



Towards an integrated approach to FASD

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I want to start a conversation...

...about what needs to happen post diagnosis, so that individuals with FASD and their families can access support when they identify a need for it.

...and about some of the possible causes of secondary disability that lie outside of brain dysfunction and how we might start to address them.

I also want to swing the lens around for a minute, away from the focus on managing the individual with FASD to what **we**, as professionals, families and researchers might be able to do within our various services, systems and homes that will have a positive impact on people living with FASD.

“They get the piece, but not the picture”



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Sam, Age 10

- Sam had been placed with her family (“mum and dad”) as an infant
- Her carers have two older biological children
- Carers had a strong relationship with Sam but felt frustrated and ‘burnt out’
- Family was financially secure
- Sam had always struggled at school
- Good relationship with current school but increasing tensions



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Reason for referral

- Suspected FASD
- Aggressive and violent outbursts
- Compulsive lying
- Inappropriate social relationships
- Difficulty making and keeping friends
- Disruptive in classroom
- Disrespectful to teachers
- Stealing
- School truancy
- Self harm

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Strengths and likes

- Friendly
- Artistic
- Creative
- Lots of energy
- Tries hard
- Supportive family
- Loves teddy bears and working with clay.



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Concern	Interventions /Approaches
Aggressive and violent outbursts	CBT, Anger management, emotional regulation training
Compulsive lying	Privileges removed
Inappropriate social relationships	Isolated from peers at school breaks No social activities outside of school
Disruptive in classroom and disrespectful to teachers	Suspension, detention, principals office, loss of privileges, reward system
Stealing	Pay back the cost, grounded, engagement with Police
School truancy	Detention, extra homework
Self harm	Talk therapy, mindfulness

Plus various parenting programs and carer training programs

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LA TROBE UNIVERSITY AUSTRALIA All kinds of clever

When these interventions did not work Sam was labeled: **Reluctant to change, willfully defiant, oppositional, difficult**



Her carers felt they had been labeled as: **inconsistent, ineffective, demanding**

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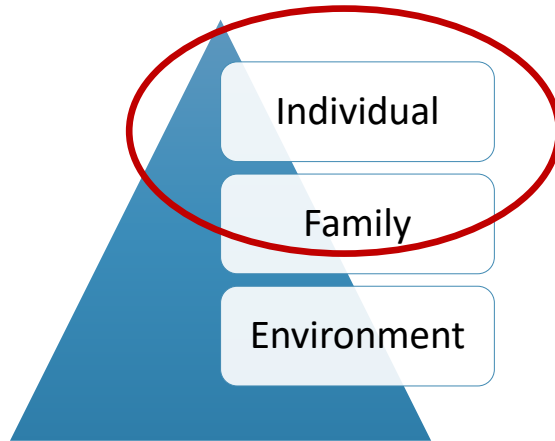
Sam and her carers felt:

- Fed up
- “Nothing works”
- Frustrated
- Exhausted
- Angry
- Hopeless
- Worried



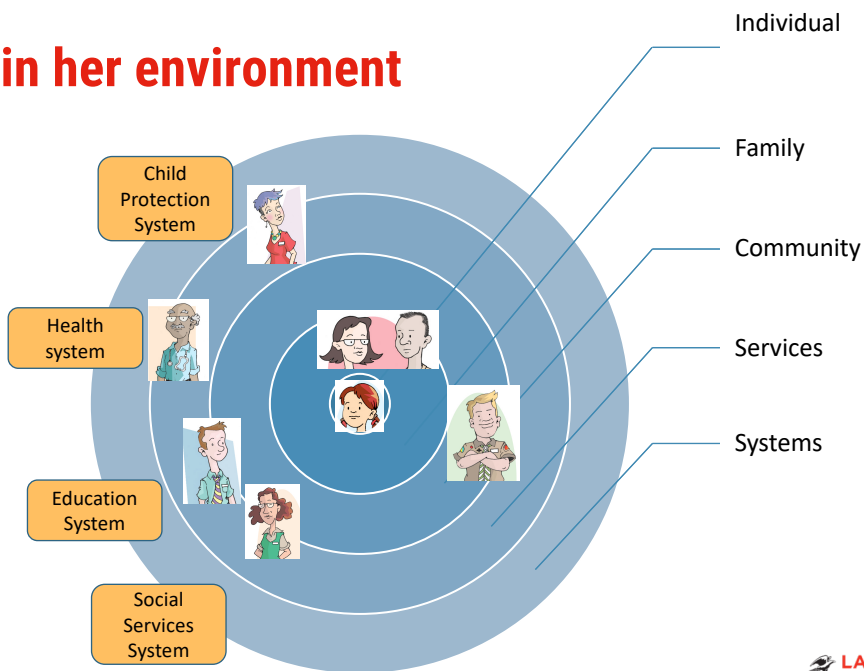
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When we looked at the types intervention to date:



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Sam in her environment



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Looking at the whole picture allowed us to:

- Identify possible points for intervention and support
- Consider the changes 'we' might be able to make to Sam's environment, so that it was a better fit for Sam and met her needs
- Consider how we might work together, so everyone was 'one the same page' – consistency for Sam, and an integrated approach

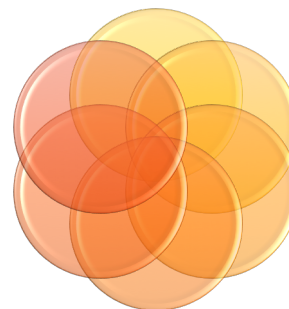
FASD assessment



Academic
achievement

Language

Executive Function



Memory

Attention

Adaptive behaviour
Social skills and
communication

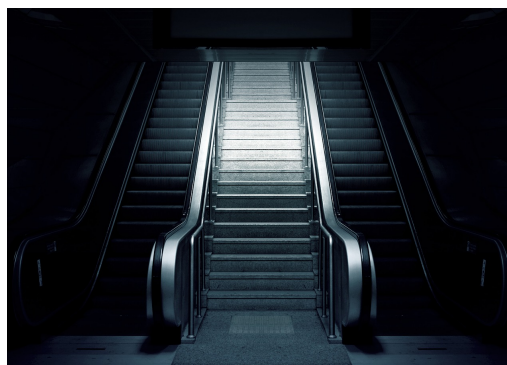
What does Sam's brain have to do?

Concern	Interventions/Approaches
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Compulsive lying	Privileges removed
Inappropriate social relationships Difficulty making and keeping friends	Isolated from peers at school breaks. No social activities outside of school
Disruptive in classroom Disrespectful to teachers	Suspension, detention, principals office, loss of privileges
Stealing	Removal of privileges, pay back the cost, engagement with Police
School truancy	Detention, extra homework
Self harm	Safety contracts, Talk therapy, mindfulness

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Social model of disability:

- Environmental structures and attitudes need to be adjusted to accommodate integration of individuals with disabilities
- Societal barriers may exacerbate disabling conditions
- People may be born with or acquire impairments, but society creates disability



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What did we do? We worked in partnership and...

- **Switched the focus** from changing the child to changing our responses
- Focused on **preventing** problems by understanding the triggers
- Began to **examine** and **question** whether behaviours were willful or part of brain dysfunction
- Family elected to temporarily stop all clinical interventions

Won't?	OR	Can't?
Lazy, unmotivated	or	Tired of failing
Attention seeking	or	Needs support
Doesn't care	or	Can't show feelings
Acting immature	or	Being young
Compulsive lying	or	Confabulating
Willfully defiant	or	Frustrated, challenged

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Home

- Emotional regulation and de-escalation strategies with parents. "Don't poke the bear!"
- Worked with Sam to **understand herself** and FASD in a positive **strengths based** perspective - brain diversity
- Charted and documented all 'melt downs'
- Did lots of problem solving
- Decreased they 'why did you?' questions
- Developed clear and consistent family routines



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Child protection

- Strong advocacy for extra financial support drawing on the diagnostic report
- Engagement of mentor (also acted as respite)



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School

- Developed a plan on how we communicate and best work together. Sam's mum was the coordination point.
- Developed an IEP based on Sam's strengths and challenges with a focus on making reasonable adjustments to the school environment
- Ran an 'understanding' session for all teachers and staff engaged with Sam
- We placed a strong focus on re-building relationships



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School

- Adapted curriculum
- More challenging work at the start of the day
- Allowed more time to complete tasks
- Regular break times
- Monitored during breaks or structured activities
- Fostered a relationship between Sam and the school counselor
- 'Special helper' for younger students
- No homework



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Community

- Structured activities for developing social relationships and positive experiences
- Ran a mini training with scouts on FASD
- Identified strengths (art and drawing) and built on them

Safety:

- Increased supervision (stealing).
- Police relationship and awareness.



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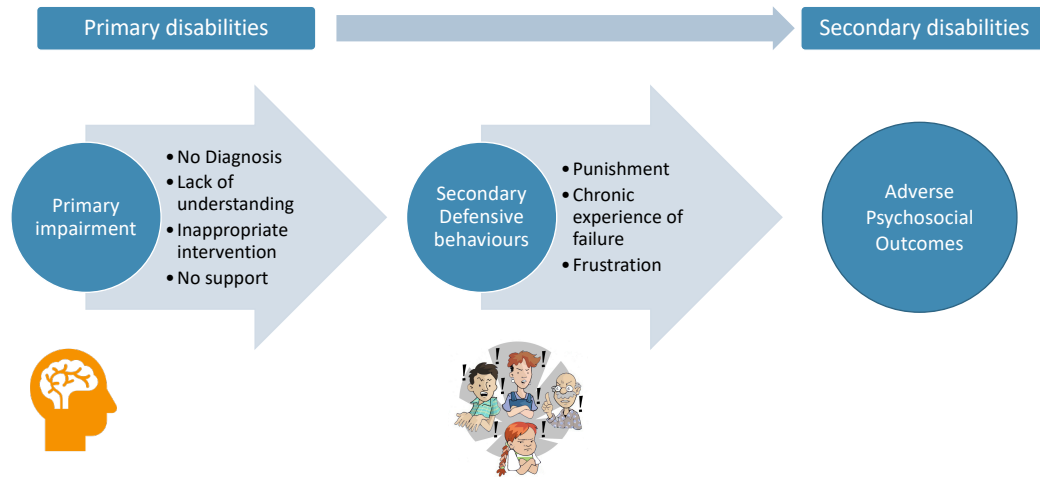
Some outcomes

- Increased positive self regard and mood
- Increased opportunities and experiences of success
- Significant decrease in aggressive outbursts at home and school
- Decreased parent stress (from a consistent 9/10 to a 3/4)
- School reported increased confidence and skill in managing behaviors
- Increased ability to calm down after an outburst
- Improvements in behavior at school, and minor improvements academically
- No further stealing
- Expansion of social circle. Development of a friendship!
- No absconding from school

Two observations:

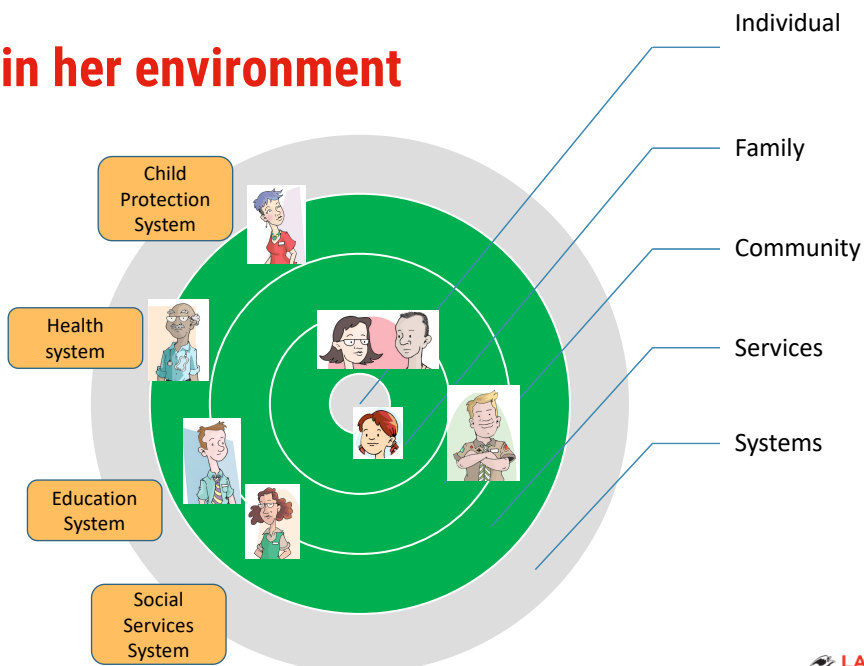
- Sam and her family's experiences and feelings are not uncommon.
- Chronic frustration and experiences of failure for people with FASD and their families are a source of considerable impact.

Primary and secondary disability: the pivotal importance of diagnosis and appropriate support



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Sam in her environment



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Challenges going forward:

- We are getting better at providing professional development for FASD. However, this knowledge can be lost when professionals move jobs/retire/change roles. How can we embed policy and practice standards for FASD across systems?
- Our practice and research frameworks are mainly focused on children, but FASD remains a life-long condition. How should we plan for a pivot towards the needs of adults?
- How can we advance research approaches that enable consumer collaboration (parent/carer and those with FASD) and produce applied outcomes?
- Answering these questions will help to piece the puzzle together.

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With acknowledgements to Nick Buttfield for the cartoon images

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Thank you

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