Athabasca University Master of Arts - Integrated Studies

PARENTAL ATTITUDES AND BELIEFS ABOUT AUTISM AND THEIR CHILD'S BEHAVIOURAL INTERVENTION

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Integrated Studies Project

submitted to Dr. Lorraine Stewart

in partial fulfillment of the requirements for the degree of

Master of Arts – Integrated Studies

Athabasca, Alberta

July, 2011

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Abstract

This paper is comprised of a literature review and the collection of data from parents of children with autism. A brief summary of research on the subject of autism is presented related to aetiological theories, neurological mechanisms and underpinnings, the efficacy of behavioural intervention for children with autism, and quality of life outcomes for these individuals. Data was collected and analyzed from 38 Canadian participants using an online survey to discover what parents of children with autism know about the disorder, what they understand about the outcomes of behavioural intervention and whether they felt they were receiving a comparable behavioural treatment to what they believed they should be receiving. . **Conclusions:** The results demonstrated that many parents are well-informed on current autism research, but there is a percentage of parents who still believe claims that have been well-refuted by the research. It was also discovered that many parents are not receiving the behavioural service they feel they ought to be receiving. The implications of these results are that there is still a need for extensive research in regards to quality of life for the autistic population, as well as wider dissemination of information from the scientific fields of research to the general population since they are the ones who benefit most from this knowledge.

Parental Attitudes and Beliefs about Autism and their Child's Behavioural Treatment

Autism remains a complex and often devastating disorder for both the individual affected and his or her family. In the last 3 decades, this disorder has earned much attention for many reasons. One of the reasons is the unknown cause or aetiology of this disorder. Although many hypotheses have been proposed, a singular or specific combination of causes has yet to be identified. Another reason for the attention is the alarmingly high rate of this disorder now being reported; about 60 in every 10,000 children will be diagnosed with a Pervasive Developmental Disorder (PDD), which includes Autism, Asperger's Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (Chakrabarti & Fombonne, 2001; Fombonne, Quirke, & Hagen, 2009). This number is double the estimation recorded between 1966-2001. This aspect of the disorder alone is one that evokes much attention from the media and from academics. Lastly, treatment for this disorder has always been the source of much controversy, with treatments ranging from behavioural interventions that became popular after a landmark study in the 1980's, to the biomedical treatments that are becoming more popular as a path to a 'cure'.

With the increased awareness of this disorder, there has been a surge of information for parents and professionals. The first part of this paper will offer a summary of the current literature on the aetiology of autism, as well as a brief summary of recent neurobiological findings that can be said to explain the mechanisms or characteristics of autism. It will then discuss the empirical evidence that currently exists on behavioural treatments for this population.

Original data that has been obtained through an online survey administered to parents of children with autism who are currently in behavioural treatment programs, will then be presented. This survey explored parental attitudes and beliefs about their child's autism and how parents believe their behavioural intervention program will affect their child's future. Through the literature review and the survey, this paper will attempt to answer the following questions: (a) what do the parents of children with autism know about the causes and characteristics of autism and how does it compare to what the evidence suggests? (b) What do parents of children with autism know about the effectiveness of behavioural intervention programs and in what ways do parents think the behavioural intervention program will benefit their child? And (c) is there a discrepancy between what parents believe their child with autism should be getting in regards to behavioural treatment and what they are actually getting?

Autism Definition

Leo Kanner and Hans Asperger independently studied children with a certain set of characteristics different from typical mental retardation on the basis of significant social impairment. The names they gave this newly discovered disorder were astonishingly similar: Kanner called the syndrome 'Infantile autism' and Asperger, 'autistic psychopathology' (Folstein & Risen-Sheidley, 2001). These two physicians independently pinpointed the social isolation that these individuals demonstrated, leading them both to give it a name derived from the Greek word 'auto', meaning 'self'. Since then, advances in the research of this disorder have led to the understanding of autism as a spectrum disorder or, Autism Spectrum Disorder (ASD) given how differently the characteristics affect each individual. Current medical opinion defines autism as a disorder in which impairments are evident in the three categories: social interactions, communication, and restrictive and repetitive behaviours (DSM IV, 1994). The autism spectrum includes autistic disorder, pervasive developmental disorder, not-otherwise-specified (PDD-NOS) and Asperger's syndrome.

This perplexing disorder has been the focus of much debate and research. Theories regarding its cause were abundant when recognition of it was in its infancy. To truly understand how this disorder has impacted the families, it is important to look at the theories that have been developed.

Causes: Theory and Evidence

Psychodynamic Theory

One of the first and most unforgettable etiological theories of autism was the 'Refrigerator mother' syndrome described by Bettleheim (1967). In his book, "The Empty Fortress", Bettleheim proposed that the mothers of these autistic children were 'cold' and the resulting psychiatric illness was due to the deficiencies in this mother-child relationship. This theory might have gained popularity due to the anecdotal reports of the parents of these children as social introverts, although since then it has been empirically validated that the parents of these children are no different than others in their parenting approaches (Rutter, 1979). However, it is important to note that although most professionals moved beyond this theory, some countries remained attached to this concept and continued to treat parents of children with autism as if they were the source of the problem. In some countries, this theory persisted as late as the 1990's (Chamak et al., 2011).

Genetics and Patterns of Inheritance

When explaining the genetics of ASD, it is important to understand what is referred to in the scientific field as ‘phenotypes’. A phenotype can be described as the observable characteristics of a living organism, due to the genetic make-up of the organism (Webster’s Online Dictionary, n.d.). When discussing the phenotype of ASD one can describe either the *narrow phenotype*, that is, the observable, clinically significant traits of the disorder, or one can use a *broad autism phenotype* (BAP), meaning observable traits that are of the same nature, but to a lesser degree. For example, an individual that demonstrates the BAP may suffer from impaired friendships, impaired social play, odd behaviour, language delays or language based cognitive deficits (Micali, Chakrabarti, & Fombonne, 2004) but none of these traits would be significant enough that they could be considered debilitating in itself, or a symptom of a serious disability.

In terms of heritability, it has been clearly established by twin and family studies that there is a high heritability estimate for autism. Concordance rates for identical (MZ) twins is anywhere from 60-80% which results in a heritability estimate of around 90% (Freitag, 2007). For other siblings, if one sibling is diagnosed with autism, there is about a 3% chance that another sibling will be diagnosed with autism as well, and when this criteria is broadened to any of the ASD’s, this percentage goes up to 6-7% compared to the risk of this disorder found in the general population of 0.5% (Micali, Chakrabarti, & Fombonne, 2004). However, there is a confounding variable called ‘stoppage’, which is the tendency for a family to stop having children when they have a child who has a significant disability (Spence, 2004). Thus, it might be the case that the actual recurrence rate is either higher or lower than the numbers that have been reported. With the patterns of genetics that currently exist researchers have hypothesized somewhere between 3-12 susceptibility genes for autism that act collectively to result in ASD (Rutter, 2005). When one sibling is affected but others are not, this is likely because the unaffected siblings do not have all of the pertinent genes.

Studies have also shown strong evidence for genetic linkage in non-autistic family members who demonstrated characteristics for the BAP. For example, there have been twin studies that looked at identical (MZ) twins where only one had autism. The vast majority of the twins who did not have autism still had significant BAP difficulties (Le Couteur et al., 1996). This means that even though the twin did not have a formal diagnosis of autism, he/she still had some characteristics of the disorder, and further, these characteristics were similar to their twin's predominant autistic characteristics. Le Couteur et al. (1996) also reported that for non-identical (DZ) twins, this number was considerably less, although still significant as compared to rates in the general population. Micali, Chakrabarti, & Fombonne, (2004) looked beyond immediate family members to first and second degree relatives and found that children with Pervasive Developmental Disorders (PDD), which included autism, were more likely to have first and second degree relatives that had language problems, that were described as being eccentric or having odd personality features but with a specific talent or gift. Similarly, Murphy et al. (2000) found that first degree relatives of individuals with ASD were significantly more anxious, aloof, and eccentric than relatives of individuals with Down's Syndrome who were often used as control subjects to offer comparable environmental factors, without the genetic factors. In a review of several studies, Freitag (2007) reports a rate of somewhere between 10-45% of social impairment (including aloofness and shyness) as well as pragmatic language impairments in parents of ASD children.

Lastly, a number of studies have documented an increased prevalence for other psychiatric and medical illness such as social phobia, depression, and obsessions, in family members of individuals with autism (Yirmiya & Shaked, 2004; Brimacombe et al., 2007; Micali, Chakrabarti, & Fombonne, 2004). Given this evidence we can ascertain that there is a strong genetic bias for autism, as with other development disabilities, but that these genetic factors alone do not account for the existence or development of this disorder.

Environmental Causes (toxin exposure): MMR, Thimerosol, and other Mercuries

Since the report by Wakefield (1998) in which he linked the onset of regressive autism with the Measles, Mumps & Rubella (MMR) vaccine, this topic has received enormous attention from parents and clinicians. Following this study was a fearful reaction from parents who refused to immunize their children with the MMR. This consequently resulted in outbreaks of the measles virus, which until then had been under control (Parker et al., 2005; Macdonald, 2007). The decade following the publication of this study also saw a wave of research that opposed these claims (Honda et al, 2005; Uchiyama et al, 2007; Smeeth et al, 2004; Fombonne & Chakrabarti, 2001). As it turned out, the opposing research was much more convincing than Wakefield’s (1998), who was found to have falsified his data from the small number of subjects that were included in his study (Deer, 2011). In 2010, the journal that published Wakefield’s paper finally retracted it after more than a decade of questions about its integrity, and Wakefield’s medical license was revoked. The medical community clearly no longer accepts this etiological hypothesis, with even Wakefield himself claiming his research was grossly misunderstood (Deer, 2011).

Thimerosal has also been the subject of much debate in regards to autism. Thimerosal is an ‘organomercury’ compound that acts as an antiseptic and antifungal agent (Baker, 2008). In the 1940’s it became popular against other similar agents because it did not decrease the effectiveness of the products it was used in; it could also be used in miniscule concentrations while still retaining it’s properties. It thus became a key component in vaccines as a preservative to prevent contamination. In 1999 the United States Public Health Service (USPHS) and the American Academy of Pediatrics (AAP) stated that there was not yet any conclusive evidence that linked neurological impairments to thimerosal-containing vaccines, but nonetheless ordered the removal of it from all vaccinations (AAP, 1999). Since then it has been widely recognised that thimerosal (as an ethylmercury) is not of the same dangerous nature as methylmercuries, although some parents and parent-groups still cite this as an underlying cause of their child’s autism (Harrington et al, 2006; Mercer et al, 2006; Goin-Kochel & Myers, 2005).

Some work has been done to look at the prevalence of autism in relation to levels of methylmercury found in the environment. DeSoto (2009) found a correlation between rates of autism in school districts in proximity to sites that contained concentrated levels of mercury pollutants. Palmer et al, (2009) had similar findings in Texas when they found that the closer locations were to where mercury was released into the environment; the higher the rates of autism were in local schools. However, the very theory of mercury toxicity as a cause of autism is flawed in that the main characteristics of each one are not at all similar. Characteristics of mercury poisoning include “ataxia, dysarthria, peripheral neuropathy, visual field constriction, hypertension, rash, thrombocytopenia and psychiatric manifestations such as anxiety and depression" (Williams et al., 2008). There is therefore weak evidence that there is a causal relationship between the two and not other confounding variables such as population density or urbanicity, which are critiques of the aforementioned articles (Lewandowski, 2006). Moreover, researchers have not found any consistent nor conclusive mercury levels in children with autism as compared to controls, supporting the notion that mercury poisoning is not related to this disorder (Schultz, 2010).

Despite this, there are still many parents who believe that external events such as vaccinations are the cause of their child's autism. For example, Mercer et al., (2006) found that up to 40% of the 40 participants believed that vaccines either caused or contributed to their child's autism. Harrington et al, (2006) found that immunizations were the number one cause that parents cited for the cause of their child's autism, at 29%, and Goin-Kochel &Myers (2005) found that 70% of parents whose autistic children experienced a developmental regression (in contrast to the condition being present from birth) cited external factors such as vaccinations or environmental toxins to have caused their child's autism. However, recently the authors Dardennes et al. (2011) found that only 4% of 78 parents cited vaccines as a causal factor. It might be the case that the widespread Wakefield (1994) article had an impact on parents worldwide which only now, after its revocation in 2010, can be accepted as misinformation by the general public.

Familial Factors, Obstetric, Prenatal, Perinatal, & Neonatal Events

There is a body of evidence that some pre and perinatal factors may contribute to autism. Zhang et al. (2010) found in a study of 190 subjects with autism in China that there was a much higher prevalence of pre and perinatal factors such as maternal mental state during pregnancy, second-hand smoke exposure, gestational complications, and paternal and maternal age. Brimacombe et al. (2007) also found that numerous prenatal problems may be linked with autism, and conclude that altogether such events can be viewed as a systemic problem of maternal health. This, in turn, may lead to increased chances of autism. Additionally, a large number of other studies support the link between events in the periods surrounding the infant's birth (such as obstetric complications), and autism (Larsson, 2005; Kolevzon, Gross, & Reichenberg, 2007; Burd et al., 1999). Viral and bacterial infections during first and second trimesters (respectively) were found to be a significant risk factor in one study (Atladottir et al., 2010).

More recently, there has been a body of research that has linked maternal and paternal age with increased risk of autism (Croen et al., 2007; Durkin et al, 2008). The authors of these studies posit that this might account, in part, for the dramatic increase in the prevalence of this disorder, as people are now waiting until later in life to have children.

We have explored what is clearly a very dynamic and enigmatic relationship that genetics and environmental factors may play in the causal factors leading to autism. The fact is, given the thousands of studies to date, there is no single answer to this question. Researchers are, however, getting closer to understanding the various mechanisms of this complex disorder, and are starting to uncover what neurological systems are at work in the autistic mind, and how these differ from unaffected individuals.

Mechanisms (neurological underpinnings)

Autism is a disorder that is becoming more and more prevalent and that also expresses itself in vastly diverse ways across individuals. This diversity has made it difficult to pinpoint any exclusive-unifying mechanism, although much research has been directed at trying to uncover this. Recently some evidence has emerged that implicates three major brain regions: the cerebellum, the frontal lobe, and the temporal lobe (Schroeder, 2010).

Cerebellum Findings

The cerebellum is the part of the brain that is responsible for regulation of sequenced movements, as well as functions such as procedural learning, emotion, thought and attention (Allen & Courchesne, 2003), attention shifting (Iarocci & MacDonald, 2006) and many language skills (Katz & Steinmetz, 2002). Many individuals with ASD exhibit difficulties such as impaired language skills, impaired motor sequencing of language, shifting attention from one activity to the next (resulting in repetitive or restricted behaviours and interests), and motor planning and production; therefore, a model of cerebellum dysfunction in individuals with ASD is certainly worth investigating.

Neurological findings support this notion that the cerebellum of individuals with autism shows impairment or certainly functioning different than that of neurotypical individuals. In magnetic resonance spectroscopy (MRS) both Chugani et al. (1999) and DeVito et al. (2007) found reduced levels of a certain neural substrate in individuals with ASD, that would indicate decreased function in the cerebellum. Several authors have found decreased functioning in the vermis area of the cerebellum, based on magnetic resonance imaging (MRI), (Carper &

Courchesne, 2000; Scott et al., 2011). Brambilla et al. (2003) reviewed the current literature and found the number of Purkinje cells of this particular brain region seem to be significantly decreased. This particular part of the cerebellum is the area that receives auditory and visual information, which could in part explain the difficulty many individuals with ASD have with processing this kind of information. Additionally there appears to be an interaction between this brain region and the frontal lobes, which is another region of the brain that has yielded some evidence of dysfunction within individuals with ASD.

Frontal Lobe Findings

The frontal lobe is responsible for many higher-order cognitive functions for tasks which can together be termed ‘executive functioning’. This includes language, social and emotional functions and the frontal lobe also contains an area responsible for language mediation called ‘Broca’s area’. Researchers suspect that some of the essential ‘mirror neurons’ can be found in the frontal lobe, and that these may play a crucial part in imitation skills and; therefore, learning (Williams et al., 2006; Perkins et al., 2010). With all of the responsibilities that this brain region has, it would make sense to discover frontal lobe dysfunction in individuals with autism given the characteristic cognitive, social, and language impairments they exhibit. Neurological findings support this notion, with atypical brain activity demonstrated in functional magnetic resonance imaging (fMRI) of individuals with autism in comparison to non-affected individuals during tasks designed to test different brain functions. For example, when Baron-Cohen et al. (1999) presented a task that involved matching words that described mental states with pictures of eyes that depicted them, he found that individuals with autism used the temporal lobe structures while unaffected individuals used the amygdala for this task. The amygdala is associated with emotional reactions, whereas the temporal lobe structures are specialized for verbal labelling and processing faces. Thus, where unaffected individuals use *emotion* to engage in this task, autistic individuals treat it as a *visual* problem solving task. Similarly, Happé et al. (1996) found that during tasks in which individuals were asked to attribute mental states onto others in stories told to them (Theory of Mind/ToM tasks), individuals with autism used different areas of the frontal lobe than neurotypical individuals overall. The brain activity suggested that ASD individuals used the parts of the brain responsible for general purpose reasoning skills as opposed to using the part used for inferring mental states. Schulte-Ruther et al., (2011) had subjects perform ToM tasks as well as evaluate their own emotional state, and found that subjects with autism, although they performed equally well on the ToM tasks, activated different parts of the frontal cortex than non-autistic control subjects. Additionally, they did not perform as well for the tasks that required them to identify their own emotional response. Lastly, it seemed that non-autistic control subjects activated areas in the frontal cortex that have been associated with the mirror neurons/system for both tasks, whereas the autistic subjects activated this system only when doing the 'self' task. This evidence points to dysfunctional activity in the frontal lobe during tasks that isolate some of the core deficits of autism spectrum disorders.

Temporal Lobe Findings

Lastly, the temporal lobe is also an area associated with dysfunctional brain activity in subjects with autism. The functions of the temporal lobe include memory, auditory and visual perception, as well as the processing of speech via a specific area called Wernicke's area. It also contains three very significant regions: the amygdala, the superior temporal sulcus (STS), and the fusiform face area (FFA). These three areas are considered to be central in facial perception and social cognition (Schultz, 2005; Pelphrey & Carter, 2008). Research done on these brain areas has produced convincing evidence to support the hypothesis that they are not functioning normally in individuals with ASD. For example, Ashwin et al. (2007) discovered different activity in subjects with autism during the perception of fearful facial expressions which included a lack of differentiation in activity as the intensity of the facial expression increase, for which the converse was seen in control subjects. Castelli et al. (2002), found that autistic subjects showed significantly reduced connectivity between the STS and other regions of the brain while engaging in these tasks as compared to control subjects. Schultz (2005) proposes a model whereby the Amygdala and the STS form a system that functions together, based on the multiple fMRI results attained that indicate that this system is dysfunctional in ASD individuals. They therefore conclude that the STS is central to the core deficits seen in autism.

Research has now demonstrated a strong genetic basis for autism, as well as underlying neurological dysfunction associated with the core symptoms of this disorder. The research presented here is in no way exhaustive; rather, it is a very brief summary of a selection of the research that may help parents and service providers to ASD individuals shed some light on their condition from the perspective of the current evidence.

Behavioural Treatment and Autism

Behaviour Analysis is a scientific field that measures environmental variables and how they effect and change behaviour; Applied Behaviour Analysis (ABA) is the application of this science in socially significant ways (Miller, 2006). Essentially, the field of ABA helps to change an individual’s behaviours by identifying and modifying the triggers and consequences that co-occur with behaviour. Behaviours are analyzed and are identified as either requiring a decrease (problematic behaviours) or an increase (positive behaviours that include learning, communication, and other adaptive behaviours). Procedures are then put into place to do so accordingly. Behaviour analytic interventions are now the most recommended for children with ASD, particularly Intensive Behavioural Intervention (IBI), an intervention approach which utilizes all of the principals of ABA, in addition to specific sets of teaching methods that are intensively applied (20 hours or more a week). Within the large ‘umbrella’ of ABA-based treatments for children with autism, there are several popular ones that can be applied as an IBI program which include the Lovaas approach, Verbal Behaviour, and Pivotal Response Training (Autism Society of Canada, n.d.). Although behaviour-based interventions offer some promising results for this population, the evidence is not as straightforward as one might expect.

For the purposes of this paper, and as it pertains to intervention programs for children with autism that are based in applied behaviour analysis, all of these interventions will be hereafter called ‘ABA’, regardless of whether they were IBI programs as well.

Positive findings

The most prominent study that evoked the initial interest in ABA for children with autism was the study published by Lovaas in 1987. In this study, Lovaas gave 19 children in the experimental group 40 hours of one-to-one behaviour modification , and compared results against two control groups, one of which received 10 hours or less of one-on-one intervention, and one that received none. The results, as reported by Lovaas, were that 47% of his experimental group, in contrast to 2% of the control groups, achieved normal ‘intellectual and educational functioning’ (Lovaas, 1987). McEachin, Smith, & Lovaas (1993) followed up on these subjects and found that the gains made by the experimental group were retained years later. In these studies, the authors originally used the term ‘recovery’ for the optimal outcome individuals, and since then there has been much controversy about the use of this word to describe the results of this study (Shea, 2004; Herbert & Brandsma, 2002). Although many more studies have contributed to the evidence that exists on the efficacy of ABA intervention to improve cognitive, verbal, and other adaptive skills, none have used the term ‘recovery’ since.

One such study is Smith, Groen & Wynn (2000), in which 15 children with ASD received intensive behavioural intervention and were compared to a group of children whose parents received training in the same basic principles and procedures for 3-9 months. The results of this study were that the subjects in the intensive behavioural group outperformed the parent-training group in the areas of intelligence, visual skills, language, and academics and they also tended to require less support in the educational environments. Eikeseth et al., (2002) found that 13 subjects with ASD who received behavioural intervention showed larger increases in IQ and adaptive functioning as compared to a group of 12 controls who received eclectic treatment. Similarly, Cohen, Amerine-Dickens & Smith, (2006) reported that 21 children with ASD obtained higher IQ and adaptive functioning scores than 21 children matched for IQ and age who received unspecified special education services in their local schools. Howard et al. (2005) also found that intensive behavioural intervention produced significantly better results in all skill areas when compared to a group receiving eclectic treatments. Several other studies and meta-analyses’ showed overall positive results that range from increased IQ scores to improvements in adaptive behaviours and communication skills (Harris et al., 1991; Howlin, Magiati & Charman, 2009; Makrygianni & Reed, 2010; Kelley et al., 2009; Virués-Ortega, 2010).

Researchers have investigated intensity of hours as a variable of intervention, as many believe that the more hours a child receives of this intervention weekly, the better the outcome of the child (Granpeesheh et al., 2009; Lovaas, 1987; Smith, 2000). However, there has also been a body of research to show that ABA can be effective even if not done with the intensity of hours that was initially prescribed by the early researchers in the field such as Lovaas (1987). For example, Eldevik et al, (2006) as well as Peters-Scheffer et al., (2010) both found positive outcomes associated with low intensity ABA intervention (12.5 hours and 5-10 hours, respectively). These outcomes included gains in intellectual and adaptive functioning, and in the Eldevik (2006) study found that these gains were maintained over the 2 year follow up period. Another variable of intervention is the amount of parent training received in basic behaviour principals as well as the specifics of their child's individual program. In their meta-analysis Makrygianni & Reed (2010) found that the difference between an ABA program and a comparison/eclectic program was greater if the behavioural program had a parent-training component. They also found that although most service providers stated that this was an integral part of their program, only half of them actually provided these services to parents. Other variables that have been shown to predict outcome are variables such as pre-treatment receptive language scores (Itzchak et al., 2008), cognitive and social interaction levels (Itzchak & Zachor, 2007), intelligence levels (Gabriels et al., 2001; Goin-Kochel et al., 2007), and age at onset of treatment (Kelley et al., 2009; Granpeesheh et al., 2009).

Other findings

The most noteworthy point to make in terms of negligible findings is in relation to the original Lovaas (1987) study which is most commonly cited in the research. Since the publication of this study, Lovaas has been criticized by some for the methodological weaknesses of the study. These included the selective assignment of subjects to both the treatment or control groups, and the outcome measurements not being indicative of actual changes in functioning or severity of impairment (Herbert & Brandsma, 2002). Another methodological flaw that has been revealed is that a clinical rating scale that was used to measure outcomes was created by the authors of the study, implemented by a psychology graduate student, and has never been used since causing weakness to the study's internal validity and reliability (Shea, 2004). The 47% of Lovaas' subjects who achieved this 'normal educational functioning' has been a goal sought after by many researchers. Smith, McEachin & Lovaas (1993) explained that in the case of this study, 'normal educational functioning' meant that no extra provisions were made for the child in a regular, mainstream classroom. Unfortunately, no other study could replicate these results, and the closest was Sallows & Guptner (2005) who had 33% of their 24 subjects succeeding with no assistance in a regular classroom (all of whom were categorized by the authors as 'rapid learners'). Currently, a great number of children who have received ABA are integrated into regular classrooms, but the overwhelming majority of them require support in some shape or form to be able to perform in this environment (Magiati et al., 2011; Smith, Groen, & Wynn, 2000; Cohen et al, 2006). Further, this normal educational functioning that was achieved by the best outcome subjects is questionable given that there were no teacher or peer interviews reported with the findings (Lovaas, 1987; Shea, 2004).

Other research has added to the doubt about this intervention's supposed efficacy. For example, Goin-Kochel et al., (2007) found that even though there *were* a proportion of children that made significant gains across all skill areas following ABA treatment, the number of them who did not make gains was sobering. Likewise, in the Magiati et al., (2011) study mentioned above, the authors admitted that despite what appeared to be significant improvements in a range of skills, the rates of these gains for the children with ASD were not comparable to the rate of their typical peers' rates and that most made relatively small gains.

Zachor & Itzchak, (2010), found that the progress made by young, children with ASD in ABA intervention was comparable to the progress made by children with ASD in eclectic intervention groups, leaving the authors to surmise that if intervention is given early enough, the type of intervention might not matter. In a meta-analysis done by Spreckly & Boyd, (2009), they determined that there is insufficient evidence to claim that behavioural intervention offers a better prognosis than standardized care, although there has been some controversy on how their meta-analysis was conducted and the details that were overlooked may have resulted in such a statement (Kimball, n.d.).

In a review of the research on early intensive behavioural intervention (EIBI) Matson & Smith (2008) posit that although there seems to be strong evidence to support this treatment approach, there is a distinct lack of evidence on how these gains are maintained over decades and into adulthood. Matson & Smith (2008) also point out that although almost all of the evidence that exists uses IQ scores as a measurement of pre and post-test gains, a more valuable measure might be changes in core symptoms of ASD and challenging behaviours as these would give a better picture of the everyday functioning of these individuals. Given the enormous cost of this therapy which can range from a few thousand up to $50,000 per year, this should be taken into consideration before making the financial and emotional commitment. Parents should also be informed of-the current statistics and outcomes.

Quality of Life findings

Quality of life (QoL) is a term that is used to describe a set of characteristics in an individual’s life that offers some measurement of that individual’s general well-being in all domains of their life (Schalock, 2004). Most of the research on autism intervention has offered outcome measurements that are fairly uni-dimensional as Matson (2004) points out, with IQ scores being the most prolific. Ruble & Dalrymple (1996) argue that using traditional outcome measures might not be the most telling measurement of outcomes, and that using measurements of QoL, might offer more perspective on how individuals with autism fare as adults. At the present time there are a handful of studies that have looked specifically at the QoL of adults with autism which offer mixed opinions. What is missing from the current literature is research that demonstrates a relationship between childhood ABA intervention and adult QoL outcomes. To date, there does not seem to be even a single study. This means that currently no inferences should be made as to whether or not this intervention actually does lead to a better QoL for individuals with ASD when they reach, or as they transition into, adulthood. Therefore, in the absence of this research, the current literature on the general QoL of adults with ASD will be examined instead, in an effort to offer a vision of what the lives of these individuals look like as adults.

Employment and Living Situation

Although mixed, it is fair to say that the majority of the findings on QoL for adults with autism are disheartening. For example, when looking at the living situation of these individuals, studies found that, in general, there were very few individuals who lived independently, and most lived with their parents or required much support (Engstrom, 2003; Howlin, 2004; Renty & Royers, 2006; Eaves & Ho, 2008; Saldana et al, 2009). The literature demonstrates that regular employment is not an expected outcome for adults with ASD. Rates of regular employment range from 6% (Engstrom, 2003) to up to 50% for adults with ‘high functioning’ autism (Howlin, 2004), with other findings ranging between these rates (Renty, 2006; Jennes-Coussens et al, 2006; Orsmond, Krauss & Seltzer, 2004; Eaves & Ho, 2008; Saldana et al, 2009). In all of these studies many of the individuals held either supported employment or were in employment programs. Thus, although it is fair to say that these individuals have not achieved a high quality of life in these regards, programs that aim to improve this aspect of QoL seems to be a common goal for support workers and resources.

Relationships

Perhaps the most problematic area of QoL for individuals with autism is in regards to relationships and social interactions. In one meta-analysis, it was determined that only about 5-10% of individuals with ASD were married or in intimate relationships (Levy & Perry, 2011). Virtually every study on outcomes for adults with ASD has demonstrated that the greatest concern is poor social outcomes and few to no peer relationships for these individuals (Engstrom, Ekstrom & Emilsson, 2003; Orsmond et al. 2004; Howlin, 2004; Billstedt, Gillberg & Gillberg, 2007; Eaves & Ho, 2008; Saldana et al., 2009).

Although there is a body of research that demonstrates that variables such as performance and verbal IQ's are predictors for positive outcomes in adult life (Billstedt, Gillberg & Gillberg, 2007; Howlin et al, 2004; Eaves & Ho, 2008), it cannot be said that better outcomes are a direct result of these interventions (Howlin et al, 2004). To date there does not seem to be any published research on parental beliefs regarding behavioural intervention outcomes. This study aimed to provide some information on this topic, as well as to add to the information in regards to parental beliefs about their child's autism. With this in mind, and given the distinct lack of research that shows a relationship between the kind or quantity of early intervention and the outcomes in adult life, it is clear that the field of autism research must provide clear, long-term outcomes resulting from ABA interventions, for this population.

Parent Survey:

Parental Attitudes and Beliefs about Autism and their Child's Behavioural Treatment

Methods

Participants

Participants of this study were parents of children who met the following criteria: were 18 years or younger, diagnosed with ASD and were in a behavioural intervention program. A total of 38 parents completed the survey. Of these parents, 9 were from Quebec, 13 from Ontario and 16 from British Columbia. Known contacts of the principal investigator from these three provinces (professionals working in the field and ex-clients) were sent an email which contained the link to the online survey, and were asked to send this email out to any potential participants who met the criteria. In addition to this contact, a listing with a link to the survey was posted on various online forums such as AutismOntario, AutismSupportOttawa, and ABAtherapyOntario. The results were accessible in an online database only by the principal investigator and then downloaded onto her personal computer, after which they were erased from the database.

Parent Questionnaire

The survey was delivered as an online questionnaire to the participants. Questions in the survey consisted of open ended/short answer, multiple-choice, and Likert response scales (5 choices). There were 11 questions in total. Two of these questions consisted of 37 statements that required rating on a Likert scale. The questionnaire was divided into the following sections: i) demographics and ABA program characteristics ii) parental beliefs on the cause(s), the characteristics, and the mechanisms of their child's autism iii) parental beliefs about ABA therapy and their child's future as a result of having received this therapy. The survey, when tested by separate evaluators, took between 4-7 minutes to complete. It was tested by some parents of children with ASD as well as service providers to make sure that the questions were easily understood and to check for any obvious missing response choices.

Data Analysis

The data was analyzed across several response categories. Some of the data was analyzed as a whole, to see what, in general, the parental beliefs and attitudes were about ABA and their child's autism. Other responses were analyzed according to the location of the participant (province): hours of services received, type (private or government), and approach in ABA used. Percentages of the ratings were calculated and graphs were created to visually demonstrate the relationship between the variables.

Results

Age and program characteristics

The earliest age of diagnosis for the children in the study was 18 months, and the eldest was 5 years 5 months. The majority of children received a diagnosis when they were between the ages of 2 and 3 years. The largest group of respondents (28.9%) had children who were receiving between 20-30 hours of intervention weekly. When analyzed province by province, there are large differences across the number of hours of intervention received. In Quebec, 33% of participants are receiving either 3-6 or 6-9 hours; 22% are receiving 15-20 hours; and 11% are receiving 9-12 hours. None of the participants in Montreal were receiving more than 20 hours of intervention weekly. In Ontario, 53% receive between 20-30 hours of intervention weekly, and in British Columbia, 25% received 20-30 hours of intervention, and a further 6% received more than 30 hours (appendix A).

Almost a quarter of parents (n=9) were not able to classify their child's program approach, although one parent responded using the 'other' category, and then offered a short response that was in one of the multiple choice responses listed (although the parent used an acronym for this approach). This may have been because the participant did not read the choices thoroughly, or may not have understood what the acronym stood for. Almost half of all participants (47%) had programs supervised by Board Certified Behaviour Analysts (BCBA), with Psychologists accounting for a further 18% (n=6). This is in contrast to the 76% of participants who believed that the person in charge of their program *should* be a BCBA and the 8% who believed this person should be a psychologist. Only 8% of participants responded using the option 'Behaviour Consultant with no specific certification' as the title of the supervisor of their program (appendix B), but 18% used the 'other' response choice.

Most striking of all the results were the responses given when participants were asked to rate how much they agreed with the statement "ABA is an intervention program in which parental involvement is essential" 86% agreed with this statement. However, at the same time, 84% of participants responded 'no' to the question "Do you or your spouse spend more than 1 hour a week being trained by your service providers for your child?" (Appendix C). Likewise, 50% of parents disagreed with the statement "IBI/ABA intervention is best left to the professionals; procedures implemented by parents may inadvertently sabotage any work done by them".

Parental Beliefs on Cause and Mechanisms of Autism

When asked about what they felt was the cause of their child's autism, roughly a third of participants (28%) felt that it was a combination of genetic predisposition combined with environmental exposure, followed by 'unknown' (26%), genetics (18%), and finally environmental exposure (13%) (Appendix D). When asked how much they agreed with the statement "Social impairments in autism are caused because of an excess of heavy metals such as mercury in their blood", most participants did not know or remained neutral (44%), while 17% agreed with this statement. However, the majority of participants agreed that autism was primarily a disorder of social impairment (76%), and that its characteristics such as impaired speech, social interactions, and disruptive or repetitive behaviours were caused by neurological differences in brain functioning (86.9% - 95.6%).

Parental Beliefs Regarding ABA and their Child

73% of participants agreed that ABA was currently the only successful, evidence-based intervention for ASD. However, 29% of them agreed with the statement that about half of all children in ABA programs have been shown to recover from autism, and a further 31% did not know. In contrast, when presented with the statement "IBI/ABA intervention is the only intervention that may lead to recovery for my child", although the majority remained neutral or did not know (36%), slightly more parents tended to disagree with it (34%) rather than agree with it (29%). About a third of participants (31%) remained neutral in response to the statement “40 hours or more is the most important reason for some children recovering from autism” but more tended to agree (42%) than to disagree (26%). When asked about their attitudes towards the term ‘recovery’ in response to the statement “Recovery means being normal in every sphere of functioning”, 54% of participants agreed with this statement.

Concerning parental expectations from ABA for their child, the majority of parents agreed with statements saying that ABA is the best way for their child to learn skills such as self-help skills (toileting, eating, dressing), functional language skills, academic skills, and the self-management of problem behaviour (78% of participants and over for each statement). For the statement “IBI/ABA intervention will significantly alter my child’s future quality of life, allow them to attend a regular school, and live a relatively normal life”, the majority of participants agreed (63%). Most parents did not know whether ABA intervention would help their children get married (59.5%), but at the same time the majority agreed that ABA would help their child get a job (44%), and have fulfilling friendships as adults (47%).

The majority of parents seemed to agree with the literature on the topic of age of intervention. Most provincial governments offer this intervention to children only until the age of 6 years citing the Lovaas (1987) research as evidence that treatment after this age might not be effective. However, most parents disagreed with the statement “Doing IBI/ABA intervention with children after the age of 6 years old may not be effective” (56%), as well as to the statement “IBI/ABA intervention is only effective if started before the age of 3” (71%). Lastly, when given the statement “In some cases, IBI/ABA may not be effective”, 55% agreed.

Discussion

This survey attempted to respond to three research questions. The first one was: What do the parents of children with autism know about the aetiology and characteristics of autism and how does it compare to what the evidence suggests?

Parents seem to be more informed on some topics to do with autism than on others. For example, although the research points almost exclusively to the genetic basis of autism, 41% of parents believed that environmental exposure to toxins played at least some part in their child's autism. The percentage of parents who fully blamed environmental toxin exposure (13%) was relatively low compared to previous research on this subject (Mercer et al., 2006; Harrington et al, 2006; Goin-Kochel &Myers, 2005). However, even this percentage is worrying as there has been no conclusive evidence to support this theory at all. Similarly, there was also a percentage of participants (17%) who felt that some of the characteristics their child demonstrated were caused by an excess of certain toxins in their blood.

However, the majority of parents (86.9% - 95.6%) accepted that the characteristics their child displayed were due to neurological differences in the brain functioning, which is consistent with the research, and that autism is primarily a disorder of social engagement and interaction. Although parents displayed greater knowledge about the factors of their child's autism than was evidenced in the research, there is clearly still a need for the ongoing dissemination of information to parents that may refute the misinformation they might be getting from questionable sources.

The second research question was: What do parents of children with autism know about the effectiveness of ABA/IBI programs and in what ways do parents think the behavioural intervention program their child is in will benefit them?

The survey findings are mixed. Most parents (78%) were knowledgeable about the skill sets such as self-help, academic, and behaviour management that were likely to improve as a result of this intervention. They also agreed that intervention could be beneficial to a child even if not started before the age of 3, and if continued past the age of 6. Furthermore, 55% of parents seemed aware that a proportion of children do not make significant progress, which is in keeping with the literature as well. Also, parental attitudes about the idea of recovery seemed to be one that covers all domains of functioning, as opposed to the narrow measures of IQ that has been the focus of the majority of past research. This is a positive trend that one hopes may help guide research in the field to encompass holistic QoL issues. However, almost a third of the participants (29%) believed that, to some extent, about half of all children in these programs will make a full recovery from autism, and a majority (42%) believed 40 hours or more of therapy is the reason some children might recover. Besides recovery not being mentioned in any of the literature beyond the first Lovaas (1987) study, its findings have not been replicated in studies that are methodologically sound. Additionally there is strong evidence that measures of pre-treatment performance and verbal IQ, as well as cognitive and social interaction skills are better predictors of optimal outcome.

Lastly, many parents believed that these programs would make a considerable difference to their future quality of life in areas such as educational functioning (63%), employment (44%), and relationships (47%). In terms of educational functioning, the literature has shown that only a small proportion of children from ABA programs managed to succeed in regular classrooms without help. As there is currently no long term, controlled research on employment and relationship outcomes as a result of ABA intervention, it is difficult to say whether this belief corresponds to reality. However, as the literature has demonstrated, adults with ASD were found to have quite poor measures in these two areas of quality of life. Thus, although one might say that parents are well-informed on some topics, it is clear that further QoL research as it specifically pertains to ABA intervention is absolutely necessary; and again, the need for this information to be conveyed to parents effectively.

There is another interesting point in regards to parental knowledge of their child’s program and ABA in general. The principal researcher has been a service provider in the Montreal region for almost 10 years in both the public and private sectors, and is well-connected to the small network of other professionals in the field. It is a small community in which everyone knows the other professionals, their methodological tendencies, philosophies, and even business models. In light of this informal yet reliable information, some of the details related to ABA programs given by Montreal participants were surprising. For example, most participants described their child’s program as a Verbal Behaviour (VB) Approach. This is unusual as only two clinics are known to offer this as a comprehensive program: one government service provider and one private clinic (owned by the principal investigator and therefore from which no clients were asked to participate, due to potential conflict of interest. Other service providers have been known to claim that they were providing such a service by using a few elements of the methodology, but firsthand experience of these programs indicates that they are not the ‘package’ that has become well-known in the ABA community as VB. What makes these results more interesting is that the parents who described their programs as VB had supervisors in charge of their program that did not correspond to the details of the service providers in Montreal who do provide a recognized VB program. The problem may be that either service providers are calling programs by a name that may not be completely accurate, or parents may be confusing the qualifications or title of their supervisor, or both. These problems may be due to the lack of any regulating bodies or organizations in Quebec that may also act as sources of reliable information for consumers of ABA services, and certainly demonstrates the need for such resources.

The last research question was: Is there a discrepancy between what parents believe their child with autism should be getting in regards to behavioural treatment and what they actually are getting?

Certainly the last point made demonstrates that parents in Quebec may not be getting a service that they believe they are. Additionally, although many parents (47%) did have a supervisor who was a Board Certified Behaviour Analyst (BCBA), it was not nearly as many as the number who believed that a BCBA should be supervising their program. Of the 18% who responded that their supervisor fell under the ‘other’ category, several of the short responses offered were titles such as ‘Sr. Specialist’, ‘ABA supervisor’, or ‘Instructional therapist’. An ABA supervisor (who works in the field of autism) is, minimally, someone who has an understanding of basic behaviour principles and has experience in the application of these principles within the context of the education of individuals with autism. An apt name for this kind of individual would therefore be a Behaviour/Behavioural Consultant (with no specific certification). Some parents did not seem able to understand that their supervisor fell under this category. Thus, in this way parents may have also believed that they were receiving a service supervised by a specialized, highly qualified and credentialed professional, where in reality they were not.

In regards to hours of intervention, the majority of parents (42%) believed 40 hours or more was necessary for a chance at recovery for their child, but only one participant was receiving over 30. There is clearly, then, a very big discrepancy between what parents feel they ought to have access to in order for their child to benefit the most, and what they actually have access to. Furthermore, with almost half of all participants paying for their therapy either in part or entirely, this could place a huge financial burden on each family as they try to offer as much of this therapy as possible. The substantial differences in the number of hours of intervention received by each child across provinces (appendix A) may also speak to how each provincial government differs in their financial aid of these services. In turn, it can be seen that not all provinces in Canada have a consistent support program for this population and the services they receive.

Lastly, the most striking results (appendix C) show the difference in parental attitudes about parent training versus their actual experiences. Again, there is a large discrepancy between the involvement and training parents feel is essential (86%) and their actual involvement or training (16%). This may be due to many factors such as service provider’s willingness to train parents, requiring parents to become trained, and parent willingness and energy level to take training when offered. Whatever the reasons, it is undeniable that support is required on this level, and service providers must make steps towards comprehensive parent-training, irrespective of what the parents may say at the time. Given that both the literature and parental attitudes support overwhelmingly this factor in ABA intervention, steps such as mandating parent training might be considered.

Limitations and future directions

There are several limitations to this research. The major limitation is the small sample size of only 38 which cannot be representative of Canada as a whole. In addition, the very small Quebec sample made it impossible to create an authentic comparison across provinces. The majority of participants were from British Columbia (42%, n=16), which was surprising given that the link was given to only 2 service providers in this province. 34% (n=13) of the participants were from Ontario, and 23% (n=9) from Quebec. This is also surprising given that the principal investigator sent the link to almost 30 of her known contacts from the near-decade she had worked there. Although this might be due to possible feelings of conflict of interest due to their association with her in the past, as they were asked to send it onto parents they knew themselves who were not known contacts of the principal investigator, it seems unlikely this conflict of interest actually existed. The response rate for each province may be indicative of each individual province's willingness to participate in such research, and their general attitude to becoming involved in general. This would certainly be an area that future research might explore.

There were other limitations regarding the design of the survey. For example, the survey offered an open-ended short response for the participant's location; in the future, this question should be offered as a single response, multiple-choice question by province. This would allow for much easier classification and cross tabulation of the data, as province-by-province data is not readily available in the current literature. Also, when asked to describe their supervisor's qualifications, many participants responded using the 'other' choice, and described a supervisor who was a combination of two professions such as BCBA and Psychologist, or Speech Language Pathologist and BCBA, thus a survey designed for future use might allow for participants to choose any combination of these. Further, there are many titles that have been created to encompass the ever growing professional field of those involved in ABA and ASD’s, with many of these titles unique to a city or province. If this survey was to meet a larger audience, the ‘other’ column would certainly have been overwhelmed by these titles. Future studies might offer a better definition of an ABA supervisor with no specific qualification or specialized knowledge.

Lastly, it was impossible to verify the information that parents offered about their child’s program. This did not seem to be a problem before this study took place as the researcher took it for granted that a parent would know the details of their child’s intervention program, such as the credentials of their supervisor and the approach being used. However, given the data received from Quebec and the researcher’s knowledge of the small community that exists, it seemed that a small number of parents were so uninformed about their child’s program that they could not accurately respond to these questions. Therefore, the data is misleading. Parental knowledge about intervention is important, even essential, and this study revealed the need to ensure parents have the knowledge needed to make informed decisions.

Conclusion

This paper has offered a brief summary of some important topics in autism research, presented some original data that explored the attitudes and beliefs of parents of children with ASD, and in doing so also attempted to answer three research questions. The conclusions cannot be generalized beyond this study due to the limitations noted. However, the data gathered and the literature reviewed demonstrate the need for further research on autism to help ensure that parents and service providers make informed decisions to support children’s success.

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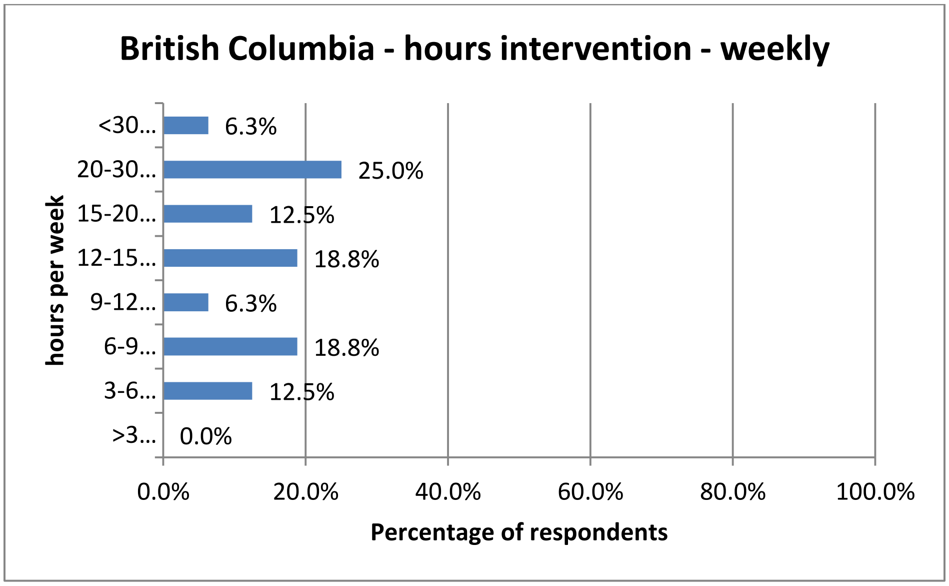
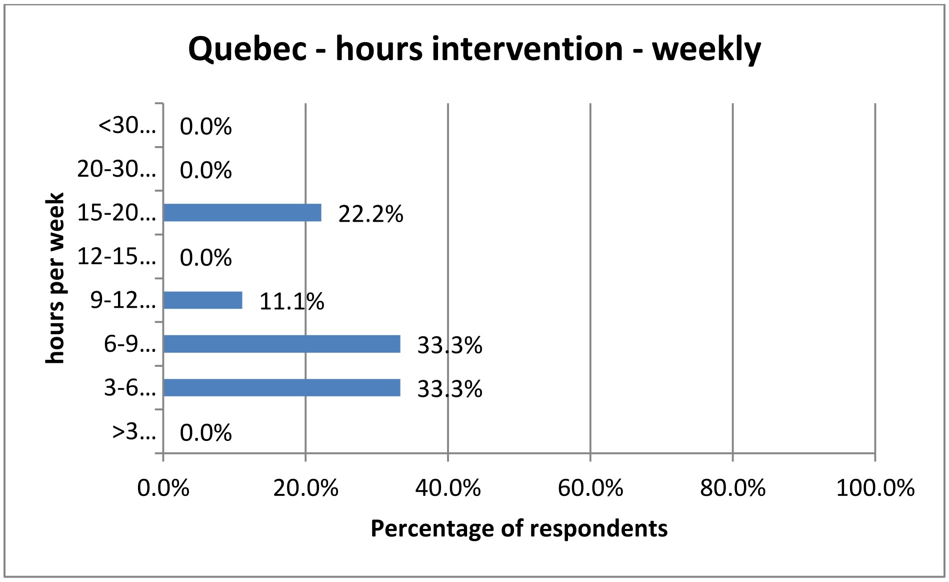
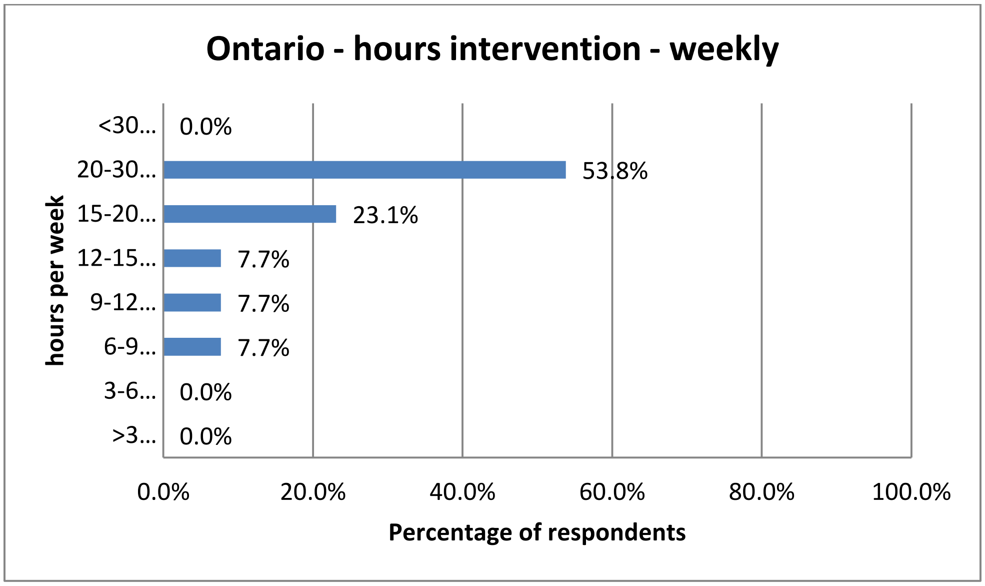
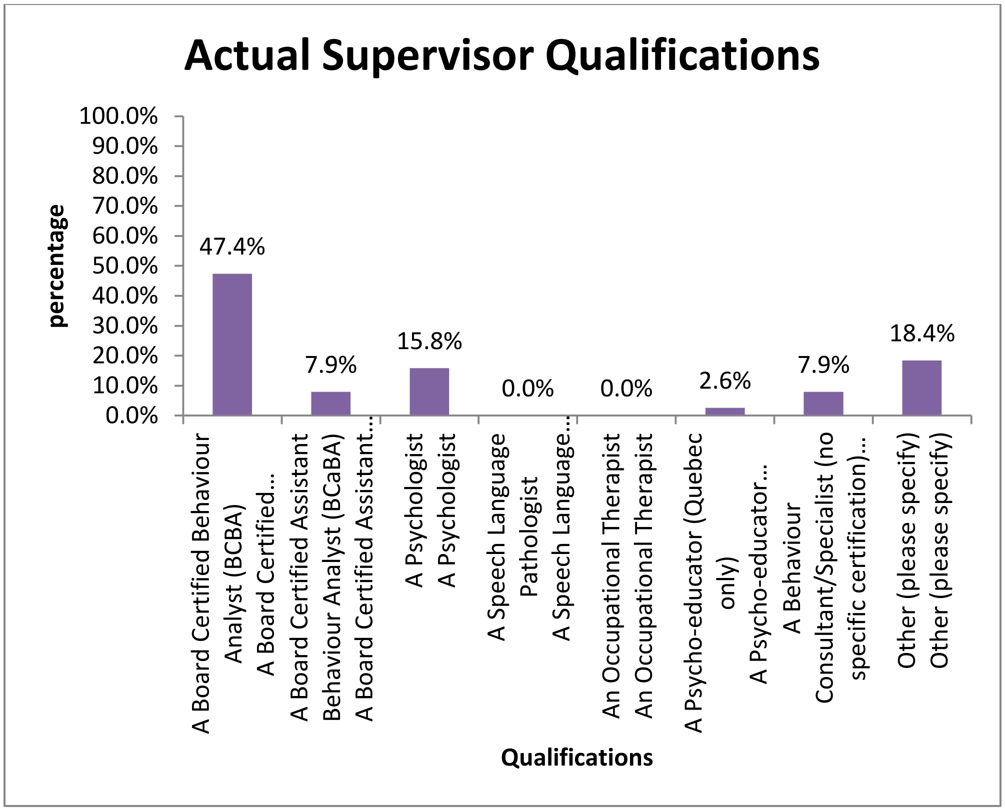


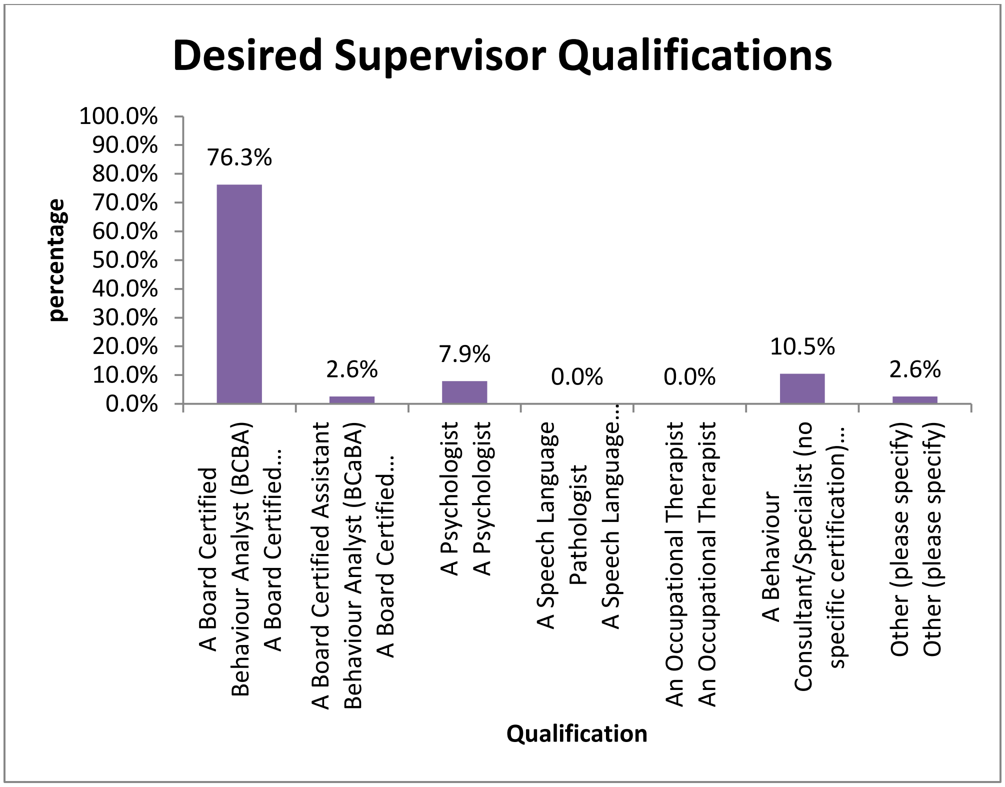


Appendix A: Number of hours of intervention weekly, by province.

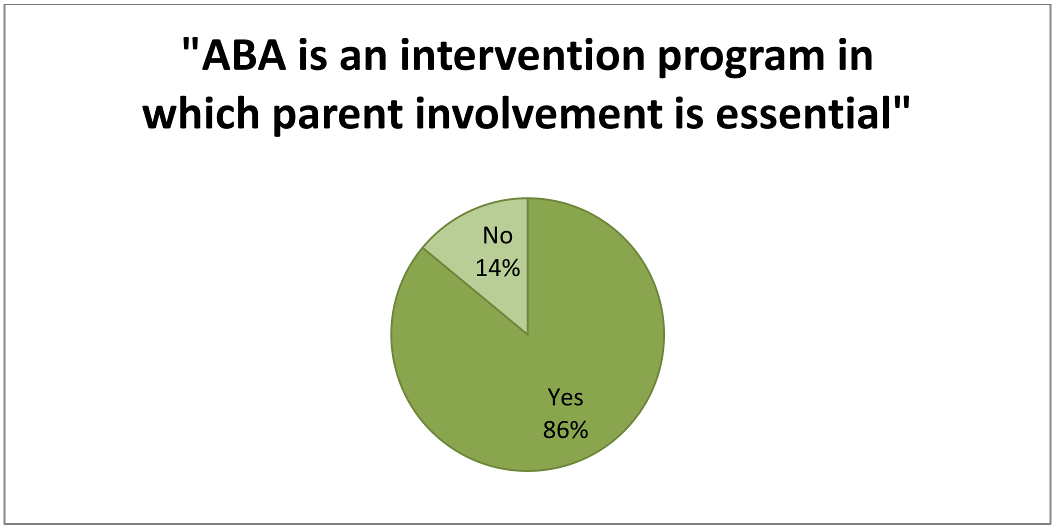


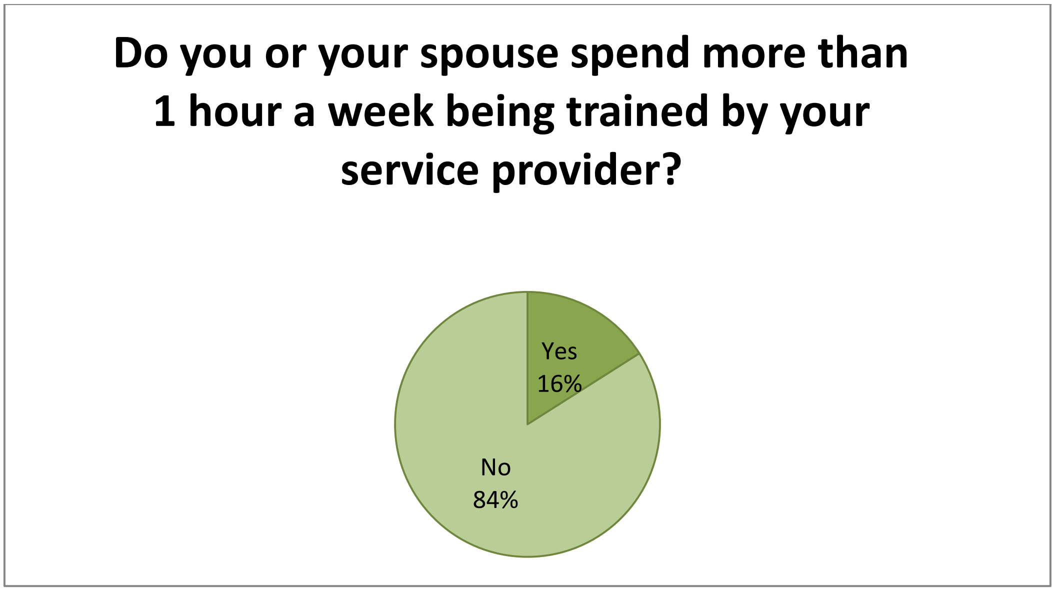
Appendix A: Number of hours of intervention weekly, by province.



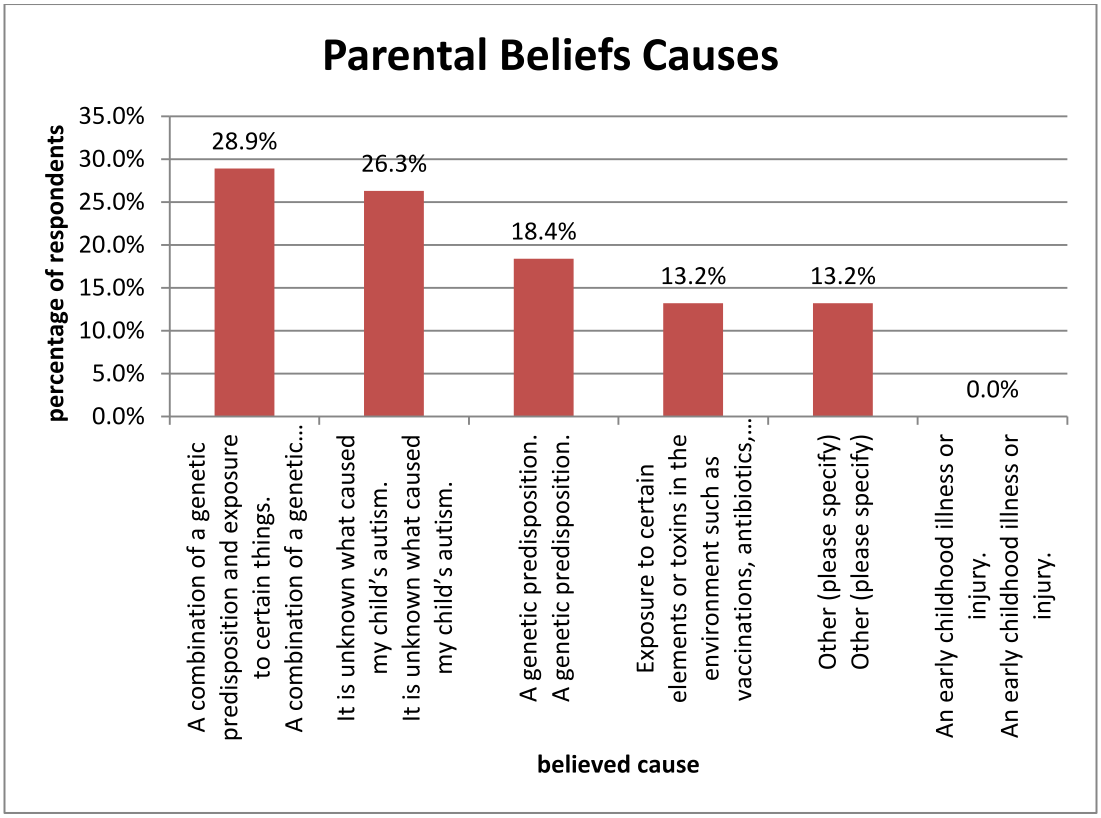


Appendix B: Supervisor qualification (by percentage) versus parent desires for supervisor qualifications





Appendix C: Percentage of parents who believe parental involvement is essential in behavioural intervention programs versus percentage of parents who receive regular training from their service provider.



Appendix D: Parental beliefs regarding the cause(s) of their child's autism (percentage).

Answer Options	strongly agree	agree	neutral or don't know	disagree	strongly disagree	Rating Average	Response Count
IBI/ABA is the only intervention that is scientifically proven for children with ASD.	14	14	4	5	1	2.08	38
About half of children in IBI/ABA programs have been shown to recover from autism.	2	9	12	12	3	3.13	38
40 or more hours per week of IBI/ABA therapy is the most important reason for some child	5	11	12	8	2	2.76	38
'Recovery' means being normal in every sphere of functioning.	5	15	5	10	2	2.70	37
Most IBI/ABA programs are equal, as long as there is a qualified professional leading the pr	4	3	6	14	11	3.66	38
IBI/ABA intervention is the best way for my child to learn functional skills such as the self-m	16	14	3	2	2	1.92	37
IBI/ABA intervention is the best way for my child to learn functional language skills.	13	17	6	1	1	1.95	38
IBI/ABA intervention is the best way for my child to learn functional skills such as self-help s	16	18	2	1	1	1.76	38
IBI/ABA intervention is the best way for my child to learn academic skills.	13	18	5	0	2	1.95	38
IBI/ABA intervention will significantly alter my child's future quality of life, allow them to atter	13	11	10	2	2	2.18	38
IBI/ABA intervention will help my child get a job in their adult life.	7	10	16	2	3	2.58	38
IBI/ABA intervention will help my child get married in their adult life.	5	4	22	3	3	2.86	37
IBI/ABA intervention will teach my child the skills they need to have fulfilling friendships.	7	11	14	4	2	2.55	38
IBI/ABA intervention can be a lifelong necessity.	7	15	13	2	1	2.34	38
IBI/ABA intervention is best left to the professionals; procedures implemented by parents n	2	8	9	13	6	3.34	38
IBI/ABA intervention is only effective if started before the age of 3.	0	3	8	17	10	3.89	38
IBI/ABA is an intervention program in which parental involvement is essential.	19	14	2	2	1	1.74	38
In some cases, IBI/ABA may not be effective.	2	19	9	4	4	2.71	38
In some cases, IBI/ABA may actually do damage to a child.	1	7	11	7	12	3.58	38
IBI/ABA intervention is the only intervention that may lead to recovery for my child.	6	5	14	9	4	3.00	38
Doing IBI/ABA intervention with children after the age of 6 years old may not be effective.	0	3	13	12	10	3.76	38

Appendix E: Responses to statements regarding beliefs and attitudes about behavioural treatment (number)

Answer Options	total agree	total disagree	total agree %	total disagree %	total neutral %
IBI/ABA is the only intervention that is scientifically proven for children with ASD.	28	6	74%	16%	11%
About half of children in IBI/ABA programs have been shown to recover from autism.	11	15	29%	39%	32%
40 or more hours per week of IBI/ABA therapy is the most important reason for some child	16	10	42%	26%	32%
'Recovery' means being normal in every sphere of functioning.	20	12	54%	32%	14%
Most IBI/ABA programs are equal, as long as there is a qualified professional leading the pr	7	25	18%	66%	16%
IBI/ABA intervention is the best way for my child to learn functional skills such as the self-m	30	4	81%	11%	8%
IBI/ABA intervention is the best way for my child to learn functional language skills.	30	2	79%	5%	16%
IBI/ABA intervention is the best way for my child to learn functional skills such as self-help s	34	2	89%	5%	5%
IBI/ABA intervention is the best way for my child to learn academic skills.	31	2	82%	5%	13%
IBI/ABA intervention will significantly alter my child's future quality of life, allow them to atter	24	4	63%	11%	26%
IBI/ABA intervention will help my child get a job in their adult life.	17	5	45%	13%	42%
IBI/ABA intervention will help my child get married in their adult life.	9	6	24%	16%	59%
IBI/ABA intervention will teach my child the skills they need to have fulfilling friendships.	18	6	47%	16%	37%
IBI/ABA intervention can be a lifelong necessity.	22	3	58%	8%	34%
IBI/ABA intervention is best left to the professionals; procedures implemented by parents m	10	19	26%	50%	24%
IBI/ABA intervention is only effective if started before the age of 3.	3	27	8%	71%	21%
IBI/ABA is an intervention program in which parental involvement is essential.	33	3	87%	8%	5%
In some cases, IBI/ABA may not be effective.	21	8	55%	21%	24%
In some cases, IBI/ABA may actually do damage to a child.	8	19	21%	50%	29%
IBI/ABA intervention is the only intervention that may lead to recovery for my child.	11	13	29%	34%	37%
Doing IBI/ABA intervention with children after the age of 6 years old may not be effective.	3	22	8%	58%	34%

Appendix E: Responses to statements regarding beliefs and attitudes about behavioural treatment (percentage), using grouping of 'Agree' and 'Disagree' categories.