

Amanda Webster · Joy Cumming
Susannah Rowland

Empowering Parents of Children with Autism Spectrum Disorder

Critical Decision-making for Quality
Outcomes

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Foreword

I have had the great fortune to meet many children and adults on the autism spectrum and their family members throughout my career. They have taught me a great deal about what it means to live with autism and about the role professionals have played in their lives. I have learned that, for many families, interacting with professionals can help or hinder, decrease or increase stress, empower or disempower, cause or resolve conflict, create or solve problems.

From a professional perspective, we would do well to be guided by the work of Carl Dunst, the Turnbills and others who have advocated for decades that family empowerment should be a primary outcome of intervention. Over the past two decades, we have amassed a large body of research supporting the use by professionals of family-centred practices that empower families. The use of a family-centred approach has been linked to improved parenting self-efficacy, parenting skills, reduced parenting stress, participation in community activities, knowledge of child development, family quality of life, access to support systems and self-advocacy. Resources are available to help professionals to learn about and adopt a family-centred approach and to assess how effective they are in implementing family-centred practices.

From the parent's perspective, there has been little available information until now to guide their interactions with professionals, who will undoubtedly vary in their knowledge and use of family-centred practices. This excellent book helps to address this gap. It is the first publication of its kind to provide parents with a framework to guide their interactions with professionals and educators in order to create effective education plans and programmes for their child on the autism spectrum.

Empowering Parents of Children with Autism Spectrum Disorder is focused on supporting parents of school-aged children to have meaningful input into their child's educational planning and programming. As pointed out by the authors, parents often report being confused by conflicting information regarding which services and programmes can best meet their child's needs. They can feel frustrated and marginalised by professionals. The Cycle of Learning framework is introduced in this book as a means to assist parents in their decision-making, to identify a future vision for their child, determine key barriers and set learning priorities. The book

uses case studies to highlight how parents can implement the framework. These case studies ensure that the book remains very practical and accessible.

While providing parents with practical strategies within a guiding framework to support their child's education, the book will also be of benefit to professionals—particularly educators. The Cycle of Learning framework is underpinned by principles of empowerment and family-centred practices, facilitating positive and productive partnerships between professionals and parents. It is through such partnerships that children with autism spectrum disorder (ASD) and their families can realise their visions.

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Part I
Parents, Effective Practice, and Critical
Decision-Making: What do we know

Chapter 1

Effective Practice and Decision-Making for Parents of Children with Autism Spectrum Disorder

Abstract This chapter provides an introduction to the first section of the book in which research and current knowledge is presented about: the challenges faced by parents of children with autism spectrum disorder; the practices that have been found to have an evidence-base for children with autism spectrum disorder, and the Cycle of Learning decision-making framework.

Parents are experts when it comes to their children and play a critical role in teaching and guiding their children's learning as they grow from early childhood into adulthood. For parents of children with autism spectrum disorder (ASD), this responsibility often starts as soon as their child is diagnosed, with more complex challenges arising as their children mature. As a result, parents are required to take on a variety of roles as they make decisions about their child's learning and advocate for their child in different settings (Stoner & Angell, 2006). Unfortunately, parents of children with ASD often face obstacles as they seek to give their child the educational opportunities that will enable them to develop their skills and achieve a high quality of life. In addition to learning about ASD and what this means for their child, parents also have to navigate a complex system of government policies, societal attitudes, educational programs, and conflicting information from health providers, educators, and other parents (Foster, Rude, & Grannan, 2012). Moreover, once their child enters school, parents often take a back seat to educators who traditionally take the lead in developing education plans and programs for their children (Fish, 2006).

ASD is a pervasive neurodevelopmental disorder, marked by impairments in social communication and restricted and repetitive behaviours, as well as differences in sensory and information processing (American Psychiatric Association, 2013). Individuals with ASD are unique, with the characteristics associated with ASD presenting in varying ways and creating different challenges for each person (Zeman, Swanke, & Doktor, 2011). The number of children diagnosed with ASD has increased significantly over the past 20 years (Matson & Kozlowski, 2011). At the same time the inclusion of students with disabilities in mainstream education settings has become the prevailing model (Renzaglia, Karvonen, Drasgow, & Stoxen, 2003). As a result, the majority of students with ASD are currently being educated in mainstream education settings. This has had a significant impact not just on the education system, but also on teachers and parents working to support these students in meaningful ways. Consequently, primary and secondary school

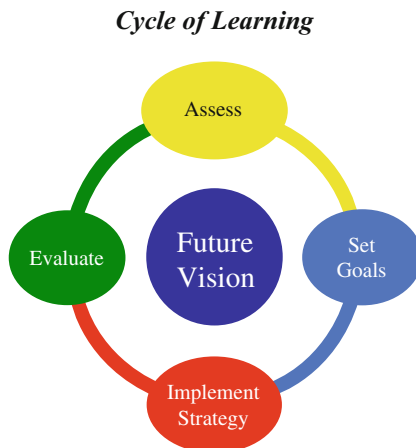
educators are being asked to cater for the needs of children with ASD in environments that present a myriad of potential stressors for these children, including, but not limited to, demands for social interaction, sensory overload, and limited levels of structure (Hull Learning Services, 2004; Whitaker, 2007).

Legislation in different countries (Rotatori, Bakken, Burkhardt, Obiakor, & Sharma, 2014) mandates that schools have a duty to include and provide supports to students with disabilities, including those with ASD, providing fair and equal opportunities to access a high quality education that allows students to reach maximum achievement on academic standards and assessments (Dempsey, 2012; Foster et al., 2012; U.S. Department of Education, 2015). Parents have been recognised as essential team members in the educational planning and decision-making process for children with ASD. Parental involvement has been consistently linked to outcomes for children with ASD, including increased social emotional learning and behaviour (Iovannone, Dunlap, Huber, & Kincaid, 2003), self-determination (Field & Hoffman, 1999), and generalisation and maintenance of skills (Lynch & Irvine, 2009). In reality, however, home-school collaboration is often more an ideal than a reality as parents struggle to be actively involved in creating education plans and programs that will enable their child to achieve meaningful goals and realise their dreams.

Parents of children with ASD are reporting high levels of stress and frustration in accessing appropriate support that will enable their children to become independent and self-determined adults (Hayes & Watson, 2013). In addition, with the increased information available in the media and on the internet (Mackintosh, Myers, & Goin-Kochel, 2005; Parsons, Lewis, & Ellins, 2009), parents of children with ASD are constantly being confronted with an overwhelming number of reports on programs and interventions claiming to help individuals with ASD or, in some cases, cure them. As a result, many parents are spending excess time and money on strategies which have been found to be ineffective and even harmful (Carlson, Stephenson, & Carter, 2014), rather than on those that have been found to consistently result in beneficial outcomes for children with ASD. At the same time, parents are stating (Tucker & Schwartz, 2013) that they often feel disengaged from school planning processes, which are often dominated by educators (Fish, 2006), and are made to feel marginalised (Oprea & Stan, 2012) by education professionals who do not view them as knowledgeable contributors to their child's education program (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010).

Parents have unique knowledge of their children's needs, strengths, interests, and current and future goals, and are their child's first teacher, supporter, advocate, and voice to the outside world. As their child grows, it is critical that parents collaborate with educators to share knowledge about their child, set key priorities and goals, determine appropriate strategies and supports, and evaluate achievement (National Research Council, 2001; Ruble & McGrew, 2015). As the most stable and influential people in a child's life (Dunlap, 1999), parents are in a unique position to ensure that education plans and programs are designed to meet their child's unique way of learning and interacting with the world, while reflecting their family's culture, language, values, and spirituality, and striving towards educational achievement, attainment of personal goals, and a better quality of life and optimal outcomes for both

Fig. 1.1 Cycle of learning framework



the child and their family (Harte, 2009; Osher & Osher, 2002; Whitaker, 2007; Zeman et al., 2011).

The primary purpose of this book is to present research and case studies illustrating how parents of children with ASD have become empowered through the use of the Cycle of Learning (CoL) framework (see Fig. 1.1) to lead educational decision-making and planning for their child. This research-based framework has enabled parents to work with educators and service professionals to establish an overall vision for their child and to select, implement, and evaluate the most effective programs that will allow their children to realise their dreams and achieve meaningful life goals. In addition, parents have increased their self-efficacy to successfully advocate for effective school, community, and home-based education programs for their child with ASD.

The book is divided into three sections. In the initial section of the book, the first chapter will provide an overview of the research on current issues faced by parents of children with ASD. This will be followed by a review of the research on evidence-based practices for students with ASD in inclusive school settings. In the last chapter in this section, the CoL framework will be discussed and the research underpinning its individual components will be presented. In the second section, case studies will be presented to illustrate how parents have utilised the CoL framework in their collaboration with educators to develop and implement education plans for their children. Finally, the last section will present case studies examining the use of the CoL by parents as they advocate for more systematic change in education programs and policies for children with ASD. This book is intended as an academic text aimed at parents, professionals, and researchers working with individuals with ASD and their families. It should be noted that while the parent contributors to this book have become further educated about ASD through university study, the framework, strategies, and ideas presented throughout the book are intended to be practical and useful for all.

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Chapter 2

Defining the Problem

Abstract This chapter presents international research on experiences and challenges reported by parents of children with autism spectrum disorder (ASD), in making informed choices and engaging with professionals regarding therapeutic and education programs that will allow their children to achieve success throughout their lifespan. Parents of children with ASD are currently confronted with an array of confusing and conflicting information about the services and programs that will best help their children. As a result, many parents feel frustrated and overwhelmed as they go about making decisions for their children, and have become disempowered in decision-making processes, particularly once their child begins school. This chapter will overview the current research on issues faced by parents of children with ASD, and will briefly examine the characteristics and implications of ASD for children with and families. The impact of the child's diagnosis and resulting stress on parents and families will be explored, followed by an examination of the particular challenges faced by parents once their children commences school. Finally, a recent study will be reviewed, which explored the satisfaction, confidence and training needs of parents of school-aged children with ASD.

Illustration 2.1



Parents sort through the piles of paperwork and literature after their child's diagnosis

The diagnosis of a child with autism spectrum disorder (ASD) is a time of tremendous uncertainty, change, and stress for parents and families. Parents are quickly faced with navigating a maze of information and bureaucratic processes as they attempt to find the best programs to support their child. Although family involvement is considered essential in programs for children with ASD, many parents report that they are increasingly being marginalised in planning processes, and are feeling frustrated with inconsistent and ineffective practices for their children. It is therefore critical that parents be provided with information and support to move into a more empowered and directive role to plan for their child, and to access the interventions and programs that will enable their child to reach their goals and dreams. For many parents, the first step is to learn what a diagnosis of autism spectrum disorder (ASD) means for their child and their family.

2.1 Introduction: Children with Autism Spectrum Disorder

There is a saying in the autism community “If you’ve met one person with autism – you’ve met ONE person with autism” - Dr. Stephen Shore. Although all individuals with autism spectrum disorder (ASD) share similarities in the core areas of impairment (i.e., social communication and restricted and repetitive behaviours and interests) associated with ASD (McAfee, 2002; Murray-Slutsky & Paris, 2000), they may demonstrate a wide range of behaviours and skills in each of these areas (Attwood, 2014). In the 1970s Lorna Wing was one of the first autism researchers to identify the “spectrum” of skills demonstrated by individuals with autism (Wolff, 2004). From Wing’s early classification of autism as a triad of impairment (Wing & Gould, 1978), the recent reclassification of autism has also seen a change in criteria to a dyad of core deficits in social communication and restricted and repetitive behaviours and interests (Attwood, 2014). Autism is no longer categorised as a group of related disorders, but as one disorder with a spectrum of characteristics (American Psychiatric Association, 2013). A diagnosis of autism will also now include an indication of the level of impairment in social communication and restricted and repetitive behaviours (Vivanti et al., 2013), reflecting the support needs of the individual in each area. This change represents a significant shift from the perception of ASD as a core set of behaviours, to a new understanding that individuals with ASD exhibit a spectrum of abilities and needs in the two diagnostic criteria areas.

In addition to the core characteristics cited in the diagnostic criteria for ASD, researchers (e.g. Freeth, Ropar, Mitchell, Chapman, & Loher, 2011; Grossman & Tager-Flusberg, 2012) have identified key differences in the way that many individuals with ASD process information. These researchers (Baron-Cohen, 1995; Happé & Frith, 2006; Minshew & Williams, 2008) argue that not only do individuals with ASD frequently exhibit differences in cognitive processing, but that these cognitive differences may actually underpin the core deficits in social communication and restricted and repetitive behaviours and interests associated with ASD. The

research in this area has primarily explored three specific theories regarding differences in cognitive processing exhibited by individuals with ASD (Rajendran & Mitchell, 2007). These theories include differences and impairments in theory of mind, executive functioning, and central coherence (Attwood, 2014). Theory of mind is also referred to as “mind blindness” (Baron-Cohen, 1995) and involves the ability to understand that other people have thoughts and feelings that are different from one’s own. People who have difficulty in theory of mind experience problems with making sense of the intentions and behaviour of others and predicting what they will do next (Attwood, 2014). Weak central coherence refers to the difficulty that many people with ASD have in understanding or seeing the overall picture (Happé & Frith, 2006). Although this has been cited as an area of difficulty, both parents and individuals with ASD have argued that the ability to focus on small details is also an area of strength. Executive functioning is another commonly cited area of cognitive difficulty for individuals with ASD (Rajendran & Mitchell, 2007), defined as the ability to engage in a sequence of problem-solving steps in order to attain a future goal. Executive functioning encompasses behaviours such as planning, impulse control, and inhibition and skills in organisation, working memory, and flexible thinking. Although difficulties in executive function, theory of mind, and central coherence are not unique to individuals with ASD, have been demonstrated to have a significant impact on the way that children with ASD engage with learning or social environments (Dodd, 2004).

Similarly, Vermeulen (2001) emphasises that individuals with autism think in much more linear ways than their neurotypical peers, demonstrating less cognitive flexibility in different contexts. He contends that rather than demonstrating a lack of skills, individuals with ASD experience “context blindness” in which they are unable to use context to create meaning (Vermeulen, 2015). Similarly, researchers with ASD, such as Temple Grandin (Grandin, 2013) and Wenn Lawson (Lawson, 2011), assert that for them, autism is characterised primarily as a difference in how they think or view their world. Research confirms that many individuals with ASD see information processing differences as their primary impairment, which then leads to secondary deficits in social communication and restricted and repetitive behaviours (Chamak, Bonniau, Jaunay, & Cohen, 2008). Parents also report that differences in thinking are a key characteristic of their children with ASD, but are often misunderstood by educators and other professionals who primarily focus on the child’s behaviour difficulties (Sciutto, Richwine, Mentrikoski, & Niedzwiecki, 2012; Stanton, 2000). Moreover, parents suggest that teachers view these behaviours as a choice, indicative of a naughty child or poor parenting, and fail to understand that they may be the manifestation of perceptual and processing differences characteristic of children with ASD. Parents also stress that their children cannot be categorised by a diagnosis or specific set of criteria, as individuals with ASD are widely diverse, each having their own unique strengths, interests, and needs.

The strengths of individuals with ASD have not received the same attention in research as areas of difficulty, but a number of researchers have begun to explore the unique skills demonstrated by children and adults with ASD. Researchers have

particularly focused on determining the prevalence and type of savant skills in this population (Howlin, Goode, Hutton, & Rutter, 2009; Treffert, 2014). Some researchers (Quirici, 2015; Scitutto et al., 2012), however, argue that it is a common misconception that all individuals with ASD have savant skills. No matter whether an individual is considered to have savant abilities or not, researchers (e.g. Frith, 1997; Joseph, Tager-Flusberg, & Lord, 2002) agree that most individuals with ASD have an uneven profile of abilities with at least some skills that are out of sync with their overall level of ability. For example, a person with ASD may have general difficulties with reading, but be very good at mathematical calculations. In addition, this disparity does not just exist between different knowledge areas, but can exist within the same academic or skill area in school or work settings. An example of this would be a child with ASD who can decode and spell words, but has difficulty with reading comprehension. Similarly some individuals might be above average in mathematical calculations but very poor at measurement of time and money.

This disparity of knowledge and skills can create even more misunderstandings for individuals with ASD. They are often assumed to be noncompliant or disruptive because they are not able to demonstrate a skill in an area that is seemingly similar to another skill in which they have previously excelled. In addition, some individuals with ASD have quite significant intellectual and language impairments (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). Ascertaining the specific profile of skills and needs of individuals with ASD starts with the initial diagnosis, but becomes particularly critical as parents begin to access services and education programs. This also marks a time of increased stress for parents as they begin the process of negotiating with schools and service providers for effective programs that meet their child's specific needs (Parsons, Lewis, & Ellins, 2009).

2.2 Challenges Reported by Parents

2.2.1 Impact of ASD: Stress Levels

A number of studies suggest that raising a child with ASD is enormously stressful and challenging for families (Baker-Erickzen, Brookman-Frazee, & Stahmer, 2005; Falk, Norris, & Quinn, 2014; Myers, Mackintosh, & Goin-Kochel, 2009; Phetrasuwan & Shandor Miles, 2009; Pozo & Sarriá, 2014). Researchers have found that parents of children with ASD experience higher levels of stress compared to both parents of typically developing children and parents of children with other disabilities, such as intellectual disabilities (Abbeduto et al., 2004; Baker-Erickzen et al., 2005; Weiss, 2002) or cerebral palsy (Hayes & Watson, 2013). Parents describe experiencing initial feelings of surprise, sadness, shock, and rejection following their child's diagnosis (Martins, Bonito, Andrade, Albuquerque, & Chaves, 2015). The impact of the initial diagnosis on families, however, has been found to

vary depending on their prior knowledge about ASD and their support structures (Myers et al., 2009; Stuart & McGrew, 2009).

Following their child's diagnosis, parents are faced with a range of extra pressures as they attempt to learn about ASD and what this means for their child. Financial strains and time pressures may lead to decreased self-efficacy and increased physical and mental health difficulties for families (Karst & Van Hecke, 2012). Other studies have found that families of children with ASD experience an overall decreased quality of life (Meadan, Halle, & Ebata, 2010; Tincani, Cucchiara, Thurman, Snyder, & McCarthy, 2014) as a result of dealing with their children's challenging behaviours. Parents also report facing hidden social costs as they decrease their engagement in social activities due to concerns for their child (Schaff, Toth-Cohen, Johnson, Outenn, & Benevides, 2011). Ewles, Clifford, and Minnes (2014) suggest that the ongoing financial, emotional, and physical responsibilities placed on parents of children with ASD put a significant strain on their psychological well-being (Myers et al., 2009). This is exacerbated by the need to continually advocate for services for their child. Parents confirm that much of their stress and exhaustion is caused by the continued necessity of having to fight for services, cope with complicated policies or negative societal attitudes, and constantly having to communicate and build relationships with education and health professionals (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004).

Parents of children with comorbid disabilities or with needs on the severe end of the autism spectrum, generally experience higher levels of stress and increased caregiver duties than do other parents of children with ASD (Zablotsky, Boswell, & Smith, 2012). Studies (Benson, Karlof, & Siperstein, 2008; Zablotsky et al., 2012) have also found that their child's level of need is linked to involvement and satisfaction of parents with their child's school, with parents of children with higher needs having the lowest level of involvement and satisfaction. Parents may feel blamed or judged by professionals or community members for their child's deficits and behaviours (Starr & Foy, 2012), making them even less likely to develop the trusting or collaborative partnerships needed to reach optimal outcomes for their child with ASD (Stoner et al., 2005).

ASD impacts family dynamics as well as parents' relationships. Divorce rates are higher for families of children with ASD (Hartley et al., 2010), with additional stress placed on families of children with particularly challenging behaviours (Rao & Beidel, 2009). Stress on siblings has also been examined, with some studies finding positive effects such as increased self-concept for siblings (Mates, 1990), whereas others have identified higher levels of loneliness and behaviour difficulties for siblings of children with ASD (Bågenholm & Gillberg, 1991). Mothers of children with ASD have been noted to experience more stress and levels of anxiety than fathers (Phetrasuwan & Shandor Miles, 2009; Pozo & Sarriá, 2014), perhaps because of the greater amount of time they generally spend with the child during their early years. Additionally, researchers have suggested that families have less time for family activities (Karst & Van Hecke, 2012), and parents often experience physical and emotional exhaustion as they struggle to cope with their child's poor sleeping and eating patterns (Stoner et al., 2005).

Accessing appropriate services and supports to help both their child and their family is another source of stress for parents. With the recent emphasis on early intervention services, parents of children with ASD are experiencing heightened levels of anxiety about choosing the right programs, or inability to access particular programs due to geography or lack of funds (Mackintosh, Goin-Kochel, & Myers, 2012). Parents also indicate that lack of support to help them access or make decisions about appropriate services (Stephenson, Carter, & Kemp, 2012) is a frequent source of frustration and anxiety. Mothers who are experiencing stress and anxiety may experience decreased self-esteem and a reluctance to engage with supportive services (Keen, Couzens, Muspratt, & Rodger, 2010). Other parents may focus on problem solving or positive aspects of their situation as a means of coping (Hastings et al., 2005), or may manage stress by networking with peers in early intervention programs and support groups (Boyd, 2002). Keen et al. (2010) also suggests that professional support is critical to alleviating the stress of parents as they access early intervention services following their child's diagnosis. In contrast, lack of communication and support from school leaders and teachers has been cited as a key cause of stress and dissatisfaction for parents of school-aged children with ASD (Starr & Foy, 2012; Tucker & Schwartz, 2013).

2.2.2 Engaging with Education Programs

Once their child enters school, parents must learn to navigate a whole new system of policies and practices. Lilley (2012) examined the experiences of 22 mothers as they enrolled their children with ASD in school for the first time, and concluded that a common thread in all of the mothers' narratives was the experience of stigmatisation both for their child and for themselves. In another study (Stoner et al., 2005), parents of children with ASD reported the change from early intervention to school-based programs was particularly difficult. They experienced high levels of confusion when attending their first education planning sessions at the school, feeling they had to fight to obtain supports for their child, which they still felt were inadequate to meet their child's needs. This led to a breakdown in trust with the school and school staff.

Collaborative partnerships between parents and educators are considered best practice, with the importance of including parents as full team members clearly documented in research and policy. (National Research Council, 2001; US Department of Education, 2015; Zablotzky et al., 2012). Often these partnerships are falling short of recommended practice, however, impacting on the achievement of optimal outcomes for children with ASD in school environments. There is much research on the multiple barriers affecting the establishment and maintenance of effective, collaborative parent-educator partnerships (White, 2014). These include poor communication; confidence and perceptions of educators; confidence and perceptions of parents; parental constraints including stress and time; conflict between parents and educators; insufficient school-based services; educators having a lack of

specific ASD knowledge and training; and a myriad of issues relating to decision-making processes and educational planning. Other factors affecting levels of parental involvement in their child's education include socio-economic standing, financial pressures, marital status, cultural beliefs, occupational rank, language barriers, a lack of parental confidence in the school system, poor communication practices between parents and educators, inadequate understanding of the impacts of ASD by educators, the number of children parents are caring for, and the level of disability of the child with ASD (Ryan & Runswick-Cole, 2009; Tincani et al., 2014; Todd, Beamer, & Goodreau, 2014).

Current legislation and policies across the world emphasise the importance of collaborative, positive partnerships between parents and educators, as a core element in shaping the educational experiences of children with autism (National Research Council, 2001; US Department of Education, 2015; Zablotzky et al., 2012). Parents have been recognised as essential team members, with their involvement in educational decision making and planning for their child consistently linked to students' cognitive development, academic achievement, attitudes, and aspirations (Brand, 1996; Foster, Rude, & Grannan, 2012; Osher & Osher, 2002; Turnbull & Turnbull, 1990; US Department of Education, 2015). Despite this acknowledgement of the important role parents play in their child's education, research (Spann, Kohler, & Soenksen, 2003; Tucker & Schwartz, 2013) suggests that educators continue to struggle to include parents or individuals with ASD in education planning and decision-making processes, and that, education plans and programs often fail to include the concerns, priorities, or values of parents (Ruble, McGrew, Dalrymple, & Jung, 2010). As a result, legal disputes regarding education programs and provisions for students with ASD have increased rapidly over the past 15 years (Turnbull, Wilcox, & Stowe, 2002; White, 2014). In a recent review of 97 complaints filed in the United States, White (2014) found that these disputes focused on parent's dissatisfaction with the identification of their children's needs, implementation of appropriate programs to meet those needs, inclusion of parents in the education planning process, inadequate evaluation of their child's learning and outcomes, and concerns about staff qualifications, and behaviour and disciplinary procedures. In Australia, Dempsey (2003) found that there was limited evidence that disability discrimination legislation had led to improved enrolment practices for students with disability, with students with ASD and other disabilities continuing to be excluded from education programs on a regular basis.

In contrast to early intervention programs which are often family centred (Stoner et al., 2005), parents often report being dismissed by school personnel as valuable contributors in assessing their child's needs, providing information about their child, setting goals, and planning for their child (Ferrel, 2012; Stoner, Angell, House, & Bock, 2007; Tucker & Schwartz, 2013). In another study, mothers of children with ASD reported they were silenced by educators by either not being given a voice or by not being listened to when they did speak (Carpenter & Austin, 2007). These mothers also felt judged by educators, reporting they were told what to do for their child rather than being included in discussions or asked to provide ideas about how to help their child. This research demonstrates a disturbing trend. Without parents as key participants in planning processes, opportunities are limited