

Managing FASD at Home

The Centre For  FASD

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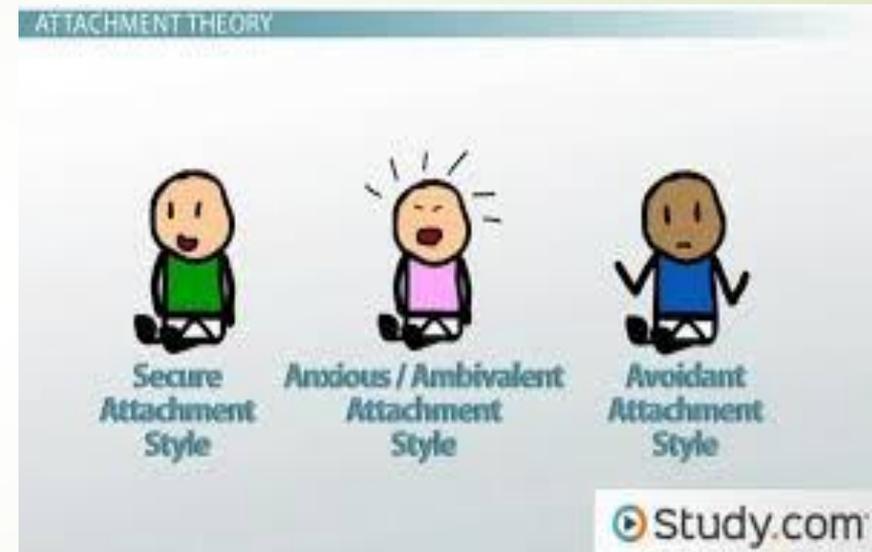
Agenda



- FASD and Attachment
- Strategies not Solutions
- Preventing burnout in parents/carers
- Therapeutic Intervention
- Group work
- Questions

Attachment

- Attachment is *part* of the picture for many children with FASD (but the neurological effects are separate – Mukerjee et al, 2018)
- It is tempting to hang everything on attachment
- Children with FASD and attachment problems tend to have more severe externalising attachment disordered behaviour due to EF impairment.





Keep in mind...

- FASD is organic brain damage
 - Children with FASD do learn, but they learn differently
 - You are your child's greatest advocate
 - You will probably be on the receiving end of the very best, and very worst of your child's behaviour
 - Parenting a child with FASD is challenging. It's ok to say that out loud and seek support
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Environment

- Easily overwhelmed in every day situations
 - Manage sensory input to reduce risk of overload
 - Decrease clutter in the home
 - Prepare for transitions; Surprises are rarely a good idea
 - Manage time spent on screens and gaming
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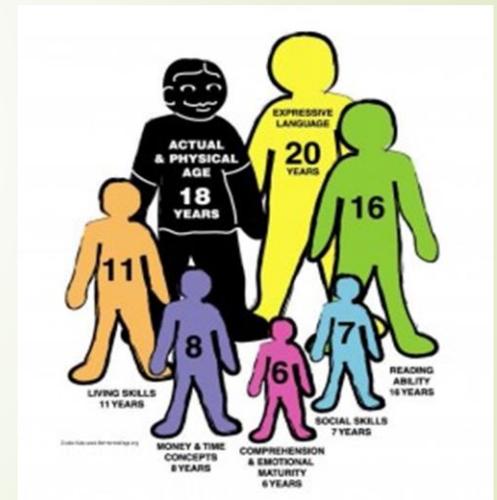


Structure, support, supervision

- Lack of supervision > trouble
- Try to keep homelife structured and consistent – this provides a sense of time passing and predictability
- Cue your child in to what will happen next throughout the day
- Remember your child will not necessarily generalise a set of rules across different settings
- Role-playing scripts and social stories

Adapt your Expectations

- ▶ The 'halve their age' rule
- ▶ There is a distinction between giving up on your child, and giving up on trying to make them do things they cannot do
- ▶ Your child will benefit hugely from learning coping and adaptation skills that accommodate their FASD (like teaching a blind person to use Braille)
- ▶ You cannot change the brain damage, so the focus must be on changing the environment





Sensory Needs

- ▶ Sensory information is frequently interpreted differently:
 - ▶ Hyper-sensitive (feeling things too much)
 - ▶ Hypo-sensitive (not feeling things enough)
 - ▶ OT Sensory processing assessment > sensory integration therapy and/or strategies
 - ▶ Refusal to participate in certain activities or to be able to manage certain environments may be a sensory issue
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Behaviour Management: Moving from Discipline to Redirection/reteaching

- Your consistency = key to their success
- Avoid making threats
- Provide a safe place for expressing anger
- Support the recognition of becoming dysregulated
- Emphasis on teaching self-regulation and self-soothing
- Keep family rules simple and positive: keep hands to self, walk up the stairs



Strategies that rarely work

- ▶ (Often done for benefit of watchful siblings)
- ▶ Traditional behaviour management techniques and reward systems:
 - ▶ Time out – will not bring about learning and not repeating the behaviour
 - ▶ Tokens and stickers – we are assuming impulse control and a concept of future earning
- ▶ If a strategy is not working, try another. Don't give up.



Calming techniques

- Create a calming down zone at home and do not use as a punishment, but as a positive strategy for learning to self-regulate
 - You may need to stay with your child initially
 - No touch or firm touch
 - Movement
 - There is no point trying to reason at a time of dysregulation
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Abstract Understanding

- ▶ These are generally life-long difficulties
- ▶ No internal concept of time
 - ▶ Talk about time by association
 - ▶ Structure days by routine events
 - ▶ Use digital and analogue clocks side by side
 - ▶ Use alarms and reminders
- ▶ Little concept of money
 - ▶ Over-seeing even in adulthood (be their external frontal lobes)
 - ▶ Impulsive buying
 - ▶ £1 and £10 both acceptable for a chocolate bar
 - ▶ Try to equate sums of money with value





Abstract Understanding

- ▶ Ownership is an abstract concept
 - ▶ 'Taking' and 'finding' behaviour occurs when your child sees something they want and the person that connects the object to the owner is absent
 - ▶ Supervision and redirection are key to prevention
- ▶ Story-telling: lying and fabrication
 - ▶ Reality and fantasy is blurry
 - ▶ Working memory is poor
 - ▶ Do not consequence lies, as you are punishing for having executive functioning and working memory deficits

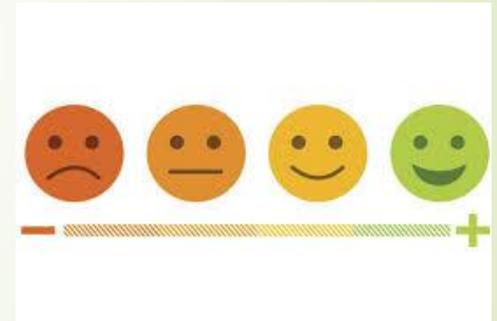


Communication

- ▶ Remember receptive language is far weaker than expressive language: they can talk the talk!
- ▶ Keep your language as concrete as possible
- ▶ Allow processing time (longer than you think)
- ▶ Jokes and sarcasm may be taken literally
- ▶ Just because your child can repeat an instruction back does not mean they understand what to do
- ▶ Match your communication to the 'halve their age' rule
- ▶ A serious chat may be aided by fidget toys

Feelings and emotions

- Struggle to put feelings into words, and to understand other's emotions
- Teach emotions in a concrete way: create a feelings dictionary
- Name emotions clearly. For teens and adults, use the technical term followed with the term their friends may use: angry vs. pissed off
- When a feeling is correctly identified, have a simple plan of action
- Do not expect:
 - Insight
 - Automatic carry over of learning from one day to the next
 - An understanding of your feeling of sadness just because they have learned to understand their own feeling of sadness



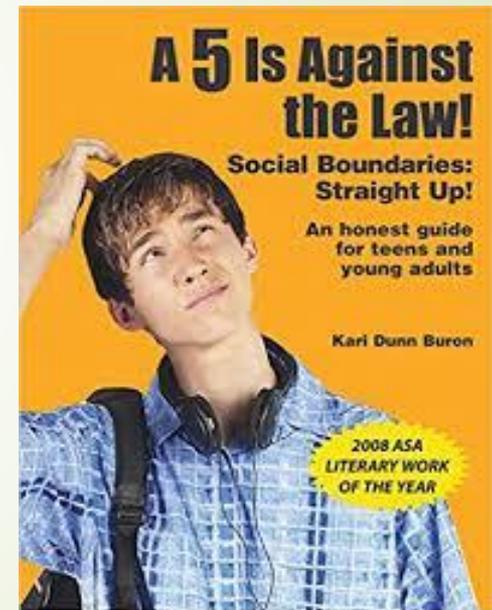


Transition planning into adulthood

- This may mean:
 - Accepting that independent living is not possible, but supported living is
 - Working out what level of help is needed with daily living
 - Realistic educational/vocational expectations based upon function, not IQ
 - Preventing drug and alcohol problems
 - Catching any mental health difficulties early
 - Financial inter-dependence

Relationships and sexuality

- ▶ EF impairment = overfamiliarity, not understanding personal boundaries, misinterpreting social cues, and being easily led/persuaded
- ▶ (Normal) sexual curiosity, but without imagining consequences of actions
- ▶ Impulsivity and reckless behaviour might be valuable traits in some less desirable groups of young people...
- ▶ Supervise outings and activities as much as possible
- ▶ Repeatable sex education lessons: be explicit and concrete. Do not assume understanding
- ▶ Book: A 5 is Against the Law! Social Boundaries Straight Up! Kari Dunn Buron (2007)





Therapeutic Intervention: What works, what doesn't

- ▶ The trouble with general talking therapies:
 - ▶ It's all very abstract
 - ▶ Learning from one session to the next is assumed
 - ▶ Receptive and abstract understanding of language is assumed
- ▶ Practical therapies:
 - ▶ May be more effective at teaching self-regulation
 - ▶ May be more accessible cognitively
 - ▶ May create more functional change
 - ▶ Remember – change is slow



Burnout in parents and carers

- Caring for a child with FASD is exhausting and relentless
 - You **MUST** take time out for yourself
 - Access support groups (or create one!)
 - Keep in touch with NOFAS-UK and other organisations who get it.
 - The Centre for FASD offers psychological therapy for parents and carers of children with FASD
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Group Discussion

Scenario One

- ▶ 11-year old child comes home from school. Shouts at Mum when asked if the day was ok. Mum asks if the child wants a snack. Child wants sweets but Mum is offering fruit or yoghurt. Child slaps the food out of Mum's hand and starts kicking and throwing. Child slams the door and breaks it. What might be the triggers in this scenario and what can mum do?

Scenario Two

- ▶ 15-year old wants to go out with friends but the last time this happened, teen stole snacks from a shop. Carer has noticed money missing from change jar, but teen denies having taken it, and accuses younger sibling of taking it. Carer knows this is not true. Carer is concerned about the group of friends, but feels like doesn't have a way to keep teen home and feels bad because teen lacks friends. What can carer do to help teen feel less angry/isolated?



Questions?

