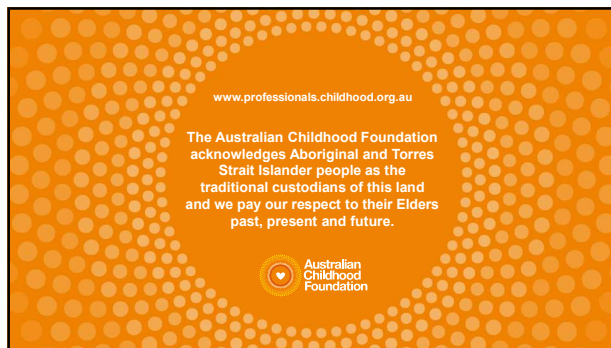
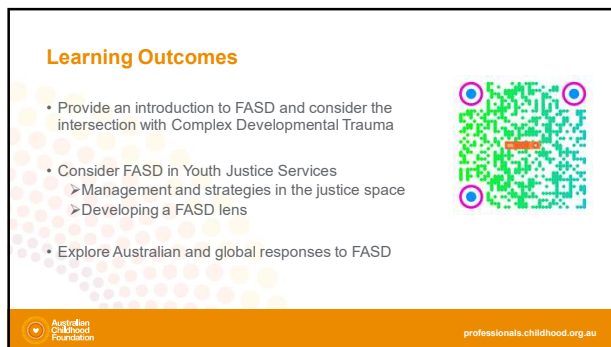


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"I love...."



4

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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5

Why are we here?

The 2013 Justice Consensus Statement, developed by legal experts across the country found that adjustments to criminal law for people with serious mental disabilities including FASD were needed.

It recommends

- protections for adults with mental disabilities similar to some existing protections for youth in the youth Criminal Justice Act;
- increased emphasis on rehabilitation as a goal of sentencing;
- recognizing mental disability as a factor in the degree of responsibility of an accused;
- and more flexibility in sentencing people with mental disabilities.




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6

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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7

What is FASD?





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8

What is FASD?

- FASD is a lifelong disability.
- Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential.
- FASD is a serious public health issue.
- There are more children born each year with FASD than with ASD, Spina Bifida, Cerebral Palsy, Down Syndrome and SIDS combined (Mather Wiles & O'Brien, 2015)




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9

Broader Life and Health outcomes

- Life expectancy for people with FASD 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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10

Aboriginal culture and disability

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11

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

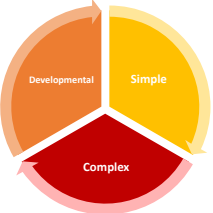
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12

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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13


Trauma impacts



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14

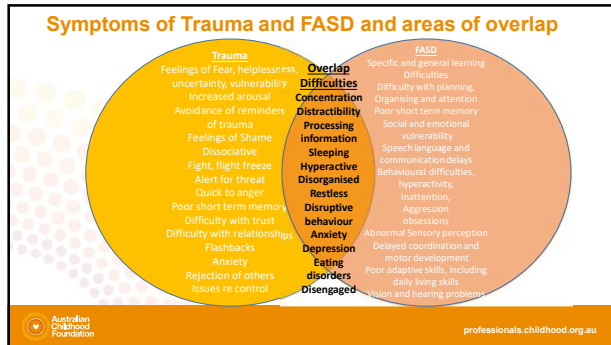
Trauma impacts



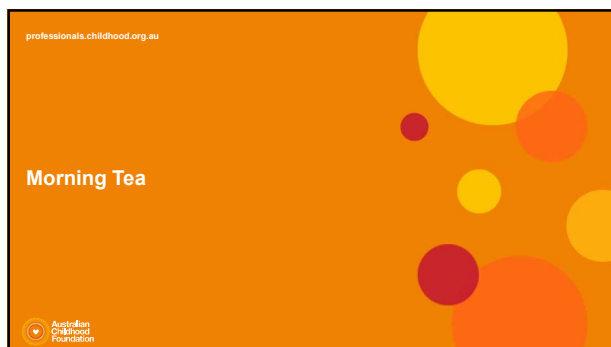
Trauma can impact all elements of children's development: brain, body, memory, learning, behaviour, emotions, relationships.

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15



16



17



18

Marulu Strategy





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19

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Assessment




20

Three diagnostic categories were recommended:

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




Australian FASD Diagnostic Instrument was developed


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21

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		
<ul style="list-style-type: none"> 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	Presence of 3 sentinel facial features	Presence of 0, 1 or 2 sentinel facial features
<ul style="list-style-type: none"> Short palpebral fissure Smooth philtrum Thin upper lip 		

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22

The Australian FASD Diagnostic Instrument contains:

Australian FASD Diagnostic Assessment Form: A form to assist in conducting an assessment and recording the information required to diagnose FASD according to the Australian diagnostic criteria.

Australian FASD Diagnostic Assessment Summary Form: A form to summarise the essential information required for diagnosis.

Australian FASD Management Plan Form: A form on which to record parent, caregiver and patient goals, referrals and intervention and support strategies.


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23

Key components of the FASD Diagnostic Assessment include the documentation of:

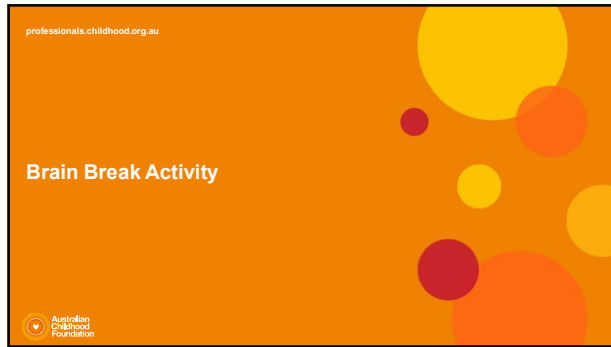
- History – presenting concerns, developmental, medical, mental health, behavioural and social
- Birth defects- dysmorphic facial features, other major or minor birth defects
- Adverse parental and postnatal exposures, including alcohol
- Known medical conditions – including genetic syndromes and other disorders
- Growth information

Infants and young children under the age of 6 and older adolescents and adults warrant special consideration during the FASD diagnostic assessment process.



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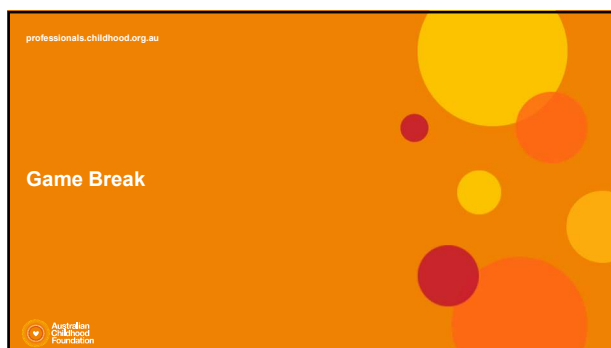
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FASD in Youth Justice

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.

A diagnosis of FASD can lead to a reduced sentence, but it can be difficult to make a diagnosis without the physical features or evidence of alcohol use during pregnancy.


A reduced sentence is more likely if the caregiver shows that action is being taken by the family to prevent criminal behavior in the offender.


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31

FASD in Youth Justice

- The Banksia Hill Youth Detention Centre Study in Western Australia found that 36% of young people detained had FASD, while 89% were found to have at least one form of severe neurodevelopmental impairment.
- International research has reported a high prevalence FASD in young people and adults in prison and correctional facilities – 60% of youth with FASD become involved with the justice system and people with FASD are 19 times more likely to be jailed compared to those without FASD.


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32





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33

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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34

Protective factors include:


- Early diagnosis, which means earlier intervention
- Eligibility for services from the state, providing financial assistance
- Stable home life
- Protection from violence

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35

Risk factors for legal trouble include:

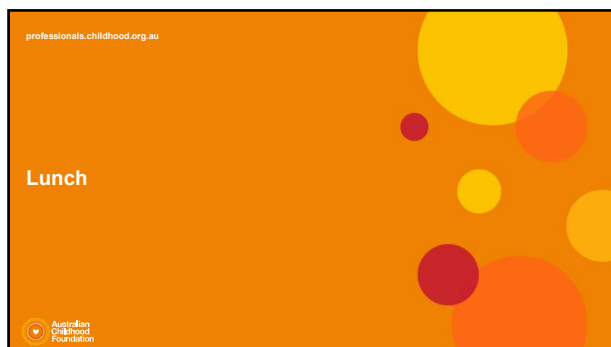
- Having an IQ over 70, perhaps because those with higher IQ's are less likely to get appropriate diagnoses and services
- Exposure to violence or abuse, which increases the risk of inappropriate sexual behavior significantly

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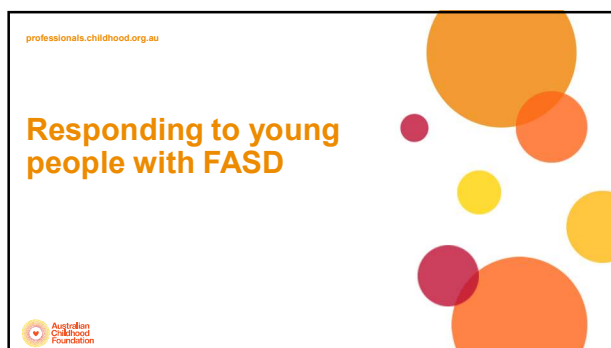
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39

Morgan Fawcett-living with FASD




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40

Developmental stages

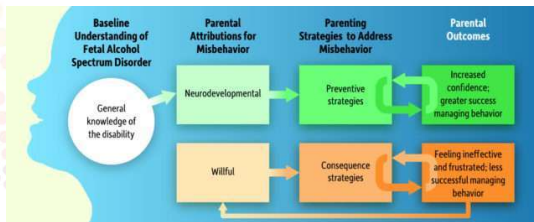
- At each developmental stage the child/young person faces developmental tasks that require the support of the adults around them
- The perceptions, abilities and behaviour of children change as they grow and every area of development affects other areas as children face each developmental task
- Developmental delays in one area can affect an individual's ability to consolidate skills and progress to the next developmental stage
- Check developmental age versus chronological age



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41

Responding to children with FASD's



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graph LR
    A[General knowledge of the disability] --> B[Neurodevelopmental]
    A --> C[Willful]
    B --> D[Preventive strategies]
    C --> E[Consequence strategies]
    D --> F[Increased confidence; greater success managing behavior]
    E --> G[Feeling ineffective and frustrated; less successful managing behavior]
    F --> H[Parental Outcomes]
    G --> H
    
```

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42

Considerations for your practice.....

Keep it simple
Avoid distractions, bright things, lighting, too much stimulus


Modify your expectations
Think could this be the brain
Think- they cannot do it: not that they wont


Focus on their strengths and work with these

Prevent problems
Do not react to the problems
Think: could this be brain?

Discard judgements or negative thoughts about behaviors and try to see them differently.

Consider the environment and its fitness for the person with an FASD.





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43


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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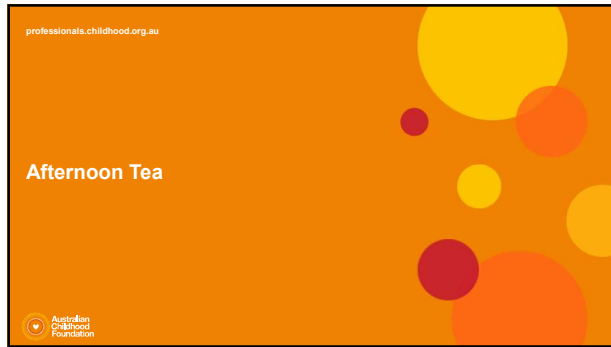
44

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Game Break



45



46

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

Sometimes when we are angry, there are other emotions under the surface.

Icebergs are giant floating pieces of ice found in the coldest parts of the ocean. What you can see from above is just a tiny part. Most of the iceberg is hidden under the surface.

Angry

Angry, Struggle Ahead!

Watch Out!

Embarrassed, Annoyed, Rejected, Scared, Guilt, Alone, Grief, Insecure, Disappointed, Shame, Blamed, Attacked, Hurt, Let's go down!

47

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.

48

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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49

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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50


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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51

Reframe Behaviour


Reframing behaviour means changing the way you or others view the conduct of the person with FASD.

This shift in thinking will allow the observer to recognize that brain damage causes the dysfunctional behaviours of the person affected by FASD.

A recent study by the Department of Justice of Canada sought to gain insights from service workers with experience working with victims with FASD. When asked what they would recommend to help provide the best services possible for clients who have FASD, most identified training for all justice professionals.

Photo by Unknown Author is licensed under CC BY-NC


"If it were required that every judge, every crown, every defence attorney, every RCMP member had to have a knowledge of FASD, that would help us greatly. Because sometimes half the battle is just trying to convince somebody that there's something going on."

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52


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Brain Break




53

Strategies for support and management

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54

Accessing alternate neural pathways



Singing therapy

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55


Common Challenges

Structure
In many cases, the FASD individual is not capable of structuring their time or schedule or even a simple multi-step task.

Even when not in a state of anxiety or defensiveness, the FASD person may be unable to structure their time appropriately.

Being left alone or given free time can be disastrous for the person with FASD. This is a significant issue for the FASD person that should be considered in any crisis intervention plan.

Unfortunately, the reality is that this is part of the reason why so many people with FASD end up in prison and do reasonably well when there.



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56

Young people need...



Relationships
Routines
Structure
Love
Nurture

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57

Understanding cause-and-effect relationships

This relates in part to the issues with sequences mentioned previously.

Not understanding cause-and-effect relationships can make it difficult for the FASD individual to learn from their mistakes or past behaviour and consequences.

The person may continue to make the same mistakes or bad decisions over and over, much to the confusion and frustration of those supporting them.



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61


Supporting young people with FASD

One suggestion for support people is that certain parts of the *COPING ModeSM* may need to be conducted immediately following an incident, as long as it's safe to do so, if we want the individual with FASD to understand the connection to their behaviour.

They likely won't make the connection if this occurs hours or days later.

How effective that communication is based on what consequences might be appropriate when dealing with issues of noncompetence due to brain damage versus wilful noncompliance or disruptive behaviour




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62


Coping model

This model guides you to take six important steps after an emotional and/or physical crisis:

- Control
- Orient
- Patterns
- Investigate
- Negotiate
- Give



The model is based on the assumption that individuals in stressful situations face two tasks: they need to solve the problem and regulate their emotions, which are reflected in two corresponding dimensions, that is, the problem coping dimension and emotion coping dimension.

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63

Understanding abstracts and generalizations

This includes everything from understanding the concept of time to understanding other people's feelings and emotions. People with FASD may appear to be very self-centered and to have a lack of compassion for other people. This could be directly related to their disability.

There may be implications here for those supporting individuals with FASD in the area of Rational Detachment.

It can take some specific skills to realize and understand that their odd or out-of-sync behavior could be directly linked to their disability.

If you truly realize and understand this, it can positively impact your ability to work well with people with FASD despite their behaviors.



64

Ongoing relearning required

One particularly challenging aspect of FASD for those who support these individuals is the fact that due to the brain damage caused by fetal alcohol exposure, individuals may spend a considerable amount of time having to relearn tasks that are taught to them.

This can be frustrating for those who support the individual with FASD. It can leave you wondering why the person could do something just fine one day and completely lose it the next day.

It can also be frustrating to have to constantly re-teach the same skills.



65

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





66

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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67

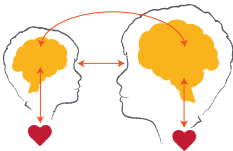
Set up an external brain


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.




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68

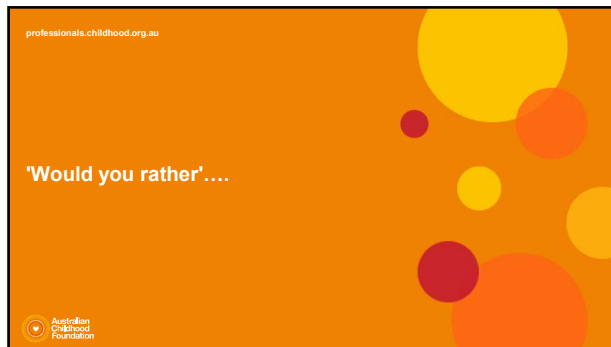
Grounding

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:

- Count to ten or recite the alphabet as slowly as you can
- Listen to calming music and pay attention to the different instruments
- List five different things that you can see around the room
- Try stretching or simple yoga exercises and focus on how your body feels
- Hold something tactile like a piece of clay, special object or a stuffed animal

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69



70

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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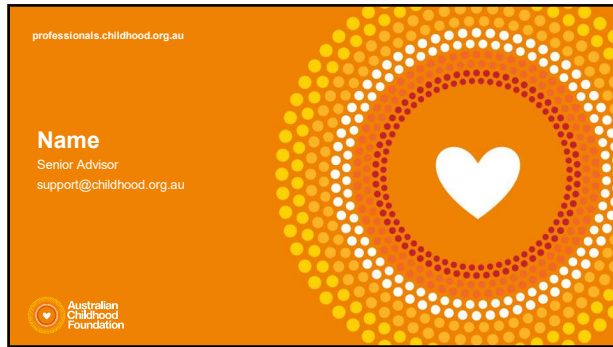
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73



74
