

# LET'S TALK FASD



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**PARENT DRIVEN STRATEGIES IN  
CARING FOR CHILDREN WITH FASD**



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# INTRODUCTION

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe the full range of permanent birth defects caused by prenatal exposure to alcohol. FASD is caused when alcohol in a pregnant woman's bloodstream circulates to the fetus by crossing the placenta. There, the alcohol interferes with the ability of the fetus to receive sufficient oxygen and nourishment for normal cell development in the brain and other body organs. Prenatal exposure to alcohol can cause intellectual deficits and learning disabilities; hyperactivity; attention and/or memory deficits; inability to manage anger; difficulties with problem solving; and prenatal and postnatal growth deficiencies.

Since 1973, the medical profession has known that drinking alcohol during pregnancy impedes fetal brain development, affecting intelligence, learning skills and behaviour and at times causing additional disabilities. Since FASD is a spectrum disorder, there is great variability in the characteristics of those affected by FASD.

In an effort to respond to the needs of those caring for and working with children and adults with FASD, VON Canada has developed parent-driven best practice parenting guidelines for children and adults with FASD as a result of a four-year project funded under the Public Health Agency of Canada's FASD National Strategic Projects Fund. These parent-driven guidelines have evolved from the first hand experience of those living with FASD and those that care for them and respond to a community need for tips, techniques and strategies that are empirically proven by parents themselves.

LETS TALK FASD presents these guidelines in a user-friendly format that parents and caregivers can easily access, understand and utilize. The sections within reflect those areas that were identified to be of key importance throughout the project research.

We hope that these practical tips, techniques and strategies will assist you in meeting the needs of your child with FASD. If you would like more information on the project research and guidelines, please visit our our web site at [www.von.ca](http://www.von.ca).

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# ROUTINE AND CONSISTENCY

## ESTABLISH A ROUTINE – AND STICK TO IT

Parents in our study told us that establishing a daily routine – and sticking to it, is one of the best approaches in raising a child with FASD.

A consistent routine can help your child learn independence, and important life skills. And it can help you cope with the unique challenges of raising a son or daughter with FASD.

Imagine how you would feel if someone re-arranged the contents of your kitchen cupboards *everyday*. And then picture what it would be like to prepare a meal, not knowing where anything was stored! If your routine were disrupted, it wouldn't take long to feel very confused and frustrated.

That's how some children with FASD feel when they have to deal with change. In fact, even the most minor changes can create major confusion for your child.

Here's an example. Each morning, Susan puts her son Adam's clothes at the foot of his bed so he can get dressed for school. One morning, she puts them on his dresser. Later, when she goes up to check on him, she's surprised to find him sitting on his bed, still in his pajamas.

By changing where she put his clothes, Susan changed Adam's routine, so he was no longer sure what to do.

Children with FASD have permanent brain damage, which can cause them to have a hard time learning and remembering new things, understanding that actions have consequences, or making the switch from one activity to another.

The key to helping your child overcome these challenges is to reduce the likelihood that they will occur by maintaining a well-structured, consistent home environment.

“Be prepared to be consistent, but once you've got those consistencies and the child knows the boundaries, that they're loved and that there's no threat in the home, life can be almost normal...of course, it's always in the back of my mind that the child has FASD.”

“We've got routines down so nicely that the kids know what's happening next. We started that right from day one and it's made it very easy and a lot better for the kids. When our child goes to bed now she'll get her socks and underwear out for the next morning...it's taken me a year, but now she'll say, 'Mum can I get them out?'”

## SUCCESS STORIES

## FROM ONE PARENT TO ANOTHER

Parents across the country have told us that creating a routine – and sticking to it, has been one of the most rewarding experiences for their families. Here are some tips to help you along the way:

### **Break down everyday tasks into simple, easy-to-follow steps.**

For example – try teaching your child how to brush her teeth in steps: Go to the bathroom. Turn on the tap. Put some toothpaste on your toothbrush. Brush your teeth. Rinse your mouth. Smile!

### **Make a checklist.**

Post lists around the house to help your child remember his routine.

### **Keep your instructions short and to the point. Try the “six words or less” rule.**

*Don't say: Can you please collect all your toys and put them over there in the basket? Try: Put your toys in the basket.*

### **Be prepared to repeat your instructions *everyday*.**

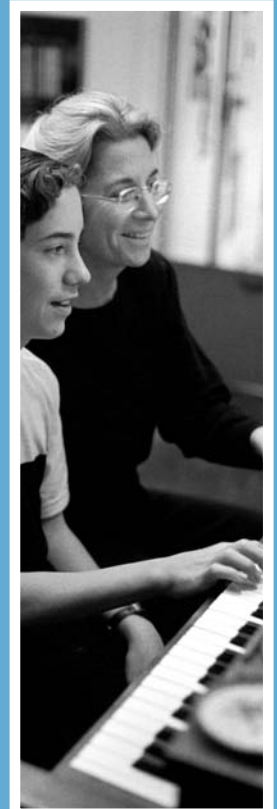
A child with FASD can easily forget things you told him only a few hours ago. Repetition helps you reinforce your instructions. If you need to remind you child what comes next, do so in a quiet, low-key manner.

### **Show and tell.**

Try using picture cards that show your child how to get dressed, how to shower, etc. Use simple language and large letters to label the pictures.

### **Take the lessons out of the house.**

Children with FASD often have a hard time generalizing routines, or applying what they learn in one situation to another. For example – your child knows he has to look both ways before he crosses his street. But he might not know he has to follow the same routine at every street. Therefore, it's important to teach your child his routine in different environments and situations.





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■ **Watch the clock.**

Audio cues such as bells and alarms can be very effective. Program a watch to ring an alarm periodically – it will help your child remember what comes next!

■ **Be creative.**

Creative, hands-on techniques such as role-playing are very helpful. For example - if your child is nervous about taking the bus to school, break the routine into steps and act them out. Have him pretend to wait by the driveway, board the bus and find a seat. Don't forget to wave goodbye!

■ **Help your child deal with transition.**

Always give your child lots of notice before switching from one activity to another. Some parents find ten-minute, then five-minute warnings to be effective. Verbal and visual cues are helpful too. You can also try role-playing transitional situations to help your

child feel more comfortable with change.

■ **Have a back-up plan.**

When you have to change your child's routine – for special occasions or birthdays, for example, always have a backup plan prepared. Try talking to your child about her fears and then remind her of a time when she overcame that fear successfully. In this way, you can help your child link her past success to the present situation.

■ **Plan for weekends.**

The weekends can present special challenges for school-aged children. Try to establish a special weekend routine to help your child cope with the change.

■ **Be consistent.**

Stick to the same routines (such as bedtime) even on special occasions, such as Christmas or other holidays.

■ **Keep a checklist just for you.**

Keep a wall chart for yourself. Use it to outline the steps needed to establish a routine with your child.





## PARENTS SAY

“Consistency makes it easier for our child, and in turn makes it easier for us.”

“It has to be A, B, C, everyday. If you throw a little wrench into the system –like a doctor’s appointment - without preparing them, you could sabotage the whole day. They go off the deep end because they don’t know what comes next.”

“We have very set routines. The morning routine is typed out, complete with pictures, then laminated. The kids can carry it around and follow the steps. I even posted one in the shower with a picture of a body and arrows pointing to the parts they need to remember to wash.”

“I say, ‘Check your list.’ If it’s the morning, check the morning list. If it’s the afternoon, check the after-school list. It gives my child a sense of independence and ownership – and I don’t have to talk so much!”

“We try and use the same words over and over again so that our child knows exactly what’s coming. “

“If there must be changes in our routine, we keep them quiet and low-key.”

“We always allow some extra time to get anything done.”

“With time, dedication, consistency and affection, my child is trained, very adjusted in school and daycare and proud of his ability to recognize numbers and letters. He’s already packed his backpack for the cottage in August - with his “homework” books to practice his printing and his math puzzles.”

## SUCCESS STORIES

# MANAGING YOUR CHILD'S BEHAVIOUR

## CHANGE THE ENVIRONMENT – NOT THE CHILD

Parents in our study told us that one of the most successful strategies for managing difficult behaviour, is to focus on changing your child's environment, not your child.

Children with FASD have *permanent* brain damage. This can lead to hard-to-manage behaviour including temper tantrums, hyperactivity, or difficulty paying attention. It's important to remember that your child can't "grow out of" her brain damage. Even though she may learn to cope with her condition, FASD is something that she will live with her entire life.

Some of the most successful parenting techniques focus on addressing things that parents actually *can* change.

Here's an example. Barry notices that his daughter Emily is very uncomfortable when she's around lots of people. She often throws tantrums in the middle of the crowded grocery store.

Rather than scolding her for throwing the tantrum, Barry decides to go grocery shopping early in the morning, when the store is less crowded.

By learning to accommodate your child's behaviour - instead of trying to change it, you can reduce some of the greatest challenges in parenting a child with FASD, and in turn successfully manage some of the most difficult behaviour.

You might have noticed that your child with FASD does not respond to parenting techniques that work well on other children. In fact, the techniques that work on one child with FASD may not work well on another child with FASD. The trick is to keep trying. Experiment with different strategies until you find something that works for you and your child.

"I have a wonderful poster with 100 different faces on it. My two most severely affected children use it to describe their feelings. They really like that, even if they don't tell me how they're feeling, but if they show me the sad face, they get an extra hug. Pointing to the picture is a trigger to get the story about how they're feeling."

"I kept saying, 'don't throw toys at the window!' He finally turned to me with huge crocodile tears and said, 'Well, what can I do?' I told him he could go to his room and rip up his bed. When he finished, I helped him make his bed again... I say to him 'I am so proud of you - you went to your room!'...I think it's huge for him to accomplish that"

## SUCCESS STORIES

## FROM ONE PARENT TO ANOTHER

No two children are the same. Parents have told us that the key to managing your child's behaviour is to experiment with different techniques until you find something that works for your family. Here are some tips to help you along the way:

### ■ **Make sure your child gets enough sleep.**

Every child has unique sleeping needs. But if your child is overly tired, he's more likely to "act up" the next day – and it's a situation that can get worse as your child gets older. You can't force your child to sleep – but eye shields, thick curtains, heavy blankets or a fan for soothing white noise can all create a sleep-friendly environment.

### ■ **Change the environment – not the child.**

For example, if your child often has a tantrum in a crowded movie theatre, take her to a matinee, when the theatre is less crowded. If it tends to happen at a noisy skating rink, bring along earplugs for your child and sit at the end of a row or in another, quieter spot.

### ■ **Reward good behaviour.**

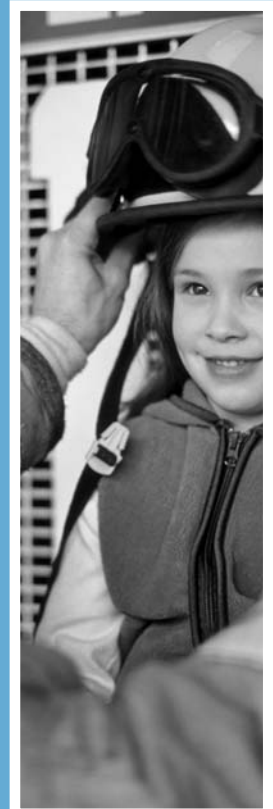
When your child behaves well, praise him for his achievement. Reward him immediately, and make sure you tell him exactly why you're rewarding him. Try and keep "rewards" on hand when you travel.

### ■ **Look for strengths.**

Every child has special strengths and abilities that deserve to be celebrated. Emphasize these strengths as often as you can. Find one area of interest or skill in your child and build on it.

### ■ **Give your child responsibilities.**

Simple tasks – such as setting the table or handing out snacks, can give your child a sense of ownership and help her see herself as a role model to others.





■ **Give your child a place to calm down.**

If your child is angry, frustrated, or needs to throw a tantrum, give him a safe place to express his feelings. Make sure there are no sharp or breakable objects lying around that could hurt him. If your child has a tantrum away from home, try to direct him to a safe environment.

■ **Cut the chatter.**

If your child chatters constantly, you can help her by giving her some firm verbal reminders. Try saying, Let's get back to talking about... or That doesn't have anything to do with what we're doing right now. You could also develop a private signal to use when your child is talking too much in public.

■ **Be aware of your child's sensitivities.**

Children with FASD are sometimes very sensitive to smells, sounds, lighting or touch. They may find flashing lights or itchy fabrics to be very uncomfortable. Try and keep your child as comfortable as possible. Buy clothing made from soft materials and remove sewn-in tags. Use solid colours around your home instead of loud patterns. Use low wattage light bulbs or light dimmers.

■ **Make sure your child understands you.**

Sometimes when a child with FASD acts up, it's because she doesn't understand what she is supposed to do – not because she's got a behaviour problem. Keep your instructions short and clear. Ask your child to repeat your instructions back to you. Try using pictures or charts to get your point across.

■ **Keep your expectations realistic.**

Remember that children with FASD are often emotionally and developmentally immature. A good rule of thumb is to expect your child to feel and behave like a child half her age.



## PARENTS SAY

“Understand that this condition involves permanent brain damage. The child’s behaviour is often due to being over stimulated; do not take the bad behaviour personally.”

“Do not push the child to go farther than her boundaries. If she can’t do it one day, well she’ll do it tomorrow. If not, well you know that’s as good as it gets. That’s our motto here.”

“These kids are not mean and bad on purpose. Dealing with them means a lot of patience, understanding, being non-reactive, and redirection instead of correction or direction. The parent or caregiver needs to stay calm, consistent and supportive.”

“Our house is decorated in solid colours - not patterns - and clutter is avoided. The toys are in plain view, in labeled baskets. We clean up constantly so not too much stuff is around. The kids’ bedrooms are also quite empty. We have safety locks on everything.”

“We always compliment the kids on something they have done well and encourage them to keep up the good work! Positives really help them.”

“I would stress that finding what the child likes to do and then letting them pursue it will make your life much more pleasant. Our daughter is one of the most creative people we know. She changes her entire bedroom around about twice a week. If it makes her happy, we’re ok.”

“When my daughter’s behaviour was most out-of-control and defiant, and our relationship strained, the best thing I did was to keep a daily log of all of her successes. I didn’t lecture, I just noted the littlest thing she might have done well, even if it was regaining control after a tantrum. My list was longest on bad days. I left it by her breakfast spot each morning, without discussion.”

“Remember, it is not that they won’t. It’s that they *can’t*.”

“He was rearranging the many pictures on the fridge this morning and took down a magnet with the 1-800 number for Fetal Alcohol Information. He read out the number accurately and stated with conviction, ‘I could call this number!’ We agreed enthusiastically that he should and he probably will. This boy has taught me a lesson about assuming anything about the origins of behaviour.”

## SUCCESS STORIES

# LEARNING STRATEGIES

## HELPING YOUR CHILD LEARN BETTER

Children with FASD think and learn differently from other children. And as a parent or caregiver, it's important to keep in mind that your child is living with unique challenges that can make learning especially hard.

Because of the brain damage associated with your child's FASD, he can't make sense of information in the way other children do. Experts might refer to this as a *cognitive deficiency*. Children with FASD often have a hard time understanding that actions have consequences and they can't always apply what they learn in one situation to another. Other challenges include poor short-term memory, lower IQ's, developmental delay and difficulties with setting goals or knowing if they are "off track".

As a parent, you probably see examples of these learning difficulties everyday. You might find yourself teaching your child the same task over and over again. In more formal environments such as school or daycare, these challenges become even more evident.

The key is to remember that your family isn't alone. There are many resources devoted to helping parents find new teaching strategies for their children. We've outlined some in the **Resource Toolbox** and **In the Community** section. And in the following pages, we'll share some valuable advice from parents on how you can help your child learn better.

"Our youngest daughter had trouble getting her shoes on the right feet. We tried and tried and tried to help her get it correct. Finally, I told her to make the shoes kiss, so the toes would touch. The concept interested her and it worked. Finding a medium that interests the child seems to help."

## SUCCESS STORIES

## FROM ONE PARENT TO ANOTHER

We all learn differently, and this is especially true for children with FASD. Here are some tips from parents who understand the unique challenges of raising a child with FASD. Experiment with them until you find some strategies that work for your family.

### ■ **Rehearse, rehearse, rehearse.**

Children with FASD often have poor short-term memories. Be prepared to rehearse new concepts as often as necessary.

### ■ **Ask your child to paraphrase.**

In order for your child to learn, she first has to understand what you're telling her. But sometimes a child with FASD will tell you she understands something even though she doesn't. Ask your child to repeat what you've just taught her – in her own words. This is also a useful tool for teaching teens and adults with FASD.

### ■ **Get creative.**

Experiment with fun, creative learning strategies such as music, pictures, dances, puppet shows or field trips. It doesn't need to be expensive – old socks can be made into exciting hand puppets. Handmade flashcards are cheap and practical.

### ■ **Avoid clichés.**

Children with FASD tend to take things very literally. This makes clichés such as “keep your nose clean,” or “toe the line,” very confusing. Use simple language and as few words as possible.

### ■ **Take baby steps.**

Break new skills and concepts down into very simple steps. Focus on teaching your child something you know she can handle and build gradually from there.

### ■ **Make lessons relevant.**

Children with FASD often need to understand why something is important before they can learn it. Help your child understand how a specific concept fits into the overall picture.





■ **Help your child use his strengths.**

Look for your child's special strengths. If your child is an excellent artist, help her use her creativity to her advantage at home and in school. Teach her new concepts with pictures, or ask her to express herself in a painting. Remember to focus on developing one skill at a time.

■ **Build bridges to success.**

Emphasize your child's accomplishments over his failures. Praise and encouragement will help your child see himself as a successful, competent person.

■ **Try alternative schools.**

Many parents find home schooling to be very effective because the routine, structure and learning can be modified to suit their child's needs. Specialized or private schools can also have smaller, more structured classes.

■ **Communicate with teachers.**

Talk to your child's teachers about her strengths and weaknesses. Invite teachers to celebrate your child's accomplishments.

■ **Avoid excessive homework.**

Remind teachers that your child learns at a slower pace. Ask them to reduce your child's homework, to give you and your child more time to focus on learning the concepts.

■ **Avoid long assignments.**

Ask teachers to break studying and projects into daily written assignments. Help your child review this information through repetition or with flashcards and diagrams. Make sure someone checks the work on a daily basis.

■ **Help your child accomplish her goals.**

Post your goals on a list and encourage your child to recognize her accomplishments by checking them off the list. Remember that in order to continue learning, your child will need support and assistance throughout his life.

■ **A picture is worth a thousand words.**

Incorporate visual learning with your child. Try using photos and illustrations to help your child learn a concept.





## PARENTS SAY

“If a dog were lying in his path on the floor, he would have to jump over it; he wouldn’t think to walk around it. This illustrates just how specific you have to be.”

“We have to tell her specifically, ‘go in your room put your clothes on the hanger and in the drawers.’ You have to be very, very specific and even then, if you give her two commands, she’ll forget one.”

“Children need hands-on, tactile learning. So if you’re trying to explain the word ‘ball’, you’re not just going to use the word or a picture, you’re going to get a ball, you’ve got to feel the ball, you’ve got to bounce the ball, you’ve got to explore the whole concept of that.”

I try to help develop my daughter's self esteem by letting her do activities that she's interested in. For instance, she wanted to play the guitar, so I put her in guitar lessons and now she can play intricate songs. She remembers anything she does with her hands.”

“For one year before our child moved out, we gave her \$100 a month. This was for groceries. I taught her to make menus and how to use the stove. She built herself a recipe book. In the meantime we worked on time management and general household duties. She learns by repetition, so we repeated.”

“Things get lost from the brain to the paper. After she has read the material, I help her by reading the worksheet questions to her and writing the answers for her. I do not give her the answers. I write down the answers she provides. She works hard and knows the material, but she cannot do 4 things at once - remember what she read, mentally organize what she read, remember how words are spelled and write the thoughts and words on paper.”

“I home school my children. I find that my children learn too differently from the ‘normal’ expectations for them to do well in a school setting. We do a lot of hands-on, fun activities. Baking and building help teach measurements. We use videos a lot, as my children seem to retain much more of what they see on TV than they do from any other medium. So we use a home school video curriculum a lot. I also let the kids direct what we learn. Same goes for spelling and penmanship. Geography consists a great deal from planning trips we would like to take someday. Science is mostly hands-on experiments. The main thing is that we have fun! There’s no timetable that must be adhered to. My kids learn!”

## SUCCESS STORIES

# MAKING AND KEEPING FRIENDS

## HELPING YOUR CHILD MAKE FRIENDS

Friendships make for a richer, fuller life. Friends teach us important lessons and support us through troubled times. But according to the parents in our study, making long-term friendships is one of the greatest challenges for children with FASD. This challenge comes from a number of different sources. The learning difficulties and possible lower IQ associated with your child's condition means that he might not understand social etiquette, or the subtle ways of friendship.

For example, a child with FASD might not understand the concept of "personal space." So when he meets other children, he stands too close to them, making them feel uncomfortable or irritated.

And because children with FASD are often less mature than other children of the same age, it can be hard for them to relate to their classmates.

You might notice that your child is lonely or isolated. In fact, parents in our study pointed out that their children were often targets for teasing or bullying. Unfortunately, as a person with FASD gets older, her inability to read social situations can make it easy for others to take advantage of her.

But as discouraging as this may sound, the good news is that, with structure and supervision, your child can enjoy positive social interaction. It will be challenging to achieve, and it will require lots of involvement from parents, but the rewards are plentiful. In fact, one parent told us that the more success her child found in friendship, the more success she had in her life.

In the following pages, we will outline some strategies for helping your child learn how to make – and keep – friends.

"While the child may know that certain behavior causes others to avoid him, the impulse control is not there. So socially unacceptable behaviors occur frequently. This often results in separation and exclusion. This will be a constant battle and one that may never improve. Key people in the person's life then become that much more important. It is very important that some of the people in their life be there because they want to be, not because they are paid to be. I find it is extremely important that a person with FASD has more than one source of confidants - someone they trust to talk to and help them in their growth. One person can easily become burnt out, frustrated and eventually want to withdraw on a permanent basis. The more people who the individual can relate to closely, the more likely they will have life-long friends and support."

## SUCCESS STORIES

## FROM ONE PARENT TO ANOTHER

Helping your child learn how to make – and keep – friends can be a challenging task. Here are some strategies you can try. Keep in mind that most of these strategies require lots of parent involvement.

### **Supervise.**

Make sure that your child's social time is supervised either by you, or another caregiver who understands FASD. If your child is in school, make sure someone supervises her during recess, and before and after classes begin.

### **Give your child helpful reminders.**

Watch your child closely when she enters a new social situation and help her behave appropriately. For example, if she hugs someone she has just met, quietly remind her that hugging is for close friends and family members. Suggest an alternative to hugging, such as shaking hands.

### **Role-play.**

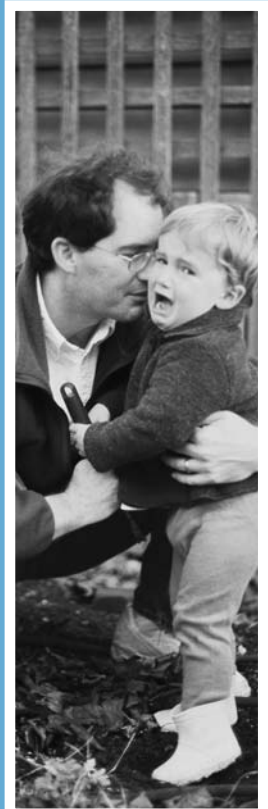
Role-playing is an effective tool in helping your child understand how to act in social situations. Role-play appropriate behaviours, such as how to share, how to disagree or how to meet new people. Your child can then draw on these experiences in real life situations.

### **Develop social stories.**

Create stories and scripts with pictures that describe common social activities such as waiting your turn or sharing. Suggest this tool to other people in your child's life

### **Make sure other parents understand your child's social needs.**

If your child goes to a friend's house to play, educate the other parents about FASD, and make sure they understand your child's needs. Teach them how they can help the children have a positive playtime experience. You may wish to show them the information sheets included in this book.Σ





■ **Build your own social safety net.**

Join – or form - a support group for families with children affected by FASD. Involve your child's support workers; they may be able to reach out to other families. Encourage the friendships your child develops at these meetings.

■ **Help your child find a buddy at school.**

Approach your child's teacher and discuss the possibility of setting up a partnership between your child and another student.

■ **Help your child get to know the opposite sex.**

It's normal - and healthy - for your child to develop relationships with the opposite sex but it's important to keep them within safe boundaries. Try supervised home visits for your teen.

■ **Educate your child about sex.**

Check out local agencies for people with disabilities – they may have helpful information on sex education that is tailored to your teen's unique needs. Make sure your teen knows the accurate word for all body parts, and provide reminders about the importance of privacy.

■ **Know what's going on in your teen's life.**

While it is important to respect your teen's privacy, it's equally important to understand what is happening in his life. Supervise any computer or Internet activity and make sure you know whom he talks to on the telephone. When it comes to TV, movies or computer games, remember that your child can't always understand the difference between reality and fantasy.



## PARENTS SAY

“It bothers me to think that in the future my daughter could get acquainted with people that would not be good with her. The most important thing for me right now is to be very careful with whom she associates.”

“My child is incredibly innocent compared to other kids her age. She’s just not worldly or sophisticated in social interactions. She does well with friends and all of that but I don’t think she understands the nuances of it all.”

“In our rural subdivision, most of the children tease my child, shun her and are mean. The bus was really hard for her because nobody was supervising her and it became a safety issue. But she went to a FASD Camp this summer with her dad. She was very popular and had a great time.”

“We have found that our church has been a great resource as far as helping our son to make friends his own age. The children there belong to friends of ours and are prompted by their parents to be tolerant of his difference. This has helped him to gain some confidence and be able to make some friends in other situations (school, day camp, soccer). We also do role playing exercises with him to help in learning social skills.”

“A support network is essential. We had a young woman, about 3 years older than our daughter, spend about 10 hours per week with her. It was important that our daughter perceived her as a friend who was ‘cool’ so ‘hanging out’ was ‘cool’. This was a major turning point, although not always a smooth road.”

“Now that we are in another province, we are finding that the children are more open to just playing. We have lots of things for the kids to do and as a result have kids around all the time playing with our children. When things go wrong we have been able to get the visiting kids to give our children a break and come back later. This year we have noticed that the more success our children experienced in social situations, the more they experienced success overall.”

## SUCCESS STORIES

# GETTING A DIAGNOSIS

## GETTING A DIAGNOSIS

It has been said again and again: knowledge is power. When we know what lies at the root of a problem, it helps us to understand the problem itself.

Knowledge makes it easier for us to find the right solutions. And according to parents, knowledge is very important when it comes to caring for a child affected by FASD.

Knowing your child has FASD can help you to understand his behaviour, and make the required adjustments to suit his needs. In fact, parents in our study told us that obtaining a diagnosis for their children was a crucial need. And the earlier the diagnosis, the better.

FASD is not a diagnostic term. There are three diagnoses that your child may receive. These include Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS) and Alcohol Related Neurodevelopmental Disorder (ARND).

Proper diagnosis can help you access health and support services you may not be able to access otherwise. It can also help you come to terms with your child's condition and start setting realistic goals for your family.

But obtaining a diagnosis isn't always easy. Since many children with FASD aren't able to live with their birth families, finding information about the child's birth mother can be difficult but it is crucial to confirming prenatal alcohol exposure, as required for a definite diagnosis. Also, symptoms of FASD may vary with age, or be related to another condition, thus complicating diagnosis. Always keep in mind that **you** are an expert on your child – so trust your instincts and keep searching for the information you need.

“She was diagnosed at the age of sixteen – by accident. She was in another province, visiting her birth family when she was hospitalized with kidney problems. The doctor that looked after her said, ‘Do you realize that you have FAS?’ She said, ‘What’s that?’ And then she called me and we talked. The doctor said she’s definitely got FAS. For me, that was a great relief.”

## SUCCESS STORIES

## FROM ONE PARENT TO ANOTHER

Getting an accurate diagnosis of your child's condition can help you understand her behaviour better. It can also help you feel better about your parenting. Parents offered this advice:

### **Start early.**

The earlier your child is diagnosed, the better. Current research suggests that a diagnosis before the age is six is most helpful. This allows you to inform teachers, support staff, and others about your child's condition. It also enables you to start implementing the right learning strategies in school.

### **Trust your instincts.**

You may have read or heard things that lead you to suspect your child has FASD. Trust your instincts and consult with a doctor. Ask to have your child assessed for FASD. If the doctor doesn't listen to your concerns, try another one. If people tell you it is "probably something else", remind them that diagnosis is a "rule-out" process, as well as a "rule-in" process.

### **Diagnosis is important at any age.**

Young children may be diagnosed with the help of your pediatrician. While it's best to get a diagnosis as early as possible, remember that it's important at every age! While it can be difficult to find health professionals to diagnose adult FASD, they are out there – so keep looking.

### **Ask for a strength assessment.**

An effective diagnosis should not only identify whether your child has FASD, but it should also assess and identify the strengths of both child and family. Make sure to request this strength assessment during the diagnostic process.

### **Look for a diagnostic team.**

A team approach to diagnosis will bring together a group of health professionals with different fields of expertise. A team approach will also give you more information on supportive services.





### **Be prepared.**

You know your child best. Therefore, the information you share with doctors will help ensure the most accurate diagnosis. Before your appointment, make a list of your child's strengths and needs. Write down important achievements and developmental milestones and keep all documentation relating to your child's condition in a file folder. Make sure that this information is considered during diagnosis.

### **Get some support.**

You don't need to go through the diagnostic process alone. Ask a friend or relative to accompany you to the appointment. You may also want to find an advocate such as your family doctor, or support worker, to help you through the lengthy process.

### **Request support even without a diagnosis.**

You may not be able to get an accurate diagnosis for your child, but a "probable diagnosis" is still very helpful in accessing support and services. Even without a firm diagnosis, you can ask for a follow-up session and referrals to qualified people who can help your child.

### **Learn about your child's birth mother.**

Diagnosis may be difficult for foster or adopted children when little is known about the birth mother's history. Most doctors require information about the birth mother before giving a diagnosis of FASD. Work with your doctor or social worker to help you learn about your child's birth mother, and whether she drank alcohol during pregnancy.

### **Help your child understand her diagnosis.**

Diagnosis is as important for your child as it is for you. Talk to your child about FASD before and after the diagnostic process. Try talking about the condition in terms of your child's strengths and weaknesses, rather than his disabilities and weaknesses.



## PARENTS SAY

“It would have been helpful if we could name some condition to explain his behaviour. The most helpful thing to us would have been a diagnosis. If some medical person over the years had said, ‘maybe he’s got this,’ or, ‘there must be a reason’ – that would have helped.”

“I needed to know what it was. I needed to know that there was something I could say was causing the problem. I felt so alone in it...like one minute I wanted to hug them to pieces because I felt so touched by what they had lived. I knew they probably had some really heavy stuff in their past but I didn’t know how to help them.”

“First and foremost, get a diagnosis as early as possible. Not only to keep you from guessing, but also because, as the child ages, he becomes less co-operative. An adolescent is less likely to agree to being taken to the extensive and often distant appointments. As well, the diagnosis by the accepted medical profession opens the doors to any assistance that the social safety net can provide.”

“When diagnosis is not possible, I still use FASD parenting strategies. If the strategies work, then that’s great.”

“In thinking about FASD, you sometimes get so caught up in the diagnosis or the assessment that you forget you’re looking at a child. You forget they’re first and foremost little kids and they need mostly the same things that all little kids need. Every moment can’t be a teaching moment, sometimes you’ve just got to play.”

As a birth mom of a child diagnosed with Alcohol Related Neurodevelopmental Disorder (ARND), this road has been filled with long uphill climbs and huge pot holes in the middle of the road. However, it is not a journey of failure or despair; it is a journey of hope, love and self-discovery. Without this journey I would not be person I am today and my daughter would still think she is stupid and no good.”

## SUCCESS STORIES

# SECONDARY EFFECTS OF FASD

## SECONDARY EFFECTS OF FASD

In earlier sections of this book, we covered some of the challenges associated with FASD. These challenges – also known as *primary disabilities*, can include poor short-term memory, trouble distinguishing between reality and fantasy, a lower IQ, or problems with speech or hearing.

Dr. Ann Streissguth, an expert in the field of FASD, has also identified eight secondary disabilities, which can occur as a result of these primary disabilities. In other words, a person isn't born with these secondary effects; rather, they can develop as the person gets older, especially when an early diagnosis has not been obtained. And some experts believe that people with FASD experience secondary effects because of the stress of not living up to the expectations of society.

Secondary effects include:

- mental health problems
- trouble in school
- trouble with the law
- confinement (incarceration, or inpatient treatment for mental health problems or drug or alcohol abuse)
- inappropriate sexual behaviour
- substance abuse
- difficulty living on their own
- unemployment or difficulty keeping a job

It's important to keep in mind that you can work with your child to reduce the risk that these secondary effects will occur. In the following pages, parents will tell you how.

“Our 16-year-old son's first job was with the youth conservation corps – it was perfect, one adult to four youths. The eight-week summer job was a lot of fun and had a lot of variety. His current job...is successful because his employer recognizes his challenges and his good will. He puts him in situations where he can succeed, and works with parents to address his limitations. For example, our son was not copying his schedule accurately and because of this, he missed a shift. Once we learned this, we started to copy his schedule. He volunteers a lot - he's currently a volunteer fireman and a volunteer with our local rescue squad. There is variety, excitement and SUPERVISION. We used to live minute by minute – but not anymore.”

## SUCCESS STORIES

## FROM ONE PARENT TO ANOTHER

Here is some advice to help you understand and reduce the secondary effects of FASD.

### Remember that secondary effects are interconnected.

For example, if your child is having problems in school, she may become socially isolated. This may lead her to become involved with a bad peer group which could in turn, lead to trouble with the law.

### Give your child the best start possible.

The way children are cared for when they're young will affect how they function as an adult. Strong parenting techniques in childhood can help reduce the chance that these secondary effects will occur. According to Dr. Streissguth, having your child diagnosed early, not exposing him to violence and creating a stable, nurturing home can reduce the secondary effects of FASD.

### Watch for warning signs of mental health problems – and address them right away.

If you suspect your child suffers from depression, anxiety or another mental health problem, ask your doctor, social worker, or support group to help you find a therapist, counselor or psychologist who understands FASD. Keep looking until you

find someone with the right experience to treat your child.

### Make sure your child is well cared for in school.

Your child may experience learning or behavioural difficulties, which could in turn affect his learning. Make sure that teachers understand the challenges your child faces as a result of brain injury associated with FASD.

### Understand the legal system.

As a parent, it's very helpful to understand the legal system and process, in case your child has trouble with the law. Offer to educate police, probation officers, lawyers and judges about FASD.





■ **Educate yourself about confinement.**

Confinement is the term used to describe either incarceration (jail or house arrest), or inpatient treatment for mental health, drug or alcohol abuse. If your child faces confinement, educate yourself about the processes involved. Call the relevant departments or offices ahead of time and offer to provide assistance in educating staff about FASD.

■ **Educate your child about appropriate sexual behaviour.**

It's very important to teach your child about appropriate and inappropriate sexual behaviour. A lack of understanding about sex can lead to sexual assault or victimization. You may find it helpful to consult with a social worker or an expert on sexuality.

■ **Encourage your child to avoid drugs and alcohol.**

Because of their brain injuries, drugs and alcohol can seriously impair people with FASD. Talk to your child about how substances can make it even more difficult for him to function. You may find it more effective to motivate him to avoid drugs and alcohol, as opposed to forbidding them.

■ **Help your child live independently.**

Life coaches, mentors, partners or roommates can all help your child achieve more independence when he's ready. If possible, plan to have your child live at home until adulthood.

■ **Help your child find suitable employment.**

People with FASD can have trouble finding – and keeping – a job. It may help to educate employers about your child's condition before the interview. Consider attending the interview with your child. If your child has a job, you can assist by helping her remember her schedule, or managing money on her behalf.

■ **Encourage your child to volunteer.**

Volunteering can teach important life skills and lead to possible job opportunities.



## PARENTS SAY

“Involved parents may be the only thing keeping your child from homelessness, sexual or other victimization, job loss, financial ruin, and personal danger. As parents age, they must ensure that their role is handed over to other capable adults.”

“As his mother I am trustee over the funds and pay his bills. This is of utmost importance as there is little or no sense of money management. He is now living on his own with supports from his parents for bills and shopping. A semi-independent living arrangement has worked quite well for him. We try to keep as light a hand as possible in supporting his day-to-day activities.”

“My daughter is currently in prison, and we are using the job opportunities there as a learning tool. She has agreed not to quit or accept a job without discussing it with me first. I leave the decision up to her, but help her make sure she is looking at all sides of the decision accurately. Each job she takes on is evaluated by us before she starts it, in terms of what she knows she does well, has trouble with, etc. And each decision to leave the job is evaluated in terms of how that decision will affect her financially and emotionally.”

“Mental health issues are always hovering unless an early diagnosis has enabled the parents to provide an environment which prevents the secondary effects from developing. Apply for disability support; do not minimize the problems - some may improve with slowly developing maturity, others do not or may get worse. Recognize that your child is entitled to the support, so don't give up. My young person can work full time - and even keeps the job sometimes! This is not common. A well-put-together application will succeed. I feel a diagnosis is crucial, the earlier the better, but any time is better than never. It made all the difference to the young person I looked after, and has changed his life for the better.”

## SUCCESS STORIES



# HELPING ADULTS AND TEENS WITH FASD

## HELPING ADULTS AND TEENS WITH FASD

As a child with FASD grows into adulthood, he and his family face a whole new set of challenges. As a society, we tend to associate “growing up” with more freedom and independence, and less supervision from parents. As young adults, we look forward to moving into our own place and living according to our own rules.

But freedom isn't really free. The price of independence is responsibility. Living on your own means buying groceries, managing a budget, holding down a job. These kinds of responsibilities can be very challenging for adolescents and adults with FASD.

When their children are young, parents are able to provide the highly structured environments people with FASD need to function best. But as their children mature, parents are no longer able to provide that level of supervision. Getting to work on time, paying rent and making friendships with good, honest people can all present significant

problems to a person with FASD. And for parents, these problems are very much on their minds as they try and figure out how their children will manage when they are no longer able to keep an eye on them.

But there are ways to prepare your child for life in “the real world.” In the next section, we'll show you how.

“For one year before our daughter moved out, we gave her \$100 a month. This was for groceries. I taught her how to make menus and use the stove. She built herself a recipe book. In the mean time we worked on time management and general household duties. She learns by repetition, so we repeated. She works part time and is on a disability pension. We fought long and hard, but at least she has a safety net. We are very strict but also very loving. We hide nothing and are honest and we expect the same from her. We don't always get it but we try.”

## SUCCESS STORIES

## FROM ONE PARENT TO ANOTHER

Preparation can help you assist your child in the transition into “the real world.” Here’s some advice from parents.

### **Meet your child on his level.**

The fact that your child is an adult doesn’t mean that he no longer needs your help and supervision. Continue to attend appointments with him – even job interviews if necessary. Have your child sign release forms so that you can be included and informed in all aspects of his life.

### **Engage your child in decision-making.**

Talk to your child about any decisions or processes that affect her. Seek her input and respect her views. Offer her options to choose from, and assist her in making decisions.

### **Involve others in your child’s life.**

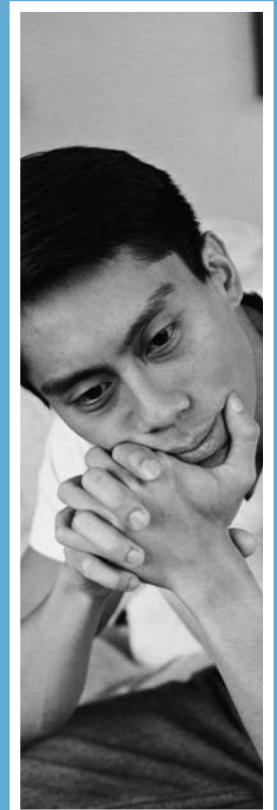
A partner, spouse, roommate or friend can all support you and your child. Ask them to take on duties such as teaching and mentoring life skills, helping with job searches, basic hygiene instruction and reminders, money management, and wake up calls.

### **Find a surrogate parent or guardian.**

Finding a good person and training him or her far in advance will help you and your child feel more comfortable about her future as you approach old age.

### **Help your child explain FASD to others.**

In our Resources section you’ll find a listing of books and website your son or daughter can use to explain FASD to the people in their lives. You can try making a card for your child that has your contact information and details about his disability.





■ **Make a will or trust fund.**

This ensures that your child's best interests are served even if you're not in the position to see to it personally. An in vivo trust is established for when you are still alive, while a will is administered after you have passed away.

■ **Help your child manage their money.**

Set up a system so that you can manage your son's earnings, and ensure that his bills are paid. Ask him to sign a release so that you can become his trustee. Find someone both you and your son trust and train that person to assist your child in money management.

Approach local groups for people with disabilities – they can help your child apply for a disability tax credit or set up a disability pension.

■ **Buy a “call me card.”**

Your child can use this to contact you if she runs out of money and is away from home.

■ **Explore possible living arrangements with your child.**

There is a range of choices: living at home or with a partner or spouse; living with a roommate or more formal assisted living situations; treatment facilities or even independent living. Experiment and find out which works best. Expect your child to become independent later than most.

■ **Connect your child with employment agencies for people with disabilities.**

A local disability network or agency for community living may have a list of “friendly” employers. Once your child has a job, he will need help keeping it. Review his schedule, role-play his duties, and check in frequently.

■ **Talk to your child about reproductive health.**

This includes providing your child with information about birth control, and suggesting preventative measures such as Hepatitis B shots. You may choose to provide your child with condoms or alternate forms of birth control. If your child is already a parent, take an active role in your grandchild's life, and support them both as much as possible.





## PARENTS SAY

“As the parent of a young adult with FASD, you need to fight everyday for him to get what he needs to have a good life. Be strong. Don't give up.”

“Just because these children can start to thrive in the right environment doesn't mean that we stop supporting them. This is a lifetime disability, which will surface again if not consistently supported.”

“My daughter has had a couple of mentors that have been wonderful. I want to be her mom, friend, and grandma to her daughter. But I think parents need to be able to let other people have some of that role.”

“I think some of the most challenging things are reminding yourself on a daily basis that you're dealing with brain differences, you are dealing with a child who's developmentally not as old as they are chronologically. You need to be able to provide the level of supervision that is needed without taking away everything that could be fun in their life.”

“I can remember many, many times having the money to go buy groceries, but not having a ride so I just order take out. Then the money for groceries is used up. Or I forget to buy the bus pass. It would be good to have a sponsor who could take that out of my cheque and send me the bus pass. They could pay my bills in case I forget.”  
(Adult with FASD)

“Our daughter lives on her own but she knows she can count on us for certain things. She also knows where we have drawn the line. Our big triumph in raising an FASD child who has some serious mental health issues is that, at 18, she has never been pregnant she has never been in jail, she has held a job for six months and gotten 19 out of 30 high school credits. She canoes with a special group once a year. This is a monumental triumph considering the extensive damage she has suffered. If she does slip, then we will help her up and hope that we can also count on recovery as a triumph as well.”

## SUCCESS STORIES

## CONNECTING WITH OTHERS

### FINDING THE SUPPORT YOU NEED

Caring for a child with FASD can be a very rewarding experience. But it is also a challenge that requires patience, creativity, and lots of love. There might be days when you feel alone, or isolated because of your family's unique situation.

The important thing to remember is that you are not alone. Across Canada, there are thousands of parents who are facing the same challenges. Parents in our study told us that reaching out to other families and sharing their experiences helped them understand their children better and find the support they needed.

Support groups for families affected by FASD can be a wonderful source of information and strength. They are a chance to learn from others, discover new parenting methods, or simply laugh – or cry – over your experiences. Unfortunately, such groups aren't accessible to everyone, particularly if you live in a rural community. Some parents in our study formed their own support groups. Others made use of

Internet support groups. While the Internet doesn't have the intimacy of face-to-face meetings, it is available 24 hours a day where accessible. General groups for parents of children with disabilities or learning difficulties can be another good source of support.

Conferences and workshops on FASD provide a wonderful opportunity to reach out to other people. Rich in information, guest speakers, and networking opportunities, some parents told us that “a light went on” when they attended a conference for the first time.

In the next few pages, we'll outline some helpful information parents gave us about how to reach out to others.

“We have started parent support groups and done a lot of public awareness. Being able to talk with other parents and share stories of what works and what doesn't, helps in the daily living with our kids.”

“I went to that conference and it was like a light came on. Looking back to the kids that have come into my care, I could see which ones were, and which ones weren't, affected by FASD. And based on all that I learned, I came to understand why the children did the things they did.”

## SUCCESS STORIES

## FROM ONE PARENT TO ANOTHER

Workshops, conferences and support groups all provide opportunities to learn about your child's condition, and network with other families affected by FASD. Here are some tips to help keep you "in the loop":

### **Network.**

Develop a list of people who understand FASD. This list can include other parents, professionals, organizations and support workers. Each time you meet a new person, add their name to the list.

### **Connect with other families affected by FASD.**

Talking to people who truly understand your situation is valuable. Teachers, doctors, resource workers, social workers and community groups can help connect you to other families. It's important to keep looking – they're out there!

### **Join a support group.**

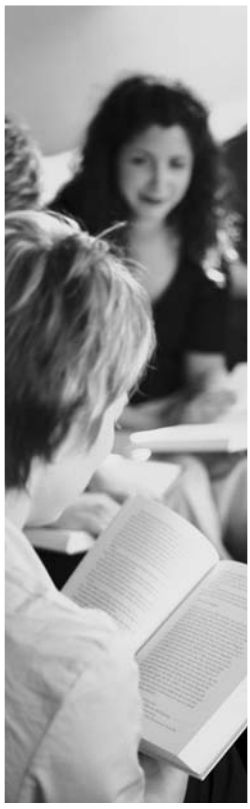
Look to local community groups and resource listings for information on support groups in your area. You may find support groups just for families with children affected by FASD, or for families with children who have special needs. Any support group that gives you the opportunity to connect with other parents who have similar concerns could be helpful. These may include

adoptive parent, learning disability and other support groups.

### **Form a support group.**

If there is no support group in your area, consider starting one. You can start small! Try and find one or two people with whom you feel comfortable, and build from there. Organizations such as the Canadian Association for Family Resource Programs and the Saskatchewan Fetal Alcohol Support Network can provide support and information. The Society of Special Needs Adoptive Parents (SNAP) has a helpful manual, *Fetal Alcohol Syndrome Support Group: A Six Module Curriculum* (Chung, Debbie, Vancouver, BC, 2002).





■ **Join a group for foster parents.**

Regular support groups may be challenging for foster parents, who are limited in what they can share because of confidentiality. Find out if there is a special group for foster parents in your community. If not, consider asking for a special group only for families affected by FASD.

■ **Look into newsletters or online discussion groups.**

If you have access to the Internet, check out online discussion forums, also known as listservs. You won't experience people face-to-face, but they're a great way to connect to other parents. You may also wish to sign up for FASD-related newsletters that can be mailed to your home

■ **Look into local and national conferences and workshops.**

Provincial or territorial government departments including Health or Community Services, or local family-oriented non-profit agencies often have information on conferences. You may wish to approach local family resource agencies about hosting a small seminar or workshop on FASD. If you know of a good guest speaker, suggest that the agency contact him or her for a presentation. Work with the agency to recruit people to attend.

■ **Look for funding assistance.**

If you're a parent, find out if conferences or seminars have special parent rates. You can also approach the conference organizers and request a sponsorship for your registration fee. Certain non-profit groups, including the Canadian Association for Community Living, may be able to offer financial assistance.



## PARENTS SAY

“I think it would have been helpful if we had known other parents in the same position as we were in. Just to talk, like ‘Okay how are you doing things today?’ or, ‘What’s happening with your child and how do you deal with the biting and the hitting?’”

“I think support groups are really important because the stress that gets built in you needs to come out.”

“People that don’t have children with FASD have no concept of what life is like with our children, they just can’t relate to it at all.”

“Become knowledgeable - go to workshops, go to seminars, get in touch with support groups and that kind of thing. There’s no way ever that a parent would be able to deal with this totally on their own.”

“You really have to check out the resources in your community and if they don’t have it ask. There are all kinds of different clubs and organizations that would love to help you out...there are just so many things that you can access, all you have to do is ask.”

“I have found the advice from the online groups that I have joined to be very valuable to me.”

“I was fortunate enough to get funding to attend a conference through sponsorship by my local Family Resource Centre. I live in a pretty isolated area and had never really met any other parents of children with FASD up to that point. At the conference, I met dozens of parents from all over the province and took home tons of information from the speakers and displays. I would have to say that the conference helped me more than anything else so far in parenting. It is also helping me feel connected to a bigger community of parents who are also living with FASD. I keep in touch with a few of them by phone.”

## SUCCESS STORIES

# CARE FOR THE CAREGIVER

## TAKING GOOD CARE OF YOURSELF

Caring for a child affected by FASD is an intense, challenging experience. Your child's unique needs and challenging behaviour may cause you to feel fatigued, overwhelmed, or lacking in energy.

As a caregiver, it is very easy to constantly put the needs of your child before your own. But the challenges of parenting a child with FASD require that you *take good care of yourself*. The better you treat yourself, the more energy and enthusiasm you will have for your child.

We have identified three best practices for self-care: de-personalizing your child's behaviour, taking breaks away from your child, and connecting with your community and parents who understand FASD.

**Don't take your child's behaviour personally.** There are many behavioural problems and challenges associated with FASD. As a caregiver, it's very important to see your child's troublesome behaviour as a symptom of their FASD, not a reflection of you as a parent.

**Take time out for yourself.** An evening out with your spouse or even a long walk can give you some much needed time to collect your thoughts, relax, and gather your strength.

**Connect with other parents who understand FASD.** In talking to other people who are facing the same challenges, you can share your frustrations, and seek advice and emotional support from people who really understand what you are going through.

"I suggest going to the movies alone without the kids, or joining a group that just gathers for breakfast or storytelling or even writing. Take a class. Take long baths. It's ok to be angry, hurt and upset at the world on days where no one is there for you. Forgive yourself. There will be wonderful moments and awful moments. Be good to you. Be gentle with you. Have faith, believe in you and have goals for you. Spoil yourself occasionally. Spoil your children occasionally. Have a pet. Most of all, love your life and live in the moment."

## SUCCESS STORIES

## FROM ONE PARENT TO ANOTHER

Taking good care of your child means taking good care of yourself. Try out the following tips and strategies we collected from parents across the country.

### **Remember that you're human.**

The challenges of parenting a child with FASD may cause you to feel frustrated, disappointed, angry or sad. Keep in mind that these are very normal, human feelings. Resist the urge to feel guilty about your emotions.

### **Find someone to talk to.**

Having a child with FASD can be very stressful on your personal life and your relationship with your spouse. That's why outside support is so crucial. Seek support or counseling from organizations such as your local Mental Health office or your church. A trusted friend, family member or elder may also be a good source of support.

### **Do your best– but don't try to be perfect.**

There are many parenting tips and strategies for children with FASD. As a caregiver, the list may seem overwhelming. You don't need to try everything! Pick the things that work for your family and do the best job you can do. Remember that your best effort will always be good enough.

### **Set aside some time just for you.**

Try and schedule some time each week to do something you enjoy, like taking a hot bath, listening to music, or having a meal with a friend.

### **Spend quality time with your spouse and other children.**

If you are married or in a relationship, schedule “dates” just for the two of you. Try and spend some one-on-one time with each of your children – not just those with FASD.

### **Get involved in your community.**

Community activities are a great way for you to enjoy yourself outside the home. Spending time away from your child is healthy both for you – and the child.





■ **Give your other children a break.**

Brothers and sisters of children with FASD also need a break. Be sensitive to how they are affected. Arrange for them to go to a friend or relative's house overnight or to have some one on one time with a parent.

■ **Investigate camp programs for children with FASD.**

Overnight, weekend or weeklong camps for kids with FASD or other disabilities may be a good opportunity for you and your child to take a break. Remember that some children with FASD cannot cope being away from home. Monitor the situation closely.

■ **Look for government-assisted childcare.**

You may have access to provincially funded care for children with developmental delays. Check with community and social services or home care services in your area.

■ **Start childcare early.**

The earlier you start exposing your child to childcare, the easier it will be on you and the child. When your child is young, leave her at home with a care provider for short periods of time. This will help you and your child get used to spending time away from each other.

■ **If you need to hire someone to care for your child, there are some things to consider:**

- a) Make sure the sitter has experience with FASD.
- b) Ensure the sitter maintains your child's routine.
- c) Make sure your child is comfortable with the sitter – look for verbal or non-verbal clues from your child.
- d) Help ease the transition by leaving your child with the sitter for short periods of time (up to 2 hours) for at least a month.
- e) Sometimes childcare is easier for children than it is for parents! Don't be surprised if your child looks forward to being with the babysitter.
- f) There may be a honeymoon period when your child is on her extra-best behaviour for the sitter. Make sure you educate the sitter about how to handle your child's more troublesome behaviour.





## PARENTS SAY

“There’s usually at least one area of my child’s life that’s going bad. But I have people around who remind me that I’m a good mom so I can really hang on to that.”

“Be sure that you have some sort of support in place as a parent. You need to be able to vent whether it be privately in a counselling session or to other people who are living the same experiences as you are.”

“I can’t manage my children’s behaviour at all if I can’t manage me. I have to have my own permission to parent in a way that’s successful for me and that breeds success in the kids. I have to feel like I’m in control of me.”

“Take care of yourself. A sick, unstable parent can’t help a needy child. Get acquainted with the services in the community. They can’t solve the problems, but can be some support.”

“Keep a sense of humor! It can be difficult when things look bleak, but laughter really is the best medicine.”

“Take time out for yourself. Have a trusted person that can come in and stay with your children so that you can have some fun. In order to be an effective caregiver you need to be happy and rested.”

“Parenting my affected child is probably the hardest thing I’ve ever done in my life but it is definitely the most rewarding because every little step that he makes...you know, when we finally have gotten to one little plateau it’s so wonderful.”

## SUCCESS STORIES

# INFORMATION SHEETS TO PROFESSIONALS/PUBLIC

In this folder you will find three information sheets that you may use to educate others about FASD. Of course, everything there is to know about FASD could not be included on each sheet but this provides a starting point for those that may work with or are involved with your child or young adult, such as:

- School system staff (teachers, principals, guidance counsellors, bus drivers, etc.)
- Medical staff (doctors, nurses)
- Legal system staff (judges, lawyers, probation officers)
- Social service providers
- Members of the public
- Respite/childcare workers
- Recreation workers
- Extended family/grandparents
- Alternative health providers (chiropractors, naturopaths)
- Employers
- Housing providers (including landlords)
- Municipal Councils
- Anyone else who works with or is involved with your child

There may be things included in the information sheets that do not apply to your child or young adult as well as things that you feel are very important to add. You can cross out any information that does not apply and use the space at the bottom to add other information. You can supplement the information sheets with the strategies in this book or from other sources if you wish.

Please feel free to photocopy any information found within this publication. It can also be downloaded at the following web site:

[www.von.ca/fasd](http://www.von.ca/fasd)

# WHAT YOU NEED TO KNOW ABOUT ME

(FOR THOSE 13 AND OVER-ADOLESCENTS AND ADULTS)

I have Fetal Alcohol Spectrum Disorder (FASD). FASD is a term used to collectively refer to a range of disabilities caused by prenatal exposure to alcohol. Because FASD is an organic brain disorder that affects the central nervous system and involved permanent chemical damage to the cells and to the connections between those cells in the brain, the effects last a lifetime. However, that doesn't mean that I cannot be successful in life. Here are some things you need to know about the way my brain works and how to understand my reality.

■ Repetition of directions, instructions and concepts is very important because it allows information to be stored in the habit area of the brain (the right hippocampus) where it will be remembered more easily.

■ Routine and consistency help me to make better sense of the world. Establishing a routine and sticking to it helps me to function more effectively.

■ I can be impulsive at times and this

can affect my relationships. Role modelling and visual cues can help enhance my interactions with others.

■ You may need to adjust some of your expectations to my developmental age, which may be different from my chronological age.

■ My receptive and expressive language may not be the same. Often, I can repeat something back but may not fully understand it. It is very important to follow through with me and ensure that understanding is reached.

■ I often have sensory issues that lead to sensory overload. I may also become overwhelmed if too much stimulus or information is entering the brain at once. This may show itself through intense frustration, anger or other emotional outbursts. I need a safe place of my choice to calm down when I'm feeling overloaded or overwhelmed.

■ I have a unique level of sensitivity to criticism. I can become very upset with a sigh or angry glance. It

helps to be aware of my sensitivity and to act accordingly.

■ Learning and retention of information is accomplished in small steps or stages. I may need you to guide me through a task in simple steps, one step at a time.

■ I can have difficulties with time and money concepts, so I may show up late or miss appointments and forget to pay bills. It helps to have things like reminder phone calls before appointments and assistance with budgeting and due dates for household bills.

■ I may request that a parent or support person accompany me during appointments, meetings and job interviews so that they can help to interpret information.

■ I have many strengths and things that I am good at. Take the time to find out what I can do, and emphasize the positive!

USE REVERSE SIDE FOR OTHER NOTES

# WHAT YOU NEED TO KNOW ABOUT THE CHILD WITH FASD

## (FOR CHILDREN 12 AND UNDER)

FASD is a term used to collectively refer to a range of disabilities caused by prenatal exposure to alcohol. Because FASD is an organic brain disorder that affects the central nervous system and involves permanent chemical damage to the cells and to the connections between those cells in the brain, the effects last a lifetime. However, that doesn't mean that the child with FASD cannot be successful in many things. Here are some things you need to know about the reality of a child with FASD and how to help.

Repetition of directions, instructions and concepts is very important because it allows information to be stored in the habit area of the brain (the right hippocampus) where it will be remembered more easily.

Routine and consistency helps the child to make better sense of the world. Establishing a routine and sticking to it helps them to function more effectively.

Children with FASD can be impulsive at times and this can affect relationships. Role modelling and visual cues can help enhance interactions with others.

There is a difference between developmental age and chronological age. The child may be 10 years old, but could have the social skills and understanding of someone who's younger. You will need to adjust some of your expectations to fit the developmental age.

Receptive and expressive language may not be the same. Often, the child can repeat something back but may not fully understand it. It is very important to follow through with the child and ensure that understanding is reached.

The child with FASD often has sensory issues that lead to sensory overload. They may also become overwhelmed if too much stimulus or information is entering the brain at once. This may show itself through intense frustration, anger or other emotional outbursts. Involve the child in making a joint decision about a safe place to calm down when they're feeling overloaded or overwhelmed.

There is a unique level of sensitivity to criticism. The child with FASD can become very upset with a sigh or angry glance. It helps to be aware of this sensitivity and to act accordingly.

Learning and retention of information is accomplished in small steps or stages. Guiding the child through a task in simple steps, one step at a time can ensure success.

The child with FASD has many strengths and things that they are good at. Take the time to find out what they can do, and emphasize the positive!

### OTHER NOTES

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# FASD-WHAT YOU NEED TO KNOW

Fetal Alcohol Spectrum Disorder (FASD) refers to the range of disabilities caused by prenatal exposure to alcohol. FASD includes the diagnostic terms Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) as well as Partial Fetal Alcohol Syndrome (pFAS), Alcohol-Related Neurodevelopmental Disorder (ARND) and Alcohol-Related Birth Defects (ARBD).

Children develop FASD when alcohol that was consumed by the mother crosses the placenta, causing damage to the developing brain and interference with the normal development of the child. These effects range from mild and hardly recognizable to very severe—this is why it is referred to as a “spectrum” disorder. FASD is often called an “invisible disability” because its effects may not be noticeable at all.

FASD lasts a lifetime, but the way it presents itself may change as the child gets older. There is **great variability** in the characteristics of those affected by FASD, which affects four common parts of information processing in those of **all ages**, but to varying degrees:

## 1. Cause and effect

Often there is great difficulty in understanding consequences of actions. Those affected by FASD may have trouble understanding

concepts such as ‘If I do A, then B will happen’.

## 2. Generalization

There may be great difficulty in taking information from one situation and applying it to another. For example, if a child is taught not to run into the street in front of their home, she may not understand that this also means that she shouldn’t run into the street at school and in other situations.

## 3. Differences and similarities

Those affected by FASD often have difficulty understanding differences and similarities between people, places and things.

## 4. Problem solving

There may be difficulty in making a decision about a situation based on a similar past experience. Those affected by FASD may also have some difficulty in understanding a situation and taking step-by-step action.<sup>1</sup>

## The “two truths” of FASD:

Although FASD involves real and permanent injury to the brain as described above, this is just one truth. The other truth is that performance exceeds expectations in many areas, including specific areas where there are strengths. Those with FASD can accomplish many things with the proper support. Some of the areas in which those

affected by FASD excel include:

- Artistic pursuits (fine arts, music, drama, improvisational theatre)
- Attention to detail
- Sensitivity and empathy
- Outgoing, exuberant, and engaging personality traits
- Higher than average IQ
- Exceptional memory

<sup>1</sup> From [www.fasdnorthwest.org/facts](http://www.fasdnorthwest.org/facts)

# IN THE COMMUNITY

## ADVOCACY

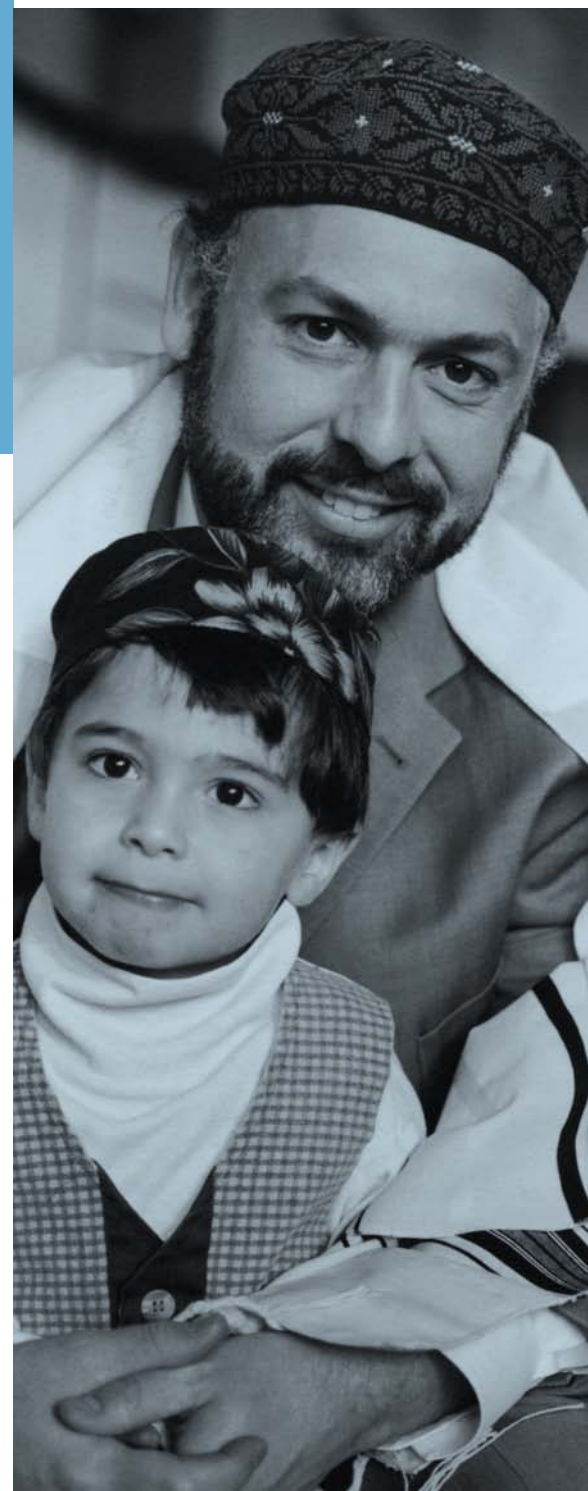
In a perfect world, teachers, health professionals, and people you meet in the street would all have an understanding of FASD – what it is, and what it means for people who are affected by the condition.

Unfortunately, we don't live in a perfect world. While you may have developed effective parenting strategies that work well in the home, you will still need to educate people in the community about FASD. In some cases, you'll need to speak up on behalf of your child or family member to ensure she has access to the services she needs and deserves. We refer to this process of educating and speaking up as advocacy. And in the following three chapters, we'll provide you with some useful parent-driven tips that will help you advocate for your child in the community.

## FASD AND PROFESSIONALS

Anyone from doctors and nurses to psychologists and professional caregivers may need you to educate them about FASD. There will sometimes be situations where YOU are the expert.

Educating a health professional about FASD may be an intimidating experience. You may feel unsure about what to say, or how to say it. The important thing to keep in mind is that both you and the health professional are working toward the same goal: your child's well being. In the following pages, we'll outline how to advocate with health professionals and achieve a situation that works well – for everyone.



## FROM ONE PARENT TO ANOTHER

As a parent to a child with FASD, you will need to educate and advocate for him throughout his life – especially with health professionals and service providers. Here are some tips:

### **Educate yourself about FASD.**

Your expertise will give you more credibility in the eyes of professionals and service providers. Our Resources section can get you started.

### **Prepare an FASD information package.**

This will introduce professionals to FASD and show that you're willing to help educate them about the condition. Use the Information Sheets provided at the end of this section. You may also wish to include specific information about your child – his strengths or things that trigger meltdowns. Be sure to emphasize that your child has permanent organic brain damage - which cannot be reversed.

### **Prepare an information file for your child.**

Include all the relevant information: diagnoses, reports, and test results. Record the details of all your meetings or appointments in the file and take it with you when you see health professionals and service providers.

### **Know what your child needs – and what you will accept.**

Get to know the systems that affect your child's life – school, the law, the health system – and develop an understanding about what services your child has a right to receive.

### **Get support from others.**

Support groups can provide you with support and ideas about how to advocate effectively. If you're in a relationship, try as much as possible to attend meetings with your partner or spouse, and allow friends and family members to assist you on days when you feel overwhelmed. You may even find another parent to attend conferences or appointments with you, and help you in explaining your child's needs.

### **Attend appointments with your child.**

This may become more challenging as your child becomes an adult. You may describe your role as that of an “interpreter.” In other words, you're there to assist your child in understanding the information. Explain to your son or daughter that this is not a sign or failure or stupidity, but a sign that he or she is adult enough to know what it takes to succeed.

### **Remember that you are the expert on your child.**

Keep looking until you find health professionals who are experts in the field of FASD and are willing to back you up.

# IN THE COMMUNITY

## FASD AND THE SCHOOL SYSTEM

The school environment can be very challenging not only for children affected by FASD – but their teachers and caregivers too. As we outlined in Chapter 3, children with FASD learn differently from other children. They may require extra attention in class, or more tailored teaching methods. For a teacher whose attention must be divided among upwards of 20 other students, giving the child with FASD the attention she needs can be a challenge.

Parents in our study identified three main challenges for children with FASD in school:

**1. Understanding the hidden curriculum** – These are building-block skills that children need in order to learn and function in school. For example, group projects require that children are able to organize themselves and work together. Such tasks can be challenging for a child with FASD.

**2. Lack of structure** – The child with FASD may require lots of structured, one-on-one attention. This can be hard to achieve in a classroom setting, where children often need to function more independently.

**3. Socialization** – As covered in Chapter 4, your child may have trouble relating to other children in his class. Difficult behaviour – like meltdowns or temper tantrums, may affect his ability to have classroom friends.

As a caregiver, you may feel that your child is not receiving adequate attention in the classroom. If your child is aggressive, you might feel that teachers are having trouble dealing with his behaviour effectively. On the other hand, if your child is quiet, you may find it hard to get teachers to pay her extra attention.

In the following pages, we'll give you some advice on how to be an advocate for your child in the school system.





## FROM ONE PARENT TO ANOTHER

Here are some advocacy tips to help you make your child's school experience a positive one – for everybody:

- **Inform and educate everyone in the school system from teachers and principals to bus drivers, about your child's condition.**

You may wish to organize regular team meetings between yourself, teachers and support staff who work with your child. Discuss your child's progress and challenges. This will create a feeling of collaboration and it will ensure that everyone is on the same page.

- **Make sure teachers know that your child may appear to grasp material she does not in fact understand.**

Share the tips and strategies outlined in the first three chapters of this book outlining learning strategies, socialization and routine. This will help teachers understand both the impacts of FASD, and how to teach your child more effectively.

- **Get involved in your child's school experience.**

Visit your child's classroom on a regular basis and keep the communication lines open with teachers. If possible, volunteer to help on class trips and special occasions. Not only are these great opportunities for you to observe your child, but they also allow teachers to get to know you as a person, not just as an advocate for your child.

- **Develop a communications book for yourself and your child's teachers.**

You can use this to record daily or weekly updates about your child's progress in school.

- **Assist your child with difficult curriculum.**

Co-op placements are a hands-on method of teaching more demanding, abstract curriculum. You may also try setting up your child with a buddy to help with academic and social skills in school. Discuss these options with teachers and other school decision-makers.

- **Encourage teachers to focus on your child's strengths** – rather than what he may be doing wrong.

# IN THE COMMUNITY

## FASD AND THE PUBLIC

From trips to the grocery store, to school concerts to doctors' appointments, we come into contact with the public everyday. But public places can be a source of over-stimulation for children with FASD, causing them to "act up," or become irritable -it's not unusual for a child with FASD to have a meltdown in the middle of a crowded shopping mall.

These temper tantrums tend to draw unwanted attention in public places. As a parent, you may feel that people are watching you deal with your child's meltdown. And because they aren't familiar with FASD, you may sense that members of the public are misinterpreting both your child's behaviour, and your own parenting methods.

Living and working with people who know little about FASD and how it affects children and adults can be very challenging for parents. This lack of understanding becomes especially painful when people mistakenly think

that parents are somehow at fault for the child's behaviour.

Educating the public about the impacts of FASD may be a lifelong task both for you and your child. But it also provides you with an opportunity to be a positive advocate for people with FASD, which in turn, can help your child participate more fully in society.



## FROM ONE PARENT TO ANOTHER

There is a great need for public education about FASD. In an effort to raise awareness about the condition, many parents take on the role of public educator and advocate. Here's how they do it:

### ■ **Educate everyone in your child's life about FASD.**

Teachers, doctors, even friends and family members need to be educated about FASD and its impacts.

### ■ **Emphasize your child's strengths.**

This will encourage others to focus on her abilities – and not her disability. Give people examples of what success means for a child or adult with FASD.

### ■ **Make FASD Information Cards.**

You can hand these out to anyone involved in your child's life, or even members of the public who witness your child having a temper tantrum. You can use the information in this book to get you started.

### ■ **Initiate conversations about FASD.**

If you don't feel comfortable talking about it, chances are that other people won't talk about it either. By opening up a discussion on FASD, you have the chance to share what you know, and dispel any myths people may have about the condition.

### ■ **Teach your child to advocate on her own behalf.**

You can give your child information cards to pass along to others. You can also role-play how she might explain FASD to members of the public.

### ■ **Ask your child to wear a MedicAlert bracelet.**

This will help identify the disorder in case of emergency.

### ■ **Start a public awareness campaign.**

You can approach local community groups and offer to do a presentation on FASD. You could also contact your local newspaper, radio or television station and offer to tell your story. Reporters are often attracted to human-interest stories.

# RESOURCE TOOLBOX

NOTE: The following resources are a good starting point for practical information on FASD.

## THE “MUST HAVE” FASD PARENT/ CAREGIVER RESOURCE LIST

### PUBLICATIONS

**Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome** by Judith Kleinfeldm, Barbara Morse and Siobhan Wescott (eds.)  
2000. University of Alaska Press

**Fantastic Antone Succeeds! Experiences in Educating Children with Fetal Alcohol Syndrome** by Judith Kleinfeld, Barbara Morse, and Siobhan Wescott (eds.)  
2001. Fairbanks, AK: University of Alaska Press

**Fetal Alcohol Syndrome: A Guide for Families and Communities** by Ann Streissguth  
2001 Baltimore, MD: Paul H. Brooks Publishing

**Living with FAS: A Guide For Parents by Sara Graefe (ed) and SNAP**  
2003 (3rd ed.) Vancouver, BC : Groundwork Press

**Trying Differently: A Guide for Daily Living And Working With FAS And Other Brain Differences** by Debbie Trudeau (ed.) and the Fetal Alcohol Syndrome Society Yukon (FASSY) 2002. Whitehorse, YT: FASSY

**Trying Differently Rather Than Harder** by Diane Malbin  
1999. Portland, OR: Tectrice Northwest

**The Broken Cord** by Michael Dorris  
1989 New York: Harper Collins

**Damaged Angels: A Mother Discovers the Terrible Cost of Alcohol in Pregnancy** by Bonnie Buxton 2004  
Toronto: Alfred A. Knopf Canada

### WEBSITES WITH ONLINE RESOURCES

**National database of FASD and substance use during pregnancy resources: Canadian Centre on Substance Abuse (CCSA)**  
[www.ccsa.ca/fas](http://www.ccsa.ca/fas)

**Fetal Alcohol and Drug Unit, Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine**  
<http://depts.washington.edu/fadu/>

**FAS Bookshelf**  
[www.fasbookshelf.com](http://www.fasbookshelf.com)

**FAS Community Resource Center (FAS-CRC)**  
[www.come-over.to/FASCRC](http://www.come-over.to/FASCRC)

**Saskatchewan Fetal Alcohol Support Network FASD Tips**  
[www.skfasnetwork.ca](http://www.skfasnetwork.ca)

**National Organization on Fetal Alcohol Syndrome (NOFAS)**  
[www.nofas.org](http://www.nofas.org)

**Project FACTS: Fetal Alcohol Consultation and Training Services**  
[www.fasalaska.com](http://www.fasalaska.com)

**Office of Fetal Alcohol Syndrome, State of Alaska, Health & Social Services**  
[www.hss.state.ak.us/fas/default.htm](http://www.hss.state.ak.us/fas/default.htm)

# VON FASD PROJECT RESOURCE TOOLBOX

We recommend that you begin your search for current up-to-date information on FASD by contacting:

## **FASD Information & Consultation Service: Canadian Centre on Substance Abuse (CCSA)**

[www.ccsa.ca/index.asp?menu=Topics&ID=150](http://www.ccsa.ca/index.asp?menu=Topics&ID=150)

The CCSA provides information on FASD through a toll-free telephone reference service (1-800-559-4514) which is also accessible by email ([fas@ccsa.ca](mailto:fas@ccsa.ca)), a website featuring news, events, and links to recommended readings and related resources. In addition, the CCSA hosts a national database of resources on FASD and substance use during pregnancy, and offers email based consultations to service providers.

## ROUTINE AND CONSISTENCY

### PUBLICATIONS

#### **Living with FAS: A Guide For Parents by Sara Graefe (ed) and SNAP**

2003 (3rd ed.) Vancouver, BC : Groundwork Press

Provides an overview of the essential FASD information for parents, tips for caregivers, information on the assessment and referral process, as well as diagnostic criteria. It also includes information pertaining to parents' needs and respite.

#### **Fetal Alcohol Syndrome: A Guide for Families and Communities by Ann Streissguth**

2001. Baltimore, MD: Paul H. Brooks Publishing

Topics covered in this book include: an overview of FAS and diagnostic process, teratology and brain damage, physical and behavioural manifestations, a model for advocacy, guidelines for employment and education, effective services for high risk mothers, and addressing public policy.

#### **Trying Differently: A Guide for Daily Living And Working With FAS And Other Brain Differences by Debbie Trudeau (ed.) and the Fetal Alcohol Syndrome Society Yukon (FASSY)**

2002. Whitehorse, YT: FASSY

Provides a general overview of FAS and offers advice for individuals affected by prenatal alcohol exposure. It provides strategies and suggestions to help them manage in a number of areas including daily routines and structure, life skills, and community issues. It also stresses self-care for parents and caregivers.

## MANAGING BEHAVIOUR

### PUBLICATIONS

#### **Recognizing and Managing Children with Fetal Alcohol by Brenda McCreight**

1997. Washington, DC: CWLA Press

Offers practical advice on dealing with FAS's lifelong effects on behaviour and learning. It covers the historical, medical, and social aspects of FAS, and details common behavioural characteristics associated with the condition. Taking a developmental approach, the guide offers specific behavioural management techniques to be used with children with FAS from infancy through late adolescence. The author's own case studies are used to clarify psychological concepts and personalize FAS for the novice.

#### **Saskatchewan Fetal Alcohol Support Network FASD Tips**

2004. Saskatoon, SK: Saskatchewan Fetal Alcohol Support Network

A set of **11 documents** that provide examples and suggestions for parents on a number of issues related to raising their children and teens with FASD.

1. Decision-making: How You can help Children with FASD make Decisions
2. Decision-making: How You can help Teens and Adults with FASD make Decisions
3. Money Management: How You can Help Adults with FASD Manage Money
4. Money Management: How You can help Teens with FASD manage Money

5. Reality or Fantasy: How You can help your Child with FASD figure out Reality and Fantasy
6. Friendships: How You can Help your Child with FASD Make and Keep Friends
7. Sensory Issues: How You can help Children with FASD Learn to cope with their Senses
8. Ownership: How You can help Children and Teens with FASD Learn about Ownership
9. Change: Making Changes with Children and Youth with FASD
10. Sport and Activities: Tips to help your Child or Teen with FASD take part in Sports and Activities
11. Care for the Caregiver of Children and Youth with FASD Saskatchewan Fetal Alcohol

Support Network, 510 Cynthia Street, Saskatoon, SK, S7L 7K7 Phone: (306) 975-0884; Email: [fas.esupportnetwork@sasktel.net](mailto:fas.esupportnetwork@sasktel.net) or download the resource from website [www.skfasnetwork.ca](http://www.skfasnetwork.ca)

## VIDEOS

### **Helping Families, Helping Children**

Yellowknife Association for Community Living (YACL)/Yellowknife Films

1998 Part 1- This video and companion guide (74 pages) provide clear information about FAS/FAE and demonstrates ways that families can support their children (aged birth to 6 years). It brings a message of hope for families that children with FAS/FAE can live productive and satisfying lives. 28 min

2001 Part 2- This video, which shows children affected by FAS and pFAS with their families and in the elementary school system, demonstrates ways that they can be supported to achieve success. 29 min

Contact: YACL, Box 981 Yellowknife, NT X1A 2N7 or Phone: 1-867-920-2644 or Email: [info@yellowknife-acl.ca](mailto:info@yellowknife-acl.ca). Also available online from YACL a manual from the Living and Learning with FASD Project: Helping Kids with FASD: Strategies for NWT Families, Schools and Communities [www.ykacl.ca/HelpingKidsWithFASD.pdf](http://www.ykacl.ca/HelpingKidsWithFASD.pdf)

### **Fetal Alcohol and Other Drug Effects: A Four-Part Training Series for Parents and Professionals**

2000. Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc. (FASCETS)

Set of 4 hour-long videos were developed to provide accessible, practical information and training to help parents, families, professionals, and to support program development. Part 1: Diagnostic Criteria: Effects of Prenatal Exposure, Part 2: Common Learning and Behavioral Characteristics, Part 3: Behaviors and Overlapping Diagnoses, and Part 4: Barriers to Identification: Historical, Cultural, Professional and Personal. Contact: FASCETS, PO Box 83175 Portland, OR 97283 Phone (503) 621-1271 or Email: [dmalbin@fascets.org](mailto:dmalbin@fascets.org)

### **Worth The Trip: Children Affected By Fetal Alcohol**

1996. Vida Health Communications, Inc.

This video presents an overview of the problems faced by both adoptive and birth parents who provide care for children with FAS. Divided into two sections, the first and longest (47 min), presents issues described by experts (Lynn Wiener and Barbara Morse), which are then discussed by parent groups. The final short section deals with problems with “Teaching and Learning.” 57 min. Contact Vida Health Communications toll free phone: 1-800-550-7047.

## WEBSITES

### **Behavior Environmental Adaptation Model (BEAM)**

[www.come-over.to/FAS/BEAM.htm](http://www.come-over.to/FAS/BEAM.htm)

The 15 BEAM Rules of FASD Behavior Management (Also known as the Fasstar Trek Model) by Teresa Kellerman 2004.

### **Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Related Conditions with Carolyn Hartness and Julie Gelo**

These Internet online training videos on FAS are produced by Washington State Department of Social Services and are part of the Foster Parent Webcast Archive. Carolyn Hartness and Julie Gelo are the presenters and they provide an overview of FAS/FAE and intervention strategies that are helpful for the care of children or adults with FASD. The training consists of 2 separate sessions consisting of 3-45 min lectures.

The FAS Online Video Training Website:  
[www1.dshs.wa.gov/ca/fosterparents/videoFAS.asp](http://www1.dshs.wa.gov/ca/fosterparents/videoFAS.asp)

### **SCREAMS Model**

[www.come-over.to/FAS/ScreamsArticle.htm](http://www.come-over.to/FAS/ScreamsArticle.htm)

How to minimize screaming, yours, not theirs by Teresa Kellerman.

### **Social Behavioral Challenges in Children with FAS/E**

<http://fasalaska.com/behavior.html>

2002. Project FACTS and Deb Evensen.

## LEARNING STRATEGIES

### PUBLICATIONS

#### **FAS/E and Education : The Art Of Making A Difference**

FAS/E Support Network of B.C. 1997. Surrey, BC: FAS/E Support Network of B.C

This booklet was written to help parents of children with FAS/E advocate for services within the school system. It outlines steps to follow in keeping records about their child, explains the IEP (individual education plan) and how to work with the teacher. Various cognitive, behavioural and language assessment scales are described. Contact FAS/E Support Network of B.C. #108, 17767- 64th Avenue, Surrey, BC V3S 1Z2, or Phone (604) 576-9911  
Email: [info@fetalalcohol.com](mailto:info@fetalalcohol.com)

#### **Fantastic Antone Succeeds! Experiences in Educating Children with Fetal Alcohol Syndrome by Judith Kleinfeld, Barbara Morse, and Siobhan Wescott (eds.)**

2001. Fairbanks, AK: University of Alaska Press

This book is a field guide to life with an adolescent or young adult with FAS/E. Chapters include information on how prenatal alcohol exposure affects children and their families; parenting approaches and strategies that work (i.e. education, counseling, sexuality, trouble with the law, & living skills); and what families need from the community.

#### **Challenges and Opportunities: A Handbook for Teachers of Special Needs with a Focus on Fetal Alcohol Syndrome (FAS) and Partial Fetal Alcohol Syndrome (pFAS) by P. Lasser**

1999. Vancouver, BC: Vancouver School Board  
Written by a teacher and reviewed by teachers, parents, and advocates of students with FAS/E, this handbook puts a “human face” on FAS/E by providing pictures and quotes of students who live with FAS/E and vignettes from their lives. It contains 200+ teaching strategies.

#### **Teaching Students with Fetal Alcohol Syndrome/ Effects: A Resource Guide For Teachers by Julie Conry and the Special Programs Branch, BC Ministry of Education, Skills, and Training**

1996. British Columbia Ministry of Education, Skills and Training: Victoria, BC

This resource guide is organized around areas of concern identified by experienced classroom and integration support teachers. Its goal is to provide teachers with a clear understanding of the needs of students with FAS/E. Includes section on social skills and how to teach them. Many of the strategies are general and may be appropriate for use with students who are not diagnosed with FAS/E, but who do share some of the learning needs of students with FAS/E. Download the resource: [www.bced.gov.bc.ca/specialed/fas/](http://www.bced.gov.bc.ca/specialed/fas/) or contact: BC Government Publication Services, 563 Superior Street PO Box 9452 Stn Prov Govt Victoria, BC V8W 9V7 Phone: (250) 387-6409

#### **Towards Inclusion: Tapping Hidden Strengths Planning For Students Who Are Alcohol-Affected by Manitoba Education, Youth and Training**

2001. Winnipeg, MB: Manitoba Education, Citizenship and Youth.

This is a planning resource intended to provide support to student service administrators, principals, classroom teachers, resource teachers, school counsellors, clinicians, and other community professionals who will help in assisting schools in developing approaches for students who are alcohol-affected. Specifically, the planning resource will provide:

- processes and systems that can be used by a school/division to address the needs of students who are alcohol-affected
- strategies and interventions for individual students
- sample tools including forms and support materials

Available in French. Download the resource: [www.edu.gov.mb.ca/ks4/specedu/fas](http://www.edu.gov.mb.ca/ks4/specedu/fas) or contact: Program and Student Services Branch: Manitoba Education, Citizenship and Youth, W110-1970 Ness Ave., Winnipeg, MB R3J 0Y9 or Phone (204) 945-2070 or Email: [lmclean@gov.mb.ca](mailto:lmclean@gov.mb.ca)

### **Teaching for the Prevention of Fetal Alcohol Spectrum Disorder, Grades 1-12: A Resource for Teachers of Health and Life Skills and CALM**

2002. Edmonton, AB: Alberta Education

The goal of this resource is to raise awareness of the effects and characteristics of fetal alcohol spectrum disorder (FASD) through learning activities that teachers can incorporate into the health and life skills, and Career and Life Management programs. It provides strategies, activities and student information sheets focusing on the prevention of alcohol use and abuse during pregnancy. A handout for community resource people offers tips for working with students and outlines the specific goals and learning outcomes for the health program. Contact: Learning Resources Centre, 12360 - 142 Street, NW Edmonton, AB T5L 4X9; Phone (780) 427-2767 or toll free 1-888-310-7777; Email: [lrccustserv@gov.ab.ca](mailto:lrccustserv@gov.ab.ca) or visit the website and purchase online [www.lrc.learning.gov.ab.ca](http://www.lrc.learning.gov.ab.ca)

## **VIDEOS**

### **Students Like Me**

Vida Health Communications, Inc. 1996. 49 min  
Students Like Me was created to help elementary and special educators understand what Fetal Alcohol Syndrome is and provide teaching methods to help children affected by fetal alcohol reach their full potential. Includes:

- How to recognize a child with FAS in the classroom
- How to modify the class environment and adjust teaching methods
- How to communicate clearly and plan transitions and unstructured time

Contact Vida Health Communications toll free phone: 1-800-550-7047.

### **Learning Disabilities and Social Skills with Richard Lavoie**

PBS Home Video 1994 62 min Subtitle is Last One Picked On. Parent's guide on helping children who have learning

disabilities address social problems these children often encounter and the video helps explain why this happens and what parents can do to help with practical solutions.

## **WEBSITES**

### **All-In-One Home School Resource Center**

[www.come-over.to/homeschool](http://www.come-over.to/homeschool)

Sponsored by FASSTAR Enterprises and Teresa Kellerman.

## **MAKING AND KEEPING FRIENDS**

### **PUBLICATIONS**

#### **My Name is Amanda and I Have Fetal Alcohol Effects by FAS/E Support Network of B.C.**

1997. Surrey, BC: FAS/E Support Network of B.C.

A book for young children with FAS/E. The booklet is about Amanda and her brother Jason who both have FAS/E. It explains in a very simple way what FAS/E is and how children are affected by it.

#### **The Best I Can Be: Living with Fetal Alcohol Syndrome-Effects by Liz Kulp and Jodee Kulp**

2000. Brooklyn Park, MN: Better Endings New Beginnings  
Text for kids and teens living with FAS/E. Also contains tips for advocating for services for children.

#### **Our FAScinating Journey by Judy Kulp**

2004. Better Endings New Beginnings

The story of a young teen diagnosed with FAE - permanent neurological brain damage due to prenatal exposure to alcohol. The book includes creative approaches in reaching and loving children with attachment issues; understand how alcohol affects the growing brains of children and become familiar with brain terminology; uncover ideas to help a child nutritionally; and wade through school and behavior issues with tears, laughter and strategies you may not have tried.

## **GETTING A DIAGNOSIS**

### **PUBLICATIONS**



**Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis by Albert E. Chudley, Julianne Conry, Jocelynn L. Cook, Christine Loock, Ted Rosales, Nicole LeBlanc – CMAJ, MAR. 1, 2005; 172 (5 suppl)**

Abstract: A subcommittee of the Public Health Agency of Canada's National Advisory Committee on Fetal Alcohol Spectrum Disorder reviewed, analysed and integrated current approaches to diagnosis to reach agreement on a standard in Canada. The purpose of this paper is to review and clarify the use of current diagnostic systems and make recommendations on their application for diagnosis of FASD-related disabilities in people of all ages. The guidelines are based on widespread consultation of expert practitioners and partners in the field. These are the first Canadian guidelines for the diagnosis of FAS and its related disabilities, developed by broad-based consultation among experts in diagnosis.

**FASD Information & Diagnosis by Alberta Clinical Practices Guidelines Program**

2004. Edmonton, AB: Alberta Medical Association  
This guideline provides an overview of issues related to the diagnosis of FAS and includes the standard diagnostic criteria that has been developed in the US. Contact: Alberta Perinatal Health Program, North Office, Suite 300, Kingsway Professional Centre, 10611 Kingsway Avenue, Edmonton, AB T5G 3C8; Phone (780) 735-1000; Email: [LoriKirkey@cha.ab.ca](mailto:LoriKirkey@cha.ab.ca) or download resource from website: [www.aphp.ca](http://www.aphp.ca)

**FAS: Guidelines for Referral and Diagnosis by the National Center on Birth Defects and Developmental Disabilities, CDC and Prevention Department of Health and Human Services and National Task Force on FAS/FAE**

2004. Department Of Health And Human Services Centers For Disease Control And Prevention  
These guidelines are intended to assist physicians and allied health professionals in the timely identification, referral, and diagnosis of persons with fetal alcohol syndrome. Contact: Centers for Disease Control and Prevention, FAS Prevention, Mail-Stop E-86, 1600 Clifton Rd, Atlanta, GA 30333, Phone (404)498-3947, Email: [FASInquiries@cdc.gov](mailto:FASInquiries@cdc.gov) or download the resource from website: [www.cdc.gov/ncbddd/fas/documents/FAS\\_guidelines\\_accessible.pdf](http://www.cdc.gov/ncbddd/fas/documents/FAS_guidelines_accessible.pdf)

**So Your Child has FAS/E: What You Need to Know by FAS/E Support Network of B.C.**

1997. Surrey, BC: FAS/E Support Network of B.C.  
FASNET Information Series. A handbook for parents of children newly diagnosed with FAS/E.

**CD-ROM**

**Fetal Alcohol Syndrome: Tutor**

2003. March of Dimes  
CD ROM helps health professionals screen and diagnose children with fetal alcohol syndrome. The CD-ROM uses descriptive text, video clips, animations and illustrations to assist users. (item #09-1266-99). Contact; March of Dimes Birth Defects Foundation 1275 Mamaroneck Ave. White Plains, NY 10605 or Phone (770) 280-4115.

**WEBSITES**

**CCSA's FAS Tool Kit**

**Basic Principles of Diagnosis:**

[www.ccsa.ca/toolkit/Children/section2e.htm](http://www.ccsa.ca/toolkit/Children/section2e.htm)

**What to do with a diagnosis once it is obtained:**

[www.ccsa.ca/toolkit/Children/section3e.htm](http://www.ccsa.ca/toolkit/Children/section3e.htm)

**Fetal Alcohol Syndrome Position Statement (11 2002-01) by the Canadian Paediatric Society**

2002. Paediatric Child Health Vol. 7 No. 3  
Download the position statement  
[www.cps.ca/english/statements/II/II02-01.pdf](http://www.cps.ca/english/statements/II/II02-01.pdf)

**SECONDARY EFFECTS OF FASD**

NOTE: Secondary effects are also known as secondary disabilities, defined by Streissguth as those [disabilities] not present at birth but which occur as a result of the primary disabilities (Streissguth, 1996). They include mental health problems, disrupted school experience, trouble with the law, confinement, inappropriate sexual behaviour, substance abuse issues, difficulty living independently and employment issues. Secondary effects can be prevented or lessened by better understanding and applying appropriate interventions. Secondary effects may also be referred to as

secondary consequences. We prefer the term effects or consequences due to the fact that the term “disabilities” is misleading. Our goal is to reduce the occurrence of secondary effects through our work.

## PUBLICATIONS

### **Tough Kids and Substance Abuse: A Drug Awareness Program for Children and Adolescents With ARND, FAS, FAE And Cognitive Disabilities by P Cook, R. Kellie, K. Jones & L. Goossen.**

2000. Winnipeg, MB: Addictions Foundation of Manitoba  
This drug awareness program targeted to “tough kids” provides educators and other youth community professionals with practical strategies related to educating this group about alcohol, inhalant and other drug issues.

### **Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome by Judith Kleinfeldm, Barbara Morse and Siobhan Wescott (eds.)**

2000. University of Alaska Press  
This is a guide to life with a teen or young adult with FAS or pFAS. The first section discusses the meaning of success for teens and adults with FAS. The second section discusses strategies that work in areas such as counselling, education, sexuality, trouble with the law, and independent living. Section three covers what families need from the community, including innovative programs that help individuals with FAS and how to get a diagnosis at adolescence. The book also contains important resources, organizations to contact, and Internet addresses.

### **Adults Living with FAS/E: Experiences and Support Issues in British Columbia by Rutman Deborah, Corey La Berge, and Donna Wheway: FAS/E Support Network of BC**

2002. Surrey, BC: FAS/E Support Network of B.C.  
This report includes excerpts of life stories of individuals with FAS as well as a discussion of a number of issues and experiences that participants have told about day-to-day living with FAS/E. These issues and experiences have been divided into different topic areas (e.g. accomplishments, employment, education, parenting with FAS/E, independence, justice.). The Implications section outlines directions for advocacy, supportive policies and effective practices for

adults living with FAS/E as identified through this research.  
**The Challenge of Fetal Alcohol Syndrome; Overcoming Secondary Disabilities by Ann, Streissguth, and Jonathan Kanter (eds.)**

1999. Seattle, WA: University of Washington Press  
A summary of recent findings and recommendations is presented by the team who conducted the largest study ever done on people of all ages with FAS/FAE. Topics include articles on diagnosis, effects of heavy prenatal exposure to alcohol, primary and secondary disabilities, medication and FAS, education of young children, practical hints for adults with FASD, preventing and treating sexual deviancy, parent advocacy, legal issues

## VIDEOS

### **FAS: When the Children Grow Up**

2002. Knowledge Network B.C & Magic Lantern.  
This program tells the stories of adults living with FAS and FAE – some who were diagnosed early and others who were not – and the events, programs, and people who made a difference in their lives. 40 min

## WEBSITES

### **Connections: Serving Adolescents and Adults with FASD**

[www.fasdconnections.ca](http://www.fasdconnections.ca)  
The website has a resource listing of FASD key documents on numerous subjects concerning adolescents and adults with FASD. Email: [info@fasdconnections.ca](mailto:info@fasdconnections.ca)

## HELPING ADULTS AND TEENS WITH FASD

## PUBLICATIONS

### **Letters To Our Children Letters From Our Children Living with Fetal Alcohol Syndrome and Alcohol Related Effects by Dorothy Badry and Liz Lawryk**

2000. Alberta Association for Community Living  
This is not a clinical textbook but a collection of stories written from the heart by parents, relatives, and caregivers

who love their children and children who know they live life with a difference.

**Damaged Angels: A Mother Discovers the Terrible Cost of Alcohol in Pregnancy by Bonnie Buxton**

2004 Toronto: Alfred A. Knopf Canada

An adoptive mother welcomes a little girl not knowing she struggled with Fetal Alcohol Spectrum Disorder.

**The Broken Cord by Michael Dorris**

1989 New York: Harper Collins

This book chronicles the life of the author's son, Adam who was born with FAS. It received the 1989 National Book Critics Circle Award and the 1989 Christopher Award.

**Faces of FAS: Putting A Personal Face on FAS by Beth McKechnie**

2001. Winnipeg, MB: Manitoba Association for Community Living (MACL)

This booklet provides a personal perspective on the daily challenges and situations that families and parents face in raising their children with FASD. Contact: MACL, #210-500 Portage Ave, Winnipeg, MB R3C 3X1, Phone (204) 786-1607 or Email: [aclmb@mb.sympatico.ca](mailto:aclmb@mb.sympatico.ca) and Website: [www.aclmb.ca](http://www.aclmb.ca)

**EMAIL LIST SERVES**

**FASlink Canadian Fetal Alcohol Syndrome Internet Information and Support Communications Link.**

[www.acbr.com/fas](http://www.acbr.com/fas)

FASlink maintains both an extensive FAS information website and a discussion listserve. FASlink's website and the FAS InfoDisk/CD ROM (resource list for purchase) are updated regularly along with other electronic publishing projects. FASlink's Archives are continually updated. FASlink also publishes brochures and electronic media for distribution. Contact: FASlink, 2445 Old Lakeshore Road, Bright's Grove, ON N0N 1C0, Phone (519) 869-8026 or Email: [FASlink@acbr.com](mailto:FASlink@acbr.com)

**OlderFAS**

[www.come-over.to/FAS/JoinOlderfas.htm](http://www.come-over.to/FAS/JoinOlderfas.htm)

Olderfas is a private support group for families and caregivers of adolescents and adults who have or are sus-

pected of having Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE).

**WEBSITES**

**FASD Strategies, Not Solutions by the Region 6 Fetal Alcohol Spectrum Disorder Child and Youth Subcommittee**

[www.region6fasd.ca](http://www.region6fasd.ca)

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.

**Fasaholics Anonymous**

[www.come-over.to/FasaholicsAnonymous](http://www.come-over.to/FasaholicsAnonymous)

Support site for parents/caregivers of children with FAS.

**Staying Alive with the FASD Survival Plan**

[www.come-over.to/FAS/StayingAlive.htm](http://www.come-over.to/FAS/StayingAlive.htm)

Sponsored by Teresa Kellerman

**CONNECTING WITH OTHERS**

**PUBLICATIONS**

**Fetal Alcohol Spectrum Disorder: A message to Police Officers about FASD. The Pas Family Resource Centre Inc. & RCMP 'D' Division**

2003. Pas, MB

Brief Description: Developed for police officers, this pamphlet on Fetal Alcohol Spectrum Disorder (FASD) is a sample of materials being developed for a policy and community training initiative. With information on the physical and mental defects caused by alcohol use during pregnancy, this pamphlet outlines: key terminology, ways to identify those who may be affected by FASD; and ideas for working more effectively with FASD individuals in emergency situations.

Download the resource:

[www.sharedlearnings.org/resources/fasd/en/27\\_5\\_3%20FAS\\_brochure.pdf](http://www.sharedlearnings.org/resources/fasd/en/27_5_3%20FAS_brochure.pdf)

## **What Early Childhood Educators, Caregivers and Doctors -- Need To Know About Fetal Alcohol Syndrome (FAS)**

Manitoba Child Care Association and the Manitoba Healthy Child Initiative, Manitoba Education and Training, 2000  
Winnipeg, MB: Manitoba Child Care Association; Manitoba Healthy Child Initiative, Manitoba Education and Training  
This guide provides an overview of the characteristics and behaviours of children affected by prenatal alcohol exposure and highlights general and specific guidelines to use in caring for infants, toddlers, and children. Available in French.

- What Educators Need to Know About FAS audio cassette and manual
- What Early Childhood Educators Need to Know About FAS audio cassette and manual
- What Doctors Need to Know About FAS - CD and laminated FAS resource guide

Contact: Healthy Child Manitoba, 219 - 114 Garry St.,  
Winnipeg MB R3C 4V6, Phone(204) 945-2266

Email: [healthychild@gov.mb.ca](mailto:healthychild@gov.mb.ca)

Website: [www.gov.mb.ca/healthychild/programs/fas](http://www.gov.mb.ca/healthychild/programs/fas)

## **WEBSITES**

### **SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence**

Download the **What You Need To Know** Series by SAMHSA:

- Independent Living for People With Fetal Alcohol Spectrum Disorders  
[www.fascenter.samhsa.gov/pdf/WYNKIndLiving.pdf](http://www.fascenter.samhsa.gov/pdf/WYNKIndLiving.pdf)
- Understanding Fetal Alcohol Spectrum Disorders: Getting a Diagnosis  
[www.fascenter.samhsa.gov/pdf/WYNKDiagnosis4.pdf](http://www.fascenter.samhsa.gov/pdf/WYNKDiagnosis4.pdf)
- The SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence  
[www.fascenter.samhsa.gov/pdf/WYNKFASDCenter3newad.pdf](http://www.fascenter.samhsa.gov/pdf/WYNKFASDCenter3newad.pdf)
- The Language of Fetal Alcohol Spectrum Disorders  
[www.fascenter.samhsa.gov/pdf/WYNKLanguageFASD2.pdf](http://www.fascenter.samhsa.gov/pdf/WYNKLanguageFASD2.pdf)
- Tips for Elementary School Teachers  
[www.fascenter.samhsa.gov/pdf/WYNKTeachersTips2.pdf](http://www.fascenter.samhsa.gov/pdf/WYNKTeachersTips2.pdf)

Contact: SAMHSA FASD Center for Excellence, 1700  
Research Boulevard, Suite 400, Rockville, MD 20850;  
Phone 1-866-786-7327 or Email: [fascenter@samhsa.gov](mailto:fascenter@samhsa.gov)

## **Advocating for the Student with FASD**

[www.come-over.to/FAS/schooladvocacy.htm](http://www.come-over.to/FAS/schooladvocacy.htm)

2001 Teresa Kellerman

## **CARE FOR THE CAREGIVER**

### **PUBLICATIONS**

#### **Fetal Alcohol Syndrome and the Criminal Justice System by Julianne Conry and Diane Fast (ed).**

2000. Law Society of British Columbia and BC FAS Resource Society, Vancouver, BC

This book provides information about people with FAS/E in the criminal justice system. Judges, Lawyers, probation, and parole officers, those working in the legal system will find this tool an excellent resource. Available from the Asante Centre Tel:(604) 467-7101

Email: [info@asantecentre.org](mailto:info@asantecentre.org)

#### **Fetal Alcohol Syndrome: Implications for Correctional Service by Correctional Service of Canada**

1998. Corrections Canada: Ottawa, ON

This report reviews the literature on Fetal Alcohol Syndrome from the perspective of the implications this condition might have for the criminal justice system and for Correctional Service Canada. The report is presented in three parts. Part 1 provides a basic background about the disorder. Part 11 traces the course and consequences of this condition, including the connection to delinquency and crime. Part 111 considers the possibility of identifying fetal alcohol syndrome and related effects in individuals who come in contact with the criminal justice system, and how institutional and post-release programs might best fit their needs.

Download the resource:

[www.csc-ccc.gc.ca/text/rsrch/reports/r71/r71e\\_e.shtml#2](http://www.csc-ccc.gc.ca/text/rsrch/reports/r71/r71e_e.shtml#2)

#### **Fetal Alcohol Syndrome and the Criminal Justice System - Understanding the Offender with FAS**

2000. Asante Centre, Vancouver, BC

Set of 3 videos Talking With Victor 43 min, A Judge's Perspective 56 min, and Mistakes I Have Made 28 min.  
Based on the publication 'FAS and the Criminal Justice

System by Conry and Fast, this series of videos explores the unique considerations facing individuals with FAS that come in contact with the criminal justice system such as: The implications of FASD in the Canadian Charter of Rights and Freedoms; The concept of “Not Criminally Responsible by Reason of a Mental Disorder”; The tendency for clients with FASD to be impressionable, suggestible and easily misled; Examples of assumptions that may seem reasonable for a typical client, but would not be appropriate for a client with FASD; and The importance of obtaining an FASD assessment.

## ACCESS TO WORKSHOPS AND CONFERENCES

The following websites keep an up-to-date listing of FASD training and conferences:

### **FASD Information & Consultation Service: Canadian Centre on Substance Abuse (CCSA)**

[www.ccsa.ca](http://www.ccsa.ca)

### **Fetal Alcohol And Drug Unit, Department of Psychiatry and Behavioral Sciences**

University of Washington School of Medicine  
<http://depts.washington.edu/fadu/Events.html>

## NEWSLETTERS

A number of newsletters are published by provincial support networks or associations, please contact the CCSA national directory of FASD information and reference service by calling 1-800-559-4514, or visit the website:

[www.ccsa.ca/fas](http://www.ccsa.ca/fas) for a more complete listing.

### **ICEBURG**

FASIS Seattle, WA

An educational quarterly newsletter published by non-profit community organization for people concerned about FAS/E; because the problems we readily see are only the tip of the iceberg.

Contact: Iceberg, P.O. Box 95597 Seattle, WA 98145-2597,  
Email: [iceberg\\_fas@yahoo.com](mailto:iceberg_fas@yahoo.com)

### **Family Groundwork**

[www.snap.bc.ca](http://www.snap.bc.ca)

The magazine is the only Canadian parenting magazine to focus on families living with special needs and the unique challenges they face. Contact: SNAP, 101-2780 East Broadway Vancouver BC V5M 1Y8, or Phone (604) 687-3114, Email: [info@snap.bc.ca](mailto:info@snap.bc.ca)

## WEB SITES

### **FAS Bookshelf**

[www.fasbookshelf.com](http://www.fasbookshelf.com)

The FAS Bookshelf Inc. is a Canadian internet and mail order business committed to providing a full range of FASD resources. Their goal is to make your search for resources and information easier and less time consuming. Contact: FAS Bookshelf Inc., #438 – 6540 East Hastings St. Burnaby, BC V5B 4Z5, Phone (604) 942-2024 or Email: [info@fasbookshelf.com](mailto:info@fasbookshelf.com)

### **FAS Community Resource Center (FAS-CRC)**

[www.come-over.to/FASCRC](http://www.come-over.to/FASCRC)

The website offers 164 articles written by Teresa Kellerman (FAS Consultant/parent and Coordinator of FAS Community Resource Centre) about FASD issues, both intervention and prevention. In addition to these, there are various non-article items such as an online quiz, an online simulation of FASD disabilities, an online store for FAS books, posters, handouts, brochures, guidelines for FAS Awareness Day, a collection of news reports and research abstracts, a collection of FASD resources, a list of online support groups, conference reports, collection of parents’ poems, a collection of families’ stories, and several photo galleries. The website also offers the following:

- Bill Dubovsky Memorial FASD Lending Library. To place an order, simply send an email to [ckbarker@ev1.net](mailto:ckbarker@ev1.net) with your selections and your mailing address. The library will send resources to Canada.

Contact: FAS Community Resource Centre Contact:  
FAS-CRC, 4710 E. 29th St. #7, Tucson AZ 85711.

### **FASlink: Canadian Fetal Alcohol Syndrome Internet Information and Support Communications Link.**

[www.acbr.com/fas/faslink.htm](http://www.acbr.com/fas/faslink.htm)

The primary objective is to be the FAS online communications network. FASlink maintains both an extensive FAS information website and a discussion listserve. FASlink's website and the FAS InfoDisk/CD ROM (resource list for purchase) are updated regularly along with other electronic publishing projects. FASlink's Archives are continually updated. FASlink also publishes brochures and electronic media for distribution. Contact: FASlink, 2445 Old Lakeshore Road, Bright's Grove, ON N0N 1C0; Phone (519) 869-8026 or Email: [FASlink@acbr.com](mailto:FASlink@acbr.com)

**Fetal Alcohol And Drug Unit  
Department of Psychiatry and Behavioral Sciences,  
University of Washington School of Medicine**  
<http://depts.washington.edu/fadu>

This website is an excellent source of technical and academic material, most of it taken from research undertaken or supervised by the famous psychology professor, researcher, and authority on FAS, Dr. Ann Streissguth at University of Washington Faculty of Medicine in Seattle. Visit this site for the most recent developments in this field of study and a listing of conferences and workshops. Fetal Alcohol And Drug Unit, University of Washing School of Medicine, 180 Nickerson St., Suite 309, Seattle, WA 98109; Phone (206) 543-7155.

**National Organization on Fetal Alcohol Syndrome (NOFAS)**  
[www.nofas.org](http://www.nofas.org)

NOFAS is a national US nonprofit organization that addresses alcohol use during pregnancy and improving the quality of life those individuals and families affected by FASD. NOFAS organization implements innovative ideas in FASD prevention, education, intervention and advocacy. The wesite hosts numerous health, educational, and advocacy resources on FASD. Including a national directory of services and links to affiliated programs and services of NOFAS online. Contact: NOFAS 900 17th Street, NW, Suite 910, Washington, DC 20006; Phone (202) 785-4585.

**Prenatal Exposure**  
[www.betterendings.org/FASFAE/parent.htm](http://www.betterendings.org/FASFAE/parent.htm)

Provides various parenting tips on FASD from parents who are raising FASD children. Topics include: managing behaviour; teen issues; teaching strategies; independent FASD

adult living and legal issues. Spiritual content.

**Project FACTS: Fetal Alcohol Consultation and Training Services**

[www.fasalaska.com](http://www.fasalaska.com)

This website provides information on Fetal Alcohol Spectrum Disorders (FASD), with a focus on intervention techniques for educators. The site has handouts to download on the following: 8 Magic Keys: Developing Successful Interventions for Students with FAS, Links to Other FAS Sites (home schooling, family, and sites on resources in Alaska, US, and International), Social/Behavioral Challenges/Schedule, Biological Basis of FAS, Common Misinterpretations, Developmental Characteristics and FAS Frequently Asked Questions. Contact: FACTS, PO Box 1092, Homer, Alaska 99603; Phone (907) 235-2544 or Email: [debevensen@alaska.net](mailto:debevensen@alaska.net)

**Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence Website. US Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA)**

[www.fascenter.samhsa.gov](http://www.fascenter.samhsa.gov)

SAMHSA centre is a US Federal initiative devoted to preventing and treating FASD. The website provides information and resources about FASD. The site offers information on training, technical assistance and materials you can use to raise awareness about FASD (fact sheets, posters and brochures). The website provides many resources including a searchable online FASD Resource library; events calendar; and resource list of what experts recommend as a starting point for caregivers and parents to begin understanding FASD. Contact: SAMHSA FASD Center for Excellence, 1700 Research Boulevard, Suite 400, Rockville, MD 20850; Phone 1-866-786-7327 or Email: [fascenter@samhsa.gov](mailto:fascenter@samhsa.gov)

**Society of Special Needs Parents (SNAP)**  
[www.snap.bc.ca](http://www.snap.bc.ca)

SNAP is a not-for-profit society that helps families with challenges through mutual support, information, sharing and advocacy. SNAP has a trained province-wide Resource Parent Network that offers mutual and one-to-one support to families with challenges, a warm line, and educational workshops, conferences and seminars on special needs-

related issues, such as FASD, attachment, and an introduction to special needs adoption. SNAP's support services include a library with up-to-date resources on many topics such as Attention Deficit Disorder, Learning Disabilities, attachment issues and FASD. The website hosts an online searchable database of SNAP's library catalogue. Contact: SNAP/Groundwork Press, 101-2780 East Broadway, Vancouver BC, V5M 1Y8; Phone (604) 687-3114 or Email: [info@snap.bc.ca](mailto:info@snap.bc.ca)

### **FAS/E Support Network of B.C**

[www.fetalalcohol.com](http://www.fetalalcohol.com)

The FAS/E Support Network of B.C. was founded and is run by three women with over 65 years combined experience parenting and working with children and adults with FASD. They operate a 24 hour "warm line" which provides parents and the professional community with consultation, support and specific information. A knowledgeable "on call" person can be reached at any time for urgent situations.

Comprehensive training programs tailored to the needs of the group or community are available on a fee for service basis. The Support Network is active in the research, design and development of resource materials about FASD including its most recent project for Health Canada, the development of a comprehensive National training manual on FAS/E entitled FAS/E: A Manual for Community Caring.

### **Syndrome d'Alcoolisation Foetale Effets Relatifs a l'Alcool (SAFERA)**

[www.safera.qc.ca](http://www.safera.qc.ca)

Syndrome d'Alcoolisation Foetale Effets Relatifs a l'Alcool est l'organisme canadien francophone de prevention du SAF et des autre anomalies congenitales causes par l'exposition prenatale a l'alcool et aux drogues. FAS/FAE resource information in French. Contact: SAFERA, 845 Chemin du Bord de l'eau St-Henri QU, G0R 3E0; Phone (418) 882-2488 or Email: [info@safera.qc.ca](mailto:info@safera.qc.ca)