

**The University of Western Australia
Graduate School of Education
PhD Research Proposal**

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A. PROPOSED STUDY

(i) Project Title

How parents deal with the education of their child with an Autism Spectrum Disorder: a constructivist grounded theory study.

(ii) The Research Aim

The aim of this study is to develop substantive theory about how parents deal with the education of their child diagnosed with an Autism Spectrum Disorder. A series of in-depth case studies, conceptualised within the social theory of symbolic interaction, will use both autoethnographic and constructivist grounded theory methods to generate thick description and explanation.

According to the Diagnostic and Statistical Manual (4th TR ed.) of the American Psychiatric Association (2000), Autism Spectrum Disorders (ASD) or Pervasive Developmental Disorders (PDD) are “characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behaviour, interests, and activities” (p.69). ASD’s are lifelong disorders which have no identified aetiology or cure (Frith, 2003). There are five complex, often severe, neurological disorders under the PDD category where manifestations vary greatly depending upon the developmental level and chronological age of the individual. These are: Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder and Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism).

Prevalence rates for all forms of ASD’s have risen dramatically over the last twenty years from 1 in 10,000 in the 1980’s to 1 in 166 today (Fombonne, 2003; Gillberg, 2004; Kirby, 2005). Such increases have, most often, been attributed to changes in case definition and an increasing community and professional awareness of the diagnostic criteria for PDD (Fombonne, 2003) although other theories (Kirby, 2005) are also now apparent in mainstream discourse. To further complicate matters families with one affected child have a 45 times greater recurrence risk of siblings also being affected by an ASD than would occur in the general population (Jamain et.al., 2003). Along with any ASD diagnosis there is also a 25% greater susceptibility of comorbidity with another psychiatric disorder and/or medical condition (Gillberg & Billstedt, 2000). Autism is associated with mental retardation in about 70% of the cases and is over represented amongst males with a male to female ratio of 4.3:1 (Fombonne, 2003). “Follow up studies suggest only a small percentage of individuals with the disorder go on as adults to live and work independently. In about one-third of cases, some degree of partial independence is possible” (American Psychiatric Association, 2000, p.73).

It is increasingly evident that there is no single best suited and universally effective educational method for all children with an ASD over time. Research has found that the best programs are those that incorporate a variety of objectively verified practices and are designed to address and support the needs of individual students and the professionals and families with whom they are linked (National Research Council, 2001; Olley, 1999; Simpson, 2005). This places families, and especially parents, in very demanding circumstances regarding adoption of appropriate and effective educational practices regarding their individual child with an ASD. Consequently there is a long standing tradition by parents of children with an ASD of accepting educational methods and strategies that lack efficacy and proven utility (Gresham et.al., 1999; Heflin & Simpson, 1998; Simpson, 2004; Simpson, 2005). Families do

not have access to educational research of specific students with an ASD which meets rigorous peer review and has a history of yielding positive results (Simpson et.al., 2004). The difficulty is that there are only limited samples of students with an ASD with similar characteristics, programs and needs because of the highly idiosyncratic nature of the disorder (Simpson, 2005).

There is a call to provide different research methodologies to answer different questions in regard to education of child/ren with an ASD so that parents are able to determine whether a particular strategy or educational method is suitable for their individual child/ren with an ASD (Horner et al., 2005; Shavelson & Towne, 2002; Simpson, 2005). The preferred source of such information is at the local level where parents and professionals who possess the most knowledge and information about individual students can be found (Simpson, 2005). Longitudinal ethnographic research tracing the development of problems and responses over a substantial period is relatively rare as compared to the many cross-sectional studies which have been undertaken (Gray, 2002; Fleishmann, 2005). This researcher has been unable to locate any research specifically focussing on how parents deal with the education of their child with an ASD over time.

Western Australia (WA) is a good site for a study of this type because WA is the only state in Australia which has a diagnostic register, established in 1999, which provides a breakdown of children diagnosed with an ASD by their autism classification, age, gender, intellectual functioning, adaptive behaviour, communication skills and origin of birth (WA Register for Autism Spectrum Disorders, 2000). This would allow future studies to use the findings of this proposed study as a basis for more extensive research into how parents deal with the education of their individual child with an ASD over time. Also WA is seen by some as currently providing some of the best support for children with an ASD in Australia (Eccleston, 2005). The government are also presently committed to providing evidence based, flexible and responsive support to students with an ASD in public schools (Banks, 2005).

Against this background, this researcher seeks to provide an in-depth understanding and explanation regarding how a limited number of WA parents in different families deal with the education of their individual child/ren with an ASD over time. The research envisaged will have an autoethnographic component which will seek to capture rich data and an insider perspective in the form of the researcher's own involvement in the field of educating her own child with an ASD over the last seventeen years. The research will also seek to develop substantive theory about how parents deal with the education of their individual child with an ASD over time. The research will provide insight into educational strategies which could be adopted to reduce stress and mental illness and improve educational outcomes in families who have a child with an ASD.

(iii) Definition of Terms

The definition of 'child with an ASD' refers to any offspring/s of differing ages with an ASD in the family. The term 'perspectives' refers to frameworks through which people make sense of their worlds (Woods, 1992). 'Inclusion' is understood to mean where the education of the student with an ASD is "embedded within the normative educative pathways within the classroom and school" (Uditsky, 1993, p.88). 'Deal with' refers to how people see, define, interpret and consequently respond to a situation (Woods, 1992). 'Education' will incorporate both formal and informal elements of the educational process used over the lifetime of the child with an ASD,

(iv) Background/Context of the Project

Historically, education of the intellectually disabled in WA has followed the linear pattern set by other states in Australia and countries in the Western world (O'Donoghue & Chalmers, 1998). The pattern has been initially exclusion (1830's to 1920's), through to segregation and integration (1930's to 1960's) and finally to limited inclusion (1970's to late 1990's) (O'Donoghue & Chalmers, 1998). Presently, WA children diagnosed with an ASD may experience a range of segregated,

integrated, inclusive or home-schooling educational settings with varying degrees of success (Chapman & O'Donoghue, 2000; O'Donoghue & Chalmers, 1998; Reilly, 2001; Wills and Jackson, 2000).

Legislation, in the form of The Equal Opportunity Act 1984 (amended 1988), Human Rights and Equal Opportunity Commission Act (1986), the Commonwealth Disability Discrimination Act (1992), the WA Disability Services Act (1993) and the WA School Education Act (1999), underpins many of the educational initiatives undertaken to provide a more inclusive schooling community for the disabled in WA. This legislation means that all schools in WA must enable all students to access educational services and schools cannot deny access where unjustifiable hardship to the school has not been proven.

Australian ASD prevalence rates indicate that incidence ranges from 2 to 21 per 10,000 births, with boys four times more likely to have the condition (Fleming, 2005). The WA Autism prevalence rate is currently being tracked by the WA Register for Autism Spectrum Disorders. The register puts the Autism prevalence rate for WA at 8 per 10,000 children compared to the lower rate of 5.1 per 10,000 recorded in NSW (Fleming, 2005). According to the National Autism Forum 2005 this translates to an average of 200 people being diagnosed per year in Western Australia with 10% being over the age of thirteen years (Palm Consulting Group, 2005).

In Western Australia the responsibility for educational service provision to children with an ASD, below school age, rests with the Disability Services Commission (DSC). To receive government funding for early intervention parents must seek a diagnosis but this has often proven to be a protracted experience with limited funding at the end of the process. Diagnosis currently involves a multi-disciplinary team made up of a paediatrician, clinical psychologist and speech pathologist conducted either privately or through the health or disability sectors (Palm Consulting Group, 2005). A representative at the Autism Centre of Disability Services Commission (DSC) confirmed on 19 July, 2005, that diagnosis of children under six could take anywhere from three to five months, whilst diagnosis of school age children could presently take twelve to twenty four months.

After diagnosis, parents who qualify for funding must choose from four accredited Autism early intervention providers who provide a choice of early intervention models (Palm Consulting Group, 2005). Funding for three of the four models offered is generally adequate, however one of the most efficacious interventions based on long term research is grossly under-funded. This model, provided by Intervention Services for Autism and Developmental Delay (ISADD), is based on the Applied Behaviour Analysis / Discrete Trial Training (ABA/DTT) method (Birnbrauer & Leach, 1993; Eccleston, 2005; Lovaas 1987; Lovaas, 2003; Lovaas & Smith, 1989; McEachin, Smith & Lovaas, 1993; Smith & Lovaas, 1998). Government funding for this model is inadequate (approximately ten hours per week) and does not cover the thirty to forty hours per week of recommended intervention needed in best practice models. Most families struggle to find up to \$60,000 per year to cover the intensive therapy needed to conduct this model (Eccleston, 2005) even though it is seen as one of the most efficacious early educational interventions (Palm Consulting Group, 2005).

Presently there are four targeted kindergarten and pre-school units for 5 year olds in the metropolitan area which offer up to two days per week of ABA (Palm Consulting Group, 2005). These Autism Early Intervention Units have had two independent evaluations undertaken with follow-up of students now in mainstream. Results indicate that students make encouraging progress and that these gains are sustained in mainstream settings with minimal support (Banks, 2005).

From the commencement of school age the major educational service provision for children with an ASD rests with the Department of Education and Training (DET). Presently students with an ASD are found in mainstream schools, schools with Education Support Units, Education Support Schools/Centres and in home schooling

environments. Present day figures indicate there are 1046 students with an ASD attending public schools throughout Western Australia (Palm Consulting Group, 2005).

A 1998 report, *Models of Educational Service Provision for students with an ASD within Government Mainstream Schooling*, sought information about existing practices so that policy and a range of educational options could be developed to cater for the varying needs of students with an ASD in WA government schools. However, most of the information gathered was from primary school and home schooling sites with only one parental response gained from a high school context. Results indicated that in order to meet the needs of a wide range of students with an ASD in a variety of mainstream schools a flexible approach to the delivery of educational services was essential. A range of issues were identified that impact on the ability of the DET to develop and implement effective models of service delivery for students with an ASD. No single approach completely addressed all the issues as many of the solutions have a degree of incompatibility with solutions to other issues (Crosby, 1998).

Parents' responses for this 1998 report indicated that there was difficulty in catering for the needs of a very diverse group of students. Areas of concern were: lack of clear guidelines for schools to follow upon enrolling students with an ASD; lack of consultation with parents about their own child's needs; lack of appropriate training of both aides, teachers and school staff; lack of expertise, continuity and coordination of support services; lack of teacher aide time; lack of social skills programs in the curriculum; and infrequent, inefficient use of case conferences devising Individualised Education Plans (IEP's). Along with highlighting many areas of concern, parents described situations where, on occasion, situations were working well. A common feature of such situations was the establishment of good communication between parties and a willingness to work together to achieve outcomes (Crosby, 1998).

The WA Autism Management Group who oversee state-wide educational services for students with an ASD indicated during the 2005 Parliamentary Estimates Hearings that there is an ever increasing number of students with an ASD attending public schools (197 in 1995 to 1047 in 2005); and that there are limited planning and strategies in place to support students with Autism in the area of transition from primary to secondary school; and there is a low level of retention and participation of students with an ASD in secondary schools (Banks, 2005). The government are presently committed to providing evidence based, flexible and responsive support to students with an ASD in public schools (Banks, 2005). Key initiatives include an Autism Intervention Team and Team Leader (Autism) based at Centre for Inclusive Schooling (CIS); specific training of school psychologists, teachers and teacher aides in knowledge and understanding of ASD's; allocation of funds to establish four Principal Consultants and 211 (0.3FTE) Learning Support Coordinators (LSC); extra support for a targeted high school group of students with an ASD; establishment of a Joint Wrap Around Project to allow agencies to be more responsive to families; and in future, education support schools will be located on mainstream school sites (Banks, 2005; Autism Management Group, 2005).

It is clear that while there is some feedback (Crosby, 1998) from parents regarding their experiences educating a child with an ASD at primary school in WA, we know little about parents' experiences with early intervention, high school and post-secondary options in regard to educating their child with an ASD in WA. Presently there is a Masters student at Murdoch conducting needs assessment research of secondary aged students diagnosed with an ASD. No researcher has attempted to develop an in-depth, longitudinal understanding or explanation as to how WA parents deal with the education of their individual child with an ASD over time.

(v) Literature Review

Research on the social impact on families having a child with an ASD has shown that the child's behaviours can be a constant source of stress to both caregivers and siblings (Sanders and Morgan, 1997; Sivberg, 2002). Parents, especially mothers, of

children with an ASD are more likely to experience serious psychological distress, including depression and anxiety, than parents of children with other developmental disabilities (Bromley et. al., 2004; Grayson, 2004). Extremely antisocial and disruptive behaviours such as self-injurious, tantrum, obsessional, compulsive and violent behaviours can often make normal family life almost impossible (Gray & Holden, 1992). Many families feel isolated (Seligman and Darling, 1997) and the self-confidence and self-esteem of family members are often at risk (Gray & Holden 1992, Powers, 1989). The most pronounced stress being experienced during initial diagnosis (and the subsequent search for appropriate treatments and education for the child with an ASD) and transition periods in the child's life (Gray, 2002). Research has shown that the stress experienced by mothers has an inverse relationship with the educational progress of their child with an ASD (Robbins et al., 1991).

Research into appropriate educational choices for parents is complicated by the heterogeneity of the condition and the accompanying comorbid conditions which may also present along with the ASD diagnosis. Reasonably comprehensive early intervention research shows that early, intensive, behavioural and psycho-educational intervention can sometimes dramatically improve the bleak prognosis given to children diagnosed with an ASD. (Birnbauer & Leach, 1993; Green, 1996; Jordan, 2005; Lovaas, 1987; Lovaas, 2003; Lovaas & Smith, 1989; McEachin et.al., 1993; Matson et.al., 1996; Smith & Lovaas, 1998). A research review of ten years of research into effective educational practices for students with an ASD revealed six best practice core elements: individualized supports and services for students and families; systematic instruction, comprehensible/structured learning environments, specialized curriculum content, functional approach to problem behaviour; and family involvement (Iovannone, et.al., 2003).

There is more limited research concerning inclusion of students with an ASD in mainstream education. This research has found that some students with an ASD benefit more from partly or fully segregated programs depending upon their individual profile, development and the educational context they must negotiate with or without support (Bondy, 1996, Jordan, 2005; Myles & Simpson, 1993; Myles & Adreon, 2001; Newson, 1995; Simpson, 1994; Simpson, 1995a; Simpson & Myles, 1993; Smith, 1996; Tomchek et.al, 1992). Research into education of students with an ASD in high school environments has shown that the most salient features of the student's autism are accentuated during adolescence and this can lead to serious academic and social problems (Adreon & Stella, 2001; Myles & Adreon, 2001).

Little research has been conducted on the post secondary circumstances of students with an ASD (Powell, 2003). In terms of students with general learning difficulties and/or psychiatric disorders, tertiary study has been found to be very challenging. Depression and anxiety are commonly reported concerns (Arthur, 1998). The more complex demands of university life often result in exacerbating the student's learning, oral communication and social interaction difficulties (Westby, 2000). Such students often show a lack of understanding of their own learning needs, lack self advocacy skills and feel uncomfortable about disclosing their conditions because of possible stigmatisation; all of which interfere with their ability to seek support (Smith et.al., 2002; Patwell & Herzog, 2000). It is therefore timely for this researcher to produce longitudinal ethnographic research which provides an insider perspective and theory to explain how parents deal with the education of their child/ren with an ASD over time.

(vi) Substantial and Original Contribution to Knowledge

The proposed study will make several substantial and original contributions to knowledge:

- This study will develop substantive theory in an area where no such theory presently exists.
- The theory will lead to an understanding and explanation of the situation faced by parents trying to educate their child/ren with an ASD.

- The theory will be relevant to the development of policies concerning parents trying to educate their child with an ASD in WA.
- This study will provide a unique, autoethnographic, in-depth perspective of the situation faced when trying to educate a child with an ASD in WA.

B. RESEARCH METHODS

This research will be conducted as a series of case studies (Stake, 2000) and will be informed by feminist, ethnographic research practice (Haraway, 1988; Olesen, 2000; Oliver (1992); Reinharz, 1992). The study is conceptualised within the social theory of symbolic interaction (Blumer, 1969; Woods, 1992), and will use both autoethnographic (Bochner & Ellis, 1999, Bochner & Ellis, 2002; Ellis, 1995; Ellis, 2004; Ellis & Bochner, 1996a; Ellis & Bochner, 2000) and ‘constructivist’ grounded theory methods (Charmaz, 1990, 1991, 1995c, 2000; Glaser, 1978; Glaser, 1992; Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1990, 1998) to achieve the dual aim of developing:

- (a) theory explaining how WA parents deal with the education of their child/ren with an ASD over time.
- (b) an authentic, credible and in-depth understanding of how WA parents deal with the education of their child/ren with an ASD over time.

(i) Case Studies

To use Stake’s (2000) terminology, it is intended that an ‘instrumental’ autoethnographic case study will be initially carried out followed by a ‘collective’ case study. The initial ‘instrumental’ autoethnographic case study will seek to examine a single case in order “to provide insight into an issue” (Stake, 2000, p.437). Following on from this a ‘collective case study’ will be undertaken in the manner described by Stake (2000) as an “instrumental study extended to several cases” (p.437). Selection of cases will be in line with grounded theory’s use of the ‘constant comparative method’ which seeks to compare different people’s views, situations, actions, accounts and experiences (Charmaz, 2000). Theoretical sampling will take place within and between cases “whereby the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges” (Glaser, 1992, p.101).

(ii) Feminist ethnographic practice

Given that much traditional research has been seen as representing ‘the disabled’ in ways which they view as disempowering (Morris, 1992; Oliver, 1990, 1992, 1996; Slee,1996), it is important that new research recognize the power dynamics that exist in all research production. Barnes (1992) calls for research into disability to become ‘emancipatory’ whereby “research is about the systematic demystification of the structures and processes which create disability, and the establishment of a workable ‘dialogue’ between the research community and disabled people in order to facilitate the latter’s empowerment” (p. 122). Such awareness is paramount in constructing a study which seeks to understand the disabled (and those who advocate on behalf of them) in ways which they view as emancipatory rather than discriminatory. Hence feminist ethnographic research practice (Haraway, 1988; Olesen, 2000; Oliver, 1992; Reinharz, 1992), will be adopted in this study. While the researcher’s voice will be inevitably privileged, every effort will be made to reduce the distance between the researcher and the researched to allow those with the least powerful voices (or their advocates) to be heard. At the same time though the researcher will “try to maintain a delicate balance between achieving as complete an understanding of insiders’ perspectives as possible and sociological distance, thus permitting rigorous analysis of them” (Woods, 1992, p.355).

(iii) Symbolic Interactionism

Chicago sociologist Herbert Blumer first coined the term “symbolic interactionism” in 1937, and this approach required the study of people in their natural environment not through abstracted forms or artificial experiments (Woods, 1992). Symbolic interactionism is understood through Blumer’s (1969) “three central principles: (1)

human beings act toward things on the basis of the *meanings* that the things have for them, (2) this attribution of meaning to objects through symbols is a continuous *process*, and (3) meaning attribution is a product of social interaction in human society” (Woods, 1992, p.338). Human conduct is always ‘situated’ and can only be understood in the context in which it is found. Such notions as self, significant others, time, place, culture and structure are key components of ‘situation’ and these exist only if the individual deems them important (Blumer, 1969). As indicated by Woods (1992) “people act on the basis of meanings that objects have for them. They do not respond to an objective reality or to how others perceive it but, rather, to how they interpret it” (p.351). This study will explore what symbolic meanings and/or actions participants share in terms of their situation; and how and why these relationships exist and if they hold over time and educational contexts.

(v) Autoethnographic Writing.

In the initial instrumental case study autoethnographic writing (Bochner & Ellis, 1999, Bochner & Ellis, 2002; Ellis, 1995; Ellis, 2004; Ellis & Bochner, 1996a; Ellis & Bochner, 2000), in combination with constructivist grounded theory methods, will be used so that the researcher may capture rich data from her own experiences of the research field spanning some seventeen years. Autoethnographic writing is described by Ellis and Bochner (2000) as “an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural” (p.739). This entwining of methods is embedded in the understanding that “discourses are about what can be said and thought, but also about who can speak, when, where and with what authority” (Ball, 1994). Slee (1996) calls for disability research to give much more consideration to the more “authentic voices” of those in the field (parents; disabled students and their advocates; and disabled activists). The researcher recognizes that autoethnographic writing cannot accomplish all representational goals but it does allow a unique, concentrated insight into one perspective of the research area and as such is a valuable addition to more traditional research.

(vi) Constructivist Grounded Theory Methods

Early grounded theory studies were conducted by its founders, Glaser and Strauss (1967), with a positivist understanding that qualitative research was an objective social science whereby some neutral observer researched an external reality which was there to be ‘discovered’ (Glaser & Strauss, 1967). By contrast, Charmaz (2000) explains that constructivist grounded theory “assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects’ meanings” (p.510). It is the intention of this researcher to follow Charmaz’s (2000) lead and “form a revised, more open-ended practice of grounded theory that stresses its emergent, constructivist elements” (p. 510). Charmaz (2000) retains the following strategies of grounded theory: simultaneous collection and analysis of data; data coding processes; comparative methods; memo writing aimed at the construction of conceptual analyses; sampling to refine the researcher’s emerging theoretical ideas; and integration of the theoretical framework (p. 510/511). In the context, theory is defined as something which “explicates a phenomena, specifies concepts which categorize the relevant phenomena, explains relationships between concepts and provides a framework for making predictions” (Charmaz, 1990, p.1164).

C. RESEARCH PLAN

(i) Guiding Questions

The three central principles of symbolic interactionism guide the initial set of general questions outlined below. The nature of this study is unfolding, emerging and open-ended and its distinctive structure, including specific questions, will develop once a particular focus has begun to emerge during the course of the study (Punch, 2000). Lofland’s (2002) suggestion of inclusion of general questions regarding type, structure, process and agency when conducting analytically ethnographically inclined research informs the construct below. The movement of questions from general to specific is organized under headings as suggested by Lofland (2002, p.143,144):

Type (What is it? What are its defining features and its varieties?)

- How do parents define 'education' in relation to their child with an ASD?
- What meanings do parents make of such terms as 'disability' and more specifically 'autism' since the birth of their child with an ASD?
- How do these meanings ('education', 'disability' and 'autism') inform parents' actions in relation to the education of their child with an ASD?
- Do parents identify more significantly with the culture of the disabled since the birth of their child with an ASD?
- What factors, if any, make parents feel an affinity and membership with the culture of the disabled?
- Do parents feel there are culture specific differences for families who have a child with an ASD versus families who have children with other varying disabilities?

Structure (What is its detailed organization?)

- What is the structure and sequence chosen by parents when educating their child with an ASD?
- Why do parents choose such structures and sequences when trying to educate their child with an ASD?
- How successful are such decisions in relation to the educational progress of the child with an ASD and/or the overall well being of the family over time?

Process (How does it operate?)

- What curriculum and pedagogy decisions are made by parents when trying to educate their child with an ASD over time?
- What underpins such decision making and do these decisions change over time?
- What factors influence parents in their decision making regarding curriculum and pedagogy over time?

Agency (How do people strategize in or toward it?)

- Is there an overarching strategy used by parents to educate their child with an ASD over time?
- Are different strategies required by parents to manage different parts of the education process of the child with an ASD?
- Does historical context impact on the strategies needed by different parents who have a child with an ASD?
- Do parents' backgrounds have any impact on their ability to deal with the education of their child with an ASD?
- Do these strategies change or remain static over time?
- Do these strategies have elements in common with other theories of how parents deal with the education of their child with a disability?
- Or would such theories need modification in relation to the task set before parents who have to deal with the education of their child with an ASD?

(ii) Selection of Participants

The study sample will be a small number of metropolitan Perth based families who are presently dealing with and have formerly dealt with the education of their child with an ASD. Ideally the families will be dealing with the education of their child with an ASD in a metropolitan primary, high school or in some post compulsory school context during 2006 and 2007. Included in those families will be an autoethnographic examination and explanation of the researcher's own family situation dealing with the education of her seventeen year old son diagnosed with an ASD. The children will have an official diagnosis of an ASD and be registered with DSC. The researcher will use her involvement with fellow parents of children with an ASD over the last seventeen years to access appropriate participants. Otherwise contact will be made with the Autism Association of Western Australia or DSC to seek direction in accessing alternative appropriate participants

Choice of families will be determined by accessibility, positioning in the formal education process and involvement in differing government, private or home schooling educational contexts. In this way any emerging theory may account for

variation across different educational contexts (Charmaz, 2000). In keeping with theoretical sampling in grounded theory, number and type of participant families will be determined by the needs of the emerging theory whereby data will be collected and analysed and subsequent collection will be guided by emerging directions in that analysis (Punch, 2005, p.158). Such sampling will continue until theoretical saturation is reached and new data reveals no additional insights (Glaser and Strauss, 1967; Punch, 2005).

(iii) Data Collection

Semi-Structured Interviews

Semi-structured interviews will be the main, preferred data collection method where participants are able to freely discuss their individual situations as to how they deal with the education of their child with an ASD over time. Interviews will be conducted as “active interactions between two (or more) people leading to negotiated, contextually based results” (Fontana & Frey, 2000, p.646). Questions will be open-ended and a relatively unstructured interviewing format will be adopted. Interviews will take place at times and in settings where participants feel comfortable to speak about important life issues (Taylor & Bogdan, 1998). The researcher will seek permission to tape record such sessions and participants will be offered an aide memoire or semi-structured interview guide prior to each interview so that they can be reflective about their responses.

Given that this is an unfolding study, grounded theory theoretical sampling principles will be used to reach theoretical saturation on any particular category being investigated. This means that interviews cannot be thoroughly planned before the study commences. The first round of interviews will be used to gain a formative understanding of each parent’s perspectives and actions with the general research questions outlined above being used as a guide. Subsequent interviews will be driven by the needs of the emerging theory whereby data will be collected and analysed according to emerging directions in that analysis (Punch, 2005). Participants will be asked to discuss and verify, individually and in groups, the accuracy of the researcher’s representation of their views and the theory emerging from such views.

Informal Group Meetings

To support the main data collection method of semi-structured interviews informal group meetings will take place. At the initial meeting a brief, general explanation of feminist ethnographic research practice, autoethnography, proposed data collection and constructivist grounded theory methods will occur. Ethical issues, informed consent, right to privacy and protection from harm will be discussed and consent forms will be distributed. Subsequent group meetings will occur occasionally throughout the research process as a form of ‘member checking’ to keep all participants informed of the progress of the research.

Observation

The researcher will also seek permission to observe educational situations in both home and school settings. Observations will be used to confirm interview data or investigate disparities between the actions undertaken by the participants and the meanings they have attributed to that situation in previously undertaken semi-structured interviews (Woods, 1992).

Document Study

Official and public documents, including organisational documents, newspaper articles, government reports (Taylor & Bogdan, 1998) will be sourced to give the researcher a broad understanding of the educational context. The researcher will also seek access to private family records and reports detailing assessments and diagnoses conducted over the history of the life of the child/ren with an ASD. This would enable the researcher to have a strong understanding of the child involved in the study and provide triangulation regarding the parent’s perspective of that child.

(iv) Data Analysis

Throughout data collection, data analysis will take place through systematic procedures regarding abstraction and comparison outlined in the constructivist grounded theory method (Charmaz, 1990, 1991, 1995c, 2000; Glaser, 1978; Glaser, 1992; Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1990). The constructivist grounded theory approach, like its grounded theory counterpart, uses an iterative pathway moving from data collection to emergent theory and back again until theoretical saturation is reached. Charmaz (2000) retains use of the three grounded theory coding methods: open coding, axial coding and selective coding with the understanding that a researcher may alternate between all three forms of analysis depending upon the changing circumstances of the study (Glaser & Strauss, 1967). Coding is seen as “the pivotal link between collecting data and developing an emergent theory to explain the data” (Charmaz, 1995c, p.37).

Charmaz (1995c, 2000) recommends line-by-line open coding to start the chain of theory development whereby actions or events are interpreted into open codes. These initial open codes serve to break open the data into categories, help the researcher to begin to see processes and keep the researcher grounded in the data (Charmaz, 1995c). Axial coding is concurrently used to reassemble the data so that relationships between categories and conditions which give rise to the category can emerge (Charmaz, 2000). Selective coding is used in conjunction with other coding to sort large amounts of data to a higher level of abstraction and to ‘check on the fit between emerging theoretical framework and the empirical reality it explains’ (Charmaz, 2000, p.516). Charmaz (2000) retains use of dimensionalizing and conditional matrices to allow researchers’ emerging theories to become more complex and precise (Strauss & Corbin, 1990). Memo writing is seen by Charmaz (2000) as occurring throughout the analytic process whereby memos elaborate processes, assumptions, and actions that are subsumed under codes. Feedback will also be sought throughout the analytic process from both participants and other researchers to ensure that analysis conducted by this researcher is grounded in the data (Charmaz, 1995).

(v) Proposed Timing

March – December 2005

- Commence literature review / Submit research proposal / Obtain ethics approval

Jan 2006 – April 2006

- Locate participants / Hold 1st informal meeting / Continue literature review

May 2006 – Sept 2006

- Conduct 1st round of interviews / Transcribe interviews / Seek feedback
- Analyse data / Observe learning environments
- Continue literature review

Oct 2006 – Feb 2007

- Conduct 2nd round interviews
- Obtain official records/public documents / Observe learning environments
- Transcribe interviews / Seek feedback / Analyse data / Continue literature review

Mar 2007 – July 2007

- Hold 2nd informal meeting/ Conduct 3rd round interviews /Transcribe interviews
- Observe learning environments/ Seek feedback
- Analyse data / Continue literature review

Aug 2007- Dec 2007

- Conduct 4th round of interviews/Observe learning environments
- Transcribe interviews / Seek feedback / Analyse data
- Continue literature review

Jan 2008 – Dec 2008

- Prepare first draft of thesis / Hold 3rd informal meeting

Jan 2009 – Feb 2009

- Revise thesis to produce final draft

Mar 2009

- Submit final thesis/ Final informal meeting

C. FACILITIES

(i) Supervision

Professor Keith Punch, of the Graduate School of Education, is a specialist in research methods and will bring significant experience and knowledge to support this study, especially in the area of grounded theory research methods.

Associate Professor Anne Chapman, of the Graduate School of Education brings significant experience and knowledge regarding qualitative research methods to support this study.

(ii) Special Literature

The majority of literature needed to assist this study will be obtained through the UWA library, either through access to their collections, or through interlibrary loans. Other literature will be sourced through relevant government and private organisations.

D. LEADING SCHOLARS

Professor Kathy Charmaz, Sociology Department, Sonoma State University.
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Professor Carolyn Ellis, Communication and Sociology Department, University of Southern Florida. **cellis@cas.usf.edu**

Associate Professor David Leach, School of Psychology, Murdoch University.
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E. ESTIMATED COSTS

GSE has made available \$1,190 per annum to cover the costs of this study. This will cover: copying (\$100); printing (\$250); telephone (\$120); email and downloads (\$120); and IT support (\$300). Application will also be made to GSE to provide \$300 per year to cover software or minor equipment. This should cover the cost of a micro audio recorder needed during this study.

F. CONFIDENTIALITY AND INTELLECTUAL PROPERTY

Throughout the study conscious efforts to maintain confidentiality will be made. All information provided by participants will be used solely for the proposed research and will be securely stored in the Graduate School of Education to ensure privacy for all families involved.

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