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Exploring decision making in intellectual disability nursing: provider and user perspectives

Williams, Ruth Wyn

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Exploring decision making in intellectual disability nursing: provider and user perspectives

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Ruth Wyn Williams
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Summary

This thesis describes a series of studies that examine how nurses who work with people with intellectual disability make clinical decisions in practice. Current research offers evidence and guidance to support clinical decision making for nurses working within mainstream healthcare services. However, the available reviews of intellectual disability nursing research have identified that evidence to support intellectual disability nursing practice is sparse. Consequently, little is known about how and what decisions intellectual disability nurses make in practice; and the types and sources of evidence they use to support their practice. In the context of intellectual disability nursing and in light of a review of the literature (Chapter 1 and 2), three studies were conducted.

The aim of this thesis was to use mixed methods (Chapter 3) to explore the process of clinical decision making in intellectual disability nursing. In Study 1 (Chapter 4), Interpretative Phenomenological Analysis was used to explore how twelve intellectual disability nurses made decisions in practice and how their decisions were influenced by evidence. Four key themes emerged: 1) getting to know the person, 2) working as a team, 3) evidence to support decision making, and 4) understanding of evidence based practice. An all Wales survey (Study 2) of nurses employed by the National Health Service intellectual disability nursing service in Wales was conducted. The survey determined the types and sources of evidence nurses used to make decisions in practice; further identifying the demographic and cognitive characteristics that influenced the use of evidence (see Chapter 5). Study 3 explored how individuals with intellectual disability perceive the role of intellectual disability nurses (Chapter 6). Seven participants engaged in semi structured interviews and the analysis of the data was guided by Foucault's concepts of dividing practice, scientific classification and subjectification. Two discursive themes emerged from the analysis: (1) Inclusion: empowering and supportive healthcare practice; and (2) Exclusion: challenges and practices that resist healthcare involvement.

The integrated findings are discussed in relation to their contribution to the literature, methodological challenges, implications for intellectual disability nursing practice, education and recommendations for future research (Chapter 7).

Acknowledgments

I fy nheulu - am eu hyder ynof a'u cefnogaeth diflino – Diolch.

Table of Contents

List of Tables, Figures and Boxes

Tables

Figures

Boxes

Chapter 1 - The context of intellectual disability nursing[1]

Author contributions

Ruth Wyn Williams [RWW] was responsible for the conception and design of this chapter. Richard Hastings [RH], Fiona Irvine [FI] and Gwerfyl Wyn Roberts [GWR] supervised the work and made critical revisions to the chapter for important intellectual content.

[1]Sections of this chapter ("The values and principles that underpin intellectual disability nursing", "A social model of impairment", "Rights", "The role of the intellectual disability nurse") have been adapted from: WILLIAMS, R.W. and COYLE, D., 2010. Community learning disability nursing. In: D. WATKINS; J. EDWARDS and P. GASTRELL (eds.) *Public Health and Community Nursing Frameworks for Practice* 3rd edition. London: Bailliere Tindall, 2010, Chapter 19, pp. 249-258. RWW was the first author of the book chapter and was responsible for writing these sections in the 2nd and 3rd Edition of Watkins et al.'s book.

Introduction

Published accounts seldom define the term intellectual disability (Griffiths et al., 2007), and an individual's understanding of the label is diverse. Presently, the term learning disability is widely used in the UK (Gates & Wilberforce, 2003), conversely, intellectual disability is often the term of choice internationally (Hamilton & Atkinson, 2009; Lunsky & Gracey, 2009; Weinbach, 2009; Edwardraj, et al., 2010), although Canadian guidelines refer to the term developmental disabilities (Sullivan et al., 2011). Such disparity in the use of the labels poses difficulty in comparing international research (World Health Organization, 2011) although there is consistency in the understanding of such terms (Department of Health, 2001a; World Health Organization, 2001; American Association on Intellectual and Developmental Disabilities, 2010). Learning disabilities, intellectual disabilities and developmental disabilities are labels that refer to a range of conditions that affect an individual's cognitive and social functioning (Department of Health, 2001a) and that are "noticeable before the age of 18 years" (Sullivan et al., 2011). In this thesis the term *intellectual disability* is used, although it is acknowledged that such a label is social constructed and is an "essential component in health and social care provision" (McClimens, 2007, p. 258) rather than a descriptor of the individual labelled with such a term.

The thesis explores decision making within intellectual disability nursing practice from the perspectives of nurses and service users, using both qualitative and quantitative research methods. This introduction (Chapter 1) will provide the context of intellectual disability nursing identifying the current value base that underpins practice; and considering the available evidence that intellectual disability nurses use as a foundation for their practice. Chapter 2, reviews the literature in relation to decision making theory and practice. The overarching methodological framework for the thesis is presented in Chapter 3, followed by three chapters (Chapters 4, 5 and 6) that present one quantitative and two qualitative studies. Each chapter relates to developing our understanding of how intellectual disability nurses make decisions in practice, an area that is rarely considered in general nursing research.

Chapter 4 describes a qualitative study whereby semi –structured interviews were conducted with twelve intellectual disability nurses to explore decision making in practice. Interpretative Phenomenological Analysis [IPA] guided the research process thus facilitating an in-depth account of how these nurses made clinical decisions in an in-patient facility. Four themes emerged from the data: 1) getting to know the person; 2) working as a team; 3) evidence to support decision making; and 4) understanding of evidence based practice.

The fifth chapter is a quantitative analysis of the types and sources of evidence nurses who work within intellectual disability nursing services use to inform decisions, with a regression analysis to predict the use of empirical or experiential evidence. The total population of nurses working within the National Health Service [NHS] intellectual disability nursing services in Wales were invited to complete the survey questionnaire.

In response to the lack of information about the perspective of service users, the sixth chapter represents the voice of seven service users and their experiences and relationship with intellectual disability nurses and mainstream healthcare services. The analysis was guided by Foucault's interpretations of the modes of objectifications (Foucault, 1973; 1980; 1994a). The analysis identified two discursive themes across the data, that is, *Inclusion: empowering and supportive healthcare practice*; and *Exclusion: challenges and or practices that resist healthcare involvement.* This study provides insight into service users' perceptions, aspirations and relationships with the healthcare service.

Chapter 7 synthesises the main findings from the three studies and reflects on the methodological challenges and implications for intellectual disability nursing practice, education and future research. It discusses the relevance of the thesis findings to Standing's (2008) revised cognitive continuum theory. Examples of how this framework could be used within intellectual disability nursing are proposed, thus relating the thesis findings to a new emerging conceptual model proposed.

Reflexivity: a personal and epistemological journey

The role of reflexivity is often discussed and advocated within qualitative research (Cutcliffe, 2003) although the term 'reflexivity' is poorly defined in the nursing literature (Carolan, 2003). Koch and Harrington (1998) suggest reflextivity is a continual progression of self-critique and self-appraisal by the researcher at each stage of the research process. Robson (2002) states that:

> "...reflexivity is an awareness of the ways in which the researcher as an individual with a particular social identity and background has an impact on the research process" (p. 22).

Fontana (2004) further suggests that researchers also consider how policy and historical factors influence the data gathered. The literature on reflexivity thus supports Rice and Ezzy's (1999) notion that the research and the researcher's role should be exposed to inquiry and analysis equally. However, the literature discussing reflexivity does so primarily in relation to qualitative research with less prominence within quantitative research. This is because traditionally, quantitative research is associated with "objectivity and detachment" (Jootun et al., 2009; p. 42) and research methods that are described as scientific and value free (Mortenson & Oliffe, 2009). Nonetheless, Walker et al. (2013) consider reflexivity as a valuable approach to critically review quantitative research and the development of an individual as a researcher as it offers transparent information about the position and influence of the researcher on the research process.

This thesis presents a mixed methods framework (see Chapter 3) incorporating quantitative and qualitative approaches to answer the research question. With reflexivity predominately advocated in qualitative research, its application across the entirety of this thesis is brought to question. Nevertheless, similar to Walker et al.'s (2013) paper that reflects on the first author, Susan Walker's PhD journey, this thesis proposes that reflextivity is a useful approach within a mixed methods framework as it offers a consistent approach across all three studies. Throughout this thesis, reflexivity enables the production of information that makes the researchers' role and position transparent (De Souza, 2004) thus adding rigour and credibility to the findings. This is in keeping with Northway's (2000) vision of reflexivity within nursing and disability research where it

is argued that, through reflexive strategies, researchers should critically question their practice and consider if the research is beneficial to individuals with disability (Northway, 2000).

Willig (2001) describes two modes of reflexivity: personal reflexivity and epistemological reflexivity (see Box 1.1 for definitions). These modes encourage researchers to reflect on the research process and acknowledge that researchers are influenced by and may influence the research process (Hand, 2003). The modes guide the novice researcher to discuss honestly, issues that may influence the research and provides direction to think about the research.

Box 1.1 Definitions of personal reflexivity and epistemological reflexivity (adapted from Willig, 2008; p. 10).	
Personal reflexivity – researcher influence as a person	**Epistemological reflexivity – researcher influence as a theorist / thinker**
Reflecting on: • own values, • experiences, • interests, • beliefs, • political commitments, • wider aims in life, • social identities that may have shaped the research. • how the research may have affected and possibly changed the researcher as a person and as a researcher	Requires the researcher to engage with questions such as: • How has the research question defined and limited what can be 'found'? • How has the design of the study and the method of analysis 'constructed' the data and the findings? • How could the research question have been investigated differently? • To what extent would this have given rise to a different understanding of the phenomenon under investigation?

The method of reporting reflexivity within a research project varies. Some authors describe the process as essential (Newbury, 2011) others pay little or no attention to the process of reflexivity. Willig (2008) suggest that reflexivity may be presented as a separate heading within the research project or incorporated within the main body of a report. Within this thesis, reflexivity is integral, however the explicit contribution of the process of reflexivity and its contribution to each study is presented separately. Thus, my role as the researcher and how that role impacts on the data gathered during the three studies within this thesis are explored in a reflexive preface offered at the beginning of each study and a reflexive summary given at the end of each study chapter (see Chapter 4, 5 and 6). Each reflexive account will highlight the researcher's role and process issues as well as providing a summary of the contribution of each study to knowledge, thereby addressing personal and epistemological reflexivity.

The values and principles that underpin intellectual disability nursing

Much is often made of the role that values have in intellectual disability practice (Department of Health, 2007a). It appears that only intellectual disability nurses rely on an articulated theory that places the person at the centre of nursing interventions. Were this the case, intellectual disability nurses would indeed be exceptional. All nursing branches have at their core a set of beliefs that inform and influence their interactions with the client or patient. Nurses and public health workers are not so different, though in the case of intellectual disabilities; the history and social legacy of the client group, may well be. Additionally, the work of intellectual disability nurses does not support a homogeneous population. There are no single records to establish the true population of people with disabilities (Bajekal et al., 2004). Thus,

> "…variations in estimates of disability may be caused by a number of factors. These include variations in what is being measured, who is being measured and how disability is measured" (Department of Work & Pensions, 2004, p. 2).

Emerson and Hatton (2008) estimate that 2% of the general poulation in England

have an intellectual disability. In addition, it is estimated that 177,000 (0.47%) adults with intellectual disability access services for people with intellectual disability (Emerson & Hatton, 2008). The 210,000 people with severe intellectual disabilities and 1.2 million people with moderate or mild intellectual disabilities (Department of Health, 2001a) intellectual disability nurses support are a heterogenous population with resulting complexity for organising services and responding to need. Nonetheless in Wales, disability "must be understood not only in numerical terms, but within wider economic, social and geographic curcumstances" (Disability Law Service, 2010). That is:

> "Wales faces its own unique challenges, including its demography and socioeconomic conditions….. Public services in Wales need to respond to the concentration of high levels of social need, the high costs of provision in areas of sparse population, a greater concentration of older people, fewer people in paid work and high levels of chronic ill-health, relative to the position in England" (Welsh Assembly Government, 2006).

Thus, the intellectual disability nurse in Wales must consider their values within the context in which they work.

It is not the intention of this chapter to retrace historical lineage of intellectual disability nursing, however it is of significance to reflect that intellectual disability nurses have, over the past three decades, shaped and focussed their practice responding to changing cultural, social and moral drivers. Intellectual disability nurses have responded with flair and innovation to meet the progressively changing needs of people with intellectual disability and continue to do so. They have achieved this without losing their health and health promotion role for the client group. Whilst we must see how history informs today's practice, we must equally look to the future free from the past's constraints (Jukes & Bollard, 2003).

The principles upon which modern intellectual disability services are founded reflect a social model of impairment (Swain et al., 2003) and the ideology of Person Centred Planning (Sanderson, et al., 1997; Sanderson, 2003a; Sanderson & Lewis, 2012). The approach can be seen to be at the heart of current legislative and social policy in all the home nations, such as Valuing People Now (Department of

Health, 2009a), The Keys To Life (Scottish Government, 2013), Statement on Policy and Practice for Adults with a Learning Disability (Welsh Assembly Government, 2007), and Equal lives (Department of Health, Social Service and Public Safety [DHSSPS], 2005). The challenge for services today is in tackling exclusion, stigma, improving quality of life and participation for people with disabilities.

The increased legislative basis of rights in society from the Human Rights Act (1998), Equality Act (2010), Personalisation (Department of Health, 2010a) and the Mental Capacity Act (2005), has shifted the balance of power from professionals to the individuals, user groups and organisations that represent their needs, wishes and rights.

A social model of impairment

It is known that health inequalities and high morbidity of preventable disease are prevalent amongst people with intellectual disabilities (Emerson et al., 2011). An understanding of the social model helps the intellectual disability nurse recognise the needs and aspirations of a population excluded from mainstream health, culture and politics. Moreover, it acknowledges the connections between social activity and health across the domains of health promotion and maintenance.

The principles of ordinary life as embodied in influential papers such as the seminal five service accomplishments (O'Brien, 1987) laid the foundation of today's intellectual disability services. Person centred approaches now form the underpinning principle of support. Indeed, John O'Brien (2004) stated that in order to achieve the keystone objectives of Valuing People (Department of Health, 2001a), person centred planning (Sanderson et al., 1997) has to exist. The one could not function without the other.

The social model of impairment does not deny the problem of disability but locates it within the wider society. In other words, for people with intellectual disabilities, their main challenge lies in overcoming the attitudes, prejudices and actions of others rather than coping with limitations in any aspect of daily living or

health maintenance. Nevertheless, the social model does not undermine nursing and health roles. On the contrary, it brings into sharp focus the action required to address inequalities in health and to develop strategies to identify and support the client. These include approaches such as health promotion and health gain that are geared towards inclusion and citizenship. It is most important that this approach should not be confused with the social model of provision (Swain et al., 2003) where health need may be overlooked with detrimental consequences for the person with intellectual disabilities (Northway et al., 2006a).

For the intellectual disability nurse, the social model provides a focus for partnership and intervention. Rather than trying to fix the person, the emphasis is on supporting access and inclusion to healthier lifestyles and developing opportunities for the indvidual to be a part of a healthier community. For example, in order for people to access and understand health promotion literature, there are two alternatives. The first approach involves a process whereby the person learns to read sufficiently well in order to engage in the material. The second and more favourable approach relies on the adaptation of the material to make it more accessible and credible to the reader. By responding in this way a more active personalised approach to health gain might be achieved; and dependence and passivity within the individual avoided.

Social policy documents such as *Our Health Our Choice Our Say* (Department of Health, 2006a) and drivers from within intellectual disability nursing itself, such as *Shaping the Future* (Northway et al., 2006a), demand that practitioners avoid adopting an individual model of care and focus instead on partnerships that lean towards a more social model approach whilst retaining and supporting the client's journey towards health (Aldridge, 2004). Succinctly put, the Department of Health (2001a) thus summarises the role of the intellectual disability nurse within healthcare:

> …"the main objective for the NHS is to 'enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a high standard, and with additional support where necessary" (p. 23).

Rights

The aim of nursing is the promotion and attainment of healthy lifestyles in which the people themselves have greater choice over their lives and are integrated into their local communities (O'Brien, 1987; Duffy, 2005). The Disability Discrimination Act 1995 and, more recently, the Equality Act 2010 are making an impact on the access to health and communities for people with intellectual disabilities. Along with the Mental Capacity Act 2005 and the existing Human Rights Act 1998, people with intellectual disabilities have never had their rights acknowledged and protected to their current extent.

Initiatives within the UK, such as In Control (Duffy, 2005) and Centre for Welfare Reform (Duffy & Fulton, 2009) provide people who have intellectual disabilities with real power through financial decision making and choice to buy individually designed services that cannot be delivered through traditional health and social care providers. The person's aspirations as the focus of service response are the basis of a rights culture that the modern intellectual disability nurse works within. In identifying health needs and developing effective individualised packages of care, the intellectual disability nurse can forge and facilitate working partnerships that empower the service user or client to experience a healthier life.

The Disability Rights Commission [DRC] (2006) (now the Equality and Human Rights Commission), have highlighted the inequality for people with intellectual disabilities in getting access to physical health services. They point to a number of failings on the part of health organisations and Local Authorities in adequately providing for this client group. They are concerned that providers are not being advised on the unique requirements of this client group. Moreover, they recommend that each NHS health organisation has a strategic health facilitator role to champion the needs of people with an intellectual disability and to provide expert clinical advice to ensure equal access to primary care services.

This case is a clear example of how rights-based culture now informs and directs services afforded to people with an intellectual disability. Rather than lamenting the high rates of clinical morbidity and low rates of uptake in preventative

screening, the rights-based approach states that it is unacceptable for the current inequity to continue. Moreover, it demands action to redress the imbalance. The Department of Health (2008a) states that:

> "a human rights based approach is one where the realisation of human rights principles is a central aim in policy and planning, where staff and patients are empowered and involved in achieving these, where accountability is clear and the most vulnerable groups are prioritised" (p. 65).

The five core values that underpin the human rights-based approach are Fairness, Respect, Equality, Dignity and Autonomy [FREDA] and such principles can inform clinical decisions (Curtice & Exworthy, 2010). The following section outlines the role of the intellectual disability nurse's practice and some of the challenges they face in providing evidence based care.

The role of the intellectual disability nurse

Current policy and practice are moving away from a paternalistic model of care to featuring individual choice as a central theme (Leadbeater et al., 2008). The essential foundation of practice for the intellectual disability nurse and others involved in supporting people with intellectual disability is person centeredness (Department of Health, 2007a). Fagan and Plant (2003) state that empowering people with an intellectual disability to identify and meet their health and social needs is the greatest challenge intellectual disability practitioners have. To be able to work in partnership, identifying what is important to and for the person with the challenges and potential for conflict inherent is equally challenging.

Intellectual disability services and practitioners in health and social care have seen profound changes in the last 20 years (Gates, 2011a). Some of these drivers have involved people with disabilities themselves demanding better treatment, raising awareness of human rights and establishing a greater understanding of disability rights. However, in spite of the great progress in promoting the rights of people with intellectual disabilities, the uncovering of poor, abusive or negligent practice still arises and is a grave cause for concern

(Commission for Healthcare Audit and Inspection, 2007; Care Quality Commission, 2011). Nevertheless, such concerns should be tempered by the fact that because of a greater expectation of rights for vulnerable people, the systems to protect individuals and expose unacceptable care are more robust and effective in safeguarding people with intellectual disability.

Intellectual disability health and social care policy can be identified as a concurrent policy; in that the NHS and Social Service provide the same function throughout the UK. As such, intellectual disability nurses are expected to work to local, (as well as individualised) levels, but also be cognisant of national policies. The intentions for policy are clear. The principles of rights, independence, choice and inclusion are clearly stated within Valuing People (Department of Health, 2001a), and reaffirmed in Valuing People Now (Department of Health, 2009a). Likewise, five areas that are central to intellectual disability services in Northern Ireland are identified: citizenship, social inclusion, empowerment, working together, individual support (DHSSPS, 2005).

Wales has developed the S*tatement on Policy and Practice for Adults with a Learning Disability* (Welsh Assembly Government, 2007) stating:

> "All people with a learning disability are full citizens, equal in status and value to other citizens of the same age. They have the same rights to:
>
> - live healthy, productive and independent lives with appropriate and responsive treatment and support to develop their maximum potential
> - be individuals and decide everyday issues and life-defining matters for themselves joining in all decision-making which affects their lives, with appropriate and responsive advice and support where necessary
> - live their lives within their community, maintaining the social and family ties and connections which are important to them
> - have the support of the communities of which they are a part and access to general and specialist services that are responsive to their individual needs, circumstances and preferences" (p. 12).

These rights should determine the value base upon which all practitioners in intellectual disability services base their practice in Wales. Joint working among these professionals is central in these policies as an example of one aspect that could improve service provided. The clear person centred vision reflected in these policies can only be achieved through the integration of services; and intellectual disability nurses have the potential to be at the heart of this development.

In practice, intellectual disability nurses work across a range of settings, including care management. However, 'good practice' (Department of Health, 2007a) dictates that there is a drawback for intellectual disability nurses working in social care, since, to be most effective, the intellectual disability nurse should have a health focus. Current literature identifies the diverse and complex roles undertaken by intellectual disability nurses, for example, community nursing (Mobbs et al., 2002; Barr, 2006), advocacy (Brooke, 2001; Llewellyn et al., 2007a, 2007b; Mitchell, 2007), annual health checks (Chapman, 2012) and challenging behaviour (Slevin & Sines, 2005) to name a few. Such complex roles require nurses to access information from a range of disciplines, theory and education. Northway et al. (2006b) acknowledges this challenge but notes that nurses should not rely solely on other disciplines' knowledge for their evidence base.

What is evidence based-practice?

There appears to be a lack of consensus about the nature of evidence based practice. Health professions have been influenced by David Sacketts' work, where evidence-based medicine is defined as:

> "the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett et al., 1996; p. 71).

Sackett et al. (1996) contend that evidence based practice is an approach whereby practitioners integrate their clinical expertise with evidence from research to make decisions about patient care. Although the decision making process is highlighted, that is, the best evidence is carefully considered and the process is clear and well

judged, the definition does not consider the way in which patients and clients may in themselves be a source of evidence who may contribute to their care.

Muir-Gray (2001) discussed the need to review the "best evidence available in the context of the prevailing values and resources available" (p. 12). Whilst, in this case, the author considers the broader meaning of values and resources, such as the organisational values of the NHS, financial resources and access to information, the nurse, her value base and the client's may be considered as the best resource to make and influence decisions about care.

Marsh (2001) develops Sacketts' ideas and defines evidence based practice as:

> "the conscientious, explicit and judicious use of current best evidence, based on a systematic review of all available evidence – including patient-reported, clinician-observed, and research-derived evidence - in making and carrying out decisions about the care of individual patients. The best available evidence, moderated by patient circumstances and preferences, is applied to improve the quality of clinical judgements" (Marsh, 2001, as quoted in McSherry & Bassett, 2002; p. 1).

This definition identifies a broad range of sources of evidence that can be used in the decision making process when caring for an individual, further suggesting that best available evidence may not be entirely research based. The concept of best available evidence is also noted in "The Code: Standards of conduct, performance and ethics for nurses and midwives" (Nursing & Midwifery Council [NMC], 2008) which states that nurses "must deliver care based on the best available evidence or best practice" (p. 4). However, the Council has failed to provide a clear definition of this concept (Woolrich, 2008).

The definitions of evidence based practice reviewed include some or all three of the following characteristics:

1. utilisation of research findings to guide practice,

2. expertise, knowledge and experience of the practitioner, and transfer of that knowledge, and

3. the opinion and wishes of the client.

Despite these three distinct attributes of evidence based practice, the majority of studies on evidence based practice in nursing are confined to exploring how nurses use research to guide their practice (see Table 1.1 for examples of studies).

Table 1.1 Studies that consider how nurses utilise research in practice

Area of nursing practice	Examples of studies
General nursing	Champion & Leach, 1989; Lacey, 1994; Rodgers, 1994; Kajermo et al., 1998 (Sweden); Adamsen et al., 2003; Hutchinson & Johnston, 2004 (Australia); Roxburgh, 2006; Bonner & Sando 2008 (Australia); Uysal et al., 2010 (Turkey); Moreno-Casbas et al., 2011 (Spain).
Midwifery	Hicks, 1993; Meah et al., 1996; Hancock et al., 2000 (Australia).
Paediatric nursing	Nagy et al., 2001 (Australia); Niederhauser & Kohr, 2005; Andersson et al., 2007.
Mental health nursing	Poster et al., 1992 (USA); Veeramah, 1995; Carrion et al., 2004; Nelson et al., 2006 (USA); Yadav & Fealy, 2011.
Nurse education	Veeramah, 2004; Milner et al., 2005 (Canada).
Intellectual disability nursing	Parahoo, 2000.

If the use of research is necessary for evidence based practice, intellectual disability nurses may find it difficult to achieve this goal. Fraser (2000), Northway et al. (2006b) and Griffiths et al. (2007) seem to suggest that there is a lack of research-based evidence for practitioners in intellectual disability nursing to guide their decisions. Furthermore, Mantzoukas (2007) suggests that evidence based practice is essential for decision making in practice in view of its aim to avoid

habitual practice and enhance clinical performance. In a rapid scoping review, Griffiths et al. (2007) identified 180 peer reviewed intellectual disability nursing articles between 1996 and 2006. The papers were categorised into three broad subject areas: research about people with intellectual disability; research about families and carers; and research about nurses. The category 'research about nurses' identified 71 papers with a primary focus on nurses. Of these only 29 considered intellectual disability nursing practice and the intellectual disability nursing service, 10 explored the 'theory practice gap' and one study examined research utilisation (Parahoo, 2000).

Northway et al. (2006b) and Griffiths et al. (2007) suggest several reasons for this dearth of literature. For example; intellectual disability nurses represent only 3% of the overall nursing population in the UK (NMC, 2005-06); intellectual disability services are marginalised, thus attracting less funding for research (Griffiths et al., 2007; Caan & Toocaram, 2008); and there is also an on-going debate about whether intellectual disability nursing should stay under the general umbrella of nursing (Department of Health, 2007a; NMC, 2007). Within this context, the challenges that intellectual disability nurses face in relation to evidence based practice will be reviewed.

Challenges facing intellectual disability nurses: evidence-based practice

The evidence base for intellectual disability nursing is

> "…not fit for purpose in terms of its extent, quantity or quality" (Griffiths et al., 2007, p. ii).

This damming statement from the Kings Fund appears to cast a doubt over the use and effectiveness of intellectual disability nursing research. However, the review makes clear some of the challenges that lie ahead for intellectual disability nursing and its use and generation of research. When thinking about evidence based practice, we need to be clear about what this means. For instance, do we mean knowledge transfer, research utilisation, best practice or critical appraisal of available evidence? Alternatively, do we mean evidence in the Cochrane hierarchy

of type one and type two evidence (see Table 1.2) whose main contributors will originate from the world of biosciences and medicine? Importantly the hierarchy of evidence would appear to exclude information and evidence from the perspective of the user, their carers and possibly the intellectual disability nurse. Griffiths et al. (2007) have been roundly criticised by Caan and Toocaram (2008) for the bias expressed by the review. They claim that the review amounts to a "cursory and superficial" account, missing out on many contributions to best practice (Caan & Toocaram, 2008, p. 78).

Table 1.2 Hierarchical classification of evidence informing treatment efficacy*

I	"Randomized controlled clinical trials
II	Well-designed trials without randomization. Nonrandomized trials or those with high alpha and beta errors
III	Analytical observational studies
IV	Multiple time-series or place comparisons, uncontrolled ('natural') experiments
V	Expert opinions, descriptive occurrence studies, case reports, case series reports"

* Jenicek (2003, p. 34, as quoted in Tucker & Reed, 2008, p. 292)

Whilst what constitutes evidence may not be entirely clear, the role of the intellectual disability nurse in utilising evidence appears even more ambiguous. The Kings Fund (Griffiths et al., 2007) states that theory and knowledge do not derive from intellectual disability nursing but that the field utilises evidence from a range of disciplines across diverse setting. Whilst it appears true that the basis for practice in intellectual disability is in the main:

> "…inspirational, theoretical or opinion based rather than evidence based" (Slevin et al., 2008, p. 59).

This does not dismiss the integrity of the interventions of the intellectual disability nurse. There are good examples of sound practice to be found within the UK where intellectual disability nurses have led innovations and contributed to real

change (for example see Taggart et al., 2011 and Chapman, 2012). The implications for intellectual disability nurses from recent reviews may appear stark. Nevertheless, nurses need to articulate their practice base, recognising that it might draw on diverse fields and unexpected origins.

To date, only Parahoo's (2000) research, conducted in Northern Ireland, explores research utilisation within intellectual disability nursing. Using a questionnaire, the study sampled 87 hospital based intellectual disability nurses. The aim of the research was to assess the attitudes of nurses towards research and to what extent they used research or related activity in practice. Parahoo (2000) concluded that there was little indication that evidence-based practice was a reality in intellectual disability nursing.

Conclusion

This chapter has presented an overview of the context of intellectual disability nursing, identifying the challenges of evidence based practice that continue to confront this area of nursing. Eleven years on from Parahoo's study, the aim of this thesis is to add to the growing intellectual disability nursing research that informs practice about how intellectual disability nurses make decisions, identifying the sources and types of evidence they access and showcase the voice and perspectives of service users in this process. Prior to presenting the three studies, the subsequent chapter will establish the theoretical and practice territory in relation to decision making (Chapter 2). This is followed by a discussion of the overarching methodological framework for this thesis (Chapter 3).

Chapter 2: Decision making: a review of the literature

Author contributions

RWW was responsible for the conception and design of this Chapter. RH, FI and GWR supervised the work and made critical revisions to the chapter for important intellectual content.

Introduction

The first chapter gave an overview of the context of intellectual disability nursing further exploring the challenges that nurses face in relation to maintaining evidence-based practice. This chapter extends beyond evidence-based practice and reviews published literature, knowledge, theory and opinion about decision making in practice-based healthcare disciplines. The review establishes a theoretical and practice territory for the thesis and underpins the literature overviews presented in relation to each separate study (see Chapter 4, 5 and 6).

The requirement for nurses to base their decisions on evidence is emphasised in healthcare policy (Welsh Government, 2012a), professional guidance (Royal College of Nursing [RCN], 2011), professional regulation in the UK (NMC, 2010) and internationally (for example, Nursing and Midwifery Board of Australia, 2006). Aitken (2003) and Lauri et al. (2001) suggest that decision making is becoming increasingly complex for nurses due to the ever changing healthcare environment, with new technology and developing methods of approaching patient care. Pearson (2013) also affirms that the healthcare setting increases the challenge of decision making due to greater workloads, diminishing resources and patient complexity. In the context of intellectual disability nursing practice, parallels can be drawn, in that there are new and developing clinical practices such as, health liaison nursing (Foster, 2005; Gaskell & Nightingale, 2010); prison nursing (Docherty, 2010); and forensic nursing (Mason & Phipps, 2010; Mason et al., 2011; Hutchinson et al., 2012) that require exploring in terms of evidence to support decision making.

As noted in Chapter 1, intellectual disability nursing has a growing research base (Griffiths et al., 2007). However, the four countries of the UK recognise that there is significant work to be done in relation to supporting "implementation of research findings in intellectual disability nursing practice" (Department of Health et al., 2012; p. 47). Thus, gaining an understanding of the evidence that nurses in practice use to make decisions within intellectual disability nursing environments contributes to the growing research base for

intellectual disability nurses. This chapter examines the broad theoretical constructs that underpin decision making in practice disciplines.

Search strategy

Aveyard (2010) describes a literature review as a "comprehensive study and interpretation of literature that relates to a particular topic" (p. 5). This chapter develops the literature review in offering a critical appraisal of the literature. That is,

> "critical appraisal is the process of carefully and systematically examining research to judge its trustworthiness, and its value and relevance in a particular context (Burls, 2009; p. 1)

Thus, a systematic approach was used throughout the search to gather, understand and interpret the literature. Related literature was identified through a combination of procedures that included:

- bibliographic searches of web-based engines such as Medline, Psychinfo, CINHAL and Web of Science that were available through Bangor University,
- "snowballing" through searches of papers cited in publications already identified; and
- the University book catalogue.

A broad based search to understand the theory associated with decision making was initiated.

Initially, databases were searched using search terms such as decision making or clinical reasoning, clinical judgment, clinical inference, critical thinking. Such searches identified an overwhelming amount of literature. It became evident that reviewing such an extensive range of literature would be a task that required more time than a doctoral timeframe allowed. For example the CINHAL database identified 54,777 publications related to the broad area of decision making. Thus, a strategy was used to reduce and limit the literature identified with a focus on providing an appropriate context for the

research presented in the thesis. On categorising major headings within the search, such as decision making; decision making- clinical; decision making-patient; professional practice, evidence based and refining the search to full text papers published in the English-language available in peer-reviewed academic journal and limited to the period 2003-2013, 2,335 papers remained within the search. Combined with the words learning (disability / disabilities) mental retardation, developmental disabilities, intellectual disabilities and mental handicap with the initial terms inputted yielded no results. Adding the term "theory" reduced the search to 486 papers, and with refinement of subject headings a total of 35 papers were identified. The abstracts of each paper were scrutinised, selecting only papers that included a discussion on the theoretical aspect of decision making.

Defining clinical decision making

From the literature reviewed, there is inconsistency in the terms used to describe decision making in nursing. *Clinical decision making* seems the most common term cited, across a range of published papers, in the UK (McCaughan et al., 2005; Pearson, 2013), internationally (Gillespie, 2010; Jahanpour et al., 2010; Jefford et al., 2011; Stubbings et al., 2012) and across child (Twycross & Powls, 2006), mental health (Hyde et al., 2009) and adult (Cioffi, 2001) fields of nursing. However, within intellectual disability nursing literature the word *clinical* in relation to decision making is not often used and *decision making* (Vallenga et al., 2008; Williams et al., 2010) seems to be the term of choice. Nevertheless, the only conclusion that can be drawn is that the literature exploring the concept of decision making does not appear to use any term consistently. Furthermore, difficulties in conducting literature reviews arise when other terms such as *clinical reasoning* (Andersson et al., 2012), *clinical judgment* (Harbison, 2006) *, clinical inference* (Wolf et al., 1996) and *critical thinking* (Chang et al., 2011) are also used in relation to the concept of decision making. However, within the literature related to healthcare practice the concepts of judgement and decisions are often

interlinked and are articulated as a single component (Thompson & Dowding, 2002).

Although a plethora of terms exist to explore and develop our understanding of decision making in healthcare practice, there is an agreement that decision making is a complex process. Simmons (2010) reflects this complexity in her review of the concept of clinical reasoning. She suggests that such "concepts all include elements of both process and outcome" (Simmons, 2010; p. 1152) and calls for further research to identify the variables that influence clinical reasoning. Standing (2005, cited in (Pearson, 2013) suggests that decision making involves "critical thinking, reflective practice, problem solving, judgment, ethical valves, professional accountability and scientific, evidence-based practice" (p. 212). Bucknall (2000) further suggests that the reality of clinical healthcare settings also make decision making a complex activity. Hamers et al. (1994) argued that the environment surrounding the nursing practice influenced decision making: such characteristics as experience, knowledge, personal skills and attitudes were noted.

The literature acknowledges the influence that practice has on the decision making process (Bowers et al., 2001; Bucknall, 2003). Furthermore, Rew and Barrow (2007) state that decisions in nursing practice are highly complex as nurses must make decisions based on inadequate or ambiguous data, thus requiring the nurse to apply an intuitive process. Thompson et al. (2008) in their study that explored the decision making characteristics of heart failure nurse specialists concluded that, regardless of the fact that the 29 nurses were given the same clinical information, the information processing and decisions reached differed. One explanation offered by Thompson et al. (2008) was that the nurses attached a different level of importance to the information presented. That is, nurses rated their information cues differently, and some nurses only made decision on the information presented. Thus, Thompson et al (2008) concludes that the specialist nurses "vary in the means by which judgements are reached and the ways in which information is processed" (p. 2182). The literature identifies that decision making in nursing

is complex. Hence, to explore decision making and its implications for nursing practice, theories of decision making need to be briefly reviewed.

Theories of decision making

There are three major theoretical approaches to analysing the process of decision making within the literature reviewed: information processing, intuitive-humanist approaches, and a cognitive continuum approach. Information processing and the intuitive-humanist approach seem to characterise the opposite ends of the cognitive continuum approach (Elliott, 2010). These theories offer an insight into how individuals process information and further consider the cognitive facets of decision making.

Information Processing

Information processing theory derives from cognitive psychology and the seminal research of Newell and Simon (1972) following a study asking participants to report verbally on how they were solving a given task. They described how the brain dealt with the reception, storage and processing of information received from the environment (Gross, 2005). Within the nursing literature, Thompson (1999) criticises this approach as "cold" and Harbison (2001) argues that it removes the human element from decision making. Therefore, the theory could be described as a scientific approach devoid of human and or emotional element. In interpreting the work of Newell and Simon (1972), their research focus was on how the human brain operated irrespectively of any valued judgment or application of those decisions that nursing often considers. Thus, this initial research was never intended to inform practice based disciplines.

The information processing model is a psychological theory that is often cited in medical decision making research (Bjørk & Hamilton, 2011). Such decision making is considered as a scientific approach to decision making. Wyer (2012) proposes that this approach provides an useful staged framework to explain the different stages of cognitive processing that occur prior to decision making. He further identifies this sequential process as

"comprehension, organization in memory, inference, integration, and the generation of an overt response" (Wyer, 2012; p. 156). Thus, this theory suggests a process of problem solving. Schunk (1996) suggests that an information processing approach focuses on how individuals attend to the context, encode the information learnt and relate this to knowledge in memory, store the new knowledge and retrieve the information needed to make a decision. Kinder and Burgoyne (2013) suggest that organisations such as the NHS consider information processing as "the gathering, interpreting and synthesis of information in the context of organisational decision making" (p. 275).

This approach is also described as a hypothetico-deductive rational process that underpins the four stages in nursing as proposed by Radwin (1990) and Hamers et al. (1994). That is: Cue acquisition, hypothesis generation, interpretation, and evaluation.

Stage 1: gathering preliminary clinical information about the patient;

Stage 2: generating tentative hypotheses about the patients' condition using short term memory based cues;

Stage 4: interpreting the cues gathered and classifying them as confirmatory, negative, or non-contributory hypotheses;

Stage 4: weighing up the decision alternatives and choosing the one most favoured by the evidence (adapted from Thompson, 1999; p. 1223).

Thus, these 4 stages represent a hypethetico-deductive process to decision making which consists of the individual using cues gathered in the short term memory to unlock "the factual and experimental knowledge in the long term memory" (Thompson et al., 2000; p17).

Such decision making based on logic, rational and objective approaches are today exemplified with the increasing emphasis on protocol based care (Rycroft-Malone, 2008; Rycroft-Malone, Dopson et al., 2009;

Rycroft-Malone, Fontenla et al. 2009; Stetler et al., 2009) that strives to standardise practice (Rycroft-Malone et al., 2010). Rycroft-Malone et al. (2010) define protocol-based care as "an umbrella term, which encompasses the use of a number of different care processes aimed at standardisation, including protocols, guidelines, care pathways, and algorithms" (p. 3).

Research by Taylor, (1997), Manias et al. (2004) and Twycross and Powls (2006) suggest that nurses do use hypethetico-deductive processes to guide their decision making. Taylor's (1997) qualitative study within a medical-surgical hospital and rehabilitation wards used the four stages mentioned to research the cognitive processes involved in nursing procedures and concluded that "the problem solving strategy used by nurses while delivering care was that of diagnostic reasoning" (p. 336). Manias et al. (2004) conducted a study in Australia with twelve first year graduate nurses in relation to decision making within medicine management on acute medical and surgical wards. The findings suggest that the nurses used a combination of decision making models. However, the hypothetico-deductive approach to decision was the most commonly used. The nurses demonstrated the hypothetico-deductive approach by making connections between various types and sources of information. Data were gathered by observation and individual semi structured interviews. In contrast, Twycross and Powls (2006) used the 'think aloud' technique and asked children's nurses to verbalise their thoughts in relation to a given clinical scenario. Although using scenarios may not portray clinical practice accurately, the authors concluded that the 27 nurse participants used a hypothetico-deductive process in their decision making. Thus, the information processing model requires the nurse to engage with their patient and clinical environment to gather information to make a decision. Such decisions are informed by nurses' professional knowledge of scientific evidence and experience (Pearson, 2013).

Therefore, the information processing theory proposes that decision making is a relationship between an *information processing system* (the individual) and the *context* (the environment in which the decision is made). Higgs et al. (2008) suggest that there are limits to the amount of information

an individual can process during a specified time, "and that effective problem solving is the result of being able to adapt to these limitations" (p. 236). Furthermore, results within cognitive research found that *experts* have an organised body of conceptual and procedural knowledge that they can access easily when making decisions (Glaser & Chi, 1988; Joseph & Patel, 1990). Gregson et al. (2002) suggest that expertise is represented by decision making that is intuitive and analytical in its approach. Benner (1984) argues that intuition, expertise and experience positively influence nurses' decision making and that critical reflection enables critical thinking that builds tacit knowledge. Avis and Freshwater (2006) also argue the case that critical reflection can be a sound basis for expert practice. The intuitive-humanist approach develops our understanding of intuition within decision making.

Intuitive-Humanist Approaches

The intuitive-humanist model of decision making can be described as the opposite to the information processing approach (Thompson et al., 2000). In that, the decision making is dependent on the individual involved rather than the decision *task* faced by the individual. This model of decision making in nursing is associated with the work of Benner (1984) and her colleagues (Benner et al., 1992; Benner et al., 1996). Based on Dreyfus and Drefus (1986) model, Benner identified the development of a nurse from novice to expert through five stages, that is, the novice, advanced beginner, competent, proficient and expert nurse (Paley, 1996). Blum (2010) suggests that the development through the stages depends on the depth and range of clinical experience and the length of time practicing, although it is acknowledged that not all nurses will pass through the identified stages. Jefford et al. (2011) suggest that the role and meaning of intuition in nursing is unclear in the literature. Numerous definitions of intuition and intuitive decision making are offered:

- "understanding without a rationale" (Benner & Tanner, 1987; p 23)

- "knowledge of fact or truth as a whole; immediate possession of knowledge; and knowledge independent of the linear reasoning process" (Rew & Barron, 1987, p. 60)

- "a perception of possibilities, meanings and relationships by way of insight"(Gerrity, 1987; p. 63)

- "immediate knowing of something without the conscious use of reason"(Schrader & Fischer, 1987;p. 45)

- "lacking underlying conscious processes and as not being able to be explained in a tangible manner" (Cioffi, 1997, p. 204).

- "intuition is 'a component of complex judgement, the act of deciding what to do in a perplexing, often ambiguous and uncertain situation. It is the act of synthesizing empirical, ethical, aesthetic and personal knowledge. Intuitive judgement is the decision to act on a sudden awareness of knowledge, that is related to previous experience, perceived as a whole and difficult to articulate" (Rew, 2000; p. 95).

- Intuition is described as responses "reached with little apparent effort and typically without conscious awareness" and which "involve little or no conscious deliberation" (Hogarth, 2001; p. 14).

These definitions only serve to demonstrate the ambiguity within the literature, thus the initial work of Benner (1984) has generated numerous interpretations of intuitive practice within the literature reviewed. Phelvin (2012) explores the role of intuitive practice in relation to working with individuals with profound and multiple intellectual disabilities that rely on non-verbal communication. Phelvin (2012) cites Young's (1987) definition of intuition as useful to intellectual disability nursing:

- "[a]…process whereby the nurse knows something about a patient that cannot be verbalized, that is verbalized with difficulty, or for which the source of knowledge cannot be determined."(Young, 1987; p. 52)

He concludes by suggesting that the intellectual disability nurses advance their skills and knowledge in working with individuals who use non-verbal communication through experience and developing a therapeutic relationship with the patient, as opposed to knowledge derived from scientific evidence.

The new knowledge is identified as *personal,* that is, "non-generalisable knowledge that is specific to particular care contexts and relationships" (Phelvin, 2012; p. 34). On this basis, he proposes, that intellectual disability nurses use intuitive and tactic knowledge when working with this specific group of individuals (Phelvin, 2012).

Gobet and Chassy (2008) suggest that the characteristics of the definitions of intuition are "rapid perception, lack of awareness of the processes engaged, concomitant presence of emotions and holistic understanding of the problem situation" (p. 130). Although Gobet and Chassy (2008) offer us some clarity regarding the definition of intuition, identifying incidents of intuitive practice could be difficult as there is no clear scientific base to intuition and no clear definition. However, there are numerous descriptive studies that explore intuition across various clinical areas (Welsh & Lyons, 2001; Traynor, et al., 2010; Nyatanga & Vocht, 2008; Pretz & Folse 2011). As the emphasis on evidence based practice within nursing is clear (NMC, 2008), there has been an attempt to measure intuition using valid and reliable instruments. Miller (1995), Rew, (2000) and Smith (2004) have developed instruments to measure intuition. Miller (1995) and Rew (2000) focused on experienced nurses in developing methods of self-report measures of intuition; whereby Smith (2004) sought to develop a measure suitable for use with student nurses. Pretz and Folse (2011) comment that the measures available are underdeveloped, and their paper offers insight into a web based survey that considered the interrelationships of self-reported measures of intuition. Within the literature reviewed, the role of intuition in decision making is acknowledged; although, "there is no reliable validated measure concerning intuition" (Pearson, 2013; p. 215). Thus, intuitive practice as an approach is not recognised within the literature as an established foundation for sound clinical decisions, although there is a growing research base that advocates that intuitive practice should be recognised in healthcare (such as Lyneham et al., 2008).

The intuitive-humanist approaches suggest that a decision is the result of the relationship between the individual and the environment and that

knowledge is embodied and embedded (Standing, 2010). This differs from the information processing approach that advocates a logical and systematic process of problem solving. From reviewing the information processing and intuitive-humanist approaches there appears to be various processes that may guide decision making in practice. However, authors such as Pearson (2013) advocate that a combination of information processing and intuitive-humanist approaches to decision making can achieve good outcomes. Both approaches seem to have different strengthens and weaknesses. Information processing may identify with scientific rigour and the ability to explain decisions, however its relevance to day-to-day practice is debatable. Conversely, the strength of the intuitive-humanist approach is its relevance to practice and its receptiveness to context. The cognitive continuum approach offers a way forward to combine these approaches.

A Cognitive Continuum Approach

The work of Hammond (1978) explored the divide between analytical and intuitive thinking that resulted in the publication of the cognitive continuum theory. Table 2.1 presents Offredy et al.'s (2008) interpretation of Hammond's cognitive continuum theory. The cognitive continuum theory (Hammond, 1978) defines intuition and analysis as distinct kinds of thinking and demonstrates how cognition may be determined by the attributes of a task. Hammond (1996) also identifies the middle ground between analysis and intuition as quasirationality: a mode of cognition that includes a combination of analysis and intuition. The theory offers six broad categories to understand decision making, thus suggesting that different types of decisions require engaging with different cognitive strategies. The decision making within modes 1 to 3 require time before outcomes or any conclusions can be drawn. In contrast, modes 4 to 6 identify with a decision making approach based on immediate information cues and tacit knowledge; thus decision making becomes an immediate process (Standing, 2010). Time is considered an important factor, in that an individual is more likely to use intuition when making a decision in a short period of time.

Table 2.1. Description of cognitive continuum theory adapted from Offredy et al. (2008; p. 858)

Mode	Description	Feature
Mode 1	Scientific experiment	A 'strong analytical experimentation' as the investigation takes place in the laboratory of the hard sciences, such as physics and chemistry (Hammond, 1978)
Mode 2	Moderately strong analytical experimentation	This refers to the types of experiments undertaken by social scientists, for example, biologists, and educational researchers. These researchers engage in a random-assignment experimental-control-group method that is based on the logic of statistical inference but involves some degree of intuition. This degree of intuition is not present in the traditional experiments suggested in mode 1
Mode 3	Weak analytical experimentation	This includes quasi-experiments (and surveys) undertaken by, social scientists, when strict random assignment, double blind, pre-post test experiments are not feasible. Quasi-experiments do not meet the rules laid down by mode 2 for the application of statistical logic and require the researcher to use their own judgement
	**Hammond (1978:16) suggests that from this point onwards an important cognitive boundary has been established because "covert judgemental cognitive activity becomes more important than the manipulation of variables". In other words, intuitive judgement plays a larger role in this mode of enquiry than the manipulation of variables. *Thus mode 4 is referred to as strong quasi-rational judgement***	
Mode 4	Strong quasi-rational judgement	Hammond (1978) claims that this mode is the strongest of the quasi-rational modes of cognition. Aids to cognition, such as computer models to manipulate variables hypothetically, can assist in reducing psychological factors such as memory loss, information overload and recency
Mode 5	Moderately strong quasi-rational thought	The cognitive activity of people in this mode is based largely on known data. Hammond (1978) suggests that these individuals act upon the data in a passive and intuitive way. Doctors practising clinical medicine are considered to act in this way. This view could also extend to nurses. Clinical inference is therefore a weaker mode of cognitive activity than aided judgement (mode 4).
Mode 6	Weak quasi-rational thought	This is the most intuitive mode and involves uncertain and inconsistent rules that are never made explicit. Hammond (1978:18) argues that this mode is the "most dangerous" for solving problems

Hamm (1988) developed Hammonds work and adapted the theory to assist doctors to understand clinical judgement. He suggested that the more structured the task, the more analytically induced the decision process may be; an ill structured task may be intuition–induced. That is, the decision task prompts the way of thinking. For instance, ill structured tasks, such as, managing unfamiliar or unexpected situations, that have no set procedure or guide would promote intuitive decision making. Likewise, structured tasks, such as, managing predictable situations that are guided by policy and procedure may be tasks that prompt analysis. From Hamm's (1988) development of Hammond's (1978) theory (see Figure 2.1), the cognitive continuum may be used as a framework that enables a practitioner to analyse their decision making. The practitioner may position different kinds of tasks and different kinds of thinking within the framework that might enable them to consider how to improve their decision making skills (Hamm, 1988). Hamm (1988) also proposed that decisions are often positioned somewhere in the middle of the continuum between analysis and intuition, further suggesting that the cognitive mode may change during a task.

Cader et al's (2005) analysis of the cognitive continuum guided by Fawcett's (1993) evaluative criteria concluded that the theory had much to offer nursing regarding the understanding of how nurses make decisions in practice. The theory offers a "compromise between analysis and intuition" (Cader et al., 2005; p. 403) and as nurses use a mix of intuitive and analytical processes to guide decision making, the cognitive continuum approach offers a tool for nurses to reflect or plan their decisions. Similar to Hamm (1988), Thompson et al. (2000) suggest that intuitive and information processing should be considered as existing at either end of a continuum rather than as separate entities. In other words, decisions are "never wholly rational or uniquely intuitive"...however decisions "are commonly located somewhere in between" (Thompson et al, 2000; p. 18). Thus, Thompson et al. (2000) support the usefulness of the theory to nursing.

Within the context of management Mahan, (1994) and Dhami and Thomson (2012) discuss the relevance of the cognitive continuum theory and

advantages of using the framework to identify the movement of a management task along the continuum. Dhami and Thomson (2012) propose that the theory should be developed to consider team decisions and the use of information technology to support decisions. This could also be relevant to nursing, as Taylor et al. (2010) note: "the rationale for introducing multidisciplinary teams is that as the management of disease becomes more complex, it is important to involve all key professional groups in making clinical decisions for individual patients" (p. 743).

The literature reviewed identified three papers that considered the application of the cognitive continuum theory to nursing (Cader et al., 2005; Offredy et al., 2008; Standing, 2008). Cader et al. (2005) provide a theoretical evaluation of the relevance of the theory to nursing. This paper was stimulated by the need to understand decision making in nursing in light of the requirement for evidence base practice. The usefulness of non-nursing theories to nursing is debated. Cader et al. (2005) remarks that such theory as Self-Efficacy Theory (Bandura, 1977), a social cognitive theory, has much to offer nursing. For example, self-efficacy is a useful predictor of health behaviour (Ashford et al., 2010), such as that exhibited in smoking cessation (Baldwin, et al. 2006) and within chronic pain management (Nash et al., 2012). It is thus, concluded that nursing should draw on theory from a range of disciplines to understand practice. Rather than debating the cognitive continuum theory, Offredy et al. (2008) used the theory to guide their analysis of how nurses made their prescribing decisions. An exploratory approach using patient scenarios were used to investigate decisions that 25 nurses made in relation to prescribing or not prescribing. Offeredy et al (2008) found that the majority of the nurses made decisions related to mode 5 and 6 (see Table 2.1) of Hammond's (1978) mode of enquiry. This was a small scale study, and the use of patient scenarios is identified as a limitation. As Friedman et al (1989; is quoted in Offredy et al. 2008; p. 866) states, "nuances of form, colour, smell and noise are not easily translated into written symbols". Further research into the usefulness of the cognitive continuum theory to explore decision making in nursing is advocated. It is the work of

Mooi Standing (2008) that develops and adapts the theory to nursing by introducing the concept of nine modes of practice (see Figure 2.2).

Figure 2.1 Clinical intuition and clinical analysis: expertise and the cognitive continuum – the six modes of inquiry

(adapted from Hamm, 1988; p. 87)

Well-structured ⇧		High ⇧
	1 Scientific experiment	
	2 Controlled trial	possibility of manipulation
	3 Quasi-experiment	visibility of process
TASK STRUCTURE	4 System-aided judgement	
	5 Peer-aided judgement	time required
	6 Intuitive judgement	⇩
Ill-structured ⇩		low

Intuition ⇦ COGNITIVE MODE ⇨ Analysis
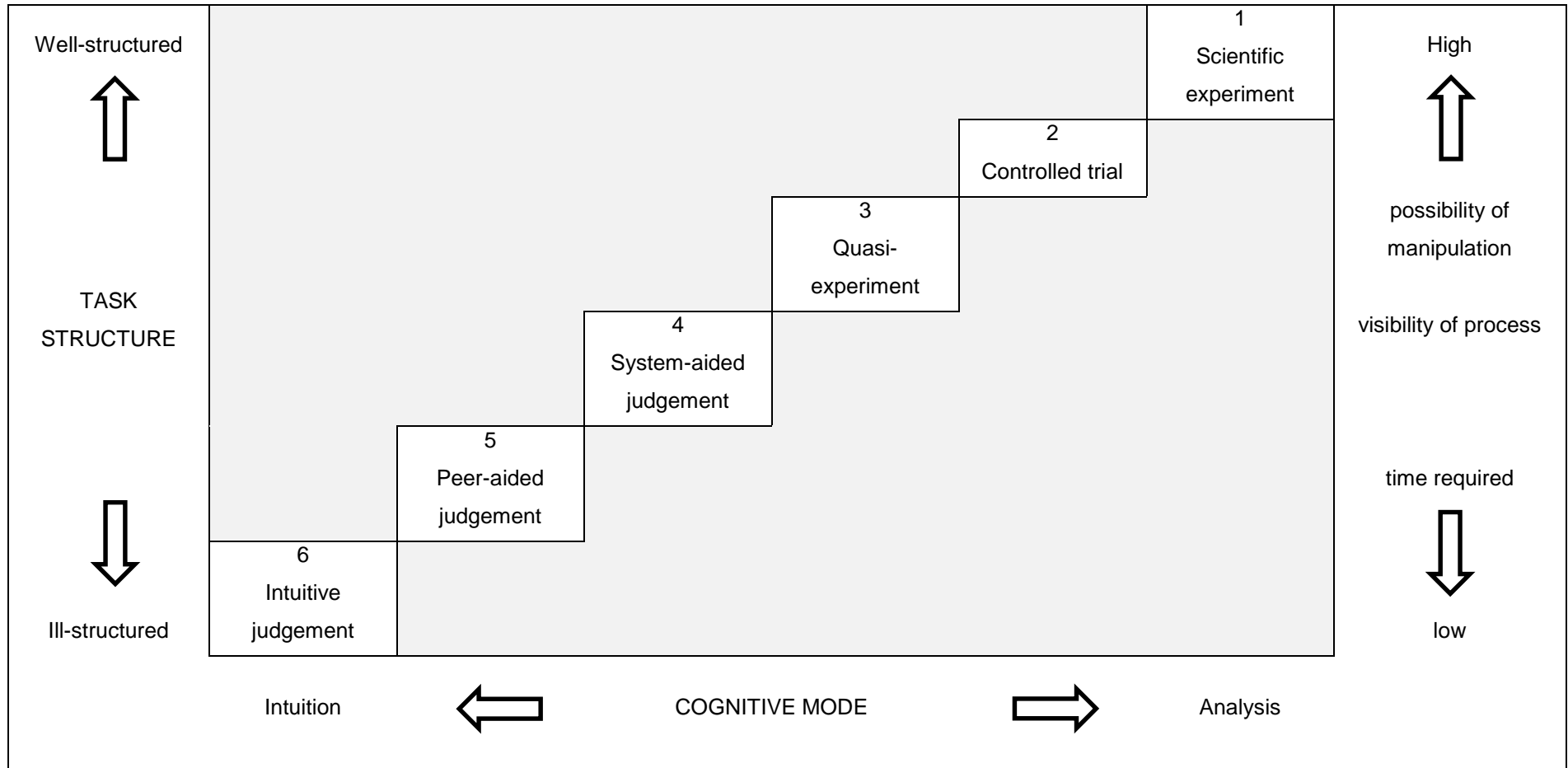
Theoretical framing: Standing's model

Mooi Standing has published three papers that consider the aspects of her unpublished PhD thesis (Standing, 2007; 2008; 2009). In 2007, Standing published a report of a study that explored student nurses' perceptions of decision making on entering the professional register (although intellectual disability nursing students were not recruited). Standing's 2008 paper evaluates the cognitive continuum theory and proposes a new way forward in the application of the theory to decision making in nursing. Revising the *modes of inquiry* to *modes of practice,* Standing proposes that the continuum now reflects the nature of nursing decisions by adding reflective judgement, patient centred judgement and qualitative research (see Figure 2.2 Standing's revised cognitive continuum of clinical judgement and decision-making in nursing – nine modes of practice (Standing, 2008)). By adding these concepts Standing (2010) suggest the modes of practice are "more patient-centred" (p. 116). The addition of three modes of practice to the existing six modes of inquiry, offers nursing a broader evidence base with greater relevance to nursing and healthcare practice (Standing, 2010). The 2009 article explores the relevance of phenomenological research to nursing (Standing, 2009). In addition to these articles, there are two informative books that give a comprehensive discussion of the revised cognitive continuum theory – nine modes of practice (Standing, 2010) and a guide for student nurses on decision making and clinical judgment (Standing, 2011). The literature search identified no studies that used the revised theory to analyse the decision making approaches used by nurses working with individuals with intellectual disability.

Standing's revised cognitive continuum theory has much to offer nursing as it has capacity to consider and value decisions that are based on intuition or analysis and decisions that are based in middle of the continuum that may include aspects of intuitive and analytical approaches. Lauri et al. (2001) in their international study of nurses' decision making skills across five countries (United States of America, Switzerland, Sweden, Finland and Canada) also advocate that nurses' decision making ranges from the middle

ground (quasirational) of the continuum to either intuitive or analytical approaches. Again, no nurses that worked directly with individuals with intellectual disability were included in Lauri et al.'s (2001) sample. Participants were recruited from adult nursing care of the older person and medical – surgical wards. Study 2 (see Chapter 5) will adapt and use Lauri et al.'s (2001) 56 item questionnaire to gather data from nurses who worked in intellectual disability nursing services across Wales.

Nurses are accountable for the outcomes of their decisions (NMC, 2008), thus, nurses need to articulate their knowledge and experience that underpins their decisions (Noon, 2013). Standing's model influenced by intuitive and analytical approaches identified along a continuum offers a way forward to understanding the cognitive strategies used by nurses.

Figure 2.2 Standing's revised cognitive continuum of clinical judgement and decision-making in nursing – nine modes of practice (Standing, 2008)

Nurses' 'live' accountability for their clinical decisions

Interpret & apply ethical & professional codes of conduct

Collective prior approval by a formal ethical committee

High

'Faceless' decisions e.g. developing policy, clinical guidelines; management; interpreting test results

TASK

STRUCTURE

'Face-to-face decisions e.g. plan, deliver & review care with patients; communicate & empathise with patients.

Low

Experimental research

Correspondence   Competence
(Practical relevance, empirical accuracy,
evidence-based,   effective outcome)

Survey research

Qualitative research

Action research & clinical audit

Critical review of experiential and research evidence

System aided judgement

Patient & peer aided judgement

Coherence   Competence
(Sound rationale, retraceable, defensible,
non-contradictory, logical process)

Intuitive judgement

High

Possibility of manipulating variables

Visibility of process

Time

required

Low

Low   **Intuition**   **COGNITIVEMODE**   **Analysis**
[Tacit]   [Source of Knowledge]   [Explicit]

Complexity of decision making in intellectual disability nursing

Nurses continually engage in decision making when caring for patients (Harbison, 2001, Lauri et al. 2001) thus Ramezani-Badr et al. (2009) state that decision making is an essential part of nursing. Tanner (2006) proposes that decision making directly affects patient care and patient outcomes. Additionally, the NHS Confederation (2012) proposes that healthcare outcomes are improved if service users are involved in decision making. The Government's transparency agenda backed by the Health and Social Care Act (2012) aims to give patients greater control and involvement in the decisions that affect their health. Healthcare professionals sharing information with their patients is advocated as good practice (Royal College of General Practitioners, 2010). Such initiatives as 'My Health Online' in Wales (see https://www.myhealthonline-inps.wales.nhs.uk/), 'cUnicalportal' in Scotland, and England's strategy to give patients access to electronic General Practice records by 2015 are ways forward to enable patients to make informed decisions about their health care (Levy & Heyes, 2010).

Tambuyzer et al. (2011) clarify the notion of patient involvement in mental healthcare, inferring that such involvement is complex and multi-dimensional, and remains a vague concept in the literature. This notion of patient involvement adopts the notion that patients are active participants within healthcare decisions. Smith et al. (2009) suggest that such involvement may require the service user to have some level of education and literacy skills to understand complex health decisions. Smith et al.'s (2009) qualitative study, conducted in Australia explored the education and health literacy of patients and their ability to be involved in decisions related to bowel cancer screening. It concluded that the professionals' ability to use various communication strategies, such as empathy, and the use of person centred approaches may be beneficial to some patients. Communication is fundamental to the nursing profession (Welsh Assembly Government, 2003; Clayton., 2006; Finke et al., 2008). However, Martin et al. (2012) argue that intellectual disability nurses are the only profession that regularly work with individuals with communication impairments. There is emphasis on developing knowledge and skills that are person driven in supporting individuals with intellectual disability to participate in decisions that influence their health.

Florin et al. (2008) suggest that there is a knowledge gap between the practitioner and the patient in relation to healthcare decisions, nevertheless, this gap might be decreasing due to the underpinning "choice agenda" (Suhonen et al., 2011), that is, giving the patients choice and involving them in health related decisions. However the practitioner and the patient may bring different types of knowledge to the decision making process.

The value base for intellectual disability nursing is clearly stated by the four countries of the UK (Department of Health et al., 2012) articulating that including the individual at the centre of care is essential. Such principles as personalisation are advocated, that is:

> "supporting the individual's control and choice over their own life and services through empowering people with learning disability, their families and carers and relinquishing 'control" (Department of Health et al., 2012; p. 8).

Crucial to this "relinquishing control" is enabling people with intellectual disability to make informed decisions, moving away from professional orientated decision making to patient centred decision making.

Werner (2012) reviewed the literature on decision making within intellectual disabilities stating that there was no evidence of models that supported decision making for individuals with intellectual disability. Furthermore, only four papers explored decision making in intellectual disability healthcare more broadly. Within these papers, the evidence to support the notion of involving individuals with intellectual disability in decisions that directly affect their lives is limited (Fisher, 2009a; 2009b; Ferguson, et al., 2010; Wagemans, 2010). Much of the discussion focuses on substituted decision-making; the role of nurses is not discussed in these studies. Goldsmith et al. (2008) offer a review of informed consent to healthcare interventions. The opportunities for individuals with intellectual disability to make decisions in healthcare are discussed. Within the literature reviewed by Goldsmith et al. (2008) there was an agreement that people with intellectual disability lacked experience in decision making. Thus, there is a clear role for nurses working with people with intellectual disability in enhancing the opportunities for individuals to

make decisions within healthcare. The literature focuses on the individual with intellectual disability and not on nurses' decisions. However, if the decisions that nurses make when they are working with individuals with intellectual disability are not *visible* it makes it difficult for individuals with intellectual disability, their family and carers to be involved in those decisions. It is often the results of ineffective care decisions that are published (for example: Death by indifference: 74 deaths and counting (Mencap, 2012); Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (Francis, 2013); Inspection Report: Ladymead Nursing & Residential Home with Dementia, (Care Quality Commission, 2013)). With new roles in nursing and the requirement for nursing practice to be based on evidence (NMC, 2008), Hancock & Durham (2007) suggest that the quality of nurses' decision making has become an essential component to improve the outcomes for patient care.

It has been argued that there is a limited understanding of how nurses make clinical decisions and the role of factors that affect them (Botti & Reeve, 2003; Hicks et al., 2003; Baxter & Rideout, 2006). Thus, it is important to explore factors that influence clinical decisions. The purpose of this thesis is to provide a deeper understanding of decision making among nurses who work with individuals with intellectual disability further exploring the patient/service user perspective.

Conclusion

The purpose of this chapter is to provide an understanding of the theoretical and practical implications of decision making. Having identified the plethora of terms that describe decision making in the literature, the three approaches to decision making were reviewed: information processing, intuitive-humanist and the cognitive continuum theory. Within the field of nursing there is a consensus that intuition and analytical approaches to decision making have elements to offer a clearer understanding of decision making, and several studies have been identified that demonstrate how nurses use intuition and analysis to guide decision making. However, there is no literature that directly addresses the decision making of nurses who work with individuals with intellectual disability. The three studies within this thesis address this gap in knowledge. The complexities of decision

making from the perspective of nurses working within intellectual disability nursing services and service users' perspectives are explored. To investigate such complexities a mixed method approach to the thesis is pursued and this is examined in the following chapter.

Chapter 3 - Methodological Framework

Author contributions

RWW was responsible for the conception and design of this Chapter. RH, FI, GWR and Jaci Huws [JH] supervised the work and made critical revisions to the chapter for important intellectual content.

Commentary

This chapter will reflect on the journey of learning and engaging with the methodology that guided the studies that were undertaken during this doctoral venture. The aim of this journey was for the novice researcher to gain knowledge and skills in different methodological frameworks that would contribute to the field of intellectual disability research. It subscribes to the view that engaging in a doctoral study equates to undertaking education and training in research (Humphrey et al., 2012). Concurrently, the chosen methodology was also driven by the need to address the initial research aim of exploring the evidence that nurses working within NHS intellectual disability services in Wales used to inform their decisions. The research questions drawn from the literature reviewed, the supervisory meetings, personal experience and consultations with service colleagues and service users informed the methodological decisions during this journey.

This doctoral venture comprised of conducting three interlinked studies that address the overarching research question. The studies are seen as building blocks; however, the studies may also be regarded as independent pieces of work, although Chapter 7 draws on the findings of the three studies and thus reflects on the implications for practice. Discussion regarding the application of each methodology that informed the three studies presented in this thesis is outlined in Chapters three, four and five. Study 1 presented in Chapter 4 introduces interpretive phenomenological analysis as a framework that enabled the exploration of nurses' views and understanding of their decision making process. Chapter 5 presents the second study that used a cross sectional survey design to gather data from the total population of nurses working in NHS intellectual disability services in Wales. The final study in Chapter 6 introduces the reader to Foucault's concepts of dividing practice, scientific classification and subjectification as a method to analyse interview data gathered from individuals with intellectual disability. This chapter will not reiterate the application of the methodology presented within each study but will consider aspects that informed the overarching methodological framework.

The framework consists of two journeys, the first focusing on gaining the perspective of registered nurses working within intellectual disability nursing services using qualitative and quantitative methodology. The second journey, guided by qualitative methodology endeavoured to listen to the service users' voice. Wales is a bilingual nation, thus the overarching methodological framework took account of the statutory and policy requirements of conducting the research in a bilingual context as well as considering the communication needs of research participants in every aspect of the research journey.

Introduction

Harding (1991) describes methodology as implementing research with reference to a set of principles that evolve from epistemological assumptions that guide decisions during the research journey. This chapter will explore the overarching methodological framework that guided this thesis. The aim of this thesis is to provide an opportunity to discuss and debate the complexities of decision making rather than generalising any findings. Thus, a *broad brush* approach to the methodology is taken, where the first methodology was essentially the *digging tool.* The second study needed to build on the first to give an all Wales representation (survey). Finally, the vital element of seeking the service user's perspective was explored. No one method would enable the researcher to fully explore the complexities of decision making within the context of nursing, thus this thesis embraced a mixed methods approach. Mixed methods research can be defined as the "integration of both qualitative and quantitative data" (Schifferdecker & Reed, 2009; p. 637). Furthermore, Creswell and Plano Clark (2007) suggest that a combination of research methods can provide a more comprehensive understanding of the research question. Yet, combining methods may be associated with a degree of intricacy as different methodologies conventionally belong to distinct paradigms (Foss & Ellefsen, 2002).

Paradigms were defined by Kuhn (1962) as a set of beliefs, that is, the philosophical bases of the research methodology that influence different research approaches that was described as a *worldview* (Mertens, 2012; p. 255). Kuhn (1962) suggested that researchers with different worldviews would be unable to relate to each other because of their differences in methodological assumptions. Thus, one of the challenges in engaging in mixed methods is that the researcher does not position themselves too firmly in relation to any particular paradigm (Cameron, 2011). Rather, there is an appreciation of the contribution of competing paradigms in enhancing our understanding of the research questions where the sum is greater than the parts.

As a researcher, there was a need to observe the set of beliefs that each methodology offered to the individual studies and the overall thesis. Thus, this

thesis, while combining mixed methods of collecting data, such as interviews and survey, also considered the mixed methodological paradigms presented. This concurs with Johnson et al.'s (2007) definition of mixed methods research:

> "Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purpose of breadth and depth of understanding and corroboration" (p. 123).

Therefore, in this thesis, mixed methods refers to the different methods used to collect data and the methodologies that guide the three studies. Furthermore, Johnson and Onwuegbuzie (2004) note that mixed method research offers "practicing researchers" (p. 15) an opportunity to develop research skills. Thus, it is relevant to students studying for a PhD who view such study as a research training ground.

Intellectual disability nursing research is described "as being at the interface between different academic and professional disciplines" (Northway et al., 2006b; p. 6) (see Figure 3.1). Both intellectual disability nursing researchers, and clinical practitioners, may draw on knowledge and experience from across disciplines. Within Northway et al.'s (2006b) review of published research by and about intellectual disability nurses between 1995-2003, 142 papers were identified from the UK and Ireland, with a further 14 international sources. A range of methodologies were used, for instance, 42 studies were qualitative in nature and 50 studies were quantitative with 25 studies using mixed methods. Nonetheless, most of the studies were small scale and offered limited information about their methodological approach and only 15 papers considered research methodology. Most of those papers considered the methodological challenges faced when seeking the views and increasing the participation of service users in research (see Chappell, 2000; Hewitt, 2000; McNally 2002; Bollard, 2003).
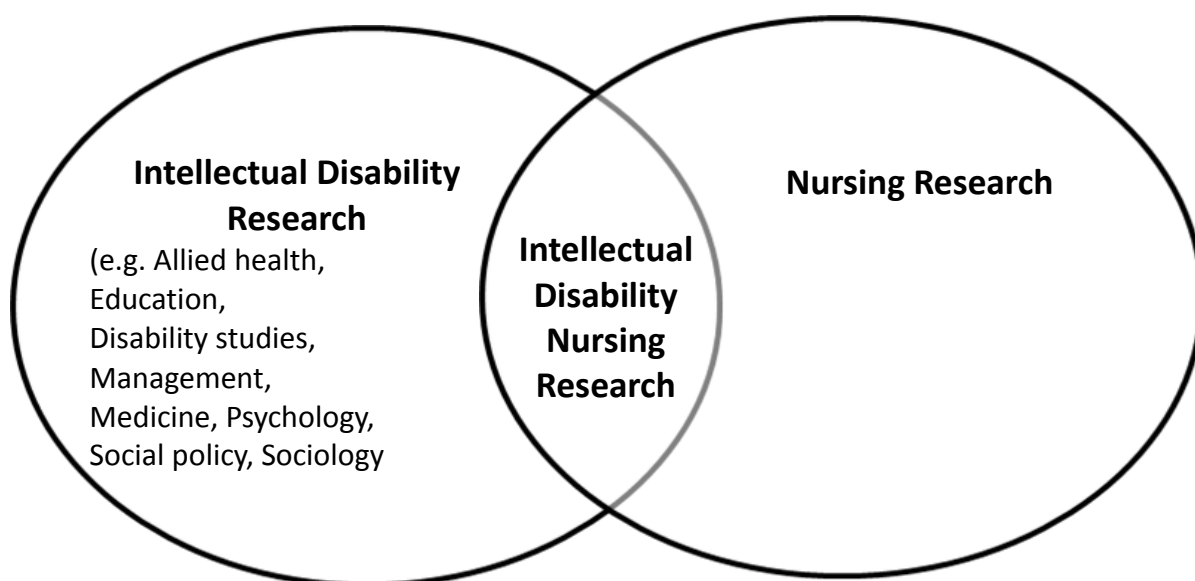
Figure 3.1: The position of intellectual disability nursing research (adapted from Northway et al., 2006b; p. 6)

Northway et al. (2006b) identify that intellectual disability nursing research has been and is influenced by disciplines other than nursing. Benner et al. (1996) suggest that nursing research requires strategies that reflect the multi-faceted nature of nursing. Thus, taking a mixed method approach had the potential to address such breadth within nursing practice. Fain (2013) proposes that using both quantitative and qualitative approaches are "complementary and provide an accurate representation of reality" (p. 7), thus enabling the researcher to collect data about a complex practice such as decision making. Each study within this thesis was conducted with reference to and guided by a set of epistemological assumptions. Guba and Lincoln (1992) proposed that, traditionally, qualitative and quantitative methods belonged to different concepts that guided research. Furthermore, Tashakkori and Teddlie (1998, p. 3) described the relationship between the two methods as a "battlefields of wars" or "paradigm wars" as described by Lincoln and Guba (1985, cited in Bergman, 2008, p. 11). Often qualitative research is defined by being the opposite of quantitative (Silverman, 2011), although Grahame (1999) suggests that "the notion that qualitative research

is non-quantitative is true but uninformative: we need more than a negative definition" (p. 4). The terms qualitative and quantitative research may highlight some preconceived ideas about the research, however this thesis took a pragmatic approach in choosing different research methods to address the research question. Mixed methods research is a developing area of research (Bergman, 2008) where qualitative and quantitative traditionalists are encouraged to debate and consider how "research approaches should be mixed to offer the best opportunity for answering important research questions" (Johnson and Onwuegbuzie, 2004; p. 15).

The framework within this mixed methods research consists of two parallel journeys, one that explored the views of nurses and the other that searched for the service users' voice (see Figure 3.2) in the decision making process. On entering the doctoral programme as a novice researcher, initially a pragmatic approach to engaging with research methodology was taken. Hence, rather than identifying with a particular methodological convention, the methods were chosen for their function to answer the research question. As Johnson and Onwuegbuzie (2004) note "choose the combination or mixture of methods and procedures that works best for answering your research question" (p. 17). Within this thesis, both qualitative and quantitative data are recognised as useful and important in exploring the research question, as such, enriching the learning experience for the novice researcher. The thesis will not contribute to the debate of qualitative versus quantitative research, but, will endeavour to connect the differences and draw from the strengths of these approaches and their contribution to understanding the nurses' and service users' perspectives as per the essence of a mixed methods approach. This thesis introduces the reader to different types of data within two qualitative and one quantitative study and both research methods are viewed as useful and important to learning.

This methodological framework recognises the importance and the necessity of conducting every aspect of the research process in the language of the participants (LLAIS, 2007). Although the Language Awareness Infrastructure Support [LLAIS] service launched in 2006 promotes the needs of Welsh speakers within health and social care research in Wales, there is now legislation and statute

that confirms the official status of the Welsh language, that is, The Welsh Language (Wales) Measure, 2011. If the Welsh Government's vision is to "strengthen the use of the Welsh language in everyday life", (Welsh Government, 2012b; p. 16), research in Wales must reflect the nature of that *everyday life.* The commitment to the Welsh language is evident across healthcare policy and guidance, for instance the Healthcare Standards for Wales (Welsh Assembly Government, 2010c) ensure that patients and families have access to language appropriate services. Within healthcare in Wales the term "active offer" is a concept adopted from Canadian legislation (see Canada (1985), Official Languages Act 1985, c. 31 (4th Supp.), Part 4 (28)). Active offer focuses the responsibility of services to offer language choice rather than expecting the patients and families to ask for a service. An example of active offer in the NHS in Wales is the addition of the 'Working Welsh' logo on the nurses' uniform (see box 3.1 for 'Working Welsh' logo). This initiative clearly identifies staff within the NHS who are able to offer a service in Welsh. Thus, in terms of conducting research in Wales the concept of active offer influenced this research process.

Box 3.1 'Working Welsh' logo

http://www.comisiynyddygymraeg.org/English/Assistance/Pages/ordercymrbadges.aspx

Taking account of the language needs of participants was considered in the "design, undertaking and reporting" of this research (Welsh Assembly Government, 2009; p. 9). The Welsh Language (Wales) Measure 2011 raised the awareness of the official status of the Welsh language and the establishment of the Welsh Language Commissioner to promote and facilitate the use of Welsh. Although, at a

strategic level, the commitment to the Welsh language and the requirement of language appropriate practice is clear (Welsh Government, 2012b); there is "a lack of language awareness in the research process" (LLAIS, 2007; p. 5). Moreover, within a qualitative research process, Smith et al. (2008) suggest that rigour can be influenced by language. For instance, Smith et al. (2008) discuss the problems associated with analysing data collected in Mandarin. Their paper offer guidance and solutions when data collected in Mandarin required translation to the common language of the whole research team. For instance, issues of capturing the meaning and the risk of misinterpretation of the participants voice is noted when using interpreters and or simultaneous translation during the interview process. De Groot (2002) proposes that translated words do not necessarily share the same conceptual interpretation. That is, translated words may be used for different purposes or in different contexts; and literal translations are often problematic as they fail to capture nuances of language and meaning. As a researcher in Wales, assuring that the "Welsh language is treated no less favourably than the English language" (Welsh Language Commissioner, 2012; p. 07) throughout the research process was central to ensuring that the meaning of all data was captured and not lost in translation. Thus, it was important to acknowledge the importance of establishing shared meaning within qualitative research and adhere to best practice guidance.

Data collected via quantitative methods also needed careful planning and consideration when working with diverse language populations (LLAIS, 2007). Translations of health measures require scrutiny to establish equivalence. Streiner and Norman (2003) propose that establishing equivalence requires the consideration of conceptual, item, semantic and operational equivalence. Although there are a growing number of such measures available bilingually in Wales (see New Welsh Translation and Adaptation of Patient Reported Outcome Measures @ http://llais.org//devolp_grp/newtranslations.php.en); Roberts (2007) suggests that few measure are rigorously tested for their reliability and validity (see Chapter 7: for discussion of conducting research in Wales, also Appendix K for an overview of the systematic ten-staged approach to translation and adaptation conducted in the second study). As more countries support a bilingual population (Bialystok et al.,

2009) the research community need to reflect this diversity in their research projects.

The purpose of engaging with doctoral level research was to learn and conduct research in a supervised safe manner that would lead to informing and contributing to the current body of knowledge within intellectual disability nursing. At the beginning there were no detailed maps, only ideas and expectations combined with curiosity and questioning initially of my own practice as an intellectual disability nurse in Wales. Hence, the first study of this thesis was the "digging tool" (Denzin, 1989 p 102) to explore nurses' perspectives.

Nursing and researching within a bilingual context?

Exploring decision making

Nursing perspective

Service user perspective

In-depth explorative study

Total population survey

Discourse analysis
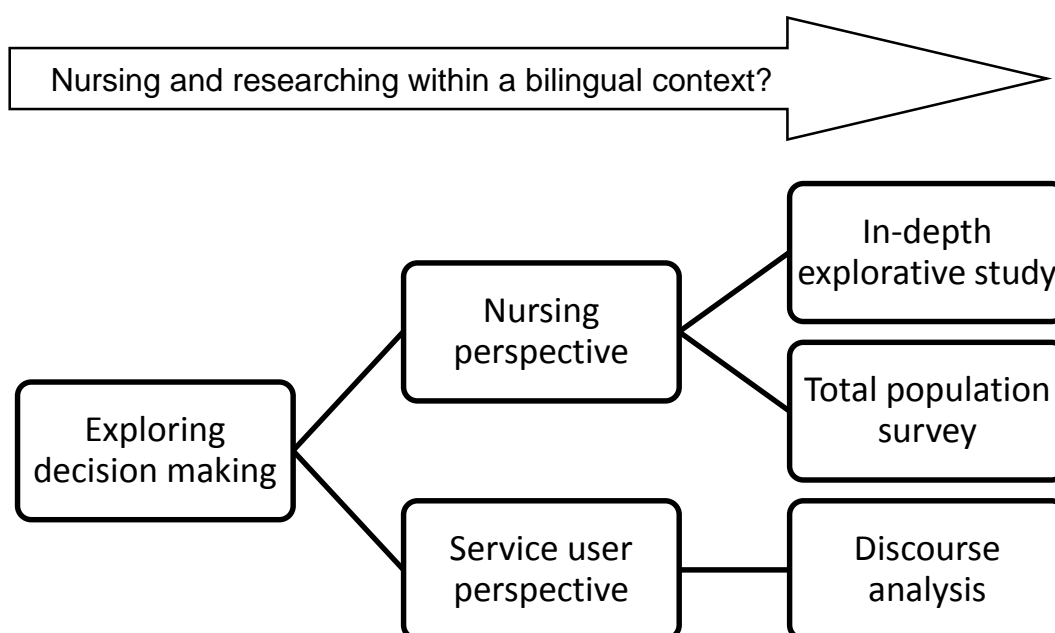
Figure 3.2 Methodological framework

Research aim

The aim of this research study was explore the complexities of decision making from the perspective of nurses working within intellectual disability nursing services and service users' perspectives. Thus, the first two studies explored the process of decision making whereby the final study considered the outcome of the nursing

relationship for the service user. Three studies were conducted within this PhD framework that addressed the following research aims:

Study 1: Explored how intellectual disability nurses made decisions in practice and how their decisions may be influenced by evidence.

Study 2: Explored the types and sources of evidence used by nurses working in intellectual disability nursing services to make decisions in practice; further determining the demographic and cognitive characteristics that influenced the use of evidence.

Study 3: Explored how individuals with intellectual disability perceived their relationship with intellectual disability nurses and how empowered individuals with intellectual disability were in making decisions when accessing mainstream healthcare.

Figure 3.3 provides a summary of the different aspects of the research in relation to the three studies.

Figure 3.3 Summary of thesis development.
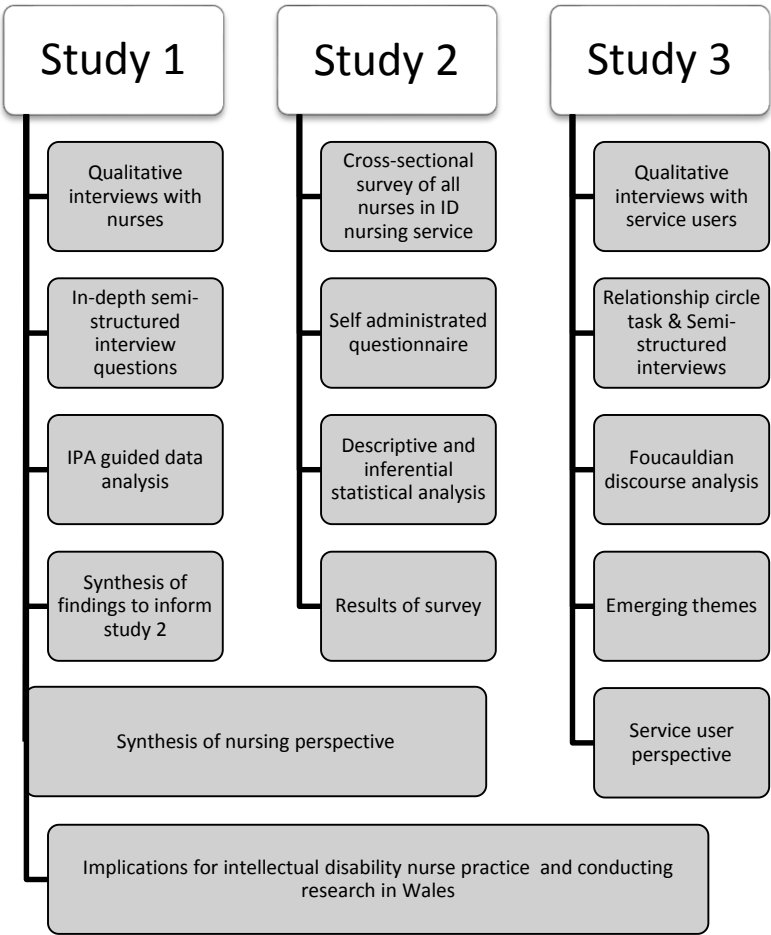
The nursing perspective – stage one

In the introductory chapter it has been noted that two recent scoping studies (Northway et al., 2006b; Griffiths et al., 2007) proposed that research within intellectual disability nursing is sparse, although increasing (Griffiths et al., 2007). Furthermore, it is recognised that nurses draw on a range of evidence from across disciplines to support and guide their practice (Kent et al., 2010). However, research about the use of evidence to inform decision making by nurses working within NHS intellectual disability nursing services is limited (Griffiths et al., 2007). Thus, the first study (see Chapter 4) required a methodology that enabled the in depth exploration of nurses' perspectives of their decision making processes.

This first study was a qualitative research study within a cross-sectional design, whereby a small sample of registered intellectual disability nurses were interviewed in depth at a single point in time. The study employed an approach called Interpretative Phenomenological Analysis [IPA], which is an idiographic mode of inquiry that examines individual participants' contribution in-depth. Maltby et al. (2010) state that

> "phenomenology emphasis an understanding of the world from the view of the individual who is viewing the world; it does not attempt to come to a consensus and an objective 'truth' about how all individuals see the world but it instead gives priority to each person's unique viewpoint of the world" (p. 50)

Thus, in view of the claim that phenomenology is able to provide an insight into the viewpoint of individuals, the approach appears to be a useful method to explore how nurses make decisions in practice.

The two broad schools of phenomenology are, transcendental and existential or hermeneutic (Spinelli, 1989). Transcendental Phenomenology has its origins within philosophy and the writings of Descartes (Koch, 1995). Edmund Husserl (1859-1938) is recognized as redefining phenomenology from a philosophical base to a methodology, examining the nature of things themselves, or "It [phenomenology] pursues, not the sense people make of things, but what they

are making sense of" (Crotty, 1996, p. 3). Dowling (2007) further provides insight into Husserl work suggesting that "the aim of phenomenology is the rigorous and unbiased study of things *as they appear*" (p. 132).

Phenomenology aims, through rigorous analysis and reanalysis, to arrive at the meaning of experience (Crotty, 1996), having filtered out cultural and personal presumptions and other lenses to arrive at the experience itself. Thus, the researcher is expected to bracket out preconceptions and see things from the person's point of view. This view is distinctively Husserl's phenomenology which suggests that in order to capture the essence of the phenomenon the researcher is requires to strip away any preconceptions (Converse, 2012). Conversely, Heidegger who studies under Husserl took phenomenology in a different direction (Smith, 2008). Heidegger discarded the notion of bracketing and adopted the view that investigation of meaning was understood as being part of our world and not separate (Converse, 2012). The hermeneutic circle was introduced by Heidegger and understood as a movement between the reader and the text (Earle, 2010). This movement backwards and forwards between the parts that are read and the understanding of the whole concept enables the researcher to understand and interpret the text and constantly revise their understating in relation to their preconceived ideas. The aim of hermeneutic interpretation is to see the things as they really are and to:

> "... understand everyday skills, practices, and experiences; to find commonalities in meanings, skills, practices and embodied experiences..."(Leonard 1994, p. 56).

IPA assumes that individuals interpret their experiences in a mode that is understandable to them. The approach also recognises that the researcher interprets what the participant articulates. Hence, the findings consider the researcher's central role in the research process and so do not require bracketing. Such reflexivity is not a one off event but an on-going process throughout the research journey (Guillemin & Gillam, 2004).

IPA offers a theoretical foundation and a detailed procedural guide (Brocki & Wearden, 2006) for researchers. The aim of IPA is to explore in detail how individuals make sense of their own experiences. Nevertheless, Baillie et al. (2000) acknowledge that an IPA approach is dependent on the participants' ability to convey their experiences and the ability of the researcher to reflect and analyse. There is an assumption that language reflects the experiences and the meanings participants attach to particular events and situations. Arguably, this can be achieved most effectively in the participant's own language, although the process of accessing participants' experiences and meaning requires the researcher to interpret the data (Smith, 1996). The literature thus supports the use of a qualitative method to explore the experiences of nurses in making decisions in practice and this can be achieved through semi-structured interviews with research participants. The majority of published research using IPA utilizes semi-structured interviews as a method.

Interviews are widely used within qualitative research and Bryman (2008) suggest that the flexibility of the interview makes it an attractive method of choice. However, it has been suggested that "the manner and the context" in which questions are asked is likely to influence how the data is collected (Gomm, 2008, p. 208). Thus, using interviews creates data that would not otherwise exist without the researcher's intervention. Silverman (2001) describes this as research provoked data in contrast to naturally occurring data that is generated from situations that exist independently of the researcher. However, Brocki and Wearden (2006) stress the importance of allowing the participant to describe their own experiences in their own words during the interview.

An interview schedule was written, however it was only used as a checklist to prompt and guide the researcher. The semi-structured interview has "flexibility in the phrasing and sequence of the questions" (Parahoo 2006, p. 473). This interview guide involved a series of open ended questions based on decision making and the use of evidence in learning disability nursing. The open ended nature of the questions provided an opportunity for the researcher and the interviewee to discuss some topics in more detail. Bowling and Ebrahim (2005)

suggest that the researcher may probe for more detail and the interviewee is allowed time to explain their ideas and perspectives. DiCicco-Bloom and Crabtree (2006) propose a facilitatory research interview style that would enable participants "to share rich descriptions of phenomena while leaving the interpretation or analysis to the investigator" (p. 314).

The interview schedule (see Appendix F) provides an overall framework and, in line with IPA, Smith and Osborn (2003) suggest that the role of the researcher should be noted during the interview. This was achieved through identifying periods of active listening and prompting for further information. Alexander and Clare (2004) described their interview process as "collaborative, emphasising that the participants were the primary experts" (p. 82). This approach supports the aims of IPA as participants are not seen as "passive perceivers of an objective reality", but human beings who attempt to make sense of their experiences (Brocki & Wearden, 2006, p. 88).

The participants were purposefully selected (Perry et al., 2007) from a homogenous sample for which the research question was significant (Smith & Osborn, 2003). Burnard (1995) defines purposive sampling as a

"….non-probability sampling method in which the respondents are chosen for the study according to the likelihood of their being able to talk with some insight on the topic in hand" (Burnard, 1995; p. 1168).

Potential participants were recruited from a local NHS hospital, where, nurses who worked with adults with intellectual disability to assess, plan, implement and evaluate their person centred plan/care/treatment on a regular basis were invited to take part in the study. This sample could be considered as a convenience sample as the nurses were easily accessible to the researcher.

Twelve nurses were recruited to this study. Although the number of participants is relatively small, Johnson et al. (2004) suggests that qualitative research may use a small well-defined sample to gather rich details of the participants' experiences. Dickson et al (2008) agrees stating that a small number of participants would provide meaningful accounts of the phenomenon. Smith et al

(1999) further suggest that the IPA process of analysis "works well with studies which employ a small sample" (p. 225) because the researcher is able to maintain an "overall mental picture of each of the individual" (p. 225) transcripts.

Within qualitative research, interviewing a homogenous group of twelve participants, the researcher would expect to reach data saturation (Turner et al 2002, Guest et al 2006). Guest et al (2006) found that data saturation was achieved after the thematic analysis of twelve transcripts. By the 12th analysis their experiment demonstrated that 92% of the codes used had been identified. IPA was chosen for this study because it focuses the researcher on the meaning and experience of the participants rather than producing an objective record of an event (Brocki & Wearden, 2006). Hence, IPA enabled the researcher to take into account the nurses' individual experiences of making decisions in practice.

Following the conventions of IPA, the researcher used an idiographic approach to the analysis, that is, focusing on specific cases and the unique traits or functions of individuals' experiences. This allows the researcher to identify the unique experiences of individuals, rather than broad generalizations. Each transcript was examined in detail, followed by a comparison across transcripts. The analysis followed the four stage process described by Smith and Osborn (2003) (see Chapter 4 for further details of analysis of interview data). The aim of interpretation was to see things as they really are and to understand the nurses' experiences and find connections and common ground related to their practice in intellectual disability nursing (Leonard 1994).

The aim of this first IPA study was to present a narrative account of the recurring themes from the interviews, using extracts from the transcriptions as evidence of those themes. An interpretative phenomenology framework allowed the researcher to accept that the interaction between the participants and researcher was acknowledged within the analytical process.

Qualitative study differs from the scientific paradigm in that the concepts of validity and reliability are not appropriate measures of a study's worth (Raudonis & Talbot, 1995). A qualitative study may be repeated, though would not seek to

reveal identical data, unlike a scientific or quantitative study. The aim of this study was to accurately represent the experiences described by the participants. Rigour was established by maintaining a record of the decision trail (Koch, 1994). All decisions before and during the research process were kept in a journal. The researcher and academic supervisors reviewed the decision trail.

Details of the study in its entirety are found in Chapter 4. Using the IPA method that focuses on an idiographic approach, the richness of data rather than the quality is valued. Furthermore, differences as well as similarities within the data were identified. Although IPA offers a detailed framework to analyse the data which is valuable for the novice researcher; acknowledging the researcher's influence in the process was demanding. In this first study that considered data from a convenience sample, knowledge of the participants and the service came with benefits and risks. Having a prior relationship with the service enabled the recruitment of participants with the minimum of effort. Availability of time and space to conduct interviews was facilitated with ease. The participant researcher relationship was informal with participants demonstrating their willingness to share their stories. Difficulty arose when one participant challenged my values of person centeredness, with comments to suggest that the participant did not ask the service user for their opinion when making decisions. As a novice researcher, listening to the audio recording of this one transcript became difficult. However, with discussion and supervision, the positive contribution of this transcript to the research was acknowledged. Thus, IPA as a methodology was a successful "digging tool" that captured rich data of how twelve nurses working within NHS intellectual disability nursing services made decision in practice. The next stage of the research required a large scale study to explore the concepts that evolved from this first IPA study.

The nursing perspective – stage two

This second stage of exploring the nurses' perspective on decision making required a wider perspective on decision making. The purpose of the second stage was to gain a profile of how registered nurses who work within NHS intellectual

disability nursing services make decisions in practice, identifying any differences or similarities in sources of information used, demographic and training characteristics. The total population of qualified nurses within NHS intellectual disability nursing services across Wales was 486 nurses working across five health boards. This offered a manageable target population within the resources and time available. A questionnaire is a research tool that has been designed to reveal specific information and is useful for describing an existing state of affairs (Bryman, 2008). This was a quantitative research study within a cross-sectional survey investigating a pre-defined population at a particular point in time. The survey consisted of one pretested questionnaire and one questionnaire developed from the first IPA study and a demographic questionnaire. The total population (n=486) of registered nurses working within NHS intellectual disability services across Wales were invited to complete a postal bilingual self-completion questionnaire. The self-completion questionnaire incorporated *Nurses use of information to improve outcomes* (developed from the first study); and *Nursing Decision-Making Instrument* (Lauri & Salanterä, 2002), followed by a measure requesting demographic information specifically designed for this study.

All measures had undergone scrutiny by academic supervisors, two learning disability nurse lecturers and eight third year learning disability nursing students for wording, comprehension, interpretation and cultural relevance of both English and Welsh versions. The process of translation was based on *The Translation and Cultural Adaptation - Principles of Good Practice* (Wild et al., 2005) (see Appendix K). Lauri and Salanterä, authors of the original *Nursing Decision-Making Instrument* (Lauri & Salantera, 2002) have approved the changes to measure 2: *Nurses approaches to decision making* (see Chapter 5 for details regarding measures). To analyse the data, SPSS version 16.0 (SPSS Inc., Chicago.IL USA) was used to calculate descriptive and inferential statistics.

The service user perspective

This project builds on the findings of the first two studies that involved exploring nurses' perspectives. Service users' perspectives are under reported in

the literature (Thorsteinsson, 2002; McDonald et al., 2009). This final study intends to add to the small but growing area of reporting on the service users' perspective, rather than a professional or non-disabled perspective.

The initial subjects of this thesis have been nurses, thus portraying a professional perspective of intellectual disability nurse practice. Asking individuals, who receive a service from this group of professionals about their experience of the service may confirm or refute some of the findings from the first two studies. However, such insight will offer a different perspective and contribute to the small, but nevertheless growing area of research reporting the service user point of view. This is a doctoral project and, as such, could not be fully inclusive, largely because of time constraints, academic regulations and requirements; however the study attempted to capture the perspective of the service user.

Within intellectual disability nursing research, service user needs, wishes and rights are often represented from a professional perspective. Björnsdóttir and Svensdóttir (2008) suggest that nondisabled scholars write most publications on intellectual disabilities, although there is an increase in the publication of inclusive research projects. Inclusive research is a term coined by Walmsley (2004) to represent the various strands of research where people with intellectual disability are seen as active participants. The researcher is the enquirer and the individuals with intellectual disability are the experts (Knox and Bigby, 2007). The impetus for inclusive research owes much to the social model theorists such as Oliver (1992) and Zarb (1992); however, Walmsley (2004) suggests that inclusive research is driven by values rather than evidence base. Atkinson (2004) proposes that inclusive research has the potential to be empowering for people with intellectual disability, whereby research enables individuals to tell their stories and reflect upon them. Moreover, Freire (1970) proposes that inclusive research does not change people's lives in a material sense but develops an awareness and view of their lives differently and can be empowering. In addition, this research addressed the language needs of participants through offering access in Welsh as well as English that further empowered individuals.

The research studies that explore the service users' perspective range from considering service provision (Smyly & Elsworth, 1997; Attree, 2001; Parkes et al.; 2007) to specific intervention approaches (McCarthy 2002; MacDonald et al., 2003; Hays et al., 2007; Taggart et al., 2007; Crossley & Withers, 2009; Healy et al., 2009). Ramcharan and Grant (2001) reviewed the literature searching for the perspectives of individuals with a intellectual disability. The literature review highlighted 3 broad areas of service user perspective within published research, that is: 1) 'testaments of life'; 2) 'user movement media'; and 3) 'research based studies' (Ramcharan & Grant, 2001). Ramcharan and Grant (2001) conclude by suggesting that "large gaps *remain* between policy, action (practice) and knowledge" (p. 357) in terms of service user perspective. Furthermore, small scale studies that explore the servicer user experience provide valuable insight however, parallel with this should be the commissioning of "formal comparative evaluations" to examine policy and practice outcomes in order to establish best practice for knowledge translation.

The literature review did not identify any research that specifically reports the perspectives of services users in relation to their relationship with intellectual disability nurses. Thus, this study intended to gain a preliminary understanding of community intellectual disability nursing practice from the perspective of the service user. Lloyd et al (2006) suggest that providing opportunities for a person to express and attempt to understand his or her thoughts, beliefs, feelings or desires can be an effective means of informing service provision. However, Brewster (2004) suggests that accessing the views of individuals who do not communicate verbally presents challenges for the researcher; and it is proposed that this is an on-going process. That is, the researcher should not regard an interview as a single unrepeated event. Such a process would require long term investment for the researcher and the participants in order to assess views, using such techniques as Talking Mats® (Lewis, 2002). Talking Mats® are a "low-technology communication framework, developed at the University of Stirling, to help people with communication difficulties to express their views" (Murphy et al., 2010; p. 10, Murphy & Oliver, 2013; p. 173). Due to the constraints of time within a PhD framework to invest in a long term project to gain a service user perspective, this

was unrealistic, thus individuals who were able to contribute verbally to the research were sought. Consequently, this final study, through the investigation of text, captures a unique glimpse of the relationship seven individuals with intellectual disability had with their local health service.

Semi structured interviews were planned to capture the data. The interviews invited servicer users to tell their life story with regard to the experience of receiving an intellectual disability nursing service. The interview involved a series of open ended questions. The open ended nature of the questions provided an opportunity for the researcher and the service users' to discuss some topics in more detail. The semi-structured interview guidelines (see Chapter 6, Table 6.4 Interview Schedule) for the service user were informed by:

- an understanding of existing literature,
- previous research and practice experience of the researcher, and
- discussion between researcher, academic supervisors and intellectual disability nurses.

Interview guidelines were used to prompt and guide the researcher. The in-depth interview is described by Hesse-Biber and Leavy (2006) as "a meaning-making endeavour embarked on as a partnership between the interviewer and his or her respondent" (p. 119) and it is considered the most appropriate technique to gather participant expertise on the issue of concern. Yet, the nature of the brief researcher participant relationship at times hindered the process of gathering in-depth data. For instance, it was difficult for the researcher to appreciate the unique communication style of each participant in such a short time. However it is important to listen to the service user's voice; as Lloyd et al (2006) stress, the importance of conducting qualitative interviews with individuals with cognitive impairment whose ability to express themselves verbally is compromised since these are less frequently included in research.

The service user could have requested that a carer(s) and or advocate attended the interview to support them. The supportive role of the carer/advocate would have been clarified with all parties present at the beginning of the interview.

The interview for the service user then consisted of four areas of questioning. However, the researcher was required to tailor the questioning style to the needs of the service user. As Hawkins et al (2005) state, the language of questions should be considered when working with individuals with communication difficulties. For instance, he proposes no double negative or layered complex questions; start with warm up questions and wind down questions at the end of the interview. Philpin et al. (2005) suggest that it might be necessary to modify and/or rephrase questions for some individuals. Furthermore, as some participants are bilingual (Welsh/English) there may be elements of code-switching that is used as a communication strategy to "convey linguistic and social information" (Grosjean, 2013; p. 19). Thus, it is important that the researcher recognises and adapts to the unique needs of the participants. Although short specific questions may be leading, Philpin et al. (2005) believe that they are justified on the grounds that this allows the individual to contribute to the discussion. Having drawn on literature and experience of working with individuals with intellectual disability and following the first interview and commencing the data analysis, difficulties in interpreting the data emerged.

Initially, using an IPA framework as a method to analyse the data was problematic. The in-depth nature of the process of exploring the data for themes of thoughts, feelings and emotion was difficult. There was no obvious reason for this difficulty. However, the participants could have felt uneasy or found it difficult to express their feelings to a *stranger* (the researcher). Possibly, the individuals had never been participants of research and had never been in a situation where they were asked direct questions about their feelings. To conduct interviews guided by IPA and be an interviewee require a set of skills that neither the researcher nor participants were particular skilled at. The data from the service user offered insight into the understanding of the nature and function of textual data. In an attempt to capture this insight, the method guiding the analysis was developed in response to the emerging data.

Michael Foucault's (1973; 1980; 1994a) insight on the issue of power has much to offer on our understanding of the relationship professionals have with

service users. Foucault's approach suggests that individuals become the subject within disciplines, for instance, nursing (Armstrong, 1994). Foucault (1980) proposed that power is exercised within disciplines and is enforced through "surveillance and subsequent objectification of the body" (Armstrong, 1994;p. 23). Drawing on the influence of Foucauldian discourse analysis [FDA] it was possible to address the research question of how service users perceived the role of the intellectual disability nurse. (The application of FDA to this final study is discussed in Chapter 6.)

Throughout data collection and analysis of this third study the *effect* of the researcher's knowledge and experience of intellectual disability nursing on the process is recognised. This further acknowledged that research supervision was a necessity during this period to clarify emerging thoughts. Research supervision is defined by Mackinnon (2004) as a relationship based on trust that can support the academic supervisor in developing student learning. However, the benefits of supervision during this project were similar to those documented about engaging in clinical supervision, that is, an increased awareness of self (Johns, 2003); enhanced professional accountability and learning (Wood, 2004), and improved problem solving (Žorga, 2002) to note a few. Within nursing, clinical supervision is an established support system for nurses in the UK and internationally (Koivu et al., 2011). Thus, engaging in the process of supervision was not a new experience for the researcher, although at times it was challenging. One of those challenges was developing and ending the research relationship with the participants with intellectual disability.

Intellectual disability nursing in the UK has a clear value base that places the individual with intellectual disability at the centre of care (Department of Health et al., 2012). Thus, this value base of person centeredness is also significant within research activity that involves individuals with intellectual disability. Sanderson (2003b) propose that person centred practices demands a shift in the source of power from professionals having *power over* people with intellectual disability to having *power with* individuals. This final study, although not truly conducted in an inclusive way strived to listen to and learn from individuals with intellectual disability

within a person centred approach. Thus, although the individuals with intellectual disability were participants of research, it is acknowledge that my presence during the interview may have influenced the data, and my experience and knowledge influenced the data analysis. However, this *effect* could not be anticipated and the method could be described as co-speaking, speaking with (Fielding, 2004). The terms of engagement (Walmsley, 2004), that is, the relationship between the researcher and the participants required negotiation from the outset. A protocol identifying the nature of the research relationship, the number of meetings required and the boundaries of the association was made explicit to the participant. Pockney (2006) suggests that the social networks of people with intellectual disability predominately include professionals rather than friends. Thus, researchers calling at participants' homes might be misinterpreted as being a friend (Stalker, 1998). As this study involved seven participants it was possible to sensitively plan each relationship to the individual with clear boundaries given as to how the relationship would involve three stages that engaged in a unique bespoke exit strategy.

Each of the seven interviews conducted required individual planning to understand and respond to the communication needs of the participant. During the *Information about the Study* meeting with potential participants field notes about the communication skills and adjustments required of the researcher were noted. Such notes enabled the researcher to prepare and plan any augmentative communication strategies that might be useful during the interview process. Completing a *relationship circle* (Sanderson & Lewis, 2012) as a warm-up activity to elicit demographic information, explore who was important to the participant and identify where they positioned healthcare professionals within their circle was informative. Each of the seven participants was able to take part in this activity. The practical task enabled the researcher to capture data that might not have been possible through the use of direct questioning or the use of a demographic questionnaire. As Boxall and Ralph (2010) suggest the use of visual methods has the potential to make participating in research accessible for people with intellectual disability. Helen Sanderson describes *relationship circles* as a person centred thinking tool that can assist the process of getting to know an individual (Kennedy

et al.,2008). The experience and knowledge gained form conducting this study advocates other researchers to use visual methodologies (Boxall & Ralph, 2010) such as the *relationship cir*cle to enhance communication between the researcher and the participant.

Although, the influential work of Michael Foucault on power did shape and guide the data analysis of this final study, it must be acknowledged that within the overarching methodological framework the influence of person centred thinking was paramount. The definition of person centred planning by O'Brien and O'Brien (2000) offers the research community insight into how researchers should *listen carefully in ways* that *strengthen the voice* of the participants when conducting research that include service users.

> "Person centred planning begins when people decide to listen carefully and
> in ways that can strengthen the voice of people who have been or are at risk
> of being silenced" (O'Brien & O'Brien, 2000; p .8).

Service user perspectives in the field of intellectual disability is a growing area of research, however, there is concern that only the views of individuals who can easily express their opinions are sought (Boxall & Ralph, 2010). It is advocated that researchers must engage in creative approaches to enhance opportunities for individuals with intellectual disability to participate in all aspects of the research process. This concurs with the work of Booth et al. (1990; p. 13) who reviewed a small number of service user studies in the 1990's and concluded that "the views of people with learning difficulties constitute as equally valid a perspective as that of the professionals, practitioners, relatives or researchers" (p. 113). Booth and colleagues (1990) statement remains relevant to the research community today. Through published articles we can map a growing interest in the involvement of people with intellectual disability in the research process. Such areas as abuse (Looking into Abuse Research Team, 2013), advocacy (Chapman et al, 2011) and quality of life (Haigh et al, 2013) have been explored. However, the service user's perspective of their relationship with healthcare practitioners was not addressed in the literature reviewed. This third study of service users' perspectives drew on principles of qualitative methodology and FDA, inclusive

research and the principles and values of person centeredness in capturing the often silenced voice of individuals with intellectual disability.

Summary

The thesis design is illustrated in Figure 3.3 that identifies the stages and sequence of qualitative and quantitative methods used. This chapter provides an overview of the methods that were used to guide the thesis. To examine the complexities of decision making, two parallel journeys were undertaken. The first journey captured the nurses' perspective using a qualitative method to explore how nurses used evidence to support their decisions. Building on those findings, the method of a survey facilitated capturing the sources of information used by nurses to make decisions; further examining the demographic and cognitive characteristics that influenced their use of evidence. The second journey represented the service user's voice whereby semi-structured interviews were used to gather data. This journey proved to be a methodological challenge; although it could be described as a traditional qualitative study, such methodology did produce some barriers whereby the relationship between the researcher and the researched required careful consideration.

The mixed methods were chosen as appropriate to answer the research questions and as an educational opportunity to learn about different methods. The following three chapters of this thesis present the methods, findings and discussion of the nurse perspective within a qualitative study (Chapter 5), the national survey (Chapter 6), followed by the qualitative study representing the service user perspective can be found in Chapter 7.

Chapter 4 – Study 1, Exploring decision making in intellectual disability practice: a qualitative study[2]

Author contributions

RWW was responsible for the study conception, design and data collection. RWW performed the data analysis supervised by FI and GWR who also conducted the audit trail. RWW was responsible for drafting the manuscripts. RH, FI and GWR supervised the study and made critical revisions to the paper for important intellectual content.

[2]A version of this chapter has been published: Williams, R.W., Roberts, G.W., Irvine, F.E., & Hastings, R.P., 2010. Exploring decision making in intellectual disability nursing practice: A qualitative study. *Journal of Intellectual Disabilities* 14(3), 197-220.

Reflexive preface

Researcher's role

This thesis represents an endeavour to explore the concept of decision making in the context of working with people with intellectual disabilities. This first study is viewed as the *digging tool* and is an effort to explore and reveal some of the multifaceted and difficult issues that nurses face when involved in decision making. This viewpoint is where I started on the journey. From past experience as an intellectual disability nurse, my own reflections on practice and from discussions with others and the doctoral supervision team, questions emerged about what evidence did intellectual disability nurses use to guide their practice and to a greater extent, what evidence did I use when making decisions. Furthermore, we needed to acknowledge the potential of the contribution of intellectual disability nursing research although it is a small but growing discipline that informs nursing practice (Fraser, 2000; Northway et al., 2006b; Griffiths et al., 2007).

From a personal background of growing up in a small close-knit supportive community, I learnt from an early age to value people for who they are. It was only when I commenced my nurse training in the 1980's that I realised that I had grown up alongside many individuals who were labelled as *mentally handicapped* (the label was used to describe people with intellectual disability at that time, indeed my nurse training led to the qualification of Registered Nurse for the Mentally Handicapped (RNMH)). Thus, at that time, nurse training developed my role and perspective to value individuals and listen to their narratives, as they are the experts of their lives. From an evolving professional perspective that valued the contribution of the individual to their nursing care, questions arose. Thus, as a novice researcher, recognising the bias towards valuing the individuals was important in order to identify the impact of such a perspective on the research process.

As a nurse and a novice researcher, this initial study would act as a springboard to further our understanding of the issues and instigate further

discussion and debate. From the beginning of this study, I needed to be aware of my background knowledge in intellectual disability nursing, further reflecting on the values, knowledge and culture that impact on this field of practice. Thus, I recognised that I did not enter this research project *value free* and that my perspective would influence the research process. Having *insider* status both enabled and hindered the process of this research study. Latimer (2002) proposes that an insider status may threaten the objectivity and validity of research conducted by nurses on nursing. Thus, Allen (2004) proposes that nurse researchers must embrace reflexivity that identifies, chronicles and makes their role transparent within the research process. Hence, through engaging in reflexivity, I am able to acknowledge my beliefs and personal bias towards valuing the individual, my knowledge of intellectual disability nursing and the requirements of practice to be evidenced based. Jootun et al. (2009) supports this stance and suggests that I as a researcher should approach the research process in an honest and open manner.

Abstract

Nurses are under increasing pressure to make decisions that result in the best outcome for patients. Due to the dearth of relevant research, intellectual disability nurses may have difficulty identifying sources of evidence on which they can base their clinical decisions. The aim of the present research was to explore how intellectual disability nurses make decisions in practice and how their decisions may be influenced by evidence. The method for this study was guided by interpretative phenomenology and the analysis adopted an idiographic approach. Twelve National Health Service intellectual disability nurses in Wales, UK participated in semi-structured interviews. Four key themes were identified: 1) getting to know the person, 2) working as a team, 3) evidence to support decision making, and 4) understanding of evidence based practice. In the context of the myriad of other professionals involved in care giving, the nurses conveyed a commitment towards ensuring that the person with intellectual disability is at the centre of the decision making process. Although using empirical evidence to support practice was acknowledged, these nurses considered person centred decision making to be paramount.

Background

UK policy and guidance require and encourage nurses to base their decisions on the best available evidence (Department of Health, 2006b; 2008b; NMC, 2008). This is also an element of guidance to nurses and healthcare professionals in other developed countries across the world (Schwartz et al., 2000; American Nurses Association, 2003; Australian Nursing and Midwifery Council, 2008; Institute of Medicine, 2009). Consequently, there is a growing commitment within the nursing literature for the use of evidence to guide nursing practice (Harvey et al., 2004; Mantzoukas, 2007; Aisenberg, 2008; Soukup & McCleish, 2008; Brown C.E. et al., 2009). The discourse has led to an accumulation of commentaries and research papers addressing concepts such as, evidence based practice (Gerrish et al., 2008), knowledge transfer (Thompson, G.N. et al., 2006; Aita et al., 2007; Rycroft-Malone, 2007), and research utilisation (Veeramah, 2004; Thompson D.R. et al., 2006; Andersson et al., 2007; Frasure, 2008). Although the concepts are unique, they are a part of a general movement reported within the literature that relates to nurses delivering the best care based on the best available information. Evidence based practice and decision making in nursing are generic concepts that are widely discussed in the general nursing literature. However, the application of these concepts in the field of intellectual disability nursing is sparse. This paper reports on a qualitative study that explored the practice of intellectual disability nurses in Wales, UK regarding decision making and evidence based practice.

Within the nursing literature and related policy there is often an assumption that best care is based on the best evidence, and this is supported by empirical findings (Heater et al., 1988; Franks, 2004; Swan & Boruch, 2004; Brown C.E. et al., 2009). However, there is a lack of clarity about what constitutes evidence (Rycroft-Malone, Seers, et al., 2004; Rolfe & Gardner, 2006; Scott & McSherry, 2008) and Girot (2000) suggests that nurses gather evidence from a range of sources to inform decisions in practice.

In an attempt to define the best evidence, a number of hierarchies exist to grade research based findings, such as the Cochrane hierarchy and Sackett's

(1996) levels of evidence. These hierarchies present and rank evidence generated from different research themes/areas/methods; that can then be used to assist nurses in determining the weight that should be placed on various forms of evidence when making decisions in practice (Evans, 2003). Whilst focussing heavily on empirical research, such hierarchies usually rank evidence gained from service users or the experience of practitioners as being of poor quality (Forbes & Griffiths, 2002). However, this stance has been criticised within the field of intellectual disability (Gates & Atherton, 2001) and methods such as life history accounts (Atkinson, 2004) and participatory research (Northway, 1998; Ham et al., 2004) are gaining ground as a valid approach towards building evidence for practice. Clearly, when applying a hierarchical approach, such research may be ranked as weak evidence to support practice. Nevertheless, a consensus is slowly emerging to suggest that no one method of research can produce all the evidence to support nursing practice. Gates and Wray (2000) emphasise the need to combine a range of research styles to produce sufficient evidence to support interventions. Hence, a mixed methods approach is espoused (Thompson et al., 2005) that offers 'a more inclusive view of evidence' (Rycroft-Malone 2008, p. 405).

There is no doubt that intellectual disability nurses need to use the best available evidence to inform their decision making (Northway et al., 2006a; 2006b; Griffiths et al., 2007). Nevertheless, finding the best evidence to support their decision making in practice may be difficult if based solely on the results of high quality research. Two recent reviews in intellectual disability nursing research, Northway et al. (2006b) and Griffiths et al. (2007) concluded that a lack of research-based evidence exists for intellectual disability nurses to guide their decisions. Alternatively, McConkey (1989) suggests that the heterogeneity of the intellectual disability population makes it difficult to research and some research papers do not clearly define disability. Emerson (2005) further states that to restrict the evidence base to specific research that addresses only the needs of individuals with intellectual disability is making an assumption that only evidence that is gathered specifically about individuals with intellectual disability is relevant to that client group. Gates and Atherton (2001) also propose that intellectual disability professionals use a range of evidence to support practice. Nevertheless, Griffiths

et al.'s (2007) review found only one research paper that specifically considered research utilisation within intellectual disability nursing (Parahoo et al., 2000). Moreover, our literature search produced no other studies in relation to the use of research in intellectual disability nursing practice. Thus, although intellectual disability nursing practice may be informed by generic nursing and healthcare research there is little known about how intellectual disability nurses use evidence to support their practice. A similar picture is emerging within primary care where McKenna et al. (2004) suggest that the lack of research funding 'has resulted in a dearth of high quality research results to underpin practice' (p. 369). Due to the lack of specific research addressing evidence based practice and decision making within intellectual disability nursing practice a qualitative approach was undertaken. This study explores how intellectual disability nurses make decisions in practice and how their decisions may be influenced by evidence.

Method

Methodological approach

The qualitative method used in the present research was interpretative phenomenological analysis [IPA] (Smith & Osborn, 2008). IPA focuses on the experience of participants, and their own understandings and interpretations of practice rather than creating an objective record of an event (Brocki & Wearden, 2006). This method also allows the researcher to explore in detail the participants' interpretation of an event (Reid et al., 2009). This enables the researcher to be an 'insider' sharing a 'common language and culture' (Irvine et al., 2008) with the participants and, in the present case, sharing practice experience. That is, the researcher had previous experience and understanding of the philosophy and policy underpinning the intellectual disability nursing practice. The researcher making sense of the participant making sense of their experience is the essence of interpretation (Smith, 1996). For the novice phenomenologist IPA offered a theoretical foundation and a detailed procedural guide (Brocki & Wearden, 2006) to conduct this research.

In the context of a bilingual Wales, all efforts were made to ensure that language sensitivity was adopted throughout the research process as a means of respecting the statutory rights of participants in Wales (Welsh Office of Research and Development for Health and Social Care [WORD], 2009) and maintaining methodological rigour (LLAIS, 2007). All research information was produced in bilingual format (Welsh/English) and interviews were conducted and transcribed in the preferred language of the participants (two in Welsh and ten in English). The analysis was completed in the language of the transcript and it was only for the purpose of reporting that an independent translator was commissioned to translate the Welsh transcriptions into English.

A University and Local Research Ethics Committees [LREC] and the Local NHS Trust Research Governance Panel approved the study. (See Appendix A)

Participants and procedure

Due to the in-depth nature of IPA, small samples are recommended (Reid et al., 2007). Smith and Osborn (2008) do not specify the number of participants required for an IPA study as the research does not seek to generalise the findings or reach data saturation but to explore the individual's unique experience. The sample size of published IPA studies varies, for example, from single person case studies (Eatough & Smith, 2006), to samples of 10 participants (Darker et al., 2007) to samples of 24 participants respondents (Timotijevic & Breakwell, 2000). The aim of this study was to find a relatively homogenous group that could express their experience about the research subject (Smith & Osborn, 2008). Consequently, individuals who were registered intellectual disability nurses worked with adults with intellectual disability and made decisions relating to the assessment, planning, implementation and evaluation of care on a regular basis were recruited to the study. Participants were recruited from a National Health Service [NHS] healthcare service in Wales, UK that provides in-patient nursing care for adults with intellectual disability. The registered intellectual disability nurses are responsible for managing the nursing service within small residential units of approximately six individuals.

Invitation packs were distributed to the intellectual disability nurses (n=20) who attended a presentation of the study's aims and objectives at their place of work. The packs contained a letter of invitation (see Appendix B), participant information sheet (see Appendix C) and a consent form (see Appendix D). In line with research governance procedures in Wales (WORD, 2009), all information was produced in bilingual format (Welsh/English). Thirteen nurses returned their consent forms by post and the first twelve nurses to respond were interviewed, in line with the local NHS Trust research governance approval. Thus although the number of participants conforms to the IPA framework, the selection of these participants was constrained by research governance restrictions.

The twelve participants were all women and their ages ranged from 20-55 years, with 11 of the participants aged from 36-55. All were registered with the UK Nursing and Midwifery Council as intellectual disability nurses; one nurse had gained a diploma in nursing and three had degree level qualifications. Five participants had been qualified for 1-6 years and seven had 19–30 years intellectual disability nursing experience (see Table 4.1). (see Appendix E supplementary data form).

Table 4.1 Demographics, educational qualification, experience

Sample characteristics	Number of participants
Sex	
Male	0
Female	12
Age (years)	
20-25	1
26-30	0
31-35	1
36-40	2
41-45	3
46-50	4
51-55	1
Professional qualification	
Enrolled Nurse ID*	1
Registered Nurse ID*	7
Registered Nurse ID* + Diploma	1
Registered Nurse ID* + Degree	3
Years of nursing experience	
0-5	4
6-10	1
11-15	0
16-20	1
21-25	4
26-30	2

* ID – intellectual disability

Interview structure

The data were collected by semi-structured interviews over a three week period during Autumn 2008. All interviews were conducted by the first author in a private area within the participants' work setting. The interviews, lasted between 22 and 38 minutes (mean-29 minutes), were audio recorded and transcribed verbatim. To ensure anonymity, identifying information was not included in the typed transcripts.

During the interview participants were asked to share their experience of decision making in practice and the use of evidence in intellectual disability nursing. The interview guide was formatted around the key concepts of the research aim and the findings of the literature review. The interview guide comprised four parts, which included a series of broad open-ended questions (see Appendix F). In the

first part, the participant was asked to describe an intervention or episode of care for which they were responsible. Part two prompted the participant to give a detailed description of their experience of making decisions during the example presented in part one. For instance, 'I am interested in knowing about the decisions you took during the intervention or episode of care you have described. Can you tell me how you made those decisions?' Part three and four asked direct questions in relation to evidence based practice, their understanding of the term and the skills required to engage in evidence based practice. For example, 'How would you define evidence-based practice? What skills are required to engage in evidence based practice?' The open ended nature of the questions provided an opportunity for the researcher and participant to discuss topics in detail. The participants were allowed time to explain their ideas and perspectives, while the researcher probed for further detail (Bowling & Ebrahim, 2005).

Analysis of interview data

The analysis followed the step by step process described by Smith and Osborn (2008) (see Appendix G). The researcher used an idiographic approach to the analysis, that is, each transcript was examined in detail allowing the researcher to focus on the unique traits or function of the individual's experience rather than on broad generalizations (Perry et al., 2007). The aim of interpretation was to see things as they really are gaining an understanding of the nurses' experiences of making decisions in practice (de Visser & Smith, 2006). Accepting that the interpretation is influenced by the researcher's (RWW) own experience (Bradbury-Jones et al., 2009), that is, of being an intellectual disability nurse.

The analysis began with reading and re-reading the transcript. Once familiar with the data, an interpretive reading of the interview transcription followed with the initial response recorded in the left margin. Reading the transcript a number of times identified emerging themes which were noted in the right margin. At this point, the whole transcript was considered as potential data. The emergent themes were listed and connections between themes clustered together to produce a table of themes. The clustered themes were then verified in the transcript to validate the

groupings (Smith & Osborn, 2008) and evidence supporting the themes from the interview was identified. A master list of themes was produced identifying sub-themes and indicating where in the transcript the theme originated. The recording was accomplished by entering a quote with the corresponding line number from the transcript in the margin of the master list. At this stage, the researcher re-grouped some themes because they were not supported by rich data within the transcript. Within IPA it is the richness rather than prevalence of data that contributes to the understanding of the theme (Smith & Osborn, 2008).

Using the same process, each transcript was then analysed independently, repeating the stage by stage process described by Smith and Osborn (2008) and resulting in twelve master lists. The master lists of each interview were then analysed together. This involved a search for patterns or conflicting data across the twelve master lists (Whitehead, 2004). On this basis, a final list of themes was produced that represented the entire data set (see Table 4.2) (see Appendix H for example of analysis).

Table 4.2 Master table of themes

Theme	Sub Themes
1. Getting to know the person:	
Nurse prepared to listen and learn	Important to the person
	Important for the person
	In alliance with family
Empowerment	
Parity	
2. Working together:	
Unilateral decision	
Informal nurse communication	
Formal nurse communication	
Inter-professional communication	
3. Evidence to support decision making:	
Client –related	History
	Nursing Process
Personal	Knowledge & experience gained from practice
	Intuition
Professional colleagues	Student / newly qualified nurses
	Individuals
	Groups
Resources	Library
	Internet
	Journals /Reading
	Courses / education
	Other
Access at Workplace / Home	
4. Understanding of evidence based practice:	
Commitment/purpose	
Source of evidence	Client
	Practice
	Research
	Others
Skills required	Practice evaluation
	Communication
	IT access
	Literature searching & critiquing

Establishing validity

In this study we aimed to interpret the experiences described by the participants. de Witt and Ploeg, (2006) in their review of interpretative phenomenological research in nursing found a 'broad range of criteria for judging the rigour of interpretative phenomenological research' (p. 215). However Webb (2003) and Webb and Kevern (2001) suggest that 'member checking' is not compatible with phenomenological methods. Stating that revisiting the data with the participants would only result in producing another version and it would not invalidate the researchers account (Bradbury-Jones et al., 2010).

To establish validity two supervisors (FI, GWR) independently completed a forward and backwards audit trail of a sample of the transcripts. The forward audit trail comprised identifying sections from four transcripts and, following the same process of data analysis as the first author, the data were trailed to the final list of themes. The backwards audit trail commenced with the final list of themes and trailed aspects of each theme back to the original transcripts. The three researchers then came together to discuss the analysis and agree on any amendments to the list of master themes.

Results

Four key themes emerged from the data analysis: 1) getting to know the person; 2) working together; 3) evidence to support decision making; and 4) understanding of evidence based practice. Table 4.2 presents the master table of themes identifying the four main themes and sub themes. The results are presented as a narrative account, with supporting extracts from the data that reflect the common and varied experiences of the 12 intellectual disability nurses.

Theme 1: Getting to know the person

The participants were consistent in their view that the person with intellectual disability is central to their decision making in practice. In the first and second part of the interview participants offered detailed accounts of how they listened to what was important to the client and the family. The nurses described the importance of getting to know the person before making decisions in practice. They stated how *'lucky'* they were to be working closely with their clients, often over a long period of time, enabling them to *'get to know the person'*. This protracted period of care enabled nurses' perspectives about their clients to change over time, as this account illustrates:

> 'Sometimes just getting to know the individual I think... and not listening to what everybody has to say about someone, it changed my perspective and the way I sort of looked towards (the person)'.

The long-term nature of the nursing relationship with the client on the units was viewed as a positive aspect of decision making. Although some of the participants had known their clients for many years, the importance of getting to know the individual was emphasised.

One participant valued the quieter times on the unit and noted the importance of using that time to get to know the clients. That is:

> '...time sitting down on a Friday evening when they're absolutely pissed off, and finding out why, well that's, I think, that's just your experience of getting to know people, and … trying your best to get, you know, their hopes and dreams, sort of thing from them.'

In a similar vein, participants reflected on developing a relationship beyond the routine physical care of a person. One nurse noted:

> 'We just don't look at one side of his care like it wasn't just about his foot and his diabetes it was about how he felt about things … I think it wasn't just about getting a care plan for an intervention for his foot, it was about him

learning to trust us and forming a relationship, and I think that was a very important step to his healing process as well'.

Daily routine of physical care was seen as an opportunity to spend time with the client *'just getting to know the real her'*. For instance, one nurse described bath time as an opportunity for the client to *'share her experiences'* of an event. Having expressed the importance of listening to the client it became apparent that the nurses thought it was necessary to ensure that the client understood the decisions related to their nursing care.

Some clients decided on their own nursing goal, as evidenced by this comment:

'I think quite often you can have the client themselves who want to take issue with something or want to … have another goal plan or what have you.'

There was consensus that the client should be involved in the decision related to their health *'right from the very beginning'*. As one participant suggested, *'if he doesn't or didn't understand then… there's no point moving forward with it really, if he didn't give it any value really.'* Involving the client and their family in any decisions entailed more than explaining a decision, it meant ensuring that the nurse had listened to the client's wishes and learnt from what they had to say. The significance of respecting the clients' wishes and always asking the clients opinion when writing nursing goals was conveyed by this comment:

'We thought about the things, he and I initially talked together and I asked what he liked doing, what he didn't like doing, how he liked people to approach him. Did he like talking on a one to one basis, and he said, 'yes', I prefer to be like that.'

Participants also identified talking to the family as a way of getting to know the person, especially during 'pre-admission assessment' or during times of illness. One account related the time spent listening and learning from a mother's experience:

'first few weeks of admission her mum, spent a lot of time, spending time with us, telling us about her daughter before the illness showing photographs. I think she really wanted us to have an idea that this wasn't her'.

The participant explained how the knowledge gained from the mother enabled her to understand the effect of illness on the client and assisted her to nurse the client during recovery.

Eleven participants considered involving the person with intellectual disability as an innate process, and could not comprehend any other way of working. Empowering the client to make decisions was important, as a nurse stated:

'there wasn't much decision making on my part really, other than to give her the opportunity to be in control of the situation'. In that circumstance the nurse described her thoughts as: '…it was almost like … like I was a student and she was my mentor.'

Such comments offer an albeit low level example of practice that supports the fact that the nurse encourages the client to make their own decisions. Throughout the interviews there were data that verified that the nurses saw the client as an equal partner in the decision making process.

For most of the participants the decision making process began with the client. Nonetheless, it became evident that these decisions were seldom unilateral as the nursing or interprofessional team also contributed to those decisions.

Theme 2: Working together

When the participants reflected on their practice, it became apparent that most nursing care decisions were a team endeavour. The team could be the nurses working on a unit or a team of interprofessional staff that supported individuals with intellectual disability. Unilateral decisions were only briefly mentioned, and this was in relation to the solitary action of writing nursing care

plans. Initially the client's needs were discussed with the client and the team, as noted by one nurse:

> 'The named nurses usually identify the problem, but then we discuss it as a team to see if it's… whether it's just yourself with a problem or whether everyone else finds it a problem and where we take it from there, you know, it was more or less team work.'

However, the practice of writing the nursing care plan occurred mostly in isolation. Hence this allowed the nurse to make some unilateral decisions regarding the actual writing of the 'guidelines' to meet the client's needs.

Every participant gave a detailed account of how they engaged other nursing staff in their decisions. Informal discussion was valued over formal nursing meetings. In each unit's office there was a 'note book' where all staff openly contributed any comments. It was generally perceived as an informal way of gathering people's opinions on a decision or a way of reminding staff of any changes in nursing care. Ensuring that all the staff were aware of any new decisions was difficult. Different shift patters for 30 staff on a unit made it difficult to guarantee that all staff knew the decisions taken regarding the care of an individual, as evidenced by this comment:

> 'There are so many shifts, different shift patterns, then, you have people doing mornings, afternoons, evenings, late, sleep-ins. People come in at different times so you have to make sure that they all know what's happening. Your traditional handover at 2 o'clock can be three handovers in one shift.'

Arranged meetings, such as the handover and monthly unit meeting, represented formal communication that supported decision making within the nursing team. Although handover was initially portrayed as a forum to pass on information between shifts, participants commented that it was a useful arena to discuss and make nursing decisions, it was described as *'quite a reflective period of time'* and an opportunity *'to think'* about the care.

The contribution of other professionals was appreciated in the process of decision making. Often the participants related complex situations with multidisciplinary decision making. One participant noted, '...*it was a complex decision that I couldn't make on my own and I needed outside, you know, more than one persons opinion.'* There was evidence of the participants using the multidisciplinary team in two ways, that is, either to review a nursing decision or to be and integral part of the decision making process. The nurses worked with a range of professionals. Some referred to the multidisciplinary team as a unit of people that support the client whilst others named individual professions (see Table 4.3).

Table 4.3 Professionals that intellectual disability nurses consult with to assist with decision making

Psychologist
Day Services, e.g. Art Therapy
Advocacy Service
Psychiatrist
Speech and Language Therapist
Physiotherapist
General Practitioner
Multidisciplinary team
Family/relatives/home support
Behavioural Support Team
District Nurse
Resettlement Staff
Intellectual Disability Community Nurse
Occupational Therapist
Specialist nurse, e.g. diabetes

There appears to be a continuum of decision making from a unilateral to an interprofessional level. However, from these data, it is difficult to identify where and when autonomous, nurse-led or interprofessional decision making took place. All

the interventions described by the participants required some level of consultation with others apart from the client. Some described informal discussions; others used formal meetings to assist with decision making.

Theme 3: Evidence to support decision making

The third theme to emerge relates to the sources of information the participants used during decision making and where the resources were accessed. The data collected relate to specific information the nurse used during the intervention described in the first part of the interview. Four sources of evidence were identified: client related information; the individual nurses' personal knowledge; expertise of professional colleagues; and other resources, such as the library.

The participants gathered evidence concerning the client through reviewing medical and nursing notes, for example:

> 'looking back at his history really, and how people used to cope with his challenging behaviour then, to see basically whether there was anything that I wasn't seeing.'

Many of the clients were known to the intellectual disability service and gaining access to their history was relatively easy. However, one participant described the admission process for a client who had never used statutory services and described her decision making as *'based on what you can physically see'*. Decisions were influenced by engaging with and observing the client using a systematic approach to evaluate the intervention. From observing and recording information, the nurses were able to plan the next stage of the intervention.

Participants discussed their experiences of working with clients who have specific needs related to intellectual disability. For instance, *'the fact really that I had much experience of having worked with people with autistic spectrum'*, suggesting the value of gaining knowledge and experience over time. Another nurse discussed at length an intervention with a client and used words such as *'I suspected'*, *'I felt'*, *'I had a suspicion'*, *'I felt there was something else'* and *'I had*

this niggle'. These feelings were interpreted by the participant as initial evidence to prompt her to assess a client: *'my evidence (re: intervention described) is, initially my niggle'*.

Approaching other professional colleagues to gain information to assist in the process of decision masking was common practice. Some identified individual nurses within the intellectual disability service who had specific expertise, whilst others accessed nurses in generic health services, such as district nurses and a nurse specialist in diabetes.

Finally, five types of resources were identified as a potential source to guide decision making, that is, the library, Internet, journals/reading, courses/education and others including electronic databases, such as CINHAL, professional nursing associations, and health promotion units. Participants stated that they accessed these resources mostly during work hours, although *'constraint of the service'* and *'staffing levels'* made it difficult to find the time to engage in searching for information. Some participants appreciated the contribution that students and newly qualified nurses make to the process of retrieving information for decision making. As one participant said: *'I will go and ask somebody who's recently qualified, how do I get the evidence for this, and because they are a bit more up to speed.'* Participants noted that finding research that was relevant to practice sometimes could be difficult.

Theme 4: Understanding of evidence based practice

Overall, the participants considered evidence based practice to be a different entity to what they were doing in practice. When asked direct questions relating to evidence based practice, participants struggled to describe the purpose or value of evidence based practice, for example:

'I think it is (evidence based practice) that our practice, what we are doing here, and that it is what people say in books … it is not that black and white.'

Nevertheless, participants used such words as *'quite keen'*, *'always kind of kept up to date'*, *'prepared to look for information'* to describe their own practice and thus expressed attitudes that were consistent with a commitment to evidence based practice.

Participants associated the term evidence with research, for instance, *'evidence is something that has been researched by somebody else'*, and a consensus noted that there was limited research available to support intellectual disability practice. For example, *'If you look up certain things you'll find that there's not a lot of information around it, so you have to start looking at other resources'*. One participant said it was important to have *'something'* to demonstrate that the intervention works in practice. In this study, the other sources of evidence that the nurses used were evidence from the client, their own practice, and other individuals.

The evidence from the client was described in relation to the extent of achieving a nursing goal, as demonstrated in this quote: *'Has there been an improvement (in the outcome for the client) that would be my evidence ... to say, yeah that's the right way of doing it.'* In addition, gathering information from their own practice was discussed and seen as a useful source of evidence and a *'basis that you can always draw upon'*. Noting such comments as *'it worked well before'*, *'something which has been done and someone has seen that something has come from it. It works well'*.

To engage in evidence based practice, the participants identified four key skills: practice evaluation, communication, access to information technology, and searching and critiquing literature. Observing and recording data regarding practice and the ability to question their practice and engage in reflection on practice were highlighted as important skills for evidence based practice. For example, one participant described her practice as a process of *'constantly thinking'* and questioning if *'it's the right way'*. Similarly *'asking questions, not just taking things at face value'* was also noted.

Communication skills were discussed in relation to the need for the nurse to have *'good communication skills'* and *'good listening skills'* when engaging in

evidence based practice. Equally, communication skills were identified as being important for *'passing on information/knowledge'*, *'accessing information'* from other staff and communicating their practice with other professionals involved in the practice.

The ability to access information in an effective way was discussed and information technology skills were seen as an essential element. However finding literature effectively was a skill that could be improved, as evidenced by this comment:

> 'Do they (nurses) sit down in the library with a stack of journals and literally you know, and go through them until they find one that they think they're going to use? …I think possible some people do. But that's time, just time isn't it? It's not knowing where to get the information, but that's just not knowing how to access it easily, isn't it?'

Moreover, having found the relevant information, respondents considered the challenges of making sense of their reading and applying it to practice. They suggested that research articles should be relevant to practice and easier to read. The ability to critique literature was articulated as applying *'detective skills'*.

The format of the interview schedule meant that evidence based practice was discussed as a separate issue during the interview. Arguably, this may have influenced the participants to perceive evidence based practice as a different entity to their own practice. Indeed, only two of the participants related the intervention they described in the first part of the interview to evidence based practice. Overall, the findings showed that the person with intellectual disability was central when the nurses discussed their own practice. However, when considering evidence based practice, their perceptions differed and many suggested that, primarily, practice should be guided by research.

Contrary case

IPA enabled the identification of similarities within the twelve transcripts whilst acknowledging the unique characteristics of each participant. For example, many of the participants gave a detailed description of how the person with intellectual disability was central to the intervention. In comparison, one account offered few data to support the inclusive nature of decision making described by most of the participants.

Initially the concept of reflexivity was considered in relation to social positioning of the researcher (Buckner, 2005), that is professional background. However, a reflexive journal assisted the researcher to 'make sense' of the unexpected emotional response encountered during the analysis. Analysing this contrasting case was difficult, because it challenged beliefs and assumptions about intellectual disability nursing practice. Nonetheless, through supervision and revisiting assumptions about decision making and evidence based practice the data proved to offer valuable insight to the overall analysis.

Consistently, as the themes emerged from the analysis, the data from this contrasting case offered the polar opposite to the main themes. For example, in relation to 'working together' these data suggested that a unilateral approach of working was adopted. Similarly, in relation to the theme 'getting to know the client', contrary to other participants, this respondent stated that she had not previously thought of involving the client in any decision.

In her discussion of a scenario of giving 'as needed' medication, her decisions were based on asking whoever was around at the time. However, this stance of gaining others' opinion did not extend to the client. The respondent stressed the fact that, before the interview, she had never thought of how she had made decisions and assumed that there must be a process but did not know what it was. Overall, this interview offered an insight into one person's opinion of decision making and evidence based practice that serves as a contrasting case to the other data gathered.

Discussion

This research explored the experience of 12 intellectual disability nurses in Wales, UK in making decisions in practice, along with their understanding of evidence based practice. Essential to decision making was getting to know the clients, consulting with others, and using various sources of evidence to guide their practice. One contrary case challenged these findings and offered a different account of decision making. Considering alternative interpretations is one way to ensuring validity (Erlandson, 1993; Drummond et al., 1994; Mayan, 2001).

How nurses make decisions is well documented, however the research has been largely undertaken within midwifery care (Cheyne et al., 2006), critical care (Lauri et al., 1998; Bucknall, 2000; Cole et al., 2005), practice nursing (McCaughan et al., 2005) and mental health settings (Lauri et al., 1999; Lowe et al., 2003; Hellzen, 2004). The only work found relating to decision making in the context of intellectual disability are the studies by Hickson and colleagues (Hickson et al., 1998; Hickson & Khemka, 1999; Hickson & Khemka, 2000; Hickson & Macleod, 2000; Khemka & Hickson, 2000; 2006; Khemka et al., 2005; 2009). However, the participants of these studies are people with intellectual disability; no study was found to explore the perspective of intellectual disability nurses.

The results of this study show that 'getting to know the person' is an important component of decision making for intellectual disability nurses. This finding relates to Luker et al. (2000) study of district nurses involved in palliative care. They too identified the role of 'knowing the patient' further suggesting that the nurse-patient relationship was crucial in providing high quality care. Acknowledging the importance of spending time to get to know and listen to the individual is also cognisant with the principles of person centred approaches (Sanderson et al., 2008). Although, as a concept, person centred planning was developed outside of services in the USA (O'Brien & O'Brien, 2000), the UK has embraced the underlying values as a tool to aid quality improvement and care planning (Kinsella, 2000). This is evident in the many strategies and policies that are underpinned by person centred thinking in the UK (Scottish Executive, 2000; Department of Health, 2001a; Department of Health Social Service and Public Safety, 2005; Welsh

Assembly Government, 2007). It is encouraging to find that the participants in this study conveyed the principles of person centred thinking during the interview. Nevertheless, given the current policy drive for evidence based practice, it is of concern that specific policies or research literature were not directly mentioned.

Usher et al. (2009) found in their study related to 'as needed' medication that staff were often unaware of the existence of guidance. They concluded that mental health practitioners appear to have a strong faith in clinical judgement rather than making use of guidance. Usher et al. (2009) identify this faith as an intuitive skill that increases with experience. Flynn and Sinclair (2005) recommend that nursing practice requires clear guidance, but equally nurses need to develop clinical judgement. Hammond's cognitive continuum theory (Harbison, 2001; Lauri et al., 2001; Cader et al., 2005; Standing, 2008) may provide a useful framework to understand such decision making. The theory assumes that decision making contains both intuitive and analytical thinking and that the context and environment have a significant influence on the process of making decisions (Offredy et al., 2008). Cader et al. (2005) suggest that the theory identifies the level of analysis associated with the process of decision making. This provides a framework for a transparent decision making process that enables others to view the process.

Working relationships within the units and with other interprofessional staff was found to be important when making decisions. These participants indicated that talking to colleagues during the process of decision making appeared to take away the uncertainty that sometimes accompanied decision making. This finding is consistent with the body of literature relating to decision making, which indicates that nurses consult others to gain another interpretation of an event or to confirm their own decisions (Thompson et al., 2001; Hedberg & Larsson, 2003). Identifiable information about the persons with intellectual disability was not recorded in this study. However, due to the nature of the intellectual disability service provided; it can be assumed that many individuals had complex needs. Tope and Thomas (2006) support the notion that people with complex needs may have many professionals involved in their care. Our study offers some support to

these findings and shows that nurses may involve other professionals in difficult decisions.

In general, our participants reported that they were supported and given time to access information when they needed. This might suggest a change in attitude amongst healthcare managers, as earlier studies identified accessibility to research and the lack of time as barriers to evidence based practice (Kajermo et al., 1998; Metcalfe et al., 2001; Bennett et al., 2003; O'Donnell, 2004). From our study it is evident that intellectual disability nurses have better access to the best available evidence. However, this does not address that fact that the evidence might not to be fit for purpose to support the nurses to make decisions in practice, since, as in Carrion et al. (2004) study of mental health nurses, our study demonstrates that the application of research findings to practice is challenging.

The data regarding the participants' understanding of evidence based practice emerged from direct questioning. In keeping with the findings of a study by O'Donnell (2004), the participants' explanation of what constituted evidence based practice varied. Whilst there was an awareness of the importance of research findings, as Henderson et al. (2006) discovered, translating findings into everyday practice was difficult.

Conclusion

This paper offers a glimpse into the complex area of decision making within intellectual disability nursing practice. Although, it may not be relevant to all nurses who work with people with intellectual disability, some of the results can be related to other studies and contexts. In this study the intellectual disability nurses placed the person with intellectual disability at the centre of the decision making process. Valuing evidence from the client and family, and their own and others' personal experience and knowledge related to the decision was paramount.

The findings of this study regarding nurses' understanding of evidence based practice, their use of research to guide practice, and faith in colleagues to

verify decisions is comparable to other research reviewed. However, this study has identified that within practice, the intellectual disability nurses consider evidence from the client as 'gold standard'.

Further research is advocated to explore decision making within intellectual disability nursing in relation to the practice of decision making; the sources of information used; the influence of person centred thinking; and the role of the nurse, the multi-disciplinary team and the individual with intellectual disability in this process.

Reflexive summary

Process issues

The explorative nature of this study suggested the use of a qualitative methodology. This approach enabled the examination of participants' understanding of their everyday decision making practice and the meaning behind those decisions. Thus, semi structured interviews produced participants' representations of their views and opinions about decision making and evidence based practice (Silverman, 2011). For a novice phenomenologist, Interpretative Phenomenological Analysis [IPA] (Smith & Osborn, 2008) offered a structured approach to the analysis that also recognises the central role of the researcher. In line with a hermeneutic approach, IPA does not support the use of bracketing in the research process (Smith, 2004). Alternatively, IPA recognises the construction of a common discourse between the researcher and the participants in relation to building and understanding the role of decision making. This shared professional background, (as an intellectual disability nurse), with the participants was considered as an asset to understanding the participants' experience within an IPA framework. However, the challenges that rose from the *inside*r status were unanticipated.

In the first instance, the insider status enables the recruitment of participants with ease. However, when recruiting from a few units within a hospital setting, Van den Hoonaard (2003) warns that researchers may have little control over whether participants talk to each other and issues of disclosure may be problematic. Such problems as maintaining anonymity of participants were highlighted. However, in this study, participants discussing their experience of the research interview created more interest in the study; consequently more nurses wanted to participate in the research. Thus, there was the potential to conduct more than twelve interviews, although ethical approval did not allow further recruitment. Interviews were conducted during work hours on the hospital units; my *insider status* made it easy for me to enter such areas unquestioned. However, on a few occasions, interviews were disrupted. I felt that at times other staff thought, "it's ok to disturb them it's only Ruth asking a few questions" possibly blurring the boundaries of the

nurse researcher role. Thus, staff did not always recognise my researcher role and approached me as an *insider*.

A core task in this qualitative study was to develop verbatim transcriptions of interviews. The verbatim transcripts were generated from listening and re- listening several times to the audio recordings of the interviews and writing down every word that was said in the interview, noting any pause or any disturbance that occurred. As a novice researcher, this was a time and labour intensive period within the study. As the research method allowed examination of individual cases (an idiographic mode of inquiry), the data analysis commenced during the transcribing of interviews. Hence, this process might unconsciously influence the transfer of data from audio to paper. Hennink and Weber (2013) consider issues of quality within the process of transcription. They recognise that often, within higher education, transcription is a task given to administrative staff and graduate students to complete, which might suggest that it is an undervalued task within the research process. Lapadat (2000) notes that transcribing is given little attention in research reports. Within this study, I perceived the process of transcribing not as a task but an integral part of the analysis, whereby I would make notes of any thoughts that emerged from listening, typing and reading the text. My approach thus supported the view proposed by Tilley and Powick (2002) that transcribing is an *interpretive act*. Furthermore, the participants quotes represented within this chapter are edited and some were translated from Welsh to English (this is issue is addressed in the discussion, Chapter 7). For example, words such as "um" and repetitive phrases are deleted for ease of reading (Tilley & Powick, 2002). Such, instances are described are 'dross' words that may move away or distract from the subject explored (Morse & Field, 1996). However, I feel that this process did not lose the participants' intended meaning and the narrative given in this chapter represents the experiences of the twelve nurses interviewed.

One interview caused personal and epistemological challenges. It was through the process of supervision that I as a novice researcher (not as a nurse) was able to make sense of the data gathered. This interview offered little data to support my belief and the position of the other 11 participants that decision making

should be inclusive. It was an emotional process, of learning, development and realisation that I was unprepared to hear narratives that did not support my own value base. Responding to the data in a practical sense enabled me to acknowledge that as a case, this one interview gave strength to the other data, and when asking questions it is impossible to anticipate individuals' answers.

Contribution to knowledge

Contribution to knowledge is twofold. There is the unique contribution of the research to the field of intellectual disability nursing research but also it is important to reflect on the personal knowledge and skills gained by engaging in this research study. This chapter presents a qualitative study that explores clinical decision making and the sources of evidence used to inform those judgments. Overall, the findings in this chapter celebrate the uniqueness and the importance that the nurses place on valuing the individual; and striving to make decisions in a person centred way. Although this was a small study of twelve nurses' perspectives, it contributes to our understanding of the process of decision making within intellectual disability nursing and lays the foundation for further research.

Qualitative research and adhering to an IPA framework appealed to me, as it seemed to offer a structured holistic approach to considering the research question. As a novice researcher, the identifying and voicing of my beliefs did not come easy. Keeping reflective notes was a challenging task, and it is only now that I appreciate their worth. Attending IPA training and meeting Jonathan Smith and Paul Flowers (who have developed IPA and published extensively about the merits of IPA) was a valuable investment and enhanced my confidence and knowledge in conducting an IPA study. Although at times, the transcribing seemed arduous, I feel I was in a privileged position to listen and learn from other nurses narratives. I hope this chapter shares some of that insight and knowledge with its readers.

Chapter 5 – Study 2, Evidence informing decision making in intellectual disability nurse practice. Results of a national survey

Author contributions

RWW was responsible for the study conception, design and data collection. RWW performed the data analysis supervised by RH who provided statistical expertise. RWW was responsible for drafting the manuscript. RH, FI and GWR supervised the study and made critical revisions to the paper for important intellectual content.

Reflexive preface

Researcher's role

This chapter builds on the findings of the previous qualitative study on decision making described in Chapter 4 (Williams et al., 2010). The first study represented the voice of twelve NHS intellectual disability nurses who worked across in-patient units that provided assessment and treatment, rehabilitation and continuing care services to adults with intellectual disability. The intention of this second study was to capture a larger sample across NHS intellectual disability nursing in-patient and community services; and consider the impact of demographic and cognitive characteristics on evidence informing decision making. A self-completion questionnaire was chosen as a method to reach a large sample that was dispersed geographically across five health boards in Wales.

Reflexivity is rarely associated with quantitative research methods (Walker et al., 2013). Mauthner and Doucet (2003) suggest that this could be explained by the philosophical dichotomy that lies between qualitative and quantitative research. Although research bias is an issue for both approaches, quantitative methods try to control for researcher influence whereas qualitative approaches acknowledge researcher influence and seek ways of making it explicit through processes such as reflexivity.

Dowling (2006) suggests that reflexivity is described in the literature as a continuous process of self-appraisal within qualitative research. However, Etherington, (2004) proposes that there are numerous levels to reflexivity, and being a researcher involves engaging in the process and product of the research journey. This stance is contrary to Ryan and Golden's (2006) suggestion that "most quantitative researchers continue to avoid explicit forms of reflexivity" (p. 1193). This quantitative study endeavoured to continue with a reflexive approach thus maintaining a consistent approach across all three studies of this thesis.

As a novice researcher, I also felt that I had nothing to lose but to gain from a reflexive perspective. The thesis is exploratory in nature and although this second study drew on quantitative methods, being open and honest within the process seemed to be in keeping with the entire thesis. Furthermore, reflexivity

had the potential to make me aware of the moment, that is personal reflexivity, but also the potential for enhancing rigour and developing insight and new learning could be noted. Thus, a PhD journey is more than completing research projects, developing as a researcher, and recording and reflecting on the skills and knowledge gained is a valuable aspect of the process.

Prior to this study, my experience of quantitative research was minimal. I commenced this second study with experience of conducting a small-scale MSc research project, attending a postgraduate course on using the software SPSS (Statistical Package for the Social Sciences) and the fear of anything mathematical has remained with me since school age. Hence, I was barely equipped with the skills and knowledge to conduct statistical analysis. However, I felt it would be valuable to gain a range of research skills other than just focusing on qualitative methods within this research training. A reflexive approach was therefore used as a means to review my knowledge and skills and identify ways to improve my future practice in conducting quantitative research. Keeping a diary that noted the decisions made during the study was invaluable. Documenting the process from survey design, sampling and negotiating the ethical approval required across Wales to surviving statistics enabled me to learn and engage fully in this quantitative research.

Abstract

Aim. This paper reports the findings of a national survey that explored the types and sources of evidence used by nurses to make decisions in intellectual disability nursing practice; further determining the demographic and cognitive characteristics that influenced the use of evidence.

Background. Healthcare practitioners are under increasing demands to base their decisions on the best available evidence. Our previous research highlighted the importance of a person-centred approach in decision-making in intellectual disability practice, but it is unclear whether this takes priority amongst practitioners in Wales, UK.

Methods. A cross-sectional survey was designed whereby all NHS nurses (n=465) working in intellectual disability services across Wales between April and June 2010 were mailed a self-administered questionnaire. This consisted of items that emerged from our previous qualitative study alongside a validated measure on clinical decision-making. Following postal reminders, 285 (61%) questionnaires were completed and returned.

Findings. Nurses' reported that evidence from the service user is of utmost importance in the process of decision making. Experiential sources of evidence, such as talking to clients and colleagues, took priority over accessing empirical evidence to inform decisions. The findings confirm a significant relationship between analytical decision making and the use of both empirical and experiential based sources of information.

Conclusion. Nurses should celebrate their diversity, flexibility and ability to critically think and work with clients when making decisions to improve health outcomes within intellectual disability nursing services. Further research is needed to identify the types of evidence that nurses use when making decisions in particular situations.

Summary statement

What is already known about this topic

- Nurses rely on colleagues and personal experience to make decisions in practice.

- Decision making is a complex process that requires engagement with different sources of information.

- Clinical guidelines and pathways to aid decision making in intellectual disability nursing are sparse.

What this paper adds

- Nurses who work in intellectual disability nursing services value evidence gained from service users and their family / carers when making decisions in practice.

- Nurses who work in intellectual disability nursing services who have an analytical orientation towards decision making use more sources of evidence across both the empirical and experiential range.

Implications for practice and /or policy

- Education and healthcare should work in partnership to support nurses to use a range of experiential and empirical evidence to support person centred decision making throughout their careers.

- Further research is needed to explore how useful nurses who work in intellectual disability nursing services find empirical and experiential sources of evidence in reducing uncertainties in clinical decision making.

- In line with the inclusive nature of nursing practice in intellectual disability services, research involving clients' perspectives on the decision making process within healthcare is advocated.

Introduction

Decision making in nursing has its roots firmly embedded in tradition, rituals and conversations with colleagues (Brown et al., 2010). However, given that, in the UK and beyond, evidence based practice has become a 'policy imperative' (Rycroft-Malone, Fontenla et al., 2009) there is an ever-increasing demand for accessible and high-quality evidence to inform nursing practice. On a global level, standards of nursing practice (Nursing Council of New Zealand, 2009; Canadian Nurses Association, 2010), and position statements (International Council of Nurses, 2007; American Nurses Association, 2010; World Health Organization, (Büscher et al., 2010)) have been issued by various nursing and health related organisations and associations to drive and support evidence based practice and the use of research to inform clinical decision making.

Regardless of such policy, evidence based practice is reliant on the ability of nurses to draw together and determine the value and appropriateness of the evidence on which to base their clinical decisions (Doody & Doody, 2011). As part of this rhetoric, the focus of nursing discourse has shifted from 'what nurses do, to how they think about what they need to do' (Standing, 2010, p. 3) and what constitutes the nature of evidence to support their thinking (Rycroft-Malone, Seers et al., 2004). Whilst this debate continues within the wider nursing context (Majid et al., 2011), less is known about the way in which nurses working within intellectual disability nursing services use evidence to guide their practice, although person-centred decision making appears to be paramount (Williams et al., 2010). In this paper, we report on a study exploring the sources of evidence used by nurses to support practice in intellectual disability nursing practice and the factors that influence the use of these sources of evidence.

For clarification, the term 'intellectual disability' is used in this paper to describe a range of conditions that affect an individual's cognitive and social functioning (Department of Health, 2001a) and that are 'noticeable before the age of 18 years' (Sullivan et al., 2011). Whilst these conditions are often described in the UK literature as 'learning disability' (Jinks et al., 2011) or in the international literature as 'developmental disabilities' (Sullivan et al., 2011), there is parity in their

interpretation (Department of Health 2001a, World Health Organization 2001, American Association on Intellectual and Developmental Disabilities 2010).

Background

Our research was carried out in Wales, UK where intellectual disability nursing is a distinct speciality. Student nurses undertake a university degree course that leads to registration with the Nursing and Midwifery Council [NMC]. The role of the intellectual disability nurse is wide-ranging and evolving in response to the changing needs of the client group. For example, an intellectual disability nurse's role may encompass working with clients in relation to safeguarding (Jenkins & Davies 2011) youth offending (Hepworth, 2009), forensic issues (Mason et al., 2011), health facilitation (Jukes, 2002), and health liaison in acute hospitals (Foster, 2005). Within these roles, nurses strive to include all clients in the decision making process, in line with the person centeredness value base of professionals working with individuals with intellectual disability (Sanderson et al., 2008).

To assist UK healthcare professionals in their clinical decision making, the National Institute for Health and Clinical Excellence [NICE] publishes guidelines, clinical pathways and standards for health care provision in an attempt to make evidence based information accessible to practitioners (see NICE, 2011). This facilitates the delivery of care based on the best evidence and reduces uncertainties, particularly where access to evidence is limited. Whilst there is undoubtedly merit to this guidance, Standing (2010) argued that, given the complexity of clinical judgement in healthcare, it would be difficult to develop guidelines for every possible decision a nurse may face.

Drawing on a theoretical base, several authors have advocated Hammond's (1978) cognitive continuum theory as a useful framework for understanding clinical decision making (Thompson et al., 2004; Cader et al., 2005). Thompson et al. (2004) suggest that one of the strengths of the theory is its scope to identify and differentiate between the types of clinical decisions taken by practitioners. In 2008, Standing adapted the theory for use within a nursing context thus offering an alternative interpretation of the theory known as the nine modes of practice (see

Standing, 2010 for detailed discussion). The theory equally values intuitive (Benner, 1984) and analytical judgement (Harbison, 2006). Such accounts as Schön's (1987) reflection in and on action and Benner's (1984) description of the intuitive skills of the expert nurse can be recognised within these modes of practice. Analytical theories, on the other hand, are based on systematic, problem solving principles that offer a logical approach to decision making practice for instance, the Bayes theorem (Savage, 1954).

Standing (2010) proposes that, alongside intuitive skills, nurses must also demonstrate their skills in questioning practice, identifying the gaps in knowledge and researching relevant empirical evidence to inform decision making. The nine modes of practice depict intuitive and analytical decision making along a cognitive continuum, whereby the type of decision and the time available to make the decision influence the mode of practice. In summary, according to the framework, a decision that is highly structured, such as a strategic decision, results in an analytical mode of decision making. Conversely, a task that is low in structure, such as daily communication with clients, is likely to be influenced by the intuitive mode of decision making.

The nine modes of practice outlined in the framework are associated with the use of a broad range of information from experiential sources, such as evidence generated from reflective practice; and empirical evidence, such as information derived from qualitative and survey research. In the context of nursing practice, Spenceley et al. (2008) defined a source of information as 'any source of knowledge, information, or evidence that a nurse would access in the practice setting in order to answer a question arising from it' (p. 956). The information that is used to guide clinical decisions is diverse and should include, according to Brown et al. (2010), a combination of research-based knowledge and client values. Nevertheless, a number of studies have focused exclusively on the barriers to research utilisation when considering the implementation of evidence based practice rather than exploring the use of experiential types of knowledge, such as information shared by the client and family (for example, Adamsen et al., 2003; Carrion et al., 2004; Thompson D.R. et al., 2006; Estabrooks et al., 2007). Moreover, the growing research base is heavily influenced by studies conducted

within the context of adult nursing practice, the exception being a study by Parahoo et al. (2000).

Parahoo et al. (2000) reported on data from intellectual disability nurses in Northern Ireland (*n*=87), the sample originated from a large survey that included adult and mental health nurses (see Parahoo, 1997). The study used two questionnaires to explore attitudes to research and the research utilisation of nurses. The results demonstrated that 18% of intellectual disability nurses agreed/strongly agreed with the statement '*Research is not relevant to the real day to day work in nursing'*, whilst as many as '23% disagreed/strongly disagreed with the statement '*Nursing should be a research based profession*' (Parahoo, 1997, p. 610). Within the initial large scale study (*n*=1368) (Parahoo, 1997) 19.5% of intellectual disability nurses reported 'never/seldom using research in their practice' (Parahoo et al., 2000, p. 610) compared with 22.8% of mental health nurses (Parahoo, 1999) and 7.3% of adult nurses. On the basis of these findings, Parahoo et al. (2000) concluded that the lack of research in intellectual disability nursing may account for these nurses' lack of engagement with research. This study is now over 10 years old and based on a relatively small sample of intellectual disability nurses that worked within a hospital environment. Today, nursing services for individuals with intellectual disability in the UK are primarily community based or delivered within small specialised short term in-patient facilities that provide individualised packages of care. In light of such advances in service provision, the practice of nurses within intellectual disability services has also developed. Further research into the decision making processes undertaken by nurses working in diverse settings is thus advocated.

Returning to the wider nursing context, Rycroft-Malone et al. (2004) contend that nurses should access a range of evidence on which to base their practice and this should include the personal knowledge and experience of patients or clients as well as a sound research base. Furthermore, researchers continue to draw our attention to the fact that nurses consult colleagues and rely on their own experiences to make clinical decisions rather than relying solely on empirical evidence to inform their practice (Egerod & Hansen, 2005; Pravikoff et al., 2005; Williams et al., 2010). Thompson et al. (2001) caution that consulting colleagues

may not be compatible with seeking research based knowledge and that human sources of knowledge might be viewed only as a medium to convey information rather than legitimate information in its own right.

In summary, there is: i) a limited availability of specific research in relation to nursing within intellectual disability nursing services to inform decision making; ii) value assigned to person centred approaches in intellectual disability nursing; and iii) a policy drive for nursing practice broadly to be evidenced based. In this context, we report on a national survey to explore the sources of evidence that inform decision making in nurse practice within intellectual disability nursing services and the cognitive factors that influence its use.

The study

Aim

The overall aim of the study was to identify the types and sources of evidence that nurses use when making health related decisions within intellectual disability nursing services in Wales, UK National Health Service [NHS] practice. This was realised through the following objectives:

1. To describe the sources of evidence nurses use.

2. To establish how demographic and cognitive characteristics are associated with the use of empirical compared with experiential sources of evidence.

Design

A cross sectional survey design was used, whereby registered nurses working within NHS intellectual disability nursing services across Wales were mailed a bilingual (Welsh/English) self-administered questionnaire (see Appendix J). The questionnaire included three sections, as follows:

1. *Nurses' use of information to improve health outcomes* (a measure developed from the authors' own research, authors' reference).

2. *Nurses' approach to decision making* (a modified version of the *Nursing Decision-Making Instrument,* Lauri & Salanterä 2002).

3. Demographic characteristics (questions designed for this study to gather data on the demographic makeup of the sample).

(See Appendix K – for process of translating the questionnaire from English to Welsh).

Sample

The total population of registered nurses who worked in NHS intellectual disability nursing services across Wales were invited to participate in the research (*n*=465). The nurses were employed within five health boards (local healthcare provider organisations across Wales); (1 *n*=183, 2 *n*=13, 3 *n*=151, 4 *n*=73, 5 *n*=45). According to Gates (2011a) there are approximately 19,000 intellectual disability nurses registered with the Nursing and Midwifery Council in the UK, hence the Welsh population of NHS intellectual disability nurse's account for 2.4% of this total. Members of the All Wales Senior Nurse Advisory Group (Learning Disability) within the five health boards facilitated the recruitment process. The senior nurses identified their staff and enabled the dissemination of the questionnaire via the health boards' internal mail systems.

The demographic characteristics of the respondents in this study are representative of the profile of nurses working within intellectual disability nursing services across Wales, according to information received from the health boards under a freedom of information request (see Table 5.2). The emerging picture is one of an experienced, older and female led profession.

Over the years, the contribution of the nursing profession within intellectual disability services has been questioned. The publishing of the Jay report (Jay, 1979) saw the first public debate about the continuing of the intellectual disability nurse registration (Mitchell, 2003). Today, with the recent publication "Strengthening the commitment" (Department of Health et al., 2012) endorsed by the four countries of the UK the vision for intellectual disability nursing is clear. This

review makes a number of recommendations about "strengthening the commitment" to intellectual disability nursing, by focusing on strengthening capacity, capability, quality and the profession. The ability of the intellectual disability nurse to continually adapt and change to meet the needs of individuals with intellectual disability is a strength (Mitchel 2003). Current services in the UK demonstrate this adeptness and ability to meet the needs of individuals with intellectual disability. Hence this study recruited from the total population of nurses working within intellectual disability services thus acknowledging that within this workforce nurses from other fields of nursing may at times contribute to the service profile. For instance, adult nurses may work alongside intellectual disability nurses in health liaison roles. Thus, to reflect the intellectual disability service the total population of nurses working within intellectual disability services were recruited.

Data collection

Data were collected between April and June 2010. A recruitment pack, containing a letter of invitation (see Appendix L), information sheet (see Appendix M), questionnaire (see Appendix J) and a pre-paid return envelope was sent to all nurses included in the sample. Each questionnaire had a unique code to assist the researcher to assess the response rate and enable reminders to be circulated according to Dillman's Total Design Method (1978) (Table 5.1; see Appendix N for further information about the process of sending out reminders).

Table 5.1 Questionnaire distribution and response according to Dillman's (1978) Total Design Method

Mailing	Week	Sent	Received	Running Total
1*				
	0	**465**	66 (14%)	66 (14%)
2 (postcard)	1	465	138 (30%)	204 (44%)
3*	3	279	48 (17%)	252 (54%)
4*	7	211	33 (16%)	285 (61%)

* At mailing 1, 3 and 4 a recruitment pack containing: letter of invitation, information sheet, questionnaire and a pre-paid return envelope was sent.

Measure1: Nurses' use of information to improve health outcomes

This measure is a 24 item questionnaire based on previous research (Williams et al., 2010) that offered insight into the complex area of decision making in intellectual disability nursing practice. The measure was designed to gather data related to the sources and type of evidence that nurses access and use when making decisions concerned with improving health outcomes for individuals with intellectual disability. Two scales are reflected in the measure, namely, experiential and empirical types and sources of evidence. The experiential based information includes such items as, 'talking with the clients/patients', 'observing clients' and information gained from 'experienced nursing colleagues'. The empirical based items incorporate, for example, information gained from 'research publications', 'university modules or courses' and 'results of audit'. The response to each item is recorded on a 3 point frequency scale where 1=never; 2=sometimes; and 3=every time (see Table 5.3 for item descriptors).

Using the data from this sample of nurses, the internal consistency of the empirical and experiential scales was explored. Three items reduced the internal consistency of both scales when they were included (*my experience as a nurse*; *popular media*; *habit or tradition at place of work)* hence they were withdrawn from the measure and used descriptively only in this study (see Table 5.3). The remaining 21 items were included in the measure with 9 empirical sources items

forming a scale with a Cronbach's alpha coefficient of .71; and 12 experiential sources items forming a scale with a Cronbach's alpha coefficient of .75. Scores on each separate scale were calculated using the sum total scores of the constituent items. Thus, total scores for empirical information sources could range between 9 and 27; and total scores for experiential information sources could range between 12 and 36.

Measure 2: Nurses' approach to decision making

This 56 item measure was adapted from the Nursing Decision-Making Instrument (Lauri & Salanterä, 2002) (see Appendix I for letter of agreement). This instrument has been developed and revised since the beginning of the1990s (Lauri & Salanterä, 1995; Lauri et al., 1997; Lauri et al., 1998; Lauri et al., 1999; Lauri et al., 2001). Researchers in seven different countries in Europe and North America, (Lauri et al., 1998; Lauri et al., 2001) have used this measure across various clinical settings, including intensive care (Lauri et al., 1998), psychiatry (Lauri et al., 1999) and public health (Lauri & Salanterä, 1995).

The measure has two sub scales containing analytical and intuitive items. Data from the current sample resulted in a Cronbach's alpha coefficient of .89 and .84 respectively. Both sub scales include 28 items each. The sub scales (analytical and intuitive) present statements that describe how nurses make decisions about clients' care across the process of nursing, from assessment to evaluation of care. Examples of analytical items are: *I collect as much information in advance as possible from the client's records* (Q1); and *In providing guidance to the client I mainly rely on clinical guidelines / care pathways that are suited to solving this client's nursing needs* (Q56). Intuitive items included: *It is easy for me to form an overall picture of the client's situation and major nursing needs* (Q27) and *It is easy for me to get the client to take part in the planning* (Q31). Response to the items are on a 5 point frequency scale from 1=never or almost never to 5=almost always or always. In line with Lauri and Salanterä's (2002) approach, reverse scoring was applied to the analytical items. Lower scores on the analytical scale indicate more analytical orientated decision making whilst higher scores on

the intuitive scale reflect intuitively orientated decision making. Scores on the analytical and intuitive scales could range from 28 to140.

Ethical considerations

Ethical approval for the study was obtained from the university and local NHS ethics committees with local site governance approval gained across five health boards in Wales (see Appendix O).

Data analysis

SPSS version 16.0 (SPSS Inc., Chicago, IL, USA) was used to analyse the data and calculate descriptive and inferential statistics. All data were screened for errors by checking the frequency for each variable to ensure that the score was within the possible range and missing cases were identified. Seventy three percent (n=207) of the 285 questionnaires returned were complete without missing data. The total number of cells of missing data was n=377 (1.34% of the total data cells). Missing data were replaced with the mean score for the variable when sufficient items in a measure had been completed. For measure 1 (24 items), mean replacement occurred when three or fewer cells were missing; and for measure 2 (56 items) the mean replacement was used when seven or fewer cells were missing. After the mean replacement procedure, n=206 (0.74%) data cells remained missing. (See Appendix P for example of record of participant missing data).

The main dependent variables were the scores for empirical and experiential types and sources of evidence identified in the first measure: Nurses' use of information to improve health outcomes. Having explored the associations between these variables and the demographic characteristics, (see Appendix Q for examples of statistical analysis undertaken), regression analyses were conducted to predict the use of empirical or experiential evidence. The variables used as predictors were: analytical and intuitive decision making, number of years since qualifying, gender, age, location of employment, academic qualification, percentage

work time in contact with clients, pay banding, and whether nurses were currently studying for an academic qualification.

Results

Demographic characteristics

The participants' characteristics suggest that the workforce within intellectual disability services in Wales consists of experienced nurses (n=273, mean=19yrs, range 1-40yrs). The majority of the nurses were female (n=211, 75%) and above the age of 40 (77.5% n=218). Forty two percent of the participants were graduate nurses and 15% (n=42) were studying for an academic qualification. The majority of nurses were employed on the NHS Agenda for Change band 5 or band 6 (a UK based pay banding system that ranges from 5 to 8 within this data set). The nurses were employed either within residential/in-patient facilities or community based services. Thirty three percent estimated that their working day involved between 76% and 100% face-to-face contact with clients. A minority (n=5) noted administration, management, education or clinical governance as their main role. The demographic characteristics of the sample appear relatively representative of the total population of NHS nurses working within intellectual disability services in Wales (See Table 5.2 for details).

Table 5.2 Demographic characteristics of participants

Demographic characteristic	n	%	All Wales profile of ID nurses in NHS ID nursing services (n=486)	
			n	%
Gender (n=280)*				
Female	211	75.4	367	75.5
Male	69	24.6	119	24.5
Location of work (n=276)*				
Residential / In-patient facility	137	49.6	292	60.0
Community	139	50.4	194	40.0
Client Contact (n=283)			**	
No client contact	11	3.9		
Client contact	272	96.1		
Estimated client contact (n=270)*			**	
1-25%of the working day	50	18.5		
26-50% of the working day	75	27.8		
51-75% of the working day	55	20.4		
76-100% of the working day	90	33.3		
Registered nursing qualification (n=282)*				
Intellectual disability nurse	276	97.9	477	98.1
Other registered nurse qualification	6	2.1	9	1.9
Mental health nurse (n=5)			5	
Adult nurse (n=1)			4	
Academic qualification (n=282)*			**	
Diploma or certificate level	163	57.8		
Bachelor Degree and/or Masters degree/Doctorate	119	42.2		
Currently studying for an award related to nursing (n=279)*			**	
Yes	42	15.1		
No	237	84.9		
Award Currently Studying (n=42)*			**	
Continuing professional development	9	21.4		
Bachelor Degree	20	47.6		
Masters degree	12	28.5		
Doctorate	1	2.3		
NHS Agenda for Change pay band (n=280)*				
5	118	42.1	227	46.7
6	92	32.9	159	32.8
7	55	19.6	77	15.8
8 (includes 8a,8b and 8c)	15	5.3	23	4.7
Age in years (n=281)*				
20-29	17	6	43	8.9
30-39	46	16.4	100	20.6
40-49	133	47.3	230	47.3
50-59	83	29.5	110	22.6
60-69	2	0.7	3	0.61
Years of experience since qualifying (n=273)*			**	
0-2 years	16	5.9		
3-5 years	20	7.3		
6-10 years	39	14.3		
10+ years	198	72.5		

*n=285 questionnaires were received; due to missing data the total n within the table of demographic characteristics of participants is inconsistent and ranges between n=270-282.
** Information not available

Description of sources and types of evidence

Experiential sources of evidence were mainly used when making decisions concerning health outcomes. For example, 85% (*n*=239) of the participants stated that they relied on their own experience when making decision compared with only 7% (*n*=21) stating that they referred to research publications. Over half the nurses (*n*=157, 57.3%) stated that they were 'sometimes' influenced by habit or tradition in the work place when making decisions. The majority of participants reported that they always chose human sources to assist them with decision making, including, talking to clients (*n*=188, 66.7%), families (*n*=155, 55.2%), colleagues (*n*=106, 37.6%); using nursing skills, such as observation (*n*=189, 67.3%), reflection on practice (*n*=127, 45%), and consulting clients' nursing documentation (*n*=193, 68.7%). Empirical sources of information were not used 'every time' by many nurses, however, most stated that they would consult research publications 'sometimes' (*n*=239, 84.8%) with only 7.8% (*n*=22) noting that they 'never' used research (see Table 5.3).

Table 5.3 Types and sources of evidence used when making decisions concerned with improving health outcomes

Rank	Source of information	Empirical (em) or experiential (exp) source of evidence	*n*	% of participants who indicated that they used the source of information "every time" when making decisions
1	my experience as a nurse*	exp	239	84.5
2	clients'/patients' nursing documents	exp	193	68.7
3	observing clients	exp	189	67.3
4	talking with the clients/patients	exp	188	66.7
5	talking with the family	exp	155	55.2
6	reflection on practice	exp	127	45.0
7	doctors/psychiatrist/GPs	exp	107	38.1
8	experienced nursing colleagues	exp	106	37.6
9	allied health professionals	exp	96	33.9
10	clinical supervision	em	84	30.0
11	my initial nurse education	em	69	24.6
12	NHS provided education	em	44	15.8
13	professional interest groups	exp	37	13.2
14	university modules or courses	em	28	10.0
15	results of audit	exp	26	9.3
16	newly qualified nurses	exp	25	9.0
17	research publications	em	21	7.4
18	externally provided training	em	19	6.8
19	student nurses	exp	18	6.5
20	Internet	em	17	6.1
21	habit or tradition at place of work*	exp	11	3.9
22	the library	em	8	2.9
22	textbooks	em	8	2.9
24	popular media*	exp	1	0.4

*item not included in either sub scale (empirical or experiential) as it reduced the internal consistency of measure.

Predicting the use of empirical or experiential based sources of evidence

      Linear regression analysis was used to explore predictors of scores for the reported use of empirical and experiential types and sources of evidence. In each regression model, the variables of intuitive or analytical decision making; experience since qualifying (in years); gender; age; location of employment; academic qualification; percentage of work time in contact with individuals with an intellectual disability; pay banding; and whether nurses were currently studying were included. The results of these analyses are summarised in Table 5.4. (Further examples of statistical analysis undertaken are available in appendix Q).

Table 5.4 Regression analyses to predict use of empirical and experiential sources of evidence in decision making

Predictor Variables	Experiential sources of evidence[1]		Empirical based sources of evidence[2]	
	Beta	p	Beta	p
Number of years since qualifying	.070	.396	.099	.240
Gender	.133	.022	.028	.637
Age	.010	.892	.012	.876
Location of employment (community or residential/in-patient)	.083	.244	-.079	.281
Diploma or graduate level academic qualification	.047	.471	-.070	.293
Percentage of contact with clients	-.046	.550	-.116	.141
NHS pay - agenda for change banding	-.012	.886	-.123	.138
current academic study	.008	.884	-.136	.018
Analytical decision making	**.488**	**<.001**	**.451**	**<.001**
Intuitive decision making	**-.098**	**.198**	**-.066**	**.396**

[1]Model R^2 =.228, $F(10, 254)$=7.517, Sig= .000, p=<.0005)

[2]Model R^2 =.193, $F(10, 254)$=6.077, Sig= .000, p=<.0005)

The regression analyses demonstrated that few demographic variables were significant independent predictors of the reported use of experiential and empirical sources of information. Female nurses reported more frequent use of experiential sources of evidence, and those nurses currently studying for academic qualifications reported more frequent use of empirical sources. In terms of decision making attitudes, nurses with more analytical attitudes reported more use of both experiential and experiential sources. Intuitive decision making attitude was not a significant independent predictor of the reported use of either type of information source.

Discussion

Study limitations

When considering the results of this study it is worth acknowledging that questionnaires may measure the nurses' knowledge of a subject rather than report directly on their practice (Junnola et al., 2002). Hence, ethnographic approaches, such as direct observation, may have provided a different account of the sources of evidence used. Future research should consider using an ethnographic design as a means of data triangulation (Silverman, 2011).

Although the response rate for this study was good and the sample recruited appeared to be representative of the nurses that work in the NHS intellectual disability nursing service in Wales, direct international comparison with other nursing services for individuals with intellectual disability is problematic. Intellectual disability nursing services in Wales predominately employ nurses with a specific qualification registered in intellectual disability nursing. Scotland, England, Northern Ireland and the Republic of Ireland are the only other countries that offer this qualification at pre-registration level. Countries, such as the USA and Canada, have only ever trained generic nurses who work across specialties (Robinson & Griffiths, 2007). Thus, in the international context, individuals with intellectual disability may not necessarily have access to intellectual disability nurses. Furthermore, services for individuals with intellectual disability are increasingly provided by the private sector in the UK. This study captured the responses of

nurses employed only by the NHS in Wales. Future studies should include intellectual disability nurses from all sectors further considering other health professionals working with intellectual disability populations internationally.

Regardless of these limitations this study offers an insight into how nurses within intellectual disability nursing services in Wales report on their use of experiential and empirical evidence to support decision making in practice; and contributes a new perspective on decision making in intellectual disability nursing practice.

Sources of experiential and empirical knowledge

The nurses in this study reported using more experiential sources of knowledge than empirical knowledge on which to base their decisions. This focus on the client and human sources of information was also identified in our qualitative study (Williams et al., 2010) where the important role of the client in clinical decision making was established. This finding is contrary to that of Egerod and Hansen (2005) who reported that study participants ranked 'patient and patients' families' seventh (by 'bedside nurses') and ninth (by 'head nurses') in the sources of knowledge used. It is likely that our findings reflect the shift in nursing perspective that has occurred in the UK since 2005, whereby the voice of the service user 'is a key component of a human rights-based approach to healthcare' (Roberts et al., 2011, p. 1). In addition, the overarching value base of person centeredness (Sanderson, 2008) within the intellectual disability field raises awareness of the necessity of including the client in decisions (Iles, 2003). Although the participants in our study were primarily intellectual disability nurses, other fields of nursing are encouraged to consider the value of person centred decision making in delivering care that is based on what is important to and for the client (Robertson et al., 2005; Robertson et al., 2007b; Sanderson & Lewis, 2012).

Discussing decisions with colleagues emerged from our data as an important feature of clinical decision making amongst the nurses and a recurring theme within similar research in the wider nursing context (Bucknall, 2000; Thompson et al., 2001; McCaughan et al., 2002; Egerod & Hansen, 2005;

Estabrooks et al., 2005; Spenceley et al., 2008). Egerod and Hansen (2005) and Thompson et al.'s (2001) studies of acute care nurses in Denmark and England respectively found that relying on colleagues was an important aspect of their work. The nurses that responded to Egerod and Hansen's (2005) questionnaire ranked colleagues as the third most frequently used source of knowledge for clinical decision-making. Moreover, Thompson et al.'s (2001), cross case analysis concluded that 'it was human sources of information for practice that were overwhelmingly perceived as the most useful in reducing the clinical uncertainties of nurse decision makers' (p. 376). These studies are based in acute hospital environments, thus it seems that, regardless of nursing discipline, colleagues are reported as a source of information to aid decision making.

Our research revealed that if nurses were currently studying, they were more likely to access empirical evidence to inform their decisions. Similarly, Banning (2005) found that nurses who were currently studying for a prescribing qualification predominantly used empirical evidence, such as research papers to support their practice. However, the explanation for Bannings' findings may lie with the content of the course rather than the timing of its delivery. It is unsurprising that Bannings' participants' primarily accessed empirical evidence to inform their practice since the educational emphasis in this case is on safe, appropriate and cost effective prescribing (NMC, 2006) with less importance given to intuitive evidence.

An alternative explanation for accessing empirical evidence relates to the level of education at which nurses are studying. Since 2004, Wales has led the way in the UK in providing nurse education at degree level. Whereas, Northern Ireland moved to all graduate entry to the profession in 2011 and England will make the change by 2013. Thus, in Wales, it may be the case that nurses' 'graduateness' explains their awareness of the importance of evidence to support practice. However, we found no significant relationship between the level of qualification and the sources of evidence used. Similarly, in a survey of hospital based graduate nurses in Turkey, participants were found to use diverse sources of knowledge to inform their practice (Altuğ Özsoy & Ardahan, 2008). Whilst 75.9% of the survey respondents stated that nursing practice should be based on research evidence, the main priority was given to information from colleagues, personal

experience and tradition (Altuğ Özsoy & Ardahan 2008, p. 606). Thus, whilst graduate nurses have a positive opinion regarding the use of research to inform practice, similar to our findings, the work of Altuğ Özsoy and Ardahan (2008) suggests that the practice of graduate nurses in Turkey is based mainly on experiential sources of knowledge. So, although in our research, nurses currently studying report using more empirical sources of evidence to support decision making, it is unclear if they will continue in this vein once they have completed their education. Moreover, further research is needed to explore whether using empirical sources results in improved outcomes for the client.

Along with other studies that examine sources of information to guide practice, this study has highlighted the value that nurses give to human engagement to support their decision making. However, contrary to the findings of other studies, the nurses in our study rank the information gathered in relation to and from the client and their family higher than information from other healthcare colleagues.

Influences on the process of making decisions: intuitive or analytical orientation

Predicting the use of various sources of evidence to inform decision making within intellectual disability nursing practice has been shown to be challenging. Nevertheless, our findings confirm a significant relationship between analytical decision making and the use of empirical and experiential based sources of information. In short, the more analytically orientated their attitudes towards decision making, the more nurses reported making use of all types of evidence. This does not appear to be the case for intuitive decision making attitudes, since this did not feature in our data as a predictor of use of sources of knowledge. Thus the nurses who scored higher on the analytical measure used more sources and types of evidence to make decisions in practice. These sources of evidence ranged from using their past experience (experiential) to accessing research papers (empirical) and this is encouraging since Sanderson and Lewis (2012) suggest that engaging in person centred practice necessitates the use of diverse sources of evidence.

Hence, it follows that intuitive practice alone does not enable the participation of the service user in the decision, and thus has no place in the person centred, shared decision making model of practice that is advocated today (NMC, 2010). Lamond and Thompson (2000), in their discussion paper on the intuitive and analytical basis of decision making, also highlighted the difficulties with including others in decisions that are based on intuition. They concluded that intuitive knowledge is invisible to others, hence the process of decision making is problematic to examine and narrate. Furthermore, due to the lack of clarity about how intuitive decisions are made, Lamond and Thompson (2000) had concerns that an intuitive approach may result in different outcomes for patients.

In an attempt to standardise care, nursing has tried to frame clinical problems into pathways so that step by step guides can be followed to deliver best practice. Due to the individualised nature of nursing individuals with an intellectual disability it is problematic to conceptualise individuals as clinical problems; and pathways may not complement the person centred approach currently promoted in intellectual disability services. However, in the context of the limited intellectual disability nursing research available (Grifiths et al., 2007; Northway et al., 2006b) further debate is needed regarding the use of such pathways to inform intellectual disability nursing practice and identify where in such pathways the voice of the service user is heard.

Conclusion

In the field of intellectual disability nursing, research examining clinical decision making amongst practitioners is sparse, with the emphasis instead on the decision making capabilities of service users (Hickson et al., 1998; Hickson & Khemka, 1999) where proxy healthcare decisions are explored. This study has given a clear indication that the client and family are important sources of evidence for nurses when making decisions about care delivery. The nature of this evidence and how it is used for the benefit of clients should be further researched and the client's voice should be heard in this debate. Nurses working within in intellectual disability services should celebrate their flexibility and ability to critically think and

work with diverse clients to problem solve and improve health outcomes. Each type and source of evidence has its own role in making evidence based practice a reality in nursing and nurses should strive to incorporate a range of empirical and experiential evidence across the intuitive analytical continuum to inform practice. This study has provided a broad perspective on decision making in intellectual disability nursing practice and therefore it offers a foundation for further in-depth research to explore the process of person centred decision making from the perspective of service users and other members of the interprofessional workforce. In this context, the findings contribute to the small but growing evidence base on decision making in intellectual disability nursing practice.

Reflexive summary

Process issues

Given that, the total population of NHS nurses within intellectual disability services in Wales is 465, this offered a manageable target sample. The survey contained two measures and a section designed to gather demographic details of the sample. In the first measure, participants identified the types and sources of evidence used to make decisions (measure developed from the findings of the first study). Building on this information to explore the cognitive processes at work, the second measure was an adapted version of Lauri and Salanterä's (2002) instrument that identifies, either intuitively or analytically, how nurses make decisions in practice across a range of situations, from assessment to the evaluation of care. Permission was granted by Lauri and Salanterä (see Appendix I) to adapt the measure to the context of intellectual disability nursing and to produce the questionnaire bilingually (Welsh / English).

The process of searching for a valid measure to include in the survey which would complement the measure developed from the first study was difficult. There was no specific measure that considered the unique nursing role when working with individuals with intellectual disability. The target group for most measures were adult nurses who worked in mainstream acute care settings. Following several avenues of investigation, I finally contacted Salanterä who, on discussion with Lauri, were happy for me to adapt and use their measure discussed in their 2002 paper (Lauri & Salanterä, 2002). An English language copy of the measure was received, however from their papers it is assumed that the measure was originally developed in Finish. From reading through the questions, the language and terminology were, at times, cumbersome and difficult to relate to intellectual disability nursing practice in Wales. The process of adapting and negotiating the terminology was carefully structured, but time consuming. Such questions as: "I confirm my first impressions by seeking for clear symptoms that support those impressions" was adapted to: "I confirm my first impressions by seeking for clear indicators that support those impressions"; and "In providing guidance to the patient I mainly rely on package instructions that are suited to solving this patient's nursing problems" was adapted to "In providing guidance to the client I mainly rely on

clinical guidelines / care pathways that are suited to solving this client's nursing needs". This process required the input from terminologists, intellectual disability nurses and academic supervisors in order to adapt the measure. Finally, in order to disseminated the measure across Wales a process of translation was undertaken.

Within this quantitative study and similar to the first study, my *insider* status facilitated the research process. As a member of the All Wales Senior Nurse Advisory Group (Learning Disability) I was supported and encouraged to conduct an all Wales survey. The members had a vested interest in also getting demographic information of their nursing workforce across Wales and an interest in the evidence that nurses use to support their clinical practice. Thus, with the process of recruitment promoted and endorsed by the All Wales Senior Nurse Advisory Group (Learning Disability), the profile of the research and the dissemination of the questionnaire within intellectual disability nursing services in Wales was relatively straightforward. All the questionnaires were coded however, some questionnaires were returned with personal notes and constructive criticism about the application of the measures to intellectual disability nursing, and thus, the respondent chose to identify themselves. Adopting the Dillman's Total Design Method (1978) along with my insider status resulted in an excellent response rate of 61%.

As this was my first attempt at statistical analysis the process was a steep learning curve. No SPSS course can envisage the data you collect, thus academic / statistical supervision was essential. With little guidance given in Lauri and Salanterä's (2002) paper on the process of data analysis for their particular measure, the work became difficult and, at times, frustrating because of my lack of knowledge and understanding of the process. Using the SPSS software is one step; yet, understanding the consequence of running some of the analysis using the package required a greater understanding of the statistical enquiry. The process of statistical analysis produced masses of null and unfruitful analyses. However, the volume of work generated to get to the published findings is rarely addressed in published literature. This thesis offers Appendix Q: "Examples of statistical analysis undertaken" as a snapshot of this process.

Contribution to knowledge

On a personal note, learning to be a researcher and engaging with quantitative methods of data collection was not easy. Although the SPSS software makes life easy to input data there is no substitute for understanding the purpose and process of the statistical analysis. Having completed this study, I remain a novice quantitative researcher who endeavours to overcome her fear of numbers.

Using the data gathered from the first study, this second study adopted an all Wales approach to explore the types and sources of evidence nurses use to support their decisions in practice, further considering the influences of an intuitive and analytical orientation to decision making. From this study, it is evident that nurses use a range of empirical and experiential evidence to inform practice and that decisions are dynamic and can be identified along a intuitive analytical continuum. This survey succeeded to explore decision making within the current NHS nursing workforce that works with individuals with intellectual disability in Wales. The opinions of nurses working with people with intellectual disabilities outside the NHS were not addressed in this thesis in either study 1 or 2. Recruitment of non-NHS nurses seemed problematic as each individual employer would have to be identified and many registered nurses may be in posts that do not identify them as nurses. However, with the launch of the "Strengthening the Commitment" report (Department of Health et al., 2012) there is commitment to engage with the independent sector that provides services for individuals with intellectual disability whereby representatives from across the UK are invited to become members of the steering groups in each of the UK's four countries. Future access to independent sector service might therefore be easier for researchers in the future.

Within these first two studies, the service user's voice has remained silent. As an intellectual disability nurse, I recognise the value of person centred practice and inclusion and now felt as a researcher that there was also a requirement for my research to be person centred. Including the perspective of the service user was something I had voiced from the initial proposal for this PhD study, thus the final study strived to address that gap and sought the service users' perspective.

Chapter 6 – Study 3, Individuals' accounts of their relationship with intellectual disability nurses and other healthcare professionals. A Foucauldian discourse analysis

Author contributions

RWW was responsible for the study conception, design and data collection. RWW performed the data analysis supervised by JH who provided expertise in FDA. RWW was responsible for drafting the chapter. JH, RH, FI and GWR supervised the study and made critical revisions to the chapter for important intellectual content.

Reflexive preface

Researcher's role

In line with the inclusive nature of decision making by intellectual disability nurses, as highlighted in Study 1 (Chapter 4) and Study 2 (Chapter 5), Study 3 sought the views of service users. Research in intellectual disability is swamped with accounts from the perspectives of professionals, where individuals with intellectual disability are professionally *known* in relation to their disability (Klotz, 2004). This chapter contributes to the small but growing area of service users' accounts of their experiences when accessing healthcare services. As a fundamental aspect of this work, developing a relationship with the service users was essential as this enabled me to gain an insight into how they perceived the services they accessed. This approach called for full commitment and patience at each stage of the research process, including gaining ethical approval for recruitment, consent, interviewing and conducting a bespoke exit strategy. As such, it was emotionally demanding and time consuming, but a worthwhile and rewarding experience for me as a novice researcher.

I have worked in various roles with people with intellectual disabilities since the age of 16, and since working within higher education, the daily face-to-face contact with individuals is what I miss most. Therefore, I felt a personal commitment towards this study to succeed and re-engage with individuals. Initially, within higher education my professional engagement with service users and their families was on an ad hoc basis; consulting with groups on curriculum design and delivery, joint teaching and meeting individuals while supporting students on placement. This study gave me a chance to be structured in the planning of my involvement and have the time to listen to individuals' stories. Although I have experience as a nurse of working with individuals with intellectual disability, this was my first experience of working in the role of researcher. The boundaries between these roles were at times unclear for me and the participants, as some identified me as a community nurse from twenty years ago. This following chapter presents the service user perspective. My gratitude goes to those individuals who gave their time to tell me their stories and, consequently, helped me to develop my

research skills and knowledge that opened the door to my interest in inclusive research.

Abstract

Background. Individuals with intellectual disability have high levels of unmet health needs, and their views about health service provision are often not sought. In the UK, intellectual disability nurses are involved in caring for individuals with intellectual disability in ways that should promote participation in decisions that influence health outcomes. However, little is known about how individuals with intellectual disability interpret this function.

Objectives. This study explores how individuals with intellectual disability perceive the role of intellectual disability nurses.

Design Foucault's concepts of dividing practice, scientific classification and subjectification were used to guide the analysis of qualitative interviews.

Setting. Participants were receiving community based intellectual disability nursing services in a predominately Welsh speaking area of Wales, UK.

Participants. Participants were seven individuals with intellectual disability (n=3 male, n=4 female) aged between 25 and 67 years.

Method Data were generated through semi-structured interviews that were transcribed verbatim. The analysis, influenced by Foucault's work, followed a pragmatic discourse analytical approach.

Results Two discursive themes emerged from the analysis: (1) Inclusion: empowering and supportive healthcare practice; and, (2) Exclusion: challenges and practices that resist healthcare involvement. These discourses provide insight into service users' perceptions, aspirations and relationships with healthcare services and healthcare professionals. Intellectual disability nurses are positioned as enabling access to mainstream health services; however, such nurse-led practices can paradoxically reinforce models of service delivery that position individuals with intellectual disability as passive recipients of healthcare.

Conclusion This study highlights the importance of listening to service users' perspectives and acknowledges that their unique contribution has meaning and significance to professionals.

Keywords: intellectual disability nursing; discourse analysis; Foucault; service user perspective, power

What is already known about the topic?

- Intellectual disability nurses play a central role in the lives of people with intellectual disabilities in the UK.
- Establishing service user perspectives in the development and delivery of healthcare is regarded as a priority in the UK.
- Individuals with intellectual disabilities have high levels of unmet health needs which are often overlooked, particularly when accessing mainstream services.

What this paper adds
- People with intellectual disability are willing participants in research and their voice has meaning and significance.
- Contrary to expectations, disciplinary power can be used by intellectual disability nurses in positive ways to enhance client access to services.
- Surveillance can be used in a constructive way to support the needs of people with intellectual disabilities.

Background

Intellectual disability is the term used to describe a range of conditions associated with limitations in cognitive and social functioning that are evident in individuals before they are aged 18 years (Department of Health, 2001a; World Health Organization, 2001; American Association on Intellectual and Developmental Disabilities, 2010). In the UK, the rights and perspectives of individuals with intellectual disability have been recognised as pivotal in decision making within healthcare practice as evident in: i) policy documents (e.g. Same As You (Scottish Executive, 2000); Valuing People Now (Department of Health, 2009a); Equal Lives (Department of Health Social Service and Public Safety, 2005) and Statement on Policy and Practice for Adults with a Learning Disability (Welsh Assembly Government, 2007), ii) legislation (e.g. Mental Capacity Act 2005; Equality Act 2010), and iii) nurse education (Nursing and Midwifery Council (NMC), 2010). However, the inequalities in health experienced by individuals with intellectual disability are on the increase (Emerson et al., 2011; Mencap, 2012), and recent reports have highlighted how some individuals with intellectual disability receive poor care that lacks respect and dignity (see Mencap, 2007, 2012; Parliamentary and Health Service Ombudsman, 2009).

In 2007, Mencap reported on the discriminatory practices that influenced the mainstream healthcare received by six individuals with intellectual disability who died in UK hospitals. The report highlighted that health professionals placed little value on the quality of life of these individuals, and many discriminatory care decisions were based on negative beliefs and judgments about quality of life rather than on evidence based practices (Blair, 2011). Mencap (2007) recommended that healthcare services needed to address such inequalities, that health staff needed to receive appropriate training, and that people with intellectual disability (and their families or carers) needed to be involved in healthcare decisions. The *Independent Inquiry into the Access to Healthcare for People with Learning Disability* (Michael, 2008) that followed Mencap's report highlighted that the "health needs, communication problems, and cognitive impairment characteristic of learning *(intellectual)* disability in particular [were] poorly understood" (Michael, 2008, p. 7). Moreover, many people with intellectual disability were experiencing significant

levels of avoidable discrimination, abuse and neglect. A recent updated report by Mencap (2012) identifies an increasing number of people with intellectual disability who have died unnecessarily because of the lack of knowledge that health professionals have about intellectual disability; it also highlights that a pervasive lack of value continues to be placed on the lives of individuals with intellectual disability.

In the UK, community based services for people with intellectual disability have developed alongside the drive for deinstitutionalisation, with community teams evolving in the 1970s as a result of policy that recognised the rights of people with intellectual disability. Policy documents such as *Better Services for the Mental Handicapped* (Department of Health and Social Security (DHSS), 1971) clearly demonstrated the governmental commitment to support ordinary patterns of life for people with intellectual disability, and this has been referred to as community care. Such changes in service provision for people with intellectual disability have been mirrored internationally, with a reduction over recent years in institutional beds in the USA (Taylor, 2001), Australia (Young et al., 2001), and Canada (Lemay, 2009). More recently, the UK Government has shown commitment to giving people with intellectual disability more input into the decisions that affect their lives, and there are planned and ongoing improvements in the standard and quality of care for people with intellectual disability (e.g., through the development of a Public Health Observatory; and the Department of Health's 'Confidential inquiry into the premature deaths of people with intellectual disabilities'). Although there is commitment to eliciting the perspectives that individuals with intellectual disability have about healthcare provision, there appears to be a paucity of published research exploring such views. This paper presents the findings of a qualitative study focussing on the views of individuals receiving a nursing service from an intellectual disability nurse employed within community specialist (as opposed to mainstream) health services for adults with intellectual disability in Wales, UK.

The Department of Health (2007a) in the UK states that intellectual disability nursing

"…is a person-centred profession with the primary aim of supporting the well-being and social inclusion of people with intellectual disabilities through improving or maintaining physical and mental health" (p. 10).

Adoption of a value based approach is advocated whereby the individual with intellectual disability is at the centre of decision making (Sanderson and Lewis, 2012) and treated as an equal partner within the therapeutic relationship. Although there is growing evidence to support the work of the intellectual disability nurse (RCN, 2011; Sheerin, 2011), with only a few studies in the UK (Richardson, 2000; Manthrope et al., 2003; Llewellyn & Northway, 2008; Gates, 2011b) explore how individuals with intellectual disability perceive their relationship with intellectual disability nurses. Gates (2011b) used a focus group interview with 23 adults with intellectual disability and 16 parents. The findings indicated how intellectual disability nurses were valued and that individuals with intellectual disability wanted to be supported by "the right kind of person" (Gates, 2011b, p. 18) that "they knew that they could trust" (Gates, 2011b, p. 18). Manthrope et al., (2003) also used focus groups to explore the views of individuals with intellectual disability and carers (i.e. family member or relatives). Eight focus groups were conducted: three focus groups consisted of people with intellectual disability; another group was made up of seven family members and two people with intellectual disability; and a further four groups consisted of family members, mainly parents of people with intellectual disability. Carers viewed intellectual disability nurses as coordinators or fixers who were able to identify and gain access to services. Individuals with intellectual disability tended to focus on the activities that they did with the intellectual disability nurse (such as, going to watch a football match). A limitation of these two studies is that the presented findings predominately focus on carers' accounts as opposed to those of the individuals with intellectual disability.

In the present study, we used a discourse analysis approach informed by Foucault's work (1973; 1980; 1994a) to explore how individuals with intellectual disability perceive the role of intellectual disability nurses. Foucault was interested in the ways that individuals subjugated themselves to inherent forms of power.

Moreover, rather than being treated as equal partners within therapeutic relationships, Foucault proposed that professionals (or experts) exercised and enforced power through 'surveillance and subsequent objectification of the body' (Armstrong, 1994, p. 23). Foucault (1994a) suggested that individuals adopt *subject* positions (either passively or actively) via three 'modes of objectification':

- dividing practice –the notion that some individuals are perceived as different from the majority in society, and the consequence of such practice (e.g. exclusion);

- scientific classification – whereby expert knowledge is constructed and influences how individuals are perceived as objects of investigation (e.g. through diagnosis);

- subjectification – the active process by which individuals identify or submit themselves as subjects (i.e. by being guided by, and internalising, cultural norms).

Modes of objectification relate to how individuals become the subject of the power of the discourses by which they are defined (Lock & Strong, 2010). These three modes function independently and collectively within a range of social relations that position individuals as *objects of knowledge* (McCloskey & van den Hoonaard, 2007). In other words, individuals construct, and are constructed, by the discourses that are available to them. Discourses are viewed as representations of thoughts and experiences, and are constructed culturally and historically through relationships; moreover, they are constituted, constructed and transformed by language (Foucault, 1994a). Power is transmitted in discourse, and this positions individuals in relation to others. Moreover, power creates knowledge (Burr, 2003); and the creation and dissemination of knowledge (along with associated language) is one way of exercising power by groups (which Foucault referred to as *disciplinary regime*s – e.g. medicine).

In Foucault's (1973) early work, healthcare institutions were portrayed as organizations where individuals were seen as objects rather than as co-constructing individuals. This view has resonance with the history of institutions for individuals with intellectual disability (Atkinson et al., 1997; Mitchell, 2003), whereby

regime-based care was harsh (Ryan & Thomas, 1995) and predominately focussed on meeting the physical needs of individuals (Howe Report, 1969). Indeed, Goffman (1961) highlighted how everyday activities in such institutions required the nurse's permission; and such regimes were often justified as being in the service user's best interests (Lau et al., 2007). Foucault (1977) suggested that institutional care was based on social discourses and the clinical gaze (Foucault, 1973), whereby the gaze related to a mode of observation or surveillance described as 'the process of exercising disciplinary power' (Davies & Allen, 2007, p. 366). Such practices (or norms) are internalised (and referred to by Foucault (1994b) as 'technologies of the self').

The notion of power from a Foucauldian perspective still has significance within today's healthcare practice, although it is underexplored in intellectual disability research. This study offers a unique opportunity to explore how people with intellectual disability perceive healthcare services and whether power differentials within their relationship with intellectual disability nurses influence service users' decision making.

Aim of study

The research presented in this paper aimed to explore intellectual disability service users' views of their relationship with healthcare professionals and the health service. The aim was to explore:

- how individuals with intellectual disability perceived their relationship with intellectual disability nurses and other healthcare professionals, and
- how empowered individuals with intellectual disability were in making decisions when accessing mainstream healthcare.

Method

Participants

A purposive sample of seven individuals who were receiving, or who had recently received, a service from a community intellectual disability nursing service in Wales were recruited to the study (Table 6.1). To gain ethical approval for the research, we were required to address specific issues that prevented us from approaching potential participants directly (summarised in Table 6.2) (see Appendix R, for letters of ethical approval; see Chapter 7 for further discussion). Participant recruitment was therefore facilitated with the involvement of community intellectual disability nursing teams across three predominately Welsh speaking localities within one health board in Wales. The first author (RWW) presented information about the study to the intellectual disability nurses at a scheduled monthly meeting where they were asked to consider disseminating information about the study to service users who had current or recent experience of receiving a nursing service from an intellectual disability nurse (see Table 6.3) (see Appendix S., for community intellectual disability nurse invitation and follow up letter). Five intellectual disability nurses identified seven possible participants, who were then contacted by telephone by RWW to arrange a convenient time and location to provide verbal and written information about the study (see Appendix T., for Initial assessment of capacity to consent conducted by intellectual disability nurses in order to identify possible participants; Appendix U., Service user: invitation letter; Appendix V., Service user: Information about the study). The potential participants were given up to 2 weeks to consider whether they wanted to participate in the study. All seven participants indicated that they wished to participate, and an assessment by RWW of capacity to consent to participate in the research study was then conducted (see Appendix W., Assessment of capacity to consent). All participants were deemed as being capable of providing consent, and subsequently agreed to take part in the study (see Appendix X., Consent form).

Table 6.1 Participants details

Pseudonym	Gender	Age	Language of interview	Community profile informed by relationship circle diagram	Service users perspective	
					Length of relationship with ID nurse service	Reason for receiving an ID nurse service
John	Male	44yrs	Welsh	Married, sheltered employment, 10 siblings.	Could not remember	Talking which helps him feel better. Checks medication
Rebecca	Female	31-35yrs	English	Shares a house run by a private organisation that offers day time support, supportive family network, active leisure and social life.	Has accessed the service for some time, and could describe three distinct episodes of care, although only knew the recent ID nurse for a few months	Helped her access social activities, using public transport. Helped her understand the importance of sexual health and wellbeing
David	Male	36	Welsh	Lives independently with overnight sleeping-in carers, supportive family network, sheltered employment that are also his network of friends	For about 18 years, but not sure, although could name all the nurses that he had contact with.	Epilepsy

Alex	Male	65	Bilingual	Retired Supportive siblings, lost contact with most friends from previous sheltered employment	Not sure, only recently met his new ID nurse.	Checks blood pressure, medication, accompanies him to doctor's appointments and explains what is said by writing information down for him.
Hannah	Female	36	Welsh	Supportive family network, married with one child.	About 10 years.	Epilepsy
Lisa	Female (carer present)	67	Welsh	Retired Minimal family contact, birthday and Christmas, social network revolves around carers in 24hr supported accommodation, used to attend social groups before present ill-health.	Received a service since she had lived in supporting housing (about 18yrs).	Nurse always ask how she is feeling, checks her blood pressure and weight. She then usually has to write notes.
Sue	Female	25	Bilingual	Supportive family network, longs for friends from school, currently attends drama and sheltered workshop 2 days per week.	Could not remember.	Physical care of PEG tube and accompanies to see the doctor.

Table 6.2 Process of recruitment and consent

Stage 1   Study outline presented to community based intellectual disability nurses. Intellectual disability nurses invited to assist with recruitment of potential participants.

Stage 2   Intellectual disability nurse approached and conducted an initial assessment of capacity to consent of individuals who are known to them or on their caseload that also meet the inclusion criteria for this study.

Stage 3   Easy read information sheet was given and explained to the potential participant, allowing between 3 to 14 days for the individuals to consider the information.

Stage 4   A protocol based on the work of Arscott et al., (1998) was used to assess the service user's capacity to consent.

Stage 5   The researcher re-read the information sheet, and asked for the participant's verbal and or written consent witnessed by both the researcher and a regular carer. Consent to audio record the interview was also sought.

Table 6.3 Study inclusion criteria

Adults who:

— have the ability to consent to participate in this study

— are currently receiving an intellectual disability nursing service or have received an intellectual disability nursing service within the last 12 months

— have received an intellectual disability nursing service for a minimum period of 2 months with a minimum of 4 contact visits from an intellectual disability nurse

— are not currently receiving treatment/intervention for mental health difficulties and or challenging behaviour

— are willing to communicate their views and experience of the intellectual disability nursing service

— are available to engage in three meetings with the researcher

— have a medical diagnosis of intellectual disability

Data collection

Once consent was gained, a face to face interview was conducted at a mutually convenient time and place. Only one participant requested that a carer be present, at which point it was made clear that the carer was welcome to attend the interview in a supportive role but would not be part of the data collecting interview. The interview schedule consisted of four areas of questioning (see Table 6.4) aimed at eliciting participants' views of their relationship with intellectual disability nurses. The schedule was informed and developed from the findings of the authors' previous research exploring nurses' perspectives of decision making (Williams et al., 2010).

The semi-structured interviews were conducted by RWW who has over 20 years experience of working with individuals with an intellectual disability. The following augmentative and alternative communication resources were used to assist the development of rapport within the interview:

– At the start of the interview, a warm-up activity was conducted whereby participants completed a *relationship circle* drawing (Sanderson and Lewis, 2012). This enabled the participants to identify who was important in their lives, and provided demographic information relating to their connections and relationships with family members, friends, carers, health professionals and their community (see Figure 6.1). The location of the nurse on the relationship circle was used as a reference point for commencing the research interview.

– The researcher's questioning style was tailored to the needs of participants. For instance, double negative or layered complex questions were avoided and the interview started with warm up questions and ended with wind down questions (see Hawkins et al., 2005; Philpin et al., 2005). The researcher also used open, but non-leading, prompts to enable participants to elaborate upon their accounts.

– O*bjects of reference* were used, that is, participants were encouraged to use objects to convey meaning and associations. For instance, one participant used a pen and paper and scribbled frantically across the paper to demonstrate how nursing notes were written.

Figure 6.1 Example of relationship circle
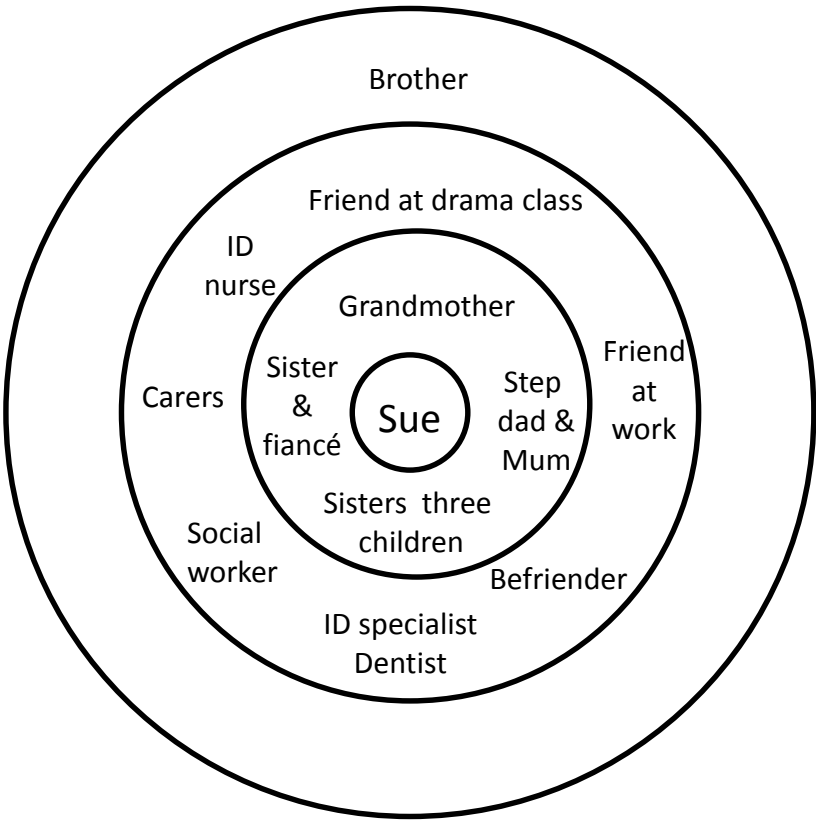
These approaches enabled questions to be expressed in ways that individuals could understand, and facilitated how participants responded. Participants were also interviewed in their preferred language: four interviews were conducted in Welsh, one in English, and two participants used Welsh and English interchangeably. Six participants gave their consent for the interviews to be audio recorded. One participant did not consent to audio recording, so extensive field-notes were taken during the interview; this was followed immediately by an audio recording of a reflective account of the interview by the researcher.

Table 6.4 Interview schedule

Part 1	Description of the intellectual disability nursing service. E.g. What do the nurses do when they come and visit you? What do you talk about with your nurse?
Part 2	Understanding of the health support role of the community intellectual disability nursing service. E.g. Has your nurse helped you to make any decisions about your health? What helps you make a decision or choice?
Part 3	Understanding of the specific role of intellectual disability nursing. E.g. What do you think community intellectual disability nurses do in their day to day job? How would you describe to someone else what they do?
Part 4	Understanding of the factors that contribute to a successful relationship with a community intellectual disability nurse. E.g. What do you think community intellectual disability nurses are good at? What do you think community intellectual disability nurses are not so good at?

Data analysis

The analysis began with transcribing verbatim the audio recorded interviews and the researcher's field notes. As fluent Welsh / English bilinguals, the lead researcher and three of the co-authors were competent in navigating between the two languages, and data analysis was thus conducted in the language of the interview – this approach concords with evidence that this practice enhances analytical rigour (Irvine et al., 2008).

A Foucauldian perspective was used to explore the language and discourses used by participants to depict their relationship with intellectual disability nurses and other healthcare professionals. Foucault did not prescribe a discrete method of analysis (Hook, 2001) but authors such as Parker (1992) and Willig (2008) offer guidance to aid analysis. In the present study, Foucault's three modes of objectification (i.e. *dividing practice*, *scientific classification* and *subjectification*) were used to frame the analysis (Table 6.5). These modes have resonance with intellectual disability practice: The history of services for individuals with intellectual disability is littered with examples of *dividing practice*, whereby individuals with intellectual disability have been segregated from their communities and have resided in long stay hospitals. Intellectual disability is also a field of scientific study, thus a s*cientific classification* of individuals may be evident. For instance individuals can be examined, observed, diagnosed, and prescribed therapeutic interventions by *experts* who demonstrate expert knowledge. The third mode of objectification is *subjectification* suggesting that individuals identify themselves with the discourse of intellectual disability.

Table 6.5 Framework to guide the analysis of the interview data

Foucault modes of objectification	Issues to explore
Dividing practice	Are there discourses that indicate: − service user / nurse relationship − dividing practices within a broader context of governmentality (Governmentality -"The ensemble formed by the institutions, procedures, analyses, and reflections, the calculations and tactics that allow the exercise of this very specific albeit complex form of power which has as its target population, as its principle form of knowledge political economy, and as its essential technical means apparatuses of security" (Foucault, 1994a, p. 219-220) − Nurse training and knowledge of intellectual disability − Disability as a concept produced as a result of the relationship with the service − Labelling - 'difference' and the implications for stigma and stereotyping
Scientific classification	Are there discourses that indicate : − Medical model of intellectual disability − How service user see nurses as "helping", interpretation of need and treatment − Perception of expert knowledge − Construction of expert knowledge and for whom − Interests served by knowledge − Existing discourses
Subjectification	Are there discourses that indicate: − Service users' depiction of themselves 'the observation' − Empowerment and autonomy

Coyle (2007) suggests that within research, participants' discourses cannot occur in isolation, and the perspective of the researcher should be identified and clarified. Factors such as the lead researcher's background as an intellectual disability nurse, the research team's familiarity with the existing area of research, and their personal value bases and knowledge of issues relating to disability all influenced the analysis and interpretation of the data. Nixon and Power (2007) suggest that 'there is little agreement about suggestions for achieving rigour in discourse analysis' (p. 75). However, to ensure transparency, RWW maintained an audit trail of the research process and engaged in the process of supervision with the co-authors; their perspectives and experiences also contributed to the emergent findings. Reflexivity was also central to the analysis (Walton, 2007) and RWW maintained a reflective account that considered the factors influencing these findings. It was also acknowledged that participants' accounts were valid accounts of their experiences (Davies & Allen, 2007) (see Appendix Y., for example of data analysis).

Findings

Although the interview schedule contained questions that focused on participants' views of intellectual disability nurses, their accounts also contained references to their experiences with other healthcare professionals. It was evident that individuals were not necessarily aware of why intellectual disability nurses were involved in their lives. This suggests the existence of an apparently *invisible* mode of observation that can be viewed as creating and maintaining power relationships; Foucault (1991) refers to this as a practice that is 'disindividualised' (p. 202). However, the participants' relationship circles located health professionals, and in particular intellectual disability nurses, in their closest or second closest circles. These two circles are viewed respectively as the Circle of Intimacy, and the Circle of Friendship (Falvey et al., 1994). The Circle of Intimacy generally contains reference to those people who are viewed as *anchor*s; typically, they will be members of close family. The Circle of Friendship generally contains reference to people who are viewed as *allies*; generally, they are close relatives and friends who are confidants. This may suggest that participants perceive

intellectual disability nurses as friends. The relationship circles set the context of our findings, whereby generally, the participants viewed intellectual disability nurses as important in their lives. Influenced by the three modes of objectification to guide the analysis (see Table 6.5), two discursive themes emerged that illustrated participants' experiences of receiving healthcare:

- Inclusion: Empowering and supportive healthcare practices; and
- Exclusion: Challenges and practices that reduce healthcare involvement.

These two discursive themes identify how participants described the healthcare services they received as inclusive or exclusionary (although these are not mutually exclusive). Inclusive practices related to the supportive role of the intellectual disability nurse in their healthcare, whilst exclusionary practices related to issues concerning reduced access and use of mainstream healthcare services. These discourses are made up of numerous constructs that are represented across the data. The analysis also provides insight into participants' perceptions, aspirations and relationships with healthcare services. Although many of the extracts detailed here were originally spoken and analysed in Welsh, they have been translated into English.

Inclusion: empowering and supportive healthcare practice

Across all transcripts, a discourse emerged that identified how participants were enabled to access mainstream healthcare services with the support of the intellectual disability nurse. For example, John described travelling to attend an out-patient's appointment at a general hospital. The intellectual disability nurse had arranged to meet John at the hospital and John had to ring the intellectual disability nurse when he was on the bus to notify her that he was on his way. This practice might suggest a level of surveillance, whereby the intellectual disability nurse adopts the role of gatekeeper; indeed, from a Foucauldian perspective, this kind of 'medical gaze' can be perceived as a form of social control (Davies & Allen, 2007). However, if this practice forms part of a person's personal plan of care, then this is an example of a practice that is enabling (Royal College of Nursing (RCN), 2011) as the use of public transport promotes greater social inclusion and independence. McConkey and Collins (2010) found that the ability of individuals with intellectual

disability to travel independently outside their homes influenced their success in achieving the goal of social inclusion. The ability to manage our activities, make decisions and choose our community networks may be taken for granted by many (Renblad, 2000). However, it is well documented that individuals with intellectual disability do not have equal access to healthcare (Healthcare Commission, 2005; Disability Rights Commission, 2006; Emerson et al., 2011; Sheerin, 2011), with Northway et al. (2006a) identifying the important contribution that intellectual disability nurses have in promoting better access to health and mainstream services.

Although Foucault describes surveillance as objectifying the individual, the analysis indicates that surveillance can be enabling. For example, John described how the intellectual disability nurse would telephone his GP surgery to organise further prescriptions of his tablets:

'Well if I need new tablets or anything he phones for me' (John)

Taken out of context, this could be seen as being 'paternalistic'; however John stated that as he could not read or write, his access to and engagement with written medication orders could be jeopardised if the intellectual disability nurse did not assist:

'…and I can't read ...nor write ...just show what ...and I tell him yes…' (John)

People with limited cognitive and intellectual ability may not be able or have the skills to navigate healthcare service. Acts of surveillance by the intellectual disability nurse can therefore be viewed as enabling individuals with intellectual disability to concord with treatment plans.

The enabling aspects of surveillance and its effects are further demonstrated in Alex's description of how the intellectual disability nurse helps him to remember appointments and advice by *'writing things down'*. The intellectual disability nurse was perceived as being central in enabling him to effectively understand healthcare advice and in making choices relating to such advice. From a Foucauldian perspective, the intellectual disability nurse's behaviour represents a mode of *scientific classification* whereby the practice of *expert* knowledge (Foucault, 1991)

can be interpreted as a demonstration of disciplinary power. However, rather than being told how to behave by *experts*, it is suggested that intellectual disability nurses engage in practices that facilitate the promotion of autonomy that acknowledge the obstacles that many individuals with intellectual disability face. Indeed, there were a number of accounts relating to the challenges that participants faced in understanding the messages given by mainstream healthcare professionals in relation to their care, and links were made by participants to how intellectual disability nurses helped them to overcome obstacles.

In Foucault's (1984, in Fornet-Batancourt et al., 1987) later work the notion of power can be understood in terms of practices of self, that is, how individuals undertake practices that they consider essential to their health and which promote self care. The discursive theme of inclusion illustrates how service users are encouraged by intellectual disability nurses to take some responsibility for their health.

Exclusion: challenges and or practices that resists healthcare involvement

This discursive theme relates to the challenges and exclusions that individuals with intellectual disability encounter when accessing mainstream services. For instance, Rebecca talked about how she attended the General Practice surgery on her own to ensure that healthcare staff communicated with her as opposed to the person who accompanied her. This adoption of an active role in engaging with healthcare professionals demonstrates the use of personal power. Nevertheless, Rebecca's concerns were for:

'…other clients and service users that are unable to talk or say what they feel, they might need staff, but they (healthcare staff) should try and talk to the clients first' (Rebecca).

Rebecca further stated that:

'Nurses in hospital and practice nurses should learn to treat people with learning disability with respect…they sometimes treat them as children by not talking to them' (Rebecca).

Even though she was able to experience choice and control over access and engagement with healthcare provision, Rebecca positioned other people with intellectual disability as being vulnerable; this vulnerability was linked to how the voices of people with intellectual disability were not always heard.

Participants also encountered practices whereby health professionals expected people with intellectual disability to make communicative adjustments, rather than adjusting their own modes of communications. David did not like the way a medical consultant spoke exclusively to his sister and not with him during a consultation:

> 'I've been there three times this year and there was this bloke I saw there the first time he spoke to my sister and not to me' (David).

Here, David wanted to be an 'active' partner during the consultation, but was excluded. Although the evidence is scarce on the aspirations of intellectual disability clients to take such active roles in decision making in healthcare (Wong et al., 2000), Fisher et al. (2009) suggest that *many* or *most* individuals with intellectual disability could contribute to a dialogue about their health to some degree.

Language and jargon also appeared to create complex barriers that individuals with intellectual disability needed to navigate. For example, David commented that a medical consultant used '*geiriau mawr' (big words)* that impacted on his understanding. Heffernan (2006) suggests that the words that people use when communicating can be weighted in ways that reflect and reinforce authority. Such discourses become normalised and are unchallenged by those who are not in authority; thus language becomes an important means of exercising power (Farquhar & Fitzsimons, 2012). This is further supported in participants' accounts of encountering mainstream healthcare professionals and not understanding what is being said to them, or about them. They relied on intellectual disability nurses to explain to them what was being discussed during such encounters. Arguably, this approach perpetuates a cycle of exclusion: When intellectual disability nurses translate what other healthcare professionals say into an accessible format,

mainstream healthcare professionals do not need to adjust their modes of communicating.

In some circumstances, participants developed their own ways of negotiating around the system to open up channels of communication. For instance, John asked the intellectual disability nurse to *'write down what she says'* because *'I don't understand a word of what they say, what they tell me, they speak too fast'*. Yet, this particular individual could not read, so could not understand what the intellectual disability nurse had written on the piece of paper. It was then necessary for him to ask a support worker to read what had been written. Having engaged in this process, John confessed that he *'doesn't really'* follow the healthcare advice given. Thus, although he could be perceived as exercising power in making this decision, an alternative interpretation may suggest that a lack of directly accessible information hinders the opportunity to make an informed decision.

As detailed earlier, it was also evident from the interviews that participants could be locked in an invisible clinical gaze (Foucault, 1973) whereby they were recipients of healthcare without knowing why that healthcare was required. This is evident in Alex's account of how he needed to take *'water tablets'* because his *'leg went bad'* but now there was *'nothing wrong with me, the doctors have told me that';* yet he still received a weekly visit from an intellectual disability nurse, but could not explain the purpose of such visits. Service users' unconditional acceptance of healthcare provision can create dependency (Lupton, 1997).

Discussion: implications of inclusive and exclusive practice

There were two aims in the present study: to explore how individuals with intellectual disability perceived their relationship with intellectual disability nurses and other healthcare professionals; and, to explore how empowered individuals with intellectual disability were in making decisions when accessing mainstream healthcare. Influenced by Foucault's modes of objectification, the findings offer new perspectives into the experiences that some individuals with intellectual disability have when accessing and receiving healthcare.

In the present study, the location of intellectual disability nurses in the first or second circles on participants' relationship circles suggested that they were perceived as what Falvey et al., (1994) refer to as *anchor*s or *allies* i.e. people who are classified as family or friends. These findings resonate with those of the Manthorpe et al., (2003) focus group study whereby intellectual disability nurses were described in terms of the friendship or companionship type activities that they did together. It is possible that individuals' cognitive abilities might hinder the appreciation of professional boundaries, and the difference between friendship and the therapeutic relationship. Nonetheless, participants in the present study showed limited understanding of aspects of the role of the intellectual disability nurse, other than specifying that intellectual disability nurses also *'see other clients'*. However, this finding resonates with the wider literature that indicates that people do not know what intellectual disability nurses do. The mainstream lay perception of nursing focuses on it as being work that is associated with caring for the sick, engaging in specific tasks such as administrating medication, or monitoring vital signs; difficulties therefore arise when people attempt to reconcile this perception of nursing with intellectual disability nursing (Mitchell, 1998; Kurzt & Wang, 2007).

Although the location of intellectual disability nurses on participants' relationship circles suggested that they were perceived as important, the interview findings also indicated that some participants did not know why the intellectual disability nurse was involved in their lives. This finding is also reflected in Goble's (1999) study where it was shown that individuals with intellectual disability did not know what staff roles were; however, this stemmed from staff assumptions that it would not be possible for individuals with intellectual disability to understand information about their roles. This assumption is disempowering, and from a Foucauldian perspective, suggests the existence of a power relationship that removes the validity of individuals' embodiment because 'expert' knowledge over-rides individuals' lived experiences. To link back to the findings of the present study, it can be suggested that if individuals do not know why they are receiving a service from an intellectual disability nurse, then they are unlikely to be in a position to communicate their needs to intellectual disability nurses. Foucault (1991) claimed that observation (or gaze) by professionals is potentially constant, and individuals who are being observed are not aware of whether they are being

observed or not. Such acts of surveillance by professionals exert power over people to create compliant 'docile' bodies. Although it is not possible to ascertain why the individuals in the present study did not know why they were receiving intellectual disability nurse services, this lack of insight might reflect the position of powerlessness that is afforded to (or by) individuals with intellectual disability.

Irrespective of whether participants knew why intellectual disability nurses were involved in their lives, there was some evidence to suggest that intellectual disability nurses enabled their participation in society, addressed their needs, and facilitated access to healthcare services. If person-centred practices that promote the well-being and social inclusion of individuals with intellectual disability are adopted (Department of Health, 2007a), then it can be suggested that intellectual disability nurse *surveillance* (Foucault, 1991) can be enabling. If such practices are to be enabling, individuals with intellectual disability need to be centrally involved in decisions that relate to person-centred practices – however, it was not possible to ascertain from the interview data and inherent discourses whether this was something that always occurred.

The findings suggest that service users could be excluded from mainstream healthcare dialogues, and this made it impossible for them to contribute to decisions relating to their health. People with intellectual disability have poorer health than people in the general population, but they encounter avoidable inequalities when accessing mainstream health services (Perry et al., 2010; Emerson et al., 2011). Such inequalities in accessing effective health care provision are reflected in the findings of the present study. For example, the accounts suggest that practices of exclusion occur in mainstream health care, whereby individuals with intellectual disability reported that mainstream health practitioners tend to talk to the person accompanying them. Individuals with intellectual disability therefore had limited opportunities to participate equally in consultations. Similar findings have been illuminated in other research. In their focus group study with service-users with intellectual disability, Hoole and Morgan (2011) found that individuals wanted to be involved in decision making; however, they were not listened to, and they felt that they were treated unfairly and in ways that differed to how they perceived people without intellectual disability would be

treated. Likewise, McConkey et al.'s (1999) analysis of videotaped recordings of forty-three staff communicating socially with individuals with intellectual disability indicated that limited opportunities were provided by staff to enhance communication, or to engage as equal partners in exchanges. Moreover, staff failed to adapt their use of language and communication according to individuals' verbal abilities and levels of understanding. Similarly, individuals with mild to moderate intellectual disability were interviewed by Jingree and Finlay (2011) about issues relating to choice and control in their lives. The interviews were analysed using a critical discursive psychology approach, and the findings indicated that people with intellectual disability positioned staff as being controlling; this made it difficult for them to voice their dissatisfactions with service provision. Such practices of exclusion perpetuate the disempowerment of individuals with intellectual disability by limiting or removing the choices and control they have in making health related decisions.

Based on these accounts, it is suggested that:

- intellectual disability nurses incorporate their roles into care delivery (for example, via liaison roles (Department of Health, 2009a) that incorporate the evaluation of the effectiveness of different models of liaison);

- intellectual disability nurses develop more insightful identities with service users and service providers;

- Individuals with intellectual disability and intellectual disability nurses proactively engage with mainstream health services by sharing exemplars of good practices (such as self-advocacy and advocacy) that consider and acknowledge the rights of the person with intellectual disability (Goodley, 2005; Llewellyn & Northway, 2008).

Intellectual disability nursing practice is informed by a value base that promotes person centred practice, autonomy, equality, citizenship and a human rights approach (Department of Health, 2007a). The first step in initiating such practices is 'to understand each person's unique way of getting their message across' (Grove & McIntosh, 2005, p. 2). However, it is apparent from the findings of the present study, and the wider literature, that this does not always occur.

Instead, it appears that in some instances, individuals with intellectual disability are required to show their competence before being given autonomy; this is a practice that contrasts with the norms of social intervention that prevail for individuals without intellectual disability (Simpson, 1999). In the evaluation of an individual planning service for people with intellectual disability, Carnaby (1997) found that individuals who could not articulate their views were often excluded from discussions. Sowney and Barr (2007) found that the lack of effective communication between individuals with intellectual disability and general nurses across five accident and emergency units had a detrimental influence on assessment, communication, and the process of consent. However, there is no doubt that individuals with intellectual disability have the capacity to participate in healthcare decisions (Wong et al., 2000).

Process issues

The use of the Foucauldian approach to analyse individuals' statements does not make assumptions about people's cognitions; therefore, we do not claim that the interpretations that we make here reflect participants' cognitions. The analyses are researcher led, and individuals with intellectual disability were not involved in the analyses of discourse; we cannot therefore claim that our interpretations would match participants' interpretations of how they position themselves within healthcare interactions. This appears to be similar to the general trend in intellectual disability research where studies tend to focus *on* individuals with intellectual disability rather than on *including* them within the process of research as well. We therefore suggest that future research utilises participatory approaches.

Without being able to directly approach individuals with intellectual disability at the start of the research, the process of meeting the community nurses, identifying potential participants, recruiting, and receiving consent was time consuming. Whilst we were also aware of the importance of understanding each participant's preferred method of communication (Ramcharan et al., 2004; Whitehurst, 2007) and preferred type of accessible information (Gilbert, 2004;

Boxall & Ralph, 2009), the nature of the brief research relationship with the participants hindered the primary researcher's (RWW) ability to possibly fully appreciate each participant's unique method of communication in such a short time. However, a range of augmentative and alternative communication resources were used, and rapport was developed with participants. Although the participants in this study had verbal skills that enabled them to share their experiences, we are also mindful of how future research needs to consider how to inclusively involve individuals who have limited communication skills, and to do this, adequate training, time and resourcing need to be accounted for during the study's conception and design.

Using a Foucauldian discourse analysis to interpret the conversations of individuals with intellectual disability was challenging because many of the participants' responses were in single words or short sentences; this required the interviewer to continually use a number of probes to clarify participants' accounts and experiences. Ideally, the interviewer should allow time to engage with the service user prior to the research interview to facilitate a process of learning and negotiation that would result in producing a shared communication environment (Bradshaw, 2001).

Conclusion

The study offers an insight into the relationship service users have with intellectual disability nurses. These discourses provided evidence that suggests that the individuals are unaware of the role of the intellectual disability nurse, although accounts of inclusive intellectual disability nurse practices are provided. Then again, accounts referring to mainstream healthcare practitioners appear to maintain exclusionary practice, for instance, examples of poor communication between the service users and healthcare practitioner are cited. While this was an inclusive study, participatory research is required to explore the impact of intellectual disability nurses role from a service user perspective.

Reflexive summary

Process issues

Gaining ethical approval for this study took time and detailed planning. It seemed at the time that the process hindered my effort in wanting to engage with service users. Ethical approval for the first two studies was straightforward. Discussions regarding the time required to attend the interview within the nurses' working day in Study 1 resulted in giving approval for only twelve participants to be recruited as opposed to the original number. Study 2 gained ethical and governance approval across five health boards with relative ease. This third study raised several questions about capacity to consent, recruitment, and my skills as a researcher to assess capacity and gain consent. Within research, people with intellectual disability are often seen as a vulnerable group where gaining informed consent is problematic; and weighing the risks and benefits of participation is fiercely debated (McDonald & Kidney, 2012). Thus, in view of the need for scrutiny and approval of all research projects, the structured process of gaining consent that was required of this third study involved four stages (see Chapter 7 for discussion).

This study drew on qualitative methods to engage with service users to gain their perspectives on their relationship with healthcare professionals and consider how empowered individuals with intellectual disability were in making decisions. Individual interviews with service users were employed as a method to collect data. This method enabled me to respond to the individual communication needs of each participant. However, verbally articulating their experience posed challenges for the interviewee and interviewer in understanding the service users' experience. Although I used prior knowledge of working with individuals with intellectual disability to aid communication throughout the research process, interpreting the data was difficult. Following the first interview, I realised that using Interpretative Phenomenological Analysis [IPA] (Smith, Osborn 2008) would be difficult with the data gathered. The data offered stark statements in single words and short sentences about the practicalities of being a service user of a community intellectual disability nursing service and of mainstream healthcare services. Thus, exploring in-depth the participants' lived experiences proved difficult. Nevertheless, the data highlighted how participants used language to construct and portray their

relationships with intellectual disability nurses and the healthcare service. Analysis of the discourse enabled me to fully engage with the data and understand the nature and function of the language service users used. Within a *disability discourse,* people with intellectual disability are often placed in the subject position of *service user* where they are consequently perceived as passive recipients of the care (Jahoda et al., 2009). This data highlighted the service user perspective of being both a recipient and driver of care. Influenced by the work of Michel Foucault (1973; 1980; 1994a) in relation to power, the service user perspective was analysed and described in this chapter.

Contribution to knowledge

On a personal level, I have learnt that, no matter how much preparation a research project entails, the participants have their story to tell and it might not have been what the research project had envisaged. I have learnt to be flexible in my approach and willing to change the way I work and consider alternatives to get the best out of the data gathered in an attempt to reflect the nature of what participants had to say.

A Foucauldian approach to the analysis (Foucault, 1973; 1980; 1994a) presented my interpretation of the data gathered, and at times, I felt that by concentrating on the discourse that I missed the experience, further worrying that the participants might not recognise their own data. Such an experience is the impetus now to engage in inclusive research. The words "nothing about us without us" is a value that I will strive to demonstrate within my research, education and practice. Much has been written about the "value base" with which intellectual disability nurses identify (Department of Health et al., 2012). However, I propose that intellectual disability nurses should not fall into this '*values trap'* accepting and being complacent. Nurses must continue to revisit, change and develop their value base in partnership with individuals with intellectual disability and their families and strive to base their practice on the best available evidence.

Further evidence of best practice in relation to the process of ethical approval is required alongside educating members of ethics committee to appreciate the unique contribution of individuals with intellectual disability to

research. With the growing number of inclusive research projects, such as the recent research exploring abuse by the Looking into Abuse Research Team (2013); there appears to be an element of co-producing research proposals for ethics committees to scrutinise thus contributing to the production of knowledge in this important area.

I hope this thesis has demonstrated how a mixed methods approach within a PhD framework can successfully explore decision making within intellectual disability nursing. On a personal and professional level, the expectation is that the knowledge and skills gained during this process will act as a stepping-stone in developing my role as a researcher and likewise as a stepping-stone to further our understanding of decision making in intellectual disability nursing and generate further discussion and research. I hope to have bridged the gap between the researcher and the participant by embracing in a reflexive approach throughout this thesis. Personal and epistemological issues were highlighted to demonstrate transparency within the research process. Although this thesis is not an inclusive research project, I feel it was a partnership in the construction of new knowledge between all the participants and myself. Future projects will build on this experience and contribute to the field of inclusive research within intellectual disability nursing.

The final chapter draws on the findings of the three studies and discusses their contribution our understanding of decision making within intellectual disability nursing.

Chapter 7 – Discussion

Author contributions

RWW was responsible for the conception and design of this Chapter. RH, FI and GWR supervised the work and made critical revisions to the chapter for important intellectual content.

Introduction

The complexities of what evidence informs decision making in intellectual disability nursing is a relatively unchartered course to date, with reviews suggesting that specific intellectual disability nursing research to support practice is limited (Northway et al., 2006; Griffiths et al., 2007). The three empirical studies presented in this thesis have begun to unravel the complexity of decision making from the perspectives of intellectual disability registered nurses (Chapter 4), nurses working within intellectual disability nursing services (Chapter 5) and individuals with an intellectual disability (Chapter 6). This discussion will summarise the findings of the three studies (Chapter 4, 5 & 6); reflect on the use of evidence to inform person centred practice; then highlight the methodological challenges encountered. A new conceptual model is introduced that incorporates the values base of intellectual disability nursing and Standing's modes of practice. The model is explored in relation to facilitating opportunities within practice, education and research. Finally, concluding remarks consider the implications of this research to the intellectual disability nursing agenda.

Summary of findings

First and foremost, the nurses' descriptions of the process of decision making demonstrated an overwhelming commitment to ensuring that individuals with intellectual disability remained central in the decisions that shaped their care (Chapter 4). However, within the in-patient units, much of the decisions also required a team approach, either at an informal or formal level. The sources of evidence used by the nurses to support the process of decision making are identified as mainly experiential rather than empirical evidence; with nurses valuing the contribution of colleagues' opinions. Overall, the participants considered evidence based practice to be associated with the use of research; thus highlighting some of the challenges in translating empirical data into their daily practice.

Concurring with the findings in Chapter 4, measure 1 of the survey also identified that nurses working within intellectual disability nursing services valued the contribution of service users in the process of decision making (Study 2, Chapter 5). The survey, in addition, revealed the important role of information within the process of decision making, such as that gleaned from observation, nursing documentation and talking to clients' families/carers. Indeed, similar to other studies conducted in mainstream healthcare (Thompson et al., 2001; Egerod & Hansen, 2005; Spenceley et al., 2008), the nurses also valued colleagues' input when making decisions in practice. The regression analysis of the data set from measure 2 (*Nurses' approach to decision making)* established that demographic variables did not predict the reported use of experiential or empirical sources of evidence. However, nurses with a high analytical orientation towards decision making reported that they used more empirical and experiential sources of evidence.

Following on from a total population survey of NHS nurses working within intellectual disability nursing services in Wales, the third study represents the important voice of the service user. The data from seven participants enriches the thesis with an alternative perspective of the relationship that service users have with healthcare professionals. The findings of the first two studies highlight the importance of person centred decision making for professionals; however this is not replicated in the service user study. These participants were mostly unaware of the professional role of the intellectual disability nurse and often talked about *their nurse* as a friend. The exercise undertaken in Study 3 whereby service users were invited to co-produce (with the researcher) their relationships circle identified that some service users perceived their relationship with intellectual disability nurses as more similar to a friendship rather than a professional relationship. On reflection, it would also have been useful to ask the nurses to draw their relationship circles and consider where or if the service users are portrayed in their circles. Nevertheless, in the relatively short time the researcher spent with the participants, their discourses of being excluded from healthcare and their examples of how intellectual disability nurses, through surveillance, enabled individuals to access their communities and nursing services were

identified. Although, this was the researchers interpretation of the service users narratives their voices were listened to, thus contributing to our understanding of the service user perspective.

Overall, the findings of the three studies highlight that decision making in intellectual disability nursing is a complex process of engaging with a range of evidence within a person centred approach that may not be fully understood by the service user involved.

Person centred decision making

Person centred planning is not a new phenomenon in the field of intellectual disability, indeed, it was the White paper in England, *Valuing People* (Department of Health, 2001a) that mandated person centred planning. In Wales, the support for person centred planning is clearly stated in the Learning Disability Strategy (Welsh Assembly Government, 2004) where person centred approaches to individual planning are advocated. Therefore, the overwhelming commitment to being person centred articulated by intellectual disability nurses in the findings of Study 1 and 2 is in line with the current thinking (Sanderson & Lewis, 2012), research based evidence (Robertson et al., 2007), policy (Department of Health, 2009; Department of Health, 2001a) guidance, (Department of Health 2001b, Welsh Assembly Government, 2004; Department of Health, 2010a) and reports (National Assembly for Wales, 2001; Dowling et al., 2006).

Underpinning person centre planning are the values of:

- 'independence and rights
- co-production, choice and control
- inclusive and competent communities' (Sanderson & Lewis, 2012, p. 24).

Such values suggest a shift in power from professionals to the person with intellectual disability (NSW Department of Ageing, Disability and Home Care, 2009). Robertson et al. (2007) offer evidence to support the

effectiveness of person centred planning, advocating that the approach increases the degree of choice and control individuals with intellectual disability have in their lives. Thus, professionals agree that person centred planning can make a valuable contribution and have a genuine impact on improving an individual's life (Robertson et al., 2005; Harman & Sanderson 2008; Wigham et al., 2008; Sanderson & Lewis 2012).

If person centred planning has an impact on individuals' lives, it seems reasonable to surmise that those individuals may be able to identify what person centred planning means to them (Robertson et al., 2007). As person centred planning is a term constructed by professionals, unsurprisingly then, the service users in Study 3 did not use the term *person centred* during the interview. However, there was evidence of person centred planning, in that some of the attributes professionals associate with the term were evident in the interview data, such as, the service users' rights to be heard during a consultation with a health professional. The service users' discourses did not convey the same ethos and commitment that professionals voiced in support of person centred planning. The researcher's familiarity with the professional terminology of person centred rather than the service users understanding of the approach might explain this finding. Thus, if person centred planning is a professional based approach, as Pete states 'what is the problem person centred planning is designed to solve?' (2002, p. 21). Ritchie (2002) further debates whether person centred planning is there to challenge the apathy sometimes found in services that maintains a status quo of 'isolation, invisibility and dependence' (p. 21) for individuals with intellectual disability. However, within the studies capturing the nursing perspectives, the participants conveyed commitment to person centeredness.

Indeed, the *Investigation into the service for people with learning disabilities* provided by Sutton and Merton Primary Care Trust, (Healthcare Commission, 2007, now called the Care Commission) provided evidence of poor care and found that:

> '…person-centred plans as described in *Valuing People* (Department of
> Health, 2001a) only existed for a minority of people. Most people did

have a plan of care, but these were not based on the principles of person-centred planning and there was little evidence of regular reviews of care plans' (p. 53).

The investigation suggests that the model of care was based on service provision rather than individual need. From the service users' perspective in Study 3, it is unclear if they perceived themselves as central to healthcare decisions that affected their lives. More so, the discourse identified the service users' struggle to access mainstream healthcare services, further identifying the role of the intellectual disability nurse as supporting their right to a service. Thus, nurses who participated in Study 1 and 2 report some loyalty towards the ethos of person centred planning, although it was not entirely clear what the impact of such an approach was for the participants of Study 3.

Methodological challenges

This thesis demonstrates that research does not have to be entirely qualitative or quantitative in approach. There are advantages for the researcher in engaging in a mixed method approach, especially when investigating a new area of practice. Studies guided by Interpretative Phenomenological Analysis [IPA],(Smith & Osborn, 2008) a survey approach and aspects of Foucauldian Discourse Analysis [FDA] (Foucault, 1980; Foucault, 1991; Foucault, 1994a; Hook, 2001; Willig, 2001; Foucault, 2002; Willig, 2008; Lock & Strong, 2010) were conducted in an attempt to produce a comprehensive account of decision making in nursing within the context of intellectual disability. Whilst the qualitative method of IPA enabled the in-depth exploration of the nurse's experience (Smith & Osborn, 2008), conversely the influence of FDA (Study 3) facilitated the critical examination of text. For instance, in relation to *positioning*, people with intellectual disability are placed in a subject position of *service users* (Coyle, 2007). The quantitative research provided detail on a large scale and enabled some comparisons with other research samples, thus the thesis offers a starting point to debate decision making within intellectual disability nursing.

Nevertheless, despite the contribution this thesis makes to the topic area, limitations exist in relation to the methodological challenges encountered.

Having worked across various roles in intellectual disability nursing and education over the last 20 years, the researcher knew, and was known to, much of the NHS intellectual disability nursing services provided in Wales. Wales is a small nation with a population in 2009 of just under 3 million (Welsh Assembly Government, 2010b). The NHS in Wales provides an intellectual disability nursing service across five health provider organisation, employing approximately 465 registered nurses (information gathered from a Freedom of Information request to the five health boards in Wales, June 2009, see Appendix Z). Thus, this is a small field of nursing that is often described as being on the 'margins of the nursing profession' (Mitchell, 2004; p. 115). However, being associated with such a small community of nurses does have its advantages. Knowledge of the services was invaluable in gaining support for the studies, from service users, nurses and senior management teams. However, such inside knowledge of services also posed challenges.

The term *Hawthorne effect* describes the phenomenon whereby behaviour may change when individuals are aware of being participants of research (Campbell et al., 1995). For instance, in the first study, the researcher had previously worked on some of the in-patient units as a qualified nurse. To minimise any possible *Hawthorne effect* on participants' behaviour, (similar to Considine et al., 2012), this study used a study presentation, information sheet and the consent process to inform participants of the researcher's new role. This was primarily in response to research governance and ethics requirements. Furthermore, the researcher engaged in minimal personal interaction with the participants, adhering to the interview schedule in each interview, which is associated with the researcher rather than practitioner role, thus maintaining professional distance.

In Study 1, one participant provided a contrasting account (see Chapter 4) of decision making compared with the other eleven interviews. The contrasting account presented no evidence of a commitment to person centred planning. Indeed, the participant had never questioned the way she

made decisions before the interview. However, the study's aim was not to seek the truth, but to describe experiences in detail. Thus, although seen as a contrast to the data generated from the majority of participants, it may be that such an opinion has equal preponderance in the general population of intellectual disability nurses in Wales but is merely underrepresented in this data. The individual who portrayed a different aspect of decision making was not known to the researcher whereas she knew most of the other eleven nurses. This might suggest that these participants may have described aspects of their work that they thought the researcher wanted to hear, whereby, the contrasting account illustrated an experience without the need to change behaviour in response to the researcher. In line with the work of Bolster and Manias (2009) there might be discrepancies between what research participants say and do. Hence, a larger sample might give a different perspective, although for IPA (Smith & Osborn, 2008) twelve participants are described as a large sample for the novice researcher.

The postal distribution of the questionnaire in Study 2 was made possible by the co-operation of members of the All Wales Senior Nurse Advisory Group (Learning Disability) following the Dillman's total design method (1978). The researcher initially travelled to each of the health boards with the questionnaires and explained to the administrative staff how the method worked. All questionnaires were coded to enable the researcher to target the non-returned questionnaires (see details of process of dissemination in Appendix N). However, during the data collection period, the researcher received emails from some respondents apologising for not returning the questionnaire within the time allocated, asking for extra copies of the questionnaire and contributing to the *further comments* section (refer to Appendix J. Questionnaire sample). Inevitably, they then identified themselves to the researcher. Because this was a self-completed postal questionnaire, it is difficult to gauge the impact of a *Hawthorne effect* on the data collected. In essence, in such a small community of nurses, confidentiality of the participants' response is essential in the research process.

The likelihood of introducing the *Hawthorne effect* in Study 3 was also considered. The researcher was known to all the community intellectual disability nurses who acted as gate keepers in the recruitment of individuals with an intellectual disability. This facilitated the relationship between the researcher and the nurses and enabled the researcher to disseminate letters and information with ease. Six of the seven participants in Study 3, were not known to the researcher. However, one participant recalled how the researcher used to work as a community nurse *'helping his friend'* some 20 years ago*.* Having a shared story enabled the researcher to build a relationship with the service user, although, at times, during the initial meetings, the service user was more interested in reminiscing about life before his retirement rather than talking about the research. Having adopted a Foucauldian perspective to the analysis of the data in Study 3, it is acknowledged that discourse does not occur in isolation, and that the texts produced during the interviews were a product of the relationship and the questioning approach of the researcher. It is unclear to what extent the researcher had an influence on the service users' contribution.

Conducting the research in Wales was challenging and rewarding. In each of the studies, a clarification of role and boundaries as a researcher was necessary. However, identifying the possibility of the *Hawthorne effect* gave strength to this research, as the researcher could provide an *insider's* view to the research process from conception through analysis to final report. Generalisability was not the intention of this thesis, but to provide an opportunity for initiating and discussing the debate about decision making in intellectual disability nursing. If we accept the view that with knowledge comes power (Foucault, 1980), then the involvement of the nurses and service users in this research has the possibility of increasing their engagement in future research projects.

Conducting research in Wales

Given the bilingual context of Wales and the legislative framework that governs the use of the indigenous Welsh language on an equal status with English in public sector services, the three studies were developed bilingually, in Welsh and English. The provision of research that is linguistically and culturally responsive is paramount to ensure participants fully engage with the research process and to enhance rigour (Welsh Office of Research and Development for Health and Social Care (WORD), 2009). As a bilingual researcher, language choice and sensitivity to participants' language needs were addressed with ease, although this required time and meticulous planning. For all three studies, the supporting documents, such as invitation letters and participant information sheets were developed bilingually. Moreover, all the interviews of both qualitative studies were conducted in the participants' preferred or required language. Indeed, the analysis of the data continued in the language of the participant; only sections of transcripts from both qualitative studies were translated into English for the purpose of publication.

Developing a bilingual questionnaire (Study 2) required a strict methodical approach. The questionnaire was developed in bilingual format with the kind permission of the original authors (see Appendix I). The translation and adaptation process was based on a systematic ten-stage approach outlined by Wild et al. (2005) (see Appendix K). This approach provided a structure for forward translation, back translation and scrutinising the measure for wording, comprehension, interpretation and cultural relevance of both English and Welsh versions. An example of the fifth stage of comparing and resolving issues between the original measure and translated measure is given in Appendix I.

Arguably, such a process is more than translation. It is a process described by Umberto Eco (2004) as a *negotiation between the encyclopaedias of two cultures,* whereby the translation should also be faithful to the original document. That is, the *natural* language is translated to another; this conveys an ethical obligation to respect the original author or the

research participants in this case. The negotiation with original transcripts, translators and terminologists was essential for the success of conducting the research in full bilingual mode.

Published research in the UK rarely details the negotiation of translation within the research process. For example, research studies involving families from ethnic minority groups tend to limit their level of reporting to offering language preference at initial contact, interview and administration of measures (for example: Hatton & Emerson, 2009; Hatton et al., 2010). Alternatively, one of the inclusion criteria for the research may specify that participants must speak the language of the researcher (for example see (Bolster & Manias, 2010) on the basis that "meaning and understanding may have been lost if an interpreter was used" (Brown J. et al. 2009, p. 219). There is little discussion in published research about the merits of analysing the data bilingually; the process of translation usually terminates when transcripts are translated into English. For example, in Hatton et al.'s (2010) research, the original data was in Gujarati, Urdu∕Punjabi, however the process of analysis was in English. Dialogue of the nature and context of translated transcripts is rarely published within nursing research although the research governance framework states:

> "Participants in Wales have the right to choose whether to have research conducted in Welsh or English in line with the requirements of the Welsh Assembly Government's Welsh Language Scheme 2006" (Welsh Office Of Research and Development for Health and Social Care (WORD), 2009, p. 9).

Clearly, the term 'research conducted' does not always identify the importance of being true to the participants' preferred language throughout the research process. Being a bilingual researcher enables the negotiation of working with two languages with relatively ease. Conducting all aspects of this research in the language of the participants enhanced the ability of the researcher to communicate effectively, understand cultural nuances and respond to the participants narratives. This thesis contributes to the debate

and highlights the important aspect of conducting the whole process of research within a bilingual framework in Wales.

The journey from recruitment to interview for individuals with an intellectual disability

The process of consent for participants in Study 1 and 2 was relatively straightforward. In Study 1, the nurses were given a letter of invitation; a participant information sheet; given time to consider their involvement; and signed a consent form which served as evidence of their consent. Study 2 participants were also given a letter of invitation; a participant information sheet; and given time to consider their involvement. However, consent was assumed when the respondent returned a completed questionnaire. In contrast, ensuring that individuals with intellectual disability consented to participate in Study 3 required detailed planning and a procedural guide to gain ethical approval for the study.

Thus, in order to gain ethical approval for Study 3, the process of recruiting and receiving consent to participate in the research occurred in four stages. Assessing the capacity to consent was an individualised process informed by pertinent literature (such as Arscott et al., 1998; Arscott et al., 1999; Moye et al., 2004; Cameron & Murphy, 2007; Dye et al., 2007; Goldsmith et al., 2008; Sowney & Barr, 2007) and advice from public bodies, such as the *Good practice in consent implementation guide: consent to examination or treatment* (Welsh Assembly Government, 2008) and the *Reference guide for consent to examination or treatment* (Welsh Assembly Government, 2010a). This literature recommends good practice when seeking consent guided by legal developments, such as the Mental Capacity Act 2005.

The notion that incapacity is related to having an intellectual disability is rejected in this Act (Hoole & Morgan, 2011). Thus, as with all research participants', individuals with intellectual disability must also consent to participate in any research project. (Department of Health, 2009) states that it

176

is a general, legal and ethical principle that valid consent must be obtained; hence the method for participants in Study 3 was explicit. The following four stages outline the journey from recruitment to interviewing individuals with intellectual disability designed for Study 3.

Stage 1

Information about the study was presented at a regional intellectual disability nurse meeting. Nurses who worked in community teams were invited to stay at the end of their meeting for a presentation of the study's aims and objectives. Similarly, other researchers have used established contacts as gate keepers to recruiting individuals with intellectual disability. For instance, (Hamilton & Atkinson, 2009) used known contacts of The National Institute for Intellectual Disability, Trinity College Dublin; Brown J.et al (2009) recruited through the NHS Trust, and Hoole and Morgan (2011) recruited from an established advocacy group.

In Study 3, the nurses were asked to facilitate a contact with one or more of their service users known to them or on their caseload that also met the inclusion criteria (see Chapter 6, Table 6.3). The intellectual disability nurses were asked to use their professional knowledge and skills to complete an *initial assessment of capacity to consent* (see Appendix T) of individuals who were interested in taking part in the study. If the intellectual disability nurse believed that the service user was likely to be able to consent to this specific study and was interested in the research, the nurse then facilitated a meeting between the service user and researcher at a mutually convenient time and place. An advocate, carer or family member could be present if the service user preferred.

Stage 2

During the initial meeting, information about the study was given to the service user verbally, supported with a bilingual (Welsh / English) easy read version of the information sheet (see Appendix V). The service user was given the choice to involve a regular carer/advocate for support during the research process. The service user was given a minimum of three days and maximum of two weeks to consider the information presented and whether or not they wanted to participate in the research. This would ensure that potential participants had sufficient time to consider their participation in the study and allow them a free, informed choice (McDonald, 2009).

Stage 3

A protocol based on the work of Arscott et al (1998) was used to assess the service user's capacity to consent (see Appendix W). Nevertheless, the assessment was an individualised process that considered the communication needs of the service user and the skill of the researcher. The information sheet was read with the service user twice. The service user was then encouraged to ask questions of the researcher. The researcher asked the service user questions to assess, as far as possible, whether the person understood, retained and used the information to arrive at a decision. If the protocol indicated that the service user had the capacity to consent to participate in the study and was willing to do so, stage 4 of the consent process was implemented. If the service user did not have the capacity to consent to this particular study or decided that they did not want to take part, the bespoke exit strategy was followed (Booth, 1998). The researcher would discuss each individual case with their community intellectual disability nurse and a bespoke exit strategy would be agreed in the best interest of the service user. This may or may not involve a return visit by the researcher and or intellectual disability nurse. (In the study presented in Chapter 6, all individuals approached consented to participate in the research).

Stage 4

The researcher re-read the information sheet, and asked for the participant's verbal and or written consent, witnessed by both the researcher and a regular carer. Consent to audio record the interview was also sought (see Appendix X., Consent form). Nonetheless, consent was not seen as a one off event and any participant who indicated a desire to withdraw from the study could do so without further questioning at any time during the study.

The complexity of conducting the four stages of receiving consent from participants was a lengthy procedure which drew on a range of communication strategies that were used to support the participants' understanding of the research process. McClimens and Allmark (2011) debate the process of including individuals with intellectual disability in research. They argue that the process of consent is often based on the principle of protection, and that such protection has often resulted in individuals with intellectual disability being excluded from research. Consequently, research that includes evidence from individuals with intellectual disability is sparse compared with the research produced by professionals about people with intellectual disability. Study 3, although not participatory in nature, is inclusive and adds to the growing and meaningful voice of service users' perspectives to nursing research.

Summary of the contribution of this thesis to understanding decision making: the application of Mooi Standing's (2008) nine modes of practice to intellectual disability nursing practice, education and research

In relation to the context of intellectual disability nursing (see Chapter 1) and the literature reviewed in relation to decision making (see Chapter 2) there is evidence to suggest that there are challenges to implementing evidence based practice within nursing. With a limited, although growing, intellectual disability nursing research base (Northway et al., 2006b; Griffiths et al., 2007) available for nurses to guide their practice it is pertinent to ask on

what evidence nurses working with individuals with intellectual disability base their decisions. Indeed, Parahoo's (2000) research is to date the only research that specifically explored research utilisation in intellectual disability nursing. Having identified a plethora of terms to describe decision making and accessed literature debating decision making, it is clear that the decision making by nurses working with individuals with intellectual disability was not addressed (Chapter 2). Nor were there any studies that asked service users for their perspective on the decision processes in which nurses engaged. This thesis addresses this gap in knowledge. This summary will consider the themes that emerged from the data of the three studies (Chapter 4, 5 and 6) and identify how these themes relate to Standing's (2008) modes of practice. A summary of the contribution of this thesis to the understanding of decision making in intellectual disability nursing is given. To conclude the thesis, a new conceptual model is offered that has the potential to enhance intellectual disability nursing's understanding of decision making within the context of practice, education and research.

Exploring intellectual disability nurses decision making – Study 1 relevance to Standing's modes of practice

Three themes that emerged from the data in Study 1 (Chapter 4) were getting to know the person; working together and evidence to support decision making. These themes developed from 12 semi structured interviews with intellectual disability nurses working in in-patient units. The nurses were asked to describe an episode of care, identifying the decisions that were taken during the nursing care. Essential to their decision making was the involvement of the patient, with participants describing how they listened to the patients' wishes to get to know the individual. The nurses valued the long term nature of the relationship they had with the individuals with intellectual disability and their family and described their relationship as an equal partnership in the process of making decisions. Overall, decisions were described as a team endeavour, whereby the patient and their family, other nursing colleagues, and members of the multidisciplinary team worked

together on decisions that would affect the health outcome for the patient. The third theme identified the numerous information sources the nurses used to guide their decisions.

Table 7.1 maps the data gathered in the first exploratory study with Standing's nine modes of practice (see Chapter 2 for discussion of Standing's (2008) revised model). As discussed in Chapter 2, intuitive and analytical decision theories are fused into a single theory known as the cognitive continuum theory (Hammond, 1978). Hamm (1988) adapted the theory to explore decision making within medicine. The final revision of the theory (see Figure 2.2) was offered by Standing (2008) who applies the theory to nursing. The nine modes of practice offer a framework to "develop, guide, or evaluate the matching of decision tactics to decision tasks" (Standing, 2010; p. 146).

Within the data gathered in Study 1, the participants referred to five of the nine modes of practice. The data in Study 1 did not demonstrate any evidence of the nurses using the research modes of practice in their clinical work, that is, action research and clinical audit, qualitative research, survey research, and experimental research. Table 7.1 shows that the most frequently used mode of practice was patient aided and peer aided judgement. For example, there was evidence that nurses spent time getting to know the patients and their family and involving them in any healthcare decisions. One participant recalled that "there wasn't much decision making on my part really, other than to give her (*the patient*) the opportunity to be in control of the situation" (Participant 4, Study 1). Current policy , strategies and guidance within intellectual disability are underpinned by person centred thinking (Department of Health Social Service and Public Safety, 2005; Welsh Assembly Government, 2007; Department of Health, 2009a; Scottish Government, 2013) although this was a small sample of intellectual disability nurses, it is reassuring to note that the nurses conveyed the principles of person centred thinking in this study.

Examples of intuitive judgement, such as "my evidence (re: intervention described) is, initially my niggle, I said I had a niggle in my head that this gentleman wasn't drinking enough" (Participant 5, Study 1) were present

throughout the data. Also, examples of reflective judgments were present, for instance "as a team we reflect as to whether something happens, or whether something works, or whether something doesn't, and we are quite good I think at looking at decisions and if they're not right to change them quickly as well" (Participant 11, Study1). Participant 6 reflected on care planning with a gentleman who had a diagnosis of autism; stating that she had searched the literature to find evidence to support the structuring of the care plan as well as using her past experience, knowledge of the individual and respecting his wishes in producing a patient centred care plan. Within this particular interview there is evidence that the nurse's decision making process fluctuates along the continuum. That is, the task of care planning identifies with five of the nine modes of practice, namely intuitive judgement, reflective judgement, patient aided and peer aided judgement, system aided judgement and critical review of experiential and research evidence. Thus, Standing's (2008) nine modes of practice seems a valuable framework to clarify, scrutinise, explain, appraise and develop decision making in intellectual disability nursing.

Table 7.1: Relating the key themes that emerged from the data of Study 1 (Chapter 4) to the cognitive continuum – nine modes of practice (Standing, 2008)

		Nine modes of practice (Standing, 2008)								
		Intuitive judgement	Reflective judgement	Patient aided & peer aided judgement	System aided judgement	Critical review of experiential and research evidence	Action research & clinical audit	Qualitative research	Survey research	Experimental research
		JUDGEMENT					RESEARCH			
Themes from study 1 (see Table 4.2)	Getting to know the person	▓	▓	▓						
	Working together			▓	▓	▓				
	Evidence to support decision making	▓	▓	▓	▓	▓				

Developing an understanding of the sources and types of information used to support decision making in intellectual disability nursing – Study 2 relevance to Standing's (2008) modes of practice

In Table 7.2 the sources and types of information used when making decisions concerned with health outcomes identified from the national survey (see Table 5.3, Study 2, Chapter 5) are represented along the nine modes of practice. This table provides a visual summary of the relationship between the sources of evidence nurses use and the modes of practice. From the data gathered in Study 2, it is apparent that most of the respondents used sources of information to engage in low structured decisions that involved intuitive, reflective, patient aided and peer aided, and system aided judgement. Low task structure represents "face–to-face" decisions and high task structure represent "faceless" decisions. Some sources and types of information suggest that nurses also critically review experiential and research evidence to inform practice, namely, nurses who access research based literature or attend education courses (see Chapter 5 for analysis of findings). Tacit and explicit knowledge are equally represented within the critical review of experiential and research evidence mode of practice (see Figure 2.2). Thus, mapping the sources and types of information used to inform decisions along the modes of practice also supports the findings of the linear regression analysis within Study 2 that identified that the nurses working with people with intellectual disability used more experiential (tacit / intuitive) sources of knowledge than empirical (explicit / analytical) knowledge on which to base their decisions.

Table 7.2: Relating the sources and types of information (Study 2) used to make decisions to the modes of practice

		Nine modes of practice (Standing, 2008)								
	Source of information	Intuitive judgement	Reflective judgement	Patient aided & peer aided judgement	System aided judgement	Critical review of experiential and research evidence	Action research & clinical audit	Qualitative research	Survey research	Experimental research
		JUDGEMENT					RESEARCH			
Types and sources of evidence used when making decisions concerned with improving health	my experience as a nurse	■	■							
	patients' nursing documents				■					
	observing patients	■	■	■						
	talking with the patients			■						
	talking with the family			■						
	reflection on practice		■							
	doctors/psychiatrist/GPs			■						
	experienced nursing colleagues			■						
	allied health professionals			■						
	clinical supervision			■	■	■				
	my initial nurse education		■	■	■	■				
	NHS provided education		■	■	■	■				

Table 7.2: Relating the sources and types of information (Study 2) used to make decisions to the modes of practice (Continued)

		Nine modes of practice (Standing, 2008)								
	Source of information	Intuitive judgement	Reflective judgement	Patient aided & peer aided judgement	System aided judgement	Critical review of experiential and research evidence	Action research & clinical audit	Qualitative research	Survey research	Experimental research
		JUDGEMENT					RESEARCH			
Types and sources of evidence used when making decisions concerned with improving health	professional interest groups		▓	▓	▓	▓				
	university modules/ courses		▓	▓	▓	▓				
	results of audit					▓				
	newly qualified nurses				▓					
	research publications					▓				
	externally provided training		▓							
	student nurses			▓						
	Internet	▓	▓	▓	▓	▓				
	habit or tradition at place of work	▓								
	the library				▓	▓				
	textbooks				▓	▓				
	popular media	▓	▓	▓						

Participants' experiences of receiving healthcare – Study 3 relevance to Standing's (2008) modes of practice

The two discursive themes that emerged from the third study were:

a. Inclusion: Empowering and supportive healthcare practices; and
b. Exclusion: Challenges and practices that reduce healthcare involvement.

The participants were able to articulate the role of the nurse in enabling them to access services. The narrative infers a process of negotiation between the nurse and service user referring to a mode of patient aided and peer aided judgement. Additionally, within inclusive practice service users would describe a routine or plan of care associated with their contact with the intellectual disability nurse suggesting that decisions may relate to a system aided judgement mode of practice.

The challenges faced by individuals with intellectual disability in having greater involvement in their healthcare were highlighted by Rebecca (participant in Study 3). Rebecca showed concern over individuals whose voices were not heard in the context of healthcare, noting that some adults with intellectual disability were "treated like children" and not listened to when visiting the General Practitioner. Such an example may indicate that health professionals do not articulate their decisions in a way that some service users may comprehend.

When examining the findings of Study 3 in relation to Standing's (2008) modes of practice there are examples within the theme inclusive practice that demonstrate how individuals with intellectual disability are involved in healthcare decisions. However, in their narratives describing the challenges in accessing healthcare, this study offers little evidence to support the inclusion of service users in decisions related to their health. Discourses identified service users as accepting and unquestioning of the service they received. Indeed, not all participants could explain why they were receiving a service from the intellectual disability nurse and conveyed their relationship as

a friendship. Thus, within the theme of exclusion, the mode of practice related to decision making is not apparent in this data. Table 7.3 maps the themes of Study 3 to the modes of practice.

The theme of inclusion in this study identified with two modes of practice, that is, patient aided and peer aided judgement, and system aided judgement. This suggests that inclusive practice in this study demonstrates that the service users' preferences influenced healthcare decisions. Furthermore, there were inferences in the data to suggest that nurses use standardised frameworks such as person centred planning and the nursing process to guide their work. The data did not suggest the presence of other modes of practice. Intuitive and reflective judgement are often invisible, thus nurses need to consider ways to convey such decisions to the service user. In addition, there was no reference to decisions based on research within this theme. Further research on how nurses convey the available evidence to enhance service users' decision making is advocated. Within the theme exclusion, the data offered little insight into the modes of practice of healthcare practitioners.

Table 7.3: Summary of the relationship of participants' experiences of receiving healthcare with Standing's (2008) nine modes of practice

		Nine modes of practice (Standing, 2008)								
	Participants' experiences of receiving healthcare	Intuitive judgement	Reflective judgement	Patient aided & peer aided judgement	System aided judgement	Critical review of experiential and research evidence	Action research & clinical audit	Qualitative research	Survey research	Experimental research
		JUDGEMENT					RESEARCH			
Discursive themes that emerged from Study 3 (Chapter 6)	Inclusion: Empowering and supportive healthcare practices									
	Exclusion: Challenges and practices that reduce healthcare involvement									

A summary of the contribution of the thesis to understanding decision making in intellectual disability nursing

Analysing the data of Study 1, 2 and 3 in relation to Standing's (2008) revised cognitive continuum – nine modes of practice has clearly identified that nurses work in partnership with people with intellectual disability. Overall, the nurses engaged in low task structured decisions, suggesting an emphasis on "face-to-face" decisions. Study 1 offered rich data to support the use of tacit knowledge and a confidence in patient and peer aided judgement. Evolving from the first study, the second study clearly identified the sources and types of information used by nurses when working with people with intellectual disability. Again, this finding supported the notion that the nurses in practice used a range of intuitive and a mixture of intuitive/analytical approaches to make decisions. Study 3 supports the notion of partnership identified within some inclusive practice in healthcare. To summarise, from the data, it is evident that nurses in practice seem to draw primarily on five modes of practice along the cognitive continuum, namely:

- Intuitive judgement,
- Reflective judgement,
- Patient aided and peer aided judgement,
- System aided judgement, and
- Critical review of experiential and research evidence.

Decision making appears dynamic and at times travels across all five modes of practice. However, from the service users' data, there is little evidence that this dynamic decision making is visible or recognisable to them. Therefore, it is proposed that nurses need to clearly articulate the available evidence to the service user, thus enabling them to be equal partners in the decisions that affect their health. Mooi Standing's (2008) revised cognitive continuum has the potential to assist intellectual disability nurses in articulating their decisions along the modes of practice. The subsequent section proposes some of those opportunities within practice, education and research.

Co-production of health-related decisions: A conceptual model of the contribution of intellectual disability nursing values to Standing's nine modes of practice (Standing, 2008); opportunities within practice, education and research.

In light of the data presented in this thesis (Chapters 4, 5, and 6), the theoretical perspective of Standing's (Standing, 2008) revised cognitive continuum theory (discussed in Chapter 2) and the values of intellectual disability nursing (discussed in Chapter 1), Figure 7.4 combines these elements to offer a model of co-producing decisions across all the modes of practice. The model offers a visual representation to identify, understand, and evaluate intellectual disability nursing decisions. At the centre of the model is the value base for intellectual disability nursing (see Box 7.1) as identified and supported by the four countries of the UK (Department of Health et al., 2012). The value base is the foundation of nursing decisions; nurses must be able to articulate their values and demonstrate that their decisions are guided by these principles within each mode of practice. The double headed arrows represent continual movement between intellectual disability nursing values and the modes of practice. The outward pointing arrows demonstrate that the values strengthen the modes of practice and the inner pointing arrows ground the decisions in the value base. Integral to the decisions is the aspect of co-production, where nurses and service users invest in a reciprocal relationship and contribute equally to the process of decision making. Co- production should be addressed across the nine modes of practice. Co-producing decisions refers to the active input of service users, a process that emphasises the assets of all individuals involved in helping to improve the outcomes of healthcare decisions (Needham & Carr, 2009). Although shared decision making seems to be the term of choice within the NHS (Department of Health, 2010b) the term co-production is presented here as a term that represents a stronger commitment from intellectual disability nursing service to enable service user to lead decisions related to their health from the outset.

Box 7.1: The values base for intellectual disabilities nursing (adapted from Department of Health et al., 2012; p. 8)

Intellectual disabilities nursing is based on clear values that include placing individuals at the centre of care and ensuring they are fully involved in all aspects of planning and intervention. It also acknowledges the critical contribution of family and informal carers. Central to this are the following underpinning principles that guide learning disabilities nursing practice.

Human rights
Placing the individual at the centre, valuing choice, inclusion, citizenship and social justice. Incorporates equality, individuality, person-centred and strength-based approaches, empowerment, self-determination, dignity and anti-oppression.

Personalisation
Supporting the individual's control and choice over their own life and services through empowering people with learning disabilities, their families and carers and relinquishing "control".

Equality and inclusion
Recognising diversity and challenging inequality and inequity by supporting people with intellectual disabilities to use the same services and have the same opportunities and entitlements as anyone else.

Person-centred
Meaningful engagement with people to identify goals significant to the person.

Strengths-based
Focusing on existing strengths, skills, talents and resources and increasing personal competence.

Respect
Valuing the whole person and the diversity of people who support and sustain him or her. Appreciating the contribution of families and carers and, where possible, enhancing the contribution of others.

Partnerships
Recognising that health and social outcomes are interdependent.

Health-focused
Focusing on the individual's health and well-being to enable inclusive lifestyles.

The arrows and modes of practice are also colour coded to identify opportunity of co-producing decisions within practice, education and research. The findings in this thesis suggest that the modes of practice that directly apply to nurse practice are: intuitive judgement, reflective judgement, patient aided and peer aided judgement and system aided judgement; these are coloured in blue. Within research the modes of practice are: action research and clinical audit, qualitative research, survey research and experimental research that are highlighted in red. In the middle of the continuum is the mode of critical review of experiential and research evidence. This central mode involves intuitive and analytical approaches to decision making and appears to be the bridge that joins practice and research within this model, thus is identified by the colour purple as a mixture of blue and red (practice and research / intuitive and analytical). This bridge is where education has an opportunity to enable practice to inform research and vice versa, thus acknowledging that the service users' voice is paramount across education, research and practice.

The three core elements that this thesis contributes to this model are: 1) the influence of person centred thinking that originates from intellectual disability nurses' value base, 2) their commitment to including the service user and their family within the process of making decisions and 3) identifying the modes of practice related to intellectual disability nursing practice. Indeed, if nurses are transparent in representing their decisions along the modes of practice, this might address the issue highlighted in Study 3 that service users were not always aware of the decisions that occurred in relation to their healthcare.

Figure 7.4: Co-production of health-related decisions: A conceptual model of the contribution of intellectual disability nursing values to Standing's (2008) nine modes of practice.
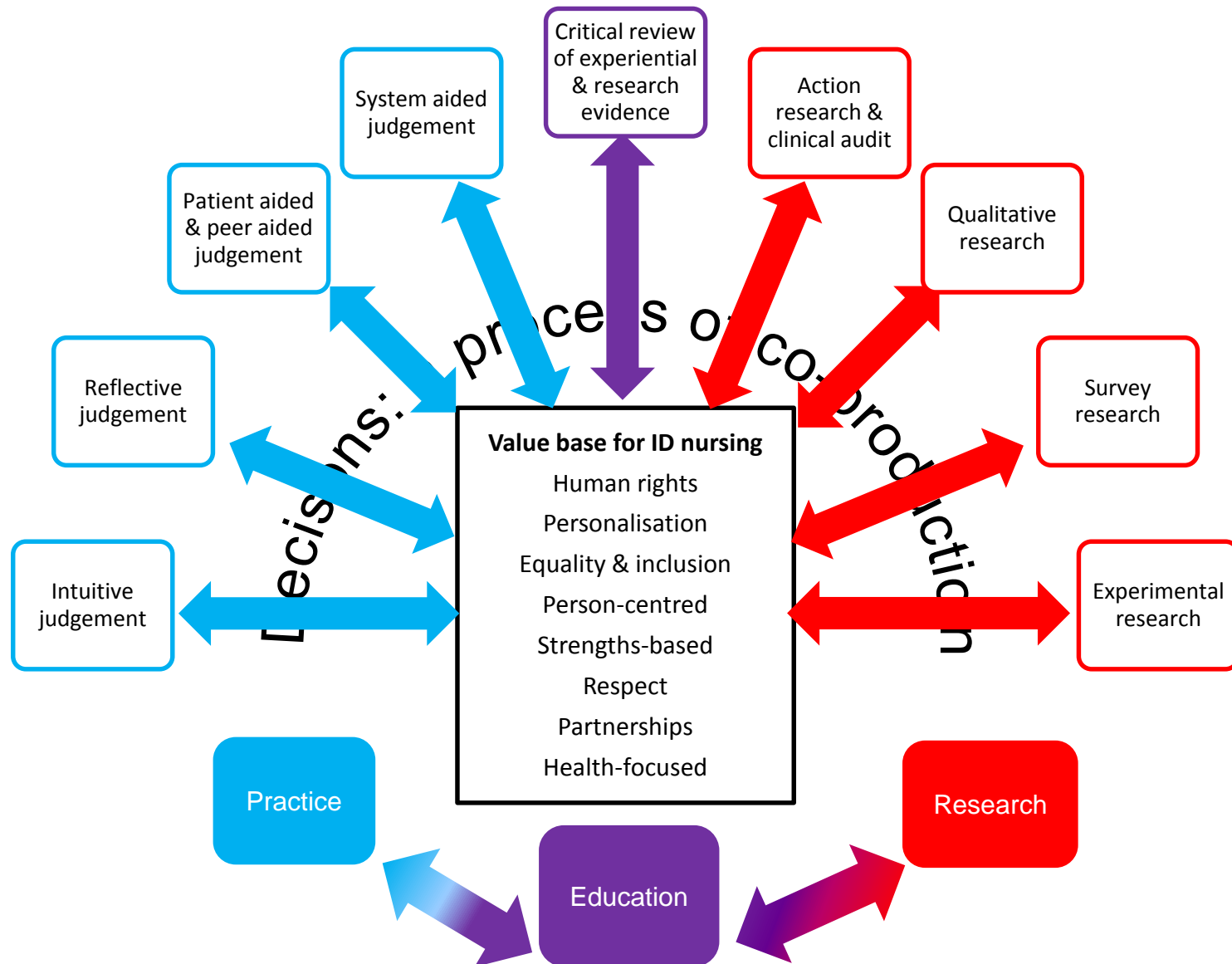
Co-production of health-related decisions: opportunities in practice

"What is it to help? It is certainly not to overwhelm, overtake or invade, but it is to strengthen and even, if necessary to carry for a little while". (Shakespeare 2000, p. 87)

Data from the three studies offer examples of how nurses who work with individuals with intellectual disabilities "help" them to meet their health needs. It is described as a process of engagement and enabling the service user to make decisions that influence health outcomes. Table 7.4 is an example of how nurses may use the modes of practice to highlight the process of decision making during a patient's journey in healthcare. This particular example focuses on the admission of an individual to an in-patient unit. The table identifies some of the opportunities nurses may have to identify areas of co-production in relation to health decisions. Although intuitive judgement is described as "implicit, invisible and based on informal systems" (Harbison, 2001; p.129) the individual's perception of the situation is an important aspect for nurses to consider. For instance, during an admission the nurse must demonstrate respect (see Box 7.1 for intellectual disability nursing value base) by appreciating the value of the contribution of the patient and their family have to the process of admission. Mapping a patient's journey to the modes of practice seems like a useful tool for the nurses in practice to articulate their co-produced decisions.

Table 7.4 Focus on the modes of practice within a patient's journey: An example relating to admission to an in-patient unit

	Stage of journey	Nine modes of practice (Standing 2008)								
		Intuitive judgement	Reflective judgement	Patient aided & peer aided judgement	System aided judgement	Critical review of experiential and research evidence	Action research & clinical audit	Qualitative research	Survey research	Experimental research
		JUDGEMENT					RESEARCH			
Nursing Journey	Admission to in-patient unit	Sense of patients distress	Account of events leading to admission	Elicit history from patient and family / carers. Enquire with related professionals	Nursing process LD nursing assessment Risk assessment Local admission policy	Ensure language requirements are met (Knowledge of previous research studies, re: language appropriate care (e.g. Raffi et al., 2010)	Peer audit of record of admission / care	E.g. service user perspectives of in-patient admission (see Longo & Scior, 2004). Highlights the service users need for clear information	A Scottish survey identifying delayed discharge and issue in in-patient services (Perera et al., 2009)	Limited research to guide practice e.g. see Brylewski & Duggan, 2004
				Co-production of health-related decisions (influenced by ID value base)						
Patient journey		Time to disclose thoughts feelings	Opportunity to reflect on admission	Time to contribute information	Understand processes Role within process	Consider the options available for assessment and treatment, propose options	Service user evaluation of admission / care	Service users and family to contribute to nursing understanding of admission and treatment	Potential for inclusive research projects	Potential for inclusive research projects

Co-production of health-related decisions: opportunities in education

As the NMC Standards for Pre-registration Nursing Education state, (see Box 7.2) all nurses are required to make decisions based on the best available evidence in partnership with all relevant stakeholders. It is therefore necessary for student nurses to develop their skills and knowledge of decision making and ensure that practice is evidenced based. Appendix AA offers an example of a session plan that enables student nurses to explore decision making in a class room setting introducing Standing's (2008) modes of practice as a framework.

Box 7.2 NMC Standards for Pre-registration Nursing Education (2010)

Domain 3: Nursing practice and decision-making

1. All nurses must use up-to-date knowledge and evidence to assess, plan, deliver and evaluate care, communicate findings, influence change and promote health and best practice. They must make person-centred, evidence-based judgments and decisions, in partnership with others involved in the care process, to ensure high quality care. They must be able to recognise when the complexity of clinical decisions requires specialist knowledge and expertise, and consult or refer accordingly.

From the literature reviewed (see Chapter 2), decision making within the context of the registered nurse is widely debated. However, research into how student nurses make decisions is limited (see Smith et al., 2004; that discusses the development of an instrument to measure intuition in student nurses, and was later translated into Turkish (Demir, 2012)). Thus, nurse academics are encouraged to publish accounts reflecting on the decision making skills and knowledge student nurses need to meet the requirements of the NMC (2010) standards. Standing's (2008) revised cognitive continuum offers a framework for nurse academics and student nurses to explore aspects of decision making. Furthermore, the conceptual model of co-production of health-related decisions will assist the student nurse to

explore the influence of the value base of intellectual disability nursing on the decision making process.

As previously noted, much of the literature regarding decision making involves experienced nurses. However, the literature rarely discussed decision making within intellectual disability nursing. With the recent launch of the *Career and Development Framework for Learning Disability Nursing* (NHS Education for Scotland, 2013) an opportunity has arisen to map the decision making skills of registered intellectual disability nurses from level 5 practitioner to level 8 consultant practitioner. This useful framework provides a guide to map the career path available to intellectual disability nurses, identifying the key skills and knowledge required at each level. There is an opportunity here to further explore decision making along the levels of the intellectual disability nursing career framework in relation to the modes of practice.

Within education, the cognitive continuum appears a useful aid for nurses to gain an understanding of their decision making processes. Nurses could examine their decisions through the application of the modes of practice to decisions encountered in practice or through given case studies or scenarios. It could also be a valuable framework for self-evaluation or used as a basis for reflection or clinical supervision. Research to support such implementation is advocated.

For intellectual disability nurse academics, the co-production of decisions with service users that influence curriculum design, development, teaching and learning is required (NMC, 2013). Bollard et al. (2012) produce one of a limited number of papers that explores the process of service user involvement in relation to development of their own BSc programme at the University of Coventry. Cumbria University also supports people with intellectual disability to present their experience of living in long-stay institutions to student nurses (Mee, 2010). There is a need to evaluate such innovations and ensure that examples of good practice are shared.

Co-production of health-related decisions: opportunities in research

Although Standing's work was published in 2008, to date research into the application of her revised model is limited. This thesis promotes the work of Standing as a useful framework to explore decision making within intellectual disability nursing. Moreover, the conceptual model of the co-production of health-related decisions links Standing's (2008) work specifically to intellectual disability nursing. Within the identified "research" modes of practice (Action research and clinical audit, Qualitative research, Survey research and Experimental research) there is a growing awareness of the need to include service users in all research, not just as participants, but also as researchers who bring their own unique experiences to the research team. There is a growing literature base that explores inclusive research, for example, reviewing the process (Tuffrey-Wijne & Butler, 2010), the barriers (McClimens & Allmark, 2011) and producing accessible articles to disseminate findings (Garbutt et al., 2010). Furthermore, the special issue of the *British Journal of Learning Disabilities* (June, 40(2) p. 83-164; 2012) that published research by and with people with intellectual disability is testament to the commitment of researchers and individuals with intellectual disability to contribute to the research agenda. However, published research where individuals with intellectual disability are co-researchers is mostly qualitative in nature. Moreover, Bain et al. (2005) considers the poor recruitment rate of people with intellectual disability to participate in their randomized controlled trial on improving health advocacy. All the authors of the paper were from an academic background, thus recruitment might have improved if individuals with intellectual disability were members of the research team. For instance, Turk et al. (2012) offer a way forward that includes individuals with intellectual disability and their family/carers within a randomized controlled trial. They conclude that, "appropriate design, strong research partnerships, adequate and flexible resources, promotion of teamwork and a strong task focus" (Turk et al., 2012; p. 1) were ways to promote the inclusion of individuals with intellectual disability as researchers and participants. The intellectual disability research community appears to embrace the concept of inclusivity and as Walmsley and Johnson (2003, p. 16) note, inclusive research "must address issues which really matter … and which ultimately lead to improved lives". Standing's (2008) modes of practice can be used as a framework to identify

the opportunities available "towards doing research inclusively" (Hind & Vinha, 2013; p. 7) along the modes of practice. Research projects that explore decision making along the modes of practice should strive to employ individuals with intellectual disability as "active participants, not only as subjects but as initiators, doers, writers and disseminators" (Walmsley & Johnson, 2003; p. 9).

The findings of this thesis suggest that nurses in practice rarely explored sources of information from the research modes of practice to support their decisions. The conceptual model (Figure 7.4) offers connections between the value base of intellectual disability nursing and the research modes of practice. Traditionally, within research, individuals with intellectual disability have been "tested, counted, observed, analysed, described and frequently pathologized, but never asked for their views" (Walmsley, 2001; p. 188). Current literature is moving away from this tradition, yet, there remains an onus on practising nurses, researchers and service users to collaborate on projects to develop the evidence base for intellectual disability nursing; this should be a journey of co-production.

Concluding remarks

The response to the three studies is evidence that nurses who work with individuals with intellectual disability and service users in Wales are eager to contribute to research. Throughout this research journey, intellectual disability nursing services were keen to advocate the involvement of their nursing staff and service users. It is therefore pertinent to propose that nurses and service users should be involved in policy, education and practice developments that strive to improve health outcomes for individuals with an intellectual disability. The nature and context of meaningful involvement should be aired and debated.

Study 3 conveys the voice of the service user. Whilst their experiences were unique and cannot be taken as representative of people with intellectual disability, readers may identify with the themes and relate the experience of inclusion and exclusion to their own practice. The challenge for intellectual disability nurses is their commitment to enable individuals to access mainstream healthcare service as people with intellectual disability:

"…must have as equal a right of access to primary, secondary and specialist health care services and routine national health screening programmes as any other citizen. The Healthcare Standards for Wales should be embraced and applied equally when the patients involved are people with a learning disability" (Welsh Assembly Government, 2007, p. 20-21)

The role of the intellectual disability nurse in supporting access to services and educating other healthcare professionals in strategies that promote inclusion is encouraged. Thus, it is important to recognise that equitable nursing care for individuals with intellectual disability is the responsibility of the whole nursing profession, not just intellectual disability nurses. The new standards for pre-registration nursing education (NMC, 2010) that stipulate that all nurses require the skills and knowledge to work with individuals with intellectual disability within the context of their care may improve healthcare access for individuals.

Decision making in intellectual disability nursing is a complex process whereby nurses use a range of experiential and empirical sources of evidence to inform practice. The way nurses interact with the evidence should be clarified. The contribution of service users to the decision making process should be explicit and recognised as a valuable source of evidence to inform practice. The application of Standing's (2010) adapted version of Hammonds (1978) cognitive continuum of clinical judgement may offer intellectual disability nurses a framework to map their decisions and identify what range of evidence they use to make certain decision in practice. Identifying the complex stages of decision making will inform future practice.

Although, current reviews (Northway et al., 2006b; Griffiths et al. 2007) identify limited intellectual disability nursing research to inform practice, it is acknowledged that intellectual disability nursing practice is informed and contributes to the broader intellectual disability evidence base. Consequently, there is a need to invest in the development of the role of the intellectual disability nurse and service user participation in the research agenda.

Future research should build on the foundations of the three studies presented in this thesis. The experiences of intellectual disability nurses in the

process of decision making have identified the importance of actively listening to the service users. Replication of the qualitative approach adopted in the first study offers scope to explore the experiences of other branches of nursing in relation to their decision making with service users. In addition, an ethnographic observation of intellectual disability nursing practice across a range of services could unravel and highlight the everyday practice of nurses, thus gathering data from a variety of sources, such as observation and nursing documents (Silverman, 2011). Exploring nurse – service user interactions and the process of decision making around specific aspects of the intellectual disability nurses role would highlight factors that influence the interactions and identify areas of good practice or areas for improvement. Essentially, intellectual disability nursing practice needs to be made explicit in order to advance nursing in this area.

Study 1 and 2 identify that the input of service users to decision making is paramount. Evidence based practice in intellectual disability nursing should acknowledge that people with intellectual disability are experts with experience (Hoole & Morgan, 2011) and are included in micro, meso and macro decisions that affect their lives. Although the thesis has provided an insight into decision making, the data were collected across a broad cross-section. Future research should consider investigating the outcomes of decisions from the services users' perspective at more than one point in time. A longitudinal design would offer information about the nature and effect of decisions taken to improve health outcomes.

Although this thesis does consider the service user perspective, it is acknowledged that the individuals were all assessed to have the capacity to consent to participate in the research. However, there exists a group of individuals who have additional complex needs and may be denied the opportunity to contribute to research because of the difficulty with establishing capacity. Future research should explore how individuals with intellectual disability and additional complex needs can contribute to research; debating issues around the *right to be heard* with the concept of *informed consent* is advocated.

To conclude, intellectual disability nurses' practice should be celebrated in their endeavour to place the service user at the centre of decision making in

healthcare. Responding to individual needs requires practitioners that use a range of experiential and empirical evidence to inform practice. Service user engagement in their own care is paramount, although the findings in this thesis suggest that service users are unaware of the intellectual disability nurse's role in their care. For some years, the role of the intellectual disability nurse has been under scrutiny, fuelling debates in education, practice and research about this small profession. Nevertheless, the current report of the *UK Modernising Learning Disability Nursing Review* (Department of Health et al., 2012), clearly identifies the direction of travel for intellectual disability nursing. It is hoped that the four countries of the UK will consider the recommendations to develop and modernise intellectual disability nursing in response to the needs of service users. This thesis lays the basis for future research and education of service users and other healthcare professionals about the valuable role of the intellectual disability nurse.

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Appendices

Appendix A – Study 1, Ethical approval letters.

Pwyllgor Moeseg Ymchwil Gogledd Orllewin Cymru
North West Wales Research Ethics Committee

North West Wales NHS Trust, Ysbyty Gwynedd
Clinical Academic Office
North Wales Clinical School
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@nww-tr.wales.nhs.uk

PRIVATE & CONFIDENTIAL
Miss Ruth W Williams
PhD Student
School of Healthcare Sciences,
Bangor University,
Bangor, Gwynedd
LL57 2EF

08 September 2008

Dear Miss Williams

Full title of study:	**Exploring decision making in learning disability nursing practice: a qualitative study.**
REC reference number:	**08/WNo01/39**

Thank you for your letter of 03 September 2008, 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 Chairman

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.

Ethical review of research sites
The favourable opinion applies to the research sites listed on the attached form.

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

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

Document	Version	Date
Application	2892/4219/1/395	14 July 2008
Investigator CV	1	17 June 2008
Protocol	5	17 July 2008
Covering Letter		17 July 2008
Summary/Synopsis	1	17 July 2008
Letter from Sponsor		17 July 2008

Compensation Arrangements		01 August 2008
Interview Schedules/Topic Guides	4	20 June 2008
Interview Schedules/Topic Guides	v.5 Welsh	02 September 2008
Letter of invitation to participant	2	07 July 2008
Participant Information Sheet: Welsh translation	5	02 September 2008
Participant Information Sheet	5	02 September 2008
Participant Consent Form: Welsh translation	5	02 September 2008
Participant Consent Form	5	02 September 2008
Response to Request for Further Information		03 September 2008
Supervisors" CV		

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review
Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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
- Progress and safety reports
- Notifying the end of the study

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/WNo01/39	Please quote this number on all correspondence

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

Yours sincerely

Mr David Owen
Chairman

Enclosures: "After ethical review – guidance for researchers"
                     Site approval form

Copy to: Sponsor's Representative; Dr Ruhi Behi, Bangor University
                     R&D office for North West Wales NHS Trust

North West Wales Research Ethics Committee					
LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION					
For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.					
REC reference number:	08/WNo01/39	**Issue number:**	1	**Date of issue:**	08 September 2008
Chief Investigator:	Miss Ruth W Williams				
Full title of study:	Exploring decision making in learning disability nursing practice: a qualitative study.				
This study was given a favourable ethical opinion by North West Wales Research Ethics Committee on 08 September 2008. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.					
Principal Investigator	*Post*	*Research site*	*Site assessor*	*Date of favourable opinion for this site*	*Notes ᵂ*
Miss Ruth W Williams	**PhD** Student	North West Wales NHS Trust:	North West Wales REC	08/09/2008	
Approved by the Chair on behalf of the REC: ....(Signature of Chair/Co-ordinatori					
(delete as applicable) ....(Name)					

(1) *The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.*

Pwyllgor Rheolaeth Ymchwil Ymddiriedolaeth GIG Gogledd Orllewin Cymru
Panel Arolygu Mewnol
North West Wales NHS Trust Research Governance Committee
Internal Review Panel

North West Wales NHS Trust, Ysbyty Gwynedd
Clinical Academic Office
North Wales Clinical School
Bangor, Gwynedd
LL57 2PW

PRIVATE & CONFIDENTIAL
Miss Ruth Wyn Williams
PhD Student
School of Healthcare Sciences
Bangor University
Bangor,
LL57 2EF

Telephone/Facsimile: 01248 - 384.877
Email: Rossela.Roberts@nww-tr.wales.nhs.uk

14 August 2008

Dear Miss Williams,

Review: ' 'Exploring decision making in learning disability nursing practice: a qualitative study

R&D ref no: Williams 08/39

The above research project was reviewed at the meeting of the Trust Research Governance Committee / Internal Review Panel held on 14th August 2008.

I have pleasure in confirming that the Internal Review Panel is pleased to grant Trust approval to proceed at the North West Wales NHS Trust sites.

The study should not commence until the Ethics Committee reviewing the research has confirmed final ethical approval (Favourable Opinion and No Objection to Site Specific Assessment).

All research conducted at the North West Wales NHS Trust sites must comply with the Research Governance Framework for Health and Social Care in Wales (November 2001). An electronic link to this document is provided on the Trust's R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the North West Wales NHS Trust.

If you would like further information on any other points covered by this letter please do not hesitate to contact me. On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Yours sincerely

Rossela Roberts

Dr K D Griffiths
Consultant Biochemist
R&D Director, Assistant to the Medical Director
Chairman Trust Research Governance Committee

Chairman/Cadeirydd – Dr K D Griffiths

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Gofal Iechyd
Prifysgol Bangor

Unedau 8 & 9, Llys y Fedwen
Ffordd Gelli Morgan
Parc Menai
Bangor, Gwynedd LL57 4BL

Ffôn: 01248 351151
Ffacs: 01248 388411

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Units 8 & 9, Llys y Fedwen
Ffordd Gelli Morgan
Parc Menai
Bangor, Gwynedd LL57 4BL

Tel: 01248 351151
Fax: 01248 388411

25 November 2008

PRIVATE AND CONFIDENTIAL

Ms Ruth Williams
School of Healthcare Sciences
Fron Heulog
Ffriddoedd Road
Bangor
LL57 2EF

Dear Ms Williams

Re: School of Health Care Sciences Research Ethics Committee
Research Proposal – Exploring decision making in learning disability nursing practice: a qualitative study

Further to your confirmation of implementation of minor amendments to your proposal I write to confirm that *ethical approval for your above research proposal has been granted and is effective as of the date of this letter.*

On behalf of the Committee, I wish you well with your research.

Yours sincerely

G A Goodman

Reverend Wynne Roberts
CHAIR
School of Healthcare Sciences Research Ethics Committee

Appendix B - Study 1, Invitation letter (Welsh and English version)

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Rhif Ffôn: 01248 388691
E-bost: hsp42e@bangor.ac.uk
19 Medi 2008

Annwyl
<u>Astudiaeth Ymchwil: Archwilio i'r modd y gwneir penderfyniadau yn ymarfer nyrsio anabledd dysgu: astudiaeth ansoddol.</u>

Rwy'n fyfyriwr PhD yn Ysgol Gwyddorau Gofal Iechyd, Prifysgol Bangor. Rwy'n ysgrifennu atoch i ofyn am help gydag astudiaeth sy'n rhan o broject eang. Mae'r astudiaeth yma yn ystyried sut mae nyrsys anabledd dysgu yn gwneud penderfyniadau yn eu hymarfer.

Rwy'n eich gwahodd i gymryd rhan mewn cyfweliad i fyfyrio ar ymarfer cyfredol ac i nodi unrhyw faes o ymchwil dylid ymchwilio ym mhellach. Amgaeaf daflen wybodaeth a ffurflen ganiatâd i chi gael golwg arnynt. Os hoffech gyfrannu at yr ymchwil llenwch y ffurflen ganiatâd a'i hanfon yn ôl ataf i'r cyfeiriad uchod erbyn Dydd Gwener, 3ydd Hydref 2008. Os oes gennych unrhyw gwestiwn, mae pob croeso i chi gysylltu â mi.
Diolch am eich amser

Yr eiddoch yn gywir,

Ruth Wyn Williams
Myfyriwr PhD
Amg: Taflen wybodaeth, Ffurflen caniatâd.

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Telephone: 01248 388691
Email: hsp42e@bangor.ac.uk
19th September 2008

Dear

<u>Research Study: Exploring decision making in learning disability nursing practice: a qualitative study</u>

I am a PhD student at the School of Healthcare Sciences, Bangor University.
I am writing to you to ask for your help with a study that forms part of my wider research project. This study explores how learning disability nurses make decisions in practice.

I kindly invite you to take part in an interview to reflect on current practice and identify further areas of research. I enclose an information sheet about the study and consent form for your consideration. If you would like to contribute to the research, please complete the consent form and return it to the address above by Friday, 3rd October 2008. If you have any questions please contact me.

Thank you for your time.
Yours sincerely

Ruth Wyn Williams
PhD Student
Encl: Participant information sheet, Consent form

Appendix C - Study 1, Participant information sheet (Welsh and English version)

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Taflen wybodaeth i'r rhai sy'n cymryd rhan

Teitl yr astudiaeth: Archwilio i'r modd y gwneir penderfyniadau yn ymarfer nyrsio anabledd dysgu: astudiaeth ansoddol.

1. Cyflwyniad
Fy enw i ydi Ruth Wyn Williams, ac 'rwy'n fyfyriwr PhD yn Ysgol Gwyddorau Gofal Iechyd, Prifysgol Bangor. Fel rhan o'm thesis rwy'n astudio sut mae nyrsys anabledd dysgu yn gwneud penderfyniadau yn eu hymarfer.

Rwy'n eich gwahodd i gymryd rhan yn y project ymchwil. Cyn i chi gytuno i gymryd rhan mae'n bwysig i chi ddeall pam y gwneir yr ymchwil a beth mae cymryd rhan yn ei olygu i chi. Cymerwch amser i ddarllen y wybodaeth isod. Siaradwch ag eraill a gofynnwch i ni am eglurhad o unrhyw beth nad ydych yn ei ddeall. Cymerwch amser i benderfynu a ydych am gymryd rhan.

2. Beth yw pwrpas yr astudiaeth?
Bydd yr astudiaeth yn edrych ar sut mae nyrsys anabledd dysgu cofrestredig yn gwneud penderfyniadau yn eu hymarfer. Bydd y wybodaeth yn helpu'r ymchwilydd i ddeall ymarfer cyfredol, a nodi unrhyw bwnc y gellir ei ymchwilio ymhellach.

3. Oes rhaid i mi gymryd rhan?
Eich dewis chi yw cymryd rhan ai peidio. Os byddwch yn cymryd rhan, byddwch yn cadw'r daflen wybodaeth yma a byddaf yn gofyn i chi arwyddo ffurflen ganiatâd. Er hyn, mae gennych hawl o hyd i dynnu allan o'r astudiaeth unrhyw bryd heb roi rheswm. Byddaf yn cadw'ch manylion cyswllt tan ddiwedd yr astudiaeth, wedyn yn eu dinistrio. Er hynny, byddaf yn cadw trawsgrifiad o'r cyfweliad heb enw nag unrhyw beth arall o'r hyn y gellir eich adnabod am 3 blynedd ar ôl gorffen yr astudiaeth PhD.

4. Beth fydd yn digwydd os cymeraf ran?
Rwy'n eich gwahodd i gymryd rhan mewn cyfweliad. Gallwn drefnu i gyfarfod mewn lle ac amser sy'n gyfleus i chi. Pwrpas y cyfweliad yw eich galluogi i rannu enghraifft o'ch ymarfer ac ystyried y penderfyniadau a wnaethoch yng nghyd-destun y gofal. Bydd y cyfweliad tua 45 munud, ac os byddwch yn cytuno, byddaf yn recordio'r cyfweliad ar dâp sain. Rydych yn rhydd i stopio'r cyfweliad, unrhyw adeg heb reswm. Ar ôl y cyfweliad, gyda'ch caniatâd, efallai y byddaf yn cysylltu â chi eto i gael eglurhad o rai o'r pwyntiau y buom yn eu trafod.

5. A fydd fy nghyfraniad yn cael ei gadw yn gyfrinachol?
Bydd y wybodaeth am eich holl gyfraniad yn yr ymchwil yn cael ei gadw'n gyfrinachol. Bydd y tapiau sain a'r wybodaeth ysgrifenedig yn cael eu cadw'n ddienw mewn cwpwrdd dan glo. Dim ond Ruth Wyn Williams a goruchwyliwr academaidd sydd â hawl i gael mynediad i'r cwpwrdd yma. Bydd y wybodaeth ar y cyfrifiadur yn cael ei diogelu â chyfrinair. Bydd y wybodaeth i gyd yn cael ei ddinistrio 3 blynedd ar ôl dyfarnu PhD.

6. Beth fydd yn digwydd i ganlyniadau'r ymchwil?

Project ymchwil myfyriwr yw'r astudiaeth. Bydd y wybodaeth a gasglwyd a'ch sylwadau yn cael eu cyflwyno'n ddienw fel rhan o thesis PhD i Brifysgol Bangor.
Ni fydd gennyf hawl i newid darpariaeth y gwasanaeth. Ond ar ôl gorffen yr astudiaeth, rwy'n gobeithio y bydd y wybodaeth newydd yn gwella a datblygu ymarfer yn y dyfodol. Gobeithiaf hefyd gyhoeddi a chyflwyno'r canlyniadau mewn cynhadledd a chylchgrawn proffesiynol i rannu'r wybodaeth â'r proffesiwn.
Byddwch yn derbyn taflen yn crynhoi canlyniadau'r ymchwil os byddwch yn penderfynu cymryd rhan.

7. Beth yw'r manteision a'r peryglon posibl wrth gymryd rhan?

Byddwch yn gallu lleisio'ch barn ynglŷn â phenderfyniadau sy'n digwydd mewn ymarfer cyfredol yn nyrsio anabledd dysgu. Nid oes unrhyw risg mewn cymryd rhan yn yr astudiaeth ac rydych yn rhydd i orffen y cyfweliad unrhyw adeg. Er hynny, os fydd adlewyrchu ar ymarfer yn achosi unrhyw bryder, neu os fyddwch yn trafod unrhyw fater a fydd yn achosi pryder, mae'r ymchwilydd yn adlynu wrth "Y Cod Safonau ymddygiad, perfformiad a moeseg ar gyfer nyrsys a bydwragedd" (NMC 2008) ac yn trafod y camau i ddatrys unrhyw broblem gyda chi.

8. Pwy sydd wedi goruchwylio'r ymchwil?

- Pwyllgor Rheoli Ymchwil Ymddiriedolaeth GIG Gogledd Orllewin Cymru / Panel Arolygu Mewnol.
- Pwyllgor Moeseg Ymchwil Lleol Gogledd Orllewin Cymru.
- Pwyllgor Moeseg Ymchwil, Ysgol Gwyddorau Gofal Iechyd, Prifysgol Bangor

Bydd tri pherson yn goruchwylio'r ymchwil: Athro Richard Hastings, Athro Fiona Irvine a Gwerfyl W Roberts

9. Beth sy'n digwydd os oes problem?

Mae'n annhebygol iawn y bydd problem. Os oes problem ynglŷn â'r ffordd y mae'r ymchwil yn cael ei gynnal, gallwch gyfeirio unrhyw bryderon heb eu datrys at Mr Ruhi Behi, Pennaeth yr Ysgol Gwyddorau Gofal Iechyd, Prifysgol Bangor, Fron Heulog, Bangor, Gwynedd. LL57 2EF
Mr Ruhi Behi   Ffôn: 01248 351151   e-bost: r.h.behi@bangor.ac.uk

10. Manylion cyswllt am fwy o wybodaeth:

Cysylltwch â Ruth Wyn Williams am fwy o wybodaeth ar 01248 388691 neu e-bost hsp42e@bangor.ac.uk

**Diolch am gymryd amser i ddarllen y daflen
ac ystyried cymryd rhan yn yr astudiaeth hon.**

Coleg Iechyd a Gwyddorau Ymddygiadol		College of Health and Behavioural Sciences
Ysgol Gwyddorau Iechyd		**School of Healthcare Sciences**
Prifysgol Bangor		Bangor University
Fron Heulog, Ffordd Ffriddoedd		Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF		Bangor, Gwynedd LL57 2EF
Ffôn 01248 351151		Tel: 01248 351151
Ffacs 01248 383114		Fax: 01248 383114

Participant Information Sheet

Study title: Exploring decision making in learning disability nursing practice: a qualitative study.

1. Introduction

My name is Ruth Wyn Williams and I am a PhD student at the School of Healthcare Sciences, Bangor University. As part of my thesis, I am currently undertaking a study to explore how learning disability nurses make decisions in practice.

You are being invited to take part in this research study. Before you decide whether or not you wish to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish and ask us if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

2. What is the purpose of the study?

This study will explore how registered learning disability nurses make decisions in practice. The information gathered will assist the researcher in understanding current practice, and identify further areas for research.

3. Do I have to take part?

It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. Your contact details will only be kept for the duration of the study, then destroyed and written transcripts of the interviews will be anonymised and kept for 3 years after completion of PhD study.

4. What will happen to me if I take part?

You are invited to take part in an interview. This will be arranged at a time and place convenient to you. The purpose of this interview is to explore your thoughts on decision making in learning disability nursing practice. You will be invited to share an example of practice and consider the decisions you took during that episode of care. The interview will take approximately 45 minutes and will be audio-taped if you agree. If you wish to terminate the interview at any time, you are free to do so without giving a reason. After the interview, with your consent, I may contact you again to clarify some of the points discussed.

5. Will my taking part in the study be kept confidential?

All the information about your participation in this study will be kept confidential. All audio-tapes and written information about individuals will be anonymised and kept in a locked cabinet accessed only by Ruth Wyn Williams and academic supervisors. Data kept on a computer will be password protected. All the data will be kept for 3 year after the completion of the PhD study; the information will then be destroyed.

6. What will happen to the results of the research study?

This study is a student research project, the information gathered, and your comments will be anonymised and form part of a PhD thesis submitted to Bangor University.

I have no authority to effect any change in service provision. However, once the study has been completed, the findings will be disseminated through conference presentations and professional journals in order to inform future practice.

If you decide to take part in the study, you will receive a feedback sheet highlighting the key findings.

7. What are the possible benefits or risks of taking part?

This study provides an opportunity for you to voice your opinion regarding the way in which learning disability nurses make decisions in practice. There are no risks for you in taking part in this study and you are free to withdraw at any time. However, if reflection on practice causes distress, or should you raise any issues that may cause concern, the researcher will adhere to the Nursing & Midwifery Council "The Code, Standards of conduct, performance and ethics for nurses and midwives" (2008) and discuss with you the steps to be taken to resolve any matter.

8. Who has reviewed the study?

- North West Wales NHS Trust Research Governance Committee / Internal Review Panel.
- North West Wales Research Ethics Committee.
- Research Ethics Committee, School of Healthcare Science, Bangor University

Three supervisors will monitor the research: Professor Richard Hastings,Professor Fiona Irvine and Gwerfyl Roberts.

9. What if there is a problem?

It is unlikely there will be any problems. However if you do experience any problems regarding the way the research is being conducted you can direct any unresolved issues to Mr Ruhi Behi, Head of School, School of Healthcare Sciences, Bangor University, Fron Heulog, Bangor, Gwynedd. LL57 2EF

Mr Ruhi Behi   Tel: 01248 351151   email: r.h.behi@bangor.ac.uk

10. Contact details for further information:

Please do not hesitate to contact Ruth Wyn Williams for further information on 01248 388691 or email hsp42e@bangor.ac.uk

**Thank you for taking time to read this information sheet
and considering taking part in this study.**

Appendix D - Study 1, Consent form (Welsh and English version)

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114
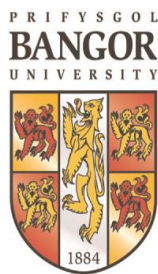
College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

FFURFLEN CANIATÂD

Teitl prosiect myfyriwr ymchwil: Archwilio i'r modd y gwneir penderfyniadau mewn ymarfer nyrsio anabledd dysgu: astudiaeth ansoddol.

Enw'r Ymchwilydd: Ruth Wyn Williams

Llofnodwch y bocs

os gwelwch yn dda

1. Rwyf yn cadarnhau i mi ddarllen a deall y ffurflen wybodaeth ddyddiedig 02:09:08, Fersiwn rhif 5 ar gyfer yr astudiaeth a enwir uchod. Rwyf wedi cael amser a chyfle i ystyried y wybodaeth, gofyn cwestiynau ac wedi derbyn atebion boddhaol.

2. Rwyf yn deall fod fy nghyfraniad yn wirfoddol ac rwyf yn rhydd i dynnu 'nôl o'r astudiaeth ar unrhyw adeg, heb roi rheswm. Ni fydd tynnu nôl o'r astudiaeth yn effeithio ar fy swydd broffesiynol.

3. Rwyf yn cytuno i'r cyfweliad gael ei recordio ar dâp sain.

4. Rwyf yn cytuno cymryd rhan yn yr astudiaeth a enwir uchod.

Diolch am eich amser.

_____   _____   _____
Enw'r Cyfrannwr   Dyddiad   Llofnod

Manylion Cyswllt y Cyfrannwr, ffôn/e-bost: _____

_____   _____   _____
Ymchwilydd   Dyddiad   Llofnod

Coleg Iechyd a Gwyddorau Ymddygiadol		College of Health and Behavioural Sciences
Ysgol Gwyddorau Iechyd	PRIFYSGOL **BANGOR** UNIVERSITY	**School of Healthcare Sciences**
Prifysgol Bangor		Bangor University
Fron Heulog, Ffordd Ffriddoedd		Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF		Bangor, Gwynedd LL57 2EF
Ffôn 01248 351151		Tel: 01248 351151
Ffacs 01248 383114		Fax: 01248 383114

CONSENT FORM

Title of Student Research Project: Exploring decision making in learning disability nursing practice: a qualitative study

Name of Researcher: Ruth Wyn Williams

Please initial box

1. I confirm that I have read and understand the information sheet
dated 02.09.08, Version No 5 for the above study.
I have had the opportunity to consider the information, ask questions
and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to
withdraw at any time, without giving any reason. Withdrawal from the
study will not affect my professional position.

☐

3. I give my permission for the interview to be audio recorded.

☐

4. I agree to take part in the above study.

☐

Thank you for your time.

_____   _____   _____
Name of Participant   Date   Signature

Participant contact details telephone/email:_____

_____   _____   _____
Researcher   Date   Signature

Appendix E - Study 1, Participant supplementary information form

Supplementary Information

1. Are you: *(please tick)*

Male ☐ or Female ☐

2. How old are you?

18–25	26-30	31-35	36-40	41-45	46-50	51-55	56-60	61-65

3. What professional and /or educational qualification do you have?

4. How long have you worked as a registered learning disability nurse?

5. What is you present post and how long have you worked there.

Appendix F - Study 1, Interview schedule (Welsh and English version)

**Canllawiau ar gyfer cyfweliad â
Nyrsys Anabledd Dysgu Cofrestredig (NADC)**

Croeso
Diolch am gytuno i gymryd rhan, pwrpas y cyfarfod yma ydi holi am eich profiad o wneud penderfyniadau yn eich ymarfer. Byddaf yn gofyn cyfres o gwestiynau, ond cofiwch ofyn a ydych eisiau trafod unrhyw fater perthnasol arall.

Rheolau sylfaenol a gweinyddol
      Cyfrinachedd a chadarnhad o fod yn ddienw
      Recordio â thap sain
      Ffurflen ganiatâd a thaflen wybodaeth

Rhan 1:
Gofynnir i'r cyfranogwr i ddisgrifio beth wnaethant mewn ymyriad neu gyfnod o ofal yn ddiweddar â pherson ag anabledd dysgu.

E.e., A fedrwch roi esiampl o ymyriad neu gyfnod o ofal yr oeddech yn rhan o honno? Gallwch chi ddisgrifio esiampl o'ch ymarfer.

Rhan 2:
Fe anogir y cyfranogwr i ddisgrifio yn fanwl eu profiad o wneud penderfyniad yn ystod yr enghraifft a gyflwynwyd yn Rhan 1.

E.e., Mae gennyf ddiddordeb yn y penderfyniadau a wnaethoch yn ystod yr ymyriad neu gyfnod o ofal a ddisgrifioch. A allwch chi ddweud wrthyf sut y gwnaethoch y penderfyniadau yma? Pa wybodaeth a ddefnyddioch i wneud y penderfyniadau yma? A wnaethoch nodi unrhyw gwestiwn ynglŷn â gofal yr unigolyn, a sut wnaethoch eu hateb?

Rhan 3:
Gofynnir cwestiynau uniongyrchol am eu dealltwriaeth o ymarfer ar sail tystiolaeth ym maes nyrsio anabledd dysgu.

E.e., Mae gennyf ddiddordeb yn beth rydych chi yn feddwl yw ystyr ymarfer ar sail tystiolaeth? Sut fuasech chi yn diffinio ymarfer ar sail tystiolaeth?

Rhan 4:
Gofynnir cwestiynau uniongyrchol i'r cyfranogwyr i ddisgrifio pa sgiliau maen nhw yn feddwl sydd angen i ymarfer ar sail tystiolaeth.

E.e., Pa sgiliau sydd angen arnoch i ymarfer ar sail tystiolaeth? Ydych chi wedi cael hyfforddiant/addysg sy'n berthnasol i ymarfer ar sail tystiolaeth.

Rhan 5:
Gofynnir i'r cyfranogwr rannu ei syniadau a'u hargymhellion ar sut gall ymchwilwyr cynorthwyo NADC yn ei gwaith o ddydd i ddydd.

Fuasech chi'n hoffi gwneud unrhyw sylw arall cyn i mi ddiffodd y tâp sain?

Diolch a diweddu.

Interview schedule for
Registered Learning Disability Nurses (RLDN)

Welcome
Thank you for agreeing to take part, the purpose of this interview is to ask about your experience of making decisions in practice. I will ask a series of questions, but if there are any issues that you would want to raise please ask.

Ground rules and Admin
      Confidentiality and anonymity
      Audio-recording
      Consent form and information form

Part 1:
The participant will be asked to give a description of what they did during a recent intervention or episode of care with a person with learning disability.

E.g., Could you give me an example of an intervention or episode of care you were involved in recently? Could you describe an example of your practice?

Part 2:
The participant will be prompted to give a detailed description of their experience of making decisions during the example presented in Part 1.

E.g., I am interested in knowing about the decisions you took during the intervention or episode of care you have described. Can you tell me how you made those decisions? What information you used to help you make those decisions? Did you identify any questions regarding the care of the individual, and how did you answer them?

Part 3:
The participant will be asked direct questions about their understanding of evidence-based practice within learning disability nursing.

E.g., I am interested in knowing more about what you think evidence based practice means. How would you define evidence-based practice?

Part 4:
The participant will be asked direct questions to describe what skills they think are required to engage in evidence-based practice.

E.g., What skills are required to engage in evidence based practice? Have you received any training/education related to evidence based practice?

Part 5:
Participants will be asked to share their ideas or recommendation on how researchers could best help RLDN's in their day-to-day work.

Any other comments that people would like to make before I switch the tape off.

Thanks and Closure.

Appendix G - Study 1, Diagram of Step by step process of IPA analysis (Smith & Osborn 2008)

Data Analysis
Idiographic approach

Independent analysis of each transcript

1. Looking for themes

2. Connecting the themes

3. Table of themes

4. Produce a master table

Analysis across 12 transcripts
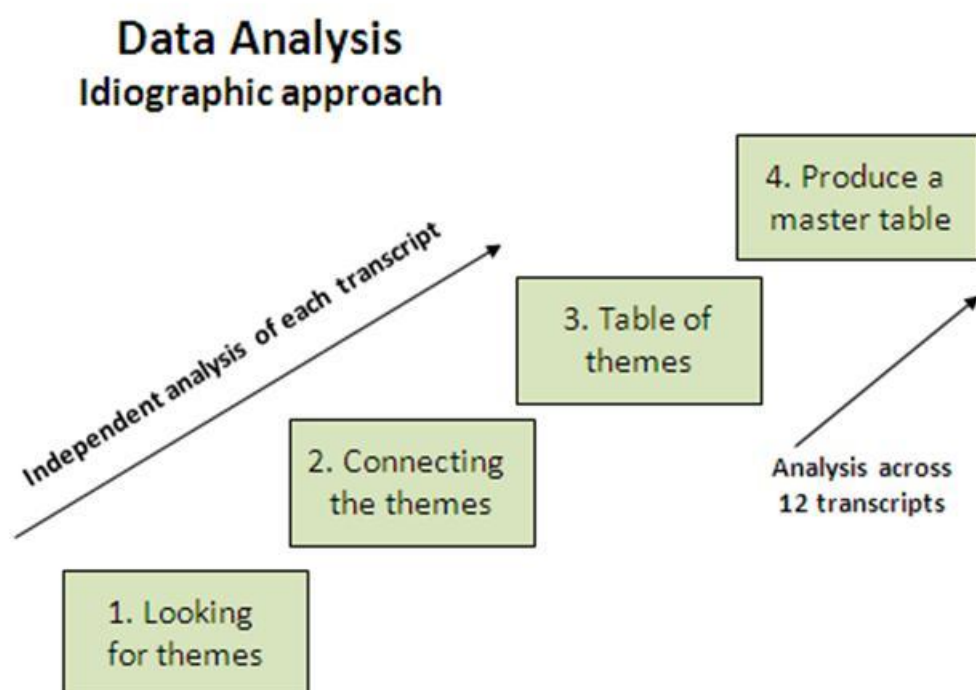
Appendix H - Study 1, Example of IPA analysis

The analysis followed the step by step process described by Smith and Osborn (2008). Adopting this approach, the following key documents were produced:

Stage 1   Initial response and emerging themes (transcripts 1-12)

Stage 2   Emerging themes and clustering (transcripts 1-12)

Stage 3   Table of themes and identifiers (transcripts 1-12)

Stage 4   Master table of themes for the group

Examples are provided for each of these stages of analysis, as outlined below:

Stage	Process	Examples
Stage 1	Initial response and emerging themes	Excerpts from transcripts 02; 04; 06
Stage 2	Emerging themes and clustering	Transcripts 02; 04; 06
Stage 3	Table of themes and identifiers	Transcripts 02; 04; 06
Stage 4	Master table of themes for groups	Super ordinate theme 1: Person at the centre

Example of Stage 1 - Study 1. Transcript 02: Initial response & emerging themes

		Initial Response		**Emerging theme titles**
1	10.40hrs		*Part 1, I'm going to ask you to describe an area of*	
2			*your practice, an intervention or episode of care you*	
3	0:00.23		*did with a client, recently*	
4		Health intervention, diabetes	… Let me think… this is an intervention, ..., we have	Type of intervention – health, physical task
5			a client that has diabetes that recently ... lost his	
6			toes through the diabetes. So, we ... have to dress	
7		R: unsure	the toes and things like that, ... is that the sort of	
8			thing you want…	
9			*Yes if it and intervention you've done*	
10			Yes, ok. When he first came he was quite	Intervention more than a physical task
11		Intervention more than just physical intervention, addressing behaviour & understanding why / purpose client need toes dressed.	aggressive and very unnameable to any sort of	
12	00:01:03		intervention, we've now got him where he's now	

13			asking sort of like to have his toes dressed so it's	
14			coming along fine, you know (long pause). Yes I	
15		R: participant needed reassurance, why, nobody asked about practice before? why volunteer to take part in interview?	really don't know if that's the sort of thing you…	Participant unsure of what an intervention is? use of language?
16	0:01:16		*Yes, that's fine. What I'm interested now is in the*	
17			*decisions you made about his care plan, so if the*	
18			*goal was to redress his toes*	
19			All right. Yes, yes, yes….	
20	0:01:38		*How did you go about, how-.*	
21		Work with other professionals to learn how to assess, treat physical problem	We brought in the district nurse. Who then showed	Working with other professionals, taught by others
22			us how to redress, what to look for and how to clean	Joint decision making on physical care
23		Plan of physical care written with District nurse	the wound, ... that was done … by the district nurse.	
24			And then we took over that role as we got more and	

281

25				more confident in doing it, that we weren't doing any	Assessment of own (nursing) skills
26				harm, we were actually following their plan of care.	
27				And ..., yeah it's worked out quite well you know it	
28				wasn't just about cleaning his toes, really, with him.	
29			Intervention not just physical care, importance of forming relationship with client, trust Client centred care- helped the healing process?	It was about ... forming a bit of a relationship and	Forming relationship with the client, trust
30	0:02:20			that he had trust as well because he came in when	
31				he was very aggressive, you know he'd been	
32				pushed from pillar to post and I think part of the	
33				reason why his foot wasn't getting better to soon	
34				was because, he didn't have that relationship with	
35				the cares to let them clean his foot, you know, and	
36				things. So, I think it wasn't just about getting a care	
37				plan for an intervention for his foot, it was about him	Affect of relationship on the care process
38				learning to trust us and forming a relationship, and I	

Example of Stage 2 - Study 1. Transcript 02: Emerging themes & clustering.

Transcript 02: Emerging themes titles	Clustering of themes
Type of intervention – health, physical task Intervention more than a physical task Participant unsure of what an intervention is? use of language? Working with other professionals, taught by others Joint decision making on physical care Assessment of own (nursing) skills Forming relationship with the client, trust Affect of relationship on the care process Involve the client Explained to the client what was going to happen Unsure how to describe the building of trust between client & nurse Holistic approach Include the client in the process Underling ethos, value base Understanding the clients emotional needs Person centred Value base Intuition Decisions made by the team Sources of information for decision making Pre admission information Care plan evolves around needs Client centred Sources of information- to get to know the person Best interest of client Joint decision making – named nurse & charge nurse – in care planning process Information from previous notes, past history Care planning and evolving process Sources of information to identify needs of client Reading The person Other people Team effort Team members – all nursing staff on villa No specific/organised team meeting to discuss clients Handover - a safe arena for staff to share thoughts, feelings about clients care Handover – "I'm not happy", "what do you think" Open discussions among staff Acknowledge limitations, referral to others Values handover, supportive decision making "that sort of thing" unsure of EBP Relates EBP to research Relates research to newly qualified nurses Utilises other staff to find evidence/research Unsure of relevance of research to her practice Definition of evidence - review care, value client/staff opinion, skills required - people skills Supporting research accessed by newly qualified staff Willing to ask for help to find research Does not use computers to access information Team work needs a skill mix Participant experience of research and practice	Type of intervention – health, physical task Intervention more than a physical task Participant unsure of what an intervention is? use of language? Working with other professionals, taught by others Joint decision making on physical care Include the client in the process Decisions made by the team Joint decision making – named nurse & charge nurse – in care planning process Acknowledge limitations, referral to others Team work needs a skill mix Assessment of own (nursing) skills Intuition Sources of information for decision making Pre admission information Sources of information- to get to know the person Information from previous notes, past history Care planning and evolving process Sources of information to identify needs of client Reading The person Other people Team effort Team members – all nursing staff on villa No specific/organised team meeting to discuss clients Handover - a safe arena for staff to share thoughts, feelings about clients care Handover – "I'm not happy", "what do you think" Open discussions among staff Values handover, supportive decision making Does not use computers to access information Forming relationship with the client, trust Affect of relationship on the care process Involve the client Explained to the client what was going to happen Unsure how to describe the building of trust between client & nurse Holistic approach Underling ethos, value base Understanding the clients emotional needs Person centred Value base Care plan evolves around needs Client centred Best interest of client

Skills for EBP - IT Nurses need to understand why EBP is valuable Give practice example of EBP- demonstrate it's usefulness Need for practical examples to teach the importance of EBP Relates EBP to accountability EBP as a requirement? EBP more than research, personal aspect , intuition, people skills, observation Difficulty in describing what intuition is. The need for nursing to use "human skills" not just academic skills. Person centred – value base – "the need to bring out the best" Importance of skill mix in a team Service provision, close-knit community Research areas: Person centred – "what it's like", loss of independence, community, culture, language How do people with LD explain their thoughts feelings Client centred	"that sort of thing" unsure of EBP Relates EBP to research Relates research to newly qualified nurses Utilises other staff to find evidence/research Unsure of relevance of research to her practice Definition of evidence - review care, value client/staff opinion, skills required - people skills Supporting research accessed by newly qualified staff Willing to ask for help to find research Participant experience of research and practice EBP more than research, personal aspect , intuition, people skills, observation Difficulty in describing what intuition is.
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	Research areas: Person centred – "what it's like", loss of independence, community, culture, language How do people with LD explain their thoughts feelings Client centred

Example of Stage 3 - Transcript 02: Table of themes and Identifiers

Themes	Keywords from transcript	line number
1. Type of intervention health, physical task Intervention more than a physical task	we have a client that has diabetes that recently ... lost his toes through the diabetes.	4-6
2. Worthing with others Working with other professionals,	We brought in the district nurse	21
Learning from others Joint decision making on physical care	we took over that role as we got more and more confident in doing it, that we weren't doing any harm, we were actually following their (district nurses) plan of care.	24-26
Team decisions	Well I think we all sit down, and we say - well initially, I think the charge nurse along with who's allocated to him ... writes and initial care plan.	68-71
Acknowledge limitations, referral to others	might be right bring in a psychiatrist, go and see the doctor or …. maybe physio or what ever.	146-147
Include the client in the process	I just think that's how we tend to do it here, we do a lot of explaining of what is going to happen	50-52
3. Information that helps decision making Assessment of own (nursing) skills	we took over that role as we got more and more confident in doing it, that we weren't doing any harm, we were actually following their (district nurses) plan of care.	24-26
Team effort	I think we (staff team) all sit down,	68-69
	charge nurse along with who's allocated to him.	70
	Somebody would of met him before he came in. To see if he's actually, not suitable, but, whether he would, is it the right place for him,	96-98
	you actually do sit down and discuss it, with a lot of other people. I don't think it's just one person really, although that one person might be writing the care, I think it takes a team effort to say I've noticed this…	119-123
	We have change over, and I think a lot of things get discussed that not actually (related to the usual handover routine)	129-130
	. I never analysed that (handover) but I think we do, do a lot of decision making or ... the thoughts are there for us to think,	152-154
	I think all teams have different	215-216

	dimensions that they can bring in anyway.	
	your skill base on the ward is in valuable your skill mix.	298-299
	You can have a load of academics or you could have a load of good people skills, it's got to be a good mixture	307-309

Sources of information for decision making
  get to know the person
  Reading, The person, Other people
  Intuition, handover
Care planning and evolving process
	bit of background information	75

	so you do look in his notes and see what's happened in the past..	77-78
	a little rough idea of what the gentleman's needs are before you actually see him.	80-81
	you're not really fishing in the dark	83-84
	just make a very sketchy care plan of his needs	85-86
	And I will go and ask somebody who's recently qualified, how do I get the evidence for this, and because they are a bit more up to speed-	170-172
	I do rely on a lot of other people	195-196
	research from the net to back up certain things	209-210
	, you're talking about well established little ... hospital here, that doesn't have a lot of change over of staff. So people do get to know about other peoples skills and other peoples knowledge,	313-316
4. Person centred Forming relationship with the client, trust Affect of relationship on the care process	it wasn't just about cleaning his toes, .	27-28
	It was about ... forming a bit of a relationship and that he had trust,	29-30
	I think it wasn't just about getting a care plan for an intervention for his foot, it was about him learning to trust us and forming a relationship, and I think that was a very important step to his healing process as well.	36-40
	we just don't look at one side of his care like it wasn't just about his foot and his diabetes it was about how he felt about things,	52-54
Involve the client	I think he needed … to know that (long pause) I think ... he didn't know what to expect from us.	43-44

	we do a lot of explaining of what is going to happen .	47
	Somebody would of met him before he came in. To see if he's actually, not suitable, but, whether he would, is it the right place for him,	96-98
Underling ethos, value base	he just learnt that we cared about him as a person not just is foot or his diabetes or… just little aspects of his care.	61-63
	I don't know why how we come to it we just do it do, you know what I mean, it's just, I think it's just part of (pause)	63-65
5. Definition of EBP		
unsure of EBP	I do use that sort of thing (EBP)	166-167
	When you've been in the job a little bit longer, I think it is (research) relevant, but, I'm not so sure.	178-180
Relates EBP to research & newly qualified nurses	I think the newer qualified are very much up to speed on that	167-168
	They (newly qualified) tended to do a lot more research than I have ever done.	169-170
	They (newly qualified) will say evidence says, if there is a new research out, that says this that and the other. And sometimes I think ... that is an excellent tool. But also (long pause). When you've been in the job a little bit longer, I think it is relevant, but, I'm not so sure.	175-180
	I do rely I've got to say, maybe I'm wrong I don't know. But I've got a really, good, newly qualified staff nurse, who is really into it. And I'll say can you, can you get me some … research from the net to back up certain things, do you know, what I mean	206-211
Definition of evidence - review care, value client/staff opinion, skills required - people skills	Has there been an improvement that would be my evidence ... to say, yeah that's the right may of doing it, you know. And also I would ask other people is there a better way of doing this, you know I wouldn't be frightened to say. That been successful down on another villa, how did they do it, and why was it. So, I do rely on a lot of other people (long pause) people skills as well. Is that the right sort of thing?	189-197
EBP more than research, personal aspect , intuition, people skills, observation	evidence based practice is probably got to be a bit …it's got to be done. As much as possible, yeah- -Ok-	268-287

Difficulty in describing what intuition is.	-but you see, sometimes you can lose the …, personal aspects of things as well. Do you know what I mean. And, I think you've got to have a balance as well, I think you've got to have a bit of intuition with things as well. I don't think it can … I don't know I think, you've got to have a lot of people skills as such, if… a bit of observation as well ...- *Could you measure or record intuition-* ...m….. *How do we know that a nurse has good intuition?* I know, I know it very difficult isn't it. Well observations skills then, is that the same…mmm… I think you cant just be academic in nursing. And sometimes I think we've gone down to much that road of academia that you lose a lot of human skills. I don't know how to say that really (long pause).	
6. Skills for EBP		
Communication skills	ask other people is there a better way of doing this,	192
	people skills	196
Nurses need to understand why EBP is valuable	observations skills	283
Need for practical examples to teach the importance of EBP	show them (nurses) that it's a valuable thing(EBP)	227
	open to ideas	235
	show them an example of why you need it (EBP)	237-238
Relates EBP to accountability &requirement?	legal aspects of evidence based practice	258-259
Intuition	I think you've got to have a bit of intuition with things	275-276
Human skills		
	you lose a lot of human skills.	286
	(people lacking in people skills – academic) they don't know how to bring out the best in a person.	293-294
7. Research areas:		
Person centred – "what it's like", loss of independence, community, culture, language How do people with LD explain their thoughts feelings	I often wonder what it's like for	329
	he's lost everything	336
	And he's now totally dependent on us as a team to fill certain things in his life that he's always taken for granted and always have	343-346

Example of Stage 1 - Study 1. Transcript 04: Initial response & emerging themes

		Initial Response		Emerging theme titles
1 2 3	12:41hrs	R: participant has just changed jobs, will relate these questions to previous role as a staff nurse on the assessment & treatment unit.	*The first part is about asking you to give an example* *of your practice, some intervention that you've* *recently done, I know you've recently changed jobs,*	
4	0:00.21		Mmm	
5 6 7			*but if you could remember something you've done* *with a person with learning disabilities, an* *intervention or an episode of care*	
8			yeah, ok	
9			*an example-*	

10			an example of that, now, …	
11			*yes*	
12		Intervention: initial thought =support with personal hygiene More to it than that	ok, ok probably the last thing I did, was to support	Intervention, health, support & wellbeing
13			a lady to have a bath,	
14			*ok*	
15	0:00:49		she had been, do you want some background-	
16			*yes*	
17		R: omit details re: physical problem, client could be identified	ok. She'd been admitted to the unit, due to a	Admitted: challenging behaviour caused by physical problem
18			deterioration in behaviour and they discovered it	

19			was caused by a physical problem, … (named	
20			problem)	
21			*right*	
22	0:01:10	Client recovering from surgery	and …she had a spell of intensely disturbed	Needed to get to know the client
23			behaviour, aggression, …when she was first	
24			admitted. Then I didn't see her in the process of	
25			her having an operation to (named procedure) , so	
26			that morning, I hadn't seen her, and she hadn't	
27		Nurse hadn't worked with client for some time, felt she didn't know the person, supporting with the bathing seemed a good way to get to know the person	remembered me. Although I had worked with her	Acknowledging the client
28			for weeks and weeks and weeks. It was like	
29			meeting completely new different person-	
30			*mmm*	
		Nurse expressing personal		Emotional involvement in care

31		feelings about the person, empathy	-she was completely different. Calm, compos	
32		Nurse enjoyed the company of the client "lovely … sort of hour"	mentis, happy relaxed, and it just took me by	
33			surprise, because the last time I'd seen this lady,	
34			she'd , you know, was so distressed. So it was	Genuine emotion
35			really really, lovely … sort of hour that I spent with	
36	0:01:57	Physical intervention wasn't the goal = getting to know the person	her. Helping her get into the bath, washing her hair,	
37		PCP	supporting her to do the things she couldn't quite	Build a relationship with the client
38			manage to do yet. And just getting to know the real	
39			her, not this person that was affected by like a build	
40			up of toxins in her body.	
41			*Ok. Good. What I want to do now is to break down*	
42			*that intervention, that hour you spent with her, into*	
43			*stages and consider what decisions you took*	

Example of Stage 2 - Study 1: Transcript 04. Emerging themes & clustering.

Transcript 04: Emerging themes titles	Clustering of themes
Intervention, health, support & wellbeing Admitted: challenging behaviour caused by physical problem Needed to get to know the client	Intervention, health, support & wellbeing Admitted: challenging behaviour caused by physical problem
Acknowledging the client Emotional involvement in care Genuine emotion Build a relationship with the client Decisions taken at handover , sharing of responsibility for the care Gathered information from others before intervention Valued information from other people that had worked with the client Client enabled to control intervention Nurse as facilitator Client led intervention PCP empowerment Empowering client Decisions based on assessment, family, observation Knowledge of client background informed decisions Acknowledge clients ability Importance of involving the family, listening Working with others, information from medics Information from psychiatrist & Google Access to internet in work , searches for information exclusively on the internet No access to databases in work Ability to critique information gathered from the internet Questions source of information on internet Skills in fostering a relationship with client, share experience, ask questions Mutual relationship – nurse also giving of herself , empathy Giving time to the client to talk, nurse listening Valuing the person Nurse protective of clients feelings Values person, caring Decision, in clients best interest – not agreed by team but an ethos of the care – to do no harm Decision based on best interest – intuition, experience Persons best interest Valuing the person, to do no harm Moral/ethical dilemma for nurse Experience & intuition Clients insight to care Client involvement in sharing own story with other professionals Clients wishes respected Client and immediate family - involvement in decisions Ask other staff known to client for information Sources of information Intuition & experience Experience of working with others Influence of nurse value base on decision making Value of PCP Ethos of care different between services	Needed to get to know the client Acknowledging the client Emotional involvement in care Genuine emotion Build a relationship with the client Client enabled to control intervention Nurse as facilitator Client led intervention PCP empowerment Empowering client Acknowledge clients ability Importance of involving the family, listening Skills in fostering a relationship with client, share experience, ask questions Mutual relationship – nurse also giving of herself , empathy Giving time to the client to talk, nurse listening Valuing the person Nurse protective of clients feelings Values person, caring Decision, in clients best interest – not agreed by team but an ethos of the care – to do no harm Decision based on best interest – intuition, experience Persons best interest Valuing the person, to do no harm Moral/ethical dilemma for nurse Experience & intuition Clients insight to care Client involvement in sharing own story with other professionals Clients wishes respected Intuition & experience Influence of nurse value base on decision making Value of PCP Ethos of care different between services
	Decisions taken at handover , sharing of responsibility for the care Gathered information from others before intervention Valued information from other people that had worked with the client Decisions based on assessment, family, observation Knowledge of client background informed decisions Working with others, information from medics Information from psychiatrist & Google Access to internet in work , searches for information exclusively on the internet No access to databases in work Ability to critique information gathered from the internet Questions source of information on internet Client and immediate family - involvement in decisions

Other professionals involved in care Relates EBP to research, use of "obviously" Critiquing of research papers to find evidence Also a non-academic side to EBP Sharing practice ideas Online resource to share practice Gathering information from other people Local group to share practice innovation Practitioner involvement in task & finish group Nurse demonstrate ability to search literature Local groups disseminate information Skills needed for EBP: IT, find & critiquing research Training & Education in EBP: university course, modules Allowed time in work to access information Research area – emotional care LD limited research available	Ask other staff known to client for information Sources of information Experience of working with others Other professionals involved in care
	Relates EBP to research, use of "obviously" Critiquing of research papers to find evidence Also a non-academic side to EBP Sharing practice ideas Online resource to share practice Gathering information from other people Local group to share practice innovation Practitioner involvement in task & finish group Nurse demonstrate ability to search literature Local groups disseminate information
	Skills needed for EBP: IT, find & critiquing research Training & Education in EBP: university course, modules Allowed time in work to access information
	Research area – emotional care LD limited research available

Example of Stage 3 - Transcript 04: Table of themes and identifiers

Themes	Keywords from transcript	line number
1. Type of intervention Intervention, health, support & wellbeing	to support a lady to have a bath,	12-13
Admitted: challenging behaviour caused by physical problem	admitted to the unit, due to a deterioration in behaviour and they discovered it was caused by a physical problem,	17-19
2. Valuing the client		
Forming a relationship, empathy, listening	(nurse identified need to form a relationship with the client) so that morning, I hadn't seen her, and she hadn't remembered me. Although I had worked with her for weeks and weeks and weeks. It was like meeting completely new different person	25-29
	she was completely different. Calm, compos mentis, happy relaxed, and it just took me by surprise, because the last time I'd seen this lady, she'd , you know, was so distressed. So it was really really, lovely … sort of hour that I spent with her.	31-36
	just getting to know the real her, not this person that was affected by like a build up of toxins in her body.	38-40
	at the time I probably said it several times how nice it was to see that she had made a good recovery and she shared her experiences of the whole process.	169-172
	And we kind of we, we, it was all very informal really and we kind of …, and we had a bit of a laugh about that. You know, I said, well I've been with you, sat with you, helped you do things for sort of a long period of time and, isn't it strange that how you don't remember me and how overwhelming that, that physical illness must of been for you	175-181
	So you were asking about her feelings and thoughts? Yeah, yeah… She (pause) thought that she (pause) she was able to say that she knew that she had been on this journey.	184-188
Empowerment	She said I would like to have my breakfast now, I would like to have such and such for breakfast … and then I'd like to have my bath… So it was more, more of a process of her facilitating the activity than me.	64-68

	…it was almost like I was like … like a student and she was my mentor (laugh),	70-71
	She needed some assistance to get in the bath, but she told me exactly what I needed to do.	76-78
	And then, I asked her what she needed support with, and she told me just to help her to wash her hair and would I kindly come back in 10 minutes, then … she would be ready for me to wash her hair.	81-85
	So it was very much, there wasn't much decision making on my part really, other than to give her the opportunity to be in control of the situation.	87-89
	in her room she had a hundred or so get well cards and well wish cards from people in her community. So I knew that she would be someone who had a lot of independent skills herself, and the way she was presenting ,her articulation, confidence and everything is just … *-gave you the cues,*	98-104
Family involvement	first few weeks of admission her mum, spent a lot of time, spending time with us, telling us about her daughter before the illness showing photographs. I think she really wanted us to have an idea that this wasn't her	114-118
Value base/ethos of care Nurse protective of clients feelings	, in some respects.. and I'm sure she would feel the same, and I'm quite glad of that, because her distress and her behaviour was so extreme at time, that I'm sure she'd be devastated to understand some of the things that she had done and said.	193-198
Decision, in clients best interest – not agreed by team but an ethos of the care – to do no harm, ethical dilema	some things we really didn't want her to know about because she had been physically aggressive *Ok* towards people, and she had, *so why did you decide that* because we felt that she was such a lovely caring lady, … that it would just upset her too deeply to think that she had ever hurt her mum	205-213
Decision based on best interest – intuition, experience	I think it was, probably not discussed as a team, because it is almost impossible to, to, to discuss everything as a team. But, I think, intuitively people will not of wanted her to have that insight	223-226
Valuing the person, to do no harm	I suppose we would of told here in	243-246

	general terms maybe that she had been aggressive towards people but we wouldn't be specific about who, or what, or where	
Client involvement in sharing own story with other professionals	she was asked, because it was such an interesting … case, I suppose, from the medical side, the consultant psychiatrist asked if they could present it as a case study to other psychiatrists. And they invited her to be a part of that process.	264-269
Clients wishes respected	she wanted to take pride in telling people about her journey, but, she felt that there were too many missing pieces at that time.	275-278
Influence of nurse value base on decision making Ethos of care different between services	But we didn't feel that maybe they'd look at her as a person, they looked at her more of, as a problem. You know when she arrived her hair, her hair hadn't been washed and things. She hadn't been looked after properly, so the information that came from them we didn't feel was valid.	313-318
3. Sources of information that influence decision making		
Decisions taken at handover ,	… before she got up there was a period of handover and there always a period of … deciding who's going to do what during the day. Just so we've got a clear idea of who's responsibility it is to do various things.	47-51
Gathered & valued information from others	I chatted to the team that had been working more closely with her in recent weeks … to find out where she was at in her recovery. So I got quite a lot of information from the staff, and I asked one particular health care assistance who had supported her in the morning, yesterday, the previous day.	52-58
Decisions based on assessment, family, observation, background information	Because I'd been involved with the pre-admission assessment for this lady and I'd spent a lot of time with her mum and I was aware that she had been a very independent lady.	93-96
	she had a job, she was a member of… and operatic society.	97-98
Information from other professionals	obviously it was discovered by medics. But we were given information about on … what, what likely to happen to a person with that particular condition, yeah, yeah,	123-126
	From where did you get that information	127-128

Information from psychiatrist & Google	… the consultants psychiatrists, and .. Google	
Internet access	*do you have access to Google in work* Yes,	132-134
	we exclusively used the internet and the information we got from the medics really	139-140
No access to databases in work	No, I think they've just stopped access to Athens.	143-144
Questions source of information on internet	… I think it was an NHS website, you know, it was a valid website, yes I'd always look at where the information is coming from	155-157
Intuition & experience	*there's a lot of intuition and passed experience that get you to make decisions in a certain way,* yeah,	295-297
4. Defining EBP		
Relates EBP to research, use of "obviously"	Obviously looking at research	335
Critiquing of research papers to find evidence	I would always look at the scope of the study, you know, if you say, if there's something … in a newspaper and it says: there's been a study into such and such and 43 people were interviewed on- and it's like big headline news. And you think mmmm 43 people, perhaps that not, not enough. So I make, there's a decision making process there when I'm looking at … evidence	337-344
Also a non-academic side to EBP Sharing practice ideas Online resource to share practice Gathering information from other people Local group to share practice innovation	*So what is evidence, what is good evidence* Mmmm *Is it just looking at research* (Pause) -no I guess, that's the academic side of it, isn't it; and there's sharing, sharing experiences with colleagues. We've tried to set up a kind of peer clinical supervision group…there are all sorts of ways I suppose… I use the Janet Cobb networking system	348-356
Practitioner involvement in task & finish group Nurse demonstrate ability to search literature	… I've been involved in task and finish groups where you would do, …one of the tasks would always be like a literature search	372-374
Local groups disseminate information	one group produced, I think it was the sexuality one, they produced a couple of workbooks, really good, easy to use pictorial …guides for people to use. They were rolled out across the all the teams,	381-386

	that was about a year ago.	
5. Skills for EBP		
Skills needed for EBP: IT, find & critiquing research	I think more and more you'd have to teach them IT skills. And as I was saying before… weighing …deciding whether a source is … valid and reliable or not. I think you'd, I think you have to apply a bit of detective skills when you're looking for evidence and research. …	390-395
	just not knowing how to access to it (information) easily,	420-421
Training & Education in EBP: university course, modules	(access to EBP education or training) I must of done (laugh) I must of done (laugh)	399
	you're taught how to use the systems in the university. But I think unless you do modules, I'm just trying to thing about people who maybe did their training before the era of IT and internet and things, and they haven't done much further study or modules. I think they're the ones that really struggle.	401-407
Allowed time in work to access information	*you get time in work to look for information and read* Yeah, yeah	422-424
6. Research areas		
Research area – emotional care	emotional care, so I think that would be one area that I would advocate for more research in. how to provide emotional care for people with learning disabilities. How do we teach people to be there for people with learning disabilities	442-446
	I think it's hard sometimes to to explain to an 'old school' nurse or support worker that it's ok just to be with a person to sit with them, and you don't have to actually be running around doing things, doing tasks,	448-452
LD limited research available	if you do a literature search for something to do with learning disabilities you tend to get a lot back from the mental health side of things.	458-461

		initial response		Emerging theme titles
1	10:25hrs		*Yn y rhan cynta' dwi isho chdi feddwl am dy ymarfer,*	
2	0:00.11		*"practice" bob diwrnod*	
3			Ok	
4			*Meddwl am rhywun ti di gweithio hefo yn ddiweddar*	
5			*a fedri di ddisgrifio unrhyw ymyriad "intervention" ti'*	
6			*di gynllunio ar gyfer y person yna*	
7			Ok	
8		Autistic spectrum	… dyn sy'n di dod i fewn hefo ni, mae yn cael ei	Intervention, structure to care plan
9			dischargio heddiw, i fod yn onest. A mae wedi dod i	
10			mewn o dan yr ambarela o'r autistic spectrum. Ag	
11			tua 6 wythnos yn ôl roedd pawb yn deud: da ni'm yn	

12		Cefnogi'r client	gneud llawer i syportio dyn yma. So nesi i ddeud	
13			wel, os di'o yn dod o dan fatha yr label austistic, felly	
14			dyla'ni roid ychydig bach mwy o structure yn ei	
15		Trefn i fywyd y client	fywyd a trefn i gynllun gofal o felly. A dyna be nasi i.	
16	0:01:10		Yn y dechrau roedd yn gweithio yn grêt. (chwerthin)	
17			ond ti'n gwybod, mae o'n anodd am bo na tîm mor	Working as a team to deliver care plan difficult – over 30 staff
18		Gweithio mewn tîm mawr – effeithio ar y cynllun gofal	mawr yna, so doedd pawb ddim yn cadw i'r ru'n un	
19			cynllun y cynllun o ni di roid yn y cynllun gofal.	Client involvement Client consented to care plan, agreement signs care plan
20			Oedd o wedi cytuno hefo fo, wedi arwyddo fo, wedi	
21		Wedi cael cytundeb ar client - gweld gwerth yn yr ymarfer = mwy i neud	hapus braf i ni ddechrau hyn hefo fo. Cos oedd o'n	
22			mynd i helpu fo hefo cael ychydig mwy o … mwy o	Care plan = benefit to client
23			'activities' a pethau yn eu ddyddia pan doedd gen o	
24			ddim gwaith i fynd i.	
25			*Meddyliad yn nol i pan nes di ysgrifennu y cynllun*	
26	0:01:23		*yma, sut ne s'di roi y cynllun hefo'i gilydd*	

27			Reit, nathon ni feddwl am y pethau, fo a fi yn siarad	PCP – initial discussion with client
28		Cychwyn a sgwrsio ar client	hefo'n gilydd i ddechrau a gofyn be oedd o'n licio	
29		Gofyn barn y client	neud, be oedd o ddim yn licio neud. Sut oedd o'n	Client led care plan
30			licio pobol approacho fo, os o'n licio rhywun jyst	
31			siarad un i un, a nath o deud: yndw, well gen i fod	
32			fela. A mae o'n ddyn sy'n gallu colli ei dempar yn	
33			reit hawdd hefyd	
34			*Reit*	
35	0:02:01	Gofyn i'r client	So, nes i ofyn iddo: be 'sy'n gora' pan ti'n teimlo yn	Involve client in writing care plan
36			reit anhapus, :sa ti'n licio pobol siarad hefo chdi	
		Gofyn barn y client	adeg yna, wyt ti'sho pobol ddeud wrth tha ti am fynd	
			i 'stafell ta ti'sho rhywun 'ista hefo chdi …	

Example of Stage 2 – Study 1: Transcript 06. Emerging themes & clustering.

Transcript 06: Emerging themes titles	Clustering of themes
Intervention, structure to care plan Working as a team to deliver care plan difficult – over 30 staff Client involvement Client consented to care plan, agreement signs care plan Care plan = benefit to client PCP – initial discussion with client Client led care plan Involve client in writing care plan Plan care using words that the client knows, recognises, used computer to generate guidelines for client Accessed computer / working with another newly qualified nurse Care plan in a format that the client would understand and use Care plan geared towards individual Nurses previous experience, questioning practice during morning shift, Shift team of nurses agreed with new care plan, nurse presented in handover 2pm Disseminate information – communication book Initially questioned what the unit was doing for the client Nurse had responsibility for shift, not named nurse Previous experience of autism influenced questioning of practice Influence decision making - Previous experience and talking to the client Joint decision making on care plan – nurse/client Ways to disseminate information within the unit – handover, communication book Background information – previous placement/home Empathy with client, who's trying to understand a system Care plan reviewed by treatment team on a weekly basis Treatment team members, multi-disciplinary Treatment team works in 2 ways, review existing care plan or discuss new ideas for the care plan A multi-disciplinary agreement on all care plans although some decisions will be done before being discussed at meeting Joint working with SALT, assessment of language understanding	Intervention, structure to care plan Nurse had responsibility for shift, not named nurse<hr>Working as a team to deliver care plan difficult – over 30 staff Accessed computer / working with another newly qualified nurse Shift team of nurses agreed with new care plan, nurse presented in handover 2pm Joint decision making on care plan – nurse/client Care plan reviewed by treatment team on a weekly basis Treatment team members, multi-disciplinary Treatment team works in 2 ways, review existing care plan or discuss new ideas for the care plan A multi-disciplinary agreement on all care plans although some decisions will be done before being discussed at meeting Joint working with SALT, assessment of language understanding Process of decision making Multi-disciplinary review or pre-discharge meeting to review care 30 staff – requires joint up thinking Different shift patterns Changes in service provision, unsettling for staff, skill mix of staff<hr>Client involvement Client consented to care plan, agreement signs care plan Care plan = benefit to client PCP – initial discussion with client Client led care plan Involve client in writing care plan Plan care using words that the client knows, recognises, used computer to generate guidelines for client Care plan in a format that the client would understand and use Care plan geared towards individual Initially questioned what the unit was doing for the client Empathy with client, who's trying to understand a system

Process of decision making Multi-disciplinary review or pre-discharge meeting to review care Named nurse writes a weekly report – summary of what's happened re: care plan Clear system of decision making Nurse in-charge on the day of the treatment team meeting will present named nurse care plan. A book for qualified nurses to specify any ideas, request for ideas, support, questions Definition of EBP Definition Related EBP to own practice, reading re Aspersers Research to influence practice Supporting evidence available for intervention Previous experience influences EBP Unsure if EBP could use experience or just published research No session, training on EBP EBP – skills =communication, patience, hard work Important to have support of others, staff & client Agreement that everyone will take part in care plan Need to be able to explain why the intervention is necessary to other staff – to gain support Skilled in working together, & teaching advising staff why the intervention is important Working together Commitment to the individual and to the care plan process Changes in service provision, unsettling for staff, skill mix of staff 30 staff – requires joint up thinking Different shift patterns Handover more than passing information on, a place to consider make decisions Communication book compared to the bible White board as a notice board for non-confidential messages for staff Access to internet in the office Use internet to find information e.g. re: diagnosis Time in work to access internet for information because the unit is not full Information gathered is places in rota file, Plus a clinical interest file – with diagnosis, medical info Participant doesn't use the computer Scared of using the computer Need training to use computer, many staff on ECDL course Research areas Personal effort to find information on subjects relevant to practice, attends modules, read Information on internet for specific disorders Much info comes under MH Research Research into what service caters for people who have LD & MH	Nurses previous experience, questioning practice during morning shift, Disseminate information – communication book Previous experience of autism influenced questioning of practice Influence decision making - Previous experience and talking to the client Ways to disseminate information within the unit – handover, communication book Background information – previous placement/home Named nurse writes a weekly report – summary of what's happened re: care plan Clear system of decision making Nurse in-charge on the day of the treatment team meeting will present named nurse care plan. A book for qualified nurses to specify any ideas, request for ideas, support, questions Handover more than passing information on, a place to consider make decisions Communication book compared to the bible White board as a notice board for non-confidential messages for staff Access to internet in the office Use internet to find information e.g. re: diagnosis Time in work to access internet for information because the unit is not full Information gathered is places in rota file, Plus a clinical interest file – with diagnosis, medical info Participant doesn't use the computer Scared of using the computer
	Definition of EBP Definition Related EBP to own practice, reading re Aspersers Research to influence practice Supporting evidence available for intervention Previous experience influences EBP Unsure if EBP could use experience or just published research
	No session, training on EBP EBP – skills =communication, patience, hard work Important to have support of others, staff & client Agreement that everyone will take part in care plan Need to be able to explain why the intervention is necessary to other staff – to gain support Skilled in working together, & teaching advising staff why the intervention is important Working together Commitment to the individual and to the care plan process Need training to use computer, many staff on ECDL course

	Research areas Personal effort to find information on subjects relevant to practice, attends modules, read Information on internet for specific disorders Much info comes under MH Research Research into what service caters for people who have LD & MH

Example of Stage 3 - Transcript 06: Table of themes and identifiers		
Themes	Keywords from transcript	line number
1. Type of intervention Intervention, structure to care plan (Nurse had responsibility for shift, not named nurse)	mae wedi dod i mewn o dan yr ambarela o'r autistic spectrum. Ag tua 6 wythnos yn ôl roedd pawb yn deud: da ni'm yn gneud llawer i syportio dyn yma. So nesi i ddeud wel, os di'o yn dod o dan fatha yr label austistic, felly dyla'ni roid ychydig bach mwy o structure yn ei fywyd a trefn i gynllun gofal o felly. A dyna be nasi i.	9-15
2. Working together **Unit team** Working as a team to deliver care plan difficult – over 30 staff	Yn y dechrau roedd yn (ymyriad) gweithio yn grêt. (chwerthin) ond ti'n gwybod, mae o'n anodd am bo na tîm mor mawr yna,	16-18
Accessed computer / working with another newly qualified nurse	ges si help gan un o'r staff nurses newydd, a nath hi roid o (cynllun gofal)ar y cyfrifiadur, roedd o gyd fel, ti'n gwybod, y geiriau oedd o'n nabod,	46-49
Shift team of nurses agreed with new care plan, nurse presented in handover 2pm	nath y tîm oedd ar y bore yna, cytuno hefo fo, wedyn es ia fo drwadd i handover wedyn am 2 o'r gloch a wedyn rhoi o yn y "communication book" wedyn i'r named nyrsys ar y tîm yna cytuno hefo hefyd. A nath bawb cytuno hefo fo.	70-74
30 staff – requires joint up thinking	*Faint o staff* 30 *30* Oes. ... *Felly mae cydweithio yn bwysig iawn* Ydi, ydi	284-289
Different shift patterns	mae yna gymaint o shift, patrwm shift gwahanol yna, mae gen ti bobol yn neud bore, pnawn, nos, hwyr, ...sleep-ins, mae'na bobol yn dod i fewn gwahanol amseroedd, so ti'n goro' neud yn siwr bod hei'n i gyd yn cael gwybod be sy'n digwydd. Mae dy traditional handover am 2 o'r gloch yn gallu bod yn 3 handover mewn 1 shift.	292-298
Changes in service provision, unsettling for staff, skill mix of staff		
Treatment team Care plan reviewed by treatment team on a weekly basis	Sa' di cael ei riviewio bob wythnos, a wedyn sa' cael ei riviewio gan y treatment team hefyd.	137-138
Treatment team members, multi-disciplinary	Mae gen ti seicoleg, mae gen ti speech and language, mae gen ti... day services a ... clinical team o nyrsys i fewn.	143-145

Treatment team works in 2 ways, review existing care plan or discuss new ideas for the care plan	*Mewn ffordd reviewio bethau da chi di 'sgwennu yn barod, ta wyt ti'n mynd i fano i ofyn os di hyn yn iawn.* Gei di neud o dwy ffordd.	146-149
MDR A multi-disciplinary agreement on all care plans although some decisions will be done before being discussed at meeting Joint working with SALT, assessment of language understanding	Ti'n gwybod mae na wythnos o un i'r llall, sa ti'n gorfod gwneud rhyw fath o gynllun os di rhywbeth wedi digwydd, ti'n gorfod actio arno fo, so, sa ti'n roid o fewn a gofyn am gytundeb nhw hefyd, a gofyn sa gyn nhw rwbath arall sa'n nhw'n meddwl sa'n helpu hefyd. Yn enwedig hefo'r dyn yma, oedd gen o'm ni waith oedd speech and language therapist wedi neud yn barod i useio pa fath o , ...sut oedd o'n cymryd information i fewn a faint oedd o'n gallu cymryd i fewn ar un adeg, ti'n gwybod. Roedd hwna gynai yn barod pryd rotho ni y cynllun i fewn.	149-160
Multi-disciplinary review or pre-discharge meeting to review care	Eith o drwadd wedyn, mewn mis da ni'n trio cael ... MDR neu fatha pre-discharge fasa fo fwya. Ond pryd mae'r amser yn dŵad da ni'n meddwl bod y person yn barod pre-discharge ydi hynny a sa hynny i gyd yn cael ei reviewio, y treatment goals i gyd yn cael eu reviewio yn yr MDR. Ond pethau sy'n digwydd o un wythnos i llall ... mae hwnnw yn cael ei reviewio gan dy named nurses. Weekly report 'llu.	175-183
3. Information that helps decision making		
Previous experience Nurses previous experience, questioning practice during morning shift,	Wel o'n ni'n meddwl bod o'n bwysig i rhywun fatha fo, bo fo … y consistency yna er mwyn iddo cael deall er mwyn iddo cael deall lle mae on sefyll.	67-69
Previous experience of autism influenced questioning of practice	ar ffaith really bo fi hefo lot o brofiad o wedi gweithio wedi hefo pobol a autistic spectrum	84-85
Client Influence decision making - Previous experience and talking to the client	*Felly ddoth dy brofiad di i fewn i helpu neud y penderfyniad o'r angen am "structure" yn y cynllun gofal* ia, ia *A wedyn ne s'di 'ista lawr hefo'r client* Do, *A penderfynu ar strwythur bob diwrnod*	86-92
Background information Background information – previous placement/home	Lle oedd o'n byw cynt, oedd o'n gallu bod yn ei waith mewn rhyw hanner awr o cael tacsi. Ond o lle ni oedd o'n gorfod cael	120-124

	bus a pethau, ond oedd trafferthion yn y tŷ hefyd, sa'n hwyr yn mynd i waith a pethau felly.	
Disseminate information, clear system		
Disseminate information – communication book	es ia fo drwadd i handover wedyn am 2 o'r gloch a wedyn rhoi o yn y "communication book" wedyn i'r named nyrsys ar y tîm yna cytuno hefo hefyd.	71-74
Ways to disseminate information within the unit –handover, communication book	A wedyn sa chdi jyst yn deud hefyd yn y "communication book" bod yna "treatment goal" newydd yn relatio i so and so felly	110-113
Named nurse writes a weekly report – summary of what's happened re: care plan	pethau sy'n digwydd o un wythnos i llall ... mae hwnnw yn cael ei reviewio gan dy named nurses. Weekly report 'llu.	180-183
Nurse in-charge on the day of the treatment team meeting will present named nurse care plan. A book for qualified nurses to specify any ideas, request for ideas, support, questions	Mae'na wybodaeth, mae gennom ni lyfr ... fatha deud bod rhywun di ... wedi sgwennu adroddiad neu treatment goal newydd i fewn a mae nhw 'isho ... fath a support y treatment team cyn roid o fewn a gofyn am dipyn bach fwy o help llu. A mae gennom ni jyst llyfr os oes gan rhywun cwestiynau i ofyn, a mae hwna yn cael ei roid drosodd i'r treatment team.	195-202
Handover more than passing information on, a place to consider make decisions	mae 'na benderfyniadau yn cael eu gneud, fatha bore 'ma. Mae yna bethau wedi cael, maen na benderfyniadau wedi cael eu gneud, neu fel arall ti'm yn gwybod pa bryd mae benderfyniadau yn cael eu gneud. Wel sa ti'n gallu deud : yes will do that tomorrow, a wedyn ti'n gobeithio bod rhywun arall wedi neud o fory ond wyrach so fo ddim wedi cael ei neud.	301-310
Communication book compared to the bible	*Felly mae'r communication book yn bwysig* Wel mae'n beibl (chwerthin) beibl i rai i honno ni de.	
White board as a notice board for non-confidential messages for staff	bwrdd gwyn ond dos dim byd confidential yn mynd ar hwna. Jyst negas i staff	312-313
Access to internet in the office	Oes, oes. Yn y swyddfa.	317
Use internet to find information e.g. re: diagnosis	oedd y staff nurse neithiwr wedi bod ar yr internet ac wedi cael llwyth o wybodaeth am yr ... oedd o yna i staff y bore i ddarllen a cael gwybod,	321-324
Time in work to access internet for information	Ar y funud mae yna amser i neud o,	326-329

because the unit is not full	mae'n dibyn, ar y funud mae na 6, 7 pobol sydd gen o ni fewn, does na ddim major difficulties yna ar y funud, so mae'na amser yn dy shiftiau i neud hynna.	
Information gathered is places in rota file, Information on internet for specific disorders Plus a clinical interest file – with diagnosis, medical info	Mae o'n (gwybodaeth) mynd i ffeil rota wedyn, memos and rotas. Felly mae bob dim yn fanaf, a mae gen o ni ffeil arall hefyd, fel clinical interest ydo.	332-334
Participant doesn't use the computer Scared of using the computer	mae rhai o ni dal ofn nhw (chwerthin), ond mae 'na access yno ac mae lot o'r staff wedi neud yr ECDL, ac mae'r staff yn cael eu pwshio i neud hwna, os du nhw isho neud o.	344-347
4. Involving the client		
Client involvement Client consented to care plan, agreement signs care plan Care plan = benefit to client	Oedd o (client) wedi cytuno hefo fo, wedi arwyddo fo, wedi hapus braf i ni ddechrau hyn hefo fo. Cos oedd o'n mynd i helpu fo hefo cael ychydig mwy o … mwy o 'activities' a pethau yn eu ddyddia pan doedd gen o ddim gwaith i fynd i.	20-24
PCP – initial discussion with client Client led care plan	nathon ni feddwl am y pethau, fo a fi yn siarad hefo'n gilydd i ddechrau a gofyn be oedd o'n licio neud, be oedd o ddim yn licio neud. Sut oedd o'n licio pobol approacho fo, os o'n licio rhywun jyst siarad un i un, a nath o deud: yndw, well gen i fod fela. A mae o'n ddyn sy'n gallu colli ei dempar yn reit hawdd hefyd	27-33
Involve client in writing care plan	So, nes i ofyn iddo: be 'sy'n gora' pan ti'n teimlo yn reit anhapus, :sa ti'n licio pobol siarad hefo chdi adeg yna, wyt ti'sho pobol ddeud wrth tha ti am fynd i 'stafell ta ti'sho rhywun 'ista hefo chdi … wedyn nath o ddeud : sa well gen 'ista i lawr a pobol ddeud wrtha i am roid fy mhen i lawr a meddwl be dwi'n ddeud. So, nei si yn siwr fod hynny yn y cynllun gofal, so fod pawb yn nabod so, fatha de-escalating skills hefo fo really	35-43
Plan care using words that the client knows, recognises, Care plan in a format that the client would understand and use	roedd o gyd fel, ti'n gwybod, y geiriau oedd o'n nabod, fatha	48-49
Care plan geared towards individual Initially questioned what the unit was doing for the client	Oedd, oedd, mewn geiriau syml, dim lot o jargon, fatha short and simple llu	57-58
Empathy with client, who's trying to understand a system	ia, so doedd o ddim yn siwr o'r ...be dwi fod i neud rwan,os ydi un person yn deud wrtha' i am neud hyn a person arall yn deud na na' fo fel'na heddiw. Oedd jyst	130-134

	yn bwysig	
5. Definition of EBP Definition of EBP Definition	... mae o rwbath sydd wedi cael ei neud a mae rhywun wedi gweld bod na rwbath wedi dod o honno fo. Mae o'n gweithio yn dda, dwi'n meddwl, ia ? *ia, does gen i'm ateb iawn* ia, evidence based practice ydi ti di gneud rwbath a Ma' gen ti rwbath i ddangos ma' hyn di gweithio yn fama llu.	207-214
Related EBP to own practice, reading re Aspersers	Fatha sŵn i'n meddwl, dwi di darllen lot am bobl hefo aspergers neu rwbath felly	216-217
Research to influence own practice	Mae'r research mae pobl wedi gneud yn profi bod pobol (ag awtistiaeth) yn functiono felna (angen strwythur) oherwydd communication problem a petha felly.	219-221
Supporting evidence available for intervention	*mae yna dystiolaeth, evidence wedyn yn deud fod pobl a autism sydd ar y spectrum yn elwa o strwythur* ia, ia mae yna evidence yn backio fo i fyny, dyna pam nes i roid o yn y cynllun.	222-226
Previous experience influences EBP Unsure if EBP could use experience or just published research	Wel na dwi'n meddwl fod dy brofiad di yn deud hefyd, ella bod na ddim byd wedi sgwennu ond ti'n gwybod o'r profiad ti di gael dros y blynyddoedd : os nawn ni... mi nath hyn weithio o'r blaen, ella bod na lot o bethau da ni di neud o'r blaen... mae dy brofiad yn deud tha' ti, ti'n cofio nath o ni huna a nath o weithio really yn dda do, a ... dwi'm yn gwybod ond dydio ddim yn gorfod bod lawr ar bapur, dwi'm yn gwybod, dwi'm yn siwr	229-237
6. Education & Skills for EBP Education No session, training on EBP	Dwi 'rioed wedi cael rhyw fath o sesiwn ar evidence based practice neu rwbath	240-241
Skills EBP – skills =communication, patience, hard work Important to have support of others, staff & client Agreement that everyone will take part in care plan Need to be able to explain why the intervention is necessary to other staff – to gain support Skilled in working together, & teaching advising staff why the intervention is important	communication skills chdi really. Dy fynadd di (chwerthin), ti isho dipyn, lot o fynadd really, mae'n waith caled ... ar peth sy'n bwysig hefyd bod gen ti y backup tu ôl i ti. Ella bo chdi'n meddwl bo chdi yn meddwl bo chdi yn rhoi rhywbeth da mewn cynllun gofal rhywun ac mae gen ti gytundeb y person sy'n, mae'r gofal yn mynd i, ond mae rhaid i ti cael y staff tu ôl i chdi yn meddwl ru'n fath ac dyna pam da ni yn neud o. Bo nhw yn cael eglurhad tu ôl iddo. Achos nes i neud wrth y staff bo fi di gweithio yn reit agos hefo pobol sydd yn y, dan yr un ambarela a'r dyn yma, mae'n profi pam mae pethau cael eu rhoid yn eu lle ac yn	253-276

	clir iddyn nhw mae nhw yn manageio i fyw yn well llu.	
Working together Commitment to the individual and to the care plan process	*Felly mae'r sgil o gydweithio hefo pobol eraill a addysgu staff eraill am be ti'n neud yn rhan pwysig o dy waith* ia os dwi'n rhoi rhywbeth i fewn yn y cynllun gofal, ac os a'i drwy y drws fydd neb yn cario fo ymlaen, wel, so'm llawer o bwynt rhoi o fewn nag oes. *Felly dyna un sgil o gydweithio* ia, a'r commitment, really	
7. Research areas:		
Personal effort to find information on subjects relevant to practice, attends modules, read	i fod yn onest, y bethau dwi di meddwl dwi isho gwybod mwy am hwna dwi wedi cymryd o i fyny ac wedi mynd ar modules, di neud do so, ar y funud yr un dwi isho neud ydi'r autism... ond dwi wedi neud lot o waith ar ben fy hun, jyst ran darllen oherwydd bo fi di gweithio hefo rhywun reit ... one to one felly	353-358
Much info comes under MH Research into what service caters for people who have LD & MH	Faint o waith mae pobol wedi neud hefo pobol, ac ydyn nhw yn cael ei edrych ar ôl gan y gwasanaeth ni ta y gwasanaeth mental health.	382-385

Stage 4: Example of Master table of themes and quotes for the group

Super ordinate Theme	Theme	Sub Themes
1. Person at the centre	Nurse prepared to listen / learn	Important to

Trans-cript	Line No	Quote
01	151	followed his (client) lead
02	52-54	we just don't look at one side of his care like it wasn't just about his foot and his diabetes it was about how he felt about things,
03	22-23	*How did you write those guidelines* .... with herself,
	26-28	so as a team and with the lady herself they (the goals) would have been written down (in the care plan).
	34-36	*So, between the staff and the client, the decision was made* Yes,
	59	it's an issue that the lady brought in.
	64-67	it's getting to know the person herself. Luckily I was on nights in a sense, when this lady came in, so I got to know her in a very relaxed ... , sort of way, sort of thing
	190	(gain information from) the person themselves
	233-244	But I think again, we're working with people, we're caring for people so that a very personal sort of element to goal setting, and what have you, if somebody, you know, if somebody self esteem, even though there is a lot of work there that we can follow, it's getting to know the person, sitting down on a Friday evening when they absolutely pissed off , and finding out why, well that's, I think, that's just your experience of getting to know people, and … trying your best to get, you know, their hopes and dreams, sort of thing from them.
	381-384	(In an MDR meeting) I think quite often you can have the client themselves who want to take issue with something or want to … have another goal plan or what have you …
	449-454	we try and emphasis in the MDR, because it's that person, it's their treatment, it's their goals really, and I think if these people are not involved with their goal setting, well, really it's not achievable, if somebody is not, if they don't want to do it, they're not going to, whatever
04	38-40	just getting to know the real her, not this person that was affected by like a build up of toxins in her body.
	64-68	She said I would like to have my breakfast now, I would like to have such and such for breakfast … and then I'd like to have my bath… So it was more, more of a process of her facilitating the activity than me.
	76-78	She needed some assistance to get in the bath, but she told me exactly what I needed to do.

	81-85	And then, I asked her what she needed support with, and she told me just to help her to wash her hair and would I kindly come back in 10 minutes, then … she would be ready for me to wash her hair.
	169-172	at the time I probably said it several times how nice it was to see that she had made a good recovery and she shared her experiences of the whole process.
	184-188	*So you were asking about her feelings and thoughts?* Yeah, yeah… She (pause) thought that she (pause) she was able to say that she knew that she had been on this journey.
05	N/A	
06	27-33	nathon ni feddwl am y pethau, fo a fi yn siarad hefo'n gilydd i ddechrau a gofyn be oedd o'n licio neud, be oedd o ddim yn licio neud. Sut oedd o'n licio pobol approacho fo, os o'n licio rhywun jyst siarad un i un, a nath o deud: yndw, well gen i fod fela. A mae o'n ddyn sy'n gallu colli ei dempar yn reit hawdd hefyd
	35-43	So, nes i ofyn iddo: be 'sy'n gora' pan ti'n teimlo yn reit anhapus, :sa ti'n licio pobol siarad hefo chdi adeg yna, wyt ti'sho pobol ddeud wrth tha ti am fynd i 'stafell ta ti'sho rhywun 'ista hefo chdi … wedyn nath o ddeud : sa well gen 'ista i lawr a pobol ddeud wrtha i am roid fy mhen i lawr a meddwl be dwi'n ddeud. So, nei si yn siwr fod hynny yn y cynllun gofal, so fod pawb yn nabod so, fatha de-escalating skills hefo fo really
07	101-108	*Ydi'r client yn rhan o hynny, os yna rhyw rôl am ddysgu nhw am y cyffuriau mae nhw yn gymryd?* ..... dwi'm yn bersonol, na dwi heb di gofyn, na nai jyst roid o iddyn nhw,... ond dwi'n siwr . Dwi'm yn gwybod os oes gennyn nhw y capacity i ddall pam llu. *Reit* Ella dylwn i ofyn, dwi'm yn gwybod (chwerthin)
08	35-39	so we planned one day to go, early in the morning when it wasn't busy, because he doesn't get stressed out by a lot of people and when it's busy, so we learnt that from experience,
	123-125	one particular individual who is now his key worker as well, because he's got a good relationship with him, tends to go.(supports client to access community)
	187-192	there was lots of different staff going with him, which didn't suit him, so we had to sort of re-adjust it slightly, so it's, touch wood at the moment, it's going well again, because we've got the right staff, to go with him, and he feels safe with.
	193-197	*Was the decision about the staffing an observation from the staff or from the client.* …Probably an observation from the staff based on how the client was interacting and behaving when he went with different staff really.
	197-201	People who know him well, his behaviour was different when he didn't feel as comfortable, because he needs a lot of reassurance, and maybe certain staff give him more reassurance and make him feel comfortable,
	402-408	sometimes just getting to know the individual I think.. and not listening to what everybody has to say about someone, … it changed my perspective and the way I sort of looked towards him. Well you know, you know you say there isn't any evidence of what everybody has been saying all these years.
	410-414	looking at the individual, getting to know them, because sometimes this information has come from staff, 20 years ago, and they tell the new staff, and those new staff become the old staff, and they tell the new staff and so it goes on, you know

	494-500	You don't want to stress people out needlessly, do you, and put them in situations that could make matters worse. *No* So if we'd of done it wrong the first time, it could have been a total disaster, hated it and he wouldn't go out again, you know, so.
09	10-14	what we did really, I did, we did as a team, was to work out what was effective with him. Because we couldn't always de-escalate the situation because it happened so quickly.
	21-22	We had to talk to the gentleman concerned, and then write up a plan.
10	N/A	
11	80-84	*you had a long spell in work with him* Yes a long spell *So you got to know him quite well* Yes I did
	107-109	into his care plan we wrote that he needed plenty of time to absorb the information that we were giving him
12	60-61	going up the shops in the village which is a big part of her daily life, weekly life, you know,

Stage 4: Master table of themes for the group

Super ordinate Theme	Theme	Sub Themes	\multicolumn Transcript No & Line No											
			01	02	03	04	05	06	07	08	09	10	11	12
1. Person at the centre														
	Nurse prepared to listen / learn	Important to	151	52-54	22-23 381-384 449-454 64-67 233-244 26-28 34-36 190 59	38-40 169-172 184-188 64-68 76-78 81-85		27-33 35-43	101-108	35-39 193-197 197-201 123-125 410-414 494-500 402-408 187-192	21-22 10-14		80-84 107-109	60-61
		Important for	30-32 118-119 68-70 99-104 152 50	96-98 27-28		193-198 205-213 243-246	52-57 187-188 156-161 165-167	20-24 86-92		49-54 63-71 42-47	14-15 155-164 168-173 177-180 101-107	101-110 208-212 25-26	100-105 331-343	48-56 112-115 123-127 58-65
		In alliance with family			188-190 398	114-118 93-96	363-372					152-159		
	Empower-ment			50-52 29-30 36-40	129-131 233-244	70-71 87-89	128-131 142-149 176-180 194-201 170-172	48-49 57-58		458-464 32-34	132-135	114-119 97-99	115-121	175-179
	Parity		49 152-155	61-63 63-65 43-44 47	190 344 347 16-17	264-269 313-318 25-29 31-36 175-181 275-278 98-104	234-244	130-134		25-26 110-111 350-360	34-39 110-113			

Super ordinate Theme	Theme	Sub Themes	01	02	03	04	05	06	07	08	09	10	11	12
2. Team approach														
	Independent decision making								321-326 35-43 77-82 45-53 59-61	212-217		75-79		
	Nursing	Nurse informal communication	7-8 31 96 102-104	119-123 307-309	26-28 155-159 112-114 34-36	52-58	86-87 305-309 269-273 311-313 256-259	16-18 70-74 110-113 292-298 284-289 312-313	88-100	98-103 103-107 469-472	10-14 24 47-51 64-78	75-79	202-204 208-220 231-234 243-247 321-322 388-391	95-97 416-430 433-440 158-161 107-109
		Nurse formal communication	156	68-71 129-130 152-154 298-299	80 81 125-126 86-87 90-91	47-51	277-284	137-138 180-183 301-310 70-74 195-202	153 58-59 114-115 193-196 154-156	172-177 246-257 267-271 212-217	86-89 192-195 211-222 60-62 199-202	68-70 162-169	142-145	144-150 435-437 165-168 314-318 135-142
		Inter-professional communication	108 110 112-115 179-180 397-398 63	21 24-26 146-147	41 365-370 403-410 437-441 375-376 390-401 187-190		34-35 93-97 230	143-145 146-149 149-160 175-183	120-121	58-61 79-87 88-94 159-165	95-97 117-122	134-136 138-141 159-160 191-197 201-204	258-261 269-275 279-286	151-156

Super ordinate Theme	Theme	Sub Themes	01	02	03	04	05	06	07	08	09	10	11	12
3. Information source														
	Client - related	History	185-187	75 77-78 80-81 83-86	55-59 64-67 51-52	97-98		120-124		25-32 136-139	41-45 34-36		13-16	
		Assess Plan Implement Evaluate	8-9		64-67	93-96	39-41 63-66 298-304 221-223 81-85 108-111 183-188		309-320	242-245 193-197 491-496	17-20 45-51 82-83 225-228	44-51	30-36 44-49 61-64 68-76 352-353 378-386 58-59	40-43 314-318 158-161 165-168 107-109
	Personal	Knowledge/ experience gained from practice		24-26	151-159		204	67-69 84-85	321-326	34 155-160			171-173 65-68	
		Intuition		268-287		295-297 223-226	26-27 42-43 105-108 180-183 187-191 333-335						349-352 400-411 370-373	
	Professional colleagues	Student nurses / newly qualified		170-172 206-211	196			46-49				377-380 330-331		321-326
		Individuals	13	195-196 313-316	151-159 51-52 202-209	127-128 52-58 123-126 139-140	444-448				117-122	278-281 287-296 305-312 324-328	91-94	390-394 376-382 376-382

			01	02	03	04	05	06	07	08	09	10	11	12
		Groups	248-250 82 242-246		277	372-374 381-386				285-292 300-303	34-36			
	Resources	Library	237		276 278		430			314-316		277 246		
		Internet	431-433 227	209-210	275	127-128 139-140 155-157	431	321-324		334-335 446-454 320-324 467-468	258-262	321-323 246-250	134	175-177
		Journals Reading	142-145 77-78 73-74 317 426-428 213-232		192-193 197-203			332-334	292 193-196	284 336 331-333			174	
		Courses education	265-267 188-190				422-428					269-271	64-68 173	
		Other	467-471 439-446 18-20		279	143-144				333-334				
	Access	Workplace	231-236			132-134 422-424	433-440	317 326-329 344-347	237-239		263-266	276	544-548	271-277 281-286
		Home	230 236								258-262	247	544-548	

Appendix I - Study 2, Letter of agreement between Sanna Salanterä and Ruth Wyn Williams about the use of the *56-item nurse Decision-Making Instrument* by Sirkka Lauri and Salanterä

Letter of agreement

This is a letter of agreement between Sanna Salanterä and Ruth Wyn Williams about the use of the *56-item Nurse Decision-Making Instrument* by Sirkka Lauri and Sanna Salanterä.

By signing this letter of agreement Sanna Salanterä gives permission to Ruth Wyn Williams, PhD Student of Bangor University Wales to use the *56-item Nurse Decision-Making Instrument* for research purposes. All modifications or rephrasings have to be approved by Sanna Salanterä

To obtain permission to use the *56-item Nurse Decision-Making Instrument* Ruth Wyn Williams commits to clearly identify the *Nurse Decision-Making Instrument's* source in the text and in the reference list of any document naming the *56-item Nurse Decision-Making Instrument* as follows: *56-item Nurse Decision-Making Instrument* by Sirkka Lauri and Sanna Salanterä. Article in <u>Journal of Professional Nursing</u>: 2002, 18(2):93–100: Lauri S, Salanterä S: Developing an instrument to measure and describe clinical decision making in different nursing fields.

By signing this letter of agreement Ruth Wyn Williams also commits to share results from her research with Sanna Salanterä and Sirkka Lauri (via Salanterä).

This agreement should not be deemed as a copyright transfer.

On behalf of Sirkka Lauri and Sanna Salanterä

Date 11th August 2009

Sanna Salanterä
PhD, RN
Professor of Clinical Nursing Science
Department of Nursing Science
20014 University of Turku
Finland

Ruth Wyn Williams, MSc, BN, RN, RNID
PhD Student/Welsh Medium Scholarship Holder
School of Healthcare Sciences
Bangor University
Gwynedd
Wales. LL57 2EF

Appendix J – Study 2, *Decision making in learning disability nursing practice. All Wales nursing questionnaire (Welsh and English version)

*With thanks to:

- Canolfan Bedwyr, Bangor University for their input in translating this questionnaire
- Robert Williams, Magna Books for the art work and design of the questionnaire

Gwneud penderfyniadau ym maes ymarfer nyrsio anabledd dysgu

Holiadur Nyrsio Cymru Gyfan

Cynlluniwyd yr holiadur hwn i gasglu gwybodaeth a safbwyntiau ynglŷn â gwneud penderfyniadau a chynllunio person ganolog a'r dystiolaeth a ddefnyddir ym maes ymarfer nyrsio anabledd dysgu. Mae'n hollol ddienw.

Nid oes atebion cywir nac anghywir, rwyf eisiau clywed eich safbwyntiau chi a chlywed am eich profiadau o ddefnyddio tystiolaeth a gwneud penderfyniadau i wella canlyniadau iechyd pobl ag anabledd dysgu.

Mantais
Canolfan Addysg
Uwch Cyfrwng Cymraeg
Centre for Welsh
Medium Higher Education

PRIFYSGOL
BANGOR
UNIVERSITY
1884
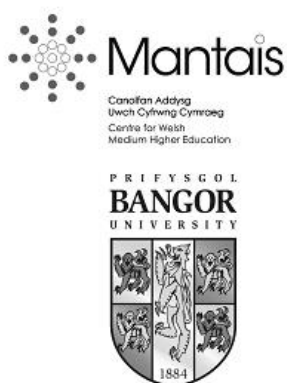
Byddwn yn ddiolchgar pe baech yn cymryd amser i ateb y cwestiynau canlynol ac yn dychwelyd yr holiadur yn yr amlen rhadbost a ddarparwyd. Os hoffech wneud sylw ar unrhyw un o'r cwestiynau, defnyddiwch y lle gwag a ddarparwyd ar ddiwedd yr holiadur.

Diolch am eich cefnogaeth wrth gwblhau'r holiadur.
Os oes gennych gwestiynau am yr holiadur cysylltwch â:
Ruth Wyn Williams, Myfyriwr PhD,
Ysgol Gwyddorau Gofal Iechyd,
Prifysgol Bangor, Gwynedd LL57 2EF
✆ 01248 383132   ebost hsp42e@bangor.ac.uk

Adran 1 : GWNEUD PENDERFYNIADAU

→ **Pan fyddaf yn gwneud penderfyniadau sy'n ymwneud â gwella canlyniadau iechyd, byddaf yn defnyddio gwybodaeth o'r canlynol:**

... rhowch ✔ yn erbyn yr ateb sy'n adlewyrchu eich defnydd o wybodaeth

	Byth	Weithiau	Pob tro	
fy mhrofiad fel nyrs				1
dogfennau nyrsio'r cleientiaid/cleifion				2
siarad gyda'r cleientiaid/cleifion				3
siarad gyda theulu/gofalwyr y cleientiaid/cleifion				4
arsylwi cleientiaid/cleifion				5
myfyrwyr nyrsio				6
nyrsys newydd gymhwyso				7
cydweithwyr nyrsio profiadol				8
grwpiau diddordeb proffesiynol				9
gofalwyr iechyd proffesiynol cysylltiedig (megis therapyddion galwedigaethol, ffisiotherapyddion, seicolegwyr, therapyddion lleferydd ac iaith)				10
meddygon/seiciatryddion/meddygon teulu				11
y llyfrgell				12
cyhoeddiadau ymchwil				13
gwerslyfrau				14
gwefannau ar y rhyngrwyd				15
cyfryngau poblogaidd, megis rhaglenni dogfen ar y teledu a chylchgronau				16
fy hyfforddiant cychwynnol fel nyrs				17
addysg a ddarparwyd gan y GIG (hyfforddiant mewn swydd)				18
modiwlau/cyrsiau prifysgol				19
hyfforddiant a ddarparwyd yn allanol				20
arfer neu draddodiad yn y gweithle				21
canlyniadau archwiliad				22
myfyrdod				23
goruchwyliaeth glinigol				24

Appendices

Wedi ei addasu o waith Lauri a Salanterä (2002)

Adran 3 : HOLIADUR AR WNEUD PENDERFYNIADAU YM MAES NYRSIO

Mae'r gosodiadau isod yn disgrifio sut mae nyrsys yn gwneud penderfyniadau ynglŷn â gofal cleientiaid mewn sefyllfaoedd gwahanol.

*… darllenwch bob gosodiad yn ofalus a rhowch ✔ yn y blwch
sy'n rhoi'r disgrifiad gorau o'r hyn y byddwch yn ei wneud*

CASGLU GWYBODAETH I DDIFFINIO CYFLWR CLEIENT

→ **Pan fyddaf yn casglu gwybodaeth ynglŷn â'r cleient ac yn diffinio ei gyflwr a'i iechyd:**

	Byth neu bron fyth	Yn anaml	Ddim yn anaml na'n aml	Yn aml	Bron bob tro neu bob tro	
Byddaf yn casglu cymaint o wybodaeth ymlaen llaw â phosibl o gofnodion y cleient						1
Ar sail y wybodaeth byddaf wedi ei chasglu ymlaen llaw, byddaf yn nodi'r eitemau i gyd rwyf yn bwriadu eu harsylwi a holi'r cleient amdanynt						2
Byddaf yn asesu'r wybodaeth rwyf wedi ei chasglu ymlaen llaw yn erbyn fy nealltwriaeth fy hun						3
Byddaf yn datblygu fy argraffiadau cyntaf trwy chwilio am wybodaeth ynglŷn â'r cleient sy'n wahanol i'r wybodaeth a gasglais ymlaen llaw						4
Byddaf yn cadarnhau fy argraffiadau cyntaf trwy chwilio am arwyddion amlwg sy'n cefnogi'r argraffiadau hynny						5
Byddaf yn gofyn i'r cleient a wyf wedi dehongli'r wybodaeth a gasglais ynglŷn ag ef/hi yn gywir						6
Byddaf yn casglu'r un wybodaeth ar gyfer pob cleient yn ystod y cyswllt cyntaf						7
Byddaf yn casglu llawer o wybodaeth ynglŷn ag anghenion â chwynion y cleient						8
Byddaf yn casglu llawer o wybodaeth ynglŷn â barn y cleient ynglŷn â'i anghenion a'i iechyd						9
Byddaf yn ceisio cadw'r wybodaeth a gasglais ymlaen llaw mewn cof						10
Byddaf bob amser yn dibynnu ar fy nehongliadau fy hun wrth ddiffinio cyflwr y cleient						11
Byddaf yn rhagdybio'r anghenion nyrsio i ddod yn ystod y cyswllt cyntaf gyda'r cleient						12
Byddaf yn cael gwybodaeth ychwanegol i gadarnhau fy syniadau ynglŷn â sefyllfa'r cleient						13
Rwy'n ei chael yn hawdd gwahaniaethu rhwng gwybodaeth bwysig a gwybodaeth ddibwys wrth ddiffinio anghenion ac iechyd y cleient						14

324

Adran 3 : HOLIADUR AR WNEUD PENDERFYNIADAU YM MAES NYRSIO

Mae'r gosodiadau isod yn disgrifio sut mae nyrsys yn gwneud penderfyniadau ynglŷn â gofal cleientiaid mewn sefyllfaoedd gwahanol.

*... darllenwch bob gosodiad yn ofalus a rhowch ✔ yn y blwch
sy'n rhoi'r disgrifiad gorau o'r hyn y byddwch yn ei wneud*

CASGLU GWYBODAETH I DDIFFINIO CYFLWR CLEIENT

➔ **Pan fyddaf yn casglu gwybodaeth ynglŷn â'r cleient ac yn diffinio ei gyflwr a'i iechyd:**

	Byth neu bron fyth	Yn anaml	Ddim yn anaml na'n aml	Yn aml	Bron bob tro neu bob tro	
Byddaf yn casglu cymaint o wybodaeth ymlaen llaw â phosibl o gofnodion y cleient						1
Ar sail y wybodaeth byddaf wedi ei chasglu ymlaen llaw, byddaf yn nodi'r eitemau i gyd rwyf yn bwriadu eu harsylwi a holi'r cleient amdanynt						2
Byddaf yn asesu'r wybodaeth rwyf wedi ei chasglu ymlaen llaw yn erbyn fy nealltwriaeth fy hun						3
Byddaf yn datblygu fy argraffiadau cyntaf trwy chwilio am wybodaeth ynglŷn â'r cleient sy'n wahanol i'r wybodaeth a gasglais ymlaen llaw						4
Byddaf yn cadarnhau fy argraffiadau cyntaf trwy chwilio am arwyddion amlwg sy'n cefnogi'r argraffiadau hynny						5
Byddaf yn gofyn i'r cleient a wyf wedi dehongli'r wybodaeth a gasglais ynglŷn ag ef/hi yn gywir						6
Byddaf yn casglu'r un wybodaeth ar gyfer pob cleient yn ystod y cyswllt cyntaf						7
Byddaf yn casglu llawer o wybodaeth ynglŷn ag anghenion â chwynion y cleient						8
Byddaf yn casglu llawer o wybodaeth ynglŷn â barn y cleient ynglŷn â'i anghenion a'i iechyd						9
Byddaf yn ceisio cadw'r wybodaeth a gasglais ymlaen llaw mewn cof						10
Byddaf bob amser yn dibynnu ar fy nehongliadau fy hun wrth ddiffinio cyflwr y cleient						11
Byddaf yn rhagdybio'r anghenion nyrsio i ddod yn ystod y cyswllt cyntaf gyda'r cleient						12
Byddaf yn cael gwybodaeth ychwanegol i gadarnhau fy syniadau ynglŷn â sefyllfa'r cleient						13
Rwy'n ei chael yn hawdd gwahaniaethu rhwng gwybodaeth bwysig a gwybodaeth ddibwys wrth ddiffinio anghenion ac iechyd y cleient						14

TRIN GWYBODAETH A DIFFINIO ANGHENION NYRSIO

→ **Pan fyddaf yn trin y wybodaeth rwyf wedi ei chael ynglŷn â'r cleient ac yn diffinio'r anghenion nyrsio disgwyliedig:**

	Byth neu bron fyth	Yn anaml	Ddim yn anaml na'n aml	Yn aml	Bron bob tro neu bob tro	
Byddaf yn cymharu'r wybodaeth rwyf wedi ei chael gyda fy ngwybodaeth am gleientiaid unigol tebyg						15
Byddaf yn cymharu'r wybodaeth rwyf wedi ei chael gyda fy ngwybodaeth o ymddygiad cleientiaid mewn sefyllfaoedd gwahanol						16
Byddaf yn cymharu'r wybodaeth rwyf wedi ei chael gyda'r model nyrsio rwyf wedi ei greu ar sail fy mhrofiad fy hun						17
Byddaf yn cymharu'r wybodaeth rwyf wedi ei chael gyda gwybodaeth feddygol am anghenion y cleient						18
Byddaf yn cymharu'r wybodaeth rwyf wedi ei chael gyda'r modelau nyrsio rwyf wedi eu dysgu						19
Byddaf yn cymharu'r wybodaeth rwyf wedi ei chael gyda fy ngwybodaeth am ofal iechyd a chymdeithasol						20
Byddaf yn dadansoddi'r wybodaeth rwyf wedi ei chael yn ofalus cyn diffinio anghenion nyrsio'r cleient						21
Rwy'n ei chael yn hawdd gweld, hyd yn oed heb ddadansoddiad mwy manwl, pa wybodaeth sy'n berthnasol wrth ddiffinio anghenion nyrsio'r cleient						22
Rwy'n ei chael yn hawdd adnabod pwysigrwydd profiad goddrychol y cleient wrth ddiffinio ei anghenion nyrsio						23
Byddaf yn trefnu'r wybodaeth rwyf wedi ei chael mewn blociau er mwyn hwyluso'r dasg o ddiffinio'r anghenion nyrsio						24
Byddaf yn diffinio anghenion nyrsio'r cleient yn wrthrychol ar sail y problemau dan sylw						25
Byddaf yn trafod gyda fy nghydweithwyr i sicrhau fy mod wedi dod i'r casgliad cywir ynglŷn â statws iechyd y cleient						26
Rwy'n ei chael yn hawdd ffurfio darlun cyffredinol o sefyllfa a phrif anghenion nyrsio'r cleient						27
Byddaf yn defnyddio syniadaeth y broses nyrsio i ddiffinio anghenion nyrsio'r cleient						28

CYNLLUNIO

→ Pan fyddaf yn cynllunio ar gyfer nyrsio cleient:	Byth neu bron fyth	Yn anaml	Ddim yn anaml na'n aml	Yn aml	Bron bob tro neu bob tro	
Byddaf yn defnyddio'r cynllun ar gyfer triniaeth/gofal y cleient fel fframwaith gyfeirio						29
Yn fy nghynllunio, byddaf yn anelu at gwella y sefyllfa gyfredol						30
Rwy'n ei chael yn hawdd cael y cleient i gyfrannu at y cynllunio						31
Byddaf yn canolbwyntio mwy ar ddyfodol y cleient yn hytrach nag ar yr anghenion nyrsio cyfredol						32
Byddaf yn defnyddio barn y cleient ei hun ar ei ofal a'i driniaeth fel fframwaith cyfeirio ar gyfer fy nghynllunio						33
Byddaf yn seilio fy nghynlluniau nyrsio cyfundrefn a bennwyd ar gyfer diagnosis y cleient						34
Byddaf yn seilio fy nghynlluniau nyrsio ar fy mhrofiad fy hun o drin cleientiaid tebyg						35
Ni fyddaf yn cael anhawster amlinellu cyfeiriad cyffredinol y nyrsio yng nghynllun gofal y cleient						36
Byddaf yn pennu targedau ar gyfer y nyrsio sy'n hawdd eu mesur						37
Rwy'n tueddu i bwysleisio mesuriadau o nodau uniongyrchol						38
Byddaf fel rheol yn cofnodi cynllun nyrsio'r cleient yn unol â model y broses nyrsio						39
Ni fyddaf yn cael anhawster paratoi cynlluniau nyrsio tymor hir unigol						40
Byddaf yn rhagweld yr effeithiau o fesurau nyrsio gwahanol ar y cleient						41
Byddaf yn dibynnu i raddau helaethach ar wybodaeth ynglŷn ag iechyd nag ar wybodaeth ynglŷn â salwch/anabledd						42

DARPARU GOFAL NYRSIO A MONITRO A GWERTHUSO CYFLWR Y CLEIENT

→ Pan fyddaf yn darparu gofal nyrsio:	Byth neu bron fyth	Yn anaml	Ddim yn anaml na'n aml	Yn aml	Bron bob tro neu bob tro	
Byddaf yn ymddwyn yn rhesymegol ac yn gyson hyd yn oed mewn sefyllfaoedd annisgwyl						43
Byddaf yn glynu mor agos â phosibl wrth gynlluniau nyrsio sydd eisoes yn bodoli ar gyfer sefyllfaoedd gwahanol						44
Rwy'n ei chael yn hawdd asesu effaith fy ngweithredoedd ar sefyllfa ac ar iechyd y cleient						45
Byddaf yn rhagweld newidiadau yn sefyllfa'r cleient ar sail cliwiau gwahanol hyd yn oed cyn i unrhyw arwyddion clir ddod i'r amlwg						46
Rwy'n gwybod sut i ysgogi'r cleient i ofalu amdano ei hun ac i gymryd cyfrifoldeb am ei ofal ei hun						47
Rwy'n gwybod sut i ysgogi teulu'r cleient i gymryd rhan yng nghynllun triniaeth/gofal y cleient						48
Byddaf yn glynu mor agos â phosib wrth gynllun triniaeth/ gofal unigol y cleient						49
Byddaf yn defnyddio gwybodaeth benodol ynglŷn â thrin anghenion y cleient wrth wneud penderfyniadau nyrsio						50
Rwy'n hyblyg a byddaf yn newid fy nghynllun gweithredu ar sail adborth ar sefyllfa'r cleient						51
Byddaf yn aml yn ceisio egluro'r newidiadau rwyf wedi eu gweld yng nghyflwr y cleient						52
Gallaf weld newidiadau yng nghyflwr y cleient, ond ni fyddaf bob amser yn gallu egluro sut rwyf yn gwybod hynny						53
Ni fyddaf yn cael anhawster trefnu blaenoriaethau mewn sefyllfaoedd nyrsio gwahanol						54
Byddaf yn rhoi arweiniad i'r cleient yn bennaf trwy roi gwybod iddo/iddi am y broblem a sut i'w thrin						55
Wrth roi arweiniad i'r cleient byddaf yn dibynnu'n bennaf ar ganllawiau clinigol/llwybrau gofal sy'n addas i ateb anghenion nyrsio'r cleient						56

Adran 4 : GWYBODAETH AMDANOCH CHI

1 **Yn eich gwaith bob dydd a ydych chi'n darparu gofal nyrsio ar gyfer blant neu oedolion gydag anabledd dysgu** ... ✔ *un blwch*

YDW ☐ *ewch i 2*   NAC YDW ☐ *ewch i 3*

2 **Pa mor aml yn ystod eich oriau gwaith ydych chi'n cael cyswllt uniongyrchol gyda chleientiaid?** ... ✔ *un blwch*

1% — 25% ☐
26% — 50% ☐
51% — 75% ☐
76% — 100% ☐

3 **Ticiwch y teitl sy'n rhoi'r disgrifiad gorau o'ch cefndir o ran hyfforddiant proffesiynol**

a Nyrs Restredig ——————— ☐   ... ✔ *un blwch*

   neu Nyrs Gofrestredig ———————

b Nyrs Anabledd Dysgu ——————— ☐

c Nyrs Iechyd Meddwl ——————— ☐   ... ✔ *pob un sy'n berthnasol*

d Nyrs Oedolion (Cyffredinol) ——————— ☐

e Nyrs Plant ——————— ☐

f **Cymhwyster cofnodedig:**

   Ymarferwr arbenigol –
   Nyrs anabledd dysgu cymunedol ——— ☐

   neu gymhwyster cofnodedig arall ——— ☐

g Bydwraig gofrestredig ——————— ☐

h Nyrs iechyd y cyhoedd
   cymunedol arbenigol, ———————— ☐
   e.e. Ymwelydd iechyd, nyrs ysgol

4 **Y flwyddyn y gwnaethoch gymhwyso yn nyrs am y tro cyntaf** _____

5 **Eich cymhwyster addysgol uchaf** ... ✔ *pob un sy'n berthnasol*

a Gradd ——————— ☐
b Gradd Meistr ——— ☐
c Doethuriaeth ——— ☐

6 A ydych chi'n astudio ar gyfer cymhwyster addysgol ar hyn o bryd?

... ✔ un blwch

YDW ☐ ewch i *7*   NAC YDW ☐ ewch i *8*

7 Ar gyfer pa gymhwyster addysgol ydych chi'n astudio?

... ✔ un blwch

a Gradd ———— ☐
b Gradd Meistr ——— ☐
c Doethuriaeth ——— ☐

8 Am faint o flynyddoedd ydych chi wedi bod yn gweithio ym maes gwasanaethau anabledd dysgu?

_____ *blwyddyn*

9 Ble byddwch yn treulio'r rhan fwyaf o'ch amser gwaith?

a Gwasanaeth cleifion mewnol, e.e. Uned
Asesu & Triniaethau, gofal tymor byr ☐
b Cymuned ————————— ☐
c Preswyl (gofal hir dymor) ————— ☐

d Os arall, nodwch beth _____

10 Eich band cyflog *Agenda ar Gyfer Newid* ... *rhowch gylch o amgylch eich ateb*

4   5   6   7   8a   8b   8c   8d   9

11 Nodwch eich rhyw ... *rhowch gylch o amgylch eich ateb*

GWRYW   BENYW

12 Eich ystod oedran ... *rhowch gylch o amgylch eich ateb*

20 – 29   30 – 39   40 – 49   50 – 59   60 – 69

**Diolch am gymryd amser i lenwi'r holiadur hwn.
Rwy'n gwerthfawrogi eich cymorth.**

Os hoffech wneud unrhyw sylwadau am yr holiadur neu ynglŷn â gwneud
penderfyniadau ym maes ymarfer nyrsio anabledd dysgu, yna nodwch hwy isod.
(Croeso i chi ysgrifennu eich sylwadau yn Gymraeg neu Saesneg).

Anfonwch eich holiadur yn yr amlen rhadbost a ddarparwyd, neu ei anfon at:
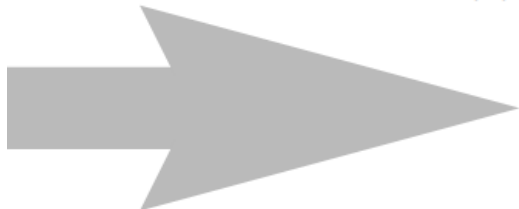
Ruth Wyn Williams, Myfyriwr PhD,
Ysgol Gwyddorau Gofal Iechyd,
Prifysgol Bangor, Gwynedd LL57 2EF
☎ 01248 383132   *ebost* hsp42e@bangor.ac.uk

Caiff yr holl wybodaeth ei thrin yn gyfrinachol ac ni fydd modd ei holrhain yn ôl at unigolion.

Decision making in learning disability nursing practice

All Wales Nursing Questionnaire

This questionnaire is designed to gather information and opinions on decision making and person centred planning and the evidence used within learning disability nursing practice.

It is entirely anonymous.

There are no right or wrong answers. I am interested in your opinions and your own experience of using evidence and making decisions to improve the health outcomes for individuals with a learning disability.

Mantais

Canolfan Addysg
Uwch Cyfrwng Cymraeg
Centre for Welsh
Medium Higher Education

PRIFYSGOL
BANGOR
UNIVERSITY

1884

I would be grateful if you would take the time to answer the following questions and return the questionnaire in the pre-paid envelope provided. If you wish to comment on any questions, please use the space provided at the end of the questionnaire.

Thank you for your support in completing this questionnaire. *If you have any questions please contact:*

Ruth Wyn Williams, PhD Student,
School of Healthcare Sciences,
Bangor University, Gwynedd LL57 2EF

✆ 01248 383132   *email* hsp42e@bangor.ac.uk

Section 1: **MAKING DECISIONS**

→ **When I make decisions concerned with improving health outcomes, I use information from:**

... please ✔ the response that reflects your use of information

	Never	Some times	Every time	
my experience as a nurse				1
clients' / patients' nursing documents				2
talking with the clients / patients				3
talking with the family / carers of the client / patient				4
observing clients				5
student nurses				6
newly qualified nurses				7
experienced nursing colleagues				8
professional interest groups				9
allied health professionals (such as occupational therapist, physiotherapist, psychologist, speech & language therapist)				10
doctors / psychiatrists / GPs				11
the library				12
research publications				13
textbooks				14
Internet websites				15
popular media, such as documentary programmes on television and magazines				16
my initial nurse education				17
NHS provided education (in-service)				18
university modules or courses				19
externally provided training				20
habit or tradition at place of work				21
results of audit				22
reflection on practice				23
clinical supervision				24

Section 3 : NURSING DECISION-MAKING INSTRUMENT — *adapted from Lauri & Salanterä (2002)*

The statements below describe how nurses make decisions about clients' care in different situations.

... please read each statement carefully and ✔ the square that best describes your own action

COLLECTING INFORMATION FOR DEFINING CLIENT'S CONDITION

➔ **When I am collecting information about the client and defining his/her condition and health:**

	Never or almost never	Rarely	Neither rarely nor often	Often	Almost always or always	
I collect as much information in advance as possible from the client's records						1
On the basis of my advance information, I specify all the items I intend to observe and ask the client about						2
I assess all advance information against my own knowledge						3
I clarify my first impressions by seeking information about the client that is different from the advance information						4
I confirm my first impressions by seeking for clear indicators that support those impressions						5
I ask the client whether I have made the right interpretations about the advance information concerning him/her						6
I collect the same information for all clients on first contact						7
I collect a lot of information about the client's needs and complaints						8
I collect a lot of information about the client's views of his/her needs and health						9
I try to keep all the advance information in my mind						10
I always rely on my own interpretations when it comes to defining the client's condition						11
I make assumptions about forthcoming nursing needs during the first contact with the client						12
I acquire additional information to confirm my own assumptions of the client's situation						13
It is easy for me to make a distinction between important and unimportant information in defining the client's needs and health						14

HANDLING INFORMATION
AND DEFINING NURSING NEEDS

→ **When I am handling the information I have obtained about the client and defining expected nursing needs:**

	Never or almost never	Rarely	Neither rarely nor often	Often	Almost always or always	
I compare the information I have received with my earlier knowledge of similar individual clients						15
I compare the information I have received with my earlier knowledge of client behaviour in different life situations						16
I compare the information I have received with the nursing model I have created based on my own experience						17
I compare the information I have received with medical knowledge about the client's needs						18
I compare the information I have received with the nursing models I have learned						19
I compare the information I have received with my own knowledge about health and social care						20
I carefully analyse the information I have received before defining the client's nursing needs						21
It is easy for me to see, even without closer analysis, which pieces of information are relevant to defining the client's nursing needs						22
It is easy for me to recognize the importance of the client's subjective experiences in defining his/her nursing needs						23
I organize the information I have received into blocks for easier definition of nursing needs						24
I define the client's nursing needs objectively based on the problems observed						25
I check with my colleagues that I have made right conclusions about the client's health status						26
It is easy for me to form an overall picture of the client's situation and major nursing needs						27
I draw on nursing process thinking to define the client's nursing needs						28

PLANNING

→ **When I am planning the nursing of a client:**

	Never or almost never	Rarely	Neither rarely nor often	Often	Almost always or always	
I use the plan for the client's treatment / care as a frame of reference						29
I aim in my planning to improve the current situation						30
It is easy for me to get the client to take part in the planning						31
I focus more on the client's future rather than on current nursing needs						32
I use the client's own views on his / her care and treatment as the frame of reference for my planning						33
I base my nursing plans on the regimes prescribed for the client's diagnosis						34
I base my nursing plans on my own experiences of the treatment of similar clients						35
I have no difficulty in outlining the general directions of nursing in the client's care plan						36
I set out targets for nursing that are easy to measure						37
I tend to emphasize measures of immediate goals						38
I normally record the client's nursing plan according to the nursing process model						39
I have no difficulty in preparing individualized long-term nursing plans						40
I anticipate the impacts of different nursing measures on the client						41
I rely on information about health to a greater extent than on information about illness / disability						42

IMPLEMENTING NURSING AND MONITORING AND EVALUATING CLIENT'S CONDITION

→ When I am implementing nursing care:	Never or almost never	Rarely	Neither rarely nor often	Often	Almost always or always	
I act rationally and consistently even in unexpected situations						43
I follow as closely as possible existing nursing plans for different situations						44
It is easy for me to assess the impacts of my actions on the client's situation and health						45
I anticipate changes in the client's situation on the basis of individual cues even before there are any clear indicators						46
I know how to motivate the client to take care of him / herself and to take self-care responsibility						47
I know how to motivate the client's family to take part in the client's treatment / care plan						48
I follow the client's individual treatment / care plan as closely as possible						49
I use specific information about the treatment of the client's needs when making nursing decisions						50
I flexibly change my line of action on the basis of feedback on the client's situation						51
I often try to explain my own observations of changes in the client's condition						52
I can see changes in the client's condition, but I am not always able to explain how I know this						53
I have no difficulty in sorting out the priorities in different nursing situations						54
I provide guidance to the client chiefly by informing him/her about the problem and its treatment						55
In providing guidance to the client I mainly rely on clinical guidelines / care pathways that are suited to solving this client's nursing needs						56

Section 4 : SOME INFORMATION ABOUT YOU

1 **In your day-to-day work do you work with children or adults with learning disability?** ... *please* ✔ *one box*

YES ☐ *go to 2*   NO ☐ *go to 3*

2 **Please estimate how much of your working time involves direct client contact** ... *please* ✔ *one box*

0% — 25% ☐
26% —- 50% ☐
51% —- 75% ☐
76% — 100% ☐

3 **Tick the title that best describes your professional training background**

a Enrolled Nurse ——————— ☐ ... *please* ✔ *one box*
  or Registered Nurse ———————

b Learning Disability Nurse ——— ☐
c Mental Health Nurse ————— ☐ ... *please* ✔ *all that apply*
d Adult (General) Nurse ———— ☐
e Children's Nurse ————— ☐

f Recorded qualification:

Specialist Practitioner –
Community Learning Disability Nurse —— ☐

or other recorded qualification ——— ☐

g Registered Midwife —————— ☐

h Specialist community public health nurse ☐
  e.g. Health Visitor, School Nurse

4 **The year you first qualified as a nurse** ——————

5 **Have you been awarded a Degree, Masters Degree or Doctorate degree related to nursing?** ... *please* ✔ *all that apply*

a Degree ————— ☐
b Masters Degree — ☐
c Doctorate ——— ☐

6 Are you currently studying for an award related to nursing?

... *please ✔ one box*

YES ☐ *go to 7*   NO ☐ *go to 8*

7 Which award are you currently studying for?

... *please ✔ one box*

a Degree ——————— ☐

b Masters Degree —— ☐

c Doctorate ————— ☐

8 How many years have you worked within learning disability services?

_____ *years*

9 In which location do you spend the majority of your working time?

a In-patient facility, e.g. assessment & treatment unit, short term care ☐

b Community ——————————— ☐

c Residential (long term care) ———— ☐

d Other, please state _____

10 Your *Agenda for Change* pay band ... *please circle your answer*

4   5   6   7   8a   8b   8c   8d   9

11 Are you ... *please circle your answer*

MALE   FEMALE

12 Your age range in years ... *please circle your answer*

20 – 29   30 – 39   40 – 49   50 – 59   60 – 69

**Thank you for taking time to complete this questionnaire.
Your help is appreciated.**

If you would like to make any comments about this questionnaire or about decision making in learning disability nurse practice, please write them below. (Comments are welcomed in English or Welsh).

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Please return your questionnaire in the pre-paid envelope provided, or forward to:

Ruth Wyn Williams, PhD Student,
School of Healthcare Sciences,
Bangor University, Gwynedd LL57 2EF
✆ 01248 383132   *email* hsp42e@bangor.ac.uk

All information will be treated as confidential and will not be traceable to individuals.

Appendix K - Study 2, Process of translation

1. Process of translation based on The Translation and Cultural Adaptation - Principles of Good Practice (Wild et al., 2005)

2. Example of Stage 5, back translation review (Wild et al., 2001) of the Welsh version of the Questionnaire (Study 2)

Involved in the process of translation were 2 translators, a terminologist, project supervisors, the principal researcher and a group of individuals to test the instrument.

This is an example of the documentation that supported Stage 5 of the translation process. That is the comparing of the back translation with the original version of the instrument, discussing wording, comprehension, interpretation and cultural relevance of the Welsh translation.

	Step	Description of process	Staff	Timetable
1	Preparation	Permission to use 56 item instrument Adapt terminology to LD practice Agree changes with author	RWW	√
2	Forward translation	Translation from English to Welsh x1 due to cost & time limit	Translator 1	Send 16.09.09 Returned 02.09.09
3	Reconciliation	Proof reading of Welsh translation & agreement	N/A	
4	Back translation	Translation of Welsh version into English	Translator 2	Send 05.10.09 Returned 09.10.09
5	Back translation review	Compare back translation with original version, revise and resolve issues	RWW GWR	12.09.09
6	Harmonization	Comparison of back translations of multiple language versions	N/A	
7	Cognitive debriefing	Test instrument with 3rd year Learning Disability students and lecturers for wording, comprehension, interpretation and cultural relevance of the translation.	RWW LD students LD lecturers	Week commencing 19.10.09
8	Review of cognitive debriefing results and finalization	Comparison of students interpretations of the translation with the original to highlight and amend discrepancies	RWW GWR Terminologist	12.10.09
9	Proofreading	Check for typographic grammatical or other errors	RWW GWR Terminologist	12.10.09
10	Final Report	Documenting the process of translation	RWW	30.11.09

Process of translation based on *The Translation and Cultural Adaptation - Principles of Good Practice* (Wild et al 2005)

*ADOLYGU'R GYMRAEG – Holiadur (*Esiampl /Example of stage 5 documentation of process.)

CYFIEITHIAD GWREIDDIOL	SYLWADAU GWR / RWW	SYLWADAU 12.10.09
ADRAN 2: Holiadur ar wneud penderfyniadau ym maes nyrsio wedi ei addasu o waith Sirkka Lauri a Sanna Salanterä 2002	**ADRAN 2: Holiadur ar wneud penderfyniadau ym maes nyrsio** wedi ei addasu o waith Lauri a Salanterä 2002	**ADRAN 2: Holiadur ar wneud penderfyniadau ym maes nyrsio** wedi ei addasu o waith Lauri a Salanterä 2002
1. Rwy'n deall yr hyn mae canolbwyntio ar unigolion yn ei olygu.	1. Rwy'n deall yr hyn mae bod yn berson canolog yn ei olygu.	1. Rwy'n deall yr hyn mae bod yn berson ganolog yn ei olygu.
2. Rwy'n credu bod canolbwyntio ar unigolion yn effeithiol.	2. Rwy'n credu bod canolbwyntio ar unigolion yn effeithiol.	2. Rwy'n credu bod gweithredu'n berson ganolog yn effeithiol.
3. Gwnaf frwydro i barhau i ganolbwyntio ar unigolion yn fy ymarfer.	3. Mi wnâi frwydro i barhau i fod yn berson canolog yn fy ymarfer.	. Mi wna i frwydro i barhau i fod yn berson ganolog yn fy ymarfer.
4. Gwnaf barhau gyda'm hymdrech i ganolbwyntio ar unigolion hyd yn oed pan fydd popeth yn mynd o'i le	4. Mi wnâi barhau gyda'm hymdrech i fod yn berson canolog hyd yn oed pan fydd popeth yn mynd o'i le	4. Mi wna i barhau gyda'm hymdrech i fod yn berson ganolog hyd yn oed pan fydd popeth yn mynd o'i le
8. Mae gan bawb yr hawl i gymryd rhan lawn yng nghymdeithas	8. Mae gan bawb yr hawl i gymryd rhan lawn mewn cymdeithas	8. Mae gan bawb yr hawl i gymryd rhan lawn mewn cymdeithas
12. Byddaf yn rhagdybio'r anghenion nyrsio i ddod yn ystod y cyswllt cyntaf gyda'r cleient.	12. Byddaf yn rhagweld yr anghenion nyrsio yn ystod y cyswllt cyntaf gyda'r cleient.	Byddaf yn rhagdybio'r anghenion nyrsio i ddod yn ystod y cyswllt cyntaf gyda'r cleient. (negyddol: rhagdybio; positif: rhagweld; niwtral: syniadau)

|		
28. Byddaf yn defnyddio barn ar brosesau nyrsio i ddiffinio anghenion nyrsio'r cleient.	28. Byddaf yn ==defnyddio barn ar brosesau nyrsio i== ddiffinio anghenion nyrsio'r cleient.	Byddaf yn defnyddio syniadaeth y broses nyrsio i ddiffinio anghenion nyrsio'r cleient
Rhoi nyrsio a monitro ar waith a gwerthuso cyflwr y cleient	==Gweithredu a monitro nyrsio, a gwerthuso cyflwr y cleient==	Darparu gofal nyrsio a monitro a gwerthuso cyflwr y cleient
46. Byddaf yn rhagweld newidiadau yn sefyllfa'r cleient ar sail ciwiau unigol hyd yn oed cyn i unrhyw ddangosyddion clir ddod i'r amlwg.	46. Byddaf yn rhagweld newidiadau yn sefyllfa'r cleient ar sail ==cliwiau== unigol hyd yn oed cyn i unrhyw ==arwyddion== clir ddod i'r amlwg.	46. Byddaf yn rhagweld newidiadau yn sefyllfa'r cleient ar sail cliwiau gwahanol hyd yn oed cyn i unrhyw arwyddion clir ddod i'r amlwg.

Appendix L - Study 2, Participants letters of invitation

1. Study 2, Initial letter of invitation (Welsh / English)

2. Study 2, Postcard reminder

3. Study 2, Second mailing letter of invitation (Welsh / English)

4. Study 2, Third Mailing letter of invitation (Welsh / English)

Appendices

Coleg Iechyd a Gwyddorau Ymddygiadol	**College of Health and Behavioural Sciences**
Ysgol Gwyddorau Iechyd	**School of Healthcare Sciences**
Prifysgol Bangor	Bangor University
Fron Heulog, Ffordd Ffriddoedd	Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF	Bangor, Gwynedd LL57 2EF
Ffôn 01248 351151	Tel: 01248 351151
Ffacs 01248 383114	Fax: 01248 383114
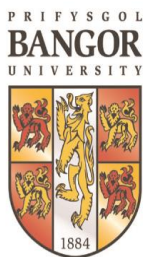
Ffôn: 01248 383132
Ebost: hsp42e@bangor.ac.uk

31 Mawrth 2010

Annwyl Syr/Fadam,

<u>Parthed: Gwneud penderfyniadau ym maes ymarfer nyrsio anabledd dysgu: Holiadur Nyrsio Cymru Gyfan</u>

Myfyrwraig PhD ydw i yn Ysgol y Gwyddorau Gofal Iechyd, Prifysgol Bangor, a hoffwn ofyn am eich cymorth gydag astudiaeth sy'n rhan o'm project ymchwil ehangach ar wneud penderfyniadau ym maes ymarfer nyrsio anabledd dysgu. Fe'ch gwahoddir i gymryd rhan mewn arolwg sy'n edrych ar sut mae nyrsys anabledd dysgu yng Nghymru'n gwneud penderfyniadau ymarfer. Dim ond rhyw chwarter awr dylai gymryd i chi lenwi'r holiadur amgaeedig. Amgaeaf amlen rhadbost.

O'u gwirfodd y mae pawb yn cymryd rhan ac ni fydd eich penderfyniad i ymateb neu beidio yn cael unrhyw effaith ar eich swydd broffesiynol. Byddwn yn trin eich atebion yn gwbl gyfrinachol.

Rydych wedi cael gwahoddiad i gymryd rhan yn yr arolwg hwn oherwydd eich bod yn nyrs sy'n gweithio mewn gwasanaeth anabledd dysgu GIG yng Nghymru. Mae'ch barn yn bwysig iawn oherwydd ei bod yn ein helpu i ddarganfod mwy am sut mae nyrsys anabledd dysgu'n gwneud penderfyniadau a sut mae'r penderfyniadau hynny'n effeithio ar fywydau unigolion gydag anabledd dysgu.

Os hoffech gyfrannu at yr ymchwil, a wnewch chi lenwi'r holiadur a'i anfon yn ôl yn yr amlen rhadbost a ddarparwyd erbyn **dydd Mercher, 21 Ebrill 2010**. Os oes gennych unrhyw gwestiynau o gwbl ynghylch yr astudiaeth hon, croeso i chi gysylltu â mi. Mae fy manylion cyswllt ar frig y llythyr hwn.

Diolch i chi am eich amser.

Yr eiddoch yn gywir,

Ruth Wyn Williams
Myfyrwraig PhD

Amg: Taflen wybodaeth cyfranwyr, amlen rhadbost, holiadur

Appendices

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Telephone: 01248 383132
Email: hsp42e@bangor.ac.uk

31 March 2010

Dear Sir / Madam,

Re: Decision making in learning disability nursing practice: An All Wales Nursing Questionnaire Survey

I am a PhD student at the School of Healthcare Sciences, Bangor University and asking for your help with a study that forms part of my wider research project into decision making within learning disability nurse practice. You are invited to take part in a survey that explores how learning disability nurses in Wales make decisions in practice. The questionnaire enclosed should only take about 15minutes to complete. A pre-paid envelope is enclosed.

Participation is entirely voluntary and your decision as to whether to respond or not will not impact on your professional position. Your answers will be treated in absolute confidence.

You are being invited to take part in this survey because you are a nurse working within a NHS learning disability service in Wales. Your views are very important in helping us find out more about how learning disability nurses make decisions in practice and how those decisions impact on the lives of individuals with learning disability.

If you would like to contribute to the research, please complete the questionnaire and return in the pre-paid envelope provided by **Wednesday 21st April, 2010**. If you have any questions at all about this study, please do not hesitate to contact me. My contact details are at the top of this letter.

Thank you for your time.

Yours faithfully,

Ruth Wyn Williams
PhD Student

Encl: Participant information sheet, pre-paid envelope, questionnaire

Text on Postcard reminder card:

Dear colleague,	Annwyl gyfaill,
About a week ago, I sent you a questionnaire about how learning disability nurses make decisions. If you have returned the questionnaire, please accept my thanks. If you haven't, I'd be grateful if you could take some time to complete and return the questionnaire, it's not too late!	Tua wythnos yn ôl, fe anfonais holiadur atoch ynglŷn â sut mae nyrsys anabledd dysgu yn gwneud penderfyniadau. Os ydych wedi dychwelyd yr holiadur, llawer o ddiolch. Ond os nad ydych, byddwn yn ddiolchgar pe baech yn treulio ychydig o'ch amser yn llenwi a dychwelyd yr holiadur, nid yw'n rhy hwyr!
Your views are very important in helping us find out more about how learning disability nurses make decisions in practice and how those decisions impact on the lives of individuals with learning disability.	Mae'ch barn yn bwysig iawn oherwydd ei bod yn ein helpu i ddysgu mwy am sut mae nyrsys anabledd dysgu'n gwneud penderfyniadau a sut mae'r penderfyniadau hynny'n effeithio ar fywydau unigolion ag anabledd dysgu.
Thank you for your time,	Llawer o ddiolch am eich amser,

<div align="center">

*Ruth Wyn Williams

Myfyriwr PHD Student

Prifysgol Bangor University

hsp42e@bangor.ac.uk / 01248 383132

</div>

*Each postcard was signed by hand.

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114
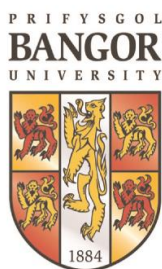
College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Ffôn: 01248 383132
E-bost: hsp42e@bangor.ac.uk

10 Mai 2010

Annwyl Gyfaill,

Parthed: Gwneud penderfyniadau ym maes ymarfer nyrsio anabledd dysgu: Holiadur Nyrsio Cymru Gyfan

Os ydych wedi dychwelyd yr holiadur amgaeedig, **diolch** am gyfrannu tuag at y prosiect ymchwil, a ymddiheuraf am ail bostio. Os nad ydych wedi cael cyfle eto, fuaswn yn ddiolchgar pe baech yn treulio 15 munud i gwblhau'r holiadur a'i ddychwelyd yn yr amlen rhadbost.

Rydych wedi cael gwahoddiad i gymryd rhan yn yr arolwg hwn oherwydd eich bod yn nyrs sy'n gweithio mewn gwasanaeth anabledd dysgu GIG yng Nghymru. Mae'ch barn yn bwysig iawn oherwydd ei bod yn ein helpu i ddarganfod mwy am sut mae nyrsys anabledd dysgu'n gwneud penderfyniadau ymarfer a sut mae'r penderfyniadau hynny'n effeithio ar fywydau unigolion gydag anabledd dysgu.

Os hoffech gyfrannu at yr ymchwil, a wnewch chi lenwi'r holiadur a'i anfon yn ôl yn yr amlen rhadbost a ddarparwyd erbyn **dydd Mercher, 26 Mai, 2010**. Os oes gennych unrhyw gwestiynau o gwbl ynghylch yr astudiaeth hon, croeso i chi gysylltu â mi. Mae fy manylion cyswllt ar frig y llythyr hwn.

Diolch i chi am eich amser.

Yr eiddoch yn gywir,

Ruth Wyn Williams
Myfyrwraig PhD

Amg: Taflen wybodaeth cyfranwyr, amlen rhadbost, holiadur

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Ysgol Gwyddorau Iechyd
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Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114
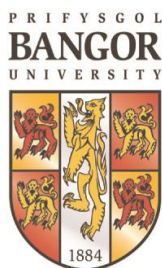
College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

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Bangor, Gwynedd LL57 2EF

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Telephone: 01248 383132
Email: hsp42e@bangor.ac.uk

10 May 2010

Dear Colleague,

Re: Decision making in learning disability nursing practice: An All Wales Nursing Questionnaire Survey

If you have returned the questionnaire, **thank you** for contributing to the research project and apologies for the second mailing. If you have not had the opportunity, I would be grateful if you could find 15 minutes to complete the enclosed questionnaire and return in the prepaid envelope.

You are being invited to take part in this survey because you are a nurse working within a NHS learning disability service in Wales. Your views are very important in helping us find out more about how learning disability nurses make decisions in practice and how those decisions impact on the lives of individuals with learning disability.

If you would like to contribute to the research, please complete the questionnaire and return in the pre-paid envelope provided by **Wednesday 26 May, 2010**. If you have any questions at all about this study, please do not hesitate to contact me. My contact details are at the top of this letter.

Thank you for your time.

Yours faithfully,

Ruth Wyn Williams
PhD Student

Encl: Participant information sheet, pre-paid envelope, questionnaire

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Ysgol Gwyddorau Iechyd

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Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

PRIFYSGOL
BANGOR
UNIVERSITY

1884

College of Health and Behavioural Sciences

School of Healthcare Sciences

Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Ffôn: 01248 383132
E-bost: hsp42e@bangor.ac.uk

07 Mehefin 2010

Annwyl Gyfaill,

Parthed: Gwneud penderfyniadau ym maes ymarfer nyrsio anabledd dysgu: Holiadur Nyrsio Cymru Gyfan

Os ydych wedi dychwelyd yr holiadur amgaeedig, **diolch** am gyfrannu tuag at y prosiect ymchwil, a ymddiheuraf am yrru nodyn atgoffa olaf. Os nad ydych wedi cael cyfle eto, fuaswn yn ddiolchgar pe baech yn treulio 15 munud i gwblhau'r holiadur a'i ddychwelyd yn yr amlen rhadbost.

Mae'ch barn yn bwysig iawn. Drwy gyfrannu at yr astudiaeth byddwch yn ein helpu i ddarganfod mwy am sut mae nyrsys anabledd dysgu'n gwneud penderfyniadau a sut mae'r penderfyniadau hynny'n effeithio ar fywydau unigolion gydag anabledd dysgu.

Os hoffech gyfrannu at yr ymchwil, a wnewch chi lenwi'r holiadur a'i anfon yn ôl yn yr amlen rhadbost a ddarparwyd erbyn **dydd Mawrth, 22 Mehefin, 2010**. Os oes gennych unrhyw gwestiynau o gwbl ynghylch yr astudiaeth hon, croeso i chi gysylltu â mi. Mae fy manylion cyswllt ar frig y llythyr hwn.

Diolch i chi am eich amser.

Yr eiddoch yn gywir,

Ruth Wyn Williams
Myfyrwraig PhD

Amg: amlen rhadbost, holiadur

351

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
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Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Telephone: 01248 383132
Email: hsp42e@bangor.ac.uk

07June 2010

Dear Colleague,

Re: Decision making in learning disability nursing practice: An All Wales Nursing Questionnaire Survey

If you have returned the questionnaire, **thank you** for contributing to the research project and apologies for sending this last reminder. If you have not had the opportunity, I would be grateful if you could find 15 minutes to complete the enclosed questionnaire and return in the prepaid envelope.

Your views are very important. By contributing to the study you will help us find out more about how learning disability nurses make decisions in practice and how those decisions impact on the lives of individuals with learning disability.

If you would like to contribute to the research, please complete the questionnaire and return in the pre-paid envelope provided by **Tuesday 22nd June, 2010**. If you have any questions at all about this study, please do not hesitate to contact me. My contact details are at the top of this letter.

Thank you for your time.

Yours faithfully,
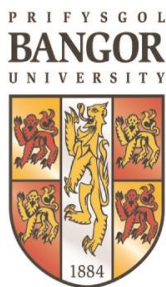
Ruth Wyn Williams
PhD Student

Encl: pre-paid envelope, questionnaire

Appendix M - Study 2 Participants information sheet (Welsh / English)

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

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Fax: 01248 383114

Taflen Wybodaeth i Gyfranwyr

Gwneud penderfyniadau ym maes ymarfer nyrsio anabledd dysgu: Arolwg Holiadur Nyrsio Cymru Gyfan

1. Cyflwyniad

Fy enw yw Ruth Wyn Williams ac rydw i'n fyfyrwraig PhD yn Ysgol Gwyddorau Gofal Iechyd, Prifysgol Bangor. Fel rhan o'm project ymchwil ehangach, rydw i'n cynnal arolwg ar wneud penderfyniadau ym maes ymarfer nyrsio anabledd dysgu yng Nghymru.

Fe'ch gwahoddir i gymryd rhan yn yr arolwg ymchwil hwn trwy lenwi holiadur. Cyn i chi benderfynu a ydych yn dymuno cymryd rhan ai peidio, mae hi'n bwysig i chi ddeall pam mae'r ymchwil yn cael ei gwneud a beth fydd yn digwydd. Cymerwch amser i ddarllen y wybodaeth ganlynol yn ofalus. Mynnwch air ag eraill am yr astudiaeth os dymunwch a holwch fi os ydyw rhywbeth yn aneglur neu os hoffech gael mwy o wybodaeth. Cymerwch eich amser i benderfynu a fyddech yn hoffi cymryd rhan ai peidio.

2. Beth ydy pwrpas yr astudiaeth?

Bydd yr astudiaeth hon yn edrych ar sut mae nyrsys yn gwneud penderfyniadau ymarfer. Rydw i'n gofyn am farn pob nyrs gymwysedig sy'n gweithio mewn gwasanaeth anabledd dysgu GIG yng Nghymru. Bydd y wybodaeth a ddaw i law yn helpu i ddeall ymarfer presennol, a chanfod meysydd ymchwil pellach.

3. Oes raid i mi gymryd rhan?

Chi sydd i benderfynu a fyddech yn hoffi cymryd rhan ai peidio. Os gwnewch hynny, fe gewch y daflen wybodaeth hon i'w chadw, a gofynnir i chi lenwi a dychwelyd yr holiadur amgaeedig. Cedwir y data o'r holiadur am 3 blynedd ar ôl cwblhau'r astudiaeth PhD.

4. Beth fydd yn digwydd i mi os byddaf yn cymryd rhan?

Fe'ch gwahoddir i gymryd rhan mewn arolwg Cymru gyfan trwy lenwi holiadur a ddylai gymryd tua chwarter awr o'ch amser. Pan fyddwch wedi llenwi'r holiadur, a wnewch chi ei anfon yn ôl ataf erbyn Dydd Mercher, 26 Mai, 2010, gan ddefnyddio'r amlen â stamp a amgaeaf. Trwy lenwi a dychwelyd yr holiadur, byddaf yn cymryd eich bod wedi cytuno i gymryd rhan yn yr astudiaeth.

5. Fydd y ffaith fy mod i'n cymryd rhan yn yr astudiaeth yma'n cael ei chadw'n gyfrinachol?

Bydd cyfeirnod unigol ar bob holiadur y byddaf yn ei anfon allan. Defnyddir hwn yn lle eich enw er mwyn sicrhau fy mod yn cadw'r atebion a rowch i mi'n gyfrinachol. Bydd yr holl ddata'n cael ei gadw am 3 blynedd ar ôl cwblhau'r astudiaeth PhD; yna dinistrir y wybodaeth.

6. Beth fydd yn digwydd i ganlyniadau'r astudiaeth ymchwil?
Project ymchwil myfyrwyr yw'r astudiaeth hon. Bydd y wybodaeth a gesglir a'ch sylwadau'n cael eu cadw'n gyfrinachol a bydd yn rhan o draethawd PhD a gyflwynir i Brifysgol Bangor.
Nid oes gennyf unrhyw awdurdod i sicrhau newid yn y ddarpariaeth gwasanaeth. Ond, unwaith y bydd yr astudiaeth wedi dod i ben, lledaenir y canfyddiadau trwy gyflwyniadau mewn cynadleddau a chyfnodolion proffesiynol er mwyn iddynt roi sail i ymarfer yn y dyfodol.

7. Beth ydy manteision a risgiau posibl o gymryd rhan?
Mae'r astudiaeth hon yn rhoi cyfle i chi leisio eich barn ynghylch y ffordd y mae nyrsys anabledd dysgu'n gwneud penderfyniadau ymarfer. Nid oes dim risgiau i chi o gymryd rhan yn yr astudiaeth hon. Os nad ydych yn dymuno cymryd rhan yn yr arolwg hwn, a wnewch chi ddychwelyd yr holiadur heb ei lenwi gan ddefnyddio'r amlen rhadbost. Os gwnewch hynny fyddwn ni ddim yn anfon nodyn atgoffa atoch heb fod angen.

8. Pwy sydd wedi adolygu'r astudiaeth?
Pwyllgor Llywodraethu Ymchwil Bwrdd Iechyd Prifysgol Betsi Cadwaladr / Panel Adolygu Mewnol.
Pwyllgor Moeseg Ymchwil Lleol Gogledd Orllewin Cymru.
Pwyllgor Moeseg Ymchwil, Ysgol Gwyddorau Gofal Iechyd, Prifysgol Bangor.

Bydd tri goruchwyliwr yn monitro'r ymchwil: Yr Athro Richard Hastings, yr Athro Fiona Irvine a Gwerfyl Wyn Roberts.

9. Beth os bydd problem yn codi?
Mae'n annhebygol iawn y bydd unrhyw broblemau'n codi. Ond os digwydd eich bod yn cael problem gyda'r ffordd y mae'r ymchwil yn cael ei gwneud ac nad oes modd ei datrys gallwch gysylltu â Mr Ruhi Behi, Pennaeth Ysgol y Gwyddorau Gofal Iechyd, Prifysgol Bangor, Fron Heulog, Bangor, Gwynedd. LL57 2EF

Mr Ruhi Behi   Ffôn: 01248 351151   E-bost: r.h.behi@bangor.ac.uk

10. Manylion cyswllt i gael mwy o wybodaeth:
Diolch i chi am gymryd yr amser i ddarllen y daflen wybodaeth yma. Os oes gennych unrhyw gwestiynau ynghylch yr astudiaeth croeso i chi gysylltu â mi ar y cyfeiriad isod. Edrychaf ymlaen at dderbyn eich holiadur wedi ei lenwi.

Croeso i chi gysylltu â Ruth Wyn Williams i gael mwy o wybodaeth ar 01248 383132 neu e-bostiwch hsp42e@bangor.ac.uk

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Participant Information Sheet

Decision making in learning disability nursing practice:
An All Wales Nursing Questionnaire Survey.

1. Introduction
My name is Ruth Wyn Williams and I am a PhD student at the School of Healthcare Sciences, Bangor University. As part of my wider research project, I am undertaking a survey of decision making within learning disability nursing practice in Wales.

You are being invited to take part in this research study by completing a questionnaire. Before you decide whether or not you wish to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish and ask me if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

2. What is the purpose of the study?
This study will explore how nurses make decisions in practice. I am seeking the opinions of all qualified nurses who work within an NHS learning disability service in Wales. The information gathered will assist in understanding current practice, and identify further areas for research.

3. Do I have to take part?
It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to complete and return the questionnaire enclosed. The data from the questionnaire will be kept for 3 years after completion of the PhD study.

4. What will happen to me if I take part?
You are invited to take part in an all Wales survey by completing a questionnaire that should take about 15 minutes of your time. When you have completed the questionnaire, please return it to me by Wednesday 26 May 2010, using the prepaid envelope, which is enclosed. By completing and returning the questionnaire, I will assume that you have consented to take part in the study.

5. Will my taking part in the study be kept confidential?
Each questionnaire that I send out is labelled with an individual reference number. This is used in place of your name to ensure that I keep the responses that you give confidential. All the data will be kept for 3 year after the completion of the PhD study; the information will then be destroyed.

6. What will happen to the results of the research study?

This study is a student research project, the information gathered, and your comments will be anonymised and this will form part of a PhD thesis submitted to Bangor University.
I have no authority to effect any change in service provision. However, once the study has been completed, the findings will be disseminated through conference presentations and professional journals in order to inform future practice.

7. What are the possible benefits or risks of taking part?

This study provides an opportunity for you to voice your opinion regarding the way in which learning disability nurses make decisions in practice. There are no risks for you in taking part in this study. If you do not wish to take part in this survey, please return the uncompleted questionnaire using the prepaid envelope. This will prevent us from sending you unnecessary reminders.

8. Who has reviewed the study?

Betsi Cadwaladr University Health Board Research Governance Committee / Internal Review Panel.
North West Wales Research Ethics Committee.
Research Ethics Committee, School of Healthcare Sciences, Bangor University

Three supervisors will monitor the research: Professor Richard Hastings, Professor Fiona Irvine and Gwerfyl Wyn Roberts.

9. What if there is a problem?

It is unlikely there will be any problems. However if you do experience any problems regarding the way the research is being conducted you can direct any unresolved issues to Mr Ruhi Behi, Head of School, School of Healthcare Sciences, Bangor University, Fron Heulog, Bangor, Gwynedd. LL57 2EF

Mr Ruhi Behi   Tel: 01248 351151   email: r.h.behi@bangor.ac.uk

10. Contact details for further information:

Thank you for taking time to read this information sheet. If you have any questions about this study please feel free to contact me at the address shown. I look forward to receiving your completed questionnaire.

Please do not hesitate to contact Ruth Wyn Williams for further information on 01248 383132 or email hsp42e@bangor.ac.uk

Appendix N - Study 2, Guidelines for disseminating questionnaire

Guidelines for disseminating questionnaire in
XXXX Health Board.

These guidelines will facilitate the dissemination of the *Decision making in learning disability nursing practice: An All Wales Nursing Questionnaire Survey* to the qualified nursing staff of the learning disability services.   All staff will receive a research pack containing a bilingual invitation letter, participant information sheet and questionnaire. There are four stages to the distribution:

1st Stage – all recipients receive a research pack –**DATE**

2nd Stage – all recipients receive a Thank You / Reminder postcard one week after initial mailing –**DATE**

3rd Stage - three weeks after initial mailing of questionnaire a replacement questionnaire is sent to non-respondents –**DATE**

4th Stage - a replacement questionnaire sent to non-respondents seven weeks after initial mailing of questionnaire – **DATE**

Any problems please do not hesitate to contact Ruth Wyn Williams at the School of Healthcare Sciences, Bangor University on:

Email: **hsp42e@bangor.ac.uk**

Tel: **01248 383132**

Mob: **XXXXXXXX**

Thank you for distributing this questionnaire your time
and effort is appreciated.

Stage 1. – DATE

All research packs are sealed and ready for posting via internal mail to all qualified nurses (n=XXX) working within the learning disability services of XXX. XXX research packs are provided.

On the front left corner of each envelop there is a unique identification code. All envelopes are marked with a numerical code from **1XXX** to **1XXX**.

When addressing each research pack envelope with an individual's work address please note the name of the recipient and the department or place of work on the enclosed Reference Sheet. The reference sheet is titled *"Reference sheet for distributing questionnaire in XXX XXX Health Board".*

For example, complete the Reference Sheet as follows for all recipients:

Unique ID code	Name of Staff	Area / Dept of work
1001	John Jones	.....community team
1002	Bob Williams	.....unit

Completing the Reference Sheet will avoid sending out any unnecessary reminders to staff.

Stage 2. – DATE (1 week after initial mailing)
Postcard sent one week after initial mailing of the questionnaire to all potential participants, thanking those who returned the questionnaire and reminding those who have not, to do so.

> Please address and post the Thank you / Reminder postcard provided to all recipients via internal mail.

Stage 3. – DATE (3 weeks after initial mailing)
Second letter, enclosing a replacement questionnaire sent to non-respondents three weeks after initial mailing of questionnaire.

- Ruth Wyn Williams will email XXX the Unique ID Codes of the recipients that will receive a second mailing of the questionnaire.

- On the envelope of each research pack to be sent out at this stage the words **MAIL 2** will be written on the front left corner of the envelope.

- The envelope is not sealed, but contains all the necessary paper work and is ready to be sent out once the Unique ID Code is written on the questionnaire enclosed.

- Please write the Unique ID Code provided by Ruth Wyn Williams in the boxes on the top left hand side of the questionnaire (on the English version). The first number, that is, **1,** is already written on the questionnaire.

For example:

1	1	0	3

- Please seal and address the envelope to the recipient of the allocated Unique ID Code, and send via internal post.

Stage 4 – DATE (7 weeks after initial mailing) Final Reminder
Third letter, again enclosing a replacement questionnaire sent to non-respondents seven weeks after initial mailing of questionnaire.

- Ruth Wyn Williams will email XXX the Unique ID Codes of the recipients that will receive a third mailing of the questionnaire.

- On the envelope of each research pack to be sent out at this stage the words **MAIL 3** will be written on the front left corner of the envelope.

- The envelope is not sealed, but contains all the necessary paper work and is ready to be sent out once the Unique ID Code is written on the questionnaire enclosed.

- Please write the Unique ID Code provided by Ruth Wyn Williams in the boxes on the top left hand side of the questionnaire (on the English version). The first number, that is, **1,** is already written on the questionnaire.

For example:

1	1	6	7

- Please seal and address the envelope to the recipient of the allocated Unique ID Code, and send via internal post.

Appendix O – Study 2, Ethical approval letters

NHS

Pwyllgor Moeseg Ymchwil Gogledd Orllewin Cymru
North West Wales Research Ethics Committee

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

PRIVATE & CONFIDENTIAL
Miss R Wyn Williams
PhD Student, Bangor University
School of Healthcare Sciences
Fron Heulog, Ffordd Ffriddoedd,
Bangor, Gwynedd
LL57 2EF

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk

22 February 2010

Dear Miss Williams

Study Title:	**Decision making in learning disability nursing practice. An all Wales Nursing Questionnaire Survey.**
REC reference number:	09/WNo01/51
Protocol number:	1

The Research Ethics Committee reviewed the above application at the meeting held on 18 February 2010. Thank you for attending to discuss the study.

Ethical opinion

Scientific design and conduct of the study
The Committee concluded that the research design is suitable for answering the research question. A query was raised regarding the intuitive and analytic regression model. The CI clarified that LAURI questionnaire results are grouped into two categories: intuitive or analytic; regression is used to analyse results for these groups. No further ethical issues were raised.

Suitability of the applicant and facilities; community considerations
The Committee concluded that the Chief Investigator is qualified and adequately supervised to carry out this research. The local facilities and arrangements are suitable, and community issues have been considered. No further ethical issues were raised.

Anticipated benefits/risks for research participants
The Committee discussed the anticipated benefits and potential risks to participants and were satisfied that the applicant has suitably identified the risks and benefits and highlighted them in the information given to participants. No further ethical issues were raised.

Care and protection of research participants (welfare and dignity)
The Committee was satisfied that the welfare and dignity of potential participants has been taken into account in a professional manner.

363

The Committee noted that no compensation arrangements are in place, but as this is a questionnaire study it is unlikely that any such arrangements are necessary.

A query was raised regarding the reminders to be sent to non-responders. The CI clarified that as no personal details are available to the researcher, the questionnaire pack will go to senior nurses who will then disseminate to their staff. To avoid coercion the questionnaire is sent in the name if the student, not the nurse.

The Committee questioned if sending 3 reminders is appropriate. The CI explained that in recently published literature it is suggested as an efficient method to augment response rate. No further ethical issues were raised.

Adequacy and completeness of Participant Information
The Committee agreed that generally the language used is clear and understandable and all the procedures described in the protocol have been addressed in the Information Sheet.

Informed Consent process
The Committee noted that written informed consent is taken as part of a process - with participants having adequate time to consider the information, and opportunity to ask questions.   The information is clear to what the participant consents and there is no inducement or coercion. No other ethical issues were raised.

Data protection and participant's confidentiality
The Committee discussed where and for how long will data be stored, and clarified who will have access to the data. No further ethical issues were raised

General comments/ missing information/ typographical errors/ application errors

No comments were made spelling mistakes on welsh PIS.

Members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Sponsors are not required to notify the Committee of approvals from host organisations.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		07 January 2010
REC application: 23961/88001/1/886		07 January 2010
Protocol	1	14 December 2009
Participant Information Sheet	3	22 January 2010
Letter of invitation to participant	2	26 November 2009
Summary/Synopsis	1	01 December 2009
Questionnaire: All Wales Nursing Questionnaire	8	18 December 2009
Referees or other scientific critique report	No version	03 February 2010
Investigator CV	No version	07 January 2010
CV Prof Richard Hastings	No version	No date
CV Prof Fiona Irvine	No version	No date
CV Academic Supervisor Mrs Gwerfyl Roberts	No version	08 January 2010
Evidence of insurance or indemnity - UMAL - Employer's Liability & Public Liability	No version	01 August 2009
Letter from Sponsor	No version	22 December 2009

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet. All members present at the meeting were present for the review of this application. It was noted that absent members have not submitted written comments.
No conflicts of interest were declared in relation to this application.
No observers were present during the review of this application.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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
- Progress and safety reports
- Notifying the end of the study

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/WNo01/51	Please quote this number on all correspondence

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

Yours sincerely

**Mr David Owen
Chair**

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"

Copy to: *Sponsor's representative: Mr R Behi, Bangor University
R&D Department for Betsi Cadwaladr University Health Board – West Division*

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Gofal Iechyd
Prifysgol Bangor

PRIFYSGOL BANGOR UNIVERSITY
1884

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Fron Heulog, Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Ffôn: 01248 383162
Ffacs: 01248 383182
E-bost: r.h.behi@bangor.ac.uk

Tel: 01248 383162
Fax: 01248 383182
E-mail: r.h.behi@bangor.ac.uk

3 February 2010

Ms Ruth Williams
PhD student
The School of Healthcare Sciences
Bangor University

PRIVATE AND CONFIDENTIAL

Dear Ms Williams

Re: School of Healthcare Sciences Research Ethics Committee
**Decision Making in Learning Disability Nursing Practice: an all Wales
nursing questionnaire survey**

Thank you for your submission to the Ethics committee which committee
members considered by virtual means. Following comments made by the
committee regarding the fact that three reminder letters could be seen as a
little excessive, the committee noted your response letter regarding the 'follow
up reminders method. Members accept your comments and are in agreement
that the study should proceed

I am pleased to inform you that you now have approval to proceed with your
research proposal.

Yours sincerely

Reverend Wynne Roberts
Chair
School of Healthcare Sciences Research Ethics Committee

Cc   Mrs Gwerfyl Roberts, Senior Lecturer

Ruhi H. Behi (Mr)
Pennaeth yr Ysgol • Head of School

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D – Y Gorllewin
R&D Internal Review Panel – West Division

Ysbyty Gwynedd
Clinical Academic Office
North Wales Clinical School
Bangor, Gwynedd
LL57 2PW

PRIVATE & CONFIDENTIAL
Miss R Wyn Williams
PhD Student
School of Healthcare Sciences
Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd
LL57 2EF

Telephone/Facsimile: 01248 - 384.877
Email: Rossela.Roberts@nww-tr.wales.nhs.uk

4 February 2010

Dear Miss Williams,

Review: Williams 09/51 Decision making in learning disability nursing practice: An All Wales
Nursing Questionnaire Survey
Chief Investigator: Ms R Wyn Williams

Documents reviewed: R&D Application form 23961/88005/14/789 07/01/2010; NHS SSI Application
form 23961/88006/6/838/34409/162147 07/01/2010; Protocol v.1 14/12/2009; Lay Summary v.1
01/12/2009; Letter of Invitation v.2 26/11/2009; Letter of Invitation - welsh v.2 26/11/2009;
Participant Information Sheet v.3 22/01/2010; Participant Information Sheet – welsh v.3 22/01/2010;
Questionnaire – All Wales Nursing Questionnaire v.8 18/12/2009; Questionnaire – All Wales
Nursing Questionnaire – welsh v.8 18/12/2009; Sponsor letter 22/12/2009; Evidence of
insurance/indemnity 01/08/2009; Investigator CV; Supervisor CV; Investigator CV
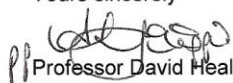
I have pleasure in confirming that the Internal Review Panel is pleased to grant approval
to proceed at this site (BCUHB – West Division)

The study should not commence until the Ethics Committee reviewing the research has confirmed
final ethical approval - favourable opinion.
All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the
Research Governance Framework for Health and Social Care in Wales (November 2001). An
electronic link to this document is provided on the Trust's R&D WebPages. Alternatively, you may
obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of
this research. Failure to comply with the approval conditions will result in the withdrawal of the
approval to conduct this research at this site.
If you would like further information on any other points covered by this letter please do not hesitate
to contact me. On behalf of the Committee, may I take this opportunity to wish you every success
with your research.

Yours sincerely

Professor David Healy
Consultant Psychiatrist, Professor of Psychological Medicine
Chairman Internal Review Panel

Chairman/Cadeirydd – Professor D Healy

368

**Gwent Healthcare
NHS Trust**

**Ymddiriedolaeth GIG
Gofal Iechyd Gwent**

The Friars
Friars Road
Newport
South Wales
NP20 4EZ

Tel: 01633 234234

Y Friars
Ffordd Friars
Casnewydd
De Cymru
NP20 4EZ

Ffôn: 01633 234234

Aneurin Bevan Local Health Board

**Research & Development
Research Risk Review Committee
Tel: 01633 234768**

Ruth Wyn Williams
PhD Student
School of Healthcare Sciences
Bangor University
Fron Heulog
Ffordd Ffriddoedd
Bangor
Gwynedd
LL57 2EF

Ref: RRR.10.10
7th January 2010

Dear Ruth

**Decision making in learning disability nursing practice: An All Wales Nursing
Questionnaire Survey
Reg: SA/129/09**

The Health Board Research Risk Review Committee considered your project at their
meeting held on Wednesday 6th January 2010.

The Committee agreed that your study did not appear to pose any risk to the Health
Board & agreed that your study be given a favourable opinion.

If you require any further assistance please do not hesitate to contact the R&D Office.

Yours sincerely

pp.

Professor Alex Anstey
Chairman
Research Risk Review Committee

www.gwent-tr.wales.nhs.uk

The Friars

NHS
WALES
GIG
CYMRU

Y Friars

369

GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Ysbyty Glan Clwyd Hospital, Ysbyty Maelor Wrexham Hospital
Adran Ymchwil a Datblygu,
Ysbyty H M Stanley, Llanelwy,
Sir Ddinbych, LL17 0RS

Research and Development Department,
H M Stanley Hospital, St Asaph LL17 0RS

Miss R Wyn Williams
PhD Student Bangor University
School of Healthcare Sciences
Fron Heulog
Ffordd Ffriddoedd
Bangor
Gwynedd LL57 2EF

Ein cyf / Our ref: LTJ

Eich cyf / Your ref:

Rhif Ysbyty / Hospital Number:

Rhif GIG / NHS Number:

☎:   01745 589624

Gofynnwch am / Ask for: Lona Tudor Jones

Ffacs / Fax: 01745 589717

E-bost / Email:
  Lona.TudorJones@wales.nhs.uk

Dyddiad / Date: 2 March 2010

PRIVATE & CONFIDENTIAL

Dear Miss Williams

Re: Decision making in learning disability nursing practice. An All Wales Nursing Questionnaire Survey
Ref: williams09/WNo01/51

The above research project was reviewed at the meeting of the Research Governance Committee / Internal Review Panel held on 2 March 2010 at Glan Clwyd Hospital.

I have pleasure in confirming that the Internal Review Panel has approved the study to proceed at the Betsi Cadwaladr University Health Board at Ysbyty Glan Clwyd Hospital and Ysbyty Maelor Wrexham Hospital.

The study should not commence until the Ethics Committee reviewing the research has confirmed final ethical approval (favourable opinion and no objection to site specific assessment).

As part of the regular monitoring undertaken by the Research Governance Committee you will be required to complete a short progress report. This will be requested on a six monthly basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research. Whilst the Health Board is keen to reduce the burden of paperwork for researchers failure to produce a report may result on withdrawal of approval.

All research conducted at Betsi Cadwaladr University Health Board must comply with the Research Governance Framework for Health and Social Care in Wales (November 2001). An electronic link to this document is provided on the Trust's R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research at the Betsi Cadwaladr University Health Board.

If you would like further information on any other points covered by this letter please do not hesitate to contact me. On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Cyfeiriad Gohebiaeth ar gyfer y Cadeirydd a'r Prif Weithredwr / Correspondence address for Chairman and Chief Executive:
  Swyddfa'r Gweithredwyr / Executives' Office,
Ysbyty Gwynedd, Penrhosgarnedd
Bangor, Gwynedd LL57 2PW   **Gwefan:** www.pbc.cymru.nhs.uk / **Web:** www.bcu.wales.nhs.uk

Appendices

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Yours Sincerely

Lara Tudor Jones

Dr D A Parker
Director R&D

Cc Mr Ruhi Behi, School of Healthcare Sciences, Bangor university, Fon Heulog, Ffordd
Ffriddoedd, Bangor LL57 2EF

GIG CYMRU **NHS** WALES | Bwrdd Iechyd Addysgu Powys

Powys Teaching Health Board

Research and Development Department
Adran Ymchwil a Datblygu

Direct Line: 01874 712638
Internal Extension: 2638

E-mail: marian.bough@wales.nhs.uk

04 March 2010

Miss R Wyn Williams
School of Healthcare Sciences
Fron Heulog,
Ffordd Ffriddoedd,
Bangor
Gwynedd
LL57 2EF

R&D Management Approval

Dear Miss Williams,

Re: Decision making in learning disability nurse practice: study 2
Ethics Reference: 09\WNo01/51

This project has now received R&D management approval from Powys Teaching Health Board. This R&D approval applies only to Powys Teaching Health Board and does not cover research at other locations. The approval is offered subject to the conditions set out below.

Standard Conditions of R&D Management Approval

1. The appropriate Ethics Committee approval must be obtained prior to commencement of research.

2. The R&D Department will be advised of any changes to the project for example changes to the research protocol, research staff or funding arrangements.

3. Any adverse events should be reported following Powys Teaching Health Board procedures and the R&D Department should also be informed.

Pencadlys y Bwrdd Iechyd
Y Plasty, Bronllys, Aberhonddu, Powys LD3 0LS
Ffôn: 01874 711661 Ffacs: 01874 711601

✓ CYFLOGWR YSTYRIOL
MINDFUL EMPLOYER
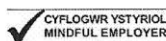
Health Board Headquarters
Mansion House, Bronllys, Brecon, Powys LD3 0LS
Tel: 01874 711661 Fax: 01874 711601

Rydym yn croesawu gohebiaeth Gymraeg
Bwrdd Iechyd Addysgu Powys yw enw gweithredd Bwrdd Iechyd Lleol
Addysgu Powys
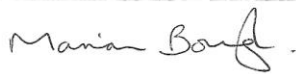
We welcome correspondence in Welsh
Powys Teaching Health Board is the operational name of
Powys Teaching Local Health Board

373

4. Please would you give recognition to the involvement of Powys Teaching Health Board, where appropriate.

5. The R&D Department will receive regular progress reports annually and a final report on completion of the research.

Please note that Powys Teaching Health Board is required to monitor research projects to ensure compliance with the Research Governance Framework. This is achieved by randomised audit of research projects.

We wish you every success in your research and look forward to hearing about its progress.

Yours sincerely,

Marian Bough

Marian Bough
Research and Development Coordinator
On behalf of Powys Teaching Health Board

GIG
CYMRU
NHS
WALES

Bwrdd Iechyd
Hywel Dda
Health Board

Ein cyf/Our ref:	CT	**Ysbyty Cyffredinol Llwynhelyg**
Gofynnwch am/Please ask for:	Chris Tattersall	Heol Abergwaun, Hwlffordd,
	Research & Development Manager	Sir Benfro, SA61 2PZ
Rhif Ffôn /Telephone:	01437 773823	Rhif Ffôn: 01437 764545
Email:	chris.tattersall@wales.nhs.uk	

Withybush General Hospital
Fishguard Road, Haverfordwest,
Pembrokeshire, SA61 2PZ
Tel: 01437 764545

Wednesday 10 March 2010

PRIVATE & CONFIDENTIAL

Miss R Williams
PhD Student
Bangor University
School of Healthcare Sciences
Fron Heulog
Ffordd Ffriddoedd
Bangor
Gwynedd
LL57 2EF

Dear Miss Williams

R&D Ref: HD/10/016
Project Title: Decision making in learning disability nursing practice. An all Wales
Nursing Questionnaire Survey

Thank you for submitting your proposal to us for approval for the project to be carried out
within this Health Board. I have received the comments from the Board review panel and
have not received any objections to the project going ahead.

Please accept this letter as approval for the project to proceed here according to the
protocol, as approved by the Research Ethics Committee.

Under Research Governance, and as lead researcher at this site, you are required to:

1. Adhere to the protocol approved by the REC and inform the R&D office of any changes (including changes to the end date of the project) and any changes referred to the Research Ethics Committee(s).

2. Inform the R&D Office of any relevant adverse/serious adverse events that may occur, whilst also reporting these through the proper channels in the Health Board, and according to the sponsor's protocol and procedures.

3. Complete any interim and final reports requested by the R&D Office. If sponsored by this Health Board, you will be asked to present your findings on completion.

4. Comply with the Research Governance Framework and co-operate with any audit inspection of the project files.

5. Ensure that your research complies with the Data Protection Act 1998.

Please note that if you wish to extend your project to other Health Boards or NHS bodies you must obtain the approval of all NHS bodies concerned. If the project is sponsored by this Health Board you must notify the R&D Office. Failure to notify may result in suspension or closure of the project.

With all good wishes for the research.

Yours sincerely

Chris Tattersall
R&D Manager

Research & Development Department **NHS**

Please reply to: Research & Development Department
Clinical Research Unit
Abertawe Bro Morgannwg University
Health Board
Morriston Hospital
SWANSEA
SA6 6NL

Telephone: 01792 704056
Fax:
E-mail: jemma.hughes@abm-tr.wales.nhs.uk

Miss Ruth W Williams,
PhD Student
School of Health Sciences
Bangor University
Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd
LL57 2EF

04 February 2010

Dear Miss Williams,

ID: 09Psyc31   **Decision making in Learning Disability Nursing practice. An all Wales Nursing Questionnaire Survey**

I am pleased to inform you that the above research study, which you recently submitted for review, has been approved by Abertawe Bro Morgannwg University Health Board.

This approval has been granted subject to the study receiving a favourable ethical opinion. Please send a copy of your ethics approval letter to the R&D office.

Bangor University is Sponsor for this study, as required under the Research Governance Framework.
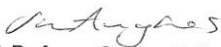
As a requirement of the Research Governance Framework, all research studies registered as active within ABM University Health Board will be subject to a randomised audit procedure to ensure appropriate standards of Research Governance (RG) and Good Clinical Practice (GCP) are being applied throughout the conduct of the research. Research Active Personnel must therefore ensure they familiarise themselves with the standards of RG and GCP.

Researchers employed by ABM University Health Board, including those holding Honorary Contract status are indemnified against actions for negligent harm via standard arrangements with Welsh Risk Pool (WRP). Provision for 'no-fault' compensation is limited under the scheme and is only available on an ex gratia, discretionary basis.

ABM University Health Board reserves the right to suspend approval of any research study where deviation from appropriate RG & GCP standards is uncovered.

May I take this opportunity to wish you well in undertaking the research. We will write to you in the future to request updates on the progress of the research and look forward to receiving outcomes of the study.

Yours sincerely

Professor Stephen Bain
Associate Medical Director (R&D)
Abertawe Bro Morgannwg University Health Board

Appendix P – example of participant missing data record

SPSS No/ Participant ID	Cells missing	Decision	Total No ? (sect 1-3) missed & % completed (n?=98)	No cells left after mean replacement (Sect 1-3)
1008		Complete		
1010		Complete		
1011		Complete		
1012		Complete		
2/1013	COLLECT 04	1 missing section 3 157/55=2.85 1 Replaced with 3	1= 99%	
1014		Complete		
1017		Complete		
1018		INFO02-Complete		
1019		Complete		
213/ 1021	HAND23 PLAN34, 38	3 missing section 3 144/53=2.71 3 Replaced with 3	3=97%	
1022	MD19	1 missing section 1	1=99%	1
81/1026	HAND23	1 missing section 3 147/55=2.67 1 Replaced with 3	1=99%	
1027		Complete		
1028		INFO03a- Complete		
1029		Complete		
4/1030	HAND20	1 missing section 3 186/55=3.38 1 Replaced with 3	1=99%	
1032		Complete		
215/1035	MD08, 09, PLAN34, 35	2 missing section 1 2 missing section 3 151/54=2.79 2 Replaced with 3	4=96%	2
100/1036	HAND17, 23 IMPLEM44, 46, 50, 53	6 missing section 3 151/50=3.02 6 Replaced with 3	6=94%	

1037	HAND16, 17, 23 IMPLEM44, 46, 50, 53	7 missing section 3 144/49=2.93 7 replaced with3	7=93%	
212/1038	PLAN32,	1 missing section 3 157/55=2.85 1 Replaced with 3 INFO02	1=99%	
1041		Complete		
130/1042	HAND16	1 missing section 3 149/55=2.70 1 Replaced with 3	1=99%	
1045		Complete		
6/1046	HAND17 HAND19, 20,23,25	5 missing section 3 150/51=2.94 5 Replaced with 3	5=95%	
1047		Complete		
1048		Complete		
18/1050	COLLECT05	1 missing section3 146/55=2.65 1 Replaced with 3 INFO02-		
1053		Complete		
1054		INFO03a- Complete		
1064	MD03 MD14	2 missing section 1 INFO03a	2=98%	2
1098	MD16	1 missing section 1	1=99%	1

- Total number of questionnaires received: n=285 (61.2%)
- Total number of questionnaires in FINAL data set: n=284
- (Total number of cells in questionnaire 98 x 284 = 27832)
- Total missing cells before replacement: 377 = 1.34%
- Total missing cells after mean replacement of 7 or less missing cells in Section 3: 267 = 0.95% of total questionnaire
- Total missing cells after mean replacement of 2 or less missing cells in Section 2: 239 = 0.85% of total questionnaire missing.
- Total missing cells after mean replacement of 2 or less missing cells in Section 1: 206= 0.74% of total questionnaire

Appendix Q – examples of statistical analysis undertaken

Descriptive statistics

This initial descriptive phase was used to describe the characteristics of the sample.

For example with categorical variables such as gender and age range frequencies were noted. Furthermore frequencies were also noted for the samples response to all items within the first and second measure.

See examples of SPSS output below:

Gender

		Frequency	Percent	Valid Percent	Cumulative Percent
	Male	69	24.3	24.6	24.6
Valid	Female	211	74.3	75.4	100.0
	Total	280	98.6	100.0	
Missing	System	4	1.4		
Total		284	100.0		

Age

		Frequency	Percent	Valid Percent	Cumulative Percent
	20-29	17	6.0	6.0	6.0
	30-39	46	16.2	16.4	22.4
Valid	40-49	133	46.8	47.3	69.8
	50-59	83	29.2	29.5	99.3
	60-69	2	.7	.7	100.0
	Total	281	98.9	100.0	
Missing	System	3	1.1		
Total		284	100.0		

Measure 1: Nurses' use of information to improve health

Item 1:When I make decisions concerned with improving health outcomes, I use information from my experience as a nurse

		Frequency	Percent	Valid Percent	Cumulative Percent
	Sometimes	44	15.5	15.5	15.5
Valid	Every time	239	84.2	84.5	100.0
	Total	283	99.6	100.0	
Missing	System	1	.4		
Total		284	100.0		

Measure 1: Nurses' use of information to improve health

Item 13: When I make decisions concerned with improving health outcomes, I use information from research publications

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	22	7.7	7.8	7.8
	Sometimes	239	84.2	84.8	92.6
	Every time	21	7.4	7.4	100.0
	Total	282	99.3	100.0	
Missing	System	2	.7		
Total		284	100.0		

Measure 2: Nurses' approach to decision making

Statistics

Item 9: I collect a lot of information about the client's views of his/her needs and health

N	Valid	282
	Missing	2

Measure 2: Nurses' approach to decision making

Item 9: I collect a lot of information about the client's views of his/her needs and health

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never or almost never	3	1.1	1.1	1.1
	Rarely	4	1.4	1.4	2.5
	Neither rarely nor often	26	9.2	9.2	11.7
	Often	121	42.6	42.9	54.6
	Almost always or always	128	45.1	45.4	100.0
	Total	282	99.3	100.0	
Missing	System	2	.7		
Total		284	100.0		

With continuous variables, such as years since qualified, a summary of mean, median and standards deviation was noted. See example of SPSS output below:

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
Years since qualified	273	1	40	18.59	9.695
Valid N (listwise)	273				

Independent t-tests

The first measure: Nurses' use of information to improve health outcomes consisted of 24 items that reflect two scales namely, experiential and empirical types and sources of evidence. The following is an example of the t-tests performed to compare the mean scores of a continuous variable for two groups. The results were not significant, that is, the majority of the p-values were above 0.05 in the t-tests performed.

An independent-samples t-test was conducted to compare the experiential sources of information scores for participants currently studying and participants not currently studying. There was no significant difference in scores for currently studying participants (M=31.03, SD=2.948) and participants not currently studying (M=31.22, SD=3.124); t (271) = -.366, p= .715 two-tailed). See SPSS output below:

Measure 1 Nurses' use of information to improve health

Group Statistics

	Currently studying	N	Mean	Std. Deviation	Std. Error Mean
Experiential sources of evidence	Yes	40	31.03	2.948	.466
	No	233	31.22	3.124	.205

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means					95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Experiential sources of evidence	Equal variances assumed	.475	.491	-.366	271	.715	-.194	.530	-1.238	.850
	Equal variances not assumed			-.381	55.138	.705	-.194	.509	-1.214	.826

Similarly various t-test were conducted to compare the scores of empirical based resources with other demographic characteristic such as agenda for change pay banding. See example of SPSS output below. The results were not significant.

Measure 1 Nurses' use of information to improve health

Group Statistics

	Agenda for change pay banding	N	Mean	Std. Deviation	Std. Error Mean
Empirical based sources of evidence	1 (Bands 5&6)	206	17.84	2.322	.162
	2 (Bands 7& 8)	67	17.91	1.564	.191

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Empirical based sources of evidence	Equal variances assumed	7.014	.009	-.232	271	.816	-.071	.304	-.669	.528
	Equal variances not assumed			-.282	166.953	.778	-.071	.250	-.565	.424

Measure 2: Nurses' approach to decision making consists of 56 items. During the initial process of data analysis the 56 items were divided into four sections of 14 items each. The sections were:

i. Collecting information for defining client's condition;
ii. Handling information and defining nursing needs;
iii. Planning; and
iv. Implementing nursing and monitoring and evaluating client's condition.

Numerous t-Tests were performed that incorporated the total score of the 56 items and total score of the individual sections (14 items) named above in relations to the demographic characteristics. The following is an example of some of the results. The results were not significant.

Total score of Measure 2: Nurses' approach to decision making (56 items) and gender

Group Statistics

	Gender	N	Mean	Std. Deviation	Std. Error Mean
Total score	Male	66	155.2576	9.74018	1.19893
Measure 2	Female	205	155.9561	8.44492	.58982

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Total score Measure 2	Equal variances assumed	.281	.596	-.562	269	.574	-.69852	1.24195	-3.14370	1.74666
	Equal variances not assumed			-.523	98.433	.602	-.69852	1.33616	-3.34994	1.95290

On average, male participants were more analytic in their decision making (*M*=155.25, *SE*=1.198) than female participants (*M*=155.95, *SE*=.58982) across the four stages of the nursing process from assessment to evaluation. This difference was not significant t(269) =-.562, *p*=>.05, and represented no effect *r*=.034.

Total score of *Collecting information for defining client's condition* (14 items Measure 2) and gender

Group Statistics

	Gender	N	Mean	Std. Deviation	Std. Error Mean
Total score of Collecting information	Male	67	41.1940	3.62750	.44317
	Female	208	40.8846	3.50654	.24313

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means					95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Total score of Collecting information	Equal variances assumed	.754	.386	.623	273	.534	.30941	.49674	-.66851	1.28734
	Equal variances not assumed			.612	108.574	.542	.30941	.50548	-.69248	1.31131

On average, females were more analytical in their decision making (*M*=40.8846, *SE*= .24313) than the males (*M*=41.1940, *SE*=.44317) during the collecting information for defining client's condition phase of nursing. The difference was not significant t(273) = .623, *p*=>.05, and represented no effect *r*=.03768

The 56 items in *Measure 2: Nurses' approach to decision making* also incorporated 2 sub scales (analytical orientated decision making and intuitive orientated decision making) of 28 items (Lauri & Salanterä, 2002). T-tests were then performed to compare the scores for analytical and intuitive items in relation to the demographic data and measure 1 scores. See example of SPSS output below; again the differences were not significant.

Total score of Measure 2 analytical orientated decision making items (28 items) and gender

Group Statistics

	Gender	N	Mean	Std. Deviation	Std. Error Mean
Measure 2 analytic orientated decision making	Male	67	53.85	12.039	1.471
	Female	206	52.23	10.047	.700

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Measure 2 analytic orientated decision making	Equal variances assumed	1.715	.191	1.089	271	.277	1.618	1.486	-1.308	4.544
	Equal variances not assumed			.993	97.674	.323	1.618	1.629	-1.615	4.850

Total score of Measure 2 intuitive orientated decision making items (28 items) and gender

Group Statistics

	Gender	N	Mean	Std. Deviation	Std. Error Mean
Measure 2 intuitive orientated decision making	Male	66	101.48	12.132	1.493
	Female	205	103.73	9.118	.637

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Measure 2 intuitive orientated decision making	Equal variances assumed	8.363	.004	-1.599	269	.111	-2.247	1.405	-5.014	.520
	Equal variances not assumed			-1.384	89.846	.170	-2.247	1.623	-5.472	.978

Correlations

Correlations were conducted to explore the relationship between variables. See examples below:

Descriptive Statistics

	Mean	Std. Deviation	N
Measure 1: experiential source of evidence	31.20	3.107	277
Measure 1: Empirical source of evidence	17.83	2.172	276
Measure 2: Intuitive decision making	103.24	10.170	275
Measure 2: Analytical decision making	52.64	10.643	277

Correlations

		Measure 1: experiential source of evidence	Measure 1: Empirical source of evidence	Measure 2: Intuitive decision making	Measure 2: Analytical decision making
Measure 1: experiential source of evidence	Pearson Correlation	1.000	.438**	.231**	-.443**
	Sig. (2-tailed)		.000	.000	.000
	N	277.000	273	269	271
Measure 1: Empirical source of evidence	Pearson Correlation	.438**	1.000	.235**	-.383**
	Sig. (2-tailed)	.000		.000	.000
	N	273	276.000	267	269
Measure 2: Intuitive decision making	Pearson Correlation	.231**	.235**	1.000	-.645**
	Sig. (2-tailed)	.000	.000		.000
	N	269	267	275.000	275
Measure 2: Analytical decision making	Pearson Correlation	-.443**	-.383**	-.645**	1.000
	Sig. (2-tailed)	.000	.000	.000	
	N	271	269	275	277.000

**. Correlation is significant at the 0.01 level (2-tailed).

Appendix R - Study 3, Ethical approval letters

NHS

Pwyllgor Moeseg Ymchwil Gogledd Cymru (Y Orllewin)
North Wales Research Ethics Committee (West)

PRIVATE & CONFIDENTIAL
Miss Ruth W. Williams
PhD Student
Bangor University
School of Healthcare Sciences
Fron Heulog, Ffordd Ffriddoedd,
Bangor, Gwynedd, LL57 2EF

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk

24 May 2010

Dear Miss Williams

Study Title: The experience of receiving a learning disability nursing service: a service user and carer perspective.
REC reference number: 10/WNo01/18
Protocol number: 1

Thank you for your letter of 11 May 2010, 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.

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.

Mental Capacity Act 2005
I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

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

Document	Version	Date
Covering Letter		22 March 2010
REC application 47478/106276/1/481		22 March 2010
Protocol	1	18 March 2010
Summary/Synopsis	3	15 March 2010
Initial assessment of capacity to consent	2	15 March 2010
Assessment of capacity to consent (protocol)	2	15 March 2010
Letter of invitation to participant (Service user)	2	15 March 2010
Letter of invitation to participant (carer)	2	13 March 2010
Letter of invitation to participant (community learning disability nurse)	2	15 March 2010
~~Participant Information Sheet (service user)~~ Superseded	~~3~~	~~15 March 2010~~
Participant Information Sheet (Service User)	4	10 May 2010
Participant Information Sheet (Service User) - Welsh Translation	4	10 May 2010
~~Participant Information Sheet (carer)~~ Superseded	~~2~~	~~15 March 2010~~
Participant Information Sheet (Carer)	3	10 May 2010
Participant Information Sheet (Carer) - Welsh Translation	3	10 May 2010
~~Participant Consent Form (service user (1))~~ Superseded	~~2~~	~~15 March 2010~~
Participant Consent Form (Service User 1)	3	10 May 2010
Participant Consent Form (Service User 1) - Welsh Translation	3	10 May 2010
~~Participant Consent Form (service user (2))~~ Superseded	~~2~~	~~15 March 2010~~
Participant Consent Form (Service User 2)	3	10 May 2010
Participant Consent Form (Service User 2) - Welsh Translation	3	10 May 2010
Participant Consent Form	3	10 May 2010
Participant Consent Form: Welsh Translation	3	10 May 2010
Interview Schedules/Topic Guides (service user)	2	15 March 2010
Interview Schedules/Topic Guides (carer)	2	15 March 2010
Response to Request for Further Information		11 May 2010
Evidence of insurance or indemnity	UMAL	01 August 2009
Letter from Sponsor		16 March 2010
Suprevisor CV (Prof. Richard Hastings)		
Supervisor CV (Prof Fiona Irvine)		
Supervisor CV (Ms Gwerfyl Wyn Roberts)		
Investigator CV - Ruth W Williams		17 March 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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
- Progress and safety reports
- Notifying the end of the study

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

| 10/WNo01/18 | Please quote this number on all correspondence |

Yours sincerely

Mr David Owen
Chair

Enclosures: "After ethical review – guidance for researchers"
Copy to: *Sponsor's Representative: Mr Ruhi Behi, Bangor University*
                  R&D office for BCUHB - West

Chairman/Cadeirydd – Mr David Owen, CBE, QPM

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D
R&D Internal Review Panel

Ysbyty Gwynedd
Clinical Academic Office
North Wales Clinical School
Bangor, Gwynedd
LL57 2PW

PRIVATE & CONFIDENTIAL
Miss Ruth Wyn Williams
PhD Student
Bangor University
School of Healthcare Sciences
Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd, LL57 2EF

Telephone/Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk

3 June 2010

Dear Miss Williams,

Re: Amendment Review: Williams 10/18 Further Information review – The experience of receiving a learning disability nursing service: a service user and carer perspective
Chief Investigator: Miss R Williams

Documents reviewed: Service User - Participant Information Sheet Version 4 10.05.10; Service User - Participant Information Sheet – Welsh Version 4 10.05.10; Carer - Participant Information Sheet Version 3 10.05.10; Carer - Participant Information Sheet Version 3 10.05.10 – Welsh; Consent Form Carers Version 3 10.05.10; Consent Form Carers Version 3 10.05.10 – Welsh; Service User Consent Form (1) Version 3 10.05.10; Service User Consent Form (1) Version 3 10.05.10 – Welsh; Service User Consent Form (2) Version 3 10.05.10; Service User Consent Form (2) Version 3 10.05.10 - Welsh

The Committee discussed the amendment and is satisfied with the scientific justification for this amendment, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the amendment.

I have pleasure in confirming that the Internal Review Panel has considered the above amendment, and is pleased to grant **Trust approval to continue** at this site. The amendment does not affect local management approval previously given to this research.

As part of the regular monitoring undertaken by the Internal Review Panel you will be required to complete a short progress report. This will be requested on an annual basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research. Whilst the Trust is keen to reduce the burden of paperwork for researchers **failure to produce a report may result in withdrawal of approval.**

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (November 2001). An electronic link to this document is provided on the Trust's R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office. On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Yours sincerely

Professor David Healy
Consultant Psychiatrist, Professor of Psychological Medicine
Chairman Internal Review Panel

_____

Chairman/Cadeirydd – Professor D Healy

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Gofal Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn: 01248 383162
Ffacs: 01248 383182
E-bost: r.h.behi@bangor.ac.uk

PRIFYSGOL
BANGOR
UNIVERSITY
1884

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog, Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 383162
Fax: 01248 383182
E-mail: r.h.behi@bangor.ac.uk

17 May 2010

Ms Ruth Williams
PhD Student
School of Healthcare Sciences

PRIVATE AND CONFIDENTIAL

Dear Ms Williams

School of Health Care Sciences Research Ethics Committee

The experience of receiving a learning disability nursing service: a service user and carer perspective

Thank you for submitting further information required by the Committee for their consideration.

Following this, the Committee were in agreement that the study should proceed and I am pleased to confirm that *ethical approval for your above research has been granted.*

Yours sincerely

Reverend Wynne Roberts
Chair
School of Healthcare Sciences Research Ethics Committee

Ruhi H. Behi (Mr)
Pennaeth yr Ysgol • Head of School

Appendix S - Study 3, Community intellectual disability nurse invitation letters

1. Community intellectual disability nurse initial invitation letter (Welsh/English)

2. Community intellectual disability nurse follow up letter (Welsh/English)

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Ffôn: 01248 383154
e-bost: hsp42e@bangor.ac.uk

04 Hydref 2010

Annwyl

<u>Teitl yr Astudiaeth: Y profiad o dderbyn gwasanaeth nyrsio anabledd dysgu:
safbwynt defnyddiwr gwasanaeth</u>

Rwy'n fyfyriwr PhD yn yr Ysgol Gwyddorau Iechyd, Prifysgol Bangor ac rwy'n gofyn
am eich help gyda recriwtio ar gyfer astudiaeth sy'n rhan o'm project ymchwil
ehangach, sy'n edrych ar y ffordd mae nyrsys anabledd dysgu yn gwneud
penderfyniadau. Mae'r astudiaeth hon yn edrych ar ystyr a phrofiad derbyn
gwasanaeth nyrsio anabledd dysgu o safbwynt defnyddwyr gwasanaeth.

Rwy'n eich gwahodd i gymryd rhan mewn recriwtio defnyddwyr gwasanaeth. Mae
eich ymwneud â hyn yn gwbl wirfoddol ac ni fydd eich penderfyniad p'un ai i helpu
neu beidio yn cael effaith ar eich safle proffesiynol.

Ar gyfer yr astudiaeth hon rwy'n gobeithio recriwtio hyd at wyth o ddefnyddwyr
gwasanaeth. Dylai'r defnyddwyr gwasanaeth gyflawni'r meini prawf canlynol;

- medru cydsynio i gymryd rhan yn yr astudiaeth ymchwil arbennig hon;
- yn derbyn gwasanaeth nyrsio anabledd dysgu ar hyn o bryd neu wedi
  derbyn gwasanaeth o'r fath o fewn y flwyddyn diwethaf;
- wedi derbyn gwasanaeth nyrsio anabledd dysgu am o leiaf 2 fis gydag o
  leiaf 4 ymweliad cyswllt gan nyrs anabledd dysgu;
- ddim yn derbyn triniaeth/ymyriad ar hyn o bryd am anawsterau iechyd
  meddwl ac/neu ymddygiad heriol;
- bod ganddynt rwydwaith cymdeithasol cefnogol ac yn fodlon trafod eu barn
  a'u profiad am y gwasanaeth nyrsio anabledd dysgu
- ar gael i gyfarfod â'r ymchwilydd ar dri achlysur: i) cyfarfod cyflwyniad i'r
  project ii) cyfweliad casglu data iii) cyfarfod diwedd project

Os hoffech helpu gyda phroses recriwtio'r astudiaeth hon, gofynnir i chi wneud y canlynol:

1. Nodi defnyddiwr gwasanaeth y credwch fyddai'n barod i gymryd rhan yn yr astudiaeth hon.
2. Ar ôl darllen y taflen defnyddiwr gwasanaeth "*Gwybodaeth am yr Astudiaeth"*, llenwi'r *Ffurflen Asesiad Cychwynnol o Allu i Gydsynio* yn ymwneud â'ch defnyddiwr gwasanaeth.
3. Os yw'r ffurflen *Asesiad Cychwynnol o Allu i Gydsynio* yn dangos y gall y defnyddiwr gwasanaeth fod â'r gallu i gydsynio i'r astudiaeth hon, gofynnir i chi ofyn i'r defnyddiwr gwasanaeth a hoffent gymryd rhan yn yr astudiaeth.
4. Os oes gan y defnyddiwr gwasanaeth ddiddordeb, byddwch yn trefnu iddynt gyfarfod â'r ymchwilydd i rannu gwybodaeth am yr astudiaeth.

Er gwybodaeth i chi, amgaeaf gopïau o daflen wybodaeth i ddefnyddiwr gwasanaeth am yr astudiaeth, ffurflen Asesiad Cychwynnol o Allu i Gydsynio a ffurflen Asesu Gallu i Gydsynio.

Os oes gennych unrhyw gwestiynau o gwbl ynghylch yr astudiaeth, neu os ydych yn fodlon fy helpu gyda'r broses recriwtio, mae croeso i chi gysylltu â mi. Mae fy manylion cyswllt ar ddechrau'r llythyr yma.

Diolch i chi am eich amser

Yn gywir

Ruth Wyn Williams

Myfyriwr PhD

Amg: Taflen gwybodaeth i Defnyddiwr Gwasanaeth, Ffurflen Asesiad Cychwynnol o Allu i Gydsynio

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Telephone: 01248 383154
Email: hsp42e@bangor.ac.uk

04 October 2010

Dear colleague,

<u>Title of Study: The experience of receiving a learning disability nursing service: a service user</u>

I am a PhD student at the School of Healthcare Sciences, Bangor University and I am asking for your help with recruitment for a study that forms part of my wider research project into decision making within learning disability nurse practice. This study explores the meaning and experience of receiving a learning disability nursing service from the perspective of service users.

I kindly invite you to take part in the recruitment of service users. Your involvement is entirely voluntary and your decision as to whether to help or not will not impact on your professional position.

For this study, I am hoping to recruit up to eight service users. The service users should meet the following criteria;

- have the ability to consent to participate in this specific research study;
- are currently receiving a learning disability nursing service or has received a learning disability nursing service within the last year;
- have received a learning disability nursing service for a minimum period of 2 months with a minimum of 4 contact visits from a learning disability nurse;
- are not currently receiving treatment/intervention for mental health difficulties and or challenging behaviour;
- have a supportive social network, are willing to communicate their views and experience of the learning disability nursing service.
- are available to engage in three meetings with the researcher: i) introduction to project meeting ii) data collecting interview iii) end of project meeting.

If you would like to help with the recruitment process of this study, you will be asked to:

5. Identify a service user that you think might be willing to participate in this study.
6. Having read the service user "*Information about the study*" sheet, complete the *Initial Assessment of Capacity to Consent Form* in relation to your service user.
7. If the *Initial Assessment of Capacity to Consent* form indicates that the service user might have the capacity to consent to this study, you are asked to approach the service user and ask if they would like to be take part in the study.
8. If the service user is interested, you would arrange a meeting with the researcher to share information about the study.

For your information, I enclose copies of the service user information sheet about the study, consent forms and the Initial Assessment of Capacity to Consent form.

If you have any questions at all about this study or are willing to help me with the recruitment process, please do not hesitate to contact me. My contact details are at the top of this letter.

Thank you for your time.

Yours sincerely

Ruth Wyn Williams
PhD Student

Encl: Service User Participant information sheet, Initial Assessment of Capacity to Consent Form

Appendices

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Ruth Wyn Williams
Ffôn / Tel: 01248 383132
E-bost / Email: hsp42e@bangor.ac.uk

16.07.10

Annwyl,

Dear,

Teitl yr Astudiaeth: Y profiad o dderbyn gwasanaeth nyrsio anabledd dysgu: safbwynt defnyddiwr gwasanaeth

Title of Study: The experience of receiving a learning disability nursing service: a service user

Diolch am aros ar ôl y cyfarfod XXX yn XXXXXXX am sgwrs yn ddiweddar. Gan ei fod yn adeg gwyliau ar lawer, rwyf yn deall gall fod yn anodd iawn recriwtio pobl ar gyfer fy astudiaeth ymchwil. Ond os gewch chi gyfle buaswn yn ddiolchgar be fyddech yn ystyried os oes gennych gleientiaid a gofalwyr a fydda â diddordeb mewn cymryd rhan.

Thank you for staying for a chat after the XXX meeting at XXXXXXX recently. As its holiday period for many, I understand it might be difficult to recruit possible participants to be involved in my research project. However, if you do get a chance I would be grateful if you could consider if you have any clients or carers that may be interested in participating.

Rwyf ar fy ngwyliau tan 17 Awst, tan hynny gallwch yrru negas i mi ar e-bost fydd orau.

I am on annual leave until 17th of August, until then, if you would like to leave me a message, email is best.

Diolch am eich amser,

Thank you for your time,

Ruth Wyn Williams
Myfyriwr PhD Student

Appendix T - Study 3, Initial assessment of capacity to consent (Welsh/English)

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

PRIFYSGOL BANGOR UNIVERSITY
1884

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

ASESIAD CYCHWYNNOL O ALLU I GYDSYNIO
(Mae'r ffurflen hon i'w llenwi gan y nyrs gymunedol anabledd dysgu)

Teitl yr astudiaeth: Y profiad o dderbyn gwasanaeth nyrsio anabledd dysgu: safbwynt defnyddiwr gwasanaeth a gofalwr

Hoffem wahodd client ar eich baich achosion, neu faich achosion diweddar, i gymryd rhan mewn astudiaeth ymchwil. Hoffem i chi wneud asesiad annibynnol cychwynnol o allu'r cleient i gydsynio i gymryd rhan yn yr astudiaeth ymchwil.

Enw'r darpar gyfranogwr...

Enw'r nyrs gymunedol anabledd dysgu: ....

Darllenwch y daflen "Gwybodaeth am yr Astudiaeth" a nodi, yn eich barn broffesiynol chi, a yw'r cleient:

1. Yn gallu deall a chadw gwybodaeth sy'n berthnasol i'r penderfyniad:

   Ydi ☐ Nac ydi

2. Yn gallu defnyddio a phwyso a mesur y wybodaeth hon wrth wneud penderfyniadau:

   Ydi ☐ Nac ydi

Os ydych wedi ateb un o'r gosodiadau isod yn **negyddol**, bernir nad yw'r cleient yn gallu cydsynio neu beidio â chydsynio i drefn yr ymchwil arfaethedig.

Rydym yn amgáu protocol (Asesu Gallu i Gydsynio) y bydd yr ymchwilydd yn ei ddefnyddio os bydd yr atebion i'r cwestiynau uchod yn **gadarnhaol**. Mae'r protocol hwn yn asesu gallu'r cleient i gydsynio i drefn benodol yr ymchwil.

Darllenwch y protocol *Asesu Gallu i Gydsynio.*

3. A ydych yn credu y bydd y cleient yn gallu dilyn y drefn a ddisgrifir yn y protocol?

Ydw ☐ Nac ydw ☐ Ddim yn siŵr ☐

Os ydych wedi ateb cwestiynau 1, 2 neu 3 yn **negyddol**, nid yw'n debygol bod gan y cleient y gallu i gydsynio i gymryd rhan yn yr astudiaeth hon.

Os ydych wedi ateb cwestiynau 1, 2 a 3 yn **gadarnhaol**, yna mae'n debygol bod gan y cleient y gallu i gydsynio i gymryd rhan yn yr astudiaeth hon.

Os ydych yn meddwl bod gan eich cleient y gallu i gydsynio ac yr hoffai gymryd rhan yn yr ymchwil hon, a fyddech cystal â chysylltu â'r ymchwilydd, Ruth Wyn Williams, drwy e-bost neu ffôn i drefnu'r cyfarfod cychwynnol hwn i gyflwyno'r project.   Trefnir cyfarfod gyda'r cleient a'u prif ofalwr i alluogi'r ymchwilydd i rannu gwybodaeth am yr astudiaeth.   Manylion cyswllt Ruth yw:

e-bost: hsp42e@bangor.ac.uk
Ffôn: 01248 383154

	Nyrs Gymunedol Anabledd Dysgu	Ymchwilydd
Printiwch eich enw:		
Llofnod:		
Dyddiad:		
Rhif ffôn:		

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Ffôn 01248 351151
Ffacs 01248 383114

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School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

INITIAL ASSESSMENT OF CAPACITY TO CONSENT
(This form to be completed by the community learning disability nurse)

Study Title: The experience of receiving a learning disability nursing service: a service user and carer perspective

We would like to invite a client on your caseload or recent caseload to take part in a research study. We would like you to undertake an initial independent assessment of the capacity of the client to consent for participation in the research study.

Name of potential participant...

Name of community learning disability nurse:...

Please read the "Information about the Study" sheet and indicate whether, in your professional judgement, the client:

1. Is able to comprehend and retain information material relevant to the decision:

   Yes ☐   No ☐

2. Is able to use and weigh this information in the decision-making process:

   Yes ☐   No ☐

If you have answered **No** to one of the above statements, then the client is judged to lack the capacity to give or withhold consent to the proposed research procedure.

Please find attached a protocol (Assessment of Capacity to Consent) that the researcher will use if the answers to the questions above are "**Yes**". This protocol assesses the capacity of the client to consent to the specific research procedure.

Please read the protocol *Assessment of Capacity to Consent*.

3. Do you think that the client will be able to complete the procedure described in the protocol?

Yes ☐   No ☐   Not sure ☐

If you have answered '**No**' to questions 1, 2 or 3, the client is likely not to have the capacity to consent to participate in this study.

If the answer is '**Yes**' to questions 1, 2 and 3, then the client is likely to have the capacity to consent to participate in this study.

If you think your client has the capacity to consent and would like to take part in this research, please contact the researcher Ruth Wyn Williams by email or telephone to arrange this initial introduction to project meeting. A meeting will be arranged with the client and their main carer to enable the researcher to share information about the study. Ruth's contact details are:

    email: hsp42e@bangor.ac.uk
    Tel: 01248 383154

	Community Learning Disability Nurse	Researcher
Print name:		
Signature:		
Date:		
Contact tel:		

Appendix U - Study 3, Service user invitation letter (Welsh/English)

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Ysgol Gwyddorau Iechyd
Prifysgol Bangor

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Ffôn 01248 351151
Ffacs 01248 383114

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Ffôn symudol: 07935305902
Ffôn: 01248 383154
E-bost: hsp42e@bangor.ac.uk

19.10.10

Annwyl

Teitl yr Astudiaeth: Y profiad o dderbyn gwasanaeth nyrsio anabledd dysgu: safbwynt defnyddiwr gwasanaeth a gofalwr

Rydw i'n fyfyriwr ymchwil yn yr Ysgol Gwyddorau Gofal Iechyd, Prifysgol Bangor, ac rydw i'n gofyn am eich help gydag astudiaeth. Mae'r astudiaeth yma'n rhan o broject mwy sy'n edrych ar y ffordd mae nyrsys anabledd dysgu yn gwneud penderfyniadau. Mae'r astudiaeth eisiau gweld beth rydych chi'n ei feddwl am nyrsys.

Chi sydd i ddewis a ydych am gymryd rhan ai peidio. Os byddwch yn dweud Ie neu Na, ni fydd yn effeithio ar y gwasanaeth nyrsio rydych yn ei gael. Bydd bob dim a ddywedwch yn cael ei gadw'n gyfrinach.

Rydw i'n eich gwahodd i siarad efo mi, yr ymchwilydd, am y nyrsys sy'n eich helpu. Rydw i'n anfon taflen wybodaeth am yr astudiaeth a ffurflen ganiatâd i chi feddwl am gymryd rhan yn yr astudiaeth.

Cymerwch o leiaf 3 diwrnod, ond dim mwy na 14 diwrnod, i feddwl am gymryd rhan yn yr astudiaeth. Os ydych eisiau, gofynnwch i rywun arall beth maen nhw'n ei feddwl.

Os hoffech gymryd rhan yn yr astudiaeth yma, fe wnaf ofyn cwestiynau i chi i wneud yn siŵr eich bod yn deall y rhesymau pam rydw i'n gwneud yr astudiaeth a beth y gellwch ei ddisgwyl gen i.

Os oes gennych unrhyw gwestiynau am yr astudiaeth yma, cysylltwch â mi os gwelwch yn dda.   Mae fy manylion cyswllt ar ddechrau'r llythyr yma.

Diolch i chi am eich amser

Yn gywir,

Ruth Wyn Williams
Myfyriwr PhD

Amg: Gwybodaeth am yr astudiaeth, ffurflen ganiatâd

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Ysgol Gwyddorau Iechyd
Prifysgol Bangor

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Ffôn 01248 351151
Ffacs 01248 383114

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Mobile: 07935305902
Telephone: 01248 383154
Email: hsp42e@bangor.ac.uk

18.10.10

Dear

Title of Study: The experience of receiving a learning disability nursing
service: a service user and carer perspective

I am a research student at the School of Healthcare Sciences, Bangor
University and asking for your help with a study. This study is the part
of a larger project looking at how learning disability nurses make
decisions. This study wants to find out what you think about nurses.

It is your choice if you want to take part. Whether you say Yes or No it
won't affect the nursing service you receive. Everything you say will be
kept secret.

I kindly invite you to talk to me, the researcher, about the nurses that
help you. I enclose an information sheet about the study and consent
form for you to think about taking part in the study.

Take at least 3 but no more than 14 days to think about taking part in this study, and if you want, ask someone else to say what they think.

If you would like to take part in this study, I will ask you questions to make sure you understand the reasons why I'm doing the study and what you can expect of me.

If you have any questions at all about this study, please contact me. My contact details are at the top of this letter.

Thank you for your time.

Yours sincerely,

Ruth Wyn Williams
PhD Student

Encl: Information about the study, Consent form

Appendix V - Study 3, Service user information sheet (Welsh/English)

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Ysgol Gwyddorau Iechyd
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Ffôn 01248 351151
Ffacs 01248 383114

BANGOR UNIVERSITY

College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Gwybodaeth am yr Astudiaeth

**Enw'r Astudiaeth: Y profiad o dderbyn gwasanaeth nyrsio anabledd dysgu:
safbwynt defnyddiwr gwasanaeth a gofalwr**

Cyflwyniad

Ruth Wyn Williams ydi fy enw i.

Rydw i'n fyfyriwr nyrsio ym

Mhrifysgol Bangor.

Diben yr Astudiaeth

Rydw i'n ysgrifennu am nyrsys, fel

_____, sy'n helpu pobl

gydag anabledd dysgu.

Dwi eisiau gwybod beth ydych chi'n

ei feddwl am nyrsys sydd yn gweithio

yn y gwasanaeth nyrsio anabledd

dysgu. Beth ydych chi'n ei feddwl

mae nyrsys yn ei wneud yn dda a

ddim yn ei wneud mor dda.

Oes rhaid i mi gymryd rhan?

Eich dewis chi ydi cymryd rhan, gellwch ofyn i rywun arall ddweud beth maen nhw'n ei feddwl. Gellwch ddweud GWNAF neu NA WNAF. Os dywedwch GWNAF ac yna newid eich meddwl, mae hynny'n iawn. Dim ond dywedwch NA WNAF wedyn, ni fydd rhaid i chi ddweud pam wrtha i.

GWNAF   NEU   NA WNAF

Beth fydd yn digwydd os cymerwch ran?

Byddaf yn eich cyfarfod 3 gwaith. Yn gyntaf i egluro'r astudiaeth, yn ail, gyda'ch caniatâd, i ofyn i chi am y nyrsys sy'n eich helpu. A'r trydydd cyfarfod, i chi gael gofyn unrhyw gwestiwn am yr astudiaeth a chyfle i mi ddeud diolch a hwyl fawr.

Gallwch orffen ein sgwrs unrhyw bryd heb ddweud pam wrtha i, neu trefnu i orffen y sgwrs rhyw dro arall os ydych eisiau.

1

2

3

Gallaf ddod i'ch gweld pryd bynnag rydych chi eisiau.

2

414

Gellwch ofyn i rywun ddod efo chi os ydych

eisiau. Byddaf yn gofyn i chi a yw'n iawn recordio

ein sgwrs ar dâp sain.

Byddwn yn gofyn i'r person sy'n eich cefnogi

fwyaf, a ydyw'n iawn i siarad efo nhw hefyd.

Cyfrinachedd

Bydd pob dim y byddwch yn ei ddweud yn cael

ei gadw'n gyfrinach. Os bydda i'n ysgrifennu

am yr hyn y gwnaethoch ei ddweud, fydda i ddim

yn dweud eich enw wrth neb. Ond os fydd

rhywbeth a ddwedoch yn achosi pryder i mi, mi

fyddaf yn dweud wrth rhywun arall.

Beth ydi manteision neu risgiau cymryd rhan?

Mae cymryd rhan yn rhoi cyfle i chi ddweud wrtha

i beth rydych yn ei feddwl o nyrsys. Ond, weith-

iau, mae pobl yn ypsetio wrth siarad am bethau.

Os byddwch yn ypsetio wrth siarad am y nyrsys,

bydd Ruth yn eich helpu efo unrhyw broblemau.

Fersiwn 4. 10.05.10

3

Pwy sydd wedi edrych ar yr astudiaeth yma?

Y rhain ydi'r bobl sydd yn gwneud yn siŵr ei bod yn iawn i mi siarad efo chi. Y rhain ydi:

- Pwyllgor Moeseg Ymchwil Gogledd Orllewin Cymru
- Panel Adolygu Mewnol Bwrdd Prifysgol Betsi Cadwaladr
- Pwyllgor Moeseg Ymchwil, Ysgol Gwyddorau Gofal Iechyd, Prifysgol Bangor

Fy athrawon ydi: Yr Athro Richard Hastings, Yr Athro Fiona Irvine a Gwerfyl Wyn Roberts

Beth os bydd yna broblem?

Dwi ddim yn disgwyl y bydd unrhyw broblemau. Fodd bynnag, os oes gennych unrhyw gwynion, cysylltwch â:

Dr Malcolm Godwin, Pennaeth Ysgol, Ysgol Gwyddorau Gofal Iechyd, Prifysgol Bangor, Fron Heulog, Bangor, Gwynedd. LL57 2EF

Ffôn: 01248 351151

E-bost: godwin.malcolm@bangor.ac.uk

Os oes gennych unrhyw

gwestiynau am yr astudiaeth yma,

mae croeso i chi ofyn

unrhyw gwestiynau i Ruth.

Ruth Wyn Williams

Myfyriwr PhD,

Ysgol Gwyddorau Gofal Iechyd,

Prifysgol Bangor,

Fron Heulog,

Bangor,

Gwynedd. LL57 2EF

Ffôn: 01248 383154

Ffôn symudol: 07935305902

E-bost: hsp42e@bangor.ac.uk

Diolch i chi am roi eich amser i ystyried cymryd rhan yn yr astudiaeth yma

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Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114

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College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Information about the Study

Name of Study: The experience of receiving a learning disability nursing service: a service user and carer perspective

Introduction

My name is Ruth Wyn Williams

I am a nursing student at Bangor

University.

Purpose of Study

I am writing about nurses that help

people with learning disabilities like

_____.

I want to know what you think about

nurses that work in the learning

disability nursing service. What you

think nurses are good at and things

that they are not so good at .

Version 4. 10.05.10

1

418

Do I have to take part?

It is your choice to take part, you can ask someone else to say what they think. You can say YES or say NO. If you say YES then change your mind, that's OK. Just tell me NO later on, you won't have to tell me why.

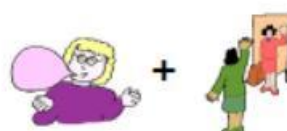**YES   OR   NO**

What will happen if you take part?

I will meet with you 3 times. First to explain what the study is about, second meeting, with your OK, I will, ask you about the nurses that help you. And the third meeting will give you a chance to ask questions and for me to say thank you and good-bye.

You may stop the meetings at any time without giving me a reason or resume later if you wish to do so.

1

2

3

I can come and see you whenever you want.

2

419

You can ask someone else to come with you if you want. I will ask you if it is OK to record our conversation on a audio-recorder.
We will also ask the person who supports you the most if it's OK to talk to them too.

Confidentiality

Everything you say will be kept secret.
If I write about what you say I won't tell anyone your name. But if something you say worries me I will have to tell someone else.

What are the benefits or risks of taking part?

Taking part gives you an chance to tell me what you think of nurses. But, sometimes people get upset talking about things. If you feel upset talking about the nurses, Ruth will help you to sort out any problems.

420

Who has looked at this study?

These are the people who make

sure that it's OK for me to talk to

you. They are called:

- North West Wales Research Ethics Committee
- Besti Cadwaladr University Health Board Internal Review Panel
- Research Ethics Committee, School of Healthcare Sciences, Bangor University

My teachers are: Professor

Richard Hastings, Professor Fiona

Irvine and Gwerfyl Wyn Roberts

What if there is a problem?

I don't expect there will be any

problems. However, if you have

any complaints please contact:

Dr Malcolm Godwin, Acting Head of School, School of Healthcare Sciences, Bangor University, Fron Heulog, Bangor, Gwynedd. LL57 2EF

Tel: 01248 351151

Email: godwin.malcolm@bangor.ac.uk

If you have any questions about this study, please feel free to ask Ruth any questions.

Ruth Wyn Williams

PhD Student,

School of Healthcare Sciences,

Bangor University,

Fron Heulog,

Bangor,

Gwynedd. LL57 2EF

Tel: 01248 383154
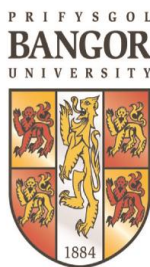
Mobile: 07935305902

Email: hsp42e@bangor.ac.uk

Thank you for your time in considering to take part in this study

Appendix W - Study 3, Assessment of capacity to consent (Welsh/English)

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5. Darllenwch y darn canlynol o'r daflen wybodaeth: "

   Gofynnwch i'r darpar gyfranogwr: **"Pan fyddaf yn siarad efo chi, ydych chi'n hapus i mi recordio ein sgwrs?"**

   Ateb YDW neu NAC YDW.

6. Darllenwch y darn canlynol o'r daflen wybodaeth: "Eich dewis chi ydi cymryd rhan, gellwch ofyn i rywun arall ddweud beth maen nhw'n ei feddwl.   Gellwch ddweud GWNAF neu NA WNAF.   Os dywedwch GWNAF, ond eich bod yn newid eich meddwl wedyn, mae hynny'n iawn. Dim ond dywedwch NA WNAF wrtha i wedyn, ni fydd rhaid i chi ddweud pam wrtha i".

   Gofynnwch i'r darpar gyfranogwr: **"Beth fyddwch yn ei wneud os newidiwch eich meddwl?".**

   Sgoriwch 1 am ateb tebyg i: "Dweud Na wrtha chi".
   Sgoriwch 0 os bydd yr ateb yn amherthnasol neu heb fod yn ddigon clir.

Sgorio Cyffredinol
Os bydd y cyfranogwr yn sgorio 0 i unrhyw un o'r cwestiynau dan eitemau 2, 3, neu 6, yna bernir nad yw'r gallu gan y cyfranogwr i gydsynio yn y cyd-destun penodol hwn, a bydd yr ymchwilydd yn gadael, gan ddiolch i'r cyfranogwr am ei ddiddordeb. Ni fydd unrhyw gyswllt pellach â'r darpar gyfranogwr.

Os bydd y cyfranogwr yn sgorio 1 ym mhob cwestiwn dan eitemau 2, 3 a 6 ac yn ateb y cwestiwn dan eitem 4 yn gadarnhaol, bernir fod y gallu gan y cyfranogwr i gydsynio a'i b/fod yn dangos ei (d)dymuniad i gymryd rhan yn yr astudiaeth benodol hon.   Bydd YDW neu NAC YDW i'r cwestiwn dan eitem 5 yn dangos p'un a ydyw'r darpar gyfranogwr yn hapus ai peidio i'r cyfweliad gael ei recordio.

Os bydd y cyfranogwr yn sgorio 1 ym mhob cwestiwn dan eitemau 2, 3 a 6 ac yn ateb y cwestiwn dan eitem 4 yn negyddol, bernir fod y gallu gan y cyfranogwr i gydsynio a'i b/fod yn dangos nad yw'n dymuno cymryd rhan.

(Mae'r protocol hwn yn seiliedig ar y drefn a ddilynir gan Arscott et al (1998)).

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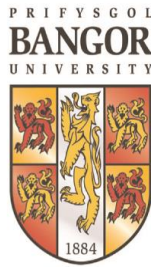
College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Assessment of capacity to consent

This protocol outlines the procedure for the assessment of the capacity to consent in relation to the specific study: <u>The experience of receiving a learning disability nursing service: a service user and carer perspective</u>.

7. Read the information sheet once to participant.

8. Read the following part of the information sheet: "I am writing about nurses that help people with learning disabilities like (*name of CLDN*)"

    Ask the potential participant: **"Why do I want to come and talk to you?"**

    Score 1 if the person gives an answer similar to "To ask me about the nurse"; "To ask me how the nurse helps me"; "So you can write about how nurses work".
    Score 0 if the answer is irrelevant or too vague, for instance: "To see me".

9. Read the following part of the information sheet: "I want to know what you think about nurses; what you think nurses are good at and things that they are not so good at"

    Ask the potential participant: **"What do I want to ask you about?"**

    Score 1 if the person gives an answer similar to "Things that the nurses are good at"; "Things that the nurses are not so good at"; "What the nurses do".
    Score 0 if the answer is irrelevant or too vague.

10. Read the following part of the information sheet: "...if you take part I will ask you about the nurses that help you. I can come and see you whenever you want. You can ask someone else to come with you if you want."

    Ask the potential participant: **"Are you happy for me to come and talk to you?**

    Answer YES or NO

11. Read the following part of the information sheet: "

   Ask the potential participant: **"When I talk with you are you happy for me to record our conversation?"**

   Answer YES or NO

12. Read the following part of the information sheet: "It is your choice to take part, you can ask someone else to say what they think. You can say YES or say NO. If you say YES then change your mind, that's OK. Just tell me NO later on, you won't have to tell me why"

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

   Score 1 for an answer similar to: "Tell you No".
   Score 0 if the answer is too relevant or too vague.

Overall scoring
If the potential participant scores 0 for any of the questions under items 2, 3 or 6, then the participant is assessed as not having the capacity to consent in this specific context and the researcher will initiate a bespoke exit plan, thanking the participant for their interest. There will be no further contact with potential participant.

If the potential participant scores 1 for every question under items 2, 3 and 6, and states YES to the question under item 4; then the potential participant is assessed as having the capacity to consent and is indicating his/her wish to participate in this specific study. YES or NO to the question under item 5 will indicate whether or not the potential participant is happy for the interview to be recorded.

If the potential participant scores 1 for every question under items 2, 3 and 6, and states NO to the question under item 4; the potential participant is assessed as having capacity to consent and is indicating his/her refusal to participate.
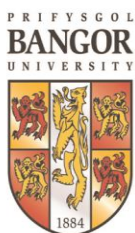
(This protocol is based on the procedure followed by Arscott et al (1998)).

Appendix X - Study 3, Service user consent form (Welsh/English)

Coleg Iechyd a Gwyddorau Ymddygiadol		College of Health and Behavioural Sciences
Ysgol Gwyddorau Iechyd	PRIFYSGOL **BANGOR** UNIVERSITY 1884	**School of Healthcare Sciences**
Prifysgol Bangor		Bangor University
Fron Heulog, Ffordd Ffriddoedd		Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF		Bangor, Gwynedd LL57 2EF
Ffôn 01248 351151		Tel: 01248 351151
Ffacs 01248 383114		Fax: 01248 383114

Ffurflen Gydsynio Defnyddiwr Gwasanaeth

Teitl yr Astudiaeth: Y profiad o dderbyn gwasanaeth nyrsio anabledd dysgu: safbwynt defnyddiwr gwasanaeth a gofalwr

Enw'r Ymchwilydd: Ruth Wyn Williams
(Yn dilyn Asesiad o Allu i Gydsynio, llenwch y ffurflen hon gyda defnyddiwr y gwasanaeth a'r prif ofalwr yn bresennol)

Yn y bocsys isod rhowch √ i ddweud IE neu X i ddweud NA

1. Rydw i wedi darllen a deall y Wybodaeth am yr Astudiaeth Fersiwn 4 dyddiedig 10.05.10 ar gyfer yr astudiaeth hon. Rydw i wedi cael cyfle i feddwl am y wybodaeth, gofyn cwestiynau a chael ateb iddynt.

2. Rydw i'n deall mai fy newis i yw cymryd rhan ac y gallaf newid fy meddwl unrhyw bryd. Ni fydd peidio â chymryd rhan yn effeithio ar fy mherthynas gyda'r nyrsys.

3. Rydw i'n rhoi fy nghaniatâd i'r sgwrs gyda Ruth gael ei recordio ar dâp sain.

4. Os byddaf yn dweud rhywbeth fydd yn poeni Ruth, dwi'n deall bydd rhaid iddi ddweud wrth rhywun arall.

5. Rydw i'n cytuno i gymryd rhan yn yr astudiaeth uchod.

Diolch i chi am eich amser

_____   _____   _____

Enw'r Cyfranogwr –   Dyddiad   Llofnod
Defnyddiwr gwasanaeth

Rhif ffôn/e-bost y cyfranogwr:_____

_____   _____   _____

Ymchwilydd   Dyddiad

                                       Llofnod

Rwyf wedi tystio bod (*enw'r defnyddiwr gwasanaeth*) .... wedi cydsynio :

...llofnodwch y bocs

1. i gymryd rhan yn yr astudiaeth uchod

2. i'r cyfweliad gael ei recordio ar dâp sain.

3. i'r ymchwilydd ddatgelu gwybodaeth os ydyw yn credu fod rhywun mewn perygl o niwed.

Tystiwyd gan (llofnod)………………………………………………………………

Dyddiad ....

Enw mewn priflythrennau ………………………………………………………

Perthynas i ddefnyddiwr y gwasanaeth ....

Cyfeiriad ac/neu rif cyswllt:……………………………………………………

....
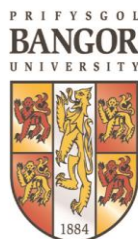
Hoffai'r cyfranogwr gael adborth ar yr astudiaeth   Byddai ☐   Na fyddai ☐

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
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Tel: 01248 351151
Fax: 01248 383114

Service User Consent Form

Title of Study: The experience of receiving a learning disability nursing service: a service user and carer perspective

Name of Researcher: Ruth Wyn Williams
(Following an Assessment of Capacity to Consent, complete this form with the service user and main carer present)

In the boxes below please √ to say YES or X to say NO

1. I have read and understood the Information about the Study Version 4 dated 10.05.10 for this study.
I have had the opportunity to think about the information, ask questions and have had my questions answered.

2. I understand it is my choice to take part and I can change my mind at any time. Not taking part will not affect my relationship with the nurses.

3. I give my permission for the conversation with Ruth to be audio recorded.

4. If something I say worries Ruth I understand she will tell somebody.

5. I agree to take part in the above study.

Thank you for your time.

_____   _____   _____
Name of Participant –   Date   Signature
Service user

Participant contact details telephone/email:_____

_____   _____   _____
Researcher   Signature   Date

I have witnessed that (*name of service user*) .... has consented to:

...please initial box

1. participate in the above named study

2. the interview being audio recorded.

3 the researcher disclosing information if she believes that

someone is at risk of harm.

Witnessed by (sign)..

Date....................................

Name in capitals..

Relation to service user...

Address and/or contact number..

....

Participant would like to receive feedback about study   Yes ☐ No ☐

Appendix Y - Study 3, Example of analysis (bilingual)

Interview 1: 15/07/10 (Time: 18m)

Discursive constructions	Discourses	Action orientation	Positioning	Practice	Subjectivity
Highlighting the transcript for references to the relationship with RNLD		What is gained by talking this way?		Practical implication	
Perthynas a'r nyrs a gweithwyr iechyd eraill/ *Relationship with the nurse & other health professionals* *Function of the relationship* • One way • Lead by • Instigated by the nurse • Passive recipient • Adrodd yn ôl /reporting back to nurse • E.g. gofyn "is that ok to eat" "no"L109 • Dim bwysa ar y client i neud dim/little expectation-not required to do much to sustain relationship with the health professional e.g. o blaen o ni yn cael ymmm... prosac yma a	Biomedical Tablets Hospital Salwch gwella Superficial dependency- engaging in – rhoi'r ateb iawn, chwarae'r gêm Accepting of multiple and transient within role of the nurse. Paternalistic relationship "wel mae o'n gofyn sut ydw'i bob tro a gofyn os dwi'n well bob tro, a wedyn mae o'n gofyn...ym...ba bryd dwi isho, pa bryd ma .... y ....pa bryd dwi fod i fynd i hospital eto i weld y doctor eto" L17-18. "helpu fi hefo tablets llu" L20. "a mynd i dd....dietician a ballu"L22	Gwella - responsibility lies with the nurse to get him better e.g "neud chi fynd yn well ma' nhw, ia" L7 "siarad...y... fel helpu chi ..i .. hefo ... dod a chi i fyny" L11. "os da chi yn down mae nhw yn helpu chi yn dydi" L13. "neud fi fyny, neud fi deimlo yn well 143	Derbyn y sefyllfa bod lot o bobl yn ei fywyd, darn o'i social network – paid friends Paternalistic relationship Intimate / close relationship *reit... sut sa ti'n deud wrth rhywun arall be ydi gwaith nyrs, be sa ti'n ddeud? 204* Ymm neud injections a ballu chi, tynnu gwaed chi a a a ... checio chi edrych da chi'n iawn a ballu, ia? *Oce, sydd angen help. ... Sut fath o help mae xxx (nyrs AD) yn gallu rhoi* Wel fel da chi yn fel da chi isho ymm ymm 'ath a hefo fi i hospital ta tri gwaith i checio wyddoch chi a mae o di sgwennu fo i lawr yn y papur be o gin i *Nath o help chdi i ddeall be oedd yn mynd ymlaen* Yndi, 214	Hospital appointment: nurse as gate keeper Mynediad i ofal Ffonio y nyrs i ddeud fod o ar y bws *"Ydi xxx yn helpu chdi ddeall be oedd hi'n ddeud 50* Yndi, dwi di gofyn i xxx sgwennu i lawr be mae hi'n ddeud a ballu i mi" L51 *"o reit, mae xxx yn helpu chi ddeall be ti gael fwyta a be ti ddim yn cael" L63* "ia, dwi'n meddwl neith o sgwennu nhw i lawr i mi" L64 "Ymm os da chi methu mynd i lle doctor neith o fynd a chdi" L229 Be mae o'n dda... mae o'n gwrando ar na chi, a gofyn cwestiynau i chi, "da chi isho fi help chi" ta "wyt ti'n iawn" ne gweld chi L220-221 Nathom deud llawer o	Nyrs LD yn wahanol Reflexivity: Researcher & participant active in interview process. Knowledge of RNLD practice influences perception of client empowerment Wel mae o'n mynd i weld fel clients mae o yn de 172 *Mynd i weld clients* Ia, wyddoch chi be dwi'n feddwl ... neud nhw yn hapus a cael gwaith iddyn nhw a gofyn iddyn nhw os ydyn nhw isho mynd i rhywla a llu, ia *Wbath arall?* Ymm... dydio ddim yn rhoid injections na dim byd, nac ydi? *Dwi'm yn gwybod,... gofyn i chdi dwi* Na dwi'm yn gwbod , na *Ydi yn wahanol i'r nyrs ti'n ei weld yn Ysbyty xxx*

mae hei'ni mae doctor wedi stopio nhw, roedd hei'ni yn neud i fi anghofio po peth L138-9 exteranl attribution – anghofio – dim byd i neud a fi –bai ar y Prosac • Facilitative	"yndi a fel helpu fi hefo po beth da chi'n gwybod be dwi'n feddwl" L 57 *"reit, sut fath o bethau po beth" L 58* "wel as dwi isho tablets newydd a ballu mae o'n ffonio drosta fi" L59 Wel ma nhw yn nyrsys da, wel ma nhw yn dda, mae nhw yn checio blood pressure chi ma nhw yn checio ymm ymm bob man i chi dydynt, ma nhw yn neud siwr bo chi'n iawn L258-9 dwi'm yn gofio ei henw hi, nath hi'm deud ei henw ... ...218 deud bo fi'n mynd yn sâl neu rwbath neu sa rwbath mawr ... ... ia ffonio i xxx sw ni yn neud ne pobol sydd yn gweithio yn nos, wyddoch chi be dwi'n feddwl 199-200 *ydw*		Ia 239 *Be ti'n meddwl ddyla nyrsys wybod?* Wel dwi'm yn gwybod be ma nhw neud *Ti'm yn gwybod be ma nhw neud* Nac dw dwi erioed di bod fel ... ... *Ond sa ti isho deud wrthyn nhw am wrando yn well?* Wel mae xxx *(nyrs AD)* yn gwrando yn iawn ar nai L245 Dwi'm yn gwbod, dwi'm yn... roedd hi'n sgwennu rhy fast a sgwennu rhy fast a dim yn gymryd amser ond sgwennu notes sydyn fel (nol papur a dangos i mi sut oedd yn sgwennu yn gyflym, drwy symud ei law dros y papur yn gyflym heb pensil) 47-9 wedyn rhaid i mi fynd i ymm ar y twentith ma o, dwi isho mynd i weld dietician eto ia, i mi gael gwybod be gai i fwyta ballu a be dwi ddim yn cael L61-2 Na helpu hefo peth dwi'n cael fel, cael gi'n pobol, wchi ymm, deud os dwi	ddim byd wrthaf i, dwi'n deall dim o ohoni'n siarad 43 (dietician) *Oeddet ti ddim yn ei ddeall yn siarad44* Nagon, oedd hi dipyn bach yn mhobman dwi'n meddwl polish neu rwbath oedd hi L45 dwi'n deall dim be ma nhw, be nhw yn siarad hefo mi, mae nhw'n siarad rhy fast L55 *a ti'n da am sticio i'r pethau sy'n dda 96* na dw really *mae'n job (chwerthin)* yndi mae'n job dwi'n bwyta lot o iogwrt a ballu L100 Wedyn dwi'n meetio fo, meetio fo yn ysbyty XXX ....Mae rhaid i mi ffonio fo yn gyntaf .i ddeud bo fi ar y bws 34-5 am bo fi yn methu darllen na sgwennu na ddim byd fel'na chi, wyddoch chi be dwi'n feddwl, 113 *ia* fedrai sgwennu enw, fedrai'm sgwennu dim byd arall	Yndi *Yndi?* Yndi, mae gen nhw fel ymm...pethau fel ...(gafael yn ei crys) *Uniform?* Uniform a pethau yn eu gwddw yn does *Stethescope, peth i wrando...186* *A ti'n hapus hefo'r gwasanaeth nyrsio ti'n gael* Yndw, yndw 261 Yndi, wel weithia nai ddim siarad hefo neb, ond nodio, wel na i'm siarad tan gai i keep clear, wyddoch chi be dwi'n feddwl,... mynd o na ... a nai siarad wedyn ylwch L252-3

435

			be rhaid i mi neud wchi, da chi'n gwybod be dwi'n feddwl 75-6 Client yn ddibynnol ar y nyrs mae o'n ffonio drosta fi 59 (nyrs yn ffonio am y tabledi) dim yn gwybod rheolau'r perthynas - nyrs bob amser yn ffonio perthynas un ffordd wel mae o yn ffonio mi i ddeud pa bryd mae o'n dod, a deud a dwi'n disgwyl o.... *o na chdi, os ti isho weld o fwy amal ti'n gallu neud hynna* Wel dwi'm yn gwybod chi *Ti'm yn gwybod* Na dw chi *Wyt ti'n ffonio xxx (nyrs AD)* Na xxx *(nyrs AD)* sy'n ffonio fi, mae'n gofyn pa bryd dwi'n rhydd ac ati *O reit... Ti'm yn ffonio fo i ddod i weld chdi* Nac dw', nac dw *Oce, sa ti'n licio gallu ffonio fo neu ti'n hapus ar drefn* Na dwi'n hapus fel ydwi ar y funud rwan tan dwi	*oce,* os fysa chi'n sgwennu llythyr i mi rwan de, faswn ni deall uffern o ddim byd o ohono oce fuaswn i yn dangos i xxx (gofalwr yn y gwaith) a gofyn be mae'r ddynes ma'n feddwl *na chdi* fel dwi bob tro, bob tro dwi'n cael petha' drwy'r post *ia* dwi'n dangos nhw i xxx(gofalwr yn y gwaith) a mae xxx yn deud wrth a i yn dawel, yn dawel be eudodd nhw, a dwi'n deud dim byd ond "thank you" wedyn *felly fuasan helpu chdi* ia sgwennu, fath a chi rwan, da chi'n siarad hefo fi rwan dydach, wedyn mae hi'n siarad a mae hi'n gofyn i chi cwestiynau yn de (gafael darn o bapur o'i flaen) fel dim byd arall mae hi'n ddeud 102-3 *ia... .... sut fath o wybodaeth, pethau sa' helpu chdi..* fel, fel copi o'r	

| | | | isho, raid i mi ffonio fo rhyw dro i ddeud bo fi di cael appointments i weld y ddau o' honyn nhw , y nyrs ar hospital
O reit
Mae o yn sgwennu nhw i lawr i mi, 159

L33 mae o'n ffonio mi a pa bryd dwi isho meetio fo a ballu

Llawer o bobl yn ei fywyd | computer i ddangos i mi be dwi fod i fwyta a be dwi'n mynd i fwyta *fel lluniau ti'n feddwl* ia 107

a wedyn rhaid i mi fynd a nhw i xxx(gweithwyr yn ei le gwaith) i ddangos be dwi ddim i fod i gael 66
Wedyn mae xxx yn helpu chdi 67
Ia 68 | |

438

Appendix Z – Information gathered from Freedom of Information requests 23rd September 2009

Demographic Information: Registered Learning Disability Nurses working within the NHS in Wales, June 2009

Qualification

X = no information given

NHS	Total No. of RN	RLDN	RNMH	RN Adult	RN Child
North West Wales	87	X	X	X	X
Gwent	80	77	1	2	0
North Central & East	61	59	0	2	0
Powys LHB	15	15	0	0	0
Hywel Dda	45	41	4	0	0
ABM	198	X	X	X	X

Total in Wales	486

Gender

NHS	Male	Female
North West Wales	23	64
ABHB/Gwent	17	63
North Central & East	15	46
Powys LHB	4	11
Hywel Dda	13	32
ABM	47	151

Total in Wales	119	367

Age

NHS	Age 20-29	Age 30-39	Age 40-49	Age 50-59	Age 60-69
North West Wales	8	10	36	33	0
ABHB/Gwent	5	19	36	18	2
North Central & East	7	18	28	8	0
Powys LHB	3	10	0	2	0
Hywel Dda	0	7	24	13	1
ABMUHB	20	36	106	36	0

Total in Wales	43	100	230	110	3

Demographic Information: Registered Learning Disability Nurses working within the NHS in Wales, June 2009

X = no information given

Pay Band

NHS	Band 5	Band 6	Band 7	Band 8	Band 8a	Band 8b	Band 8c / 8d
North West Wales	52	18	12	x	4	1	0 / 0
ABHB/Gwent	38	30	10	x	2	0	0 / 0
North Central & East	15	25	20	1	x	x	x / x
Powys LHB	4	7	3	1	x	x	x / x
Hywel Dda	13	21	6	x	4	1	0 / 0
ABMUHB	105	58	26	9	x	x	x / x
Total in Wales	227	159	77	11	10	2	0

Location

NHS	Hospital based	Community based	Central Support	Residential	Specialist Service	Management	Assess & Treat
North West Wales	59	24	4	x	x	x	x
ABHB/Gwent	x	31	x	32	5	2	10
North Central & East	x	42	x	19	x	x	x
Powys LHB	x	9	x	x	x	x	6
Hywel Dda	x	17	x	28	x	x	x
ABMUHB	x	65	x	133	x	x	x
Total in Wales	59	188	4	212	5	2	16

Appendix AA: Example session plan with undergraduate pre-registration nurses (Year 2, level 5)

Example session plan with undergraduate pre-registration nurses (Year 2, level 5)

Person centred decision making

Aim

To develop skills and competence in person centred decision making.

Objectives

- Develop an understanding of the process of decision making.
- Develop an ability to analyse the process of decision making using Standing's revised cognitive continuum theory (2008).
- Develop an understanding of current research/evidence within decision making literature and learning disability.
- Discuss ways of how to improve the visibility/person centeredness of decisions and the application of person centred principles to decision making.

Session Plan

1. Introduction to session: Definition of decision making

2. Activity 1, work in pairs: Give a detailed description of the experience of making decisions, feedback.
   What are the main themes?
3. Introduce Standing's revised cognitive continuum theory (2008).
4. Activity 2, application of theory to process of decision making identified in Activity 1.
5. Current research in learning disability
6. Relevance of theory to person centred thinking.

7. Group work: Identify ways to promote co-production in health-related decision making.

Activity 1: Identifying the process of decision making (working in pairs)

From your experience during your last placement, describe a recent intervention or episode of care with a person with learning disability that you were involved in.

Each pair should choose **one** intervention to describe and consider in detail.

Give a detailed description of the experience of making decisions during the example presented.

You may want to consider the following:
- What decisions you/others or the client took during the intervention or episode of care you have described
- How those decisions were made
- What factors influenced the decision making process
- Can you explain why you/others or the client made a particular decision
- Could the choice(s) be justified to the recipient of the decision
- What information was used to help make those decisions
- Were any questions identified regarding the intervention / care of the individual, and how were they answer

Present (in any form, e.g. map, graphics) the process of decision making on a flip chart.

Activity 2: Application of theory to the process of decision making

This activity is intended to help you understand and apply cognitive continuum theory to your own practice.

(Adapted from Standing M. (2010) Cognitive continuum theory – nine modes of practice Chapter 5 In Standing M. (Ed.) Clinical Judgement and Decision-Making in Nursing and Interprofessional Healthcare. Open University Press, Maidenhead: 100-128.)

1. Using the same practice example that you identified in Activity 1, refer to the Diagram of the *cognitive continuum of clinical judgement/decision making - nine modes of practice* (Standing 2005, 2008), identify the tasks associated with your practice example.

2. Refer to the source of knowledge continuum at the bottom of the Diagram, identify whether you used tactic, explicit knowledge or a combination of the two in dealing with your situation and give examples of knowledge. Look at the cognitive range from intuitive to analysis and decide whether you used analysis, intuition or a mixture (if so, what proportion did you use?).

3. Look at the diagonal series of practice modes and explain which one / ones were used in dealing with the situation and why. Explain why you chose not to use alternative modes.

4. Refer to the right of the Diagram and describe how much time you had to make a decision, the degree to which your judgement/decision-making process was open to scrutiny / checking by others, and whether or not you consciously controlled or manipulated the situation.

5. Look at the top of the Diagram and reflect on the ethical / moral issues or dilemmas associated with the situation, plus implications for practice in applying your professional nursing code.

6. Self assessment of your clinical judgement / decision making skills:

   • What did you observe about the client that made you choose the mode/s of practice?

   • What observations did you make to check their effectiveness? (Correspondence competence).

   • What is the theoretical justification for choosing and applying the mode/s of practice rather than others? (Coherence competence).

7. In the diagram, low structured tasks are linked to: tactic knowledge, intuition, intuitive judgement, little time for decisions / lack of transparency / lack of conscious manipulation, individual 'on the spot' accountability, and more correspondence than coherence competence. High structured tasks are linked to: explicit knowledge, analysis, research experiments, enough time / visibility of decision-making process / conscious manipulation, shared professional / ethical responsibility, and more coherence than correspondence competence. Having reflected on a situation using the cognitive continuum, do you support or refute the above pattern of intern-related factors?

8. Are there any modes of practice that you need to develop further? How might you develop you intuitive and analytical judgment / decision-making skills? What can you do to monitor and enhance the relevance and rigour of your clinical judgement/decision-making? How useful is the cognitive continuum as a tool to guide, examine, explain and develop decision-making skills?

9. Identify the opportunities for co-producing decisions with the service user across the modes of practice.

10. Examine the influence the value base of intellectual disability nursing has on the co-production of health-related decisions.