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Piecing Together the Puzzle of Autism: Aspects of Its Effects on Children with the Condition and their Caregivers

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Canada

Piecing together the puzzle of autism: Aspects of its effect on children with the condition
and their caregivers

by

Roula Markoulakis

Bachelor of Science, Wilfrid Laurier University, 2007

THESIS

Submitted to the Department of Kinesiology and Physical Education
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Master of Science

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STATEMENT OF PROBLEM

As one of the most prevalent developmental disorders, extensive research exists concerning Autism Spectrum Disorders (ASD). However, gaps are still evident in a number of areas. Information pertaining to any costs and benefits associated with the experience of caring for a child with autism is inadequate. In *Study 1*, the lived experiences of married female primary caregivers of children with autism were explored, specifically by examining the costs and benefits of caregiving and its influence on the women's situations. Furthermore, motor control deficits are apparent in many children with high functioning autism (HFA) and Asperger syndrome (AS), but need to be delineated further to determine the extent and effects of these impairments. As such, *Study 2* addressed the areas of fine-motor ability as a function of handedness, in addition to dominance as determined by handedness, footedness and eyedness. As well, motor planning and indices of laterality were examined.

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CHAPTER 1

The Autism Spectrum Disorders

Autism spectrum disorders (ASDs) manifest themselves differently among those afflicted, and consequently these individuals are considered to fall within a spectrum of disorders. The use of the term “spectrum” implies that individuals may display certain shared social and communication impairments, but vary in terms of the severity of their signs (visible indicators) and symptoms (non-visible indicators the individual can feel), the number of signs and symptoms present, the age of onset of symptoms and etiological profiles (American Psychiatric Association, 2000; Casanova, 2007; Williams & Brayne, 2006). As a whole, ASDs are the most common developmental disorders, affecting over 200 000 Canadians in total. Approximately 1 out of every 165 Canadian children born will be affected by some type of ASD (Autism Society Canada, 2005). As such, individuals with ASD may fit into one of the following categories:

Autistic disorder or childhood autism involves impairments in reciprocal social interaction and communication. Individuals with autistic disorder also display stereotyped behaviours, interests and activities. Age of onset is typically prior to three years (American Psychiatric Association, 2000; World Health Organization, 2007). Autistic disorder is the most common of the ASDs, and affects approximately 20 in every 10 000 Canadian individuals (Autism Society Canada, 2005; Fombonne, 2005).

Asperger’s syndrome also involves impairments in social interaction, but with no delay in acquisition of language skills and no delay in cognitive development. Similar to autistic disorder, these individuals will have very restricted interests and activities (American Psychiatric Association, 2000; World Health Organization, 2007). Asperger’s

syndrome is fairly common, and has been reported to affect approximately 3 - 5 in every 10 000 Canadians (Autism Society Canada, 2005; Fombonne, 2003a; Fombonne, 2005).

Rett's disorder is unique in that it has only been found in females. Such individuals typically develop as expected until anywhere from 5 to 48 months in age, at which point a loss of previously acquired skills occurs (American Psychiatric Association, 2000; World Health Organization, 2007). Purposeful movement of the hands is then lost, and replaced with repetitive hand movements. In addition, partial or complete loss of speech may occur, and may be accompanied by deceleration of head growth (World Health Organization, 2007). Rett's disorder is considered rare, and has a prevalence of approximately 0.5 - 1 in every 10 000 female Canadians (Autism Society Canada, 2005; Tidmarsh & Volkmar, 2003).

Childhood disintegrative disorder involves a sudden loss of previously acquired skills, but is preceded by a period of typical development lasting at least two years (American Psychiatric Association, 2000). Affected individuals display a loss of interest in the environment, stereotyped and repetitive motor mannerisms and deficits in social interaction and communication (World Health Organization, 2007). Childhood disintegrative disorder is considered rare, and affects approximately 0.17 - 2 in 10 000 (Autism Society Canada, 2005; Fombonne, 2003a; Fombonne, 2005; Tidmarsh & Volkmar, 2003).

Pervasive developmental disorder – not otherwise specified (PDD-NOS) is often diagnosed when marked deficits in certain behaviours are present, but the child does not fit the criteria presented for the other disorders of the spectrum. There are apparent problems with social interaction, communication, repetitive behaviours, and potential

language delays as well (American Psychiatric Association, 2000). About 15 - 21 in every 10 000 Canadians are affected (Autism Society Canada, 2005; Fombonne, 2003a; Fombonne, 2005).

Characteristics and Varying Severities of Autism Spectrum Disorders

Autism Spectrum Disorders are highly variable and individualized. Some individuals may have small personality differences, while those with increased severity may display more obvious characteristics, such as self-injurious and aggressive behaviours. Individuals with ASD can show altered interests in interaction with others. Some have no interest in pursuing social interaction, and may prefer being left alone (Nicholas et al., 2008). Others show interest, but will not know how to react to others and experience difficulty joining social experiences. Interactions are also difficult because of the individuals' altered abilities to control their own emotions and respond to the emotions of others (Scambler, Hepburn, Rutherford, Wehner & Rogers, 2007). Individuals with ASDs also tend to display ritualistic and repetitive behaviours, and may become anxious if these routines are interrupted in some way. They might also display a lack of anxiety and take risks, such as wandering off or crossing the street unsafely, as a result (see, for example Gillott, Furniss & Walter, 2001; Nicholas, 2008).

The severity of deficits in communication ability can also vary. Some individuals communicate with gestures rather than words, while others do not understand non-verbal gestures. Certain individuals will have no speech at all, while others may speak extensively about something they like, not maintaining a back-and-forth conversation. They may also use words and speech intonations inappropriately (Barrett, Prior & Manjiviona, 2004). People with ASD might also have altered sensory input, and can

experience mild to severe hypo- or hypersensitivities. Senses can be affected in many combinations, and individuals with ASD may experience altered reactions to certain sounds, touch, scents, tastes and even visual settings (Nicholas et al., 2008).

Diagnosis of Autism Spectrum Disorders

Establishing confirmed diagnosis of an ASD is an involved process. Ideally, evaluation of the individual will involve a multidisciplinary team, members of which have some background in the diagnosis of the disorder; however this ideal situation may not always be the case (see, for example Nicholas et al., 2008; Volkmar, 1998). The team often includes a neurologist, psychologist, pediatrician, speech/language therapist, learning consultant or others with knowledge in the area. These professionals will work together with parents and other caregivers to obtain a complete picture of the individual's abilities and developmental history, and will combine this information with any of the tests described below in order to provide a diagnosis (Autism Society Ontario, 2006).

Diagnosis relies heavily on observation of a number of symptoms in combination with one another, according to DSM-IV criteria and/or ICD-10 criteria (see Appendix A and B, respectively). In Canada and the United States, diagnosis is typically based on DSM criteria, whereas countries in Europe and other parts of the world rely on criteria listed in the ICD (Autism Society Canada, 2005). In addition, many other measures are available to aid in diagnosis. The Autism Diagnostic Observation Schedule (ADOS-G) allows for the assessment of social interaction, communication, play, and imaginative play in a semi-structured format and across a broad range of ages and developmental levels, and is usually administered by a clinical psychologist and/or childhood psychiatrist. One of four modules is administered to individuals suspected of having

autism, and is chosen based on their developmental and language levels. The test is highly reliable and valid on individual test items as well as domain items. In addition, it is very sensitive and specific to Autism, PDD and non-spectrum disorders. For a full breakdown of scores see Lord et al. (2000).

The Childhood Autism Rating Scale (CARS) was developed as a measurement tool that does not rely strictly on Leo Kanner's initial definition of Autism, and so accounts for advances in knowledge of the disorder (Shopler, Reichler, DeVellis & Daly, 1980). There are 15 scales used, including, but not limited to impairment in human relationships, imitation, inappropriate affect, resistance to environmental change, peculiarities in auditory and visual responsiveness, verbal and nonverbal communication, and general impressions, which are administered by trained raters. The children are rated from 0 for normal behaviour to 4 for severely abnormal behaviour on each scale. The test also has a high level of internal consistency ($\alpha = .94$), and a high average interrater reliability ($r = .71, p < .001$). Finally, the correlation between the scale scores and clinician perceptions was $r = .84, p < .001$ and the correlation between child psychiatrist and psychologist scores with the scale scores was $r = .80, p < .001$. This is indicative of a high degree of validity (Shopler et al., 1980).

The Checklist for Autism in Toddlers (CHAT) was developed for children aged 18 months, and can detect the subtleties of the disorder much earlier than the typical age of diagnosis of three years. The test takes 5 to 10 minutes to administer and is based on yes/no scoring (see Table 1.1).

Table 1.1
CHAT Test Items

Section A: Ask parent		
1. Does your child enjoy being swung, bounced on your knee, etc.?	Yes	No
2. Does your child take an interest in other children?	Yes	No
3. Does your child like climbing on things, such as up stairs?	Yes	No
4. Does your child enjoy playing peek-a-boo/hide-and-seek?	Yes	No
5. Does your child ever PRETEND, for example, to make a cup of tea using a toy cup and teapot, or pretend other things?	Yes	No
6. Does your child ever use his/her index finger to point, to ASK for something?	Yes	No
7. Does your child ever use his/her index finger to point, to indicate INTEREST in something?	Yes	No
8. Can your child play properly with small toys (e.g. cars or bricks) without just mouthing, fiddling or dropping them?	Yes	No
9. Does your child ever bring objects over to you (parent) to SHOW you something?	Yes	No
Section B: general practitioner or health visitor observation		
i. During the appointment, has the child made eye contact with you?	Yes	No
ii. Get child's attention, then point across the room at an interesting object and say 'Oh look! There's a [name of toy]!' Watch child's face. Does the child look across to see what you are pointing at?	Yes	No*
iii. Get the child's attention, then give child a miniature toy cup and teapot and say 'Can you make a cup of tea?' Does the child pretend to pour out tea, drink it, etc.?	Yes	No ¹
iv. Say to the child 'Where's the light?', or 'Show me the light'. Does the child POINT with his/her index finger at the light?	Yes	No ¹
v. Can the child build a tower of bricks? (if so how many?) (No. of bricks:)	Yes	No
*To record Yes on this item, ensure the child has not simply looked at your hand, but has actually looked at the object you are pointing at.		
¹ If you can elicit an example of pretending in some other game, score a Yes on this item.		
² Repeat this with 'Where's the teddy?' or some other unreachable object, if child does not understand the word light. To record Yes on this item, the child must have looked up at your face around the time of pointing.		

(Baron-Cohen et al., 2000).

A general practitioner asks the parent or caregiver to answer the items in part A, then completes the items in part B based on direct observation. This test is useful because of its ease of administration and ability to refer high-risk individuals to further, more intensive diagnostic procedures. Of the high-risk group, nearly all will receive a diagnosis of autism or some other ASD, while about half of those in the medium risk group will receive a diagnosis of autism or some other ASD. There is a low false-positive rate, with a sensitivity of 18%, a specificity of 100%, a positive predictive value of 75% and a negative predictive value of 99.7% for the autism high-risk criteria. For all PDDs, there was 21.3% sensitivity, 99.9% specificity, and 58.8% positive predictive value. This indicates a fairly high false negative rate, but this is not overly concerning as the condition is not life-threatening and will likely be detected at a later date (Baron-Cohen et al., 2000). This may, however, have implications in other areas of the affected individuals' functioning as it will affect access to early intervention strategies.

The Autism Diagnostic Interview-Revised (ADI-R) is designed for administration by a trained interviewer to parents and caregivers of those aged 18 months to adulthood who are suspected of having autism or some other PDD. It is based on both DSM-IV and ICD-10 criteria (Lord, Rutter & Couteur, 1994). Multirater kappa levels for most social items were higher than .70, higher than .69 for all communication items, and equal to or higher than .63 for restricted and repetitive behaviour items (Lord et al., 1994). The algorithm for cutoff values was designed such that both sensitivity and specificity would exceed .90 (Lord et al., 1994).

The Social Responsiveness Scale (SRS) is a screening tool that can be completed by parents/caregivers or teachers in 15 to 20 minutes, and obtains information regarding

the child's ability to participate in reciprocal social interaction. Each item on the scale is scored as 0 for "sometimes true" and 3 for "always true". Upon completion, the SRS can aid in distinguishing a child with some PDD from a child with another psychiatric disorder. Correlation coefficients range from .75 to .91 for agreement between mothers, fathers and teachers when using the SRS. Additionally, there was a strong two-year stability of the tool ($r = .83$). This test is also unlikely to be affected by age or IQ, making it a useful tool for parents and teachers or in a clinical setting (Cosantino et al., 2003).

Finally, the Social Communication Questionnaire is another useful test for the diagnosis of ASDs, and is a widely used and reliable first-level screening tool designed to be administered by the parent. Its development was based on items found in the ADI-R (Chandler et al., 2007). Initial tests revealed it discriminates between ASD and non-ASD cases with .85 sensitivity and .75 specificity (Berument, Rutter, Lord, Pickles & Bailey, 1999). Further studies revealed .88 sensitivity and .72 specificity in distinguishing between ASD and non ASD cases, as well as .90 sensitivity and .86 specificity in discriminating between autism and non-autism cases (Chandler et al., 2007).

This is by no means an exhaustive list, as a large number of screening and diagnostic tests have been developed that can be administered in a variety of settings (Williams & Brayne, 2006). The key is early recognition and diagnosis by a team of specialists using a variety of resources, thereby providing the individual with early access to any necessary effective therapies and treatments (Autism Society Canada, 2005).

Etiology of Autism Spectrum Disorders

Although a great deal is still unknown about the causes of ASD, it has been found to be unrelated to race, ethnicity, family income, lifestyle, or parenting styles (Fombonne, 2003a). There have been many potential causes or risk factors found for ASD such as neurological causes, genetics, birth complications and toxins, and research is ongoing in this area (Fombonne, 2003b).

Neurological differences are being researched, as people with ASD are known to have certain structural and chemical differences in the brain. Such differences may affect brain areas associated with social interaction and communication. A large proportion (approximately 87%) of individuals with autism have hypoplasia of the cerebellar vermis, while the remainder may experience hyperplasia of the cerebellar vermis. Abnormalities of the cerebellar vermis are important to consider, as the cerebellar vermis itself has been linked to one's affect, social interaction, motivation, learning, as well as processing and regulation of sensory and motor information. Medial temporal lobe lesions have also been found in individuals with autism, and have been implicated as a predictor of the severity of symptoms. Finally, there have been rare findings of frontal lobe lesions, leading to the belief that these abnormalities occur transiently during postnatal development (Trottier, Srivastava & Walker, 1999). Findings in neurochemical research have also gathered attention. Hyperserotonemia, an increase in serotonin levels, may be related to observed repetitive and obsessive behaviours. Decreased dopamine transmission has been found in individuals with autism, leading to delayed growth-hormone response. Overactive brain opioid systems have also been found, and have been

implicated in hyperactivity, the presence of stereotypies and self-injurious behaviours (Trottier et al., 1999).

Genetic research is examining the potential role of inheritance in this disorder. No gene has been explicitly implicated in leading to ASDs at this time, however twin studies and sibling studies strongly indicate the potential for a genetic cause. Sibling studies often contain a high prevalence of twins within the dataset. Furthermore, monozygotic twins are often present in higher proportions than dizygotic twins in populations with ASD, providing additional support for a genetic cause (Greenberg, Hodge, Sowinski & Nicoll, 2001). Additionally, a gene isolated for Rett's Disorder has been found, where mutations in the methyl-CpG binding protein 2 gene (MECP2) have been found to be associated with development of the disorder (Laurvick et al., 2006).

The influence of the immune system is also being examined as a potential contributing factor to the development of an ASD. It has been found that the brains and nervous systems of some individuals with ASDs show inflammation, as biomarkers of neuroinflammation (such as quinolinic acid, neopterin and biopterin) have been found to be significantly elevated in individuals with autism compared to controls. This indicates a potential problem with the immune system, such as an immune deficiency, an autoimmune response, or the presence of a persistent, chronic virus (Zimmerman et al., 2005).

Birth complications can also be a risk factor for ASD, and research has focused on the effects of the mother's health and problems during delivery on ASD development. The effects of such complications on the sensory, language, social and mental functioning of the child can be examined in terms of incidence of ASD. Medical conditions such as

fragile X syndrome, tuberous sclerosis, and mitochondrial disorders are being examined as comorbidities with similar origins, potentially arising early in the first trimester of gestation (see, for example Casanova, 2007; Trottier et al., 1999). Rare cases of congenital rubella have also been implicated in ASD development (Trottier et al., 1999).

Exposure to toxins is also another potential risk factor that researchers have been examining. There has been a great deal of debate as to whether exposure to thimerosal, a mercury-based preservative found in many childhood vaccinations, can actually cause autism. Thimerosal has been used since the 1930s, and is required by the FDA to prevent bacterial or fungal infection of all vaccines, other than live-virus vaccines (Immunization Safety Review Committee, 2004). There is confusion as to whether increases in prevalence of ASD are due to increased vaccination or other factors, such as a broader diagnostic concept of ASD, increased recognition, or imprecisions in data collection methods (Fombonne, 2003b). In 2004, after many years of debate, the Immunization Safety Review Committee concluded that there is no causal relationship between autism and thimerosal-containing vaccines (Immunization Safety Review Committee, 2004).

Conclusion

Two separate studies were completed as part of this thesis project. An understanding of the above was essential in the design and execution of both studies. *Study 1* is a qualitative study examining the experiences of female primary caregivers of children with autism. *Study 2* is a quantitative study evaluating the motor abilities and deficits of children with high functioning autism and Asperger syndrome. More specific related work and information pertaining to each study will be presented in turn. Chapter 2 will address *Study 1* in its entirety, followed by *Study 2* in Chapter 3. Chapter 4 will

include general conclusions that can be made by compiling information obtained from both studies.

CHAPTER TWO

STUDY 1

An Examination of the Costs and Benefits Associated with Caring for a Child with Autism

Abstract

Although the lived experiences of the caregivers of children with autism have been examined to some extent, a more thorough investigation of the costs and benefits of this experience in terms of financial implications, social life, family life, personal well-being, employment and effects to family life from the perspective of the primary caregivers is warranted. The lived experiences of eight married female primary caregivers of children with autism were assessed through background questionnaires and one-on-one semi-structured interviews. The first two themes identified included children's communication and social skills. These affected the experiences of caregivers, through subthemes of providing initial triggers to seek diagnosis, revealing autism-specific tendencies in the children, affecting the children's peer interactions and accessing therapy. The third theme, the tasks taken on within the caregiving role, were also an important influence in the lived experiences of these women, through managing the children's behaviours, routine and environment. Finally, both costs (Theme 4) and benefits (Theme 5) arose to many facets of their lives as a result of caring for children with autism. These were comprised of financial effects, social effects, health effects, employment effects, effects to family and effects to activities or involvements. Results have broader implications for the understanding of the primary caregiver situation and ways to create support services that foster a positive experience for caregivers, the children they care for and their families.

Introduction

Caring for children with autism can present an added burden to families, in addition to providing an environment for the children's optimal growth and development (Jarbrink, Fombonne & Knapp, 2003; Sen & Yurtsever, 2007). Children with disabilities are generally dependent on others, and may require a great deal of care (Sen & Yurtsever, 2007). The purpose of the current study was to explore the lived experiences of married female primary caregivers of children with autism by specifically examining: (1) the children's functioning and behaviours, and potential influences on the caregivers' experiences, (2) the costs associated with caring for children with autism, where costs are defined as adverse or negative effects on any or all aspects of the caregivers' lives; and (3) the benefits, or favourable effects, associated with caring for children with autism.

Challenges to caregivers and families

It is well documented that raising a child with autism can affect family life (see, for example Higgins, Baily & Pearce, 2005; Jarbrink et al., 2003; Sen & Yurtsever, 2007). Sen and Yurtsever (2007) reported that mixed emotions can accompany the discovery that a child has a disability, including shock, denial, suffering, depression, guilt, indecision, anger, shame, bargaining, acceptance and adaptation. Furthermore, parents of children with any disability may feel burdened with the added responsibilities presented in parenting (Sen & Yurtsever, 2007). This burden may also arise from the fact that children with disabilities often require a great deal of care, and commonly depend on others (see, for example Gray, 2006; Higgins et al., 2005). Thus, all members of the family make sacrifices, and may experience effects on their daily lifestyles, social

relationships, economic situation, health, and goals or expectations for the future (Norton & Drew, 1994; Sen & Yurtsever, 2007).

Due to the difficulties brought about by raising a child with autism, Bromley, Hare, Davison and Emerson (2004) reported that mothers experienced many areas in which there was a need for help or for more help. Unmet needs reported by 80% or more of participants included: (1) help with care, (2) doing things they enjoyed, (3) advice on the child's education, (4) advice on how to best help the child, (5) breaks from care, (6) having someone to talk to and (7) managing the child's behaviour. A table of all reported unmet needs and the percentage of mothers who experienced them can be found in Table 2.1.

Children with autism present with a variety of social and communication impairments unique to the condition, as previously discussed. These characteristics naturally give rise to many challenges for the primary caregiver of the child (Norton & Drew, 1994). It has been suggested, however, that ASD-specific behaviours alone do not lead to maternal distress, but rather, that the association lies with non-specific ASD characteristics, such as higher levels of challenging behaviours presented as a whole (Bromley et al., 2004, Konstantareas & Homatidis, 1989). Therefore, it is important to consider costs incurred in all aspects of the caregiver's experience as a result of caring for a child with autism, including family life, physical well-being, psychological well-being, financial situation and social life. The results of research concerning costs and benefits will each be presented in turn. The area of costs has been investigated mainly in terms of financial costs, social costs, costs to physical and psychological well-being, and costs to

Table 2.1
Unmet Needs Reported by Mothers

	% of all mothers
Help with care during holidays	93
To do things parent enjoys	91
Advice on best way to help child	87
Break from caring for child	87
Someone to talk to	85
Advice on child's future education	83
Help plan for child's future	81
Managing child's behaviour	80
Advice on which services are available	79
Money	71
Planning for child's future	69
Meeting other parents	69
To enable parent to spend more time with other children	63
To enable parent to spend more time with partner	61
Parent's education, skill and interests	60
To travel/holiday with child	55
Respite care	55
Child's sleep pattern	52
Transporting child	48
Look after child at family and community events	48
Emergency child care	48
To enable carer to get employment	45
Housework	44
Emergency health care	43
Adapting house	39
Finding a school for child	37

(Bromley et al., 2004).

family life for families of children with autism. Although much less prevalent, benefits to the experiences of family members of children with autism have also been explored to some extent.

Costs

Financial Costs

When caring for a child with a disability there were often increased economic issues because of the added financial burden of the disability itself, as well as the fact that one parent often left the workforce to act as the primary caregiver for the child (see, for example Jarbrink et al., 2003, Sen & Yurtsever, 2007). Moreover, support in managing these additional costs may be difficult to come by. Sen and Yurtsever (2007) found that approximately 40% of Turkish families with a child with autism received some financial support, while others did not receive subsidies because they were unaware of the programs or believed they were not eligible. Other families would withdraw applications for support because of the lengthy legal process involved (Sen & Yurtsever, 2007).

In a small study of 17 parents in the United Kingdom, it was found that all participants experienced negative effects to their overall financial situations in some way (Jarbrink et al., 2003). All participants reported that their income and employment had been negatively affected by their children's disorders. Other costs presented themselves in the form of lost leisure time and out of pocket expenses. For instance, 40 hours per week were forfeited due to lost opportunities, paid work, leisure time and unpaid work. In terms of unpaid work, parents stated that they would not otherwise have become involved in volunteer work, but did so due to their children's disabilities. Overall, parents reported that over 50% of total costs incurred were either directly or indirectly

their own responsibilities and not subsidized in any way, and that of these costs, monetary costs for health and social services were small compared to those for education (Jarbrink et al., 2003). Time losses, out of pocket expenses and service cost findings from this study are indicated in Tables 2.2, 2.3 and 2.4, respectively (Jarbrink et al., 2003).

Financial costs were also found to arise because of lost employment opportunities. Mothers of children with autism were much less likely to be employed than fathers, with approximately half of all mothers working outside of the home. Even then, employment tended to be part-time or working for family members that could offer flexible scheduling. Although some mothers had never planned to return to work after having a child, those that had planned to indicated that it was the children's conditions that influenced their decision to stay home, as they were unable to balance both demands (Gray, 2003).

Social Costs

Families of an individual with a disability often experience adverse effects to their social lives. They are also often subjected to social reactions to the individual that are negative and stereotypical. Some have experienced a "courtesy stigma", where they are also stigmatized as a result of their association with the individual with a disability (Gray, 1993). In Gray's (1993) study of 29 participants (8 fathers and 21 mothers of children with autism), 16 perceived that they were subject to stigma as a result of their children's condition, while 13 did not. There was an uneven division between men and women however, with only 2 of 8 fathers perceiving stigma and 14 of 21 mothers perceiving that they were subject to stigma.

Table 2.2
Time spent in informal care per child per week

	No. of children	Mean weekly hours	Standard deviation, hours	Median weekly hours
Question 1. Informal care in different activities, n = 11				
Personal care, e.g., dressing, toileting, meals	9	21.97	29.91	11.67
Providing transport	5	2.65	4.52	0.00
General housework and shopping	6	3.55	4.64	2.00
Supervision/companionship/emotional support	7	28.11	33.99	20.00
Other	4	3.64	6.64	0.00
Total 1	9	59.92	40.51	58.00
Question 2. Categorising informal care in alternative time, n = 17				
Paid work	15	21.77	15.54	20.00
Unpaid work	13	0.37	16.88	0.00
Other such as leisure	14	17.22	11.46	18.00
Total 2	16	39.36	22.35	39.00
Diary, n = 16				
Personal care, e.g., dressing, toileting, meals	13	8.89	8.54	6.58
Providing transport	12	2.15	2.24	1.29
General housework and shopping	12	3.00	4.39	1.38
Supervision/companionship/emotional support	15	23.84	23.57	19.38
Other	8	5.27	6.47	2.63
Total	15	43.15	30.62	43.01

Table 2.3
Families' Average Weekly Out-of-pocket Expenses for Services

Items/services	Questionnaire (n = 17)				Diary (n = 16)			
	Number of children	Mean cost, £	SD, £	Median cost, £	Number of children	Mean cost, £	SD, £	Median cost, £
Damages, certain food, clothes, extra laundry	13	14.26	15.98	10.00	12	33.17	32.15	23.50
Extra help	8	26.88	48.98	0.00	9	22.52	28.92	5.00
Transport	8	9.02	15.72	0.00	8	9.34	13.02	0.25
Special activities	10	6.52	7.03	5.00	3	2.48	6.02	0.00
Additional costs for therapy/education	6	4.69	7.73	0.00	4	12.03	28.99	0.00
Extra costs for siblings	1	1.47	6.06	0.00	0	0.00	0.00	0.00
Court cases/solicitor	2	3.07	12.11	0.00	2	1.43	5.30	0.00
Other	0	0.00	0.00	0.00	6	19.22	64.46	0.00
Total out-of-pocket expenses	16	65.91	54.24	56.38	15	100.15	83.91	73.10

Table 2.4
Total costs per average week

	No. of children	Mean weekly cost, £	Standard deviation, £	Median £
Education	16	223.82	304.92	84.08
Early interventional therapy	10	144.38	173.83	100.00
Health and Social services	17	20.12	21.92	12.53
Voluntary support	7	2.14	3.89	0.00
Medication	11	1.67	1.89	1.04
Other costs paid by parents	16	65.91	54.24	56.38
Income losses	11	231.18	292.32	200.00
Total	17	689.21	406.87	649.53

(Jarbrink et al., 2003).

Such stigma was perceived to be experienced in shops or restaurants, when the child behaved inappropriately and workers were unaware of the cause. The most important and unique aspect of the stigma experienced by parents of children with autism was due to the outward appearance of the child, which is often considered typical. Onlookers would then perceive the child as disability-free, and would assume that the parents simply had an extremely disobedient child they could not control (Gray, 1993).

In addition to the stigma experienced, social interactions with other families were also made difficult when the children with autism would misbehave or say something inappropriate, embarrassing the parents. Moreover, other families would not ask about the children with autism and would avoid questions about their own children. This would result in the families of children with autism isolating themselves, thereby negatively impacting the siblings of the children with autism due to forfeited family outings and holidays (Gray, 1993). Social withdrawal was also used by some families as they began to experience a decrease in the size of their social circles, and chose to keep to themselves rather than risk awkward social situations (Gray, 1994). Over and above that, Duarte, Bordin, Yazigi and Mooney (2005) found that among mothers of children with autism, the lack of motivation to develop social relationships may serve as a more important predictor of stress than the lack of resources to develop these relationships, which could then hold consequences for other aspects of their lives.

Support from extended family members was found to be important for the emotional support it offered to those raising children with autism, particularly from individuals who understood the problem (Gray, 1994). It was also found that although family support was important, support from friends could be just as important for

caregivers of children with autism (Gray, 2003). Results from surveys of parents of children with autism indicated that higher levels of social support, along with other coping strategies, are especially important in difficult and stressful times (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001). However, in the Sen and Yurtsever (2007) study of families of children with disabilities, such as those with cerebral palsy, intellectual disability and autism, it was noted that family support was often inadequate, and that families could stand to benefit more from the help of a professional. Parents also reported that they felt supported and invigorated when professionals treated them as an expert concerning their child's condition (Sen & Yurtsever, 2007).

Costs to Well-Being

Simply caring for a child with autism can be a source of stress, as parents of children with autism generally report a great deal of stress from all of the demands placed on them. Typically, stressors experienced are greater than those of parents of children with no disabilities and parents of children with disabilities other than autism (Allik, Larsson & Smedje, 2006; Duarte et al., 2005; Hastings et al., 2005). Oftentimes, the more severe the child's condition in terms of level of functioning, the greater the stress experienced by the parent (Dunn et al., 2001; Plant & Sanders, 2007). This may be attributed to the difficulty of the caregiving task presented by increased problematic behaviours rather than the child's low functioning in particular, and the lack of confidence in handling these behaviours. Furthermore, stress in these families could come from sources not only internal to the family but those external to the family as well, such as a lack of support services and the lack of a cure for the condition (Higgins et al., 2005; Plant & Sanders, 2007; Sivberg, 2002; Tway, Connolly & Novak, 2007).

More specifically, influences on the caregiver's stress included problems with public behaviours which made it difficult to go shopping, tantrums and aggressions that could lead to destruction of property, violence that resulted in isolation or institutionalization, problems with sexual expression that could be embarrassing in public situations, and obsessions with eating and toileting which could result in problems training the child and maintaining a clean home environment. Moreover, problems with language and communication led to a great deal of stress, and these issues were usually what sparked the parent seeking diagnosis for the child. Problems with communication also lead to frustration and tantrums on the child's part, leading to increased stress for the parent (Gray, 1994). Plant and Sanders (2007) found that the most caregiver stress was experienced due to roles such as helping with and supervising meals, cleaning up after the child, putting the child to bed at night, toileting, and dealing with professionals. These roles could take an overall toll on finances and physical or emotional well-being, even perpetuating marital stress in some instances, factors which could lead to higher overall levels of stress in the family (Higgins et al., 2005). Thus, it becomes apparent that the children's levels of functioning and behaviour may in fact directly influence costs experienced by primary caregivers.

Many factors can influence the impact of individual stressors, such as the positive perception of and actual availability of social support, high self-efficacy and esteem, and positive expression of affection (Duarte et al., 2005; Dunn et al., 2001). Stress results when a threat is perceived in the environment, and how this threat is dealt with is what determines the level of stress that will be experienced (Plant & Sanders, 2007). Predictors of stress can be mediated and moderated in different ways, altering the

eventual stress outcome. For instance, greater stress could be present if the situation was perceived as overwhelming or uncontrollable, or if there was a belief that there were no resources available and parenting skills were not adequate (Duarte et al., 2005; Plant & Sanders, 2007).

Mothers were frequently reported to be the more significantly affected parent when caring for children with autism, and were at an increased risk of compromised physical or mental health and well-being (Allik et al., 2006; Dunn et al., 2001; Gray, 2003; Hastings et al., 2005). Fathers generally worked full-time, and day-to-day aspects of caring for a child with a disability in general did not tend to be their responsibility. Fathers were more aware of life outside the home and were not as emotionally or socially affected (Sen & Yurtsever, 2007). Fathers also tended to experience less physical and mental distress, and were often unaffected by deficits in the children's prosocial behaviours and conduct problems (Allik et al., 2006).

A study of gender and coping in caregivers of children with autism revealed many differences in strategies employed by men and women. It was noted that stressful events had the tendency to cause distress and depression in women more so than men, especially where family and friends were involved. Mothers differed from fathers even further in that they were much more likely to indicate that the children's conditions had affected their own well-being, and that they experienced a great deal of stress even when the circumstances were not extreme. Mothers would also blame themselves more than fathers when the problem was with the children, and felt less in control of situations than the men in the study. They did perceive their husbands' contributions in a favourable light; however, they felt that their share of responsibilities in the home was unequally

balanced with their husbands. Since mothers were home more, they often dealt with the referral and diagnosis appointments and were thus more likely to be negatively affected by the diagnostic process. They also experienced difficulties conveying information they received to fathers, making them feel incompetent and leading to guilt and depression that often dissipated upon official diagnosis. Mothers were also left to deal with conflict in the home and at school, and this increased role left them with the greater burden of the children's behavioural problems (Gray, 2003).

Fathers did not experience personal repercussions as often as mothers, however fathers reported that they were personally affected when their marriage was threatened. Fathers believed effects on them were more indirect, as through the disruption of their everyday lives, and that the biggest consequence was through the stress imposed on their wives. Nearly all fathers were employed, and indicated that work was very important to them as it gave them a role outside the home. They also reported that their careers were unaffected, and in fact worked more hours than they previously had as a way to be able to leave the house. As such, fathers were not as involved in raising the children as the mothers. They preferred to serve as a resource for the wife, and only became involved when things went wrong instead of being involved on a daily basis (Gray, 2003). It is apparent that the experiences of the fathers of children with autism and those of mothers of children with autism may be vastly different, and thus warrants individualized investigation.

Higgins et al. (2005) speculated that the individual's outlook and cognitive appraisal of the situation were important factors in alleviating stress. Hastings et al. (2005) presented similar findings stating that positive reframing was important in

situations that would not change. It was also found that positive reframing was directly associated with lower levels of depression in the parents of children with autism. Dunn et al. (2001) however, suggested that both appraisal and coping were important in stress reduction for parents of children with autism, as appraisal determined whether the situation was deemed as stressful, while coping mechanisms affected how much of an impact the stressful events had on the individuals. Individualism was also important for many as they participated in individual activities like advocacy for the child, social activities and work, which allowed not only for respite but a sense of self-worth (Gray, 1994). As a whole, the well-being of caregivers is important since decreased levels of stress are directly related to positive coping, emphasizing the importance of teaching parents appropriate coping strategies in order to alleviate stress in families of children with autism and to foster more effective family systems (Sivberg, 2002).

Costs to Family Life

Caring for a child with autism can impact family life in a number of ways. Attention is often focused on the child with autism, and less time becomes available for other family members. In addition, caring for a child with autism can lead to a restructuring of roles and responsibilities among family members (Higgins et al., 2005).

In the Higgins et al. (2005) study of 52 primary caregivers of children with autism, these caregivers were found to differ from those with typically-developing children on a number of factors. Scores of overall marital happiness, family adaptability and family cohesion were below the norm, while self-esteem scores were not significantly lowered. Additionally, it was noted that participants reported lower levels of marital satisfaction than normative data. However, 87% of participants reported that

they were in a stable relationship, and 76% of the participants had never been separated or divorced. Authors speculated that lower scores came about because caregivers focused their attention on the needs of the child rather than the needs of other members of the family, or even their own relationship or partner's needs. Moreover, low scores on measures of family functioning were thought to be due to less engagement in family outings or not including all family members in outings in order to avoid placing added stress on the children with autism (Higgins et al., 2005).

Gray (1994) reported that as a whole, strategies used by parents of children with autism were varied. The use of treatment services taught children useful skills that helped maintain order in the family life, and provided respite as well as professional expertise for parents. It was also noted that those dealing with a less severe disability were more likely to experience positive coping (Gray, 1994).

Benefits

Most studies did not specifically set out to examine the benefits experienced by caring for a child with autism. Rather, they may have investigated, for example, the benefits of programs for children with autism (see, for example, Diggle & McConachie, 2003), or moderators of negative effects for caregivers (see, for example Dunn et al., 2001; Hastings et al., 2005; Higgins et al., 2005), and have revealed benefits that arose as a result of these factors. For example, although not the main focus, benefits emerged in a study conducted by King et al. (2005), which investigated the changes in belief systems of families of children with autism or Down's syndrome. Although participants had diverse beliefs, themes of adapting over time, changing worldviews and changing priorities were revealed. Participants indeed had a life-changing experience and lost

dreams, but were prompted to see the possibilities that were ahead of them. This provided them with a sense of hope, control and empowerment that allowed them to refocus on what they deemed to be important in life. It becomes increasingly apparent that studies tended not to examine the benefits of the experience of caring for a child with autism where discernable benefits may indeed exist. In this way, an interesting research direction is presented and will be explored along with costs.

Conclusion

Determining costs and benefits that present themselves to married female primary caregivers of children with autism as a result of caring for their children will be important in understanding the lived experiences of these women from their perspectives. Results from this study may be important for policy makers and individuals designing or implementing services for these women and those in similar circumstances, as well as their families, so that they may develop a greater understanding of these women's experiences and therefore their potential needs.

Methodology

Purpose

The objective of this study was to describe the lived experiences of female primary caregivers of children with autism, specifically through the examination of the costs and benefits of their experiences. In addition, information on their experiences was also obtained through background information pertaining to their children's functioning and behaviours.

Participants

In order to gather data to fulfill the purpose of this study, it was necessary to connect with those “who have *directly* experienced the phenomenon of interest” (Patton, 2002, p. 104). In total, 8 caregivers of children with autism were recruited from autism support organizations in both Waterloo Region and York Region. Potential participants in the Waterloo Region received a flyer from KidsAbility indicating a request for participants in the mail, and those in York Region received a request for participants through a regular electronic newsletter from the Autism Society of Ontario – York Region Chapter. Once interested individuals identified themselves to the researcher, criterion sampling, a method of purposefully selecting cases for participation, was employed. This method was of use to “review and study all cases that meet some predetermined criterion of importance” (Patton, 2002, p. 238).

All participants were married females who identified themselves as the primary caregivers of a child with autism. These inclusion criteria were used in order to ensure homogeneity of the sample, and to ensure that information gained was not subject to confounding factors (i.e. gender) wherever possible. In light of these criteria, one participant was contemplating separation from her spouse at the time of the interview, but was still living in the same household. It was determined that this case could be included in the analysis, as the experience of single parenthood had not yet begun.

Research Tools & Procedure

The Qualitative Method

A qualitative method of inquiry was selected due to the idea that it “can use naturally occurring data to find the sequences...in which participants’ meanings...are

deployed and thereby establish the character of some phenomenon” (Silverman, 2006, p.44), thus making it the best method by which participants’ experiences as caregivers of children with autism could truly be understood and represented. Through qualitative inquiry, individuals are each given a voice and provided with the opportunity to relay their unique experiences. The interview was chosen as the main method for data collection, as the need for information pertaining to these individuals’ experiences lent naturally to “extensions of normal human activities: looking, listening, speaking, reading and the like” (Lincoln & Guba, 1985, p. 199). In this way, the description of the experiences obtained would be constructed solely by the participants, which would provide a great deal of insight into their reality. Along with the interview, a number of methods, including background questionnaires, field notes and member checks were employed in order to identify and describe the essence of the experiences of these individuals.

Ethics

All tools and procedures used were approved by the Wilfrid Laurier University Research Ethics Board. Prior to participation, all participants read and signed an informed consent statement, and were provided with the opportunity to ask the researcher any questions prior to participation in the study.

Background Questionnaires

Each participant initially completed a background questionnaire consisting of items pertaining to (1) demographic information such as age, education, employment and marital status, (2) the diagnostic process for the child with autism, as well as brief information on the child’s siblings and any existing conditions, if any, and (3) the

caregiver's well-being, which involved items regarding physical and mental health, social activities and daily routines, and support available through family and friends (Appendix C). The questionnaire was intended to guide the interview by determining areas of further focus and provide context for each interview.

Interviews

Each participant took part in a one-on-one, semi-structured interview conducted by RM. Interviews were arranged at a time and place convenient to the interviewee, and were conducted in person ($n = 2$) or by telephone ($n = 6$). Interviews ranged in length from 40 minutes to 3 hours, with an average length of 1 hour 11 minutes. The length of the interview depended mostly on the length of participants' responses. All participants completed the interview in its entirety. Each one-on-one interview was digitally recorded and subsequently transcribed verbatim, for a total of 178 pages of interview transcripts.

Each interview involved seven open-ended questions designed to obtain information on the lived experiences of the primary caregiver of a child with autism, and these questions addressed a number of topic areas (Appendix D). The first of the topic areas touched upon was the history of the child's diagnosis and abilities, which was intended to provide the interviewer with information pertaining to the children and some insight into the challenges in caregiving faced by the participants. Next, participants were asked to describe their children's typical daily routines and the roles they would take within these routines, which was intended to put the participants in the mindset of their caregiving roles and provide a better understanding of their individual experiences. Participants were then asked to describe any costs associated with the experience of caring for a child with autism. These included costs in areas such as lifestyle, finances,

employment, social lives, health or well-being and family life. The last area of questioning involved benefits associated with caring for a child with autism, and touched on the same areas as discussed in the costs section.

During the interviews, brief feedback was given to let the participants know that they were providing valuable information and to maintain the flow of the interview. If participants provided insufficient information, they were asked to elaborate and provide as much detail as in previous responses (Patton, 2002). At the end of the interview, participants were given the opportunity to add any information that was not addressed within the interview. The recorder was typically turned off at the conclusion of this portion of the interview, and participants were informed when this was done. Participants were also able to pose any questions they had for the researcher. This portion of the interview took the form of an informal conversation, with no standardized questions (Patton, 2002).

Data analysis for each interview was begun promptly following its transcription, so that the data collection process could be monitored for saturation of the information obtained. Following the completion of eight interviews, it was determined that theoretical saturation had been reached, as the goal was to find sources of information until “new sources [led] to redundancy” and no additional interviews would contribute to data quality (Patton, 2002, p. 466).

Field Notes

Data collection was enhanced further through field notes, which were taken by the interviewer prior to, during and immediately following each interview. Each set of field notes included the date, setting, individuals present, the physical setting, social

interactions, and activities that occurred. Furthermore, anything considered “to be worth noting” (Patton, 2002 p. 302) was taken down, which included such things as key phrases and major points made, as well as key terms and words used by the interviewee. The interviewer’s “feelings, reactions to the experience and reflections” (Patton, 2002 p. 303) were noted during and following the interview as well, along with initial interpretations, insights and analyses that came to mind. Such interpretations were indicated with an asterisk (*) to distinguish them from other notes. These notes also included reflective thoughts made following the interview (Patton, 2002).

Member Checks

Member checks were conducted to give interviewees the opportunity to add, clarify, or omit information from their transcripts. Participants were sent a copy of their interview transcript to “correct, amend or extend it” (Lincoln & Guba, 1985, p. 236) where necessary. Providing participants with this option lends credibility to the data obtained (Lincoln & Guba, 1985). Additional questions or clarification points were also asked in the margins for the participant’s response. The process of returning the transcripts to the participants also established trustworthiness, ensuring the study remained ethically sound by allowing individuals to only divulge information they so chose (Holloway, 2005).

Participants were asked the form in which they preferred to receive a copy of their transcript, and most chose an electronic form. Some then printed their transcripts and submitted a hard copy once the member check was completed ($n = 3$), while the others chose to submit their responses electronically ($n = 5$). All transcripts were returned, all containing either no changes or very minor changes for clarification purposes. Most

clarifying questions that had been asked were answered, but in a few instances participants chose to not elaborate further on personal information. Two participants also chose to remove some small details pertaining to information they no longer wished to divulge. Responses to questions and any changes to the transcripts were entered by RM, and the edited versions were subsequently put forth for analysis. Once preliminary analysis was completed, participants were given the opportunity to review a summary of the overall findings and provide comments or feedback if they felt it necessary. A total of four participants responded, and all confirmed that they agreed with the findings.

Triangulation

Triangulation is a method by which multiple sources of data are collected to ensure they “corroborate one another” (Silverman, 2006 p. 290) and provide strength to the data. Three forms of triangulation were used in this particular study. Data triangulation was employed by using multiple data sources for all participants and in this case involved a background questionnaire, field notes, one-on-one interviews and member checks. Furthermore, all participants were sent a general summary of preliminary themes found across all interviews, and allowed the chance to comment. In addition, investigator triangulation was used to strengthen the study by having two researchers individually review data and provide their interpretations of the findings (Patton, 2002). Evaluation and triangulation of multiple individual perspectives on the information obtained thus enhanced credibility.

Credibility

In order to obtain significant findings, credibility was established and rigorous methods were maintained in every aspect of the study, as described by Patton (2002). It is important to convey trustworthiness to participants, and this was accomplished through the methods described above, namely through the informed consent and member check processes. Additionally, credibility was enhanced through consistently focusing on obtaining quality data. Each participant was “understood as a unique informant with a unique perspective” (Patton, 2002, p. 347). As such, information-richness of cases was aimed for rather than sample size, with a concentration on achieving theoretical saturation of information obtained.

The researcher is also an integral tool in ensuring a cohesive study is completed, and must be qualified to do so. In order to ensure this was indeed the case, a number of steps were taken. An extensive review of literature related to conducting valuable qualitative research was performed, and was provided with individual supervision and guidance by experienced faculty members throughout the course of the study. An extensive review of literature was also carried out pertaining to autism and caregiving for children with autism. Consistent communication was maintained with participants for the duration of their involvement, fostering a positive rapport with the contributors and allowing them to provide input at various points in the study. The researcher also regularly completed field notes, ensuring that any information worth noting was recorded, thereby providing a valuable supplement for the other data sources. Finally, the researcher maintained neutrality and eliminated bias in analysis, which was accomplished

in this case by following the steps to analysis outlined by Patton (2002), detailed in the Data Treatment section.

Data Treatment

Qualitative Analysis: Phenomenology

A phenomenological approach was the theoretical orientation used to guide this research concerning care for a child with autism. Phenomenology is the “explication of phenomena as they present themselves to consciousness,” as “consciousness is the only access human beings have to the world” (van Manen, 1990, p. 9). Phenomenology also involves the assumption that there is an essence to a lived experience of a phenomenon, and focuses on discovering this essence in the individual or group. This is accomplished by exploring

“how human beings make sense of experience and transform experience into consciousness, both individually and as shared meaning. This requires methodologically, carefully, and thoroughly capturing and describing how people experience some phenomenon – how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others” (Patton, 2002, p.104).

Phenomenology allows for the understanding of a particular phenomenon through the examination of its characteristics and complexities (van Manen, 1990). This study explored how primary caregivers of children with autism have internalized the experience of caring for their children in their own consciousnesses, and for this reason the phenomenological approach presents an appropriate method of analysis (Patton, 2002).

Data obtained from the participants’ background questionnaires were used to provide context for and guide each individual’s interview, particularly in terms of where participants could be probed to elaborate further on a topic of discussion. Background questionnaires were also used when later reviewing transcripts in order to ensure the

appropriate frame of reference was maintained while reviewing the participants' responses. Similarly, field notes were used to maintain context when reviewing interviews and interview transcripts. Field notes were useful in the transcription process, particularly where distractions or other interruptions had arisen, and also in providing information about setting and potential interactions that would be useful in providing context for the review of interview transcripts. Moreover, field notes contained information pertaining to key phrases and terms that arose during interviews, as well as initial interpretations that were worthwhile to remain mindful of when engaging in the analysis of interview transcripts.

Information obtained from transcripts of individual interviews was analyzed for information that provided a general account of the experience of the primary caregiver of a child with autism. A combination of case-by-case and cross-case analysis was employed (Patton, 2002). Both stages involved multiple readings of interview data in order to gain as much clarity as possible in the findings. Interviews were initially analyzed individually to identify salient themes, after which individual responses to various areas of the interview were compared and contrasted to further delineate sub-themes. This involved "grouping together answers from different people to common questions, or analyzing different perspectives on central issues" (Patton, 2002, p. 440). The use of the semi-structured interview guide naturally allowed for the grouping of responses to decipher relevant themes, which in turn allowed for a fair representation of the data and communication of what the data revealed.

The approach to analysis involved a number of steps, as outlined in Moustakas's *Phenomenological Research Methods* (1994) and cited in Patton (2002). First, *epoche*

was established, which involved gaining clarity about judgments and preconceived notions of the subject matter in order to refrain from the ordinary way of perceiving things. This was completed first through mental reflection, followed by taking note of thoughts related to pre-existing perceptions. These notes were set aside and remained available for review at all stages of analysis. Once this was accomplished, the next step involved *phenomenological reduction*, which required that preconceptions identified in the first step were set aside, allowing for the data to be identified in its pure form, without disruption from extraneous factors. At that point, key phrases and statements were identified in the transcripts that would represent the phenomena of the costs and benefits, as well as the children's functioning and behaviour within the experiences of caring for children with autism. The meanings of these phrases were then interpreted, and examined for revealing information about the features of the experience. A preliminary interpretation of the essence of the phenomenon was then made to guide further analysis. The third step involved *horizontalization* and *delimitation*. Horizontalization was accomplished by considering the data as a whole and organizing information into clusters. Delimitation then allowed for repetitive and redundant data to be eliminated. It was then possible to identify enduring themes and enhance preliminary themes that had been developed. The fourth step was the development of a *textural portrayal* of the experience - a description of the experience that did not contain the experience itself. This illustrated the experience, but did not yet involve the *essence* of the experience. The fifth step was then the establishment of a *structural description*, the "bones" of the experience. Deeper meanings for the individuals involved in the experience were searched for so that their representations could be even more meaningfully understood.

Once the above five steps were accomplished, the composite textual and composite structural descriptions were integrated (Moustakas, 1994; Patton, 2002), thereby synthesizing the meanings and essences of the experiences of the married female primary caregivers of children with autism.

Results

Summary of Background Questionnaires

All 8 participants returned the background questionnaires, providing useful contextual information for the subsequent interviews and analyses of the data. Pseudonyms were used for all participants. All participants were female, ranging in age from 28-49 (M=40.5) and were either married both pre- and post-diagnosis, or in one case, in a common-law marriage. As briefly mentioned above, one participant indicated that she and her spouse had discussed separation. All participants had undergone either high school, university undergraduate or college education. Occupations indicated included two homemakers, a home daycare provider, a civilian employee of a police agency, a retail worker, an office administrator, a customer service representative, and a former secretary who was on disability leave at the time of the interview.

Participants had anywhere from 1 to 3 children ranging in age from 1 month to 12 years old. Each participant was caring for one child with a diagnosis of autism, and these children ranged in age from 4 to 10 years. Two of the children with autism had a confirmed co-morbid condition. One child was diagnosed with pragmatic language disorder, another was afflicted with seasonal allergies and asthma. A third child had suspected obsessive compulsive disorder as well as attention deficit hyperactivity disorder (ADHD).

The most recent diagnosis of autism had been made 1.5 years prior to the interview, while one child had been diagnosed 7 years prior to the interview. All had noticed signs and symptoms 1 to 2.5 years prior to receiving confirmed diagnosis for their children. Such signs included language deficits (n = 8), impaired communication abilities (n = 6), motor skill deficits (n = 5), resistance to changes in routine (n = 6), difficulties sleeping (n = 2), lack of imaginative play (n = 4), disinterest in socializing (n = 4), restricted interests and activities (n = 3), abnormal responses to sensory stimulation (n = 3), behavioural problems (n = 5), and other indicators, such as difficulty following instruction (n = 1).

Questionnaire information pertaining to the caregivers themselves revealed that one had experienced depression prior to the child's diagnosis, while another had experienced a benign brain tumour after the child's diagnosis. No other participants had experienced any illnesses, conditions or impairments pre- or post-diagnosis. Three participants indicated they had experienced mental health effects as a result of the diagnosis, while 2 indicated that they might have experienced such effects. Similarly, 3 participants had experienced physical health effects as a result of the diagnosis, while 2 indicated that this may be the case. One participant felt that she was frequently unable to participate in daily routines or activities, while 4 felt this was sometimes the case, 2 indicated this was rarely the case, and 1 participant felt she was never hindered in that way. One participant indicated that her social relationships had been affected as a result of the diagnosis, while 3 indicated that their social relationships were not affected, and 4 indicated that they might be affected. A total of 6 of the 8 participants had at least one family member to talk to for support, and all participants indicated they had at least one

friend to talk to for support. All participants had accessed some form of resources at some point, either for themselves or their children. The most prominent types of resources accessed were seeking information and therapy for the children, such as occupational therapy, physical therapy, speech therapy or applied behavioural analysis/intensive behavioural intervention.

Findings

Analysis of the data revealed five major themes in the collective experiences of the women with respect to caring for their children with autism: (1) the children's social abilities, (2) the children's communication abilities (3) the caregiving role, (4) the costs of caring for the children and (5) the benefits of caring for the children. Along with the effects these aspects had on the caregivers' lived experiences, they were all found to interact with one another as part of the lived experience as well.

Each major theme had a number of subthemes. For example, (1) triggers to seek diagnosis, (2) autism-specific tendencies, (3) peer interactions and (4) accessing therapy were found to influence both the themes of social and communication abilities. The subthemes of the third theme, the role the caregiver took in daily functioning, were (1) managing behaviours, (2) managing the routine, and (3) managing the environment. Costs and benefits of the lived experience became most apparent when considering the subthemes of (1) financial, (2) social, (3) health, (4) employment and (5) familial aspects, along with (6) activities and involvements as a whole. Each theme and subtheme will be discussed in turn.

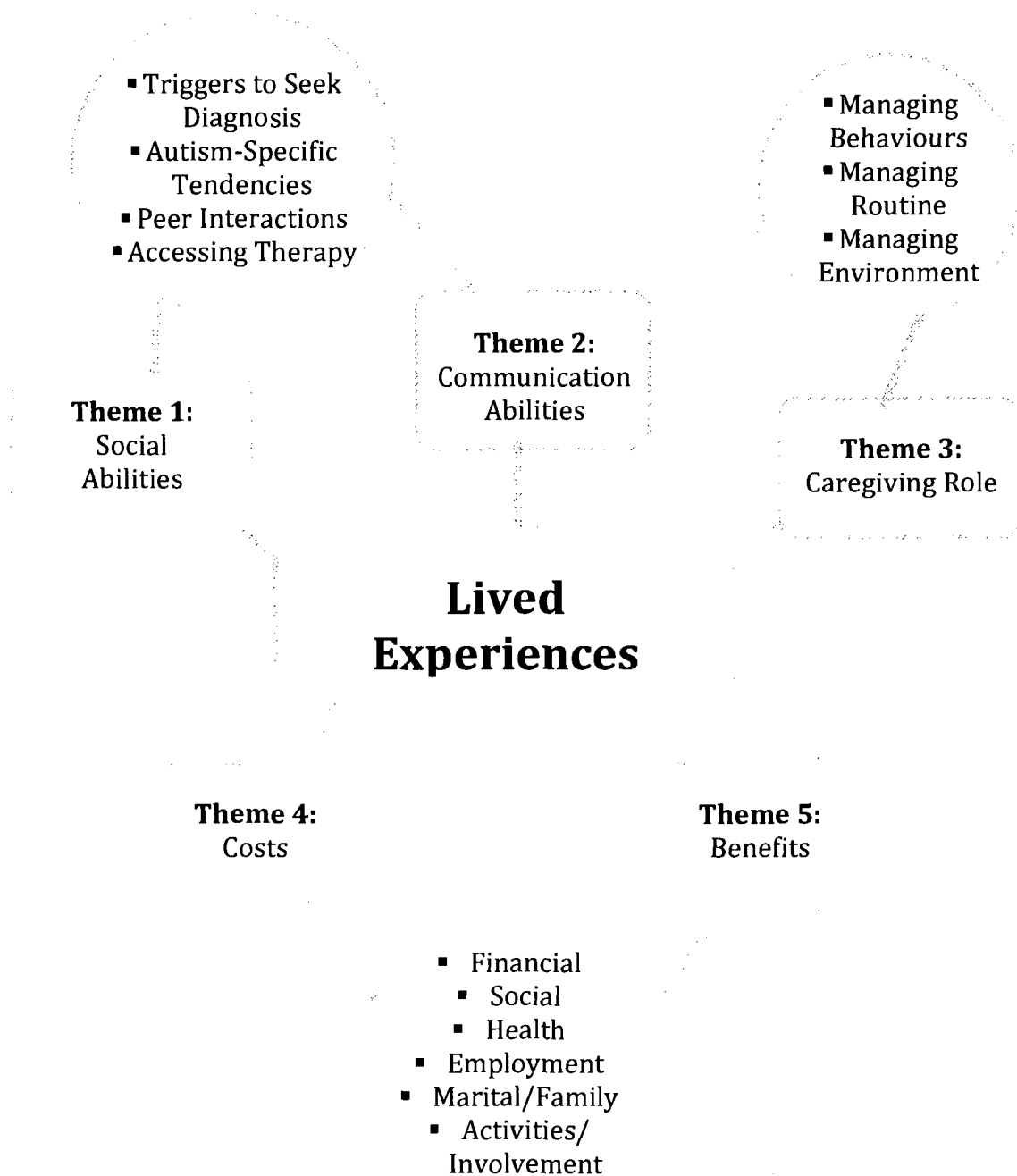


Figure 2.1. Model of the lived experiences of female primary caregivers of children with autism

Theme 1: Communication Abilities

Autism affects a child's functioning and behaviour. For the female caregivers interviewed, communication abilities were among the most affected areas for their children, which went on to affect their experiences in a number of ways.

Subtheme 1: Triggers to Seek Diagnosis

Communication deficits were of concern in some way to all of the caregivers. Communication was a major indicator to seek diagnosis for all of the participants.

Um actually when she was young she wasn't uh, she didn't talk a whole lot...And we just thought oh you know maybe she's just (pause) quiet. But then it was like no, she's, you know, getting on three years old and she's not talking a whole lot. ~**Emma**

But there were some things that uh got our attention. One of them was that um she didn't have very much um, interactive speech. She would say things by memory from a movie that she saw or a book that we read to her. Um but she would not interact with us. She didn't have the dialogue concept... ~**Emily**

For many, comparing their children's progress with that of other children helped with initially detecting differences, as they were able to create a standard on which to contrast their children's accomplishments with typically expected milestones.

He didn't give us eye contact, um, he was often aloof, um, he was only doing a little bit of babbling and his [twin] sister was talking. ~**Anita**

And even saying mom or- mom or dad or momma or something, tho-those things weren't, weren't there as early as you would expect with the, the average child. So um (pause) yeah about the time he was around two I think was the first time we officially said to our family doctor, you know, we're kinda concerned about the communication, uh, the lack of communication, so yeah. A-n-and, it basically I think came down to communication. ~**Cathy**

He got to be, you know, two and he still wasn't talking very much, like not like not compared to our other two sons um, at that age. And we were just a little bit concerned, um, about that... ~**Charlotte**

For the caregivers, their children's communication abilities played an important part in recognizing differences and initially seeking diagnosis for the children.

Subtheme 2: Autism-Specific Tendencies

The most common language and communication deficits reported included reciting or scripting and inappropriate intonation or volume.

Uh, he um, he has sort of a monotone to his voice, he can't control the volumes and there is an annunciation uh problem, some people don't quite understand what he's saying a lot. Um, I'd say he's talking like a three year old (pause) when he's ten, you know. ~**Anita**

Yes, um, one of the current problems with his communication is, uh, we call it reciting or repeating... Um, normally when he is doing that it's because he does not have his own words to describe what he's feeling or thinking, and he will simply recite something... if another person hears this reciting, they are not going to have a clue what he's talking about. ~**Cathy**

Um (pause) I think I talked about the uh, like her, her volume, like she talks in a loud voice... But even then her speech in general, she is very exuberant and she um, needs reminders repeatedly to, that uh, she's sitting right beside her friend, she doesn't need to use a loud voice and can you please tone it down and that sort of thing. So again, she ju-she just forgets. ~**Emily**

Oftentimes, overall communication deficits would lead to challenges in outings because the children were unable to express their feelings, such as frustration or boredom. The inability to communicate such emotions would often result in tantrums, causing caregivers to feel helpless at times.

Um, just going out to the mall if he's I guess like any kid if he's tired, and if he's tired or if he's hungry he's gonna freak out a little bit more. The only thing was when he was younger I couldn't reason with him because he couldn't speak. ~**Anna**

Yes, um (pause) the tantrums, uh basically is what it comes down to. The (pause) um (pause) for instance, if we took him out uh somewhere, shopping... when uh, when he was that young where he wasn't able to communicate verbally with us, we would not know what happened that suddenly he would start crying or get angry and uh fall to the floor and kick and scream. We wouldn't know what to do... ~**Cathy**

In this way, the children's conditions were playing a part in their communication abilities, which then played a part in the experiences of the caregivers.

Subtheme 3: Peer Interactions

As a result of these deficits, mothers reported that although they had learned to sufficiently communicate with their children, the children sometimes had problems communicating with those unfamiliar with their language abilities.

Say he's at school and maybe the teacher mentions about the class running late. [My child] would relate that to the part of the train stories when the controller would say something to one of the trains who was running late, and would start reciting something from the story. Well, the teachers and other students aren't likely to know what he's saying or why he's saying it, although it does relate, at least to [my child]. ~**Cathy**

...her communication skills are lacking n' that probably makes a great deal of difference because she can't get across what she wants to do or what she's trying to say. Um, it's hard for someone else to understand what she wants. So that definitely makes a big difference. ~**Elizabeth**

Caregivers expressed concerns for how their children's communication abilities could affect the successfulness of the children's peer interactions, particularly when their abilities to communicate effectively was compromised.

Subtheme 4: Accessing Therapy

Fortunately for those parents who were accessing Intensive Behavioural Intervention and other therapies, they were aided in understanding their children's communication deficits, in improving communication and in altering behaviours associated with communication deficits. They were thankful for the availability of such resources and the positive influences to their children's communication skills.

...She's, she's uh, I-I can't even imagine where she would be without having the uh, the help that she's gotten since she was diagnosed because we had um I keep bringing up KidsAbility because they were so instrumental at first, um. Like when, when we first started going there and [my child] was basically non-verbal, um, you know they tried so many different things an- she even,

they even started teaching [my child] sign language as a way to communicate... ~**Emma**

Um, yes, his communication is much better now after the three years of IBI um, than when he started. When he started he was, he was almost non-verbal, and what he was saying, we often couldn't understand. He couldn't even answer a yes or no question or make a choice... And uh, it took a long time to even get him to understand about yes or no... So it's come a long way...

~**Cathy**

We did occupational therapy at KidsAbility, speech therapy, um, those were really helpful because at that time [my child] was just begin- beginning to develop in those areas and so um, speech therapy was, was a huge benefit to her. ~**Emily**

Caregivers involved in therapy for their children's communication abilities felt that such learning opportunities were essential in aiding them to help their children develop their abilities.

Overall, the communication abilities of the children played a definite part in the experiences of the women interviewed. This was due to the role communication skills played in seeking diagnosis, and later, the child's ability to communicate with the caregiver and others.

Theme 2: Social Abilities

The female primary caregivers interviewed clearly viewed their children's social skills as an issue that affected their children's functioning and behaviour, which then affected the women's overall experiences in caregiving for their children.

Subtheme 1: Triggers to Seek Diagnosis

The children's social abilities, much like communication abilities, were also an initial indicator that prompted seeking diagnosis. This was also often accomplished through comparisons to other children. In this way, caregivers were able to differentiate between expected and unexpected social behaviours.

Um, just that when she was younger um, we really noticed after we put her in daycare. That was probably about the same time that she got um, she was diagnosed. And that, she would not acknowledge other people so she would um literally walking into people with her head down because she was pretending they weren't there. ~Emma

...when he would have been about 8 months old I remember, um, with, with some friends, um, their kids had, I always just called my daughter the peanut 'cause she was so tiny um being premature. And uh, they said well you gotta have a nickname for your son because they're twins, if you give a nickname to one you gotta give one to the other. I said, well, he's called the other one. And they said oh that's terrible! I said, you watch...I said you watch how many times today they'll make a fuss for her and then they'll say oh and there's the other one and make a fuss on him. He won't seek the attention. And it happened five times that afternoon. So, you know at the time we joked about it, thinking ok, he's just a little bit aloof, you know, you know he's just not as outgoing but (pause) afterwards we realized those were some early signs. ~Anita

The children's social skills, and their progression in comparison to other children, allowed caregivers to detect differences and triggered their desire to seek diagnosis for their children.

Subtheme 2: Autism-Specific Tendencies

Many of the children were unwilling or unable to approach social situations, or once they were in social situations, would be presented with too much sensory stimulation. The caregivers attributed such mannerisms to the presence of a diagnosis of autism.

Um, she could not handle going out to the grocery store, she would have meltdowns...uh, at Christmas time or birthday parties, she would disappear from the room. She couldn't handle when everybody was sitting around in a group and opening presents and there were voices everywhere and um, it was just complete overload for her and she would disappear and play by herself. ~Emily

Well, um, we took the kids to a parade when they were, it would have been 10 months old. And, they were in their, their tandem stroller and clowns coming over to them...My son turned away and looked up at the sky. Marching bands came by, he turned away from them. And at the time we sort of chuckled that, ok, he's bored. But in realizing, it was just way too much stimulation for him and he couldn't handle it... ~Anita

Many children also displayed an interest in and concern for others, which was attributed either to a high level of functioning, or due to progression in social abilities over time. Such pro-social behaviours aided caregivers in viewing their children's level of functioning more positively.

...he's very concerned about people, he's ver-, about their welfare, if you're outside playing with him he says "watch for cars!" you know "look both ways!" so he's very, he's very high functioning. ~**Anna**

I-I'm trying not to brag but he's apparently like a model student in the classroom. And they've been asking [my child] to help the new students, uh, to show them what to do. ~**Cathy**

Um she's, she's um (laughs) very very empathetic. If she sees, if there's another child in the room who is um on the periphery she will go and she will take that child by the hand and bring them into uh activities...So she's, she's really really empathetic. And she knows, she can tell when there's a kid who's not um (pause) who's not comfortable or who's not involved and she uh, she definitely tries to get them. ~**Emma**

The children's social abilities, as related to the diagnosis of autism, affected the caregivers overall experiences in caring for their children. The more positive the social abilities, the more favourable the women's experiences.

Subtheme 3: Peer Interactions

When caregivers reflected on the children's social abilities, they felt that as the children increased in age, they seemed to express more interest in social interactions than they had at a younger age.

...Uh she has lots of friends, she gets invited to her classmates' birthday parties, she um works really hard at school to keep up with everybody. So um she, they, they're great incentives for her to learn and to develop skills... So I think that her interactions with peers now are, are very, very good, providing that they're in an environment that she's comfortable with. ~**Emily**

Ok, um, I would say, I know [my child]'s progressed a lot. Um he, he likes to have friends over, um, you know, although it's not the first thing. Like if he, if he uh thinks about it for a while, you know, he'll ask me you know, mommy can I have a friend over but he never thinks to ask me ahead of time

(laughs)...So yeah socially he's um, he's really good. He's, he uh has really come a long way... ~**Charlotte**

Although many children had developed their social skills, some caregivers continued to express concern for their children's peer interactions. This was less so the case for the children's interactions with adults.

Um, I'm (pause) he doesn't really have, I don't know if four year olds have (pause) friends per say, but um, I don't know how to- he's very social and he's very, he'll talk to you and he'll wanna talk to you and he wants to play, but I'm, I'm, I'm scared for his social, you know, well-being at a normal school with normal kids (pause) who don't understand so are gonna make fun of him, so that's something that I worry about... ~**Anna**

...So um, however socially with adults he is more comfortable and more accepted let's put it that way too, than with other children. It depends on the other children's understanding and acceptance of autism, and about how kids with autism communicate differently than the typical child... ~**Anita**

Since social abilities held the potential to affect how children interacted with their peers, such abilities were of concern for caregivers. Caregivers were enthusiastic in relating positive social experiences.

Subtheme 4: Accessing Therapy

As with communication, those accessing various therapies, such as speech therapy or IBI, found it was instrumental in improving their children's social abilities. As children developed their abilities in a number of areas through therapy, caregivers felt that the children were more likely to pursue and experience success in social interactions.

At eight he is comple- he is uh, for us uh, it really helped to go to KidsAbility and for him to go to Open Sesame. Uh now, that really kick started his, his social skills and um allowed him to uh, you know, to become mu-much better now at, now he's, you wouldn't even know. He plays, uh you know some speech stuff, but uh, he has no problems interacting with other kids... ~**Jane**

Access to therapy was important in developing the children's social abilities, and caregivers viewed such contributions in a positive manner.

Together, the themes of social and communication abilities each influenced the lived experiences of the caregivers by contributing to the children's overall functioning and behaviour. The resulting level of functioning and behaviour presented challenges that, in turn, affected the tasks the women would take on in their caregiving roles for their children.

Theme 3: Caregiving Role

Aside from the everyday tasks typically performed by caregivers, these women took on additional tasks specifically related to the functioning and behaviour of their children. As such, the caregiving role and the tasks associated with it were an important aspect of the participants' lived experiences.

Subtheme 1: Managing Behaviours

Oftentimes, the caregiving role included tasks that involved managing autism-related behaviours within the daily routine. Managing behaviours required tasks such as the repetition of instructions, explaining expectations to the children and keeping the children on task. This facilitated the progression of the routine, and enabled caregivers to maintain control over the expected regimen.

...he tends to dawdle and not wanna eat in the morning (laughs)...Um, it's, it's difficult because I have to keep him on track...So um, he'll start, this is when he'll start his scripting sometimes, is at this point and uh, so I'll have to keep him on time... ~Cathy

Again I'm so used to giving uh, you know instructions "ok time to brush your teeth and make your bed." Uh because if I don't repeat instructions continuous, um he will forget. So w-with, with constant instructions, repetitions he gets his morning routine done... ~Jane

I guess the one thing that I would add is that um with kids like [my child], it, it's really important to repeat the um, whatever the strategy is in coping...So for, so for example if I decide that um routine is important to help her cope and therefore to create less emotional frustration for me, then keep on with it. And when you're gonna change the routine, when I'm gonna change the

routine I need to explain to her why so that she's prepared for it and can uh process that in advance. ~**Emily**

For those parents accessing Intensive Behavioural Intervention or Applied Behaviour Analysis for their children, they developed useful strategies and were better able to handle their children's behaviours. Such services were of value in the tasks of managing behaviours as part of the caregiving role.

But behaviours have been, oh my, so I'll tell ya the IBI was a great great help at reducing some of the behaviours and finding out what's the purpose of the behaviour is such a big part of it. To be able to figure out how do you reduce and eliminate the behaviour to know why are they doing it... ~**Cathy**

Without ABA principals being applied to our parenting style and our son's life in all the things he does, we would have a much more difficult situation to deal with... We do everything we do for our son in order for him to cope better with his autism, and that in turn allows us to cope better because it reduces his anxieties and therefore behaviours. So this all goes hand in hand. ~**Anita**

Caregivers took on many tasks involving managing their children's behaviours, which influenced their overall experiences.

Subtheme 2: Managing Routine

Caregivers felt that managing the children's behaviours were important in maintaining the daily routine. A good deal of the caregiver role involved the task of managing the routine itself in order to allow for comfortable progression of the day's activities. This was accomplished through keeping the child on task, involving the child in the routine and through planning the routine. Consistency in routine was valued by caregivers, as they felt it was an important part of their caregiving role and aiding in the children's functioning.

We have picture schedules to help him keep focused on his routines, which I also do up all the time, and teach him and the others in the household the expectations... ~**Anita**

Um I am, I, I have to- (laughs) I have to be there for certain parts of the, the routine um, but it's also, I (pause) I um, I tell her when it, when, you know, I give her cues about what, what, when, what part of the routine we're in and when it's time to do certain things. Or if there's a change in the routine, um, I have to explain to her what's, what the change is and stuff like that...

~**Emma**

Looking after any child requires at least some planning, but with autism it's a top priority because you can't just throw a change in there without expecting some behaviour problems. ~**Cathy**

Routine was important for many of the children with autism, and as such, managing the children's routine to allow for optimal functioning was an important task within the caregiving role.

Subtheme 3: Managing Environment

Other tasks often had to do with coordinating with those working with the children and managing the children's environments to allow for optimal functioning. This was often accomplished through communicating with services and managing information coming in and going out. In this way, caregivers were aware of resources outside the home and were able to coordinate outside environments to the benefit of the children.

...Um it's doing things like going through um all the emails and occasionally there's updates from let's say his, his um Kinark staff...Um sometimes it's updates from the local autism society or it's updates or questions from friends, family, whatever. Um, uh, it's looking up information, occasionally on autism or schooling, or whatever, going to places for uh for help with autism issues... ~**Cathy**

...I probably am the most knowledgeable as far as how to deal with him in the household so I'm sort of taking the lead on um, just, behaviour management and everything within the house, um co-ordinating his school team and his home team, trying to get them to work together...So, co-ordinating it all.

~**Anita**

Handling the children's environments often meant managing both the home and outside environment. These tasks also aided in maintaining the child's functioning,

by creating an optimal environment for functioning or avoiding environments proven to create difficulties.

...you know, I-I don't vacuum for example. She's afraid of the vacuum cleaner, it bothers her uh, um, her auditory sensitivities. So I don't vacuum when she's here. But that really doesn't um, extend to any other part of, you know, I just basically remove the obstacle and, you know, or work around... Actually we're removing to, to facilitate that we're just replacing all of our carpets with hardwood anyway, so, we don't have to worry about it.

~Elizabeth

...Even, even um, we've tried to take her to Brownie camp, you know, but she has uh, we call them episodes, where she gets um, she gets stuck in a repetitive behaviour that she can't break out of and the only way to fix that is to leave the situation... ~Emma

The children were exposed to a variety of environments in their daily routines, and so caregivers engaged in managing these environments in order to ensure that their children had positive experiences in these settings.

It became increasingly apparent that the women's roles as primary caregivers for children with autism had a direct link to their children's functioning and behaviour. The caregiving role was heightened in addition to "regular" care, particularly through tasks associated with the children's social and communication skills, and functioning related to the children's diagnosis of autism.

Theme 4: Costs

Participants identified several costs associated with caring for a child with autism. Many of these costs stemmed from limitations placed on typical family functioning and restrictions on aspects of the caregivers' lives, resulting from the children's special needs. Subthemes in this area included financial, social, health and employment costs, as well as costs to family life and activities or involvements.

Subtheme 1: Financial Costs

All participants reported that there were financial costs associated with caring for a child with autism. Costs accrued as a result of the children's diagnosis were related to supporting their development and managing their autism-related behaviours in some way. For example, the cost of therapy was an issue for those that were accessing therapies and related services for their children.

Umm, a lot the IBI. Because we had to um, I went from going to his, two to seven years for my child to talk, I didn't know if he was going to talk, so um that was big, uh cost and that was 7 or 8 thousand dollars for one year, but, you know, my therapist said basically take out a line of credit to pay for your, you're starting therapy you know. Um, I wasn't gonna just you know sit around and not get him help so that cost...that hindered us from buying a house for a long time, and we finally just able to do that. ~**Anna**

Financial definitely. Um, because of the wait-list for ABA and uh, th- it's not full funding that we receive. We've spent about um, hundred and twenty, hundred and thirty thousand dollars on [my child] in the last five years out of our own pockets...That's strictly just for his ABA or IBI whatever you want to call it. We've also touched on speech therapy... Um, you know there's all those kinds of costs. ~**Anita**

Some women also stated that finances were a limiting factor in the provision of therapy for their children, even though they would have liked to be able to access such services.

Uh, like I-I know I looked into um getting him more regular occupational therapy uh, but it's like ninety dollars an hour or a hundred dollars or something or things like that where it would be really nice if we could do something more for [my child] like that. Um but we really can't afford to... Um but I, sometimes I feel like we've um, maybe we haven't, we're not doing enough... ~**Charlotte**

...We would be getting more private help for him if we had the means. ~**Jane**

The high cost of therapy clearly held a negative financial effect on the experiences of these women, and emphasizes the need for monetary support services, along with access to affordable therapy. Many women also reported additional financial strain associated

with supplies required resulting from the children's behaviours and delayed levels of development.

...when anyone says to us, especially therapists or whatnot say, you know, this would really benefit [my child] in this way, and we go out and we buy it (laughs). Um, uh costs, another financial thing is because she took so long with her toileting, that we maybe bought diapers a lot longer than we needed to or Pull-Ups and that in that sense. ~**Elizabeth**

Such supplies were also associated with special diets used as a means of managing the child's behaviour.

Well I did put him on the gluten-free, casein-free diet, so that was, holy moly, that was, that added probably \$150 you know, to my grocery bill every 2 weeks. Um, but that didn't, it didn't help him in any way. ~**Anna**

...there are supplements that [my child] needs to help with food intolerances and helping him calm down and control the behaviours, we see a naturopath to help there, and the supplements have helped him focus to do better at school and benefit from the IBI therapy. Well, some of those supplements are costly, so we've had to sometimes look at juggling the money...if [my child] doesn't get his supplements, he is going to get uh, more behaviours coming out because he won't be able to focus better... ~**Cathy**

Um, we try and, our, our eating uh, we try and keep that as healthy as possible, so lots of fruits, lots of vegetables. Very little of the packaged stuff that is more cost effective but less health, and so our uh alternative eating habits are more costly. ~**Emily**

Damages to the home environment also presented a financial cost resulting from the aggressive behaviours displayed by a few of the children.

Um, there's, there's the issue (laughs) one of the issues that has become prevalent in the last while because of his aggressions is the damage he's causing around the house. We're going to have to replace all doors in our house because he is pounding and banging and charging at doors if you go behind the door. Um, you know, there's those issues that we've had to deal with. ~**Anita**

Um, yeah, I never even mentioned about some of the costs of cleaning costs, and furniture replacement and damage to household walls, furniture, et cetera during his worst tantrums. ~**Cathy**

Additionally, financial costs presented themselves when seeking supplemental care for the children, either in the home or for outside activities. This was due either to the unavailability of qualified individuals, or even the high monetary cost associated with hiring someone of such expertise. Anita stated the following.

...oh there's extra costs even with um, trying to get somebody to sit with him or, you know, work with him outside of therapy, like, you know if, um, you can't just hire the teenager on the street to look after your kids when one of them's got autism. You've gotta get somebody who has better um training or capabilities, higher capabilities which costs you more money. Um you know when he goes to camp in the summer you have to send a support worker with him to camp, it costs you to do that. Swimming lessons, he can't take group lessons like his sister, they have to be private lessons that we have to pay for.

The women were presented with a number of financial costs as a result of raising a child with autism. Many of these costs resulted from the children's behaviours in some way, either by trying to alleviate problem behaviours through therapy or other preventive measures, by correcting problems caused by negative behaviours, as with damages to the home, or by finding individuals qualified to work with such behaviours. All such financial costs contributed to the lived experiences of the women interviewed.

Subtheme 2: Social Costs

Many participants experienced social costs as a result of caring for a child with autism. Some mothers experienced difficulty in social situations, often due to the children's behaviours.

Especially on friendships, um, and, and and, before everyone knew about that [my child] had autism, it's, you know, you're sometimes embarrassed because people look at you like, your kid's having a tantrum, and (pause) he's not having a tantrum, you know, so. ~**Anna**

Mothers also expressed difficulties in social situations when there was a stigma related to the condition or when there was no understanding of the condition. Such negative social reactions were upsetting for the caregivers.

And uh yeah there was one time in the playground apparently when my husband took [my child] there interesting how it happened. He said [my child] was playing with another child that was there, and uh, whatever [my child] did it w- or did, it was something kind of unusual, so he kind of commented to the other parent just to say um, “oh I’m sorry about that, [my child], [my child], you know, has autism”. And this other parent called their child over and left the park... That person acted as if [my child] had a contagious disease and they had to get their child away from him as soon as possible. You know what, there was another parent and child in the playground and it turned out that parent was the supervisor of the early interventionist that was working with [my child] at the time and it was like, [my spouse] said, “gosh, you know, that was kind of an unusual response” and she says “that was an ignorant response” (laughs)...so uh, so he says “wow”, and she says “well, that unfortunately might not be the last time you run into this socially, people will pull back”. ~Cathy

Some women experienced difficulty maintaining a social life in general, because of their children’s needs. Many were unsure if this would have been the case, had they not been raising a child with autism.

We don’t um, we don’t go out a lot, just [my spouse] and I because we’re not, first of all we have three kids the oldest of which has autism, and so how many babysitters are there available other than family who have grown up with her that are willing to step into that situation. So we don’t have a great, a huge social life... ~Emily

Yeah, and then just as far as um, uh, me not being able, I don’t know, I just, I don’t really, I don’t really do a whole lot socially myself. And I don’t know if that would (pause) like I don’t know, I guess I-I think it’s something you kind of get used to. ~Charlotte

A few women lost some friendships entirely because of a friend’s inability to handle social situations involving the child. For example, Anita reported that:

We have seen, um, some friends drift away, um simply because they can’t handle, the social situations for my, with my son. I mean he’s high, high needs um (pause) it’s not like a typical social situation where two families get together. So we found some families have drifted apart from us, old time friends that just couldn’t handle it anymore.

Such accounts revealed that caregivers of children with autism experience negative effects to their social lives for a variety of reasons. The children’s behaviours presented difficulties in social situations, particularly in situations where the caregivers and/or their

children were stigmatized as a result of the condition. The nature of the children's needs also made it difficult for the caregivers to maintain active social lives, which along with the aforementioned social costs, influenced their experiences.

Subtheme 3: Health Costs

All of the women except for one had experienced costs to their health as a result of their children's diagnoses in some way. Most often these health detriments were physical in nature. Such physical health effects could take the form of decreased immune function and fatigue.

When he freaks out, not wanting to get dressed, I get tired. I feel run down and that then makes me catch colds and I do get headaches a lot... ~**Anna**

...I mean, you do, it sort of affects in, in many other ways you know like just you-you're constantly run down, so you get the colds easier. I had my first bout of pneumonia a year and a half ago and, you know I'd never had anything like that before. You know like so, so your whole being is just, you're barely holding it together just from sheer exhaustion. Mental exhaustion. ~**Anita**

Participants also experienced issues with weight, often attributed to overeating and lack of physical activity.

...I'm an emotional eater, so the added stress compounded that weakness; it also distorted my perspective of life and myself. I placed more value on caring for my daughter than on caring for myself. I didn't exercise regularly, I chose easy food rather than healthy food, my energy was low. ~**Emily**

There's been health issues that have come up. I've gained about sixty, seventy pounds with the stress and the overeating that comes with that stress...Um, I-I eat when I'm stressed, um, I dunno you get sort of into a destructive side of things, just because the world around you is so out of control. Um, I-I used to ride, like you know, cycle a lot you know, go out for walks a lot. Um, now I have time for none of that. Absolutely none. So, I mean (pause) physically you just keep packing on the pounds, the low energy, all those kinds of things. Um, it just becomes that vicious kind of cycle... ~**Anita**

One participant was dealing with a pre-existing health condition prior to her son's diagnosis, and the added stress of the diagnosis may have affected her recovery.

Um there's a whole issue, you know, um, the, the health-related things, related to the stress that comes in from dealing with special needs, um my immune system has never recovered. Whether it would have, had I um had a typical child I don't know. But my immune system has never recovered. Radiation treatments and steroids did it to my system but I don't know how much the stress of autism added to the mix. ~Cathy

The mental health of several of the caregivers was also compromised by the challenges presented by caring for a child with autism. The additional stress placed on caregivers negatively affected mental well-being, sometimes to the point of perceived depression.

I have been diagnosed with depression. Um, again, all the stress, and I remember the doctor sitting down and talking about, you know, some people you don't think they'd ever have it affect them, but uh, you know, in their life, but sometimes it can be, you know, sometimes it can be a chemical imbalance...sometimes it's just the shock of dealing with something short term, um, which she felt I sort of fell into, like you know with, with dealing with this issue, with how autism presented itself, it sort of brought on the imbalance. ~Anita

Ok, so from a costs perspective, definitely my mental health (laughs) and I say that tongue in cheek, I don't feel like I, I'm psychotic or anything, um, definitely a different level of stress. I have needed to rethink every parenting technique that I thought I knew, um, and implement a lot of new ones. Um it's a, it's a, I guess I'll say twenty four seven sort of stress... ~Emily

Mothers attributed their physical and mental health detriments to focusing time and energy on their children's needs rather than their own health and well-being needs.

So I wanna make sure he gets what he needs. He is the priority rather than me getting what I need. So for instance um, I get a sore back, sore shoulders, sore neck from using a cane to walk. Um but I don't get in for maybe as many massage therapy or um acupuncture treatments as I would benefit from because I would rather [my child] gets the treatment and the supplements that he needs so that he can do his best at school and we are dealing with fewer problem behaviours... ~Cathy

The lack of exercise because I, I put all my attention, it, it's dragged in to take care of my son's needs and I don't have the time or opportunity to go for walks, to take exercise classes, to you know, get on my treadmill.
~Anita

Health effects were a prominent cost related by caregivers of children with autism. These health effects were often due to stressors experienced, which would then negatively alter

one or both of their physical or mental health statuses. Such effects emphasize the need for support services that aid in alleviating caregiving stress experienced, so that health costs may be minimized.

Subtheme 4: Employment Costs

There were costs related to employment for all participants and/or their spouses. Many women related that they had felt the need to decrease their hours of work or give up employment entirely, or that they may need to do so in the future due to their children's needs. For many, these employment costs stemmed out of a desire to be there for the children as much as possible.

Um, we've given up a lot of, you know the 12 hours a week that [my child]'s in therapy you know we uh you know we can't go out and do things like that um, taking him to his therapy, you know booking appointments, taking time off, you know, when I, when I, when I do work at home but even taking time off my work at home, that could strain on my uh, on my partner who helps me with the daycare. ~**Anna**

Well, um, I think perhaps because uh, I-I would say that I didn't try as hard as I could have to get full-time employment 'cause I really wanna be a part of his life. So (pause) that was, that's been my number one priority, I-I did work part-time for a while...yeah I just wanted to be there for him...so, I didn't try as hard as I might have had [my child] been more independent... ~**Jane**

Like I haven't been able to work a whole lot outside the home um because I can't. I just don't, I never knew, especially when he was younger, um, I never knew what I would be called to the school for or whatever, and I just couldn't be in a full-time job...Just because I really feel, we both really feel strongly that one of us needs to be here with [my child], um, you know so I haven't been able to uh work as much as I probably would like to... ~**Charlotte**

Others expressed the potential need to alter their work schedules in the future, depending on the needs of their children.

...although I foresee um some uh effects a little later...but I do not foresee [my child] being fine being left home until she's, you know, well in her teens. So that's gonna, a little bit later on, you know prevent me from, from uh maybe working more or working different hours or whatever. ~**Emma**

In one case, the participant felt it necessary to maintain full-time employment as a means to cover the costs of therapy.

Um, I work full time so that we can uh afford to pay for the therapy that he gets. So that is also, you know, he's an in-, a huge influence on the fact that I'm still doing that. ~**Anita**

Additionally, many women stated that their spouses might have lost certain opportunities or experienced additional stress related to their employment as a result of the challenges presented by raising a child with autism.

I mean he is self-employed, um there's a lo- he really feels the stress. Um, because, I mean it's hard to make the bills, it's hard to make ends meet when we have such high expenses for my son. He feels as though he's doing fairly well in his business, but yet everything is being sucked right back out. ~**Anita**

...there's the stress of, we have to clump a lot of appointments and things into those times when he is off and we have to sometimes ask him to take time off for [my child]'s appointments and for reasons to do with [my child]... The company, you know they say they're understanding...but you know, maybe the next day he he can dumped more work on or later down the week, you know (laughs). And, and he just tries to deal with it as best as he can, but there is that extra stress. ~**Cathy**

I mean I know he's applied for different uh, like promotions within the company and I know he hasn't got the jobs but I don't, I can't say that that's because of anything going on here because of his ab- avail- huh availability to maybe do certain things at work. Um 'cause you know, I need him here as well and uh, I-I don't know that's really, that's kind of really hard to say. ~**Charlotte**

Negative effects to employment not only arose for the female primary caregivers, but potentially for their spouses as well. Aside from the financial implications this could hold, participants were concerned with lost opportunities experienced, and feeling pressure to either maintain or give up employment, based on the needs of the children with autism.

Subtheme 5: Costs to Family

All of the women interviewed stated that there were some costs to their family unit. For example, costs to the marriage were apparent for several women as a result of the perceived blame because of a potential genetic link, problem behaviours, or additional stresses and strains presented by autism.

Umm, the biggest strain pretty much is um, his blame, that he blames himself and he thinks I blame him and I don't, you know. ~**Anna**

Um (pause), I mean, the toll that it's taken on marriage, I think the statistic is now 90% of marriages fail (cough) when autism comes in. It's um, a huge strain on the marriage. We're committed to each other, but it, I'm telling you, it's not easy... Well, um, when you deal with such intensity coming from one child, an-and such anger and frustration, um, it builds the stress level up. And it's really hard that, to, to just break that off at one person. ~**Anita**

Uh, it can be strained at times. Um, but honestly what marriage isn't. Um (pause) it has affected my libido, um, but uh (pause) [my spouse]'s very good about it, being patient and accepting. Yeah, this is the way it is, this is the way, you know, we can't change everything. ~**Elizabeth**

Further, it was difficult to obtain alone time with a spouse, often because of the child's behaviours or because of the difficulty in finding respite care. This was thought to decrease opportunities to focus on the marriage itself.

...Um, uh there has been stress in the marriage because of the fact that we can't just leave [my child] to play while we talk or something like you might with a typical eight year-old child... There are few times we've been able to have a date night although parents of children with autism are strongly encouraged to do that. But you have to have the money for dinner plus a special babysitter and arrange for our schedule plus fit in with the babysitter's schedule, so good luck... ~**Cathy**

Such destabilizing effects to a marriage may decrease a couple's capacity to deal with extraneous challenges that present themselves.

...Um, uh well I think at this point it's not all, my uh my husband and I have, you know, marriage is uh not an easy thing. And uh it's an ongoing voyage, that's for sure. So there have been other circumstances that have affected us. [my child]'s autism has kind of made me much more fragile... ~**Jane**

Aside from challenges to the marriage, costs also presented themselves other aspects of the family unit, particularly to the siblings of children with autism.

Um, again maybe some stress on my daughter's part if I can't take her somewhere because [my child], like when he was younger he was flipping out, or um, if he has therapy you know, I can- I can't leave or um (pause), you know she has to come with me some of the time to his appointments so that's kind of boring for her... ~**Anna**

Um, it was a little bit difficult for [her brother] but that um, he's, he's dealt very well with it, realizing that yes we have to do a little bit extra for [my child]... ~**Emma**

Caregivers were aware that siblings were receiving less attention from parents than they otherwise would have.

...Um, you know an-and she doesn't get the attention that she really should get. Um, I do find when I try to give her any one-on-one attention, if my husband isn't here my son won't let me do it, he gets very jealous and i-like he'll just becomes a, such a problem and a bother, interrupting, that we just can't do it. We'll get fleeting moments here and there and that's about it. So she does miss out on a lot. ~**Anita**

...I know uh with [my child], because he needs extra time, I know the other two, especially [his brother], who's very quiet, he's my middle son, our middle son, and uh I sometimes feel I'm not paying, I'm not giving him the attention I would like to...you know the fi- my oldest seems to need attention and so does [my child], and then I-I just have nothing left for my middle son which is very sad and I'm very conscious of it, and I really try you know, not to, you know not to have that happen but it just sometimes happens. ~**Charlotte**

Maintaining a focus on autism in the family also resulted in lost opportunities for some siblings. In one case, a sibling had not only experienced negative effects to her lifestyle, but was expected to lose out on educational opportunity due to the high financial cost of therapy for the child with autism.

It takes opportunities away from his twin sister because we can't do some of the typical things that families would typically do, or we have to do them in such a different way to make sure that he can get through it...Education for my daughter is not pa- is not going to be paid for. We haven't got money set aside for that. She's going to suffer later in life because we're not going to be able to afford to send her to university. She's going to have to try to earn that

money herself because we can't save when we're spending so much money on our son. ~**Anita**

In some cases, siblings felt jealousy as a direct result of the situation.

...they'll, [his oldest brother] will say you know, what about [him], he's so lazy and, and I say well, you never did that stuff when you were seven, so, you know what I mean, like taking out the garbage, like, I never made [him] take out the garbage when he was seven (laughs) but he just sees it as, you know, I'm just paying more attention or being more lenient with [my child], uh, you know, because of his disabilities. ~**Charlotte**

She is understanding in some ways, but in other ways she is very jealous. She does feel that everything is for autism and her brother. And in some ways it is true because even things for her have to work around her brother and his needs. ~**Anita**

Some siblings also had increased responsibilities placed on them, often related to the child with autism.

You know the one who's probably taken more of the burden, more of the toll is probably his older brother, it always is. Yeah, I-I if I were, just because we've probably taken it for granted that he'd, he'll, he'd always be there, you know, be willing to help and he mostly has...So I think it, it has taken its toll in positive and negative ways, 'cause it must be a lot for him. ~**Jane**

And my oldest son has just turned twelve and he did, he took a babysitting course in the fall, so that's really helped us a lot. Um he's very good with [my child], and it's really gave us, it's given me a little bit of freedom...So that's been really really nice. ~**Charlotte**

In one case, the diagnosis of autism resulted in a purposeful decision not to have any more children. This was decided in order to eliminate the risk of having another child with autism, or to prevent a sibling without autism from being disadvantaged, especially since the caregiver herself had experienced being the sibling of a child with special needs.

...Because of her diagnosis, she's an only child whereas, you know, we were planning at first to have more than one but we felt that uh, it would be best for her to get all of our attention. And um having come from a family that had, my youngest sister had special needs, I know how much the child, the children without special needs lose out as well. And uh, also, um w-we didn't wanna risk having another child with autism... ~**Elizabeth**

Raising a child with autism undoubtedly affects all family members involved. Caregivers felt that their marital stability was compromised at times, and that the siblings of the children with autism were also experiencing negative effects. Such family effects contributed to the overall experiences of the women interviewed.

Subtheme 6: Costs to Activities/Involvement

Many participants experienced costs through difficulties or the inability to take part in certain activities. These challenges were often the result of the child's level of functioning and behavioural abilities. For some, it was stated that they were not living the lifestyle they would have expected in terms of vacations and other activities.

Well there's not the money to do the things that we would have thought life would have brought us by now, or you know, like, um, overall lifestyle, I mean, there are very few vacations. ~**Anita**

It is, one of the things that um, one of [my child]'s routine things is that she can't sleep um anywhere else, except for her own room. So that's uh, it's kind of impacted in that we can't go for like a family vacation anywhere overnight. ~**Emma**

Um, you know, there's certain things you can't do. Like we can't take her to movie because with her, with her auditory sensitivity they're just too loud for her, and she just doesn't have the patience to sit for that long in one place. So things like that we can't do, but, we do other things that she, she likes to do. ~**Elizabeth**

We don't go on vacations. Um, we uh keep our environment, especially at home, pretty um boring some people would say...there's a lot of things that we don't do because, um, or haven't done because [my child] would not be able to handle, um, for example, [my spouse] and I being away on vacation for a week, um, or she would not be able to um live in, in another environment herself for an entire week. ~**Emily**

Caring for a child with autism also presented challenges in completing daily activities and in finding respite care in order to complete necessary tasks. Activities were sometimes limited to those that could be accomplished after accounting for difficulties that could be presented by the child with autism.

It um, it restricts even your daily life with, with um, you know like how we shop, how, like you know, everything we do, because we have to worry about where we take him and how we take him and how much time we're going to be, where we are, so, everything has to be planned and organized and it doesn't matter...Basically autism rules our home. ~**Anita**

Again it comes to the fact that you can't hire just anybody, and if you do hire a stranger through an agency, you want to spend time with them and see how your child reacts with the person before you leave them alone together, and you start small by leaving them alone just while you go to the bathroom, then maybe for a walk around the block, work up slowly. So you have to cope by yourself most of the time if you don't have family or friends nearby. ~**Cathy**

Participants recounted negative effects to various activities and involvements as a result of raising a child with autism. Participation in many activities was limited, and often dependent on the child's functioning. Such costs to activities and involvements held repercussions for the caregivers' experiences.

It is apparent that several costs surfaced from the experiences of caring for children with autism. However, despite these costs, all participants identified benefits from their experiences parenting a child with autism.

Theme 5: Benefits

Although many costs were associated with the experience of caring for a child with autism, several benefits were salient as well. Such benefits were identified in all of the same areas in which significant costs were described, and each will be explained in turn.

Subtheme 1: Financial Benefits

Although there were many financial costs associated with caring for children with autism, some financial benefits were also brought about as a result of their children's needs. Nearly all participants mentioned the availability of financial assistance, which

was considered a financial benefit to some extent, although often not enough to cover all financial costs incurred.

They pay, um, they pay you a little bit a month, umm, on the, on the Child Tax Benefit, it's just from the government...then there's help from umm Easter Seals...So there are some resources out there, it's not very much, 2 or 3 hundred dollars a month (pause) compared to the, you know 5 hundred I'm spending every 2 weeks on therapy, but there is... ~**Anna**

We have uh been able to tap into, uh through the government a li- a little bit of help because of [my spouse]'s income, so we, we're able to get a little bit of help to help send him to camp, that kind of thing. So in a way I guess um, and you get an extra little bit from the federal government as well for having a child with a disability. So, they, they give you a little bit more because they realize that it'll probably cost a little bit more, a lot more. ~**Jane**

Since participants were presented with financial challenges, some stated that they benefited in that they had found better uses for their money.

Y-you really, y-you invest invest that time and money into your child, and when you see the results it's that much better. ~**Cathy**

In one case, financial benefits were identified where family members provided monetary assistance.

If we really needed something like the psych assessment, things that really needed to be done, we just stuck out our hands and asked our family to help. And they did. No questions. ~**Jane**

Although negative financial effects arose in many instances, participants related some positive financial effects of raising a child with autism. Such positive effects were most apparent where financial assistance was received in some form, enabling participants to provide for the children's needs. In addition, caregivers were prompted to manage their funds more effectively. As was mentioned in relation to financial costs, such benefits further reiterate the need for monetary support services for these individuals.

Subtheme 2: Social Benefits

All of the women reported benefiting socially from their experiences. For some, these benefits were the result of new social experiences, such as new friends or new social situations that they became involved in as a result of caring for a child with autism.

...we have also developed some new friendships within the autism community because when you do get together with those families there's not as much stress because they understand when your child behaves differently. They're not judgmental they, they just get what's happening. ~**Anita**

...I think it's (pause) she's really (pause) enriched our lives because we've come into contact with so many fantastic people and organizations and you know, there's this whole other um, it's like a whole other level of society that most people don't get to meet and don't get to have anything to do with...It's, it's all been a very positive experience. ~**Emma**

Um, yeah I've made a very good friend who also has a child with special needs. And uh, yeah, so, I spend quite a bit of time with her. And through her I've met other, not people with special needs, but other, sort of her friends and uh, so I yeah, I've, my social circle has expanded. ~**Elizabeth**

In one case, the child's lack of social inhibition even prompted the formation of a new friendship.

Um, well I think it-it's helped us become closer with uh, again Neighbour E...And uh, so in that way it has, uh, helped, benefited uh us being better neighbours with uh, with people... You know, and that's, [my child]'s like that because he has no (pause) no worries about social stuff like that. Which is, yeah, it's very interesting, he doesn't get hung up on a lot of stuff that, um, the rest of us do. ~**Jane**

Others experienced social benefits in that some of their social relationships became strengthened. Also, some tended to become closer with friends who took an interest in children with special needs.

We have found closer relationships with other people that have the um, you know that care about special needs an-and enjoy, you know seeing that development. ~**Anita**

...Neighbour E, her husband passed a few years ago and the two of them, uh, espec-, well she was a, she's a retired schoolteacher, so um she was very lonely, it was very difficult, and the boys just started to hang with her (pause)

and sit on the porch with her. And then [my child], because he needed extra help, with reading, so she, her teacher skills came out. So it really, you know, and then, then we've, so we've started to hang out more with her. ~Jane

Lastly, situations where there was common ground and understanding of their children's behaviours, and situations where the caregivers were given the opportunity to create a general awareness of their children's conditions resulted in benefits to social experiences.

You'd be surprised at how many people know autistic people or how many people you know have autistic children or are related to special needs people. And it's just, it's a, it's not like it's a great way to meet people but I mean it's great to connect to people on that sort of different level... ~Emma

I guess one thing that I think about is when I'm out with my friends. I (pause) it's a, it's a lot more beneficial for me to talk about things like this and how to advance the cause and how to advocate for [my child] and all that sort of thing rather than you know, let's go have a drink, let's go talk about fashion you know superficial, what's that word, superficial stuff. There's, there's more of a sense of um, uh (pause) um what's the word, purpose.

~Emily

Social costs often arose in situations when there was a lack of understanding of the condition of autism, and when the opposite was the case, participants were able to realize benefits to their social lives. These women benefited from experiencing new social situations and expanding their social networks as a result.

Subtheme 3: Health Benefits

Even with the unmistakable costs to health presented, certain benefits to health arose as well. For example, a renewed focus on physical health was described.

Benefits to health and well being, accepting this diagnosis as a part of my life has caused me to focus on achieving health long term, it has helped me search out resources and strategies to make lifestyle changes relating to my health...

~Emily

There were benefits to mental health as well, in that many of the caregivers felt they had more of a reason to overcome mental health issues and deal with challenges more effectively.

I think my overall, li-like, again, going back to what he's brought to my, the joy and uh, so my overall (sigh) well-being mentally um, psychologically, um, he has a lot to do with me trying to be a little more positive, seeing the glass half-full routine. He really does. I mean, both, uh both of them do and, but [my child] just has a way of uh, he's done, he's contributed greatly to my um, to my uh desire I guess to try harder... ~**Jane**

I, I would definitely say yes. I mean, it's expanded my abilities to um (pause) you know, emotionally deal with uh, you know, problems as they come up and stuff, and um, well because I have to. ~**Elizabeth**

Many participants sought alternative health strategies to aid in improving their children's functioning. As such, benefits to overall health also came about for the caregivers themselves from a willingness to pursue alternative approaches in taking care of their health, either through alternative therapies, changes in diet or even the pursuit of health-related information.

...when we looked into some of the food intolerances and had to have him tested...And that was a reminder to me about when I got tested and was told I should avoid this and that. Some of the things [my child] is intolerant to are things I should avoid, too, so it's improved our diet in some ways...you can phone up for free, a toll free number and you call, talk to a dietician and they will send you information...Would I have phoned up the health board to ask about my own lactose intolerance? Probably not. ~**Cathy**

Um I don't know and as far as our eating and stuff, like i-if we're talking about health issues, I think with [my child] um, you know, from different things I've read we try to keep him um away, not away from wheat products but just we try not to eat a lot of wheat products...but anyways, that's, we try to eat fairly healthily. And uh I think that's, you know, that's a good thing, a positive thing. ~**Charlotte**

Benefits to health arose in many forms, typically because the women were more likely to be conscious of their own health statuses as a result of caring for children with autism. Participants were then more likely to take measures to improve their physical and mental well-being, and created further benefits to their overall experiences.

Subtheme 4: Employment Benefits

Some benefits to employment emerged as a result of the children's needs. New employment opportunities came about through exploring different career options and adopting different schedules.

Um (pause) well I guess, I guess I made the choice to stay home um with him (pause) after my home daycare provider retired last September. So I decided I might as well stay home, uh and watch the kids and get to stay home with [my child] and help him, cuz I went to school to be an Educational Assistant so I you know, have taken autism courses and how to, how to help them so, so, that yeah, I got to stay home... ~**Anna**

...um yeah, it's made me look at what, I mean, what it comes down to is uh, in a lot of ways I can track back and say it's made me look at what kind of job should go into next because there's this whole area where there's all these people with all these needs, you know, now I've got some experience with it, could I somehow go into something that could help them... ~**Cathy**

For one participant, employment was viewed positively because of the escape and sense of accomplishment it could provide.

Um I like going to work just because it gives me a different perspective in life. I-I can go and I have concrete evidence that I have done something that day. Um, whereas, with [my child], seeing the results are, they-they're more subtle or they're not as obvious... Um (pause) working part-time is a coping strategy for me um it helps balance me out to be a better mom the rest of the time that I am home. Uh it gives me a break mentally and emotionally an-and everything. ~**Emily**

Another participant experienced benefits to relationships at work as a result of caring for a child with autism.

...it's funny because my boss's son has just been assessed through KidsAbility, my, one of my co-workers, her son who is now nineteen, he's autistic, um, you know. And it's, it's funny because my work, my work um place is (laughs) almost like a little social group for people with um special needs children... Um I think that's another, possibly it's, it's benefited work just because that's another layer, level that we can all get along on. ~**Emma**

Finally, many women stated that their spouses experienced increased motivation for success in their employment, as part of their roles as primary income-earners.

My husband is happy that he has developed his own business, and gets much satisfaction out of it. Without the push to make ends meet that autism has brought us, he might not have had the drive to succeed as much as he has.

~**Anita**

Um but for, but for him, because he's the primary um, he brings in the primary income, he needs to stay more focused on, to keep his career separate from home a little more than I do...I-I know that for his employment it definitely gives him a vision for what he's doing outside of being just a job because he wants to be able to care for his family. And because for [my child] there are you know, there are greater needs than somebody who (trails off). ~**Emily**

Benefits to employment came about in many forms. The participants valued employment for what it contributed to their experiences, and had even considered employment options they otherwise not have. A few of the women interviewed also felt that their spouses had benefited from increased motivation as a result of their children's autism. Although costs to employment had come about, such employment benefits were also worthwhile in realizing overall benefits in their experiences.

Subtheme 5: Benefits to Family

Various benefits were identified for the caregivers' family units. Many of the participants experienced benefits to their marriage as a result of caring for a child with autism. One such benefit was an increased commitment to the marriage and to one another.

Um, and sometimes, I mean I know for my husband and I, we often laugh at (pause) in some ways emotionally we're more committed to each other because we're in this together. ~**Anita**

Another benefit that emerged for the marriage was an increased sense of unity in the marriage by working together for a common goal, namely caring for the child with autism.

But um, we tend to work together, so that helps. We have the same sort of ideas in the way she needs to be managed... So, kinda see eye to eye on most things... It might have brought us closer together in that respect. ~**Elizabeth**

Um (pause) I-I would say in ways it's drawn um you know [my spouse] and I closer together because we have a common, a common purpose uh with [my child], you know, among other things with our other boys of course. It's not just all about [my child], but um, you know we, we try and stay on the same page with each other as you know as to how we're um raising [my child] and the other boys. And um, I don't know I think in ways it's been good for our relationship... ~**Charlotte**

One participant found that caring for a child with autism promoted communication with her spouse.

Um so it's be- it's been um kind of a talking issue that it'll open up discussion sometimes... So um, so it's been sometimes, a talking point... it's, but it's, in both families it's been something that's opened up discussions and that, yeah. ~**Cathy**

Caring for a child with autism was found to benefit participants' marriages by encouraging a focus on the big picture.

...It's um, it's helped uh [my spouse] and I to focus together, to bring our strengths and our weaknesses together to, and, in a vision for a cause. Um, specifically in advocating for her, we have um, it's, it's helped us kind of lay aside the petty stuff that could become issues. Because there's, um, a lot more at stake... ~**Emily**

In some cases, benefits arose to other members of the family as well. For instance, siblings of children with autism benefited from more involved parents.

I wanna say yes there's benefits for everybody in our family with it. Specifically, um (pause) they have their parents at home um probably a lot more than what some kids do... Um they aren't at babysitters a whole lot, um (pause) our extended families are involved in their lives as opposed to people they don't know as well. ~**Emily**

...Um, yeah, I-I don't know, um I think it spurs you to spend, as a parent I think it spurs you to spend maybe more time with your child than it, than you maybe normally would, um when they're, when they're home and I think that's a really positive thing. ~**Charlotte**

Siblings of children with autism also benefited from developing increased patience with their siblings with autism, which could be applied to their interactions with others.

...They too have gained in patience. Many times I see my daughter as very mature for her age... ~**Anita**

...it's up to me you know, up to me, to [my spouse] and t-to [his brother] to try and uh be more helpful, be more patient, be much more tolerant. Um an- and I think, I think we've come a long way. So in that way it has been a benefit, even when, even when we deal with each other, we're tending to be a little more gentle, so, perhaps it has be- had a positive fallout. When you learn to deal with somebody that is not, you know um, that has some difficulties you, and you learn to be more patient and be more uh, giving an- and understanding, it starts to rub off on the other people you deal with and that's a good thing. ~**Jane**

Raising a child with autism can affect many facets of family life. In these cases, benefits to family life came about in a variety of ways, as families communicated more, were more unified, and were more sensitive in their interactions with others. Such positive effects were felt by caregivers to be important aspects of their experiences.

Subtheme 6: Benefits to Activities/Involvement

The female primary caregivers of children with autism identified benefits associated with various involvements and activities that came about as a result of their children's needs. For many, such benefits arose from both formal or informal involvement with autism advocacy.

Um, I mean, autism takes control of your family and your life. And somehow you have to sort of (pause) get control back somehow. So my advocacy I find gives me something about autism that I can control or can try to find control in...advocacy has given me a feeling of being able to make a difference in a world that is sadly lacking for my son and others affected by autism. That gives you a feeling of contributing to society for the better. ~**Anita**

My whole van, the back of the van is autism, I've got autism plates and stickers and (laughs) and everything I can do. So if you stop at a light and see. You know, maybe someone will go oh what is autism? And then they'll go look it up. ~**Anna**

Um and um, just, the, advo-advocacy part is huge, too. Um 'cause that really has a lot to do with coping strategies 'cause the more we can prepare other people to, to help her, the less quote unquote burden there is for us to do it all independently. And um, it, it just kind of balances out, the, the uh, the mental and emotional strain. ~**Cathy**

The women benefited from involvement in the autism community and the opportunities provided to teach others about their children's functioning and behaviour. In this way, they felt that they could help individuals in the same situation, or even encourage dialogue and increase understanding of autism in general.

For Christmas I...I read all those books, right. And then in December I wrapped every single book and I gave one to each of my family members and I said to make them switch. So that um, they would all understand about it, um (pause) pretty much just being able to talk and say like all the things that [my child]'s doing all the milestones he's meeting, everything that he's overcoming. Being able to go there and everyone being proud of him and um, and them, not, not being afraid of it either...so that really helps. ~**Anna**

Um, that takes on different um dimensions for us and just making people aware...Um a lot more dialogue with the teachers. Um, and uh just exposing ourselves to other people helps them to understand [my child]. ~**Emily**

The more all aspects of society is exposed to autism, the better it is for my son and our family when we are out and he is behaving in an odd manner. When we first had diagnosis, nobody seemed to know what autism was...Now, people understand that perhaps your sons behaviours are not from bad parenting, or just a poorly behaved child, but understand that what is happening is out of the child's control and out of the parents control and needs understanding, accommodation and acceptance instead of the hurtful comments that used to come at us. Every chance we get to show someone anything about autism makes a more inclusive society, building opportunity for our children to live in. ~**Anita**

Taking part in autism-related active learning activities also benefited many of the caregivers in that they were able to learn more about autism and about techniques that would aid them in raising their children.

I had mentioned, uh, during, that when we went to KidsAbility, um, speaking to the Therapists there that were helping him. Uh so we did, I, we did various little, you know, homework assignment...Um, uh then later um, I would attend meetings, parent meetings... And uh, y- I mean, things that learn, to help us to teach him become uh, you know, a good little guy... ~**Jane**

You know I do go, I did wind up going to KidsAbility and we've taken, [my spouse] and I had taken a course um, More Than Words, uh to learn how to communicate better with [my child]. Um, so there was a lot of reference material from there that we looked up at the library and online and stuff like that, and. I get a lot of, I do meet a lot of other parents and I get a lot of information from other parents... ~**Emma**

Along with these activities and involvements, an inherent process of experiential learning occurred through caring for a child with autism, whereby participants benefited with an improved outlook on many aspects of their lives. For all participants but one, this included increased patience.

Um, you know, a funny thing, it is, a-a he, in some ways and it's gonna sound so patronizing but uh he has been a gift. I have grown because of, because of him...If anything it has helped me to become a much more patient and um, uh k- you know hopefully yeah tapped into a, a more kind, more thoughtful. And I know that sounds so corny but...When you learn to deal with somebody that is not, you know um, that has some difficulties you, and you learn to be more patient and be more uh, giving an-and understanding, it starts to rub off on the other people you deal with and that's a good thing...it's been probably the best learning experience of my, of my life to uh, to watch him...To watch, to share, learn how to be patient (laughs)... ~**Jane**

But uh, it's taught us, her being autistic has taught us to be a lot more patient um and to be more open-minded and uh tolerant of ah just to realize that people do things at different speeds and to you know, just kind of take a step back...~**Emma**

But, um, it's opened up, like it was a life experience that I otherwise would never have gotten. Um, which, and i-it was a great life experience, you know, to do that. Um, it's (pause) I dunno it's brought me a lot more patience, patience I never knew I had and my husband agrees he feels the same way...like I say I think I've found more patience and those kinds of things... ~**Anita**

Others stated that they had gained open-mindedness and become less judgmental as a result of caring for a child with autism.

Um and then sometimes I wish you know, they would ask, rather than pull their kids away...As long as they ask in a non-judgmental tone, like yeah, I-I'm willing to discuss yes he is diagnosed with autism...So, it's, it's also opened my mind to the uh, you never know what someone else is battling, uh because you can't see every disability or every problem that someone is facing. So, it has just opened my mind to that. ~**Cathy**

Um I think that I've learned to be much more accepting of people, um not to judge what I see on the outside, um, I-I definitely something that I've learned with [my child] is that the behaviour you see in public is not just an incident....Um so I'm much less um judgmental of who I see, of what I see.
~Emily

Finally, because of their involvement in their children's development, participants learned to be more appreciative, especially of their children's accomplishments. They were more conscious of how much effort their children's accomplishments required, and hoped to not take anything for granted, particularly in terms of their children's development.

...I also understand that kids um (pause) are not- are not stupid and I think many parents treat their kids like they are and they do too many things for them where um, they take a lot for granted...I will never ever let a child answer me without speaking because parents just take it for granted 'cause their kids just talk, my kid didn't, you know, so. ~Anna

...when things work, when things go well for him, when you see him advance, you see things click for him, there is no, I can't even explain the joy and pride that you have for your child when that happens, and it's an amazing experience...Many parents of children with autism will never hear their child speak, or tell them they love them. I will never forget when my son spontaneously told me he loved me for the first time. He was about 6 years old. I was tucking him in at night, and every night I had told him how much I love him. This particular night he said it first to me, and I cried about it for a few weeks. It was so joyous to hear your child tell you they love you. It's something that every parent wants to hear from their child, but so many autism families will never get that experience. Through our son's hard work, and all the support he receives, he was able to do it all for himself. I don't think there could be any stronger benefit to help explain this. ~Anita

And with [my child], we know now, we can ask him what he wants. Other parents take that for granted with their kids, and we never take it for granted. And there are times when my husband and I look at each other and it's like, whoa, you know, uh he is able to do something. Uh, the other day he floored us, he put together a twenty piece figurine, it had small pieces and it says ages five and up...so he is finally catching up uh, yeah...So, our, our prayers have been answered, like how else could we appreciate our child so much and all of the small things he does, would be just taken for granted if he did not have autism so, there you go (laughs). ~Cathy

Um, I think in general, it's made me appreciate uh, it's made me appreciate things a little better because I don't take her learning for granted and when,

you know, when she does pop up that she knows something new, it's like wow, that's you know, you realize how much that she, effort she's put into it and she's, it's, very, it's, it's kind of eye opening that I just don't assume a lot, but uh, stop and say yeah you know what that's pretty fantastic (laughs).
~**Emma**

And um, and just our overall outlook I think is really good. Um I don't know, it's pretty positive I think. Like we know there's a few issues and we, we know what we have to do, and um, to work with [my child] on those. And uh I think in general it's been, we're more appreciative of um things that do go well in our lives and I think overall that's a really positive thing. ~**Charlotte**

Rather than focusing on activities or involvements that were surrendered, it became more apparent that benefits arising from activities and involvements gave the women purpose, allowing them to learn from the community they had become involved in, and to give back to this community in turn. These experiences contributed greatly to a process of personal growth, and all of the women saw themselves as having become better people as a result.

Examples of interactions between themes

The themes of social and communication abilities were important aspects of the children's functioning and behaviour. These behaviours, along with the resultant costs and benefits to different aspects of the caregivers' lives, were found to be mutually influential. For example, overall costs often arose as a direct result of features of the children's functioning and behaviour, as related to the diagnosis of autism, and as a result of the additional burdens experienced in the caregiving role.

I don't know what else you can say, autism affects everything we do. We have to plan everything around how our son can handle it, or how it will affect him. Our entire life lives for how autism affects it... You know there's, there's a lot of times I-I just wish we could be a typical family and that autism would just go away. Um, we don't know any different as a family, this is our family...I mean, it-it's autism is an extremely challenging and frustrating thing to be around all the time. ~**Anita**

...you don't think that it affects you. But, it's, it's there, more of an undercurrent...So, he's not the only part of it, but having had a-an

extra bit of a burden to, to deal with but it has been tough too, you know, so I have to be honest about it. ~**Jane**

Similarly, general benefits also came about as a result of overall characteristics of the children's functioning and behaviours, as associated with their diagnoses. The caregiving role and its potential associated challenges were also viewed favourably.

...Everything we've done has always progressed out of her abilities n' out of her interests, so. But I think you wou- anybody does that with any child so I-I wouldn't say there have been any costs for it yeah. I would say there has been benefits. ~**Elizabeth**

Um we know that [my child] is a little bit different than other kids, so we just have to know how to deal with it, and it's, and he's, he's great...And because we had him diagnosed fairly, you know fairly young, he wasn't like a baby or anything, but, you know, I think it's just helped us immensely. Um just to deal with um our daily lives and we know what we need to do. Um, uh, I don't know, it's just um, it's been kind of really an enriching experience, I guess, for us, to look at it positively (laughs). ~**Charlotte**

...you know, you thought you could love, but 'til you found somebody who challenged, who challenged other parts of your life and uh who challenged every other part of your life, and it's not so, you know, and wow. So, you know, I thank God every day for my, for all my, for both of them. But uh, [my child] has opened some other little doors so, big doors, little doors (laughs) a couple of windows. ~**Jane**

When considering all of the above, it is clear that benefits existed in all of the same areas where costs had arisen as part of the lived experience of females acting as primary caregivers to children with autism. This was illustrated when participants would describe the ways in which benefits emerged in spite of costs presented to them.

Um and the spectrum is so huge and so, you know, there, there are lots of people out there that just, they can't get beyond today or they can't get beyond the, the loss, if that's something you wanna say of their, their dreams for their children. Um but um for [my spouse] and I, and for our family, we, we've been blessed with um family support, friends that support us, um people that got us going down this path in the beginning, um, yeah, it, it's all about perspective and and taking the challenge of, that presents itself an-and making life good... ~**Emily**

I mean, I, I've centered on a lot of the negative things, I mean (pause) I want it, I want it to be left with, I wouldn't trade it for the world, and, and you know like, um, you know he's my son I adore him, he's an amazing kid, um it's amazing what he has succeeded in in life an-and it's, it's very, um, as a parent it's hard to even explain the joy that you have when your special needs child achieves things. Um, it's, it's absolutely an amazing feeling that way. So as much as I've touched on so many of the negative aspects and the extra challenges it's put in...um, I don't want to take away from, I-I don't want you to be left with the feeling that this is just all drudgery... ~**Anita**

It's been (pause), it's been rough and fun and uh (pause) educational (laughs) um, it's um, probably made me a better person (pause) um, I dunno everything happens for a reason so (pause) that's all I can say. ~**Anna**

It's hard to, like you can't explain what it's like to live with someone, you know, an autistic child...every single autistic child is different you know...So there's, you can't go by stereotypes. Um, yeah, I think, uh, definitely, with [my child], I, if given the choice, I wouldn't make her not autistic, because, she's, that's part of who she is, and we've just learned so much from everything, from all of the experiences with her, with her autism, you know, that it's just been, it's, yeah, it's been all good. ~**Emma**

Benefits were often present in conjunction with costs. The presence of benefits, while not always in direct contrast to the costs, somewhat dampened the effects of many of the costs and enabled participants to view their overall experiences more favourably. This demonstrates the importance of the benefits that arose for participants, where although associated costs were not necessarily negated entirely, participants were still able to experience positive outcomes.

Discussion

Raising a child with autism will undoubtedly have an effect on the primary caregiver and those involved in the family life of the child (see, for example Higgins, et al., 2005; Jarbrink et al., 2003; Sen & Yurtsever, 2007). As this study progressed, it became increasingly apparent that there were both positive and negative effects on the financial situations, social lives, health, employment, family lives and activities for married female primary caregivers of children with autism. These positive and negative

outcomes, along with the children's functioning and behaviour, affected the women's lived experiences as a whole.

Autism presents with an inimitable set of characteristics for the child, which create unique challenges for the caregivers (Norton & Drew, 1994). For many of the caregivers in this study, one or both of the deficits in social and communication skills were important triggers for initially seeking diagnosis for the child. This is speculated to have been due to the fact that these sets of skills can have a direct impact on parent-child bonding (Norton & Drew, 1994), causing mothers to personally feel the effects of these impairments and therefore seek to help the children, and themselves by extension. As such, health care practitioners should aim to make parents aware of the milestones their children should be reaching and when they should be expected in the children's development. Although intuition helped the interviewed caregivers initially recognize problems in many instances, this may not always be the case for all parents. It is essential that parents are able to recognize when their children are straying from typical development, as early diagnosis and intervention is key in improving the children's social and communication skills (Ben-Itzhak & Zachor, 2007). Findings here indicate that the child's social and communication skills can have a profound effect on the lived experiences of caregivers of children with autism, typically through additional tasks that would be taken on in caregiving roles, as will be discussed below, as well as outcomes in terms of costs and benefits. This presents an added benefit to be gained from early diagnosis, by further emphasizing the importance of prompt access to effective interventions, as suggested in previous work (Ben-Itzhak & Zachor, 2007).

Mothers also experienced effects to their experiences through additional tasks presented in their caregiving roles, which for many, were heightened beyond that of “mother”, and often morphed into “manager” roles that allowed mothers to control routines and environments in which the children were involved. Oftentimes, these tasks were also geared specifically to the children’s individualized needs, in order to prevent disruptions in daily functioning. The need for resources and services to aid mothers in caring for children with autism has been previously demonstrated (Bromley et al., 2004), as well as the need for therapy to improve the children’s functioning (Ben-Itzhak & Zachor, 2007), and the awareness of these needs remains an issue among the mothers. There was a resounding need for outside assistance in caregiving and the availability of individuals adequately and specifically trained to aid in the care of a child with autism. Caregivers either felt that this was something difficult to come by, cited it as very costly, or occasionally allowed the responsibility to fall on siblings. Many also sought therapy to increase the children’s functioning but described it as extremely expensive, while others simply could not access therapy for their children because of the associated financial costs. The availability of affordable assistance in caregiving, along with affordable therapy would potentially improve the overall health statuses and financial situations of these women. This could also be of benefit for the siblings of children with autism by removing barriers they may have experienced, for instance, due to lack of finances and opportunities.

Jarbrink et. al (2003) found that raising a child with autism can greatly affect a family’s financial situation through costs of informal care, service usage and out of pocket expenses, which was echoed by the finding that financial effects were a primary

cost for participants in this study. The costs of therapies and products that would aid in the children's functioning and behaviour, and for some, damages to the home environment presented costs for the caregivers that would otherwise not have been of concern. Had their situations been different, many felt that the money would have been spent elsewhere, such as vacations, improvements to the home, or opportunities for siblings. However, some also felt that seeing the benefits for their children's abilities coming out of the use of their finances was positive. Participants also did feel that the availability of assistive funding was a benefit, however it was still not enough to alleviate financial strains they were experiencing. Lengthy wait lists and low levels of funding had put some individuals in precarious financial situations, which calls attention to the need for more readily available government funding. Individuals caring for children with autism also need to be made aware of what funding options are available to them at the onset of the children's diagnostic process, rather than being left to discover such sources on their own. Such measures may help relieve the financial strains associated with caring for a child with autism, thereby more positively affecting the experiences of the female caregivers.

Caregivers of children with autism have been found to experience negative effects to their social lives, usually through decreased social circles (Gray, 1994), stigma (Gray, 1993; Hastings et al., 2005) and lack of time or motivation for socializing (Gray, 1994, Duarte et al., 2005). In this study, costs to the social lives of these women, in the form of decreased social opportunities, were also found to potentially arise due to the children's level of functioning and behaviour, or in some cases, out of difficulty finding care for the child. In spite of these costs, benefits arose where friendships were strengthened and new

friendships were born. Although many participants did not access support groups, they viewed social interactions with other families of children with autism as a positive social experience. It seemed as though participants sought social support in a less formalized manner, striving to further develop preexisting friendships or spontaneously initiating new friendships, rather than seeking structured social support. Service providers for families of children with autism may consider this in conjunction with support groups, or even when social event planning for families of children with autism, where opportunities might be provided for less formal gatherings rather than support group settings.

Stresses associated with caring for children with autism created a great deal of identified mental strain for the primary caregivers, which for many, seemed to manifest themselves into physical health costs, particularly weight gain. Allik et al. (2006) reported decreased scores on measures of health-related quality of life compared to controls, and found that these were related to conduct problems in the child with HFA/AS. They did not find a statistically significant difference between mothers of children with HFA/AS and controls on measures of mental health; however, it was acknowledged that this was unexpected and likely due to low statistical power. Furthermore, no statistically significant health-related effects were found for fathers of children with HFA/AS (Allik et al., 2006). In the present study, however, many participants believed that their spouses had experienced health effects in some way as well. Even though for some participants, no benefits to health arose, others then saw the negative health costs experienced as motivation to renew their focus on health. Some even inherently benefited from focusing on their children's health, whereby they were able to apply health strategies to themselves. Service providers may be mindful of

providing information to caregivers not only on strategies for maintaining the child's health status, but their own as well, in order to ensure that female primary caregivers of children with autism experience minimal health costs. In this way, improved health may mean that mothers will be better equipped to care for the needs of their children, thereby leading to more positive outcomes for their children in turn.

Participants reported effects for all members of the family in some way, such as through marital stresses or challenges, as well as strains presented to the siblings of children with autism. Higgins et al. (2005) also found effects to families of children with autism, and indicated that scores of family adaptability and family cohesion were much lower than expected. Those women also rated their marital satisfaction much lower than women with TD children (Higgins et al., 2005), which was echoed somewhat by women in this study, who did report that there were strains on their marriages. Some participants described strains directly related to their children's autism, such as perceived blame, decreased communication and generalized stress. Many also stated that numerous marital tensions were not necessarily due to the experience of raising a child with autism, as strains could be expected in any marriage. Strains were also presented in the family for the siblings of children with autism, where siblings were described as taking on added responsibilities or had experienced lost opportunities in some cases. For most of the siblings, aside from one description, this seemingly did not result in resentment of the brother or sister with autism. Despite the strains to the families brought about by raising a child with autism, benefits arose, where the primary caregivers felt that if anything, they had been brought closer together with their spouses by working towards a common goal, and as a family unit by focusing on family life. Sen and Yurtsever (2007) had

similar findings, where divorce rates were found to be lower than expected due to a supposed culturally implicated desire to protect family unity. In these families, a positive outlook and focus on family unity allowed them to reap benefits from the experience. The family units were evidently affected by raising a child with autism, the costs and benefits of which went on to shape the women's lived experiences.

Employment was another issue discussed at length with most participants, and has been found in the past to be greatly influenced by raising a child with autism (Gray, 2003; Jarbrink et al., 2003). This was found to be the case in the present study as well, as both the female primary caregivers and, to a lesser extent, their spouses had their employment affected in some way. The mothers reported that employment was typically given up, or for those who were employed as well as for many spouses, had become more difficult to maintain. In light of these costs, participants felt that some benefits to employment had arisen, where some had explored alternative options with employment, and for others, felt that there was more incentive to be successful in their careers, particularly for the husbands of participants. As autism awareness in the general public increases, employers ideally should be aware of the special requirements of families with children with autism or any other condition, especially since many benefits were experienced by participants and their spouses when employers were understanding of their situations.

Caregivers of children with autism undeniably experience negative consequences to their regular activities and involvements, typically arising from difficulties with the children's functioning and behaviour (see, for example, Gray, 1993; Higgins et al., 2005). This was also found to be the case among this set of participants, where effects to their

lifestyles became apparent through regular activities and involvements, such as decreased vacations, leisure time and difficulties accomplishing small tasks. Such difficulties arose, for instance, because of the financial implications of required therapies, or because of the lost time and challenges presented by the children's behaviours when taking part in outings or errands. However, these difficulties were generally accepted, and benefits were seen as arising in other aspects of their involvements. Participants benefited from getting involved in advocacy or taking part in autism-related activities, which many stated they would otherwise not have done. The learning that occurred through these involvements was seen as invaluable, and participants felt that they had become better people overall for having been involved in these experiences. This process of personal growth was unmistakably an integral part of the rewards described by the women as a result of caring for a child with autism.

There was an innate interplay between the children's functioning and behaviours and the costs and benefits for the caregiver, which each affected the lived experiences of female primary caregivers of children with autism in turn. The children's functioning and behaviour affected the caregivers' experiences because of the additional roles and tasks they took on to handle the caregiving of the children. The children's functioning and behaviour then affected the costs and benefits experienced by caregivers because the nature of the children's functioning could affect the monetary requirements, stresses placed on the parent, parent employment, family functioning and activities the caregivers were involved in as a result of their children's needs. The ways these costs and benefits presented themselves to families and the manner in which measures were taken to handle them would then mutually affect the children's functioning and behaviours.

All participants stated that they had experienced benefits in some form, as revealed by the examples above. Such benefits were often stated in such a way that would counteract costs previously discussed. This indicates that many participants likely were partaking in a process of positive reframing, which allowed them to view their experiences in an overall favourable light. Hastings et al. (2005) found that caregivers of children with autism may engage in positive reframing in some way, which was associated with overall positive coping. This process would involve mentally restructuring events in order to make them seem more reasonable and manageable (Hastings & Johnson, 2001). Positive reframing has also been suggested to be useful in decreasing levels of negative mental effects, such as depression (Dunn et al., 2001). It is surmised that the use of positive reframing and the overall favourable outlook maintained by participants also showed resilience, which was important in all aspects of their experiences.

As a whole, it appears as though the female primary caregiver of a child with autism naturally undergoes a discovery process and learning experience by which costs and benefits interplay with the child's functioning and behaviour to contribute to the overall lived experience. Providing these individuals with tools and information early on in their experiences can help prepare them to deal with the costs and therefore reap the potential benefits. This is accomplished best, once again, through early diagnosis and intervention, which not only benefits the child but can benefit the lived experiences of the female primary caregivers as well.

Limitations

Although measures were taken to ensure quality data, some limitations exist. The sample obtained was restricted to married female primary caregivers of children with autism, and so very little is known about the perspectives of unmarried women who are acting as the primary caregiver for a child with autism, and how these may differ from the women recruited. Similarly, little is known about how males in a primary caregiver role for a child with autism view their experiences. Additionally, by providing these women with a voice, costs and benefits to other family members were told from the women's perspectives, so it remains unknown whether these individuals would have related their own effects and experiences differently. Participants were also asked to recall events that had occurred some time in the past. As a result, retrospection may have affected the way in which these events were recollected and thus recounted, potentially influencing the accuracy of the data collected.

The aim of this qualitative study is not to obtain generalizable findings, however one must still consider that all participants were recruited from some form of autism support services. It is thus expected that these women were interested in autism and in sharing their experiences with autism, as well as active in seeking assistance in providing the best possible care for their children. It is unknown if this would be the case for women who have not accessed such services. Furthermore, self-selection of participants may be an issue. Women who responded to recruitment communications were obviously willing to share their experiences, but there is no information from women who also received recruitment communications but did not have the time or could not commit to the study for whatever reason. It is not known whether these women are experiencing

more costs, more benefits, if they are not accessing services as their children's functioning levels differ in some way, and so on; as such their perspectives remain unknown.

Future Directions

This was the first study to comprehensively examine the benefits of acting as a primary caregiver for a child with autism in addition to exploring the costs. It may be of use to further examine benefits of the experiences without directly contrasting them to similar costs, in order to gain more detailed information on benefits alone. The idea of the use of positive reframing among primary caregivers of children with autism would also be valuable to pursue. It may be worthwhile to determine if this is indeed a useful strategy for these individuals and if so, how to best implement it. Additionally, this study was completed from the perspective of married female primary caregivers only. It may be useful to obtain the information from women in other situations, as well as obtaining a "family unit" perspective which would include information from other family members pertaining to their own experiences and their perceptions of their families' experiences. In this way, a more complete picture of the costs and benefits of the experiences of family life with a child with autism may be obtained.

It may also be worthwhile to involve service providers in the process and attain their perspectives of the impact the functioning and behaviour of a child with autism may have on the experiences of female primary caregivers and their families. It is suggested that this be accomplished through both individual interviews and through focus groups involving the caregivers as well, in order to gain independent perspectives as well as details from group interactions. Involving service providers alongside caregivers in data

collection through focus group interviews could introduce viewpoints not yet explored. Not only would the views of service providers come to light, but through focus group interactions with caregivers, they would then be made increasingly aware of services and resources that are perceived to be of most benefit to families of children with autism. This information would therefore aid them in being more mindful of where to focus their attentions when working with children with autism and their families.

Conclusion

The participants were an inspirational group of women who had been placed in a challenging, yet by all accounts, rewarding situation. Despite the demands placed on them, they managed to view their roles as caregivers sensibly and positively, and maintained an enthusiastic attitude toward their experiences. This may have been a coping mechanism in itself, where the participants may have been taking part in a process of positive reframing in order to alleviate caregiving stress associated with costs experienced (Hastings et. al, 2005). Regardless, examining the benefits of their experiences was highly worthwhile, as it shed light on an unconventional aspect of the effects of raising a child with autism. This allowed for the realization that although the children's functioning and behaviour may present costs to the experience, costs are not predominant. Benefits do arise and go on to interact with costs as well as the children's functioning and behaviour, which mutually interact with the caregivers' experiences as a whole. Overall, the results from this study provide valuable information concerning the experiences of married female primary caregivers of children with autism. This may begin to reveal how to best support female caregivers, their children with autism and their

families in their endeavours, so that they may realize benefits in their experiences to an even greater extent and consequently, provide the best possible care to their children.

CHAPTER 3

STUDY 2

An Examination of Motor Control Variations in Children with High Functioning Autism and Asperger Syndrome

Abstract

Motor control deficits have been noted in children with high functioning autism and Asperger syndrome (HFA/AS), but the extent to which these afflictions affect the children's handedness, eyedness, and footedness must be delineated. A total of 12 typically developing (TD) children and 12 children with high functioning autism or Asperger Syndrome, ranging in age from 6-9 years, were recruited. All children recruited were free from cerebral palsy, congenital anomalies of the central nervous system, schizophrenia, focal epilepsy, tuberous sclerosis and neurofibromatosis. Motor control skills of the children were assessed through a variety of handedness, eyedness and footedness tasks in order to determine where impairments lie and the nature of such impairments, particularly in terms of fine-motor abilities, dominance and motor planning. Participants with HFA/AS were found to have some fine-motor impairment, as evidenced in decreased performance ability. Overall, greater inconsistencies in dominance arose in children with HFA/AS, through decreased lateralization and disparities in measures of preference. Finally, children with HFA/AS displayed similar motor planning ability in comparison to their TD peers. Results will have broader implications for understanding of motor impairments of children with HFA/AS as determined by comparing performance on handedness, footedness and eyedness tasks, as well as for the understanding of the design of interventions to account for these deficits.

Introduction

Autism Spectrum Disorders and Motor Control

Motor deficits in children with autism spectrum disorders (ASD) have been well documented (e.g. Jansiewicz et al., 2006). However, the extent of impairments in many areas has not been determined. Researchers are becoming increasingly interested in motor development differences in children with autism spectrum disorders (ASD), especially as motor deficits have potential implications for diagnosis and treatment of the disorder (Provost, Lopez & Heimerl, 2007). Some motor difficulty and delay undoubtedly exists in individuals with ASD, but the extent of the impairments in coordination, gait and motor preparation that are reported vary (see, for example Jansiewicz et al., 2006; Manjiviona & Prior, 1995; Miyahara et al., 1997; Provost et al., 2007; Schmitz, Martineau, Bathelemy, & Assaiante, 2003). Delays and difficulties with motor skills are of concern because of the potential to lead to difficulties in navigating through the environment, as well as difficulties with fine motor skills and social play (Jansiewicz et al., 2006), which as a whole may affect outcomes for children with HFA/AS. For instance, such impairments can lead to problems with social skills for children with the condition, arising from decreased peer interaction (Provost et al., 2007). For this reason, it is important to consider the overall delays present, how these may be affected by factors such as IQ and specific problems with handedness, footedness and eyedness.

What is known about potential differences in motor abilities between children with HFA/AS and TD children?

Overall Motor Impairments

Much work has focused on assessing motor delay in young children with autism in comparison to age-matched children who are TD, and it is clear that some motor delay exists when compared to a TD sample (e.g. Jansiewicz et al., 2006; Schmitz et al., 2003). For example, Jansiewicz et al. (2006) reported motor impairments ($p < .05$) in individuals with AS and HFA ($N = 40$) when compared to controls ($N = 55$) on measures of gait, balance, speed of timed movements and overflow, which Hoy, Fitzgerald, Bradshaw, Armatas & Georgiou-Karistianis (2004) describe as involuntary movements that accompany voluntary movements. Such impairments are suggestive of developmental problems in neurological areas responsible for motor execution, or potentially deficits in motor learning abilities rather than execution (Jansiewicz et al., 2006).

In a study conducted by Provost et al. (2007), children with ASD ($N = 19$) were compared to children without ASD but with some other developmental disability and motor delay ($N = 19$), as well as children with some other developmental disability but no motor delay ($N = 18$). All children in the sample with ASD showed motor delay to some extent, in one or both areas of fine and/or gross motor skills. Observed delays did not differ significantly from the age/gender/mental development-matched children with developmental disabilities and motor delay, but did differ significantly from children with developmental disabilities but no motor delay ($p < .001$). It was thus implied that motor delays of children with ASD may not be distinctive from children with other motor impairments but no ASD. Furthermore, patterns of skill development may vary amongst

the groups experiencing motor difficulty, and even possibly within the group with ASD itself. Motor skill development was considered to be of importance for these children because of its potential to affect the successfulness of peer interactions (Provost et al., 2007).

Relationships between motor impairment and the severity of the disorder have also been compared in children with AS in particular. In one study, varied research results were addressed, which had claimed anywhere from 50-100% of children with AS experienced some motor impairment, but did not necessarily account for differences in AS severity (Hilton et al., 2007). Upon analysis of overall motor impairment, manual dexterity impairment, ball skills impairment and balance (static and dynamic) impairment in children with AS (N = 51) compared to TD controls (N = 56), it was found that 65% had a definite impairment, 25% had borderline impairment and 10% had no impairment. Impairments were most likely to present in ball skills and manual dexterity, while they were least likely in balance skills. Researchers then employed the Social Responsiveness Scale (SRS) to measure the child's ability to participate appropriately in reciprocal social interactions, and the Movement Assessment Battery for Children (MABC) was used to determine motor skill problems. A significant correlation was found between the MABC scores and the SRS ($r = -.856, p < .01$), which showed that increased motor impairments are correlated with decreased social reciprocity. The relationship between the MABC and each of the SRS subscales was: social awareness ($r = -.745, p < .01$), social cognition ($r = -.770, p < .01$), social communication ($r = -.764, p < .01$), social motivation ($r = -.735, p < .01$), and autistic mannerisms ($r = -.788, p < .01$). All TD controls were classified as having no impairment. Authors stated that the fact that even small variations in motor

impairments existed for small variations in AS severity might be important, and should be looked into further as it may indicate that the overall severity of the condition can have bearing on the severity of motor impairment experienced (Hilton et al., 2007).

Motor abilities in children with AS have also been compared to those of children with other disabilities. Miyahara et al. (1997) found that there was a significant difference between children with AS ($N = 26$) and those with learning disabilities (LD) ($N = 16$) in manual dexterity ($p = .04$), and a difference that was approaching significance for ball skills ($p = .09$). Manual dexterity skills involved two manipulative tasks and one drawing or cutting task, while the ball skills involved one throwing and one catching task. Authors speculated that observed results were because children with AS may seek out individualized tasks, and as such may develop manual dexterity through activities like video games, while they may not develop ball skills due to a lack of desire to play with a partner (Miyahara et al., 1997). Contrarily, Parlow and Robertson (2008) found that children with ASD generally would not even attempt tasks on the WatHand Cabinet Test requiring finer motor control, such as opening a small padlock, aside from participants who exhibited a right-hand preference.

Motor Planning

Motor planning ability in children with an autism spectrum disorder is also important to consider because of the implications it may have for an individual's ability to limit clumsiness in movement. Dziuk et al. (2007) reported that dyspraxia, the impaired performance of skilled motor gestures, was been found to be of concern in children with ASD and AS when compared to TD controls. However, this was not attributed to lack of basic motor skill; rather, the deficits observed were considered to be

a result of the co-existing characteristics of autism, such as the impaired social abilities of the participants. It was suggested that the lack of motor planning ability could mutually contribute to deficits in social and communication abilities because of an impaired performance of skilled gestures, which may be of use in social interactions (Dziuk et. al, 2007). Parlow & Robertson (2008) examined motor planning abilities of children with ASD through the WatHand Cabinet Test, particularly the open door-remove object task. This task inherently includes a planning component, and a decreased right-hand preference was found in the children with ASD when performing the task. Although clumsiness in movements is apparent, it has been suggested that motor impairments observed amongst individuals with HFA and AS may be due to a qualitative as opposed to quantitative clumsiness that is related more so to social awkwardness than true motor deficits (Ghaziuddin, Butler, Tsai & Ghaziuddin, 1994).

IQ & Motor Impairment

Research has also been conducted examining the relationship between intelligence quotient (IQ), a standardized measure of intelligence, and motor skills in children with HFA or AS. Some studies have noted increased motor difficulties with decreased IQ (see, for example Manjiviona and Prior, 1995; Jansiewicz et al., 2006), while others have found no relationship (Miyahara et al., 1997). Manjivionia and Prior (1995) examined motor problems in individuals with AS (N = 12) and HFA (N = 9). Of the children with AS, 50% experienced some motor problems, while 66.7% of the HFA children experienced motor problems. There was also a significant correlation found between full-scale IQ measures (as measured using the Weschler Intelligence Scale for Children – Revised) and motor difficulty (as measured using the Test of Motor Impairment –

Henderson Revision), where individuals with lower IQ were more likely to experience motor problems ($r = -.53$, $p = .013$).

In the Miyahara et al. (1997) study comparing children with AS to children with LDs, no significant correlation was found between the total IQ scores and the Movement Assessment Battery for Children scores for both groups. Although there was no relationship, a high incidence of motor difficulties in both individuals with AS (85%) and individuals with an LD (88%) was apparent. Additionally, a comparison of a group of individuals with AS ($n = 10$) and a group with HFA ($n = 8$) with similar IQs revealed that there were no significant differences between the two groups on tests of clumsiness, comprised of gross motor, fine motor, upper limb coordination and battery composite scores (Ghaziuddin et al., 1994).

It is important to keep in mind, however, that children with autism as a whole have been found to have a wide range of IQ scores, ranging from severely impaired to very high intelligence. There is no IQ level that should call the diagnosis of autism into question (Siegel, Minshew & Goldstein, 1996). IQ in individuals with autism may be transient, however, as in a cross-sectional study conducted comparing a low-IQ (< 80) to high-IQ (> 80) group of children with autism, IQ appeared to increase with age in both groups, typically stabilizing around the age of 8. Furthermore, any apparent gaps between verbal and non-verbal IQ closed by the age of 6 for the high-IQ group, and by the age of 9 for the low-IQ group (Mayes & Calhoun, 2003). This was also shown by Siegel and colleagues (1996), where both verbal (VIQ) and performance (PIQ) IQ were examined, and the expected $VIQ < PIQ$ pattern was not found. The lack of VIQ-PIQ differences was attributed to the high-functioning nature of their sample, where all

participants had an IQ of at least 70. Individuals with lower abilities and autism, amongst whom this may have been expected to occur, were thereby eliminated. A later study by Ghaziuddin and Mountain-Kimchi (2004) revealed that although individuals with AS in particular were expected to display a $PIQ < VIQ$ pattern, this was not always the case, or not significant where the pattern was displayed. Similar patterns are sometimes seen amongst individuals with HFA, and the two groups may not differ significantly from one another in IQ profiles.

What is known about children with HFA/AS in terms of lateralization and dominance as determined by handedness, footedness and eyedness?

Handedness

Handedness is the term used for the hand an individual prefers to use for daily unimanual tasks he or she may come across. It is a measure that can be reflected by two aspects, preference and performance. However, individuals may occasionally prefer to use a hand in which performance is not as adept, and the two measures will not be in agreement (Elliot & Roy, 1996). For instance, such situations may occur when performing skilled rather than less skilled tasks, where skilled tasks, requiring manipulation of an object are more likely to be performed with the preferred hand than less skilled tasks that may only require that an object be picked up (Steenhuis & Bryden, 1989).

Children with autism display a notable increase in left-handedness compared to TD children, often with an incidence of over 15% (Gillberg, 1983, Hauck & Dewey, 2001). Rates of left-handedness in individuals with autism are thus much higher than the expected 11% in the TD population (Elliot & Roy, 1996). Where there is a lack of hand

preference, the individual is described as having ambiguous or inconsistent handedness (Hauck & Dewey, 2001). Inconsistent handedness has also been defined as the tendency of some left-handers to choose the left hand for fine-motor activities and the right hand for more gross movements that require strength (Elliot & Roy, 1996). Approximately 40% of children with autism present with ambiguous or inconsistent handedness, however similar levels have been reported in other developmentally delayed populations (see, for example Dane & Balci, 2007; Hauck & Dewey, 2001). Moreover, in TD populations, inconsistent handedness is seen in young children but is expected to dissipate once they reach school age. At that point, only 4% of TD children are expected to continue to display ambiguous or inconsistent handedness (Hauck & Dewey, 2001). Leconte and Fagard (2006) in particular reported that a group of children with intellectual deficiency (ID) displayed an increased incidence of 'mixed handedness' over TD controls, however this difference did not reach significance.

In the Hauck and Dewey (2001) study comparing children with autism ($n = 20$) to children with other developmental delays ($n = 20$) and TD children ($n = 20$), no significant differences were found between gross and fine motor skill scores. It was found that children with autism who had developed a definite hand preference had significantly better performance on fine motor skills than those who had not developed hand preference ($t(18) = 2.11, p < .05$), and a similar trend toward significance was indicated for gross motor skills ($t(18) = 1.85, p = .08$). Findings for developmentally delayed and TD populations were not significant (Hauck & Dewey, 2001). The authors also examined whether ambiguous handedness was the result of poor motor skills, culminating in an inability to display distinct preference. This was disproven because

there were similar fine and gross motor skill levels amongst the groups that were developmentally delayed or groups with autism, but very different distributions of hand preference. It was stated that further research is required to determine whether earlier development of hand preference in these children could result in increased functioning in the future (Hauck & Dewey, 2001).

De Agostini and Dellatolas (2001) have suggested that discordance between hand, foot, and eye preference may be indicative of the presence of some developmental disorder. Their study of 1158 TD 3 to 6 year old children revealed that handedness was related to both foot and eye preference. However, consistency in hand and foot preference was increased in right-handers over left-handers. No such trends were evident in hand and eye preference, where the proportion of consistent preference was nearly identical among TD right- and left-handers (De Agostini & Dellatolas, 2001). Typically developing children may be expected to display more concordance between hand, eye and foot preference, as a study comparing 'clumsy' children to 'normally coordinated' children revealed that the controls displayed more congruency in hand-eye and hand-foot preference (Armitage & Larkin, 1993). As a whole, these findings lend naturally to the discussion of footedness and eyedness in turn.

Footedness

Footedness is another measure by which cerebral organization may be predicted. It has been suggested that footedness may in fact be a better predictor than handedness of cerebral organization, such as through measures of language or emotional lateralization (Elias & Bryden, 1998a; Elias & Bryden, 1998b). This is thought to be a result of fewer neural resources dedicated to lower limb control than upper limb control, as well as the

lack of bias introduced through a dextral environment, as is the case with handedness (Gabbard, 1993). As such, its examination is useful to aid in determining dominance (Elliot & Roy, 1996), as well as to draw direct comparisons to handedness and eyedness. Examining such aspects of individuals with HFA and AS is also of importance because of the clues footedness can provide about cerebral organization, considering that autism has been referred to as a cerebral lateralization abnormality (Dane & Balci, 2007). It has been suggested that for those who would naturally have been less likely to exhibit right-hand dominance, this difference may reveal itself more clearly with the feet, typically through mixed-sidedness. Accordingly, examining footedness patterns in children with HFA/AS can be of use, for as previously mentioned, prior work has suggested that these individuals may not display strong right-hand dominance.

Past research in footedness of TD children aged 3 to 11 years, however, indicates that they tend not to favour one foot over the other. Moreover, they do not increase in foot lateralization as they mature, as would be expected with handedness (Gabbard, 1993). Leconte and Fagard's study (2006) comparing children with intellectual deficiency (ID) to a TD group found that there were no significant differences between groups amongst measures of foot preference or frequencies of crossed hand-foot preference. There is no knowledge of any research regarding footedness in children with HFA or AS having been conducted to date. Determining if similar patterns in the footedness of children with HFA/AS compared to TD controls will provide further clues pertaining to their patterns of dominance.

Eyedness

Eyedness may also aid in predictions of cerebral organization or laterality, as previous work has indicated that eye dominance and hand preference may be related to one another. Leconte and Fagard (2006) found that children with ID had increased frequencies of left-eyedness than the TD controls, along with increased incidence of crossed hand-eye preferences. When Armitage and Larkin (1993) compared 'clumsy' to 'normally coordinated' children, it was found that there were no significant differences in the degree of eyedness between the groups. This was attributed to the fact that eyedness is a sensory index rather than a motor measure, hence clumsiness should not have an effect. Eyedness differences in children with differing developmental abilities are thus useful to examine because of the clues that can be provided pertaining to differences in patterns of dominance. These can then potentially lead to a greater understanding of the connections of cerebral organization to the outcomes of the disabilities experienced.

One recent study was the first to examine eyedness in children with autism ($n = 37$) compared to TD controls ($n = 20$) by noting which eye was used to look through a keyhole. Measures of eyedness were deemed to be useful to compare to handedness as additional predictors of lateral dominance. It was determined that rates of left eye dominance were much higher in the participants with autism than the TD population. Left eye preference was found in 83.7% of participants with autism vs. 30% of the TD participants ($p < .001$). Left-dominance was stated to be a potential contributor to autism and early language difficulties experienced by individuals with autism (Dane & Balci, 2007). No other studies to date have attempted to replicate these findings in individuals with autism.

Conclusion

Determining trends in motor control deficits is imperative as it can allow for more focused intervention strategies for children with HFA/AS, and can potentially alleviate problems associated with these deficits. Interventions such as applied behavioural analysis (ABA) have been found to be integral in skill development in children with ASD (Ben-Itzhak & Zachor, 2006), and focusing such strategies to these children's developmental abilities and skill level will allow for more favourable outcomes to be realized.

The purpose of this study was to further elucidate the differences between children with HFA or AS and the TD population with respect to motor ability variations, where TD children were considered to be those who are free of any condition that may affect their development. Specifically, differences between children with HFA/AS and TD children on measures of handedness, footedness and eyedness were investigated in order to examine fine-motor abilities, dominance as determined by preference and performance, and motor planning abilities in order to learn where potential impairments lie and the nature of such impairments.

Given previous research, it was hypothesized that there would be a difference on these measures between children with HFA/AS and TD controls. Children with HFA/AS were expected to display increased left-dominant tendencies in comparison to their TD peers, in addition to impaired fine motor abilities and motor planning abilities. Potential differences were examined through a number of tasks. Fine motor abilities, hand performance and laterality were observed through Grooved Pegboard tasks, along with the WatHand Box Test (WHBT), which specifically provided an adjunct measure of

laterality. The WHBT also provided a measure of motor planning through the Bimanual task component. Foot performance was considered by way of a foot tapping task, and overall hand, foot and eye dominance of participants was examined through a combination of the above tasks in addition to distinct eyedness and footedness tasks.

Methodology

Participants

Children with HFA or AS were recruited from a childhood disability support organization in Southern Ontario, of which they were discharged clients. A total of twelve children with HFA/AS were recruited, eleven of which had a diagnosis of HFA and one with a diagnosis of AS (6M, 6F, $X_{age} = 7.0$). Children with HFA/AS were age and dominance-matched to TD children recruited from an elementary school in Southern Ontario as part of an ongoing study being conducted by PB and ER (5M, 7F, $X_{age} = 7.0$). All participants except for one in each group were also gender-matched, and participants ranged in age from 6 to 9 years. All potential participants with HFA/AS were screened for cerebral palsy, congenital anomalies of the central nervous system, schizophrenia, focal epilepsy, tuberous sclerosis and neurofibromatosis by background questionnaire filled in by a parent (Appendix E). This was done in order to ensure no other underlying conditions would affect motor performance, as was suggested in Freitag, Kleser, Schneider and Gontard (2007). No participants were found to have such a co-existing condition. The Wilfrid Laurier University Research Ethics Board approved all recruitment and testing procedures, and informed consent was obtained from the parents or guardians of all participating children.

Procedure and Instruments

Testing of participants with HFA/AS was conducted at WLU and testing of TD controls was conducted at their school during class time, outside of the classroom. RM was involved in data collection with all participants. Parents of participants with HFA/AS were given the option to remain present for the duration of the study, and all chose to remain present for testing. Additionally, all participants were given the opportunity to remove any test or procedure and/or to stop testing at any time. These measures ensured participants remained comfortable and motivated with regards to the procedure and what was asked of them. All participants completed all tasks except for one participant in the HFA/AS group, who did not complete the second trial of any small Grooved Pegboard tasks, or the second trial of the Large Grooved Pegboard tasks performed with the non-dominant hand.

Of the following instruments listed, all tasks were administered to all participants except for the CARS and WASI, which were conducted only with participants with HFA/AS. All of the tasks were performed in randomized order with each participant.

Childhood Autism Rating Scale

The Childhood Autism Rating Scale is a quickly delivered test including scales of human relationships, imitation, affect, resistance to change, communication ability, and general impressions (Shopler et al., 1980). The CARS was administered to all participants with HFA/AS as a means of obtaining information regarding the severity of their condition and in order to be able to ensure comparisons could legitimately be made between participants with HFA/AS. RM administered this test, and was trained by PB.

Wechsler Abbreviated Scale of Intelligence (WASI)

An abbreviated form of the Wechsler Intelligence Scale (PsychCorp, 1999) was included as a tool for the determination of the IQ of participants with HFA/AS. The average score on this test for any age group is 100, with a standard deviation of 15. Since it was only necessary to ascertain that participants with HFA/AS had an IQ of 70 or above, Verbal and Performance IQ scores were not required. The WASI 2-Subscale was conducted, which provides an overall IQ score. The WASI 2-Subscale is comprised of a Vocabulary test, where participants orally define words, and a Matrix Reasoning test, where participants complete a series of pictures through pattern recognition. By ensuring that all participants with HFA/AS had an IQ of at least 70, it was determined that all participants could be considered high-functioning (Ghaziuddin & Mountain-Kimchi, 2004). In this way, participants with HFA/AS and control groups could be matched with one another for ease of comparison. All WASI tests were conducted by RM, who was trained by PB in properly administering the test.

Grooved Pegboard

The Grooved Pegboard consists of five rows of five keyhole shaped holes in various orientations. Both the large (Oud, Roy, & Bryden, in preparation) and small (Lafayette instruments #32025) Grooved Pegboards were used. The small pegboard has of a 10cm x 10cm metal surface, while the large pegboard has a 20cm x 20cm surface. The Grooved Pegboard involves the standardized place task, which allows for the examination of manipulative dexterity and requires considerable visual-motor coordination. The Grooved Pegboard also involves the remove task, which is used to assess motor speed as it does not require the dexterity and coordination necessitated by

the place task (Bryden & Roy, 2005). The Grooved Pegboard tasks provide a valuable measure of motor performance (Brown, Roy, Rohr, Snider & Bryden, 2004).

For both boards, participants completed the place and remove task. The place task involved placing the 25 pegs into the holes as quickly as possible; from left to right when using the right hand, and from right to left when using the left hand according to standardized instructions. Pegs were removed directly following the place task, and were removed one by one, using the same hand and in the same order in which they were placed (Bryden & Roy, 2005). Two timed trials were completed for each hand, and the starting hand was randomized.

WatHand Box Test

The WatHand Box Test (WHBT) is a performance-based measure of hand preference, and also allows for the elucidation of trends in hand preference with development (Bryden, Roy & Spence, 2007; Brown et al., 2004). Along with the Grooved Pegboard tasks, one measure of hand preference and one measure of hand performance would be obtained.

Measures of hand dominance and lateralization can be obtained from the tasks involved in this test. The WHBT consists of a cabinet containing a number of items, such as a small lock, a ball and a toy hammer (Bryden et al., 2007). The cabinet measures 15.5”X12”X24” and is divided into two compartments, one on top of the other. The top compartment is covered by a swinging door, which is opened by a handle centered on the bottom edge. A latch and padlock are found along the top edge of this door. The bottom compartment is not covered. The back of the cabinet has a Velcro bulls-eye target and ball attached near the top. The left side of the cabinet has two cup-hooks near the top and

three inches apart vertically, while the right side of the cabinet has a screw centered near the top.

Participants were instructed to open the cabinet door and perform a number of tasks involving the items within the cabinet and items in the compartment below. The “open door” task was performed a total of four times. The other tasks performed included placing rings on a hook, tossing a ball at a target, opening a lock with a key, using a screwdriver, pushing buttons on a gadget and using a toy hammer. Finally, two bimanual tasks were performed. First, participants were instructed to open the cabinet door to retrieve a candy dispenser, and then instructed to open the cabinet door to retrieve a crayon and colour on a piece of paper. The hand used to open the cabinet door and the hand used to perform the task were both recorded and compared to the hand that performed the initial cabinet lift as well as the dominant hand. Participants were expected to plan the movement so that the non-dominant hand would be used to open the cabinet, and the dominant hand would be used to perform the task.

The number of times each hand was used to complete each task was recorded, and assigned a score as indicated in Bryden, Roy and Spence (2007). First, a Bimanual score was calculated to compare the hand used for the initial cabinet lift to the hand used to open the cabinet door when retrieving an object inside the cabinet, thus providing information on motor planning. Secondly, a Consistency score provided information on the number of times the right hand was used to open the cabinet door, allowing for the examination of the consistency of the participant’s hand preference. Next, the Skilled score provided information on the hand preference for tasks requiring manual dexterity. Finally, the Total score was calculated using a laterality quotient, allowing for the

determination of which hand was used to complete more tasks. For further information on the calculation of WHBT scores, see Bryden, Roy and Spence (2007).

Footedness Tasks

Footedness measures involved hopping on one foot, kicking a ball, squashing an imaginary bug, and tracing imaginary letters. Observational methods of preference such as this can provide more information than questionnaires when working with children, where comprehension may become an issue. The foot used for the task was recorded, and each task was completed three times while standing and three times while seated, in order to observe preference with and without the requirement of a stabilizing foot. The hopping task was only completed while standing. A preference measure was obtained across all three trials for each task, which was indicative of the degree of preference for the tasks.

Foot Tapping

The foot tapping procedure was used as an indicator of foot performance. Along with the footedness tasks, one measure of foot preference and one measure of foot performance was thereby available. A foot pedal resembling a car accelerator, connected to a computer running LabView software. Participants were instructed to begin with a particular foot, and the first tap initiated a 10 second trial. They were instructed to tap as quickly as possible with their heel resting at the base of the pedal. Peters and Durning (1979) used a similar procedure. A total of 2 trials were conducted randomly with each foot. The computer software recorded the number of foot taps in every 10-second frame, as well as the mean and standard deviation for the tap duration (the amount of time the foot pedal was pressed with each tap), lift duration (the amount of time the foot pedal was

released with each tap) and the interval duration (the sum of the tap duration and lift duration) for each 10-second trial.

Eyedness Tasks

Two sets of eyedness tasks were completed where participants were asked to look, with one eye, through a tube with coloured tissue paper on one end and tell the experimenter what colour they saw. The first task used a tube mounted on the table, held in position at near-eye level, and was completed three times. The next task involved a smaller tube that the participants were asked to bring up to their eye. The eye that was used was recorded, as well as the hand used, to account for the motor component of the task. This task was also completed three times. A preference measure was obtained across all three trials for both the tube-lift and hands-free task, which was indicative of the degree of eye preference for the tasks in a similar manner to the footedness tasks.

Results

How do children with HFA/AS compare to TD children on a task of motor precision and motor speed?

In order to answer the first question, the data from the two Grooved Pegboards was examined using a mixed-models repeated measures ANOVA between the two groups (TD controls and children with HFA/AS) and within hands (dominant and non-dominant). Initially, the mean performance times were compared between the two groups (mean performance times can be found in Table 3.1 below). Here, a significant main effect of group ($F(1, 22) = 9.51, p < .01$) was apparent, where participants with HFA/AS ($M = 71.19s, SD = 48.03$) performed all Grooved Pegboard tasks significantly more slowly than TD controls ($M = 52.85s, SD = 31.19$) (Figure 3.1). For all

Table 3.1
Mean Grooved Pegboard Performance Times

Size	Hand	Task	HFA/AS	Control
			Mean (s) (Standard Deviation)	Mean (s) (Standard Deviation)
Small Grooved Pegboard	Dominant	Place T1	124.95 (43.52)	77.1 (18.80)
		Place T2	99.33 (26.76)	72.71 (15.67)
		Replace T1	33.74 (8.98)	24.51 (7.92)
		Replace T2	27.93 (4.64)	21.88 (5.83)
	Non-Dominant	Place T1	135.03 (55.44)	95.76 (27.05)
		Place T2	125.92 (63.81)	91.02 (27.26)
		Replace T1	34.38 (9.25)	26.7 (5.53)
		Replace T2	31.47 (7.95)	24.21 (4.71)
Large Grooved Pegboard	Dominant	Place T1	94.22 (23.00)	72.76 (19.27)
		Place T2	94.3 (29.86)	64.43 (11.28)
		Replace T1	36.36 (11.00)	29.16 (7.43)
		Replace T2	30.58 (6.96)	24.81 (5.36)
	Non-Dominant	Place T1	109.81 (27.10)	82.22 (19.01)
		Place T2	90.27 (15.68)	80.1 (18.45)
		Replace T1	39.24 (11.24)	31.57 (8.82)
		Replace T2	33.50 (10.57)	26.67 (5.15)

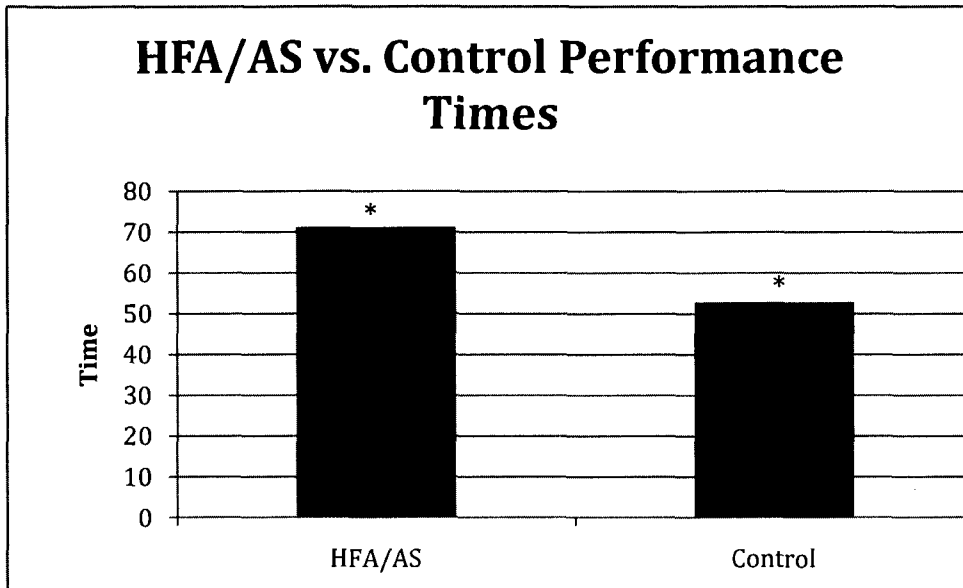


Figure 3.1. Grooved pegboard performance times.

participants, a significant main effect of hand was revealed ($F(1,22) = 14.49, p < .01$), where the dominant hand ($M = 57.99s, SD = 39.94$) performed all tasks in less time than the non-dominant hand ($M = 66.05s, SD = 45.29$). In addition, significant main effects of task ($F(1, 22) = 295.92, p < .001$) and pegboard ($F(1, 22) = 8.05, p < .05$) were revealed, where the place task ($M = 94.25s, SD = 35.78$) consistently took more time than the remove task ($M = 29.79s, SD = 8.94$), and the large Grooved Pegboard ($M = 58.75s, SD = 32.98$) required less time to complete than the small Grooved Pegboard ($M = 65.29s, SD = 48.36$). There was also a significant interaction effect between pegboard and task ($F(1, 22) = 2.23, p < .001$). As previously described, the remove task was performed in less time than the place task, which was the case with both pegboards. However, the place task was performed more quickly with the large pegboard ($M = 86.01s, SD = 13.25$) than the small pegboard ($M = 102.48s, SD = 22.08$) ($p < .01$), while the remove task was performed more quickly with the small pegboard ($M = 28.10s, SD = 4.23$) than the large pegboard ($M = 31.49s, SD = 5.34$).

The logarithms of the performance times were then taken for analysis in order to account for the heterogeneity of variance between the groups, and the two self-declared left handed participants were removed from analysis. Furthermore, the two pegboards were separated to avoid disparities in performance times presented by the varying difficulties of the two boards. No significant interactions were apparent for the small Grooved Pegboard in this analysis. However, a number of significant interaction effects emerged with the large Grooved Pegboard performance times. A significant interaction effect between trial and task ($F(1,20) = 8.18, p < .05$) was apparent, where the place task

took consistently more time than the remove task ($p < .001$) as expected, and performance times were higher overall on the first trial than the second trial ($p < .01$).

An interaction effect was present which varied across levels of task, creating a four-way interaction between groups, trials, hands and tasks ($F(1,20) = 5.30, p < .05$). Participants with HFA/AS had significantly higher log performance times than TD control participants when completing the first trial of the place task with the dominant hand ($p < .05$), but no such differences were apparent on the remove task ($p > .05$). The second trial performance times were significantly different between groups for both the place ($p < .01$) and remove tasks ($p < .05$) with the dominant hand, where TD participants saw greater decreases in log performance times ($M = -.05, p < .01$) from the first trial than did participants with HFA/AS ($M = -.04, p < .05$), although both decreases were significant. When considering the non-dominant hand, participants with HFA/AS once again showed significantly higher log performance times than TD control participants for the first trial of the place task ($p < .01$) (Figure 3.2), with no such differences between participants for the remove task ($p > .05$) (Figure 3.3). Unlike the dominant hand, no differences between groups were apparent on the second trial of either the place or remove tasks with the non-dominant hand ($p > .05$).

A number of interactions involving groups were also evident. A three-way interaction between trials, groups and hands ($F(1,20) = 5.38, p < .05$) was present. When considering the dominant hand, participants with HFA/AS displayed higher log performance times than TD children on both trial 1 ($p < .05$) and trial 2 ($p < .01$). With the non-dominant hand, participants with HFA/AS showed significantly higher performance

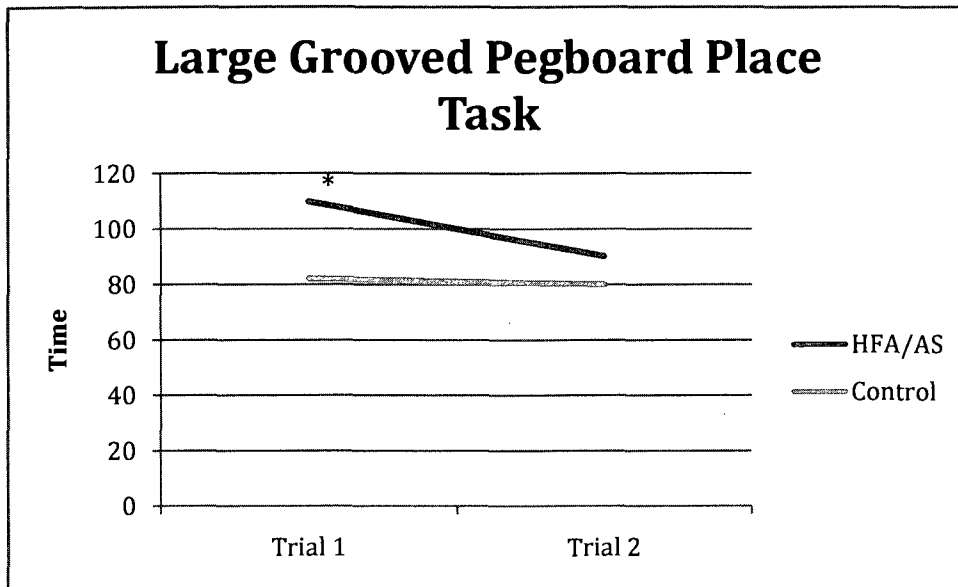


Figure 3.2. Large grooved pegboard place task, non-dominant hand

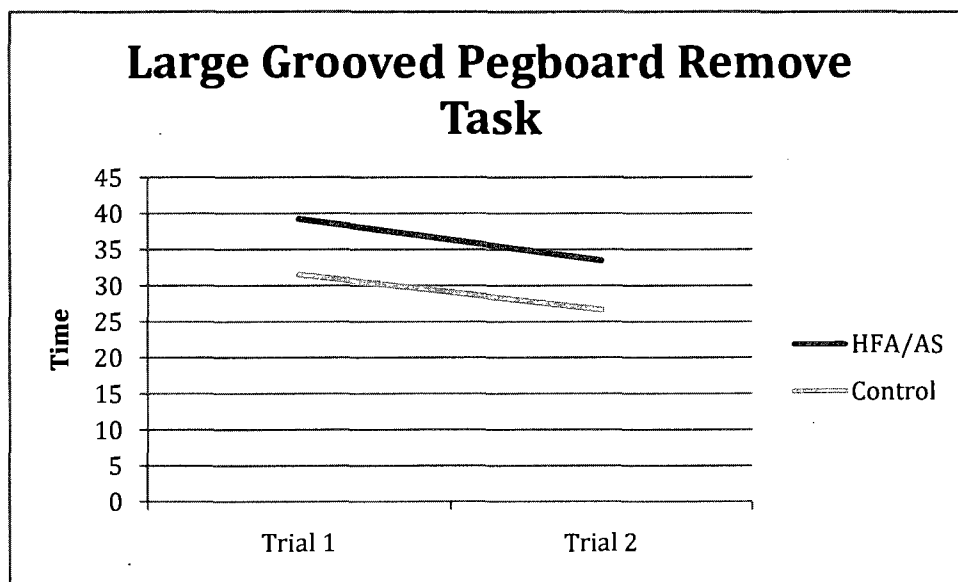


Figure 3.3. Large grooved pegboard remove task, non-dominant hand

times than TD children on trial 1 ($p < .05$) only, while differences only approached significance for trial 2 ($p = .067$).

This analysis also revealed a main effect of group on overall log performance time, where participants with HFA/AS had significantly higher log performance times than TD participants on both the small Grooved Pegboard ($F(1,20) = 12.07, p < .01$) and the large Grooved Pegboard ($F(1,20) = 7.00, p < .05$). A significant main effect of hand was also apparent, where the dominant hand performed the tasks in less time than the non-dominant hand for both the small Grooved Pegboard ($F(1,20) = 15.37, p < .01$) and the large Grooved Pegboard ($F(1,20) = 16.15, p < .01$). There was a significant main effect of trials, where the second trial was performed consistently in less time than the first trial for both the small Grooved Pegboard ($F(1,20) = 12.62, p < .01$) and the large Grooved Pegboard ($F(1, 20) = 19.86, p < .001$). A significant main effect of task also arose, where the place task consistently took more time than the remove task on both the small Grooved Pegboard ($F(1, 20) = 1477.81, p < .001$) and the large Grooved Pegboard ($F(1, 20) = 2338.00, p < .001$).

How do children with HFA/AS compare to TD children on measures of lateralization through performance and preference tasks?

First, laterality scores were calculated in order to determine strength of lateralization when performing the pegboard tasks, as performance times alone would not reveal such differences, if any. These scores were calculated by subtracting the performance time of the dominant hand from the non-dominant hand and dividing the result by the sum of the performance times ($ND-D/ND+D$). Only data for right-handed participants was analyzed in order to remove discrepancies in laterality scores that would

be presented by the small numbers of left-handed participants (Table 3.2). The logarithms of the performance times were then obtained, followed by the calculation of laterality scores in order to account for the degree of inconsistency of variability between groups. Additionally, the two pegboards were considered separately in order to avoid inherent discrepancies in performance times. It was found that there were no significant main effects in the log laterality scores between groups ($p > .05$), tasks ($p > .05$) or trials ($p > .05$) for either the large or small Grooved Pegboard.

There were also no significant interaction effects ($p > .05$) when considering the small Grooved Pegboard. In the analysis of the large Grooved Pegboard, a significant interaction of trial and group was found ($F(1, 20) = 4.33, p = .05$). There were no significant differences between participant groups on either trial ($p > .05$), however, participants with HFA/AS showed slightly higher log laterality scores on the first trial of the large Grooved Pegboard than TD participants, while this trend reversed in the second trial, with TD participants showing higher log laterality scores than participants with HFA/AS. Furthermore, participants with HFA/AS showed decrease in their log laterality scores from the first trial to the second, although this difference only approached significance ($p = .06$). Although non-significant, TD participants showed the opposite trend, where log laterality scores increased from the first trial to the second ($p > .05$). There was also an interaction found approaching significance between trial, task and group ($F(1, 20) = 3.809, p = .065$). Participants with HFA/AS showed a significant decrease in log laterality scores from the first trial of the place task to the second trial ($p < .05$), while no such difference was seen with the remove task. TD participants did not display any such differences in log laterality scores between trials for either task. No

Table 3.2
Mean Grooved Pegboard Laterality Scores

Size	Task	HFA/AS	Control
		Mean (Standard Deviation)	Mean (Standard Deviation)
Small Grooved Pegboard	Place T1	0.045 (0.15)	0.088 (0.062)
	Place T2	0.095 (0.132)	0.095 (0.152)
	Replace T1	0.022 (0.057)	0.054 (0.068)
	Replace T2	0.041 (0.118)	0.054 (0.077)
Large Grooved Pegboard	Place T1	0.086 (0.042)	0.066 (0.066)
	Place T2	-0.004 (0.126)	0.107 (0.114)
	Replace T1	0.037 (0.079)	0.034 (0.042)
	Replace T2	0.029 (0.095)	0.032 (0.063)

significant differences were seen in log laterality scores between the place and remove task on either the first or second trial for both groups ($p > .05$). Furthermore, participants with HFA/AS and TD controls did not show significant differences in laterality scores from each other except for the second trial of the large Grooved Pegboard place task, where participants with HFA/AS displayed significantly lower log laterality scores than did their peers ($p < .05$).

WatHand Box Test

Next, lateralization measures were obtained from the Consistency Score, Skilled Score and Total Score of the WHBT in order to further delineate potential differences in lateralization between groups through preference measures. All WHBT scores were analyzed using an independent samples t-tests, with the exception of the Bimanual Score, for which frequency of scores was tabulated. Mean values for all computed scores can be found in Table 3.3. No significant differences were found between participants on any of the four calculated scores. Both participants with HFA/AS and TD controls obtained a Consistency Score of 2.83 out of a possible score of 4.00 ($t(22) = 0.00$, $p > .05$). There were also no significant differences between participants with HFA/AS ($M = 48.61$, $SD = 58.13$) and TD controls ($M = 69.44$, $SD = 50.17$) on the WatHand Skilled Score ($t(22) = -.94$, $p > .05$), despite a large difference in the mean scores. Furthermore, no differences were revealed between participants with HFA/AS ($M = 48.33$, $SD = 48.59$) and TD controls ($M = 58.33$, $SD = 55.57$) on the WatHand Total Score ($t(22) = -.47$, $p > .05$). Such differences in WatHand Box measures may have been expected to reach significance if overall variability in scores had been lower, and with increased numbers of participants in each group.

Table 3.3
Mean WatHand Box Test Scores

	HFA/AS	Control
	Mean	Mean
	(Standard Deviation)	(Standard Deviation)
Consistency Score	2.83 (0.94)	2.83 (1.59)
Skilled Score	48.61 (58.13)	69.44 (50.16)
Total Score	48.33 (48.59)	58.33 (55.57)

How do children with HFA/AS and TD children compare to one another on measures of motor planning?

WatHand Box Test: Bimanual Scores

Motor planning was examined through analysis of the WHBT Bimanual scores. The task involved lifting a cabinet door to retrieve an object for use from within. This was performed for two trials and compared to the initial cabinet lift, which was completed without retrieving an object.

Few notable differences were found between participants with HFA/AS and TD controls in terms of Bimanual Scores. When basing hand dominance on self-declared handedness (Table 3.4), nine (75%) participants with HFA/AS performed the initial cabinet lift with their dominant right hand. Of these nine participants, three (25%) performed both bimanual tasks by lifting the cabinet with the left hand, opposite to the initial cabinet lift, while two participants (16.6%) performed at least one of the bimanual tasks by lifting the cabinet with their left hands. Four (33.5%) used the right hand for the cabinet-lift on both bimanual tasks.

Similar results were seen with the TD controls, where ten (83.3%) participants performed the initial cabinet lift with their self-declared dominant right hand. Of these ten participants, one (8.3%) performed both bimanual tasks by lifting the cabinet with the left hand, opposite to the initial cabinet lift. Moreover, six (50%) of these participants performed at least one of the bimanual tasks by lifting the cabinet with their left hands, slightly more than participants with HFA/AS, while three (25%) used the right hand for the cabinet lift on both bimanual tasks.

Table 3.4

Bimanual Score Frequencies Based on Self-Declared Handedness

WHBT Lift 1	WHBT BM1	WHBT BM2	Hand Dominance	
			Right Hand	Left Hand
Right Hand	Same Hand as Lift 1	Same Hand as Lift 1	HFA/AS 4 (33.3%)	
		Control	3 (25%)	
		Opposite Hand to Lift 1	HFA/AS 1 (8.3%)	
		Control	4 (33.3%)	
	Opposite Hand to Lift 1	Same Hand as Lift 1	HFA/AS 1 (8.3%)	
		Control	2 (16.6%)	
		Opposite Hand to Lift 1	HFA/AS 3 (25%)	
		Control	1 (8.3%)	
Left Hand	Same Hand as Lift 1	Same Hand as Lift 1	HFA/AS 1 (8.3%)	
		Control	1 (8.3%)	1 (8.3%)
		Opposite Hand to Lift 1	HFA/AS 1 (8.3%)	
		Control		
	Opposite Hand to Lift 1	Same Hand as Lift 1	HFA/AS	
		Control		
		Opposite Hand to Lift 1	HFA/AS	1 (8.3%)
		Control		

Two (16.6%) right-handed participants with HFA/AS used their left hands for the initial cabinet lift, however one continued to use the left hand for the cabinet lifts in both bimanual tasks. One right-handed participant with HFA/AS (8.3%) used the left hand to lift the cabinet for the first bimanual task and the right hand for the second. One TD right-handed participant (8.3%) and one TD left-handed participant (8.3%) both used the left hand for the cabinet lifts in both bimanual tasks. The one left-handed participant with HFA/AS completed both bimanual tasks using the right hand to lift the cabinet. When considering Bimanual Scores based on WHBT-determined handedness, the frequencies of each condition are slightly altered (Table 3.5). One self-declared right-handed control (8.3%) and two self-declared right-handed children with HFA/AS (16.6%) were instead classified as left-handed based on the WHBT. The TD child had performed the initial cabinet lift with the right hand, however proceeded to complete the cabinet lifts associated with the two bimanual tasks with the left hand. Both participants with HFA/AS had completed the initial cabinet lift with the left hand, one of whom completed both of the following bimanual cabinet lifts with the left hand, while the other performed the first bimanual cabinet lift with the left hand and the second with the right hand.

How do children with HFA/AS and TD children compare on measures of dominance?

Handedness, Eyedness & Footedness

Comparisons of frequencies of right or left handedness, footedness and eyedness between groups revealed no key differences, whether by self-declared hand preference (Table 3.6) or by hand preference determined through the WatHand Box Test (Table 3.7). A total of 91.6% (n = 11) of participants in each group were self-declared right-

Table 3.5

Bimanual Score Frequencies Based on WHBT Handedness

WHBT Lift 1	WHBT BM1	WHBT BM2	Hand Dominance	
			Right Hand	Left Hand
Right Hand	Same Hand as Lift 1	Same Hand as Lift 1	HFA/AS 4 (33.3%)	
		Control	3 (25%)	
		Opposite Hand to Lift 1	HFA/AS 1 (8.3%)	
		Control	4 (33.3%)	
	Opposite Hand to Lift 1	Same Hand as Lift 1	HFA/AS 1 (8.3%)	
		Control	2 (16.6%)	
		Opposite Hand to Lift 1	HFA/AS 3 (25%)	
		Control		1 (8.3%)
Left Hand	Same Hand as Lift 1	Same Hand as Lift 1	HFA/AS	1 (8.3%)
		Control	1 (8.3%)	1 (8.3%)
		Opposite Hand to Lift 1	HFA/AS	1 (8.3%)
		Control		
	Opposite Hand to Lift 1	Same Hand as Lift 1	HFA/AS	1 (8.3%)
		Control		
		Opposite Hand to Lift 1	HFA/AS	
		Control		

Table 3.6

Handedness, Eyedness & Footedness Frequencies Based on Self-Declared Handedness

	HFA/AS				Control			
	Right Handed		Left Handed		Right Handed		Left Handed	
Right Eyed	6 (50%)	1 (8.3%)	1 (8.3%)		4 (33.3%)	1 (8.3%)		
Left Eyed	3 (25%)	1 (8.3%)			4 (33.3%)	2 (16.6%)	1 (8.3%)	
	Right Footed	Left Footed	Right Footed	Left Footed	Right Footed	Left Footed	Right Footed	Left Footed

Table 3.7

Handedness, Eyedness & Footedness Frequencies Based on WHCT Handedness

	HFA/AS				Control			
	Right Handed		Left Handed		Right Handed		Left Handed	
Right Eyed	5 (41.6%)	1 (8.3%)	2 (16.6%)		4 (33.3%)	1 (8.3%)		
Left Eyed	2 (16.6%)	1 (8.3%)	1 (8.3%)		4 (33.3%)	1 (8.3%)	1 (8.3%)	1 (8.3%)
	Right Footed	Left Footed	Right Footed	Left Footed	Right Footed	Left Footed	Right Footed	Left Footed

handlers, while based on results of WHBT, 75% (n = 9) participants with HFA/AS and 83.3% (n = 10) of TD controls were found to be right handed. Overall, 66.6% (n = 8) of participants with HFA/AS were found to be right-eyed, while the remaining 33.3% (n = 4) were left-eyed. Of the TD children, 41.6% (n = 5) were right-eyed, and 58.3% (n = 7) were left-eyed. A total of 83.3% (n = 10) of participants with HFA/AS were right-footed, while the remaining 16.6% (n = 2) were left-foot dominant. Seventy-five percent (n = 9) of TD children were right-foot dominant, while the remaining 25% (n = 3) were left-footed.

When basing hand dominance on self-declared handedness, 91.6% (n = 11) of children with HFA/AS and 91.6% (n = 11) of TD children were right-handed, with 8.3% (n = 1) of participants in each group reporting left-hand dominance. When hand dominance was assessed through the WHBT, however, 75% (n = 9) of participants with HFA/AS and 83.3% (n = 10) of TD controls were right-handed. The remaining 25% (n = 3) of participants with HFA/AS and 16.6% (n = 2) of TD controls were found to be left-handed.

Fifty percent of participants with HFA/AS (n = 6) and 33.3% of TD controls (n = 4) identified themselves as right-handed and were also found to be completely right-side dominant (right handed, eyed and footed). Using the WHBT to determine hand preference, however, resulted in frequencies of 41.6% (n = 5) and 33.3% (n = 4), respectively. No participants who identified themselves as left-handed were found to be completely left-side dominant, however based on the WHBT, 8.3% of TD controls (n = 1) were found to be left handed, eyed and footed.

Next, participants displaying mixed-dominance were considered. Overall, 33.3% of participants with HFA/AS ($n = 4$) and 41.6% of TD controls ($n = 5$) were found to be right-handed and mixed-preference on the other measures (either left-eyed and right footed or right-eyed and left-footed) based on self-declared hand preference. This value dropped to 25% of participants with HFA/AS ($n = 3$) when based on the WHBT, but remained unchanged for control participants. No participants with HFA/AS (0%) were found to be left-handed with mixed foot- and eye- preference, while 8.3% of TD controls ($n = 1$) were revealed to be left-handed based on self-declared hand preference. When considering WHBT-determined hand preference, this value changed to 8.3% of participants with HFA/AS ($n = 1$), and remained unchanged for TD controls.

Finally, handedness with opposite foot- and eye- preference was considered. Self-reported handedness measures revealed that 8.3% of participants with HFA/AS ($n = 1$) were right-handed but left-eyed and footed, while this was the case for 16.6% of TD controls ($n = 2$). This value remained unchanged for participants with HFA/AS when using WHBT-determined handedness, however dropped to 8.3% ($n = 1$) of TD controls. Finally, 8.3% ($n = 1$) of participants with HFA/AS were found to be left handed but right-eyed and footed, which climbed to 16.6% ($n = 2$) when based on handedness as determined by the WHBT. No TD controls were found to be left-handed with opposite eye- and foot-dominance in either scenario.

How do foot performance abilities compare between children with HFA/AS and TD children?

Foot Tapping

Foot tapping data was analyzed by conducting a 2x2 ANOVA to determine performance abilities through differences in foot tapping events between the feet and between the participant groups. Mean tapping data for all measures can be found in Table 3.8. There were no significant main effects of group ($F(1, 22) = .239, p > .05$) or of foot ($F(1, 22) = 2.366, p > .05$) found in terms of number of tapping events. There was a significant interaction effect of group and foot used ($F(1, 22) = 5.377, p < .05$) in that participants with HFA/AS alone had a significant difference between the right foot and the left foot in the number of tapping events, where the left foot ($M = 23.46, SD = 9.73$) had significantly fewer tapping events than the right foot ($M = 26.96, SD = 9.22$). There was no such difference found with the TD controls ($p > .05$) (Figure 3.4).

Comparisons of mean interval durations revealed no significant main effects of participant type or foot ($p > .05$), while the interaction effect approached significance ($F(1, 22) = 4.051, p = .057$). The difference in mean interval durations between the left ($M = 448.47, SD = 196.28$) and right ($M = 398.11, SD = 145.80$) foot in participants with HFA/AS approached significance, with a shorter mean interval duration in the right foot ($p = .082$). There were no such differences found with the TD controls ($p > .05$). There were no significant main effects ($F = .003, p > .05$) or interaction effects ($F(1, 22) = 1.17, p > .05$) when considering the interval duration standard deviations. When considering the left foot alone, however, the difference between participants with HFA/AS ($M = 224.06,$

Table 3.8
Mean Foot Tapping Events and Durations

		HFA/AS	Control
		Mean (Standard Deviation)	Mean (Standard Deviation)
Right Foot	Mean Tapping Events	26.96 (9.22)	26.63 (9.50)
	Interval Duration Mean (ms)	398.11 (145.8)	427.65 (196.28)
	Interval Duration Standard Deviation (ms)	196.54 (144.48)	147.91 (146.29)
	Lift Duration Mean(ms)	117.17 (67.42)	195.6 (146.14)
	Lift Duration Standard Deviation (ms)	70.97 (74.23)	91.81 (112.94)
	Tap Duration Mean (ms)	279.56 (122.55)	234.62 (91.97)
	Tap Duration Standard Deviation (ms)	179.18 (129.73)	105.52 (75.51)
	Mean Tapping Events	23.46 (9.73)	27.33 (8.09)
Left Foot	Interval Duration Mean (ms)	448.47 (196.28)	399.46 (156.76)
	Interval Duration Standard Deviation (ms)	224.06 (174.23)	117.67 (55.28)
	Lift Duration Mean (ms)	113.57 (71.52)	167.55 (88.19)
	Lift Duration Standard Deviation (ms)	57.84 (89.48)	70.57 (38.4)
	Tap Duration Mean(ms)	333.65 (151.70)	230.33 (86.44)
	Tap Duration Standard Deviation (ms)	209.26 (154.29)	90.73 (49.25)

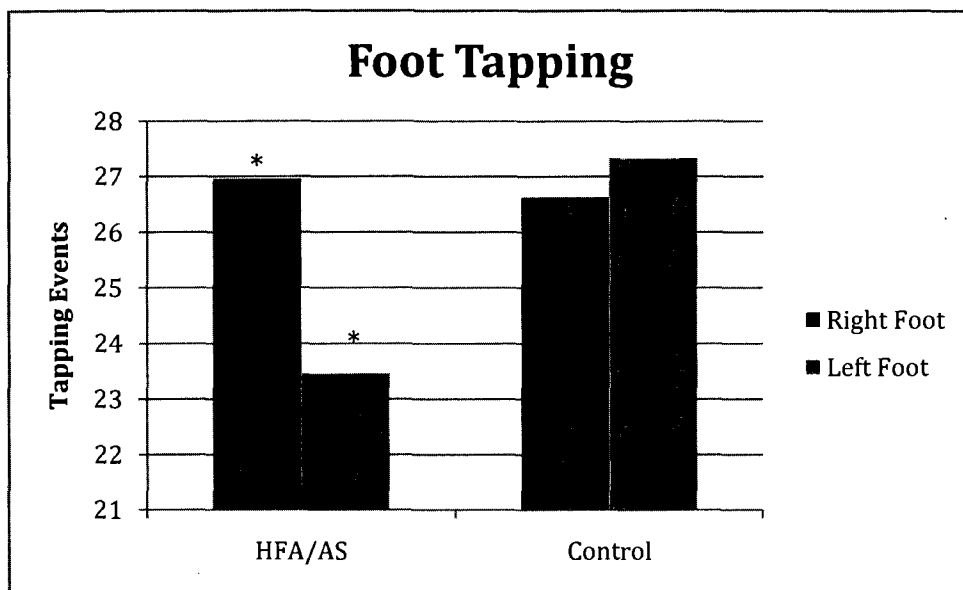


Figure 3.4. Mean foot tapping events.

SD = 174.23) and TD controls (M = 117.67, SD = 55.28) was found to approach significance ($p = .056$).

There were no significant main effects ($F(1, 22) = 1.10, p > .05$) or interaction effects ($F(1, 22) = .65, p > .05$) of the mean lift durations within subjects. However, differences between groups approached significance, where participants with HFA/AS (M = 115.37, SD = 69.47) were found to have a lower overall mean lift duration than TD controls (M = 181.58, SD = 117.17), $p = .089$. No significant differences were found for the lift duration standard deviation.

Although the interaction effect of foot and group was non-significant ($F(1, 22) = 2.64, p > .05$), this interaction was examined to a greater extent, due to the exploratory nature of this study. Differences in tap duration means between groups approached significance when considering the left foot only, where TD controls (M = 230.33, SD = 86.44) showed a shorter tap duration than participants with HFA/AS (M = 333.65, SD = 151.70), where ($F(1, 22) = 4.201, p = .052$). When considering participants with HFA/AS alone, it was found that they showed a lower tap duration with the right foot (M = 279.56, SD = 122.55) than the left (M = 333.65, SD = 151.70), where ($F(1, 22) = 4.55, p < .05$).

There was a significant main effect of group when considering the tap duration standard deviation, where participants with HFA/AS (M = 194.22, SD = 142.01) showed higher standard deviations than their TD peers (M = 98.13, SD = 62.38), ($F(1, 22) = 5.83, p < .05$). No other significant effects in the tap duration standard deviation were found, although some differences were found in the interaction of foot and group once again. These differences lay particularly in the left feet, where participants with HFA/AS (M =

209.26, SD = 154.29) had higher standard deviations than TD controls ($M = 90.73$, $SD = 49.25$) ($F(1, 22) = 6.43$, $p < .05$). There were no such differences among participants with the right feet.

Does hand preference relate to hand performance abilities?

As previously mentioned, of 91.6% ($n = 11$) of participants in each group were self-declared right-handers. However, results of the WHBT indicated that 75% ($n = 9$) participants with HFA/AS and 83.3% ($n = 10$) of TD controls were right-handed. As such, 13.3% more participants with HFA/AS than TD controls displayed discordance between self-declared handedness and demonstrated hand preference.

The small Grooved Pegboard place task was used as an added index of hand preference, as it presents the greatest level of difficulty of all Grooved Pegboard tasks performed. Preference was calculated by subtracting right hand performance times from left-hand performance times, where resultant positive scores would indicate a right-hand preference. Hand preference based on small Grooved Pegboard performance was then compared to both self-declared hand preference (Table 3.9) and WHBT hand preference as determined through the skilled score (Table 3.10). When comparing self-declared hand preference to small Grooved Pegboard hand preference, 7 participants with HFA/AS and 9 TD participants displayed right-hand preference on both measures. The one self-declared left-handed TD participant displayed left-hand preference on the small Grooved Pegboard as well, however, the self-declared left-handed participant with HFA/AS displayed right-hand preference on the small Grooved Pegboard. Similarly, greater numbers of participants with HFA/AS than TD participants displayed small Grooved Pegboard hand preferences that did not correspond with their self-declared hand

Table 3.9

Self-Declared Hand Preference Compared to Small Grooved Pegboard Hand Preference

		Small GP Preference		
	Self declared preference	Right-handed	Left-handed	Total
HFA/AS	Right-handed	7	4	11
	Left-handed	1	0	1
	Total	8	4	12
Control	Right-handed	9	2	11
	Left-handed	0	1	1
	Total	9	3	12

Table 3.10

WHBT Hand Preference Compared to Small Grooved Pegboard Hand Preference

		Small GP Preference		
	WHBT Preference	Right-handed	Left-handed	Total
HFA/AS	Right-handed	7	2	9
	Left-handed	1	2	3
	Total	8	4	12
Control	Right-handed	8	2	10
	Left-handed	1	1	2
	Total	9	3	12

preferences, where a total of 5 participants with HFA/AS displayed a disagreement in the measures, while only 2 TD participants showed such a disagreement.

When preferences were compared based on the WHBT, contradictions in preference were not as prominent. A total of 7 participants with HFA/AS and 9 TD participants displayed right-hand preference on both measures. When left-hand preference was considered, 2 participants with HFA/AS and 1 TD participant displayed left-hand preference on both measures. This led to a disagreement between measures for 3 participants in each group, where 2 participants with HFA/AS and 2 TD participants displayed right-hand preference on the WHBT but left-hand preference on the small Grooved Pegboard, and 1 participant with HFA/AS and 1 TD participant displayed left-hand preference on the WHBT but right-hand preference on the small Grooved Pegboard. Correlation of the WHBT total score and small Grooved Pegboard place task hand difference was then obtained. Measures revealed significant effects for TD participants ($r = .519, p < .05$) but not for participants with HFA/AS ($r = .183, p > .05$).

All participants with HFA/AS were also classified as having definite right-hand preference or weak right-hand preference based on a high WHBT total score of 80 or above, or a low WHBT total score below 80, respectively. Strength of preference was then compared to small Grooved Pegboard performance on both the place and remove task, with both the dominant and non-dominant hand. Independent samples t-tests revealed that there were no significant differences between individuals with definite or weak preference on either the place or remove task with both the dominant and non-dominant hands ($p > .05$).

Does foot preference relate to foot performance abilities?

When comparing foot preference (as determined from all foot preference items) to performance (as measured through the foot tapping task), some trends in the relationship between foot performance abilities and foot dominance were noted (Table 3.11). Right-footed TD children ($n = 9$) were able to perform better with the left foot ($M = 28.61$, $SD = 8.43$) than the right ($M = 26.72$, $SD = 10.34$), while right-footed participants with HFA/AS ($n = 10$) performed much better with the right foot ($M = 27.15$, $SD = 9.14$) than the left foot ($M = 23.05$, $SD = 10.10$). The right foot ($M = 26.33$, $SD = 9.22$) of left-footed TD children ($n = 3$) outperformed the left ($M = 23.5$, $SD = 6.76$), while this was not as clearly the case with left-footed children with HFA/AS ($n = 2$), where the left foot ($M = 25.5$, $SD = 10.61$) performed nearly as many taps as the right foot ($M = 26.00$, $SD = 13.44$).

In order to determine whether foot preference, as determined through a performance measure, related to foot preference determined through other tasks, tapping preference and seated preference were compared. Foot preference, as determined through the foot-tapping task, was calculated by subtracting the number of taps performed by the left foot from the number of taps performed by the right foot. Resultant positive scores would then indicate a right-foot preference. Preference assigned was then compared to foot preference as determined through the footedness tasks performed while sitting (Table 3.12). Overall, a higher percentage (66.6%, $n = 8$) of participants with HFA/AS displayed a right foot preference while tapping, while only 6 control participants (50%) showed this preference. Of the participants with HFA/AS, 6 participants (50%) continued to display this right foot preference during the seated

Table 3.11

Foot Tapping Performance Based on Foot Preference

	HFA/AS		Control	
	Events		Events	
	(Standard Deviation)		(Standard Deviation)	
Right	27.15	23.05	26.72	28.61
Footed	(9.14)	(10.1)	(10.34)	(8.43)
Left	26	25.5	26.33	23.5
Footed	(13.44)	(10.61)	(8.28)	(6.76)
	Tapping Right	Tapping Left	Tapping Right	Tapping Left

Table 3.12

Foot Tapping Preference Compared to Foot Preference While Seated

Seated foot preference				
	Tapping Preference	Right-footed	Left-footed	Total
HFA/AS	Right-footed	6	2	8
	Left-footed	3	1	4
	Total	9	3	12
Control	Right-footed	3	3	6
	Left-footed	4	2	6
	Total	7	5	12

footedness tasks, however, 3 TD children (25%) did the same. A total of 4 participants (33.3%) with HFA/AS presented a left foot preference while tapping, and of these, 1 (8.3%) also displayed a left foot preference while performing seated footedness tasks. A greater number of TD children demonstrated a left foot preference ($n = 6$, 50%) while tapping, and 2 (16.6%) maintained this preference while performing the seated tasks. The remaining participants ($n = 5$, 41.6%) with HFA/AS showed discordance in preference when comparing tapping and footedness tasks, of which 2 (16.6%) showed a right foot tapping preference but left foot task preference, and 3 (25%) displayed a left foot tapping preference but right foot task preference. More control participants showed a discrepancy between the two measures ($n = 7$, 58.3%), where 3 (25%) were right-footed while tapping but left-footed while performing seated tasks, and 4 (33.3%) were left-footed while tapping but right-footed while performing seated tasks. Further, Pearson correlation revealed no significant relationship between preference from foot tapping and preference determined from all footedness measures for both the group of participants with HFA/AS ($r = -.04$, $p > .05$) and TD controls ($r = -.28$, $p > .05$).

Discussion

The current study was conducted to determine if children with HFA/AS differ from their TD peers on measures of fine motor ability, motor planning, and lateral preference and performance. Studies have found that children with HFA or AS may not differ consistently from age-matched peers on motor tasks, yet there exists an overall agreement that general delays in motor ability exist (see, for example Jansiewicz et al., 2006; Schmitz et al., 2003). Areas of interest and findings among tasks performed will be discussed in turn.

How do children with HFA/AS compare to TD children on a task of motor precision and motor speed? Do these abilities relate to hand preference?

Previous work has indicated that children with HFA/AS may exhibit impairments in the performance of motor tasks (Hilton et al., 2007). Comparison of mean performance times on the Grooved Pegboard tasks supported these findings, where children with HFA/AS performed all tasks significantly slower than control participants. These differences are also indicative of delays in fine motor performance, as was also found by Provost et al. (2007) in children with ASD. All participants performed all tasks in less time with the dominant hand than the non-dominant hand, and this was explored further through the examination of laterality scores. Trends in the HFA/AS group performance times of these tasks were also similar to that of the TD children, where tasks that placed fewer demands on motor precision resources, were performed in less time than those that were expected to be more challenging. In this case, less demanding tasks were found to be all large Grooved Pegboard tasks and the peg removal tasks, and tasks that required increased use of motor resources were those with the small Grooved Pegboard and peg place tasks. Such increased performance times in more challenging motor tasks have been speculated to be due to the increased spatial task demands presented (Bryden & Roy, 1999). One exception surfaced, where the small Grooved Pegboard removal task was performed more quickly than the large Grooved Pegboard removal task among all participants, likely due to a smaller distance between each individual peg and the receptacle and therefore less required travel time.

Considering the high degree of variability in performance times of participants, the logarithms of all performance times were taken in order to reduce this factor. There

was also variability in performance times introduced by inherent differences between the large and small Grooved Pegboard, as previously discussed. For this reason, the two pegboards were analyzed separately. Additionally, data for only one left-handed participant in each group was available; as such removing these participants from analysis allowed for a clearer investigation of right-handed participants. Once these adjustments were made, it was found that participants with HFA/AS continued to display decreased fine motor ability in comparison to their TD peers, as indicated by significantly higher performance times on both pegboards. Other expected trends also held for all participants, such as decreased performance times with the dominant vs. the non-dominant hand, slower performance times on the place task than the remove task and overall improvements in performance times in later trials. Such trends indicate that the dominant hand is more adept at fine motor tasks than the non-dominant hand, but that both can generally be expected to improve with practice, as was seen in Peters' (1981) study examining improvements in finger tapping ability with practice.

Participants did not differ on the first trial of the large Grooved Pegboard remove task with both the dominant and non-dominant hands, indicating similar abilities in motor speed. However, TD children were able to outperform children with HFA/AS on the second trial of both the place and remove task with the dominant hand, as they were able to improve their performance times to a greater extent. Contrastive trends appeared with the non-dominant hand, however, where children with HFA/AS appeared to be able to increase the fine motor abilities of the non-dominant hand to a greater extent than were their TD peers, even though their overall performance abilities were reduced in comparison. More specifically, children with HFA/AS appeared to improve their non-

dominant hand on the second trial of the large Grooved Pegboard to the extent that there were no differences between the dominant and non-dominant hands, which was not the case in the group of TD children. Furthermore, the TD children did not outperform the children with HFA/AS on the second trial of the large Grooved Pegboard with the non-dominant hand, as children with HFA/AS were able to improve on both the place and remove tasks to a greater extent than were their TD peers.

Other work has indicated that the non-dominant hand of TD individuals may improve in performance of tasks, but that the relative amount of performance time between hands should be expected to remain consistent (Peters, 1981). This was indeed the case with the TD children observed, however this trend was not present in the children with HFA/AS. Such results reveal that children with HFA/AS may have a greater capacity to develop motor abilities of the non-dominant hand than their TD peers, indicating that motor precision and speed abilities may be less lateralized in this population. Motor precision and speed tasks are ordinarily expected to be performed asymmetrically, with a dominant-side advantage (Annett, 1985), and such an advantage did not seem to be consistently present where the performance of children with HFA/AS on these tasks was considered. The discussion of lateralization will further explore this point.

Trends of increased non-dominant hand ability did not come about in the examination of the small Grooved Pegboard, likely because the greater difficulty of the task did not allow for these potential non-dominant abilities to surface. The small Grooved Pegboard tasks did not present any interactions as the increased challenge and

task demands may have presented more distinct levels of difficulty and therefore performance times for each combination of factors.

Such information about impaired performance and differences in abilities between the preferred and non-preferred hands may be important for consideration by Occupational Therapists and other such interventionists when working with children with HFA/AS. These individuals may find this to be of particular use in designing strategies to develop abilities for the completion of finer motor tasks.

How do children with HFA/AS compare to TD children on measures of lateralization?

In order to examine laterality scores, logarithms of scores were taken, left-handed participants were removed from analysis, and both pegboards were analyzed separately, as described above. Examination of laterality scores pertaining to Grooved Pegboard performance revealed that children with HFA/AS displayed little to no differences from TD children in lateral performance and preference. Although inconsistent with previous findings by Hauck and Dewey (2001), which showed increased left-handed tendencies in individuals with autism, this sample appeared to show comparable lateralization to the dominant right side when performing finer motor tasks. Furthermore, all participants showed an increased reliance on the right side when performing the more involved place task. There were, however, differences between trials that arose in the large Grooved Pegboard, where children with HFA/AS were lateralized less strongly to the dominant side in later trials, while the opposite was the case for TD control participants. Inconsistencies in dominance are thus indicated when approaching a novel fine motor task, with an increasing ability to use resources lateralized to the non-dominant side as the task becomes more learned or familiar. The trend applied particularly to the place

task, which shows that individuals with HFA/AS may more readily access resources on the non-dominant side for tasks requiring motor precision, but may do so to a lesser extent for tasks of motor speed. It appears that children with HFA/AS do experience an increased ability to perform to the level of the dominant hand with the non-dominant hand, which was not the case with the TD children even though their overall motor performance abilities remained increased. Both groups of participants generally followed the same trends in lateralization across tasks and trials of the small Grooved Pegboard, likely because of the increased level of difficulty presented by the task, making it more challenging for participants with HFA/AS to access potential non-dominant motor resources.

Measures of lateralization from the WHBT produced mixed results. Consistency scores of the two groups were equal, which contradicts previous findings by Hauck and Dewey (2001) that demonstrated children with autism as being more inconsistent in handedness than their peers. Consequently, TD children in this age range may be more inconsistent than previously thought, or children with ASDs that are classified as higher-functioning, as was the current sample, may be more consistent in their handedness than their lower-functioning peers. Similarly, there were no significant differences on either the Skilled or Total scores, despite the fact that children with HFA/AS had lower scores on both measures. It was also noted that with the addition of two tasks to make up the Total score, mean laterality scores for TD controls dropped, while the scores for children with HFA/AS remained lower than controls, but unchanged from the Skilled score. Although not a significant finding, there is some indication of ambiguity in handedness for children with HFA/AS.

How do children with HFA/AS and TD children compare on measures of motor planning?

Motor planning abilities of the children were assessed through Bimanual tasks, as part of the WHBT. In order to indicate motor planning ability, children were expected to use the non-dominant hand to lift the cabinet in order to be able to use the dominant hand to retrieve and use the object within. Similar numbers of children in both groups performed the bimanual task at least once in such a way that would indicate motor planning ability, which held whether handedness was self-declared or based on WHBT findings. Overall, the task was performed more often without motor planning in both groups, demonstrating that children in this age range in general may not have highly-developed motor planning ability. The results support findings by Dziuk et al. (2007) who suggested that dyspraxia may be of concern in children with autism. However, this was not seen in this case to the extent that would suggest impaired motor planning abilities in comparison to their TD peers. Moreover, Bryden et al. (2007) described similar findings in motor planning abilities based on WHBT results in adult populations. It was speculated that the task may not be motorically ‘complex’ enough to warrant the expected hand switching patterns, where participants were expected to select the non-dominant hand to open the cabinet door and use the preferred hand to use the candy dispenser. Participants did not exhibit a strong reliance on the dominant hand when opening the cabinet to obtain the object within, as the task of opening a door was supposed to be highly practiced by adulthood. Younger participants, aged 3-11 years, showed only a slightly higher reliance on the dominant hand to open the cabinet for the Bimanual task (Bryden et al., 2007). The addition of the more meaningful colouring task

to the Bimanual tasks in this case also did not bring about the expected patterns of hand use. Both groups of children may not have been motivated to form a motor plan because of the low level of difficulty presented in opening the cabinet door with either hand, as was also supported by the equally low Consistency scores found among groups. Children with HFA/AS may not differ from their peers in motor planning ability, or may possibly contrast in ways that are not discernable through this task alone.

How do children with HFA/AS and TD children compare to one another on measures of dominance?

When comparing the hand-, eye- and foot- dominance of participants in either group, no major differences between groups were found. Participants were matched on self-declared handedness, resulting in an equal number of right-handers in each group. When handedness was assessed through the WHBT, the numbers of left-handed individuals in both groups increased, but to a slightly greater extent in the group with HFA/AS. This is likely the result of encouragement to perform tasks with the right hand beginning at an early age, especially where a bias to develop right-handedness already exists (Annett, 1985). Children may then view themselves as right-handed and perform most tasks with the right hand, even where several left-handed tendencies exist. Again, this is important for interventionists working with children with HFA/AS, where a focus should remain on establishing true dominance in performing tasks, rather than pressing the use of one hand over the other.

When considering foot and eye dominance, similar numbers in each group displayed left or right tendencies. When considering the combined hand, foot and eye dominances, similar numbers of participants in each group showed opposite or crossed

dominance among right-handed participants. Left-handed participants, however, differed in that those with HFA/AS showed increased likelihood of opposite dominance than did controls, where footedness and eyedness would both not match up with handedness.

Overall, most participants displayed ambiguities in dominance, as less than half of participants in both groups were purely left- or right-dominant, but there were no group differences of note in these ambiguities. Participants with HFA/AS do not seem to differ from TD children on measures of laterality, although the contrary has been affirmed in previous work (Gillberg, 1983).

How do foot performance abilities compare between children with HFA/AS and TD children?

Foot performance ability was measured through a foot-tapping task, which examined performance through speed of tapping (Peters & Durning, 1979). Although significant differences arose between groups in performance of the hands, as measured through Grooved Pegboard performance, no significant differences were apparent in overall observed tapping performance of the feet. There were differences between groups in abilities of the individual feet, where controls performed similarly with both feet, but participants with HFA/AS showed significantly better performance with the right foot than the left. However, Peters and Durning (1979) found that right-handed individuals in general performed better with the right foot than the left, yet participants in that study were in a considerably older age group than the present sample, and may have established foot preference more distinctly. Conversely, Gabbard (1993) indicated that TD children aged 3-11 do not prefer one foot over the other, which was also generally

seen in the present sample through their performance, even where preference was assigned.

Differences between feet in the interval durations only approached significance for participants with HFA/AS, indicating that although the right foot was able to tap more quickly, each individual tap was not necessarily executed more quickly. There were no differences between feet in the group of TD children. Additionally, differences between groups with the left foot only approached significance. It appears that although overall left foot interval duration was increased in participants with HFA/AS, that alone does not explain their decreased left foot tapping ability. Overall execution of the tapping movements may not be impaired, but rather it is the summative effect of small differences that result in the overall impairments observed. In this way, it was determined that overall tapping ability itself was comparable between feet and between groups.

No differences between arose in the examination of the lift duration, indicating that foot performance when lifting the foot was similar between groups. Some differences emerged amongst participants in the tap duration, particularly with the left foot. Participants with HFA/AS showed higher tap durations and tap duration standard deviations with the left foot than the right, while TD children showed no such differences. Children with HFA/AS may be less able to exert control over the left foot, contributing to decreased left foot tapping ability and therefore performance. This supports suggestions that the inability to control the efficiency of motor output, rather than a lack of feedback processing, is instrumental in the increased difficulties typically witnessed in non-preferred limbs (Annett, 1985)

Does hand preference relate to hand performance abilities?

In order to address this question, it was first essential to compare self-declared hand preference and hand preference determined through the WHBT. Such comparisons revealed that more children with HFA/AS seemed to declare one hand as dominant where a performance-based measure of handedness indicated otherwise. This difference was fairly small, however, necessitating the comparison of hand performance, as measured through the small Grooved Pegboard place task, to hand preference through both self-declared hand preference and the WHBT. Findings from these comparisons demonstrated that children with HFA/AS are much more likely than their TD peers to misreport their dominant hand. When hand performance was compared to hand preference assigned by the WHBT, these differences dissipated somewhat, indicating that children with HFA/AS do indeed display characteristics of possessing a preferred limb that can perform well, but are not always aware which limb this is. It appears as though hand preference in children with HFA/AS has not yet matured to a level that would be expected. This, along with the lack of correlation between the WHBT total score and Grooved Pegboard performance further evidences the notion that children with HFA/AS may not be more highly left-dominant, as has been suggested in previous work (Gillberg, 1983), but that their motor difficulties actually arise from ambiguities or inconsistencies in dominance which are typically expected to fade by this age (Hauck & Dewey, 2001). Concerns arise at this matter, for children with HFA/AS may be practicing skills and performing day-to-day tasks using the hand with which performance is not as adept, and are likely receiving well-intentioned encouragement to do so by therapists and interventionists.

Given that strength of hand preference has been found to be related to the level of development of motor ability in children with autism (Hauck & Dewey, 2001), participants with HFA/AS in the present sample were classified as having definite or weak hand preference. It was determined that strength of hand preference did not play a role in motor ability in this case. Increased age of the participants and possibly a higher level of functioning in comparison to those in the Hauck and Dewey (2001) study are viable contributing factors to the lack of observable difference in this case. As participants age and motor ability naturally develops, strength of hand preference may be less of a determinant in skill level. Particularly, this is the case for individuals with HFA/AS if they do maintain ambiguous or inconsistent dominance as they age, as they may have learned to accommodate for such differences in performance with time.

Do these foot performance abilities relate to foot preference?

Nearly all children did not match their foot performance abilities to their foot preference, aside from right-footed participants with HFA/AS. Right-footed TD control participants showed increased ability with the left foot, while those who were left-footed showed increased tapping ability with the right foot. Right-footed participants with HFA/AS performed much better overall with the right foot, as expected, while those who exhibited left foot preference performed nearly as many taps with the left foot as the right, with the right foot outperforming the left. It appears that left foot-dominant individuals with HFA/AS tend to exhibit more ambiguities than do those who are right foot-dominant. While left foot preference may be present, performance measures will not necessarily reflect this. Peters and Durdin (1979) speculated that such findings may be the result of increased use of the right foot for manipulative skills, while measures that do

not require as much control of the foot and leg may not be reflective of foot preference. Such a finding is also often present when considering discrepancies between hand preference and performance (Elliot & Roy, 1996), where preference and performance measures are not necessarily expected to be in accordance with one another. In the present sample, the foot chosen to perform tasks requiring more gross motor ability and strength, as in the preference measures, did not tend to reflect the foot that would be selected for motor speed tasks, such as foot tapping.

Foot preference as determined through foot tapping performance was compared to foot preference from tasks performed while seated. Seated tasks were examined in order to remove any alterations in foot preference brought about by a need to use a stabilizing foot while performing the tasks. Overall, similar numbers of participants in each group showed disagreement between foot preference from tapping and from footedness tasks, and the two preference measures were not correlated. Much like hand preference, this is indicative of a lack of maturity in foot preference. In this case, however, children with HFA/AS do not seem to experience delays in foot preference development compared to their TD peers, as TD children have also not yet fully developed their foot preference. Foot preference will presumably not lateralize in either group for some time (Gabbard, 1993). To a certain extent, this may imply that a lack of definitive foot preference in children with HFA/AS is not worthy of consideration. However, such information must be evaluated with that presented above, indicating that as a whole preference is not as clearly established in children with HFA/AS.

Limitations

There were a variety of limitations in the findings of this study. First and foremost, the small number of participants in either group contributed to low overall statistical power, making it increasingly difficult to obtain statistical significance, even where it may exist. There was also a high level of variability in data collected from participants with HFA/AS, necessitating the adjustment of scores in order to avoid violation of the assumptions of certain statistical tests. The variability found is likely due to the wide range of development and ability levels present in children with HFA/AS. Although a narrow age span was maintained, children of all developmental abilities within that range may still be expected to show varying levels of performance and abilities. These limitations were accounted for as described wherever possible, however continue to exist in data collection and analysis.

Future Directions

Findings and subsequent conclusions made would benefit from the additional, more in depth measures of preference and performance. For instance, comparison of hand and foot data against measures such as the Waterloo Handedness Questionnaire and the Waterloo Footedness Questionnaire, respectively, would have provided an additional means of comparison for preference. These were not asked of participants with HFA/AS in this study due to time limitations and potential difficulties in comprehending the questionnaire items, which is also of concern with TD children in this age range. Information obtained from the Grooved Pegboard tasks can also be compared to additional handedness measures, such as the Annett Pegboard and Finger Tapping tasks, which are not considered as complex. Further information could also have been gathered

regarding eyedness and performance, for instance through the use of eye tracking equipment which could provide information about eye gaze patterns during the eyedness tasks. This information was outside the scope of the current study, but such a comparison presents an interesting future research direction.

Conclusion

In summary, children with HFA/AS do experience delays in motor performance compared to their TD peers, but this was not observed to the same extent as what has been indicated in the literature (see, for example Jansiewicz et al., 2006). Motor deficits that arose seemed to lie in execution of the tasks, however motor learning may be affected as well, thereby impairing downstream processing ability and subsequent execution of motor tasks, as posited by Jansiewicz et al., 2006. The children with HFA/AS were indeed capable of performing all assigned tasks; discrepancies merely lay in how well they were performed and the manner in which the performance of tasks was lateralized.

Increased left-dominant tendencies that have been described in previous work (Hauck & Dewey, 2001) also do not seem as prevalent, but some inconsistencies and ambiguities were indeed present. Differences in dominance that have been indicated in previous work may, however, arise at later ages, as TD children at the age examined may also not yet have clearly established dominance in some respects. Additionally, discrepancies in findings may be due to the high-functioning nature of the children in the study, which may indicate that these children with HFA/AS may function better motorically overall than their peers who are lower-functioning, which supports studies that have linked decreased IQ to decreased motor skills of participants with ASD

(Manjiviona & Prior, 1995), and increased AS severity to decreased ability on motor measures (Hilton et al., 2007).

Interventionists working with children with HFA/AS should remain cognizant of differences that may arise in the motor abilities of these children when compared to their TD peers. Since children may present in such a way that motor deficits are not immediately apparent it is essential to be aware that some differences certainly do exist, particularly for those working with these children. Such differences, although not necessarily immediately noticeable in daily functioning, may still require specialized support in order to allow these children to reach their full potential.

CHAPTER 4

Summary

In summary, findings from both studies conducted indicated that autism has a profound effect for those who experience it, either first hand or through involvement with a family member. Effects experienced by individuals affected may not be immediately apparent. Caregivers experienced effects to many aspects of their lives. Mothers of children with autism experienced both costs and benefits as a result of their children's diagnoses, and proceeded to take on specialized caregiving roles as a result of the children's functioning and behaviour. The women identified effects in a variety of aspects of their own and their families' lives. Caring for a child with autism thus shaped the women's experiences.

Children with high-functioning autism or Asperger syndrome were found to experience unobvious consequences, as through first-hand effects to their motor control abilities. Although impairments were not as extensive as expected, differences in some aspects of fine motor abilities and dominance were distinguishable from that of TD children, which may hold implications for the motor functioning of children with HFA/AS. In turn, there may also exist ramifications for the children's peer interactions due to the effect motor skill may have on the ability and desire to play with other children. If motor ability can be developed further, children may more readily play with their peers and therefore reinforce their social and communication abilities.

These facts reiterate the importance of ensuring that appropriate support systems are in place for children and families affected by autism and other disorders of the spectrum. Early intervention has been found to be key in bringing about positive

outcomes for children with ASD. Understanding the specific intervention needs of these children and how they may differ from their TD peers, in terms of motor abilities in this case, can help these children achieve their true capabilities. Appropriately fostering development in their functioning and behaviour may subsequently allow the mothers of children with autism to experience more benefits, and to take on roles that will also promote favourable outcomes for their children. Through increased knowledge of the effects autism spectrum disorder may have on those who experience it in some way, more advantageous resources can be put in place for their use. Consequently, those affected by ASDs will be better equipped to cope with challenges that they may encounter.

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APPENDIX A: DSM IV-TR Diagnostic Criteria for the Pervasive Developmental Disorders

Diagnostic Criteria for 299.00 Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

1. qualitative impairment in social interaction, as manifested by at least two of the following:

1. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
2. failure to develop peer relationships appropriate to developmental level
3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
4. lack of social or emotional reciprocity

2. qualitative impairments in communication as manifested by at least one of the following:

1. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
2. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
3. stereotyped and repetitive use of language or idiosyncratic language
4. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

3. restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. apparently inflexible adherence to specific, nonfunctional routines or rituals
3. stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)
4. persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Diagnostic Criteria for 299.80 Asperger's Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

1. marked impairment in the use of multiple nonverbal behaviors such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction
2. failure to develop peer relationships appropriate to developmental level
3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
4. lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus
2. apparently inflexible adherence to specific, nonfunctional routines or rituals
3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
4. persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism" - presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Diagnostic Criteria for 299.80 Rett's Disorder

A. All of the following:

1. apparently normal prenatal and perinatal development
2. apparently normal psychomotor development through the first 5 months after birth
3. normal head circumference at birth

B. Onset of all of the following after the period of normal development:

1. deceleration of head growth between ages 5 and 48 months
2. loss of previously acquired purposeful hand skills between 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)
3. loss of social engagement early in the course (although often social interaction develops later)
4. appearance of poorly coordinated gait or trunk movements
5. severely impaired expressive and receptive language development with severe psychomotor retardation

Diagnostic Criteria for 299.10 Childhood Disintegrative Disorder

A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.

B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:

1. expressive or receptive language
2. social skills or adaptive behavior

3. bowel or bladder control

4. play

5. motor skills

C. Abnormalities of functioning in at least two of the following areas:

1. qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)

2. qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)

3. restricted, repetitive, and stereotyped patterns of behavior, interest, and activities, including motor stereotypes and mannerisms

D. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia

(American Psychiatric Association, 2000).

APPENDIX B: WHO ICD-10 Diagnostic Criteria for the Pervasive Developmental Disorders

F84 Pervasive developmental disorders

A group of disorders characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual's functioning in all situations.

Use additional code, if desired, to identify any associated medical condition and mental retardation.

F84.0 Childhood autism

A type of pervasive developmental disorder that is defined by: (a) the presence of abnormal or impaired development that is manifest before the age of three years, and (b) the characteristic type of abnormal functioning in all the three areas of psychopathology: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour. In addition to these specific diagnostic features, a range of other nonspecific problems are common, such as phobias, sleeping and eating disturbances, temper tantrums, and (self-directed) aggression.

Autistic disorder

Infantile:

- autism
- psychosis

Kanner's syndrome

Excludes: autistic psychopathy (F84.5)

F84.1 Atypical autism

A type of pervasive developmental disorder that differs from childhood autism either in age of onset or in failing to fulfil all three sets of diagnostic criteria. This subcategory should be used when there is abnormal and impaired development that is present only after age three years, and a lack of sufficient demonstrable abnormalities in one or two of the three areas of psychopathology required for the diagnosis of autism (namely, reciprocal social interactions, communication, and restricted, stereotyped, repetitive behaviour) in spite of characteristic abnormalities in the other area(s). Atypical autism arises most often in profoundly retarded individuals and in individuals with a severe specific developmental disorder of receptive language.

Atypical childhood psychosis

Mental retardation with autistic features

Use additional code (F70-F79), if desired, to identify mental retardation.

F84.2 Rett's syndrome

A condition, so far found only in girls, in which apparently normal early development is followed by partial or complete loss of speech and of skills in locomotion and use of hands, together with deceleration in head growth, usually with an onset between seven and 24 months of age. Loss of purposive hand movements, hand-wringing stereotypies, and hyperventilation are characteristic. Social and play development are arrested but social interest tends to be maintained. Trunk ataxia and apraxia start to develop by age four years and choreoathetoid movements frequently follow. Severe mental retardation almost invariably results.

F84.3 Other childhood disintegrative disorder

A type of pervasive developmental disorder that is defined by a period of entirely normal development before the onset of the disorder, followed by a definite loss of previously acquired skills in several areas of development over the course of a few months. Typically, this is accompanied by a general loss of interest in the environment, by stereotyped, repetitive motor mannerisms, and by autistic-like abnormalities in social interaction and communication. In some cases the disorder can be shown to be due to some associated encephalopathy but the diagnosis should be made on the behavioural features.

Dementia infantilis

Disintegrative psychosis

Heller's syndrome

Symbiotic psychosis

Use additional code, if desired, to identify any associated neurological condition.

Excludes: Rett's syndrome (F84.2)

F84.4 Overactive disorder associated with mental retardation and stereotyped movements

An ill-defined disorder of uncertain nosological validity. The category is designed to include a group of children with severe mental retardation (IQ below 35) who show major problems in hyperactivity and in attention, as well as stereotyped behaviours. They tend not to benefit from stimulant drugs (unlike those with an IQ in the normal range) and may exhibit a severe dysphoric reaction (sometimes with psychomotor retardation) when given stimulants. In adolescence, the overactivity tends to be replaced by underactivity (a pattern that is not usual in hyperkinetic children with normal intelligence). This syndrome is also often associated with a variety of developmental delays, either specific or global. The extent to which the behavioural pattern is a function of low IQ or of organic brain damage is not known.

F84.5 Asperger's syndrome

A disorder of uncertain nosological validity, characterized by the same type of qualitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. It differs from autism primarily in the fact that there is no general delay or retardation in language or in cognitive development. This disorder is often associated with marked clumsiness. There is a strong tendency for the abnormalities to persist into adolescence and adult life. Psychotic episodes occasionally occur in early adult life.

Autistic psychopathy

Schizoid disorder of childhood

F84.8 Other pervasive developmental disorders

F84.9 Pervasive developmental disorder, unspecified

(World Health Organization, 2004).

APPENDIX C: Background Questionnaire for Primary Caregivers

1) What is your age? _____

2) What is your occupation?

3) What is the highest level of education you have completed? Check one.

◇ Elementary school

◇ High school

◇ Undergraduate

◇ College

◇ Graduate

◇ Doctoral

4) What was your marital status prior to diagnosis?

◇ Married ◇ Divorced ◇ Separated ◇ Common-law ◇ Single

What is your marital status post-diagnosis?

◇ Married ◇ Divorced ◇ Separated ◇ Common-law ◇ Single

5) How many children do you have? _____

6) What are the ages/genders of your children? Please indicate with an * which child(ren) has/have ASD (i.e. 8yrs/Male*, 6yrs/Male, 4yrs/Female)

The next series of questions deal with your child's condition...

7) What is your child's diagnosis?

◇ Autism

◇ Asperger's

◇ Childhood Disintegrative Disorder

- ◇ Rett's Disorder
- ◇ Pervasive Developmental Disorder – Not otherwise specified

8) How was your child diagnosed? Please indicate the tests used and the types of medical professionals involved.

9) Are there other conditions present in the child with ASD?

- ◇ Yes (please specify)

- ◇ No

10) How long ago was your child diagnosed with an ASD?

11) How long prior to diagnosis were signs/symptoms noticed?

12) What signs or symptoms were present at that time? Check all that apply.

- ◇ Language deficits
- ◇ Impaired communication
- ◇ Motor skill deficits
- ◇ Resistance to change in routine
- ◇ Difficulty sleeping
- ◇ Lack of imaginative play
- ◇ Disinterest in socializing with family/other children
- ◇ Restricted interests/activities
- ◇ Abnormal responses to sensory stimulation
- ◇ Behavioural problems
- ◇ Other (please specify) _____

This section deals with information about yourself...

13) Do any of your other children have other conditions?

- ◇ Yes (please specify)

- ◇ No

14) Did you have any illnesses/conditions/impairments prior to diagnosis?

◇ Yes (please specify)

◇ No

Do you currently have any illnesses/conditions/impairments?

◇ Yes (please specify)

◇ No

15) Do you feel as though your mental health has been affected as a result of your child's diagnosis?

◇ Yes

◇ No

◇ Maybe

16) Do you feel as though your physical health has been affected as a result of your child's diagnosis?

◇ Yes

◇ No

◇ Maybe

17) Are you ever unable to participate in daily routines/activities because of your child's autism?

◇ Frequently

◇ Sometimes

◇ Rarely

◇ Never

18) Do you feel as though your social relationships have been affected as a result of your child's diagnosis?

◇ Yes

◇ No

◇ Maybe

19) Do you have any family members that you can talk to about personal issues or call for assistance?

◇ Yes (how many?)

◇ No

20) Do you have any friends that you can talk to about personal issues or call for assistance?

◇ Yes (how many?)

◇ No

21) Have you accessed any resources to help you cope with your child's ASD? Please indicate which, if any, you have used.

- ◇ Support group
- ◇ Support Organization/Society
- ◇ Seeking information
- ◇ Humour
- ◇ Journal
- ◇ Exercise
- ◇ Spiritual Methods
- ◇ Family
- ◇ Psychological treatment (for yourself)
- ◇ Monetary support (specify type)

◇ Educational services (for the child) specify:

◇ Treatment services (for the child) specify:

◇ Other (please specify)

*****Thank you for your time!*****

APPENDIX D: Interview Guide

1) Please describe for me what made you initially seek diagnosis for your child.

-General behaviour? Aggression? See participant's background questionnaire to gain info.

2) Can you please describe your child's level of functioning and behaviour with respect to his/her social abilities?

-Has this changed at all over time? If so, why?

3) Can you please describe your child's level of functioning and behaviour with respect to his/her behaviour or mannerisms (where mannerisms can include habits like picky eating, different toileting habits, and so on)?

-Has this changed at all over time? If so, why?

4) Describe a typical day for your child with respect to his/her routine.

-Is your child accessing or involved in any resources/interventions? Please describe.

-What is your role in this routine?

5) Do you feel that there have been any costs associated with your child's diagnosis for you? Costs in this case refers not only to financial costs, but costs or effects to all aspects of your life.

- Probes as listed below.

your family?

-Probes as listed below.

-Has this affected your lifestyle? How?

- Has this affected your health/well-being? How?

- Has this affected your social life? How?

- Has this affected your family unit/marriage? How?

- Has this affected your employment? How?

- Has this affected your finances? How?

6) Has caring for your child had any benefits for you?

-Probes as listed above.

your family?

-Probes as listed above.

7) Is there anything at all that you would like to add that you feel will help me better understand your personal experience?

Appendix E: Background Questionnaire for parents of children with HFA/AS

BACKGROUND QUESTIONNAIRE

1) Please indicate your child's diagnosis (circle one)

-High Functioning Autism

-Asperger Syndrome

2) How long ago did your child receive confirmed medical diagnosis of HFA or AS?

3) Does your child have a history of any of the following? (Check all that apply)

☐ Cerebral Palsy

☐ Congenital anomalies of the central nervous system

☐ Schizophrenia

☐ Focal epilepsy

☐ Tuberous sclerosis

☐ Neurofibromatosis