Parents' perspectives on adaptive behaviour changes in their child with autism following their transition to school

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A thesis submitted in fulfilment of the requirements of the degree

Masters of Education and Professional Studies Research

School of Education and Professional Studies

Griffith University

August 2017

Abstract

Purpose: Transitioning to school is one of the biggest changes in a child's life. A successful transition can have an impact on future educational outcomes. Transition support is an educational need for a child with autism. There are many simultaneous changes in the environment and expectations placed on the child in the new environment, which can affect adaptive behaviour development. The aim of this study is to explore parents' perceptions of the changes in a child's adaptive functioning during the transition to school. Determining the reasons behind these changes can provide important insight into how the child is coping throughout the transition.

Method: This study set out to qualitatively explore parent perspectives through semi-structured interviews. The participants were 14 parents with a child with autism in the first year of school. Each parent was asked about their child's transition to school including any perceived changes in the areas of daily living skills, social abilities, and language and communication skills; and possible explanations for any reported changes. The interviews were recorded then transcribed and underwent thematic analysis.

Results: Three themes emerged from the thematic analysis. The themes represent factors that influenced changes in adaptive behaviour, as perceived by parents. Theme one was child willingness. Parents stated that when their child showed a desire to participate in school life there were gains in adaptive behaviour development. Theme two was quality stakeholder engagement, which captures the roles that each key stakeholder had when supporting adaptive behaviour during the transition. The role of the parent was coordinating the transition and advocating strategies for the transition to school. This included preparing a transition timeline and coordinating and advocating for high quality communication with educators. The educator's role was as the collaborator and the implementer to support adaptive behaviour during the transition. This role involved

developing high quality collaborative relationships with the parent, the child's team, and the child's preschool educators. Following this, the educator's role was to implement any agreed individualised support strategies, utilising resources, and addressing the core characteristics of the child including adaptive behaviour to ensure inclusion while transitioning to the new school environment. Theme three was school-wide support. This theme defined the school's role as the supplier and enabler of funding and environmental support during the transition, meeting the needs of the child and all the key stakeholders.

Conclusion: Factors affecting adaptive behaviour development during the transition to school for a child with autism can be represented as an integrated model of support for a child-centred transition, starting with child willingness, extending to active engagement of parents as coordinators and collaborators, and teachers as collaborators and implementers, with all parties being supported through the supplying and enabling role of the school. The results are represented as an integrated model of support. These results highlight the value of identifying roles and responsibilities that ensure quality engagement of all involved, with a prepared transition to school using a transition timeline, child profile and the integrated model of support, to give the best opportunity for positive outcomes. Strategies for supporting child willingness, adaptive behaviour development and key stakeholders' roles are discussed, along with implications for future practice and future research.

Keywords

Adaptive behaviour, autism, daily living skills, language and communication, parent perspectives, social skills, transition to school

Statement of originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

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Acknowledgements

The researcher would like to acknowledge the individuals and organisations that contributed to the production of this dissertation. Firstly to Griffith University, the Autism Centre of Excellence and my supervisors: Prof Jacqueline Roberts and Dr David Trembath. I would like to thank AEIOU Gold Coast and the individuals and organisations involved in the Autism CRC's Longitudinal Study of Australian Students with Autism (LASA). I would like to acknowledge the support from the Australian Government Research Training Program Scholarship. Thanks to editor Kate Leeson, who provided copyediting and proofreading services, according to the guidelines laid out in the university-endorsed national "Guidelines for editing research theses". Finally and most importantly I would like to thank the parents who participated in the interviews. Without their time and support for furthering research and advocating for their child, none of this research could have happened.

For Bowie

List of acronyms and definitions of terms

ACECQA	Australian Children's Education and Care Quality Authority
ACARA	Australian Curriculum Assessment and Reporting Authority
APA	American Psychiatric Association
ASD	Autism spectrum disorder or autism
ADHD	Attention deficit hyperactivity disorder
CDC	Centres for Disease Control
DSM	*Diagnostic and Statistical Manual of Mental Disorders* of the American Psychiatric Association
DSM-V	5th edition of *Diagnostic and Statistical Manual of Mental Disorders* of the American Psychiatric Association
DSM-IV	4th edition of *Diagnostic and Statistical Manual of Mental Disorders* of the American Psychiatric Association
EBP	Evidence-based practice
ECDP	Early childhood development program
Educator	Can include members of the school team including teachers, teacher aides, head of special education services or school support staff, depending on the case.
EI	Early intervention
GPA	Grade point average
ID	Intellectual disability
IEP	Individualised Education Program
LASA	Longitudinal Study of Australian Students with Autism
MEPS	Masters of Education and Professional Research Studies
Multi-disciplinary team	Members of the team associated with the child during early intervention. This includes parents, carers, and professional staff such as social workers, psychologists, speech pathologists, occupational therapists, early intervention specialists and early intervention educators, depending on the case.
NAC	National Autism Center
NSP	National standards project
OT	Occupational therapist

Parent	Refers to the child's birth parent, foster parent or legal guardian or carer or individual that has custodial rights such as a grandparent, depending on the case.
VABS	Vineland Adaptive Behaviour Scale
VABS2	Vineland Adaptive Behaviour Scale 2

Chapter 1: Introduction

1.1 Introduction to this study

A parent plays an integral role when their child is transitioning to a primary school setting (Brown & Woods, 2015; Carlon, Stephenson & Carter, 2015; McConachie & Diggle, 2007; Prior, Roberts, Rodger, Williams, & Sutherland, 2011). A child with autism is highly likely to have difficulties with transitions, both horizontal transitions such as transitioning between activities, and vertical transitions, which include transitions between preschool and school, or adolescence into adulthood (Prior et al., 2011; Saggers et al., 2015; Volkmar, 2014). During the transition to school there are many changes, including new settings, new people, different routines, often higher expected levels of independence and higher expectations placed on the child (Docket & Perry, 2004; Fabian, 2002; Pianta, Kraft-Sayre, Rimm-Kaufman, Gercke, & Higgins, 2001). A child's experience of these changes may slow down or speed up the development of, or occasionally lead to regression of, social, communication, daily living and motor skills, collectively known as adaptive behaviour (Sterling-Turner & Jordan, 2007). Observing or assessing a child's adaptive functioning prior to and following the school transition can indicate how the child is coping, and the extent to which previously taught adaptive behaviour skills are being or have been generalised (McIntyre, Blacher, & Baker, 2006; McCumber, 2011; Volkmar, 2014). These assessments, when done qualitatively through parent interviews, can explore parents' perspectives in depth and give insight into how and why these changes are happening, and how they are affecting the child and the family unit. Assessments can help to identify any contributing factors that affect adaptive behaviour during a transition. Exploring the parents' perspectives may also help identify any factors that influence adaptive behaviour and highlight effective strategies and practices to encourage

continuing adaptive behaviour development for a child with autism when transitioning to school. This chapter outlines the background and context (Section 1.2) of the study, the objectives of the study (Section 1.3), and defines the research question and related questions (Section 1.4). Finally, the significance of this study is discussed (Section 1.5).

1.2 Background

Autism spectrum disorder (referred to as autism from here on in) is currently defined as a neurodevelopmental disorder characterised diagnostically by challenges in social communication, social interaction, and restrictive and repetitive behaviours (APA, 2013). Early intervention before school age is one of the key approaches for supporting an individual with autism (National Autism Center [NAC], 2011, 2015; Stahmer, Schreibman, & Cunningham, 2011; Volkmar & Weisner, 2009; Volkmar, 2014; Wong et al., 2014). Parents are involved in the process of selecting early intervention therapies and are usually the integral decision makers and collaborators in how, where and when an intervention is implemented (Brown & Woods, 2015; Carlon et al., 2015; McConachie & Diggle, 2007; Prior et al., 2011). As parents are key stakeholders in the transition process of their child with autism, it is important to examine their perceptions of the changes to their child's behaviours and functioning during and after the transition to school.

Adaptive behaviour is defined by the extent to which an individual is capable of being self-sufficient in real-life situations, including the functional use of communication, socialisation, and daily living and motor skills (Sparrow, Balla, & Cicchetti, 1984). Adaptive behaviour development is a main area for goal setting and intervention for an individual with autism (Kanne et al., 2011). Adaptive behaviour skills assist an individual to be as independent as possible, and include daily living

skills, social skills, and language and communication skills (Sparrow, Cicchetti & Balla, 2005). Because these areas are some of the main goal areas for intervention, it is important to observe and assess adaptive functioning skills for a child with autism from an early age (Flanagan et al., 2015; Szatmari et al., 2015). Teaching new skills and focusing on interventions to develop adaptive behaviour are positively associated with a child with autism becoming more independent, with flow-on effects through to adolescence and adulthood (Carothers & Taylor, 2004; Pugliese et al., 2016; Rauf, Anis-ul-Haq, Aslam, & Anjum, 2014; Volkmar, 2014). Conversely, behaviour problems can arise when a child with autism is delayed in the development of adaptive behaviour or experiences negative changes (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Rauf et al., 2014).

Starting school is a major transition in a child's life (Fabian, 2002; Pianta et al., 2001). Not only are there differences with the educational setting like the school, classroom, classmates and educators, but there are also changes to the type of social interactions, the expectations placed on the child and the degree of expected independent daily functioning (Docket & Perry, 2004; Pianta et al., 2001). Transitioning to school can be a particularly difficult time for a child with autism and they often require comprehensive support (Prior et al., 2011; Roberts & Williams, 2016; Quintero & McIntyre, 2011; McCumber, 2011). Accordingly, governments have education and disability policies and guidelines aimed at assisting a child with autism with the transition to school (Australian Children's Education and Care Quality Authority [ACECQA], 2011).

Transitions can also lead to anxiety or anxiety symptoms for a child with autism (Stoner, Angell, House, & Bock, 2007). Stoner et al. (2007) claim that parents are aware of their child's anxiety during difficult transitions. The stress of a transition can bring

about inappropriate or maladaptive behaviour due to this anxiety (Greenberg, 2011; Hanline, 1993). Anxiety can be shown in behaviours including refusal to go to school, an increase in restrictive behaviours, social phobia, avoiding an object or situation, perfectionism, or seeking reassurance (Magiati et al., 2016). Additionally, lower adaptive functioning has been linked to anxiety symptomology for a child with autism (Davis et al., 2011; Dubin, Leiberman-Betz & Michele Lease, 2015; Magiati et al., 2016). Challenging or maladaptive behaviours including hyperactivity, agression, agitation, increased obsessiveness, increased restrictive behaviours and attention problems can also have an impact on the child's family by elevating parental stress, can challenge the learning environment, negatively affect learning outcomes, and prevent a child from accessing relevant community services (Allen, Lowe, Moore, & Brophy, 2007; Felce & Kerr, 2013; Lecavalier, Leone, & Wiltz, 2006; O'Connor & Healy, 2010).

1.3 Objectives

This study sets out to examine the way a parent views and experiences the transition to school of their child with autism, in relation to changes, if any, they have observed in their child's adaptive behaviour and skill development, and their opinion as to why these changes have occurred. The study contributes to the knowledge base about supporting the transition to school for a child with autism through in-depth qualitative research, exploring the insights of parents at this potentially stressful time for the child, parents, family and all others involved. This study is not concerned with academic outcomes, but focuses on parents' views of their child's adaptive behaviour changes, what factors influence these changes, and possible explanations for these changes, from the perspective of the primary caregivers. Exploring parents' perceptions of these

changes in adaptive behaviours will potentially help to identify and clarify the specific needs of a child with autism during the transition to school, and address the relationship between a successful or unsuccessful transition and changes in adaptive behaviour.

1.4 Research question

The central question in this research is: What are parents' perceptions of adaptive behaviour changes in their child with autism following their transition from a preschool setting to school? In order to answer this question the author will explore the reasons behind any gains or losses in the adaptive behaviours of their child with autism throughout the transition to school and discuss the factors that might contribute to those changes

1.5 Significance of this study

There is a gap in research regarding parent perceptions of changes in their child resulting from the transition to school, specifically regarding the effects on adaptive behaviour and any impact the transition process has on skills previously acquired during the preschool years, particularly in Australia; however, transitioning to school for s child without a disability in Australia has been extensively researched (Dockett & Perry, 1999, 2002, 2003, 2004). Internationally, there have been studies about transitioning to school for a child with a disability which have included autism but also an array of other disabilities (Janus, Lefort, Cameron, & Kopechanski, 2007; Schischka, 2011; Schischka, Rawlinson, & Hamilton, 2012; Villeneuve et al., 2013). The results of these studies may not provide information specific to a child with autism, or specific to a child with autism in Australia. Internationally, the transition to school for a child with autism has been researched with regard to effective strategies and practices leading up to the start of school such as a transition timeline (Denkyirah & Agbeke, 2010;

McCumber, 2011; Sterling-Turner & Jordan, 2007). Again, this is not specific to Australia, and only includes information about the time leading up to the start of school. Some recommendations from these studies outline strategies for educational environments to use when preparing to assist a child with autism to have a smooth transition to school. There are some studies about parents' perspectives on their child with autism at school in general (Azad & Mandell, 2016), but only a few studies focus on parents' perspectives on transitioning to school (Kemp, 2003; Greenberg, 2011; Janus et al., 2007; Rous, Meyers, & Stricklin, 2007; Walker et al., 2012), and most are not Australian studies. Most previous studies of adaptive behaviour involve quantitative measures of adaptive behaviour but do not explore the reasons any changes occur (Flanagan et al., 2015; Liss et al., 2001; McIntyre, Blacher, & Baker, 2006). These studies have not measured changes in adaptive behaviour after the transition to school.

Longitudinal studies examining changes in adaptive behaviours over time tend to focus on quantitative measures that identify changes but do not expand on how or why these changes occurred (Magiati, Moss, Charman, & Howlin, 2011; Matthews et al., 2015; O'Connor & Healy, 2010; Szatmari et al., 2015; Turner, Stone, Pozdol, & Coonrod, 2006). To illustrate, O'Connor and Healy (2010) investigated longitudinal outcomes for a child with autism who received intensive early intervention in the preschool years and then enrolled in mainstream settings. The authors explained some participants maintained the gains they had made following intensive intervention and some regressed or slowed in their adaptive behaviour development. The findings of this study raise an important unanswered research question about why there is a difference in results, and suggest further research is needed to examine the possible factors resulting in these mixed findings. A study of parents' perceptions of their child's adaptive behaviour in relation to the transition process may provide insights into factors

that affect the success of the transition-to-school process, and outline ways to improve support while transitioning to school for a child with autism (Falkmer, Anderson, Joosten, & Falkmer, 2015; Villeneuve et al., 2013).

There are limited previous studies of parent perspectives that involve examining the area of adaptive behaviour at school but do not study the transition to school period (Towle, Vacanti-Shova, Shah, & Higgins-D'alessandro, 2014; Fontil & Petrakos, 2015). None of these studies were conducted in Australia. Qualitative studies of transitions for a child with autism exist but none of these specifically focus on the transition to school (Stoner et al., 2007). There is a gap in research using in-depth qualitative methods to examine parents' perspectives of adaptive behaviour changes and the reasons behind these changes in relation to the transition to school for a child with autism. The aim of this study is to partially fill this gap by contributing to the knowledge base about the complex process of the transition to school for a child with autism and changes in adaptive behaviour at this time. The results of this research provide additional insight into the factors that support adaptive behaviour development for a child with autism and the strategies that support a child with autism while transitioning to school. It can provide this information in regards to a child with autism transitioning to school in Australia. It also potentially assists with the identification of roles for the key stakeholders, and the training or support that might help parents and educators. It also helps to identify the factors that can optimise communication and collaboration between the key stakeholders during the transition process. The research could also help identify any differences in environments or environmental supports and adjustments that have an affect on adaptive behaviour development in the new educational setting.

1.6 Summary and organisation of this study

This chapter has provided an introduction to the current study and the background to the research question. It outlined the objectives, research gaps and the research question relevant to this study. It outlined the significance of this study, particularly in relation to contribution to practice. The following chapters contain a review of relevant literature (Chapter 2), exploring autism, adaptive behaviour and transitions to school. It also covers the topic of parent perspectives and how researching parent perspectives can provide insight and information about the topic of this thesis. Chapter 3 explains and describes the methodology chosen for this study, including the study design and the choice of a thematic analysis process for data analysis. In Chapter 4, the results of the study are presented as themes relating to the factors that influence changes in adaptive behaviour, as perceived by parents. Chapter 5 presents a discussion of each theme and of the study as a whole, and includes the researcher's reflections about the results of the study, the possible implications of this study and how it aligns and contrasts with other current relevant research. Finally, Chapter 5 also presents the limitations of this study and suggests possible future directions for research.

Chapter 2: Literature review

2.1 Autism

2.1.1 Introduction to autism

As noted in Chapter 1, autism is a neurodevelopmental disorder characterised by difficulties in social communication, social interaction, and restrictive and repetitive behaviours. However, autism may also be characterised by cognitive processing difficulties (e.g., organisation skills, flexibility), information processing difficulties (e.g., auditory processing, information sequencing) and executive functioning difficulties (e.g., working memory, impulse control) (NAC, 2015; APA, 2013). An individual may also have a comorbid diagnosis with their autism diagnosis such as an intellectual disability (ID), anxiety or ADHD. Individuals with autism have a wide range of intellectual abilities, ranging from gifted to having an ID (Attwood, 2008; Autism Society, 2013). In 2016, the Centers for Disease Control and Prevention identified that 1 in 68 children were diagnosed with autism spectrum disorder in the USA. In Australia, the most recent data from the Australian Bureau of Statistics (2014) indicated that 115,400 Australians (0.5 per cent) were diagnosed with autism. This is a 79 per cent increase on the figures from 2009, which estimated 64,400 people in Australia were diagnosed with autism (ABS, 2014). Research suggests contributing factors to the increase in prevalence are likely to be the change in diagnostic criteria in the DSM-IV, which widened the diagnostic spectrum, as well as sustained increased awareness about autism (ABS, 2014; NAC, 2015; Volkmar, 2014). Because of this increase, there is a growing demand for effective practices and programs for teaching new skills and adaptive behaviours (Wong et al., 2014).

2.1.2 Diagnosis, early intervention, and Evidence-Based Practices (EBP)

An accurate diagnosis of autism can be given as early as two years of age, but most children are diagnosed around the age of four (CDC, 2016 NAC, 2015; Turner et al., 2006). Early intervention before school age is a key approach for individuals with autism (NAC, 2011, 2015; Stahmer, Collings, & Palinkas, 2005; Volkmar, 2014). In Australia the term "early intervention" is applied to interventions up to the age of seven years (Prior & Roberts, 2012; Prior et al., 2011). Once diagnosed, further assessments are important to establish the child's strengths, needs and abilities; determine what services may be necessary for intervention; establish a baseline for goals; and build an in-depth picture of the child's characteristics and functioning (Odom, Collet-Klingenberg, Rogers, & Hatton, 2010; Volkmar & Weisner, 2009; Volkmar, 2014). Assessment and goal selection can lead to the appropriate selection of intervention services (Ogletree, Oren, & Fischer, 2007; Volkmar & Weisner, 2009).

There are a range of evidence-based interventions and strategies for a child with autism (NAC, 2015; Wong et al., 2014). These include Applied Behaviour Analysis (ABA), behavioural intervention, video modelling, naturalistic teaching strategies, parent-implemented intervention, visual schedules and strategies, self-management, scripting and story-based intervention (NAC, 2015; Stahmer et al., 2005; Volkmar, 2014; Wong et al., 2014). Interventions generally target core characteristics associated with autism depending on the child's needs, and aim to teach a new skill or behaviour. Intervention areas often include social skills, motor skills, communication and language skills, cognitive development, joint attention, executive functioning skills, and addressing restrictive and repetitive behaviours such as rigidity or difficulties with transitions (Flanagan et al., 2015; Myers & Johnson, 2007; NAC, 2011, 2015; Stahmer et al., 2005; Volkmar, 2014; Wong et al., 2014).

In addition to the selection of established interventions, recent guidelines (Roberts & Williams, 2016) identify broader intervention elements that constitute good practice. For instance, it is current good practice to ensure an intervention for a child with autism involves a multidisciplinary team (Prior et al., 2011; Roberts & Williams, 2016). Using a child's natural environment for an intervention or therapies (i.e., home and school) has been shown to be more effective than intervention in clinical environments, and enables parents and educators to embed and implement naturalistic evidence-based teaching strategies in everyday routines (Brown & Woods, 2015; NAC, 2001; Schreibman et al., 2015). Teaching new skills and behaviours in this way ensures intervention goals are achieved more rapidly, and promotes social development and generalisation of skills (Brown & Woods, 2015; Schreibman et al., 2015).

2.1.3 Parent roles in the early years

Parents are usually the integral decision makers and collaborators in how, where and when early intervention is implemented (Brown & Woods, 2015; Carlon et al., 2015; McConachie & Diggle, 2007; Prior et al., 2011). Recent studies about parenting a child with autism have shown parents report feeling more under pressure and have higher stress levels than parents of a typically developing child (Benson, Karlof, & Siperstein, 2008; Fontil & Patrakos, 2015; Hall & Graff, 2011; Meirsschaut, Roeyers, & Warreyn, 2010). However, there is also evidence to suggest that parents of a child with autism are more active than parents of a typically developing child in promoting their child's development, and some research has shown active involvement in a child's development can lead to lower parental stress levels (Kuhn & Carter, 2006).

2.2 Adaptive behaviour

2.2.1 Adaptive behaviour in children with autism

A child with autism can have an irregular adaptive behaviour profile compared to typically developing children of the same age (Flanagan et al., 2015). A child's ability to perform daily living skills is determined by their ability to understand and perform the skill, their ability or desire to comply with requests, and the parent or caregiver's expectations regarding the routine performance of the skill (Green & Carter, 2014). Communication and social issues may prevent a child from understanding what is being asked and why (Green & Carter, 2014). In addition, behaviour problems can arise when a child with autism shows delays in the development of adaptive behaviour (Dyches et al., 2004; Rauf et al., 2014). Felce and Kerr (2013) investigated the potential link between low adaptive behaviour and future challenging behaviours in adults with intellectual disabilities (ID) and found that adaptive behaviour levels can significantly predict challenging behaviours for individuals with autism who are also diagnosed with an ID. Carothers and Taylor (2004) conclude that everyone in the lives of a child with autism should collaborate to provide consistent, appropriate training in the area of adaptive behaviour.

Studies examining adaptive behaviour development in a child with autism tend to focus on social-communication skills, given these are central to the diagnostic criteria and have a strong bearing on independence and participation in daily life. However, an individual with autism can also exhibit motor difficulties that can affect daily living skills (Travers et al., 2016). Travers et al. (2016) explain that severe manual motor difficulties can negatively impact independent living skills, and manual motor performance, especially grip strength, is associated with adaptive skill development and predictive of future daily living skills, even after controlling for age and IQ. Travers et

al. (2016) argued that even subtle motor difficulties impact adaptive daily living skills from childhood to middle adulthood. Jasmin et al. (2009) also highlight that motor and sensory difficulties in preschoolers with autism are correlated with adaptive skills.

2.2.2 Adaptive behaviour intervention

Teaching new skills and focusing on interventions in the area of adaptive behaviour is positively associated with a child with autism becoming more independent both in the short term and into adulthood (Carothers & Taylor, 2004; Pugliese et al., 2014; Rauf et al., 2014; Volkmar, 2014). Assessments of adaptive behaviour changes arising from intervention are arguably the most important outcome measures, as they measure personal independence and social responsibility and give the best indication of the child's everyday functioning (McIntyre et al., 2006; McCumber, 2011; Volkmar, 2014). Farley et al. (2009) completed a 20-year longitudinal study of adults with autism and an IQ in the average range. The authors found that adaptive behaviour skills were more closely associated with successful independent daily living as an adult than cognitive skill level. Research has shown an increasing number of individuals with autism are achieving levels of independence in adulthood; however a majority experience a range of challenges associated with independence throughout their life (Kanne et al., 2011).

2.2.3 Assessment of adaptive behaviour

There is a range of approaches to assessing adaptive behaviour in a child with autism, including both quantitative and qualitative methods. Quantitative measures of adaptive behaviour include standardised assessments such as the Vineland Adaptive Behaviour Scale (VABS & VABS2) (Fenton et al., 2003; Lopata et al., 2013; Sparrow et al., 1984, 2005; Tomanik, Pearson, Loveland, Lane, & Shaw, 2007; Volkmar, 2014). The VABS and VABS2 have both been shown to be quantifiably reliable measures of adaptive

behaviour for a child with autism (Balboni, Tasso, Muratori, & Cubelli, 2016) and include scales assessing communication, socialisation, daily living skills and motor skills (Sparrow et al., 2005). The scores are combined to form an overall Adaptive Behaviour Composite (ABC) score, where the mean is 100 and standard deviations are 15, where measured delay is more than 2 standard deviations below mean. The more severe early social delays are, the more severe the current adaptive behaviour impairments are (Kanne et al., 2011).

Qualitative inquiry can also be used to assess changes in adaptive behaviour and can have particular value in identifying how and why changes occur (Brantlinger, Jiminez, Klingner, Pugach, & Richardson, 2005). Qualitative studies with in-depth interviews can explore the real-life experiences, processes and attitudes that occur in natural, rather than experimental, situations (O'Brien, Harris, Beckman, Reed, & Cook, 2014). Qualitative studies into parent perspectives and adaptive behaviour have been used previously and have gone beyond the quantitative measurements to explore a deeper understanding in this area (Towle et al., 2014; Fontil & Petrakos, 2015).

2.2.4 Adaptive behaviour development and cognitive development

Previous studies have shown that the adaptive development trajectory of a school-aged child with autism can differ from their cognitive development trajectory (Flanagan et al., 2015; Magiati et al., 2011; Pugliese et al., 2014). This indicates that the cognitive abilities of an individual with autism may develop faster than his or her adaptive behaviour skills, giving the impression of a decrease in adaptive behaviour skills relative to his or her age and cognitive ability (Kanne et al., 2011; Matthews et al., 2015). In fact, there is no actual decrease but a growing gap in adaptive skill development compared to increasing age and cognitive ability (Green & Carter, 2014;

Matthews et al., 2015). Longitudinal studies measuring adaptive behaviour have shown a child's rate of adaptive behaviour development may decrease over time (Charman et al., 2005; Magiati et al., 2011; Sigman & McGovern, 2005). Green and Carter (2014) investigated predictors of daily living skill development in toddlers with autism. One hundred and sixty-two toddlers were assessed at three annual time points. They found that daily living skill development decreased over time (compared to peers) but still increased in a linear way, that is, it increased at a slower rate to typically developing peers. Green and Carter (2014) conclude that autism severity and behavioural problems are predictors of daily living skills beyond IQ in young children with autism.

2.2.5 Adaptive behaviour and anxiety

A recent international study's results stated "Anxiety-related problems are among the most frequently reported mental health difficulties for individuals with autism" (Magiati et al., 2016, p. 306). Anxiety and anxiety symptomology have been linked to adaptive behaviour and functioning in studies with participants ranging from young people with autism attending a special school, including those with an ID, to those with a lower level of support in a mainstream school (Dubin et al., 2015; Magiati et al., 2016). Magiati et al. (2016) examined anxiety symptoms in young people with autism attending special schools including associations with adaptive functioning. Anxiety relating to adaptive functioning has been explained as social phobia in a study of young people with autism attending a special school, and the researchers suggest that enhancing adaptive skills for individuals with social phobias and anxiety could lower their anxiety levels (Magiati et al., 2016).

2.3 Education

Changes in behaviour for a child with autism can arise when transitioning from a preschool or early intervention preschool to a school setting (Fabian, 2002; Pianta et al., 2001). The policies, curriculum, educational settings and transition-to-school procedures of the new school setting must be considered as factors that can affect a child's development in the area of adaptive behaviour. The following sections (2.3.1 to 2.4.4) cover these areas, and review how and why school factors may affect a child with autism and their adaptive behaviour development.

2.3.1 Legislative policy and curriculum for an individual with autism

There are international agreements, and national and state legislation describing the rights of a child, education standards, and the rights of an individual with a disability that apply in Australia (ACECQA, 2012; United Nations, 2006). The Commonwealth *Disability Discrimination Act 1992* outlines the rights of people with disabilities, their access to community services, and their inclusion within the community. The Commonwealth *Disability Standards for Education 2005* outline the legal policies an education provider is expected to implement; however these standards are not mandated. The aim of these policies is to set out consistent expectations and standards, but in reality the manner in which these policies come together and are interpreted differ in each case, affecting schools, families and children, and thus influencing the transition-to-school experience in different ways also. Currently, the government is rolling out the NDIS (National Disability Insurance Scheme). It is individualised for each learner with a disability, and promotes inclusion of and support for the individual, their family and the community to meet the individual's needs and achieve their personal goals (Roberts & Williams, 2016).

In addition to policies and schemes that exist to support a child with autism in the educational system, there are curriculum standards, policies and guidelines which influence the experiences of a child at school (ACECQA, 2012). The Australian curriculum has been developed to ensure that curriculum content and achievement standards establish high expectations for all students. The Australian curriculum also provides the framework for teachers when developing teaching and learning programs, and outlines their professional obligation to ensure that all students, including those with a disability, are able to access and participate in education on the same basis as those without a disability (ACARA, 2013). The curriculum provides flexibility for teachers to take into account the different rates at which students with diverse learning needs develop. Many students with additional needs are able to achieve educational milestones, provided the necessary adjustments are made to instructional processes and to the means through which they demonstrate their learning (ACARA, 2013). The Australian education standards are developed and monitored by national and state government bodies such as the Australian Curriculum and Reporting Authority (ACARA) and the Australian Qualifications Framework or AQF (ACECQA, 2012).

The national curriculum aims to ensure that "all young Australians are equipped with the skills, knowledge, and capabilities to provide a foundation for successful and lifelong learning and participation in the Australian community" (ACARA, 2012, p. 1). The goal is to create an environment that facilitates the highest learning outcomes, future learning and growth for all who participate (Education Services Australia, 2015). The educational system also must accommodate the diversity of students, that is, the developmental diversity and the needs of each individual learner, to enable the successful implementation of the curriculum (ACARA, 2013). The curriculum addresses specific academic areas, but also general capabilities such as critical and

creative thinking, personal and social capabilities, ethical and intercultural understanding, and information and technology capabilities (Education Services Australia, 2015).

When transitioning to school, a child is moving from one educational framework into another. In Australia, the National Quality Standard (NQS) for Early Childhood Education and Care and School Age Care (ACECQA, 2012) links the Early Years Learning Framework with the School Age Care Framework (Dockett & Perry, 2014a; 2014b). The National Quality Framework developed by ACECQA outlines the areas addressed, including collaborative partnerships with families and communities. Quality Area 6.3.3 promotes "continuity of learning and transition for each child by sharing relevant information and clarifying responsibilities" (ACECQA, 2016). ACECQA's *The Guide to Education and Care Services National Law and National Regulations* (2011) specifically mentions transitioning at the start of the year and suggests,

> at times, a service may need to provide additional educators to adequately supervise and support children. For example, at the beginning of the year when a number of children are transitioning to new rooms, a service may need to roster educators in excess of minimum ratios. This could assist educators to respond to children's needs and foster children's sense of security and belonging. (p. 65)

2.3.2 Educational settings

Due to the legislation in place in Australia, reasonable adjustments need to be made and support given to a child with autism to maximise inclusion and learning opportunities and allow the child their right to access the curriculum (ACARA, 2013). Creating an

effective learning environment involves adjustments that align with international, national and state educational legislation and policy (ACECQA, 2012). The question of how to modify learning environments, curriculum and methods of assessment when attempting to accommodate the needs of all individuals, including those with a disability, becomes paramount (Australian Government Department of Education, 2012). The Australian Advisory Board on Autism Spectrum Disorders (2012) has stated that students with autism may experience significant challenges in educational environments where few or no autism-specific provisions or curricula modifications are in place. Schools are facing demands and expectations that they will provide services to meet the needs of a child with autism (McCumber, 2011).

There are several main early education pathways for a child with autism to transition to school, which differ primarily in their intensity (e.g., days per week), child–staff ratios, and the extent to which children with and without autism are educated together or separately. Although many children with autism do attend a regular preschool setting with inclusion support in place, autism-based preschools or kindergartens are also available as an alternative, specialising in providing intervention and evidence-based teaching for a child in the preschool years (AEIOU, 2016; ASPECT, 2016). Autism-specific early intervention preschools are available across Australia and comply with relevant educational policies and frameworks, while tailoring the learning environments to meet the needs of each child. In previous studies, children with autism attending autism-specific early intervention preschools have shown significant improvements in autism-specific intervention areas (e.g. social communication skill development) and educational goal areas including adaptive behaviour skills (Paynter, Riley, Beamish, Scott, & Heussler, 2015).

Specialist early intervention programs for children with autism tend to feature a

higher teacher-to-student ratio than a mainstream preschool, and staff in early intervention preschools have usually received additional training in autism. There is an increased focus on developing a child's adaptive functioning skills to become as independent as possible, now and in the future. Evidence-based interventions are provided to children using a multidisciplinary collaborative approach, and skills and goals are constantly formally and informally assessed and monitored, providing support and tailoring goals, therapies and intervention (ASPECT, 2016; Paynter et al., 2015). At the end of a child's time at an autism-specific early intervention preschool, there is often continued support from the preschool for the child and their family throughout the transition-to-school process. This includes information about future educational options, whether they be mainstream schools, special education schools, home schooling or other options, coordination of visits to the new educational setting, and sharing of relevant information with the new school (Paynter et al., 2015). As one service provider claims, "Each child is supported to transition to their next school environment" (AEIOU, 2016).

2.4 Transitions to school

2.4.1 Introduction

There is no single definition of the transition to school but generally it includes a series of steps that start with planning and begin before the first day of school and continue until the child is settled into the new environment (Fabian & Dunlop, 2007). Fabian and Dunlop (2007) specifically describe it as "a complex process made up of continuous social activity in which the individual lives and learns to cope, by adapting to the given social conditions" (p. 13). A transition timeline and plan should include a behaviour

support plan that aims to maintain and generalise behaviour and adaptive skills needed for the new setting (Fox, Dunlap, & Cushing, 2002).

Governments in Australia, America, UK and other nations have policies and guidelines for education and disability in place to assist a child to make the transition to school (ACECQA, 2016). Government education departments have information available for planning the transition to school including recommended timelines, meetings, goal setting and planning. In Australia the National Quality Framework 2016 contains specific guidelines that recommend collaborative partnerships with families and communities. Transitions for each child are better supported by sharing relevant information and clarifying responsibilities (ACARA, 2013; ACECQA, 2016). Education Queensland (2016) policies outline that "schools have a responsibility to plan and enact transition strategies effectively supporting each child and meet their individual needs so every child succeeds" (p. 35). Parents should consider the student's learning profile and needs, school district policy and availability of resources when choosing the future educational setting (Janus et al., 2007). Resources to be considered include special education programs in mainstream schools or special education schools in the area (Towle et al., 2014). In their study, Towle et al. (2014) conclude the suitability of the educational setting for the child is likely to have an effect on long-term outcomes.

As noted in Chapter 1, starting school brings changes in many areas simultaneously, including educational settings with a new school, classroom, classmates and educators (Fabian, 2002; Pianta et al., 2001). Changes occur in social interactions within classrooms, and expectations of the child in the classroom and school, including their level of independence, following new rules and daily functioning (Docket & Perry, 2004; Pianta et al., 2001). There is a shift from play-based learning to a more

academically oriented learning environment with a higher student to teacher ratio. Children at school are expected to complete tasks more independently and to require less instruction (Quintero & McIntyre, 2011). They need to adjust to and manage these changes (Pianta et al., 2001).

The diversity of children's lives, backgrounds and characteristics means each child experiences the transition process differently (Rimm-Kaufman, Pianta, & Cox, 2000). As many as 48 per cent of children without a disability have some difficulty in adjusting to the new kindergarten routine, have trouble following classroom rules, or have behavioural issues or social problems (Rimm-Kaufman et al., 2000). Previous studies about the child's perspective on school transitions speak about the importance of developing friendships, and report that the expectations the child has about the social aspects of the new school environment is an important factor to consider (Docket & Perry, 2004). Figure 1 summarises the differences between autism-specific early intervention preschool settings, mainstream preschool settings and school settings.

A successful transition to school for all children requires a collaborative process and emphasises the importance of the educators including the perspectives, experiences and expectations of all involved (Docket & Perry, 2004; Pianta et al., 2001). Purposeful coordination between the old education environment (e.g. early intervention day care or preschool/day care setting) and the new educational setting, and connections between schools and families, maximises gains for children during the transition (Pianta, Cox, Taylor, & Early, 1999; Bogard & Takanishi, 2005). In addition, there is evidence that a smooth transition to school can positively influence later school outcomes (Alexander & Entwisle, 1988; Docket & Perry, 2004; Pianta et al., 2001; Tizard, Blatchford, Burke, Farquhar, & Plewis, 1988).

Early Childhood Setting

- High staff child ratio
- Highly structured playground, diverse activities
- Strict sign in-out procedures for parents/ guardians
- Furtniture and fittings at child height
- Secure physical environment, child-proof gates
- Staff often called by first names
- Attendence variables - no. of days / duration of day
- Bathrooms located inside building
- Choice of clothing, shoes not always required
- Parental choice of centres, no boundaries or legislation re enrolment
- Specialist early childhood educators employed
- Fewer children in setting
- Learning focus on child's interest, child-initiated learning
- Age of children is consistant
- Supervised eating time, socialisation focus, child-child interaction
- Different rates of child development acceptable
- Descriptor "child" is always used

Additional practices of an early intervention Preschool Setting

- Targeting child's goals in small group context with ratio of at least 2 adults to 6 children
- Assessment of strengths and needs to inform programming
- Individualised programming based on review, evaluation and adjustment of program
- Relavent program content addressing autism features e.g. communication
- Highly supportive teaching environments and generalisation strategies
- Predictability and routine using EBPs e.g. visual schedules
- Functional approach to challenging behaviour
- Family involvement
- Transition support
- Use of visual supports and EBPs embedded into daily routine
- Multidisciplinary collaborative approach
- Staff with knowledge and experience of ASD

School Setting

- Lower staff to child ratio in class. Ratio changes between classroom & playground (reduces)
- Less structured playground, less play equipment, children rostered on equipment on different days
- Drop off/pickup procedures less regulated. No sign-in/out.
- Furniture height more generic to suit wider group of students
- Little/no childproof measures. Child released from school when bell rings.
- Staff usually addressed as "Mr/Ms" and surname
- Students usually expected to attend 5 days per week
- Toilets outside classroom space
- School uniform usually required
- Reduced options for parents to choose place of schooling, dependant on government policies/legislation (zoning)
- General education teachers employed
- More children in setting
- School day structured around curriculum and subjects
- Greater independance required, child required to look after itself
- Changes in disciplinary policies and language used at school
- Child required to achieve certain education milestones in standard time period
- Descriptor "student" used

Figure 1: Differences between early childhood, autism-specific early intervention preschools and school settings

Source: adapted from Ody (2016); Paynter et al. (2015); Prior and Roberts (2012).

2.4.2 Transitions and autism

The topic of transitions for a child with autism needs to be considered, whether these are vertical transitions such as transitioning to school or horizontal transitions such as moving between activities. A child with autism is diagnostically characterised as showing restrictive behaviour, and this can be displayed as rigidity (APA, 2013; NAC, 2011, 2015; Prior et al., 2011; Stahmer et al., 2011; Volkmar, 2014; Wong et al., 2014). Rigidity includes difficulties with transitions, that is, difficulty managing changes in one's environment, whether it is changes to places, people or routines (Volkmar, 2014). An individual with autism often has difficulties with transitions (Prior et al., 2011; Saggers et al., 2015; Volkmar, 2014), and this can lead to anxiety symptoms for a child with autism (Stoner et al., 2007). A child may display inappropriate or maladaptive behaviour due to this anxiety (Hanline, 1993; Greenberg, 2011; Stoner et al., 2007). Previous studies have claimed up to 94 per cent of children with autism display a challenging behaviour related to transitions if there are no supports in place (Lequia, Wilkerson, Kim, & Lyons, 2015).

Davis et al. (2011) examined transitions and anxiety longitudinally with 131 participants with autism and compared the results with levels of anxiety in various age groups. They found that there is a rise in anxiety from toddlerhood to childhood; anxiety decreases from childhood to young adulthood, but increases again from young adulthood to adulthood. The researchers suggest a multifaceted explanation for this, but include developmental milestones and environmental factors as possible contributors. The researchers suggest more focused investigations of the transitions from toddlerhood to childhood and childhood to early adulthood to fully understand and expand on these results.

2.4.3 Supporting a child with autism when transitioning to school

There are many differences between an early intervention (EI) preschool setting, a preschool setting and a mainstream school setting, as seen in Figure 1. Providing transition support is vital to meet the educational needs of a child with autism as they begin school, and a comprehensive support plan and strategy can vastly increase the likelihood of a positive outcome (Prior et al., 2011; Roberts & Williams, 2016; Saggers et al., 2015; Volkmar & Weisner, 2009). Transition support means teaching the child to be as independent as possible, while actively supporting the transition using evidence-based interventions individualised to the child's specific strengths and needs (Quintero & McIntyre, 2011; Prior et al., 2011; Roberts & Williams, 2016; Rous, Meyers, & Stricklin, 2007; Volkmar & Weisner, 2009). Evidence-based interventions used for transitions specifically include individualised visual activity schedules, visual supports, verbal or auditory cues, video modelling and priming (NAC, 2011, 2015; Prior et al., 2011; Roberts & Williams, 2016; Sterling-Turner & Jordan, 2007; Volkmar, 2014; Wong et al., 2014).

Transition support must be individualised to meet the needs of the child, the family and the new education setting through collaboration and communication with relevant stakeholders about the child's current skills, strengths and needs (Azad & Mandell, 2016; Prior et al., 2011; Education Queensland, 2016; Roberts & Williams, 2016; Stoner et al., 2007; Volkmar, 2014). There needs to be systematic connection and integration between the child's preschool setting and the new school setting (Fontil & Petrakos, 2015; Rous, Meyers, & Stricklin, 2007; Stoner et al., 2007; Prior et al., 2011). Education Queensland (2016) proposes that a transition timeline is a useful tool for coordinating the transition to school, and states that:

> collaboration between the family, teachers and other relevant people may assist in ensuring the very best start to schooling for a child with ASD. This ensures that everyone is on the same page and aware of what supports are in place and who is responsible. (p. 36)

Education Queensland (2016) specifies that the transition is a journey that starts before the first day of school and continues over a twelve-month period. This time gives everyone the opportunity to plan, develop, resource and reflect on the transition strategies and supports used in the timeline.

In their study, Forest, Horner, Lewis-Palmer and Todd (2004) identified twenty-five stages in the transition-to-school process by reviewing previous literature about transitioning to school for a child with autism. They then built their summary into a survey instrument, and used it with parents, preschool teachers and school teachers for three children with autism while they transitioned to school. The twenty-five stages included choosing the new school. Twelve to six months before the transition to school, parents had chosen the new school. Visits and meetings took place within this time. The child was assessed for school readiness and a timeline for the transition was created. Classroom visits were arranged, and related services were identified. Six months before the transition Forest et al. (2004) identified several transition points including the collaboration between old and new educational environments, starting to expose the child to the new school environment including classroom and educators, and the opportunity for the new teacher to observe the child in their preschool environment. Also, an instructional curriculum was created, and materials specific to the child's needs were identified and created (Early, Pianta, Taylor, & Cox, 2001; Forest et al., 2004). The survey showed that the parents and teachers considered the twenty-five stages to be

important to a smooth transition. However, the perceived level of implementation varied between elements. This study provides an index of the twenty-five transition elements to guide future research when studying the process of transitioning to school.

According to Volkmar (2014), the transition to school should also include identifying the skills the child will need in the new educational setting, and increasing exposure to the new setting through longer visits. Volkmar (2014) also highlighted that the most effective strategies for a successful school transition include time for planning and preparation, sharing information with the family, preparing the child for the changes in services, and preparing the new school and educators so they can make reasonable adjustments for inclusion. Planning ahead using evidence-based interventions before starting school as part of the transition timeline assists a child with autism (Kemp, 2003; McCumber, 2011; Stoner et al., 2007; Volkmar, 2014). Some children also transition to kindergarten, starting the year on a part-time basis, gradually building attendance from 2–3 days per week to 5 days to meet the needs of the child (Walker et al., 2012).

Given the importance of evidence-based interventions and strategies for a child with autism, some research has examined the integration of these practices beyond autism-specific early intervention preschool settings into a mainstream school setting. For example, Grindle et al. (2009) investigated the possibility of integrating intensive evidence-based practices into mainstream school settings with two intended outcomes: access to the national curriculum, and inclusion with peers in a mainstream setting. They proposed using evidence-based interventions such as positive behaviour support, task analysis, discrete-trial training and generalisation, together with functional behaviour assessments, data-driven teaching and learning, and high quality training and supervision. The results were a practical example of how these EBPs can be integrated

into a mainstream classroom while supporting access to the national curriculum. Grindle et al. (2009) highlight the lack of research into the benefits of providing evidence-based behavioural instruction beyond the early intervention years. Grindle et al. (2009) also suggest that an evidence-based educational pathway throughout the school years would be useful (including primary and secondary school). This is, so far, an under-researched area.

2.4.4 Supporting adaptive behaviour for a child with autism during the transition to school

Assessing adaptive behaviour changes related to the transition to school can help us understand how a child with autism is coping and the extent to which they have developed, maintained or lost adaptive behaviour skills. The stress of a transition can bring about maladaptive behaviour due to anxiety (Hanline, 1993; Greenberg, 2011). Because measures of adaptive behaviour levels can also help to predict challenging behaviours for a child with autism (Felce & Kerr, 2013), the child's social, cognitive and adaptive functioning should be measured before, during and after the transition to the new educational setting (Prior et al., 2011; Flanagan et al., 2015). Effective and efficient transitions are important for improving independent functioning and adaptive behaviour for a child with autism (Sterling-Turner & Jordan, 2007).

McIntyre et al. (2006) state that adaptive functioning is a predictor of a positive school adjustment. Parents notice and are aware of their child's anxiety during a difficult transition (Stoner et al., 2007). O'Connor and Healy (2010) investigated the longitudinal outcomes for individuals with autism who had intensive early intervention behavioural therapies and then attended a mainstream setting, and reported mixed results. Some participants maintained gains they had made following intensive

behavioural intervention and others' adaptive behaviour development slowed or regressed. Although this study is relatively small, with five participants, it is interesting to note these findings, as they raise an important question, and suggest future research in this area is important to determine the factors influencing these mixed results. The researchers concluded that there is a "need for ongoing access to a multidisciplinary team to provide extra specialist input to both the home and school environment" (p. 602). They go on to sugest "continuing comprehensive intervention in the school setting to address "social skills training, daily living skills, communication training, behavioural intervention and support, psychological and psychiatric support" (p. 602). Areas to be supported should include adaptive behaviour, as in some cases skills gained in the EI setting were lost once attending a mainstream setting (O'Connor & Healy, 2010). A child who continues to have difficulties with social skills may present as having reduced motivation to seek social interactions or difficulties because of developmental delay when compared to peers. All participants in this study showed varying degrees of anxiety syptoms in both the school and home settings (O'Connor & Healy, 2010).

2.5 Parents, their role and perspectives

2.5.1 Parental roles throughout the transition to school

Although there are good guidelines and suggested practices for supporting a child with autism in their transition to school the amount these practices are utilised varies, as do opinions as to why this is the case (Kemp, 2003; Pianta, Cox et al., 1999; Roberts & Williams, 2016; Walker et al., 2012). In Kemp's (2003) study on children with a disability transitioning into an inclusive school environment, the educators nominated the attitude of the family as the most important factor determining a successful

relationship with the school. In other studies, parents' and educators' opinions differed on the optimal amount of support for a child with autism's transition to school. Parents of a child with autism were surveyed in previous studies, and expressed they wanted more collaboration to take place, and more preparation and understanding of autism from the educational staff (Early et al., 2001; Forest et al., 2004; Quintero & McIntyre, 2011; Walker et al., 2012; Zablotsky, Boswell, & Smith, 2012). However, educators claimed that one of the biggest barriers to a successful transition is time to prepare and implement any transition interventions or strategies (Early et al., 2001; La Paro, Kraft-Sayre, & Pianta, 2003). Other barriers outlined by educators in previous studies are late class list confirmations, making any transition support before school starts difficult, large class sizes and lack of teacher training (Early et al., 2001). These factors can all affect a successful transition to school.

An important area of consideration when a child starts school is communication between the parents and the new school. Azad and Mandell (2016) claimed that both parents and educators agree that once a child has started school parent–teacher communication, rather than agreement with each other, is the positive contributing factor to a successful home–school collaboration in the new setting. There is some evidence to suggest that parents of a school-age child with autism are more likely than other parents to attend parent-teacher conferences, meet with school guidance councillors and help with homework (Zablotsky, Boswell, & Smith, 2012). The frequency and quality of parent–teacher communication and the parent–teacher relationship in the new educational environment is of key importance (Azad & Mandell, 2016; Brewin, Renwick, & Fudge Schormans, 2008; Kamimura & Ishikuma, 2007; Saggers et al., 2015; Stoner et al., 2007). Parents of a child with autism are also more likely than other parents to be dissatisfied with the level of ongoing communication and

collaboration with the school (Stoner et al., 2007; Zablotsky, Boswell, & Smith, 2012). Parents of a child with autism who have a more active role in their child's education have a higher level of satisfaction with the school, and lower levels of stress (Benson et al., 2008; Dempsey & Sandler, 1997; Kasari, Freeman, Bauminger, & Alkin, 1999; Kuhn & Carter, 2006; Zablotsky, Boswell, & Smith, 2012). This shows that a high quality of communication between parents and educators can help support the child with autism in the new school environment (Stoner et al., 2005; Stoner & Angell, 2006).

Stoner et al. (2007) investigated the perspectives and concerns of parents of a young child with autism in relation to transitions and described parents of a child with autism felt transitions were effective when they were child-centred, with communication being vital to success. In this study, parents explained that preparations for the transition involved ensuring educators understood the child, and parents were able to identify potentially effective transition strategies for their child (Stoner et al., 2007). This study also found parents felt the individual characteristics of the child with autism needed to be considered, including their strengths and weaknesses (Stoner et al., 2007). Developing this information into a "child profile" meant parents did not have to repeat important information about their child, such as their likes and dislikes, and strengths and weaknesses (Stoner et al., 2007). Including the child profile in a transition timeline can improve outcomes for a child with autism and support them through the transition effectively (Stoner et al., 2007).

The relationship between the parents and educators is complex and dynamic (Stoner et al., 2007). Stoner et al. (2007) also report that parents identified lack of communication, lack of recognition of transition strategies by educators, and lack of preparation of the education professionals as major barriers to a successful transition. Parents also wanted educators to have more flexibility to give their child with autism

time to make transitions, expertise to implement the transition strategies outlined, and sensitivity to recognise that successful transitions at an early age would be likely to help the child with transitions in the future. Parents described transitioning from one schooling environment to another as one of the biggest transitions their child would make, aside from the transition into adulthood (Stoner et al., 2007). Stoner et al. (2007) state that parents commonly used an "identify – observe – explore" strategy for vertical transitions. This gave all involved in the transition to school an opportunity to connect before the start of the school year. The use of the "child profile" was of key value during vertical transitioning in this study. It is, however, unclear whether this would help support adaptive behaviour throughout the transition, or whether adaptive behaviour skills should be included on the child profile (Stoner et al., 2007).

The parents' expectations of the educators are a factor when attempting to understand the parent–teacher dyad. Falkmer et al. (2015) studied parent perspectives on inclusive schools for a child with autism. They found that parents believe that educators play a vital role in the inclusion of their child. Parents believe an inclusive educational environment is created through positive peer relations, detailed bullying policies (Zaboltsky, Bradshaw, Anderson, & Law, 2012), and help from support staff, with trust being developed through high quality communication and their everyday relationship with their child's teacher (Stoner et al., 2005; Stoner & Angell, 2006). Funding, legislation and policies are considered important also, and parents are aware of the financial strains mainstream schools are under (Stoner & Angell, 2006). Parents have expressed a need and willingness to partner with the educators and the school and want to provide information specific to their child to enhance the teacher's ability to individualise classroom activities or classroom adjustments (Stoner & Angell, 2006). Parents also commonly stated their desire for information sharing between staff, and

frustration at having to constantly repeat information about their child (Falkmer et al., 2015).

Previous studies show there is benefit in encouraging parents to be fully engaged in their child's education, and the level of involvement should suit the parents' and family's situation and needs (Stoner & Angell, 2006). Stoner and Angell (2006) asked parents about the role they played in their child with autism's educational programs. They found that parents predominantly played the roles of negotiator, monitor, supporter and advocate. The parents' degree of trust in the educators affected the extent of their involvement and the type of role the parents took on. If the parent trusted the educators, they played a more supportive role, and advocated for their child. If there was a low level of trust, parents played the roles of negotiator and monitor as their dominant roles. The parent's primary motivating force was to communicate the changing needs of their child (Stoner & Angell, 2006).

2.5.2 Parental stress

Challenging or maladaptive behaviours including hyperactivity, agression and attention problems can have an impact on the child's family by increasing parental stress. Challenging behaviour also negatively affects learning outcomes, and may prevent the child from accessing relevent community services (Allen et al., 2007; Felce & Kerr, 2013; Lane, Paynter, & Sharman, 2013; Lecavalier et al., 2006; O'Connor & Healy, 2010). Teaching daily living skills to a child with autism has been shown to reduce parenting stress and potentially improve family functioning, and therefore is another reason it should be a target goal for intervention (Green & Carter, 2014). O'Connor and Healy (2010) argue parents benefit from the social network and connection with other parents in the EI setting, and often experience high levels of stress and and a sense of

isolation in the new mainstream setting. There is substantial evidence that parents with a child diagnosed with autism with low adaptive behaviour scores experience high stress levels and that these factors may be linked (Hall & Graff, 2010, 2011). Hall and Graff (2011) found that 62.7 per cent of parents surveyed had total stress scores above the 90th percentile, indicating high levels of stress for parents of a child with autism who had low adaptive behaviour skills.

2.6 Implications and conclusion

Parents have a major role in a child with autism's transition to school and can be a key factor in the child's achievements (Stoner & Angell, 2006). Parents are involved with all aspects of the transition, and are essential for an effective school transition (Defur, Todd-Allen, & Getzel, 2001; Stoner & Angell, 2006). This chapter has covered all aspects of the research question from previous literature, and highlights the importance of assessing the adaptive behaviours of a child with autism. The literature review includes the topics of autism, early intervention, parent roles, adaptive behaviour and intervention, anxiety for a child with autism, educational policy and frameworks, transitions, and transitioning to school for all children. This chapter covered the changes involved in a transition to school, the challenges a child with autism may face with transitioning, and previous studies that outline evidence-based strategies to support a child with autism when transitioning to school. The literature review investigated previous studies about changes in adaptive behaviour and the importance of understanding why these changes may occur.

The exploration of parents' attitudes and experiences will help to achieve a deeper level of understanding of the issues raised in previous studies, presented in the introduction (Brantlinger et al., 2005). Understanding parents' perspectives about the

changes they observe in their child during and after a transition to school using qualitative measures has been an important method of inquiry in previous studies, and addresses the questions of how and why these changes occur. Exploring the perspectives of parents of their child's adaptive behaviour changes during a transition can contribute valuable insight into the reasons any changes occur. Researching the area of adaptive behaviour changes related to the transition to school can help us understand how a child with autism copes and the extent to which they develop, maintain or lose adaptive behaviour skills. Research is needed to determine whether a child with autism loses skills, shows a decline in the rate of skill development, or no change in skill development, and to look for possible explanations for this. These results will contribute a deeper understanding of changes during and after the transition to school by means of the qualitative methods, which provide powerful descriptions and explanations from parents (Miles & Huberman, 1994). Using qualitative information about a child with autism transitioning to school, a broader and deeper knowledge and understanding is possible, contributing meaningful information on how to support adaptive behaviour in this time of transition.

Chapter 3: Methodology

3.1 Introduction

Chapter 3 explains the methods chosen to achieve the aims, process and objectives of investigating the way parents perceive the changes, if any, in the adaptive behaviour of their child with autism following the transition to school, including their opinion of the reasons behind any changes. Section 3.2 explains the research design used in the study and how this was implemented; Section 3.3 details the inclusion criteria of the participants; Section 3.4 outlines the data collection procedures and measures; Section 3.5 discusses how the data was analysed and indicators of the quality of the thematic analysis; and Section 3.6 discusses the ethics clearances, participant consent and confidentiality, and data collection, storage and security procedures.

3.2 Design

A qualitative design was chosen to determine the nature of the experiences of parents of a child with autism regarding transitioning to school from an autism-specific early intervention preschool setting. This design was chosen because it is a "systematic approach to understanding qualities or the essential nature of a phenomenon within a particular context" (Brantlinger et al., 2005, p. 195). There are quality indicators within interview studies using qualitative research. These include ensuring that appropriate participants are selected, the interview questions are reasonable, adequate mechanisms are used to record and transcribe the interviews, the participants are represented sensitively and fairly, and sound procedures are used to ensure confidentiality (Brantlinger et al., 2005).

Before the interview, parents filled out a survey, which included information about the transition. The survey was intended to help describe the participants and

encourage parents to think about the issues relating to the transition (see Appendix C). A semi-structured interview conducted by phone was selected (Limperopoulos, Majnemer, Steinbach, & Shevell, 2006). In-depth interviewing by way of semi or unstructured interviews that are open ended in nature is a method of data collection in qualitative research that allows the parents to put their views in their own words (Kumar, 2014). The process of qualitative research gives meaning to and enables understanding of participants' experiences, which in the current study included the questions "how" and "why" any changes in adaptive behaviour may have occurred (Brantlinger et al., 2005; Creswell, 2013; Kumar, 2014; O'Leary, 2014). Qualitative methods of investigation such as semi-structured interviews, narratives and life histories are appropriate for research focusing on a participant's personal perspective or experiences (Creswell, 2012; Kumar, 2014; Silverman, 2013). When doing qualitative research by way of interviews, critical subjectivity is needed, respecting the collaborative nature of the research, and creating an environment that is respectful of the reciprocity of trust and sensitivity involved in sharing information (Creswell, 2013).

3.3 Participants

The participants recruited were fourteen parents who had a child diagnosed with autism who was in their first year of primary school. Primary school could mean a mainstream public or private school with or without special education units, a special school, or an autism-specific school. Refer to Table 1 below for demographic information about the school settings. Parents with a child who fit the participant criteria were contacted via email via already established communication channels and invited to volunteer to participate in the study. Participants were recruited between four and seven months following their child's transition to school. Purposeful sampling was used, and an initial

cohort of participants was recruited through an early intervention centre. Seven parents agreed to participate. A second cohort of participants was recruited to achieve the desired sample size (n = 10–15). The second cohort was recruited through the Longitudinal Study of Australian Students with Autism (LASA). A subgroup of the second study who fit the inclusion criteria were contacted and from this group seven agreed to participate. See Appendix A for the recruitment email.

Recruiting from the two cohorts also gave the researcher an opportunity for data triangulation in the form of "perspective triangulation". Patton (1999) explains that purposeful sampling involves "studying information-rich bases in depth and detail" (p. 1197). Perspective triangulation allows the researcher to use data obtained from different preschool and school settings and differing backgrounds and demographics, mixing purposeful samples and multiple perspectives. The triangulation strategy within a qualitative method of enquiry involves collecting and checking information collected from multiple sources for consistency of evidence across those sources (Mertens, 2010). This leads to a more unbiased range of experiences being reported to reflect a range of views and experiences, and gives more opportunity for a result reflective of a larger community.

Parents were invited to participate via an email (see Appendix A) and given information about the study (see Appendix B). Parents who were interested in participating then contacted the research team. Parents had the opportunity to ask questions about the study before agreeing to participate, and then were given a short survey to complete with basic demographic information, the child's current educational setting, and general information about the transition to school process (see Appendix C). This helped the participants to recall the time leading up to and following the start of school. Each participant was given the interview questions list in advance (Kumar,

2014). See Appendix D for the semi-structured interview questions. The parents were made aware the transition to school covered the events involving the transition leading up to the start of school, and then the first school term after starting school. This meant the changes in adaptive behaviour once their child had started school could be discussed, as well as whether the parents perceived that the changes in adaptive behaviour related directly to the transition. Different schools have different programs for transitioning a child to school, and some school transitions encompass the entire first year of school as a transition period, gradually exposing the child to the new school environment as the year progresses. Although there is no precise time limit for the transition to school, each participant was directed to discuss changes in relation to starting school and being in the new school setting, and the related period of adjustment. Participants were also directed to discuss their individual situation in relation to the transition program their child's school had provided.

Table 1: Demographic information on the participants' child and school settings

No.	Parent	Child's gender	Preschool setting	School setting
1	Father	Female	Autism-specific preschool	Mainstream + aide
2	Mother	Female	Autism-specific preschool	Mainstream + classroom aide
3	Mother	Male	Autism-specific preschool	Mainstream + aide + support class
4	Mother	Female	Autism-specific preschool	Mainstream + aide + support class
5	Mother	Female	Autism-specific preschool	Mainstream + classroom aide
6	Mother	Male	Autism-specific preschool	Mainstream + aide + support class
7	Mother	Male	Autism-specific preschool	Mainstream + aide + support class
8	Mother	Male	Preschool & ECDP	Special school (not ASD specific)
9	Mother	Male	Autism-specific preschool	Bridging (mainstream 2 days, special school 3 days)
10	Mother	Male	Preschool	Private mainstream school
11	Mother	Male	Preschool & ECDP	Mainstream + aide
12	Mother	Male	Special school & preschool	Mainstream + aide + support class
13	Mother	Male	Autism-specific preschool	Mainstream school no aide
14	Mother	Male	Preschool & EI	Mainstream + aide

3.4 Data collection

3.4.1 Procedures

Interviews were conducted over the phone by the author at a time convenient to each participant. A phone interview can be an adequate approach to achieve a desirable response for qualitative inquiry (Limperopoulos et al., 2006; O'Leary, 2014). The researcher referred back to the semi-structured interview questions as necessary during the interview to ensure all necessary points regarding adaptive behaviour changes and the research topic were covered. Each interview was recorded by the author then transcribed using an external transcription service.

3.4.2 Interview guide

The semi-structured interview questions started by asking for general information about their child's transition process, whether they thought the school is a good fit, and what communication methods they have with the current educational setting. Each parent was then asked to give information about any perceived adaptive behaviour changes in the areas of daily living skill development, social skill development, and language and communication development around the time their child started school. The researcher asked the parent for details surrounding any perceived adaptive behaviour changes and their opinion about the impact and possible causes of those changes. At the end of the interview the parent could add anything else they felt was relevant. Each parent was also offered an opportunity to suggest ways the transition process could have been improved for their child (see Appendix D for interview questions).

The interview questions were designed to address the research question, covering each area of adaptive behaviour. Care was taken to ensure the questions were presented with sensitivity and in a non-threatening manner. The questions were clearly worded, were not leading, and were appropriate and sufficient for exploring this topic in a semi-structured format (Brantlinger et al., 2005). Although it was unlikely, each participant was alerted to the fact that some questions might be stressful or distressing to answer. Each parent was reassured that they had the option of not answering any questions that made them feel uncomfortable or upset. No parent declined to answer any questions.

During the interview, the researcher ensured she did not speak over or interrupt participants, to give them as much opportunity as possible to communicate their views and express their opinions. This was done with the intention of increasing the quality of the data (Kumar, 2014). The researcher did not want to interfere with possible

unexpected ideas or themes that might arise as a result of their willingness to participate, and also did not want to influence a participant's response (O'Leary, 2014). Because each participant received the questions beforehand, many participants had taken notes or prepared their answers in advance (Kumar, 2014), which was likely to have improved the flow of the interview and generally made the participant appear more relaxed and talkative.

3.5 Data analysis

During the interview, the researcher made notes on paper when possible areas of interest for codes arose, or information regarding the topic question was addressed (Braun & Clarke, 2006; Kumar, 2014). The interview recordings were sent to a professional transcription service to be transcribed. After the data set was transcribed, it was imported into NVivo for analysis. NVivo is a highly effective and efficient way to code and analyse qualitative data (Bazeley & Jackson, 2013). The researcher completed an online course in NVivo and met with fellow researchers who use NVivo professionally, for credibility checks and to confirm the author's organisation of data in NVivo and utilisation of NVivo's features.

The data was analysed according to Braun and Clarke's (2006) approach to thematic analysis, systematically, including full immersion in the data, to identify codes and possible themes through the transcripts. Themes capture something important about the data that relates to the research question, and represent a meaning within the data set (Braun & Clarke, 2006). Themes relevant to the research question were analysed and reported using coding. Braun and Clarke's (2006) six steps to thematic analysis were followed. In phase one, the researcher familiarised herself with the data by listening back to each recording in its entirety to get an overall sense of the interview, noting any

themes or points repeated by the participant (Braun & Clarke, 2006). A journal of every phase of the thematic analysis was kept in NVivo, ensuring that any codes and themes that emerged could be explained at any point of the analysis process. The notes the researcher took during the interviews were also imported into NVivo. The notes thus became part of the data, and could be read and reread as part of the analysis.

The research generated codes following phase one and two outlined by Braun and Clarke's (2006) phases of thematic analysis, that is, by becoming familiar with the data by listening back to the original recordings, and reading and re-reading transcripts. Braun and Clarke's (2006) methods were used to find patterns of meaning and issues of potential interest. The content of the transcripts was analysed by coding data in a systematic fashion, with initial coding including the key areas of the research questions. The transcripts were then read and re-read, exploring the data more thoroughly to identify codes and possible future themes (Braun & Clarke, 2006; Creswell, 2013; O'Leary, 2014; Kumar, 2014). Other secondary codes were also identified by noting when a participant repeated the same information, terms that sounded unfamiliar, transitions in topic by the participant, similarities or differences between participants' answers, metaphors or analogies the participants used, and linguistic connectors like "because" or "since", which can eventually indicate a theme (Ryan & Bernard, 2003).

In phase two of the thematic analysis the researcher set up codes based on four paradigms. The first was attitudes and experiences, which was then renamed "response". This had sub-codes of "positive", "negative" and "mixed". Coding in this way assists exploring future themes or potential correlations in relation to positive, negative or mixed reactions. Codes relating to the research question were created using each of the key words in the research question as a code category. For example, "changes" was a code, "adaptive behaviour" was a code with sub-codes of daily living

skills, social abilities and language and communication, and "transition to school" was a code. The researcher used "changes" as a code when there was a change due to the transition, outlining whether it was positive or negative, which was useful for exploring future themes or potential correlations. Possible themes were noted from the notes taken during the initial interviews, and from listening back to all the interviews. These have been called "secondary codes".

Phase three was the refinement of the emerging themes. Once potential themes were found, the data were highlighted then analysed and coded into one of the potential themes, then the themes were reviewed and checked again with the coded extracts, moving on to phase four of Braun and Clarke's thematic analysis, which is reviewing themes and generating a thematic map of the analysis (Braun & Clarke, 2006). The researcher drew up thematic maps, representing each possible theme. Each of the primary and secondary codes was then coded into these themes. The notes in the journal at this time explain the four themes that were emerging. The original interview recordings were listened to again, to ensure the original data were represented correctly (Kumar, 2014). The transcripts, the primary and secondary codes, and the final themes were re-read one last time to ensure full immersion in the data. Phase five of thematic analysis was when the research refined and named the final themes, and checked all data in those themes for their coding accuracy, and coherence within the theme (Braun & Clarke, 2006). Finally, phase six involved a final analysis, producing a report of the data, extracting relevant, compelling extracts as examples of the themes, and relating this back to the research question and literature review (Braun & Clarke, 2006).

3.5.1 Quality indicators in qualitative research and thematic analysis

Throughout this project, the researcher's goal was to maintain an extremely high level of professional integrity in all stages of the analysis process. The researcher ensured rigorous data collection procedures were employed with high quality recordings in the interviews, and maintaining consistency in data collection methods throughout (Creswell, 2013). The researcher framed the study within the assumptions and characteristics of the qualitative approach to research. This included an evolving design, the presentation of multiple realities, the researcher as an instrument of data collection and a focus on the participants' views. An appropriate qualitative approach to the enquiry was used by way of semi-structured interviews and thematic data analysis. The researcher started by exploring a single focus or concept, which was the research question. The study included detailed methods and a rigorous approach to data collection, data analysis and report writing. The data was analysed using multiple levels of abstraction. The researcher attempted to write persuasively so that the reader could feel like they were there. The researcher attempted to make sure the study reflected her history, culture and personal experiences in some way without allowing this to influence the results. Finally, this study was ethical and followed ethics guidelines and policies.

Braun and Clarke (2006) outline quality indicators within thematic analysis. The researcher ensured each theme was given equal attention and enough time was given to thoroughly describe and confirm each theme. Coding was thorough, inclusive and comprehensive, using NVivo to thoroughly code the process of thematic analysis. A journal was kept in NVivo at all times in the form of memos so that each code and theme could be explained and explored at any stage of the analyses process. The researcher took care to select and collate extracts that were rich in detail, and to link with and represent each theme accurately to create an insightful picture of each theme.

All themes were crosschecked and re-checked to ensure their accuracy and authenticity in representing the original data. The themes are internally coherent, consistent and distinct. Once some initial themes were outlined, the researcher crosschecked and reanalysed the data on multiple levels to ensure the descriptions and explanations of each theme were accurate and meticulously described. The data were analysed and not simply described by utilising NVivo to fully dissect and analyse the data to generate a deeper understanding of the themes. Once the final analysis was made, the researcher ensured it was a solid and precise representation of the original data by re-reading the original data throughout the analysis process and at the final analysis stage. During the analysis, the researcher attempted to accurately describe the experiences of the parents interviewed, with a goal to compile the results into a compelling discussion representing the voices of the participants.

Extreme care was taken to balance the extracts and narrative component of the final report. An extended amount of time was spent in the thematic analysis process, taking time to read, re-read, and move to and from the codes, themes, recordings and transcripts. Time was also spent drawing thematic maps of each theme, and having breaks away from the data, coming back with a fresh mind to confirm and explore all previous notes, memos and thematic analysis. A highly detailed journal was kept throughout the thematic analysis process, including findings, reasons, approaches, links to literature, and any assumptions or observations that were made along the way. This allowed for reflection on the process but also justification of the analysis. There was a fit between the claim to answer the research question and what was undertaken during the study, including the thematic analysis, which explains and covers what the researcher set out to do, that is, exploring parent perspectives of changes in all areas of adaptive behaviour in their child with autism, exploring why these changes may have

occurred, and investigating any associations or correlations between these changes and the transition to school.

The researcher's supervisory team did credibility checks at several points throughout the analysis of the data to enhance the trustworthiness of the researcher's analytic process and results. This was done firstly when the data were initially coded. The supervisory team and the author coded the first two interviews and crosschecked initial notes and ideas on coding already done by the author. Secondly the supervisory team reviewed the coding and theme selection during each of the six phases of the Braun and Clarke (2006) method. Phase one is finding patterns of meaning and potential areas of interest using data familiarisation and noting initial ideas. Phase two is generating initial codes in a systematic fashion. Phase three is searching for potential themes and organising the data. Phase four is reviewing the potential themes, finding coded extracts and generating a thematic map of analysis. Phase five is further refining and clearly defining the themes. Phase six is the final analysis and report, checking back to the original research question and literature reviewed.

The author made certain that her approach to the analysis was consistent especially with regard to its methods, validity and scope, and the distinction between justified belief and opinion. The researcher saw herself as active in generating the themes rather than passively witnessing themes emerging in several ways, including learning NVivo, to ensure that a rigorous process of thematic data analysis was employed and recorded during every phase of the analytic process. In-depth progress notes of the process of data analysis were kept as memos. These included keeping a detailed journal every step of the way, which included notes, literary references, ideas, thoughts, emerging concepts, the coding and analysis process, the emergence of themes, photos of the paper notes taken during the interviews, and photos of the thematic maps

created throughout the analysis process. This was an active analytic process that contributed to a high quality qualitative study and thematic analysis.

3.6 Ethical considerations

The following section contains information about the ethical considerations of the study, and how ethical standards were maintained including ethics involving participation, consent and confidentiality; question design; and data collection, storage and security.

3.6.1 Ethical clearance

Section 5.2.23 of the National Statement on Ethical Conduct in Human Research 2007 specifies that an appropriate ethical review body must approve all participant information and consent materials prior to their use. Ethical clearance was required for this research project as it involved human subjects. Ethical clearance for both cohorts was applied for and granted by Griffith University's Human Research Ethics Committee (GU ref no: 2016/676 and 2015/32), and included all information in alignment with Section 5.2.23 of the National Statement on Ethical Conduct in Human Research 2007. This included information about participation, consent, confidentiality, question design, data collection and storage, and data security. Creswell (2012) states that "participants and their human rights must be respected during the research process" (p. 1360). The Griffith University HREC ethics policy ensures that participants are aware of their rights as a participant, including the right to withdraw.

3.6.2 Participation, consent and confidentiality

All participants were informed that their participation in this study was voluntary and they had the right to withdraw at any time throughout the process without consequence. An email was sent to possible participants, providing information about the nature of the study and how it would be conducted, how the data would be collected and recorded, and the voluntary nature of their inclusion in the project. Participants were informed that the findings might be published or available in print; however, anonymity would be maintained, and no institution or individual would be identified. Sound measures are in place to ensure the confidentiality and anonymity of participants (Brantlinger et al., 2005). Individuals' names have been changed with the use of pseudonyms.

3.6.3 Data collection, storage and security

Ethical policy outlines the need to stipulate how data is collected, stored and secured. Data collection, storage and security in this study are in alignment with these policies. There is an audit trail and all interviews and data analysis have been kept in case findings need to be reviewed or justified (Brantlinger et al., 2005). All audio recordings, documents, analysis and results are stored on the researcher's computer under password protection. Any hard copies of this information in any form including the researcher's notes taken during the interviews, or printed information of any form, is stored in folders in a secure location. Data will be destroyed in accordance with Griffith University's ethics policies.

Chapter 4: Results

4.1 Introduction

Parents often reported adaptive behaviour changes in their child with autism during the transition to school. Some of these were gains where new skills were seen, some were changes in developmental rates such as a slowing of development, and some were regressions such as the loss of a skill or behaviour previously learned. From the thematic analysis, three themes emerged as factors that influenced changes in adaptive behaviours as perceived by parents. The first theme, "child willingness", represents the parents' accounts of the different levels of each child's willingness to go to school. This ranged from being excited to attend through to school refusal. The presence of child willingness was a factor in adaptive behaviour changes. This theme shows, from both the positive and negative experiences of the parents and child, that the voice of the child is an important part of the transition process and is pivotal in determining whether adaptive behaviour will continue to develop in the new school environment during and post transition.

Theme two, "quality key stakeholder engagement", accounts for the particular roles of the parent as coordinator and advocate and of educators as collaborators and implementers and the effect these roles have on adaptive behaviour. The final theme, "school-wide support", captures the parents' perceptions that the school's role as supplier and enabler is important not only in meeting the needs of their child, but also in supplying resources and funding and enabling each key stakeholder to actively engage in their role during the transition to school. School-wide support facilitated continued adaptive behaviour development. This content of this chapter describes the results of the process of thematic analysis described in the previous chapter. Names have been changed for any person or institution mentioned to maintain confidentiality.

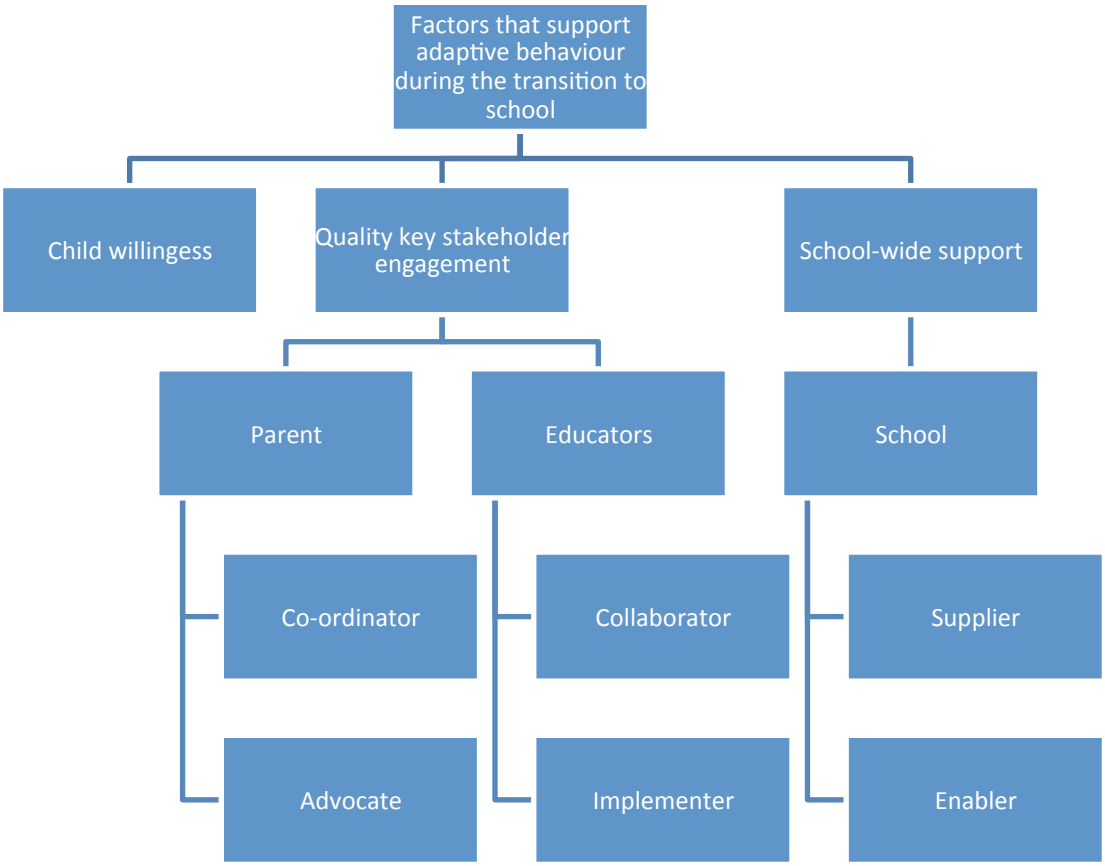

Figure 2: The results of this study as three main themes

4.2 Theme 1: Child willingness

4.2.1 Introduction

> *What it really comes down to, and I've talked to all the parents from her class last year about what worked and what didn't work, and overwhelmingly what worked was the child was willing and able.* (Alan)

Parents discussed their child's transition-to-school process, what their child liked and disliked about school, whether their child was enthusiastic about attending the new school setting or if he or she was showing signs of school refusal. Some parents spoke of their child wanting to go to school or performing tasks that they had not previously seen him or her perform. Gina described how she tried to facilitate her child's willingness during transition, making school a positive experience for her child:

> *I'm greatly surprised he put his uniform on and he got all excited. We tried to make it an exciting thing: oh, you're going to big school.*

Parents described child willingness as encompassing a range of experiences, for example the child's enthusiasm about attending from day to day, their increase in daily living skill development such as an eagerness to prepare for school, an increase in self-care or independence while at school, or their child wanting to make friends and fit in with peers. When there was no school refusal from the child, parents claimed there were gains at home with daily living skills, getting ready for school, taking care of belongings and following routines. Elizabeth's comment below reflects how much her child wanted to go to school:

She hates being on school holidays. Even when she's sick she wants to pull herself out of her death bed and go to school, so to be honest she loves school.

When a child displayed school refusal, in most cases adaptive behaviour development reportedly slowed or sometimes regressed. There was usually a form of social withdrawal, or loss of skills previously learned and unwillingness at home. Many parents attributed these changes to stress or anxiety in their child. Sharon described her child showed anxiety symptoms during the transition to school period:

So Rebecca shows a lot of anxiety still on the trip to school. She'll keep it to herself or her face drops, she goes very quiet.

Parents described the way refusal to go to school was actually vocalised by some children. Sophie talked about how distressing school refusal was for her and her child:

He definitely was the most anxious we've ever seen him and he was really crying himself to sleep that whole first term really and then he'd wake at 4:30, 5:00 in the morning and he'd start straight away, "Don't want to – don't want to go to school. Why do I have to? Why does Johnny go to school?", this type of thing over and over and over and over. It was really unnerving because he just never had that about anything.

Some parents argued they felt their child was very well supported during the transition to school, in particular with the transition-to-school program and strategies

the school had in place. Some claimed this helped with their child's willingness to attend school, and reduced anxiety symptoms. Stephanie talked about the transition to school program working for her child, and how important she felt the program was:

> *I think running a good transition program leading up to the start of school is a good thing, particularly for kids on the spectrum. They want to know and feel comfortable and to remove a lot of that anxiety.*

Most of the schools that parents spoke of provided some level of support during the transition-to-school process. The amount of support varied, however, in time allocated and strategies used in the transition. In many cases part of the transition to school plan was for the child to have a gradual exposure to the mainstream environment, through a separate special education program, and to transition into the mainstream classroom gradually when the individual child was willing and able. Elizabeth also talked this about in relation to anxiety levels:

> *He's in what they call a little studio room as opposed to being mainstream straight away. I think that's just reduced the whole anxiety of the whole thing so much, because it's not overwhelming for him. There's five or six kids in the class and there's a teacher aide. They're doing their curriculum. They're doing the Prep curriculum. They work alongside with the Prep teachers and they tend to do it that way until they feel that the kids are ready to start sitting into mainstream, as opposed to putting them straight into the mainstream and then plucking them out.*

This theme reflects the relationship between a child's willingness to go to school and their adaptive behaviour development. When school refusal occurs it is related to a slowing of adaptive behaviour development or in some cases a regression in skills and behaviours previously acquired. The following sections (4.2.2, 4.2.3, 4.2.4) each describe a specific area of adaptive behaviour in more detail, including what factors parents perceived as affecting daily living skill development, social ability development, and language and communication development.

4.2.2 Child willingness and daily living skill development

Parents reported that when their child was willing to go to school and there was little or no school refusal, independence at home and at school increased. The skills that increased were usually embedded within the daily routine, like getting ready for school, putting bags away at school and following the daily class routine. Parents argued that these gains in daily living skill development were linked to their child's willingness to attend school and, the more they were willing to participate, the more an increase in development was seen. Lisa explained the specific gains in daily living skill development in her child:

> *He's eager to unpack his bag and belongings of a morning and pack them up at the end of the day, which is something we could not have witnessed this time last year.*

Parents expressed that using evidence-based strategies like teaching the daily routine at home and school and using visual schedules supported gains in independence,

self-care and following routines. The strategies enabled their child to comply with demands at school. Another parent, Melinda, shared a similar experience she had with her child, while also elaborating further about the evidence-based strategies she used at home to support him:

> *He was waking up early to want to go to school. He's not so happy with school holidays because he doesn't get to go to school. So he does seem to enjoy school and he knows what day of the week it is and what he's going to do. He has his little schedule on the fridge.*

When there was school refusal, as described by some parents, daily living skills reportedly regressed. Examples included not being willing to get ready for school, refusal to complete tasks, and regression in toileting skills both at home and at school. Jolene spoke of her child's regression in toileting:

> *In the toileting area she's probably gone down a little bit. She's starting to wet the bed at night. I've got to put her back in nappies so that's a bit of a change because before she was going quite well with that.*

4.2.3 Child willingness and social skill development

Many parents stated that their child was willing to socialise with peers in the transition to school period, but there was a range of social ability changes. Some parents indicated that their child had fitted right in to the social environment of the new school and that the child's social abilities continued to develop. Other parents described a time of adjustment for their child during the transition, when she or he initially withdrew in

social environments and situations, and then continued to develop social ability once some time had passed, as Elizabeth explained:

> *We quickly identified just the love that she had and how much she enjoyed it, how much she was getting out of it, that we weren't stressed for very long. We quickly identified that she's fitted in, she's getting along with kids, she loves going to school, she's excelling.*

Further in-depth data exploration is needed to understand the range of experiences of these children and their social ability development, and why some children's social abilities did not develop even when they were willing to adapt to school life. Parents with a child who were not making social skill developmental gains either initially or at the time of being interviewed found their child felt 'overwhelmed' or 'lost'. Sharon talked about the dramatic shift in class sizes for her child, and so did Lisa:

> *I think merging into a new school, a new class with double the class size, a reduction in number of the teachers, I think she got a little bit lost because things weren't specifically directed towards her.*

Those parents mentioned that, once their child was in a setting that was not overwhelming for them, their willingness to socialise increased, and they saw their social skills developing. Social skill development was reported to progress when the new school environment aligned with the individual social preferences of the child. Parents stated they felt their child was better included in the new environment. Parents

claimed advocating for their child by asking the educators to make adjustments to the educational setting in size or structure as an effective strategy for improving social skill development. They communicated with the educators when they were aware their child was not coping in a social environment such as the classroom or the playground. Parents spoke of their child having a preference for small groups of peers instead of large groups, and one-on-one time or time in special education classes instead of whole-class times. For example, Jolene explained her child's social setting preferences:

> *She is quite shy when she's around new people. It did take a little while for her to make a couple of little friends. Even when she's in the class, when she's in small groups, she's better than just the whole class.*

Parents spoke of unstructured lunchtimes and large playgrounds with too many children being an issue for their child. Some schools were described to have small lunchtime play areas instead of whole-school playgrounds and ensuring these experiences were not overwhelming for the child. This assisted in supporting a child's willingness to socialise and in turn presented more opportunities to scaffold or expand on social abilities, as Sharon explained, sharing her child's experience:

> *Right near the Prep playground was the ECDP unit and they had a playground, which connected to Prep One. There were eight ASD kids in there. They'd open that playground and they'd allow four to eight neurotypical kids to come in, and then they would rotate the neurotypical kids because they were lining up at the gates to play in this special*

playground as well. So it was socialising them as well, but letting them feel comfortable, which was fine.

Some parents reported gradual exposure to mainstream environments or tailoring exposure to a larger size class or school by way of a continued transition timeline throughout the first year of school. This improved opportunities for social engagement and built confidence in their child, resulting in a willingness to participate, thus continuing or increasing social skill development. Parents spoke of their child wanting to fit in with peers and suggested this also influenced their social ability development. Many parents spoke of their child making at least one friend or a group of friends. One parent spoke of the widening gap between the social abilities and play preferences of her child and the other children in the mainstream school:

I think kids that at five are much more sophisticated in their play and are a bit more snarly when someone's approach is a bit odd. In some ways it seems like he's gone backwards in his ability to keep up the connection. Even though he's certainly made some progress in terms of his play skills and his pretend play – he has come a long, long way, but the division I suppose between him and his peers is becoming wider.

In another case, a child attended a mainstream school with fewer than 20 children in the whole school, one of whom was his brother. His parent highlighted that he was having a hard time making friends even though he wanted to and was only just starting to "fit in":

I think he interacts with the other kids. I think it took the other kids a little while to understand Damian, but now that they understand him, he's happy to give them high fives or give them hugs and stuff, which is nice.

4.2.4 Child willingness and language and communication skill development

Many parents indicated that their child was willing to engage with other children in the new school setting. Most of the parents reported significant gains in language and communication development and an increase in the rate of development, as reflected in this comment by Stephanie:

Definitely he's talking a lot more. He answers and asks a lot of questions and has longer sentences and a bit more back and forth. Still very limited but definitely that's probably been one of the biggest improvements this year, at least in terms of the amount of change.

Parents perceived that peers from the new education setting were a primary cause of these gains. Second to this was inclusion in classroom settings. This was in most cases linked to the child's willingness to interact in class or with peers. For some children the new environment was overwhelming, as Sharon explained. Her child withdrew when talking to peers at first, but because her child was willing her adaptive development increased and the parent facilitated this by encouraging her:

I could really see the change … When kids would come up even in the playground to start with in the morning and she'd want to but she knew

she wasn't saying it properly, so she'd hide behind me and try and tell me. Then she's just started doing stuff and practising and now she's the one that runs off and sees someone and runs to them … I put a lot of emphasis on "Rebecca's going to big school now. You're a big kid", this whole thing as the transition was happening.

Parents saw peers as role models for their child's language and communication skill development. Parents noticed their child imitating or "mimicking" other children from the new school setting when at home. The gains in language and communication were more pronounced when moving from an autism-specific early intervention preschool to a mainstream school. Lisa commented on the gains in her child's language skills:

Positive. Lots. We've noticed his speech especially. His speech has come such a long way. I guess that he's been in an early intervention preschool for so long and the kids there, they don't talk a lot. So him going into mainstream where he's surrounded by peers who don't have any vocabulary issues, his speech has come quite far, and his understanding of everyday things has also enhanced a lot. So he's doing well in that aspect.

Jolene spoke about the other children in her child's mainstream school:

I think she's just probably learning a little bit because she's around neurotypical children. I think she's just picking it up from them.

Several parents referred to gains in language and communication coming from mimicking or imitating peers. Lisa described the spike in language and communication in her child after starting school as a result of peer influence:

> *Moving into this environment with kids who were all very verbal, that just accelerated that even further, so we certainly didn't have any issues with her language or her communication which was good.*

Another parent, Elizabeth, spoke of the specific language acquisitions made by her child including sarcasm and humour that had not been previously seen:

> *There were concepts and things that five year olds were talking about, as opposed to what teachers were talking about previously at school. So we found little expressions coming home and even things like she was bringing humour and sarcasm home which was very interesting, yeah. So it was all very positive and I think it was just because she had that continual interaction and feedback from her peers that really further enriched her level of communication.*

One parent stated her child did not like school and showed school refusal. Sophie described her son still making gains in language and communication skills, despite this unwillingness to participate at school. She also described how much it is influencing their school choice as parents:

The reason we haven't pulled him out of the mainstream school despite the professional people around us suggesting maybe we should, is that we do see on those days he's a little bit wound up but he's quite sparky in other ways, for want of a better, more professional term, and he talks more and he uses his language to communicate more. He just says things that, I think: you've heard another child say that. We do see that benefit of him modelling typically developing children. So we just thought, well, we'll sit it out for the year and see if things improve. Certainly, his anxiety around things has lessened about going but he doesn't seem to love it.

4.3 Theme 2: Quality key stakeholder engagement

4.3.1 Parents' roles: coordinator and advocate

Most parents reported that the school chosen must be a good fit for the child most importantly and that the school's ability to meet the parents' needs was also important. They identified choosing a school that met the child and family's needs as the first step to coordinating a successful transition. Parents expressed the benefit of doing careful research when selecting a school. Lisa talked about the first step of the transition process, choosing a school:

What worked for us was we did a bit of research into schools. So I would suggest do your research, because I think every school's different, and they cater for so many different needs of children. So what may work for us might not work for somebody else.

Another parent, Sonya, had doubts about the school choice she and her partner made for their child:

> *The one thing we are actually wondering now, though, is whether mainstream or a large school was the wrong choice because we chose a school that had a lot of layers of support. It's a bigger school and growing so he never seemed to have much problem with being in crowds or noise and things and it's become a problem for him this year. He's now saying things like, "People are too big for me", which I think means there's too many people. And he says, "It's too noisy", and, "I'm scared", and, "The kids are angry at me".*

Many parents spoke of engaging with their early intervention preschool or specialists to help guide them through the elements of the different types of schools that would suit their child's strengths and needs. Parents assessed the school in terms of what resources they could supply, how the school could support their child, how they enabled the parents to coordinate and advocate for their child, and how the educators might best perform their roles as collaborators and implementers. Alan described the people he consulted with:

> *So all the therapists and teachers at the EI preschool and all the teachers and special aide teachers at school to make sure that number one she enjoys her school day and number two that she's learning.*

Parents believed they are a key part of the transition process and are key to deciding what is included or not included in their child's transition to school. Parents who coordinated the transition with professionals who were trained in autism felt they were supported during this process compared to some parents who were not in consultation with autism professionals about the transition. Parents mainly understood the importance of a good transition to school and were also well equipped to plan, coordinate and advocate for a transition timeline. Parents took the role of advocate during the transition and shared a range of experiences in this role. Some were positive and some were negative. Sonya explained how advocating for their child was a struggle:

> *I think the teacher said to me, oh look, you have to remember she's got 23 students and there's several other kids with issues who aren't funded, and I'm like, yeah, I'm sympathetic to that but I've got to fight too. Because we just sense that, if the next couple of years don't go well, we sense he's the sort of kid that will just hate school. He is a bit like that; he can become a bit despondent on stuff. So that's why I keep stressing to them, this has got to go well or else.*

In the initial survey each parent completed, the parents selected the parts of the transition which were included in their transition timeline (see Appendix C). All parents had utilised many of these steps, but selected only the ones that suited their child. For example, one child reportedly likes social stories so the parents worked to build a social story about starting school. Melinda talked about different strategies working for different children:

The biggest challenge I found was a lot of people didn't understand that autism could be a spectrum. So one child didn't present the same as another child. One child could do well with just visiting the school or one might need a social story, one might need a visual.

As noted in Section 3.3, the first cohort of parents recruited to the study were parents whose child attended an autism-specific early intervention preschool. Part of the preschool program involved educating parents and communicating with the future educational setting about the transition to school, specifically supporting that child's individual transition needs. The preschool also assisted in preparing the child for the transition while they were still at preschool. Alan talked about a year-long preparation with his child's EI preschool:

Last year the whole year was preparing for the transition … We sat through several meetings and we did a lot of training about driving past the school, talking to Simone about the school, having the EI teacher go to the school and meet with the teacher, maybe having Simone meet with the new teacher before. There was so much advice what makes a good transition.

Parents who had this level of support were well equipped to coordinate the transition and advocate for their child in the new school environment. This reportedly supported the child in multiple ways, including supporting the child's skill level with specific skills like toileting, self-care, communication style, language acquisition, sensory processing, and transition support throughout the day. Melinda mentioned that

teeth brushing was an important issue when her son's IEP was being developed, and the teacher then included it in her child's IEP at school:

> *The teacher's really been open to any suggestions we've had with his IEP. We were having issues with teeth brushing at home so that's been added into his IEP and so after lunch he brushes his teeth. I think for them to be open to suggestions, ask, just ask the family and that can make all the difference.*

The communication with educators often included discussing and sharing strategies that had already been found to align with the child's style of learning. Parents stated that when their child's educators utilised this information and continued communicating with the parents about these strategies, fewer incidents of maladaptive behaviour occurred. Alan spoke of a meeting with the educators and his child's multidisciplinary team to set strategies in place for the new school environment to support their child:

> *We've had one major meeting where we all sat down with the OT, the teacher, the teacher aide and the special aide teacher and the six of us sat down and just came up with some strategies.*

Many parents expressed a sense of anxiety leading up to the transition. These parents had knowledge about the potential challenges of transition for a child with autism. Parents were concerned about how their child would react to the transition itself and about their child fitting in to the new school environment, which included not only

the classroom setting, but the other children as well. Once their child started school, parents argued that communication quality was important when monitoring adaptive behaviours, and also in keeping parents informed of any issues that arose. Elizabeth described how the level of communication reduced the parents' stress about the transition to school:

> *I guess it's a case of mum and dad are always a little bit more stressed than everybody else because they overthink things. We did. The first couple of weeks we were quite anxious but the communication between the teacher kept us informed and kept us up to date which was fantastic.*

Parents claimed that when there is clear and honest communication from the school they can deal with any issues the child has as they arise. Parents expressed frustration and anger over misleading or false communication, with all parents stating that high quality communication during and after the transition was essential. Loraine explained her experience with miscommunication:

> *There was a lot of miscommunication. There was a lot of communication but it was conflicting between teachers … we were told that he would get support in the classroom, and when he got there he didn't get any.*

Miscommunication and misinformation often led to negative outcomes for the child including a lack of support in the areas of adaptive behaviour and maladaptive behaviours being seen. Again, Loraine highlighted that her child's behaviour escalated as a result of the miscommunication:

The effect it had on us was that I had to give up work to look after him, to deal with his behaviour. It put a tremendous amount of stress on the family because we were in a good place and then we were regressing. So it put stress on the entire family.

4.3.2 Educators' roles: collaborator and implementer

Parents saw the educators as key stakeholders in determining a successful transition and called for educators to collaborate with them to implement strategies and supports nominated by the parent and the child's multidisciplinary team. Parents considered the most important aspects of the educator's role were to establish quality communication between educator and parent, take the time to implement strategies outlined by parents, utilise resources, and ensure all staff in contact with their child have sufficient knowledge and understanding of autism to support the child throughout the transition. Naomi described their situation after changing schools to an environment where she knew her child was being supported:

There's decreased stress with regards to Mathew's education. Because now I can send him to school and know that he's getting support. Whereas at his old school I used to send him and I used to be in tears thinking he's in there on his own not getting any support.

Parents expressed a desire to have education staff who listened and collaborated with them, and also who had a better understanding of autism. Parents reportedly felt educators needed to understand how their child's individual characteristics could be

supported in their new school environment during transition and throughout the year, and that their child's characteristics may differ from other children on the autism spectrum, as Elizabeth explained:

> *I know that nearly every class in every school now has a child on the spectrum and I think teachers are very good, but I think what they need to do is understand each child, so their own little idiosyncrasies; not just say, yeah, no worries, we've had kids with ASD before, I think we'll be right. I think they need to probably spend a little bit more time with the parents, talking about the behaviours, talking the challenges and concerns. I think that would help them up front and would certainly help the children. So once again it comes down to communicating.*

Parents indicated that supporting the needs of their child includes addressing the core characteristics of autism and adaptive behaviour skills, and most importantly individualising strategies for their child. Parents argued that when the educators are not collaborating with parents, or implementing strategies to support the child during the transition, there is a decline or halt to adaptive behaviour development, particularly in daily living skills previously learned such as toileting, and the amount of classroom and social inclusion during the school day. Parents expressed that having this individualised support also affected the academic achievements of the child. If the child's needs are not met, it can also negatively affect other behaviours, as Elizabeth described:

> *The first two days that she was at school she didn't go to the toilet at all, because nobody had told her to go to the toilet. So it was just getting her*

used to a different environment where she hasn't got four or five teaching staff or aides around her all day and she's just back to two staff and a lot bigger classroom setting. So it was about encouraging her and educating her to be more independent.

Kelly mentioned there are no strategies in place for her child and the change in environment means toileting became an issue for her son:

The toilets are a long distance away from the classroom for him. So by the time he can request to go to the toilet, sometimes it's too late. Yeah, by the time he requests and they realise that he needs to go.

When daily living skills needed for the new educational setting were not specifically taught in an evidence-based individualised way, adaptive skills such as toileting regressed.

4.3.2.1 Educators as collaborators

During the transition process, parents reported that having the educator to collaborate with to orchestrate the transition helped support the child and his or her specific needs. All parents viewed communication as a key factor to a smooth transition and supporting adaptive behaviour skill development during this time, as one parent, Alan, outlined:

What makes a successful transition is just a willingness from all parties to be on the same page.

Parents described a variety of communication methods they used with the educators. Most parents spoke of utilising a communication book, coupled with daily informal conversations and one or two formal meetings during the transition period. When communication and collaboration was individualised for the parents and the educators, the educator's role as the collaborator was evident. Elizabeth emphasised the importance of communication for her, not only benefiting her son, but herself as well:

> *Communicating with the teachers is absolutely integral; whether it needs to be daily, weekly, whatever. I think it's more just for the parents to alleviate any doubt, any concerns. Keeping those open lines of communication I think is the most important aspect of that transition.*

Parents claimed that regular collaboration about the areas of adaptive behaviour development meant adaptive behaviours were well supported. Parents expressed this also meant that the collaboration supported the individual transition needs of the child. Educators could adapt strategies had worked previously in other environments for the new educational environment. Gina described how a combination of formal and informal communication methods suited her family:

> *If you need a 10-minute talk after school, they're always more than happy to accommodate anything like that. Otherwise, we have a communication book, so if there's just minor little things that need to be discussed, we use that as well as a form of communication. Sometimes there's a couple of minutes of chat on pick-up, just an informal chat.*

4.3.2.2 Educators as implementers

Parents expressed their child's adaptive behaviours were not supported if the educators did not implement the strategies or goals or utilise the tools that were discussed with parents. Parents indicated that if educators understood and were educated in strategies and why they work then it was more likely they were utilised in the classroom environment. Sharon spoke of providing materials to her child's educator that go unused:

> *We gave them all the resources, like the picture schedules, [and] toolboxes of laminated stuff. That box is still sitting under the teacher's desk today, six months later, not being used. So don't ask us for help, don't get all the stuff that works, and then after the fact, after you've had two bad days because you haven't started using the tools that you're meant to start with, and come to me with meetings and say how do I fix this.*

Parents believed that using strengths-based methods was very effective to support classroom inclusion and adaptive behaviour such as communication and social abilities, for their child in the new educational setting. Some parents described that strategies discussed in collaboration with the educators were implemented in a class-wide approach.

> *The kids were all interested in bugs. They were doing bugs and she'd put him in charge of that. So when he got to school he knew exactly what to*

do. So, yeah, he'd get his little bugs out and that would help initiate conversation. The other kids would come over and have a look.

In this example, Stephanie talked about using the child's interest in bugs to create opportunities for social skill and communication development. Collaborating with the parent and implementing a strengths-based teaching approach was reported to better support the child's adaptive behaviours.

4.4 Theme 3: School-wide support

4.4.1 Schools' roles as supplier and enabler

Parents felt the school's role was to supply the services needed to enable the transition to school for their child and expressed frustration and irritation if the school was unable to supply support to the key stakeholders during the transition-to-school process. Parents suggested that without adequate support their child's adaptive behaviour would deteriorate, as Melinda explained:

I think with the supports in place, he's been doing really well but then – if you took them away, it will just fall apart.

Support for the child includes any adjustments that need to be made to the environment or the level of support to ensure inclusion and adaptive behaviour development. Support for parents refers to the level of communication with the parent, and is related to the amount a parent trusts, and is satisfied with, the school. Support for educators includes funding, education and time collaborating with parents throughout

the transition. Cassandra talked about what support she would like to see for her and her child:

> *As a parent, I would appreciate a structured response from any school environment; well-written individual education plans, and planned learning activities for all educational staff. Providing ongoing feedback about Simon's progress, or lack of progress, would also assist me when coaching Simon at home. I need to know what areas he is struggling in so that I can target my response and therapies to assist him.*

Parents expressed that they understand that there are many students in a classroom with many different needs. Parents also understood that educators have to deal with the political aspects of the school environment and administration, need to follow school policy and have limited funds available for inclusion and support. However, parents requested open and honest high quality communication from the schools, including open and honest communication if support cannot be given to their child. This sentiment was repeated often in relation to both success stories when parents and educators worked respectfully and collaboratively, and times when support was promised but never delivered. Parents suggested it was not the educators' fault and may not be the schools' fault, but rather a school-system failure, particularly to do with the ability to access funding for their child. Melinda discussed the stress their child went through, which was severe enough for her to move him to another school:

> *There was absolutely no support in the classroom for him whatsoever. The teacher that he had had zero experience with special needs, in*

particular autism. There was a teacher aide in the classroom for a maximum of 12 hours a week and she had zero experience with special needs as well. So that was his first term at school. He actually didn't complete the first term because I took him out.

Parents mainly felt that educators are time poor, under-resourced, under-supported and under-staffed, and struggling to meet the individual needs of their child, particularly in mainstream schools. When the schools could not provide support for educators, more maladaptive behaviours were seen in a child. Parents who reported an adequate amount of support for the teacher reported fewer maladaptive behaviours in their child, as their adaptive behaviours were better supported with strategies and tools utilised through collaboration with the parents and the child's multidisciplinary team. Cassandra claimed her bad experience with the lack of support for her child and the key stakeholders, and lack of education of staff:

I would like to see the head of special education at our school given some feedback and training on how his lack of support for the teachers and Stephen have affected his year at school as a whole. I would like the school to educate him in the use of external supports for children with ASD and ensure that, even if the local school doesn't have experience in being able to "fund" support for a child, there is support for children available and it needs to be sourced proactively by him in his role to support teachers, children and their parents as soon as the child is identified as having a diagnosis and displaying any difficulty coping in the school environment.

4.5 Summary

This chapter has described the results of the thematic analysis, and reported on each theme, and the variables within each theme. The results were reported in terms of the factors that effect positive or negative changes in adaptive behaviour when a child with autism is transitioning to school as perceived by parents. Theme one was child willingness, theme two was quality engagement of key stakeholders, where parents are coordinators and advocates, and educators are collaborators and implementers, and theme three was school-wide support where the school enables and supplies a supportive environment for all involved. The following chapter discusses the results of this study, referring back to previous studies outlined in the literature review.

Chapter 5: Discussion and conclusion

5.1 Findings and interpretation

5.1.1 Overview

The aim of this study was to explore parent perspectives regarding any changes they have perceived in adaptive behaviour in their child with autism and possible explanations for these changes. The parent interviews about these changes provided a rich amount of data, which produced three main themes. Many similarities in responses emerged, but also differences in experiences as well. In the previous chapter, results were presented that provide evidence that active and willing engagement from all involved in the transition process, starting with the child and branching out to the parents and educators, and finally extending to the school community, are supportive of a successful transition. The results also indicate that the roles engaged in by each of the parties affect adaptive behaviour outcomes during the time of transitioning to school for the child. See Figure 3 below for a visual representation of the results, modified into a simplified model of support. This figure is a visual representation of the results and shows the first theme of child willingness as the theme that is central to all others. The theme of child willingness emphasises the importance of a child-focused model of support when supporting adaptive behaviours during the transition to school as perceived by parents. The second theme of quality key stakeholder engagement describes the active role of the key stakeholders directly involved with the child, that is, the parents and the educators, and how active engagement of high quality can support adaptive behaviours during the transition to school. The third theme describes the role of the wider community, namely, the school. This is a supporting role, supplying resources and time, and enabling the child and key stakeholders to perform their roles during the transition to school. This chapter includes a discussion and examination of

these results theme by theme, the researcher's interpretations of these findings, the relationship between the results and the research question, and literature relevant to the research question and findings. Finally the chapter outlines the limitations of this study, discusses potential implications of the results, presents the researcher's reflections and outlines some implications for future research.

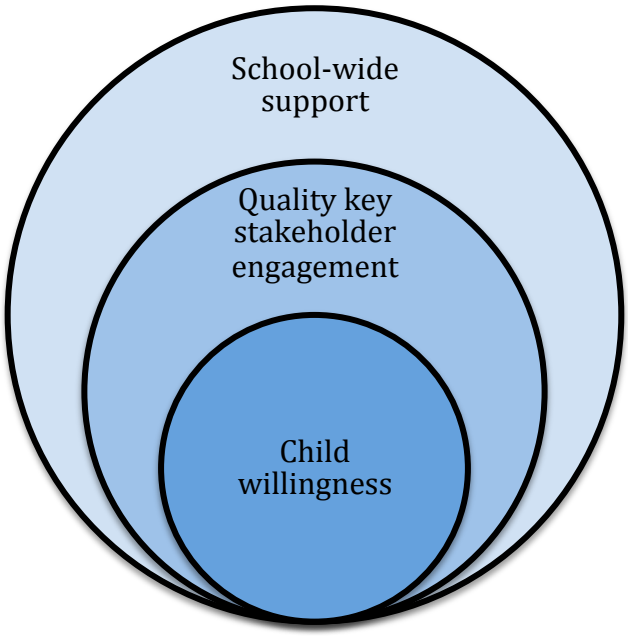

Figure 3: Research results as a simplified model of support

5.1.2 Child willingness

In this study, the theme "child willingness" to engage in school life emerged from the parent interviews as one of the factors that parents perceived as being supportive of adaptive behaviour development during the process of transitioning to school. Many parents perceived child willingness as the first step in supporting their child's adaptive behaviour development. Parent accounts described the observation of adaptive behaviour gains or losses and helped guide key stakeholders to choose strategies to employ during the transition to school process. This is reflected in previous research,

which showed that adaptive behaviour changes are indicative of a child with autism's ability to adjust to and cope with transitions (McIntyre et al., 2006). Saggers et al. (2015) report that the educators, specialists and parents they surveyed indicated that school refusal and passive resistance are two of the factors which have the most impact on the capacity of students with autism to participate in school. Parents in the current study described attempting to make the transition to school an exciting experience, while at the same time they coordinated an individualised transition timeline, and utilised evidence-based strategies like visual schedules. Coordinating school visits with their child and sharing reports using a child profile helped facilitate a smooth transition and ensured the new educational environment was one that the child was willing to attend. It gave the best chance of inclusion within the school environment, while also supporting adaptive behaviour. The following sections discuss the theme of "child willingness" in each of the areas of daily living skills, social abilities, and language and communication in more detail.

5.1.2.1 Child willingness regarding daily living skills

Child willingness had an impact on daily living skill development. When a child was perceived to be willing to participate in and attend school, they made reported gains in daily living skills, especially independence. Previous research suggests that supporting development in the area of daily living skills is positively associated with a child with autism becoming more independent now and in the future (Carothers & Taylor, 2004; Pugliese et al., 2014; Rauf et al., 2014; Volkmar, 2014). Green and Carter (2014) highlight that a child's ability to perform daily living skills is determined by several factors, including his or her desire to comply with the request, which relates to the theme of child willingness.

5.1.2.2 Child willingness regarding social abilities

Parents all reported a willingness in their child to socialise, but the changes in developmental trajectories in this adaptive behaviour domain varied depending on the suitability of the environment and whether it met the environmental preferences of the child. Within this range, there were children who fitted into the new environment, some who went through a period of adjustment, and some who did not adjust and continued to display social withdrawal and school refusal. In the current study, some children who had difficulties with social skills adaptation appeared to have reduced motivation to seek social interactions or increasing developmental delay. This is consistent with the findings of O'Connor and Healy (2010) who found mixed results regarding the gains and losses made from previous early interventions. In most cases in the current study, the environmental design for the first year of school related to the transition program each school had, for example lunchtime play areas and exposure to other students and classes. Transition for the child was effective if the transition program aligned with the child's social abilities and developmental stage. Many parents expressed that social skill development was well supported during the transition when the new educational setting suited the child, fostering child willingness and inclusion.

In many cases parents expressed that, once their child started school, the exposure to the mainstream environment continued at a pace individualised to the child throughout the first year of school as part of the transition. Parents described varying levels of social inclusion within the whole-school environment during the transition to school and gains were made when the environment was tailored to the social preferences of the child with autism and supported social skill development. Adjustments parents spoke of included modifying the physical environment, class size and playground size, as well as choosing effective activities, routines and strategies to

support social skill development within those environments. Volkmar (2014) discussed the importance of identifying the skills the child will need in the new setting, and increasing exposure time to the new setting, including social skill ability. In most cases in the current study, social skill development was an area for early intervention in the preschool years. Including social ability development needs into part of the transition to school timeline improved outcomes and greatly increased the likelihood a child would be willing and also able to participate in a social capacity and develop their social abilities throughout the transition to school.

5.1.2.3 Child willingness regarding language and communication skill development

Parents in the current study perceived an association between their child's willingness during the transition to school and their child's changes in language and communication development. The second association to language and communication development that parents spoke of was that peers were influential role models once their child had started at the new school. Parents argued they believed the skills were acquired by peer influence in the classroom environment or in a social setting such as in the playground. Several parents used the term "mimicking" of peers to describe the gains in language and communication skills. However, there was one child who showed signs of school refusal and still made language and communication gains. When reviewing the entire transcript of the interview to determine why this might have been the case, it became clear that the parent expressed that the child was not unwilling to interact with peers, it was more a case of the child not liking the school environment as the parent claimed it did not meet his needs in other ways. The parent did speak of their child showing a desire to fit in at times, so the child's willingness could, in this case, be associated with

willingness to interact with peers.

There is no previous research regarding the influence of peers on language and communication skill development during the transition to school for a child with autism. Evidence has shown peers to be effective mediators during an evidence-based intervention such as peer-mediated instruction or a peer training package (McConnell, 2002), and this may relate to the results of this study for similar reasons. Peer-mediated interventions involve teaching peers strategies for facilitating play and social interactions with a child with autism (McConnell, 2002; NAC, 2011). These interventions create an opportunity for peers to teach a child with autism new skills by exposing them to the new skill or behaviour, modelling and reinforcing the new skill or behaviour in a naturalistic environment for the child (NAC, 2011). Language and communication is one of the core areas for teaching new skills and behaviours in the early intervention years (Wong et al., 2014). Peers who are developmentally more advanced than a child with autism may naturalistically model new skills and behaviours in the area of language and communication. The results of the current study also may provide preliminary evidence that the skills learned in the early years at places such as early intervention preschools may be generalised and scaffolded within the context of the new school environment, through the modelling and naturalistic reinforcement of peers. More research could determine whether peer-mediated interventions would be useful during the transition to school, and whether they may additionally support adaptive behaviour.

5.1.2.4 School refusal and anxiety

In the current study, anxiety was not included in the parent questions; however when parents spoke of their child wanting or not wanting to participate at school it was

usually accompanied by descriptions of their child being anxious or having anxiety-related symptomology. Therefore, it is important to reflect on and review research about anxiety. In some studies anxiety is reported as an inappropriate or maladaptive behaviour (Hanline, 1993; Greenberg, 2011; Stoner et al., 2007). Hapopian and Jennett (2008) describe anxious responses as "behavioural avoidance of the feared situation, affective states involving subjective fear and panic, cognitions of worry and dread, and states of aversive and intense physiological arousal" (p. 468). Anxiety and anxiety symptomology have been linked to adaptive behaviour and functioning in previous studies (Dubin et al, 2015; Magiati et al., 2016). For instance, O'Connor and Healy (2010) claimed children with autism showed varying degrees of anxiety syptomology in both the school and home settings during the transition to school. Previous studies have suggested school refusal is a sign of anxiety for a child with autism (Fujii et al., 2013; Langley, Bergman, McCracken, & Piacentini, 2004; Ollendick, 1979). Anxiety has also been linked to poorer adaptive outcomes (Langley et al., 2004). The current study also makes a link between anxiety and adaptive behaviour, suggesting anxiety during the transition to school for a child with autism may affect adaptive behaviour negatively.

Transitions frequently cause anxiety for a child with autism. Stoner et al. (2007) stated that parents stated their child's anxiety was a factor in difficult transitions, and that they recognised this and used strategies to reduce that anxiety. Saggers et al. (2015) claim that educators and specialists indicate anxiety is the comorbid condition that has the most impact on the amount of support, assistance, adjustments and accommodations required, with parents rating it secondary only to the impact of learning difficulties. Among typically developing children, those with anxiety disorders are more likely to display school refusal (Mychailyszyn, Mendez, & Kendall, 2010), and poorer adaptive outcomes (Langley et al., 2004). In the current study, when parents explained whether

their child displayed anxiety symptomology, they did not disclose a formal anxiety diagnosis. This may mean their child is not typically anxious and during the transition to school they are showing signs of fear and anxiety symptomology. This is being reportedly displayed as school refusal or unwillingness to participate at school. In cases where the child was showing willingness to participate and attend the new school setting, parents did not highlight anxiety-related symptomology.

5.1.3 Quality engagement of key stakeholders

5.1.3.1 Parents' roles: coordinator and advocate

The parental roles that emerged during thematic analysis that support adaptive behaviour were actively engaging in the roles of coordinator and advocate. When parents described they engaged in the roles of coordinator and advocate, adaptive behaviour was supported during the time of the transition to school. This also supports previous research that indicates that parents of a school-age child with autism are more likely than other parents to actively engage with the educators, aides or other key stakeholders at the school (Zablotsky, Boswell, & Smith, 2012). When parents act as a coordinator this implies that they are in the "driver's seat" of the transition process and coordinate

all the components of the transition together into a transition timeline. Because the schools that parents spoke of in this study all had different processes regarding the transition to school, parents did not initially know the exact steps involved. This may be because the transition process at each school that each parent spoke of was different in duration or execution, even though there are state and national transition-to-school guidelines in place (ACECQA, 2012; Education Queensland, 2016). In the current study, when parents played a role of coordinator during the transition to school, they

decided on the information they thought would assist the transition to school. This included sharing information about the characteristics, strengths and needs of their child regarding transitions; information from the child's multidisciplinary team; and previous professional assessments and reports.

Parents researched the future school and made contact with them to coordinate visits to the school with and without their child. They arranged meetings with the educators before the new school year. Parents also used evidence-based teaching strategies at home as part of the transition to school timeline, such as social stories, visuals and teaching routines. The reported benefits of sharing this information and the strategies used are consistent with the results of previous studies regarding the content of a transition-to-school process (Denkyirah & Agbeke, 2010; Sterling-Turner & Jordan, 2007; Volkmar, 2014). The findings of this study suggest that the inclusion of information and strategies that support adaptive behaviour during the transition to school may be important to the overall success of a transition to school, and parents were the coordinators of the content and implementation of the transition-to-school timeline.

Many parents in this study used evidence-based transition strategies that would specifically work for their child using the knowledge they had gained from the early intervention years. Some parents in this study utilised visual schedules and social stories while others did not, and some used other resources they felt suited their child. All parents, whether they used the terms or not, developed, coordinated and advocated a transition to school timeline they had individualised for their child. Transition timelines have proved effective in previous studies (Denkyirah & Agbeke, 2010; McCumber, 2011; Sterling-Turner & Jordan, 2007). In the initial survey (see Appendix C), many parents in the current study describeded using a child profile, professional reports or

meetings with EI preschool educators to outline the individual characteristics of their child, their likes and dislikes, strengths and weaknesses, and other particular information about their child that they considered important to communicate with educators (Stoner et al., 2007).

The findings of this study also indicate a parent who is actively involved as advocate for their child during the transition to school can improve the likelihood of not only a successful transition, as seen in previous studies, but also supporting adaptive behaviour development. Stoner and Angell (2006) found that the parents in their study predominantly felt they played the roles of negotiator, monitor, supporter and advocate when dealing with educators. A child whose parent advocates and shares information before, during and after the transition process is more likely have their specific needs met, including support for daily living skills and independence, social abilities, and language and communication skills (Stoner & Angell, 2006).

The primary motivation for parents to communicate with educators is to communicate the ongoing needs of their child (Stoner & Angell, 2006). Previous research supports the importance of frequent high quality communication (Azad & Mandell 2016; Brewin et al., 2008; Kamimura & Ishikuma, 2007; Saggers et al., 2015; Stoner et al., 2007). In the current study, parents valued quality communication with the educator and in many circumstances advocated regarding the amount of communication and the way they communicated with educators, such as a communication book or emails, or a more informal approach such as a daily chat. When the information parents thought relevant was developed into a transition timeline and child profile, a parent could then coordinate and advocate for their child during the transition to school. These two specific roles parents played were factors in determining whether adaptive behaviour development was supported.

5.1.3.2 Educators' roles: collaborator and implementer

The roles of educators as collaborators and implementers emerged from the thematic analysis of parent perceptions of the factors that support adaptive behaviour development during the transition to school. Parents viewed educators as their point of contact at the school and the people they collaborated with throughout the transition. Parents claimed that, when educators were successful collaborators, they were able to share and discuss strategies advocated by the parents. Stoner et al. (2007) found parents identified communication, recognition of transition strategies by educators, and preparation of the education professionals as factors facilitating a successful transition, reflecting the results of the current study. Parents were asked for suggestions about how to make a successful transition to school for a child with autism based on their experience, and they suggested educators should listen to parents more. Previous studies reflect this information, indicating that parents want more collaboration during the transition-to-school process (Early et al., 2001; Forest et al., 2004; Quintero & McIntyre, 2011; Stoner et al., 2007; Walker et al., 2012; Zablotsky, Boswell, & Smith, 2012). Stone et al. (2007) claimed that parents want educators to understand their child, and also argued parents can identify effective transition strategies. Parents in the current study considered high quality communication and collaboration as the key to a successful transition, which supports previous study results (Azad & Mandell, 2016; Brewin et al., 2008; Kamimura & Ishikuma, 2007).

Previous research shows collaboration between the school and the preschool environment can be a valuable part of the transition process (Forest et al., 2004). Parents in the current study reported that collaboration between the preschool setting and the new educational setting were valuable for sharing information about their child,

including information about their child's current level of adaptive behaviours and strategies that are already in place to support them. Parents also expressed it was important for an educator to collaborate with the school administration about the amount of support available versus the amount needed for their child. In the current study, some parents claimed educators told parents their child would receive a certain amount of support, for example a one-on-one teacher aide, or funding, which did not eventuate, and this was seen as miscommunication by the parents. In previous studies, educators reported one of their biggest barriers to assisting in a successful transition is time to prepare and implement transition practices (Early et al., 2001; La Paro et al., 2003). As it is not the child's teacher who decides how much funding or support a child receives but rather the school and their ability to provide support, educators who collaborate with the school administration have more chance of not providing false or misleading information to the parents about the support for their child. Parents expressed that knowing the amount their child could be supported was important in deciding on a school.

The role of educators as implementers of support for adaptive behaviours during the transition to school also emerged from this study. Previous studies have claimed that up to 94 per cent of children with autism struggle with transitions if there are no supports in place (Lequia et al., 2015). Parents expected educators to implement the strategies that were identified when collaborating with the parent and the child's team as an effective part of the transition timeline. This supports the results of previous studies (Denkyirah & Agbeke, 2010; Volkmar, 2014). Educators implementing strategies throughout the transition to school to support adaptive behaviours ensured continued opportunities for inclusion of the child in the new school environment. The parents in the current study described success when strategies that were discussed while

collaborating were utilised, and frustration when strategies advocated by parents were not used. This was also true for class placement and exposure to the new school environment during the transition. Parents could see their child was not being supported in many areas including adaptive behaviour resulting in maladaptive behaviours. Parents reported that daily living skills such as toileting were being affected and social and communication development was regressing when the environment was too overwhelming for the child and the child withdrew from the environment, reducing opportunities for development. Not making reasonable adjustments and implementing effective strategies is likely to lead to an environment that is not inclusive or does not meet the needs of the child with autism. A previous study's results showed parents believed educators play a vital role in the inclusion of their child (Kasari et al., 1999). Grindle et al.'s (2009) study showed how educators can implement EBPs in mainstream school settings, allowing access to the national curriculum, and inclusion with peers in a mainstream setting. Having teachers and aides implement evidence-based strategies that support adaptive behaviour development while transitioning to school increased the likelihood of a successful transition in the current study. The results provide preliminary evidence that educators performing the roles of collaborators and implementers during the transition to school can support adaptive behaviour in a child with autism, when the collaboration includes information about adaptive behaviour, and the strategies implemented support adaptive behaviour.

5.1.4 School-wide support

In the current study, another theme that emerged was the role the school played in supporting adaptive behaviours during the transition to school. Parents saw school-wide support as important. The school-wide community includes the school administration,

principal, other heads of staff, and the policies and practices each school adheres to. Parents wanted the school to supply opportunities for educators to support their child and to provide an enabling, inclusive environment. Previous studies have shown that transition-to-school support is an educational need for a child with autism (Prior et al., 2011; Roberts & Williams, 2016; Saggers et al., 2015; Volkmar & Weisner, 2009).

Parents felt the school was an enabling factor to facilitate active engagement from the key stakeholders during the transition to school. Research shows that a smooth transition to school can affect future school outcomes (Alexander & Entwisle, 1988; Docket & Perry, 2004; Pianta et al., 2001; Tizard et al., 1988). Therefore, if the school does not supply the funds, resources, staff and time to provide key stakeholders with adequate opportunity to actively engage, coordinate, collaborate and implement a successful transition timeline and to facilitate the child's willingness, the child's needs will not be met. In the current study, when parents argued educators were time poor, under-resourced, under-supported and under-staffed to meet the individual needs of their child, not only was the transition to school not as successful, adaptive behaviours were not supported and maladaptive behaviours were seen. This was because educators did not have the time to learn about the child and implement strategies during the transition, were not allocated the funds to access resources or training about autism, or supported through extra staff or aides. Previous studies describe similar findings, with educators highlighting one of the biggest barriers to assisting in a successful transition is time to prepare and implement transition strategies, and lack of teacher training (Early et al., 2001; La Paro et al., 2003).

Without the school supplying and enabling what is needed to facilitate an optimal transition to school, the schools appeared to fail to meet standards set out by legislation such as the Commonwealth *Disability Discrimination Act 1992* regarding a

child with a disability and their right to access the curriculum (ACARA, 2012). Facilitating inclusive environments has been a topic for local, national and international discussion and is addressed in policies such as the Commonwealth *Disability Standards for Education 2005* and through international bodies such as the United Nations. The United Nations' Convention on the Rights of Persons with Disabilities recognises the right of a person with a disability to an inclusive education (United Nations, 2006) Article 24.1 of the convention states:

> State Parties recognise the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, State Parties shall ensure an inclusive education system at all levels.

In 1994 the United Nations released the Salamanca Statement, which made specific reference to school management:

> Local administrators and school heads can play a major role in making schools more responsive to children with special educational needs if they are given necessary authority and adequate training to do so. They should be invited to develop more flexible management procedures, to redeploy instructional resources, to diversify learning options, to mobilize child-to-child help, to offer support to pupils experiencing difficulties and to develop close relations with parents and the community. Successful school management depends upon the active and creative involvement of teachers and staff, and the development of

effective cooperation and teamwork to meet the needs of students.

(UNESCO, 1994, p. 23)

In some cases in this study the parents raised questions as to whether policies and procedures are being implemented in any way, if at all. Schools must be able to supply and facilitate an inclusive and supportive environment for a child with autism and this was a factor that determined whether adaptive behaviour development was supported or not in the current study.

5.1.4 Conclusion of the discussion

The ACECQA (2016) outlines specific guidelines for the transition to school and states: "The continuity of learning and transitions for each child are supported by sharing relevant information and clarifying responsibilities".

The results of this study clarify and outline parents' views of the responsibilities and roles of the key stakeholders and the school-wide community that may help support the important area of adaptive behaviour development of a child with autism during the transition to school. The discussion has introduced a model of support, starting with a child-centred approach of observing and encouraging child willingness, while valuing quality active key stakeholder engagement, and identifying the importance of school-wide support in supplying time, staff, funds and resources. This enables all involved to fulfil their roles during the transition to school, supporting the child with autism including his or her adaptive behaviour development.

5.2 Researcher reflections

The author of this dissertation had some basic research skills before engaging in this project; however these skills have been greatly improved as a result of the current study. This includes all aspects of qualitative research design, data collection and analysis, discussing results and academic writing. The author completed coursework in designing a research dissertation and research methods, and the assessment results were both GPAs of 7, the highest grade possible. This coursework was a launch pad to understanding the process of conducting a research study, and underpins the author's adherence to aligning with what the research world defines as quality indicators, at every stage of the study.

Being supervised by two supervisors who have an extensive amount of research experience and whom have both worked with many children, families and teachers through practice was a much valued and important factor in supporting the author during the study, through regular individualised contact, ongoing support and credibility checks throughout the data analysis. Professor Roberts and Dr Trembath consistently guided the author through expert advice and discussion while never inflicting personal opinion or bias. This meant the author was able to learn to successfully conduct research, data collection and analysis independently while feeling supported throughout. This has contributed to the author's significant gains in the understanding and execution of high quality outcomes in these areas.

The author attempted to remain neutral throughout the study, making sure she noted and questioned any bias or assumptions during the process to ensure they were not influencing the results in any way. This started in the research design process, when choosing questions, interview style and approaches with participants. During thematic analysis any assumptions were noted in NVivo, and later reviewed and analysed as part

of the data, to make sure they were not influencing the author's analytic process. As a mother of a child with autism who is transitioning to school next year, I have been influenced by the results of this study when designing my son's transition to school. The author believes this may possibly strengthen the integrity of the analytic process even further, as the search for themes and results was not only a professional quest, but also a personal one.

After reviewing the results of research studies from the literature review, the author was expecting more negative experiences during the interviews, when many of the experiences of these children and their families were positive or had positive elements, and this was a good surprise in some ways. Although some of the children and families in the current study were struggling with educational outcomes for their child, perhaps the positive experiences suggest some gains have been made in understanding and implementing transitioning to school for a child with autism. Surprisingly there is no standardised state or national transition process and, although each individual school is following the same guidelines and policies, there seems to be a vast array of transition strategies employed, some very good, some not supportive of the needs of a child with autism. The author believes much of the process is heavily reliant on the parent and their knowledge of the process and if they do not coordinate the transition to school and advocate for their child then there will be no thoughtful individualised execution of a transition timeline to suit the needs of their child.

5.3 Implications for the transition to school process and the support of adaptive behaviour

The results from this study contribute meaningful information about the factors that support adaptive behaviours in a child with autism in the transition to school process.

The results of this study show the importance of monitoring and supporting adaptive behaviour during the transition to school. It contributes important details about supporting adaptive behaviour when developing a standardised or formalised transition to school timeline and strategy, by developing an integrated model of support to integrate into the transition-to-school timeline of a child with autism. The integrated model of support is built from the simplified model of support and includes the roles of each stakeholder and how the themes relate to each other (see Figure 4).

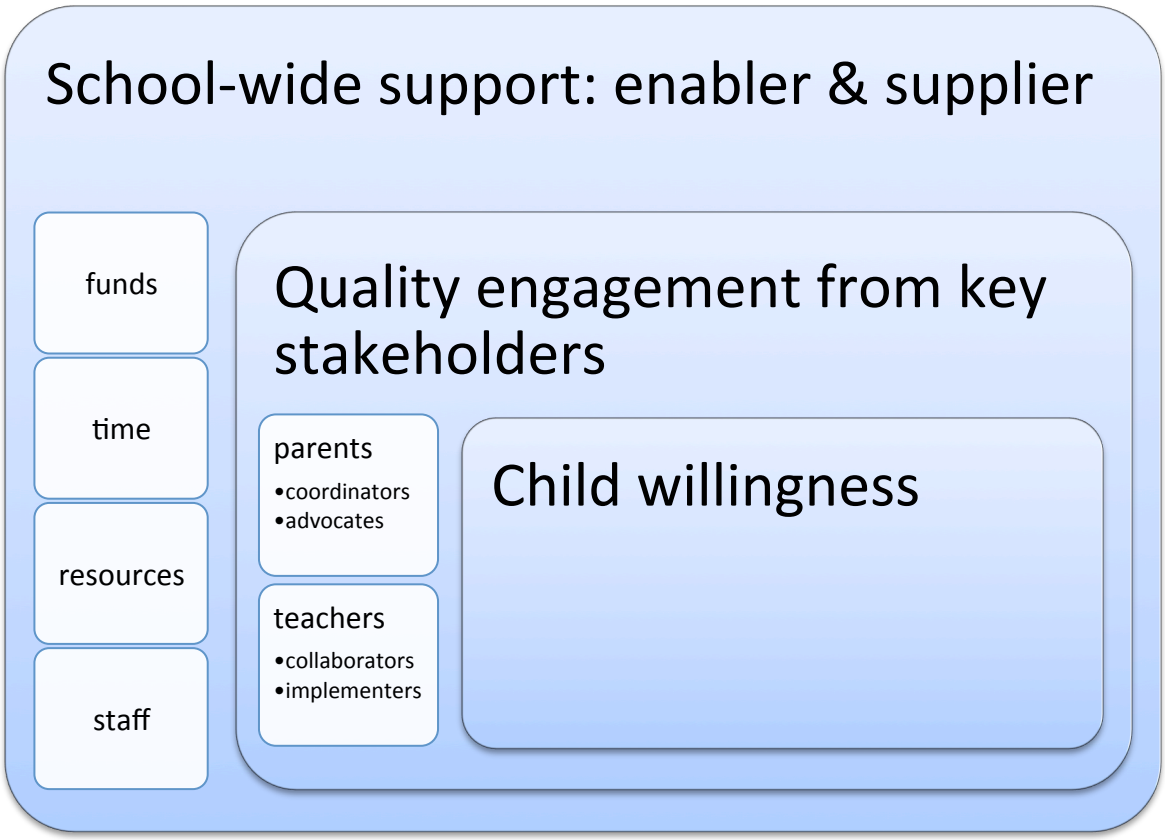

Figure 4: The integrated model of support of adaptive behaviour during the transition to school

The results show the importance of identifying the roles of each key stakeholder and of supporting each stakeholder to actively engage and contribute by performing their role. They also reinforce the importance of encouraging the child and reducing

unwanted behaviours such as school refusal, adaptive behaviour regression and maladaptive behaviours. Assessing whether the child is a willing participant in the transition to school is important. If school refusal is shown, identifying what behaviours are being seen and why would support the child and their adaptive behaviour development. Parents are the coordinators of the whole transition-to-school process, and need education, time and support to effectively coordinate their child's transition to school and advocate for their child. Identifying the school-wide support an educator needs in order to be able to actively engage in the transition process is vital, whether it be further education, additional staff, additional time or additional resources to be able to communicate, collaborate and implement the child with autism's transition timeline. School-wide support is essential to supplying an enabling environment to support these key stakeholders, the child, and everyone involved to enable a successful transition through meeting the needs of the child with autism and the key stakeholders. Finally, the results of this study show including adaptive behaviour development support throughout the transition-to-school process is an important part of the transition-to-school timeline.

5.4 Limitations

A qualitative study is an appropriate choice for this study to gain a deeper understanding of the experiences of parents with their child's adaptive behaviour after the transition to school from an early intervention preschool. Even though the sample size of this study is appropriate for qualitative enquiry of this size (n = 10–15), the data from this study may not represent all views on the research topic, and parents who were not interviewed may have different views and therefore possible themes may have been missed. Although purposeful sampling has been used, parents were not chosen based on

any knowledge about their opinions regarding the research topic and parents had not met or spoken to the researcher prior to the study.

5.5 Future research directions

The results from this study could guide future research about adaptive behaviour and transitioning to school for a child with autism. Future research could study the implementation of the integrated model of support in practice during a child with autism's transition to school. More investigation is needed in the area of school refusal and anxiety for a child with autism at this age, and how to facilitate a child's willingness to participate at school is also under-investigated. Parental roles have been researched in the past (Stoner & Angell, 2006), but future research could further investigate and define the roles of educators and schools, and could develop and test the role identification outlined in the results of this study. Interviewing educators in similar future studies, may build a more in-depth picture of the roles each of these stakeholders plays from other views, rather than only parents' perceptions of those roles. Future research could also include the view of the child with autism, researching what factors are needed to facilitate the child's willingness, giving the child a chance to contribute their own voice in this area of research. Finally more quantitative as well as mixed methods evaluations of the transition to school and its impact on adaptive behaviour may be needed, as these findings provide good insights into the sorts of issues that can, and perhaps should, be measured as part of such research.

5.6 Summary and conclusion

The current study contributes valuable and in-depth parent perspectives on the transition-to-school process, and how this transition affects the skill development of a

child with autism in the areas of daily living skills, social skills, and language and communication skills. It introduces the integrated model of support for adaptive behaviour development during the transition to school. This study supports previous evidence that adaptive behaviour skill development should be a key goal area for support, especially during one of the most significant transitions a child makes, that is, the transition to school. This study shows that some areas of the transition process are well supported, but there are variations between schools and transition procedures, and these may not always be individualised to suit the child's needs.

The findings from this study produced three main themes: child willingness, quality engagement of the key stakeholders and school-wide support. These themes have been combined into an integrated model of support, which shows the importance of encouraging school willingness for a child with autism, and troubleshooting school refusal, with parents actively engaged as coordinators and advocates, educators as collaborators and implementers, and the school enabling and supplying what is needed to support adaptive behaviour development. These three themes are drawn from parents' perceptions of the factors that bring changes to adaptive behaviours, when their child with autism is transitioning to school.

Appendix A: Parent recruitment script

Dear parent,
We hope you and your family are well.

We are commencing a follow-up study and we are hoping to learn about how the transition to school has gone, as an extension of the existing longitudinal study. In particular, we are interested to learn if you have noticed any changes in your child's social, communication, and daily living skills during this time, as an effect of the big change that is the transition to school.

You are being contacted as you have indicated previously that you may be interested in participating in additional research. Would you be willing for us to follow up with you about how the process has gone? This shouldn't take more than 30–45 minutes of your time. We would be asking you to:

1. Complete a **brief (2–5 minutes) initial survey via email** so that we can ensure we have up-to-date information about the new school setting and transition
2. Participate in a **phone interview (approximately 30–45 minutes** at a time convenient to you) in which we would ask approximately 13 questions, which you will receive in advance. This will be about the transition and any changes in your child's social, communication, and/or daily living skills.

We have attached an **information sheet** that explains what we are planning, including potential risks and benefits, in more detail. This study is under ethical clearance GU ref no: 2016/676.

The interviews will be conducted by Rebecca Poulsen, who is completing her Master of Educational and Professional Studies at Griffith University. She is very interested in the transition to school process and is also the mum of a child on the autism spectrum.

As always, participation is completely voluntary and please do not hesitate to let us know if you have any questions.
Best regards,

Appendix B: Parent/caregiver information sheet

Dear Parents/Caregivers,

As noted the in the email you have received, we are contacting parents/caregivers who are part of the Longitudinal Study of Australian Students with Autism (LASA) whose child started school this year, to ask if we can talk with you about how the transition has gone. This is an extension to the existing study, and participation is voluntary.

The following is a summary of what would be involved.

Who is conducting the research?

The overall project is led by Professor Jacqueline Roberts, Dr David Trembath at Griffith University, and Rebecca Poulsen at Griffith University. Rebecca will work on the project as part of her Master of Educational and Professional Studies at Griffith University. She is very interested in the transition to school process and is also the mother of a child on the autism spectrum.

Why is the research being conducted?

We are following up with families whose child started school this year. We are hoping to learn about how the transition to school has gone and if you have noticed any changes in your child's social, communication, and daily living skills. Transitioning to school is a major part of a child's life, and also involves major changes for parents and families.

What you will be asked to do?

There are two parts to participating in this study:

1. Complete a brief (2–5 minute) initial survey via email so that we can ensure that we have up to date information about the new school setting and transition.
2. Participate in a phone interview (approximately 20–30 minutes) at a time convenient to you, in which you would be asked 10 questions. These questions are about the transition and any changes in your child's social, communication and/or daily living skills.

The expected benefits of the research

We do not expect that there will be any direct benefits to you or your child as a result of participating in this follow-up study; however, we do expect that the findings will contribute important knowledge about the impact of transition on a child's skills that will be relevant to parents, caregivers, teachers, clinicians, and researchers. By hearing about your experiences, and those of other parents/caregivers, we also expect to identify strategies for better supporting children and families during the transition to school, that we will look to test in future studies.

What are the risks to you?

We do not foresee any major risks to you participating in the study. If your child's transition has been difficult, we understand that talking about this could be difficult. Therefore, we would encourage you to share only as much information as you would feel comfortable sharing. We hope that sharing your experiences will be a positive experience and help us, teachers, and other parents/caregivers to understand the experience of supporting children as they make the transition to school. You will receive the interview questions in advance also, to ensure you are informed about all topics that may be covered. You can choose to edit this if there are sections you would like not to answer. To ensure that you are happy with the information collected in the interview, we will provide you with a copy of the transcript that you can then edit as you see fit, prior to us using it in the research.

Your confidentiality?

We plan to publish and present the findings of the research so that they can be used to improve the transition process for families in the future. Your confidentiality and anonymity will be maintained and no parent/caregiver, child, teacher, other person, or school will be identified.

Audio recordings, de-identified transcripts, and analysis of the interviews will be stored on password protected computers belonging to the research team, with any hard copies of documents stored in a locked filing cabinet in Professor Jacqueline Roberts' office. All data will be destroyed after five years following the final ethics report submitted to the Griffith University HREC.

Your participation is voluntary

Your participation in the study is voluntary and you have the right to withdraw at any time through the process, without question or consequence.

How do you participate?

If you are willing to participate, please reply directly to Robyn Garland r.garland@griffith.edu.au or Rebecca Poulsen rebecca.poulsen@griffithuni.edu.au via email to organise an interview.

How do I provide informed consent?

You have already provided informed consent for your child's participation in the broader study. Accordingly, no additional consent is required and your completion of the parent questionnaire and participation in the interviews will be taken as you providing consent to participate in these activities.

Questions / further information?

If you have any questions about this study, please contact LASA Project Coordinator Robyn Garland; or the team leader Jacqueline Roberts.

The ethical conduct of this research

For your information ethics is cleared under GU ref no: 2016/676.

Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research*. If potential participants have any concerns or complaints about the ethical conduct of the research project they should contact the Manager, Research Ethics on 3735 4375 or research-ethics@griffith.edu.au.

Feedback to you

Opportunity for feedback will be provided at the end of the interview, and we will provide each parent with a summary of the findings.

Privacy statement – non-disclosure

In accordance with Queensland Information Standard 42 (which applies where the data will be collected or generated in an identified form and applies to human research conducted under the auspices of the University), "The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes." Your anonymity will at all times be safeguarded.

For further information consult the University's Privacy Plan at

http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan or telephone (07) 3735 4375."

It is recommended that you retain this information sheet for your own records.

Thank you for considering this invitation to participate in this study.

Appendix C: Parent survey form

Please provide the following details so that we can match these with your child's existing information already collected in the study.

Child's name:	
Gender:	
Date of Birth:	
Current Postcode:	

Please tell us about you, the person completing this questionnaire.

Your name:	
Relationship to the child:	
Would you be considered the primary caregiver?	
Contact phone:	
Primary email:	

CURRENT SCHOOL ENVIRONMENT

We are interested to know what services and supports your child has received over the years. To the best of your knowledge, please indicate if s/he received any of the following, at any time, during each year of life. Please tick all boxes that apply.

Service/Support Accessed	**Age**							
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Attendance at preschool/childcare attendance								
Aide support at childcare/preschool								
Attendance at autism-specific preschool/childcare (eg AEIOU, ASPECT)								
Attendance mainstream school								
Aide support in mainstream school								
Attendance support class in mainstream school								
Attendance satellite class in mainstream school								
Attendance at school for a child with ASD								
Attendance at special school								
Occasional centre-based early intervention program								
Intensive centre-based early intervention program								
Occasional home-based early intervention program								
Intensive home-based early intervention program								
Private speech pathology sessions								
Private psychology sessions								
Private occupational therapy sessions								
Private tutoring sessions for school work								
Medication to address symptoms of ASD								
Special diet (e.g., gluten free)								
Respite services								
Helping Children with Autism Funding Package								
NDIS funding								

INFORMATION ABOUT THE TRANSITION

We are interested to know what services and supports s/he has received for transitioning to school. To the best of your knowledge, please fill in the table below.

Which of these did you do before the first day of school	Please tick if yes
Driving past the school with your child	
Visiting the school	
Visiting the classroom without your child	
Visiting the classroom with your child	
Meeting the teacher without your child	
Meeting the teacher with your child	
Using a social story to teach your child about their new school/classroom/teacher	
Using a video to teach your child about their new school/classroom/teacher	
Teaching your child about the new school routine with any type of visual schedule	
AEIOU staff meeting the new teacher	
Other therapists or professionals meeting with the new teacher	
Providing copies of previous assessment reports to your child's new school	
Providing a child profile / checklist / information regarding your child's strengths, abilities and needs to the new school	
Practising wearing the new uniform	
Agreeing on a communication plan with the new teacher, whether formal or informal, to assess changing needs and goals (e.g., once a month/term meetings, regular emails)	
Other (please list using bullet points	

Appendix D: Parent interview questions

- How has the transition to the new school been for your child? What has been positive? What has been negative?
- Do you feel this educational setting is a good fit? Why?
- How much communication do you have with your child's current educational setting? Do you feel this is enough?
- Did you notice any effects on your child's behaviour, positive or negative, following the transition to school? What does he/she like/dislike about their new school?
- Did you notice any effect (changes/gains/losses) on your child's daily living skills following the transition to school, for example, toileting, dressing, or changes in self-care or independence? Was this a focus of intervention in the EI setting?
- Did you notice any effect (changes/gains/losses) on your child's social abilities, for example, their willingness to socialise, getting on with classmates, or changes to their social interactions? Was this a focus of intervention in the EI setting?
- Did you notice any effect (changes/gains/losses) on your child's communication or language skills following the transition to school? For example language development, expressing needs or wants (expressive communication) or following & understanding instructions (receptive communication)? Was this a focus of intervention in the EI setting?
- What effects did any of the changes due to the transition we have talked about have on you as a parent and as a family?
- What suggestions do you have (if any) to improve the likelihood of a successful transition? For example what worked for you, or what would you have liked for your child / you / family at the time?
- What suggestions do you have (if any) for schools and teachers to improve the support available for a child with autism when transitioning to a new school setting?
- Is there anything else you would like to add?

Thank you for your participation. Any questions, comments or feedback please contact the research team.

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