

Autism Services in Alberta Working Document



Statement of purpose

- To provide an overview of ‘the facts’ surrounding Autism Spectrum Disorder (ASD), the current state of research, and services in the Province of Alberta.

Background and rationale

- In 2013, an ASD service provider working group was formed in Calgary (Society for Treatment of Autism, Lead Foundation, & Renfrew Educational Services). Their primary task was to come to consensus on key principles on using evidence-informed practice to guide interventions for individuals with ASD.
- In 2015, additional ASD service providers from Edmonton (Centre for Autism Services Alberta) and Calgary (Buds in Bloom) joined the initiative. Fragmentation in ASD service provision was identified as impacting multiple regions of the province.
- This same year, advocacy organizations in Edmonton (Autism Edmonton) and Calgary (Autism Calgary) also joined the initiative, as they also identified fragmentation and conflicting messaging on support needs.
- In 2017, there has been growing interest province wide from other stakeholders in the autism community to unite under an Autism Alberta Alliance. This may form in parallel to analogous national efforts (the Canadian Autism Spectrum Disorders Alliance). An initial goal is to gain consensus on key messages that identify evidence-informed supports for individuals with ASD and strengthen other great work that is happening in Alberta.

A brief introduction to Autism Spectrum Disorder (ASD)

- ASD is a medical condition, typically diagnosed in childhood, based on formal assessment of delayed social-communication and social interaction abilities, and restricted, repetitive patterns of behavior. To receive a formal diagnosis symptoms must cause clinically significant impairment in current functioning (American Psychiatric Association, 2013).
- According to the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5) criteria, individuals with ASD, as part of their formal diagnosis, are also given a support score (1 - 3) ranging from ‘requiring support’ to ‘requiring very substantial support’ in each of the two major domains (social communication and behavior). This reflects the ‘spectrum’ of the disorder, a change formally adopted in 2013 with the publication of the DSM-5 (American Psychiatric Association, 2013).

- ASD symptom presentation is diverse and may differ significantly from individual to individual. It is a spectrum disorder. Not all children respond equally to intensive therapies and specific child and environmental factors are still being explored by research.
- Like any person, individuals with ASD have unique strengths and support needs. Carter et al. (2015) indicate individual strengths are related to having access to positive relationships, active coping skills, and a positive outlook. Person and family-centered planning and access to home, community and meaningful activities are recommended for better well-being overall.
- Despite these strengths, ASD is often associated with a wide range of other psycho-social and medical concerns including Attention Deficit/Hyperactivity Disorder (AD/HD), anxiety, intellectual disability, gastro-intestinal dysfunction, feeding difficulties, sleep disturbance, motor problems, immune dysfunction and unusual sensory processing that may or may not be present in any given individual (Centers for Disease Control and Prevention, 2012; Geschwind, 2009). Additionally, families of children with ASD often report higher levels of stress than other disability groups, and mothers in particular, are at higher risk for mental health issues (Dunn et al., 2001; Harper et al., 2013).
- Most recently, ASD prevalence rates are one in 68 children (CDC, 2012). International estimates vary somewhat though consistently are around 1% of the general population.
- In Alberta, the average age of diagnosis is between three to four years of age, and males outnumber females by a ratio of five to one (5:1) (Burstyn et al., 2010). With the right resources, children with ASD can be reliably diagnosed as young as 2 years of age (CDC, 2016).

How are individuals with ASD supported in Alberta?

- There is no autism-specific funding in Alberta. Access to funding is based on the individual and the family's identified needs as determined by clinical and government assessments, as well as consideration of other available supports that are funded by different ministries and private organizations. Funding supports vary widely across the province both in terms of qualification requirements and the types and quality of supports available. Autism support is a cross ministerial responsibility.
- This funding model contrasts with many other provinces that do provide dedicated ASD funding, particularly for early intervention for children 6 years of age and under (e.g., BC, Ontario, Quebec, and Nova Scotia – see Madore & Pare, 2006 for full summary). To our knowledge, Alberta is the only province with this unique model of funding. Of particular concern, there is no dedicated autism-specific funding for early ASD intervention in Alberta.
- In Alberta, if children are significantly impacted by ASD, they may qualify for services from multiple levels of government (e.g., Education, Health, and Community and Social Services) whereas for children mildly or moderately impacted, they may qualify for lesser supports. A multi-disciplinary team (including medicine) is typically involved in both the diagnostic and

assessment processes and written recommendations are provided on types and intensity of support needs. The diagnostic process varies regionally as do support qualifications.

Health Care / Medical

- In general, acute medical needs and diagnostic services are funded through Alberta Health Services (e.g., diagnostic assessments and medical follow-up). Regional hospitals may have specialized doctors, nurses, and other health care professionals to provide support, though specialist care is often restricted to larger municipalities. Older teens and adults often report more difficulty in accessing specialist care than parents of younger children. In Northern Alberta, the Glenrose Rehabilitation Hospital in Edmonton is the primary hospital for medical care for individuals with ASD. In Calgary, there is a dedicated autism diagnostic clinic at Alberta Children's Hospital.

Educational / School

- Educational needs are funded through Alberta Education. Program Unit Funding (PUF) is available, in addition to the Base Instructional Funding, for young children who are two and a half to six years (2.5 to 6) by September 1 who have been identified with a severe disability/delay. Children are eligible for up to three years of Early Childhood Services (ECS) funded programming, depending on age, severity of the disability/delay and its impact on the child's ability to function within an ECS program. Funding for school age children is provided to schools on the basis of the coding of each student who require specialized supports and services. Coding decisions are made on the basis of diagnosis and standardized and/or functional assessments (e.g. how the disability/disorder affects learning in an educational environment) and the purpose of the funding is to help prepare children for school entry (Alberta Government, 2015).

Home / Family / Community

- Home and community needs are funded through Family Support for Children with Disabilities (FSCD) – a branch of Regional Disability Services operated through the Ministry of Community and Social Services. In Alberta, FSCD has historically funded intensive interventions for children with ASD through 'Specialized Services' (SS), though this policy has been applied differently throughout the province. Eligibility for SS is based on the individual needs of the family and their child and is not ASD specific. SS are provided to families when their child has a severe disability and presents with critical service needs in two or more areas (e.g. behaviour, communication and social skills, physical abilities, cognitive abilities or self-help skills). FSCD also funds other non-therapeutic supports such as respite and work-related child care (Alberta Government, 2004).
- Adult needs are primarily funded through Persons with Developmental Disabilities (PDD) – a branch of Community and Social Services. PDD and FSCD have recently been merged as Regional Disability Services. It is important to note that there is an IQ requirement of 70 or less in order to qualify for this funding. Not all adults with ASD qualify. As diagnostic criteria have shifted, fewer adults with ASD have cognitive delays than in previous decades (Marriage et al., 2009).

- All associated legislations that involve health care professionals in education, health care and social services provide reference to evidence-based (or established / effective) rehabilitative care as a requirement of service provision.

What does best practice literature say about ASD supports across the lifespan?

The best practice models of ASD support all involve the use of evidence-based practice (EBP). According to the American Psychological Association (2005), one agency of many, EBP is the integration of:

1. Clinical expertise/expert opinion;
 2. The current, best available scientific evidence;
 3. Patient/child characteristics (e.g., values, preferences).
- EBP recognizes the importance of individualizing interventions based on the individual, family, disability, context (e.g., not 'one size fits all'), and is person and family centered.

Diagnosis

- A comprehensive diagnostic assessment by a multi-disciplinary team with clear recommendations on needed levels of support as early as possible so that early intervention and family support can be provided (Goldstein, Naglieri, & Ozonoff, 2009).
- “When an ASD is suspected through developmental surveillance, parent report and /or the use of screening tools, referrals for assessments and services should occur immediately. If unsure, pediatricians and GPs should over- rather than under-refer” (Nachshen et al., p. 37, 2008).
- “The delay between the emergence of symptoms, screening, assessment and diagnosis must be as short as possible to prevent delays in treatment” (Nachshen et al., p. 62, 2008).

Birth – Early Childhood (0-2.5 years)

- A major component of intervention involves a heavy emphasis on parent coaching and family involvement for really young children (birth to 2.5 years of age). The focus is on increasing parent-child responsiveness, introducing a functional language system, teaching play and social skills, addressing sleeping and feeding difficulties, and to ensure behavioral rigidities are addressed (Rogers & Wallace, 2011; Zwaigenbaum et al., 2015). The intensity of support for this age group is not agreed upon and will vary depending on child presentation.
- “Evidence-based interventions should be made available to children who have been identified through a secondary screen as being high-risk, and who are on the wait-list for a formal diagnosis by a multi-disciplinary team” (Nachshen et al., p. 37, 2008).

Preschool (2.5–5 years)¹

- An emphasis on comprehensive early intervention, particularly for the pre-school population (two and a half to five years of age), based on both the developmental and behavioural sciences that provides a critical dose of adult-directed attention (typically between 15-25 hours per week). For maximal effectiveness, intervention uses EBP across home, school and community settings for a minimum of one to two years, and may be needed throughout the preschool years and beyond.
- The preferred model of practice is one that is highly personalized and person centered, where caregivers are encouraged to be heavily involved in selecting and applying individualized measurable goals for their child within family, school and community life. There are also a pool of strategies that are implemented across multiple settings and people, in a consistent fashion, to allow for good generalization of learning.
- A number of published curriculums can be used to ensure goals are developmentally appropriate and sequential in delivery. Practical examples with an established evidence base include *The Early Start Denver Model* (ESDM; Rogers & Dawson, 2009), *Early Intensive Behavioral Intervention* (EIBI; Reichow & Wolery, 2009) and *Learning Experiences: An Alternative Program for Preschoolers and Parents* (LEAP; Strain & Bovey, 2011). This is not an exhaustive list.
- Minimum intensity (dose) of intervention is controversial. The National Research Council (2001) recommends 25 hours per week as a minimum of structured individualized teaching. A review by the Canadian Pediatric Society (2004) recommends a minimum of 15 hours. For children with more mild/moderate impairments, less intensive approaches may be appropriate, though this is unclear as it is difficult to predict how specific children will respond to specific interventions. Infancy and preschool are when children are typically most responsive to ASD specific therapies. The majority of ASD focused interventions are developed for this age group based on review of over 8,000 scientific abstracts (National Autism Centre, 2009; 2014).
- There is emerging evidence that high quality intensive EBP intervention in the early years can actually influence neurodevelopmental (brain) changes (Dawson, 2008) and that positive effects on cognitive skills, social skills, communication and language skills, adaptive functioning, and quality of life maintain into the school years (Reichow et al., 2012).

School age (6-17 years)

- As children enter school full time, there is more of an emphasis on academics, social skills training, relationship skills, and developing age-appropriate interests and participation in community life, with a de-emphasis on the family as the child ages (Davies, 2004). The school takes over increased responsibility for individual learning. Family involvement decreases further as adolescents prepare for adulthood.

¹ The literature for preschoolers and ASD supports is vast. A concise and publicly available overview written for pediatricians is published by Myers et al. (2007) entitled *Management of Children with Autism Spectrum Disorders*, American Academy of Pediatrics, www.pediatrics.org/cgi/doi/10.1542/peds.2007-2362.

- There is an emphasis on the provision of an inclusive learning environment, with increased support needs provided, based on the unique learning needs of the child (Smith, 2012).
- Support models in the teen years have more of an emphasis on mental health, peer relations and prevocational support models, with a focus on building independent living skills. This is a time when many mental health issues may emerge as up to 70 percent of individuals with ASD may qualify for a diagnosis of depression or anxiety (Geschwind, 2009).
- Many interventions for this age are group based. Practical examples with an established evidence base are *PEERS*, a social skills group (Laugeson & Frankel, 2010) and *Facing Your Fears*, a cognitive-behavioral therapy group for seven to 14 year-old individuals with anxiety (Reaven et al., 2009).

Adult (18 years+)

- The adult literature for ASD is still an emerging field, but the emphasis is on improving quality of life, self-determination, building naturalistic supports systems, and finding workplaces that are a good fit for those with ASD traits and/or symptoms. Mental health is a major concern for adults, as are high levels of social isolation and unemployment. Up to 80 percent of adults with ASD are reported to be under or unemployed.
- Lifetime costs can be substantial, with the bulk of those costs incurred during adulthood if an individual does not have the skills and supports to participate in society. Estimates range as high as \$2.4 million in the USA (Buescher et al., 2014).

What is the role of parents/caregivers in ASD intervention?

- Parent and family involvement is essential for any comprehensive program for a child with ASD, though different models emphasize the role of parents in different capacities. Some programs focus exclusively on coaching parents on how to embed strategies in everyday routines, whereas other programs focus on having parents generalize individualized learning after they have been taught to the child by a well trained staff.
- Most exclusive parent training programs are designed to augment intensive child-focused intervention programs, school programs, or to ‘fill the gap’ for those families that are on waitlists for more intensive supports. Given the spectrum of ASD, a wide array of supports are necessary to meet different child and family needs.
- Most parent coaching programs impact the parent-child relationship in a positive way. Although parent coaching as a method of delivery for intervention is considered to enhance children’s outcomes, intervention programs that rely solely on parent coaching (i.e., no additional one-to-one time between an adult and the child) have limited evidence outside of comprehensive child-focused supports (Schreibman, et al., 2015).

- In fact, in 2013 the Cochrane Group, a non-profit EBP review panel, reviewed 17 randomized controlled trials of parent training programs for young children with ASD. They found that parent training models can positively impact parent-child responsiveness and improve parental participation in child learning, but do not change standardized child test scores over time in the same manner that is found in the comprehensive intensive child teaching programs (Oono, Honey, McConachie, 2013).
- To manage the complexity of ASD presentation, parent coaches must be highly trained to be effective. Steiner et al (2012) summarized effective parent coaching literature and identified that parent coaching was beyond the scope of most para-professionals and required specialized training and experience to maximize benefit and minimize potential harm.

What else is known about the quality and quantity of intervention?

- Prior to 1960s it was generally accepted that children with autism were unlikely to respond to intervention, regardless of the model, intensity or duration of treatment, and institutionalization was standard practice. However, during the 1960s and 1970s several researchers demonstrated that operant learning techniques could be used to teach children with autism new skills. This work grew into what is now referred to as "applied behaviour analysis" (ABA).
- One of the better known ABA models was The Young Autism Project (TYAP) representing the first comprehensive application of ABA with children with ASD. This model was peer-reviewed and demonstrated that when provided with intervention that was early, intensive, rigorous and delivered by well-trained staff, children with ASD were capable of learning as evidenced by significant gains in IQ and placement in inclusive classrooms (Lovaas, 1987).
- This model has been replicated with positive effects in numerous settings and countries around the world (Reichow and Wolery, 2009) and is the foundation for many contemporary models of autism therapy. It is typically referred to as Early Intensive Behavioral Intervention (EIBI) and is publicly funded in many provincial and state jurisdictions.
- Since the 1990's many other autism programs have also emerged out of the behavioral and developmental sciences, with more of a focus on the relational dynamics and environmental supports. These include Social Communication / Emotional Regulation / Transactional Supports [SCERTS] (Prizant et al., 2003); Pivotal Response Treatment [PRT] (Koegel & Koegel, 2006); Joint Attention, Symbolic Play, and Attention Regulation [JASPER] (Kasari et al., 2014), Early Start Denver Model [ESDM] (Dawson et al., 2012); Incidental Teaching (McGee et al, 1999), enhanced milieu teaching (Ingersoll, 2010); Early Achievements (Landa et al., 2011) and Project ImPACT (Ingersoll & Wainer, 2013). This is not an exhaustive list. In these models, the focus builds on child teaching and extends to caregivers and other communication partners on how to respond appropriately to individual needs, as well as how to modify the environment to improve social communication in natural settings. It is important to understand that these models all generally incorporate operant teaching principles into their implementation and most contemporary models incorporate both child and caregiver teaching in order to be maximally effective.

- Many of these models were recently merged under an umbrella term called "Naturalistic Developmental Behavioral Interventions (NDBI)" (Schriebman et al., 2015). Several have been evaluated using Randomized Controlled Trials (RCT) – the highest level of research evidence, providing a moderate level of support for their implementation. Response to therapy is still inconsistent across groups and current research has focused on trying to better match therapies to specific child and family characteristics. So, flexibility and individualization are called for when choosing and implementing an intervention.
- More highly trained staff are associated with better child outcomes, adoption of EBPs and enhanced collaboration between education, medical, home and community setting (Stahmer et al., 2005; Swiezy et al., 2008).

What is the history of ASD support in Alberta?

- Provincial professional associations and practice groups have adopted EBP as a guiding framework for responsible and ethical practice, particularly for vulnerable populations (e.g., College of Alberta Psychologists, Alberta College of Occupational Therapists, Alberta College of Speech-Language Pathologists and Audiologists). The term ‘established rehabilitative practice’ is used in the FSCD Act (Government of Alberta, 2003).
- Approximately 20 years ago, a series of lawsuits were launched across Canada and the United States regarding access to publicly-funded ASD therapies. In Alberta, the Government of Alberta was ordered to provide intensive behavioral intervention (IBI) services for children with ASD (C.R. v. Alberta [Child Welfare Appeal Panel], 1996; R.R and E.R. v. Alberta [Child Welfare Appeal Panel], 2000; L.S. v. Alberta [Child Welfare Appeal Panel]).
- Evidence regarding the effectiveness of interventions for young children with ASD was the initial impetus for the FSCD Act (e.g., Intensive Behavioral Intervention [IBI] Pilot Project). The government of Alberta commissioned an Expert Panel in 2002 with recommendations on service structure for children with ASD (Alberta Children’s Services, 2002). Select recommendations were to implement a developmentally based system of care with Enhanced Early Intervention (18-30 months of age), Intensive Early Autism Intervention (2.5 years to Grade 1 entry) and School Aged Services (6 years +).
- In 2006, the Parliament of Canada conducted a review and identified the funding mechanisms used for autism therapy across the country. In Alberta, ASD therapy was said to be funded by Family Support for Children with Disabilities (FSCD), specialized services, and provided up to \$40,000 per year, per child (Parliament of Canada, 2006). In the Government of Alberta’s News Release for the funding (July 29, 2004), it was clear that the FSCD legislation was to provide two levels of funding – one for family support services and one for child-focused services.

- Specialized Services is a term specific to the Province of Alberta so there is no empirical literature specific to this type of support/intervention. It is a pan-disability descriptive term that refers to a package of multi-disciplinary services provided to children with ‘a severe disability’ that is based on assessed need, is complex, is ‘integrated and coordinated,’ has an individualized plan, is likely to achieve child progress in daily living skills, is ‘based on established rehabilitative practices,’ and ‘least intrusive and demonstrated to be effective.’ Specialized Services is described in detail of Section 10-77 of the FSCD Policy and Procedure manual (Government of Alberta, 2003). Child focused services are described in Section 4(1) of the FSCD Act and Regulations (Government of Alberta, 2004).
- Specialized Services intent (Section 10-3 of the FSCD Policy and Procedure Manual) has changed numerous times since FSCD Act was proclaimed in 2004, with a stronger emphasis on family coaching and family support services, and a corresponding de-emphasis on child-focused services (Government of Alberta, 2009; 2015).
- In 2003, Alberta Education published a dedicated resource on teaching students with ASD. This resources summarizes diagnostic information, ASD characteristics, the importance of parental collaboration, writing individualized program plans (IPP’s), how to modify classroom instruction, managing challenging behavior, facilitating inclusion, and transition planning.
- In 2011, the Glenrose Regional Hospital in Edmonton and the University of Alberta were identified as Autism Treatment Network (ATN) sites. The ATN is a network of hospitals and physicians focused on comprehensive medical care for children and adolescents with autism (Autism Speaks, 2011).
- Specific roles and responsibilities between school supported programs (Alberta Education) and home and community support programs (Community and Social Services) are implemented quite differently across regions in Alberta, particularly for those individuals severely impacted by ASD with higher support needs.

What is Canada providing for autism supports?

- In 2007, the Senate of the Government of Canada commissioned a review of autism therapy and supports across Canada. In the report entitled *Pay Now or Pay Later: Autism Families in Crisis*, it was highlighted that:
 - 1) ASD is a complex condition and often creates stress for families.
 - 2) There has been an increased rate of diagnoses though increased prevalence is unclear.
 - 3) There is some disagreement about what therapies are most effective and there is a need to identify those that have a solid evidence base for public investment.
 - 4) There is a need to identify inherent strengths associated with ASD as well as treatment needs.
 - 5) Effective treatments that are available are expensive and can cost up to \$60,000 per year if public funding is not available.

- 6) Given the complexity of the condition, multi-disciplinary care is often required.
 - 7) There was a strong emphasis on the federal government playing a role in ensuring evidence-based, publicly-funded ASD therapy was available across Canada, recognizing that health, education and social services are provincial jurisdictions.
- In 2014, as a result of the Senate work, a *National Autism Needs Assessment* was commissioned across Canada and identified the following national priorities:
 - 1) Preschoolers – Early intervention (EIBI and non-EIBI) and social skills training.
 - 2) School-aged – Social skills, activity-based and recreation programs.
 - 3) Adults – Employment or day programs, social and life skills training.
 - 4) Self advocates (Adults with ASD) – Mental health treatment, employment services and social skills training.
 - In Alberta, *the National Needs Assessment* (2014) identified the following priority areas:
 - 1) Preschoolers - Activity-based programs, social skills, early intervention (EIBI and non-EIBI), recreation programs.
 - 2) School aged - Activity-based programs, recreation programs, specialized summer programs, life skills training, respite care.
 - 3) Adults with ASD - Employment or day programs, life skills training, social skills programs, housing/residential options, post-secondary educational programs.
 - 4) Professionals reported that the top service needs were: Early detection of ASD, early intervention, social skills programs, parent/training programs.
 - Top barriers to service were also identified including:
 - 1) Preschoolers - Lack of resources, being too young to access services, lack of trained professionals.
 - 2) School Aged - Lack of resources, lack of trained professionals, difficulty affording services.
 - 3) Adults - Lack of trained health professionals, lack of services, being too old to access service.
 - 4) Professionals - Lack of resources, difficulty affording services, lack of trained health professionals.
 - The Government of Canada (2016) is in the process of setting up a national autism surveillance system through the Public Health Agency of Canada and provides publicly available information on signs and symptoms, causes, health effects and support.
-

KEY CONTRIBUTORS

The key service providers involved in this document have been (in no particular order):

Kimberley Ward, Ph.D, R.Psych, Deputy Executive Director & Director of Treatment Services
Society for Treatment of Autism, Calgary

Nicki M. Wilson, M.Sc., R.Psych,
Associate Executive Director
Renfrew Educational Services, Calgary

Arlene Klooster, MSLP, R.SLP, SLP (C)
Executive Director
Lead Foundation, Calgary

Michael Stolte, Ph.D (Special Education), R.Psych,
Director of Clinical Services
Centre for Autism Services Alberta, Edmonton

Shane Lynch, Ph.D (Special Education), R.Psych,
Director of Southern Services
Centre for Autism Services Alberta, Calgary

Michèle Hébert, Ph.D, OT, erg., Founder and
Director, Buds in Bloom | Bourgeons en Éclat,
Montreal and soon in Calgary

The key advocacy organizations involved in this document have been (in no particular order):

Lyndon Parakin, Executive Director
Autism Calgary

Carole-Anne Patenaude, Executive Director
Autism Edmonton

References

- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th Ed.). Washington, D.C.: Author.
- American Psychological Association (2005). *Policy statement on evidence-based practice in psychology*. Washington, D.C.: Author. Retrieved from: <http://www.apa.org/practice/guidelines/evidence-based-statement.aspx>.
- Autism Speaks (2011). Autism speaks autism treatment network. *Autism Intervention Research Network on Physical Health (AIRP)*. Retrieved from: www.asatn.org/node/1655
- Buescher, A. V. S., Cidav, A., & Knapp, M. (2014). Costs of Autism Spectrum Disorders in the United Kingdom and the United States, *JAMA Pediatrics*, *168*, 721-728.
- Burstyn, I., Slithole, F., & Zwaigenbaum, L. (2010). Autism spectrum disorders, maternal characteristics and obstetric complications among singletons born in Alberta, Canada. *Chronic Diseases of Canada*, *30*(4), 124-134.
- C. R. v. Alberta (Child Welfare Appeal Panel), LII 10456 (Cal. 1996)
- Canadian Pediatric Society (2004). Early intervention for children with autism. *Pediatrics and Child Health*, *9*, 267-270.
- Carter, E. W., Boehm, T. L., Biggs, E. E., Annandale, N. H., Taylor, C. E., Loock, A. K., & Liu, R. Y. (2015). Known for my strengths: Positive traits of transition-age youth with intellectual disability and/or autism. *Research and Practice for Persons with Severe Disabilities*, *40*(2), 101-119. Doi: 10.1177/1540796915592158
- Centers for Disease Control and Prevention (2016). Community report from the autism and developmental disabilities monitoring (ADDM) network: A snapshot of autism spectrum disorder among 8-year-old children in multiple communities across the United States in 2012. United States Department of Health and Human Services: Atlanta, GA. Downloaded from <https://www.cdc.gov/ncbddd/autism/documents/comm-report-autism-full-report.pdf>.
- Centers for Disease Control and Prevention (2012). *Prevalence of autism spectrum disorders: Autism and developmental disabilities monitoring network, 14 sites*, United States, 2008. Morbidity and Mortality Weekly Report Surveillance Summary, *61* (3), 1-19.
- Davies, D. (2004). *Child development: A practitioner's guide* (2nd Ed.). New York, NY: The Guildford Press.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, *37*(1), 39-52.
- Freeman, N. & Perry, A. (2010). Outcomes of intensive behavioral intervention in the Toronto preschool autism service. *Journal on Developmental Disabilities*, *16*(2), 17-32.
- Gabriels, R. L. (2011). Adolescent transition to adulthood and vocational issues. In D. Amaral, G. Dawson, & G. Geschwind (Eds.), *Autism Spectrum Disorders*. (pp. 1167-1181). New York, NY: Oxford University Press.
- Geschwind, D. H. (2009). Advances in autism. *Annual Review of Medicine*, *60*, 367-380.
- Goldstein, S., Naglieri, J. A., Ozonoff, S. (Eds.) *Assessment of Autism Spectrum Disorders* (2009). The Guilford Press: New York.

- Government of Alberta (2002). A system of care for children with Autism: Expert Panel Report. Edmonton, AB: Government of Alberta.
- Government of Alberta (2003). Family Support for Children with Disabilities Act. Edmonton, AB: Government of Alberta. Retrieved from: <http://www.qp.alberta.ca/documents/Acts/F05P3.pdf>
- Government of Alberta (2003). Family support for children with disabilities: Policy and procedures manual. Retrieved from: <http://www.humanservices.alberta.ca/documents/FSCD-Policy-and-Procedures-Manual.pdf>
- Government of Alberta (July 29, 2004). News release: New legislation introduces two service levels for children with disabilities. Retrieved from: <http://www.alberta.ca/release.cfm?xID=16866168F20D5-9BCC-40F0-AA0C230DADE6587E>
- Government of Alberta (2004). Family support for children with disabilities: Policy and procedures manual. Retrieved from: <http://www.humanservices.alberta.ca/documents/FSCD-Policy-and-Procedures-Manual.pdf>
- Government of Alberta (Oct. 27, 2009). Family Supports for Children with Disabilities, Specialized Services: Redesign (powerpoint presentation). Edmonton and Area Child and Family Services, Region 6: Edmonton, AB.
- Government of Alberta (Oct 27, 2015). Family Supports for Children with Disabilities, Specialized Services (powerpoint presentation). Edmonton and Area Child and Family Services, Region 6: Edmonton, AB.
- Government of Alberta (2015). Special education coding criteria. Retrieved from: <http://open.alberta.ca/dataset/ee2ccea8-97fe-41a1-aa11-ed9f21421364/resource/22551585-a8d1-4b54-bdc3-7b21067cdaa7/download/3656041-2015-Special-Education-Coding-Criteria-2015-2016.pdf>
- Government of Canada (2016). Autism spectrum disorder. Retrieved from www.canada.ca/en/public-health/services/diseases/autism-spectrum-disorder-asd.html
- Harper, A., Taylor Dyches, T., Harper, J., Olsen Roper, S., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43, 2604-2616. Doi: 10.1007/s10803-013-1812-0.
- Hodgetts, S. (2013). *Navigating systems of care for young persons with ASD in Alberta*. Retrieved from https://policywise.com/wp-content/uploads/resources/2016/07/259ExecutiveSummary_10sm-Zwaigenbaum.pdf
- Howlin, P. (2005). Outcomes in autism spectrum disorders. In F. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders*. (3rd ed., pp. 201-220). Hoboken, New Jersey: John Wiley & Sons, Inc.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcomes for children with autism. *Journal of Child Psychology and Psychiatry*, 45, 212-229.
- Jack, M., & Ady, J. (2006). *A guide to choosing interventions for children with autism spectrum disorders*. Edmonton, AB: Alberta Center for Child, Family, and Community Research.
- L.S. v Alberta (Child Welfare Appeal Panel), LII 1102 (Cal. 2002)
- Laugeson, E. A., & Frankel, F. (2010). *Social skills for teenagers with developmental and autism spectrum disorders: The PEERS treatment manual*. New York, NY: Routledge.

- Lovaas, O. I. (1974). A behavior modification approach to the treatment of autistic children. *Journal of Autism and Childhood Schizophrenia*, 4, 111-129.
- Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.
- Lowry, L. (2011). *Parents as interveners: Does it really work?* Retrieved from <http://www.hanen.org/SiteAssets/Helpful-Info/Articles/parents-as-interveners.aspx>
- Madore, O., & Pare, J. R. (2006). *Provincial and territorial funding programs for autism therapy*. Ottawa, ON: Library of Parliament.
- Marriage, S., Wolverton, A., & Marriage, K. (2009). Autism Spectrum Disorder grown up: A chart review of adult functioning. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 18(4), 322-328.
- Myers, S. M., & Plauche Johnson, C. (2007). Management of children with autism spectrum disorders, *Pediatrics*, 120, 1162-1182. Doi: 10.1542/peds.2007-2362.
- Nachshen, J., Garcin, N., Moxness, K., Tremblay, Y., Hutchinson, P., Lachance, A., Beaurivage, M., Breitenbach, M., Bryson, S., Burack, J., Caron, C., Condillac, R. A., Cornick, A., Ouellette-Kuntz, H., Joseph, S., Rishikof, E., Sladeczek, I. E., Steiman, M., Tidmarsh, L., Zwaigenbaum, L., Fombonne, E., Szatmari, P., Martin-Storey, A., & Ruttle, P.L. (2008). *Screening, Assessment, and Diagnosis of Autism Spectrum Disorders in Young Children: Canadian Best Practice Guidelines*. Montreal Quebec: Miriam Foundation.
- National Autism Center. (2009). *National standards project findings and conclusions*. Randolph, MA: Author.
- National Autism Center. (2015). *Findings and conclusions: National standards project findings project, phase 2*. Randolph, MA: Author.
- National Research Council (2001). *Educating children with autism*. Washington, DC: National Academic Press.
- R. R. & E. R. v. Alberta (Child Welfare Appeal Panel), LII 28258 (Cal. 2000)
- Reaven, J. A. et al. (2009). Cognitive-behavioural group treatment for anxiety symptoms in children with high-functioning autism spectrum disorder: A pilot study. *Focus on Autism and Other Developmental Disabilities*, 24(1), 27-37.
- Reichow, B. & Wolery, M. (2009). Comprehensive synthesis of early intensive behavioral interventions for young children with autism based on the UCLA young autism project model. *Journal of Autism and Developmental Disorders*, 39, 23-41.
- Reichow, B., Barton, E. E., Boyd, B. A., & Hume, K. (2012). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD) (Review). *The Cochrane Collaboration*, John Wiley & Sons, Ltd. Doi: 10.1002/14651858.CD009260.pub2
- Rogers, S. J. & Dawson, G. (2009). Play and engagement in early autism: The early start denver model. New York: Guilford Press. <http://www.ncbi.nlm.nih.gov/pubmed/19948568>, <http://www.ncbi.nlm.nih.gov/pubmed/19948568>
- Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child and Adolescent Psychology*, 37(1), 8-38.
- Rogers, S. J. & Wallace, K. S. (2011). Intervention for infants and toddlers with autism spectrum disorders. In D. Amaral, G. Dawson, & G. Geschwind (Eds.), *Autism spectrum disorders*. (pp. 1081-1094). New York, NY: Oxford University Press.

- Schreibman, L. et al. (2015). Naturalistic developmental behavioral interventions: Empirically validated treatments for autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(8), 2411-2428.
- Smith, T. (2012). Making inclusion work for students with autism spectrum disorders: An evidence-based guide. United States: The Guilford Press.
- Smith, T., & Iadarola, S. (2015). Evidence base update for autism spectrum disorder. *Journal of Clinical Child and Adolescent Psychology*, 44(6), 897-922.
- Stahmer, A. C. et al. (2015). Training teachers to use evidence-based practices for autism: Examining procedural implementation fidelity. *Psychology in the Schools* 52(2), 181-195.
- Steiner, A. M., Koegel, L. K., Koegel, R. L., & Whitney, A. (2012). Issues and theoretical constructs regarding parent education for autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(6), 1-15.
- Strain, P. S., & Bovey, E. H. (2011). Randomized, controlled trial of the LEAP model of early intervention for young children with autism spectrum disorders. *Topics in Early Childhood Special Education*, 31(3), 133-154.
- Swiezy, N., Stuart, M., & Korzekwa, P. (2008). Bridging for success in autism: Training and collaboration across medical, educational, and community systems. *Child & Adolescent Psychiatric Clinics*, 17(4), 907-922.
- The Standing Senate Committee on Social Affairs, Science and Technology. (2007). *Autism Families in Crisis*. Ottawa, ON: Library of Parliament.
- Weiss, J. A., Whelan, M., McMorris, C., Carroll, C. and the Canadian Autism Spectrum Disorders Alliance. (2014). Autism in Canada: National needs assessment survey for families, individuals with autism spectrum disorder and professionals. Retrieved from http://www.casda.ca/wp-content/uploads/2015/12/NationalNeedsAssessmentSurvey_July-30.pdf
- Wong, C., Odom, S. L., Hume, K. A., Cox, C. W., Fettig, A., Kurcharczyk, S., et al. (2015). *Evidence-based practices for children, youth, and young adults with autism spectrum disorder*. Chapel Hill, NC: The University of North Carolina.
- Zwaigenbaum, L. et al. (2015). Early intervention for children with autism spectrum disorder under three years of age: Recommendations for practice and research. *Pediatrics*, 136(1), 60-81.