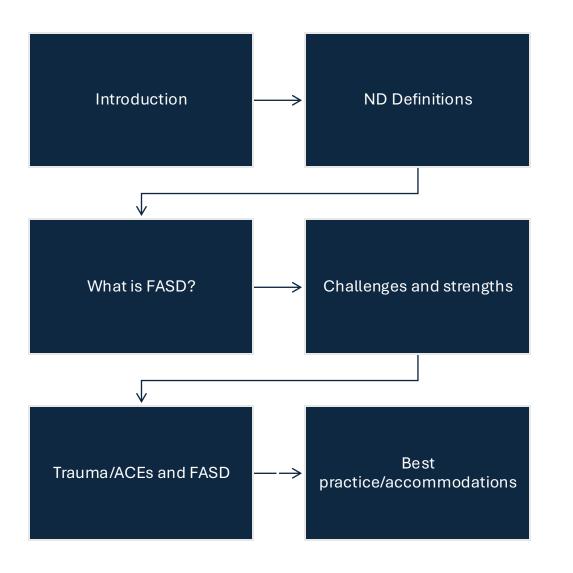


FASD at the nexus of disability and neurodivergence, the impacts of trauma, risk and protective factors and the journey to enable a good life for individuals and their whānau.

Professor Anita Gibbs, Criminology and Social Work

# Session Overview



## Introduction/Ko Wai Au?



# I might swear lol.....



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D W -

Using swear words can have a wide range of positive effects on your well-being, including pain relief and helping you cope with emotionally challenging situations. LWA / Dann Tardif / Getty Images

- Studies show cursing during a physically painful event can help us better tolerate the pain.
- · Experts say using curse words can also help us build emotional resilience and cope with situations in which we feel that we have no control.
- Swearing can also provide a range of other benefits, including as a means of creative expression, relationship development, or simply as a way to allow different identities to harmonize by signaling that you're relaxed around the other person.

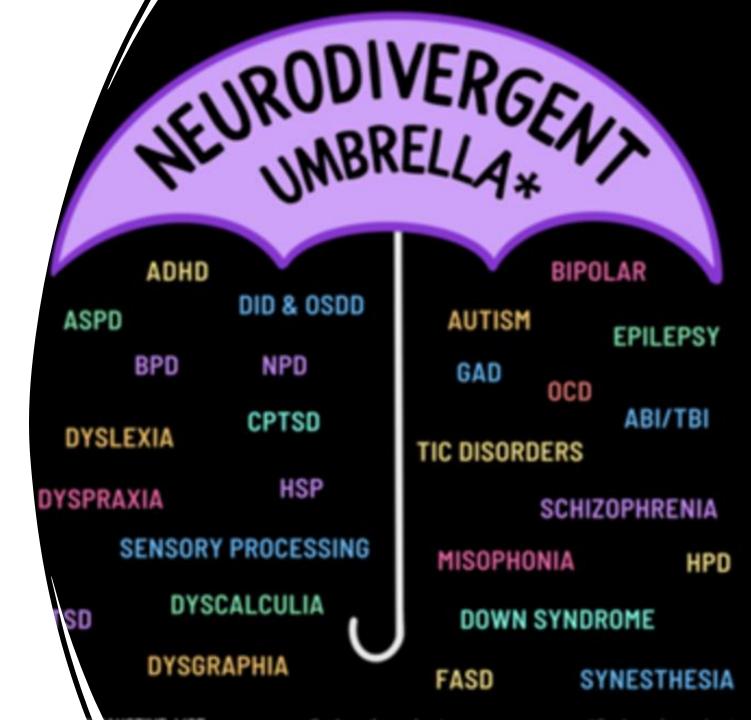
### **Important Terms and Definitions**

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Neurodiversity	the diversity of human minds; no mind is the same; there is no one standard mind or brain.
Neurodiverse	a term to describe a group of people who's minds all differ to one another; a variety of minds.
Neurodivergent	an identity term to describe a person who functions in a way that diverges from neuronormativity.
Neuronormativity	a system of beliefs that reinforce a set of standards, expectations, norms and ideals that centre a particular way of functioning as the right way to function.

#### Kanorau ā-roro

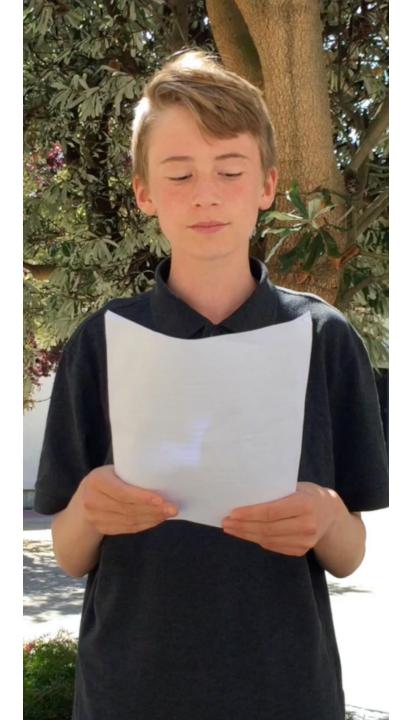
https://www.healingumbrellapsy chotherapy.com/queer-mentalhealth-blog/what-is-theneurodiversity-umbrella



### Fetal Alcohol Spectrum Disorder (Te Iho Tātai ā Rongo)

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. 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. Each individual with FASD is unique and has areas of both strengths and challenges.

https://canfasd.ca/2019/11/13/public -definition-of-fetal-alcohol-spectrumdisorder-fasd/



### Dima 13 years

https://www.youtube.com/watch?v=oPGGIOilB98

### **Cluster of Symptoms**

Inattention

Poor Planning

Poor social understanding

Receptive language deficits

obsessionality

Hyperactivity

Cognitive flexibility problems

Poor imagination

Impulsivity

Expressive language deficits



Dr Raja Mukherjee - FASD, Do I need to know about it?



What is FASD?

Supporting Students with Fetal Alcohol Spectrum Disorders FASD – Edmonton Regional Learning Consortium -<u>https://www.youtube.com/watch?v=i3753eblUv0</u>

### Screening

#### The FASD 4-Digit Code Caregiver Interview Checklist: Profiles of FASD https://www.ncbi.nlm.nih.gov/bo oks/NBK344229/

NOFASD checklist https://www.nofasd.org.au/wpcontent/uploads/2018/02/FASD\_ checklist.pdf

G. Koren, I. Zelner, K., Nash, & Gal Koren **Foetal alcohol spectrum disorder: identifying the neurobehavioral phenotype and effective interventions** 

Curr. Opin. Psychiatry, 27 (2014), pp. 98-104

#### Neurobehavioural Screening Tool (NST): Guidelines and Scoring

The NST form is designed to be administered with caregivers of children and youth suspected of having a Fetal Alcohol Spectrum Disorder based on behavioral observations. The caregiver should know the child well enough to be able to answer all questions contained in NST. The form should be administered to the respondent by a qualified health or social services professional, such as a social worker, law enforcement personnel, psychologist, or child and youth worker in the context of a clinical interview. The form should not be scored by the caregiver. The user should explain that its aim is to gain a picture of the child's behaviour within the last 6 months.

<ol> <li>Has your child been seen or accused of or thought to have acted too young for his or her age?</li> <li>Place a check in <b>all columns</b> if 'YES' was endorsed</li> </ol>	YES	NO
<ol> <li>Has your child been seen or accused of or is thought to be disobedient at home?</li> <li>Place a check in columns 'A' and 'C' if 'YES' was endorsed</li> </ol>	YES	NO
3. Has your child been seen or accused of or is thought to lie or cheat?	YES	NO
4. Has your child been seen or accused of or is thought to lack guilt after misbehaving? Place a check in columns 'A' and 'C' for each 'YES'	YES	NO
5. Has your child been seen or accused of or thought to have difficulty concentrating, and can't pay attention for long?	YES	NO
6. Has your child been seen or accused of or is thought to act impulsively and without thinking?	YES	NO
7. Has your child been seen or accused of or is thought to have difficulty sitting still is restless or hyperactive? Place a check in <b>column 'A'</b> for each 'YES' endorsed	YES	NO
8. Has your child been seen or accused of or is thought to display acts of cruelty, bullying or meanness to others?	YES	NO
9. Has your child been seen or accused of or is thought to steal items from home?	YES	NO
10. Has your child been seen or accused of or is thought to steal items outside of the home?	YES	NO
Place a check in <b>column 'B'</b> for each 'YES' endorsed		

# 10 Brain domains

https://www.fasdcoalition.ca/wpcontent/uploads/2016/10/Ten-Brain-Domains.pdf

#### Ten Brain Domains (Functions) Affected by FASD

Alcohol affects the growth and formation of the brain, and this is often seen in an individual's behavior and development. The following brain functions or domains are evaluated by a diagnostic team during an FASD assessment.

#### ACADEMIC ACHIEVEMENT

May have difficulty in school: reading, math, comprehension (understanding) and abstract concepts

#### ATTENTION

 Can be easily distracted, difficulty paying attention and sitting still

#### COGNITION

- Difficulty reasoning, planning, solving problems and understanding complex ideas
- Wide rage of IQ scores are found

#### LANGUAGE (Expressive and receptive)

- Delay in language development
- Difficulty understanding lengthy conversation and instructions
- May speak well, but not fully grasp the meaning
- Can repeat instructions or rules, but may not follow
  - through

#### MEMORY

- Difficulty with long-term, short-term and working memory
- May appear to lie, but is actually filling in the blanks when unable to remember
- Trouble with memorizing and may seem forgetful
- Difficulty with accessing, selecting and organizing information when needed

#### NEUROANATOMY/NEUROPHYSIOLOGY (Brain structure and function)

 Could have a smaller head, brain size, seizure disorder and/or abnormal findings on a scan (ex: MRI or EEG) consistent with prenatal alcohol exposure

#### EXECUTIVE FUNCTIONING

- May have trouble with planning, sequencing, problem solving and organizing
- May be impulsive and/or hyperactive
- Difficulty understanding cause and effect and controlling behaviour
- Challenges with transitions and change
- Often repeats mistakes
- Difficulty with concepts, abstracts ideas, consequences and managing time

#### ADAPTIVE BEHAVIOR, SOCIAL SKILLS AND SOCIAL COMMUNICATION

- May not understand personal boundaries and have difficulty reading social cues
- May be socially vulnerable and easily taken advantage of
- Difficulty seeing things from another's perspective
- Socially and emotionally immature and may behave younger than actual age
- May have trouble with hygiene, money and coping skills

#### MOTOR SKILLS

- Difficulty with balance, strength, endurance, coordination, reflexes and muscle tone
- Difficulty with printing, using pencil and scissors

#### AFFECT REGULATION

Includes anxiety, depression and mood imbalance in the severe range meets Diagnostic and Statistical Manual-V criteria

The Canadian FASD Diagnostic Guidelines were revised in 2015 and the Sensory Doman has been removed from the list above; however, the Manitoba FASD Centre will continue to measure and consider sensory functioning (see below) during an FASD assessment.

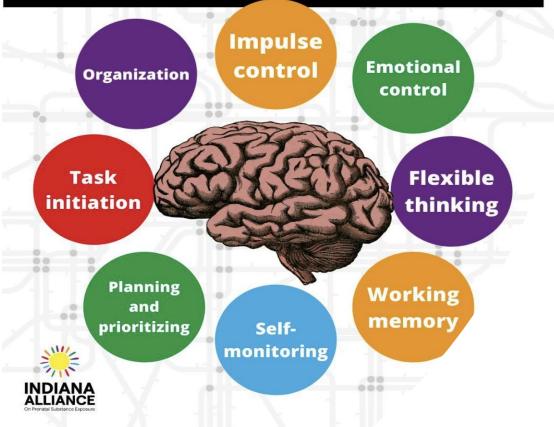
#### Sensory Processing

Student with Sensory processing issues may be over or under sensitive (or both) to different sensory stimuli eg. Touch, taste, visual, auditory, smell, movement and body awareness. This may present as:

- May be easily overwhelmed by bright lights, people, noisy crowded overstimulating environments (eg. recess, gym and music class, lunchroom, assemblies, field trips)
- Easily startled by loud sudden noises or unexpected touch
- Avoids touching people or hugging them. Refuses to wear certain clothing or touch certain textures
- Invades other people's personal space
- High or low tolerance for pain
- Clumsy and uncoordinated
- Gets upset by small changes in routine or environment and avoids trying new things
  - Difficulty self-regulating
  - Overwhelming sensory experiences may trigger a fight, flight or fright response

### **Primary Issues/Challenges**

# **Executive Functioning**



### **Social functioning**

Communication, recognition of social cues, boundaries or expectations, social skills, dysmaturity, self-regulation

### Adaptive functioning

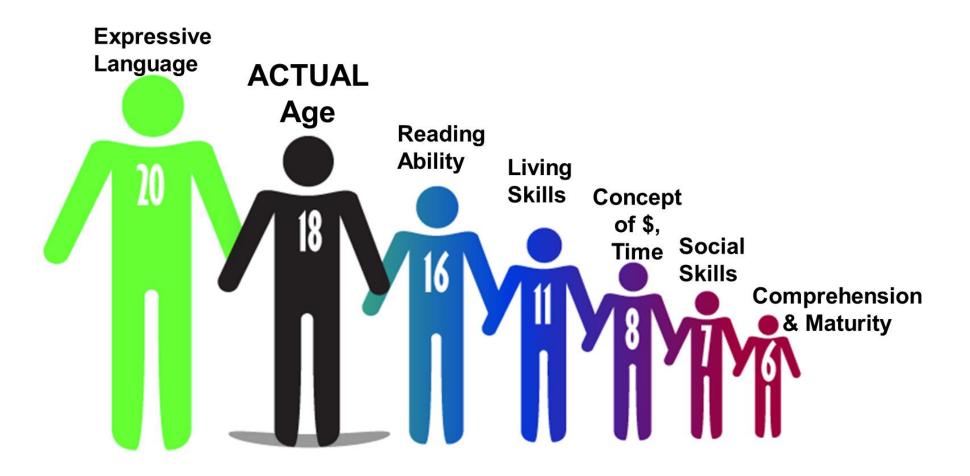
Ability to adapt to new situations, day-to-day functioning, esp, cf. to peers.

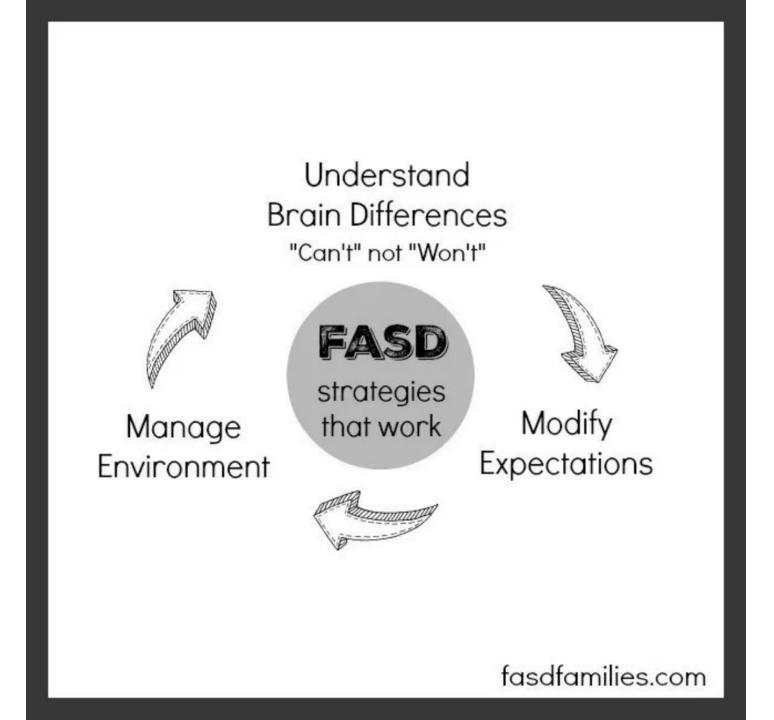
# Secondary challenges and co-occurring issues



### What you see is NOT what you get

Colleen Burns (2016) (unpublished slide)





## ACES and FASD

- Brain-based vulnerability from pre-birth throughout lifecourse.
- Those with FASD far more likely to experience more ACEs than gen population or those with other disabilities.
- Those with FASD and ACES, have poorer outcomes across physical, psycho-social and behavioural domains.
- FASD seems to increase chances of ACEs and ACEs make FASD worse.
- Diagnostic clinic WA: 70% been involved with Child protection, 40% been in trouble with the law. 70% had been exposed to substance misusing homes and 50% violence at home, 39% had 4+ ACES and substantial numbers had disengaged from education.

# **Risks and Protective Factors**

- Parent with FASD, or welfare or justice experienced, violence and substance misuse – increased risk for FASD as well as adversities.
- Unsafe or disrupted care/living experiences.
- PAE impacts attachment typical attachment not always seen (disorganised/insecure common)
- Society's denial of impact of alcohol harm/stigma towards birth mums and those living with FASD (session)

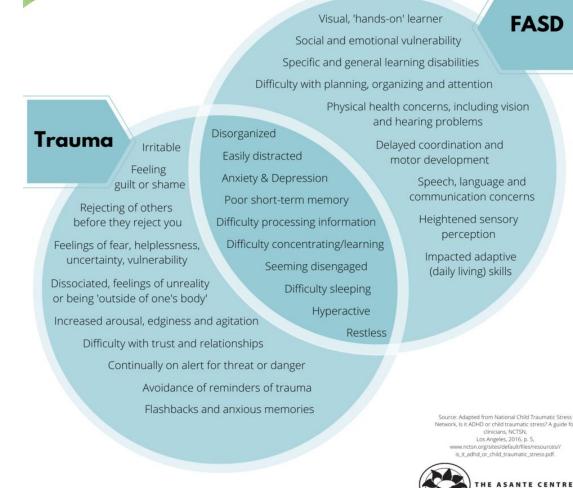
- Protections early diagnosis, stable, safe and nurturing homes, staying in education for longer, being supported over the lifecourse, interdependence and independence
- Promotion of resilience, emotional regulation and adaptive coping strategies, selfdetermination/autonomy, participation (activities and interests that promote wellbeing), social acceptance and social supports, find your 'tribe'



# Promoting resilience in the face of ND adversity....

- Resilience is not just an individual quality, it is systemic in nature.
- How people navigate and negotiate resources, individually and collectively.
- A dynamic process.
- Risk and protective factors change over time.

### **Fetal Alcohol** Spectrum Disorder & Trauma



Speech, language and communication concerns

FASD

(daily living) skills

Source: Adapted from National Child Traumatic Stress Network, Is it ADHD or child traumatic stress? A guide for clinicians, NCTSN, Los Angeles, 2016, p. 5, .nctsn.org/sites/default/files/resources// is\_it\_adhd\_or\_child\_traumatic\_stress.pdf.

2020

Traumainformed practice for FASD

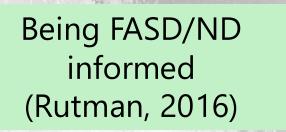
1] Understand how trauma impacts your loved one or person you are supporting

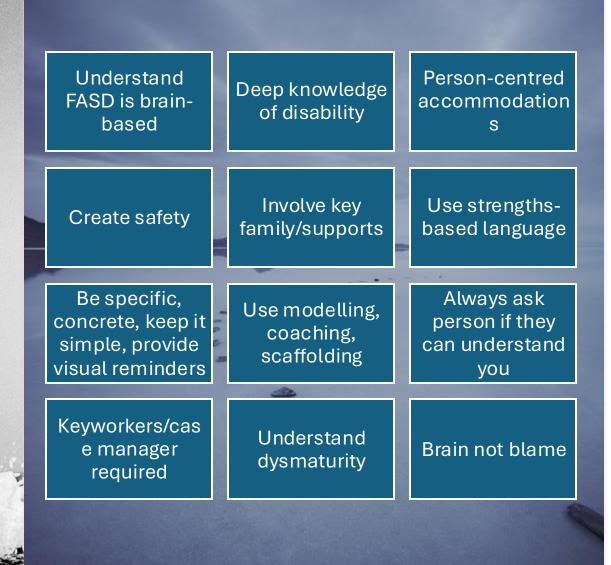
2] Promote safety and trustworthiness at all times

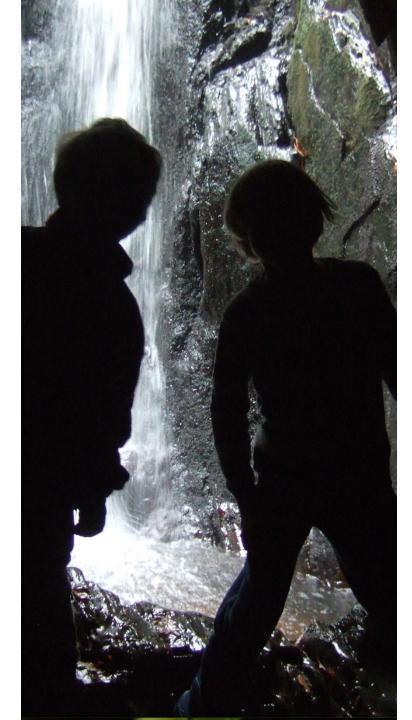
3] Empower people for choice and opportunity

4] Find out what works for them and build skills and capacity

https://canfasd.ca/2025/01/22/what-istrauma-informed-practice/







# Think Strengths or Gifts

- Persistence
- Determination
- Energetic / High Velocity
- Commitment
- Courage
- Unique perspective
- Strong sense of self
- Rich fantasy life
- Great storytelling
- Highly sensitive
- Spontaneity



# Calming the chaos...

- Appreciating the good qualities of kids... loving, fun, arty, sporty, funny, loves school,
- Laugh in the face of chaos
- Lots of prayers and meditation
- Medication sometimes
- Self-care
- Being a Warrior
- Everyone needs to reframe....
- Challenges to gifts

# Caregiver quotes -

You become a warrior, and you have your invisible protective gear on, really, to have the strength to get through, until you can get to bed, and get to sleep.

> We're finding coping strategies or making choices that empower"

I have medication plus my religion itself.. I have to keep myself always fed, my soul fed, spiritually... We would laugh in the face of adversity.. you have to have that resilience, and humour, and get over it quickly We've been enriched with these three mokopuna...it has changed our lives...being thankful for what we've got, for the simple things."

Retraining your brain.....constantly

I know it's a huge commitment obviously, but..... if they've got they're not afraid, they're in a place of security, they're loved, they're busy. Yes, they've got their challenges, but hey, we can offer them something of a flourishing life."

#### Figure 3: Berry Street Education Model: Developing an effective self-care plan



#### **Emotional needs**

Make time for friends and family Write gratitude lists Reflect with a close friend for support Stay in contact with important people in your life Find things that make you laugh Allow yourself to cry

### Self-care plan

#### Spiritual needs

Engage in mindfulness Go on a bushwalk Do yoga or meditate Be open to inspiration Have awe-filled experiences Practise your religion

#### **Energy needs**

Engage in a non-work hobby

Don't check your emails outside of work hours Arrive at and leave work on time

#### **Cognitive needs**

Do some research in an area of interest

Engage in professional development

Engage in regular supervision or peer consultation



# Strategies / models

Implementing models eg. using T. Kellerman's SCREAMS acronym –

Māori models

5s model

Have a toolbox

Tag teaming

Reframe

# Strategies / models

Prevention and distraction

Swearing and humour

**Reach out and care for others** 

Develop advocacy skills

**Become activists**/ call out system-wide abuse

### FASD Fact #38:

Many behavioral symptoms of FASD are due to a combination of differing brain functions.

50 FASD Facts is a creation of FAFASD, Families Affected by Fetal Alcohol Spectrum Disorder. #fafasd #50fasdfacts #tellthetruth #fasdfamilies fafasd.org/50facts

### For example, explosive rages could be:

- Sensory overload
- Overactive limbic response (fight or flight)
- Difficulty communicating
- "Age" appropriate developmental differences (meaning a reaction appropriate for developmental age, vs. chronological)
- FRUSTRATION due to being misunderstood or punished for behaviors directly related to a person's disability
- Stress response due to inappropriate consequences over time
- Low blood sugar, mitigated by sugar cravings and a need for more frequent meals/higher quality foods

Or any combination of the above (plus many other possibilities!)...

### WHAT IS CO-REGULATION?

A Guide to Nervous System Harmony

#### The Role of Co-regulation

Co-regulation is a supportive process where one person helps another manage their emotions, behavior, and physical responses through warm, connected interactions.

This shared experience helps individuals gradually develop self-regulation skills, making it easier to handle life's challenges on their own.

#### Why It Matters

Co-regulation fosters a sense of safety, especially for people with attachment challenges or trauma backgrounds.

It provides tools to help us understand and regulate our emotions, which supports overall emotional resilience.



A regulated client is better able to engage in therapeutic activities and learning, and participate in daily life tasks.

#### The Science of Co-regulation

The autonomic nervous system is key in regulating our emotional responses.

Co-regulation helps balance our sympathetic ("fight or flight") and parasympathetic ("rest and digest") systems.

This helps us achieve a state of safety and calm.

#### **Barriers to Co-regulation** and How to Avoid Them

**Provider Dysregulation** Use grounding techniques to stay calm when a client is highly dysregulated.

#### **Sensory Overload**

Simplify the environment or use soothing sensory tools to ease co-regulation.

#### **Emotional Escalation** Respond to aggressive

behavior with empathy and clear boundaries to encourage calm.

### **CO-REGULATION STRATEGIES**

**Tips for Providers. Parents and Caregivers** 



#### **Modeling Regulation**

#### Demonstrate calm behavior: Practice slow breathing. • Maintain a steady tone of voice. • Keep a relaxed posture.

• Sit with them.

#### **Grounding and Breathing Exercises**

Provide strategies they can practice on their own at home, school, etc.:

- Practice deep breathing techniques.
- Use grounding techniques that engage their senses: "What can you see, hear, or feel right now?"

#### **Creating a Co-regulating Environment**

safe space:

music).

of safety.



#### **Sensory Regulation** Support

**Provide sensory strategies to help** them regulate.

- Teach them deep pressure exercises on hands, feet, and other joint areas.
- Engage in proprioceptive activities, like jumping or pushing.



#### Verbal and Non-verbal Communication

#### Pay attention to your body language.

- Use a calm, steady voice, and gentle eye contact to convey safety.
- Provide physical reassurance if appropriate, such as a gentle hand on the back or sitting close by.



#### https://integratedlistening.com/resource-center/?content=infographic

1\_4

Special thanks to Daphne Boucher BA, MScOT, OT Reg. Visit unyte.com for more educational resources and to learn more about therapeutic tools for nervous system regulation.





Consider these when creating a

 Reduce overwhelming stimuli and introduce calming sensory

elements (soft lighting, calm

Maintain clear routines and

expectations to create a sense

• Designate a quiet space to go

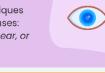
to with calming objects when

Use listening therapies like the

regulate the nervous system.

Safe and Sound Protocol to help

feeling overwhelmed.



# Tips to Regulate

Avoid saying	Try saying	What it communicates
Calm down!	"I'm here with you now"	Safety and presence, co-regulate
Stop crying! Stop shouting!	"It's OK to be upset, I can see this is hard for you."	Emotional expression/strong feelings are allowed
Don't be mad!	"It's ok to feel angry, how can I help?"	Normalises angry and promotes problem- solving
You're overreacting.	"It's understandable you'd feel like this, we're in this together, we'll find a way through it."	Co-regulation, team-based solutions
You're fine, there's nothing to be upset about.	"I can see that this is upsetting and difficult for you, let's chat"	Validates their emotional reality. Encourages communication.
That's enough now!	"Let's take a break, shall we move around a bit, go for a stroll?"	Supportive, offers a sensory/physical distraction
Relax!	It's ok to be upset, let's try a breathing trick to get through it together.	Offers a tool for regulation instead of a command.



### Dima aged 20 😊

# Wellbeing

"Well, I guess I would want to see people thriving, doing the things that they love doing, feeling good about themselves, knowing where they fit."

"Wellbeing for those with FASD looks like being who they are meant to be... being accepted.. being valued...being tolerated... being supported.. having the chance to fully participate in all aspects of life."



### The hope for a future

"Every parent wants their child to be happy, healthy and well, and feel secure... they should be able to have the same life and enjoyment out of life and so on, that somebody who does not have a disability has."

"They are valuable humans, they are beautiful, they are worth it, [we have to] fight for them, so they can be acknowledged"

