

Autism Spectrum Disorders and Occupational Therapy

Presented by

Dr. Mary Law

Professor and Associate Dean (Health Sciences) Rehabilitation Science, McMaster University
Director, School of Rehabilitation Science, McMaster University
Co-Director, *CanChild* Centre for Childhood Disability Research, McMaster University
John and Margaret Lillie Chair in Childhood Disability Research

Canadian Association of Occupational Therapists

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The Canadian Association of Occupational Therapists

Brief on Autism and Occupational Therapy for the Senate Standing Committee on Social Affairs, Science and Technology

Canadian Association of Occupational Therapists (CAOT) is a national and voluntary professional organization. Along with its provincial and territorial affiliates, it represents over 10,000 occupational therapists and close to 1100 students. We strive to advance excellence in occupational therapy practice and to promote access to quality occupational therapy services for all people of Canada. Our Association recognizes occupational therapy's intrinsic value to the social and economic health of Canada. CAOT recognizes that children and youth have the right for opportunities to participate in meaningful activities that support their development.

Background Information

Prevalence

The autistic child ... he may be the child who is standing in the middle of the field at recess spinning around in circles, or she may be the child who can't stand the way a certain fabric feels on her body or the way a certain texture of food feels in her mouth, or it may be the child who is throwing a severe temper tantrum because they just can't communicate their needs. Autism Spectrum Disorder (ASD) is a class of developmental disabilities which cause severe impairments to a child's communication, their social interactions, and in their play and behaviour. This disorder presents itself differently in each child with respect to severity and symptoms. ASD encompasses the following disorders: autism, Asperger's disorder, and Pervasive Developmental Disorder – Not Otherwise Specified. Other related disorders include: Rett's syndrome, and childhood disintegrative disorder.

Over the past decade, autism has received more and more attention by the medical community and the media due to its perceived rate of increase within the population. In the 1960's, studies estimated the prevalence rate of autism at approximately 0.4 per 1,000 (Fombonne, 2005, William et al., 2005, Williams et al., 2006). In the subsequent years, the number of studies on autism has increased dramatically, and so has the prevalence rate of autism. In the 1990's, the prevalence of autism was being estimated from anywhere between 0.5 per 1,000 to 7.3 per 1,000 (Williams et al, 2005, Williams et al, 2006).

CanChild Centre for Childhood Disability Research at McMaster University recently completed a systematic review of the literature regarding the prevalence of autism. Today, the currently accepted prevalence rate for ASD is estimated at 6.0 per 1,000 (Fombonne, 2005). For example, this represents approximately 12,500 children between the ages of 0-18 years of age living with ASD in Ontario. Using an estimated prevalence rate of 5 – 6.5 per 1,000, there will be between 14,700 – 19,110 children less than 18 years of age with ASD in Ontario over the next 5 years (*CanChild*, 2006). According to the California Department of Development Services (2003), autism is now more prevalent than childhood cancer, diabetes and Down Syndrome. The overall prevalence rate for children with disabilities in Canada is estimated from 3.6 percent (Statistics Canada 2001 Participation and Activity Limitation Survey) to 7.7 percent (1996-97 National Population Health Survey) (range depends on how functional disability is defined).

What has caused such a significant increase in the prevalence of autism and are there really that many more individuals with autism today than there was 30-40 years ago? In a systematic review on prevalence studies of autism spectrum disorder determined many factors that explain the variability between the studies. Between the 1960's to the early to mid 80's, autism was determined using the Kanner or Rutter descriptions of autism (Fombonne, 2003, Williams et al, 2006). These descriptions were much more conservative and narrower in focus, often only focusing on typical autism, and excluded any child who had an intellectual impairment. Today, the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, 4th ed.) and the ICD-10 (International Classification of Diseases) are the most widely accepted methods of diagnosing autism. They use a broader definition of autism. This system requires a child to exhibit six of the twelve listed behaviors. These behaviors include qualitative impairments in social interaction, communication and repetitive or stereotyped behavior (ANI, 2002). This broader definition has now encapsulated many disorders previously labeled. Therefore, as prevalence rates for autism are increasing, the prevalence rates of other disorders, such as mental retardation and global developmental delay, have decreased (The Economist, 2003, Fombonne, 2003a, Williams et al, 2006). We may attribute some of the increase in autism to improved diagnosis of the disorder. (Lingam et al., 2003).

Other factors influencing the increased prevalence of autism include: increased public and professional awareness, methodological issues within the studies conducted (i.e. ascertainment methods, sample size and power), and age of the included population (Williams et al., 2005, Fombonne, 2005, Fombonne, 2003, Hanna et al., 2006). Increased funding for services and development of services specifically for children with a diagnosis of autism could also be a factor. A diagnosis of autism may be given by a physician to meet a need for service, particularly when specialized services are solely offered to those individuals connected with the label (Jick et al., 2006). Methodological issues, such as small sample size, poor power, and single source ascertainment, can also have a huge influence on the results of the study (Fombonne, 2003, Fombonne, 2005). Fombonne (2003) has stated that "most of the existing epidemiological data are however inadequate to properly test hypotheses on changes in incidence of autism in human populations" (p 376). Age of the included population in the study also has an impact on the prevalence of autism. If the age range is broad or includes children between the ages of 0-2 (an age when few diagnoses of autism are made), it would increase the total population number, thereby decreasing the overall prevalence rate (Williams, 2005).

Characteristics

ASD is characterized by four main categories: impairment in social interaction, impairment in verbal and nonverbal communication, restricted repetitive and stereotyped behaviours, interests and activities, and delays in development (ICD-10, 1992). The delays or abnormal functioning must have been present before the age of 3 years for the diagnosis to be made. Difficulties in sensory processing, emotional regulation and motor may also be demonstrated (DSM-IV). Children with ASD may demonstrate a variety of behaviours which affect their ability to participate in their daily occupations. These behaviours may show themselves by the tendency to impose rigidity on daily activities, habits and patterns of play; preoccupations with interests; and motor and sensory problems such as rocking, spinning, sensitivity to food or clothing, or a strong attachment to an object (Clark, Miller-Kuhaneck, & Watling, 2004). As a result, there may be a resistance to changes in routine or the environment (such as furniture in the home or bedtime routines) (ICD-10, 1992). Children with ASD may also demonstrate a range of other difficulties such as "fear/phobias, sleeping and eating disturbances, temper tantrums, and aggression" (ICD-10, 1992, p. 2). The characteristics of autism may change as a child grows older,

however the difficulties in socialization, communication, and interests continue in adulthood (ICD-10). It is important to note that every child is different; occupational therapy services are client-centred and focus on the individual and family's needs, goals, values and priorities. When working with children with ASD, occupational therapists look at the interaction of the child/youth within their environment which includes the family, school system, community programs, and other health professionals. Due to the complexity and range of difficulties in areas of function, an individualized evaluation and treatment program is required for the individual with ASD which promotes collaboration among all professionals involved.

Occupational Therapy

Occupational therapy is a health profession that is directed toward enabling people to participate in daily occupations, including taking care of oneself (e.g., dressing, bathing), contributing to society (e.g., paid and unpaid work, school) and enjoying life (e.g., hobbies, sports). Occupational therapy addresses barriers to participation of an individual, group or community that may occur as a result of illness or disability and/or obstacles in the social, institutional and/or physical environment (CAOT, 2002a; CAOT, 2005). Research evidence indicates that participation in everyday occupations is an important determinant of health and well-being and helps give meaning to life (Law, Steinwender & Leclair, 1998).

Occupational therapists understand that the ability to perform meaningful activities is complex and is influenced by factors involving the person (such as an individual's physical or emotional ability), the environment (safety, supports available to carry out activity, accessibility) and the nature of the activity itself (size and texture of objects) (Whiteford, Townsend & Hocking, 2000; Wilcock, 1998). Occupational therapists address barriers to participation by enhancing people's ability to do what is important to them, modifying the activity and/or the environment to support participation.

Occupational therapy focuses on the needs of children/youth with autism and the needs of families (Appendix A-insert case studies). Occupational therapy evaluation is designed to gain an understanding of the individual's abilities and difficulties in performing daily occupations such as play, school, leisure and personal care activities. The evaluation process looks at the child's development in a number of domains including motor, perceptual, communication and interaction skills; habits, and routines. An understanding of the child's abilities, needs, and goals is gained through interviews with the child, parents, siblings, teachers, and/or caregivers; standardized tests; and observation of the child during activities at school and home such as classroom tasks, mealtimes and play.

Interventions for Children with Autism Spectrum Disorder - Treatment Effectiveness:

Research in the area of autism has developed a great deal over the past decade. There are currently several studies going on within Canada which have potential to provide valuable information for the planning and implementation of health services for these children and their families.

Intervention for Challenging Behaviour

In the past, the use of intrusive treatments, such as seclusion or restraints, were once used to treat problem behaviour (Perry et al., 2003). It is now the practice to use non-intrusive methods emphasizing positive-based strategies. Intrusive methods are used only as a last resort (when non-intrusive methods are ineffective) (Perry et al., 2003).

In the late 80's, the National Institutes of Health commissioned a consensus panel to assess the medical knowledge on effective treatments for challenging or problematic behaviour for the developmentally disabled (some of the reviewed medical knowledge included populations with autism spectrum disorder) (Perry et al. 2003). This review concluded that the most efficacious strategies for problematic behaviour were: behaviour enhancement strategies, behaviour reduction strategies, educational strategies, and ecological strategies (NIH 1991).

The Children's Mental Health Ontario completed an analysis of interventions for challenging behaviours in children with autism (Perry et al., 2003). Positive behavioural supports, which are non-intrusive methods for treating such behaviour, were recommended as the first course of treatment. Several studies conducted in Ontario support its effectiveness in treating symptoms of self-injury, aggression, and disruptive behaviour (Perry et al., 2003). Horner et al (2002), in a research synthesis on problem behaviour intervention for young children with autism, found that the most common problem behaviours were aggression/destruction, disruption/tantrums, self-injury, and stereotypy. Stimulus-based or instruction based interventions are the most common form of treatment for autistic children with problem behaviour. Horner et al. (2002) also reported that early use of behavioural interventions may reduce problem behaviour by 80-90%.

Comprehensive Programs

Intensive Behavioral Intervention (IBI) has been researched extensively and has been shown to be an effective intervention with children with autism. This intervention teaches children to respond to specific words and environmental stimuli using repetition. According to Couper and Sampson (2006), IBI is thought to provide a superior outcome since it specifically targets the deficit areas in children with autism. McEachin et al. (1993) conducted a matched-pairs design study in which they compared Intensive Behavioural Intervention to no treatment at all in a group of children with autism. Their research indicated that children in the Intensive Behavioural Intervention group had positive gains in IQ, class placement and adaptive behaviour. These positive gains persisted 7 years post therapy. Results should be interpreted with caution due to methodological flaws in research design such as selection bias, and lack of random allocation to treatment group.

Another study by Howard et al. (2005) conducted a nonrandomized comparison trial of 3 intervention groups (IBI, eclectic therapy (30 hours), and non-intensive eclectic therapy (15 hours). This study also reported positive gains in children receiving IBI that lasted 14 months after intervention commenced. The IBI group scored significantly higher than the other two groups on all measures (cognitive skills, non-verbal skills, receptive and expressive language, adaptive skills), with the exception of motor skills, where there was no difference among groups.

In 2003, Finch & Raffaele conducted a literature review on IBI for children with autism. This review included 7 experimental studies which matched the author's inclusion criteria. Their review indicated the following: children who received IBI from a less experienced instructor did not make as significant gains as those with a more experienced person, the home setting was a less effective environment for therapy (fewer positive gains) than IBI in a community setting (such as a university centre), children receiving less than 25 hours of intensive therapy attained less significant results. All 7 studies indicated some positive gains in IQ and class placement for the majority of children receiving IBI (gains were variable).

Although there is a plethora of literature indicating IBIs' effectiveness, there are some concerns with this intervention. It is not clear from the evidence that the skills developed by the children actually translate

or generalize to other environments and to other skills. Even though these children may have achieved significant improvements, most children remain with developmental difficulties. As well, research is not available to indicate which children benefit from IBI (severity level) and the optimal amount of time of treatment. Treatment needs to become more naturalistic, and within the child's own environment.

Occupational Therapy Intervention for Children with Autism

The goal of occupational therapy interventions is to enable individuals to participate in everyday occupations. This may be achieved through a range of therapy approaches such as modification of tasks and/or the environment to match individuals' abilities, developing skills such as posture and coordination, or development of daily routines to facilitate adaptive behaviours (National Institute of Child Health and Development, 2005). Occupational therapists work with children in their natural settings; in the home with their families, in the school and in the community.

Research suggests that the behaviours of children/youth with ASD have a significant impact on family roles and activities (Werner DeGrace, 2004). The effect of having a child with ASD varies among family members and depends on available community supports (Galvin-Cook, 1996). Families are devoted to the needs of the child and consequently may have difficulty engaging in positive family experiences (Werner DeGrace, 2004). Interventions are important resources for parents, however parents face challenges gaining access to appropriate services, including finding professionals in the community which can provide the services, and knowing what kind of intervention is best for their child and family (Galvin & Miller-Kuhaneck, 2004). Health professionals must develop supports for families to enable them to participate in satisfying shared occupations, to ensure the well-being of family.

There is a need for more research and evidence to support best approaches to enhancing the participation of children with autism in the occupations of daily life. In this section, we summarize what is known to date in terms of best practice for occupational therapists working with children with autism.

The current practice of occupational therapy for children with autism in the USA was examined in a research study by Watling et al. (1999). This study used a survey questionnaire to address the following questions: What is the current practice of OT's working with children with autism? What are the assessments and intervention techniques currently being used with this population? What are the educational and training requirements needed to effectively serve this population? The survey was sent to 127 occupational therapists across the U.S., with a return rate of 68.5%. The results of this survey indicated that: the majority of occupational therapists (82%) use direct (1:1) intervention and the skill areas addressed by occupational therapists were praxis, self-regulation, language and communication, oral motor/feeding, and interaction style.

Within Canada, occupational therapy treatment has focused on two main areas:

1. Sensory Motor Integration

In the past, one of the more frequent sensorimotor interventions in occupational therapy was sensory motor integration. Baranek (2002), in a review of the literature on sensory integration therapy for children with autism, concludes that some of the sensory/motor interventions reviewed "provide questionable rationale for their use with children with autism." (p 415). There is little evidence to support this type of treatment for children with autism.

However, there is evidence that children with autism do process sensory information differently from other developing children (National Institute of Child Health and Development, 2005). Therefore, the focus in occupational therapy has shifted to understanding how and when a child is reacting poorly to a sensory experience and structuring the environment to accommodate or minimize such reactions. Occupational therapists can use a mediator or consultation approach to work with parents and teachers to provide strategies to prevent reactions to sensory experiences from limiting daily activities. For example, if a child with autism is upset by excess noise that may occur at end of a school day, they could get ready to go home before everyone else. If a child is bothered by a specific clothing material (e.g. wool), this type of material could be avoided in their clothing.

By adapting the tasks and environments as well as working with the families on how to teach new skills and build calming or alerting activities into their everyday routines, occupational therapists can make a difference in the family's day to day life. In particular, occupational therapy focuses on self care issues, feeding, bathing, hygiene and sleep which are significant issues for children and enormous stressors for the family. In the school setting, a student's occupational performance may be impaired by sensory, developmental, attentional and/or learning challenges (Sahagian Whalen, 2003). Occupational therapists may adapt classroom tasks and the school environment to promote a child's participation. Occupational therapists can assist teaching assistants and teachers with understanding the impact of sensory processing difficulties on daily functioning and how they can modify what they do to maximize the child's participation and reduce behavioural difficulties.

As some children with autism find changes to routines, or unstructured time difficult to comprehend and adjust to, environmental supports and structures can improve the quality of life for children with autism. A review of environmental supports was done in 1995 by Dalrymple. This review suggested 4 types of supports that could potentially have a positive impact on the lives of children with autism. The environmental supports suggested were: temporal supports (events over time – this would allow a child to prepare themselves in advance for a change in activity), procedural supports (including instructions for activities or relating people to events), spatial supports (allowing the child to organize themselves within the environment), and assertion support (aiding the child in social interactions) (Perry et al., 2003, Dalrymple, 1995).

A focus on IBI treatment alone neglects other important areas of development and has, in some cases, led to the marginalization of other health professionals. This does not recognize the critical aspect of how the child's abilities and needs integrate with the nature of the activity and the environment, to enable function in daily activities. Some IBI therapists welcome occupational therapy and others may view it as counteracting their therapy and do not recognize approaches which are not strictly behavioural in nature.

2. General Skill Building

Occupational therapists work with children with autism and their families to provide intervention that improves the child's ability to participate in activities of daily living, play and school. In occupational therapy, the focus is on task analysis, breaking down a task into manageable steps for the child, teaching those steps to the key people in the child's environment and structuring task and/or environment to support successful completion. For example, if a child with autism is having difficulty dressing himself, the occupational therapist could use a backward chaining behavioural approach which teaches skills by breaking the tasks down into manageable steps which are always performed in the exact same order

(*CanChild*, 2006). Occupational therapists work as collaborative consultants, providing strategies for intervention to families, teachers, in order to develop a child's skills within their natural environments. The focus of therapy intervention is consultation rather than direct intervention.

CAOT Member Data

CAOT 2004-05 membership data indicates that of a total membership of 5440, 19.1% report that they work with preschool age children and 28.6 % work with school age children. On a national basis, 23.8% of the members report that they work in the area of "developmental disabilities". This category is not exclusive to ASD but includes children and youth with varying abilities to participate in every day activities and routines. The participation rate of occupational therapists working in developmental disabilities is quite variable across the provinces and territories. These data are based on the actual number of CAOT members in each province. Alberta, Ontario, Manitoba have the highest number of occupational therapists that provide services to children whereas the Atlantic provinces are noted to have fewer occupational therapy resources for children and youth in the community because of the lack of provincial funding for school and community care. The territories have a very small number of occupational therapists overall.

Access to occupational therapy

There are many barriers to accessing occupational therapy services.

1. Pan-Canadian Shortage of Occupational Therapists

There is a an overall shortage of occupational therapists in Canada (von Zweck, 2002) CAOT recognizes that a sustainable and effective integrated health human resources workforce is essential to respond to the health needs of the Canadian population. With respect to ASD, CAOT believes that children and families should have access to the right professionals at the right time in their communities throughout their lifetimes. One of the most significant problems, with respect to access, is the availability of occupational therapists with advanced education to work with children, parent and teachers in the home and school.

2. Funding

Occupational therapy is considered a "noncore" service under the Canada Health Act. Each jurisdiction is free to include or exclude services from its noncore services. The provinces and territories are not required to fund occupational therapy. As a result, funding levels for occupational therapy services vary from one province to another. Even where funding may exist, it is subject to fluctuation depending on provincial/ territorial government fiscal policy. Sustainable funding is required to support access to occupational therapy services.

3. Provincial Ministerial Mandates

Traditionally, publicly-funded services for children and youth are driven by a needs-based approach administered by individual programs or one delivery system. Occupational therapists and their clients have come to realize that a needs-based program does not achieve sustainable gains for children and youth with disabilities.

In many provincial/territorial jurisdictions, the ministerial mandates for children and youth lack a coordinated approach. Over the course of a lifespan, people living with ASD may deal with different ministries such as health, social services and education depending on their age. The result of this “silo” approach to ASD treatment results in fragmented service delivery, long wait lists for services and funding. As the children make transitions from preschool to school age and to independent living, they come under the mandate of another ministry and more wait lists. The current system of mandated services results in delays, and loss of critical periods when children and youth may be more amenable to certain interventions. Coordinated services at the ministerial level could result in more efficient and cost-effective services.

4. Wait lists

Wait lists for assessment and treatment services are at an unacceptable level for families and children. In many provinces families are waiting for up to one year for a medical or psychological assessment. The medical and /or psychological assessment is required in most provinces to access provincial funding for services at home, preschool and school. A further wait of 2-3 years for treatment services means lost therapeutic time. In response to this untenable situation, many parents will access private services often at great personal and financial sacrifice.

Childhood is comprised of a series of highly sensitive developmental periods that are unique to each child. A missed opportunity to support a child’s development at any stage in the cycle will have negative impacts across the life span. Early detection of developmental problems coupled with an immediate intervention is critical to a healthy future.

5. Treatment services

Most of the publicly funded treatment services for children with ASD are behaviorally focused and available primarily for preschoolers and children of early school age. While there are merits to these programs, they are intensive and expensive programs services and may need to include other components to meet the needs of the child and the family. Families are looking for collaborative interprofessional teams that address the global needs of the child: behavioural, developmental and sensory. Parents want help with daily routines at home such as calming a very agitated child before bedtime in order to sleep the night and developing routines without tantrums so the family can enjoy mealtimes and playtimes together.

Throughout the country there are very few treatment services for youth. Services to this age group should be strategic in addressing their transitional needs to adulthood. ASD is a life long condition and requires ongoing treatment services to support these individuals to engage in meaningful work, leisure and community living.

CAOT Key Messages

1. Participation by children in valued occupations is a determinant of health.
2. Collaborative teams are critical for delivery of services for children with ASD and their families; occupational therapists are a critical member of this collaborative team.

3. Collaborative research is required to identify best practices in ASD evaluation and treatment based on client-centred values.
4. Increase access to occupational therapy services for children and youth with ASD throughout their lifetimes.

Recommendations

It is recommended that the federal government take a leadership role to:

1. Develop a National Strategy for Children with Disabilities including a national vision and action plan for ASD. It is recommended that the ASD action plan address the following areas: system issues including access and funding; integrated health human resource planning; wait list management strategy, research to develop evidence for ASD evaluation and intervention; and coordination and integration of ASD services provided by health, education and social sectors.

Within the strategy, address the following:

2. Promote comprehensive family interventions and supports for families which emphasize positive, shared occupations (Werner DeGrace, 2004).
We must always remember that children live within the context of family, so support provision, information and education for families are critical.
3. Establish guidelines for the development of integrated collaborative services among health, education and social services to provide a continuum of care for the child with ASD and their family.
4. Promote education for consumers, health professionals, funding agencies and government, to ensure a comprehensive approach to treatment which addresses functional skills rather than the fringe skills that are targeted in singular approaches.
5. Ensure that there are opportunities for interprofessional collaboration among clinicians and researchers and policy makers to advance evidence and knowledge of ASD interventions.
6. Create mechanisms to develop treatment pathways based on evidence. For example, if the child has not improved significantly from a behavioural intervention, such as IBI, over a set period of time, focus could shift to environmental adaptation and life skills to improve fit with environment and skills.
7. Increase research capacity around developmental trajectories. This area is currently being studied across 4 provinces in research led by Dr. Peter Szatmari from McMaster University. The key treatment issue is -how much treatment, at what age(s) and when is it appropriate to discharge or decrease treatment intensity (how long is enough).

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