



Supporting Success

for Adults with Fetal Alcohol Spectrum Disorder (FASD)



COMMUNITY LIVING
BRITISH COLUMBIA



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The most basic human needs are to matter, to be heard, and to belong. The key to successful outcomes for people with Fetal Alcohol Spectrum Disorder (FASD) and other brain-based conditions is having successful relationships and living in communities that are informed, accepting and supportive.

This booklet is a values based commitment. It is also a vehicle to provide information and basic, practical accommodations that can lead to good lives for those we support who live with FASD, and those we have yet to meet and welcome into our communities.



The Community Living British Columbia (CLBC) Vision

CLBC's vision is one of full citizenship in which people with developmental disabilities lead good lives, have rich relationships with friends and family, financial security, choices in how they live their lives, employment opportunities and are accepted and valued as citizens.

This is best described as people leading “good lives in welcoming communities.” As a steward of this vision, CLBC is committed to fostering the growth of inclusive, supportive communities.



Welcoming a New Mandate

In early 2010, a regulatory change expanded CLBC eligibility criteria to include adults with Fetal Alcohol Spectrum Disorder or Autism Spectrum Disorder. Adults who meet these new eligibility criteria receive services through the Personalized Supports Initiative (PSI). PSI is separate from other CLBC services. It focuses specifically on this new group of individuals, who do not have intellectual disabilities but face significant challenges in daily life.

PSI provides an individualized and personalized approach to meeting the needs of eligible adults by coordinating existing community supports to help people maintain or increase their independence. For more information about the PSI, contact your local CLBC office or go to www.communitylivingbc.ca.

About this Resource

This booklet offers an introduction to Fetal Alcohol Spectrum Disorder and suggested accommodations to assist in supporting these citizens. It is intended for CLBC staff, service providers, community members and others who care about and work with adults with FASD.

The ideas offered are based on the assumption that each person with FASD is an individual with a unique history and situation, and that actions and supports must reflect this. The ideas are therefore not prescriptive, but rather, ways to think about offering support. FASD presents very differently depending on the person, their circumstance, and the day. Successful support recognizes these individual differences and adapts in response.

We encourage you to use this resource as a starting point in your understanding of individuals with FASD, and as a tool as you develop your own knowledge and ways to support success. At the back, there is a list of other resources and websites that may also be helpful along that journey.

Historically, many adults with Fetal Alcohol Spectrum Disorder (FASD) have not had appropriate understanding or supports throughout their lives.

This may be due to a lack of access to responsive and informed professionals in their communities. We now have more information about how the brain is damaged from prenatal exposure to alcohol. We also have more knowledge and experience with successful ways to provide support in light of the profound differences in brain functioning that people with FASD experience.

The life experiences of individuals with FASD vary greatly. Many are successful, happy, contributing members of families and communities—electricians, teachers, counsellors, parents, skilled workers and others. However, without identification and appropriate supports, there is often a sad trajectory of failure, loss, and confusion. This often results in multiple placements and in secondary defensive behaviours that lead to involvement with the justice system and multiple mental health diagnoses. **The key difference between success and failure is the presence of appropriate accommodations to assist people to live successfully in community.**

Crafting successful supports for individuals with FASD requires a clear and compassionate understanding that FASD is a **brain-based physical disability** caused by prenatal exposure to alcohol. By understanding this, we bear the responsibility to change our expectations of the person, and therefore our actions and reactions. We can expand our range of options and interventions and shift our perceptions from “*won’t*” to “*can’t*,” improving the potential for success and reducing frustration for the individual with FASD. This has the added benefit of reducing frustration and the potential for burn out for support people as well.



A Word about Labels

While assessments and diagnosis can be supportive for individuals living with FASD, labels are not. Labels limit. Identification is only a beginning, a start for exploring the question “Who is this person?” and developing appropriate person-specific accommodations. Used compassionately and supportively, naming the disability helps us understand the unique learning needs of the person in order to craft appropriate accommodations and individualized supports in response to these needs.

Although it is important to acknowledge that similarities in behaviour, learning challenges and brain functioning do exist for people with FASD, it is equally important to understand that, just like everyone else, no two people are exactly alike! Understanding FASD is important; learning about the individual is essential to creating successful supports and respectful relationships.



Understanding Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term. It covers all diagnoses that refer to the set of physiological and cognitive symptoms that directly result from the use of alcohol during pregnancy.

Many individuals who have been exposed to alcohol during pregnancy may have significant brain differences, yet only manifest their disability through their behaviours. As such, FASD has been referred to as an “*invisible handicapping condition.*”ⁱ



Common developmental profile for an adolescent with FASD

Chronological Age	18 Years
Expressive Language	23 Years
Social Maturity	12 Years
Math Skills	8 Years
Reading Decoding	14 Years
Reading Comprehension	9 Years

(Reprinted with permission, Malbin 2002)



The brain is highly sensitive and very susceptible to prenatal exposure to alcohol. We now know that there is no safe time, nor safe amount of alcohol that can be consumed during pregnancy. Because brain development occurs throughout pregnancy, alcohol consumption can cause changes over the entire nine months, affecting different aspects of growth and development. In addition, the timing of the alcohol exposure, quantity of alcohol consumed, maternal nutrition, stress, and other variables contribute to the outcomes of exposure. So too does potential exposure to other drugs in addition to alcohol, which is not uncommon.

Alcohol can also affect the development of other parts of the body and contribute to chronic health issues. While some individuals have facial characteristics, in particular,

that distinguish their exposure to alcohol, most do not. Because there are often few if any distinguishing physical characteristics of the disability, the invisibility of the brain damage creates many more challenges for the individual. Others expect them to be like everyone else, so they are often punished for symptoms of their invisible physical disability.

While the range of damage to the brain from exposure to alcohol during pregnancy varies, it is important to understand that it is **permanent**, and the individual cannot change it. As with any other physical disability, with recognition of the nature of the condition and provision of appropriate accommodations based on their strengths, people with FASD are able to live full, happy lives as contributing members of their communities.



Primary Characteristics of Brain Differencesⁱⁱ

Primary behaviours most clearly reflect underlying brain dysfunction. They include learning, developmental, sensory responses and other neurobehavioural symptoms that indicate changes to the brain associated with FASD. (A neurobehavioural symptom is a behaviour that is a result of a brain dysfunction, not one that the person can change or control.)

The following are the primary behaviours most characteristic of the brain differences associated with FASD:

- Significant memory problems
- Gaps in the thinking process including difficulty forming associations, predicting, abstract reasoning, cause and effect reasoning, and generalizations
- Slower pace of thinking, understanding and listening
- Impulsivity and distractibility
- Different responses to stimuli including sensitivity to lights, sounds, temperature, taste and touch
- Challenges in managing free time
- Difficulty weighing and evaluating, resulting in possible difficulty understanding safety and danger and possible heightened risk for victimization and exploitation
- Difficulty managing time, money, and schedules
- Dysmaturity (wide variation between developmental and chronological age)

Alcohol kills developing cells. When alcohol is consumed during pregnancy, the brain is significantly compromised, smaller, and may have lesions and differences in structure. This damage results in the learning, developmental and other neurobehavioral symptoms associated with FASD. In particular, there is typically a considerable gap between a person's chronological age and their developmental age. The diagram on the opposite page shows a common developmental profile for an adolescent with FASD. You can see that the 18 year old has the social maturity of a 12 year old and the math skills of a 8 year old and so on. Notice also that he or she has the expressive language of a 23 year old — many people with FASD are very gregarious and talkative.

While the damage from exposure to alcohol is permanent, the brain continues to change throughout life and so abilities and behaviours may also change. With respectful and individualized supports, people with FASD can learn and adapt to their disability, make meaningful contributions to their communities, have positive relationships, and achieve personal success in many aspects of their lives.

They will, however, **live with the affects of prenatal exposure for their entire lives and may therefore always require assistance to ensure lives of dignity in community.** Supporting individuals with FASD requires a different perspective and accommodations that emphasize *“trying differently, not harder”*ⁱⁱⁱ to compensate for the difference in how people learn.



Secondary Brain Differences and Behaviours^{iv}

Defensive behaviours are normal responses to chronic pain, failure and frustration. They develop in response to the disconnect between the needs of a person and his or her world. These are not intrinsic to FASD but rather **reactions to chronic failure and frustration**. These behaviours are not inevitable and can be prevented or significantly reduced with strategies designed with the FASD brain in mind.

Just like those with other physical conditions, people with FASD benefit from accommodations that build on strengths in all settings.

As one mother said, “Oh, I get it. My daughter has the invisible disability. I get to do the changing.”

— (D. Malbin 2010)

The most common secondary defensive behaviours are:

- Fatigue and frustration
- Anxiety
- Anger and aggression
- Withdrawing and avoidance
- Poor self esteem
- Isolation
- Depression and other mental health concerns including suicidal tendencies and self-destructive behaviours
- Opposition and defiance
- Self aggrandizement

Given that the brain of an individual with FASD functions differently due to prenatal exposure to alcohol, descriptions of behaviour **must** be recognized as indicators of this difference.

Often behaviours are misinterpreted as wilful, intentional, or manipulative and the result of emotional problems. Thus interventions focus on changing the behaviours. It is important to recognize that behaviours are the result of **primary differences in the brain or secondary defensive symptoms** indicating where there is a poor fit. Therefore **interventions should focus on changing the environment to enhance the potential for success, decrease frustration and maximize creative support options**. If the individual with FASD also lives with mental health challenges, treatment options must also be chosen with a view to considerations of the neurological differences. How many of these are actually patterns of secondary behaviours?

Meet the FASD Brain



Typical brain development is complex. In a typical brain, the fundamental structure supports learning, storage of information, and linkages that allow generalization, abstract thinking and reasoning, and assist with organization, sequencing and evaluation. Opposite is a picture of a typical brain.

Learning Theory is based on the belief that most brains function in a similar way:

- Rapid processing speed
- Storage/retrieval of information
- Abstract thinking
- Ability to generalize
- Ability to predict
- Congruent words and actions
- Understanding and comprehension



In the brain of someone with FASD, the neural pathways and connections are compromised and these executive functions are altered in irreparable ways. There are gaps that prevent connections and compromise processing, retrieving, and storage capacities. As a result, **individuals with FASD are literal, concrete learners who tend to grasp pieces, rather than concepts.** opposite is a picture of the brain of a person with FASD.

Neurological differences often appear as:

- Slower thinking and hearing speed
- Problems storing and retrieving information
- Difficulty forming links, associations
- Difficulty generalizing
- Difficulty with abstract concepts
- Difficulty seeing next steps/outcomes
- Disconnections: says one thing and does another
- Grasps pieces rather than concepts

(Reprinted and adapted with permission, Malbin 2002)

As a result of the differences in brain function, an individual with FASD must work much harder than others to process information, respond to directions, make decisions and cope with the world around them. The energy consumed by the brain of someone with FASD can result in exhaustion by the end of the day.

Exhaustion may come after achieving just one task. It is rare that a person with FASD has sufficient stamina to put in a whole day without a rest. Emotional exhaustion may occur at a different rate than physical

exhaustion, resulting in confusing responses by the person, such as needing physical exercise but being unable to handle any more emotional activity.

The variability in capacity of people with FASD is frequently compounded by frustration, anxiety, and a chronic sense of being different than others in ways that are judged negatively. Successful support respects these unique differences and learning needs and emphasizes partnership and dignity through individualized accommodations.



Lessons Learned

Over the past thirty years or so, we have learned a lot about the brain differences that affect people with FASD.

We also know a lot more about what works and does not work in providing successful support. This knowledge comes from individuals living with FASD, their families, friends and service providers, and from research. On the next page are some key collective lessons learned. Keep them in mind as you consider more specific suggestions later in this booklet.



- People with FASD have an invisible, brain-based physical disability with behavioural symptoms. They also have the same hopes, dreams and needs as everyone else. Living successfully with FASD means recognizing strengths and what each person brings to the community. It is about focussing on **ability over disability**.
- Each person with FASD is uniquely affected. Each individual experiences the effect of the brain damage in different ways on different days, depending upon other stressors, levels of fatigue, distractions in the environment, and the competency and appropriateness of supports.
- Individuals with FASD do not experience risk and reward in a typical way. They may not be able to make informed decisions consistently, are highly suggestible, and are often lonely and vulnerable. This creates opportunities for exploitation. Respectful supports recognize this vulnerability, are based on individualized planning, and provide safeguards to assist people with decision making and building interdependent lives in their communities.
- It is important to understand the hallmark neurobehavioral symptoms of FASD **before** developing accommodations. **With FASD, there are brain differences which require support, rather than problem behaviours that must be eliminated.**
- Adults with FASD have often experienced chronic failures and wounding. Trust may therefore come slowly. Building on successes is vital to promoting and maintaining positive self-esteem.
- Quality of life concerns— safety, recreation, employment and stable relationships— are as important as support to manage tasks like dishwashing and laundry.
- If certain life skills have not been acquired by adulthood, they may not be either teachable or retained. Arranging assistance to support daily living, such as housekeeping, does not represent failure and may make the difference between keeping and losing a place to live.
- Successful supports involve positive role modelling by carefully selected, informed, understanding and accepting mentors who are in **relationships** with the person, not custodial roles.
- Active participation of the individual in setting up plans and supports, as appropriate for their learning strengths, abilities and **developmental age**, is key. Building on what has worked in the past is important. Solutions may be found in their interests, identified needs, family members, and community contacts.

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What successful support can look like...

Sharon, 24, is unaware of the accumulating leftover food, debris, and garbage in her apartment. An infestation of mice and ants results. Her landlord threatens her with eviction and the costs of exterminators. Sharon's 65 year old mother and grandmother intervene and spend two days cleaning to meet the inspection timeline and retain her apartment.

An alternative would be to find a way to provide regular housekeeping services to help maintain a healthy home environment. This could reduce stress on the family and safeguard Sharon's rental accommodation.

- Structure is vital to success. Structure organizes the environment, reducing the demand on the individual to have to react and respond to unplanned situations. Lists, schedules, timers, and supportive technology can be very helpful. Assistance in managing these aids may **always** be needed.
- Structure should demonstrate respect, partnership and participation wherever possible. It should **not** be about trying to control the individual's life and actions. Attempts at control are not only disrespectful but can potentially generate power struggles.
- Some degree of assistance that reflects the person's developmental age may always be required. The person may not ask for help, even when essential. Why? Initiating, even to ask a question, requires executive functioning. Asking for help may also make the person feel incompetent and remind them of other times they felt that way. It is important to teach how to ask for help and that it is okay to need it. The focus should be on competencies, relationship, mutuality, and **working with, rather than at the person**. We all require help from others in varying degrees and most of us live interdependently in our communities. **The focus for individuals with FASD should be on interdependence to support success.**
- Change in routines, structures and environments must be supported very individually. For some, change must occur slowly and in small steps in order to prevent or lessen inappropriate behaviours, reduce anxiety, maximize success, and support transitions. For others, limited notice is preferable in order to reduce distress and anticipatory anxiety. Always ask yourself— *Who is the person?*
- Everyone providing assistance to people with FASD should be engaged in on-going **training and teaching opportunities**— including teaching others who interact with the person. Supporting someone transitioning to adulthood is very different than supporting someone in their late twenties or thirties. The goal of independence may need to be revised to interdependence.



Creating Environments that Support Success

We may have learned a lot about the brain differences in people with FASD, and what they need to be successful. However, attitudes about FASD and those who live with it, have been slow to change, and access to appropriate services is still limited.

This section offers some important **ways to think** when creating environments and accommodations that support success. These suggestions may not work for every person — it is always important to tailor them to the uniqueness of the individual and the day.





Build on Gifts

While it is important to recognize the differences in brain functioning that people with FASD live with, it is equally important to honour the unique gifts and abilities they demonstrate. Many people with FASD display important and valued strengths and abilities including:

- Artistic and musical talent
- Creativity
- Gregariousness
- Curiosity
- Tenacity
- Generosity and caring about others

In addition, they often have success with hands-on tasks and benefit from concrete, experiential learning situations and visual cues. Individuals with FASD often work well alongside another person who is positive and encouraging and who offers encouragement and cueing in a natural way.

Stay Curious

Respectful support begins with honouring the uniqueness of each individual. It is important to ask:

- Who is this person? What are their strengths and abilities? What challenges do they face in managing aspects of their lives?
- What part does their brain injury play in their behaviour and in this situation? Are the behaviours primary or secondary?
- What works for them? What accommodations from other situations might apply here?
- What feelings and behaviours am I bringing to the interaction? Are they negative or positive?
- What does the person think would help them be successful in this situation?

Success is built on staying curious about the person and building a relationship of trust that is about working **with the person, rather than at them.**



Language Matters

A key characteristic of FASD is differences in how language is processed and used. The nature of brain development in a person with FASD creates challenges with understanding and interpreting abstract words or concepts. Here are some ways to think about and use language to support success:

- Remember that language processing often takes much longer. Use fewer words, slow down, and give time for the person to answer one thing at a time.
- Be direct, concrete and forthright, emphasizing specifically what is required *e.g. Meet me at the front desk of the college at 5 pm*. Suggesting you meet *around 5 in the college lobby* does not provide specific enough information and is too vague.
- Avoid conditional words such as *however, instead of, provided that, probably, likely*.
- Avoid abstract words, innuendos, sarcasm or euphemisms such as *I'm going to hit the hay* or *I'm dog tired*. The person may have a literal interpretation and misunderstand the statement.
- Keep it simple. Give only one or two directions at a time, at the most.
- Augment what you are saying with visual cues or placing the topic in a context that is immediate, understandable and of interest to the person.
- Support the individual to put their feelings into words. For example, teach the person how to identify where they feel their anxiety *e.g. Does your head hurt? or Show me where it hurts*. Then teach how to identify the feeling in the location and what to do in response *e.g. ask for a 5 minute break, walk away, count to 10, put on ipod, etc.*
- Don't over-explain things. Save the "whys" and avoid grey areas. Stick with black and white, yes and no, bad and good. Be specific *e.g. You cannot smoke when you are with me. or Be home at 6 pm for dinner.*
- Limit choices. Too many choices may cause confusion about what to do. For example, say *I will give you a ride to college. Be ready by 8 am and we will leave then*. Don't say *How about a ride tomorrow? Say 8 am?*
- Provide positive choices. The individual then feels they can succeed either way and that they have some control in the decision-making. For example, *Will we clean your apartment now or at 2:00 pm tomorrow?*
- Be consistent with how you describe things, make requests, and set expectations. Daily reminders **will be necessary**. If the person is a visual learner, incorporate visual reminders, rather than only language-based ones.
- Strike a balance between honouring the person's adulthood and creating safety in a way that avoids power struggles. Use language choices that reflect a younger developmental stage of maturity while still interacting in a respectful manner. It is essential that interventions are respectful and positive while remembering that the typical cumulative acquisition and storage of information does not apply for these individuals.



Environment Makes a Difference

Difficulty with executive functioning may make it hard for a person with FASD to prioritize, clarify, organize, and initiate. External disorder and clutter can easily translate into heightened confusion and internal disorder. This leads to feeling overwhelmed which equals frustration, increased anxiety and inappropriate behaviours, often anger. Here are some suggestions that may help:

- Keep the environment simple and uncluttered. Minimalist lifestyles can help avoid struggles with cleaning and caretaking. Clutter is distracting and heightens the challenge of locating items and using simple schedules.
- Put things away in the same place each time and as soon as they are used. Label cupboards, drawers, etc. to help locate items. This helps keep disorder from building and with remembering where useful and necessary items are.
- Create lists to help support memory. Maintain a central location for important lists and numbers. Make it easy to find and obvious to use.
- Be sensitive to the impact of light, colours, sounds, smells, textures and décor. Many people with FASD have a tendency to be easily over-stimulated by their environment, which contributes to stress and distraction. Find ways to block or limit identified sensitivities such as sunglasses, headphones, curtains, and closed cabinets or containers.



Safeguards are Important

Safeguards are things that people intentionally do to reduce vulnerability in their own lives or someone else's. Safeguards can be personal and individual, or community-wide. Everyone needs safeguards in their lives. Many of the accommodations that promote success for individuals with FASD are safeguards.

For a person with FASD to experience the benefit of safeguards, different accommodations and actions have to come together in a way that works. All the people involved in supporting the person have to know about what the others are doing and work together so that the person experiences a familiar and reliable network of care and support that they can trust.

CLBC recognizes that **formal** safeguards are important to ensure the safety and well being of individuals with FASD, but we know that formal safeguards aren't enough. We also need to think about **informal** safeguards. Informal safeguards are about relationships outside the formal service system. They enhance and enrich people's lives, and their sense of connectedness, self-worth, value and safety. Informal safeguards include:

- Friendships
- Personal support networks
- Relationships with colleagues or neighbours
- Community connections outside the service system
- Social connections and networks through clubs or volunteering

A good life in community for a person living with FASD must include informal safeguards, working together as **informed networks of care**. The key to successful formal and informal networks is understanding behaviours from a brain-based perspective. **Understanding is the cornerstone for acceptance and acceptance is essential for relationships.**

Having people in our life who care about us is one of the most important ways to feel safe and valued. Having friends to talk to, places to go for fun, and the opportunity to be involved in our community not only adds to the satisfaction we feel about life, but also helps build protection and provides support for us when we feel vulnerable. This is especially important for adults with FASD. Informal safeguards are an essential aspect of ensuring they succeed, are able to contribute in meaningful ways, and achieve a sense of belonging in an interdependent community.

The key to successful formal and informal networks is understanding behaviours from a brain-based perspective. Understanding is the cornerstone for acceptance and acceptance is essential for relationships.



Life's Daily Routines

In supporting people with FASD, the emphasis should be on establishing functional and supportive structures rather than imposing control.

Structure emphasizes routines and patterns that help people make sense of their days and weeks, and be successful. Routines should be followed by each person who interacts with the individual with FASD in order to decrease the potential for confusion and frustration.

Sometimes certain actions will work for awhile but not forever. Expect to go “back to the drawing board” to find other creative approaches. Meeting regularly with a team of support people will help to ensure that everyone has the same understanding of this person, how FASD impacts them, and what works for them.



Here are some general actions that may work when figuring out how to support someone with the routines of daily life:

- Maintain the same schedule each day and each week. This provides predictability and safety and supports routine and retention. For example, scheduling appointments with a job counsellor for the same day and time each week helps with remembering and actually getting to the appointment.
- Use visual reinforcements for daily activities if they assist with success. These can include daily schedules, calendars on the fridge, and day books. Don't make schedules too overwhelming. Organize lists and schedules in simple order, to reduce the potential for the person to be overwhelmed.
- Ask before labelling drawers and cabinets to support locating items and putting things away. Some people may appreciate labels, and make them themselves; others may be offended. Give the person a camera to take pictures of the actual items to provide a concrete reference for themselves.
- Keep an observation log to identify "stuck" points and work toward prevention. Over time, work with the person to identify physical responses and reactions to engage and empower them in understanding and advocating for themselves.
- If the individual is frustrated with a task or activity, **stop, observe what is causing the frustration, and then try a different action.** Use few or no words as words may escalate frustration. If appropriate for the person, ask questions to gain understanding.
- Use cell phones, palm pilots, 2-way radios, and other technology to support safety, give reminders, and assist with routines. Cell phone alarms and texting can be used as reminders and cues.
- Find ways to cue that work **and** are respectful. Some people with FASD have difficulty "shifting set." They may be rigid and become frustrated if they are interrupted when doing something or when a plan changes. It is important to find ways to cue that work for them. Leaving notes, lists, using humour, technology, etc can help preserve their self-esteem and self-respect. Invite the person into problem solving with you. Give autonomy whenever possible. If a person can use a checklist, write one out with them, for instance.
- Consider the individual's developmental age rather than chronological age. What if the 25-year-old is actually a competent 12-year old? What accommodations would be provided for an adolescent? Think younger and adjust your expectations. However **always acknowledge and treat the individual as an adult.**
- Break down tasks into small steps. Reinforce learning by asking the person to show you and/or showing the person how the task is to be done successfully. The steps may need to be taught and re-taught in order for learning to occur. Even then, it may be forgotten or not generalized to other situations, so focus on reminding with respectful cues and reinforcing the skills or lessons regularly. Modify expectations accordingly.
- Reduce the number and complexity of decisions the individual has to make. This can prevent them becoming overwhelmed.
- Reinforce success and support self esteem. Offer encouragement and praise often.
- Build a circle of support around the individual including friends, neighbours, relatives, and supportive professionals to increase the breadth of resources the person can draw upon.
- Coach slowly. Check for understanding frequently.



It is essential to build in-depth knowledge about how FASD impacts each person as an individual. Their history, successes and challenges can be learned from talking to the person's family members, care providers, and others who have supported them in the past. Always ask the question *"What has the brain got to do with this?"*



One step at a time....

At 29, Carol wore shoes that were two sizes too big for her. As a result, she kept twisting her ankle and regularly ended up at the doctor's office. With assistance, Carol found a "clothing mentor" to routinely help her to purchase properly fitting shoes to reduce her potential for injury.

Be careful of assumptions...

Carl recently moved into his own supported apartment. The support worker cooked the meals with him for microwaving during the week. On her return, she found several meals in the garbage. Although she had written the heating time on top, the meals were either cooked too long or not long enough. Carl would get frustrated and throw them out.

Realizing that Carl required further accommodations in order to manage his meals more successfully, the support worker explored what might help him understand the cooking instructions. Together, they came up the idea of using photos of the correct microwave settings to support Carl in his meal preparation.

Better late than never....

Marilyn loved coming to work and she was doing a good job. However, she was frequently late. Although her employer was understanding, Marilyn's frequent lateness was causing issues with her co-workers.

Reviewing the situation indicated that she needed assistance at home to ensure she was up in the morning to get to work on time. Marilyn's job coach also helped her co-workers understand that a primary characteristic of FASD is difficulty in managing time and Marilyn's being late was not purposeful. This additional support and accommodation meant success in Marilyn keeping her job.

Sleep

Many adults with FASD have poor sleep patterns. This can include mixed up schedules, a lack of structure to ensure they get to bed at a reasonable time, and a lack of self regulation without assistance. This may be due to an inability to block out sensory information; not being able to understand cause and effect (e.g. do not understand they should get to bed early because they have to work in the morning); memory problems; or other brain-based issues. Here are some accommodations which may help to manage these challenges:

- Establish evening routines and maintain them. Emphasize calm activities to help with relaxation and restful sleep. Keep the bedroom uncluttered and limit stimulating distractions.
- Avoid conflicts or rushing in the morning as it may impact on the entire day. Provide assistance with ensuring the person has clean clothing, packing lunches, and organizing packs/satchels so that the morning routine is as calm as possible.
- Ask what might help during transitions between sleeping and waking. Decide with the person on creative methods for waking them, to reduce their reactions to your assistance.
- Discuss motivators for getting up and getting ready to help encourage successful responses to wake up calls. All of us need a reason or a purpose to get up in the morning. If a person is engaged in their work/ activity, and it's a good fit, the motivation is intrinsic.
- Arrange work schedules to accommodate sleep patterns. Some individuals do better sleeping all morning and then going to a dishwashing job at a restaurant later in the afternoon and evening.

Self Care

People with FASD often have difficulty remembering regular routines, making plans and organizing themselves. They may also have sensitivities to touch or to tastes or smells of products associated with self care activities. Here are some suggestions for ways that may help support self care routines:

- Encourage showering and shampooing every day so that judgement calls aren't required.
- Encourage the use of toothpaste, floss, deodorant. Be specific about how often and long to brush e.g. *Brush your teeth two times a day for two minutes each time*. Poor dental hygiene is often a significant health issue which is heightened because toothbrushing requires a great deal of fine motor coordination and involves sensory issues.
- Check regularly to ensure that clothing is clean and personal hygiene is completed thoroughly. Establish a routine that underwear, socks, and shirts are changed daily. Decide with the person what clothing likes and dislikes they have and then help them choose comfortable clothing that respects sensory concerns.
- Place clothing on labelled, open shelves so that the individual can see items. Clothing in drawers can be a case of "out of sight, out of mind."
- Develop creative ways to support the person with their clothing selections. Color coding clothing on hangers to help with selection and appropriate outfit choices may be helpful. Some adults may find this too controlling and object.
- Medications may need to be packaged bubble packages by the pharmacy to ensure they ensure they are taken daily.
- Cell phone restricted calling is a great way to 'check in' and add reminders.

Money and Budgeting

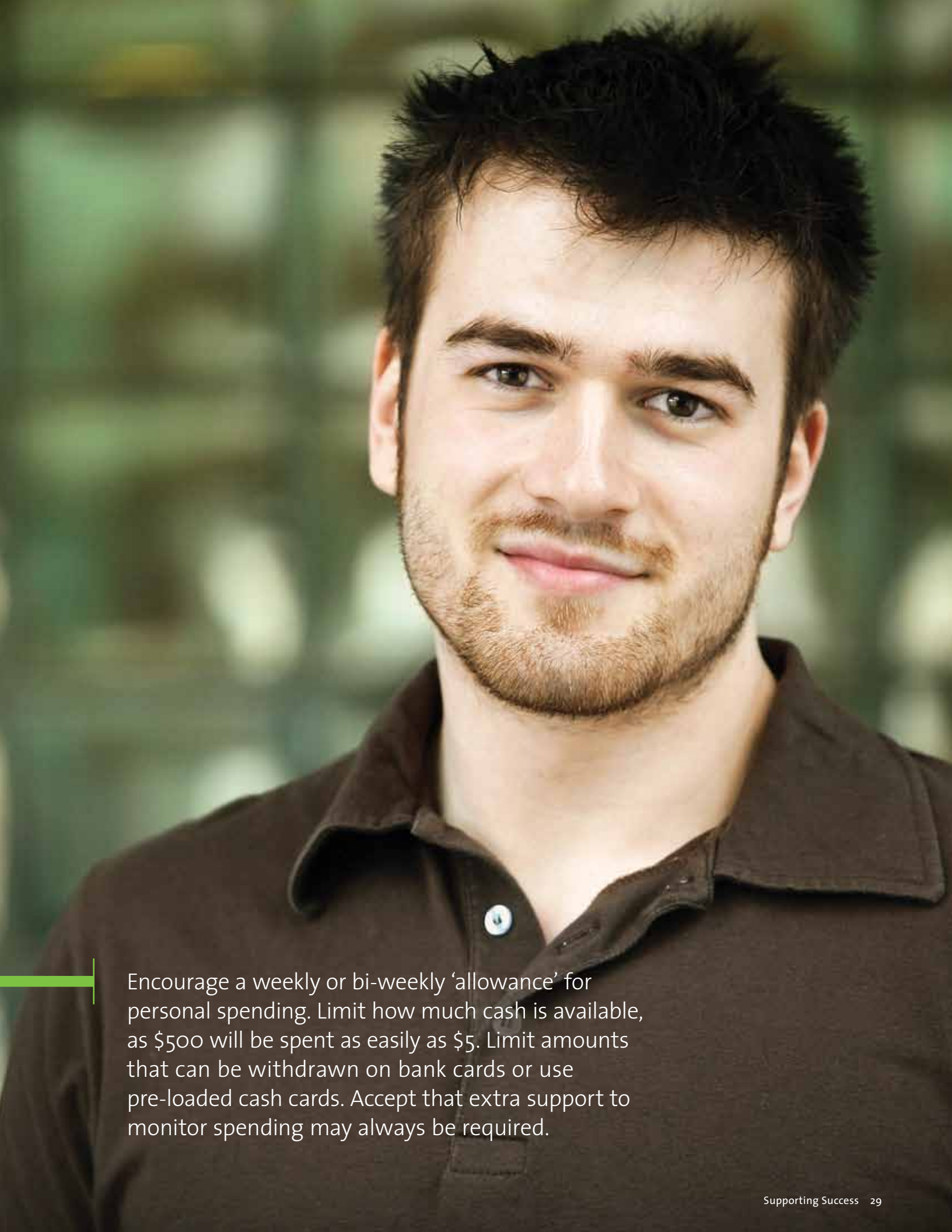
People with FASD often have difficulty with abstract concepts. Money is a very abstract concept and must be made concrete to support success. Some individuals are also very generous, spontaneous and impulsive. Preventing problems is the art. Some ideas that may work include:

- Support the person to be part of budgeting and tracking spending. Generate goals for saving and support the individual to understand the process towards achieving their goals. Use simple presentations e.g. diagrams.
- Find a bank plan that has low or no monthly fees and a savings plan that delays money transfers into the chequing account until the next day to prevent the account being overdrawn.
- Establish support to manage money. Helping the individual to develop a Representation Agreement to designate a trusted advisor to assist with minor financial affairs is a possible safeguard.
- Arrange for rent, phone, and utilities to be paid directly. Find creative ways to monitor bank accounts to ensure that shortages don't occur.
- Shop at the same stores regularly. Make up lists with items matching the layout of the store. Shop when it isn't too busy.
- Consider buying healthy frozen foods and items that are easy to prepare. Poor nutrition is a frequent problem and while the individual may be able to talk about nutrition, follow through is not always successful. Regular physicals are needed to check for high cholesterol, diabetes, etc.
- Link the grocery list with weekly menu planning so that purchasing and meal preparation are connected.

Shopping and Meal Preparation

The compromised executive function in the brain of a person with FASD results in difficulties with remembering, planning, initiating and organizing. He or she likely does not easily understand the link between cause and effect—for example that foods requiring refrigeration will go bad if you leave them on the counter. The over-stimulating environments of many stores can also be challenging. Here are some suggestions that may work:

- Shop at the same times and days each week. Break down the process into smaller tasks e.g. using the carts that require money, sticking to the grocery list, putting items away after shopping. Provide support and company to complete tasks successfully.
- Encourage regular routines in meal choices. Support the individual to participate in meal planning and preparation, choosing selections that maximize success and reflect their tastes and preferences. Preparing meals with the person creates opportunities for teaching and reinforcing important skills e.g. washing hands before touching food.
- Assist the person to check the expiration dates on all foods.
- Microwaves are easier to learn to use than stoves and much safer. Purchase only dishes without metallic rims.
- Package and label leftovers in meal size portions with instructions for reheating on each package.
- Purchase foods that use pictures to support success in following instructions.
- Regularly check the fridge, freezer, and cupboards to ensure food has not spoiled.



Encourage a weekly or bi-weekly 'allowance' for personal spending. Limit how much cash is available, as \$500 will be spent as easily as \$5. Limit amounts that can be withdrawn on bank cards or use pre-loaded cash cards. Accept that extra support to monitor spending may always be required.



Start simple, keep it simple, and add to the routine as the person is able. Make the focus of support successful and respectful interdependence, rather than expecting independence.



House Maintenance

When considering the “fit” between the person and the environment, spend time listing all the things the person is expected to do, and then simplify, simplify, simplify. **Start simple, keep it simple, and add to the routine as the person is able.** Make the focus of support **successful and respectful interdependence**, rather than expecting independence. Here are some suggestions that may work:

- Work together to establish routines for cleaning e.g. bathrooms every Monday.
- Work alongside the person to reinforce skills and success.
- Break tasks into small steps and use picture cues when appropriate e.g. photos of laundry sorted into lights and darks with steps illustrated for the process.
- Some individuals are reluctant to throw anything out, including food, which results in serious problems with mice, ants, bedbugs, etc. Accept and address this as a necessary and preventative health issue. A mentor or care provider may be able to assist them in cleaning. If possible, paying for a house cleaner every 2 weeks will help ensure a healthy, clean home and lessen the number of times the person loses their housing.
- Use unscented products to minimize sensitivities.
- Provide assistance with a deep spring and fall cleaning to compensate for the difficulties individuals have in making choices about what to dispose of, and to prevent the build-up of clutter.
- Ensure that the person’s living situation provides support and/or supervision to prevent injury. The individual may not be able to problem solve an appropriate or safe response in the event of a fire or smoke alarm going off.

Time and Schedules

Like money, time is an abstract concept. It must be made concrete through specific accommodations and supports to promote success for the individual with FASD. Be aware of fatigue, and work to structure the day to prevent exhaustion. Here are some suggested accommodations:

- Relate time to relevant routines e.g. waking up, going to bed, favourite television shows, days the person goes to work.
- Buy inexpensive digital watches that can be easily replaced.
- Review the next day’s activities and schedule the night before to assist with preparation and readiness. Use text messages, cell phone/watch alarms, email and other technology to provide cues and reminders.
- Use day books and written schedules to assist with memory.

Work Life

As with any physical disability, creating a good fit between ability and environment is the key to success. Some jobs may work for some, not for others. Success in finding and keeping work requires clarifying this fit and providing appropriate accommodations specific to the job situation. **Keep in mind that fatigue will be a factor.** The person cannot change, however job requirements can be modified to support success. Here are some considerations that may assist with creative accommodations:

- Spend time with the individual considering abilities, interests and aptitudes. Look for concrete applications of skills and work sites with opportunities for regular breaks or modified work to reflect health, distractibility, and fatigue levels. Emphasize opportunities that will offer success and build self-esteem. Match the person with the job. Jobs with uniforms or dress codes can be very successful because they provide discrete external cueing regarding appearance.
- Look for volunteer situations or jobs with trial periods that provide opportunities to learn about different jobs and to observe the person's responses to stress and task management.
- Look for jobs that emphasize routine and tasks with few judgement calls.
- Look for jobs with regular hours on the same days to reinforce consistency and routine. Part time work is typically most successful for many individuals. Look for jobs and employers where starting times can be flexible.
- Be very cautious with stimulating environments. For example, fast food restaurants may be too noisy and busy for some individuals. These environments can lead to anxiety and frustration.
- Increase the capacity to maintain attention to the job by shutting out distracting sounds. If possible, use headphones which screen out extra noise or if the person enjoys it, play relaxing music.
- Provide job site coaching and support the individual with concrete, defined directions. Individuals with FASD succeed when they can work alongside someone who can provide natural cues and positive reinforcement to stay on task. Be available for support if issues arise.
- Provide multiple demonstrations of how to complete the task. **Recognize that the individual may always require some assistance to succeed at work.**
- Look for support people who are interested in ensuring the success of the individual and who can help with transitions and anxiety. Identify one or two "go to" people on the job site who can advocate and support the individual, and answer questions.
- Provide initial and ongoing information on FASD to employers and co-workers to encourage support and understanding in the workplace. If necessary, agree on accommodations with the employer to support success. These could include more frequent breaks, a quiet area to rejuvenate in, etc.
- Ensure sufficient rest to manage the recovery from the day's demands and exertions.



Extra support makes the difference...

Robert recently secured part time employment at a grocery store. His duties include sweeping, getting carts from the parking lot, and helping to bag groceries. He is well liked by customers and staff due to his friendly and helpful nature.

It soon became obvious that Robert became overwhelmed and frustrated if someone asked him to bag groceries when he was already sweeping or doing something else. This was affecting his success at work. His support worker realized that his brain could not accomplish the transition between tasks, and worked with the employer to accommodate his needs.

Robert's job has been modified to support him completing one task at a time. His co-workers have learned what accommodations are helpful and actively support him to manage the transitions between duties with less frustration.



Look for jobs with regular hours on the same days to reinforce consistency and routine. Part time work is typically most successful for many individuals. Look for jobs and employers where starting times can be flexible.



Relationships and Community Involvement

A good life is rich with meaningful relationships and opportunities to socialize and contribute.

These elements of adulthood contribute to positive self-esteem and help build informal safeguards through the networks of interaction they provide. **For people with FASD, there is often a large gap between what it seems the person can do (as indicated by what they say), and their actual understanding or application.** For example, a person may be able to state a rule, and state the consequences of breaking that rule, yet break it anyway. Longer processing times inhibit understanding of cause and effect and present challenges in generalizing concepts to their own situation(s).



Here are some general suggestions that may support success:

- Make sure all the people supporting the individual are reinforcing the same ideas. As much as possible, everyone should be coached about best practices and required accommodations for the unique learning needs of the person.
- Assist the person to participate in the ordinary activities of day-to-day living in their home and community e.g. gardening, volunteering, and other leisure pursuits. Individuals with FASD are often extremely successful and motivated when helping others, and benefit from the positive imaging these roles provide.
- Build peer support to assist with participation in community activities.
- Provide support for transitions. Initiate new activities in steps to support success and confidence.
- Assist with interpersonal interactions. Practice for all types of social interactions and in natural environments where the skills are actually used. Individuals with FASD can often be quite impulsive both in their actions and their statements. They often cannot filter what's on their mind with what they say. Monitor both what is said and done and accept that this kind of support will be required throughout adulthood.
- Promote good role models among friends and peers to avoid exploitation and vulnerability; either of the individual or of others.
- Avoid “down time” as it invites problems. Individuals will naturally seek out others to be with, so it is essential to support healthy lifestyles and assist them to keep busy in positive activities.

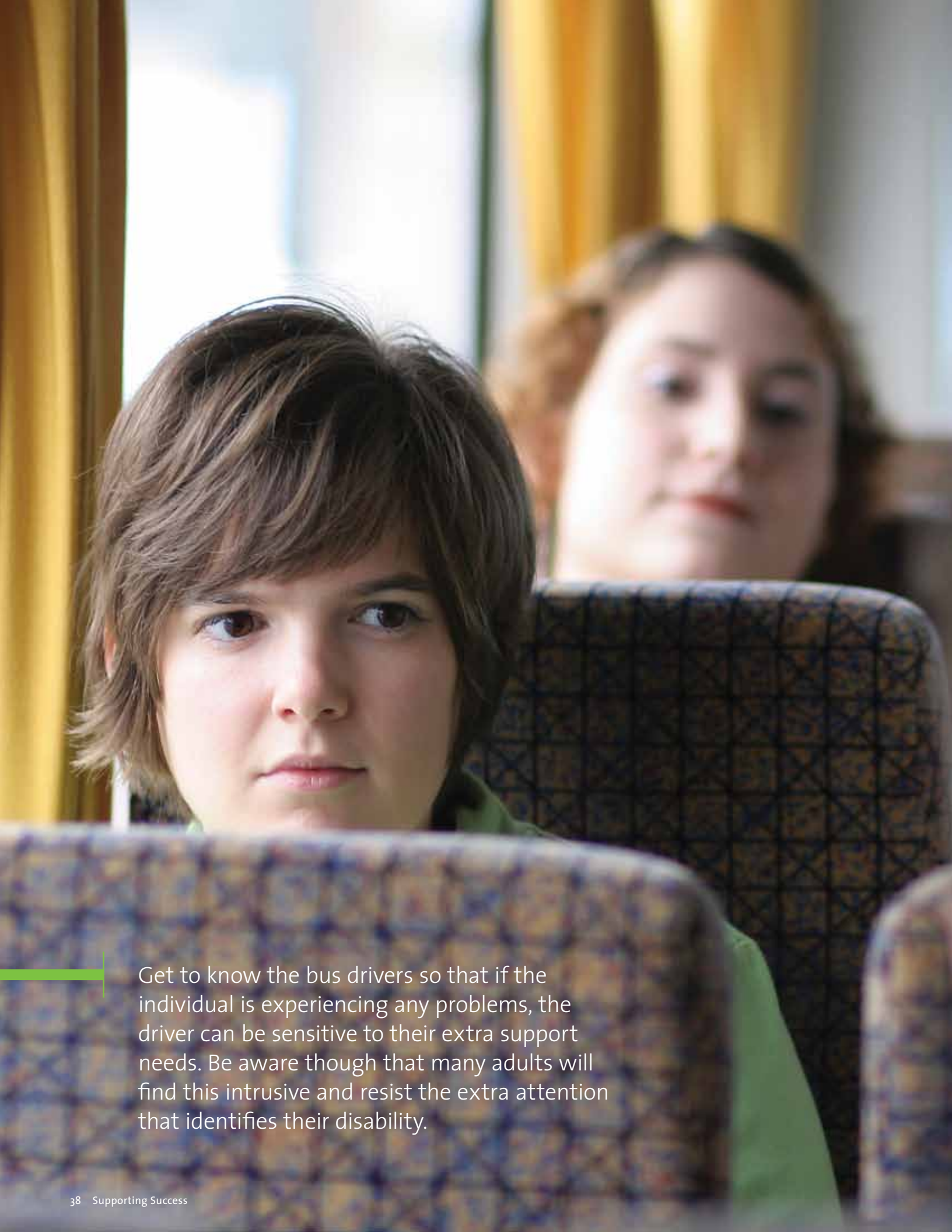
Social Relationships

Social skills based on the **developmental level** of the person are learned by teaching, guidance and on-going support. Do not assume that the individual will figure them out on their own. Social skills are essential to success in work, school, and the community. Individuals with FASD are generally very social people. However they will typically require support to explore this attribute successfully. **Educating others about the developmental level of functioning of the person is important for social success.** Here are some suggestions to support social relationships:

- Teach the basics like: how to phone someone and invite them for coffee; how to try to ignore someone who is bothering you; successful ways to handle anger; what to do when you are scared or confused; how to get a storekeeper's attention in an appropriate way, etc.
- Be conscious of role modelling appropriate behaviours at all times.
- Set firm expectations to support and guide the individual. For instance, no alcohol or drugs at all is best. Interacting with other adults will involve negotiating the issues of alcohol or drugs. Teach simple strategies and scripts, such as *We don't drink alcohol at my house.*
- Teach ways to identify friends and non-friends and how to keep safe in complex or stressful situations that might involve peer pressure. Wanting to please others can be dangerous for someone who has difficulty making good judgements. Provide support if possible in these circumstances.
- Be proactive talking about birth control. With a woman, actively support her to decide which method is best for her and provide the appropriate supports to ensure it works. This could mean ensuring that her pill is taken each day or providing support to go to her doctor for her shots. For men, provide direct, concrete language about using condoms. Teach about STDs such as AIDS. Intimacy, including sex, is a human need. The people we support will find companions somehow. It is essential that support is offered that both respects the need for relationships and addresses safety and health.



Teach who to seek out if lost or confused while alone in the community. Identify key kinds of safe individuals (e.g. police officers, security personnel) and reinforce, reinforce, reinforce this information.



Get to know the bus drivers so that if the individual is experiencing any problems, the driver can be sensitive to their extra support needs. Be aware though that many adults will find this intrusive and resist the extra attention that identifies their disability.



Transportation

Difficulties with remembering, planning and organization present challenges for people with FASD getting around the community and home again. Their lack of judgement also means they may not recognize socially unsafe situations and require extra safeguards. Here are some suggestions that may help:

- Provide support to the individual in learning how to use public transportation. This will involve repeated practice to learn the routes and times. Laminated cards with directions for specific bus routes and landmarks may prove helpful.
- Use the same route each time for each location.
- Get to know the bus drivers so that if the individual is experiencing any problems, the driver can be sensitive to their extra support needs. Be aware though that many adults will find this intrusive and resist the extra attention that identifies their disability.
- Pre-arrange rides at night to reduce vulnerability at public bus stops. Depending upon the individual's level of vulnerability, using a service like Handi-dart can provide a safeguard for transportation in and around the community.

Safety in Community

Individuals with FASD generally have a hard time managing free time. They are easily exploited and victimized and can also victimize others. Helping the person to keep themselves busy and active doing positive things that they like and are good at is key. **Unsupervised, unstructured and unscheduled time is asking for trouble.** Here are some suggestions that may help:

- Arrange and organize successful social experiences to help avoid the need to screen friends for appropriate role models and activities.
- At community events, use support from friends and others to monitor the individual's whereabouts. Establish a meeting place if lost and use the same one all the time if possible.
- Teach who to seek out if lost or confused while alone in the community. Identify key kinds of safe individuals (e.g. police officers, security personnel) and reinforce, reinforce, reinforce this information. Identify a "go to" person if there is any problem and make it situation-specific, e.g. who to go to at the mall.
- Practice how to keep safe and ways to support that. Use a cell phone with a primary number to use in the event of a problem. Identify a "go-to" person to call and have their number pre-programmed into the phone.



In Conclusion

Supporting adults with FASD as neighbours, employees, volunteers, and friends in our communities begins with knowledge and understanding about this brain-based disability. Successful support involves “trying differently, not harder” and focussing on success, dignity, self-esteem, and creativity.

In most ways, adults with FASD share the same basic needs and desires we all do:

- To make a difference
- To be cared about
- To be heard and understood
- To contribute to their communities

If these basic needs are not met, adults with FASD experience frustration, isolation, increased vulnerability, and failure. So too will their families and support persons. We believe that our communities are stronger when all citizens are well supported.

CLBC is committed to building awareness and acceptance of how citizens with disabilities can contribute to our communities. We hope you have found the information included in this resource booklet helpful and that you will continue to explore successful ways to support good lives for individuals with FASD.

Written Resources

Boyle Street Education Centre & Olszewska, A. (2007). So You Have Been Diagnosed with FASD. Now What?: A Handbook of Hopeful Strategies for Youth and Young Adults. Free PDF available at www.bsec.ab.ca

Graefe, S. (2006). Living with FASD: A Guide for Parents. Vancouver, B.C.: Groundwork Press.

Malbin, D. (2002). Trying Differently Rather than Harder. (2nd edition). Portland, Oregon: Tectrice.

Mitchell, Kathleen T. (2002). Fetal Alcohol Syndrome: Practical Suggestions and Support for Families and Caregivers. Washington, D.C.: National Organization on Fetal Alcohol Syndrome.

Rutman, D., LaBerge, C., & Whewey, D. (2005). Parenting with FASD: Challenges, Strategies and Supports. Victoria, B.C., Canada: University of Victoria and FAS/E Support Network of B.C.

Streissguth, A. (1997). Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore: Paul H. Brookes Publishing Co.

Trudeau, D. (2005). Trying Differently: A Guide for Daily Living and Working with FASDs and other Brain Differences. Whitehorse, Yukon: FASSY.

Web-based Resources

The Asante Centre for FASD
www.asantecentre.org

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

FASCETS, Inc. (Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc.) www.fascets.org

FASD Connections: Serving Adolescents and Adults with FASD www.fasdconnections.ca

NOFAS (National Organization on Fetal Alcohol Syndrome)
www.nofas.org

Whitecrow Village FASD Society
www.whitecrowvillage.org

Endnotes

ⁱ Streissguth, A. (1997). Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore: Paul H. Brookes Publishing Co

ⁱⁱ Adapted from FASCETS, Inc. & Malbin, D., 2002, 2007 & FASSY, 2005

ⁱⁱⁱ Malbin, D. (2002). Trying Differently Rather than Harder. (2nd edition). Portland, Oregon: Tectrice.

^{iv} Ibid.

Contact us and find out more.



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