



Fetal Alcohol Spectrum Disorder in Adults

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Overview

- Definition and Aetiology
- Identification and Diagnosis
 - guidelines, assessment approaches, sources of information, and common challenges
- Treatment Implications for therapy
 - Profile variability, secondary consequences, modification of traditional treatments
- NDIS and FASD
 - FASD in NDIS literature,
 - NDIS issues/adjudications that influence our reasoning
 - Key points for clinical communications



What is FASD?

Formal Definition

- Severe and Pervasive
- Neurodevelopmental impairment
- Due to pre-natal alcohol exposure

Real Life Definition

- **Non-specific** disorder
- Severe and pervasive impact
- motor, cognitive, academic achievement, memory, attention, language, executive function, social, affective, and adaptive skills
- **Attributable** to pre-natal alcohol exposure

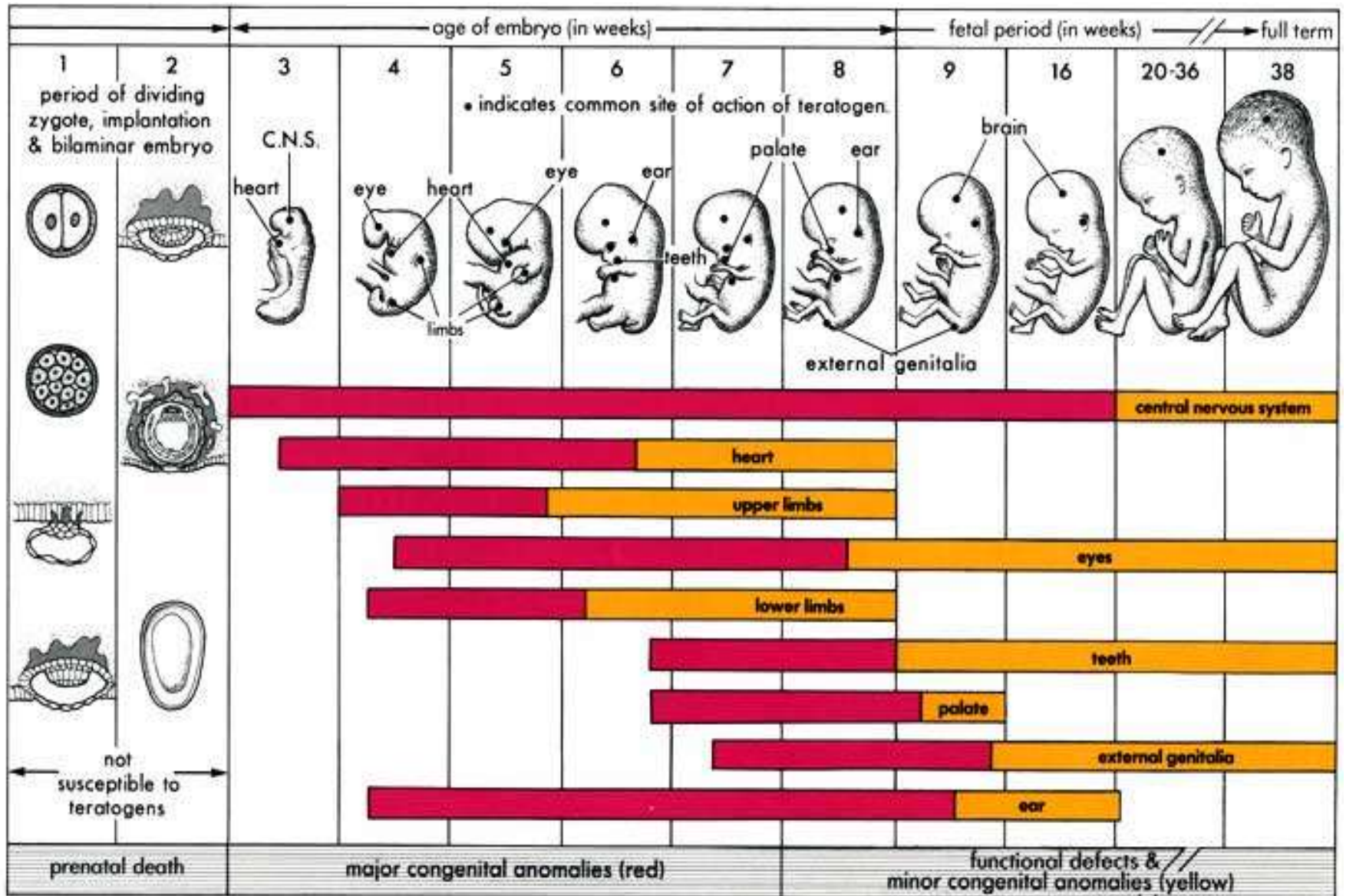


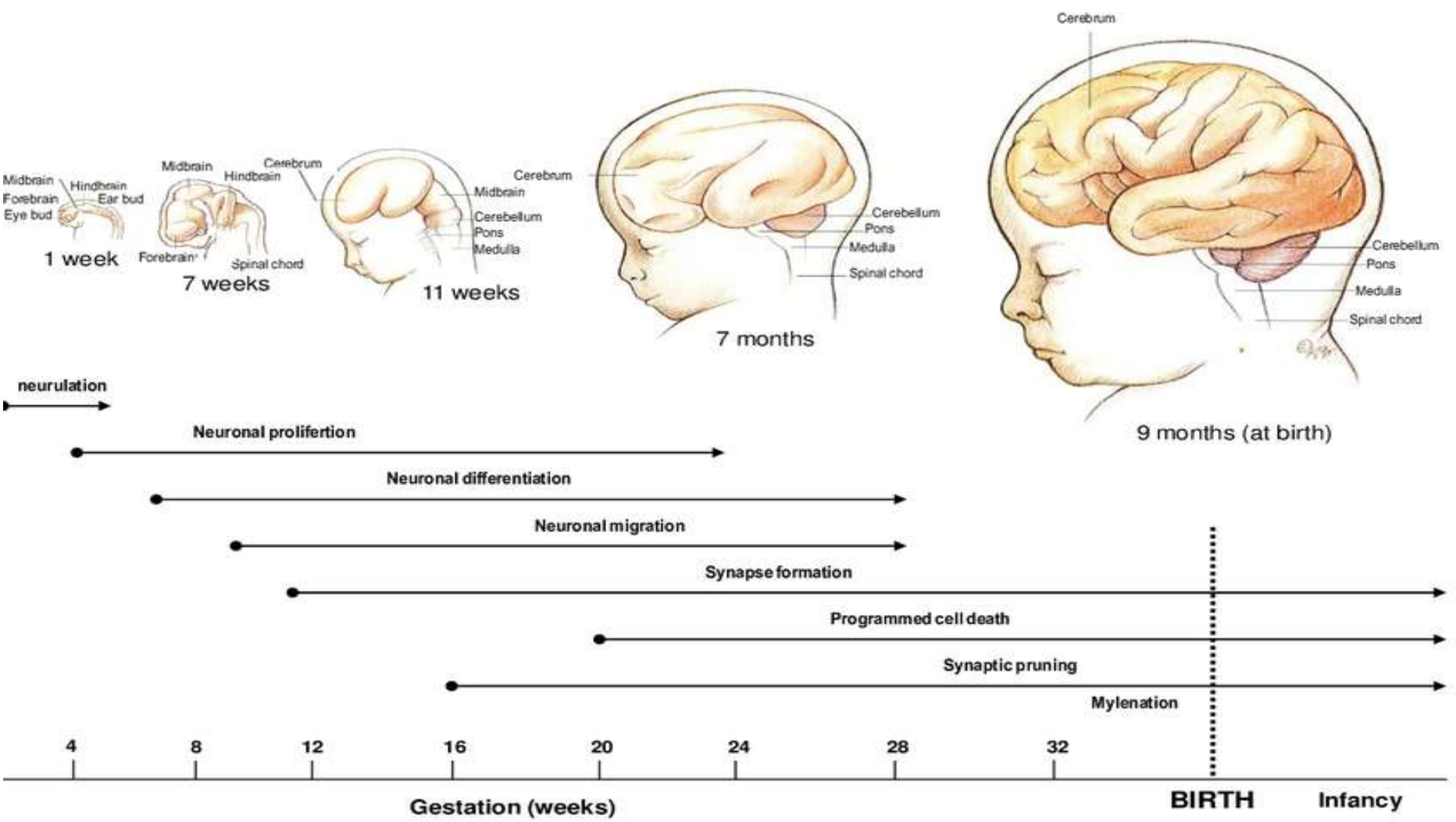
Aetiology

- Alcohol
 - Strongest teratogen in general use
 - More frequent use than any other teratogen
 - Crosses placenta easily
- Rate of Unintended Pregnancy
 - 2005 - 18% ^[1]  2013 - 26% ^[2]
- Alcohol use in Pregnancy
 - 2013 - 47% consumed some alcohol before knowing and 26% continued use after knowing they were pregnant^[3]

Why is this important to you?

[1] Hewitt et al 2010; [2] Taft et al 2018; [3] FASDHUB 2017





Nutton et al (2011)



Assessment and Diagnosis

- **USA** (CoFASP Study) – **2-5%** depending on city
- **Canada** (CanFASD) – **4%**, specific groups much higher
- **WA** The Lililwan Project (Fitzpatrick et al, 2015) – **12%**
- **WA** Youth Detention (Bower et al, 2018) – **36%**
- **Qld** Population 5,000,000 (2018)
 - 2% = 100,000**
 - 5% = 250,000**

**There is a better than reasonable chance
that you are treating a person who has
FASD**

Regions Impacted by Alcohol



HIPPOCAMPUS

- Visuospatial & Verbal Memory
- Emotion Control

BASAL GANGLIA

- Motor Skills
- Perception
- Behaviour Inhibition

CEREBELLUM

- Motor Control, Balance, Coordination
- Learning

CORPUS CALLOSUM

- Attention
- Intelligence
- Learning
- Verbal Memory
- Motor Coordination
- Visuospatial Organization & Coordination

FRONTAL LOBES

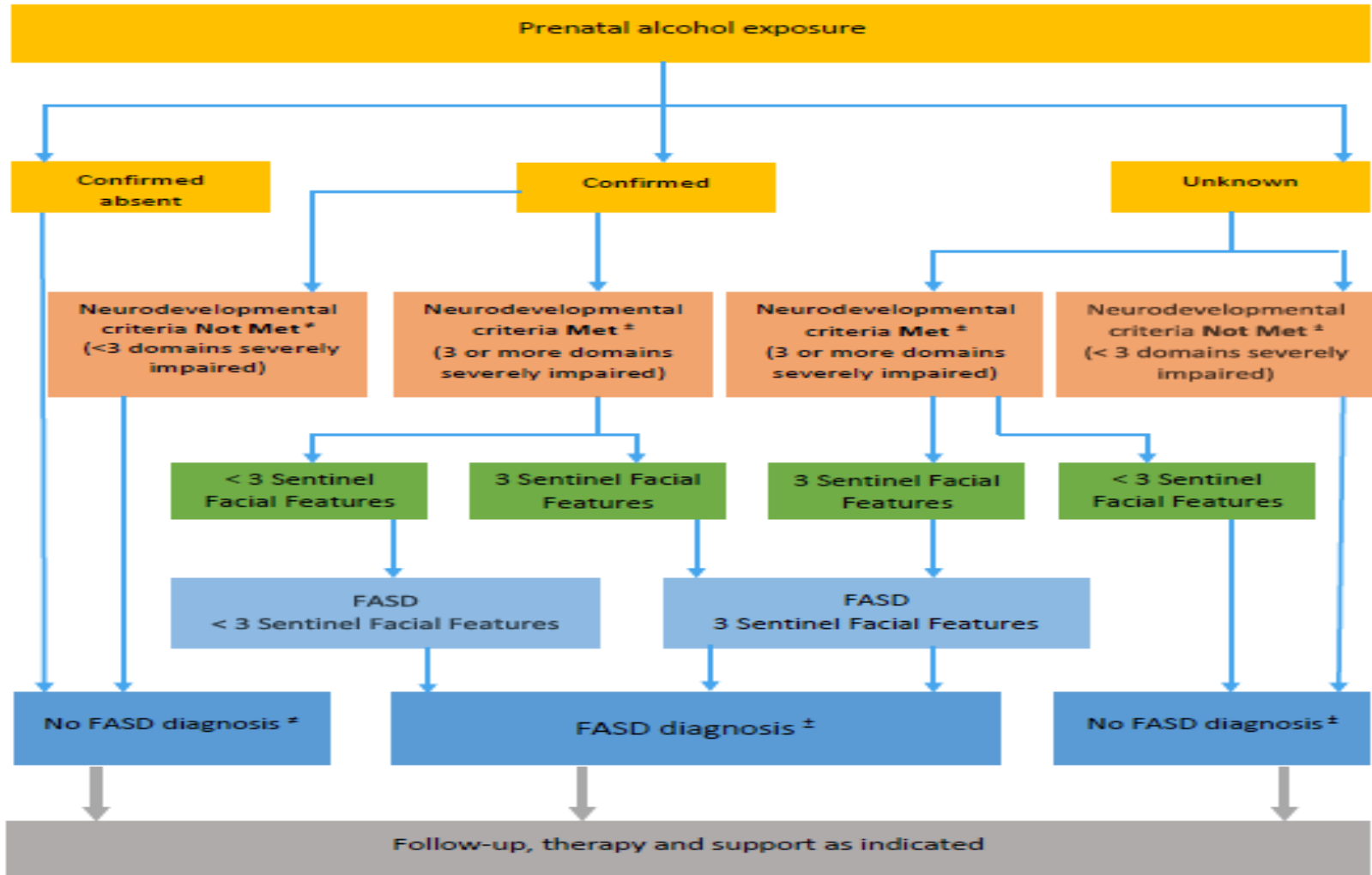
- Executive Functions
- Emotion Control
- Impulse Control
- Social Skills/Coping
- Communication



Why Do You Need to Diagnose?

- Early diagnosis is a protective factor against development of secondary disabilities
- Offers an explanation of the person's difficulties, i.e. "organic basis" rather than family or person factors
- Allows formulation of concrete recommendations to improve the quality of life of the affected individual and their family
- Allows interventions to be tailored to the complex needs and individual capabilities of the person
- Improves service quality and provision
 - via increased awareness in disability, education, justice, social services

Diagnostic Criteria





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



Complexity Complexity Complexity

- No single “FASD profile”
 - Variability in brain domains affected and degree of impairment within domains
- FASD is often misdiagnosed
 - Attention Deficit/Hyperactivity Disorder
 - Oppositional Defiance Disorder/ Disruptive Behavior Disorder, Conduct Disorder
 - Mood Disorders
 - Borderline Personality / Antisocial Personality Disorders
 - Attachment Disorders /
 - Trauma Disorders
 - Communication Disorders
 - Autism Spectrum Disorder

There are few easy FASD diagnoses



Some Resources You Will Need to Make a Diagnosis

- Health colleagues
 - Clinical Neuropsychologist
 - Speech Therapist
 - General Practitioner +/- Specialists
 - Other Allied Health Practitioners
 - +/- Physiotherapist
 - +/- Occupational Therapist
 - +/- Social Worker
- A diagnostic system
- Specific training
- A desire to get on with it



- 40 Hours
 - Ax = 14 hrs
 - Sc = 4 hrs
 - Int = 4 hrs
 - Cse = 1 hrs
 - FB = 2 hrs
 - Rpt = 12 hrs
 - Oth = 3 hrs



Assessment Needs to Cover

- **Pre-natal factors**
 - Confirm parental ETOH use, timing, level, etc.
 - Exclude:
 - exposure to other teratogens
 - poor prenatal care
 - birth complications
 - alternate genetic / congenital conditions
- **Post-natal factors**
 - Understand impact of other factors
 - abuse (physical, sexual)
 - acquired brain injury
 - chronic substance abuse



- **Clinical Features**
 - Face
 - *Growth*
 - Brain (microcephaly)
 - Milestones (achieved and when)
- **Formal and Informal assessment of Brain Domains**
- **Functional Impairments**



Functional Impairments

- Verbal skills can appear better than they are/may be able to “talk a good game”
- Can be very literal/concrete in their thinking and interpretation
- May appear oppositional or uncooperative because:
 - They often do what they think they need to based on the pieces of information that they have processed
 - They don’t understand instructions
 - They cannot remember what to do
 - They have difficulty translating verbal instructions into action
 - They get easily distracted and can’t focus on the task at hand
 - They don’t have the cognitive abilities to complete tasks



- Repeatedly make the same mistakes because:
 - They can't link cause and effect
 - They can't generalise because they cant see similarities
- Show poor social judgment/ are overly familiar/ have social difficulties because:
 - They are not able to interpret social cues
 - They don't know what to do in social situations
 - They don't filter/censor what they are thinking
 - They can be naïve, gullible, act much younger than their age
- Seem overactive
 - Their sensory system seeks movement or conversely is overloaded



- Experience sensory problems
 - Reacting unusually to temperature, sounds, bright lights, pain or busy places

- Tardiness
 - They have difficulties understanding time
 - They need assistance organising themselves to be ready

- Have learning difficulties
 - Reading comprehension and written expression

- Poor decision-making abilities
 - They have no filter for disclosures
 - They lack the ability to foresee the impact of high-risk situations

- Inability to self-advocate



- Core Impairments mnemonic
 - **A**daptive Behaviour
 - **L**anguage
 - **A**ttention
 - **R**easoning (executive functioning)
 - **M**emory
- difficulties that you may observe include distractibility, restlessness, attending to competing demands, abstract reasoning, not learning from mistakes, not understanding consequences of actions, un-empathic, can't explain actions.

Conry, J. L. et al (2000)



- **Red Flags**
 - a repeat history of “fail to comply”
 - lacking empathy
 - poor school experiences
 - unable to connect actions to consequences
 - does not seem to be affected by past punishments
 - opportunity crimes rather than planned crimes
 - crimes involve risky behaviour for little gain
 - superficial relationships

Harvie, M.K., et al (2011)



Diagnostic Challenges - Secondary Disabilities

- FASD is a two part condition

Organic Brain Disorder + Secondary Disabilities

- Secondary Disabilities might include:

Mental health problems

Alcohol and drug issues

Poor educational attainment

Unemployment

Relationship problems

Poor friendship choices

unplanned pregnancies

sexually transmitted diseases

Involvement with the justice system

Homelessness or needing supported accommodation

- The perils of being distracted by Secondary Disabilities

**The Wrong Treatment
The Right Treatment at the Wrong Time
The Right Treatment Delivered the Wrong Way**



Treating Individuals with FASD

- People with an FASD are often challenging patients

They repeat the same negative behaviors

They are always surprised when in trouble

They appear to be non-compliant, uncooperative, resistant,
manipulative, or unmotivated

etc

BUT MOSTLY BECAUSE

**They have an organically based brain disorder
AND secondary disabilities**



Step 1

Adopt a Neurobehavioural Formulation Framework

Genetics + NDAE = Structural + Functional deficits

then

Structural + Functional deficits + Life Experiences = FASD adult



Step 2

Make Accommodations in Your Perceptions

From They Won't

- Bad/annoying >
- Lazy / unmotivated >
- Lying >
- Fussy >
- Acting young >
- Attention seeking >
- Restless >
- Doesn't care >

To They Can't

- Frustrated, challenged
- Trying hard / tired of failing
- Confabulating
- Sensitive
- Being cognitively young
- Needs support
- Overstimulated
- Can't show feeling

FASD is an invisible disability and like all other disabilities ACCOMMODATIONS must be made!



Step 3

Follow Some Foundation Rules

- Common themes in successful FASD intervention programs:
 - Reframing the primary intervention focus from changing the person to adapting their environment
 - Focus on support frameworks
 - Include the person's family (where possible) to build their understanding and support
 - Employ multi-disciplinary and multi-systemic intervention approaches (i.e., the best practice treatment for a condition might not be appropriate for a person with FASD)
 - Access health practitioners with specific FASD training



Step 4

Use Their Weaknesses to Inform Therapy

- What is the implication of their deficit in

Attention and Concentration,
Intellectual Processing Speed

Working Memory

Language

Memory and Learning

Executive Functioning

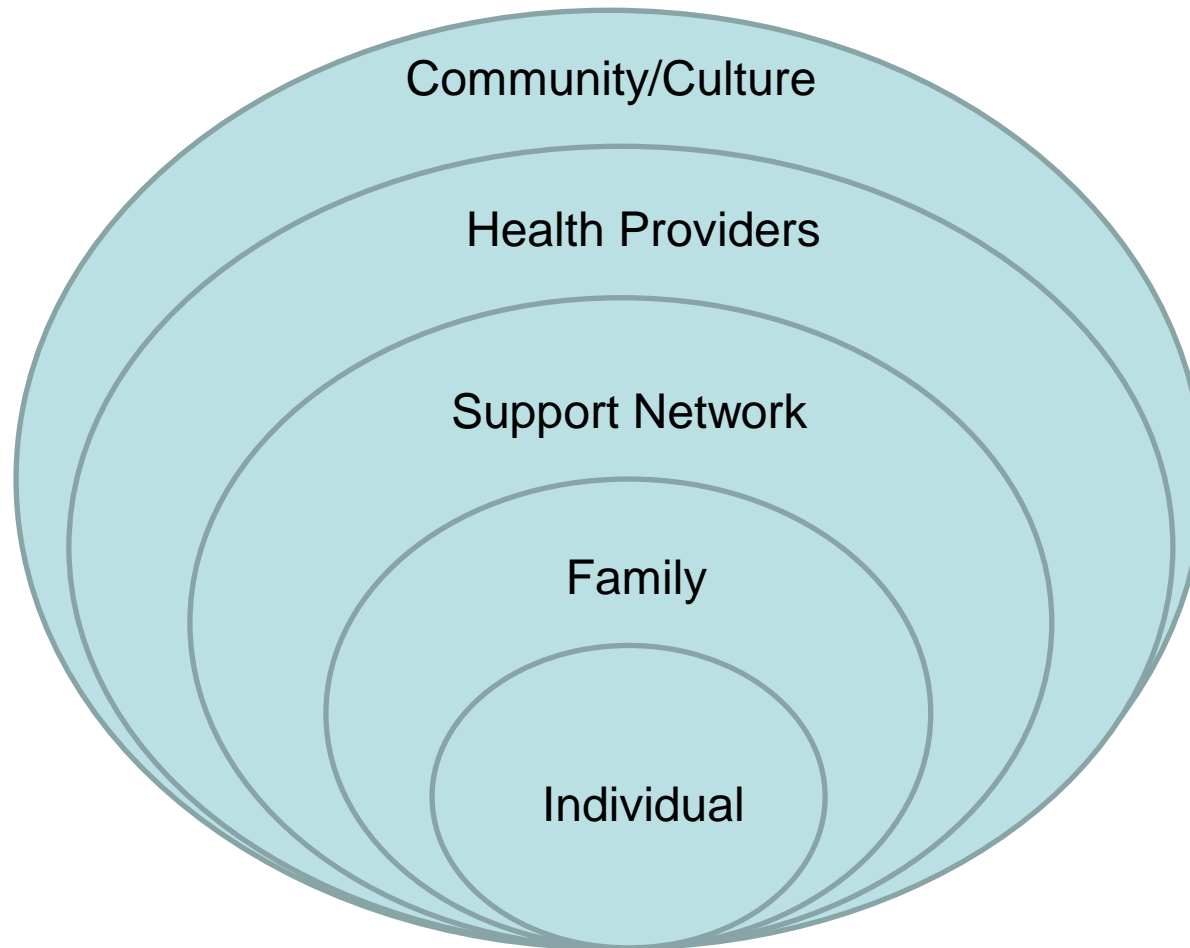
Knowledge and Educational Attainment

to their participation in particular types of treatment



Step 5

Use Their Strengths to Scaffold For A Positive Life





NDIS and FASD

- FASD listed under congenital disorders not neurodevelopmental disorders
- Adults with FASD are eligible under NDIS when they have a significant and permanent disability that reduces their functional (ability to perform age appropriate tasks and activities) or psychosocial capacity (ability to relate to others in personal relationships, work or school)
- Key areas to address:

Communication

Learning

Self-care

Social Interaction

Mobility

Self-management

