



Public Health  
England

Protecting and improving the nation's health

# Children of alcohol dependent parents: Webinar

28 January 2021



Public Health  
England

Protecting and improving the nation's health

# Introductions and setting the scene

*Dawn Gordon, Programme Manager*



Department  
of Health &  
Social Care

# **FASD Webinar**

**Andrea Duncan**

**Head of Alcohol, Sexual and Reproductive Health**

28 January 2021

# Prenatal Alcohol Exposure

- **Foetal Alcohol Spectrum Disorder (FASD)- umbrella term**
  - Foetal Alcohol Syndrome (FAS)
  - Alcohol-related birth defects (ARBD)
  - Alcohol-related neurodevelopment disorder (ARND)
  - Partial foetal alcohol syndrome (pFAS)
  - Neurodevelopmental disorder – prenatal alcohol exposure (ND-PAE)
- PAE affects 7.7 per 1,000 population worldwide with prevalence of FASD in the UK rising to 32.4 per 1,000 [ref SIGN guideline Jan 2019]
- One of the commonest preventable causes of impairment in the UK. Lasts a lifetime (not just children)

# Stakeholder engagement

- In 2018/19 DHSC held two events led by Professor Gina Radford with health experts, stakeholders and people with FASD

## **Main messages from the events**

- Not doing enough on the prevention front- people still think they can drink when pregnant
- Education and awareness is poor in the health and care system on FASD
- Not just a health and care problem- education, employment, benefit system and justice
- Diagnostic and Treatment pathway is often too lengthy and poor
- Data on FASD prevalence doesn't exist

## **We listened and responded by:**

- Funding 5 voluntary organisations to support grassroots initiatives to prevent cases of FASD, raise awareness among professionals and help improve support for those living with its consequences.
- The organisations have a track record of managing and working in the field whose work is expected to have an impact at local or national level and provide value for money.
- The bids include across sector working, with health and care, education and individuals affected by FASD and will cost £533k.
- We are in the last quarter and have received great feedback on the work to date.

## **Other relevant work includes:**

- NHS Maternity Transformation Programme
- NHS Long Term Plan- prevention focused and Alcohol Care Action Teams
- NICE Quality Standard on FASD

# Many challenges remain:

- A need to better understand the epidemiology of the condition
- The needs of individuals vary greatly, and may change over the life course
- There is a continuing need to improve training and awareness among healthcare professionals
- The need to develop services that support diagnosis and management
- There is a need to develop innovative approaches to supporting those with FASD.





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# FASD Webinar

*Monica Davison: National Programme Manager  
Maternity, Public Health England*

# Background

- Publication of Better Births in Feb'16
- NHS England formed the Maternity Transformation Programme (MTP)

## **National Maternity Ambition**

**To reduce the rate of stillbirths, neonatal and maternal deaths, and brain injuries occurring during or soon after birth by 50% by 2030; and 20% by 2020'**

- PHE lead on Improving Prevention and Population Health, Workstream 9 of the MTP

## **PHE Maternity Ambition**

**To increase action on prevention to improve wellbeing, reduce risk and tackle inequalities from preconception through to 6-8 weeks postpartum and ensure every woman is fit for and during pregnancy and supported to give children the best start in life.**

# Rationale

## **A whole systems approach to prevention**

- Illustrate the opportunities for prevention and health improvement from pre-conception through pregnancy to 6-8 weeks postpartum.

## **Joined up working and commissioning between NHS and Local Authorities**

- To embed and support prevention across Local Maternity Systems (LMS's)

## **Part of the refresh of the Healthy Child Programme**

- Gather evidence to extend the HCP back into the preconception period

# Aims and objectives

**Aim:** Collate information, key evidence, guidance, and supporting resources relevant to our priority areas, organised around women's key points and times of contact with LMS's.

**Aspects:**

1. Design
2. Content for the pathway
3. Development of High Impact Areas

**Iterative process:** Adopted a double diamond methodology in order to ensure iterative stakeholder feedback and continuous improvement throughout the project cycle

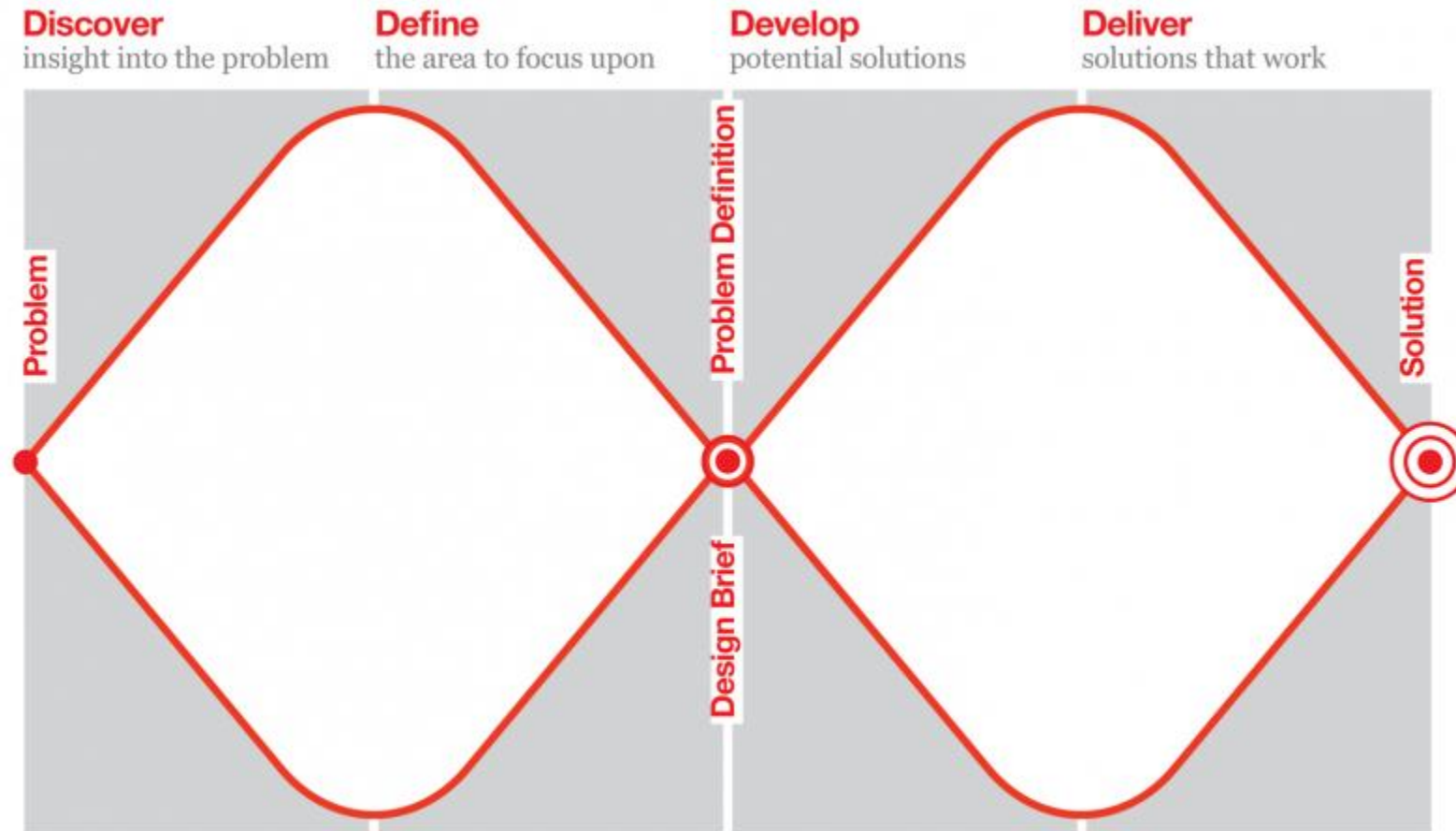


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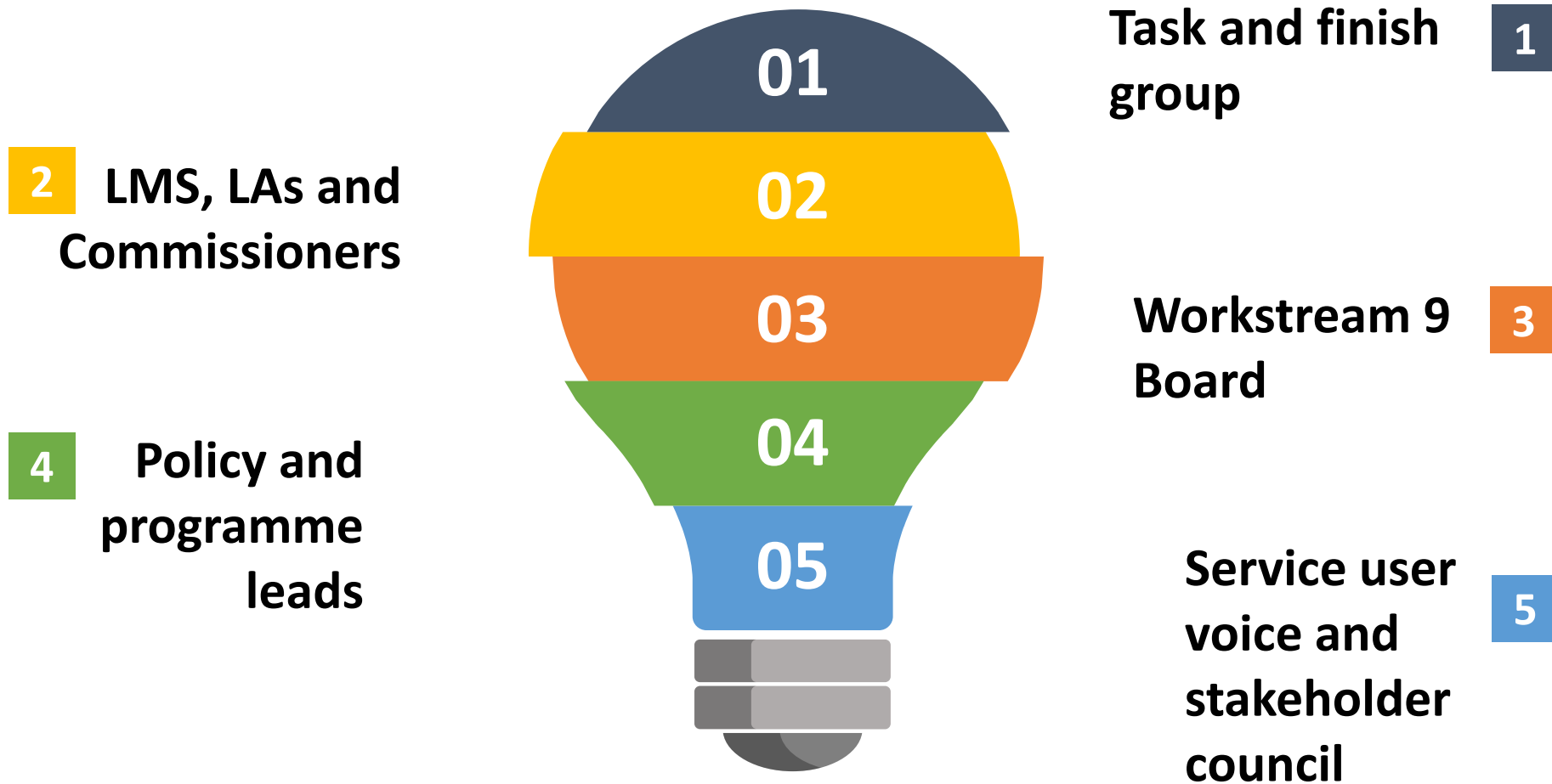
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# Healthy Pregnancy Pathway

# Methodology



# Stakeholder engagement



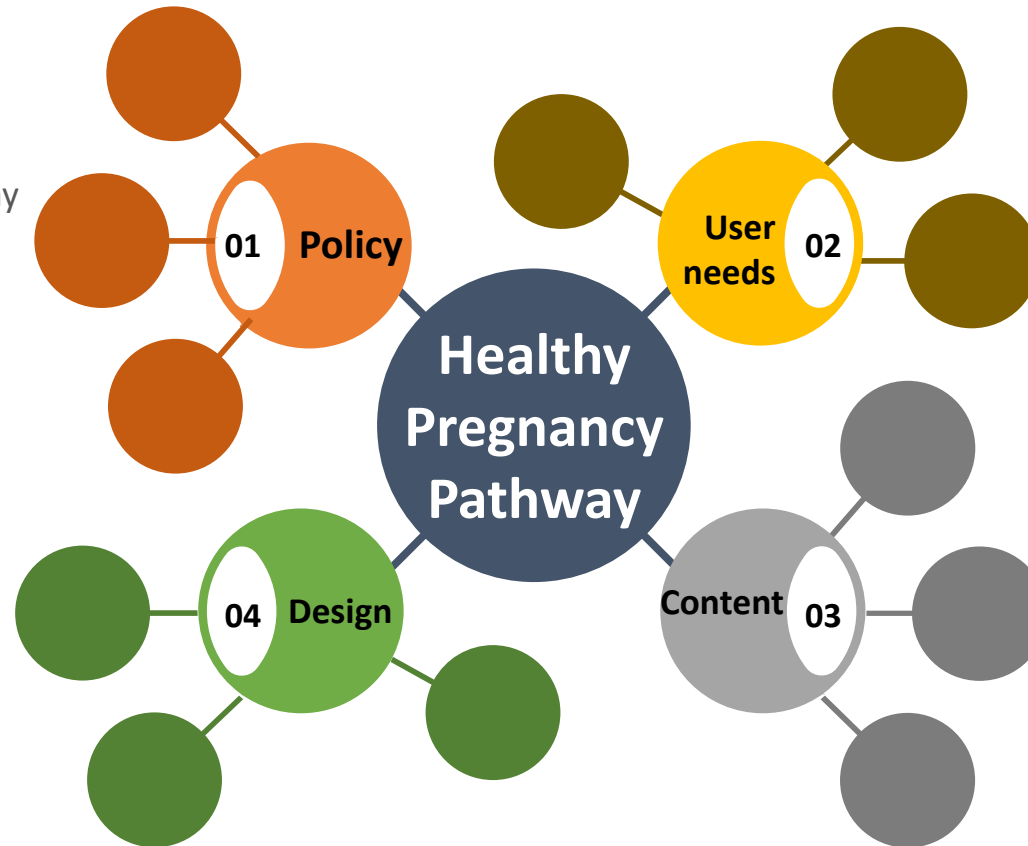
# Discover

## Policy context

- Update of the Healthy Child Programme
- MTP
- NHS LTP

## Design

- Where to host
- How to access
- Navigation



## User needs

- Preconcieved ideas – what is the problem, what is the solution
- How do users find the information now?
- What is needed to embed prevention?

## Content

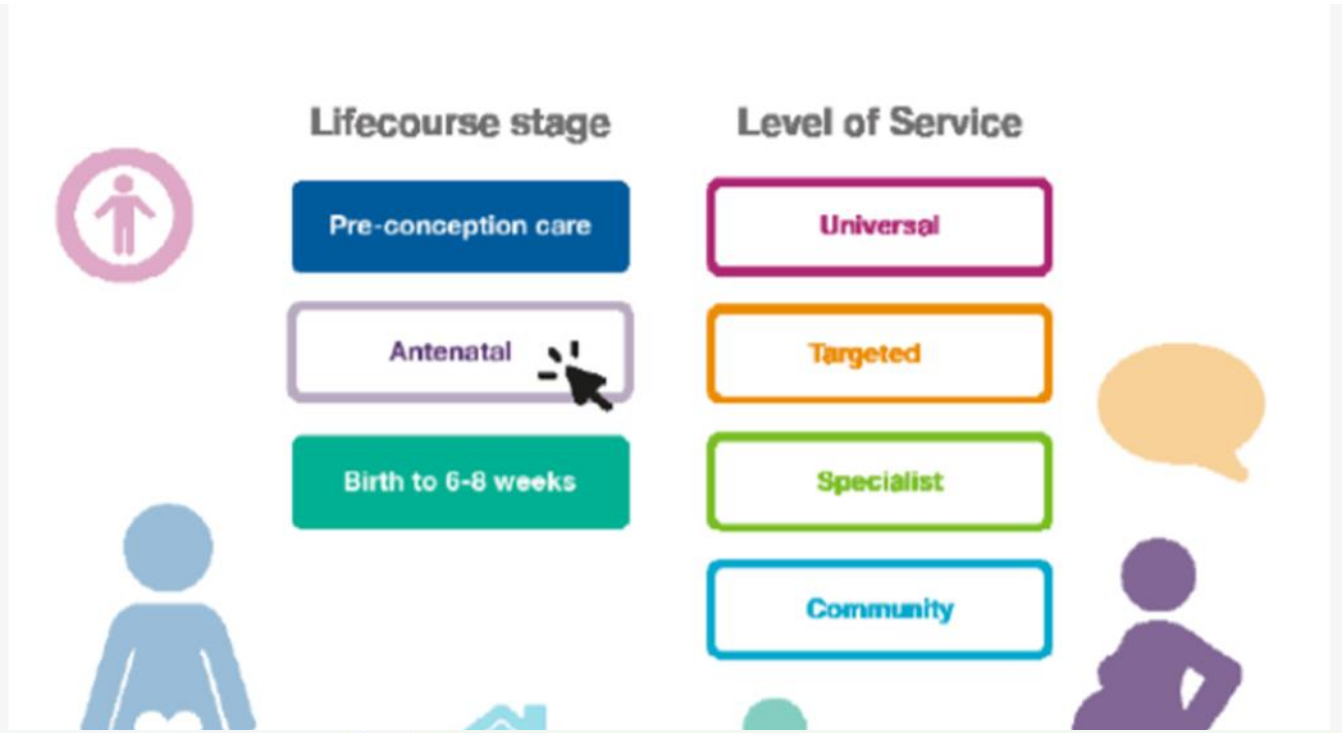
- Topics
- Levels of service
- Audience, purpose, context



# Define




# Develop



## Antenatal

**Universal**

Antenatal Screening IDPS, SCT & FASP.  
Needs led midwifery care and parenting preparation.  
Choice of place of birth.  
Infant feeding education and planning.  
HV antenatal visit\* new born screening programmes  
NBS, NIHP, NIPE.  
Midwife and HV continuity of care discussion.



## Antenatal

**Universal**


Midwife and HV Continuity of care discussion  
Click through to external resources

Antenatal  
Needs led  
Choice of place of birth  
Infant feeding  
HV antenatal visit\* new born screening programmes  
NBS, NIHP  
Midwife and HV

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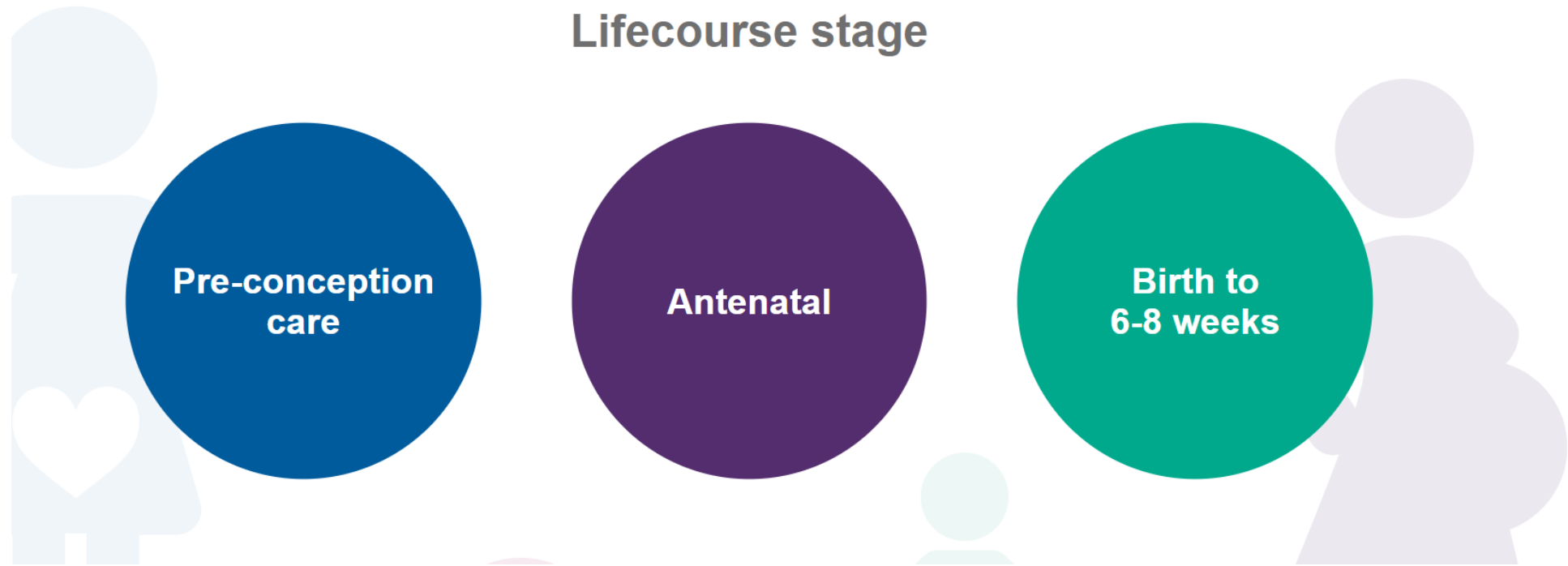
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# Deliver

## Healthy Pregnancy Pathway

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Lifecourse stage > Antenatal



Place-based approaches are delivered in the local community by a range of frontline workers, providers and commissioners working collaboratively to deliver a personalised continuity of carer model for all people.



Lifecourse stage > Antenatal > Universal

**HV Antenatal  
Visit**

**Immunisations  
- Seasonal Flu  
and Pertussis**

**Maternal  
Weight**

**Nutrition (and  
Supplements)**

**Oral Health and  
Dental Care**

**Physical  
Activity**

**Tobacco**

**Alcohol and  
Drugs**

**Supported Referral  
and On-going Joint  
Working/Liaison  
with Specialist  
Alcohol/Drug  
Treatment Services  
Where Indicated**

**Inclusion  
Health Groups**

**Inclusion  
Health: Black,  
Asian and  
minority ethnic  
(BAME) women**

**Making Every  
Contact Count**

**Safeguarding**

Ask all women and their partners: 'Are you drinking at the moment?' Identify their response according to alcohol guidelines, provide brief advice and signpost to information and support if necessary.

Alcohol use screening tests can be used by health professionals as a tool to assess a service users level of risk to alcohol harm. See PHE Guidance - Alcohol use screening tests

Alcohol Identification and Brief Advice e-learning (Alcohol IBA) helps professionals to identify those individuals whose drinking might impact their health and deliver simple, structured advice aimed at reducing this risk

UK Chief Medical Officers' Low Risk Drinking Guidelines: The Chief Medic

The Chief Medical Officers' guideline is that: If you are pregnant or think you could become pregnant, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum. See Guidelines here

Encourage women to abstain from alcohol use during pregnancy and where necessary referring to further, specialist, support (including specialist clinical support to withdraw from alcohol).

Ask about illicit drug and medicine misuse, providing information, advice and help including advising women to abstain from drug use during pregnancy and referral into specialist treatment where indicated. If you remain in contact with a patient who has reported using drugs, review their drug use at each session.

# How to use it and where to find it

- All interactive pathways are available here: <https://www.e-lfh.org.uk/programmes/interactive-pathways/>
- Google: [Healthy Pregnancy Pathway elfH](#)



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# Maternity High Impact Areas



# Maternity High Impact Area documents

## **Audience**

Local Maternity Systems professionals who wish to acquaint themselves with the latest evidence and good practice guidance on maternity priority topics in England.

## **How?**

As a guide to support the early signposting of evidence-based actions that can be practically applied according to local population needs.

# Maternity High Impact Area topics

- Reducing the inequality of outcomes for women from Black, Asian and Minority Ethnic (BAME) communities and their babies
- Supporting healthy weight before, during and between pregnancies
- Supporting parents to have a smokefree pregnancy
- Improving planning and preparation for pregnancy
- Supporting good parental mental health
- **Reducing the incidence of harms caused by alcohol in pregnancy**

# Stage 1: Rapid review

Scopus and PubMed databases

**Aim:** to identify international reviews and UK empirical studies published since 2014 on supporting pregnant women to not drink alcohol. Journal of Health Visiting hand searched.

**Inclusion criteria:** Focus on issue, any research design, healthcare professional/woman/partner

## Stage 2: Identification of relevant reports, guidelines and good practice examples

- Searched Institute of Health Visiting, NICE, NHS England, Royal College of Midwives, Royal College of Obstetricians and Gynaecologists and Public Health England
- OpenGrey database
- Examples were deemed good practice if they were in line with current guidelines and provided information on positive outcomes for women
- The most recent MBRRACE checked for relevant information

## Stage 3: Document review & stakeholder engagement

1. Reviewed by topic experts, public health experts and healthcare professionals: 24 representatives from Local Maternity Systems, national bodies and Public Health England attended a review workshop in January 2020
2. Documents were revised and improved
3. Reviewed by a small number of topic experts within PHE before being finalised

# Content

Maternity high impact areas: overview

Executive summary

Summary of key actions

Measuring success

Access

Effective delivery

Outcomes

User experience

# Content

Evidence-based approaches to reduce incidence of harms

Individual and familial

Training of healthcare professionals

Community

Population

Associated tools and guidance

Resources for women

Resources for healthcare professionals

Policy

Guidance

Research

# Where to find it

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/942477/Maternity\\_high\\_impact\\_area\\_4\\_Reducing\\_the\\_incidence\\_of\\_harms\\_caused\\_by\\_alcohol\\_in\\_pregnancy.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/942477/Maternity_high_impact_area_4_Reducing_the_incidence_of_harms_caused_by_alcohol_in_pregnancy.pdf)



# Next steps

- The pathway is being considered as a Beta version and will be updated next year based on user feedback from this year
- Any feedback please send to: [monica.davison@phe.gov.uk](mailto:monica.davison@phe.gov.uk)

A stylized sun graphic with a large yellow circle and several short yellow dashes radiating from it, set against an orange background.

# The first UK-funded research studies into FASD: pilot studies in prevention and treatment

Lesley Smith (University of Hull) and Penny Cook (University of Salford) on behalf of the UK FASD Research Collaboration



University of  
**Salford**  
MANCHESTER



# Outline


- Introduce the UK FASD Research Collaboration
- Outline the state of play in terms of research and research funding in the UK
- Two UK funded research projects:
  - CHAMPION - Prevention of alcohol harm to the foetus (Lesley Smith)
  - SPECIFIC - parenting intervention for families affected by FASD (Penny Cook)

# UK FASD Research Collaboration

- An informal group of ~30 researchers and ~8 representatives of families affected by FASD
- No funding or formal structure
- 2 meetings so far—packed with talks and lots of ideas
- Outcomes as a collective:
  - Paper outlining the state of play for UK research—accepted for publication in Archives of Childhood Disease
  - A major contribution to The report of the Commission on Alcohol Harm's report "It's everywhere' – alcohol's public face and private harm'
  - Submitted evidence to the WHO 'Action plan to strengthen implementation of the Global Strategy to Reduce the Harmful Use of Alcohol'



## UK research

- Prevention—interventions to reduce alcohol use in pregnancy
  - Diagnostics—studies on dysmorphology (funded by USA)
  - Prevalence—active case ascertainment study, active surveillance of FAS through the British Paediatric Surveillance Unit, use of biomarkers (e.g. meconium)
  - Impacts—sleep, criminal justice system involvement, stigma
  - Interventions—parenting intervention
- 

# UK Research funding for FASD

- Money spent on autism research (£10.4m in 2016)
  - Funding for autism research was awarded to 17 universities and NHS Trusts across the UK
  - £5 (2013) to £15 (2016) per autistic person
  - <https://www.autistica.org.uk/downloads/files/Autistica-Scoping-Report.pdf>
- Money spent by the UK on FASD research in UK (~£500K in 2019-2020)
  - Funding awarded to 3 universities in the UK
  - UK population of 13m children and young people aged 0-17y; estimated 390,000 with FASD
  - £0.79 per child with FASD (2019) to £0.59 (2020)
  - £0.44 per person (2019) to £0.33 per person (2020) (assuming similar prevalence to autism)

# CHAMPION - AlCohol HArM PreventiOn iN pregnancy

Professor Lesley Smith

Institute of Clinical and Applied Health Research

Faculty of Health Sciences

University of Hull



Hull University  
Teaching Hospitals  
NHS Trust



UNIVERSITY  
OF HULL

**NIHR** | National Institute  
for Health Research



Lifecourse  
approach to  
prevention

Improving  
prevention is  
one of 10  
workstreams in  
the Maternity  
Transformation  
Programme



# Midwives' assessment of expecting mothers' alcohol use (MAMA)

“If you are pregnant or think you could become pregnant, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum”

## ALCOHOL GUIDELINES FOR PREGNANT WOMEN

Barriers and enablers for midwives to deliver advice



Lisa Schölin, Julie Watson, Judith Dyson and Lesley Smith



# CHAMPION - AlCohol HArM PreventiOn iN pregnancy

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Aims and objectives:

- To co-design a theoretically informed intervention to support midwives in implementing an alcohol care pathway
- To evaluate the feasibility of implementing such an intervention in practice; and acceptability of intervention delivery and content to maternity service users and providers.

# Iterative approach to co-design



Intervention mapping  
exercise



Sequential workshops  
and feedback



Final content of  
intervention agreed



Early feasibility and  
acceptability of the  
intervention

# Anticipated impact

Scale up alcohol care pathway across the NHS



Facilitate informed choice; and reduce alcohol-related harm to maternal and infant health



# Development and feasibility testing of an FASD parents/carers training programme

Dr Alan Price (Research fellow)

Professor Penny Cook (Principal Investigator)

Dr Raja Mukherjee (co-investigator)

Et al

University of Salford



# **SPECIFIC: Salford Parents and carers Education Course** **for Improvements in Fasd outcomes In Children**

Seven session programme delivered online (Microsoft Teams):

Themes by session:

1. Introduction
2. Sensory processing
3. Self-regulation
4. Communication
5. Abstract and concrete thinking
6. Routine, structure and consistency
7. Social relationships

Themes throughout:

Advocacy

Self care

Keeping in touch

Strategies for managing

FASD

Diary of strategies

Reading list



# Expert steering group

+Professor Penny Cook

+Dr Larry Burd

+Joanna Buckard

+Dr Jennifer Shields

+Dr David Tate

+Suzanne Bell

+Dr Raja Mukherjee

+Sandra Butcher

+Dr Larry Burd

+Susan McGrail

+Dr Clare Allely

+Anna Webster

# Feasibility study

## Group 1

- +5 families (6 participants)
- +Run by
  - + Alan (research fellow)
  - + Anna (FASD parent, experience of designing and delivering training)

## Group 2

- +4 families (4 participants)
- +Run by
  - + Maria (FASD parent and teacher)
  - + Sarah (therapist, teacher, Autism background)



# Assessment measures

- + Parenting Stress Index
- + Eyberg Child Behaviour Inventory
- + Strengths and Difficulties Questionnaire
- + Tool for Measuring Parenting Self-Efficacy
- + CORE-OM (treatment outcomes)
- + EQ-5D-5L (health-related quality of life)
- + Session evaluation forms
- + Homemade FASD knowledge questionnaire (based on course content)
- + Semi-structured interviews

# Participant feedback

- +Overwhelmingly positive
- +Participants appreciated the opportunity to meet and talk to other parents of children with FASD
- +Advice provided in the course was immediately useful – participants were able to make changes to the way they supported their children, with noticeable positive effects (examples on next slide)

# Examples of feedback

- + Son was refusing to wear school coat – realised sensory issue – let him choose his own coat – now he wears it
- + Tipping Lego over and rummaging through – realised this was a sensory need – helps parent understand her son's needs
- + Decluttered daughter's bedroom – improved sleep
- + Fiddle toy for calming on way to school
- + Picture charts helpful for bedtimes, mealtimes

# Quantitative results

- +Every metric we used showed some improvement
- +Some improvements reached statistical significance, even in this small sample:

|   | % change | <i>d</i> | <i>p</i> |
|---|----------|----------|----------|
| Parental Stress Index – total stress      | 12.08    | .74      | .06      |
| Parental Stress Index – parent domain     | 17.41    | .78      | .047     |
| SDQ (child behavioural difficulties)      | 14.07    | .77      | .05      |
| TOPSE (parenting self-efficacy)           | 9.26     | 1.59     | .001     |
| CORE-OM (mental health symptoms - parent) | 51.90    | .75      | .06      |
| FASD knowledge (parent)                   | 19.73    | 1.16     | .01      |

# Next

- + Paper describing development and feasibility stage
- + Revisions of manual based on feedback from trainers, participants and steering group
- + Applying for funds for randomised controlled trial

# Thank you

**Penny Cook** [p.a.cook@salford.ac.uk](mailto:p.a.cook@salford.ac.uk)

Twitter: @profpennycook @FasdSalford

**Lesley Smith** [Lesley.Smith@hull.ac.uk](mailto:Lesley.Smith@hull.ac.uk)

Twitter: @OxBUMP



# **Growing Resilient Families & prevention of FASD**

**Katherine Wadbrook     January 2021**



**Change  
Grow  
Live**

## *Today's presentation:*

# **West Sussex CGL Growing Families Service – part of West Sussex Drug & Alcohol Wellbeing Network**

- **What we do & how it came about**
- **Pathways and relationships made**
- **Challenges**
- **Data and Outcomes**
- **Case studies & feedback**
- **What we are looking forward to**



# Our Services – West Sussex Drug & Alcohol Wellbeing Network

We are the commissioned provider of services for alcohol and other drug users in West Sussex

We run a birth to end of life service

Hubs in Crawley, Worthing, Bognor and Chichester and satellites across the county

- **Over 25s Drug & Alcohol Service**
- **Under 25s Drug & Alcohol Service**
- **Children and Young Persons Therapeutic Service**
- **Family Services (including Growing Families)**

We were one of the areas successful at winning a share of the Innovation Fund, to support families whose lives have been affected by alcohol

We submitted a multi faceted bid incorporating face to face work, therapeutic work, a training event and a digital approach.

**The focus of today is our Growing Families Service which provides pre-birth support for parents drinking alcohol – *aiming to reduce potential harms to unborn* and other children and look at reducing parental conflict**

## Where we started:

- *WSX has **higher than national average** numbers in service of people with **dependent children** (NDTMS data)*
- *CGL WSx DAWN already working in **family focused** way – established family team*
- *Some well established **working relationships** between CGL and West Sussex and partners (peri-natal services, MASH, schools etc)*
- *Projects sit well alongside the wider West Sussex approach to **Reducing Parental Conflict***

## Growing Families Service

- Live since August 2019
- Working across the county
- 2 full time workers
- Managed by a Social Work Lead
- Outreach, flexible and intensive where needed
- Small caseloads
- Led by the person wanting the service
- Tenacity!



***Aiming to reduce potential harms to unborn & improve family relationships***

# The work offered

**Tailored  
package  
of support**

**1-1  
support  
with  
named  
worker**

**Home  
visits**

**Advocacy  
& support  
@  
meetings  
e.g. CPC**

**Links with  
wider CGL  
services  
e.g.  
groupwork**

**Care  
planned  
approach**

**Medical  
intervention  
inc detox**

**Parental  
conflict &  
relationship  
support**

**Alcohol  
education  
and  
advice**

**Multi-  
agency  
working**

## Pathways and links with

Pathways for maternity services and now Healthy Child Programme and Family Nurse Partnership - age range extended to baby up to 12 mths

Attendance at monthly safeguarding midwives meetings – info sharing and gathering

Peri-natal Mental Health Service

Pre-birth Social Workers & Childrens Social Care

Working within existing CGL services including alongside therapeutic service for children

**2020-2021 (to end Q3)**

**We have undertaken 19 assessments**

**Over 153 appointments have been attended**

**There have been 13 positive closures, of which 5 were pregnant people  
(4 high risk)**

**We are currently engaging 20 people, of whom 7 are pregnant**

# Challenges

- Geography – only two workers covering county
- Ability to network (due to above)
- Working with 3 different hospital trusts – e.g. midwives SG meetings configured differently
- Four different CGL hubs
- Covid 19 and lockdowns





## Outcomes:

- My knowledge about alcohol has increased
- I have reduced or stopped my alcohol use
- I know how to reduce the risks associated with alcohol use
- I know more on other available services
- Conflict with my partner has reduced
- My physical health has improved
- My emotional wellbeing has improved
- Family dynamics have improved



## Case study – short term brief intervention

*27 year old woman, M, referred by pre-birth Social Worker*

**Presenting issues:** previous successful treatment for alcohol use; mental health issues; historic domestic abuse and trauma; newly pregnant and wanting to maintain alcohol free lifestyle

**Assessment session:** used to explore situation and what wanted by M plus professional judgement by worker. Agreed that one off relapse prevention session useful at this stage – M currently in positive place, mental health stable and positive current relationship but aware of risks of past alcohol use

## Case study – short term brief intervention



**Session focus:** safety planning, coping strategies, mindfulness & relaxation techniques, understanding of cycle of change, relapse prevention – exploring possible triggers and high risk situations; current relationship, staying safe and healthy boundaries; what support available in community e.g. C&F Centre, PNMHS

Liaison with Social Worker and midwife to ensure no concerns and acknowledge engagement and work completed

**Outcomes:** abstinence maintained, increased knowledge & understanding of risks plus support available; safety plan in place in case of risk of relapse; other professionals aware of support offered – information shared as needed

**Positive feedback** received that M enjoyed the sessions and discussions

# Case study – long term complex intervention

36 year old woman, D (self referral)

**Presenting issues:** previous unsuccessful attempts at treatment for alcohol use; 20 year history of alcohol & cannabis misuse plus other complexities; currently drinking daily & poly drug use; in very early stages of pregnancy

**Assessment:** identified a range of issues – possible physical dependence on alcohol, long history of substance misuse, unstable accommodation, mental health issues including high anxiety levels and past trauma, historic domestic abuse, partner with substance use issues of own & struggling to provide support for D

**Immediate intervention:** advice & guidance around risks of alcohol use to unborn, booking in for fast track medical assessment with doctor due to pregnancy & possible dependency, request to GP for LFTs & other blood tests

# Case study – long term complex intervention

## **Additional & ongoing support & intervention:**

- *Support to explore risks in relation to alcohol use - nurse appointment for safe reduction plan to avoid alcohol related seizures and any chance of miscarriage in first trimester*
- Regular phone contact and home visits to build trusting relationship
- *Referral into MASH & subsequent liaison with CSC in relation to risk to unborn*
- *Application to fast track detox and rehabilitation programme*
- *Exploration of alternative coping mechanisms, root causes and triggers for alcohol & substance use, relationship conflict*
- *Liaison with maternity services throughout pregnancy*
- Identification of risky situations and safety planning put in place
- Support to access housing advice and, ultimately, accommodation

# Case study – long term complex intervention

Father of unborn, self referred into CGL and engaged with own support.  
As she stabilised, D chose not to continue the relationship but felt that she was able to maintain good communication

While D was in detox & rehab (out of county) regular communication with CGL Family Worker was maintained, including a visit for the midway review.  
Support given to D to plan for her discharge from rehab and move back to West Sussex

D went into temporary accommodation on return from rehab (as part of Covid response) and had daily contact from staff (CGL & wider partners)

Support given post rehab to maintain abstinence through 1-1 and groups (inc specialist women's group) plus referral to ETE support within CGL

# Case study – long term complex intervention

## Outcomes:

- Healthy baby was born May 2020
- Abstinence maintained
- D reports improved physical and mental health and improved family relationships (e.g. with her parents)
- Now in stable accommodation
- Volunteering for AA
- Dad is having contact with baby
- D engaged with PNMHS and referred to Time to Talk
- Baby moved from Child Protection to Child In Need

***I have found having weekly appointments useful and having weekly objectives and sessions around topics that I needed support on, like coping strategies, boundaries, healthy relationships, warning signs and how to continue on with not using.***

***I have been able to use these tools in my day to day life to continue with being abstinent..and to say no to alcohol***





***You got me into rehab very quickly  
When you came to my house when I didn't  
want to go out, this made me feel you've  
been on my side  
Never felt judged by you  
Stuck to it in rehab, you came to visit me  
when I was there  
It has to be the right person - this made such  
a difference, I felt we really connected  
I've got my baby with me...***



***I'm so grateful for everything  
you've done***



# What we are looking forward to

- Re-establish presence within MASH
- Get back to face to face working
- Specialist group support – pregnancy
- Planning for service delivery beyond April 2021, beyond lifetime of grant
- Final evaluation of project

# Contact us

Growing Families:

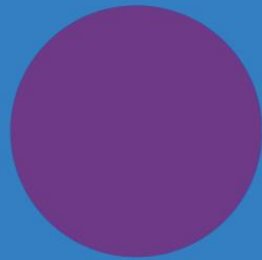
[familyteam.wsxdawn@cgl.org.uk](mailto:familyteam.wsxdawn@cgl.org.uk)

Service Manager

[katherine.wadbrook@cgl.org.uk](mailto:katherine.wadbrook@cgl.org.uk)



# Seashell



## Supporting children and young people with FASD – an overview of new resources

Michelle Jones – [michelle.jones@seashelltrust.org.uk](mailto:michelle.jones@seashelltrust.org.uk)  
Sandra Butcher – [sandra.butcher@nationalfasd.org.uk](mailto:sandra.butcher@nationalfasd.org.uk)



NATIONAL  
ORGANISATION  
— F O R —  
**FASD**



# Seashell

## A unique partnership

Funded by



Department  
of Health &  
Social Care

### A little bit about **Seashell**

Our charity is dedicated to providing a creative, happy and secure environment for children and young people with complex and severe learning disabilities which include little or no language abilities.

### A little bit about **The National Organisation for FASD**

The National Organisation for FASD (formerly NOFAS-UK) is dedicated to supporting people affected by Fetal Alcohol Spectrum Disorder (FASD), their families and communities. It promotes education for professionals and public awareness about the risks of alcohol consumption during pregnancy.



## Guided by experts

Including advisory committee of those with FASD

**Dr Carolyn Blackburn**, Education Specialist, Birmingham City University

**Joanna Buckard**, Trainer, Red Balloon Training, Specialist Projects Coordinator National FASD

**Sandra Butcher**, National Organisation for FASD

**Jan Griffin**, birth mother to teen with FASD, member of the EU Birth Mums group

**Brian Roberts**, Foster Carer/adoptive parent/former Virtual School Head, Field of Enterprise Training

**Dr Cassie Jackson**, Psychologist, Centre for FASD

**Sharon Jackson**, Foster Carer/adoptive parent, Much Laughter: Standing Up for FASD, Trainer

**Michelle Jones**, Seashell Trust

**Susan McGrail**, Foster Carer/adoptive parent, FASD Greater Manchester

**Dr Raja Mukherjee**, Psychiatrist, National FASD Clinic

**Dr Inyang Takon**, Paediatrician, E. Herts NHS





## UK language guide

### Stigma-free

- Created with input from those with lived experience;
- Terms that are stigma-free and blame-free;
- A common description of FASD;
- Additional terms that should be used with caution;
- Sample sentences using the preferred language; and
- A glossary of frequently used terms.





## Best practice in FASD training guide

To help CCGs & others determine if the training they are engaging is based on best practice

- A checklist for FASD training;
- An overview of best practice in FASD training;
- Essential content for an introduction to FASD training course; and
- A fact and fiction section, debunking myths about FASD.



## One-day training: Introduction to supporting children and young people with FASD

For professionals across Health, Education and Social Care

### Dates

One day training:

25 January 2021  
1 March 2021  
22 March 2021  
17 May 2021  
14 June 2021  
12 July 2021

### Time

9:30 am – 3:30 pm

### Cost

£95 per person  
(bulk rates available)

### Venue

Via zoom until further notice

### Details

This one-day course is uniquely co-designed by experts from the Seashell Outreach team and The National Organisation for FASD.

Based on “Best Practice in FASD Training Guide” and the “FASD: UK Preferred Language Guide” – also co-produced under the Seashell/National FASD partnership project funded by the Department of Health along with the “Me and My FASD Toolkit” ([www.FASD.me](http://www.FASD.me)) for young people with FASD.

### Course Content

- Causes of FASD, its prevalence and terminology
- Identification of signs and symptoms across the lifespan
- How to get a diagnosis
- Strategies for supporting a person with FASD
- Voices from the FASD community
- Quality endorsed via Seashell’s Open College Network licence

### Contact Us

[outreach@seashelltrust.org.uk](mailto:outreach@seashelltrust.org.uk)

“The day was well paced and had a good variety of presentation styles.  
Because people present were actively involved with children and young people who have FASD, it gave it a really strong context. I learnt a great deal.”



# Seashell

## Also launching a unique 3-day training

Using the “Me and My FASD Toolkit” to help young people understand and own the diagnosis





# Me and My FASD: A Three-Day Course

## Seashell

For practitioners supporting a young person to understand their FASD diagnosis

### Dates

- 10-12 February 2021 (pilot)
- 23-25 June 2021

### Time

- 9:30 am – 3:30 pm

### Cost

- £250 (Pilot)
- £350 June (Bulk rates available)

### Venue

- Via zoom until further notice

Voices from the FASD community are woven throughout this course.

### Details

- This three-day course is uniquely co-designed by experts from the Seashell Outreach team and The National Organisation for FASD.

### Course Content

- The course reviews basic information about causes of FASD, its prevalence and terminology; signs and symptoms; how diagnosis is made; strategies for supporting a person with FASD.
- Introduces the "Me and My FASD Toolkit" ([www.FASD.me](http://www.FASD.me)) developed under this partnership. Participants will be given access to supplemental items designed to help them use these materials.
- Based on "Best Practice in FASD Training Guide" and the "FASD: UK Preferred Language Guide" – also co-produced under the Seashell/National FASD partnership project funded by the Department of Health.
- Quality endorsed via Seashell's Open College Network

### Contact

[outreach@seashelltrust.org.uk](mailto:outreach@seashelltrust.org.uk)

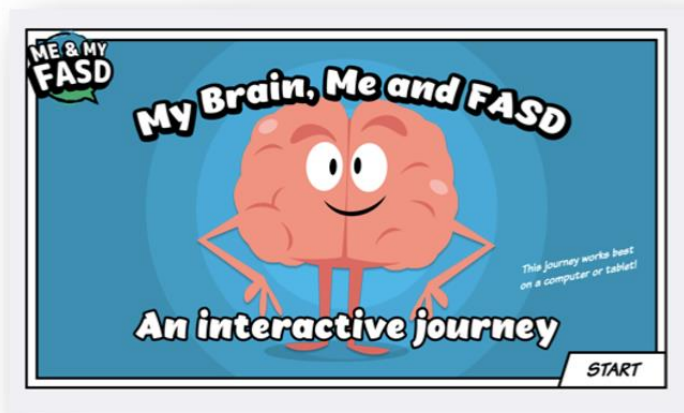
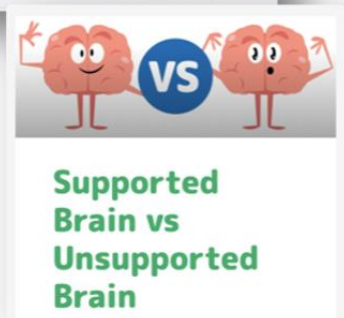
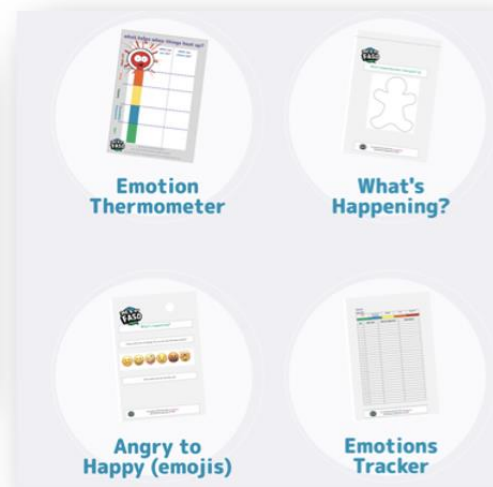
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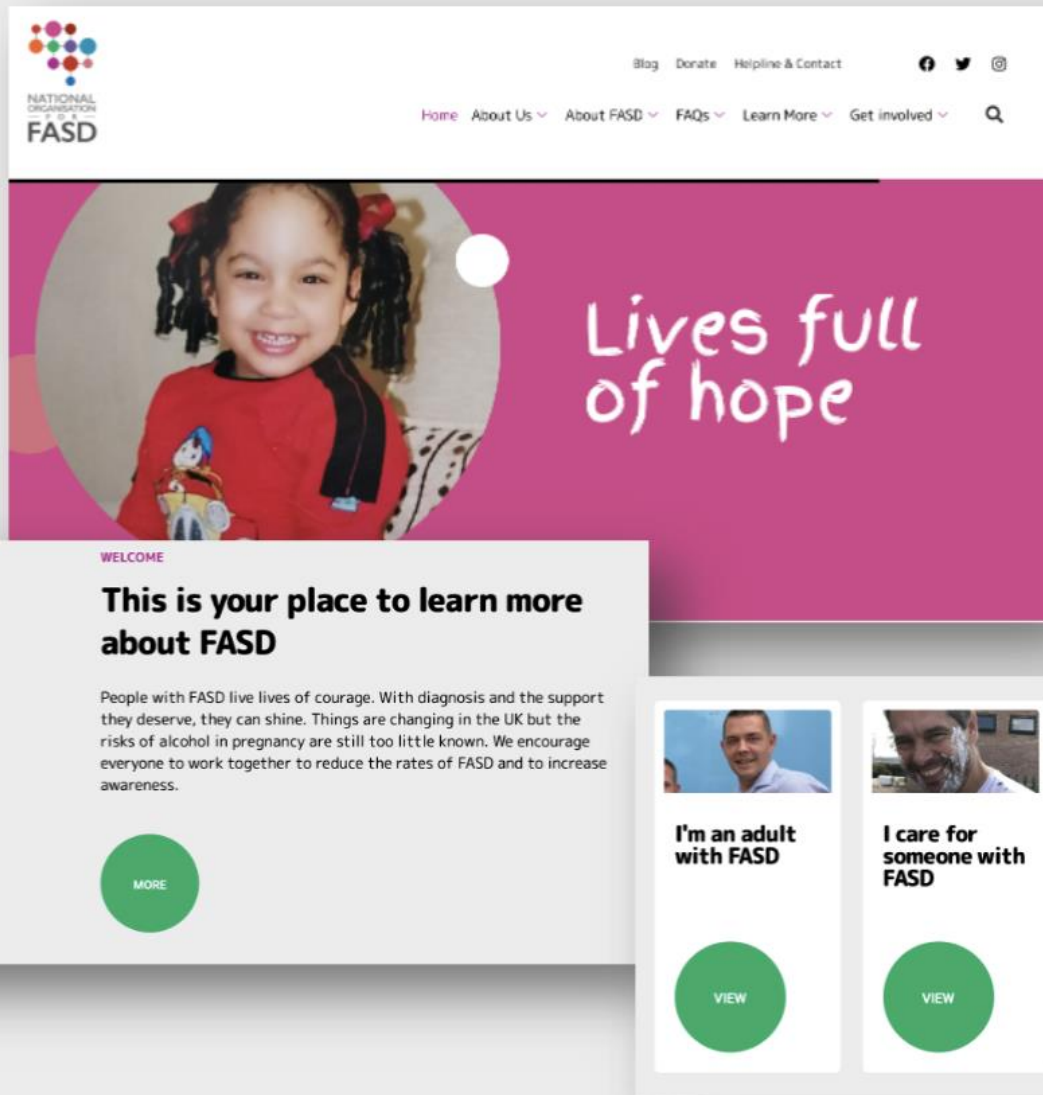


In a moment we'll tour  
[www.FASD.me](http://www.FASD.me)  
"Me and My FASD Toolkit"

# Seashell



# National FASD Updated website



1

Other resources are available from The National Organisation for FASD • [www.nationalfasd.org.uk](http://www.nationalfasd.org.uk)





**Lots of content!**

**FASD**  
**IN FOCUS**

Social workers are the primary profession to work with children and young people affected but it's little understood

**SOCIAL CARE**

**AREAS OF SW AFFECTED**



- > FASD and you
- > Diagnosis for adults
- > Health
- > Coping strategies
- > Adulthood
- > Relationships
- > Work and volunteering
- > Easy read resources

- > Legislation
- > Education
- > Benefits
- > Legal issues

- > Caregiver wellbeing
- > Parenting tips
- > All shapes of families
  - > Birth mothers
  - > Foster carers
  - > Adoptive families
  - Kinship
    - > carers/special guardians
- > School years
- > Transition to adulthood
- > Medical
- > #HearOurVoices
- > Getting support

- > Face to face
- > E-learning

- > NICE
- > CCGs & NHS Trusts
- > Department for Education
- > Department of Health and Social Care
- > Parliament
- > APPG on FASD

- > Midwives
- > GPs and healthcare professionals
- > Educators
- > Social care workers

- > Easy read
- > Research
- > Publications
- > Reports from roundtables
- > Posters
- > Videos
- > Social media assets

# Recognising FASD – a pamphlet explaining new guidance

## Diagnostic algorithm SIGN 156

### Listen, support, refer

**FASD is more common than autism according to international studies. (May et. al, 2018)**

A screening prevalence study here in the UK showed more than 6% may be affected. (McQuire et. al, 2018)

The UK has the 4th highest rate of alcohol in pregnancy in the world. (Popova et. al, 2017)

There is no proven safe amount of alcohol in pregnancy. The developing brain is particularly vulnerable throughout the pregnancy.

All levels of alcohol exposure should be recorded.

FASD is a full-body diagnosis; more than 428 conditions can co-occur. (Popova et. al, 2016)

**Concerns? Refer for a neurodevelopmental assessment**

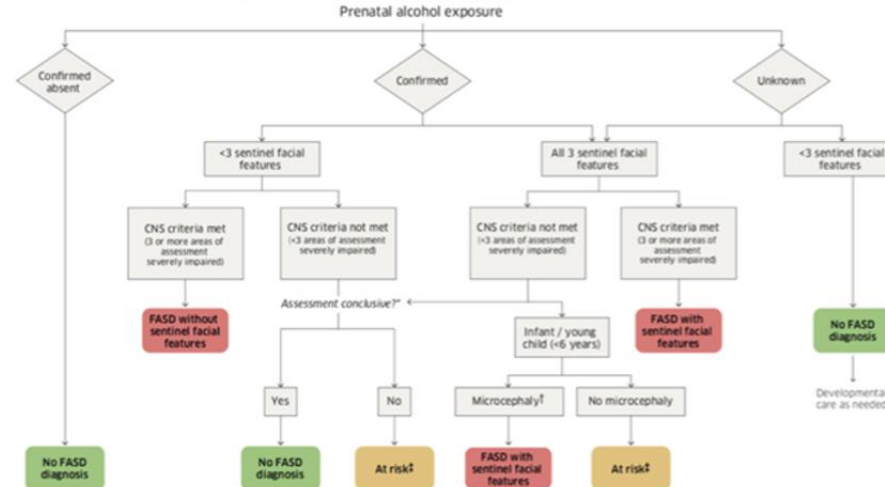
According to SIGN 156, "a diagnosis/descriptor of FASD is made only when there is evidence of pervasive and long-standing brain dysfunction, which is defined by severe impairment...in three or more of the following neurodevelopmental areas of assessment":

- motor skills
- cognition
- memory
- neuroanatomy/neurophysiology
- executive function, including impulse control and hyperactivity
- affect regulation, adaptive behaviour, social skills or social communication
- academic achievement
- language
- attention

**SIGN 156 states: "The diagnostic /descriptive criteria for FASD are the same for adults as for younger individuals".**

### Diagnostic Algorithm

Found at: <https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol.html>



\* Assessment conclusive = clinician conducting the neurodevelopmental assessment is satisfied that the session was a true representation of the person's ability and that any deficits reported were not due to extenuating circumstances. Assessments may be inconclusive for children under six years of age, because some areas of assessment cannot be investigated with confidence until the person is older or because of other confounding factors, such as temporary life stress or illness.

† Microcephaly is not the only pathway to diagnosis for infants and young children; these individuals may also receive other FASD diagnoses, as specified elsewhere in the algorithm, if they show three areas of substantial impairment on neurodevelopmental tests.

‡ At risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure. An at-risk designation includes situations where a full neurodevelopmental assessment is not conclusive because of age or situational factors; therefore, FASD may not be the diagnoses. Clinical judgement is recommended.

Contribution of genetic factors should be considered in all cases and referral may be indicated in typical cases or where PAE is uncertain.

### Diagnostic terms used by SIGN

Likely to be used more in England after the NICE Quality Standard on FASD

FASD without sentinel facial features, also known as:

- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Partial Foetal Alcohol Syndrome (pFAS)
- Neurodevelopmental Disorder-Prenatal Alcohol Exposure (ND-PAE)

FASD with sentinel facial features, also known as:

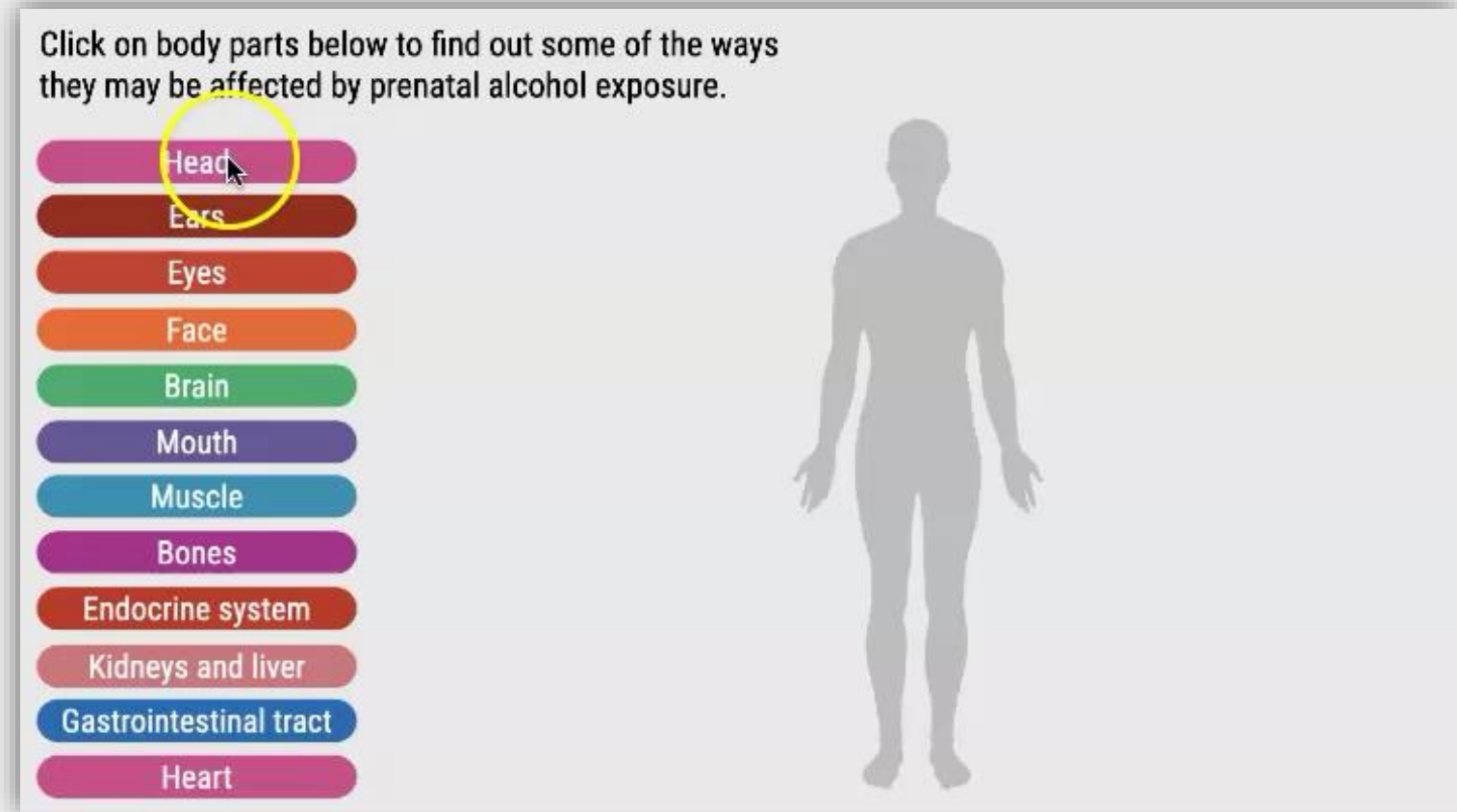
- Foetal Alcohol Syndrome (FAS)
- palpebral fissure length  $\geq 2$  SD below the mean
- philtrum rated 4 or 5 on 5-point scale of the University of Washington Lip-Philtrum Guide
- upper lip rated 4 or 5 on 5-point scale of the University of Washington Lip-Philtrum Guide

Source: <https://nationalfasd.org.uk/documents/RecognisingFASDPamphlet.pdf>



## Interactive

### A full-body diagnosis



Source: <https://nationalfasd.org.uk/learn-more/wellbeing/adults-with-fasd/health/>

**National FASD  
e-learning  
Coming soon!  
April 2021**



First course will be an intro to FASD course (3.5 hours)

Followed by an e-course for midwives

And more!

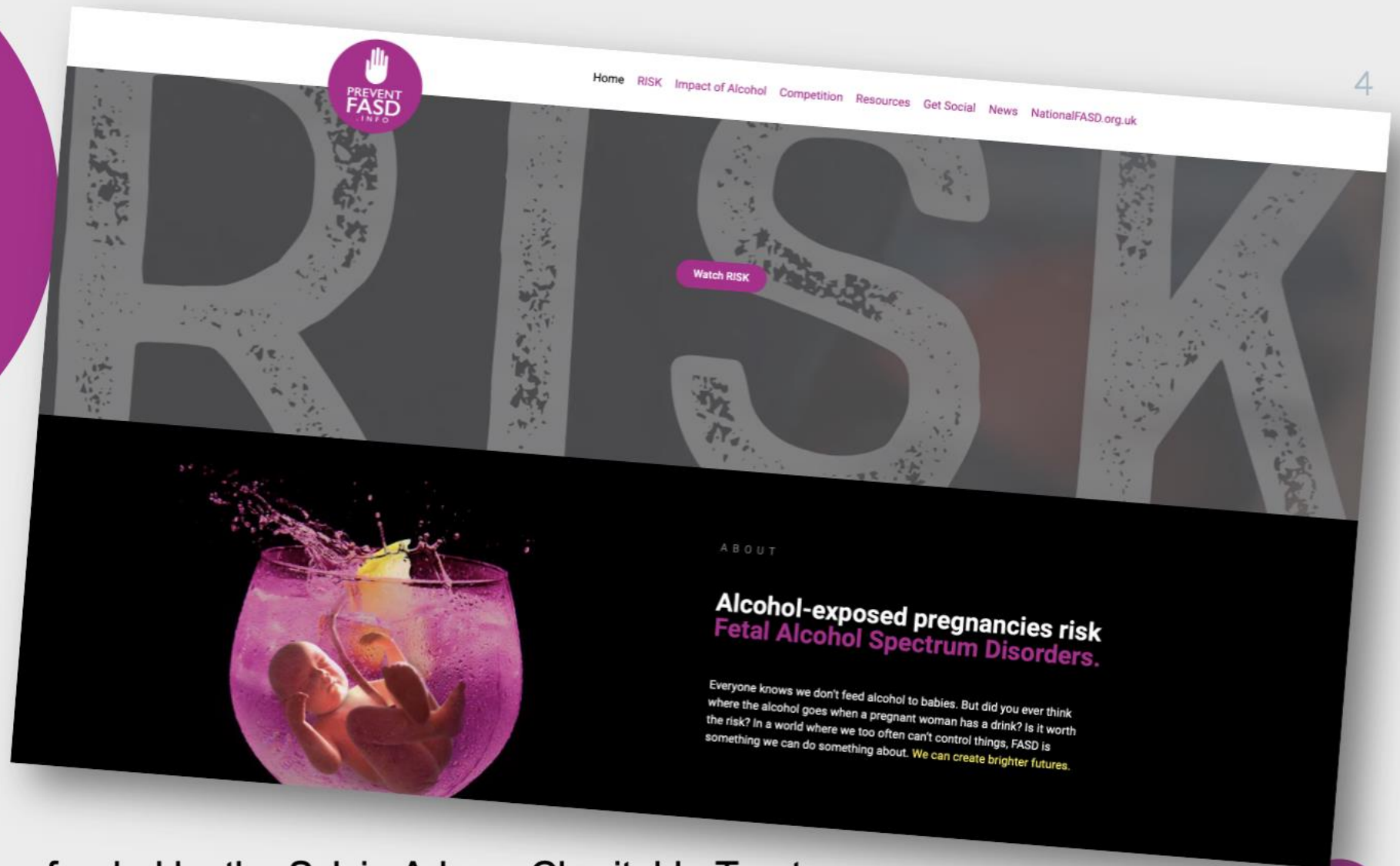
<https://nationalfasd.org.uk/learn-more/training/e-learning/>

# Prevention website & project about risk for 15-25 year olds



3-year campaign funded by the Sylvia Adams Charitable Trust

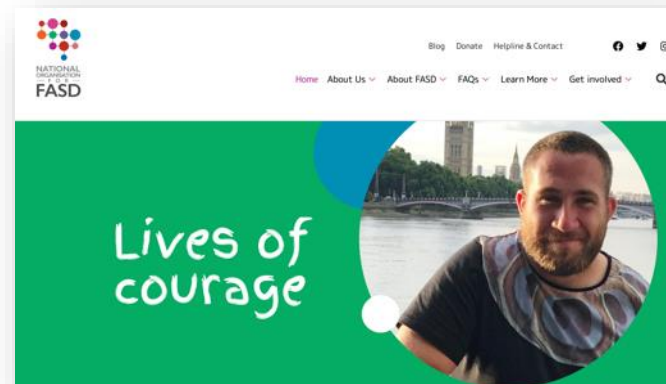
[www.PreventFASD.info](http://www.PreventFASD.info)



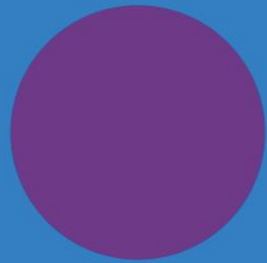
## Support is available

You are not alone

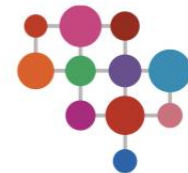
- FASD UK Alliance support groups - [www.FASD-UK.net](http://www.FASD-UK.net)
- FASD UK Facebook group
- [www.NationalFASD.org.uk](http://www.NationalFASD.org.uk)
- [www.PreventFASD.info](http://www.PreventFASD.info)
- [www.FASD.me](http://www.FASD.me)



# Seashell



Extra slides in case we  
can't do the live tour of  
FASD.me



NATIONAL  
ORGANISATION  
— F O R —  
**FASD**



# Easy to navigate

# Seashell



**ME & MY  
FASD**



Music



Games and  
Activities



NATIONAL  
ORGANISATION  
FOR  
**FASD**

# Fun and informative

## Seashell

### What does FASD mean to you?

Fetal Alcohol Spectrum Disorder (FASD) is lifelong. It happens when people were affected by alcohol in pregnancy before they were born. Learning about FASD and strategies can help make things easier.

It can even be fun!

Me & My FASD

**ME & MY  
FASD**



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**FASD**

# Hear their voices

# Seashell



Source: [www.FASD.me](http://www.FASD.me)





# Seashell

## See it from their perspective



<https://fasd.me/me-and-my-fasd/interactive-comic/>



## Flip the narrative

Positive self-image is critical and depends on people with FASD understanding their condition

**Playing up** I'm overwhelmed.

**Don't care** I don't understand.

**Impulsive** I act without thinking.

**Fussy** I have sensory needs.

**Rude** I don't understand emotions.  
I say the first thing I think of.

**Lying** I confabulate, which means my brain fills in gaps in my memory.

**Lazy** I get tired or can't remember what to do.

When people don't understand FASD they might say things about you that aren't true.

**Wow!**



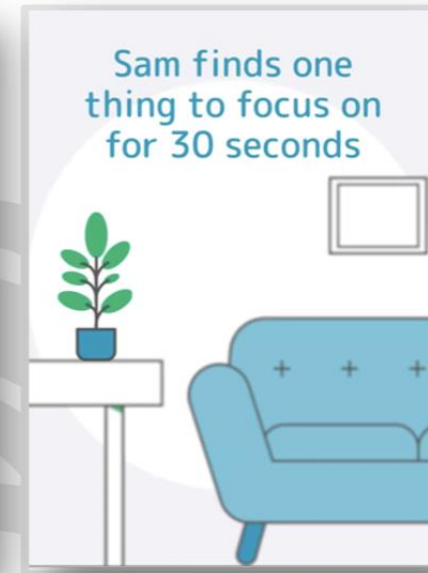
<https://fasd.me/me-and-my-fasd/interactive-comic/>



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— FOR —  
**FASD**

# Seashell

## ME & MY FASD

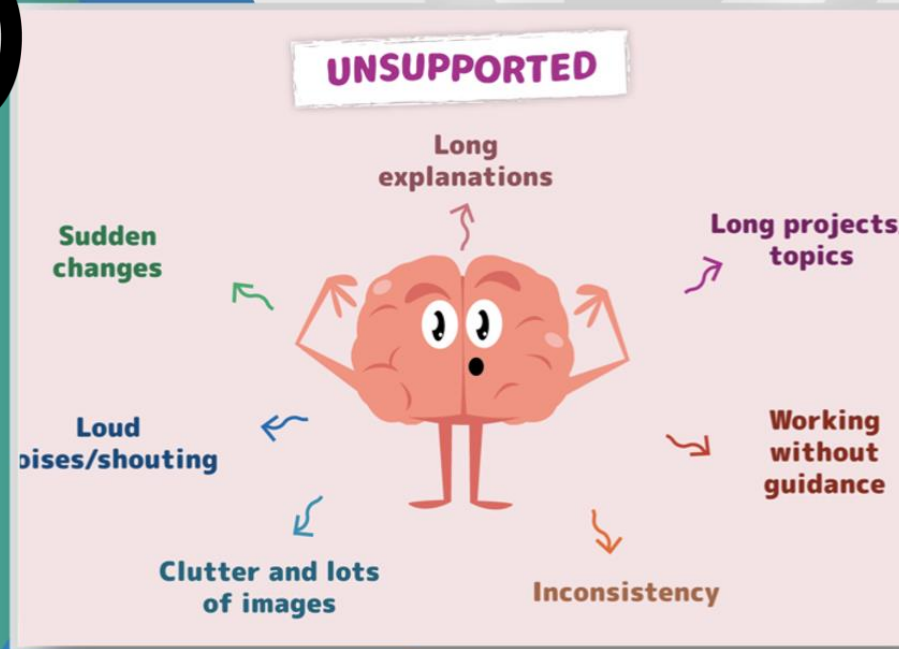
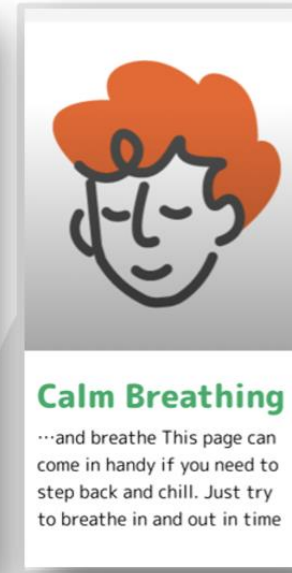
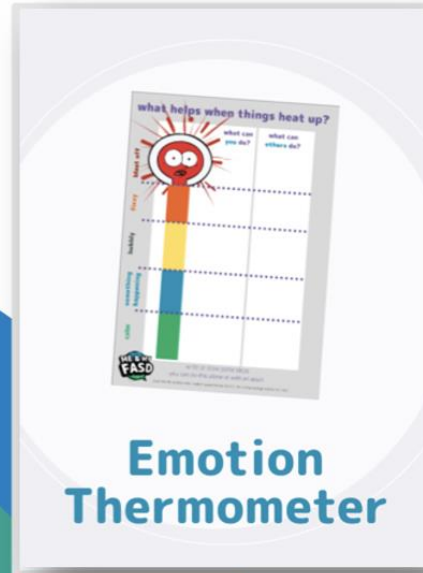


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FOR  
**FASD**



# Seashell

## ME & MY FASD



# Seashell

## Thank you!

Together we can create brighter futures.

**ME & MY  
FASD**



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ORGANISATION  
FOR  
**FASD**

# Q&A

- If you want to ask questions then please do so via the Q&A option.
- Alternatively you can **email questions** to [innovationfund@phe.gov.uk](mailto:innovationfund@phe.gov.uk). PHE colleagues will read them out on your behalf.