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Supporting Success for Adults with Fetal Alcohol Spectrum Disorder

NOFASD Australia acknowledges and pays respect to the past, present, and future Traditional Custodians and Elders of this Nation and the continuation of cultural, spiritual, and educational practices of Aboriginal and Torres Strait Islander peoples

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Introduction

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 and other brain-based conditions is having successful relationships and living in communities that are informed, accepting, and supportive.

NOFASD Australia's vision is one of supportive inclusion in which people with neuro-developmental disabilities lead engaged, healthy, happy 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 community members.

NOFASD Australia is committed to raising awareness and education of the prevalence of FASD in Australia; by assisting the support of individuals living with FASD, and those who interact with them in the community, and within the wider context of prevention of prenatal alcohol harm.

Welcoming a New Strategy

Australia's National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028 provides a clear pathway of priorities and opportunities to improve the prevention, diagnosis, support, and management of FASD in Australia. The plan aims to reduce the prevalence of FASD and the impact it has on individuals, families, carers, and communities.

NOFASD Australia aims to continue being a strong and effective voice for individuals and families living with FASD, by providing education and training, and supporting initiatives across Australia to promote prevention, diagnosis, intervention, and management.

About this Resource

This booklet offers an introduction to Fetal Alcohol Spectrum Disorder and suggested accommodations to assist in supporting individuals living with FASD. It is intended as a starting guide for all 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 set of skills and barriers, history, and situation; and that interventions 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. Each individual has specific needs but will have difficulties receiving, processing, and responding to information and stimuli. Successful support recognises 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 further resources and websites that may also be helpful along that journey.

Introduction



Historically, many adults with Fetal Alcohol Spectrum Disorder (FASD) have not had the appropriate understanding or supports throughout their lives leading to significant barriers to successful community participation.

This is, in part, 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: working with their strengths, interdependently. However, without identification and appropriate supports, there is often a sad trajectory of failure, loss, and confusion. This can often result in multiple placements and in secondary defensive behaviours that lead to involvement with the justice system and multiple mental health diagnoses.

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 modify our expectations of the person, and therefore our actions and reactions.

We can then 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 and sensory needs of the person, in order to craft appropriate accommodations and individualised supports in response to these needs.

Although it is important to acknowledge that similarities in behaviour, learning 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 yet learning about the individual is essential to creating successful supports and respectful relationships.

FASD is an invisible disability where a person lives with significant and permanent brain differences, most often evidenced in their behaviour.

As a result, expectations are often much higher than what is reasonable given the person’s brain differences.

The key for individuals to successfully live in the community is the presence of appropriately tailored and respectful accommodations and supports.

Understanding FASD

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 is largely invisible, too often inviting unreasonable expectations of the person's capacity. Stigma and harmful biases, act as a barrier to early identification and treatment, which are both important for positive long term outcomes. It is important to realise that the science is clear: FASD does not discriminate, it impacts generations and is found in all communities where alcohol is consumed.

Understanding FASD

Meet the FASD Brain

Meet the FASD Brain

Typical brain development is complex.

In a typical brain, the fundamental structure supports learning, storage of information, and the linkages that allow: generalisation, abstract thinking, and reasoning, and assist with organisation, sequencing, and evaluation.

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 generalise
- 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.

Neurological differences often appear as:

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

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.

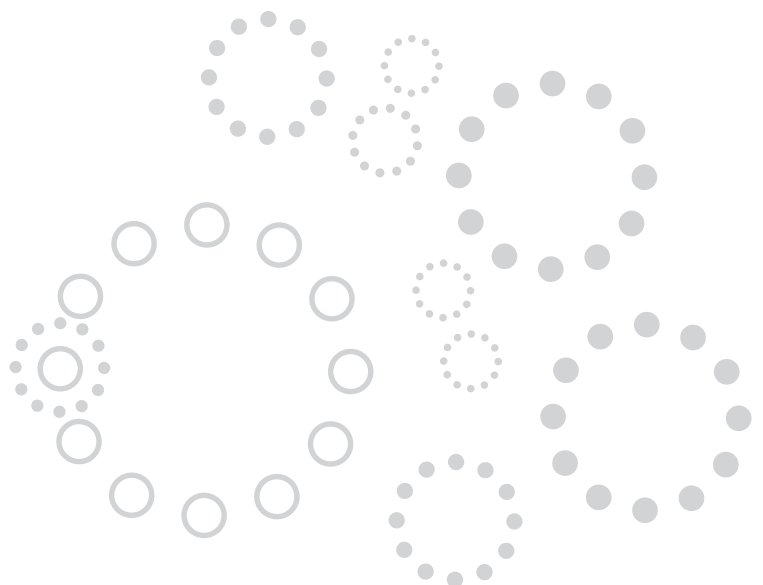
The energy consumed by the brain of someone with FASD can result in exhaustion by the end of the day.

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.

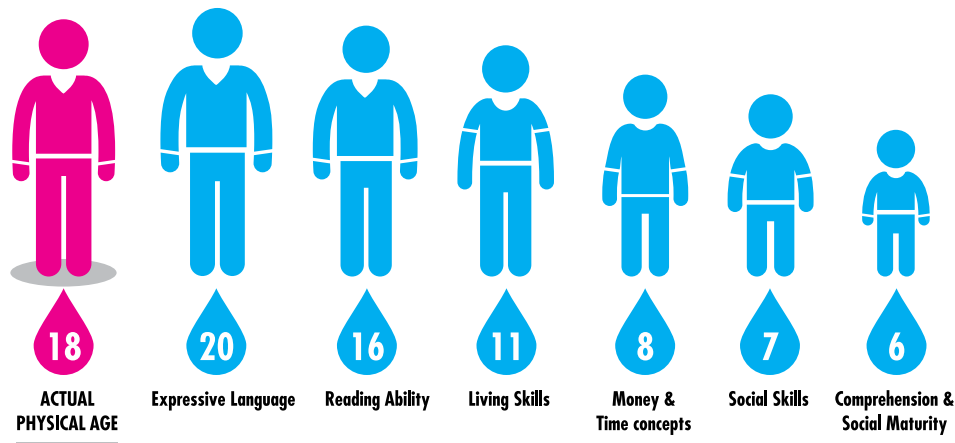
Emotional exhaustion may occur at a different rate than physical exhaustion, resulting in confusing responses by the person, such as: needing physical exercise but being unable to handle any more emotional activity.

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 emphasises partnership and dignity through individualised accommodations.



Common Developmental Profile



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.

Brain development occurs throughout pregnancy, and 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. As does potential exposure to other drugs in addition to alcohol, which is not uncommon.

Around 50% of pregnancies are unplanned; pre-natal exposure to alcohol can and does often happen before a woman is aware of her pregnancy.

Alcohol can also affect the development of other parts of the body and contribute to chronic health issues.

While some persons have facial characteristics (in particular), that distinguish the timing of their exposure to alcohol, most do not.

As 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, and so they are often punished for symptoms of their invisible physical disability, adding to the frustration and confusion of the person living with FASD.

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, the recognition of the nature of the condition and the provision of appropriate accommodations based on an individual's strengths and interests, support people with FASD to live full, happy lives as contributing members of their communities.

Common Developmental Profile

Primary Characteristics of Brain Differences

Primary behaviours most clearly reflect underlying brain dysfunction. They include learning, developmental, sensory, and other neurobehavioural symptoms which 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 some of 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 generalisations
- 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 heightened risk for victimisation and exploitation
- Difficulty managing time, money, and schedules
- Dysmaturity (wide variation between developmental and chronological age)

Individuals with FASD will live with the effects of prenatal exposure for their entire lives and may therefore always require some assistance to participate in the community, and have healthy, meaningful connections.

Alcohol kills developing cells.

When alcohol is consumed during pregnancy, the brain is significantly compromised, smaller, and may have lesions as well as differences in structure.

This damage results in the behavioural, learning, and other neurobehavioural 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 previous page shows a common developmental profile for a person with FASD. It shows an 18 year old who has the living skills of an 11 year old and the social skills of a 7 year old and so on. Notice that they also have the expressive language of a 20 year old... Many people with FASD are very gregarious and talkative.

A key characteristic of FASD is an uneven neuro-psychological profile, which holds clues to the unique strengths and weaknesses of an individual with FASD.

The person in this example may "talk a good talk" but may become overwhelmed, anxious, frustrated, angry and perhaps even meltdown (exhibiting behaviours in line with their developmental age) when unable to meet the expectations of their environment.

Be careful of assumptions

The assumption here is that this person is a bright 18 year old, due to their 20 year old expressive language. Expectations will match that assumption... but that is not the whole story of this person:

What would you expect of an 11 year old? of a 7 year old? Would you be more patient? How would your emotions, language, and tone change? Would you assist them in problem solving? Adjust accordingly...

While the damage from exposure to alcohol is permanent, the brain continues to change throughout life and so abilities and behaviours may also change, yet some may not.



Common Developmental Profile

Secondary Characteristics of Brain Differences



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 their 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.

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 aggrandisement

Given that the brain of an individual with FASD functions differently due to prenatal exposure to alcohol, descriptions of behaviour must be

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

recognised as indicators of this difference.

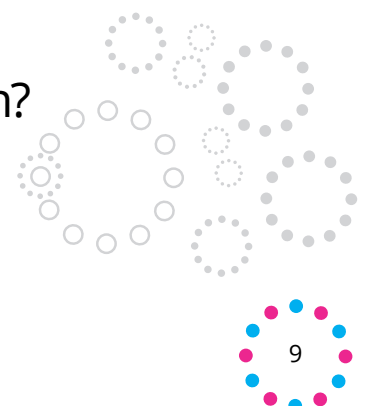
Often behaviours are misinterpreted as wilful, intentional, or manipulative and the result of emotional problems. Thus, interventions focus on changing the behaviours.

It is important to recognise that behaviours are the result of primary differences in the brain and secondary defensive symptoms indicating where there is a poor fit.

Interventions should focus on changing the environment with effective supports to enhance the potential for success, decrease frustration and maximise creative support options.

If the individual with FASD also lives with mental health challenges, the neurological differences of the individual must be taken into consideration to ensure suitable treatment options. Individuals with FASD are each unique in their functioning as a result of the brain differences caused by prenatal alcohol exposure. In order to secure positive outcomes, we must ask:

Who is this person?



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, service providers, and from research.

The following 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 recognising strengths and mitigating weaknesses in partnership with respectful, individualised supports, allowing each person to participate in the world around them. It is about focusing on a person's strengths and compensating for their brain differences.
- 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 recognise this vulnerability, are based on individualised planning, and provide safeguards to assist people with decision making and building inter-dependent lives.

- 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 such as safety, recreation, employment, and stable relationships – are as important as support to manage tasks like dish washing 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 include 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 the person's interests, identified needs, family members and community contacts.

Supporting an individual with FASD requires a different perspective and accommodations that emphasise “trying differently, not harder” to compensate for their brain differences.

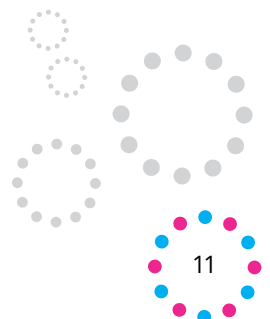
Diane Malbin

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 organises the environment and reduces 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 detrimental 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 which is impaired in FASD. 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 unwanted and/or inappropriate behaviours, reduce anxiety, maximise success, and support transitions. For others, limited notice is preferable in order to reduce distress and anticipatory anxiety. Always ask yourself – Who is this 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

Build on Gifts / Stay Curious

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

This section offers some important ways to think when creating FASD 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 recognise 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, individuals with FASD often have success with hands-on tasks and benefit from concrete, experiential learning situations and visual cues. They often work well alongside another person who is positive and who offers cueing and encouragement 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?

Positive outcomes and success are built on staying curious about the person and building a relationship of trust that is about working “with” the person, rather than “at” them

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.



Creating Environments that Support Success

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, particularly if stressors and fatigue are present.

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, emphasising specifically what is required. e.g., "Meet me at the front desk of the college at 5pm." Suggesting you meet "around 5 in the college lobby" does not provide specific enough information and is too vague.
- 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.
- Avoid conditional words such as however, instead of, provided that, probably or likely.
- 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.
- Limit choices. Too many choices may cause confusion about what to do. For example, say:
 - "I will give you a ride into town.
 - Be ready by 8 am and we will leave then." Avoid saying "How about a ride tomorrow? Say 8 am?"

Strike a balance between honouring the person's adulthood and creating safety in a way that avoids power struggles.

Use language choices that reflect the developmental age of the person, and conditions on the day, 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.

- Support the individual to put their feelings into words. Ask the person to identify where they feel discomfort, e.g. "Does your head hurt?" Assist the person to identify the feeling in the location and then - what to do about it - such as: 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."
- 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.



Creating Environments that Support Success

Environment Makes a Difference & Safeguards are Important

Environment Makes a Difference

Difficulty with executive functioning make it hard for a person with FASD to prioritise, clarify, organise, 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.

NOFASD recognises that formal safeguards are important to ensure the safety and wellbeing of individuals with FASD, but we know that formal safeguards are not 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 and neighbours
- Community connections outside the service system
- Social connections and networks through clubs or volunteering



Creating Environments that Support Success

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 positive outcomes and enriching relationships.



A good life in community for a person living with FASD must include structured supports as well as 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. This understanding is the cornerstone for acceptance and allows for the flexibility to “try differently, not harder”.

Managing FASD brain differences in this way is essential for positive outcomes.

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 success, and that individuals are able to contribute in meaningful ways, having a sense of achievement and belonging in an interdependent community.

Life's Daily Routines

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

Structure emphasises 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.

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 safety and predictability and supports routine and retention. For example, scheduling appointments with service providers and other supports 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. Avoid making schedules too overwhelming. Organise lists and schedules in simple order, to reduce the potential for the person to be overwhelmed.

Sometimes certain strategies will work for a while 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 the person, how FASD impacts them, and what works for them.

- 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. Assist the person to provide a concrete reference for themselves that works for them, such as taking photos.
- 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 mobile phones, tablets, 2-way radios, and other technology to support safety, give reminders, and assist with routines. Mobile phone alarms, apps and texting can be used for 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.

Life's Daily Routines

Coach Slowly

Check for understanding frequently

- 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 for the task being asked of them? What accommodations would be provided for an adolescent performing that task? Adjust your expectations based on the person. However always acknowledge and treat the individual as an adult.
- Break down tasks into small steps. Reinforce learning by mentoring and modelling how the task is to be done successfully. The steps may need to be taught and re-taught in order for learning and retention 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.



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?"



Life's Daily Routines

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.

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

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.

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 and able 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.





Life's Daily Routines

Sleep & Self Care

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., that 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. Emphasise 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 have an impact on the entire day. Provide assistance with ensuring the person has clean clothing, packing lunches, and organising 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 community through friendships, work, and activities, 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 work later in the afternoon and evening.

Self-Care

People with FASD often have difficulty remembering regular routines, making plans, and organising themselves. They may also have sensitivities to the feel, to the taste or to the 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 are not required.
- Encourage the use of toothpaste, floss, and deodorant. Be specific about how often and long to brush e.g., "Brush your teeth two times a day for two minutes each time." Electric toothbrushes with timers are a useful support for this. Poor dental hygiene is often a significant health issue which is heightened because it 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.
- For some, it may be helpful to 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. Colour coding clothing on hangers to help with selection and appropriate outfit choices may be helpful for some. Other individuals may find this too controlling and object.
- Medications may need to be packaged by the pharmacy to ensure they are taken daily.

Life's Daily Routines

Money and Budgeting / Shopping and Meal Preparation

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 decisions and in 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 help develop a savings plan that sequesters savings (e.g., having a savings account automatically added to, that is not linked to a debit card).
- 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 do not occur, and individuals stay on track with their goals.

[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.](#)

[Establish limits on 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.](#)

Shopping and Meal Preparation

The compromised executive function in the brain of a person with FASD results in difficulties with remembering, planning, initiating, and organising. They likely are not easily aware of the link between cause and effect — e.g., that foods requiring refrigeration will go bad if you leave them on the counter. It may simply not enter the person's awareness. The over-stimulating environments of many stores can also be very 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., sticking to the grocery list, putting items away after shopping. Provide support and company to complete tasks successfully.
- Shop at the same stores regularly. Create lists with items matching the layout of the store.
- Shop when it isn't too busy. Some stores have "quiet hours" to cater to individuals with sensory issues.
- 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. Some individuals will always need assistance with healthy eating. 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.
- Encourage regular routines in meal choices. Support the individual to participate in meal planning and preparation, choosing selections that maximise success and reflect their tastes, preferences, and abilities. 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

Life's Daily Routines

House Maintenance / Time and Schedules

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.

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:

- Work together to establish routines for cleaning e.g., bathrooms every Monday. Be mindful of the individuals sensory issues and provide supports.
- Work alongside the person to reinforce skills and success.
- Break tasks into small steps and use supports when appropriate e.g., laundry baskets with dividers to sort laundry into lights and darks.
- 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 with cleaning.
- If possible, paying for a house cleaner and/or maintenance person regularly will help ensure

a healthy, clean home and help the individual with FASD retain their housing.

- Use unscented products to minimise sensitivities. Be mindful that the person may not be able to identify a sensory trigger, the clue will be in their behaviour.
- 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 suggestions:

- Relate time to relevant routines e.g., waking up, going to bed, favourite t.v. shows, days the person goes to work.
- Digital watches can be programmed with alarms and reminders and some can help monitor physical activity.
- Review the next day’s activities and schedule the night before to assist with preparation and readiness.
- Use text messages, mobile phone/watch alarms, email, and other technology to provide cues and reminders.
- Use day books and written schedules to assist with memory.

Life's Daily Routines

Work Life



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.

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:

- Emphasise 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 for some 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 emphasise 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, e.g., 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. Recognise 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.

Spend time with the individual considering abilities, interests, and aptitudes. Look for concrete applications of skills, and work opportunities with options for regular breaks, or modified work, to reflect health, distractibility, and fatigue.

Life's Daily Routines

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 realised 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 in 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 learn, socialise and participate. 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 how they speak), and their actual capacity to understand or execute a task. For example, a person:

- may be able to state a rule, and state the consequences of breaking that rule, yet break it anyway; or
- may want to do something, talk about how to do it, yet be unable to do (execute) it.

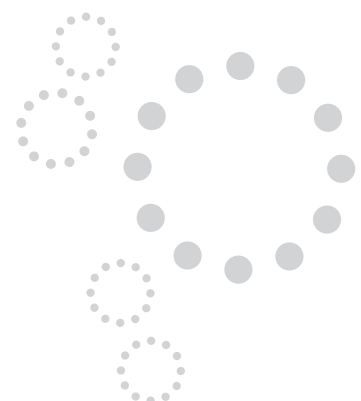
Longer processing times inhibit understanding of cause and effect and present challenges in generalising concepts to their own situations.

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 to support the unique needs of the person living with FASD.
- 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 and provide mentoring to assist with participation in community activities. Repetition is key.
- 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, 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 is 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.
- Individuals may frequently require rest and recovery time from environmental stimuli however, best to avoid too much “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 with positive activities.





Relationships and Community Involvement

Social Relationships

A good life is rich with meaningful relationships and opportunities to learn, socialise and participate. These elements of adulthood contribute to positive self-esteem and help build informal safeguards through the networks of interaction they provide.

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 in the community; a person with FASD requires support to navigate these.

Individuals with FASD are generally very social people. However, they will typically require support to explore this attribute successfully.

Educating others about accommodations and supports, based on the developmental level of functioning of the person, is a key factor for social success.

Here are some suggestions to support social relationships:

- Teach and support the basics such as: how to phone someone and invite them for coffee; how to ignore someone who is bothering you; successful ways to handle anger; what to do when you are scared or confused; and how to get a shopkeeper's attention in a friendly and appropriate way, etc.
- Be conscious of mentoring and role modelling appropriate behaviours at all times.
- Set firm expectations to support and guide the person. For instance, "no alcohol or drugs at all is best". Interacting with other adults will involve negotiating the issues of alcohol or drugs. Help implement 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 and provide ongoing support.
 - 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.
 - with a man: provide direct, concrete language about using condoms and actively encourage and support their use.
- Teach about STDs such as herpes, chlamydia, and AIDS. Intimacy, including sex, is a human need. The people we support, will find companions, and it is essential that the support offered both respects the need for relationships, and addresses safety and health concerns.

Teach the person what to do, if lost or confused while alone in the community. Program phone numbers and help identify key kinds of safe individuals (e.g., police officers, security personnel), if possible, have emergency transport options (uber/taxi) and reinforce, reinforce, reinforce this information.

Relationships and Community Involvement

Transportation

Difficulties with remembering, planning, and organising present challenges for people with FASD as they get around the community. It is also possible that a lack of judgement leave them vulnerable, as they may not recognise socially unsafe situations and require safeguards.

Here are some suggestions that may help:

- Provide support to the individual to learn how to use public transportation. This will involve repeated practice to learn the routes and times. Laminated cards with directions or phone apps may prove helpful.
- Use the same route each time for each location. Provide encouragement and support to the person to become more familiar and comfortable with regular drivers.
- Pre-arrange rides at night to reduce vulnerability at public bus stops. Depending on the individual's abilities and level of vulnerability, using a service like Uber or Taxi vouchers can provide a safeguard for transportation in and around the community.

Accept that an individual living with FASD may require frequent repetition and that this is not something over which they have any control.

The impact of the person's brain differences is such that they may require support throughout their life, this will vary depending on the day and the stressors present.

Understanding this helps to address behaviours with respect, compassion, and effective strategies – providing better outcomes and quality of life.

Safety in Community

Individuals with FASD generally have a hard time managing free time. They are easily exploited and victimised and can also victimise 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:

- Arrange and organise successful social experiences to support the individual participating in the community and to help reduce 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 mobile 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.





Conclusion

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 focusing on success, dignity, self-esteem, and creativity.

In most ways, adults with FASD share the same basic needs and desires we all do: To live a life with meaning in a safe, supported environment, with opportunities to belong, participate and contribute in the community.

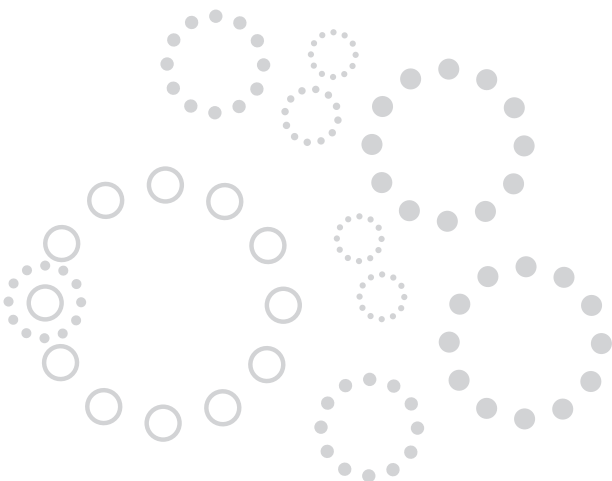
Individuals with FASD are affected by stressors differently than neurotypical individuals, and the consequences can be significant. As a result of their brain differences a person often lives much of their time in a state of high anxiety as they try to adapt to expectations in their environment; without an understanding of the impact of these brain differences, and the tailored supports and interventions needed to assist the person to negotiate their environment, the person too often faces a sad trajectory of frustration, loss, confusion and isolation; **it need not be so**: understanding the factors related to the person’s brain damage can help inform us of the supports and interventions needed to improve quality of life and have more successful outcomes.

NOFASD is committed to building awareness of the consequences of prenatal alcohol exposure in our communities; and to opportunities to improve the education, prevention, diagnosis, and support of Australians living with FASD.

We hope you have found the information included in this booklet helpful and that you will continue to explore successful ways to support good, healthy lives for individuals with FASD.

Contact us and find out more:

Call our free number: 1 800 860 613
Download our Free: FASD toolkit
or visit our website: www.NOFASD.org.au



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.*

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

Australian Web-Based Resources

- NOFASD
- FASD Hub
- FARE
- Telethon Kids
- FASD Research Australia
- Pregnant Pause

International Web-based Resources

- CanFASD
- Oregon Behaviour Consultation
- Cognitive Supports
- Asante Centre

Fascets.org - FASCETS, Inc. (Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc.)

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

Whitecrow Village FASD Society
www.whitecrowvillage.org



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Endnotes/References

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