



Turning the Corner

18 September 2019, ACAMH, London

Sandy Butcher, Chief Executive, NOFAS-UK



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Could talk all day – it's an intense topic
but I won't, no worries 🙅

Here's what I will cover:

- Our personal journey – it was grim and now it's not
- What helped us turn the corner – professionals/insight/support
- Perspectives from others who are walking this path
- Resources/support available

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Some say a diagnosis is just a label, but I see it as a lens. Without that lens you may look at me and make judgements based on what you see but with the lens of my diagnosis you can look at me with greater understanding of what you're really seeing.



Unknown source

Information is power

- Informed individuals and families can rise to the challenges of FASD
- Minimizing evidence of exposure to alcohol in the womb and/or playing down possible lifelong challenges helps no one

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"We Knew"

- "Our guy used to laugh when he felt the wind on his face because he had never felt it before. He came into our lives silent, not walking, unable to know when to stop eating, rocking, jumping, falling, throwing himself into walls, and clinging desperately to me once he understood he had someone of his own, finally."

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"We knew. But we didn't know then that no amount of sensory therapy, occupational therapy, speech and language therapy, physical therapy, or love could wind its way deep enough to readjust the wiring of his brain."

Ex - playing with blocks and puzzles – I knew something wasn't 'right' but I didn't know what I was seeing.

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A confusing journey



- Professionals have been all over the map due to spiky profile, sensory/physical needs and dysmaturity
- "Precocious" – First expert consultant
- "Incapable of learning" - First educational psychologist
- ADHD (meds help him immensely, not true for all)
- Autism diagnosis Great Ormond Street
- 100% facial features, Foetal Alcohol Syndrome diagnosis from National FASD Clinic

He was 10 when we received the diagnosis of an FASD
Through it all his strengths have led us forward

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We love a child with #FASD

Some moments are fast, furious,
unpredictable, bewildering, overwhelming.
We need tools to help us help him.

Our story is a positive one - about finding those tools

This only happened because people (esp professionals) listened to us
(We were never sent on a 'parenting' course)

Our experience is atypical (but you can help change this)

His resilience, his 'reset button' was the single-most important strength in this whole process

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Life with a Sensory Seeker



Life is never dull

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His growing distress
had great impact at
home

He held it together at school, but ...

He was spiraling:
refusing school, stealing, running away, destroying things, cursing, hitting, playing with fire

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Mainstream school
increasingly became
torture for him

We love a child with #FASD

He did **cartwheels** when he learned he can
go to a new school

And we were gobsmacked by the speed, compassion,
and goodwill we encountered during this process.
It CAN happen the way it should

New blog post:
FASDLearningWithHope.wordpress.com

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FASD is a 'full body' diagnosis
(more than 400 conditions can
co-occur)

Other systems are affected
and children's lives become
very 'medicalised'

This affects the whole family's
stress and wellbeing

It's confusing for the person
with FASD to understand

And heartbreaking for the
whole family

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Sometimes we have unusual outings



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Family experiences are greatly impacted



Even a simple car ride can spiral

I learned the word "hypervigilance"

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Please
don't judge
our copying
mechanisms

"Since then I've managed to go through three monitors and at least two-three pairs of headphones if that tells you anything." JB

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Family wellbeing is too easy to ignore

Dad's story:

Sinking into the sofa exhausted at the end of the day, every day, had become my normal. Having a little afternoon nap had become normal. I got extremely thirsty all the time. I felt below par every day. This was my normal. And I wrote it off to the stress of living with a child with FASD (and another with chronic fatigue).

I did nothing.

A couple of weeks ago I went to the doctor complaining of a persistent cough, which had lasted since a virus knocked me flat in February and triggered my asthma. She asked a lot of questions, and sent me for blood tests and chest x-rays.

Fast forward a few days and the doctor's surgery calls and tells me to come in that morning. An hour later she tells me I have Type 2 diabetes, and after discussion, I have probably been in an acute phase of the condition for at least 18 months.

Looking at the blood sugar results she tells me it's 'a bloody miracle' I'm not in a coma.

Dad became dangerously ill

Elder brother battling Chronic Fatigue Syndrome

Mum had been hospitalized for neurological issues



We have had NO RESPITE - though thankfully some family & friends do help

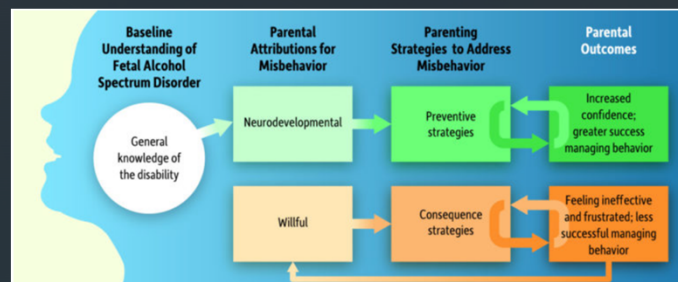
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What helped us turn the corner

- 1. Greater understanding (learning from experts, research)
- 2. Empowerment (tools, brain-base strategies)
- 3. Building our own resilience & trusting his (finding support from other families, creating support network around us)
- 4. Finding hope (learning from adults with FASD, 'positivi-t')

Study: How thinking about behavior differently can lead to happier FASD families



<https://www.rochester.edu/newscenter/how-thinking-about-behavior-differently-can-lead-to-happier-fasd-families-189582/>

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He was speaking his truth

Me (shouting): "Why are you doing this to me?"

Him (crying): "I don't know Mummy, I don't know!"

Memories like this haunt me, we
had years of wasted opportunity

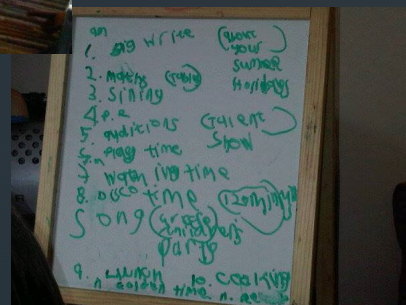
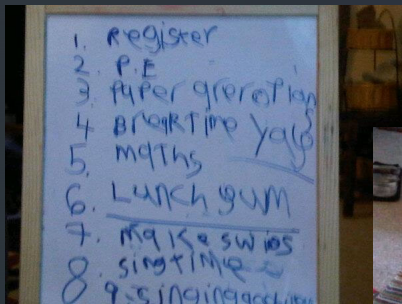
*"I did then what I knew
how to do. Now that I
know better, I do
better."
– Maya Angelou*

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Seeing with new eyes: he has always shown us what he needs

We have been too slow
to learn what he is
showing us

We have learned to
listen more



modelling & practicing behaviour

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It's so important to listen, even if the words are not what we want to hear

Being receptive as he is slowly finding the words for complicated feelings

CHANGE OF ROUTINE • LIGHTS • SMELLS • PARTIES • PLAYS
 • FEARS • ANTICIPATION • STRANGE FOOD • NEW MUSIC • DARK DAYS • LESS EXERCISE • UNCLEAR EXPECTATIONS • EXTENDED FAMILY • RANDOM SCHEDULE • TRANSITIONS • PARENTAL STRESS
 • LONG MEALS • ANXIETY • Pantomimes • ITCHY JUMPERS • ABSTRACT CONCEPTS • EXCITEMENT • CAN'T ESTIMATE TIME • DIDN'T GET WHAT EXPECTED • NEW TOYS BREAK • CAN'T SLEEP
is he real?
was I naughty?
 TIRED • FRUSTRATED • DIDN'T GET CARDS FROM FRIENDS • FLASHING LIGHTS • LOUD ROOMS • CAN'T SIT STILL • SPILLED GLITTER • NO CHIMNEY • DESPERATE FOR SNOW • TRYING SO VERY EXTRA SPECIALLY HARD TO BE GOOD

FASD
 @nofasuk
 Member FASD UK Alliance

December is hard
 for children with brains that are wired differently

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"This is what I feel like sometimes"
 (from Tom and Jerry – after watching clip 100 times)

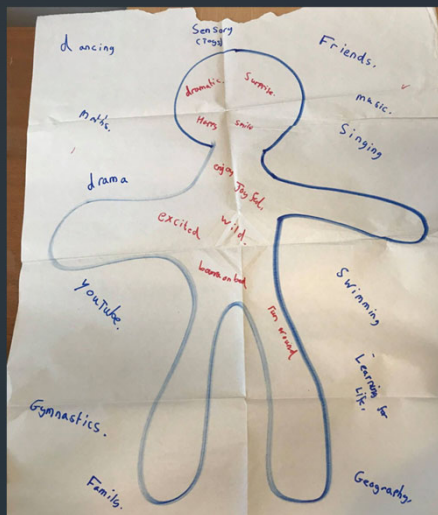
"Sorry, I was dysregulated" – after cursing at deputy head at new school

Giving him time and space to express himself

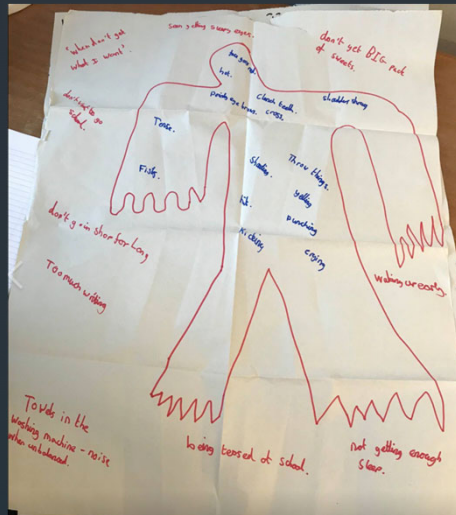
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- Professionals (learning disability nurse) helping him develop greater self-awareness/self-regulation



What's happening when I feel good



...and when I am upset

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- Professionals helping identify multi-sensory strategies – sharing across services/school

		Looks like	Feels like	I can help myself by:	Other people can help me by:
Kettle explodes	6	Start ruining things, breaking things, punching, kicking, hitting, very loud, bad words, bullying, run away.	Not very pleasant, uncontrollable, need help	Listen to music Do some colouring Watch movies	Relaxation- spaghetti Foot rub Pillow sandwich
Steaming	5	Banging objects, throw things, very loud, swearing, clench fists, clench teeth	Pointy eye brows, cross, very dysregulated, hot and sweaty.	Punch a pillow Play with sensory toys Go on phone	Star jumps Leg itch Relaxation- tense body
Starting to boil	4	Clench teeth, crying, say nasty things, storming out of room, clenched fists.	Frustrated, sad, angry, headaches, very tense	Do some colouring Sit in quiet place Play with sensory toys	Star jumps Squeeze fingers Give sensory toy
Turning kettle on	3	Obnoxious, more tense, yelling, shouting, shoulders shrug	Dysregulated, start getting hot	Watch a movie Watch YouTube Tell Mum and Dad	Foot rub Give me music Pillow sandwich
Filling with water	2	Voice gets louder, shoulders shrug, tense	Cross, start to get head ache, stressed	Ask to go sensory room Fidget spinner Drawing	Squeeze each other's hands Give sensory toy Give me movie to watch
Turned on the tap	1	Fidgety, Chatty	Start to feel sad	Play with fidget cube Sit in quiet place Go to hub	Give me sensory toys Listen to music Give me colouring book
Kettle in the cupboard	0	Smiling, relaxed, sensible, gentle	Happy, calm	Listen to music Read books Play with Joy	

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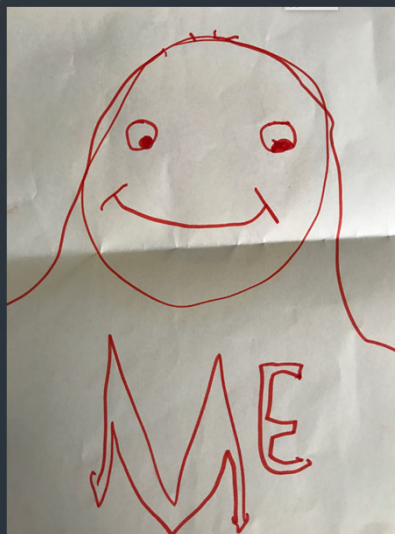
“My brain can’t handle that”



Honouring what he tells us is not always easy nor convenient (at home or school) but it's essential. Otherwise, what's the point of learning the strategies?

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Positive self image
is our top priority

Thankfully we have a team of
practitioners helping – this has
been life-changing, invaluable

“Who has the problem, your child or
society?” – Tavistock psychologist

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But AFAICS, the single crucial thing here was that you stepped right outside the conventional "special needs" model of trying to finding a framework to accommodate the difficulties posed for muggles by people who don't fit the norms.

Instead, you set out to celebrate T's talents -- both the talents which might be celebrated in anyone, and those which are part of T's differences.

It seems to me that everything else flowed from having a network of people who shared that simple but rare insight.

To put it in the language of LGBT politics, it's like the move from 1959 model of "keep a low profile and we won't persecute you" to the Pride model of actively celebrating the difference.

This is what Audre Lorde spent her life saying, in various ways

"It is not our differences
that divide us. It is our inability
to recognize, accept, and celebrate
those differences."

Audre Lorde

He wanted to play Wembley. Maybe he will. In the meantime, for his 13th birthday we created the

Flashing Lights Tour



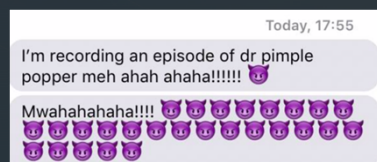
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- Technology is a key tool for his future & the main way he communicates with school friends & with us at times



Though technology
has its down sides:

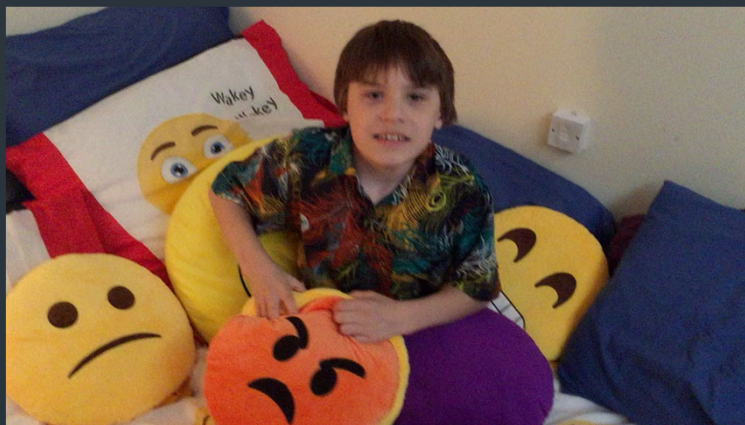


...and we ALWAYS buy the insurance

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- Helping ourselves by helping others
Making videos has always been big part of his learning



We ALL need to be about something bigger than ourselves

These days he's been making some ASMR videos with relaxing sounds – something he's researched on his own

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"Our entire family (cousins, aunts, grandmother, etc) helps others understand FASD. It helps others understand my brother and also to try to help prevent FASD." JB (sibling)

Helping him have words to explain his condition to others



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We love a child with #FASD

When we could no longer pretend everything was 'normal' We found courage to reach out to find & build support...and it's working here's how

New blog post: www.FASDLearningWithHope.wordpress.com

East Hertfordshire & Area FASD Support Network
eastherts.fasdfamilies@gmail.com

FASD BLOG
FASDLearningWithHope.wordpress.com
100,000 VIEWS
Thank you for sharing this journey with our family. We are truly humbled and inspired by your goodwill.
February 2019

"FASD CLUB" – growing up knowing others with FASD

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Building on strengths

What a marvelous "sensory" story! Wish I had had some of that as a kid growing up. I would have been the biggest "slime ball"!

We love a Slime Whisperer who has #FASD

At a critical moment he saved the day through his leadership and unique way of learning

New blog post:
FASDLearningWithHope.wordpress.com
@SB_FASD @MB_FASD

3.9★ average rating

FASDLearningWithHope.wordpress.com

The Slime Whisperer

He used to get into shampoo, perfumes, washing up liquid, etc.

Parental nightmare!

He craved the sensory input.

We gave him a 'slime lab'

His slime workshop at the Brain Base has been the highest rated activity two years in a row

Developing leadership comes in many forms

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■ If you take away one thing from this talk please remember:

Our lives are richer and we are all better people because we are together



Though it's part of our mosaic, FASD does not define our family

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■ BUT...WE ARE THE LUCKY ONES

FASD

What I want the world to know

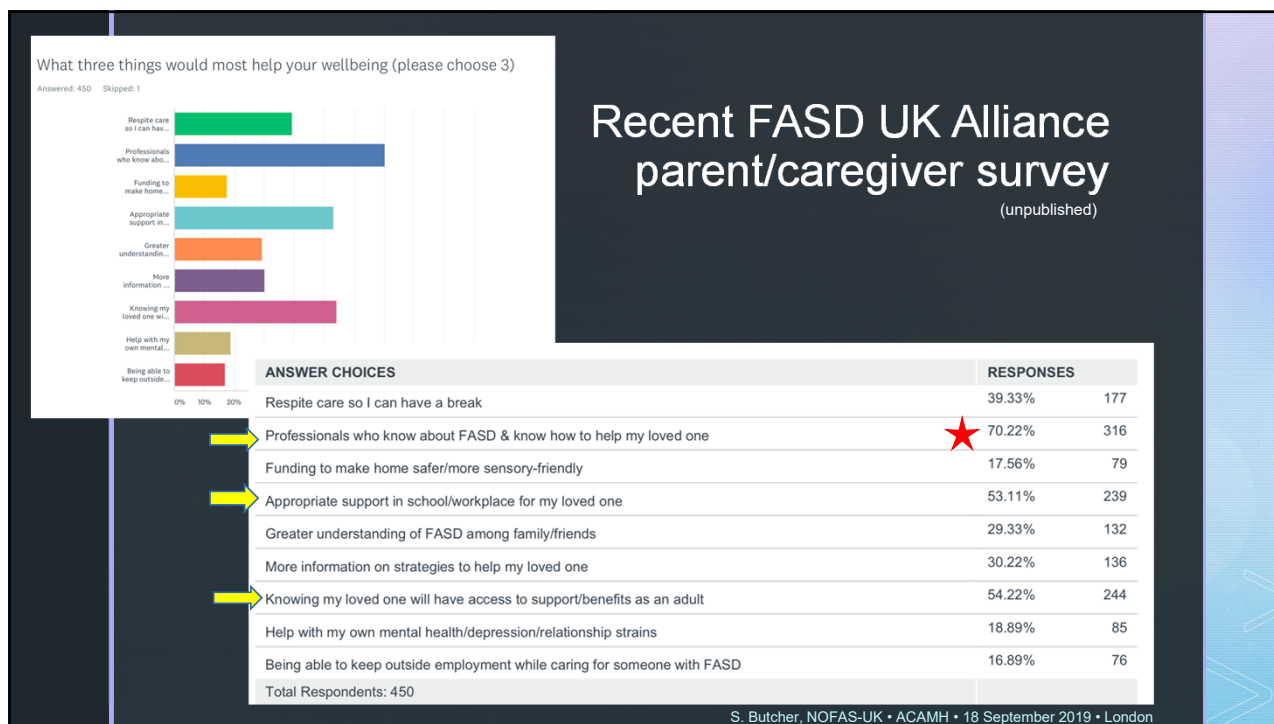
"I WOULD BE SO GRATEFUL IF YOU WOULD LISTEN TO WHAT WE TELL YOU AND ACT UPON IT RATHER THAN JUST HAVING MEETINGS AND CHANGING NOTHING"

Hear Our Voices • NOFAS-UK • FASD UK Alliance

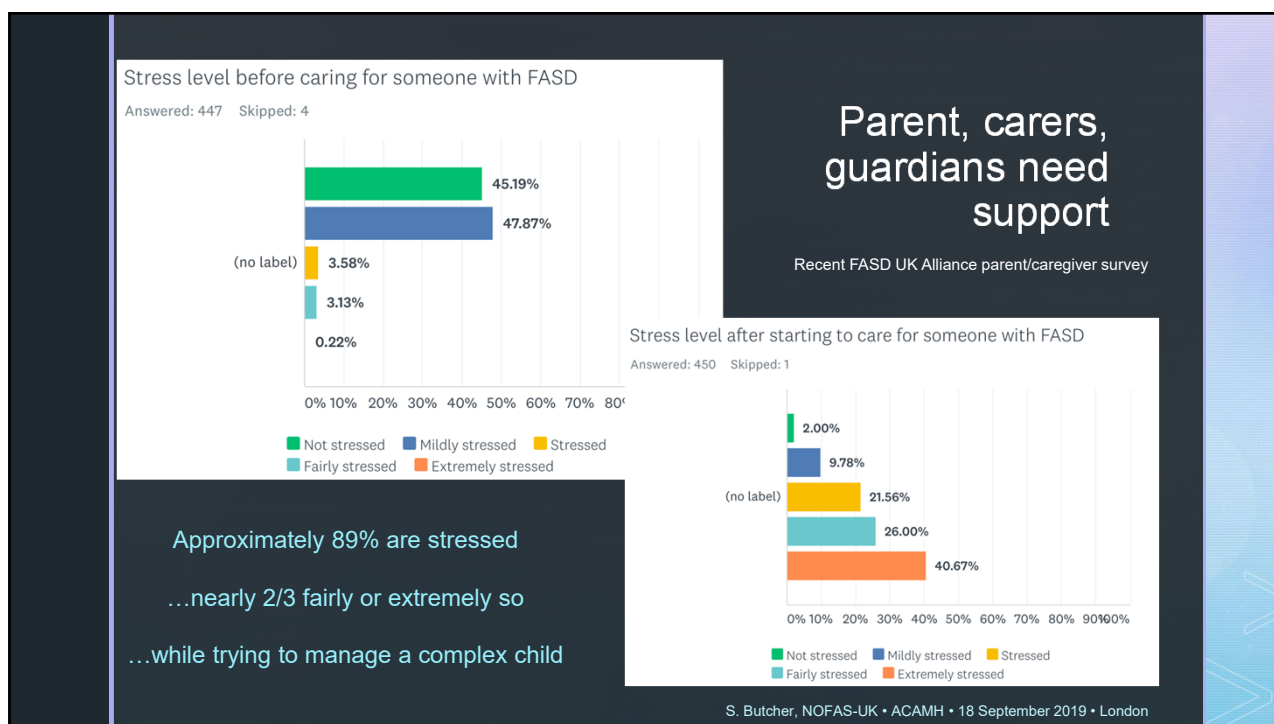
- There are families who have not accessed support, who are actively being denied assessments, respite, EHCPs and being told it's their fault things are so horribly challenging
- These families are in crisis and you are the gatekeepers to help
- The statistics are grim for those who are denied diagnosis & support – we are fighting for our children's lives

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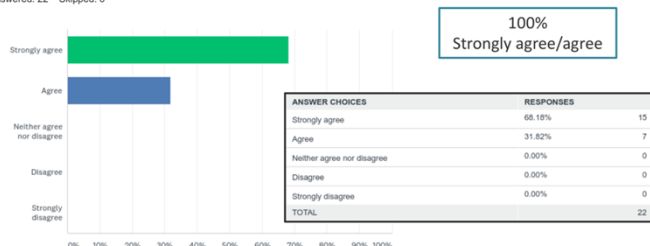
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Q6: "As an adult, I struggle because people don't understand my condition."

Answered: 22 Skipped: 0



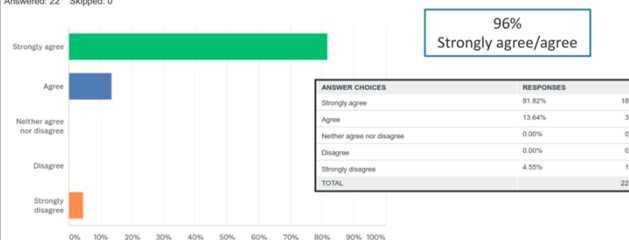
Adults with FASD
are struggling,
even those with diagnoses

Addressing issues related to adults with FASD (diagnosed and undiagnosed) is not a 'backburner' issue. It's urgent.

Insights from UK Adults with FASD(or Suspected FASD), National FASD Advisory Committee, Presented in Meeting 22 October 2018 with Deputy Chief Medical Officer Prof. Gina Radford.

Q4: "I needed more support in school. My teachers did not understand my needs."

Answered: 22 Skipped: 0



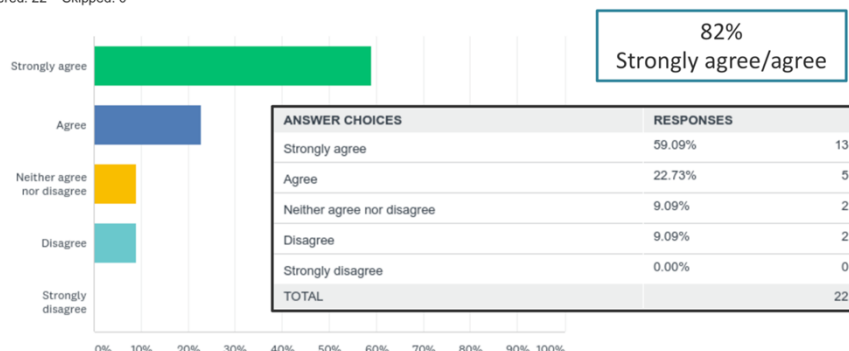
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Adults with FASD are stressed too

Q12: "I worry about the future."

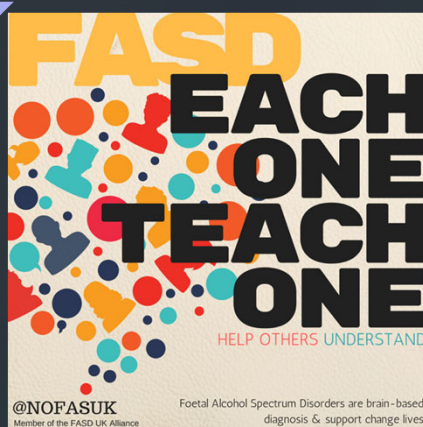
Answered: 22 Skipped: 0



Insights from UK Adults with FASD (or Suspected FASD), National FASD Advisory Committee, Presented in Meeting 22 October 2018 with Deputy Chief Medical Officer Prof. Gina Radford.

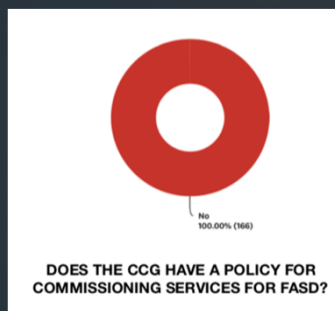
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CHANGE IS COMING:
NICE Quality Standard on FASD is
coming in September 2020

- Every professional who interacts with families must train up
- Thank YOU for being here



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#HearOurVoices

I was told by my son's paediatrician that a diagnosis for FASD would serve no purpose. That it only helps to ease the mother's guilt [about parenting].
Birth Mother, South East

I am still fighting to get a sensory assessment. I don't know where to go to get an adaptive or executive functioning assessment.
Foster Carer, Yorkshire & the Humber

We were told he did not need an EHCP as children with FASD are fine in school.
Special Guardian, East Midlands

Come and spend a week here, see what we live with and what we are up against in getting the right support. Then you will understand.
Foster Carer, West Midlands

Professionals definitely need up-to-date training and they need to drop the myth that FASD is only present with facial features.
Grandmother, Yorkshire and the Humber

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Individuals with FASD need to be heard



Claire

I struggle with friendships. It's hard to keep a job



Lee

We are affected daily but to the outside world we look 'normal.' It was hardest in that transition period after leaving school



Nyrene

I love my children but maybe I might not have had a child at 17 if I had more support



Andy

It's important to advise and support others with the struggles of living with FASD

National FASD Advisory Committee
#NFAC @NOFASUK info@nofas-uk.org

#HearOurVoices

fasd awareness

I am
Gust one of the million
Children with this problem ,
It's hard with this condishon
As you can see I have problem
With, spelng and sleep problem
And lerning getting a long
With people, so are brane is
Like a messe filing cabnet
And I all was in troboll
At school Becaese
Thay din not now about fasd

You may not get to help me but you
can help children in the fucher so
pleas don't
Drenk throw pregnasey so children
have less risk of having FASD

FASD Awareness Kent & Medway
info@FASDAwareness.com

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#HearOurVoices

- Me (to our son): "We are going to a speak at a conference about FASD. What do you think we should say?"
- SuperT: "You need to go on the radio. More people need to hear."



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RESOURCES & SUPPORT

- NOFAS-UK - www.nofas-uk.org or info@nofas-uk.org
- Online support – FASD UK Facebook group (>2300 families)
- FASD UK Professionals Facebook group
- Local and regional support: FASD UK Alliance - www.fasd-uk.net
- Oregon Behaviour Consultation videos on YouTube
- Diane Malbin “FASD Trying Differently Rather Than Harder”

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