

# THE TIME IS NOW:

The National Perspective on  
Ramping up FASD Prevention,  
Diagnosis and  
Support Services

The report of a series of  
roundtables hosted by the  
National FASD Experts  
Committee engaging  
practitioners, policy makers,  
commissioners, public  
health experts and people  
with lived experience.

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## WELCOME!

21 March 2022

The National Liberal Club  
London

**Welcome**

# Kevin Price

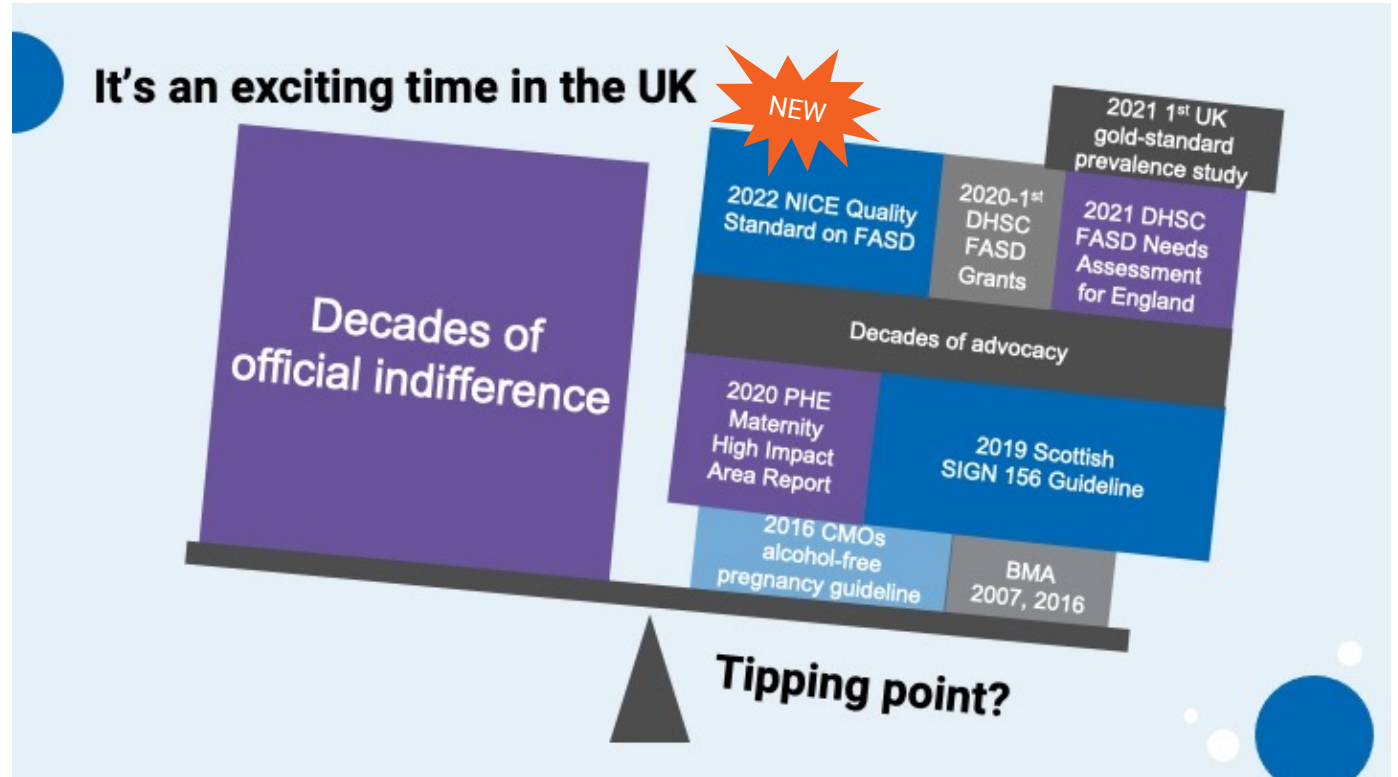
Acting Chair  
National FASD Trustees

**Welcome**

# **Sandra Butcher**

Chief Executive National FASD  
Member National FASD Experts Committee  
NICE Quality Standard on FASD Committee

# Tipping point



# A fast-paced project



You want to do what by when?!?

- We all felt a little like this at the beginning
- But goodwill overcame hectic schedules
- Collectively, we created something much bigger than any of us anticipated

# How the report came about

## **“The National Perspective on Ramping Up FASD Prevention, Diagnostic and Support Services”**

- 9 roundtables between Dec 21 – Mar 22
- Convened by the National FASD Experts Committee
- Co-chaired by Prof Raja Mukherjee and Sandra Butcher
- Made possible thanks to the generous support of The Sylvia Adams Charitable Trust



# How the report came about

## Participants

- 61 participants – incl. paediatricians, psychiatrists, GPs, commissioners, public health experts, researchers and leaders from Third Sector (charities)
- Overall, 21 percent have lived experience (average 25% in each session)
- Participants took part in their individual capacities
- Substance could be reported out but not attributed to any individual (Chatham House rules)

Just  
released  
16 March  
2022

Hot off the  
presses!

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on Ramping up FASD  
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**#FASDTimeIsNow**



# Key themes

## #1

There has been unprecedented work done by all major public health bodies in recent years. This work is ground-breaking. To be transformative it is now the time for joined up thinking and a clear political message to operationalise the recommendations.

# Key themes

## #2

FASD is preventable and increased attention is needed to ensure the CMOs' guidance on alcohol in pregnancy is understood across healthcare professions, in education and in the general public.

# Key themes

## #3

For the first time the UK has a solid active-case ascertainment prevalence study conducted by the University of Salford. This is a wakeup call.

## #4

The SIGN 156 FASD diagnostic guideline for children and young people exposed prenatally to alcohol has been accepted by NICE. Training and awareness across Government and Public Health bodies is required.

## #5

Integrated Care Systems (ICSs) and NHS trusts now have the foundation they need to start to build a case for developing local pathways for prevention, diagnosis and support.

## #6

People with lived experience need to be at the core of planning and those with FASD expertise should be engaged at all levels.



## #7

Urgent attention needs to be given as to how to set up FASD diagnosis pathways (possibly using a Hub and Spoke model) so that individual practitioners can access the multidisciplinary resources and can have appropriate peer support as required for FASD diagnosis.

## #8

Care management plans are included in the NICE Quality Standard - these require special attention by policymakers.

## #9

Policy progress is extremely welcome, but action is also needed for those areas not covered.

## #10

Public policymakers must use joined up thinking to meet the identified needs of this vulnerable population and give this issue profile.

8-year  
journey  
for  
diagnosis

# Nyrene Cox

Member National FASD  
Adults & Young Adults with FASD  
Advisory Committee

# Prof Raja Mukherjee

Consultant Psychiatrist

National FASD Clinic

NICE Quality Standard on FASD Committee

Member National FASD Experts Committee



# Prof Raja Mukherjee



# Dr Patricia Jackson

Honorary Fellow University of Edinburgh  
Dept of Child Life and Health  
Co-Chair SIGN 156 Guideline Group  
RCPCH FASD Training Faculty

# What is SIGN?

## Scottish Intercollegiate Guidelines network (Health Improvement Scotland)

- The SIGN process: The SIGN review group considered all the relevant international research evidence over the past 10 years in relation to the diagnosis of children affected by prenatal alcohol exposure.
- Review groups are multidisciplinary and include appropriate parent and child representation.

### Key questions:

- Best available way to record accurate alcohol histories
- Current, most reliable way to assess for the possibility of Fetal Alcohol Spectrum Disorder
- Post-diagnosis outcomes

# Benefits of the SIGN guideline

- NICE have felt able to build on this work to develop the recently published standard
- Provide a standardised approach for clinicians.
- Terminology used now mirrors Canadian Guidelines, and those used in Australia, New Zealand and S. Africa:
  - *FASD with sentinel facial features*
  - *FASD without sentinel facial features*
  - *At risk from neurodevelopmental delay related to prenatal alcohol exposure*

# Benefits of the SIGN guideline

- This will allow consistency in information gathering internationally as data collection will be key to evidencing improved outcomes.
- Evaluation of the post diagnosis benefits possible for this patient group especially educationally, and in relation to prevention of secondary mental health problems
- Identified the need for research in this area of work.

# SIGN 156 (2019)

## Three areas to be explored

- Alcohol exposure
  - Confirmed
  - Confirmed absent
  - Unknown
- Facial Features
- CNS areas of assessment or domains (requires multidisciplinary skills)

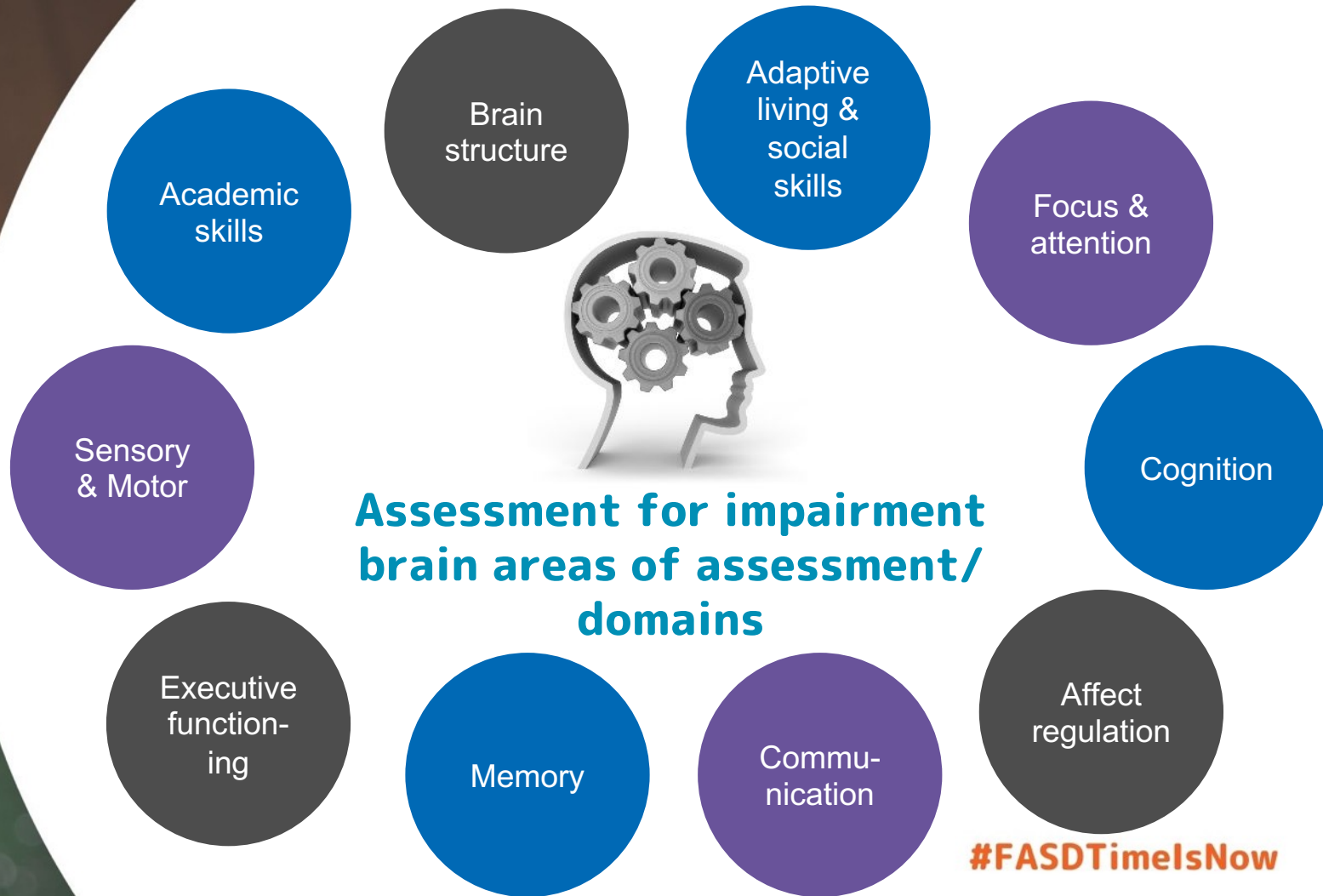
## Four Outcomes (previously possible 256 diagnostic codes, 22 categories)

- FASD with sentinel facial features
- FASD without sentinel facial features
- At risk
- No FASD diagnosis (still need a support plan)

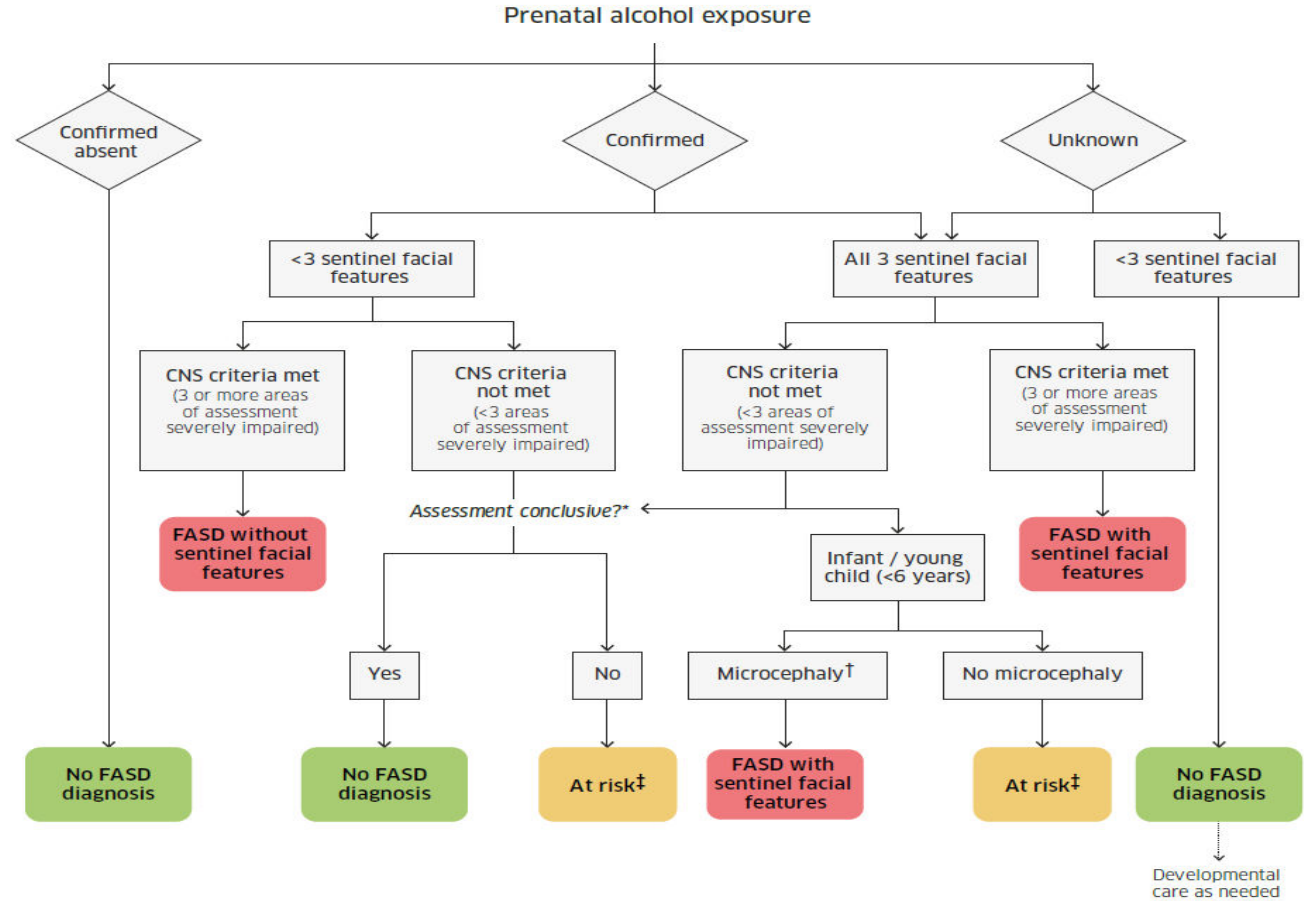


# SIGN 156

## Recom- mendation 3.4



# SIGN Diagnostic algorithm for FASD



# Training

## Training is key to successful implementation

- FASD awareness training should be available to everyone.
- Parents, Social work, Education, Judicial services, Third Sector organisations..... All need to be trained to assist in the recognition and support of this common, but commonly unrecognised condition.
- For all health staff we should be aiming to provide training about FASD at the earliest possible stage. This requires an involvement from curriculum development departments for Nursing, Midwifery, AHPs, GPs, Paediatricians, Psychiatrists
- Multi/interdisciplinary working among all those who can contribute to assessments and support plans should be encouraged, and funding should facilitate this way of working.
- Training needs to be ongoing and sustained, and properly funded, with more specialised training developed as we become more aware of the myriad needs of those living with FASD.
- Royal College of Paediatrics and Child Health has undertaken new FASD training courses – positive response

**Commis-  
sioning  
services**

# Richard Clements

Primary Care Manager  
NHS North East London  
Clinical Commissioning Group

# Improving the quality of care

## The time is now: for service development and delivery

### What is the need?

- ✓ Estimates of prevalence
- ✓ Population and inequalities data

### How to meet the need?

- ✓ Current service models; preventative, diagnostic and care
- ✓ Service users (and future users)
- Workforce development

### What change is achieved?

- Performance reporting and review
- Service user feedback
- Whole-life condition...whole life benefits (Quality of Life)

# Róisín Reynolds

National FASD Trustee  
Sr Advisor, Alcohol Exposed Pregnancies, Greater  
Manchester Health & Social Care Partnership  
NICE Quality Standard on FASD Committee



# GM Alcohol-Exposed Pregnancies Programme

## Programme approach



## GM AEP: Learning to date

# The experiences of the programme to date have elicited the following areas of insight:

GM ALCOHOL EXPOSED  
PREGNANCIES

Greater Manchester Health  
and Social Care Partnership

- **It's not (just) about the money:** Whilst investment allowed us to test new ways of working (and got some people around the table), it wasn't what drove the greatest transformation.
- **It's about hearts and minds:** Don't underestimate the importance of engagement, the voices of lived experience and the need for a compelling narrative.
- **Evidence matters (but only a bit):** Use the evidence that exists, but accept it has limitations, and commit to contributing to the evidence base.

# GM AEP: Learning to date

- **Be brave:** Some of this felt like jumping into the unknown. That requires a learning culture and a willingness to fail, learn and adapt.
- **It's complicated:** Driving change is difficult and requires tenacity and resilience.
- **Push at the open doors:** Build momentum by initially engaging those who are most open to engagement.
- **Unlock the closed doors:** Find ways to reach those who are influential, but disinterested. Avoid the “*echo chamber*”.
- **Think ‘whole system’:** Make it everyone’s business. Understand who can make positive changes and who benefits.

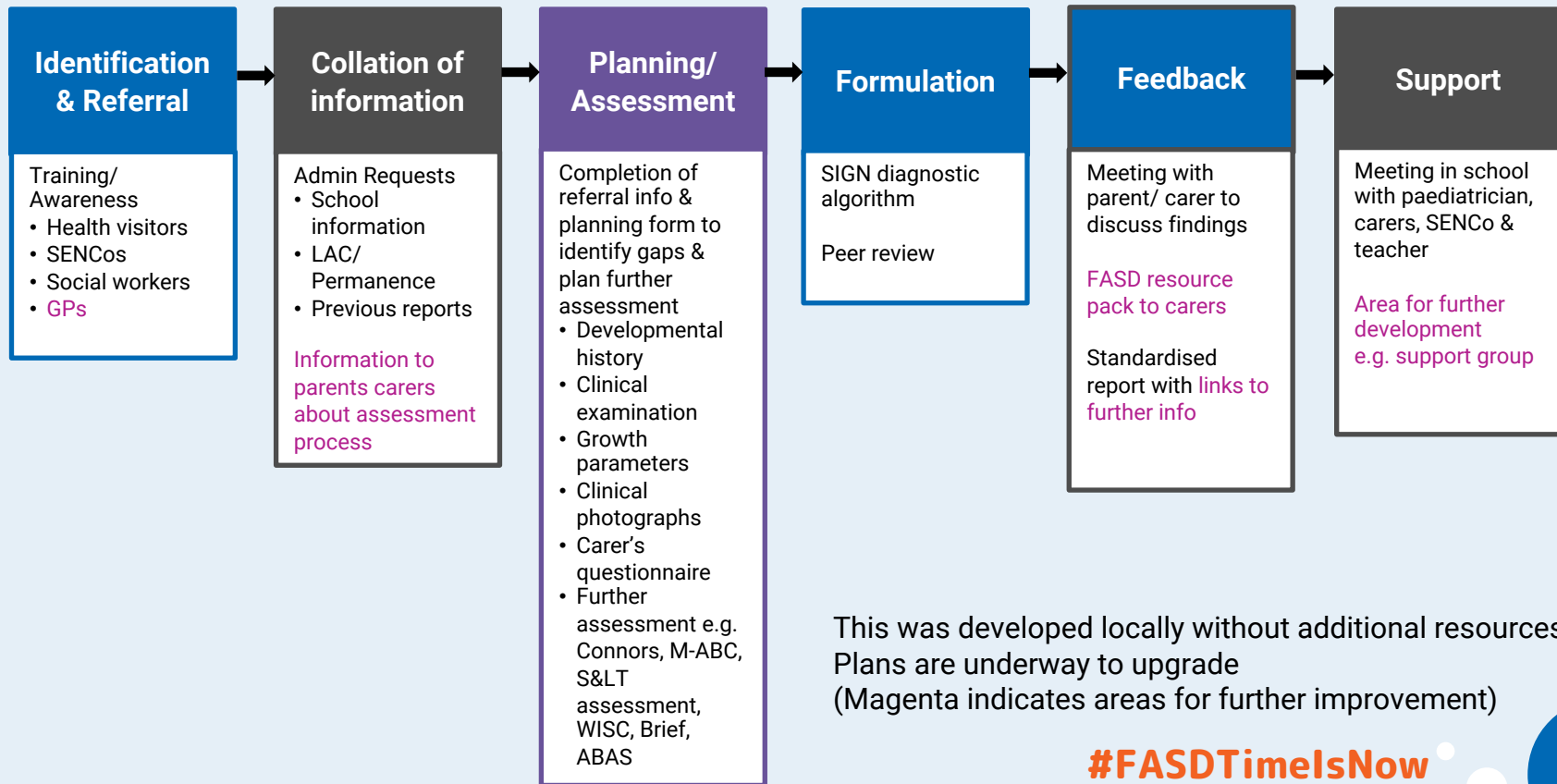
## Dr Michelle Bond

Consultant Paediatrician  
Sussex Community NHS Foundation Trust  
RCPCH FASD Training Faculty

## Experience setting up pathway with no additional funding

- Recognition that some children who had been referred to the CDC with developmental problems had PAE
- No clear pathway or process for assessing these children
- 3 paediatricians & psychologist underwent University of Washington on-line training Feb-May 2016 (\$110 each)
- Facial analysis software, philtrum guides and rulers purchased (\$100)
- Input from neonatologist with interest in FASD & limited psychology/OT input
- Pathway developed
- No additional funding therefore had to be within parameters and resources of existing service

# Brighton/Hove – Sample FASD clinical pathway



# Service Evaluation

## Comparison of 15 patients seen prior to setup of pathway and 14 patients who have been through new pathway

- Improved documentation of growth parameters
- Improved formulation and clearer outcomes
- Improved time to reaching conclusion
- Consistent provision of written information to parents and schools

## Parent/ Carer satisfaction survey (ongoing)

- Most parents/ carers happy with time taken to complete assessment and all found assessment process and report useful
- Areas to improve include information about the assessment process
- Some parents/ carers felt they needed more post diagnosis support

## Pathway Challenges and Limitations

- Currently no additional resource for FASD assessment
- Children assessed must meet existing referral CDC criteria
- Reliance on assessments already carried out
- Limited access to psychology assessments
- Very limited post diagnosis support
- NICE quality standard should help to highlight commissioning gap



**Families  
struggle  
while  
system  
changes**

# Aliy Brown

Project Manager  
FASD Hub Scotland  
FASD Lead for Adoption UK

# About FASD Hub Scotland

## Support service for all Funding by Scottish Government

### Tier 1 Services

#### FASD Helpline and Online Resources

Helpline providing information, signposting and advice  
Online multi media resources through Website & Social Media

### Tier 2 Services

#### Direct Support for Parents/Carers and Professionals

Online peer support community for parents/carers  
1:1 Family Support  
Training and workshops for parents/carers and professionals  
Adults with FASD peer support online community

### Tier 3 Services

#### Therapeutic Services

Access to enhanced therapeutic services.

# About FASD Hub Scotland

**Wednesday Webinar**  
**Road2FASD – The Road Trip**



Jo Garofalo



Jan Griffin

Hosted by  
Aliy Brown  
FASD Hub Scotland  
Project Manager

**6TH APRIL,  
8PM**

#FASDHearMe  
#FASDWorkingTogether



**Wednesday Webinar**  
**Fetal Alcohol Advisory, Support & Training  
(FAAST) Team**



Dr. Jennifer Shields  
Principal Clinical  
Psychologist



Aliy Brown  
FASD Hub Scotland  
Project Manager

**20TH APRIL,  
8PM**

#FASDHearMe  
#FASDWorkingTogether



## FASD Bitesize Cafe

Grab your lunch and  
join us for a short  
session on FASD and  
the work of the  
FASD Hub



All parents, carers and professionals welcome

**Tuesday 26th April  
12.30–1.30pm**

**FREE!**



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0300 666 0006  
(Option 2)



fasdhub.scotland@adoptionuk.org.uk

www.fasdhub.scot

**Lived  
experience**

## **One family's journey... that is typical of many**

- Family had concerns, ASD assessment
- Family left unsupported and misunderstood
- Stumbled upon FASD
- Received support through FASD Hub Scotland
- Revolving door through services resulting in long waiting times and uncertain outcomes

Lived  
experience

## What do we need, to see these succeed, and make lasting change for families?

SCOTLAND

SIGN 156  
Jan 2019

Children's Neurodevelopmental  
Pathway (Sept 2021)

NICE Quality Standard  
March 2022

# For better outcomes

- Lose the stigma
- Engage with lived experience to improve professional understanding of PAE and FASD
- **Experts by experience** embedded in every part of the process



**Women &  
informed  
choice**

# Jan Griffin

Birth Mum & Son  
Member National FASD Experts Committee

# Rossi Griffin

Road2FASD  
Birth Mum & Son  
Member National FASD Adults & Young Adults with  
FASD Advisory Committee

Beyond  
stigma

LET'S REMOVE THE STIGMA



ASK ABOUT ALCOHOL



# Beyond stigma

## Give us the facts

- Facts cannot hurt my feelings
- Not having them has hurt my child

## It's not about blame

- It's not about blame
- It's not about poverty/ S.E.S
- It's not (always) about addiction
- It's all about knowing
- If I knew then what I know now



Raising  
awareness

## RossiLici roadtrip – summer 2023



Road2FASD

It's safest when pregnancy's alcohol free.



<https://www.facebook.com/RossiLiciroad2fasd>

**Diagnosis  
with no  
assessment**

# Susan McGrail

FASD Greater Manchester  
Member National FASD Experts Committee

Speaking  
for those  
who  
cannot  
speak

# Joanna Buckard

Director of Innovation, National FASD  
Member National FASD Experts Committee  
Director, Red Balloon Training

**Sensitive content warning**

Un-  
recognised,  
un-  
diagnosed,  
un-  
supported

## Who was Aaron? How did he (eventually) come to be diagnosed?

- Diagnosed with ARND (*FASD Without Sentinel Facial Features*) aged 18
- Diagnosis did not include neuropsychological assessments
- Diagnosis did not include a care management plan



# Areas of difficulty when unsupported



Housing



Employment



Social Relationships



Finance



Health



Risk Taking

## What could have made a difference?

- Trained professionals to recognise FASD symptoms
- FASD pathways
- Early diagnosis
- Psychological and Speech and language assessments
- Care Management Plan
- EHCP
- Understanding own diagnosis
- MCA assessment that considered the frontal lobe paradox
- Suitable Post 18 support



**Engaging  
those with  
lived  
exper-  
ience**

# Brian Roberts

Consultant, National FASD  
Member National FASD Experts Committee  
Field of Enterprise Training

# Georgia Roberts

Member National FASD Adults & Young Adults with  
FASD Advisory Committee

Engaging  
those with  
lived  
exper-  
ience



**#FASDTIMEISNOW**

Engaging  
those  
with lived  
exper-  
ience





## "Resources and Training to Support Children and Young People with FASD"

Funded by first-ever Dept of Health grants for FASD



- A special partnership Seashell and National FASD
- Externally evaluated
- Training





[www.fasd.me](http://www.fasd.me)

Our vision is to help people with FASD to understand their diagnosis and become self-advocates.

We are helping to build a community and bridge the loneliness too many with FASD feel.

**Practical  
steps  
forward**

# Iain Armstrong

Alcohol Programme Manager  
Office for Health Improvements & Disparities (OHID)



Office for Health  
Improvement  
& Disparities

Iain Armstrong, Alcohol Programme Manager, Office for Health Improvement & Disparities

21<sup>st</sup> March 2022

**#FASDTimeIsNow**

Well done!



Take time to  
recognise  
how far  
you've come

Look ahead  
to the next  
challenge





# Implementation – changing practice

65

## A plan for changing practice

- stakeholder mapping – engaging with the right people
- empowering the workforce – skills, knowledge and understanding
- mechanisms to change procedures - carrots and sticks
- data collection – ways to see if change is happening



# Implementation – changing practice

66

## Key actions from our experience of implementing national change and improvement:

- Working with specialists and experts with lived experience, engage with e.g.
  - NHS England & NHS Improvement
  - Health Education England,
  - Royal Colleges and professional bodies
- what are they already doing? Can they support changes in practice? Are there frameworks through which the QS can be implemented?
- clearly describe what skills and knowledge are required – to specify and quality assure training
- make good quality learning resources and patient information freely and easily accessible
- set up a way to develop clinicians' competence, share learning and system improvements - e.g. a community of practice
- seek out and engage with mechanisms that facilitate improvement – e.g. quality improvement initiatives, Care Quality Commission, maternity framework, CQUINs.
- identify or develop data indicators to monitor change and effectiveness



**Moving  
forward**

# **Bill Esterson MP**

Chair, All-Party Parliamentary Group on FASD

video

**Final  
thoughts**

# Dr Inyang Takon

Consultant Paediatrician  
East and North Hertfordshire NHS Trust  
Member National FASD Experts Committee  
NICE Quality Standard on FASD Committee

# Hope for the future

“I hope this is the start of the journey not the end. This document for me is there to help shape others’ thinking and to begin the conversation so people are not all starting at a zero place as I and others had to in the past. Hopefully, it will accelerate the progress.”

Prof Raja Mukherjee

Thank  
you!



WE MUST BE THE CHANGE

... we wish to see in the world.

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**#FASDTimeIsNow**

