**West Sussex – Practice Guidance**

IROs are qualified social workers with at least five years’ experience, and who have acquired the right skills to carry out this role.

**Diagnosis and Treatment of FASD**

Guidelines for Working With Individuals With an FASD

A shift in how we understand children with an FASD may help those who work with children with an FASD. The table shows differences between how behaviour is perceived and what actually is occurring[6](http://fasdcenter.samhsa.gov/educationTraining/courses/FASDTheCourse/module6/mod6_ref_pg1.aspx).

Perceived Behaviour vs. Actual Situation in Persons With an FASD

|  |  |
| --- | --- |
| **Perception** | **Actual Situation** |
| Resisting | Can't understand or process verbal directions |
| Bad  | Frustrated, defensive, challenged |
| Lazy  | Doesn't understand, doesn't remember |
| Lies | Fills in, has memory problems |
| Doesn't try  | Exhausted, can't start, or afraid of failure |
| Mean, rude | Defensive, hurt, abused, unable to interpret social cues |
| Constantly late | Can't tell time, can't get organized, doesn't get the concept of time (for example, if you need to leave by 1:00 to get to a 2:00 appointment, that's an hour away) |
| Doesn't care  | Cannot show feelings, is protecting himself or herself |
| Refuses to sit still  | Overstimulated, needs to move while learning, doesn't know what he or she is expected to do |
| Fussy, demanding  | Oversensitive |
| Trying to make me mad  | Can't remember |
| Trying to get attention  | Needing contact, support |
| Immature  | Doesn't understand social cues and rules |
| Thief  | Doesn't understand ownership |
| Doesn't get the obvious | Needs many reteachings, doesn't understand, despite intelligence  |
| Makes the same mistakes over and over | Can't link cause to effect, can't see similarities, has difficulty generalizing |
| Doesn't work independently | Has chronic memory problems, can't translate verbal directions into action |
| Is overly physical | Is hyper- or hyposensitive to touch, doesn't understand social cues regarding boundaries |
| Uses poor social judgment | Is not able to interpret social cues, needs help organizing |

**Source:** Adapted from Malbin, D. 1993. *Fetal Alcohol Syndrome, Fetal Alcohol Effects: Strategies for Professionals.* Center City, MN: Hazelden.

Understanding FASD: Six Concepts

*(This information is taken from the*[*This Is Me*](http://www.mefasd.com/)*interactive program tool manual.)*

Foundational concepts about FASD have emerged from the growing body of experience and research in diagnosing and working with children, adults and families living with FASD. These concepts are based on the work of Diane Malbin (FASCETS Inc.).

Understanding these six concepts is critical to achieving the maximum benefit from the [This Is Me](http://www.mefasd.com/) interactive presentation and important in understanding and working with individuals living with FASD to effectively improve and develop supportive environments.

FASD is Caused by Physical Changes to the Brain

Over 30 years of research has found FASD to be a physical brain-based disability that is usually invisible. In most cases, primary and secondary behavioural characteristics are the only indicators of underlying brain dysfunction. Primary behaviours reflect brain dysfunction, e.g., memory problems, inconsistent performance, slow auditory or cognitive processing pace, delayed maturity in some areas, difficulty with abstract thinking, predicting or generalizing.

Secondary defensive behavioural symptoms include: chronic frustration, failure or exhaustion, irritability, anger, anxiety, shut down, aggression and others. Secondary defensive behaviours may be prevented and interventions are possible by adapting environments to achieve a better fit.

Tertiary symptoms reflect the cumulative effect of chronic frustration and failure and are often preventable.

Differences in brain function are not the problem. Each brain works differently, and we are each normal unto ourselves. The problem arises when others view behavioural symptoms through a moral lens that assigns intention – “he/she did it to me on purpose” – without recognizing the brain’s role in behaviours.

Most interventions target behaviours for change. When behaviours are symptoms of a physical disability, it is like punishing a paraplegic for refusing to do a high jump.

Failing to recognize the brain-based condition often leads to effort without results with everyone becoming increasingly frustrated.

FASD is Best Characterized by 3 Layers of Behavioural Characteristics

FASD is characterized by primary neurobehavioural symptoms, which are permanent, as well as secondary and tertiary characteristics that are often preventable and can be changed. (Diane Malbin’s concept of Tertiary Characteristics compares to Dr. Anne Streissguth’s work on Secondary Disabilities.)

Primary Symptoms

These symptoms reflect how the brain works. Some primary neurobehavioural symptoms of FASD include:

Learning disabilities

Slow auditory processing

Slow cognitive processing

Hyperactivity

Attention or memory deficits

Difficulties with problem solving

Delayed growth

Impulsive behavior

Difficulty with abstraction

Easily distracted

Inconsistent performance

Sensory challenges

Dysmaturity (developmentally younger – 1/2 their chronological age in some areas).

Secondary Characteristics

Without identification and accommodations, secondary defensive behavioural characteristics can develop over time as a result of chronic frustration, trauma and/or failure. These preventable behaviours are normal protective responses to pain, indicating a “poor fit” between the needs of the person and his or her environment, including:

Easily frustrated (short fuse, anger)

Easily fatigued (may show as over-activity, irritability, and/or tantrums)

Confused

Anxious

Aggressive

Destructive behaviours (not due to curiosity or just taking things apart)

Lonely, isolated

Easily manipulated and set up by others

Disruptive in class or at work

Fearful, avoidant, withdrawn

Disengaged (distant, shut down)

Sad.

Tertiary Characteristics

Tertiary characteristics reflect the cumulative effect of chronic frustration and failure and are often preventable. These include:

In trouble at home

Running away from home

In trouble at school or in the community

Delinquent or involved in criminal activity

At risk of unplanned or teen pregnancy

Involved with social services

Involved with legal/justice system

Alcohol/drug problems

Depression

Mental health problems

Suicide contemplation

Chronic self injury

Multiple diagnoses.

Multiple Diagnoses Often Mask FASD

Because an accurate diagnosis for FASD requires the expertise and involvement of several professionals involved in a comprehensive, multidisciplinary evaluation process, only a fraction of those affected currently receive a complete and accurate diagnosis. Many individuals with FASD may have been given multiple and differing diagnoses over time.

While none of the diagnoses may be wrong, each describes observed behavioural symptoms, but they have not identified FASD as the common source of behaviours. Accordingly, standard interventions are often ineffective. The greater the number of differing diagnoses, the greater the confusion and frustration experienced by people with FASD, their families, caregivers, educators and others. The greater the likelihood of underlying brain dysfunction, the stronger the recommendation for a neurobehavioural assessment for FASD.

In early childhood, because of similar behaviour patterns, individuals with FASD are often diagnosed with one or more of the following conditions:

Failure to thrive

Attention deficit disorder/hyperactivity

Speech and language disorder

Learning disability

Autism Spectrum disorder.

In the absence of correct identification, over time, people with FASD are often diagnosed with one or more of the following disorders, which reflect the patterns of secondary defensive characteristics. These may include:

Reactive attachment disorder

Emotionally disturbed

Conduct disorder

Oppositional defiant disorder

Bi-polar disorders.

Standard Learning Theories Do Not Easily Apply

Most standard parenting or clinical techniques are based on standard learning theories which do not make allowances for brain dysfunction. Two of the prominent learning theories are behaviourism and cognition.

With behaviourist “stimulus-response” learning theory, learning is conditioned by what occurs after the behaviour. Rewards for good behaviour encourage more good behaviour. This approach assumes the individual can learn rules, understand underlying principles, remember concepts and be able to generalize to other situations or behaviours. However, many individuals with FASD have difficulty with both memory and generalizing from one situation to another.

Cognitive learning theory relies on the person’s internal mental processes. New information enters a sensory register where it is transferred to short-term memory if it is deemed important or interesting. New information is compared to existing cognitive structures that can be combined or altered to accommodate the new information. Useful information is then transferred to long-term memory and storage for use. Insight, information processing, short- and long-term memory and perception are required for cognitive learning practices. These areas are often compromised when a person has FASD.

Common symptoms of FASD include a slow processing rate, difficulty making links or forming associations, difficulty storing and retrieving information, associated difficulty generalizing, and difficulty with abstraction and prediction.

In order for a person to change their behaviours, the brain must process language quickly, form associations, store and retrieve information, generalize and predict. For many people with FASD this will be an impossible task.

Such standard teaching techniques as lecturing, time out, star charts, or consequences are all based on various learning theories that do not fit with FASD. The application of these types of learning theories contributes to a general impression that “nothing works”. The real problem is that these learning tools all require the same cognitive abilities that are often not available to those with FASD and are variations of the same theme.

Many widely used treatment programs also use a cognitive-behavioural approach and similarly will not be appropriate without significant adaptations.

Effective techniques emerge from understanding the neurobehavioural characteristics of each person. If the person learns visually, use visual techniques and build on strengths. If the person learns visually and hands-on, use these techniques in working with the person. Teaching methods that show a skill in a step-by-step process and allow for practice – one step at a time – until confidence is gained in the entire process is appropriate. Remembering that practice and many repetitions of any new learning will be necessary.

Enhancing Strengths and Understanding Challenges Promotes Positive Outcomes

People with FASD may be very good at many things. They may be loving, affectionate, friendly, artistic, musical, work well with animals and plants, be very loyal and show a great determination to succeed in life. Learning strengths vary by individual. Strengths can be enhanced by the quality of a child’s environment and learning experience.

Some Common Learning Strengths

Visual learner: learns by being shown, rather than being told

Learns best one-to-one

Operates well with multimodal learning – hear, see, touch

Hands on, concrete, experiential, learns by doing

Learns well when integrated with other activities.

Some Common Learning Challenges

People with FASD can have a range of symptoms that may affect their ability to learn and retain information. For example, they may appear to learn a new task one day and not remember it the next. Other common problems include having trouble:

Understanding abstract concepts i.e. math and money

Thinking/reasoning

Learning from experience

Understanding consequences of their actions

Remembering.

People wth FASD may have special needs that require
life-long help regarding:

Managing money

Making decisions

Creating a context of safety

Understanding timelines

Educating employers.

Changes to Environment is Central to Success

People with FASD have a physical brain-based disability that prevents adapting to the environment.   Accordingly, it is necessary provide adaptations to the environment that fit for each person with FASD. This is the same approach applied to others with more obvious physical disabilities. Since environments are comprised of many components, each of which can have specific impacts on people with FASD, knowing and understanding those components can help us identify which changes can be most effective.

The most obvious component is the physical environment, which includes the shape and size of physical space, colour, lighting, furnishings and other aspects.

Less obvious but more impactful components are the human-environment factors that govern the way we live and function as a society. These include our personal circle of contacts, our way of thinking, our schedules and routines, our rules and expectations, and our communications style.

The Impact of Environment on Your Way of Thinking

The lens through which we view the world is shaped by values and deeply held beliefs or standards. Those expectations, understandings and values are a very important part of the environment for people with FASD. Changing and adapting these personal attributes in order to effectively interact and work with individuals with FASD is essential for success.

Understanding the brain-based nature of FASD can provide helpful adjustments to our incorrect assumptions and unrealistic values. For example, as children age, we expect more independent functioning. For those individuals with FASD, their developmental level of functioning often does not correlate with their chronological age (dysmaturity).

Changing our way of thinking is not easy. Nor can it occur only on a superficial level if it is to be effective in helping someone with FASD. For example, you may have a deeply held commitment to an extended family which has a cherished ritual of a large annual family picnic. However, a child with FASD may not be able to cope with the change in environment and over- stimulation of too many new adults. Tension between one’s family values and one’s value to support the child with FASD is likely to occur.

Physical Surroundings

This component includes the physical structure (the wall, windows, floors), colour, lights, sound, furniture and equipment. The organization of the physical structure of a space, furnishings and equipment dictate activity areas and traffic patterns. Individuals with FASD can use the physical environment to cue them about rules and expectations. Physical environments that provide a variety of spaces, some for movement and others for quiet, calming time are optimal.

Schedules and Routines

Fast-paced, lengthy and unpredictable activities can create problems for people with FASD. Making an organized routine for activities is best. Such routines make events predictable and can ease transitions from one activity to another.

Expectations and Rules

Each environment has rules that influence how individuals are expected to behave. For example, families may have rules or expectations about what can be spoken of in public and what remains exclusively within the family domain. When a person with FASD has difficulty weighing and evaluating what is private and what is public, other family members need to exercise greater discretion in discussing personal family matters in the presence of the member with FASD.

Language and Communication

People with FASD may have difficulties comprehending language, be overwhelmed by too many words or instructions and be confused by inconsistency in word use. Using fewer words and slowing down when communicating can be very effective.

Family, Friends and Community

People connected to individuals with FASD are the most important environmental asset with the power to shift their own thinking and that of others. They can analyze the other components of environments and adapt them specifically for people with FASD. Often simple accommodations can have a profoundly positive impact.

**Reference Points;**