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# Exploring the Perception of Asperger's Disorder

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**W**ith current preparation for the release of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) in 2013, many changes have been proposed for the diagnostic criteria, including changes to the pervasive developmental disorder category — of which Asperger's disorder is a part. Using focus group discussions this study explored how Asperger's disorder is perceived by Australian health and education staff, parents of children diagnosed with Asperger's disorder and community members. A total of 51 people participated in eight focus groups. Theory-led thematic analysis of the discussions revealed five themes of aetiology uncertainty, challenging behaviour, barriers in service provision, terminology confusion and label stigma. These themes are discussed in relation to the proposed diagnostic changes and implications for future research.

**Keywords:** Asperger's disorder, DSM, stakeholder perceptions

Asperger's disorder is considered to be a pervasive developmental disorder and is currently grouped in the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.; DSM-IV-TR) with the conditions of autism and pervasive developmental disorder not otherwise specified (PDD-NOS). The key characteristics of Asperger's disorder are relatively typical language and cognitive development, with impairments in social interaction and restricted or stereotyped patterns of behaviour or interests that impact on life functioning. The DSM-IV-TR diagnostic criteria for Asperger's disorder and autism are identical in relation to social impairments and stereotyped patterns of behaviour (American Psychiatric Association [APA], 2000). The key area of difference relates to the diagnosis of autism requiring a significant impairment in communication prior to 3 years of age, which often results in earlier identification (Dahle & Gargiulo, 2004; Szatmari, Bartolucci, & Bremnar, 1989). The diagnosis of PDD-NOS occurs when the behaviours are not at the severity level to meet the diagnostic criteria for autism or Asperger's disorder.

Despite the recognition of Asperger's disorder as a distinct diagnostic disorder, there has been vigorous debate in the literature as to whether Asperger's disorder and autism are actually synonymous conditions (Ghaziuddin, 2005; Howlin, 2003; Macintosh & Dissanayake, 2004). Much of this debate has arisen through the comparison of Asperger's disorder to high-functioning autism, which is a term that

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has evolved to describe the 11–34% of autism diagnoses where there is no significant intellectual disability and general language skills are acquired, despite initial language delays (Gillberg & Ehlers, 1998). The term, high-functioning autism, is not officially recognised as a diagnostic category but is a term that regularly appears in research and is used by education and health professionals, as well as parents of children with autism (Macintosh & Dissanayake, 2004; Russell & Sofronoff, 2005). Further to this, autism spectrum disorder (ASD) is another term that has also been frequently used in publications, by those working in the clinical settings and by community members (Paxton & Estay, 2007). This term places autism, Asperger's disorder and PDD-NOS at differing levels on the same spectrum (Macintosh & Dissanayake, 2004; Paxton & Estay, 2007) and has resulted in research and the literature frequently grouping these conditions together.

The impact of grouping the conditions of autism and Asperger's disorder in research and of using a combination of formal diagnostic labels and unofficial terms becomes particularly evident when reviewing the literature on how autism and Asperger's disorder are perceived in society. The literature reflects a clear shift from initially focusing on community, professional and parental beliefs about autism (Furnham & Buck, 2003; Gray, 1995; Stone, 1987) to focusing on the views health professionals and parents hold about the unofficial term of autism spectrum disorder, in which autism, PDD-NOS and Asperger's disorder are combined (Goin & Myers, 2004; Preece & Jordan, 2007; Whaley, 2002). It is only in recent years that questions have been raised about the benefits of grouping these conditions in research (Klin, Pauls, Schultz, & Volkmar, 2005; Woodbury-Smith & Volkmar, 2009) and that research specifically exploring how education staff perceive Asperger's disorder has occurred (Agyapong, Migone, Crosson, & Mackey, 2010).

The need for further research specifically exploring how Asperger's disorder is perceived in society has become particularly relevant with the current proposal to combine autism, Asperger's disorder and PDD-NOS into the one diagnostic label of autism spectrum disorder in the new DSM (APA, 2010). The proposal to collapse these three categories into the one diagnostic label has resulted in mixed reactions from professionals working in the area and those diagnosed with the condition (Autism Support Group, 2010; Wallis, 2009). These reactions have included concern that the label of autism has a stigma attached to it, whereas Asperger's disorder tends to have a fairly positive connotation in society (Wallis, 2009). Although research specifically comparing beliefs around autism and Asperger's disorder are currently lacking, anecdotal evidence from those working diagnostically in this area tends to support the positive view of Asperger's disorder, with parents displaying a sense of relief when their child receives a diagnosis of Asperger's disorder rather than autism. Health professionals have also been reported to display a preference to use the labels of PDD-NOS and Asperger's disorder rather than autism when making a diagnosis (Rosenberg, Daniels, Law, Law, & Kaufmann, 2009).

The apparent reluctance by some professionals in using the autism label when diagnosing, and the concerns expressed about the stigma associated with the autism label, indicate that despite the diagnostic commonalities between autism and Asperger's disorder these conditions may actually be perceived differently. This variation in how autism and Asperger's disorder are perceived could be attributed to the intellectual delays that frequently co-exist with autism (Gillberg & Ehlers, 1998) and the underlying communication delays associated with autism (Dahle & Gargiulo, 2004). Whereas Asperger's disorder is described as a 'non obvious disability' (Portway & Johnson, 2005, p. 73), which is often accompanied by a splintered cognitive profile that is not within the intellectual disability range (Gallagher & Gallagher, 2002). Research that focuses on

understanding how autism is perceived or that treats autism and Asperger's disorder as a single construct therefore risks obtaining beliefs relating to the intellectual disabilities and communication delays associated with autism, rather than the less obvious but often challenging social impairments associated with Asperger's disorder.

To gain a greater understanding of the actual perception of Asperger's disorder, studies that specifically focus on Asperger's disorder are required. Agyapong et al. (2010) recently identified the need for research in this area when they explored, through a quantitative study, how Irish teachers perceive the characteristics of Asperger's disorder and the needs associated with the condition. While Agyapong and colleagues' research provides valuable insight into teachers' perception of the condition, there is a current dearth in research exploring how the broader community perceives Asperger's disorder. Gaining an understanding of how health and education professionals view Asperger's disorder may identify commonalities and differences in the views held by those involved in the identification, diagnosis, treatment and management of the condition. Knowledge about the perception of Asperger's disorder may also assist in answering some of the current concerns around the stigma associated with the condition and identify areas of need in relation to community and professional education. This need for knowledge around community and professional education has particular relevance when it is considered that those with Asperger's disorder have reported a desire to change others' perceptions about the condition rather than themselves (Clarke & van Amerom, 2008).

The aim of the current study is to develop a better understanding of how Asperger's disorder is perceived by health and education professionals, community members and parents of children diagnosed with Asperger's disorder. Given the limited literature in this area a focus group design was utilised to permit the expression of thoughts using descriptive terms in a social context (Wilkinson, 2008).

## **Method**

### *Participants*

A total of 51 people from regional Australia participated in the focus group discussions; the participants comprised 16 who were employed in the education setting (teachers, speech pathologists, social workers), 15 allied health professionals, 12 community members and eight parents of children diagnosed with Asperger's disorder. The participants' ages ranged from 19 to 68 years, with 92% of participants being below 59 years and 90% of participants being female. Precise details of the participants are shown in Table 1.

The number of participants allocated to each of the eight focus groups was based on Willig's (2006) recommendations of between four to eight participants to encourage social interaction between participants without being overwhelming (Merton, Fiske, & Kendall, 1990). It was evident at the commencement of the focus groups that some of the participants knew each other, with this being particularly evident in the parent, education and health groups. Some of the community members also appeared to have a basic knowledge of each other. This prior knowledge was not discouraged or controlled for in this study, as knowledge of each other in focus group discussions has been identified as enhancing the openness of discussions (Kitzinger, 2005; Willig, 2006).

### *Procedure*

After receiving ethical approval from Charles Sturt University Human Research Ethics Committee, participants were recruited through flyers placed on public community

**TABLE 1**  
**Characteristics of the Focus Groups**

Descriptive characteristics	<i>n</i>	(%)
<b>Overall sample (51 participants)</b>		
Gender		
Male	5	10%
Female	46	90%
Age		
18–29	13	25%
30–39	12	23%
40–49	11	22%
50–59	11	22%
60–69	4	8%
Overall mean knowledge of Asperger's disorder 2.1		
Overall mean experience of Asperger's disorder 1.8		
<b>Health sample (15 participants)</b>		
Gender		
Male	—	—
Female	15	100%
Age		
18–29	8	54%
30–39	1	7%
40–49	2	13%
50–59	2	13%
60–69	2	13%
Occupation		
Occupational therapist	4	25%
Speech pathologist	2	13%
Physiotherapist	1	7%
Social worker	6	40%
Mental health nurse	1	7%
Health assistant	1	7%
Mean knowledge of Asperger's disorder 2.2		
Mean experience of Asperger's disorder 1.8		
<b>Education sample (16 participants)</b>		
Gender		
Male	2	12.5%
Female	14	87.5%
Age		
18–29	4	25%
30–39	4	25%
40–49	3	19%
50–59	5	31%
60–69	-	-
Occupation		
Teacher	12	75%
Speech pathologist (Edn employed)	3	19%
Social worker (Edn employed)	1	6%
Mean knowledge of Asperger's disorder 2.1		
Mean experience of Asperger's disorder 1.9		
<b>Parents sample (8 participants)</b>		
Gender		
Male	2	25%
Female	6	75%

(continued over)

**TABLE 1 (CONTINUED)**

**Characteristics of the Focus Groups**

Descriptive characteristics	<i>n</i>	(%)
Age		
18–29	—	—
30–39	2	25%
40–49	5	62.5%
50–59	1	12.5%
60–69	—	—
Child’s age		
Primary	6	75%
Secondary	1	12.5%
Adult	1	12.5%
Occupation		
Home duties	3	37.5%
Manager/advisor	3	37.5%
Trade	1	12.5%
Education department	1	12.5%
Mean knowledge of Asperger’s disorder	3.1	
Mean experience of Asperger’s disorder	2.75	
Community sample (12 participants)		
Gender		
Male	1	8%
Female	11	92%
Age		
18–29	1	8%
30–39	5	42%
40–49	1	8%
50–59	3	25%
60–69	2	17%
Occupation		
Manager/consultant	7	59%
Admin/clerical	3	25%
Nurse	1	8%
Teacher	1	8%
Mean knowledge of Asperger’s disorder	1.4	
Mean experience of Asperger’s disorder	1	

notice boards and circulated through Australian autism services. The participants who responded were allocated to either the parents of children diagnosed with Asperger’s disorder group, allied health professional group, education professional group or the community member group. The community member group consisted of those who responded to the flyers but did not fit the criteria for the other groups. Participants allocated to the community group were from administrative, clerical and management positions in various organisations. Given the number of participants, two sessions were made available for each of the groups, resulting in a total of eight focus group discussions with participants only being allocated to the one group. The moderator for all groups was the principal author, with the moderator’s key role being the facilitation of discussion between the participants, which is consistent with guidelines recommended for conducting focus groups (Kitzinger, 2005).

At each group, participants were provided with a cover letter about the research, which explained the voluntary nature of participation and the procedure for ceasing

involvement. Prior to commencing the discussion the participants signed a consent form and completed a demographic information sheet, which included questions relating to gender, age, occupation, their level of experience with Asperger's disorder and their knowledge of the condition. The knowledge and experience questions required the participants to rate their level of knowledge and experience with Asperger's disorder on a rating scale 0 (*none*) to 5 (*a great deal*). Consistent with Wilkinson's (2008) recommendations for conducting focus groups, clear ground rules for all groups were discussed at the beginning of each session relating to the limits of confidentiality and the participants' right to only disclose what they felt comfortable in doing so. The use of audio recording equipment was explained.

The focus group sessions ranged between 70 to 90 minutes, with a series of questions developed by the principal author used as a guide for topics to cover. The questions were developed from an analysis of the literature relating to aetiology, characteristics and prognosis based on Gray's study (1995) of lay theories of autism. The questions were presented in an open-ended format to generate discussion between participants, with the first question relating to what participants thought Asperger's disorder was being put to all groups. The subsequent questions relating to aetiology, characteristics, treatment, educational needs, prognosis and labelling are detailed in Table 2 and were only presented to the focus groups if the topics were not naturally generated in discussion by the groups. As these questions were considered to provide a guide for the discussion, rather than a strict interview protocol, it was decided that piloting the questions was not required.

At the end of the discussions the participants were provided with an Autism SA information brochure on Asperger's disorder. This was provided to ensure participants left the session with accurate information on the condition.

### *Data Analysis*

Thematic analysis was used to 'identify, analyse and report patterns (themes) within the data' (Braun & Clarke, 2006, p. 79). As the researcher had familiarity with the subject area and was keen to explore particular concepts, a theory-led thematic analysis approach was adopted. This approach enables an exploratory position to be taken while coding for specific research questions (Hubermann & Miles, 1994).

The analysis process followed the guidelines provided by Hayes (2000) in conducting theory-led thematic analysis, with research questions around the causes, characteristics, areas of need and nomenclature being selected as the key research areas prior to explor-

**TABLE 2**

**Focus Group Guide Questions**

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Introduction: What do you think Asperger's disorder is?

Aetiology: What do you think causes Asperger's disorder?

Characteristics: What are the key characteristics of Asperger's disorder?

Treatment: How do you think Asperger's disorder can be managed and/or treated?

Education setting:

What type of education setting do you think a child with Asperger's disorder requires?

How do you think the current education system is working for those with Asperger's disorder?

Prognosis: What do you perceive the future would be like for a child with Asperger's disorder?

Additional question: What are your thoughts about a person having a diagnostic of label of Asperger's disorder?

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ing the interview data. These areas were selected by the principal researcher after reviewing the previous research on autism and autism spectrum conditions and considering the current interest in the proposed diagnostic changes for Asperger's disorder. The data were read and codes identified for each of the research questions, before rereading and reviewing the codes and grouping the like codes until themes were identified for each of the key research questions. An independent psychology-trained second rater familiar with thematic analysis techniques read the data relevant to the research questions to assist in refining the themes. The themes and codes reported here are those agreed on through a process of discussion and negotiation between the principal author and second rater.

## Results

Before describing the results of the focus group discussions, it is important to comment on the range of experience and knowledge of Asperger's disorder as self-reported by the participants on a scale of 0 (*none*) to 5 (*a great deal*) on the demographic information sheet. Parents of children diagnosed with Asperger's disorder reported a high level of knowledge and experience of Asperger's disorder (knowledge  $M = 3.1$ ,  $SD = 0.9$ , experience  $M = 2.75$ ,  $SD = 0.9$ ) and not unexpectedly the community groups reported a low level of knowledge ( $M = 1.4$ ,  $SD = 1.3$ ) and experience ( $M = 1.0$ ,  $SD = 1.4$ ). The educational professionals and allied health professionals reported a similar level of knowledge ( $M = 2.1$ ,  $SD = 1.3$  and  $M = 2.2$ ,  $SD = 1.7$ , respectively) and experience ( $M = 1.9$ ,  $SD = 1.3$  and  $M = 1.8$ ,  $SD = 2.5$ , respectively). This range in self-reported levels of knowledge and experience about Asperger's disorder was expected given the nature of the research population and was considered an important aspect in gaining a broader understanding of how this condition is perceived by a range of people.

From the focus group interviews the five themes of aetiology uncertainty, challenging behaviour, barriers in service provision, terminology confusion and label stigma were extracted from the data. These are discussed in turn in the following section.

### *Aetiology Uncertainty*

The first theme related to a level of uncertainty that was identified across the groups in their discussions around the causes of Asperger's disorder. While the groups identified genetic and neurological factors as causes, which are consistent with the current research consensus on the cause (McAlonan et al., 2008), numerous other factors were also discussed, with participants questioning pregnancy and birth-related factors, the role of parenting and environmental influences. Community group members nominated premature births to be a cause and parents of children with Asperger's disorder raised questions about the impact of pregnancy difficulties and delivery complications on the development of the condition, as evident in the following extract:

*P2: And like for us the whole pregnancy bit was difficult, the birth was difficult.*

*P3: I had difficulty with our son, at the birth, I had a drip and he didn't like it.*

*P4: He ended up in an emergency Caesarean section and we wonder if that contributed.*

*P1: See my pregnancy was fine and delivery was fine — although he took a long time to come out, I always wondered was it trauma to his head or whatever. (Parents, Group 6)*

There was also a focus on parenting skills, with the discussion in this area being somewhat reflective of the, now refuted, historical psychoanalytic belief that symptoms of autism arise from parenting interactions (Jacobsen, 2003):

*P5: Parents have doubted their belief and confidence to be parents and socially crippled their kids from interacting with their environment, subsequently the kids then appear to have Asperger's traits. (Health, Group 5)*

*P5: I also think some family dynamics like, some parenting, some expectations, setting limits. (Community, Group 3)*

*P4: Development of the wiring of the brain — through the attachment process. (Community, Group 2)*

Participants also raised concerns around environmental factors such as toxins, diet and immunisations in the development of Asperger's disorder:

*P1: There are screeds and screeds of evidence about toxification and nutrients deficiencies and our gut/brain connection. (Parents, Group 8)*

Uncertainty around the role of immunisation as a cause was also apparent, despite this being refuted as a cause in recent years (Rutter, 2005), with the following extract from the education group highlighting the ongoing uncertainty around immunisations:

*P5: I've spoken to some parents and they said there was a change in their child once they had their immunisations — I'm not sure if that is true?*

*P3: I've done some reading on general toxicity factors and alike and it seems to have been proved that immunisations don't cause autism conditions, but that is where the whole susceptibility comes into it and then there is the environmental issues happening and perhaps the vaccine for some children might be the last straw — I think this is the thinking about it as a last straw. (Education, Group 4)*

Within the theme of aetiology uncertainty, it was evident that participants hold a range of beliefs about the causes of Asperger's disorder. Despite participants being able to identify beliefs about the causes that are consistent with the current research views of genetic and neurological links, they currently still question the influences of pregnancy and birth complications, parental nurturing and environmental factors in the development of Asperger's disorder.

### **Challenging Behaviour**

Participants identified a range of characteristics that are considered to be consistent with the diagnostic criteria for Asperger's disorder, including social skills deficits, intense interests and challenges with emotional and social reciprocity (APA, 2000). The key theme that emerged when discussing the characteristics of Asperger's disorder, however, was not one of the key diagnostic characteristics but rather the identification of challenging behaviour. Challenging behaviour such as noncompliance, disrupting others, aggression, violence towards others and property damage were frequently mentioned:

*P5: They can be very emotional, get violent, get very upset and agitated. (Education, Group 1)*

*P2: We have had computers thrown, tables upturned and a lot of time they run out of the room and take off and you have to try and find them, not just within the school they will actually leave the school — just completely leave. (Education, Group 1)*

*P3: There have been times when I have had to physically restrain our son. (Parent, Group 6)*

When describing the behavioural challenges it was noted that the education staff and parents of children diagnosed with Asperger's disorder became particularly animated, with the participants talking simultaneously as they agreed with each other and competed against each other to provide additional examples of the challenging behaviour. While doing this, participants collectively agreed that the behavioural challenges faced by those with Asperger's disorder can result in opinions being formed about the child being naughty. This perception of the child as being naughty was not

considered by participants as being particularly beneficial to the child or those working with the child. It was, however, somewhat explained by the participants discussing the challenges they experience in differentiating between behaviours related to Asperger's disorder symptoms and the behavioural challenges related to normal child development:

*P7: I can't remember who I was talking to yesterday but someone said it would be good and handy if the Asperger's/autism behaviour changed colour — be bright red or purple — so you can see it — whereas if you are in a wheelchair people can see it all the time, wearing hearing aids they can see it, but it is a hidden disability, people say he has got Asperger's and he is just being naughty and there is no doubt that sometimes he will be naughty but how do we separate these. (Education, Group 4)*

*P4: And that is the other hard bit — to tell which bit is Asperger's and what is just a normal 10-year-old. (Parent, Group 6)*

While the identification of challenging behaviours, particularly externalised behaviours of violence and aggression, have been previously discussed in association with Asperger's disorder (McGill, Papachristoforou, & Cooper, 2006; Solomon, Ono, Timmer, & Goodlin-Jones, 2008), the robust nature of the discussion across the groups in this study indicates that this is still an area of current concern. The participants' discussion around the challenges faced in recognising the reasons for the child's behaviour also highlights the unique experiences of having what Portway and Johnson (2005) describe as a non-obvious disability.

### **Barriers in Service Provision**

Barriers in service provision refer to the challenges and difficulties that occur in the provision of and access to services for those with Asperger's disorder and their families across home, education, employment and community settings. In this study the barriers identified included a lack of funding, the availability and access to health professionals and the unique challenges health professionals encounter when providing therapy to clients with Asperger's disorder. In considering these areas in more detail, it is important to identify that participants displayed overwhelming support for children with Asperger's disorder to be educated in mainstream education systems, which is consistent with views expressed in previous research (Agyapong et al., 2010; Shah, 2001). While identifying this need for mainstream education the participants expressed concerns similar to those found in Brewin, Renwick and Fudge Schormans (2008) and Little's (2003) research, with the lack of financial funding being considered a barrier to provide the desired level of assistance at school:

*P2: If there was more financial support there would be people coming in and working with them for half the day but that sort of funding is just not available. (Education, Group 1)*

The participants also reported the lack of access to services due to high workloads of health professionals and the lack of availability of services in regional areas of Australia as being barriers to services for those with Asperger's disorder:

*P2: I think more support for parents is required in regional areas — as you don't have all those government services available. (Parent, Group 8)*

*P5: The health professionals are so strapped as well — like was said on the early intervention stuff — we know that early intervention makes the biggest difference so we focus on that end and then we don't have room to support kids that are in school. (Health, Group 7)*

The finding in relation to a lack of access and availability of services for those with Asperger's disorder in regional areas of Australia is not particularly surprising given the limited numbers of allied health professionals in the rural areas (Harvey & Hodgson, 1995; Mathews, Stokes, Crea, & Grenyer, 2010). The difficulties that the health profes-

sionals in this study reported experiencing in providing services to those with Asperger's disorder are, however, an underreported area. These difficulties relate to the stress of having to allocate additional time to work collaboratively with other agencies when working with clients diagnosed with Asperger's disorder:

*P5: I think each time I get a new allocation of an autism/Asperger child I have to do so much work with the school — it often takes 50% of the time I spend on that particular case and you just go over and over the same information and there has been a number of times. (Health, Group 5)*

As well as the stress of having to allocate additional time, health professionals also reported pressure associated with providing therapy to clients who experience deficits in social skills and often do not understand the unwritten rules around therapy. These unwritten rules relate to understanding reciprocal relationships, holding relevant conversations, regulating emotions, acting in a predictable manner and having some flexibility in the interactions. For health professionals these areas present unique challenges when working with clients who experience Asperger's disorder:

*P5: So if you are working with someone who is having trouble engaging with others and you have to think of all these things that engage them and then how are you going to get your goals met, as well at the same time you are trying to make it look like it is not work and that it is fun, so the child is interested in it as well — that is tiring. (Health, Group 7)*

*P7: You might just need to be a bit more careful about your non verbal cues and then the tone of your voice, the way you set up your room, transitioning between activities and just generally trying to make it look easy when it is hard. (Health, Group 7)*

*P5: You always have to be on your toes and trying to predict what will happen. (Health, Group 7)*

The identification of the challenges faced by health professionals in providing therapy for those with Asperger's disorder is considered to be an underreported area, particularly when compared to the array of literature detailing the difficulties that families of children with Asperger's disorder and those teaching them experience (Brewin et al., 2008; Hillman, 2006; Lasser & Corley, 2008). The combination of a lack of health professionals in rural areas, high work demands, the time required by health professionals to work collaboratively with other agencies when working with clients with Asperger's disorder and the challenges of managing the client's social skill deficits in the therapeutic setting are all reported to be barriers in the provision of services to those with Asperger's disorder. The perceived lack of financial support to increase support in mainstream education settings further compounds the challenges faced by those with Asperger's disorder and those working with them, particularly in regional and rural areas.

The final two themes relate to the participants' views on the label of Asperger's disorder, with participants across the professional and lay populations all expressing confusion about the range of terminology used around Asperger's disorder. They also discussed their views on the stigma they perceived to be attached to Asperger's disorder. Both of these themes are discussed in turn.

### *Terminology Confusion*

Given the range of terminology that is currently used around the condition of Asperger's disorder and the debate in the professional literature surrounding terminology, it is not surprising that the participants in this study expressed a level of confusion around the diagnostic labels and terminology being used to describe behaviours considered to be consistent with Asperger's disorder. The participants' confusion around Asperger's disorder related to their uncertainty around what terminology to use, diffi-

culties in differentiating between the differing labels and questioning as to whether the various terms are synonymous:

*P5: I often have difficulty interpreting what high functioning autism is and what is Asperger's. I think they are similar. (Health, Group 7)*

*P3: I find that really confusing between high function autism and Asperger's. (Education, Group 4)*

*P6: There has certainly been hot debate about is that on the autism spectrum or is that Asperger's or is it a reactive attachment disorder and some people clearly say that it is attachment disorder and not autism or Asperger's. (Health, Group 5)*

Uncertainty around terminology was also evident through the participants' framing some of their responses as questions directed towards the moderator and other participants:

*P4: Is it one child can have both autism and Asperger's disorder — I don't know? (Community, Group 3)*

*P5: There are different ranges of autism, isn't there? (Health, Group 5)*

*P3: Like everybody talks about a spectrum, but what is a spectrum? (Community, Group 2)*

As previously mentioned, this finding of terminology confusion is not particularly unexpected, given the professional debate around terminology that has occurred over a number of years. This study does, however, provide some evidence that the confusion around the terminology associated with Asperger's disorder goes beyond that of a literature debate that is restricted to professionals with specialist interests in this area to actually impacting on education and health professionals working in the field and the lay population.

### **Label Stigma**

The theme of label stigma refers to the level of stigma participants attach to the diagnostic label of Asperger's disorder. In this research, participants clearly identified that they considered the label of Asperger's disorder to be less severe and have less of a stigma attached to it than the label of autism:

*P4: Parents would be more accepting of Asperger's disorder and see autism as more severe and that they have got less capacity in the child with autism than Asperger's disorder. (Health, Group 5)*

*P6: Asperger's is milder — not as disabled. I know that sounds horrible but yeh kids with autism are severely disabled they can't interact with people at all, whereas Asperger's seems to have better social skills. (Health, Group 7)*

*P3: I don't think Asperger's name has a disability sort of status that autism has. (Education, Group 4)*

*P1: I think people tend to see Asperger's — they are not too bad there is nothing really wrong with them. (Parents, Group 6)*

The view that Asperger's disorder is perceived to be a less severe condition than autism suggests that despite the diagnostic commonalities between autism and Asperger's disorder they are perceived differently, particularly in relation to the stigma attached to them. It is, however, noteworthy that in this study the parents of children diagnosed with Asperger's disorder reported receiving increased sympathy from others when they described their child as having autism rather than Asperger's disorder:

*P4: You tend to get more recognition out of someone if you say that your son has high functioning autism than if you say Asperger's. (Parents, Group 6)*

*P1: When they hear autism they kind of have a little more empathy. They don't realise that Asperger's have just as huge difficulties as well. (Parents, Group 6)*

Some of the parents of children diagnosed with Asperger's disorder subsequently reported using the term of autism to explain their child's condition:

*P3: That is the way I describe it to people — when they say what is Asperger's — I say it is part of the autism range and that is when they click. (Parents, Group 6)*

The parents' use of the term autism to assist in explaining the significance of their child's condition is an interesting finding, as it has been suggested that due to the stigma associated with autism the change to the new diagnostic label of autism spectrum disorder will reduce the numbers of those seeking a diagnosis for their children (Wallis, 2009). The discussions in this study, however, indicate that the autism term has been of use to some parents involved in the focus group discussions.

## Discussion

Asperger's disorder is a complex condition that is often masked by a typical physical appearance but tends to become acutely obvious during social interactions. This study identified five themes relating to aetiology uncertainty, behaviour challenges, barriers in service provision, terminology confusion and label stigma.

Firstly, in relation to the perceived causes of Asperger's disorder, participants identified causes consistent with the commonly identified and currently validated causes of genetic and neurological links (Paxton & Estay, 2007; Woodbury-Smith & Volkmar, 2009). Participants also identified causes that have been refuted such as measles, mumps and rubella injections and loveless families with poor attachment (Jacobsen, 2003; Rutter, 2005). Further to these causes, they also proposed a range of causes that currently are not supported in research-based evidence, including diet, toxins, parenting, birth and pregnancy experiences. The finding of a broad range of views being held about the causes of Asperger's disorder is consistent with previous research on the perception of the causes of autism, in which a range of causes were proposed (Gray, 1995; Helps, Newsom-Davis, & Callias, 1999; Stone, 1987). It also reflects a concern expressed by Paxton and Estay (2007) about counselling those with autism spectrum, namely, that community members and professionals may hold differing beliefs about the causes, which in turn may impact on therapeutic decisions when working in a multi-agency and collaborative manner. This work suggests that a range of beliefs are held about the causes of autism and that further research would be beneficial to clarify if differing groups hold differing perceptions of the causes.

The second theme of challenging behaviour associated with Asperger's disorder is not a new finding, as volatile behaviour has been well documented in previous research (McGill et al., 2006; Moynahan, 2003; Paxton & Estay, 2007). What was interesting in this study was that the discussion around challenging behaviour occurred during conversations on what participants thought the characteristics of Asperger's disorder were. This connection of challenging behaviour with the characteristics of Asperger's disorder occurred despite behaviours of aggression, disruption, property damage and violence not being considered to be part of the diagnostic criteria for the condition. The participants' enthusiastic input into the discussion indicates that challenging behaviour in those with Asperger's disorder does appear to be of particular significance to parents of children with this diagnosis and education staff. Further research to explore how a range of people perceive the characteristics of Asperger's disorder and behavioural concerns

would be considered beneficial, particularly given the link between behavioural challenges and parental and teacher stress (Lecavalier, Leone, & Wiltz, 2006).

The third theme, barriers in service provision, revealed results consistent with previous research findings in relation to the perceived lack of financial support to enable additional staff to work with those with Asperger's disorder in mainstream education settings (Brewin et al., 2008; Little, 2003). The lack of access to health professionals in regional and rural areas was also perceived to be a barrier to those with Asperger's disorder being able to receive the desired support. In this study, the health workers discussed unique challenges that they face when providing therapy to clients with Asperger's disorder. These challenges related to the client's difficulties in seeking to engage in reciprocal interactions and in understanding the rules associated with therapy — with the rules of therapy referring to skills around engagement in conversations, personal space, predictability of behaviour and self-regulation. Health professionals in this study reported finding it challenging having to constantly self-monitor their own body language and verbal cues, while also monitoring the client's sensory needs, behavioural cues and anxiety levels.

While the pressures and challenges faced by staff and parents of children with autism spectrum disorder have been relatively well documented (Pas, Bradshaw, Hershfeldt, & Leaf, 2010; Lecavalier et al., 2006), the challenges described by the health workers in this study have received less attention. Those with specialist expertise working with clients with Asperger's disorder certainly have acknowledged the challenges of conducting therapy with those with Asperger's disorder (Attwood, 2003; Hare & Paine, 1997; Paxton & Estay, 2007), but away from these specialists the challenges are possibly not as well known by those working in community and privately based health services. Factors such as therapists having increased time for session preparation for these clients, increased access to visual-based resources, awareness of a range of therapy strategies to regulate emotions, knowledge and skills in managing sensory needs and developing perspective-taking skills are all important considerations. Additionally, extra time to enable collaborative interagency discussions was also identified as a factor that this preliminary study raised as possibly needing more consideration when working with clients with Asperger's disorder.

The last two themes relate to how participants perceive the label of Asperger's disorder, with terminology confusion and label stigma being identified as the themes. Participants expressed confusion around the terms of Asperger's disorder, autism spectrum disorder, autism and high-functioning autism, indicating uncertainty around when to use the various labels and what they mean. This confusion is not unexpected given the professional debate that has occurred in this area and it is somewhat supportive of one of the arguments given for modifying the diagnostic criteria in the new DSM (APA, 2010). In making this comment it is, however, important to acknowledge that the current DSM only actually has the three terms — autism, Asperger's disorder and PDD-NOS — with the additional terms emerging independent to the DSM. It will therefore be interesting to see if the proposed modifications in the labelling in the new DSM will streamline terminology in this area, resulting in less confusion, or if the range of current unofficial and official terminology will remain in general use.

The second theme associated with the perception of the label of Asperger's disorder related to label stigma, with the term of autism being perceived to have a greater stigma and disability level attached to it than that of Asperger's disorder. It was also interesting in this study to note that many of the parents reported regularly using the term of high-functioning autism to describe their child's condition regardless of the stigma attached.

They described the use of the autism term as resulting in an increased level of sympathy and understanding of the challenges experienced by the child than what they received when the label of Asperger's disorder was used.

The findings of uncertainty around the terminology used for Asperger's disorder and the apparent interchanging of terminology, particularly by parents, could be interpreted in two ways. This could be used to support the need for changes in the diagnostic terminology, to try and reduce the level of confusion and need to interchange terms. It could, however, also be used to suggest that more professional and community education is required in educating people about the differing labels and the needs of those with Asperger's disorder.

In conclusion, this focus group study has enabled a greater understanding of how a range of people view Asperger's disorder. The generalisations of the results are, however, limited by the exploratory nature of the study and the participants being regionally based. The perceptions of Asperger's disorder held by the participants may be different to the views held by those living in metropolitan and rural areas or other regional areas within Australia. The use of the theory-led thematic analysis also needs to be mentioned, as some might be critical of its use due to the risk of producing 'a less rich description of the data overall' (Braun & Clarke, 2006, p. 84). In this preliminary study it was deemed beneficial to use the theory-led method as it provided a clear focus on specific areas of the data.

Finally, the data obtained from this study will enable us to develop a quantitative questionnaire to further explore the beliefs about Asperger's disorder using a larger and more representative sample of health professionals, education professionals (teachers and classroom staff), community members and parents of children with Asperger's disorder.

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