

## 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; Scituito 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

for children with ASD to achieve goals, which are meaningful for both the child and their family. More importantly, parents may have differing ideas and values from educators, but lack the confidence to voice them, resulting in education programs that focus on outcomes that are not supported at home (Osher & Osher, 2002; Todd et al., 2014).

When communication and collaboration between parents and schools break down, tensions can quickly escalate into conflict. Lake and Billingsley (2000) found that nearly 90 % of parents reported that conflict with schools occurred due to schools and parents having differing perceptions of children's needs. Parents revealed dissatisfaction with school teams who did not recognise their child's individuality (individual strengths and limitations), and felt schools often operated from a deficit perspective, placing too much emphasis on what their children could not do as opposed to focusing on their strengths. Parents also report tensions arise when schools fail to meet legislative or policy requirements that they plan and provide strategies and support so that students are able to participate and achieve in education programs (Lilley, 2015; White, 2014). Lack of planning and support for children during transitions has been particularly highlighted as an area of concern (Lilley, 2015; Parsons et al., 2009). Parents also indicate they experience conflict with school leaders and teachers about what education programs and supports are reasonable and appropriate for their child in the school environment, and highlight a need for improved mediation processes to avoid the need for legal action to ensure their child is provided with the entitled supports (Tincani et al., 2014).

Parents frequently cite the limited level of knowledge of ASD and evidence-based strategies exhibited by teachers and school leaders as a source of concern and dissatisfaction with their child's education programs (Starr & Foy, 2012; Tincani et al., 2014; Whitaker, 2007). Starr and Foy found that parents felt most of their child's teachers lacked training or knowledge about ASD. Almost half of the parents expressed the need for school personnel to have more disability-specific knowledge in order to understand their children's needs, and felt they needed information and training on effective intervention techniques. Parents also report high rates of dissatisfaction with the level and quality of autism-specific support provided by schools for their child (Renty & Roeyers, 2006). These parents stress that educators often fail to provide programs which address the core characteristics of ASD, such as deficits in social communication and restricted and repetitive behaviours (Tincani et al., 2014; Tucker & Schwartz, 2013), and are unable to appropriately address their children's behaviour difficulties or even recognise that the cause of these behaviours might be linked to the characteristics of ASD (Whitaker, 2007).

By contrast, communication between parents and schools is often cited as a pivotal element in parents' satisfaction. Researchers suggest that good communication can help parents and educators to develop trust and collaborative relationships (Angell, Stoner, & Shelden, 2009; Renty & Roeyers, 2006), whereas poor or insufficient communication with educators is one of the most commonly mentioned sources of parent frustration and dissatisfaction (Whitaker, 2007; Zablotzky et al., 2012). Parents cite many issues with communication with schools, including fre-

quency of communication, general lack of communication, lack of follow up, misunderstood communications, dishonest communication, and non-reciprocal communication, as factors that escalate conflicts between parents and schools (Lake & Billingsley, 2000). Given that parents of children with ASD already report higher stress levels, it is understandable that they may require more frequent or different types of communication than parents of typically developing children. When communication is limited, parents are not provided with the information they need to determine how their child is progressing compared to his/her peers and what supports or services they may need to address specific needs. Research suggests that parents often rely on communication with educators and service providers to help them make decisions about practices that will enable their child to become more independent across different education and social settings (Jindal-Snape, Douglas, Topping, Kerr, & Smith, 2005).

### ***2.2.3 Planning and Decision-Making***

Much effort has gone into providing information to parents of children with ASD on the importance of accessing early intervention services and quality education programs to help their child to achieve better long-term outcomes. Several websites and training packages (e.g. National Autism Center, 2011; Positive Partnerships, 2014) focus on providing parents with information on programs and practices that have a strong research base confirming their effectiveness for children with ASD. This has enabled parents to become aware of the positive outcomes that are possible for children with ASD. As a result, parents are beginning to question the appropriateness of support and practices for their child and are asking whether these programs will help their child reach their full potential. At the same time, parents report feeling pressured to make sure they access the best interventions available for their child, and worry that their child will suffer if they do not have access to these programs (Mackintosh et al., 2012). Parents utilise a variety of information sources to make decisions for their child, and often seek the recommendations of other parents or professionals to help them make these decisions (Deyro, Simon, & Guay, 2014; Miller, Schreck, Mulick, & Butter, 2012). Recently Carlon, Carter, and Stephenson (2014) found that parents cited advice from others as the most significant factor in influencing their decisions about interventions for their children.

Unfortunately, in another recent study, mothers of children with ASD who attend mainstream schools (Lilley, 2015) indicated that teachers and school staff rarely provide parents with information about research-based practices. They report being provided with limited feedback about their child's individual progress, and reveal that decisions about interventions have often been solely made by school staff without any consultation with parents. Stoner et al. (2005) also note that parents are viewed by school staff as being peripheral to the education decision-making process, and in some cases, as "obstacles or adversaries" to the process. Berquist and Charlop (2014) emphasise that parents are the most stable figures in their child's

life. Teaching parents to choose and evaluate interventions for their child equips them with the tools they need to make empirically-based decisions about their child's services, which in turn increases the outcomes for the child with ASD, their family and community. Although studies have suggested that parents may lack knowledge about evidence-based practices, recent research (Berquist & Charlop, 2014) suggests that when parents are provided with information and are supported to participate equally in education teams, they develop self-efficacy and are able to participate fully in decision-making processes and to select and implement effective strategies and supports for their child.

### **2.3 Parent Issues, Confidence and Need for Training – A Recent Study**

Recently, Australian parents were surveyed to determine the key challenges they faced in working with schools to plan and implement education programs for their children with ASD. Specifically, parents were surveyed about their experiences in negotiating with schools for their child; their confidence in assessing their child's needs, setting goals for their child, and selecting interventions and evaluating outcomes for their child; and their needs for training and support that would increase their self-efficacy in these areas. Over the course of 4 weeks, 317 parents from across Australia completed the survey. The majority of respondents (56 %) were from the state of Queensland, with the next largest groups from New South Wales and Victoria (14 % & 13 % respectively). Parents also responded from South Australia (5 %), Tasmania (4 %), Western Australia (4 %), the Northern Territory (2.5 %), and the ACT (1 %).

Approximately 63 % of respondents had children in public state schools, but a surprisingly high number (13.4 %) reported they home schooled their children either on their own or under the guidance of distance education programs. A similar proportion indicated their children were attending Catholic schools. The majority of parents (70 %) reported their child had some type of individual education plan. Although 56 % of respondents indicated their child had accessed some type of early intervention service, 44 % stated that their child had not. This is a particularly significant finding as it suggests that school may be the first type of formal support and intervention that many children with ASD may be able to access. Respondents indicated their children were enrolled in a variety of school programs, with the majority (87.6 %) enrolled in a mainstream class on a full-time basis. Parents reported their children received support in the mainstream class both from teacher aides (35.1 %) or another teacher (20.9), however, 31.6 % of parents reported their child received no support. A few students (14.2 %) were enrolled part-time in a special education class and part-time in a mainstream class, and 17 % were enrolled full-time in a special education unit or school. Details on enrolments in education programs are provided Fig. 2.1. Participants indicated that the primary type of support their chil-

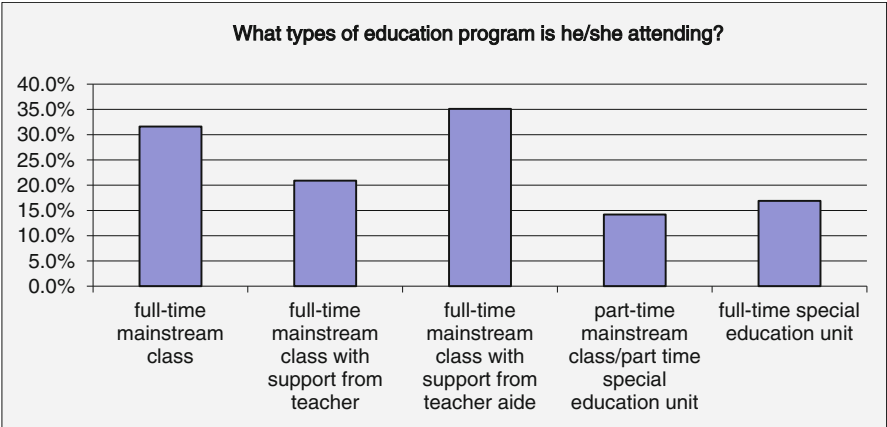


Fig. 2.1 Enrolment in education programs

dren received in school was 1:1 support or tutoring from a teacher aide, followed by support from special education teachers, class teachers, and school therapists. Special education teachers and teacher aides primarily provided support for curriculum adjustments or social/behaviour skills.

Respondents were also asked about their satisfaction with different aspects of their child’s education program. Responses were very mixed, with some participants indicating they were satisfied with most aspects of their child’s education program, while other participants reported they were dissatisfied with many aspects. The majority of respondents (67 %) indicated they were knowledgeable about their child’s education program and what their child was learning in the curriculum (61.5 %). The majority of parents also knew how the school was or was not supporting their child (63.9 %). Only half of the parents felt the school valued their knowledge and that they played an equal part in their child’s team. It is interesting to note that of the majority of parents who felt they were included had children in primary school, whereas almost no parents of children in secondary school felt they were included in education team processes for their child. In contrast to the number of parents who said they were included in planning teams, only 42 % felt the school consulted them when developing their child’s education program. Parents reported the lowest level of satisfaction with the support and instruction their child was receiving to address their needs in ASD-specific areas such as social communication skills, sensory needs, and information processing, with only 30 % of respondents stating they were satisfied the school was addressing their child’s needs in these areas. Participants also indicated they had limited choice about the type of school or program their child attended and were provided with little information about the types of programs that were available. Parents also indicated low levels of satisfaction with the knowledge their child’s teachers had about ASD and were not confident in the teachers’ ability to support their child. Many parents did not feel their child looked forward to going to school or that the school provided them (the parents) with meaningful information about their child’s progress. When parents

were asked how the school involved them, many respondents discussed being invited to meetings, but suggested they were only included in meetings as a formality, rather than as an equal member of the team.

Parents were also asked about their feelings of self-efficacy in planning for their child's education needs. Overall, participants reported much higher levels of satisfaction with their own knowledge and skills, than in the knowledge and skills of their child's school and teachers. Almost all parents (93.5 %) felt they had good knowledge of the characteristics of ASD and were able to assess their child's needs (90.6 %). They also expressed confidence in setting short-term goals (88 %) for their child, but were slightly less confident in identifying priorities and evaluating their child's progress (77 %). When they were asked, however, to discuss ways in which they assessed their child's needs and set goals for their child, participants often reported they relied on professionals and educators. They also stated they primarily focused on developing their child's social emotional skills and overall well-being. Only two respondents discussed focusing on their child's academic learning. Participants felt less confident in selecting appropriate interventions or strategies to support their child's learning in different areas. Respondents also expressed limited knowledge regarding their child's rights, ways to advocate for their child, and services and supports that could be employed by schools to help their child. Not surprisingly, parents felt they needed the most training and support to enable them to communicate with education professionals, and to advocate for their child in school settings. Many participants also strongly expressed their opinion that they possessed the necessary knowledge and skills to help their child, but that school personnel and staff needed to change.

Overall, the findings of this study are consistent with previous research indicating that parents of children with ASD feel they have adequate knowledge about their child's characteristics and are able to gather information to assess their child's needs and set goals for their child. They are knowledgeable about their child's education program, particularly as it pertains to the academic curriculum. They are less satisfied, however, in the support that schools are providing to help their child learn skills related to the particular characteristics of autism. In addition, parents often do not feel that schools include them in developing education programs for their child, or provide them with information about supports or strategies that are available and will help their child in school settings. Most importantly, parents need help to be able to advocate for their child and to communicate their priorities and knowledge with education providers.

## 2.4 Conclusion

In this chapter, research on key issues faced by parents of children with ASD has been presented. Research indicates that their child's diagnosis of ASD and subsequent challenges impact parents in a variety of ways. Many parents experience significant levels of stress, which affects their well-being and family dynamics, and

drains their emotional, physical, and financial resources. In addition, parents feel pressure to obtain accurate information and to make the best decisions and access the best programs for their child. As their child grows and enters formal education, many parents encounter additional challenges as they attempt to work with school leaders and teachers to develop and implement education programs for their children with ASD. Parents often report high levels of frustration and dissatisfaction with the knowledge their child's teachers have about their child's needs and the characteristics of ASD, as well as in the support their child is provided, particularly to address ASD-specific areas of learning. Even more concerning, parents feel their knowledge is not valued and they are not included in decision-making processes about their child's education program.

Although parents report being more confident in their own skills, they do indicate a need for information to help them make decisions about appropriate interventions, supports, and strategies that will help their child, particularly in school settings. In addition, parents of children with ASD report a need for training and support to be able to communicate their priorities and knowledge about their child in education planning meetings, to know their child's rights, and to be able to advocate for their child in education programs.

In the next chapter, the research on evidence-based practice for children with ASD will be presented, followed by a discussion of the types of practices that can be utilised to support students with ASD in inclusive school settings.

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2017, XII, 254 p. 33 illus., 19 illus. in color., Hardcover

ISBN: 978-981-10-2082-7