

MODULE EIGHT



Primary Disabilities and Secondary Disabilities

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Primary Disabilities and Secondary Disabilities

OVERVIEW

Due to damage to the central nervous system (CNS) during fetal development, individuals with FASD experience several primary disabilities. These are characteristics that a person has at birth due to prenatal exposure to alcohol. Effects of these may show up at varying degrees throughout a person's life, depending on their stage of development.

Secondary disabilities are not present at birth. Unlike primary disabilities, they occur after birth. Primary disabilities and the challenges that these present, interact with the environment surrounding the individual (e.g., social and family) and can play a role in the development of secondary characteristics.

In some literature, you will find that these terms are referred to as primary and secondary neurobehavioural characteristics. There is a shift to change to this terminology for two reasons. First, the characteristics listed below are a direct result of damage to the individual's brain. Secondly, this language provides a more comfortable and respectful base of understanding from which accommodations can be made.

Individuals with FASD have on and off days and this can be a source of frustration for the individual, caregivers and other professionals working with them. For example, one day a child may be able to understand and carry out complex instructions, but they may not be able to do this the next day. This is difficult for an individual with FASD. Sometimes they exceed others in their age groups on certain tasks and at other times they will fall far below them on the same tasks.

The effects of FASD can be equated to the domino effect, with one effect having an impact on other areas. To fall a row of dominos, all pieces are lined up so that when the first one is knocked over the rest fall in sequence. Each domino acts in coordination with other dominos, and each is an essential part of the structure. If we were setting up dominos that resembled FASD, individual pieces would be placed randomly. When the first was knocked over, it would not necessarily knock the group down in sequence. Instead, dominos that fall would scatter in different directions and some dominos would remain upright.

For example, children who cannot remember what they were doing earlier in the day may tell stories instead of admitting that they do not know. If children are weak in cause and effect reasoning, they may not be able to think through the consequences that telling stories may have. If they do not understand time, they may not have been able to piece together when it was morning.

Another example of this can be seen with language comprehension skills, which have been found to decrease as children with FASD age (Rasmussen, Horne & Witol, 2006). This may be because older children, adolescents, and adults use more complex language. In order to comprehend language, individuals must also use skills in memory, understand concepts, understand body language, link cause-and-effect, and be able to generalize. Language development and comprehension relies on basic information encoded early in the learning process (Mattson & Roebuck, 2002).

PRIMARY DISABILITIES

Primary disabilities refer to the characteristics and birth defects an individual is born with due to prenatal exposure to alcohol. These are due to damage to the brain during fetal development. Primary neurobehavioral characteristics may impact cognitive, behavioural, or physical/sensory functioning (FASD Support Network of Saskatchewan, 2007).

Cognitive Function

Cognitive function refers to the intellectual processes and mental tasks like thinking, reasoning, and remembering. The following are areas of common *cognitive impairments* caused by FASD:

- lower IQ, specifically in the areas of language comprehension and mathematics (Rasmussen, Horne & Witol, 2006)
- conceptual and abstract thinking (Mattson & Roebuck, 2002; Saskatchewan Learning, 2004; Schonfeld, Mattson, Lang & Delis, 2001)
- cause and effect reasoning (Burden, Jacobson, Sokol, & Jacobson, 2005; Carmicheal Olson, Morse & Huffine, 1998; Saskatchewan Learning, 2004)
- generalization (Burden et al., 2005; Koditwakku, Kolberg & May, 2001; Schonfeld, Mattson, Lang & Delis, 2001)
- time (Saskatchewan Learning, 2004)
- memory (Mattson & Roebuck, 2002; Saskatchewan Learning, 2004)

Conceptual and Abstract Thinking

Concepts are the ways that humans organize and make sense of the world (Eysenck & Keane, 2005). For example, we have a general concept for “table” and all items that fit into our concept of table are called such. We do not call each table we see something different because one table looks different from another. Concepts can be concrete, organizational, social or abstract.

- **Concrete concepts** are those that can be experienced with the five senses. They can be seen, touched, smelled, moved, and heard. Concrete concepts do not stand alone, but consist of many concepts. For example, the concept of “cup” also contains the concepts of a handle or no handle, clear or opaque, a mug or a cup, and glass or plastic.
- **Organizational concepts** are rules and structures that make small units part of a bigger structure. For example, to understand how a non-digital watch works you have to understand that the numbers represent hours, that there are 60 minutes in every hour and that there are 60 seconds in every minute. You also have to understand that the space between each number is equal to 5 minutes. Organizational concepts include time, numbers, money, phonics, colour, patterns, and measurement. Organizational concepts are hard because they can hold multiple meanings in multiple contexts. For example, “blue” can mean light blue, dark blue, feeling blue, turning blue from lack of oxygen, and singing the blues.
- **Social concepts** are rules that define and set limits. They are made by and for human beings. These allow individuals to relate to one another and provide a code of behaviour so that we can function in our communities and in interpersonal relationships. Social rules change with time and situations. An example of a social concept is an understanding of consequences. Social concepts include, but are not limited to: truth, honesty, social manner, equality, hygiene, nutrition, respect, responsibility, and trust.
- **Abstract concepts** are thoughts or knowledge that are apart from, but connected to, a real concept. For example, a lump of sugar (concrete concept) is sweet (abstract construct). Abstract thinking allows a person to look forward, to plan, and to think critically. Conditional words are also considered abstract concepts e.g., “why” and “if”. Conditional words modify or adapt the meaning of a sentence. They change associations, provide small bits of information, and are contingent on an uncertain event (FAS/E Support Network of BC, 2002)

Cause-and-Effect Reasoning

Cause-and-effect reasoning requires reflection, an understanding of all the facts, accepting responsibility for actions, and forward thinking (Eysenck & Keane, 2005). Cause-and-effect thinking is the root of empathy, understanding consequences, being motivated, and impulse control. Difficulty in this area causes an individual to: live in the present, be impulsive, not accept responsibility (as they cannot link outcome to themselves and their behaviour), and be unmotivated. For example, “If (*abstract*) I pull Sally’s hair (*concrete*) then (*time*) she (*concept*) will...tell on me, yell at me, pull my hair (*future*). This example requires an understanding of concrete concepts, social concepts such as right/wrong, and abstract concepts (conditional words: if).

Generalization

Generalization is the ability to take what we have learned in one situation and apply it to another. For example, I touched the stove at my mom's house, it was hot and I burned my hand. Therefore, the stove at my grandpa's house might hurt me too and therefore I will not touch it. Generalization is the basis of decision-making, problem solving, and choices (Eysenck & Keane, 2005). In order to generalize, an individual must first understand the concepts of the original situation, understand cause-and-effect reasoning, learn the link between the two situations, and be able to connect this lesson to the new situations. All adaptive functions, life skills, language comprehension, and social interactions require that generalization be applied. If we did not generalize, each lesson would have to be relearned for every new situation a person encounters. By generalizing, people learn to adapt to new situations by finding similarities to past situations. Generalizing requires that people think quickly, react quickly, and be flexible thinkers.

Some examples of generalization may help to demonstrate where deficits in this skill may be problematic:

- if a rifle is dangerous, then a handgun will be too
- if you can read this book then you probably can read that one
- if you forget your pencil, you can probably borrow one
- if I got in trouble for being late today, I will probably get in trouble if I am late tomorrow
- if I poke the cat, he scratches me. If I pull his ear, he will probably scratch me too
- when I pushed #2 from that team, I got a foul so if I trip #5, I will probably also get a foul
- if I like spaghetti, I will probably like penne

Problems with generalization result in inflexibility. New routines or situations (even if they differ only slightly from other routines or situations) can seem entirely new, and past learning is not applied to help the person adapt. It is hard for a person with problems in this area to think about alternative behaviours or actions. This leads to frustration and difficulty understanding personal limitations. Critical thinking, reasoning, social interactions, problem solving, adaptation, comprehension, judgment, and insight each rely on the ability to generalize.

Time

Time provides structure and stability. It is the way that we relate to others and to our environment. It allows us to function properly, to work, to complete tasks, to engage in social interactions, and to take care of ourselves. Time, for many, becomes internalized. We know how long it takes for us to complete our morning routine and can get ready for work effectively without constantly looking at the clock. Usually, we just look at the clock for confirmation (FAS/E Support Network of BC, 2002).

If a person does not have an internal sense of time, instructions may not make sense, appointments may be missed, there is no understanding of the concepts of past and future, and everything becomes the immediate. For example, if you have no sense of time and were told to be ready to leave in 15 minutes, this may prove an impossible task without prompting. Not only is an understanding of time needed for day-to-day functioning, but a person must also understand concepts of time to comprehend language. The following are concepts of time used in our language: after, always, early, first, if, late, middle, never, until, beginning, before, end, future, last, maybe, next, someday, tomorrow, and when. In order to understand the concept of time being measured, a person has to understand multiple concepts, including:

- the concept of time is something that governs events and it occurs even though we cannot see, touch, smell, feel or hear it
- understanding the numbers 1 – 12 and their sequence forwards and backwards
- before and after concepts (e.g., one o'clock comes before two o'clock)
- early and late, both in terms of the time of the day and in terms of meeting timelines
- the relationship between seconds, minutes, and hours (as discussed in an earlier example)
- time is measured in many cycles, and they all are called one. 1 minute = 1 minute, 1 hour = 60 minutes, 1 day = 24 hours, 1 year = 8760 hours.
- having a physical awareness of time passing, such as feeling tired as it gets closer to bedtime
- being aware of your surroundings and clues that they give about time (e.g., the bell rang and the other children are lining up, so recess must be over)
- being aware of how much time it takes to do things
- being aware of the different words used to describe time (e.g., quarter to 12 = 11:45 = 15 minutes before 12 = 45 minutes after 11)
- understanding AM and PM
- understanding right and left
- half hour = 30 minutes
- two hands represent different things but point at the same things
- every hour and every minute happens twice in one day

Memory

Memory is essential to survival. Memory helps us learn through trial and error, past consequences, and informal and formal lessons. Memory provides a “road map” so that we can adequately negotiate every day living as well as new situations. Generally, two different types of memory are looked at in the area of FASD. They are:

- **Procedural (implicit) memory** which is recalling how to do something (e.g., ride a bike).
- **Declarative (explicit) memory** which is recalling information that is applicable to a new situation and that can be generalized. Difficulty in this area can create large problems in adjusting to the world surrounding us and functioning on a day-to-day basis (Eysenck & Keane, 2005).

Declarative memory helps us to be able to think of many things at the same time and still accomplish what we need to. For example,

- thinking about a presentation you have to give, WHILE
- walking down the hallway to a meeting, WHILE
- saying hello to a colleague, WHILE
- making sure you are going into the right room, WHILE
- scanning to see who is already there; WHILE
- getting coffee, WHILE
- thinking about what you will have for dinner that night; WHILE
- sitting down to listen

When individuals have problems with concepts they may not understand the meaning of a situation. We store memories based on meaning, concepts, or situations. This can lead to inappropriate action or comments. Problems in memory can cause the individual to live in the here and now. In a way, the saying 'fly by the seat of your pants' is essentially what someone without the ability to draw on and generalize from memory must do. Problems with memory can also cause confusion about identity affecting self-concept, sense of belonging and self esteem.

Behavioural Function

Human behaviour is highly variable and includes an assortment of actions, reactions, voluntary, and involuntary activities all controlled by brain functions. Behaviour is related to social and emotional development and is visible through social and emotional interactions. The following are areas of common *behavioural impairments*:

- interpersonal skills (Carmicheal Olson et al. 1998a)
- reading social cues (Carmicheal Olson et al., 1998a)
- impulsive actions (Saskatchewan Learning 2004)
- emotional regulation (FASD Support Network of Saskatchewan Inc., 2007)
- rigid and inflexible behaviour patterns (Rasmussen et al., 2006)
- sleep problems (Chudley et al, 2005)
- over-activity/attention problems (Rasmussen et al., 2006)
- dysmaturity (Malbin, 2008)

Interpersonal Skills

Interpersonal skills are needed to function in society. They are used in every interaction that a person has within a family, with friends, in school, with colleagues, and during casual interactions. Interpersonal skills include intuition, interpreting context, communication, following social norms, and reading body language.

Several areas that are impacted by FASD are needed to relate with others, such as memory, problem solving and the ability to generalize (McGee, Fryer, Bjorkqvist, Mattson & Riley 2008).

Impulsive Actions

Impulsiveness has long been seen as one of the key behaviours associated with FASD. Research suggests that such problems are the result of problems encoding and retaining information (Leech, Richardson, Goldschmidt, & Day, 1999).

Dysmaturity

Dysmaturity can be defined as being “socially or developmentally younger than chronological age” (Malbin, 2002, pp 22). Children and adolescents with FASD often display behaviours which are seen as “inappropriate for their age”, but which may actually reflect their *developmental age*. Unfortunately, the goal of most parenting and professional interventions focus on helping children “act their (chronological) age”. The interventions may be ineffective and/or inappropriate and may become the source of frustration for children and adolescents with FASD. It takes children with FASD longer to grow up. If they are supported developmentally, frustration may be prevented (Malbin, 2008, pp 37).

Physical and Sensory Impairments

From the time of conception until the time of death, each human continuously develops and changes physically. Physical development includes growth of the body, body organs, body systems, sensory system, and motor development.

The sensory system begins to develop during gestation and continues to develop throughout childhood. The human sensory system allows us to take in information about where we are in the world and what is going on around us. The brain receives information from each of the five senses as well as proprioception (sense of body position) and vestibular input (sensation of movement).

The following are areas of common *physical* and *sensory impairments*:

- delayed motor development (Mattson & Riley, 1998)
- poor motor control (Chudley et al., 2005)
- lower weight and height (Chudley et al., 2005)
- hearing impairments (Saskatchewan Learning, 2004)
- auditory processing problems (Rasmussen et al., 2006; Saskatchewan Learning, 2004)
- damage to various systems (e.g., skeletal) (Saskatchewan Learning, 2004)
- high or low pain tolerance (FASD Support Network of Saskatchewan Inc., 2007)
- sensitivity to light, sound, texture, or stimulation (Saskatchewan Learning, 2004)

Motor Control

Motor control challenges associated with FASD can affect balance and fine motor control. For those who have been heavily exposed to alcohol prenatally, this remains throughout the lifespan and is accompanied by other neuropsychological effects. For those with minimum exposure, the effects seem to lessen as the child grows (Connor, Sampson, Streissguth, Bookstein & Barr, 2005).

Auditory Processing

Auditory processing relies not only on the amount of information someone can hear, but also the way that they interpret or process the information. Problems with concepts (particularly organizational, abstract and social) can affect auditory processing. For example, when starting a sentence with an abstract concept such as 'if', an individual who has deficits in the area of understanding such concepts will be immediately lost. Complex concepts and compound sentences or instructions will not be processed properly. Auditory processing also relies on memory of concepts, past events, social interactions, and the ability to generalize. For example, a mother tells her child to clean his room. She is relying on the fact that the child remembers past occasions when they have cleaned his room together so that he can perform this task by himself.

Auditory processing also relies on the length of time someone is able to maintain attention. For example, instructions broken into simple steps and given one step at a time will be easier for someone with attention problems to follow than complex instructions with several steps relayed at one time.

Remember

Each individual with FASD will be affected differently from prenatal alcohol exposure, and the impact of the primary disabilities listed above will differ from person to person.

SECONDARY DISABILITIES

Individuals living with FASD are living in a world that often does not "fit" them very well. Society often does not recognize their primary disabilities or understand their unique blend of strengths and struggles. Over time, this persistent lack of understanding combined with high unattainable expectations, ineffective support strategies, and limited accommodations leads to a state of chronic "poor fit" (Malbin, 2002). This can result in secondary disabilities.

Secondary disabilities arise later in life and develop over time as the individual living with FASD matures. When demands and high expectations of others that cannot be met because of brain differences are placed on individuals with FASD, they repeatedly experience failure. Continued failure in an environment that is confusing, overwhelming, and frustrating contributes to the development of secondary disabilities.

Secondary disabilities include (Streissguth, 1997):

- involvement with the legal system
- mental health concerns
- trouble with the law and confinement
- inappropriate sexual behaviour
- substance use and misuse
- trouble at home
- trouble in school or in the community
- social services involvement

Mental Health

Research has shown that youth and adults who were prenatally exposed to alcohol have a high incidence of psychiatric disorders (Famy, Steissguth & Unis, 1998; Lockhart, 2001; O’Malley, 2008). It is not uncommon for a person with FASD to have two or more diagnoses on either axis of the DSM-IV (O’Malley, 2008).

Table 8. 1: Mental Disorders that Commonly Co-occur with FASD

Axis I	Axis II (Personality Disorders)
ADHD - Attention Deficit Hyperactivity Disorder Mood Disorders Anxiety Disorder Alcohol or drug dependence Passive/Aggressive Pervasive Developmental Disorder Psychotic Disorder	Avoidant Dependent Schizoid Passive/Aggressive Borderline

Trouble with the Law and Confinement

Mattson and Riley (2000) found that there were significant rates of delinquency in children and youth prenatally exposed to alcohol. Schonfeld, Mattson and Riley (2005) confirmed what has been found in many studies. Specifically, children and youth with FASD who are raised in a stable home environment are less likely than those raised in foster care environments or unhealthy home environments to develop delinquent behaviours. This is similar in populations of children and youth who do not have FASD (Lynch, Coles, Corley & Falek, 2003).

Inappropriate Sexual Behaviour

“Inappropriate sexual behaviours refer to: sexual advances, inappropriate sexual touching, promiscuous sexual behaviour, exhibitionism, compulsive sexual behaviour, public masturbation, voyeurism, incestuous behaviour, obscene phone calls, sexual activity with animals, ‘unusual or worrisome’ sexual behaviours, and contact with the law regarding sexual offending” (Novick-Brown, 2008, pp. 135). Studies have shown that inappropriate sexual behaviours associated with FASD increase with age: 39% in children, 48% in adolescents, and 52% in adults (Streissguth et al., 2004). Novick-Brown (2008) believes that one of the reasons this occurs is the lack of appropriately timed sexual health education for individuals who have cognitive disabilities.

Substance Use

Fetal exposure to alcohol is a predictor to later substance use and misuse (Baer, Barr, Bookstein, Sampson & Streissguth, 1998). Not only is this a concern for the individual, but it may also result in generations of children in one family being born with FASD.

PROTECTIVE FACTORS

Protective factors are those things that help to keep individuals with FASD safer and healthier. Protective factors serve to cushion against the negative effects of prenatal alcohol exposure and redirect or block the risk factors from causing harm. In direct contrast, risk factors are things that make a situation worse (e.g., negative peer group, lack of supports and services). Streissguth (1997) notes that there are five universal factors that can protect individuals with FASD from developing secondary disorders. These are:

- living in a stable and nurturing environment
- not having frequent changes in households
- not being victims of violence
- receiving developmental disabilities services
- being diagnosed before the age of six

Remember

Many children with FASD have an invisible disability. Because it is invisible, some people may not realize when someone has an FASD and get frustrated and/or angry when difficult behaviours occur. However, individuals with FASD do not need to change to fit into our environment. In fact, they cannot. We need to change our environments so that they can function to the best of their abilities.

Given the right opportunities and accommodations, individuals with FASD can have improved outcomes. Individuals with FASD are working as teachers, in offices, as electricians, musicians, artists, athletes, and are in successful relationships and parenting. When appropriately accommodated, they can lead happy, productive, and fulfilling lives (Malbin, D., in personal conversation, 2009).

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