

Neurodivergence intersecting with justice, care, education and mental health systems: lessons to learn for better life course outcomes for those living with FASD.

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ŌTĀKOU WHAKAIHU WAKA

Session Overview



Introduction



Ableism and systemic abuse



Systems Issues/Common Experiences



Systems best practice



Questions



Introduction/Ko Wai Au?

Language matters

Neurodiversity is the diversity of human brains. My brain might work differently than yours because of neurodiversity. Neurodiversity is a fact of life!

A person is neurodivergent when their brain works in ways that differ from what is considered "normal". People with developmental, intellectual, psychiatric or learning disabilities can be considered neurodivergent. It's the opposite of neurotypical.

Neurodiverse describes a group of people with different brain types. Our world is neurodiverse. One person alone cannot be neurodiverse, they can only be neurodivergent or neurotypical.

Want to learn more? A good resource is:
[cosmopolitanism.com/neurodiversity-some-basic-terms-definitions/](https://www.cosmopolitanism.com/neurodiversity-some-basic-terms-definitions/)

Neurodivergent, neurotypical, neurodiverse? What does it all mean?



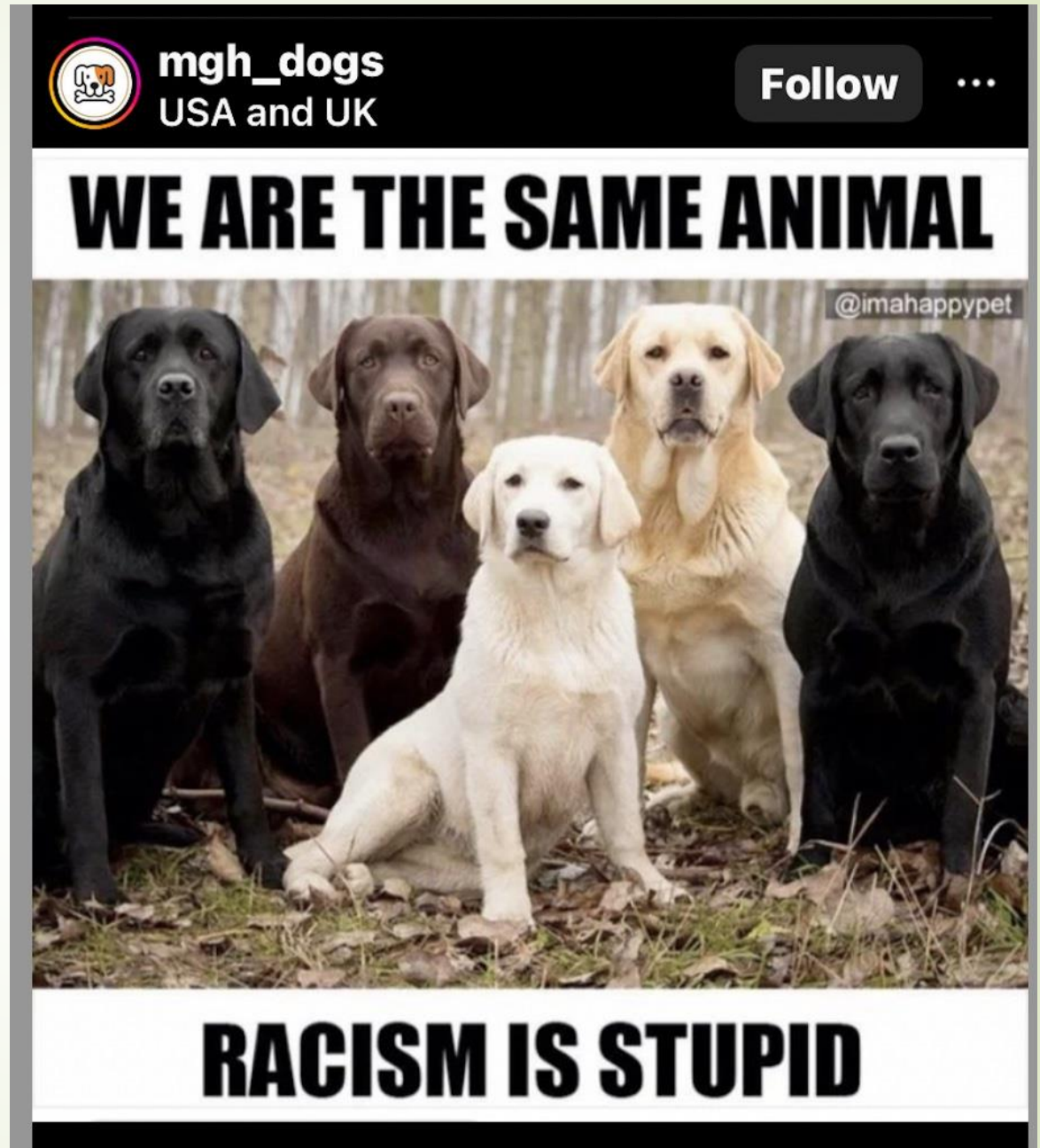
Ableism and Neuronormativity

Ableism – the favouring of non-disabled people

Dis-ableism – direct conscious acts and microaggressions towards disabled people

Neuronormativity – beliefs, standards, 'norms' and ideals that centre what it is to function in acceptable ways

Ableism is
stupid



Systemic abuse
and
neurominorities



PREVALENCE IN SYSTEMS

10-50% in child welfare system (screening and actual prevalence, UK, Eastern Europe, Canada, USA.)

36% with FASD in one youth detention centre in Australia.

Most undiagnosed or missed diagnosed.



It has long been suspected many detainees at Banksia Hill suffer from Foetal Alcohol Spectrum Disorder. (

News: Gavin Johns)



Abuse in care and justice

Startling link revealed between state care and prison



By Laura James, 1News Reporter

Wed, Aug 24 • Source: 1News



State care and ending up in prison is directly linked, according to new data revealed by the Abuse in Care Royal Commission of Inquiry.



Prison generic (Source: istock.com)

PRIMED FOR (IN) JUSTICE

PRIMARY ISSUES

- Vulnerable to being a victim, exploited, peer influenced
- Executive functioning and problem-solving challenges
- Not comprehending cause and effect
- Impulsivity and lack self-control
- Struggling to learn or follow instructions or keeping to conditions
- Poor adaptive daily skills, money, living skills
- Difficulty comprehending legal concepts, or giving statements (communication issues)
- Layer on trauma and systemic abuses
- Add in substance misuse, ACEs, trauma, Care experience etc



Disabling and criminalising systems

New Zealanders who had been placed in State residential care as children were approximately **five to nine times** more likely to be imprisoned than those who had not.



Abuse in Care
Royal Commission of Inquiry

Abuse in education (A. Marie-Day)

- Education is a known protective factor yet our kids with NDs are excluded and punished for learning differently!
- Children are dealing with labelling/stigma; isolation; exclusion; neglect and harm with their schooling (or lack of).

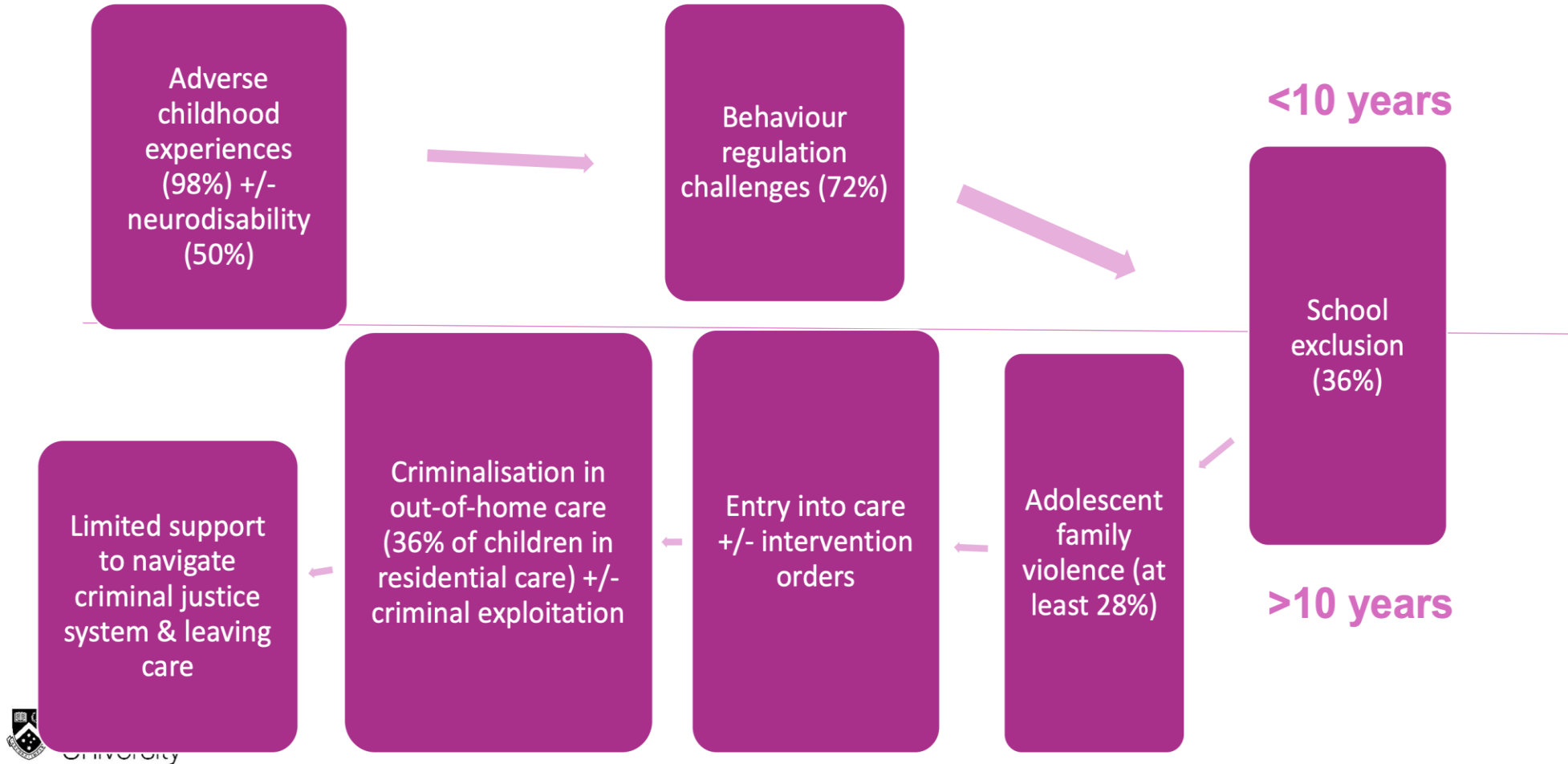


Welfare (Care and Protection)

- FASD and other NDs are a substantial risk to/for children in care - before, during and after.
- Placement disruption and a lack of FASD-informed practice.
- Over representation of indigenous children.
- Children, youth and adults with *“FASD have been constructed as both victims and dangerous, and their parents, particularly mothers, as neglectful and immoral.”* (Badry et al. 2022: e102)
- Setting them up to fail.....net widened into justice

PATHWAYS TO CRIMINALISATION

CHILDREN WITH DISABILITY IN CHILD PROTECTION



Baidawi, S. (2024) <https://www.youtube.com/watch?v=gNcWVCB6VF8&t=2764s>

Parent Blaming

Parent blaming – *‘That’s one thing that I remember, was that when your kids are behaving like complete brats, everybody blames the parents....that makes parents reluctant to come forward for help. Because it looks as though they can’t cope, they haven’t done the job properly...but it’s the stigma with badly behaved kids.*

‘Because many caregivers feel - caregivers feel blamed, not just the child but the caregivers blamed, poor parenting, you haven’t bought your child up right. So, they also end up retreating into their shells in many cases, because their social circles become a lot more closed because of that broader lack of understanding.



Research and social workers

- Lack of awareness, knowledge, skills and training
- Lack of referral pathways or capacity to get anyone assessed
- Lack of pathways for interventions or supports
- Lack of funding for any of the above
- Working effectively or not in multi-agency contexts
- Barriers to FASD-informed practices?
- Lack of agency policies or guidelines
- Social workers get frustrated with the children and youth and caregivers

Gilbert et al. (2021). Exploring the experiences of social workers in working with children suspected to have fetal alcohol spectrum disorders. *Adoption & Fostering*, 45(2), 155-172.

Mental Health



- Co-Occurring – up to 90%
- ADHD 61%,
- Suicidality/self-harm 35%,
- Self-medication ie substance misuse 48%
- Victimisation – 70%



Gatekeepers

Diagnosis issues- delayed,
missed, misdiagnosed,
misunderstood, mismanaged,
maligning, medical models

Disability Sector

Stigma issues

Lack of funding

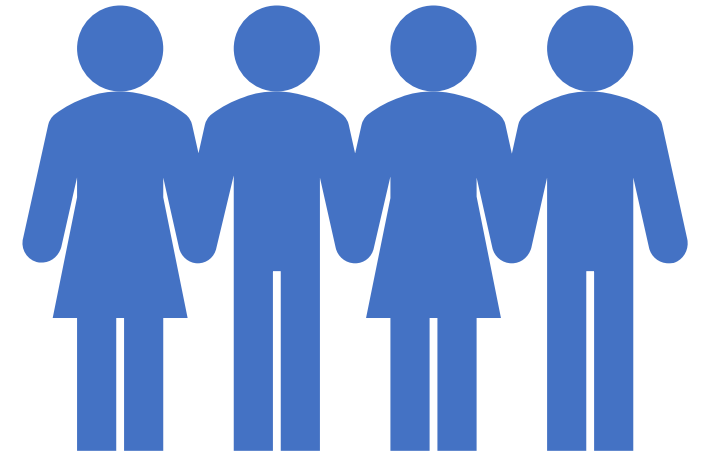
High turnover of support staff

Risk adverse

Acceptable disabilities and
unacceptable ones- FASD the ND
elephant in the room

No co-ordination

No accountability





Dima - Justice System

Dima's recent youth justice experiences and how to help young people involved in justice.





EXPERIENCES OF YOUTH JUSTICE-DIMA



Across Systems

- *‘when you get a diagnosis of FASD, there are still no services you can access, as of right. Our kids have all of the needs but none of the services.’*
- *‘Unfortunately, they tend to work in different organisations and everybody’s protecting their own patch. You know, this is our patch. You can’t tell us what to do with our money.’*
- *‘I think (Agency) following through with the respite that they promise you would help.’*



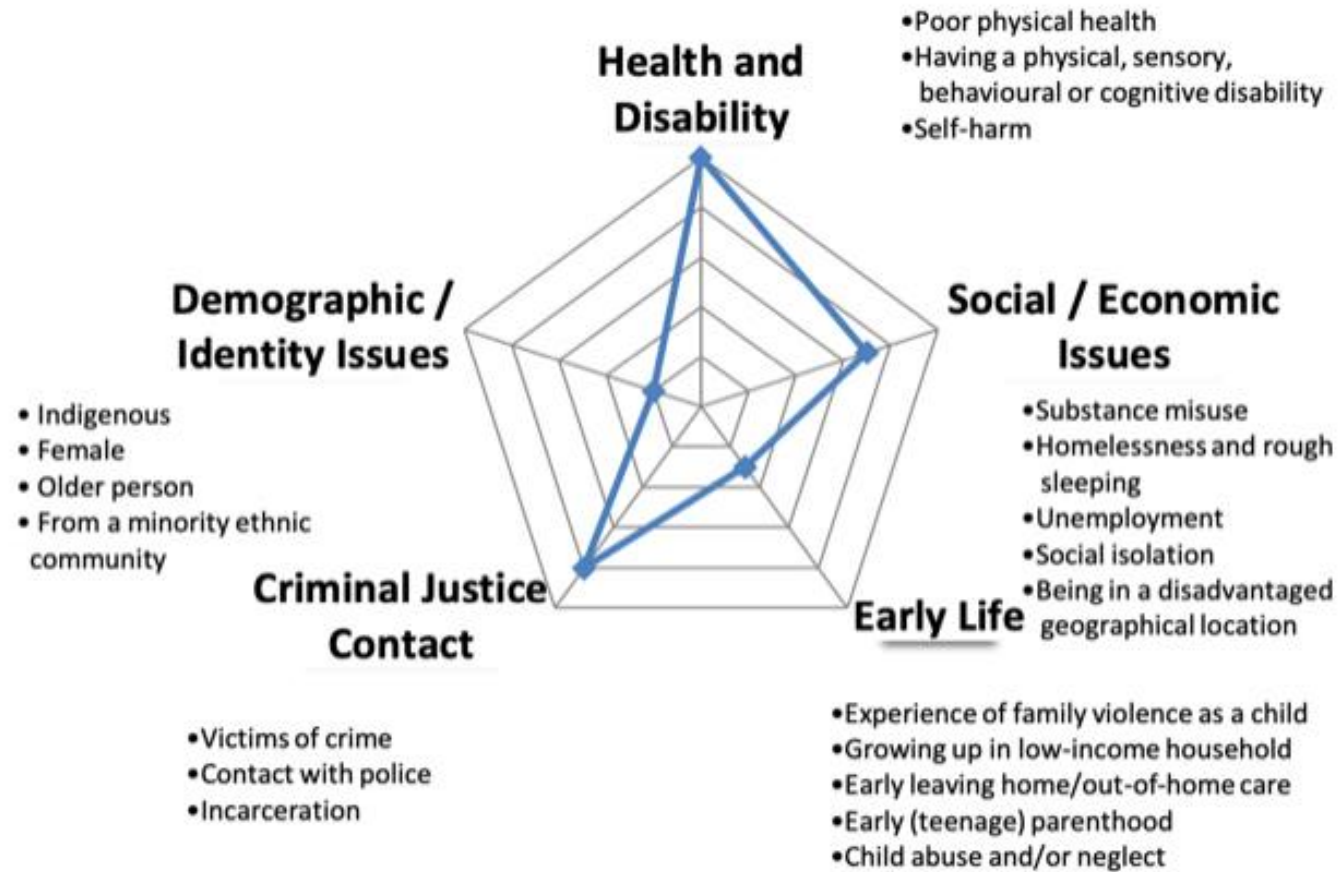


Figure 1: Web of criminalisation (created by authors Baldry et al. 2013a)

Social determinants of Justice Involvement (Criminalisation)



- 1] Out of home care
- 2] Poor education
- 3] Being Indigenous
- 4] Early contact with police
- 5] Unsupported mental health/cognitive disability
- 6] Problematic substance misuse
- 7] Unstable housing/homelessness
- 8] Living in disadvantaged location

Ruth McCausland
and Eileen
Baldry, UNSW
Sydney



Systems fail our
children...

If this were my
child (Anne-
Marie Day)

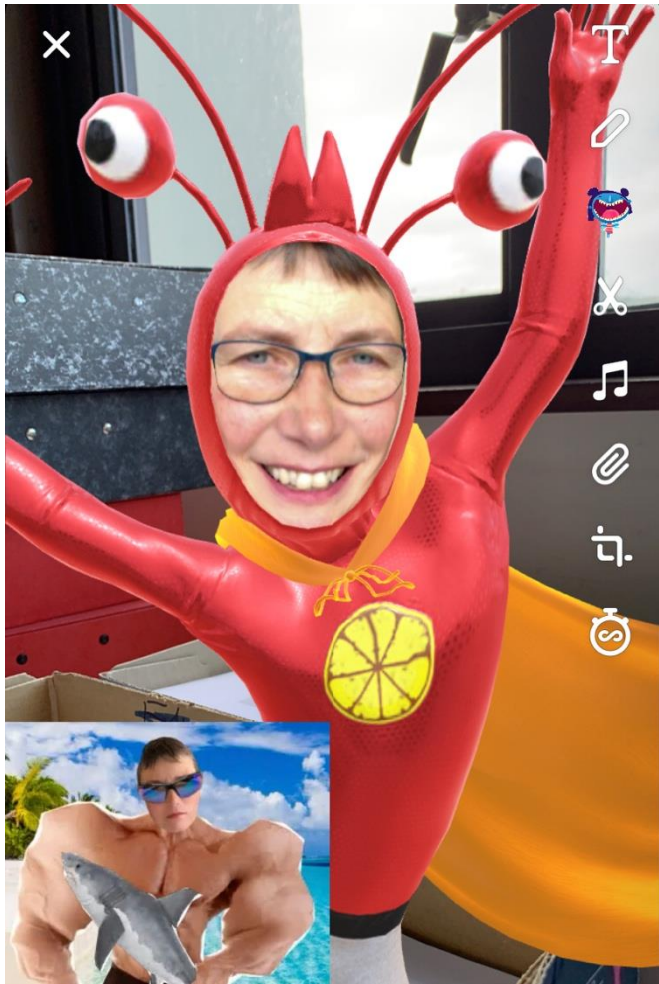


Feels like an unstoppable wind

'There is no light at the end of the tunnel..it is just chaos all of the time'

'I think that has lead to exhaustion, to burnout. Because you never have downtime. It is always in your face....you can feel trapped.'

'Caregivers feel blamed, not just the child but the caregivers blamed, poor parenting, you haven't bought your child up right...end up retreating into their shells in many cases'



Parents/caregivers are
superheroes

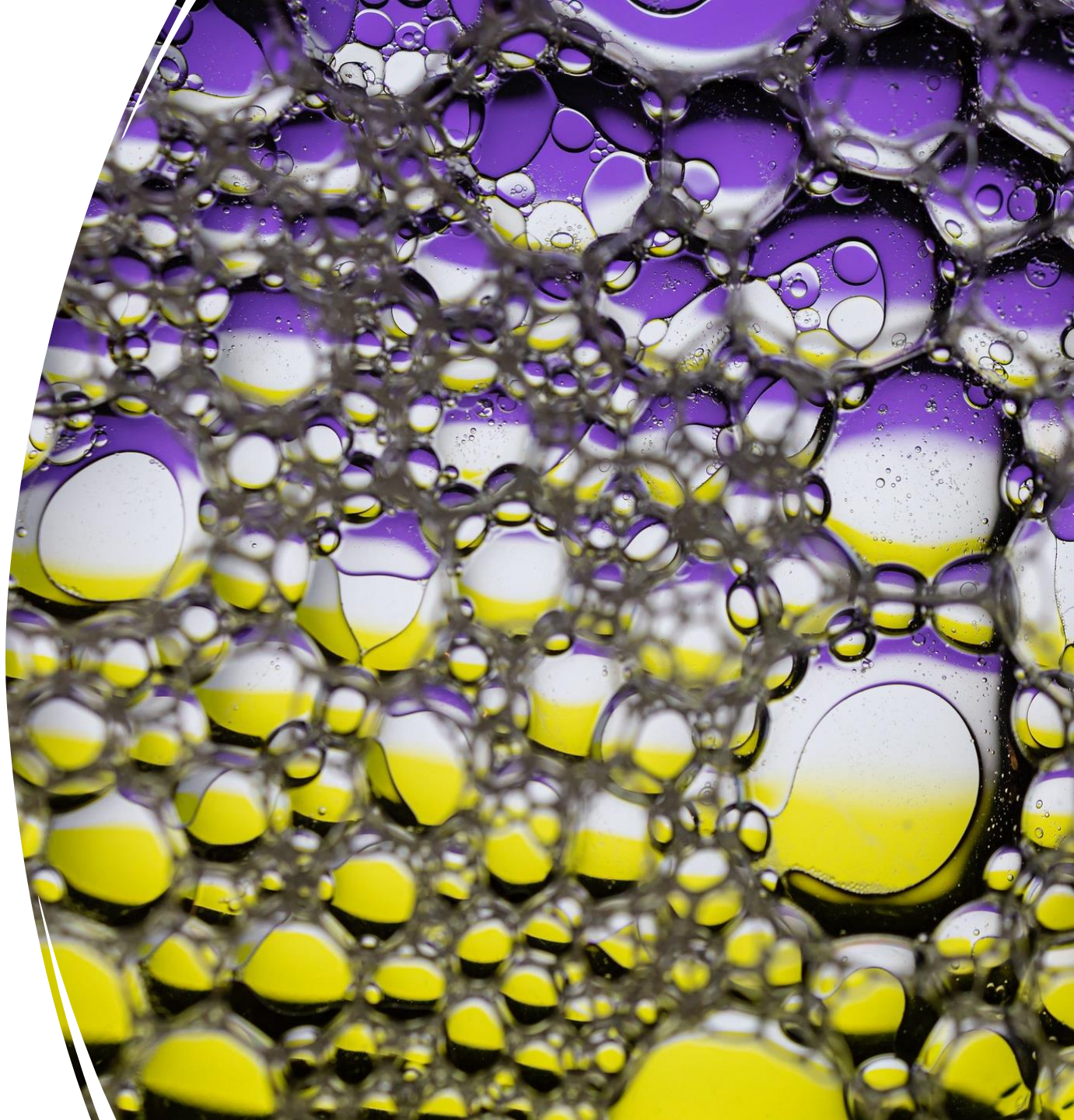


What caregivers want to see?

- Knowledge and Quals
- Support – navigators, DSS funding, respite, living hubs, support groups, specialised interventions,
- Maintain stable placements
- Develop the peer/coaching workforce
- National and regional strategies/communities of practice
- Systems change

BELIEVE US

- *“Treat us with dignity and respect, we know our child better than [everyone], be transparent, open and honest with us, work with us not against us, support us to support our child, look at our child through a neuro-behavioural lens, listen, educate yourselves, put accommodations and supports in place”.*
- *‘But I think they need to - I don't know - just be more supportive of caregivers. See them as professionals. Because that's really what we are.’*





Building ramps instead of walls

REFRAME, RETHINK, RESPECT

Behaviour/What we see	What we think	What's really going on
Not keeping to the rules/expectations		
Making same mistakes over and over		
Late/ absent		
Fidgety/distracted		
Not working independently		
Poor social judgement		
Interrupts		

Adapted from: Evensen, D.L. (1994). Integrated Active Learning and the Child with FAS/FAE: Help for Tired Teachers: Homer, Alaska

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THINGS ABOUT ME

Dear Support Staff

You might not know me very well yet but here are 11 things about me that might help you understand and bring out the best in me.

MEMORY AND ORGANISATION

- | | | | | | |
|----------|---|----------|--|----------|---|
| 1 | I have trouble organising my thoughts.
You can help me by giving me extra time. | 2 | I can become overwhelmed by multi-step instructions and I forget what to do.
Chunk it down into smaller steps. | 3 | My working memory is not as good as my peers.
You can help me by prompting me and / or using visuals. |
|----------|---|----------|--|----------|---|

FOCUS AND ATTENTION

- | | | | | | |
|----------|--|----------|---|----------|---|
| 4 | I can easily lose track of time.
You can help me by checking in with me throughout a task. | 5 | I find transitions tough.
Please give me warnings of any changes coming up. | 6 | I get distracted.
Have patience and kindly repeat instructions. |
|----------|--|----------|---|----------|---|

IMPULSIVITY AND INHIBITION

- | | | | | | |
|----------|--|----------|---|----------|--|
| 7 | My hands and legs feel like they have a life of their own.
You can help me by agreeing on a way to keep them busy so I don't disrupt others. | 8 | My body needs to move so my mind can be calm.
You can allow me to have regular movement breaks. | 9 | I can be very chatty and I won't know when to stop.
You can help me by agreeing with me on a discreet signal to remind me to be quiet. |
|----------|--|----------|---|----------|--|

EMOTIONAL REGULATION

- | | | | |
|-----------|--|-----------|---|
| 10 | I hear negative comments all day.
You can help me by finding positive things to build my confidence. | 11 | I find it hard to control my emotions.
You can help me by providing a safe space for me to cool down without shame. |
|-----------|--|-----------|---|

You are my safe adult and I hope you can see that I am more than the sum of my deficits.

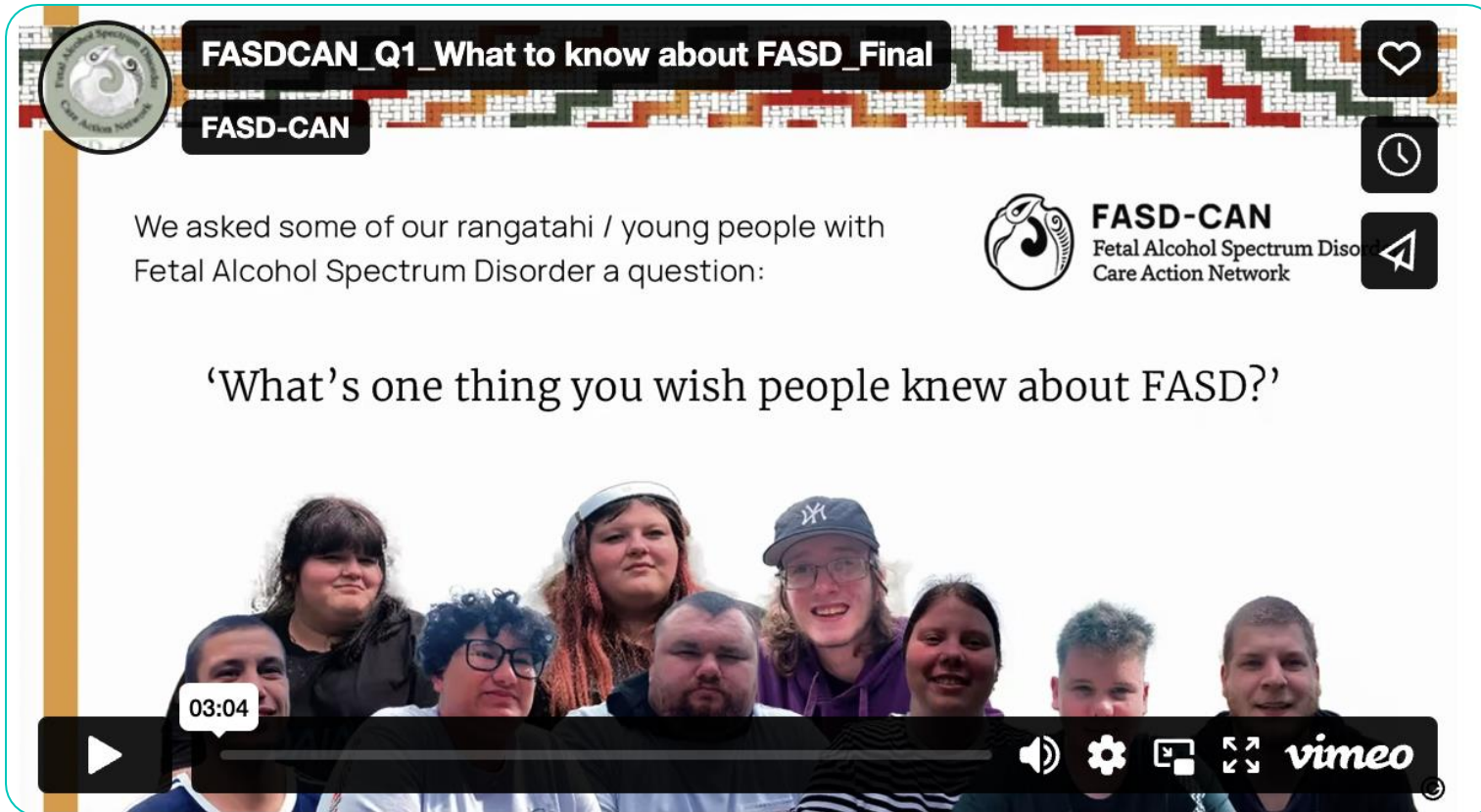
Support Staff

https://assets.nationbuilder.com/fasdcan/pages/443/attachments/original/1693256369/Dear_Support_Staff.pdf?1693256369
9

Needs in the child welfare system

(Badry et al. 2022)

- Support families
- Address multiple placements
- Use Disability-informed lens
- Address diagnosis issues
- Create collaborative environments and relationships
- Tailor individual case plans/management
- Provide lifelong ongoing supports
- Proactively plan pre-birth
- Address gaps between child welfare system and Indigenous communities
- Provide public education and awareness of FASD
- Training on FASD for all child serving professionals



**What people need to know
about FASD?**

○ <https://vimeo.com/941407338>



Lived experience: needs and priorities

Stop

- Stop making us invisible

Recognise

- Recognise our oppression

Listen

- Listen to us, give us pathways

Involve

- Involve us, we are the experts



New Zealand young people with FASD

- *** Be aware of the consequences of prenatal alcohol exposure.**
 - * There must be quick access to affordable and accurate diagnosis.
 - * We need mandatory training on FASD**
- *** Schools and teachers must understand young people and rangatahi with FASD**
- *** Our whānau, carers and families need more support.**
 - * We need specialist support
- *** We need pathways and support for transitioning into adulthood,**
 - * People with FASD must be represented in all decisions and policies that affect us.

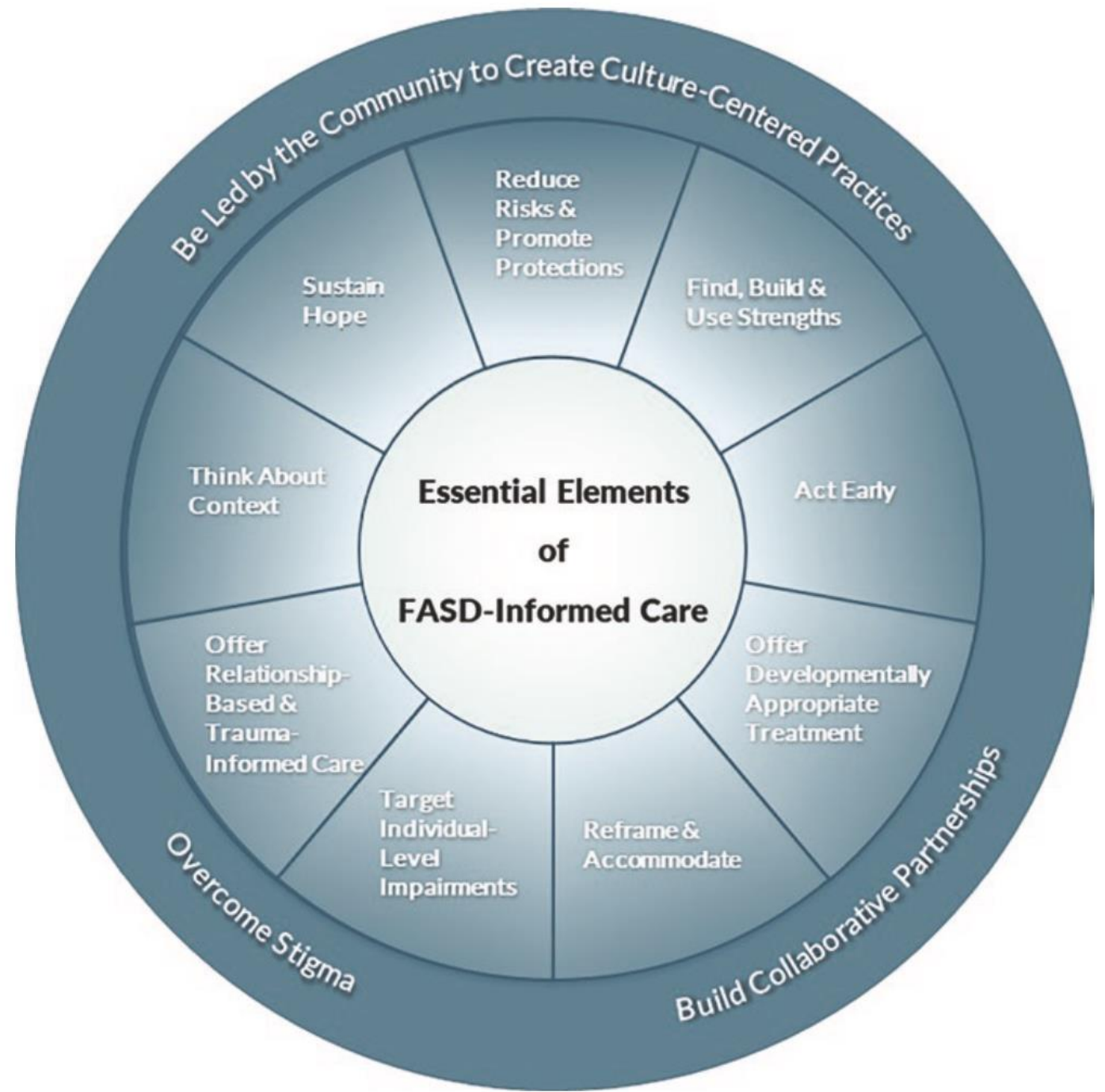
Thriving and Growth



Essential Elements of FASD-Informed Care for Intervention with Individuals and Families

Olson, H.C., Pruner, M., Byington, N., Jirikowic, T. (2023). FASD-Informed Care and the Future of Intervention. In: Abdul-Rahman, O.A., Petrenko, C.L.M. (eds) Fetal Alcohol Spectrum Disorders . Springer, Cham.

https://doi.org/10.1007/978-3-031-32386-7_13



Healthy outcomes in systems

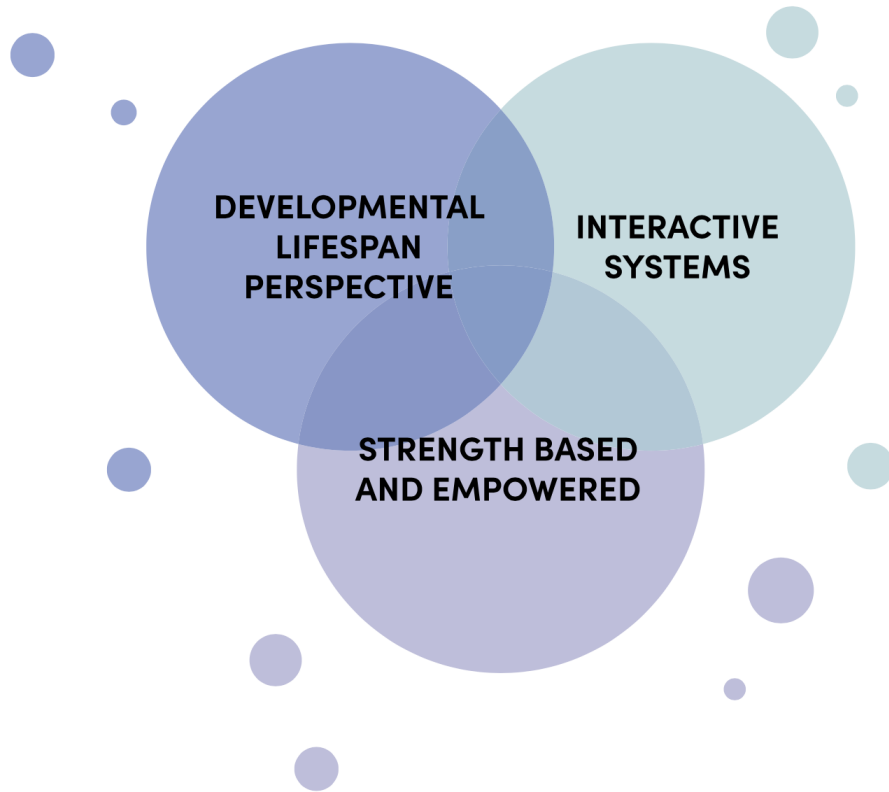
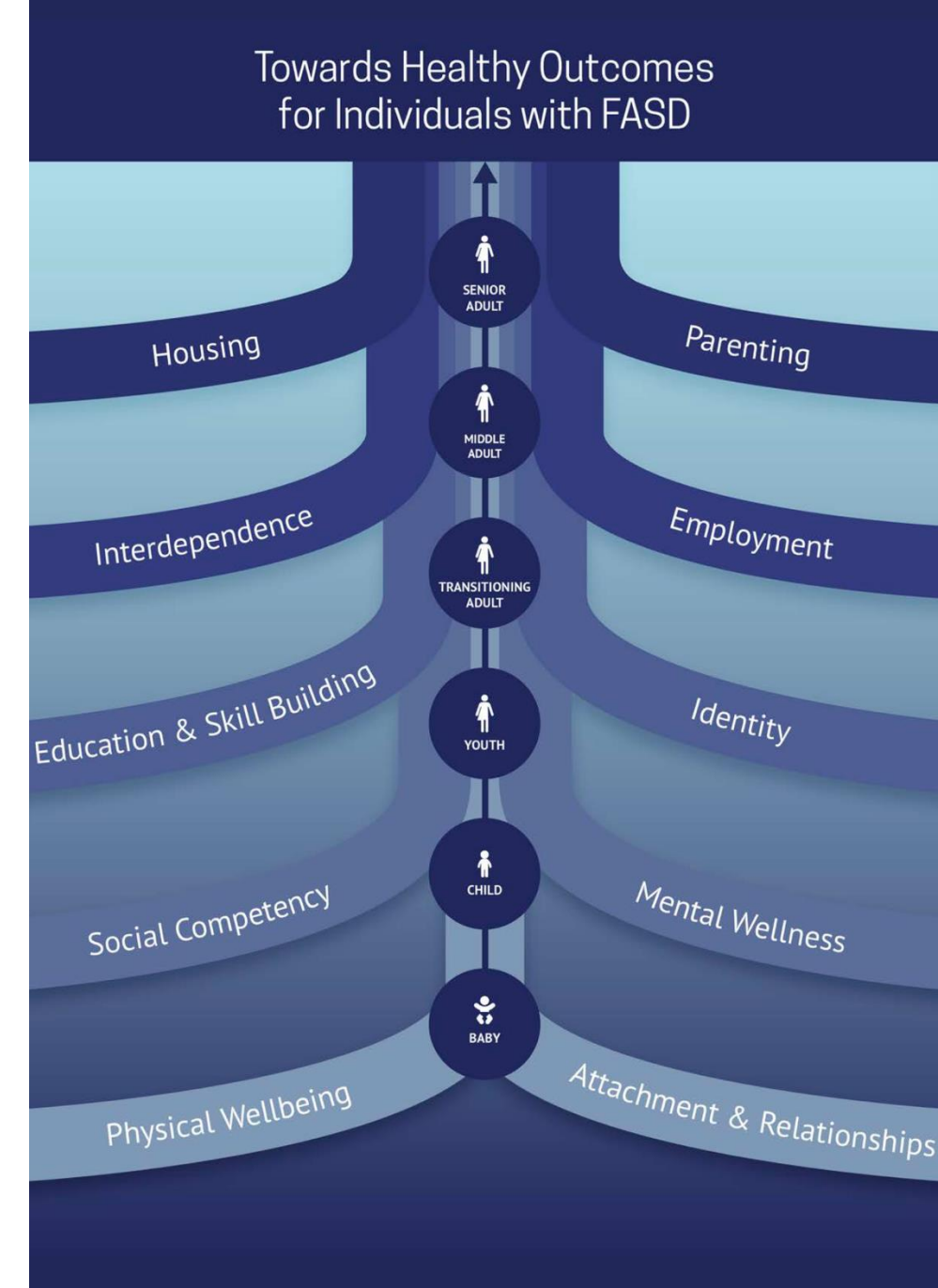


FIGURE 1. Philosophical Model



NEUROBEHAVIOURAL LENS

- Unexpected behaviours and difficulties are *symptoms* of FASD/NDs
- Use a brain-based “lens” to understand the person.
- Ask the person about their strengths and challenges.
- Make reasonable accommodations to ensure that they feel safe and regulated.
- Building and maintaining connection priority.
- If you find yourself becoming frustrated reframe
- Adapt verbal and non-verbal communication to meet the person’s receptive language needs.





Finally...Build intergenerational resilience.....

- Decolonising
- Prevention of alcohol harm
- Breaking cycles
- An inclusive disability system, no hierarchy's no exclusions.
- Collective wellbeing / hauora
- Nothing about us without us – learn the lessons of the past

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