

# *Supporting Adaptive Behaviour in Children with Complex Disabilities*



## **Unit 1: Overview**

## UNIT 1: OVERVIEW

### CLUSTER #1 – DISABLING CONDITIONS

#### Topic 1.1 Fetal Alcohol Spectrum Disorder (FASD)

**Description** - Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that refers to the range of behavioural, physical, and cognitive difficulties that can result when the developing fetus is exposed to alcohol during pregnancy. Fetal Alcohol Syndrome (FAS) is the medical diagnosis used to refer to children and youth who: 1) were exposed to alcohol prior to birth; 2) display growth deficiencies; 3) present with specific facial features; and 4) demonstrate central nervous system dysfunction. The spectrum includes individuals who have the full syndrome (i.e., FAS) to those that display only a few issues or characteristics (i.e. FAE). As an Aide you may encounter the following terms:

- **Alcohol related birth defects (ARBD)**- associated with a confirmed history of alcohol exposure; and specific physical problems (e.g., visual issues, hearing loss, motor issues, heart problems)
- **Partial Fetal Alcohol Syndrome (pFAS)** – associated with a confirmed history of alcohol exposure; some, but not all, of the physical features associated with FAS; and behavioral and learning difficulties
- **Alcohol-Related Neurological Disorder (ARND)** or **Fetal Alcohol Effects (FAE)** – associated with a confirmed history of alcohol exposure; and the learning and behavioral issues commonly associated with central nervous system damage (e.g., impulsivity, attention and problems, limited social skills)

**Characteristics** – Children and youth with FASD often display:

- Growth deficiencies – weight and/or height are below average for age
- Specific facial features – small eye slit openings; thin upper lip; flattening of the groove between the nose and upper lip (also know as the philtrum)
- Central nervous system dysfunction – microcephaly; lesions; structural abnormalities; seizures; tremors
- Motor issues – decreased muscle tone; swallowing/sucking problems; poor balance and coordination (i.e., clumsy); poor eye-hand coordination
- Sleep issues – difficulties falling asleep and sleeping through the night
- Behavioral challenges – tend to display oppositional and defiant behaviour; are easily frustrated; may display mood swings, anxiety, and/or impulsivity; a short attention span; hyperactivity; distractibility; difficulty managing emotions; tend to have a low frustration tolerance; and often engage in risky/potentially dangerous behaviours
- Learning challenges – difficulty connecting cause and effect; difficulty understanding the consequences of their behaviour
- Memory difficulties – difficulties storing and retrieving information

- Communication challenges – delayed language development; expressive skills may be misleading as individuals with FASD may not comprehend all that they or others say; they may have a hard time expressing feelings verbally; difficulties understanding and using social language, sarcasm, metaphors, etc.
- Cognitive skills – approximately half of children with FASD score in the below average range; they tend to have difficulty comprehending abstract concepts and can be quite concrete and literal
- Adaptive functioning – often require assistance to complete age appropriate self care tasks and household chores
- Social Skill – difficulties making and maintaining peer friendships

**Cause** - Alcohol crosses the blood brain barrier during pregnancy and adversely affects the developing fetus. The amount and duration of alcohol intake, genetics, and lifestyle (e.g., diet, use of other drugs) tend to influence the degree of damage and syndrome expression. There is no known “safe” amount of alcohol that can be consumed while pregnant and there also does not appear to be a safe time to drink during pregnancy. Therefore, it is recommended that women abstain from drinking alcohol throughout the pregnancy.

**Prevalence** - FASD is found in approximately 1 in 200 births. FAS, the full syndrome, is less common, occurring in approximately 1-2 per 1000 births, while FAE is estimated to occur in approximately 3-5 per 1000 births.

**Websites -**

[www.phac-aspc.gc.ca/fasd-etcaf/index-eng.php](http://www.phac-aspc.gc.ca/fasd-etcaf/index-eng.php)

[www.education.alberta.ca/admin/special/resources/fasd.aspx](http://www.education.alberta.ca/admin/special/resources/fasd.aspx)

**Topic 1.2 Down syndrome**

**Description** - Down syndrome, also called Trisomy 21, is a chromosomal disorder. Individuals with Down syndrome have extra genetic material (i.e., 47 chromosomes, instead of 46) which impacts physical and mental development. Although Down syndrome cannot be prevented, it can be detected during pregnancy.

**Characteristics** – Although there is wide variability, children and youth with Down syndrome often display:

- Physical features – poor/low muscle tone; small stature; flat nasal bridges; protruding tongues due to a small oral cavity and/or an enlarged tongue; short necks; an upward slant to the eyes; flat facial profiles; single, deep creases across the palms of their hands
- Medical issues – congenital heart defects are present in approximately 50% of children with Down syndrome; increased risk of pulmonary hypertension,

Alzheimer's disease, childhood leukemia and thyroid problems; hearing and vision problems are also common

- Cognitive skills – most individuals with Down syndrome present with some level of cognitive delay; most have a mild to moderate degree of intellectual impairment
- Adaptive skills – low muscle tone often results in sucking and feeding problems; often delayed in developing self care skills and toilet training
- Communication skills – receptive skills tend to be stronger than expressive communication skills; reduced intelligibility is also common
- Motor skills – often delayed in achieving motor milestones; fine motor skills tend to lag behind the development of gross motor skills
- Learning – often slower than that displayed by typically developing peers of the same age

**Cause** - At present, the cause of the chromosomal anomaly associated with Down syndrome is unknown. Maternal age is the only factor that has been linked to an increased chance of having a baby with Down syndrome. However, due to the fact fertility rates are higher for younger women, 80% of children with Down syndrome are born to women under the age of 35.

**Prevalence** – The incidence of Down syndrome is estimated at one in 800 births in Canada. However, the risk of having a child with Down syndrome is associated with maternal age. For women 20 to 24 the probability of having a child with Down syndrome is one in 1563; at 35 to 39 the probability is one in 214, and at age of 45 the probability is one in 19.

#### **Websites -**

[www.cdss.ca](http://www.cdss.ca)

[www.ndss.org](http://www.ndss.org)

### **Topic 1.3 Fragile X Syndrome**

**Description** - Fragile X Syndrome is genetic disorder that is caused by mutation of the FMR1 gene on the X chromosome. It is the most common form of inherited mental impairment and results in a range of issues (i.e., learning disabilities to severe cognitive deficit). Fragile X is also the most common known cause of Autism. Given that males typically have only one copy of the X chromosome, syndrome expression tends to be more pronounced in boys versus girls. Only 30% of women with Fragile X are symptomatic. Fragile X is diagnosed via a blood test.

**Characteristics** – Children with Fragile X often display:

- Physical features – large and/or protruding ears; soft skin; low muscle tone; flat feet; elongate faces; large testicles; and a prominent jaw and forehead

- Cognitive skills – approximately 95% of males and 10% of females with Fragile X display a clinically significant cognitive deficit; males often require long term supports and display limited personal independence; memory issues are also common
- Medical issues – approximately 20% of males with Fragile X develop seizures; heart defects (i.e., mitral valve prolapse) are also common
- Behaviour – individuals with Fragile X often display impulsivity; stereotypic movements; a short attention span; hyperactivity; hypersensitivity to certain forms of sensory input; distractibility; inflexibility; and/or difficulty managing emotions
- Social-communication skills – delayed speech development; limited eye contact; tend to be socially anxious; have difficulty forming peer friendships; often display echolalia, a communication impairment beyond what one would expect given developmental level; and/or tangential speech

**Cause** – Fragile X is an X-linked dominant condition. Males with Fragile X cannot transmit it to their sons, but will transmit it to all daughters. Females carrying one copy Fragile X (one X chromosome is typical) can transmit to both their sons and daughters.

**Prevalence** – Mutation of the FMR1 gene on the X chromosome occurs in one in 2000 males and one in 259 females. Approximately 3-6% of children with Autism have Fragile X syndrome.

**Websites -**

[www.fragile-x.ca](http://www.fragile-x.ca)

[www.fragilex.org](http://www.fragilex.org)

**Topic 1.4 Attention Deficit Disorder (AD/HD)**

**Description** – Attention Deficit/Hyperactivity Disorder (AD/HD) is a neurobiological condition. Symptoms include: inattention, hyperactivity and impulsivity. There are three subtypes:

- Predominantly inattentive
- Predominantly hyperactive/impulsive
- Combined type (demonstrate inattentiveness as well as hyperactivity/impulsiveness)

**Characteristics –**

- Inattention - difficulty following instructions and completing tasks that require sustained attention; tend to be distractible; display organizational difficulties; tend to make careless mistakes; often fail to attend to details
- Hyperactivity - difficulty remaining seated; restless; excessive talking; frequent squirming/fidgeting

- Impulsivity – acting before thinking; not considering the consequences of an action; blurting out inappropriate remarks or answers; impatient; tend to have a low frustration tolerance; and often engage in risky/potentially dangerous behaviours
- Social-emotional difficulties – limited confidence; emotionally overactive; easily frustrated; limited social success; often misinterprets social cues; tend to be viewed as oppositional
- **Executive functioning challenges** – have difficulty regulating level of arousal; display limited self monitoring skills; and have difficulty delaying gratification

**Cause** – AD/HD tends to run in families, suggesting that the disorder is genetic in origin. If a parent has AD/HD, there is a 57% chance that their child will also have AD/HD. Parents and siblings of children diagnosed with AD/HD often demonstrate similar symptoms. AD/HD has also been associated with trauma to the developing fetus (e.g., disease), exposure to alcohol/toxins, and prematurity/low birth weight.

AD/HD appears to be a result of abnormalities in certain neurotransmitters in the brain (e.g., dopamine) and/or subtle structural differences (e.g., frontal lobe).

**Prevalence** – Approximately 4 - 12% of school-aged children present with AD/HD. It occurs in both males and females; however females are more likely to fall in to the predominantly inattentive category. Approximately 30 to 50% of children and youth with AD/HD also present with learning disabilities, and 40% present with Oppositional Defiant disorder.

**Websites** –

[www.education.alberta.ca/admin/special/resources/adhd.aspx](http://www.education.alberta.ca/admin/special/resources/adhd.aspx)

[www.adhd.ca](http://www.adhd.ca)

### **Topic 1.5 Autism Spectrum Disorders (ASD)**

**Description** – Children and youth with ASD display difficulties with respect to their communication and social interaction skills, as well as restricted, repetitive and stereotypic patterns of behaviour. However, syndrome expression tends to vary dramatically. The following conditions are generally accepted as Autism Spectrum Disorders:

- Autistic Disorder
- Asperger's Disorder
- Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS)

It is important to note that Rett's Disorder and Childhood Disintegrative Disorder are also classified as Pervasive Developmental Disorders by the medical profession. However, these conditions are quite rare and the course is often different (i.e., poorer

prognosis) than that observed with Autistic Disorder. For this reason, some use the term Autism Spectrum Disorder to refer to all Pervasive Developmental Disorders, while others use the term to refer to only those children and youth with Autistic Disorder, Asperger's Disorder and PDDNOS. The situation is further complicated by the fact that the term PDD is sometimes used: to refer to a category of disorders, as a diagnostic term, and as the abbreviated name of a specific program in Alberta (i.e., services for adults with developmental disabilities). For this reason, it is important to seek clarification when terms such as ASD and PDD are used. For the purposes of this website, ASD is used to refer to children and youth diagnosed with Autistic Disorder, Asperger's Disorder, or PDDNOS.

Asperger's Disorder is characterized by marked impairments with respect to social interaction and restricted, repetitive and stereotypic patterns of behaviours. However, children and youth with Asperger's Disorder differ from those diagnosed with Autism or Autistic Disorder in that they have at least average cognitive ability and no clinically significant communication delay.

PDDNOS is often referred to as "atypical autism". It is used to describe children who present with the social, communication and behavioral characteristics associated with Autistic Disorder, but do not meet the established diagnostic criteria due to late age of onset or atypical symptom expression.

**Characteristics** – Children and youth with ASD often display:

- Communication impairments – a delay in, or lack of expressive communication skills; difficulties with nonverbal forms of communication (e.g., gestures, facial expression, body posture, eye contact); difficulties initiating/maintaining conversations with others; idiosyncratic language/echolalia; they tend to use language for instrumental purposes (to get needs met), rather than for social purposes; difficulties with topic maintenance
- Social impairments – limited ability to use nonverbal social behaviours (e.g., eye contact); difficulties forming peer friendships; impaired joint attention; difficulty engaging in reciprocal interactions (i.e., one sided interactions)
- Behaviour- preoccupations; repetitive motor mannerisms; obvious desire to follow established routines; tendency to focus on parts of objects, rather than the whole
- Sensory – often display hyper (over reaction) or hypo (under reaction) sensitivity to specific forms of sensory input
- Cognitive skills – approximately 70% of children and youth with ASD present with cognitive deficits (approximately 40% have severe to profound impairments; 30% have mild to moderate impairments; and 30% have average or above average intelligence)
- Attention – difficulty disengaging and shifting attention; often focus on irrelevant aspects of environment, rather than social cues
- Anxiety – unusual fears; high need for predictability

**Cause** – Current thinking is that no single abnormality can account for all of the characteristics associated with ASD or for the variability demonstrated across the spectrum. It is generally accepted that ASD is a biologically based neurodevelopmental disorder. There is growing evidence that Autism is a genetic condition, but the mode of transmission is complex and several different genes are likely involved.

**Prevalence** – Depending on the definition used, prevalence rates range from 16 per 10 000 to as high as 30 to 60 per 10 000. A figure of 1 in 165 has been reported for a Canadian sample (please see [www.cairn-site.com](http://www.cairn-site.com) for additional information). ASD is three to four times more common in males than females.

#### **Websites -**

[www.autismsocietycanada.ca](http://www.autismsocietycanada.ca)

[www.autismspeaks.org](http://www.autismspeaks.org)

[www.cairn-site.com](http://www.cairn-site.com)

#### **Topic 1.6 Cerebral Palsy (CP)**

**Description** – Cerebral Palsy is a term used to describe a group of movement or posture disorders. Cerebral refers to the cerebrum, which is one of the primary areas of the brain that is affected, while palsy refers to disorders of movement. There are four basic subtypes; each is based on the type of motor impairment displayed:

- Spastic – evidenced by difficult or stiff movement. This subtype is further categorized based on the limb(s) involved:
  - Hemiplegia – one side affected
  - Diplegia – lower body affected
  - Quadriplegia – all four limbs affected
- Ataxic – involves loss of balance and depth perception
- Athetoid/Dyskinetic – refers to uncontrolled or involuntary movements and changing patterns of muscle tone
- Mixed – refers to a combination of two or more of the movement categories described above

Spastic CP is the most common form of the disorder.

**Characteristics** – CP is characterized by abnormal muscle tone, motor development, and coordination. In addition to the motor issues, individuals with CP often demonstrate:

- Perceptual Issues – visual impairments, hearing impairments
- Speech and Language difficulties – speech problems are often associated with poor respiratory control and restricted movement in the oral facial muscles



- Cognition/learning – intellectual level varies dramatically; some individuals demonstrate average to above average intelligence, while others present with some degree of cognitive deficit
- Adaptive functioning – the level of personal independence achieved is often dependent on the severity of the CP; feeding issues are also common.
- Behavioural issues – range from hyperactivity to self-injurious behaviours
- Medical conditions – seizures, epilepsy, joint and bone deformities are common

**Cause** – CP is not a disease with a single origin or cause. It is caused by damage to the motor control centers of the developing brain. The damage occurs during pregnancy approximately 75% of the time (e.g., intrauterine infection, genetic syndromes, and chromosomal abnormalities) during delivery approximately 5% of the time (e.g., preeclampsia, delivery complications) and after birth and prior to age three approximately 15% of the time (e.g., head injury, meningitis, encephalitis). When the damage occurs after the child has been born, the condition is often referred to as “Acquired CP”. Approximately 40 to 50% of all children with CP were born prematurely

**Prevalence** – The incident of CP is about 2 per 1000 births. The disorder is more common in males than females, at a ratio of approximately 1.33 to 1.0.

#### **Websites -**

[www.ofcp.on.ca](http://www.ofcp.on.ca)

[www.cerbralpalsycanada.com](http://www.cerbralpalsycanada.com)

[www.cerbralpalsy.org](http://www.cerbralpalsy.org)

#### **Topic 1.7 Developmental Delay, Global Developmental Delay and Mental Retardation**

**Description** - Developmental delay is a term used to describe the situation when a child fails to achieve developmental milestones at expected times. That is, the child’s skills are not comparable to those displayed by peers of the same age. The term global developmental delay is generally used when a child presents with developmental delays across all/most domains (e.g., cognitive skills, motor skills, communication skills, adaptive functioning). These terms are generally applied after a child’s skills have been formally assessed and the degree of deficit (i.e., mild, moderate, severe) has been identified.

Although many find the label distasteful, the term Mental Retardation is a currently employed diagnostic term. It is used when a child presents with: a clinically significant cognitive impairment (i.e., based on an individually administered test of intelligence), a clinically significant impairment in adaptive functioning; and the condition developed prior to age 18.

**Characteristics** – The support needs of individuals with developmental delays tend to vary depending on the level of severity. Those with mild deficits generally require intermittent support to be successful, while those with severe to profound deficits generally require extensive, ongoing support to function effectively. Those individual who present with extensive support needs often display associated impairments that further impact functioning. These include: visual impairments, seizure disorders, speech and language impairments and behavioural issues.

**Cause** – Although socioeconomic status and environment (e.g., nutrition, stimulation) appear to play a role, more severe developmental delays tend to be biological in origin. The most common (i.e., accounting for approximately one third of the population) conditions/diagnoses are: Fragile X, Down syndrome and FASD. Other factors include: early pregnancy problems, perinatal insults and post natal brain damage.

**Prevalence** – Prevalence rates tend to vary depending on the specific definition employed. Based on statistics, one would expect approximately 2.5% of the population to meet the criteria for Mental Retardation. The ratio of males to females is estimated to be 2 to 1.

**Websites –**

[www.kidsgrowth.com/resources/advisedetail.cfm?id=2136](http://www.kidsgrowth.com/resources/advisedetail.cfm?id=2136)

[www.cdc.gov/ncbddd/dd/ddmr.htm](http://www.cdc.gov/ncbddd/dd/ddmr.htm)

[www.aamr.org](http://www.aamr.org)

## UNIT: OVERVIEW

### Introduction:

- **Spectrum of severity in behaviour**
- **Website covers full range from mild to severe**
- **Many treatment approaches out there, many lack scientific validation**
- **Principle of starting with least intrusive use based on child's needs, family's preferences, mandate and philosophy of agency**

### TREATMENT APPROACHES

#### Topic 2.1 Continuum of Approaches

For children with disabling conditions, the main goal of intervention is to increase the child's social, communicative and adaptive functioning. In achieving this end, there exists a continuum of available intervention approaches. Best practice suggests that you always start with the least intrusive approach necessary to change the behaviour. More intrusive approaches would be used only as needed.

Treatment strategies range from traditional behavioural approaches (i.e., those adhering to the guidelines of applied behavioural analysis) to relationship/developmental strategies (i.e., based on child's developmental level) with a variety of combined approaches in between.

Treatment models vary based on:

- Who (child or adult) controls the flow of events during therapy (i.e., who determines which materials or activities to use)
- The context of therapy (naturalistic versus artificially designed)
- Use of Reinforcement
- Repetition
- Structure

#### Topic 2.2 Traditional Behavioural Approach

##### Philosophy

Traditional Behavioural Approaches is based on the principles of Applied Behavioural Analysis. Applied Behaviour Analysis involves the application of behavioural principles to change problematic behaviours and increase skills. This approach incorporates behavioural observation and a variety of teaching strategies to assist in the learning of a specific skill. It is *applied* as it involves an evaluation of a child's current skills and behaviours to determine goals and desired outcomes. It is *behavioural* in its planning and implementation of strategies to teach and bring about measureable change in skills. It is *analytic* as data is evaluated to determine whether strategies have been effective in eliciting desired outcomes. ABA programming should also be valid in that it can be replicated, conceptually systematic, following the principles on which it is based, effective in that the intervention affects meaningful change, and should display generality (i.e., behaviour changes observed in more than one environment).

##### Key Concepts

- **Discrete Trial Teaching**

**Discrete Trial Teaching** involves breaking down skills into component sub-skills. Each sub-skill is taught using prompting, reinforcement and repeated practice until it is mastered. Skills are mastered when the child successfully acquires several component sub-skills. Discrete trial teaching occurs in a structured one-on-one setting. Each trial is performed in a systematic manner, with a specific antecedent (usually the instruction), a target response (behaviour) is expected (prompting may occur to ensure target response), and a consequence follows depending on what behaviour is displayed. The trial is “discrete” in that it is distinct from what goes on before or after the trial.

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- **Massed Trials**

**Massed trials** are periods of highly structured teaching in which several discrete trials occur in succession. A specific sub-skill is targeted repeatedly until the child can produce the target behaviour independently or with less intrusive prompting.

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- **Reinforcement**

**Reinforcement** refers to the presentation or removal of an event following a particular behaviour to increase the likelihood the behaviour will occur again.

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**Positive reinforcement** is the presentation of a desired event immediately following a behaviour to strengthen the desired behaviour e.g., a child is instructed to complete a puzzle, once she finishes the puzzle her aide gives her a high five and tickles). **Negative reinforcement** occurs when an unpleasant or aversive is removed following a particular behaviour in order to increase the likelihood of the behaviour recurring (e.g., a child finds her mother’s nagging aversive, every day the mother asks her daughter to pick up her clothes, one day the daughter picks the clothes up before her mother tells her to, the mother does not nag).

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### **Specific Examples**

- **Lovaas Technique**

The Lovaas technique is a traditional behavioural approach based on applied behaviour analysis. It involves discrete trial teaching in a highly structured one-on-one setting. Treatment is intensive, beginning with 10-15 hours of structured instruction per week for children under three and increasing to 35-40 hours per week for older children. During a therapy session, specific tasks are targeted for 2-5 minutes, and then the child is given a short break before the next task is presented. Within a session, the adult determines where the intervention will occur and what materials or activities will be used. For each trial, the adult provides a concrete instruction (e.g., clap hands) to elicit a specific target response (e.g., child claps hands) from the child. Reinforcement is provided for correct responses, but is not related to the activity (e.g., child receives a pretzel for clapping hands). Success is gauged by the child’s correct response to the stimulus (adult instruction).

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While this approach is useful in specific skill development, it has been criticised for its lack of generalization of skills from the teaching environment to other

situations. As well, it fails to encourage spontaneous use of social and communication skills.

For additional information:

<http://www.lovaas.com>

- **Verbal Behaviour**

Verbal behaviour is a treatment approach based on the language acquisition theories of B.F. Skinner. This approach uses behavioural principles to teach and reinforce speech. In his functional analysis of language, Skinner divided language in four primary operants; echoics (echo of a word), mands (requests), tacts (labels), and intraverbals (responses to language of others). Verbal Behaviour is distinct from Lovaas/ABA in that it attempts to teach the function of language rather than just the form. Verbal behaviour techniques can be used in conjunction with ABA/Lovaas therapies. For additional information:

<http://www.marksundberg.com/>

<http://www.autismspeaks.org/whattodo/index.php#vbi>

<http://www.dr carbone.net/>

### **Topic 2.3 - Naturalistic Behavioural Strategies**

#### **Philosophy**

Naturalistic Behavioural Strategies, like the more traditional approaches, follow the principles of applied behavioural analysis. However, an attempt is made to teach skills in the child's natural environment (e.g., their home, the playground, their classroom), rather than in an isolated, segregated setting. Naturalistic teaching is also referred to as activity-based instruction or embedded instruction as teaching occurs within the context of the child's daily routine. The Aide generally follows the child's lead and takes advantage of "teachable moments". It is also important to note that this approach attempts to utilize more "natural" forms of reinforcement that are related to the skill being taught. For instance, if a child is being taught to request a specific toy, she would be given the toy to play with to reward her for communicating. One of the drawbacks of naturalistic teaching approaches is they require careful planning on the part of the Aide to ensure that children have multiple opportunities to practice and master specific skills. That is, the Aide is required to identify and present activities and materials that are likely to create teachable moments. However, multiple skills can be worked on during a single activity. For instance, during a playdough activity you could work on requesting (i.e., expecting the child to ask for different materials), imitation (i.e., by modeling interesting play acts), turn taking (i.e., having a limited number of materials available) and colour identification (i.e., by utilizing different coloured play dough). One of the benefits of this approach is that skills are taught in the "real world", therefore generalization is less of an issue. This approach is also much easier to implement in inclusive settings.

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#### **Specific Examples**

- **Pivotal Response Training**

Pivotal response training is a naturalistic behavioural approach used in the treatment of autism spectrum disorders. This approach recognizes specific behaviours/skills as necessary for a wide range of functions. The approach suggests that by increasing these behaviours or factors, other skills will also

improve. Within pivotal response training, strategies which may include child choice, reinforcement, and interspersing previously mastered tasks between trials, increase the child's motivation.

For more information:

<http://psy3.ucsd.edu/~autism/prtraining.html>

- **Peer Mediated Strategies**

This naturalistic application of behavioural teaching involves using typically developing peers to model appropriate behaviours or skills to children with disabling conditions. This approach tends to be most effective when: children display interest in other children and are motivated to imitate them and when adults provide encouragement and reinforcement to the peers for their efforts.

Peer mediated strategies tend to be useful when you are attempting to teach play skills, classroom routines and social- communication skills.

## **Topic 2.4 - Relationship/Developmental Based Approaches**

### **Philosophy**

Relationship based, developmental models focus on typical childhood development. A child's developmental level (current skills) is determined using standardized assessments. Goals are then established based on the child's developmental level. Central to the developmental approach is that children acquire skills through exploration and positive social interaction. Within the relationship-based model, teaching occurs in natural and motivating environments. The child selects which materials and activities will be used, and the adult may support the child in their use. Teachable moments are guided by the child's play. Instruction occurs in the form of reciprocal interaction between the adult and child and is initiated by the child. The continuation of a preferred interaction serves as reinforcement to the child.

This approach has been criticised for its dependence on children initiating interactions. As well, children require pre-cursor skills of imitation and joint attention to benefit from this approach.

### **Specific Examples**

- **DIR/Floortime**

The DIR(Developmental Individual difference Relationship based)/Floortime model is a specific approach created by Dr. Stanley Greenspan and Serena Wieder. This model focuses on children's social, emotional and intellectual abilities rather than skills and behaviours. The child's emotions and interests are essential to this model. Floortime refers to the aide or parent getting down to the child's level on the floor for teaching sessions. This approach encourages several intensive 20-30 minute floortime sessions per day. Four main goals of Floortime are encouraging attention and intimacy (i.e., child enjoying adult's presence), two-way communication (i.e., child response to adult presence), encouraging expression and use of feelings (i.e., develop child's emotional ideas through play), and logical thought (i.e., connecting thoughts to sequence, predict and conceptualize real-world circumstances).

For more information:

<http://www.autismspeaks.org/whattodo/index.php#ft>

<http://www.icdl.com/dirFloortime/overview/index.shtml>

- **Relationship Development Intervention**

Developed by Dr. Steven Gutstein, the RDI, relational development intervention approach, focuses on enhancing the social experience of children with autism spectrum disorders. As in DIR/Floortime, this approach focuses on the child's developmental level and builds skills based on this. Unlike the Floortime model, this intervention is adult directed and does not focus on the child's emotions.

For more information:

<http://www.rdiconnect.com/RDI/default.asp>

[http://www.chicagofloortimefamilies.com/index.php?option=com\\_content&task=view&id=75&Itemid=57](http://www.chicagofloortimefamilies.com/index.php?option=com_content&task=view&id=75&Itemid=57)

## **Topic 2.4 – Other Models**

### **Philosophy**

There are a variety of models that utilize elements associated with applied behavioural analysis, but also incorporate elements associated with the relationship and developmental models.

### **Specific Examples**

- **SCERTS**

The Social Communication Emotional Regulation and Transactional Support model incorporates strategies from a variety of treatment models and strives to encourage child initiated communication in naturalistic settings.

<http://www.scerts.com/>

- **TEACCH**

Project TEACCH, Treatment and Education of Autistic and related Communication Handicapped Children, is a school-based approach based at the University of North Carolina. Other programs are modeled and run by TEACCH accredited teachers. TEACCH focuses on improving adaptive functioning in a modified classroom setting. Specifically, a TEACCH classroom is highly structured and routine-oriented; it offers a predictable daily schedule, utilizes visual supports, and individual workspaces to facilitate learning.

<http://www.teacch.com/>

- **Picture Exchange Communication System**

The Picture Exchange Communication System is a treatment approach used to expand a child's communication skills. It involves the use of picture cards (can be hand drawn, cut from a magazine, or trademark PECS), to provide children with autism spectrum disorder with an effective means of communication.

Specifically, the child gives a picture or sentence strip to an adult to make a request and the adult responds by giving the desired item. This system can be used within the context of a variety of treatment models.

<http://www.pecs.com>

## **Topic 2.5 – Comparing and Contrasting Different Approaches**

The following chart summarizes the treatment approaches reviewed in this section.

**Treatment Approach Comparison**

|                                     | <b>ABA/Lovaas</b>                                                                    | <b>Verbal Behaviour</b>                                                    | <b>Pivotal Response</b>                                                             | <b>Peer Mediated</b>                                                                                   | <b>DIR/Floortime</b>                                                                  | <b>RDI-Relationship Developmental Intervention</b>                                           |                                                                |  |
|-------------------------------------|--------------------------------------------------------------------------------------|----------------------------------------------------------------------------|-------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------|----------------------------------------------------------------|--|
| <b>Philosophy/ Goal of approach</b> | Increase child's skills using discrete trial training and massed trial teaching      | Teach function of language using behavioural principles                    | Emphasizes specific skills as necessary for improving a variety of functions        | Uses typically developing peers to model appropriate behaviours for children with disabling conditions | Considers the role of child's emotions and natural interests as essential to learning | Focuses on enhancing the social experience of children with disabling conditions             | Str<br>pro<br>foci<br>imp<br>ada<br>funi<br>mo<br>clas<br>sett |  |
| <b>Who controls materials</b>       | Adult                                                                                | Adult                                                                      | Adult and child (child choice)                                                      | Adult or Peer                                                                                          | Child                                                                                 | Adult                                                                                        | Te<br>in c                                                     |  |
| <b>Context of Therapy</b>           | Highly structured one on one instruction                                             | Highly structured one on one instruction                                   | Structured Variety of settings                                                      | Variety of settings, naturalistic environment                                                          | Child-directed, unstructured, Variety of social settings                              | Structured activities within a variety of naturalistic settings (e.g., at the grocery store) | Str<br>clas<br>sett                                            |  |
| <b>Reinforcement</b>                | Determined by adult<br>Not related to activity                                       | Related to use of speech (e.g., child says "cookie" and receives a cookie) | Based on child's interests- choice of activities, preferred toys                    | Reinforced by peer interaction<br>Adult reinforces peer for participation                              | Social reinforcement, continuation of activity based on child's interest              |                                                                                              |                                                                |  |
| <b>Repetition</b>                   | Determined by adult- specific number of trials                                       |                                                                            |                                                                                     |                                                                                                        | Determined by child's level of interest                                               | Determined by adult                                                                          |                                                                |  |
| <b>Positives</b>                    | Teaches several skills based on mastery of sub-skills<br>Scientifically proven to be | Children are taught function of language                                   | Skills are taught in the "real world" for greater generalization, child's interests |                                                                                                        |                                                                                       |                                                                                              | Mo<br>clas<br>sett<br>chil<br>to k                             |  |



|                   |                                                                                        |  |                                                       |                                                       |                                                                                                                                                 |  |  |  |
|-------------------|----------------------------------------------------------------------------------------|--|-------------------------------------------------------|-------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|--|--|--|
|                   | effective                                                                              |  | are incorporated into learning                        |                                                       |                                                                                                                                                 |  |  |  |
| <b>Criticisms</b> | Skills do not generalize<br>Does not encourage spontaneous or functional communication |  | Requires careful planning to create teachable moments | Requires motivated peers and careful planning by aide | Relies on child initiation of interactions.<br>Children require precursor skills of joint attention and imitation to benefit from this approach |  |  |  |

## **Topic 2.6 – Alternative and Complementary Approaches**

In addition to the “traditional” treatment approaches some families choose to explore other types of interventions. Often there is limited (if any) research to demonstrate the effectiveness of these approaches. Generally, these approaches fall into two categories:

- **Complementary Treatments:** undertaken in combination with traditional treatments (e.g., dietary interventions, vitamins, etc.).
- **Alternative Treatments:** used instead of more established, conventional and researched treatment methods

It is important to adopt a cautious, “buyer beware” attitude when considering alternative and complementary interventions that are not well researched and/or are not considered to be “established or best practice”. Here are some points to consider:

- Be cautious of any treatment that claims to “cure”.
- Determine if there are any potential negative side effects associated with the treatment (consider emotional investment and time as well as financial costs).
- Consider if there is any research that demonstrates the effectiveness of the approach.
- Consider the theory behind the treatment – does it make sense to you?
- Talk to professionals who work in the field and families that are familiar with the treatment to gain “first hand” knowledge.

## **UNIT: OVERVIEW**

### **CLUSTER #3 - PROGRAMS, SERVICES & FUNDING**

To be effective in your role, it is important to have a working knowledge of the programs, services and funding sources that are often accessed by families of children with disabling conditions.

For a summary of Government of Alberta services for preschool children with special needs please refer to the “Distinct but Linked” brochure available at:

[http://www.education.alberta.ca/media/511321/linked\\_services.pdf](http://www.education.alberta.ca/media/511321/linked_services.pdf)

#### **Topic 3.1 – Children’s Services**

- **Family Support for Children with Disabilities (FSCD)**

##### **Program Description**

One of the programs offered by the Ministry of Children and Youth Services is the Family Support for Children with Disabilities (FSCD) Program. This program works in partnership with parents and provides a range of services and supports for children with disabilities and their families. It also assists families to coordinate supports and services and, in some situations, assists with some of the extraordinary costs associated with raising a child with a disabling condition. Services are individualized based on the child and family’s needs. Legal authority for the FSCD program is provided by the Family Support for Children with Disabilities Act which was proclaimed on August 1, 2004. The copy of the act can be found at:

[www.qp.alberta.ca/574.cfm?page=F05P3.cfm&leg\\_type=Acts&isbncln=9780779727988](http://www.qp.alberta.ca/574.cfm?page=F05P3.cfm&leg_type=Acts&isbncln=9780779727988)

##### **Location**

The FSCD program is delivered across the province of Alberta by ten different Child and Family Service Authorities (CFSA). To determine which CFSA serves your area, please refer to:

<http://www.child.alberta.ca/home/806.cfm>

##### **Eligibility & Intake Process**

In order for a child to be eligible for the supports and services associated with the FSCD program the child must be a Canadian citizen, under the age of 18, and

have a documented disability (requires a letter or report from a medical professional indicating that the child has a disabling condition). Having a diagnosis does not automatically mean that a child will be eligible for services. Rather, there must be evidence that the diagnosis results in a disability. Here is how “disability” is defined in the FSCD Act:

*“disability” means a chronic, developmental, physical, sensory, mental or neurological condition or impairment that does not include a condition for which the primary need is for medical care or health services to treat or manage the condition, unless it is a chronic condition that significantly limits a child’s ability to function in normal daily living.*

In addition, the parent must maintain full guardianship and reside in the province of Alberta.

To apply for the program, parents or guardians are required to call the FSCD program in their region and talk to an FSCD intake worker. The intake worker will complete an intake application on the phone and, if appropriate, an FSCD worker will be assigned to the family. The assigned worker will meet with the child and family to provide information about the FSCD program, discuss the child and family’s unique needs, review existing documentation, and discuss what government and community supports and services may be of assistance to the child and family.

### **Supports & Services**

FSCD works in partnership with families to identify what supports and services would be most beneficial. The supports and services provided by the FSCD program fall into three categories. For specific information about services (e.g., hours, rates, required forms, qualifications and documentation) please refer to the Family Supports for Children with Disabilities Policy and Procedures Manual:

[http://www.child.alberta.ca/home/images/childrenwithdisabilities/FSCD\\_PolicyProceduresManual\\_20080409.pdf](http://www.child.alberta.ca/home/images/childrenwithdisabilities/FSCD_PolicyProceduresManual_20080409.pdf)

- Information and Referral Support

FSCD workers are very knowledgeable about local and provincial programs and the services offered by the government, as well as community agencies (e.g., counseling services, treatment programs, advocacy groups, disability associations, etc.). They can also assist families to obtain and coordinate supports and services and plan for transitions (e.g., entering the school system, becoming an adult).

- Family Support Services

These services assist parents/guardians to care for their child with a disability and may include providing funding for:

- Family and/or individual counseling
- Extraordinary clothing or footwear costs that are related to the child's disabling condition
- The costs associated with medical appointments or hospitalizations (e.g., mileage, parking, some travel expenses)
- Respite services

- Child - Focused Services

These services are available to children and families when there is a confirmed diagnosis. The types of services provided are based on: the impact of the child's disabling condition on their activities of daily living; the family's identified needs, and the assessment information and documentation provided by the professionals involved with the child. More intensive services, such as specialized services for children with severe disabilities (see description below) required more detailed assessment information and documentation of the child's service needs. Child - Focused services include:

- Respite services – These services are intended to provide parents with a temporary break from their supervision and care responsibilities (e.g., providing care for the child in or outside of the family home, support to complete household tasks)
- Child care supports – When a child has a disabling condition, it is often difficult for families to find and pay for child care. Child care supports are intended to address this issue by providing assistance with child care costs, providing an aide to assist the child in a child care facility, etc.
- Aide supports – These services are intended to assist parents in addressing and managing their child's needs or to assist the child to generalize their skills. There are different types of supports to address the assessed needs of the child. These include:
  - Personal care supports – to assist the child with personal hygiene and daily personal care routines (e.g., eating, bathing, grooming, lifting, positioning, medical procedures).
  - Community supports – to assist the child to participate in community programs and activities.
  - Behavioural supports – to assist the child to display more adaptive, appropriate behaviour and to assist parents to manage their child's behaviour.
  - Developmental supports – to assist the child and teach the parent to assist the child to reach a developmental goal (i.e., skill development).

- Health-related supports – These services are designed to reduce the financial impact of disability related costs and to ensure that children receive required medical services (e.g., dental care, orthodontic treatment, prescription drugs or formula, special diets, ambulance). Parents are responsible for the costs typically associated with raising a child. They must also make use of any benefits or insurance plans before accessing supports from FSCD.
- Specialized supports for children with severe disabilities – These services are intended to ensure that children who have severe disabilities receive appropriate, coordinated and effective services. To be more specific, these services are provided only in situations where a child has a severe disability resulting in significant limitations and services needs in two or more of the following areas:
  - Behaviour
  - Communication and socialization skills
  - Cognitive abilities
  - Physical and motor development
  - Self-help skills and adaptive functioning

The services provided must be based on established rehabilitative practices, least restrictive, and demonstrated to be effective. Specialized service programs typically involve a detailed, coordinated and individualized program plan that is developed, monitored and revised by a multidisciplinary team.

- Out-of-home living arrangements – These services are provided in situations where the child’s needs cannot be met in the guardian’s home. They are generally provided only when other alternatives have been explored and exhausted (e.g., respite, in-home supports).

**Food for thought** – Think about the supports and services described in this section, which would likely involve the services of an Aide? Also, try to identify what skills and knowledge an Aide should possess to provide the required service (e.g., community support versus specialized supports). Think about your interests and skills, what might be the best fit for you at this time?

- **Child Disability Resource Link**

The Child Disability Resource Link was created to make disability-related information more accessible. They have a toll free line and can be reached at 1-866-346-4661. The service is available on weekdays from 8 am to 8 pm and Saturdays from 8:00 to 4:00. Information and referral specialists are able to provide information about both government and community programs and services.

## **Topic 3.2 Seniors and Community Support**

- **Alberta Aids to Daily Living**

The AADL program is designed to assist Albertans with long-term disabilities or chronic/terminal illnesses to purchase required medical equipment and supplies. Each child must be assessed by a health care professional to determine eligibility and parents are expected to cost share. Families of children accessing Aide services may access AADL to purchase bathing and toileting equipment, hearing aids and FM systems, incontinence supplies (e.g., diapers), wheelchairs, etc.

For additional information:

[http://www.seniors.gov.ab.ca/AADL/benefit\\_eligibility/index.asp](http://www.seniors.gov.ab.ca/AADL/benefit_eligibility/index.asp)

- **Persons with Developmental Disabilities Program**

This program provides support to adults who have a developmental disability to assist these individuals to live, work and participate in the community. Supports vary in terms of hours, how they are managed (e.g., family managed) and where they are delivered. Six community boards deliver local programs. To determine which board serves your area please refer to:

<http://www.pdd.org/communityboards/default.shtml>

The PDD program defines developmental disability as a state of functioning that began in childhood and is characterized by significant limitations in both intellectual capacity and adaptive functioning. The following three criteria are used to make the determination of developmental disability for PDD Program purposes:

- Significant limitation in intellectual capacity;
- Onset prior to age 18; and
- Significant limitation in adaptive skills in two or more of the following adaptive skills areas;
  - communication
  - home living
  - community use
  - health and leisure
  - leisure
  - self-care
  - social skills
  - self-direction
  - functional academics

- work

For additional information about the PDD program please refer to:

<http://www.pdd.org/default.shtml>

### **Topic 3.3 Health & Wellness**

- **Health Link**

This service provides telephone health information and advice. Calls are typically answered by nurses. The service is available 24 hours a day and seven days a week.

There is also an online library of health topics:

[www.healthlinkalberta.ca](http://www.healthlinkalberta.ca)

### **Topic 3.4 Education**

The ministry of Education provides a variety of programs and services for children with disabling conditions. The Learning Team: A Handbook for Parents of Children with Special Needs is a useful resource for parents and Aides as it outlines: services and activities for meeting learning needs; suggestions for supporting and enriching learning; and strategies to facilitate successful transitions. This document can be accessed at:

<http://www.education.alberta.ca/media/448939/Learning.pdf>

- **Early Childhood Services (ECS) & Program Unit Funding (PUF)**

Children identified with disabilities/delays are eligible for up to three years of ECS programming. For children with severe delays/disabilities, Program Unit Funding (PUF) is accessed to provide this service. Program Unit Funding (PUF) is available to approved ECS operators for young children from 2½ to age 6. To be eligible for PUF funding the child must be at least 2 ½ by September, present with a severe disability/delay and their disability/delay must significantly impact their ability to function in an ECS program. Program Unit Funding is provided in addition to Base Instruction Funding. Parents are not required to apply for PUF funding as this done by the ECS operator.

Funding for children with mild to moderate disabilities/delays (i.e., in addition to the Base Instruction funding) is also available. This funding is not available until a child is 3 years, 6 months of age (by September).



- **School Placement**

The School Act specifies that school boards are responsible for determining if a child is in need of a special education program. This is based on the child's communication skills, intellect, learning profile, behaviour in the classroom, and physical characteristics. School boards are also responsible for ensuring that students with special needs are placed in educational programs that best meet their needs. According to policy, the first placement option considered by school boards, in consultation with parents, is to educate students with special needs in a regular classroom in their neighbourhood or local schools. However, other options are often available (i.e., special programs/classes).

An education program for a student with special needs is based on the results of ongoing assessment/evaluation and includes an Individualized Program Plan with specific goals, objectives, and recommendations for educational services to meet the student's identified needs.

Alberta Education provides funding to school boards, private school operators, and charter school operators to deliver educational programs for students that require special education programs. School authorities allocate the funding to support the local programs and services. Different school boards offer different programs to meet the needs of the special education students in their area. A list of schools and school boards can be found at:

<http://www.education.alberta.ca/apps/schoolsdir/>

Parents can also opt to home school their children. However, Alberta Education does not provide additional funding for special education in home education programs.

Each student is assessed and considered in light of established coding criteria to determine the level of funding provided. For additional information please refer to the Alberta Education website.

<http://www.education.alberta.ca>

There are a number of helpful Special Education resources available from Alberta Education, a list can be found at:

<http://www.education.alberta.ca/admin/special/resources.aspx>

### **Topic 3.5 Other Programs/Services**

- **Alberta Child Health Benefit**

The Alberta Child Health Benefit plan provides funding to families with limited incomes for health services that are not covered by Alberta Health Care Insurance (e.g., dental care, eyewear, prescription drugs, ambulance services, diabetic supplies). If a family's application is accepted, they are sent an identification card to use at medical visits and when purchasing medical supplies. For additional information:

<http://employment.alberta.ca/cps/rde/xchg/hre/hs.xsl/2076.html#1>

- **Child Disability Benefit**

The Child Disability Benefit is a tax free benefit for limited income families who have a child with a severe and prolonged disabling condition. It is a federal program, administered by the Canada Revenue Agency, and the application process involves a qualified professional to complete a form to certify that the child has a severe and prolonged impairment in physical or mental function. The benefit is calculated according to base income.

For additional information:

<http://www.servicecanada.gc.ca/eng/goc/cdb.shtml>