CTRC
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RESOURCE CENTRE DE RESSOURCES

Intellectual/Developmental Disability Psychological Resource Book

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CTRC Psychological Services

Table of Contents

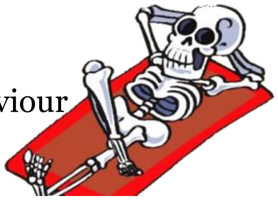
Applied Behaviour Analysis (ABA)

What is ABA?

- The application of principles of behaviour to provide a measurable change in behaviour through the manipulation of the environment.

- Identify functional relationships between behaviour and the environment.

But first, what is behaviour?
Something that can be, objectively defined, accurately measured, and easily observed.
- Everything people do, including how they move, what they say, think and feel



Does it pass the dead mans test? → only a **living organism** can emit behaviour

- **If a dead man can do it – it is not behaviour**
- Example of behaviour definition: "non-compliance": failure to comply with the demand within a certain amount of time
    - Can a dead man fail to comply with a demand? Yes.
    - "Refusal" could be used instead.
    - Let's define what refusal looks like – "responding with a vocal 'no' when a demand is placed". Only a living being can say no!

Functional Behaviour Assessment – understanding *functional relationships*

We use a variety of methods to understand WHY a behaviour may be occurring.
- Interviews;
- Data collection;
- Questionnaires;
- Rating scales;
- Observations, etc.

Why are these methods helpful?
- To **identify and understand** patterns of behaviour to create an appropriate intervention.

EXAMPLE: ABC analysis (antecedent, behaviour, consequence)

what happens before, during, and after a behaviour

Whenever I see a bag of Reece's mini's, I stop and eat the whole thing!

Antecedent: I see the bag of chocolate in my pantry.

Behaviour: I eat the whole bag.

Consequence: The chocolate taste delicious! I know this wasn't a healthy choice.

This problem could easily be remedied through an antecedent strategy. You guessed it... don't buy chocolate.

BUT chocolate is my roommates' favourite – so I can't not buy it. How else can we change the environment to help me with this problem?

A: I put a visual representation of my fitness goals next to the chocolate in the pantry. Some people choose pictures of themselves, others may write a specific weight goal, etc.

B: I go to get chocolate and I see the visual. I decide not to eat the chocolate.

C: I put a dollar in my "good decision" jar, which can be cashed in for new clothes every week!

By changing the environment and adding a reinforcing consequence (rewarding myself with a dollar) for a good decision, I have changed a bad habit!

References:

Cooper, J. O., Heron, T. E., & Heward, W. L. (2019). *Applied Behavior Analysis (3rd Edition)*. Hoboken, NJ: Pearson Education.

Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a neurological and developmental disorder associated with these symptoms:

- Difficulty with communication and interaction with other people
- Restricted interests
- Repetitive behaviours
- Symptoms that affect the ability to function in school, work, and other areas of life
- Sensory issues

Symptoms of ASD typically appear in the first two years of life.

ASD is known as a “spectrum because there is wide variation in the type and severity of symptoms people experience.

Social Communication/interaction behaviours may include:

- Making little or inconsistent eye contact
- Appearing not to look at or listen to people who are talking
- Infrequently sharing interest, emotion, or enjoyment of objects or activities (including by infrequently pointing at or showing things to others)
- Not responding or being slow to respond to one’s name or to other verbal bids for attention
- Having difficulties with the back and forth of conversation
- Often talking at length about a favorite subject without noticing that others are not interested or without giving others a chance to respond
- Displaying facial expressions, movements, and gestures that do not match what is being said
- Having an unusual tone of voice that may sound sing-song or flat and robot-like
- Having trouble understanding another person’s point of view or being unable to predict or understand other people’s actions
- Difficulties adjusting behaviors to social situations
- Difficulties sharing in imaginative play or in making friends

Restrictive/Repetitive behaviours may include:

- Repeating certain behaviors or having unusual behaviors, such as repeating words or phrases (a behavior called *echolalia*)

- Having a lasting intense interest in specific topics, such as numbers, details, or facts
- Showing overly focused interests, such as with moving objects or parts of objects
- Becoming upset by slight changes in a routine and having difficulty with transitions
- Being more sensitive or less sensitive than other people to sensory input, such as light, sound, clothing, or temperature

Some strengths may include:

- Being able to learn things in detail and remember information for long periods of time
- Being strong visual and auditory learners
- Excelling in math, science, music, or art

Supporting someone with ASD

- Be consistent in how you communicate as well as in your interactions.
- Understand and know their schedule, so that you can be part of their routine and not disrupt it.
- First/Then cues. This can help motivate to engage in a less preferred task before engaging in a more fun activity.
- Practice social skills.
- Assist with providing positive reinforcement by knowing what behaviour is expected and rewarded. Then praise accordingly.
- Use pictures, sounds, gestures or facial expressions, to encourage interaction with others and communication skills. In this way, you will be able to better understand what is needed and when it is being asked for.

Think of fun things to do that keep in mind the sensory sensitivities specific to the person and schedule time to enjoy being with them.

References:

Autism spectrum Disorder. (n.d.). National Institute of Mental Health (NIMH). https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd

Signs & Symptoms | Autism Spectrum Disorder (ASD) | NCBDDD | CDC. (2023, January 11). Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/autism/signs.html#:~:text=Autism%20spectrum%20disorder%20(ASD)%20is,%2C%20moving%2C%20or%20paying%20attention

What is autism spectrum disorder? (n.d.). https://www.psychiatry.org/patients-families/autism/what-is-autism-spectrum-disorder

Behaviour Support Plans

A Behaviour Support Plan is a document that is **based on a written functional assessment** of the person that considers historical and current, biological and medical, psychological, social and environmental factors (a bio-psycho-social model) of the person with a developmental disability that outlines intervention strategies designed to focus on the development of positive behaviour, communication and adaptive skills. (QAM, s.15(2) definitions)

The written functional assessment refers to a detailed analysis of the behaviour relative to the environmental factors at play and as a best practice should be based on direct observation and data (as described above – although with behaviours more complex than eating Reese's minis).

Positive Behaviour Intervention

- Means the use of non-intrusive behaviour intervention strategies **for the purpose of reinforcing positive behaviour and creating a supportive environment, with a goal of changing the behaviour of the person with a developmental disability**.

- The following are examples of non-intrusive behaviour intervention strategies:
    a) Teaching or learning components, including teaching proactive skills and communication strategies to maximize the person’s abilities and to minimize challenging behaviour.
    b) Reinforcement.
    c) A review of the person’s living environment, including the physical space, and support and social networks, to identify possible causes of challenging behaviour and making changes to the living environment to reduce or eliminate those causes. (QAM, s.15 (5))

Intrusive Behaviour Intervention

- Means a procedure or action taken on a person in order to address the person with a developmental disability’s challenging behaviour, when the person is at risk of harming themselves or others or causing property damage. (QAM, s.15(2) definitions)

- For purposes of the definition of “intrusive behaviour intervention”, the following are examples of intrusive procedures or actions:
  a) Physical restraint
  b) Mechanical restraint
  c) Secure isolation or confinement time out in a designated, secure space.

Prescribed medication to assist the person in calming themselves, with a clearly defined protocol developed by a physician as to when to administer the medication and how it is to be monitored and reviewed (QAM, s.15(4))

References:

Ministry of Community and Social Services. (2017). BEHAVIOURAL SUPPORT PLAN REFERENCE GUIDE for ADULT DEVELOPMENTAL SERVICES. In *Ontario Regulation 299/10 Quality Assurance Measures (QAM) and the Policy Directives for Service Agencies*. https://www.mcss.gov.on.ca/documents/en/mcss/developmental/EN_BSP_REFERENCE.pdf

Bipolar Disorder

Bipolar disorder is a mental illness that causes unusual shifts in mood, energy, activity levels, concentration, and the ability to carry out day-to-day tasks.

Bipolar disorder is typically diagnosed during late adolescence (teen years) or early adulthood. Occasionally, bipolar symptoms can appear in children. Although the symptoms may vary over time, bipolar disorder usually requires lifelong treatment. Following a prescribed treatment plan can help people manage their symptoms and improve their quality of life.

Types of bipolar disorder

- **Bipolar I disorder:** is defined by manic episodes that last at least 7 days (most of the day, nearly every day) or by manic symptoms that are so severe that the person needs immediate hospital care. Usually, depressive episodes occur as well, typically lasting at least 2 weeks. Episodes of depression with mixed features (having depressive symptoms and manic symptoms at the same time) are also possible. The experience of four or more episodes of mania or depression within a year is termed “rapid cycling.”
- **Bipolar II disorder:** is defined by a pattern of depressive episodes and hypomanic episodes, but the episodes are less severe than the manic episodes in bipolar I disorder.
- **Cyclothymic disorder:** (also called cyclothymia) is defined by recurrent hypomanic and depressive symptoms that are not intense enough or do not last long enough to qualify as hypomanic or depressive episodes.

Sometimes a person might experience symptoms of bipolar disorder that do not match the three categories listed above, and this is referred to as “other specified and unspecified bipolar and related disorders.”

The table below provides list of **manic** and **depressive** symptoms

Symptoms of a Manic Episode	Symptoms of a Depressive Episode
Feeling very up, high, elated, or extremely irritable or touchy	Feeling very down or sad, or anxious
Feeling jumpy or wired, more active than usual	Feeling slowed down or restless
Decreased need for sleep	Trouble falling asleep, waking up too early, or sleeping too much
Talking fast about a lot of different things ("flight of ideas")	Talking very slowly, feeling unable to find anything to say, or forgetting a lot
Racing thoughts	Trouble concentrating or making decisions
Feeling able to do many things at once without getting tired	Feeling unable to do even simple things
Excessive appetite for food, drinking, sex, or other pleasurable activities	Lack of interest in almost all activities
Feeling unusually important, talented, or powerful	Feeling hopeless or worthless, or thinking about death or suicide

The table below outlines the major symptoms for a **manic episode** and appropriate interventions:

Mania & Hypermania Symptoms & Intervention

Symptom	Presentation	Intervention
Inflated self-esteem or grandiosity	Unusually positive outlook about self, the future, and surroundings. False sense of well-being, highly confident.	Orient client to reality
Decreased need for sleep	Feeling rested after only a few hours of sleep.	Promote sleep hygiene - providing routine meals and sleep schedule. Provide sleep aid medication if ordered.
Talkative	More talkative than usual or pressure to keep talking.	Allow client to communicate as needed. Request for client to speak slowly, and repeat request as a reminder during conversations
Flight of ideas	Speaks rapidly about multiple subjects and experiences racing thoughts.	Provide focus for the client during conversations.
Distractibility	Attention is easily drawn to unimportant or irrelevant external stimuli.	Repeatedly redirect to important stimuli as needed.

Mania & Hypermania Symptoms & Intervention

Symptom	Presentation	Intervention
Goal-directed	Increase in goal-directed activity (either socially, at work/school, or sexually) or psychomotor agitation (purposeless non-goal-directed activity). Excessive involvement in activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments).	Set limits, boundaries, and redirection. Redirect to more appropriate behaviors. Promote a different, more appropriate activity, such as exercise.

References:

Ontario Shores Foundation for Mental Health (2023). Common Mental Illnesses: Assessment and Documentation. *Bipolar Disorder*. Ontario Tech University.

Borderline Personality Disorder

Borderline personality disorder is a mental illness that severely impacts a person's ability to regulate their emotions. This affects the way someone thinks and feels about themselves and others. This causes problems with functioning in everyday life.

Individuals with borderline personality disorder have an intense fear of abandonment, instability and may have difficulty tolerating being alone.

They may experience inappropriate anger, impulsiveness, frequent mood swings, may push others away even though they want to have loving and lasting relationships.

Borderline personality disorder typically begins in early adulthood.

Symptoms:

- An intense fear of abandonment, even going to extreme measures to avoid real or imagined separation or rejection
- A pattern of unstable intense relationships, such as idealizing someone one moment and then suddenly believing the person doesn't care enough or is cruel
- Rapid changes in self-identity and self-image that include shifting goals and values, and seeing yourself as bad or as if you don't exist at all
- Periods of stress-related paranoia and loss of contact with reality, lasting from a few minutes to a few hours
- Impulsive and risky behavior, such as gambling, reckless driving, unsafe sex, spending sprees, binge eating or drug abuse, or sabotaging success by suddenly quitting a good job or ending a positive relationship

Symptoms (Continued):

- Suicidal threats or behavior or self-injury, often in response to fear of separation or rejection
- Wide mood swings lasting from a few hours to a few days, which can include intense happiness, irritability, shame or anxiety
- Ongoing feelings of emptiness
- Inappropriate, intense anger, such as frequently losing your temper, being sarcastic or bitter, or having physical fights

References:

Borderline Personality Disorder (BPD). (n.d.). CAMH. https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/borderline-personality-disorder

Cluster B disorders. (n.d.). PsychologyToday. https://www.psychologytoday.com/ca/basics/cluster-b

MindYourMind. (2016, October 13). *Personality Disorders - Cluster B -* https://mindyourmind.ca/mental-health-wellness/personality-disorders-cluster-b/

Dementia

"Dementia is not a specific disease but is rather a general term for the **impaired ability to remember, think, or make decisions that interferes with doing everyday activities**. Alzheimer's disease is the most common type of dementia. Though dementia mostly affects older adults, it is not a part of normal aging." (CDC, 2019).

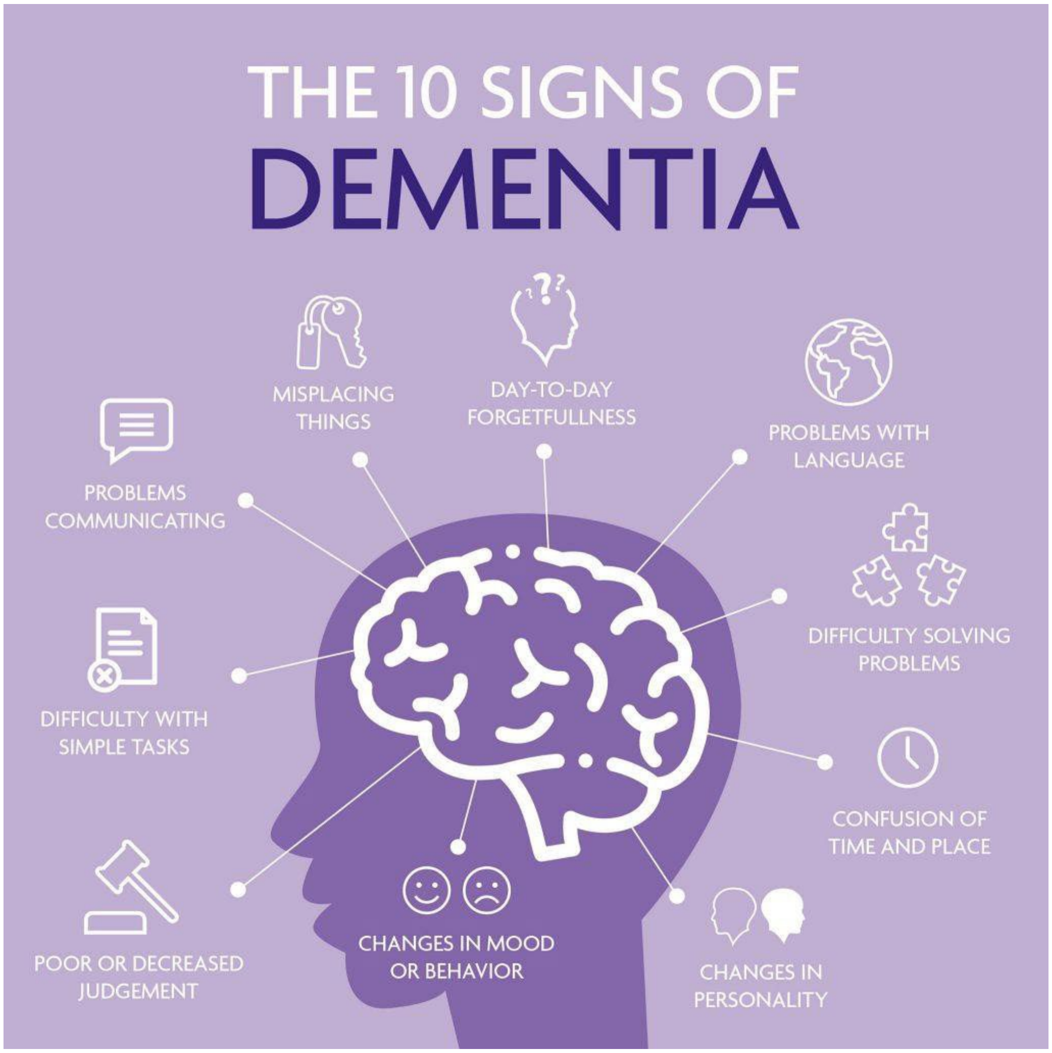


Image from: *What are the symptoms of dementia How is it diagnosed*. (2022). Dementia Talk Club. https://dementiatalkclub.weebly.com/blog/what-are-the-symptoms-of-dementia-how-is-it-diagnosed

What are the signs and symptoms of dementia?

Because dementia is a general term, its symptoms can vary widely from person to person. Some signs that may point to dementia include:

- Getting lost in a familiar neighborhood
- Using unusual words to refer to familiar objects
- Forgetting the name of a close family member or friend
- Forgetting old memories
- Not being able to complete tasks independently

Supporting Someone with Dementia

Environmental Strategies:

- Encourage the individual to maintain their independence.
- Promote a stress-free and calm environment; designed with a person's sensory and other problems in mind.
- Daily routines should be maintained but avoid teaching new skills.
- Pictures and signs can be used to help a person find their way around the house (e.g. Clients pictures on their doors, pictures of content of drawers, closets, cupboards that person usually uses)
- The bathroom door could be painted a bright colour to make it easy to find.
- Continue using familiar community resources and leisure activities for as long as possible.
- Mirrors can be removed or covered, as a person may not recognize their own reflection, lighting should not glare.
- Avoid words like "remember when…, what did we talk about earlier…, I just told you…" or engaging in power struggles about something that happened.
- Keep in mind that if they don't remember it's like it didn't happen in their world.
- Keep photographs and other items that are comforting around (this varies per person).
- Focus on successes and be mindful of body language.
- People who the person spends time with, including other people with intellectual disabilities, should be helped to understand the condition and how they can be involved in the person's support.

Maintaining Skills:

- The emphasis with a person with dementia should be on maintaining abilities, NOT on teaching new skills.
- Tasks should not be time-limited. They should take place in a calm environment free of bustle and distraction.
- Having a consistent routine can help maintain skills longer and reduce challenging behaviour related to anxiety.

- The environment itself should be organized in a way that makes it easy to know where things are, important items like the TV remote control should be kept in the same place.
- Tasks that are repetitive and simplistic can be soothing and help maintain confidence.

Coping with Sundowning (*a state of confusion occurring in the late afternoon and spanning into the night)*

- Reduce noise, clutter, or the number of people in the room.
- Try to distract the person with a favorite snack, object, or activity. For example, offer a drink, suggest a simple task like folding towels, or turn on a familiar TV show.
- Make early evening a quiet time of day. You might play soothing music, read, or go for a walk. You could also have a family member or friend call during this time.
- Close the curtains or blinds at dusk to minimize shadows and the confusion they may cause. Turn on lights to help minimize shadows.
- If the person likes to have something to cuddle, consider a soft toy.
- Gentle exercise may help someone to sleep – but try to avoid exercise too close to bedtime.
- Make sure the person's home is safe – leave a light on in the hall and toilet; consider a nightlight in the bedroom and remove any tripping hazards.

Being too tired can increase late-afternoon and early-evening restlessness. Try to avoid this situation by helping Client:

- Go outside or at least sit by the window—exposure to bright light can help reset the person's biological clock
- Get physical activity or exercise each day
- Get daytime rest if needed, but keep naps short and not too late in the day

Avoid things that seem to make sun downing worse:

- Do not serve coffee, cola, or other drinks with caffeine late in the day.
- Do not plan too many activities during the day. A full schedule can be tiring.

References:

Tips for coping with sundowning. (2017, May 17). National Institute on Aging. https://www.nia.nih.gov/health/alzheimers-changes-behavior-and-communication/tips-coping-sundowning

Understanding and supporting a person with dementia. (2022, June 27). Alzheimer's Society. https://www.alzheimers.org.uk/get-support/help-dementia-care/understanding-supporting-person-dementia

What is dementia? | CDC. (2019). https://www.cdc.gov/aging/dementia/index.html

Down Syndrome

Definition: Down syndrome is a genetic disorder where the individual is born with an extra chromosome (47 instead of 46). This extra chromosome causes physical and developmental delays and disability. Physical characteristics Include: pronounced folds of skin in the inner corners of the eye, almond shaped eyes that slant up, wide set eyes flattened appearance of the face, large protruding tongue, short stature and small ears.

Common developmental and health concerns:

- neurological and cognitive differences
- mild to moderate intellectual delays
- behavioural issues
- speech deficits
- memory impairment
- higher prevalence of autism spectrum disorder
- heart defects
- vision and hearing impairment
- thyroid problems
- respiratory issues
- sleep disorders
- mental health issues
- gastrointestinal issues
- dental problems
- early-onset Alzheimer’s and dementia

Supporting someone with Down syndrome:

- set routines for daily activities as routine helps ease stress
- speak clearly and calmly giving extra time to comprehend what is being said
- praise goes a long way
- watch for changes in mood or behaviour as they may not be able to communicate when something is wrong
- visually showing how to complete a task as opposed to just giving verbal instructions
- provide extra practice time when learning a new task or skill
- encourage healthy eating and physical activity
- monitor/follow dietary restrictions closely (due to difficulties with oral motor skills, including chewing, drinking and swallowing)

References:

Baksi, L. & Symbol UK. (2005). *Supporting people who have Down syndrome to overcome communication difficulties* (pp. 2–4). https://downsyndromedevelopment.org.uk/wp-content/uploads/2021/01/Overcoming_communication_difficulties.pdf

Down Syndrome Resource Foundation. (2022, May 9). *Frequently asked questions - Down Syndrome Resource Foundation*. https://www.dsrf.org/faq/

Stumbo, E. (2014, January 14). *A closer look at the physical characteristics of Down syndrome - Ellen Armendáriz Stumbo*. Ellen Armendáriz Stumbo. https://www.ellenstumbo.com/closer-look-physical-characteristics-down-syndrome/

Fetal Alcohol Syndrome (FASD)

Please find the following resources for this section below:

- FASD Slideshow (34 pages)
- Eight Magic Keys to Planning for Students with FASD (2 pages)

References:

FASD - Fetal Alcohol Spectrum Disorder. (n.d.). Attached

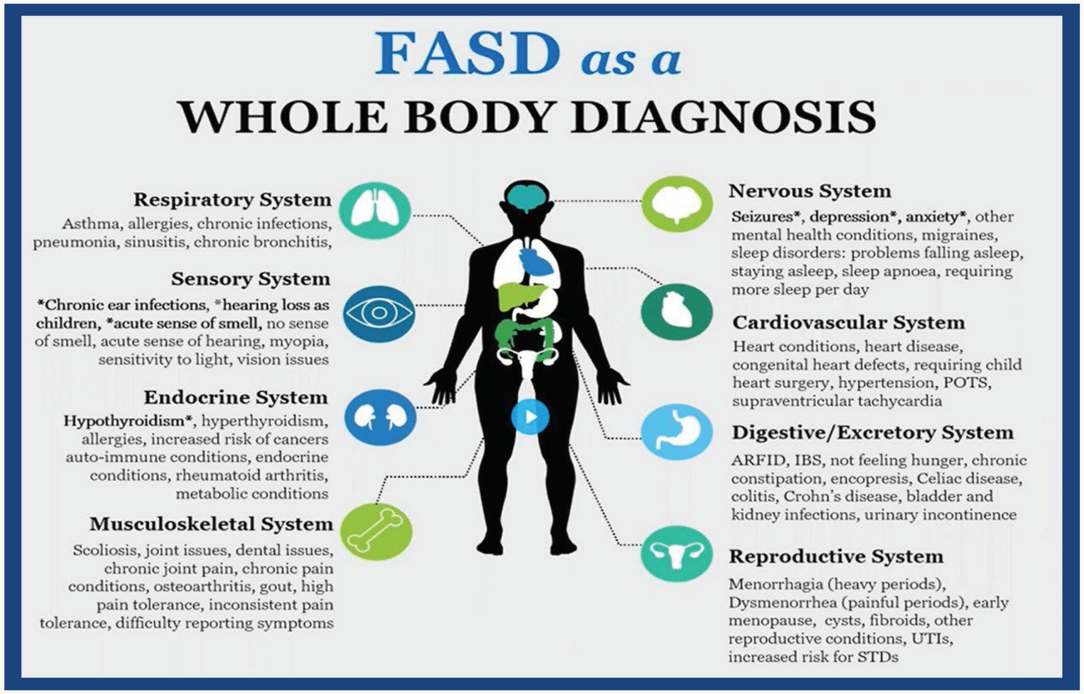
Eight Magic Keys - Planning for Students with Fetal Alcohol Spectrum Disorder. (1997). Evenson, D. & Lutke, J., Attached

Information Resources with Permissions From Sources CANFASD
POPFASD

FASD

Fetal Alcohol Spectrum Disorder

What is FASD?



FASD *as a*

WHOLE BODY DIAGNOSIS

Respiratory System
Asthma, allergies, chronic infections, pneumonia, sinusitis, chronic bronchitis,

Sensory System
***Chronic ear infections, *hearing loss as children, *acute sense of smell,** no sense of smell, acute sense of hearing, myopia, sensitivity to light, vision issues

Endocrine System
Hypothyroidism*, hyperthyroidism, allergies, increased risk of cancers auto-immune conditions, endocrine conditions, rheumatoid arthritis, metabolic conditions

Musculoskeletal System
Scoliosis, joint issues, dental issues, chronic joint pain, chronic pain conditions, osteoarthritis, gout, high pain tolerance, inconsistent pain tolerance, difficulty reporting symptoms

Nervous System
Seizures*, depression*, anxiety*, other mental health conditions, migraines, sleep disorders: problems falling asleep, staying asleep, sleep apnoea, requiring more sleep per day

Cardiovascular System
Heart conditions, heart disease, congenital heart defects, requiring child heart surgery, hypertension, POTS, supraventricular tachycardia

Digestive/Excretory System
ARFID, IBS, not feeling hunger, chronic constipation, encopresis, Celiac disease, colitis, Crohn's disease, bladder and kidney infections, urinary incontinence

Reproductive System
Menorrhagia (heavy periods), Dysmenorrhea (painful periods), early menopause, cysts, fibroids, other reproductive conditions, UTIs, increased risk for STDs

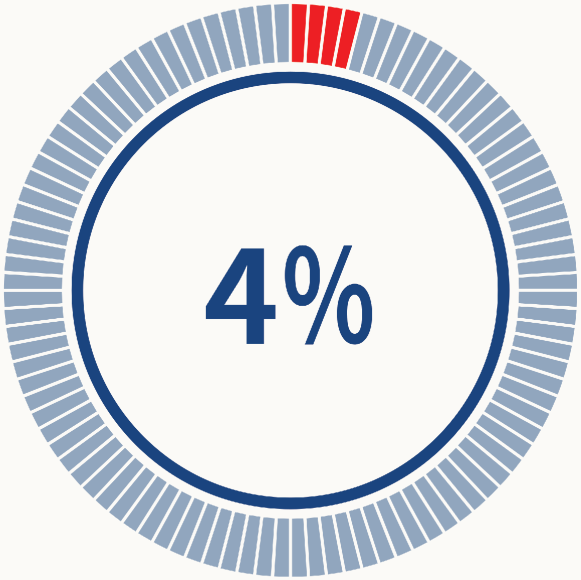
Fetal Alcohol Spectrum Disorder (FASD) is a lifelong disability that affects the brain and body of people who were exposed to alcohol in the womb.

Each person with FASD has both strengths and challenges and will need special supports to help them succeed with many different parts of their daily lives.

FASD IS ...

- A group of effects that can occur when an individual was prenatally exposed to alcohol
- Brain-based therefore it is known as an invisible disability
- Diffuse organic brain damage
- The leading cause of developmental disability
- Unpredictable in its developmental outcomes
- Not curable
- A lifelong disability
- Known to have better outcomes with early diagnosis and intervention
- Found in all cultures and levels of society

Prevalence of FASD in Canada



Current studies suggest that up to 4% of individuals in Canada have FASD.

Did you know?

FASD is recognized as one of the leading known causes of developmental disability in the western world. Compared with other common disabilities, at an estimated prevalence of 4%, FASD is:

2.5X more common than Autism (1.52%)

28X more common than Down Syndrome (0.14%)

19X more common than Cerebral Palsy (0.21%)

40X more common than Tourette's Syndrome (0.10%)

Prenatal Alcohol Exposure is a Risk Factor

It does not link directly to a diagnosis. The Spectrum of damage depends on:

- Amount and pattern of alcohol use
- Timing in gestation
- Maternal genetics, cross generational epigenetics changes, nutrition, other teratogens, stress

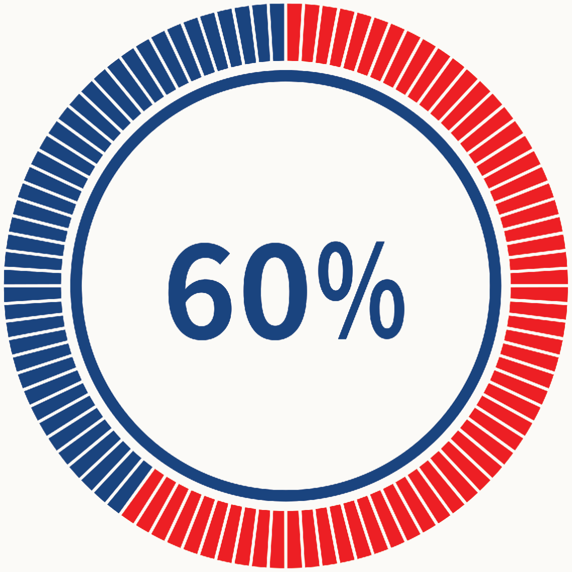
Additional Risk Factors

There are a variety of factors that can impact why a woman consumes alcohol during pregnancy.

- Women are unaware they are pregnant (Unplanned pregnancy)
- Unaware of the extent of damage alcohol can cause the fetus
- Underestimate the harm alcohol can cause on a fetus
- Know other women that drank during pregnancy and their children appear healthy
- Alcohol use is the norm in their social group, abstaining can be difficult
- May be using alcohol to cope with difficult life situations
- May be struggling with alcohol addiction

No Blame, No Shame

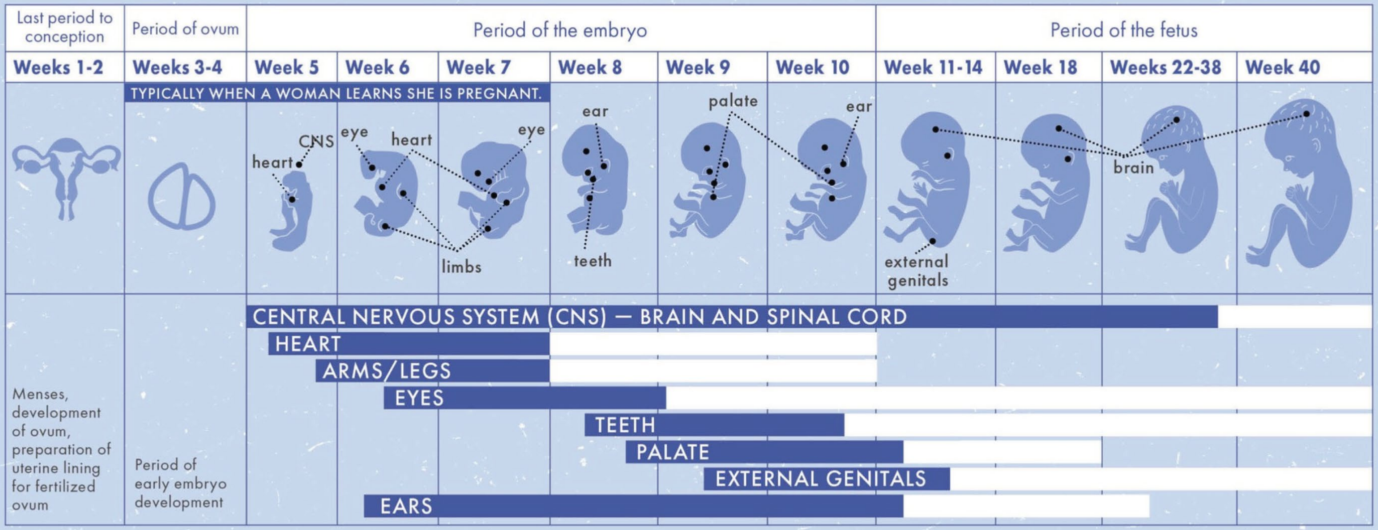
Did you know?



More than 60% of pregnancies are thought to be unplanned, and, in the early stages, most women do not know that they are pregnant.

FETAL DEVELOPMENTAL CHART

THIS CHART SHOWS VULNERABILITY OF THE FETUS TO DEFECTS THROUGHOUT 40 WEEKS OF PREGNANCY.



■ **PERIOD OF DEVELOPMENT WHEN MAJOR DEFECTS IN BODILY STRUCTURE CAN OCCUR**

□ **PERIOD OF DEVELOPMENT WHEN MAJOR FUNCTIONAL DEFECTS AND MINOR STRUCTURAL DEFECTS CAN OCCUR**

● **MOST COMMON SITE OF BIRTH DEFECTS**

Adapted from Moore, 1993 and the National Organization on Fetal Alcohol Syndrome (NOFAS) 2009.

*This fetal chart shows the 38 weeks of pregnancy. Since it is difficult to know exactly when conception occurs, medical providers calculate a woman's due date 40 weeks from the start of her last menstrual cycle.

Let's Talk alcohol & pregnancy
letstalkfasdak.org

Trust
Alaska Mental Health Trust Authority

Alaska Center for
Fetal
Alcohol
Spectrum
Disorders

Information sourced from the Centers for Disease Control and Prevention.

Understanding Alcohol Effects

- 100% of the alcohol crosses the placenta
- Full concentration of alcohol remains in the amniotic fluid up to 3 days
- A fetus does not have a fully functioning liver therefore it is unable to eliminate alcohol from the environment
- Effects of prenatal alcohol exposure:
- Cell death, altered cell structure, altered brain chemistry, reduced interconnections among brain cells, reduced myelination
- Damage can occur in any region of the brain
- The fetal brain is always vulnerable to damage from alcohol exposure
- Extent of damage depends on timing and level of exposure

Important Facts About Brain Cells

1) They come with their own version of a GPS (they kow where to go in the brain

2) They have their job description in the brain (they know which cells they need to connect with in the brain)

What Happens when Alcohol and the Brain Mix?

- The GPS is lost or damaged so the cells don't know where to go
- The brain cells no longer have a job description, they don't know what to do
- Worst case scenario: alcohol kills the brain cells altogether which is known as necrosis and apoptosis in the developing embryo and fetus

Alcohol Exposure & the Brain

On the left hand side we have a brain of a child that was not prenatally exposed to alcohol

On the right we have the brain of a child that was severely prenatally exposed to alcohol

Photo credit: Sterling Clarren, MD

Please note that not all individuals with FASD have the similar brain appearance as this slide. Think of this as a worse case scenario.

Alcohol Affects Every Part of The Brain

Brain Stem	Regulation of States
Cerebellum	Motor Skills & Coordination
Limbic System	Attention
Cerebrum (Left temporal lobe)	Speech & Language
Frontal Lobes	Executive Functioning & Reasoning
Multiple areas	Learning, Memory, Cognition
Whole Brain	Adaptive Skills - Using what you have

Sentinel Facial Features

DID YOU KNOW?

Only 7% of individuals with FASD have Sentinel Facial Features.

The facial features associated with FASD only occur if the fetus was prenatally exposed to alcohol at a specific time (between days 19-21)

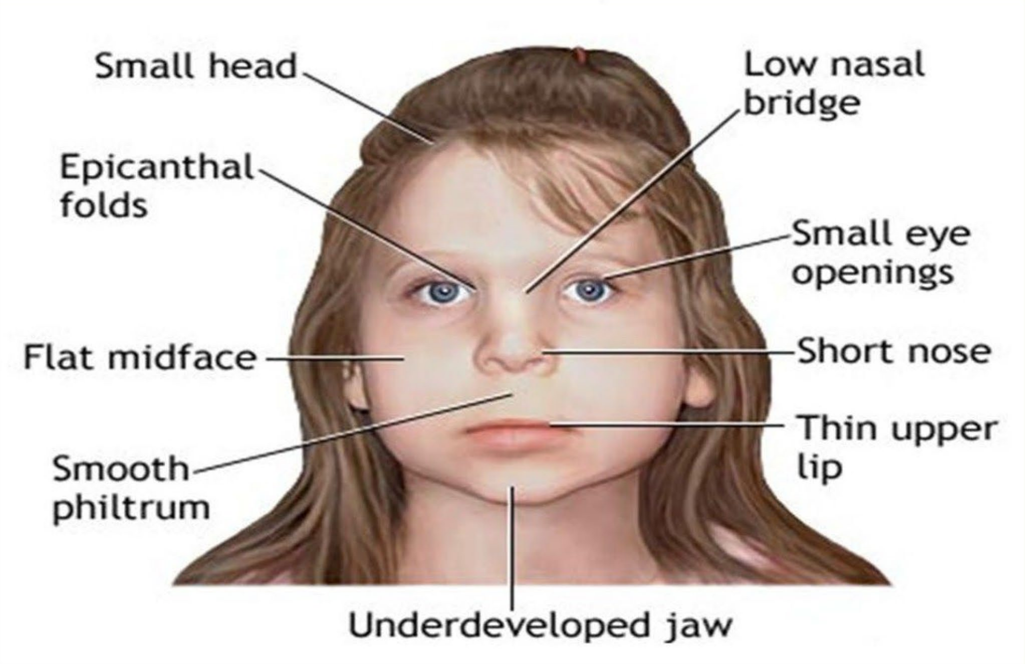


Image Courtesy of the National Library of Medicine, NIH

Primary Characteristics

Learning, developmental, and physical responses to the environment and other behavioral symptoms associated with underlying differences in brain structure and function.

- Learning Difficulties
- Difficulty understanding abstract concepts
- Problems with attention
- Delayed auditory processing
- Difficulty storing or retrieving information
- Inconsistent performance
- Distractibility
- Memory problem
- Difficulty predicting outcomes
- Developmental dysmaturity
- Impulsivity
- Difficulty understanding natural or logical consequences
- Difficulty generalizing, forming links and making associations

Secondary Characteristics

These characteristics are not caused my prenatal alcohol exposure, but can develop over time. Individuals with FASD often experience continuing frustration, these patterns of defensive behavior commonly develop.

- Mental health diagnosis
- Easily frustrated
- Aggressive, acts out
- Anxious, fearful
- Quick to fatigue
- Irritability
- Over or under active
- Poor scholastic performance
- Isolated, few friends, picked on
- Rigid, resistant, argumentative
- Overwhelmed, shut down (may demonstrate a flat affect and appear to not care)
- Poor self-concept, feelings of failure and low self-esteem
- Self-aggrandizement, attempts to look good

These are characteristics that develop over time (not born with).If an individual is not diagnosed by high school, they are at higher risk of having more adverse outcomes as it’s a vulnerable time in their lives.

Tertiary Characteristics

These characteristics can happen when those with FASD are left unsupported or fall through the cracks. These include:

- Trouble at home, school or in the community
- May run away from home or placements
- May be in and out of custody
- Substance use or abuse
- Homelessness
- Women are at higher risk of unplanned pregnancies

Learning theory is based on the belief that most brains function in a similar way:

- Rapid processing speed
- Store and retrieve information
- Think abstractly
- Generalize
- Predict
- Congruence between words and actions
- Understand and comprehend

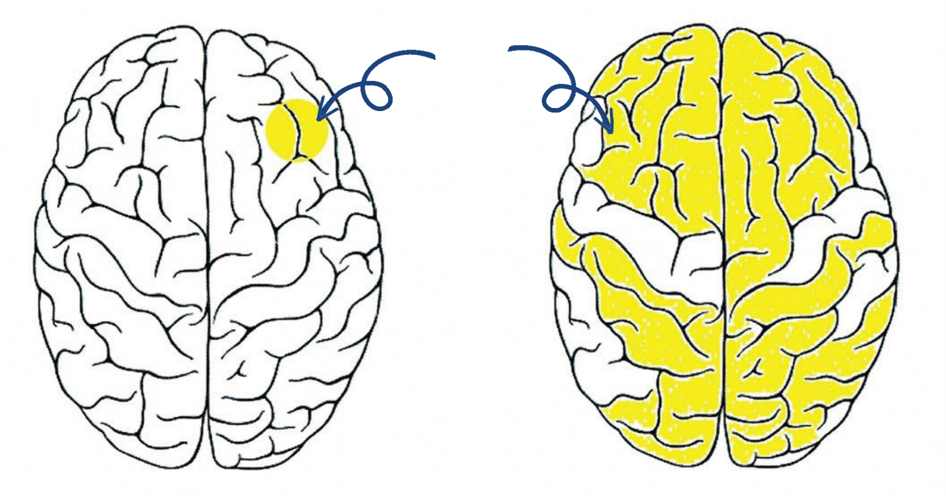
Normal brain development is complex, orderly and sequential. Rich neural networks provide mechanisms for basic abilities: storing, remembering, integrating and retrieving information.

Neurological differences often appear as

- Slower processing speed (thinking, hearing)
- Problems storing, retrieving information
- “Gaps”, difficulty forming links, associations
- Difficulty generalizing
- Abstraction is difficult
- Difficulty seeing next steps, outcomes
- Disconnections: says one thing, does another
- Grasps pieces rather than concepts

With FASD there is often undergrowth, overgrowth, gaps and tangles. Because of fewer cells, brain structure and chemistry may be altered, affecting basic cognitive abilities and sensory responses.

Working Brain Area

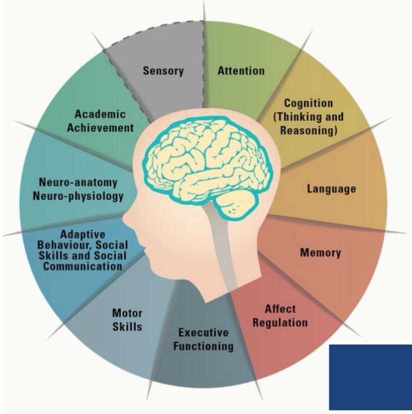


Neuro-Typical Brain

Brain of Individual with FASD

Diane Malbin explains that “Disorganization in the brain may mean that the brain has to work harder to achiev simple tasks. For one person, a task may be as tiring as going for a 5 minute stroll. For another person with FAS that same task may require the same energy as performing a triathlon.

This is why individuals with FASD are often tired and have difficulty sleeping because their brains have to work harder to complete tasks.



Brain Domains

There are 10 brain domains that are potentially affected by alcohol use during pregnancy that can lead to a diagnosis of FASD.

1.Academic Achievement

→ May have difficulty in school

2.Attention → May be easily distracted and have difficulty paying attention

3.Cognition (Thinking & Reasoning) → Difficulty with problem solving and understanding complex ideas

4.Language (Expressive & Receptive) → May speak well but notfully understand the meaning

5. Memory → May have difficulty with long-term, short-term and / or working memory

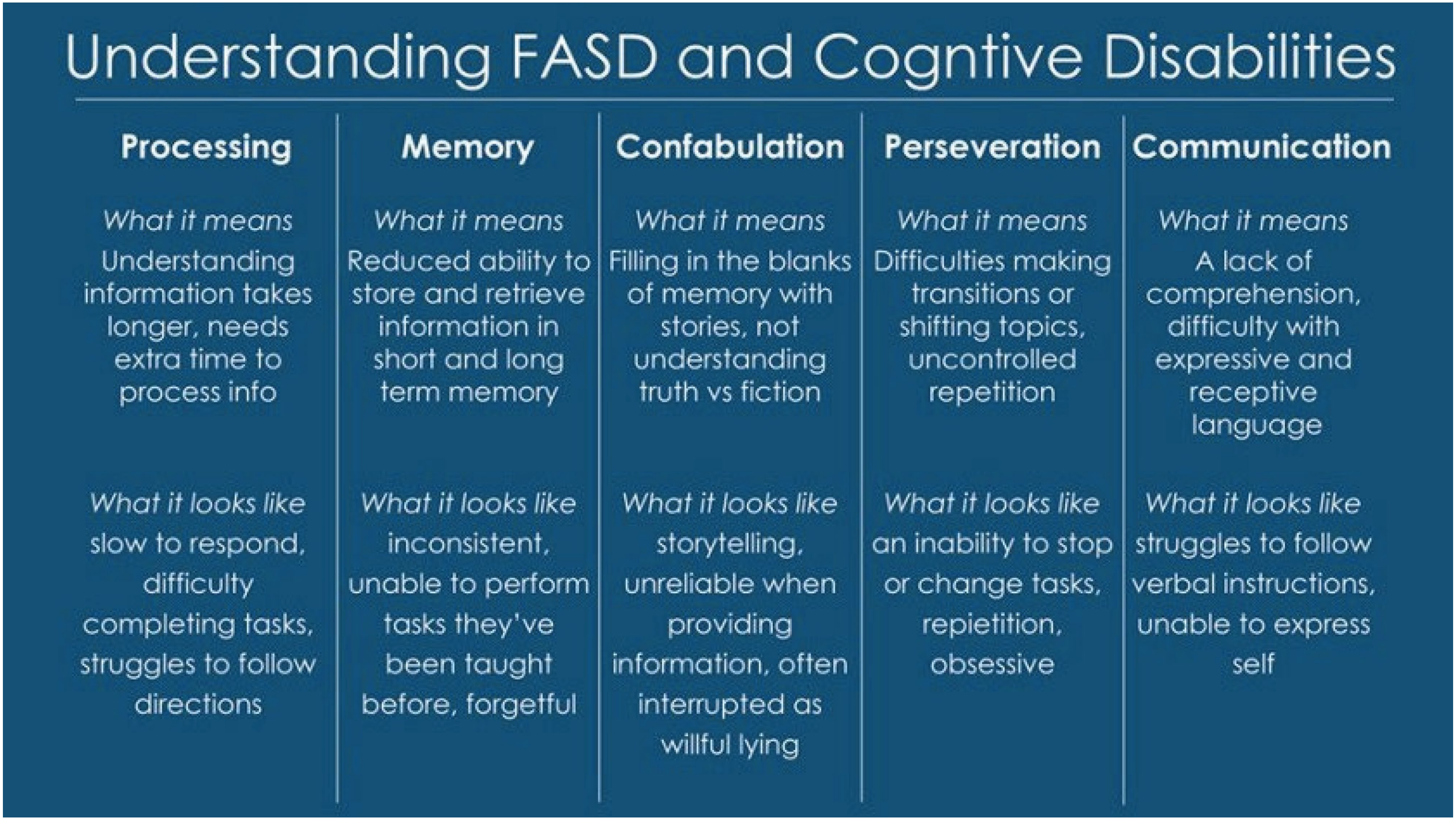
6. Affect Regulation → Ability to control and adjust emotions

7.Executive Functioning → May have difficulty planning and organizing, impulsivity

8.Motor Skills / Sensory → Poor coordination, poor body awareness, abnormal muscle tone

9.Adaptive Behavior, Social Skills, Social Communication → Difficulty with hygiene, cleaning

10.Neuroanatomy / Neurophysiology → Brain structure, head circumference



Understanding FASD and Cogntive Disabilities

Processing	Memory	Confabulation	Perseveration	Communication
What it means Understanding information takes longer, needs extra time to process info	*What it means* Reduced ability to store and retrieve information in short and long term memory	*What it means* Filling in the blanks of memory with stories, not understanding truth vs fiction	*What it means* Difficulties making transitions or shifting topics, uncontrolled repetition	*What it means* A lack of comprehension, difficulty with expressive and receptive language
What it looks like slow to respond, difficulty completing tasks, struggles to follow directions	*What it looks like* inconsistent, unable to perform tasks they've been taught before, forgetful	*What it looks like* storytelling, unreliable when providing information, often interrupted as willful lying	*What it looks like* an inability to stop or change tasks, repietition, obsessive	*What it looks like* struggles to follow verbal instructions, unable to express self

FASD & Adulthood Here’s what it can look like

•Difficulty maintaining employment •Difficulty with Independent living needs (ex: household chores, remember to pay bills/rent) •Housing Problems or Transient Behaviour •Legal Problems (Victim or Accused) •Criminal behaviour or incarceration •Struggle with mental health (depression, suicidal ideation, etc.) •Often late for appointments or forget to attend • Inappropriate sexual behaviour •Misuse of drugs or alcohol •Difficult obtaining FASD diagnosis (if not yet diagnosed)

FASD & Adulthood Here's what it can look like

•Difficulty maintaining employment •Difficulty with Independent living needs (ex: household chores, remember to pay bills/rent) •Housing Problems or Transient Behaviour •Legal Problems (Victim or Accused) •Criminal behaviour or incarceration •Struggle with mental health (depression, suicidal ideation, etc.) •Often late for appointments or forget to attend • Inappropriate sexual behaviour •Misuse of drugs or alcohol •Difficult obtaining FASD diagnosis (if not yet diagnosed)

Did you know?

12.8

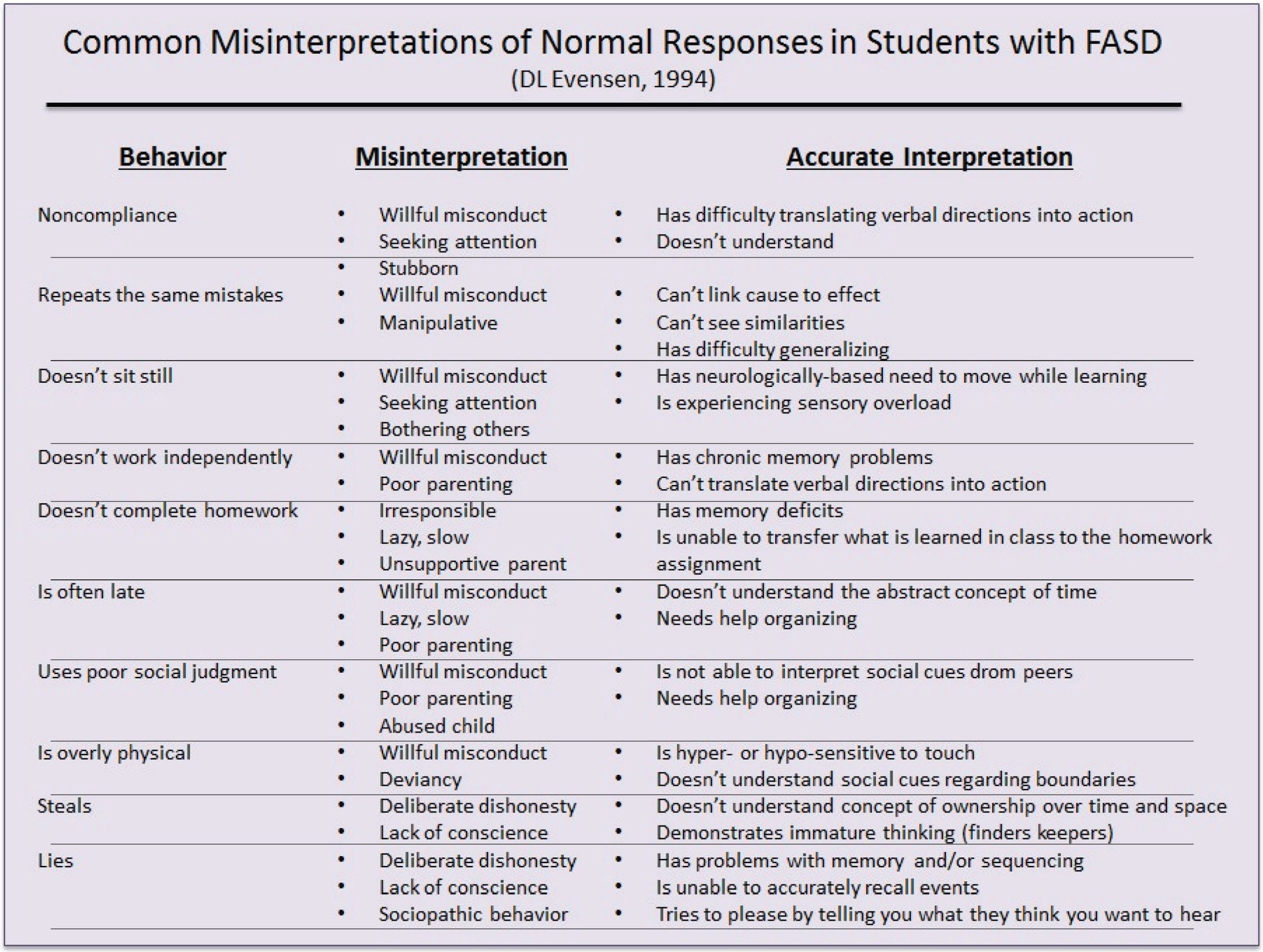
The average age that children with an FASD begin having trouble with the law

50%

The percentage of individuals with an FASD that have a history of confinement in a jail, prison, chemical health treatment facility or psychiatric hospital.

Brain not Blame - Reframing Perceptions

Interpreting behavior as:	To Understand the individual:
Won’t	Can’t
Bad	Frustrated, Challenged
Lazy	Tries hard, tired of failing
Lies	Confabulation, Fills in the blanks
Doesn’t Try	Exhausted, Can’t start
Mean	Defensive, Hurt
Doesn’t Care - Shuts down	Can’t show feelings
Refuses to sit still	Overstimulated
Resistant	Doesn’t get it



Common Misinterpretations of Normal Responses in Students with FASD

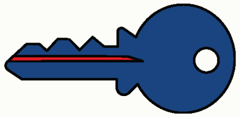
(DL Evensen, 1994)

Behavior	**Misinterpretation**	**Accurate Interpretation**
Noncompliance	• Willful misconduct • Seeking attention	• Has difficulty translating verbal directions into action • Doesn't understand
Repeats the same mistakes	• Stubborn • Willful misconduct • Manipulative	• Can't link cause to effect • Can't see similarities • Has difficulty generalizing
Doesn't sit still	• Willful misconduct • Seeking attention • Bothering others	• Has neurologically-based need to move while learning • Is experiencing sensory overload
Doesn't work independently	• Willful misconduct • Poor parenting	• Has chronic memory problems • Can't translate verbal directions into action
Doesn't complete homework	• Irresponsible • Lazy, slow • Unsupportive parent	• Has memory deficits • Is unable to transfer what is learned in class to the homework assignment
Is often late	• Willful misconduct • Lazy, slow • Poor parenting	• Doesn't understand the abstract concept of time • Needs help organizing
Uses poor social judgment	• Willful misconduct • Poor parenting • Abused child	• Is not able to interpret social cues drom peers • Needs help organizing
Is overly physical	• Willful misconduct • Deviancy	• Is hyper- or hypo-sensitive to touch • Doesn't understand social cues regarding boundaries
Steals	• Deliberate dishonesty • Lack of conscience	• Doesn't understand concept of ownership over time and space • Demonstrates immature thinking (finders keepers)
Lies	• Deliberate dishonesty • Lack of conscience • Sociopathic behavior	• Has problems with memory and/or sequencing • Is unable to accurately recall events • Tries to please by telling you what they think you want to hear

8 Magic Keys

Intervention Strategies for Individuals with FASD

Developed by Deb Evenson and Jan Lutke (1997)



1. Concreate
   - Individuals with FASD do well when parents and educators talk in concreate terms
   - Avoid using words with double meanings
   - Social-emotional understanding is often far below the student's chronological age. It helps to "think younger" when providing assistance, giving instructions, settings expectations, etc.

2. Consistency
   - Individuals with FASD experience difficulty generalizing learning from one situation to another
   - Minimize changes to the environment and language/words used
   - Teachers and caregivers can coordinate with each other to use the same words for key phases and oral direction

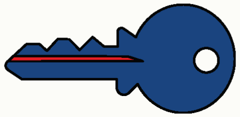
3. Repetition
   - Individuals with FASD have chronic short-term memory difficulties, they often forget things they want to and need to remember
   - Repetition and re-teaching will help information make it to long-term memory.

4. Routine
   - Stable routines that don't change from day to day will make it easier for individuals with FASD to know what to expect next and decrease their anxiety, enabling them to learn.

8 Magic Keys

Intervention Strategies for Individuals with FASD

Developed by Deb Evenson and Jan Lutke (1997)



5. Simplicity
   - Remember to “Keep it short and sweet (KISS method)
   - Individuals with FASD are easily over-stimulated, leading to
   - "shutdown" at which point no more information can be taken in.

6. Specific
   - Say exactly what you mean.
   - Individuals with FASD often have difficulty with abstract concepts, generalization and have a hard time "filling in the blanks" when given directions.
   - Provide instructions step-by-step. This also supports developing appropriate habit patterns.

7. Structure
   - An environment with structure and boundaries help keep the individual with FASD on track.
   - It’s the “glue” that helps the world make sense.

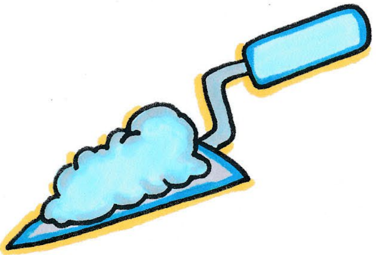
8. Supervision
   - Because of cognitive impairments and dysmaturity, individuals with FASD are often naïve in everyday life situations and are easily taken advantage of by others.
   - Consider developmental age and supervision requirements.
   - Supervision is required to develop habit patterns of appropriate behaviour.

DEB EVENSON AND JAN LUTKE'S

EIGHT MAGIC KEYS

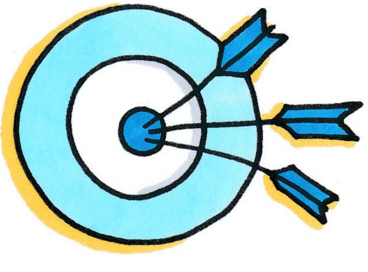
@kwiens62

PLANNING FOR STUDENTS WITH FETAL ALCOHOL SPECTRUM DISORDER



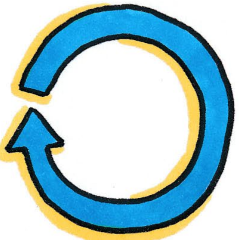
CONCRETE

TALK IN CONCRETE TERMS
AVOID ABSTRACT LANGUAGE



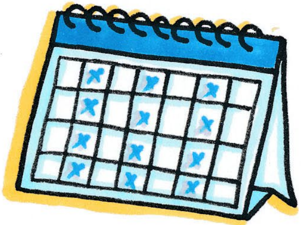
CONSISTENCY

PARENTS & EDUCATORS USE
THE SAME WORDS & STRATEGIES



REPETITION

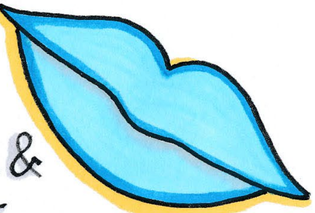
RE-TEACH MANY TIMES TO RETAIN
IN LONG-TERM MEMORY



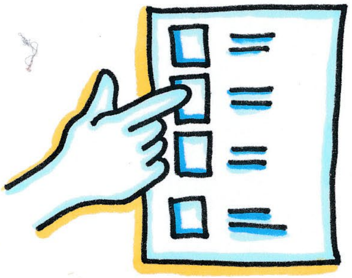
ROUTINE

HELP REDUCE ANXIETY

Keep
It
Short &
Sweet

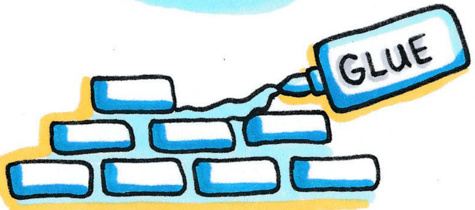


SIMPLICITY



SPECIFIC

SAY EXACTLY WHAT YOU MEAN
GIVE STEP BY STEP DIRECTIONS



STRUCTURE

THE GLUE THAT MAKES THE WORLD
MAKE SENSE... THEIR FOUNDATION

SUPERVISION

SCAFFOLD INDEPENDENCE

Kristin Wiens 2017

EIGHT KEYS: Developing Successful Interventions for Students with FASD

1. **Structure**
2. Concrete
3. Consistency
4. Repetition
5. Routine
6. Simplicity
7. Specific
8. Supervision

While there is no recommended "cookbook approach" to working with students with FASD, there are strategies that work, based on the following guidelines:

1. Structure - Structure is the "glue" that makes the world make sense for a student with FASD. If this glue is taken away, the walls fall down! A student with FASD achieves and is successful because their world provides the appropriate structure as a permanent foundation.

2. Concrete - Students with FASD do well when parents and educators talk in concrete terms, don't use words with double meanings, idioms, etc. Because their social-emotional understanding is far below their chronological age, it helps to "think younger" when providing assistance, giving instructions, etc.

3. Consistency - Because of the difficulty students with FASD experience trying to generalize learning from one situation to another, they do best in an environment with few changes. This includes language. Teachers and parents can coordinate with each other to use the same words for key phases and oral directions.

4. Repetition - Students with FASD have chronic short-term memory problems; they forget things they want to remember as well as information that has been learned and retained for a period of time. In order for something to make it to long term memory, it may simply need to be re-taught and retaught.

5. Routine - Stable routines that don't change from day to day will make it easier for students with FASD to know what to expect next and decrease their anxiety, enabling them to learn.

6. Simplicity - Remember to Keep it Short and Sweet (KISS method). Students with FASD are easily overstimulated, leading to "shutdown" at which point no more information can be assimilated. Therefore, a simple environment is the foundation for an effective school program.

7. Specific - Say exactly what you mean. Remember that students with FASD have difficulty with abstractions, generalization, and not being able to "fill in the blanks" when given a direction. Tell them step by step what to do, developing appropriate habit patterns.

8. Supervision - Because of their cognitive challenges, students with FASD bring a naiveté to daily life situations. They need constant supervision, as with much younger children, to develop habit patterns of appropriate behavior.

When a situation with a student with FASD is confusing and the intervention is not working, then:
- Stop Action! • Observe.
- Listen carefully to find out where he/she is stuck.
- Ask: What is hard? What would help?

Video Resources

8 Magic Keys of Success
WRaP Schools http://bit.ly/217jHob

8 Magic Keys of Success
Anchorage School District and ASDtv
http://bit.ly/1R6RgSE

The 2 x 10 Strategy - Relationships

The 2 x 10 strategy is simple: spend 2 minutes per day for 10 days in a row talking with an at-risk student about anything she or he wants to talk about. http://bit.ly/1KoeDHX

The FIND, REMIND, and BIND strategy. FIND a student that you want a relationship with, REMIND them why you are grateful for the, and this will BIND you. http://bit.ly/1SCEQCC.

What is FASD?

FASD describes a spectrum of disorders caused by prenatal exposure to alcohol.

Three or more domains of the central nervous system are impacted when you are living with FASD.

Children living with FASD have a brain-based disability.

Developed by Deb Evenson and Jan Lutke 1997

Adapted by POPFASD 2016

Master Key – Trusting Relationship

Resources

CanFASD
CANADA FASD RESEARCH NETWORK

Scan me

Resources

POPFASD

Provincial Outreach Program Fetal Alcohol Spectrum Disorder (POPFASD)

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Resources

POPFASD

Fasd Outreach Tools

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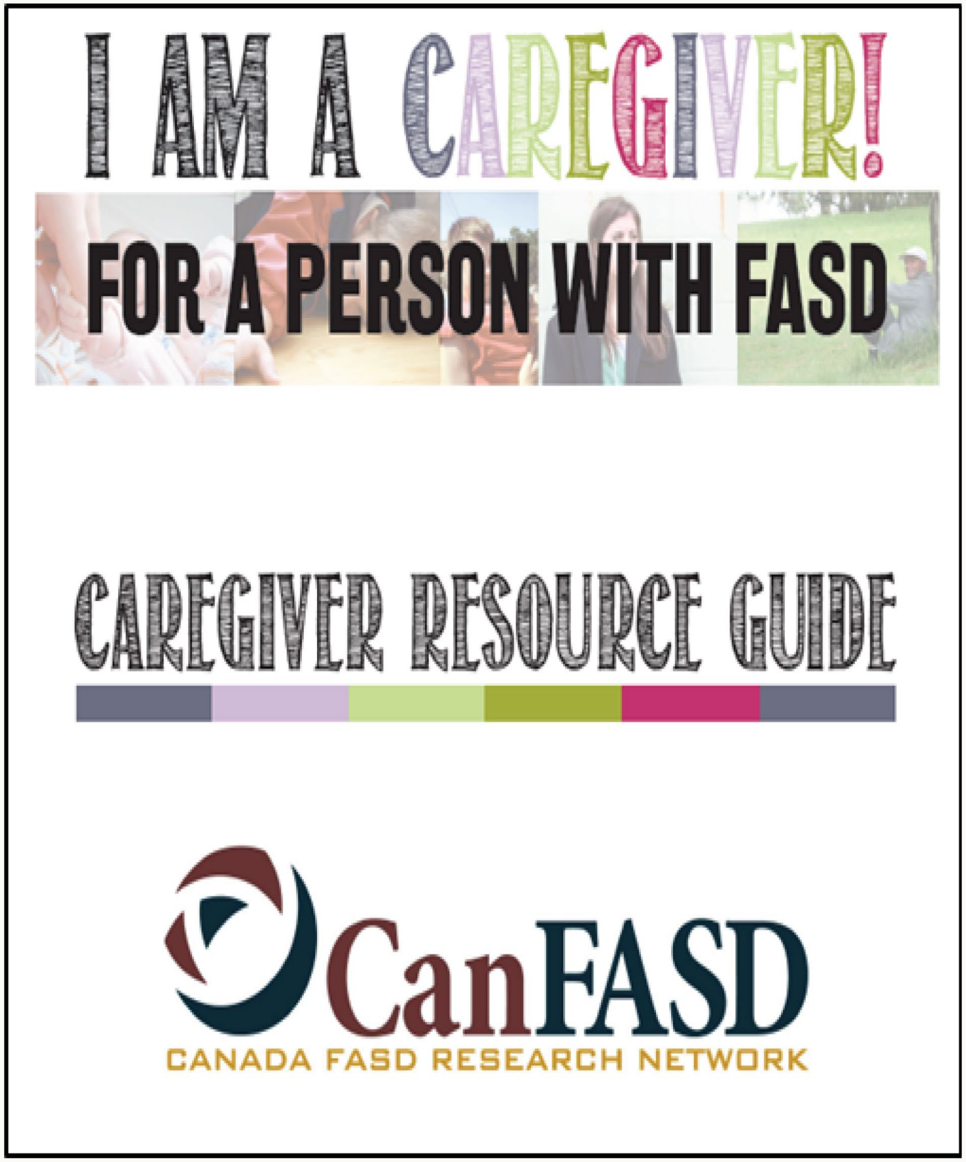
Resources



I AM A CAREGIVER!

FOR A PERSON WITH FASD

CAREGIVER RESOURCE GUIDE

CanFASD

CANADA FASD RESEARCH NETWORK

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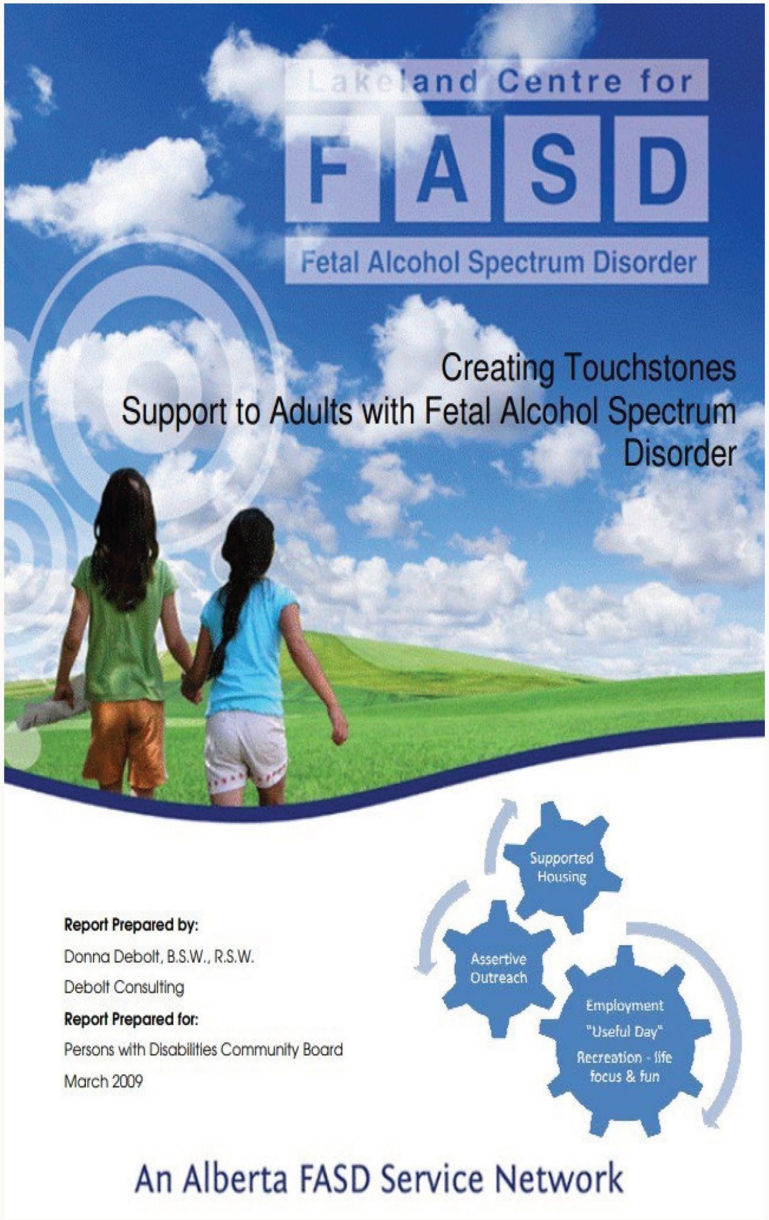
Resources



Lakeland Centre for

FASD

Fetal Alcohol Spectrum Disorder

Creating Touchstones
Support to Adults with Fetal Alcohol Spectrum Disorder

Report Prepared by:
Donna Debolt, B.S.W., R.S.W.
Debolt Consulting
Report Prepared for:
Persons with Disabilities Community Board
March 2009

An Alberta FASD Service Network

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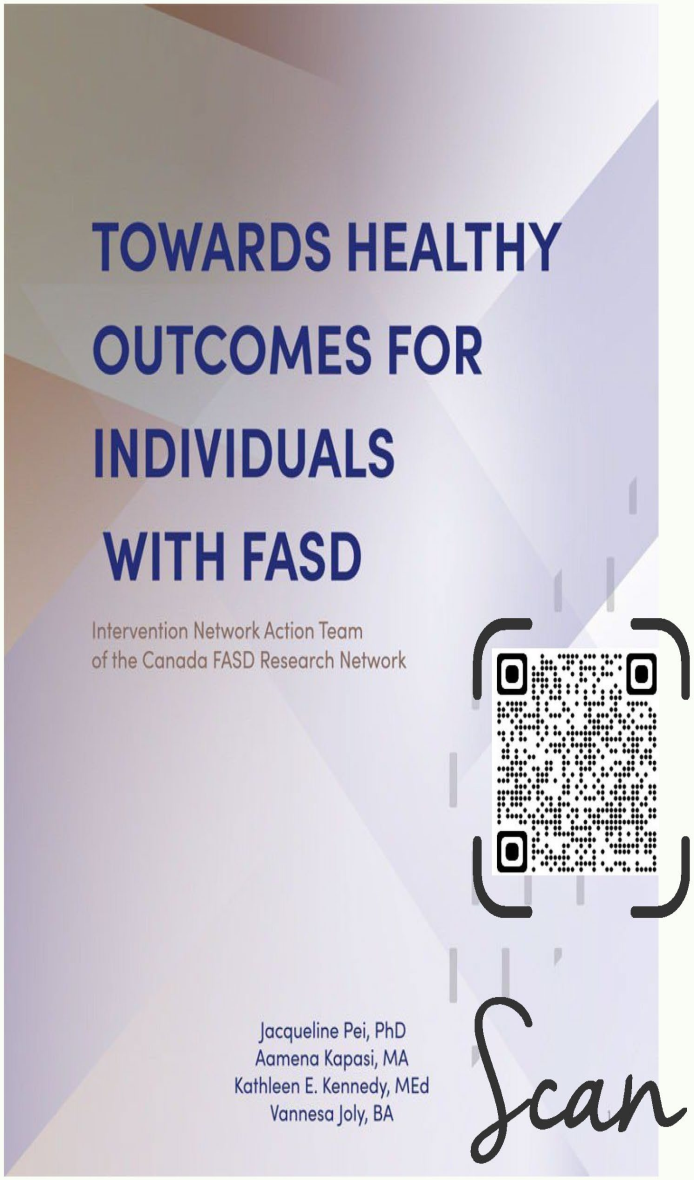
Resources



TOWARDS HEALTHY OUTCOMES FOR INDIVIDUALS WITH FASD

Intervention Network Action Team
of the Canada FASD Research Network

Jacqueline Pei, PhD
Aamena Kapasi, MA
Kathleen E. Kennedy, MEd
Vannesa Joly, BA

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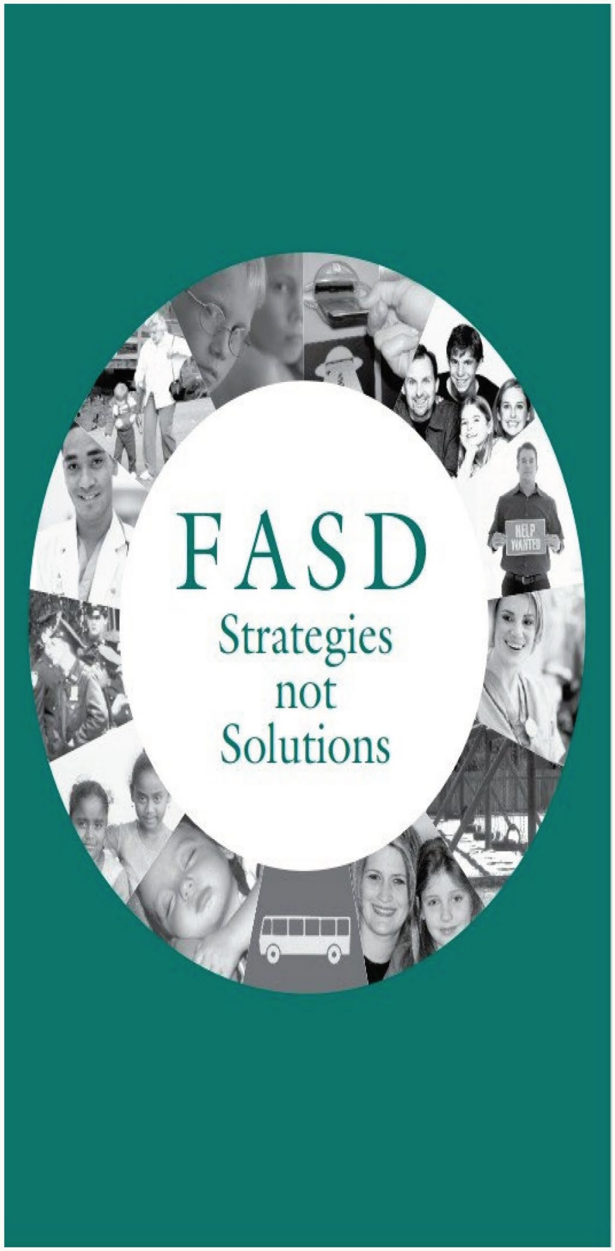
Resources



FASD

Strategies not Solutions

Scan me

FASD Program Information Sheet

Eligibility Criteria:

- Children and youth from birth to 18 (21 if still in school) throughout the catchment area (Hearst to Latchford, ON)
- Children and youth with FASD or suspected FASD – formal diagnosis is not required.
- Children and youth with Neonatal Abstinence Syndrome (NAS) or suspected NAS – formal diagnosis is not required.

FASD Worker can provide support to families in the following ways:

- Work with child/youth and their families to develop a support plan based on individual strengths and needs, and informed by the child/youth and family's vision, goals and concerns
- Support connections to diagnostic supports (if available), and provide post-diagnostic support
- Coordinate service planning for child/youth and families
- Support connections to other services and, with consent, share information and the service plan so the family doesn't have to repeat their story.
- Provide information to parents/caregivers about characteristics associates with FASD and assist to view things with an FASD lens
- Work with youth, their family and service providers across sectors to plan for a transition from child and youth services to adult services, if required.
- Facilitate parent-to-parent connections

Worker can provide support to the community in the following ways:

- Provide information and education to frontline staff and educators about FASD
- Provide information to community members about characteristics associates with FASD and assist to view things with an FASD lens
- Advocate to reduce the stigma of children, youth and families affected by FASD
- Work to improve awareness of FASD and support local cross-sectoral planning tables to identify gaps and opportunities for improving supports for FASD
- Be an active member of various FASD committees and/or coalitions

Referral Process:

- Parents/caregivers, community agencies and/or schools can make a referral.
- Community agencies and/or schools must obtain parental or guardian informed consent prior to making the referral.
- Referrals will then be handled using CTCTC's internal referral process and will be redirected to the FASD Worker.

Fragile X Syndrome (FXS)

What's Fragile X Syndrome (FXS)?

Fragile X syndrome (FXS), also known as Martin-Bell syndrome, is the most common cause of inherited intellectual disability. FXS is caused by a change in a gene on the X chromosome. This change means the body cannot make a protein needed for normal brain development.

Facts about FXS

There are not always interventions for the below symptoms, however, **seeing a decrease/absence of symptoms may indicate if a patient/client's medications are working.**

It can lead to:

- developmental delays
- learning disabilities
- social and behavioral problems
- intellectual disabilities

People with FXS also may have other conditions, including:

- autism
- attention deficit hyperactivity disorder (ADHD)
- seizures

Students with FXS may:

- need accommodations and assistive or adaptive equipment
- need extra learning support
- have problems with planning, problem-solving, and impulsivity
- be very sensitive to sounds, lights, textures, tastes, and smells
- require occupational, physical, and speech therapies
- may need frequent breaks to help cope with anxiety and worry
- need small-group or one-on-one instruction for new concepts or tasks

What Workers Can Do

Individuals with FXS work best in a calm, structured learning environment without distractions.

- Using visual cues in addition to verbal instructions.
- Making time for extra breaks.
- Letting them wear noise-reduction headphones, dimming lights (if possible), providing quiet areas, and limiting distractions.
- teaching the individual self-calming strategies to avoid emotional outbursts
- Providing consistency and maintaining routines in the home
- encouraging participation in all appropriate activities

References:

Gavin, M. L. (2020, September). *Fragile X syndrome factsheet (for Schools) (for parents) - nemours kidshealth*. KidsHealth. https://kidshealth.org/en/parents/fxs-factsheet.html

Generalized Anxiety Disorder (GAD)

Generalized anxiety disorder is chronic anxiety, with symptoms occurring for at least 6 months. A person with GAD has excessive worry that is difficult to control. It impairs work, ability to sustain relationships, and daily functioning. It is twice as common in the **female population** than it is for the male population.

Major Symptoms and Interventions of GAD

Symptom	Presentation	Intervention
Fatigue	Feeling easily tired	Encourage sleep hygiene, adequate nutritional and fluid intake. Refer to dietician if needed
Concentration and restlessness	Difficulty concentrating or patient's mind going blank. Pacing, inability to stay still	Grounding, and mindfulness. Refer to psychologist or CBT programming if available
Irritability	Being easily agitated	Encourage client to attend to enjoyable activities - refer to recreational therapist
Muscle tension	Feeling stiff	Relaxation techniques, meditation
Sleep	Sleep disturbance (difficulty falling or staying asleep, restless, unsatisfying sleep)	Encourage routine meals, and sleep schedule

Interventions for all Anxiety Disorders

- Provide a safe and low stimulus environment, and privacy during a panic attack or during a heightened state of anxiety.
- Stay with patient/client to provide validation and reassurance.
- Remind client of coping skills.

Treatment for GAD

If the GAD disorder is mild, no treatment may be required, and the physician may follow up every 3 months to observe for any worsening symptoms.

If treatment is required, cognitive behavioral therapy (CBT) can be used as treatment on its own, or in combination with medication (selective serotonin reuptake inhibitors or serotonin-norepinephrine reuptake inhibitors).

References:

Ontario Shores Foundation for Mental Health (2023). Common Mental Illnesses: Assessment and Documentation. *Generalized Anxiety Disorder (GAD)*. Ontario Tech University.

Intellectual Disability

What is Intellectual Disability?

Intellectual disability is a developmental disability. It can affect people in different ways and at different levels. Intellectual disability is a life-long condition. There are three criteria that need to be identified to provide a diagnosis.

1. The individual's general intelligence needs to be developing/or have developed at a slower rate.
   This can be seen through difficulties at school, special education classes, etc.
2. There needs to be significant difficulties in the individual's everyday living skills.
   Difficulty maintaining employment, social skills, communication, self-care, self-direction, home living, functional academics, etc.
3. Challenges with intelligence and everyday living skills prior to age 18.
   If working with an adult, the difficulties listed above must have been noted in early life

Causes

There are many causes of intellectual disability; however, sometimes the causes may be unknown. Some causes are:

- Genetic syndromes (e.g. Down syndrome or Fragile X)
- Could develop following an illness (e.g. meningitis, whooping cough, measles)
- Could result from head trauma
- Difficulties during pregnancy or delivery (e.g. not getting enough oxygen)
- Environmental influences during pregnancy (e.g. alcohol or drug use)

Different Severities of Intellectual Disability

Intellectual disability has four different severities. The most common severity of intellectual disability is "mild". People with intellectual disability in the mild range learn at a slower rate but with early intervention and support from adults throughout their childhood and early adulthood, can live an independent or semi-independent life. They may graduate high school, have relationships, or maintain a job.

"Moderate", "severe", and "profound" are the other severities of intellectual disability. These are less common but usually make it harder for the individual to live an independent life.

Supporting someone with Intellectual Disability

Everyone is different and intellectual disability can affect everyone differently. Therefore, individualized plans and getting to know how the individual learns are important in supporting them the best way possible. Listed below are some general strategies for supporting individuals with intellectual disabilities.

- Use clear, simplified language
- Do not raise your voice unless asked to
- Be polite and patient – do not rush the conversation
- Speak directly to the person
- Be flexible – reword if needed rather than repeating yourself
- Ask the individual how they communicate best (e.g. visually, verbally, or a combination)
- Ask questions if you do not understand what they are saying

References:

Do2Learn. (1999-2021). *Intellectual Disability, Strategies*. Do2Learn. https://do2learn.com/disabilities/CharacteristicsAndStrategies/IntellectualDisability_Strategies.html

Major Depressive Disorder

What are Mood Disorders?

Before we get into the clinical details, remember that patients/clients may have no control of their own behavior/speech, so it is important to always take your time, and be patient when caring for them. Keep in mind that they may not be in a state to fully appreciate what you are saying now, and they will not forget how you made them feel.

Mood Disorders are a class in mental illness that broadly encompasses various types of **bipolar disorders** and **depression**. This disorder can affect all ages of patients/clients, where the symptoms of mood disorders may be expressed differently by each age group.

Major Depressive Disorder

Major depressive disorder (otherwise known as depression), is a common and recurring **mood** disorder that impacts a person's daily functioning. The World Health Organization (WHO) ranks major depression as the 11th cause of disability and mortality.

- Five (or more) of the following symptoms represent a change from previous functioning of a person; at least one of the symptoms is either **(1) depressed mood or (2) loss of interest or pleasure.**

Major Symptoms and Interventions of Depression

Symptom	Presentation	Intervention
Depressed Mood	Depressed mood most of the day (e.g., feels sad, empty, hopeless) or observed by others (e.g., appears tearful). In children and adolescents, it may display as irritable.	Observe and assess for fluctuations in mood, worsening mood. Document in MSA/MSE, and in progress note.

Major Symptoms and Interventions of Depression

Symptom	Presentation	Intervention
Diminished Interest	No longer interested in any activities.	Encourage client to attend recreational groups and activities, even if it's passive participation. Connect with a recreational therapist for client-centered activities.
Weight loss	Significant weight loss, weight gain, or change in appetite.	Collaborate with a dietician to increase caloric intake, provide food or beverages that interest client.
Insomnia / Hypersomnia	Insomnia: difficulty falling asleep, waking up too early, waking up in the middle of the night, difficulty paying attention.	Assist with providing good sleep hygiene. Maintain routine times of waking up, going to bed, and regular timed meals. Connect with an occupational therapist. Advocate for and provide medication to aid with sleep. Provide medication if all other non-pharmacological interventions are not effective.

Major Symptoms and Interventions of Depression

Symptom	Presentation	Intervention
Psychomotor Agitation	Psychomotor agitation, slow speech, slow movement, slow thought processes.	Staff should allow adequate time to accommodate for slow movement and thought processes. Use of de-escalation techniques, distraction, and redirection if client becomes agitated. Offer medications if non-pharmaceutical methods do not reduce agitation.
Fatigue	Fatigue or loss of energy.	Encourage adequate food and fluid intake, low impact exercise or mobility.
Worthlessness / Guilt	Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional).	Provide validation for emotions and support. Connect with a psychologist or advocate for referral to psychotherapy/CBT programming. Build therapeutic relationships and rapport. Use positive affirmations change negative thinking processes. It is easier to change negative thinking processes if you have a therapeutic relationship and rapport with the client.

Major Symptoms and Interventions of Depression

Symptom	Presentation	Intervention
Lack of concentration / Indecisiveness	Diminished ability to think or concentrate, experiences indecisiveness.	Be mindful of the client's limitations at this time; providing patience, dignity, and respect. Be clear and speak slowly during interactions. Repeat important information. Provide frequent reminders.
Suicidal Thoughts	Recurrent thoughts of death, suicidal ideation, suicide attempts.	Perform daily or more (depending on facility's policies and client acuity) suicide risk assessment. Observe any environmental safety concerns, remove items that pose a risk. May need to advocate to increase observation depending on suicide and self-harm risk.

Interventions for Depression

- Reflect on your own personal bias, avoid including your own biases during interactions with clients.
- Encourage food and fluid intake, mobility, exercise.
- Provide psychoeducation for dietary and mobility needs.
- Encourage good sleep hygiene - routine schedule.
- Assess daily for MSA, specifically for mood fluctuations, improvements.
- Assess daily for suicidal risk assessment, thoughts of self-harm.
- Use the Recovery Model of care for treatment planning and interventions.
- Evaluate effectiveness of interventions, and revise plan of care as needed.
- Inform psychiatrist and interdisciplinary team for worsening mood, functioning, or suicide thoughts.

Treatment for Depression

Treatment for Depression: **Psychotherapy**

Cognitive behavioural therapy (CBT) is a psychotherapeutic treatment originally developed for depression. It is assumed that behaviour is mediated by one's thoughts. Therefore, changing the behaviour will affect one's thoughts, and vice versa. **The goal of CBT is to change a person's negative thought process.**

Treatment for Depression: **Pharmacology**

Antidepressants, typically **Selective Serotonin Reuptake inhibitors (SSRI)**, are prescribed for depression. If one medication is not effective, the physician trials another, until one of the medications improves depression symptoms with the least side effects. Antidepressants in general take 2-6 weeks to observe any improvements in mood.

Types of medications for major depressive disorder:

- Selective serotonin reuptake inhibitors
- Cyclic antidepressants
- Tetracyclic antidepressants
- Atypical antidepressants
- Monoamine oxidase inhibitors (MAOIs)

References:

Ontario Shores Foundation for Mental Health (2023). Common Mental Illnesses: Assessment and Documentation. *Major Depressive Disorder*. Ontario Tech University.

Obsessive-Compulsive Disorder (OCD)

Obsessions or compulsions are **time-consuming** (e.g. they take more than 1 hour per day) or cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

*It is important to note that OCD symptoms are not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition.

Obsessions:

- Recurrent and persistent thoughts, urges, or images that are experienced, at some time during the disturbance, as intrusive and unwanted, and that in most individuals cause marked anxiety or distress.
- The individual attempts to ignore or suppress such thoughts, urges, or images, or to neutralize them with some other thought or action (i.e., by performing a compulsion).

Compulsions:

- Repetitive behaviors (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly.
- The behaviors are aimed at preventing or reducing anxiety or distress, or preventing some dreaded event or situation; however, these behaviors or mental acts are not connected in a realistic way with what they are designed to neutralize or prevent, or are clearly excessive.

OCD Important Symptom & Presentation	
Symptom	**Presentation**
Intrusive thoughts (obsessions)	Recurrent and persistent thoughts, urges, or images that are unwanted, and causing high levels of anxiety.
Compulsive Behavior	Attempts to ignore or suppress unwanted thoughts with some other thought or action. Use of repetitive behaviour or mental acts in response to an obsession (for example, hand washing, prayer). Behaviour is time consuming and impacts social and occupational functioning.

Treatment for OCD

- Antidepressants are commonly prescribed, such as:
- SSRI
- SNRI
- CBT to augment medication therapy.

References:

Ontario Shores Foundation for Mental Health (2023). Common Mental Illnesses: Assessment and Documentation. *Obsessive-Compulsive Disorders*. Ontario Tech University.

Oppositional Defiant Disorder (ODD)

Definition: ODD is a behaviour disorder in which a person displays a pattern of angry or irritable mood, defiant or confrontational behavior, and vindictiveness toward people in authority. The exact cause of ODD is not known, but a combination of biological, genetic, and environmental factors may contribute to the condition.

Common behaviours:

- Throwing repeated temper tantrums
- Excessively arguing with persons with authority
- Actively refusing to comply with requests and rules
- Trying to annoy or upset others, or being easily annoyed by others
- Blaming others for mistakes
- Having frequent outbursts of anger and resentment

Behaviour Intervention Strategies:

Provide Choice

Demands may be better received if they are presented as a choice rather than a direct instruction. In this way, the client experiences an opportunity for control without having to engage in challenging behaviours. For example:

- Do you want to get dressed first or brush your teeth first? *vs*. Go get dressed then brush your teeth.
- Do you want to clean your room before or after supper? *vs*. Go clean your room.
- We have to put the shoes away and sweep – which one do you want to do and I will do the other one? *vs*. Go put the shoes away so I can sweep.

Avoid Power Struggles ('Time In')

- When the client shows dislike for a task or is argumentative, walk away. After a few minutes, return and ask them if they would like some help or ask if they are ready to follow through on the request. If they say they are not ready, inform him/her you will check in again in a few minutes.
- Remain **neutral** in your reactions and disengage when he/she starts to become argumentative. Inform them you will be available to talk *when they are ready* (i.e., time in). It is important to eliminate deliberate directives (demands) at this point. Any of the client's attempts to argue or engage in a power struggle are ignored, and he/she is merely reminded of how they can access the enriched environment of attention and control.

- As soon as they calm, staff should immediately praise the client for their efforts with self-regulating and making great choices.
- When they are showing agitation, calmly but firmly remind the client that you are on their side and are there to help them solve their problems calmly when they are ready.

Transitions (Changing from one activity to the next)

- Prepare the client with upcoming transitions by ensuring you have his/her attention and clearly stating the expectations (e.g., “In 10min, we are going to clean up to get ready for supper, sound good?”) and waiting for their acknowledgement before moving on.

References:

K. Barloso, Autism Parenting Magazine. Oppositional Defiant Disorder Treatment Plan (October 18, 2023). Accessed at: https://www.autismparentingmagazine.com/oppositional-defiant-disorder-treatment/

Mayo Clinic, Oppositional defiant disorder (ODD) (January 4, 2023). Accessed at: https://www.mayoclinic.org/diseases-conditions/oppositional-defiant-disorder/symptoms-causes/syc-20375831

ODD: A Guide for Families by the American Academy of Child and Adolescent Psychiatry: Oppositional Defiant Disorder (2009). Accessed at https://www.aacap.org/App_Themes/AACAP/docs/resource_centers/odd/odd_resource_center_odd_guide.pdf

Panic Disorder

When a person has **recurring rapid attacks** of intense anxiety, fear, and discomfort that becomes debilitating.

The table below outlines the major symptoms and appropriate nursing interventions:

Panic Disorder Symptoms & Intervention		
Symptom	**Presentation**	**Intervention**
Fear	Sweating, fear of losing control, fear of dying, restlessness.	Teach coping skills or strategies when patient/client is not in a heightened emotional state. Remind client of these strategies when in a heightened state. Provide privacy, decrease stimuli.
Derealization or depersonalization.	Patient feels detached from surroundings	During interaction, you may need to speak loudly, clearly, and slowly. You may need to repeat sentences multiple times.
Physiological Symptoms	Paresthesia, feeling dizzy/unsteady/lightheaded/faint, trembling, shaking, palpitations, shortness of breath, smothering, chest pain or discomfort, nausea, abdominal discomfort.	Use grounding techniques such as providing ice for bodily comfort, focus on the moment (mindfulness). Model deliberately slow breathing exercise to reduce physiological symptoms. Offer medication for anxiety if available and necessary.

Treatment for Panic Disorder

Best practice treatment is:

- **Selective serotonin reuptake inhibitor (SSRI)** and **Cognitive behavioral therapy (CBT)** (either on its own or taken together)
- **Benzodiazepines** for when the patient is in acute distress.

References:

Ontario Shores Foundation for Mental Health (2023). Common Mental Illnesses: Assessment and Documentation. *Panic Disorders*. Ontario Tech University.

Pica

Definition: Pica is an eating disorder where a person persistently eats or craves things that are non-food items. The behaviour must be present for more than a month, developmentally inappropriate or not culturally practiced. Items that are commonly eaten are: glass, paint chips, clay, cigarette butts, hair, feces, dirt, coins, ice, paper, grass, rocks, plaster and toys. Pica is not limited to this list and almost anything could be consumed.

Common health concerns:

- Parasites
- Damage to teeth
- High lead levels on blood from eating items containing lead
- Nutritional problems
- Poisoning from ingesting something harmful such as a household cleaner
- Infections in the mouth, stomach, or intestines

Supporting someone with Pica:

- make the environment safe
- redirecting individual when a non-food item is present that they may want to eat
- nutritional supplements
- restricting access to harmful items
- make sure all staff are aware of the diagnosis
- teach danger awareness skills to the individual
- teach different behaviours (picking up an item and throwing it away or putting it

Supporting someone with Pica (Continued)

- back in its place instead of eating it) and provide positive reinforcement when the appropriate choice is made
- skill building- teach the individual how to identify food from non-food items
- offer snacks on a consistent schedule
- vacuum or sweep floors daily

References:

Autism Speaks Autism Treatment Network, Autism Speaks, & Massachusetts General Hospital. (2014). *Pica* (p. p.1-1). https://thompsoncenter.missouri.edu/wp-content/uploads/2016/11/PICA-PROFESSIONALS-GUIDE_FINAL.pdf

George Timlin and Joanna Burden. (2017). *PICA Information Sheet*. https://www.sendsupported.com/wp-content/uploads/2017/09/PICA-doc.pdf

PICA - National Eating Disorders Association. (2024, March 22). National Eating Disorders Association. https://www.nationaleatingdisorders.org/pica/

Pica (eating non-edible items). (2023, November). https://www.cambspborochildrenshealth.nhs.uk/services/cambridgeshire-community-paediatrics/pica-eating-non-edible-items/

Prader-Willi Syndrome

Definition: This is a rare genetic condition in which the person has a constant sense of hunger. They want to eat constantly because they never feel full (hyperphagia). Many of the health complications that persons with Prader-Willi syndrome have are due to obesity.

Common signs and behaviours:

- Food cravings, excessive interest in food, and weight gain. This is almost always present and causes the individual to constantly seek food and eat food.
- Frustration, agitation, mood fluctuations, temper outbursts
- Needing to have things done a certain way, including in a particular order, time, or place
- Difficulty with changes in schedule or routine
- Difficulty transitioning from one activity to another
- Poor growth and physical development. Often short in height, low muscle mass and high body fat.
- Mild to moderate intellectual disability
- Speech problems
- Sleep disorders e.g. sleep apnea, which may cause daytime sleepiness and worsen behaviour issues.

Behaviour Intervention Strategies

- A supportive living environment sensitive to this problem of overeating is essential. They will require constant supervision to decrease overeating. Access to food should be as limited as possible. Constantly seeking food becomes an obsession. They may forage food that most people would consider inappropriate / excessive, such as a bag of sugar, frozen food.
- Consult with a dietician or nutritionist who can provide guidelines for healthy portion sizes for meals and snacks.
- Post the schedule of the day’s events & set of rules. Be sure to include meal and snack times so that the person knows when food is available. Read and discuss these events and rules at the start of the day so they are clearly understood. It is important to establish clear expectations that remain consistent day to day.
- Give praise and encouragement to ensure positive aspects of their day is recognized to help them feel successful and teach what behaviours will result in social validation.

- Access to food should not be contingent on behaviour i.e. do not use food as a reward. Instead, reinforcements (rewards) should be activities or items the client enjoys.
- Give transition prompts (e.g. 5, 3, then 1 minute "warnings") before moving on to the next activity.
- Less preferred tasks should always be followed by preferred tasks in order for the person to have something to look forward to. Again, do not use snacks or meals as reward.
- Provide concrete choices throughout the day.
- Avoid ambiguity e.g. instead of saying "later" or "in a while", say "after lunch at about 2:00".

References:

National Organization for Rare Disorders. Prader-Willi Syndrome (July 12, 2023) Accessed at: https://rarediseases.org/rare-diseases/prader-willi-syndrome/

Prader-Willi Syndrome Association. Applied Behaviour Analysis and Prader-Willi Syndrome, Part 1: Explaining ABA (October 3, 2018). Accessed at: https://www.pwsausa.org/applied-behavior-analysis-and-prader-willi-syndrome-part-1-explaining-aba/

Schizophrenia

What is Schizophrenia?

Schizophrenia is defined as a psychiatric disorder involving **chronic psychosis**. Little is known on what causes Schizophrenia, however, researchers believe that it may be a combination of the individual's brain chemistry, family disposition and environmental contributors.

Symptoms of Schizophrenia

There are not always interventions for the below symptoms, however, **seeing a decrease/absence of symptoms may indicate if a patient/client's medications are working**.

Positive Symptoms:

A change in behavior/thought which is observably present in a patient. These are delusions, hallucinations, and disorganized speech.

1.) Delusions

Described as fixed false beliefs; not culturally sanctioned, intensity can vary, described as though it exists.

Persecutory/paranoid: believes one is in danger, being followed/monitored, harassed/conspired against. May involve a government agency/family/neighbours/friends. If paranoid, they believe they will be harmed by others and will be exhibited by suspiciousness (ex. Need all food items to be unopened in order to take their medications)

Referential

Grandiose: patient believes that they have a special power/talent/abilities/identity (ex. They believe they are God)

Thought broadcasting/insertion/withdrawal

- **Somatic**: believes that one's body is diseased/changed (ex. Getting a cut means they are going to get staph infection and die)
- **Erotomania**: the patient believes they are loved intensely by the loved object (normally one who is married, with a higher socioeconomic status and/or unattainable)
- **Misidentification**
- **Religious**: preoccupation with religious ideas/behaviours
- **Control**: believes they have been taken over and are not under their own control (they have been possessed by ghosts)

2.) Hallucinations

- Hallucinations are a perception-like experience, without external stimulation of the sensory organ (can be any sensory modality). The patient is the only one hearing a voice/voices talking to them.

Auditory 👂

Visual 👁️

Olfactory 👃

Gustatory 👅

Tactile ✋

3.) Disorganized Speech

- Disorganized speech is indicative of disorganized thought process. This means that it's hard to follow a patient/client's train of thought or be able to respond coherently to questions asked.
    - **Loose Associations:** patient goes from one unrelated topic to another during conversation, unable to follow a logical/meaningful pattern.
    - **Perseveration**: keeps repeating the last word, phrase or ideas in response to different questions.
    - **Circumstantial**: extra, unnecessary, sometimes tedious details added. While there is a clear, recognized link between associations, the speech takes a circuitous route before reaching its goal.
    - **Flight of Ideas**: the patient is talking fast and continuously; the ideas go from one to another.
    - **Clang Associations**: puns/rhymes - speech is guided by sounds of words rather than the response making sense in response to the conversation/question asked (e.g. How now brown cow).
    - **Tangential**: similar to circumstantial but does not reach a goal.
    - **Thought Blocking**: sudden interruption with flow of speech. The patient may appear like they are having a hard time completing their thought - may not recall what they were talking about.
    - **Word Salad**: extreme form of loose associations; speech is incomprehensible and incoherent because of lack of logical and meaningful connection between words.
    - **Concrete Thinking**: literal thinking; unable to think abstractly and interpret simple proverbs.
    - **Neologisms**: making up nonsensical-sounding words (ex. I 'examplishied' the food).
    - **Perseveration**: persistently repeating the last word, phrase or ideas in response to different questions.

Negative Symptoms:

Negative symptoms are functions that have been diminished or are not present in the patient.

1.) Lack of Motivation

2.) Diminished emotional expression

3.) Apathy

4.) Lack of energy

Treatment for Schizophrenia

Antipsychotic medications are part of the main line of treatment for individuals with schizophrenia, along with Cognitive Behavioral Therapy (CBT) in helping with residual symptoms. The family/caregiver should also be provided support as **Schizophrenia is a lifelong illness**.

Inpatient Treatment:

- Conducting a Mental Status Assessment on a daily basis - helps to establish a patient's baseline and deviations from it. Always assess for risk
- When symptoms prove to be excessive/environment may be overstimulating the patient → decrease stimuli, provide distractions such as music, accompany the patient for a walk, ask the patient what can help. Medications should not be the first line of nursing interventions

Outpatient Treatment:

- ACTT (Assertive Community Treatment Teams)
- Community Treatment Orders
- Long-Acting Injections
- Substance use treatment as Schizophrenia may be accompanied by concurrent disorders

References:

Ontario Shores Foundation for Mental Health (2023). Common Mental Illnesses: Assessment and Documentation. *Schizophrenia*. Ontario Tech University.

Social Anxiety Disorder

Social Anxiety Disorder refers to a high level of anxiety/fear during or around social situations.

The table below outlines the major symptoms and appropriate interventions:

Social Anxiety Symptoms & Intervention

Symptom	Presentation	Intervention
Avoidance of Social Situations	Tries to leave social situations before or while they occur.	Promote participation, can be passive participation in group programming. Provide exposure and routine to social situations. Promote use of items that may distract the client during social situations, such as an item that can be used as a fidget device.
Fear and feelings of anxiety	They fear that anxiety symptoms that will be negatively evaluated, and lead to rejection by others.	Assist by changing negative cognitive constructs to positive ones. For example, if voicing thoughts that people are not enjoying their company, you can say that their company has been pleasant.

Treatment for Social Anxiety Disorder

Treatment may fall between Cognitive Behavioural Therapy (CBT) and/or medication (SSRI or SNRI) for initial therapy, based on availability and patient preferences.

References:

Ontario Shores Foundation for Mental Health (2023). Common Mental Illnesses: Assessment and Documentation. *Social Anxiety Disorder*. Ontario Tech University.

Stepping into the Role of Direct Support Professional

Please find below the following resources for this section:

- HANDS & Vita CLS - The international Journal for Direct Support Professionals: Volume 9 – Issue 3 – March 1, 2020 (6 pages)

References:

The international Journal for Direct Support Professionals. Volume 9 – Issue 3. (March, 2020). HANDS & Vita CLS. Attached

Volume 9 – Issue 3
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The International Journal for Direct Support Professionals

Stepping into the Role of Direct Support Professional

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You have worked hard for the past two years, learning theories, discovering new ideas, and studying late into the night – now you have graduated from college and are just about to embark on your new career supporting people with disabilities. As new direct support professionals (DSPs) we know there can be many challenges – it can feel like you're just being thrown into the job. After three days of orientation training, you find yourself on your own; it can be intimidating to feel the pressure of all this new responsibility in your hands. Having a few months under our belts now, we are ready to share what we learned as we stepped into the role of direct support professional. We found that it helps to remember that you will be okay, you will recall what you learned during your college courses, you will make a positive difference in people's lives, and you will make it through the shift work with no sleep – just depend on that coffee for a little bit longer. Here is some advice we can offer as rookies to the field!

Build Strong Connections

Making connections is something that starts from day one. Get to know each person you support by spending time with them, really be present with them so that you get to know that person's unique interests, personality, and preferences. Do fun activities together that they enjoy whether that be baking cookies, going for a walk, or doing crafts. Although reading 'the file' may be a part of your orientation and can provide important information, it does not tell you who this person is. In fact, the file may end up tainting your perception of the person you are supporting. One of us read a file during our first days on the job in which the person's doctor had written about how unattractive they were, and that he had 'low social status.' What a horrible way to be 'introduced' to someone! Do not base your opinion of this person on other people's biases, rather, be sure to build your own connection with people – one that is based on empathy, relatedness, and finding common ground. Use your own life experience to understand the people you are supporting. Your own difficult life experiences can help you to relate to people you support who also have had tough things happen to them – use your experiences to build these connections. Do not take the spotlight or make it about you, but your perspective may be valuable as someone who has gone through something similar.

**Editors: Dave Hingsburger, M.Ed.
Angie Nethercott, M.A., RP**

Hands | Mains
TheFamilyHelpNetwork.ca
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vita
community living services
mens sana
families for mental health

Building connections with your coworkers is also important to invest in from the beginning. Ask for insights from other staff – “How do you handle this?” “Have you experienced this?” Don’t be afraid to ask for help and advice from your coworkers, they may be able to provide much needed perspective or offer particularly useful suggestions. Strong connections with a supportive team of coworkers also support your personal wellness as you share experiences, struggles, and insights. As professionals, we need to remember to effectively support each other to prevent burnout. Relying on this interdependence can create a healthy work environment for everyone.

Another area to build connections – or use the ones you already have – is in your community. Your connections with people in your community can help to create access. If you are a member at the local curling club, get to know the guy who organizes volunteers to help out at community events or, if you are aware of a great group of folks that get together to walk their dogs every Monday, you may be able to connect those you support to some great social opportunities.

Don’t be afraid to ask questions

Getting started can be very overwhelming – paperwork, reading files, getting to know each person, and connecting with staff. With all of that comes lots of questions that you should not keep to yourself – the more you know, the more comfortable you will be in your transition to your new experience. Use your training with supervisors and other staff to the best of your advantage. Be honest with yourself and with your coworkers about your challenges and comfort level, while ensuring that you are open to learning what you need to know. Check things out with your coworkers but know too that they are not the only source of information in the place that you are now working. When one of us was working a first overnight in an unfamiliar house, many questions came up that we had not anticipated. Some were answered by reading files but, the one thing that was most helpful was asking the people who lived in the home about their routines, the support they needed, and what they preferred to do.

Although other, more experienced staff can be an excellent resource for you, you may also feel at times that your ideas get dismissed or not taken seriously because of your newness. Respect their experience but also make sure that you value your own knowledge and understand that it is okay to question anything that does not feel right.

Responsibility and Mistakes

Each of us has had that moment early on when we think to ourselves, “I can’t believe they’re letting me do this by myself!!” There is a lot of trust put into DSPs, and it is up to us to uphold the standard. We can trust in our education, our training, and our judgment to meet the responsibility we are given. However, college does not always prepare you for the little hiccups that happen along the way; for instance, the first time one of us used the company credit card, the wrong PIN number was given, and this ended up resulting in a frozen credit card. Each of us has a similar story of getting the work truck stuck in a snowbank, taking home the only keys to the program, or getting lost while driving people somewhere important. Recognizing that mistakes will happen, and that you will figure it out is part of the learning experience, as is taking responsibility for that mistake, apologizing, and ensuring it does not happen again.

Bring Yourself to Work

People will be more drawn to you if you are genuinely yourself when interacting with them; this is the best start to building a strong rapport. Often people think that, as a DSP, you have to be constantly perky and outgoing to keep things entertaining for those you support. While it is important to always bring your best self to work – make sure it is also your true self, otherwise you risk burn out. Some of us are naturally quiet people and have learned that this is often a gift rather than a detriment in our work. We have found that many people respond very positively to someone who brings a calm and quiet presence to an often busy and even chaotic environment. Sometimes silence is key – your calm presence can be much more beneficial in times of crisis than someone who jumps in talking, often overwhelming the person. Fixing the problem is not always the best place to start – listening is a better first response.

Occasionally, we may feel genuinely disgruntled, or frustrated, or exhausted. In these situations, it is necessary to remember that the people you are supporting deserve your very best, and it is up to you to pull that out of where you may be feeling in that moment. Check your attitude, the things that are worrying you, the annoyance you felt at the construction you encountered on your drive in and take a deep breath. Remember your mood can set the tone for someone else’s entire day. If those attitudes, worries, and annoyances are really important to you, you can pick them up again after your shift but, in the meantime, step back from them and focus on the work you are called to do today.

Know Your Role – and Your Boundaries

It is easy to start off in this field thinking that our job is to be friends with people with disabilities. We learn in college that, while we hope to have a friendly relationship with the people we support, our role is quite different than that of a friend. Friends are not paid to be with people, and don’t collect data on their friend’s behaviours and don’t leave when a position with better hours comes along. We found that was important to remember when we started working – you will likely really enjoy the people you are supporting and may be anxious to show them how likeable you are. We want them to like us, but we need to be honest about our relationship. We like each other and enjoy spending time together, but it is not the same as friendship. It is important to start off with clear boundaries – and be able to communicate these boundaries without offending or seeming mean.

Equally important is not to assume we are in a position above the person we support. It can be helpful to remember that we are working for the people we support; it’s a professional relationship rather than a friendship. We have found it important to get to know what respect means to the people we are supporting and demonstrate that – respect is an excellent deterrent to power trips. It is also okay if someone does not like us – our job is to support not befriend. In this case, it is necessary to be self-reflective, asking ourselves, “Is it just that we are different people with different interests, or am I doing something that annoys or triggers them?”

Speaking of Self-Reflection…

We highly recommend making self-reflection a daily habit. There are different ways to do this – it may be in the car on your way home from your shift, it may be through conversation with a trusted coworker, or it may be in writing via a journal. We find that regular self-reflection ensures that we are continuously learning, recognizing that everything, every day is a learning opportunity. Self-reflection can often lead to a better understanding of our own motivations or where we might do something differently or better next time. Those of us that choose a written form of self-reflection find it can be useful to go back and review how we coped with a previous situation, or all that we have learned over the past few months.

Be Open to Awkward Moments and Being Surprised

It can be surprising when people you support have questions about their bodies, or feel awkward when they ask about something to do with sex. We did not expect sex to be such a big topic, and often felt timid when the subject came up, being unsure of how to respond. When working with teens and adults though, these questions are common and reflect the natural sexuality of all people. Taking the time to listen to what they are saying, having a sex-positive attitude, and supporting people to find resources to answer their questions helped to increase our comfort level and build trust. We have learned to follow the person’s lead, ensuring they lead the conversation, while also making sure they know we are open to discuss these things with them without bias or judgment.

Another surprise was around providing personal care. For some of us, this was something we just did not see ourselves doing, especially when our only experience of it was in a lab with mannequins at school. However, after graduating and finding ourselves working in situations where personal care is needed, we learned the importance of being honoured in this aspect of our jobs as in all other aspects. When supporting people in personal care routines, it is essential to make sure the person is comfortable with you and the way you are supporting them. We do this through taking our time, asking the person for both direction and permission all through the process and, where the person is okay with it, making the task fun with chatting, listening to music, and respectful humour. We went from being nervous about having to provide personal care support to recognizing it as simply another type of support a person may need.

Make Time for Fun

There is more to life than doing laundry, dishes, and cleaning the floors. As new staff, we can get caught up in the duties that need to be checked off the list, sometimes forgetting that the most important work is connecting with the people we are supporting. Check to see if the person you are with is happy – do they experience happiness frequently? What brings them joy? If there isn’t something immediately obvious that makes them happy, work on filling that gap. If there are things that you know make them happy – do those things with them. Chores can wait – maybe not forever, but at least until a little fun has been had.

Prioritize Personal Wellness

We will wrap up our list of things we have learned with wellness – not because it belongs at the bottom of the list – but because ensuring time for focusing on our personal wellness has been something so important to us that we wanted to leave you with this as a lingering thought after you close the article and continue doing the work that you do. The job we do is rewarding but can also be challenging and sometimes draining. As a DSP, we experience a diverse and intense series of emotions – both our own and those that the people we support share with us. It is important to acknowledge how these can affect us. It is perfectly okay, even essential, to have that trait of empathy right on our tool belt, but it is also necessary to know how to process the emotional work that we do. As fellow DSPs, we can relate to how much you as the reader want to help people but remember, ultimately, when it comes down to it, you will not be able to support others effectively if you do not take care of yourself. Make personal wellness a priority. Take time to be quiet, to do something completely separate from work, like play with your pets, read a good book, take a walk in the forest, eat well, and get enough sleep. But also, do not let yourself become a hermit – you need a social support system. Get out with people! Plan time to spend with friends. Go to the beach. Modelling personal wellness is also great support work – practice wellness so that you can support wellness.

About the authors

Jodie, Susie, Kate, Shakira and Tyler all graduated from Nova Scotia Community College's (NSCC) Disability Supports and Services Program earlier this year and are now employed as direct support professionals in a variety of roles at various organizations on the south shore of Nova Scotia.

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Answers to FAQ's about the journal

1) The journal is intended to be widely distributed; you do not need permission to forward. You do need permission to publish in a newsletter or magazine.
2) You may subscribe by sending an email to dhingsburger@vitacls.org
3) We are accepting submissions. Email article ideas to either the address above or to anethercott@handstfhn.ca
4) We welcome feedback on any of the articles that appear here.

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vita
community living services
mens sana
families for mental health

Trauma

Please find below the following resources for this section:

- Chanda Dunn - Trauma and Individuals with Intellectual and Developmental Disabilities (2 pages)

References:

Chanda Dunn. (2018). Trauma and Individuals with Intellectual and Developmental Disabilities. *University of Tennessee Center on Developmental Disabilities, Vanderbilt Kennedy Center for Excellence in Developmental Disabilities*. https://vkc.vumc.org/assets/files/tipsheets/traumatips.pdf

Trauma and Individuals with Intellectual and Developmental Disabilities

TIPS AND RESOURCES

What is trauma?

Trauma is understood as experiences or situations that are emotionally painful and distressing. Trauma can overwhelm an individual's ability to cope, leaving him or her to feel powerless. Adverse childhood experiences (ACEs) describe traumatic experiences in a person's life occurring before the age of 18.

Examples of traumatic events that can have lasting impact on an individual's ability to cope and their psychological well-being include: global disasters, unexpected loss, physical, sexual, and emotional abuse, neglect and abandonment, divorce, parental incarceration, substance abuse in the home and gun violence.

People respond to traumatic events differently. The long-term effects of painful experiences can vary, even in the brains of individuals who have experienced the same exact event. Successful navigation through traumatic events occurs most often when the individual has a support system in place; be that personal and/or professional.

What are developmental disabilities?

Developmental disabilities are conditions that are typically diagnosed in childhood and limit functioning in thinking, learning, growing, behaving, communicating, feeling, and relating. Developmental disabilities include conditions like autism spectrum disorder, brain injury, cerebral palsy, Down syndrome, fetal alcohol syndrome, intellectual disabilities, and attention-deficit/hyperactivity disorder, and spina bifida.

Are individuals with developmental disabilities at risk for trauma?

Individuals with intellectual and developmental disabilities (IDD) experience traumas. The forms of trauma most commonly experienced among people with IDD include:

- Adverse Life Events: poverty, abuse/neglect
- Social: bullying, name-calling, other forms of verbal abuse
- Restraint and Seclusion
- Victimization specifically during violent events and crimes
- Institutionalization including foster care placements
- Abandonment/Isolation
- Loss of parent of caregiver

How to recognize trauma in an individual with IDD

Individuals with IDD experience a variety of trauma-based responses similar to those who do not have an IDD. The impact of trauma exposure on individuals may have:

- Cognitive effects: memory problems that may include gaps in time or even gaps in personal history; difficulties acquiring new skills or processing new information; poor verbal communication skills as a result of deficits in language development and abstract reasoning skills.
- Physiological effects: stomachaches and headaches; nightmares or difficulties with sleep; regression of milestones (loss of acquired developmental skills); bed-wetting and soiling.
- Behavioral effects: aggressive externalizing behaviors; acting out in social situations such as screaming or crying excessively; irritable mood, sadness and anxiety; verbally abusive behavior; fearful and avoidant of people or situations.

For an individual, dealing with the ongoing effects of the trauma is often more painful than the original event. Long after the event has passed, the brain may keep alerting the body to escape a danger that no longer exists. Feeling unsafe, the body may respond through:

- Flight: shaking legs, anxiety/shallow breathing, big/darting eyes, fidgety-ness, restlessness, feeling trapped, tense.

Trauma and Individuals with Intellectual and Developmental Disabilities

TIPS AND RESOURCES

- Fight: crying, hands in fists, flexed/tight jaw, grinding teeth, snarl, fight in eyes, glaring, fight in voice, desire to stomp, kick, smash with legs, feelings of anger/rage, homicidal/suicidal feelings, and knotted stomach/nausea.
- Freeze: Feeling cold/frozen, numb, sense of stiffness, heaviness, holding breath/restricted breathing, sense of dread, heart pounding, trying to hide (which can be mistaken for non-compliance).

These responses to past traumas in the body may occur due to present triggers such as use of restraints, teasing, parental tones, judgments, labels, sarcasm, rejection, lack of relationships, inappropriate touching, and lack of attention, loss, death, and staff turnover.

What types of treatments are available?

People affected by trauma can feel unsafe in their bodies and in their relationships with others. Regaining a sense of safety, creating a new sense of self, and redefining oneself in the context of meaningful relationships are the necessary steps toward recovery.

While there is not an adequate amount of research on how to best adapt current trauma treatments for individuals with IDD, there is promise in a variety of common interventions. Eye Movement Desensitization and Reprocessing (EMDR), Positive Identity Development, Parent-Child Interaction Therapy, Psychodynamic Psychotherapy, and adapted Trauma-focused Cognitive Behavioral Therapy (CBT).

Learning how to relax the body and calm the mind may also help in building stronger coping skills. Yoga, walking outside, sitting quietly, taking calming breaths, mindfulness, and meditation are some examples of common relaxation practices.

Techniques that may help clinicians deliver effective treatments to individuals with IDD

- Understand differences in developmental and chronological ages
- Speak slowly and clearly
- Introduce tasks, information, and skills one at a time and avoid compound statements
- Allow time for practicing skills, which may take time before competency is met
- Utilize caregivers in treatment
- Avoid assumptions in comprehension. The individual may say “yes” or nod even when they don’t understand
- Utilize repetition in unique and creative ways
- Increase parent’s education about behavioral issues as well IDD
- Conduct thorough, developmentally appropriate and in-depth assessments

Resources

- **National Child Trauma Stress Network** Established to improve access to care, treatment, and services for traumatized children and adolescents exposed to traumatic events. www.nctsn.org
- **Tennessee Disability Pathfinder** Provides free information, resources, support, and referrals to Tennesseans with disabilities and their families. Assistance in multiple languages available. (800) 640-4636, TNPathfinder.org
- **University of Tennessee Center on Developmental Disabilities**: (901) 448-6511, toll-free (888) 572-2249, uthsc.edu/cdd
- **Vanderbilt Kennedy Center for Excellence in Developmental Disabilities**: (615) 322-8240, toll-free (866) 936-8852, vkc.vumc.org/ucedd

This tips and resources fact sheet is a product of the University of Tennessee Center on Developmental Disabilities (Chanda Dunn, LCSW) and the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

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