



Autism Diagnosis in a Rural Community: Are There Opportunities for Improvement?

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Abbreviations

ASPECT	Autism Spectrum Australia
Autism CRC	Autism Cooperative Research Centre
ASD	Autism Spectrum Disorder
ECE	Early childhood educator
HCWA	Helping Children with Autism
MCHC	Mudgee Community Health Centre
MWRC	Mid-Western Regional Council
P	Parent
PHP	Private health professional
PUHP	Public health professional
SACS - R	Social Attention Communication Surveillance Revised
WLHD	Western Local Health District
WNPHN	Western NSW Primary Health Network

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Abstract

Aim

Diagnosis of autism at the youngest possible age can reduce family stress, provide earlier access to intervention services and lead to better developmental outcomes for children. This study aims to understand the barriers and enablers in the autism diagnostic pathway of children in a rural area. It seeks to understand the underlying issues that cause delay in diagnosis, and look for opportunities for improvement.

Methods

Using a critical realist approach, semi-structured interviews were conducted with parents of children who were diagnosed with autism after January 2007, whilst living in a rural community. Nine parents were interviewed about their child's diagnostic pathway and any opportunities they saw for improvement in the process. Three focus groups were then conducted with a total of 22 local health and early education professionals about their experience of identifying, referring and/or diagnosing children with autism. Possible improvements to practice were identified by the group members. Thematic analysis was used to analyse the data.

Results

Four major themes emerged from the data:

- **Labels-** The label of autism provided a description of behaviours, but also some stigma. For parents, it gave them and others greater understanding of their child and assisted them to access help. Parents were keen to pursue a diagnostic pathway when they considered that a label of autism could assist in explaining the behaviours of their child in an education context.
- **Process-** The process of diagnosis was problematic for most participants. It was characterised by confusion, lengthy delays, multiple steps, travel and expense.
- **Relationship-** Professionals were concerned about building and maintaining relationships with families. They considered this crucial when they needed to raise developmental concerns with parents. Professionals found it very confronting to discuss these concerns with families. Parents valued professionals who were honest, non-confrontational and whom they considered knowledgeable.
- **Knowledge-** There was a lack of knowledge about the process, and also about the indicators and characteristics of autism of both parents and professionals. Parents lacked knowledge in the diagnostic process of what was being assessed. They wanted to know that professionals were considering autism when concerns were first raised. Most professionals said they would never use the word autism in a conversation with a parent, unless they used it first.

Conclusion and Implications for Practice

There are several opportunities to improve the process of autism diagnosis for children in rural communities. Further training about early autism indicators, and having challenging conversations, is important for health and early childhood professionals. Consideration needs to be given to trialling innovative models of accessing autism assessment professionals in rural communities. Families require written and verbal evidenced based information during the diagnostic process, and would like to understand that autism is being considered during assessment. Both families and professionals require clarification of the autism diagnostic process.

Keywords

Autism, autism diagnosis, early intervention, rural, early diagnosis

Executive Summary

Implications

This study suggests that there are clear opportunities to improve the process of autism diagnosis for children in rural communities. If these strategies are implemented, it may be possible to reduce the age at which children are diagnosed with autism in rural communities, giving them earlier access to intervention services and reducing family stress. Current estimates suggest that 1 in 100 people in Australia have an autism spectrum disorder (ASD), making this an important public health issue. Federal funding for intervention services can be accessed if a child is diagnosed by their sixth birthday, making timely diagnosis crucial.

It is recommended that:

1. A working party is established at MCHC to trial and develop collaborative and innovative models of identifying and diagnosing local children who are at risk of autism. The group comprises at least one early child and family nurse, one doctor, one parent of a child with autism, one public allied health professional and one private health professional. The group considers the findings of this report and local opportunities for improvements in the diagnostic process including options such as tele-health and public-private partnerships.
2. WLHD and the Western NSW Primary Health Network (WNPHN) promote the Raising Children Network app, “Children with ASD and Disability” through early childhood clinics and medical practices, and on the WLHD Facebook page.
3. WLHD and the WNPHN make written information in the form of one page flyers available to parents about early indicators of autism through early childhood clinics, community health centres and private medical practices.
4. WLHD provide staff who work with children with training about the early indicators of autism, including a component about communicating these concerns with parents, through a HETI online module. That this module also address the issue of having challenging conversations about developmental issues with parents. That is also highlights the usefulness of discussing educational contexts when raising concerns with parents.
5. WLHD and the WNPHN develop a directory of local autism assessment services in the western region of NSW, including specialist services that can be accessed in Sydney. That this directory include a flow chart of the steps needed for diagnosis. That this directory be made available to health and early childhood professionals in the WLHD.
6. The WNPHN provide education to local health professionals about early indicators of autism and the benefits of early intervention through their professional development programs.
7. Further research be undertaken about the use of the word autism by professionals when they identify a child as being at risk of autism, and are discussing concerns with parents.
8. The NSW Government make Isolated Patients Travel and Accommodation Assistance Scheme payments available to families when travelling to ASPECT in Sydney for diagnostic assessment for their child when a referral has been made to ASPECT by a paediatrician.
9. The NSW Department of Family and Community Services increase funding for ASPECT to provide low-income autism diagnostic assessments to families of children in rural areas.

Background

Diagnosis of autism at the youngest possible age can reduce family stress, provide earlier access to intervention services and lead to better developmental outcomes for children at risk of autism. The recognition of this has led to research about identification tools for children who have a possible ASD. There is, however, little understanding about the experiences during autism diagnosis of families in rural communities, and the perceived enablers and barriers for local health and early

education professionals in the process of identification, referral and diagnosis of autism in young children. The bringing together of the experiences, attitudes and insights of local parents and professionals from rural communities is important in understanding what needs to be considered when aiming to reduce the age of autism diagnosis.

It is important that health services and researchers understand the identification and referral pathway of children with a possible ASD in rural communities, and work with appropriate health professionals to look for opportunities for improvement, so that developmental outcomes for children in rural areas can be maximised.

Approach

Using a critical realist approach, semi-structured interviews were conducted with nine parents of children who had been diagnosed with autism since January 2007, whilst living in a rural area in NSW. Parents were interviewed in October 2014 about their child's diagnostic pathway and any opportunities they saw for improvement in the process. Three focus groups were then conducted with a total of 22 local health and early education professionals about their attitude to early diagnosis, and their experience of identifying, referring and/or diagnosing children with autism. Possible improvements to practice were identified by the group members. Thematic analysis was used to analyse the data.

Findings

Four themes emerged from the data after analysis. These were:

Labels

This theme was about recognising that a diagnosis of autism provided children with a label that described particular behaviours. Some parents and professionals viewed the label of autism as stigmatising, but for most the label of autism provided access to help and understanding. Most parents were motivated to pursue a diagnosis when they thought about how their child would be treated in the education system.

Process

Process was about the steps that were needed to be taken to receive an official diagnosis of autism. Parents felt the process took too long, was costly, involved too much travel and was confusing. Professionals were also confused by the process and felt it involved too many steps.

Relationship

The theme of relationship was about the connection between parents and professionals, within families and support networks, and also between professionals. Parents found it helpful when professionals approached them in an honest, yet non-confrontational manner about their concerns, and spoke about specific behaviours. Both parents and professionals believed that professionals should communicate more, and work together where possible. Some professionals felt overwhelmed by the responsibility of raising concerns about autism with parents, and placed emphasis on building rapport with parents so they could continue to monitor developmental progress of children.

Knowledge

Parents started the diagnostic process with little knowledge about autism. Parents reported receiving little information during the process, with many parents not being told by professionals that there was concern that their child had autism until close to the final diagnosis being made. Most professionals were very reluctant to use the word autism, unless a parent had already used the word. This even occurred when the professional had a strong belief that the child had autism. Both parents and professionals discussed the challenge of having little knowledge of the process.

Introduction

Diagnosis of autism at the youngest possible age can reduce family stress, provide earlier access to intervention services and lead to better developmental outcomes for children at risk of autism. The recognition of this has led to research about tools to identify children at risk of autism (Barbaro et al 2011). There is, however, little understanding about the diagnostic experiences of families in rural communities, and the perceived enablers and barriers for local health and early education professionals in the process of identification, referral and diagnosis of autism in young children. The bringing together of the experiences, attitudes and insights of local parents and professionals from rural communities is important in understanding what needs to be considered when aiming to reduce the age of autism diagnosis.

This report details qualitative research about the process of autism diagnosis in a rural community. It adds to the limited qualitative literature about the barriers and enablers in autism diagnosis in a rural community, and any opportunities for improvement. This report is for health professionals, policy makers and researchers who want further understanding about the underlying causes of diagnosis delay in rural communities.

Background

Autism

Autism Spectrum Disorder (ASD or autism) is a life-long neurodevelopment disorder characterised by repetitive behaviours and restricted interests, and varying degrees of difficulty with social communication (American Psychiatric Association 2013). Long-term trajectories of those affected can include increased levels of anxiety and depression, and significantly reduced employment outcomes (Gotham, Unruh, & Lord, 2014 and Baldwin, Costley, & Warren, 2014). For diagnosis, impairments must be evident from childhood and hinder daily functioning. As biological testing is currently not possible, autism in Australia is diagnosed through clinical assessment of behavioural features, as defined by the DSM-5 (American Psychiatric Association 2013). A diagnosis can be made by a paediatrician, child psychiatrist, or psychologist as part of an approved multidisciplinary team. International estimates suggest that 1 in 100 people have autism (Baio 2012).

Recently published research from the United Kingdom analysed survey responses from 1000 parents about their satisfaction with the autism diagnostic process. At least half of the parents surveyed reported experiencing stress during the diagnostic process due to factors such as length of time taken to make a diagnosis, lack of information provided, manner of the professionals involved, and post-diagnosis support (Crane et al 2015).

Early intervention

There is evidence that earlier intervention for children with autism results in better outcomes. Children who have had therapeutic intervention at a younger age, have shown better developmental progress (Dissanayake 2012), and have a greater chance of developmental improvements over time (Koegal et al 2014). Large scale studies have also examined the benefits of early intervention, and the importance of early diagnosis (Howlin et al 2009; Rogers and Vismara 2008). It is argued that the best approach to minimise the effects of autism on a child's development is to identify autism as early as possible and then implement appropriate intervention and support. (Dissanayake 2012).

There is financial support for parents to access therapy and early intervention services for their child if they are diagnosed with autism before their sixth birthday. The Helping Children with Autism (HCWA) package provides access to up to \$12 000 over a two year period for privately provided early intervention therapy services (Department of Social Services 2015).

Age of diagnosis

In Australia, the mean age for diagnosis of autism is approximately four years of age, with many children not being identified until after commencing school (Dissanayake 2012). Diagnosis of autism often occurs at ages considered to be later than ideal (Mandell et al 2005; Williams et al 2008). There is some evidence that children are diagnosed at a slightly younger age in large cities than in regional areas (Bent et al 2015)

Autism can be reliably diagnosed from approximately two years of age (Frenette et al 2013, Guthrie et al 2013). To facilitate earlier diagnosis, recent research in Australia has focused on developing and testing screening and developmental surveillance tools to identify children at risk of autism at the youngest possible age (Barbaro et al 2011 and Eapan et al 2013). Currently the Australian Autism Cooperative Research Centre (Autism CRC) and several program partners are undertaking the training of 400 community based primary health care professionals across four states, in the use of a developmental surveillance tool, the SACS-R. This tool can be used at 12, 18 and 24-months of age during routine health assessments to identify children at risk of autism. In this study, if children are identified as at risk of autism using the SACS-R, they will be referred to local paediatric and diagnostic services for further assessment. It is hoped that this will result in 50% of children with autism being identified and diagnosed by the age of two years, and 70% by the age of three years (Autism CRC 2015).

Where are the gaps in the research about earlier autism diagnosis?

In a recently published article in the Medical Journal of Australia, Bent et al examined the frequency and age at diagnosis of ASD in children under seven years of age in Australia (Bent et al 2015). Her article concluded “...there may be a substantial gap between the age at which a reliable and accurate diagnosis is possible and the average age at which ASD is diagnosed in Australia. Future research should examine this gap, and investigate barriers that delay the diagnosis of ASD to ensure that families and communities can benefit from best-practice approaches to early intervention” (Bent et al 2015 p. 320).

Despite numerous quantitative studies to address issues of earlier diagnosis of autism, there is scant qualitative research addressing this in the Australian context. To the best of the researchers knowledge, there are no qualitative studies that examine the enablers and barriers in this process in Australian rural areas. The insights and experiences of parents of children with autism, and primary health and education professionals can add a valuable dimension to existing and future research about earlier diagnosis. In a qualitative study, participants may discuss issues that may not be accounted for in a survey, or addressed in a trial. An analysis of the perspectives of parents and professionals affords the opportunity to better inform policy and practice about how to move children and their families through the diagnostic process at the earliest possible age.

Research Aim and Question

This study aimed to examine the experience of parents of children in a rural area of being identified and diagnosed with autism, including the enablers and barriers along that pathway. The aim of the study was to gain an understanding of issues involved and any opportunities for improvement in the diagnostic process. It aimed to consider what is required to reduce the age of autism diagnosis in a rural community.

The researcher set out to answer the question, “What are the enablers and barriers in the diagnostic pathway of children who have been identified as being at risk of autism in a rural community? Are there opportunities for improvement?”

Method

Methodology

This was a post-positivist, qualitative study, undertaken from a critical realist perspective. This approach was chosen because of its focus on researching people in their social context (Walsh and Evans 2014). Through being informed by informal and expert knowledge (in this study of parents and professionals), critical realism seeks to discover the causal factors of surface phenomena, and then aims to facilitate collaborative design of improvements to policy and practice (DeForge and Shaw 2012). Critical realism also acknowledges the importance of personal factors and structural factors, and the interplay of these in health outcomes. It has a focus on understanding the causal factors that underlie these relationships (Sword and Clark 2012).

In this study, a critical realist approach allowed the researcher to acknowledge that individuals have the ability to make decisions and initiate change, but that they are also constrained by structural factors. It provided a theoretical underpinning to accommodate the complexity of the diagnostic process and examine it from multiple perspectives. In searching for generative mechanisms that underpin surface phenomena, critical realism allowed the researcher to construct knowledge about possible causes for delay in autism diagnosis. It provided a framework that recognised that social, psychological and physical domains can all contribute to causation (Walsh and Evans 2014).

The researcher aimed to use the stratified ontology of critical realism to look for the hidden causes and delays in the autism diagnostic process by gathering information from parents and health and education professionals about what they observed and perceived. The knowledge that the researcher was then able to construct from a thematic analysis of this data allowed recommendations for improved policy and practice around autism diagnosis to be formulated.

Study Design

Using a critical realist framework, semi-structured 1:1 interviews were undertaken with nine parents of children who had been diagnosed with autism since 1st January 2007, whilst living in the Mid-Western Regional Council (MWRC) area. They were interviewed about their experience of having their child diagnosed with autism and the pathway this diagnosis followed. Three focus groups were then conducted with 22 health and early education professionals from the same rural area about their attitude to early diagnosis and their experience of identifying, referring and/or diagnosing children with autism. Some initial analysis from the parent interviews was also discussed in the focus groups.

Sampling and Participants

Saturation sampling was used for recruitment for both the parent interviews and focus groups. Parents were approached for participation in the study through a database held at Mudgee Community Health Centre (MCHC). The database contained names and addresses for 81 parents of children diagnosed with autism, who had consented to their details being on the list and to receiving information related to autism. It covered families who had accessed MCHC and included people living in smaller surrounding towns. One invitation letter, participation information sheet and consent form, were sent to each parent in the database, and were signed by the manager of MCHC. Inclusion and exclusion criteria was included in the information, and this was verbally checked again if parents contacted and expressed interest in participating in the study. Parents met inclusion criteria if they were the legal guardian of a child under 18 years who had been diagnosed with an ASD since 1st January 2007 whilst living in the MRWC area. Parents were excluded if they were younger than 18 years of age or not proficient in English.

Participants for three focus groups of health and early education professionals were recruited by sending an invitation letter, participation information sheet and consent form to workplaces of possible participants. The addresses of private health professionals were obtained from local health directories and included all known local general practitioners, private practice nurses, private allied health professionals and paediatricians who provide services in the MWRC area. Public health professionals were invited through internal mail, and were permitted to participate during work hours. Contact details for early education centres were obtained through a local directory of services. Focus group participants met inclusion criteria if they worked within the MWRC area and worked in a health, education service or practice in a professional and early intervention capacity with children under the age of five years for at least some of the time. They were excluded if they had less than 12 months experience in this role, or if they worked solely with children who already had an autism diagnosis.

All nine parent interviews and three focus groups took place at MCHC. All interviews were audio recorded and conducted solely by the researcher. The 1:1 interviews were pilot tested with two of the researcher's work colleagues. Due to time constraints, the focus group questions were not pilot tested and participants did not have an opportunity to view transcripts. The interviews and focus groups were not repeated. Feedback is scheduled to be given to participants in September 2015 in both a verbal presentation and a written summary.

Ten mothers responded and consented to participate in the interviews, and all met the inclusion criteria. One mother withdrew from the study due to personal commitments that did not allow time to be interviewed. Reasons for others choosing not to participate are unknown as ethical approval was only given to make contact through the initial invitation letter, with further communication allowed with participants who made contact with the researcher. Thematic saturation was reached after nine mothers had been interviewed. This was determined through initial analysis of the data and discussion about themes with the researcher's mentor. Further recruitment would have been considered, including an appropriate ethics amendment, if saturation had not been reached. All nine mothers had a son who had been diagnosed with autism, and one mother also had a daughter with an autism diagnosis. The age of their children at the time of diagnosis ranged between two years old and nine years old. Interviews were between 30 minutes and 65 minutes in duration.

There was a total of 22 participants across all three focus groups. There were eight participants in the early education focus group. This group comprised four pre school educators, two family day care educators and two child care educators. Another child care educator agreed to participate but

withdrew due to illness. In the early education and public health focus groups there was one observer/note taker. She recorded observations that she shared with the researcher after completion of the focus groups. She was unavailable for the third focus group. The participants in the early education group were representing five different services. There were eight participants in the public health focus group. In this group there were two speech pathologists, five child and family nurses and a social worker. All these participants worked at either Mudgee or Rylstone Health Services. The private health focus group comprised six participants including one general practitioner, two speech pathologists, two psychologists and one occupational therapist. All participants in all the focus groups were female. Focus groups were between 90 minutes and 105 minutes in duration.

Data Analysis

The data obtained from parent interviews and focus groups was recorded and transcribed verbatim. A process of thematic analysis was utilised for this research, in accordance with Braun and Clarke (Braun and Clarke 2006). This involved familiarisation with the data through listening to recordings and repeatedly reading transcripts. Manual coding was undertaken by writing observations and then cutting up the transcripts. Eighty three initial codes were identified from all the data. Initial codes, relationships between codes, and emerging themes were discussed with the researcher's mentor. Codes were then further analysed by the researcher and sorted into themes using a visual mind map. This map was repeatedly reviewed until four major themes, which also incorporated several sub-themes, emerged.

Ethics Approval

Ethics approval was received on 30th June 2014 from Greater Western Human Research Ethics Committee (HREC/14/GWAHS/13). Site specific assessment approval was granted on 24th July 2014 (SSA/14/GWAHS/55).

The Researcher

In accordance with a critical realist perspective, the researcher engaged reflexively with her own assumptions. The researcher is a female social worker at MCHC and has extensive clinical experience in child and family assessment and counselling, group work and case management. As a social worker, the researcher facilitates an education and support group for parents of children with autism. She does not have any previous formal research experience. Through participation in the HETI RRCBP, the researcher received training in research methods, question design, interview techniques and focus group facilitation. The researcher has a daughter with autism. The researcher remembers a positive experience of the process of having her daughter diagnosed with autism. Most of the interview and focus group participants were known to the researcher either through her role as a social worker, or through other community networks. Most participants also knew about the diagnosis of the researcher's daughter. As a social worker and parent, the researcher has a commitment to effective service delivery for children with autism and their families. The researcher remained aware throughout the research process of the impact that her personal experiences, views and knowledge may have on the data collection and analysis. To engage in this process of reflexivity, she discussed these issues on a regular basis with her mentor and program support officers from the RRCBP. She also recorded notes about these issues and reflected on their possible impact in her research journal. The researcher acknowledged her prior experience and connection with all research participants. All participants indicated that they felt comfortable in the interview and focus group situation.

Findings

After analysis, four major themes emerged from the data. These themes were labels, relationship, process, and knowledge. There was connection and overlap amongst the themes. These themes captured the experience of most participants, however there was variation in the degree to which they were experienced by those involved. The analysis of these experiences allowed the researcher to interpret some possible causality for delay in autism diagnosis.

Labels - “A diagnosis is a label”

The theme of labels was about recognising that a diagnosis of autism provided children with a label that described particular behaviours. It also encompassed other labels that are ascribed to children displaying challenging behaviours, for example “naughty”, “disruptive” or “incompetent”. Participants recognised that labels ascribed to a child could influence perceptions of their child by others, providing a lens through which others viewed their child. All parents and most professionals discussed labels, although their perspective about the usefulness of labels, and which should be attributed to children varied. The desire to seek the “correct” label for their child was often a driving force for parents in trying to obtain a diagnostic assessment.

A label of autism provides access to help and understanding

Most parents interviewed felt that the label of autism helped them, and others, to have a better understanding of their child and their behavioural characteristics. Parents explained that people often labelled children, particularly when they exhibited challenging or unusual behaviour, and they wanted to make sure the assigned label fairly represented their child.

“I’d rather he get the right label than the wrong label.” (P2)

For most parents, this understanding of autism also extended to their comprehension of how to parent a child with these behaviours, and consequently feel more competent as a parent.

“Somehow having him diagnosed, it’s probably a very selfish thing, but it helps me because it makes me feel less ridiculous and incompetent”. (P7)

Many professionals agreed that a label of autism could provide parents with greater understanding. A private health professional described the reaction of some parents when she discussed an autism diagnosis.

“I need to know what to do here, and if I have a label - that helps me know what to do here.” (PHP1)

Not all participants agreed that a label of autism was beneficial or necessary. Some parents encountered resistance from their partners, friends, and other family members when they discussed developmental concerns or they initiated the autism assessment process. This resistance was often explained in terms of labelling, and concern that a label was unnecessary and would bring stigma. A parent explained the reaction of her husband to the suggestion their son should be assessed for autism.

“He said he didn’t want him to be labelled and treated as a label. But the trouble is without the label he wasn’t getting much understanding....as someone who’s autistic there’s a little

bit more understanding than a child who's just misbehaving. So I think having the label isn't such a catastrophe." (P7)

Several professionals also encountered stigma from parents about the labelling of developmental issues when they raised social or language concerns about a child.

"There's a stigma, so it's not like you're saying the child's got asthma" (PHP3)

In contrast, however, there were some professionals who felt that it was currently "fashionable" to be diagnosed with autism, and felt that some parents were trying to get a diagnosis, of either autism or another disorder for their child, even when it was not warranted.

"...that compulsion from some of those parents to get a label of some description." (PHP2)

The degree to which parents felt the label of autism helped themselves and others understand their child was an important enabler in the diagnostic process. Many parents viewed the label of autism as necessary to access help for their child. Most parents did not appear to understand during the diagnostic process what type of help they needed to access for their child, but generally understood that they needed to find out what would be useful. Despite most being entitled to HCWA funding for their child once a diagnosis had been made, only one parent mentioned access to this funding as a motivation to pursue diagnosis. Most parents explained that they did not know about the funding until told at the point of diagnosis by the paediatrician, or sometimes later. For them, the motivation for assessment was the generic idea of "help".

"I just pushed through it because I knew he was probably going to need help..."(P8)

A label of autism is useful for school and early childhood settings

All parents acknowledged that obtaining support in the school, preschool or childcare setting was at least a partial motivator, and usually the major motivator, in pursuing a developmental assessment for their child.

"So we decided to put him into daycare and that was the push for the actual diagnosis, knowing that if he was to get a place in day care and they needed the aide, they'd need that official letter". (P3)

For many parents, the starting of school and the need for school to both understand their child and access funding for extra support was a catalyst. Professionals overwhelmingly agreed that parents were often motivated to participate in a diagnostic process when their child was at school or about to begin school, and that parents were more willing to consider following the diagnostic process when they understood the possible benefits at school for their child of an autism label.

"Its when they start that transition to school that a lot of them will go, 'Okay, I get what you mean.' Because its basically explaining that all I want to do is get that in place before they start school" (ECE8)

Many of the professionals, particularly allied health who provide therapy in addition to assessment, considered it important that parents understand the benefits of an autism label, as well as the potential stigma. They felt that the label was useful at school, for a child's understanding of their own identity, and in receiving targeted intervention. They felt that this was even more crucial than access to funding.

“To label or not to label kind of thing, and try to help them make their decision, taking on board how they are processing it, and what their needs are, and where they’re at with it, and trying to help them make that decision about whether they do investigate further.”
(PHP1)

Labels and their application to children was an overwhelming issue for most participants. Labels, either positive or negative, appear to influence the interaction of many children in their social world. There is a reasonable amount of literature about autism as a label. Some research addresses the positive nature of a label leading to more understanding. Other studies examine the stigma of the diagnosis (Calzada et al 2011). There are several studies that explore the recent change in the diagnostic criteria for ASDs and the removal of the term “aspergers” (Kite et al 2012). The amount of consideration this has been given, and the discussion it has generated, suggests that labels do have significant meaning for people. In this study, participants recognised that labels not only help them and others to understand their child’s behaviour, but also have currency in structures such as education settings and therapy services in providing access to support.

There are opportunities, through discussion of labels, to provide parents with incentive to pursue developmental assessment of their child when concerns are raised. It appears that when parents are aware that assessment and possible diagnosis may provide more support in education and child care settings, more understanding about their child’s behaviour and access to help, they are more likely to engage in this process. This may be important for health and education professionals to consider when raising concerns with parents.

Relationship

The theme of relationship was about the connection between parents and professionals, within families and support networks, and also between professionals. It encompassed the way these people communicated with each other and the regard they had for each other. These relationships were perceived as both barriers and enablers in how quickly the diagnostic process progressed.

Within families and friendship circles

Although professionals made little reference to relationships they had observed within families, some parents described family members or friends who were discouraging about them pursuing assessment of their child. Many parents advised that this discouragement delayed the diagnosis of their child. All parents did eventually receive a diagnosis for their child, but for those with discouraging family, this occurred when they had gained more knowledge about the potential concerns for their child, and received support or pressure from an outside person, such as a health or education professional. For a few parents, this then meant they had to go against the wishes of their partner or extended family to have their child assessed. One parent explained:

“Well, there was my husband - he was completely against, like totally against it...Then I happened to tell my mother what I had done and she said, how ridiculous and how silly I had been, and what a ridiculous thing to do and that the GP was absolutely right and that she forbade me to get him diagnosed because it was such a ridiculous thing to be doing. So I just thought, well, its too hard anyway. But the trouble was his teacher, who was lovely, kept pushing and pushing and pushing and pushing.....In the end I tried again and we got a referral to a paediatrician” (P7)

There was some mention of family being supportive, and sometimes raising initial concerns about a child with a parent:

“My sister brought it up with me. She works with disabled adults, and she said something is not quite right. And I said the same thing, and she encouraged me to go and seek help through the paediatrician.” (P9)

Between professionals

Parents described their surprise that professionals didn't communicate more with each other during the diagnostic process. They spoke about seeing many professionals, who would sometimes communicate by letter, and sometimes not at all.

“They talk to each other in a letter or they may not actually physically talk to each other about this one child....They don't actually communicate about what's probably best for the child, they just all work separately, and not really as a group” (P8)

Professionals from all fields recognised that they did not communicate regularly with each other, and when they did, it was usually by letter. They also felt that not only would more regular communication allow them to make more rigorous decisions, it would possibly make diagnosis simpler because the process may be shortened.

“you've got all these fragmented people that need to come together and put it on the one page.” (PUHP3)

“I probably should pick up the phone more often and make that phone call. We all should, really, like, if that's what's going to work why aren't we all doing it.” (PUHP2)

Whilst parents and professionals recognise the positive contribution that team work and verbal communication between professionals could make to the diagnostic process, it seems this is very limited for the children diagnosed in this community. There was a commitment, however to working on innovative models, and improving practice to address this.

“...thinking outside the square in that regard, you know, about how we can provide services” (PHP3)

Early education professionals also felt that the communication between professionals was problematic and that there needed to be someone to assist with this process. One commented:

“Is it just up to the parent, or are these people speaking to each other? There almost needs to be like a case worker to guide...” (EEP6)

Opportunities to improve the communication and relationship between professionals was considered a priority for many focus group participants. There was an emphasis on what could be changed by individuals, with most recognising there are underlying factors that can impede working more closely, including lack of time and organisational policies. Professionals felt that more verbal communication with other professionals would be particularly useful.

“In private practice you're not funded for cold case discussions, so people will just chat about it in between clients ...If they're all assembled on the one day it should make people smarter because they are learning from other professionals as well.” (PHP1)

Between parents and professionals

Parents emphasised the importance of the communication that occurred between themselves and early education and health professionals in their decision to pursue diagnostic assessments for their child. Several parents talked about enablers in the process as being professionals who were able to describe specific concerning behaviours, those who appeared to care and listen and those who were able to share personal experiences of autism. One participant explained this by describing what her child's pre-school teacher initially said to her:

"It was very much, 'I've noticed that he lines the toys up while he's playing'. So it was very specific, and I found that was quite helpful." (P1)

Whilst parents liked professionals identifying specific behaviours in their child, they generally agreed that it was more useful when the discussion with the professional was carried out in a non-confrontational manner. A parent described the manner of the education professional who spoke with her about her son:

"...she was very approachable, very non-confrontational about that, just pointed out some things, and then we went from there." (P1)

For a small number of parents, both of whom had family who strongly resisted pursuing diagnosis, it was helpful that concerns had been mentioned over a period of time by a number of different professionals. This was possibly because with resistant family, they needed more time to consider pursuing an assessment and to attempt to get support from their families.

Parents particularly appreciated professionals who were honest about their knowledge and expertise, feeling this allowed them to move through the process more quickly. When asked what advice she would give to health professionals, one parent replied;

"Be honest. If you can't help, don't waste your time and the family's time trying." (P3)

As discussed in "labels", all parents were motivated to follow-up the concerns of professionals, when they discussed concerns in terms of impact in educational settings. Overwhelmingly, parents were much more likely to pursue diagnostic assessment when professionals explained that assessment was important so that appropriate support could be provided for child care, pre school, and particularly school. This was particularly important for parents when describing their communication and relationship with professionals.

Parents found it helpful when professionals provided them with written information about autism, although they said that this rarely occurred. Parents found this difficult, as they had nothing concrete on which to consider their options.

"I don't think we were ever given any reading material. It was sort of almost, you were left to your own devices and interpret it as you would." (P6)

Early childhood educators mainly agreed with the usefulness of written information.

"Yeah, so if they ask for information it would be nice to be able to hand out one sheet that had, go to these websites and have a look, rather than type it into google and be horrified of what comes up". (ECE7)

Overwhelmingly, parents described feeling unheard in the diagnostic process, particularly with medical professionals. Most participants suggested that these professionals should take the concerns of parents more seriously. They felt that not being listened to had been a barrier in the process, as they often had to see professionals more often, or find a different professional to have their voice heard. A parent described the advice she would give to medical professionals:

“Its more listen to the parents. You strike a lot of - they probably don’t mean to but you do struggle across a lot of ‘you don’t know what you’re talking about’. We don’t know the medical term for it as parents; we know our child; they don’t really know our child....be a bit more parent-friendly and maybe listen to them a bit more.” (P8)

When they considered raising concerns about a child with their parents, most professionals considered their relationship with parents to be of paramount importance. They explained that they tried to maintain their relationship with parents so that concerns could be brought up gently, and over time. They perceived this was important as it allowed them to continue monitoring the child’s development, even if the parents did not follow up diagnosis at that time. Most had experience of families where parents were keen to listen to concerns about their child’s development, and families who were very resistant to hearing any concerns about their child. Professionals explained that they often tried to judge the reaction of parents when discussing concerns with them, tailoring their approach and suggesting further steps accordingly.

“...if you’ve got a good rapport with them and they don’t - they’re not ready for that diagnosis, they’re not ready for that, because of the relationship base they will come back when they’re ready. Thats what good I think that if they’re not ready at that time or they’re not prepared to deal with that, with the knowledge that we know them and they feel safe and comfortable to talk to us, they will come back. I think that’s supportive too, in a way which, you know, you can’t force anyone” (PUHP4)

They described the difficulty that had in raising concerns, even when they had a good relationship with parents:

“I get very anxious”(EEP8)

“Heart in the mouth sort of thing”(EEP1)

Public health professionals, particularly child and family health nurses, strongly agreed that they found raising concerns extremely confronting. A couple who felt more comfortable about discussing concerns with parents, explained that they were able to deal with their anxiety by keeping the positive aspects of the diagnosis in mind whilst having the discussion. One explained:

“I think its always, you know, its always confronting. But, I don’t know, sometimes I think if you look ahead and, say, you can see that this process - there can be a really positive outcome from it. So, if don’t sort of fall back into that, oh my God, that despair sort of thing, thinking, you know, this family - how are they going to cope?” (PUHP3)

Some, although not all, private health professionals agreed:

“you certainly do have to think about how I am going to say this, how am I going to deliver this, you try and predict how its going to be received...” (PHP4)

Professionals described how negative experiences could affect future approaches to parents;

“if you had had a parents that is a bit aggressive and doesn’t want to know about it, then that makes you more apprehensive for approaching parents another time because you just never quite know” (EEP2)

The importance of relationship between parents and professionals has been examined in other studies. As found in this study, there is emphasis on the importance of the rapport between parents and professionals, and the support that parents have for themselves (Osbourne et al 2008).

The researcher could find little other research about the feelings of front-line professionals when raising concerns about possible autism for the first time, as much of the research focuses on the parents’ perspective of the professional. When professionals in this study were confronted with the responsibility of discussing developmental concerns with a parent, this often generated feelings of anxiety for them. They felt that this discomfort sometimes impacted on their communication and relationship with the parent. Due to the structure of the health and child care systems, it is unavoidable that many front-line professionals are the first people to raise concerns with parents. Their confidence and ability to communicate concerns clearly and effectively, however, are potentially changeable with training and support. Professionals also recognised and respected the choice of parents in the diagnostic process, and their ability to make decisions for their children.

Process -“The mess”

Process was a theme about the steps that were needed to be taken to receive an official diagnosis of autism. It included the requirements to see particular professionals and undertake assessments in order to receive a diagnosis, and the way in which these were undertaken. It included the enablers and barriers in the process of diagnosis.

The process of having a child diagnosed with autism was problematic to varying extents for all parents in this study. Most professionals acknowledged that the process itself was a barrier to diagnosis for many families. Participants talked about the process involving structural factors such as length of waiting time for appointments, long distances to travel to appointments, the lack of local specialist services, the cost of accessing services, and the amount of steps involved in the process. Parents described the impact this had on their family life, their work, in addition to a financial burden. They also commented that there seemed to be a lack of support in the process.

“It was pretty much go it alone” (P4)

At the time of their initial concerns about their child, most parents had little knowledge about the process and did not understand what was required to receive a diagnosis. Consequently, they felt they had little control. One participant explained that lack of knowledge about the process, made it very difficult:

“...when you’re going through the diagnosis, like, you just push to here, push to there and told to do this, do that, and you don’t actually know if you are doing the right thing...” (P8)

One participant had knowledge of the process due to her professional background. She explained:

“I guess the process of that diagnosis was fairly straightforward, but probably because I knew what was involved and who to talk to, and was not at all surprised that it was coming up. So all of that helped” (P1)

Length of time

Most parents felt that the length of time it took for their child to receive a diagnosis, from the time they first spoke with a health professional, to the time their child was diagnosed, was too long. Some participants recalled receiving no strategies during the process, that often took between 18 and 24 months, and they described this with disappointment, frustration and anger. Participants who were given strategies by health professionals to use with their child during the assessment process, found the process easier and more supportive, and felt encouraged to continue through the process. Parents and professionals generally agreed that there are too many steps involved, and that this, coupled with the waiting time for appointments, contributes to an overly lengthy process.

Some private health professionals, however differed in opinion. They generally agreed that a process that took 1 - 2 years was not too lengthy as the diagnosis was a complex one and should not be undertaken lightly. They also felt this gave more time to ensure the diagnosis was not made too hastily.

“Its not the kind of diagnosis you want to get wrong because its a big diagnosis and its a lifelong diagnosis” (PHP3)

Some parents discovered, usually by chance, that they could speed up the process by accessing private speech therapists, psychologists and other services such as Autism Spectrum Australia (ASPECT). They then felt they had some choice in the process. This was not the case for some parents who could not afford to pay for private services. One participant explained what was helpful in moving towards a diagnosis:

“Well, certainly being able to get into ASPECT so quickly, that was certainly one, as much as you had to pay, and I don’t like the idea of, if people can’t afford it, or they don’t understand they can do it that way.” (P6)

Cost and distance

Many families in this rurally based study found the cost of accessing services, travelling long distances to appointments, and having time away from work expensive and challenging. Most participants discussed the difficulty of families having to travel to services, as there were often not enough local services. Most families needed to travel to either Sydney or regional centres to access at least some of the professionals in the diagnostic process. During the process, some parents realised that they may be able to access private services more quickly than public services. Several parents, however, could not afford to do this, and lack of personal income became yet another structural barrier in the process for them.

“The process itself wasn’t - it was lengthy and I think distance was a big part of it. We had and the different professionals you had to see before you got the diagnosis. So you started off and saw the local GP, who referred you to the Paediatrician, who then referred you to the diagnostic centre aspect, but prior to going to Aspect, you had to go and have hearing, sight, speech, OT, you had to get school counsellors reports, you had to get teacher reports, and it was in gathering all the information, and because you had to wait two

months to get an appointment for an OT, you had to wait just as long again for all the others...”(P6)

Professionals, particularly those who provided private services, were very aware that it could be a costly process for parents. They acknowledged that some parents could not afford to pay for their services, but felt stuck because that was their only means of service delivery. Professionals agreed that they hesitated to refer some families through private services, although they were often quicker, because of the associated cost.

“If I know out and out they can’t afford it, I won’t discuss that, but if I know that the parents are quite well off then I’ll suggest going the quick route” (PHP3)

Many professionals were particularly critical of the process. They agreed that there were too many steps and too much travelling required of parents. From a few professionals in the early education sector, there was some concern that if they raised concerns with parents, that turned out to be invalid, they could be exposing parents to unnecessary expense and travel.

“Its very complex, they talk about navigating the maze” (EEP8)

“I think there’s a struggle to then say ,”well yes, you can go and see someone, they’re just up the road’, because they’re not. It’s quite a bit of organisation to go, ‘you’ve actually got to travel to a different town or to the city.’ It’s not always just, ‘Oh yeah theres a, just...” Its not easy. And you may have to wait months to be seen, it takes so long.” (EEP3)

Professionals and parents were generally in agreement on what could be done to improve the process. Suggestions focused on reducing the number of steps and making the process simpler. Private professionals suggested trying to attract more service providers to town, particularly for multi-disiplinary joint assessments that were autism specific. Suggestions about better utilisation of tele-health were also made.

Professionals agreed that ideally a service such as community health would facilitate all the services. There was acknowledgement, however, that in a rural town with both private and public services, this was not possible. Whilst services are not funded and structured across a public-private divide, new models would have to be trialled to achieve this collaboration. Professionals agreed, however, around the bringing together of services.

“with all the services went under one roof to make it easier for clients so they weren’t speared all over the place trying to get help and lose momentum because it’s too hard” (PHP4)

The experiences of parents and the barriers they perceive in the process, are similar to many in a recent United Kingdom parent survey (Crane et al 2015). The professionals in this study report also finding the process confusing and having too many steps. Parents found travel to see specialists a challenge in this study. That is probably unsurprising considering the study is based in a rural area. It does suggest, however, that perhaps the location of services and innovative ways of bringing them together could be of benefit to both the parents and local professionals.

Knowledge - “Don’t say the A word”

Knowledge was a theme about understanding and comprehension of the indicators of autism and how it is diagnosed, by both professionals and parents. It encompassed the skill and expertise of professionals in this area. This theme included the general knowledge that parents and professionals had about autism.

Parents knowledge about autism

In addition to lacking knowledge about the process, most parents explained that they had little knowledge about autism. Many did not realise that there were concerns that their child had autism until a psychologist or paediatrician made the final diagnosis, often one to two years from when concerns were initially raised. Parents described their lack of knowledge in this area as very disempowering. For many it meant that they could not exercise influence in the process because they did not fully understand the situation. A parent explained that it was not until the final diagnosis by a paediatrician, in a process that had involved over 12 months of assessments by various professionals, that the word autism was used:

“That was the light bulb moment, to say yes, this is what it is, there is an actual name for it...you know the diagnosis wasn’t a scary diagnosis, but I didn’t know it at the time, and that’s what was worrying me.” (P2)

This was not an unusual experience for parents, with many not hearing the word autism until close to official diagnosis:

“Well, I’d never heard of the autism spectrum disorder before I got him diagnosed, so I was just grasping at straws” (P9)

For a small number of parents, the possibility of autism had been referred to, but often late in the process, and without any supporting information. Even for these parents, when earlier concerns had been raised by others, they had often been discussed without any mention of autism. One mother explained:

“But they didn’t really, no, they don’t really say what it is, or whatever. They dodged around what they were thinking for a bit and then said, “Oh, it might be autism. He shows signs of autism”, and that was it....they don’t really tell you what autism is at all”. (P8)

Parents found that not understanding what the concerns were about had not only made the process more difficult, but had slowed down their seeking of help because they did not understand why they should try to seek further assessment.

Most professionals validated this experience. They were firm that they would not use the word “autism” unless a parent used it first.

“I think if the parent has said the word autism then I’ll happily use it. If it hasn’t been brought up I’d rather just refer to the behaviours” (PUHP7)

“normally I wouldn’t unless the parent brings it up” (PHP4)

“I think you leave yourself wide open if you use that word, because if its not you actually put yourself in a position where it could come back...” (EEP1)

Many professionals discussed not feeling that they had enough knowledge to let parents know that they were concerned about autism, and felt that it was the job of the paediatrician or psychologist to articulate what the concerns were about. Many thought that parents might realise what the concerns were about, despite the word autism not being used in the discussion by the professional.

“Yeah, sometimes I kind of rely on the paediatrician to bring that up. But I think with, like, the preschools, their notes and with our report on - I think the behaviours are all there and quite obvious. I think sometimes parents are often able to put it all together themselves and kind of go, “well you know, those behaviours mean.” (PUHP2)

A very small number of professionals did not agree, and said that they would discuss concerns about autism in the context of broader developmental concerns, and as the reason why a referral for further assessment was necessary.

“I would say that, yeah, “There are some behaviours that your child displays that could be autism, but there are other things that might explain that behaviour.” (EEP5)

Although most professionals advised that they would not make any mention of autism, some agreed that if the parent appeared willing to know more about the concerns, they may give more information, but would try to gauge the parent first.

To the best of the researcher’s knowledge, there is little literature that directly addresses the use of the word autism (or similar) during the diagnostic process. Parents and professionals, however, both had very strong, and opposing opinions about this in this study. Parents felt very disempowered through not knowing what the concerns about their child were related to, yet many professionals were adamant that they would not use the word autism unless a parent said it first. Inadvertently this often resulted in the process of diagnosis being more stressful and lengthy because parents were unsure of the direction in which they were being pushed. It is an important issue to examine in further research, as based on parent perspectives in this study, discussion of autism at the time a child is first identified as being at risk of autism could give parents impetus to pursue further assessment. This issue needs to be addressed with a wider group of parents, and possibly include the perspectives of parents of children where concerns were raised but autism was not diagnosed.

Professionals knowledge of autism

Parents described having mixed experiences with professionals in the diagnostic process in terms of their expertise in autism. Many were referred to professionals who did not appear to have expertise in autism assessment:

“there were a lot of I don’t knows, too many I don’t knows” (P2)

For parents who travelled to autism specific services, they described this as being of great benefit. They described this as being of benefit, even when extra cost or travel was involved.

“If you could aim for specialists in the area of ASD I would go with them” (P6)

Knowledge was also a theme in a qualitative study undertaken by Micaela Connolly and colleagues about the process of autism diagnosis. In addition, they also had similar themes about process and relationships with professionals. They discussed the desire by parents for more information about autism to be available as soon as concerns are raised, and not just at the point of diagnosis

(Connolly and Gersh 2013) In their study, however, parents knew that they were on a waiting list for an autism diagnosis, and hence they knew that autism was being considered.

Study strengths and limitations

This study contributes to the limited qualitative research about earlier autism diagnosis, and the diagnostic process in rural areas. To the best of the researcher's knowledge, it is the first study to bring together the perspectives of both parents and professionals about the diagnostic pathway in a rural area.

Due to the manner in which participants were recruited to the study, interviews were only undertaken with parents of children whom had already been diagnosed with autism. It is possible that parents who did not act on concerns raised by health and education professionals and therefore received no diagnosis for their child, could add additional insight into barriers in the diagnostic process. Some professionals, however, did discuss experiences of parents in this situation.

All participants in the study were female. This may be representative of the role of many mothers as primary carers, and the vast majority of the local allied health and early education work being female. It is not representative of the local medical population, which is predominately male. No paediatrician participated in the study.

The researcher was known to most participants, and this can be perceived as both a strength and limitation. It is possible that this changed the responses of participants. The researcher, however, made it clear to those involved that participation was voluntary and encouraged them to be as open as possible.

Conclusion

This study demonstrates that in this rural area, the diagnostic experience of children, as described by their parents, is often challenging and requires improvement. Parents described a process that is lengthy, confusing, costly, and often requires travel. Study participants agree that professionals do not communicate with each other enough. Parents have a strong desire for more knowledge about the process of diagnosis, and autism. Professionals are strongly committed to their relationship with parents and the developmental progress of children, but some feel they lack expert knowledge of the early indicators of autism. Many find it confronting to discuss developmental concerns with parents.

Barriers in the process include the lack of clarity about where to go next, the number of steps involved, travel and cost for families, lack of communication between professionals and lack of knowledge about autism and the process. Enablers for parents moving along the diagnostic pathway include understanding the usefulness of a diagnosis in terms of accessing help, educational support and understanding, and professionals who communicate in a non-confrontational manner and provide good quality information on autism. Parents indicated that they would be more inclined to pursue a diagnosis if they knew that a professional was concerned that their child had autism.

Recommendations:

As a result of this study it is recommended that:

To develop innovative models of diagnostic assessment:

1. A working party is established at MCHC to trial and develop collaborative and innovative models of identifying and diagnosing local children who are at risk of autism. The group comprises at least one early child and family nurse, one doctor, one parent of a child with autism, one public allied health professional and one private health professional. The group considers the findings of this report and local opportunities for improvements in the diagnostic process including options such as tele-health and public-private partnerships.

To improve awareness and knowledge about autism and the diagnostic process:

2. WLHD and the Western NSW Primary Health Network (WNPHN) promote the Raising Children Network app, “Children with ASD and Disability” through early childhood clinics and medical practices, and on the WLHD Facebook page.
3. WLHD and the WNPHN make written information in the form of one page flyers available to parents about early indicators of autism through early childhood clinics, community health centres and private medical practices.
4. WLHD provide staff who work with children with training about the early indicators of autism, including a component about communicating these concerns with parents, through a HETI online module. That this module also address the issue of having challenging conversations about developmental issues with parents. That is also highlights the usefulness of discussing educational contexts when raising concerns with parents.
5. WLHD and the WNPHN develop a directory of local autism assessment services in the western region of NSW, including specialist services that can be accessed in Sydney. That this directory include a flow chart of the steps needed for diagnosis. That this directory be made available to health and early childhood professionals in the WLHD.
6. The WNPHN provide education to local health professionals about early indicators of autism and the benefits of early intervention through their professional development programs.
7. Further research be undertaken about the use of the word autism by professionals when they identify a child as being at risk of autism, and are discussing concerns with parents.

To improve timely access to specialist diagnostic services for rural families:

8. The NSW Government make Isolated Patients Travel and Accommodation Assistance Scheme payments available to families when travelling to ASPECT in Sydney for diagnostic assessment for their child when a referral has been made to ASPECT by a paediatrician.
9. The NSW Department of Family and Community Services increase funding for ASPECT to provide low-income autism diagnostic assessments to families of children in rural areas.

References

- American Psychological Association (2013) Diagnostic and Statistical Manual of Mental Disorders 5. Washington, DC: American Psychiatric Association.
- Autism CRC. 2015. Developmental surveillance for autism. [ONLINE] Available at: <http://www.autismcrc.com.au/developmental-surveillance-autism>. [Accessed 13 June 15].
- Baio J (2012) Prevalence of Autism Spectrum Disorders - Autism and Developmental Disabilities Monitoring Network, United States, 2008. Centers for Disease Control and Prevention.
- Baldwin S, Costley D, & Warren A (2014) Employment activities and experiences of adults with high-functioning autism and asperger's disorder. *Journal of Autism and Developmental Disorders*, 44(5): 1-10.
- Barbaro J, Ridgway L, & Dissanayake C (2011). Developmental surveillance of infants and toddlers by maternal and child health nurses in an Australian community-based setting: Promoting the early identification of Autism Spectrum Disorders. *Journal of Paediatric Nursing*, 26 (4): 334-347.
- Calzada L, Pistrang N, Mandy W, (2011) High-Functioning autism and asperger's disorder: utility and meaning for families. *Journal of Autism and Developmental Disorders* 42(2): 230 - 243.
- Crane L, Chester J, Goddard L, Henry L and Hill E (2015) Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, 2015, doi 10.1177 / 1362361315573636.
- Dissanayake, C (2012) The trouble with autism: delays in early identification and diagnosis. *InPsych* 6
- Bent C, Dissanayake C and Barbaro J, (2015) Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010 - 2012. *Medical Journal of Australia* 202(6): 317 - 321.
- Braun V and Clarke V (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3(2): 77-101.
- Connolly M, and Gersch I.,(2013) A support group for parents of children on a waiting list for an assessment for autism spectrum disorder. *Educational Psychology in Practice: Theory, Research and Practice in Educational Psychology* 29 (3): 292 - 308.
- De Forge R and Shaw J (2012) Back and fore-grounding ontology: exploring the linkages between critical realism, pragmatism, and methodologies in health and rehabilitation sciences. *Nursing Inquiry* 19(1): 83 - 95.
- Department of Social Services (2015). Early Intervention Services for Children with Disability. [ONLINE] Available at: <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/early-intervention-services-for-children-with-disability>. [Accessed 12 June 15].
- Eapen V, Crncec R, Walter A. (2013) Clinical outcomes of an early intervention program for preschool children with Autism Spectrum Disorder in a community group setting. *BMC Pediatrics*, 13(3): 1-9.
- Frenette P, Dodds L, MacPherson K, Flowerdew G, Hennen B, Bryson S (2013) Factors affecting the age at diagnosis of autism spectrum disorders in Nova Scotia, Canada. *Autism*, 17 (2): 184-195.
- Guthrie W, Swineford L, Nottke C, Wetherby A (2013) Early diagnosis of autism spectrum disorder: stability and change in clinical diagnosis. *Journal of Child Psychology and Psychiatry*, 54(5): 582-590.
- Gotham K, Unruh K, & Lord C (2014) Depression and its measurement in verbal adolescents and adults with autism spectrum disorder. *Autism*. 19(4): 491 - 504.
- Howlin P, Magiati I, Charman T (2009) Systematic review of early intensive behavioural interventions for children with autism. *American Journal of Intellectual and Developmental Disability* 114(1): 23-41.
- Kite D, Gulifer J, Tyson G (2012) Views on the diagnostic labels of autism and asperger's disorder and the proposed changes in the DSM. *Journal of Autism and Developmental Disorders*, 43(7): 1692-1700.
- Koegel K, Koegel R, Ashbaugh K, Bradshaw J (2014) The importance of early identification and intervention for children. *International Journal of Speech Language Pathology and Psychiatry*, 54(5): 582-590.
- Osbourne L, Reed P (2008) Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism*, 12 (3): 309 - 324.
- Rogers S, Vismara L, (2008) Evidence-Based Comprehensive Treatments for Early Autism. *Journal of Clinical Child & Adolescent Psychology* 37(1): 8 - 38.
- Sword W, Clark A, Hegadoren K, Brooks S, Kingston D (2012) The complexity of postpartum mental health and illness: a critical realist study. *Nursing Inquiry* 19 (1): 51 - 62.
- Walsh D and Evans K (2014) Critical realism: An important theoretical perspective for midwifery research. *Midwifery* 30(1): 1 - 6

Appendix A - Parent interview guide

Parents - Semi Structured 1:1 Interview Questions

(Initial review with Parent/Carer of confidentiality, informed consent and opportunity to ask questions about the project. Remind Parent/Carer about recording of interview)

Additional information may be sought, or topics explored that are in keeping with the research question, as Parents/Carers provide information and discuss their experiences.

- Can you tell me about your experience of your child being diagnosed with an ASD?
- How did you first become concerned about your child?
- (If someone else raised these concerns) Who raised these concerns?
- (If the Parent/Carer had concerns first) Who did you initially express these concerns to?
- How old was your child when concerns were first raised?
- Can you tell me about the length of time taken from when concerns were first raised (either by a Health or Education Professional with the Parent or by the Parent with a Health or Education Professional), until your child received an official ASD diagnosis, and what steps were involved? (Drawing out how long steps took from when concerns were raised with or by a Professional, until an official diagnosis was received)
- What influenced your decision to continue taking the steps that led to the diagnosis?
- Was there anything that made you stop the process of moving towards a diagnosis at any time?
- As you and your family moved through the process from becoming concerned about your child to receiving a diagnosis, what did you find helpful?
- What made the process more difficult?
- If you were able to put forward suggestions for consideration to improve the process of having your child diagnosed with an ASD, what would they be?

Appendix B - Focus Group Guide

Focus Group Questions and Topics

Group to last approximately 90 minutes

Some of the discussion in focus groups will be informed by the data collected and analysed in Parent/Carer interviews. General topics, however for discussion will fall broadly into the following areas:

Topic: Knowledge and attitude towards ASD (15 mins)

- Brainstorm - What is your understanding of ASDs? – a starting point for discussion
- At what age do you see signs or behaviours that may point to an ASD in a child?
- What do you notice about a child when you are concerned they may have an ASD? What behaviours do you look for?

Topic: Experiences in the screening, referral and diagnostic process (25 mins)

- Can you recall a time when you identified a child with an ASD?
- How did you go about raising this with the child's Parents?
- In your experience, how have families responded when you have raised these concerns?
- How have your colleagues responded when you have raised concerns about a child?
- What does it feel like for you when you identify a child with a potential ASD?

Discussion of Case study (30 mins)

Case Study/studies to be presented to participants, after analysis of data from Parent/Carer interviews. To include main features/issues that come from Parent interviews.

Discussion:

- What are your thoughts about this?
- Where are the opportunities for improvement?
- At which point could we intervene to improve this process?

Topic: Referral Pathway from Parents/Carers interviews (30 mins)

A rough “map” of what the local diagnostic pathway of children to be presented, to be drawn from Parent/Carer interviews

- This is the referral experience of a sample of Parents/Carers in our area. What do you think?
- What is working well?
- Is there anything that could be done differently?
- Are there opportunities for improvement?

Conclusion/debrief (10 mins)

- Ask each participant if there is anything else they would like to add, and any further questions.
- Remind participants that results will be available in the form of a report, and will be presented at an information session at Mudgee Community Health Centre.