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'Mamiaith': The Lived Experiences of Mothers of Children with Autism in Wales.

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'Mamiaith': 'Mother tongue'

Abstract

An Interpretative Phenomenological Analysis (IPA) methodology was employed in order to explore the lived experience of bilingual parents of children and young people with Autism in Wales. This is an initial exploratory study aimed to explore a previously un-researched area. Due to the bilingual status of Wales, it was thought that an exploration in this area was pertinent. Much of the international research on bilingualism and ASC has focused on quantitatively examining the effects of bilingualism on children with ASC (Yu, 2016). However, this qualitative research has taken a social constructionist approach. Five semi-structured interviews were carried out with a homogeneous sample of parent participants (all Mothers). Interpretative Phenomenological Analysis was conducted following the guidelines from Smith, Flowers and Larkin (2009) and the study demonstrates research validity under Yardley's (2000, 2008) qualitative criteria. The super-super ordinate IPA themes were: *Making Sense of Autism: The Winding Path, Making Sense of Bilingualism, and Ni a Nhw [Us and Them]: Navigating the Social World.* A complex and multifaceted process was interpreted from the parents' sense-making, which raises questions that warrant further exploration.

Summary

This thesis will be made up of three parts namely the literature review, the empirical paper and the critical review. Part one will aim to critically explore the current research pertaining to Autism and bilingualism. The review will then go on to explore the theoretical underpinnings of Autism and bilingualism concluding with a critical evaluation of the current research relating to parental perceptions of bilingualism, and how all of these explorations resulted in the research questions for this piece of research.

Part two, the empirical paper, will provide a detailed account of the process undertaken to explore the chosen research questions surrounding the lived experience of bilingual parents of children with Autism. The rationale, methodology and results will be discussed and explained and then considered in terms of their relevance to the current research as well as to Educational Psychologists' practice.

Part three, the critical review, will aim to provide a reflexive account relating to two main premises: the unique and exploratory contribution of the current study to the lived experiences of bilingual parents with a child with Autism in Wales; and a critical account of the research practitioner. Rather than separating these premises into two distinctive sections, both are discussed in conjunction with one another, highlighting the personal development of the research-practitioner throughout the process of research.

Acknowledgements / Diolchiadau

Contents Page

List of Tables and Figures

List of Appendices

List of Abbreviations

APA	American Psychiatric Association
ASC	Autism Spectrum Conditions
CYP	Children and Young People
DD	Developmental Disabilities
DSM-5	Diagnostic and Statistical Manual of Mental Disorders: 5th Edition
EF	Executive Function
EP	Educational Psychologist
EPS	Educational Psychology Service
FLP	Family Language Policy
IPA	Interpretative Phenomenological Analysis
LA	Local Authority
SEN	Special Educational Needs
ToM	Theory of Mind
TD	Typically Developing
WCC	Weak Central Coherence
WG	Welsh Government

Welcome to Holland

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this…

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!" you say. "What do you mean, Holland?" I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to some horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy a new guidebook. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I had planned."

The pain of that will never, ever, go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

(Written by Emily Perl Kingsley)

'Mamiaith': The Lived Experiences of Mothers of Children with Autism in Wales.

Part One: Introduction and Literature Review

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1. Introduction

1.1 Amplification of the Title and Rationale for the Research

During the last century a noted paediatrician and child psychologist described two distinct groups of children who seemed "happiest when left alone" (Kanner, 1943, as cited in Lai, Lomardo & Baron-Cohen, 2014, pg. 896) and in Hans Asperger's eyes appeared "never able to become integrated into a group of playing children…Another strange phenomenon…was the occurrence of certain stereotypic movements and habits" (as quoted in Frith, 1991, pg. 40). Both Kanner and Asperger were alluding to what is now recognised as Autism Spectrum Disorder (ASD) or what will be referred to in this research as Autism Spectrum Condition (ASC). It is recognised that the research into understanding Autism has evolved significantly during the past seven decades (Lai et al., 2014).

1.2 Structure of the Literature Review

This literature review begins with a consideration of the clinical definition of ASC and a selection of psychological theories that underpin the field of exponential research in this area. Furthermore, the prevalence of ASC and rate of increased diagnosis will be considered, along with its relevance to current Educational Psychology (EP) practice.

The review will then lead to a brief exploration of the "difficulties in social communication and interaction" (Lai et al., 2014, pg. 896) documented in individuals with ASCs, before relating these to the current literature based on bilingualism. Theoretical models and literature related to bilingualism will be considered in addition to Family Language Policy.

The review proceeds to provide an overview of the psychological theory and

limited quantitative and qualitative evidence that relates to ASC and bilingualism. Yu

(2016) states that much of the research on bilingualism and ASC has focused on

quantitatively examining the effects of bilingualism on children with ASC. The limited

research which directly explores the experiential perspectives of parents who have a child

with ASC have also been included in the discussion.

The review will conclude with a rationale for the current study and an outline of

the research questions. Actively listening to parents' perceptions of their experiences will

be central. It is hoped that this initial qualitative research will explore the lived experience

of bilingual parents who have a child with ASC in Local Authorities (LAs) in Wales.

1.3 Databases, Web-based Sources and Search Engines Used

The types of documents applicable to this area of research were established prior

to commencing the literature search. These included academic journal studies and

doctoral theses. Further literature was drawn from published books on autism,

bilingualism and language. The search parameters went beyond the UK and incorporated

studies published in Europe, North America and Asia, primarily targeting publications from

the last decade. Both quantitative and qualitative designs were considered, in addition to

systematic reviews and meta-analyses papers. A comprehensive search was conducted

using evidence from a variety of sources and the academic databases, PsychINFO 1806-

2016, PsycArticles Full Text, Cardiff University Books@Ovid and ERIC in December 2015,

January 2016, and in December 2016 and January 2017. The search was updated in March

and April 2017. Additional peer reviewed journal articles were sourced using Google,

Google Scholar, alongside Government policies. These sources were chosen to include a variety of empirical research articles available in peer-reviewed journals and publications. The search for literature detailing theoretical perspectives utilised a broad range of dates to accommodate historical perspectives that have informed research and practice.

1.4 Inclusion and Exclusion Criteria

Combinations of the search terms – 'Autism,' 'Autism Spectrum Disorders,' 'Autism Spectrum Condition,' 'Bilingualism', 'Parents', 'Parenting' and 'Wales' were used. Throughout the searching process relevant literature was filtered by using the following inclusion criteria:

- Published in the English (or Welsh) language

- Published in the period 2000-2017

- Including children or young people with a documented diagnosis of ASC

Conversely, studies were not included if they met the following exclusion criteria:

- Published in a language other than the English (or Welsh) language

- Published outside the period 2000-2017

- Not including children or young people with a documented diagnosis of ASC

1.5 Identification of Studies Relevant to this Literature

Boolean phrases and a 'snowball' method (Creswell, 2009) were used to locate previous studies relevant to this topic area. Reference lists of relevant articles were also searched for additional articles and references to further literature. Titles were screened

by using the research abstract and then secondary screening took place by the researcher reading the articles in full. It was noted that there was a dearth of literature relating to ASC and bilingualism in the U.K. and therefore the review is heavily reliant on articles that were published outside of the U.K., the majority of these originated from North America. It is acknowledged that the socio-cultural landscape in other countries may differ to the one in the U.K.

2 Theoretical Review

2.1 Terminology

The term Autism Spectrum Conditions (ASC) will be used in place of Autism Spectrum Disorder throughout this research and literature review. Within mainstream literature, the growing emphasis on focusing upon the spectrum of both strengths and areas of need has led to a recent move whereby the term 'disorder' has been replaced by 'condition' (National Autistic Society (NAS), 2015). As highlighted by Baron-Cohen et al. (2009), the term 'disorder' highlights and promotes the potential areas of weakness posed by the condition. This revision in terminology is an attempt to reduce some of the stigma(s) associated with the condition and echoes the need to support some of the challenges individuals with ASC may face, whilst simultaneously promoting their unique strengths (e.g., Baron-Cohen et al., 2009; (See also) Silberman, 2015). However, recognising the findings of Kenny et al. (2016), it is acknowledged that that there is no single way of describing Autism that is universally accepted and preferred by the UK's Autism community.

2.2 Definition of ASC

       According to the World Health Organisation (WHO, 2013), ASCs are considered to be pervasive, neurodevelopmental disorders, which result in the impairment or delay in functions that are largely related to the central nervous system. The WHO (2013) states that neurodevelopmental disorders occur in early infancy and are often present throughout life.

       The diagnostic criteria for ASC was reviewed by the American Psychiatric Association (APA) and was updated in the fifth edition of the Diagnostic and Statistical Manual (DSM-V, 2013). Consequently, the APA (2014) now identifies ASC by two broad diagnostic categories. Lai et al. (2014) describe the two diagnostic categories as being "restricted and repetitive patterns of thoughts and behaviour" (p. 896), and "difficulties in social communication and interaction" (p. 896). These two broad diagnostic categories are frequently referred to as the "dyad of impairment" and are considered to highlight the dimensional nature of ASD (Lai et al., 2014, p. 896).

      Volkmar and McPartland (2014) state that the majority of published studies suggest that the DSM-5 criteria offer greater specificity but may result in reduced sensitivity, especially for specific subgroups, including very young children, "cognitively able individuals"(pg. 196), and individuals meeting criteria for DSM-4 Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) (Frances & Widiger, 2012, Jones, 2012, Regier, Narrow, Kuhl, Kupfer & American Psychopathological Association,

2013). However, it is noted that these studies were limited in terms of using historical data and a reliance on out-dated versions of the proposed DSM-5 criteria.

Furthermore, other researchers have commended the reviewed diagnostic criteria in the DSM-5 for its clear symptom descriptors, its consideration of the dynamic nature of development, and have speculated on the beneficial effect of having a unitary label on planning support and intervention for individuals with ASC (Lai et al., 2014). On the other hand, researchers have also outlined a number of features associated with ASC that are not incorporated within the updated DSM-V diagnostic criteria (Buxbaum & Baron-Cohen, 2013; Lai et al., 2014). These features are outlined in Figure 1, on the following page.

2.3 Prevalence of ASCs

An epidemiological research conducted by Baron-Cohen et al. (2009) concluded that the prevalence of ASC is rising across the UK, implying that the number of pupils with ASC diagnoses in schools has increased. Indeed, ASC has been highlighted as the most prevalent primary special educational need amongst pupils who have statements of Educational and Health Care Plans (EHCPs) in England (Department for Education [DfE], 2014).

In terms of the Welsh context, Latif and Williams' (2007) analysis of the diagnostic trends in ASC for children and young people under 17 years in the South Wales Valleys, estimated the prevalence of ASC within schools in Wales at 60 pupils in every 10,000. Furthermore, ASC is the most prevalent special educational primary need of maintained

Figure 1 **Behavioural characteristics of ASC according to the DSM-V, and an overview of associated features not included in the DSM-V criteria (adapted from Lai et al., 2014).**

Core Features in DSM-V: Criteria for diagnosis of ASC (APA, 2013)

Criteria A: Persistent deficits in social communication and social interaction across multiple contexts.

-Deficits in social-emotional reciprocity.

-Deficits in non-verbal communicative behaviours used for social interaction.

-Deficits in developing, maintaining, and understanding relationships.

Criteria B: Restricted, repetitive patterns of behaviour, interests, or activities.

-Stereotyped repetitive motor movements, use of objects or speech.

-Insistence on sameness, inflexible adherence to routines or ritualised patterns of verbal or non-verbal behaviour.

-Highly restricted, fixated interests that are abnormal in intensity or focus.

-Hyper-reactivity or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment.

Associated Features not in DSM-V

Atypical language development and abilities.

-**A**ge <6 years: frequently deviant and delayed in comprehension; two thirds have difficulty with expressive phonology and grammar.

-Age >6 years, deviant pragmatics, semantics, and morphology, with relatively intact articulation and syntax (i.e. early difficulties are resolved).

Motor abnormalities.

Motor delay; hypotonia, catatonia; deficits in co- ordination, movement, preparation and planning, praxis, gait and balance.

Excellent attention to detail.

school pupils who have statements of Special Educational Needs (SEN) in Wales (Welsh Government Statistics for Wales, 2016). Holtom et al. (Forthcoming) report a sharp increase in the rates of diagnosis among school age pupils in Wales, from approximately 0.2 per cent in 2003/2004 to 1 per cent by 2012/13.

The Welsh Government (WG) (2008) reports the number of people who are diagnosed with an ASC is increasing. However, the WG recognise that it is unclear if this increase is due to rising awareness and improved diagnosis or an increase in prevalence. Baron-Cohen et al. (2009) attribute the increase in prevalence to seven factors: improved recognition and detection; changes in study methodology; an increase in available diagnostic services; increased awareness among professionals and parents; growing acceptance that autism can coexist with a range of other conditions; and a widening of the diagnostic criteria.

Regardless of the debated contributing factors, the increase in prevalence has led to a significant rise in ASC provisions and research into Autism within the UK (Pelicano, Dinsmore, & Charman, 2014). Relating to this, Greenway (2000) reports a dramatic increase in the number of referrals to Educational Psychologists (EPs) from centres for ASCs and for pupils with ASC in the mainstream. Consequently, frequent opportunities for EPs to collaboratively work towards supporting individuals with ASC and their families in terms of their learning and social and emotional wellbeing now exist (Wilkinson, 2005).

2.4 Outcomes and Prognosis of Individuals with ASCs

The question of outcome and prognosis has been raised since the very first studies on ASC (Kanner, 1971). It is understood that outcomes for those with an ASC vary considerably based on the severity of their condition, as well as their cognitive ability, language ability and the presence of co- morbid factors such as Attention Deficit Hyperactivity Disorder or Epilepsy (Howlin et al., 2004). Arguably, studies exploring general outcomes are difficult to compare due to the variance in terms of measures of 'good' or 'poor' life outcomes.

Levy and Perry (2011), in their large scale review of the literature, conclude that outcomes are based on a complex relationship between symptom severity, cognitive and language outcomes, social outcomes, education and training, living situation and social integration. Moreover, Levy and Perry (2011) suggest that general life outcomes for those with ASCs are generally better for those who receive good quality support and interventions that assist the development of language, communication and self- help skills. Independent living and being in a meaningful relationship, as well as academic and employment prospects were included in these outcomes.

However, careful consideration is required before generalising these findings, as Levy and Perry (2011) included various populations and samples from various cultures, several levels of socio-economic status, and numerous levels of ASC severity, including various profiles of language skills and cognitive abilities in their review. Furthermore, the studies that were examined as part of Levy and Perry's (2011) review involved a participant pool that had spanned an extensive period of time. Consequently, there were

large differences in the services available to the individuals studied, and, therefore, the results may not accurately reflect the outcomes for more recent cohorts of individuals with earlier and more comprehensive diagnosis and service provisions (Levy & Perry, 2011).

2.5 Psychological Theories of Autism

Theoretically, ASC research appears to center around three main social-cognitive theories, namely, Theory of Executive Dysfunction (Ozonoff, Pennington & Rogers, 1991), Weak Central Coherence Theory (Frith, 1989; 2003; Happé & Frith, 2006) and the Theory of Mind Hypothesis (Baron-Cohen, 2001; Baron-Cohen, Leslie & Frith, 1985). A detailed discussion of these theories is beyond the scope of this report, however the key aspects have been summarized in the following section.

2.5.1 Theory of Executive Dysfunction in ASC

Executive function (EF) is considered to involve self-reflection, planning and representation of abstract concepts (Liss et al., 2001). However, there is no consensus in the literature regarding the exact definition. The theory of EF attempts to explain the key characteristics associated with ASC in terms of difficulties in executive functioning skills, such as working memory, planning and inhibition.

Research exploring the theory of EF in ASC has been typically based on tasks focusing on inhibition, intentionality and executive memory (Burgess, Alderman, Evans, Emslie, Wilson, 1998). However, evidence for this theory appears to be mixed, and has

been widely criticised due to the variability in the definition of EF, difficulties in establishing the ecological validity of EF testing materials and a focus on group characteristics (Typically Developing (TD) controls v ASC) rather than individual differences (Liss et al., 2001; Rajendran & Mitchell, 2007).

Pellicano (2012) reports that following substantial empirical exploration of this theory, it is now thought that impairments in EF do impact on the development and functioning of an individual with ASC, however, it is plausible that it is not the primary cause of their difficulties. Furthermore, White, Burges and Hill (2009) suggest that the varied findings may be due to a range of executive functioning deficits that combine with the social communication difficulties experienced by individuals with ASC, in contrast to an universal executive functioning impairment.

2.5.2 Weak Central Coherence Theory

The Weak Central Coherence Theory (WCC) hypothesises that individuals with ASC have difficulties in employing global cognitive skills. According to Frith (1989, 2003) one of the key strengths of the WCC theory is that it can explain both non- social (e.g. attention to detail) and social characteristics of ASC. The theory essentially proposes that, while TD individuals process information by extracting an overall meaning, individuals with ASC lack this drive for coherence and thus process things in a detail-focused or piecemeal way (Rajendran & Mitchell, 2007).

It is argued that one positive feature of WCC theory is that it can be used to explain higher-level conceptual abilities such as language. López and Leekam (2003) suggested

that the ability to detect WCC in individuals with ASC was reliant on whether the task used

was verbal and/or visual. The authors found no evidence for WCC using a visual task and

consequently argued that WCC in ASC is specific to complex verbal stimuli, particularly

sentences that rely on context to disambiguate word meaning, and thus not a general

deficit in Autism (López & Leekam, 2003).

2.5.3 The Theory of Mind Hypothesis

The Theory of Mind (ToM) hypothesis is the most cited, and is considered to be the

most prevalent theory within the ASC literature (Anderson & Cushing, 2013). ToM was

originally posited to account for all deficits in ASC (Baron Cohen, 1989) and attempts to

rationlise the apparent difficulties faced by individuals with ASC in adopting the internal

perspective of others (i.e., difficulty in mentalising another person's feelings, perceptions

and beliefs; Rajendran & Mitchell, 2007). Some researchers have suggested that pervasive

social difficulties in ASC may be the result of this deficit in mentalising the internal states

of others, and consequentially, interpreting and responding appropriately to social

situations (Peterson & Bowler, 2000).

However, debates exist about the validity of ToM, specifically with regard to

whether ToM develops in individuals with ASC in a similar way to TD individuals, yet at a

later chronological and mental age, or whether the development is deviant and

incomplete (Paynter & Peterson, 2010; Scheeran et al., 2013). Some critics of the ToM

hypothesis suggest that delay in developing ToM could be related to individual verbal

ability, as participants with ASC were reported to require a higher level of verbal ability

than their TD peers to correctly solve false belief tasks (tasks in which the participant is required to infer the perspective of another when presented with incongruous information) (Happé, 1996).

Furthermore, the ToM hypothesis has been criticised in terms of its failure to demonstrate whether the deficit is generalised, or whether it is a specific, discrete cognitive mechanism which is directly and solely accountable for difficulties with reflective thinking and empathy (Shanker, 2004). Nevertheless, despite the criticism, it could be argued that ToM remains the most influential social-cognitive theory which has been developed to explain the social communication and interaction needs associated with individuals with ASC.

3. An Overview of Bilingualism

3.1 Definition of Bilingualism

The last two decades have seen an explosion in research on bilingualism (Kroll & Bialystok, 2013). Bilingualism is a multidimensional and dynamic construct that has been defined in numerous ways. For the purposes of this review, Grosjean's (1992) definition, which states that bilinguals are those people "who use two or more languages…in their everyday lives" (pg.4) will be employed. It is argued that through emphasizing language use rather than language proficiency, Grosjean's definition is appropriate when discussing bilingual children with ASC. Terms specific to bilingualism and those used within this review are defined in Table 1.

Table 1 Definitions of Terms Relevant to Bilingualism. Adapted from Bird et al. (2016b).

Term	Definition
Majority language	Languages highly valued in society. Spoken by a majority of people in a society, including the power elite. Predominate in mass media and public institutions.
Minority language	Less valued by society. Spoken by fewer people. Not present or less evident in the media and public institutions.
Official language	Designated by law as the language of the society.
Simultaneous bilingual	Both languages learned from birth or soon after.
Sequential bilingual	Exposure to a second language (L2) after a considerable period of exposure to the first language (L1). There is no single agreed-upon age at which this transition is thought to occur, although researchers often use 3 years of age.
L1 and L2	L1 refers to the first language learned by a sequential bilingual. L2 refers to the second language learned.

3.2 The Context of Bilingualism

The most recent census of England and Wales in 2011 recorded that 4.2 million people (7.7% of the national population) spoke languages other than English as their main language (Office of National Statistics, 2013).

Historically, there has been considerable debate surrounding the impact of bilingualism on general educational outcomes for children with typical development (Drysdale, van der Meer, & Kagohara, 2015; Greene, 1997; Rossell & Baker, 1996). While details of the debate are far beyond the scope of this review, recent research has suggested that supporting both (or multiple) languages in the preschool years is related to cognitive, academic, and social advantages (Kohnert, 2010; Soto & Yu, 2014). Bilingual

children score as well as, and in some cases better than, monolingual children across domains, including cognitive and reasoning tasks (Barac & Bialystok, 2012; Kapa & Columbo, 2013; Kováks & Mehler, 2009), mathematical tasks (Han, 2012; Leikin, 2013), reading outcomes (Davison et al., 2011), and language skills (David & Wei, 2008; Unsworth, 2013).

Despite the considerable evidence to support bilingualism in children who are TD, Yu (2013) reports that parents and professionals are still fearful of speaking more than one language with children who have specific language impairments and other developmental disabilities (DD). Furthermore, professionals working in the area of communication and language disorders have not always felt competent with how to work with bilingual families (Moore and Perez-Mendez, 2006).

3.3 Bilingualism in Typically-Developing Children and Young People

Bird et al. (2016b) state that the timing of bilingual exposure impacts bilingual development. With relatively equal exposure to both languages, TD simultaneous bilinguals (exposed to both languages before 3 years of age) are reported to achieve language milestones at roughly similar ages to monolingual children and demonstrate differentiated and language-appropriate morphosyntactic (involving both morphology and syntax) development (De Houwer, 2009; Paradis, Genesee, & Crago, 2011).

Abrahamsson and Hyltenstam (2009) report that TD sequential bilinguals, exposed to a second language after three years, require time for their L2 abilities to catch up with those of same-age monolingual peers acquiring the same languages; and, in fact, may

never achieve parity with monolingual native speakers. According to Baker (2011) learners tend to achieve higher levels of proficiency in their L2 if they are exposed earlier in childhood rather than later or in adulthood. However, it is argued that age effects are, in part, attributable to differences in the length of time and the amount and quality of L2 exposure in younger versus older L2 learners (Marinova-Todd, Marshall, & Snow, 2000).

The literature relating to bilingualism seems to pay particular attention and highlights the links between the amount of exposure to language(s) and the development of language(s) in children. The use of several metrics of amount of exposure have been reported, such as the percentage of time a child is currently exposed to or using each language, the percentage of life-time exposure to or use of each language, or the amount of time since first exposure to the second language (L2) in sequential bilinguals (Bedore, Peña, Summers, Boerger, Resendiz, Bohman & Greene, 2012; Bedore, Peña, Griffin & Hixon, 2016). Parental questionnaires, in which parents are asked to estimate how much time they spend with their children and what languages they are using when they do so, seems to be the most prevalent measure of collecting information relating to exposure.

However, Carroll (2015) has questioned the validity of such questionnaires, arguing that temporal units are crude measures of exposure and that "they tell us nothing about input" (pg. 6). Furthermore, Carroll (2015) argues that the notion that language use can be neatly divided into the use of one language or of the other is flawed. One aspect of the reasoning behind this argument is that bilinguals code-switch on a regular basis and can do so, controlling their speech choices phonetically, lexically or syntactically (Grosjean, 1982; Auer, 1998). Carroll (2015) posits that it is doubtful that questionnaires that force a

choice between one language and the other will provide an accurate picture of amounts of use of each language.

4. Socio-linguistic Models and Bilingualism

4.1 Bioecological Systems

The complex relationship between the family dynamic, perceptions relating to language, and linguistic practices will be explored in the following section. Bird et al. (2016a) argue that Bronfenbrenner's Bioecological Systems model (Bronfenbrenner & Morris, 2007; previously the Ecological Systems Model, Bronfenbrenner, 1977) provides an appropriate framework for exploring the influence of various contributing factors, at differing levels, on bilingualism in children with developmental disabilities (DD).

To understand human development, Bronfenbrenner (1977) argued that researchers need to examine the influence of three nested systems on a person: microsystems which include the influences of the family, school, and peers; the exosystem which includes the local community, the school system and the medical system; and the macrosystem which includes laws or policies and social and cultural values of the larger society. These three systems have a dynamic interconnectivity, achieved through various avenues of communication and influence (Bird et al, 2016a). In 2007, Bronfenbrenner and Morris elaborated on the original model by stressing the importance of child-internal characteristics on development, particularly what was referred to as dispositions, resources (e.g., abilities, knowledge), and demands (i.e., invite or discourage reactions). Furthermore, they emphasized the distinctive contribution of more proximal

(microsystem) influences on the development of a child. Figure 2 outlines an adaptation of

Bird et al.'s (2016a) interpretation of the Ecobiological Systems model, as it applies to

bilingual development. The child is positioned at the center of the representation; the

other components represent layers of contextual factors that may influence the child's

opportunity and ability to become bilingual.

Figure 2   A representation of context for bilingual access and participation and

avenues for bilingualism of an individual within the family, school, community, and

larger society. Adapted from Bird et al. (2016a).

Macrosystem

Society e.g., wider cultural context, status of language(s) (official, majority/minority), language-in-education & special education laws and policies

Exosystem

Community e.g., regional language(s) and culture(s), local school boards, local special education and language-in-education laws, policies, guidelines

Microsystem

Child

e.g., age, development, abilities, motivation, psychological factors, attitudes, beliefs regarding L1, L2 and bilingualism

School e.g., staff and staff attitudes towards bilingualism, special education and L2 services, L2 programs, supports for special needs

Family e.g., language(s) spoken in the home and cultural background; family socio-demographic characteristics, attitudes, beliefs about L1, L2 and bilingualism

Bird et al. (2016a) state that in research and practice, there is a tendency to focus

upon the individual child when considering how best to support language development in

bilingual children with additional learning needs. This focuses upon providing direct and

indirect interventions to the child to reduce difficulties and enhance strengths; barriers to

participation in the activities of daily life are eliminated or reduced by changing the

immediate environment to better support learning and communication. Bird et al. (2016a)

argue that despite the critical importance of these efforts, there are systemic and

programmatic barriers in terms of accessing and participating in bilingual opportunities.

Thus, it is plausible to argue that it is critical to widen the lens beyond the individual child

to include the broader context—the family, the local community, the educational context,

and the larger society and relevant policies—and when we encounter systemic bias, be

agents for change (Bird et al., 2016a).

Within the context of 'family' – the interaction between family members has

arguably been viewed as the 'private' or 'backstage' of social life, to use Goffman's (1959)

metaphor. Hua and Wei (2016) posit that due to globalisation, advancement of media and

information technology, and transnationalism, that the boundaries between the public

and the private, the front and backstages of social life (Goffman 1959) have become

"blurred" (Hua & Wei, 2016, pg. 656). It has been argued that there is an increased

diversity of family structures (Vertovec, 2007). Different generations and individuals

within the same family have vastly different sociocultural experiences. Arguably, the

impact of the different experiences of individual members of the family on how it adapts

to and perceives the challenges of contemporary society remains largely under-explored.

The next section outlines an emerging framework that proposes to explore one aspect of

this 'contemporary society' - linguistic planning within family units.

4.2 Family language policy

Family language policy (FLP) is an emerging interdisciplinary field that provides a

framework for examining issues of explicit language planning in families, typically within

the context of heritage language maintenance (Schwartz, 2010; Spolsky, 2012). Family

language policy can be defined as explicit (Shohamy, 2006) and overt (Schiffman, 1996)

planning in relation to language use within the home among family members.

FLP draws from and contributes to two distinct areas of study that have

traditionally had little overlap: language policy, which has its roots in sociology, and child

language acquisition, which has been traditionally situated in developmental

psycholinguistics (Yu, 2016). The primary aim of FLP is to bridge the gap by investigating

the impact of family interactions on child language development while also monitoring

how family language use reflects broader social conditions and attitudes. FLP does so by

focusing on three interrelated components of intergenerational language transmission—

ideology, management, and practice.

Woolard and Schieffelin (1994) state that the first aspect of FLP, language

ideology, refers to culturally organized beliefs about language that involve "common

sense notions" and "self-evident ideas" that are "derived from, rooted in, reflective of, or

responsive to the experiences or interests of particular social positions" (pg. 3–4). For bilingual children, parental ideologies are also theorized to play a crucial role in determining language outcomes (King, Fogle & Logan-Terry, 2008). De Houwer (1999) draws on a model from developmental psychology to illustrate the relationship between beliefs, practices, and outcomes (see Figure 3) in childhood bilingualism.

Figure 3   Relationship between parental beliefs/attitudes and children's language development (adapted from De Houwer, 1999).

Parental beliefs and attitudes

Parental linguistic choices and interaction strategies

Children's language development
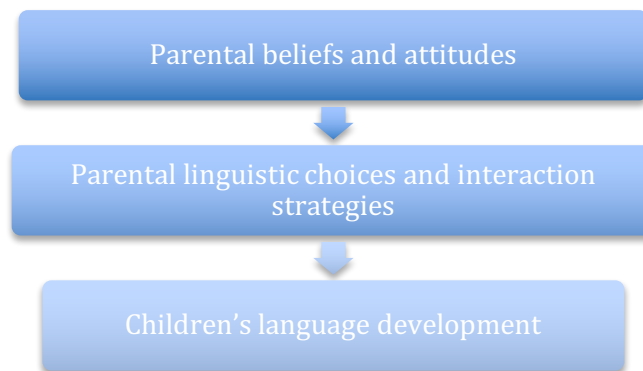
However, as De Houwer (1999) notes, the representation in Figure 3 is overly simplistic as these processes are interactive and not unidirectional; for instance, children's own language behavior is shaped by parental language but also in turn impacts parents' beliefs and strategies. Nevertheless, it is argued that ideologies underlie language management efforts, which are considered as calculated interventions for language use among family members (Yu, 2016). Both ideology and management are related to, yet distinct from the third aspect of FLP, language practice, which is described as face-to-face and habitual patterns of language use that may or may not be conscious to the speakers. In other words, FLP is the study of what people think about language, what they wish to do with language, and what they actually do with language (Yu, 2016). According to

Schwartz (2010) the linkages between the three aspects are complex, non-linear and even conflicting.

Arguably, as a consequence of the complexity of the above issues, bilingual families of children with ASC often seek advice, and professionals just as often give advice, about family language use (Yu, 2016). However, there is currently no framework for guiding research or clinical practice in this area. The studies on bilingualism and ASC to date are largely limited to clinical contexts and narrowly focused on the performance of bilingual versus monolingual children with ASC on specific developmental measures. Zentella (1997) states that living across linguistically marked social boundaries is a complex experience for parents whose children are TD. Yu (2013) argues that parenting a child with a diagnosis of ASC can both intensify and complicate this experience. Yu (2016) highlights, in terms of the process of supporting families in their language use with children with ASC and other developmental disabilities, that there is an urgent need for more contextualized research.

5. ASCs and Bilingualism

5.1 ASCs and Social Communication and Interaction Skills

Difficulties in social communication and interaction relating to ASC have been repeatedly reported in the literature (Travis & Sigman, 1998; Bauminger-Zviely et al., 2013; Baron-Cohen, 2010; Koning & Magil-Evans, 2003). These can also include difficulties in initiating conversation, asking appropriate questions, commenting on the activity of

23

others, responding when spoken to, and attention skills (Chung, Reavis, Mosconi, Drewry, Matthews & Tasse, 2007). Furthermore, there is agreement in the literature that those with ASC struggle to interpret and use non-verbal communication such as eye-contact, tone of voice, posture, and facial expression as well as other context- based cues that are crucial for reciprocal communication, referred to as pragmatics (Baron-Cohen, 1988; Eigsti, de Marchena, Schuh & Kelley, 2011; Kanner, 1943; Tager-Flusberg, 1981; Tager-Flusberg & Caronna, 2007; Koning & Magil-Evans, 2003). Extensive research and evaluation has been undertaken in an attempt to understand and support the development of these key challenges in social communication and interactions associated with ASC (Rajendran & Mitchell, 2007).

5.2 ASCs and Language

Despite ASC presenting differently in each individual, Baker (2013) argues that there are certain idiosyncratic language patterns associated with ASC – from pronoun reversals, unusual prosody, and perseveration on particular topics to lack of verbal language altogether. It is therefore plausible to state that ASC is linked inextricably to language and communication (American Psychiatric Association, 2013).

Delayed development and/or abnormal use of language is reported to be typically observed in children who later develop ASC (Whetherby et al., 2004). Furthermore, the literature states that language impairments in ASC are variable, can be seen at very young ages, and include impairments in both verbal and nonverbal forms of communication (Larson & Suchy, 2014; Luyster et al., 2008; Rapin and Dunn, 2003). It has been suggested

that these language and communicative deficits might contribute, to at least some degree, to the impairments in social interaction associated with ASC (Bigler & Liben, 2007; Pelphrey, Morris & Mccarthy, 2004). From a sociocultural perspective (Vygotsky 1978), this delay in social interaction could arguably lead to unsuccessful internalization of social speech, which in turn could result in delayed or abnormal development of self-directed speech (i.e., private and inner speech), and a subsequent delay in, or an abnormal emergence of higher-order cognitive functions, including executive and motor functions (Larson & Suchy, 2014).

However, Sterponi, de Kirby and Shankey (2015) advocate a "theoretical reappraisal of language in autism" (pg. 517) that arguably offers a corrective to what they argue is a dominant and largely tacitly held view that language, in its essence, is a referential system and a reflection of the individual's cognition. Sterponi et al. (2015) posits that there is a need to broaden the current picture of language in ASC by advocating an appreciation of language's "interactional, praxeological, and experiential dimensions ("praxeological" referring to the idea of language as a form of social action) (pg. 517). They argue that neglecting the listed dimensions of language, has important consequences, and could potentially be very limiting to what researchers can learn from studying the verbal behaviour of children with ASC.

Stereponi et al.'s (2015) argument draws on linguistic anthropology, which suggests that language is more than a "symbolic medium", and that it is also a "constitutive component of our experience" (pg. 518). The proposed

"saturated entanglement of experience and language" (Ochs, 2012, pg. 143) will be

explored in this review in the context of ASC and bilingualism.

5.3 An Overview of ASCs and Bilingualism

Yu (2016) argues that in today's global society, the ability to communicate in more

than one language is considered as an asset; however, the rhetoric surrounding

bilingualism in children with ASC has remained "strongly subtractive" (p.424). A multitude

of research findings document a common, albeit empirically unsupported belief among

parents and professionals, that bilingual exposure may be detrimental to the language

development of children with neurodevelopmental and other related disabilities

(Drysdale, van der Meer, & Kagohara, 2015; Reetzke et al., 2015; Fernandez y Garcia,

Breslau, Hansen, & Miller, 2012; Hambly & Fombonne, 2012; Bird et al., 2012; Kremer-

Sadlik, 2005; Wharton, Levine, Miller, Breslau, Greenspan & Wieder, 2000; Yu, 2013,

2016). North American qualitative ethnographic and survey-based studies indicate that

parents of children with ASC express uncertainty when making decisions about bilingual

exposure for their children (Reetzke et al., 2015; Bird et al., 2012; Kremer- Sadlik, 2005;

Yu, 2013).

Reetzke et al. (2015), argue that one of the main reasons for this reported

uncertainty is a lack of robust information discussing whether children with ASC have the

ability to thrive in an environment in which more than one language is spoken. In the past,

a lack of information to guide bilingual parents of TD children resulted in parents limiting

language input to only one language (Bird et al., 2012; McCabe et al., 2013). It is plausible

to suggest that this parental practice is likely to be exacerbated in families who are raising

children with diagnosed neurodevelopmental and other related disabilities (Reetzke et al.,

2015).

5.4 Empirical Studies Relating to Bilingualism and ASC

Table 2 summarises the quantitative and qualitative research that will then be

discussed in the following section.

Table 2   A summary of the key features of the quantitative and qualitative

research explored in this literature review.

Study	Methodology	Participants	Location and Languages Explored
Hambly & Fombonne (2012)	Quantitative parent report measures to compare social abilities and language levels of children with ASC from bilingual and monolingual environments.	Families of 75 children with ASC (36–78 months). Monolingual (n=30; 24 boys, 6 girls), bilingual (n= 45) subgrouped simultaneous bilingual exposure from birth to 1 year (n=24; 20 boys, 4 girls) versus sequential post-infancy bilingual exposure (n= 21; 17 boys, 4 girls).	Canada, North America (French, English, Chinese, Farsi, Hebrew, Italian, Romanian, Spanish and/or Tamil.
Petersen Marinova-Todd and Mirenda	Administration of four quantitative language instruments to	14 (13 boys, 1 girl, aged 43–73 months) bilingual (simultaneous exposure	Canada, North America (Chinese and

(2012)	investigate lexical comprehension and production and overall language skills in the bilingual and monolingual groups.	from birth to 3 years) and 14 (13 boys, 1 girl, aged 44–73 months) monolingual children with ASC.	English).
Reetske, Zou, Sheng and Katsos (2015)	Quantitative parent report measures (mainly questionnaires) to evaluate their child's competence in structural language and pragmatic ability in their dominant language, and a questionnaire to assess their child's social functioning. Also, parents completed thorough interviews regarding the linguistic environment of their children.	The parents of 54 children with ASC exposed to 1 (n = 31) or 2 (n = 23) Chinese languages.	China, Asia (multiple Chinese languages).
Drysdale et al. (2015)	A survey review which evaluated eight studies.	The review evaluated 8 studies identified as addressing bilingual lan- guage development in 182 children with ASCs and issues/ perceptions of bilingualism in 62 parents of children with ASCs.	Canada and the U.S.A, North America; (Mi'kmaq, French, English, Croatian, Cantonese, Greek, Urdu, Arabic, Italian, Spanish, Mandarin, Japanese, Berbere, Chinese, Farsi, Hebrew, Romanian, Tamil, Korean Bangla, Hindi, Arabic, Urdu, Katch, Gujarati).
Yu (2013)	In-depth phenomenological interviews with thematic and narrative analyses to yield	10 bilingual, immigrant (to the USA; sequential bilingual exposure after preschool age) mothers and their children with	U.S.A., North America (English and Chinese).

		ASC, aged 3–8 years with some verbal abilities; 9 boys, 1 girl.	
Yu (2016)	An ethnographic and discourse analytic case study.	A bilingual, minority-language family of a 6-year-old child with ASC whose family members were committed to speaking English with him.	U.S.A., North America (English and Mandarin-Chinese).

Caution is warranted when interpreting the findings of this literature because the literature review was limited to English-language journal articles only, potentially restricting a truly international perspective of bilingualism in children with ASC. It is noted that the vast majority of the research discussed was conducted in North America thereby limiting the generalisability of findings to other countries and cultural and linguistic contexts. The researcher's literature searching unveiled a significant dearth of literature exploring language development of children with ASC from bilingual families and perspectives of bilingualism for these children from European countries.

5.5. Quantitative Studies Relating to Bilingualism and ASC

Previous studies have investigated whether bilingual exposure is associated with additional difficulties for the language development of children with ASC (Hambly & Fombonne, 2012; Ohashi et al., 2012; Petersen et al., 2012; Valicenti- McDermott et al., 2013). These studies have employed parental questionnaires and direct testing focusing

predominantly on structural language (vocabulary, grammar, and pronunciation). A quantitative study exploring the impact of bilingual environments on children with ASC was conducted by Hambly and Fombonne (2012). They hypothesised that the social impairments associated with ASC could potentially limit the ability of children with ASC to learn a language in bilingual environments at the same rate or to the same level as children with ASC in monolingual environments (Hambly and Fombonne, 2012). However, the research concluded that there is no adverse association between bilingual exposure and language development.

On the other hand, it is important to recognise that the conclusions of this study are limited by a number of factors; e.g. the need to rely on ASC diagnoses from clinical reports (rather than through direct ascertainment), the relatively small sample size in each participant group, the lack of direct measures of exposure in the children's environments, and the unavailability of direct standardized measures of language in children's L1 and L2 (Hambly and Fombonne (2012).

Petersen et al. (2012) undertook a differing approach to explore bilingualism in children with ASC. They argued that studying lexical diversity in bilingual children with ASC could contribute important information to our understanding of their language development. In their exploratory study, lexical comprehension and production and overall language skills were investigated in 14 English–Chinese bilingual and 14 English monolingual preschool-age children with ASC in Canada (Peterson et al., 2012). Their results suggest that bilingual children may have a larger vocabulary if total vocabulary is

taken into account and conclude by implying that children with ASC have the "potential" to be bilingual, and that speaking Chinese at home and English at school and in therapy does not appear to disadvantage their language development. Furthermore, Petersen et al. (2012) advise that the diagnosis of ASC in a child who is raised bilingually should not result in an immediate recommendation to eliminate one of the languages. However, Petersen et al. (2012) suggest that support for two languages does not necessarily mean treating both in the same way at the same time; rather, that language goals should be consistent with the child's previous experiences and current and future needs.

Reetske et al. (2015), sought to extend the previous findings by exploring bilingual exposure's effect on both structural language and pragmatic language competence of pupils in China. In their study, Reetske et al. (2015), report that bilingual exposure is not associated with additional structural and pragmatic difficulties in young children with ASC. However, Reetske et al. (2015) recognise that it is not possible to generalise their findings to the whole range of the ASC continuum due to the fact that nonverbal participants and/or participants with intellectual disabilities were excluded from the study. A further limitation in the study is that only data from the children's dominant language was obtained, and therefore the conclusions do not extend to the children's non-dominant language.

Drysdale et al. (2015) conducted a survey review which evaluated eight studies (including Hambly and Fombonne, 2012) identified as addressing bilingual language development in 182 children with ASC and explored issues and perceptions of bilingualism

31

in 62 parents of children with ASC. The survey concurred with the previous literature, with none of the studies reviewed indicating negative outcomes in terms of language development for bilingually raised children with ASC.

Furthermore, Drysdale et al. (2015) shared that the perception of parents appeared to be contrasting at times. Some parents conveyed a belief that it was important for their children to grow up in a bilingual environment, whereby English would allow for participation in mainstream life and the home language would allow for participation in cultural and religious ceremonies (Jegatheesan, 2011). On the other hand, other parents explicitly stated that it was more important for their child to learn English than the home language as English was seen to lead to success in school and in life (Yu, 2013). It is argued that these findings reflect how cultural values impact decisions regarding language use.

Additionally, Baker (2013) posits that language practices that work well for one family may not be suited to another. As a result, it is argued that bilingual service provision for children with ASC needs to be individualised. Drysdale et al.'s (2015) survey recommend that a bilingual approach should start with an accurate assessment of the child's communicative ability, followed by collaborative goal setting, and intervention considerations, which could include coaching parents, family members, teachers, and peers to implement language facilitation strategies (Baker, 2013; Pickl, 2011; Seung et al., 2006; Soto & Yu, 2014; Wilder et al., 2004).

Moreover, it is important to stress that Drysdale et al.'s (2015) review was limited to English-language journal articles only, potentially restricting a truly international

perspective of bilingualism in CYP with ASC. Half of the studies considered were

conducted in Canada thereby limiting the generalisabilty of findings to other countries and

cultural and linguistic contexts.

A further critique is that a multitude of different measures were used to assess

language ability and to diagnose ASC. Petersen et al. (2012) suggest that future research

should use the same diagnostic criteria for ASC and comparable measures in all languages.

Furthermore, Drysdale et al. (2015) recognise the need for longitudinal studies with larger

sample sizes in order to explore the impact of bilingual exposure on language

development over time. It is also argued that research is needed to identify autism-

specific characteristics that might impact outcomes e.g. the lack of flexibility and need for

routine, characteristic of some CYP with ASC might in fact allow for systematic learning of

a second language and thereby enhance bilingual ability (Wire, 2005). Conversely, Baker

(2013) suggests that as a result of the hypothesis that ToM skills are weak in children with

ASC, the perspective-taking requirements of bilingualism might make learning a second

language incredibly difficult for children with ASC. Drysdale et al. (2015) reiterate that

further research is needed in order to assess this complex interplay between

metalinguistic processes and child-specific ASC characteristics.

As discussed, much of the research on bilingualism and ASC has not supported the

notion that bilingualism is detrimental for children with ASC. Furthermore, in a survey of

parents of children with ASC from 37 families, Bird, Lamond and Holden (2012) found that

over 75 % of the respondents who were raising their children bilingually rated their efforts

as successful to some degree.

5.6. Qualitative Studies Relating to Bilingualism and ASC

There is limited research that seeks to explore the broader parent perspective and evolving life experience of what it is like to raise a child with ASC (Corcoran, Berry & Hill, 2015; Hoogsteen & Woodgate, 2013; King, Zwaigenbaum, King, Baxter, Rosenbaum & Bates, 2006; Safe, Joosten & Molineux, 2012). Specifically in terms of the research on bilingualism and ASC, much of the literature has focused on quantitatively examining the effects of bilingualism on children with ASC (Yu, 2016). However, a brief overview of identified qualitative studies in this area will be discussed in this section.

In relation to the exploration of parental or family experience, studies show that professional advice that is incongruent with the needs of families caused significant problems (Yu, 2016). For example, in a case study presented by Wharton et al. (2000), a Spanish-speaking mother of a child with ASC stated:

> *"I would love to speak Spanish to him, but ... I am afraid of what it might do to him. . . . He already has such a confusing world, . . . I'm afraid to add to the confusion" (pg. 143–144).*

Wharton et al. (2000) studied parents of children with ASC from three minority-language families who had been advised to speak English and found that the parents were less effective in expanding the length and complexity of their children's utterances and more muted in their affective displays when using English compared to their native

languages. Similarly, Kremer-Sadlik (2004) observed four sets of parents of children with ASC who were advised to speak English and found that the parents' limited proficiency in English prevented them from having a smooth exchange of ideas and shortened their interactions. Furthermore, she observed that some of the children were left out of family conversations conducted in their parents' native languages.

In an attempt to expand on this research, Yu (2013) investigated the language practices of 10 bilingual, Chinese/English-speaking, immigrant mothers with their children with ASC. Yu (2013) employed in-depth phenomenological interviews with thematic and narrative analyses to yield themes relating to understanding the nature of the language practices; their constraints, and their impact. Mothers reported that whether their children learned Chinese or English did not matter as long as the language(s) led to success in school and in life. For 9/10 mothers, English was seen as the most important language for their children to learn in order to meet societal demands and access special education services that are usually provided in English only (in the context of the U.S.A.). Yu (2013) stated that all mothers had reservations about bilingualism (that it might confuse or further delay their child) and conveyed a belief that a monolingual environment would be better for their child.

Despite proficiency in English language, parents' use of English was more constrained than their use of Chinese, which impacted the use of English with their child. While 20 % of mothers reported that practitioners did support bilingualism, the majority of advice was given against providing a bilingual environment.

In a more recent ethnographic and discourse analytic case study of a bilingual, minority-language family of a child with ASC, Yu (2016) further explored this finding. Her findings yielded an interpreted complex and often conflicting relationship between what the family members believed about language use with their child, what they set out to do with the child, and the language practices in which they were actually immersed.

These explorations led Yu (2016) to conclude that professionals should not advise parents to speak only one language with their child with ASC. Moreover, Yu (2016) questions the assumption that parents are at liberty to choose to speak one or two languages with their children—and whether parental language choice is a viable object for intervention. She argues that the notion that one language can be isolated from another in a speaker's repertoire is a formalistic view of language that only partially corresponds with how speakers experience bilingualism as a lived phenomenon (Yu, 2016). Rather, it is argued that language is a dynamic entanglement of culture and linguistics that is not reducible to parts.

The discussed qualitative studies employed various strategies to increase the validity of the findings, including the use of triangulation. However, Yu (2013) acknowledges that the principal use of interviews to collect data captures only the information participants chose to represent at any given time. Furthermore, the participants represented a highly educated and affluent group of parents whose experiences may be different from many other minority-language parents (Yu, 2013). Moreover, the studies were conducted in the U.S.A. with immigrant families, a factor

which is arguably not generalisable to the linguistic and cultural context of a country such as Wales.

Secondly, there were inconsistencies in terms of the setup of interviews in Yu's (2013) study. Some of the mothers were interviewed alone, whereas others were in the presence of family members. It is plausible that these differences might have had an impact on the information participants were willing to share, which raises questions in terms of the validity of the findings.

 In both of Yu's (2013, 2016) studies, information relating to professional practices was obtained solely from the parents' reports, which may not have represented actual practices. Furthermore, Yu's (2013) study did not include observations of actual language practices between the participants and their children. It focused only on reported practices, which may or may not have accurately represented the participants' day-to-day communication with their children. However, in an attempt to correct this methodological issue, Yu (2016) included participant observation field-notes, video-recordings of naturally occurring meal- time interactions in the family's home. Arguably this enabled a more holistic exploration of the family's linguist dynamic within the single case study. Despite this, it is important to stress that the study documents the experience of a single bilingual, minority-language family of a six-year-old child with Autism in the U.S.A., therefore its generalisability is significantly limited.

On the other hand, it is argued that Yu (2016) raises an important argument when suggesting that the development of heritage languages and bilingual competencies may

be especially important for children with ASC given their core challenges in socialisation, communication, and relational development. Zentella (1997) states that in bilingual contexts, choices in language are important pragmatic resources and means of affiliation. It is unknown at this time how children with ASC navigate bilingual contexts and acquire bilingual competencies and whether they face unique needs. Yu (2016) posits that an examination of this kind would represent a shift in framing—from a focus on assumed deficits to potential competencies—"offering new directions in the conversation about bilingualism in ASC" (pg. 434).

6. The Context of ASCs and Bilingualism in Wales

6.1 The Linguistic Context of Wales

Since 1993, Wales has two official languages: English and *'Cymraeg'* (Welsh) (Welsh Language Act, 1993). The 2011 Census figures report that English is the most widely spoken language in Wales, with Welsh spoken by nearly one fifth (19%, 562,000) of usual residents in Wales aged three and over (Census figures, 2011). Gwynedd was reported to be the unitary authority with the largest percentage of residents who reported they could speak Welsh (65%, 77,000) (Census figures, 2011). In addition to English and Welsh, Polish was reported to be the third most reported main language (0.6%, 17,000) followed by Arabic (0.2%, 7000) (Census figures, 2011).

Recently, as a part of its language planning policy, the Welsh Government (WG) has actively promoted bilingualism and the sustainment of the Welsh language. *A language for living: A living language* (WG, 2012) signifies the WG's Welsh Language Strategy. Education and parenting are highlighted as core and vital instruments in promoting and developing a fully bilingual culture. Leighton Andrews, Former WG Minister of Education and Skills stated that the WG:

> *"…must ensure that parents/carers and families better understand how the language can benefit their children, to enable them to make informed decisions with regard to their upbringing and education"* (WG, 2012, p.4).

Furthermore, *More than just words* (WG, 2012), the WG's original strategic framework for Welsh language services in health, social services and social care was launched in 2012. The aim of this strategic framework was to encourage recognition among service providers that many people in Wales can only communicate and participate in their care as equal partners effectively through the medium of Welsh. Consequently, the WG (2012) stated that the use of the Welsh language is not just a matter of choice but also a matter of need. The WG (2012, 2016) recognise that having access to services in their first language is especially important for many vulnerable people and their families, such as older people suffering from dementia or stroke who may lose their second language or very young children who may only speak Welsh.

The WG (2012) outlined key objectives relating to the strategic framework, including:

- implementing a systematic approach to Welsh language services as an integral element of service planning and delivery;

- building on current best practice and planning;

- increasing the capability of the workforce to provide Welsh language services in priority areas and language awareness among all staff;

- creating leaders who will foster a supportive ethos within organisations, so that Welsh speaking users receive language sensitive services as a natural part of their care;

- providing education, learning and development programmes which reflect the services' responsibility to plan and provide Welsh language services; and

- ensuring that all national strategies, policies and leadership programmes mainstream Welsh language services.

In relation to families' experience of bilingualism, it is argued that these strategies may influence change in terms of the macrosystem (Bronfenbrenner & Morris, 2007; Bird et al., 2016a).

6.2 Welsh Government Policy and Strategy in Relation to ASCs

ASC is the most prevalent special educational primary need of maintained school pupils who have statements of Special Educational Needs (SEN) in Wales (WG Statistics for Wales, 2016) (3,095 pupils in total). Furthermore, analysis of Pupil Level Annual School

Census (PLASC) data shows that the prevalence of ASC in school-age pupils for the academic year 2015/16 may be approximately 1.22 per cent.

In April 2008, the WG published the Autistic Spectrum Disorder Strategic Action Plan (ASD SAP); an all-age strategy intended to improve understanding and provision of services for individuals with ASC in Wales (WAG, 2008). The strategy led to the establishment of a local and national ASC infrastructure including ASC leads in each local authority (LA), local co-ordinating groups and the development of local action plans. According to the WG one rationale for launching the strategic action plan was that:

> "Studies suggest that the lives of children and adults with ASD may only improve if society has a better understanding of their condition. Raising awareness and understanding of ASD is one of the key elements in ensuring that each individual's needs are fully identified and assessed; that all care packages are appropriate to meet each individual's needs"(pg. 9).

In 2016 the WG published an outcome evaluation of the ASD SAP, and concluded that it had directly contributed to raising the profile and awareness of ASC, enabled the development of a local infrastructure and perceived to have had a positive impact upon people with ASC, their families and on professionals (WG, 2016). However, a number of ASD SAP shortcomings were also identified, including a lack of explicit priorities, a lack of detail on what was required, and weak governance and accountability structures, arguably making it difficult to direct developments across Wales (WG, 2016).

Consequently, the WG identified a number of priorities for improving outcomes for people with ASC and their families, including:

- Increasing awareness and understanding of ASC;

- Improving assessment and diagnosis of ASC for children and adults;

- Improving the education of children and young people with ASC;

- Improving the transitions of young people with ASC;

- Improving employment outcomes for people with ASC;

- Improving adult services for people with ASC;

- Improving information and support for people with ASC and their

parents and carers; and

- Consolidating the ASC infrastructure and sustaining progress across

    Wales.

6.3 Bilingualism and ASCs in Wales

In their strategic action plan for ASC in Wales, the WG recognises and emphasises that there is a need for more bilingual (Welsh/English) language information to be available on ASC (WG, 2008), this need is reiterated in the outcome evaluation of the ASD SAP (WG, 2016). It is an interesting observation that there are no details concerning how to provide for this need included in the WG's strategy.

In their small-scale case study, Jones and Hoerger (2009) explored the challenges

and benefits of establishing Applied Behaviour Analysis (ABA) programmes in a Welsh context. The study was based in the unitary authority of Gwynedd, and parents had requested that their children with ASC could attend their local schools and be taught through the medium of Welsh.

Jones and Hoerger (2009) state that it is "ethically imperative" (pg.251) that provision for pupils with ASC is available in a language that is spoken at home by a child's family and community. It is suggested that this would result in more effective and meaningful service delivery.

The researcher's initial literature search has revealed that no research has been conducted in the United Kingdom (U.K.) to directly explore bilingual exposure in children and young people with ASC. It is suggested that such research might provide an important contribution to the literature, particularly in the context of Wales.

7. Parental Perceptions

7.1 Parental Experiences of Raising a Child / Children with ASCs

Research in terms of parental experience of raising a child or children with ASC conveys a complex and extremely challenging journey. Siegel in his exploration of coping with a diagnosis of ASC commented that 'Many traits of autism exacerbate the most challenging aspects of parenting any child' (1997; pg. 753). The literature conveys that for some parents, the recognition of there being something 'different' about their child has

been followed by confusion as the journey to official diagnosis begins and various explanations for their child's differences are explored (Jardine, 2008). Hence, some parents have reported finding the diagnostic process complicated and lengthy (Abbott, Bernard & Forge, 2013; Hutton & Carron, 2005; Osborne & Reed, 2008). The literature states that the immediate reactions to the diagnosis, as described by parents, tend to be characterised by mixed emotions, predominantly fear and shock, often accompanied by feelings of isolation and uncertainty and, in some cases, guilt or anger (Jardine, 2008). However, parents have also described diagnosis being accompanied by a sense of relief, in terms of aiding their understanding of their child's behavior and symptoms (Osborne & Reed, 2008).

Some parents have likened receiving the diagnosis to a process of grieving (Carter, 2004; Nissenbaum, Tollefson & Reese, 2002). Siegel (1997) presented a theoretical model for the stages of healthy versus complicated coping with the diagnosis of ASC. It is similar to existing grief models and suggests that during healthy coping, parents will go through stages of outcry, denial, intrusion and working through, before finally achieving a state of stasis. At this stage, Siegel (1997) suggests that parents reach an acceptance of the autism as part of their child and, whilst some residual sadness may remain, the parents are able to accept the reality of their child's future.

There is a growing body of literature about the multiple factors that influence a family's adaptation process (Navot et al., 2016). Most of this literature highlights parental maladaptation and negative outcomes. It has been documented that parents of a child with ASC are at an elevated risk of experiencing increased depressive symptoms and negative

affect (Ekas & Whitman, 2011; Estes et al., 2009). Furthermore, raising a child with ASC is associated with psychological problems in parents such as deterioration of self-esteem, feelings of helplessness, anxiety, and marital dissatisfaction (Cohen & Tsiouris, 2006; DeLong, 2004; Gray & Holden, 1992; Hoppes & Harris, 1990; Risdal & Singer, 2004;).

However, a more limited number of studies have focused on positive mediators and adaptive resources, promoting restoration of positive balance and adjustment, including personal growth, increased tolerance, compassion, a change in philosophical and spiritual values, and, ultimately, becoming a better parent (Abbott et al., 2013; Nelson, 2002; Rolland, 1998; Stainton & Besser, 1998). Most studies on parental responses have focused on measuring specific factors that contribute to the outcome of the adaptive or maladaptive response to the birth of a child with ASC (Bekhet & Zauszniewski, 2013; Faso et al., 2013).

There is limited research, most of it qualitative, that seeks to explore the broader parent perspective and evolving life experience of what it is like to raise a child with ASC (Corcoran et al., 2015; Hoogsteen & Woodgate, 2013; King et al., 2006; Safe et al., 2012). Rutter (2007) highlighted that when studying parental reactions to adversity, it is important to consider the life span perspective in addition to individual traits and experiences. It is argued that this type of exploration allows detecting more expansive themes such as isolation, confusion, lost dreams, and change in parent's self (Navot et al., 2016; Cashin, 2004; King et al., 2006; Midence & O'Neill, 1999; Woodgate, Ateah & Secco, 2008).

7.2 The Voice of Parents

Included in the WG's Draft Additional Learning Needs (ALN) Code of Practice (2015) is the statement:

"…the views, wishes and feelings of the child, child's parent or young person, should be at the heart of all decision making processes" (p.9).

Similarly, the *Special Educational Needs and Disability (SEND) Code of Practice: 0 to 25 years* (Department for Education, 2014) advocates the importance of the child or young person, and their parents, participating as fully as possible in decisions; and being provided with the information and support necessary to enable participation in those decisions (Fox, 2015).

It is argued that the development of autonomy is clearly supported by both the SEND code (Department for Education, 2014) and draft ALN code for Wales (WG, 2015). A core focus in both codes is that it is imperative to actively listen to the views of children, young people and parents. It is plausible that providing service users with relevant evidence-based information can enable them to make informed choices and participate fully in decisions.

8. The Current Study

8.1 Overview

This review has examined the various factors that may influence the lived experience of parents with a child with ASC, considering varying exploratory research studies, theories and systems. The review has also highlighted recommendations for future research. Notably, the researcher's initial literature search indicates that no research has been conducted in the United Kingdom (U.K.) that directly explores bilingual exposure in CYP with ASC. It is suggested that such research might provide an important contribution to the literature, particularly in the context of Wales, a country with two official languages.

8.2 Research Aims

Actively listening to parents' perceptions of their experiences will be central to the current study. Much of the research on bilingualism and ASC has focused on quantitatively examining the effects of bilingualism on children with ASC (Yu, 2016). Moreover, it is hoped that this initial exploratory qualitative research will investigate the lived experience of bilingual parents who have a child with ASC in LAs in Wales.

8.3 Research Questions

In order to explore the lived experience of bilingual parents who have a child / children with ASC in Local Authorities (LAs) in Wales, the present research will be driven by the following research questions: -

8.3.1 Primary Research Question

What is the lived experience of bilingual parents raising their children with ASC in Wales?

8.3.2 Secondary Research Questions

1. How do parents make sense of the factors constraining and/or facilitating their language practices with their children with ASC?

2. How do parents make sense of the advice they receive from professionals about raising / not raising their child / children with ASC bilingually?

3. What are parents' perceptions in terms of how successful individuals with ASC are in becoming bilingual?

4. What do parents perceive to be the impact of their language practices on their children with ASC and on their family?

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'Mamiaith': The Lived Experiences of Mothers of Children with Autism in Wales.

Part Two: Empirical Study (5993)

1. Abstract

An Interpretative Phenomenological Analysis (IPA) methodology was employed in order to explore the lived experience of bilingual parents of children and young people with Autism in Wales. This is an initial exploratory study aimed to explore a previously un-researched area. Due to the bilingual status of Wales, it was thought that an exploration in this area was pertinent. Much of the international research on bilingualism and ASC has focused on quantitatively examining the effects of bilingualism on children with ASC (Yu, 2016). However, this qualitative research has taken a social constructionist approach. Five semi-structured interviews were carried out with a homogeneous sample of parent participants (all Mothers). Interpretative Phenomenological Analysis was conducted following the guidelines from Smith, Flowers and Larkin (2009) and the study demonstrates research validity under Yardley's (2000, 2008) qualitative criteria. The super-super ordinate IPA themes were: *Making Sense of Autism: The Winding Path, Making Sense of Bilingualism, and Ni a Nhw [Us and Them]: Navigating the Social World.* A complex and multifaceted process was interpreted from the parents' sense-making, which raises questions that warrant further exploration.

2. Introduction

Epidemiological research conducted by Baron-Cohen et al. (2009) concluded that the prevalence of Autism Spectrum Conditions (ASCs) is rising across the UK, and that the number of pupils with an ASC diagnoses in schools has increased. In terms of the Welsh context, Latif and Williams' (2007) analysis of the diagnostic trends in ASC for children and young people in the South Wales Valleys, estimated the prevalence of ASC within schools in Wales at 60 pupils in every 10,000. Furthermore, ASC is the most prevalent special educational primary need of maintained school pupils who have statements of Special Educational Needs (SEN) in Wales (Welsh Government Statistics for Wales, 2016).

This increase in prevalence has led to a significant rise in ASC provisions and research into Autism within the UK (Pelicano, Dinsmore, & Charman, 2014). Relating to this, Greenway (2000) reports a dramatic increase in the number of referrals to Educational Psychologists (EPs) from centres for ASCs and for pupils with ASC in mainstream education. Consequently, frequent opportunities for Educational Psychologists (EPs) to collaboratively work towards supporting individuals with ASC in terms of their learning and their social and emotional wellbeing now exist (Wilkinson, 2005).

2.1 ASCs and Social Communication

At present, the American Psychiatric Association (2013) identifies ASC by two broad diagnostic categories. Lai, Lomardo and Baron-Cohen (2014) describe the two diagnostic categories as being "restricted and repetitive patterns of thoughts and behaviour" (p. 896), and "difficulties in social communication and interaction" (p. 896).

These difficulties in social communication and interaction have been repeatedly reported in the literature (Travis & Sigman, 1998; Bauminger-Zviely Eden, Zancanaro, Weiss & Gal, 2013; Baron-Cohen, 2010; Koning & Magil-Evans, 2003). Despite Autism presenting differently in each individual, Baker (2013) argues that there are certain idiosyncratic language patterns associated with ASC – from pronoun reversals, unusual prosody, and perseveration on particular topics to lack of verbal language altogether. It is therefore plausible to state that Autism is linked inextricably to language and communication (American Psychiatric Association, 2013).

This link to language, social communication and interaction skills was explored in Hambly and Fombonne's (2012) quantitative study on the impact of bilingual environments on children with ASC. Hambly and Fombonne (2012) hypothesized that the social impairments associated with ASC could potentially limit the ability of children with ASC to learn a language in bilingual environments at the same rate or to the same level as children with ASC in monolingual environments.

2.2 Existing Literature on ASCs and Bilingual Exposure

Yu (2016) argues that in today's global society, the ability to communicate in more than one language is considered as an asset; however, the rhetoric surrounding bilingualism or multilingualism in children with autism has remained "strongly subtractive" (p.424). A multitude of research documents a common, albeit empirically unsupported belief among parents and professionals, that bilingual exposure may be detrimental to the language development of children with neurodevelopmental and other related disabilities (Drysdale, van der Meer, & Kagohara, 2015; Reetzke, Zou, Sheng & Katsos, 2015; Hambly & Fombonne, 2012; Bird, Lamond & Holden, 2012; Yu, 2013, 2016). North American qualitative ethnographic and survey-based studies indicate that parents of children with ASC express uncertainty when making decisions about bilingual exposure for their children (Reetzke et al., 2015; Bird et al., 2012; Kremer- Sadlik, 2005; Yu, 2013).

Reetzke et al. (2015) argue that one of the main reasons for this reported uncertainty is a lack of robust information discussing whether children with ASC have the ability to thrive in an environment in which more than one language is spoken. In the past, a lack of information to guide bilingual parents of typically developing children resulted in parents limiting language input to only one language (Bird et al., 2012; McCabe et al., 2013). It is plausible that this parental practice is likely exacerbated in cases of families who are raising children with diagnosed neurodevelopmental and other related disabilities (Reetzke et al., 2015).

Previous studies have investigated whether bilingual exposure is associated with additional difficulties for the language development of children with ASC (Hambly & Fombonne, 2012; Ohashi et al., 2012; Petersen, Marinova-Todd & Mirenda, 2012; Valicenti- McDermott et al., 2013). These studies have employed parental questionnaires and direct testing focusing predominantly on structural language (vocabulary, grammar, and pronunciation). The consistent finding is that there is no adverse association between bilingual exposure and language development. Furthermore, in a survey of parents of children with ASCs from 37 families, Bird et al. (2012) discovered that over 75% of the respondents who were raising their children bilingually rated their efforts as successful to some degree.

At present, the researcher's initial literature search has revealed that no research has been conducted in the United Kingdom (U.K.) that directly explores bilingual exposure in children and young people with ASC. It is suggested that such research might provide an important contribution to the literature, particularly in the context of Wales, a country with two official languages.

3. The Current Study

Much of the research on bilingualism and ASC has focused on quantitatively examining the effects of bilingualism on children with ASC (Yu, 2016). This explorative research into parental experiences will take into account participants' perspectives without predefining outcomes to offer further insight into understanding the lived experience of bilingual parents who have a child / children with ASC in Local Authorities

(LAs) in Wales. The primary research question is open to exploration to reflect the phenomenological and interpretative aspects of the IPA method. A further four secondary research questions have also been explored in an attempt to enrich the interpretation, in addition to reflect the more applied perspective of an EP.

4. Research Questions

4.1 Primary Research Question

What is the lived experience of bilingual parents raising their children with ASC in Wales?

4.2 Secondary Research Questions

1. How do parents make sense of the factors constraining and/or facilitating their language practices with their children with ASC?

2. How do parents make sense of the advice they receive from professionals about raising / not raising their child / children with ASC bilingually?

3. What are parents' perceptions in terms of how successful individuals with ASC are in becoming bilingual?

4. What do parents perceive to be the impact of their language practices on their children with ASC and on their family?

5. Methodology

5.1 Theoretical Framework

Embedded in the study's research strategy (Silverman, 2000) is the philosophical basis of the current study, which is demonstrated in Figure 1.

Figure 4   The Philosophical Basis of the Current Research Study.

Ontology			
Relativist	**Epistemology**		
	Social Constructionism	**Theoretical Basis**	
		Interpretative Phenomenological Perspective • Phenomenology • Hermeneutics • Idiographic	**Method** Semi-structured Interviews
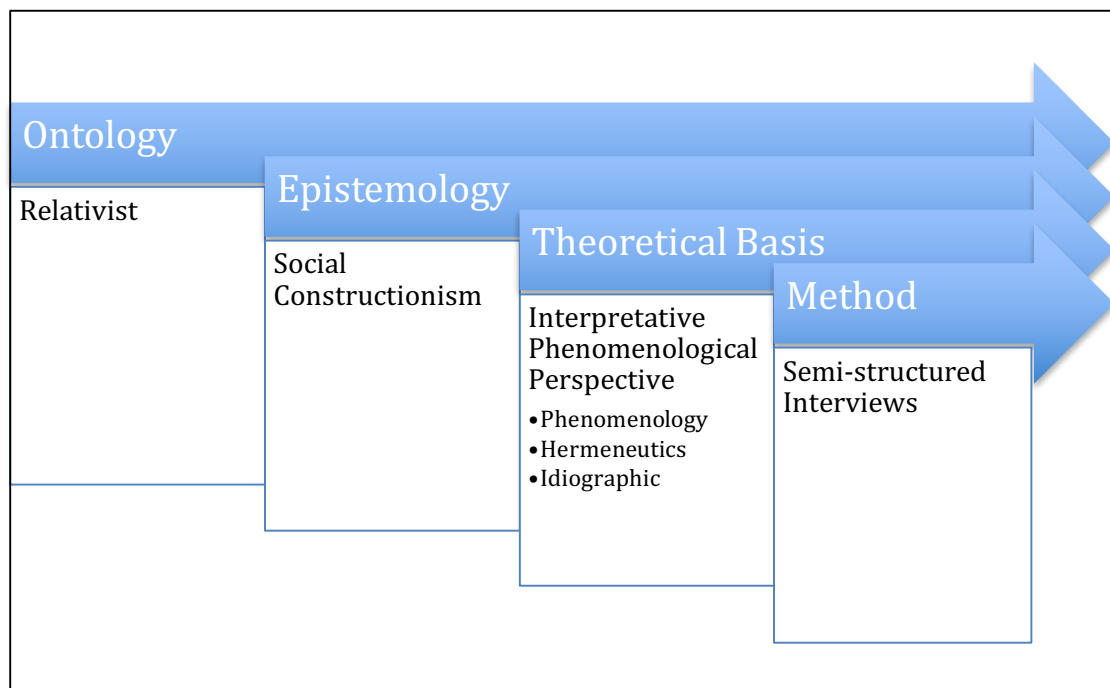
5.2 Ontology and Epistemology

The ontological basis of the current study takes a relativist stance, supporting the perspective that research should be an exploration of individuals' different versions of experience (Willig, 2008) and that there are no definitive realities. Furthermore, a social

constructionist epistemological position underpins the exploration of the lived experience of bilingual parents with a child / children with ASC located in LAs in Wales. Within this viewpoint language is considered a pre-condition for thought (Burr, 2015). Furthermore, it is argued that concepts and categories are acquired by individuals as they develop the use of language, and are thus replicated daily by everyone who shares a culture and a language (Burr, 2015). It is therefore argued that a social constructionism positioning fits well within the exploration of perspectives towards bilingualism.

5.3 Method

Interpretative Phenomenological Analysis (IPA) is recognised as an established method in clinical, health and social psychology, which provides a stance and protocol for the analysis of experiential qualitative data (Reid, Flowers, & Larkin, 2005; Smith & Osborne, 2003; Smith, Flowers & Larkin, 2009). Flowers, Davis, Larkin, Church and Marriott (2011) state that IPA has been employed in numerous studies that address personal and under-explored topic areas, wherein its participant-led focus "facilitates the emergence of novel and useful insights" (p. 1380).

5.4 Data Collection

Smith et al. (2009), advocate that IPA is best suited to a data collection method which invites participants to offer a "rich, detailed, first-person account of their experiences" (p.56). Reid, Flowers, and Larkin (2005) state that semi-structured, one-to-one interviews have been a popular and preferred method for collecting such data. This

use of semi-structured interviews was preferred over structured interviews in an effort

not to lead participants, and to ensure that the researcher will be "speaking with" rather

than "speaking for" the participants (Fielding, 2004, p.305). Reviewing previous literature,

and following Smith et al.'s (2009) recommendations enabled the researcher to design an

interview schedule (see Appendix A).

5.5 Pilot Research

Following the pilot interview the researcher felt that the semi-structured interview

schedule had allowed for sufficient exploration of the participant's experiences.

Reflections on the pilot interview emphasized a need for the researcher to be more

mindful in terms of encouraging clarification or elaboration on areas of interest. However,

as no amendments were made to the interview schedule following the pilot, it was

decided to include the participant in the main sample.

Table 3 Demographics of the Pilot Interview Participant.

Participant	Relationship to child / children	Child / Children's Pseudonym(s)	Child / Children's Key Stage* (KS)	Parent – child language use	Language use with other members of the family
Pilot 1	Mother	Lowri	3	Welsh	Welsh
Specific details relating to the child / children's age has not been provided in an attempt to maintain participant confidentiality.					

5.6 Participants

IPA is recognised as an idiographic approach (Smith et al., 2009), concerned with understanding a particular phenomena in particular contexts, therefore a small, select and homogeneous convenience sample was recruited. A sample size of five participants was recruited from two LAs in Wales. The two LAs were selected due to the high percentage of Welsh speakers in their population (according to the 2011 Census). The rationale for focusing on this group of parents is that they will be most likely to live and socialise in bilingual environments and thus are more likely to make conscious and intentional decisions regarding language use. Table 3 presents the participant demographics in addition to information relating to language use[1]. It is important to note that all the participants' children had a documented diagnosis of ASC but did not have additional significant learning difficulties and were educated in a mainstream class or specialist base within a mainstream setting.

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[1] For confidentiality purposes pseudonyms have been used for each of the participants and their child / children.

Table 4 Research Participant Demographics and Information Relating to Language Use.

Participant	Relationship to child / children	Pseudonym	Child / Children's Pseudonym(s)	Child / Children's Key Stage* (KS)	Parent – child language use	Language use with other members of the family
1	Mother	Catrin	Lowri	3	Welsh	Welsh
2	Mother	Elen	Lili	Foundation Phase	Welsh	Welsh (English with own Mother)
3	Mother	Anna	Robin	Foundation Phase	Mainly English	English with partner and mainly Welsh with extended family members
			Aaron	2	Welsh	
4	Mother	Lisa	Tomos	2	Welsh	Welsh
5	Mother	Beryl	Hari	2	Bilingual – Welsh / English	Welsh
	Specific details relating to the child / children's age has not been provided in an attempt to maintain participant confidentiality.					

5.7 Research Procedure

In accordance with data protection legislation (Data Protection Act, 1998), the participants were recruited via the two LAs' Educational Psychology Service (EPS). Once consent was obtained from both EPSs, the LA considered a number of potential participants who would meet the inclusion criteria. The researcher provided the required number of information leaflets (see Appendix C) and consent forms (see Appendix D) to the LA. The researcher did not receive any details regarding potential participants pending

receipt of the participants' consent forms.

Five out of the six participants who consented to the research project went on to participate in a semi-structured interview within a school or a LA building of the participant's choice. The participants were asked to state in which language they would prefer the researcher to conduct the interview. All the participants asked to be interviewed in Welsh, and all the interviews were voice recorded with an iPad and lasted between 45 – 72 minutes. All the participants were debriefed and provided with debrief forms (Appendix E).

5.8 Analysis

The interview audio-recordings were transcribed verbatim (Appendix F) and analysed in accordance with the step-by-step IPA procedure drawn from Smith and Osborne (2003) and Smith et al. (2009) (Appendix G). Each participant's analysis was conducted separately to ensure that engagement with the data began at the earliest transcription stage, before full group analysis took place.

5.9 Translation

All the interviews in this study were transcribed verbatim and subsequently analysed in Welsh. This was in an attempt to reduce the suggested 'subtle alterations' in meaning suggested by Pugh and Vetrere (2009, p. 313), which would arguably be detrimental, particularly in the context of an IPA study. For the purpose of this study, all relevant quotations have been translated, and an example of an analysed extract of the transcript has been included in Appendix G.

5.10 Ethical Considerations

The research study met the ethical requirements of the University Ethics Committee and is in accordance with the principles of ethical practice set out by the BPS (2009, 2014). A number of ethical issues were considered in the development of this study and a summary of the pertinent issues can be found in Table 4.

Table 5   Overview of Ethical Issues and Researcher Actions.

Ethical Consideration	Researcher Actions
Informed consent	The researcher informed all participants of the objectives of the study and clearly explained what participation would entail (see Appendix C & D). Gatekeeper's permission and informed consent was sought prior to any engagement with participants. All stakeholders were aware of the title and aim of the research and were sent information sheets (see Appendix C). Smith et al. (2009) consider it to be good practice to revisit the issue of consent within the interview itself, with specific oral consent being sought for unanticipated emerging sensitive issues.
Right to withdraw	When confirming consent, participants were reminded that they had the right to withdraw from the study and given information regarding who to contact and how to withdraw from the study. The researcher explicitly stated that following the transcription of the semi-structured interview, it would not be possible for the participant to withdraw from the study. An estimated date of transcription was provided to all the participants. However, no participants withdrew from the study.

Ethical Consideration	Researcher Actions
Debrief	All the participants received a debriefing letter (see Appendix E) outlining the aims of the research, and offering the opportunity to receive more information regarding the research findings.
Confidentiality and anonymity	To ensure anonymity, pseudonyms have been used in interview transcripts and a code has been used which links the pseudonyms to personal data; this information was stored separately. The personal data is stored securely in a locked cabinet in order to maintain confidentiality. Pseudonyms have also been used in the reporting of findings. Participants were informed of the limits of confidentiality when consenting to the research. The participants were also informed of the circumstances in which confidentiality may need to be broken, for example, if it is judged that an individual was at risk of harm to themselves or others.
Data management and retention	In order to maintain confidentiality and adhere to data protection legislation, all electronic recorded files were password protected, and the device used to record the interviews was stored in a locked cabinet until the files were deleted upon transcription and analysis. The researcher has not discussed any identifiable individual's views with anyone, and has not transcribed any information that might enable an individual to be traced. Stating this explicitly to the participants was important in order to establish rapport and trust during the semi-structured interviews.

Ethical Consideration	Researcher Actions
Risk to participants	There was a potential risk that some of the interview questions might have led to upsetting experiences being recalled, and therefore the researcher ensured careful planning and sensitivity. Participants were appropriately signposted to information or services if any participants wished to seek further information or support e.g. school ALNCo or EP. Furthermore, the participants were offered a wind down period following the interviews. The wind down period involved giving the participants the option to watch a short (3-5 minute) un-evocative clip of the nature documentary 'The Blue Planet'.
Privacy and safety	Relating to the nature of the questions and potential issues that may have arisen, semi-structured individual interviews were held rather than focus groups or any other method of data collection that would not afford this privacy. The interviews were conducted in a quiet room within a school or a LA office or building of the participant's choice.

5.11 Validity

Within the current study validity has been demonstrated by following the

qualitative criteria framework for research validity (Yardley, 2000, 2008) (Appendix I).

Furthermore, a demonstration of validity was applied through the flexible use of an

"Independent Audit" (Yin, 1989). A chain of evidence for the IPA process was developed,

which was then checked by an independent colleague to clarify that the analysis was

credible of the data set.

5.12 Researcher's Position

Due to the important role the researcher plays in IPA and its double hermeneutic approach, where "the researcher is trying to make sense of the participant trying to make sense of what is happening to them" (Smith et al., 2009), the researcher's position has been highlighted. The researcher is a sequential bilingual individual, who received Welsh-language education until the age of 18. At the time of the research, the researcher was living in one of the LAs where 40% of the participants were recruited, and had worked in the LA as an Assistant EP for a period of 6 months. The researcher is conscious that her background and previous experiences have influenced the interest for the topic in relation to bilingualism.

A research journal was kept to bracket any reflective and reflexive comments from the research process itself, as advised by Smith et al. (2009). These were referred to during the analysis process, in order to ensure the interpretation was kept as close as possible to the participants' constructs.

6. Results

The following section examines the interpreted themes from the IPA exploration of the primary and secondary research questions. The primary research question relates to the overall lived experience of bilingual parents raising their children with ASC in Wales, whereas the secondary research questions are based more specifically on the participants' reflections and meaning-making in terms of language use. During the analysis process it was noted that the experiences parents in this study described as meaningful for them

were, by their nature, interlinked with their lived experience of language in relation to their child / children, to the family and also to the wider social systems around them. As a result of this multifaceted interaction the researcher determined it was inappropriate to assign these experiences definitively to specific research questions, and thus they are presented together.

A thematic map (Figure 5) presents the results of the IPA: the super-super-ordinate themes[2], super-ordinate themes[3], and sub-ordinate themes[4]. These themes represent higher order concepts and thematic patterns developed from the individual analysis. Refer to Appendix H for an overview of the identification of superordinate themes (with subordinate themes), for each participant.

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[2] Presented in **<u>bold and underlined</u>** in the results section. The super-super-ordinate themes for the purpose of this research are overarching themes of the super-ordinate and sub-ordinate themes.

[3] Presented in **bold** in the results section, the super-ordinate themes are the broader, group defining themes.

[4] Presented in *italic* in the results section, the sub-ordinate themes are the themes that are secondary to the super-ordinate theme, but are the defining elements of it.

Figure 5   Thematic Map to Represent the Themes for the Group of Participants.
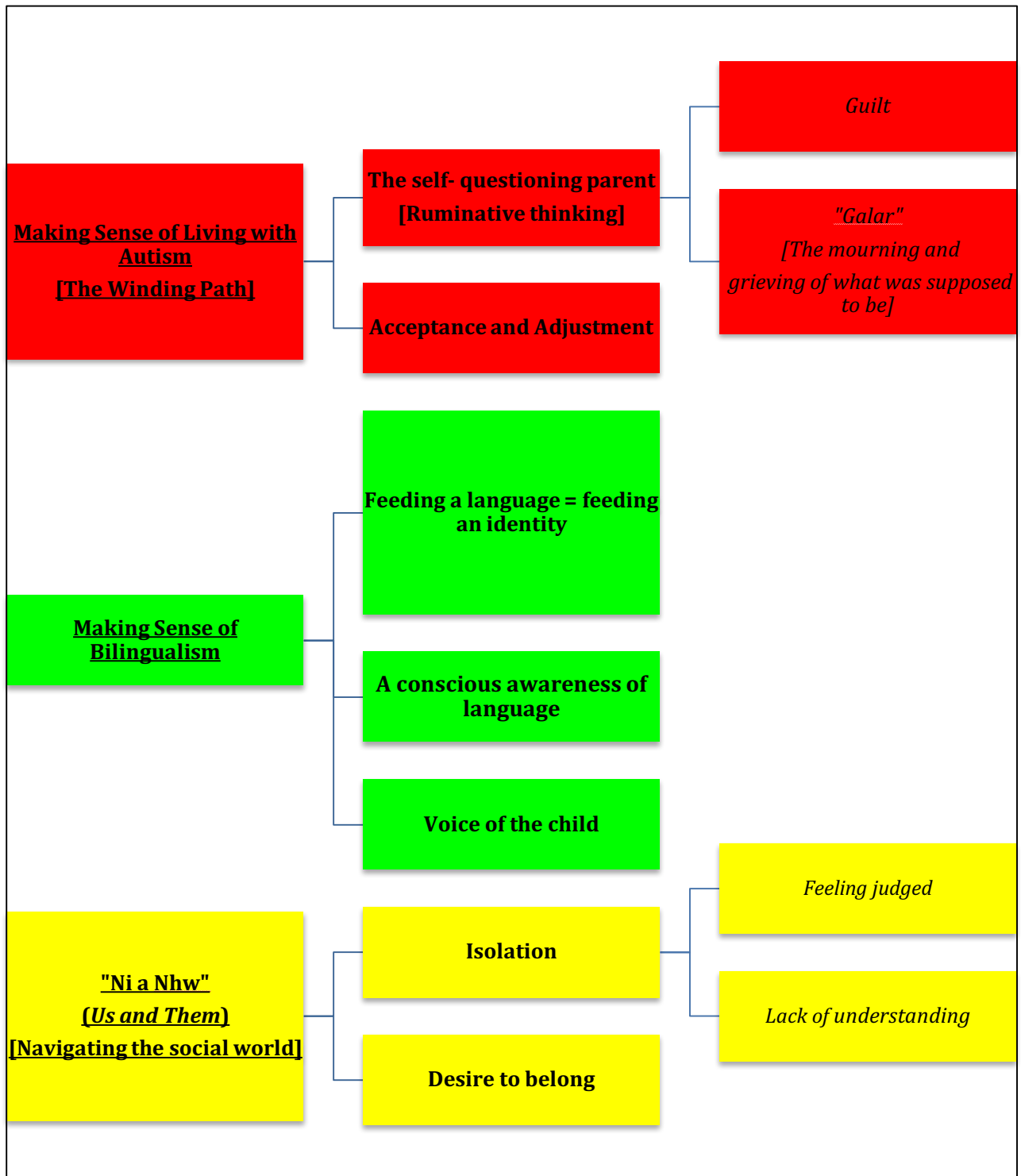
6.1 Making Sense of Living with Autism: The Winding Path

The notion of partaking in a journey or process of understanding featured strongly across all the participants' narratives. Lisa discussed the power of paths when discussing the process of understanding her own son:

> *"he likes paths, he likes walking, as it's obvious, it's not confusing, you follow the path. I go this way…and he's the one leading, because in school, perhaps, or in everyday life he just has to follow behind, or follow what everyone else is doing […], walking paths, it's an opportunity for him to be confident, to be a leader, and everyone follows him, because it's obvious – the path goes that way – so we're going that way" (Lisa).*

Within all the participants' narratives this desire for a clear-cut, straightforward journey with explicit navigations and directions features strongly. The parents at many levels seemed to discuss a quest of understanding, both in terms of understanding their child's journey and how they interact with the social world, in addition to understanding how their role as a parent intertwines in supporting their child to follow this journey. A sense of searching for answers is conveyed in the parents' discourse; this was interpreted as an attempt to re-establish control and agency in a time of uncertainty. Consequently a sense of finding comfort in information, and reassurance in the explicit was conveyed in the participants' dialogue:

> *"I've been reading about…I'm a bit obsessed, looking into things you know to do a bit of research […] But it's…any little thing I think right, OK, I understand that…"* (Anna*).*

This desire to understand was reiterated when discussing the diagnosis, Catrin shared *"I was glad that there perhaps was…not to label it, but glad that there was a term I could research…"*.

This sense-making process also continued for the participants after the diagnosis. Beryl reflected *"I think that I still, still haven't accepted it a hundred per cent. Because I still worry and ask why us?"* It is interpreted that this illustrates the construed unfair and unpredictable reality of raising a child with Autism.

These times of uncertainty were often characterised by difficult and strong emotions, which in the majority of cases led the participants to **question their own parenting skills** as they became increasingly desperate to know why their child was having difficulties.

In many cases the participants equated receiving their child's diagnosis of autism with the experience of *"Galar" (Grief)* and the *mourning and grieving of what was supposed to be*. The participants described their sense of bereavement in the context of suddenly losing the future that they had imagined for their child. Anna reflected:

> *"I remember crying a lot, I remember crying with 'Robin', oh, what could've been, you know, what you lose…it was sort of like, no, this sounds melodramatic, but you know, you get, erm, miscarriage, I've had a miscarriage before, you cry not because of what's happening at that moment- but all your hopes you know…so, it was something like that".*

For a parent, a child is commonly considered to be a personification of the future, however the participants somewhat conveyed a sense of time collapsing. It could be said that time in Newtonian terms is absolute. However, if considering the nature of time in linear, cause-and-effect terms (past memory, present events, future expectations), the parents conveyed a sense that their future expectations had been devastated. Elen reflected:

"…the future's something that I can't think about, because I panic, because I don't know what her future will look like…will she be able to live independently, what happens after we're gone…wow, you don't go there!"

This was conveyed as a difficult part of the 'path' to contemplate – *"we'll cross that bridge when we get there"* (Beryl). Venturing into the future was construed as a complex endeavor – considering the assorted un-answerable questions and prospects was overwhelming for the participants. This highlighted the sense that there is no explicit direction to the 'path', and that anticipating the future is a complex and painful process.

All the participants seemed more at ease when discussing present events during the interviews. This was a more familiar part of the 'path' - which they were exploring in the here and now. Despite conveying a sense of being more at ease, the mothers conveyed a sense of constant reflection and self-questioning – am I doing the right thing? Elen stated *"I feel guilty that I should know what to do, but when it comes to your own child- och!"*

The sense of over-whelming *guilt* is reiterated by Lisa in describing her memories of the past:

"I look back to when he was a toddler […] and the way I was trying to get him to understand, and they're not happy memories, I cringe at times…"

It is interpreted that this conveys the parents' self-awareness, and the frustrations that are entwined with the fact that they are finding it truly difficult to understand their own child, despite their best efforts. Four of the five parents reflected that they had not noticed that their child was 'different' until someone else, within the extended family, within school or a Health Visitor had alluded to this. Catrin recalled being told by the school's Head Teacher during a parents evening *"oh Lowri has problems. Yes, I said – she's hard of hearing. No, she said – Lowri has problems".*

Elen on the other hand described an epiphany when her Mother-in-law said:

"well, she doesn't respond to her name, and suddenly – I thought, oh Gosh, she doesn't respond to her name, and it was like she was a shell you know, nothing, she just went completely blank".

Relating to this, Beryl conveyed a deep sense of shame or *guilt – "I felt so embarrassed that I hadn't picked up on my own child".* These self-recriminations are almost tangible as the mothers consider their child as others might see them, and how others might perceive them as mothers. The participants in this study show evidence of considerable reflection on the symbiotic relationship of self and other selves. This will be

further discussed within the third super-ordinate theme presented.

All the parents' sense-making seemed to be discussed in temporal terms, and consequently explored in the context of a process. The participants acknowledged that along the journey, there will be *"a step forward and step backwards…"* (Lisa). It seems that an important aspect in this process is to accept the reality of life with Autism. Elen reflects on this, and states that, for her, **acceptance** eventually inspired **adjustments** in her and her family's life:

"You know full well the reality that your child's Autistic, but you go through these stages. You go through the denial, you go through being angry and you go through the…oh please no, please no – you're begging please no, that you have to go through this…and then you go through the things when you're being really proactive and you're like – we have to do this, we have to do this, and you must…and then you accept and then you're like – that's it".

Throughout the interviews, the participants sense-making of difficult experiences was quickly counteracted with frequent and enthusiastic references to their child's progress with an implicit sense of their own progress, of the parents traveling further down the path of making sense of living with Autism. Progress was representative of a sense of pride in their child's achievement:

"I was just proud of him, because he's my child, and he seems to be a very talented child" (Lisa).

Moreover, despite celebrating this progress, it is interpreted that the use of the words *'he seems to be'* in the above quote by Lisa is indicative of an uncertain process of learning and sense-making for the mothers.

6. 2 Making Sense of Bilingualism

Within this theme, there were apparent similarities and differences in terms of how the parents made sense of bilingualism at the individual and family level. This was co-constructed to be inherently linked to the notion of an identity and a sense of belonging. To an extent, this theme also coincided with the notion of following a journey.

In the initial stages (before the diagnosis), talking to their child in the parents' first language (Welsh) was discussed in terms of being a natural, intuitive process by all participants, although it could be interpreted that it was a more conscious decision for Anna and her partner:

"When Steve and I moved to this little village, to the Welsh school, Welsh community, we had hoped to put our children in a Welsh school, speak Welsh, grow up completely Welsh".

The repetition of 'Welsh' in Anna's discourse conveys a strong sense that 'Welsh' was originally a core aspect of her and her partner's preferred future for their sons, and that they had purposely moved to the *'little village'* in order to realise this dream. It is interpreted that the repetition of 'Welsh' suggests that their lived experience is in contrast to their expectations and hence warranted some adjustments.

86

A sense of adjustment was also conveyed when the parents described the period following the diagnosis, where a more **conscious awareness of language** was interpreted. Elen reflected that *"the conversation is not as natural any more because you're constantly trying to teach something to her".* This suggests that the parent and child relationship was not viewed as an instinctive, reciprocal relationship.

This interpreted exaggerated awareness of language was reinforced during some conversations with professionals:

"No, we are a Welsh family, erm, erm, when I was discussing with experts after the diagnosis, erm, they…they did not warn me, but they said that the majority of the children that they knew spoke in English because, it's just easier to cope, English is the main language that they will hear…and they were shocked to hear that he could understand [Welsh]" (Lisa).

This suggests that during this particular conversation with an expert, language was discussed in a more mechanical sense i.e. English was the more dominant language in the community, consequently it seemed a more practical and realistic expectation for the child to speak English.

It seems that following the diagnosis some parents adjusted their views on language, and actively reflected and tried to make sense of their priorities for their child. Beryl shared:

"…to be completely honest, he is bilingual, he can speak Welsh if he chooses to do so,

and I would like him to use more Welsh, but, erm, if he can communicate effectively it doesn't matter to me which language he uses…"

This view is reiterated in Anna's discourse, as she reflects that she is *"disappointed"* that she has switched to speaking English with her youngest son, Robin, however she reframes this to state that her main priority is that *"he can communicate with people".*

However, Elen in particular went on to voice a strong, deep-rooted sense that the Welsh language would become a core part of Lili's upbringing, and conveyed as something to nourish and protect – *"and I know how lucky I am, to speak Welsh and raise my child in Welsh, and that's something that's very important to me".*

This conveyed a sense of language being more than a mechanical mode of communication, that language is loaded with emotional meaning, and a central aspect of people's internal sense of self and identity.

In some cases the parents equated **feeding a language to feeding an identity:**

"it's a part of who I am, it's a part of who he is [Elen's partner], it's a part of…without the language I wouldn't be me" (Elen).

It is interesting to note the change of direction in Elen's quote, it seems that she is at this point unsure if Welsh is 'a part' of Lili's identity. Furthermore, the hesitation suggests that this is a difficult prospect to contemplate. It seems that for Elen language not only reflects who she is, but in some sense it *is* who she is. Plausibly Elen perceives

that if Lili will not share the same sense of identity, that this will impede the connection

and sense of belonging between them as Mother and daughter.

Elen's feelings towards Welsh being a part of an identity are so strong that she

reflects on her efforts to 'protect' the same sense of identity for her daughter, Lili:

"…she's not allowed to watch any English television program because you know with

Autistic children, with the scripts, that's where she'd learn her language, and it

scares me, it really scares me that she's going to turn around and not speak Welsh".

It is interpreted that the strong feelings conveyed relate to the core desire for her

child to *perthyn* (to belong), and to be accepted in a community who share similar values.

Interestingly, this multifaceted need to *perthyn* (belong) has led Elen to isolate her

daughter from the English language. This need to *perthyn* (belong) and to be accepted will

be further discussed within the final theme.

A further sub-theme interpreted encompassed the concept of the child being able

to use language(s) as a vehicle to communicate their thoughts and feelings. When asked

about language, much of the participants' discourse focused on reinforcing and facilitating

the **voice of the child**, particularly during involvement with various professionals. This

featured strongly in Catrin's interview:

"Lowri will always respond better when someone is speaking to her directly [in

Welsh]…instead of me having to say – oh what she's saying now…it's difficult. Yes, so

when Lowri gets to speak or share her own feelings, she's much better within

89

herself".

Catrin conveys that being able to talk in her first language is a source of comfort during potentially unfamiliar situations (for herself and her daughter), and reflected that Lowri *"didn't respond at all to someone that spoke in English with her"*. It is interpreted that being able to talk in your first language aids the therapeutic relationship between a professional and client, and that Catrin attributes this to the progress she's noticed in her daughter:

> *"I don't think, in terms of the Hospital, we would've reached where we are now […] it was important for her that XXX [Name of Surgeon] could go through everything with Lowri in Welsh…and she was happier then".*

It seems that not being able to speak in your first language is perceived as a barrier that impedes progress. It is also interpreted that Catrin is conveying a sense of isolation for her daughter, as her daughter was not able to share her thoughts and feelings. This sense of isolation would plausibly be exacerbated due to the social and communication difficulties associated with Autism.

6. 3 Ni a Nhw [Us and Them]: Navigating the Social World

The third theme relates to contrasting, but inherently related concepts – **isolation**, and the **desire to belong**. The parents described a pervasive lack of awareness of Autism in society at large, which led them to believe that the majority of people do not understand the condition. Other people (including the extended family) and negative

90

social experiences were central to many of the participants' accounts.

All the participants conveyed a sense of isolation in their discourse, Beryl shared:

"I sometimes feel that I don't have a lot of support, so it can be difficult, and because Hari looks normal, it's a hidden disability isn't it […] I think there's a need to raise more awareness of autism, definitely".

It was interpreted that there are two significant contributing factors to this feeling of isolation – the sense of being *exposed to judgment* and a *lack of understanding within society*. Both of which relate to Mead's (1934) view of the self, which is both relational and symbiotic. This implies the dynamic interdependency between the participants' perceptions of themselves and the perceptions of others.

An awareness of being negatively evaluated by people around them featured strongly in participants' accounts, and was clearly a significant issue for some of the parents. Some participants conveyed a sense of having to justify their child or their own actions to others. As Catrin illustrates:

"I find myself sometimes having to say – she has Autism […] well I went in to the disabled toilets [with Lowri], and you could see these people looking at us […] so the letter [confirming diagnosis] is always with me in my pocket"

Furthermore, Beryl conveys a feeling of being judged relating to her son preferring to speak English in a predominately Welsh speaking community:

"I speak Welsh with him, so he takes in the information and he answers me in English. Lots of people find that difficult…it's difficult, especially in the Mainstream schools…"

This demonstrates an incident where language can contribute to the sense of isolation (for both parent and child). Hari's preference to speak in English is perceived to be a barrier to fully accessing and belonging to the community, particularly the school community.

In the context of raising a child that often finds it difficult to understand social situations, the parents seemed to have a heightened awareness and sensitivity to the opinion of others. The participants' children, in light of the lack of social understanding that often accompanies Autism, may not be aware of some social judgments or will not have the same emotional response, yet their parents are still very much affected by them.

Within the majority of parents' discourse, it was notable that this feeling of being judged was often related to conversations with school staff and other professionals. In many respects the concept of feeling judged by other people was intertwined with the feeling from all the participants that other people lack awareness of autism and do not understand the experiences they are going through.

This sense was relevant at many levels; for some participants there was an acknowledgement that they would like people, family or otherwise, to be more aware of their need for their situation to be understood. The majority of the participants discussed

the difficulty of coping with members of the extended family not truly understanding or accepting their child's diagnosis:

"I could accept it, but it was more difficult for other people to accept it…like Mam and Dad, Mam – she was OK, but Dad – no way, just he's naughty, he's spoilt!" (Anna).

At times some participants reflected that an apparent lack of understanding from school staff led them into sometimes challenging conflict regarding how a situation or behaviour ought to be managed.

"…so I tried to get the school to understand – that's an ongoing battle. They're very kind but they don't understand" (Anna).

This ongoing battle resulted in Anna moving her younger son to another educational provision, illustrating the significance of the parent-school relationship. Another notion highlighted was the desire for the school to see and understand the individual prior to understanding the diagnosis. Beryl recalled a teacher commenting *"I've never had one before"* when her son started attending school. Therefore, she argued that:

"The most important thing, is not generic training, but providing training on the child […] you've met one child with Autism, you've met one […] They're all so different"

This lack of understanding extended to other professionals, with parents reflecting that the majority do not 'truly' understand, and recognised significant gaps in terms of the support provided to parents. These gaps tended to revolve around the notion of not being

listened to, which reinforced their feeling of isolation – *"I didn't have anyone I could turn to and ask- am I doing this right?"* (Beryl). Parents raised the need for more therapeutic interventions and more accessible parent support groups.

However, recognising and staying true to the ideographic nature of IPA, it is important to highlight that some of the participants stressed that the school environment has been instrumental in ensuring progress for their child. Elen shared:

"…the school is just fantastic, you know. She's got a fantastic teaching assistant, erm, she's settled in the school, we haven't had any difficulties in taking her to school…we've been very lucky…"

It is interesting to note the use of the words ' very lucky' in Elen's praise of school, it is construed that this implies that this particular situation is not the norm for other parents.

All the participants conveyed the importance of **perthyn (belonging)** and being accepted. Nearly all the participants reflected how important it was for them to be a part of their community:

"Hari is a part of the community…even though he doesn't have many friends, he's not bothered either, but the children of the town, every time we pass they say 'ti'n iawn Hari?' (how are you Hari)?" (Beryl).

The parents conveyed a sense that they were reassured by this sense of belonging, and bilingualism was seen as a social lubricant, reinforcing their child's access to being a

recognised member of their community.

One of the strongest messages conveyed in four of the parents' discourse was the power of being able to speak with other parents with a child with a disability:

"speaking with other parents is the most supportive thing, and, erm, the most effective way of sharing information…you can read and talk with experts as much as you like, but other parents' experiences are the most useful things…" (Lisa).

Elen described a sense of relief when talking with other parents – *"everyone's the same and everyone understands […] I like going there – everyone's the same, it's ok".* It is interpreted that this social sense of belonging is a part of a process of normalisation – where parents realise that their sense-making is not isolated, and that they are not alone when traveling along the winding path.

7. Discussion

It is hoped that this initial exploratory study has contributed an insight into the lived experience of bilingual parents with a child with ASC in Wales, an area which was previously unexplored. Due to constraints in word length, the discussion has been restricted to those themes presented within the analysis. It is argued that the analysis has yielded information that applies to both the primary and secondary research questions. However, it could be stated that the analysis has not fully addressed the secondary research questions. Smith et al. (2009) state that due to the "open nature of qualitative data collection" (p.48) it is not an assured expectation that secondary research questions

will be answered. It is an interesting observation that the participants' sense-making tended to revolve around their child's Autism. It seems that the parents are still engaged in that sense- making journey on an on-going basis, and that seems at the forefront of their minds, more so than bilingualism.

Arguably, much of the participants' experiences relating to Autism reiterates what has been reported in the broad literature, with the complex interaction between the parent and child being conveyed as a journey or process of understanding and acceptance (Hutton & Carron, 2005; Osborne & Reed, 2008). Furthermore, all the participants recognised the need for more awareness and information – in the context of the general population, school staff and the extended family. This has been recognised within the WG's Autism Spectrum Disorder Strategic Action Plan for Wales outcome evaluation (2016).

Relating to this, isolation seemed to feature particularly strongly in the participants' discourse. This was linked to lack of information, in addition to a perceived need for more Welsh-medium resources and opportunities. This was strongly conveyed in Catrin and Lisa's discourse, where they highlighted that the voice of the child was lost during meetings with professionals who did not speak Welsh. In contrast, Beryl and Anna implied that the fact that their sons displayed a preference for speaking in English led to some feelings of isolation within the community and to an extent within the extended family context. It is suggested that the occurrence of children with ASCs preferring to talk in English, despite a Welsh (language) upbringing warrants further exploration.

In contrast to previous studies in North America, all the participants expressed a desire for their child to become bilingual, although the priority given to bilingualism differed. It is interpreted that the importance placed on bilingualism related to two aspects – the desire to fully belong and function in a bilingual community, and a perception that language is a core aspect of an individual's identity. Interestingly, the Welsh word for identity – *hunaniaith,* contains the word – *iaith,* which translates into 'language'. Smith et al. (2009) note that identity often emerges as a central concern in the growing corpus of IPA literature, this is in line with the current study as identity featured strongly in the participants' discourse. In the context of language, Llamas and Watt (2009) state that "the connection between language and identity is a fundamental element of our experience of being human" (p.1). It is argued that this is evidenced in the participants' sense-making, particularly in the case of Elen.

Previous studies have documented participants' accounts of receiving advice from professionals to 'stick with one language' (Yu, 2016; Wharton et al., 2000; Kremer-Sadlik, 2004). To a large extent, this finding was not reiterated in this study – however one participant (Elen) shared that a Specialist Teacher had advised her to only expose her child to Welsh, if she aspired for her child to talk in Welsh. A number of the participants also conveyed professionals' sense of shock when they learned that their child was bilingual. A study by Moore and Perez-Mendez (2006) documents that professionals working in the area of communication and language disorders have not always felt competent in dealing

with bilingual families; it is plausible that there is a need for further research in order to guide professionals' training in this area.

Participants conveyed a need to be listened to – and expressed the need for therapeutic interventions for parents. Notably, the majority of the participants alluded to the fact that talking with other parents (who have a child / children with DD) had been the most valuable source of support and comfort. Zaidman-Zait et al. (2016) documents the need for such targeted, parent-focused interventions, and that early identification of parents' needs can lead to early interventions that are designed to provide families with more individualized and appropriate support services.

8. Research Limitations and Future Research

It is argued that the current research findings provide a valuable and unique insight into the gap in the literature relating to bilingual parents with a child with an ASC's lived experience in the U.K. However, despite the ecological validity of these results the interpretations that have been made are limited to the small, homogeneous group of mothers who were interviewed (Smith et al. 2009). It is also recognised that the participants' sense-making was explored in terms of the mother's experience, which is distinct and arguably not representative of a father's experience. Furthermore, the results should be considered with caution in relation to professional practice, as they remain un-generalisable.

Plausibly a next step would be to develop a questionnaire on the basis of the

current findings, which could then be completed by a much larger sample of parents in order to determine their level of agreement with the reality of these findings. This would thus assess how well the current findings represent the wider population of bilingual parents of children with ASCs. However, there would also be value in doing further qualitative research in this area, perhaps using focus groups as a way of generating greater volumes of data from a larger sample, or collecting longitudinal data in order to enrich our understanding of the parental 'journey'.

A limitation that has limited the capacity of this study is that the views of the parents were not triangulated with those of their children or young people's perspectives and other relevant professionals. This would have plausibly enabled a more holistic validation of the findings. It would be constructive for further research to build on this study using triangulation to contribute further to the exploration of the lived experience of parents and to better inform future practice.

9. Implications for EP Practice

Smith et al. (2009) state that due to the idiographic nature of IPA research, the reader must be aware not to generalise from the findings, but make cautious links between the IPA analysis and their professional practice. Notably, only two of the five participants mentioned EP involvement, suggesting that EPs have not featured strongly along their journeys with ASC and bilingualism. From the research it is suggested that there are three key things to consider in relation to the role of the EP, which are outlined in Figure 6.

Figure 6 A figure outlining possible implications to the role of the EP and EPSs in supporting an individual within the family, school, community, and larger society (model informed by Bronfenbrenner & Morris, 2007)

Macrosystem

- In light of the recently proposed Autism (Wales) Bill (National Assembly for Wales, 2017), it is argued that EPs may be well-placed in terms of conducting empirical research in order to explore best practice and areas of support that need to be further developed in Wales.
- It is also argued that EPs could be well-placed in terms of collaboratively discussing and implementing frameworks relating to working with multilingual families.

Exosystem

- In line with NAS Cymru's (2015) recommendations, it is argued that EPs, as part of a multi-agency framework, could contribute to establishing explicit and accessible 'ASC Pathways' within LAs.
- It is suggested that EPs could collaborate in terms of implementing evidence-based practice within school-systems and in terms of supporting parents.

Microsystem

- All the participants conveyed stressful experiences or emotional strain in their discourse, a feature replicated in a recent study by Zaidman-Zait et al. (2016). Another finding in their longitudinal study was that high or increasing levels of social support predicted a decrease in parenting stress (Zaidman-Zait et al., 2016). This relates to the sub-ordinate theme of '*Perthyn:* A desire to belong" in the research. The participants identified that sharing experiences with other parents was their greatest source of comfort, a factor that I interpreted to facilitate this feeling of belonging. It is suggested that EPs have a role in actively listening to parents, and furthermore in collaboratively facilitating opportunities for parents to come together to learn and share their experiences of living with ASC. It is argued that this would not only provide a therapeutic opportunity for parents, it would also provide the opportunity for parents to be positive change agents in other families' lives.
- It is argued that EPs have a key role in terms of facilitating training, and providing information on research-based practices. EPs could be instrumental in upskilling school staff and supporting school systems to instill an inclusive and person-centered ethos. EPs could collaboratively provide information to various stakeholders (e.g. in the form of information booklets, training sessions and 'drop-in' sessions). It may be good practice to involve parents and school staff in the delivery of such training sessions. It is also recognised that EPs could potentially be involved in facilitating evidence-based programmes such as the National Autistic Society's (NAS) Early Bird programme (Shields, 2001).

Child

- Active listening and enabling dialogue (Rhydderch & Gameson, 2010); it is argued that this study has highlighted the importance of providing the opportunity for CYP to communicate their thoughts and feelings in their first language, if possible. If this is not possible, it could be argued that it is important for EPs and other professionals to familiarise themselves with the multilingual literature and actively seek research-based methods of facilitating the therapeutic alliance with CYP.
- "You've met one child with Autism, you've met one" was arguably a key message in this study. It is suggested that EPs are well placed as being 'Person-Centred Planning' (Sanderson, 2000) advocates for CYP, and that collaboratively facilitating change in ways that are tailored to individual CYP is a key aspect of an EP's practice.

10. Final Conclusions

The participants in this study were looking to share their experiences in order to improve the understanding of others, and plausibly to facilitate their sense-making journey of living with Autism. It is hoped that the current research findings provide a valuable and unique insight into the gap in the literature relating to bilingual parents with a child with an ASC's lived experience in the U.K. However, it is important to stress that the results are perhaps most appropriately considered as a foundation for further research to build upon. Hopefully, these findings could encourage EPs and other relevant professionals to be more cognisant of the experiences of bilingual parents, and how these could impact upon other areas of their lives. To conclude, although there are aspects of raising a bilingual child with autism that are common across the participants' experiences, it is important to stress that there are also many aspects that are unique to the individual child and their family.

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Part Three: Critical Reflection (5996)

1. Overview

The critical review contains a reflexive account relating to two main premises: the unique and exploratory contribution of the current study to the lived experiences of bilingual parents with a child with Autism Spectrum Conditions (ASC) in Wales; and a critical account of the research practitioner. Rather than separating these premises into two distinctive sections, both are discussed in conjunction with one another, highlighting the personal development of the research-practitioner throughout the process of research. Onwuegbuzie and Leech (2005) reiterate that a qualitative researcher makes subjective decisions and justifications at each stage of the research process. The critical review offers an in-depth account of the process of conducting the research, detailing the researcher's epistemological position, methodological choices and discussing the challenges and limitations which impacted on the research process. The research outcomes and the research's exploratory insight into the lived experiences of bilingual parents with a child with ASC in Wales, and what this means for professional practice will also be discussed. The contribution of knowledge recognises how my own beliefs and personal experiences influenced the piece of research. The critical review will be written in the first person to reflect that this section of the doctoral thesis provides a reflective and reflexive insight into development of the research and of the research-practitioner.

2. Research Development

2.1 Initial Conception of the Research Topic

My initial research area for this research project emerged from a particular experience during my role as an Assistant Educational Psychologist. During a home visit I met a family (a Mother and two young sons). One of the sons had received an ASC diagnosis. I was struck with the linguistic dynamic within the family –with the Mother communicating in Welsh with both sons; both sons were attending a Welsh medium mainstream school; and all the immediate family and community communicated in Welsh. However, the young boy with ASC communicated exclusively in English, with a broad American accent. This immediately inspired me to question, research, and reflect on the multifaceted relationship of language and ASCs. However, mindful that this was a very broad area of interest I acknowledged that there was a need to narrow the focus somewhat.

Through my work as an applied psychologist in Local Authorities (LAs) in Wales, working with schools to facilitate change through the use of Psychology, I came across some parents who had a child with developmental difficulties (DD) that expressed concerns for a perceived lack of Welsh-medium supportive resources and opportunities. I decided that this warranted further exploration. However, I was mindful that it was important for my research to address a gap in the literature, as opposed to meeting the objectives of a particular Educational Psychology Service (EPS). To address this difficulty I turned to the existing literature to identify if this was an area in need of further

investigation.

Exploration of the extant literature revealed no research that directly explored the concept of ASC and bilingualism within the context of the U.K. Considering that the most recent census of England and Wales in 2011 recorded that 4.2 million people (7.7% of the national population) spoke languages other than English as their main language (Office of National Statistics, 2013), and Baron-Cohen et al. (2009) reporting that the prevalence of ASC is rising across the U.K., I was somewhat surprised by this finding. However, I had certainly found a 'gap' in the literature.

Broadening the horizons of my literature searching, I came across Hambly and Fombonne's (2012) quantitative study on the impact of bilingual environments on children with ASC. Interestingly, Hambly and Fombonne (2012) hypothesized that the social impairments associated with ASC could potentially limit the ability of children with ASC to learn a language in bilingual environments at the same rate or to the same level as children with ASC in monolingual environments.   Further exploration of North American qualitative ethnographic and survey-based studies indicated that parents of children with ASC express uncertainty when making decisions about bilingual exposure for their children (Reetzke, Zou, Sheng & Katsos, 2015; Bird, Lamond & Holden, 2012; Kremer- Sadlik, 2005; Yu, 2013). This parental experience of uncertainty interested me, and I reflected if this might be an issue in Wales, a country with two official languages (Welsh Language Act, 1993).

In relation to this parental experience, I came across Bird et al.'s (2012) survey

instrument to examine parents' (of a child with ASC) perspectives on bilingualism. The survey contains open and closed-ended questions relating to the choices parents made regarding bilingualism for their children with autism; the reported success of raising children with autism bilingually; and the advice parents received from professionals regarding bilingualism. Bird et al.'s (2012) survey concluded that parents acknowledged that living in a bilingual community and the need to communicate with various people in a variety of venues supported a bilingual choice (for their child with ASC), along with the perceived enrichment and job opportunities that bilingualism afforded. Parents also reported concerns around choosing bilingualism for their children with ASC, such as lack of services and supports and concerns about whether their children would be able to learn two languages. Bird et al. (2012) recognized that there is limited information about bilingualism and children with ASC, and that further research was needed in order to guide decisions and better support the needs of families.

Following further reading of the literature I considered the possibility of utilising a similar survey in order to complete an initial exploratory piece of research into the experiences of bilingual parents with a child with ASC in Wales. Initial research planning revolved around the idea of designing and utilising a modified version of Bird et al.'s (2012) survey questionnaire in conjunction with a qualitative interview. The rationale for using a multi-strategy design related to Bryman's (2012) assertion that it could support the research in producing a more comprehensive picture of the topic of research, descriptively referred to as 'putting meat on the bones'. Furthermore, I hypothesized that using a combination of qualitative and quantitative methods could generate a more

comprehensive picture of bilingualism in children and young people (CYP) with ASCs in Wales.

However, following extensive reflection and seeking supervision, I came to the conclusion that the use of a survey questionnaire would assert predefined outcomes. Due to the fact that no previous studies had researched this area in Wales, and that my research would very much be an initial exploratory study, I wanted to produce a piece of research that did not measure predefined parental perceptions of bilingualism in CYP with ASCs in Wales. As such, I reflected that it would be more helpful to explore the experiences relating to ASCs and bilingualism, which other research could be based on and developed.

2. 2 Development of Research Position

2.2.1 Undergraduate Education

Prior to and during the process of designing the research, I maintained an awareness on the impact of my current and past psychological training on my epistemology and ontological position. During my undergraduate education, my teaching of research methods and data collection were based primarily in post- positivism and focused solely on quantitative measures and statistical analysis. Breakwell, Smith & Wright (2012) highlight that this hypothetico-deductive method is the most widely used research paradigm used in psychology, where theories and hypotheses are tested and where the reliability and the replicability of the findings are vital.

Robson and McCartan (2016) state that post-positivists largely rely on quantitative methods and believe it is possible to describe causal relationships between factors. Therefore, the post-positivist approach takes the stance that there is a measurable reality and that research is the process of making claims which are refined or abandoned in light of evidence, while acknowledging the bearing of the researcher's perspective on experimental outcomes (Reichardt & Rallis, 1994).

2.2.2 Postgraduate Education

Central to my current training as a Trainee Educational Psychologist (TEP) is the Constructionist Model of Informed Reasoned Action (COMOIRA) which employs a social constructionist framework for practice (Gameson & Rhydderch, 2008). This social constructionist stance to practice, which is based in relativism, posits that each person's view of the world is socially constructed, is subjective and phenomenological (Burr, 2015). Gameson and Rhydderch (2008) highlights that in practice embedded in social constructionism, it is not possible to establish facts or truths without acknowledgement that individuals and groups are likely to "construct many different, sometimes conflicting, but equally convincing 'truths' or 'realities,' all of which may be accepted as appropriate, relevant and valid" (pg. 101).

2.3 Ontology

Consistent with the framework that underpins my current practice as a TEP, this research has adopted a relativist ontology, taking a stance that reality is construed through social experience (Mead, 1934). In relation to my hope of eliciting and exploring

'experience' in an under-researched area, I felt it would be appropriate to acknowledge

that there are multiple realities derived from different versions of experience (Willig,

2008), as opposed to taking a realist ontology with an overarching law of reality.

2.4 Epistemology

Thomas (2009) argues that constructionism is not concerned with making grand

claims about generalisation or causation, instead the focus is on understanding the

experiences of a specific sample. In accordance with Gergen (2009) and Burr's (2003)

position, I took a subjective view that knowledge is socially constructed through

interactions between people, rather than having a separate existence. It is argued that

this is appropriate as the intention of my research was to explore the participants'

(parents) interactions with their child with ASC, and how they make sense of this.

In consideration of alternative paradigms, Condelli and Wrigley (2004) argue that

positivist or empirical paradigms are not suitable for research being conducted in real-life

contexts. Robson (2011) corroborates this view and states that this is often due to the

limited control over confounding variables and meeting experimental rigour.

Post-positivists allow for more flexibility around the idea of 'truth' and share a

social constructionist belief that there are never ultimate truths. Nevertheless, by applying

predefined theory and hypothesis testing to research, the paradigm is still considered

objective. In the context of the current study, it was felt that due to the exploratory

nature of this initial study, taking a positivist or post-positivist approach to research by

searching for objective knowledge and testing hypotheses would have been incongruous.

Robson and McCartan (2016) claim that social constructionist and social constructivist approaches share very similar philosophical underpinnings; I felt that both fitted with the explorative direction I hoped to take with the research journey. The focus of a social constructivist is on how the *individual* constructs and makes sense of the world. On the other hand, social constructionist believe that research participants are viewed as helping to construct reality with a researcher. Admittedly, taking a social constructivist view may have been beneficial in order to provide the opportunity for each participant's voice to be heard from a more open-ended structure. However, I felt that it was important to acknowledge that the researcher would play a central part in the research and consequently influence the results. Furthermore, within the social constructionism viewpoint, language is considered a pre-condition for thought (Burr, 2015). Moreover, there is a view that concepts and categories are acquired by individuals as they develop the use of language, and are thus replicated daily by everyone who shares a culture and a language (i.e. relevant to a *group of people*) (Burr, 2015). It is therefore argued that a social constructionism positioning fits well within the exploration of perspectives towards bilingualism.

2.5 Qualitative Rationale

Robson and McCartan (2016) refer to the concept of "real world research" (pg.3) which they defined as research projects which are typically small in scale and modest in scope. Furthermore, according to Robson and McCartan (2016) these real world research

endeavor to understand the lived-in reality of people in society and its consequences. I felt that this focus on the lived-in reality of people fitted in well with my constructionist epistemology.

Despite claims by Robson (2011) that "almost all of the research under this heading [social constructionist research] uses qualitative data collection methods" (p.24), Burr (2003) reported that both quantitative and qualitative research can fit with a social constructionist paradigm.

Despite this, it has been suggested that research employing constructionist or relativist approaches lends itself well to qualitative methods, such as interviewing and focus groups, as the central aim of this approach is to obtain multiple perspectives with awareness of the researcher's own constructs and belief systems (Robson & McCartan, 2016). The literature revealed that there exists no literature into bilingualism and ASC in the UK. Therefore, it could be argued that it would be difficult for meaningful quantitative research to be carried out at this initial stage, due to the limited understanding and that other research in the area has been mainly based in North America with immigrant families (Drysdale, van der Meer & Kagohara, 2015) which would plausibly lack generalisability to the U.K. context.

Smith and Dunworth (2003) propose the usefulness of qualitative research when investigating a novel area. I feared that by reducing the data to numerical values the research would be limited to purely testing for predefined categories (Smith, 2008). This would lose the detailed and meaningful data, which is rich in exploratory power (Denzin

and Lincoln, 2000); a component which could be considered vital when initially exploring a 'phenomena.'

Despite this, it was important for me to display criticality, and consider alternative methods. Qualitative constructionism research in its extreme form has been criticised for being incompatible with the concept of evidence-based practice (Fredrickson, 2002); which is encouraged within the EP's applied role (Kelly, 2008). Furthermore, Condelli and Wrigley (2004) argue that qualitative findings are restricted because of small sample sizes, their time consuming nature, the lack of generalisability and the interpretation bias of the researcher. Therefore, by adopting a quantitative approach such pitfalls could have been overcome due to the ability to research larger sample sizes, provide statistical representation of the population and to perform reliability measures of the research findings.

However, I felt that using pre-defined concepts based on North American research, through the use of a quantitative approach would not have beneficially added to the literature at this stage. To address the identified gap in the literature, it was therefore felt that this piece of initial exploratory work fitted well into a qualitative research design.

2.6 Interpretative Phenomenological Analysis (IPA)

My interest in exploring 'experiences' led me to research various methodologies that enabled the exploration of participants' constructions (Smith, Flowers & Larkin, 2009; Denzin & Lincoln, 2011, were helpful resources). One such method explored was the use

of thematic analysis (Braun & Clarke, 2006). In terms of my professional development as a researcher, I had conducted thematic analysis as part of the course's requirement to complete a collaborative and small-scale piece of research. Therefore, I was mindful not to limit my experience to one methodology. Moreover, as a bilingual (Welsh / English) individual living in Wales, I felt that it would be essential to fully recognise the influence of my interpretation within the research. It is argued that the ability to do so would be somewhat limited within thematic analysis.

Further exploration of qualitative research led to the consideration of IPA (Smith, 1996; Smith et al., 2009) and Grounded Theory (GT, Glaser & Strauss, 1967), I felt that both approaches offered a clear, sequential guide towards qualitative analysis for the exploration of individual accounts of a phenomenon, in particular where little is known about a topic. Moreover, both methods provided iteratively related analysis processes which are believed to strengthen the rigor of qualitative analysis (Carter & Little, 2007).

GT is based on developing theory from the data itself as opposed to previous research informing the research questions. However, at this point prior engagement with the literature had been made and although the research aim remained exploratory it was not felt to meet the theoretical groundings of GT. Furthermore, GT was interpreted as being on a large scale, due to the sample size being determined by when one achieves saturation of information (Strauss & Corbin 1990), which I felt that it would unlikely to be effectively met by this study, as at this point, due to the initial exploratory nature of the research, I was unsure of the limitations of the participant pool.

On the other hand, IPA is recognised as an established method in clinical, health and social psychology, which provides a stance and protocol for the analysis of experiential qualitative data (Reid, Flowers, & Larkin, 2005; Smith & Osborne, 2008; Smith et al., 2009).

It is argued that IPA is an appropriate method of analysis as where discursive approaches focus on how an object of interest is being construed through an analysis of language, social interaction and/or through the identification of patterns of discursive action, IPA is an interpretation of the meaning for a person in a particular context (Smith et al, 2009). In IPA the researcher is trying to make sense of the participant's sense-making of their experience; this is the double hermeneutic and Smith et al. (2009) recognise that the truth that IPA analysis can claim is subjective and always tentative. However, despite this subjectivity, Smith et al. (2009) argue that IPA is dialogical, systematic and rigorous.

Despite this, I also had concerns around the use of IPA because of sacrificing the breadth of research and sample size reductions for the depth of analysis (Smith & Osborne, 2008). Pringle, Drummond, McLafferty and Hendry (2011) argue that this raises issues with how understanding can be generalised or even replicated. However, although the results cannot be generalised from, they can cautiously be applied to professional practice (Reid, Flowers & Larkin, 2005; Smith et al., 2009); adding contextual insight and important detail to existent literature (Lander & Sheldrake, 2010).

IPA was felt to match with the epistemological approach of the research process. Its theoretical underpinnings deriving from Phenomenology, Hermeneutics and Idiography

(Smith et al., 2009) offered a sound approach for addressing a newly developing area of research. Robson and McCartan (2016) support this assertion, and shared that a social constructionist approach fits with the Phenomenological and Hermeneutics theories of knowledge underpinning IPA.

2.7 The Researcher's Historicity

In terms of Phenomenology -the importance of context has been highlighted by Moran (2000), who, in citing Heidegger states:

"...that phenomenology must be attentive to *historicity*, or the *facticity* of human living, to *temporality*, or the concrete living in time" (pg.20 – original italics).

Therefore, in essence, Phenomenology must include an awareness of context in time. However, it could be argued that context is not a static entity, as personal biographies, and the research context, influences which subjective self will perceive the world at any given time (Grbich, 1999). Presumably, this applies as much to researcher as to participant. With this in mind, my own 'historicity' is now briefly considered:

I am a bilingual (Welsh / English) individual, who received Welsh-language education until the age of 18. I was brought up, and continue to live in a predominately Welsh speaking area – where I socialise with family and friends almost exclusively in Welsh. Reflecting back on my childhood, the Welsh language, and inextricably the Welsh culture was a central aspect of my upbringing- competing in *Eisteddfodau* (a Welsh festival at which competitions are held in music, poetry, drama, and art) and singing, reciting and

folk dancing were ever-present in my education, within and outside the home environment.

Now, in my late twenties, I reflect that the Welsh language (and culture) continues to be a core aspect of my identity; and plausibly completing this study has reinforced this notion. At the time of the research and at present I am living in one of the LAs where 40% of the participants were recruited. Furthermore, I have previously worked in the LA as an Assistant EP for a period of 6 months. During my time as an Assistant EP, bilingual communication was considered an essential asset for the role.

Autism is not something that I have direct personal experience with, in the sense that no member of my immediate family or friendship circle has received an Autism diagnosis. However, in my role as an Assistant EP, and currently in my role as a Trainee Educational Psychologist (TEP), supporting individuals with ASC feature strongly in my casework. I reflect that supporting individuals with ASC (and their families) is something that I have become particularly interested and passionate about.

Heidegger (1962) highlighted that bringing your own fore-conceptions (prior experiences or pre-conceptions) to the research can be important to interpretation. Therefore, following the advice of Smith et al. (2009) a research journal was kept to bracket (treat separately) any reflective and reflexive comments I had during the analysis. In these reflections it was noted that as a researcher, once you are aware of your own identity and language use these issues, in themselves, can be a focus for exploration.

3. Methodology

It could be argued that IPA does offer flexibility for the research process, however, it does recommend quite a prescriptive path for best practice. Once chosen, the IPA approach guided the method of data collection and the research question. I considered Smith et al. (2009) an invaluable resource in this respect, particularly as a novice IPA researcher.

3.1 Research Questions

A primary research question open to exploration of the topic of bilingual parents' experiences of raising a child with ASC in Wales was chosen, as required in an IPA approach, to reflect the phenomenological and interpretative aspects of the method. Furthermore, I decided to include four secondary research questions. These were more theory-driven, and related to Family Language Policy (Schwartz, 2010; Spolsky, 2012) and included in order to reflect the more applied perspective of the research.

Despite the decision to include secondary research questions, I was fully aware that due to the open nature of qualitative data collection it would not be certain that I would be able to answer them, as this would be done at the more interpretative stage (Smith et al., 2009).

3.2 Data Collection

The phenomenological approach advocates using methods that enable the collection of naturalistic first-person accounts of experience (Langdridge, 2007). This is

also reiterated in Smith et al. (2009), who states that the IPA researcher aims to design data collection events that elicit detailed stories, thoughts and feelings from the participants. Exploring the literature, I noted that semi-structured, one-to-one interviews have been a popular and preferred method for collecting such data (Reid, Flowers & Larkin, 2005).

Interviews also offer consistency with IPA's beliefs that the researcher plays a key role in the research process and that interviews are not neutral means of data collection (Rapley, 2001). Although focus groups could have been used, I reasoned that this would have not allowed for a truly idiographic process during analysis.

3.2.1. Semi-structured Interviews

Described as a "purposeful conversation" (Bogdan & Biklen, 1982, as cited in Scheurich, 1997, p.61), the qualitative research interview is considered a method that allows the gathering of rich, detailed information about human experience. Thomas (2009) states that semi-structured interviews enable an interviewer to design an interview schedule that specifies topics to be covered in an interview, with the freedom to probe and ask follow-up questions. Reviewing previous literature, and following Smith et al.'s (2009) recommendations enabled me to design an interview schedule (see Appendix A). Seeking supervision was essential in order to refine this schedule. Furthermore, a pilot data analysis was conducted to ensure that the data collection was effectively carried out.

Another important aspect of the interviews was that the participants were encouraged to choose in which language they would like to complete the interview (either

Welsh or English), and were able to code-switch between each language if they wished to do so. Llamas and Watt (2010) state that individuals are better able to share or express emotions in their first or native language. Making sense of experiences, and consequently emotions is a central aspect of IPA, therefore it is argued that providing this linguistic choice was essential in order to collect rich data.

3.3 Participants

IPA is recognised as an idiographic approach (Smith et al., 2009), concerned with understanding a particular phenomena in particular contexts, therefore a small, select and homogeneous convenience sample was recruited. A sample size of five participants was recruited from two LAs in Wales. The two LAs were selected due to the high percentage of Welsh speakers in their population (according to the 2011 Census). The inclusion criteria in terms of the participants was parents who met the following criteria:

(a) have at least one child between the ages of 2 and 14 who has received a documented diagnosis of ASC;

(b) are members of a bilingual family living in a LA in Wales (bilingual defined in this context as the use of both Welsh and English in the home and outside the home environment).

An important rationale for focusing on this group of parents is that they were most likely to live and socialise in bilingual environments and thus are more likely to make conscious and intentional decisions regarding language use. A common methodological

approach documented in the literature is to assess current bilingual exposure and to select participants who are exposed and use a certain percentage of bilingualism each week (Gutierrez-Clellen, Simon-Cereijido & Wagner, 2008). However, a major limitation of this approach is that it does not account for changes in language use over time. Hambly and Fombonne (2012) document that numerous families in their sample made changes in language use proportions from year to year, so bilingual exposure was not constant across time. Therefore, it is proposed that assessing the exposure to and the use of both languages was not appropriate in the case of this study.

In reflection, I was not sure how easy it would be to recruit a sample for this study. However, recruiting the participants was a relatively straight-forward experience, and all the mothers seemed very eager to partake in the research and make sense of their experiences.

3.4 Ethical Considerations

The literature documents the stress that is often related to the experience of parenting a child with ASC (see Zaidman-Zait et al., 2017). Therefore, there was a potential risk that some of the interview questions might have led to upsetting experiences being recalled. Consequently, careful planning and sensitivity was required (as demonstrated in Section 2). Following guidance from both the BPS (2009, 2014) and Felzmann (2009) I ensured any ethical issues were addressed and all elements of risk reduced.

3.5 Difficulties Addressed During the Research Process

From my research experience I have reflected on two difficulties or challenges, which I have construed as significant to the research process. Throughout my research journey, regular supervision was sought, which was invaluable for supporting me with the challenges I experienced.

The first challenge related to language. As discussed, I had made a conscious and informed decision to enable the participants to communicate in the language of their choice (Welsh or English) during the interviews. All the participants shared their lived experience in Welsh during the interviews. This reinforced the free-flowing dialogue, as all the participants communicated in their first language; and on reflection plausibly the fact that I (as the interviewer) was also communicating in my first language enabled a more naturalistic conversation, which enabled the collection of richer data.

All the interviews were transcribed verbatim, as advised by Smith et al. (2009). This raised important questions in terms of the next steps relating to analysis. Pietkiewicz and Smith (2012) recommended that the researcher should completely immerse themselves in the data or in other words, try to step into the participants' shoes as far as possible. This strongly suggested that analysing the data should be done in the Welsh language, as I felt this would strengthen the double hermeneutic, enabling me to make sense of how I was making sense of the participants' sense-making in the language of the interview.

However, this raised questions, as the language in which I would present the

interpretation of the results would be English. Therefore, following seeking supervision I researched the literature in the search for guidance. However, unfortunately, this yielded very limited information, with Halai (2007) reporting a dearth of research relating to the process of generation, conversion and utilization of bilingual data in educational research.

Nevertheless, I came across an IPA study in the field of mental health that explored professionals' experiences of empathy in clinical work with an interpreter (Pugh & Vetere, 2009). Their findings implies that subtle alterations likely occur in the client's message during translation may lead to important qualitative changes in the content [of therapeutic conversations] (Pugh & Vetere, 2009). In light of this, I decided to analyse the data in Welsh, as I felt that these "subtle alterations in meaning" (Pugh & Vetrere, 2009, p. 313), could be very detrimental, particularly in the context of an IPA study.

For the purpose of this report, all relevant quotations have been translated. In order to ensure rigor, the translations were completed by a professional translator- who has been certified by a English / Welsh translating society (*Cymdeithas Cyfieithwyr Cymru*) . In hindsight, I reflect that it would have also been good practice in terms of validity to certify these translations with the participants, to ensure that there was no alteration in meaning.

The second challenge also related to the analysis of the data. Hefferon and Gil-Rodriguez (2011) criticise an apparent lack of understanding in both students and supervisors that IPA is primarily an interpretive approach. This misconception, accompanied by a lack of confidence in raising the level of interpretation in analyses,

according to Hefferon and Gil-Rodriguez (2011), results in broadly descriptive IPA that lacks depth. My anxieties relating to this criticism of the IPA literature was discussed in depth during supervision sessions.

These anxieties, I reflect relates to the fact that in many respects I am a novice qualitative researcher. I have outlined an example of a perceived limitation of being a novice IPA research in the following paragraph.

Willig (2008) criticises IPA for being dependent on verbal expressions of experiences, whereas Smith and Osborne (2008) defend IPA researchers as being able to interpret non-verbal gestures and comment on unspoken communication during the interviews. However, I don't feel that this was done during the analysis. In hindsight I would have benefited from additional training in this form of non-verbal interpretation in order to have strengthened the application of IPA during the interview process.

Nevertheless, I feel confident that my analysis shows evidence of interpretation, this was achieved through supervision and meticulous reading of a number of theoretical papers that demonstrate how higher levels of interpretation might be achieved (e.g. Smith, 2004), along with a number of examples of what Hefferon and Gil-Rodriguez (2011) perceive as good- quality published empirical IPA that "demonstrate a depth of analysis with a good level of interpretation" (pg. 757) (e.g. Chapman, Parameshwar, Jenkins, Large & Tsui, 2007; Dickson, Knussen & Flowers, 2008; Eatough & Smith, 2006; Smith & Osborne, 2007).

4. Contribution to Knowledge

4.1 Contribution to the Literature

This research has provided a novel insight to the lived experience of bilingual parents raising a child with ASC in Wales. To my knowledge, this research is the first in the UK, to provide a qualitative, IPA exploration within this area. Therefore, it has contributed to a gap in the literature, and hopefully provided a helpful stepping stone for other research to be developed, in addition to highlighting the need for further exploration of particular concepts. These will be outlined within the following section.

The results from the study both served to support existing international literature on bilingualism and ASC as well as providing some interesting insights into the parents' constructions of living with ASC in Wales. In terms of contribution, I hope that the study has provided a (bilingual) 'voice' to the parents, which has raised important issues that warrant further exploration.

It was an interesting observation that the participants' sense-making tended to revolve around their child's Autism. It seems that the parents are still engaged in that sense- making journey on an on-going basis, and that seems at the forefront of their minds, more so than bilingualism. Much of the participants' experiences relating to Autism reiterates what has been reported in the broad literature, with the complex interaction between the parent and child being conveyed as a journey or process of understanding and acceptance (Hutton & Carron, 2005; Osborne & Reed, 2008).

In terms of North American research into ASC and bilingualism, one of the most notable features is that parents have been advised to only communicate in one language with their child (Yu, 2016). Furthermore, studies demonstrate that professional advice that is incongruent with the needs of families caused significant problems within the family context (Wharton et al., 2000; Kremer-Sadlik, 2004).

This study corroborates this finding to an extent, parents shared incidents where professionals seemed 'shocked' that their child could communicate bilingually, and one parent had received advice that she had to limit her communication with her daughter exclusively to Welsh if she wanted her to be a Welsh-speaker in the future. It seems that this suggests a lack of coherent framework of guidance for professionals in providing advice on bilingualism, as the literature suggests that this advice is not evidence-based. The *National Autism Plan for Children* (NAPC) (Le Couteur, 2003) and Baird, Douglas and Murphy's summary of the The National Institute of Health and Care Excellence (NICE) guidelines (2011) both emphasise the importance of giving accurate and high-quality information to parents. Furthermore, in a study by Brogan and Knussen (2003), the quality of information provided correlated with parental satisfaction. It is argued that this identifies an area which warrants further exploration.

Another finding I found interesting, and admittedly resulted in an epiphany of sorts within myself, is the interdependent relationship of language choice and identity conveyed in the participants' discourse. This relationship between language and identity is being increasingly researched. Llamas and Watt (2009) claims that this connection between language and identity is "a fundamental element of our experience of being

human" (pg.1). Therefore, arguably, it is important for professionals to be mindful of the inherent meaning of language for clients when making recommendations to families.

4.2 Contribution to Future Research

As stated in the empirical study, it would be constructive for further research to build on this study using triangulation to contribute further to the exploration of the lived experience of parents and to better inform future practice. Guion (2002) suggests that triangulating the views of different stakeholders can highlight differences and similarities in experiences, and therefore enrich our understanding. Triangulating the constructions of the parents with plausibly the CYPs and professionals (e.g. teachers, EPs, and Speech and Language Therapists) would seem a logical next step in terms of the research journey.

Furthermore, the participants in this study were purposefully recruited from LAs with a high percentage of Welsh speakers, due to the rationale that they would be most likely to live and socialise in bilingual environments and thus are more likely to make conscious and intentional decisions regarding language use. It is suggested that exploring the lived experience of bilingual parents in other LAs in Wales would be insightful.

Also, a further direction for future research would be conducting a longitudinal case study of one or two of the parents. This would have provided a richer insight into the participants' journeys, and plausibly would have yielded more information in terms of the parent-child relationship.

4.3 Contribution to Educational Psychology Knowledge and the Relevance to EP Practice

Smith et al. (2009) caution that practitioners must be aware of not generalising from IPA findings, but they should allow them to guide their understanding of the explored experience and to cautiously integrate the knowledge into their professional practice. This section highlights my reflections of how this research could have implications for the role of the EP.

Fallon, Woods and Rooney (2010) state that EPs were previously seen as gatekeepers to statutory assessments for children with special educational needs (SEN) specifically. However, in recent years, partly due to ever changing legislation and policies, EPs have been more involved in systemic multi-agency working as well as therapeutic work over and above simply providing assessments. Included in the WG's Draft Additional Learning Needs (ALN) Code of Practice (2015) is the statement:

"…the views, wishes and feelings of the child, child's parent or young person, should be at the heart of all decision making processes" (p.9).

It is argued that EPs are well-placed in terms of seeking, listening and acting on those wishes. In the context of this study, I have suggested broad areas in which EPs and EPSs could facilitate change in terms of the issues raised by the participants, and I have related those to Bronfenbrenner and Morris' (2007) Bioecological Systems model.

Due to constraints in word length I will not elaborate in detail on these areas, and the reflections shared are by no means exhaustive. However, I will reflect on a comment

that one of the parents shared following completing the interviews. Elen stated that she had felt that she had "just had therapy", suggesting that partaking in the study had been a cathartic experience for her.

All the participants conveyed stressful experiences or emotional strain in their discourse, a feature replicated in a recent study by Zaidman-Zait et al. (2016). Another finding in their longitudinal study was that high or increasing levels of social support predicted a decrease in parenting stress (Zaidman-Zait et al., 2016). This relates to the sub-ordinate theme of '*Perthyn:* A desire to belong" in the research. The participants identified that sharing experiences with other parents was their greatest source of comfort, a factor that I interpreted to facilitate this feeling of belonging. It is suggested that EPs have a role in actively listening to parents, and furthermore in collaboratively facilitating opportunities for parents to come together to learn and share their experiences of living with ASC. It is argued that this would not only provide a therapeutic opportunity for parents, it would also provide the opportunity for parents to be positive change agents in other families' lives.

It is also argued that EPs are well-placed in terms of providing information and training at many levels- to parents, school staff and possibly in terms of the extended family and wider community (e.g. in the form of information booklets, training sessions, mini-conferences, workshops and 'drop-in' sessions). It may be good practice to involve parents and school staff in the delivery of such training and awareness raising sessions. EPs could also be instrumental in upskilling school staff and supporting school systems to

instill an inclusive and person-centred ethos (Sanderson, 2000) and implement research-based practices. It is also recognised that EPs could potentially be involved in facilitating evidence-based programmes such as the National Autistic Society's (NAS) Early Bird programme (Shields, 2001).

Another argument is that EPs, as evidence-based practitioners could be well-placed in terms of informing policy changes and in terms of consulting, planning and implementing support frameworks and pathways for CYP with ASC and their families. In light of NAS Cymru's (2015) recent call for an Autism Act for Wales, it is suggested that this is timely in the context of Wales.

4.4. Concluding Notes

The reflective summary aimed to present both reflective and reflexive comments about both the process of conducting research and the research itself. In addition to contributing to the doctoral award, it is hoped that the research paper can be shared through an academic journal. I am looking forward to receiving constructive feedback on the research so that I can ensure its suitability for publication. It is hoped that my key reflections and themes which informed my research choices have increased the transparency of these decisions for the reader, in a way that rationalises the reasoning for the research and the underpinning factors which informed my research journey.

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<u>Before commencing interview:</u>

- Introduce myself more fully – explain why I am doing the research

I'm interested in your experiences connected to having a child / children with ASC, and your thoughts and feelings towards bilingualism. I will aim to ask you questions that will explore your feelings, experiences and the meaning different things had for you. I hope, by sharing your experiences, it will contribute to the identification of what the barriers and facilitators are for raising children or young people with ASC bilingually.

- Give the participant an opportunity to re-read the consent form, and explain the limits of confidentiality.

- Give the participant the opportunity to ask any questions that they may have.

- Inform the participant that there are no right or wrong answers to questions and that I am interested in their story, views and experiences

- Check it is still OK to record the interview and that I may note things down during the interview   that I'm interested in, to come back to.

- Inform participants that they may take a break at any time if they wish to, and that they are free to stop the interview and withdraw from the study at any time, without providing reason, up to the point of transcription. Provide estimated date of transcription.

<u>Plan for Interview:</u>

The general plan for the interview – the areas I hope to cover:

I was wondering if we could begin by drawing a timeline and adding key events etc. onto the timeline which we can then refer to throughout the interview as we talk about specific parts of your timeline. Would that be OK?

Using A3 paper to draw a timeline: mapping out key events on timeline in order to refer to it throughout the interview: e.g. when child or siblings were born, ASC diagnosis, schooling, decisions regarding language use.

Possible questions:

1. Can you tell me what it's like to be a parent with a son / daughter who has been diagnosed with ASC?

Possible prompts: What was your experience with autism prior to your child's diagnosis? / *How did your child become diagnosed with ASC?* /*How has your child's diagnosis affected your life?*

2. Can you tell me about your experience of bilingualism, and about your hopes in terms of language use for your child / children?

Possible prompts: How does it feel to be bilingual? How do you perceive the importance of your child with ASC being bilingual? Would this be different if your son / daughter did not have an ASC diagnosis? In what way?

3. Has your son / daughter's ASC diagnosis changed the way you think or feel about bilingualism?

Possible prompts: In what way(s)?

4. Have you changed the way you use language with your son / daughter over time?

Possible prompts: In what way(s)? How do you feel about these changes? Does anything help in terms of your language use? Does anything restrict your language use?

5. Has professionals' advice changed the way you use language with your son / daughter?

Possible prompts: In what way(s)? How do you feel about their advice? How do you make sense of their advice?

6. What would be for you a positive development in terms of your child's language use?

Possible prompts: How could your experience in terms of language with your child improve? Can you imagine what it would feel like?

7. In terms of the future, how would you describe your best hopes in terms of your son / daughter's language use?

Possible prompts: In what way would your best hopes be different if your son / daughter did not have an ASC diagnosis? What are your best hopes in terms of language use for your other children?

Generic prompts to build on every question:

How? How did this feel? What did that mean to you? Can you tell me more about this? Can you tell me how you were feeling? Can you tell me what you were thinking? Can you say more about this? What was that like? What do you mean by...?

End of interview:

I do not have any other questions to ask you. I would like to thank you for your time today and I wish you and your family the very best. Do you have any questions you would like to ask me?

Refer participant to relevant support service / services if needed (e.g. school ALNCo, EP).

Appendix B: Gatekeeper letter

School of Psychology
Cardiff University
Cardiff
CF10 3AT

School of Psychology

XXXX, 2016.

Dear Sir / Madam [Principal or Senior Educational Psychologist],

My name is Aranwen Griffiths and I am an Educational Psychology Doctorate student in the School of Psychology, Cardiff University. As part of my doctorate I am currently on placement at XXXX Educational Psychology service. One aspect of the course is to conduct a major research project.

I am currently interested in exploring the perceptions of parents with a child / children with Autism Spectrum Condition (ASC) towards raising, or not raising their child bilingually in Wales.

In terms of current research, I have as yet to come across any research that has explored this area in the U.K., and more specifically in Wales. Due to the fact that Wales has two official languages, I will be arguing that research in this area could be considered pertinent.

Of the limited research that has been conducted in this area, the majority have been conducted in North America, mainly in Canada.

It is suggested in this research that professionals advise parents not to raise their children bilingually with the reasoning that this could be detrimental for their language acquisition. However, there currently exists no research that supports this assertion.

I am writing to enquire whether you would be interested and willing for me to recruit participants in XXXX?

The title of the proposed research will be:

Exploring Parental Perspectives on Bilingualism in Children and Young People with Autism Spectrum Conditions in Wales: An Interpretative Phenomenological Analysis.

I will be working under the supervision of Dr Ian Smillie (see contact details below).

I am hoping to use an Interpretative Phenomenological Analysis (IPA) approach to my research, and will be collecting my data via in-depth semi-structured interviews.

If you are interested, consenting to this research project would entail providing me with an estimated number of participants that would meet the following inclusion criteria; parents who:

(a) have at least one child between the ages of 3 and 14 who has received a documented diagnosis of ASC;
(b) are members of a bilingual family who live in a Local Authority in Wales (bilingual defined in this context as the use of both Welsh and English in the home and outside the home environment).

The rationale for focusing on this group of parents was that they were most likely to live and socialise in bilingual environments and thus are more likely to make conscious and intentional decisions regarding language use.

I would provide the Local Authority with the requested number of information pamphlets and consent forms for the participants (I have attached bilingual copies of both), with stamped envelopes. I would then kindly ask you to distribute the information pamphlets and consent forms to the possible participants.

The possible participants would be asked to return a signed consent form to XXXX (a stamped envelope will be provided). I would collect the consent forms from XXXX Office on a pre-arranged date.

I am hoping to conduct 9 semi-structured interviews in total (in addition to a pilot interview to verify the validity of my semi-structured interview schedule). I would contact the participants directly and arrange to conduct the interviews in a local school or Local Authority Office, if this would be considered acceptable?

If you would like to receive more information, or discuss my proposed project please do not hesitate to contact me (see contact details below).

Many thanks in advance for your consideration of this project.

Regards,

Aranwen Griffiths.

Contact details of researcher:

Aranwen Griffiths: GriffithsAM4@cardiff.ac.uk

Contact details of Professional Tutors:

Dr Ian Smillie, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3AT.
Tel: +44(0) 29 2087 4007, E-Mail: Smillie@cardiff.ac.uk

Contact details of Cardiff University's Research Ethics Committee:

Secretary of the Research Ethics Committee, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3AT.
Tel: +44 (0)29 2087 0360, E-Mail: psychethics@cardiff.ac.uk

Appendix C: Participant Information Leaflet (Side 1)

Parent Information Leaflet

Exploring Parental Perspectives on Bilingualism in Children and Young People with Autism Spectrum Conditions in Wales: An Interpretative Phenomenological Analysis.

Aranwen Griffiths
Educational Psychologist in Training

If you have any questions or would like to discuss the research, please do not hesitate to contact me (see contact details below)

Contact Details:

Aranwen Griffiths

E-mail: GriffithsAM4@cardiff.ac.uk

Ian Smillie (Research Supervisor)

E-mail: smillie@cardiff.ac.uk

School of Psychology

Cardiff University

Tower Building

70 Park Place

CF10 3AT

Tel: 02920874007

Thank you for reading this pamphlet

If you have any concerns or complaints about the research you can contact the School of Psychology Research Ethics Committee in writing at:

Secretary to the Research Ethics Committee, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT.

Tel. 02920874007

Who am I?

My name is Aranwen Griffiths and I am a Trainee Educational Psychologist from Cardiff University. As part of my doctoral research I am hoping to explore parental perceptions of bilingualism in children and young people with Autism. I am inviting you to take part in this study.

Why am I interested in this area?

As far as I am aware, there has been no research into bilingualism and Autism in Wales. I think that it is an important area to explore as Wales has two official languages (Welsh and English). I am interested in finding out more about your thoughts and feelings towards raising or not raising your child / children with Autism bilingually.

What have you found to be barriers, or what has supported you in this respect?

What do you think are the benefits and disadvantages for your child to be exposed to two or more languages?

⊞

What will the study involve?

You will be asked to take part in an interview.

I would like to interview you, so that I can learn more about your thoughts and feelings, and your experiences.

The interview should take approximately 60 minutes to complete, and will be audio recorded,

You will be able to decide if you would like to be interviewed at a school or at XXXX's Office.

The parents who will be interviewed will be selected at random, so even if you give your consent for me to interview you, you might not be selected.

In the interview, I would like to listen to your story, and I might ask you about:

- **Details about your family and child / children with Autism.**

- **Your family's use of language in and outside the home.**

- **Your thoughts and feelings towards bilingualism**

- **Advice you have received from professionals.**

What will happen to the information collected?

Data:

All information will be held confidentially and no one will have access to it other than myself. On completion of the study, the data will be anonymised and no one will be able to trace the data to you or your child/ children.

It is important for you to know that once the data is anonymised, the data cannot be withdrawn and it may be kept indefinitely. You will be provided with the estimated date when the data will be anonymised.

Confidentiality:

All the information that you will share with me will be kept confidential. The only occasion where I will have to break confidentiality is if I suspect that you or another person / child might be at risk of harm. ⊞
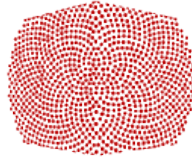
Consent:

If you would like to withdraw your consent to take part in part of/ all the study, then you can do so at any time. You can do so by contacting me or Cardiff's School of Psychology. ⊞

148

Appendix D: Participant Consent Form

School of Psychology
Cardiff University
Cardiff
CF10 3AT

School of Psychology

PARTICIPANT CONSENT FORM

Please read the following statements and circle your answers.

I have read and understood the information leaflet.	Yes	No
I understand that my participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason.	Yes	No
I understand that I am free to ask any questions at any time (contact details can be found on the information leaflet).	Yes	No
I also understand that I am free to discuss any concerns with Dr Ian Smillie (contact details can be found on the information leaflet)	Yes	No
I understand that the information that I provide will be held confidentially, such as that only the researcher can trace this information back to myself individually.	Yes	No
I understand that the researcher would like to conduct an interview. This interview should last approximately 60 minutes and will be audio recorder. I am happy to take part in an interview, but understand that if numerous parents provide their consent to partake in the study that participants will be selected at random and I might not be selected.	Yes	No
I understand that the data from the interview will be transcribed. Once this has happened the data will be anonymised and the audio recording will be deleted.	Yes	No
I understand that my data will be anonymised by the XXXX and that after this point no-one will be able to trace the information back to myself. After this point, it will not be possible to withdraw my interview data from the study.	Yes	No
I understand that I can ask for the information I have provided to be deleted / destroyed or I can request access to the information at any time up until the data has been anonymised.	Yes	No

I, _____ (FULL NAME) consent to be interviewed as part of this study conducted by Aranwen Griffiths, School of Psychology, Cardiff University with the supervision of Dr Ian Smillie.

Personal details	
Surname:	Forename(s):
Preferred Name (if applicable):	Title:
Date of birth:	
Preferred language of correspondence? Welsh / English (delete as appropriate)	Preferred method of correspondence? Postal / Telephone / E-mail (delete as appropriate)
Home Address:	
Postcode:	
Home Telephone:	
Mobile:	
E-mail address:	

Appendix E: Participant Debrief Form

School of Psychology
Cardiff University
Cardiff
CF10 3AT
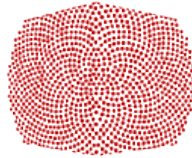
School of Psychology

PARTICIPANT DEBRIEFING LETTER

Exploring Parental Perspectives on Bilingualism in Children and Young People with Autism Spectrum Conditions in Wales: An Interpretative Phenomenological Analysis.

Thank you for taking part in my study.

The aims of this study were to gather information relating to parents' perceptions on bilingualism in children and young people with Autism Spectrum Conditions (ASC). I hope that the experiences, thoughts and feelings you shared with me within this research will help us to better understand your experience and possibly suggest ways that can further support parents and their children with ASC.

The experiences, thoughts and feelings you shared with me will be held confidentially in a secure location, to which only the researcher will have access to. The audio recording of the interview will be transcribed, after which it will be anonymised. This means that it will be impossible for people to know what you told me. If you want to withdraw your data from the study this can only be done up until I have transcribed and anonymised the interview. If you would like to withdraw your data then contact me by (Date), which is within X days.

If you can think of any questions you would like to ask, please do not hesitate to ask either myself or my research supervisors (see contact details below).

Additionally, if you would be interested in receiving further information regarding the results of the study, please do not hesitate to contact me.

Thanks again.

Yours sincerely,

Aranwen Griffiths (researcher).

Contact details of researcher:

Aranwen Griffiths: GriffithsAM4@cardiff.ac.uk

Contact details of Professional Tutor:

Dr Ian Smillie, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3AT.
Tel: +44(0)29 2087 4007, E-mail: Smillie@cardiff.ac.uk

Contact details of Cardiff University's Research Ethics Committee:

Secretary of the Research Ethics Committee, School of Psychology, Cardiff University, Tower Building, 30 Park Place, Cardiff, CF10 3AT.
Tel: +44 (0)29 2087 0360, E-Mail: psychethics@cardiff.ac.uk

Appendix F Interview Transcriptions

(See encrypted USB attached)

Appendix G Interpretative Phenomenological Procedures
(Followed in accordance with Smith, Flowers and Larkin, 2009)

1. Forming primary IPA research questions:
   - The research questions were developed in line with IPA's explorative nature and focuses the analysis on the individual participants' attempt to make sense of their experiences of being a bilingual parent raising their child / children with Autism in Wales.

2. Finding a sample:
   - Samples for IPA research are selected purposefully and are a homogeneous sample who 'represent' a particular experience to whom the research question is meaningful.
   - A homogeneous opportunity sample was recruited through two EPSs located in two LAs in Wales. A sample of five participants were used for analysis, which is within the suggested range of participants for doctoral research (Smith et al., 2009).

3. Selecting a suitable method of data collection:
   - It was decided that semi-structured interviews would be appropriate in terms of inviting participants to offer a rich, detailed, first person account of their experiences.
   - At this stage audio recordings were made of the interviews.

4. Transcription of the data:
   - The interviews were transcribed verbatim from the audio recordings of the interviews conducted (Appendix G). Whilst transcribing the researcher noted down initial thoughts and comments about the data as well as bracketing own perceptions of the topic and participants' experiences in a research journal [The transcription and research journal entries were written in Welsh].

5. Reading and re-reading the transcripts:
   - This stage involved the researcher familiarising herself with the data by listening to the interview and reading and re-reading the transcript in detail. This enabled the researcher to immerse herself in the analysis and actively engage with the individual's experience.

6. Initial Noting:
   - The research questions were developed in line with IPA's explorative nature and focuses the analysis on the individual participants' attempt to make sense of their experiences of being a bilingual parent raising their child / children with Autism in Wales.

7. Developing emergent themes:
   - At this stage, the researcher focused on reducing the detailed exploratory comments to look towards the connections, patterns and interrelationships between the initial notes and identifying these as emergent themes. Emergent themes were developed using a summarising phrase or word to represent the comments associated with the transcript. This work was carried out primarily with the exploratory comments but considered the recommendation from Smith et al (2009) that highlights the importance of this process still representing the transcript itself. An example of developing emergent themes is provided to demonstrate this process in Catrin's translated transcript (Example 2).

8. Searching for connections across emergent themes:
- This stage involved the researcher extracting the emergent themes from the transcript, and then developing an evidence table to match the themes back up with the verbatim extracts of the transcript that supported the themes (see Example 3). This ensured the themes remained grounded in the data. A hard copy was then used to colour code the emergent themes as the same or similar. Some examples of the means of drawing the emergent themes together was by the similarity or parallel understandings of the themes, the frequency of occurrence, apparent contradictions between themes and contextual consideration of the themes. Following this each cluster of emergent themes was labelled as a super-ordinate theme, with other clusters becoming sub-ordinate themes as they were grouped in similarity. During this process there was close consideration of Smith et al.'s (2009) processes of abstraction, subsumption, contextualisation, numeration and polarisation processes. Throughout this process some themes were discarded as it became clear they were not relevant to the research questions or there was not sufficient evidence or interest for it to develop as a theme.
- A thematic map was then produced to illustrate the super-ordinate and subordinate themes that had been developed for the individual participant.
-

10. Searching for patterns across cases
- This stage involved bringing together the thematic maps for each participant and looking across them for thematic patterns and how individual participant's themes may share or highlight similarities and differences. A similar process to the individual analysis was used where the researcher brought together all participants' emergent themes and colour coded them based on the parallel meanings, similarities and frequencies of the themes. This led to the re- configuring and re-labelling of super-ordinate and subordinate themes for the group. Overarching super-super-ordinate themes were also interpreted. These themes were then presented in a theme table (see Table 4 in results section of report). At this stage some individual themes were discarded or merged with other themes. To stay true to the idiographic approach of the analysis once themes were determined the researcher did not refer back to the individual transcripts to identify further evidence for the themes. A final thematic map was then produced to illustrate the group super-super-ordinate themes, super-ordinate themes and subordinate themes (see Figure 1 in results section of report).

11. Consideration of secondary research questions

- At this point it was felt that the research questions were not sufficient in order to fully capture the lived experience of the participants. Therefore, the researcher introduced a primary research question that openly 'explores' the participants' attempt to make sense of their experiences of being a bilingual parent raising their child / children with Autism in Wales.
- The existing research questions were then set as secondary research questions, as on reflection they presented as being more theory driven questions.

12. Writing up the analysis

- Throughout the writing up process it was ensured that the analysis kept with an idiographic approach by focusing on the unique experiences of the individuals involved and what these tell us about the participant's experience but also how it is these unique experiences that have informed the group themes across the participants' data to form the higher order qualities identified. Following Smith et al.'s (2009) recommendation a number of quotes has been used to support the researcher's account, and has attempted to capture something of the lived experience of the participants, while being mindful that this inevitably invokes interpretations on the researcher's part.

Example 1:

Translated Transcript	Exploratory Comments
I: If I asked you if, and if yes, how getting the label or diagnosis changed your life…	
C: Well, yes, it does in that, having a child with a disability now, I have a form saying that she is on the spectrum – that's true. I try…the sons we have, the eldest gives in to 'Lowri' and accepts…our *moto* at home is- if 'Lowri' is happy – we are all happy. 'Huw' then…he challenges 'Lowri' with everything. Why should I give in to 'Lowri', and we don't give in to her, but we try to…adapt. 'Lowri', she's… she's a big, strong girl, and she never says she has had enough food. You know…*so* it then becomes time for food, everyone gets two sausages and we cut 'Lowri''s into small pieces and place one in the middle of the table – and that's what we call *seconds* then. *So* she thinks she's getting more food, but she doesn't- she gets [ ]. *So* it is a *challenge* but…I see myself sometimes having to say- *she has autism* and erm, I take her up…*Strictly Come Dancing* – she has obsessions, *Strictly Come Dancing* is the obsession- you can ask her anything about which year, what they wore, dances, whatever. And we go up to Birmingham annually – that is her *treat*, going to see the *live tour*…and the first year, as we were in this huge place and we were in the Bull Ring shopping, and I went into the disabled *toilets*, and you can see these people looking at us. 'Lowri' doesn't have a wheelchair or anything…so I always have the letter in my pocket then- you know, just because…I don't know if it's changed our lives, but we have to…adapt, you know. Yes.	-Receiving a diagnosis / label resulting in a change of how C see's her daughter – implies some sort of change in her identity. -A suggestion that meeting Lowri's needs has to be the family's priority – Lowri (and her ASC) is central to the family dynamic. -Adapting- interesting choice of word, C seemed to carefully consider which word to use – 'adapting' suggests a natural process; however, her hesitation may imply a more complex process. -Repeating 'obsessions' – trying to make sense of Lowri's ASC? - Having to justify her daughter's behaviour – an acute awareness and sensitivity to other people's perceived judgement. - A strong sense of self-awareness and having to justify and 'prove' to others that her daughter is disabled. 'Lowri' 'normal' appearance exuberating the sense of judgment from others - A lack of awareness and empathy in the general population contributing to a sense of isolation – us and them.
I: What then, to move from autism to bilingualism. What is your experience of bilingualism? And what are your hopes regarding 'Lowri's use of language?	
C: Well, OK…I can tell you a story about bilingualism. From 2004/5, she had to wear a hearing aid and had to go to hospital at XXXX, and we went through three *specialist[s]* before we met XXXX [Specialist] who is completely bilingual, speaks Welsh. The two first men were of Indian origin and they wanted to know how she…they had a *tuning fork* on the table, and he said – *Can you ask your daughter to tell us if she can hear this at the back of her ear, middle of her ear or front of the ear*… and then I had to ask 'Lowri'- and it's difficult to	- Involvement with numerous professionals – not a consistent key worker. - Voice of the child lost during meetings, and professionals not being able to communicate directly with Lowri – negative impact on 'therapeutic alliance'? - C having to mediate between professional and Lowri frustrating – especially during a potentially emotion-evoking consultation. - 'Not working' – therefore lack of bilingual service plausibly impeding on Lowri's development.

explain to a child *back, middle*…and I had to say then – *I don't think this is working*…We are a family, five of us speaking Welsh, and of course we do have relatives who speak English, but in our unit and around XXXX [The local village] 'Lowri' didn't study English in School until she was seven, say. *So*, you know, in 2011, say, when she moved from the reception class..they began to study English when they are seven years old. Erm, there was a television at home, but I believe, at that time, that we liked everything in Welsh. *So* what we did, we asked at the Hospital- *possibly having someone speaking Welsh would be beneficial to 'Lowri'*…because he could see that things were not…and indeed, once we had XXXX [Bilingual specialist] 'Lowri' then responded. Yes, there is autism, but she didn't respond at all to someone who spoke English with her.

I: So, there was a difference then?

C: Yes, yes. And we saw a difference when we had a Welsh speaker, because she could talk to 'Lowri' directly, not just speaking through us. It was difficult to know where she heard the sound with the *tuning fork* but between me having to translate for her and everything, you know, I believe from then on …she responds now, better to things in Welsh, but I have a friend, and this best English comes out with 'Lowri' now, as she is in the Secondary School, there are girls who speak Welsh but English at home maybe, and the English comes through. *So*, yes, you know- there was not a lot of English around XXXX [Local village] and in our little unit.

I: How was the experience, you know, after having the first appointment with XXXX [Bilingual specialist], what sort of experience was that- how did you feel?

C: Well yes, waw- someone who can…because she's quite- she made me frightened! [Laughs]. You know, she has undertaken two operations on her, we go to see her every three to four months and she asks – *shwt iti 'Lowri', oh ti'n tyfu!* [How are you 'Lowri', oh you are growing!] And they remember her since she was young, erm, and she… yes, it *just* great that we could get someone who spoke directly with the child and…

- Welsh language a core aspect of family unit's identity.
- English seen as a 'foreign' language – it was not part of Lowri's world until she was 7.
- Parents having to be proactive – asking for Welsh professional.

- Being able to speak in first language reinforcing the Voice of the Child, and reinforcing medical treatment – first language providing some sort of comfort- and plausibly enabled Lowri to trust professional?

- Voice of the child reinforced – aiding therapeutic relationship.

- Conveys a sense of belonging to a unit – both in the sense of the village, and their family unit.
- Bilingualism reinforcing this sense of belonging – enabling Lowri to expand on her social circle in school.

- Laughing – humour a source of relief / a shield when discussing difficult situations / concepts.
- Conveys a sense of relief – reinforced by maintaining the same professional, and the fact that she can have a direct conversation with Lowri.

157

Example 2:

Emergent Themes	Translated Transcript	Exploratory Comments
	I: If I asked you if, and if yes, how getting the label or diagnosis changed your life…	-Receiving a diagnosis / label resulting in a change of how C sees her daughter – implies some sort of change in her identity.
.SC diagnosis impacting on child's identity	**C:** Well, yes, it does in that, having a child with a disability now, I have a form saying that she is on the spectrum – that's true. I try…the sons we have, the eldest gives in to 'Lowri' and accepts…our *moto* at home is- if 'Lowri' is happy – we are all happy.	
.SC diagnosis impacting on family's identity	'Huw' then…he challenges 'Lowri' with everything. Why should I give in to 'Lowri', and we don't give in to her, but we try to…adapt. 'Lowri', she's… she's a big, strong girl, and she never says she has had enough food. You know…*so* it then becomes time	-A suggestion that meeting Lowri's needs has to be the family's priorit Lowri (and her ASC) is central to the family dynamic.
	for food, everyone gets two sausages and we cut 'Lowri''s into small pieces and place one in the middle of the table – and that's what we call *seconds* then. *So* she thinks she's getting more food, but she doesn't- she gets [ ]. *So* it is a *challenge* but…I see	-Adapting- interesting choice of word, C seemed to carefully consider which word to use – 'adapting' suggests a natural process; however, he hesitation may imply a more complex process.
A process of adjustment	myself sometimes having to say- *she has autism* and erm, I take her up…*Strictly Come Dancing* – she has obsessions, *Strictly Come Dancing* is the obsession- you can ask her	-Repeating 'obsessions' – trying to make sense of Lowri's ASC?
A process of understanding	anything about which year, what they wore, dances, whatever. And we go up to Birmingham annually – that is her *treat*, going to see the *live tour*…and the first year, as we were in this huge place and we were in the Bull Ring shopping, and I went into	- Having to justify her daughter's behaviour – an acute awareness and sensitivity to other people's perceived judgement.
	the disabled *toilets*, and you can see these people looking at us. 'Lowri' doesn't have a wheelchair or anything…so I always have the letter in my pocket then- you know, just	
Exposure to others' judgement	because…I don't know if it's changed our lives, but we have to…adapt, you know. Yes.	- A strong sense of self-awareness and having to justify and 'prove' to others that her daughter is disabled. 'Lowri's 'normal' appearance exuberating the sense of judgment from others
Other people not understanding		- A lack of awareness and empathy in the general population contributi to a sense of isolation – us and them.
Us and them - Isolation	**I:** What then, to move from autism to bilingualism. What is your experience of bilingualism? And what are your hopes regarding 'Lowri's use of language?	
		- Involvement with numerous professionals – not a consistent key work
	C: Well, OK…I can tell you a story about bilingualism. From 2004/5, she had to wear a hearing aid and had to go to hospital at XXXX, and we went through three *specialist[s]*	- Voice of the child lost during meetings, and professionals not being a to communicate directly with Lowri – negative impact on 'therapeutic
Voice of the child	before we met XXXX [Specialist] who is completely bilingual, speaks Welsh. The two first men were of Indian origin and they wanted to know how she…they had a *tuning*	alliance'?
Not being able to talk in first language a barrier to progress	*fork* on the table, and he said – *Can you ask your daughter to tell us if she can hear this at the back of her ear, middle of her ear or front of the ear…* and then I had to ask 'Lowri'- and it's difficult to explain to a child *back, middle*…and I had to say then – *I*	- C having to mediate between professional and Lowri frustrating – especially during a potentially emotion-evoking consultation. - 'Not working' – therefore lack of bilingual service plausibly impeding
solation	*don't think this is working*…We are a family, five of us speaking Welsh, and of course we do have relatives who speak English, but in our unit and around XXXX [The local village] 'Lowri' didn't study English in School until she was seven, say. *So*, you know,	Lowri's development.
	in 2011, say, when she moved from the reception class..they began to study English when they are seven years old. Erm, there was a television at home, but I believe, at	- Welsh language a core aspect of family unit's identity. - English seen as a 'foreign' language – it was not part of Lowri's worl until she was 7.
Language a core aspect of an individual's identity	that time, that we liked everything in Welsh. *So* what we did, we asked at the Hospital- *possibly having someone speaking Welsh would be beneficial to 'Lowri'*…because he could see that things were not…and indeed, once we had XXXX [Bilingual specialist]	-Parents having to be proactive – asking for Welsh professional.
Language being a part of a family's identity	'Lowri' then responded. Yes, there is autism, but she didn't respond at all to someone	- Being able to speak in first language reinforcing the Voice of the Chil and reinforcing medical treatment – first language providing some sort

Proactive parents	who spoke English with her.	comfort- and plausibly enabled Lowri to trust professional?
	I: So, there was a difference then?	
	C: Yes, yes. And we saw a difference when we had a Welsh speaker, because she could talk to 'Lowri' directly, not just speaking through us. It was difficult to know where she heard the sound with the *tuning fork* but between me having to translate for her and everything, you know, I believe from then on …she responds now, better to things in Welsh, but I have a friend, and this best English comes out with 'Lowri' now, as she is in the Secondary School, there are girls who speak Welsh but English at home maybe, and the English comes through. *So*, yes, you know- there was not a lot of English around XXXX [Local village] and in our little unit.	- Voice of the child reinforced – aiding therapeutic relationship. -Conveys a sense of belonging to a unit – both in the sense of the villag and their family unit. -Bilingualism reinforcing this sense of belonging – enabling Lowri to expand on her social circle in school.
Voice of the child reinforced through first language use Bilingualism reinforcing sense of belonging	**I:** How was the experience, you know, after having the first appointment with XXXX [Bilingual specialist], what sort of experience was that- how did you feel?	
	C: Well yes, waw- someone who can…because she's quite- she made me frightened! [Laughs]. You know, she has undertaken two operations on her, we go to see her every three to four months and she asks – *shwt iti 'Lowri', oh ti'n tyfu!* [How are you 'Lowri', oh you are growing!] And they remember her since she was young, erm, and she… yes, it *just* great that we could get someone who spoke directly with the child and…	- Laughing – humour a source of relief / a shield when discussing diffi situations / concepts. - Conveys a sense of relief – reinforced by maintaining the same professional, and the fact that she can have a direct conversation with Lowri.
Humour as a shield? Significance of relationships		

Example 3:

Table of emergent themes relating to 'Beryl'

Themes	Page / line	Key Words and phrases
Process of understanding	2 / 107 - 110	*I think that I still, still haven't accepted it a hundred per cent. Because I still worry and ask why us? But, once you accept the diagnosis, then you can help 'Hari' can't you, you can go to find out what's available, who's available to help.*
The necessity of proactive information seeking	3 / 145 - 147	*and then the more you go researching yourself then, and I don't know if that's a good thing sometimes, you look on the internet and you get the worse-case scenarios, you know.*
	8 / 381 - 382	*it's so difficult to find out what's [available] out there, erm, and you just give up.*
Active search for an explanation	1 / 9 - 14	*a very difficult birth with him, and sometimes I look back and think if there was something to do with the birth that had…Looking for some sort of, not excuse, but…*
The Battle to get others to understand	2 / 83 - 85	*what's difficult is, that his Dad has never accepted…so, it's been very difficult, and his Dad just thinks that I'm making a fuss.*
	6 / 291 - 295	*Erm, I don't think that the staff always understands him in the school. I think that the staff think, well if he's in the Mainstream, he will be treated as a Mainstream child, and I think sometimes that I come across as a pushy parent…and I say again - hidden disability, they don't see, you know.*
	8 - 9 / 448 - 450	*And I don't want to have to start apologising on his part, because it's not his fault he has Autism, and that is who 'Hari' is. People who don't understand him that can be difficult.*
	11 / 574 - 575	*I had one teacher saying when I was thinking about taking him to school; I've never had one before.*
Time to understand	2 / 107 - 110	*I think that I still, still haven't accepted it a hundred per cent. Because I still worry and ask why us? But, once you accept the diagnosis, then you can help 'Hari' can't you, you can go to find out what's available, who's available to help.*

Table of emergent themes relating to 'Beryl'

Themes	Page / line	Key Words and phrases
The psychological consequences of your child receiving an ASD diagnosis		
Shock and depression		*When I got the diagnosis I don't think it hit me until the Autumn, and I had depression for a bit and I was off my work for a bit, because, as I was saying I didn't have any awareness of Autism and the only think I knew was Rain Man, you know- the film?*
Guilt	1 / 44 - 45	*And I'm a teacher, I felt so embarrassed that I hadn't picked up on my own child. But I didn't have any awareness of it at the time.*
Ruminative thinking	1 / 32 - 34	*I had videos of him as a little baby the other night, and 'Hari' and myself sat down to watch it, and I was so upset, because now, it was so obvious that he was* [on the Autistic spectrum].
The self-questioning parent	3 / 141	*And I didn't have anyone I could turn to ask am I doing this right?*
Mourning and grieving the child that should have been	2 / 71 - 74	*So I mourned for a child…you know, I was a teacher, my child was going to read before he started school, he was going to write, compete in the Eisteddfod, and I grieved I think for the child I wanted, and the child that I had had.*
Future as a daunting prospect	2 / 77 - 79	*and you know what, I still worry, I worry everyday about him, and I worry about the future, I try not to, we just take one week at a time*
Seeing the child and not the diagnosis	5 / 271 - 272	*He's a very clever little boy you know, he wants to learn, but I think when he got the diagnosis, they did not see that in him, they just saw him as a little child with quite severe needs.*
Voice of the child	9 / 473 - 474	*And the voice of the child…you know, 'Hari' has a voice, 'Hari' can tell me what's bothering him.*

Table of emergent themes relating to 'Beryl'

Themes	Page / line	Key Words and phrases
The need for child centred training	6 / 324 - 330	*But possibly the most important thing, is not generic training, but providing training on the child…even though Autism, they all have the triad of difficulties and this and the other. But again, you've met one child with Autism, you've met one, you know what I mean? They're all so different, so I think if there's a need for whole-school training- base it on the child- what are his strengths - and what strategies work for this particular child.*
Understanding the child before understanding the condition	4 / 198	*and I don't think I'm going to be able to change that within 'Hari', but 'Hari' - that's who 'Hari' is…*
	9 / 482 - 485	*I think that knowing the child is the important thing. Once you…I try to tell 'Hari's school staff, start getting to know him, give them the opportunity to get to know him. And, through getting to know him you'll come to understand how exactly 'Hari' ticks.*
Copying Strategies		
A step by step process	11 / 586	*we'll cross that bridge when we get there*
Flexible approach to life	11 / 565 - 568	*I want 'Hari' to conform as everyone else, to a degree, but with…erm, the mentality that 'Hari' is not like every other child. And I think that that's the important thing, that we remember, and that he has needs, and these needs can be quite…it's very difficult for him from day to day…but, as I'm saying, because he looks ok, we forget that sometimes.*
Humour as a shield	2 / 98	*he was angry with the judge for not giving him the first place [Laughing]*
Changing expectations	2 / 71 - 74	*I was a teacher, my child was going to read before he started school, he was going to write, compete in the Eisteddfod, and I grieved I think for the child I wanted, and the child that I had had.*
	10 / 531 - 534	*my best hopes for 'Hari' has changed since receiving the diagnosis you know, before receiving the diagnosis I wanted him to go to University…and now, my best hopes for the future is that he is happy, that he has life skills and that he is able to live a quite independent day to day life.*

Table of emergent themes relating to 'Beryl'

Themes	Page / line	Key Words and phrases
Seeking positives and celebrating them	3 / 147	*But, the way he's developed, it's amazing!*
	3 / 157 - 160	*and he's had Star of the Week this week for writing a good letter and for controlling his emotions…Oh my God, I cry every time I see these things coming home with him…the things he can do and achieve he is…so, I'm so proud of him.*
Desire to belong	11 / 599 - 602	*Hari' is a part of the community…even though he doesn't have much friends, he's not bothered either, but the children of the town, every time we pass they say 'are you ok 'Hari'?*
Connecting with other parents who have a child / children with ASD a great source of reassurance	3 / 121 - 123	*Erm, speaking with other parents I think, because you know the teachers and experts offer advice and things to you, but until you have a child with Autism, you don't understand, you don't.*
Bilingualism	4 - 221 - 224	*Well, to be completely honest, he is bilingual, he can speak Welsh if he chooses to do so, and I would like him to use more Welsh, but, erm, if he can communicate effectively it doesn't matter to me which language he uses to be completely honest.*
The need to be listened to	3 / 141	*And I didn't have anyone I could turn to ask am I doing this right?*
	7 / 338 - 339	*and another thing I think is important, is, the parents' opinion, that the parents are a part of this [school training].*
Isolation	2 - 3 / 112 - 117	*I sometimes feel that I don't have a lot of support, so it can be difficult, and because 'Hari' looks normal, it's a hidden disability isn't it, if he was in a wheelchair everyone would see what's the disability, but they don't see it with 'Hari', and sometimes he can appear to be a naughty boy, or rude, but I think there's a need to raise more awareness of autism, definitely.*

Table of emergent themes relating to 'Beryl'

Themes	Page / line	Key Words and phrases
Relationship with extended family potentially problematic	2 / 110 - 112	*I think sometimes, my family doesn't understand how much work there is with 'Hari'. Because at the moment he's showing a lot of challenging behaviours, you know- he hits himself and…and they don't see that side you know.*
	7 / 380	*I feel that there's no provision out there for parents like me*
	8 / 435 - 438	*my family does not understand that much about Autism, and I get, God, 'Hari' is OK, and 'Hari' is not OK. So possibly it would be worthwhile to look at the extended family as well, and possibly providing more training for them as well.*
The process of 'finding' own child	9 / 456	as the years go by, I understand 'Hari' better'
The need for more training and therapeutic interventions for parents	3 / 132 - 135	*once we got the diagnosis, that's it! Get on with it! We never had a Support Group, and if there was a Support Group it was within work hours, and I couldn't go. So, I feel that there hasn't been enough support for us, after the diagnosis, and I would like to see that being developed*
	3 / 141	*And I didn't have anyone I could turn to ask am I doing this right?*
Feeling exposed to judgement	3 - 4 / 167 - 173	*Erm, he can express himself better in English…his word finding is stronger in English, but I speak Welsh with him…so he's very clever, but I speak Welsh with him, so he takes in the information and he answers me in English. Lots of people find that really difficult…it's difficult, especially in the Mainstream schools, or where the language policy exists you know.*
A conscious awareness of language	4 / 186 - 189	*For a completely Welsh family, it's amazing…because there's so many children with Autism who speak English and who come from Welsh homes…and the language use he has, erm, refrigerator, recess, that's what he calls break.*
Bilingualism seen as an added bonus, not essential	4 / 167 - 168	*he can speak two languages amazingly*
Part of an individual's identity		
The influence of television on language	4 / 194	*it's got to be from the television and you know, technology these days.*

Table of emergent themes relating to 'Beryl'

Themes	Page / line	Key Words and phrases
Tensions between family members and school	4 / 195 - 196	*and Dad you know, Dad is a farmer in his seventies and he says- why does this child call me Granddad?*

Interviewee	Super-ordinate Themes _Sub-ordinate Themes_				
Catrin	**The psychological impact of your child receiving an ASC diagnosis** _Guilt; Ruminative thinking; The self-questioning parent; The mourning and grieving for the child that should have been; Comparison; Humour as a shield._	**A process of understanding** _Parents as proactive information seekers; Process of 'finding' your child; Small steps; Diagnosis as a relief; Comfort in the explicit; The need for practical advice._	**Isolation and quest for acceptance** _Exposure to others' judgement; A process of justification; 'It's difficult' – the relationship between mother and daughter; Lack of specific support for parents; Loss of the voice of the child during meetings with professionals who don't speak Welsh; Lack of Welsh medium resources and opportunities._	**Making sense of bilingualism** _Language as a core aspect of identity; Language as a social lubricant; 'She's more likely to trust them' - communicating in your first language aiding therapeutic relationship with professionals; Voice of the child reinforced through the use of first language; An unconscious / instinctive process; Belonging._	
Elen	**The psychological consequences of your child receiving an ASC diagnosis** _Guilt; Ruminative thinking; The self-questioning parent; A process of grieving; Comparison; Diagnosis altering core beliefs; Learning to live an enriched life._	**A lifelong process** _Understanding; Reflection; Small steps; Thinking about the future as a no go area; Seeking information._	**Isolation** _Exposure to others' judgement; Extended family not truly understanding; Professionals not fully understanding; Difficulty in 'finding' your own child._	**Belonging** _The need for reassurance; Other parents fully understanding; Seeing the individual not the diagnosis; Welsh language an aid in belonging; Lack of specific support for parents._	**A conscious awareness of language** _Language a core aspect of the family and the individual's identity; Feeding a language = Feeding an identity; Maintaining control in the midst of chaos; Being able to communicate in first language aiding therapeutic relationship with professionals; Language becoming a more conscious and purposeful process following diagnosis; Welsh language is something to nurture and protect._

	A lifelong process	The psychological implications of your child receiving an ASC diagnosis	A process of understanding	A quest for acceptance	The conscious and unconscious use of language
Anna	*Process of 'finding' your child; Small steps; Time to cope; Humour a shield; Relationships; Celebrating the individual child.*	*A core sense of loss; Ruminative thinking; Grief; Future a source of anxiety; Diagnosis altering core beliefs; Comparison.*	*Parents as proactive information seekers; Seeing the individual and not the diagnosis; The quest for why and how?*	*Exposure to others' judgement; The need to raise awareness; The need for more expertise in schools; The fight; Isolation; Connecting with other parents as a source of comfort; Professionals not truly understanding.*	*Adapting expectations; Bilingualism desirable but not completely essential; Seeking to belong; Evolution of language use coinciding with educational provision for children.*
	Path of understanding	**The psychological implications of your child receiving an ASC diagnosis**	**Desire to belong**	**Isolation**	**Conscious awareness of language**
Lisa	*Proactive information seeking; Process of 'finding' your child; Time to understand; Desire for expert advice; Understanding the individual not the diagnosis; Learning to live an enriched life; A step by step process; Letting the child take the lead; Seeking positives and celebrating them.*	*Shock; Guilt; Ruminative thinking; The self-questioning parent; Frustration.*	*Connecting with other parents who have a child / children with ASC a source of reassurance – they understand; Bilingualism; Living with ASC central to family dynamic.*	*Relationship with extended family as potentially problematic; Developing parent and child bond a difficult process; Lack of understanding.*	*Language acquisition; Surprise of professionals (relating to bilingualism); Voice of the child reinforced through first language use; Welsh language core to family identity*

	Process of understanding	The psychological consequences of your child receiving an ASC diagnosis	A conscious awareness of language	Desire to belong	Isolation
Beryl	*The necessity of proactive information seeking; Active search for an explanation; Time to understand; A step by step process; Humour as a shield; Flexible approach to life; Changing expectations; Seeking positives and celebrating them; Voice of the child; The need for child centred training; Understanding the child before understanding the condition.*	*Shock and depression; Guilt; Ruminative thinking; The self-questioning parent; Mourning and grieving the child that should have been;*	*Language part of an individual's identity; The influence of television on language; Tensions relating to language within the extended family.*	*Connecting with other parents who have a child / children with ASC a great source of reassurance; Bilingualism; The need to be listened to.*	*Relationship with extended family as potentially problematic; The process of 'finding' your child; The need for more training and therapeutic interventions for parents; Feeling exposed to judgement; The Fight to get others to understand*

Appendix I: Core Principles for Evaluating the Validity of Qualitative Psychology

Core Principles	Considerations for Validity	Researcher Actions
1. Sensitivity of context	• The reading of relevant theoretical and empirical literature. • Purposive sampling. • Sensitivity to socio-cultural, historical and linguistic factors. • Awareness of the potential power imbalance between the researcher and the participant. • The researcher's commitment to listen and attempting to understand the participant's lived experiences. • Empathy.	• The researcher carried out an extensive literature review. • It is argued that the rationale for selecting IPA as a methodology centers upon the perceived need for sensitivity to context through close engagement with the idiographic and the particular (Smith et al., 2009). • A purposive sample was recruited using an explicit inclusion and exclusion criteria. In accordance with IPA guidelines (Smith et al., 2009; Langdridge, 2007) the researcher aimed to recruit a sample that was as homogenous as possible in relation to the topic of interest. • As a bilingual individual living in Wales, the researcher argues that she had some awareness of the socio-cultural, historical and linguistic factors- which potentially enabled the researcher to display sensitivity. Moreover, as an IPA researcher it was imperative that the researcher strived to "bracket off" previous knowledge and connotations in order to commit to the understanding of the participants' lived experience . • The researcher adapted a number of steps in an attempt to put the participants at ease; holding the interviews in jointly agreed venues that the interviewee was familiar with; providing detailed information (see Appendix B) so that the participants could make an informed decision and

		provide informed consent; providing the participants with the opportunity to ask questions; sing-posting the participants to relevant professionals if it was needed; providing explicit reminders that the participant had a right to withdraw at any time.
2. Commitment and rigour	• A thorough approach to data collection. • Depth / breadth of analysis. • Methodological competency / skill. • Rigour in terms of interpretation. • In-depth engagement with the topic.	• A total of five interviews were conducted, which is within the recommended range for a doctorate level IPA study (Smith et al, 2009). • It is argued that the data are complete as there were no questions that were not asked or not answered by any participant. • Smith et al. (2009) states that an IPA approach requires the researcher to attend carefully to the participant throughout the data collection process and the nature of analysis means that the research should demonstrate rigour. • The researcher followed Smith et al.'s (2009) guidance in terms of the analysis. A step by step outline of the data analysis is provided in Appendix H, a chain of evidence for the IPA process was developed, which was then checked by an independent colleague to clarify the analysis was credible of the data set. It is argued that this reflects Yin's (1989) use of "Independent Audit".
3.Transparency and coherence	• Clarity and power of your argument. • Transparency and coherence in the reporting of the research. • Appropriate-ness	• Langdridge (2007) posits that transparency is one of the key elements of IPA, as the methodology does not aim to make grand claims about the nature of reality and therefore research needs to be accessible and transparent for critical interrogation by peers.

	of sample. • Fit between theory and method. • Transparent methods and data presentation. • Reflexivity.	• In an attempt to ensure transparency, the researcher has made the research's interpretivist epistemological stance explicit, in addition to the orientation of the present study as an IPA study with its associated relativist assumptions. • The researcher has included a section of transcript which has been fully analysed (see Appendix G). Furthermore, a step by step outline of the data analysis is provided in Appendix H, a chain of evidence for the IPA process was developed, which was then checked by an independent colleague to clarify the analysis was credible of the data set. It is argued that this reflects Yin's (1989) use of "Independent Audit". • The researcher strived to "bracket off" previous knowledge and connotations in order to commit to the understanding of the participants' lived experience. However, Willig (2008) comments that IPA does not offer a way to operationalise 'reflexivity'. • The researcher has presented the findings of the analysis of data. In an attempt to aid transparency, themes identified through IPA, are evidenced through the use of translated quotes from transcripts to demonstrate how the final theme links back to interview data.
4. Impact and importance	• The 'usefulness' of the research - is it practical / can the results be applied? • Does the research provide information relating to the nature of subjective reality?	• The researcher has considered what the implications are for future research and for the profession of educational psychology [Critical Appraisal].