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The Role of the Nurse in Preschool Autism assessment

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Dedication

This work is dedicated to the late Professor Jean McFarlane, Baroness McFarlane of Llandaff, who by her inspirational example taught a generation of her 'Manchester university nurses' to strive for excellence in nursing by combining academic rigour and clinical expertise with love in action.

The role of the nurse in preschool autism assessment

ABSTRACT

Not all community child health teams carrying out preschool autism assessment have nurses as part of the team. The stimulus for this study was the need to make plain to commissioners and managers in one NHS Foundation Trust what nurses bring to the multidisciplinary assessment process which is unique to the nursing profession.

It is known that the process of assessment and diagnosis of preschool children for autism can be difficult for parents. Parents have described the kind of professional care they find helpful during the process. The aim of the study was to define the particular role of the nurse in preschool autism assessment.

This interpretive, hermeneutic study included all six nurses involved in preschool autism assessment as part of community teams in the Trust. They each generated texts for analysis by writing a reflective account of an episode of care, and by transcripts of one to one and group discussions with the researcher. Kim's (1999) critical reflective inquiry method was adapted for this study by including the researcher as participant. The beliefs and values which underpin the practice of these nurses and some dissonance between their ethical intentions and their actions in practice were made explicit through analysis of the texts, informed by relevant literature around autism, models of disability and models of nursing.

This is a study of nurses, by nurses and for nurses. It contributes to nursing knowledge in four ways: by examining the beliefs and values which inform the practice of the nurse participants; by analysing the source of dissonance between the nurses' intentions and actions in practice; by defining the unique role of the nurse in preschool autism assessment from a nursing perspective; and by showing that the beliefs and values espoused by the nurses in this study motivate them to deliver care with the particular characteristics which parents find helpful.

The findings are that these nurses hold in common a set of beliefs, values and intentions which, combined with a breadth of knowledge and clinical skills, prepare them to deliver, as part of an assessment team, the quality of care that parents have said they need.

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CHAPTER ONE: INTRODUCTION

In this chapter the stimulus for the study, its context and scope are introduced, and the purpose of the research is made explicit. The focus of this study is an analysis of the particular role nurses play in assessment for autism in preschool children, based on the reflections of a group of nurses practising in this field.

The personal motivation to focus on this subject originated from a challenge to my role as a nurse in child development within community child health (community paediatrics), specialising in preschool autism assessment. The pathway for preschool children to be assessed for autism by the community paediatric teams within the NHS Foundation Trust was developed in collaboration with the specialist autism team, which itself carried out assessment for school aged children (Golding et. al. 2011).The pathway was designed to allow preschool children to be assessed locally and to receive a working diagnosis of autism before referral to the autism specialist team at school age. In other areas, much of the assessment here carried out by nurses in community paediatrics will fall within autism specialist services and this study is equally relevant to this context. Community child health services are not configured consistently across the UK (Parr et. al. 2013) and many community paediatric and autism assessment teams function without nurse members. Within my own teams, particularly when financial constraints increased and cost improvements were sought, questions were raised around exactly what qualified nurses did which members of other professions such as paediatricians, speech therapists, nursery nurses or social workers could not do, why nursing posts should be retained, and what value was added to the teams by nurses. Nurses were involved in each of the community paediatric teams, carrying out initial assessment following referral of a preschool child with social and communication difficulties. They worked slightly differently between teams, but their roles included listening to parents' concerns, taking an autism specific early developmental history, visiting and observing the child at home and in a

peer group situation, liaising with the child's nursery or playgroup, referring to therapists and other agencies as necessary, giving the family initial advice and preparing a report for the paediatrician and the rest of the team. They supported parents to contribute their views to the team around the child, and were the main point of contact for the parent through the assessment and diagnostic process. Local feedback from parents about their experience when a nurse had been involved in their child's assessment was overwhelmingly positive (Golding et. al. 2011) and on internal audit, nurses made a difference to the efficiency of the teams and reduced waiting times. However, when it became necessary to make a case for including nursing posts in the budget during team restructuring, I was not able to find evidence from the literature that the role of a nurse in this context had previously been examined. The nurses themselves did not find it easy to articulate their role, despite being confident that they had a unique skill set and way of working which somehow made a positive difference to the experience of families. This study was therefore motivated by a need to make plain what nurses add to assessment teams, and the particular contribution nurses bring to the assessment process.

The background context for this study is the social surveillance of children which currently occurs in developed countries in order to identify those who are in some way different from the majority (Nadesan 2005). In the UK, both government and professional bodies recommend that preschool children who show unusual patterns of social interaction, communication and a preference for sameness should be referred to a team of professionals in child development for assessment for possible autism spectrum disorder, so that diagnosis can be made and intervention offered as early as possible (Le Couteur 2003; DH 2004). The medical perspective on autism is that it is a pattern of impairments characteristic of an underlying pathology, and a diagnosable mental health disorder or condition (WHO 1992; APA 2013) leading to lifelong disability. In this study the term 'autism' is used to encompass the various terms in common use including 'autism spectrum disorder '(ASD) and 'autism spectrum condition' (ASC). The medical model of disability, although it has been challenged for decades by those who propose an alternative, social model (Oliver 1983; 1990;

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2009) underpins child development and autism diagnostic services. Community child health provision in the UK varies between areas; some, but not all community paediatric teams and autism assessment teams include specialist nurses or health visitors (Parr et al 2013) but the particular contribution nurses in community child health teams in the UK make to the process of autism assessment and diagnosis for preschool children has not previously been explored. The research question suggested by this gap in knowledge is

'What do nurses identify as their particular professional contribution to the assessment of preschool children for autism?'

As I began to explore the literature around autism and disability in relation to nursing, I found myself facing the question of whether and why it is appropriate for nurses to be engaged in this arena at all, either as practitioner or indeed as researcher. Workers in any health-related discipline who venture into this area, particularly non-disabled workers, have been critiqued as 'disabling' by authors such as Illich et al (1977), and Davis (2004). Davis presents health professionals as parasites on people with disabilities, intent, for the sake of personal gain, on maintaining a position of power and control over those whom they purport to serve. He suggests they conceal their 'programmes of social control' behind the 'myth' and language of care and concern, whilst all the time being engaged in

> self-styled, self-seeking efforts to elevate their second-hand
>
> knowledge about disability into a 'profession' (Davis 2004 p.205).

Other authors highlight the role health professionals play, by not being critical of the status quo, in perpetuating the institutionalised oppression of disabled people, and suggest professionals should be conscious of the effect of their professional practices (Abberley 2004; Goble 2008; McLaughlin 2008). McLaughlin describes 'medical othering' of children who are different from the majority, by practices which categorise children in a way which places them 'outside of normal society' (McLaughlin et al 2008, p.61). However some authors have a somewhat less negative view of health care and its practitioners

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in relation to people with disabilities. Goble (2008) identifies the moral imperative which should drive professionals to work towards the emancipation of those under their influence, whether individuals or groups of people, suggesting that those who diagnose should also seek to mitigate the stigma of diagnosis. Swain and French (2008), develop the argument for an affirmative model of disability and impairment, based on the social model (Oliver 1983; Barnes 2003), which if used to underpin professional practice, would challenge professionals to relinquish power and to change services in the direction of user involvement, empowerment and partnership. I am encouraged by these authors that there may after all be a place for nurses, who have an obligation to uphold the principles of biomedical ethics: autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress 1994) to practice in the field of disability without losing all moral credibility.

As far as engaging in research in this field is concerned, Bricher (2000) acknowledges the discomfort felt by health professionals who attempt to use the social model of disability to underpin their research, in the face of the negative perception of health professionals which has emanated from disability discourse. She points out that for alternatives to the individual, tragedy model of disability to become widely disseminated among health professionals and to begin to effect positive change, a dialogue needs to develop between health care professionals and disabled people, and this may be promoted by research based on the social model. Northway (2000) argues that as nurses and nurse researchers have been regarded as contributing to the oppression of disabled people, reflexivity must play an essential part in the design and execution of any nursing research in the field of disability in order to avoid further contributing to oppression. Unless nurse researchers ask themselves whose interests are being served by a particular piece of research they are in danger of being guilty of the 'parasitism' of which Davis (2004) writes. My own understanding of disability has been profoundly influenced by the process of engaging with the existing literature and undertaking this research. The thesis reflects my position at present, still working within a system based on a medical model but now with

more critical awareness of its implications and of other ways of conceptualising the issues particularly around diagnosis.

After reflection on these issues, my personal contention for this study is that if nurses do indeed positively influence families' experience of early autism assessment, as I believe and have heard from parent feedback, then research to articulate what nurses do and why indirectly serves the interests of children and families. It does this by clarifying the unique contribution nurses offer to quality in child development and autism assessment services; thereby influencing employers to include nurses in teams. My observation is that the demand for evidence based practice and efficiency in the NHS supports the development of measures based on empirical research, and on outcomes rather than process. Recently there have been calls for patient experience to be taken much more seriously in health services (Francis 2013), and this may well promote more qualitative research with patients. It is unlikely to promote research which gives voice to the professionals, or explores how they perceive their rolès. This study gives nurses a voice. It serves the interests of nurse participants, who benefit personally and professionally from the opportunity which reflection on practice affords to come to understand the complexities of their role more fully (Oelofson 2012). As a study of nurses, by nurses and for nurses, the work also benefits the profession, by increasing the body of nursing knowledge about the role of the nurse in this context.

This study, therefore, does not set out to engage with families, whose views have been articulated elsewhere (Howlin and Asgharian 1999; Carter et al 2005; Murray 2010), but to focus upon nurses who spend their working lives embedded in the machinery of the National Health Service, operating within a system which is underpinned by and immersed in a medical model of disability.

I ask nurses to reflect on their practice and to write a reflective account of an episode of care. I then bring a social, affirmative model to bear on an exploration of the literature around the values and beliefs made evident through the data generated. By this means not only is the way in which these nurses presently understand their role elucidated, but participants are also empowered

to explore whether and how their practice is presently constrained by predominant cultures, both in society and within their teams, and to consider how practice might be developed.

I position myself in the study as both researcher and participant. This is because I was very much part of the nursing team, wanting to include my own perspective in the analysis as part of the group rather than to attempt to stand outside. I sought a methodology which would allow me openly to bring my own experience, prejudices and beliefs to a reflective analysis of practice which clarifies how nurses see their role. Critical reflective inquiry is a research method which combines knowledge development in nursing science with personal development for participants, resulting in improved practice (Kim 1999). Analytic autoethnography (Anderson 2006) includes the researcher as a complete member of the group being studied and demands reflexivity and visibility from the researcher. Although this is not an autoeothnographic project because it involves narratives other than my own, both of these have informed the development of the methodology for this study, a full account of which is provided from page 45.

The findings of the study are that the beliefs and values which underpin the practice of the nurse participants are common to them all. The context in which the nurses work, is found to give rise to some dissonance between their intentions and their actions in practice. However, it is concluded that the nursing beliefs and values espoused by the participants prepare them to deliver the quality of care parents say they need (Sloper and Turner 1993;Gray et al 2008;Harnett et al 2009)

To the extent that the study raises consciousness and promotes reflection in participants and readers around the issues raised, it aspires to be emancipatory and a catalyst for change. To the extent that it is informed by the contradiction between the discourse of the health community and the agenda of disability movement, I hope it will promote awareness of alternatives to the medical model of disability within the heart of a medically dominated system. However the main emphasis of the study is on nursing itself, in the context of assessment

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and diagnosis for autism in preschool children. It has not previously been made clear how nurses in community child health teams conceptualise their work, and what it is that nurses feel they are offering to parents and children going through assessment. By addressing the research question, 'what do nurses identify as their particular professional contribution to the assessment of preschool children for autism?' this study contributes to nursing knowledge

In this introduction the motivation for this study has been identified and its focus and scope described. The context of the study within the community child health teams assessing preschool children for autism in one NHS Foundation Trust area has been explained. The aims of the study have been made explicit, particularly its aspirations to add to nursing knowledge and to inform policy and decision makers concerning the value nurses perceive they add to assessment teams. The subjects of nursing and preschool autism are rarely addressed in the same study; the literature review which follows outlines the existing knowledge about both subjects which is the background for this work.

CHAPTER TWO: LITERATURE REVIEW

The purpose of this review of the literature is to provide an analysis of current knowledge around diagnosis of autism in preschool children and around the role of nurses in the process of diagnosis, in order to make clear the context of the research question, and the gaps in knowledge that the study addresses. The subjects of autism and nursing are drawn together within this study, and the literature review includes topics which arise as the connections between early diagnosis and nursing are explored. It begins with an analysis of the ways in which autism is currently defined, conceptualised and diagnosed, in order to determine the various accounts of autism which have a bearing on nurses and the way in which they are socialised into their role and conceptualise their work in early diagnosis. As the study progressed, new issues emerged and some areas demanded fuller or wider exploration and discussion. The literature which was drawn on during this process is presented separately within the relevant chapters.

In order to present the research background, this review of the literature focuses first on medical and psychological accounts of autism and its current definition as a condition based on impairment. It therefore includes research grounded in the medical model within which autism and childhood disability is presently located in Western society. Diagnostic criteria, methods and markers are mentioned because of the implications for assessment teams and for parents of recent changes to the American Diagnostic and Statistical Manual of Disorders, now in its fifth edition (DSM-5, American Psychiatric Association 2013). The concept of the autism spectrum as an inclusive label for a range of dissimilar ways of being is discussed as it affects the way in which nurses perceive the children with whom they work. Some of the arguments for and against diagnosis are explored in the context of modern and postmodern trends of thought, language, narrative and metaphor, and the concepts of normalcy and ableism are introduced and discussed in relation to nursing, as these were

used in the analysis of the data. The positioning of diagnosis as either an oppressive practice or a sociological necessity by those adhering to different models of disability is discussed and the demand for diagnosis is reviewed in order to shed a critical light on the established assessment process. Literature around the effect of assessment and diagnosis on families and possible ways in which negative effects can be ameliorated is presented, including models for improving the process, because these directly relate to the area in which nurses feel they should have influence (Halpin and Nugent 2007). The potential function of nurses within the assessment process is discussed in the light of the history of nursing as a profession and of a range of current philosophies, theories and models of nursing so that this may be considered in relation to nurses' present roles in practice. Various models of working across and between disciplines are also described in order to identify the present model of assessment team working. The review concludes by summarising the gaps in knowledge about what nurses do in this context, and the way in which some of the issues raised in the literature may be addressed by this study through exploration of the perceived and potential role of the nurse in the assessment team.

Autism: definition and diagnosis.

The medical definition of autism is predominant in the NHS environments within which nurses work, underpins nurse education about disability (Secombe 2006) and is likely to influence the practice of the nurses in this study, so this viewpoint is described first.

Since Kanner (1943) first observed a consistent pattern of characteristics in a group of children he described as having 'early infantile autism', the dominant discourse around children who have markedly unusual patterns of social interaction and communication and also show a preference for detail and sameness has been a medical voice. When a year later Hans Asperger wrote his paper on older children and adolescents with a similar but, he believed, distinct presentation, they too were included in the medical discourse of the day (Frith 1991). Nadesan (2005) argues that although people with similar

behaviours and ways of being in the world have probably been present in every generation, the identification and articulation of childhood autism as an entity could not have taken place before the emergence, in the 20th century, of certain social practices and institutions around the concept of childhood and standards of normality within it. These include the formalisation of education as a compulsory part of childhood and the identification of children who deviate from the norm for the purpose of remediation. Increasing social surveillance of children led to the pathologising of deviance by the newly emerging professional specialities of child psychology, child psychiatry, and paediatrics. To the present time, children with similar characteristics are described in medical terms as having a pathological condition with impairments resulting from a neurologically based disorder, which arises within the individual child and can be diagnosed and treated by various therapies (Baird et al 2003). As the nurses in this study work within community child health teams which are informed by this understanding of autism, and which rely on international diagnostic criteria, these will now be outlined.

Autism spectrum disorder (ASD) or autism spectrum condition (ASC) has until recently been defined under the American diagnostic and statistical manual of mental disorders 4th edition (DSM-1V, APA1994), as well as the European International classification of diseases 10th edition (ICD-10, WHO1992). For a diagnosis to be made, the individual was identified as having qualitative impairments in social interaction, social communication and social imagination, with a restricted repertoire of interests and activities. Depending on the particular presentation, one of several different diagnoses were commonly applied to children and adults with this 'triad of impairments' (Wing and Gould 1979) across the world. These diagnoses, still used in countries following the ICD-10 are; (Childhood) Autism, Asperger syndrome, Childhood Disintegrative Disorder, Rett syndrome and Pervasive Developmental Disorder (Not Otherwise Specified) (PDD(NOS), (using DSM-1V), or atypical autism (using ICD-10) . Children with difficulties on all areas of the triad, but having average or above average intellectual abilities and good spoken language, are usually given a

diagnosis of Asperger syndrome, but if they have a history of language delay, they may be given a label of 'high functioning autism'.

The next edition of DSM has now been published (American Psychiatric Association 2013), and changes have been made to the diagnostic criteria. Instead of dividing autism into the five separate diagnostic entities already mentioned, all of these diagnoses except Rett syndrome have been subsumed within a single diagnosis of Autism Spectrum Disorder (ASD) or Autism Spectrum Condition (ASC) .The diagnosis of Social (pragmatic) Communication Disorder (APA 2013 p.47), may be applied to children with persistent difficulties in the social use of verbal and nonverbal communication but without fulfilling the other criteria for ASD.

There has been some concern around the new criteria, both from some people who value their diagnosis of Asperger syndrome, and from some parts of the medical research community (Ghaziuddin 2010; McPartland et al 2012; Tsai 2012, Barton et al 2013). Baron-Cohen (2009) pointed out in a correspondence to the New York Times that as Asperger syndrome has only been recognised since 1944, there has not been sufficient time for ongoing genetic studies to clarify whether or not Asperger syndrome and autism are two separate conditions, with different aetiologies which give rise to different but overlapping behavioural characteristics. There have been concerns that although specificity using the new criteria will be high, the requirement for children, including toddlers whose presentation is changing month by month, to fulfil all the criteria, will lead to less young children receiving a diagnosis of ASD, and many who would have had a diagnosis of PDD (NOS) will not now fulfil diagnostic criteria (Matson 2012).

This will directly affect the work of the nurses in this study, as long as preschool children are dependent on a diagnosis to qualify them for early support and intervention. The changes will not yet affect countries such as the UK where diagnosis is based on ICD-10, but there is every expectation that its revision, ICD-11, will be 'harmonised' with DSM-5 (APA 2013 p.11). The ongoing debate may, however, prompt renewed focus on the reasons behind the demand for

diagnosis, its significance and its effects. The diagnostic criteria are a major reference point for nurses as they carry out preschool assessments of children with possible autism. However, there are other discourses around autism which also inform nurses, and these will next be briefly discussed in order to have a clearer picture of the context of the study.

Psychological accounts of autism.

Nurse education in the UK includes an understanding of psychological models and psychological care (NMC 2010); the following brief overview is included because it describes models which inform the way nurses involved in early assessment understand autism.

The three main models of autism to emerge from the field of cognitive psychology are: a theory of mind deficit (Baron-Cohen et al 1985); a lack of central coherence (Frith1989; Frith and Happe 1994) and executive dysfunction (Ozonoff 1995). Various links have been suggested between a difficulty in understanding the mental states òf others (theory of mind) and a tendency to concentrate on detail rather than the 'bigger picture' (weak central coherence) including the proposal that autism represents an extremely male brain type (Baron-Cohen 2002). However these findings are not replicated by other investigators (Jarrold et al 2000), and on the whole the three accounts have been used to explain different aspects of cognition and behaviour in people with autism in a modular way.

Although the three accounts are couched in negative terms, it is by no means clear that weak central coherence on its own is necessarily a disadvantage. In later work, Happe and Frith (2006) suggest that having weak central coherence should be thought of as a processing bias towards local processing, rather than a total inability to grasp the gestalt of a situation. As such it can be a useful trait, which could be described as a difference rather than a deficit, giving individuals an unusually good 'eye for detail', a characteristic which also occurs often in the families of children with autism (Happe et al 2001) and which they suggest may be one aspect of a broader autism phenotype. Health professionals are

encouraged by parents to point out the positive aspects of a child's particularities as part of the assessment process (Nissenbaum et al 2002; Harnett et al 2009), but it is not clear whether nurses feel this is part of their role. The analysis of the data for the present study adds to knowledge in this area. However, markedly weak central coherence, particularly in combination with an inability to 'mind-read', must make the world a very confusing and unpredictable place and would be accurately described as a deficit rather than as a difference. This supports the concept of the existence of an autism spectrum including both children with obvious severe cognitive impairment, and also those whose difference might not give rise to disability if their social environment was more inclusive. Nurses' attitudes to the emerging diagnosis are explored during this study.

Diagnostic methods and genetic markers

This section is included in the literature review because nurses are expected by their professional body to be aware of and to share with patients current research about conditions (NMC 2008); the nurse participants in this study attempt to answer parents' questions about the causes of autism. However as the following brief overview indicates, neurobiological science is unlikely to provide all the answers to their questions in the near future. There appears to be a divergence between the conclusions of genetic research and the formulation of diagnostic criteria, which might give rise to confusion for diagnosticians, and so is outlined here.

Although the evidence for a genetic aetiology or at least a correlation between genetic profiles and autistic characteristics is strong, the positivist quest for a single definitive physical or physiological diagnostic marker for autism continues (Johnson et al 2013).

Genetic studies of people with autism have indicated many possible candidate genes and gene mutations (Feliciano 2012).Those attempting to identify genetic causes for autism have so far struggled to identify definite genetic commonalities within what they term a 'heterogeneous syndrome', despite

indications that there may be common pathways from specific variations in brain circuitry which lead to similar developmental outcomes (Geschwind 2011).

The search for a single biological marker which could be used as a definitive diagnostic test for ASD is also, so far, elusive and it could be said to have uncovered more evidence for heterogeneity than homogeneity between people who have received diagnoses on various parts of the autism spectrum. The scientific evidence to date indicates that although autism appears to be highly heritable, possible genetic causes are heterogeneous and their expression is affected by internal and external environments (Johnson et al 2013).

Happe et al (2006) suggest that the search for a single cause for the triad of behavioural traits described as autism spectrum disorder is in vain. Their argument is that the heterogeneity found within the spectrum reflects variation along three separate dimensions of impairment which should be addressed separately rather than being viewed as aspects of a single condition. They observe that genes which have been found to correlate with one part of the triad are different genes from those thought to correlate with another trait, and note that in their twin study, children in middle childhood who demonstrated difficulties in one area of the triad were only moderately likely to have difficulties in both of the other areas. They also point out that none of the current cognitive accounts of autism can explain the whole triad of social difficulties, communication difficulties, and rigidity of thought and behaviour, focussing either on a social cognition deficit or a processing deficit.

The concept of the 'autism spectrum' places more emphasis on the commonalities than the differences between people with difficulties in social interaction and communication, plus a narrow range of interests and a liking for sameness. Far from looking at these difficulties separately, using the concept of an autism spectrum encourages diagnosticians to consider them to be different expressions of a common underlying disorder, and encourages therapists and educators to look for interventions that will be useful for anyone 'on the spectrum'. It is not clear from the literature whether or not nurses are aware that at the same time as the genetic scientists are leaning towards separate

neurobiological explanations for similar outward characteristics, the diagnostic and therapeutic communities appear to be continuing in the opposite direction. Nurses' confidence in the information they share with parents may be affected by this dissonance, but the literature to date does not make this clear. The analysis of the data from this study includes nurses' attitudes to advising parents about early intervention strategies relating to the 'autism spectrum'.

As members of those diagnostic and therapeutic communities, nurses could be seen as promoting and perpetuating the practice of pathologising difference, but it is not known how nurses themselves conceptualise their contribution to diagnosis. The next section of the literature review explores the connection between current ways of thinking, language and the perceived need for diagnosis.

Normalcy, ableism and the diagnostic imperative: the effect of contemporary language and metaphor on attitudes to autism

Nurses, as much as parents, are members of society and enter nurse education having been influenced by current ways of thinking about autism and by the way in which language moulds and frames common assumptions (Brillhart et al 1990).The data analysis reveals some of these assumptions. In this section some of the influences on contemporary attitudes to autism are presented in order that nursing in this field, and the beliefs of nurses in this study, can be seen in the light of these underlying ways of conceptualising difference in general and diagnosis of autism in particular. However, in the course of their professional education, nurses undergo a process of socialisation which also affects their beliefs and attitudes to disability (Dinmohammadi et al 2013), so the literature around this process is also introduced here.

The postmodern trend of thought arising in the 1960s and '70s includes an antipathy towards the discourses of all kinds of professional groups, including medicine, and particularly psychiatry. The postmodernist sees professional discourses as agents of power and authority, and diagnosis as a prime example of the exercise of the power of the doctor to define an individual as aberrant and to subject them to oppressive treatment regimes (Foucault 1970).

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Foucault describes how the interaction of knowledge and power in the hands of an intellectual elite creates subordinate identities for those who fall outside of defined norms. He is particularly critical of psychiatry, which he sees as an outworking of the tendency for society to silence, condemn and control those who transgress contemporary standards of normality (Foucault 1965). More than this, Foucault's concept of the 'episteme' suggests that at any point in time, the boundaries of possibility in terms of thinking differently are restricted by contemporary language, which underpins power structures. His study of the archaeology of thought concludes that individual original thought is constrained by the concepts created and maintained by the language of the day. These concepts have significantly influenced nursing for decades, particularly in the fields of psychiatry and learning disabilities (Gastaldo and Holmes 1999) but also in other fields (Henderson 1994). However it is not clear whether or how they affect the practice of nursing in assessment for autism where a comparison is made between a particular child's behaviour and behaviour which is defined as 'normal'.

Davis (2010) observes that the use of the word 'normal' to mean typical rather than as a workman's measure did not emerge until around 1840. Davis suggests that the trend away from aspiring to an ideal of personhood (an aspiration which cannot be attained by anyone, and was thus inclusive) towards aspiring to be at least 'normal', created 'normalcy' by characterising people who fall outside the 'norm' as less than human. He links this way of thinking to the development of the politics of industrialisation and the power exercised by the bourgeoisie over the rest of the population. This link between the use of language, ways of thinking, politics and power recurs in Nadesan's contention that the assumption that any behaviour which deviates from an accepted 'norm' needs to be identified, measured, categorised by diagnosis and treated with an aim of normalisation is a product of 20th and 21st century thinking (Nadesan 2005). Some have warned that the trend to diagnose ever more children who differ from the majority as having a 'disorder' is a dangerous progression towards imposing 'normality' on a population via a combination of overdiagnosis, overmedication and eugenics (Weiner et al 2009). Others have

posited that health professionals including nurses play a part in perpetuating negative views of impairment as tragic and undesirable because not only do they hold this position themselves, but by virtue of professional power they maintain and promote negative views (French and Swain 2001). Tervo (2004) found that of health professionals, nurses had the least positive attitudes to people with disability. They could be described as perpetuating normalcy and also ableism, defined by Campbell (2009) as

... a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as perfect, species- typical and therefore essential and fully human. Disability is then cast as a diminished state of being human (p.5).

Ableism as a concept also includes the exclusion, discrimination against and oppression of those who fall outside societally defined norms (Campbell 2009). The challenge to the oppressive structures created by ableist attitudes in society represents a resistance to the unthinking adoption of narratives around difference which assume that everyone wants to be 'normal'. Barnes and Mercer (2010) argue that the dominant cultural narrative around autism is one of disorder or disease framed by a medical model of disability. Professional socialisation involves the internalisation of values as well as customs, obligations and professional responsibilities (Dinmohammadi et al 2013) and there is concern (Goodall 2004) that some nurses have internalised reductionist and medical models of disability which imply deviancy and dependency (Scullion 2010). Secombe (2006) calls for nurse educators to consciously influence student nurses to resist negative attitudes through professional socialisation, by including disability studies as a core component in undergraduate nursing courses. This study suggests how the way in which the nurse participants use language about autism reflects the cultural narrative they have adopted, and the extent to which they embrace alternatives.

An alternative narrative of autism as an example of neurodiversity, framed by the social model of disability (Finkelstein1980; Oliver 1990) which emerged from

the disability movement and disability studies, has been taken up by some within the autistic community (Oliver 1996; Broderick and Ne'eman 2008). These authors advocate for an understanding of autism as a legitimate way of being in the world, not requiring treatment, therapy or normalisation, and argue that autistic people are disabled by others, informed by currently dominant metaphors around autism. These metaphors include seeing autism as a foreign space into which a person has withdrawn, eg. a shell, or a fortress; and alternatively, a person with autism being seen as an alien. The first of these metaphors implies that the child has retreated from something, perhaps echoing the discredited early theory that autism was caused in children by cold and affectionless parenting (Bettelheim 1967). An implication from this metaphor is that the child might be able to be 'brought back' in some way, perhaps by medication or therapy, resonating with the medical model of autism. In contrast, the metaphor of the 'alien' has been used both by neurotypical observers and members of the autistic community to describe the 'otherness' of children with autism (Sainsbury 2009) and to legitimate and self-advocate for difference . The metaphor paints a picture of a child who is, and will remain, different from most people around him, but who has his own legitimate culture and language which might be learnt, and possibly friends elsewhere who are similar to him. These two opposing metaphors represent two opposing schools of thought and activist groups around autism. The first are those who, following a medical model, see autism in terms of a lifelong neurologically based impairment leading to disability (WHO 1980), whose 'sufferers' are in need of early diagnosis, prompt therapy and lifelong support so that they become as similar to neurotypical peers as possible. Pressure groups from within this school of thought, such as Autism Speaks (www.autismspeaks.org) support research to identify biological causes and markers for autism, and have hope that one day a cure may be found. It is notable from this website that most supporters of this school of thought seem to be people who are related to, advocate for, or are involved in diagnosis, treatment or education of children or adults with autism, particularly those with significant associated learning difficulties and challenging behaviours. It could be said that those who subscribe to this school of thought

have chosen to opt out of the social model on behalf of those whose condition would be categorised under the new DSM impairment levels as 'severe'. Goodley (2001) found similar distinctions being drawn between people with learning difficulties, and warned that a preoccupation with levels of impairment meant that while people with 'mild learning difficulties' were viewed through the lens of a social model of disability, others were "left in the realms of static, irreversible, individualised biology" (p.213).

The alternative proposition, informed by the social model of disability and by the concepts of normalcy and ableism, that autism as a diagnosis has been created, medicalised and stigmatised by a society which seeks to pathologise difference, operates on the assumption that all children should be valued for their uniqueness and individual strengths, and places the onus on the majority to adapt to accommodate the full range of human diversity. The supporters of this point of view tend to be people who have a diagnosis of high functioning autism or Asperger syndrome, their family members, or those involved in their education; and academics in disability studies (Molloy and Vasil 2002; Moloney 2010). The Autistic self-advocacy network (ASAN) founded by Ari Ne'eman in the U.S.A (http://www.autisticadvocacy.org) advocates for ASD as a form of neurodiversity to be embraced and accommodated in this way, and is in direct opposition to organisations such as 'Autism Speaks', which seeks a 'cure'. The 'Autism friends' group (http://autismfriendsnetwork.biz/portal.php) does not oppose diagnosis, but this appears to be primarily because identifying people with autism is a prerequisite to forming an autistic community and culture. The group seeks to emphasise the 'spectrum of ASD' rather than more specific diagnoses; this is a pragmatic approach as it perceives that sub-grouping may lead to barriers to and rationing of services and support, which it recognises are needed. The members advocate for individual needs assessment within the broad diagnosis of ASD, and recognise that certain forms of 'treatment' can help some people with ASD to live more fulfilling lives. However they promote the concept that autism need not be a disability, and strongly oppose the idea of the need to 'cure'. These ideas resonate with the biopsychosocial model of disability reflected in the International Classification of Functioning, Disability

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and Health (WHO 2001)(ICF), which attempts to synthesise the individual and social models to some extent (Barnes and Mercer 2010). For nurses to take a position on these issues they would have to be conscious of the opposing schools of thought, but as Smeltzer (2007) points out, in the USA as much as in the UK, nurse education around disability within general nurse training is minimal, and tends to promote only a medical model. She calls for all nurses to be introduced to alternative models of disability during their training. Goodall (1995) had raised similar issues in the UK more than a decade earlier, noting that using a social model of disability could appear to leave nurses with no role at all with people with disabilities, and calling for a collaborative, 'interface' model to be taught so that nurses would act as 'informed partners'. This is another example of using language to shape thought around disability.

Van Hove et al (2009), working in Europe, found that parents used different metaphors to envisage themselves and their children, such as 'the traveller', 'the manager', 'the trainer', 'the bridge builder', 'the tight-rope walker' ,'the strategist' 'the warrior', and 'the explorer'. Van Hove et al suggest parents use these metaphors as tools with which to confront, to work with, and also to resist the normalising discourses they encounter around disability and education. Their work illustrates the different stances taken by different families as they become aware of the dominant attitudes in society towards their children and are an insight into the agency parents actually exercise. It is not presently clear which stance nurses take around the same attitudes and whether nurses demonstrate any resistance to diagnostic practices around autism which could be seen as oppressive, so any evidence of such resistance in the nurse participants was sought during data analysis.

The positioning of diagnosis as an oppressive practice has been resisted by those who point to the sociological utility of diagnosis as a ritual which legitimises those who are different from the majority (Rosenburg 2002). Nadesan (2005) points out that children in developed countries are subjected to such a degree of social surveillance that any 'irregularities' are bound to be noticed, positioned within a medical and/or psychological framework and potentially pathologised (p.133). She suggests pragmatically that as

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eccentricities are less well tolerated, early identification and 'remediation' are increasingly necessary for the social and economic success of the individual. Similarly Rosenberg (2002) suggests that criticism of diagnosis has already become a cliché, and that the time has come to recognise that diagnosis is useful both for those so labelled, and for the society in which they live,

...we are not simply victimised, alienated and objectified in the act of diagnosis. Disease categories provide both meaning and a tool for managing the elusive relationships that link the individual and the collective, for assimilating the incoherence and arbitrariness of human experience to the larger system of institutions, relationships and meanings in which we all exist as social beings (p.257).

Other medical sociologists suggest that the expansion of the boundaries of medicine by a process of medicalisation of certain patterns of human behaviour and redefining them as syndromes or disorders is more likely to driven by collective action than medical imperialism (Conrad 1992; Conrad and Potter 2000). As Conrad and Potter suggest, the way in which patterns of behaviour come to be classified in the DSM as psychiatric disorders has more to do with socio-political factors and the need of 'patients' and their relatives to legitimate difference and to have their rights recognised than to do with a clearly scientifically proven case for a new disease category. They describe the creation of the diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) and its expansion into the adult field, driven by a demand to legitimise behaviour which is difficult to manage, especially within a school system that demands conformity, and supported by a modernist assumption that there would be underlying biological causes. The same authors also note that disease categories in the DSM are elastic. They may expand, depending on the political, social and economic forces driving the inclination of society to legitimate and accommodate a wider range of human differences while avoiding blame, and in the same way they also contract from time to time, as they did when homosexuality was decategorised. The creation and then subsumation of Asperger syndrome may be driven by similarly complex forces.

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There is evidence from the language used in the literature that there is not a neat dichotomy between a pathologising medical establishment and a resistant oppressed minority. A psychiatrist writes a book entitled 'How to be yourself in a world that's different' (Yoshida 2007). A person with Asperger syndrome writes of her experience of diagnosis,

> *I had finally reached the end of my race to be normal. And that was exactly*
>
> *what I needed* (Willey 1999 p.89).

However whatever the shape and size of current categories of difference, the demand for diagnosis persists and the nurse participants in this study, as members of a diagnostic team, respond to demand. It is the origin and nature of this demand which is explored in the following section.

The Demand for diagnosis

Autism is conceptualised variously as a disorder, a difference, or a disability. Through the medical, individual model lens it is seen as a personal tragedy; in the light of the social model, as a reflection of human neurodiversity which should be celebrated and accommodated by society; or using the biopsychosocial model which informs the International Classification of Functioning, Disability and Health (WHO 2001), as a disability with many components. It is not known how nurses in assessment teams perceive autism. From any viewpoint, however, there is still a perceived need in the UK to diagnose or identify children with these characteristics, on the one hand to attempt to intervene or treat them, and on the other hand to be aware of their particular traits and to accommodate them more comfortably within their community. Children are referred to assessment teams after concerns have been raised about possible autism. This section outlines the issues around the demand for diagnosis which impact on the work of the nurses in the study.

Parents are often the first to have concerns about their child's development, and frequently express these concerns within the first two years, usually in terms of 'awareness of difference', and often around language development or difficult behaviour (Charman and Baird 2002; Young et al 2003; Braiden et al 2010).

Studies have confirmed that where parents notice their child is 'different' from others, they are usually right (Glascoe and Dworking 1995; Glascoe 1997).

Having noticed a difference, the reason parents seek diagnosis is not only because of difficulty in managing behaviour, but because of pressure from others, whether family members, friends, or the child's nursery or school (Braiden et al 2010). Parents report feeling 'blamed and shamed' when their child does not develop typically, particularly if the child's behaviour is perceived as inappropriate or challenging (Gray 2002; Blum 2007). They seek diagnosis to find an explanation for the child's atypical behaviour in medical terms, both to find ways to manage the behaviour in order to enjoy life with the child more, and to avoid personal blame. Although after diagnosis, stigma may remain (Gray 2002), there is sense in which diagnosis repositions parents as well as children, in their own eyes and in the view of society. Drawing on the dominant medical discourse, they may create a new personal narrative of their parenting experience, from neglectful or bad parents, to victims of fate or heroes battling challenging circumstances (Landsman 2003; Fleischmann 2004). Fleischmann's (2004) narrative analysis of parent stories, although perhaps relating to an unusually articulate and communicative group of parents, identifies diagnosis as a positive turning point from guilt, frustration and distress to a new sense of direction and purpose, with new determination to take up the challenge. Farrugia (2007) describes the way in which diagnosis helps parents experiencing enacted stigma, acts of social exclusion by others, to resist felt stigma, the internalisation of these negative attitudes towards their child and their parenting (Scrambler and Hopkins 1986; Gray 1993, 2002). As Farrugia comments,

> *without a medical definition of their children, parents are once again*
>
> *positioned as 'bad parents with naughty children'.* (Farrugia 2007 p.1022)

Brown-Wright and Gumley (2007) also indicate how a diagnosis of autism can be a positive help to parents in understanding and celebrating their child's individual characteristics and personality. Macdonald (2009), in discussing the

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life stories of people with dyslexia, considers the effect of the resistance exerted by some educationalists and academics towards 'labelling' children and observes that labelling could offer the support needed for children to overcome stigma, which was generated by the impairment itself more than by the label or diagnosis. Similarities with autism are evident, in that both are invisible differences which become impairments when situated within a contemporary social environment. Obtaining a diagnostic label can have a liberating and positive outcome for children as well as parents.

Far from diagnosis being a 'tyrranny' imposed on a resistant population (Rosenburg 2002), some parents speak of their struggle to obtain a diagnosis, and their relief once it was given (Midence and O'Neill 1999; Avdi et al 2000; Hutton and Caron 2005). In a postal survey of members of a regional autistic society, just under half reported that their initial approach to health professionals had been met not with an eagerness to impose a diagnosis, but with inappropriate reassurance and an implication that they were worrying unnecessarily (Smith et al 1994). It is debateable whether this is always because of ignorance of the presenting features of autism on behalf of the clinicians, or whether in some cases there may be a reluctance to pathologise behaviour prematurely (Matson et al 2008). As McLaughlin comments,

...clinicians are often more aware of the degree to which the categories and criteria within which they work are socially produced than social scientists give them credit for. (McLaughlin 2005 p.286).

Northway (1997; 2010) calls for nurses to resist the oppression of disabled people by a process of awareness of and alignment with the disability movement beginning with education and reflection on practice. Unless nurses are aware of the issues around diagnosis, and conscious of the socially produced nature of diagnostic categories, they are unlikely to adopt an alternative model (Scullion 1999). Scullion found that nurse students were disposed to adopt a more socially oriented model of disability, but the nursing curriculum at the time did not support awareness of the issues. During this

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study models of nursing recollected from student days by the participants are reflected upon and the impact of these models on their awareness of the issues, and their beliefs about the effect of diagnosis is discussed.

The effect of diagnosis on the family

Although diagnosis is often pursued by a child's family, and nurses as part of the diagnostic team are encouraged by professional guidelines to support families in obtaining a diagnosis (National Institute for Health and Care Excellence 2013) it is not clear from the literature that the effect of receiving it is unequivocally positive. Avdi et al (2000), in analysis of parents' discourse from a constructionist viewpoint, found that in talking about their child's 'problem', parents employ three main discourses; that of normality in development, which constructs the child as different in relation to expectations; that of the child in relation to medical diagnosis, which adds a new label; and that of the child in relation to disability, with associations of permanently locating the child as 'other' and different. The diagnosis is seen as an antidote to the uncertainty, self blame and search for a cause which had arisen when parents noticed the child was different from others at the same age. It validates their anxieties and by labelling the 'problem', makes it real, and somewhat more understandable and predictable. It also represents a 'ticket' to services. However, there is a perception that the child has been turned by the diagnosis into "an object of monitoring and scrutiny" (p.249), and that the parents have been turned into teachers or therapists, to the detriment of their experience of parenting. Hodge (2005) found that parents can feel disempowered regarding their ability to parent their children once they are labelled as autistic and in need of 'expert' intervention. Nurses are expected to empower patients (DH 2001a) and represent themselves as empowering (RCN 2003), so this dissonance is an area explored in this study in the reflection and discussion of participants' perceptions of their role.

Other writers reiterate the tension for parents between seeking diagnosis as a gateway to understanding and support and resisting the accompanying change of perception of the child, family, and future expectations that a diagnosis incurs

(Landsman 1998). Many writers over the years describe disclosure of a diagnosis as traumatic, and the effect on parents as similar to a bereavement reaction (Moses 1983; Fortier and Wanlass 1984).The medical model is seen as defining autism as an existing pathological state, which diagnosis uncovers, leading parents to expect a life of burden and stress (Dunn et al 2001). Authors from the disability movement have opposed this concept, concluding that the process of diagnosis creates pathology. For example, Molloy and Vasil (2002) observe that diagnosis of children with Asperger syndrome pathologises their behaviour in the eyes of adults including parents, so that instead of an expression of personality, the behaviour is regarded as 'symptoms'. Despite this research focus on the meaning of diagnosis to parents, there has been less work on what it means to the professionals working within the diagnostic system. This study draws out in reflection whether these nurses' attitudes towards diagnosis are similarly ambivalent to parents' attitudes and how nurses understand the implications for families.

Gray (1993) describes an autism service in which staff continuously sought to modify parents' perceptions of their children as affectionate and having potential to improve, to conform with the medical view of the children as affectionless and having a gloomy prognosis. Parents who remain positive and optimistic about their child, and do not display characteristic grief and loss reactions, are sometimes themselves labelled as being 'in denial' or unrealistic (Darling 1979; Larson 1998). Oppenheim et al (2007) interviewed parents of preschool children diagnosed with ASD using a model based on attachment theory which proposed that parents needed to work to alter their 'internal working model' of the child in order to reach a state of 'resolution' in which they could have a realistic view of the child whilst still maintaining hope, and cease searching for reasons for the child's condition. They conclude that only 33% of parents were 'resolved' and therefore capable of accepting the child realistically, and they suggest parents should have therapy to help them to reach 'resolution'. The stance of the nurses in this study on these issues is discussed in terms of the language they use and their perceptions of their role with parents.

A middle ground between these positions is suggested by academic researchers who are also mothers of children with disabilities: Ryan and Runswick-Cole (2008) argue that the search for a diagnosis by mothers does not represent an acceptance of the medical model of disability, but rather is a pragmatic way of engaging with society and negotiating the best outcome for their children. They point out that although taking the stance of the social model theorisers to its logical conclusion would lead to the disappearance of oppressive structures (presumably including diagnosis), it would also leave children with impairments. Landsman (2005) also describes mothers complying with the medical model when their children are newly diagnosed, in order to engage with the dominant medical discourse to which they, too, had subscribed before they had a child with a disability. She points out that the social model, whilst drawing some parents in as activists, does not provide the immediate change that would positively affect the life of a child and family. She suggests that mothers use both models whilst living in reality constructed from neither. Diagnosis is therefore but the beginning of a process in which the concept of normalcy is challenged and redefined around what is 'normal for us'. The way parents manage this transition can be profoundly affected by the way in which assessment and diagnosis is carried out, which is core to the role of the nurse in the assessment process, as the literature discussed in the following section demonstrates.

The assessment and diagnostic process: power and powerlessness.

It has been found from studies from various countries over many years that parents' perception of the process of diagnosis of a variety of long-term childhood conditions, and to some extent their perception not only of the diagnosis, but of the child, is affected by the quality of their interaction with professionals involved in the diagnostic process (Taanila et al 1998; Brogan and Knussen 2003; Braiden et al 2010; Abbott et al 2012). Hodge (2005) describes the negative effect on the parent's perception of their own parenting skill brought about by a diagnosis that was unexpected, but he also suggests that

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professionals may be able to ameliorate some of these effects by adjusting the way they interact with parents. Many harrowing accounts of unsatisfactory interviews between one or both parents and apparently offhand, unhelpful professionals with an apparent dearth of empathy or compassion have been published over the past half century (Cunningham et al 1984; Pearson et al 1999; Davies et al 2003). In response, training programmes around best practice, including the 'Right from the Start template' launched by Scope UK at the British Paediatric association annual meeting in 1995 (DH/Scope 1995) have been introduced, and government guidance such as 'Together from the Start' (DH/DFES 2003) published. It is not known how many diagnostic teams have availed themselves of the training. Medical and nursing education both in the UK and elsewhere has altered to include more 'people skills' and psychological care as essential skills, and attempts are made to assess these skills in practice (Cox and Mulholland 1993; NMC 2007). There are moves to include patient satisfaction or service user experience much more widely in outcome measurements for all sorts of NHS services, and these will be used to rate and develop services. Despite all these improvements, some parents continue to relate narratives of despair, sometimes including the unsatisfactory imposition of a diagnosis they do not fully understand or agree with (Huws et al 2001; Mansell and Morris 2004). It is not known whether having nurses as part of the assessment teams makes a difference to the experience of parents in this respect, or whether the emphasis on the empathy, compassion and building of a positive nurse-patient relationship which is characterised in the notion of nurses 'being there for' patients in 'skilled companionship' (Kitson 1996) ameliorates the negativities of the experience of diagnosis in the way Hodge (2005) suggests might be possible. In this study the nurses' perceptions of how parents experience assessment and their perceptions and intentions regarding their role and relationship with parents are explored.

It is notable that the majority of discussion around how to improve the diagnostic process and the experience of parents still begins with the assumption that after a process of assessment, doctors and other professionals have access to facts about the child of which the parents are ignorant, and that

the power rests with the professional to judge whether, when and how much of this information to disclose to the parent, as it did decades ago (Nursey et al 1991). This is less clearly the case when a diagnosis is based on interpretation of behaviour rather than on physiological testing, and much of the research relates to children with congenital conditions which are discovered on neonatal testing. However, diagnosis is often portrayed as something done to the child and family, and literature around how to improve the process is consistently couched in terms such as 'disclosure', and 'telling parents' (Brogan and Knussen 2003; Braiden et al 2010). Perhaps in response to parents' indignation about this enforced helplessness and alienation, and also because research has shown that parents are reliable observers of their children (Glascoe 1999; McConkey et al 2008), there has been a trend to take parents' views into account which has cast parents in the role of 'expert' regarding their child, and 'best practice' guidance on diagnosis of ASD in the UK calls for partnership with parents (Le Couteur et al 2003). However the putative partnership with parents has sometimes been seen as less than equal, and some parents have found themselves in the position of seeking a medical opinion to confirm their own conviction that the child was not developing typically, but waiting helplessly for a doctor or a team of professionals to pronounce a diagnosis (Midence and O'Neill 1999; Murray 2000; Audit Commission 2003; Goin-Kochel et al 2006). In contrast, where parents have been pressured into seeking a diagnosis, perhaps by a nursery or school in search of funding to deal with difficult behaviour, they have reported feeling almost as if they have betrayed their child by collaborating with a diagnostic process which has resulted in a label they perceive as negative or stigmatising (Halpin and Nugent 2007).

These issues are explored by Avdi et al (2000) in their discourse analysis of parents' talk about the knowledge, expertise and authority of professionals at a child development centre, which demonstrates the ambivalence of parents' feelings as they engage with the diagnostic process, particularly over the question of whose understanding of the child is the most valid. The parents' and the professionals' constructions of the child seem frequently to be contradictory, and the balance of power within the diagnostic system is weighted in favour of

the professionals, who are perceived to be in possession both of information and the power to withhold or disclose it. In this study the parents' discourse gives the impression that they feel that they, as well as their child, are being assessed by the 'experts'. Despite all this, parents represent the professionals as friendly, approachable, thoughtful, supportive, genuinely interested, perceptive and non-judgemental. The ambivalence and tensions in the relationship between parents and professionals appears to be inherent in the established process of assessment of children for autism within a child development centre, rather than dependent on the expertise or interactive style of the individual professionals. Unfortunately, the study in question does not extend to eliciting the perceptions of the professionals involved. However, the conclusion is drawn that professionals should not try to deny the power differential between them and the parents of children undergoing assessment, but should rather accept that " the position of expert is paradoxical" (p.336) and that

> *acknowledging the ambivalence inherent in constructions of expertise and scrutinising one's assumptions and practice, rather than denying the authoritarian aspects of health care, would provide the basis for more ethical and respectful clinical practice* (p.336).

This insight may well have contributed to the debate over how best to improve the assessment process at a time when efforts were being made to work towards a more collaborative and transactional model of diagnosis (Bartolo 2002; Nissenbaum et al 2002).

The study by Bartolo (2002) examines the way in which professionals at two London assessment centres negotiated a diagnosis with parents, but does not report the parents' view of the process. .Although the author states that both sites were 'parent centred', and that parents 'at times' participated in the assessments, the study's title, including the words "Communicating a diagnosis of developmental disability to parents.." (p.1) indicates that the professionals are understood to be the experts with the knowledge about the child and the power and responsibility to decide how much of the 'bad news' to tell the

parents, and how. During the post assessment interview with parents, the professionals are described using hopeful formulation or defocusing frames, depending on the professional's perception of the parent's readiness to receive a diagnosis, and also depending on the stance of the professional group towards diagnosis. With one child and family, the education professionals are reported to use a defocusing frame, meaning avoiding using diagnostic labels despite agreeing with the previous medical report and diagnosis of autism, and despite

.... the lament by his father, unaware of the report, about the many

inconclusive investigations and his son's 'abnormal' behaviour (Bartolo 2002

p.70)

The study demonstrates the extent to which professionals from a range of fields who genuinely believe themselves to be 'parent-friendly' nevertheless exercise the power which was acknowledged by Avdi et al (2000) and condemned by earlier critics of the medical profession (Foucault 1977; Foucault 1980; Cunningham et al 1984). It is not clear from the study whether the professionals involved have 'scrutinised' their assumptions and practice, as recommended (Avdi et al 2000 p.336), but both studies demonstrate that having compassionate and thoughtful professionals on a diagnostic team does not in itself guarantee either power sharing or full parent participation in assessment.

Nissenbaum et al (2002) contribute one of very few studies which uses naturalistic inquiry to give a voice both to parents and non-medical professionals about their experience of the 'interpretive conference', as they describe the interview during which the results of assessment are communicated to parents. Their insights concerning the stress this generates for the professional as well as for the parents explain the reasons for discomfort generated by the 'disclosure' model of sharing assessment results. Professionals describe how being in the position of power and having to disclose a diagnosis to parents causes emotional and physiological changes to themselves which were "so overwhelming that professionals dread the interpretive conference" (p.36). The negative effects on their interactive skills

caused by this stress included "rushing, failing to give relevant information, jumbling words, presenting an unclear diagnosis, and using poor eye contact" (p.36). These are remarkably similar to the characteristics of the diagnostic style of medical and other diagnosticians which has been found so unhelpful by parents and criticised in the literature (Cunningham et al 1984; Sloper and Turner 1993). It is notable that the reactions of both parents and professionals are more emotional and more stressful when parents are not aware of the likely diagnosis before the interview. It may be that for nurses there are particular stresses in this situation, as they find tension between the professional imperative to share power and information with parents and to build a relationship of trust and collaboration (RCN 2003) and their socialisation into their role as a member of a diagnostic team led by a doctor, who traditionally retains the right to make and disclose a diagnosis. The role of the nurse, seen through the sociological lens of dramaturgy (Goffman 1959) has tensions between the 'front-stage performance', in which the nurse before an audience of children and families coming for assessment plays the part of the professional fluent in the diagnostic script built on a medical model, and two separate 'backstage' performances. In the 'backstage' of the team, the nurse plays the role of loyal and subsidiary cast member supporting and deferring to the powerful 'star', who is the doctor, but in the 'backstage' of the group of nurses, he or she plays the role of autonomous professional, expressing frustration over role limitations and at times deviating from the diagnostic script.

These areas of tension are explored in the present study, and the issue of power and empowerment was found to warrant a separate chapter, in which further literature on the subject is discussed. Although Nissenbaum et al (2002) offer a comprehensive list of recommendations for practice, they continue to frame this in terms of 'Recommendations for practices when informing families their child has autism', rather than examining the possibility of changing the assessment model to avoid the situation of 'disclosure' of autism to an unsuspecting parent occurring at all. The same emphasis on finding the best way to disclose or 'share' a diagnosis with parents occurs in other guidelines around 'best practice' (Hedderly et al 2003; Le Couteur 2003).

An alternative model of exploring possible reasons for a young child's unusual behaviour, and considering potential diagnoses in a meaningful partnership between parents and professionals is offered by Gray et al (2008). Although designed to sit within the American 'medical home' model of primary care, the principles they suggest are applicable more widely. They support the observation by Avdi et al (2000) that parents are "experts....in need of expert input" (p.3). Gray et al (2008) adopt the position of facilitating the family and allowing them, rather than professionals, to retain the lead in the process of assessment and diagnosis, and in decisions about followup support and education. They suggest that assessment should be based on the ICF strengths and supports based model framework (WHO 2001), which includes functional strengths, social role activity, community participation and environmental facilitators, thus accounting for the 'fit' of the child within his family and community to a greater extent than a diagnosis based purely on the DSM or ICD criteria. Their model keeps in mind that it is the family who have embarked on the diagnostic process, and it is they who will have the ongoing relationship with and care of the child, so the professionals are in the position of lending their expertise rather than taking over the process. They suggest that

keeping the child and the child's behaviour as the central focus.......helps

parents recognise their child's personhood in the diagnosis process (Gray et.

al. 2008 p.265).

Perhaps this would help to avoid the perception that the child the parents thought they knew has been replaced by another with a label (Landsman 1998; Baird et al 2000), or as one parent in a focus group of UK parents who had experienced diagnosis in the South of England between 2000 and 2007 poignantly put it,

Anything that people could say to me wouldn't have been helpful, I wanted

my son back (Osborne and Reed 2008 p.319).

Most pertinent is the observation by Gray and colleagues that using their model,

....no parents will suddenly face as part of the diagnostic process the reality of uncovering a problem that they did not suspected (sic)(Gray et. al. 2008 p.265).

Where there is disagreement or parents feel the diagnosis of ASD is premature, Gray et al suggest using a 'working diagnosis' perspective to allow the child and family access to services. They further point out that, if parents are appropriately supported through the assessment and diagnostic process, it can be a therapeutic rather than destructive experience.

The question of what constitutes 'appropriate support' through the process of assessment has been answered sometimes by professionals speaking on behalf of parents (Charman and Baird 2002; Baird et al 2003) and sometimes by parents themselves (Howlin et al 1997), but there is considerable consensus regarding what parents find helpful. Parents require professionals to recognise their need to be fully involved in the diagnostic process, to have their views and perceptions listened to and respected, and to have the right to information about their child (Brogan and Knussen 2003). This includes honesty when there is uncertainty about a diagnosis (Sloper and Turner 1993) or where the assessment takes place over time, leading to an 'evolutionary' diagnosis (Cottrell and Summers 1990). Parents would like their child's strengths and unique personality to be recognised and celebrated rather than concentrating the assessment only on deficits, and they need to reach a realistic perception of the child's development which nevertheless retains hope for the future (Harnett and Tierney 2009). They would like all the professionals from different agencies involved in the assessment to be working together in a coordinated way and to be communicating effectively between themselves (DfES1999; Braiden et al 2010). They need professionals to recognise that the assessment and diagnostic process is a difficult time for them and to respect this by giving the parents undivided time, sensitive communication, and emotional support where necessary. They would like to be in control of the amount of information around autism that they need, and the opportunity to revisit information in stages using professional expertise as necessary (Osborne and Reed 2008). They need to know how best to help their child enjoy being in the world and to protect him or

her from unnecessary stress, whilst also meeting their own needs and those of the rest of the family. They need to know about any services including family support networks that are available in their area, and to be able to choose if and when to access these. Many parents over time have expressed the need for a single point of contact with heath, education and social care; a service coordinator or key worker who will get to know them and their child, understand their perceptions and priorities and advocate for them if necessary; and ensure that the complex multidisciplinary and interagency processes that are begun during assessment and diagnosis are coherent, effective and not overwhelming for the family as a whole (Sloper 1999; Limbrick-Spencer 2001;Le Couteur 2003; Greco and Sloper 2004).

The current literature does not indicate whether nurses have in common a particular set of beliefs, values or intentions which could enable them to meet the expressed needs of these particular parents and families, and it is one aim of this study to explore this possibility. However there is an extensive literature around core values in nursing, including (in the USA) human dignity, integrity, autonomy, altruism and social justice (Fahrenwald et al 2005); and the values expressed in the UK Nursing and Midwifery Council Code of conduct (NMC 2008). These values are reflected upon by the nurses in this study as they impact on their socialisation and professional expectations and their actions in practice, although nurses are not acknowledged to have a particular role in this field, as the next section demonstrates.

The function of nurses in the assessment team

Literature from the USA and Australia (Pinto-Martin et al 2005; Inglese 2009; Barbaro et al 2011) indicates that nurses in primary care in these countries are expected to carry out screening for autism, whereas in the UK screening of the general paediatric population for autism has not been recommended. Again in the USA, Giarelli and Gardner (2012) describe nurses screening for autism, and then planning and implementing care. These authors claim to follow a social model of disability, and consistent with this claim, they do mention nurses developing strategies to accommodate the environment to the child; but they

also describe people with autism as patients with symptoms, and autism itself as a 'growing public health problem' (p.xiv), which seems to indicate a medical model possibly reflecting local assumptions of normalcy. They envisage the role of the nurse as providing evidence based, integrated care across the lifespan, within an American 'medical home' model (Larson and Reid 2010) which may not be easily transferable to the UK context.

It is notable from the research around families and children at the time of assessment and diagnosis, that few if any British authors consider the place of nurses in the assessment team, whether as part of the diagnostic service or as key workers for families during assessment. One report of a successful hospital based key worker service which was shown to improve the experience of parents whose children were being assessed for visual impairment (Rahi et al 2004) states that the two key workers who made such a difference were "coincidentally both with nursing training" (p.478). The assumption implied was that any professional with relevant training around autism could have done a similarly successful job as key worker. The present study adds to knowledge in this respect by exploring the qualities nurses have in common which may prepare them to be particularly effective in this context. There are studies around the role of the nurse as key worker once diagnosis is completed, for example Davies (1996) found that the specialist nurse has a pivotal role to play in meeting unmet need and reducing stress experienced by families after diagnosis. Carter et al (2007), using an Appreciative Inquiry approach, confirm that most families with children with complex needs at home feel the need for a care coordinator after diagnosis to help them to "plan the journey ahead" (p.534), and in this study, most families had a community childrens' nurse who had a long term involvement with the child and family and who may have acted as care coordinator by default. They also suggest that families should decide whether they need such a person, and who would be most appropriate.

Despite the assumption which underpins UK government guidance (DH/DfES 2002; DfES 2007; Le Couteur 2003) that professionals from any discipline can be effective key workers given the right training and support, it is health visitors

(specialist community public health nurses), rather than other professionals, who have voiced the opinion that being a long term support and advocate for families going through preschool assessment and diagnosis for autism is part of their core role (Halpin and Nugent 2007). Nurses (health visitors) are certainly, in the UK ,the professionals most commonly first approached by parents who are concerned about their child's development and are responsible for the majority of referrals to child development teams for assessment (Chakrabarti and Fombonne 2001; Thompson and Ni Bhrolchain 2013).

There is little literature to date exploring whether there are values and beliefs common to nurses, reflecting underlying nursing philosophy and theoretical models transmitted in nurse education and training, which are pertinent to this particular area of practice.

In order to explore whether the suggestion that nurses could have a unique role to play in this field is supported by nursing theory, some of the philosophies, theories and models of nursing which may have a bearing on the role of the nurse for this group of families are now reviewed.

Nursing models related to disability and autism

The role and unique function of the nurse (Henderson 1966) has developed considerably since Florence Nightingale wrote her 'Notes on Nursing' (Nightingale 1889), and yet in the public perception nursing may still be encumbered by historical images of nurses as either 'ministering angel' or 'handmaid of the doctor' which reflect earlier eras (Kitson 1996). Whereas Nightingale conceptualised nursing as a public health role involving campaigning and advocacy for the vulnerable in society, as well as maximising the health of individuals, Kitson observes that the development of nursing was subject to political and societal constraints. In a climate in which women had very limited power and no vote, nurses negotiated the twin difficulties of contemporary attitudes to women, and the established power of the largely male medical profession by conceptualising their work in terms of vocation, and of loyal supporter of the doctor. Later, in order to fight for full professional

status, the body of knowledge that developed emphasised the scientific and evidence base of nursing and Kitson suggests this also tended to align nursing with medical models of health and of disability. According to a review by Boyles et al (2008), this still remains the case in most areas of practice, although learning disabilities nursing has championed the social model of disability (Aylott 2004;Camus 2008), and may have faced challenges to its professional status as a result (Mitchell 2000). Mitchell states that learning disability nursing, which has never adopted a medical model of care, has suffered from 'parallel stigma'. This means this branch of the profession has been devalued and marginalised by association with the care of people also devalued and marginalised as deviant, rather than with the cure of the sick. There have been suggestions from those who would separate social care from nursing that working with people with learning disabilities is not nursing at all (Jay 1979). This could be applied to work with children with autism, and nurses in this field who disassociate themselves from the medical model could be at risk of similar marginalisation. However Scullion (2010) suggests that adopting a social model of disability would empower nurses to fulfil the social advocacy role which, as he points out, is a professional, moral, and in some countries a legal responsibility on them. Ballou (2000) observes that the three prevailing ideologies that have informed the development of nursing since Florence Nightingale; moral endeavour, caring and advocacy, are all underpinned by a social contract doctrine of a covenant with clients on the basis of equality, and include a strong call to use socio-political force to promote justice where inequality and oppression exists. As Mitchell (2004) states, 'ultimately it becomes an issue of identity' (p.117). The next section examines the literature for nursing theory and models which could inform nurses in preschool autism assessment who wish to retain their identity as nurses and develop a role distinct from medicine within this field.

As nursing has 'come of age' as a profession, philosophies and theories of nursing have been more clearly articulated, and the distinction between medicine and nursing has been ever more sharply delineated. Although several well-established nursing philosophies and theories have an origin in biological

sciences (Henderson 1966; Orem 1971; Abdellah 1973), nursing as a human science frequently encompasses a broader view of health. Several nursing theories and models, if consciously utilised by nurses in child development, would facilitate their alignment with a social or biopsychosocial model of disability and help to clarify the unique contribution to assessment and intervention that nurses, in collaboration with children and families undergoing autism assessment, could make. Some of these theories and models are reviewed here to ascertain whether models of nursing can provide a framework within which nurses could conceptualise their work in assessment of autism using an alternative to the medical model.

For example, King (1981) proposes a goal attainment theory for nursing based on the understanding of nursing as a process of human interaction between nurses and patients, who communicate to set goals and together explore ways to achieve them. Her theory of nursing is based on her understanding of health as a dynamic state of adaptation to stresses in both internal and external environments, which resonates with the social model of disability.

A theory which has possibly done more than any to inform the development of advanced nursing practice is Benner's (1984) model of skill acquisition. Developed from acute hospital based nurse-patient observation, it brings into focus the way in which nurses who develop advanced levels of expertise use intuition (rather than rules or 'tick-lists') based on the combination of an expert grasp of their subject, and close communication with and understanding of their patients. This was later developed into phenomenological theory describing 'caring' (Benner and Wrubel 1989), which, although known to be at the heart of good nursing, has consistently been hard to define. Nurses in autism assessment who operate at the level of expert practice described in this model would go further than using 'tick-lists' of symptoms, towards understanding the meaning of the child's particularities for the child and family within their social environment.

Neumann's theory of nursing (1980) includes a systems model using Gestalt theory and stress theory which aims nursing intervention at promoting wellness

through the reduction of stress factors and adverse conditions. According to this theory, nurses focus on helping people manage their response to stress, which would include the stress experienced by a child with autism living in an ableist society.

Watson (1994) in her theory of nursing for a postmodern era, proposes a philosophy and science of caring which draws on an existential phenomenological view of psychology and the humanities. Her theory views nursing in terms of a human science, based on the operation of ten 'carative factors', and distinct from a medical emphasis on curing. She describes 'caring' as only effective within a transpersonal relationship, depending, among other factors, on a moral commitment to enhance human dignity to allow people to determine their own meaning, and the nurse's affirmation of the subjective significance of the person. Using this theory in assessment of children for possible autism would align nurses with a biopsychosocial model more than a medical model of disability.

Roy's model (Roy and Andrews 1999) conceptualises the person as an adaptive system. To maintain the integrity of the system, there is a regulator subsystem of physiological processes and a cognator subsystem of cognitive and emotional processes. The person uses adaptive processes in four modes; physiological/physical function; self concept/group identity; role function; and interdependence. According to Roy's model, health is a reflection of adaptive responses to the environment which promote the integrity of the person. Her definition of health is as a "process and a state of being, and becoming, an integrated and whole human being" (p.54) in a way that reflects the mutuality of person and environment. The goal of nursing, using this model, is to promote adaptation for individuals and groups (including families). Nursing assessment is done in collaboration with the individual or group so that their particular adaptive goals can be clarified, and so that they can work with the nurse to identify and promote effective adaptive behaviours towards this end. Again, this resonates with a biopsychosocial model of disability.

Kitson (1996), from her position as director of the Royal College of Nursing Institute, calls on Campbell's (1984) characterisation of the nurse as the 'skilled companion on the illness journey' to suggest a new slogan for the role of the nurse; 'we'll be there for you.' She reflects that the term 'companion' avoids sexual stereotying but does suggest closeness, and sensitivity to the other's goal and direction, as well as the possibility of movement and change. Kitson points out that to 'be there for' someone involves commitment and personal cost for the duration of the relationship, but she suggests this is manageable for the professional because it is to be expected that "when the patients are ready to move on they say farewell" (p1649). This reflects Henderson's (1966) insistence that part of the 'unique function of the nurse' was to assist the patient towards independence.

Although nurses in community child health, including those in this study, may avoid the term 'patients', which calls to mind individuals who are sick, any one of these nursing theories and models could usefully inform the values and practice of the nurse wishing to work in meaningful partnership with parents as described by Avdi et al (2000) and Gray et al (2008). Kim (2000) proposes an integrative framework to address the confusion caused by the multiple alternative ways of conceptualising nursing, and to reintegrate theory with practice. She suggests a metaparadigm concept of 'human living' to articulate the way in which nurses become involved with people who have health needs in the broadest sense, and distinguishes this orientation from the more technical focus on client states in order to care and cure which characterises medicine and paramedical professions.

It is beyond the scope of the present work to attempt to evaluate or recommend particular models, but it is clear that nurses do not need to adopt a medical model of disability for their work by default or association, as any one of a number of nursing philosophies and theories could underpin practice informed by a social or biopsychosocial model. During the study nurses reflect on the model of nursing they have internalised from student days, the extent to which there is dissonance between their intentions as nurses and their actions in

practice, and the possible reasons why these may be different, including their socialisation as part of a multidisciplinary team.

Models of team working

Recommendations around 'best practice' in assessment for autism state that this should be done by a team of professionals, rather than by an individual clinician, however skilled (Le Couteur 2003). There are various ways of working across disciplines, resulting in team structures which are on a continuum between multidisciplinary, interdisciplinary and transdisciplinary models (Hall and Weaver 2001). Multidisciplinary teams exist where professionals from various disciplines work in parallel to each other, but their assessments are not shared and communication between them is generally only through the team leader, usually a doctor. Interdisciplinary teams work more closely together and communicate frequently, being organised around solving a common set of problems. While retaining strict boundaries between their areas of expertise, members take into account the others' contributions in order to provide holistic care. In transdisciplinary teams, however, the team is functioning so closely together that each understands and can carry out aspects of each other's roles, and role distinction becomes blurred as professional functions overlap. A transdisciplinary team can deliver a unified assessment which uses the expertise of each member in a more seamless and flexible way and in which the balance of input of particular members can be tailored to the need of the family. For example, where the child seems to have particular difficulties with communication, a speech therapist could lead, whereas if difficult behaviour was the family's main concern, a psychologist might coordinate the assessment. However, to work effectively in a transdisciplinary model, each professional must be confident enough in his or her own role and have enough understanding of and respect for the particular skills of fellow team members to be comfortable to share their own expertise, and to learn from that of others. This is not always the case, and where professionals are not clear about what the particular contribution of each professional skill set is to assessment, they tend to be more comfortable in teams which are multidisciplinary and often hierarchical.

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Hudson (2002), although positing an optimistic hypothesis around interprofessionality in teams of health and social care professionals working in the community, notes that the status of doctors within teams has traditionally been higher than that of other professionals. There has often been an expectation that within a team of professionals, the doctor will be the team leader, and to a greater or lesser extent, dictate the scope of the roles of other team members. These teams will then work as multidisciplinary teams, in which it has been shown that there is less team member participation, and less opportunity for role negotiation and shared, child focused assessment than in transdisciplinary teams (Rosen et al 1998). Issues around power and empowerment with respect to parents and professionals, and between professionals, became apparent during the research process as a factor influencing the work of the nurses within child health teams, to the extent that it warranted a separate exploration of the literature. This is presented separately in chapter 6 (page 109), reflecting the way in which the subject imposed itself on the shape of the study.

Summary

Although there are nurses in some child development teams and autism assessment teams in the UK, the literature offers little evidence around the particular part they play within the team, the way they work with parents and children during the process of assessment, or how they conceptualise their role. Although Halpin and Nugent (2006) found that nurses working as health visitors in the community felt they had a part to play in identifying children who were developing atypically and referring them for assessment, and particularly in supporting families with children with autism, they were not involved in the assessment process itself. Other studies concerning nurses and early autism have largely not been based in the UK, and have highlighted the role of the nurse in screening rather than assessment (Pinto-Martin et al 2005; Inglese 2009; Barbaro et al 2011).This study explores the perceptions of nurses themselves around their role in assessment teams in one particular area of the U.K..

It is less than clear from the literature whether or not nurses in this field adhere to or are even aware of various models of nursing, and whether they are conscious of a 'unique function of the nurse' (Henderson 1966) in the team. One aim of the study is to explore this with participants in order to clarify the meanings the role has for them and their perception of the contribution of nursing to the assessment process.

The literature does not demonstrate whether or not nurses in assessment of preschool children for autism have in common a particular set of beliefs and values which might enable them to deliver nursing actions which address the needs parents have identified and the sort of service they find helpful.

The contribution of the present study to furthering knowledge in this area is to analyse how nurses in community child health teams in one area of the UK who have been involved in the preschool autism assessment process conceptualise what they do. It also identifies nursing beliefs, values and intentions for action which are common to nurse participants, and relates these in the light of theoretical nursing models to the actual and potential role of nursing in this field. It addresses the gaps in knowledge highlighted by this review of the literature by addressing the research question:

'What do nurses identify as their particular professional contribution in the assessment of preschool children for autism?'

CHAPTER THREE: METHODOLOGY

In this chapter the reasons for the choice of critical reflective inquiry as the methodology for this study are explained, beginning with the philosophy behind the tradition, and its relevance to 'insider' nursing research. The influence of considering analytic autoethnography and action research on the final choice of critical reflective inquiry as a means to structure this study is discussed. The methods used are described in some detail, with the intention of demonstrating the efforts that have been made to achieve transparency and credibility in the study. Some possible criticisms of the methods are considered and a rationale is offered for choosing these methods despite their limitations.

The philosophical underpinning of the methodology for this study comes from the branch of phenomenology which was differentiated from Husserl's transcendental phenomenology by Heidegger (1962) and taken forward by Gadamer (1977), that of philosophical hermeneutics. This interpretive tradition was chosen because it would allow me to be both researcher and fully involved participant alongside the other nurses working in community child health teams in the area. I was working across the teams as clinician alongside the other nurses, and wanted my own reflections on clinical experience to contribute to the data. I realised that the definite opinions I held regarding the role and value of nurses would be hard to 'bracket out', and instead decided to acknowledge these as prejudices and analyse them as part of the data. In philosophical hermeneutics, rather than attempting to 'bracket out' the experience and prejudices of the researcher in search of the essence of the lived experience of the participant, as Husserl did in exploring 'lifeworlds' (Cohen et al 2000), Heidegger and then Gadamer took the position that interpretation of experiences described in text is bound to take place in the context of the pre-judgements of the interpreter,

The important thing is to be aware of one's own bias, so that the text can

present itself in all its otherness and thus assert its own truth against one's

own fore-meanings. (Gadamer 2004 p.271).

Hermeneutics, or the study of the interpretation of texts, as extended by Gadamer, uses the metaphor taken from Heidegger of the hermeneutic circle, moving from a part to the whole and back again in gaining understanding of a text in context. In this tradition the researcher is included in the hermeneutic circle and brings his or her prejudices (value positions) to the interpretive project. The interpreter questions the text, and in turn has his or her presuppositions questioned and challenged. Understanding occurs through the fusion of horizons, or coming together of points of view, of the interpreter and interpreted (Gadamer 1976; Koch 1996). As Koch puts it, describing her own study,

Stories are told by self-interpreting patients, who have brought to them their

pre-understandings. At the same time, I bring my pre-understandings and

prejudices to the research process. No attempt is made to disguise these.

My own mode of thought is something that cannot be eliminated or

bracketed. I participate in making the data. (p.178).

Although he did not consider nursing as a separate discipline, Gadamer's views fit well with a study of nursing practice. Gadamer (1996) had a view of medicine which reflects the conception of nursing originating with Florence Nightingale, who posited that the role of good nursing was to put the patient in the best possible condition for nature to heal them (Nightingale 1889). Gadamer wrote,

The goal of the art of medicine is to heal the patient, and it is clear that

healing does not lie within the jurisdiction of the doctor but rather of nature.

Doctors know that they are only in a position to provide ancillary help to

nature. (Gadamer 1996 p.128)

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In his essays on 'The Enigma of Health' (1996), Gadamer elaborated his conception of medicine as an art as well as a science, in a way which directly reflects Watson's description of nursing as 'the art and science of caring' (Watson 1994).

It is understandable, then, that Heidegger and Gadamer's branch of hermeneutics has informed the development of influential models of nursing including that of Benner and Wrubel (1989). Benner (1994) and Benner et al (1996) drew from the work of Dreyfus and Dreyfus (1980) on skill acquisition, which was itself informed by Heideggerian phenomenology. Benner et al used narratives of care and interpretive phenomenological methods in their extensive work exploring nursing practice in hospital settings, and note,

> *Narrative accounts of actual situations give a closer access to practice and practical knowledge than questions about beliefs, ideology, theory or generalized accounts of what people typically do in practice.* (Benner et al 1996 p.110).

Their work differs from the present study not only in scale and context, but also in that the nurse researchers who gathered data from their groups of nurses were interviewers rather than participants.

The present study is also underpinned by Gadamerian hermeneutics, but its method in one respect borrows from the tradition of analytic autoethnography, in that as researcher I am a participant alongside others, and contribute my own narrative and reflections directly to the data. Autoethnography has been attractive as a research method in psychiatric nursing (Foster et al 2006) because of its rejection of claims to objectivity and its acknowledgement of the researcher as a co-constructor of the meaning derived from narratives. The present study was influenced by analytic autoethnography, as conceptualised by Anderson (2006), which represents a divergence from the 'evocative' autoethnographic method because,

> *Unlike evocative autoethnography, which seeks narrative fidelity only to the researcher's subjective experience, analytic autoethnography is grounded in*

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self-experience but reaches beyond it as well (Anderson 2006 p.386).

Therefore analytic autoethnography has resonance with the present study because it seeks to go beyond self-experience to develop theoretical understandings of a culture or social phenomenon. This is unlike the aims of evocative autoethnography and has caused controversy in the autoethnographic research community (Ellis and Bochner 2006; Atkinson 2006; Denzin 2006). Other distinguishing features of analytic autoethnography are also relevant here: the researcher is a complete member of the community under study, analytic reflexivity is used throughout, the researcher is visible in the narratives, and there is involvement of participants other than the researcher (Anderson 2006). These features occur in the present study. However, although this methodology influenced the design of this study, this is not an autoethnographic project; as researcher I did not intend to be the 'professional stranger' of the ethnographic tradition (Agar 1980), and several other narratives in addition to my own are used as data. This study is in essence a hermeneutic project: an interpretation of narrative texts, not an ethnographic project of direct observation of a culture supported by field notes. I found a need to look elsewhere for a methodological framework which would provide a better 'fit' with the aims and situation of the study.

Although Gadamer (2004) insisted that truth is not to be found in method but in dialogue, and did not recommend any particular research method, nevertheless a structure needed to be found around which to progress this study. The choice of critical reflective inquiry as a method by which to explore the issues was informed by the example of its presentation by Kim (1999) as a way to use nurses' written accounts of their experience of practice, not only to understand what nurses do and to develop nursing knowledge, but also as a means by which to empower nurses to improve practice. As a nurse embedded in the assessment teams and committed to service improvement as well as to research, this potential resonated with my personal aims and prejudices, as well as offering a framework which would fit the intended study.

Critical reflection is well established as a tool to enable nurses and other professionals to evaluate and improve their practice, both individually (Dewey 1938; Powell 1989; Schon 1991) and in action learning groups (Graham 1995).

Kim's (1999) method of critical reflective inquiry engages practitioners in creating knowledge as they reflect on their practice and generate better ways of working. It is presented as an appropriate vehicle for collaborative work and shared learning between researchers and nurses (Kim 1999). There is little literature describing research using Kim's particular method, and it is useful that this study will now provide researchers with an example of its effectiveness. The current study also informs the methodology by illustrating how it can be adapted to include the researcher as a participant.

There has been some criticism of reflective practice from those influenced by Foucault (1980), who represented reflective practice as a form of coercion to confess (Gilbert 2001). Another critic is Taylor (2003), who points out that narratives of nursing produced in the course of reflective practice are versions of reality 'artfully constructed' as the practitioner makes sense of an event and claims an identity within it. He states that these narratives should not be uncritically regarded either as being a superior form of truth-telling, or as representing the stance of the patient or client. Taylor (2000) describes three types of reflection; technical, practical, and emancipatory; based on Habermas' critical theory of knowledge and human interests (Habermas 1978). Technical reflection as described by Taylor (2000) refers to critical review of procedures using empirical knowledge and scientific methods. Practical reflection uses interpretive knowledge to review the lived experience of practice, and to learn from it. Emancipatory reflection uses critical knowledge to analyse the experience of work to identify forces, hegemonies or reified conditions which limit the effectiveness of practice. The types of reflection remain relatively distinct. In the method used here, however, similar types of reflection are combined into phases of a process. Kim defines the term 'reflection' as

...a process of consciously examining what has occurred in terms of thoughts,

feelings and actions against underlying beliefs, assumptions and knowledge

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as well as against the backdrop (i.e. the context or the stage) in which

specific practice has occurred. (Kim 1999 p.1208)

Kim describes three phases of the process: descriptive, reflective and emancipatory. A strength of her method is that it encourages progress between the phases.

Credibility and the limitations of the methodology

This study may be open to criticism in that it relies upon the experience, reflections and conversations of relatively few participants, and the researcher acknowledges her influence on the construction and interpretation of the data, and makes no claim to objectivity. However, as Ashworth (1997) observes,

> *...experience is already shot through with interpretation. We live*
>
> *interpretatively: it is part of the make-up of human beings* (p.222).

Ashworth suggests that in any attempt to investigate the world of humans using qualitative methods and a non-positivist approach, reflexivity, in the sense of the way in which researcher and participants co-construct the data, and also in the sense of the researcher's interpretation in formulating findings, is not a bias to be controlled, but is necessary and appropriate.

Levering (2006) points out that basing research on the perceptions of human beings can be problematical and asks, in the title of his paper, "how authoritative are people's accounts of their own perceptions?" He observes that the first epistemological starting point of phenomenology is subjectivity, acknowledging that each person has their own conception of reality and assigns to events meanings that are unique to the individual. He agrees with Heidegger and Gadamer that each person's perspective on reality is influenced by their particular set of prejudices. However, for Levering, the second epistemological starting point is intersubjectivity; the sharing of meaning, such as that demonstrated in common languages and social rituals. It is possible to reach

some level of shared conclusion through the analysis of personal narratives, because it is acknowledged that the narratives themselves are already interpretations by the narrator of the events that actually occurred; it is this interpretation which serves as data. Levering posits that the question of whether the stories themselves are in every detail factual accounts of what transpired is irrelevant. This is very pertinent to the current study, which intentionally involves an interpretive analysis of data drawn from personal recollections. The question of how many personal accounts are necessary for the conclusions to be robust does not arise; the study involved the totality of the qualified nurses in the teams, and the conclusions drawn are based on the sharing of experiences and interpretations among the whole group.

Koch (1996; 1998) addresses the legitimacy of hermeneutic inquiry in nursing and suggests that it is important that the method used is congruent with its philosophical underpinnings, but that each study in such a varied field must determine its own criteria for rigour. She suggests the trustworthiness of a study based on hermeneutic tradition depends on the extent to which the context and the way the research is carried out is described in enough detail for the reader to be able to judge its believability and transferability. Green et al (2007) argue that transparency in the analysis of data and anchoring of themes, both to their origins in the data and also to theory, produces the strongest evidence in qualitative research. In this study, my aim is for transparency and credibility. To this end, the methods are presented in some detail in the following section.

Methods

The participants in this study were a purposive group, in that all the nurses currently working in preschool autism assessment within the community child health teams in the NHS Trust were asked to consider participating. Four were from community paediatric teams and one from a child and adolescent mental health team. They were given an information sheet about the study (Appendix 1) after a nurse team meeting, and asked to contact me within two weeks if they wished to be involved in the study. All five expressed interest and were then given a consent form (Appendix 2) to sign and return to me if they still

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wished to participate. Again, all returned their consent forms, and the study began. I was working both as a nurse in one of the teams, and as a clinical leader (but not line manager) for nurses in the directorate, and was careful to emphasise that there was no obligation to take part, and that my role as researcher was distinct from my professional role. The nurses came from various professional backgrounds: health visiting, school nursing, paediatric nursing, learning disabilities nursing and mental health nursing. They all had in common extra training and experience in assessment of preschool children for autism, and had all contributed to the assessment and diagnostic process within their teams. The participants knew each other and were accustomed to discussing their work together, including peer group clinical supervision over difficult issues. However they were in most cases the only nurse on their multidisciplinary team. They were very willing to be involved in the study, and told me this was because they anticipated some benefit from taking time to reflect alone, and also from discussing their role with each other.

Data collection and analysis

The phases of the study, in keeping with Kim (1999), were as follows: first there was a descriptive phase in which each participant wrote an account of an episode of their clinical practice in preschool autism assessment, in which they felt that their role as a nurse was in some way significant. I asked them for an account which included their own thoughts and feelings at the time as well as a description of the circumstances of the interaction, and of exactly what happened. The written narrative was the first text for analysis. It was given to me as researcher; I read it thoroughly and identified whether there were areas that needed clarification, for example, how the nurse felt at the time, if this had not been described. If so, contact was made with the participant by phone or email to request elaboration. In my own case, I read and re-read the narrative and re wrote it until it adequately described my experience, before analysing it alongside the other narratives.

Each participant and I as researcher then went together into the reflective phase, in which the written narrative was re-examined by the participant during

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an audiotaped one-to-one discussion with the researcher which was subsequently transcribed verbatim. During the discussion the participant was invited to elaborate on the thoughts, feelings and intentions she had during the interaction, and particularly on the beliefs and values that informed her practice, checking that my impression of these was congruent with hers. We reflected on her understanding of nursing in the situation, and how the context of practice may have affected her actions. The transcript of this discussion was the second text for analysis.

An example of this process is given here:

Researcher: *When you spoke to M and J, you talked about 'we'... 'we' did things together, you and the parent or grandparent...was your impression that you were assessing with them, or for them, or what?*

Participant: *Both, both...she wasn't...she didn't seem to be aware that there was an autistic kind of trait, she thought it was just speech, and then it came out that she was terrified that it was because he'd rolled off a changing mat...about neglect on her part, that she could have caused it.*

Researcher: *How did you, as a nurse, get that information from her...what kind of listening?*

Participant: *Well I knew she was very anxious, and I was being as reassuring as I could, without, you know, erm... 'Oh you know, he'll be fine, just speech and language, why are you worrying...'*

Researcher: *That, to me, was you enabling her to share what she was really worried about...and the values that underlay that nursing, as I would look at it, are about respect and allowing parents to share their feelings...is that how you see it or...*

Participant: *Yes, absolutely, yes.*

Researcher: *You said you came away from that visit very worried?*

Participant: *Yes, mmmm*

Researcher: *So you'd taken that worry...why were you worried, personally?*

Participant: *I was worried about the whole setup....really...I was worried 'cos I could see how the child was, and I could see this little family and thought how on earth will they cope with this situation on top of what they've dealt with already..*

Researcher: *So there was empathy going on there? And it seemed you were almost...being very careful about how much information you shared, and judging when to share....is that right... or not...?*

Participant: *yes, oh yes..*

Researcher: *Do you think that is part of what a nurse does? Because other people might say...well, whose information is it anyway, kind of thing...how do you feel the nurse....*

Participant: *I just feel the nurse is there to support and carry it, until they have enough support to cope with it.* (N2 disc 17 – 50)

Following the discussions, I analysed the transcripts systematically, first as a whole and then line by line, against five parameters:

- this nurse's beliefs about the context of the interaction;
- this nurse's values;
- ethical principles which may be underlying her actions;
- possible tensions between beliefs, values, principles and actions;
- nursing models which may be applicable to this nurse's way of working.

These parameters were derived from models of reflexivity which have already been used in reflective practice in nursing (Bolton 2010; Oelofsen 2012). Bolton (2010) describes a 'through the mirror' model of reflexive writing which enables practitioners to clarify their values, professional identity and boundaries. She suggests reflective practice can enable enquiry into:

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- What you know but do not know you know
- What you do not know and want to know
- What you, think, feel, believe, value, understand about your role and boundaries
- How your actions match up with what you believe
- How to value and take into account personal feelings (p.4).

Oelofsen (2012) uses a three step reflective cycle of:

- curiosity (noticing, asking questions and questioning assumptions);
- looking closer (articulating the beliefs and values uncovered in step 1);
- transformation and feedback (using the reflective experience to allow positive changes to be made) (p.8).

Informed by both of these models, I decided upon the five parameters for examining the accounts of practice. Examining the transcripts line by line, I identified any possible beliefs, values, ethical principles, tensions, and nursing models which could be applicable, named and numbered them. A summary of the nursing beliefs and values that, in my view as researcher, were emerging from the initial analysis, was sent back to the participant for review and comment. Participants were asked to confirm by email or by telephone whether they considered the emerging findings to be truthful. This meant that that participants agreed with my interpretation of the narrative and the reflective discussion and that they were happy for the findings to be used in the next phase. I also, as researcher participant, wrote an account of an episode of practice, and subjected it to the same scrutiny.

The third phase was the critical or emancipatory phase (Kim 1999). Participants all took part in an audiotaped group discussion, to explore, in the light of our individual reflections and the emerging findings, how we viewed our role as nurses in preschool autism assessment. The discussion group was similar to an action learning set, found to be effective in facilitating reflexivity in

groups of nurses (Haith and Whittingham 2012), in that it was made clear that all views were to be respected, there were no right or wrong answers, and that information shared during discussion was confidential to the group. As part of a discussion about nursing in preschool autism assessment, we considered how our nursing beliefs and values were reflected in our actions and were influenced by the context of our practice; and whether any particular models of nursing have influenced us. We tried to identify any incongruence between our values or beliefs and our actions in practice; between intentions and actions; and between families' needs and nurses' actions. The aim was that by engaging with this challenging process, the underlying beliefs, principles and understandings of the participants about our nursing practice in preschool autism assessment would be made explicit and could be compared with our actual way of working in these specific instances. There was an opportunity for 'fusion of horizons' (Gadamer 1976; Koch 1996) to be achieved and new understandings to be reached, as participants engaged in question and answer, discussion and reflection. At the same time, practitioners had the opportunity to achieve self-emancipation from routine or habituated forms of practice which may not reflect their real beliefs or aspirations, and were enabled to identify areas of practice that they felt need to be challenged or changed within their clinical setting. The transcript of this discussion was the final text for analysis, and it was also sent to the participants for review and comment. During this phase the advantages of being participant as well as researcher became clearer, as I was able openly to contribute my own thoughts and points of view as well as facilitating the discussion. This eliminated any need for me as the researcher to stand aside from the discussion or to attempt to 'bracket' my own preconceptions, which would have been problematic considering my immersion in the team and in the subject (Gadamer 2004). As participant researcher I co-constructed the dialogue and the text alongside the other nurses.

I then analysed all the texts, searching for nursing beliefs and values that were held in common by some or all of the participants. Reflecting the hermeneutic circle, the texts were analysed as a whole and then line by line, and once again, when possible beliefs and values emerged in the judgement of the researcher,

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they were identified by number, and confirmed by reference to the bigger picture of the sense of the whole of the text, and also their 'fit' with the analysis of the other transcripts. The way in which this was done is exemplified in the findings of the study, which are discussed one by one in chapters 4 (page 61) and 5 (page 85). There is also reference to nursing literature and models, once again using the hermeneutic circle in a reflexive progression from the specific part of the narrative that reflects a belief or value, to the bigger picture drawn by nursing and other scholars, in order to answer the research question, 'what is the role of the nurse during assessment of preschool children for autism?'

Critique of the methods

Chang and Horrocks (2008) argue that to take analysed study data back to 'informants' for validation, as was done here, is antithetical to a Heideggerian hermeneutic phenomenological research framework. Ashworth (1993) suggests participant views are not a reliable form of evidence to validate research findings because of participant anxiety over 'face', the presentation of a worthy self to other people. However, in this case the participants co-construct the findings by contributing to the interpretation of the texts they have generated, both alone and in discussion. They agree that the selective identification of particular beliefs and values by the researcher from the narratives fits with their reflections on the experience. The parts of the narrative subjectively identified as indicative of beliefs and values are made explicit and traceable: each quotation is identified by participant number, followed by 'narr' (narrative), 'disc' (one to one discussion), or 'gp disc' (group discussion), a page number and a line number. Individual participants are not identified in the quotations from the group discussion in order to protect their identity. As both researcher and participant my selection of narrative sections and identification of beliefs and values were informed by my own immersion in the field. This could be seen as a sense check or member check (Lincoln and Guba 1985) and therefore a strength of the study, or as bias and therefore a weakness, but my contention is that my prejudgements have been openly recognised as far as it was possible for me to do so, and form part of the interpretive process. Readers may judge

whether they agree with participants that the findings represent a credible interpretation of the text presented. The findings are examined and conclusions drawn using insights from theory and research, and the context for the interactions is made plain so that readers may judge whether the findings have relevance to other situations.

There could also have been a concern that I had too much influence on the direction of the discussion because rather than being an equal participant I am also the researcher. However the evidence from the text indicates that the other participants were very capable of redirecting the conversation towards their own experience and the points they wished to make. An example of this occurred in the group discussion when I was initiating a conversation around the skills specific to nursing; the direction of the discussion was changed by another participant interjecting,

> *I know it's going a bit off tack but coming back to the doctor's attitude....(gp*
> disc 22 16).

The conversation was effectively steered by this participant at this point.

Ethical issues

Reflective professional practice has been used as an action research approach, particularly in education (Wong and Choong Kwai Fatt 2010), and where reflection on practice overlaps with action research, some have warned that ethical issues regarding the use and ownership of knowledge about clients need to be addressed as robustly as is the case for any other research process (Hargreaves 1997). In this case, I had no concerns about the possibility that patients would be identified, or that knowledge about them would be used inappropriately. All references to patients were anonymised and the reflection centred on the practice of the nurses rather than the characteristics of the families. I did have an ethical imperative to protect the identity of the nurses involved, because there are few nurses in this field and there might be a possibility that readers could surmise about the origin of various comments. This was addressed with the nurses and was the reason that I decided not to

identify which nurse made which comment in the group discussion. On one occasion the professional background of the nurse became obvious through her comments, so I did not reveal the participant number in this case.

There could have been an ethical difficulty if nurses had felt coerced or obliged to take part in the study, but neither I nor the participants, as far as was reported by them, felt that this was an issue in this case; although a colleague and a clinical leader I did not line manage any of the participants and our relationship was such that they assured me they felt free to decline to take part, but in fact they all looked forward to the opportunity to take time for reflection.

The study was subjected to the NHS research ethics process and both national and local requirements for research governance were satisfied.

Summary

I found in this methodology and these methods a vehicle to enable me to be fully involved in the present study as both researcher and participant, and a means to reach a fuller understanding of how these nurses work in preschool autism assessment. The method espoused by Kim (1999) also has the advantage of linking reflection on practice with an 'emancipatory project' (Habermas 1984). In this case, the 'project' which developed alongside the elucidation of what nurses feel they are doing in this field is one of consciousness raising among participants regarding their situation as health professionals in a particular social context, and reflection on how this affects their nursing actions. It may perhaps enable participants to develop their actual and potential role as nurses within this situation. However, the study is not aligned with an action research approach, because to go on and evaluate changed practice is not its aim: the research question is around understanding how the nurses practice at present. Critical reflective inquiry provided an appropriate vehicle for use in this context.

This chapter has outlined the reasons for choosing the methodology for this study, and I have explained in some detail the methods by which it was conducted, in order for the origins of the findings to be transparently evident to

readers. The next chapter begins the presention and discussion of the findings which emerged from the data, by considering the beliefs held in common by the nurse participants.

CHAPTER FOUR: NURSES' BELIEFS

The following three chapters present the findings of the study and relate them to existing literature. The beliefs (this chapter) and then the values (chapter 5), which underpin the practice of these nurses, are identified as they emerged from the data and their effect on practice is discussed. As the analysis progressed, issues around power and empowerment emerged as significant for the participants and appeared to influence the practice of the nurses, so a separate data chapter and discussion is included on this subject (chapter 6).

In this chapter, the beliefs about their role which emerged from the data as those held in common by the participants are each positioned within the context of current knowledge and understanding reflected in nursing theory and the literature. Beliefs are related to the nurses' comments, self reported feelings and actions-in-practice. The next chapter applies the same gaze to nursing values. The intention is that by exploring beliefs and values in some depth, their effect upon day to day practice, and any tensions or discrepancies between beliefs and values and how nurses describe their actual experience of practice in their narratives are elucidated. As Schon (1991) argues, there are often complex reasons why the actions of professionals in day-to-day practice do not correlate with their espoused ideals and theories. In critical reflective inquiry (Kim 1999), the value of bringing discrepancies to light is to enable participants and readers to progress from the description of practice and reflection on practice towards the critical/emancipatory phase in which practice may be improved.

Beliefs are conceptions of the world which the believer holds to be true, and if strongly held, they affect behaviour (Habermas 1978). For Habermas,

the definition of a belief is that we orient our behaviour according to it

(Habermas 1978, p.120).

For the purposes of the present study, the beliefs examined are those of the nurse participants, contained within statements concerning nursing and parents and children with autism which the participants hold to be true, and which inform their actions. These beliefs are part of the 'know-that' knowledge (Polyani 1958) they possess about the episode of care. According to Polyani, 'know-that' knowledge is the theoretical understanding which may be possessed but not consciously utilised as nurses go about their daily interaction with patients using 'know-how' or practical knowledge. In this study the data indicates these nurses 'know that'; autism is real; parents want 'perfect'; diagnosis is protective; diagnosis is the 'least-worst' option; nurses are knowledge-brokers; nursing is key. These are the beliefs which are explored in this chapter.

Autism is 'real'

These nurses share a belief that autism is a diagnosable medical condition or spectrum of conditions based on a particular pattern of variation from a valid set of norms around child development and behaviour, both of which are empirically based; but they also believe that there are 'grey areas' where the diagnosis, or the need for diagnosis, is not clear. There is a tension here which is reflected in the following comment,

> *Something like autism...unless there's changes on a brain scan or whatever, it's not black and white, is it?* (N1 disc 12 16)

N1 frames autism as a behavioural diagnosis, which is open to interpretation, and possibly to challenge. She differentiates a diagnosis of autism from diagnoses which are unequivocal and based on measurable biophysical evidence.

> *I reminded them about the triad of impairments ...*[child] *did at present have difficulties in all three areas.....the conclusion of the team would be that a working diagnosis of ASD would be the best way to understand his needs at the moment...* (N6 narr 5 23)

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Here the nurse uses the diagnostic criteria and attempts to engage parents with them so that the reason for diagnosis is transparent and shared. There is a hesitancy in "at present" and "at the moment" which may indicate an attempt to use a defocusing or hopeful frame to facilitate this negotiation of a diagnosis with parents, as observed elsewhere by Bartolo (2002).

Despite their reservations about autism as a definitive diagnosis for these very young children, the nurses subscribe to the concept of autism as a group of developmental disorders with strong genetic underpinnings (Lintas and Persico 2008; Miles 2011). They believe there is a biomedical explanation for the different way people with autism experience the world, possibly reflecting the widespread acceptance of neuroscientific claims which Ortega (2009) suggests presently reach all domains of life and mould identities throughout the developed world.

The participants believe that autism can be identified and diagnosed in the preschool years (Lord et al 1995; Cox et al 1999; McConachie et al 2005; Lord and Luyster 2006), and they go further to distinguish between different diagnoses within the autism spectrum in terms of patterns of behaviour they would expect and different ways of helping parents,

> *...children who present with Asperger's I find more difficult...autism presenting in children with LD (*sic Learning Disabilities) *I feel more comfortable with. I also feel comfortable advising their parents on their child's behaviour...*(N3 narr 2 5)

The nurses accept the current medical conceptualisation of autism, and despite being aware of the limitations of the diagnosis, still believe in its authority. N3 here expresses a belief that parents of children with a diagnosis of Asperger syndrome need specific advice which would not be appropriate for all children on the autism spectrum. This echoes the argument against the changes to the DSM which remove Asperger syndrome as a diagnostic entity (Baron-Cohen 2009).

Few educational courses about autism have been developed specifically for nurses (Barber 2001). The nursing press, nursing education curriculae and books about autism for a nursing readership have frequently supported the assumptions of the medical model (Thompson 2002; Morton-Cooper 2004; Scullion 2010). Not only have these nurses been taught about autism by doctors and psychologists, for example being trained in the use of diagnostic psychological tools such as the ADI-(R), but they are also embedded within medical and psychological assessment and diagnostic teams. It is therefore not surprising that in their accounts of practice they use terminology such as 'diagnosis', 'condition', 'symptoms' and 'behaviour difficulties', which suggest they view autism as a pathology, situated within the child. They have adopted the cultural narrative of the medical voice, and it might appear that they are one of the forces involved in the 'pathologising of difference' (Molloy and Vasil 2002). It has been suggested by Shaw (2009), in the field of learning disability, that the medicalised language used by nurses in stories about practice may be an attempt to justify the control exerted by health professionals. Learning disability nurses have been leaders in advocating for nursing care situated within a social or human rights based model of disability (Northway 2000; Camus 2008), but from the current study it appears these nurses adhere in practice to the medical model which informs the diagnostic team during the assessment and diagnostic process.

However, deviating from an essentialist view, the nurses in this study also give indications of awareness of the way in which autism is socially constructed (Nadesan 2005), and they were inclined to 'pathologise' only if the 'difference' was giving rise to distress for the child or family,

..it wasn't necessarily to diagnose or anything, it was to think actually let's just see what are we dealing with, what are the family's interpretation of it, because that's really important. (N5 disc 2 19)

*..labels are just semantics...its not always necessary. (*N5 disc 25)

..its not so much about a diagnosis, it's about what the child and family need. (N1 disc 7 6)

Therefore although the nurses operate in the context of a medical model, there are elements of their beliefs in practice which resist 'labelling' and align them more with a social model of disability, depending on their perception of the needs of the child and family.

In their daily work, these nurses are responding to a demand for assessment and diagnosis which comes from outside the team, reflecting a society which does problematise difference (Nadesan 2005). Children are referred for assessment because of parental concern, or following health visitors noticing atypical development and raising concerns, or because of behaviour identified as unusual or troublesome at nursery or preschool. The nurses believe it to be part of their role to take these concerns seriously and to be sensitive to what the parents are actually seeking from the team,

> *It was mum's worry. It was behaviour, at home...she could see he wasn't the same as other children, she could see he was similar to her niece, but not the same, and she was concerned...she wanted a diagnosis of what was wrong, that was the main thing.* (N4 disc 1 9)

This reflects the predominant position in the UK in the 21st century that there are valid norms in child development and that children whose presentation is atypical should be identified, categorised (diagnosed) and normalised (treated) as far as possible (Nadesan 2005). This is seen by some as a reflection of the ableism that characterises the societies of the developed world (Campbell 2009). Through a Foulcaultian lens the diagnostic team is an oppressive arm of a medical elite which seeks to exercise and maintain its power through discourses of normalism (Nunkoosing and Haydon-Laurelut 2012). However, many parents share the dominant view at the time of referral, and far from unsought-for diagnosis being imposed on children by a powerful medical team, parents consistently complain that it is delay in diagnosis of children with

atypical development which is a source of stress (Howlin and Moore 1997; Most et al 2006). According to mothers themselves, the longer the delay before parents' concerns are acted upon, the more stressed families become (Bingham et al 2012). This is partly because parents feel a need for the reason for the child's behaviour to be located within the child rather than within parenting (Gray 2002; Blum 2007). It is also because the reactions and behaviours which parents and others have identified as atypical (which may include sleeplessness, extreme temper tantrums, screaming, extreme anxiety, aggression towards peers) are causing distress both to the child and family. These nurses believe it is their role not only to listen to parents' concerns but to take time to observe the child alongside the parent,

...to her the difference was knowing that I was prepared to come and see it, I wasn't questioning that the behaviour wasn't usual, but the degree of it was quite severe. (N4 disc 4 18)

Early identification and diagnosis has for some time been prominent in government policy and guidelines as an imperative and a marker for good practice (Le Couteur 2003; Dfes/DH 2004; NICE 2011), and these have informed the development of the service within which these nurses practice. The day to day practice of these nurses reflects a belief that diagnosis is a gateway to recognition and acceptance of neurodiversity (Ortega 2009); that diagnosis can be the factor that releases the child from being problematised by the behaviours so that their underlying personality can be appreciated,

It's an explanation of symptoms, an explanation of behaviours (gp disc 10 3)

Yes it's an impairment, but it has good aspects, every time, no matter how severe (gp disc 10 7)

I like Dr ... he says this is your child's personality. (gp disc 9 29)

These comments appear to represent some resistance on the part of these nurses to the assumption usually associated with the medical model that identifying children as autistic amounts to a personal tragedy (Oliver 1996). It may be that the two are not inextricably linked, or it may indicate that these nurses hold dualist views. These nurses point out the positive attributes of the children in a way which has been identified as helpful to parents (Nissenbaum et al 2002; Harnett et al 2009). The attitude reflects the observation of McLaughlin et al (2008), in their work on identifying the sort of care that parents find enabling,

Recognising the child as a personality and as an identity, of which disability is a part, helps parents move from just seeing and experiencing burden and resentment. (p.61)

Parents want 'perfect'

These nurses believe that parents perceive variation from typical child development to be undesirable and that because of this perception, the assessment process itself is stressful.

It is a very hard thing to go through assessment, because no matter how hard you try to convince yourself as a parent that it's not as bad as it seems, when you are in the assessment and you witness the behaviour, it's really hard (N2 disc 2 26)

The literature consistently indicates that most parents of children who later receive a diagnosis of ASD notice that their child is different from the majority, and most raise concerns, before the age of three (Glascoe 1997; Charman and Baird 2002; Eaves and Ho 2004). However, the assessment and diagnostic process which follows identification has been described as a difficult journey for parents, involving re-imagining the child, deconstructing their previous picture and expectations, and reinventing the child and indeed the whole family in

another way (Avdi et al 2000). The diagnosis, once arrived at, may be perceived positively or negatively, but the process of 'othering' the child is frequently a painful transition (Nadesan 2005), and the "trauma of dashed expectations" (Landsman 1988 p.76) is real. In later work Landsman (2005) describes the way in which the mothers in her ethnographic study begin as subscribers to the medical model of disability as an individual tragedy, but later learn to challenge it. Parents, as part of society, are also likely to share the ableist assumptions which Campbell (2009) suggests underpin a perception of children with disabilities as less than 'perfect'. An awareness of these concepts is reflected in the nurses' narratives and in the subsequent discussions,

She'd talked about it through the assessment, but when it was actually raised as a real possibility, I could see she wasn't dealing with it as well as everybody else thought she was. Her pain was sort of coming out as they were talking about it. (N4 disc 1 19)

...she was very very tearful. Especially when he was out on the playground, which she could see quite clearly, even though the children who were at the nursery all had additional needs themselves, he really did stand out, quite considerably, with some of the things he was doing. (N1 disc 5 18)

Nobody wants their child not to be perfect, and you know yourself, if there's something wrong, even if it's something minor, your emotions just run free don't they? (N3 disc 7 18)

These three quotations demonstrate the nurses' belief that parents very much wanted their children to be developing typically, and their empathy with parents' emotional pain.

There is a tension for the nurses between their empathy for the parents' reluctance to accept that their child has autism, and their belief that parents will inevitably come to change their perception of the child to include autism,

...Well I knew she was very anxious, and I was being as reassuring as I could, without, you know...er... 'Oh you know he'll be fine, just speech and language, why are you worrying.'(N2 disc 1 23)

This nurse was aware that the parent's internal working model of the child (Oppenheim 2007) was changing, and she was trying to support the parent through the anxiety caused by the process, rather than encouraging her to resist it.

Nurses also believe that prompting parents to change their perception is best done by a nurse,

It's taking off their rose tinted glasses...
...but that's part of why we do it, because we do it gently... (gp disc 5 9,15)

The participant implied that a nurse would be 'gentler' than another professional in this process, but it is not clear why this should be so. Glaser and Strauss (2005) discussing disclosure of the news that a patient is dying, posit

gentleness may be accomplished by delegating disclosure to the nurse... (p.148)

Glaser and Strauss made the assumption that the nurse would be female and the doctor male, and apparently also assumed that a woman would be more gentle in approach than a man, but they did not offer evidence on which to base either assumption.

Breaking significant and stressful health news to a patient has been described as 'a gentle art' (Stott 2007) but again, there is no evidence that nurses have a monopoly on gentleness.

However, although they expect the parents to find assessment stressful, the nurses do not believe the diagnosis, once arrived at, is always 'bad news ' for a family,

Researcher: *...we all assumed this would be bad news for the family, right?*

Participant: *No, not necessarily*

Participant: *Relief or grief...* (gp disc 9 16)

Not poor parenting, not something I've done or did in pregnancy, or didn't do when he was a baby...so although they are sad, they are often...well not often but sometimes...there is a cause, and this is it, and you know we can do something to help him. (gp disc 9 21)

This is borne out by Landsman's study (2005), where parents of children with autism were an exception among parents who found a diagnosis of permanent disability hard to accept, in that they sometimes welcomed the diagnosis because although it 'othered' the child, it exonerated the parent from blame.

There is no evidence that these nurses believe they should encourage parents to accept a gloomy prognosis for their children, as has been observed elsewhere (Gray 1993), or that they believe that parents who do not express grief or a bereavement reaction after diagnosis are 'in denial', as others have found (Darling 1979; Larson 1998). On the contrary, there is dissonance between the nurses' personal belief and nursing action in that although nurses are personally sometimes apprehensive about the implications for the family of raising a child with autism, and they personally share the parents' assumption of the dominant 'tragedy' discourse around autism (Oliver 1996), they nevertheless offer a hopeful construction of the diagnosis to the family. This might be seen as a taking a stance of resistance to the tragedy model.

...I was worried cos I could see how the child was and I could see this little family and thought how on earth will they cope with this situation on top of what they've dealt with already ... (N2 disc 2 8)

I think you focus on the positive elements of the condition, especially with your high functioning ASD...you know, like sometimes the intelligence, or the ability to structure...you pull out all the positives, because when they

come to the medical appointments you know it's all the negative list, and it's
like ok let's see the positive list, so you're giving them the other side of it
(gp disc 10 12)

The nurses could be said to be taking a 'counter-ableist' stance as described by Campbell (2012),

> *a counter-ableist version of impairment might explore what the experience*
> *of impairment produces and ask how does disability **productively colour***
> ***our lives***? (p.216) (original emphasis)

There is again a dualism in these nurses' beliefs about autism. They personally perceive it as 'bad news', but in their role as nurses they present a counter-ableist view to parents. This dissonance could be said to be positive in that despite their personal beliefs, nurses are nevertheless able to act in the way parents say is helpful, delivering 'sensitive, honest communication, which maintains hope' (Kearney and Griffin 2001). Through the dramaturgical lens (Goffman 1956), in their frontstage performance of their role as nurses they deliver the script they believe parents need to hear, although backstage they express personal doubts.

 Chambers and Narayanasamy (2007), in their discourse analysis of nurses' constructions of health, identify dualist accounts of health and attitudinal fragmentation as the personal beliefs of nurses conflict with those taught as part of socialisation into a nursing role. They conclude that for nurses to truly adopt a social model of health within which to work, nurse educators must be aware that primary socialisation into an individual or medical model is more
enduring than secondary socialisation through education. They suggest that in nurse education, nurses' lay formulated beliefs should be exposed and interrogated by reflective learning strategies so that alternative ideological models may be consciously applied and adopted.

 Some nursing models of the person and of health support a stance resistant to normalcy, particularly those which envisage the person as an adaptive system interacting with others, and health as a process of adaptation or

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personal and interpersonal development towards individual and group potential (Roy 1999; King 1981; Peplau 1988). There is no evidence here that the beliefs of these particular nurses are consciously informed by such models, or that their actions in practice are affected by reflection in the light of them. However it is by no means inevitable that nursing should be aligned with normalcy or ableism, as those who do take a counter-ableist stance are supported by theories of nursing such as those mentioned.

Diagnosis is protective

These nurses believe that without a diagnosis to explain them, there are negative consequences for children with unusual perceptions and behaviours. They face distress at school entry resulting from being placed in an unsympathetic school environment; families face difficulty in understanding, and are frequently blamed for, the atypical behaviours of their children; and these stresses sometimes lead to family breakdown.

> *No, we don't want to stigmatise. We're trained in that way...labels are semantics...but I felt actually on this occasion...in relation to him starting school and things like that, a label would actually benefit him in his education as well as in his family life. Because the family was breaking down, and there was a family support worker...who I felt was just labelling parents...he was 'naughty'...'they just don't know how to manage a four year old'. (N5 disc 5 25)*

Parents report feeling blamed, and sometimes blame themselves, when children do not behave in ways society has come to regard as acceptable, and for some this is the reason that a diagnosis comes as a relief and a protection from guilt (Gray 2002; Blum 2007; Midence and O'Neill 1999). This is reflected in the nurses' comments,

...there are many families in which the child just doesn't interact, and the diagnosis is a relief because they feel it's not their fault, for not parenting adequately. (N3 disc 8 3)

...she didn't seem to be aware that there was an autistic kind of trait, she just thought it was speech, and then it came out that she was terrified that [it was] *because he'd rolled off a changing mat, and she was worried about neglect on her part, that she could have caused it.* (N2 disc 1 19)

Nadesan (2005) traces the development of the concept of normality in children in the first half of the twentieth century, and relates it to the drive to ensure the new generation grew up healthy and therefore economically productive. Not until the expansion of the scope of child psychiatry at that time could children with autism have been brought into the diagnostic fold at all. Although some would see the expansion of pathological categories such as 'personality disorder' as an oppressive act (Foucault 1965), Nadesan reminds us that without the protection of a medical diagnosis, children who deviated from accepted behavioural norms were simply labelled 'troublesome' (Nadesan 2005,p.70). There may be parallels with the current economic and social environment, in that there are similar pressures to produce a healthy workforce, and to do it with as little expense as possible. There is a neoliberalist trend towards a market approach to human services which has been found to be problematic for families of children with disabilities elsewhere (Swenson 2008). Mallett and Runswick-Cole (2012) describe the process of assessment and diagnosis of autism using tools such as the ADI-R in terms of abstraction, so that autism is caused to exist as a 'thing' and to be commodified for the market. Possibly this is necessary in a society where health, education and social care are subsumed within in a market driven economy. In difficult economic times, for example, when children are expected to fit in to the kind of school system which suits the majority, any who deviate are problematised. Recently there has been a retreat from the level of universal child surveillance of the last few decades, and the government has instead placed the onus on parents to seek

medical help if their child does not develop as expected. 'Parent blaming' for children's atypical behaviour is still evident, and it may be that these nurses try to protect the families from having their parenting abilities examined and judged, by encouraging diagnosis,

> *So, I just think this family didn't need putting under the microscope, as if they'd done something wrong...* (N3 disc 6 8).

The dissonance between the nurses' belief that the autism label can sometimes be stigmatising in itself, and their concomitant belief that the label is necessary if the family is to avoid stigma, is reflected in a paradox in the literature: Gray (2002) described the persistence of stigmatising attitudes in society towards individuals with disabilities and their families; while Farrugia (2009) found that a child's diagnosis of ASD was critical for parents seeking to resist stigmatisation.

Diagnosis is the 'least worst' option

These nurses agree in their belief that, although possibly stigmatising, diagnosis is the 'least worst' way forward for these children and families, giving access to understanding and appropriate support, as well as avoidance of blame,

> *...because there's nothing more distressing or hurtful than to see your child in total and utter distress at the environment they're in* (N1 disc 8 1)

The nurses' attitude to diagnosis appears to be equivocal, with awareness of the possibly negative effect of labelling on the family, but the nurses' unease about being involved in the diagnostic process is overcome by pragmatism. They believe diagnostic criteria are robust, and certainly where the child has classic autism they are not concerned about a negative effect of diagnostic labelling on the family, but about the effect on the family of living with a child with the condition,

I came away from the visit very worried as I could see [child]*'s difficulties were looking like a spectrum disorder and wondered how* [mum]*...would cope with the diagnosis and its long term implications.* (N2 narr 1 29)

...its empathy with her really...he's a big lad...a big young man, and you know this ever increasing chick...and he does have some challenging behaviour (N2 disc 4 22)

There is an awareness of the perception of stigma around diagnosis that some parents felt,

[the doctor asked parents] *if they agreed that a working diagnosis would fit* [child]. [father] *said yes, for now, but he also said "I want to know, if he gets better, he won't have this on his record for ever." I cringed inwardly at this! It sounded perjorative, and reminded me how negative a label can be. I hoped I had not said anything that would have reinforced the family's assumption that to be different was to be 'wrong', but it is the way most people look at difference.* (N6 narr 6)

However this awareness is outweighed for these nurses by their belief that without a diagnosis the children and families would be blamed and would not get the help they needed or an appropriate school environment. In the one case described where parenting support and schooling was already appropriate because the child had already been accepted into a specialist school where parents felt his needs had been met, the diagnostic label was seen by the nurse as negotiable. She did not see diagnosis as necessary to the extent that it needed to be imposed on an unwilling family, despite her own opinion that the diagnostic criteria had been met,

...I mean you could read through that [the child's file] *and think how ridiculous that child hasn't got a diagnosis, but tell me what would have been different, for that child now, and that family, if he had got a*

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diagnosis...nothing...because the way the communication systems are
put in, the way he's spoken to, the way his whole day runs, is because he
probably is on the autism spectrum, but all of that is taking place without him
having a diagnosis. (N1 disc 12 22)

The nurses believe that access to early intervention is vital and that if a label is needed in order to gain access to this support and information, then diagnosis is necessary even if it causes upset to parents initially. Most of the nurses were, at the time of the study, also engaged in delivering early intervention and parenting education and empowerment programmes to parents of preschool children with an autism diagnosis, and despite the paucity of unequivocal evidence of long term effectiveness of early interventions (Bryson et al 2003; Keen et al 2010; McConachie et al 2005a; Mills and Marchant 2011), the nurses are convinced by their own experience of parent feedback that the families benefited from the programme. These nurses are not suggesting the interventions 'normalise' children, but that they enable families and children to understand each other better,

> *...I always remember doing an EarlyBird course where there was a mum*
> *going 'well he doesn't communicate at all – he just does not*
> *communicate'...and I can't remember now but I think it's week 4 on*
> *EarlyBird when we do communication, and afterwards she was in absolute*
> *floods of tears... '...he DOES communicate, he communicates ALL the*
> *time...'* (gp disc 10 17)

There is also a perception that diagnosis is necessary politically and economically, as resources for children with autism and their families would not be made available without evidence of the existence of this group of the population and their claim for equality and justice,

> *...even if it's negative we do still need the DSM and ICD10...because*
> *otherwise we have lost input from government for funding, for*

acknowledgement, for training, because it's not a disorder...the negatives of diagnosis, there are some, but if we don't have a diagnosis and a disorder, and notification of that, we have no prevalence, and without prevalence we don't have training, we don't have support groups, we don't help parenting...so we do need, as harsh as it sounds, to tick a box on the ICD 10 (gp disc 10 29)

The nurses here experience some dissonance between their reluctance to pathologise young children, and their perception that diagnosis is a 'necessary evil' and the 'least worst option', given current social and political realities, reflecting the view of Landsman (1998) who observed similar tensions in parents. Overall, nurses take a pragmatic approach which echoes Ryan and Runswick-Cole (2008) who then, as both parents and academics, took a similar line, suggesting that the search for diagnosis by mothers does not represent an unquestioning acceptance of the medical model of disability, but a way of negotiating the best possible outcome for individual children.

Nurses are knowledge-brokers

These nurses believe that although parents know their child better than professionals, nurses have specific information and practical expertise around autism, which they have a professional and moral responsibility to share with the parents.

My intention is to pass on the skills, and to help them have the sort of life they want to, to the extent they can...get along...go on holiday, ordinary things... (N4 disc 6 22)

There is a belief among these nurses that any information professionals have about the child, including their framing of the child as autistic, rightfully belongs to parents, and that the professionals have no right to withhold their opinion even though parents might find it hard to accept. The NMC code states,

You must share with people, in a way they can understand, the information they want or need to know about their health (NMC 2008 section 12).

This reflects nursing values of honesty with parents, and parent empowerment, which will be discussed later (page 120). However, the belief that parents should be encouraged to share the knowledge possessed by professionals includes changing parents' perception of the child accordingly, which could be seen as manipulative or oppressive. When challenged about this in discussion, the nurses voiced robust opinions,

...it's about empowering them to hypothesise themselves, with the evidence you are presenting...I mean instead of giving them a paragraph saying 'does this describe your child?', you are planting seeds for them to come up with their own conclusions...so you're not manipulating, you have all the knowledge, and it could be seen as more manipulative if you then just read out your paragraph and you forced your hypothesis on to them. (N5 gp disc 4 1)

Nursey (1991) describes how after assessment, professionals possess knowledge about the child of which parents are unaware, and they use their discretion in deciding how much information to share and when. The description of the nurse 'planting seeds', above, depicts the nurse controlling the flow of information about autism during assessment in such a way that the parent comes to the same conclusion as the professionals. This is influenced by the nurses' belief that before diagnosis, parents, like most of the population, regard autism as a 'tragedy' and the diagnosis would be a blow to the family so information should be shared sensitively.

...but I would say you don't have to say the words? You can say we're looking at these difficulties, these behaviours, go all ways round saying it and eventually come up with the words...when they're ready for it. (gp disc 9 10)

I asked [mum] *and* [dad] *whether they had any further thoughts about the next stage, and* [dad] *replied, a little aggressively "well, you think there's something wrong, don't you?"* (N6 narr 3 34)

I didn't ever not share anything with them, so I did actually talk about...the triad of impairments....I also felt they were intelligent parents and I could lose them through not sharing information with them, although I had to be careful...

Researcher: *what were you careful about ?*

That I wasn't damning their child....(N1 disc 4 15)

In common with others (Avdi 2000; Nissenbaum et al 2002; Hodge 2005; Osborne and Reed 2008), the nurses believe that the way information is shared with families could influence their perception of the diagnosis, their interaction with professionals in the future, and ultimately, their relationship with their child,

... if they'd gone in to see a paediatrician first, and the paediatrician had talked about a diagnosis of ASD, it could have shut the family down (gp disc 4 8)

The dissonance resulting from the possession of knowledge and the unease with the power that gave the nurses will be addressed in the discussion of parent empowerment (page 120), but it is clear from nurses' comments that they believe the knowledge they have is real and that parents need it. They do not see their role in terms of manipulating parents to collude in the 'othering' of their child, as it might be regarded by critics of the medical model, but in terms of fulfilling their obligation to share information and to be honest with parents.

There was no evidence to indicate that the nurses were or were not aware of the debates around whether the autism spectrum represents different expressions of a common underlying disorder or separate entities (Baron-Cohen 2009). They appeared to have confidence in the information they shared with parents. This is particularly the case with information and expertise around

understanding why children behave in atypical ways and in encouraging communication. These nurses believe that parents were asking for help managing difficult behaviours, that they needed to be taught how to interact with their child and that nurses could do this,

> *...I suggested assessment would explain more and perhaps lead us towards a diagnosis if that was necessary, but that in the meantime we should work on communication.* (N6 narr 4 24)

> *I don't think I've ever gone into a family home...and they've not had some problem there and then with the child and how he behaves. I don't think there would be any case where there's no concern...*(N3 disc 4 9)

> *...the nitty gritty, how do they manage on a day-to-day basis with their child, obviously I can link them into support groups and things like that, but it's about how they are every day.* (N4 disc 6 25)

These nurses, then, are confident in a belief that children with a diagnosis of autism have in common certain ways of experiencing the world and reacting to it, which could cause distress to children and difficulties for families; and they are confident that the knowledge they possess based on autism specific training, is something they have a responsibility to pass on to parents. This creates some dilemmas for the nurses, given their equivocal stance on diagnosis, but again they take a pragmatic view, that even before diagnosis they will seek to help parents to improve interaction and daily life with children, while encouraging parents along the road to assessment and diagnosis and thence to appropriate schooling.

Nursing as key

These nurses believe that nurses have a unique role in the child health team which involves working with parents in a way which positively influences the

parent experience of assessment and diagnosis. First, they believe that interactions between parents and professionals affect the way parents feel,

I think any contact affects the way parents feel about future diagnosis or future interventions. (gp disc 7 30)

Secondly they believe that nurses interact with families in a distinctive way,

[nurses] *...they've got a very wide area of assessment skills, observational skills and medical skills...I think that's why a nurse would be more suitable than any other discipline at that point, because the way they gain information, in assessing, is I think a fundamental skill to nursing* (gp disc 2 3)

These nurses believe they offer a skill set and way of interacting which is distinct from every other profession. As an 'insider', I am aware that the broad range of knowledge and skills they possess, in addition to core nursing training, includes education in typical and atypical child development, family dynamics, counselling, parenting skills training, behaviour management, and an understanding of the expectations of early years education settings. They are also skilled in the use of specific assessment tools for autism and in strategies to promote communication and social interaction. They believe the particular combination of values which are discussed in the next chapter (knowledge development, the centrality of the nurse-patient relationship, empathy, respect, advocacy, honesty, parent empowerment and holistic care) make nursing intervention particularly appropriate in the context of preschool assessment, diagnosis and early intervention. The belief in the uniqueness of nursing is shared by all the nurses, although they came from a range of nursing backgrounds,

...it was like key working...you're gathering your evidence from the start, you assess it, but then you are involving...and signposting to the right people...

but you're not letting go at the same time, so they've got the continuity, so it's seeing something through to the end, which I think a nurse does extremely well. (N5 disc 10 21)

Sometimes you see once the initial assessment's over, the parents need help with the plan, and I think the nurse is the right one to work in that house. (N4 disc 2 15)

I suppose the difference is for a nurse I think... they don't always have to plan for everything...they're very good at going off-spec, having the knowledge and tools to deal with what's presented to them, whereas other disciplines are quite regimented. (N5 disc 9 6)

There is within their comments a passion for their profession which appears to include a sense that they feel their skills are undervalued by other professionals,

Nurses ...are seen as a generic dogsbody...anything that doesn't need a specialism goes to a nurse...but actually, we get the complex ones...you know, the others are strict about their referral acceptance. (gp disc 18 2,7)

...because the doctors don't always understand what we can do, they see us as the dogsbody, mopper-upper, but actually, we can input from very early on. And those doctors who understand that can get a heck of a lot from the information we have collected. (gp disc 22 16)

The nurses express a belief that at the heart of the role of the nurse in this context is the nurse's orientation to the perspective of the family as well as the child, and the holistic care they offer as 'key workers' with an enduring responsibility to the child and family.

...you pick up whatever the need is and you work with it...it's impossible to

look at that family and say you've only been referred for this problem...(gp disc 18 20)

There is some indication of a power differential within the teams which puts nurses at a felt disadvantage vis a vis doctors (even when the nurse was officially the team leader). There is a sense that because nurses want to collaborate within teams, and also because they acknowledge and respect the expertise of the paediatricians, they accept their traditional subordinate place in the professional power hierarchy; but they are not content for their view to remain subordinate when they have confidence in their judgement,

I think I felt that my opinion wasn't being listened to, a medic who had never met this family was making a statement and they were listening to that more than actually seeing the evidence I'd collated...I'd spent time 'cos I knew I'd have to argue it. (N5 disc 4 3)

The power relationships between nurses and doctors are complex, have been discussed elsewhere, (Benner et al 1996; Freshwater 2000), and will be visited again in the chapter on 'Nurses, power and empowerment' (page 109), but the discomfort felt by these nurses indicates an underlying belief that they have a unique body of knowledge which is complementary to but should not be subordinate to the body of medical knowledge. This uneasy collaborative interface between professions is not unusual in multidisciplinary teams (Hanson et al 2000), and the power differential has an effect on the service delivered to children and families (Hudson 2000). In this study, the nurses demonstrate some dissonance between a belief that they possess a unique field of knowledge and range of competencies which enables them both to contribute to the diagnostic process and also to support families as 'key workers', and a belief that historical professional hierarchy and status assumptions continue to operate and have to be negotiated rather than directly challenged.

In this chapter the beliefs held by the participants about their role with parents and children undergoing assessment have been explored. The key beliefs emerging were; that autism is 'real', and diagnosis valid; and that parents, who also subscribe to this essentialist view, find assessment and diagnosis stressful because they view children with a diagnosable condition as less than 'perfect'. These nurses believe diagnosis to have a protective function for children and families and to be necessary for access to understanding, support and intervention, so despite their equivocal feelings about diagnosis and concerns about stigmatising families, these nurses believe diagnosis to be the 'least worst option' for families. They believe themselves to have knowledge about autism which it is their professional and moral duty to share with parents, and they believe that parents should be encouraged to accept and share the framing of their child as autistic, so that communication and behaviour issues can be addressed by autism specific interventions. These nurses believe they have a unique professional skill set which enables them to carry out a particular role in the assessment team, complementing the roles of other professionals.

Nursing knowledge has been defined as knowing that is in a form that can be shared or communicated with others (Chinn and Kramer 1999). This chapter contributes to nursing knowledge by identifying and communicating the beliefs held by a particular group of nurses in child health, including elements of each pattern of knowing (Carper 1978), and positions them within an analytical theoretical framework. It highlights the dualist views about autism held by these nurses, and suggests that nurse education could promote the adoption of a social model of disability by exposing this dissonance in beliefs to critical reflection.

Beliefs are affected by personal and professional values, which in turn are underpinned by ethical standards and assumptions which may be informed by models of nursing. The next chapter aims to uncover the values and standards which inform these nurses' beliefs.

CHAPTER FIVE: NURSES' VALUES

Values held by members of a profession have been defined as "standards by which our actions are selected" (Mason et al 2010, p.71). According to the International Council of Nurses (2012), the nurse demonstrates professional values such as respectfulness, responsiveness, compassion, trustworthiness and integrity. Snellman and Gedda (2012) describe the 'value ground of nursing' in terms of trust, nearness, sympathy, support, knowledge and responsibility. Alongside beliefs, nursing values affect the way nurses conceptualise their role, so understanding the values underpinning the beliefs and actions of these participants will help to address the research question, 'what is the role of the nurse during assessment of preschool children for autism?'

This chapter explores and enlarges on nursing values which were identified in the analysis of participants' accounts of practice and in the discussions. These are: developing nursing knowledge; the nurse-patient relationship; empathy; respect; honesty; advocacy, and holistic care. The other value to emerge, that of patient empowerment, was found to be embedded in the concept of power, and is discussed separately (page 109). In this chapter the values these nurses hold are related to nursing values acknowledged in professional standards as underpinning good practice, and to models of nursing. The values espoused by these nurses are also related to principles of biomedical ethics (Beauchamp and Childress 2008) which may underlie them. Tensions which emerge between these nurses' espoused values and their actions in practice are discussed in this chapter.

Developing nursing knowledge as a valid body of knowledge; the nurse has a responsibility to develop and improve her own nursing knowledge and practice.

...I felt comfortable to advise freely knowing that it might sound ad hoc advice but it was researched and from...you know, the triple P or from a research background, it wasn't just willy-nilly advice (N3 disc 1 25)

I think as nurses we constantly reflect on our own practice because we want to constantly improve...if I'm not a good practitioner, I'm actually abusive to that family, because there's something I'm not doing right (gp disc 16 12,17)

The data makes clear that these nurses feel personally responsible for delivering a good standard of care based on up to date knowledge to the children and families. The Nursing and Midwifery Council (NMC) code of practice states,

As a professional, you are personally accountable for actions and omissions in your practice, and must always be able to justify your decisions. (Introduction)

You must deliver care based on the best available evidence or best practice. (Standard 35)

You must keep your knowledge and skills up to date throughout your working life. (Standard 40)
(NMC 2008).

There is an onus on nurses in the code to ensure they work within their 'scope of practice', and level of competence, and the participants have worked to acquire relevant skills. All the participants are qualified nurses and all have further post registration training in a field relevant to child development and autism. Three have further qualifications as health visitors, one as a paediatric nurse, and one as a school nurse. One nurse has an advanced diploma in child development, two have masters level qualifications in autism and two are ADI-R trained. All have training and experience in assessment and early intervention for children with autism, including EarlyBird (Shields 1997), Portage (Cameron 1997), behaviour management and sleep counselling. The psychiatric nurse is qualified in family therapy, and others have counselling training.

However, there is, in the UK, no recognised academic route specifically to prepare nurses wishing to specialise in child development or autism, and no national job description or competency framework directly pertaining to this role. The specific body of nursing knowledge or skills that these nurses bring to their work is not easy to identify. This is not unique to this field; Mitchell (2004) suggests that learning disabilities nurses gain their identity from their client group because there is no body of knowledge which is specific to them. However the analysis of data from the present study suggests that it is the combination of a broad range of skills and expertise, including skills learnt from other disciplines, delivered through a relationship of care, which is a strength distinct to nursing, rather than a narrow area of specialism,

> *I think its the combination of the assessment skills and the underlying family support...*(gp disc 6 17)

> *...a lot of disciplines don't feel they can learn off anyone else...whereas I think nurses have a complete openness to want to absorb from lots of people, not just other nurses, but everybody* (gp disc 16 29)

This echoes the view of Virginia Henderson (Henderson 1978), whose definition of nursing (Henderson 1966) has influenced nurse education not only in the

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USA but also in the UK for many years. Henderson (1978) suggested that as well as a sound knowledge of anatomy, physiology, nutrition, microbiology, chemistry and physics, nursing students needed a grounding in social sciences, including human development, psychology and sociology, anthropology, government and economics; also an appreciation of how history shapes the present day, and an understanding of a wide range of philosophical positions, world views and religions. Henderson recommended that nurses study these subjects in the company of students of other health professions in order to develop an appreciation of their differing contributions to health care, and most importantly, insisted that nurses should develop the 'habit of inquiry' so as to be prepared to continually develop and widen their knowledge base. It appears that these nurses are continuing this tradition.

Nursing theory also offers insights into the specific knowledge nurses bring to their work. Carper (1978) describes four fundamental patterns of 'knowing' in nursing: empirical knowing, the science of nursing; ethical knowing, the individual's moral compass applied to nursing; aesthetic knowing, understanding the meaning of the episode of care for both patient and nurse (the art of nursing); and personal knowing, becoming self-aware in order to be able to use the self therapeutically. The conception of nursing knowledge as involving a synthesis of all four forms of knowing is reflected in Peplau's conception of 'the art and science of nursing' (Peplau 1988) which was recollected by these nurses in discussion and which may underlie this nursing value,

> ...the art and science of nursing, I remember (gp disc 15 16)

> I remember that one... (gp disc 15 17)

However, the one nursing model these nurses remember from student days to the extent that they can name it is that of Roper et al (1980).

Researcher: *Can any of you actually remember any nursing models that you were taught back in the day?*

(four nurses together*) Roper, Logan and Tierney!!*

...you must remember activities of daily living! (gp disc 13 5,6,9)

This model includes a tool for assessing a patient's ability to perform activities of daily living independently, and if that alone is retained by students, it could be said to promote a positivist, medical model of assessment. However, the Roper-Logan-Tierney model, as it is known, is based on the way in which five factors affect health: biological, psychological, sociocultural, environmental and politicoeconomic. The model is a biopsychosocial model, but the extent to which it influences nurses to think differently from a medical model will depend on the way it is taught, retained and used in practice.

In practice, there are constraints on the way the nurses work within teams and the extent to which they are able to develop or exercise their nursing skills, which will be considered later in the discussion around power relationships in this field. The extent to which a biopsychosocial nursing model will prevail over a medical model in multidisciplinary team culture is not within the scope of this study to explore. However, there is a tension here between the nursing value of giving excellent care; the nurses' belief that they give care based on research evidence and a broad knowledge base; and the way they feel they are perceived within the team,

> *...We are (thought to be) a Jack of all trades*
> *...Master of none?*
> *...Yes but actually we always get the complex ones...* (gp disc 18 5,6,7)

The nurses feel that their breadth of field and ability to adapt to the priorities of the family, to "pick up whatever the need is and work with it" (gp disc 18 20) is

one of the strengths of nursing. They contrast this with the way in which they perceive other professionals work with families according to the agenda of the professional,

> *...that is where perhaps it is a nursing thing, because we're not going in saying we're here to do abc and d...*

> *There's lots of research about scripted consultations, isn't there, and generally, not to be disrespectful, but doctors do generally have a scripted consultation.*   (gp disc 19, 13 15)

The participants express a confidence in their knowledge and their ability as nurses to address the priorities of families, particularly in the pre-diagnostic stage; their observations of each other's practice apparently stimulating their reflections and reinforcing their confidence,

> *...when I've worked with S on a home visit, I find it fascinating, and I think a) I hope I portray those same skills, and b) if I was that family, I'd want that visit.* (gp disc 16 1)

The comments reflect Beauchamp and Childress' (2008) ethical principles of beneficence (to do what is best for the patient) and non-maleficence (to do no harm by giving less than excellent care), which are shared by most 'caring professions'.

The nurse-patient relationship as core to nursing.

This reflects the view expressed by these nurses that holistic care for the child under assessment entails working with the whole family, and for most of them, the family becomes the 'patient',

Researcher: *Who is your patient?*

Participant: *The whole family really...I don't think you can actually split...the parents, the actual child, and the siblings.* (gp disc 6 18)

There is some difference between the nurses on the use of the words such as 'patient' which indicates an appreciation of the significance of the language used to define a child (Nadesan 2005). As the following exchange shows, the assumption of some of these nurses is that 'patient', which medicalises the child, is a more benevolent and respectful term than 'client', which implies for one participant overtones of impersonality or exploitation. However as the nurses interact in group discussion, they agree that simply to refer to 'children and families' is more appropriate. In this instance the various participants have been distinguished by a number in order to clarify the interactive quality of the conversation;

P2: *Can I put in here, how glad I am, throughout this conversation, nobody has said the word client or service user!*

[general laughter]

P4: *Families and children!*

P3: *Families and patient...*

P2: *Patient is what we're talking about, yes.*

P6: *Why is that....?*

P5: *It sounds wrong, service user....*

[general agreement]

P3: *I always think it sounds like Skinners rat if you say client...an object for experimenting on!*

P2: *Hate it!*

P5: *And how would you feel yourself, you know, if you was termed 'client'?*

P6: *Well I think originally...it's like using words like handicap isn't it? Originally it was in order to give them power, but it's gone full circle now hasn't it, and it's sort of...*

P5: *Sort of insulting!!*

P4: *I never say patients, but I would say the families I work with, or the children I work with.*

P2: *Yes, yes, absolutely...*

[general agreement] (gp disc 14 5 – 22)

The exchange is a demonstration of the way in which critical reflection in a group can enable nurses to be more aware of their actions in practice (Kim 1999), but in this instance it did not go further to explore the implications of the use of this terminology on the relationship between the nurse and the families. I later reflected that if the discussion had been part of an ongoing series of reflective practice sessions, the meaning of medicalising discourse could have been more fully explored.

The relationship described by these nurses involves a personal moral responsibility to the child and family which outweighs responsibility to the team or the employer. This is exemplified by the way in which most of these nurses feel morally responsible to respond to families long after they have been discharged from the service,

> *...if that person phoned in two years time and asked to speak to me I would deal with that...* (gp disc 7 13)

The responsibility of the nurse towards the child and family described here does not depend on the quality or depth of the relationship, but the fact that it exists.

> *...even if there wasn't a lot of contact and a really good relationship there, I'd still take it on as my responsibility* (gp disc 7 14)

There is evidence from this study that these nurses do not overestimate their importance in the eyes of families, and they are willing to adjust their availability to the needs of the individual families,

...I wouldn't say all of them were there to build a relationship, as such, but I think there had to be a point of contact for them within the team, and I was the most approachable point of contact. (N3 disc 5 21)

It does seem from the study that the nurses 'need to be needed' to some extent. The nurses are happy to let families move on after intervention, and in fact have as a nursing aim that families learn new skills and exercise them independently,

...if I've done my job right, she will naturally grow away from me because I've given her the skills...to manage the behaviours.(N4 disc 6 13)

However where families do not express a need for nursing help at all, it leaves the nurses uneasy and unsure of their role,

*I felt inadequate as this family appeared to be managing so well (*N3 narr 2 24)

I felt there was some hostility towards me as a health professional, which was uncomfortable (N6 narr 21 2)

This reflects a central theme of many models of nursing, which is that nursing responds to a patient's felt need, rather than imposing itself on another human being. To Peplau (1988) for example, a patient is an individual with a felt need; to Henderson (1966) the patient is an individual who requires help towards independence in health; to Roy and Andrews (1999) the patient is a person who needs help in adapting to a threat to his or her health or wholeness,

...nurses promote the right of individuals to define their own health-related goals and seek out health care that reflects their values. (Roy and Andrews 1999 p.64).

It is unsurprising that with such models of nursing informing nursing values, the

participants feel uneasy when patients are not asking for help, and are then unsure how to initiate and develop a relationship with the family, without which they feel unable to nurse effectively.

The nurse-patient relationship is a central theme of many models and theories of nursing, one of which, via the concept of the 'art and science of nursing' (Peplau 1988) was recalled by the nurses in discussion and, as has been suggested, may have also helped to form their values around nursing knowledge.

To Peplau (1952) the nursing process is by definition both interpersonal and therapeutic. The patient is an active partner in goal setting. The nurse-patient relationship moves in stages from orientation of nurse and patient to the 'problem'; identification of the meaning of the problem to the patient; exploitation by the patient of the resources offered by the nurse; and finally resolution or achievement of independence from the nurse, who has been the 'maturing force' or 'medium for change'. Other examples of the centrality of the nurse-patient relationship for nursing theorists include Travelbee (1971), who describes nursing as an interpersonal process in which nurses are involved in the 'therapeutic use of self' to help the patient, which could be an individual, a family or a community, to deal with and find meaning in their situation. The nurse-patient relationship is at the heart of Watson's (1994) view of nursing for a postmodern era, of Campbell's (1984) description of the nurse as the 'skilled companion on the illness journey', and of Kitson's (1966) 'we'll be there for you' slogan for nursing. As health care environments have changed, reducing the opportunity for long term, trusting relationships between nurse and patient to develop and progress in a linear fashion, Hagerty and Patusky (2003) suggest a revised framework for nurse-patient interaction. Their model is based on the theory of human relatedness, and would support brief but effective interactions including a greater emphasis on reciprocity and mutuality.

However it is conceptualised, there are few if any models of nursing which do not hold the nurse-patient relationship as a central concept, so it is hardly

surprising that it should be one of the underlying values and assumptions of the nurses in this study.

The nurses here articulate a high emotional cost to them of commitment to a relationship with families, and also a cost to them in terms of prioritising the needs of children and families over time for their own education, personal development, and off-duty time. This nursing value has an ethical dimension, which the nurses consider is unique to nursing. As they put it,

> Researcher: *So it's this thing of the patient...*
> [ALL in chorus]: *Comes first!!* (gp disc 25: 24, 25)

There are some differences between the nurses in relation to this nursing value, in that for the psychiatric nurse, the child is the patient, and the family takes second place although they are valued because of their primary effect on the child. The same nurse reported that within her team, the nurse-patient relationship was only expected to continue until the end of the episode of care, and patients phoning the service after discharge would not necessarily be seen by the nurse they had previously known. For the community paediatric team nurses, the patient is the family, and the family unit including the child is the main focus of the nursing intervention, as the nurse seeks to positively influence outcomes for the child by working through the family. This difference in culture between the community paediatric teams and the mental health team was quite marked. It would be interesting to explore whether this reflects different internalised models of nursing springing from the disparate educational streams of the nurses, or whether it reflects different sets of values originating in the multidisciplinary environments of the teams.

These nurses may see the nurse-patient relationship as fulfilling the ethical imperatives of beneficence, non-maleficence, autonomy and justice (Beauchamp and Childress 2008), although as Kitson (1996) points out, others would disagree, identifying nurses as agents of control, or caricaturing them as manipulative sirens or tyrannical mother figures. The subject of nurses' power is addressed in a following chapter, but it is notable that nursing models and

theories agree that the nurse-patient relationship is at the heart of nursing and is the agency through which effective nursing care is delivered. One of the key contributions these nurses bring to the diagnostic process is their felt commitment to the child and family.

Empathy for parents who were perceived to be under stress. Part of the role of the nurse as these nurses understand it, is to offer emotional support through the assessment process.

> *I just feel the nurse is there to support and carry it, until they have enough support to cope with it.* (N2 disc 2 16)

> *Like this mum wanted a diagnosis, but the reality of it was too difficult for her to cope with. I felt that being with her, getting to know her, I enabled her to carry that on, being involved in the assessment process...so she knew what was happening from beginning to end.* (N4 disc 3 2)

These nurses empathised with the parents of the children as human beings in a difficult situation. It may be the case that many of the professionals in the team feel similarly if they appreciate the enormity of the assessment and diagnostic process for the families involved. Nurses cannot claim a monopoly on human warmth. However the difference lies in the way in which according to nursing theory empathy is not an optional extra for the nurse, dependent on personal life history, personality or mood, but is part of the core business of nursing. Travelbee (1971) based her theory of nursing on the interpersonal relationship which develops between nurse and patient. For her, the purpose of nursing, to enable others to cope with and find meaning in the experience they are going through, is achieved through the empathy of one human being for another. Watson (1994) has as one of the conditions for a transpersonal caring relationship between nurse and patient, the nurse's ability to detect feelings of

another's inner condition. Benner and colleagues (1996) discuss the 'skill of involvement' (p.243) and the fine line nurses learn to tread in their development from novice to expert, as they move from concentrating on perfecting tasks and technical skills to being able simultaneously to recognise and address the emotional needs of their patients.

Using the patterns of knowing outlined by Carper (1978), aesthetic knowing comes into play here, as nurses seek to understand the meaning of the situation for the patient. Nurses then need to learn to judge between disengagement and overinvolvement or overidentification, resisting 'leaping in' or 'taking over' and instead being in tune with the 'patient family' needs and wishes around the relationship with the nurse.

These nurses feel dissonance between what they feel should be their role in this regard and what they are actually able to do, when the 'systems' set up within the organisation prevent them offering the support they judge parents need. One nurse expresses this forcefully regarding the way appointments for 'team around the child' meetings at which diagnoses were discussed with parents were organised,

> *She* [mother] *appeared to be finding the discussion of diagnosis difficult in the meeting. This was not apparent to the other professionals...I felt annoyed, frustrated and a bit upset that I could not offer Mum support immediately...I would like to be able to ensure that parents...have appointments at times when we can offer some follow up time with a nurse known to them to gather their thoughts before going out.* (N4 narr 1 11)

Another feels similar frustration that lack of resources prevent her offering more ongoing support to parents

> *There are frustrations because there is so much more that nurses could do. I think really it would be good practice to contact these*

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families periodically...but if there's only one of you, part time...that's 500 on the caseload plus 200 new referrals per year...so my frustration is not having a bigger team. (N3 disc 6 19)

The nurses are using 'personal knowing' (Carper 1978) to reflect on their unease as they empathise with the family at this point, and this leads them to challenge some of the processes involved in assessment. However the data does not indicate that these challenges represent a deviation from the underlying medical model within which both the diagnostic team and the family are embedded.

Respect for parents' views, and an intention to listen to parents and address their concerns, including giving practical strategies to manage behaviours that trouble families, even before completing assessment.

> *Literally listening to them...was an immense support, and they often said they'd been to clinics and HV sessions and all other appointments, and no-one had really listened, and they felt it was the first time someone acknowledged their worries* (N3 disc 4 19)

> *...because I just respected, really, what she wanted for her child...she never said to me "what do you think?" Or if she did I would have said "well you go and look M"...I don't think its fair to give them your ten penn'orth as well.* (N2 disc 6 15)

These nurses hold as a nursing value the importance of listening to and respecting the views and priorities of parents, and imply that this is something which is particularly characteristic of nursing,

> *...doctors very often do... set out what they're going to do and what they want to get out of an appointment...I still remember from my health visiting, that whatever your objectives might be for that visit, what the family's objectives are...are paramount.* (gp disc 19 2)

Many have reported on the distress caused to families where they do not feel this has happened, but that their views have been disregarded or marginalised (Midence and O'Neill 1999; Murray 2000; Avdi et al 2000; Hutton and Caron 2005). To address the concerns of parents before the agenda of professionals demonstrates respect. For example, Hodge (2005) noted that parents sometimes present their children to professionals because of their concerns over the child's language development rather than a query over possible autism. Others have found that many preschool children with autism are first referred for speech and language delay (Chakrabarti and Fombonne 2001). In this study also, the issue concerning one family was that their little boy was not talking, and although it was clear to the nurse that he was showing many signs of autism, she addressed the parents' priority first,

> *...I suggested assessment would explain more and perhaps lead us towards diagnosis if that was necessary, but that in the meantime we should work on communication.* (N6 narr 4 23)

Nursing models reflect this perception, for example King (1981) described nursing as a process of interaction and transaction between nurse and patient, involving social exchange, bargaining and negotiating, and developing a shared frame of reference so that there can be mutual goal setting relating to health promotion.

However there is some dissonance between this espoused value, and the nurses' actions in practice, as where parents do not share the professionals' framing of their children's unusual behaviours as pathological, nurses attempt to influence parents to align their views with the professional view,

> *It's taking off their rose tinted glasses...*(gp disc 5 9)

Some would identify this reframing process with oppressive practice and with the medicalisation and problematisation of children who are different (Molloy

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and Vasil 2002; Swain and French 2008), but the nurses in this study rationalise it in terms of the ethical imperative of beneficence, doing what they believe is in the best interests of the child and family, and articulate it in terms of non-maleficence, as they believe failing to do this would be unethical,

> *I think that not to do so is an act of omission in the same way that you wouldn't not give them a drug...* (gp disc 8 15)

> *...mum was for the first time seeing with her own eyes ...seeing things which we as professionals could see but parents hadn't been able to up to that point, so it was support, but it was support in a way to say but we can do things to be of help* (N1 disc 5 27)

There are direct links with the next nursing value identified in the study, that of honesty.

Honesty with parents and sharing information regarding autism and the assessment process; nurse as interpreter, teacher, guide.

> *I felt I had to be honest with the family. I said I felt that T's behaviour was not typical for his age, and though that did not necessarily mean there was something 'wrong' with him, and that children often change as they mature, at this stage it was a difference that needed understanding....*(N6 narr 6 9)

> *It's in the NMC guidance, it's an act of omission not to...[share information]...not to do it in a blunt way, or to do it in a certain time frame, it's to do it in the best way for that family, but it has to be done.* (gp disc 9 6)

> *And if you're thinking that, as your professional opinion you think...oh, autism...and you're not sharing that, that is dishonest.* (gp disc 8 22)

The NMC code states,

You must share with people, in a way they can understand, the information they want or need to know about their health (Standard 12, NMC 2008).

These nurses feel that the information they have about children and the diagnostic conclusions which were emerging from assessment belongs not to the professionals, but to the family, and that it would be unethical to fail to share the results of assessment. This view is corroborated by the literature around parents' opinions; parents claim a right to information about their child, held by professionals (Brogan and Knussen 2003), including honesty when there is some debate over diagnostic conclusions (Sloper and Turner 1993). Parents wish to be in control of the amount of information about autism they receive, and when. Part of the reason for openness and honesty during assessment is to enable parents to be fully involved in the process rather than passive recipients of medical expertise awaiting 'disclosure' of the professional 'verdict' on their child (Gray 2008). If knowledge is a form of power (Foucault 1980), respecting the knowledge possessed by parents and sharing knowledge and information possessed by professionals should reduce the power differential between them, unless the knowledge is unwanted and imposed. This will be further discussed in the chapter on power (page 109).

Nurses in this study take seriously the imperative placed upon them by their professional body to share information (NMC 2008), relating to the ethical principle of promoting patients' autonomy (Beauchamp and Childress 2008) but it was notable that they still defer to paediatricians with regard to the decision to communicate a diagnosis to parents. Once again, this has connections with the balance of professional and personal power between professions and between individuals in the team.

Advocacy for parents views to the team and more widely, to other organisations. This included advocating for a choice the nurse might perceive as unwise.

...say in a meeting, she might not say anything or might not put things very well, so her view might be brushed aside, and I might say "we have discussed this and M did say..."(N4 disc 3 19)

Participant: *I see it as part of my role...*
Researcher: *What...advocacy?*
Participant: *Campaigning.* (gp disc 12 14)

The Nursing and Midwifery Council Code states,

You must act as an advocate for those in your care, helping them to access relevant health and social care, information and support (Standard 4 NMC 2008).

These nurses say they act as advocates for the position and views of parents in multidisciplinary discussions, even when they believe parents are making unwise decisions. They feel that as a result of the relationship they have with the parent, they are the professional best able to be the 'voice of the voiceless' (Henderson 1966), but more importantly, to enable the family to grow in confidence to speak for themselves, as suggested by some models of nursing (Henderson 1966).

N1: *We've had two or three TAC meetings and I've always gone out and seen them before, and discussed their wishes with them...they spoke to me before to say they'd changed their mind, they didn't want a referral to* [ASD diagnostic team].

Researcher: *So they were able to talk to you even if they might think the official line would be to disapprove of their decision...but you as a nurse were felt to be ...? what?*

N1: *Their advocate really, I think they felt I would speak up for them.* (N1 disc 8 15)

These nurses appear to take this advocacy role for granted, but also articulate a growing need to act as advocates on a wider stage. As the economic situation has worsened and resources are cut, these nurses feel they are increasingly having to act politically in campaigning for resources for families and children,

> P1: *I think it's more than advocacy, 'cos agencies like parent partnership could be gone in 6 months, SENS is gone, the educational psychologists have gone by 50%...*

> P2: *Portage is as well...*

> P1: *So you've got no independent advocates, or even advocates within education that can support you as they did before...I think its a nursing instinct with us, that we do a holistic plan and intervention plan, and part of that is if we do not get a child successfully in education, then they're missing out in one of their key areas...if it was nutrition we'd be doing the same... (gp disc 12 17)*

However there was some dissonance here between what nurses feel they should do and actions in practice, as none of them give an example of how they have actually become more politically active as a result of their concerns.

There has been an assumption from the days of Nightingale (1889) that advocacy on behalf of patients is part of a nurse's role. However the ability of nurses to act as advocates has been restricted by their relative powerlessness (Woodrow 1997; Hewitt 2002). As nursing emerged as a profession separate from and less subservient to medicine, advocacy has been increasingly promoted as part of nursing (Mallik 1997). Mallik found, in her qualitative study of the perceptions of nurses about advocacy, that nurses undertake advocacy as a response to patients' requests, patients' fear of medical authority, patient vulnerability, the nurses' judgement about patient need, or the nurse's

perception that they were obliged by their role to advocate on behalf of the patient. However, she warns that nurses often engage in advocacy in situations where there is at least the potential for conflict, and there are risks of negative consequences for the nurse in 'sticking their neck out' for the patient. Willard (1996) suggests that nurses should be wary of undertaking an advocacy role, as representing the interests of one patient as their advocate may compromise the nurse's duty of beneficence to another patient (for example, where resources are finite), and also may conflict with the moral autonomy of the nurse. Willard suggests there has been confusion in the literature between advocacy and the duty of beneficence, and that nurses should concentrate on the latter. Hewitt (2002) adds that while the professional body of nursing places an onus on nurses to act as advocates, nurses in fact have limited power to do so effectively, and attempting to do so may bring them into conflict with more powerful bodies such as their employer (who holds the budget, has concerns about relationships between organisations, and may not look kindly on 'troublemakers') and doctors (who still claim supremacy over clinical decision making).

Others (Buettner-Schmidt and Lobo 2012) suggest that advocacy for social justice is part of the ethical basis and heritage of nursing, and that it was the rise of the medical model, with most nurses providing inpatient care, that diminished nurses' involvement in social justice. They see this 'fourth ethical principle' as vitally important and call for the development of a social justice framework for nursing, together with including social justice in nursing educational curriculae and competencies. It remains to be seen whether this USA based analysis and comment will have influence in the UK at present.

In this study, there is some indication that nurses advocate for patients to the extent of articulating the family's views in team meetings, but not that they practice, or have fully thought through the possible implications of advocacy on a wider scale.

Holistic care as central to and unique to nursing.

> *We are all brought up, trained, to do holistic care which covers everything.* (N5 disc 5 10)

> *I am there to complete the requested proforma, but if I am unable to advise on the spot about parent queries I feel my job has not been worthwhile, as in my opinion what help is a diagnosis if it doesn't help the parent and child?* (N5 narr 2 8)

> *I still had this thing about holistic care...you're looking at the whole family, because it's the environmental aspect and all those type of things, which is a core value for any type of nursing* (gp disc 2 23)

> *It's inbuilt into you from day one, especially in paediatric training, that you see the child and family as a whole* (gp disc 2 20)

To some nurses, 'holistic nursing' is a separate discipline (Slater 2005; Smith 2006), with its own association and journal, which differentiates other nurses, described as 'caregivers', from practitioners of 'holistic nursing' who are described as 'holistic healers' (Smith 2006). Slater, in an editorial for the Journal of Holistic Nursing, describes holism as a way of understanding human beings as either a series of inter-related bio-psycho-social-spiritual dimensions, or as an integrated whole, acted upon by the environment (Slater 2005).Proponents of holistic nursing in the sense of being an agent of healing trace their roots back to Florence Nightingale, whom they describe as a mystic, among other attributes (Dossey et al 2005).

Although the nurse participants in this study see themselves as looking at the child as part of a family within a community, and are clear that the social environment affects the meaning the assessment process and diagnosis has for the family unit, there is no evidence in the transcripts that these nurses see

themselves as 'healers', or indeed, that they feel the child with possible autism is in need of healing. It may be that in the UK there is a different understanding of the word 'holistic', or a different understanding of the function of the nurse as a practitioner. A UK wide consultation to gather views from groups and organisations around the future of mental health nursing (Brimblecombe et al 2007) defines holistic care as,

care that recognises people with mental health problems as whole persons with interrelated psychological, social, physical and spiritual needs (p.340).

The questions asked of respondents to Brimblecombe's consultation were around: how mental health nurses could best promote physical well-being in people with mental health problems; whether mental health nurses should practice psychological therapies; how they could promote social inclusion; and how they could support spiritual needs or religious beliefs which may assist in coping with illness. It could be argued that these questions, devised for the UK context, reflected the bio-psycho-social-spiritual domains described by holistic nursing practitioners in the US, but perhaps did not encourage responses around nursing as a healing art in itself. The responses did not envisage the nurse as a healer, except as a practitioner of defined skills such as cognitive behaviour therapy, when nursing practice was described by some respondents as therapeutic in itself. The nurse was expected to have the awareness to recognise needs and signpost service users to specialist help in the physical, social and spiritual domains, rather than carry out any form of 'holistic healing' in these areas.

Brimblecombe et al (2007) observe that nurses need a 'holistic understanding' of the needs of people, and a broad knowledge and skill base, including actively signposting people to sources of help and information, and a willingness to influence the social and political environment that affects health outcomes for their patients. This understanding of holistic care resonates more with the comments of the nurse participants in the current study than the concept of holistic nursing espoused by Dossey et al (2005), Slater (2005) and Smith

(2006). The nurses participants here are clear that holistic care characterises their practice, and differentiates them from other professionals, whom they see as engaging only with a specific area of the child or family's presentation or story, applying a narrow band of specific knowledge and expertise,

I think in other professions...thinking of the other roles in the team...other professions have a limited...they sort of do their bit, whether it's speech therapy or physio, they haven't got the same...I suppose responsibility really, they are only responsible for their bit.(N2 disc 5 7)

The value of giving holistic care overlaps and resonates with the other espoused nursing values of these participants, and could be said to summarise them. 'Holistic care' in this context includes using nursing expertise, delivered within a respectful, honest, empathetic relationship of care, to empower the child and family to move through the assessment and diagnosis, towards a positive health outcome; and to advocate for them when this is necessary to achieve their goals. It reflects the intention of these nurses to uphold the ethical principle of beneficence (Beauchamp and Childress 2008), in doing what they see as best for families and children.

In this chapter the values which emerged from the data as underlying these nurses' beliefs and actions have been discussed with reference to a selection of relevant literature. The data indicates these nurses hold in common values including: nursing knowledge as unique; the nurse-patient relationship; empathy; respect; honesty; advocacy, empowerment of families and holistic care.The meaning of the term 'holistic care' has been defined for this context. The values have been shown to relate to particular nursing models and ways of knowing, as well as to biomedical ethical principles. The study has highlighted some values which differ between nurses, possibly as a result of differing models used in nurse education, or because of absorption of the disparate values and ways of working of separate teams, but it is notable that the majority of the values of these nurses are common to them all. In relation to the research

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question, this chapter has demonstrated that the role of the nurse in preschool autism assessment is underpinned by a particular set of nursing values which inform the way in which nurses define their role, and their unique contribution to the assessment team. However, their actions in practice are affected by other factors, particularly issues around power and empowerment which will be discussed in the next chapter.

CHAPTER SIX: NURSES, POWER AND EMPOWERMENT

As this study progressed and the beliefs and values of the nurse participants emerged, issues of power and empowerment occurred and recurred to the extent that they demand fuller examination. In critical reflective inquiry (Kim 1999), which informed the methodology for this study, critical reflection on practice is intended both to contribute to nursing knowledge and to lead to emancipation. As both researcher and participant, I cannot stand outside the data. As data analysis and interpretation contribute to nursing knowledge, I bring my own preconceptions and experience to be questioned by the data within the 'hermeneutic circle' (Gadamer 2004). My previous experience of listening to advanced nurses developing roles within a mental health care Trust (Halpin et al 2008) had left me with a preconception that there are hierarchies of power within multidisciplinary teams which can be a barrier to nursing practice, but before carrying out this study I was not fully aware of the significance of these issues to nurses within child health teams. This chapter presents an analytical discussion of three issues of power and empowerment which emerged for me from the data.

The first topic is the powerlessness expressed in the narratives by the nurse participants, and the effect that has on their interactions with other professionals as well as patients. Tensions between nurses, although not a dominant theme, are revealed in the group discussion, and caused me to look to the literature for an interpretation, and to reconceptualise part of the dialogue as evidence of 'horizontal violence' between members of an oppressed group (Roberts 1983).These nurses also express in their narratives a perception of being a powerless group vis a vis the doctors in the team. I share this experience, and relate it to the literature on the hierarchy of professions.

The second topic, in contrast, emerged as the text demonstrated the power the participants hold and exercise over patients, and the extent to which this power is not perceived or is denied by the nurse participants.

The third topic related to power is that of empowerment, which emerged from the data framed as a form of beneficence, an assumption I shared but which the literature caused me to question.

A wealth of research and opinion has generated a considerable literature around power and empowerment in health services, and there is scope here for inclusion of only a selection of writings which for me were particularly relevant to the context of the present study.

The concepts of power and empowerment in nursing are generally held to be closely related (Gilbert 1995; Powers 2003; Bradbury-Jones et al 2008). It has been suggested (Bradbury-Jones et al 2008) that using a poststructural lens in critique of nursing practice would promote better understanding of power and empowerment in nursing, and lead to the development of new practices. In this chapter the issues around power and empowerment which emerge from the data are addressed with reference to the work of Foucault and a few of the many authors informed by his work, and by Freire's (1970) critical social theory about oppression, which originated as a Marxist critique of education, but which can be used to examine a wide range of professional practice. As nurses in this study could be seen as powerless and oppressed in some situations, as powerful and oppressive in other circumstances, and at other times, as themselves empowering, or disempowering, others, each of these scenarios will be visited in turn.

Nurses as a powerless or oppressed group

The most prominent account of nursing in the literature relating to power and powerless is that of nurses as an oppressed, powerless group (Holmes and Gastaldo 2000; Freshwater 2000; Dong and Temple 2011). Nurses have been observed acting in ways typical of oppressed group behaviour, such as being exploited and silenced by more dominant and privileged groups such as doctors and managers (Fulton 1997; Dong and Temple 2011), and in their frustration inflicting 'horizontal violence' on each other (Roberts 1983). Freire (2000) conceptualises horizontal violence as the aggressive behaviour of powerless people towards each other which stems from displacement of

negative feelings about the dominant group on to others in the oppressed group. Horizontal violence in nursing is described as overt and covert nonphysical hostility, for example criticism, sabotaging, undermining, infighting, scapegoating and bickering (Duffy 1995). There is one possible indication of horizontal violence observed between the nurses in this study, in this exchange in the group discussion between the psychiatric nurse and another participant,

Psychiatric nurse: *I think I do have a different stance...because of the difference between psychiatric nurse training and general nurse training...because psychiatric nurses from day one are taught to question medics....*

Participant: *We're taught that though, and I've been hauled over the coals in meetings because I've argued with a consultant. I've been wetting myself, but I would not back down.*

Psychiatric nurse: *Well that's my ignorance in relation to general nurse training then, because I know that when I did a general placement I got told off for talking to patients, and I got told off because I spent time feeding patients...and I'd tell families ...to bring in soup for them...*

Participant (emphatically): *But I do think a lot of us would have done that!*
[General agreement, hubbub]
Psychiatric nurse: *I didn't mean to be derogatory. (gp disc 20 20 – 21 3)*

The horizontal violence here is the suggestion that psychiatric nurses are encouraged by their training to be confident and assertive whereas general nurses are compliant, and that psychiatric nurses value relating to patients as individuals, whereas general nurses do not. These implied criticisms are immediately and robustly rebuffed by the other nurses, who claim to share the values of the first speaker and to have acted on them. The speaker rapidly retracts her criticism, and seeks to regain a position of solidarity with the group,

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and the exchange is curtailed. This exchange could be seen as horizontal violence between members of an oppressed group of nurses, in danger of splitting the group down the fault lines of tensions between those from different branches of nursing.

However there is more evidence in the text for solidarity between the nurses than for divisions between them, for example in agreement over their frustration when medical opinion is privileged over nursing opinion despite clinical evidence, and nurses are effectively 'silenced', their knowledge 'disqualified' (Foucault 1980).

...I felt that my opinion wasn't being...listened to...a medic who had never met this family was making a statement and they were listening to that more than actually seeing the evidence I'd collated...(N5 narr disc 4 3)

There was evidence of resistance to this silencing, and a determination to present nursing knowledge as valid and distinct from medical knowledge,

I think all nurses should go and present at the medical forums...its daunting, but it does come round, because questioning makes you think actually I know more than you. (gp disc 23 5)

Other authors report similar perceptions voiced by nurses in hospital environments, where the medical voice in discussions around patient care consistently overwhelms the contributions of nurses, and doctors assume the power to make, delegate and override decisions even in areas where nurses have specific expertise (Fulton 1997;Coombs and Ersser 2003; Atwal and Caldwell 2006).

Frustrations such as these could be said to reflect the ongoing dominance of medicine as a profession alongside the slow transition of nursing from vocation to profession (Yam 2004). Freshwater (2000) observes that the cultural narrative of nursing is to be subordinate to doctors. This is associated with a

lack of the autonomy in decision making within a distinct area of expertise, which is one of the hallmarks of a mature profession (Keogh 1997). Nursing has progressed from the semiprofessional status it was judged to possess in the 1960s (Katz 1969). Since then the research base of nursing has grown enormously and nursing knowledge has been widened and consolidated. The level of education of nurses has increased so that many nurses in the UK are now prepared at degree level and many go on to master's and doctorate study, strengthening the claim of nursing to a unique body of knowledge and professional education, which is essential if an occupation is to be recognised as a profession. Achieving full professional status brings with it power, autonomy and respect from other professions (Friedson 1986). Still there is resistance from medicine to the concept that nursing has a unique body of knowledge which is distinct from a lower level of medical training, and a persistence of patriarchal ideologies which "reflect the notion that women should be supervised in their work by those outside their profession" (Carter 1994 p. 371). The traditional medical domination of health care has been maintained partly by recourse to issues of accountability and responsibility; in the days when the overall responsibility for the patient legally rested with the medical consultant, who was accountable for mistakes made by subordinate team members, including the nurse, the consultant could reasonably claim primacy over all decisions regarding care. However, as nursing has matured as a profession, nurses are beginning to claim autonomy over their practice field, and also to assume distributed rather than delegated responsibility and accountability for their own practice within a team, a move supported by the government in its search for new (and more cost-effective) ways of working (DH 2010). This is exemplified in a comment by one participant,

I could have signposted to paediatrics...I could have sent him direct to (specialist team) but why, when I'm ADI-R trained...actually paediatrics wouldn't be able to do the emotional regulation as well as I could, and that's not bigging myself up, that's 'cos my training is about those things.
(psychiatric nurse disc 8 7)

This could also be interpreted as a desire on behalf of nursing to move towards the transdisciplinary model of team working described in the literature review (Rosen et al 1998; Hudson 2002). Stein (1990) observed that the rules of the 'doctor-nurse game', in which nurses are expected to show unilateral respect for doctors and to offer input regarding diagnosis in such a way as to allow the doctor to appear to have made the decision, are changing as nurses begin to challenge traditional medical dominance. Using the dramaturgical metaphor (Goffman 1956), the frontstage performance towards children and families as a team speaking with a unified medical voice is intact, but backstage the nurse is less willing to play a traditionally subservient role.

Four of the participants in this study work at NHS band 7 or above, a level which is associated with advanced nursing practice (DH 2010), one at band 6, clinical nurse specialist level, which again is a higher level of practice and should involve a high degree of autonomy (Bryant-Lukosius et al 2004), and one at band 5, which is staff nurse level. However only three out of the six participants hold their own clinics, or play a decision making role within their teams. This indicates some tension between the nursing value of excellence in practice, the level of expertise these nurses feel they possess, particularly around working with children and families before diagnosis; and the roles they actually play in practice within the multidisciplinary team. Participants acknowledge a lack of assertiveness on their part,

...nurses are really poor at highlighting what we do... (gp disc 19 24).

Although the traditional hierarchy of professions gives rise to the assumption that in an interdisciplinary team, the doctor is the natural leader, there is evidence from a working party on medical professionalism (Royal College of Physicians 2005) that physicians in the UK are aware of the need to adapt to changing times. They recommend doctors develop skills in teamworking including 'followership' where a member of another profession is the designated team leader. However, traditional hierarchies take time to change. There is an

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assumption on the part of some nurse leaders that nurses with specialised knowledge are ready and waiting to adopt advanced roles and to accept the concomitant responsibility and accountability that goes with true professionalization (Brykczynski 2000). The data on the subject from the present study is inconsistent and does not fully support the assumption, in that some of the participants appeared to be resigned to allowing doctors not only to lead teams, but to take the clinical decision making role,

...I was hoping the paediatrician would say well no...enough's enough, I do think we need to make that referral...and I'd built them up to the thought that maybe that was going to happen, but he didn't. (N1 disc 10 13)

The nurse here does not challenge the doctor's right to make the decision. It is not clear whether this was a source of frustration to her or whether she was happy for him to take the decision and for her to be relieved of the responsibility. According to Freire (1972), this attitude represents the internalising by an oppressed group (nurses) of the discourse of the dominant group (doctors) about the low status of nurses in this situation.

On the other hand there is evidence from the discussion that this model does not wholly fit the nurse participants here. Although they show only limited signs of frustration over the right to diagnostic decision making, they do show resistance over their perception that doctors and psychologists do not understand nursing in this context as having a distinct clinical contribution to make which is different from, and not inferior to, their own, and not consisting of delegated medical tasks. Analysis of the data indicates that this distinct contribution is the ability to bring a wide knowledge base to the holistic assessment of the child within the family, and then to address their felt

health needs within a professional relationship of care. Doctors are perceived to undervalue nursing expertise, in a way which inhibits the development of a mature collaborative relationship. It appears to be important to these nurses to have their professional input and opinion valued by the rest of the team, even

when they do not feel the need to challenge the doctor's position as team leader,

> *With a medical doctor, there's more of a discussion, and you are seen as an equal person, you're not 'the nurse'...so you need to be pulled down in front of the patients and everybody...(gp disc 21 11)*

This comment arose from reminiscences by the nurses around their early experiences nursing on surgical wards where humiliation and lack of respect for other team members were commonly used as means of maintaining the autocratic power of the surgical consultant over subordinates. These nurses feel they can be assertive where they are confident in their own knowledge and judgment,

> *I think nurses are very good team players, but they're also very strong characters individually, and if they have a theory, they will go for it, and have a voice.* (N5 disc 9 27)

However there are situations where these nurses felt themselves the subjects of oppression by the dominant group. One nurse reflects on her experience of delivering a presentation at a medical meeting, where the nurses find doctors in a group much more challenging and disrespectful than the same doctors in the individual team situation ,

> *...I was terrified, and I'm quite a confident speaker...I don't know if it was this thing about I'm a nurse and they're a medic, you know, that old historic thing, but I instantly felt intimidated* (gp disc 23 8)

However, resistance is evident in the way another nurse reflects a growing awareness and confidence in her expertise in a similar situation of presenting at a medical forum,

...but actually, when the questions start to come, you think do you know what? I do know about this subject and I do know more than you...(gp disc 23 3)

There are signs in the discussion that any internalising of a position of subservience by nurses could be changing as nurses become more confident of their unique expertise. Nurses comment about attending medical meetings,

Researcher: *So given that you are all sure what you're good at, and you're saying other people aren't, how do we make people aware then?*

Participant: *I think you have to put yourself in their arena, even though you feel sometimes like you're in a bowl of piranhas, you have to. (gp disc 22 19)*

Another issue over which the nurses in this study express frustration is around their lack of power to act autonomously because of organisational and resource constraints,

...There are frustrations because there is so much more that nurses could do...I think really it would be good practice to contact these families periodically that are on our caseload, but if there's only one of you, part-time...so my frustration is not having a bigger team.(N5 narr disc 6 19 20)

Attree (2005) articulates the paradox over autonomy and control of their own practice which is currently faced by nurses, and is reflected in this study. According to their own professional body (NMC 2008) and also the government's policy of devolving responsibility for clinical standards down to clinicians via the clinical governance agenda (DH 1999), nurses are autonomous professionals who are responsible and accountable for the standard of service they deliver. However they are simultaneously disempowered from any meaningful control over the factors influencing that

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standard, such as the resources available and the ability as nurses to take decisions which determine outcomes for patients.

These issues and the tensions between them, all impact on the research question, as the role of the nurse in preschool autism assessment is shown to be defined not only by the skills, knowledge and clinical expertise of the nurse, but by the constraints of the interdisciplinary team environment and those of the wider health economy within which the nurse practices.

Nurses as powerful oppressors

By their involvement in early identification, assessment and diagnosis of children with autism, nurses are agents of the health service which Foulcault (1977) saw as exerting 'disciplinary power' over patients. Using Foulcault's concepts, 'hierarchical observation and normalising judgement' (in this case, identification of children developing atypically and referring them for assessment) is followed by 'the examination' (assessment and diagnosis). From this standpoint it can be seen how the assessment process 'others' the child, and how by making the child the subject of written notes, nurses are fixing their 'othered' identity using words. Nurses are here involved in using the dominant discourse of medicine (not a discourse of nursing) to redefine the child. At this point they align themselves with the medical model inherent in the diagnostic process. Gillman et al (2000), from a social constructionist standpoint suggest that diagnosis creates the identity of the person diagnosed. There is evidence from the data that the nurses are aware of the significance of the process for children and families, and of the way in which diagnosis can "bring forth pathology" and "construct careers as patients and cases" (Gillman et. al. 2000, p.389),

I think to go into their environment and bring about emotional turmoil for

them, 'cos on reflection...it does make them recognise the child's difficulties...

(N3 disc 1.19)

I was aware that this process was going to change their perception of their

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child, and I had sympathy for them in resisting that...(N6 narr 5 7)

Nurses here justify their involvement in this process by their belief that diagnosis is in the best interests of the child, but on condition that it leads to understanding and help,

In my opinion what use is a diagnosis if it doesn't help the family and child?
(N5 narr 2.10)

The nurses here go no further towards challenging the necessity for diagnosis, or resisting their part in steering families through the assessment process. On the contrary, they voice the opinion that harm and injustice is done to children whose parents' concerns about unusual behaviour and demands for diagnosis are ignored by professionals,

She talks to other people and they say yeah, yeah, but they don't know, they don't have a real picture of this mum and what she has to put up with at home, he was really difficult .(N4 disc 4 2)

Dong and Temple (2011) in their concept analysis of oppression and its implications for nursing, use a specific example of parents of children with autism 'not being heard' by professionals when they voiced concerns, leading to late diagnosis and missed opportunities for early access to resources. They suggest that this is a case closely related to oppression, although falling short of actual oppressive practice because parents have been ignored rather than actively silenced. However, there are many examples of parents repeatedly voicing concerns and being effectively silenced by inappropriate reassurance from various professionals with little awareness of autism (Baird et al 2003).
Nurses in this study appear to be aware of the imperative to listen to parents, but to be less conscious of the power they hold by virtue of their specialist knowledge (Foucault 1977). Avdi et al (2000), in their discourse analysis of parents' talk about the knowledge, expertise and authority of professionals at a

child development centre, express the opinion that professionals should be aware of, and should not deny the power differential between them and parents in the assessment situation. At no point in the narratives or dialogues in this study do the nurses give the impression that they see themselves seeking to maintain power over patients, or that they perceive the health care system within which they are working as oppressive. Neither is there evidence that familiarity with discourses around power and empowerment in health services developed from critical social theory (Freire 1970) or a poststructuralist viewpoint (Foulcault 1980, 1988) affect the day to day thinking of these nurses. They do recognise a power differential, and where possible they seek to reduce it by sharing knowledge with parents in the belief that this will empower them,

...it's about empowering them to hypothesise themselves, with the evidence you are presenting...(gp disc 5 1)

However empowerment is not universally considered to be an act of beneficence (Lam and Kwong 2012), and merits discussion in the following section.

Nurses and empowerment.

The Royal College of Nursing (RCN 2003) describes empowerment of patients as central to good nursing, and this is in accord with government policy, which speaks of 'shifting the balance of power' (DH 2001a) towards patients. Patients, and in the case of children, those responsible for them, are encouraged to become experts in their condition (DH 2001b). This trend away from paternalism in health care may be related to the loss of unquestioning trust in health care professionals following crimes committed by individual health professionals such as Harold Shipman (Smith 2005); and also corporate failures such as those uncovered in mid Staffordshire (Francis 2013).

The nurses in this study believe that they are actively putting families into a

position of power, for example by going to see them at home,

> Participant 1: *I think going into the home they are on a better footing than coming in to see you in the clinic.*
> Researcher: *There's a power differential?*
> Participant 1: *Yes, where you are coming into my home.*
> Participant 2: *Yes, they have the power, which is how it should be* (Gp disc 3 17)

Nurses also indicate that they deliberately empower families to set objectives by addressing families' felt needs before following their own agenda,

> *Doctors very often do...set out what they're going to do and what they want to get out of an appointment. And we don't...we have an objective in our head...but you may make another three or four visits before you ever get around to that objective...whatever your objectives might be for that visit, what the family's objectives are of you going round is paramount.* (gp disc 19 2)

They believe that by engaging parents in the assessment process, they are empowering them to keep an element of control,

> *I ended up sending...this dad...to go and look on the NAS website and tell me whether he thought we were on the right track here or not, so it was almost giving him back the power.* (gp disc 6 9)

This nurse did not seem conscious of the limited parameters of the empowerment being offered to this father. It seemed to be expected that he would visit the suggested website and align himself with the diagnostic process and the medical perspective on his child. It is not clear how the team would react if this parent informed himself from a different viewpoint and took a different stance.

Murray (2000), reflecting on her experience as a parent interacting with education professionals asked the question, 'disabled children, parents and professionals: partnership on whose terms?' The present study supports her view that true empowerment and genuine partnership may be difficult to negotiate.

However, there is evidence from the data that parent empowerment is taken seriously by the nurses in the study. When another parent did resist diagnosis, the nurse acted as her advocate at a team around the child meeting, because it was clear the child was having his needs met in school despite having no diagnosis,

Researcher: *And you felt as a professional, you and the paediatrician felt, that was ok that the diagnosis was rejected by the parents, even though the professionals would all say it fitted?*

N1: *Yes, and I think...well I know because we spoke at length about it...it's not to the detriment of the child...* (N1 disc 11 1)

However, the view that empowerment of patients is an entirely beneficent or transparent act is contested. Freire (1970) describes the way in which oppressive regimes perpetuate their power by apparently valuing the oppressed. It has been suggested (Christensen and Hewitt-Taylor 2006) that the apparent support of patient empowerment by medicine could be a covert attempt to preserve the dominant position of medicine by recruiting patients as allies against the government. Powers (2003) argues that the concept of empowerment is used as a coercive strategy, and that rather than having genuinely free choices, patients are subtly coerced into making the choices health care professionals want them to make. Powers relates this to Foucault's concept of governmentality, by which populations can be regulated by an administrative state offering security (or in this case, the promise of what is 'best for the child') rather than controlling by physical force (Gastaldo 1997).

Patient empowerment can be seen as a form of self regulation, and nurses as

using it to exercise disciplinary power, making it uncomfortable for patients who fail to make the 'approved' choices (Holmes and Gastaldo 2002). The process of nurses exerting power over patients through the language they use in interaction has been observed in other contexts, for example, in Hewinson's observational study of nurses nursing elderly patients, who are overtly invited to choose a course of action, when in fact "the decision has been made, and the patient is invited to agree" (Hewinson 1995 p.78) . From her symbolic interactionist stance, Hewinson sees social reality being created through these nurse-patient interactions.

There is some evidence in the present study that nurses are aware that they are influencing parents to accept a diagnosis of autism, and also to accept the interventions the professionals feel are appropriate.

> ...*very often you see mum and child, and spend a lot of time as the nurse with the mum, and going through things, very often a mum will get to the place you'd like them to get to way before the dad. (gp disc 5 20)*

They frame this as parent empowerment, and believe they are giving parents genuine choice, and although they appear uncomfortable when there is resistance, they justify their actions in terms of the moral duty of beneficence, as they firmly believe that aligning the parent view with the professional view is in the best interests of the child and family,

> [nursing goals for the mother]...*To accept...to be able to accept, that the child's got this condition, and to be able to deal with the child, because it is hard* (N4 disc 5 31)

> [giving parents information]...*so that they answer their own questions, and they come back to you for verification, and you say yes, that's what I'm seeing... (gp disc 20 17)*

I was aware I was starting the family on a path they did not want to take at all, but were inevitably going to have to accept eventually. I was uncomfortable about steering them on to this path, but believe it was better for the family to be steered and accompanied at this point than to be forced to change track abruptly when T started school (N6 narr 7 6)

Parent empowerment in the context of assessment and diagnosis of autism in preschool children includes actively involving parents in the process and ensuring that their knowledge of the child is respected and their views are heard in a collaborative, transactional model of diagnosis (Bartolo 2001;Nissenbaum et al 2002). This is in contrast to the traditional, paternalistic model of professionals carrying out the assessment and 'disclosing' the diagnosis to parents, which causes dissatisfaction and stress to all parties, and may have long-term negative effects on the family (Nissenbaum 2002; Hodge 2005).

Gray et al (2008) offer a collaborative model of assessment based on the ICF strengths and supports framework (WHO 2001). Their model, based on the American 'medical home', aims to empower parents to play a full part in the assessment and diagnostic process, so that a diagnosis is never 'disclosed' as a shock to parents, but is negotiated and co- constructed with them.

There is evidence that the nurses in the current study subscribe to such a parent empowerment model, and that the working practices of their teams allow similar aims; although there is still a diagnostic meeting of the 'team around the child', parents are designated as part of the team and are expected to participate in the meeting. However, it is still the role of the paediatrician to finalise the diagnosis,

...I saw him with her in the nursery, I talked it all through with her, I made sure she knew what we were looking for...I was able to sit with her then and go through what we were seeing and her views were part of it too (N4 disc 3 10)

...during the assessment process, we kind of start to drip feed it, so there is not a big shock at the end...I have a one to one with the family before they

go in to the meeting with the consultant, and we go through all that we've seen over the fortnight, and what we've observed, and do they agree with this...although you know that probably they expect the diagnosis by then...(N2 disc 3 3)

The nurses in this study demonstrate that genuine empowerment of parents is a nursing aim of theirs, both in the assessment process, as above, and in enabling parents to understand and 'manage their child's behaviours' independently,

...if I've done my job right, she will naturally grow away from me because I've given her the skills...to manage the behaviours (N4 disc 6 13)

There is no evidence from the data that nurses attempt to empower parents to resist the medical model of disability, or raise their consciousness of the issues around expecting the children and their behaviours to change rather than challenging the social environment which deems autistic traits to be unacceptable.

However, there is an argument that parent empowerment in itself may become an oppressive practice. Christenson and Hewitt-Taylor (2006) note that for parent empowerment to be effective, it is necessary both for professionals to be convinced of the patient's right to self-determination and committed to sharing information which is meaningful to patients; and also for the patient to accept the obligation to make choices, and take responsibility for them. Lam and Kwong (2012) describe a 'paradox of empowerment' in the context of parent education in Hong Kong. Their observation is that in imposing their ideology of empowerment on to parents, when in fact parents were resistant, the educators were actually exercising oppressive power over them. Lam and Kwong's recommendation that professionals should "provide expert knowledge and advice with epistemic reflexivity" (p.65) is relevant here, as is their observation that "Parents *feel* empowered when they feel competent and with a sense of agency and control, rather than *being* empowered by professionals." (p.71). It

could be argued that if parents ask for diagnosis and help managing behaviours, that is the felt need that nurses should address, rather than trying to influence them in other ways.

Summary

In this chapter, ideas from critical social theory and poststructuralism have been used to inform a critical reflection on issues around power and empowerment arising from the data .This study seeks to understand the role of these particular nurses in the preschool autism assessment process, and demonstrates that towards their patients, nurses here exert considerable power, although they are only partly conscious of it. They base their actions on their nursing values and their beliefs regarding the best interests of the child and family. Although the nurses act as a powerless and oppressed group whose professional autonomy is limited by their low status in the multidisciplinary team, there are signs that they may be beginning to challenge this scenario where they have confidence in their nursing knowledge and skills. They value and practise parent empowerment in the sense of sharing knowledge, teaching and encouraging parents to normalise the child's behaviour. They show few signs of challenging, or of empowering parents to challenge the medical model of disability within which the service operates.

CHAPTER SEVEN: CONCLUSIONS

This closing chapter addresses the research question, 'what do nurses identify as their particular professional contribution to assessment of preschool children for autism? by offering my reflections on the study, its findings and conclusions based on my interpretation of the data generated. The background to the work, including my preconceptions and intentions for the study, is first revisited in order to inform my reflections on the strengths and limitations of the methods used and to identify directions for further research. The findings and four ways in which they contribute to nursing knowledge are then presented, including consideration of the way they address and answer the research question. Finally, I draw implications from the findings for other professionals, for nurse educators, for commissioners and managers of preschool assessment services, for the assessment teams and for nurses working within them.

The study was initially stimulated by a challenge to nurses working in child health community paediatric teams to make plain what nurses bring to the process of autism assessment which is of value and unique to their profession. It was influenced by further challenges I found in the literature: by the antagonism of some in the disability movement to the discourse and practice of the health community around autism, immersed as it is in a medical model of disability (Davis 2004); by the tendency of the present model of care to promote ableism (Campbell 2009); and by the stimulus to develop a more affirmative model of practice (French and Swain 2008, Gray et al 2008).

I started with a preconception that nurses offer a particular contribution to families going through the process of assessment and diagnosis, which can make the experience a more positive one and ameliorate some of the negative effects of the process on families which have been described in the literature (Taanila et al 1998; Hodge 2005; Sices et al 2009). There was a lack of research evidence to support or refute my presupposition, and no clarity on whether or not nurses have a 'unique function' (Henderson 2006) in this field. I chose to conduct a hermeneutic study and critical analysis of the reflective

accounts of nurses working with children and families during assessment. An analysis of relevant nursing literature was brought to bear on the beliefs and values which were made evident by the data generated through critical reflective inquiry. The methods were chosen so that not only would the way in which these nurses understand their role be articulated, and the research question answered but that participants might also be empowered to explore whether and how their practice is presently constrained and to consider how it might be developed. As the study progressed I found that not only beliefs and values, but also issues around power and empowerment were influencing the roles of the nurse participants to such an extent that I felt it necessary to include an exploration of these issues in addressing the research question.

On reflection on the methods used, I am confident that the decision to study written accounts of practice as data rather than carrying out an ethnographic, observational study was appropriate. Although an ethnographic study might have answered the research question from an 'outsider' perspective, this is a study of nurses, by nurses and for nurses. Writing and reviewing their own texts helped the nurses to reflect on their experiences and to articulate their values and intentions in a way that may not have been possible based on a researcher's observations of their practice. I found Kim's (2009) critical reflective inquiry a very effective method upon which to base the data collection, particularly as it has clear benefits for the participants in terms of personal development, as well as just for the researcher.

I feel the decision to position myself as both researcher and participant within the study was both an advantage which strengthened the study, and a disadvantage or limitation of the study, but I would use this approach again as I found the advantages to outweigh the disadvantages. An advantage was that it allowed me to use 'insider' information about nursing. As an 'insider', I have experienced a process of socialisation into nursing similar to that experienced by the other participants, and I therefore adopted similar beliefs and values to theirs (Dinmohammadi et al 2103). I have confidence as researcher that the findings of the study about the beliefs and values common to the nurses are credible, because of this insider information: the findings resonate with my own

beliefs and values. However as Koch points out (1996) it is ultimately for the reader to decide whether the study is believable. She reminds the reader that the researcher's responsibility in hermeneutic inquiry is not to deny bias but to make it explicit, and the methodology allowed me to do so in this case. The disadvantage of being a participant in the discussion was that on reflection I felt that had I been simply a researcher I might have steered the discussion more strongly and perhaps explored some of the thinking behind the nurses' comments more fully.

As a consequence of this reflection, an area for further research emerged for me from this study. One aim of the present study was to promote awareness of alternatives to the medical model within the heart of a medically dominated system, and to the extent that the findings of the study are disseminated in nursing and paediatric circles, this aim can be fulfilled. However, it was not clear from the data whether all the nurses were cognisant of the difference between medical and social models of disability. Scullion (2009) suggests that nurses are not conscious of the debates emanating from the disability movement around assessment and diagnosis, and this issue was not fully explored during the discussion. An action research study could explore whether and how education around disability issues followed by further opportunity for critical reflective discussion might result in changed attitudes and practice. There would be implications for nurse education if attitudes and practice were in fact changed following this process, supporting Secombe (2006) and Northway (1997;2010) in suggesting that disability studies should be included as a core component in undergraduate nurse education, and revisited in postgraduate reflection on practice.

The findings of the study are that these nurses hold in common a number of beliefs and values which underpin their practice. Some dissonance was found between the intentions of the nurses and their actions in practice, resulting from the context of their practice, but the nurses are found to be equipped by their beliefs and values, combined with their clinical expertise, to offer the kind of care parents have said they need during their children's assessment for autism

(Brogan and Knussen 2003;Osborne and Reed 2008;Harnett et al 2009; Braiden et al 2010).

The study contributes to nursing knowledge in four ways:

1 The study contributes to nursing knowledge firstly by elucidating which common beliefs and values underpin the practice of this group of nurses:

The nursing values expressed in the NMC Code of Conduct (2008) and the literature around values in nursing agree that human dignity, integrity, autonomy, altruism and social justice are at the core of nursing and are included in nurse education and socialisation (Fahrenwald et al 2005). However, there is little literature around either beliefs or values pertinent to nurses working in preschool autism assessment, possibly because few if any studies have been reported in the UK relating to the role of nurses in this particular field. This study contributes to knowledge in this area, and I suggest it may also be relevant to nurses in other related fields.

The following are the beliefs that according to my 'insider' interpretation were common to the nurse participants in this study: they hold a belief in the existence of autism as 'real', as a diagnostic entity which 'fits' as a description of the way certain children experience and act in the world. They believe that parents want their children to be 'perfect' (or 'normal'). The disability literature indicates this is because parents and nurses are part of an ableist society and their thinking is shaped by a medical, 'tragedy' model of disability at the time of assessment. These nurses believe that diagnosis protects children and their families from misunderstanding and from blame, and is the gateway to obtaining services they expect the child will need in order to negotiate life in society. They believe that although diagnosis may be stigmatising, it is the 'least-worst' option for families, and they should be encouraged to come to terms with the need for diagnosis and to seek it. They believe that they as nurses have skills and information which parents need in order to make their lives with their children as stress free and enjoyable as possible, and they believe nurses have a duty to share their skills and knowledge with parents. These nurses believe 'nursing is key' to good care in the assessment period because nurses offer a skill set

and way of interacting which is distinct from every other profession and is especially helpful to parents during assessment, as well as having the assessment skills needed by the team. They believe the unique combination of skills and values nurses hold make nursing intervention particularly appropriate in the context of preschool assessment, diagnosis and early intervention.

The values, defined as standards underpinning practice, which by my interpretation emerged from the data as held in common by the nurses in this study were as follows: Nurses feel their nursing knowledge base is unique in its breadth; and they assume a personal responsibility to see to it that they possess and update the wide range of knowledge, including knowledge from other disciplines, which excellence in nursing practice demands. These nurses value the nurse-patient relationship as the core of good nursing; they feel a moral responsibility to be therapeutically available to the child and family to the extent of their felt need, within professional boundaries. The nurses value empathy with and emotional support for patients as core to nursing rather than as an 'optional extra', and they expect to manage the emotional strain under which this places them, as part of their professional expertise. They hold as a nursing value respect for patients, which in this context involves listening to parents and the promotion of the family's agenda and priorities over those of the service. This is related to the value of honesty with parents which these nurses feel underpins a relationship of trust between nurse and family; these nurses hold that any information the professional team possesses about the child belongs to the family and must be shared with parents in an appropriate way. The nurses here value advocacy and accept it uncritically as a nursing value, although in practice their advocacy role is limited to articulating families' views in meetings when they cannot do so for themselves. There is limited evidence that participants have thought through the implications of advocating for patients on a larger stage, which would involve becoming politically active, and no evidence that they consciously challenge the medical frame within which assessment is carried out. The value of holistic care is strongly felt by these participants to be a core nursing value which could be said to encompass all the other values identified here.

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Holistic nursing care is found (page 105) to mean using clinical expertise, delivered within a respectful, honest, empathetic relationship of care, to empower the child and family to move through the assessment and diagnosis towards a positive health outcome; and to advocate for them when this is necessary to achieve their goals.

2 The study contributes to nursing knowledge secondly by using critical reflective inquiry to elucidate the source of variance between the intentions of nurses in this study, informed by their beliefs and values, and their actions in practice. Kim (1999) developed critical reflective inquiry as a method suitable to use for this purpose in nursing, but there have not previously been studies published in the UK which describe its effectiveness in community child health or assessment teams.

The extent to which there is dissonance and tensions between the espoused nursing beliefs and values of the nurses in the study and their actions depends largely on the environment within which they practice, and particularly on the values, hierarchies and power relationships which characterise the teams, the organisations, and the wider political structures within which the nurses are embedded. From a postmodern viewpoint the nurses sometimes act as an oppressed group, whose status within the child development teams is low and whose professional autonomy is compromised by this position; this study suggests they are beginning to challenge this situation as and when they are confident that increasing their own autonomy benefits children and families.

Nurses could be seen as oppressive themselves, because they uncritically perpetuate a system informed by ableist assumptions (French and Swain 2001). These nurses value and practise parent empowerment in the sense of sharing skills and knowledge, and supporting parents in their desire to normalise the child's behaviour. They show no signs of being themselves empowered, or of empowering parents, to challenge the assumptions which underpin the service. However there is an argument (Lam and Kwong 2012) that imposing an ideology of empowerment on to parents can in itself be oppressive. Nursing models (Henderson 1966; Neumann 1980; King 1981; Benner 1984;

Watson1994; Roy and Andrews 1999) suggest that nursing should meet the felt needs of the patient and assist them to attain their own health goals, rather than imposing the nurse's ideology upon the patient. If families consider the best outcome for children with autism is prompt diagnosis and early intervention towards normalisation, then according to Lam and Kwong's (2012) argument, whatever nurses' personal stance on the medical or social models relating to autism, they should still assist the families in attainment of these goals.

This study has led me to reflect critically on my own beliefs, values and practice, particularly through the challenge to the medical model of disability posed in the literature of the disability movement. Although I share most of the beliefs and values of the other participants, and I agree that diagnosis will continue to be the 'least worst' option for children until attitudes change and society becomes truly inclusive, the process of undertaking the study has made me more critical of the current framing of autism as a medical 'problem' and more inclined to use a social model of disability in understanding the issues raised by. parents. If all nurses had the same opportunity for informed reflection, they might become agents of change in attitudes within teams, schools and wider society. One conclusion I draw from my own involvement in this study is that opportunity for critical reflection, informed by broad education around disability helps nurses to be aware of the issues and empowered to align their ethical intentions with their actions in practice in the field of early autism assessment.

On reflection around the effectiveness of Kim's method used here in exploring the variance between intentions and actions, the data indicates that the opportunity for critical reflection on practice in a supportive group did enable these nurses to begin to analyse their actions more critically. This led to increasing awareness of the issues and towards a challenge to factors which compromise nursing practice. The nurses in this study began to approach this level of 'emancipatory reflection' (Kim 1999; Taylor 2000) towards the end of the group discussion, as they articulated their own realisation of the uniqueness of the nursing role and their need to insist on taking time out together for professional development and reflective learning. (Appendix 3, p.145) The study

demonstrates the effectiveness of the method, and also one way in which it can be adapted, to include the researcher as participant.

3 The study contributes to nursing knowledge thirdly by addressing the research question, because the unique contribution of nurses to the process of assessment for autism of preschool children in the U.K. has not previously been articulated by nurses. Previously there have been definitions of nursing in general, such as that posited by Henderson (1966) as an assistant towards health; characterisations such as Campbell's (1984) 'skilled companion on the illness journey'; and slogans such as Kitson's (1996) 'we'll be there for you'; but there has not been a definition of the unique role of nurses in this particular field, informed by an analysis of the reflections of nurses themselves.

From my interpretation of the data generated during this study, the essential response from a nursing perspective to the question 'what do nurses identify as their particular professional contribution to assessment of preschool children for autism?' is: .

The unique role of the nurse during assessment of preschool children for autism is to bring a broad range of knowledge, skills and clinical expertise, underpinned by nursing beliefs and values, to a holistic assessment of the child within the family which contributes to diagnosis, and to address the felt needs of the child and family through a professional relationship of care.

4 The study contributes to nursing knowledge fourthly in that it demonstrates that the beliefs and values espoused by the nurses in this study give rise to intentions and actions which correlate with the desire expressed by parents for care with particular characteristics (Brogan and Knussen 2003;Osborne and Reed 2008;Harnett and Tierney 2009; Braiden et al 2010). This correlation has not previously been made in the literature from the UK around nurses and early autism assessment.

The characteristics include care which allows parents to be fully involved in the diagnostic process; to have their views and perceptions listened to and

respected; to have a right to information about the assessment, including honesty where there is uncertainty; to have their child's strengths and uniqueness recognised; to be in control of how much information around autism they wish to receive; to have sensitive care which respects their feelings and offers undivided time and emotional support; to be assisted to learn about how to help their child enjoy being in the world and avoid unnecessary stress; to be given information about available services, and a single point of access to coordinated care, with advocacy if required.

The study does not show whether or not nurses deliver this kind of care in practice, but does demonstrate that the beliefs, values and intentions held by the nurses in this study prepare them to do so particularly effectively. These combined with clinical knowledge, comprise a uniquely valuable skill set brought by nurses to the assessment team. This link between nursing values and beliefs and the kind of care parents say they wish to experience during the assessment process has not previously been made explicit.

I do not claim that the findings of this interpretive study are generalisable, but, true to the methodological underpinnings of the project, using the hermeneutic circle, when the findings and conclusions drawn from them are examined in the light of the bigger picture, they are found to be consistent with many models and theories of nursing, and with the kind of care parents say they want. The conclusions may have relevance for other professionals and the work is being cited by other researchers (Hodge 2014). I believe the conclusions are credible, and that they have the following implications.

Implications for nurse educators

As well as suggesting directions for further research which may have implications for nurse education, the findings of this study indicate that student nurses may benefit from opportunity to learn to use critical reflection in a supportive group as part of professional education and socialisation. Through emancipatory critical reflection both pre- and post-registration nurses can learn to recognise dissonance between taught nursing models, nursing values, their

intentions and their actions in practice, and can be empowered to take action to align them.

Reflection needs to be informed by a broad based nurse education which will include elements of other disciplines, as the breadth of nursing knowledge has been shown here to be one of the strengths of nursing. For example, the findings here imply that nurses should be taught to critically evaluate the medical model relating to disability and consider how adopting alternative social or biopsychosocial models would affect their practice.

Advocacy is expected by their governing body to be part of the role of every nurse (NMC 2008). The study found that these nurses have not fully engaged with thinking about what advocacy for patients might entail, when patients' best interests are not being served by prevailing social attitudes and existing health, education and social care systems. By including discussion about the wider implications of advocacy on a socio-political level within the nursing curriculum, nurse educators could empower nurses to consider the extent to which they engage with these issues.

Implications for commissioners and managers

The study demonstrates the view of nurses that they have a unique contribution to make to assessment teams, bringing a broad range of clinical knowledge and skills based on nursing values and beliefs. Nurses believe their presence on a team enhances the quality of care offered to children and families by enabling the team better to respond to the voices and needs of patients. Nurses would like commissioners and managers to be aware of this.

The findings also highlight the need to build time for critical reflection on practice, particularly in a supportive group, into job descriptions and work plans for nurses.

Implications for assessment teams

The findings demonstrate the value nurses consider they bring to the team, both in clinical assessment and in holistic care for families and children. The findings are that these nurses do not wish to compete with or undermine the expertise

of other professionals, but they increasingly expect that their own professional expertise is similarly respected. The implication is that nurses feel they would practice more effectively within a transdisciplinary team structure within which nurses assume distributed rather than delegated authority over and responsibility for their role in assessment, diagnosis and followup.

Implications for nurses in assessment teams

This study has demonstrated the effectiveness of critical reflection on practice in a supportive group for a particular group of nurses in this field. The implication is that taking time for critical reflection on practice in a group may be similarly informative and emancipatory for other nurses, and they would benefit from including it in personal development planning.

The unique role of the nurse in the assessment team has been defined in this study in a way which has not been articulated before. The study concludes that nurses may with confidence practise their profession within assessment teams, knowing that their particular combination of breadth of knowledge, skills and values underpins the kind of care families say they need. Nurses elsewhere may feel this definition resonates with their own practice and experience, and choose to use it to articulate their roles in similar situations.

WORD COUNT : 44,144

South Staffordshire and Shropshire Healthcare NHS

<u>The Role of the Nurse During Preschool Assessment for Autism</u>   version 3: 27.3.12

PARTICIPANT INFORMATION SHEET

The aim of this study is to explore with a group of nurses how they perceive their role with families whose preschool children are being assessed for possible autism, and to draw out from reflection on practice, the unique contribution nurses make or could make to the process.

<u>Background to the study</u>

It is known that parents can sometimes find autism assessment a stressful experience which can change the way they perceive their child, and cause them to lose confidence in their parenting ability. It is known that professionals find disclosure of a diagnosis to parents stressful, but it is also known that the way in which professionals interact with parents can substantially affect the parent experience to the extent that some find the process of assessment therapeutic and helpful.

As nurses we have an ethical imperative to do no harm, and many nursing models suggest that nurses, of all professionals, should be best placed to engage with parents in a respectful and collaborative way which enables them to play a meaningful part in the assessment. It is not known how nurses understand their role in assessment for autism, or how the context in which they work affects what they do in practice.

<u>Method</u>

The method for the study is based on the exploration of experience through studying writing or text. The texts used will be accounts of practice written by nurses who participate in the study, and also transcripts of discussions between the participants about their experience. All qualified nurses who have worked in assessment and diagnosis of preschool children for autism within South Staffs and Shropshire Healthcare NHS Foundation Trust and who offer to be part of the research will be included as participants.

Each participant will be asked to write a descriptive account of an episode of practice in which they were involved in assessment of a preschool child for possible autism, and in which they feel that their role as a nurse with the family was in some way significant, including how the nurse felt, thought and acted, and why they felt it appropriate to act in that way. The narrative need not be a specific length, but should give a comprehensive description of the experience. I will also be writing a similar account of practice, acting as both participant and researcher.

If you choose to participate in the study then your narrative will be sent to me as the researcher, and I will then meet with each participant individually. We will reflect together on the text, particularly about what you feel it reveals about beliefs and values underlying your practice, in the light of nursing theories. We will also seek to reflect on how you feel the context in which nurses practice in this field affects the way they act. The discussion will be audiotaped and later transcribed. I will summarise the findings and send them to you for further reflection, clarification and any additional comments.

The next stage will be for all the participants to meet with me as a group, to discuss the findings from the first stage in the light of the beliefs and values participants may hold in common regarding their roles, and to consider how these relate to nursing theories and models. We will discuss any ways in which the participants feel their nursing skills bring a particular contribution to the assessment process, and also whether the circumstances in which they work support their practice as nurses or constrain their practice in any way. We will explore any possible ways in which participants feel practice could be changed to become more emancipatory, i.e. freeing nurses to exercise their skills further, or enabling families to use the assessment process more positively. This session will be audiotaped for transcription. After the session I will produce a synthesis of the findings which will be circulated to the group for comment and revision before a final version is prepared and circulated.

Confidentiality and review of data

To protect the confidentiality of participants and families, all data will be anonymised. However as there are so few nurses in child development within South Staffs and Shropshire Healthcare Foundation NHS Trust, it is not possible to completely ensure that participants could not be identified. All participants will review the findings and the way in which their thoughts are to

be presented in the draft report which will inform the thesis. They will be free at the point of review and for three weeks following the review, to remove any data they feel may breach their anonymity. After review by the participant and their

agreement, data contributed will remain in the study covered by the participant's original informed consent.

Participants will be free to withdraw from the study at any point before the audiotaped group discussion, at which point their contribution will influence the combined data. This data will be used in the thesis and may also be included in publications, in conference presentations and possibly on academic websites. Until submission of the thesis the raw data will be kept securely at the researcher's home, and thereafter it will be stored in Sheffield Hallam University research data archive according to the university protocols.

Extent of commitment asked of participants;

1. Writing of narrative	up to 2 hrs
2. Possible elaboration at researcher's request	up to 1 hr
3. Meeting individually with researcher	up to 1 hr
4. Group discussion	up to 2 hrs.
5. Review of report, give comments/revisions	up to 1 hr
6. Review of final report.	up to 1 hr

Benefits to participants.

Participating in the study will give nurses an opportunity to take time to stand back and reflect on the values and views that underlie their practice, and to think about and articulate the particular skills they contribute as nurses to the assessment process for children with possible autism. Through discussion within a mutually supportive group, they may see more clearly whether and how the circumstances surrounding assessment affect their work in this area. It is hoped that this will be a positive experience for nurses which will enable them to further understand and progress their practice. By participating in research, these nurses will also gain the opportunity to contribute to the development of nursing knowledge.

<u>Contacts for further information;</u>

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Version 3: 27.3.12

The role of the nurse during preschool assessment for autism

PARTICIPANT CONSENT FORM

I have read the information sheet regarding this study and understand the purpose of the research and the extent of the commitment asked of participants.

I am willing to participate in this study and for my written account and reflections on practice to be used as data in the research. I am willing to participate in individual and group discussions, which I understand will be audiotaped, transcribed and will then form part of the data. I am willing for data generated during this study, including direct quotations, to be used in fulfilment of a PhD thesis, in presentations for conferences, and in publications, including possibly on the internet.

I understand that I will be offered the opportunity to review data and the emerging findings of the study, and to ensure these are an accurate representation of my reflections. From the point of review I will have 3 weeks during which I will be free to withdraw any data which I consider may lead to my identity being revealed. Once I have reviewed and agreed the data to be included I understand it will remain part of the study. I understand that following the submission of the thesis the data will be stored in the Sheffield University data storage archive, and prior to this it will be kept securely at the researcher's home.

Signed;   Dated;

Group discussion p.23 line 27

Participant 1   *And I think that us being here together, the [named] team... nurses together, you might have a different opinion, we can share experiences more. I'm a bit of an oddity, because I've worked with everyone, and not many have done that, but you do gain from the opportunity to work with one another.*

[general agreement]

Participant 2 *That's true – it's a bit like divide and conquer isn't it because the medics have always had forums where they all meet.*

Participant 3 *Every month...*

Participant 4 *And they never let a supervision go, no matter how long the waiting list is...*

Participant 2   *Whereas if we want a meeting they say 'what do you want a nurses' meeting for?'*

Participant 1   *And you know, if you have a doctors' meeting, every doctor attends, whereas if you have a nurses' meeting, how many of us send apologies because we're too busy?*

[general hubbub, agreement]

Participant 2   *Yes, we'll cancel it, we'll cancel to go to a CAF, it always happens because we instinctively prioritise the patient over everything else.*

Page 24 line 26

Participant 2 *But I also think about our job plans as nurses...we drop our admin and CPD times to see patients all of the time.*

[General agreement]

Participant 2 *A psychologist would not compromise on any of those things ever. If there was a crisis with one of their own patients, they would not give up their CPD time even if they were just sat in a room with a book.*

Participant 3 *Really?*

[general quiet, shock,disapproval]

Participant 2 *And a lot of the medics in* [named team] *are like that, you know, there are these slots, and no matter what....because to us an admin slot is an opportunity to catch up on phone calls, get everything on our list to do, because we can't sleep unless we've done those things.*

Participant 3 *Absolutely*

Participant 1 *I was doing my lookout...outlook...*

[general laughter]

Participant 1 *...diary!.....and like there were all these admin slots, and I thought, you know what, if all of those admin slots got used for admin, I'd be well ahead of everything, but it never does, does it, never ever ever?*

Participant 2 *In* [named team] *there was a real emphasis that everyone had to work to a job plan, and everyone did a job plan, and we got told the most we could see in a day was five patients, that was including new, and they were booking half a day admin and we were going no, if you see five you've got all your admin time there, and the psychologists were going no, we can only see three and then we'll need another half day of admin,,,and were were saying you are actually going to see less work from us. I can't work to this job plan. Ethically, I can't do it, because me,* [name] *and* [name] *would be seeing 7,8 at least AND doing our phone calls, we wouldn't be blocking out separate admin time, but its just the way...different people...work. Other disciplines, their focus is on admin and personal development...we don't spend that time.*

Researcher *So it's the thing of the patient...*

[All in chorus] *Comes first!*

Researcher *Above all these other things...*

Participant 2 *And its not only our emotional cost, it's our educational, development cost...*

Researcher *Maybe we have to be a little bit reflective about that...*

Participant 2 *How many have cancelled courses, because there's a big*

meeting coming up?

[general agreement]

Participant 1 *And supervision as well, you know...*

Participant 4 *We feel guilty about supervision...I do.*

Participant 2 *It just doesn't sit well, does it?*

Participant 1 *And yet, we could have an hour, and there might be a few little snippets about so and so did this and that...but the majority of that time is real supervision, and yet we feel bad we've spent an hour talking...*

Participant 4 *And you will apologise at least 10 times in that hour for taking time...*

Researcher *So we've got professional...everything...being subordinate to the immediate needs of the patient?*

Participant 4 *But is that our fault?*

Researcher *...it's about reflective practice, isn't it?*

Participant 2 *That's what I see a proper nurse is...*

Participant 5 *Right!*

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