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Fetal Alcohol Spectrum Disorders
Territory Families Induction
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Learning Outcomes
• Provide an introduction to FASD and consider the intersection with Complex Developmental Trauma
• Consider FASD in Child Protection and Youth Justice Services
➢Management and strategies in the justice space
➢Developing a FASD lens
• Explore Australian and global responses to FASD
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Why are we here?

- Children with FASD have high rates of mental illness and trauma due to neglect, abuse and inappropriate interventions.
- Behaviour and learning challenges are often addressed as only trauma or behaviour disorders; the disability is missed.
- Without interventions tailored to incorporate the areas of impairment and strengths, interventions fail. This contributes to further trauma and adverse outcomes.

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Why are we here?

- Lack of an appropriate judicial response to the disability makes them vulnerable to cycling in and out of the family and criminal justice system.
- Youth with FASD are 19 times more likely to be incarcerated than non-affect peers;
- High rates of false confessions; FASD affects as many as 30% of incarcerated adults; those adults had an average of 15 convictions as youth[6].

Once involved in the youth justice system, often the result of disordered behaviour, petty crimes, and or manipulation by others, individuals with FASD remain in the system.

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What is FASD?

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What is Fetal Alcohol Spectrum Disorder?

FASD is a lifelong disability caused by alcohol exposure in utero.

Key characteristics caused by brain impairments may include:
- impulsivity
- memory challenges
- slower processing
- difficulty with abstract thinking and predicting skills.

Secondary behavioural characteristics may include:
- fatigue
- the appearance of a lack of motivation
- depression and frustration that may lead to aggression.

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Who is at risk?

Prenatal alcohol exposure is a risk to babies from all cultures and socio-economic backgrounds……

…….wherever there is alcohol, there is the potential for FASD

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The History of terms used in Australian for FASD

- Fetal Alcohol Syndrome (FAS);
- Partial Fetal Alcohol Syndrome (PFAS) and
- Neurodevelopmental Disorder-Alcohol Exposed (ND-AE).

It is important to remember that facial features are considered rare, and many children may not display any obvious facial features

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Sentinel facial affects

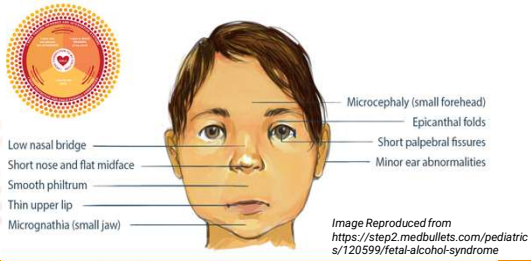

Image Reproduced from https://step2.medbullets.com/pediatrics/120599/fetal-alcohol-syndrome

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Diagnostic assessment

To assess an individual with prenatal alcohol exposure and/or suspected FASD, the following essential criteria must be considered:

1. Prenatal alcohol exposure and other exposures
2. Neurodevelopmental impairment
3. Facial and other physical features

Alternative diagnoses that might explain neuro developmental impairment MUST be excluded however, FASD may co-exist with other conditions.

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FASD Diagnosis

FETAL ALCOHOL SPECTRUM DISORDER		
Diagnostic criteria	Diagnostic categories	
	FASD with 3 Sentinel Facial Features	FASD with < 3 Sentinel Facial Features
Prenatal alcohol exposure	Confirmed or unknown	Confirmed
Neurodevelopmental domains - Brain structure/Neurology - Motor skills - Cognition - Language - Academic Achievement - Memory - Attention - Executive Function, including impulse control and hyperactivity - Affect Regulation - Adaptive Behaviour, Social Skills or Social Communication	Severe impairment in at least 3 neurodevelopmental domains	Severe impairment in at least 3 neurodevelopmental domains
Sentinel facial features - Short palpebral fissure - Smooth philtrum - Thin upper lip	Presence of 3 sentinel facial features	Presence of 0, 1 or 2 sentinel facial features

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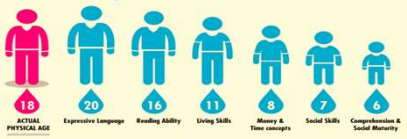
Dysmaturity



- A classic sign of FASD – individuals appear to be acting 6, 8, 16, and 20 all at the same time.
- An individual may have the language skills of a 20 year old but the social skills of a 7 year old.

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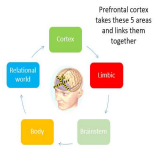
Broader Life and Health outcomes

- Life expectancy for people with FASD on average is 34 years
- 19% of deaths caused by mental health issues and completed suicide
- 92% of individuals living with FASD will have a co-occurring mental health issue. (Depression and suicidal ideation are most common)
- Young people with FASD are 19 times more likely to be incarcerated than those without FASD
- FASD is often misdiagnosed with ASD, ADHD, ODD and CD

(*Thanh & Jonsson, 2016*)



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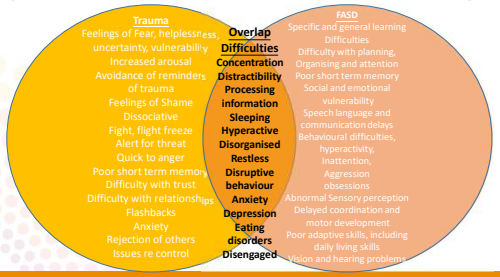
Symptoms of Trauma and FASD and areas of overlap



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Comparing ODD, ADHD and FASD

Dan Dubovsky - Comparing ODD, ADHD, and FASD

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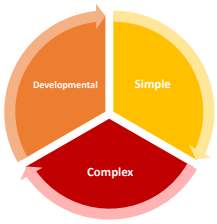
Defining trauma

Any single, ongoing or cumulative experience which:

- is a response to a perceived threat, usually to the level required for survival
- overwhelms our typical capacity to cope
- feels/is outside our control
- often evokes a physiological and psychological set of responses based on fear or avoidance



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Trauma and FASD….

"The trauma our communities have sustained has brought into being complex harms, of which FASD is one of the most damaging. With better understanding of trauma, we will overcome its harmful effects and 'Make FASD History' . We will allow our societal strengths to flourish again, as we confront, heal and put an end to all forms of harm caused by intergenerational trauma."

June Oscar AO, Aboriginal and Torres Strait Islander Social Justice Commissioner, 2017

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Trauma impacts

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Aboriginal culture and disability

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Trauma impacts

Trauma can impact all elements of children's development: brain, body, memory, learning, behaviour, emotions, relationships.

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FASD and 10 neuro-sequential development areas affected

1.Neuro-sequential development
- Cerebellum and Corpus Callosum

2.Fine and gross motor skills
3.Cognition/memory/Learning
4.Language
5.Attention
6.Prefrontal cortex executive function
- impulse control and hyperactivity

7.Affect regulation – emotional regulation and sensory processing
8.Adaptive behaviour – daily living skills,
9.Relationships/friendship-social skills and social communication
10.Physical development

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Hemispheric integration

Left Hemisphere
- Evaluates language content
- Optimistic hemisphere
- Understands beginning, middle and end
- Learns from the past and expects the future
- Looks for patterns

Right Hemisphere
- In the present moment
- Eye contact
- Facial expression
- Tone of voice
- Posture
- Gesture
- Intensity
- Is mute
- Grasps the whole

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FASD in Youth Justice Northern Territory

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What is currently happening in Youth Justice in the NT?

- Assessment when young people are detained…
- Court requested for Youth Court – using to inform sentencing
- Telehealth - PATCHES

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FASD in Youth Justice

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FASD in Youth Justice

Those with FASD benefit from education and therapy rather than the punishment provided by imprisonment. These alternative methods are particularly important because reasons for incarceration may be confusing to a person with FASD.

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CHAPTER 15 | Page 357 Royal Commission into the Protection and Detention of Children in the Northern Territory

- Recommendation 15.1 1. Amend regulation 57 of the Youth Justice Regulations (NT) so that comprehensive medical assessments can be delayed or postponed for a further 72 hours post admission but that an initial risk assessment occur within 24 hours of admission.

. an assessment of both physical and mental health, and …….

- 3 b. a behavioural questionnaire to determine whether a formal assessment for Fetal Alcohol Spectrum Disorder should be conducted, and if so determined and if the detainee has not previously been the subject of a formal assessment, that assessment to be conducted.
- https://alcoholpregnancy.telethonkids.org.au/our-research/fasd--justice/professional-development/

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Responding to young people with FASD

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Morgan Fawcet-living with FASD

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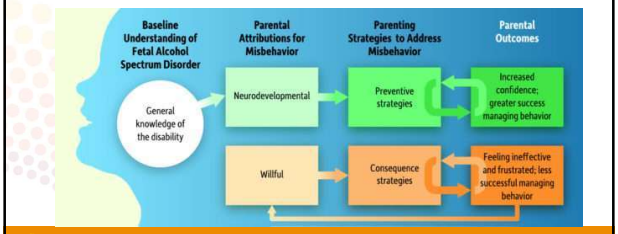
Responding to children with FASD's



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Considerations for your practice……

- Consider the environment and its fitness for the person with an FASD.
- Prevent problems instead of reacting to them.
- Think: could this be brain
- Discard judgements or negative thoughts about behaviors and try to see them differently.
- Think "can't" not "won't"
- Modify expectations.
- Focus on strengths

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How to help

Start with a clean slate: Don't have any assumptions as to why the person is behaving the way they are. There is a good chance you may be incorrect

Don't get Frustrated: Don't get frustrated that you just dealt with this same type of issue yesterday. It may seem like the same issue, but to the person it's likely a completely unique and unrelated crisis. It's not that they aren't paying attention; it's that their brain isn't letting them make the connection.

Remember nonverbals: Be extra attentive to your nonverbal and paraverbal communication. The person with FASD may not understand all the words you're using when they're going through a crisis, but they are likely tuned in to your appearance and sound.

Keep in mind the strong Precipitating Factors related to the person's brain damage as a result of prenatal alcohol exposure. It can help you maintain your Rational Detachment in a tough situation.

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Brainstorming accommodations- questions you may ask.

- What is the task or expectation the child is expected to do (and failing at/"refusing" to do)?
- What does the brain— anyone's brain— have to be able to do in order to successfully complete that task or meet that expectation?
- What do you know about how your child's brain functions in those areas? Do they have those skills?
- How old is your child developmentally (which might be different than their chronological age)?
- What are the secondary behaviours you see in this environment or with this specific situation?
- What are your child's strengths and interests?

Based on all the information gathered from the above questions, what accommodations need to be implemented to help this child be successful?

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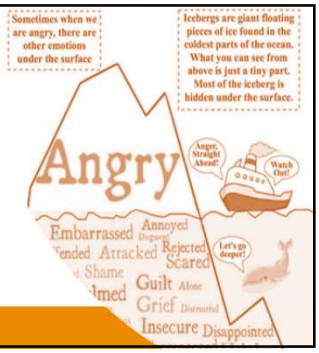
Behaviour – understanding and responding

- **Behaviour tells a story!**
- Behaviour = communication
- Every behaviour has a meaning
- Learning how to understand a child's behaviour is a more effective tool than memorizing a list of prescribed responses for common "challenging behaviours "
- We need to learn to ask "What is this behaviour telling me?" and be curious about what it might mean so that we can best respond



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Behind the behaviour

Behaviour: Saying "no" or refusing requests, asking the same question over and over, saying "huh?" or "what?" a lot, not acting when requests are made Not listening, ignoring, defiance, opposition, daydreaming.

Reason: Slow auditory processing

Response: Talk less. Slow down. Give time. Provide visuals, timetables and lists. Teach using hands-on and kinesthetic methods.

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Behind the behaviour

Behaviour: Socially and emotionally like a younger child, interest in activities similar to that of a younger person, unable to "act their age," overly friendly with people, misunderstanding personal boundaries. Immaturity, babyishness, laziness, irresponsibility, disregard for consequences, purposefully irritating, pushy.

Reason: Dysmaturity, or developmental delay. Poor adaptive functioning

Response: Recognize developmental age (vs. chronological) Adjust expectations to match developmental age. Provide opportunities for friendships/social situations that match person's developmental age vs. their chronological.

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Behind the behaviour

Behaviour: Aggression, anger, opposition, disrespect, depression. Over responsive to stimuli and under responsive to stimuli, often both in the same person, hyperactivity, distractibility, inattention, social difficulties, learning difficulties, emotional reactivity, clumsiness, and poor organizational skills. Irritability, opposition, "pickiness," manipulation, tantruming, rule breaking, anxiety, aggression, avoidance

Reason: Difficulty modulating emotions

Response: Look for triggers to prevent problems. Anxiety can look like anger or irritability. Allow breaks. Figure out what helps soothe and reset, and provide opportunities for this.. Sensory differences Look for triggers. Remove or avoid to prevent problems. Figure out what helps soothe and reset, and provide opportunities for this.

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Behind the behaviour

Behaviour: Difficulty waiting turn, difficulty complying with rules, interrupting, "see it-want it-take it," blurting, inappropriate language, risk taking Rudeness, opposition, lying, disrespect, danger seeking.

Reason: Impulsivity

Response: Provide structure and support. Understand. Provide non-verbal reminders

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PACE

PACE
Playfulness
Acceptance
Curiosity
Empathy

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Empathy

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Strategies for support and management

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Accessing alternate neural pathways

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Young people need…

Relationships

Routines

Structure

Love

Nurture

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Sequences

FASD individuals often have significant challenges with understanding even a simple sequence of more than two steps.

They will often end up getting into trouble because they will appear competent to complete a task and may even tell you that they're able to complete the task with no problem, but they can't actually get past the second step before becoming confused, distracted, or frustrated.

This will have significant implications when it comes to verbal interventions and how you give instruction or direction to people with FASD.

Some helpful strategies include breaking tasks down into two-step units and doing more modelling in your instructions.

Simple written or visual cues may also be helpful for some individuals with FASD.

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Strategies for building healthy brains

Brainstem & Diencephalon	Basic survival & sensory processing	Pacification or stimulation. Activities in the child's preferred sensory modality
Cerebellum	Coordination of movement	Using music, rhyme and movement activities
Limbic	Emotional processing	Building relational connection through plays, animals, games
Cortex	Thinking processes	Linking experiences and sensations to words and descriptions
Prefrontal cortex	Analytical and abstract thinking	Challenges and safe risk taking activities

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Developmental milestones

Some aspects of the developmental age of a child with FASD is unlikely to match their chronological age. Explore WA Child Development and Trauma Guide.

Use flexible, thoughtful approaches when working with child. Maybe 9 years of year but developmentally 4 yrs.

Effective workers adapt to the child and assess developmental milestones and select strategies that support individuals to develop knowledge, skills and understandings they need.

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Practical approaches

- Provide explicit simplified, and clear verbal prompts
- Break tasks into smaller components
- Pitch to a level appropriate for the child's developmental stage
- Provide repetition of instructions and rules, both verbally and through visual support materials
- Incorporate co-operative strategies and opportunities for modelling and mentoring

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Working with cognitive impairment

Children with FASD require explicit strategies to counteract cognitive impairments that may impact:

- processing speed –slow things down:; use visual and communication tools
- abstract thinking – may not understand future options or goal setting be concrete
- language skills and comprehension – check, use drawings, whiteboard

You will need to provide building blocks that connect new information to child's current knowledge and skills to support cognition and the storing of new information into long term memory.-Repetition, regulation, rhythm and RELATIONSHIP (fun).

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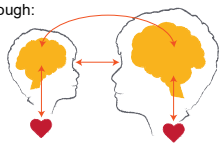
Building on strengths

Child should be provided with multiple opportunities to develop their expressive communication skills through:

- Modelling,
- Positive relationship
- Fun and play
- Practising in real life situations and
- Role playing across different contexts
- Communication is receptive and expressive language.
- Attunement



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FASD and impact on memory

Memory relates to the brain's ability to store, correctly sequence events, manipulate and retrieve information as well as make associations and generalise.

FASD impacts child's ability to process information, strategies and new knowledge.

Memory comprises a number of components:

- Short-term memory
- Long-term memory
- Working memory

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Memory activity- I went shopping

- The first player starts the game by saying, "I went shopping and bought a ____," identifying an item they would buy.
- The second player continues, "I went shopping and bought a (names the first player's item) and a ___ (adding a new item to the list)."
- Players continue taking turns to remember the items purchased in order as the list gets longer and longer.

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Memory

All members of child's environments need to:

- provide daily repetition of instructions and rules
- use 'think alouds' to model how information is processed and organised
- use 'think alouds' so child learns the steps in problem solving processes
- provide scaffolding, concrete materials and visual prompts.

All of these strategies support the child with FASD to develop the skills required to comprehend abstractions, generalisations and to 'fill in the blanks' when processing instructions.

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Proprioception- building body awareness

Closely monitor child to ensure personal safety and the safety of others in settings

Ensure child has regular, short breaks away from tasks

Include physical activity such as obstacle courses, ball games and running races

Use weight bearing activities such as wall push-up or wheel barrow races to build upper body strength.

Teach Breathing regulation

These activities will also support to remain calm.

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Challenges of working with children with FASD

Challenges faced by children with FASD are a result of injury to the brain.

Take care not to misinterpret these challenges, as the student being wilful, egocentric or lacking in empathy.

Focus on strengths and supporting the child to develop the knowledge, skills and understandings required for:

- learning
- communication
- personal and social capability including self-regulation.

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Focussing on strengths

In small groups, discuss your role in enabling children to develop/use their:

- Identified strengths
- Strong **visual** memory
- Unique creative skills
- High energy

How would you integrate this your role.

Picture source -unknown

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Ongoing relearning required

An ongoing task for those supporting individuals with FASD is to find space for ongoing repetition of tasks that have been forgotten.

Individuals may spend considerable time having to relearn tasks that are taught to them.

- Repetition is KEY

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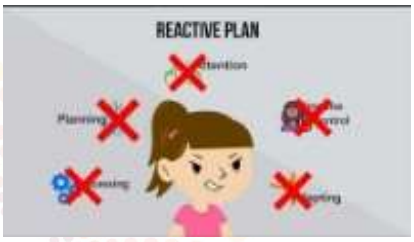
What works



CELEBRATION of LEARNING

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How to help…

- Use as few words as possible.
- Always clearly state what you want to happen—the desired behavior.
- Don't argue, debate, or negotiate.
- Being direct is good, but don't become too authoritarian, or doors will close quickly.
- Don't expect the person to be reasonable or to act their age.
- Go for a few "Yes" responses first. Use short questions you think the person will answer "Yes" to, just to get them out of being stuck in the "No" loop.
- Be nonjudgmental.
- Anticipate and include days for neural rest/neural exhaustion

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Adapt the environment

Multiple stimuli can cause distress for people with FASD. There are likely to be better results when the environment is adapted and the stress level reduced.
Consider using the strategies listed to work with a person with FASD to get relevant information and a cogent version of events.

- Check out the individual's understanding of what he or she is being asked
- Verify the person's story
- Don't assume that what you see is indifference
- Prepare the person repeatedly for court
- Provide one direction or rule at a time
- Use a lot of repetition
- Establish a mentor/buddy/ role model system

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Set up an external brain

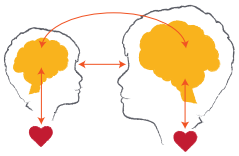
Young people with FASD require comprehensive and consistent supports to provide them with ongoing advice, direction, and structure, as well as to advocate on their behalf.

This sort of comprehensive support is often referred to as an "External Brain."

Supportive people can help the FASD-affected person recognize and avoid situations that cause stimulus overload and/or help them regain emotional control.

Court orders for diagnostic clinic assessments and referral to community support agencies may be appropriate.

Support people can help an affected person to meet a court-ordered curfew every night or be a "job coach" at work.



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Grounding-Activity

Grounding techniques are designed to help us focus on the present during stressful situations. Here are a few grounding activities for young people with FASD to try if they seem agitated:

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Hand on heart grounding activity

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In my work

In small groups, consider what you now know about FASD and determine:

- What are the activities/approaches/changes that you will undertake to enable better outcomes for the child
- What assessment approaches and tools that provide you with a better understanding of the child's development across key areas?
- What do you need to implement across reports/interviews/care options?

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