PROFESSIONAL DOCTORATES

Examining psychological therapies adapted for adults with intellectual disabilities

Patterson, Christopher

Award date:
2019

Awarding institution:
Bangor University

Examining psychological therapies adapted for adults with intellectual disabilities

Christopher Wynne Patterson

North Wales Clinical Psychology Programme

PRIFYSGOL
BANGOR
UNIVERSITY

Submitted in partial fulfilment for the degree of

Doctorate in Clinical Psychology

May 2019

Table of Contents

Acknowledgments…… 3

Declarations…… 4

Thesis abstract…… 5

Chapter 1 – Literature review…… 6

Abstract…… 8

Introduction…… 9

Methods…… 12

Results…… 20

Discussion…… 41

Conclusion…… 45

References…… 46

Chapter 2 – Empirical study…… 55

Abstract…… 57

Introduction…… 58

Methods…… 60

Results…… 63

Discussion…… 70

References…… 76

Chapter 3 – Contributions to theory and practice…… 84

Clinical implications…… 85

Research implications…… 90

Personal reflections…… 91

References…… 95

Appendices…… 99

Word count…… 143

Acknowledgments

I want to extend my deepest gratitude to all those who enabled me to write this thesis. First, I want to thank those who generously participated in the empirical study. I hope that I have done your invaluable accounts justice. Second, I want to thank James Preston, Su Thrift and Ursula McCann for tirelessly helping me to recruit participants. Third, I want to thank my ever-available, highly responsive and incredibly knowledgeable supervisors, Jonathan Williams and Rob Jones. I have learnt so much about research and academic writing from you both. Hopefully this is not the end of our work together. Fourth, I want to thank my training coordinator, Renee Rickard, and the programme's research team, Chris Saville and Mike Jackson for all the support and feedback they have provided. Finally, a huge thank you to my family, friends and wife-to-be. Dad, as always, you have been a sounding board for ideas. What I would have done without our long walks and drinking sessions spent discussing phenomenology? Mum, you have always showed unwavering faith in me, which has definitely made times of uncertainty a lot easier. Nanna, David, Harry, Sarah, partners and children, you have a fantastic ability to remind me of what is truly important in life when I am obsessing with my work. You are all probably due missed birthday/Christmas cards/presents! Dan, Al, George, Aaz, and my course mates, thank you for keeping me grounded, and providing lots of opportunity for ranting and laughter. Rosie, thank you for your continued support and encouragement. I know it has not been easy planning a wedding with someone who is totally immersed in work! Now, let's get on with making the most of the rest of our lives together. Wilf, my dog, you were the ghostwriter of this thesis. One day you will get the credit you deserve. This thesis is dedicated to you all, as I could not have managed to get to this point without each and every one of you.

Declaration

I hereby declare that this thesis is the result of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

Signed:

Thesis abstract

This thesis examines the use of psychological therapies adapted for adults with intellectual disabilities (ID). The systematic review identified that four third-wave therapies had been adapted for use with adults with ID: mindfulness-based approaches, Dialectical Behaviour Therapy, Compassion Focused Therapy, and Acceptance and Commitment Therapy. These therapies were found to significantly improve challenging and offensive behaviour, smoking, and mindfulness and acceptance skills. Third-wave therapies appeared to improve mental health problems for some but not all participants. While these findings are promising, they must be interpreted with caution due to the 'weak' quality of included studies.

The empirical study explored the views of six sex offenders regarding the adapted Sex Offender Treatment Programme (aSOTP) using Interpretative Phenomenological Analysis (IPA). Analysis revealed three themes: choice, disclosure and 'It's like being back at school'. This study identified that sex offenders with ID learn to deny their sexual offences to avoid experiencing shame. The disclosure process requires them to drop this defense mechanism. Participants either experienced relief or shame after disclosing, determined by the level of group safeness. Low levels of safeness appear to be associated with experiences of shame. Recommendations are put forward for aSOTP developers and facilitators based on findings from the empirical study.

The final paper integrates findings from the systematic review and empirical study to discuss implications for clinical practice and future research in greater depth. The final paper ends with a personal reflection on the whole research process.

Chapter 1 - Literature Review

Third-wave Therapies and Adults with Intellectual Disabilities: A Systematic Review

Chris Patterson, Dr. Jonathan Williams[1] and Prof. Robert Jones[2]

1. Forensic Adolescent Consultation and Therapy service, North Wales Adolescent Service, Abergele Hospital, Abergele, UK
2. North Wales Clinical Psychology Programme, School of Psychology, Bangor University, Bangor, UK

Corresponding Author: Chris Patterson, North Wales Clinical Psychology Programme, School of Psychology, Bangor University, Bangor, UK. Email: psuc1a@bangor.ac.uk

---

This paper has been published in the Journal of Applied Research in Intellectual Disabilities (https://onlinelibrary.wiley.com/doi/full/10.1111/jar.12619)

Abstract

Background: Third-wave therapies appear to produce positive outcomes for people without intellectual disabilities (ID). This systematic review aimed to establish which third-wave therapies have been adapted for adults with ID and whether they produced positive outcomes. **Method:** Four databases were searched systematically (PsycINFO, Web of Science, Medline, and PubMed), yielding 1395 results. Twenty studies (N = 109) met the present review's inclusion/exclusion criteria. **Results:** Included studies used mindfulness-based approaches, Dialectical Behaviour Therapy, Compassion Focused Therapy, and Acceptance and Commitment Therapy. Due to considerable heterogeneity in the designs and outcome measures used, a meta-analysis was not possible. **Conclusions:** Evidence indicated that third-wave therapies improved mental health symptoms for some; and improved challenging/offending behaviour, smoking and mindfulness/acceptance skills for most. These findings must be interpreted with caution due to the low methodological quality of included studies. Future research should build on the current evidence-base, using scientifically rigorous designs and standardised measures.

Keywords: third-wave therapies; intellectual disabilities; systematic review; mental health problems; aggression; mindfulness/acceptance.

Introduction

In 2004, Hayes' landmark paper reported the emergence of a new wave of behaviour therapy, the third-wave. According to Hayes (2004), the first wave was characterised by the application of behavioural interventions to treat certain mental health problems (e.g., exposure for specific phobias). In contrast, cognitive theorists argued that the relationship between environment and behaviour is more complex than this (Bandura et al., 1969; Beck, 1979). They theorised that cognition served as the mediator between the environment and behaviour (and emotion), and believed that illogical thinking was the cause of maladaptive behaviour and emotional suffering. This cognitive revolution was the catalyst for the second-wave of behaviour therapy, namely Cognitive Behaviour Therapy (CBT; Beck, 1979). While CBT retained elements of behaviourism, it focused on challenging illogical thinking to evoke change (Meichenbaum, 1977). Following its inception, CBT became the subject of considerable research attention. By the early 2000s, CBT had developed a considerable evidence base (e.g., Butler et al., 2006) and established itself as the most widely used form of psychotherapy.

Considering the success of CBT, the emergence of a third-wave of behaviour therapy was surprising to many. This paradigmatic shift was prompted by a critical appraisal of its reported outcomes (Jacobsen et al., 1996), and evidence indicating that some of its propositions were possibly unsound (Hayes, 2004). A series of component analysis studies critically examined CBT's effectiveness (e.g., Borkovec et al., 2002) and questioned whether the purely cognitive components added any extra value to therapy.

Many questioned the proposition that changes in illogical thoughts preceded changes in symptoms (Longmore & Worrell, 2007). Clinical research reported that the process of

challenging illogical thinking was often failing to produce an emotional shift for clients: a phenomenon that became known as the 'head to heart problem' (Branch & Wilson, 2010). The field of cognitive neuroscience has gone someway to explain this phenomenon (Cozolino, 2017; Longmore, 2007; Teasdale, 1997). According to Teasdale (1997), the head to heart problem is a consequence of CBT solely focusing on altering a client's propositional meanings (explicit memory system; semantic) through exposing them to the logical flaws in their thinking. Teasdale (1997) highlighted that CBT fails to engage a client's emotional processes as a result of ignoring their implicational meanings (implicit memory system; emotional). It is this process that results in clients being able to acknowledge that their thinking is illogical, but feeling no different emotionally as a result.

Although the same issues are relevant to adults with intellectual disabilities (ID), it is only in recent years that attempts have been made to adapt these therapies. Considerable effort was afforded to adapting second-wave therapies such as CBT for people with ID. Although it has been reported that people with ID can benefit from CBT as long as necessary adaptations are made (Taylor et al., 2012), Sturmey (2004) argued that CBT is reliant upon clients possessing high-level communication and abstract reasoning ability, as they are required to verbally report on their thoughts and feelings, and weigh evidence for and against thoughts (Sturmey, 2004). Reduced ability in these areas is likely to act as a barrier to people with ID engaging meaningfully with CBT (Boulton et al., 2018; Chinn, et al., 2014).

Third-wave therapies address these issues by focusing on clients' implicational meanings using acceptance, mindfulness, cognitive defusion, dialectics, values, spirituality, and relationship (Hayes, 2004): areas that were previously neglected, as they were viewed as unscientific. According to Hayes (2004), third-wave therapies also focus on "the context and functions of psychological phenomena (not just their form); emphasise contextual and

experiential change strategies (instead of more direct and didactic ones); and seek the construction of broad, flexible and effective repertoires (over an eliminative approach to narrowly defined problems)". Originally, Hayes et al. (2003) cited Mindfulness-based Cognitive Therapy (MBCT; Teasdale et al., 2000), Dialectical Behaviour Therapy (DBT; Linehan, 1993) and Acceptance and Commitment Therapy (ACT; Hayes, Strosahl & Wilson, 1999) as examples of third-wave therapies (Hayes, 2004). Importantly, however, whether or not engaging in these processes also requires similar levels of communication and abstract reasoning ability -- cited by Sturmey (2004) as criticisms of CBT -- is an empirical question.

Two systematic reviews have examined the use of third-wave therapies with the ID population. Chapman et al. (2013) reviewed the use of mindfulness-based approaches with people with ID, as well as parents of children with ID and staff supporting people with ID. Although they reported consistent positive effects for mindfulness, they stated that their findings must be interpreted with caution due to the low methodological quality of included studies. McNair et al. (2017) reviewed studies reporting on the use of DBT with people with ID, concluding that additional high-quality research is needed before deciding whether DBT is an effective intervention when used with the ID population.

The present review had two main aims: (1) to ascertain which third-wave therapies had been used with adults with ID, and (2) to establish how effective third-wave therapies, as a collective, have been when used with adults with ID. This review, therefore, expands on reviews by Chapman et al. (2013) and McNair et al. (2017), which only reviewed the use of individual third-wave therapies (e.g., DBT only) with people with ID.

Methods

This systematic review was conducted in accordance with PRISMA guidelines for guidelines and was registered with Prospero (project number: CRD42018110443).

Search strategy

PsycINFO, Web of Science, Medline, and PubMed, were searched systematically on 23 April 2018, using the following search terms: 'intellectual disabil*' 'learning disabil*' 'mental retard*'; and 'mindfulness', 'acceptance', 'dialectical', 'compassion', 'metacognitive', 'behavio* activation'; or 'MBCT', 'ACT', 'DBT', and 'CFT'. Studies had to be written in English and published in a peer-reviewed journal. No limit was set on publication date. As illustrated in Figure 1, this initial search returned 1395 studies.

Eleven additional papers were identified through: searching the reference lists of unsystematic reviews of psychological therapies for people with ID (Leoni et al., 2015) or systematic reviews of particular third-wave therapies for people with ID, such as mindfulness-based approaches (Chapman et al., 2013; Hwang et al., 2013) and DBT (McNair et al., 2017); hand searching journals of interest; and contacting key authors in the field.

After removing 82 duplicates, 1321 studies remained. Then, the titles and abstracts of the remaining studies were screened to remove any obviously inappropriate studies. Next, the full-texts of 63 studies were read. At this stage, 43 studies were excluded. The first author was responsible for carrying out this process. The second and third authors were consulted regarding four papers, which reported on interventions that were amalgamations of different third-wave therapies, as the first author was unsure as to whether they met the review's inclusion/exclusion criteria or not. Thorough discussion resulted in these papers being

excluded, as all three authors agreed that they were reporting on interventions that were not recognised third-wave therapies.

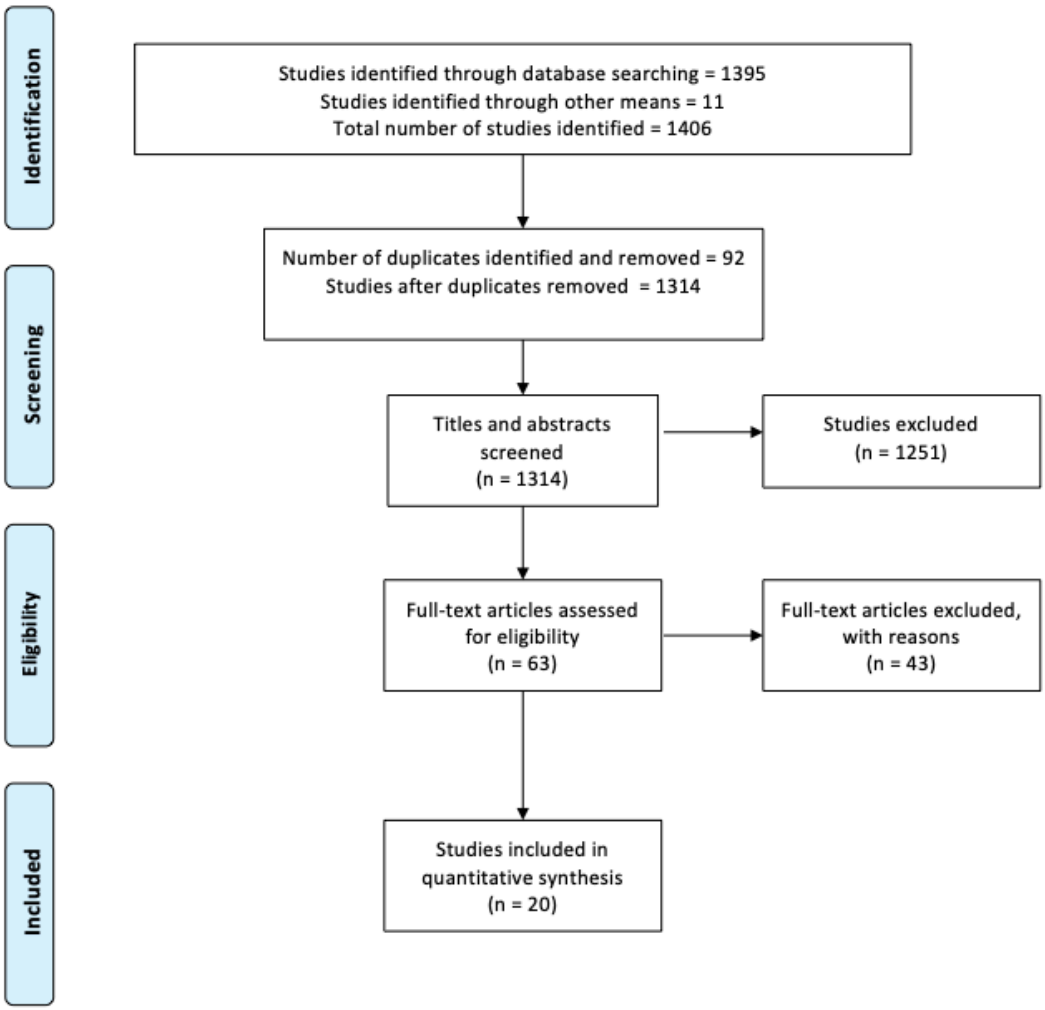
Inclusion criteria:

- Studies with participants aged 18 years or over.
- Studies with samples comprised of adults with ID.
- Quantitative studies, measuring the effect of an intervention (i.e., pre- and post-measurement).
- Studies reporting on third-wave therapies.

Exclusion criteria:

- Studies with participants under the age of 18 years.
- Studies with samples that included individuals with IQs of 70 and above.
- Studies with samples including individuals with 'borderline' ID.
- Non-primary research (e.g., review papers).
- Unplanned interventions.
- Studies reporting on an intervention that included an element inconsistent with the third-wave therapy definition (e.g., studies that included cognitive restructuring).

Figure 1. PRISMA flow of studies through the systematic review



Quality appraisal

As this review included a mixture of studies using single case study and group designs, it was necessary to use a quality appraisal tool that was designed specifically to assess both of these methodologies. Examination of existing reviews (Chapman et al., 2013; McNair et al., 2017) revealed that Reichow et al.'s (2008) Evaluative Method for Determining Evidence-based Practices in Autism had been used to assess the quality of single case and group studies reporting on the use of psychological therapies with people with ID. Other tools have been used to assess the quality of studies included in reviews of psychological therapies for people

with ID. For example, Patterson (2018), Nicoll et al. (2013) and Shepherd and Beail (2017) all used Cahill et al.'s (2010) adaptation of Downs and Black's (1999) Methodological Quality Checklist. However, Cahill et al.'s (2010) adaptation was not deemed appropriate for this review, as some of its criteria seemed irrelevant to studies employing single case study designs.

Reichow (2011) uses different criteria for assessing single case and group study designs. However, both designs are scored against primary and secondary indicators of quality. Studies can be given scores of 'unacceptable', 'adequate' or 'high' for each criterion. Then, unacceptable, adequate and high ratings are tallied for each study to compute an overall research report strength: 'weak' (high quality ratings on less than half of the primary and secondary indicators), 'adequate' (high quality ratings on most primary indicators and about half of the secondary indicators) or 'strong' (high quality ratings on all primary indicators and most secondary indicators). Reichow (2011) also developed a means of determining the overall quality of an evidence-base. The two possible outcomes are 'established' and 'promising'. To be considered established, an evidence-base must have substantial number of single case and/or group studies that have strong research report strength. Whereas, a lower number of single case and/or group studies with adequate research report strength can be considered promising.

Tables 1 and 2 provide in-depth summaries of each study's ratings on Reichow et al.'s (2008) primary and secondary quality indicators. Out of the 11 studies that employed a group design, 10 studies were rated as having 'weak' research report strength and one was rated as having 'adequate' strength. In terms of primary indicators, participant characteristics, comparison condition, use of statistical tests mainly received unacceptable ratings. This suggests that group studies did not (a) provide sufficient demographic and clinical

information about participants, (b) employ control groups and (c) apply appropriate statistical tests to measure the effectiveness of interventions. However, independent variable, dependent variable, and link between research question and analysis mostly received acceptable and high ratings. This means that group studies provided sufficient information regarding their intervention (i.e., to allow for replication) and outcome measures, and chose appropriate outcome measures given their stated aims.

In terms of secondary indicators, there was little if no evidence of random assignment, inter-observer agreement, blind raters, fidelity, attrition, and effect size. Given that only one study utilised the randomised controlled trial (RCT) design, it is unsurprising to find that there was scant evidence of random assignment and blind raters. The lack of control conditions, random assignment and blind raters makes it difficult to establish the true effect of an intervention without the influence of individual differences and biased scoring on outcome measures. There was some evidence of generalisation, meaning that participants were followed-up to establish whether their outcomes were stable. Group studies consistently demonstrated evidence of social validity.

All nine studies that employed a single case design were rated as having 'weak' research report strength. In terms of primary indicators, there was only one area that received solely weak ratings, participant characteristics. The other primary indicators (independent variable, dependent variable, baseline condition, visual analysis, and experimental control) all received high ratings. This means that single case design studies: described their interventions and outcomes in sufficient detail to allow for replication; were well controlled; and provided necessary data visually. In regard to secondary indicators, there was no evidence of fidelity or blind raters, and little evidence of kappa. There was some evidence of inter-observer agreement and generalisation. Similar to the group studies, single case design studies

obtained high ratings for social validity. Due to having only one study with adequate research report strength, the evidence-base for third-wave therapies for adults with ID cannot yet be considered established or promising. This means "practices should be employed with caution and should be closely monitored until a greater accumulation of evidence is present" (Reichow, 2011; p. 1315).

Table 1. Group studies' ratings on Reichow et al.'s (2008) quality appraisal tool

	Primary quality indicators						Secondary quality indicators								
	Participant characteristics	Independent variable	Comparison condition	Dependent variable	Link between research question	Use of statistical tests	Random assignment	Inter-observer agreement	Blind raters	Fidelity	Attrition	Generalisation and/or maintenance	Effect size	Social validity	Quality
ACT															
Brown & Hooper (2009)	U	A	U	A	A	U	N	N	N	N	N	E	N	E	Weak
Pankey & Hayes (2003)	A	A	U	U	A	U	N	N	N	N	N	E	N	E	Weak
DBT															
Ashworth et al. (2017)	U	H	U	H	A	U	N	N	N	N	N	N	N	N	Weak
Crossland et al. (2017)	U	H	U	H	H	U	N	N	N	N	N	E	N	E	Weak
Hall et al. (2013)	U	A	U	A	A	U	N	N	N	N	N	N	N	E	Weak
Lew (et al. (2006)	U	A	U	A	H	U	N	N	N	N	N	N	N	E	Weak
Sakdalan et al. (2010)	U	A	U	A	H	U	N	N	N	N	N	N	N	E	Weak
Mindfulness															
Chilvers et al. (2011)	H	A	U	A	H	H	N	N	N	N	N	E	E	E	Weak
Singh et al. (2014)	A	H	H	H	H	H	E	N	N	E	E	E	N	E	Adequate
CFT															
Clapton et al. (2017)	A	H	U	H	H	H	N	N	N	N	N	N	N	N	Weak
Cooper & Frearson (2017)	U	H	U	H	U	U	N	N	N	N	N	E	N	E	Weak
Hardiman et al. (2018)	U	A	U	A	H	U	N	N	N	N	N	E	N	N	Weak
Total	U=8	U=0	U=11	U=1	U=1	U=9	N=11	N=12	N=12	N=11	N=11	N=6	N=11	N=3	
	A=3	A=7	A=0	A=6	A=4	A=0	E=1	E=0	E=0	E=1	E=1	E=6	E=1	E=9	
	H=1	H=5	H=1	H=5	H=7	H=3									

Table 2. Single-case design studies' ratings on Reichow et al.'s (2008) quality appraisal tool

	Primary quality indicators						Secondary quality indicators						
	Participant characteristics	Independent variable	Dependent variable	Baseline condition	Visual analysis	Experimental control	Inter-observer agreement	Kappa	Fidelity	Blind raters	Generalisation and/or maintenance	Social validity	Quality
Mindfulness													
Adkins et al. (2010)	U	H	H	H	H	H	N	N	N	N	E	E	Weak
Singh et al. (2007)	U	H	H	H	H	H	E	E	N	N	E	E	Weak
Singh et al. (2013)	U	H	H	H	H	H	E	E	N	N	E	E	Weak
Singh et al. (2011a)	U	H	H	H	H	H	E	E	N	N	E	E	Weak
Singh et al. (2008)	U	H	H	H	H	H	E	N	N	N	N	E	Weak
Singh et al. (2003)	U	H	H	H	H	H	E	N	N	N	E	E	Weak
Singh et al. (2011b)	U	H	H	H	H	H	N	N	N	N	N	E	Weak
DBT													
Florez & Bethay (2017)	U	H	H	H	H	H	N	N	N	N	E	E	Weak
Total	U = 8	U = 0	U = 0	U = 0	U = 0	U = 0	N = 3	N = 5	N = 8	N = 8	N = 2	N = 0	
	A = 0	A = 0	A = 0	A = 0	A = 0	A = 0	E = 5	E = 3	E = 0	E = 0	E = 6	E = 8	
	H = 0	H = 8	H = 8	H = 8	H = 8	H = 8							

Results

Twenty studies met the inclusion/exclusion criteria. Table 3 provides summaries for each study.

Design

A range of study designs was employed. One study employed the 'gold-standard' RCT design. Seven studies employed a single group pre- and post-test design. Five studies used a case study design. The remaining seven studies used single case designs: multiple-baseline (N = 3), changing criterion (N = 2) or AB/ABAB single case designs (N = 2). As identified in the quality appraisal, twelve studies measured generalisation by conducting follow-up assessments (range: one week to three years). Nearly all of the studies were conducted in either the USA (N = 10) or the UK (N = 9). The remaining study was conducted in New Zealand. Samples were typically recruited from either the community (N = 14) or inpatient settings (N = 6).

Participant group

In total, these studies reported on 109 participants. Out of the 102 participants whose gender was reported, 60 (58.8%) were female. Participants' ages ranged from 18 to 61; however, three studies failed to report age. Although only four studies reported on IQ (range: 44 to 69), all studies reported that participants had been diagnosed with an ID/were accessing an ID service. Presenting problems ranged from psychological distress/mental health problems, to challenging/offending behaviour, to smoking.

Table 3. Data extraction form

Reference/Country	Study design	Participant(s)/Setting	Intervention	Outcomes Measured	Rigour
Adkins et al. (2010); USA	Multiple-baseline	**N** = 3 (2 = male) **Age**: mean = 29.7 (range = 22-42) **ID**: mild **Presenting problems:** maladaptive behaviour causing their placement; and obsessive-compulsive disorder, anger, and depression **Setting:** community	Mindfulness **Format:** individual **Manual:** Soles of the Feet **Length:** 1 hour **Frequency**: training, 5 per week **Duration:** training, up to 5 weeks; practice, up to 26 weeks	**Behavioural measures:** • Target behaviour • Other behaviour **Subjective measures:** • Subjective Units of Distress Scale • Yale-Brown Obsessive Compulsive Scale • Beck Depression Inventory – Second Edition • State Trait Anxiety Index **Follow-up:** 9-12 weeks	Weak
Ashworth et al.	Case study	**N:** 1 (1 = male)	Dialectical	**Behavioural measure:** • Observations	Weak

(2017); UK		**Age:** not reported **ID:** mild (IQ: 67/69) **Presenting problems:** emotionally unstable personality disorder; extensive offending history (i.e., arson); and aggression and self-harming behaviour **Setting:** inpatient	behaviour therapy **Format:** group and individual **Manual:** I Can Feel Good **Length:** 2 hours **Frequency:** 1 per week **Duration:** 47 weeks	**Subjective measures:** • Emotional Problems Scale-Behaviour Report Scale • Cognitive and Affective Mindfulness Scale-Revised • Emotional Control Questionnaire • Coping Response inventory • Chart of Interpersonal Reactions in Closed Living Environments **Follow-up:** none	
Brown & Hooper (2009); UK	Case study	**N:** 1 (0 = male) **Age:** mean = 18 (range = 18) **ID:** IQ = 44 **Presenting problems:** anxious and obsessive thoughts.	Acceptance and commitment therapy **Format:** individual **Manual:** none **Length:** not	**Subjective measure:** • Adapted version of the Acceptance and Action Questionnaire – 9 **Behavioural measure:** • Parents' observations **Follow-up:** 4 months	Weak

		Setting: community	reported **Frequency:** 2 per month **Duration:** 6 months		
Chilvers et al. (2011); UK	Single group pre-post	**N:** 15 (0 = male) **Age:** range = 18-47 **ID:** mild-moderate **Presenting problems:** psychosis, mood disorders and autism spectrum disorder. **Setting:** inpatient	Mindfulness **Format:** group **Manual:** none **Length:** 30 minutes **Frequency:** 2 per week **Duration:** 26 weeks	**Behavioural measures:** Proxy measures of institutional aggression: • Observations • Physical intervention • Seclusions **Follow-up:** none	Weak
Clapton et al. (2017); UK	Single group pre-post	**N:** 6 (2 = male) **Age:** mean age = 38.5	Compassion focused therapy	**Subjective measures:** • CFT-ID Session Feasibility and Acceptability Measure • Self-Compassion Scale-Short Form	Weak

		(SD = 15.6) **ID:** mild (IQ: 51-69) **Presenting problems:** anxiety and mixed anxiety and depression **Setting:** community	**Format:** group **Manual:** none **Length:** 90 minutes **Frequency:** not reported **Duration:** 6 sessions	• Psychological Therapy Outcome Scale – Intellectual Disabilities • The adapted Social Comparison Scale **Follow-up:** none	
Cooper & Frearson (2016); UK	Single case AB	**N:** 1 (1 = male) **Age:** '40s' **ID:** moderate **Presenting problems:** low mood and overeating **Setting:** community	Compassion focused therapy **Format:** individual **Manual:** none **Length:** 1 hour **Frequency:** not reported **Duration:** 13	**Subjective measures:** • CORE-LD • Forms of Self-criticising and Self-reassuring Scale • Idiosyncratic mood monitoring scale **Follow-up:** 1 week	Weak

			sessions		
Crossland et al. (2017); UK	Single group pre-post	**N:** 4 (1 = male) **Age:** range = 24-48 **ID:** not reported **Presenting problems:** Interpersonal differences and emotion regulation difficulties **Setting:** community	Dialectical behaviour therapy **Format:** group **Manual:** I Can Feel Good **Length:** not reported **Frequency:** 1 per week **Duration:** 18 weeks	**Subjective measures:** • Health of the Nation Outcome Scales for People with Learning Disabilities • Psychological Therapy Outcome Scale – Intellectual Disabilities **Follow-up:** 4 months	Weak
Florez & Bethay (2017); USA	Single case ABAB	**N:** = 1 (0 = male) **Age:** 28 **ID:** mild **Presenting problems:** challenging behaviours,	Dialectical behaviour therapy **Format:** group and individual **Manual:** none	**Behavioural measures:** • Frequency of challenging behaviour **Follow-up:** 1 year	Weak

		emotional dysregulation, generalised anxiety disorder, intermittent explosive disorder, uncooperative behaviour, aggression, self-injury, and elopement. **Setting:** community	**Length:** 45 minutes **Frequency:** 2 per week **Duration:** 1 year		
Hall et al. (2013); UK	Single group pre-post	**N:** 7 (gender not reported) **Age:** not reported **ID:** not reported **Presenting problems**: not reported **Setting:** community	Dialectical behaviour therapy **Format:** group **Manual:** none **Length:** not reported **Frequency:** not reported	**Subjective measures:** • Glasgow Depression Scale – Learning Disability • Glasgow Anxiety Scale – Intellectual Disability • Cognitive and Affective Mindfulness Scale - Revised **Follow-up:** none	Weak

			Duration: not reported		
Hardiman et al. (2018); UK	Single group pre-post	**N:** 3 (1 = male) **Age:** range = 31-48 **ID:** mild-moderate **Presenting problem:** clinically significant anxiety **Setting:** community	Compassion focused therapy **Format:** not reported **Manual:** none **Length:** not reported **Frequency:** not reported **Duration:** 12-15 weeks	**Subjective measures:** • Self-compassion scale • Glasgow Anxiety Scale – Intellectual Disability **Follow-up:** 3 months	Weak
Lew et al. (2006); UK	Single group pre-post	**N:** 8 (0 = male) **Age:** range = 25-61 I**D:** mild-moderate **Presenting problems:**	Dialectical behaviour therapy **Format:** group and individual	**Subjective measures:** • Adapted version of Youth Risk Behaviour Survey **Follow-up:** none	Weak

		Axis 1 diagnosis of mental disorder, additional need issues, considered as high risk. **Setting:** community	**Manual:** none **Length:** group, 2 hours; individual, 30-60 minutes **Frequency:** group, 1 per week; individual, 2 per week **Duration:** 69 weeks		
Pankey & Hayes (2003); USA	Case study	**N:** 1 (0 = male) **Age:** mean = 22 **ID:** = mild (IQ: 58) **Presenting problem:** undifferentiated psychosis **Setting:** community	Acceptance and commitment therapy **Format:** individual **Manual:** none **Length:** not	**Behavioural measures:** • Compliance with medication • Eating • Ceasing taking apart appliances • Sleeping **Subjective measures:** • Believability • Distress • Frequency of symptoms	Weak

			reported **Frequency:** not reported **Duration:** 4 sessions	• Simple ACT process measure **Follow-up:** 1 month	
Sakdalan et al. (2010); New Zealand	Single group pre-post	**N:** 6 (5 = male) **Age:** range = 23-29 I**D:** mild-moderate **Presenting problem:** violent offending behaviour **Setting:** inpatient	Dialectical behaviour therapy **Format:** group **Manual:** none **Length:** 90 minutes **Frequency:** not reported **Duration:** 13 weeks	**Subjective measures:** • Short-term Assessment of Risk and Reliability • Vineland Adaptive Behaviour Scales -Second Edition • Health of the Nation Outcomes Scale for People with Learning Disabilities • DBT assessment and feedback form **Follow-up:** none	Weak
Singh et al. (2014); USA	Randomised controlled	**<u>Experimental group</u>** **N** = 25 (20 = male)	Mindfulness **Format:**	**Behavioural measures:** • Number of cigarettes smoked	Adequate

	trial	**Age:** mean = 32.6 (SD = 10.3) **<u>Control group</u>** **N:** 26 (21 = male) **Age:** mean = 34.4 (SD = 10.5) **ID:** mild **Presenting problem:** smoking **Setting:** community	individual **Manual:** Soles of the Feet **Length:** training, 30 minutes **Frequency:** training, 2 per day **Duration:** training, 5 days; total intervention, 36 weeks	**Follow-up:** 1 year	
Singh et al. (2007); USA	Multiple-baseline	**N:** 3 (2 = male) **Age:** range = 27-43 I**D:** moderate **Presenting problems:** at risk of losing their	Mindfulness **Format:** individual **Manual:** Soles of the Feet	**Behavioural measures:** • Physical aggression **Follow-up:** up to 2 years	Weak

		community placements because of their aggressive behaviour, bipolar disorder, schizophrenia, psychotic disorder, and post-traumatic stress disorder. **Setting:** community	**Length:** not reported **Frequency:** not reported **Duration:** 35 weeks		
Singh et al. (2013); USA	Changing criterion	**N:** 3 (3 = male) **Age:** mean = 27 (range = 23-31) **ID:** mild Presenting problems: long-term smoking **Setting:** community	Mindfulness **Format:** individual **Manual:** Soles of the Feet **Length:** training, 30 minutes **Frequency:** training, 2 per day	**Behavioural measures:** • Number of cigarettes being smoked per day **Follow-up:** 3 years	Weak

			Duration: training, 5 days; total intervention, up to 24 weeks		
Singh et al. (2011a); USA	Changing criterion	**N:** 1 (1 = male) **Age:** mean = 31 **ID:** mild **Presenting problem:** smoking **Setting:** community	Mindfulness **Format:** individual **Manual:** Soles of the Feet **Length:** training, 30 minutes **Frequency:** training, 2 per day **Duration:** training, 5 days; total intervention, 12 weeks	**Behavioural measures:** • Number of cigarettes smoked each day **Follow-up**: 3 years	Weak

Singh et al. (2011b); USA	Case study	**N:** 3 (3 = male) **Age:** mean = 23.3 (range = 23-34) **ID:** mild **Presenting problem:** sexual offending **Setting:** inpatient	Mindfulness **Format:** individual **Manual:** Soles of the Feet **Length:** 30-60 minutes **Frequency:** 4 per week **Duration:** up to 40 weeks	**Subjective measures:** • Self-report data on the level of sexual arousal **Follow-up:** none	Weak
Singh et al. (2008); USA	Multiple-baseline	**N:** 6 (6 = male) **Age:** mean = (range = 23-36) **ID:** mild **Presenting problem:** physical aggression	Mindfulness **Format:** individual **Manual:** Soles of the Feet **Length:** not	**Behavioural measures:** • Physical aggression **Follow-up:** none	Weak

		Setting: inpatient	reported **Frequency:** not reported **Duration:** 27 months		
Singh et al. (2003); USA	Case study	**N:** 1 (1 = male) **Age:** mean = 27 I**D:** mild **Presenting problem:** **c**onduct disorder **Setting:** inpatient	Mindfulness **Format:** individual **Manual:** Soles of the Feet **Length:** training, 30 minutes **Frequency:** training, 2 per day **Duration:** training, 5 days	**Behavioural measures:** • Physical aggression • Verbal aggression • Incidents • Self-control • PRN • Physical restraints • Injuries • Socially integrated activities • Physically integrated activities **Follow-up:** 12 months	Weak

Intervention

The breakdown of interventions was as follows: nine (45%) used a mindfulness-based approach; six (30%) used DBT; three (15%) used CFT; and two (10%) used ACT. As identified by the quality appraisal, only one study (Singh et al., 2014) employed fidelity checks. This means that there is no way of knowing whether the interventions described in the rest of the studies contained the necessary elements and were delivered as prescribed. While over half of the interventions were conducted on an individual basis (N = 11; 55%), under a quarter were conducted on a group basis (N = 5; 25%). Out of the remaining studies, three (15%) included both individual and group components, and one (5%) did not report this information. In terms of duration, 16 studies reported the number of weeks whereas three reported the number of sessions. One study did not provide details on the format of their intervention. Those that reported the number of weeks ranged from one week to 117 weeks (M = 34.7). Studies that reported the number of sessions lasted between four and thirteen sessions (M = 7.7). Sessions lasted between 30 to 120 minutes.

Only one of the approaches identified in this review was specifically developed for people with ID, Soles of the Feet (SoF). This manualised mindfulness-based approach (Singh et al., 2003) involves teaching people with ID to notice signs of difficult private experience and rapidly shift their attention to the sensations in the soles of their feet. Teaching is conducted on a one-to-one basis for 30 minutes a day once a week. Then, people with ID are encouraged and supported to maintain daily practice for a substantive period of time. The other approaches were adapted from mainstream.

Prior to describing the DBT approaches found in the review, it is important to note that to be considered DBT an intervention must contain individual therapy, group skills training, team

consult, and 24-hour telephone support. While some of the DBT interventions in this review contained all of these elements, some did not. Despite this, two studies followed a manualised approach ('I Can Feel Good'; Ingamells & Morrissey, 2011).

Common adaptations

- Simplifying language
- Making abstract concepts more concrete
- Chunking information
- Using physical/visual prompts
- Providing additional time to process information
- Checking whether participants understood
- Using role play and experiential exercises
- Reducing the duration of sessions
- Involving carers.

Outcome measures

To evaluate the effectiveness of interventions, studies used either behavioural (N = 8), subjective (N = 8) or a combination of behavioural and subjective measures (N = 4). Behavioural measures were used when the target of the intervention was behaviour change; for example, reducing incidents of aggression or the number of cigarettes smoked. Subjective measures were used when intervention were targeting psychological constructs (e.g., psychological distress). In total, 29 different subjective measures were used: 21 were self-report; eight were informant-report. Despite the use of behavioural and subjective measures (self-report and informant-report) there was little evidence of inter-observer agreement or blind raters, as highlighted in the quality appraisal section. Resultantly, it is

difficult to ascertain the extent to which individual differences and cognitive biases influenced scoring. The majority of the identified subjective measures were only found in single studies (N = 25). The most frequently used subjective measures were as follows (psychometric properties presented in parentheses):

- Glasgow Anxiety Scale – Intellectual Disability (GAS-ID; Mindham & Espie, 2003): internal consistency = .93; test-rest-reliability = .93; concurrent validity = .75
- Psychological Therapy Outcome Scale – Intellectual Disabilities (PTOS-ID; Vlissides et al., 2017): internal consistency = .76-81; concurrent validity = .85
- Health of the Nation Outcome Scales for People with Learning Disabilities (HONOS-LD; Roy et al., 2002): internal consistency = .96; concurrent validity = .66-76
- Cognitive and Affective Mindfulness Scale – Revised (CAMS-R; Feldman et al., 2017): internal consistency = .76; concurrent validity = .66

The GAS-ID, PTOS-ID and HONOS-LD were among the 12 subjective measures with robust psychometric properties that were specifically developed for people with ID. Notably, the GAS-ID and PTOS-ID are self-report, whereas the HONOS-LD is informant-report. The CAMS-R was one of the seventeen measures that were originally developed for people without ID (four of which were adapted for use with people with ID).

Effectiveness

In the quality appraisal section, it was highlighted that very few studies used appropriate statistical tests and only two studies (Chilvers et al., 2011; Singh et al., 2014) reported effect sizes. However, significance levels and effect sizes will be presented, when possible, to aid the reader's interpretation. In addition, all reported findings should be interpreted with

caution as all but one of the studies (Singh et al., 2014) included in this review obtained weak ratings on the quality appraisal.

Challenging/offending behaviour

Results from two single case design (multiple baseline) studies, indicated that, participants were able reduce their aggressive behaviour to 'near zero-levels' in the community after completing the SoF mindfulness intervention, (Adkins et al., 2010; Singh et al., 2007). Prior to this intervention, these participants' placements were at risk due to the severity of their aggression. Chilvers et al. (2011) and Singh et al. (2008) reported similar findings when mindfulness-based approaches were used to treat aggression in inpatient settings. Aggression reduced significantly in both of these studies following intervention, as evidenced by: reduced observations (r = -0.47), physical interventions (r = -0.45) and seclusions (r = -0.42) in Chilvers et al.'s (2011) study; and reduced emergency medication, physical restraint and injuries in Singh et al.'s (2008) study. Benefit-cost analysis revealed a 95.7% reduction in workforce costs (i.e., sickness and injury) following Singh et al.'s (2008) mindfulness intervention.

Florez and Bethay (2017) described the outcome of their DBT programme with an individual with an adult with a complex presentation (i.e., emotional dysregulation, generalised anxiety disorder and intermittent explosive disorder) who was exhibiting 'challenging behaviour' (i.e., aggression and self-harm) in the community. Results from their single case design study (ABAB) indicated that DBT eliminated their participant's challenging behaviour to zero, twice, within two months of implementation.

Two studies conducted by Singh and colleagues (Singh et al., 2003; Singh et al. 2011b) examined the use of their SoF intervention in inpatient settings. They wanted to establish

whether this intervention could increase self-control in individuals with offending histories. Singh et al.'s (2003) participant managed to stop themselves from displaying aggression for six-months, which enabled them to step down into a community setting. At follow-up, one year later, their participant was still living in the community, as they had not exhibited any aggression. Results from Singh et al.'s (2011b) single case design (changing criterion), suggested that their participants were able to regulate their deviant sexual arousal better following the SoF intervention. Moreover, Sakdalan et al. (2010) and Lew et al. (2006) investigated whether DBT could reduce participants' level of risk. Notably, these studies used considerably different formats: Sakdalan et al.'s (2010) intervention was administered in a group format over 13 weeks, whereas Lew et al.'s (2006) intervention comprised both group and individual work over 69 weeks. Despite this, they both reported considerable reductions on measures of risk following intervention.

Psychological distress and mental health problems

The picture is mixed when it comes to the impact that third-wave therapies have when used with people with ID who are experiencing psychological distress and, or, mental health problems. For instance, Hall et al. (2013) and Hardiman et al. (2018) both reported that scores on measures of anxiety and depression improved following intervention. Similarly, Crossland et al. (2017) reported that all four of their participants demonstrated improvements on the psychological distress scale of the PTOS-ID following group DBT.

However, only two out of Adkins et al.'s (2010) three participants reported reductions on measures of anxiety, depression, and Obsessive Compulsive Disorder symptoms following SoF, and although Pankey and Hayes' (2003) intervention reduced the level of distress their participant experienced as a result of their hallucinations, it did not stop the participant from

experiencing hallucinations. It is important to note that two studies did not find any improvement on subjective measures of psychological distress/mental health problems following intervention (Ashworth et al., 2017; Cooper & Frearson, 2016). In fact, Cooper and Frearson (2016) reported that their participant's scores on both an idiosyncratic mood measure worsened throughout their intervention.

Smoking reduction

Results from the only study that received an adequate rating on the quality appraisal, Singh et al.'s (2014) RCT, indicated that SoF effected a statistically significant reduction in smoking when compared to treatment as usual ($p < .05$, $d = .70$) (Singh et al., 2014). Follow-up revealed that, compared to those in the TAU group, those in the mindfulness group were significantly more successful in abstaining from smoking at one-year follow-up. Singh et al.'s (2014) results were supported by results from two single-case design studies (changing criterion) conducted by the same researchers (Singh et al., 2011a; Singh et al., 2013) using the same mindfulness intervention (SoF). Singh et al. (2011a) reported that their participant was able to reduce the number of cigarettes he smoked from an average of 12 a day at baseline to zero within three months. Furthermore, Singh et al.'s (2013) three participants were able to reduce their cigarette smoking from daily averages of 28.4, 34.8, and 13.8 at baseline to zero within 111, 165, and 77 days, respectively. Follow-up data, collected every three months, showed that the participants in both of these studies (Singh et al., 2011a; Singh et al., 2013) were able to abstain from smoking for three years.

Psychological skills

§Results from several studies using a range of third-wave therapies converge to indicate that such interventions can significantly increase various psychological skills: acceptance and

non-judgment towards experience (Hall et al., 2013); self-compassion (Hardiman et al. 2018); reduced in self-criticism and unfavourable social comparisons (Clapton et al., 2017); willingness to experience aversive cognitions and emotions (Brown & Hooper, 2009; Pankey & Hayes, 2003); defusing from aversive cognitions and emotions (Pankey & Hayes, 2003); and taking action to meet behavioural goals (Pankey & Hayes, 2003).

Discussion

This systematic review identified 20 studies reporting on third-wave therapies for adults with ID. The most researched third-wave therapy with this population was mindfulness. Other third-wave therapies that have been used with adults with ID, but researched to a lesser extent, are DBT, CFT and ACT. Third-wave therapies were delivered across a range of formats. Mindfulness and ACT were typically delivered on an individual basis, whereas DBT and CFT were delivered on both individual and group bases. There was marked variation in the length of interventions, however, on average, they lasted 35 weeks/8 sessions. Sessions lasted between 30 and 120 minutes. Shorter sessions were associated with interventions that were conducted on an individual basis (i.e., mindfulness), and longer sessions were associated with interventions conducted on a group basis (i.e., DBT). Only one intervention was designed specifically for people with ID, SoF. All other interventions were adapted from mainstream. Common adaptations accounted for reduced language abilities, less abstract thinking, poorer working memory, and slower processing speed.

Interventions were used to treat a number of problems, ranging from mental health problems/psychological distress, to challenging/offending behaviour, to smoking. In terms of mental health problems and psychological distress, the evidence for third-wave therapies was mixed: third-wave therapies improved some symptoms of mental health for some adults with

ID. Conversely, third-wave therapies were shown to be highly effective at reducing challenging and offending behaviour in the community, enabling participants to maintain 'at-risk' placements. Similarly, inpatient studies reported third-wave therapies improved participants' aggression and self-control. Some participants were able to stop displaying aggression for six months following intervention, enabling them to be transitioned into the community. Inpatient services reportedly used lower levels of observation, physical restraint, emergency medication and seclusion following intervention, resulting in a significant reduction (95.7%) in workforce costs (e.g., sickness and injury). Third-wave therapies (i.e., SoF) were shown to be highly effective when used to help people with ID stop smoking. Results from a RCT demonstrated that the SoF produced a significant reduction in smoking compared to TAU. Two other studies reported that their participants were able to stop smoking altogether following the SoF intervention, maintaining this at three-year follow-up.

Moreover, third-wave therapies have been used to increase the use of a range of psychological skills with the adult ID population, including non-judgment and acceptance, self-compassion, reduced self-criticism, unfavourable social comparison, willingness to experience aversive cognitions and emotions, defusing from aversive cognitions and emotions, and taking action to meet behavioural goals.

Limitations

A comprehensive evaluation of the methodological quality of the included studies revealed that the current evidence-base is not yet at the stage where it can be considered established or promising (Reichow et al., 2008). The majority of studies, single case and group, were found to have weak research report strength. As such, findings reported in the present review should be interpreted with caution.

Due to the considerable heterogeneity in the designs and outcomes used by studies, it was not possible to conduct a meta-analysis. Meta-analysis would have strengthened this review, as it would have enabled individual study effects to be pooled together to increase statistical power, which would have, in turn, helped generate an overall effect size that could have been generalised to the wider adult ID population. Moreover, meta-analysis enables the investigation of publication bias, but at present, there is no way of knowing how publication bias might have influenced the results of this review, as research reporting that certain third-wave interventions are ineffective might not have been published (i.e., the file-drawer problem). This issue has been encountered in other reviews (e.g., Chapman et al., 2013; Dagnan et al., 2018).

While the majority of studies recruited participants in the mild ID range, some recruited participants in the moderate ID range. The results of the present review, therefore, cannot be reliably extrapolated to adults with severe or profound ID. Sturmey (2004) raised this issue in his critique: people with more significant degrees of ID, who have significantly limited language and abstract reasoning abilities, may not benefit from psychological therapies.

Comparison with previous reviews

The results from the present review are consistent with the results reported in previous reviews (Chapman et al., 2013; Hwang et al., 2013): although third-wave therapies have been found to produce positive outcomes for some clinical presentations, such a finding cannot be reliably extrapolated due to the poor methodological rigour of studies.

Research implications

It is important to consider that the different third-wave therapies are at different stages in their empirical evaluation. While research is still attempting to establish whether ACT and CFT can be adapted for use with adults with ID, it has already been established that mindfulness-based approaches and DBT are feasible with this population. For example, mindfulness and DBT both have manuals. Moreover, Singh et al.'s (2008) study has suggested that third-wave therapies may be cost-effective. Researchers should continue to develop the evidence-base for each of the third-wave therapies evaluated in this review. Research on mindfulness-based approaches and DBT should continue to focus on establishing whether these interventions are more effective than other evidence-based interventions (i.e., CBT) and/or TAU using RCTs. The utility of future research will be maximised by employing more rigorous designs and using standardised outcome measures with sound psychometric properties, as this will enable a meta-analysis to be conducted. Notably, several outcome measures with sound psychometric properties that can be used with people with ID have been identified (Vlissides et al., 2016).

Additionally, it is vitally important qualitative methodology is used to ask adults with ID about their experiences of third-wave therapies. Only so much can be learnt from looking at changes in behaviour and scores on subjective measures. The invaluable views of adults with ID who have attended groups will help to identify (a) whether the different third-wave therapies have been adapted sufficiently, and (b) which aspects of these interventions are most/least helpful.

Clinical implications

Results of this review's quality appraisal suggested that practice should wait for substantive high quality research evidence indicating that third-wave therapies are effective when used with people with ID. However, the dissemination of this finding may be too late to halt the practice of third-wave therapies with people with ID. Instead, it may be more useful to point practitioners toward the best evidence identified in this review. The only study that received an adequate research report strength rating and reported a significant effect was Singh et al.'s (2014) RCT on the use of SoF to stop smoking.

Conclusion

The present review has found a number of third-wave therapies that have been used with adults with ID. In terms of effectiveness, available evidence indicates that, as a collective, they can (a) sometimes improve symptoms associated with some mental health problems, (b) significantly reduce challenging behaviour and aggression across a range of settings, (c) stop smoking altogether, and (d) increase a range of mindfulness skills. However, findings from the present review should be interpreted with caution due to the poor methodologies of included studies.

References

*Adkins, A. D., Singh, A. N., Winton, A. S. W., McKeegan, G. F., & Singh, J. (2010). Using a mindfulness-based procedure in the community: Translating research to practice. *Journal of Child and Family Studies, 19*(2), 175-183. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1007/s10826-009-9348-9

*Ashworth, S., Mooney, P., & Tully, R. J. (2017). A case study demonstrating the effectiveness of an adapted-DBT program upon increasing adaptive emotion management skills, with an individual diagnosed with mild learning disability and emotionally unstable personality disorder. *Journal of Forensic Psychology Research and Practice, 17*(1), 38-60. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/15228932.2017.1251098

Bandura, A., Blanchard, E. B., & Ritter, B. (1969). Relative efficacy of desensitization and modeling approaches for inducing behavioral, affective, and attitudinal changes. *Journal of Personality and Social Psychology*, *13*(3), 173. doi: http://dx.doi.org/10.1037/h0028276

Beck, A. T. (Ed.). (1979). *Cognitive therapy of depression*. New York, US: Guilford press.

Borkovec, T. D., Newman, M. G., Pincus, A. L., & Lytle, R. (2002). A component analysis of cognitive-behavioral therapy for generalized anxiety disorder and the role of interpersonal problems. *Journal of Consulting and Clinical Psychology*, *70*(2), 288. doi: 10.1037//0022-006X.70.2.288

*Boulton, N. E., Williams, J., & Jones, R. S. (2018). Could participant-produced photography augment therapeutic interventions for people with intellectual disabilities? A systematic review of the available evidence. *Journal of Intellectual Disabilities*, *22*(1), 74-95. doi: https://doi.org/10.1177/1744629516663027

*Brown, F. J., & Hooper, S. (2009). Acceptance and commitment therapy (ACT) with a learning disabled young person experiencing anxious and obsessive thoughts. *Journal of Intellectual Disabilities, 13*(3), 195-201. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/1744629509346173

Butler, A. C., Chapman, J. E., Forman, E. M., & Beck, A. T. (2006). The empirical status of cognitive-behavioral therapy: a review of meta-analyses. *Clinical psychology review*, *26*(1), 17-31. doi: https://doi.org/10.1016/j.cpr.2005.07.003

Cahill, J., Barkham, M., & Stiles, W. B. (2010). Systematic review of practice‐based research on psychological therapies in routine clinic settings. *British Journal of Clinical Psychology*, *49*(4), 421-453. doi: 10.1348/014466509X470789

Chapman, M. J., Hare, D. J., Caton, S., Donalds, D., McInnis, E., & Mitchell, D. (2013). The use of mindfulness with people with intellectual disabilities: A systematic review and narrative analysis. *Mindfulness*, *4*(2), 179-189. doi: https://doi.org/10.1007/s12671-013-0197-7

*Chilvers, J., Thomas, C., & Stanbury, A. (2011). The impact of a ward-based mindfulness programme on recorded aggression in a medium secure facility for women with learning disabilities. *Journal of Learning Disabilities & Offending Behaviour, 2*(1), 27–42. doi: 10.5042/jldob.2011.0026

Chinn, D., Abraham, E., Burke, C., & Davies, J. (2014). IAPT and learning disabilities. *King's College and Foundation for People with Learning Disabilities, London*. Retrieved from: https://kclpure.kcl.ac.uk/portal/files/64264538/iapt_and_learning_disabilities_report.PDF

*Clapton, N. E., Williams, J., Griffith, G. M., & Jones, R. S. (2017). 'Finding the person you really are… on the inside' Compassion focused therapy for adults with intellectual

disabilities. *Journal of Intellectual Disabilities*, *22*(2), 135-153. doi: https://doi.org/10.1177/1744629516688581

*Cooper, R., & Frearson, J. (2017). Adapting compassion focused therapy for an adult with a learning disability—A case study. *British Journal of Learning Disabilities, 45*(2), 142-150. doi:http://dx.doi.org.ezproxy.bangor.ac.uk/10.1111/bld.12187

Cozolino, L. (2017). *The neuroscience of psychotherapy: Healing the social brain*. New York, US: WW Norton & Company.

*Crossland, T., Hewitt, O., & Walden, S. (2017). Outcomes and experiences of an adapted dialectic behaviour therapy skills training group for people with intellectual disabilities. *British Journal of Learning Disabilities, 45*(3), 208-216. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1111/bld.12194

Cuthill, F. M., Espie, C. A., & Cooper, S. A. (2003). Development and psychometric properties of the Glasgow Depression Scale for people with a learning disability: Individual and carer supplement versions. The British Journal of Psychiatry, 182(4), 347-353. doi: https://doi.org/10.1192/bjp.182.4.347

Dagnan, D., Jackson, I., & Eastlake, L. (2018). A systematic review of cognitive behavioural therapy for anxiety in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, *62*(11), 974-991. doi: https://doi.org/10.1111/jir.12548

Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of epidemiology and community health*, *52*(6), 377-384. Retrieved from http://jech.bmj.com/content/52/6/377

Feldman, G., Hayes, A., Kumar, S., Greeson, J., & Laurenceau, J. P. (2007). Mindfulness and emotion regulation: The development and initial validation of the Cognitive and

Affective Mindfulness Scale-Revised (CAMS-R). *Journal of Psychopathology and Behavioral Assessment, 29*(3), 177. doi: https://doi.org/10.1007/s10862-006-9035-8

*Florez, I. A., & Bethay, J. S. (2017). Using adapted dialectical behavioral therapy to treat challenging behaviors, emotional dysregulation, and generalized anxiety disorder in an individual with mild intellectual disability. *Clinical Case Studies, 16*(3), 200-215. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/1534650116687073

Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in psychiatric treatment, 15*(3), 199-208. doi: https://doi.org/10.1192/apt.bp.107.005264

*Hall L., Bork N., Craven S. & Woodrow C. (2013). People with learning disabilities experiences of a dialectical behaviour therapy skills group: a thematic analysis. *Clinical Psychology & People with Learning Disabilities, 11*, 7–11.

*Hardiman, M., Willmoth, C., & Walsh, J. J. (2018). CFT & people with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, *12*(1), 44-56. doi: 10.1108/AMHID-07-2017-0030

Hayes, S. C. (2004). Acceptance and commitment therapy, relational frame theory, and the third wave of behavioral and cognitive therapies. *Behavior therapy*, *35*(4), 639-665. doi: 10.1016/S0005-7894(04)80013-3.

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). *Acceptance and commitment therapy*. New York, US: Guilford Press.

Hwang, Y. S., & Kearney, P. (2013). A systematic review of mindfulness intervention for individuals with developmental disabilities: Long-term practice and long lasting effects. *Research in developmental disabilities*, *34*(1), 314-326. doi: https://doi.org/10.1016/j.ridd.2012.08.008

Idusohan‐Moizer, H., Sawicka, A., Dendle, J., & Albany, M. (2015). Mindfulness‐based cognitive therapy for adults with intellectual disabilities: an evaluation of the

effectiveness of mindfulness in reducing symptoms of depression and anxiety. *Journal of Intellectual Disability Research*, *59*(2), 93-104. doi: https://doi.org/10.1111/jir.12082

Leoni, M., Corti, S., & Cavagnola, R. (2015). Third generation behavioural therapy for neurodevelopmental disorders: review and trajectories. *Advances in Mental Health and Intellectual Disabilities*, *9*(5), 265-274. doi: https://doi.org/10.1108/AMHID-06-2015-0031

*Lew, M., Matta, C., Tripp-Tebo, C., & Watts, D. (2006). Dialectical behavior therapy (DBT) for individuals with intellectual disabilities: A program description. *Mental Health Aspects of Developmental Disabilities, 9*(1), 1-12. Retrieved from: https://search-proquest-com.ezproxy.bangor.ac.uk/docview/621145185?accountid=14874

Leyin, A. (2011). Improving access to psychological therapies for people with learning disabilities. *Tizard Learning Disability Review*, *16*(5), 29-37. doi: https://doi.org/10.1108/13595471111185747

Linehan, M. M. (1993). *Cognitive behavioral therapy of borderline personality disorder* (Vol. 51). New York, US: Guilford Press.

Longmore, R. J., & Worrell, M. (2007). Do we need to challenge thoughts in cognitive behavior therapy? *Clinical psychology review*, *27*(2), 173-187. doi: https://doi.org/10.1016/j.cpr.2006.08.001

Meichenbaum, D. (1977). Cognitive behaviour modification. *Cognitive Behaviour Therapy*, *6*(4), 185-192. doi: https://doi.org/10.1080/16506073.1977.9626708

McNair, L., Woodrow, C., & Hare, D. (2017). Dialectical behaviour therapy [DBT] with people with intellectual disabilities: A systematic review and narrative

analysis. *Journal of Applied Research in Intellectual Disabilities*, *30*(5), 787-804. doi: https://doi.org/10.1111/jar.12277

Mindham, J., & Espie, C. A. (2003). Glasgow Anxiety Scale for people with an Intellectual Disability (GAS‐ID): development and psychometric properties of a new measure for use with people with mild intellectual disability. *Journal of Intellectual Disability Research*, *47*(1), 22-30. doi: https://doi.org/10.1046/j.1365-2788.2003.00457.x

Nicoll, M., Beail, N., & Saxon, D. (2013). Cognitive behavioural treatment for anger in adults with intellectual disabilities: A systematic review and meta‐analysis. *Journal of Applied Research in Intellectual Disabilities*, *26*(1), 47-62. doi: https://doi.org/10.1111/jar.12013

Pankey, J., & Hayes, S. C. (2003). Acceptance and commitment therapy for psychosis. *International Journal of Psychology and Psychological Therapy*, *3*(2), 311-328.

Patterson, C. (2018). Does the adapted sex offender treatment programme reduce cognitive distortions? A meta-analysis. *Journal of Intellectual Disabilities and Offending Behaviour*, *9*(1), 9-21. doi: https://doi.org/10.1108/JIDOB-08-2017-0018

Reichow, B., Volkmar, F. R., & Cicchetti, D. V. (2008). Development of the evaluative method for evaluating and determining evidence-based practices in autism. *Journal of autism and developmental disorders*, *38*(7), 1311-1319. doi: https://doi.org/10.1007/s10803-007-0517-7

Reichow, B. (2011). Development, procedures, and application of the evaluative method for determining evidence-based practices in autism. In *Evidence-based practices and treatments for children with autism* (pp. 25-39). Boston, MA, US: Springer.

Roy, A., Matthews, H., Clifford, P., Fowler, V., & Martin, D. M. (2002). Health of the nation outcome scales for people with learning disabilities (HoNOS–LD). *The British Journal of Psychiatry, 180*(1), 61-66. doi: https://doi.org/10.1192/bjp.180.1.61

*Sakdalan, J. A., Shaw, J., & Collier, V. (2010). Staying in the here-and-now: A pilot study on the use of dialectical behaviour therapy group skills training for forensic clients with intellectual disability. *Journal of Intellectual Disability Research, 54*(6), 568-572. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1111/j.1365-2788.2010.01274.x

Shepherd, C., & Beail, N. (2017). A systematic review of the effectiveness of psychoanalysis, psychoanalytic and psychodynamic psychotherapy with adults with intellectual and developmental disabilities: progress and challenges. *Psychoanalytic Psychotherapy*, *31*(1), 94-117. doi: https://doi.org/10.1080/02668734.2017.1286610

*Singh, N. N., Lancioni, G. E., Myers, R. E., Karazsia, B. T., Winton, A. S. W., & Singh, J. (2014). A randomized controlled trial of a mindfulness-based smoking cessation program for individuals with mild intellectual disability. *International Journal of Mental Health and Addiction, 12*(2), 153-168. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1007/s11469-013-9471-0

*Singh, N. N., Lancioni, G. E., Winton, A. S. W., Adkins, A. D., Singh, J., & Singh, A. N. (2007). Mindfulness training assists individuals with moderate mental retardation to maintain their community placements. *Behavior Modification, 31*(6), 800-814. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/0145445507300925

*Singh, N. N., Lancioni, G. E., Winton, A. S. W., Karazsia, B. T., Singh, A. D. A., Singh, A. N. A., & Singh, J. (2013). A mindfulness-based smoking cessation program for individuals with mild intellectual disability. *Mindfulness, 4*(2), 148-157. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1007/s12671-012-0148-8

*Singh, N. N., Lancioni, G. E., Winton, A. S. W., Singh, A. N. A., Singh, J., & Singh, A. D. A. (2011a). Effects of a mindfulness-based smoking cessation program for an adult with mild intellectual disability. *Research in Developmental Disabilities, 32*(3), 1180-1185. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1016/j.ridd.2011.01.003

*Singh, N. N., Lancioni, G. E., Winton, A. S. W., Singh, A. N., Adkins, A. D., & Singh, J. (2011b). Can adult offenders with intellectual disabilities use mindfulness-based procedures to control their deviant sexual arousal? *Psychology, Crime & Law, 17*(2), 165-179. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/10683160903392731

*Singh, N. N., Lancioni, G. E., Winton, A. S. W., Singh, A. N., Adkins, A. D., & Singh, J. (2008). Clinical and benefit-cost outcomes of teaching a mindfulness-based procedure to adult offenders with intellectual disabilities. *Behavior Modification, 32*(5), 622-637. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/0145445508315854

*Singh, N. N., Wahler, R. G., Adkins, A. D., & Myers, R. E. (2003). Soles of the feet: A mindfulness-based self-control intervention for aggression by an individual with mild mental retardation and mental illness. *Research in Developmental Disabilities, 24*(3), 158-169. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1016/S0891-4222(03)00026-X

Sturmey, P. (2004). Cognitive therapy with people with intellectual disabilities: A selective review and critique. *Clinical Psychology & Psychotherapy: An International Journal of Theory & Practice*, *11*(4), 222-232. doi: https://doi.org/10.1002/cpp.409

Taylor, J. L., Lindsay, W. R., Hastings, R. P., & Hatton, C. (Eds.). (2012). *Psychological therapies for adults with intellectual disabilities*. New Jersey, US: John Wiley & Sons.

Teasdale, J. D. (1997). The relationship between cognition and emotion: The mind-in-place in mood disorders. In D. M. Clark & C. G. Fairburn (Eds.), *Oxford medical*

publications. Science and practice of cognitive behaviour therapy (pp. 67-93). New York, NY, US: Oxford University Press.

Teasdale, J. D., Segal, Z. V., Williams, J. M. G., Ridgeway, V. A., Soulsby, J. M., & Lau, M. A. (2000). Prevention of relapse/recurrence in major depression by mindfulness-based cognitive therapy. *Journal of consulting and clinical psychology, 68(*4), 615. doi: 10.1037//0022-006X.68.4.615

Vlissides, N., Beail, N., Jackson, T., Williams, K., & Golding, L. (2017). Development and psychometric properties of the Psychological Therapies Outcome Scale–Intellectual Disabilities (PTOS-ID). *Journal of Intellectual Disability Research, 61*(6), 549-559. doi: https://doi.org/10.1111/jir.12361

Vlissides, N., Golding, L., & Beail, N. (2016). A systematic review of the outcome measures used in psychological therapies with adults with ID. In Beail, N. (Ed.) (2016). *Psychological therapies and people who have intellectual disabilities.* Retrieved from: https://www1.bps.org.uk/system/files/Public%20files/id_therapies.pdf.

Chapter 2 – Empirical Paper

How do people with intellectual disabilities experience the adapted sex offender treatment programme? A qualitative study using interpretative phenomenological analysis

Chris Patterson, Dr. Jonathan Williams[1] and Prof. Robert Jones[2]

1. Forensic Adolescent Consultation and Therapy service, North Wales Adolescent Service, Abergele Hospital, Abergele, UK
2. North Wales Clinical Psychology Programme, School of Psychology, Bangor University, Bangor, UK

Corresponding Author: Chris Patterson, North Wales Clinical Psychology Programme, School of Psychology, Bangor University, Bangor, UK. Email: psuc1a@bangor.ac.uk

---

This paper was submitted to the Journal of Applied Research in Intellectual Disabilities

Author guidelines can be found using the following address: https://onlinelibrary.wiley.com/page/journal/14683148/homepage/forauthors.html

Abstract

Background: The main form of treatment for sex offenders with ID is the adapted Sex Offender Treatment Programme (aSOTP). Extant research is limited to quantitative studies employing small samples sizes and weak methodology. How sex offenders with ID experience various important aspects of the aSOTP, therefore, remains relatively unknown. **Method:** Six male adult sex offenders with ID, living in the community, were asked about their experiences of the aSOTP using a semi-structured interview. **Results:** Interpretative Phenomenological Analysis identified three themes: Choice, Disclosure and 'It's like being back at school'. **Conclusions:** Sex offenders with ID often feel coerced to join the aSOTP. Facilitators need to further adapt content to ensure that group members understand. Disclosure is an anxiety-inducing process that can lead to either relief or shame depending on group safeness. Considering that the denial has a protective function and shame is associated with victim blaming and withdrawal behaviour, facilitators should approach offence disclosure carefully.

Keywords: intellectual disabilities; sex offending; interpretative phenomenological analysis; qualitative research.

Introduction

Issues relating to sexual offending elicit strong reactions from the general public (Brown, 1999). This is partly due to the extent and nature of media coverage of the topic (Willis et al., 2010). Undoubtedly, public opinion has and will continue to influence legislation and policy surrounding the treatment of sex offenders (Shackley et al., 2014), contributing societal and organisational pressure to effectively treat people who have offended sexually. The main form of treatment for sex offenders over the past 30 years has been the group-based, cognitive-behavioural Sex Offender Treatment Programme (SOTP; Friendship et al., 2003). Early evidence indicated that the SOTP significantly reduced rates of reoffending (Hall, 1995; Hanson et al., 2002; Losel & Schmucker, 2005). Recently, however, results from a large-scale meta-analysis suggested the SOTP significantly *increased* reoffending rates at eight-year follow-up (Mews et al., 2017). Although this finding is yet to be fully explained, there have been suggestions that normalisation (Yalom, 1995), as part of the group therapy process, may be a factor. Members may find that their pro-offending beliefs are shared by others, and thus could be bolstered despite treatment focus on addressing such beliefs (Mews et al., 2017). Nevertheless, qualitative research suggests people completing the mainstream SOTP have typically reported that they found the programme acceptable and beneficial (Collins et al., 2010; Wakeling et al., 2005).

Although the SOTP was initially developed in the UK by prison services to treat sex offenders without intellectual disabilities (ID), it has since been adapted into two similar programmes: Lindsay's *Treatment of Sex Offender with Developmental Disabilities* (Lindsay, 2009), and the more prevalent *Sex Offender Treatment Services Collaborative Adapted Sex Offender Treatment Programme* (SOTSEC-ID aSOTP, Murphy & Sinclair, 2009). There are fewer high quality studies evaluating adapted group treatments compared with the

mainstream SOTP programmes (Jones & Chaplin, 2017). Research on the adapted programmes are characterised by case studies and non-controlled studies using small samples (e.g., Keeling et al., 2006; Lindsay et al., 1998). Nevertheless, studies evaluating the aSOTP have been systematically reviewed twice in recent years. Both reviews tentatively concluded that the aSOTP improves a number of risk-related variables including sexual knowledge, victim empathy and cognitive distortions (Jones & Chaplin, 2017; Patterson, 2018).

People who have committed sexual offences are not always offered a choice regarding whether they attend the aSOTP (Burdon & Gallagher, 2002; Day et al., 2004). Literature is mixed regarding choice as pre-requisite for effective therapy (Burdon & Gallagher, 2002; Day et al., 2004). However, there are examples in forensic literature where people who have offended have benefitted from forced treatment (Terry & Mitchell, 2001). Indeed, results from a meta-ethnography conducted by Evans and Randle-Phillips (2018) indicated that the majority of people with ID do not initially choose to be referred for psychotherapeutic interventions in general.

Increasingly, it is being acknowledged that, given the opportunity, people with ID can provide invaluable insights into key aspects of their care and treatment (Vereenooghe & Langdon, 2013). However, there is a paucity of qualitative research exploring how people with ID view the aSOTP (Hollomotz, 2014). Thus far, two qualitative studies have been conducted in this area, providing useful descriptions regarding what people with ID find helpful and unhelpful about the aSOTP (Hays et al., 2007; Large & Thomas, 2011). Hays et al. (2007) identified that one of the aSOTP's main strengths is that it puts sex offenders with ID in contact with others who have similar problems. This is striking considering that Mews et al. (2017) cited normalisation as a potential cause for the increased reoffending rates found in non-ID samples. Large and Thomas (2011) reported that their participants found the

following group components important: shorter blocks and planned breaks, frequent repetition of key concepts, interactive exercises, and the opportunity for more experienced group members to share their knowledge with less experienced group members. However, neither of these studies (Hays et al., 2007; Large & Thomas, 2011) provided in-depth accounts of how people with ID experience particular aspects of the aSOTP.

This study, therefore, aims to discover how sex offenders with ID, a small and hard to reach population, experience entering, being a part of, and sharing their offences in the aSOTP using Interpretative Phenomenological Analysis (IPA; Smith et al., 2009). IPA is an emerging methodology in the field of ID (e.g., Giesbers et al., 2019; Groves et al., 2018; Thackeray et al., 2018). IPA studies seek to gain rich accounts (phenomenology) of how a particular group of people (idiography) come to make sense of (hermeneutics) a specific experience (Smith & Osborn, 2004).

Method

Participants

In accord with IPA, a small purposive sample was selected, comprising six males aged between 25 and 62 years (M = 36.2; SD = 15.3) with mild ID, living in the community, after completing the aSOTP in the last 12 to 24 months (M = 18.2; SD = 4.7). To obtain a relatively homogenous sample, participants had to meet the following inclusion criteria.

Inclusion criteria:

- English speaking
- Male

- Aged 18 or over
- Diagnosis of Intellectual Disability
- Living in a community setting
- Completed the aSOTP
- Convicted of at least one sexual offence

Exclusion criteria:

- Assessed as not having capacity to consent to participate
- Suffering from an acute mental health problem
- Detained in an inpatient setting

Procedure

This study was given ethical approval by the required university and NHS panels. The first author contacted researchers in the field to find out where aSOTP groups were running. The first author was pointed toward two NHS Trusts in England. The first author then contacted clinicians working within these Trusts who had either run or were running aSOTP groups to provide them with full information about this study. These clinicians contacted individuals who met the study's inclusion criteria and used the 'I'm interested form' (Appendix 1) to provide basic information about the study to establish whether they were potentially interested in participating. The details of those who met the inclusion criteria and declared an interest in participating were then passed on to the first author, who later contacted them to arrange a meeting. Subsequently, the first author contacted potential participants over the phone to arrange a meeting where they could be provided with further information about the

study. Agreement was sought from the participant's care team to ensure there was no foreseeable impact on ongoing care.

The first author met with potential participants at their place of residence. All potential participants were offered the choice of having a member of their care team present. Three participants took up this option. Potential participants were provided with an easy-read information sheet and assisted to understand the contents as required (Appendix 2). Subsequently, the first author completed an assessment to establish whether a participant possessed the capacity to consent to participate in the study (Arscott et al., 1998; Appendix 3). Participants who demonstrated capacity and a willingness to consent were asked to complete the consent form (Appendix 4). These individuals were then interviewed and the interviews were recorded using a Dictaphone. The first author spent between 31 and 77 minutes (M = 53.5; SD = 14.6) interviewing participants using a semi-structured interview schedule (Appendix 5), which was structured as follows: (1) background information; (2) understanding; (3) the wider impact of group affiliation on life; (4) within group experiences; and (5) group evaluation. Participants were debriefed and thanked upon completion (Appendix 6).

The first author started the analysis process by transcribing interviews on a line-numbered Microsoft Word document in accordance with guidance put forward by Smith et al. (2009). Transcripts were read and reread while listening to the original recording. Then, the first author made initial notes (descriptive, linguistic and conceptual) on the transcripts before developing themes. Emergent themes were grouped, discussed and agreed with the third author.

Materials

Easy-read documentation and the semi-structured interview schedule were initially constructed with the support of a person with an ID who had attended the aSOTP, a clinical nurse specialist who had facilitated a group, a speech and language therapist, and a researcher experienced in using IPA. Prior to applying for ethical approval, the materials were presented to a panel of service-user representatives for their feedback. The above process resulted in changes to the interview schedule, consent form, participant information sheet, and debrief sheet.

Reflexivity

IPA acknowledges that the researcher is an active participant in the research process who attempts to make sense of what their participant is telling them about an experience (double-hermeneutic; Smith & Osborn, 2004). Undoubtedly, researchers' pre-suppositions shape the way they interpret participants' accounts (Smith & Osborn, 2004). As such, the first author kept a reflective diary throughout the study (Smith et al., 2009), identifying pre-suppositions such as: participants would be sexually aroused by discussions about sexual offending. This process reduced the likelihood that the first author's pre-suppositions influenced the way in which participants' accounts were interpreted.

Results

Analysis of participants' accounts revealed three themes: (1) Choice, (2) Disclosure and (3) 'It's like being back at school'. These themes and related sub-themes are described in turn below.

Theme 1: Choice.

This theme was present in all interviews. Before starting the group, participants who were detained in inpatient settings reported that they met with senior clinicians and managers to discuss the aSOTP. These participants reported being able to choose whether they attended the aSOTP. However, they reported their understanding that the only alternative to joining the aSOTP was to remain in inpatient care indefinitely.

P: I had a choice of if you don't want to do it, you know, you'll be here forever – a long time (Nicky: 91-94).

Participants believed that they had a choice between two paths: one path leading to serious problems for them and the other to a better life.

P: I would never do it again; I'd never go down that path.

I: Where do you think that path would lead you?

P: If I done it again, probably prison or [name of inpatient service] for a very, very, very long time.

I: So one path goes that way, what's the other path?

P: The other path goes back. So if you do it again you go back to where you started from and you might have to do the process again.

I: What about the path you're on now, where does that take you?

P: It's taking me to a better future (Phil: 591-599).

Sub-theme (b): Commitment.

Most participants described the aSOTP as a substantial commitment that required them to alter their lifestyle for a prolonged period of time.

*P: My alarm clock used to go off at, 6.45 in the morning. […] I used to have a fancy one that used to light up the room saying the time, but I thought f*** it - out of the window. (Paul: 918-921)*

P: I used to just sit there and think, "Am I ever going to get out of here?" If it's going on for that long… It was quite daunting in a way. I used to say to my mum, "I don't think I'm ever going to get out – it's dragging and dragging" (David: 696-698).

Sub-theme (c): Overcoming doubt.

For many participants, there were points where they experienced doubt, questioning the value of the group: "Why am I coming back?" (Phil: 1003). Some participants appeared to respond to this inner doubt by providing themselves with encouragement. Such inner dialogue seemed to help participants to continue with the group despite the degree of commitment required.

P: I was thinking: "I don't want to do this, I can't be arsed, I'm just going to leave and not come back" you know? But then I decided "no I will do it because it will help me in the future… progress with my life… let me know who I can and can't speak to at certain times" if you know what I mean? (Phil: 463-466).

Theme 2: Disclosure

Sub-theme (a): Denial.

Participants discussed how they had historically denied sexual offending to avoid feelings of shame.

P: I always used to try and lie about things because I felt very embarrassed, very ashamed (Paul: 379-381).

Sub-theme (b): Confidentiality: a double-edged sword.

Across interviews, confidentiality was seen as an essential group rule. Although participants were aware that group facilitators were likely to maintain confidentiality beyond the boundaries of the group setting, they were not always confident that this would be true of their fellow group members. When this rule was not adhered to, participants did not feel safe to disclose their offences because of the huge potential negative consequences of their disclosures being more widely known outside the group.

P: They'd ask you for something. If you wouldn't give it them they'd be like "I'll tell them what you're in here for, and I was like "really?" (David: 620-621).

*P: There was one guy in there that said he beat a sex offender up in prison, and I thought, "what the f***, s***". He said that he'd nearly killed him, and I thought "what?" So it is quite scary – it's daunting (David: 544-568).*

Sub-theme (c): The build-up.

Participants described their experience of the build-up to disclosure in very similar terms, having thoughts such as:

P: What are they going to think of me? […] If I tell them then they go back and tell everybody else on the unit then it makes it hard for me, staying there and living there (David: 202-206).

This resulted in anxiety for participants, and an urge to leave the room during the group:

P: I felt nervous at the time […] I felt really tense in the belly and I got up to go out of the room (Gary: 120-121).

Associated physiological sensations were intense and difficult to tolerate.

P: If you keep it inside, it's going to keep bottling up […] and explode like a volcano (Ryan: 266-268).

Sub-theme (d): Reactions.

Participants' accounts revealed two different reactions to disclosing in the group, relief and shame.

P: My anxiety dropped and that and I thought, "ooo, that's a relief" you know? (Phil: 446).

*P: When I got home after the group. I was like I don't want to talk to people. Just f*** off and leave me alone.*

I: Why do you think that was?

P: Because I was just ashamed of what I've spoken about – shame of what I've done (Paul: 362-366)

Theme 3: 'It's like being back at school' (Nicky: 501).

This theme was prominent across participants. For some, it was the practical aspects of the group that reminded participants of being back at school. For others, it was the content that was being covered.

P: It was just like going back to sex education course. That's what it was. "Oh by the way when you have sex you need to use a condom, or if you don't want to do that, ask the woman to go on the pill." It's, ahh, it's just like "I've already gone through all of this at school" (Paul: 993-997).

Some participants reflected on how they did not like school.

I: And what was that like for you having to do things that you did in school?
P: Terrible - I didn't like school. Yeah, I didn't like school (Nicky: 501-515).

Sub-theme (a): Not understanding.

Nearly all participants shared examples where they struggled to understand and/or keep up with work. This was related to the use of long words and difficult questions, and not being given enough time to process information. A few participants explained that they did not want to tell facilitators that they did not understand because they felt embarrassed.

I: Did you always understand what people were talking about in the group?
P: No. No. Cos they were speaking too loud and that, and too fast.

I: And what kind of words were they using?

P: Long words… membership and all this… Long words…

I: Was that when the facilitators were talking?

P: Yes. They put them on the board - the long words.

I: Then what?

P: We had to get them and then put them on paper.

I: I'm wondering, what was it like for you when you didn't understand what people were talking about?

P: You can ask them to repeat it.

I: And how did it feel, asking them to repeat it?

P: It made me sick.

I: And where did you feel that?

P: I don't like asking. I don't like asking.

I: When you felt sick, did you feel it in your body at all?

P: Yeah, all over - terrible. Wanted to get out of the room (Nicky: 218-257).

Sub-theme (b): Challenging group dynamics.

P: I think that it was because it was more the other group members in there. A lot of them would mess around in the group and it was just like… If there was someone stood up, trying to do stuff, they'd make silly noises, and it was like "it's hard enough standing up here anyway" […] and I'd think, "Are they laughing at me or just laughing at something I've said?" It was horrible (David: 483-491).

Sub-theme (c): Maturation.

Half of the sample described feeling like they had matured as a result of completing the aSOTP.

P: I always used to care what people thought about me. Now I just look at it - "I messed up". What I did has been done and I can't take things back. If they don't like it they don't have to talk to me, whereas before I didn't really want people to know because I cared what people think about me. Now it's just you know there's plenty of other people out there to talk to (David: 108-113).

Discussion

Participants' accounts highlighted the many ways in which sex offenders with ID join the aSOTP. More widely, those living in the community are often mandated to attend the aSOTP by the criminal justice system (Day et al., 2004; Toman & Hawkins, 2008), whereas those who are detained in inpatient settings are presented with a choice: to join or not to join. However, this choice is strongly influenced by the belief that refusal to attend the aSOTP will be met with significant negative consequences. Therefore, this is a *Hobson's choice* (Keywood, 1998), considering that there is no real alternative to not attending (Birgden & Vincent, 2000).

This study showed that the aSOTP is a significant commitment. Due to the apparent paucity of groups in the UK, some members may have to travel substantial distances to attend. Moreover, the weekly aSOTP lasts for approximately 12 months. As of yet, these issues have not been identified as barriers to completing sex offender treatment. Participants suggested that these issues caused them to experience doubt. Half of the sample discussed

how they practised self-encouragement to overcome doubt. This inner dialogue, identified in mainstream group psychotherapy literature (Gilbert, 2006), seemed vital in enabling participants to complete the physically and emotionally challenging aSOTP.

Nearly all participants spoke of how the aSOTP reminded them of school. This is particularly important considering that they, like many people with ID, had negative experiences of school (Milsom, 2006). Participants did not always understand group content due to reduced language abilities and slower processing speed. Such experiences may have been reminiscent of difficult school experiences, triggering feelings of anxiety and embarrassment. Participants typically responded to this by pretending that they understood the content of the work. It is well established that such acquiescence is a common barrier in therapy with people with ID (Haddock & Jones, 2006; Kroese, 1998). This finding raises a serious question of whether we expect the aSOTP to improve various risk-related outcomes, if treatment completers did not understand the work.

The most salient aspect of the aSOTP for all participants was offence disclosure. As highlighted by Blagden et al. (2014), offence disclosure is widely viewed as the most essential component of sex offender treatment. Consistent with mainstream literature, participants described how they initially denied or minimised their sexual offences (Mann & Beech, 2003; Marshall et al., 2009; Thakker et al., 2007) to avoid experiencing shame, characterised by thoughts about being negatively judged or victimised by others (MacDonald et al., 2003; Tangney & Dearing, 2003). All participants thought that group members would label, blame and judge them for their sexual offences. Moreover, participants thought that group members would tell other patients on the unit about their offences, jeopardising their safety. These thoughts elicited anxiety for all participants, but were so intense for some that they temporarily left the group (Kletner & Harker, 1998). Participants' reactions to

disclosing were mixed, as one half experienced relief and the other half experienced shame. Relief was experienced after disclosing to supportive groups that strictly adhered to confidentiality. Shame, however, was experienced after disclosing to groups that were perceived as less robust, in which other members were reported to transgress group rules (e.g., mocking during disclosure and threatening to break confidentiality).

Clinical implications

Presently, the implications of coerced sex offender treatment are yet to be fully understood (Burdon & Gallagher, 2002). Although some studies suggest that coerced sex offender treatment leads to low internal motivation, which, in turn, reduces treatment outcomes (Birgden & Vincent, 2000), others indicate that coerced and non-coerced treatment produce similar outcomes (Terry & Mitchell, 2001). Nevertheless, when meeting with people with ID to discuss embarking on the aSOTP, senior clinicians and managers should consider how the choice they present might be perceived (Stalker & Harris, 1998).

This study highlighted that participants struggled to understand long words and awkwardly phrased questions, and to process the information provided to them quickly enough. They were also often too embarrassed to ask group facilitators to simplify, slow down or repeat what they were saying. Therefore, group facilitators should be more conscious of the language they use to convey information in sessions and the speed at which they do so. They should also regularly check whether group members have understood content and repeat information if necessary (Patterson et al., 2019).

Adapted SOTP group facilitators should consider the importance of creating an environment and atmosphere of safety for group members. Despite confidentiality being a group rule, group members might threaten to, or actually tell, other patients about other group members'

offences. Often these inpatient settings have a mixture of patients, including sex offenders and violent offenders. There is a real risk that the safety of group members may be compromised if other patients find out about an individual's offences. Participants may, therefore, be reluctant to drop their defences and disclose the true nature of their sexual offence for pragmatic self-protection (Blagden et al., 2014; Marshall et al., 2009).

Considerable emphasis is placed on confronting denial and minimisation in sex offender treatment (Beech & Fisher, 2002). However, neither of these variables has been shown to predict sexual recidivism (Hanson & Bussiere, 1998; Hanson & Morton-Bourgon, 2005). There is increasing support for a less confrontational way of working with such defenses (Winn, 1996), which involves initially acknowledging the protective function of denial and minimisation. Arguably, facilitators should not confront denial or minimisation where challenging group dynamics prevail, as this could have adverse consequences.

Sex offender treatment should move from eliciting shame to eliciting guilt. Research demonstrates that sex offenders who experience shame are likely to deny or minimise their offences, blame victims and withdraw. This is because shame is associated with global, negative self-evaluations ("I am a bad person"; Gilbert, 2006). Conversely, sex offenders who experience guilt are likely to consider how their offences might have affected others and want to apologise and make reparations. This is because guilt is associated with the acknowledgement that a behaviour enacted by the self has had negative consequences for others ("I did a bad thing"). This move could be accomplished by "distinguishing offenders from their inappropriate behaviour, making behaviours the focus of treatment, distinguishing the experiences of shame and guilt for clients, avoiding a confrontational approach, and explicitly targeting self-esteem" (p. 664; Proeve & Howells, 2002).

Limitations

Recruitment required clinicians to approach potential participants and ask them whether they wanted to take part in a study examining the aSOTP. Notably, three potential participants refused to participate. It is not possible to know whether the sex offenders with ID who chose to participate shared characteristics that would bias the results of this study (sampling bias).

Interviews were conducted between 12 and 24 months after participants had finished the aSOTP. This timing might have made it more difficult for participants, who already have reduced cognitive abilities, to recall in detail how they experienced particular phenomena in the aSOTP. However, as can be seen in the results section, participants provided a substantial level of detail. This may be due to the emotional saliency of their experiences in the group (Buchanan & Adolphs, 2002).

It is important to consider that the participants in this study were at the milder end of the ID continuum, who have stronger communication abilities, as can be identified from reading the quotes. Therefore, it is possible that the voices of people with moderate-severe ID remain unheard. This reflects a wider sampling bias across ID qualitative literature.

Research implications

This study's findings were mainly contextualised using evidence from mainstream sex offender literature. For example, participants' accounts of denial and shame were interpreted using previous accounts from mainstream sex offender treatment. This could possibly impact upon the validity of such interpretations, as the role of denial and shame may be different with people with ID who have offended sexually. Reliance upon mainstream research,

however, was unavoidable because the field is yet to develop a strong body of evidence on these issues. This field should consider how rigorous the ethics process is for studies wanting to examine sex offenders with ID and how it might prevent research of this kind (Brown & Thompson, 1997; Hays et al., 2003; Hollomotz, 2014).

As highlighted elsewhere (e.g., Patterson, 2018), there is a desperate need for randomised controlled trials (RCTs) evaluating the aSOTP. Notably, rates of reoffending should be included as an outcome measure, as existing studies have measured outcome using psychometric tests only (e.g., cognitive distortions). Results from RCTs, measuring rates of reoffending, will provide a more accurate picture of whether the aSOTP is effective. Increasingly, third-wave therapies are being adapted, used and empirically evaluated with people with ID (Patterson et al., 2019). Despite offering particular promise in this field, as they offer ways of managing urges and states of high arousal, the use of third-wave therapies for sex offenders with ID appears to have been neglected. Future research should fill this gap.

References

Arscott, K., Dagnan, D., & Kroese, B. S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *11*(1), 77-83. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1111/j.1468-3148.1998.tb00035.x

Beech, A. R., & Fisher, D. D. (2002). The rehabilitation of child sex offenders. *Australian Psychologist, 37*(3), 206-214. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/00050060210001706886

Birgden, A., & Vincent, J. F. (2000). Maximizing therapeutic effects in treating sexual offenders in an Australian correctional system. *Behavioral sciences & the law*, *18*(4), 479-488. doi: 3.0.CO;2-J" TARGET="_blank">http://dx.doi.org.ezproxy.bangor.ac.uk/10.1002/1099-0798(2000)18:4<479::AID-BSL388>3.0.CO;2-J

Blagden, N., Winder, B., Gregson, M., & Thorne, K. (2014). Making sense of denial in sexual offenders: A qualitative phenomenological and repertory grid analysis. *Journal of interpersonal violence*, *29*(9), 1698-1731. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/0886260513511530

Brown, H., & Thompson, D. (1997). The ethics of research with men who have learning disabilities and abusive sexual behaviour: A minefield in a vacuum. *Disability & Society, 12*(5), 695-707. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/09687599726994

Brown, S. (1999). Public attitudes toward the treatment of sex offenders. *Legal and Criminological Psychology*, *4*(2), 239-252. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1348/135532599167879

Buchanan, T. W., & Adolphs, R. (2002). The role of the human amygdala in emotional modulation of long-term declarative memory. In S. C. Moore, & M. Oaksford (Eds.), *Emotional cognition: From brain to behaviour; emotional cognition: From brain to behaviour* (pp. 9-34, Chapter vi, 348 Pages) Amsterdam, Netherlands: John Benjamins Publishing Company. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1075/aicr.44.02buc Retrieved from https://search-proquest-com.ezproxy.bangor.ac.uk/docview/619961186?accountid=14874

Burdon, W. M., & Gallagher, C. A. (2002). Coercion and sex offenders: Controlling sex-offending behavior through incapacitation and treatment. *Criminal Justice and Behavior*, *29*(1), 87-109. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/0093854802029001006

Collins, E., Brown, J., & Lennings, C. (2010). Qualitative review of community treatment with sex offenders: Perspective of the offender and the expert. *Psychiatry, Psychology and Law*, *17*(2), 290-303. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/13218710903421282

Day, A., Tucker, K., & Howells, K. (2004). Coerced offender rehabilitation–a defensible practice? *Psychology, Crime & Law*, *10*(3), 259-269. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/10683160410001662753

Smith, J. A. Flowers, P., & Larkin, M. (2009). Interpretative phenomenological analysis: Theory, method and research. Callifornia, USA: SAGE Publications Ltd.

Friendship, C., Mann, R. E., & Beech, A. R. (2003). Evaluation of a national prison-based treatment program for sexual offenders in England and Wales. *Journal of Interpersonal Violence*, *18*(7), 744-759. Retrieved from https://search-proquest-com.ezproxy.bangor.ac.uk/docview/620148676?accountid=14874

Giesbers, S. A., Hendriks, L., Jahoda, A., Hastings, R. P., & Embregts, P. J. (2019). Living with support: Experiences of people with mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *32*(2), 446-45. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1111/jar.12542

Gilbert, P. (2006). A biopsychosocial and evolutionary approach to formulation with a special focus on shame. In *Case Formulation in Cognitive Behaviour Therapy* (pp. 97-128). Abingdon, Oxfordshire, UK: Routledge.

Groves, E., Rayner, K., & Muncer, S. (2018). "It's good, they're like me; the same but different." An interpretative phenomenological analysis of the identities of women with Down's syndrome. *Journal of Applied Research in Intellectual Disabilities*, *31*(3), 445-453.

Haddock, K., & Jones, R. S. (2006). Practitioner consensus in the use of cognitive behaviour therapy for individuals with a learning disability. *Journal of Intellectual disabilities*, *10*(3), 221-230. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/1744629506067612

Hall, G. C. N. (1995). Sexual offender recidivism revisited: a meta-analysis of recent treatment studies. *Journal of consulting and clinical psychology*, *63*(5), 802. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1037/0022-006X.63.5.802

Hanson, R. K. (2002). Recidivism and age: Follow-up data from 4,673 sexual offenders. *Journal of interpersonal violence*, *17*(10), 1046-1062. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/088626002236659

Hanson, R. K., & Bussiere, M. T. (1998). Predicting relapse: a meta-analysis of sexual offender recidivism studies. *Journal of consulting and clinical psychology*, *66*(2), 348. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/088626002236659

Hanson, R. K., & Morton-Bourgon, K. (2005). The characteristics of persistent sexual offenders: A meta-analysis of recidivism studies. *Journal of Consulting and Clinical Psychology, 73*(6), 1154-1163. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1037/0022-006X.73.6.1154

Hays, S. J., Murphy, G. H., Langdon, P. E., Rose, D., & Reed, T. (2007). Group treatment for men with intellectual disability and sexually abusive behaviour: Service user views. *Journal of Intellectual and Developmental Disability*, *32*(2), 106-116. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/13668250701413715

Hays, S., Murphy, G., & Sinclair, N. (2003). Gaining ethical approval for research into sensitive topics: 'two strikes and you're out?'. *British Journal of Learning Disabilities, 31*(4), 181-189. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1111/j.1468-3156.2003.00255.x

Hollomotz, A. (2014). Sex offenders with intellectual disabilities and their academic observers: popular methodologies and research interests. *Journal of intellectual disability research*, *58*(2), 189-197. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1111/j.1365-2788.2012.01644.x

Jones, E., & Chaplin, E. (2017). A systematic review of the effectiveness of psychological approaches in the treatment of sex offenders with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1111/jar.12345

Keeling, J. A., Rose, J. L., & Beech, A. R. (2006). An investigation into the effectiveness of a custody-based cognitive-behavioural treatment for special needs sexual offenders. *The Journal of Forensic Psychiatry & Psychology*, *17*(3), 372-392. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/14789940600658293

Keltner, D., & Harker, L. (1998). The forms and functions of the nonverbal signal of shame. In P. Gilbert, & B. Andrews (Eds.), *Shame: Interpersonal behavior, psychopathology, and culture; shame: Interpersonal behavior, psychopathology, and culture* (pp. 78-98, Chapter xiv, 288 Pages) Oxford University Press: New York, NY. Retrieved from https://search-proquest-com.ezproxy.bangor.ac.uk/docview/619394910?accountid=14874

Keywood, K. (1998). Hobson's choice: reproductive choices for women with learning disabilities. *Med. & L.*, *17*, 149.

Kroese, B. S. (1998). Cognitive-behavioural therapy for people with learning disabilities. *Behavioural and Cognitive Psychotherapy*, *26*(4), 315-322. Retrieved from https://search-proquest-com.ezproxy.bangor.ac.uk/docview/619382594?accountid=14874

Large, J., & Thomas, C. (2011). Redesigning and evaluating an adapted sex offender treatment programme for offenders with an intellectual disability in a secure setting: preliminary findings. *Journal of learning disabilities and offending behaviour*, *2*(2), 72-83.

Lindsay, W. R. (2009). *The treatment of sex offenders with developmental disabilities: A practice workbook*. John Wiley & Sons: New Jersey, USA.

Lindsay, W. R., & Smith, A. H. (1998). Responses to treatment for sex offenders with intellectual disability: a comparison of men with 1‐and 2‐year probation sentences. *Journal of Intellectual Disability Research*, *42*(5), 346-353. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1046/j.1365-2788.1998.00147.x

Lösel, F., & Schmucker, M. (2005). The effectiveness of treatment for sexual offenders: A comprehensive meta-analysis. *Journal of Experimental Criminology*, *1*(1), 117-146. doi:http://dx.doi.org.ezproxy.bangor.ac.uk/10.1007/s11292-004-6466-7

Macdonald, J., Sinason, V., & Hollins, S. (2003). An interview study of people with learning disabilities' experience of, and satisfaction with, group analytic therapy. *Psychology and Psychotherapy: Theory, Research and Practice*, *76*(4), 433-453. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1348/147608303770584764

Marshall, W. L., Marshall, L. E., Serran, G. A., & O'Brien, M. D. (2009). Self-esteem, shame, cognitive distortions and empathy in sexual offenders: Their integration and treatment implications. *Psychology, Crime & Law*, *15*(2-3), 217-234. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/10683160802190947

Mews, A., Di Bella, L., & Purver, M. (2017). *Impact evaluation of the prison-based core sex offender treatment programme*. London: Ministry of Justice.

Milsom, A. (2006). Creating positive school experiences for students with disabilities. *Professional School Counseling, 10*(1), 66-72. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.5330/prsc.10.1.ek6317552h2kh4m

Murphy, G., & Sinclair, N. (2009). Treatment for men with intellectual disabilities and sexually abusive behaviour. *Assessment and treatment of sex offenders: A handbook*, 369-392.

Patterson, C. (2018). Does the adapted sex offender treatment programme reduce cognitive distortions? A meta-analysis. *Journal of Intellectual Disabilities and Offending Behaviour*, *9*(1), 9-21.

Patterson, C., Williams, J., & Jones, R. (2019). Third-wave therapies and people with intellectual disabilities: a systematic review. *Journal of Applied Research in Intellectual Disabilities, 00*(0), 00-00.

Shackley, M., Weiner, C., Day, A., & Willis, G. M. (2014). Assessment of public attitudes towards sex offenders in an Australian population. *Psychology, Crime & Law*, *20*(6), 553-572. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/1068316X.2013.793772

Smith, J. A., & Osborn, M. (2004). Interpretative phenomenological analysis. In G. M. Breakwell (Ed.), *Doing social psychology research; doing social psychology research* (pp. 229-254, Chapter viii, 379 Pages) British Psychological Society Blackwell Publishing, Leicester Malden. Retrieved from https://search-proquest-com.ezproxy.bangor.ac.uk/docview/620356059?accountid=14874

Stalker, K., & Harris, P. (1998). The exercise of choice by adults with intellectual disabilities: A literature review. *Journal of Applied Research in Intellectual Disabilities, 11*(1), 60-76. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1111/j.1468-3148.1998.tb00034.x

Tangney, J. P., & Dearing, R. L. (2003). *Shame and guilt*. Guilford Press.

Terry, K. J., & Mitchell, E. W. (2001). Motivation and sex offender treatment efficacy: Leading a horse to water and making it drink? *International Journal of Offender Therapy and Comparative Criminology*, *45*(6), 663-672. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/0306624X01456003

Thackeray, L. A., & Eatough, V. (2018). 'Shutting the world out': an Interpretative Phenomenological Analysis exploring the paternal experience of parenting a young adult with a developmental disability. *Journal of Applied Research in Intellectual Disabilities*, *31*, 179-190. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1111/jar.12313

Thakker, J., Ward, T., & Navathe, S. (2007). The cognitive distortions and implicit theories of child sexual abusers. In T. A. Gannon, T. Ward, A. R. Beech & D. Fisher

(Eds.), *Aggressive offenders' cognition: Theory, research and practice; aggressive offenders' cognition: Theory, research and practice* (pp. 11-29, Chapter xxi, 273 Pages) New York, USA: John Wiley & Sons Ltd. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1002/9780470746295.ch1 Retrieved from https://search-proquest-com.ezproxy.bangor.ac.uk/docview/621971029?accountid=14874

Toman, P., & Hawkins, K. (2008). Building a golden bridge for resistant sexual offenders. *Sexual Abuse in Australia and New Zealand*, *1*(1), 20.

Vereenooghe, L., & Langdon, P. E. (2013). Psychological therapies for people with intellectual disabilities: A systematic review and meta-analysis. *Research in developmental disabilities*, *34*(11), 4085-4102. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1016/j.ridd.2013.08.030

Wakeling, H. C., Webster, S. D., & Mann, R. E. (2005). Sexual offenders' treatment experience: A qualitative and quantitative investigation. *Journal of Sexual Aggression*, *11*(2), 171-186. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/13552600412331321323

Willis, G. M., Levenson, J. S., & Ward, T. (2010). Desistance and attitudes towards sex offenders: Facilitation or hindrance? *Journal of Family Violence*, *25*(6), 545-556. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1007/s10896-010-9314-8

Winn, M. E. (1996). The strategic and systemic management of denial in the cognitive/behavioral treatment of sexual offenders. *Sexual Abuse: Journal of Research and Treatment, 8*(1), 25-36. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1007/BF02258014

Yalom, I. D. (1995). *The theory and practice of group psychotherapy*. New York, US: Basic Books.

Chapter 3 – Reflective Paper

Contribution to theory and clinical practice

This thesis critically examines psychological therapies adapted for adults with intellectual disabilities (ID), integrating findings from a systematic review and an empirical study. The systematic review explored third-wave therapies adapted, used and empirically evaluated with adults with ID. Previous reviews had only examined individual third-wave therapies, making the systematic review the first of its kind. The empirical study was the first to use a qualitative methodology, Interpretative Phenomenological Analysis (IPA), to gain an in-depth understanding of how adults with ID experience the adapted Sex Offender Treatment Programme (aSOTP). The current paper begins with a discussion regarding how findings from the systematic review and empirical study contribute to theory and clinical practice, ending with a personal reflection relating to the process of conducting the empirical study.

Clinical implications: Enhancing the aSOTP

Making adaptations

Sturmey (2004) argued that adults with ID are unlikely to benefit from cognitive therapies, as they often possess significant language and cognitive deficits. Taylor et al. (2012) identified that adults with ID could access and engage meaningfully in psychological therapies as long as the following adaptations were made: simplifying language, making abstract concepts more concrete, and focusing on behavioural rather than cognitive interventions. The systematic review identified additional adaptations that should be made:

- Breaking information down into chunks
- Using visual and physical prompts to augment understanding (i.e., instructions and exercises)

- Frequent checks for understanding
- Changing the structure of sessions to account for limited attention and slower processing speed (e.g., having breaks in, shortening and having additional sessions)
- Using role-plays and other experiential exercises
- Involving the wider care team and providing training.

However, the empirical study identified that such adaptations might not be applied routinely or thoroughly in clinical settings. The empirical paper revealed that participants were sometimes unable to understand and keep up with the content of aSOTP sessions. Participants attributed this to their language difficulties and slower processing speed. However, as pointed out by advocates of the social model of disability: adults with ID may enter therapy with 'impairment', yet it is therapy that can disable them (Oliver et al., 2013). The empirical study highlighted how the aSOTP may have therefore disabled participants, using complicated language to deliver complex information at too fast a rate (Paterson & Hughes, 2006; Shakespeare, 2006).

Participants likened attending the aSOTP to being back at school. For many people with ID, schooling can be a difficult experience, characterised by academic failure, as well as ostracisation and victimisation (Milsom, 2006). To avoid embarrassment, many people with ID learn to acquiesce (Prosser & Bromley, 1998). When participants could not understand or keep up with the content of sessions, they apparently stayed quiet and pretended that they were following the content instead of bringing it to the attention of facilitators. Facilitators should consider that the aSOTP is unlikely to be effective if group members cannot always understand or keep up with the content of sessions. It is important, therefore, that they routinely and thoroughly apply adaptations identified in research. By accommodating for the

language and cognitive difficulties experienced by this population, facilitators will be increasing the likelihood that ID sex offenders will benefit from the aSOTP.

Motivation and safeness

Participants reported feeling as though they had little choice about attending the aSOTP, believing that non-attendance was likely to result in negative outcomes such as continued detention. This issue, discussed extensively in mainstream literature (e.g., Burdon & Gallagher, 2002; Terry & Mitchell, 2001), raises an important issue regarding motivation and ID sex offender treatment. Sex offenders with ID who do not believe that they require treatment may be reluctant to engage with group processes (incl. group rules). Notably, it is essential that members buy-in to the aSOTP and its processes, as this is a condition of creating a safe group.

A participant in the empirical study described being threatened with disclosure by another member who had not bought into the group and its rules. He was told that unless he gave the other group member something they wanted, the other group member would tell all of the patients on the unit about his sexual offence. This would have undoubtedly compromised the safety of the participant, as one particular patient had already told him that he nearly beat a sex offender to death in prison. This participant suggested that the group would be improved if the offence disclosure process was situated toward the end of the programme. This way, unmotivated group members may have left the group before motivated members disclose their sexual offences, increasing group safeness (Mann et al., 2002).

Working with denial and shame

As identified in previous research, participants described how they had learnt to deny their sexual offences to avoid shame, negative judgment from others and to keep themselves safe (Gilbert, 1998; Langton et al., 2008; Marshall et al., 2009; Ware et al., 2015). However, the SOTP focuses on offence disclosure and challenging denial (Salter, 1988), requiring group members to drop their defences, share the details of their sexual offences and experience underlying feelings. The empirical study revealed that participants experienced either relief or shame after disclosing their sexual offences, seemingly determined by the level of perceived safeness in the group. Groups perceived as nurturing and robust (i.e., where group rules were adhered to strictly) fostered relief, whereas groups perceived as unsupportive and chaotic (i.e., where group rules were regularly transgressed) harboured shame. This finding is important because shame has been found to be associated with indicators of sexual recidivism, such as, victim blaming and withdrawal from therapeutic engagement (Marshall et al., 2009; Proeve & Howells, 2002).

Clinical researchers have put forward an alternate way of working with sex offenders who deny their offences that can be incorporated into the aSOTP (Blagden et al., 2011; Blagden et al., 2014; MacDonald et al., 2003; Winn, 1996). Winn (1996) argued that group facilitators should move away from directly confronting denial, as direct confrontation is likely to elicit further experiences of shame (Winn, 1996). Rather, Blagden and colleagues (Blagden et al., 2011; Blagden et al., 2014) encourage facilitators to identify the deployment of such defence mechanisms, acknowledging their self-protective function. Over the course of treatment, facilitators can then gradually and carefully direct attention toward negative consequences associated with defence mechanisms used by group members (Winn, 1996). For example, facilitators could highlight how denial prevents them from engaging in the group and getting

the help they, or a part of them at least, might want. Members can only practise dropping their defences once safety has been established in the group (Winn, 1996).

Clinical researchers have also suggested that aSOTP facilitators should move from eliciting shame toward eliciting guilt. This is because, unlike shame, guilt is associated with victim empathy and reparative behaviour (Marshall et al., 2009; Proeve & Howells, 2002). Proeve and Howells (2002) advise facilitators to make this shift by helping group members to make circumscribed guilt-related evaluations (e.g., "I did a bad thing") instead of global shame-related self-evaluations (e.g., "I am a bad person").

Future directions

Participants described experiencing difficulty with regulating intense emotional states (e.g., shame). Furthermore, they all discussed, in a positive light, how they matured as a product of attending the aSOTP. It, therefore, seems important that aSOTP groups focuses on building emotion regulation skills and positive identities (Hollomotz & Greenhalgh, 2019). As highlighted in the systematic review, third-wave therapies may offer particular promise in developing these capacities (Sakdalan & Gupta, 2014). Thus far, there have been two studies piloting third-wave interventions with ID sex offenders. First, Singh et al. (2011) piloted a mindfulness-based approach with a small sample of ID sex offenders in an inpatient setting. Their 10-month intervention targeted deviant sexual arousal. Results indicated that participants were much better able to regulate their deviant sexual arousal following the mindfulness-based intervention. Second, Sakdalan and Collier (2012) piloted a seven-month aSOTP augmented with DBT with ID sex offenders detained in an inpatient setting. In addition to standard cognitive-behavioural strategies, they taught emotion regulation, interpersonal functioning and distress tolerance skills. Sakdalan and Collier (2012) reported

that their sample demonstrated significant improvements on a number of risk-related variables post-intervention (i.e., cognitive distortions, sexual knowledge and victim empathy). It is, therefore, possible that third-wave therapy techniques could be used to augment the aSOTP (Sakdalan & Gupta, 2004).

Research implications

Both the systematic review and the empirical study identified that there is a paucity of high quality research examining psychological therapies and adults with ID. Consequently, it can be difficult to conclude whether particular psychological therapies are effective with this population and make recommendations. Without clear conclusions and recommendations, practitioners working therapeutically with adults with ID have no specific guidance to follow.

As aforementioned, the empirical study was the first to use a qualitative methodology, IPA, to map out the lived experience of being on the receiving end of the aSOTP. The empirical study adds to the increasing body of literature attesting the use of IPA with the ID population. Research should continue to use IPA with people with ID, as it provides them with a rare opportunity to have a say on their care and treatment (Rose et al., 2019). Eventually, however, the gold-standard empirical study of the aSOTP would be a randomised controlled trial (RCT). In particular, researchers should conduct a RCT comparing the group-based cognitive-behavioural aSOTP (Murphy & Sinclair, 2009) with a third-wave approach such as Sakdalan and Collier's (2012) SAFE-ID and treatment as usual (TAU). Due to the scarcity of the ID sex offender population, this RCT would need to be conducted across multiple UK sites.

Previously, research has evaluated the effectiveness of the aSOTP by measuring changes on measures of risk-related variables (e.g., cognitive distortions, victim empathy and sexual

knowledge) at pre- and post-treatment. A future RCT should extend upon this by measuring changes in observation/supervision levels, discharge and reoffending, at pre-treatment, post-treatment and follow-up. As the NHS is increasingly looking to provide services that produce better outcomes at a lower cost, it would be useful for the RCT to also measure the cost of the aSOTP versus SAFE-ID and TAU.

Personal reflections

Prior to starting the Doctorate in Clinical Psychology (DClinPsy) course, I worked with adults with ID with offending histories. During this time, I started thinking critically about psychologically informed treatments used with this population; namely, the aSOTP. My involvement with the aSOTP involved multi-disciplinary team discussions about the appropriacy of patients joining the group, observing and co-facilitating sessions, and deciding whether patients should be discharged based on their engagement with the group. I learnt that patients often had little or no choice regarding whether they joined the aSOTP, prompting thoughts about how this might impact upon motivation. For example, "If a patient does not want, or feel the need, to join the group, then how can we expect them to engage?"

Initially I only observed aSOTP sessions. Having only ever worked with adults without ID, facilitators focused on teaching complex cognitive models. Finding it difficult to understand the group content myself, I looked around the room to see how patients were faring. Out of a group of six, two were actively engaged, not fully understanding, but asking questions nonetheless. Another two appeared to be acquiescing, indicating that they understood what was being talked about when they actually did not. The remaining two seemed to have totally disengaged and were drifting off to sleep. Level of engagement in the aSOTP was one

of the main factors considered when discussing patient discharge. Those who did not engage with the group were unlikely to be discharged.

An occupational therapist and I took over the aSOTP, under the supervision of experienced clinicians. Both of us had extensive experience of working with adults with ID and, therefore, had a strong understanding of how to adapt the group to match the language and cognitive capabilities of patients. We used experiential rather than didactic teaching methods where possible; increased group discussion; used visual materials; made sessions shorter; simplified language; made abstract concepts more concrete; regularly repeated information; and checked for understanding. One of the main challenges of facilitating a group of people with ID is the considerable range in language and cognitive functioning. The content and pace of sessions had to be delivered in such a way that ensured higher functioning members were stimulated and lower functioning members could understand and keep up. Within a short period of time, all patients were engaging, which significantly impact in their chances of being discharged.

I was in my early 20s when I worked as an assistant psychologist in an open rehabilitation hospital for offenders with ID. I wanted to prove to more experienced members of staff, many of whom had worked in the highest security settings (e.g., Ashworth Hospital), that I had what it took to work in such an emotionally challenging service. I remember initially feeling shocked and disgusted hearing patients disclose their offences for the first time in the aSOTP. Never before had I heard anyone talk about such things. I remember thinking, "How could anyone be capable of that?" Looking back, I learnt to cope with these difficult emotions using a defense mechanism, suppression. As with any defense mechanism, suppression worked in the short-term, enabling me to work effectively with this population. In fact, my ability to remain 'unaffected' by the work was positively reinforced, as my

supervisors and managers often praised me for being so mature. I worked in this service for three years, going in early and leaving late, without having a single day of sickness. I was proud of this, thinking that I had proved myself. However, I was unaware of how emotional suppression would affect me in the long-term.

Shortly after finishing this job, I started to experience rushes of disgust, anger and fear while thinking about disclosures that had been made in the group. I also started to think about the possibility that sex offenders might be living in my local community. This was difficult because my siblings had started to have children. Then, on the DClinPsy, I started working with adults without an intellectual disability whose presenting problems were associated with histories of trauma. In fact, I learnt that the majority of patients seen by clinical psychologists in community mental health teams had experienced at least one trauma. For the first time, I was witnessing first-hand the true impact of sexual offending.

Due to the pressure of having to decide on a viable empirical study for course requirement, I probably did not think about how I might experience meeting with sex offenders to explore their views of the aSOTP. After interviewing my first participant, it occurred to me that I had developed a strong rapport with a sex offender: somebody who had sexually abused someone and seriously affected their life. At the time, I was on placement in a substance misuse service, working with people who had been abused. This brought me into contact with some difficult thoughts and emotions. Luckily, I had personal therapy and supervision to help me work through this issue. Keeping a journal of my personal reflections throughout this research process helped me to bracket off my thoughts and emotions to the extent that they would not significantly influence my interpretation of the accounts of participants.

Upon reflection, I think that conducting my empirical paper has taught me invaluable lessons. I have developed my ability to be mindful of my personal reactions to difficult situations, learning that while suppression may be helpful in the short-term, it is unhelpful in the long-term. Increased self-awareness, a better understanding of how to react in difficult situations will without doubt help me in my career as a clinical psychologist.

References

Blagden, N. J., Winder, B., Thorne, K., & Gregson, M. (2011). 'No-one in the world would ever wanna speak to me again': an interpretative phenomenological analysis into convicted sexual offenders' accounts and experiences of maintaining and leaving denial. *Psychology, Crime & Law*, *17*(7), 563-585. doi: https://doi.org/10.1080/10683160903397532

Blagden, N., Winder, B., Gregson, M., & Thorne, K. (2014). Making sense of denial in sexual offenders: A qualitative phenomenological and repertory grid analysis. *Journal of interpersonal violence*, *29*(9), 1698-1731. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/0886260513511530

Burdon, W. M., & Gallagher, C. A. (2002). Coercion and sex offenders: Controlling sex-offending behavior through incapacitation and treatment. *Criminal Justice and Behavior*, *29*(1), 87-109. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/0093854802029001006

Gilbert, P. (1998). What is shame? Some core issues and controversies. In P. Gilbert & B. Andrews (Eds.), *Series in affective science. Shame: Interpersonal behavior, psychopathology, and culture* (pp. 3-38). New York, US: Oxford University Press

Hollomotz, A., & Greenhalgh, J. (2019). A realist analysis of treatment programmes for sex offenders with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 00(0), 000-000, doi: https://doi.org/10.1111/jar.12618

Langton, C. M., Barbaree, H. E., Harkins, L., Arenovich, T., McNamee, J., Peacock, E. J., ... & Marcon, H. (2008). Denial and minimization among sexual offenders: Posttreatment presentation and association with sexual recidivism. *Criminal Justice and Behavior*, *35*(1), 69-98. doi: https://doi.org/10.1177/0093854807309287

Macdonald, J., Sinason, V., & Hollins, S. (2003). An interview study of people with learning disabilities' experience of, and satisfaction with, group analytic therapy. *Psychology and Psychotherapy: Theory, Research and Practice*, *76*(4), 433-453. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1348/147608303770584764

Mann, R. E., Ginsburg, J. I., & Weekes, J. R. (2002). Motivational interviewing with offenders. In *Motivating offenders to change: A guide to enhancing engagement in therapy* (pp. 87-102). Chichester, West Sussex, England: John Wiley & Sons Ltd.

Marshall, W. L., Marshall, L. E., Serran, G. A., & O'Brien, M. D. (2009). Self-esteem, shame, cognitive distortions and empathy in sexual offenders: Their integration and treatment implications. *Psychology, Crime & Law*, *15*(2-3), 217-234. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/10683160802190947

Murphy, G., & Sinclair, N. (2009). Treatment for men with intellectual disabilities and sexually abusive behaviour. In *Assessment and treatment of sex offenders: A handbook* (pp. 369-392). Chichester, West Sussex, England: John Wiley & Sons.

Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & society*, *28*(7), 1024-1026. doi: https://doi.org/10.1080/09687599.2013.818773

Paterson, K., & Hughes, B. (2006). The social model of disability and the disappearing body: Towards a sociology of impairment. In *Overcoming disabling barriers* (pp. 101-117). London, England: Routledge.

Proeve, M., & Howells, K. (2002). Shame and guilt in child sexual offenders. *International journal of offender therapy and comparative criminology*, *46*(6), 657-667. Doi: https://doi.org/10.1177/0306624X02238160

Prosser, H., & Bromley, J. (1998). Interviewing people with intellectual disabilities. In *Clinical psychology and people with intellectual disabilities*, (pp. 99-113). Chichester, West Sussex, England: John Wiley & Sons:.

Rose, J., Malik, K., Hirata, E., Roughan, H., Aston, K., & Larkin, M. (2019). Is it possible to use interpretative phenomenological analysis in research with people who have intellectual disabilities? Journal of Applied Research in Intellectual Disabilities, 00(0), 000-000. Doi: https://doi.org/10.1111/jar.12605

Sakdalan, J. A., & Gupta, R. (2014). Wise mind—risky mind: A reconceptualisation of dialectical behaviour therapy concepts and its application to sexual offender treatment. *Journal of sexual aggression*, *20*(1), 110-120. Doi: https://doi.org/10.1080/13552600.2012.724457

Sakdalan, J. A., Shaw, J., & Collier, V. (2010). Staying in the here-and-now: A pilot study on the use of dialectical behaviour therapy group skills training for forensic clients with intellectual disability. *Journal of Intellectual Disability Research, 54*(6), 568-572. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1111/j.1365-2788.2010.01274.x

Salter, A. (1988). *Treating child sex offenders and victims: A practical guide* (pp. 96-111). London, England: Sage.

Shakespeare, T. (2006). The social model of disability. *The disability studies reader* (pp. 197-204). New York, US: Routledge.

Singh, N. N., Lancioni, G. E., Winton, A. S. W., Singh, A. N., Adkins, A. D., & Singh, J. (2011). Can adult offenders with intellectual disabilities use mindfulness-based procedures to control their deviant sexual arousal? *Psychology, Crime & Law, 17*(2), 165-179. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1080/10683160903392731

Sturmey, P. (2004). Cognitive therapy with people with intellectual disabilities: A selective review and critique. *Clinical Psychology & Psychotherapy: An International Journal of Theory & Practice*, *11*(4), 222-232. doi: https://doi.org/10.1002/cpp.409

Taylor, J. L., Lindsay, W. R., Hastings, R. P., & Hatton, C. (Eds.). (2012). *Psychological therapies for adults with intellectual disabilities*. Chichester, West Sussex, England: John Wiley & Sons.

Terry, K. J., & Mitchell, E. W. (2001). Motivation and sex offender treatment efficacy: Leading a horse to water and making it drink? *International Journal of Offender Therapy and Comparative Criminology*, *45*(6), 663-672. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1177/0306624X01456003

Ware, J., Marshall, W. L., & Marshall, L. E. (2015). Categorical denial in convicted sex offenders: The concept, its meaning, and its implication for risk and treatment. *Aggression and violent behavior*, *25*, 215-226. doi: https://doi.org/10.1016/j.avb.2015.08.003

Winn, M. E. (1996). The strategic and systemic management of denial in the cognitive/behavioral treatment of sexual offenders. *Sexual Abuse: Journal of Research and Treatment, 8*(1), 25-36. doi: http://dx.doi.org.ezproxy.bangor.ac.uk/10.1007/BF02258014

Appendices

Appendix 1 – ‘I’m interested’ form

Appendix 2 – Participant information sheet

Appendix 3 – Functional assessment of capacity

Appendix 4 – Consent form

Appendix 5 – Interview schedule

Appendix 6 – Debrief

Appendix 7 – Proposal for the ethics committee

Appendix 8 – Ethical approval

Appendix 9 – HRA approval

Appendix 10 – Excerpt of noting on transcript

Appendix 1: I'm interested form

"I'm Interested" Form

I would like to find out more about the research

Please get in touch to tell me more

Name:.....

Address: .....
.....
.....

Email address: .....

Telephone Number: .....

Signed: .....

Date: .....

Appendix 2. Participant information sheet

Information Sheet

Title of Study: Exploring the understandings and experiences of sex offenders attending an adapted Sex Offender Treatment Programme group.

Investigator: Mr. Chris Patterson (psuc1a@bangor.ac.uk)

Supervisors: Dr. Jonathan Williams (jonathan.williams@wales.nhs.uk), & Prof. Robert Jones (r.s.jones@bangor.ac.uk)

University: North Wales Clinical Psychology Programme, Bangor University

I am Chris Patterson. I work at Bangor University. I am doing a research study. I want to talk to men with learning disabilities that have been to adapted Sex

Offender Treatment groups.

This is why I want to meet with you. I want to ask you what you think and feel about the group.

If you agree to take part, we will meet in your local learning disability service.

We will speak for one hour.

I will record our conversation using a Dictaphone. A Dictaphone is a piece of equipment that records sound.

I will use it to make sure I

remember everything you tell me.

I may also need to access your medical records. We will only keep information from your medical records for three months.

Bangor University is responsible for this research study. This means that Bangor University is responsible for looking after your information and using it properly.

Benefits and risks

Your views will help me find out which parts of the group are helpful.

Your views will also help me find out which parts of the group are unhelpful.

I hope that the results of this study will be used to improve the group.

I expect that you will enjoy talking to me about the group.

I do not expect you to find my questions distressing.

I will not ask you any questions about your past.

If you do find any of the questions difficult, you can say you don't want to answer.

You can also stop our conversation at any point.

You can even end the study early if you want.

This is because your involvement in this study is voluntary.

Up until June 2019, we will destroy your information if you choose to end the study early.

After June 2019 you will not be

able to end the study. This is because the results will already have been written in a report.

If you are still attending a group, your involvement in this study will not affect your involvement in the group.

Confidentiality

It is important that you know the limits of confidentiality.

Confidentiality is a long word, but it means 'what is said in the room, stays in the room'.

I would only break confidentiality if you tell me something that makes me think you or somebody else is at risk of serious harm.

I would have to tell your group facilitator and GP.

This is just to keep everybody safe.

<u>Telling you about the findings</u>

I want to write a report about what you have told me.

Hopefully, lots of people will read the report to find out what it

is like being a part of the group.

Nobody will be able to know that you met with me and talked about the group.

I will not use your real name.

If you would like, you will be given an easy-read report that tells you the findings of this study.

I can arrange for somebody to meet with you and talk to you about the findings.

If you have any issues

If you are unhappy with any part of this study, you can speak to Huw Ellis.

He is one of my managers at Bangor University.

Phone: +44 (0) 1248 388339

Address: Bangor University, Brigantia, Building, Penrallt Road, Bangor, Gwynedd, LL57 2AS

Email: huw.ellis@bangor.ac.uk

Appendix 3. Functional capacity assessment

Guidelines for the Functional Assessment of Capacity Diagnostic Threshold

The Mental Capacity Act (2005) acknowledges that an established diagnosis of mental illness, intellectual disability or some other condition, is sufficient to confirm "impairment or disturbance of the mind".

Nature of decision

Assessors should record the key decisions facing clients/patients.

Test

1. **Understanding the information**

   The assessor is required to help the person understand the information relevant to the decision. Information should be presented in a clear and simple way or with the use of visual aids. Cultural and linguistic considerations should be included and family, friends, carers or support staff of the person being assessed should be used to assist the process.

2. **Retaining the information**

   Information only needs to be held in the mind of the person long enough to make the decision.

3. **Use or weigh the information**

   Some people can understand the information, but impairment stops them from using it. Alternatively, others may make a decision without understanding it. A person capable of using or weighing the information would also need to demonstrate that they could foresee the consequences of making, or failing to make, that decision.

4. **Communicate the decision**

Communication can be whatever the assessor accepts. Assessors should consider using specialist workers to assist in communication (for sensory impairment etc.).

Protocol for Assessing Capacity (Screening)

Read Information Sheet once to/along with the potential participant, then say:

"To take part in this research I need to be sure you understand what I am asking you to do. If it is ok, I will just ask you some questions about what we have just read."

Questions

1. Read the following part of the Information sheet: "***I am doing research to find out what you thought and felt about being a part of, and going to, the adapted Sex Offender Treatment Programme group. This means that I will ask you questions about the group***."

Ask the participant: "***Why do I want to meet you and ask you some questions?****"*

Score 2 for a clear and accurate answer such as "*To find out what the group was like for me*".

Score 1 if the person gives an answer similar to but less clear than above response.

Score 0 if the answer is irrelevant or too vague (e.g. "See me").

2. Read the following part of the information sheet: "***I will meet with you to ask you questions about the group. I will be recording everything you say. I will keep the recording equipment very safe. When I get back to university, I will listen to the recording and write it out. I will not use your real name or any other information that would show who you are. I will then look at what other people thought of, and felt about, the group. This will help me to see if you thought and felt the same or different to others.***"

Ask the participant: "***What will happen?***"

Score 2 for answer similar to "You will see me and ask me questions. You will record it. You will ask other people who attended questions too."

Score 1 if the person gives an answer similar to but less clear than above response.

Score 0 for incorrect answer or an answer that is too vague.

3. Read the following part of the information sheet: "***We will keep what you tell us confidential. This means what is said in the room stays in the room. But, if you tell us something that makes us think that you or somebody else it at risk of serious harm, we will have to break confidentiality and tell your group facilitator and GP."***

Ask the participant: ***"What will happen?"***

Score 2 for an answer similar to "you will not tell anyone else what I tell you, unless something I tell you makes you think that me or someone else could be badly hurt. If you think that me or someone else could be badly hurt then you will tell my group facilitator and GP".

Score 1 if the person gives an answer similar to but less clear than the above response.

Score 0 for an incorrect answer or an answer that is too vague.

4. Ask the participant "***Are you happy for me to interview you?***"

Answers **Yes** or **No.**

For consent to be given the participant needs to answer 'Yes' to question 4.

5. Read the following part of the Information sheet: "If you do not want to take part, just say no. If you say yes, but then you change your mind, that is OK too."

Ask the participant: "***What will you do if you change your mind*?**"

Score 2 for a clear and accurate answer such as “tell you I don’t want to do it anymore”.

Score 1 if the person gives an answer similar to but less clear than above response.

Score 0 if the answer is irrelevant or too vague.

Overall scoring

		2	1	0
Question 1	Why do we want to meet you and ask you some questions?			
Question 2	What will happen?			
Question 3	What will happen if you tell me something that makes me think that you or somebody else is at risk of serious harm?			
Question 4	Are you happy for me to interview you?			
Question 5	What will you do if you change your mind?			

If the participant scores 0 to any of the questions under items 1, 2, 3 or 5, then the participant is assessed as not having the capacity to consent in this specific context.

If the participant scores 2 in every question under items 1,2, 3 and 5 and answers “*Yes*” to question 4, then the participant is assessed as having the capacity to consent and s/he is indicating their wish to participate. If the participant scores 2 in every question under items 1, 2, 3 and 5 but answers “*No*” in question 4, the participant is assessed as having the capacity to consent and is indicating their refusal to participate.

If an individual scores 1 on all questions it would indicate that their responses are not very clear indicating that perhaps they do not adequately understand the information. In this situation, you will need to discuss the individual’s potential involvement with their carer or a member of staff who knows them well. Use your judgment to decide whether the individual has provided a sufficiently

coherent understanding of the questions in the context of their level of intellectual disability, memory ability, and potential for suggestibility and acquiescence.

This protocol is based on the procedure followed by Arscott, Dagnan & Kroese (1998).

Arscott, K., Dagnan, D., & Kroese, B.S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 11(1)*, 77- 83.

Appendix 4. Consent form

Informed Consent

Title of Study: Exploring the understandings and experiences of sex offenders attending an adapted Sex Offender Treatment Programme group.

Investigator: Mr. Chris Patterson (psuc1a@bangor.ac.uk)

Supervisors: Dr. Jonathan Williams (jonathan.williams@wales.nhs.uk), and Prof. Robert Jones (r.s.jones@bangor.ac.uk)

Please write initial if you agree with the sentence

Have you read the information sheet?	
Have you had the opportunity to consider the information and ask questions?	
Have you agreed to your interview being recorded using audio equipment?	
Do you understand and consent to your anonymised quotes being published?	
Do you understand that your participation is voluntary, and that you may withdraw at any time without penalty or explanation?	
I understand that a break of confidentiality will occur in the case of any incidental disclosures.	
Do you agree to take part in the above study?	

Date: _____

Name of Participant: _____

Signature of Participant: _____

For Researcher use

Date: _____

Investigator's Name:_____

Signature of Investigator: _____

Appendix 5. Interview schedule

Interview Schedule

Background Information

- Please could you tell me how old you are?
- How would you describe your gender?
- Please could you tell us how long you have lived at your current residence?
- Do/did you attend an adapted Sex Offender Treatment Programme group?
    - What do/did you call the group?
    - How long have you attended/did you attend the group for?
    - Why did you start attending the SOTP group?
        - Would you be able to say whether your most recent conviction involved either an adult or a child?

Understandings

- Did you think that it was right for you to join this group?
- What is the group?
    - What is the aim of the group?
    - Does the group have any rules?
        - What do you think about the rules?
    - What is the role of the facilitator?
    - What is the role of the group member?
    - How do you know when you have finished the treatment?

The wider impact of group affiliation on life

- How does being a part of this group affect your everyday life?
- What is it like being a part of this group?
    - If you had to describe what the group means to you, what would you say?

Within group experiences

- Could you describe what happens in the group, in your own words?
    - Do you always understand what is being spoken about in the group?
- How do you feel when you are in a group session?
    - How did you know when it was right for you to first start talking about yourself?
    - What did it feel like when you first started talking about yourself in the group?
        - Physically (in your body); emotionally (feelings); cognitively (how you think about things)
    - How do you feel when you are talking about yourself?
        - Physically (in your body); emotionally (feelings); cognitively (how you think about things)
    - How do you feel after you have told the group something personal?
        - Physically (in your body); emotionally (feelings); cognitively (how you think about things)
- How does it feel to be in a group with men who have similar experiences?
    - What were your thoughts after first hearing other members tell you something personal?

Group evaluation

- Have you ever found the group useful?
    - Have you learnt anything from attending the group?
        - What have you learnt?
- Is there anything that you would change about the group?
- Has being a part of this group changed the way in which you see yourself?
- Do you think that your attendance at this group will have changed the way in which others see you?

Appendix 6. Debrief sheet

Debrief Form

Name of Study: Exploring the understandings and experiences of sex offenders attending an adapted Sex Offender Treatment Programme group.

Investigator(s): Mr. Chris Patterson, Dr. Jonathan Williams, and Prof. Robert Jones

Contact Email: psuc1a@bangor.ac.uk

University: North Wales Clinical Psychology Programme, Bangor University

The reasons why we are doing this study:

Very few people have tried to find out what it is like to attend an adapted Sex Offender Treatment Programme group.

People usually try to show how effective these

group using results from assessments.

We wanted to explore your understandings and experiences as a member of this type of group.

We asked you questions about:

- What it is like to be a part of this group
- How it feels to take part in this group
- How you feel when you to talk about yourself in the group
- Things of the group that have helped you
- Areas of the group that you would change

Your involvement in this study could help change the way that these kinds of groups are delivered.

Possible Benefits

We hope that you feel as though you have had an opportunity to have your opinions heard.

We hope that this can make you feel empowered.

Possible Risks

Speaking about your involvement in the Sex Offender Treatment Programme might have been difficult for you.

If you feel upset now or at a later point in time, you will have access to support.

If you decide after the interview that you do not want to take part any more, the researchers will destroy your results.

You have up until June 2019 to decide this.

Support

If you are upset, please tell the researcher.

The researcher has worked with your care team to

make sure that you have access to support if this study has made you feel upset.

Confidentiality

Remember: ‘what happens in the interview stays in the room’.

The researcher will only tell others what you have told him, if he thinks that it places yourself or others at risk.

All of your personal information will be kept safe in a locked cupboard – only the researcher will have access to it.

No-one will be able to know that you took part in this study.

When the results are published, you will be given a fake name.

Results

When the study is finished, you will be asked whether you want to know about the results.

Your adapted Sex Offender Treatment Programme facilitator will ask you if you are interested.

If you are interested, you will be given a written summary of the results. This will be written in a way that best suits you.

If you have any questions about the results, a researcher can come and talk you through the findings.

Thank you for taking part in our study!

Appendix 7. Proposal submitted to the ethics committee

Project title

The experiences of ID sex offenders who have attended aSOTP groups

Chief investigator

Chris Patterson (Trainee Clinical Psychologist, Bangor University and Betsi Cadwaladr University Health Board) will be the chief investigator in this project.

Supervision

Dr Jonathan Williams (Clinical Psychologist, Betsi Cadwaladr University Health Board) and Professor Robert Jones (Programme Director, North Wales Clinical Psychology Programme) are joint-supervising this project.

Background

The main form of treatment for individuals with intellectual disability (ID) who have sexually offended is the adapted sex offender treatment programme (aSOTP). This is a group-based cognitive behavioural intervention adapted from treatment of mainstream sex offenders in prison. This intervention aims to identify and challenge offenders' attitudes that condone offending (i.e., cognitive distortions).

There was initially some contention surrounding the use of cognitive behaviourally informed interventions with people with ID. This was due to the possibility people with ID might not have the cognitive ability to understand abstract concepts and techniques. Now, there is convincing evidence

that people with ID can benefit from receiving cognitive behaviour therapy, as long as necessary adaptations are made.

Similarly, there was a debate as to whether the aSOTP was effective. This was perhaps due to the fact that majority of studies examining the effectiveness of this treatment were either case studies or uncontrolled studies with small sample sizes. A recent meta-analysis, however, reported that the aSOTP produced reliable, robust and stable reductions in attitudes that condone sex offending. The effect that this has on rates of reoffending, which is the key indicator of treatment success, remains unknown however.

In a systematic review, Hollomotz (2014) identified that there is a dearth of qualitative research exploring the experiences of individuals who have completed the aSOTP. This seems to be a blind spot in the literature. Researchers are yet to ask those who receive the treatment fundamental questions about whether they understand why they were referred to the aSOTP, whether they agreed to their referral, whether they understood the content being covered, or whether they found it helpful.

Research question

To explore the understanding and experiences of male adult sex offenders with ID who completed the aSOTP. More specifically, this study will aim to: (1) explore participants' understanding of how they came to be involved in the aSOTP; (2) examine how aSOTP involvement impacted upon participants' every day life; (3) gain an in-depth and rich insight into participants' mental, emotional and physical experiences of group participation (e.g., sharing personal information); and (4) identify which aspects of this treatment participants found most/least helpful in assisting them to control their behaviour and reduce their risk of reoffending.

Participant recruitment

Local clinicians will help to identify and recruit participants. They will (i) get in contact with clients who have attended an aSOTP group, (ii) provide these clients with a brief overview of the study, and (iii) ask them whether they would be interested in taking part in the study. Local clinicians will complete an 'I'm interested form' for clients who declare their interest in participating in this study. This form will then be sent to the chief investigator securely. The chief investigator will liaise with the local clinician to organise a time and place to meet with the client/potential participant.

Design and Procedures

I want to use Interpretative Phenomenological Analysis – semi-structured interview (please find attached). I am looking to recruit up to 10 participants. Participants must be male adults with ID (mild) with histories of sexual offending who have attended an aSOTP group. Participants must be considered capacitous enough to consent to participating in this study. Due to potential issues with recall, participants' must have recently completed the programme. Participants must be first-language English and possess sufficient receptive and expressive communication skills. Participants will be interviewed for one hour at their place of residence. Interviews will be recorded and later transcribed. Transcripts will be analysed using IPA methods.

Data management and analysis

As mentioned, interviews will be recorded on encrypted audio recording equipment. Participants must consent to this first, however. Only the investigators will be allowed to access the audio files or transcripts. These will be transported in a locked briefcase and stored in a locked cupboard in a locked office. Investigators will only listen to the audio recordings and work on the transcripts in a private office. Participants' data will be anonymised at the earliest point. Participants will be informed that they can withdraw from the study and have their data destroyed at any point up until the paper has been submitted to the university.

Feedback

On the debrief sheet, I will ask participants whether they would like to receive feedback on the study's results once they have been written up. If participants indicate that they would like feedback, I will provide them with an easy-read written summary of the results with pictorial cues/visual aids. If necessary, it can be arranged for somebody to go through the easy-read written summary of the results with them.

Risk Assessment

Although participants are expected to experience their involvement in this study as positive, there is a slight risk that they may become distressed when discussing sensitive topics during the interview. Prior to starting interviews, the chief investigator will agree participants how they will communicate their distress. If a participant communicates that they are distressed during the interview, the interview will be halted immediately. The chief investigator will remind participants that their participation is voluntary and that they can withdraw from the study at any point without consequence. The chief investigator will manage the distress by employing active listening, and encouraging and supporting the use of basic coping strategies. With the consent of the participant, the chief investigator will share the participant's situation with their lead clinician and GP. The investigator will share this information without the participant's consent if they have serious concerns about significant risk to the participant or others. A protocol for managing undue distress and incidental disclosures has been developed for this study.

Timetable

I am aiming to have full ethical approval by December 2018. As soon as I have ethical approval, I would like to start recruiting participants. I will attempt to interview participants as soon as possible. This will then enable me to transcribe the interviews. After analysing and interpreting the data, I will

write a first draft of my empirical paper. I aim to have this completed by April 2019. Subsequently, I will continue drafting my paper until it is ready to submit as my thesis in May 2019. Finally, I will submit my paper to a peer-reviewed journal.

References

Hollomotz, A. (2014). Sex offenders with intellectual disabilities and their academic observers: popular methodologies and research interests. *Journal of intellectual disability research*, *58*(2), 189-197.

Appendix 8. Ethical approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

Wales Research Ethics Committee 5
Bangor

Mailing address:
Health and Care Research Wales
Castlebridge 4
15-19 Cowbridge Road East
Cardiff, CF11 9AB

telephone: 07825 244673
email: WalesREC5@wales.nhs.uk
website: ww.hra.nhs.uk

Please note:
This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

12 November 2018

Mr Chris Patterson
Trainee Clinical Psychologist
Bangor Univesity
School of Psychology
Brigantia Building
Bangor Gwynedd
LL57 2AS

Dear Mr Patterson

Study title:	**Exploring the understandings and experiences of sex offenders with intellectual disabilities who have attended the adapted Sex Offender Treatment Programme.**
REC reference:	**18/WA/0342**
Protocol number:	**2018-16352**
IRAS project ID:	**170948**

Thank you for your letter of 9 November 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.
We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering letter on headed paper [Cover Letters]	1	06 November 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University Indemnity 1]	1	02 June 2018
GP/consultant information sheets or letters [Professional Undue Distress Letter]	1	20 September 2018
GP/consultant information sheets or letters [GP Professional Notification Letter]	1	20 September 2018
Interview schedules or topic guides for participants [Interview Schedule]	1	20 September 2018
IRAS Application Form [IRAS_Form_09102018]	-	09 October 2018
Letters of invitation to participant [Letter of Invitation to Participants]	1	20 September 2018
Participant consent form [Participant Consent Form]	1	20 September 2018
Participant information sheet (PIS) [Participant Information Sheet]	2	06 November 2018
Research protocol or project proposal [Project proposal]	1	20 September 2018
Summary CV for Chief Investigator (CI) [CV - Chief Investigator]	1	21 September 2018
Summary CV for supervisor (student research) [CV - Supervisor 1]	1	21 September 2018
Summary CV for supervisor (student research) [CV - Supervisor 2]	1	21 September 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Process for managing undue distress and incidental disclosures]	1	20 September 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Functional Assessment of Capacity to Consent]	2	06 November 2018

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

18/WA/0342	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr Philip Wayman White, MBChB, FRSM
General Practitioner
Chair Wales REC 5

E-mail: WalesREC5@wales.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

SL-AR2 After ethical review - research oth

Appendix 9. HRA approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Mr Chris Patterson
Trainee Clinical Psychologist
Bangor Univesity (North Wales Clinical Psychology Programme) and NHS Wales (Betsi Cadwaladr University Health Board)
School of Psychology
Brigantia Building
Bangor Gwynedd
LL57 2AS

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

15 November 2018

Dear Mr Patterson

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Exploring the understandings and experiences of sex offenders with intellectual disabilities who have attended the adapted Sex Offender Treatment Programme.**
IRAS project ID:	**170948**
Protocol number:	**2018-16352**
REC reference:	**18/WA/0342**
Sponsor	**Bangor University**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Participating NHS organisations in England and Wales will not be required to formally confirm capacity and capability before you may commence research activity at site. As such, you may commence the research at each organisation 35 days following sponsor provision to the site of the local information pack, so long as:

- You have contacted participating NHS organisations (see below for details)
- The NHS organisation has not provided a reason as to why they cannot participate
- The NHS organisation has not requested additional time to confirm.

You may start the research prior to the above deadline if the site positively confirms that the research may proceed.

If not already done so, you should now provide the local information pack for your study to your participating NHS organisations. A current list of R&D contacts is accessible at the NHS RD Forum website and these contacts MUST be used for this purpose. After entering your IRAS ID you will be able to access a password protected document (password: **Redhouse1**). The password is updated on a monthly basis so please obtain the relevant contact information as soon as possible; please do not hesitate to contact me should you encounter any issues.

Commencing research activities at any NHS organisation before providing them with the full local information pack and allowing them the agreed duration to opt-out, or to request additional time (unless you have received from their R&D department notification that you may commence), is a breach of the terms of HRA and HCRW Approval. Further information is provided in the "*summary of assessment*" section towards the end of this document.

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

IRAS project ID	170948

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Mr Huw Ellis
Tel: 0124 838 3229
Email: huw.ellis@bangor.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **170948**. Please quote this on all correspondence.

Yours sincerely

Kevin Ahmed
Assessor

Telephone: 0207 104 8171
Email: hra.approval@nhs.net

Copy to: *Mr Huw Ellis, Sponsor Contact, Bangor University*
Mrs Debra Slater, R&D Contact, Betsi Cadwaladr University Health Board (BCUHB)

IRAS project ID	170948

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Covering letter on headed paper [Cover Letters]	1	06 November 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University Indemnity 1]	1	02 June 2018
GP/consultant information sheets or letters [Professional Undue Distress Letter]	1	20 September 2018
GP/consultant information sheets or letters [GP Professional Notification Letter]	1	20 September 2018
HRA Schedule of Events	1	06 November 2018
HRA Statement of Activities	1	06 November 2018
Interview schedules or topic guides for participants [Interview Schedule]	1	20 September 2018
IRAS Application Form [IRAS_Form_09102018]		09 October 2018
Letters of invitation to participant [Letter of Invitation to Participants]	1	20 September 2018
Participant consent form [Participant Consent Form]	1	20 September 2018
Participant information sheet (PIS) [Participant Information Sheet]	2	06 November 2018
Research protocol or project proposal [Project proposal]	1	20 September 2018
Summary CV for Chief Investigator (CI) [CV - Chief Investigator]	1	21 September 2018
Summary CV for supervisor (student research) [CV - Supervisor 1]	1	21 September 2018
Summary CV for supervisor (student research) [CV - Supervisor 2]	1	21 September 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Functional Assessment of Capacity to Consent]	2	06 November 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Process for managing undue distress and incidental disclosures]	1	20 September 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Functional Capacity Assessment]	1	20 September 2018

IRAS project ID	170948

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	Although formal confirmation of capacity and capability is not expected of all or some organisations participating in this study, and such organisations would therefore be assumed to have confirmed their capacity and capability should they not respond to the contrary, we would ask that these organisations pro-actively engage with the sponsor in order to confirm at as early a date as possible. Confirmation in such cases should be by email to the CI and Sponsor confirming participation based on the relevant Statement of Activities and information within this letter.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study

IRAS project ID	170948

Section	Assessment Criteria	Compliant with Standards	Comments
4.3	Financial arrangements assessed	Yes	No study funding will be provided to sites, as detailed at Schedule 1 of the Statement of Activities.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

IRAS project ID	170948

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.
All sites will undertake the same research activities therefore there is only one site type. The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).
A Local Collaborator should be appointed at study sites. GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

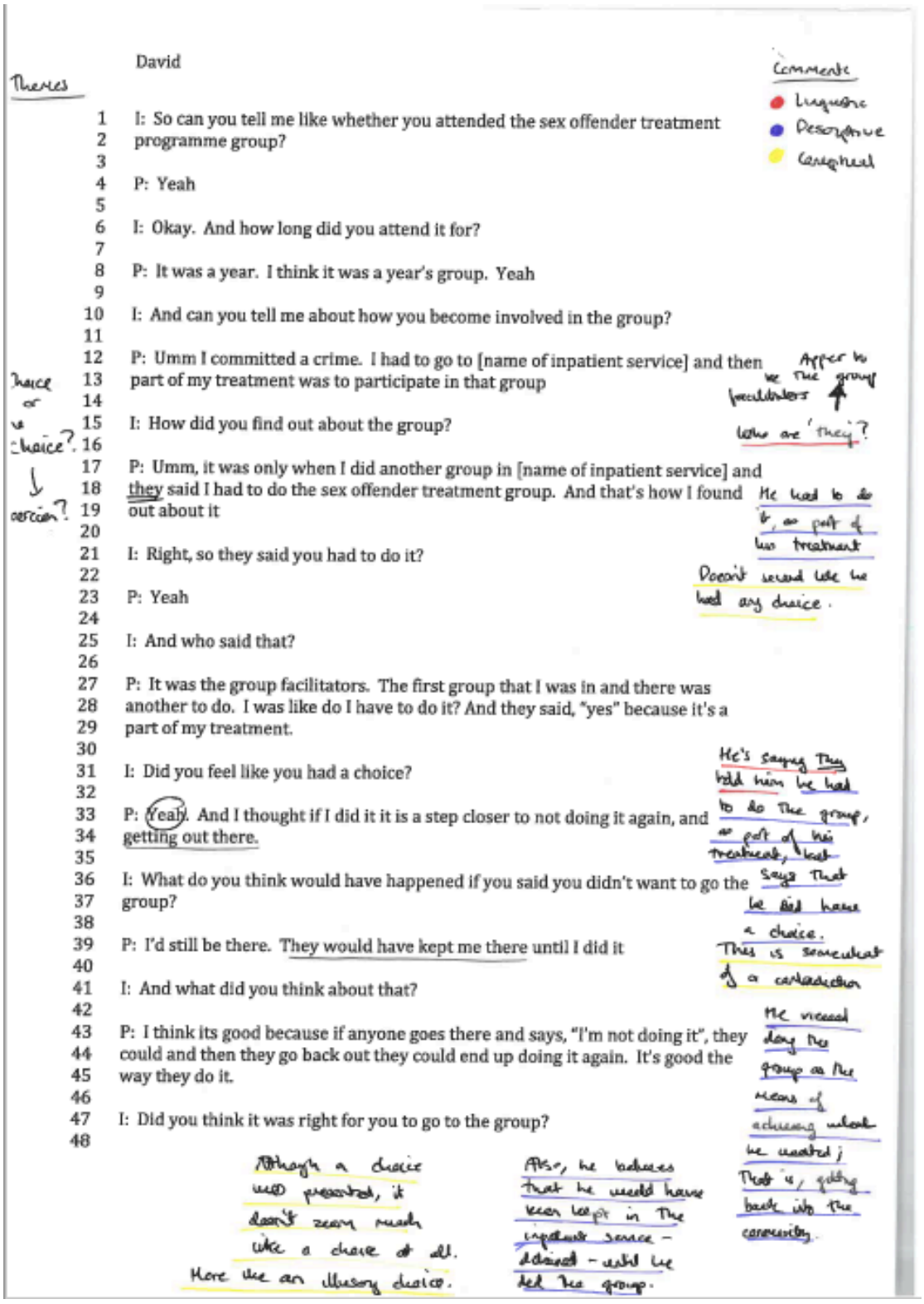
HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
Where arrangements are not already in place, network staff (or similar) undertaking any of the research activities listed in A18 of the IRAS form would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 10. Excerpt of noting on a transcript



David

Themes

Comments
- Linguistic
- Descriptive
- Conceptual

I: So can you tell me like whether you attended the sex offender treatment programme group?

P: Yeah

I: Okay. And how long did you attend it for?

P: It was a year. I think it was a year's group. Yeah

I: And can you tell me about how you become involved in the group?

P: Umm I committed a crime. I had to go to [name of inpatient service] and then part of my treatment was to participate in that group

Choice or no choice? ↓ coercion?

Appear to see the group facilitators as 'they'

Who are 'they'?

I: How did you find out about the group?

P: Umm, it was only when I did another group in [name of inpatient service] and they said I had to do the sex offender treatment group. And that's how I found out about it

He had to do it, as part of his treatment

Doesn't sound like he had any choice.

I: Right, so they said you had to do it?

P: Yeah

I: And who said that?

P: It was the group facilitators. The first group that I was in and there was another to do. I was like do I have to do it? And they said, "yes" because it's a part of my treatment.

I: Did you feel like you had a choice?

He's saying they told him he had to do the group, as part of his treatment, but says that he did have a choice.

This is somewhat of a contradiction

P: Yeah. And I thought if I did it it is a step closer to not doing it again, and getting out there.

I: What do you think would have happened if you said you didn't want to go the group?

P: I'd still be there. They would have kept me there until I did it

I: And what did you think about that?

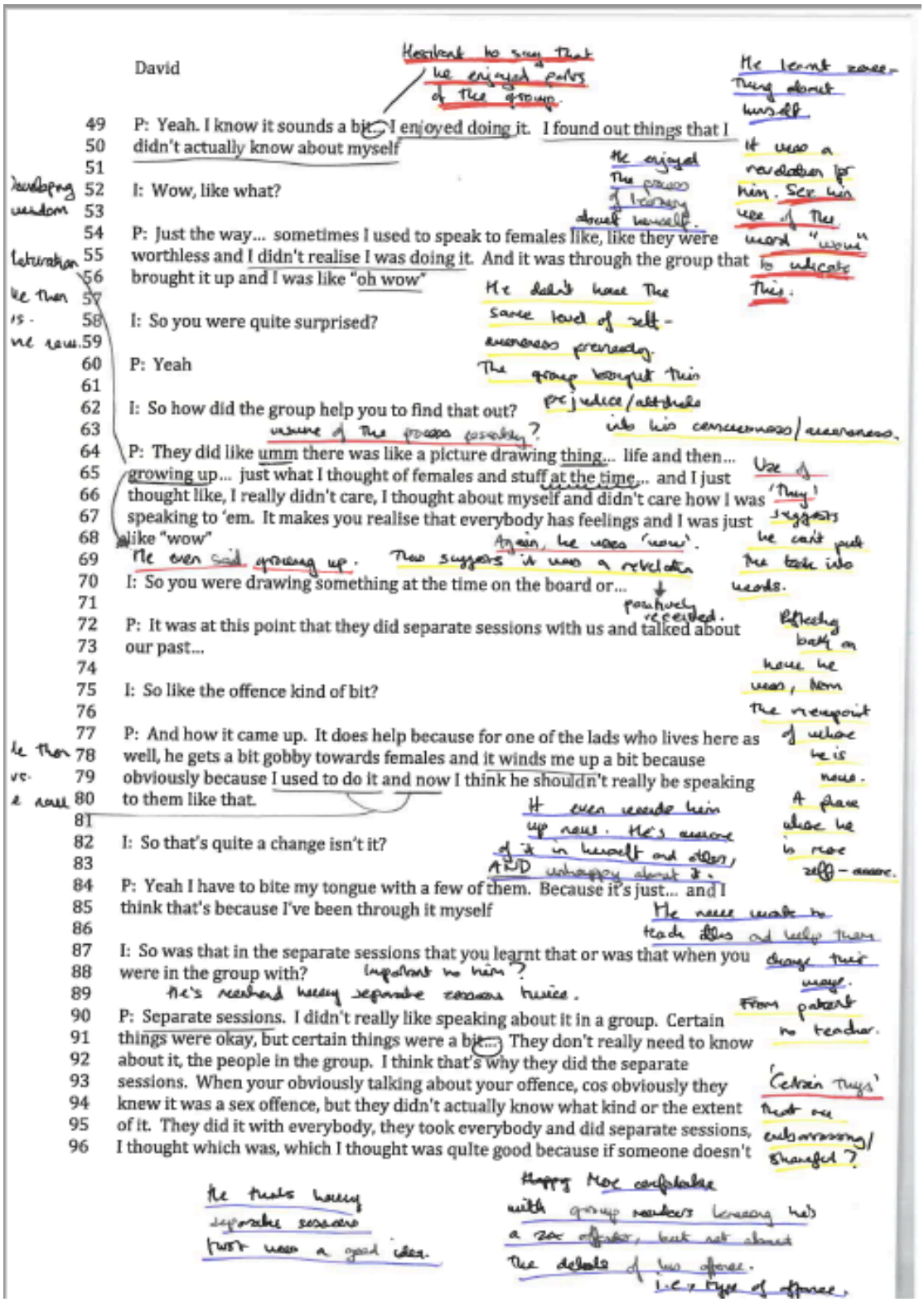
He viewed doing the group as the means of achieving what he wanted; That is, getting back into the community.

P: I think its good because if anyone goes there and says, "I'm not doing it", they could and then they go back out they could end up doing it again. It's good the way they do it.

I: Did you think it was right for you to go to the group?

Although a choice was presented, it doesn't seem much like a choice at all. More like an illusory choice.

Also, he believes that he would have been kept in the inpatient service - desired - until he did the group.



David

P: Yeah. I know it sounds a bit... I enjoyed doing it. I found out things that I didn't actually know about myself

I: Wow, like what?

P: Just the way... sometimes I used to speak to females like, like they were worthless and I didn't realise I was doing it. And it was through the group that brought it up and I was like "oh wow"

I: So you were quite surprised?

P: Yeah

I: So how did the group help you to find that out?

P: They did like umm there was like a picture drawing thing... life and then... growing up... just what I thought of females and stuff at the time... and I just thought like, I really didn't care, I thought about myself and didn't care how I was speaking to 'em. It makes you realise that everybody has feelings and I was just like "wow"

I: So you were drawing something at the time on the board or...

P: It was at this point that they did separate sessions with us and talked about our past...

I: So like the offence kind of bit?

P: And how it came up. It does help because for one of the lads who lives here as well, he gets a bit gobby towards females and it winds me up a bit because obviously because I used to do it and now I think he shouldn't really be speaking to them like that.

I: So that's quite a change isn't it?

P: Yeah I have to bite my tongue with a few of them. Because it's just... and I think that's because I've been through it myself

I: So was that in the separate sessions that you learnt that or was that when you were in the group with?

P: Separate sessions. I didn't really like speaking about it in a group. Certain things were okay, but certain things were a bit... They don't really need to know about it, the people in the group. I think that's why they did the separate sessions. When your obviously talking about your offence, cos obviously they knew it was a sex offence, but they didn't actually know what kind or the extent of it. They did it with everybody, they took everybody and did separate sessions, I thought which was, which I thought was quite good because if someone doesn't

97 want to sit and speak about it in front of everybody else, then they've got the
98 opportunity to do it on their own.
99
100 I: So did you have to share it in the group?
101
102 P: We did eventually but I think it was more easy reading it out than in was
103 talking about it in front of them
104
105 I: So what's the difference there?
106
107 P: I don't know I think again now I don't care what people think, but I used to
108 think, used to have a thing where I would always think, I always used to care
109 what people thought about me. Now I just look at it "I messed up... what I did
110 has been done and I can't take things back... If they don't like it they don't have to
111 talk to me, whereas before I didn't really want people to know because I cared
112 what people think about me. Now it's just you know there's plenty of other
113 people out there to talk to
114
115 I: So see if I got this right. So when you were in the group you were more
116 concerned about what other people thought about you?
117
118 P: Yeah. Towards the end it was just like, you don't like it then, we're all here for
119 the same thing so... I worked out, what's it, in the end if they pull me about it,
120 they say anything to me, then they're here for the same thing, they can't really
121 judge me.
122
123 I: That change that your describing there about going from being really
124 concerned about what people think about you to not caring so much, why did
125 that happen, when did that shift?
126
127 P: I think because of [name of facilitator] and the group saying "be yourself don't
128 worry about what they think because they're there for the same thing". Still to
129 this day I look at it and think nobody's perfect, everybody's made mistakes in life
130
131 I: Did the group help you realise that everyone's made mistakes and things like
132 that?
133
134 P: Yeah.
135
136 I: Because I was going to ask you what was it like being in a group with other
137 people who'd done similar things
138
139 P: Ummm.. It was quite difficult because there were some in there that obviously
140 did it young-younger kids. And obviously having a son. Sometimes they asked
141 me to speak about my son in the group and I was just like "no, not with..." There
142 was one lad in who was blatantly honest and said that he's always looking out his
143 window at kids walking to school n' that. And I'm thinking "and they're asking
144 me to talk about my son? No way!" He was blatantly honest and open that he

David

I: What was that like for you? How did you feel?

P: It wound me up because the fact of having a son and I thought... obviously yeah I've done a sex cri... ac... sex offence/crime, but I have a son and I think it was... if I had daughter and she come home to that it'd be... but he was blatantly honest and said that he'd get up at a certain time to look outta' the window and be back at the window when they finished school and watch them and all that. "What!?" It's a bit weird. It all wound me up a little bit, but I managed to bite my tongue and just... I think they knew as well because I told [name of facilitator], one of the, who was actually on the same unit, worked on the same unit, and I sort of told him... and he was like just ignore them. It was quite hard.

I: What do you think about different types of offenders being in the same group? As you said, some people might have offended against adults and some might have offended against children.

P: Yeah, in know mine was against a... I think 15. And there was one in there who done it against, I cant remember the age, but it was quite young. I always said that there is obviously all offences are bad but there's some, some sex offences, I just think. There all bad, but some of them against kid kids are worser than others. Even though they're the same. I think some that did it against young young kids who done even know the meaning of sex – it's just bang out of order. But they pulled me up in that group. They said all sex offences are the same, but I'm thinking not against kids though cos there's people out there that do it to baby babies and they need locking up for life.

I: Do you think that, you know, those types of sex offenders should be in the same group?

P: No. Cos' it's like I think, obviously, one was bad, she was 15 but she kind of obviously knew what sex was but kids at a young age they don't even know. They're not even ready for it. They don't even... so it's quite worse. So there are some worser that others but they are all the same sort of things. If that makes any sense?

I: I'm wondering what makes sense to you, so it's really good that you're talking me through this.

P: It just.... I didn't like it, it was just that I've got a little niece as well. It winds me up thinking, thinking that someone can honestly admit that they stand by a window waiting for kids to go past. If they can do it I wonder how many people there are out there that sit doing it. It's crazy.

I: So it was a bit of an eye opener for you?

David

P: Yeah, cos I won't even let my niece, she's seven and she's got an iPhone, when she comes and I tell my mum don't let her get it out in front of me cos' she's on, she uses the internet and everything, and you never know who's on that internet. It winds me up.

I: Right, okay, umm, so that was what it was like when you heard other people talk about some of their offences, how did you feel in the build up to telling them yours?

P: I was a bit nervous. I was nervous. It was more how do I say it and what are they going to think of me. A lot of them didn't actually, cos obviously there was some of them in there that was on the same unit as me, and I was thinking if I tell them then they go back and tell everybody else on the unit then it makes it hard for me, staying there and living there. Especially cos' there was different people in there. There was people in there for attempted murder. So it wasn't just a unit for sex offen... It was for all sort of people in there. So you're thinking you go back and tell them that were doing that group, obviously it's not just me who's going to get crap for it... You could have just made something up and not made it worse. Cos' some of the staff that are here when they first read about, before I first starting coming for my introduction days here, they read it and the way it had been writ from [name of inpatient service] made it sound like it was worse than it was. I was like "what do you mean?" and they read through the report and it does actually sound a lot worse than it was. Because they've got it down there as rape, but I think it was touching her with clothing, but they had it down there as actual rape, and I was like that didn't happen, and I think it's just the way it's written as well.

I: So there's something about the way that others think about you outside of the group for being a part of it?

P: Still to this day, people know that I've been to prison and they are like what did you go to prison for. I don't really tell them, I just make something up I say it was something else. Because as soon as you tell them you're going to get hell for the rest of your life really. Obviously if I meet somebody in the future obviously I will need tell them because it's part of my order thing, but I'm nowhere near that yet. Cos' they say here now, some of the staff are like – being my age – "you don't really talk about sex" they say to me... I've been put off, put off because... even though they say ask for ID, there's no point asking for ID, there's that many ways now people can get fake IDs, and you go to nightclubs people are getting in there that shouldn't be in there. You see it all the time. Girls walk past here and they look older than they are, and it's just like what the hell how could you let your kids walk out like that, its not right. It's not right and it does need to change because more and more people will end up getting into trouble. It's not right.

I: Sounds like you're saying that's put you off?

P: Yeah cos' even though they say that obviously I can watch porn and everything, I don't even want to watch that I've been put off that much. And they say, they say to me, it's going to happen soon. It will, but obviously in time, when

Word Counts

Thesis Abstract:	243
Chapter 1:	
Word count without references:	7016
Word count with references:	8863
Tables and figures:	678
Chapter 2:	
Word count without references:	4408
Word count with references:	5948
Chapter 3:	
Word count without references:	2609
Word count with references:	3416
Appendices:	
Word count:	9417
Total:	
Total word count without references (incl. thesis abstract, tables and figures):	14954
Total word count with references:	18470
Overall thesis word count:	27887