FASD UK
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Family perspectives on Care Management Plans

FASD UK Alliance
University of Salford
30 March 2023

About us

- We are all members of FASD UK Alliance Steering Group
- The FASD UK Alliance is an informal coalition of 28 groups and individuals from across the UK who are united together for positive social change.
- We support all with FASD and all of their families
- Co-administer the FASD UK Facebook group – nearly 3,700 families

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#StrongerTogetherFASD

Birth Mum & Son
Carolyn Blackburn SEND Consultancy
coram BAAF ADOPTION & FOSTERING ACADEMY
FASD ELUCIDATE TRAINING SHINING A LIGHT ON FETAL ALCOHOL SPECTRUM DISORDER
ÉNDpae
Family Futures
FASD AWARENESS FETAL ALCOHOL SPECTRUM DISORDERS
FASD CYMRU
FASD Dogs UK
FASD FIFE
FASD Grampian
FASD Scotland
FASD Network UK
FASD Ireland
FASD HUB South West
FASD hub Scotland
Fasd Greater Manchester
much Laughter
NATIONAL ORGANISATION FOR FASD
Notts and Lincs FASD family group
Hertfordshire FASD Support Network
Hampshire FASD Support Group
GM FASD NETWORK Supported by 10GM
Oshay's FASD
Peterborough and Area FASD Support Group
RedBalloon TRAINING
FASD South Lakes FASD Support
Stoke & Staffordshire

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#FASDUK

https://fasd-uk.net

The FASD UK Alliance is a coalition of groups and individuals from across the UK united together for positive social change for those with Fetal Alcohol Spectrum Disorder (FASD).

POSITIVE SUPPORT

Affiliates include small local, regional and virtual groups as well as some of the country's longest standing national organisations, with links to international networks. We also stand with affiliated sister organisations from Ireland.

Drawing on our diversity and our strength, together we contribute to the vibrant and growing online FASD UK Facebook Support Group, connecting more than 3,600 birth parents, foster carers, adopters, kinship carers, extended families, and adults with FASD.

PEOPLE WITH FASD
KINSHIP CARERS
BIRTH PARENTS
EXTENDED FAMILIES
ADOPTERS
FOSTER CARERS
OTHERS PROVIDING AWARENESS & SUPPORT

This is an informal coalition. Each organisation is independent and responsible for its own activities.

Bulk copies available from the info table – please take extras to hand out at events or in clinic, etc

Hands up

If you are part of an FASD UK Alliance group

or if you have lived experience with FASD

What we’ll cover

- NICE Quality Standard Statement 5 – Sandy Butcher
- Why Care Management Plans are important – Maryelen McPhail
- Feedback from160 families – Cindy Perkins
- Next steps – Susan McGrail
- Questions – Tracy Allen

NICE Quality Standard Statement 5

- Sandy Butcher

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NICE Quality Standard Statement 5

"Children and young people with a diagnosis of fetal alcohol spectrum disorder (FASD) have a management plan to address their needs."

NICE National Institute for Health and Care Excellence

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NICE National Institute for Health and Care Excellence

“An individualised management plan sets out the intervention and support needs identified during assessment and diagnosis of FASD.

“The plan signposts the child or young person with FASD and their family to resources and services.

“It covers the basic and immediate needs of the child or young person after assessment as well as their long-term needs.

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“Because FASD has lifelong effects, a staged management plan may be needed to anticipate upcoming problems at planned intervals and revision should be considered at all transition stages in the person's life.

“A management plan also helps people with FASD, their families, carers and service providers to understand and address the associated challenges.

“It covers the basic and immediate needs of the child or young person after assessment as well as their long-term needs.

NICE National Institute for Health and Care Excellence

“The plan **helps to coordinate care** across a range of healthcare professionals, as well as education and social services, and improves outcomes.”

NICE National Institute for Health and Care Excellence

Measures to assess quality of care

- “Evidence of local frameworks for managing FASD that ensure healthcare professionals **coordinate care across disciplines and organisations**.
- “Evidence of local arrangements for communicating and **sharing management plans between providers of health, education and social services**.

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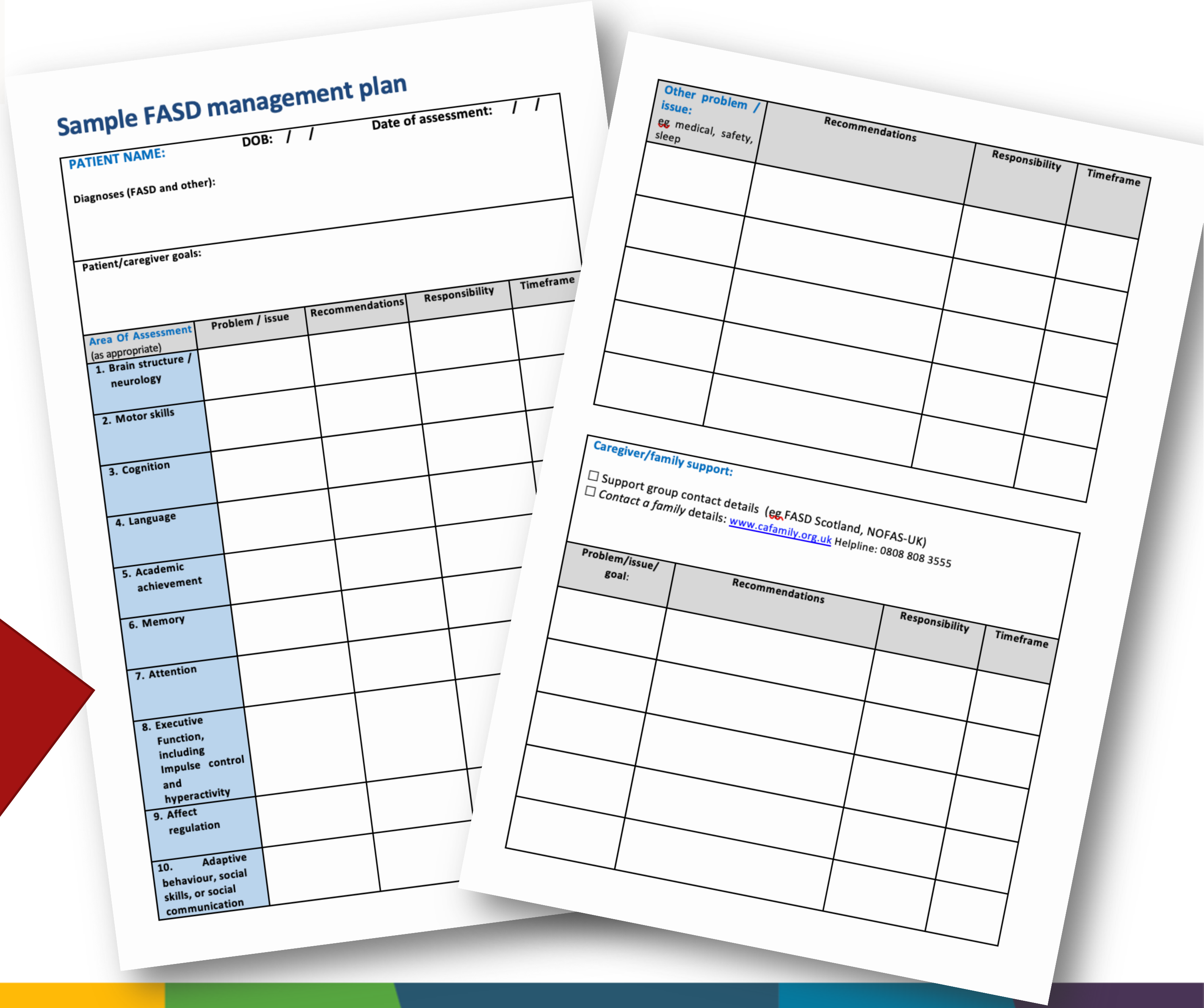
- “Data can be collected … from **local audits** of patient records
- “Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, **a survey of people with FASD using a quality of life questionnaire**”

??Great project for researchers?

NICE National Institute for Health and Care Excellence

- “The Scottish Intercollegiate Guidelines Network's sample FASD management plan has been produced to support the source guideline”

??Families are concerned this is too medicalised, though a good starting point



Sample FASD management plan

PATIENT NAME: DOB: / / Date of assessment: / /

Diagnoses (FASD and other):

Patient/caregiver goals:

Area Of Assessment (as appropriate)	Problem / issue	Recommendations	Responsibility	Timeframe
1. Brain structure / neurology				
2. Motor skills				
3. Cognition				
4. Language				
5. Academic achievement				
6. Memory				
7. Attention				
8. Executive Function, including Impulse control and hyperactivity				
9. Affect regulation				
10. Adaptive behaviour, social skills, or social communication				

Other problem / issue: eg medical, safety, sleep	Recommendations	Responsibility	Timeframe

Caregiver/family support:

☐ Support group contact details (eg FASD Scotland, NOFAS-UK)
☐ *Contact a family* details: www.cafamily.org.uk Helpline: 0808 808 3555

Problem/issue/ goal:	Recommendations	Responsibility	Timeframe

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OUTCOME =
“quality of life for people diagnosed with FASD”

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NICE QS 5 CALLS FOR:

- Training specifically on managing FASD
- Frameworks for managing FASD working across disciplines and organisations (health, education, social care) – including further referrals and education support
- Working with children, young people and their families on priorities and goals and who the plan should be shared with

This is why the FASD UK Alliance is doing this project, while recognising historic diagnoses need CMPs too

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NICE National Institute for Health and Care Excellence

WHAT NICE QS MEANS FOR COMMISSIONERS

Management plans are not meant to be an afterthought

- “Ensure that they **commission services that provide a management plan** and support for children and young people diagnosed with FASD”

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DHSC is on board too

“Work from **NICE** … should go some way towards building consensus, as it recognises important general principles around assessment and diagnosis that **maximise the chances of success; when an effective plan of care is implemented**, **it should create adequate scaffolding for people with FASD to flourish.** This means supporting **children and adults** with their limitations, and creating opportunities to utilise their strengths.”

Department
of Health &
Social Care

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Families speak out – why care management plans matter

We are fighting for our loved one's lives

- Maryelen McPhail

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#HearOurVoices

”I am tired of every service thinking that we are **someone else’s problem**”

“A hot potato. **I'm like a hot potato** … in the end you just feel like you're going around in circles, banging your head against the wall”

(Tracy)

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"We don't have any care management, plan, strategies. In fact we have no help at all with our little one. ...**we cry for help and meet a series of closed doors**"

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"Our son ....
feels very **afraid for his future**
at the moment"

"I was going around brandishing a lovely letter from Raja explaining why people with FASD need revised cognitive assessments and yet **nobody would take responsibility**. You know, I mean the adult mental health team … tried to help, even referred me to a neuro team and they said sorry, no, not our remit. And this is what happens time and time again"

(Cindy)

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"A Care Management Plan is non-existent but MUCH needed. My consultant just looked at me **as if I'd asked for the moon** and had no idea"

"If the FASD had been diagnosed earlier and a clear care management plan been implemented, the last 6-7 years of my child's life would have been very different … **Instead, they have struggled** and had several school moves and completely gone off education"

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"Now in 16+ education, there is **no effective plan for anything outside of education**"

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“My son has been languishing in his bedroom for 8 years now… Until FASD is tackled this will continue. At 23 he feels his life is passing him by and this is challenging for all our mental health. **He desperately wants to take his place in the world** and gain independence. He also worries about who will look after him and ‘understand him’ after we have died”

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"My son burnt out in Year 5 … he was at home for 18 months. School refused EHC plan. Took this out myself… During covid…he was so hyperactive there was safeguarding, behaviours became more extreme. I'm clean since 2009, but **keep being put in meetings blaming his behaviours on after-pregnancy trauma not PAE**. He's been put 200 miles away from me…He was asked to do 9 moves and go to boarding school, another burn out. …

(cont.)

(cont.)

"…He's in foster care and now they're going for full care order. … Everything my son has got has had to come with such a push and shove from education and social care. They don't follow the legislation for Disabled children. **I'm about to lose the love of my life**."

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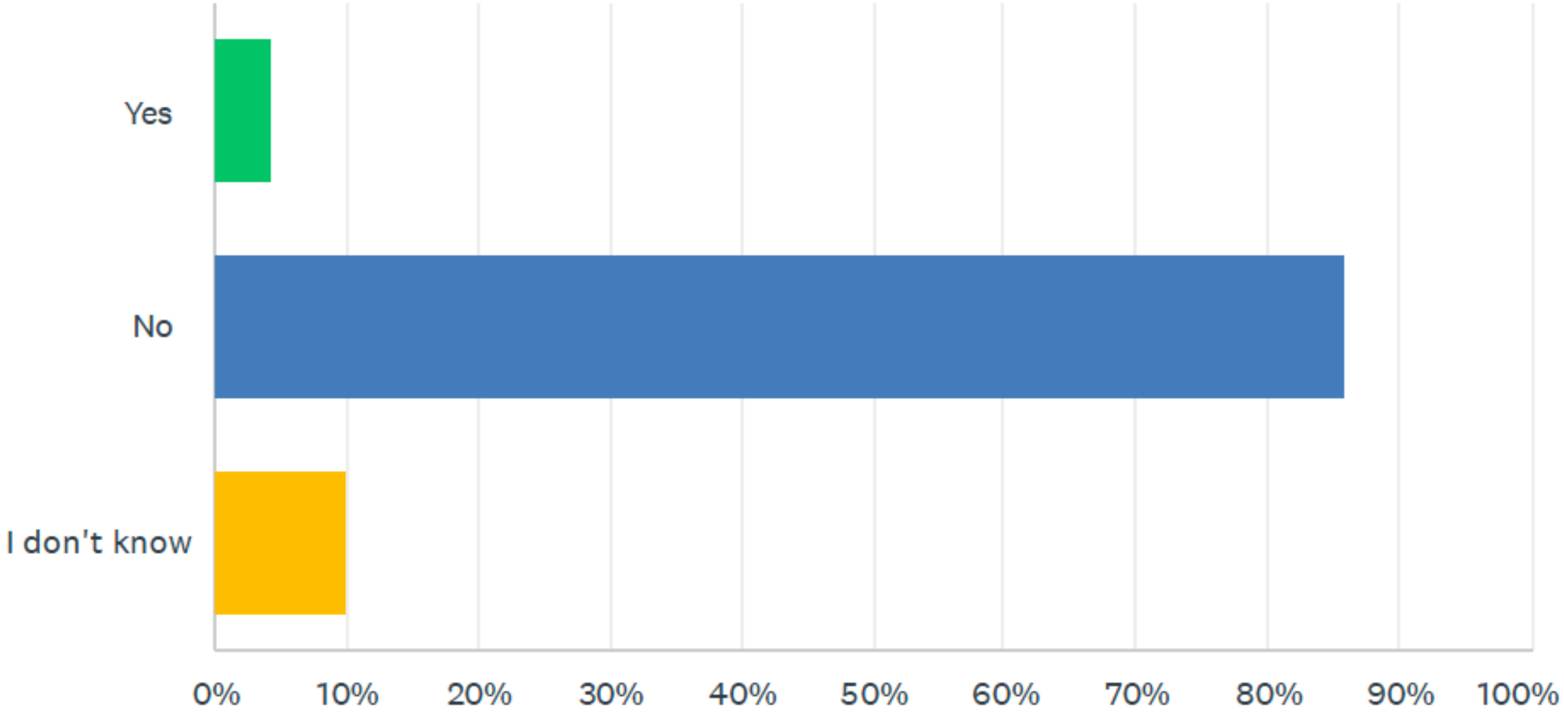
Survey feedback

We received 161 responses to an informal survey that was open from 2 February 2023 – 3 March 2023

- Cindy Perkins

Q5 Does your FASD diagnosis include a care management plan? (This might be in the diagnosis letter or a separate document)

Answered: 120 Skipped: 41



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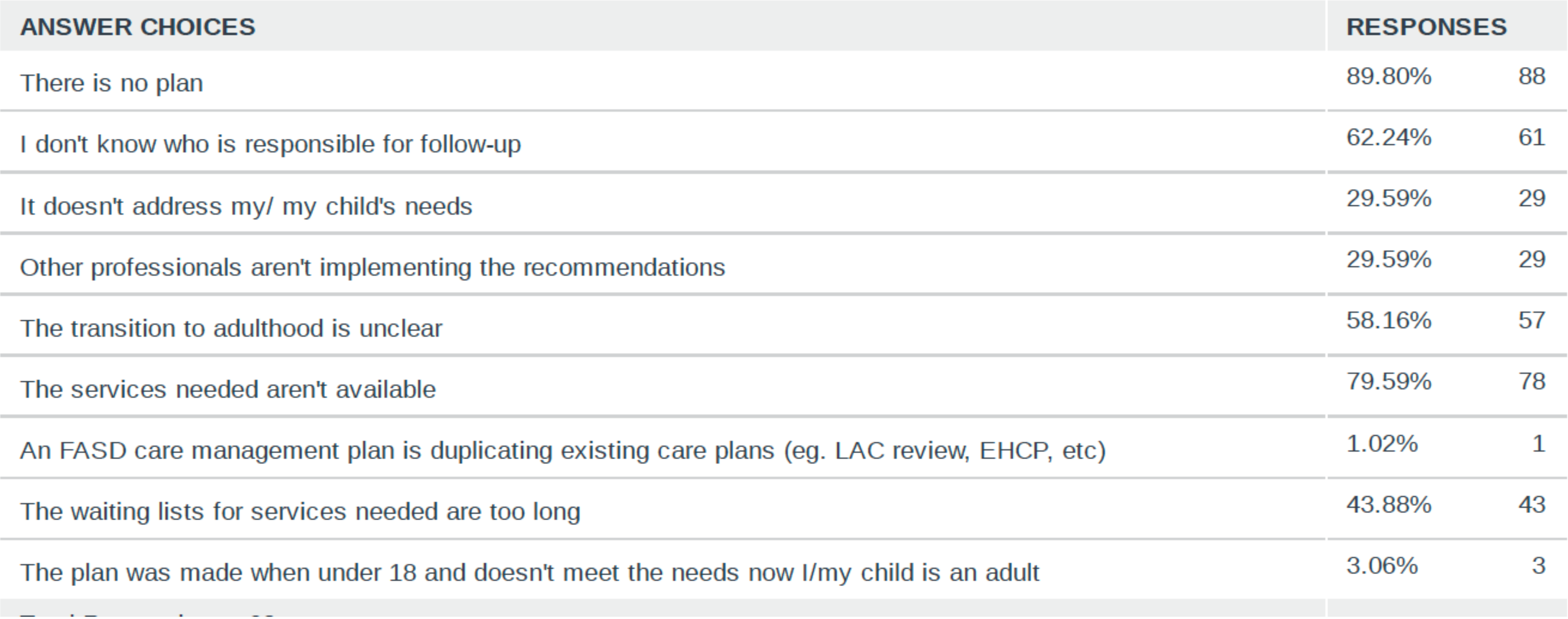
NOT ONE FAMILY COULD GIVE DETAILS OF A “GOOD” CARE MANAGEMENT PLAN

- Families are clearly confused
- Even when there is a plan, they often don’t recognise it in the documents
- This is an area that **NEEDS SIGNFICANT ATTENTION**

Biggest frustrations re: care management

following the FASD diagnosis? (Tick all that apply)



ANSWER CHOICES	RESPONSES	
There is no plan	89.80%	88
I don't know who is responsible for follow-up	62.24%	61
It doesn't address my/ my child's needs	29.59%	29
Other professionals aren't implementing the recommendations	29.59%	29
The transition to adulthood is unclear	58.16%	57
The services needed aren't available	79.59%	78
An FASD care management plan is duplicating existing care plans (eg. LAC review, EHCP, etc)	1.02%	1
The waiting lists for services needed are too long	43.88%	43
The plan was made when under 18 and doesn't meet the needs now I/my child is an adult	3.06%	3

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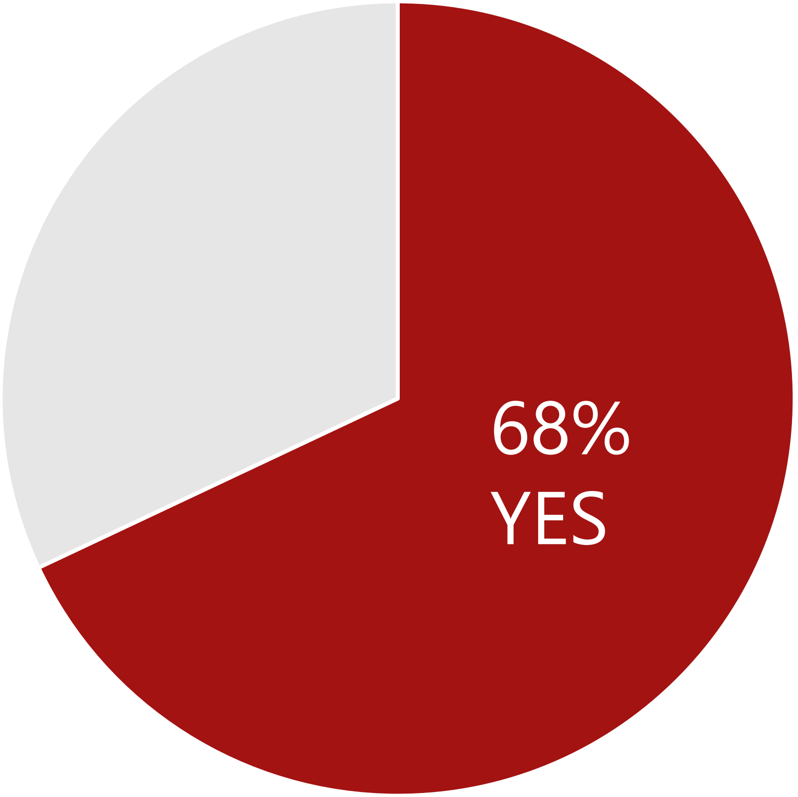
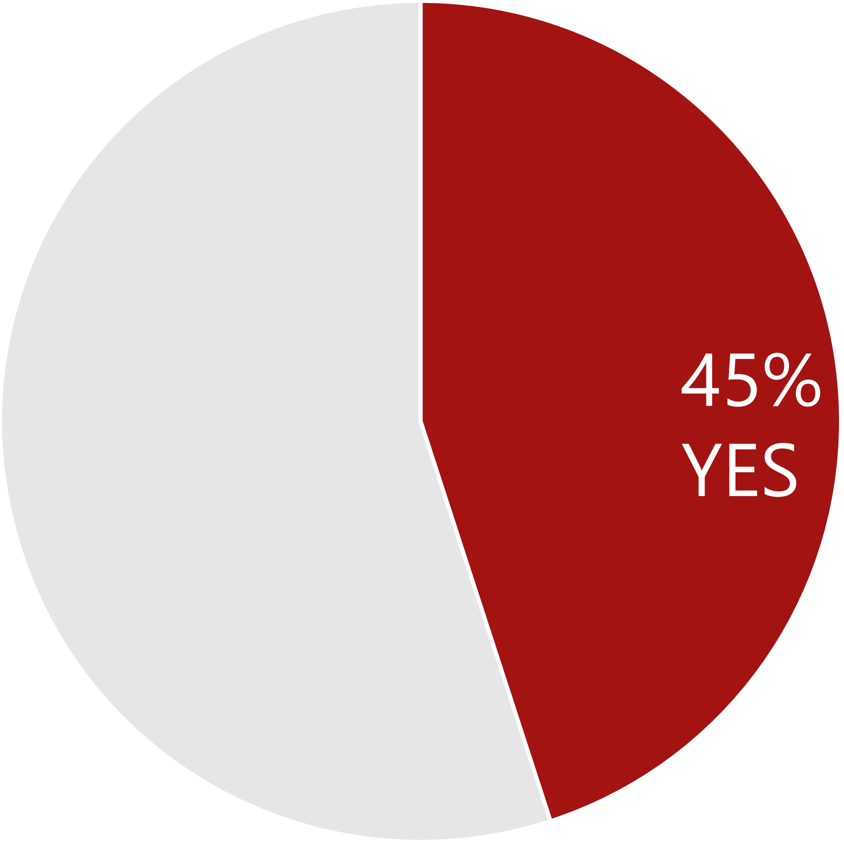
Mental health services involved?



care management matters

“My family is in crisis”



care management matters

What families want in Care Management Plans

- A named professional responsible for oversight
- Clear guidelines and timescales, including for reassessment (annual review?)
- Multi-disciplinary involvement
- Global plan incorporating emotional, social, educational, physical and mental health needs
- ?? Mandatory or some legal duty on someone to produce the plan as NICE QS is not legally enforceable (FASD Act?)

What families want in Care Management Plans

- Ongoing, lifelong support
- Signposting to professionals who understand FASD
- Robust medication plan, if needed
- Neurodevelopment assessments at key stages
- Full sensory integration and speech/ language assessments
- A ”this is what you need to do next" section with appropriate contacts

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“Umbrella care”

- Coordination of services not being left to parents - “unified action rather than having to deal with lots of different departments”
- Regular review with school with experienced SEN education psychologist with FASD knowledge to check they are being properly supported
- Education plan is being followed & any changes needed identified
- Access to mental health support
- Needs assessed by social services
- Training across all services on care management, including Criminal Justice

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Support for families included as part of plan

- Respite
- Parent/carer training
- Strategies for behaviour management
- Local support groups
- Local groups for kids
- Crisis management

For person with FASD

- Person-centred plan - easy-access/ visual
- Positive language
- Help for person to understand how their brain works
- Ongoing, lifelong support, incl. for everyday activities - e.g. travel training, daily living skills, supportive living planning etc
- Appropriate mentors for mental/ physical health
- Support with annual check up with GP/ paediatrician to discuss health and mental wellbeing

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Next steps

- Susan McGrail

Will you work with us to create a model care management plan?

- The FASD UK Alliance welcomes the NICE Quality Standard’s focus on the importance of care management plans for people with FASD

- We believe in meaningful collaboration to ensure these are fit for purpose

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FASD community – we need help!

- We call on the community of FASD researchers, practitioners, policy makers and all those with lived experience to work with us this year to draft a best practice guide to FASD Care Management plans
- We need examples of best practice of care management plans from other neurodevelopmental conditions
- We need examples of FASD care management plans from practitioners who are providing them already

You're invited!

- Join us for a roundtable discussion about Care Management Plans

SIGN UP NOW!

27 June 9:30 - 11:00 Zoom

https://www.eventbrite.com/e/care-management-plans-tickets-602141771247

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Policy makers

- We call on **NICE** to create guidance about FASD Care Management across the lifespan (and remind you we still need guidance on adult FASD diagnosis)

- **Commissioners** across the UK – please commission the services called for in the Quality Standard and align all national policies, include quantifiable measures to assess progress as in the QS … and include attention to care management!

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Care management is too important to be an afterthought

Thank you!

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Questions & answers

We invite questions from the audience.

- Tracy Allen