

Fetal Alcohol Spectrum Disorder:
A Guide to
Awareness and Understanding

FASD Support Network
of Saskatchewan Inc.



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A Letter to Our Readers

FASD: A Guide to Awareness and Understanding includes a selection of materials gathered and prepared by the FASD Support Network of Saskatchewan (the Network). The intention of this guide is to provide basic information about Fetal Alcohol Spectrum Disorder for a variety of readers including parents, caregivers, family members, professionals, students, frontline workers and members of the general public. We hope that by increasing awareness and understanding of FASD, we will help to improve the lives of individuals and families living with FASD.

This booklet may not answer all of your questions. A list of suggested websites, organizations and print resources has been included to aid in your information gathering. If you are left with further questions, or you are interested in doing additional reading, please contact the Network. We can send you an information package with materials related to a specific topic.

The Network has a range of educational support materials. These materials are available for distribution at workshops and conferences or in schools, health centres and community based organizations. We have a set of 20 FASD Tips in a pictorial plain language version that is very popular. A quarterly newsletter is distributed by email and a twice yearly publication titled *Living with FASD* helps to keep people informed and up to date throughout the province and across Canada.

Finally, we offer support and information to parents, caregivers, individuals with FASD and professionals on our toll free warm line at 1-866-673-3276. Feel free to contact us.

Sincerely,

FASD Support Network of Saskatchewan



Introductory Comments

About the FASD Support Network of Saskatchewan

The FASD Support Network of Saskatchewan (the Network) is a parent-led community based provincial organization with an office in Saskatoon. Like many community based organizations, a group of dedicated parents came together in the early 1990's with common concerns about the challenges related to parenting children affected by prenatal exposure to alcohol. Little was known about FASD at that time. Families faced stigma, lack of services and misunderstanding. Over the years the level of knowledge and understanding has grown and changed along with the growth of the Network. The Network is led by a 12 member board of directors. The majority being parents of children, youth or adults living with FASD. The Network also maintains a group of dedicated staff who carry out organizational objectives.

Close ties and partnerships with community members, professionals, funding bodies and all levels of governmental departments aid the Network to accomplish activities aimed at improving the lives of individuals and families living with FASD. Since the early days of this organization, and up to the present day, there have been critical lessons learned along the way. Individuals affected by FASD have been our generous teachers; families, parents, and caregivers our dedicated leaders.

Vision Statement of the Network

The vision of the FASD Support Network of Saskatchewan, a parent-led organization, is for individuals with Fetal Alcohol Spectrum Disorder and their families to recognize themselves as safe, supported, valued and contributing members of the community. To reach this vision we provide support to people with Fetal Alcohol Spectrum Disorder, their families and circles of support by:

- Providing information and education
- Promoting early assessment, diagnosis and intervention
- Advocating for the development of life-long support services for individuals with FASD
- Establishing partnerships
- Working to increase awareness of FASD

Individuals affected by FASD have been our generous teachers; families, parents, and caregivers our dedicated leaders.

Preface

In recent years the public has learned more about Fetal Alcohol Spectrum Disorder (FASD). There seems to be a good understanding that drinking alcohol during pregnancy can harm a developing fetus, however, people still have many questions:

- What is the diagnostic process and which terminology is best?
- What are the lifelong implications of FASD?
- What is the difference between primary and secondary disabilities?
- Why is FASD called an invisible disability?
- Why do I see such confusing behaviour?
- Which strategies might work best?
- How can I support and accommodate individuals and families?
- What will help to address and eliminate the shame and stigma associated with FASD?

We recognize the multiple areas of confusion surrounding FASD. It is our aim to help others to increase awareness and to develop a more complete understanding of FASD.

FASD: What does this mean to me?

Self Reflection

Pause for a moment, and ask yourself, “Why is it important that I am aware of and have an understanding of Fetal Alcohol Spectrum Disorder? Why should I be concerned or knowledgeable about FASD?” Each of us might have different reasons why FASD is important. There are several compelling reasons why all of us should be concerned and why it is vitally important to become aware of and have a good understanding of FASD. Below a few reasons are briefly outlined .

Service Providers and Individuals will have Greater Success

Those who choose careers in human services such as education, community or family support, healthcare, justice, social services or mental health and addictions treatment will be in contact with individuals with FASD. If various professionals are aware of FASD and understand the signs, symptoms and implications of living with FASD, they can modify their daily practice in order to better serve individuals and families. Through improved services and by making accommodations for a brain injury, the frustration of individuals and the professionals will be lowered and chances for success will be improved.

Over the years many children, youth and adults have been poorly served due to widespread lack of awareness and misunderstanding of FASD. Affected individuals often present very well. The “soft signs” of FASD can go undetected by professionals, even though the individual has a significant cognitive disability and may really be functioning quite poorly in the outside world. These individuals are often said to have slipped between the cracks. The reality of slipping between the cracks can be very dangerous especially as individuals grow and mature into adolescence and adulthood. Many youth and adults develop secondary disabilities and have lives characterized by isolation, poverty, hardship and even premature death due to unacknowledged and unrecognized disabilities related to prenatal exposure to alcohol. This situation is unacceptable and must be changed.

Economic Costs Related to FASD

If individuals with FASD are not supported and needs are not met, it is likely that secondary disabilities will arise. There are huge economic costs associated with provision of emergency healthcare, justice services, addiction treatment, unemployment supports and homelessness. Through prevention of further cases of FASD these costs can be lowered. In addition, improved understanding and awareness of FASD will lead to improved service provision and more effective interventions and support. Economic costs are greatly reduced as a result of proactive approaches and improved services. If services are effective from the start, services do not need to be provided over and over again. Repeated emergency room visits, incarceration and addiction supports are extremely costly and in many cases could be avoided by implementing the necessary support and accommodations from the start.

We are Members of Diverse Communities

We know that the rates of FASD are high. If 1 in 100 individuals is affected by prenatal alcohol exposure, think about the number of people you encounter each day in your personal, professional or public life. People with FASD are members of our communities. They are friends, family members, volunteers, students, brothers, sisters and workers. It may sound cliché, but it is true that each of us is unique and we each contribute to our communities in our own way; we each have strengths and struggles and rights and responsibilities. In Canada, all citizens are protected by the Canadian Charter of Rights and Freedoms and therefore we each have a right to be a part of our community along with the responsibility to be a good citizen. Because of perceived differences, individuals with disabilities, like FASD, have historically been excluded, marginalized, and denied full participation in community life. People with FASD have a disability, but they also have a right to be treated fairly and to be accepted as they are. Acceptance of diversity, gained through improved understanding and awareness of FASD, will create strengthened and inclusive communities and improve individual lives.

Understanding FASD: Basic Information

What is FASD?

Fetal Alcohol Spectrum Disorder (FASD) is a complex disability and one that is not quickly explained. The term Fetal Alcohol Spectrum Disorder is an **umbrella term** referring to the continuum of effects that can occur in children, youth or adults prenatally exposed to alcohol. The spectrum of effects includes mild to severe cognitive, behavioural, physical and sensory disabilities. The disabilities caused by alcohol exposure are present from birth but, in many cases, are not identified until later in life. FASD is considered the leading cause of developmental and cognitive disabilities among children in Canada. (Health Canada 2006). FASD is a life-long disability for which there is no cure. This means that people do not grow out of their unique disabilities and the brain injury cannot be fixed.

How does alcohol harm a fetus?

Alcohol is a **teratogen**, meaning that this substance is toxic to, and can negatively influence, prenatal development. When a woman is pregnant and drinks alcohol, the alcohol not only enters her system, but also passes freely through the placenta and enters the system of the developing fetus. Alcohol remains in the system of the fetus longer than that of the mother. The alcohol injures the body systems and organs that are developing at that stage of the pregnancy. The **Central Nervous System (CNS)** is particularly vulnerable for two reasons **1.** The CNS develops throughout the entire pregnancy so injury to neurological functions can occur over the entire nine months **2.** Alcohol acts as a solvent on the rapidly developing cells of the CNS and causes significant injury, primarily to the brain. Our brain continues to develop after birth, so alcohol should also be avoided when breastfeeding. Many factors influence the amount of injury resulting from prenatal exposure, including the amount of alcohol consumed, how often alcohol is consumed, the timing of consumption, the general health of the mother, stress levels, exposure to other substances and genetic makeup.

Can FASD be prevented?

Clearly, prevention of FASD is important. The public requires clear and accurate information about the harmful affects of alcohol on a fetus. There is no known safe amount of alcohol or a known safe time during pregnancy to consume alcohol. For these reasons, it is best for women to abstain from alcohol throughout the entire pregnancy. This information needs to be widely available in the community and through health-care services. Women will need support from family, friends and partners to abstain from alcohol. This can be difficult as alcohol use is accepted and common in our culture. Women and families affected by addictions need specialized services during pregnancy. We very well know that many in our communities have an addiction to alcohol. People become addicted to alcohol for a variety of reasons, and the nature of addictions makes it extremely difficult for women to stop drinking when they become pregnant.

How many people are affected by FASD?

In Saskatchewan, it is believed that 1 in 100 people may be affected by prenatal alcohol use. (Saskatchewan Prevention Institute, 2005). However, it is difficult to know just how many families are affected as FAS has only been recognized in the last 30 years and the idea of a spectrum of disorders resulting from prenatal alcohol exposure is even more recent. In addition, the signs and symptoms of FASD often go unnoticed, are masked by other factors in the individual's life or are attributed to other causes. This is why FASD is often called an **invisible disability**. Individuals with invisible disabilities in many cases do not receive the support and accommodation they need to succeed in life. Research shows that those most at risk are individuals with no visible signs of disability (Malbin 2006). Many people with FASD have an IQ in the normal range, but the various cognitive processes have been altered. With appropriate supports and changes to their environment, individuals can be productive and successful members of society.

Diagnostic Terms and Criteria

In 2005, a team of professionals developed the *Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis*. This was a major accomplishment that will aid many families and individuals in the journey to access diagnosis. Diagnosis and assessment of prenatal exposure is a complex process best completed by a multi-disciplinarian team of professionals that must include a physician specially trained in diagnosis and assessment. Diagnostic and assessment services are available throughout the province but families continue to face barriers to these services. Barriers include long wait lists, services that are more widely available to children and youth rather than all age groups, lack of trained professionals, difficulty for families in remote and rural regions to access diagnostic and assessment services due to cost of travel and long distances to services.

Despite the problems accessing diagnostic and assessment services, this is an important process that can improve outcomes for individuals and families. A common area of confusion for families and professionals is the language used around diagnosis. The term Fetal Alcohol Spectrum Disorder (FASD) is not a diagnostic term. FASD is an umbrella term used to describe the range of disabilities caused by drinking alcohol during pregnancy. The following are some commonly used terms associated with diagnosis within the spectrum of FASD. The criteria for diagnosis are those used across Canada.

Fetal Alcohol Syndrome (FAS)

1. Information showing the birth mother drank during pregnancy
2. Characteristic facial features
3. Below normal weight, height and small head
4. Problems with learning and /or problems with behaviour

Fetal Alcohol Syndrome (FAS) without Confirmed Maternal Exposure

Sometimes the fact that the mother drank during the pregnancy cannot be proven but there is good reason to believe she did. If the other 3 characteristics for FAS are present then the diagnosis of FAS without confirmed maternal exposure can be made.

Partial Fetal Alcohol Syndrome (pFAS)

Information showing the birth mother drank during pregnancy and two out of three of the following characteristics:

1. Some of the characteristic facial features found in FAS are present.
2. 'Much' below normal weight, height and small head
3. Problems with learning and/or problems with behaviour

Alcohol Related Neurodevelopmental Disorder (ARND)

1. Information showing the birth mother drank during pregnancy
2. Problems with learning and/or problems with behaviour

A term used in the past that is no longer used as a diagnostic term is **Fetal Alcohol Effects (FAE)**. This is a term that has been replaced by the diagnostic terms **pFAS** and **ARND**.

Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis is available online at www.cmaj.ca/cgi/content/full/172/5_suppl/S1

Developed by FASD Support Network of Saskatchewan (2003, Revised 2005)
Adapted from Chudley, A.E., Conry, J., Cook, J., Looch, C., Rosales, T., Leblanc, N. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. Canadian Medical Association Journal (March 2005).

Paradigm Shifts and People with FASD

Fetal Alcohol Spectrum Disorder describes a range of disabilities caused by prenatal alcohol exposure. The disabilities are brain based. When families, caregivers, professionals and community members change their own understanding or perception of the individual with FASD, this is called a “paradigm shift.”

The following chart shows how we can shift our understanding of FASD. With realistic expectations we can give individuals with FASD every opportunity to be successful.

From seeing the child as...

Won't

Bad, annoying
Lazy, unmotivated
Lying
Fussy
Acting young, babied
Trying to get attention
Inappropriate
Doesn't try

To understanding the child as...

To Can't

Frustrated, challenged
Trying hard, tired of failing
Story telling , filling in the blanks
Oversensitive
Being younger
Needing contact, support
Displays behaviours of a younger child
Exhausted or can't get started

From personal feelings of...

Hopelessness
Fear
Chaos, confusion
Power struggles
Isolation

To feelings of...

Hope
Understanding
Organization, comprehension
Working with
Networking, collaboration

Professional shifts from...

Stopping behaviours
Behaviour modification
Changing people

To...

Preventing problems
Modeling, using visual cues
Changing environments

“The first step toward change is awareness. The second step is acceptance.”

Nathaniel Branden

Prepared by FASD Support Network of Saskatchewan Inc. (2006).
Chart reprinted with permission from Malbin, Diane V., (2002, 1999) Trying Differently Rather Than Harder, Second Edition. Portland, Oregon: FASCETS. p.42. Permission granted March 2006.

Common Beliefs about FASD that are NOT TRUE

1. **Belief:** All people who have FASD have below average IQ. This is NOT true.

What is true is that:

- Some children with FASD have below average IQ.
- Some children with FASD have average or above average IQ's.
- Their brain has been injured.
- Children who have FASD do some things well and but can have difficulties with some things.
- It can be helpful to think of your child as having difficulties similar to someone who has brain injury because of an accident.

2. **Belief:** The behaviour problems of children who have FASD happen because their parents are not doing a good job of parenting. This is NOT true.

What is true is that:

- Brain damage can lead to behaviour problems. This is because a person with brain damage does not think the same way most people do. They don't always behave as others expect them to.
- Children with brain damage are difficult to parent.
- As a parent of a child who has FASD you need the support of your family, friends and the community. It is very difficult to go it alone.

3. **Belief:** Children with FASD will out grow their difficulties. This is NOT true.

What is true is that:

- FASD lasts a life time.
- The difficulties children face change as they grow older.
- Your child will continue to need your support well into adulthood.

4. **Belief:** Because a person with FASD has brain damage there is no point helping them. This is NOT true.

What is true is that:

- Children with FASD can learn if we give them help and if we teach them in the way they learn best. We can adjust our teaching style to match their learning style.
- Children with FASD learn best in a quiet place where they can practice skills. They need a routine that seldom changes.
- You can help your child by talking about FASD with family, friends, and professionals. This should help them understand your child's behaviour.

Common Beliefs about FASD that are NOT TRUE

5. **Belief:** A diagnosis of FASD is a label that will make people want to give up on the individual. This is NOT true.

What is true is that:

- A diagnosis tells you what the problem is.
- A diagnosis helps you figure out what to do to help your child.
- A diagnosis can be a relief to a child because now he or she will know the reason for difficulties.
- You can use the diagnosis to help you find supports for both you and your child. For example your child may qualify for extra help in school or you may be able to get respite care for your child so you can stay well and strong.

6. **Belief :** People with FASD are unmotivated or unwilling to take responsibility for themselves. This is NOT true.

What is true is that:

- Children with FASD are not trying to be difficult. They often have difficulty paying attention or remembering instructions. This is usually the reason for the behaviour.
- It is important to understand that people with FASD suffer from brain damage and that this affects their ability to be responsible for their behaviour. It's not that they won't, it's that they can't.

7. **Belief :** Mothers had an easy choice not to drink while they were pregnant and that they purposely set out to damage their baby. This is NOT true.

What is true is that:

- Pregnant women do not purposely harm their baby.
- Family, friends and the community all play a role in helping the pregnant mother overcome problems with addiction.
- Stopping drinking at any time during pregnancy will be helpful for the development of the baby.
- Changing drinking patterns during pregnancy is not a simple matter. There are many reasons why drinking alcohol is a part of a person's life at a particular time. Addiction can be a way of trying to manage an unmanageable life. For many mom's drinking and started long before they became pregnant. In fact, the pregnancy may be happening within a well developed addiction.

Prepared by FASD Support Network of Saskatchewan Inc. (2005) Adapted from Streissguth, A. (1997). Seven Common Misconceptions about FAS/FAE. Permission granted September 2005.

Primary Disabilities and Secondary Disabilities

Fetal Alcohol Spectrum Disorder (FASD) describes a range of lifelong disabilities resulting from prenatal alcohol exposure. Maternal alcohol consumption injures the structure, function and design of the brain, resulting in a physical disability, that is mostly invisible to us. What is visible to us are the behavioural signs and symptoms for which accommodations need to be made. (Malbin 2006). It can be helpful to understand the various primary disabilities as well as the secondary disabilities associated with FASD.

Primary disabilities

Primary disabilities are those disabilities that one is born with that are directly caused by the prenatal exposure to alcohol. Primary disabilities may impact cognitive, physical, behavioural, or sensory functioning. The most significant primary disabilities are those that result from neurological injury to the central nervous system. Some examples of primary disabilities are impaired **cognitive functioning** (how we think, mental tasks, intellectual functioning) including:

- slower cognitive pace and reduced ability to pay attention
- difficulty with judgment, perception, prediction, and planning
- trouble with abstract thought and generalizing information from one setting to another
- difficulty with learning and memory, leading to story telling, filling in the blanks

In addition to impaired cognitive functioning, **behavioural disabilities** are an issue. Some examples are:

- problems with interpersonal skills and reading social cues
- impulsive actions along with a lack of inhibitions
- poor understanding of boundaries and ownership
- struggles with regulating emotion
- rigid and inflexible behaviour patterns
- being easily influenced, overly trusting and **dysmaturity**, meaning individuals act younger than they are
- sleep problems and being overly active

While many of the disabilities relate to cognitive functioning and behavioural issues, there are some **physical and sensory disabilities** that are worth noting, such as:

- delayed motor development and poor motor control
- lower height and weight along with characteristic facial features
- hearing impairments and auditory processing problems
- injury to body systems, skeletal, renal, and circulatory systems
- high or low pain tolerance, sensitivity to light, sound, texture or stimulation

This is a rather long list. Keep in mind that no two people are alike and each person will experience varying affects; some individuals will be affected mildly and others will be significantly affected.

“Keep in mind that no two people are alike and each person will experience varying affects.”

FASD: Primary Disabilities and Secondary Disabilities

Secondary disabilities

Secondary disabilities are those difficulties that arise later in life due to a poor fit between the individual's needs, level of functioning and the environment. Complications arise most often because of:

- undiagnosed primary disability,
- lack of intervention,
- lack of services,
- ineffective strategies,
- and unrealistic expectations.

Some common secondary disabilities and characteristics related to FASD are mental health problems, low self esteem, difficulties with school, trouble with the law, being a victim of crime, substance use and abuse, addictions, employment problems, inappropriate sexual behaviour, housing problems and homelessness (Streissguth et al. 1997).

“By acknowledging the brain injury individuals will be better served by the various systems.”

Each of the secondary disabilities is concerning and the various service providers working within these sectors must become aware of the underlying brain injury associated with FASD. By acknowledging the brain injury individuals will be better served by the various systems.

Most individuals experience greater difficulties in life due to the secondary disabilities than the primary disabilities associated with

FASD. Fortunately, secondary disabilities can be prevented. The presence of protective factors like a stable nurturing home, early diagnosis, effective support and environmental accommodations will help to prevent secondary disabilities and help to minimize the impact of the secondary factors. With the recognition that FASD is a disability there is a greater likelihood that accommodations will be made and therefore the outcomes for youth and adults can be improved.

Common Secondary Disabilities

- Mental health problems
- Substance use
- Addictions
- Legal problems
- Employment problems
- Inappropriate sexual behaviours
- Emotional problems and violence
- Housing problems and homelessness

Streissguth, A. (1997) *Fetal Alcohol Syndrome: A Guide for Families and Communities*. Baltimore, MD: Paul H. Brookes Publishing. pp 270 -275.

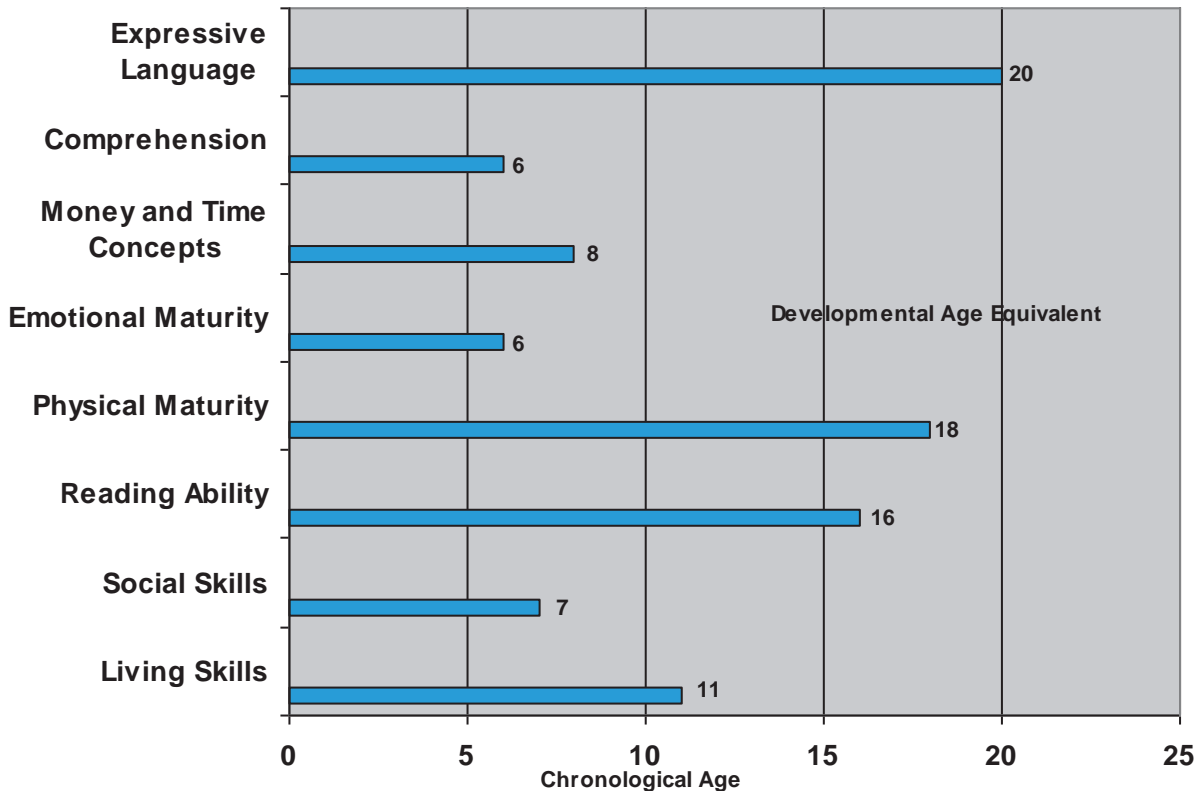
Developmental Age and FASD

Research has shown that people with Fetal Alcohol Spectrum Disorder (FASD) are developmentally much younger than indicated by their chronological age. To further complicate this, there is often a noticeable difference in development or ability in the various areas. Most of us, whether professionals or parents, expect children and youth to develop and grow according to an accepted chronological schedule and for physical, cognitive, and psychosocial development to occur at about the same rate. Unfortunately for individuals affected by prenatal alcohol exposure, these assumptions about development create a “poor fit” between abilities and the expectations placed upon individuals.

In the example below, the chart indicates the development of a youth of 18 years. You can see that the physical development seems to be “on time” yet emotional maturity and social skills lag far behind. This is not uncommon and can create difficulties.

Think about the amount of supervision you might typically provide for an 18 year old, yet consider the emotional maturity and comprehension skills of the 18 year old affected by FASD. Clearly, additional structure and supervision would be required. Another example, picture an 18 year old, articulate and clear in her ability to express herself, yet unable to complete and submit assignments by the due date or get to school on time.

Diane Malbin suggests that we adjust our expectations and “think younger” when we assign responsibilities, intervene, and support those with FASD. By adjusting our expectations, thinking younger, and making accommodations in the environment for the existing brain injury, we create a good fit and promote better outcomes for individuals with FASD. Each of us, regardless of our area of service provision can engage in this process of creating a “good fit.”



Chronological Age = 18 Years

Source: Malbin, D. (2002) *Trying Differently Rather than Harder*. 2nd Edition. Portland, Oregon: FASCETS.

8 Magic Keys to Supporting Individuals with FASD

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

Concrete – Individuals with FASD do well when people talk in concrete terms; do not use words with double meanings, or idioms. Because their social-emotional understanding is far below their chronological age, it helps to “think younger” when providing assistance and giving instructions.

Consistency – Because of the difficulty individuals with FASD experience trying to generalize learning from one situation to another, they do best in an environment with few changes. This includes language. For example, teachers and parents can coordinate with each other to use the same words for key phrases and oral directions.

Repetition – Individuals 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 re-taught.

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.

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 assimilated. Therefore, a simple environment is the foundation for an effective school program.

Specific – Say exactly what you mean. Remember that individuals 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.

Structure – Structure is the “glue” that makes the world make sense for an individual with FASD. If this glue is taken away, the walls fall down! An individual with an FASD achieves and is successful because their world provides the appropriate structure as permanent foundation.

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

Not Working?

When a situation with an individual with FASD is confusing and the intervention is not working, then:

**Stop Action!
Observe.**

Listen carefully to find out where he or she is stuck.

Ask: What is hard? What would help?

Reprinted with Permission. Evensen, D. & Lutke, J. (1997). 8 Magic Keys. Adapted version, (2005) Minnesota Organization on Fetal Alcohol Syndrome.

Hints for Communicating Clearly

Clear communication is important when supporting individuals with FASD. The words and actions we use to send messages can help or hinder communication. For people affected by FASD, communication can be difficult due to the many chances for misunderstandings of words and actions. There are a number of things that parents, caregivers and support people can do to improve communication. Here are a few ideas for you to try.

Use clear concrete words and short sentences. Say exactly what you mean with fewer words and you will find your messages are better understood. This is sometimes referred to as using plain language. Plain language does not mean that you talk down to someone; you simply speak clearly and briefly. Try to keep sentences to 10 words or less.

Be specific. General terms and abstract concepts are difficult to understand. Be precise and specific especially with times, locations, and tasks. When giving directions, or teaching a skill, tell the person step by step exactly what to do, in the order that the tasks need to be done.

Use repetition in your words and language. Key phrases used in the same way for the same activities are helpful. Regular use of key phrases helps to ensure understanding, builds routines and creates predictability in a world that is often chaotic and unpredictable.

Avoid puns, metaphors and words or phrases with double meanings. The use of figures of speech, phrases where the literal meaning is very different than the intended meaning, causes confusion and frustration. Equally confusing are idioms. Idioms are phrases with a meaning that seems unrelated to the actual words that are used. Examples of commonly used idioms: It's raining cats and dogs out there! This is as easy as pie. Let's ditch class. I feel antsy. (Source: <http://www.eslcafe.com/idioms/id-mngs.html> ESL Idiom page). Individuals with FASD may feel lost in a conversation that includes figures of speech because they can not decipher the subtle meanings of these phrases.

Avoid jargon and acronyms. Terms and acronyms that are known only to groups with specialized knowledge exclude others from the conversation. This is an especially important reminder for those who are having meetings with teens or adults with FASD.

Sarcasm, exaggeration and jokes can be puzzling. What is intended as light humour or a joke may leave a person with FASD feeling hurt or angry. It is uncomfortable when others are laughing and you do not understand what is funny. An offhand comment may be taken as an insult or a joking comment might be understood as the truth.

Keep questions short and clear; calmly prompt for answers. Questions, by their very nature, require thought in order to give an answer. If a person with FASD needs to think hard to figure out what is being asked or if they forget the question, they will not be able to come up with an answer. This is not because they do not know the answer, but because they could not figure out the meaning of the question.

Use a calm and clear voice. Messages can be lost when given in a highly emotional or excited tone. Simple gestures along with clear and direct phrases may be helpful.

Use varied nonverbal language. Figure out the nonverbal language that works such as eye contact, touch, gestures and facial expressions. This will differ with each individual.

Listen carefully. You can pick up on lack of understanding, miscommunication or confusion more quickly and address the problem rather than letting things escalate.

Source: *Network News* (2006) FASD Support Network of Saskatchewan Inc.

Mentoring Individuals with FASD

Each of us requires guidance and support in our lives. Individuals with FASD require guidance more often and require a level of guidance that is more structured and long term due to the disabilities that result from prenatal alcohol exposure. Those living with FASD need, and have a right to, the support of a mentor in their lives. The relationship between a trusted mentor and an individual with a disability, such as FASD, can result in a variety of positive outcomes. Over time the relationship can grow and reduce the feelings of isolation, loss, and failure that so often characterize the lives of individuals with FASD.

“Many people do not understand that FASD is a lifelong disability...life lessons need to be learned over and over again.”

Young children with FASD rather naturally receive support. Perhaps not as much support as they require, but the chances that parents, caregivers, family members, educators, coaches, and school peers create a circle of support around that individual are greater than that of teens and adults with FASD. As a child with FASD becomes a teenager, the need for guidance actually may increase yet the guidance and support received decreases. Reasons for this vary, but it is likely that those within that youth’s circle begin to have changing expectations. A coach or educator may be less willing to provide direction and guidance in decision-making and problem solving as they want to promote independence. Many people do not understand that FASD is a lifelong disability and that life lessons need to be learned over and over again. The youth herself may have changing needs and expectations. She might see her peers gaining autonomy and making decisions and understandably, she wants a degree of independence in her life. Peers may lack the knowledge or skills to support a friend affected by FASD because the issues faced become very serious. Issues such as violence, substance use, sexuality and dating are complex even for adults.

Due to these reasons, young people with FASD commonly begin to experience struggles during the teen and young adult years. In addition, by the time the teen years roll around, stress and frustration may be mounting for parents, family members, and caregivers. Members of the circle of support can become less resilient and feel that they have tried everything and have no answers, thus the level of support decreases. It is also likely that families receive conflicting messages from professionals. The result is often confusion and self doubt about how to best guide their child. This can take quite a toll.

A mentor can make a difference in the life of a person with FASD, particularly during the teen and adult years. A mentor is a person who is willing to care about, guide, and support a young person or adult with FASD. Mentors share in the life of the individual, they provide opportunities for a variety of experiences, implement the necessary structure, assist with learning daily living skills, guide decision making, and support individuals when mistakes are made. The support is provided in a genuine and encouraging relationship. The mentor does not replace other members of the individual’s circle of support; a mentor becomes one of the people in that circle. This is an important process for the youth with FASD and the parents or caregivers. The parents remain actively involved, as they know their child best, but the involvement, insight, and energy of the mentor can provide a different kind of support along with fresh ideas.

Clearly mentoring is an important and worthwhile venture. There are many areas yet to explore and questions left unanswered, however, mentoring seems to be a strategy that could make a real difference in the lives of people with FASD.

Source: *Living with FASD* (Fall 2005) FASD Support Network of Saskatchewan Inc.

Notes from a Mentor: Lessons Learned

When I first became involved in mentoring youth and adults with FASD, I found myself wondering what a mentor really does. Even in my first few weeks, I was unsure about what my days would look like as a mentor. By reading and talking with others about FASD, I thought about how I could help adults to create routines, break down daily tasks and go to appointments. I had no idea of the real impact that a mentor could have on someone's life and how different mentoring can look for different people. For those of you who may be looking for a mentor, hiring a mentor to work with your family member or considering becoming a mentor, here are some of the lessons I have learned along the way that every mentor supporting people affected by FASD should know.

- **Our brains are amazing!** They control all behaviours, thoughts and emotions that we have. We truly don't understand how an average brain works, let alone a brain affected by FASD. When frustrated with behaviours, think about what you know about the brain and how FASD changes the way it works.
- **Friendships cannot be replaced by a mentoring relationship.** Everyone needs meaningful relationships. However, this can be one of the most difficult things in life for many people with FASD.
- **Mentorship cannot replace the hard work of families and caregivers.** Keep in touch with family members and listen to their stories – remember that they have lived with this individual and know him or her better than you do. As a mentor you can learn so much and avoid many problems by connecting with the family wisdom.

“I had no idea of the real impact that a mentor could have on someone's life and how different mentoring can look for different people.”

- **Individuals affected by FASD can be very insightful.** They may have insight about their strengths, weaknesses and also in which areas they need support or what kind of support works best. Despite this fact, they may not always want to accept the support in every situation. But be persistent! Mentors must be there to remind individuals what their long-term goals are when that individual is stuck in the moment.
- **Success has a different meaning to every person.** Success really can be felt for one moment.
- **No one is independent.** We all create natural circles of support around ourselves and we all need reminders and encouragement sometimes. For people with FASD, this support often needs to be created and carefully planned.
- **And the most important thing I've learned so far is that one person really can make a difference in someone's life.** That difference won't make hardship go away, but it can create moments of happiness.

FASD Websites

The FASD Support Network of Saskatchewan Inc. www.skfasnetwork.ca

Download FASD Tips for Parents and Caregivers, articles, or the latest issue of Network News. Updated regularly with information about upcoming workshops and events.

The Saskatchewan Prevention Institute www.preventioninstitute.sk.ca

A provincial non profit organization that works in the area of awareness and education of prevention of disabling conditions including FASD. Resources and materials available to order or borrow.

Saskatchewan Association for Community Living www.sacl.org

Lending library with an extensive collection of resources related to disability issues.

Saskatchewan Learning www.sasked.gov.sk.ca/

Look in the Special Education section and follow the links to this publication:

[Planning for Students with Fetal Alcohol Spectrum Disorder: A Guide for Educators](#)

Alberta Children's Services FAS Page www.child.gov.ab.ca/whatwedo/fas/page

A page dedicated to FASD, includes access to ordering free information like Strategies not Solutions booklet.

FASLink www.faslink.org/ www.acbr.com/fas/index.htm

FASlink maintains an extensive website of more than 100,000 FASD documents in a searchable database.

FAS Bookshelf www.fasbookshelf.com

An excellent site to order FASD related books, articles, videos, and posters.

FAS Community Resource Centre www.come-over.to/FASCRC/

Site includes information, strategies and stories, parent support, and documents to download.

FASD Connections www.fasdconnections.ca/ A website specifically dedicated to information related to adolescents and adults with FASD. This site is an excellent source for articles on a wide variety of topics. A good collection of PDF manuals and guides.

Canadian Centre on Substance Abuse www.ccsa.ca/fasgen.htm

This is the national clearinghouse on substance abuse. This site has a searchable database of information and articles related to FASD, and a National Directory of FASD Services can be downloaded or ordered.

The FASD Center of Excellence www.fascenter.samhsa.gov/gg/index.cfm

The Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence is a project of the Substance Abuse and Mental Health Services Administration.

FASWorld www.fasworld.com

Information about International FASD Awareness Day and much more. Lots of good ideas for projects.

Lakeland Centre for FASD www.lakelandfas.com

Northern Alberta site with links to a wealth of information from around Canada and the world.

Better Endings New Beginnings www.betterendings.org

This site has been created by an author and parent of a young woman affected by FASD. Of interest is a downloadable workbook on the topic of FASD and grief, with more workbooks to come.

University of Washington Fetal Alcohol and Drug Unit www.depts.washington.edu/fadu/

A good source of research articles.

Suggested Resources

Materials developed by the FASD Support Network of Saskatchewan Inc.

Fetal Alcohol Spectrum Disorder: A Guide to Awareness and Understanding (2007)
FASD Tips for Parents and Caregivers #1-20 Text Version
FASD Tips for Parents and Caregivers #1-20 Pictorial Version
Lifeguard Strategies for Supporting Adolescents and Adults Affected by FASD (2006)
Living with FASD Publication (Published twice yearly)
Network News (quarterly newsletter available by email)

Additional Resources

Why Me? Why My Child? (2006) Anita Grosse Saskatoon District Health.
Let's Talk FASD (2005) VON Canada.
FASD Strategies not Solutions Booklet (unknown date) Region 6 FASD Committee.
Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. (March 2005) Chudley, A.E., Conry, J., Cook, J., Looock, C., Rosales, T., Leblanc, N. CMAJ Canadian Medical Association Journal.
FASD A Framework for Action (2005) Public Health Agency of Canada.
FASD Booklet (2005) Public Health Agency of Canada.
we CARES Manual Practical Skills for Frontline Workers (2004) Anne Wright and Associates.
FASD Toolkit for Aboriginal Families (2005) Jennifer Wemigwans Ontario Federation of Indian Friendship Centres.
Trying Differently (2005) Fetal Alcohol Syndrome Society Yukon FASSY 3rd Edition.
Beautiful Smiles, Gentle Spirits Fetal Alcohol Spectrum Disorder (2003) Margaret A. Michaud and Sacha K. Michaud Ed.
Damaged Angels: A Mother Discovers the Terrible Cost of Alcohol in Pregnancy (2004) Bonnie Buxton.
Finding Perspective...Raising Successful Children (2005) Liz Lawryk.
FAS: When The Children Grow Up (DVD) A Knowledge Network Production NFB Canada Release Directed, Produced and Written by Sharon Bartlett and Maria Lerosé.
FASD in the Workplace. (2006) FASD Centre Regina Community Clinic.
Tough Kids and Substance Abuse (2000) Paula Cook, Richard Kellie, Kathy Jones, Laura Goossen.
Living with FASD A Guide for Parents (2004) Sara Graefe.
Fantastic Antone Succeeds! (1993) Judith Kleinfeld and Siobhan Wescott Fairbanks, AK: University of Alaska Press.
Fantastic Antone Grows Up (2000) Judith Kleinfeld, Barbara Morse, Siobhan Wescott Eds. Fairbanks, AK: University of Alaska Press.
The Challenge of Fetal Alcohol Syndrome Overcoming Secondary Disabilities (1999) Ann Streissguth and Jonathan Kanter Eds.



FASD Tips for Parents and Caregivers

Numbers 1-20

Downloadable on our website:
www.skfasnetwork.ca

Fetal Alcohol Spectrum Disorder

Developed by:

FASD Support Network
of Saskatchewan Inc.

FASD Tips for Parents and Caregivers

- Tip #1 How You can help Children with FASD Make Decisions
- Tip #2 How You can help your Child with FASD Make and Keep Friends
- Tip #3 How You can help Teens with FASD Manage Money
- Tip #4 How You can help Adults with FASD Manage Money
- Tip #5 How You can help Teens and Adults with FASD Make Decisions
- Tip #6 How You can help your Child with FASD Figure out Reality and Fantasy
- Tip #7 How You can help your Child with FASD Learn to cope with their Senses
- Tip #8 How You can help Children and Teens with FASD Learn about Ownership
- Tip #9 Making Changes with Children and Youth with FASD
- Tip #10 Tips to help your Child or Teen with FASD take part in Sports and Activities
- Tip #11 Care for the Caregiver of Children and Youth with FASD
- Tip #12 How to help Children and Teens with FASD Succeed in Community Groups
- Tip #13 How You can help Children with FASD Understand Time
- Tip #14 How You can help Children with FASD Understand Structure
- Tip #15 How You can help Children and Teens with FASD Develop Routines
- Tip #16 How You can help Children with FASD be Successful at Camp
- Tip #17 Healthy and Safe Sexuality for Teens and Adults with FASD
- Tip #18 How you can Help a Teen or Adult Avoid Drug and Alcohol Use and Abuse
- Tip #19 How you can Help a Teen or Adult Avoid Trouble with the Law
- Tip #20 Understanding Fetal Alcohol Spectrum Disorder (FASD)

How You can help Children with FASD Make Decisions

Good decision making is very hard for children with FASD. Every-day decisions are difficult for them to make. Because their brains work differently, children with FASD may not be able to clearly understand the outcome of their actions. They may also have trouble sorting out the facts when they make decisions.

Most parents help their children to learn how to make good decisions and wise choices. Parents and caregivers of youngsters with FASD soon discover that their children need extra help learning how to make decisions. They might need this help for a longer time than other children do. This sheet offers you some tips on how to teach your child about how to make good decisions and wise choices.

First, some 'real life' examples...

Example #1

It's a cold winter day and your child doesn't want to put on her coat, hat or mitts.

How you can help

Your child may not understand that she is cold because she doesn't have enough clothes on. In the cool fall weather, start teaching her to wear her mitts and hat. Let her hands get a little chilly and then have her put on her mitts and hat. Say to her, "When my hands are cold I always put mitts on. When my body and head feel cold I always wear a hat. Don't your hands and head feel warmer with your mitts and hat on?" Do this over and over again. You can help her stay safe in cold weather.

Example #2

You're in a grocery store and your child opens a bulk candy bin full of bright coloured candy. He reaches for some candy to eat. You tell him that you'll first need to pay for the candy - it's not free. A few minutes later, he picks up an apple and takes a bite.

How you can help

This little boy didn't understand that you have to pay for ALL the food you take in the store. He needs a very clear and simple direction. "We don't put things in our pockets until we've paid for them. We need to pay for everything we take from every store. After we pay for our food at the check out you can eat something."

FASD Tip #1

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Please feel free to photocopy
and use these sheets.

Some Tips to Improve Decision-Making:

1. A child with FASD takes longer to learn some things. Routine is important. Try to do things the same way every day. For example, your child needs to put his dirty clothes in the laundry hamper every time he gets into his pyjamas. Repeat, repeat, repeat- it will help your child develop a good life skill.
2. Try to keep your explanations short. Use the same words each time. A rhyme or rap may help your child remember the order of things to be done. For example, “Feed the cat, outside there’s snow, wear your hat, off to school you go.”
3. Use visual cues or hints whenever you can. For example, put a picture of a coat over the coat hook where your child should put her coat.
4. Offer only 2 choices at a time. For example, “Do you want to wear your blue sweater or your red sweater today?”
5. Try to cut down on things that distract the child with FASD. It’s hard for them to think straight when a lot is going on. For example, if a few children are getting ready to go outside, it will be easier for you and the child with FASD to get ready before or after the other children.
6. It is important to leave enough time for a child with FASD to move from one activity to another. It may help to set a timer for 3 minutes and let your child know that when it rings it’s time to stop playing and get ready for school.
7. Point out good decisions and good choices made by your child. For example, “That was great that you didn’t run into the street after your ball! You made a good decision. I’m proud of you.”
8. Try to stay calm and cool. If you get angry or lose it your child may become excited or confused and lose control of his or her behaviour.

How You can help your Child with FASD Make and Keep Friends

It can be hard for children with FASD to get along with others their own age. Children with FASD tend to have the social skills of a child much younger than their peers. To cope with daily life, children with FASD need to use a lot of energy focusing on themselves. And sometimes this leads them to miss the subtle messages and habits of friendship. For example, they may not wait their turn. Or they may stand too close to others and get into their 'personal space'.

It can be very lonely and frustrating when other children don't want to play with them. This makes them in danger of being taken advantage of or bullied by others. For a parent it is hard seeing your child not 'fit in'. Here are some tips on how you can help your child become more aware of how friends act with each other.

First, some 'real life' examples...

Example #1

A child with FASD is on the schoolyard all alone. The children ignore him.

What is happening

This child doesn't know how to ask to be part of the other groups. He finds it hard to just join in. The other children don't make the effort to include him. He needs help knowing and practicing what to say to join a group.

Example #2

When your 10 year-old with FASD comes home from school he wants to play with the 6 year-old down the street and not with his 10 year-old neighbour. He feels more comfortable playing with someone younger. He likes the games played by the 6 year-old more.

What to do

Your child just may not be able to play well with children his own age. Avoid situations where his lower maturity level makes it hard for him, such as in competitive sports.

Example #3

Your 7 year-old son is at the pool and he's trying to join a group of teenage boys who are jumping off the diving board.

What to do

He doesn't understand that the teens don't want him. Help your child become sensitive to body language and facial expressions. Look at pictures of people in books and magazines together and ask them what they think the people are thinking or feeling. Explain how humans 'talk' in many ways not just by using words. Play act together and see if your child can figure out what emotions you are expressing.

FASD Tip #2

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Please feel free to photocopy
and use these sheets.

Some Tips for Friendship:

1. Find games and activities that help your child build social skills. Safe and supervised groups such as Scouts, Girl Guides, Air Cadets or swimming or skating lessons are great.
2. Don't expect that your child will have a large group of friends. One or two close friends who have known her for many years will not only be good friends but, care enough about her to help her stay safe.
3. Keep an eye on your child when he plays with others. This way you can explain why things may have gone wrong and, how he might want to act the next time to get along better with his friends. You could also protect a child from children who are too rough or cruel.
4. Children with FASD usually feel best in a place they know and in situations they can predict. Avoid large sleepovers and parties because they can be too confusing and overwhelming to a child with FASD. A sleepover with one friend in her own home would be best. A birthday party with 2 friends over for a short time would be more successful than a large party with many children and a lot of chaos for a long time!
5. Over and over again teach them the social skills of listening, taking turns, not talking when others are and taking an interest in other people by asking them questions. Your child will need help and lessons on all these subtle ways of friendship.
6. Talk to your child's teachers and ask them to make efforts to include your child in activities and groups. And, thank them for their efforts. Your child's teacher will be more likely to help if she sees you notice her extra care.
7. Sometimes children don't notice that they are different. Even though we know they are less mature than their peers, if they are happy the way they are then that's where they are at and that's great.
8. If you see that some children are being cruel to your child, you may need to step in and stop them. Try to do this gently, so that your child is not embarrassed. Then, when there's a chance, talk to the children about how great it is that we're all different, how boring it would be if we were all the same. Ask the other children how they might feel if they were left out or teased.
9. From a very young age, children learn a lot from their friends. All parents need to keep an eye on the friend their children make. Like other parents, you may need to forbid your child from being with certain kids and be happy they are with others.
10. Supervise, supervise and supervise. Keeping a close eye on your child and their play mates so you can step in and help them sort things out at the first sign of overexcitement, stress, exhaustion, misunderstanding or trouble.

How You can help Teens with FASD Manage Money

Managing money can be very confusing for people with FASD. Money and the value of money are hard to understand. \$20.00 for a chocolate bar and \$20.00 for a pair of new shoes may both seem like good prices to the teen or adult with FASD. Money is an abstract concept. That means while you can touch money and hold it in your hand, what money can buy or what money can do are ideas.

How much is something really worth? What happens if you don't pay your phone bill and your phone gets cut off? Why should we try to save money? How do you get out of debt?

This sheet offers some tips on how you can guide and teach your teen or adult about managing money.

But first some 'real-life' examples...

Example #1

A 14-year old lends money to a friend. She is surprised and confused when she doesn't get the money back. This is not the first time she has lost money this way.

How you can help

It is okay to let this girl make mistakes by 'lending' small amounts of money. If she is broke because she never gets back the money she lends, maybe she will learn that lending money is not a good idea. If she is not learning from her mistakes, make it a rule that she needs to ask a parent or trusted friend before she lends money to anyone.

Example #2

A teen sells his new \$100 running shoes to a friend for \$5.00. He doesn't understand what he did wrong.

What you can do

Go with the teen and ask that his shoes be returned for \$5.00. Explain that we don't sell our things to other people without asking a parent or trusted adult.

FASD Tip #3

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and use these sheets.

Some Tips to help with Money Management:

Teens with FASD usually 'live in the moment'. Living in the moment means that when they want something they do not think about past mistakes or understand that what they do affects the future. You'll need to be patient and explain over and over again how to spend money wisely. You can help your teen or adult with FASD get into the habit of thinking before he spends his money.

If your teen lives at home:

1. You can help your teen understand the value of money. Go shopping together. Give her a small list of items your family needs and tell her she only has \$20.00 to spend. Have her write down the prices of the items she puts in her cart and add the prices up on a calculator. This will help her understand that the food she puts in the cart all cost money. You can then guide her to choose healthy food that fits in her budget.
2. Teach your teen with FASD to write in a notebook which bills need to be paid and when they need to be paid. This will become his budget book. Have the teen write down when he spends money on his bills, food, clothes, medicine or fun. Staple an envelope to the back of the notebook to keep all receipts in. Try to get him into the habit of writing totals in this notebook. It is important to keep the notebook in the same place all the time. Teach him to have a trusted family member or friend help him with his money.
3. Do not to give her large amounts of money to spend all on her own. If she get gifts of money at Christmas or birthdays, help her spend it wisely. If the teen insists on an expensive item like a stereo, have her save it in the bank for one month. This will allow her time to think things over before she spends a lot of money. Praise her when she makes good decisions.
4. Have your teen spend some of the money she earns or receives from allowance (her money) on the things she wants or needs. This will help her understand that shampoo, clothes and treats all cost money.
5. Have your teen pay for a magazine subscription or his own phone or internet. When the bill comes in the teen's name, help him to read the bill and find out what amount of money must be paid and on what date it must be paid.
6. Teach your teen important money skills like how to use a pay phone, coin operated laundry, or pay for a bus or a cab ride. Teach her to look up a phone number in a phone book so she is not spending money to call directory assistance. Teach your teen to take back video and game rentals on time. Show him how quickly the charges add up every day they are not returned.
7. Teach your teen that it is cheaper to spend \$80.00 on food for 2 weeks than to spend \$5.00 a meal each day eating out.
8. When your teen is about to leave home set up a system to support her. She will need to know who she can call anytime she needs help. Make sure she takes her budget book and keep checking to see if she is paying her bills.
9. Give your teen the freedom to make small mistakes but try not to bail him out. We all learn from mistakes. Teens and adults with FASD need to make more mistakes before they really understand and remember.

How you can Help Adults with FASD Manage Money

When an adult moves out of the family home money is an important issue. Many adults with FASD have very little money so when money problems start, things can get bad in a short time. Managing money can be very confusing for people with FASD. Money and the value of money are hard to understand. \$20.00 for a chocolate bar and \$20.00 for a pair of new shoes may both seem like good prices to the adult with FASD. Money is an abstract concept. That means while you can touch money and hold it in your hand, what money can buy or what money can do are ideas. How much is something really worth? What happens if you don't pay your phone bill and your phone gets cut off? Why should we try to save money? How do you get out of debt?

Plan ahead the best you can to avoid serious money problems. Lack of money can lead to poor health, isolation, and dangerous situations for adults with FASD.

This sheet offers some tips on how you can guide and teach an adult about managing money.

But first some 'real-life' examples...

Example #1

An adult has just spent her entire cheque on things she wanted but didn't need. Now she doesn't have enough money to pay her power bill. She thought her bill was paid because last month she gave the money to a friend to pay it. Her power bill is now 2 months behind.

What you can do

If she is on social assistance arrange with her worker to have rent, power, water and energy bills paid directly. Cheques for personal cash can be given every 2 weeks instead of once a month.

Example #2

An adult meets a really nice person and begins to spend time with this person and thinks of him as a friend. He spends money on activities and invites his friend to his home. After a few visits things start to disappear. CDs, movies, clothes, and even food disappear. Sometimes the new friend asks to borrow things, but mostly they are just taken.

What you can do

Teach that not everybody can be trusted. Hopefully this lesson will be learned when items are taken again and again, but expect that this will be hard to learn. Explain over and over that it is best not to lend your things out and that these items cost a lot of money. At Christmas and birthdays the items can be replaced as gifts. It is best not to give expensive gifts because they may disappear.

FASD Tip #4

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www.skfasnetwork.ca

Please feel free to photocopy
and use these sheets.

Some Tips to Help with Money Management:

1. Find a trustee. It's better if the trustee is not a family member or friend. A trustee can help to manage money before it becomes a problem. The trustee will give him small amounts of money and supervise bill paying. There are agencies that act as trustees, call community organizations for ideas or referral to organizations that provide this service. You can also look under lawyers in the phone book for this service.
2. If the adult is having trouble spending money wisely, you can help her out in many ways. Do not lend her money. If you do, do not expect to get your money back. You can buy food, a bus pass, or gift certificates for a food store, a haircut, or entertainment services that are in her neighbourhood. Never give her cash.
3. Do not give expensive gifts. These are often pawned for small amounts of cash and never bought back.
4. If she is receiving social assistance it can help if she is designated as a person with a disability. A doctor needs to fill out a form that states that this person has a disability that makes it hard for her to find and keep a job, and that the disability will last for longer than one year. There may also be rental supplements available also. Call the Network at 1-866-673-3276 for information.
5. Avoid debit cards and personal cheques. It is harder to spend money if he has to go to the bank when it is open. If a debit card is used set up a daily withdrawal limit with the bank. Make a rule that credit cards are not a good choice.
6. Teach that gambling does not make you rich, it makes you poorer. Gambling makes the government, casinos and bingo's rich. Make a rule that gambling is not a good choice.
7. Avoid big phone bills. Set up account restrictions with the phone company including no long distance calling out and no additional features like caller ID, call waiting etc.
8. Teach an adult with FASD to use a notebook to write down which bills need to be paid and when they need to be paid. This will become his budget book. Teach that bills are paid first. Have him write down everything else that he spends his money on like food, entertainment, clothes, and medicine. Teach him to staple an envelope to the back of the book and keep all receipts. Help him to keep track of where he is spending money.
9. Teach him to keep his budget book in the same place all the time. Have a trusted family member, friend or support person check that the bills are getting paid and help with purchasing items.

How You can help Teens and Adults with FASD Make Decisions

Good decision making is a life-long challenge for a person with FASD. They will need the aid of someone who can be trusted to help them make good decisions. But how do you help your teen or adult to be independent?

Teens with FASD are like most teens: they want to feel good about themselves, have friends and be independent. But, because of the way their brains work, they are likely to act first and think later. They are often more impulsive than their peers and, quick decisions can lead to trouble. This sheet offers some tips on how you can guide and teach your teen or adult to make good decisions.

But first some 'real-life' examples and tips...

Example #1

A teenager has a paper route. He does a great job delivering papers everyday after school! But, he forgets to pick up the customer's monthly payments. Collecting money is not part of his daily routine.

How you can help

Help him make collecting money part of his routine. On collection day a parent or trusted friend could walk his route with him. This way he'll be reminded to collect the money. And, he'll have someone to help if he needs to make change for a customer. Explain that his job includes delivering papers, collecting money and paying the newspaper business their share.

Example #2

An adult is on her way home from work and she has just enough money for the bus. While she's waiting for the bus to come she gets hungry. She goes into the store and buys a chocolate bar. Now she doesn't have enough money for the bus and she is going to have to walk home.

How you can help

You can help this woman learn to budget her pay. A monthly bus pass, or enough bus tickets to last her the whole month, would help her get home safely from work.

FASD Tip #5

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Some Tips to Improve Decision Making:

1. Youth and adults with FASD need a long time to learn some things. You can help by being patient and explaining some things over and over again.
2. A person with FASD may need a lot of time to make good decisions. Try to give them plenty of time to make up their mind. You can also explain how the decisions we make effect how our life turns out.
For example, you can explain how a bus pass really works. Even though a bus pass seems to cost more money than bus tickets, it can sometimes be cheaper. Explain how a bus pass will let them use the bus as many times a day as they want and, on any day of the week. It's less hassle finding the right change too. Help them consider the pros and cons.
3. Try to have fewer things to distract them when they have to make a decision.
For example, before the family orders food in a restaurant, talk about what meals are on the menu and help them decide what they want to eat and drink. Then let them order food first from the waitress or waiter. If you go to the same restaurant every time they may feel more relaxed and less confused. (Foods that have food colouring or additives and preservatives can effect behaviour in negative ways.)
4. Help them understand that everyone makes mistakes. And, that it's good to stay calm when you've made a mistake.
Teach them to look around and see if there is someone they know who they can ask for help. If they don't know anyone, teach them that it is okay to ask for help from a mom or a grand mother. Help them understand that getting angry or rude will make things more confusing for them.
5. You need to show them why it is best to think things over before they do something they are not sure of. Good decisions often aren't easy to make. Life is complicated. But, good decisions sure are easier to live with. Make sure you point out when they make good decisions. Talk about different situations and how what they decide to do could be a good choice or a poor choice. For example, what would you do if you missed the bus? Would you stay in the bus shelter and wait for the next bus? Or, would you walk to work even if it's really cold out?
6. Point out how everyone has responsibilities to ourselves and to others.
For example, it is our job to keep our bodies clean and to wear clean clothes. And, it is our job to try to keep our homes clean and tidy. Talk together about the important life skills people need to live well with others and with them self.
7. Talk and show them about what it means to be a grown-up. Explain that it takes time to learn to be a mature adult. In life, everyone needs help from a family member or trusted friend. Tell them how you, or friends or Elders have learned to manage adult life. Try to make your examples short and clear.
8. Take time to explain what can happen when money is spent on the wrong things or when a job is not done right. For example, if all the money is spent on new clothes, how will the rent be paid and food bought?
9. Life skills, Life Skills. Life Skills. Make their chores and responsibilities habits in their lives. If they have good habits and clear routines they will have less decisions to make every day.

How You can help Your Child with FASD

Figure out Reality and Fantasy

All children tell stories. Children see the world differently than adults do. But, children with FASD have a hard time knowing the difference between reality and fantasy.

Your child may lie, over and over again, about many things. But, they probably aren't doing it because they are a 'bad kid'. They may be having trouble with their short-term memory, so they are filling in the blanks. They may be trying to please you by telling you what they think you want to hear. Or, they may be having trouble thinking in a logical way. Because of the way their brain works, they might really believe the lies that they are telling you.

This can be very frustrating and confusing for parents and others. Sometimes it's hard to feel close to someone whom you can't trust or believe. This tip sheet offers you some ideas on how to cope and teach your child about reality and fantasy.

Example #1

You ask your son if he has brushed his teeth. He says he has. But, you see that his toothbrush is still dry. You feel mad because he seems to be willfully lying.

What is happening

He is telling the truth as he sees it. He HAS brushed, many times in the last month. Because of the way his brain works, his sense of time is different from yours. He doesn't connect your question with something that has happened in the last half hour. His answer shows that he processes information differently.

Example #2

One member of the family has lost \$20 while doing laundry. The rest of the family has been told that the money is missing. The next day your child with FASD finds the money. She insists that this \$20 was not the one that had been lost, even though she found it in the laundry room.

What is happening:

The child with FASD may believe she is telling the truth. She can't connect the money she has found with the lost cash. After all, in her mind that money is lost - the money she found isn't lost!

Even when something seems clear and obvious to you, it might not be to your child. You'll need to make an effort, over and over again, to fill in the gaps of what your child can't understand. For example, when talking to your child, ask questions like, "Do you think it might be that _____'s money fell out onto the floor when she was loading her clothes into the washer? Could this be her money? Could you have found _____'s lost money?"

FASD Tip #6

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Some Tips to Help with Telling the Truth:

1. Can your child tell you when she has made a mistake or lied? There are times when you will need to help a child sort out the truth from a lie. It helps to have an open and honest relationship with each other.
2. Learn to give very clear instruction like, “Go brush your teeth please.” A clear order is less confusing than asking questions.
3. Encourage your child to tell you what is true, not what they think you want to hear.
4. Practice story telling with your child. Have your child tell you stories and praise them for having a good imagination. Tell them that there are good times to make things up and bad times. Offer real life examples.
5. Read stories with your child every day. Many books are based on make believe. Have your child tell you when he thinks the story might be true or when it is made up. If you go to the library, the librarian can help you pick some good books that work for kids your child’s age.
6. Be very careful about what you allow your child to see, read and hear. Your child may have a lot of trouble separating reality from fiction in the things they see. Be aware that a child may believe that what they see on TV shows, movies and video games are “real”. Music and pictures can be very suggestive and confusing to a child with FASD. Some video games are very violent and /or sexually inappropriate for children. Take the time to sit and watch the TV or a movie with your child. You will be able to help them sort out fact from fiction.
7. Be careful about what games you allow your children to play.
8. Be your child’s ‘external brain’. Know what they have been doing and need to do next. This way you will know what really happened and be able to guide your child to remember the facts.
9. Help family members and school staff understand that your child may not remember things as they really happened. Be positive about it if you can and suggest some of the ideas mentioned here. Do this before there’s a problem, if you can.
10. If you catch your child lying, try to remain calm. If you yell they will get distracted and find it harder to understand what they have done wrong.
11. Every child needs love and responds to love. If you speak with compassion they may be more open to listening to you.

How You can help Children with FASD Learn to Cope with their Senses

Some children with FASD are very sensitive to touch, movement, light or sound. Because of the way their brains work, children with FASD may be so focused on what they hear, see or feel on their skin that they can't focus on other things. When children have over-sensitive senses, they may need to shut down. Or they might act out and act badly as they try to stop the thing that is bothering them. This can be very hard for parents to cope with, especially when you are out in public.

It is important to remember that some children with FASD have senses that don't work well or that are numb. They really can't tell when they are hot or cold. And some may not feel pain as much as other children can. Try to help these children dress in the right way for the weather and to check them for illness or injury.

Here are some 'real-life' examples and strategies...

Example #1

A parent takes her child to a puppet show at the library. All week they've wanted to go! But, when they get there the room is noisy and crowded and the child gets nervous. He plugs his ears and as he gets more frustrated he starts to yell, "shut up" at the kids around him.

What you can learn

This child is over-sensitive to sound. The noise in a crowded room is too much for him. He tries to cope by covering his ears. His sensitivity to noise makes him frustrated and over-stimulated.

Example #2

A 7-year old child takes off her socks as soon as she gets home from school. Sometimes she takes her socks off at school. When the girl is asked why she takes off her socks she says, "I can't stand to wear them".

What you can learn

She is over-sensitive to the clothing she's wearing. She can feel even the small seam in a sock and can't 'tune out' that feeling. This means she can only focus on the clothes that bother her and nothing else. She needs to wear clothes that are comfortable for her.

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Tips on How to Adapt to Sensitivities:

Try to find out what your child is reacting to so that you can avoid what's causing them trouble. Try not to go to places where your child may be over-stimulated by noise, light etc.. You may also want to be pro-active and have sunglasses or headphones ready. If a child is showing signs of over-sensitivity to something, and heading to a 'meltdown' try to leave before the meltdown happens. As the child gets older, he or she can be taught why they are feeling over-sensitive, and how they can avoid these situations. An Occupational Therapist may be able to suggest some exercises or ways to reduce the child's sensitivities.

Sensitivities to Noise:

1. If you want or need to go to public places like malls or fast food restaurants try to go at quiet times of the day. Fewer people go mid-afternoon or early in the day.
2. Holding the child's hand will help them feel calmer and less confused by the hustle and bustle around them. Plan to stay for a short time only.
3. Turn down the TV, radio, telephone etc. Do not have the TV and video games on in the same room. It is too much for the child with FASD to hear at one time.
4. Speak to your child in a quiet voice .

Sensitivities to Light:

1. If a child seems sensitive to light offer sunglasses, tinted goggles or a big sunhat.
2. Use dim lighting when you can.
3. Avoid flickering or blinking lights like the ones on Christmas tree decorations.
4. Avoid TV shows, movies and video games that use flashing lights and flashing things to make you notice the screen.

Sensitivities to Touch:

1. Wash all clothing a couple of times before wearing.
2. Turn socks and gloves inside out so the seams won't bother them.
3. Comfort is the most important thing for your child. Buy soft feeling clothes and avoid stiff and scratchy clothes. Remove all tags. Bedding needs to feel comfortable for the child. Some children like heavy blankets on their beds (even in summer) and, some like light blankets on their bed (even in winter).
4. To some children firm touch feels better than light touch. Some children like their hair stroked while some children like a firm backrub. Find out what kind of touch your child likes.

How You can help Children and Teens with FASD Learn about Ownership

Children and teens with FASD often have trouble understanding what 'ownership' means. There are many reasons for this. First, because they might be 'living in the moment', if they see something they want and it's available they take it. Or, because of problems with short-term memory, they might not remember taking it. Or, they might have thought that it was theirs or that someone had given it to them. They also might lie and deny stealing because they are afraid of being in trouble. Finally, because each day is new and different to someone with FASD, the child or teen may not remember that they had stolen before and that this was the wrong thing to do.

It is hard to know what to do when a child or teen with FASD steals something. Are they stealing because they are behaving badly? Or, because they really didn't understand that it is wrong to take things that belong to other people? You will need to use your judgment in each case. And, you'll need to teach them over and over again about what ownership means.

Here are some tips on how you can do this and some 'real life' examples...

Example #1

A child sees a blue jacket he likes at school. So, he takes it and wears it.

What happened

The jacket doesn't seem to belong to anybody. He doesn't consider who owns it. It looks at that moment that no one does and, his thinking is based 'in the moment'. Because of the way his brain works, he doesn't think ahead to what would happen when the owner of the jacket sees him wearing it.

Example #2

A teen with FASD asks her older sister if she can wear her sweater. The sister says, "Yes", but she assumes that she is loaning it and not giving it to the little sister. She may not give it back. She argues that it's now hers and that her big sister 'gave' it to her.

How to help

People in this teen's life need to be very clear when they lend her things. "Yes, you can borrow my sweater for the dance. But, I'll need it back tomorrow. This is not a gift to keep."

Example #3

Some children are on the playground. One child has a skipping rope. Another child with FASD takes the skipping rope.

How to help

The child with FASD wants the skipping rope and even though she knows it belongs to someone else she picks it up and puts it in her backpack. This is something we might expect from a 2 year-old child. This may be the age this child functions at. Talk, over and over again, about how ownership works. Describe things as your jacket, my wallet, Jane's skipping rope.

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Tips to Teach about Ownership:

1. Most children will take something that is not theirs at least once while they are young. It is up to the parent or caregiver to teach a child about ownership and right from wrong. Be patient. Ownership is a hard thing to learn from children and teens with FASD.
2. If your child takes something that is not theirs, ask her how she would feel if her favourite toy or shoes were stolen. Help them to understand that no one likes to have their things stolen.
3. If your child takes something which doesn't belong to her, make sure she returns it with an apology. Practice how she will say sorry. Go with her for support.
4. Mark the things your child owns with a sticker. For example, everything with blue stickers are his. If they don't have his sticker on them, he should not take or use them.
5. If your child takes something that is not theirs, do not get caught up in an argument. Simply say, "This ... belongs to ...". Have them return the item. Stealing needs to be dealt with quickly, firmly and with appropriate consequences.
6. Valuables should not be left around where a child may come across them. Lock up things like coin or stamp collections, cameras, money and jewelry.
7. Stores and malls are not good places for children and teens to "hang out". A good rule is that a parent must always go with the child or teen to the store or mall. Shoplifting can be a big problem with children and teens with FASD.
8. Supervise, supervise, supervise. Children and teens with FASD need supervision at home, at school, during free time, and all the time.

Making Changes with Children and Youth with FASD

Life is full of change. For children and teens, adults control many of the changes. Moving to a new home, starting school, changing classrooms or teachers, changes in the family or moving to the next grade are changes children often face. But for children and youth with FASD, change can be very difficult to cope with. Along with the big changes, they may really struggle with simple every day changes such as, stopping play to go eat. There are many ways you can help your child or teen learn to cope with change.

Here we offer some 'real life' examples and tips...

Example #1

At school a child with FASD is working on his math. The teacher tells all her students to stop and get ready to go to gym class. The girl with FASD starts shouting that she's not done with her math!

What is happening

It is hard for this child to get into her math work and then have to leave. Changing from one activity to another is harder for her than for most children. It would help if the teacher would give her advance notice before a change in class needs to be made.

Example #2

A teenaged girl with FASD is being given a ride to a friend's home. On the way she asks, over and over again, which streets they will be going down and at which corners they will turn.

What is happening

She wants to make sure she'll get home. She's nervous about not having control of getting there and she believes there is one 'right' way to get to her house.

Example #3

One day a child with FASD gets to school late. She is really upset about being late. But instead of going into her classroom, she stands just inside the door and she can't move.

What is happening

Being late has changed her routine. She doesn't know what to do so she does nothing. She is a concrete thinker. It is hard for her to problem solve about what she should do next. If she usually hangs her coat up at 8:50, and it is now 9:05, what should she do?

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Some Tips to help Your Child Deal with Change:

1. Create routines so your child knows what comes next in the day. Try hard to stick to the same routines. This way no matter how much change is in their life, their home life will be secure. Structure helps ease stress.
2. For young children, it is helpful to have a board with pictures that show the daily routine. (Many preschools and daycares have picture boards.)
3. Tell your child ahead of time if the routine has to change. Some children may need a full day's notice of change, and others may do best with just a few minutes warning.
4. Sometimes plans change. Talk with your child or teen about what might happen if the plan doesn't go the way you hope. For example, "What will we do if our car isn't fixed by tomorrow?"
5. Sometimes it makes sense to plan for problems. Talking about a plan B or C can teach your child or teen about how decisions need to be flexible. For example, "Since our car is always breaking down, do you think we should look into getting a bus pass?" Have a 'plan B' and maybe a 'plan C' too.
6. Break changes into small steps. For example, "First you need to put away your toys." "Okay, now let's go brush our teeth." "Good, here are your pajamas." A long list of things to do is very confusing for children and teens with FASD
7. Instructions need to be simple and clear. It helps to look each other in the eye.
8. A countdown may be helpful for younger children. For example, "Play for five more minutes and then it's time for your bath. ...three more minutes... Time to put the toys away your bath is ready."
9. Using an egg timer may help your child or teen 'see' how much time is left for a certain activity. For example, if you ask them to do homework for 15 minutes, they will hear the bell when the time is up.
10. When you can, let your child finish the thing they are working on. Some children really like and need to take their time to finish things. They enjoy working on things at their own pace and like to finish a project.
11. Organize yourself for the morning. Have school clothes out and ready to wear. Have backpacks packed and ready to go.
12. Use photos of real people and places to help prepare a child for moves from one grade to another or to a different school or home. For example, a 'transition book' can help get a child ready for a move to the next grade. This book can have pictures of the child with this year's teacher and pictures of the child with next year's teacher. The book can hold pictures of the child's new classroom, where he should put his boots, what door to come in etc. This may make it easier for him to adapt to a big change in his life.

Tips to help your Child or Teen with FASD Take part in Sports and Activities

Many children love sports and want to join team sports and group activities. But, for some children with FASD the demands of teamwork, following instructions, improving skills quickly and competition leads to more stress than fun. Here are some tips that can guide you in helping a child who is really keen to take part in sports and activities.

First, some 'real life' examples...

Example #1

A child really wants to take swimming lessons. She's like a fish in water and loves swimming. But, the swimming teacher says that she can't move to the next level because she didn't master all the skills she was supposed to. She is really upset by this.

What is happening

This child is gaining some new skills in the class. Regular lessons are quite rigid about what needs to be learned in a set amount of time. This can be frustrating for the child because she wants to do well and move up to the next level.

What to do

As a child moves up the levels in swimming, the skill level becomes more difficult. Many children need to repeat levels. If this child doesn't want to repeat a level until she gains the needed skills, many communities offer one-on-one lessons for children with special needs. The YMCA or YWCA would be able to help you find out more about lessons in your area. Some small towns will offer one class just for children with special needs.

Example #2

A 12 year-old boy wants to join a school soccer team because his best friend is on the team. You are nervous because the last time he tried a team sport the coach complained that he didn't follow directions well and he wasn't focused enough.

What to do

Should he get another chance, but what if he fails again? This boy is coping in the best way he can and he just wants to do what other kids can.

His coach needs to watch him carefully and get to know his strengths. A parent or caregiver can talk to the coach to explain how FASD limits what he can do but also talk about what strengths he has that could help a team. The parent may want to explain how important emotionally is to this boy to play on the team. The coach wouldn't know this without some background information.

FASD Tip #10

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Tips on how to have Fun with Sports and Activities:

1. Don't be shy to talk to your child's coaches or teachers about the things that are hard for your child. Coaches and teachers care about children and want your child to have a good season on the team. If you share information about your child with the coach or teacher, they will know more about how to help your child succeed.
2. Share some information about FASD with the group leader or coach. They need to understand why your child needs longer to do things or has some trouble following directions.
3. If your child has a close friend, try to have them join a group together. It will help your child to go with someone she or he knows.
4. Your child's friends and team mates can be a support to your child and can help him make good choices.
5. Help your child to choose activities that she enjoys and has fun doing. This gives her a chance to be successful.
6. Supervise, supervise, supervise. Go to your child's team practices and games.
7. Be there and help her by explaining things. Watch for inappropriate behaviour and help her if she misunderstands something.
8. Practice with your child to help him learn the new skills.
9. Ask your child to tell you all about his or her activities. Ask many questions about the coach and the other players. Listen for things that are challenging for him and also things that he is doing well.
10. Cheer her on because she's an awesome child.

How to Care for the Caregiver of Children and Youth with FASD

Being a parent or caregiver can be a great experience, but it is also tiring and challenging. Families with children with FASD are often under a great deal of stress. Others don't always understand the issues they face everyday. This can make one feel alone and overwhelmed. You and your family need you to take care of yourself. If you are stressed and tired you won't be able to see clearly or give your kids all that they need. And, stressful times seem even worse when you are exhausted. Here are some tips on how you can take time to care for yourself.

First, some 'real life' examples...

Example #1

Your son's teacher tells you that he's doing fine, but you know that he has a 'meltdown' most days when he gets home from school. You dread the time between school and supper.

What is happening

Your son is probably trying really hard at school. He's putting so much effort into his work that he's exhausted. He knows that home is safe place and he can relax. He does this by letting his feelings loose and letting go of feelings that have been building up all day.

What to do

You can help your son develop some good relaxation habits. Listening to his favorite music with the headphones on or quietly watching a favorite movie can help him unwind. Maybe some quiet time in his room is what he needs to help him calm down or a bike ride will help him relax after school. Find out what works for your son and encourage him to relax in a positive way.

Example #2

Your family has been invited to spend Christmas Day with your partner's parents. You know your children will be uncomfortable there and out of their routine. But, you don't want to upset your in-laws. You lie awake at night worrying about how you can keep everyone happy.

What to do

You know from experience that your children need structure and routine but your in-laws don't understand this. Share information about FASD and how it relates to your child. Ask them to come to your home for Christmas. Or go to their home for a short visit-maybe for breakfast and then spend the rest of your day at home.

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Some Tips on How to Care for Yourself:

1. All parents have dreams for their kids. It may be hard for parents of children with FASD to deal with disappointment or guilt. A counselor, religious leader or Elder may be able to help you.
2. Think about what helps you to relax and make a real effort to do it every day or at least every week. Have coffee with a friend, take a long bath with the bathroom door locked, call a parent you like, go out with your partner, go to a support group, hire a babysitter or share and swap childcare.
3. Find someone to talk to who understand what it's like living with children with FASD. This could be a family member who is close to you, or another parent of a child with FASD. If you don't know any other parents, call the FASD Support Network of SK (our number is 1-866-673-3276 or 975-0884). We'll connect you with another parent. It is amazing how many experiences parents share.
4. Sometimes, the only place your children can truly 'shine' is in your own home. Let them be at home a lot and don't feel badly about celebrating holidays and birthdays at home where your children feel safe and comfortable.
5. Many children with FASD become very stressed when a family leaves home to go on holidays. It can be hard for them to leave a familiar area and routine or stay in a strange hotel room. It will be good for everyone if your children can stay in their routine.
6. Give your relatives some information to read about FASD. Or, have them call us at the FASD Support Network Saskatchewan .
7. Arrange for a break for you and /or your partner. Hire a mature babysitter who understands your child and train them about FASD and the importance of routine.
8. Take time to laugh. Rent a funny movie. Think about the funny side of some of the things your kids do.
9. Rest, relax, exercise, walk and try to look at the big picture. You are doing the very best job you can.
10. Think about all the things that you love about your children and all the things you admire.
11. Phone the FASD Network and get involved. Other parents need support and you may be the perfect person to support them. Another parent may be able to help you too.
12. Educate yourself. Knowledge is empowering.

How to Help Children and Teens Succeed in Community Groups

This FASD Tip was written for parents to give to a group leader, coach or community member. The tips will help those in the community understand the behaviours and needs of a child or teen with an FASD.

Being a part of a community group is good for children and teens. Children and teens with FASD may have trouble joining in community activities like Brownies, Cubs, 4-H and community sports teams. It is important for group leaders and their helpers to understand and support a child with FASD. This will help the child or teen be successful, make friends, and enjoy the activities in their community.

Here are some 'real life' examples of what might happen...

Example #1

The group meets in the school gym at 7pm. The children can play with the skipping ropes and basketballs until the meeting is ready to start. One child cannot settle down when the leader asks that the balls and ropes be put away. She runs out of control and hits the other children with the rope. This upsets everyone in the group.

What is happening

This child is over-excited. The noise, bright lights and the confusion of all the children playing are hard for her to cope with.

What you can do

Understand what is happening and help the child before there is a problem. Organize a quiet activity for all the children as they arrive. This will help the child with FASD to keep from getting over-excited. Or, arrange for the child to arrive right at 7pm or a few minutes late so the pre-meeting activity will not get her over-excited.

Example #2

You are Ryan's soccer coach. For the past 3 weeks, the teens have been learning a new skill. Ryan learns it well each week, but at the next practice, he has forgotten what he learned. Ryan doesn't want his team to know that he's forgotten, so he fools around and it looks like he's not trying. The other teens are annoyed at him and don't want him on the team anymore.

What's happening

Many children with FASD need to be taught a new skill many times before it is mastered. Ryan wants to be part of the team and do well. But, FASD causes poor memory and he really has forgotten what he knew last week. Ryan wants to be liked so he acts silly to hide his poor memory.

What you can do

Be patient and give Ryan lots of time to learn a new skill. Maybe he can practice the new skill at home or before the other children arrive for practice. Maybe Ryan could have success if he is allowed to be a supporting player rather than a key player. Community groups help all children learn teamwork and gain confidence.

FASD Tip #12

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Things I would like You to know about FASD

My child has Fetal Alcohol Spectrum Disorder (FASD) and I would like you to know some things about this disability. FASD is a permanent, lifelong brain injury. However, with support, encouragement, and understanding, people with FASD can have many successes.

People with FASD:

- Usually have an average IQ, are friendly and outgoing, and want to do what everyone else is doing.
- Have some special skills – some are very athletic, some artistic, some have a great sense of humour.
- May have developmental delays, behavioural problems, or learning difficulties. These are often invisible and misunderstood.
- Can experience failure and miss the opportunity to enjoy activities with their peers due to their disability.
- Friendship and community support is important to all children and youth.

Here are some things that might help:

When _____ feels stressed, you may see him/her _____
(child's name)

_____.

What I do when this happens is _____

_____.

Sometimes _____ will _____

This is because _____.

What I find works best is _____

_____.

If you have any questions or concerns please call me at _____

_____.

For more information about FASD call the FASD Support Network of Saskatchewan at **1-866-673-3276** or visit the website at www.skfasnetwork.ca.

How to Help a Child or Teen Understand Time

Understanding time is hard for people with Fetal Alcohol Spectrum Disorder. Time is an abstract idea. There is the telling of time, like reading a watch or a clock on the wall and the passage of time, such as playing for 30 minutes while waiting for supper. There is also being on time, being early or late! Time involves numbers and numbers can be very confusing. People with FASD learn best when they can touch and see things – time cannot be touched or seen.

Here are some ‘real life’ examples and tips...

Example #1

A parent tells a child that he may go bike riding after lunch. The child really wants to ride his bike, so he makes a peanut butter sandwich, eats it for lunch, and is out riding his bike by 9:30am.

What is happening

The parent gave clear and simple directions for when the child could ride his bike. The child knew he could not go riding until after lunch. He made lunch, ate it and left. The parent used the word ‘lunchtime’ to mean the child could ride his bike in the afternoon, after 12. The child understood he needed to eat his lunch before he could ride his bike!

What you can do

If your child can tell time, say “You can ride your bike at 1 o’clock” instead of after lunch. Many watches have simple alarms that can be set to ring to notify a child when they can do an activity.

Example #2

Your child asks you over and over again when an event is going to happen. “When is Barney on?” “When is it supper time?” “When is Daddy coming home?” are just some examples. You are going crazy because he asks the same questions twenty times a day!

What is happening

A child with FASD has no internal clock. Passing time, 10 minutes or 1 hour both feel the same to him. He looks at the clock on the microwave and it says 8:00. He does not know if it means 8:00 in the morning or 8:00 in the evening. He needs help keeping his day organized. Many children with FASD get thoughts stuck in their heads, (this is called perseveration). This causes them to ask the same question over and over again.

What you can do

A digital clock is much easier for a child to understand than a clock with hands. Be very consistent with how you say the time to your child. We understand that 2:45, fifteen minutes to one and quarter to one all means the same time. A child with FASD may think you are giving him 3 different times.

FASD Tip #13

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Some Tips to Help your Child Understand Time:

1. Establish routines that will help to develop habits. The habits will serve in place of the inner clock.
2. Use an egg timer for activities like showering and brushing teeth. Teach your child how to set the timer.
3. Use an egg timer or the timer on the oven to remind the child when it is time to pick up toys or go to bed.
4. Write down what time the child is to leave for school. Tape this paper under the digital clock on the microwave. Tell your child, "When the numbers match it's time to leave for school."
5. Compare the passing of time to something the child might understand. "We will be at Grandma's house in the time it takes to watch Rugrats."
6. Use the radio or TV to help the child understand when it's time to do something. "It's time to go when The Magic School Bus is over." "We will clean up for one more song."
7. Link the time of day to an activity such as brushing teeth before bed or washing the dishes after breakfast. This will help the child develop good lifelong habits.
8. FASD causes faulty memory. Teach your child to write down appointments and events in an agenda or day timer and to refer to it often during the day.
9. Be your child's 'external brain'. They need your help to understand what they need to do and when they need to do it.

How You can use Structure to Help Children with FASD

Children with Fetal Alcohol Spectrum Disorder often have a hard time without structure in their lives. When we structure our day, we arrange our busy lives into an order that makes sense to us. Some people get up early and go to bed early. Some people get up late and go to bed late at night. We like to do what works well and helps us in our day-to-day tasks.

A child with FASD needs structure to help with all their daily activities. The use of reminders is helpful in giving structure to our daily lives. These reminders can be like having an 'external brain'. An external brain can be very helpful. Things like day planners, wall charts, timers, verbal reminders and school agendas all help us to make sense of our day.

Here are some 'real life' examples of how to use structure in your home...

Example #1

A child with FASD is playing in the yard. Her father calls out that it is time to go to the doctor. The child has been told many times that they will visit the doctor today. The child becomes upset and does not want to go. She refuses to leave the back yard.

What is happening

The child has trouble remembering she has an appointment and gets upset because she does not want to leave the fun she is having in the yard. She may not have understood the words that were used to tell her of the appointment. The child with FASD often does not understand the days of the week or the structure of the day without external reminders. She does not understand that most appointments need to be booked ahead for a set time during the day.

How you can help

When your child gets up in the morning, use both a verbal and visual cue to remind her about the appointment. Help her understand what time the appointment is. Use words she understands such as after breakfast, before morning recess, or after her favourite TV show. Remind her several times. Write it in her school agenda or on the back of her hand. If you use a visual calendar, write it down so she can see when the appointment will be in her day.

Example #2

A child with FASD always wants to eat and asks over and over again when the next meal is. Mom has said that lunch is not for another hour, yet the child keeps asking for food.

How you can help

Use visual reminders for meal times. If a meal has just ended, show the child on a chart when the next meal is. Teach your child that we eat meals at set times. You may have to watch how much food your child eats.

FASD Tip #14

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Tips on How to use Structure in Your Home:

1. Meals can be a simple way of having some structure in daily life. Plan meals for the same time everyday. For example mealtimes could be 7 a.m. breakfast, 10 a.m. snack, 12 p.m. lunch.

Having this structure can cut down on the child's stress about eating. The child could also learn to see structure in their day by using meal times as markers. You can explain that an activity is happening "before lunch" or "after supper".

2. A weekly calendar that has pictures can help children with FASD understand the days of the week. It is helpful to split the day into 3 parts: morning, afternoon, and evening. You can place a picture of an event on the day it will happen.

For example a picture of a church on Sunday morning or a picture of a child in their Brownie uniform on Monday evening. This will help the child remember activities.

3. Keep the same activity patterns every day. Children with FASD thrive on routine and structure. School gives structure to the day. Staying up really late on weekends or holidays can make your child feel out of sorts. This can lead to poor choices and behaviours that are upsetting for the whole family.
4. When your child keeps asking about an activity, have him check the calendar and then tell you what activity is on the calendar. Every time he asks have him check the calendar. It can be his job to check the calendar and let you know what his schedule is. This teaches him to use the calendar as an "external brain".
5. Family activities can be colour coded. All activities for Jamie are blue and all activities for Anna are in red. Mom's activities in green and Dad's in orange.
6. When changing from one activity to another, children with FASD need time to adjust. Warn your child about a change in plans.
7. Helping your child use structure in her day will lead to a better understanding of the passage of time, the days of the week, the weeks in the year and even the seasons of the year.

How You Can Help Children and Teens with FASD Develop Routines

Routines are important in everyone's life. Understanding that we do specific things at certain times everyday helps keep us organized. Knowing what time the school bus comes on school mornings or what time we go to bed helps us feel secure because we know what to do.

Children and Teens with FASD have a hard time being organized. Parents or caregivers can help them by creating routines. Routines will help a child learn good habits. A child with FASD may never fully understand why it's important to brush and floss their teeth everyday, but what is important is that they develop the good routine of brushing and flossing their teeth everyday.

Visual aids that show routines are very helpful. A chart with pictures of what a child needs to do can help the child see the steps needed to complete an activity. For example, a visual chart in the bathroom could include pictures of washing their face and hands, brushing and flossing their teeth, combing their hair, and putting on deodorant. Verbal prompts, when used with visual aids, are very helpful.

Here are some 'real life' examples and tips to help children, teens or adults with daily routines....

Example #1

Every morning Brad has trouble getting ready for school. When he goes to his room to get dressed, he needs to be called several times to hurry up and get ready for school. He forgets to brush his teeth and wash his face. Then he can't find his school bag. The more the parent or caregiver tries to hurry Brad along the more stressed and upset he gets. Brad often leaves for school in tears.

What is happening

To get ready for school, Brad needs to do many things. He doesn't have a routine, so he is very unorganized. He knows he needs to get ready and out the door by 8:40 a.m., but can't understand all the steps needed to get him organized. Brad shows his confusion and frustration by becoming loud or angry, maybe even aggressive. He may even shut down because he feels so overwhelmed by everything, that he can't do anything.

What you can do

With your child, make a plan of what needs to be done to get ready for school. The night before school, help him pack his book bag and get his clothes ready. Some children like to lay their clothes out in the order the clothes go on. This activity helps them stay on track when they are getting dressed. A toaster on the counter with the bread, butter, and jam beside it, or a cereal bowl and spoon on the table will remind him what he is having for breakfast. Pictures of his bathroom routine will help him to leave home clean and neat.

FASD Tip #15

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Some Tips to Help Use Routines in Daily Activities:

1. Decide which parts of your day need routines. Some ideas are wake up and bedtime routines, mealtime routines, when to watch TV, play, or do chores. Simple routines like sitting in the same seat at the table or in the car are important.
2. It is important for parents and caregivers to have routines in their own lives if they want to help children with FASD develop routines. Adults who have good routines have more energy to teach children how to develop good routines and habits.
3. Keep routines simple and basic. Develop routines that build on your child's strengths.
4. Think and plan ahead. Think about what could go wrong and make changes to the environment. For example, it can be noisy and confusing for a child when the entry bell rings at school. Having an adult routinely meet the child with FASD at the door to lead them through the maze of children to their classroom can be helpful.
5. When asking your child or teen to do something use the same plain and simple phrase each time, "Sandra, time to get ready for bed."
6. Teach the steps of a task in the same order every time. For example when doing the dishes, teach the child to use 3 steps: scrape, rinse, and wash in hot soapy water. Your child may not understand why they should scrape the food off the plate, but we know it's a good way to do dishes.
7. For some children the first way they learn something is the only way they can successfully do something. Always plan for the future when you teach a child with FASD a new skill. They may not be able to change a routine once it is locked in their brain.
8. Routines help children and teens with FASD to succeed and feel good about their life.

How You can Help Create Success at Camp

Summer camp, whether it is a day camp, or a sleep away camp, can be fun and exciting. Camp can be a great way for children to explore the world. However, children with FASD have trouble in the less structured setting of camp. Children may find it hard to get used to not being in their own home with routines they are used to. Meeting so many new children and adults is stressful to a child with FASD. All these stresses may cause the child to behave in ways we find difficult to understand. Some children act aggressively. Some may be in your face, invading your space. Some children ask questions and talk non-stop. Other children may shut down because they feel so overwhelmed by everything.

Unsupervised free time may be a problem. The excitement and high energy of the activities can also be difficult. This does not mean that children with FASD can't enjoy camp. It means that they need extra support and understanding to have a good time at camp.

Here are some 'real life' examples and some tips about camp...

Example #1

A camper wants to be helpful. She gets up very early and vacuums the cabin while others are sleeping and the counselor is at a staff meeting.

What is happening

The child wants to be liked and believes that by doing extra chores the kids in her group will like her more. She knows it makes her mom happy when she vacuums at home. She does not grasp that waking up her cabin mates very early will annoy them.

How you can help

An unsupervised child usually means trouble! Make sure there is always someone in charge in the cabin. FASD causes a child to be impulsive and make poor choices. A child with FASD tends to 'live in the moment' and not see how her actions can upset others.

Example #2

A camper is sitting alone on a bench while other campers are having fun making tie dyed t-shirts. He is just sitting there and it looks like he doesn't want to be with the other campers. Some of the other children think he is mad at them or doesn't like them anymore.

What is happening

The child with FASD often misses all or part of the instructions. He may not know where he is supposed to be or what he is supposed to be doing. The more he sees the others having fun, the more frustrated he gets with himself. He really wants to join in but is too confused to know what to do.

How you can help

Ask staff to be clear in their words and use actions to show how to complete the steps of an activity.

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Some Tips for Success at Camp:

1. Pick a camp with as much structure as possible. Call the camps in your area to ask questions about their programs. Ask about what kinds of structures and routines they have.
2. Tell the Camp Director that your child has FASD and explain what this means to your child. Offer to answer all their questions and send them more information about FASD. Let them know they can contact the FASD Support Network of SK so the camp staff learn about FASD and can make plans and be prepared.
3. Supervision, supervision, supervision. Supervision at all times even 'free' time. Rules and supervision keep everyone safe. Supervision will help the child to follow the rules.
4. Camp staff or counselors should meet the child and have plans ready to put into place as soon as the child arrives at camp.
5. A 'buddy' system with an older camper or a junior counselor could be set up to give the child with FASD some extra help and a feeling of security.
6. Verbal instructions must be short and simple. Be precise and concrete. Clearly tell the child what to do, rather than what not to do.
7. Be consistent and clear with rules. Rules should be as few as possible, but safety for everyone is important so there will need to be some rules.
8. Be ready to repeat and demonstrate instructions as many times as needed. Instructions may be needed each time an activity is presented as learning can take longer for children with FASD.
9. Consequences for poor choices need to be immediate and short-term. Children with FASD have a poor understanding of cause and effect.
10. Enjoy the creativity of children with FASD. They may excel in some areas such as crafts and drama.
11. An excellent booklet for parents and camp staff is *Your Victory: A Happy Child Supportive Strategies for the Staff of Children's Summer Camps*. For information on how to purchase, call the Network office.

Healthy and Safe Sexuality for Teens and Adults with FASD

Sexual feelings are normal and healthy. Youth and adults with FASD share the same physical changes and desires as everyone else but because of their brain injury, they are less mature socially and emotionally. For this reason people with FASD need extra support to learn about healthy and safe sexuality. Youth and adults naturally have a desire to have a boyfriend or girlfriend, to love, marry, or have a child. We can help them try to understand that not all of us marry, not all of us have children, and that relationships take a lot of work. We know that relationships can be hard for people with FASD. They become even more complicated when there are sexual feelings involved. Teaching and talks about sexuality needs to happen early and often. Sexuality is a sensitive topic and all talks about sexuality need to maintain the self esteem and dignity of the person. Issues of health and safety must be stressed. The young person must feel that it is safe to share such personal details with you. Problems around sexuality may arise.

Here are some 'real life' examples...

Example #1

Your son is attracted to an older girl at school. She smiles at him and is nice to him so he thinks they are boyfriend and girlfriend. He follows her home from school and phones her in the evening. He has tried to hug her at a school event. His actions at first bother her and then begin to frighten her.

What is happening

Because of brain differences some people with FASD may have trouble reading social cues, facial expressions, or knowing who is a good choice as a partner or date. They may think of a friendly smile as a sexual advance and then respond with behaviour that is inappropriate to the other person or situation. Individuals with FASD may be at high risk for committing sexual offences or being sexually exploited due to lack of understanding of social boundaries and socially accepted ways of showing affection. Be aware of relationships between older teens and younger children. It is important to stop all risky behaviour, like following or sexual advances before the behaviour becomes criminal.

Example #2

Your son comes home from school upset one day. The next day you are called to the school for a meeting to discuss concerns about your son masturbating in the locker room at school.

How you can help

Masturbation is a sensitive topic. Occasional masturbation is not cause for concern at any age. People with FASD need clear direction about safe and healthy masturbation. Your son or daughter may have trouble distinguishing when and where it is OK to masturbate. A clear rule like "Masturbation is only done in private, in your bedroom, at home." This will help remove confusion between private and public spaces.

FASD Tip #17

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Example #3

Your daughter has a boyfriend. You have just found out that she has been sexually active with her boyfriend. You are concerned about her decision to be sexually active, her sexual health and about possible pregnancy.

How you can help

Individuals with FASD may have trouble knowing when physical affection is right for them. They will need extra help from family and caregivers to stay safe and be responsible. Consistent and rigid social rules about physical affection work best, but this can be difficult as the rules will change as people grow up. Due to memory problems, a daily birth control pill may not be the best option. A family doctor can give information about kinds of birth control that do not need to be taken each day. This might be a better choice. A support person, sister, or trusted friend could attend appointments with a young woman and then pair the appointment with a positive outing like going for lunch. Teach that birth control is the responsibility of both partners. Condoms are effective birth control and also prevent sexually transmitted diseases. Whatever kinds of birth control are used, young women and men with FASD will need continued support and external reminders about how and why to use birth control.

Some Tips and Teaching Strategies:

1. Practice things like how to shake hands, hug and touch others respectfully.
2. Teach to always ask permission to touch. Never touch without asking.
3. Know where your kids are and who they are with when they go out.
4. Ensure that the school reinforces what is being taught at home about sexuality and that as parents you know what is being taught at school.
5. Use role play to teach about how to ask someone out on a date or how to say no to sexual advances.
6. Supervision is important. A trusted friend, cousin or sibling might be willing to double date or even go on practice dates.
7. Encourage young couples to attend family events, meet up with friends or get involved in community activities. Let others know to provide extra supervision at events like school dances or camping trips.
8. Be aware of the danger of the internet. Monitor internet activity, set time limits and set rules that limit or avoid chat rooms. Look into parental controls to block dangerous internet sites.
9. Talk about sexuality even if it is uncomfortable. If your son or daughter doesn't get information from you he or she will get it from someone else. If this is hard for you, find a friend or another parent to help you in this task, you do not need to do this alone.
10. When talking about sex, use language that is clear and simple. Use the appropriate name for sexual acts and body parts to avoid confusion and misunderstandings.
11. Rules about sexuality need to be simple, consistent, absolute, and concrete. For example, teach that unprotected sex is never safe. Always use a condom.
12. Demonstrate use of birth control methods and show what birth control looks like.

How you can Help a Teen or Adult Avoid Drug and Alcohol Use and Abuse

Drug and alcohol use is dangerous for youth and adults with FASD because they become addicted quickly. For this reason, it is best if they completely avoid using alcohol and illegal drugs. Because alcohol use is widely accepted in our culture and drugs are readily available it is difficult to avoid them. Most Canadians drink some alcohol some of the time but in amounts that do not cause problems. People with FASD may have friends and family members that drink alcohol on a regular basis. Because those with FASD are easily influenced they will want to join in. This is a big problem because of the differences in how their brains work. Addictions are resistant to change and treatment, especially because traditional treatment approaches don't work well for people with FASD. Remember too that they are at greater risk when under the influence of alcohol or drugs. Drug and alcohol misuse can lead to criminal behaviours, victimization, poverty, disrupted relationships and homelessness.

Here are some 'real life' examples...

Example #1

Your daughter has gone out to a party with friends that you thought were trustworthy. She is 17 and has been taught that drinking is not allowed. When she comes home you can tell that she has been drinking.

How you can help

Stay calm—wait until the alcohol has left her system before you talk about this. Remind your daughter that drinking alcohol is an illegal activity for a 17 year old. Let her know that she does not have to use alcohol to fit in. Teach her about her health and taking care of herself. Help her understand that alcohol will make it hard for her to make good decisions and look after herself. Teach her to never ride in a car if the driver has had anything to drink. Help your daughter to go to events where there will not be drinking. In the future provide additional supervision for parties.

Example #2

Your 24 year old son has begun a new part time job. He is very eager and wants the job to work out. He begins spending time with two of his new co-workers. You notice he smells like smoke quite often. He seems disoriented and confused when he comes home one day. You suspect he has been smoking pot with his new friends though he denies this.

How you can help

People with FASD are easily influenced and learn by watching and imitating what others do. Your son may not have known the difference between cigarettes and pot when he first tried it. He may also be trying to fit in and be accepted by his new coworkers. Remind him that marijuana is illegal and that it is against the law to have it in your pocket, in your home, or to use it. Try to find out if he is using and why he is using pot. This will help you to decide what to do. Some people use pot to feel better about themselves or to calm down.

FASD Tip #18

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Some Tips and Teaching Strategies:

1. Begin to teach and talk about drugs and alcohol early and often. Use clear and direct language along with real life examples.
2. Be specific about which drinks are alcohol and which drugs are illegal drugs. It can be confusing to know the difference between medicine and illegal drugs.
3. Create family rules about drugs and alcohol. Be a good role model to members of your family.
4. Teens need to know that it is against the law for them to use alcohol or drugs and that it is also against the law to have alcohol or drugs in their backpack, purse, room or car.
5. Help teens and adults to find good role models and friends that do not use drugs and alcohol.
6. Help them to find other activities that are fun and provide opportunity to experience success and feel a sense of belonging. A music group, team sport, or other recreational activity is a good choice and gives them something to do and can build positive experiences.
7. When problems arise, like sadness, boredom or feeling alone, deal with these things in positive ways so that drugs or alcohol are not used to self medicate or dull feelings of emotional pain.
8. Use role play, practice and rehearsal to help teens or adults learn to avoid drugs and alcohol. Practice over and over how to say no and how to stay safe.
9. Have a plan in place to deal with situations where drugs or alcohol are available and they find it is hard to say no to using. Encourage them to phone home or leave immediately.
10. Support a healthy sense of self so teens and adults do not use drugs and alcohol to fit in or be accepted. Encourage safe alcohol-free activities with positive role models.
11. If a person with FASD develops an addiction, contact the Network for information about FASD to share with the addictions counsellor. To improve the chances of success, the counsellor will need to accommodate the unique needs and recognize the brain differences of a person with FASD.
12. Find someone to talk to and to support you. Other parents can share ideas and help you to feel that you are not alone. Call the Network for support.

How you can Help a Teen or Adult Avoid Trouble with the Law

Supporting a teen or adult with FASD can be difficult. There are many tough issues faced by families and caregivers. Helping a teen or adult stay safe and avoid getting into trouble is one of these tough issues. Even when you do your best to help avoid trouble with the law, it can happen. Because of brain differences, those with FASD are easily convinced to do things that are unsafe or illegal. They may take the blame for things they did not do, things they do not remember or events they do not understand. Risky activities with peers can also create a sense of belonging. Teens and adults with FASD are commonly charged with theft, property damage, and assault. Risks of carrying out criminal behaviour or being the victim of criminal acts are greater because they may:

- be impulsive and take risks,
- have a poor understanding of what might happen next,
- not understand which actions might get them into trouble,
- have a poor understanding of ownership and personal boundaries
- repeat offences due to problems generalizing and learning from mistakes.

Here are some 'real life' examples and tips...

Example #1

You find several music CDs that do not belong to your teen in her backpack. The CDs are still wrapped and not the kind of music she listens to. You know she does not have the money to buy these items. At first she claims that a friend gave them to her then later says that she found them.

How you can help

STAY CALM. Seek support or guidance if you feel unsure. It usually takes a bit of talking, but try to find out how the CDs got into her backpack. Once you find out, the police may be involved but it helps if FASD and your teen's unique needs are explained to the police. If at all possible, the teen should not be charged. Alternative measures can be used instead of legal charges. Some sort of supervised restitution should be carried out. The items must be returned by your teen to whomever she took them from. A letter of apology, written by your teen, should be given to the victim. FASD is not an excuse for getting away with something illegal. A person with FASD must realize there are consequences; the consequences just need to be ones that are understood.

Example #2

Your 25 year old son Brian has been charged by the police because of damage to property. He was at a party and was involved in a fight. Later, the headlights of a car were smashed. Brian admits that he smashed the lights and witnesses confirm that it was him.

How you can help

There is no easy answer or quick solution. Brian needs to be supported to understand his emotions and to learn ways of solving problems without violence and aggression. Many people with FASD have trouble making friends, understanding and using social skills, solving problems and controlling emotions. Advocate for a person with FASD when they get involved with police, lawyers and judges. Gather resources and provide information to those who need to understand FASD.

FASD Tip #19

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Please feel free to photocopy
and use these sheets.

Some Tips to Help Avoid Trouble with the Law and Tips if Trouble Happens:

1. Talk about important issues like safety, ownership, right and wrong. Begin these talks early and repeat often.
2. Teach about these ideas in real life settings. Practice the skills by using role play and demonstration to teach about right and wrong. Consider videotaping the practice sessions to watch at other times.
3. Create a few clear and direct rules that are understood.
4. Create a circle of support with friends and family. Each member can act as an “external brain” for a person with FASD. An external reminder, like a phone call to remind about curfew, can help with decision-making and help avoid impulsive acts.
5. Minimize negative influences. Get to know who your son or daughter hangs out with. Make a list of names addressees and phone numbers in case you need to contact them.
6. Some adults carry a card that states they have FASD. The card has contact information for a support person or parent and explains that due to a brain injury they do not understand their legal rights and do not consent to a search or admit to criminal acts.
7. It is the right of an individual charged with an offence to understand the charges and the legal process. Everyone has a right to fair representation. Because of the brain injury, people with FASD will need things explained in a way they understand and is fair.
8. Police officers, lawyers and judges should always use plain language. What they say is very important and needs to be stated clearly to help with understanding.
9. Be prepared. Gather documents and information about diagnosis, assessments, the supports available and the supports needed. Provide information to lawyers, judges, police officers and others involved. Inform others that FASD is a permanent brain injury and by punishing we do not teach. No amount of jail time will rebuild brain cells.
10. Advocate for restorative justice, mediation or a sentencing circle. Try to make sure that the individual understands what to do and is actually able to do what is instructed or expected. They will need support in carrying out or complying with conditions.
11. Look for ways to create structure and build stable routines into everyday life. Provide chances for safe activities that promote success. Look for strengths. Everyone has things that they are good at. When we can use our strengths and are supported we can avoid problems or deal with our legal troubles in better ways.
12. Remember, you do not have to face difficult situations alone. Look for support and someone to talk to. Call the Network to be matched with another parent.

Understanding Fetal Alcohol Spectrum Disorder (FASD)

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe the range of disabilities that can occur in a person whose mother drank alcohol while pregnant. Some women do not know that alcohol can injure their unborn baby; others may not be able to stop using alcohol. Other women stop drinking when they find out they are pregnant but some injury may already have happened. There is no safe amount or safe time to use alcohol during pregnancy. In Saskatchewan, one in 100 people may be affected by prenatal alcohol use. (SK Prevention Institute 2005). Women need to be supported and encouraged to avoid alcohol use during pregnancy and breastfeeding.

Individuals affected by alcohol exposure before they were born are unique and will have different amounts of brain injury and disability. The disabilities caused by alcohol exposure are present from birth and can include physical, learning and behavioural difficulties. Possible diagnoses for those affected by FASD are: Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), or Alcohol Related Neurodevelopmental Disorder (ARND).

FASD is often called an invisible disability. The signs and symptoms of FASD may go unnoticed or be masked by other things in the individual's life. Most people with FASD look just the same as everyone else, but they have some differences in how their brain works and that makes life difficult for them. Most individuals with invisible disabilities do not get the support they need to succeed in life. Many people with FASD are very smart. Even though FASD is a lifelong disability, with the right changes to the environment, individuals can be productive and successful members of our communities. They can make friends, get jobs and reach the goals they set.

Signs and Symptoms of FASD

A child or adult with a Fetal Alcohol Spectrum Disorder may:

- Have memory problems (especially short term memory)
- Have difficulty with math, telling time and managing money
- Be very impulsive
- Act younger than her or his age
- Have poor judgement and poor decision making skills
- Be depressed
- Be hyperactive
- Have sensory problems like how they react to temperature, sounds, bright lights or busy places
- Be slow processing information and need more time to learn things
- Have trouble with social skills, knowing/using boundaries and maintaining friendships
- Be a concrete thinker; learns best by doing

**THERE IS HOPE AND
THERE IS HELP.**

CONTACT THE NETWORK FOR INFORMATION AND SUPPORT.

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8 Magic Keys

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

- 1. Concrete** – Individuals with FASD do well when people talk in concrete terms; do not use words with double meanings, or idioms. Because their social-emotional understanding is far below their chronological age, it helps to “think younger” when providing assistance and giving instructions.
- 2. Consistency** – Because of the difficulty individuals with FASD experience trying to generalize learning from one situation to another, they do best in an environment with few changes. This includes language. For example, teachers and parents can coordinate with each other to use the same words for key phrases and oral directions.
- 3. Repetition** – Individuals 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 re-taught.
- 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.
- 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 assimilated. Therefore, a simple environment is the foundation for an effective school program.
- 6. Specific** – Say exactly what you mean. Remember that individuals 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.
- 7. Structure** – Structure is the “glue” that makes the world make sense for an individual with FASD. If this glue is taken away, the walls fall down! An individual with an FASD achieves and is successful because their world provides the appropriate structure as permanent foundation.
- 8. Supervision** – Because of their cognitive challenges, individuals with FASD bring a naïveté to daily life situations. They need constant supervision, as with much younger children, to develop habit patterns of appropriate behaviour.

Not Working?

When a situation with an individual with FASD is confusing and the intervention is not working, then:

Stop Action!

Observe.

Listen carefully to find out where he or she is stuck.

Ask: What is hard? What would help?



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