



FASD

Strategies
not
Solutions

Acknowledgements

The Edmonton and Area Fetal Alcohol Network (EFAN) works to enhance the capacity of our community to prevent Fetal Alcohol Spectrum Disorder and address FASD related issues through coordination, education, support, and advocacy. EFAN is a collaborative venture made up of individuals from numerous community agencies and government departments. The Child and Youth Working Group (one of three within EFAN) works to provide education and support to children and youth with FASD and their families.

The Child and Youth Working Group has produced *FASD Strategies, not Solutions*, a resource to educate caregivers and the community in managing the behaviours associated with FASD.

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For more information about this booklet, please contact fasdsolutions@hotmail.com. To download the booklet, please visit www.region6fasd.ca. Additional copies can be ordered through www.child.alberta.ca/.

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Foreword

This Booklet is designed for caregivers and professionals who, in their **everyday** lives, encounter children and youth affected by **Fetal Alcohol Spectrum Disorder**. Readers should be aware that this Booklet provides strategies and suggestions for people who **already have a base understanding** of FASD. If you would like more information on FASD, please visit www.region6fasd.ca. For ease of reading, the child will be referred to as female.

As you refer to the strategies outlined in this Booklet please keep the following in mind:

1. **Children and youth affected by FASD do learn, but they all learn differently. FASD is permanent brain damage. In order for us to understand how children with FASD function, we need to remind ourselves of that.** Every child affected with FASD is different and has her own unique strengths and challenges. Therefore, not all of the strategies mentioned in this Booklet will work with your child. The best approach is to keep trying different strategies until you find the ones that work for you and your child. Once you find the best fit, stick to it. Remember that the strategies listed are not set in stone and can be modified to suit your child's individual needs.
2. **Children and youth with FASD need to know and feel that it's okay to talk about their disability.** If you keep it a secret the child may grow up to be ashamed and not want to let others know what her needs are. Keep the communication open and encourage your child to be open with others.
3. Alcohol exposure in utero can affect every system in the body, so it is important to keep a watchful eye for any sign of health problems.
4. While all children with FASD have their own unique challenges and strengths in terms of behavior and health related issues, there are a few key strategies that we know work for all children. You will notice that some concepts such as routines are repeated over and over in this Booklet.
5. You know your child best and therefore are your child's best advocate. Talk with your child's teachers and other professionals; find out if they are FASD-friendly. If you think the professionals are not helping your child, do not be afraid to get a second opinion. Try your best to develop a relationship with the professionals in your child's life.
6. **Play is an important function for all children, especially those with FASD.** Encourage playfulness in your child and include play into your child's day. Children with FASD may continue to play well into their teens, and it is important that this be supported and encouraged by caregivers.
7. **Strategies included in this Booklet may apply to any chronological age.** Remember that although a child may have a chronological age of 14, developmentally, she may be close to an 8 year old. This might mean that your teenage child with FASD still enjoys playing with toys, and it may mean that leisure activities need to be altered to take developmental level into account.

When teaching new skills, remember that learning is more fun if the teaching can be made into a game!

8. This Booklet does not include strategies for school because specific school strategies can be found on the Alberta Learning Resources Branch website. Four key resources are:

- a) The Learning Team,
- b) Teaching for the Prevention of FASD,
- c) Teaching Students with FASD, and
- d) Building on Success.

Information about all four resources is available at www.lrc.education.gov.ab.ca

Words to Live By

- Create structure, routine and consistency.
- Be positive; laugh whenever you can.
- Argue with them less.
- Engage them in activities that they enjoy.
- Hug them and tell them you love them, even when you are upset or angry.
- Crying is OK.
- Monitor and regulate what they watch on television, video, computer, internet, etc.
- Focus on positive decisions they make.
- Set realistic expectations; do not ask too much of them.
- Get enough sleep, good food, and exercise. They need you to be at your best to help them be their best.
- Get support for yourself!
- Never give up!!!!

Environment

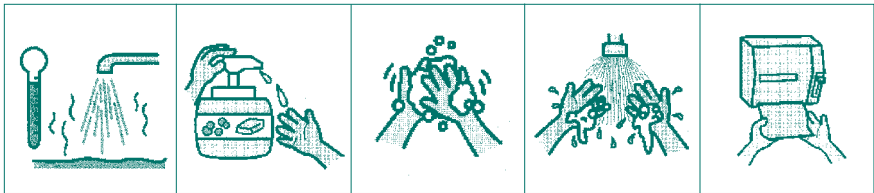
A family I was working with had arranged a surprise birthday party. Well, this youth had arrived home from school to discover that a bunch of people/family were in her living room. She was extremely upset, angry and stomped off swearing into her bedroom [her quiet place] ... Mom went to talk to her and explain not only what a surprise birthday party was but also that it meant she was special ... Dad was left to explain to the guests ... After about half an hour she was able to leave her bedroom. She attempted to understand but she certainly was not comfortable.

Children with FASD may **become easily overwhelmed** in everyday situations, which can result in unpredictable behaviors. Here are some ideas to help your child cope in their everyday environments.

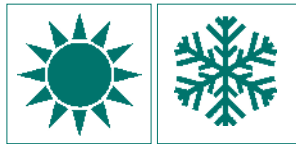
- It is important to look for potential distractions, especially in places such as classrooms. Things such as an open window, door or scraping chairs can be very distracting to a person with FASD, and those things make it difficult to concentrate on the task. To prevent distractions, close doors and windows and try cutting tennis balls in half and placing them under the chair legs to prevent the scraping noises.

- Before going out, consider the location and **the amount of stimuli that your child could encounter**. Highly stimulating environments (those that have music playing, lots of people, lots of things to look at) such as malls, fast-food restaurants, video arcades, and grocery stores may be too much for your child to take in and process.
- If you have to go to a highly stimulating place, try to go **during times that are less busy**, and each time you go, try to have a set route in the store, or go and play the same arcade game, or order the same food. This will help the child make sense of a potentially scary experience.
- **Control the number of people that your child will have to deal with** on an immediate, one-time as well as ongoing basis. Limit the number of people or visitors to your home and wherever possible, try to have people over when your child is elsewhere or sleeping. If you take your child to a party, some parents suggest taking a snuggle time in a quiet place or room.
- One way to understand **how your child understands her environment** is to take a piece of paper and have her describe everything she smells right now. With another piece of paper, do the same thing with what she sees, then with what she hears, and then with what she can taste. This will give you a better idea of how your child experiences all that is around her, and is a fun game as well!
- When considering how to decorate your home, **think “less is more”**. This means less noise, people, stuff, activity, etc.. It also means absolute order and always keeping things in the same place.
- **Reduce the number of items mounted on the wall** and hanging from the ceiling, especially in areas where your child is expected to focus and attend. If required, hang items behind your child’s line of sight or parallel to them. Store everything that you don’t use regularly out of sight such as in cupboards or behind sheets or curtains.
- Choose neutral colours for paint and furnishings rather than bright colours. Or get the **child’s input**, especially with her room, so that she can feel that she is able to make choices. This will also help your child enjoy and feel calm in her room.
- If furnishings in your home must be moved, **consider how your child will best tolerate the change**.
- **Have only one item out at a time** (for example, toys, games, etc.) and insist that an item must be put away before another comes out.
- Store all things together by type only, not by size or space. For example, put all dolls together; all trucks together; **all reading books together; all colouring books together**; all socks together; all shirts together.
- Try to **make space visually concrete**. You can do this by using masking tape, hula-hoops and floor mats to map out your child’s space. It also helps if rooms have definite divisions rather than an open-concept design. Masking tape can be used to map out your child’s areas. For example, masking tape can be used to map out areas such as where the child sits at her desk or her locker space.
- To indicate where each item goes, tape, in that spot, a symbol or word that your child will understand as saying “This is where it goes.” Also place **visual labels** on the outside of drawers and cupboards. Use single words and a picture line-drawing (do not use a cutout from a magazine) to indicate contents. Often such labels are more successful when they are the child’s own drawings.

- To indicate that this is your child’s possession, put a photo of the child on that article (for example, on a locker door, on cubbies, and so on).
- Use **line-drawings**, outline drawings, and picture symbols for memory support (for example, where boots go, where hands and feet go, where spoons go, where food goes). Break down each task into steps and use line-drawings to depict each step in a sequence.
 - For example, the “washing hands pictures” above the taps might show (i) turn on the tap, (ii) put soap on hands, (iii) rub hands, (iv) rinse under water, (v) turn off tap, and (vi) dry hands with towel.



Use a symbol system for hot and cold taps (for example, sun and snowflake).



- Use full-spectrum lighting or **natural light** instead of fluorescent light. Lava lamps are recommended, as they are engaging and soothing to look at.
- **Vanilla and lavender extracts** have a calming effect; therefore a light wash of water and vanilla extract for the garbage pails, for instance, can reduce agitation. Dryer sheets or a Kleenex with a drop of essential oil placed under a pillow at bedtime helps with relaxation.
- Use red and green (stop and go) colour-codes on push buttons on **tape recorders, VCR’s, DVD’s and TV’s**.
- **Control TV and video games.** Cartoons especially can be problematic; the characters portrayed are not real but your child may not understand that. The child **may have difficulty separating the real world from a fictional world**. Therefore, strictly control exposure to all violence on TV and in videos.
- Use large permanent ink arrows to indicate which direction to turn knobs.
- Have a telephone answering machine with a record function, which is used for each phone call your child takes. This way messages do not get lost or the numbers mixed up.
- Purchase an iron with an automatic shut-off.
- Install an automatic timer in the shower.
- Put a permanent ink line on the sides of the bathtub to prevent overflowing the bath.

Structure, Support, Supervision

When a child with FASD is not supervised, she may get into trouble. We often become satisfied when she has successfully accomplished something five times in a row. It is **the unreliability that fools many of us**. We think, “Wow, she’s mastered that”, but on the sixth try, it may all fall apart. Therefore, always think, “What would the consequence be if she failed at this task?” If the consequence is dangerous, then it is your responsibility to ensure that adequate supervision and support is in place to prevent failure.

■ Routine is important.

- It is a normal tendency to keep trying different things, but this approach of trying new things only confuses a child with FASD. It is best to **set up a logical and simple structure, develop consistency and then stick with it**. Consequence or rewards should be immediate, certain, predictable and unchanging. Try to go to the same stores, theatres, park, mall, pool, playground. Do the same activities on the weekends. Using the same long-term approach consistently and forever is what will most likely work.
- It is important to have **set routines for meals**. Make mealtimes a “habit” rather than a response to hunger. Your child may not reliably respond to her body’s cues of hunger or fullness. The same may apply for rest/sleep. It is important to have routines (good habits) around bedtimes/rest/sleep, as your child may not recognize body cues of being tired.

Remember: Routines and schedules create anchors in time and space and help predict what comes next.

- **Monitor free time.** Provide structured and supervised activities with friends; for example, go to the movies, bowling, or swimming. Remind the school that your child may need supervision during lunch and recess too.

Your child’s day needs to be supervised to avoid opportunities to make poor choices. For example, riding the bus can be particularly difficult to supervise. Pair your child up with a responsible buddy or, if possible, have your child sit behind the bus driver.

- Provide gentle reminders as part of her everyday life. **Cueing** can happen in the form of hand gestures, pictures, or simple verbal commands (for example, “bum on chair” to remind your child to finish eating).
- **Do not generalize strengths.** Be wary of making assumptions about exceptional skills and translating them into independence and self-reliance. Your child may be able to complete her routines at home, but she may not generalize this to other settings.
- When a child successfully completes her routines in one setting, for example, at Grandma’s or at school, the next step as a caregiver is to think in terms of encouraging and supporting the development of these same abilities in other settings.
- If things are not working well with your child and she seems “out of sync,” then look at changing her environment or circumstances.

Remember: we cannot change behaviour that is caused by organic brain damage. With support through structure, supervision, routine, and consistency, your child may experience success.

Assessment and Support

As difficulties or delays are noted, talk to your family doctor or pediatrician about what services or help is available. Resources such as an occupational therapist, speech language pathologist and physiotherapist can be assessed through community health programs. An assessment will identify **where your child's strengths and challenges are** so that you can focus on the positives while also getting the right supports in place to help with the challenges.

An assessment can give you validation when **advocating with the school** for services, a **direction to go** for the future, and what to expect so you can plan ahead (whenever possible). The assessment will also give you knowledge of the disability and an understanding of the language of FASD so you can talk more easily to other professionals.

Preschool services and supports are available without an FASD diagnosis.

- As a parent it is your responsibility to coordinate the support team. The team might include a teacher, caregiver, recreational activities expert, family doctor, counselor/therapist, and a youth worker or probation officer for adolescents involved with the criminal justice system.
- It is beneficial to have a pediatrician or a doctor who is knowledgeable in FASD.

Remember, you know your child best and are your child's best advocate.

- Because your child may have a **weakened immune system**, consider having her immunized for the flu.
- Seek **early interventions regarding dental problems**. A prearranged visit to the dentist to get to know the staff and discuss ways to reduce environmental stimulation will go a long way to make your child feel comfortable during check-ups and other dental procedures.
- Watch for chronic **ear infections** and **eye problems** because she may not feel the pain or head ache (some affected children and youth do not feel pain like other people do; this is called HYPO-SENSITIVITY and will be discussed later in this Booklet). Ensure consistent follow-up on any medical conditions.
- Some physicians may want to prescribe medications for your child. **Discuss and understand the intended use and side effects of the medications**. It may be difficult to find effective medications for your child.
- Your child may have reactions to the medication that doctors may not expect. Remember your child's brain is not wired the same as others. Your child may not even react like other children with FASD on the same medication.
- **Monitor your child and her medication** by keeping a journal that documents changes in medication, effectiveness, side effects and changes in your child's behaviour. Keep in close contact with your physician.

Changing our Way of Thinking

Some people become offended when it is suggested that their child cannot do something and will likely never learn to do it. They see this as giving up on their child.

There is a distinction between giving up on your child versus giving up on trying to make her do things that she CANNOT do.

Your child benefits most by learning coping or adaptation skills that accommodate her disability. A good comparison would be like teaching a blind person how to use Braille instead of constantly wasting energy and creating frustration by trying to teach them to read “normally.”

Shift from:

Traditional management
Applying consequences
Changing people

To:

Recognizing brain differences
Presenting problems
Changing environments

Common Misinterpretations of Normal Functions

Behaviour	Misinterpretation	Accurate Interpretation for FASD
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What We See	What We Think	What's REALLY Going On
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<ul style="list-style-type: none"> • Noncompliance- (e.g., Not obeying rules) 	<ul style="list-style-type: none"> • Doing it purposely and maliciously • Attention seeking • Stubborn 	<ul style="list-style-type: none"> • Difficulty translating verbal directions into action • Doesn't understand
<ul style="list-style-type: none"> • Repeatedly making the same mistakes 	<ul style="list-style-type: none"> • Doing it on purpose • Manipulative 	<ul style="list-style-type: none"> • Cannot link cause to effect • Cannot see similarities • Difficulty generalizing from one event to another.
<ul style="list-style-type: none"> • Often late 	<ul style="list-style-type: none"> • Lazy, slow • Poor parenting • Doing it on purpose 	<ul style="list-style-type: none"> • Cannot understand the abstract concept of time • Needs assistance getting organized
<ul style="list-style-type: none"> • Not sitting still 	<ul style="list-style-type: none"> • Seeking attention • Bothering others • Doing it on purpose 	<ul style="list-style-type: none"> • Neurologically based need to move while learning • Sensory overload
<ul style="list-style-type: none"> • Poor social judgment 	<ul style="list-style-type: none"> • Poor parenting • Abused child • Doing it on purpose 	<ul style="list-style-type: none"> • Not able to interpret social cues from peers • Does not know what to do in social settings
<ul style="list-style-type: none"> • Overly physical 	<ul style="list-style-type: none"> • Doing it to bother other people • Deviancy 	<ul style="list-style-type: none"> • Hyper- or hypo-sensitive to touch (feels things too much or not enough; refer to pages 9-10). • Does not understand social cues regarding boundaries
<ul style="list-style-type: none"> • Does not work independently 	<ul style="list-style-type: none"> • Poor parenting • Doing it on purpose 	<ul style="list-style-type: none"> • Chronic health problems • Cannot translate verbal directions into action

1994, Debra L. Evenson, MA

Sensory Dysfunction – Feeling Things Differently

Children and youth with FASD often have problems with the way they interpret sensory information. They may show signs of being **hyper-sensitive (feeling things too much)** or of being **hypo-sensitive (not feeling things enough)** to the senses of touch, taste, smell, sight and sound. Children may be hyper-sensitive in one area, but hypo-sensitive in another. For example, a child might be over-sensitive to light, but under-sensitive to touch.

If you suspect that your child is experiencing difficulty with sensory processing, it is important to have her assessed by a professional who specializes in this area. (Please refer to page 46 for sensory products.)

- **Hyper-sensitive children easily feel everything** (for example, clothing tags scratch, bright sunlight blinds, spicy food burns, loud intercoms startle). A back rub might feel like hammers so use a gentle hand and ask or let the child know of your intention to touch her before you do.
- **Hypo-sensitive children have a difficult time feeling anything.** (For example, they may have high pain thresholds, not feel heat or cold, or hold a pencil very tightly and push very hard onto the paper to see and feel the pencil make a mark.) A back rub might feel like ants crawling. If your child is hypo-sensitive, use a big firm hand when touching.
- Often as the environmental stimulus increases or decreases, so does your child's behaviour.
- Teach your child to recognize her sensory issues and encourage her to ask for things that will help such as sunglasses or turning down the volume.
- **For more specific methods to deal with your child's unique hypo- or hyper- sensitivity levels, consult with an Occupational Therapist.**

Hyper-sensitive (Feeling Too Much)

- Place your child first or last in line.
- Use **dark sunglasses indoors to lessen visual distractions** and the glare of lights.
- Tint the windows of your vehicle.
- Wash new clothing a couple of times before wearing.
- Select **soft bedding** and wash new linen.
- If children are sitting together in a group, provide little mats to provide boundaries for the children and to respect personal space.
- Keep children close to an adult at all times. **Limit exposure to crowds** and places with many people and high activity levels. Plan and prepare prior to going to these places.
- **Recognize children may be refusing to participate in an activity or game due to impairment in the functioning of their sensory system, not because they are trying to be difficult.**
- Consult with an Occupational Therapist.
- Use headphones to block out loud noises.

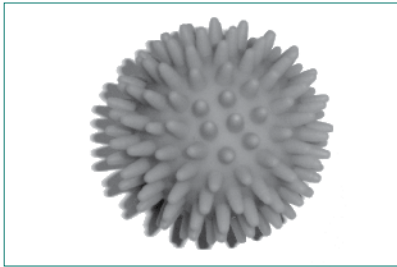
Be cautious of the following:

- Tickling (for some children this may be painful).
- Material that does not breathe (polyester or other synthetic fibres).
- Balloons.
- Elastics in waistbands as well as tight sleeves and leotards.
- Jeans.
- Appliqués on shirts (scratchy back).
- Ties under the chin.
- Thick seams in clothing.
- Wool clothing.
- Turtlenecks.
- Bright lights **and** sunlight reflecting off snow, metal, water, cars, glass (wear sun glasses or tinted prescription lenses) .
- Elastics in the hair as well as hair bands or barrettes.

Hypo-sensitive (Feeling Too Little)

- Supervise child carefully as **she may not feel pain or cold**.
- Provide **oral stimulation** – crunchy pretzels, applesauce or Jell-O through a straw, stir sticks to chew on, or gum.
- Brush hair before combing.
- Use **weighted vests** and blankets.
- **Avoid overdressing** in the summer and remove extra clothing when she comes inside in winter to prevent overheating.
- Help your child recognize **the importance of personal space and the need to “check” before touching someone**.
- Provide opportunities throughout the day for your child to have her **need for deep pressure / intense experiences** met. Encourage activities such as snow shoveling, yard work, and moving furniture. Try putting a full water bottle in your child’s back pack for extra weight. Often jumping, climbing, rolling, and running can help to satisfy the body’s need for these experiences. These types of activities may help to decrease inappropriate “crashing and banging” play.
- Giving a child **“Bear Hugs”** may also assist in meeting her need for touch and deep pressure.

Allow the use of **“fidget items”** such as a stress ball, koosh ball, bean bag, spiral shoelace, elastic band, plastic spiral key ring when a child is expected to sit and pay attention for long periods of time. Be cautious that “fidget items” do not cause additional distraction.



How to Guide Your Child's Behaviour

What is needed is a change in thinking from discipline to redirection or re-teaching.

Consider why you might be disciplining. In reviewing the reasons for the disciplining action, remember your child does not do the things she does deliberately. **Once you've disciplined the child, it is best to forget about it as the child has moved on, so why continue to be upset yourself?**

- **Maintain firm limits** that are consistently applied. Do not do the “just this once” routine. No exceptions – the rule is the rule. If you do make exceptions to the rule, then expect the child to be confused and problems to arise.
- **Being consistent is a caregiver's challenge, but it is critical to your child's success.**
- **Emotional rewards work well.** A big smile or a touch on the shoulder can mean more than any material reward.
- Because individuals with FASD are usually very literal, avoid making threats. Your child will expect you to follow through with any threat and will wait for it to happen.
- Never give the child an option you are not prepared to allow.
- Strictly limit choices (see “Choice Making,” p.12 for details).
- If anger is a problem, **try to have a safe place for the child to express the anger in a physical manner where she is not penalized** for acting out. For instance, kicking a ball or hitting a punching bag or pillow may be acceptable activities. It is important to emphasize that the “safe space” is the only place that venting of aggression should occur.
- Use one clearly understood consequence for all misbehaviour. Typically, using both natural and logical consequences seldom works.
- **Don't get sucked into your child's tantrums** Disengage and walk away. **YOU ARE THE ADULT.** Allow the tantrum to run its course, as it will eventually. Hooking in always extends the length of the tantrum. Make sure the child is in a safe place where she can't hurt herself. If necessary, pick up and remove the child to a safer place such as a carpeted floor.
- Learn to recognize the signs of a problem before the tantrum begins.
- The technique of over-correcting the behaviour may work. For example, if your child always **runs** down the stairs, she may need to practice **walking** up and down a dozen times.
- Some teachers and parents use “thumbs up” or “thumbs down” (with the actions) to describe a good or bad behaviour right away.
- Don't debate, negotiate, or try to explain rules or infractions. Just do it. Remember, impaired memory means your child has trouble learning from both positive and negative experiences.
- Have a set of house rules; for instance, “One toy must be put away before another is taken out,” or “You hit, you sit.” Post the rules where they can be seen.

- **Keep the rules simple and few in number.** The fewer rules there are, the fewer rules that can be broken and the fewer rules to be remembered. Rules should state the behaviour you want to see. Example, “Keep hands to self” rather than “Don’t touch”.

Strategies That May Not Work

Traditional behaviour management techniques and traditional reward systems including tokens, stickers, money and star charts do not work. For these approaches to be effective, the child must understand the concept of “future earning” and have the impulse control to change her behavior for the future. A child affected by FASD does not have this ability.

- **Time outs.** Use of a time out is not likely to prevent the behaviour from happening in the future. Do not expect any learning from the time out. It may give the caregiver time to regroup.
- Physical punishment.
- **Taking things away.**
- Natural and logical consequences.
- Situation-specific consequences.
- Grounding, although this might have to be used if there is a safety issue involved.
- **Contracts.**
- Loss of privileges (for example, missing out on important events, dates, treats, etc.).
- **Threats.**
- Canceling or changing trips or activities because of a behaviour. It is better to wait until your child has calmed down and then say, “We’ll go when you’re ready.” It’s okay to be late.

Try differently not harder. If the strategy is not working, try another.

Choice Making

Children affected with FASD may be very linear in their decision-making. This means that they have difficulty choosing from a variety of options. Too many choices can cause confusion and intense frustration for the child and that can lead to behavioural problems. **If you know that an event may have too many choices and will cause frustration for your child; talk about the event ahead of time and make a plan.**

- **Limit choices.** Go to the same restaurant every time. Once inside, you choose two options for your child.
- Whenever possible, reduce the number of times your child needs to make a choice.
- **Allow extra time for important decisions.** If the first choice is impulsive and inappropriate, say no and wait a few minutes. Your child will figure it out and choose properly the next time.
- Talk about and model the steps to choice making. For example, help her write out a pro and con list and compare the two, or do a “good/bad” list for younger kids.

Impulse Control

Many children are hyper-active and mimic ADHD (Attention Deficit Hyperactivity Disorder) behaviour (i.e. always fidgeting, can't sit still, excessive talking). Often these impulsive behaviours can be reduced and/or controlled through the use of calming techniques and environmental modification (see p.20).

- **Allow for active and rest times.** Break up activities requiring attention with physical exercise such as running, tumbling, dancing, or jumping on the trampoline. **Many children with FASD seem to have a neurologically based need to move even though** they can be capable of watching a 90 minute movie!
- **Teach and provide positive physical activities** such as raking leaves, vacuuming, or shoveling snow. Don't just instruct your child to "go play."
- Sometimes chewing gum and/or playing with a fidget toy such as a stress ball, beanbag or a spiral shoelace can help an FASD child pay better attention.
- Children and youth affected with FASD may have **a difficult time controlling impulses in social situations.** Try developing "role-playing scripts" for a few common situations. For example, taking turns when talking: act out with your child the process of conversation. When one person is talking, the other person is listening.
- **Children affected by FASD seem to need more "down time" than others.** However, it is important to ensure that down time is structured; for example, after school is snack-time, then homework time, then outside playtime, etc. Keep extra-curricular activities to a minimum to keep your child from becoming hopelessly over-tired or overwhelmed.

Communication

While many children with FASD develop a large vocabulary, they often have problems with both receptive and expressive language. This means **they often have trouble understanding what you are saying both verbally and non-verbally, and in turn have difficulty telling you what they need, feel, or want, verbally or non-verbally.**

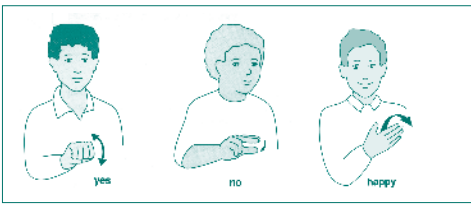
When giving a child affected with FASD information:

- **Eye contact** is essential for your child to process verbal information because she is "reading" you (picking up every clue they can as to your meaning). Eye contact also helps your child to focus on what you are saying.
- **Use exaggerated facial and body language** to convey your feelings and to express such things as "I don't know" with a big shoulder shrug.
- Use as many **visual cues** as possible, at all times, to aid your child's understanding and to trigger her memory.
- Your child may not realize she is supposed to follow instructions given to a group; therefore, always give your child separate instructions using her name at the beginning of the sentence.
- Always refer to all persons in any group discussion by name (not "they" or "them").
- Always use the same words for the same instruction every time it is given. This helps to place the instruction into your child's long-term memory.

- **Make your point in 5 seconds (10 words).**
- **Drop all extra words** or place them at the end of your instruction. For example, “please” goes at the end of a sentence, not at the beginning.
- **Always state what you want your child to do rather than what not to do.** Example, “John, put your feet on the floor” instead of “Get your feet off of the couch.”
- Reduce abstract speech. If your child needs to clean up a mess, he **must be told exactly what to do**. Instead of saying “ Go and clean your room” say something along the lines of “Put all your cars in the car box. Then, put all the books on the book shelf, and then put all the shirts in the laundry.” **By listing off specific tasks one by one, you will have more success, as your child will not be confused and feel overwhelmed. As well, she will see what she has accomplished quicker and therefore will be happier.**
- When interrupted in the middle of giving a direction, always go back to the beginning and start over again.
- When you have completed a thought, come to a complete stop and wait a few seconds before you move on to another topic.
- End all instructional conversations with the word **“now.”** Never give instructions for any other time frame except if your child needs “transitioning.”
- **Remember that just because your child can repeat instructions back does not mean she understands them.**

When you are seeking information from a child or youth affected with FASD:

- **Don't interrupt** your child (even if there is a swear word or an insult) because she may have to start over again at the beginning. If you interrupt, your child may forget what she was going to say. It may take her a while to get the information out.
- **Frame your questions in terms of the actual answer you want. For example, you might say,** “Susie where is Mr. Smith?” rather than “Have you seen Mr. Smith?” If you ask, “Have you seen Mr. Smith?” the answer will likely be yes rather than telling you where he is. You might, for example, say, “John, tell me your address,” rather than “Do you know your address?” or “Where do you live?” If you ask “Where do you live?”, the answer will most likely be “In a house.”
- **Children with FASD may not express their thoughts in a proper order or sequentially.** You may need to ask additional questions in order to determine what really occurred.
- **Try to match your communication level to the child's.** If the child uses two-word phrases, you can use three word phrases. These “speech expansion” techniques should be used very gradually. Only expand by one or two words at a time; for example, “coat hook” to “coat on hook” to “hang coat on hook.”
- Although some children have wonderful senses of humour, they **may not understand joking, kidding around, or teasing.** You may have to explain that you were kidding. Use your sense of humour with care and respect.



Use sign language – verbal language should not be the only communication/learning tool.

Things That Might Help

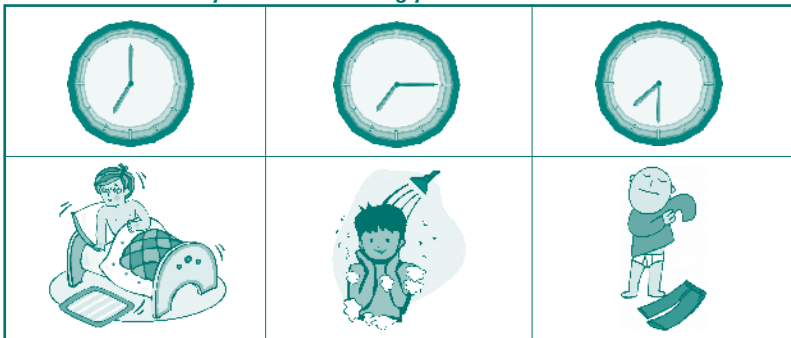
- Squeezing a sponge in the right hand stimulates the left brain and often helps your child tell you better what it is they need.
- **Playing with fidget toys such as** bean bags, elastics, koosh balls, stress balls, a spiraled shoe lace, or a plastic coil key chain.
- If your child interrupts during a conversation, explain that “their words are **bumping** into your words”. This will help your child to visualize good conversation skills.
- **Talking items.** Holding the item (e.g., a stick or a ball) indicates that it is your time to talk.

Time

The internal structure of time, which is missing in individuals with FASD, is what directs us through the day. For children or youth with FASD, a sense of time must be imposed by external means. Ensure consistent routines to create a sense of time.

- Children who have an **established routine** are better able to create a sense of time but they still can’t make allowances for changes or things done out of the usual order. For instance, if your child sets the table at 4:30 for dinner (after homework), he will set the table for dinner after homework, even if the homework was done at noon instead of 4:00 p.m. **The order of events is what sequences and structures time. This helps your child understand what to do next and eliminates the surprise of what comes next.**

A morning routine chart hung on the bathroom door can be very effective in showing your child what to do next.



- **Teach time by association.** Measure periods of time by, for example, the length of time it takes to drive to grandma’s or how long it takes to watch a favorite video.
- When talking about time, use the same words. For example, say “Ten minutes after four,” “Thirty minutes after two,” or “Forty-five minutes after eight.” Do not mix up the way you talk about time by occasionally saying “Five to nine” or “Half past eleven.”
- **Use simple face clocks for different places.** For example in school the first number seen on the clock would be 9 and the last number would be 3. No other numbers would be visible; thus making the beginning and end clear. The fewer numbers your child can see on a clock, the less processing is required to make sense of it.

Hang digital clocks and face clocks side by side so your child can easily compare the two clocks and begin to learn the different ways to tell time.

■ **Make passing of small time blocks “visual.”**

- **Paper or plastic chains** are one of the best ways to do this. Each link represents a period of time from one to five minutes in blocks of no more than thirty minutes. The adult takes the responsibility of removing one link every one to five minutes so the FASD child can “see” time passing.
- The object is to **have your child complete a task by the time the links of paper chain are gone**. The chain should be hung in front of your child but out of her reach; when you remove the link, you must ensure the child sees you do it – “time is passing.”

■ Another way to make small blocks of time “visual” is **to use a sand egg-timer or colour shaded clock** or a visual **egg-timer** that shows the time in a colour block that gets thinner as time goes by.

■ Digital watches work only if the child is looking at the watch when the specified time occurs on the watch face (otherwise, your child is reading numbers, not telling time). Telling time or reading numbers on a watch is not the same thing as having a “sense” of time (“how long”). **Having a digital watch with an alarm may help to remind your older child or adolescent when to call home.**

■ The responsibility for ensuring your child arrives at her destination on time rests with an unaffected adult. Even most adults with FASD require help in getting places on time.

■ For older teens and adults, consider a **colour coding system** when using a calendar or day-timer to assist them in keeping track of things that occur over larger blocks of time such as paying the rent or seeing the dentist, doctor, probation officer or counselor, etc.

■ **Using a Colour-Coding System**

- a) Assign a colour specific to the subject (e.g., yellow for rent)
- b) Block off the rent-due date in yellow
- c) “X” off each day just before bedtime each evening
- d) Have a reference list for colours beside the calendar

When the colour is beside the X, the time is “seen.”

Money

\$40.00 dollars went missing out of the volunteer helper’s purse at the school. The next day the teacher said to our client, “I’m really sad that Mrs.... lost her money. I wonder if we put an envelope on the desk and then the person who took the money could just put it in the envelope and there would be no blame or questions.” The child agreed it was a good idea, adding that the person was probably scared of getting in trouble and wouldn’t want anyone to know it was them. Later the money appeared in the envelope with a note signed Love Mary. So much for not wanting to be known.

Understanding money and its value day to day, week to week or month to month requires **abstract thinking skills**. Children and youth with FASD often cannot grasp these skills; their **ability to manage money can be very poor**. Such skills are important, though, because the ability to manage time and money are keys to becoming an independent adult.

A person must be able to understand that a certain amount of money must last a certain amount of time. For someone who doesn't understand the "value of money," the concept of "worth," or the concept of "time" this is an impossible expectation. This problem with understanding can't be "fixed," and it is only through the use of the **"external brain" (another person in FASD individual's life who constantly monitors and reminds)** that the individual with FASD will succeed in this area.

It is crucial that caregivers understand that they will likely be handling their child's money for the rest of their child's life.

The consequences of not doing this are huge, with homelessness being one of the most severe. It is extremely important that when money is to last for a long time (for example, a month) that it not be distributed in one large amount. Almost without exception, **the individual with FASD will make impulsive purchases without considering the days and weeks ahead.** Try to break it up into smaller payments, even once a week.

- Individuals with FASD may have problems handling money concepts such as the names and values of coins, computing the value of a pile of change, knowing how much change to get back for a purchase, and judging the value of items. For example, **\$10 for a candy bar or for a bicycle may both appear acceptable to your child.**
- Help your child spend wisely by providing a small learning allowance. Plan out exactly where the money should go. Write it down and **supervise your child's purchases. Praise good spending decisions.** If your child wants to save for something, introduce money concepts as concretely as possible; for example, have two piggy banks: one for saving and one for spending.
- Teach your child how to be thrifty.
- All basic needs requiring monies should be paid directly to a program official rather than through the FASD individual. Start a **joint account** with your child so that she gets used to having somebody help her manage her money.
- Teach handling money in the places where it will be used such as in the grocery store, Laundromat, department store, etc.
- Teach grocery shopping by going to the same store every time and doing the aisles in the same order every time. If you go to a different store, expect shopping to take longer.
- Teach your child to shop for groceries using a **systematic routine** for covering the store in order and work from a list that will not exceed a set amount of money. **Use a calculator to keep track.**
- Try to **equate sums of money with value.** Work on this at home, using real money (not play money) and a variety of items (e.g., \$20 is equal to one CD and \$100 is equal to a stereo).
- If you notice your older child or adolescent is stealing from you, consider a keyless entry lock on the bedroom and store all liquor, medications, credit cards, and money there.
- Do not use much cash, and if credit or bank cards go missing, report them right away and get new ones.
- **For more tips on teaching money skills, see the websites listed at the back of this Booklet.**

Ownership

One of my nephews had FASD; he passed away from heart problems when he was ten. I still like the story of him taking a bike from the rack at school and going to the store instead of to class. When he got back he was furious that the teacher accused him of stealing the bike. He said he wouldn't have brought it back if he was stealing it and to make matters worse she said that he missed class and he said he didn't, he was there for the last five minutes.

Ownership is an abstract concept. How does a child know that a toy placed in a room with no one else around belongs to anyone? No one is sitting with it or around it, therefore, “It’s mine – I found it.” If there was another person in the room beside the toy, the child may have a better opportunity to “see” a concrete visual cue to reinforce the concept of ownership.

Stealing is often related to the lack of understanding of ownership over time and space for a child with FASD. The child’s understanding is that a specific person owns a specific object only as long as the person and the object are together. Remove the person and the connection to an owner disappears. **Real “stealing” occurs when the person and the object are together and someone else still “steals” it.**

“Taking” or “finding” behaviour occurs when your child sees something she wants and the visual cue (the person) that connects the object to the owner is absent.

■ **When you have discovered that something has been taken**, simply and calmly state, “This (description of item) belongs to” And then return the item to the owner. If you do not know who it belongs to, say “This (description of item) is not yours,” and take it away. Throw it away or donate it to a charity or to the school.

■ **Be alert to new acquisitions!**

■ **Assign a colour and/or symbol to each person in the home.** For your child, use that colour or symbol to indicate what is hers in terms of personal items such as toothbrush, comb, etc. The symbol helps the child understand what is his and what is not. “John this is yours; see, it has your symbol on it. This is not yours; see, it does not have your symbol on it.”

■ **It is easier to teach a child what is hers, rather than what is not hers.**

■ A lot of taking behaviour is the result of the child not being able to distinguish her own from another person’s similar possessions. Where possible, give the child her own object first before removing what is not hers.

■ Objects of value should never be left where the child can “find them.”

■ **Avoid asking “why” questions.** Instead ask “how” and “where” so you can return the item and prevent future occurrences.

■ **Supervision and redirection remain the keys to prevention.**

■ Other common sense approaches to prevent “ownership” issues include providing pants without pockets or backpacks or bags without lots of pockets; you may try not taking your child’s coat in the store or sewing pockets closed.

■ Recognize that if she does not understand the ‘borrowing’ event, that one can not take things without returning them, **you will have to walk her through the scenario step by step.**

Story Telling

It is important to realize that **some children affected with FASD have significant memory problems**. They may not recall what they are asked to tell or have the language to explain what occurred. Children also learn that good stories get them attention. To please you, your child **may make up a story**.

Your child may not recall if she made up a story or if it was a dream or if it actually occurred.

Such memory difficulties cause great problems for some children who are not sure what really happened, thus, some “lies” are actually ways a child or youth deals with a memory problem.

- **Avoid asking redundant questions** such as “Are you sure that happened?” Such questions may cause your child to feel cornered. When she feels cornered, she may instinctively answer what she thinks the adult wants to hear.
- Help your child distinguish storytelling from lying by **providing her with positive opportunities to tell stories**. When you suspect she may be “storytelling,” ask her a simple choice question such as “Truth or story?” This cues her to stop and think before continuing. Asking “What would your teacher say?” or “What would your mother say?” may also help your child get at what really happened.
- Another technique is to get your child to **draw** the sequence of events in the story. This may help both of you to understand what happened.
- Another way to help your child distinguish between “truth or story” is to establish a **“Truth Table.”** Your kitchen table could act as a quasi-court. Your child knows that the event is very serious and needs to come to the “Truth Table” to get all the facts out and decide together what to do next.
- **Avoid asking questions that you already know the answer to**, especially when the answer does not affect the consequence. For example, if you know that two individuals were involved in a physical altercation and fighting is against house rules, little will be accomplished by trying to ascertain who did what to whom first. Figure it out, give appropriate punishments and MOVE ON.
- **As a general rule, do not consequence lies. You are consequenceing short-term memory deficits.**
- **Be a good listener**, and role model good listening skills. When your child tells a story, ask questions and clarify. When the issue is important, **check your child’s answers with others**.

Calming Techniques

It is important to be aware that children with FASD often have **difficulty with sensory overload and self-regulation**. Consequently, they often find themselves unable to control large emotional outbursts. They will create situations to get themselves removed when over-stimulated, which often leads to negative consequences (usually time outs).

- Your **child may not know how to stop tantruming**. Say things like “Open your eyes” and “close your mouth” to help.
- It is important that you do not appear angry.
- Try to avoid situations where your child will be over-stimulated. Instead of saying “over-stimulated” you may want to use the words “frantic,” “panic,” and “overwhelmed” which may make more sense for everyone involved.
- **Be careful touching armpits** (even as an escort) as there are lots of nerves and blood vessels in that area which can put the child on high alert.
- The use of sensory environments such as **“comfort corners”** may work for the child to self regulate, calm down, and avoid sensory overload. This **in no way should be viewed as punishment** and should be comfortable, quiet and cozy.
- Consider having your child go to the “happy chair” (rather than a time-out chair) because it is a place where your child can calm down and become “happy” again.
- Wrapping your child in a blanket and repeatedly saying “calm down” can be effective. Eventually your child will go get the blanket when she is getting agitated to calm herself.

It is more appropriate to reduce the stimulation in a non-punitive way. This can be done using **sensory environments** in the following ways:

“Comfort corners” can consist of:

- Bean bag chairs
- Old, soft quilt
- Dark sunglasses
- Headphones with serenity tapes
- Located in a quiet space

While in this corner, the child affected with FASD is taught to:

- Recognize internal feelings
- Go to comfort corner
- Wrap in a blanket
- Cuddle in a bean bag chair
- Put on dark glasses
- Put on headphones with tape of bird sounds, waves, etc.

This allows her to:

- De-stimulate (calm down) and self-soothe
- When calm, rejoin the activity

Tents and caves can consist of:

- A large appliance box turned on its side
- Small tent

Your child can calm herself by having:

- Nothing in her sight
- Dim lighting
- Old quilts and cushions inside for comfort, or outside to place over top of “tent” space

Your child is taught to:

- Use equipment to create a safe space
- Use headphones and calming music

Sensory “de-stimulation” room can be:

- A small room but larger than a closet
- Have bare walls, soft muted colour
- Recessed, dim lighting
- Minimal and comfortable furnishings (overstuffed chairs, large floor pillows, bean bag chairs, rocking chairs)
- Repetitive serenity music
- Outside windows covered with dark blinds

- Initially a **support person may need to stay with your child** until she can manage the entire process successfully on her own; after that the support person simply stays close. Allow your child to **use the comfort corner as often as necessary**, whenever necessary.
- It is **important that you direct your child to use the sensory environment to calm herself**. Your child will learn to use it only when necessary to self-soothe.
- These sensory environments should **not be the same place as a “time out place”** as this can confuse your child.
- Other ways to create your child’s calming area include the use of weighted lap blankets (see back of Booklet for instructions), a hammock, coloured light bulbs, a big pile of cushions, a tape recorder, etc.
- Hypo-sensitive kids (kids who don’t feel enough) may benefit from firm backrubs.
- Children may **hold stress in their feet**; therefore, a foot massage and eucalyptus bath oil bath may relieve their stress before it translates into behaviour.
- **Oral stimulation** (crunchy pretzels, applesauce or Jell-O through a straw, chewing gum, mints for stomach upset) can be soothing for some children.
- **“Foot wars”** where you and your child lie on your backs and put your feet together in the air and push against each other helps with muscle resistance and relieves tension.



- When your **child is angry**, fill a large pail with dried beans and she can dig through to find one of 3 marbles inside. The **digging provides muscle work**, which can be calming. She then can trade the marble for time to talk with an adult but usually by the time she finds one marble, the resistance work has done the calming.
- Provide **a thinking chair** where she can go and choose a 1 minute, 3 minute or 5 minute timer to sit and collect herself. She can choose whether or not to come and talk about the behaviour afterwards.

Feelings and Emotions

I thought I had done a great job of bringing the Sunday school's lesson to life. I talked about how we have been blessed and there are others less fortunate all over the world. While at the store I allowed the kids to each pick a special treat and then really laid it on about how some people are so poor they can't go to the store and get whatever they want the way we did. One of our girls seemed really concerned about this so that night at supper, when she said grace, she asked God to look after the poor people and then she said "And please, help them find out where the stores are."

Understanding feelings and emotions is vital to good communication, but both are very abstract concepts. A child or youth with FASD may need concrete methods to help recognize what she is feeling. Therefore, **teach emotions in a concrete way (e.g., smiling means happy.)**

- A **"check-in" time** for internal feelings will help in stating which feelings are physical and concrete.
- **After an outburst, talk about what your child felt during the meltdown;** for example, a beating heart, sweaty hands, hot face. Attach the concrete feeling to the meltdown so she can begin to identify what feelings are connected to certain behaviours.
- In order to be able to act appropriately to any emotion, your child must first have some way to recognize concretely what she is feeling. That feeling must then be named and "rules" for appropriate reaction to that feeling must be made.
- Create a **"feelings" dictionary**, using line-drawings of complete stick men rather than just facial expressions for those most common feelings the child is likely to experience. **A complete body can show more than just a face** and is much easier for the child to associate with what he is feeling. Have one emotion per page.
- Always **name emotions very clearly**. With teens and adults, name the emotion first and then follow with the words their friend's use ("angry" vs. "pissed off").
- To encourage emotional expression, use a gingerbread man outline drawing and simple **colour codes** (e.g., red for anger, blue for sad, yellow for happy, and gray for blank). **Have your child colour on the gingerbread man where he has those feelings**. This can give you a quick and immediate idea of the state of emotional health (e.g., red in the head and the hands is a good indicator of being ready to "lose it"; gray in the head and on the body is a good indication of being "shut down"). This will help, especially when the child is not able to verbalize her thoughts and feelings.
- **Once the feeling is identified correctly, have a simple plan to help the child.** For instance:
 - "Losing it" – use calm down technique
 - Caregiver is "ticked off" – stand still, look at caregiver and listen
 - "Tired" – lie down and rest
 - "Frustrated" – have a list of physical activities that she can do and have her choose between two
 - "Angry" – express it physically in a previously identified acceptable and safe manner

Do not expect:

- Insight
- Application of yesterday's learning to today's experiences
- That the child will remember a feeling from one time to the next without support

The child will not necessarily be able to understand the emotions of others just because we were able to help her understand her own.

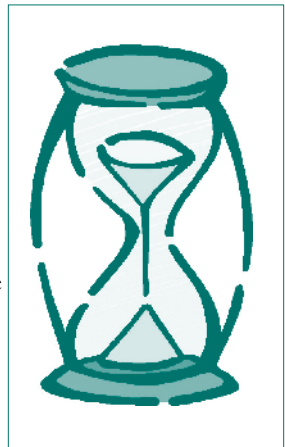
Transitions

The first time our 5-year-old foster daughter was invited out to play with her new school friend, she was very excited and happy to go. We picked her up and brought her back home to find that she was not very happy at all. She told us that she was upset with us for "ruining her fun." This was unexpected and we did not know what to make of it. The next week her friend came over to our home to play. When her mother came to pick her up, our foster daughter started to cry and was begging her friend's mother to let her friend stay longer. Our foster daughter then turned to us and said "You ruined my fun." It was not until we shared this information with our Family Coach, did we learn about transitioning. As silly as it sounded to us at the time, we noticed the tantrums stopped when we let her know ahead of time that she was going to start something different.

There are two kinds of transitions: From one activity to another and from childhood to adulthood.

Daily Transitions Between Activities

- **Routines and schedules create anchors for children in time and space.** Try to keep everything the same; for example, come at the same time, park in the same spot, put bags in the same place, etc.
- If your child is not getting ready, role model it yourself; for example, say "See, I have my coat on, and I'm ready to go."
- When trying to transition your child to a different activity, consider using a **timer to indicate length of time until transition.**
- Plastic **chain links** can be used to indicate time. Five links might equal five minutes, and when your child finishes taking them apart, it's time to go. Or, one link might be five minutes of reading. When you take the link away then your child can actually see time moving.
- If a transition didn't go well, it's okay to try it again or have a "do over." For example, if a meltdown happened from the car to the house, put your shoes back on and



go with your child, sit in the car, talk it out, get out of the car and walk in the house. It's okay to do this many, many times until your child feels calm, relaxed, able to process the transition and knows what to expect and what is expected next time this happens.

■ **Consider the following in the transitioning process**

- a) **Forewarn:** Warn your child of the upcoming change. Wait a few minutes.
- b) **Anticipate:** Restate the change. Expect and plan for resistance.
Wait a few minutes.
- c) **State:** Tell your child exactly what action is required next. Use visual cues specific to the change itself. For instance, transition from indoors to outdoors by holding out the child's coat; from bed to wake by pulling back the bed blankets; from spelling to math by taking out the arithmetic book, etc. Wait only a minute.
- d) **Act:** State the immediate action.

STATE AND ACT COME VERY CLOSE TOGETHER.

Perseveration (locking into a behaviour) may occur during a transition period. Children who are affected by FASD may often **perseverate**. Trying to talk sense, rationalize or otherwise intervene, especially using language, makes the situation worse. The child is unable to let go, no matter what the negative consequence and she is unable to see other possibilities of how to get interested in something else.

■ **To avoid perseveration, think PREVENTION!!! – anticipate to avoid problem behavior.**

- Beware of emotional thresholds – if the child is **perseverating**, it may be because **the next step is too difficult**. Present your child with an easier task.
- For each child, the pattern of perseveration is usually **predictable**. Know what that pattern is and head off problems at the very first sign. Do not wait or be deterred by others who cannot see it coming.
- Use guidance techniques:
- **Follow the three D's: Displace, Divert and re-Direct the child's behaviour when locked into a behaviour.**
- **Create routines** – for example, to keep her from wearing the same clothes everyday, colour code her wardrobe to correspond with a calendar with coloured dots. **Transitions need to be built into daily routines** and should be considered a part of that routine.
- When moving or going on a trip, use a **book with photographs of actual people**, places, and important things. Use the book for preparing the child (ahead of time) for such things as moving to a new home; seeing a doctor or dentist; going to a hospital or school; or taking part in family traditions around Christmas. Prepare your child for things new to her or for events which don't happen very often (e.g., plane rides, traveling to new places, hotel stays, etc).
- Moves, when they cannot be avoided, should be planned between the homes, but the actual move should usually be done quickly.
- When a move to a new foster or adoptive home must be made **try to keep routines in the new home the same.**

■ **Do such things as:**

- Sit her in the **same spot** at the dining table, etc.
- Make use of the same colours/symbols
- Paint/decorate the new bedroom in the same colours as the old
- **Arrange furniture in the same places**
- Allow her to **take familiar things** – like bed quilts – to aid in settling in
- Keep her in the **same school**
- Keep transportation arrangements the same
- Find out if she is used to hugs, handshakes, etc
- Have the new caregiver spend as much time as possible getting to know the child in the previous home; this is more important than extensive visiting out of the home or in the new home

The more you keep things the same—the less impact the transition will have

- Remember that things like Christmas, birthdays, Halloween, the circus, concerts, field trips, assemblies, dentist appointments, haircuts, and so on will require advanced preparation.
- When planning for **Christmas**, it is important to put Christmas items out slowly. In other words, you can't bring the decorations into the main part of the house all at once. **Decorations must be put out slowly over a period of approximately one month.** Once Christmas is over, Christmas should disappear slowly using the same process. This allows the child to transition in and out of Christmas.
- When traveling, stay at the same hotel every time.

Transitioning from Childhood to Adulthood

When trying to transition your youth to adulthood, do not generalize strengths. **Be wary of making assumptions about exceptional skills which you believe can be translated into independence and self-reliance.**

If your youth is very good at carpentry, for example, don't generalize this into "We have to encourage her to develop these skills so she can get a job and become independent and self-reliant." Rather, think in terms of, "We need to encourage him to develop his carpentry abilities so that she has a positive hobby and can perhaps earn a wage at some point. With that skill, plus our continuing support with her living skills, she may work towards semi-independence and self-confidence."

Steps to take before transition planning into adulthood

- Arrange **Freedom of Information disclosure letters** with the individual with FASD. This will allow you to talk with service providers (lawyers, social workers, etc.) about programming and other issues that may arise. This is essential under Alberta's new legislation FOIP (Freedom of Information and Protection of Privacy Act).
- Identify members of a **transition team** and **set clear objectives and goals that EVERYONE understands.**
- Identify actual performance levels (functional abilities) in key areas of the person's life.
- **Develop a history of any illnesses of the individual or family members,**
- **Consult the individual about her own hopes, dreams, wishes and desires.**
- Identify key stumbling blocks or problems that you may run into.
- **Maintain a history of all treatment, including medical, addiction and mental health.**
- Develop a history of supports. **Figure out what worked, what didn't,** and who is still around today. Search for any new supports – funders, people, services, resources and agencies. Identify "friends" and "enemies."
- Identify skills training that is needed and what has been done already.
- **Make sure all needed assessments are completed and current.**
- Remember that it's okay for this kind of transition planning to happen several times in your child's (adult) life. Don't put all your hopes and dreams into this one plan for your child.
- Start to make transitions for semi-independence at an early age (around 16). Investigate opportunities at Human Resources and Employment (HR&E), Persons with Developmental Disabilities (PDD) and Assured Income for the Severely Handicapped (AISH).
- Help your child find close, supported housing, with a supportive roommate. Look for a supportive landlord, employer, and colleagues.
- Have a **public trustee** pay the individual's rent.

- Focus on life skills, job training, apprenticeship, and supervised work experience rather than on academics.
- Educate her work place and those involved in her life that would benefit from knowing about FASD. For example, different tasks will keep the youth affected with FASD interested in her work. Moving her to a position of more responsibility may overwhelm her and result in frustration and eventually quitting the job.
- Avoid busy or overwhelming work places such as McDonald's.

Transition planning into adulthood is NOT meant to lead to:

- Living alone
- Working at several different jobs over a short time period
- Dropping out of school
- Alcohol and drug problems
- Other mental health diagnosis
- Financial self-sufficiency
- Needing no support
- Parenting without help
- Relationships without problems
- Avoiding all trouble with the law

Transition planning into Adulthood CAN lead to:

- Understanding and acceptance of the **need to live at home** into adulthood.
- Understanding and acceptance that **supportive living** is necessary.
- Understanding and acceptance of the **need for help with daily living**,
- Understanding of abilities and what type of job placement the person is suited for, which leads to having fewer problems on the job.
- When needed, **allowing a trusted person to interact with employers**, social workers, probation officers, etc.,
- **Realistic educational / vocational programming based on function, not IQ.**
- Staying in school, which is more important than actual completion of a program.
- **Catching drug and alcohol problems early**
- Accessing **mental health diagnosis** and **treatment** before problems become entrenched and resistant to effective intervention.
- Acceptance of some sort of **financial inter-dependence** such as joint signatures, parent or financial trustee as payee, etc.
- Less financial victimization.
- Increasing the number of people who know the totality of the individual's situation and increasing the circle of people around her that understand her needs. **The more people involved the stronger the team, the better the ideas.**
- Acceptance of some sort of creative **co-parenting of children** if needed
- Increasing the chances of success.

Roadblocks to successful transition planning into adulthood:

- **Not starting soon enough** or not allowing enough time
- **Unrealistic expectations**
- Failing to adequately address mental and physical health needs
- Expecting steady, forward progress (**there likely will be many 'bumps' in the road, be prepared for them!!**)
- Not identifying key people to be involved in the process
- **Losing track of the common goal**

Keep these points in mind when bringing a team together to support an individual affected with FASD:

- **Who is responsible for each task**
- The **main objective**
- **HOW** each goal will be achieved
- Identify any and all agencies and organizations that will be involved
- **Prioritize actions in terms of time (for example, individual and guardian will talk with a career counselor by January)**
- Give dates for start and end
- **Be clear as to deadlines** – never open-ended or on-going
- Provide an **overall timeline**

Adolescents Involved with the Criminal Justice System

Unfortunately, it is common for adolescents with FASD to come into contact with the criminal justice system. Although the criminal justice system is making strides in FASD awareness and training, it is, like most systems, designed for dealing with the “average” or “typical” person, not the unique being who is your child.

It is important that you advocate on behalf of your child because you know your child best!

For Caregivers

- As soon as possible, **tell** police, courts, and correctional staff that your child is **affected with FASD**. This information can ensure more appropriate treatment at all levels. Informing the system about your child also improves the chances of the assignment to a defense lawyer, probation officer, or key worker in a correctional center who is more knowledgeable or skilled in the treatment of youth with FASD. It is important, for example, that you avoid conditions on a probation order that would be very difficult for the youth to follow and therefore set the youth up for failure.
- If possible, educate your child’s peers and talk to them (along with your child) about what FASD is as well as its challenges and its joys. Such discussions can go a long way toward avoiding stigmatization and preventing contact with the criminal justice system.

- Provide your child with a laminated card with personal identification and the name and telephone numbers of an emergency contact. Instruct your child that when he is stopped by the police, he is supposed to show this card to the police.
- Supervise your child's peers and provide appropriate social opportunities with those peers.

For Corrections Staff

- **Case planning at all levels must include the important adults in the life of a youth with FASD.**
- Keep **interviews** with the young person as **short** as possible. An interview that requires obtaining a lot of information (e.g., a pre-sentence report interview) ideally should be done over several interviews.
- Routine probation interviews or counseling sessions should consistently be held the **same day and time** (e.g., every 2nd Tuesday at 4:00 p.m.)
- Ensure any direction given to the youth is **in writing** and is also given to the caregiver.
- Try to limit tasks or expectations and give limited choice where possible (For example, "You must attend counseling. Do you want to attend AADAC or see a psychologist?").
- Make expectations very clear and reinforce expectations at each appointment or meeting.
- When fulfilling a court instruction is a concern, talk to the youth and caregiver about **what things could be done to make it easier** for the youth to follow the conditions set by the court.
- **Set limits and follow through.** Avoid debating or arguing over rules. Make consequences immediate and consistent and remind the youth of the reason for the consequence. **Know that she will continue to experience difficulty learning from consequences.** The brain damage that made this difficult in childhood may remain.
- **Anticipate and prevent problems** by providing close supervision and monitoring. Whenever possible, obtain the support of a youth worker, mentor, curfew surveillance staff, etc., to help supervise your youth.
- Use language that is familiar. **Avoid open-ended or "why" questions.** Using cueing and prompting techniques, you can assist your child when she is having trouble remembering something. You can also teach strategies for remembering such as using notepads, lists, etc.
- Provide your child with a laminated card with personal identification and the name and telephone numbers of an emergency contact. Instruct your child that when she is stopped by the police, she is supposed to show this card to the police.
- Supervise your child's peers and provide appropriate social opportunities with those peers.

Age Specific Strategies

Eating

One of the kids in our house would sample any baking left within reach and unsupervised. We talked about locking the baking up, consequences, etc. The solution was to cut a bit of cake or cookies and put it on a side plate, then telling her if she needed to sample she should take it from that plate. As long as she had a side plate she never ran his fingers through the icing on another cake.

Things You May Notice

Babies with FASD are often not big eaters or are disorganized eaters. They have a **poor suck reflex**, are slow to breast feed, and **unable to gain weight**. Many babies have a high cleft palate and **weak cheek muscles** that make it difficult to eat and swallow properly.

Younger children may **gorge and starve**, forget to eat, become easily distracted at meals, won't eat multi-textured foods, **can't tell if the food is too hot or too cold**, often stand when eating or need their feet to swing under the table.

Older children may overeat, never feel full, try to be in other people's eating space at the table, forget to eat for days, **want lots of salt or spice on food**, offer or show interest in helping to make food, or want to set the table or do dishes but they don't follow through or get distracted while doing the task.

If your child has difficulty with eating or is either underweight or overweight, it is important that you speak to a health care professional. Do not try to diagnose the problem on your own.

The following are some general strategies that might help make mealtimes easier if your child is having trouble in this area.

Strategies for Babies

- Prepare **food with neutral flavors**, heat and texture.
- Hold your baby upright as much as possible so she doesn't swallow air. She may choke easily.
- Feed your baby slowly and burp her often.
- Avoid fatigue and limit feeding time. Try frequent small amounts of nourishment throughout the day.
- **Feed your baby as soon as she shows signs of hunger.**
- Have your baby face away from you when eating.
- If there are problems with sucking, use "preemie" nipples.
- Due to stomach sensitivity, your baby may need a soya-based formula.
- **Use the same bottle, same type of nipple, cloth, and bib – everytime.**
- Have an ample supply of the same nipples.
- Your baby may need a bigger nipple due to problems with the palette.

- Infants may not “feel” nipples or a spoon in their mouth. Try to find a way to change the texture of the nipple or spoon (e.g., use an emery board to roughen).
- Reduce outside stimulation (for example, close windows, turn off TV).
- **Gradually introduce new food**; for example, put pabulum in the bottle (with bigger hole in the nipple); then mix fruit with the pabulum (one change at a time).
- Remove labels and put food in bowls so baby won’t become attached to particular brand labels. **Ignore food labels that suggest particular age groups.**
- Watch for reaction to tastes as babies may be orally hypo- or hyper-sensitive.

Strategies for Children

- Consider developing **a mealtime walk routine either before or after the meal**. Getting physical exercise can help children settle at mealtimes and go a long way in developing lifelong habits in healthy living.
- **Never give food or withhold food as reward or punishment.**
- Have **meals at the same time** every day, including weekends.
- Consider having the **same meals on the same days** for both dinner and lunches (for example, chicken on Monday). This helps children to “know” the days of the week through association with other senses.
- Consider **simple rules at mealtimes** (e.g., “Eyes on your food, hand on your plate. “ or “bum on seat.”).
- **Avoid long mealtimes**; they are distracting.
- No TV or radio at mealtime. Unplug the phone or move it to another room if possible. **Keep interruptions to a minimum.**
- Always serve three meals a day.
- Always serve regular snacks. **Make eating a habit**, reducing the need to rely on internal hunger cues.
- Seat the child with FASD next to the most tolerant individual.
- Assign your child **a specific seat at the table**, preferably at the end of the table, and never change it.
- Put a stool under your child’s feet if her feet don’t reach the floor.
- Allow an older child to sit on an exercise ball when at the table.
- If your child has trouble sitting for a long time, let her stand at the table.
- Use placemats or masking tape to delineate personal space at the table.
- Put tennis balls under the table and chair legs to reduce noise.
- Use a Fisher Price pretend razor to stimulate the cheek muscles for children with low muscle tone.
- Let your child start eating before others if she is distracted by many people at the table.
- Allow your child to stop and start eating many times during the meal if necessary.
- Serve your child first if she has trouble waiting.
- Caregivers should serve portions for those children who tend to overeat.

- Place the food on her plate to eliminate the need to make a choice, unless she can cope.
- Some children like to use a **plate with separations so foods don't touch** each other. Separating foods may also help to regulate portion size.
- Eating in front of a mirror may help your child to see where her hand and mouth are to more easily direct the food.
- Your child may respond well to highly acidic/spicy/hot foods or may only respond to very bland foods. Experiment!
- Hypo-sensitivity to certain food textures, especially smooth things like mashed potatoes or yogurt, can problems. Try adding things like bacon bits, bran buds or granola for texture and crunch.
- **Children with FASD may chew and chew without swallowing. Remind your child of the need to swallow.**
- If your child has difficulty manipulating eating utensils, give her a spoon, or try utensils with larger, rounder handles which are easier to eat with. You may also have to pre-cut the meat.
- Have your child wear a one-pound wrist weight to feel where her hand is with the utensil.
- Never put dessert on the table. Explain that “Dessert comes after pork chops.”
- Depending on the child, use hardest or softest toothbrush when brushing.
- If necessary, advocate strongly for your child to be allowed to **eat on the school bus**.
- You may consider having your child take a **vitamin supplement**. Be careful of vitamins that might have coloring agents or cause constipation (iron) or stomach upset. Give vitamins at bedtime.

Strategies for Adolescents

- **Continue to use what works from childhood.**
- Supervise food preparation and clean up. **Lower your age expectations.**
- **Practice making food from packages using the picture directions when possible.**
- Practice making food in the microwave.
- Use non-metallic wrap in the kitchen.
- **Consider supervising the refrigerator. Some caregivers find it helpful to lock the fridge over night.**
- Inquire or check-in to eligibility for meals-on-wheels.

Play-Time

Things You May Notice

Younger children affected by FASD often get into arguments with siblings over toys (issues of ownership arise). They may be unable to choose what to play with so everything is played with. They may have **difficulty understanding when play time starts and when it stops**, which leads to arguments about when it's time to go and when clean-up needs to happen. Additionally, children may not know how to play with other children. They may talk about playing together but end up in “parallel play.”

Older children often “borrow” CDs, DVDs, etc. and want to play video games all night. They may not want to go to bed. In addition, they may **have difficulty paying attention to a shared activity. Older children sometimes use the computer inappropriately and can be easily manipulated in chat rooms.**

Strategies

- **Supervise family time.** This includes free play with siblings, TV time, computer time.
- Make your own lap blanket for watching TV or playing games. (See page 45 for directions on how to make one.)
- Provide two options of things to do. **Put everything else away or out of sight.** Sheets are great to cover book shelves, TV, etc. when not in use.
- **Teach how to take turns.** You may need to literally lean over and tell your child what to say to another child; for example, “May I have the ball?” “Yes, in two more minutes.”
- Provide the child with **her own seat** in the family room. “Susie, this is your seat, this is where you sit”.
- Many children enjoy sitting in a chair with arms that can wrap around their bodies. You can make your own chair like this by pulling a comfy sweater over a chair.
- If your child doesn't like sitting in a chair, you can buy spine wedgies made out of foam to provide lumbar support while sitting on the floor.
- Use a pictorial timer to show when play time starts and ends.
- **Label toys** with different stickers for different siblings to visually show ownership.
- **Make boundaries visual** in the room with masking tape on the floor.
- Plan out movie nights, game nights, etc. and teach your child what to do so she knows what is expected of her during this time in the future.
- If you have a clean-up schedule, create a “chores chart” to remind your child or youth what needs to get done throughout the week.
- **For sensory stimulation**, take a bulletin board and glue on different fabrics. Put it on the floor and let your child feel each fabric with her feet while watching TV or playing a game.
- **To work core body muscles**, play tug of war with her arms and have ‘foot wars’ on the floor.
- When you see an outburst coming, distract your child with a short funny story or provide something else to look at, touch, eat, etc.

- If your teen has gotten worked up about something and is angry, redirect her with deep muscle work (for example, floor washing or allow her to stomp around in an “angry room”).

Sleep/Wake Time

I had a bed wetter and dressing at night was impossible. I used a “game” and instead of raising my blood pressure and stressing myself out, I used a watch or clock with a second hand. The first time she woke with the usual ... “I don’t wanna” or to better put it “can’t” attitude, and I calmly told her that I wanted to play a game. She loved challenges and spontaneous ideas. I bet her that she couldn’t get herself dressed and downstairs in 15 minutes ... of course she said, “okay, watch me. Start the clock, mom!” Of course she beat the timer, and was in an upbeat mood to eat and leave for the bus. Then I gradually added incentives to: make her bed (remove the wet sheets), brush her teeth, etc.). She loved the idea that she could actually beat the clock. I also made sure that she did, and eventually within a few months she was able to do more on her own. I gradually “weaned” her from each challenge and added more challenges. She was 6 when I started this, and by the time she reached age 10 she was completely able to set her own alarm, get herself dressed properly, get her own breakfast, wash up, and help make her own lunches.

Things You May Notice

Younger children with FASD often have **trouble with falling asleep and waking. They may suffer from** irregular sleep patterns, **respiratory distress**, trouble settling, arching back-stiff, cuddling/being held, mood swings or unpredictable reactions, eye contact, **hypo- or hyper-sensitive to touch**, light, sounds, smells, fussy, colicky, and **difficulty adapting to change**.

Older children often **continue to have difficulty falling asleep, staying asleep and waking up**. They want to be like their friends and sneak out during the night or stay up late on the Internet or watching TV all night.

Strategies

- In the bedroom, **limit what is on the bedroom wall, keep furniture to a minimum**, use sheets to cover bookshelves, etc. when not in use. Store toys in bins or boxes, but not in the bedroom.
- Always have your child **sleep in her own bed**. Never allow her to fall asleep elsewhere. Get her used to sleeping in one place.
- Allow **only one toy or book in bed** with your child. Some may sleep better with no toys or books.
- **Night-lights are NOT recommended** because shadows can lead to night terrors. Use small lamps with colored lights (pink, blue) instead.
- **Shower or bath at night so there isn’t a rush in the morning**. Try using lavender or vanilla scented shower gel or bubble bath to calm the child before bed.
- Many children will need 10-12 hours of sleep per night at the age of 10 or 12;

others need very little sleep (3 to 5 hours or less) and may become nighttime wanderers. **Sleep disturbances are serious and continue throughout life.** Melatonin may be helpful so check with your doctor to see if this is appropriate. (**Melatonin** is a natural hormone secreted by the brain's pineal gland. It controls **sleep cycles** in people and animals. It can be **prescribed** and is often effective with FASD affected individuals.)

- **Fleece throws** are very comforting and soothing to infants.
- Rocking the baby side to side may be over-stimulating, so **try rocking the child gently up and down.**
- Wrap the child firmly with knees bent towards her tummy.
- Babies and children with FASD **may need tight swaddling or very loose clothing. A sleeping bag may be appropriate for older children.**
- Children may need to be in a crib longer than average or will sleep better with guard rails on the bed.
- A rocking crib or a swinging hammock may also be helpful.
- Many children with FASD like **only one quilt or comforter** (with no extra sheets) or a sleeping bag. (A sleeping bag can be sewn out of a fleece blanket.) Some children like the feel of a heavy blanket.
- Prepare for daylight savings time by putting darker curtains on windows.
- If your child is not sleeping, ask her what she hears so you can identify the problem.
- **Monitor your teen's sleeping patterns.** She may need to be told when to go to bed and like many teens may need help getting up and ready.
- Use the **same routine sequence for sleeping and waking** (even on weekends and vacations).
- Your older child may want to "sleep in" on weekends like her peers. Let her do this because it is not worth the fight.

Going to Sleep

- **Establish rituals for saying good night** which allow the child to transition from the routine to the bed. Use the same words, gestures, touch. Follow the same order every night (for example, supper, activity, bath, snack, brush teeth, story, bed).
- Consider the time between dinner and bed as a transitional time with slow down activities.
- Start a **calming bedtime routine an hour before bedtime** (put toys away, have a warm bath, brush teeth, put on pajamas, read a story, hug and tuck in).
- A **vibrating foot bath** may also be calming before bed.
- Give older children a light snack before bed.
- Many children are soothed by eucalyptus or lavender oil/spray on the pillow at night.
- Put a **ticking object such as a clock in bed with the infant. 85 beats per minute** simulates the heartbeat. Soft music such as Mozart and Bach has regular calming rhythms.
- There is an item on the market called **Sound Therapy Relaxation System** (it can be

purchased from any major retail outlet). This electronic device has 10 sound recordings to choose from that range from a heart beat sound, to rain and white noise. This device is similar to the concept of a relaxation tape, only with more options.

- For a child who wakes up at night, have a list of acceptable things for her to do in the bedroom.
- **Childproof the house for night wanderers.** For instance, move door knobs to the tops of the doors or use plastic child-proof door knobs.
- Install alarms in the bedroom to indicate when the child has left her room. Alarms on the outside of windows and outside doors may also be required. Inexpensive ones are available at many stores. Chimes and bells can also be hung on doors.
- **Accept that the child may be in bed but may not be asleep.**

Waking Up

- **Wake up the child at the same time and in the same predictable way every morning.** This could look something like this:
 - Enter room and say “Chris, time to get up.”
 - Open the drapes
 - Turn on the light
 - Gently nudge or stroke your child
 - Pull the covers back to ease transition from sleep to awake
 - Help your child in sitting up; make sure her feet are on the floor
 - Tell her what comes next

Clothing

Things You May Notice

Younger and older children with FASD may be hypo-sensitive (not feeling enough) or hyper-sensitive (feeling too much) to touch. This sensitivity might lead to **wanting to wear certain clothes** and refusing to wear certain shoes, socks and other clothing items. They **may dress inappropriately** for weather or want to wear the same clothes everyday without necessarily washing them (e.g., your child loves to wear a hooded sweater). Children may also have difficulty sensing fabric on their bodies such as socks, etc. or they may feel that the clothing is too much to handle and overloads their senses.

Strategies

- **Take off all clothing tags and wash new clothes a few times.**
- Stick to soft, **simple colours** with clothing; red, for example, can be alarming. Avoid patterns.
- Teach small children to dress by **putting on clothes in the same order every time either from top to bottom or vice versa.** Use a hand-over-hand left-right approach with a singsong voice: “socks, left foot; socks right foot,” “undies, left leg, right leg,” etc. **They learn more and retain more if you sing.** Use the left-right approach because reading and writing are left to right exercises (in most cultures).

- Some fabrics or elastics might exert too much pressure. If your child is hyper-sensitive, use seamless socks, jogging pants. **Avoid turtle-necks and denim.**
- Put curtain weights on the hem of her pants so she can feel her pant legs better.
- If your child can't choose appropriate clothing to wear, **put all the clothes on a hanger in the order they go on** (inside clothes on the outside) with a colour-coded tag to the days of the week on a colour-coded calendar.
- If tying shoelaces is a problem, **use Velcro shoes or elastic laces.**
- Teach your child how to **button from bottom to top** so she can see them match up better. Also, zippers always go from bottom to top to reduce confusion.
- **Rotate winter and summer clothes in and out of the child's room.** Store seasonal clothes in a separate closet.
- If your child or you are having trouble putting clothing away in a drawer, consider open shelving with a large piece of material such as a sheet draped over it instead.
- For winter climates, use a **hand-drawn thermometer** on the inside of a window, with a red line to the temperature where heavy clothing must be worn. Have a real thermometer immediately outside at the same spot as the drawn one. When the **two lines are equal or the outside one is lower, the clothing goes on.**
- Post a pictorial sign at the front door. Start with boots, then hat, then coat so that she knows what order to put outdoor clothing on.
- **Set up an area for her coat and boots that is all her own so she knows exactly where to put everything when she comes in the door.**
- Have a rule such as "All clothes go in the hamper every night" so there is no clean/dirty confusion.
- Make it a routine to set out clothes with the child prior to bedtime..
- **Don't fight it – the hoodie may be used to self-calm.**

Self-Care

One time, one of our girls was being very quiet in her room and when she came out her hair was spiked out in all directions with a faint hint of raspberry. We wondered about it and asked her what she did to her hair. She told us that she gelled it. As far as we knew, there was no hair gel in the house so we asked her to show it to us. She brought it in and said, "Look, it's gel". On the other side of the container was the words 'Lip Gel'.

Things You May Notice

Younger children affected with FASD are often hypo- or hyper-sensitive (don't feel enough or feel too much) to touch, light, sounds and smells. They have difficulty adapting to change, have problems with toilet training or with sequencing the steps for hygiene routines such as washing hands.

Older children may show signs of poor self-care such as odors, cuts from shaving, and an **overall appearance of poor hygiene.** They may forget to shower or to brush their teeth.

Strategies for Babies

- With diaper changing, follow same routine (for example, low light or more light).
- Once the diaper is taken away, put a warm cloth on your baby's bum immediately to reduce cold air.
- Keep diaper wipes over heat register to keep them warm.
- Use same brand and type of diaper. Never use a scented diaper.
- Be **aware of allergies** to creams. **Zinc oxide** may be a good choice in creams.
- Your infant **may need changing often** if she can't handle a wet diaper for very long.
- After bathing, wrap your child in a large towel and rub her with lotion.
- Due to your child's possible skin sensitivities, use mild/ no /phosphate free detergent.
- Too much noise or too many people may confuse the child during changing or bathing

Strategies for Children

- **Post routines with pictures that outline each step of the task.** This is a great idea for the back of the **bathroom door** to refer to in the morning.
- **Demonstrate** how to do routines and personal hygiene such as how to wash hair, how to put on a band-aid, etc.
- **Maintain routines that will carry into adulthood.**
- **Vanilla-scented** bath can be used for all ages because the smell is calming and often pleasing.
- Vanilla laundry soap or softener can be used for all ages, again, because the scent is therapeutic for them.
- Practice shaving often with no actual razor blade to get your child in the routine for his teen years.

Strategies for Adolescents

- **Don't assume** your adolescent has retained what to do in what order in the shower. Periodically check to make sure these routines are consistent.
- **Post a checklist of steps in the morning/evening hygiene routine.**
- Remind your adolescent about self-care routines if she is going away for the weekend or vacation. **Make a mini bathroom chart for her to take to sleep-overs or on trips.**
- **Mark her menstruation cycle on a calendar so you know if she has missed any periods.**
- **Practice menstruation hygiene.**
- **Practice and teach the importance and ease of using condoms and birth control.**
- Show videos that demonstrate proper hygiene techniques.
- Develop daily/weekly routines for cleaning, cooking, laundry, vacuuming, and grocery shopping.
- **Post pictorial instruction cues on the machines.** Use "cue cards" to give step-by-step simple instructions of how to do things. Cue cards might show how to use the **washer/dryer**: "open door, put in clothes, add 1 soap (only have one measure available), shut lid, turn

dial to dot, push in knob.” All of this should also be made visual with line-drawings and a red dot painted on the washer/dryer for the proper spot to turn the knob to.

- Cue cards should be kept in the area they apply to, in a specific spot.
- Buy food packages with pictorial instructions.
- Use recipe books with pictures and written instructions broken down into sequential steps.
- Use chores and “helping” to fill in small gaps in time between events.
- Cue cards can be used for unexpected situations and a few of the ones of more concern can be carried with your child in a pocket. These cards tell your child what to do in an unexpected situation.

Transportation

Things You May Notice

Younger children with FASD often do not deal with vehicle transportation very well for long periods of time. They often get into **fights in the back seat** with siblings. They may become upset when they can’t see what everyone is pointing at. They **lack fine motor coordination** and spill food while the car is in motion. The seat belt often can be something that is very uncomfortable for them to wear.

Older children and adolescents often do not get to the place (school, mall, appointments) on time or at all. They may **forget the bus/LRT routes and times** consistently. They **may lose their ticket** and/or money. They may get distracted once off the bus and never make it to their final destination.

Strategies for Young Children with FASD

- Determine whether or not the front seat is appropriate by measuring the child’s weight and height. **Don’t work with chronological age, as children affected with FASD are often much smaller than normal children.**
- Consider seat belt restraints which your child can’t undo. Try wrapping a **piece of material around the seat belt to make it more comfortable to wear.**

Strategies for Older Children and Adolescents

- **Offer as much space to the child with FASD as possible.** For example, allow her to sit in the front seat of the car, if there is no air bag. If she must sit in the back, make sure no one is beside her.
- Use **games to keep older children occupied.**
- Use headphones and relaxation tapes.
- Provide a **“back up card” with what to do or who to call in unexpected situations** (e.g., if you miss your bus, go to the school office and tell the secretary and sit there until mom picks you up).
- Provide **bus tickets, not money.**
- **Have someone wait at the destination to pick the child up before she is distracted.**

Recreation

One of the social workers insisted that she wanted her client to be involved in team sports as at 8 she lacked basic social skills. You could tell her from the rest of the kids running up and down the soccer field – she was the one squatting in the grass yelling “don’t step on the ants.”

Recreation is important not only because it provides the child with physical activity, but also provides opportunities for “teachable moments” and opportunities for experiencing success.

Things You May Notice

Young children often do not know how to use swings, slide, or monkey bars. They are **uncoordinated, late in reaching gross and fine motor developmental** milestones for their age, and need extra time to start and finish activities. Children with FASD are often left out by their peer group, and they often **prefer parallel play (playing side by side but not interacting)** rather than direct play with other children. Many children with FASD have trouble taking turns.

Older children usually like to follow the lead of their friends. They can easily make friends, but they **have trouble keeping friends**. If older children affected with FASD are in organized activities, they **may forget they have a practice or a game**, may forget to bring the proper equipment, or may forget the rules.

Strategies

- Teach your child how to use the swings and slide at the park during less busy times.
- For help in increasing your child’s **fine and gross motor skills**, consult with an Occupational Therapist. You can also encourage your child to **pick up marbles with her toes**, swing her arms like a windmill with each arm going a different way, practice balancing on a balance board (kids can often read better while standing on it), **have foot wars**, or make bread dough or bannock to **provide deep muscle work** and relieve tension.
- Tape a big metal nut on the end of her pencil or art supplies so it is easier to manipulate.
- Give your child **thicker crayons for easier manipulation**.
- When your child is drawing/painting/colouring, tape a three-ring binder to the table for her to use as a “desk.” The writing angle often helps.
- **Plan out regular recreation and take your child there**. Acknowledge difficulty with teens accepting help. There is a need for supervision which must be balanced with your teen’s need for independence. Provide independence in other ways.
- Go to cheap movie theatres because they have fewer people, posters, and noise.
- Be careful with activities like Tae Kwon Do or other martial arts that may encourage your child to punch and kick at home.
- Some parents suggest horseback riding or having a pet because it encourages a one-to-one relationship and is animal-based.

- **Supervise birthday parties** to avoid meltdowns. Birthday parties can be problematic because there is no pattern for all parties, each time the event is new and different and your child won't know what to expect. Your child may get upset because she did not receive a present.
- **For your child's own birthday, do the same thing every year.** Consider booking a party room at a water park. That way, home is still a safe and predictable space to come back to when the party is done.
- Make **Friday night "treat night."** Your child can pick one movie and one treat. If she picks another treat, that's okay, but the first treat has to go back. The rule must be "only one treat."
- **Watch your child play**, and she will give you clues about what she needs to make her body feel good; for example, swinging, running, pulling, or pushing.

Relationships and Sexuality

Things You May Notice

Younger children may have **no fear of danger**, do not respond to verbal warnings, and have no stranger anxiety. **Younger children** are **highly tactile** and **may explore their bodies** at inappropriate times (for example, during Kindergarten class time). They may also be very curious about the opposite sex. **Older children** may **seek close personal contact with everyone**, share inappropriate information, and have **difficulty distinguishing how to talk to or what to talk about with strangers**, professionals, family, neighbours, school staff, etc.

Older children with FASD are **sexually curious** (as all older children and adolescents are) but they have difficulty maintaining friendships. They may have difficulty interpreting social cues from the opposite sex ("He smiled at me, so he's my boyfriend"). Adolescents may have trouble remembering to use a condom every time and can't foresee pregnancy in order to take precautions every time.

Adolescents often **change friends quickly**, and they are often prone to hanging out with a rougher group. They may also enjoy playing with younger children, may engage in **high risk behaviour**, may take dares from friends, and may want to help out friends. Often, they can be easily manipulated by their peers. **Gangs are particularly welcoming to youth with FASD.** In gangs, there is often greater acceptance for difference between peers; impulsiveness and recklessness are valued and expectations or demands are minimal.

Strategies for Younger Children

- **Constant supervision.** Most sexual abuse does not happen from strangers.
- Teaching personal boundaries is very important and must be taught at a young age and constantly reinforced.
- Teach relationships at home and wherever you go. If your child approaches strangers, **deal with it on the spot**, in front of the stranger. Clearly state that this is not a familiar person. Say, "This is a stranger. You do not talk to strangers." Or use a phrase such as "Stranger Danger."
- For **kids who run away**, provide them with a marked spot to run to so they can run to the spot, calm down and come back when they're ready.

- **Teach “private bodies” rather than private parts** so that children are not confused.
- Teach the names of body parts.
- **Explain to your child that everyone must be an arm’s length away.**
- Ask your school board about resources that teach “how to make a friend, how to be a friend.” Get the print outs and take them home to use.
- As caregivers, we need to role model social interactions step by step; for example, handshakes and hugs. Watch to see if your child is getting it; if not help her to see the connection. If your child or adolescent is sensitive about touching, tell your relatives in advance what your child prefers.

Strategies for Older Children and Adolescents

- **Supervise outings and activities as much as possible.**
- Use of chairs with arms may help to delineate personal space.
- Provide cues for boundaries such as masking tape on the floor and furniture.
- Consider making some simple rules (for example, **“Everyone has to be an arm’s length away.”**).
- **Arrange a friendship as early as possible with a peer who is responsible** and can act as a buddy when you are not around. Keep in mind to consider a friendship that can be taken into adulthood.
- Educate your child’s peers about FASD and educate your child about what is a good request from a friend.
- **Your child may want to have an injury like someone she knows.** She may want to hurt herself to try and be like this person. And when she does, you have to validate this and take her to the doctor or put an ice pack or a tensor bandage on the injury. Keep in touch with her friends so you know what to expect.
- Provide **safe activity options** for your teen to get involved in (it’s not about what she can’t do; it’s what she can do).
- Be aware of the grade in which sex education is taught. Reassure your daughter that she will not get her period if she goes to school and learns about menstruation.
- **Be open and willing to talk about menstruation.** Explain it in ways your daughter will understand. One parent says, “There’s a baby nest inside and if you don’t need it, it melts away.” Other parents stick to the very basic facts.
- Let your daughter know that **it’s okay to practice with panty liners** months or years before her period begins.
- **Mark her period on a calendar.** It will remind you and her.
- Show your daughter strategies for menstrual cramps like using a hot water bottle.
- **Keep books about sex education all around the house.**
- Practice with condoms and birth control months before required.
- **Give lessons in sex education every week.**
- **Cover every topic from putting on a condom to scripts about sex.**
- **Provide longer acting Birth Control than the traditional daily pill (Depo-Provera the Patch or an IUD).**

Self Harming

For my daughter, with older children she will try to act older to fit in. She may want to be like the others or worse than the others and make up stories to fit in. With younger children she will act like them to fit in. Or she will try to be like an older sister or mother them, which could be a good thing. When she tells bigger stories than the others about eating disorders, drugs, sex, suicide and cutting someone will call her bluff. Then she will have to decide to do it or be rejected. She will not want to be rejected. The older children will tease her if they get a reaction from her. Best to avoid older children and children that also have issues with conduct, suicide, cutting, psychotic behavior.

Things You May Notice

Younger children with FASD often have difficulty expressing their frustration with words and may get it out by biting, scratching, banging their heads on the wall, punching and kicking, not eating, etc. Anything to feel in control again.

Older children and adolescents face the same problem with verbal expression and **often have years of poor self-esteem built up**. Sometimes children will have had a diagnosis at a very young age and only later will question why they are different. Older children and adolescents may feel in control by cutting, not eating, throwing up, drinking, doing drugs, taking dares from anyone, etc.

If your child is engaging in self-harming behaviours, seek professional help.

Strategies for Young Children

- Constant supervision.
- Show your child what she can do when she is angry. For example, show her she can stack wood, dance, crush pop cans, have a bath, call a friend, swing or jump rope, etc.
- Point out good ways others get out their frustration.

Strategies for Older Children and Adolescents

- **Attend suicide prevention courses.** Learn about self-mutilation and why they do it. Learn when it becomes serious.
- If you suspect your child/youth is at risk for self harm, **check out their room** for blades from pencil sharpeners, glass from light bulbs, glass from picture frames, broken c.d.'s, glass from nail polish bottles, paperclips, tacks, etc. Remove all such items. Keep the room safe for your child and others.
- Also **check for tissues and towels with blood on them.** This will give you an indication about how much mutilating is happening. Remove all tissues and towels regularly without comment as they act as triggers.
- **Do not ask to see the wounds** because this may act as a reminder of failures. If you see wounds, do not stare or make funny faces or comments; calmly talk to your child.
- Give your adolescent **books to write stories in or to use as diaries.** If your adolescent allows you to read them you will get an idea as to what is troubling her. This will act

as an **outlet for your adolescent to express herself** and will help you see what is troubling her. Encourage her to put dates on the stories.

- Pictures of negative times or dead relatives can act as **triggers** as well. Repair all the damage that your adolescent has done around the house during her tantrums. If left un-repaired, it will just act as a trigger. She will not need this as a reminder of the day a poor choice was made; she already feels bad enough.
- **Computer time needs to be monitored.** Computers provide easy access to negative interaction with strangers regarding suicide and self-mutilation.
- If your adolescent runs away do not get angry when she is found. She needs to feel that **home is always a safe place to go to.**

How to Make a Lap Blanket

Materials

- cotton fabric about 0.7 meters wide and 1.4 meters long
- fleece fabric 0.5 meters wide and 0.8 meters long
- beans or rice to fill the bag made out of cotton fabric

Directions

1. Make cotton fabric into a pillowcase-like bag and sew up three sides.
2. Fill cotton bag with beans or rice and sew shut.
3. Make fleece into a pillowcase-like bag and sew up three sides.
4. Sew Velcro strips along the top of the fleece bag so the top can be closed and later opened if needed. (i.e. to wash).
5. Centre cotton bag with beans or rice inside fleece bag and fasten Velcro into place.

Note: Inner bag must be removed prior to washing fleece outer bag.

Glossary

Abstract Thinking: To think symbolically, to reason, to predict. Examples of abstract speech would be , “Go get ready”, “Watch out”, “Don’t hurt her feelings”

Concrete Learning: “Hands on”, needing to see, touch or do to learn

Environmental Modification: Changing the environment or surroundings

In Utero: In the uterus, before birth, during pregnancy

Hypo sensitive: Less than normal ability to respond to stimuli or touch; don't feel enough

Hyper sensitive: Overly responsive to stimuli or touch; feel too much

Linear Thinking: Thinking in a way that one thought or event follows the other. For example, put the key in the car and the engine will start.

Logical Consequences: Punishment that relates to the behaviour. For example having to clean up while others get to watch a movie because the mess was supposed to be cleaned up before the movie started.

Natural Consequences: Punishment that happens as a result of the behaviour. For example, going hungry at school because the adolescent forgot to make his lunch the night before.

Neuropsychologist: A professional who studies how the brain affects the behaviour. A neuropsychologist studies the domains of executive functioning. An assessment done by a neuropsychologist is the most important step in a diagnosis of FASD and understanding a person's level of functioning.

Occupational Therapist: A professional who looks at how we function in our daily activities such as school, work, social outlets and helps to change the environment or our skills to help us succeed.

Perseverate: To do the same thing over and over, to be stuck on a behaviour or thought.

Public Trustee: A government official who monitors an individual's finances.

Regrouping: Having the child collect herself (rather than being punished) in a quiet, calm way in order to deal with the event and start fresh again.

Sensory Stimulation: Things that arouse the senses (touch, taste, hear, see, and feel-on the skin, inner balance and body awareness).

Transitioning: There are two types of transitioning.

1. To transition from one daily activity to the next. For example from school to home.
2. To transition from childhood to adulthood.

Other Resources

FASD Websites for Teens

- www.betterendings.org/FASFAE/
- www.acbr.com/fas/

Websites for Teaching Money Management

- www.workshopsinc.com
- www.moneyinstructor.com
- www.practicalmoneyskills.com
- www.core-learning.com
- www.TheCanadianTeacher.com

Sensory Products

- www.toolsforkids.ca

Health Care Solutions: (780) 434-3131

Elephants Never Forget etc. (780) 453-5121

On Line Support

FASLINK Mail List

<http://www.acbr.com/fas/faslink.htm>

Large discussion list for parents, professionals and persons with FASD

FAS Resource Mail List

<http://health.groups.yahoo.com/group/FASResource/>

Open list to learn more about FAS (77 subscribers, 5-10 messages/day)

FAS FORUM Mail List

<http://health.groups.yahoo.com/group/fasforum/>

For discussion of FAS/FAE (168 subscribers, 10 messages/day)

AdoptFASD2 Mail List

<http://health.groups.yahoo.com/group/AdoptFASD2/>

For families who have adopted kids with FAS or FAE (46 subscribers, 10 messages/day)

RAD-FASD Mail List

http://health.groups.yahoo.com/group/RAD_FASDkids/

For families whose adopted children are alcohol exposed and have symptoms of Reactive Attachment Disorder (33 subscribers, 5 messages/day)

OLDER FAS Mail List

<http://come-over.to/FAS/JoinOlderfas.htm>

Support list for parents of teens/adults only (100 subscribers, 6-10 messages/day)

FASHOMED Mail List

<http://www.topica.com/lists/FASHOMED>

For parents who wish to home school their children with FAS/FAE (60 subscribers, 3-5 messages/day)

HISFAS Mail List

<http://health.groups.yahoo.com/group/HISFAS/>

Christians who are either family members or individuals with FASD or who have been diagnosed themselves (50 subscribers, 1 message/day)

PrimoMadre Mail List

<http://health.groups.yahoo.com/group/FASDBirthparents/>

For birth moms of kids with FAS/FAE (6 subscribers, 1-2 messages/day).

Just Managing Mail List

<http://health.groups.yahoo.com/group/justmanaging/>

For families saying 'no' to psychiatric drugs for their hyper, spirited, explosive, difficult or neurologically challenged child (14 subscribers, 1 message/day).

Books

The following books were used to compile the list of concerns:

- Dinning, Bonnie. L. et al. (2004). *we cares practical skills for front-line workers working with adults affected by fetal alcohol spectrum disorder*. Ottawa: Anne Wright and Associates inc.
- Graefe, Sara. (2004). (Ed.). *Living with FASD: A Guide For Parents*. British Columbia: Special Needs Adoptive Parents. Groundwork Press.
- Government of Canada. *Fetal Alcohol Spectrum Disorder Guidebook for Police Officers*.
- Government of Manitoba. *What Early Childhood Educators Need to Know about FAS*
- Health Canada. (1999). *Alcohol-Related Birth Defects. 4th Edition*.
- Klienfeld, Judith & Wescott, Siobhan. (Ed.). (1993). *Fantastic Antoine Succeeds- Experiences in educating Children with Fetal Alcohol Syndrome*. Anchorage: University of Alaska Press.
- Kock, Gregory C. & Kupesky, Regina H. (2002). *Parenting the Hurt Child: Helping Adoptive Families Heal and Grow*. Pinon Press
- Kranowitz, Carol Stock. & Silver, Larry B. (1998). *The Out-of-Sync Child: Recognizing and Coping with sensory Integration and Dysfunction*. Perigee Books.
- Kranowitz, Carol Stock. & Wylie, T. J. (2003). *The Out of Sync Child Has Fun* Perigee Books.
- Kulp, Liz & Kulp, Jodee. (2000). *The Best I can Be: Living with Fetal Alcohol Syndrome/ Effects*. New Mexico: Better Endings New Beginnings.
- Malbin, Diane. (1993). *Fetal Alcohol Syndrome Fetal Alcohol Effects: Strategies for Professionals*. Minnesota: Hazelden.
- Mayer, Lorna. (1999). (Ed.). *Living and Working with Fetal Alcohol Syndrome / Effects*. Manitoba: Interagency FAS/E Program
- Schneider, Barb. (1999). *Alcohol Related Birth Defects*. Breton, Alberta: Health Canada Health Promotion and Programs Branch.
- Tudeau, Debbie. (Ed.). (2002). *Trying Differently: A Guide for Daily Living and Working with FAS and other Brain Differences (2nd Ed.)*. Yukon: Fetal Alcohol Syndrome Society Yukon.
- Williams, Mary Sue & Shellenberger, Sherry. (1996). *How does your Engine Run*. Albuquerque, Therapy Works Inc.

Conference Notes

Pay, Vicki. *What Do Appropriate Supports Look Like?*

Community Health Services of the Capital Health Authority Region

Community Health Services provides neurodevelopmental assessments for children (5-18 years). Some locations will assess preschool children under 5 years old. At most sites a referral is required from a physician. In addition, school aged children may require a referral from the school principal at some locations. Testing by the school is necessary to further clarify the concern. Neurodevelopment works closely with the family and the school.

Preschool and School Age Neurodevelopmental Clinics

Glenrose FASD Project Clinic

10230 – 111 Avenue
Edmonton, AB T5G 0B7
(780) 471-2262 ext 2328
FAX (780) 491-6077

Pediatric Neurodevelopmental Clinic

Grey Nuns Community Hospital & Health Center
Unit 23A, 1100 Youville Drive West
Edmonton, AB T6L 5X8
(780) 450-7117 FAX (780) 450-7444

Neurodevelopmental Clinic

Misericordia Community Hospital & Health Center
16940 – 87 Avenue
Edmonton, AB T5R 4H5
(780) 930-5613(780) 930-5794

Neuro-Psychology Services

D-V Massey and Associates

Dr. Val Massey and Dr. Don Massey
(780) 471-1860
Suite 316 Kingsway Garden Mall
Edmonton, AB T5G 3A6
Neurodevelopmental psychologists who provide assessment to adults and children with FASD.

Neurodevelopmental Clinic, Northeast Quadrant

Eastwood Public Health Center
7919 – 118 Ave. NW
Edmonton, AB T5B 0R5
(780) 413-5114 FAX (780) 474-5760

Strathcona County Health Center

Brower Drive
Sherwood Park, AB T8H 1V4
(780) 417-6211 FAX (780) 449-1338

Pediatric Neurodevelopment Clinic

Sturgeon Community Hospital & Health Center
201 Boudreau Road
St. Albert, AB T8N 6C4
(780) 460-6349 FAX (780) 460-6304

Dr. Gail Matazow

(780) 488-7476
Suite 607 10240-124 Street
Edmonton, AB T5N 3W6
Neuro-psychologist who provides assessment to adults and children with FASD.

Physicians

Dr. Linda Der

Hope Medical Clinic
12214 – 82 St. NW
Edmonton, AB T5B 2X1
(780) 479-1944 FAX (780) 479-1964
Dr. Der specializes in addictions and practices in the inner city area. She works with adults to help them stop substance use, particularly women who are pregnant and using substances such as alcohol.

Dr. Ben Malinowski, Pediatrician

Allin Clinic
10155 – 120 St. NW
Edmonton, AB T5G 0B7
(780) 482-7551 FAX (780) 488-2056
Dr. Malinowski deals in general pediatrics, but does assessments and referrals as necessary. A referral is not required to see him.

Dr. Alan Murdoch

3 Bellevue Crescent
St. Albert, AB T8N 0A5
(780) 460-3059 FAX (780) 460-4004
On physician referral basis Dr. Murdoch will provide diagnosis investigation and management for FASD. Appointments made through Castledowns Medi-Centre, (780) 457-5511.

Dr. N.J. Witt, Neurologist

Offers diagnostic services for FASD. These services are paid by Alberta Health Care. A family physician must refer. To refer call: (780) 454-3800.

Bosco Homes

Fetal Alcohol Spectrum Disorder (FASD) Assessment: includes neuropsychological assessment and administration of additional tests necessary for diagnosis (medical costs are covered by Alberta Health Care), collateral interviews; full report including recommendations; parent/teacher debriefing as specified in Psycho-Educational Assessment Standards.

For more information, please contact Central Intake at (780) 440-0708 ext 259 or cwood@boscohomes.ca

In Closing

We had a young girl in our care who came from a pretty sad past, one day at a staff meeting we were talking about her constant asking people to love her, poor boundaries and how she was constantly seeking caring from others. I suddenly remembered all the times in my life where I gave up because I didn't feel "special". It was a pretty humbling realization that even with all the rejection, abandonment, abuse and neglect, she had gone through this little girl still believed there was love out there for her and was out there daily, looking for it.

FASD Strategies not Solutions

The strategies listed are not exhaustive; there are many other possibilities. Footnotes were not used throughout for ease of compilation. For more information about this booklet, please e-mail: fasdsolutions@hotmail.com.

To download electronic copies of this booklet in Adobe Acrobat (pdf) format, please visit www.region6fasd.ca.

Additional copies of the printed booklet can be ordered through www.child.alberta.ca/.

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