

1 **“Leaps of Faith”: Parents’ and Professionals’ Viewpoints on**
2 **Preparing Adolescents on the Autism Spectrum for Leaving**
3 **School**

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Abstract

21 **Background:** Adolescents on the autism spectrum experience difficulty transitioning from
22 secondary school to post-school activities, often due to transition planning processes that do
23 not meet their unique needs. This study identified parents' and professionals' viewpoints on
24 transition planning for adolescents on the autism spectrum.

25 **Methods:** Interviews were completed with nine parents of adolescents on the autism
26 spectrum and four professionals who worked with adolescents on the autism spectrum. A
27 constant comparison approach was used to analyse the transcripts.

28 **Results:** Four themes were identified, reflecting parents' and professionals' viewpoints on
29 how to meet the transition planning needs of adolescents on the autism spectrum.

30 Supporting adolescents *to grasp the big picture* can enhance motivation to participate in
31 transition planning. Autism can be an 'invisible disability'; therefore encouraging adolescents
32 to be active participants and *to be seen* in transition planning ensures their individual needs
33 are met. Encouraging adolescents *to have high aspirations* in transition planning develops
34 their self-determination. Finally, *to be prepared* for the transition from school may reduce the
35 adolescents' anxiety.

36 **Conclusions:** Adolescents on the autism spectrum face unique challenges in transition
37 planning. The themes identified in this study provide insight into how parents and
38 professionals might support adolescents with these challenges.

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40 **Key words:** Asperger Syndrome, Autism Spectrum Disorder, disability, employment,
41 interviews, transition planning.

Authors' contribution

MH, MC, TF, MF contributed to the design of the study. MH collected the data and drafted the manuscript. MH, MC, TF, MF reviewed the manuscript. The manuscript has been read and approved by all authors.

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Introduction

Transition planning in secondary school involves preparing adolescents for leaving school and moving into activities such as vocational training, tertiary education, and employment (Cobb & Alwell, 2009). It involves setting goals and engaging the adolescent in activities that will teach them skills so that they feel confident about leaving school. When transition planning is undertaken in secondary school, it can assist adolescents to successfully negotiate the move from school into adult life (Hagner et al, 2012). Transition planning can lead to improved self-determination, increased rates of employment, enhanced success in post-secondary settings, greater happiness, and improved participation in the community (King, Baldwin, Currie & Evans, 2005; Wei, Wagner, Hudson, Yu & Javitz, 2016).

A lack of transition planning is a common barrier to successful employment for adolescents on the autism spectrum (Morningstar & Clark, 2003). Autism is characterised by difficulties in socialisation and communication, as well as restricted interests and repetitive behaviours (American Psychiatric Association, 2013). People with autism have difficulties coping with change due to a preference for routines; even minor changes in the environment and daily activities can cause anxiety (Test, Smith & Carter, 2014). Therefore, periods of transition can be difficult, and during these times there is a need for strong preparation and communication to ensure anxiety is reduced (Dann, 2011). Transition can be even more difficult for adolescents on the autism spectrum who do not have an intellectual disability (ID), as schools tend to focus on academic performance rather than on engaging in transition planning (Lee & Carter, 2012). As a result, these adolescents often do not successfully transition to employment; only 16% of adolescents on the autism spectrum without an ID in Australia are employed full-time after leaving school, with 33% being employed part-time (Neary, Gilmore & Ashburner, 2015). Those who do have a job are often under-employed

and in roles that do not reflect their level of education (Cederlund, Hagberg, Billstedt, Gillberg & Gillberg, 2008; Howlin, Goode, Hutton & Rutter, 2004). In addition, young adults on the autism spectrum without ID are three times less likely to have post-school vocational activities when compared to their peers on the autism spectrum who have an ID (Taylor & Seltzer, 2011). This contradicts the common assumption that adolescents on the autism spectrum without ID have better outcomes because of their intellectual abilities. Parents of adolescents on the autism spectrum have reported that the most serious problems arose when their adolescents were transitioning from secondary school, and that they felt unsupported in transition planning (Browning, Osborne & Reed, 2009). People with autism often do not qualify for adult services, and few adult services have the specialised knowledge to meet the needs of people on the autism spectrum (Chen, Leader, Sung & Leahy, 2015; Rydzewska, 2012). In addition, little is known about the effectiveness of adults employment support programs, with current evidence limited by small sample sizes, lack of randomisation and control groups, and poor conceptualisation of outcomes (Hedley et al, 2016). Overall, transition is a difficult period for adolescents on the autism spectrum (Benitez, Morningstar & Frey, 2009).

One reason for the difficulty transitioning out of school could be that individuals on the autism spectrum without an ID have unique transition planning needs that are currently not being met. While neurotypical adolescents reported feeling stressed about academic achievement; adolescents on the autism spectrum reported stress concerning getting a job, interpersonal relationships and transport, and also reported feeling that they were likely to fail in the future (Browning et al, 2009). This suggests that adolescents on the autism spectrum may have poor self-determination, a key predictor of successful transition into an independent adult life (Sands & Wehmeyer, 1996). In addition, one study in the United States

of America (USA) found that even when general transition planning requirements were met, adolescents on the autism spectrum still experienced inferior outcomes in comparison to other disability groups (Cameto, Levine & Wagner, 2004; Newman et al, 2011). Parents of adolescents on the autism spectrum have reported feeling more worried about the transition from school than parents of children with other disabilities (Blacher, Kraemer & Howell, 2010). They are less likely to perceive the transition planning process as being useful (Shogren & Plotner, 2012), and more likely to report that they would have liked to be more involved in the process (Blacher et al, 2010; Cameto et al, 2004). These results indicate that adolescents on the autism spectrum have unique transition planning needs, and further research needs to be conducted to determine what these unique needs are.

Two groups that often are involved in the transition planning process for adolescents on the autism spectrum are their parents and the professionals who work with them. However, there is very little research exploring their viewpoints on the transition planning process. One study examined barriers and facilitators of transition planning for adolescents on the autism spectrum (Havlicek, Bilaver & Beldon, 2016). However it focused specifically on youth in foster care. Further to this, most current research exploring the transition planning needs of adolescents on the autism spectrum is from the USA (Ankeny & Lehmann, 2010; Cameto et al, 2004; Cheak-Zamora et al, 2015; Nuehring & Sitlington, 2003; Weidenthal & Kochhar-Bryant, 2007). Given the legislative differences between countries, there is a need to explore this topic in an Australian context. Overall, there is a gap in the literature exploring parents' and professionals' viewpoints on preparing adolescents on the autism spectrum for leaving school.

Aim

To investigate views about the transition process for adolescents on the autism spectrum from the perspectives of their parents and the professional staff who assist in this process.

Methods

This study sought parents' views of transition planning for adolescents on the autism spectrum, and how they make sense of the transition planning process. Therefore, the literature was reviewed after data collection to minimise assumption or conjecture in interpreting results and to maintain an openness (Bailey, 1997).

This study included parents/carers of adolescents and young adults on the autism spectrum without a diagnosis of ID, and professional staff that were involved in the transition planning process for this group. Study participants were recruited from across Australia via dissemination of study information on the websites of autism service providers; local autism advocacy groups; at conferences and community events; and via government and non-government secondary schools in Western Australia.

Participants who consented to be interviewed were a subset of respondents to an online survey about transition planning for adolescents on the autism spectrum. At the end of the online survey, respondents had the opportunity to nominate their interest in participating in the interviews. Thirty parents indicated in the survey that they would like to participate in an interview. These parents were contacted in a random order generated in Microsoft Excel. Nine parents were interviewed before saturation was reached, or when the collection of additional data did not reveal any new issues (Liamputtong, 2013), so no further parents were interviewed. Six professionals who completed the survey indicated that they

would like to participate in an interview. The first author contacted all six professionals; two declined and four agreed to be interviewed.

Adolescents and young adults on the autism spectrum were invited to complete the online survey to provide their information about their experiences in transition planning, the results of which are reported elsewhere (Hatfield, Ciccarelli, Falkmer & Falkmer, 2016).

Nine guiding questions were used in the semi-structured interviews (see Figure 1), along with interview techniques such as probing and cross-checks (Taylor & Bogdan, 1998). The interview guide was applied in a flexible way depending on the participants' role and experience in the transition planning process. Interviews were completed either by telephone or conducted in person. The duration of the interviews ranged between 30 and 60 minutes.

Insert Figure 1 about here

Interviews were audio-recorded, transcribed verbatim and analysed using NVivo 10 to identify key themes that emerged from the data. Transcripts were read several times by the first author and initial codes were developed and labelled by category; these were further condensed or sorted into sub-categories as needed (Liamputtong, 2013). The constant comparison approach was used to refine themes within and between the transcripts, and emergent themes were named and revised by the first author and peer-reviewed by the co-authors (Harding, 2013).

A number of steps were taken to improve the trustworthiness of the data. An in-depth description of the study participants is provided in Table 1 and data collection methods are described in detail above, to provide sufficient detail to allow readers to determine the extent to which the current research is applicable to other settings (Lincoln &

Guba, 1985; Shenton, 2004). Use of a purposive sample (i.e., parents and professionals with first-hand experience in the transition planning process) further improved the transferability of the study findings. Dependability and credibility of the findings were improved through peer examination of the data to ensure 'fresh perspectives' on emergent themes, and through the use of an audit trail during data coding (Shenton, 2004). In addition, a journal was kept by the primary researcher to practice reflexivity and to improve confirmability of the findings.

Ethics approval was obtained from Curtin University Human Research Ethics Committee in Western Australia (approval number HR110/2014), the Catholic Education Office of Western Australia, and the Western Australian Department of Education. Informed written consent was provided by all participants. This consent procedure was approved by all aforementioned ethics committees. An Adverse Events Management Plan was utilised, which included steps to follow if a participant became distressed during interviews and general information about how interviewees could seek support following the interview, if required.

Results

Participants

Thirteen participants were interviewed for this study. A detailed description of the nine parents (mothers= 8; fathers= 1) and four professionals is provided in Table 1. Parents were mainly from Western Australia (WA), with two from Queensland (QLD). Their adolescent children were majority male and still in secondary school, two parents had adolescents who had recently left school. Professionals were all from WA, and had a range of job titles and experience working with adolescents on the autism spectrum, ranging from three years to 13 years.

Insert Table 1 about here

Themes

Four core themes were derived from the interviews; *to grasp the big picture*; *to be seen*; *to have high aspirations*; and *to be prepared*. Each represents the participants' experiences and viewpoints on transition planning with adolescents on the autism spectrum. Data analyses revealed considerable agreement between parents and professionals, and therefore the data were considered together and the themes are representative of both groups.

To grasp the big picture

Grasping the big picture was described by parents and professionals as the ability to anticipate how current actions may influence future prospects, and hypothesising what life might be like after school. For example, understanding what might be involved in a job or what skills might be needed to live out of home: *"He needs to understand what's going to happen after school and what will be expected of him as an adult"* (Parent 7). Participants described how their experience was that adolescents on the autism spectrum may not understand these concepts intuitively, and that this may impact on their motivation to engage in the process of planning for their future. One parent described how her son appeared content to imagine a future where he continued living at home and did not have a job, because this was the current situation; *"He's not very receptive to the idea of one day having to provide for himself 'cause he's quite comfortable where he is; he doesn't have the big picture"* (Parent 2). This parent described how part-time work provided her son with the motivation to engage in transition planning. Part-time work helped her son to understand

the intrinsic reward related to being productive in the workplace and earning one's own money. Participants described how supporting adolescents to understand the big picture motivated the exploration of new opportunities in the community and active involvement in transition planning.

Real-life experiences emerged as the best way of assisting adolescents to see the big picture. Volunteering, work experience, part-time work, and after-school community activities were all powerful tools for providing adolescents with insight into life after school. These activities also assisted adolescents to develop life and employability skills, and promoted autonomy, self-esteem and resilience. Volunteer work and community activities provide an opportunity to learn skills without too much pressure and were perceived as a stepping stone into paid employment. Part-time work after school or on weekends was sometimes seen as "unrealistic" for adolescents on the autism spectrum, but was described as an important part of teenage development:

"Neurotypical teenagers are expected to get a job of some form around fourteen or fifteen, you know they're working for two or three years of their high [secondary] school life, and they're much better set up when they leave school" (Professional 4).

Overall, the importance of real-life experiences in transition planning could not be overstated, *"It's more difficult to have less experience no matter if you have a diagnosis or not"* (Professional 3).

Career exploration was also described as helpful to assist adolescents to see the big picture, including activities such as exploring higher education options, meeting people working in the area of interest and having a mentor. Life and employability skills training in areas such as personal care, social skills and organisational skills was also reported to assist the adolescents' understanding of what life would be like after school.

To be seen

To be seen was an important theme that emerged from the study, as autism was described as an invisible disability by both parents and professionals, that is not immediately apparent to an everyday observer, *"The biggest thing is they look so normal and they can sound for the most part very normal, until you know them well enough ... it's the invisible disability"* (Parent 4). Therefore, adolescents on the autism spectrum without an ID often *'fly under the radar'* because they appear to be coping well and do not receive support to prepare for leaving school. This leads to a feeling of helplessness and abandonment: *"It's a black hole. The Abyss... And that's the time the parents are least equipped for"* (Parent 3). Participants described how each adolescent on the autism spectrum is unique and multi-faceted, emphasising the importance of individualising the transition planning process to the person, rather than using a generic approach: *"He doesn't fit a box"* (Parent 3).

To ensure the adolescent is seen and supported as the unique individual they are, it is important to include the adolescent on the autism spectrum in the transition process. Involving the adolescent gave them a sense of control and therefore increased their motivation to participate: *"The more input that he has, the more likely he is to want to do it ... he needs to feel that he has control"* (Parent 7). Participants suggested strategies to assist the adolescent to successfully participate in transition planning, which included; discussing the agenda with the adolescent prior to the meeting, and providing the adolescent with choices about where meetings are held, who attends, and how they want to communicate in the meeting. In addition, the team should also alter their communication style to meet the adolescent's needs, taking into account learning styles, ensuring questions are concrete and providing choices in discussions.

To have high aspirations

Participants described the value of encouraging the adolescent *to have high aspirations* and supporting them to aim high: *"We look at whatever the student's dream is and help them so that they can achieve that ... we never say anything's impossible"* (Professional 2). Adolescents were more engaged and motivated when the focus was on their aspirations, and this increased the chance of success post-school. An optimistic approach was helpful, in which "failures" were viewed as learning experiences:

"That their mindset is in a positive mode, where rather than looking at it as 'Oh, God, this is just another thing that I've got to, that I can't do'; looking at it as 'This is something that I haven't learnt how to do yet' " (Parent 5)

Having high expectations was important for developing the adolescent's self-determination and resilience: *"We always encouraged him to take those leaps of faith and we're always there to help him if he fails, but never took the experience of failing away from him ... High expectations but flexible"* (Parent 3). Another important part of having high aspirations was supporting the adolescent to feel they could change their mind, and that there was more than one way to achieve their aspirations:

"We've talked about the different pathways to get to one point, but we said all of those pathways can give you lots of different options, so it's not an issue if you change your mind about what you want to be part way through. Yeah, he's feeling like 'oh you know it's only gonna be good' " (Parent 7).

To be prepared

Participants reflected on the importance of *being prepared* for leaving school. This included starting transition planning early, because adolescents on the autism spectrum: *"Suffer from much higher anxiety than the average child, so to be forewarned is to be prepared, so that would help lower their anxiety"* (Parent 1). Parents and professionals felt that formal

transition planning should start in Years 9 or 10 and should involve planning the pathway for the last few years of secondary school; choosing subjects, planning further study and developing a career plan. Informal transition planning should start in primary school; working on life skills, resilience and self-advocacy.

Having a clear process for the transition period was also important: *"A flowchart of activities they go through, a suggested timeline of how long things take"* (Professional 3).

According to participants, the transition planning process should include setting goals, which keeps everyone task-orientated and on track. Goals were perceived as particularly important for adolescents on the autism spectrum, as they assist them to understand the big picture. However, goals must be broken down, as participants reported that adolescents on the autism spectrum preferred this so that they could understand the smaller concrete steps required and see that they are making progress towards their goal.

Having a team of people around the adolescent was an integral part of preparing for leaving school. A strong transition team was described as cohesive and collaborative, with each team member providing a different, but equally useful, perspective. Parents were regarded as pivotal team members because in their view they need to drive the process and advocate for their child. The team should also include community members and other people in the adolescent's natural networks: *"They've got their networks and realising who's in their community who can support them"* (Professional 2).

Discussion

The findings of this study provide insight into the unique challenges that adolescents on the autism spectrum face in transition planning from the perspective of parents and professionals. These included; difficulty seeing the big picture, the 'invisibility' of their

diagnosis leading to a lack of support, and anxiety which can be heightened by the prospect of leaving school. The four key viewpoints represent how parents and professionals felt they may be able to assist adolescents to overcome these difficulties, which include supporting adolescents *to grasp the big picture, be seen, have high aspirations and be prepared*. This is one of the first studies to identify the unique factors that assist transition planning for adolescents on the autism spectrum; previous studies have mostly explored transition planning experiences of adolescents with other disabilities, such as intellectual disability or developmental delay (Ankeny & Lehmann, 2010; Lindstrom et al, 2007; Weidenthal & Kochhar-Bryant, 2007). There are some commonalities between the findings in these studies and the current study, including the importance of setting goals, participating in community-based experiences and encouraging adolescent participation in transition planning. Some studies have explored transition planning for adolescents on the autism spectrum in the USA (Cheak-Zamora et al, 2015; Giarelli & Fisher, 2013). These studies also describe how transition planning can increase anxiety for adolescents on the autism spectrum, and that motivation for this group can be challenging. However, the findings of the current study highlight some unique transition planning viewpoints that may be specific to parents of and professionals who work with adolescents on the autism spectrum in an Australian context.

To grasp the big picture was a new finding from this study, which has not previously been discussed in the literature. This might be because this is an issue that is specific to adolescents on the autism spectrum, who may not intuitively understand the big picture due to their difficulties with gestalt processing, or the tendency to focus on the details rather than the whole, meaning they can miss the overall meaning or significance in a task (Brosnan et al, 2004). This may result in a difficulty understanding why an activity like part-time work may assist them with gaining a job after school, hence reducing motivation to participate in

transition planning. In addition, adolescents on the autism spectrum struggle with abstract thinking (Fullerton, Stratton, Coyne & Gray, 1996), and consequently may not be able to conceptualise what life may be like after school. Difficulties with abstract thinking and gestalt processing are distinct characteristics related to autism, and therefore a focus on the big picture could potentially be lacking in current transition planning processes, which are generic and not tailored specifically for adolescents on the autism spectrum. To develop understanding of life after school, participants recommended that adolescents should engage in real-life experiences, such as volunteering, work experience, part-time work, after-school community activities and having a mentor. Participants described how these real-life activities provided adolescents with concrete, hands-on experience of what life might be like after school, hence increasing their understanding of the need for transition planning and developing their self-determination. This in turn enhanced adolescents' motivation to participate in transition planning.

Another key viewpoint for adolescents on the autism spectrum is *to be seen*, and to be actively involved in the transition planning process. Student involvement in transition planning is linked to greater success post-school (deFur, 2003), as well the development of self-determination (Test, Smith & Carter, 2014). When adolescents are actively involved in transition planning they are more likely to take ownership of their post-school plans, leading to increased autonomy, relatedness and competence, all of which promote intrinsic motivation (Ryan & Deci, 2000). Furthermore, goals that are determined by the adolescent themselves are linked to increased motivation and persistence in reaching that goal (Cuskelly & Poulsen, 2012). This is especially relevant to adolescents on the autism spectrum, as motivation to participate in transition planning has been identified as a significant barrier (Cheak-Zamora et al, 2015). Autism is often an invisible disability, making it difficult to for

adolescents to get the support they need during the transition planning process. The concept of autism as an invisible disability has not been explored in-depth in the transition planning literature to date; however it is acknowledged that adolescents on the autism spectrum without an ID frequently lack access to formal post-school services (Lee & Carter, 2012). Participants described strategies to support adolescents on the autism spectrum to be actively involved in transition planning. Strategies included preparing the adolescent for what to expect and providing choices in relation to meeting location, attendees and their communication method in the meeting. These strategies augment another recent study, which affirms the use of preparation, flexible meeting agendas and alternative means of communication as key to increase participation for adolescents on the autism spectrum (Hagner, Kurtz, May & Cloutier, 2014). Further research on this topic should explore the perspective of adolescents on the spectrum in regards to active participation in transition planning meetings, and further strategies that they feel would support in this process.

To have high aspirations was another crucial theme that emerged from this study. There is a strong relationship between high expectations and improved employment outcomes amongst people on the autism spectrum, as well as in the general population (Grigal, Hart & Migliore, 2011; Hagner et al, 2012; Lee & Carter, 2012). In addition, having a strengths-focus has been found to increase success in post-school avenues (Browning, Osborne & Reed, 2009; Hagner et al, 2014; King et al, 2005). However, there is evidence that parents of adolescents on the autism spectrum have lower expectations for their children (Ivey, 2004), and interestingly participants in this study focused more on what issues arose related to autism and transition planning, rather than the unique strengths of the adolescents. Parents who have low expectations may not provide their children with opportunities to develop life skills and the sense of self-determination required for

successful transition (Hagner et al, 2012). For example, some parents of children on the autism spectrum may remove their children from social, academic or employment situations because these may cause stress for their children; inadvertently reducing exposure to important social- and resilience-building opportunities (Marriage, Wolverton & Marriage, 2009). Therefore, it is particularly important to support adolescents on the autism spectrum *to have high aspirations* and have high expectations during transition planning.

To be prepared is particularly important for adolescents on the autism spectrum, as they frequently experience high levels of anxiety associated with transition, change and unpredictability (White et al, 2009). This anxiety is likely to be amplified by the uncertainty of not knowing what will happen after leaving school. Therefore, early preparation and having a plan is expected to assist in reducing uncertainty and anxiety. The important elements of being prepared were to have clear and concrete goals and a strong team, all of which have been linked to improved transition outcomes (Hagner et al, 2014; Nuehring & Sitlington, 2003; Taylor-Ritzler et al, 2001). Having a team is important for increasing feelings of relatedness, and achieving goals increases competence, all important elements for developing a strong sense of self-determination (Ryan & Deci, 2000).

Goals are also important, because the range of choices available after school may be overwhelming for people on the autism spectrum who have difficulty with uncertainty and prefer a pre-determined path. Setting goals is associated with increased odds of attending college after secondary school for adolescents on the autism spectrum (Wei et al, 2016). Having a clear plan with defined goals breaks the task of transition planning into manageable portions, and provides the adolescent with a sense of progress, appealing to the adolescents' preference for concrete and tangible steps (Fullerton et al, 1996). Goal setting

may also lead to increased motivation to participate in transition planning due to greater ownership of the plan, and increased self-determination (Martin & Williams-Diehm, 2013).

The findings of this study reflect the viewpoints of parents and professionals, and therefore it is important to consider how their views may differ from those of adolescents on the autism spectrum. Waltz (2005) describes how professionals may describe experiences from a position of power, and parents may present their viewpoints in alignment with a deficit-based and normalcy paradigm, rather than one of acceptance. Parents and professionals may also have different views, with an example being what term should be used to describe autism; whilst people with autism and parents preferred the term 'autistic', professionals endorsed the term 'people with autism' (Kenny et al, 2015).

A recent shift in autism literature advocates movement away from deficit-based discourse to supporting people on the autism spectrum to embrace their unique culture and diversity (Jaarsma & Welin, 2012). Whilst parents and professionals in this study advocated for the individualisation of transition planning and high expectations, they also placed importance on adolescents developing skills for life, employment, and social situations. These are skills that are valued in Western society, and therefore the underlying presumption is that adolescents on the autism spectrum need to change their behaviours to better fit norms and social expectations. An alternate perspective is that the focus should shift from the individual to society, and how workplaces and post-secondary institutions can modify environments to be more 'autism-compatible' (Jaarsma & Welin, 2012). Prior studies support the view that the environment plays a significant factor in supporting people with autism to successfully transition from school (Ankeny & Lehmann, 2010; Giarelli, Ruttenberg & Segal, 2013). These studies also suggest that adolescents have some similar views to parents and professionals, such as the importance of being prepared, having a strong team, and being

actively involved in the process (Ankeny & Lehmann, 2010; Giarelli & Fisher 2013; Giarelli, Ruttenberg & Segal, 2013). Adolescents in these studies had similar aspirations to those in the current study, including wanting to go to college and get a job, and they perceived their personal characteristics as presenting both barriers (social skills, sensory preferences) and facilitators (cognitive abilities, kindness) to achieving these goals. Therefore, there are likely to be similarities and differences between the views of parents and professionals, and adolescents, which require further exploration.

Most of the parents who participated in this study were mothers, who perceived that the responsibility for transition planning was often left to them. They felt it was their role to advocate for their child, to organise team meetings, and to follow-up on goals. The pressure felt by mothers is also apparent in how they often feel scrutinised by services to ensure they are meeting their child's 'needs' (Goodley & Runswick-Cole, 2011). Traditional gender roles are still apparent in the differences between how mothers and fathers respond to having a child with autism. Mothers take the role of the active carer in daily matters and this directly impacts on their emotional well-being (Gray, 2003). In contrast, fathers describe feeling concerned about their child's future, but that this has less of an impact on their emotional well-being. It appears that traditional gender roles may be present in transition planning, with the mother often taking the leadership role in supporting their adolescent on the autism spectrum to prepare for leaving school.

It is important to acknowledge the complexity of transition, and the many factors that contribute to the outcome of transition from secondary school to post-school activities. Contextual determinants of expectations for young people have evolved in the past few decades, including enhanced educational opportunities, shifting cultural norms for women, and increased inclusion and participation opportunities for people with disabilities

(Asbjørnslett, Engelsrud & Helseth, 2015; Crider, Calder, Bunting & Forwell, 2015). This has led to life stages becoming increasingly blurred, with significant shifts in the times of expected milestones for young people that no longer follow cultural or social expectations (Rydzewska, 2012). The themes presented in this paper represent the participants' experience of transition planning related to leaving secondary school, and cannot represent the entirety of the influences that may impact on the outcomes in transition to adult life.

Limitations

The study information was disseminated to potential participants across Australia; however, most interview participants came from one state; Western Australia. As education is managed at a state government level, there may be differences in school transition planning processes between states. This could limit the generalisability of our findings.

Only six of 53 professionals who participated in the survey indicated an interest in being interviewed, and only four actually participated in the interviews. Therefore, fewer professionals were interviewed than parents, when ideally it would have been preferable to have a more even range of participants.

Conclusion

This study identified viewpoints related to the unique transition planning difficulties faced by adolescents on the autism spectrum from the perspective of parents and professionals. These include supporting adolescents to grasp the big picture; be seen; have high aspirations; and be prepared. It is suggested that future studies explore the viewpoints of adolescents on the autism spectrum in relation to transition planning, and how these compare to the views of parents and professionals.

Recommendations for Future Research

Including young people on the autism spectrum in interview-based research is crucial to ensure their voice is heard (Harrington, Foster, Rodger & Ashburner, 2014), and therefore it is recommended that future research related to transition planning focuses on using more in-depth methodologies to obtain insights from adolescents on the autism spectrum.

Techniques to support this group to participate in interviews include preparation during pre-interview home visits; and questions that embed visual supports, provide concrete examples and allow for extra time to respond (Harrington, Foster, Rodger & Ashburner, 2014). Other methods that have been successfully utilised are 'walking interviews' that include walking around a location relevant to the topic whilst taking photographs of important landmarks; 'activity based' interviews that involve discussions using activities such as drawing (Winstone, Huntington, Goldsack, Kyrou & Millward, 2014); and card sorting activities (Shepherd, 2015) or Q-sorts (Cross, 2005).

References

- Asbjørnslett, M., Engelsrud, G. H., & Helseth, S. (2015) 'How children with disabilities engage in occupations during a transition phase.' *Journal of Occupational Science*, 22, pp. 320-333.
- American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders* (5th edn). Arlington, VA: American Psychiatric Publishing.
- Ankeny, E. M. & Lehmann, J. P. (2010) 'Journey toward self-determination: Voices of students with disabilities who participated in a secondary transition program on a community college campus.' *Remedial and Special Education*, 32 (4), pp. 279-289.
- Bailey, D. M. (1997). *Research for the Health Professional: A Practical Guide* (2nd edn). Philadelphia: F. A. Davis Co
- Benitez, D., Morningstar, M. & Frey, B. (2009) 'A multistate survey of special education teachers' perceptions of their transition competencies,' *Career Development and Transition for Exceptional Individuals*, 32, pp. 6-16.
- Blacher, J., Kraemer, B. & Howell E. (2010) 'Family expectations and transition experiences for young adults with severe disabilities: does syndrome matter?' *Advances in Mental Health and Learning Disabilities*, 4, pp. 3-16.
- Brosnan, M. J., Scott, F. J., Fox, S. & Pye, J. (2004) 'Gestalt processing in autism: failure to process perceptual relationships and the implications for contextual understanding.' *Journal of Child Psychology and Psychiatry*, 45 (3), pp. 459-469.
- Browning, J., Osborne, L. & Reed, P. (2009) 'A qualitative comparison of perceived stress and coping in adolescents with and without autistic spectrum disorders as they approach leaving school.' *British Journal of Special Education*, 36, pp. 36-43.
- Cameto, R., P. Levine & M. Wagner (2004) *Transition planning for students with disabilities. a special topic report of findings from the National Longitudinal Transition Study-2 (NLTS2)*. Menlo Park, CA: SRI International.
- Cederlund, M., Hagberg, B., Billstedt, E., Gillberg, I., & Gillberg, C. (2008) 'Asperger syndrome and autism: A comparative longitudinal follow-up study more than 5 years after original diagnosis.' *Journal of Autism & Developmental Disorders*, 38, pp. 72-85.
- Cheak-Zamora, N., Teti, M. & First, J. (2015) "'Transitions are scary for our kids, and they're scary for us': family member and youth perspectives on the challenges of transitioning to adulthood with autism.' *Journal of Applied Research in Intellectual Disabilities*, 28 (6), pp. 548-560.
- Chen, J., Leader, G., Sung C., & Leahy, M. (2015) 'Trends in employment for individuals with autism spectrum disorder: A review of the research literature.' *Review Journal of Autism and Developmental Disorders*, 2, pp. 115-127.
- Cobb, R. B. & Alwell, M. (2009) 'Transition planning/coordinating interventions for youth with disabilities: A systematic review.' *Career Development and Transition for Exceptional Individuals*, 32, pp. 70-81.
- Crider, C., Calder, C., Bunting, K., & Forwell, S. (2015) 'An Integrative Review of Occupational Science and Theoretical Literature Exploring Transition.' *Journal of Occupational Science*, 22 (3), pp. 304-319.
- Cross, R. M. (2005) 'Exploring attitudes: the case for Q methodology.' *Health Education Research*, 20 (2), pp. 206-213.

- Cuskelly, M. & Poulsen, A. (2012) 'Children's understanding of purpose: A matter of choice.' In J. Ziviani, A. Poulsen, M. Cuskelly and A. Hayes (eds), *The Art and Science of Motivation : A Therapist's Guide to Working with Children*. pp. 59-89. London: Jessica Kingsley Publishers.
- Dann, R. (2011) 'Secondary transition experiences for pupils with Autistic Spectrum Conditions (ASCs).' *Educational Psychology in Practice*, 27 (3), pp. 293-312.
- deFur, S. (2003) 'IEP transition planning-from compliance to quality.' *Exceptionality*, 11 (2), pp. 115-128.
- Fullerton, A., Stratton, J., Coyne P. & Gray, C. (1996) *Higher Functioning Adolescents and Young Adults with Autism*. Austin, Texas: Pro-ED, Inc.
- Giarelli, E. & Fisher, K. (2013) 'Transition to community by adolescents with Asperger syndrome: Staying afloat in a sea change.' *Disability and Health Journal*, 6 (3), pp. 227-235.
- Giarelli, E., Ruttenberg, J. & Segal, A. (2013). 'Bridges and Barriers to Successful Transitioning as Perceived by Adolescents and Young Adults With Asperger Syndrome.' *Journal of Pediatric Nursing*, 28 (6), pp. 563-574.
- Goodley, D. & Runswick-Cole, K. (2011) 'Problematizing policy: conceptions of 'child', 'disabled' and 'parents' in social policy in England.' *International Journal of Inclusive Education*, 15 (1), pp. 71-85.
- Gray, D. (2003) 'Gender and coping: the parents of children with high functioning autism.' *Social Science & Medicine*, 56 (3), pp. 631-642.
- Grigal, M., Hart, D., & Migliore, A. (2011) 'Comparing the transition planning, postsecondary education, and employment outcomes of students with intellectual and other disabilities.' *Career Development and Transition for Exceptional Individuals*, 34 (1), pp. 4-17.
- Hagner, D., Kurtz, A., Cloutier, H., Arakelian, C., Brucker, D. L. & May, J. (2012) 'Outcomes of a family-centered transition process for students with autism spectrum disorders.' *Focus on Autism and Other Developmental Disabilities*, 27 (1), pp. 42-50.
- Hagner, D., Kurtz, A., May, J. & Cloutier, H. (2014) 'Person-centered planning for transition-aged youth with autism spectrum disorders.' *Journal of Rehabilitation*, 80, pp. 4-10.
- Harrington, C. Foster, M. Rodger, S. & Ashburner, J. (2014). 'Engaging young people with Autism Spectrum Disorder in research interviews.' *British Journal of Learning Disabilities*, 42, pp. 153-161.
- Harding, J. (2013) *Qualitative Data Analysis from Start to Finish*. London: Sage Publications Ltd.
- Hatfield, M. Ciccarelli, M. Falkmer, T. and Falkmer, M. (2016) 'Need for comprehensive transition planning for adolescents with high functioning autism in Australia.' *Journal of Research in Special Educational Needs*, early view.
- Havlicek, J., Bilaver, L. & Beldon, M. (2016) 'Barriers and facilitators of the transition to adulthood for foster youth with autism spectrum disorder: Perspectives of service providers in Illinois.' *Children and Youth Services Review*, 60, pp. 119-128.
- Hedley, D., Uljarević, M., Cameron, L., Halder, S., Richdale, A. & Dissanayake, C. (2016) 'Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature.' *Autism*, 0, pp. 1-13.
- Howlin, P., Goode, S., Hutton, J. & Rutter, M. (2004) 'Adult outcome for children with autism.' *Journal of Child Psychology and Psychiatry*, 45 (2), pp. 212-229.

- Ivey, J. K. (2004) 'What do parents expect? A study of likelihood and importance issues for children with autism spectrum disorders.' *Focus on Autism and Other Developmental Disabilities*, 19, pp. 27-33.
- Jaarsma, P. & Welin S. (2012) 'Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement.' *Health Care Analysis*, 20 (1), pp. 20-30.
- Kenny, L. Hattersley, C. Molins, B. Buckley, C. Povey, C. & Pellicano, E. (2015) 'Which terms should be used to describe autism? Perspectives from the UK autism community.' *Autism*, 20(4), pp.1-21.
- King, G., Baldwin, P., Currie, M., & Evans, J. (2005) 'Planning successful transitions from school to adult roles for youth with disabilities' *Children's Health Care*, 34, pp. 195-216.
- Lee, G. & Carter, E. (2012) 'Preparing transition-age students with high-functioning autism spectrum disorders for meaningful work.' *Psychology in the Schools*, 49, pp. 988-1000.
- Liamputtong, P. (2013) *Qualitative Research Methods* (4th edn). South Melbourne: Oxford University Press.
- Lincoln, Y. & Guba, E. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- Lindstrom, L., Paskey, J., Dickinson, J., Doren, B., Zane, C. & Johnson, P. (2007) 'Voices from the field: Recommended transition strategies for students and school staff.' *The Journal for Vocational Special Needs Education*, 29, pp. 4-15.
- Marriage, S., Wolverton, A. & Marriage, K. (2009) 'Autism spectrum disorder grown up: a chart review of adult functioning.' *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 18, pp. 322-327.
- Martin, J. & Williams-Diehm, K. (2013) 'Student engagement and leadership of the transition planning process.' *Career Development and Transition for Exceptional Individuals*, 36, pp. 43-50.
- Morningstar, M. & Clark, G. (2003) 'The Status of personnel preparation for transition education and services: what is the critical content? How can it be offered?' *Career Development and Transition for Exceptional Individuals*, 26, pp. 227-237.
- Neary, P., Gilmore, L. & Ashburner, J. (2015) 'Post-school needs of young people with high-functioning autism spectrum disorder.' *Research in Autism Spectrum Disorders*, 18, pp. 1-11.
- Newman, L., Wagner, M., Knokey, A., Marder, C., Nagle, K., Shaver, D., Wei, X., Cameto, R., Contreras, E., Ferguson, K., Greene, S. & Schwarting, M. (2011) *The post-high school outcomes of young adults with disabilities up to 8 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2) (NCSE 2011-3005)*. Menlo Park, CA: SRI International. Available at www.nlts2.org/reports/.
- Nuehring, M. L. & Sitlington, P. L. (2003) 'Transition as a vehicle: Moving from high school to an adult vocational service provider.' *Journal of Disability Policy Studies*, 14, pp. 23-35.
- Ryan, R. & Deci, E. (2000) 'Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being.' *American Psychologist*, 55 (1), pp. 68-78.
- Rydzewska, E. (2012) 'Destination unknown? Transition to adulthood for people with autism spectrum disorders.' *British Journal of Special Education*, 39, pp. 87-93.
- Sands, D. and Wehmeyer, M. (1996). *Self-determination across the life span: Independence and choice for people with disabilities*. Baltimore: Paul H. Brookes Publishing Co.

- Shenton, A. (2004) 'Strategies for ensuring trustworthiness in qualitative research projects.' *Education for Information*, 22 (2), pp. 63-75.
- Shepherd, J. (2015) 'Interrupted Interviews': listening to young people with autism in transition to college.' *Exchanges: the Warwick Research Journal*, 2 (2), pp. 249-262.
- Shogren, K. & Plotner, A. (2012) 'Transition planning for students with intellectual disability, autism, or other disabilities: Data from the National Longitudinal Transition Study-2.' *Intellectual and Developmental Disabilities*, 50, pp. 16-30.
- Taylor, S. & Bogdan, R. (1998) *Introduction the Qualitative Research Methods: A Guidebook and Resource* (3rd edn). New York: John Wiley & Sons, Inc.
- Taylor, J. & Seltzer, M. (2011) 'Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood.' *Journal of Autism & Developmental Disorders*, 41, pp. 566-574.
- Taylor-Ritzler, T., Balcazar, F. E., Keys, C. B., Hayes, E., Garate-Serafini, T., & Ryerson Espino, S. (2001) 'Promoting attainment of transition-related goals among low-income ethnic minority students with disabilities.' *Career Development and Transition for Exceptional Individuals*, 24, pp. 147-167.
- Test, D., Smith, L. & Carter, E. (2014) 'Equipping youth with Autism Spectrum Disorders for adulthood: Promoting rigor, relevance, and relationships.' *Remedial and Special Education*, 35, pp. 80-90.
- Wei, X., Wagner, M., Hudson, L., Yu, J. W. & Javitz, H. (2016) 'The effect of transition planning participation and goal-setting on college enrollment among youth with autism spectrum disorders.' *Remedial and Special Education*, 37 (1), pp. 3-14.
- Weidenthal, C. & Kochhar-Bryant, C. (2007) 'An investigation of transition practices for middle school youth.' *Career Development and Transition for Exceptional Individuals*, 30, pp. 147-157.
- White, S., Oswald, D., Ollendick T. & Scahill L. (2009) 'Anxiety in children and adolescents with autism spectrum disorders.' *Clinical Psychology Review*, 29, pp. 216-229.
- Winstone, N. Huntington, C. Goldsack, L. Kyrou, E. & Millward, L. (2014) 'Eliciting rich dialogue through the use of activity-oriented interviews: Exploring self-identity in autistic young people.' *Childhood*, 21 (2), pp. 190-206.
- Waltz, M., (2005) 'Reading case studies of people with autistic spectrum disorders: a cultural studies approach to issues of disability representation.' *Disability & Society*, 20 (4), pp. 421-435.

Table 1. Participant information (Parents n=9, Professionals n=4)

Parent Participant ID	State or Territory	Relationship to adolescent	Adolescent's gender, age (years) and grade at school
1	Western Australia (WA)	Mother	Male, age 15, Year 9
2	WA	Mother	Male, age 14 , Year 9
3	Queensland (QLD)	Mother	Male, age 17, First year university
4	WA	Mother	Male, age 14, Year 9
5	WA	Mother	Male, age 19, Left school Female, age 21, Left school
6	WA	Mother	Male, age 17, Year 12
7	WA	Mother	Male, age 15, Year 9
8	WA	Father	Female, age 15, Year 10
9	QLD	Mother	Female, age 15, Year 11

Professional Participant ID	State or Territory	Job title	Years working with people with autism
1	WA	Job support coordinator	3 years
2	WA	Teacher at an education support school	13 years
3	WA	Occupational therapist	5 years
4	WA	Speech pathologist	4 years