FASD Durham Committee

Strategies for Assisting Individuals with Fetal Alcohol Spectrum Disorder



Authors:

- This Guide was created in response to a request from parents and caregivers in Durham Region. Thanks to the members of the Durham FASD Parent Support Group for their ongoing insight and input, and for providing some of the quotations found within this guide.
- ◆ The authors of this Guide comprised the Kids Working Group, a working subgroup of the Community Capacity Subcommittee of the FASD Durham Committee.
- Members of the Kids Working Group were:
 - Nancy Luciano from Infant and Child Development Services Durham

 - ⇒ Carol Hepburn from the Durham District School Board
 - ⇒ Eileen Deveau from Resources for Exceptional Children and Youth—Durham Region
- ◆ Thanks for the early contribution from Sandra Riggers from the Peterborough Victoria Northumberland and Clarington Catholic District School Board, and Sheila Burns from the FASD Durham Committee.
- Any updates to this guide will be posted at http:// www.rfecydurham.com/fasd.htm

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How To Use This Guide

This Guide is for parents, family members, friends, teachers, child care workers, faith community, children's mental health workers and all others who strive to meet the needs of individuals with this complex but manageable disability. For more detailed information on FASD, please check the resources listed in Appendix 2.

Individuals with Fetal Alcohol Spectrum Disorder (FASD) have strengths and positive characteristics that are often overshadowed by their actions and our interpretation of their behaviour. This Guide was developed to improve the reader's understanding of FASD, and give insight and strategies to enhance the potential of individuals with FASD.

The complex nature of the brain means that no two people with this disability will have the same strengths, impairments or capacity. This Guide will increase understanding of the disability by framing behaviour and actions in the context of brain injury. It is divided into four sections reflecting common challenges related to the disability.

This is a collection of strategies from many sources. As FASD is not a gender specific disability, throughout this document, the pronouns he and she have been used interchangeably. We have included a blank page at the end of each section so that you may add additional strategies, contacts and information that are of value to you. Please feel free to photocopy and give this resource to other people who live and work with individuals with FASD.

Not all individuals with FASD will have the same challenges. Not all strategies will work for everyone with FASD. This Guide does not have all the answers but we hope that it will be a starting point.

What is FASD?

Individuals with Fetal Alcohol Syndrome Disorder (FASD) may have brain impairments in some or all of the following areas:

- 1. Memory which may include:
 - gaps in short and long term memory
 - inconsistent memory knowing something for a few days, then forgetting it
 - * difficulty learning from experience
- 2. **Sensory integration**. Individuals with FASD may be either too sensitive (hyper) or not sensitive enough (hypo) to the environment. These sensitivities may be in the following areas:
 - Vision: kinds of lighting (fluorescent or incandescent), intensity or brightness, decorations, colours, movement
 - * <u>Hearing:</u> volume of sounds, inconsistent sounds, background noises, lights buzzing, computer fans, talking, frequency of interruptions, loud noises (fire drills)
 - * <u>Touch:</u> textures, clothing, crowding (personal space), bumping into furniture...
 - * Smell: perfumes, food, markers ...
- 3. **Processing** which may affect what an individual hears and sees and understands. This may be:
 - * inconsistent
 - disorganized
 - * slow

- 4. Communication that may include problems with:
 - Conversations out of context
 - Difficulty with understanding language
 - Not understanding the consequences of their words

Individuals with FASD may present as age appropriate in appearance or through their superficial communication but may have skills or emotional development that are much younger. The brain impairment of FASD results in broad and inconsistent achievement of skills. This discrepancy between how individuals present themselves and how they perform is known as **dysmaturity**.

As a result of these impairments individuals with FASD have significant difficulty with **Executive Functioning**. Executive Functioning is the brain's ability to absorb information, interpret this information, and make decisions based upon this information. Individuals with FASD have challenges with:

- Predicting, sequencing, and organizing
- Taking information, processing it, putting it in context, weighing potential outcomes, recalling past outcomes, making correct assumptions, and then determining the appropriate response
- Distinguishing between reality and fantasy

FASD affects an individual's judgment and response to the environment, which translates into behaviour. **Brain impairments** may manifest themselves in some of the following ways:

- physical or verbal aggression
- impulsivity
- defiance
- arguing
- over-activity
- destruction of property
- teasing or bullying
- foul language
- cruelty to animals
- inappropriate touch

BRAIN IMPAIRMENTS

+

EXECUTIVE FUNCTIONING DIFFICULTIES

+

DSYMATURITY

BEHAVIOUR SYMPTOMS OF BRAIN INJURY

Strategies based on Learning Theory and Behaviour Modification are not always successful in teaching new behaviour to individuals with FASD in the same way they would be with a typically developing people. This is because the strategies based on Learning Theory require consistent memory, the ability to sequence events, and the ability to learn from experience.

Things That Are Not Successful

(because they are based on Learning Theory)

- Star charts
- Time-outs
- Spanking
- Withdrawing possessions or events
- Bribes
- Rewards
- Natural consequences
- Easing up on structure or supervision
- Contracts
- Punishing

Strategies based on changing the environment, modifying expectations, and providing ongoing supports will be more successful.

KEY POINTS TO REMEMBER

When strategies aren't working,
don't try harder,
try something different.
Teach, repeat, re-teach,
repeat, re-teach.
~ Diane Malbin ~

- * When giving directions:
 - •Give one or two directions at a time.
 - Use concrete words, e.g., instead of "Pay attention" say "Sit down and look at me."
 - •Use the same phrases and words for the same thing (for example, is it a "toque" or a "hat"?).
 - •Give directions immediately prior to the activity.
 - Repeat the directions during the activity.
 - Supplement instructions with pictures or gestures when needed (e.g. holding up your hand in a "stop" gesture).
 - Give instructions in the environment where they will be used.
 - •Tell him what you want him to do, not what you don't want him to do (for example instead of saying, "Don't run on the road", say "Stand at the curb").

In addition, remember...

- * Speak slowly and wait for the individual to understand and respond. Some individuals need time to process information before they can understand it. For example, allow the individual 15 seconds "think time" before helping.
- Understand that what appears to be willful disobedience may actually be an inability to translate verbal directions into action.
- * Teach skills carefully, consistently and repetitively through modeling, role playing, and practice in the situation where they will be needed.

Remember he is not "misbehaving" on purpose to make you mad, the behaviour is a symptom of the brain injury.

"Think brain not blame."

~ Diane Malbin ~

- * Be patient with how long it takes to learn a concept.
 You may have to accept that she may never learn it.
- * Focus on teaching skills in the areas of communication, problem-solving, social, life, and self advocacy.
- Use communication, patience, compassion, understanding, and creativity when teaching any skill.
- * Teach self-calming or self-soothing techniques
- Ensure you can follow through with your consequences.

Accept that you can't change the individual, but you can change your expectations and the environment.

Notes

BEHAVIOUR STRATEGIES

- * Adjust expectations to developmental age, not chronological age (see Appendix 1).
- * Have adult supervision at all times. Avoid and/or limit unsupervised free time as much as possible and plan for this time. Use a baby monitor if direct supervision isn't always possible.
- * Give extra attention, whether it's eye contact, or a thumbs up, etc.
- * Be prepared to take longer to do routines. A routine that may take an individual ten minutes (e.g., putting on outdoor clothes) may take the individual with FASD 20 minutes.
- * Look at underlying causes of behaviour (frustration, sensory, misunderstanding, memory). Teach him to learn his own body cues and what to do when he feels that way.

- * Be aware of sensory needs and watch for over stimulation or the individual looking for stimulation. Help the individual find an appropriate way to meet his sensory needs (speak with an Occupational Therapist).
- Model appropriate behaviours in a calm manner. Practice and demonstrate strategies in as many environments as possible.
- Deliver a predetermined signal when the individual begins to demonstrate impulsive behaviour. Use visual cues to remind her of appropriate behaviour (e.g., finger over lips for "no talking" in class).
- Forewarn for change by using pictures, rehearsal, same song, or action cue.
- Laminate visual cues for routines and use as prompts for what they need to do next.
- * Have the student act as a leader, line monitor, etc., when moving with a group. Encourage the child to participate by helping the adult.

- * Involve the individual in designing strategies and ask him what helps him.
- * Give her a choice of two appropriate consequences when providing discipline. For example, when she throws a truck the choice would be to pick the truck up and drive it on the ground or to pick it up and put it on the shelf.
- * Maintain an appropriate physical distance from the individual when interacting with him, especially during a tantrum. Do not touch him during a tantrum. Give him space.
- * Tell him what happened and tell him what he should be doing, e.g., "You coloured on the wall. Colour on the paper."
- * Mark boundaries on floors and in hallways if inappropriate touching and poking is a problem. For example, use tape on the floor to mark where to line up or where to stand for particular routines.

- * Design a visual chart to show consequences for inappropriate behaviour and leave it where she can see it. A visual chart can also be used to show outcomes for positive behaviour.
- * Help the individual problem solve: "Where did the problem start?", "What did I do?", "Who did it affect?", "What else could I have done?", and "What else could I do next time?" Don't ask "why". Individuals with FASD don't understand "why".
- * Provide the individual with as many high-interest activities as possible, especially during low supervision times, to keep him from becoming physically aggressive towards others.
- * Avoid violent and sexually explicit movies, video games, and television programs.
- * Limit the individual's opportunities to use others' property if he is unable to care for his own property.
- Secure all items of value (keep temptation out of the way).

<u>Motes</u>

PERSONAL HEALTH AND SAFETY

Personal Care:

- * Try to ensure she is getting enough sleep.
- * Keep outside clothes in the same place and hang outfits together in the closet (tops with bottoms).
- * Prepare for the next morning the night before by laying out clothes.
- * Teach buttoning from bottom to top to help avoid missing buttons.
- * Post a thermometer outside the door or window with a line drawn on the thermometer indicating when cold weather clothes (for example, mitts, hats, jacket) need to be worn.
- * Establish meal time rules or routines.
- * Allow ample time to eat.

- * Teach personal hygiene habits from an early age. For example, teach "a bath every day" instead of "on an as needed" basis.
- * Keep all personal grooming products together in the same place.
- * Use visual schedule strips for bathroom routines with basic step by step instructions of what needs to be done. To brush teeth, the schedule may show:
 - ✓ Get out toothbrush
 - ✓ Take lid off toothpaste
 - ✓ Put toothpaste on brush
 - ✓ Put lid on toothpaste
 - ✓ Wet brush
 - ✓ Brush teeth
 - ✓ Rinse toothbrush
 - ✓ Turn off water
- * Monitor the individual's money. Talk to your financial institution about options that would limit access to the individual's accounts.

<u>Motes</u>

Safety:

- * Keep the environment safe. Put away any item that could be dangerous such as lighters, matches and scissors.
- * Ensure that education includes life skills training.
- * Use stop signs for visual reminders not to leave the room or to indicate what not to touch.
- * Talk to him about what he will do to keep himself safe.
- Review safety rules before going out and use reminders during an outing.
- * Provide structured opportunities that match the individual's strengths and interests. For an individual with an interest in baseball, sign up for organized camps or leagues rather than unsupervised games at the local park.
- Place alarms on the doors if he likes to wander.
 Consider personal locator technology.

- * If he takes something that is not his, state who owns the object and return it.
- * Do not leave objects of value unprotected.

<u>Notes</u>

Social Relationships:

Teach about social relationships by modeling and rehearsing in a variety of social situations.

- Teach about relationships, social skills and sexual health.
- * Teach appropriate:
 - physical contact (for example, handshake, pat on the back)
 - polite conversation (greeting, social niceties)
 - sportsmanship (for example, taking turns and winning and losing)
- * Teach her to read facial expressions and nonverbal social cues and how to respond to these.
- * Teach the student the necessary skills to successfully participate in particular games (e.g., volleyball, basketball, football, baseball, etc.)

- Provide opportunities for the individual's strengths (e.g., sports, creative talents).
- * Help him meet others who will be a positive influence.
- * Look for safe social situations that have appropriate role models, appropriate supervision, and an activity that give him success.
- * Avoid violent and sexually explicit movies, video games, and television shows and cartoons.

"Enjoy them, love them, laugh with them. Celebrate their strengths and each accomplishment because you will have trials and tribulations."

J.M., Mom & Foster Parent

<u>Motes</u>

Self-Control:

- * Teach him relaxation or self-soothing techniques.
- * Teach him to recognize how his body feels when he is starting to get frustrated or angry (for example, clenching his teeth or his fists).
- * Provide a safe, low-stimulus, uncluttered, comfortable place for the individual to use to calm down.
- Teach him to make a "pros and cons" list to problem solve a situation.
- Model appropriate behaviours in a calm manner.
 Demonstrate and practice strategies often.
- * Encourage positive self talk, for example, "I can do this"; "It's OK to make mistakes"; "I can have another turn later".

<u>Motes</u>

Personal Possessions:

- * Limit the individual's use of other people's property. Give him the materials necessary at any given time.
- * Teach her the concept of borrowing by requiring her to ask and then to return those things she has taken from others.
- * Teach ownership by labeling his possessions with his initial or colour. Teach him that he can only take objects marked with these.
- * Teach that a person owns an object even when that person is not with the object.
- * If he wears glasses, have two pairs, one at home and one at school.
- * Have an extra supply of mitts, hats, lunch containers, pens, pencils, etc. for when she loses belongings.
- * Do not leave objects of value unprotected.

<u>Motes</u>

ATTENTION AND LEARNING

Adjust expectations to developmental age, not chronological age (see Appendix 1).

Giving Instructions:

- * Get her attention by using her name or getting eye contact.
- * Give the individual your full attention when talking with her in order to prevent the individual's need for physical contact.
- * Give one instruction at a time such as "read the first paragraph". After it has been read, instruct, "Now answer question one."
- Ask the person to explain the directions in their own words.
- * Highlight key words in written information.

- * Use a bookmark, ruler or sheet of paper to cover the rest of the page when reading or reviewing directions.
- Use him to demonstrate for the other children when giving group instructions
- * Simply state what he is doing wrong. Tell him what he should be doing. Long verbal explanations and reasoning are not effective. For example, "Stop screaming. Use your words."
- * Consider the person's verbal and memory limitations when working through an incident with the person and deciding what the consequences should be.
- * Ask "What did I forget to help you with?" instead of "Do you need some help?"
- * Give extra attention when you can. For example, a wink or a smile as often as possible.
- * Forewarn for change. Use visual cues for schedules. Give ample preparation for change in routines, use pictures, rehearsal, or action cue.

- Have a consistent, predictable schedule of events.
- * Tape simple cue cards of daily class routines on a person's desk.
- Use calendars to remember events.
- * Relate an event to the time of day to create a sequence, for example, wash your hands before lunch.
- * Be aware that people with language difficulties may not understand announcements made on the public address system even though they are listening attentively. Get a print copy of all announcements and review the information and its implications with the class.
- * Use file cards with key messages, such as "Talk in a low voice" or "Keep working." If the individual needs reminders, lay the cards on his desk, without comment. After five minutes, if his behaviour has improved, quietly remove the card.

- * Have the individual act as a leader or line monitor when moving with a group. Encourage the individual to participate by helping the adult (for example, carrying the attendance book).
- Ensure regular bathroom breaks.

"As a parent, learn to forgive yourself if you have said the wrong thing, felt inadequate, made the wrong decision."

J.M., Mom & Foster Parent

Notes

Teaching Strategies

- * Use repetition when teaching.
- * When teaching new concepts make a connection to information she already knows. Link one task with another to establish sequences.
- * Plan new activities around activities that he can be successful with. "Build on successes."
- Take into consideration the person's attention span and plan each activity accordingly.
- * Alternate times of concentration with activity or relaxation breaks (whatever works for the person).
- Break the task into shorter steps, providing breaks to help the individual be successful.
- * Give her the opportunity to teach the skill to someone else.
- * Ask "What did I forget to help you with?" instead of "Do you need some help?"

- * Teach the concept of time by using timers to define the length of an activity. Use objects to represent passage of time, e.g., sand filled timers, paper chains where one link is removed every time period (every 5 minutes, 10 minutes, etc.).
- * Teach how to tell time using an analog watch. If the person does not understand an analog watch, have him use a time line with a digital watch.
- * Limit homework.
- * Look for learning material in video form.
- Keep the instructional group size as small as possible.
- * Teach in a manner that interests him, using examples and materials. Personalize the lessons as much as possible.
- * Use assistive technology to support learning whenever appropriate. This may include keyboarding, calculators, graphic organizers, tape recorders and computer programs.

- Spend time teaching and re-teaching cause and effect at all ages.
- * Include sensory strategies when teaching. For example, a person who needs the stimulation of movement could sit in a rocking chair to read. A person who needs to fidget with their hands can hold an object while listening.
- * Rhythmic activities such as choral reading, spelling and math chants are effective at holding attention. Teach him to repeat instructions to himself, experiment with rhythm and rhymes.
- * Use a visual and verbal cue to signal the start and end of an activity.
- Provide strategies to avoid losing items but also plan for lost items.

Be matter of fact about mistakes.

<u>Motes</u>

Organization:

- * Be organized. Use labels or photographs to show where objects should be stored. Materials not in use should be stored out of sight in boxes or cupboards, not on counter tops.
- * Define and organize a space that belongs to the person.
- * Make certain that all personal property is labeled with the student's name.
- * Give the individual a checklist of materials necessary for each activity and have these materials available.
- * Limit materials on desks and workplaces.
- * Write down or use a visual to-do-list with step by step instructions of what needs to be done to complete an activity.

- * Teach the student to use "self-talk" to help him stay focused (e.g., "The first thing I have to do is.....) and to curb impulsive behaviour (e.g., "Stop and think"). Model this behaviour in order to encourage the student to do this.
- * Seat the student in the best spot to support supervision and teaching.
- * Have daily or weekly organization of the student's desks, workspace and living space.
- * Provide a calm, low stimulus, uncluttered, organized, structured environment.

<u>Motes</u>

SOCIAL SKILLS

Friendship:

- * Teach the concept of "your turn" by using a physical object the person holds when it is his turn. Play turn taking games. Pass an object around and when someone has the object it's his turn.
- * Have the individual engage in a game activity with one person and gradually increase the size of the group as the individual demonstrates success.
- Provide opportunities for supervised play with people with similar developmental abilities.
- * Assign outgoing, non-threatening people to interact with the individual in structured games.
- * Have the individual interact with these people for short periods of time in order to enhance success. Gradually increase the length of time as the individual demonstrates success.

- * Have the individual walk with arms crossed, arms against her side, hands in pockets, etc., if touching others is a problem.
- * Teach, model and re-teach the individual problemsolving skills in order that he can better deal with problems that may occur when playing with others (e.g., talking, walking away, calling upon an arbitrator, compromising, etc.).
- * Practice verbal responses, behaviours and social scripts to help individuals avoid risky behaviour. For example, when offered drugs or alcohol, "I have an allergy".
- * Teach social skills in the social situation where the individual will need them.
- * Teach appropriate:
 - physical contact (for example, handshake, pat on the back)
 - polite conversation
 - sportsmanship (for example, taking turns and winning and losing)

<u>Motes</u>

Getting Along with Others

- * Teach social skills that include how to:
 - ask for help
 - interpret facial expressions, tone of voice, posture, etc.
 - deal with rebellious behaviour in others
 - react when there is a disagreement with a supervisor
 - make choices
 - ask others if they can join an activity
 - say "no"
 - accept "no"
 - get someone's attention in a positive way
 - handle frustration, disappointment, fearful situations
 - ignore someone who is bothering you
 - negotiate what you want
 - accept criticism

- * Teach telephone manners with role play or a "how to answer the phone checklist" near the phone. Have a large erasable message board beside the phone.
- * Teach appropriate physical contact. "Circles" is a program to teach personal space. Hula-hoops can also be used to demonstrate personal space.
- * Encourage individuals to shake hands when greeting and saying good bye, rather than hugging or kissing. Since they have difficulty differentiating between family members, acquaintances, and strangers, this will lessen the potential for initiating or participating in inappropriate social behaviour.
- * Substitute other forms of reassurance instead of physical touch; e.g. a wink, thumbs up.
- * Help him to express emotions in an acceptable way.
- * With permission, use a video camera to capture individuals in positive social situations. Individuals can watch themselves using appropriate skills.

- * Limit opportunities for interaction in groups on those occasions when the individual is not likely to be successful (e.g. if the student has experienced academic or social failure prior to the scheduled group.)
- * Limit opportunities to enter areas or situations where she is more likely to be physically aggressive.
- * Include the individual as often as possible in the process of developing solutions to problems.
- * Encourage and teach the individual to "help" as a valued member of the classroom.
- * Develop social scripts that they can use in high stress situations, such as getting on the wrong bus or hurting themselves. They can keep these scripts in their wallets and use the scripts when necessary.

Adapted from research findings of Streissguth, Clarren et al.

Notes

What to Do if You Suspect Someone has FASD

FASD is a complex disability requiring a coordinated intervention of services and strategies from a variety of individuals.

If you suspect that someone has FASD or if someone you love has been diagnosed with FASD, it may be helpful to seek out the following professionals to help you.

- A physician who is familiar with FASD and who can monitor the physical and health issues that may be related to FASD.
- A Speech Pathologist to assess understanding and use of language (receptive and expressive language).
- An Occupational Therapist to assess fine motor skills. Some individuals may experience challenges in this area that may impact on their ability to write and to care for themselves.

- A Sensory Integration Therapist to help understand the individual's sensitivities to his environment such as sounds, textures and smells which may in turn cause behaviour issues.
- Early Intervention Programs that can help monitor and guide your child's development.
- Behavior Management Programs to assist you with changing your environment and helping you to learn techniques to redirect inappropriate behaviours.
- School personnel to assist with adjustments to the educational program. Individuals with FASD may have undiagnosed learning challenges potentially due to issues with memory, communication, processing of information, and executive functioning.

Websites dedicated to FASD, reading materials available on the topic, and linking with other parents through webboards and support groups can be valuable sources of information and support (see Appendix 2 for some suggestions). It is also important to be aware of the potential for addiction and secondary disabilities. Secondary disabilities occur when the individual suffers ongoing stress, frustration, and lack of support. These secondary disabilities may include addictions, mental health illness, unlawful behaviour, and inappropriate sexual behaviour. Services that may be able to support individuals with FASD experiencing these issues include:

- ⇒ Centres for Addictions and Mental Health
- ⇒ Alcoholics Anonymous
- ⇒ Legal Aid
- ⇒ Community Social and Recreational Programs
- ⇒ Supported Housing and Employment Programs

For information on some of the services available in the Durham Region, please visit http://www.region.durham.on.ca/departments/social/childcare/AgencyListing.pdf

<u>Motes</u>

Final Thoughts

"Knowledge is power. Learn as much as you can."

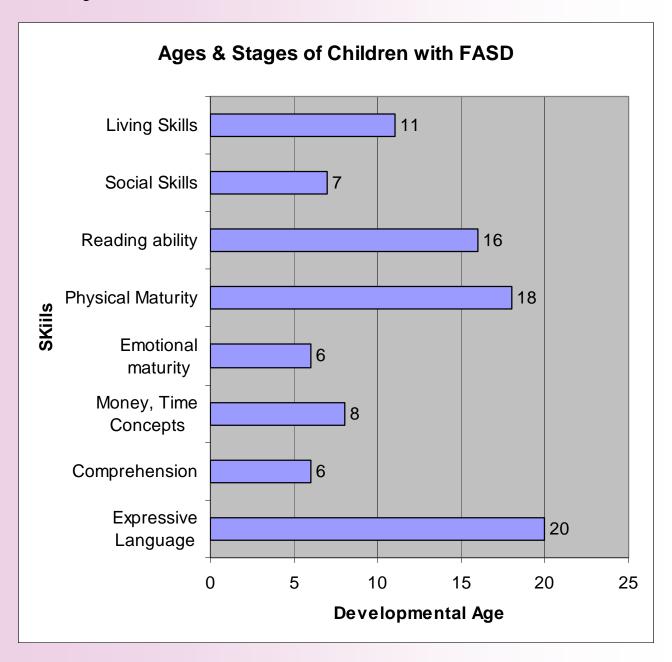
J. M., Mom & Foster Parent

"Recognize that FASD is part of a continuum of <u>strengths</u> and challenges. Your job as a parent, teacher, or someone else living or working with an individual affected by FASD, is to discover that person's unique abilities. Find out what works for him, help build on those strengths and help others look for additional ones. Don't let anyone tell you 'there's nothing that can be done'".

Mother of 7 year old with unconfirmed FASD.

Appendix 1

This dysmaturity chart reflects the developmental age of an 18 year old individual with FASD.



Created by Diane Malbin from the research findings of Streissguth, Clarren et al. (1994). Found at http://fasdjustice.on.ca/media/dysmaturity.pdf

Appendix 2

There are many sites and much information on Fetal Alcohol Spectrum Disorder available on the Web. We have selected a few sites that may be helpful. While we cannot monitor the contents of these sites, they have been known to provide credible information in the past. These sites were active as of the first printing of this resource.

It is suggested that, before ordering any resources from online sites, check to see if they are available free of charge through a government service.

http://www.fasdconnections.ca/

http://come-over.to/FAS/fasonline.htm

http://www.fasworld.com

http://www.faslink.org/index.htm

www.fetalalcoholsyndrome.org

www.arbi.org

www.education.gov.ab.ca/fasd

http://www.fasdjustice.on.ca/

http://www.bced.gov.bc.ca/specialed/fas

http://depts.washington.edu/fadu/

http://www.ccsa.ca

http://www.motherisk.org/

http://www.von.ca/index2.html

http://www.acbr.com/

http://www.fasbookshelf.com/new.html

http://www.fasdconnections.ca

http://www.fascenter.samhsa.gov

http://www.asantecentre.org

http://www.fasalaska.com/linkscanada.html

http://fasstar.com

http://www.skfasnetwork.ca/

http://www.fasdoutreach.ca

http://www.fascets.org/

http://www.do2learn.com/

http://davidboulding.com

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