

AUTISM SPECTRUM DISORDER: SUPPORTING FAMILIES IN BC

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PRESENTATION OVERVIEW

- Autism Spectrum Disorder
- MCFD Autism Funding
- Autism Information Services BC
- Intervention for Children with ASD – Key Elements
- Program Planning for Toddlers and Preschoolers
- Program Planning for School-Age
- Program Planning for Teens



WHAT IS AUTISM SPECTRUM DISORDER?

- Autism Spectrum Disorder (ASD):
 - Is a complex neurobiological condition;
 - Impacts typical brain development; and
 - Affects social relationships, communication, interests, and behaviour
- Individuals with ASD exhibit any combination of symptoms and characteristics in any degree of severity
- Symptoms present in a wide variety of combinations and can look very differently for each person



AUTISM SPECTRUM DISORDER

- In general, a person with ASD typically:
 - Has difficulty with communication and social interaction; and
 - Displays other behaviours that may include:
 - over dependence on routines;
 - highly sensitive to changes in environments;
 - unusual attachments to objects; and/or
 - engaging in restrictive and/or repetitive behaviours



DIAGNOSIS OF ASD IN BC: ELIGIBILITY

- **Public Diagnosis:**
 - BC Autism Assessment Network (BCAAN), Provincial Health Services Authority (PHSA)
 - Requires Physicians Referral
- **Private Diagnosis**
 - Contact Local Private Diagnostician/Clinic
 - Private Assessment for Diagnosis must adhere to BC Standards and Guidelines for Assessment of ASD for Young Children to be eligible for government services
- **Confirmation of Diagnosis**
 - If a child had a diagnostic assessment of ASD from another province or country a Confirmation of Diagnosis must be completed by a qualified B.C. specialist (paediatrician, psychiatrist or registered psychologist).
 - If the out of province diagnostic assessment is incomplete or if the the qualified B.C. specialist does not agree with the diagnosis, s/he may require the child to undergo additional assessment or recommend that a new diagnostic assessment be implemented.

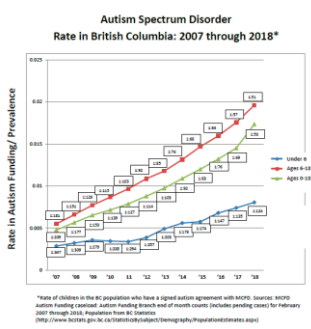


ASD: PREVALENCE

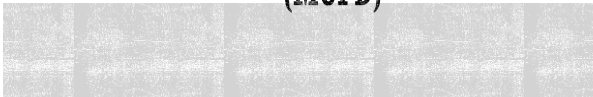


- Affects 1:68 children and is considered one of the most common developmental disabilities
- The prevalence of ASD has increased over the past two decades:
 - 2/10,000 in 1980
 - 1/68 presently (according to latest report from U.S. Center for Disease Control and Prevention)
- In BC ASD affects 1:51 children aged 6 through 18 (as identified by the MCFD Autism Funding Program)





**PROVINCIAL AUTISM FUNDING:
MINISTRY OF CHILDREN AND FAMILY DEVELOPMENT (MCFD)**





MCFD AUTISM FUNDING

- In BC, services to children with autism are provided through an individualized funding model
- MCFD provides families' access to Autism Funding and families then use these funds to purchase eligible services from private practitioners.

MCFD AUTISM FUNDING



- BC is the only province in Canada that has a no waitlist policy for families to access autism funding once their child or youth has received a diagnosis of ASD



MCFD AUTISM FUNDING



- **Autism Funding: Under Age 6** – began in 2002
 - Families can receive up to \$22,000 per year
 - Intended to assist with the cost of purchasing autism intervention services, based on best practices
 - Intervention is intended to support their child's communication and language, social and emotional skills, pre-academic, and functional life skills
- **Autism Funding: Ages 6-18** – began in 2003
 - Families can receive up to \$6,000 per year
 - Intended to assist with the cost of purchasing out-of-school autism intervention supports
 - Intended to promote their child's communication and language, social and emotional skills, academic, and functional life skills



MCFD CHILDREN AND YOUTH WITH SPECIAL NEEDS (CYSN) SERVICES

- Families of children with ASD are also eligible for a variety of other services and supports through MCFD, such as Early Intervention Therapies, School-Aged Therapies, Infant Development, Supported Child Development and Family Support Services, including Respite
- Families should contact their local CYSN Worker to discuss eligibility



MCFD AUTISM FUNDING: WHAT CAN FAMILIES PURCHASE?



- Funding is to assist families with the cost of purchasing **autism intervention** services that promote their child's development based on accepted **best practices**
- Details of what families can purchase can be found in the online parent handbook
- Handbook is available in 9 Languages at:

Autism Information Services BC

<http://autisminfo.gov.bc.ca/>





AUTISM INFORMATION SERVICES BRITISH COLUMBIA (AIS BC)





AIS BC – WE'RE HERE TO HELP



- Families know their child best and with autism funding they are able to take an active role in creating an intervention program that best meets the needs of their child and their family



- But, making decisions about intervention and navigating the BC service system can be challenging

- AIS BC is there to help families along their journey – it is there to support families to make informed decisions





AIS BC – WE'RE HERE TO HELP

What Do We Do?

- A provincial information centre for autism and related disorders that provides best practice information, supports and training to:
 - Families
 - Service providers (MCFD and related staff; etc.)
 - Community professionals
- Experienced staff are available by:
 - Phone
 - In person
 - Email
- Staff speak three languages (Mandarin/Cantonese; Punjabi; and Tagalog) and we have access to interpreters for over 50 additional languages



AIS BC – WE'RE HERE TO HELP



Common Topics/Areas of Support

- Pre-diagnosis
- New diagnosis
- Preschool-aged
- Autism Funding
- Transition times
- School-aged
- Dual Diagnoses
- Transition to adulthood
- Employment





AIS BC – WE'RE HERE TO HELP

- Launched July 1, 2017
- Located at 3688 Cessna Drive, Richmond at the Pacific Autism Family Network Goodlife Fitness Family Autism Hub

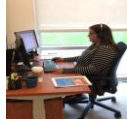
FIVE COMPONENTS OF SERVICE





AIS BC – WE'RE HERE TO HELP

Supports to Families



- AIS BC staff assist the growing number of B.C. families affected by autism who need support in making informed decisions about treatment options for their children





AIS BC – WE'RE HERE TO HELP

Supports to Service Providers



A central resource for service providers to support the families they serve. AIS BC promotes collaboration and coordination between ministry and autism-related service organizations and community support providers across B.C.





AIS BC – WE'RE HERE TO HELP

Management of the Registry of Autism Service Providers (RASP)

- Management of a vetted listing of qualified professionals including:
- Behaviour Analysts/Consultants (Supervised & Non-Supervised)
 - Speech-Language Pathologists (Supervised & Non-Supervised)
 - Occupational Therapists (Supervised & Non-Supervised)
 - Physical Therapists
- Over 750 professionals listed – new professionals frequently added
 - Searchable on <http://autisminfo.gov.bc.ca/> by:
 - City
 - Accepting new clients
 - Willing to travel to remote areas
 - Provide services via videoconferencing





AIS BC – WE'RE HERE TO HELP

Outreach Workshops Across BC





AIS BC – WE'RE HERE TO HELP

Community Connection Events





AIS BC – WE'RE HERE TO HELP



- Connect with us: 8:30am–4:30pm (M-F)
- In-Person: No appointment necessary
- Toll-free: 1 844 878-4700
- Website: autisminfo.gov.bc.ca
- Email: AutismInformation@gov.bc.ca



INTERVENTION FOR ALL CHILDREN WITH ASD

What do we Know?



WHAT WORKS BEST?

- Research shows that there is no ONE treatment that has 100% effectiveness for all individuals with autism.
- But, approximately two-thirds of treatments proven to be effective in the literature are developed from behavioural theories and include the theoretical learning model of **Applied Behaviour Analysis (ABA)**. (Ingersoll, et al. 2001; Williams et al., 2014)
- **Applied Behaviour Analysis (ABA)** is a science that involves systematically applying the principles of learning to bring about meaningful and positive change in social behaviours.
 - For example, the principle of positive reinforcement tells us that behaviour that is followed by a reward will occur more often, so we use positive reinforcement to help individuals with autism learn new, important skills.



AUTISM -- WHAT TO DO?

- Although there is no 'cure' for ASD, there are effective treatment and intervention methods available that can help individuals and their families address the characteristics of this disorder
- **No single intervention program** will suit all children with autism and their families
- Intervention for children and youth with ASD is a politically heated and scientifically multi-faceted topic
- Generalizations about the effectiveness of interventions can be misleading



GOAL OF INTERVENTION

- Each child with autism is unique
- Intervention planning should be tailored to the child's strengths and needs
- Intervention will need to change over time and may involve:
 - 1-1 therapy
 - Home-based programs
 - School-based programs
 - Skills-based programs
 - Social programs
 - Group-based programs
 - Community/Recreation programs
 - Vocational/employment supports
 - Complementary therapies that address your child's specific needs
 - Or any combination of these or other approaches



EVIDENCE-INFORMED KEY ELEMENTS

- Numerous studies and panel reports have examined various early intervention programs with empirical support
 - Dawson and Osterling, 1997
 - Strain, Wolery, & Izeman, 1998
 - Rogers, 1998
 - Hurth et al., 1999
 - U.S. National Research Council, 2001, 2009, 2015
 - U.S. Healthcare Research and Quality Review, 2011
- Identified several key elements or "promising practices" that are common to *all* successful approaches



EVIDENCE-INFORMED KEY ELEMENTS

1. Begin as early as possible
2. 1-1 instruction (at least initially)
 - Carefully planned to meet specific, developmentally-appropriate goals
 - Individualized
 - Systematically executed
 - Regularly evaluated
3. Evidence based skill instruction



EVIDENCE-INFORMED KEY ELEMENTS

- 4. Problem behaviours should be addressed with **Positive Behavior Support (PBS)**
 - PBS is used to increase quality of life and decrease problem behavior by teaching new skills and making changes in a person's environment
 - PBS can be used by a wide range of trained service providers.
 - PBS combines the principles of Applied Behaviour Analysis with those of other disciplines to decrease problem behaviour, primarily by teaching new skills and making changes in a person's environment.
 - PBS often focuses on *why* problem behaviours occur and then teaching new skills to replace those behaviours
 - The focus is on proactive, reinforcement-based interventions and supports across settings to improve behaviour so that it is meaningful, durable, and sustainable in natural settings.
 - For more information, please refer to www.apbs.org/ or www.pbis.org



EVIDENCE-INFORMED KEY ELEMENTS

- 5. Provide regular, planned opportunities to interact with typically developing same-age peers
- 6. Amount, (i.e., quantity) of intervention should match individual needs, but should be available year-round (50-52 wks/yr)
- 7. There is some evidence that for young children, more intervention is better (20-40hr per week)
- 8. Services should be delivered in many different contexts
- 9. Parents should ideally be involved in implementation
- 10. Scope and sequence of instruction should cover all areas of developmental needs
- 11. Multidisciplinary; Multiple, integrated therapies (BA, BC, SLP, OT, PT etc.)



THE BOTTOM LINE

- All children and families have differences
- There is no “one-size fits all” treatment
- Look beyond the “name-brand”
- Decisions should be based on sound evidence and knowledge of the child and family



INTERVENTION ACROSS THE AGE RANGES



PROGRAM PLANNING FOR THE TODDLER/PRESCHOOL YEARS

- Intervention should provide direct emphasis on the core areas of difficulty in autism
- Think about the child's ability in each of these areas and set goals accordingly
 - **Paying attention and coordinating attention with others** (e.g., looking towards a person when they are communicating; looking at an object when the adult is also looking at and talking about the same object)
 - **Engaging in social play** (e.g., songs, turn taking games, etc.)
 - **Reciprocal enjoyment** (e.g., social smiles) during social games and routine activities
 - **Communicating** by using eye contact, gestures, sounds, and/or words
 - **Imitating others** (e.g., imitating physical actions; imitating actions with objects)
 - **Playing with toys** in the way they were intended (e.g., driving a car on a car mat instead of spinning the wheels of a car)



PROGRAM PLANNING FOR THE TODDLER/PRESCHOOL YEARS

- Whenever possible, parents and caregivers should be involved in intervention planning and implementation.
- Well-designed goals and intervention strategies should also be carried out during daily routines (e.g., mealtimes, bath time, play time, while reading books, etc.).
- For young children with ASD it can be highly effective to find a trained professional to coach parents in using the intervention techniques during natural routines, so that parents can better support their child's learning in daily life routines



PROGRAM PLANNING FOR THE SCHOOL-AGE YEARS



Importance of Inclusion

- Research has consistently demonstrated that the inclusion and support of students with special needs in general education classrooms results in positive outcomes.
- “Inclusive education means that all students attend and are welcomed by their neighbourhood schools in age-appropriate, regular classes and are supported to learn, contribute and participate in all aspects of the life of the school” (Inclusion BC: <http://www.inclusionbc.org/>)



PROGRAM PLANNING FOR THE SCHOOL-AGE YEARS



Setting Goals

- When developing your school-aged child's intervention program, think about what **environments** the child spends time in or would like to spend time in, and what **skills** the child needs to learn to interact and be successful across a range of settings.

Common intervention goals for in the school age years include:

- Communication (using and understanding)
- Socially interacting with peers
- Self-regulating and self-managing behaviours
- Attending to key elements of the environment (at home and school)
- Organizational skills
- Supporting sensory needs



PROGRAM PLANNING FOR THE SCHOOL-AGE YEARS



Effective teaching strategies

- Common and effective teaching techniques for children with ASD include but are not limited to:
- **Social skills training** (for children with ASD and/or social skills training for their neurotypical peers)
- **Visual schedules and visual supports** (can help create a more structured environment to help with organization, preparedness, anxiety, and/or challenging behaviors)
- **Video Modeling** (video demonstrations of positive behaviors)
- **Visual Scripts and Social Stories™** (can help teach social rules and social understanding)



PROGRAM PLANNING FOR THE TEEN YEARS



Goals to Consider

Life Skills

The teen years are an important time to discover what interests and motivates your teen. Important areas of focus include:

- Developing routine-based life skills such as taking transit, folding laundry, taking out garbage and helping with meals
- Supporting independence in personal care
- Supporting and teaching self-advocacy skills to learn how to make independent choices and problem solve
- Supporting and teaching self-determination (i.e., helping teens to understand their goals, strengths and limitations so that they are able to create their own life path)



PROGRAM PLANNING FOR THE TEEN YEARS



• Volunteer and Work Opportunities

Finding opportunities to volunteer, attend vocational training programs and /or start paid employment.

• Leisure and Recreation

- Finding opportunities to participate in a range of leisure and recreational activities outside of the home
- Learning social skills to engage with others and understand others non-verbal cues.
- Social skills training grounded in research such as PEERS® and Social Thinking® teach these skills through modeling, practice and reinforcement of desired behaviors.



PROGRAM PLANNING FOR THE TEEN YEARS



Mental Health

Youth with autism are often at increased risk for mental health issues such as anxiety and depression. These conditions may be exacerbated by the onset of puberty or starting a new school.

• For more information on mental health disorders and ASD, there are two webinars developed for families and mental health practitioners available through ACT-Autism Community Training:

• Recognising Mental Health Disorders: actcommunity.ca/education/mentalhealth/recognising/

• Treating Anxiety Depression & OCD: actcommunity.ca/education/mentalhealth/treating

• To find your local mental health office to support teens with intellectual disability, contact AIS BC at 1-844-878-4700 or autisminformation@gov.bc.ca



PROGRAM PLANNING FOR THE TEEN YEARS



Start Planning for Adulthood:

Transition planning to adulthood typically starts when a child turns 14. View detailed steps here: https://www2.gov.bc.ca/assets/gov/family-and-social-supports/roles_tasks_transition.pdf

- Discuss with your CYSN worker if your child is eligible for *Services to Adults with Developmental Disabilities (STADD)*. This program supports eligible youth age 16-24 with transition planning to adulthood and is now available in several communities across B.C. For details view: www2.gov.bc.ca/gov/content/family-social-supports/services-for-people-with-disabilities/transition-planning-for-youth-young-adults



PROGRAM PLANNING FOR THE TEEN YEARS



Consider Making the Most of Technology

- Video-based interventions such as video-modeling and the use of targeted applications on personal digital devices are promising tools to teach greater independence for teens with autism.
- For more information on intervention approaches and supporting teen learners, visit: autismspeaks.org/sites/default/files/sctk_supporting_learning.pdf



Thank you