of young people and their parents through the transition process.

There were varied interpretations of applying the content of a transition protocol. Many felt, as with other types of protocols that because the transition process was perceived to be one of such a complex and difficult to navigate nature, no one was taking responsibility for ensuring that local protocols were being followed. Transition Key Workers believed that they were not in a position to ensure the protocol was being adhered to at a senior management level or that the protocol was steering the work via a

local multi-agency Transition Planning Group. They considered that a protocol was not an active agent and that what '*happened locally really on the ground rather than the protocol itself added to the realisation that something needed to be done about transition and still needs to be done about it….there is the perception that the cliff edge is still there. The protocol suggests avoiding the cliff edge'* (TKW12).

There was a diverse interpretation of when the transition process began. It was felt that starting at the age of 14 was too soon, but it was associated with not having time to work across the transitional age spectrum due to high caseload numbers (Key Finding 1). The age of 16 was considered to be the earliest to engage and commence planning, despite converse protestations of planning early. Moreover, there were concerns that local caseload systems did not take into account the individuality of each case, principally where the young person had complex needs (learning, medical and co-morbity). Most of the designated workers considered an optimum number of young people per caseload to be circa 20 with non-designated key working for up to 3 which felt comfortable so that every young person had their dedicated input. However, one non-designated individual was managing a caseload of 30, with two designated key workers supporting 60 young people through transition. The higher caseload made it difficult to plan effectively with all.

Most young people and parents demonstrated the non-existence of a Transition Plan as discussed in Chapters Five and Six. The existence of a Transition Plan and the role the plan played was not always seen as important by other professionals. There was an absence of emphasis on direct transition planning with young people. The absence of a Transition Plan particularly frustrated Transition Key Workers. Most Transition Key Workers appreciated a structured planning approach via the use of a Transition Plan to capture the detail in readiness for decision-making. However, where a young person had a Transition Plan there was inconsistency:

> ***'Variability in information is a problem and sometimes some of the plans I've seen the quality of the plans are poor. I know having some detail is important and often it's really missing or the information is different to what I know to be true'.***
>
> **TKW9**

There were numerous examples of Transition Key Workers who considered that their local authority had not, despite training, embraced a person-centred approach to support a holistic transition framework. Where person-centred thinking tools were being used to create a One-Page Profile the wealth of information gathered was not being translated into a Transition Plan. The view was that '*One-Page doesn't really make a Transition Plan'* (TKW2). The training received appeared not to have been converted into practice, which was a surprising given the input of trainers across Wales and the subsequent support provided by CCN Cymru to develop person-centred practice. The perpetual request to keep transition on organisational agendas, with the creation of a single Transition Plan had made it difficult for Transition Key Workers, given the number of plans that needed completing, made it not only frustrating for Transition Key Workers, but also for young people and parents. There was some awareness amongst the Transition Key Workers of the plans to replace the Statutory Statement of Special Educational Needs with an Individual Development Plan (0-25 years of age), but there was a concern that the new process would not significantly improve local transition planning processes.

The eligibility of and then access to adult social care was a thorny issue. Transition Key Workers reported that they had struggled with the demands and opaqueness of differing structures and commissioning processes between children and adult service. They saw it as *'a deficit assessment process which is based on what a young person can't do which is the traditional key to resources and flies in the face of person-centred practice'* (TKW12). Problems of eligibility and access stemmed from difficulties in referral through to, for example, a disabled children's team pre-transition as the referral processes were seen as ambiguous or prohibitive to parents who were unsure how or who to tackle to gain entry. In some cases where entry had been secured and an assessment had taken place it had taken so long that they did not *'want the service….then they will just close the case, so we get families really missing out……..then when you come to Transition they haven't necessarily….got services or they haven't got a social worker or anyone to help them with that process'* (TKW7). Where access was better managed it was where young people were already in contact with a social worker. They were likely to be individuals with a learning disability, but with no certainty of access to an adult learning disability team. Many were subsequently

routed through to an adult mental health team which was seen as *'a real issue…….it's more difficult to engage with parents especially as their son or daughter is unlikely to be eligible, so what are they transitioning into?'* (TKW11).

Trying to effect change for many had been demanding. They were dealing with organisational change, re-structuring at a local and regional level and staff redundancy. Transition Key Workers wanted to change the structure and systems they were working within and that change was driven by young people rather than by agencies or services. Transition Key Workers aspired to seek the power to change, and where they did forge influence they found it slow moving. The more significant change influenced by the Transition Key Worker was how they had worked with schools to deliver person-centred Annual Reviews and Transition Plan development by demonstrating person-centred methodology, even though they felt *'on the edge of school…….it might have been a lot easier because it felt that for me to be on the outside trying to change things and I think that's quite a hard position to be in'* (TKW7). There was the concern that having developed new ways of working that once the Transition Key Workers were no longer in post that schools would revert back to their old methods of working with young people. Transition Key Workers considered that there was the hope that other professionals would see, by witnessing a new practice model, it was a more positive approach to direct young people through transition into adulthood.

Transition Key Workers, to deal with new ways of working, needed a supportive management structure; a manager who understood their role and the work they were undertaking. They also wanted a manager who was committed, who *'understands the importance of Key Working'* and is open to hear the *'grassroot stories'* (TKW1). However, there was variability of manager commitment and understanding. In two cases the manager had not had previous experience of both Key Working and the transition process. Two of the Transition Key Workers felt that they had not been well supported and the lack of support and interest had led one Transition Key Worker to take time off from work due to additional pressures of reorganisation and downgrading transition as a local priority. Similarly, the other Transition Key Workers felt unsupported and vulnerable, but were comfortable to maintain support. However, that was becoming increasing difficult as resources were being stretched:

'(I'm) confident in my own self-belief about what I am doing. I feel that I have confidence to continue to support young people in the way I have been doing, but there are gaps in provision and that is a tangible problem'.

TKW9

To summarise Transition Key Workers considered that the transition process was complex, which had not been made clearer by having a local transition protocol. They felt that the protocol lacked the detail of how to plan effectively with young people. Transition Key Workers struggled to traverse differing structures which existed between child and adult services, but transforming practice was problematic. Many Transition Key Workers felt unable to effect change. Transition Key Workers considered that what had worked well, but by unequal measure what had not was the commitment of managers to support the development of a workable local transition process and maintain transition key working. Modelling person-centredness to other professionals was seen as a crucial to promote the individual nature of the transition process. Young people and parents were more likely to adopt person-centred transition planning as a consequence of being shown, although there were mixed results. There was a cohort whom Transition Key Workers considered still followed their *'own agendas'* (TKW4) and failed to take on board person-centred thinking, citing that *'there's always the same barriers* (TKW4) to plan and review in a person-centred way. Modelling change from the outside and the slowness and acceptance of change frustrated many.

7.2.3 Key Finding 3: Transition Key Workers need to understand the *'whole picture'* (TKW2)

Transition Key Workers were required to be skilled individuals to hold the balance between providing support alongside promoting the independence young people. Transition Key Workers needed to be aware of the *'whole picture'* (TKW2) and have a 360 degree view to effectively support both the young person and their parents through changing circumstances as the young person became an adult. They needed the skills and knowledge to be able to broker, tease out and differentiate the family's views from that of the young person, but that *'it's really different for each parent, Mum can tell you*

one thing and Dad will tell you something different, they have different agendas so it makes it difficult to manage, to actually understand what it is they are trying to tell you' (TKW9). Transition Key Workers found it difficult to negotiate the parental view to discover what young people thought and wanted, as parents were imposing their own judgements. Transition Key Workers observed that parents were not prepared for change and were concerned about *'power and control….Is it with the parents controlling, making the choices, or is it with the young person, who is making the choices…..who is making the decisions?'* (TKW2).

Transition Key Workers were being asked to work with young people and their parents with varying needs. The individual dimension was recognised and that preparing the young person and their parents drew upon all their skills. Transition Key Workers cited Year 9 as pivotal and that there was a need to put *'all the cards on the table, often we don't, but we have to be clear it's a big change for young people and for everyone and we need to think about their function (parents)'* (TKW9) and the changes ahead. Person-centredness was seen as an important element to untangle differences of opinion and to reveal the voice of the young person and their individuality. Where person-centredness was being applied, Transition Key Workers were able to centre the young person at the heart of their own transition and that *'their services should be tailored for them rather than….the young person just being put in a day centre because that is what their criteria means; it's about what they want out of life'* (TKW5). Transition Key Workers valued that by focusing on the young person they appreciated the individual nature of the transition process and how they could act within the confines of local systems and assessment processes to think more creatively by sourcing other community-based activities. However, the Transition Key Workers found it *'difficult to know sometimes what to do or what will help as there are lots of people involved……so it is difficult to understand or gauge who has done what'* (TKW11).

Transition Key Workers were conscious of understanding parental anxieties; what their worries were and recognised that parents had issues with comprehending and managing the transition process and got *'confused about it all…one of the big worries is the cut off at 18 and many of them worry about losing services….often they hark back to the same things, and those same things are written on the same pages'.* (TKW10). This was the only inferred suggestion that what had happened to parents previously was affecting

their thinking and change management, which was a significant finding reported in Chapter Five. There was recognition that:

> ***'Some parents struggle with it (transition)….more than perhaps their son or daughter. They find it hard to think about moving on or about those changes that might or certainly will happen for them. We try to coax them to start thinking about it, but they do find it hard to'.***
>
> **TKW14**

Parents were, in the view of Transition Key Workers, reluctant to let go to wholly embrace supporting their child to be self-governing. There was the view that where parents had received support from children's services they had a sense of them feeling relatively contented and protected pre-transition having dealt with previous transition points (e.g. primary into secondary education). Once there was the suggestion that they needed to start thinking and planning for their child's future adulthood parents considered that they were going *'into the unknown….people are always afraid that they won't know my child, they won't think the same as the teachers and it is that process from going through school into adulthood where are they going to college are they going to day services?'* (TKW1).

There was an opinion that where parents were used to receiving services and there was an expectation that, post transition, there would be a continued entitlement. Therefore, they would not need to plan. Further to this Transition Key Workers considered that parents, despite discussing the transition process with them that they *'find they can't plan for the future; it's restricting them and they need to be told how to plan and have people doing it for them.....there are big worries for them., parents still get confused about it all'* (TKW10) and they needed to understand parental situations. As Transition Key Workers became more confident in their role they could begin to unstitch parental resistance to preparation and letting go, but parents needed support to do this otherwise it was felt that young people would continue to *'be prisoners in their own homes, not being able to become independent because parents not wanting it and because we don't have the necessary resources always to help with that'* (TKW9).

Transition Key Workers considered that as they had explained their role and focused individually on the young person that young people expressed that the Transition Key Worker was the *'the key...."if I need anything you've got the doors to walk in and speak to these people….you've got that key to walk in. I haven't got a key"* (TKW3). This was reflected by a number of Transition Key Workers who sensed that young people seemed *'to be more positive about the future than their parents; that it will be okay for them'* (TKW9), which echoed the view of young people explored in Chapter Six. Transition Key Workers were conscious of having to meet the expectations of young people, triggered by person-centred practice, but that realistically what they wished for may not be possible, which was exacerbated by others not taking on board the need to re-direct or offer alternatives once they understood the *'whole picture'*:

> ***'It's their expectations as well….it's lovely for a child to have hopes and dreams, but some of them do genuinely believe they can achieve….this one young lad thinks he's going to be an Aerospace Engineer. So no one's saying "Let's think about something else"? No, no one's tackling that'.***
>
> **TKW3**

Transition Key Workers recognised that the catalyst to promote preparation and trigger planning was the Annual Review. Transition Key Workers felt that they had taken away young people's and parental misgivings by explaining what would happen at a Review, that they could express themselves, that it would not be all professionals *'talking about them; it was all going to on a much friendlier level and we found out that they did enjoy being there and being part of it'* (TKW5). More broadly, Transition Key Workers felt that both young people and their parents struggled to conceptualise transition and as a result the conception of the future was vague and unconstructed. Therefore, the Annual Review was neither perceived as a key focus nor as being important to attend. Transition Key Workers reported a negative parental attitude, fed by a lack of aspiration. Where there had been attendance at reviews Transition Key Workers recounted examples of where parents had voiced negativity in front of their child or contradicted the young person's responses. Transition Key Workers considered that some parents were accepting their lot, not questioning decisions or support offered which, in their view, they did not understand the needs of their child. Where Transition

Key Workers were able to extend support to a parent, confidence was gained in working with both the parent and young person to incrementally empower their abilities as advocates of their own care during transition to adult services and doing so '*to develop their confidence, their independence, to speak up instead of just accepting things'* (TKW1). But, it was dependent upon the proactivity of the parent, but their proactivity often led to suppressing their child's involvement in decision-making by them not attending their Annual Review, and as a consequence Transition Key Workers felt that they and others may not gain a rounded knowledge of the young person.

In summary Transition Key Workers needed to work with confidence and aim to transfer this to the young person and their parents to manage their changing circumstances. Transition Key Workers understood that they needed to get to know the young person and their parents to have the full and rounded picture to be able to effectively support both parties through the transition process. Transition Key Workers utilised their previous and more recent bank of knowledge and skills gained so they could deal with the tension between managing parental letting go and their change to their function as parents post adolescence and supporting the independence of the young person. Transition Key Workers understood that parents were largely justified in their concerns about the future and that their reluctance was based upon their difficulty hypothesizing the future and the transition process. Working within a person-centred ethos Transition Key Workers were able to gather the views of and manage the difference of opinion between young people and their parents. Modelling person-centredness, whilst not always accepted, had given young people and their parents the opportunity to take part and had given them the confidence to commence thinking about and sharing their ideas about the future. As parents gained confidence Transition Key Workers saw a reduction in their anxiety levels and they began to see the positive outcomes of engaging with the transition process and provide Transition Key Workers with more in-depth information about their children to support preparing for adulthood:

'I've seen parents with high anxiety levels and seen them reduce as I don't block the information flow. I've seen many a negative state of mind and information given can be lost. I've seen and parents have seen it can be different. I've been really happy to see some of the barriers they put up come down'.

TKW6 (Non-Designated TKW with a caseload of 30 alongside project co-ordination)

7.2.4 Key Finding 4: Preciousness and non-acceptance hinders joint working, local co-operation and planning with young people and their parents

Transition Key Workers considered there were a number of barriers to the acceptance of their role. Generally, it had arisen by the confusion as to the Transition Key Worker role and the belief that the role, in some instances, had not been fully explained to other professionals, teams and organisations. Transition Key Workers were conscious that other professionals were reluctant to engage and commence thinking about changing ways of working facilitated by the Transition Key Worker, but where new practice had been modelled (Key Finding 1) there was a greater probability of acceptance. Transition Key Workers reported that they experienced a preciousness that they sensed pervaded through agencies where *'they like to think of us as separate; they (reference to specific schools) don't like the joint working'* (TKW3) and would not actively co-operate. Where Transition Key Workers were accepted and recognised for their skills and knowledge other professionals were more willing to engage as the Transition Key Workers held a deposit of information that they could benefit from receiving and using. The Transition Key Workers acknowledged that they felt that it was just as important *'building relationships with the key professionals, because you need as much engagement and support from them as you do families'* (TKW14) to support young people and co-ordinate effectively. However, building relationships with other agencies has not been straightforward, but as other professionals got to know the Transition Key Workers their doubts and concerns about the Transition Key Worker role subsided.

There was a belief that Transition Key Workers were not always welcomed by professionals they came into contact with, particularly teaching staff, although in one particular school they had re-structured their curriculum and annual reviews to become person-centred. A school-based key worker was seen as a key member of the team who had received favourable responses from their school colleagues. Where acceptance was more prevalent it was based upon previous contact or prior knowledge, for example where the Transition Key Worker had been a social worker within an adult learning disability team and had a willing disabled children team eager to learn and joint work. A critical factor of acceptance was correlated to where the Transition Key Worker was based and the role a Team or Service Manager had in explaining the role to other professionals, which supported Transition Key Worker integration and encouraged joint working across the team and other agencies. Where there had been previous experience of supporting young people it was seen as a *'massive bonus'* (TKW1) and allowed the Transition Key Workers to quickly embrace their new role. This was particularly the case for those who were in a designated post. However, the non-designated were also able to draw up their previous experiences and existing relationships with agencies, which aided recognition and acceptance of their role.

Overall, Transition Key Workers, especially in the initial stages, were apprehensive; they felt others were guarded, inhospitable and threatened by their presence. Schools were singled out, but also other agencies. Transition Key Workers observed that there was reticence to share information, assessments and be open to their presence as contributing colleagues to support young people. There was a belief that *'social services were saying "What do you need to know that for?" Why do you need to know that? Why do you need the Statement?" and it's….because they didn't have an understanding'* (TKW3). Furthermore, one Transition Key Worker was asked for her Curriculum Vitae by a number of schools as to her qualifications and that *'they were trying to think you weren't qualified to be looking after them (young people)'* (TKW4). This Transition Key Worker experienced a social worker refusing to speak to her about young people she was working with, which made for an increasingly difficult situation in terms of supporting and co-ordinating services around particular young people. Similarly, another Transition Key Worker experienced difficulty in establishing a working

arrangement with other professionals who were unwilling to co-operate and typified how many of the Transition Key Workers felt:

> ***'At times I have felt quite unconfident and not kind of particularly welcomed or relaxed within departments, which isn't an easy role to have. I just felt that there hasn't been a great working relationship and I don't know why that is. I think it is because maybe partly because they just feel just a bit threatened….that I'm telling they should be doing things differently maybe'.***
>
> **TKW7**

Many Transition Key Workers described that they were aware that some agencies (reference to children and adult social care) *'just got very precious initially'* (TKW3), which was qualified by *'we were someone new coming in asking…. "Can you go and visit one family, they're concerned about something?" It was like "Who is this person? Who do you think you are?"* (TKW4) and barriers were erected that took time to come down. When engagement materialised from previously resistant organisations they used the Transition Key Workers when it suited them, usually for an activity or undertaking an action that was not in their role description or responsibility. Transition Key Workers were aware that certain professionals were stretched by a large remit and caseload and complied with requests to endeavour to build a firmer relationship and acceptance. Transition Key Workers also expressed that they were subjected to a *'changing the goalpost'* (TKW4) approach from specific schools where they had collected a wealth of information to contribute to young people's Transition Plans, but if that information was not related to education it was ignored and that '*they weren't interested in what was happening outside of School; that's a direct quote, so they didn't use any of that work'* (TKW4). This left many Transition Key Workers frustrated and young people's Transition Plans lacked detail of how a young person wished to be supported in the community or information about what their health needs were.

Finally, from a positive perspective Transition Key Workers, as they grew in confidence and were based in a team with a varied skill mix it engendered further joint working with other teams by providing *'a better understanding and more of an insight into the family and the challenges within the family'* (TKW1). Transition Key Workers

considered that it helped to *'remember also to listen and act, especially when things are getting difficult for the family'* (TKW14) and that by being accepted by other professionals involved with a young person and their family promoted co-ordination and co-operation to flourish to the benefit of all involved in the transition process.

7.2.5 The 'Insider' Analytical Reflective Perspective: the professional experience

In the introductory chapter I declared an interest and the ability to interpret the findings from multiple perspectives. In Chapter Four I shared my parental opinion and experiences of the transition process. I was conscious, whilst interviewing and subsequently analysing and reporting the findings, that my professional opinion, as with parental viewpoint did not influence my questioning, commentary or carry *'conceptual baggage'* (Kirby and McKenna, 1989). As the former Director of a charity promoting key working, intent on delivering the outputs agreed with the Welsh Government, I understood from the researcher perspective that I had a vested interest professionally to ensure that the development of transition key working was as successful as possible and the challenges this presented and how I would address potential bias. I declared that I knew nearly all of the Transition Key Workers interviewed. There was a previous history, they had an awareness of my parental and professional experiences and I felt that they trusted me to report honestly and diligently their views. This I felt was an important factor as they were able to disclose freely their experiences of being a Transition Key Worker.

I was aware as a contributor to Cost and Benefit Analysis of Transition Key Working (Welsh Government, 2012) of the initial five Transition Key Worker pilot sites funded by the Welsh Government post the recommendations posed. This was post approval of my doctoral study proposal. Many of the recommendations had been previously highlighted in my own reporting responsibilities as the project lead, which has been frustrating. The overall analysis revealed that young people and their parents benefited from the support of a Transition Key Worker. However, it was in my view too early in the development to ascertain the full impact, as many of the young people had not reached the age of 18/19 and moved into adult service provision or had only been receiving the intervention for a short period of time. The issue of addressing the impact was latterly highlighted in the final report and identified that the *'benefits of transition*

key working and the potential cost savings are severely constrained by structural factors' (p.80) and it was expected that organisational and operational issues would be addressed by the upcoming reform of the statutory framework related to children and young people with Special Educational Needs. It remains to be seen whether the new framework proposed in the White Paper: Legislative proposals for additional learning needs (Welsh Government, 2014) will deliver structural improvements to the transition process called for by Transition Key Workers within this evaluation. I would qualify this as being a crucial necessity and this was advocated from my professional perspective. Overtime, I have called for a transformation of current transitional processes to bring child and adult services closer together to provide flexibility of delivery and funding, which is largely missing across Wales.

Transition Key Workers reported that they felt that they faced the same structural barriers as parents and had similar frustrations endeavouring to implement change from the grassroots whilst at the same time dealing with higher level change within county, regionally and nationally (Key Finding 2). These frustrations were also voiced directly and without reservation to me in my professional capacity. I was not surprised by this as I faced those same frustrations and obstructions professionally to attempt to change thinking and embed new ways of working. The opposition and lack of commitment at a higher level brought further frustrations in terms of access and support to initiate change and sustain transition key working on a more formal basis, which was my key professional aim.

Modelling change was a crucial aspect to support successful transition for young people. Transition Key Workers were trained in person-centred approaches, but were not always applying the skills learnt to support young people. It was disconcerting that not all of the Transition Key Workers were using those skills to support transition plan development. I was surprised by the lack of evidence of examples Transition Plans. I had developed, as a response to the absence of a plan for my son, a person-centred holistic Transition Plan. I shared anonymous copies across the sites. There were disappointedly very few examples of what would be considered a good multi-perspective person-centred Transition Plan. This was a disappointing and somewhat surprising finding. The will to be person-centred was evident yet, dampened by the non-acceptance of other professionals to think about changing ways of working with

young people and their parents. I will explore this aspect further in the next chapter from the perspective of the Site Leads.

There were some unexpected findings that professionally I had not fully considered as being significant or pivotal, such as the role time potential plays in achieving successful transitions for young people (Key Finding 1). From a professional viewpoint I should have focused more attention to this particular aspect and promoted it more actively. The unexpected outcomes of the *'hands-on'* approach (e.g. taking then out or supporting then to travel train) applied by many of the Transition Key Workers was not a function of the Transition Key Worker role advocated by CCN Cymru. Therefore, there was a varying interpretation of the Transition Key Worker role; predominantly amongst those newly initiated and fidelity issues would need to be addressed. I considered that many of the Transition Key Workers had subsumed the tasks of a Support Worker. Parents in Chapter Five similarly described an element of traditionally what would be considered a Support Worker role. I appreciated, by incorporating some of the function of a Support Worker, it had enabled them to get to know the young people they were working with and build longer-lasting mutually trusting relationships; a key function of a Transition Key Worker and reiterated by parents. It raises the question as to why related young people were not accessing a Support Worker to help with practical elements of care and support packages. However, having time to support the practicalities of daily life enabled the Transition Key Worker to have the opportunity to understand the needs of the young people, which they reported as being valuable (Key Finding 3).

An interesting, yet an unforeseen finding, that despite in my professional capacity relating the importance of professional boundaries, Transition Key Workers expressed that they were a *'friend'* (TKW5) or seen as a '*friend'* to the young person or the parent or both and appeared not to be overly concerned or aware of a potential breach of the l boundary that should exist between themselves as professional and the client (young person and/or parent). The issue of *'friend'* had been explored in the Transition Key Working training designed and delivered by CCN Cymru, in association with Helen Sanderson Associates; key exponents of person-centred practice. Nearly all the Transition Key Workers received the training prior to being interviewed for this evaluation. The issue of *'friend'* was not isolated to one Transition Key Worker, but

was prevalent, with parents and young people similarly describing the Transition Key Worker as a friend.

From a professional perspective, in the absence of reasonable alternatives, key working through the transitional years remains as a good practice workable model. However, the parental stories and experiences have not significantly changed from when I first became involved professionally nearly 20 years ago. The issue of past, given the parental findings, reported in Chapter Five, it was somewhat unexpected not to be referenced by Transition Key Workers or seen as an inhibitor to achieving successful transitions. Where there was mention of parents' previous experiences the Transition Key Worker had not recognised that parents found it difficult to plan as a consequence. A further perspective will be reported in the chapter next as the former project lead for the development of transition key working in Wales.

7.3 SUMMARY

In summary Transition Key Workers had varied experiences, both positive and negative in their role. They identified elements they considered would contribute to a successful transition, which mirrored many of the aspects expressed by the professional participants attending the Stakeholder Workshop such a having a workable transitional structure and system. Having the time to spend with young people and their parents; building a relationship was seen as a crucial factor in aiding their understanding of the transition process alongside the Transition Key Worker gathering a rounded view of the young person; their needs and wishes. However, involving parents took time, particularly where there was resistance to engage and plan for their child's future. Transition Key Workers acted as the counterbalance to parental opposition to planning for the future and could draw upon a young person's enthusiasm and their clear ideas to plan with them by using a person-centred approach. Transition Key Workers who were adopting person-centredness used their skills and knowledge to draw in the reluctant parent. Transition Key Workers had to be skilled individuals to manage the individual nature of each young person's transition; understanding parental anxieties and the worries of young people. The Annual Review process was a particular vehicle for Transition Key Workers to model new ways of working, but also for sharing and communicating with others the wishes of young people. There had been notable

successes in establishing a person-centred review process in both special and mainstream schools.

There was a mixed understanding of the transition process, with a number of Transition Key Workers, upon initial recruitment, expecting that young people were having smooth transitions into adulthood, not expecting it to be fragmented or challenge their skills. Likewise, there were Transition Key Workers who were not aware of their local Transition Protocol and where there was an awareness many Transition Key Workers felt that they did not provide them with information or guidance as how to transition plan with young people and their parents. Transition Key Workers struggled to deal with and manage the differences between the support and services provided in childhood and that it was unlikely to be matched in adulthood for many young people, but used their skills and knowledge to think creatively to consider other options. A Transition Key Worker had to be a specialist, but also a generalist at the same time. This was specifically the case for Transition Key Workers supporting young people with Asperger's Syndrome who were unlikely to access adult social care.

Finally, Transition Key Workers reported that there had been barriers to them undertaking their role. The barriers were specifically related to their role being accepted by other professionals and as a result they struggle to engage especially in the early days of their employment. Nonetheless, Transition Key Workers were persistent and built relationships with key professionals. Transition Key Workers also felt that there was a level of professional preciousness which made it difficult for the Transition Key Worker to gain a holistic view of the young person. Transition Key Workers recognised that there had been confusion about their role initially. The persistence of the Transition Key Workers to prove their worth had won over unwilling colleagues.

The next chapter will build upon the findings from Transition Key Workers with the perspective of the Site Leads (e.g. project managers, service managers and local commissioners) by exploring their experiences of developing transitional and key worker services, the impact on themselves, the Transition Key Workers and the young people and parents who were being supported.

CHAPTER EIGHT
INTERVIEWS WITH SITE LEADS

8. INTRODUCTION

This chapter builds upon the findings described in the preceding three chapters by reporting the qualitative findings from interviews with professionals identified as the Site Leads[18]; the responsible local co-ordinators for developing Transition Key Working and Transition Services in Wales. In the context of the previous chapters, including the Review (Chapter Three), the Site Leads provided their own unique contribution to ascertain what constituted a successful transition into adulthood for young people. Parents and Transition Key Workers identified consensually the importance of having a transitional structure, but that the current framework was not as workable as expected nor did it provide a seamless experience. Parents called for a better understanding of the transition process. Transition Key Workers worked towards ensuring that both young people and their parents understood and encouraged their engagement and participation.

Transition Key Workers and parents considered that by building relationship, getting to know both the young person and their parents they gained the *'whole picture'* (TKW2), which contributed to achieving good outcomes and a potential successful transition. The evidence suggested that Transition Key Workers were not feared by parents as other professionals had been through previous contact, which had left parents anxious, worried and resistant to change. Transition Key Workers similarly experienced episodes of tension between themselves and other professionals involved in local transition processes, often experiencing non-acceptance of their expertise, which left them disconcerted, but determined to be recognised.

The Transition Key Workers indicated that they needed a committed, knowledgeable and understanding manager to support their enterprise. Transition Key Workers promoted an ethos of working together and endeavoured to remove professional and organisational barriers to be active co-ordinators, but required support to achieve that

[18] To be referred to as Site Leads unless otherwise stated throughout this chapter.

aim. The Site Leads acted in this capacity encouraging and supporting the Transition Key Workers, laying down a conduit through their interaction with strategic leads and organisations to promote their role.

This chapter explores the perceptions, experiences and contribution of the Site Leads and expands to provide an inclusive understanding of *'What makes a successful transition into adulthood for disabled young people?'* by reporting 5 key findings. The chapter concludes with my professional perspective as the project lead and supporter of the Sites Leads. This is the third perspective to be presented and upon my personal parental and professional viewpoints described in Chapter's Five and Seven. A further perspective will be described more latterly in Chapter Eleven.

8.1 INTERVIEWS

7 interviews were conducted, which encompassed 11 local authority areas. Site 2 covered 4 local authority areas, with one Site Lead. In total 12 individuals took part in the interviews across the 7 Sites. The Site Leads were interviewed concurrently with the Transition Key Workers interviews over a period of 12 months which commenced in October 2012. 5 of the interviews were conducted, as agreed, in their place of work. Two interviews were conducted via teleconferencing. All interviews were audio recorded. Interview times varied from 67 minutes to one lasting 1 hour and 55 minutes

8.1.1 Characteristics of Site Leads

Table 14 sets out the basic physiognomies of the Site Leads interviewed. To avoid recognition and maintain confidentiality each site as with other participants in this research were issued with an identification code.

Table 14 Sites Characteristics

Site ID	Interviewee status	Location	No of TKWs	No of young people supported*
S1	Project Manager	South Wales valley county	2	26
S2	Project Co-ordinator	South East Wales counties	3	94
S3	Principal Officer (Adult Services)	North Wales county	1	31
S4	Head of Service (A) Commissioning Manager (B) Transition Team Manager (C)	North Wales county	4 (check)	No data available as a newly formed service
S5	Project Co-ordinator	North Wales county	8✦	89
S6	Head of Service	South Wales county	1	19
S7	Project Manager (A) Teacher (B) College link (C) Transition Key Worker (D)	South Wales county	3	97

*at end March 2013 when funding ceased

✦Non-Designated Transition Key Worker

8.2 MAIN FINDINGS

Table 15 represents the key findings and descriptive themes, which are reported in this section. A detailed thematic map is presented as an appendix to this thesis (Appendix Twenty-Nine).

Table 15 Key findings and descriptive themes

KEY FINDINGS				
Steering change	**Continuity of provision**	**Working together**	**Tailor-making Transition**	**Sustainability & Legacy**
DESCRIPTIVE THEMES				
• Having a structure • Local Transition Protocol/ procedures • Managing change	• Reforming provision and delivery • Multiple exit points • Differing eligibility criteria	• Building relationships • Working in partnership • Personalised approach	• Challenging service-led mindsets • Value of person-centredness • Individualism • Involving young people & parent participation	• Short-termism • Making it *'doable'* (S5) • Monitoring the delivery

8.3.1 Key Finding 1: A clear strategic steer was required to support the management of change to deliver a workable transition process

The Site Leads worked within the same structure and systems as young people, parents and Transition Key Workers explored in preceding chapters. The Site Leads felt strongly, from their perspective, that there needed to be a clear steer from both the Welsh Government and at a local level to drive forward the development of transition key working and support the management of change in transitional practice across multi-agency partnerships. Site Leads took *'several stages to move forward to strengthen partnerships….it's been a bit of a scatter gun approach'* (S6) to obtain support for the implementation of transition key working. They felt that unless *'it is all mapped together'* (S6) they were anxious about advancing key working and transition services at a local level. Site Leads considered it would be a real challenge to meet the expectations raised by what would be for many a short-term intervention and needed more time to embed key working within transitional practice. Positively, in some local authorities, having a local definable pathway through the process, with the benefit of the

Transition Key Worker intervention, had *'helped social services planning, but more importantly it's helped the family feel that they're not in no-man's land come their (young people) 18th birthday'* (S1), but there were concerns about sustaining delivery without strategic commitment.

Site Leads wanted an overall vision established by the Welsh Government for transition processes so that they could clarify their remit and the role of the Transition Key Worker in the context of current and prospective policy. It was suggested that teams across children and adult service providers and other adjunct organisations were *'fearful or maybe that they didn't understand'* (S2) their responsibilities and wanted to maintain current provision before considering an ambiguous future. Site Leads felt that policy leads did not have a full understanding of the complexities of the transition process and were too education-focused, not appreciating the implications for all involved, especially adult social care. There were concerns that proposed reforms[19], where there was little reference to transition in *Forward in Partnership* (2012) and within the Social Services and Well-being (Wales) Act (2014) would continue the tendency for young people to *'fall(ing) through the gaps, the one's we are now trying to pick up (reference to young people with Asperger's Syndrome)'* (S6), as they would continue to not meet the threshold of current local authority eligibility criteria. It was felt that transition needed to be high and a constant priority on the strategic agenda, but that, for example, the National Services Framework (NSF) for Children and Young People and Maternity Services (2005) had become outmoded and not being driven as an important policy framework. Site Leads considered that the key principles and transition key actions remained sound and pertinent to them as direction-finders.

Site Leads called for the development and implementation of an agreed national transition process, which would set out who should be co-ordinating local transition procedures by setting out the responsibilities clearly in providing support services during and in the post transition phase. At a local level many of the Site Leads introduced a strategic and operational multi-agency transition structure (e.g. Transition

[19] Legislative proposals for additional learning needs (2014) (replacing the Statement of Special Educational Needs and the Social Services and Well-Being (Wales) Act (2014) due to come into force in April 2016

Planning Groups). It had forged improved relationships between child and adult services, which had been previously tenuous and guarded. This had provided an early win in progressing Transition Key Worker development. Having regular meetings functioned well in identifying and prioritising young people and nominating a Transition Key Worker to support individual young people, but it only worked well when there was commitment from agencies to attend. This was especially problematical where complex cases were being discussed and required health representation. Their absence was frequently recorded, as were representation from adult social care.

The commitment to steer the work and forward plan was varied, with senior management support being dependent upon an individual's interest in driving forward transition as a local priority; that *'it's the personalities; it's the individuals that are involved'* (S1) and *'there are some personalities involved at a senior level who just don't seem to be able to resolve things amongst themselves in a very easy way'* (S2) to agree and support the local transition agenda. One Site Lead felt that as the *'work needs energy'* (S5) not being supported or having the work directed or supervised, in an atmosphere of uncertainty due to organisational re-structuring, led to periods of ill-health, morass and concern that:

> ***'We've given young people and their parents a vision of what it could be like and now we might have to take it away if we are not able to sustain it'.***
>
> **S7: A**

Site Leads struggled to maintain their *'energy and momentum up and morale…..I've tried to keep it hugely enthusiastic, but I've hit the wall myself now…..of disappointment……It really is a wall and because I get no support internally from my manager'* (S1) made it problematical to continue to instil fervour amongst Transition Key Workers as senior management interest and support appeared to diminish. Conversely, where there was senior management commitment and proactive interaction, the need to consider the further development of transition key working was growing and a local priority. Site Leads felt valued and their work commended.

Site Leads reported that there was a varied local understanding of the transition process, despite Transition Protocols being in place or in development with multi-professional

involvement. A number of protocol examples were selected from the participating local authority areas and represented in Chapter Three. However, one Site Lead felt that *'it was just a word (Transition) before and there was no background understanding or knowledge'* **(**S1). All of the Site Leads considered that having a local protocol gave them some direction in operationalising the transition process; giving a framework to build upon. Where protocols were considered a comprehensible guide, consultation processes had taken place, including with young people and parents and attempts had been made to find a balance between *'giving people all the information, but without overwhelming'* (S3). Site Leads considered that a protocol had been useful in directing professionals and had resulted in less inappropriate referrals and better understanding of the process of transition. Nonetheless, it was felt that a protocol, in itself, had not majorly provided a better understanding of the differences in legislation or how to effectively plan with young people and their parents. Where organisations or teams were not referencing the local protocol *'they either ignore it completely and start from scratch and re-invent the wheel so many times, and so much energy has been wasted re-inventing the wheel'* (S4:B). Site Leads considered that a Protocol was not seen as a multi-agency tool despite multi-agency sign-up and mirrored the findings described in Chapter Three, where many of the protocol examples were extensively education-focused. A number of the Leads cited that there were examples of professionals, both working with child and adult services that were unaware of the existence of the local protocol as the directing framework. Awareness was more prevalent where a Transition Team had been developed and issues related to differing legislation and funding streams were beginning to be addressed, but that:

> ***'It's quite complex…because you're mixing children's services legislation with adult services legislation and you're dabbling in them both, which is not easy'.***
>
> **S4: C**

There was an acceptance that there needed to be change and that they had to *'jump at some point'* (S4) and transform structure and systems and transitional practice and embed Key Working, but there was resistance; set against a backdrop of what was coined local '*politicking'* (S1). This reflected the findings reported in the previous chapter as other professionals were *very 'precious about their domain and their role,*

and people didn't understand that we were there to complement not duplicate or pinch roles' (S1). There were frustrations amongst Site Leads as there was a reluctance to consider changing ways of working or that professionals and agencies considered *'like "it's all sorted now", but it's not, is it? It's never going to be sorted?'* (S3). They described tensions and conflict where they had not expected it and the Transition Key Worker role had not been readily welcomed by certain schools, social workers and other professionals supporting young people:

> ***'At the beginning it was not easy, we were new to key working and also to person-centred thinking and needed to get practice and culture changes to happen. There was a danger that the role (Transition Key Worker) would become dumb downed if there wasn't organisational change. I suppose people taking on the change, in some cases there was scepticism, but they are now our key advocates of key working and person-centred planning'.***
>
> **S7:A**

However, there were citations of acceptance and the ability of professionals to change working practices. Particularly noted were mainstream schools, rather than special schools, in which Transition Key Workers were seen a *'complimentary service'* (S1). Site Leads strived to embed Key Working and person-centred approaches, and although there were schools who were more acquiescent and co-operative, others were less so and having an *'open mind'* (S7: A) was not always apparent. They challenged assumptions, but were *'managing the spinning plates, because of the number of people involved and it needed someone at the centre to keep the plates spinning'* (S7: A) to take forward change. The pressure to succeed was largely left to the Site Leads, rather than a more global multi-agency responsibility.

As a final point, Site Leads considered that it was '*clear in that we need to maintain and further develop transition planning and person-centred key working and also it's about further developing relationships'* (S6), but that to do so they required the direction being set by the Welsh Government to enable local strategic leads to prioritise and act.

8.2.2 Key Finding 2: Continuity of provision remained elusive

The continuousness of provision from children to adult services remained as one of the most significant challenges for Site Leads; how to manage a transition process whilst they simultaneously attempted to reform the provision and delivery. Inconsistencies in local delivery, lack of engagement and professional and parental wariness were set against an environment of uncertainty, impending redundancies, decreasing resources and funding and Welsh Government reform. Site Leads attempted to manage change by modelling and promoting continuity within a culture they considered was resistant to transformation. They had to deal with or pre-empt local re-organisation and the move towards regional delivery. They were concerned about how the Welsh Government reform of Special Educational Needs would impact on attempts to improve continuity between child and adult services with the continued existence of multiple exit points for young people through transition into early adulthood.

Tracking young people was seen as an important element to aid continuity; looking *'at provision from a young person in children's services coming through to adult services has helped them to figure out the type of support young person is going to need into adulthood'* (S2). However, Site Leads highlighted that it was not always easy to predict or prioritise as young people had to wait many months for adapted accommodation for example. Therefore, continuity of provision from a social housing perspective was difficult to manage to *'generate the sort of detailed planning information we need….we haven't figured out a way of doing that'* (S2). Positively, planning continuity of continuing healthcare provision, in some areas, had pinpointed young people at the age of 14 or 15 who would be likely to meet the continuing healthcare criteria. It gave Continuing Healthcare Leads advanced notice of young people who would require a significant adult care package enabling them to start planning, having gained the willingness of Health Boards to engage at the earliest opportunity. This was not the case in other local authority areas where Site Leads found it difficult to engage at a senior level and have early conversations to ensure a seamless transfer of health care support and services.

Site Leads confronted and challenged the differing structures, systems and eligibility criteria between child and adult services which they saw was an inhibitor to continuous

service provision. Moreover, and reported under Key Finding 1, there was a concern and disappointment that the Social Services and Well-being (Wales) Act (2014) focused on those with the most complex of needs where there was an expectation that they would be *'more or less guaranteed some kind of service, but if national eligibility criteria framework[20] is set at substantial it's going to make things worse on the ground and we aren't going to be able to do prevention work'* (S6) and continuity of support is less likely despite an all age framework. They considered the content of the Act to be adult-focused in language and description and did not address the late engagement of adult services, which was the current default.

The Transition Plan was seen as the young person's vehicle to plan in a co-ordinated way to promote continuity. Site Leads considered that more training for schools was required to understand the importance of continuity and their role in planning with young people. In terms of continuity, the Transition Key Worker was seen as an antidote to disconnection and discontinuation; that *'they were the continuity who could explain to new staff or new professionals or anyone who became involved in the young person and the family, holistically the background, summing up very succinctly, which took away from the family being exhausted answering the same questions time and time again'* (S1).

8.2.3 Key Finding 3: Working together challenged professionals and organisations

Similarly, reported in the previous chapter working together and developing relationships and partnerships featured as an important factor in developing transitional key working practice and support. However, Site Leads considered that it was limited by the time people could give to commit, develop, share and support to build a personalised approach, but that it *'did take some time….we've actually got to the stage now where we're pretty well solid….but it's took a long time (reference to 8 years in the development and acceptance of a Transition Team)'* (S4: C). Site Leads had coherent

[20] National Eligibility Criteria for Social Care will replace the current criteria used by a local authority to determine eligibility for services, which is based on definitions of low, moderate, significant and critical levels of need.

and consistent messages about the importance of working together; but it challenged their communication and persuasive skills to gain credibility and acceptance of the tasks they were set. They needed to invest time to build on current and develop new working relationships with professionals, teams and organisations, but highlighted that there had not been enough time to embedded transition key working in the timespan of the grant, but that the *'skills developed has exceeded expectation (reference to the Transition Key Worker)'* (S7: A). They appreciated that clearer guidance could have been given to partners agencies; that it *'was so vague, it didn't inspire them either (reference to local response to develop transition key working)'* (S1). Two of the Site Leads were managing two ESF funded projects which, for both, caused issues with apportioning time and conflict between the rationale of managing two ESF projects with two reporting mechanisms, and the *'aggressive attitude'* (S7: A) Site Leads encountered from the other ESF funding initiative.

Building relationships was a significant issue, particularly with schools. Certain schools were not the only reluctant partner. Social services were also reported as being difficult to engage. Site Leads considered that a paper-based partnership approach materialised rather than early active engagement beyond original organisation sign up to develop transition key working and, '*in reality that wasn't (reference to working together face to face) that didn't happen on the ground, a lot of things were said, but didn't happen and...(we were) always viewed with suspicion'* (S1). Site Leads worked hard to build relationships and were open to dialogue to dispel doubt. In addition to organisational reluctance there were accounts, that although both child and adult services had the skills and a mixed knowledge of the transition process, there was a refrain of *'I can't even touch that element of it because that's transition or that's for the Key Worker to do'* (S3). A global responsibility to ensure that young people were supported by all through transition into adulthood was absent.

A number of the Site Leads reflected that the development of transition key working had acted as the means to bring key professionals and organisations together, that it challenged the relationship between child and adult services, which was seen as a key affiliation, *'but the culture wasn't there'* (S5), *'the relationship between the two wasn't there, it seemed that they didn't want a relationship, they (reference to adult services) didn't want the referrals'* (S6). The Site Leads needed to have *'confidence in other*

agencies, but that they also know that when we say we can deliver and that we will deliver….getting to know the senior manager in adult care, building that relationship has been important' (S5) and supported their work in bringing people together.

Nonetheless, there was an attitude of leaving it to others, of tasks attributed ignored entirely or not always delivered as planned. The Site Leads reported issues with competition between organisations, which hindered working together; that schools *'think partnership working is they direct and dictate'* (S1). There were more successful attempts to work together and other agencies had seen the value of transition key working and the role it played in bringing people and organisations together. It was felt that it was important that organisations wanted the same course of action to improve transitional practice, but that it had not been straightforward with local re-structuring, especially the re-organisation of Local Health Boards during the early stages of Transition Key Worker development. One Site reported that they felt it had taken two years to:

> ***'Unearth the people who were going to be taking forward, as they didn't know themselves. Once we started identifying the people who can deliver on those….to try and make things work better'.***
>
> **S2**

Engagement was dependent upon organisational priorities; not always being the same due to varying target driven frameworks. Site Leads considered that funding was a barrier to working together even when there was a joint signed-up responsibility. It was made more difficult when set against a *'financial backdrop where anything which isn't a statutory duty is going be squeezed out, so, as the Welsh Government cements it (reference to transition key working) in as something that has to be done it probably won't be done'* (S2). Despite the reluctance to work together, the Leads considered that there was a willingness to endeavour to collaborate but that the pressure on individuals such as high caseloads and resource restrictions inhibited co-operation and consistent attendance at meetings due to capacity issues (adult services cited) and was *'causing a few issues, but if there is a lack of capacity, then it makes it really difficult for us'* (S6).

To conclude, providing a personalised approach was seen as the main mechanism to encourage working together, not only with other professionals, but with young people

and parents; planning together. The direct contact allayed fears by taking a practical stance, ensuring that when a promise was made it was not reneged upon, which engendered trust. Site Leads praised the dedication of the Transition Key Worker in challenging the lack of engagement; that they had been resourceful *'turned difficult things into positive situations and that even though knowing the short-term funding is there they have kept the momentum going until very recently, and still been coming up with new things……they're quite an inspiration'* (S1). Valuing each other's contribution promulgated relationship building and joint working, which Site Leads considered important.

8.2.4 Key Finding 4: The implementation of person-centred practice tailored to an individual's transition challenged a prevailing service-lead mindset

Site Leads were conscious of organisations maintaining a service-led mindset rather than considering the individual nature of a young person's transition. Site Leads struggled to achieve early parental involvement, but understood the importance, but the *'hardest bit is where parents don't get involved and aren't interested or don't appear to be interested that is really hard'* (S2), which often led to a traditional service response to provide services. Fitting young people into the available services, rather than creating specific person-centred support and services continued to be the norm, despite modelling alternatives. It was considered that the transition process was not sufficiently personalised and not based within the spirit of the social model of disability. Nonetheless, Site Leads supported Transition Key Workers to think creatively, drawing upon a person-centred approach to think about alternatives to standardised support to shape individual provision. Site Leads called for *'clear pathways for each young person, which flows all the way through, but the Transition Plan needs to be simplified….we mustn't see the protocol and transition plan in isolation'* (S6) and perceived such pathways to be ones which needed to be characterised by a bespoke rather than a more generic approach. However, within current structures and systems Site Leads felt that pathways were not malleable to individualism, but developing a person-centred approach to conduct Annual Reviews offered an opportunity to focus on the young person individually. There was a cohort of teaching staff who undertook the training that *'knew nothing about it (reference to person-centred thinking and planning), at the end of the second day (reference to the training) although I didn't feel*

that the training was everything we could adopt in school….I did feel we wanted to look at it' (S7: B) and took forward delivering a more person-centred style Annual Review. There was an alternative the view that schools, in particular, were not listening and responding despite having received Person-Centred Review training; melding it to suit their requirements rather than for the young person and parent.

Small pockets of good practice in conducting person-centred Annual Reviews were reported, which had grown as professionals became confident to think beyond the traditional way of holding a review, usually without the presence of the young person and in some cases the parent. Previously, young people had been unable to share their thoughts about what they wanted to happen in the future, with decisions being made based upon the views of their parent, if in attendance, or by professionals drawing upon what was traditionally available in-house (e.g. Day Opportunities) without considering broader options. From a positive perspective, where person-centred reviews were being conducted Site Leads reported that parent participation increased. Improved attendance at Annual Reviews, whether conducted in a person-centred way or not was considered to be as a direct result of Transition Key Worker proactivity, but there was a concern that when Transition Key Workers were no longer in post that parents would be less likely to be present. Nevertheless, Site Leads witnessed a changing parental attitude as transition planning became more thorough and parents changed their way of thinking, became more upbeat and happier to talk about the future and alternatives to standardised support. The Transition Key Worker was seen as the person that made them *'feel comfortable, make them feel a valued human being who (have) got a contribution to make, that we will listen to and we won't shout them down, or fob them off'* (S1). One Site Lead reflected that:

> ***'Having the support of a dedicated Transition Key Worker has given the family the opportunity to openly discuss many issues that they may have been afraid to raise with some professionals. They are working with no statutory agenda; gives the opportunity that the Transition Key Workers can hear everything, reflect back and share as appropriate with other professionals'.***
>
> **S1**

There was a lack of recognition that the young person's Transition Plan was their own; adjudging that the content was sparse, generic and regularly unrelated to the young person named. Developing a Transition Plan was considered as an exercise to *'just tick the box of "I've met, I've done this, I've done that"..... it was almost the School's, hidden on a shelf, in a box'* (S4). The Transition Plan was not seen a *'living document'* (S1) to tailor-make a young person's transition. However, with the training received and the persistence of the Site Leads and the Transition Key Workers parents began to voice that it was the first time, through person-centred thinking, that they were being listened to and the *'one- page profiles that the staff have created parents (were) saying "You've summed up my child there in a nutshell" and that is so valuable to pass on to anyone who is going to work with that young person because it gives them a real good snapshot and it's so succinct and simple....because they're so personal'* (S1). It was noted that parents had not realised what their child's interests were and their thoughts about the future and were able to think about supporting the young person to move forward by planning around a particular interest or activity.

Tailoring transition to the individual young person was a relatively new concept for services as young people had been *'slotted into whatever services are out there for them'* (S3) and defied a service's ability to respond with bespoke provision based upon choice. A wider horizon-thinking was missing. Individualism, alongside providing wide-ranging opportunities was considered, but Site Leads felt it to be too complex and raised expectation. They felt it was important to have realistic conversations about what was possible to achieve a young person's hopes and dreams:

> ***'Being given more opportunities brings its own complexities to it. There are more choices to be made, so that can be difficult for any young person, never mind someone with special needs. In some ways, when they were being done too their world was limited and their expectations and aspirations were low. Now we've raised expectations and aspirations and supported them to dream….to dream realistically. That's difficult'.***
>
> **S1**

Site Leads considered that they had provided a *'gold service'* (S3) through the provision of Transition Key Working. There was the expectation that an adult services professional would make regular home visits or take young people to an activity as the Transition Key Worker had and a personalised approach would remain. Therefore, when young people moved into adult services *'there was a massive shock'* (S3), with the need to *'almost weaning off at the other end of transition to make sure, for all the will in the world, the numbers that are in Adult Services, they're not going to get the same person-centred kind of service'* (S3). Site Leads were faced with young people having to fit in with what was available irrespective of what had been identified in the young person's Transition Plan. This had added to the frustrations Site Leads felt trying to persuade organisations to consider creative alternatives. Their persuasiveness was limited by their position in the local authority hierarchy and what they perceived to be a service-led attitude to delivery. Nonetheless, their cogency continued and they were not deterred and worked towards creating alternatives, which adult services had not anticipated.

To conclude, the transition process is *'extraordinarily individual for each young person, for each family'* (S5). However, the Site Leads experienced a service-led approach to providing support and services beyond adolescence. Tailoring transition challenged organisations to comply with young people's wishes outlined in their Transition Plan where such a plan existed. Implementing person-centred Annual Reviews had for some young people and their parents encouraged involvement and opened up discussions about the future. Individualism was seen as complex as conformity; providing support and services based upon needs as opposed to accepting what was available and traditionally delivered. Where person-centred Annual Reviews were being conducted it had given young people the opportunity and space to think about where they fitted into their family structure and within local community. There was the view that organisations needed to acknowledge that *'one size doesn't fit all and the Transition Key Workers role demonstrated that beautifully; that working at different paces with different people at different times is what people value and is vital for them'* (S1). In some cases the Site Leads were able to support young people *'who don't actually fit into the boxes we've created'* (S6) and individualised their transition, but to sustain that

support required the continuation of funding and commitment to transform the transition process.

8.2.5 Key Finding 5: Achieving sustainability was problematical

The Site Leads indicated that, whilst grant funding was helpful in the short term, sustaining Transition Key Worker provision post-funding was difficult due to the local authority deficit and resource-based worries faced by Health Boards. Site Leads considered that there was the danger organisations would resume what was customary prior to grant funding and that the Welsh Government might *'turnaround and say look we've spent £3m on this (reference to transition key working), so therefore we have done our bit and then lets carry on as normal'* (S2) and the gains accomplished would dissipate. Site Leads suggested, although grant funding was a means to change practice or develop innovation, the short-termism of grant funding was a significant issue. A *'small investment…..we've had a big output; it's always difficult to measure preventative interventions'* (S6) was an accorded message, but that time was needed to embed new ways of working, particularly when dealing with a complex intervention. Site Leads appraised that grant funding did not foster sustainability; it was a short fix, based upon their experience of other grant funded work. The Early Support programme funding was highlighted as an example of creating a scheme of work, which was not being sustained locally.

Site Leads felt there was a lack of appreciation of the benefits of the Transition Key Worker intervention in changing the life course of young people and their parents by policy leads, not accepting what they considered to be significant and reportable outcomes of the their outputs.. They believed that they had achieved good outcomes for some young people who had received the intervention of the Transition Key Worker. Sites Leads resolutely held that a *'huge effort has gone into it, concentrated effort in a really short space of time, and huge leaps made'* (S1), but were concerned that the momentum they had created would wane and the expertise would be lost without continuation of funding. Nonetheless, it was believed that a *'ripple effect'* (S2) had been generated amongst organisations who had the *'clearest idea of what it was that they wanted because they were the ones who first had those discussions with parent carers'*

(S2) about what the transition process should look like and were guided by parental views and experiences.

Site Leads reported that there was a tangible shift towards moving the focus from the negativity expounded by parents and professionals of the transition process to a more positive stance by *'making key working doable'* (S5). A negative attitude amongst parents was recounted, but that through the delivery of key working parents had seen it could be different and *'some of the barriers they put up have come down'* (S6). From a hierarchical perspective, one Site Lead felt that, at a senior management level, they only wanted to hear about the negatives to *'fix them'* (S1); to be shown in good light and the positives achieved were taken for granted, but that did not mean key working would be sustained at a local level. There was a lack of acknowledgment of the local effort to create positive outcomes for all involved, especially supporting parents to see the progression their child had made towards leading independent lives. Site Leads felt that, whilst parents may have become more positive in their use of language to describe their children, professionals (teaching staff), despite training received, maintained a focus on the negatives to prioritise key actions, without taking into account what the young person or their parent felt to be important to take forward.

In terms of legacy, bringing people together to review, remodel or develop a new local Transition Protocol was seen as a positive outcome of the development of transition key working and:

> ***'The fact that we got a Transition Protocol and a multi-agency transition group in each area so that they become part of the structure or legacy to make a difference or got a chance of making a difference'.***
>
> **S2**

Ancillary to the existence of a Transition Protocol/Pathway, but seen as a critical factor to achieve a successful transition for young people was that the Transition Key Worker role had '*exposed and pulled together a number of partners to have clearer open communication with one another'* (S1). Adopting a person-centred style of working had *'demonstrated the importance of continual communication flowing freely back and forth*

so everyone is at the same place rather than waiting for an Annual Review to be told something huge has happened in the youngster's life' (S1), whereas the administrative course was to wait until the young person's next Annual Review.

Site Leads had a sense of satisfaction in young people gaining confidence. Parents also began to have the confidence to let go and support independence. They considered that this was as a direct result of the creativity and flexibility of the Transition Key Workers, who were not *'capped by parameters'* (S4) and had the time to spend with young people to gain their confidence and nurture a trusting client/professional relationship. Site Leads suggested that the Transition Key Worker had demystified many of the assumptions parents held, based upon their previous poor contact with services and had taken the fear away. One Site lead firmly believed as an outcome:

> ***'I am convinced that for some of the young people who X (Transition Key Worker) is working with (that) it's avoided the likely reality of breakdown. She's had time to visit to problem solve and work with the families, introduced strategies. What has worked well is that she isn't case managing as the social workers in the team here…She can go in at short notice to hold families together and we need that. The transition social worker in those terms has too many cases and with X's (Transition Key Worker) post we can move forward transition planning'.***
>
> **S6**

It was believed that the Transition Key Worker role added a certain *value to the work....it is quite an important role and as the time has gone on I feel quite strongly about the importance of maintaining that type of key worker or support worker type of role* (S7: A) to support young people and their parents through the transition process. The biggest outcome and sustainable legacy was that *'there has been a transformation; the quality of people working with young people has been effective and the key working with young people, young people are now attending their own reviews….parents are now attending….contributing more than they did before. Before the school weren't always able to keep in touch with parents'* (S7: B).

The impact of Transition Key Working for young people and their parents had been significant through the lenses of the Site Leads. They had been diligent, thoughtful and committed and had drawn in people who had previously been dismissive or wary of changing their practice after seeing the benefit of Transition Key Worker practice. However, Site Leads were fearful that converted professionals and their organisations would:

> ***'Revert quite quickly…we've made a beautiful garden and it won't be tended and it will go back to rack and ruin really quickly. You could have a forest really… it will revert back to wilderness because there's no one there to tend it There's no Gardener, there's no one to water it and that was the beauty of the Key Worker'.***
>
> **S1**

Site Leads were convinced that the work they had developed had given excellent value for money, avoided potential crisis situations for some young people and that the Transition Key Worker had avoided the likely reality of breakdown. Site Leads valued the Transition Key Worker role and that *'home visits aren't all outcome-focused, there are some that you just have to go and listen to somebody's story'* (S3), but there was a lack of understanding of the value of achieving soft outcomes, which were difficult to measure due to their individual nature. There was an entreaty, to ensure as an endowment, internal and external regulation of local transition processes. Site Leads suggested that collating information from Transition Plans would promote consistency, quality and monitor the outcome of a young person's destination. Where local data had been collected it highlighted that they were now conversing with young people and their parents and *talk(ed) about the child as a whole child rather than just the education of the child'* (S7: B) and their Transition Plans reflected their holistic approach. Quality checking Transition Plans to evaluate their impact was seen as a sign to develop local performance indicators to begin to measure the progress of young people through into a supported adulthood, but Site Leads considered that there was no signal or movement from the Welsh Government to support such a development.

Higher level monitoring was also called for, but Site Leads recognised that one of the problems was that, at a local strategic level, the Children and Young People's Partnerships appeared not to be the active body or had the status to monitor or act as the delivery arm of the transition key actions of the National Service Framework for Children and Young People and Maternity Services (2005). There was a concern that to continue to prioritise and sustain transition services and maintain Transition Key Working there was the danger it would be *'sucked into some sort of larger planning framework so obviously the priorities are going to be sort of less focused on'* (S2). It was considered that irrespective of the Welsh Government trying to keep transition issues high on the political agenda; local prioritisation had degenerated and sustaining transition key working post grant funding unlikely.

Finally, new thinking emerged to develop and utilise the skills of Transition Key Workers to work across the lifespan from birth to older age to cover the many transitions that take place, for example, from Special Care Baby Unit to home, through into nursery, primary, secondary into early adulthood and onwards. Site Leads considered that the transition key working model was transferable to give people of all ages and needs dedicated time as currently *'it's so unknown in today's fast society; it's a luxury….it shouldn't be a luxury….because it makes (Transition Key Worker) a positive difference and it saves, it's less to spend and it gives people a purpose'* (S1).

8.2.6 The 'Insider' Analytical Reflective Perspective: Joint Project Lead

I reported in previous chapters my ability to provide commentary from multiple perspectives; conveying firstly my parental observations (Chapter Five) and secondly (Chapter Seven) as a professional supporting Transition Key Workers in their endeavours to support young people and their parents through the transition process. In this section I consider, as the former joint project lead with the Support for Learners Division, Welsh Government, my experiences supporting the Site Leads in developing transition key working. My professional position made it possible for me to gain an insight into the workings and priorities of the Welsh Government, Local Authorities and Health Boards to support Site Leads and Transition Key Workers by bringing all parties together on a regular basis to share information, expertise, consulting on specific aspects and evaluating progress. I had an established longstanding relationship with a

number of the Site Leads through my role as the Director of CCN Cymru which assisted in gaining their involvement in this research.

My knowledge of key working and the transition process was well known and when approached to consider the use of the £1.5m allocated by Welsh Ministers, in the form of a grant to develop Transition Key Worker services, my response was *"please do not pilot"*. I had previous experience of allocating grant funding at a local level in a related field, where sustainability of funding in perceived comfortable economic times, was not always successful. Issuing grant funding and instigating a pilot approach was and remains the Welsh Government's rationale to respond to deficient or poor practice or provision, usually on the basis of consultation recommendations, by trialling new initiatives as an antidote. However, geographical inequities were apparent from the outset as there were counties with established key working precepts, with knowledge of what worked, particularly pre-transition with three counties having long-standing key worker provision. Two of those counties received the original pilot and matched ESF Reaching the Heights grant funding against those counties, which had not had a history or experience of key working with nominal amounts offered. In my view it created a classified order of those counties well established to develop key working through the transitional years, a middle order of those counties which were open to change and a lower rank of counties who were not fully able to express how they would best use the grant funding. Non-ESF Objective 1 status, apart from one county, received no funding. From my perspective, it was the counties that were open to change or lacked an understanding or where transition provision was considered inadequate (Data Unit Wales, 2007) where there was a need to provide support to improve local delivery. I considered that, by providing at least a seed amount to all, conversations could begin and would provide the opportunity to bring people and organisations together locally to think about improving their co-ordination and relationships across child and adult services. This could be achieved by demonstrating and, in turn, cultivating an acceptance to change transitional practice through transition key working.

Site Leads highlighted the importance of modelling to gain acceptance and change both strategic and operational working practices (Key Finding 2). A level playing field for access to key worker support should have been the goal. Yet, a hierarchy was in the making by piloting, placing a number of local authorities who were already active as the

expected frontrunners. It could be argued that those active counties would create a chain reaction effect, and whilst expertise was shared, those counties without experience struggled due to the lack of understanding and commitment of local strategic leads (Key Finding 1) and non-acceptance of the Transition Key Worker role by other professionals (Key Finding 3), which made the early stages of the development drawn-out and fraught.

Site Leads expressed the same frustrations I felt. I faced similar obstacles related to acceptance. However, I was somewhat surprised by the reluctance of certain organisations to engage, as the need to improve the transition process was widely agreed and reported as a local priority area. There was a culture of blaming each other (Child and adult services) for the lack of involvement to progress improvement. This was more prevalent that I expected. Nevertheless, it was heartening that where there were pockets of early resistance amongst professionals they became the principal local activists. This enabled the Site Leads, supported by the project leads, to work with them to progress improved practice.

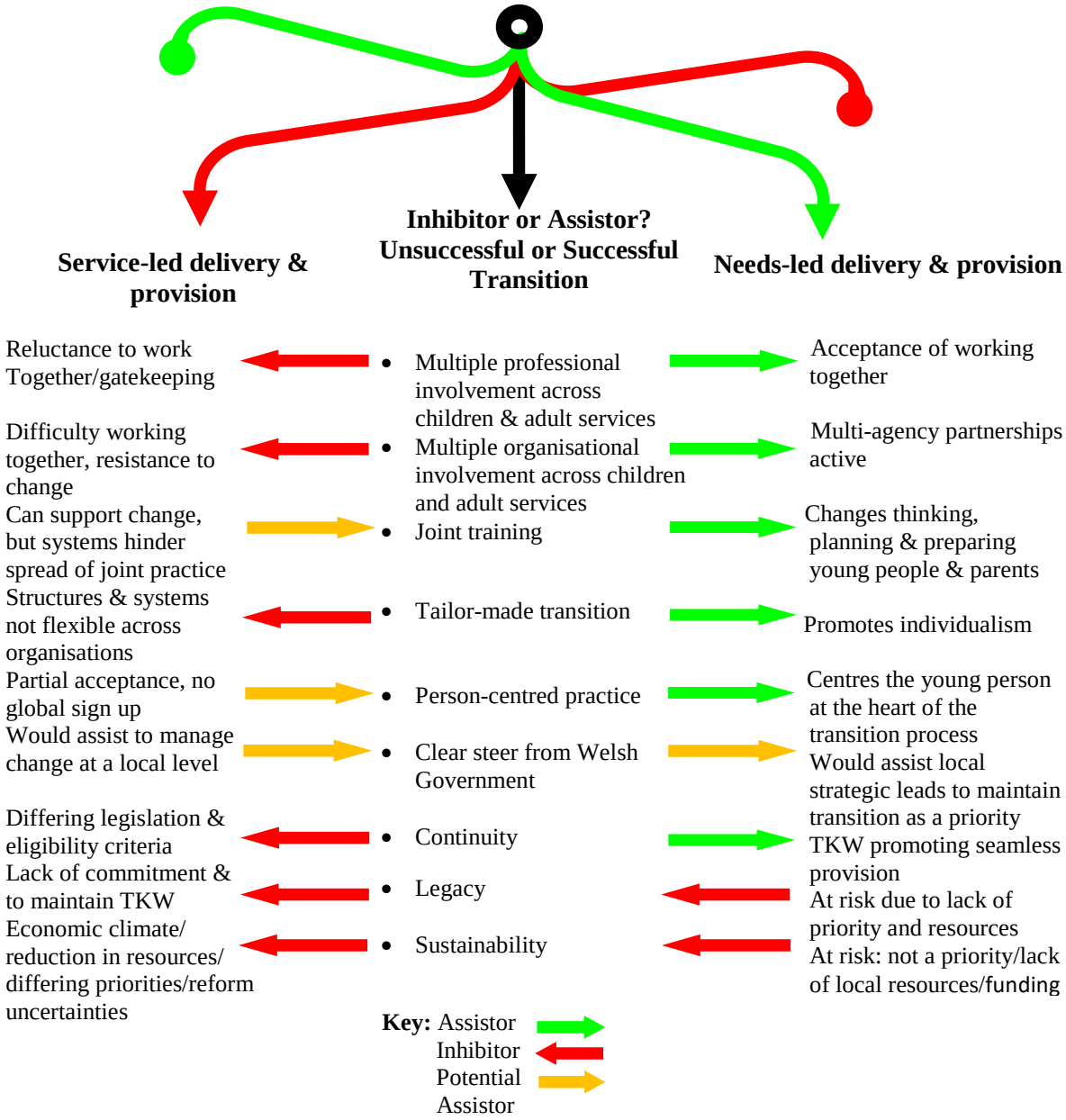
It would have liked more time to spend across all the Sites. Site Leads, similarly appreciated the need to have to time to develop and embed new ways of working. Time-limited grant funding acted as an inhibitor to maintain development or sustainability (Key Finding 5), especially as the local priorities changed. Site Leads were dealing with diminishing funding as I faced in managing a charity in a competitive voluntary sector market. In that climate, the Site Leads, in my view, produced good outcomes with a relatively small amount of funding; many outstripping their expectations. I empathised with their struggles, their efforts and how they began to seen how their work was supporting an improved experience for young people. However, they strived for a vision from the Welsh Government, yet it was in the words of their grant application and their subsequent actions to change transitional practice through the intervention of a Transition Key Worker. However, the complexities of the transition process, many reported by Site Leads, such as operational differences between child and adult services, having a vision and an agreed national transition framework with a statutory duty, would have been helpful to those who wanted to change local practice, but felt that they had little leverage. I understood the exasperations the Site Leads exhibited. I felt that there was a shift in the Welsh Government's commitment to Key Working. This was

echoed by Site Leads. The emphasis was on reforming the Statementing Process for children and young people with Special Educational Needs, but there was insufficient detail as to how transition planning arrangements across organisations (education, health and social care) would be dealt with or articulated with the provisions of the impeding Social Services and Well-being (Wales) Act (2014).

I would agree with the Site Leads that expectation had been raised, particularly amongst parents, that there would be a continuation of Transition Key Worker support, despite ensuring that parents understood that it was grant funded for a specific time period. It was pleasing to see the Site Leads embrace person-centredness and share their enthusiasm and wanted the transition process tailored to the individual. There was the realisation that time was running out; my own time was running out and the impetus to progress and sustain that inertia would prevail. I would echo Site Leads concerns regarding losing the expertise nurtured and the progress made in improving a young person's transition into adulthood. Figure 20 offers my perspective on Site Leads call for a needs-led transition and the inhibitors and assistors to achieve individualised transitions for young people. I professionally and as a parent I considered that the balance needs to shift to a needs-led rather than maintaining a service-led transitional process for disabled young people.

Lastly, as an observation, although there had been progress in bringing key professionals and organisations together, many Site Leads were concerned about the reduction in attendance. Given the complexities of the transition process and the multiple professionals and organisations involved I considered that without further support, the ability to tailor the process and promote individualism would continue to be a hope, rather than the reality looking forward. Prevention, protection, proactivism and preparation; key components of the candidate programme theory (the 4 P's), whilst Site Leads considered important, they did not take into account the impact the past played particularly for parents and how this potentially compromised and inhibited young people's preparations for adulthood.

Figure 20. Service-led versus a needs-led transition process



8.3 SUMMARY

Site Leads identified a number of factors, which they considered would support young people to make a good transition into early adulthood. Having direction and commitment from the Welsh Government who set out an agreed transition framework was seen as a requirement. There was concern that the reforms related to Special Educational Needs and social care in Wales would not facilitate improved transition processes due to the way services and organisations were structured. The differences between the types of support and services offered by children and adult service

providers and the current inconsistencies in accessing them due to the differing application of local eligibility criteria frameworks concerned Site Leads.

It was felt that where local Transition Operational Groups had been established it had encouraged multi-agency collaboration and impetus to improve transitional practice, but that commitment diminished overtime, and non-attendance of key individuals was an issue, which hampered progress and wider planning. Site Leads expressed similar views to Transition Key Workers about the role of Transition Protocols and the omission of setting out how to plan with young people and their parents. Site Leads faced the same barriers and resistance as the Transition Key Workers. Site Leads identified that their main challenges were unravelling the barriers to continuity; the complexities of the transition process itself and the opposition to change ways of working to a more person-centred approach.

There were positives that the Site Leads pinpointed which could increase the likelihood of young people achieving a successful transit into adulthood service provision. Establishing relationships between professionals and organisations was seen as a critical factor to promote acceptance of transition key working and person-centred practice. Sceptics metamorphosed into advocators by their participation in training and were the local flag bearers. They considered that where schools had changed their style of Annual Reviews to a more person-centred approach it had encouraged the attendance of young people and parents and their active participation. Site Leads considered that there needed to be a more customised approach to the planning and delivery of bespoke services in transition and in early adulthood, but that whilst Transition Key Workers had been creative and resourceful, they were bound by what was traditionally available. A service-led provision continued to exist, rather offering a needs-led delivery of services; despite assertions to the contrary and represented within the context of local Transition Protocols. Nonetheless, Site Leads tried to keep the conversations alive with strategic leads, but were often thwarted by a lack of interest and commitment to developing transition key working and changing transitional practice.

Finally, Site Leads were concerned about being able to sustain Transition Key Worker provision post grant funding. They felt that they needed more time to ensure that person-centred practice became the accepted way across multi-agency partnerships.

They considered that there was the threat of reverting back to previous ways of working, with a lack of a professional's ability, whoever that might be, to spend time with young people and their parents to get to know them and plan with them. Site Leads suggested that achieving a successful transition for many young people would be compromised by the current climate of reduced resources expecting more to be done with less.

The next chapter will bring together a synthesis of the overall findings across the key stakeholders. I will present a synthesis matrix across four key findings.

CHAPTER NINE
SYNTHESIS OF FINDINGS ACROSS THE STAKEHOLDERS GROUPS

9. INTRODUCTION

This chapter presents an empirical synthesis of the evidence across the participant stakeholders by focusing on four key findings. The previous four chapters highlighted mitigating factors, both positive and negative of stakeholder experiences and identified components of what would constitute a good transition. Parents, Transition Key Workers, and Site Leads suggested that a workable structure would promote continuity between children and adult. Although, a framework existed in local transition protocol/pathways, it was felt that it was not understandable to all. Many parents felt muddled as to when to begin to think about planning for the future and struggled to deal with many changes that were occurring in their lives. Contrary, young people reported that they were clear about what they wanted for the future, were making plans and attending their own Annual Reviews. Positively, implementing a person-centred approach to planning had encouraged participation. Young people appeared to understand what would happen next for them, unlike many of the parents. However, Transition Key Workers observed that involving parents had not been straightforward and were candid about having found it difficult to manage, especially where parents resisted their intervention. Building relationships across the stakeholders was seen as a determinant of a successful transition, particularly between young people and parents and Transition Key Workers.

This chapter presents a synthesis matrix of the evidence (Table 16) across the participant stakeholders by focusing on four interlinked key findings which are mapped to the mid-range theory areas and the candidate programme theory (the 4 P's).

9.1 MAIN FINDINGS

The synthesis across the participant stakeholders represented in Table 13 identified that the candidate programme theory (the 4 P's) was relevant and the core components were characterised through the intervention of a Transition Key Worker. Nevertheless, while Transition Key Workers attempted to protect young people by being proactive in planning together to prepare them through the transition process they were prevented in some instances by a reluctance of parents to engage and participants as partners and by the late involvement of adult social care. An epigrammatic narrative of three findings begins this next section to support the synthesis matrix.

Table 16 Synthesis Matrix across the stakeholders

Key Findings	Synthesis across the evidence	Relevance to the mid-range theory areas	Relevance to the 4 P's (candidate programme theory)
1. Time played an important role during the transition process	• Young people wanted to spend time with Transition Key Workers, so that they would get to know and understand them. • Young people found it difficult to grasp the concept of time. Their parents needed time to adjust to them becoming adults and manage their changing circumstances. • Young people wanted support and opportunities. • Protected time needed to respond in a timely manner from age of 14. • Competing pressures and responsibilities across agencies was time-consuming. • *'Hands on'* time offered by a Transition Key Worker. • Transition Key Worker appreciated that Social Workers did not have time to spend with young people and their parents; parents less than appreciative. • Social Workers once accepting Transition Key Worker role appreciated the time Transition Key Workers were able to give. • Developing relationships & partnership working took time. • Parents, in particular, felt that the transition process had not been fully explained. Parents wanted to remove the burden placed upon them by a process they found difficult to understand. • A hierarchy of pace setting	**Having a structure:** - Parents confused by the pace of transition - Multiple changes on all levels; large-system change. - Young people were less concerned about the transition process; understanding that transition meant change and were clear about what they wanted to happen. **Continuity of support:** - Young people and parents wanted continuity of support to manage change. - Caseload differences between Transition Key Workers and between other professionals - Transition Key Worker, prior to appointment, perceived that that the transition process ran smoothly between child and adult services. **Support arrangement:** - High caseloads, less time with young people - Parents and young people wanted support to manage change **Active decision-making:** - Young people and parents needed time to be in readiness for change and make decisions **Planning well:** - Last minute planning, improved through Transition Key Worker supporting young people.to plan early. **Governance and accountability:** - Impact of legislative change, local implementation and re-structuring through the transition timeline.	**Prevention:** - Vagueness as to how the transition process worked and the timescales involved. Not all Transition Key Workers were fully conversant with the transition process. - Parents were cynical and distrustful of what they called the *'system'*. *'System'* issues related to differing legislation and policy between child and adult services, based upon education timescales. **Protection:** - Parents and young people have trust and confidence in the Transition Key Worker (regular contact time) - Protected time (Transition Key Worker) to be able to respond in a timely manner. **Proactivism:** - Most Transition Key Workers were proactive - Translating the transition process through information and support provision empowered young people and parents **Preparation:** - Increased levels of confidence and skills reported. - Solution-focused: young people gaining skills towards independence. - Time problematic due to higher caseloads.

2. Transition Key Workers and Site Leads were unaware of the impact of parental past experiences which had impeded their positive thinking about the future	• The past was present in the foreground of parental experiences; their focus was on previous poor contact and the lack of support pre-transition. • Parents traumatised by past contact experiences. • Parental focus on the past how they think, discuss and prepare for change. • Parental difficulty with dealing with their own transition. • Transition Key Worker had an unawareness of the impact of the past on parents, yet acknowledging prior poor contact experiences reported by parents and in some cases young people. • Young people generally not focusing on their past, more focused on thinking about the present and growing up; having their own independent life. • Parental resistance to participation; particularly at Annual Reviews. It was felt that parents were likely to sabotage attempts to plan due to their previous experience. • Parents wanted to be like other parents of non-disabled. • Positive outcomes for young people through Transition Key Worker support not celebrated; frequent return the vulnerability of child. • Deal with and avert other episodes of parental reporting of poor contact with services.	**Having a structure:** - Parents not understanding the transition process; what happens and when. - Parents, in particular, felt that the transition process had not been fully explained. Parents wanted to remove the burden placed upon them by a process they found difficult to understand. - Parents, like Site Leads, Transition Key Workers and other professionals had to work within the same structural and procedural constraints across child and adult services. **Continuity of support:** - Multi-professional involvement had not been conducive towards co-ordination in the absence of a Key Worker pre-transition. - Presence of a Key Worker does not fully remove the negativity emanating from parents. **Support arrangement:** - Parents seeing the young person as vulnerable due to previous poor contact experiences with services. - Presence of a Transition Key Worker likely to improve co-ordination **Active decision-making:** - Parents dictating the pace of transition and their child's prospective independence - Some young people signalled that they found it difficult to find their voice and be listened to **Planning well:** - Parental defensiveness to think and discuss the future - Parents struggling to let go; wanting to keep their child close and safe. **Governance and accountability:** - Parents felt that there was unfairness in the 'System'; why the need to fight.	**Prevention:** - Parents stuck in the past and likely to shape what happen next. - Scepticism; not expecting the transition process to improve experiences or result in further support. - Maintaining the 'Steady State' problematical - Reliability; of process, worker and responses with varied interpretation and use of transition protocols/pathways. **Protection:** - Some parental absence of emotional stamina and self-reliance. - Lack of trust and confidence a stumbling block. **Proactivism:** - The past acting as an inhibitor. - Early support pre-transition often absent - Working with young peoples' and parental strengths. **Preparation:** - Parents unable to focus their attention on the future and prepare themselves for their child's early adult life. - Although some parents wanting to discuss the future they find it difficult. - Difficulty planning: lack of evidence of examples of Transition Plans. - Annual Reviews less than transparent and consistent unless person-centred approaches adopted.

3. The future was indeterminate for stakeholders and managing change difficult for all	• Parents experiencing their own transition; difficult visualising the future. • Future a difficult concept with many young people struggling with the notion of time, but wanting to grow up. • Young people not too concerned about the future expecting it to go well and achieve their hopes and dreams. • Young people appear to be able to deal with change better than their parents having a clear idea about their futures. • Adjustments needed by all involved, especially young people and parents. • Transition Key Workers needed to know the *'whole picture'* to plan well. • Understanding that parents may have justification to worry about the future	**Having a structure:** - Site Leads sought direction from the Welsh Government. - Multiple transition points. - Need for skilled/knowledgeable individuals - Structure not conducive for a personalised approach. **Continuity of support:** - Concern about the continuation of support post childhood. - Transition Key Workers concerned about the level of support provision. **Support arrangement:** - Concern about the continuation of Transition Key Worker involvement. **Active decision-making:** - Parents doing the thinking for young people; young people wanting to make their own decisions. - Parents specifically resistant to discussing the future **Planning well:** - Parents nervous, parents having a little sense of their child's being in the future - Young people feel that they have the opportunity to discuss their plans for the future. - Variable use and quality of a Transition Plan; parents and young people unaware of the existence of a plan. - Some Transition Key Workers not applying person-centred transition planning and developing plans with young people. **Governance and accountability:** - Decision-making rests with others who may not know the individual young person.	**Prevention:** - Parents report continued need to fight for support and services through transition into adulthood. - Parental resilience despite poor experiences - Parent's anxiety, seeing obstacles in the way. **Protection:** - See the child as vulnerable. - General underlying concerns - Early intervention of adult services an issue. - Early support of a Transition Key Worker. - Unawareness that parents often determine the rate of transition into adulthood by lack of engagement. **Proactivism:** - There was a working assumption that parents would be proactive. - Regular contact of the Transition Key Worker important. - Building relationships important across the stakeholders. **Preparation:** - Intervention of the Transition Key Worker a catalyst for change and preparation. - Parents wanted to take small steps rather than look at the *'whole picture'*. - Planning together critical to prepare young people and their parents for the future. - Late planning: late or no involvement of Adult Social Services, parent engagement, Transition Key Worker not developing a Transition Plan

9.2.1 Key Finding 1: Time played an important role during the transition process

The transition process was time critical on a number of levels and a specific finding reported in Chapter Seven. Time was intellectualised variously and performed a crucial role through the transition process for young people, their parents and those supporting them to plan within a specific time-frame and parameters. Nonetheless, there was confusion about implementing the process, with examples of late planning with young people on the cusp of early adulthood. Not all parents were ready for change or solution-focused and harked back to times of poor contact experiences with services, which Transition Key Workers and Site Leads had not explored. Parental uncertainties gathered momentum, accruing a bank of angst and had plenty to proffer about times unsupported to illustrate what had occurred to them and that their '*anxiety levels have increased over the years, it's been going on since X (young person) was little'* (P18). Pessimism materialised as insecurities increased not only for parents but for Site Leads who struggled to respond from age of 14 due to competing pressures and responsibilities. However, it was counterbalanced by the hands on time offered by Transition Key Workers who attempted to placate parental concerns about future planning.

Many parents were tentative about what steps they needed to take to progress through the transition process, not understanding the choices open to their child and when various transition exit points would occur. Although, young people found it difficult to conceptualise time, they did understand that transition meant moving on, growing up and that they needed to work towards independence. The passage of time was not an issue for young people. They were aware that there would be change for them and wanted to be ready and Transition Key Workers who were free to give their time to individual young people could concentrate on preparing and planning for early adulthood. Keeping the conversation going, explaining the transition process helped all involved to contemplate the future. Building relationships could be a lengthy process, but was seen as an imperative and reflected by the professional stakeholders as a significant constituent to facilitate and capture the involvement of young people and their parents through the transition process.

There was a recognition that to be dependent upon one individual (Transition Key Worker) was precarious through the transition timeline from 14 through to 25 and where not dependent upon one person the focus was on *'the role and the knowledge that come….to shape the services to the way we wanted to shape it'* (S4: B) through the transition period. Having time to develop new ways of working and service delivery provided the opportunity to reflect, re-group and *'go down a different path'* (S4:B) to the one originally proposed. Transition Key Workers considered that:

'I think transition planning is just so simple actually….I think a lot could be done quite easily really by just spending a bit of time with young people on a one to one, not huge amounts of time and also a few phone calls to families…..In fact I found the work has been fine; I just got frustrated with sometimes feeling that I can't achieve as much as I want to and I would have liked to have think spent more time with the young people and their families'.

(TKW7)

9.1.2 Key Finding 2: Transition Key Workers and Site Leads were unaware of the impact of parental past experiences which had impeded their positive thinking about the future

There was awareness amongst some Transition Key Workers and Site Leads of parental past contact experiences of services pre-transition, but generally little appreciation of the true impact and consequences. Transition Key Workers had dealt with parental negativity and resistance to involvement by giving their time, which had helped them to move on and think about the future more positively. It had been felt that *'parents sometimes and I'm not generalising or it's not a criticism or anything, but they don't see a role from themselves'* (TKW1) in promoting the participation of their child in planning for their own futures and aimed to prevent further parental detachment were it existed. Yet, some Transition Key Workers reasoned that time taken to encourage parent participation was time taken away from working directly young people. While, they were cognisant with the importance of addressing parental concerns and worries, not only of services currently but future provision, they focused on listening and responding to the wishes of young people who were able to have positive discussions about their futures.

There was a perception that parents were not co-operative, which Site Leads considered impeded their ability to change what parents perceived to be a service-led mindset, particularly by adult social care. Parents felt that they were not being listening to and where there had been engagement their views were not always considered or enacted upon. Parents felt that they were being labelled as *'difficult'*. Transition Key Workers observed that parents were identified as obstructers and were not being co-operative, but that:

'I think it is all down to the conversations we have and when we have them and if we come in, particularly adult services and say oh right this is how we do things either put up with or shut up then they are bound to be upsetting parents. I think what is massive as a problem is the fact that adult services do have a totally different approach to the status of the parent'.

(S2)

Nonetheless, Site Leads appreciated that the Transition Key Worker had worked hard and had spent time to encourage parental participation in transition planning, and *'whilst parents do get involved anyway inevitably, but the hardest bit is where parents don't get involved and aren't interested or don't appear to be interested that is really hard; we've struggled with that as well'* (S3), not always fully appreciating the difficulty parents had in visualising the future for their child in early adulthood post transition. Parents and Transition Key Workers needed time to adjust to one another as many parents had negative expectations of professional involvement. Transition Key Workers appreciated that parents needed to able to *'vent to someone who would be at the end of the phone'* (TKW8) to deal with their distress and anger to obviate further adverse episodes with professionals and services.

Transition Key Workers attempted to deconstruct the transition processes to make it understandable and less complex to prepare them for the changes ahead. Conversely, one parent presumed *'how some people (parents) don't want people interfering and don't understand the process….it means that you have to let people into your lives….to sort give them a full proper picture of yourselves, your family and the person with the disability, which is hard. I can understand how some people don't want people interfering'* (P6). Some parents did not want to have further conversations about

themselves and their children, not wanting to invoke their past history and disappointment. This was contrary to other parents, where the past was their focus wanting to talk about and intermittedly raised the need to think, discuss, plan and prepare for their child's early adulthood but not knowing how to go about it.

9.1.3 Key Finding 3: The future was indeterminate for stakeholders and managing change difficult for all

Overarching, with the exception of young people, it was felt there was an indeterminate future and found managing changing circumstances both personally and organisationally was difficult for stakeholders. Changes within the local authorities, the move and potential effects of departmental or service mergers within and between counties were upsetting the equipoise which had begun to emerge between child and adult services and between Transition Key Workers and parents. Transition Key Workers, particularly, felt that *'there are too many changes….other changes happening like all the reform…..with the changes there is not complete stability'* (TKW10) and that supporting young people in the future was tentative or non-existent post grant funding. Transition Key Workers and Site Leads were concerned about maintaining continuity and a personalised approach without direction from the Welsh Government.

Gaining the trust and confidence of young people, but especially parents was a critical factor to support the psycho-social and practical changes that would occur as their children became adults. Transition Key Workers and Site Leads felt that parents would *'trust the way forward if they can see that it is going to work, I think that it's too easy for services to sort of present the way forward as being the way they should agree to and if they're not 100% comfortable with it then they will resist and in some cases they will sabotage it'* (S2) if they were uncertain and opposed planning. One parent attested that her son's future was unclear despite her wanting to prepare, after being, as she saw, it let down by a stalled housing process and previous encounters with services, despite him doing well at college, it did not override how uncertain she felt about the future and the changes ahead.

Transition Key Workers understood that transition was about *'what the young person wants, which can be very different from what the parents think the young person should have or do and managing that is quite often difficult'* (TKW9), but they did need to be

acquainted with the views of parents so not to suppress their involvement. Transition Key Workers appreciated they needed to cultivate involvement due to the parental concerns related to change and doubt. Moreover, there was an understanding that individuals coped with change in different ways, but it was associated with the proactivity of the parent, rather than their non-involvement or avoidance. The association of proactivity and coping raised issues as to whose transition was it; the young person or the parent or both. Many parents were making decisions and were determining their child's future, even where there was capacity. Transition Key Workers felt that parents coped with change by dictating the direction of their son/daughter's transition and their future adulthood:

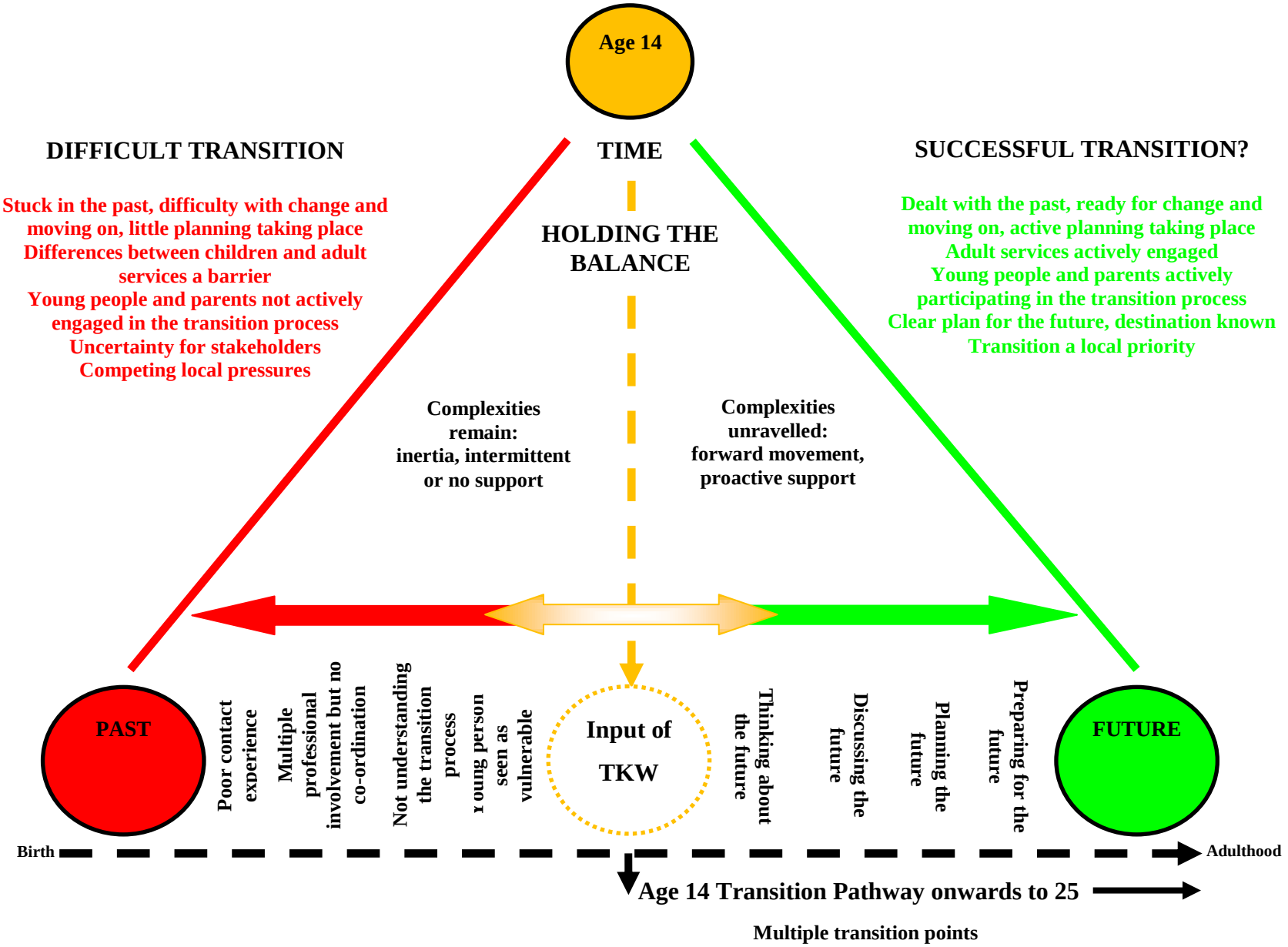
'Difficulties we face are when parents don't let them make their own decisions – whose voice is it? A lot of depends on the young person and their families. Some families are so proactive in ensuring that their son or daughter is at the forefront; their voice is heard and it's about them. Whereas others are totally different they need real help to prepare for some of the changes….sometime we forget that….there are extra things we need to think about, their vulnerability, needing that specialised support and that is sometimes where the trouble starts'.

(TKW2)

Ultimately, Transition Key Workers and Sit Leads considered that parents were justified in their concerns about future provision and that they need support to manage the many changes that they faced. They were hearted that young people appeared to deal with change better than their parents and had a clear picture of their life beyond adolescence. Site Leads were cautious, due to multiple exit points that maintaining continuity and access to adult social care provision young people would continue to fall through gaps in services.

The next section sets out a final finding which triangulates the key aspects of a past, time and future continuum to conclude this chapter.

Figure 21. Diagrammatic visualisation of the Past/Time/Future continuum



9.1.4 Key Finding 4: A Past/Time/Future continuum was present, which may determine whether a successful transition is achieved (Figure 21).

The relationship between the past experiences of parents and the absence of forethought about the futurity of their adolescent child was likely to be held in balance by the time given by Transition Key Workers to support young people and their parents to lessen the incidences of further poor experiences and their past history of poor contact with services being cited in the present. The absence of recognising the impact of past contact and events meant that parental self-absorption was not being addressed. A difficult transition was equated with the intricacies of parental adjustment to their changing relationship with services as their child moved towards early adulthood, but also as their child matured and had a voice of their own particularly at Annual Reviews. The complexities of the process had led to parental inertia and disengagement due to intermittent support. Site Leads and Transition Key Workers similarly, struggled to develop and manage relationships with services, predominantly adult social care and were based upon previous problematic engagement. They needed to take time to cultivate partnerships and remove the barriers created through differing eligibility between children and adult services to support parents who found it difficult to envision or comprehend a destination point:

'We have massive uncertainty because we'll never have peace of mind until it's, well until somebody says to us, right he will be able to go to this house at this address on this date. I can't see it happening at the moment you know so in our heads we are thinking what are we going to do'.

(P9)

The complexities of the transition process remained present for many, including for those who were enacting and delivering. The ambiguity of local implementation and the sometime passive engagement of parents, who continued to describe their child as vulnerable, made it difficult for parents to realise an independent future even with the pre-emptive support of a Transition Key Worker from the age of 14. Parents were suppressing or not celebrating their child's progress towards adulthood. However, as Transition Key Workers understood young people's wishes and ambitions, *'doing things on their own, especially going to college and although they can have door to*

door transport, the young person at this stage, my experience, is that they want to do it on their own' (TKW1) celebrated with them their achievements and the next stage in planning. Young people were not caught up in the same anxieties as their parents and did not dwell on the past; their focus was determinedly on the future.

Achieving a successful transition was dependent upon many factors. The active engagement of adult services was signalled as determinant of a successful transition; accessing support in early adulthood, with young people and parents participating fully in a transition process that they understood. Having a detailed and agreed transition plan, with young people and their parents knowing what would happen next, avoided unease about the future and the likelihood of a successful transition. Whereas *'this time last year I felt very nervous and I think going on visits to the college and catching buses helped a lot, getting to know the staff and finding my way around….helps to build your confidence'* (YP13), so that young people were able to take the next step towards independence. Yet, not all young people were likely to transit smoothly into adult services, which caused further anxieties for Transition Key Workers and Site Leads as adult services were recurrently inactive and late arrivers to discussions about individual young people. This increased the probability of parental frustrations or possible disengagement knowing that there was not a brave new world waiting for their child and themselves based upon their previous poor contact experiences with services.

The presence of a Transition Key Worker was seen as an influencing factor to support successful transitions. They maintained a *'steady state'* between parental inactivity and disinterest due to intermittent or no support pre-transition and their ability to accept change and move forward positively with proactive support. Parents needed support to deal with and suppress regressive thoughts and the negative aspects pre and during the transition process so that they are ready for change and be able to think and discuss the future to plan and prepare; key features of a forward moving continuum. Transition Key Workers were seen a crucial intervention due to the time they were able to spend getting to know young people and their parents to facilitate change and more hopeful thoughts about the future.

9.2 CONCLUSION

The Past/Time/Future continuum was significant finding. The forward movement towards young people achieving a successful transition was determined by moderating parental apprehensions about the future. Transition Key Workers, who gave their time, countered parental unease and had worked proactively to nurture, cajole and protect their participation. They found young people more open, but they needed time to adjust to make decisions about what they wanted to do in the future. However, parental past experiences had coloured the next steps both backwards and forwards, but frequently backwards to previous unsettling times, which affected a young person's journey throughout transition into adulthood. Parents appeared to be one of the main protagonists in determining whether a young person's transition into adulthood was successful or not irrespective of the presence of Transition Key Worker and the delivery of transitional support post the age of 14 into adulthood.

Many Transition Key Workers construed that the transition process ran smoothly and conceded their miscalculation as they realised the complexities of the transition process. This meant that not all young people would achieve a successful transition as adult services did not always respond or engage and were also seen as protagonists in achieving or limiting successful transitions. Whilst, the candidate programme theory (the 4 P's) applied through the transitional years and the 4 components are recognisable (Table 16) it is the 'P' in the Past which was as a determining factor. This was, in part, moderated by the time Transition Key Workers provided who held the balance so that young people could think, discuss, plan and prepare for their future. However, it was dependent upon a stakeholder's position and experience and parents who were grounded in the past needed support to remove their negative expectations. These had been based upon what they perceived to be poor contact experiences and previous deficient provision.

The next chapter presents the overarching synthesis across the Realist Review and the Stakeholder Evaluation and centres on three key findings. The chapter concludes delineating a revised integrated programme theory.

CHAPTER TEN
OVERALL SYNTHESIS ACROSS THE REALIST REVIEW AND EVALUATION

10. INTRODUCTION

'What makes a successful transition into adulthood for disabled young people?' was the central question the Stakeholder Workshop participants considered and the findings of the workshop were described in Chapter Three. The question continued to be the relevant focus of interest to apply across the Realist Review and Stakeholder interviews. The attention largely associated with the problems encountered with the transition process; the challenging aspects such as continuity of provision and working together featured. The challenges, both in the literature and by stakeholders were identified and reported. Various attempts to find solutions or pay attention to the positives and build thereafter were evident in the literature and through the narrative accounts of Site Leads and Transition Key Workers, but were outweighed by negativity, which emanated from the parental accounts due to their previous and current experiences and contact with services.

The previous chapter identified that the candidate programme theory (the 4 P's) was of relevance, but did not fully explain why parents specifically found it difficult to both understand and be active partners in the transition process. Parental recounting of unsatisfactory past contact experiences with individuals and services was a hindering factor and their retreatment to the past stalled their thinking and discussions about the next steps towards transition into adulthood. The presence of past parental experiences fully emerged as a constraining dynamic of the transition process.

This chapter firstly presents three overall findings which explored:

- An alternative interpretation of the transition pathway process,
- with or without support the transition process remained complex, and

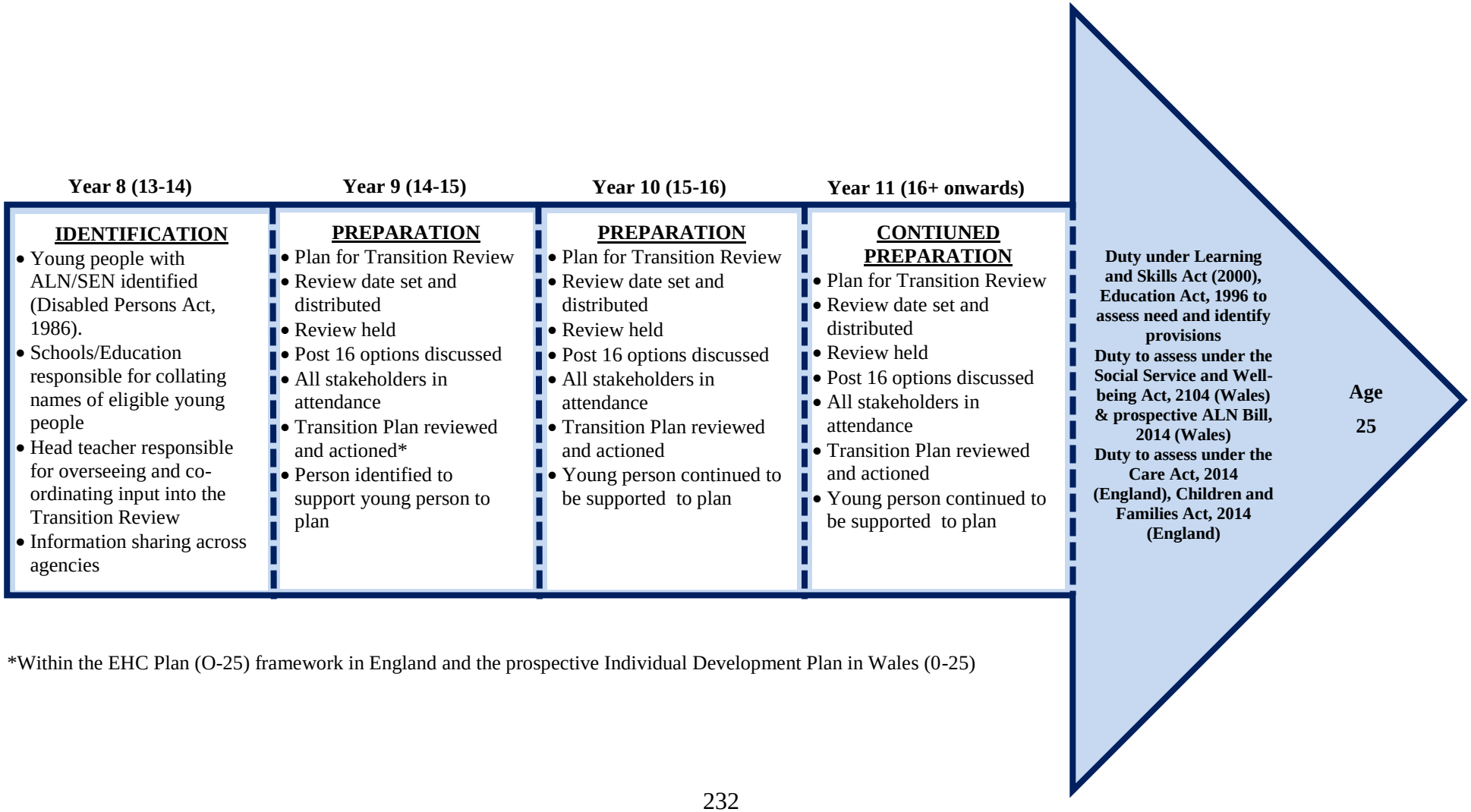
- whether from a legislative or organisational perspective or more personally stakeholders need to deal with and to be ready for the change between young people moving from childhood into adulthood.

Secondly, a revised programme theory by introducing a further component; person-centredness as the fifth 'P' and the integration of the mid-range theory area into the model is outlined. This chapter will conclude with mapping the overall findings against the revised integrated programme theory, alongside a proposed Context, Mechanism and Outcome (CMO) configuration, which may or may not achieve successful transitions for young people, their parents and those supporting them.

10.1 MAIN FINDINGS

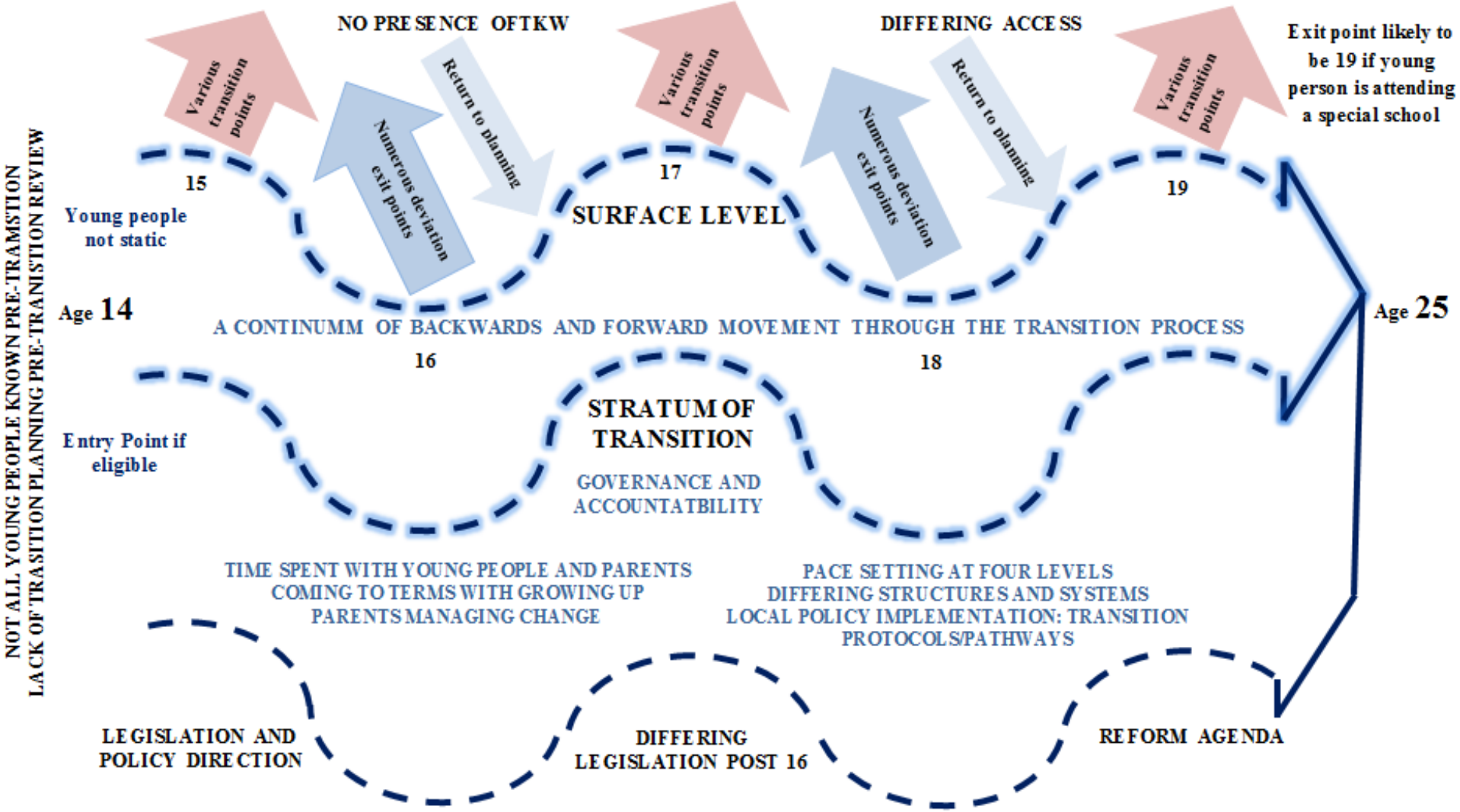
This section opens with a diagrammatic representation of a standard transition pathway (Figure 22) described in national, regional and local documentation, and illustrated as a linear occurrence. Figure 23 presents an alternative, which suggests that the pathway requires a foundation starting with legislation and local policy implementation in setting the direction, and is built layer upon layer thereafter to the surface, which takes young people and those supporting them forward into adulthood. In terms of context, there was an apparent mismatch between the perceived; following a seamless standardised transition pathway (Figure 22) process into adulthood and the lived experience (Figure 23). The formation and direction of a 'standard' transition pathway is historically set within the SEN Code of Practice (England, 2001, Wales, 2002 - archived in October 2014) which set out expectation as discussed in Chapter Three, with legislation; existing and emerging (Children's Act, 1989; Education Act, 1996; Community Care Act, 1990; Learning and Skills Act, 2000 Social Service and Well-being Act (Wales), 2104: ALN Bill (Wales), 2014; Care Act (England), 2014 Children and Families Act (England), 2014) guiding agencies and professionals in identifying and assessing and supporting young people's needs. Local transition policy (protocols/pathways) portrayed and incorporated the notion that the transition process is an uninterrupted route. A pathway is more often than not visually represented as a line taking the young person directly through the transition process. Yet, young people are not static on entry (Abbot and Heslop, 2008; DOH, 2008), they are likely to be known at least by education as requiring transition planning post the age of 14.

Figure 22. Diagrammatic representation of a standard Transition Pathway



*Within the EHC Plan (O-25) framework in England and the prospective Individual Development Plan in Wales (0-25)

Figure 23. Diagrammatic representation of the transition process experienced by stakeholders



10.1.1 Key Finding 1: The transfer from children to adult services is depicted as linear. However, the stakeholder experience is somewhat different.

Mitchell (1999) highlighted that the transition process is complex and that it is not *'precise and linear, thus over simplistic'* (p.755). A linear representation remained a current phenomenon in transition protocols/pathways to depict the continuity of provision across child and adult services (ACT, 2007; Education Act, 1996; Children Act, 1989; DOH, 2006; DCSF, 2007; DOH, 2008; Council of Disabled Children, 2009), but young people rarely experienced a continuous transition. Moreover, Mitchell (1999) commented fifteen years ago that it was *'important to explore both the "processes" that young people can pass through and wider social and structural inequalities, which can influence these processes'* (p.755). Yet, young people and parents continued to report disparity, lack of eligibility, with Transition Key Workers and Site Leads struggling with organisational differences. Some Transition Key Workers expressed that they had '*never heard of them (the local authority) saying any problems there (with the transition to adult social services) I just thought, you know, it all went smoothly. I was quite naïve to it',* never expecting to be challenged by a system, which they discovered was not structured or seamless. The process was described as complicated (Morris, 1999; Morris, 2000; Forbes *et al*, 2002; Beresford, 2004) and readily defined as such by parents, Transition Key Workers and Site Leads.

Site Leads considered that *'unfortunately the policy makers haven't got a deep understanding of day-to-day life for people with disabilities, of the very basic needs of just getting out of bed to School….the complexities and the knock-on effect….writing a strategy, a plan, is easy, making that a reality and making it operational is the gift and I don't think the two marry together. It's too much of a leap of it'll be fine'* (S2). Yet, there was the expectation that a transition pathway would take them on a journey from A to B rather than from A to D to S and so on; a characteristic realist depiction of a complex construct, but the pathway assumes the transition process to be straightforward. A transition pathway process is largely articulated within the domain of education rather than more holistically across other areas of their lives (O'Brien, 2007). It predominately guided educationalists in managing young people's transition from school to college, using a year on year review framework to review until a young person

moves into adult services which was variable depending upon when they leave school. Parents, whilst concerned about educational transitions, were focused on the difficulties gaining the interest and the presence of social services, particularly adult social care at annual reviews or other meetings related to their child's transition. This was a likely cause for departing from a linear transition due to lack of engagement of a social care professional and variable pathways into services (Carpenter and Abbott, 2010). Transition pathways were not providing a *'good framework for collaboration'* (Kaehne and Beyer, 2009, p.143). Transition Key Workers were mindful of the challenges of adult social care engagement in the transition process and that encouraging their participation, despite paper-based partners, was time-consuming and difficult and *'it seemed that they (adult services) didn't want a relationship'* (TKW6), which saw parents heading towards a dead end.

Figure 24. Diagrammatic 'close up' of pathway experience

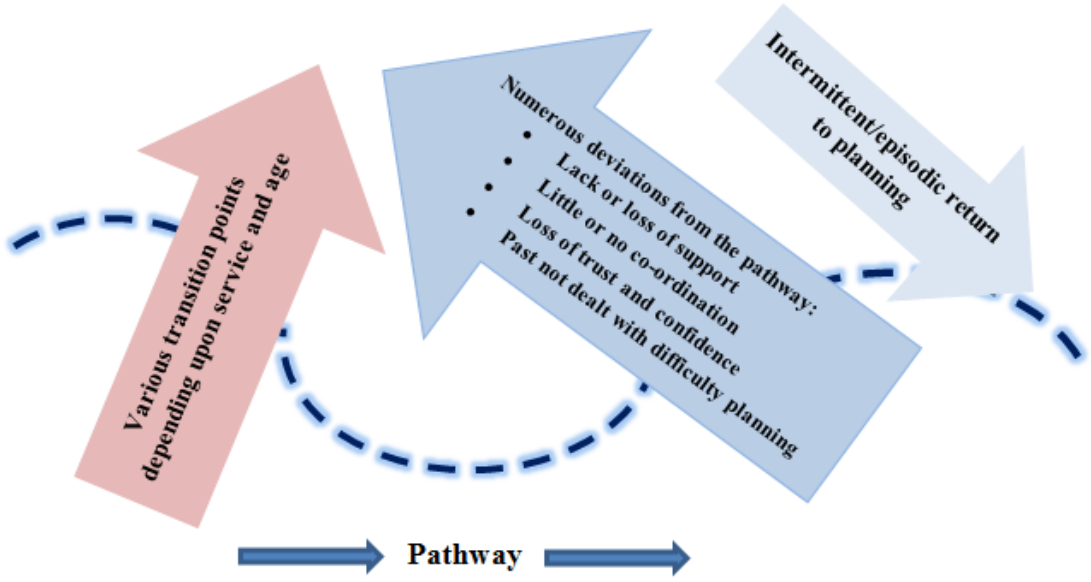


Figure 24 represents a close up of critical points which occurred along the pathway and where the transition process was likely to become a problematical interchange. Young people experienced various exit points depending upon which service and the age criteria for access and rarely experienced one holistic co-ordinated transition. In actuality, young people and parents fluctuated between maintaining progress for certain periods depicted in Figure 23, with alternative times when they seemed to be moving

backward or deviating from the pathway due the lack or loss of support to maintain movement. Parental lack of trust and confidence in professionals and services caused them to retreat, which took young people away from their intended path only to return at another point in time when parents were conducive to think, discuss, plan and prepare for their child's transition.

A transition pathway, in reality, has depth; layers of activity or processes not fully represented in the literature or in linear pathway examples included in the Realist Review. Protocols/pathways did not fully represent the intensity of work required beneath the surface of the transition process. Transition Key Workers and other professionals needed to have the necessary time to spend with young people and their parents to support them to manage major changes in their personal relationship, but also with services. Young people and parents needed a solid foundation bolstered by the enactment and implementation of legislation and local policy. Nevertheless, the subsequent layers (stratum of transition) continued to make the process complex and an unclear pathway to a young person's destination point post 19 with or without support.

10.1.2 Key Finding 2: The transition process remains complex with or without transitional support.

Across stakeholders, their experience of the transition process was different depending upon their individual situation and presentation. While it may be different for young people and parents receiving transitional support, it was not necessarily less complex or understandable even with Transition Key Worker support. Young people and parents wanted those working with them to listen to them and respond through *'close multi-agency collaborations'* (Everitt, 2007, p.2). They wanted their knowledge valued and taken into account and were identified as a key mechanism of a Transition Key Worker intervention in the Realist Review. Parents wanted to do what was right:

'We are doing our best, but we are always open to more help because it seems to be up to the parents to know what is best and if they don't know then nobody comes rushing up to you with advice and help'.

(P21)

The lack of support had made the transition process drawn out and unsatisfactory despite the intervention of a Transition Key Worker. Parent proactivism; a do-it-yourself school of thought was evident, where there was a view that *'I think most of the support comes from ourselves, from his parents, but we are trying to network with other people and to get to understand how the system works* (P21). One parent was trying to absorb information to be informed; knowing by reading, she had *'done her bit'* (P15) and could now, with more confidence, hold their own in review meetings. The necessity to understand the transition process had driven some parent to extremes, because of poor contact experience with agencies who had not translated the process. A proactive parent had got to the stage that until provoked, had got annoyed and spoken out as *'we were just hitting our heads against a brick wall'* (P24) that they began to feel listened to. This parent had felt confident to speak after her contact with a Transition Key Worker and knowing what options were likely around post 16 education opportunities, but it remained a complex situation for this parent even with an active supporter.

However, the presence of a Transition Key Worker did enable some parents to deal specifically with the many ups and downs they experienced. Parents and Transition Key Workers considered that co-ordination was a crucial mechanism; connecting people and bringing them together to discuss the future. The Transition Key Worker had the ability to *'cajole education, health and social care to be in the same review and the same room having one review'* (P6) which parents considered a major achievement. Parents suggested that the Transition Key Worker *'opened doors which weren't there before'* (P17). It had initiated a more sustained dialogue and involvement of other professionals, predominantly Adult Social Workers, and that they were more likely to work together with the same aims. The ability of Transition Key Workers to connect and build relationships with other professionals was seen by Site Leads as a major contributory factor in supporting young people through transition. Parents felt that *'there needs to be some work done on giving the Transition Key Worker role more status and importance and giving X (Transition Key Worker) more power, more power to act'* (P6) to make sure all the key players were involved and co-ordinated to minimise the complexity of the process. Parents wanted Transition Key Workers to challenge not only them as parents, but also other professionals and have the confidence to do so to act in the best

interests of the young person; to *'fight our (parents) corner'* (P24) and have the clout to do so to make the journey through transition less tortuous.

The effective support from the Transition Key Worker had initiated an unexpected addtitionality; that of carrying out some of the functions of a Support Worker. Those functions appeared to provide better outcomes in the short and medium term and the level and types of support being received. The Transition Key Worker who got to know a young person well was usually through activity-based sessions such as cooking and had acted as a contributing factor to young people understanding the transition process and working towards independence, but not necessarily their Transition Key Worker function. Transition Key Workers did initiate additional support from other professionals and agencies to take on practical tasks they had begun. Parents who were accessing Transition Key Worker support within school had received other forms of support previously not experienced, which had lessened the impact of the complexities initially posed in traversing the transition process. The ad hoc or disjointed approach previously experienced did become less rocky with Transition Key Worker support, but it was often transitory as the next episode of disappointment or crisis arose, which Transition Key Workers struggled to alleviate without the commitment of other professionals involved.

The biggest challenge expressed by parents was the impending loss of Transition Key Worker support as their child reached 19 or when the grant funding to employ them ended. Increased anxiety levels were reported as the loss of support and no sign of continuation emerged just as young people and their parents were beginning to understand the transition process and feeling less scared of the future. Parents become apprehensive as they were unsure if their son/daughter would fit into services with or without Transition Key Worker support. Parents wanted the Transition Key Worker support to be maintained to deal with the challenges they faced. Transition Key Workers wanted to be there to support young people and their parents as they knew many would not successfully transit into adult services before the end of their tenure.

Lastly, many parents conceded that they needed to know what to do about the future. They were unsure as to what they should be asking for, and combined with some

ambiguity as to whether an active Transition Plan was in place, made planning difficult in manifold due to *'problems with past, current and future transition plans'* (Abbott and Heslop, 2009, p.49). All describe meetings that took place to discuss their child overtime, but very few were happy that the professional cohort supporting them who they thought were working in *'different directions'* (P6) from what the family or young person wanted and *'invisible to statutory services'* (Beresford *et al*., 2013, p.VI). Similarly, there was a lack of awareness as to the role of the Transition Annual Review and, in turn, parents felt unprepared as to what to expect (Carnaby *et al*., 2003). Commonly cited (Beresford and Cavert, 2007; Heslop and Abbott, 2007; Carpenter and Abbott, 2010) was the lack of effective planning or an ongoing written plan, which had left many parents feeling confused, but still hoping things would run smoothly if a plan existed or was about to be developed. Nevertheless, parents considered that they were running to a timetable which they were not in control of, with others regulating the transition of their child. One parent described that they *had 'to go from week to week and I think of the future constantly, I can only really cope now in small chunks. There is no certainty about anything is there?'* (P18). Positively, where a young person was clear about the future and ready for change; what they would like to occur and '*wants to be a rock star or a hairdresser..... because I would like him to be able to follow his dream, but we just don't know how much of that is going to be able to achieve'* (P26 Parent of a 14 year old commencing the transition process), most parents were keen for their son's or daughter's to fly the nest in the future and follow their dreams, but were unsure how they would come true; how it could be achieved even with Transition Key Worker support.

Nevertheless, the inability of parents to acknowledge and, in turn, deal with the past, no matter how much input and support they received made it difficult for them to accept the progress their children were making towards adulthood. Their focus was on their own responses and their own transition. Parents endeavoured to support their child to adjust to their changing relationship not only with themselves as parent but with others (Beresford, 2004; Cowen *et al*., 2010) and needed to support to do this. However, it did not mean that relationships with services and transition processes resulted in fewer complexities where parents accessed Transition Key Worker support.

10.1.3 Key Finding 3: All stakeholders needed to be ready for change (Mid-Range Theory area 7)

It was apparent that all stakeholders needed to be ready for change, irrespective of their position and involvement. Site Leads had to deal with and manage multiple organisational changes alongside promoting the importance of prioritising transitional practice and new ways of working. Transition Key Workers like their colleagues were obliged to work within the same structure and system, whilst endeavouring to model change and gain the acceptance of their role. The catalyst for change was the delivery of the transition key working training and modelling person-centred styled transition Annual Reviews within schools. There was an awareness of the Welsh Government's intention to replace the Statement of Special Educational Needs with an Individual Development Plan (IDP) and with a person-centred approach. Therefore, Site Leads felt that they wanted to be prepared for changes in Annual Review processes as they had been successfully demonstrated. They were concerned that the IDP was not sufficiently robust to capture the complexities of transition planning processes to support young people and parental adjustments.

Transition Key Workers, cognisant of change within their own organisations, were dealing with numerous changes and then were expected to support young people and their parents though their own changing circumstances. Actual and prospective changes within local authorities, the move towards department/service rationalisation and likely county mergers (Williams Commission, 2014) in Wales was upsetting the equilibrium with *'too many changes here…..and other changes happening like all the reform…..with the changes there is not complete stability'* (TKW10). Fragmentation was evident and there were concerns that the Social Services and Well-being (Wales) Act (2014) and the development of a national eligibility criteria framework would not resolve the issue of the lack of replication within adult services provision of that provided by children's services. It was felt that by extending the age range to 25 (White Paper: legislative proposals for additional learning needs, 2014) would create another transition point and *'it's still going to be a big change even though we've made it somewhat smoother'* (TKW10).

Transition Key Workers felt that that they did not *'think that they (Transition Key Workers) got enough clout to change people'* (TKW4), but wanted to move away from what they described as a dependency model operated by children's services, as they felt parents in particular were *'under their umbrella and they're protected by it'* (TKW5), whilst recognising that service provision into adult services needed to be seamless. Parents found it difficult to make the move and *'get thrown'* (TKW5) when their relationship with services post 16 changed when young people with capacity could make their own decisions. Parents needed support to manage their changed relationships with their child and with services (Fiorentino *et al*., 1998).

Young people were clear that they felt ready for change, despite some apprehension; that it was *'going well, from school to college, like I was ready for change, but didn't want to leave school…….I was worried, but it went well and it was local to me'* (YP6). In some situations, it took *'a lot of hours, but worth the changes you see in their confidences, seeing timid young people become confident and voice their opinion'* (TKW8) so that young people would be prepared for life post adolescence. But, this was not always the case and those young people in residential schools/colleges after a period of stability faced transferring to unfamiliar settings often with little preparation to manage the change to a new environment (Carnaby *et al*., 2003; Beresford and Cavet, 2007).

Against a backdrop of legislative and organisational change, parents, from birth or diagnosis onwards towards transition had been managing shifting circumstances exponentially year on year. As the intensity to deal with change increased and parental recollections of their struggles to gain support surfaced. Dealing with the convolutions of their growing caring role was daunting for many; one which they could see no end if they were not supported through the transition process. The mounting demands; on their time, spirit and fortitude as their child reached adulthood and after *'21 years of screaming, shouting, worrying, fretting'* (P4) left parents adrift, less resilient, frustrated and challenged by any change they faced (Hirst and Baldwin, 1994, Morris, 1999, 2002, Beresford, 2004, Forbes *et al*., 2004, Sloper *et al*, 2010; Beresford *et al*., 2013).

The facilitator of change for parents was the active involvement of a Transition Key Worker, who familiarised them with concept of transition planning as many had little contact with a social worker. There was a mixed reaction as to whether discussions took place about the transition process, prior to Transition Key Worker involvement and more than one parent could not remember whether a transition Annual Review took place as *'we've had so many (meetings)'* (P10). In nearly all cases no Transition Plan appeared to be in place or in development, contrary to the suggested procedures set out in the SEN Code of Practice (England, 2001 (now archived); Wales, 2002). In some cases a One Page Profile[21] was perceived to be a Transition Plan. No parent was able to show what they perceived to be a Transition Plan apart from paperwork which related to assessments or reports from school for example. Parents did, however, take notice of the changes that were being made to the Annual Review process and highlighted their previous experiences of taking part; usually from a negative standpoint. The alterations being made were expressed positively, particularly where led by a school with Transition Key Worker involvement. They felt that their children were happier as they were themselves. Parents often felt dismissed and that the reviews had been very basic and had been *'given a piece of paper (whereas), the last two review…. it's the different way it's worded (person-centred); it's assessed from X's (daughter's) point of view as well as ours'* (P13). Those who had experienced more person-centred approach Transition Key Workers observed that:

'The biggest change to see actual people's lives changing and its massive that from other staffs point of view they can see that happening to and for that that is what drives you forward. That is what makes you think right this is why we are doing this; this is why we are putting this in place because this is the difference it makes to these people lives. It isn't just about making them happier in school that day; it is actually changing a path of their life which is huge'.

(TKW8)

[21] A One Page Profile captures what is important to a person and how best to support them. The profile provides a précis of the young person, their likes and needs and what other admire about a person.

In some instances, parents felt ready to move on and see their child living independently in their own supported housing. They wanted to have time back to pursue a career or having less caring responsibilities, but were tempered by having been a full-time carer over many years. They wondered if their child is ever going to leave home and live on their own. One parent demonstrated that achieving supported independence could be a reality with a *'specifically trained'* (P20) support team, which had decreased anxiety levels and could handle other changes due to the support in place. Those parents who felt informed considered it had made them more resilient and able to cope, they knew where to go, who to speak to and felt comfortable to *'creat(ed) a fuss'* (P7). These parents had built a bank of knowledge and experience, which they felt had given them some protection. Yet, despite their own individual skills and expertise it had not fully prepared them for the additional worries attributed to the uncertainty of the transition process and what provision would be available.

Managing the changes remained a key concern particularly for parents. Whilst, making adjustments continued throughout a life course parents suggested it became more magnified as they were looking towards achieving independence for their child. Parents felt more confident if support was more forthcoming to transport them through the transition process. But, several parents reported that they had little support to enable them to manage their shifting relationship with their child but also with services and that there were a multitude of changes that parents had to consider and deal with. One parent felt that there needed to be a *'little more understanding from where we are coming from, we're shouldering this alone, you know, and it's hard. It's hardwearing'* (P4) and professionals should understand and acknowledge this. The sensation of being alone and knowing that they needed to move on was associated with a bereavement and with an overwhelming sense of powerlessness in dealing with their change in status. Parents expected to have a void in their lives once their child left home, but that they wanted the best for them. They expected a massive change in their lives and could equate how other parents might feel when a child was undertaking something new in their lives, for example going off to University or having a gap year in another county.

In summary, to deal with the change young people and parents required continuous input from professionals and services to enable them to adjust to new circumstances.

Having uninterrupted worker involvement was problematical and many had *'gone through a few social workers and transition workers'* (P15) and that *continuity was a big issues and there has been a turnover of staff in the team, which doesn't help me or X (son named)'* (P18) due to service changes also experienced by Transition Key Workers and Site Leads. Parental frustration proliferated with them seemingly moving from one social worker to another and not having the contact time they wished for *'the last one I only saw just the once and then that's it'* (P12) so they valued the continuity of Transition Key Worker support. However, proxy reported by parents, young people needed the consistency of input from one person; the Transition Key Worker. Where that was absent it caused issues for them in establishing a new relationship with another worker, which also affected the tempo of the transition process. Parents were also challenged by having a change in worker, having also built up a rapport only to have to start again with a new incumbent.

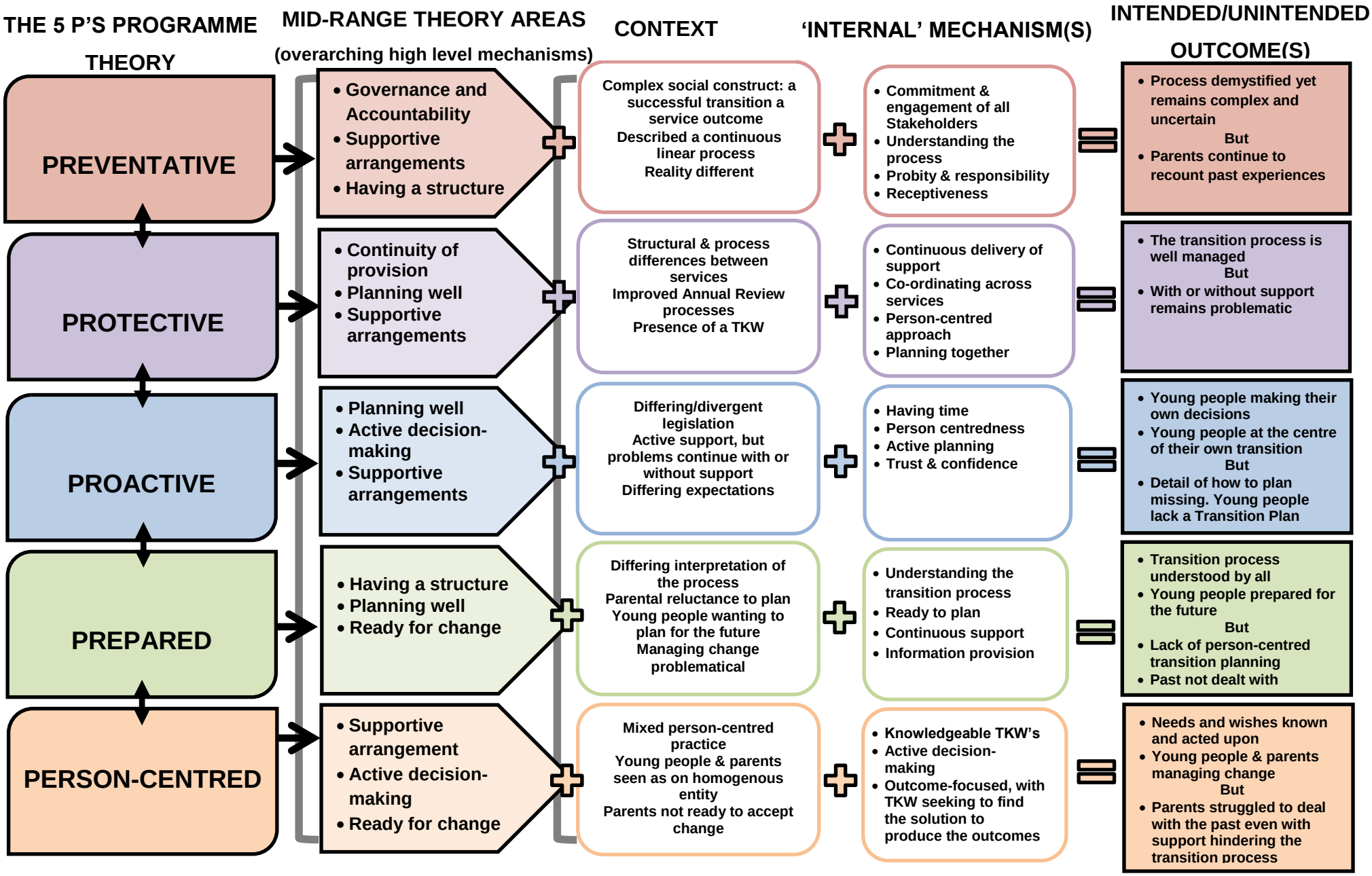
Most parents were keen for their child to fly the nest in the future, follow their dreams and aspired for future independence. If a young person was clear about the future; what they would like to occur and parents wished for them to have the support to achieve their ambitions. Parents recognised that *'it's hard holding a balance really, as X (name of son) concepts of time and future and planning are limited. So as parents we feel we have to do quite a lot of the thinking for him'* (P21), but many parents found it difficult to conceptualise their child's future as an adult.

Table 17 provides a representation of the Context, Mechanism and Outcome (CMO) configuration for the seventh and final mid-range theory area; an addition to Table 6 (Chapter Three) which represented the CMO of the first six mid-range theory areas.

Table 17 Mapping the seventh and final mid-range theory area

MID RANGE THEORY AREA	CONTEXT	MECHANISM(S)	INTENTED/ UNINTENDED OUTCOMES
7. Ready for change	• Legislative change • Lack of co-ordination • Organisational change • Parents unprepared for change • Young people wanting to be ready • Lack of continuity • Some progress change annual review processes	↓ Dealing with the past ↓ Accepting change ↓ Continuous input ↓ Co-ordination ↓ Giving time ↓ Active support (Transition Key Worker)	• All ready to accept and manage change • All stakeholders confident about the future • Parents dealt with the past and ready to move on • Resilient individuals **But** • Parents struggled to deal with the past and reluctance to move forward to think, discuss, plan and prepare for the future

Figure 25. Overall mapping: The CMO configurations of the candidate programme theory and mid-range theory areas



10.2 CONCLUSION: THE OVERALL MAPPING OF THE CMO CONFIGURATIONS

To conclude this synthesis I return to realist principles to untangle the transition construct. Figure 25 provides a visual representation of the overall contextual mapping against a revised programme theory, highlighting the CMO configuration for each element of the theory. The 5 'P's' are overlapping, intersected by the mid-range theory areas (high level mechanisms). Whilst, the mid-range theory areas are mapped to a particular 'P', they can be applied more globally across each of the five components of the programme theory. The context is complex; the pathway to adulthood convoluted, rather than as linearly described in protocol/pathway examples explored in Chapters Three. Structural and organisational differences between child and adult services contributed to the complexities where differing interpretations and implementation of transitional policy varied.

The overarching high level mechanisms (Figure 25) were identifiable and concomitant with the mid-range theory areas and were the probable structural triggers to achieve successful transitions and were largely policy and or service-orientated in nature. Identifying the mechanisms was not straightforward as they have different meanings depending where you are located in the transition process. The underlying 'internal' mechanisms were likely to be activated by the intervention of Transition Key Worker or in combination through their co-ordinating role. However, they were unlikely to be fired once or singularly; rather they are continuously stimulated to achieve a particular outcome for young people and their parents. Conversely, a Transition Key Worker may not have calibrated the impact or miscalculated. For example, a Transition Key Worker is proactively supporting a young person, but what they are delivering might not be within their remit or what the young person wants, but are those of their parents or the context changes as it is delivered. Given the fidelity issues with the Transition Key Worker role, the mechanisms were also being 'fired' at different rates and proportions depending upon their relationship with a young person. The overall mapping suggests an alternative formula for a CMO configuration. A further representation of the revised theory will be reported in the concluding chapter and presents an alternative formula.

The next chapter reports the critical analysis and a discussion across the Realist Review and the Stakeholder Evaluation. In the chapter I provide a final reflection on my multiple perspectives I reported in previous chapters.

CHAPTER ELEVEN
CRITICAL ANALYSIS AND DISCUSSION

11. INTRODUCTION

This penultimate chapter addresses two essential elements of this research and is presented in four sections:

1. A critical analysis of the methodology.
2. A critical analysis of the reporting across the Realist Review and the Stakeholder evaluation.
3. A reflection on my multiple perspectives undertaking the study.
4. A comprehensive discursive inquiry across the synthesis of findings of the review and the stakeholder evaluation within the context of the broader literature.

11.1 STRUCUTRE OF THE CHAPTER

11.1.1 The Critical Analysis

Section One commences with a critical analysis of the methods and findings of the Realist Review by using The RAMESES (Realist and Meta-review Evidence Synthesis: Evolving Standards) Quality Standards for Realist Synthesis for researchers and peer reviewers (Wong *et al*., 2014).

Section Two provides a critical analysis of the Stakeholder Evaluation using the CASP (Critical Appraisal Skills Programme) appraisal tool for qualitative research (2013). The CASP 10-item framework provided focused question, which were purposeful to consider the validity of the evaluation.

Section Three builds upon the analytical personal perspectives offered in Chapter's Five, Seven and Eight. I drew upon Jack's Reflection and Conflict Framework (2008) to answer six key questions concerning my parental and professional viewpoints.

11.1.2 The Discussion

Section Four builds upon the critical analysis across both the Realist Review and the Stakeholder Evaluation with a discussion of the high level findings in the context and in comparison with the wider literature, including new legislation. This Chapter will conclude by summarising the main findings.

11.2 SECTION ONE: THE REALIST REVIEW

I applied the RAMESES publication standards (19-items) for Realist Synthesis (Appendix Eight) in reporting the findings of the *A Realist Review: 'What makes a successful transition into adulthood for disabled young people? Do transition protocols/pathways help to achieve successful outcomes?*' outlined in Chapter Three. I have adopted the RAMESES project partners eight quality standards (Table 18) for realist synthesis for researchers and peer reviewers (Wong *et al*., 2014), which aims to ensure that research subjects are appropriate for a realist approach and can be classified as a realist synthesis. In the following section the eight quality standards guide the critical analysis of the Realist Review and I refer to applying the 19-items within the context of those standards.

Table 18 Quality Standards for realist synthesis for researchers and peer reviews

Item	Item description (the principles	Criterion
1.	The Research problem	• Research topic is appropriate for a realist approach • Research question is constructed in such a way as to be suitable for a realist synthesis
2.	Understanding and applying the underpinning principles of realist reviews	• Review demonstrates understanding and application of realist philosophy and realist logic which underpins realist analysis
3.	Focusing the review	• Review question is sufficiently and appropriately focused
4.	Constructing and refining a realist programme theory	• Initial realist programme theory is identified and developed
5.	Developing a search strategy	• Search process is such that it would identify data to enable the review team to develop, refine and test programme theory or theories
6.	Selection and appraisal of documents	• Selection and appraisal process ensures that sources relevant to the review contain material of sufficient rigour are identified to allow the reviewers to make sense of the topic area; to develop, refine and test theories; and to support inferences about mechanisms
7.	Data extraction	• Data extraction process captures the necessary data to enable a realist review
8.	Reporting	• Realist synthesis is reported using the items listed above

As a reminder, the aim of the review was to:

- Understand what young people, their parents and those working with them considered to the key elements of achieving successful transition into adulthood (Stakeholder Workshop).
- Through three types of evidence understand the role a Transition Protocol/Pathways plays in achieving better outcomes for young people and to determine what worked for whom, how it worked and in what particular circumstances to answer the overarching question.

11.2.1 Quality Standard 1: The Research Problem

This standard sets out two criterions, which are critical conditions to establish whether the transition process was an appropriate subject to review. Realist synthesis/review methodology is theory-driven and aims to understand and answer the 'why', but equally important the 'what', 'how', 'whom' and 'in what circumstances' a complex intervention works. Chapter One identified that the transition process for young people is a complex social, health and education programme, which involved decision-making

and a multi-organisation response and was particularly appropriate to adopt a realistic approach. In undertaking a realist review the RAMESES publication standards for realist synthesis (Wong *et al*., 2014) makes it clear that the title of a realist publication (Item 1) should be identified as a realist synthesis or review to enable reviewers and users to locate to a publication. Therefore, for future reference I adopted the title prefix of 'A Realist Review'.

11.2.1.1 Criterion 1: The research topic is appropriate for a realist approach

In Chapter Two I set out the rationale for using a realist approach rather than undertaking traditional systematic review to explore the process of transition and the use of transition protocols/pathways. The use of realist methodology, to unravel a complex programme such as transition, with the multiple perspectives of individuals and organisations involved locally and nationally was an intuitive and a *'logic-in-use'* (Pawson and Tilley, 1997:37) decision, which enabled a flexible, overt and reflective approach to inquiry across the evidence. The realist approach applied aimed to understand causation and *'that causal mechanisms are shaped and constrained by social context'* (Wong *et al*., 2014, p.1). With that at the forefront, and the need to answer why a programme works or not, the transition process was an ideal subject due to numerous individuals and organisations involved across child and adult services over number of years from the age of 14 into young adulthood. Furthermore, undertaking a realist review resounded with my person-centred beliefs and the value, within a realist approach, that is placed upon stakeholder engagement from the outset. Gaining stakeholder views and understanding their experiences was a key strength of the Review and subsequently the evaluation, which supported the early development of the mid-range theory areas reported and tested through the research.

11.2.1.2 Criterion 2: The research question is constructed in such a way as to be suitable for a realist synthesis

A fundamental aspect of realist synthesis is the fashioning of the research question, one which is as broad as possible, but which retains clarity and succinctness. *'What makes a successful transition into adulthood for disabled young people?'*, as the overarching research question, from the perspective of stakeholders, was constructed in a way to be

as encompassing as possible and easily understood by all. It was consequently substantiated as a valid research question by participants at the Stakeholder Workshop and used to explore their experiences of transition into adulthood.

11.2.2 Quality Standard 2: Understanding and applying the underpinning principles of realist reviews

Chapter Two outlined the underpinning principles of realist reviews and the methods location within the realist philosophy of science. I sited realism between and overlapping with the principles of positivism and constructivism and focused on drawing upon what is known about the transition process through lived experiences; a key realist principle. I applied realist methodological principles to review the literature and, in turn, through the stakeholder analysis. I focused on identifying the Context, Mechanism, Outcome (CMO) configuration to understand how the transition process functioned and the role a protocol/pathway played as an intervention. I identified the contextual relationships and the mechanisms triggered to create successful transitions for young people, which were key objectives of the review. Figure 25 (p.246) cumulatively provided an understanding of the context, the key mechanisms and the intended and unintended outcomes of the transition process and a key contribution to knowledge.

An essential feature of the underpinning principles is the repeated testing and the refinement of a candidate theoretical paradigm developed from and applied to the empirical findings. I made one deviation to the review process in that, a programme theory pre-existed, based upon the key working model and relevant to transition (the 4 P's) outlined in Chapter One. At the 3-day Cares Conference (2014): 1st International Conference on Realistic Approaches it was proposed that there were no hard and fast rules to develop a candidate theory. Realist synthesis is an evolving methodology and the pre-existing theory I presented at the conference was accepted as valid, which endorsed the rationale to apply realist methodology to review the literature and further test through the empirical stakeholder evidence.

The 4 P's candidate programme theory was my starting point, which I set out in Chapter One rather than undertake a review of candidate theories to identify a single programme

theory or develop a composite to explain a successful transition. Transition Protocols/Pathways all express and present similar programme logic (i.e. pathway components) across a timeline that expects a young person to move from A to B in a seamless fashion. Forbes *et al*. (2002) six dimensions of continuity[22] were helpful from the perspective of seamlessness as a successful outcome of the transition process. However, as Forbes *et al*. acknowledged the six dimension partly represented the *'dynamic relationships as core to the experience of continuity'* (p.14) and did not fully represent the core elements of the 4 P's. In my view the 4 P's encapsulated the notion of continuity and developing a composite model would not have changed the direction of the research or the overall findings.

The pathway approach also assumes that by the time young people transfer to adult services they are now functioning as an adult and that their desired outcomes have been achieved. I made a priori assumptions, through my personal and professional experiences that the transition process was not a linear phenomenon or that young people attained their desired outcomes as intended, and in the absence of underpinning theory for existing Transition Protocols/Pathways, the 4 P's were developed as the initial theoretical starting point.

I tested out the candidate programme (conceptual framework) and mid-range theory areas through the review and the evaluation of stakeholder interviews to answer the overarching research question. I subsequently refined the programme theory and integrated the mid-range theory areas into an adjusted model, in line with the criterion for this quality standard and reported the refinement in the concluding chapter. The integration was a pivotal conclusion to explain the central constituents required to achieve successful transitions for young people, but also explained why it may be more problematic for others due to the influencing presence of the past evoked principally by parents reported in Chapter Five. I will return to theory development in the concluding chapter.

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[22] Experienced continuity, continuity of information, cross boundary/team continuity, flexible continuity, longitudinal continuity and relational or personal continuity.

11.2.3 Quality Standard 3: Focusing the review

Undertaking a realist review is likely to generate many potential avenues of enquiry and produce a large data corpus. A critical guide is the research question in directing the scope and depth of the review. The question needs to be focused, but without limiting the opportunity to gather rich data from a number of sources. The review question *'What makes a successful transition into adulthood for disabled young people?'* was broad-based to focus on three types of evidence to answer the overarching research question.

I adopted a realist review framework (Table 4, p58), outlined in Chapter Two to structure the review over two phases to appraise the evidence and develop mid-range theory areas which I tested through the literature and subsequently applied to the Stakeholder Evaluation. The structured approach focused the review on the three types of evidence, but was flexible and iterative, which ensured that appropriate material could be continually extracted and explored to support seminal transition-related literature mined from various sources.

11.2.4 Quality Standard 4: Constructing and refining the realist programme theory

Chapter One outlined the initial development of the candidate programme theory; the 4 P's and set out how and why it might work to achieve successful transitions for young people. Following the principles of realist synthesis each refinement of the theory and the development of mid-range theory areas were reported. I built a sequential theoretical base which resulted in a revised paradigm (Figure 27, p.301); the 5 P's integrated model, which is reported in the concluding chapter. The revised paradigm was influenced by the overall mapping across the programme theory, mid-range theory areas and the multiple patterned CMO configurations identified through the Review and Stakeholder Evaluation (Figure 25, p.246), which was presented in the previous chapter.

Theory building was not straightforward due to the complex nature of the transition process. Identifying the core of causation; accounting for what happened for

stakeholders and in what circumstances for those involved in such a complex programme was challenging. This was due to the multiple numbers of individuals and organisations involved and the context within which the programme was sited. Explaining the patterns; the demi-regularities of CMO configurations was dependent upon being able to identify the context and what were the mechanisms which would trigger a successful transition. I found this took skill, time and familiarisation, but having prior knowledge of the transition process was an asset, as was expeditious learning and clarifying conversations with my supervisors to ensure that I understood the concept and language of realist approaches. Nonetheless, I returned to my reflective journal, supervision notes and to the work of Pawson and Tilley (1997) Pawson *et al*. (2004), and more latterly Best *at al*. (2012), Greenhalgh et al. (2012) and Wong *et al*. (2014) to continually re-clarify my understanding so I could adapt to a changes in context (emergence), related to education and social care legislation or the way a service changed its implementation and delivery of the Transition Key Worker intervention for example.

11.2.5 Quality Standard 5: Developing a search strategy

Realist methodology initiates an iterative approach to searching for evidence; a continuous or repeated delve into new or previously extracted evidence to develop a greater understanding and knowledge base of the subject area (Item 7 and 8, RAMESES publication standards). The aim was to uncover additional data to further develop or refine the programme theory, support the CMO configurations and answer the overarching research question. The search strategy, set out in Table 3 (Chapter Two, p.54) was a two-phased, three-pronged search approach and initiated the extraction of a broad range of documentation that elicited the same or similar descriptions of likely mechanisms, in the context of the transition process, which could or would trigger a successful transition for young people as the specific outcome. The strategy was helpful to contain the ongoing search, but it also posed an initial problem as I had accumulated a substantial data set at an early stage, including the inclusion of hand-held material gathered over time due to my personal and professional interest. Making a coherent decision about which documentation to select was aided by the development of bespoke

tools and joint decisions with my two supervisors to avoid data saturation, which I detail under the next point.

11.2.6 Quality Standard 6: Selection and appraisal of documents

Item 9 of the RAMESES publication standards (2014) highlighted that a *'Realist review is not a technical process – i.e. merely following a set protocol will not guarantee that a review will be robust. Rather, it requires a series of judgement about the relevance and robustness of particular data for the purposes of answering a specific answer'* (p.16). This was of particular importance to make reasoned judgments on the inclusion and exclusion of data to minimise the potential of data saturation. To select and appraise the documentation five bespoke data extraction tools (Appendices Three to Seven) were developed to assist in drawing together material which was of relevance, contributed to theory building, refinement and testing and was sufficiently reliable. I discussed the development of the tools with my supervisors to ensure that they were transparent and robust and would produce material of relevance to the research question. At each phase of the selection produced various types of data from full extraction of legislation, initial citations and the extraction of full text journal paper to a series of transition-related publications, mostly hand-held. The tools developed, asked a series questions related to the programme theory and the mid-range theory areas which emerged throughout the research or were developed using a set of criteria, which helped to focus my selection and appraisal. To augment rigour I used the AACODS Checklist (Tyndall, 2010) to appraise grey material pertinent to the research question.

11.2.6.1 Legislation, policy and consultation documentation tool (Appendix Three):

This tool was particularly useful in identifying both the specific documentation and those of indirect interest, which contributed to the initial testing of the mid-range theory areas identified by stakeholders and the identification of two additional mid-range theory areas. These were then tested out through the broader literature.

11.2.6.2 Transition and Key Working individual extraction tool (Appendix Four):

This tool selected and appraised the individual documentation in detail under seven main headings, which included the main properties and key findings. In using this tool it gave a focus to identifying their relevance to the programme and mid-range theory areas.

11.2.6.3 Included studies/publication tool (Appendix Five)

The material was selected and appraised under five headings, which ensured their relevance to the programme and mid-range theory areas and to the CMO configurations. This tool was valuable as it had a dual purpose and provided a summary of the included studies and publications.

11.2.6.4 Transition Protocol/Pathway criterion tool (Appendix Six)

The tool set out eighteen criteria and established the scope and range of anonymised local, regional and national examples. It was an effective exercise to focus on a smaller selection in detail. However, whilst comprehensive and giving a real sense of the breadth and depth of the narrative and drawing out what I judged to be reasonable or good examples of Transition Protocols/ Pathways, it was a time-consuming exercise. The tool was valuable in identifying the deficiency in detailed information in many protocol/pathway examples reported in the Review.

11.2.6.5 Individual Transition Protocol/Pathway tool (Appendix Seven)

I found the development of this tool enabled me to make a judgement on the selection of the smaller sample based upon the findings of the criterion tool. It enabled me to focus on local, regional and national examples in further detail for which I built a picture and the story of Transition Protocols/Pathways; their purpose and relevance.

11.2.7 Quality Standard 7: Data extraction

During the realist process, the extraction of data contributed to the overall analysis across the three types of evidence. I followed the principles expounded in Item 10 (RAMESES publication standards, 2014) to explain and justify the inclusion and exclusion of material outlined Chapter Two and reported in Table 3. The extraction

tools, highlighted in the previous Quality Standard, provided a description of the findings of previous work in the field (Appendix Five). This enabled me to explain what works or not and for whom, how, why and in what contextual circumstances through the transition process. The data extraction, supported by a adopting a realist logic of enquiry, identified data on CMO configurations and helped to identify patterns within the data (demi-regularities). Throughout the data extraction, joint decisions were made with academic supervisors which ensured that the data extracted had been purposeful and internally valid for the purposes of answering the overarching question. It was a continual logic of enquiry learning process to understand realist terminology such as asking what the demi-regularities were. I revisited data regularly, re-reading and documenting inferences previously not captured. It was a painstaking and complex exercise to unravel a complex programme, but I understood the importance of extracting suitable data to understand the CMO configurations of the transition process and to theory build and test through the review and throughout the stakeholder evaluation.

In terms of the protocol/pathway search many examples were available. Further extraction would not have added to the selection due to similarities in their presentation. A joint decision with my supervisor to focus on 26 examples which represented local, regional and national types was made. No specific modification to the search process was necessary, apart from extracting and including, at a later stage, a regional protocol/pathway example.

11.2.8 Quality Standard 8: Reporting

The review followed the reporting processes outlined in the RAMESES publication standards for realist synthesis. Although, not presented in chronological order due to the structure of the thesis, but nonetheless reported as per the guidelines. An Abstract (Item 2) was developed, submitted and accepted for oral presentation at the Cares Conference 2014: 1st International Conference on Realist Approaches and was successfully delivered on 30th October 2014 (Appendix Thirty-One**).** The attendance at pre-conference workshops and the conference itself further supported and clarified my understanding and insight of realist approaches. It enabled me to refine my methodological comprehension and my analysis and synthesis processes (Item 11) and

reporting (Items, 12-17), which ensued in a parallel fashion to ensure I generated an explanation of the CMO configurations and could be in a position to further develop and present an integrated theoretical model. Subsequently, I successfully submitted an Abstract and presented at the 7th International Cardiff Paediatric Palliative Care Conference on 9th July 2015. The presentation was well-received and included reference to the findings of the Realist Evaluation of stakeholder interviews.

I reported by focusing on mid-range theory building to support the candidate programme theory and mapping to the key findings across the three types of evidence. Utilising realist concepts, I considered that the 4 P's, validated in consultation with stakeholders, was a justified starting point. I reported the theory building sequentially to provide coherence and rigour to explain why the complex process of transition into adulthood generated certain outcomes in particular contexts. I explained how the relationships between the CMO configurations and the theoretical premises evolved, but importantly identified the 'how' to plan effectively with young people was largely missing across the literature I explored.

To summarise, the Realist Review contributed to answering the research question *'What makes a successful transition into adulthood for disabled young people?'* by identifying the key mechanisms likely to trigger a successful transition or not for young disabled people, within the overall context of the transition process. Adopting the RAMESES publication standards for realist synthesis (2014) brought together a range of source material that was broad and flexible enough to make inferences rather than follow a more prescriptive approach such as those employed in a systematic review, whilst still retaining a replicable framework. The bespoke tools were critical to preserve rigour and transparency so that judgements reached were based upon an understanding of the methodological approach to reporting.

Realist synthesis is an evolving method to synthesise a variety and depth of evidence. Although, a flexible and iterative approach it is nonetheless challenging, particularly to an early career researcher. I initially struggled to grasp the core concepts; what they meant and how to apply them. Delivering a presentation of my review findings at the Cares Conference (2014) was critical in determining how I would present the review in

this thesis, but also being clear that I understood realist approaches and could articulate that understanding in Chapter Two (Methodology). I wrote following the Cares Conference in my reflective journal that *'At last I'm beginning to get it……in the real world there are no neat boxes or arrows that is helpful….. I need to be clearer about the context and what mechanisms are fired to achieve a particular outcome, then I think I might have got it and then may be not!*' Finally, I drew upon my previous life as a textile designer, which was valuable in pattern matching throughout the Review and Stakeholder Evaluation. My two diverse 'world's' came together.

11.3 SECTION TWO: THEMATIC ANALYSIS OF QUALITATIVE INTERVIEWS - STAKEHOLDER EVALUATION

I considered and reflected on the comparative analysis of three online appraisal tools undertaken by Hannes et al. (2010) and adopted the use of the CASP (Critical Appraisal Skills Programme) Tool (2013) to assess the methodological quality of the thematic analysis of the Stakeholder Interviews. The tool presents three broad issues to consider when reporting qualitative research, which are direct, succinct and relevant to thematic analysis:

- The rigour: the thoroughness of the research method applied.
- The credibility: that the findings were set out in a transparent and meaningful manner.
- The relevance: how useful were the findings.

The tool, formulated over 10 key questions (Table 19**)** commenced with two questions which are screening questions to ascertain the relevance of use. I report my response to those screening question to set the context in the next section. The latter eight questions ask the user to think about the questions in a systematic manner.

Table 19 CASP appraisal tool for qualitative research (2013)

Item no.	The 10 Items
1.	Was there a clear statement of the aims of the research?
2.	Is a qualitative methodology appropriate?
3.	Was the research design appropriate to address the aims of the research?
4.	Was the recruitment strategy appropriate to the aims of the research?
5.	Was the data collected in a way that addressed the research question?
6.	Has the relationship between researcher and participant been adequately considered
7.	Have ethical issues been taken into account?
8.	Was the data analysis sufficiently rigorous?
9.	Is there a clear statement of findings?
10.	How valuable is the research?

11.3.1 Question 1: Was there a clear statement of the aims of the research?

To remind the reader, the main aims of the research from the thematic analysis perspective were to:

- Understand what young people, parents and those working with them considered to be the key elements of achieving successful transition into adulthood.
- Draw upon the experiences of young people, their parents and professionals working in the field of transition into adulthood by exploring role of a Transition Key Worker as an intervention.
- Explore the views of young people's, parents, Transition Key Workers and Site Leads of their experiences of transition into early adult life.

The transition process was experienced as a complicated route into adulthood despite numerous policy-driven initiatives including transition key working in Wales. Therefore, there was a need to understand how the role of the Transition Key Worker contributed to achieving successful transitions for young people. The aims were framed as a result of stakeholder participation and were designed to be broad enough to encapsulate the complex nature of the transition process and to capture the experiences of all stakeholders.

11.3.2 Question 2: Is a qualitative methodology appropriate?

Adopting qualitative methodology, in the form of thematic analysis of semi-structured interview material, was based on the need to address the aims of the research and the method of data collection. This enabled the active interpretation of the subjective experiences of the participants to answer the research question. Using qualitative methodology enabled the continuous location of the patterns (demi-regularities) within the data corpus (across the stakeholder interviews); a key focus of thematic analysis and was compatible with the realist approach employed to review the literature reported in Chapter Three to understand the CMO configurations of the transition process and the role of a Transition Key Worker in supporting successful transitions for young people.

11.3.3 Question 3: Was the research design appropriate to address the aims of the research?

I drew upon and reported in Chapter Two the work of Boyatzis (1998), which aided my understanding of thematic analysis for the purposes of exploring the experiences of all stakeholders involved in the transition process. Although, Boyatzis argued that while thematic analysis was often applied by researchers, the application had not been specifically defined as with other forms of qualitative analysis, such as grounded theory. However, more latterly the work of Ryan and Bernard (2000) and Braun and Clarke (2006) provided a structure to and legitimised the use of thematic analysis, alongside other narrative methodological forms. Braun and Clarke (2006) developed a 15-point checklist, within a 6-phase framework and I adopted this checklist and described the research design step-by-step in Chapter Two, taking into account the reflective and iterative nature of the analysis to address the aims of the research.

Nonetheless, as with other qualitative methodological forms to describe a social phenomenon such as the transition process, there were advantages and limitations (Table 17), which I considered in developing the research design. I considered the two positions outlined by Braun and Clarke (2006), firstly, that the theoretical position is pre-set or secondly, the methodology is independent of theory before analysis. I took the position that thematic analysis could be applied within a realist construct, and while a candidate theoretical model existed, it could be tested, refined and revised through

thematic analysis processes. I was keen that the research design would uphold the theory-driven flexible realistic approach I employed for the Review; searching for the demi-regularities (patterns in the data) to understand the CMO configuration(s) of the transition process. Thematic analysis gave me continued flexibility and was instrumental in pattern searching across rich and detailed material, whilst still having form and validity to address the aims of the research.

The advantages were that thematic analysis was understandable to me as a relatively new researcher to manage a potentially large data corpus. Importantly, the pattern searching and matching acted as the means to extract and report similarities and differences across the four datasets and uncover unanticipated explanations of why the transition process was successful or not for young people such as the unforeseen manifestation of the past for parents which hindered their thinking about the present and critically the future.

I considered there were limitations to the research design (Table 20) in two key areas which needed to be regulated to reduce their potential impact. Firstly, to manage the data corpus, I sought advice from Dr Gemma Griffith (Bangor University) to develop a coding framework to ensure that the coding process was rigorous and reliable to mitigate bias in searching for themes. Secondly, I was aware that having previous knowledge may cloud my judgement on sensing and determining prevalence or the significance of themes. I reflected that to disregard my own perceptiveness, experiences and prior knowledge would not support the reporting of my multiple analytical perspectives or the rigour of identifying the patterns in the data, which I considered was a key strength. I presented the initial coding maps to my supervisors and had active discussions on the appropriateness of the high level themes to ensure that I was transparent and credible throughout the analysis and reporting.

Table 20 Advantages and Limitations of Thematic Analysis

ADVANTAGES	LIMITATIONS
• Flexible analysis method to manage large richly detailed and complex data corpus • Identifying repetition; the patterns in the data corpus • Straightforward to understand as an early researcher • Ability to have participants; those who are experience a phenomenon as collaborators • Able to, through a potential large data corpus to present a rich description of the data • Ability to extract and report similarities and differences across datasets • Uncovers unforeseen observations • Analysis and reporting to inform policy and practice development • Compatible with a realist approach	• Managing large data corpus without robust structuring to make sense of the evidence • Reliability where there are multiple researchers interpreting data • Sole researcher as coder and interpreter of the data • Potential for researcher bias: projecting own thoughts and ideas on the participant data • May miss nuances within the data • Interpretation may be hindered if a robust theoretical framework is absent or weak
MANAGING THE CHALLENGES	
• The development of a thematic analysis framework to manage multiple datasets across the 4 stakeholder groups • Being transparent within the Methodology chapter • Following the phases of Thematic Analysis • Acknowledging my own perspective, my prior knowledge of the transition process, ensuring it did not cloud my interpretation or see themes which suited my own ends • Having active supervision important	

(Ritchie and Spencer, 1994; Boyatzis, 1998; Braun and Clarke, 2006)

Finally, it was important to acknowledge the challenges of managing the research design. In adopting Braun and Clarke's (2006) process I found it purposeful and it engaged my thinking beyond the surface level of a complex social programme. It enabled me to examine the underlying context, mechanism and outcome configuration(s) of the transition process and presented an alternative experience of local transition protocols/pathways (Figure 23, p.233) and why young people and their parents continued to report poor transitional experiences with or without support despite, identifying the key mechanisms to achieve a successful transition (Figure 25, p.246).

11.3.4 Question 4: Was the recruitment strategy appropriate to the aims of the research?

The recruitment of participants was dependent upon their involvement and experiences of the transition process and of the intervention of the Transition Key Worker. The selection process was explained from the outset in bi-lingual participant information booklets to each participant group (Young People, Parents, Transition Key Workers and Site Leads) who originally completed a questionnaire not used in this thesis provided their consent to be contacted to take part in an interview. Subsequently, those who gave consent were contacted by the method they requested; mostly in letter format, whether posted or attached to an email address provided. Follow up calls or emails to arrange a time, date and venue were made. Individuals were selected on the basis that they were:

- Young people aged 14 to 25 who had a disability which was considered complex and who required support from two or more non-universal services through transition into adulthood and were a) able to give assent, countersigned by their parents if under 16 or b) provided informed consent if over 16.
- Parents of young disabled people aged 14-25.
- Professionals who were undertaking a Transition Key Worker role.
- Managers, who were acting as the Site Leads in developing transition key working in Wales or who were responsible for developing local transition services.

The recruitment of young people was not dependent upon their parent taking part and vice versa. However, it was helpful that both took part, which enabled me to make a comparison of parental and young person experiences of the transition process and Transition Key Worker support, which was reported in Chapter Six.

Participants were excluded on the basis that their consent form had not been satisfactorily completed, for example no contact details provided or the consent given or an assent form had not been countersigned by a parent or guardian. However, in those circumstances, where a young person wished to take part, I gained parental consent to

ensure that they were able to participate. Subsequently, there were a number of parents who were not contactable using the contact details provided and I was unable to pursue their participation. Of those contacted after providing consent, only four participants were unable to take part due to other commitments. This was largely due to coinciding non-availability which was a drawback as I was the sole interviewer. I ensured that face-to-face interviews took place with all young people and parents recruited. To encourage the participation of Transition Key Workers and Site Leads I arranged telephone conferencing to accommodate their commitments and timetable.

I developed a minimum recruitment strategy across the stakeholder groups (Table 10, p.96). I expected to be able to conduct a minimum of 42 interviews over a ten-month period, given the geographical location of participants and my available time as the sole interviewer. I was able to conduct 61 interviews (n=72 taking part across the stakeholder groups) covering 13:22 local authority areas across Wales. This had been quite an undertaking as I continued, until April 2014, to work full-time. Juggling commitments was second nature, so I embraced the challenge. But, I acknowledge that the time taken, whilst worthwhile and illuminating, was exhausting. I considered the overall recruitment and interview process sufficient to achieve a reasonable data corpus and avoid data saturation to address the aims of the research and provide a reliable source of data to analyse.

11.3.5 Question 5: Was the data collected in a way that addressed the research issue?

Semi-structured interviews were selected as the most appropriate methodological approach to acquire, with sufficient depth, the data needed to address the aims of the research and to answer the primary overarching research question. Using semi-structured interviews provided the opportunity to gather the real-life experience of both receivers and deliverers of transitional support. Although, it could be argued that the nature of semi-structured interviews leads to specific subject setting (Bryman, 2008), each interviewee responded individually to questions posed. In some instances I had to move the conversations along to avoid deviations from the schedules. This was

particularly so for parents who wanted to focus on past events to the exclusion of other topic areas within the transition process. I will return to this in the next section.

I developed four schedules (Appendices Nine to Twelve) specific to the participant groups which covered similar questions, but were also dependent upon their position in the transition process to ensure that there was consistency of delivery. While I received ethical approval for draft schedules to address the aims of the research, I was guided by the findings of the Review to sharpen the focus of the open questions. I sought to understand how all the stakeholders were approaching the future; their ideas and challenges they faced. I asked the questions in sequence using similar wording and re-worded where clarification was needed. This was particularly the case for the young people and I adjusted my questioning to aid understanding and encouraged them to voice their own experiences. I was aware that where a parent was present, some young people deferred to their parents or checked out what they were saying was acceptable. In such cases I was pre-warned by the Transition Key Worker, which enabled me to deflect parental intrusions in most cases.

A critical element of interviewing was to ensure the interviewees were comfortable to take part. The interviews were held in a location that was suited and convenient to them. Young people and parents were interviewed in their own home as the preferred option. However, three parents chose to be interviewed at the school where their child attended with the agreement of the school. All Transition Key Workers and Site Leads were interviewed in their place of work, unless they requested being interviewed via teleconferencing. In all cases I explained the purpose of the research and audio recording procedures and my note taking. For those, upon arrival, who wished not to be recorded, despite assuring them of anonymity, detailed notes were taken. Although, I considered this unsatisfactory, I honoured their requests and shared my detailed notes with participants to agree the content and that they were happy with what I described.

To ensure anonymity and confidentiality all participants were allocated an identification code; each transcript consequently coded. All audio recordings were checked and re-checked to maintain verbatim transcription and the recordings deleted to maintain anonymity in accordance with my ethics submission to the Bangor University's School

of Psychology Ethics and Research Governance Committee. I began to transcribe audio recordings as I continued to interview participants to monitor potential data saturation. I considered that, in discussions with my supervisors, the parental cohort of 26 interviews was more than sufficient, and the total number of interviews provided a rich source of material to analyse and identify themes across each data set.

11.3.6 Question 6: Has the relationship between the researcher and participants been adequately addressed?

I set out in Chapter One my personal and professional roles and in subsequent chapters I examined my own role as a researcher with multiple perspectives. I felt that it was important from the outset to disclosure my history; my personal and professional story as it was in the public domain. It should be noted that I did have an established relationship with most of the Transition Key Workers and Site Leads. Therefore, I was conscious that they were clear about my role as the researcher; that it was a different relationship to ensure that I and those interviewed were not tempted *'to fall back on familiar interaction patterns – patterns that are often counteractive to data gathering'* (Kirby and McKenna, 1989, p.122) during the interview phase.

I maintained probity, by seeking the support of Sited Leads. They distributed information about the research and asked Transition Key Workers to encourage the participation of young people and parents. The Transition Key Workers explained my involvement in supporting them to develop transition key working. In most cases I had no prior relationship with young people and parents interviewed. In a few cases I had met some of the parents and one of the young people at a local consultation event I facilitated in a professional capacity. Therefore, they had prior knowledge and that I was also a parent of a young person experiencing the transition process. I will address the issue of boundaries setting between participant and interviewer in Section Three.

11.3.7 Question 7: Have ethical issues been taken into consideration?

The research proposal was submitted to Bangor University's School of Psychology Ethics and Research Governance Committee and received approval with minor amendments to the protocol. I informed participants that I held an enhanced Disclosure

and Barring Service check that was kept up-to-date during the research. The participant information set out how participants would be involved and how consent would be sought. In addition I was clear before commencing an interview that information gathered would be kept confidential unless there was a disclosure or I observed anything which was of serious concern about the physical and emotional well-being of the individuals involved. While, parents more specifically discussed sensitive family issues, at no time were their disclosures considered to be of a serious nature. Their focus was more on the angst they felt about how they perceived they had been treated by professionals previously pre-transition.

The consent process was outlined in Chapter Two and I presented a flow diagram (Figure 12) of the process for each participating group. Gaining the consent of parents, Transition Key Workers and Site Leads was a straightforward process. However, gaining the consent of young people required more care. I based the matter of competence, to assess the autonomy of a young person to provide informed consent, within the legal framework set out in the Mental Capacity Act (2005). This guided me in developing firstly, a consent form for those young people over 16 who, in law, were deemed competent. I took the position that Transition Key Workers were best placed to initially assess the competence of young people they were working with. This worked well and all those who participated over the age of 16 were able to share their experiences in their own voice or form of communication. Secondly, an assent form was developed to take account of young people under the age of 16. Their parent and Transition Key Worker countersigned to confirm competence to participate. This worked relatively well, but in some cases consent forms were returned without being countersigned or their contact details were missing, so I was not able to pursue their involvement. I found it difficult, when using a third party to assess competence, to gauge my approach prior to interview, not knowing whether the young person would be able to participate. I countered this ethical concern by contacting their Transition Key Worker or parent to make sure that I had the materials to communicate in their preferred method. I adapted my interview methods for each young person. I addressed the issue of confidentiality by anonymising all written material and deleting the original audio recordings. I alone had access to their consent forms, transcripts and a database of

contact details and related identification codes. The database and all transcripts were password protected.

11.3.8 Question 8: Was data analysis sufficiently rigorous?

An explanation of the analysis process was outlined in Chapter Two. I adopted Braun and Clarke's (2006) 15-point checklist of criteria for good thematic analysis, which provided a phased framework. I drew upon the previous works of Boyatzis (1998) and Ryan and Bernard (2000), focusing on Boyatzis' (1998) description of thematic analysis as '*a way of seeing'* (p.1), sensing patterns in the data and thematically analysing in a structured manner. I endeavoured to sense the themes, doing it reliably, developing the codes, interpreting the information and themes (Boyatzis, 1998, p.11) in the context of the programme and mid-range theory areas across the data corpus.

I took into account the advantages and limitations (Table 20) and focused on meeting the challenge of being a novice researcher by following the phases of thematic analysis. I sought advice from my supervisors to clarify my thinking and understanding and joint decisions were made on agreeing the interpretations I propounded. As a researcher I understood that I was the active agent (Fereday and Muir-Cochrane, 2006); the instrument to identify or distil from the data through the transcribing process, the analysis to the final reporting. As the sole coder, I appreciated I needed to be clear that I understood the content of the data; including the potential for bias as I had prior knowledge and experience. I endeavoured to preserve internal quality assurance and impartiality by not deviating from the thematic approach advocated by Braun and Clarke (2008), and although it could be argued that it was a subjective *'fixed list'* (Reynolds *et al*., 2011) framework, it was also flexible to intuitively sense, but not predict the themes across the data corpus. I maintained reflective journals to appraise and document the non-linear pattern searching and documented the initial thematic mapping in diagrammatic form. I kept detailed supervision notes to document decision-making trails, the variations in meaning in the experiences of the participants, particularly parents, and recorded my personal reflections of interviewing, transcribing and analysing the data, which I discussed with my supervisors.

I transcribed the audio recordings. Therefore, I was reacquainted with the voices and the narratives of the participant's experiences, which was a crucial stage as in some instances there had been a time-lapse between conducting the interviews and transcribing. This enabled me to develop a more in-depth understanding and rigour as I began to recognise the repetition by re-listening to the audio recordings, picking up the nuances and the inflection in speech, alongside the verbatim transcripts. I chose to 'hand' analyse the transcripts line by line, rather than use a software package such as Atlas ti, despite having had training. As a visual and tactile practitioner, I firstly hand-annotated each transcript, colour coding initial interesting segments of text, which resonated with the programme and mid-range theory areas. I further annotated the next and subsequent transcripts and endeavoured to develop the *'ability to see'* (Boyatzis, 1998, p.7) patterns in the data by, at an early stage, developing visual maps of initial codes as I identified them. I read and re-read the transcripts moving backwards and forwards to identify patterns to categorise the data within each dataset. Like the transition process itself it was not a linear analytical procedure and was compatible with the realist approach I took to undertake the Review, which was flexible and iterative.

Using the coding framework, I began to build one for each transcript, extracting repetitious words or segments of text to assigning to a code and, in turn, described a theme. To aid recognition, further retrieval and cross checking, each word or segment of text was assigned the participant ID, page number and line number. Upon completing the analysis of individual transcripts, a master for each participating group was developed drawing together sections of text, which best represented particular collapsed higher level descriptive themes I reported in the Stakeholder Evaluation. It was a lengthy process sorting and eliminating coded text as numerous examples were revealed. I discussed the collapsing of numerous themes observed into higher level themes and chose appropriately matched segments to longer quotes across the four data sets. Reflecting on the data I returned to my journals as I was surprised that I had not immediately appreciated the influence of the past on parents and the impact it had on both their 'here and now' circumstances and their thinking about the future. Yet, it was in the words they spoke and their facial expressions, which I had noted but had not realised their immediate significance.

Overall, my assumptions were that the themes I reported where consistent with the master coding frameworks for each participant group. I re-checked the identified codes and the extracted text regularly against the transcripts. The candidate programme theory and mid-range theory areas identified by participants of the workshop and from the Realist Review were present in the data. The repetitious use of words such as 'support', 'continuity', 'planning' and having a 'structure' appeared throughout the data corpus. Therefore, my own prior knowledge and suppositions were helpful in making sense of the narratives of the participants' experiences to be able to collapse the myriad of potential themes into coherent thematic maps and proceed to report the findings across the four datasets.

11.3.9 Question 9: Is there a clear statement of findings?

The aim of reporting the findings was to provide a clear and coherent story of the complex nature of the transition process. I built chapter by chapter, through the analysis and the synthesis, a logical description and interpretation of the experiences of the stakeholders to answer the research question. The objective was, through thematic analysis, to further test the candidate programme theory and the mid-range theory areas established from the Review, refining and developing progressively through to the synthesis. I found this approach supported the identification of the barriers to the transition process as well as the assistors; those key features to achieve a successful transition. I presented successive findings supported by explicit extracts from participants and illustrative explanations, including the mapping of parental experiences alongside my own to identify the potential success factors.

The overall findings were presented, firstly through a synthesis across the stakeholder data corpus and secondly, across the Review and Stakeholder Evaluation. Figure 21 (Past/Time/Future configuration) explicitly précised an interpretation of a difficult and successful transition from the multiple stakeholder perspectives and how it can swing individually for young people due to the difficulties circumnavigating a complex programme. However, Figure 25 (overall mapping) presented a summary of findings, across the Review and the Evaluation, which highlighted the context, key mechanisms and the intended or unintended outcomes of the transition process, within the locale of

the refined integrated programme theory and represented the sequential reporting of findings and the theory building which commenced with the Stakeholder Workshop.

In conclusion, the advantage of choosing thematic analysis was that it was compatible with a realistic approach, and not a method that had a particular alliance to an epistemological or theoretical standpoint (Braun and Clarke, 2006, p78). Like realist synthesis, a thematic analytical approach afforded flexibility within a recognised framework, which provided a continued platform for theory testing, refining and re-building an integrated programme theory to explain what I considered to be the key elements required to achieve a successful transition not only for young people, but for all those involved in the transition process. I report the development of the revised programme theory in the concluding chapter.

There were challenges to identify the themes, without bias and prediction. I spent a considerable amount of time immersed within the raw data, listening, observing, and re-reading to ensure that, as the sole coder and theme generator, I would be confident to report comprehensible findings, based upon the stakeholder experiences. I considered that I largely achieved identifying the underlying CMO configurations of the transition process and the key features of supporting young people to think, discuss, plan and prepare for the future beyond adolescence. My multiple perspectives added value and nuance to the findings giving depth which might not have transpired without those perceptions.

11.3.10 Question 10: How valuable is the research?

I considered and reported in the final chapter my unique contribution to existing and new knowledge in the context of the current policy and the usability of the empirical findings across the Review and Evaluation. The research is of significance on two levels. Firstly, the overall findings were valuable in that they set out the CMO configurations of the transition process, which could be utilised by practitioners and commissioners in developing transition services. Further to this the alternative depiction of a transition pathway from the stakeholder perspective is the lived non-linear experience and that identifying the depth to the transition process was a valuable and usable finding to aid further pathway development.

Secondly, the realist framework I used can be applied to other populations where a complex programme or intervention is being delivered. The methods applied to this research could be replicated by other researchers interested in exploring the transition process. Although, the delivery of transitional support to young disabled people is a specialised area, the findings could be applied to other populations of young adolescents moving from child to adult services who require transitional support such as those with a mental health condition or condition specific diagnoses such as those with Epilepsy or Cystic Fibrous who require support into adult health care services. As a final comment the semi-structured interview schedules could be adapted for other populations who require support through transition into adulthood. As a concluding comment I have shared the schedules, the participant information booklets and consent processes with other PhD students and researchers exploring issues faced by young people with complex needs, which have been valuable in supporting their research design.

11.4 SECTION THREE: REFLECTIVE ASSESSMENT OF MY MULTIPLE PERSPECTIVES

This section provides reflective assessment of my multiple perspectives in conducting qualitative interviews. I drew from the work of Dickson-Swift *et al*. (2007) and Jack (2008) who considered the role of the nurse researcher in qualitative interviewing. Jack posed six key questions (Table 21) which were applicable to other researchers who have a professional affiliation to a research topic. I adopted Jack's framework to consider my multiple roles and perspectives. I kept reflective journals throughout, including specific journals related to my experiences of interviewing participants. I draw upon these in this section to assess my multiple roles in conducting the Stakeholder Evaluation.

Table 21 Reflection and Role Conflict framework (Jack, 2008)

No.	Key Questions
1.	What is the paradigmatic approach in which the research design is situated?
2.	What have been the participants' past experiences with research and researcher's profession?
3.	What kind of boundaries should be established between the researcher and the participant?
4.	How should the researcher present his/her role to a participant?
5.	Should a researcher offer practical advice during an interview?
6.	What impact did the intervention have on the nature of the relationship?

11.4.1 Question One: What is the paradigmatic approach in which the research design is situated?

Paradigmatically, the overall research design was sited within realist and interpretive methodology. This gave me the flexibility to build and move between the Review and the Evaluation to understand and explain the experiences of individuals involved as receivers and deliverers of support through the transition process. I felt it was important, given the challenges which continued to be highlighted with the literature, to hear the voices and be part of their sharing of their experiences; the good and the bad. I was especially interested to understand from an ontological perspective how the transition process and the role of the Transition Key Worker were perceived by stakeholders; their real-life experiences. Therefore, the stakeholder voice, the reality of their world, from a qualitative perspective, was crucial in disentangling the complexities posed by the linear presentation of the transition process. My assumptions were that adopting a realistic person-centred approach to the research design would contribute to understanding the context and the mechanisms which were likely to trigger a successful transition and were of particular interest. Reflection and transparency has played a crucial role in the research design to mitigate any conceptual baggage and bias I might transfer through interpreting the words of the participants. I explored my own transitional experiences alongside participating parents to provide clarity and comparison. This aspect of the research design was an illuminating experience and although my journey may have been different, it was, nonetheless, frustrating, stressful and a battle as they had articulated and a significant contribution to the overall findings.

11.4.2 Question Two: What have been the participants' past experiences with research and researcher's profession?

There was a varied stakeholder experience of taking part in research. More often, there was experience of attending local and national consultation events, including events I commissioned in my role as Director of CCN Cymru. The Site Leads and Transition Key Workers had attended a series of evaluation days to support the continuation of local Transition Key Worker provision to provide evidence to the Welsh Government on effectiveness. Many had been involved in the development of the research question posed for this research and through their participation in the validating the candidate programme theory initially proposed and then tested out during the Review and Stakeholder Evaluation.

As reported in Chapter Five, parents had had a mixed experience and contact with services pre-transition which had hindered their thoughts about their son/daughter's future and their continued engagement with services. Parents and young people were aware of my background due to their participation at consultation and evaluation days and through information provided about the research. I felt that as I was not a deliverer of local support and services to families, they would feel comfortable discussing their stories within the research context. However, I did have some concerns that as I already had an established professional relationship with many of the Transition Key Workers and specifically the Site Leads; they may not have felt comfortable expressing their feelings. I considered that our relationship was already built on trust and mutuality and all were happy to discuss their innermost thoughts to support the research without a detrimental effect on our relationship. Indeed it was strengthened as a result and many were interested to read the results of the research.

11.4.3 Question Three: What kind of boundaries should be established between the researcher and the participant?

Clear boundaries were necessary, particularly as I sought to discuss an emotive subject. I had already declared my professional background; many of the participants knew my personal and professional history. I felt that it was important to establish that, whilst I had personal and professional experience of the transition process and the intervention of a key worker, I would through quality assurance and reflection, avoid bias in my

interpretation and analysis of the data collected. To forestall role conflict I felt that it was important to declare my multiple roles to avert assumptions being made that I could, for example, help parents through the transition process based upon my prior knowledge and experiences. I had explained when interviewing participants that I was there in my role as a researcher. This was readily accepted, but did not always prevent parents asking for advice.

11.4.4 Question Four: How should the researcher present his/her role to a participant?

My background was well known; my parental experiences were in the public domain as were my professional views. I had regularly presented on topics related to disabled children and their families, including the transition process. I was attendant to the possibility of role conflict and participants' preconceptions. I concede that I struggled with my multiple roles, but acknowledging that it might influence my observations and interpretations was an important milestone and aide memoir, but that acknowledgement also prevented me from offering advice and information during interviews. I knew many of the Site Leads and Transition Key Workers well or were I was not a well-known they had received training I had facilitated. I openly referred to my background to be transparent and for participants to feel comfortable and at ease. I considered I had gained the trust of Site Leads and Transition Key Workers and that I would not be judgemental or misrepresent their views. It was more problematic in determining how to present my role to parents and young people as *'reciprocity can lessen the hierarchical nature of the research process'* (Dickson-Swift *et al*. 2007, p.334). Sharing mutual stories, while helpful to removing barriers and can establish a fleeting relationship, it was their stories that provided the rich narrative data on their direct and personal experiences which was vital to the research and not my own apart from making analytical comparisons.

I considered that being an *'insider researcher'* (Unluer, 2012, p.2) had advantages in presenting my other roles to participants; that I understood how parents might feel about the transition process as I had *'walked in their shoes'* (Reflective Journal 1, p17), and that Site Leads and Transition Key Workers would suppose that I was *'on their side'* (Reflective Journal 2, p.5) and talk spontaneously. Conversely, I considered that there

were possible disadvantages, which Unluer (2012) highlighted, such as *'role duality'* (p, 6) and that there was the risk that Site Leads and Transition Key Workers would assume that I already knew what they might relate and not respond to my questioning. I asked them to be honest in their responses as they had *'untold stories……hidden or unexplored aspects'* (Dickson-Swift *et al*., 2007, p338), which I had not heard in my role as the researcher.

11.4.5 Question Five: Should a researcher offer practical advice during an interview?

During a small number of the interviews parents vented their anger and became emotional and upset, often using expletives. I dealt with the situation by focussing on more positive events and the importance of safe communication (Kirby and McKenna, 1989) during impassioned disclosures. I returned to the root of their anger by asking them if what had happened to them could have been different; what would have made a difference and they could return to talk about and focus on the transition of their child into adulthood. As a parent, who had experienced similar frustrations, I appreciated how they felt. Their prior knowledge of my background was helpful as it enabled them firstly to openly express their feelings, and secondly to deal with anger and emotions in the here and now. I considered sharing their feelings that it had not detracted from the interview dialogue, but gave a rich insight into their personal real-life experiences. This had consequences as a few parents began to ask for specific advice about what they should do, and in one case a parent was floundering with the complexities of her family situation. At the end of this interview, after I had stopped recording, I urged her to contact the social services duty team and waited with her until she made the call.

I was aware that I had an emotional reaction post interview, particularly following the interviews with parents. I frequently sat in my car, after initially driving off, to consider what would happen to the family once they did not have Transition Key Worker support as it concerned me. I felt powerless as I knew I should not intervene. But, each journal entry after a parent interview, words such as *'vulnerable'*, *'concern'* and *'anxiety'* (Reflective Journal 1) predominated. I noted that many of the parents had a *'haunted look….were struggling to knit it all together'* (p.11) and the transition process *'should never have been a battle'* (p. 54) for them. I was happy to email them copies of

anonymised transition plans to help them think about the future and they responded with appreciation and warmth. Interestingly, young people interviewed did not seek advice; they were relatively happy and not visibly concerned about the transition process. They were concerned about losing their Transition Key Worker and about what would happen. I was honest with them that I did not know whether there would be more funding so that their Transition Key Worker would be able to continue to support them. Similarly, Transition Key Workers and Site Leads did not seek practical advice during interviews, but subsequently there was correspondence related to continued funding, which was a major concern but were directed appropriately to me as the project lead.

11.4.6 Question Six: What impact did the intervention have on the nature of the relationship?

There were occasions when parents asked my advice during an interview. However, I did not intervene with a specific intervention. I discussed under the previous question that I encouraged a parent to make a telephone call after an interview. Upon reflection, I considered this to be an appropriate action to support the parent to make contact with social services.

11.5 SECTION FOUR: THE DISCUSSION

Section Four centres on the findings across Realist Review and Stakeholder Evaluation within the context of the wider literature. Firstly, I focus on the role of Transition Protocols/Pathways as the conjectural facilitators of a implementing a multi-agency structured transition process, which were the primary source in phase two of the Review. Secondly, I locate the findings of the Stakeholder Evaluation within the main body of evidence and focus on the role the past played in influencing the destination of young people post transition.

11.5.1 The Realist Review

Transition-related evidence existed reporting both difficulties encountered and the features of a good transition (Hirst and Baldwin, 1994; Forbes *et al*., 2002; Morris, 2002; Beresford, 2004; Heslop and Abbott, 2007; DSCF, 2007; DOH, 2008; Sloper et al., 2010; Doug *et al*., 2011). However, comparably, specific literature related to

Transition Protocols/Pathways, as the intended vehicle to the structure the transition process, was largely absent. The Review highlighted that attempts to provide a robust evidence base on the effectiveness multi-agency protocols/pathways was a neglected area, despite policy directives (NSF, 2004 (England), 2005 (Wales); DSCF, 2007; Welsh Government, 2007; DOH, 2008), which aimed to remove the barriers between child and adult services that continued to be presented in the literature (Fiorentino et al., 1998; Forbes *et al*., 2002; Beresford, 2004).

Overall, narrative storylines had not appreciably changed over time in parallel with poor transitional experiences reported by stakeholders. There was the tendency to focus on the challenges and the issues related to continued gaps in transitional provision, despite the recognition within policy reviews (Welsh Assembly Government (ELLS Committee), 2007; Welsh Assembly Government (Equality of Opportunities Committee), 2007), which reinforced the need to improve the continuity between child and adult services. Further guidance had not been issued to ameliorate the issues related to the transition process highlighted in both Committee reports.

Linear protocols/pathways were seen as the means to structure the transition process across multi-agency partnerships. Although, the TransMap principles (Council for Disabled Children, 2009) [23] guide protocol/pathway development, there was a lack of analogous evidence of their role and efficacy within the wider documentation to support successful transitions for young people. Kaehne's (2010) conclusions were helpful, but were principally based on the role a protocol/pathway played in supporting multi-agency partnerships across child and adult services. There was a token regard as to their role within two more recent primary studies (Sloper *et al*., 2010; Beresford *et al*., 2013), but not a major focus. Nevertheless, the differences in the way child and adult services are configured were compounded by differing eligibility criteria and the lack of early engagement of adult services despite the emphasis within some protocols on this being an instrumental factor in facilitating 'seamless' transition.

[23] 5 principles: comprehensive multi-agency engagement, full participation of young people and their families, the provision of high quality information, effective transition planning and an array of opportunities for living life

The evidence suggested that protocols/pathways are procedurally driven; what organisations need to do to observe their responsibilities. However, they were unlikely to protect young people and their parents from experiencing a disjointed transition. There were attempts in the language to shift the balance from a service-led to a person-centred transition. Yet, high level outcomes are documented, but not outcomes directly related to a young person's transitional experience and their eventual destination point. Is it achieved as intended? The focus was on the outcomes expected of the protocol/pathway itself and not those of young people. Structurally, the overriding and main transition point documented was education-based; young people transitioning between school and further education rather than achieving holistic transitions, which could account for the lack of adult service engagement documented in the wider literature.

The reality for young people, parents and practitioners in the use, understanding and impact of a protocol/pathway was somewhat different in their overall intention to direct the transition process. Protocols/pathways made sweeping statements, with the mechanisms to promote change and achieve a successful transition for young people buried within worthy, yet verbose content. The presence of the overarching mechanisms (Figure 25, p.246) such as planning well and active decision-making were no guarantee that young people would achieve successful transitions as they will have a different effect in differing personal and collective contexts. For example, the situation of the young person, the number of practitioners and organisations involved and how they react and interact with one another are all influential. External mechanisms were required; multi-agency/organisational commitment and engagement to activate an understandable protocol/pathway. However, the quality of their narrative highlighted differences in local interpretation of transitional processes depending upon where a professional or organisation was situated. An actively used protocol could afford and enable practitioners and agencies to work with young people to achieve successful transitions and prevent disengagement and indifference.

The transition process continued to be depicted as a straight line to adulthood (Figure 22, p.232) and presented in protocols/pathways, including national examples as rectilinear and unbending to the young person's individual needs. The process and the

pathway have depth, which was not represented. The pathway, in reality, undulates backwards and forwards with many avenues and dead ends (Figure 24, p.235). It is not a clear-cut journey from A to B, but one of A to C to J and so on; a key feature of complex social programmes and experienced by young people and parents represented in the mapping outlined in Chapters Five and Six. Young people are not stationary on entry; they are already moving, have their own ideas and an expectation of their journey, but it can veer off in many directions depending upon their eligibility and the time it takes to make decisions. Current transition planning procedures from the young person's and parents' perspective, also highlighted by practitioners, appeared not to take the worry away. Although having a structure, proactive support, continuity and active decision-making to plan well, which are implicit in the policy, apprehensions remain about how that happens. Although, a protocol/pathway can act as cursory framework it was surprising to find that, despite pointers in policy, planning well as a mechanism and in detail was a minor feature. Encouragingly, the Together for Short Lives (2015) updated transition pathway for young people with life-limiting and life-threatening conditions has moved away from a visual linear representation towards a standards-based approach. Furthermore, work I commissioned in 2013, in my role as Director of CCN Cymru, presented a self-assessment tool for organisations to check their progress on delivering personalised transitional support was based on a series of rated standards which is similar to the direction taken by Together for Short Lives.

Recent legislative developments (Care Act, 2014 (England); Social Services and Well-Being (Wales) Act, 2014) are considered to be the main agents to direct the transitional arrangements between child and adult services. Health and social care working together is described, with a right to request a transition assessment to ascertain eligibility for adult social care (Care Act, 2014). However, the Care Quality Commission (CQC) report (2014, p.3) highlighted that there was the hope that the Care Act (2014) would address and improve the transition experience, but the Act is adult-focused, unlike the equivalent in Wales which incorporates the child/young person in a lifespan approach. Nonetheless, taking a lifespan approach could detract from the need to review transitional arrangements. The differing needs of young people could be overlooked with increased prioritisation of other adult vulnerable groups.

More recently NICE (2014) announced a review of transitional care and the development of practical guidance (to report February 2016) to tackle the gaps in provision for young people with health needs; recognising the lack of continuing care or the cessation of provision without being offered or replicated in adult health care (Carpenter and Abbott, 2010; Doug *et al*., 2011; Watson *et al*., 2011). The scope of the NICE review replicated the key subject headings of other transition-related reviews and research, such as joint working between child and adult services. NICE may wish to consider some of the underlying issues uncovered by this research, such as the role of and implementation of a protocol/pathway as organisation or condition-specific guidance is counterintuitive to policy advice in developing multi-agency protocols/pathways. Health-related guidance may contribute further to the complexities experienced by young people and their families rather than reduce them and confuse practitioners enacting guidance without due regard to other aspects of a young person's life. The CQC report (2014) underlined that there was variability in provision and delivery and that *'good practice guidance had not always been implemented'* (p.2). Therefore, further guidance may not, as with local protocols/pathways produce better outcomes for young people. Addressing good practice uptake was considered problematic across the transition key working sites, with professional preciousness an issue as they held onto previous ways of working and wariness of new thinking and delivery through transition into adulthood.

The Review endeavoured to provide a theoretical explanation of what makes a successful transition and to identify the mid-range theory areas to unpack the context, mechanism and outcome configuration of the process within the literature and more specifically in protocols/pathways. Preparing and planning well, critical elements of the theoretical model, were explored (Forbes *et al*., 2002; Carnaby *et al*., 2003; O'Brien, 2006; Act, 2007; Abbott and Heslop; 2009, Beresford and Cavet, 2009; Carpenter and Abbott, 2010; Sloper *at al*., 2010) and the need to have a holistic person-centred transition plan was established as an important lever to address the needs of young people and produce better outcomes (Sloper *et al*., 2010). Nonetheless, the Care Quality Commission (2014) reported that in 80% of 103 case records reviewed Transition Plan's did not record their health care needs. This was in accord with the findings of the Stakeholder Evaluation where young people and parents reported that no transition plan

was in place. Further to this, despite policy highlighting the importance of the Transition Plan; an internal component of protocols/pathways examples, they did not set out how to plan with young people which was a key finding of the Review. Whilst there was recognition and citations of the mechanisms which would generate a successful transition, the process was continually quoted as being complex (Forbes *et al*., 2002; Beresford, 2004; Everitt, 2007; Cowen *et al*., 2010).

An integral element of achieving successful transitions for young people was the support arrangements provided to young people. The wider literature highlighted the importance of a single point of contact (Key Worker) and the key intervention and a focus of this research and the likely enactor of local transition protocols/pathways. Comparatively, the literature related to key working during the transitional years was integrated into general key working research, with one example related to transition key working (Welsh Government, 2013). Numerous policy initiatives and consultations (NSF, 2005, 2006; DCSF, 2007; Welsh Government, 2007; DOH/DOE, 2014) and more recent research (Cowen *et al*., 2010; Sloper *et al*., 2010; Beresford, 2013; Care Quality Commission, 2014; Noyes *et al*., 2014) considered the need for co-ordinated support through the provision of a key worker to lead young people and families through the transition process. However, many young people continued not to access a key worker (Every Disabled Child Matters, 2012) and young people with life threatening/limiting conditions *'didn't have someone to perform key working functions during transition'* (Noyes *et al*., 2014, p.21).

The Review provided an interpretation of a CMO configuration of the transition process, but other factors were present, which either inhibited or assisted successful transitions, but were not present in the evidence. Indeed how to plan well with young people were a missing feature in protocols/pathways and a potential inhibitor to young people transferring successfully into adult service provision. The facilitation of successful transition for young people continued to be a problematical puzzle, despite the existence of local protocols/pathways and the emergence of strengthened education and social care legislation. The key mechanisms of the mid-range theory areas are likely contributors of achieving successful transitions for young people, but how they are applied may be diverse, given how they could be delivered and by whom and their

priority status; whether individually or as part of a multi-professional response. Although, all the mechanisms maybe important for the young person and can generally be applied, one could be more crucial than the others at different phases of their transitional journey.

Finally, there is the expectation that more recent legislation (Care Act, 2014; Children and Families Act, 2014; Social Services and Well-being (Wales) Act 2014; Welsh Government [Additional Learning Needs Bill[24]], 2014) will improve the transitional arrangements across agencies. In Wales, the legislative proposals for additional learning needs outlined in a White Paper, remains education-focused and without due regard to making structural changes to the way the transition process is administered and little articulation with social care reforms is evident. The Children and Families Act (2014) enacted in England in 2014, reforms the Statement of SEN by replacing it with a holistically described Education, Health and Care Plan (0-25). There is more clarity in the 2014 Act compared to the Welsh Government White Paper: legislative proposals for additional learning needs (2014) regarding transition processes, which does not detail transitional arrangements between child and adult services. The White Paper, like previous policy documentation, focuses largely on the transition of young people from school to post-16 education and reverberates back through the literature (McGinty and Fish, 1992; Carnaby *et al*., 2003) and within protocols/pathway is an issue which needs to be addressed.

11.5.2 The Realist Evaluation

What makes a successful transition into adulthood for disabled young people was dependent upon individual circumstances, the relationship with and between services and the age at which young people transferred to an adult service provider. However, notwithstanding the recognition of key worker input to support young people through the transition process, there was no guarantee that support services would transpire into adulthood for many young people. Transition Key Workers, Site Leads and Beresford (2004) recounted that adult service provision was not *'tailored'* to meet the needs or in

[24] Detail of the Bill not released at time of writing

place post transition for many young people. Many parents, had Transition Key Worker support, while this was absent for my son as I had co-ordinated his transition. Despite these differences our journeys, though different in the early stages, experienced similar frustrations and dissatisfaction in our interactions with services. Numerous exit and re-entry points along a pathway were experienced by all stakeholders, particularly for parents who habitually disengaged due to acrimonious relationships with services and non-involvement in decision-making (Abbott and Heslop, 2009). The transition process was repetitively depicted in protocols/pathways and policy guidance as a straight year-on-year line into adulthood, but rarely transpired as a linear phenomenon (Mitchell, 1999) for young people, parents and those supporting them. Some Transition Key Workers assumed that the transition process was seamless, were aware of local protocols/pathway, but soon discovered that it was a rare occurrence for young people as they too struggled to develop a relationship with adult service providers as services were not connected.

A story unfolded across the stakeholders and the literature that planning early was time critical. Young people wanted to run fast towards adulthood and to engage with support (Beresford *et al*., 2013), but a hierarchy of pace-setting was apparent which included their parents who struggled to think about the future due to previous poor contact experiences with services, which stalled the progress of young people. Early planning from the age of 14 featured within studies and parents wanted to work in partnership (Beresford, 2007), but professionals considered that *'planning early for the next move was counter-productive'* (Abbott and Heslop, 2009, p.49) due to the late engagement of adult services. Although, Transition Key Workers and Site Leads expounded this belief, the lack of planning early was not directly associated with the non-engagement of adult services, but with parents' dissatisfaction in their pre-transition experiences, which was not fully explored in the existing literature.

Whilst a lack of post transition provision was a major inhibiting factor to achieve good outcomes in early adulthood, parental poor contact experiences was a critical hindering factor to achieve successful transitions. The past inveigled itself and reverberated in the thoughts of parents. Parents expressed fervidly what had happened to them over the years, rather than forgetting and moving forward. This had constrained their ability to

have discussions about the future and their child's destination point post transition. Parents were seen *'as the most important factor in successful transfers'* (Townsley, 2004 p.44), but their inability to moderate their thoughts about the past impeded their part in planning for the future. Parents recounted that they had fought battles and placement breakdowns (Caton and Kagan, 2006; Abbott and Heslop, 2008; Abbott and Heslop, 2009; Carpenter and Abbott, 2010) and delays or a failure to get services (Morris, 1999), but the impact on their thinking and their part in transition planning was not explored within the literature or fully appreciated by Site Leads and Transition Key Workers.

Young people and their parents wanted to have Transition Key Worker time through the transition process, but the literature suggested that the key worker role was a longer term intervention (Greco *et al*., 2005) and should be accessed into early adulthood. Transition Key Workers had not seen many young people transition into adult services during their transitory tenure as their intervention became an episodic short-term phenomenon. Nonetheless, Transition Key Worker time held the balance between future thinking and parental focusing on the past, which had not been recognised by Site Leads/Transition Key Workers. Parents returned to the same or similar moments in time; what life had been like for them previously, which clouded their thoughts and actions in the present. Their avoidance was not necessarily deliberate; they wanted to talk about the future, but found it challenging to concentrate on what that would mean for them, in the first instance, as their parental control diminished (O'Brien, 2006), and secondly for their children. The longitudinal effects of caring from birth or early diagnosis onwards were a contributory factor and had impacted psychologically and physically. Like other populations of carers, parents expected that their caring situation would get worse in the following year (Carers UK, 2013). This was an issue for parents who articulated their concerns in coping with their changing relationship with services, expecting it to be difficult.

Parents expected further challenging times ahead, but wished for a different life measuring themselves against families of non-disabled children, which reinforced their return to past events in their life of caring for a disabled child. Parental interest in the past and the association with poor experiences and contact with professionals and

services left them vulnerable. They struggled to visualise their child becoming an independent adult, with or without support. There was a reticence amongst parents to support what was possible for their child's independence. They had few concrete ideas of their child's sense of being in the future, regardless of Transition Key Workers offering options and taking practical steps with young people to encourage future autonomy. However, stakeholders are discovered and documented in literature, there continued to be limited options post school (Heslop *et al*., 2002; Morris, 2002, Townsley, 2004; Kaehne and Beyer, 2009; Carpenter and Abbott, 2010), despite policy recognition to improve choice and access (Welsh Government, 2007; DOH/DCSF, 2008). Parents, as Dean (2003) highlighted, found it difficult to challenge what was presented to them and were suspicious of service rationale and availability.

Parents were experiencing their own transition; dealing with the emotional and physical impact exacerbated through caring through childhood into adolescence. The transition process was framed within the changes parents faced and young people were subordinate to how they were coping with the impending adjustments; small or large despite multiple-professional contact. The literature highlighted and this was corroborated by the experiences of Transition Key Workers that parents were overwhelmed with the enormity of the transition process (Dee *et al*., 2002; Dean, 2003) and it was easy to withdraw rather than remain contributors. There were a few examples where parents felt that they were being well supported and the impact had been significant in the short term, but had *'nothing to compare it….(I) don't know how I should be supported'* (P16).

The future was a difficult concept, particularly for young disabled people and thinking about what was to come was difficult for some young people. However, they were clear about their aspirations and what adulthood might bring for them. Unlike their parents they had not dwelt on the past and identified a range of options, which an active Transition Key Worker investigated and supported. There was a consistent strand running through the parental discourse and the included studies recognised by Transition Key Worker and Site Leads, that to get the right support there was a need to have the right person in the right role. However, this was not associated with supporting them to deal with their past issues and contact with services pre-transition. The evidence

from the Stakeholder Evaluation compared favourably with the wider literature that the Transition Key Worker was a preventative intervention driving multi-agency working (Cavet, 2007), but it was a time-consuming role (Greco *et al*., 2005) as Transition Key Workers experienced. However, stakeholders felt Transition Key Workers were well-placed and had the time to listen to parents so that they understood the needs of the young person to obtain the right support. This was also a key feature of the key worker role (Liabo *et al*., 2001; Greco *et al*., 2005). Transition Key Workers understood that once support was in place, the reliability of the support was crucial. This was challenging, increased with impending legislative and organisational change, and was an evolving dynamic. The legislative changes (Children and Families Act, 2014, Additional Learning Needs Bill, 2014) were expected to encourage developing joint partnerships, including with adult services (DOE/DOH, 2015), but how this was to be achieved is not fully explained and the advancement of key working seen more a notion of best practice and not a statutory obligation.

The loss of support and lack of continuity of provision were contributory factors (Dee, 2006), which lead to poor transitions, disengagement and poor outcomes for young people (DOH/DCSF 2008). Many young people were at risk of losing their Transition Key Worker, with the likelihood that some support would end at 16, particularly paediatric input. They wanted Transition Key Worker support to be maintained to deal with such challenges they faced Transitional health processes and the variability of transition services, from the perspective of Site Leads and Transition Key Workers, were of concern and widely cited also in the literature (Tan and Klimach, 2004; DOH/DES, 2006; Doug *et al*., 2011; Pywell, 2010; Watson *et al*., 2011; Beresford, 2013; NICE, 2014; Care Quality Commission, 2014; Noyes *et al*., 2014). Further poor contact experiences, during the transition process, continued for parents.

On the other hand, implementing or sustaining Transition Key Worker services, to ameliorate parental reminiscing and support their resistance to let go and to begin thinking about their child's independence was less certain, even where transition planning was an active enterprise. Positively, Young people, parents, Transition Key Workers and Site Leads consensually considered that the intervention of the Transition Key Worker had contributed to better outcomes for young people prior to their

transition into adult services. Knapp *et al's*. (2008) study of thirty young people supported the case that where there was key worker involvement this was equated with improved quality of life outcomes and was a *'strong predictor of family outcomes'* (Sloper *et al*., 2006, p.155). The wider literature supports the need for the intervention of a named individual to support families of disabled children and young people (Liabo *et al*., 2001; Smart, 2004; Greco *et al*., 2005; Sloper *et al*., 2006; Barnes, 2008; Cavet, 2007; Carpenter and Abbott, 2010; Cowen *et al*., 2010), especially through transition points including transition into adulthood.

11.6 CONCLUSION

To conclude this chapter, the key findings elicited from the Review and Stakeholder Evaluation revealed those factors which were likely to promote or obstruct successful transitions. The overarching high level mechanisms (continuity, planning well, active decision-making, ready for change, having a structure, and accountably and governance), in combination, are likely to be the activators, triggered by multi-agency commitment and the intervention of a Transition Key Worker, to achieve successful transitions as the predominant outcome for young people. A transition-type worker, as a supporter through the transition process, was likely to contribute to a smoother passage into adulthood, but not all young people had access to a key worker commonly cited in the literature (Liabo *et al*., 2001; Greco *et al*., 2005,) as a long-term intervention. The transition process does not improve the likelihood of achieving good transitions for all young people, with continued reports of unmet need and poor transitional experiences. Transition continues to be a *'buzz word'* (Abbott and Heslop, 2008, p.53) in policy without fully addressing the continuity issues between child and adult services.

Linear protocols/pathways do not fully explore importance of how to plan effectively with young people. The emphasis is on the process itself and the problems encountered. How to plan well, setting things out step-by-step with young people was largely missing from the literature and within Transition Protocols/Pathways. No fully-formed consensus as to what constitutes best practice transition models are entirely described in the literature. However, protocols/pathways are seen as useful tools (Everitt, 2007) setting out the responsibilities of agencies, although seldom followed. Varying structures and organisational partnerships, funding arrangements (Sloper *et al*., 2010)

and the absence of validated measures has hindered comparison between transition models (Watson *et al*., 2011). Parental poor contact experiences pre and during transition was an overriding focus, which hampered their thinking and planning for their child's future, but the consequences were not apparent within the wider literature or recognised by parents themselves or by Site Leads and Transition Key Workers as a significant contributory factor in young people not achieving a wholly successful transition into adulthood.

CHAPTER TWELVE
CONCLUSION

12. INTRODUCTION

This final chapter set outs:

- Firstly, the contribution to new knowledge from the overall synthesis across the Realist Review and Stakeholder Evaluation.

- Secondly, the viability of key worker provision and a concluding 'insider' perspective.

- Thirdly, the implications for further research in the field of transition into adulthood and key working.

- Lastly, this final chapter concludes by presenting the revised programme theory and a series of recommendations for policy and practice in transition into adulthood for young disabled people.

12.1 CONTRIBUTION TO NEW KNOWLEDGE

The Realist Review and Realist Evaluation highlighted, like other complex social and or health programmes (Pawson, 2002; Pawson *et al*., 2004; Wong *et al*., 2014), that the transition process was a complex constructed programme. Adopting a realist approach provided a unique contribution by explaining the context, mechanisms and outcome(s) configurations of the transition process not previously described. Importantly, this research highlighted, through the intervention of Transition Key Workers as the activator, the mechanisms of generative change and their relationship of these mechanisms within the overall context of a structured transitional process were dependent upon the behavioural responses and attitudes of both the receivers and contributors towards providing support through transition into adulthood.

The Review, Evaluation and subsequent synthesis distinctly identified that there was a lack of evidence on the effectiveness of Transition Protocols/Pathways, as the context source, in achieving successful transitions for young people. Protocols/Pathways did not make the transition process any less complex, rather they contributed to the complexities by supposing that the pathway into adulthood was seamless and a direct route into adult services rather than address the structural and organisational barriers between child and adult services and the lack of early adult service engagement. The actuality, represented in the literature, supported the view that the transition process was fragmented and uncertain.

The movement backwards and forwards or the stopping and starting and stalling transitional phenomena experienced by young people and parents (i.e. non-linear) were not wholly represented in protocols/pathways. The Realist Evaluation depicted the serpentine nature of the process, which was not significantly represented in the literature. The linear representation of the transition process was predominant within the literature and protocol/pathway examples, without full consideration given to the depth and breadth of the process which were the likely critical success factors of achieving good person-centred outcomes for young people. I provided an alternative view of the pathway process (Figures 23 and 24) focused on what stakeholders experienced by their own disclosure. Critically, a crucial element was largely missing from the evidence that of 'how' to plan well with young people for their own transition along the pathway; the processes and practice. Despite the promotion of person-centred approaches, the 'how' to plan effectively with young people could have been too enormous a demand for Transition Key Workers to implement and too complex for them to address in terms of the cultural changes required in some instances to facilitate a person centred approach, particularly where at a strategic level a lack of commitment to provisioning practical support with transition planning was the case. Further uncertainly compounds this with respect to local service re-organisations and impending policy reform. The Transition Key Worker role had not been sufficiently accepted or recognised as a key intervention at a local and national level.

The Realist Evaluation identified that the issue of the Past was preeminent, particularly in the lives of parents and an unforeseen and a distinguishing finding which hindered in

their thinking, discussing, planning and preparing for their child's future. The issue of the past was not represented in the literature and there was as a lack of acknowledgment amongst professionals, including Transition Key Workers and Site Leads as to the impact the past presented in the lives of parents and their management of change and future planning. There was strong evidence to suggest that the Past/Time/Future triangulation was a significant finding and the three components affected an individual's readiness for change due to previous poor contact experiences as early as neo-natal care or pre/post diagnosis onwards. The transition process became one more obstacle to overcome, expecting it to be difficult as parents reported that it had always been from their perspective. Positively, where there was the presence of a Transition Key Worker, they were able to provide the time necessary to get to know young people and their families, building a trusting relationship, which was valued. However, it did not moderate the negative impact of parental poor contact experiences with professionals and services pre-transition. The evidence on the burden of parental worries and concerns and their preoccupation with the past needs to be acknowledged and addressed. Parents specifically were concerned that their child would be well supported into adulthood. Interestingly, young people overall did not have the same apprehensions as parents. They were happy that with Transition Key Worker support, they could imagine a future, wanted to be independent and were looking forward to becoming an adult with enthusiasm and vim.

The transition process and key working is sited within the social model of disability, and notwithstanding the restraining issues of social inclusion and access to adult service provision those societal obstructions do not fully explain why not young people do not experience a smooth and successful transition. Parents, within the social model paradigm, defined their children as vulnerable and constrained their independence by controlling the rate of transition planning and decisions concerning their young adult destination points. Parents were potentially confined within in the medical model cure-based approach as they wanted a 'normal life' of parents with non-disabled children. Parents were acting as a barrier to their child achieving a successful transition as they were not exhibiting sufficient behavioural change due to their poor experiences pre-transition. The lack of recognition from professionals that parental past experiences with services pre-transition was a significant detrimental marker and was an overwhelming

factor, which pointedly contributed to a parent's struggle to let go and accept their child becoming an autonomous young adult.

12.1.1 Viability of key working provision

The longevity of key working through the transitional years (14-25) is a key question in the context of this research and within the reform of special education in both Wales and England. This research identified the benefits of young people having a single point of proactive contact, namely a Transition Key Worker in supporting them to aspire and achieve. The Special Education and Disability (SEND) reforms in England focus on local authorities adopting a key working approach and the key working functions (e.g. co-ordination, providing emotional and practical support, information and supporting and facilitating planning) are attributed to a professional who knows a young person and parent well, such as a social worker, as the prospective candidate to act as a key worker, rather than suggesting a designated key worker approach. The SEND agenda sees key working as a way of working and not a separate service and that it should be defined as a set of key functions rather than a defined key worker designated role. It could be argued that this response is due to the lack of duty within legislation on local authorities and partners to provide dedicated key worker services and the lack of available resources to provide specialist support. Key Working, in the context of the Additional Learning Needs reform in Wales, is less clear, with brief reference to local authorities considering the use of key working in supporting young people through transition into adulthood.

Underpinning the success of adopting a key working approach, as opposed to providing dedicated key worker services, is the need for a cultural change at a strategic level to embed key working functions into the role of those who are actively engaged in supporting, in this instance, young people and their parents through the transition process. I have been an advocator of care co-ordination for over twenty years and a recipient of key worker support. Co-ordination is the imperative aspect of key working and fundamental in providing solution-focus support to achieve good outcomes for young people. Interestingly, whilst this research supports the view that dedicated key worker provision is the epitome of the principles of co-ordination, where key working functions have been adopted the co-ordinated approach and provision, from my

perspective, worked well. But, it was determined by the commitment to provide professionals, such as a Speech and Language Therapist in my case, with a workable adaptive structure and acceptance of their co-ordinating role, which provided those with a key working function the time to undertake additional responsibilities. When the strategic commitment waned, the key working approach became unviable and waned.

The Children and Families Act, 2014 (England) and the White Paper (2014), which outlined proposals to introduce a new legislative framework for supporting children and young people with additional learning needs in Wales are helpful as they promote multi-agency co-ordination. Therefore, key working can act as a lever to support governments in their aspirations by promoting the model as the main intervention to improve the delivery of support and services to young people through transition into adulthood. However, key working as a concept it is suggested that it is 'everybody's business' to adopt key working functions, but without a legal duty on Local Authorities and Health Boards (Wales) or Clinical Commissioning groups (England) to implement co-ordination across professionals and organisations, the barriers between child and adult services, will remain a significant challenge. Using the term key working more generally, without embedding the functions into job descriptions to address co-ordination issues, could see no one taking on the responsibility as an imperative.

12.1.2 The revised integrated programme theory

The overall mapping (Figure 25, p.246) across the programme theory and mid-range theory areas produced the contexts, mechanisms and intended and unintended outcomes of the transition process. Jagosh *et al*. (2014) highlighted that identifying the mechanism which produce change was a not clear-cut undertaking and mapping the complexities of the transition process due to the multiple organisations and professionals involved across education, health and social care was not straightforward. Dalkin et al. (2015) suggested, building upon the work of Pawson and Tilley (1997), an alternative interpretation that *'intervention resources are introduced in a context, in a way that enhances a change in reasoning'* (p.54), alters the behavioural responses of receivers of services, which produces outcomes. Therefore, an alternative formula suggested by Dalkin *et al* is **M (resources) + C (Context) → M (reasoning) = O (Outcome)**. I concur with Dalkin *et al's* proposition, as the overall mapping of the

transition process provides a working example of their alternative formula (Figure 26) while still within the spirit of Pawson and Tilley (1997). Dalkin et al. conceptualises *'mechanisms as operating on a continuum'* (p.50); that a mechanism is not just fired once, but that is dependent upon the context remaining constant. Whilst a continuum is at the heart of the transition process for young people, one mechanism may be important or prominent depending upon their individual circumstances. Other mechanisms are likely to be intermittently fired in an environment that is subject to change which is a current key feature in terms of the emerging policy reforms related to special education needs.

Figure 26. An interpretation of CMO with the Transition Key Worker intervention

M (high level resources of the transition process) in delivering transition support e.g. an effective protocol, an agreed structured process **+** **C** (multiple organisations & professionals involved services over a number of years, limited resources and opportunities) **→** **M** (activities of transition key worker intervention) **=** **O** (successful transition)

The Transition Key Worker through their external activities were dealing with the thinking and in some instances altering the responses of those they were supporting or working with in a multi-agency partnership transition structure. Transition Key Workers need the high level resources (a structured multi-agency transition process) to function and be accepted and are the mediators through which a successful transition is likely or expected to be achieved, despite the challenges of operating across multiple child and adult service providers and within an atmosphere of limited availability of opportunities and resources (Context). Therefore, when a Transition Key Worker is present and working well for young people and their families the intended outcomes related to the young person are likely to be successful or be positively altered through proactive discussion and action (the mechanism) facilitated by the Transition Key Worker. However, where a Transition Key Worker is absent, not working well or not being implemented as intended the desired outcomes for a young person may be reduced or not present and continuity between child and adult services fragmented or non-existent.

The candidate programme theory (the 4 P's) developed in consultation with stakeholders, whilst not sufficiently developed, and in the absence of an alternative, provided the basis to test out through the evidence and to build the theory (Appendix Thirty). The candidate programme theory provided, in part, an explanation of the key elements to ensure that young people successfully transited into adult services. However, the 4 P's did not fully explain, notwithstanding the intention of policy to generate transitional provision from the age of 14 or:

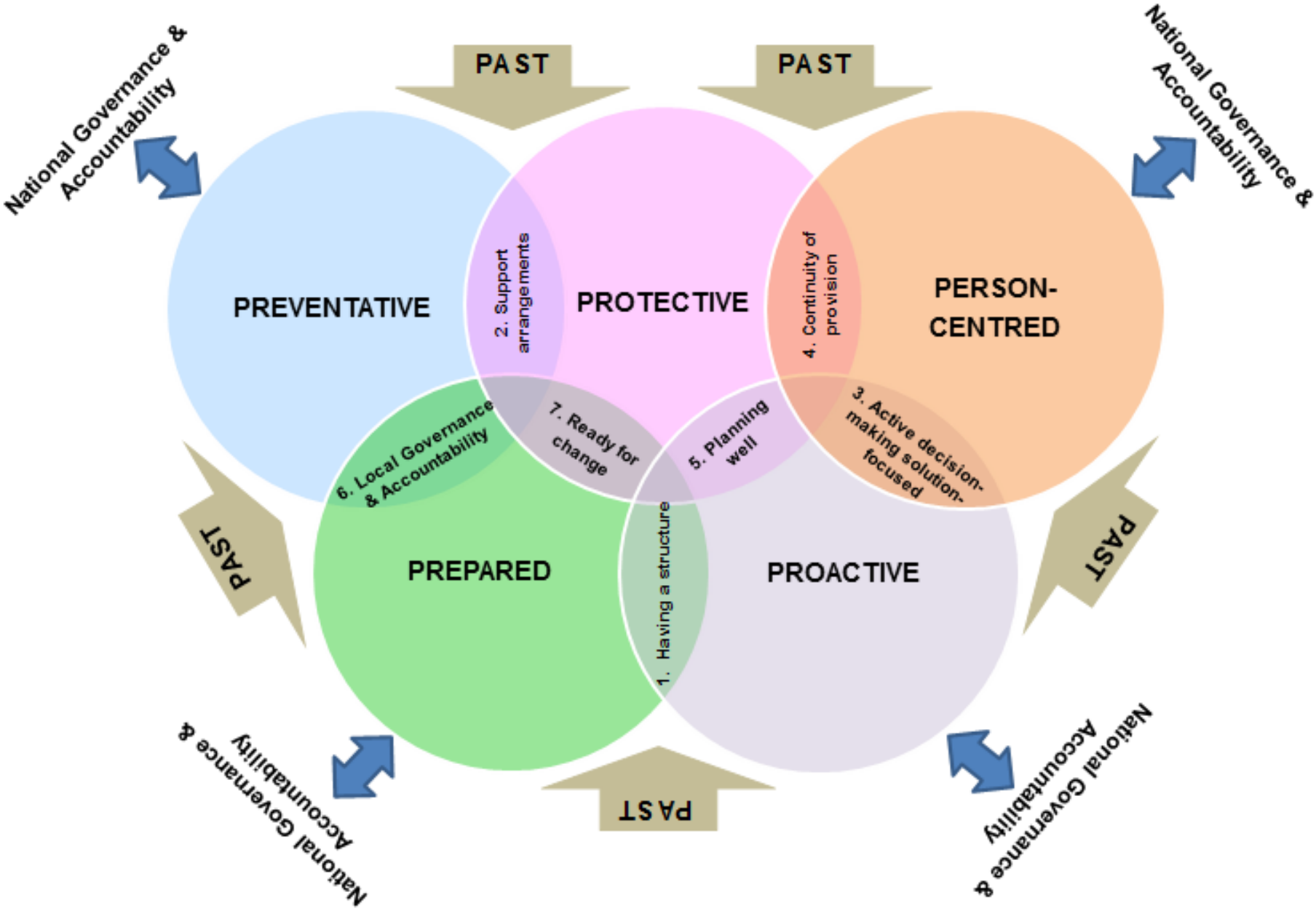
- **Prevent** fragmentation or eradicate the barriers created between child and adult services by having a local multi-agency transition protocol/pathway in place.
- **Protect** parents and young people from the frustration and anxieties felt as they worked their way through a complex process.
- **Proactive** support did not make transition processes less complex. The focus was not always on the young person as the end receiver. A service-led, rather than needs-led tailor-made delivery and provision of services and support continued to remain predominant despite the promotion of **Person-centred** approaches (the fifth 'P' integrated into the revised programme theory) to identify the needs and wishes of young people.
- **Preparing** for the future was problematical; the needs of young people and parents were often seen as homogeneous rather than them having distinct support needs and their own desires for the future.

The revised integrated programme theory (Figure 27, p.301) introduces a sixth 'P' (the Past), which exerted pressure on the five main constituents and the integrated mid-range theory areas which were important to achieve successful transitions for young people and assist parents in finding the means to plan effectively with their child and their supporters, such as a Transition Key Worker. But, the presence of the past explains why not every young person achieves a successful transition, even where support and services were available as parents struggled to assuage deep-seated mistrusted and past disappointments in their contact with services pre-transition.

The stages of the theory development (Appendix Thirty), while highlighting the complexities of the transition process, also elicited a fuller explanation of the roles and

experiences of the key stakeholders; the interacting players in the transition process. The seven mid-range theory areas were integrated into the theoretical model which gave further substance and coherence when located within context of national existing and emerging legislation and policy. This could influence transitional practice and an additional pressure or potential release value to operationalise an active transition and achieve good outcomes for young people. However, the revised theoretical model is contingent on parents being supported to deal with the past and a range of services post transition being available and accessible. The theory testing and building provided the evidence to re-model the candidate programme theory to a more fully formed paradigm, which could be tested out by subsequent researchers considering investigating the transition process or other complex social programmes for other vulnerable groups. I consider that the revised integrated theory I have presented provides a mid-range theory of what makes a successful transition and the first theoretical explanation to be developed and a crucial contribution to new knowledge.

Figure 27. Revised programme theory (5 'P''s)



12.1.3 The 'Insider' perspective

The 'Insider' perspective gave an added dimension and uniqueness to this research. Those perspectives added value by exposing my personal and professional knowledge and understanding of the transition process. The analytical process was illuminating and gave me an additional awareness of how my own past experiences where actively influencing the decisions I was making about my own son's transition into adulthood and the support he required in a supported living environment. It has been a personal learning experience and further supports the need for early intervention and co-ordinated support from birth onwards to limit parental poor contact experiences.

I referred to the work of Mitchell (1999) and found, in terms of parental experiences, that little had changed in the intervening fifteen years since she presented her findings that a *'radical revision of traditional transition models'* (p.766) is required. There is the danger that the next generation of parents will continue to experience poor contact and a lack of support at crucial points in their children's lives. It was argued by parents that starting planning at 14 was too early, and by professionals who recognised that adult services were unlikely to engage until the age of 17 or later. I would argue that starting early is an imperative, despite the reality that transition as a process is likely to be in operation until at least 19 years of age for those with the most complex needs and up to 25 years of age where Transition Services are in place. Naturally, the pace of planning is variable depending upon individual circumstances, the willingness of agencies to engage early and the available services. I started early out of necessity, knowing the transition process for my son would not be straightforward and in reality this was a justified decision.

12.2 IMPLICATIONS FOR FUTURE RESEARCH

Overall, the findings provided a deeper understanding of the transition process and how all stakeholders interacted to create opportunities to enable young people to move successfully into early adulthood. The findings indicated like other complex social programmes that not all young people were likely to achieve a successful transition as intended, as set out in policy or in practice, due to differing eligibility criteria between child and adult services and the limited or the of absence of replicated support services

received in childhood. The findings identified the need for further research in the following areas:

- Assessing the effectiveness of a paper-based Protocol/Pathway in achieving successful transitions for young people requires further investigation and contact with local multi-agency partnerships to compare the findings. This was directly outside the remit of the Review. The Stakeholder Evaluation identified that there was a mixed understanding, implementation and use of local transition protocols/pathways. Are they an effective strategic and or practice 'tool'? Are pathways outmoded?

- Develop guidance on the revised theoretical model for strategic managers and practitioners to support the implementation of key working through transition into adulthood.

- Evaluate the parental role in the transition process in the context of the social model of disability.

- In light of the NICE Transition Guidelines for Health and Social Care (2015) undertake a further review of transitional processes in the context of the new and emerging legislation in Wales and England and the implications for practice in the delivery of support and services from children into adult services.

- The ability to draw upon my own personal and professional understanding, knowledge and experiences of the transition process gave me a deeper appreciation of the struggles other parents have faced in traversing the complexities and barriers of accessing adult service provision across education, health and social care for their children. I mapped my own experiences and offered a window into my own life through this thesis and my multiple perspectives. I was particularly drawn to the personal stories of parents; invertible it could be said given my own personal experiences. Autoethnography as a method, using my own autobiographical story to analyse and interpret the narratives of other parents of disabled young people would be an invaluable exercise to provide a richer insight into the transition process from my own and other parents' perspectives.

- I will be producing at least two peer review journal papers as academic outputs from this thesis:

  - Realist Review: What makes a successful transition into adulthood for disabled young people? (Appendix 31: Abstract).

  - The role the past plays in the lives of parents of disabled young people experiencing transition into adulthood.

12.3 RECOMMENDATIONS FOR POLICY AND TRANSITON-RELATED PRACTICE

The findings from across the Realist Review and Stakeholder Evaluation make a major contribution to understanding the contexts, mechanisms and intended and unintended outcomes of the transition process through firstly, theory testing and building and secondly, presenting a revised integrated programme theory, which aimed to set out what needs to happen for whom, how, and in what circumstances through the transition process. The main implications are as follows:

- From a policy perspective, how the transition process is described and visualised requires consideration. There needs to be a move away from representing the transition process as a linear experience, by concentrating on the depth and breadth of the process. Linear descriptions of social and or health care programmes, and in this case including education do not fully represent the complexities across organisations with differing structures, systems, and practice both in child and adult services and within multi-agency partnerships.

- Commissioners and planners need to listen to those who directly experience the transition process, an age-old call, but necessary to provide effective support to and services for young people into adulthood.

- Practitioners need to acknowledge the impact of the pre-transition experiences of parents to enable parents to think more positively about their child's future post adolescence and their interaction with transitional support services. The prominence of the past was a significant finding and one that needs to be addressed through further research and through direct support to parents to

nurture their thinking, discussion, planning and preparation for their child's future. Parental past experiences with services shaped their experiences and expectations of the transition process. Contact with services from the early years onwards, particularly if the first and subsequent contact is adverse and stressful, is important indicator to recognise and resolve quickly to begin the process of developing trusting relationships between parents and practitioners across multi-agency partnerships. Parents require help to assuage and address their negative experiences with services to avoid escalation and continuation of poor contact points with services. Practitioners should consider how best to approach their first contact with parents, especially in the early years when parents are likely to be at their most vulnerable and bewildered by how to support their disabled child. A key worker intervention, to support and work with the family and translate the 5 P's conceptual framework into practice is potentially helpful to improve parental contact and engagement with services through childhood into adulthood. Early offers of counselling or other psychological interventions, such as Mindfulness, could also be helpful to improve mental well-being and resilience. Access to counselling could help parents let go of their past experiences and think more positively about how they could use those experiences to set out how they would like to shape their relationship and interaction with professionals in the future. Further to this Welsh Government programmes such as Early Support for families with children with additional learning needs under the age of 5 promotes working together with families and resources are available to families to support improving their lives. The Flying Start programme for disadvantage families with children under the age of 3 living in the lower output wards of Wales has enabled some parents of disabled children to access an enhanced health visiting service and speech and language provision. However, a being a parent of a disabled child is not dependent upon the street where you live and access to Flying Start support services in the early years beyond the parameters of a postcode could ameliorate the poor contact parents in this study experienced with services.

- There is a need to set out clearly in guidance how to plan with young people through transition into adulthood. It is not a question of presenting a young person with a template or person-centred thinking tools and asking them to fill it in. It is an interactive experience rather than a by rote undertaking where plan examples are clones of one another with young people all liking rice krispies for breakfast and pizza for tea! Professionals, including key workers need to be immersed in person-centred transition practice to engage with young people to understand their needs and wishes. As the Stakeholder Evaluation revealed there was a mixed understanding and implementation of person-centred thinking despite many Transition Key Workers being trained.

12.4 CONCLUSION

The overarching aim of this thesis was to understand what young people, their parents and those working with them consider to be the key elements of achieving successful transition into adulthood. Yet, to adjudge a successful transition is subjective and is so due to the individual nature of any one young person's transition, which by the very nature of human life is not designed, and neither should be to easily fit into organisational structures and imposed transitional systems. Successful transitions defy being neatly boxed due to the complexities and layering effects created by the multifaceted relationships between a young person, their parents and the professionals and services involved.

What makes a successful transition into adulthood for disabled young people (14-25 years of age)?' is dependent upon a number of interwoven factors which could contribute to achieving good outcomes for young people through the transition process. Understanding the transition process through having a structure and information; young people and parents knowing what will happen , how it will happen and when is likely to reduce the anxieties felt by many who were involved in this study. Having the commitment and the engagement across multi-agency partnerships to drive forward practice development and professional receptiveness to change is a key determinant of improving the transition process leading to young people and parents being ready to plan and make active decisions about the future. The provision of a Transition Key Worker developed continuity and co-ordination between child and adult services, with

the Transition Key Worker solution-focused providing young people with the opportunity to enjoy life, have friends and form relationships, have a home of their own and meaningful employment, which were seen as positive outcomes to measure whether a young person's transition was successful.

The overall findings contributed to a better understanding of the positive and negative aspects of transition as a process and acquired this from multiple stakeholder perspectives. The Review found that a Transition Protocol/Pathway did not make the transition process for young people, their parents or for those supporting them less complex or create the opportunities to achieve the features of a good transition highlighted by key stakeholders and within literature, without the support of a Transition Key Worker. However, not all young people had access to a Transition Key Worker or a person identified as the main point of contact. The long-term sustainability and viability of key working provision, especially through transition into adulthood is indeterminate and was highlighted within the wider key working literature. Positively, in England, through the SEND agenda, funding provision has been made available to further develop key working training to instil key working functions into the role of professionals supporting disabled children and young people and their families from 0-25 years of age and to begin the process of achieving what needs to be effective, sustainable and young person-centred key working.

Within the Welsh context the changing legislative framework in social care and special educational needs takes into account the transition process and the benefits of having a single point of contact. However, the continuity between child and adult services needs to be addressed to ensure that adult services engage earlier in the transition process, which was a key factor in determining whether a young person's successfully transferred to a provision of choice and would be able to lead a supported independent life.

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APPENDICES

APPENDIX ONE

SOCIAL AND MEDICAL MODEL OF DISABILITY IN THE CONTEXT OF YOUNG PEOPLE

Medical Model	What this means	Social Model	What this means
• Young people likely to be defined by 'impairment'; their disability or condition • Sees the person as the difficulty	• There is a focus on impairment; a young person's presentation • Does not seen the whole young person	• Focus on normalisation	• Sees the young person as an individual
		• Looks at the barriers young people can face and how to overcome them	• A proactive model centring on the young person
• A value judgement on access to everyday activities for young people	• Young people do not always access mainstream activities	• Focus on the holistic needs of the young person	• Focus is not a just the body and how a condition affects function
• Focused on 'cure'	• Lack of focus on social factors	• social factors create the barriers • Enables opportunity for young people to reach full potential • Focus on what a young person can do	• Other people's inability to communicate, environment aspects, transport, access to leisure, to education and training, employment • Maximises the positives, working with a young person's aspirations and desires
• Power and control lies within the domain of medics • Makes the young person 'fit' into a constructed system rather than based on needs	• Young people not in control of their health and well-being • Power to make change does not rest with the individual		
• Judgement on ability rests with others	• Based on other people's assessment or value judgement	• Society is the 'problem' • 'Unpicks' the complexity	• Challenges and changes attitudes • Embraces differences
• Emphasis is on dependence, backed up by the stereotypes of disability	• Negative view promotes lack of self-esteem and worth	• Addresses young people's difficulties	• Looks for strategies to support young people

What does it mean for young people and parents?

1. **Need for the diagnosis:** parents often strive for this above anything else, having a diagnosis of opens the gate
2. **Need to 'fix':** For parents this is around finding strategies to alleviate, some things can't be fixed, what can be are people's attitudes to what is seen as needing fixing
3. **Medical profession has all the answers:** A clinician does not always have the answers, sometimes parents find this difficult to accept
4. **Negative response to diagnosis:** A key worker needs to be prepared for this

Other factors:

Both models cannot be defined in one easy identifiable way, it can shift depending on need and:

- Who pays?
- Type of care provided
- Locus of responsibility and accountability

By the interaction of the factors:

All factors may at some point be an issue, particularly if young person requires services and funding from more than two sources. If cost pressures, often funders will stall, withdraw or move the boundaries (the

eligibility criteria). Often the medical model pervades as it is free upon access, whereas if working within the social model the care is not always free.

APPENDIX TWO

DEFINITION OF DISABILITY RELATED TO YOUNG PEOPLE

Key legislation/guidance:	Definition:
Children Act 1989: This Act, in terms of defining disability, parallels that of Section 1 (1) of the Disability Discrimination Act 1995 and is outlined in Section 17 (11) of the Children Act1989: 'A person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his/her ability to carry out normal day-to-day activities'. The Act places a duty on local authorities to provide services and support to children and young people defined as 'children in need', which includes those children and young people who are defined as disabled. Some services are provided by the local authority free of charge. Although local authorities can also decide which services you will need to pay for, or contribute to. **A 'child in need' may be:** • disabled • unlikely to have, or to have the opportunity to have, a reasonable standard of health or development without services from a local authority; or • unlikely to progress in terms of health or development; or • unlikely to progress in terms of health or development, without services from a local authority Local authorities must identify the extent of need in their area and make decisions about levels of service they provide.	**The Children Act 1989 defines disabled children and young people (0-18) as:** • 'If he/she is blind, deaf or dumb or suffers from a mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed' **Definition of the term disabled include those children and young people with a:** • 'physical impairment' including a sensory impairment; • 'mental impairment' including a learning difficulty and an impairment resulting • from or consisting of a mental illness; • 'substantial' means 'more than minor or trivial'; and • 'long-term' is defined as being 12 months or more. **Mental and physical impairments:** The definition includes a wide range of other impairments, which include dyslexia, autism, speech and language impairments, Attention Deficit Hyperactivity Disorder (ADHD). The Act also indicates that 'these are all likely to amount to a disability, but only if the effect on the pupil's ability to carry out normal day-to-day activities is substantial and long-term, as defined above. Some progressive conditions, such as cancer, multiple sclerosis and HIV/AIDS are included before they have an effect on the pupil's ability to carry out normal day-to-day activities'. **Normal day-to-day activities** The test as to whether an impairment affects normal day-to-day activity is whether it affects one or more of the following daily activities: • mobility • manual dexterity • physical co-ordination • continence • ability to lift, carry or otherwise move everyday objects • speech, hearing or eyesight • memory or ability to concentrate, learn or understand • perception of risk of physical danger
National Service Framework for Children and Young People and Maternity Services (2006)	The NSF also defines a child or young person who has a life-limiting condition to be potentially disabled (defined by ACT and the Royal College of Paediatrics and Child

	Health). The NSF adopts the Children Act 1989 definition.
Disability Discrimination Act (1995):	The Disability Discrimination Act (DDA 1995) defines a disabled person over 18 who have a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out day-to-day activities. **<u>The definition also clarifies that:</u>** • 'substantial' means neither minor nor trivial; and that • 'long term' means that the consequence of the impairment has persisted or is expected to continue for at least 12 months (there are particular rules encompassing intermittent conditions). **In terms of the normal every day activities the Act defines those as being, for example:** • eating , walking, washing (personal care and clothing), shopping and cleaning without support to do so **The Act also sets out that typical day-to-day activity must affect one of the 'capacities' set out within the Act including:** • Mobility, manual dexterity, speech, hearing, sight, memory, ability to understand or learn, and • continence, co-ordination or not able to recognise physical danger.
Equality Act (2010): This Act seeks to safeguard disabled people and prevent disability discrimination. The Act gives a legal right to disabled people in the following areas, for example: • access to goods, services and facilities • buying and renting land or property • education • employment The Equality Act 2010, from 1 October 2010, replaced large sections of the Disability Discrimination Act (DDA) 1995. The Disability Equality Duty in the DDA continues to be pertinent and is enforceable under the DDA.	**The Act defines a person with a disability as having:** • a physical or mental impairment • that the impairment has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities This definition mirrors that of the DDA enacted in 1995. The Equality Act also defines 'substantial' as being more than minor or trivial and 'long-term' as being likely to affect a person for at least 12 months. People who have had a disability in the past that meets this definition are also protected by this Act.

Mental Capacity Act (MCA) 2005:	• The MCA uses the definition outlined in the DDA 1995 and subsequent Equality Act 2010. Those with a severe learning disability could be considered as requiring the appointment of a Deputy to act in their best interest.
Education Act (1996): **The definition of special educational needs:** The definition of special educational needs is of relevance and related to the definition of disability. .	The Education Act (1996) sets out to define the term 'special educational needs' (SEN) and defines a child/young person with SEN: • As child/young person with a learning difficulty and that specific special educational provision should be made. • The Act also states that 'a disability, that prevents or hinders a child from accessing education, amounts to a learning difficulty if it calls for special educational provision to be made'. Special educational provision is a provision that is made that is additional to what is universally available. A child/young person with special educational needs is likely to learning difficulty, however the definition is broader as the definition of learning difficulties within legislation includes children and young people who have a disability and who need provision that is additional or differentiated.
European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families (2010) **World Health Organisation:** The term Intellectual Disability includes children and young people with Autism who have intellectual impairments	The Declaration defines disability as depending 'not only on the child's health conditions or impairments but also crucially on the extent to which environmental factors support the child's full participation and inclusion in society. The Declaration also defines Intellectual Disability and includes: • a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence) • a reduced ability to cope independently (impaired social function), which • started before adulthood, and has a lasting effect on development

Further description related to Special Educational Needs and disability:

The definition of disability originates from the Disability Discrimination Act (1995) and the definition of special educational needs is sited within the Education Act 1996. However, there is an overlap between children/young people who have SEN and those with a defined disability. The definition of SEN may include a variety of difficulties, but may not include all children and young people with a disability. Therefore, a disabled child/young person who has special educational needs requires special educational provision to enable them to access local education services. A child who does not meet the criteria as being regarded disabled could still be eligible for assessment as a child in need under Section 17 paragraph 10 (a) or (b):

'A child or young person with a disability is under the age of 18 and has a severe or significant delay compared with others of the same age. This is due to impairments that are expected to be life-long (but may be episodic) in one or more of the following area: hearing, vision, speech and language, physical, learning, consciousness. Behaviour of a profound nature has to be in addition to at least one of the above'.

APPENDIX THREE

DATA EXTRACTION TOOL 1: POLICY & CONSULTATION DOCUMENTATION

Policy or consultation documentation type	What it says	What it means (its relevance)
1. Children Act 1989 & 2004	The 1989 Act sets out a duty to provide for all children up to the age of 18, including disabled young people up to the age of 19. Local authorities (Social Services) have a duty to provide services to those children and young people who are seen as 'children in need'. A 'child in need' is likely to be: • Defined as disabled or a child who without the input of services from a local authority is 'unlikely to progress in terms of their health or development without provision being made. A local authority must identify the extent of need by undertaking an assessment and determine the level of services and support required'. The 2004 Act placed a further duty on local authorities to establish Children and Young People's Framework Partnerships which act as the responsible statutory body for children and young people. The 2004 Act under Section 25 placed a duty on co-operation to improve well-being (physical, mental health and emotional, as well as social and economic well-being), to protect from harm and neglect; provide education, training and recreation and enable contribution to society.	• Section 17 of the 1989 Act is of relevance to those moving from children to adult services in terms of keeping a young person safe and well and provide services for disabled young people who are defined as 'children in need' and their families and others. Section 17 also allows for a Direct Payment to be made to purchase services and support. • The 2004 Act (Section 25), place a duty on making arrangements to co-operate with partner organisations (e.g. Local Health Boards), it enables a local authority area to improve well-being by establishing and maintaining pooled budget arrangements to deliver services and support to vulnerable groups of young people, including disabled young people.
2 National Service Framework for Children, Young People and Maternity Services (2005) The NSF adopts the principles of the United Nations Convention on the Rights of the Child	**Section 5 Disabled Children and Young People** sets out to provide a range of standards that have been 'informed by an understanding of the 'social model' of disability' and that those responsible provide services that are 'designed to maximise the development of a disabled child or young person. **Key action 5.7** is of particular relevance in terms of key working in that *'Service providers jointly agree and provide a key worker service for families with disabled children with complex needs. Where appropriate and agreed, this could be the parent'*. Likewise under Transitions young	• **Young disabled people from age 14 upwards should expect that under the Transition's standards (6 key actions) that:** - an inter-organisation system is in place to identify all young people who will require transition into adulthood provision (5.32) by their 14th birthday (in year 8) - information about how to gain access to services (5.34) such as about education and training,

(UNCRC) and sets out 7 core aims based on the Convention that **every** child and young person in Wales (0-25 yrs) has a basic entitlement to: • have a flying start in life • have a comprehensive range of education and learning opportunities • enjoy the best possible health and are free from abuse, victimisation and exploitation • have access to play, leisure, sporting and cultural activities; • are listened to, treated with respect, and have their race and cultural identity recognised • have a safe home and a community which supports physical and emotional wellbeing • are not disadvantaged by poverty.	disabled people who continue to require services should be able to access under **Key Action 5.33** *'a key transition worker is appointed to all disabled young people at age 14. It is their responsibility to ensure that the young people, their families and all relevant agencies are appropriately involved in the planning process. The key transition worker co-ordinates the planning and delivery of services before, during and after the process of transition and will continue to monitor and have contact with the young person until the age of 25 years' and should be 'offered a range of co-ordinated multi-agency services, according to assessed need, in order to make effective transitions from childhood to adulthood'.*	employment, housing/independent living, leisure and the information regarding the transition to adult services (local authority and health care services). Under this action it also makes provision to maximise the use of Direct Payments to 16 & 17 year olds - there is one joint organisations transition plan produced for each disabled young person which forms the basis of the Unified Assessment within adult services and specifies arrangements for continuing support and services (5.35) - a joint organisations transition plan is reviewed at least annually or, in the case of young people who are looked after, every six months in accordance with statutory regulations *Children (Leaving Care) Act 2000.* During the year before their 18th birthday the plan is reviewed each term (5.36) - that aggregated information derived from joint organisations transition plans is sent to the area's Children and Young People's Framework Partnerships to inform strategic planning (5.37).
3. Autistic Spectrum Disorder Strategy for Wales (2007)	The strategic action plans sets out 4 actions (10.1-10.4) related to transition which aligns to the NSF, the Handbook of Good Practice for Children with Special Educational Needs and other transition related consultation documents and recommendations.	**The strategic plans identifies that for young people with an Autistic Spectrum Disorder that:** • 'commissioners and service providers should ensure there are clear arrangements for transition between services for children and young people and adult services, in line with the actions set out in the *National Service Framework for Children, Young People and Maternity Services'* (10.1). • 'the Welsh Assembly Government will produce guidance for schools and LEAs on transitional planning, which will refer to a multi-agency approach as part of the SEN handbook for schools (*Handbook of Good Practice for Children with Special Educational Needs*. Welsh Assembly Government. April 2003). This will include arrangements for transition from school to college at age 16' (10.2).

		• 'the Welsh Assembly Government will consider how the arrangements for transitional planning for disabled young people, including those with learning disabilities, might be strengthened to support the actions set out in the *National Service Framework for Children, Young People and Maternity Services'* (10.3). • point 10.4 highlighted that the Welsh Government provided £1.5m of funding (£500k per year for three years commencing 2008/09) for a number of additional key transition workers to provide support to children and young people (and their parents and carers) with SEN (including those with ASD).
4. Equality of Opportunities Committee, Why is that disabled young people are always left until last? (2007)	There are a number of specific recommendations related to transition planning and the role of the key worker and were identified as being important and led, together with the recommendations from the ELLS Committee Policy Review of Additional Needs Part 3: Transition (outlined under point 5), the Welsh Assembly Government to make the provision of the £1.5m grant to develop transition key working in Wales, which was subsequently matched funded by a European Social Fund grant **There are 40 recommendations, the following are of relevance:** • **(1)** The Welsh Assembly Government should develop a strategic policy that includes all services that young people need to help them develop the skills they need to live a fulfilling life. Young people should be involved in working out the best way of making this happen. • **(2)** The Welsh Assembly Government to produce guidance for all policy divisions, local authorities and other public bodies in Wales on involving disabled young people, their families and carers in policy making. The guidance should identify good practice (e.g. the work of the Disabled Young People's Reference Group) and emphasise the need to listen to the views of disabled young people as articulated by them rather than focussing on the views of their families and carers. • **(3)** The Welsh Assembly Government should issue guidance to all public, private and voluntary sector bodies who provide	The **9** recommendations selected in the opposite column are of particular relevance and means that disabled young people should expect the following: • A holistic strategic policy framework is developed to enable young people to gain the skills they require to lead a fulfilled adult life; and that • young people are involved in policy making. • Young people should have information about and access to organisations/agencies that provide services and support through transition into adulthood. • Local Authorities to provide a system to enable young people to be supported through the transitional process. • Young people to access Direct Payments. • Young people to be involved in deciding who works with them, and that they are • involved with the review of staff performance and be able to express their views about those who work with them.

	services, one to one, groups, projects and initiatives for young people to ensure that they are as accessible as possible for all young people. The guidance should include: - making information on projects accessible; - creating an environment that the young people feel comfortable in; - ensuring that young people's needs are fully understood; - making progress towards projects as enjoyable and challenging as desired by all young people, whilst assessing and minimising any risks involved. • **(6)** The Welsh Assembly Government should provide a holistic, co-ordinated framework policy for provision of pre-16 and post-16 (up to at least age 25) education, training and employment support and services. The framework policy should cover early identification, assessment and service provision to clearly set out multi-agency roles and protocols for sharing information and providing services. • **(9**) The Welsh Assembly Government to ensure that all local authorities in Wales have systems in place to guarantee that all young people, irrespective of any impairment, receive appropriate assistance through the transition process. • **(10)** The Welsh Assembly Government to ensure that one-to-one support is available to disabled young people as part of education, training and employment services. • **(33**) The Welsh Assembly Government should review the current mechanisms for assessing eligibility for direct payments with a view to ensuring that equal access is given to young people with learning disabilities • **(34)** The Welsh Assembly Government should require all public and voluntary bodies that provide carers for disabled young people to demonstrate how disabled young people can be and are being involved in the process to decide on the person who will work with them. • **(35)** The Welsh Assembly Government should require all local authorities to ensure that all providers of care and support services for disabled young people have mechanisms in place	

	for the review of performance of their staff and that those reviews involve the views of the young people they work with.	
5. Education Lifelong Learning and Skills Committee, Policy Review of Additional Educational Needs, Part 3: Transition, (2007):	**Part 3 of the a policy review related to special educational needs provided the means to rationalise guidance and policy related to transition planning for disabled young people in Wales with the overarching recommendation that:** • 'the Assembly Government reviews, across the range of its responsibilities, the various strands of guidance and policy on transition planning to see if it can be brought together in a simpler, clearer and more accessible way taking account of the recommendations in the Beecham review of local public service delivery in Wales (2)' **There are a total of 47 recommendations.** **The following recommendations are of particular relevance:** • **(4)** We recommend that the Assembly Government strengthens guidance to ensure that young people, their parents or carers are given in advance all the information they need to get the most out of the transition review process. • **(5)** We recommend that the Assembly Government strengthens guidance to make it clear that young people should always be involved in drawing up the transition plan, unless there are clear factors that would prevent this. • **(6)** We recommend that the Assembly Government strengths guidance to make it a requirement on all relevant agencies, including Careers Wales and social services to attend and contribute to the transition review. • **(7)** We recommend that the Assembly Government strengthens guidance to ensure that social service departments are required to make an assessment of the young person's potential needs as an adult as well as of more immediate needs. • **(8)** We recommend that key workers are appointed to support all children and young people with additional needs, their	The **10** recommendations highlighted, as of relevance, in the opposite column, means that disabled young people and their families should expect that: • Information is provided about the transition review process; • that young people are involved in developing their Transition Plan; • that Careers Wales and Social Services, and other relevant agencies attend and contribute to a young person's Transition Review; • Social Services to assess to ascertain a young person's potential and likely future needs into adulthood; • that a key worker is appointed to support young people into adulthood and that a framework for their appointment and how they operate is developed, including professional training; • that the NSF key action 5.33 is adhered to; • review of the SEN code of practice is undertaken; • that person centred approaches are embedded into transition planning; • progression goals are established as part of a young person's Transition Plan, and • training is developed to support workforce excellence in transitional issues.

	parents and carers, throughout their education. • **(9)** We recommend that the Assembly Government draws up a framework of guidance, professional responsibility and appropriate training within which key workers should be appointed and operate. • **(10)** We recommend the Assembly Government prioritises National Service Framework key action 5.33 for implementation within 6 months of their initial response to this report and considers doing the same for other key actions that involve the appointment of key workers. • **(12)** We recommend that the Assembly Government reviews the SEN Code of Practice and other relevant guidance, to emphasise the importance of a person-centred approach to additional educational needs provision, particularly in relation to planning for transition to further learning and adult life. • **(14)** We recommend that clear and consistent progression goals are established as part of the transition plan in year 9 of secondary education and that goals are communicated clearly to Further Education Colleges and are reviewed annually. • **(46)** We recommend that the Assembly Government considers and reports on what further training is needed to support professional excellence in dealing with transition issues.	
6. Special Educational Needs Code of Practice for Wales (2002):	**Chapter 9: Annual Review:** Chapter 9 is of particular significance and outlines the importance of the year 9 Annual Review and subsequent annual reviews up to the age of 19 for those in special education settings (9:45). Point 9:52 outlines that all those who are involved in the transition process should 'adhere to the principles that underpin the nature of transition and transition planning and the requirements of the young people and their families. Transition planning should address the comprehensive needs of the child'.	At the year 9 Annual Review and successive reviews the main purpose is to review a young person statement. The rationale of the year 9 review is to draw up a young person's Transition Plan and from then on yearly review (within an agreed timescale) the said plan. The year 9 review should involve all the relevant agencies (9.46) including Careers Wales and where appropriate a representative from adult social care. The head teacher is key in that he/she must make sure that a Transition Plan is developed (9.50) and must involve Careers Wales. Most importantly the head teacher must ensure that a young person's annual review documentation and the Transition Plan are distributed to the young person's, their parents and professionals attending the annual review meeting.

7. Statements or Something Better? **THE NATIONAL ASSEMBLY FOR WALES (LEGISLATIVE COMPETENCE) (EDUCATION AND TRAINING) ORDER 2008** (PREVIOUSLY ENTITLED NATIONAL ASSEMBLY FOR WALES (LEGISLATIVE COMPETENCE) ORDER 2007)	**The Legislative Competence Order (LCO) related to Additional Learning Needs set out the need to:** • strengthening the status of the Special Educational Needs Code of Practice; • reform of the Special Educational Needs Statutory Assessment Framework; and to • alter the range of individuals with the right to appeal to the Special Educational Needs Tribunal for Wales. The main purpose of the LCO was to empower the Assembly to make Assembly Measures under part 3 of the Government of Wales Act 2006 to enable the implementation of key components of the Welsh Assembly Government's Special Educational Needs/Additional Learning Needs policy in Wales, including matters dealt with in the former ELLS Committee three part review.	The Welsh Government, following a consultative process (Statements or Something Better?), is developing a holistic Individual Development Plan (IDP) to replace the Statement of Special Educational Needs. The plan will cover the 0-25 age range and will look at all aspects of a child and young person's life, with an agreed action plan to provide the best support and outcomes into adulthood.
8. Mental Capacity Act (2005):	This Act came into force in 2007. It provides a legal framework for people over 18 who lack capacity, those caring for them and for the professionals who work with them.	The Mental Capacity Act (2005) is of particular relevance, for example for those with a severe learning disability and those people with an Autistic Spectrum Disorder. The Act sets out a set of key principles which centres people, who lack capacity, at the heart of making important decision related to themselves, their care and support.
9. Special Educational Needs and Disability Act (SENDA) 2001:	SENDA (2001) established the legal right for disabled learners in both pre and post16 education.	This Act is of relevance as it gave the right to disabled learners not to be discriminated against in education and training, as well as other any services provided entirely or largely for learners whether in pre and post 16 education. It also extended their right not to be discriminated against in further and higher education and also sixth form colleges. This Act also made provision for the following: • Education in mainstream schools of children with special educational needs; as well as • other more general duties of local education authorities such as: - advice and information for parents

		- resolution of disputes - compliance with orders - appeals - unopposed appeals - maintenance of statement during appeal - identification and assessment of educational needs - duty to inform parent where special educational provision made - review or assessment of educational needs at request of responsible body - duty to specify named school
10. Children and Young People's Specialised Healthcare Services:	There are a range of Standards documents, including the All Wales Universal Standards for Children and Young People's Specialised Healthcare Services, with other Standard documents related to specialism's such a neurosciences, palliative care and inherited metabolic diseases for example. **Within the All Wales Universal Standards for Children and Young People's Specialised Healthcare Services it should be noted that the following key actions are of particular significance:** • 3.11 Transition pathways are in place to allow for seamless transition to adult services. • Children and young people, who require more than two on-going services in addition to the universal services, have their services co-ordinated by a key worker. The name of the key worker is made known to the child, young person and their family and is recorded in their care plan.	**The All Wales Universal Standards for Children and Young People's Specialised Healthcare Services Standard 3: Care of the Child and Family/Patient Experience states that:** • The child and the family receive holistic, child and family centred care, and that the following key actions are also important in terms of transition: - 3.1 Services are delivered in line with the principles of the UN Convention on the Rights of the Child. - 3.2 Children, young people and their families are aware of the options available to them in their care management to make an informed choice. - 3.3 Parents are actively encouraged to participate in care - 3.4 Information and training is available for children, young people and their families about services, their condition and care. - 3.5 Information and training is provided for children, young people and their parents who wish to be involved in delivering elements of their own/their child's care.
11. Creating a Unified and Fair System for Assessing and	The Welsh Government issued guidance to all Local Authority Social Services Departments under Section 7(1) of the Local Authority Social Services Act 1970, as well as to health organisations to ensure	This process is important to and for disabled young people in transition and the need for an assessment to be carried out as they approach adulthood to provide an integrated support pathway. The

Managing Care (2002): Unified Assessment Process (UAP)	compliance with the targets set in '*Improving Health in Wales – a Plan for the NHS with its partners'*. Integral to the guidance is the implementation of the Unified Assessment Process, firstly with older people, and in turn, with other client groups, such as learning disabilities. The UAP is applied across Wales as single and unified assessment process to provide a more consistent means to assess and provide a more person centred approach to provide care for adults over the age of 18. Who meet the criteria for adult social care.	key elements are to provide: • A person centred approach to assessment of need, with the service user and their carer(s) at the centre of the process. • A co-ordinated and unified system of assessment to ensure that service users do not have to continually repeat information about themselves to professionals involved with their care. • A fair system to agree a consistent approach to eligibility criteria throughout Wales. • The domains of the UAP are standardised and the 'layered' approach as a means to assess is seen to be the way to ensure that the assessment 'remains proportionate to an individual's need'. A user of services should expect to have a named Care Co-ordinator who is responsible for bringing together all the relevant information for the UAP and help to co-ordinate the required services and ongoing support to the users of services including those to their carers.
12. Sustainable Social Services for Wales – A Framework for Action (2011)	The framework sets out how local authorities and their partners work towards confronting the challenges that social service face now and in the future and sets out the priorities to re-focus and provide the means to support users of services.	This framework identifies two priorities under Integrated Services (3.26), which are relevant to disabled young people: • **Transition to adulthood for disabled children** • **Families with complex needs**
13. Framework for the Assessment of Children in Need and their Families, National Assembly for Wales/Home Office 2001, Children Leaving Care	Point 3.72 sets out the following that: • The Children (Leaving Care) Act states that every looked after child should have access to have a personal advisor. This included young disabled people who are deemed 'looked after' as they may be in receipt of a short break from social services. Point 3.71 is also important that a young person who leaves care and lives independently of their families is able to maintain a link with family where appropriate and that working in partnership with the young	In accessing a personal advisor a young person should have by their 16th birthday a Pathway Plan in place. The plan will be informed by an assessment of need based on the Assessment Framework. The plan should cover the young person's transition into adulthood and their transitional arrangements should be considered during a Looked After Child Review on a 6 month basis. A young person who is disabled who is 'looked after' should have access to a personal advisor up until the age of 21 and supported to 24, if they are in higher education or training.

	person and their family during transition is essential.	
14. United Nations Convention on the Rights of the Child (UNCRC)	The UNCRC sets out the rights of the child in realising their full potential. The Convention also sets out to ensure that a child is seen as an individual, with rights and responsibilities which are age appropriate and at his/her stage of development. The focus is on the whole child.	The principles outlined in the UNCRC have underpinned the Welsh Government 7 core aims for children and young people and are outlined for example in Children and Young People: Rights to Action (2003) and in the National Service Framework for Children, Young People and Maternity Services (2005).
15. United Nations Convention on the Rights of Persons with Disabilities (2010)	The UNCRPD refers to the UNCRC in the preamble that children with a disability 'should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children'. The UNCRPD contains 50 articles **Article 7: Children with disabilities** is of relevance and that 'the best interests of the child shall be a primary consideration' and in line with the UNCRC states that: • 'children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right'.	The UNCRPD principally provides an international wide dimension related to human rights and that disabled people have the very same rights (Article 8) as everyone (freedom, equality, dignity and respect). For disabled people the Convention assembles together and what they should expect in terms of basic human rights and equality (Article 5). The 50 stated articles are comprehensive and covers important aspects such as: **Article 9:** Accessibility – ensuring that provision is made to enable disabled to participate in everyday activities **Article 10:** Right to life – to enjoy life to the full **Article 12**: have the right to being treated equally before the law. **Article 13:** Justice –making provision to enable disabled people to be treated equally and that training is provided to those in the justice system. **Article 14:** Disabled people should be free to be independent and feel safe, **Article 17:** disabled people should be treated as people first **Article 23:** states that persons with disabilities should not be discriminated in 'all matters relating to marriage, family, parenthood and relationships' **Article 24.**Right to an education as anyone else **Article 25.**Health – disabled people should enjoy the same health care provision as others **Article 27:** disabled people to have the same right to work/employment
16. Children and Young People's Planning guidance 2011–14	This guidance informs local authorities and their relevant partners both from the statutory and third sector who provide services to children/young people from 0–25 in a local authority area as to what	**Identifies key themes:** • sustainability and well-being

(2011)	should be within the Single Children's Plan.	• needs-based planning • relationships with other partnerships and plans • accountability and responsibility • models of service provision • integration of planning and delivery including • joint commissioning and pooling of budgets All the above are of relevance to transition into adulthood and key working.
17. Children and Families (Wales) Measure (2010)	This Measure established means to develop the Families First programme to tackle child poverty and how local partnerships should work together to deliver on 6 principles to develop a 'coherent, integrated support for children, young people and families'. **The 6 principles are:** • **family-focused:** taking a whole family approach to improving outcomes; • **bespoke:** tailoring help to individual family circumstances; • **integrated,** with effective coordination of planning and service provision across organisations, ensuring that needs assessment and delivery are jointly managed and that there is a seamless progression for families between different interventions and programmes; • **pro-active:** seeking early identification and appropriate intervention for families; • **intensive:** with a vigorous approach and relentless focus, adapting to families' changing circumstances; and • **local,** identifying the needs of local communities and developing appropriate service delivery to fit those needs.	Young disabled people in transition and the role of the Transition Key Worker fits well into to the 6 underpinning principles. Funding for disabled children has been shoehorned into the Families First initiative. Transition and key working are areas that should be seen as a priority across the consortia.
18. European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families (2010)	The Declaration makes it clear that children and young people with an intellectual disability are more like to be a risk of discrimination and disadvantaged in accessing health care services, leading to inequality. However, highlights the need for children and young with an intellectual disability to grow up in their family home and receive community base support to improve health and well-being outcomes. The main purpose of this Declaration is that there is commitment that children and young people with an intellectual disability are treated equally and have the same right to access health and social provision, education, training,	There are 10 key actions, each with a number of sub actions outlined in the Action Plan and cover the following in brief: 1. To protect from harm and abuse 2. Grow up in a family environment 3. Transfer those in intuitional care to community based provision 4. Identify need 5. This point is of particular relevance to both transition and key working – to ensure that quality mental and physical

World Health Organisation	protection and support. The Declaration supports the enforcement of the Convention on the Rights of Persons with Disabilities (point 15)	health care is co-ordinated and sustained 6. Safeguarding the health and well-being of family carers 7. Empower to contribute to decision-making about their lives 8. Build workforce capacity and commitment 9. Collect information about needs and services and assure that it is of a high quality 10. Invest in providing equal opportunities to achieve the best outcomes In terms of transition action 10.4 specifically states that there is a need to 'establish clear transition plans that support the coordinated shifting of resources from institutions to appropriate community-based support and services.

APPENDIX FOUR

DATA EXTRACTION TOOL 2: TRANSITION AND KEY WORKING DOCUMENTATION TOOL (EXAMPLE OF A COMPLETED TOOL)

Title: Young adults with learning disabilities: a study of psychosocial functioning at transition to adult services **Reference:** O'Brien, G. (2006) Young adults with learning disabilities: a study of psychosocial functioning at transition to adult services. *Developmental Medicine and Child Neurology. 48: 195-199* or http://onlinelibrary.wiley.com/doi/10.1017/S0012162206000429/pdf	**Date extracted:** 7/6/12
Main propositions:	• 'What extent do the disabilities we see in children enable is to anticipate subsequent problems of psychosocial adjustment in later adult life?' • also considers the long term consequences of LD in childhood.
Main properties/type:	• Study non-clinic follow up of 149 young adults with LD with SEN (born between 1967-1973) at transition (18-22 years of age) • To assess further projection and care of young adults with LD
Relevance:	• Transitional experience of young adult 18-22 years of age. Most living in the family home (n=108). A good number in some kind of employment (survey carried out during a period of high employment in a reasonably affluent area)
Main findings to the prospective CMOc	• that previous reviewers of the transition of young people with LD note the emphasis on the need for 'careful planning'. • planning needs to be *'comprehensive, taking into account of all the evidence of the child's skills, attainments, progress, disabilities, health and social functioning'* • need to focus on a *'wide range of domains'* • highlights that generally that the transition into adult life usually sees the 'diminution of parental control' this is less likely for a young person with LD going through transition and that there is a greater reliance on parental involvement • half of the young people with the severe disabilities were still living at home • the main carers were not aware of any additional support services or opportunities which might be available locally. Those known were related to education and short break provision (respite). These were seem to be highly sought after and as such even if carers wished to pursue places were *'limited and constantly under competitive pressure'*
Relation to the programme theory or mid-range theory areas as they are identified: **Having a Structure:** - Need to focus on a 'wide range of domains' - Lack of long-term multi-agency inter-disciplinary co-ordination: *'high value placed on co-ordination'* **Planning Well:** - Emphasis on the need for *'careful planning,'* taking into account of all the	Highlights previous studies which have identified the challenges and similar themes: - need to shift from medical model to social model - early diagnosis and intervention (prevention) - close attention to the medical care for children with multiple disabilities - family support and engagement - career education and preparation - empowerment of young people Carers highlighted that they were not kept informed of services and options available largely due to a lack of 'cross service collaboration' Need for multi-agency transition planning and study highlighted the *'lack of long term multi-agency and interdisciplinary co-ordination and follow up for the young people involved in the study'.* This was

evidence	notwithstanding the 'high value' placed on co-ordination in the literature at the time of this study. As this study highlighted there is no real system in place in the UK.

APPENDIX FIVE

DATA EXTRACTION TOOL 3: INCLUDED STUDIES DATA EXTRACTION TOOL: (MAPPING TO THE CMO, 4 P'S AND MID-RANGE THEORY AREAS)

Black denotes the broad transition related literature ♦ Key Working related literature denoted in blue ♦ Transition Protocol/Pathway specific denoted in red

Author(s)	Type/Nature of the Research	Main Findings of relevance to the C+M=O	Relevance to the Candidate Programme Theory	Relevance to the mid-range theory areas
Abbott, D. & Heslop, P. (2008)	Empirical research across 5 regional areas (England). Small scale study of 15 families whose children were in a residential school or college setting. Focus on outcomes at one stage of transition	• Identified a plethora of legislation and policy, yet there was a lack of clarity as to whether policies are leading to better outcomes for young people and families. • Transition seen as a policy *'buzz word'* • 4:15 young people were unsure of their end destination • Limited choice and pathways • Policy promotes the progression into employment the reality is somewhat different	• Lack of evidence on achieving good outcomes for young people (prevention/protection) • Parents felt that no one told them anything • Colleges did not see their role as looking for options for young people • A quarter of placements post school/college broke down • Stress and frustration reported and emotional upheaval • Social worker scepticism regarding young people becoming independent	**Continuity of provision:** - Lack of continuity, some young people returned home **Supportive arrangements:** - Lack of a relationship with home authority social worker to support young people and families **Planning well:** - Needs *'careful planning'* **Active decision-making:** - Young people not encouraged to take part in decision-making. - Last minute funding decisions reported
Abbott, D. and Heslop, P. (2009)	Linked to Abbott and Heslop (2008) Reflective study which highlighted the barriers to achieving successful transitions and gave an insight into a problematic transition for young	• Young people in transition in out-of-county placements were being failed despite the existence of policy • Limited choices and option for young people • Parents have often had to 'fight' to	• Commitment required producing good outcomes for young people as their non-disabled peers. • Parent and professional relationships not always positive • Parents and professionals considered that there was an	**Planning well:** - Need for focusing on planning - Inconsistencies in transition planning methods - *'problems with past, current and future transition plans'* (p.49) - For some parents there were not

	people in residential schools or colleges. Study highlighted that those in such settings are some of the most vulnerable. Yet, their transitions are seen as the most difficult due to a lack of effective planning	obtain a residential school or college placement for their child (seen as a last resort due to lack of local provision). Some professionals not always entirely in agreement • Highlighted the differing statutory responsibilities through transition into adulthood	*'absence or problematic nature of good, timely or sometimes any transition planning'* (p.49) • Professionals suggested that *'planning early for the next move was counter-productive'* (p.49) as adult providers were late to engage • Late allocation of social workers • The distance of the placement from the funding authority hindered transition planning	transition plans in place - Lack of planning was equated to staff shortage and turnover which led to crisis situations - planning meetings seen as *'problematic'* **Active decision-making:** - 'Acrimonious' decision-making processes experienced by parents to have agreement on a residential placement (5 families took legal action) **Continuity of provision:** - *'Sudden and unannounced transfers'* (p.51) **Supportive arrangements:** - Not all professionals had an understanding of how a placement came about - Not all professionals had an longstanding relationship **Having a structure:** - Need for joined-up working and an understanding of peoples roles and responsibilities
ACT (2007)	Guidance to develop and address the unmet needs of young people with life-threatening and life-limiting conditions. Sets out 6 standards	• Breakdown the pathway into stages (entry phase: recognising the need to move on; Moving on and End of Life stage)	• Recognises the importance of person-centred planning • Being prepared for each stage	**Having a structure:** - In 3 stages, depicted as linear **Supportive arrangements:** - Role of a key worker or lead professional - Supported on the basis of individual need and to receive it as long as needed **Planning well:** - Young person and family have reassurance that what happens will

				be as they wishes - Joint planning - Importance of having a written plan **Continuity of provision:** - continuity and co-ordination of services including into the family home
Barnes, P. (2008)	Small-scale study to identify ways to improve outcomes for children with SEN: the perspectives of SENCo's and parents Semi-structure interviews	• Multi-agency working was seen as 'enabling and enhanced inclusive education and holistic assessment • No protocols identified in supporting a way forward • Commitment to multi-agency working, giving clear direction • Parental involvement	• Identifying individual needs • Lack of cohesion and integration • Right support as early as possible	**Having a structure:** - *'no specific set of protocols'* were available to formalise a local framework, but that *'there was general agreement that a multi-agency teamwork approach….was an effective way forward'* (p.1) to promote understanding. **Supportive arrangements:** - Identification and assessment stressful - Improvement in support as a result of multi-agency working - Parents wanted a key worker; aiding multi-agency working **Planning well:** - Multi-agency working a factor in working together, planning resources **Continuity of provision:** - Co-ordination across multi-agency partnerships
Beresford, B. (2004)	Journal paper and seminal work highlighting the problems with transition Review of literature bringing into sharp focus the key issues Calls for longitudinal	• Transition considered problematical and challenging • Adult services not *'tailored'* to meet the needs or in place post transition • Limited evidence of what works	Identifies a number of problems which limit activating the 4 Ps: • Lack of information regarding choice/options • Insufficient specialist staff • Timing of transition	**Active decision-making:** - Young people not being involved in making decisions. Those with SLD not included in transition planning leading to *'multiple inequalities'* (p583)

		regarding a seamless transition • Having policies in place does not guarantee change or service development	• Nor being able to meet demand • Positive outcomes equated to parental proactivity rather than via a professional/agency • Highlights the need for person-centred approaches	- Parents likewise not always involved in decision-making
Beresford et al. (2007)	Study related to children and young people age 2-18 with complex needs (covers the transitional age range)	• Services usually provided to the child and not parents • Identified the need for '*parent-centred outcomes'* • Little documented about what parents want of their own lives	• Identified the need for a better balance between parenting and caring roles (maintaining and enhancing personal identity) • Emotional, physical and well-being supported needed • Parents needed to be confident of services • Parents wanted to work in partnership with professionals	Supportive arrangements: - *'greater creativity is needed in thinking about parent support services'*
Beresford, B. and Cavet, J. (2009)	Considered the transition of young people from out of county residential settings Focus on identifying difference in practice, factors/impact on transition planning and outcomes	• Identified and highlighted growing evidence of poor transition planning and outcomes for young people • Lack of monitoring long-term outcomes • Health transitions problematical	• Young people poorly prepared than other young people in local special schools • Issue with geographical distance from funding authority • Distanced relationships with funding authority professionals e.g. social worker and loss of contact or allocation • Person-centred approaches to planning less likely due to distance • Funding issues	**Continuity of care:** - Earlier involvement of adult services - Tensions between school and home authority - Unmet health care needs **Planning well:** - Gaps in identification of those requiring transition planning - Managing change and transfer to new or unfamiliar settings after being in a 52 week placement for many years of stability **Having a structure:** - Lack of strategic planning to meet adult social care needs
Beresford et al., 2013	A study specific to the transition of young people with an Autistic Spectrum Condition (ASC): Survey of young people and	• Focus on: - Young people just about or have left school - Role of services identified as	• Young people with ASC not prepared for leaving school without specialist support • Concern related to suspensions,	**Having a structure:** - Systems and structures evident for young people with ASC to receive a level of support, but that not all

	parents Interviews with young people 18-24 with High Functioning Autism and Asperger's Syndrome	multi-agency transition services - The experiences of young people and parents of transition planning - Costs of provision (hampered by a low response rate typical of other studies involving disabled children/young people and their families) • Young people with ASC without a learning difficulty are likely to be unknown post transition	expulsion from school and lack of further planning. • Person-centred approached applied needed to be mindful of the specific needs of young people with ASC • Young people prepared to be engaged with help • Parental experiences of planning processes not always positive	were eligible to access support from a transition service **Continuity of provision:** - There was a danger that many young people post school who were ineligible for adult social care support became *'invisible to statutory services'* (p.VI) - Lack of post education options and employment **Supportive arrangements:** - Lack of support as young people are about to leave school - Young people were unlikely to move from the family home in early adulthood concerns related to independent living skills - High incidences of parental role in supporting young people - Need for skilled workers with ASC knowledge - Young people appreciated the support they received
Carnaby et al. (2003)	Focus on pathways from inner city special schools and the role of Transition Reviews (4 year project with 15 young people age 16-18) Mixed method study	• Identified transition as a *'critical point'* • Young people often excluded or not involved in their Annual Review • Health transitions seen as difficult and an issue	• Some parents not always prepared for their child's Annual Review • Requires an *'individualised way of working'* and for it to be person-centred.	**Planning well:** - Emphasised that there needs significant energy and planning to support young people with SLD through into adult services **Continuity of provision:** - Better co-ordination between school and adult services
Care Co-ordination Network Cymru (2014)	Provides descriptions of key working models and descriptor of the key worker role	• Sets out the differences between designated and non-designated key worker	• The key worker role seen as a preventative intervention	
Carpenter, J and	Report focusing on young men	• Young people with DMD are now	• Most of the young people were	**Supportive arrangements:**

Abbott, D (2010)	over the age of 15 with Duchenne Muscular Dystrophy (DMD) and their families. The study looked at the social and psychological aspects and the move from one service to another	likely to live longer beyond adolescence due to improved management of the condition • Variable pathways into services • Access an issue which could be breaches of the DDA • Experiences of services seen largely to be difficult • Young people and parents *'tended to live for the day'* (p.40)	living in the family home with mother providing the most support • Parents unclear about the transition process. • Parents reported 'battles' with services and their sons were aware of this and found it upsetting. Parents endeavoured to protect them • Parents were positive, but that it was because of long-standing relationships with certain professionals	- High level of multi-professional contact, only 25% had a key worker or care co-ordinator - Lack of information as to how young people would be supported - Parents providing high levels of support - Independence an issues as the young men relied on their families for support and getting about - Being able to talk to someone that was trusted **Planning well:** - Parents reported some level of transition planning in school (30% did not recall planning happening) although parents said that their sons were involved in planning for their own future but few examples were apparent - College seen as the next step but some not sure that this was the option for them **Continuity of provision:** - Difficulties obtaining reliable and sustainable care and support provision - Parents were not sure about what services their sons would transition into and the potential for losing services e.g. Physiotherapy
Caton, S. & Kagan, C. (2006)	Multi-method approach: longitudinal design and triangulation Semi-structured interviews with young people at two points.	• Difficulty tracing young people post school and their destination points. • Attributes 'attrition' starting early in the transition process for young	• High levels of exclusions presented serious challenges • Destinations unknown • Lack of engagement of young people	**Continuity of provision:** - Attrition inhibits access to services and support - Breakdown in relationships with school/college

	Focus on those with 'mild' intellectual disabilities	people • Identified as being overlooked by schools/careers services – seen as a challenge • Identifies transition as one of upheaval	• Incorrect information in the system related to attendance at college; data recorded and actual destination	**Supportive arrangements:** - Missing in the system post school; re-appearing in mid-20's (housing, probation services, family carers not coping) when crisis occurs.
Cavet, J. (Care Co-ordination Network UK) (2007)	Distance learning text developed under the auspices of Early Support which brought together the policy and research context related to Key Working: what was known	• Identified what is known • Why Key Working is important, who should receive it, what the Key Worker does • Highlights the skills and qualities required, but also the challenges of the role • Suggests an evolving picture • Provides definitions	• Prevention: Key Worker seen as one element in the drive to improve multi-agency working	**Supportive arrangements/Having a structure:** - Supports joined up working
Council for Disabled Children (2009)	Guidance to translated theory into practice Principles helpful and the guide to develop a transition protocol	• Presents what they considered to be the underlying principles of supporting young people through transition into adulthood (6 principles identified): - Comprehensive multi-agency engagement - Full participation of young people and their families - Provision of high quality information - Effective transition planning - Array of opportunities for living life	• Recognisees at the time the importance to improve transition planning processes. • Need for wider understanding of co-ordination across agencies • Having clear lines of communication • Use of person-centred approaches so that young people can make sure their voices are heard • Personalised services	**Having a structure:** - Need for a protocol and pathway to promote multi-agency working - Clear pathway facilitates clear expectations about what can be provided/delivered **Supportive arrangements:** - Need for key working or lead professional to co-ordinate planning - Advocacy support **Active decision-making:** - Involvement of young people in developing protocols and in their own transition
Cowen et al. (2010	Report on the implementation of co-production and a personalised transition in a special school	• Problems with transition are described as well-known • The term 'key worker' commonly used title and description • Premise to improve transition planning and commissioning	• Person-centred approaches and the co-production agenda encouraged involvement and proactivity: - Needs *'re-thinking the organisation of professionals input into the transition*	**Having a structure:** - Importance of joint working **Supportive arrangements:** - Expect support - Highlighted the need for services received in childhood mirrored in

		• Transition is a national problem • Lack of good outcomes for young people	*process…creating more flexible person-centred framework of professional support'* • Need for a whole-life approach	adult services **Continuity of provision:** - Having to start new relationships with professionals and managing those changing relationships
Dean, J. (2003)	Study focused on housing: the experiences, aspirations and belief. Interviews with 30 young people with learning and physical disabilities	• Leaving the family home a *'key marker'* of adulthood • Issues around feeling safe/unsafe	• Issues for parents related to proactivity due to not feeling able to challenge agencies and decision-makers: - *'sometimes despite being determined to be proactive and problem-focused, parents feel unable to challenge authority'* (p.67) • Some young people did not want to leave the family home; seen as a positive choice or there was no other option.	**Planning well:** - Needs careful planning - Parents feeling overcome with the enormity of the what is happening in their lives: - *'in the end some parents are overwhelmed with the complexities of their lives and withdraw from any engagement with the transition process'* (p.69) **Active decision-making:** - Young people wanting independence and control
Dee, L. (2006)	Focus on ways to improve transition planning. Followed the stories 12 young people	• Considered 3 models (time, agency and phase-related transitions) and the transition into what post school • Fragile networks existed: *'fragile networks that rely on relationships between individuals rather than on robust strategic and operational frameworks'* (p.104)	• Difficulty coping with change • Build upon ways of coping • Little known about what is available to young people	**Active decision-making:** - A focus on how decision are made post school - Different levels of decision-making highlighted **Continuity of provision:** - Fragmentation, confusion and uncertainty comments
Dee et al. (2002)	Three year project findings focusing on Quality of Life (QoL)/facilitating transitions for young people with severe/profound learning disabilities including a national survey of provision (4 action research sites)	• Set out the legislative context at the time recommending clear guidelines as to how legislation should be implemented • Reported 8 key messages including Transitions: the need for effective support, but that post school was inconsistent • Highlights transition acknowledged in part in policy &	• Inter-agency collaboration was essential due to the number of agencies involved, but that it was not always occurring • Geographical differences in provision • Time given to negotiate between agencies • Collective control • Parents bring differing strengths	**Local governance and accountability:** - Short term funding associated with likely dependency, uncertainty and instability. Resources not being used effectively at transition points - Cite logistical barriers causes young people to fall between the gaps **Ready for change:**

		practice • Importance place on a chronological transition	and needs as part of a partnership	- Considered that transition happens 'in spite of' and not because a young person is involved and presents many challenges **Having a structure:** - Collaboration required between multiple organisations and professionals involved; seen as an 'essential way of working, but challenges organisational systems **Supportive arrangements:** - A member of the team acting as a co-ordinator.
DOH/DES (2006)	Formed from the NSF (England) to improve the transition of young people with long-term conditions.	• Aimed to support young people make a successful transition into adulthood (education, health, development and well-being) • Highlighted the barriers young people needed to deal with more than their non-disabled peers • Defined the issues (including changes in mortality e.g. life-threatening conditions) and morbidity • Highlighted the need for a policy on the timing of transfer	• Transition needs time, resources and commitment for all involved • Appropriate environments to transit into • Young people needed someone they could trust • Issues with age of transfer (various transition points with health sometime 16 sometimes 18)	**Planning well:** - Need to *'address professional and managerial attitudes'* (p.17) - Young people wanting to play an active role in the management of condition wanting to plan early - Planning required for a co-ordinated transfer to adult health provision **Local governance and accountability:** - Need to recognise that certain health care professionals may have different perspectives - Importance of dialogue **Continuity of provision:** - Paediatricians concerned about transferring young people with rare complex conditions to adult professionals who may not have the skill s or knowledge. Adult health care professionals similarly concerned in managing such young

				people. - Young people concerned about losing continuity of care. **Supportive arrangements:** - Identifying a co-ordinator - Having to make new relationships
DCSF/DOH (2007)	Transition guide providing information for professionals	• Highlighted the variability of support, with the need of getting it right • Considered transition across education, health and social care	• Effective practice required (examples given) • Transition reviews an important element of the transition process	**Active decision-making:** - The importance of young people making decisions **Having a structure:** - Joined up and comprehensive services through the transition process - Developing local pathways **Local governance and accountability:** - Transition planning required at a strategic level **Continuity of provision:** - Across organisations and between child and adult provision
DOH/DCSF (2008)	'Guidance' document outlining health transitions	• Health-focused rather than incorporating a health/well-being related domain within one holistic transition plan, does not go into detail apart from setting out what a Health Care Plan should cover	• Young person's health care needs should be continuously addressed • Young person's needs should be at the centre of the process • Identified the ACT care pathway (standards) as a useful example • Need for integrated multi-disciplinary teams • Highlighted the need to be person-centred and goal orientated • Assesse impact of future health care needs and strategies to maintain health and well-being	**Having a structure:** - Need for inter-agency planning structures and agreed protocols for sharing information - Good practice to have joint multi-agency transition protocols **Supportive arrangements:** - Call for key worker support but not dependency **Planning well:** - Opportunities and support for independent living, flexible training and employment schemes - Young people to develop own pan with support of a key worker

				Continuity of provision: - Lack of continuity leads to poor transitions and disengagement and poor outcomes for young people - Multi-agency transition teams - Joint clinics **Local governance and accountability:** - Joint commission of posts for children and adult with complex health care need
Doug at al. (2011)	Systematic Review of the transition of young people with palliative care needs age 13-24	• Focus on experiences and outcomes • Lack of effective and evaluated models (no model in the context of transitional palliative care) • Using palliative care was not as useful in locating transition-related evidence • No long-term outcomes to measure • Similar perspective on the general principles of transition and the barriers experienced	• Variability on quality of transition services in a palliative care context • Focus on condition due to life-limiting/threatening aspect	**Continuity of care:** - Differing perspectives per condition on transition points **Having a structure:** - Transition planning not addressing the needs of young people with life limiting/threatening conditions
Everitt, G (2007) (Dimensions)	Overview of transition-related research for parents and practitioners	• Considers that transition could be defined simply *'as a process which brings together people who will ensure that families and young people with a disability can plan ahead as they enter adulthood'* (p.1). But not straightforward, but complex • Young people experiencing a chaotic transition • Identified 6 prerequisites for a successful transition (Commitment, Involvement,	• In terms of prevention and maintaining seamlessness: need for active management, co-ordination, support, monitoring and education • Listening to the needs of young people and responding through '*close multi-agency collaborations'* (p.2)	**Having a structure:** - Need for protocols/agreements setting out the responsibilities of agencies and important to outline the process - Pathways seen as a useful tool - Having a shared vision and person-centred structure **Active decision-making:** - Suggests *'lip service'* given to consulting young people about their own transition **Planning well:**

		Strategic Planning and Commissioning, Multi-agency approach, Person-Centred Planning and Monitoring)		- Importance of having a tailor-made person-centred transition plan
Fiorentino et al. (1998)	Study focused on health transitions of 87 young people Multi-method approach	• Lack of adult services despite legislation and policy • Gaps in provision with young people falling through the net • Confusion about the transition process from service to service • Difference in service provision	• No young person experienced a smooth transition • Lack of communication • Decline in service provision • Parents making series of adjustments	**Supportive arrangements:** - Support for changed relationships and specific provision for parents **Continuity of care:** - Lack of continuity and co-ordination - Lack of regular contact
Forbes et al. (2002)	Systematic Review of continuity between child and adult health care across condition specific groups	• Gaps in understanding of what works for whom • Limited evidence of good practice • Evidence in research for what works limited, focus on what does not or the problems. How or what should be done absent	• Continuity a key factor • Quality of planning variable	**Planning well:** - 1/5th of young people left school without a plan **Continuity of provision:** - Continuity around service delivery an issue **Having a structure:** - Specific services with skilled professionals - Focus on moving from one stage to another rather than from one service to another
Greco et al. (2005)	Cross sectional study to compare the implementation and operation of different key working models, assess outcomes for parents/children, investigate sources of funding 225 questionnaires distributed (70%) return rate. 7 services reviewed. Little related to transition and what works for whom, when and in what circumstances. Focus on early years	• Outcomes focused on the management of Key Worker Services, definition and understanding of key worker role, training and supervision, quality and cost of provision • Need for active partnerships • Key Worker seen as a long-term intervention • Varying interpretations of models • Inter-agency implementation • Challenged by organisational re-structuring, staff turnover,	• 30 services providing Key Workers across England and Wales: key workers providing a *'valuable service for families and had positive impacts on many families lives'* • *'Implementing a key worker services is about changes which challenge current patterns of work'* • *'Listening to families and developing supportive open relationships, promoting a sense of*	**Having a structure:** - Variation/differences in structure; differing models and implementation; differing cultures, funding structures, differing responsibilities - Key Worker services as part of system and structure **Supportive arrangements:** - Key Worker: liaison and co-ordinating support - potential overlaps with other roles - providing emotional support

	Longitudinal work would be beneficial, snapshot study	financial uncertainty, sustaining post grant funding, equity across agencies, different ideologically thinking	*trust which allowed family members to be honest and open with their key worker'* • Supporting information provision about school placements • Key Workers needed time as it was *'time-consuming and difficult role'*	- Parents with a designated key worker had higher QoL scores than those in services without **Planning well:** - Key worker needed to be giving time to carry out role to work with families
Heslop, P. and Abbott, D. (2007)	Qualitative survey in 2 strands: 1. Survey of families (283) and follow up interviews (27 parents/27 young people (experiences of planning processes, aspirations, involvement and outcomes 2. Field visits to 10 projects across England	• Highlighted the increased awareness of transitional issues related to effective planning - summarising what makes a good transition - one of many transitions, but at 14 most difficult time	• Requires staff who are determined and committed to improve the transition process • Areas covered during the process were not always the ones families wanted thought were important • Whether young people had active planning or not appeared to make little difference related to them post school • Few options available post school • Inter-agency working • Involvement of young people and families in the process needed	**Continuity of provision:** - Lack of co-ordination between child and adult services **Planning well:** - Unhappiness with transition planning - Two-thirds of young people had no transition plan **Ready for change:** - Uncertainty and stress - Concerns related to safety & risk, transport and financial aspects **Active decision-making:** - Young people had little or no involvement in planning for future - Honesty and openness **Continuity of provision:** - Key workers to support through the process **Local governance and accountability:** - Transparency
Heslop et al. (2002)	Qualitative study (283 families)	• Mismatch between what parents wanted to address and those related to transition planning such as housing • Considered that there are 5 key element which facilitates a good transition (5 'C's)	• Identifying and addressing need • Balancing risk and the safety of young people • Some parents considered that they had less independence as their child reach young adulthood than they did when they were in school	**Planning well:** - 1/5th of young people left school without a transition plan - ¼ not involved in transition planning - Lack of choice and options - Transition to adult service not

		(Communication, Co-ordination, Comprehensiveness, Continuity and Choice)		discussed within the process for many young people **Active decision-making:** - Lack of involvement of young people - Lack of advocacy provision **Continuity of provision:** - Not just a transition between one organisation to another as provision in children's services not replicated in adult services - Reduction in the quality of provision
Hirst and Baldwin (1994)	Study which brought into focus the difficulties with transition and between health and social care	• Considered the transition process to a complicated/complex process • Identified gaps between children and adult health care provision	• Young people finding it difficult to manage health care needs • Differing perspectives between young people and parents • Long-term dependency on allied health services and benefits • Feelings of lack of worth	**Continuity of provision:** - Co-ordination problematic **Active decision-making:** - Young people less likely to be independent - Lack of control of own life
Kaehne, A. (2010)	Evaluation of local Transition Protocols in Wales	• Outlines the legislation and policy context: how Transition Protocols frame and sustain partnerships • Highlighted the differences in developing effective multi-agency protocols: variability and quality of content • Protocols may not influence multi-agency partnership working • May not be used appropriately for young people to achieve their goals	• 2:22 protocols mention use of person-centred approaches in Review meetings • Lack of clarity regarding involving young people • Little mention of other agencies and the process of involving them	
Kaehne, A. and Beyer, S. (2009)	Study of professionals in strategic and operational positions involved in transition planning across 6 local	• Highlighted the problems and advantages of inter-agency partnerships and support post-school destinations	• Success factor focused on transition into paid employment yet many young people failed to gain paid work	**Continuity of care:** - No clear pathways through further education and training **Planning well:**

	authorities	• Indicated that the aim was to create a smooth transition creating opportunities and choice • Focus on inter-agency collaboration which took precedence over *'hard outcomes'* (e.g. employment as an outcome of the transition process) • Not looked at other transitions options	• Variations in partnership working in transition emphasis on organisational priorities rather than focusing on specific outcomes for young people	- Transition protocol were not seen necessarily to provide a *'good framework for collaboration'* - Developing a protocol was not seen as an easy task; a call for clearer guidance
Knapp et al. (2008)	Qualitative study of 30 young people	• Emphasised that the results of an unsuccessful transition are substantial and wide-ranging • Not enough funding or used appropriately for young people to achieve their goals • Raising educational and career aspirations	• Insufficient resources • Lottery of provision	**Continuity of provision:** - Many changes in support services **Supportive arrangements:** - Key worker involvement was equated with QoL improvements
Liabo et al. (2001)	Systematic Review of literature related to key working (current research at the time supported the key worker approach)	• Clear key working models called for • Key Worker satisfaction • Organisational obstacles problematic hindering uptake of key worker development	• Better relationships with services and access • Reduced levels of stress	**Supportive arrangements:** - Key Worker needs to have certain characteristics to support families with practical and emotional problems - Personal relationships with key worker important **Continuity of provision** - Making a positive difference - Creates leverage - Lack of co-ordination across agencies (key aspect of key working to manage this)
Maudslay, E. (2000)	Provides a basis and focus on transition related to disabled young people	• Highlighted that the term *'transition'* has become principally associated with young people who require additional support in accessing services into adulthood		**Planning well:** - Time/Future concept different for young people

		and that to facilitate and manage those transitional changes, transition planning is an essential necessity.		
McGinty, J. & Fish, J. (1992)	The main rationale for inclusion: Provided a recognised definition of transition which is helpful to describe the process, but is focused on educational transitions from school to college for example	• Provide a working definition of transition within the context of disabled young people • Focused more specifically at educational transitions but across organisations, both administratively and educationally	• Considered that transition is a process over a timespan and that preparation is important within the school environment	**Continuity of provision:** - Provision from childhood into adulthood
Mitchell, W. (1999)	Study of 17 families leaving 5 special schools over two year period (Interviews) - Focused mainly on the transition into next educational/vocational placement whilst moving to looking more broadly across other areas of transition into early adult life - Overall called for a *'radical revision of traditional transition models'* (p.766)	• Highlighted the changes that occur between child and adulthood: e.g. legally, socially, emotionally • Concepts of child or adulthood '*ambiguous and hard to define'* p.753 • Theoretically based previously on transitions between institutions moving on to schools preparing young people • Notes transition as complex an multi-dimensional • Highlights Fish (1986) that transition is both a phase (service-focused) and a process (p.755) (Social/psychological development)	• A more flexible approach required to transitional models • Transitions are not predictable • Gradual steps towards adulthood • Importance place on schools/FE colleges to prepare young people	**Active decision-making:** - Opportunities '*frequently mediated and interpreted by professional assessment and judgement of what was regarded as feasible or just being realistic'* (p.757) - Having a job was seen as a 'marker' of adult status
Morris, J. (1999)	'Hurtling into the Void' an apt title often quoted or similar analogy by parents Study of young people's experiences of transition	• Identified no specific outcome measures • Provided useful definitions such as what is meant by transition • Delays and failure to get services • Looked at all aspects of a young person's life rather than sole focus on education	• Reduced chance of becoming independent • Disparity between past and present experience and future ambitions • Risk of social exclusion and poor health outcomes	**Continuity of provision:** - Joint planning and working - Fragmentation and a lack of response to the needs of young people **Having a structure:** - Integrated approach

		• Recognised that transition is a process rather than a series of assessments and reviews (p.10)		
Morris, J. (2002)	Findings paper for Joseph Rowntree Foundation	• Gap in intention of inter-agency working in legislation/policy and that experienced by young people and families • Despite legislation young people not getting support they are entitled to • *'strategic commitment to joint working are rarely translated into effective co-operation in practice'* • Recognition of need to improve transition planning	• Lack of information to consider options • Parental or professional surveillance a barrier to independence	**Planning well:** - Young people and families not involved in transition planning - Young people wanting their own a barrier (e.g. lack of the right housing provision) **Continuity of provision:** - Young people rarely having home of their own they are more likely to be 'slotted into' what is available - Transition into adult health care problematic **Active decision-making:** - Having relationships overlooked
O'Brien, G. (2006)	What extent does the disabilities we see in children enable us to anticipate subsequent problems of psychosocial adjustment in later adult life. Considers the long term consequences of LD in childhood Study non-clinic follow up of 149 young adults with LD with SEN (born between 1967-1973) at transition (18-22 years of age) To assess further projection and care of young adults with LD.	• Transition into adult life usually sees the *'diminution of parental control'* this is less likely for a young person with LD going through transition and that there is a greater reliance on parental involvement the main carers were not aware of any additional support services or opportunities which might be available locally • Those known were related to education and short break provision (respite). These were seem to be highly sought after and as such even if carers wished to pursue places were *'limited and constantly under competitive pressure'*	• Lack of awareness of additional support or opportunities which might be available • Services highly sought after • Place limited	**Having a Structure:** - Need to focus on a 'wide range of domains' - Lack of long-term multi-agency inter-disciplinary co-ordination: *'high value placed on co-ordination'* **Planning Well:** - Emphasis on the need for *'careful planning,'* taking into account of all the evidence

Pywell, A. (2010)	A critique of Transition: Moving on Well (DCSF/DOH), 2008	• No impact assessment undertaken • Identified the importance of good services and transition from paediatrics to adult health services • Risk of disengagement despite policy encouraging early planning • Health transitions focus using a multi-disciplinary approach not multi-agency	• Shortfalls in funding highlighted • Young people may receive no support until just before transition to adults services • Health transitions would benefit from a longer term approach rather than based on chronological age: not a good indicator for change and having a defined cut-off point	**Continuity of provision:** - Importance of the role of co-ordination; to support planning and decision-making - Low expectation **Active decision-making:** - Focus on young people managing and making their own decisions about their own health **Planning well:** - Opportunities to engage lost due to detachment
Sloper et al. (2006)	Evaluation of 189 postal questionnaires from 7 key worker services in England & Wales Measures: - Demographics - Contact with key worker - Questionnaire Path Analysis	• Four path models identified: more key workers carrying out role, giving time, appropriate training and a dedicated service manage • Clear job description was associated with better outcomes • Identified that only has a minor impact on addressing unmet need; that other service factors were involved • Highlighted the emphasis in recent policy (e.g. NSF, Early Support)	• Families wanted to see the key worker often • Parent involvement is steering service development • Varied implementation of key worker services • Differing definitions and interpretation of role • Aspect of role was seen as a *'strong predictor of family outcomes'*	**Continuity of provision:** - Co-ordination across education, health and social care (average family contact with 10 professionals); co-ordinating care **Supportive arrangements:** - Active contact with key worker - Providing emotional support - Support to access services
Sloper et al, (2010) **(Journal paper Clarke et al. (2011)**	Quantitative survey of - local authorities in England to provide evidence of what works in developing and implementing multi-agency co-ordinated transition services - 143 parents and 97 young people Qualitative interviews with - 130 managers and staff across 5 case study areas	• Transition Services appeared mot to reduce the likelihood of stress for most of the parents who took part, citing over a third it had increased stress levels • Workers were more often than not were not getting involved until a young person was 16 or over and stopped involvement at 18/19 • Other local priorities and targets were attributed to the lack of consistent involvement.	• High levels of unmet needed recorded across many aspects of a young person's life including planning for the future goals • Having a worker was a factor in producing better outcomes • Use of person-centred approaches seen as a positive aspect • Having parental involvement in steering the development of transition services a positive element	**Having a structure:** - Diversity of structure and organisation and funding arrangements **Local governance and accountability:** - Multi-agency in nature, but involvement was variable - Having a manager responsible for transition services and strategic involvement an indicator of addressing need and producing

	- Six families where young person had transferred to adult services	• 34 Transition Services identified for young people with largely SLD • Considered that transition services were at an early stage in their development, but that resourced direct services to young people provided the likelihood of better outcomes. • A need to remove barriers to multi-agency approach called for	• Funding streams were an issue and how resources might be used. Therefore meeting needs in a holistic manner unlikely	better outcomes for young people **Support arrangements:** - Variability from having generic or specific transition workers - Having designated transition workers and clarity of worker role seen as a positive aspect producing better outcomes **Planning well:** - Having a Transition Plan associated with achieving better outcomes for young people
Small et al. (2003)	Study which considered choice and future	• The study focused on the *'interplay of social structure and individual agency'* (p.159) and the tensions between the individual and their families • Suggested that there had been little decision related to choice and individualisation – the focus on transition and involvement • Transition is seem as one of moving from one organisational setting to another • Seen as a *'time of anxiety'* (p.160)	• Highlighted the importance of seeing young people and parents as individuals and the role of individual planning using a person-centred approach.	**Having a structure:** - Having to *'interact with a vertical structures of the more powerful'* (p.160) and horizontal structures when interacting with users for example **Support arrangements:** - Focus not on the individual young person but on the young person and family ('*transition appears to include negotiating as a family unit rather than separating it out' p.160)* **Active decision-making:** - Focus of interest in young people with LD are involved in decision-making and the effect on young people as a results **Continuity of provision:** - Concern raised regarding translating Government policy related to continuity of care
Smart, M. (2004)	Quantitative survey of parents and young people with learning	• Young people had difficulties with the transition process	• Lack of use of person-centred planning	**Active decision-making:** - Parents involved in planning, but

	disabilities of their experience of the transition process. Parent perception of adult placements, parental and young person's involvement in the planning process, post placement breakdown Small sample of 17 parents of young people with SLD	• Many parents happy with eventual placements • Highlighted the need to work together to 'ensure that the transition process is effective' (p.128) • Placement breakdown associated with consistency of approach and information sharing • Differing opinions between parents and placing authority • Health transitions problematic	• For some young people independence was discouraged, others boundaries were in place, highlighted that the individual needs of young people need to be considered and having their own plan • Reports of less planning post 14+ Annual Review • Lack of follow up post 19 • Parents acting as advocates	struggled with consistency and obtaining basic information - Young people not being involved in decision-making, they felt *'marginalised in the planning process'* (p.128) - Transition culture puts young person's *'autonomy and independence above partnership with parents'* (p.134) **Continuity of provision:** - Various levels and different agencies involved, worries about the future and withdrawal of services **Supportive arrangements:** - Key workers involved with some families providing practical support. Parents felt more supported with their concerns, without key worker highlighted *'parental stress might be much worse'* (p.135)
Tan, M.J. and V.J. Klimack (2004)	Prospective study with 8 families which evaluated the use of portfolios (health advice and the communication of information) when transferring to adult health care	• Found the use of portfolios useful but families would have preferred more involvement in the content of their child's portfolio • Suggests that although there had been some progress in co-orientating transfer in a smooth manner within a 10 year period it remained a challenge and there were many shortfalls	• Highlighted the lack of engagement of social services and education in the study due to the non-availability of resources to have a holistic portfolio • Need for large-scale studies to develop transitional health care provision and funding	**Continuity of provision:** - Emphasised the transition from paediatrics to adult health as *'fraught'* (p.291) having previously had co-ordinated support and input to the age of 18. There was a need for a co-ordinated approach into adulthood
Tisdall, K. (1994)	Study of citizenship as a concept	• Advocated looking for transition goals; successful goals • Critical of psycho-social	• No criteria identified for a successful transition • Seen as *'needy'*	**Active decision-making:** - Young people has little control - Lack of involvement of young

		approaches and models that see young people as adolescents – sees it a individualistic • Lack of consensus as to what constitutes a successful transition • Advocated a young person-centred system	• Promotes a model passed upon citizenship by listening to young people and their needs	people - Considered young disabled people have been largely ignored
Townsley, R. (2004)	Literature review of available material related to the information needs of young people with learning difficulties and their families	• Sets the context and identifies it as a difficult time for young people and their families and the changes that will happen e.g. status and relationships • Shift in legal status for young people, but also changes to them physically and socially (p.9) • Varied way to conceptualise transition: focus on success identifying a successful transition and other on *'socially determined 'markers' of adult status'* (p.4) • Leaving school only one aspect of transitioning into adulthood • Highlighted that transition is a process not based upon a succession of events	• Few examples of young people being asked about their understanding of what I meant by transition. • Poor handovers from paediatric services • Use of person-centred planning and having personalised options • Leaving home and *'getting a place of one's own is often a transition that is fast becoming difficult to achieve for all young people often needing a lot of parental support'* (p.25) • Confusion about what services provide • Parents seen as *'the single most important factor in successful transition'* (p.44)	**Continuity of care:** - Need for seamless provision - Not automatic transfer to adult social care provision (assessment based). Health transfers difficult and policy to promote transitional arrangements not adhered to - Lack of appropriate options **Supportive arrangements:** - Lack of 1:1 support a barrier - Supporting young people with their feelings and emotional health **Active decision-making:** - Young people require support to make choices, the idea of choice can be unclear (p.27) - Clear information required
Ward et al. (2003)	Paper from the Heslop et al. (2002) Study	• Importance of planning and young people having choice	• Few transition plans in place to prevent a disjointed transition • Provides a suggestion as to what should be in a transition plan beyond	**Planning well:** Lack of planning and in some cases no planning was reported
Watson et al. (2011)	Scoping/systematic review focusing on the transition of young people with 3 conditions (C. Palsy, Diabetes and ASC) using 10 transition categories and	• Limited evidence of models of transitional service provision and none for young people with ASC • Lack of evidence to inform practice	• Transition of young people with complex heath needs seen as difficult • Some services recognised the need for flexibility	**Support arrangements:** - Highlighted the reliance on having *'single transition champions'* (p.786) to take forward implementation

	4 elements of Normalisation Process Theory	• Little service evaluation undertaken • Stressed that whilst policy existed there was a lack of evidence related to how to develop and evaluate transitional health care provision • No published validated measures of transition identified or agreed processes hindered model comparisons	• Reliance on one staff member limits sustainability	
Welsh Government (2012)	Cost benefit analysis of Transition Key Working (5 pilot sites)	• Emphasised that transition is a difficult time for young people for young people but particularly for those with a disability • Have multiple transitions • Sets the pilots in the context of Welsh policy	• Transition Key Working provided benefit to most young people (emotional and practical support) • Improved experience in transition from school to college and from school/college into adult life more generally • Better information available • Managing change more effectively • Adopting a person-centred approach helpful (what young people wanted from life), but choice limited • Being proactive to identify opportunities and activities	**Continuity of provision:** - Change in services; supporting young people and families through change, but also empowering them **Planning well:** - Working co-operatively to plan
Wood, D. and Trickey, S. (1996)	Examined the implications of the SEN Code of Practice on the transition process and the Annual Review at 14	• The Code of Practice was seen as a major review of transitional arrangements for young people with SEN (England and Wales) since the 1981 Education Act. Focus on developing a young person's Transition Plan (14-19) including the need to look not only at education but for example leisure. Age-related transition:	• Failure to form the transition process had the potential for it to be a *'paper exercise which benefits no-one'* (p.124) • Process is depicted as one that will *'never be easy'* (p.124) – no cultural rites of passage between child and adulthood. *'adult status a loose concept'* • Preparation and active	**Active decision-making:** - Young person's ownership of their own plan **Having a structure:** - Procedures dominate processes **Continuity of provision:** - Co-operation and liaison

		young people with SEN mature at differing rates	participation through the process to shape a young person's future	

APPENDIX SIX

DATA EXTRACTION TOOL 4: TRANSITION PROTOCOL/PATHWAY EXTRACTION OF 26 EXAMPLES

ID/date of protocol	multi-agency	aims/objectives/purpose	vision/principles	definition(s)	roles/responsibilities	pan disability	eligibility criteria	involvement of stakeholders	organisational decision-making	pathway process	key/transition worker	person centred approach	transition plan information	legislative context	outcomes identified	how to plan identified	age range	✓ yes	x no	* partially/ somewwhat
TP01 (2007)	*	*	✓	x	✓	x	x	x	x	✓	x	*	*	✓	*	*	x	14-19	4	7	6
TP02 (2009)	✓	*	✓	x	*	✓	*	x	*	✓	✓	*	*	✓	x	x	x	14-25	6	5	6
TP03 (2009)	x	x	x	x	✓	*	*	x	*	✓	*	*	*	✓	✓	✓	x	13-25	5	6	6
TP04 (2011)	x	✓	x	*	✓	✓	*	x	x	✓	x	*	x	x	✓	x	x	14-25	5	9	3
TP05 (2010)	✓	✓	*	x	✓	✓	*	*	✓	*	✓	✓	*	✓	✓	x	x	14-25	9	3	5
TP06 (2009)	*	✓	*	✓	✓	✓	✓	✓	*	✓	✓	✓	✓	✓	x	x	x	14-19	11	3	3
TP07 (2011)	✓	✓	✓	✓	*	✓	✓	✓	✓	✓	x	✓	*	✓	*	✓	*	14-25	12	1	4
TP08 (2011)	*	*	x	✓	✓	x	x	✓	x	✓	x	*	*	✓	x	x	*	14-19	5	7	5
TP09 (2011)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	*	*	✓	✓	x	x	14-25	12	3	2
TP10 (2007)	*	✓	✓	✓	*	x	*	✓	*	✓	*	*	*	✓	✓	✓	x	14-19	8	2	7
TP11 (2010)	✓	*	✓	✓	✓	*	*	✓	✓	x	x	x	x	✓	✓	✓	x	14-19	9	5	3
TP12 (2004)	*	*	x	x	*	x	✓	*	x	*	*	x	x	x	x	x	x	13-17	1	6	10
TP13 (2011)	*	✓	✓	x	✓	✓	*	✓	x	✓	*	x	x	✓	x	x	x	14-19	7	7	3
TP14 (not dated)	✓	*	✓	✓	✓	*	✓	*	*	✓	x	x	*	✓	x	x	x	14-19	7	5	5
TP15 (2008)	✓	*	✓	*	✓	✓	*	✓	x	✓	✓	x	*	✓	✓	x	x	14-19	9	4	4
TP16 (2010)	*	✓	✓	x	x	x	✓	x	x	*	x	x	x	x	x	✓	x	14-16	4	11	2
TP17 (not dated)	✓	✓	x	✓	*	✓	✓	*	x	✓	x	x	x	*	✓	*	x	14-19	7	6	4
TP18 (2009)	x	*	x	*	✓	✓	✓	*	✓	✓	*	*	✓	✓	x	x	x	14-25	7	5	5
TP19 (2007)	✓	*	*	x	✓	✓	✓	✓	x	✓	x	x	x	✓	✓	*	x	14-25	8	6	3
TP20 (not dated)	✓	*	✓	*	✓	✓	✓	x	x	*	✓	*	x	✓	x	✓	x	14-25	8	5	4
TP21 (2011)	*	✓	✓	✓	✓	✓	✓	*	*	x	x	x	x	x	✓	✓	x	14-25	8	6	3
TP22 (2009)	*	✓	✓	x	✓	✓	*	✓	*	✓	*	✓	*	✓	x	✓	x	14-19	9	3	5
TP23 (2008)	✓	✓	✓	x	✓	✓	✓	*	✓	✓	*	✓	x	x	✓	x	x	13-25	10	5	2
TP24 (2012)	✓	✓	✓	✓	*	✓	✓	*	✓	✓	✓	x	✓	✓	x	x	x	14-25	11	2	4
TP25 (2008)	x	x	✓	x	✓	*	✓	*	*	*	*	*	*	✓	✓	x	x	13-25	5	5	7
TP26 (2008)	✓	✓	x	x	✓	✓	*	✓	x	✓	x	x	x	*	*	x	x	14-21	6	8	3
Yes	13	14	16	10	19	17	14	11	7	19	6	5	3	19	12	8	0				
No	4	2	7	12	1	5	2	6	11	2	12	11	11	5	11	15	24				
partially somewhat	9	10	3	4	6	3	10	9	8	5	8	10	12	2	3	3	2				

18 Criterions

APPENDIX SEVEN

DATA EXTRACTION TOOL 4: TRANSITION PROTOCOL/PATHWAY INDIVIDUAL EXTRACTION TOOL

<table>
<tr><td colspan="3">Title: TP04
- in essence for young people with a learning disability rather than generically across difficulties/SEN/AN/other conditions
- opening gambit describes protocol as multi-agency the focus is largely on responsibilities of social services (children and adult)</td></tr>
<tr><td>Examine:</td><td colspan="2">Evidence:</td></tr>
<tr><td>Main programme theories of the Protocol
- Vision statement</td><td colspan="2">‘Multi-agency transition on into adulthood protocol and pathway is for all young people with LLD, their families and any professional involved in transition’.
Despite the claim get no real sense of the young person themselves given the process is theirs</td></tr>
<tr><td>Why developed:
• From multi-agency perspective
• Involvement of stakeholders in the development</td><td colspan="2">Yes, however quite specific in mentioning the role of Connexions, yet little mention of health involvement apart from individual practitioner roles such as LD nurse.
Unsure regarding the involvement of young people and parents</td></tr>
<tr><td>Main properties:
Relevance to the 4 P’s and potential CMO’s</td><td colspan="2">14-25 years of age. Purports to be for disabled young people which infers pan disability but is largely focused on young people with LD.
Provides the legislative context and identifies drawing upon the policy that ‘it makes it clear that young people and their families should play a central role, with planning early and with agencies working together’
Person centred approach mentioned but no detail as to how that happens.</td></tr>
<tr><td>Approaches used:
• Person centred
• Key worker</td><td colspan="2">• Takes the usual format approach of other protocols/pathways
• Identifies role of person centred planning facilitator
• Identifies what it’s considered to be what a good transition should look like, but does not give example of what a person centred transition plan should look like. Provides more than most protocols related to person centred planning approach. Use of PCT tools and other multi-media resources.
• Confusing as to who co-ordinates. Mentions Connexion employee as a lead professional at Yr. 9 review in the pathway(Connexions does not now exist in the same format) to co-ordinate plan development
• Gives the impression of too many roles – confusing/possible duplication of effort?</td></tr>
<tr><td rowspan="2">Type of Pathway and stages:</td><td colspan="2">• Usual staged process as others, however provides 2 pathways
- One more multi-agency the other specific to social care and identifies within the main text the 2</td></tr>
<tr><td>1: for young people who will not require long-term adult social care and Connexions taking more of a lead</td><td>2: for young people who will require long-term adult social care support and the Futures Team (a transition team – children and adult social care) involvement
Pathway for the most complex.</td></tr>
<tr><td>How used/implemented:
- Monitoring, review, evaluation
- Efficacy
- Outcomes identified
- Transition plan development</td><td colspan="2">- Provides governance arrangements, defines the role of a joint Transition Board at 2 levels (strategic and operational). Strategic to oversee future planning and commissioning to ensure seamless provision, overseeing the monitoring and review of only the protocol/pathway identified. Aims to facilitate progress where it is difficult or may be difficult to achieve.
- Highlights need for a realistic partnership to take forward the transition process and for partners to take responsibility for the part they have agreed to play.
- Transition Board is tasked to oversee transition plans and associated arrangements and receives information related to outcomes but does not define any tangible outcomes or what is expected in terms of achievement.
- No mention of how a plan is developed. No detail. Mentions developing a person centred plan but again no detail. Mentions a LD Nurse drawing up a young person’s Health Plan which doesn’t appear to be subsumed into the PC Plan mentioned. Describes briefly in the pathway the timeline, who will undertake, what activity, by when, agreement reached how the plan will be monitored and updated</td></tr>
<tr><td>Challenges/Barriers:</td><td colspan="2">LD focus and not pan disability. How the 2 pathways function or interact. Eligibility.</td></tr>
<tr><td>Outcomes:
- For young people
- Parents
- Professionals
- Agencies</td><td colspan="2">Mentions the involvement of young people and families but not how and to what level or extent.

Highlights ‘ will enable them to take their place as adult citizens where their contribution to their local community is valued’</td></tr>
</table>

APPENDIX EIGHT
RAMESES PUBLICATION STANDARDS FOR REALIST SYNTHESIS

Item	Description	Explanation/rationale
1.	Title	The title needs to be easily identifiable as a realist synthesis or review to aid retrieval.
2.	Abstract	In a style suitable to for specific journals.
3.	Introduction: Rationale for review	Why the review is needed and contribution to existing understanding of the area of study.
4.	Introduction: Objectives and focus of the review	Define and set out the rationale for the focus of the review and the objectives including the research question
5.	Methods: Changes in the review process	Describe and justify changes to the review process
6.	Methods: Rationale for using realist synthesis	Set out the reason for using realist synthesis as the most appropriate method to explore topic area.
7.	Scoping the literature	Describe and justify the initial scoping process of the literature
8.	Searching process	Rationale for how an iterative search was undertaken, sources (e.g. databases), search terms, dates, coverage. How identified and selected.
9.	Selection and appraisal of documents	Inclusion and exclusion of data and the justification. Appraise for rigour and relevance.
10.	Data extraction	Describe and explain data extracted and justify selection. Likely to provide descriptions of how and why a programme works in particular circumstances.
11.	Analysis and synthesis processes	Describe analysis and synthesis: construct analysed and description of the analytic process. Candidate programme theory derived. Identify the generative explanation for causation i.e. the patterns (demi-regularities) CMOc's. Programme theory building/refined.
12.	Results Section: Document flow diagram	Show number of documents and where documents were excluded and the steps to final the final documents included.
13.	Results Section: Document characteristics	Describe the features of the included documents.
14.	Main Findings	Findings presented with a specific focus on theory building and testing
15.	Discussion Section: Summary of findings	Main findings summarised taking into account the objectives of the review, research question, focus and intended audience.
16.	Discussion Section:	Strengths and limitations discussed, taking into

	Strengths, limitations and future research	account all the steps of the review,
17.	Discussion section: Comparison with existing literature	Compare and contrast review findings within the context of existing literature.
18.	Conclusion and recommendations	Set out the main implications of the main findings within the context of other relevant literature. Provide recommendations for policy and practice
19.	Funding	State funding source if applicable and the role of the funder(s) and conflicts of interest of any reviewers in the research

Wong et al. (2014)

APPENDIX NINE
YOUNG PERSON'S INTERVIEW SCHEDULE

SEMI-STRUCTURED INTERVIEW SCHEDULE FOR YOUNG PEOPLE

This document sets out to provide a broad outline of the semi structured interview schedule to be used with young people and will be adapted to suit the needs of each young person's communication style. It will cover for example aspects related to preparing for adulthood, the role of their Transition Key Worker (or an identified professional) in supporting them, their experiences of developing their Transition Plan and what hopes they have for the future.

The interview will last approximately 90 minutes (with a 15 minute break built into the allotted time) and will take place in an environment most comfortable to the interviewee. The interviewee will have given prior consent the interview being taped recorded. Thank you for agreeing to being interviewed as part of the Moving on Together evaluation.

Topics

- **Preparing for adult life**
- **Involvement and participation in Transition Planning**
- **The role of the Transition Key Worker (or if a comparator site – who is involved in supporting you through transition into adulthood)**
- **Well being**
- **The future**
- **Other issues, concerns or goals which you consider to be important to you in achieving the best possible outcomes as you become an adult, which have not been covered during the interview?**

Thank you again for agreeing to be interviewed and given up some of your time. I hope you found it valuable. All information discussed will remain confidential and will be anonymised.

What happens next?
A number of young people, parents and Transition Key Workers are being interviewed over a number of weeks. The taped interviews will be transcribed from the recording and notes taken during the interview. The information from the interviews will be gathered together and analysed. Once complete feedback will be provided to all those interviewed on the findings.
Would you be interested in receiving a copy?

Is there anything else you would like to ask further about the evaluation or anything you are not sure about?

End of interview

APPENDIX TEN
PARENT INTERVIEW SCHEDULE

SEMI-STRUCTURED INTERVIEW SCHEDULE FOR PARENTS/CARERS

This document sets out to provide an outline of the semi structured interview schedule to be used with parents/carers. It will cover aspects related to preparing their child for adulthood, transition planning, the role of the Transition Key Worker and the parent/carer involvement in supporting their child through adolescence into adulthood.

The interview will last approximately 60-90 minutes and will take place in an environment most comfortable to the interviewee. The interviewee will have given prior consent the interview being taped recorded.

Thank you for agreeing to being interviewed as part of the Moving on Together evaluation.

Topics for discussion (with prompts):

- **Parent experience in preparing their child for adult life pre Transition Key Worker involvement:**
  - What is your understanding of what is meant by 'transition into adulthood?
  - What was your experience of attending your child's year 9 (age 14) (Transition) Annual Review?
  - Do you feel you were well prepared prior to the (Transition) Annual Review meeting so you could openly discuss what options were available to your child?
  - What support did you receive post the review meeting?
  - What contact have you had with adult service providers or post 16 education providers? Did a representative from adult services attend your child's Year 9 (Transition) Annual Review?
- **Involvement and participation in Transition Planning:**
  - What opportunities have you had to discuss your child's needs, wishes and aspirations?
  - Do you feel that your child understands what options are available to them?
  - What level of involvement have you had in developing your child's Transition Plan?
  - Was the plan developed in a person centred way, using person centred thinking tools?
  - Is the Transition Plan reviewed regularly or at least on an annual basis?

- Have you been able to participate throughout your child's adolescence in any decision-making which could affect your child's future? If not, was there a reason for you being not part of the discussions?
- What improvements could be made to the transition planning process to enable you to fully participate?

- **The role of the Transition Key Worker (or if a comparator site – who is involved in supporting the child through transition into adulthood):**
  - How long has your child had the support of a Transition Key Worker?
  - Has the role been explained, if so what role do you think they have?
  - What role has the Transition Key Worker had in supporting your child?
  - What do you think has been the impact of this support?
  - What contact have you had with the Transition Key Worker, how regularly?
  - What role do you think person centred planning has had in identifying your child's needs or requirements? Has it helped to identify what is important to and important for them?
  - How involved was the Transition Key Worker in supporting your child to develop their Transition Plan?
  - Do you feel, as a result of developing and agreeing your child's Transition Plan, that it clearly addressed your child's needs and that actions agreed where undertaken by those named individuals?
- **Well-being:**
  - Do you feel your own health and well-being has been affected caring for and supporting your child through the transitional years?
  - What impact do you think it will have on you as a main carer once your child becomes an adult?
- **The future:**
  - How confident do you feel about your child's future?
  - How confident are you in being able to continue to support your child once he/she is an adult?
  - Do you feel you and your child have been well prepared for the future?
  - What do you think have been the key benefits of developing a Transition Plan for your son/daughter? What have been the important elements?
  - Do you feel that the actions agreed have been instigated in the agreed timescales?
  - Do you know if your son/daughter will continue to have the support of a Transition Key Worker post funding (or support of a named professional in the future)?
  - What were the outcomes of your son/daughter's Transition Plan?
- **Other issues, concerns or goals which you consider to be important in your child achieving the best possible outcomes in adult life which have not been covered during the interview?**

Thank you again for agreeing to be interviewed and given up some of your time. All information discussed will remain confidential and will be anonymised.

- **What happens next?**
  - A number of parents, as well as young people and Transition Key Workers are being interviewed over a number of weeks. The taped interviews will be transcribed from the recording and notes taken during the interview. The information from the interviews will be collated and analysed. Once complete feedback will be provided to all those interviewed on the findings.
  - Would you be interested in receiving a copy?

- **Is there anything else you would like to ask further about the evaluation or anything you are not sure about?**

End of interview

APPENDIX ELEVEN
TRANSITION KEY WORKER INTERVIEW SCHEDULE

This document sets out to provide an outline of the semi structured interview schedule to be used with a Transition Key Worker. It will cover aspects for example related to their role, the recruitment and interview process experienced, training received, their understanding of transition planning and person centred approaches to elicit information on what is important for and what is important to the young people they are supporting.

The interview will last approximately 60-90 minutes and will take place in an environment most comfortable to the interviewee. The interviewee will have given prior consent the interview being taped recorded.

Thank you for agreeing to being interviewed as part of the Moving on Together evaluation.

Topics for discussion:

1. General information:

1.1 How long have you been a Transition Key Worker?

1.2 Are you a designated (solely your role) or a non-designated? Transition Key Worker (an addition to your professional role)?

1.3 What is your professional background?

1.4 How many young people are you supporting or have supported? What contact arrangements do you have? What do you think the impact has been?

1.5 Please describe the main difficulties or disabilities of the young people you support? Have there been any challenges in engaging with those young people and their parents and if so what? How have you approached parental involvement?

1.6 Prior to your employment did you have any knowledge of key working? What is your understanding now of what key working means? Could you describe? Is there anything you would wish to change?

1.7 What is your understanding of what is meant by 'transition into adulthood?

2. Recruitment, interview process, training and supervision:

2.1 Please could you describe your experience of the recruitment process? (How you came to know about it)? Was the job description and personal specification clear as to what the role of the Transition Key Worker entailed? Can you describe the key features? Was it as you expected?

2.2 Could you please describe your experience of the interview process, what did it involve?

2.3 Were young people and or their parents involved in the interview panel? If yes what role did they play?

2.4 Since taking up your post what training have you received to enable you to carry out your role? (e.g. person centred planning training, Transition Key Worker training, Child Protection)?
2.5 What kind of supervision arrangements are provided to you? Who carries it out? How often? What does it involve?
2.6 Please describe what you feel are your strengths and skills which you bring to the role?

3. Involvement and participation in Transition Planning:

3.1 Do you feel that the young people you are supporting understand what is meant by transition into adulthood? How well do parents understand the process?
3.2 Have you worked with the young people you are supporting to prepare them for their annual reviews, especially their year 9 (Transition) Annual Review? Was the review person centred?
3.3 What level of involvement have you had in supporting young people to develop their Transition Plan? How often is it reviewed? Do you co-ordinate it?
3.4 What role do you think person centred planning has had in identifying young people's needs or requirements? Has it helped to identify what is important to and important for them? Are the young people you support aware of the choices available to them?
3.5 Have parents been able to engage with the transitional process? What have been the challenges? What concerns do they have or not (ie parental letting go and enabling young people to make their own decisions has been shown to be a problem)?
3.6 Do you feel, as the result of developing and agreeing a young person's Transition Plan, that it clearly addressed their needs and that actions agreed were undertaken by those named individuals?
3.7 What challenges do the young people face in your local authority area?
3.8 What improvements could be made to the transition planning process in your local authority area? Are there any potential challenges? Could you describe example of good practice in transition?
3.9 Do you actively use a transition protocol/pathway as the basis for guiding a young person through transition into adulthood? Can you describe it?

4. Working with others:

4.1 How well to you think your role has been accepted by other professionals you are working with?
4.2 How well able are you to co-ordinate services and support for young people?
4.3 Are there multi-agency fora you can attend to update others on your role in developing Transition Key Working?
4.4 Are there barriers to you successfully key working with young people?
4.5 What is your relationship with other adult service agencies? When are they engaging with you as a Transition Key Worker or accepting referrals (consider eligibility criteria)?

5. Well-being:

5.1 Do you feel your own health and well-being has been affected by supporting young people through transition into adulthood? If so how have they been overcome?

5.2 Are there any other issues which affect you carrying out your role? What have been the main challenges? How have you overcome them?

6. The future:

6.1 How confident do you feel about moving forward as a Transition Key Worker or named professional providing transition support?

6.2 Is there anything you would like to change, based on your experience so far?

6.3 Do you feel you are now and in the future be able to confidently prepare and support young people into adulthood?

6.4 Do you think the outcomes for the young people you have been supporting were as expected? Were their needs, wishes and aspirations met?

6.5 What do you think have been the key benefits of providing support to young people through transition into adulthood?

7. Are there any other issues, concerns or goals which you considered to be important in your child achieving the best possible outcomes in adult life which have not been covered during the interview?

Thank you again for agreeing to be interviewed and given up some of your time. All information discussed will remain confidential and will be anonymised.

8. What happens next?

A number of Transition Key Workers and other named professionals providing transition support, as well as young people and their parents are being interviewed over a number of weeks. The taped interviews will be transcribed and notes taken during the interview. The information from the interviews will be collated and analysed. Once complete feedback will be provided to all those interviewed on the findings.

Would you be interested in receiving a copy?

- **Is there anything else you would like to ask further about the evaluation or anything you are not sure about?**

End of interview

APPENDIX TWELVE

SITE LEADS INTERVIEW SCHEDULE

This document sets out to provide an outline of the semi structured interview schedule to be used with a Transition Key Worker site or a local authority providing a 'standard service' (non-funded comparator site). It will cover aspects for example related to the development of transition key working/developing transition services for disabled young people age 14-25, multi-agency structures, the recruitment and interview processes employed, training and supervision provided, assessments procedures applied, their understanding of transition planning and person centred approaches and their experience of using the Key Worker Standards Self Evaluation Tool.

The interview will last approximately 60-90 minutes and will take place in an environment most comfortable to the interviewees. The interview will be taped recorded. Prior consent will be sought.

Thank you for agreeing to being interviewed as part of the Moving on Together evaluation.

Topics for discussion:

- **Developing Transition Key Working/standard transition service:**
  - What is your understanding now of what key working means?
  - What is your understanding of what is meant by 'transition into adulthood?
  - Please explain your experiences of developing transition key working / *a transition service*?
  - Do you feel that you were provided with sufficient information or had sufficient knowledge of key working / *of transition* to develop a service? What support were you given?
  - Who was involved in developing the service?
  - Have you experienced any challenges in developing the service (key working or standard service)? If so, please describe, but also how these were overcome?
  - Do you feel that by providing a named Transition Key Worker has improved the outcomes for young people they are supporting? (funded sites)
  - Do you feel that, if you were able to, that by developing a Transition Key Worker service and providing a named Transition Key Worker to young people that there would be improved outcomes for all? (non-funded comparator sites)
- **Multi-agency structures:**
  - What organisational structures are in place to support the development of transition key working/*transition services* in your local authority area? Do they function well? If not, how do you feel this could be improved?

- What is the level of commitment of partner agencies to develop transition key working/*transition services*?
- Do you feel that current legislation and policy is well developed to support the development and delivery of robust transition services for young people in Wales?

- **Recruitment, interview process, training and supervision:**
  - Please could you describe the recruitment and interview process used to employ Transition Key Workers? (Designated Services) or Please describe the processes used to recruit non-designated Transition Key Workers/*choice of lead person (standard service)?*
  - Were young people and or their parents involved in the interview panel (Designated Service)?
  - Were person centred thinking processes used during the interview process? If so, could please describe? (Transition Key Worker Sites only)
  - Were young people involved in choosing their Transition Key Worker? (Both Designated/Non Designated)
  - Have you provided those supporting a young person through transition with training on the use of person centred tools? Are they familiar with person centred planning approaches?
  - What kind of supervision arrangements are you providing?
  - What training is provided to workers (Transition Key Workers and those providing support from non-funded sites)?
- **Assessment processes:**
  - What assessments are you currently using through transition
  - Is information captured within a young person's Transition Plan used to inform the Unified Assessment Process documentation?
  - How are you able to work through the varying eligibility criteria between services?
- **Understanding of transition planning and person centred approaches:**
  - Do you have an agreed Transition Plan and Transition Planning protocols in place? If so what do you feel are the key elements of both?
  - Do you feel that the young people you are supporting understand what is meant by transition into adulthood?
  - Do you actively enable workers to support young people at their Annual Reviews?
  - Are you a supporting young people to prepare them for their annual reviews, especially their year 9 (Transition) Annual Review?
  - What level of involvement is there to support a young person to develop their Transition Plan? Who is supporting them?
  - Are young peoples' plans being developed in a person centred way, using person centred thinking tools?
  - Are Transition Plans regularly reviewed, at least on an annual basis and who is involved in the review?

- What role do you think person centred planning has had in identifying young people's needs or requirements? Has it helped to identify what is important to and important for them?
- Do you feel, as a result of developing and agreeing a young person's Transition Plan, that it clearly addresses their needs and that actions agreed where undertaken by those named individuals?
- Do you have a process in place to evaluate the outcomes of the young people's Transition Plans?
- Are the young people you support aware of the choices available to them?
- What improvements could be made to the transition planning process in your local authority area? Are there any potential challenges?

- **The future (sustaining support):**
  - How confident do you feel about sustaining Transition Key Working post grant funding? (funded sites)
  - How confident do you feel about sustaining transition services in your local area? (non-funded sites)
  - What would you like to develop further in your local area?
  - If any, what are your main concerns/challenges?
  - Do you feel that young people have benefited from receiving a Transition Key Worker service?
  - What do you feel will be the implications of reduced funding?

- **Are there any other issues, concerns or goals which you considered to be important in achieving the best possible outcomes for young people as they prepare for adult life, which have not been covered during the interview?**

Thank you again for agreeing to be interviewed and given up some of your time. All information discussed will remain confidential and will be anonymised.

- **What happens next?**
  - All of the Transition Key Worker sites and non-funded sites are being interviewed, but also a number of young people and their parents and Transition Key Workers are being interviewed over a number of weeks to explore their experiences. The taped interviews will be transcribed and notes taken at the interview. The information from the interviews will be collated and analysed. Once complete feedback will be provided to all those interviewed on the findings.
  - Would you be interested in receiving a copy?
- **Is there anything else you would like to ask further about the evaluation or anything you are not sure about?**

End of interview

APPENDIX THIRTEEN

YOUNG PERSON'S INVITATION LETTER (SENT ON ONE SIDE OF A4)

Moving on Together
School of Healthcare Sciences
Bangor University
Fron Heulog
Ffriddoedd Road
Bangor
Gwynedd LL57 2EF
01978 753708
Email: hspa6e@bangor.ac.uk

Dear

Moving on Together: Evaluating the experiences, processes and outcomes for disabled young people receiving the support from a Transition Key Worker compared to standard service provision through transition into adulthood

I would like to invite you to take part in an interview as you have indicated on your consent form that you a happy to do so.

I would like to ask questions about your experiences and what you wish for the future as well as how you have been supported. The interview will last about 45 minutes to 1 hour.

If you are happy the interview will be recorded. After the interview the recording will be written up. The recording will not be kept.

I will contact you either by phone, email or letter as you have asked to be contacted by to arrange a time and place to meet you to carry out the interview. If you would like someone you know well to be with you we can arrange this, including your key worker X if you would like X to come along.

I look forward to meeting

Yours sincerely

Sally Rees
PhD research student /Director
Bangor University/CCN Cymru

APPENDIX FOURTEEN
PARENT INVITATION LETTER (SENT ON ONE SIDE OF A4)

Moving on Together
School of Healthcare Sciences
Bangor University
Fron Heulog
Ffriddoedd Road
Bangor
Gwynedd LL57 2EF
Email: hspa6e@bangor.ac.uk

Dear

Moving on Together: Evaluating the experiences, processes and outcomes for disabled young people receiving the support from a Transition Key Worker compared to standard service provision through transition into adulthood

I would like to invite you to take part in an individual semi structured interview. As part of the above mentioned evaluation you will have received a copy of the participant information booklet and completed a form giving your consent to take part, including being interviewed as part of the research. You will have also completed the baseline and follow up questionnaire.

The interview will cover subject matter related to preparing your child for adulthood, transition planning, the role of the Transition Key Worker or other professionals providing transitional support, your involvement in supporting your son or daughter through adolescence into adulthood, as well as aspects related to your health and well-being and future planning. The interview will last approximately 60 minutes and will take place in an environment most comfortable to you or if you would like the interview could take by telephone. The interview will be digitally recorded and will, in turn, be written up and then the recording will be deleted.

You will be contacted to arrange a time and place to meet you to carry out the interview.

I look forward to meeting you and hearing your experiences.

Yours sincerely

Sally Rees
PhD research student
Bangor University

APPENDIX FIFTEEN
TRANSITION KEY WORKER INVITATION LETTER (SENT ON ONE SIDE OF A4)

Moving on Together
School of Healthcare Sciences
Bangor University
Fron Heulog
Ffriddoedd Road
Bangor
Gwynedd LL57 2EF
Email: hspa6e@bangor.ac.uk

Dear

Moving on Together: Evaluating the experiences, processes and outcomes for disabled young people receiving the support from a Transition Key Worker compared to standard service provision through transition into adulthood

I would like to invite you to take part in an individual semi structured interview. As part of the above mentioned evaluation you will have received a copy of the participant information booklet and completed a form giving your consent to take part, including being interviewed as part of the research. You will have also completed the baseline questionnaire and have received or will receive the follow up questionnaire to complete by X.

The interview will cover subject matter related to your role, the recruitment and interview process you experienced, training received, your understanding of transition planning and person centred approaches to elicit information on what is important for and what is important to the young people you are supporting through transition into adulthood.

The interview will last approximately 60-90 minutes and will take place in an environment most comfortable to you. However, if you prefer the interview it could take place by arranging a telephone at a time suitable to yourself. The

interview will be digitally recorded and will, in turn, be transcribed. Upon completion of the transcription the recording will be deleted.

I will be contacting you shortly to arrange a time and place to meet you to carry out the interview.

I look forward to meeting you and hearing your experiences.

Yours sincerely

Sally Rees
PhD research student
Bangor University

APPENDIX SIXTEEN
SITE LEADS INVITATION LETTER (SENT ON ONE SIDE OF A4)

Moving on Together
School of Healthcare Sciences
Bangor University
Fron Heulog
Ffriddoedd Road
Bangor
Gwynedd LL57 2EF
Email: hspa6e@bangor.ac.uk

Dear

Moving on Together: Evaluating the experiences, processes and outcomes for disabled young people receiving the support from a Transition Key Worker compared to standard service provision through transition into adulthood

I would like to invite you as the project lead or manager of a transition service to take part in an individual semi structured interview. As part of the above mentioned evaluation you will have received a copy of the participant information booklet and completed a form giving your consent to take part, including being interviewed as part of the research. You will have also completed the baseline and follow up questionnaire.

The interview will cover subject matter related to the development of transition key working/developing transition services for disabled young people age 14-25 in your local authority areas, multi-agency structures, the processes employed to recruit and employ staff, training and supervision provided, assessments procedures applied, your understanding of transition planning and person centred approaches, your experience of using the Key Worker Standards Self Evaluation Tool to sustaining transition support to young people in the future.

The interview will last approximately 60-90 minutes and will take place in an environment most comfortable to you or if you prefer by telephone. The interview will be digitally recorded and will, in turn, be transcribed. Following transcription the recording will be deleted.

I will be contacting you shortly, as indicated on your consent form, to arrange a time and place to meet you to carry out the interview.

I look forward to meeting you and hearing your experiences.

Yours sincerely

Sally Rees
PhD research student
Bangor University

APPENDIX SEVENTEEN

INFORMATION BOOKLET: YOUNG PERSON

TRANSITION
MOVING ON TOGETHER

MOVING ON TOGETHER

Participant Information

YOUNG PERSON

An evaluation of Transition Key Working in Wales

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BANGOR
1884

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YOUNG PERSON'S INFORMATION

AN EVALUATION OF TRANSITION KEY WORKING IN WALES

Researcher: Sally Rees (PhD research student)

Invitation to take part and why you have been chosen:

As a young person, who will be 14 to 25 years of age and is being supported by a Transition Key Worker or by another professional you are being asked to take part in an evaluation about the support you receive

It is important for you to understand why the evaluation is taking place and what role you will have and what taking part means for you.

Take time to read this booklet. If you are not sure about taking part speak to the researcher or to your Transition Key Worker

How long will the evaluation last?

This evaluation of Transition Key Working in Wales will take place over three years. It will start in X date and will end in X date.

What is the purpose of this evaluation?

This evaluation aims to:

- Gather your experiences of having the support of a Transition Key Worker or the support of another professional through transition, as well as asking for the views your parents and those providing support to young people from age 14 through the teenage years into adulthood.

What does the evaluation involve?

Completing a questionnaire twice during this evaluation (baseline questionnaire attached to this booklet)

Times when you will be asked to complete a questionnaire:

Baseline questionnaire: commencing X date return Y date

Follow up questionnaire: commencing X date return Y date

The baseline and follow up will be given to you by your Transition Key Worker or another professional or sent to you directly.

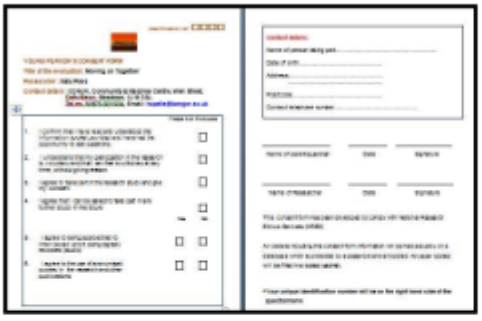
You may also be asked to take part in an interview with the researcher

You will receive information on the progress of this evaluation

Do I have to take part?

Taking part is up to you. If the answer is yes complete the attached consent forms.

You can decide to pull out at any time without notice.



Consent form:

On the consent form you will have been given a unique identification code number, which you need to quote on each questionnaire in the boxes provided.

ID code (e.g.): ☐☐☐☐

In giving a code to the information received this will ensure that any information will remain unidentified

You will be able to keep a copy of the consent form for your information, returning one to the researcher, together with the completed baseline questionnaire.

What will happen to the information I provide (questionnaire and individual interview)?

The information you provide (e.g. questionnaire) will collected and collated and will be inputted into a computer software programme which will then be studied.

If you take part in an interview all recorded speech or other information taken will be written down word for word into a Microsoft Word document. This will also be unidentifiable.

Any findings will be reported in the researcher's final PhD thesis (the evaluation report).

What are the possible disadvantages and risks of taking part?

There will **not** be any disadvantages or risks to you in taking part in the evaluation.

What are the possible benefits of taking part?

The information that you provide will be very valuable and will used to help improve transition key working and transition services for young people with additional learning needs and or complex health care needs in the future.

Will my taking part in this evaluation be kept confidential?

All information given will be kept confidential. Information will only be disclosed (letting people know) for the purpose of protecting a child or young person, family member or individual. Standard safeguarding procedures will be followed. The researcher has a Criminal Records Bureau Disclosure (CRB check).

All information received from any young person taking part in this evaluation will be kept protected on a computer. All paper based information will be kept in a locked cupboard. Your personal details will not be used at anytime during the evaluation

What will happen to the results of the evaluation?

An evaluation document (a thesis) will be produced. This may be followed by information being published, for example in other journals or used, where relevant in a seminar or conference presentation format. Any findings will be available to those taking part.

Who is responsible for the evaluation?

Sally Rees is the named PhD research student (Bangor University) responsible for the evaluation. Sally is the Wales Manager for the Care Co-ordination Network UK (CCNUK) and is responsible for developing transition key working in Wales. She is also the parent of two young people with an Autistic Spectrum Disorder. As PhD student at Bangor University she will be jointly supervised by Professor Jane Noyes (Noreen Edwards Chair in Nursing Research), Centre for Health-Related Research, School of Healthcare Sciences and Professor Richard Hastings, School of Psychology at Bangor University to ensure the research is carried out properly.

Who is funding the PhD researcher?

Sally Rees is funded to undertake her PhD by Bangor University.

Who has reviewed the evaluation?

As this is an evaluation involving young people and their parents the study has been reviewed by the School of Psychology's Ethics Committee following a submission to carry out the evaluation. The study has received the Committee's approval X date.

What should I do if I have any concerns the evaluation?

If you have any concerns about t the evaluation at any stage, please contact Mr Malcolm Godwin, Acting Head of School (Healthcare Sciences), Bangor University (01248 383117)

What do I do now to agree to take part?

You have now read this booklet and you are asked to take the following steps (if you need some help with this ask your parent, your Transition Key Worker or a professional who supports you the most)

1. Complete the two consent forms
2. Complete the questionnaire (ensuring that you have put your unique identification number in the boxes shown in Section 1 on page 4 of the questionnaire)
3. Return the complete questionnaire and one of the signed consent forms in the freepost envelope provided

Contact for further information:

Please do not hesitate to contact the researcher if you would like further information:

Sally Rees
Moving on Together
School of Healthcare Sciences,
Bangor University
Fron Heulog,
Bangor,
Gwynedd,
LL57 2EF
Email: hspa6e@bangor.ac.uk

Thank you for taking time to read this participant information booklet and agreeing to take part.

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APPENDIX EIGHTEEN
INFORMATION BOOKLET: PARENT

TRANSITION
MOVING ON TOGETHER

MOVING ON TOGETHER

Participant Information

PARENT/GUARDIAN

An evaluation of Transition Key Working in Wales

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BANGOR
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PARENT/GUARDIAN INFORMATION

AN EVALUATION OF TRANSITION KEY WORKING IN WALES

EVALUATION LEAD: Sally Rees (PhD research student)

Invitation to take part and why you have been chosen:

As a parent/carer identified as the person with responsibility for a young person aged 14 to 25, who is receiving a service funded from the European Social Fund Reaching the Heights: First Footholds grant programme, you are being asked to take part in this evaluation (details outlined in this booklet).

Your son or daughter may have been receiving the support of a Transition Key Worker, which has been funded through a grant from the Welsh Assembly Government to develop transition key working across 5 pilot sites in Wales or alternatively your son or daughter is receiving the support from a named professional within a local authority area providing a transition service.

It is important for you to understand why this evaluation is taking place and what role you will have and what taking part involves.

It is also important for you to take time to carefully read the following information contained within this Participant Information Booklet. If you wish to discuss your involvement or would like to seek further information, please contact the researcher whose contact details are outlined at the end of this booklet.

Duration of the evaluation:

This evaluation of Transition Key Working in Wales will take place over three years. The data collection will commence in X date and will end in Y date. The evaluation document (a PhD thesis) will then be developed.

What is the purpose of this evaluation?

This evaluation aims to:

- explore the disabled young persons' and their parents'/carers' experiences of the key worker model through transition into adulthood
- evaluate the outcomes of the key worker model by comparing with standard transition services
- investigate the possible differentiation in outcomes between the designated and non designated key worker model(s)

What does the evaluation involve?

- completing a questionnaire twice during the evaluation (baseline questionnaire attached to this booklet):

Data collection points:

Baseline questionnaire: commencing X date Return Y date

Follow up questionnaire: commencing X date Return Y date

The baseline and follow up will be either given to you by a Transition Key Worker or named professional providing transitional support or sent to you by the researcher.

The researcher will discuss with you which aspects of the evaluation that apply to you. Your involvement may also evolve as the evaluation progresses and you may be asked to take part in an interview with the researcher commencing in X date. You will receive feedback on the progress of the evaluation.

Do I have to take part?

Your participation in the evaluation is voluntary. However, it is important, as part of the study, to gain the views and experiences of parents or the young person's named guardian. It will be entirely up to you to decide if you would like to take part. If you decide to take part you will be asked to complete the attached consent forms. On the consent form will be a unique identification code number which you need to quote on each questionnaire in the boxes provided or in any other correspondence. You will be able to keep a copy of the consent form for your information, returning one to the researcher together with the completed baseline questionnaire. You can at any time during the lifetime of the study decide not to continue to take part.

What will happen to the information I provide (questionnaire and individual interview)?

The information you provide (e.g. questionnaire) will be collected and collated and will be inputted into a data collection software programme. You may be asked to take part in an interviewing commencing X date. Any taped interviews or other information collected during an interview will be transcribed word for word into a Microsoft Word document. **All information received from you will be coded using your identification code number and then analysed. In giving a code to the information this will ensure that it will be anonymised.**

Any findings will be reported in the researcher's final PhD thesis.

What are the possible disadvantages and risks of taking part?

It is not foreseen that there will be any disadvantages or risks to you or your son or daughter in taking part in this evaluation.

What are the possible benefits of taking part?

The information that you provide will be extremely valuable and will used to shape practice with regard to Transition Key Working and transition service development and delivery, and will be used to identify the essential components of a successful transition into adulthood for young people with additional learning needs and or complex health care needs.

Will my taking part in this evaluation be kept confidential?

All information collected as part of this evaluation will be kept strictly confidential (unless anything is discussed or observed which may raise serious concerns about the safety of a child, young person, family member or professional). Information will only be disclosed for the purpose of protecting a child or young person, family member or individual and standard safeguarding procedures will be followed. The researcher has a current Enhanced Criminal Records Bureau Disclosure.

All information received from any person taking part in the evaluation will be kept on an encrypted and password protected computer and all hard paper copies including original completed questionnaire's, transcriptions of meetings and taped recordings will kept in a locked cupboard and will only be accessible to the researcher and a named administrator, who will also hold an Enhanced Criminal Records Bureau disclosure.

No individual names or details will be used in the final evaluation. Any information including quotations from individual interviews will not be

traceable to you or any other person taking part in the evaluation. All published and unpublished information will conceal the identity of individuals.

What will happen to the results of the evaluation?

A final evaluation document will be produced. This may be followed by publication in professional and academic journals, and delivered where appropriate in a seminar or conference presentation format.

Who is responsible for the evaluation?

Sally Rees is the named PhD research student (Bangor University) responsible for the evaluation. Sally is the Wales Manager for the Care Co-ordination Network UK (CCNUK) and is responsible for developing transition key working in Wales. She is also the parent of two young people with an Autistic Spectrum Disorder. As PhD student at Bangor University she will be jointly supervised by Professor Jane Noyes (Noreen Edwards Chair in Nursing Research), Centre for Health-Related Research, School of Healthcare Sciences and Professor Richard Hastings, School of Psychology at Bangor University.

Who is funding the PhD researcher?

Sally Rees is funded to undertake her PhD by Bangor University.

Who has reviewed the evaluation?

As this is an evaluation involving young people and their parents the study has been reviewed by the School of Psychology's Ethics Committee following a submission to carry out the evaluation. The study has received the Committee's approval X date.

What should I do if I have any concerns the evaluation?

If you have any concerns about taking part in the evaluation, please contact Mr. Malcolm Godwin, Acting Head of School (Healthcare Sciences), Bangor University (01248 383117).

What do I do now to agree to take part?

You have now read this Participant Information Booklet you are asked to take the following steps:

1. Complete the two consent forms (the forms shows your unique identification number)

2. Complete the questionnaire (ensuring that you have quoted your unique identification number in the boxes indicated in Section 1 on page 4 of the questionnaire)
3. Return the complete questionnaire and one of the signed consent forms in the Freepost envelope provided

Contact for further information:

Please do not hesitate to contact the researcher if you would like further information:

Sally Rees
Moving on Together
School of Healthcare Sciences,
Bangor University,
Fron Heulog,
Bangor,
Gwynedd,
LL57 2EF
Email: hspa6e@bangor.ac.uk

Thank you for taking time to read this participant information booklet and agreeing to take part.

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APPENDIX NINETEEN
INFORMATION BOOKLET: TRANSITION KEY WORKER

TRANSITION
MOVING ON TOGETHER

MOVING ON TOGETHER

Participant Information

TRANSITION KEY WORKER/TRANSITION SERVICE PROFESSSIONAL

An evaluation of Transition Key Working in Wales

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TRANSITION KEY WORKER/TRANSITION SERVICE PROFESSIONAL INFORMATION

AN EVALUATION OF TRANSITION KEY WORKING IN WALES

EVALUATION LEAD: Sally Rees (PhD research student)

Invitation to take part and why you have been chosen:

As a professional with responsibility for providing support as a named Transition Key Worker for a young person aged 14 to 25, who is receiving a service funded from the European Social Fund Reaching the Heights: First Footholds grant programme, you are being asked to take part in this evaluation (details outlined in this booklet).

The young person you are supporting may have been receiving a service which has been funded through a grant from the Welsh Assembly Government to develop transition key working across 5 pilot sites in Wales or alternatively is receiving the support from you as a named professional within a local authority area providing a transition service not funded via the aforementioned grant funding streams.

It is important for you to understand why this evaluation is taking place and what role you will have and what taking part involves.

It is also important for you to take time to carefully read the following information contained within this Participant Information Booklet. If you wish to discuss your involvement or would like further information about this evaluation, please contact the researcher whose contact details are outlined at the end of this booklet.

Duration of the evaluation:

This evaluation of Transition Key Working in Wales will take place over three years. The data collection will commence in X date and will end in X date. The evaluation document (a PhD thesis) will be then be developed.

What is the purpose of this evaluation?

This evaluation aims to:

- explore the disabled young persons' and their parents'/carers' experiences of the key worker model through transition into adulthood
- evaluate the outcomes of the key worker model by comparing with standard transition services
- investigate the possible differentiation in outcomes between the designated and non designated key worker model(s)

What does the evaluation involve?

- completing a questionnaire at twice during this evaluation (baseline questionnaire attached to this booklet):

Data collection points:

Baseline questionnaire: commencing X date return Y date

Follow up questionnaire: commencing X date return Y date

The baseline and follow up questionnaire will be either be distributed to you by your line manager or sent to you by the researcher where appropriate.

The researcher will discuss with you which aspects of this evaluation that apply to you. Your involvement may also evolve as the evaluation progresses and you may be asked to take part in an interview with the researcher commencing in X date. You will receive feedback on the progress of the evaluation.

Do I have to take part?

Your participation in the evaluation is voluntary. However, it is important, as part of the study, to gain the views and experiences of professionals who are either acting as a Transition Key Worker or as a professional providing some form of support to a young person through the transitional age range. It will be entirely up to you to decide if you would like to take part. If you decide to take part you will be asked to complete the attached consent forms. On the consent form will be a unique identification code number which you need to

quote on each questionnaire in the boxes provided or in any other correspondence. You will be able to keep a copy of the consent form for your information, returning one to the researcher together with the completed baseline questionnaire. You can at any time during the lifetime of the study decide not to continue to take part. The researcher may also contact you to help with the distribution of questionnaires to young people you are supporting and their parents/carers.

What will happen to the information I provide (questionnaire and individual interview)?

The information you provide (e.g. questionnaire) will be collected and collated and will be inputted into a data collection software programme. You may be asked to take part in an interview in X date. Any taped interviews or other information collected during an interview will be transcribed word for word into a Microsoft Word document. **All information received from you will be coded using your identification code number and then analysed. In giving a code to the information this will ensure that it will remain anonymous.**

Any findings will be reported in the researcher's final PhD thesis.

What are the possible disadvantages and risks of taking part?

It is not foreseen that there will be any disadvantages or risks to you by taking part in this evaluation.

What are the possible benefits of taking part?

The information that you provide will be extremely valuable and will used to shape practice with regard to Transition Key Working and transition service development and delivery, and will be used to identify the essential components of a successful transition into adulthood for young people with additional learning needs and or complex health care needs.

Will my taking part in this evaluation be kept confidential?

All information collected as part of this evaluation will be kept strictly confidential (unless anything is discussed or observed which may raise serious concerns about the safety of a child, young person, family member or professional). Information will only be disclosed for the purpose of protecting a child or young person, family member or individual and standard

safeguarding procedures will be followed. The researcher has a current Enhanced Criminal Records Bureau Disclosure.

All information received from any person taking part in the evaluation will be kept on an encrypted and password protected computer and all hard paper copies including original completed questionnaire's, transcriptions of meetings and taped recordings will kept in a locked cupboard and will only be accessible by the researcher and a named administrator who will also hold an Enhanced Criminal Records Bureau disclosure.

No individual names or details will be used in the final evaluation. Any information including quotations from individual interviews will not be traceable to you or any other person taking part in the evaluation. All published and unpublished information will conceal the identity of individuals.

What will happen to the results of the evaluation?

A final evaluation document will be produced. This may be followed by publication in professional and academic journals, and delivered where applicable in a seminar or conference presentation format.

Who is responsible for the evaluation?

Sally Rees is the named PhD research student (Bangor University) responsible for the evaluation. Sally is the Wales Manager for the Care Co-ordination Network UK (CCNUK) and is responsible for developing transition key working in Wales. She is also the parent of two young people with an Autistic Spectrum Disorder. As PhD student at Bangor University she will be jointly supervised by Professor Jane Noyes (Noreen Edwards Chair in Nursing Research), Centre for Health-Related Research, School of Healthcare Sciences and Professor Richard Hastings, School of Psychology at Bangor University.

Who is funding the PhD researcher?

Sally Rees is funded to undertake her PhD by Bangor University.

Who has reviewed the evaluation?

As this is an evaluation involving young people and their parents the study has been reviewed by the School of Psychology's Ethics Committee following a submission to carry out the evaluation. The study has received the Committee's approval on X date.

What should I do if I have any concerns the evaluation?

If you have any concerns about taking part in the evaluation, please contact Mr. Malcolm Godwin, Acting Head of School (Healthcare Sciences), Bangor University (01248 383117).

What do I do now to agree to take part?

You have now read this Participant Information Booklet you are asked to take the following steps:

1. Complete the two consent forms (your identification code will be on each form)
2. Complete the questionnaire (ensuring that you have quoted your unique identification number in the boxes indicated in Section 1 on page 4 of the questionnaire)
3. Return the complete questionnaire and one of the signed consent forms in the freepost envelope provided

Contact for further information:

Please do not hesitate to contact the researcher if you would like further information:

Sally Rees
Moving on Together
School of Healthcare Sciences,
Bangor University
Fron Heulog,
Bangor,
Gwynedd,
LL57 2EF
Email: hspa6e@bangor.ac.uk

Thank you for taking time to read this participant information booklet and agreeing to take part.

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APPENDIX TWENTY
INFORMATION BOOKLET: SITE LEADS

TRANSITION
MOVING ON TOGETHER

MOVING ON TOGETHER

Participant Information

TRANSITION KEY WORKER SITE/TRANSITION SERVICE PROVIDER

An evaluation of Transition Key Working in Wales

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TRANSITION KEY WORKER SITE/TRANSITION SERVICE PROVIDER INFORMATION

AN EVALUATION OF TRANSITION KEY WORKING IN WALES

EVALUATION LEAD: Sally Rees (PhD research student)

Invitation to take part and why you have been chosen:

As a local authority area with responsibility for developing Transition Key Worker support for young people aged 14 to 25 with an additional learning need disability and or complex healthcare needs, who has received funding from the European Social Fund Reaching the Heights: First Footholds grant programme, you are being asked to take part in this evaluation (details outlined in this booklet). This evaluation will explore the experiences, processes and outcomes for those receiving the support from a Transition Key Worker, together with exploring the parent/carer and Transition Key Worker experience, as well as those of the multi-agency partnerships taking forward the development.

The young people you are supporting might have also been receiving a service which has been funded through a grant from the Welsh Assembly Government to develop transition key working across 5 pilot sites in Wales or alternatively, as a comparison, the transition support your local authority area is providing has not been funded via the aforementioned grant funding streams.

It is important for you to understand why this evaluation is taking place and what role you will have and what taking part involves.

It is also important for you to take time to carefully read the following information contained within this Participant Information Booklet. If you wish to discuss your involvement and ask any questions, please contact the researcher whose contact details are outlined at the end of this Participant Information Booklet.

Duration of the evaluation:

This evaluation of Transition Key Working in Wales will cover a three year period. The data collection will commence in X date and will end in Y date. The evaluation document (a PhD thesis) will then be developed and submitted to Bangor University.

What is the purpose of this evaluation?

This evaluation aims to:

- explore the disabled young persons' and their parents'/carers' experiences of the key worker model through transition into adulthood
- evaluate the outcomes of the key worker model by comparing with standard transition services
- investigate the possible differentiation in outcomes between the designated and non designated key worker model(s)

What does the evaluation involve?

- completing the Key Worker Standards Self Evaluation Tool (SET) twice during the evaluation (Standards, SET and guidance booklet attached):

Data collection points:

Baseline SET: commencing X date Return Y date

Follow up SET: commencing X date Return Y date

The baseline and follow up SET will be sent to you by email as identified above.

The researcher will discuss with you which aspects of the evaluation that apply to you. Your involvement may also evolve as the evaluation progresses and you may be asked to take part in an interview with the researcher commencing in X date. You will receive feedback on the progress of the evaluation.

Young people, parents/carers and Transition Key Workers/professionals providing transitional support will also be asked to participate. Those sites who have agreed to take part will be asked to distribute a series of

questionnaires to young people, their parents/carers and transition key workers/professionals providing transitional support and have been specifically designed to elicit data to evaluate against the objectives outlined on page 3 of this booklet. All questionnaires will be distributed with a freepost envelope to return directly to the researcher. All the questionnaires (young person's [2 versions – one using PhotoSymbols], parent/carer and Transition Key Worker) will be distributed during the same time periods as the Key Worker Standards Self Evaluation Tool to each site.

Contents of the baseline evaluation packs:

Parent:	Baseline questionnaire Participant Information Booklet 2 consent forms
Young Person: Version 1	Baseline questionnaire Participant Information Booklet 2 consent forms 2 assent forms (to be completed for those under 16)
Young Person: Version 2	Baseline questionnaire (PhotoSymbols version) Participant Information Booklet 2 consent forms 2 assent forms (to be completed for those under 16)
Transition Key Worker or professional providing Transition support	Baseline questionnaire Participant Information Booklet 2 consent forms

No financial costs will be incurred other than those of the researcher undertaking this evaluation. The researcher will contact you regarding the distribution of questionnaires and the process to identify young people in your local authority area who are able to provide informed consent or assent if under 16 years of age and are receiving the support of a Transition Key Worker or another professional providing transitional support.

Do I have to take part?

Your participation in this evaluation is voluntary. However, it is important, as part of the study, to gain the views and experiences of those developing local Transition Key Worker services, as well as those local authorities providing a transition service not specifically funded. It will be entirely up to you to decide if you would like to take part. If you decide to take part you will be asked to complete the attached consent forms. On the consent form will be a unique

identification code which you will need to quote in any correspondence. You will be able to keep a copy of the consent form for your information, returning one to the researcher together with the completed baseline Key Worker Standards Self Evaluation Tool. You can at any time during the lifetime of the study decide not to continue to take part.

What will happen to the information I provide (SET and individual interview)?

The information you provide (e.g. Self Evaluation Tool) will be collected and collated, and will be inputted into a data collection software programme. Any taped interviews or other information collected during an interview will be transcribed word for word into a Microsoft Word document. **All information received from each site will be coded using your identification code and then analysed. In giving a code to the information this will ensure that any information will remain anonymised.** Any findings will be reported in the researcher's final PhD thesis.

What are the possible disadvantages and risks of taking part?

It is not foreseen that there will be any disadvantages or risks to any one in taking part in the evaluation.

What are the possible benefits of taking part?

The information that you provide will be extremely valuable and will used to shape practice with regard to Transition Key Working and transition service development and delivery, and will be used to identify the essential components of a successful transition into adulthood for young people with additional learning needs and or complex health care needs.

Will my taking part in this evaluation be kept confidential?

All information collected as part of this evaluation will be kept strictly confidential (unless anything is discussed or observed which may raise serious concerns about the safety of a child, young person, family member or professional). Information will only be disclosed for the purpose of protecting a child or young person, family member or individual and standard safeguarding procedures will be followed. The researcher has a current Enhanced Criminal Records Bureau Disclosure.

All information received from any person taking part in the evaluation will be kept on an encrypted and password protected computer and all hard paper

copies, including original completed questionnaire's, transcriptions of meetings and taped recordings will kept in a locked cupboard and will only be accessible to the researcher and a named administrator who will also hold an Enhanced Criminal Records Bureau disclosure.

No individual names or details will be used in the final evaluation. Any information including quotations from individual interviews will not be traceable to you or any other person taking part in the evaluation. All published and unpublished information will conceal the identity of individuals.

What will happen to the results of the evaluation?

A final evaluation document of the development of transition key working will be produced. This may be followed by publication in professional and academic journals, and delivered where applicable in a seminar or conference presentation format.

Who is responsible for the evaluation?

Sally Rees is the named PhD research student (Bangor University) responsible for this evaluation. Sally is the Wales Manager for the Care Co-ordination Network UK (CCNUK) and is responsible for developing transition key working in Wales. She is also the parent of two young people with an Autistic Spectrum Disorder. As PhD student at Bangor University she will be jointly supervised by Professor Jane Noyes (Noreen Edwards Chair in Nursing Research), Centre for Health-Related Research, School of Healthcare Sciences and Professor Richard Hastings, School of Psychology at Bangor University.

Who is funding the PhD researcher?

Sally Rees is funded to undertake her PhD by Bangor University.

Who has reviewed the evaluation?

As this is an evaluation involving young people and their parents the study has been reviewed by the School of Psychology's Ethics Committee following a submission to carry out the evaluation. The study has received the Committee's approval on X date.

What should I do if I have any concerns the evaluation?

If you have any concerns about taking part in the evaluation, please contact Mr. Malcolm Godwin, Acting Head of School (Healthcare Sciences), Bangor University (01248 383117).

What do I do now to agree to take part?

You have now read this Participant Information Booklet you are asked to take the following steps:

1. Complete the two consent forms
2. Complete the Key Worker Standards Self Evaluation Tool (SET) quoting your identification code (located in your consent form).
3. Return the completed SET and one of the signed consent forms in the freepost envelope provided

Contact for further information:

Please do not hesitate to contact the researcher if you would like further information:

Sally Rees
Moving on Together
School of Healthcare Sciences,
Bangor University
Fron Heulog,
Bangor,
Gwynedd,
LL57 2EF
Email: hspa6e@bangor.ac.uk

Thank you for taking time to read this participant information booklet and agreeing to take part.

Moving on Together logo designed by a young person with Asperger's Syndrome

APPENDIX TWENTY-ONE
YOUNG PERSON'S CONSENT FORM

Identification number ☐☐☐☐

YOUNG PERSON'S CONSENT FORM

Title of the evaluation: **Moving on Together**

Researcher: **Sally Rees**

Contact details: c/o School of Healthcare Sciences, Bangor University, Fron Heulog, Bangor, Gwynedd, LL57 2EF
Email: hspa6e@bangor.ac.uk

		Please tick the boxes	
1.	I confirm that I have read and understood the information booklet provided and have had the opportunity to ask questions.		☐
2.	I understand that my participation in the research is voluntary and that I am free to withdraw at any time, without giving reason.		☐
3.	I agree to take part in the research study and give my consent		☐
4.	I agree that I can be contacted to be invited talk about being involved in any future studies		☐
		Yes	**No**
5.	I agree to being interviewed and it being digitally recorded (audio)	☐	☐
6.	I agree to the use of anonymised quotes in the research and other publications	☐	☐
7.	I am happy for anonymised information being used for educational purposes?	☐	☐

Contact details:

Name of person taking part.....

Address.....
.....
.....

Postcode.....

Contact telephone number.....

Email address.....

I would like to be contacted to take part in a semi structured interview by (please ✓ as appropriate):

Telephone ☐
Email ☐
Letter ☐

Name of young person	Date	Signature
Name of Researcher	Date	Signature

This consent form has been developed to comply with National Research Ethics Services (NRES) and to comply with the Mental Capacity Act (2005). All details including this consent form information will be held securely on a database which is protected by a password and encrypted. All paper copies will be filed in a locked cabinet.

Your unique identification number will be on the right hand side of this consent form, please quote on all correspondence. Two forms need completing. Return one to the researcher with the completed baseline questionnaire in the Freepost envelope. You keep the other copy.

APPENDIX TWENTY-TWO
PARENT CONSENT FORM

Identification number ☐☐☐☐

TRANSITION
MOVING ON TOGETHER

PARENT/GUARDIAN CONSENT FORM

Title of the evaluation: **Moving on Together**

Researcher: **Sally Rees**

Contact details: c/o School of Healthcare Sciences, Bangor University, Fron Heulog, Bangor, Gwynedd, LL57 2EF
Email: hspa6e@bangor.ac.uk

		Please tick the boxes	
1.	I confirm that I have read and understood the information booklet provided and have had the opportunity to ask questions.		☐
2.	I understand that my participation in the research is voluntary and that I am free to withdraw at any time, without giving reason.		☐
3.	I agree to take part in the research study and give my consent		☐
4.	I agree that I can be contacted to be invited talk about being involved in any future studies		☐
		Yes	**No**
5.	I agree to being approached to interviewed and it being digitally recorded (audio)	☐	☐
6.	I agree to the use of anonymised quotes in the research and other publications	☐	☐
7.	I am happy for anonymised information being used for educational purposes?	☐	☐

Contact details:

Name of person taking part.....

Address.....
.....
.....

Postcode.....

Contact telephone number.....

Email address.....

I would like to be contacted to take part in a semi structured interview by (please ✓ as appropriate):

Telephone ☐
Email ☐
Letter ☐

Name of parent/guardian	Date	Signature
Name of Researcher	Date	Signature

This consent form has been developed to comply with National Research Ethics Services (NRES). All details including this consent form information will be held securely on a database which is protected by a password and encrypted. All paper copies will be filed in a locked cabinet.

Your unique identification number will be on the right hand side of this consent form, please quote on all correspondence. Two forms need completing. Return one to the researcher with the completed baseline questionnaire in the Freepost envelope. You keep the other copy.

APPENDIX TWENTY-THREE
TRANSITION KEY WORKER CONSENT FORM

Identification number ☐☐☐☐

TRANISTION KEY WORKER/TRANSITION WORKER CONSENT FORM

Title of the evaluation: **Moving on Together**

Researcher: **Sally Rees**

Contact details: c/o School of Healthcare Sciences, Bangor University, Fron Heulog, Bangor, Gwynedd, LL57 2EF
Email: hspa6e@bangor.ac.uk

		Please tick the boxes	
1.	I confirm that I have read and understood the information booklet provided and have had the opportunity to ask questions.		☐
2.	I understand that my participation in the research is voluntary and that I am free to withdraw at any time, without giving reason.		☐
3.	I agree to take part in the research study and give my consent		☐
4.	I agree that I can be contacted to be invited talk about being involved in any future studies		☐
		Yes	**No**
5.	I agree to being approached to interviewed and it being digitally recorded (audio)	☐	☐
6.	I agree to the use of anonymised quotes in the research and other publications	☐	☐
7.	I am happy for anonymised information being used for educational purposes?	☐	☐

Contact details:

Name of person taking part.....

Address.....
.....
.....

Postcode.....

Contact telephone number.....

Email address.....

I would like to be contacted to take part in a semi structured interview by (please ✓ as appropriate):

Telephone ☐
Email ☐
Letter ☐

Name of parent/guardian	Date	Signature
Name of Researcher	Date	Signature

This consent form has been developed to comply with National Research Ethics Services (NRES). All details including this consent form information will be held securely on a database which is protected by a password and encrypted. All paper copies will be filed in a locked cabinet.

Your unique identification number will be on the right hand side of this consent form, please quote on all correspondence. Two forms need completing. Return one to the researcher with the completed baseline questionnaire in the Freepost envelope. You keep the other copy.

APPENDIX TWENTY-FOUR
SITES CONSENT FORM

Identification code: ☐☐☐☐

SITE CONSENT FORM

Title of the evaluation: **Moving on Together**

Researcher: **Sally Rees**

Contact details: c/o School of Healthcare Sciences, Bangor University, Fron Heulog, Bangor, Gwynedd, LL57 2EF Email: hspa6e@bangor.ac.uk

		Please tick the boxes	
1.	I confirm that I have on behalf of my organisation* read and understood the information booklet provided and have had the opportunity to ask questions		☐
2.	I understand that my organisation's participation in the research is voluntary and that I am free to withdraw at any time, without giving reason.		☐
3.	I agree on behalf of my organisation to take part in the research study and give my consent		☐
4.	I agree that I can be contacted to be invited talk about being involved in any future studies		☐
		Yes	**No**
5.	I agree that my organisation being approached to be interviewed and it being digitally recorded (audio)	☐	☐
6.	I agree to the use of anonymised quotes in the research and other publications	☐	☐
7.	I am happy for anonymised information being used for educational purposes?	☐	☐

*the use of the term 'organisation' means on behalf of a Transition Key Worker site or non funded local authourty area

Contact details:
Name of organisation taking part.....

Address.....

.....

.....

Postcode.....

Contact telephone number.....

Email address.....

I would like to be contacted to take part in a semi structured interview by (please ✓ as appropriate):

Telephone ☐
Email ☐
Letter ☐

Name of lead person	Date	Signature
Name of Researcher	Date	Signature

This consent form has been developed to comply with National Research Ethics Services (NRES), and takes into account National Children's Bureau guidelines for research with children and young people. All details, including this consent form information will be held securely on a database, which is protected by a password and encrypted. All paper copies will be filed in a locked cabinet.

Please return in the pre-paid freepost envelope provided.

***Your unique identification colour code will be highlighted within the invitation letter. Enter in the box at the top of this consent form.**

Two forms need completing. Return one to the researcher with the completed baseline Self Evaluation Tool in the Freepost envelope. You keep the other copy.

APPENDIX TWENTY-FIVE
ASSENT FORM

Identification no. ☐☐☐☐

TRANSITION
MOVING ON TOGETHER

YOUNG PERSON'S ASSENT FORM

Title of the evaluation: **Moving on Together**

Researcher: **Sally Rees**

Contact details: Moving on Together, School of Healthcare Sciences, Bangor University, Fron Heulog ,Bangor, Gwynedd LL57 2EF. **Email:** hspa6e@bangor.ac.uk

This form is to be completed by the young person under the age of 16 (or if unable, parent/guardian on their behalf). Please circle all you agree with.

Your unique identification number will be in boxes on the right hand side of this consent form, please quote on all correspondence.

Two forms need completing. Return to one to the researcher with the completed baseline questionnaire in the Freepost envelope provided. You keep the other copy.

1. Have you read (or had read to you) information about this evaluation?	Yes/No
2. Has somebody else explained this evaluation to you?	Yes/No
3. Do you understand what this evaluation is about?	Yes/No
4. Have you asked all the questions you want?	Yes/No
5. Have you had your questions answered in a way you understand?	Yes/No
6. Do you understand it's OK to stop taking part at any time?	Yes/No
7. Are you happy to take part?	Yes/No
8. Are you happy to be contacted in the future?	Yes/No
9. I am happy to be interviewed and for it to be digitally recorded	Yes/No
10.I agree to the use of anonymised quotes being used the research?	Yes/No
11.I am happy for information being used for educational purposes?	Yes/No

If you **do** want to take part, you can write your name below:

Your name _____

Date _____

Contact address _____

_____

_____

Postcode_____

Telephone number_____

Email_____

Your parent or guardian must write their name here if they are happy for you to take part in the evaluation:

Print Name _____

Sign _____

Date _____

The researcher needs to sign too:

Print Name _____

Sign _____

Date _____

The person who has explained what it means to take part to sign (if not the researcher):

Print Name _____

Role _____

Sign _____

Date _____

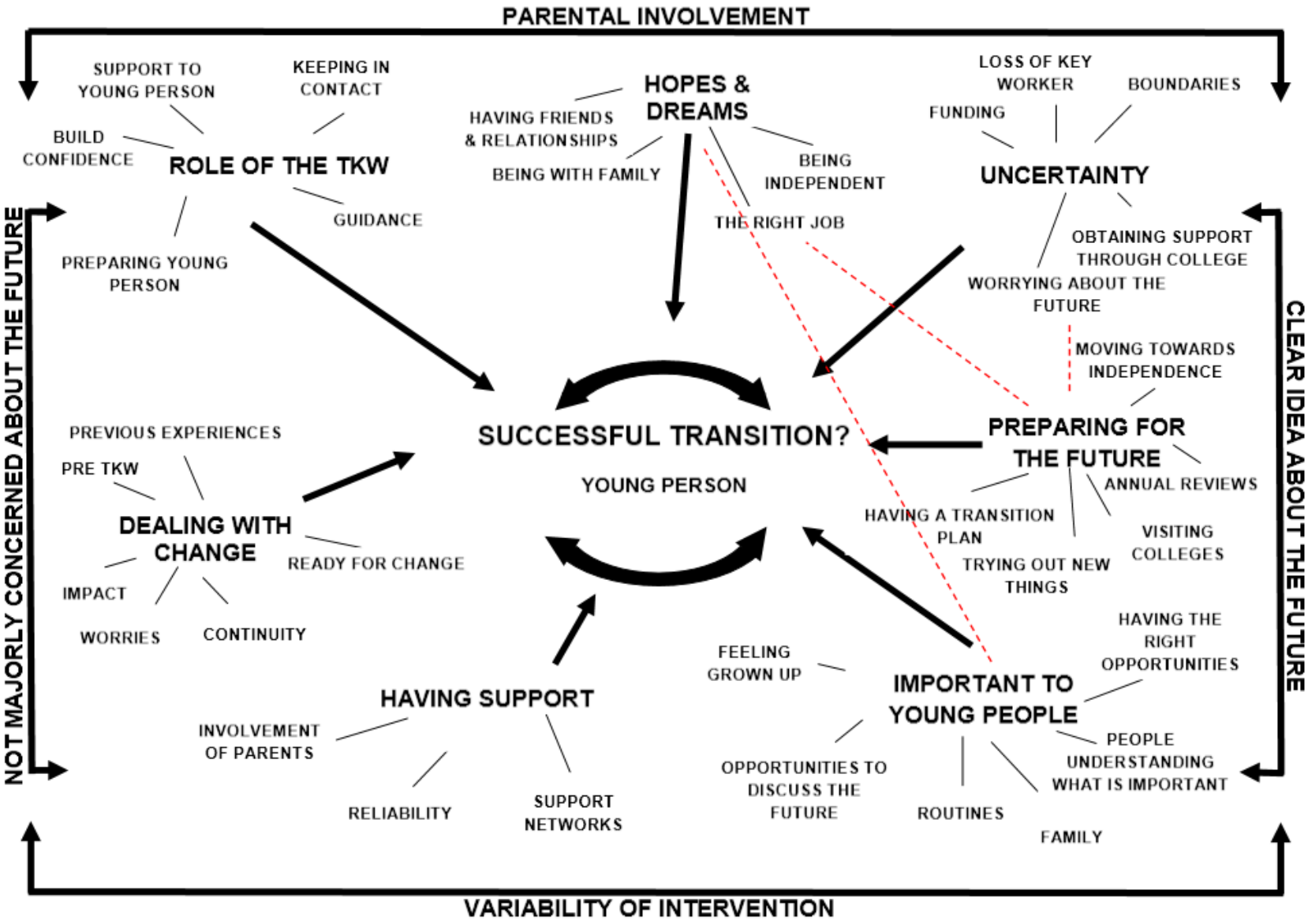
This consent form has been developed to comply with National Research Ethics Services (NRES). All details including this consent form information will be held securely on a database which is protected by a password and encrypted. All paper copies will be filed in a locked cabinet.

Your unique identification number will be on the right hand side of this consent form, please quote on all correspondence. Two forms need completing. Return one to the researcher with the completed baseline questionnaire in the Freepost envelope. You keep the other copy.

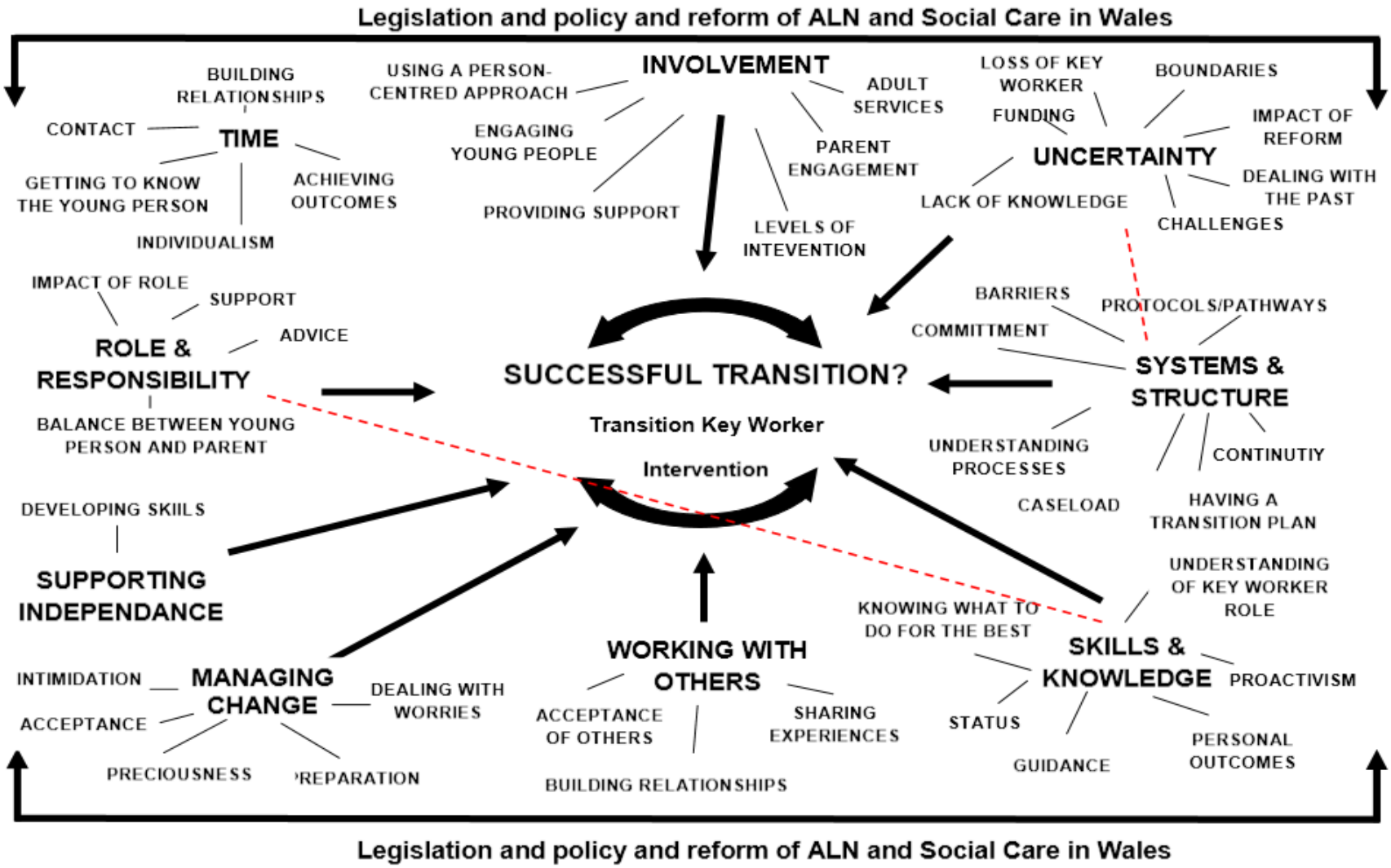
APPENDIX TWENTY-SIX
THEMATIC MAPPING: PARENTS

HIGHER LEVEL THEMES	PARENT		MAIN THEMES
PAST	• Accumulation of events • Uncertainty • Locking away difficult times • Struggle with the 'System' despite inside knowledge • Fairness • Transparency • Walking a 'wobbling line' • Differing opinion • Stress and anxieties • Being let-down • Repeating information	• Past: - Influencing feelings - Influencing thoughts - Influencing action • Thinking about the future • Discussing • Option appraising • Expecting the next problem or difficult situation • Nervous • 'Just when you thought!' • Frankness • Focus on need • Hope • Settled and happy	**FUTURITY**
DICTATING THE PACE	• Faults in the System • Stretched professionals • Working together • Self-dictating son's future • Knowledge & expertise • Waiting for answers • Frustration • Anger • Empathy • Best interests • Single-mindedness	• Own time • Wanting answers • Developing the Plan • Preparing for adulthood • Choice • Voicing concern • Self-assurance • Being person-centred • No Key Worker • Forced into a certain role	**INPUT**
VULNERABILITY	• Build-up of stressful episodes • Self-reliance • Doing it yourself • Taking on too much • Expectation • Reluctance to let go • Not listening to 'own advice'	• Autonomy • Stretched professionals • Trust and assurance • Gathering other people's views • Family networks • Trusting people to care for son • Continuity	**SUPPORT**
PROVIDENCE	• Knowledge & expertise • Good relationships with workers & services • Understanding the pressures on services • Resilience • Determination • Family/Friends Network • Outside interests	• Long term effects of caring • Comparing (with other parents experiences) • Balancing personal and professional life	**IMPACT**
		• Flawed System/Structure • Lack of consistency • Equality • Doing the right thing	**OBSERVATION**

APPENDIX TWENTY-SEVEN
THEMATIC MAP: YOUNG PEOPLE

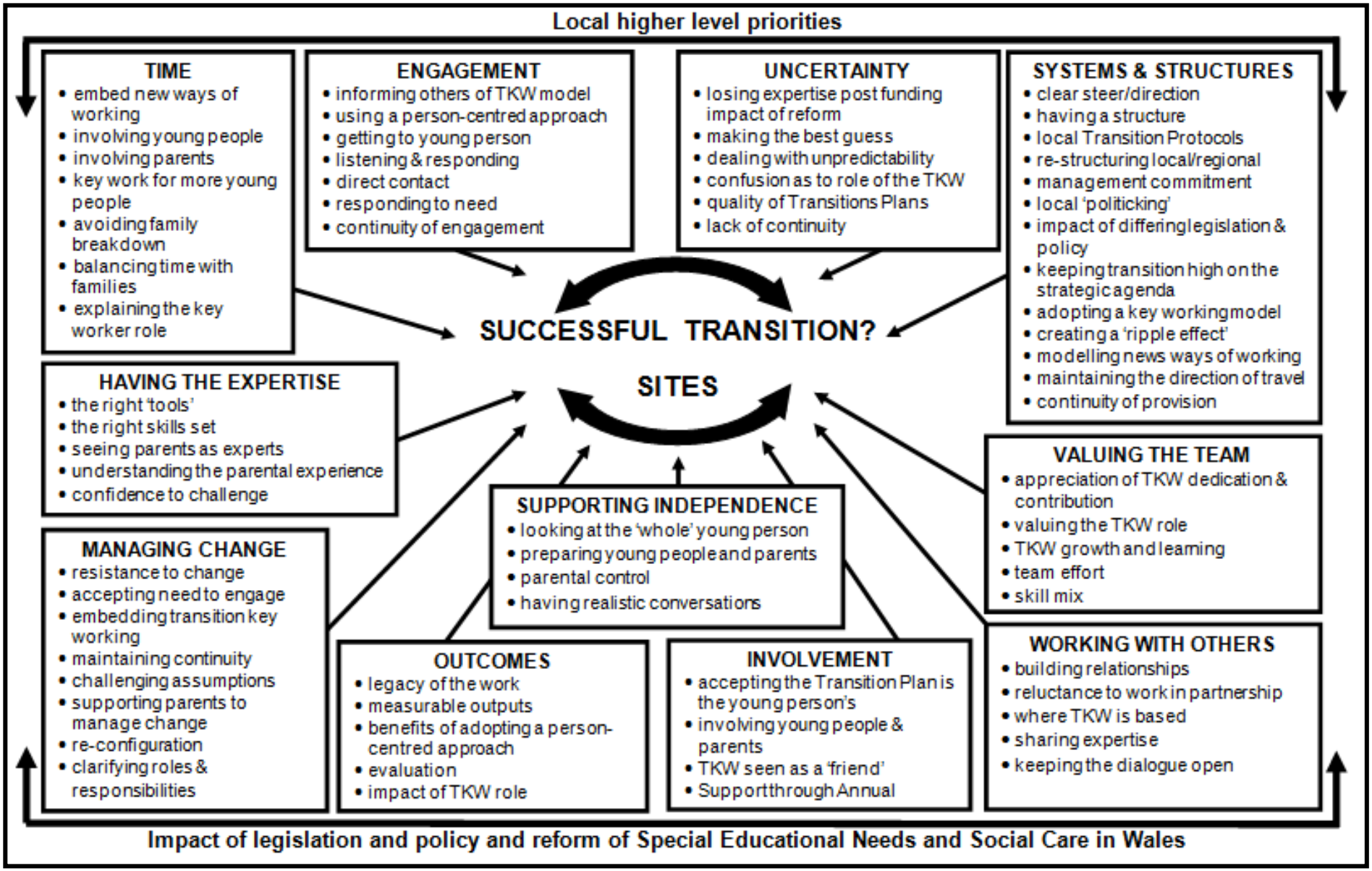


APPENDIX TWENTY-EIGHT
THEMATIC MAP: TRANSITION KEY WORKER



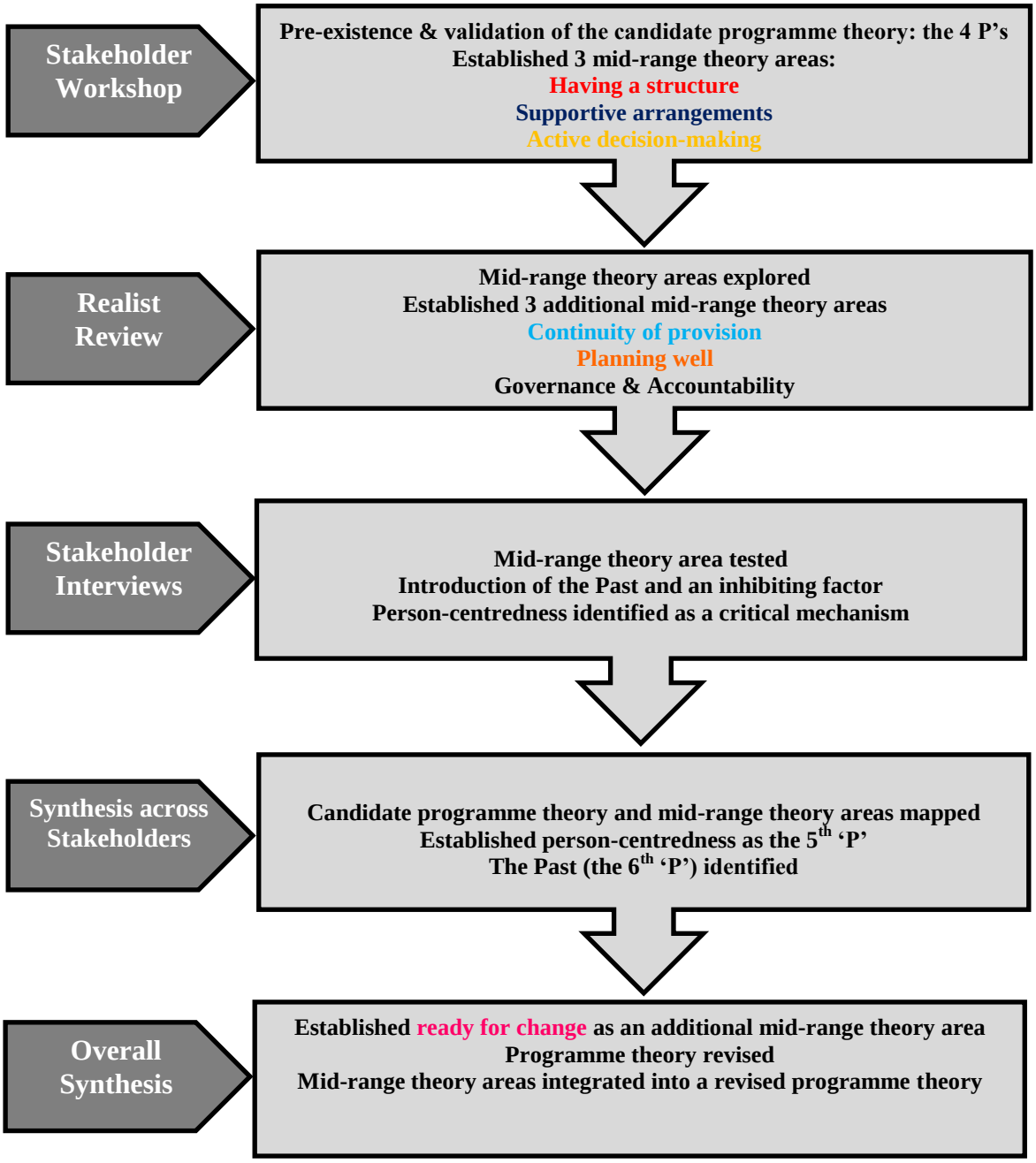
APPENDIX TWENTY-NINE

THEMATIC MAP: SITE LEADS



APPENDIX THIRTY

STAGES OF THEORY DEVELOPMENT



APPENDIX THIRTY-ONE
CARES CONFERENCE ABSTRACT

Title: Realist Review: What makes a successful transition into adulthood for disabled young people?

Background: Achieving a good transition remains a challenge for many young people. Delineating what should happen is usually described in transition protocols and/or pathways. Transition protocols and/or pathways are seen as the means to set out, from a local level across agencies (Health, Social Care, Education and the Third Sector), the transitional processes to be employed and the responsibilities of those involved in providing support and services to disabled young people age 14-25 in transition from children's to adult services. There is little evidence on the effectiveness of a transition protocol and/or pathway for those involved, especially disabled young people as the end receiver.

Realist Review Aim: To understand the circumstances within which the complex process of transition, the contextual relationships, and the external and internal causal mechanisms facilitated by a transition protocol/pathway help to create opportunities to achieve the best possible outcomes for young people entering early adult life.

Methods: A realist framework (Pawson and Tilley 1997) was used to unpick how transition protocols/pathways work to help people to better manage the complex processes and organisational fraternities in transition into adulthood. The review was undertaken in two phases commencing in the early stages with a stakeholder workshop to ascertain what participants suggested were important elements of a good transition. A rapid review of legislation, policy and consultation documentation and broad literature related to transition was undertaken to locate and understand the overall context (first phase process). The second phase included a review of 26 transition protocols and/or pathways and their underlying theories, from Wales and England followed by a more focused review of 11 specific local, regional and national examples. A synthesis of findings across the phases was undertaken to determine what worked for whom in what

contexts and whether underlying theories of how they were intended to work were supported.

Findings: Young people suggested that achieving a good transition required support and a structured process to enable them to make important decisions. They also wanted it to be their transition process. Literature suggests that a key worker is essential when using protocol/pathway. Local/regional/national transition protocols and/or pathways as an overarching intervention to operationalise the transition process when used by professionals, young people and parents (mechanism) were varied in their intentions, with some commonalties in terms of structure and outlining the steps to achieve a good transition. However, the quality of the narrative highlighted differences in local interpretation of the transitional processes. Whilst, a transition protocol and/or pathway can act as cursory framework, no example fully explored how to plan effectively and in detail with a young person from the age of 14. Many families lacked key workers and the focus was frequently primarily not on the young person.

Conclusion: Having a protocol and/or pathway does not appear to make the transition process for young people, their families nor for those supporting them less complex or create the opportunities to achieve the features of a good transition as highlighted by key stakeholders and within literature.