



# ADVOCACY

SUCCESSSES & STRUGGLES

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# Advocating

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Everyone should be granted the same rights and freedoms. Advocacy seeks to ensure that historically marginalized individuals, including those living with a disability, have a voice. Advocating on behalf of individuals living with FASD provides education and awareness that is necessary for a higher quality of life.

An advocate can be anyone who speaks up on behalf of someone else, bringing attention to their unmet needs and the changes that are needed from the public, the government, etc. This could be a caregiver, support worker, teacher, or friend. Advocates can also help individuals learn how to advocate for themselves.

Because FASD is an invisible disability and there is a lack of education within the general public, it can require more advocacy. Educating others about the disability and teaching them to put the person before their disability is the first step in advocacy. This can include providing resources, involving support workers in meetings, or providing others with specific struggles and strengths that an individual has.

Before advocating for any individual it is important to discuss disclosure with the individual and their support system. Some individuals may want to keep this information private and, as an advocate, that must be respected.

The following information walks you through different advocacy struggles and successes that caregivers have had with health professionals, education professionals, the ministry of social services, justice and safety professionals, and employers and organizations.

The content in this resource was developed by caregivers for caregivers.  
The views and opinions are not a reflection of the Network.

# Advocating to Employers & Organizations

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## Suggestions for Success

- Ask other professionals who work with your child to advocate on their behalf, for example your occupational therapist advocating in the school.
- When your child is on a team, educate the coach about FASD, so they know what to expect.
- Find camps that specialize in unique disabilities (camp Tamarack, camp Easter Seal).
- For activities, like camp, send a friend/sibling that understands their unique needs and can advocate for them.
- Programs like Early Childhood Intervention Program can help advocate and provide tips.
- Encourage and teach the ability to self-advocate to the individual living with FASD.
- Be persistent in the face of adversity.
- Maintain open and constant communication with employers and coaches.
- If possible, find them employment with someone they already know.
- Seek environments where the staff are already knowledgeable about FASD.
- Find an employer who will work long enough with the individual to get to know them.
- Utilize community organizations to support individuals in finding and maintaining employment. In some larger communities such as Saskatoon, there are agencies and programs such as Partners in Employment, Abilities Council, FASD Network, Quint, and the Partners for Workplace Inclusion Program.
- Assist employers to develop strategies that will work.
- Keep employers in the loop about behaviors and what's going on outside of work.
- Human resources can assist if you don't want to fully disclose the disability (so can the standards branch).
- Find mentors to accompany the individual or access a job coach.
- Bring materials to help educate and train co-workers. Often coworkers will be more willing to give prompts or reminders to individuals when they understand that they are trying their best and are able to do the work if given some support.

## Common Struggles

- There may be a lack of understanding of what FASD is and how it fully impacts the individual in multiple areas of their lives.
- As caregivers, setting expectations and knowing the capabilities of the individual we are caring for can be hard especially when they act a lot younger than they chronologically are.
- Sometimes it can be frustrating when coaches and program facilitators lack the necessary information.
- Sometimes it can be frustrating when you are advocating but no one seems to be listening to what you are trying to tell them. There will be people out there that don't want to listen to what you have to say. It's important to continue advocating even when it becomes difficult to.
- There are some employers that just may not read the forms or information you provide.
- It's hard to disclose the information or label your child but it's the label that makes others understand the individual and their behaviors.
- It can be difficult to know when or how much to disclose.
- Job coaching may not last long enough.
- It can be hard to get employers to understand that each day may be different in terms of their ability.
- It can be difficult to ensuring employers check that individuals really understand their instructions and tasks.
- Sometimes lack of understanding looks like lack of motivation when employers don't understand FASD.
- Employers often don't understand the impact of changes to schedules for those living with FASD.
- Finding a career that provides job satisfaction can be difficult for anyone.
- Explaining to individuals living with FASD that they need post-secondary education for some careers. Sometimes school is a struggle without proper supports in place. And it can be difficult to explain to someone living with FASD that going to school now will benefit them later on because they may have difficulties understanding cause and effect.
- Having employers understand that putting in accommodations does not have to be difficult or time consuming.
- As caregivers, it's sometimes hard to have the courage to go in and talk to employers.
- It can be difficult to teach someone how to properly interact with peers at work.
- Watching our children being passed up for promotions or career advances can be difficult
- It can be difficult to advocate for them to have access to benefits and subsidies.

# Advocating to Education Professionals

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## Suggestions for Success

- Provide teachers and educational assistants with copies of the different materials on FASD that you have so that they can become more aware of the disability.
- Make sure that the right people (classroom teachers, resource teachers, educational assistants) know what your child needs to be successful.
- Try to find schools or programs that have education and experience working with children who live with FASD or disabilities in general.
- Talk to the school and the teachers prior to school starting. This will allow you to provide them with some information and tips that can help them better understand in advance.
- Getting your child a diagnosis can really help with accessing supports and services that may be available to them throughout their school years.
- Always communicate with your child's teacher, whether it be through phone calls, emails, or daily communication books.
- See if it is possible to get an educational assistant for your child.
- Get a team together that can help support your child. This team can include teachers, principals, support workers and anyone else who you think may be able to help out.
- Contact agencies such as the FASD Network of Saskatchewan, they can provide information and resources to schools and teachers.
- Always acknowledge your child's disability to the people who need to know. This can help your child be more successful.
- If you are able to, find a tutor for your child throughout their education career. This one-on-one support can really help a child succeed.
- Create a case management or individual program plan for your child with all of the people who may need to be involved. This allows everyone to be on the same page and to know what direction things are moving in.
- Always make sure that you have extra support when you can, whether it be from family or friends. Having support can help you keep your strength while advocating.
- Make sure that your child's teacher has information about the child and how best to handle stressful situations in the class room. This will make it easier for substitute teachers to understand your child.
- Never stop talking and advocating. Make sure that the people who need to know are always reminded of your child's disability. This may seem annoying but it will help make sure your child won't be left behind.

## Common Struggles

- Many teachers do not receive specific FASD training or education, so they lack the skills needed to work with children living on the spectrum.
- Unfortunately, some teachers and professionals have a stereotype of people living with FASD because they do not have the education.
- Remember that a lot of what goes on in school and the funding they get for programs comes from government, so it can be very political. This also means that often teachers are doing the best they can, with the limited resources they have been given.
- Many schools don't have the funding for special needs classes, so there is the potential that your child may be in a large class, which is not always the best learning environment for someone living with FASD.
- Sometimes there is not a lot of dialogue between the different people your child may come in contact with in school. This can mean that important information is not being passed along.
- Teachers are often busy and are over-worked. Sometimes this can mean that there is no follow through or not enough time in the day for them to provide your child with the support they need to succeed.
- In some cases, teachers and educational professionals can think that parents are being overbearing and too protective. This results in them not taking parents seriously

# Advocating to Health Care Professionals

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## Suggestions for Success

- Start early in life with appointments to get the individual accustomed to the doctor visits.
- Research the problem first before going to the doctor.
- Document the child's behaviors so that you can have a record of it when you go see the health professional.
- Have a consistent doctor. Each doctor may change medications and this can be very taxing on your child.
- Diet, exercise, homeopathic medicine, allergy testing, physiotherapy, child psychiatry, and occupational therapy can all have a very important impact on your child so they should be considered.
- There is no medication for FASD but there may be some available to treat other issues. For example, some individuals have problems with impulse control or sleep, there are medications that can help with this.
- Educate health professionals on FASD.
- Getting mental health involved early helps the individual get used to going to these appointments and hopefully decrease the chance of major concerns coming up in the future.
- Pediatric dentists are a better choice because they are used to work with children but you need a referral so there is a wait list most of the time.
- Share knowledge of FASD with the dentist which can be very important especially for children with sensory issues.
- Encourage professionals to get to know the client before starting any treatments with the client
- Status Canada is a good resource as aged out children still can access health benefits.
- Request information on all the option for available medication so you can research the side affects.
- It is important to provide information to your pharmacist so they can understand the diagnosis and give specific instructions.
- Carry an FASD card so people understand what the disability is. A template can be found on the FASD Network of Saskatchewan's website ([www.saskfasdnetwork.ca](http://www.saskfasdnetwork.ca)).

## Common Struggles

- Coming of age gives an individual the right to make their own choices which may not always be good choices.
- There is a concern that if we put a label on a child that they will not get any help.
- A child can be tossed back and forth between agencies and not be able to get the help that they need.
- Make sure the file gets passed from foster parent to foster parent so that the child's history does not get lost and have to be restarted each time.
- Waiting lists are so long (6 months to 3 years sometimes) to get services.
- There is a lack of resources and sometimes in small towns confidentiality can be an issue (what and when do you tell).
- Biological mother has to verify drinking during pregnancy most of the time to get a diagnosis
- Medications are the first thing to be not paid for because rent and food takes up all the income.
- Privacy act can be a bad thing because it stops caregivers from being able to help with communication.
- Sometime an individual might not know if and when they are sick and need to visit the doctor's office.
- Sometimes after the diagnosis has been given, the individual and/or their caregivers are left with no help.
- Most treatment for addiction do not work for individuals living with FASD because they are abstract.
- There is a lack of trained health care professionals in the area of FASD.
- Getting referrals is difficult and can make you wait a long time.
- Assessments can be expensive (ex; travel cost and expenses).
- Teenagers may get pregnant but adult supervision is not allowed in the doctor appointment to explain things in a way the individual might understand.

# Advocating to Justice & Safety Professionals

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## Suggestions for Success

- Role playing boundaries and guidelines with children may help.
- Boundaries must be taught from a very early age and continue to be taught throughout life.
- Supervision around computer and cell phone use may be helpful
- We have to remember that individuals with FASD mature much slower than those without a disability.
- The individual can carry around a card in their wallet that explains their disability and a person that can be contacted. This will help if the individual ever comes in contact with law enforcement.
- Teaching self-advocacy to individuals can be a great tool.
- There are many different programs that can help with justice issues including the alternatives measures program (which happens in court) or the John Howard Society.
- Concrete guidelines must be set so the individual will have an easier time recognizing when they are not following the guidelines.
- Parents and caregivers should try to go to lawyer appointments and court appearances with the individual to make sure they understand.
- Mental Health Strategy can be an option for individuals charged with a crime and who live with a disability or mental illness.
- An advocacy binder with everything about the individual may be useful.
- Being a co-decision maker may help individual make better decisions.

## Common Struggles

- For certain offenses, specific sentences have to be handed down, regardless of their disability.
- Often people with FASD want everyone to be their best friend and they are easily taken advantage of. People with FASD will more often than not do anything their 'friends' tell them to.
- Abstract concepts of the justice system and legal world may confuse individuals.
- Charges may be hard to understand because they may think that they didn't do anything wrong.
- Individuals may perceive situations differently which can cause them to get in trouble with the law.
- Safe and suitable housing is very difficult to find for someone who does not have a fixed income or needs a supportive living environment.

# Advocating to the Ministry of Social Services

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## Suggestions for Success

- Get the Ombudsman involved if you think that your child's best interests aren't being met.
- Getting to know your worker and asking your worker if they have children of their own can help them put things into perspective, and understand how important your child is to you
- You can get the child to sign a consent form so that you can be a legal "co-decision makers" so you can be involved.
- Make sure that your voice is heard even if that means talking to supervisors or higher up the ladder.
- Utilize advocacy programs such as the Children's Advocate.
- When communicating copy third parties so the Ministry of Social Services is accountable and information doesn't get lost.
- Be patient.
- Educate yourself first on your rights, how the ministry works and on FASD
- Keep advocating.
- Get your MLA involved if necessary.
- You can negotiate a PSI (Person of Sufficient Interest) agreement at the start.
- SAID (Saskatchewan Assured Income for Disability) program is good when they are not able to work.
- The early child intervention and prevention program can be very useful.
- A lot of pressure on workers right now, so being mindful of that will be helpful. Remembering that they have more than just one person on their caseload is necessary.
- Educate everyone involved with your child so they know your child as well as you do (eg. make a resource binder that contains all of your child's information).
- Public guardian and trustee is very useful and helpful.
- Send it in writing and make copies.
- Assisted adoption workers can be a good resource, provides counseling for family and financial supports.
- Adoption workers do an annual review, so use this time to talk about what you want to do in the next year and how the Ministry can support you. They usually listen at these meetings, if you are planning long term.
- If you have a good worker, share their name with others.

## Common Struggles

- Workers can burn out quickly and carry a lot of burden with them.
- When you meet with workers you assume or expect that they know your child but they may not.
- Interprovincial involvement can be very stressful
- Individuals usually cannot navigate the system for themselves and lose supports because they might not really understand the rules (Ex. Losing financial support because they did something wrong).
- There may be hesitation to discuss the child's behaviours with your social workers, you may think that it reflects badly on your abilities as a parent.
- Supports are good to start with but then when you move from foster parent to adoptive parent the supports may stop.
- Too many changes can be made without caregivers being kept in the loop.
- There aren't many people who qualify to work with children/teens with FASD (especially in rural areas). They may have outdated information.
- Support is usually based on income and not the needs of the individual.
- Workers can change often.
- It is difficult to get funding through CDS because it is constantly changing parameters, the application process is difficult, and the wait is 6 months longer or more.

# FASD NETWORK OF SASKATCHEWAN

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