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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The National Organisation for FASD is dedicated to supporting people with 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.

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The Time is Now: The national perspective on ramping up FASD prevention, diagnosis and support services

Key themes

This report, “The Time is Now,” builds on an unprecedented alignment of UK public health bodies focused on the serious risks of alcohol consumption during pregnancy and the need for recognition, diagnosis and support for those with Fetal Alcohol Spectrum Disorder (FASD). Ten key themes emerged from a series of expert roundtables focused on the national perspective on ramping up FASD services.

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 from the Department of Health and Social Care (DHSC), Scottish Intercollegiate Guidelines Network (SIGN), Public Health England (PHE) (now Office for Health Improvement and Disparities - OHID), the Chief Medical Officers (CMOs), the Local Government Ombudsman and the National Institute for Health and Care Excellence (NICE).

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.** There is a need for both universal and targeted campaigns, as well as education in schools. The rates of unplanned pregnancies are high and good contraceptive advice is needed with women of childbearing age, alongside identification and brief advice around alcohol. Clear national communication about FASD has been lacking. The Drymester campaign and work in Greater Manchester is an example of how this can be done effectively. All midwives and all health professionals engaging with women of childbearing age must be trained on how to have these conversations without stigma. All areas should implement the NICE Quality Standard recommendations about discussing alcohol use in pregnancy and recording that information.

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.** Roughly 3% of the population has FASD and in every school in every year group there may be 1-2 who have undiagnosed FASD. There is a need to build on this initial small study and confirm the findings in a national active-case ascertainment prevalence study. Particular attention should be given to at-risk groups where prevalence is likely to be higher (for example looked after, care experienced and adopted children, those known to mental health services and those involved in the criminal justice system).

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.** The guidance is now the diagnostic guideline across Scotland, England and Wales (leaders in Northern Ireland need to clarify if this is also the case there.) Many, if not most, practitioners, commissioners and other policymakers are unfamiliar with SIGN 156 and the recommendations within. The Royal Colleges have a role to play. The Royal College of Paediatrics and Child Health (RCPCH) is taking a lead and can serve as an example for other Colleges. Other health professional bodies and training organisations also have key responsibilities for training. To enable a workforce with FASD understanding and awareness, it also must be incorporated into medical school undergraduate curriculum and all health and social care undergraduate courses.

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.** In Scotland, Health Boards also have national guidelines for the neurodevelopmental pathway including FASD that need to be implemented. The time is now, and policy makers across the UK need to act. In England the new ICSs (which bridge health and social care) can start afresh to explore creative ways to meet this underserved population.

6. **People with lived experience need to be at the core of planning and those with FASD expertise should be engaged at all levels.** The new organisations and entities that receive commissioning to enter this field must use best practice and ensure they are guided by existing FASD experts by experience.

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.** Special attention should be given to the training and availability of, as a minimum, clinical psychologists and, where possible, a speech and language therapist and occupational therapist alongside an FASD trained specialist. Creative thinking is needed for how services can be shared across geographies.

8. **Care management plans are included in the NICE Quality Standard - these require special attention by policymakers.** Cross-sectoral thinking and planning is needed. Transitioning to adulthood is a key point as is ensuring that education, social services, housing, criminal justice and all sectors understand that an FASD diagnosis is lifelong and that quality of life depends on the timely provision of the support that people with FASD deserve. Repeat assessments and a mental capacity assessment, where needed, will help to ensure the vital types of support that people with FASD are entitled to is available. A special focus is needed to help individuals with FASD understand their diagnosis in ways they can access.

9. **Policy progress is extremely welcome, but action is also needed for those areas not covered.** The very young who were identified at birth as at risk of FASD need special follow up. There also needs to be guidance for adult diagnosis and support. All public health bodies have recognised FASD as lifelong and FASD does not go away when the person turns 18. Adult needs also need to be supported. Society needs to step up across sectors with support from preconception through the entire life cycle.

10. **Public policymakers must use joined up thinking to meet the identified needs of this vulnerable population and give this issue profile.** Parliament should take the lead on a Green Paper on FASD to explore how Government can maximise the impact of the recent recommendations. FASD-specific funding needs to be made available for research, training, diagnosis and support. Other countries have national funding in the tens of millions because they recognise this is an invest-to-save model. Funding needs to be available at national, regional and local levels. Private charitable foundations and trusts also will need to engage.

About the roundtable series and this report

Nine remote meetings convened by the National FASD Experts Committee took place between December 2021 and March 2022. The 61 participants included paediatricians, psychiatrists, GPs, commissioners, public health experts, researchers and leaders from the Third Sector. Overall, 21 percent of the participants have lived experience with FASD as birth parents, adoptive parents and/ or as foster carers in addition to their relevant substantive and professional experience. (In individual meetings, typically 25% of attendees had lived experience.)

Participants took part in their individual capacities not as representatives of organisations or official bodies. They shared their insights and views on a range of topics that are key to joined-up thinking from a national perspective about how to ramp up FASD prevention, diagnosis and support services. There was no attempt to achieve consensus. Participants were present in their personal capacities, and the meetings were held according to a non-attribution basis (Chatham House rules).

Topics covered

- Why it’s time to think about ramping up FASD services
- Who to involve in the planning and how to get started
- What about the business case/ financing?
- Understanding elements of the diagnostic process
- Possible pathways
- Prevention
- Care management plans pre- and post-18
- How to train up locally and nationally

This report summarises those meetings. It is based on chairs’ summaries that were prepared and circulated with participants after each meeting. We have included extensive quotes and paraphrasing purposefully, to convey the range of opinions and perspectives that were shared. This report is designed to raise questions, not to provide answers. Further urgent work is needed.

**As this report went to press NICE released the new Quality Standard on FASD.
A special appendix at the end of this report explains the main elements of the NICE Quality Standard and highlights where in this report relevant information can be found for each statement in the Quality Standard.**

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Selected acronyms

ADHD	Attention Deficit Hyperactivity Disorder
AEP	Alcohol-Exposed Pregnancy
ASD	Autism Spectrum Disorder
ASF	Adoption Support Fund
BMA	British Medical Association
CAMHS	Child and Adolescent Mental Health Service(s)
CCG	Clinical Commissioning Group
CDC	Child Development Centre
CJS	Criminal Justice System
CMOs	Chief Medical Officers
CNS	Central Nervous System
DHSC	Department of Health and Social Care
FAAST	Fetal Alcohol Advisory Support & Training Service (Scotland)
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
ICP	Integrated Care Partnership
ICS	Integrated Care Systems
LA	Local Authority
LARC	Long Active Reversible Contraceptives
LD	Learning Disability
MDA	Multidisciplinary Assessment
MDT	Multidisciplinary Team
ND	Neurodevelopmental
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OHID	Office for Health Improvement and Disparities
OT	Occupational Therapy
PHE	Public Health England
QS	Quality Standard (NICE)
RCGP	Royal College of General Practitioners
RCPCH	The Royal College of Paediatrics and Child Health
RCPsych	The Royal College of Psychiatrists
SALT	Speech and Language Therapy
SENCO	Special Educational Needs Coordinator
SEND	Special Educational Needs and Disabilities
SIGN	Scottish Intercollegiate Guidelines Network

Introduction from the co-chairs

Little did I dream when we sat in Raja's office at the National FASD clinic some 8 years ago and heard that our beautiful, loving son has lifelong brain damage and that there was 'no post-diagnostic protocol' in the UK for how to support him that we'd be here, on the verge of a whole new landscape for those people with FASD, their families and those at risk of alcohol-exposed pregnancies.

At the time I was just an overwhelmed mum who had been struggling since we adopted our son at 16 months to figure out how to best help him. The FASD diagnosis was the missing link for us. Understanding that his brain was processing things differently led us to understand the need to change the environment around him and empowered us to learn how to help him better understand his own needs. Now, through my work with National FASD, I am in touch with people all across the UK who have had this same journey. What a welcome moment it is to finally have all the major public health bodies onside, recognising the risks of alcohol in pregnancy, emphasising the need for recognition, diagnosis and lifelong support for those with FASD. This report, based on input from some 60 leading professionals, clinicians, policy makers, researchers and people with lived experience who generously shared their time, insights and expertise over a series of nine roundtable meetings, shows that the time is now for action. These official documents matter greatly, but what happens next will show just what sort of society we live in. Will decision makers step up and make the needed changes? This report is packed full of ideas to help policy makers ramp up FASD services. We all stand ready to assist.

Sandra Lorna Butcher

Sandra Butcher
CHIEF EXECUTIVE
National Organisation for FASD

Twenty years can be a long time, yet it can also feel like the blink of an eye. Twenty years is the length of time that FASD has been a central part of my professional life. In that time there have been many changes in the UK's understanding and engagement with FASD, but for the most part, there has been very little to drive this change through. This now seems to be changing.

More recently there has been a ground swell of interest that simply did not exist before. Instead, for those of us in the field, whether that is professionals or Third Sector, having to fight to open doors and raise interest seems to be changing. People in wider fields have been seeking input on this important and unrecognised area, wanting to independently see change happen. This report, brings together the ideas and the information from people linked to FASD. It is a real resource for the next stage of supporting change. Taken alongside the NICE Quality Standard, we hope it will act to support people developing their own ideas and implementing change. Twenty years is a blink of an eye in some ways, but I hope that it does not take so long going forward to make the real difference that people with FASD deserve.

Prof Raja Mukherjee
CONSULTANT PSYCHIATRIST
FASD National Specialist Clinic

INTRODUCTION: How this report came about

From December 2021 – March 2022, the National FASD Experts Committee convened a series of roundtable discussions on "The National Perspective on Ramping up FASD Prevention, Diagnosis and Support Services."

These meetings occurred at a time when involvement of a wider range of policy makers, commissioners, interdisciplinary practitioners, researchers and those with lived experience could have great impact on the lives of many of society's most vulnerable – people with Fetal Alcohol Spectrum Disorder. FASD is the leading neurodevelopmental condition. Too often FASD is undiagnosed or misdiagnosed, with tragic and avoidable outcomes.

This is an important and timely opportunity to engage on these issues.

Finally, after many years of calls for policy engagement public health agencies are aligning on the seriousness of this issue, with recent steps by DHSC, the former PHE, SIGN, and the NICE Quality Standard on FASD. Specifically, when DHSC asked NICE to undertake the Quality Standard, improving commissioning and diagnostics for FASD was high on the list of expected outcomes, to help drive improvements and help the health and care system improve prevention, diagnosis and care for those affected.

This year, the UK's first gold standard prevalence study from the University of Salford showed 1.8-3.6% of young people have FASD (a rate higher than autism).

The recent (September 2021) Department of Health and Social Care FASD Health Needs Assessment for England identified needs for this population group, focusing on:

- A lack of robust prevalence estimates in England
- The importance of multi-sector working to support individuals through the life course
- Better training and awareness for health professionals
- Better organisation of services to improve accessibility
- A need to develop innovative approaches to support those living with the condition

This series of roundtables sought to help move forward these points, especially points 2-4.

> **Receiving an early diagnosis can reduce the chances of adverse life outcomes."**
>
> --DHSC FASD Health Needs Assessment

Who participated?

The roundtables brought together a range of policy makers, researchers, practitioners and people with lived experience for these sessions, which were held according to Chatham House Rules. Each participant was there in their individual capacity and not as a representative of any organisation or agency. The substance of the discussions could reported out but without attribution to any individual. Chairs' summaries of individual meetings were shared for comment and formed the basis of this final report.

Participants included 61 paediatricians, psychiatrists, GPs, commissioners, public health experts, researchers and leaders from the Third Sector. Overall, 21 percent of the participants have lived experience with FASD as birth parents, adoptive parents and/ or as foster carers in addition to their relevant substantive and professional experience. (In individual meetings, typically 25% of attendees had lived experience.) Participants took part in their individual capacities.

The roundtable meetings were one hour long, with brief introductory comments from senior practitioners experienced in FASD, along with someone with lived experience. Time was provided for questions. Participants gave feedback in the chat, via online polls and importantly via pre- and post-meeting questionnaires.

These roundtables were based on the stigma-free and blame-free language outlined in the FASD: Preferred UK Language Guide.

A high priority was placed on engaging people with lived experience, in this case parents, carers, and guardians with relevant professional experience, who comprised at least 25% of the participants in each meeting. In addition, the conversations reflected feedback National FASD has received from people with FASD through the Me and My FASD project, developed in partnership with Seashell and funded by a DHSC grant in 2020-21.

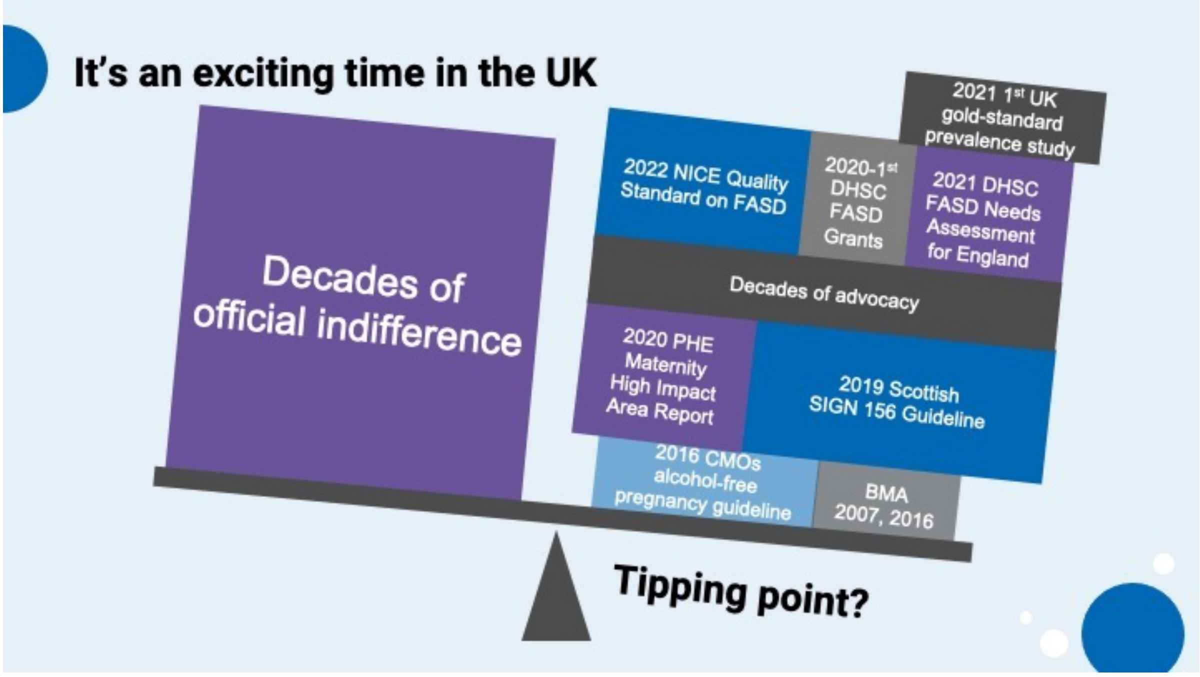
Those involved in this roundtable series believed this was an urgent undertaking.

While waiting for the NICE Quality Standard, there have been pockets of activity happening across the country as some CCGs and others have begun to prepare for its publication. There is little cross-seeding from these efforts and all believed it will be helpful to have a national dialogue so that best practices from other areas can help inform steps forward.

There was no attempt to achieve consensus.
The goal was to outline the key points for consideration.

The following meetings took place between December 2021 – March 2022:

- 15 December • Why it's time to think about local FASD services
- 5 January • Who to involve in the planning and how to get started
- 19 January • What about the business case/ financing?
- 2 February • Understanding elements of the diagnostic process
- 16 February • Possible pathways - options & possible unintended consequences
- 23 February • Prevention
- 2 March • Care management plans - pre- and post-18
- 9 March • How to train up locally and nationally
- 16 March • The NICE Quality Standard on FASD



It’s an exciting time in the UK

Decades of official indifference

2022 NICE Quality Standard on FASD

2020-1st DHSC FASD Grants

2021 1st UK gold-standard prevalence study

2021 DHSC FASD Needs Assessment for England

Decades of advocacy

2020 PHE Maternity High Impact Area Report

2019 Scottish SIGN 156 Guideline

2016 CMOs alcohol-free pregnancy guideline

BMA 2007, 2016

Tipping point?

Figure: It’s an exciting time in the UK: tipping point?

SECTION ONE: Why it’s time to think about ramping up local FASD services

1. The first roundtable featured presentations about the current policy changes in the UK. For the first time all major public health bodies are lined up about the importance of FASD. This roundtable explored some of the key areas of concern and highlighted some areas of best practice from across the country.

Overview of recent policy changes from SIGN, NICE, DHSC, PHE

2. Participants recognised the unique opportunity provided by recent policy changes, now that all the main public health bodies are on record as recognising FASD and identifying areas for action. They further identified the need for better national sharing of information and joined-up thinking to ensure that the process of ramping up FASD services goes smoothly. The goal is to be solution driven. As one person said, it's important to "work smart - align services, know what is there already and build on their capabilities."

3. One participant said, "From my experience local areas are not aware of where to start and what they need to do in relation to FASD, so it would be good to learn from those who have done it already and those with lived experience, so we can help local areas to offer the best systems they can and hopefully avoid a postcode lottery of support for those with FASD."

4. Another said they would like an idea of "where my NHS Trust is regarding delivery of services in comparison to the rest of the country and how I can use this to support a business case to make improvements."

5. "The government recognises the importance of FASD" is a core point of the new DHSC FASD Health Needs Assessment for England (2021). It recognises that the "Effects of pre-natal alcohol are known to have lifelong consequences," and acknowledges the importance of "an individualised approach." It reinforces that "The voices of people with lived experience are important."

6. The DHSC Needs Assessment identifies the following priorities:

    a. A lack of robust prevalence estimates in England

    b. The importance of multi-sector working to support individuals through the life course

    c. Better training and awareness for health professionals

    d. Better organisation of services to improve accessibility

    e. A need to develop innovative approaches to support those living with the condition

7. In addition, a NICE Quality Standard on FASD has been released. This is based on Scottish SIGN 156 (2019) which set guidelines for diagnosing and managing care for children and young people exposed prenatally to alcohol. NICE has accepted SIGN 156 so this is now also the guideline for England and Wales. (The status in Northern Ireland and Scotland needs clarification.) The NICE Quality Standard covers:

    a. Advice to pregnant women

    b. Discussing alcohol use throughout the pregnancy & recording

    c. Referral for assessment

    d. Neurodevelopmental assessment

    e. Care management plan

8. SIGN states: "Prenatal alcohol exposure should be actively considered as a possible underlying cause for neurodevelopmental delay, or an unexplained departure from a typical developmental profile." SIGN 156 changes the diagnostic terms to "FASD with sentinel facial features" or "FASD without sentinel facial features." Both diagnoses require evidence of severe impairment in three or more of the identified neurodevelopmental areas of assessment, meaning there is no "mild FASD". While it focuses on children and young people, it states, "The diagnostic/descriptive criteria for FASD are the same for adults as for younger individuals."

9. The PHE Maternity High Impact document (2020) states: "Drinking any alcohol can cause difficulties in pregnancy and can result in Foetal Alcohol Spectrum Disorder (FASD), causing lifelong disabilities for children. There is no safe time or safe amount of alcohol to drink during pregnancy." It states, "Reducing the incidences of harms caused by alcohol before, during and after pregnancy

is a public health priority." The CMOs alcohol in pregnancy guidelines (2016) said the "safest approach is to avoid alcohol if you are pregnant or could become pregnant."

10. The first UK active-case ascertainment prevalence study by the University of Salford was released in 2021, showing a conservative rate of 1.8 – 3.6%.

DHSC FASD Health Needs Assessment for England (2021)

List of priorities to improve healthcare

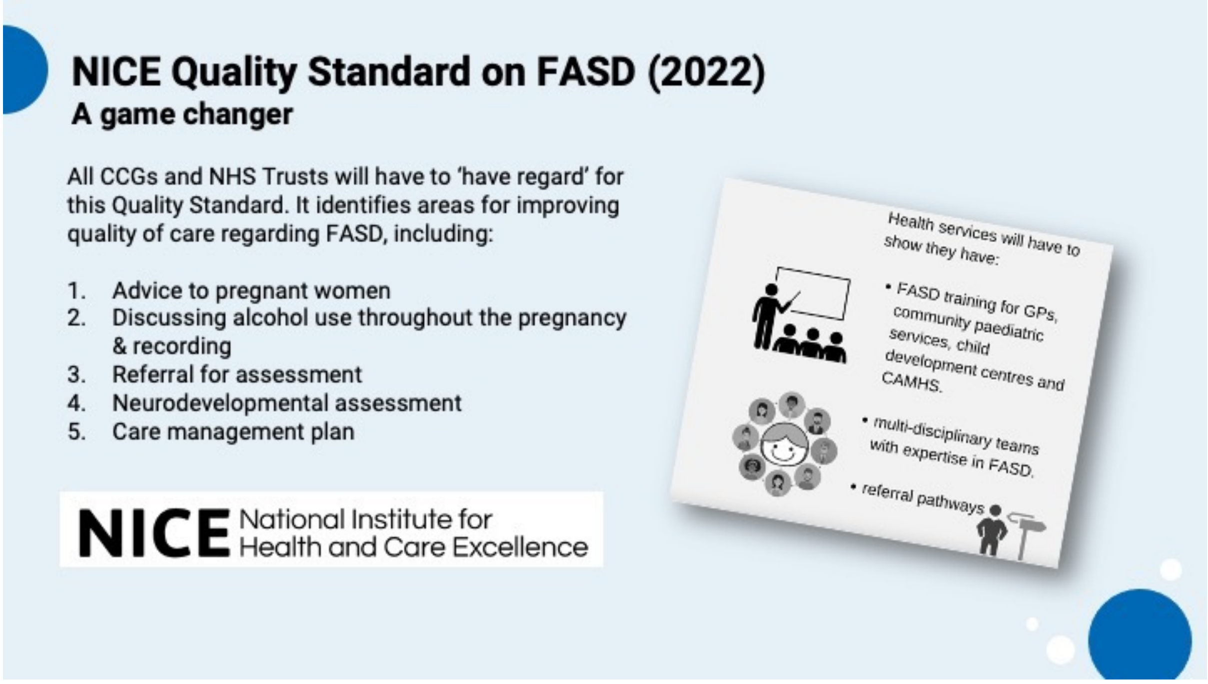
1. A lack of robust prevalence estimates in England
2. The importance of multi-sector working to support individuals through the life course
3. Better training and awareness for health professionals
4. Better organisation of services to improve accessibility
5. A need to develop innovative approaches to support those living with the condition

"The government recognises the importance of FASD"

"There is a need to develop services that support diagnosis and management. These can utilise existing resources, to make them more accessible to those in need. A strong economic case can be made to illustrate how cost-effective future investment could be."

Department of Health & Social Care

Figure: DHSC FASD Health Needs Assessment



NICE Quality Standard on FASD (2022)

A game changer

All CCGs and NHS Trusts will have to 'have regard' for this Quality Standard. It identifies areas for improving quality of care regarding FASD, including:

1. Advice to pregnant women
2. Discussing alcohol use throughout the pregnancy & recording
3. Referral for assessment
4. Neurodevelopmental assessment
5. Care management plan

Health services will have to show they have:

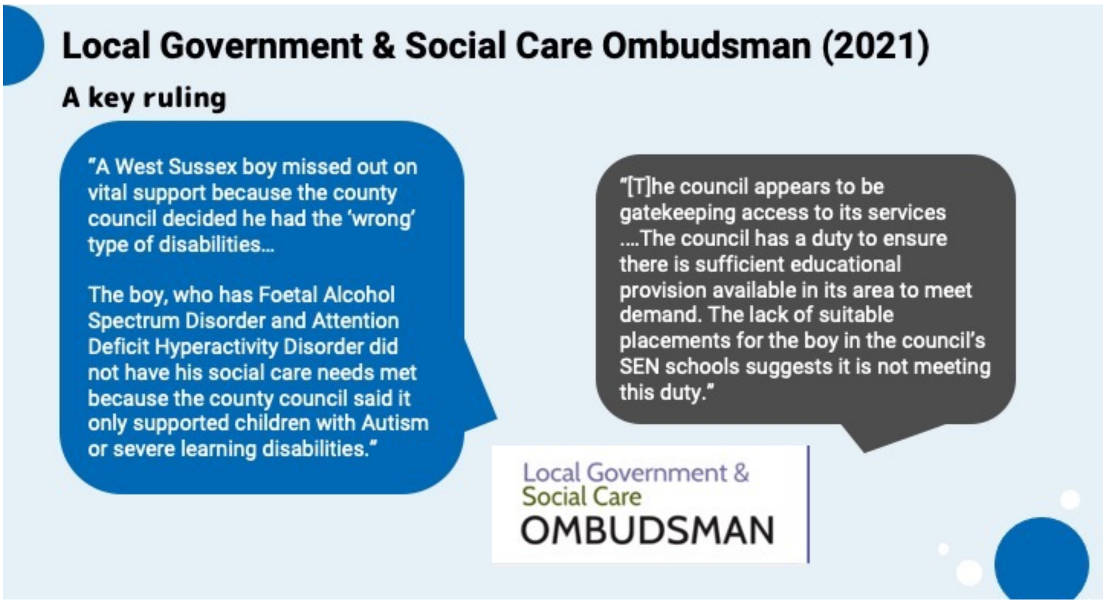
- FASD training for GPs, community paediatric services, child development centres and CAMHS.
- multi-disciplinary teams with expertise in FASD.
- referral pathways

NICE National Institute for Health and Care Excellence

Figure: NICE Quality Standard on FASD

What challenges are people facing in ramping up FASD services?

11. Participants identified areas that need particular attention:
    a. Training emerged as a key concern. One participant raised the need for “groundwork to raise professionals’ awareness, develop training, etc.” Workforce training must be addressed at scale.
    b. The need to think broadly about how to engage multiple services from the start of any effort to ramp up FASD services and especially to consider how to ensure adult services are engaged in the process.
    c. The transition to ICS (Integrated Care Systems) could be a challenge but could also be an opportunity to have FASD pathways embedded within new work streams.
    d. Recent experiences have raised some concerns about what happens when adding FASD into already overburdened neurodevelopmental pathways. One practitioner noted a key challenge is when a neurodevelopmental pathway is first set up for Autism and ADHD, trying to add FASD afterwards doesn’t work or faces special challenges. Though another noted many of these children are already in the system, but poorly or wrongly diagnosed.
    e. Overcoming the stigma that pervades discussion of FASD and stands in the way of important clinical discussions about the risks of alcohol in pregnancy.
    f. Overcoming inertia: “More often than not NICE guidelines are seen as a nice to have but the excuse is always capacity or lack of funding,” said one participant. Participants acknowledged that this must be avoided with FASD.
    g. Existing contractors for similar services lack FASD expertise. As one parent with lived experience said, “I fear that there will be organisations that will seek to become involved in FASD without the knowledge required.”
    h. The importance of including FASD in commissioning decisions. There must be opportunities for codesign and to ensure those with lived experience are invited in a meaningful way to contribute to service redesign and delivery.
    i. How to gather and note prenatal alcohol exposure evidence is a key point needing further attention.
    j. High risk populations need a special focus, including adopted children, looked after and previously look after children, those involved in the Criminal Justice System.
    k. The first 1000 days of life could be a special focus as well.



Local Government & Social Care Ombudsman (2021)

A key ruling

“A West Sussex boy missed out on vital support because the county council decided he had the ‘wrong’ type of disabilities...

The boy, who has Foetal Alcohol Spectrum Disorder and Attention Deficit Hyperactivity Disorder did not have his social care needs met because the county council said it only supported children with Autism or severe learning disabilities.”

“[T]he council appears to be gatekeeping access to its services ....The council has a duty to ensure there is sufficient educational provision available in its area to meet demand. The lack of suitable placements for the boy in the council’s SEN schools suggests it is not meeting this duty.”

Local Government & Social Care OMBUDSMAN

Figure: Local Government and Social Care Ombudsman ruling

Some examples of areas currently working on ramping up FASD services

12. Tees, Esk and Wear Valley Mental Health Trust has funded a short exploratory project to include FASD in neurodevelopmental pathways and garner parent and carer feedback. Earlier Middlesborough conducted an investigation in 2016:

    a. To examine current service provision for children with FASD / probable FASD to assist in identifying and planning for future service demand.

    b. To ensure any child with FASD / probable FASD receives the right support at the right time and can access that support in Middlesbrough.

    c. It concluded that "It is clear however from the evidence gathered that insufficient data is currently available on the follow up process for children potentially at risk of FASD following birth. There is also a need for a shift forward in service provision."

    d. The Health Scrutiny Panel put forward a series of recommendations.

13. Sheffield is including FASD in the neurodevelopmental pathway discussions with the aim of including FASD in the "single front door" alongside Autism and ADHD. The neurodevelopmental pathway task and finish group has been running for over a year and their expertise and understanding will be utilised when including FASD in the discussions.

14. Scotland provides good examples of service delivery for support services through FASD Hub Scotland and neurodevelopmental pathways in specific areas.

    a. In Scotland, FASD has been included in the national neurodevelopmental assessment pathway as part of the review of CAMHS services. This guidance recommends the importance of multi/ cross disciplinary working and is resulting in the development of pathways of assessment in each health board area. Some limited funding has been promised

    b. In addition, the FAAST web resource (Fetal Alcohol Advisory Support & Training Service) is hosted by Edinburgh University and Scottish Government

    c. FASD Hub Scotland is hosted by Adoption UK and funded by the Scottish Government

15. Derbyshire have committed to include FASD in their redesigned neurodevelopmental pathway for children. They have submitted proposals to the Integrated Care System

16. There is also work across the Midlands in the Health and Justice (Prisons) sector.

17. In Kent the National FASD Clinic (Surrey) is in the process of extending training and consultation to Kent following Hub and Spoke model.

18. Following on from its ground-breaking Alcohol-Exposed Pregnancies Programme, Greater Manchester also have identified an unmet need and are currently working with system leaders to look at how to establish pathways. Challenges include lack of identified funding, lack of understanding of the issue across the system, concern by paediatricians and other HCP that they don't have the capacity to meet demand.

    a. Greater Manchester have had a SEND Board meeting where a Greater Manchester approach was mentioned.

    b. In Stockport, the planned first meeting with the local Authority was cancelled. Getting the right people in the room has been difficult, starting a neurodevelopmental pathway and they are focusing on Autism.

    c. In Greater Manchester various areas are considering setting up new pathways for diagnosis. One participant noted, "The challenge is getting a coordinated approach over a bigger area otherwise there will be a postcode lottery. Prevention-wise in GM, work has been done over a bigger footprint, but still needs much more investment."

d. Greater Manchester have just released an evaluation of their Alcohol-Exposed Pregnancies programme. “In 2018, the Greater Manchester Health and Social Care Partnership (GMHSCP) committed £1.6m in non-recurrent transformation funding towards an initial ‘proof of concept’ programme to reduce Alcohol Exposed Pregnancies (AEP) and progress towards an ambition of ending new cases of Fetal Alcohol Spectrum Disorder (FASD).” The Drymester campaign is one of the key outcomes.

19. In Sheffield, The National Dialogue on International FASD Awareness Day: FASD Conference in September 2021, hosted by Sheffield Children’s Safeguarding Partnership, was a major step in moving the FASD agenda forward in Sheffield. The conference kick started the awareness raising with front line staff, managers and chief executives making it easier to progress. The conference has been followed by a Drymester Campaign (modelled on Greater Manchester’s flagship effort) starting before Christmas and running through till September 2022. FASD training being delivered by Red Balloon Training to 120 frontline workers and managers every month and an All Age FASD Steering Group being established - this group includes all the major partners and Third Sector services in Sheffield. Sheffield is also looking at pathways for children and adults.

20. Hertfordshire have begun the process with the new ICS to develop an appropriate action plan to ensure it has the required services for children with FASD, along with clear prevention messages and awareness raising where necessary.

21. The National FASD Clinic in Surrey continues to support and advice. Please see the box for further information.

22. The Centre for FASD in Suffolk is an example of expert local provision. However the Centre is slated for closure in April 2022 due to unforeseen changes to the way services for adopted children are to be commissioned moving forward.

Case study: the FASD National Specialist Clinic

The FASD National Specialist Clinic was established on the NHS by Professor Raja Mukherjee in 2009 (then Dr). It developed out of a research clinic being run by him to collect data for his PhD. Based on a combination of principles, it took FASD specialist practice learnt from international world experts such as Prof Ed Riley and combined the ideas with UK established multidisciplinary neurodevelopmental services, some of which he had been a part of during his training. The clinic began in 2005 with just Dr Mukherjee collating and scoring as many of the measures possible or allowed as a psychiatrist, showing that using an essentially medical model approach of bringing together information, a single practitioner was able to identify much of the information needed, collating a multidisciplinary assessment, to reach both a diagnostic conclusion but also develop a care plan that was supportive of the individual. Whilst there were other UK specialist interest clinics of this kind run by individuals locally to their own area at the time, none had offered a full national service to offer expertise wider afield, or published findings in international literature helping move the field forward .

Through changes to the structure of the clinic it became fully established as an NHS referral centre in 2009 as a Multi Disciplinary Team offering a complex neurodevelopmental assessment. This looked not only at FASD, the underlying brain, language and psychological trauma issues, but also the wider neurodevelopmental cooccurring outcomes commonly seen. Being a full MDT, it was designed to see the more complex end of the cases that would present. It has always remained small with the aim of supporting the development of other areas, offering input support and expert advice, whilst still seeing a small number (maximum 40 cases per year) of the most complex cases. Since it has started several hundred individuals from all four nations of the UK have passed through its doors. It has firmly become a centre of excellence with an international reputation and also has been able to support the development of specialist knowledge of clinical pathways in the UK.

Despite its reputation as a centre of excellence and developing processes that are fairly novel in the world to support the clinical pathways for FASD, for example it was the first clinic in the world to embed 3D facial scanning as part of the clinical pathway, its future has always been precarious year on year due to the lack of coordinated funding. As highlighted in the recent (2021) DHSC FASD Health Needs Assessment, the lack of knowledge of FASD in other areas has meant less than a quarter of enquiries to the clinic are ever funded to be seen and despite there being no local provision. The false impression by some areas that the condition was not possible to diagnose or that there was nothing that could be done left many unsupported and without help. Worse still feedback obtained suggested some areas just did not want to pay an out of area fee yet also refused to provide a local service. By being embedded and supported within a wider Surrey and Borders Partnership NHS trust the clinic has survived these inconsistencies in funding. Other clinics during the time of this clinic's life have come and gone as a result of these inconsistencies, and the lack of similar backup.

Despite this the clinic continues to survive and aims to continue to be a centre of excellence seeing local and regional cases of the greatest complexity whilst supporting local services to grow their own ability to deliver services locally. This implements the Hub and Spoke model of care to ensure expertise is linked to local availability whilst still accessing greater resource as needed.

Two formal contracts with Kent and Surrey are established on the NHS for this and the clinic continues to support development of these approaches wider afield. The long-term aim of the clinic is not to be needed as a national centre, rather to be the regional centre for the SE of England where it is established as per the DHSC FASD health needs assessment.

Figure: Case study - The FASD National Specialist Clinic

SECTION 2: “Who to involve in the planning and how to get started”

23. Roundtable 2 explored initial steps involved with starting to ramp up FASD services in a local area, focused on who to involve and how to begin developing a core group of interested stakeholders locally. It involved presentations from two different areas (Greater Manchester and Sheffield) which have both recently undertaken significant efforts to increase local services, as well as a presentation about considerations on how to build in meaningful co-creation with those with lived experience at the outset.

How to get started? The chicken or egg dilemma – what comes first raising awareness or planning a project?

24. One of the core challenges with ramping up FASD services is that while for the first time ever all the major public health bodies have recently taken or are taking steps to highlight the importance of FASD (e.g. Public Health England, now OHID, has called it a "public health priority") none have launched any sort of related publicity campaign. Most practitioners have had only minimal if any training on FASD and most are not yet familiar with the new SIGN 156 guidelines that provide updated guidance on diagnosing FASD including new diagnostic terms. In fact, the NHS only updated its website to include FASD in early March 2022. FASD still remains in the background, a situation that hopefully will be helped by the publication of the NICE Quality Standard on FASD.

25. As a result, there are areas across the UK trying to increase work on FASD prevention, recognition, diagnosis and support in a situation where most of the key decision-makers are unaware about the condition, its significant prevalence or indeed the tectonic shift in official policy about the condition.

> **We mustn't replicate. We must share from each other and build together…We can all use the experiences of others, including the brilliant work in Scotland"**

26. One participant noted, "Local areas are not aware of where to start and what they need to do in relation to FASD." These roundtables were designed to at least help highlight some options for where to start and to learn from the experiences in other areas.

27. One participant emphasised the need to ensure the individuals around the table all understand FASD. "I've seen too often at national meetings where people are still 'unbelievers' and attending meetings where other colleagues are then having to spend time explaining and convincing them FASD exists before the business at hand can begin. There needs to be an acceptance from all in the room that FASD is a valid and appropriate causational diagnosis for individuals, and that where the individual meets the criteria they should be given this diagnosis without any stigma in the same way as ADHD, ASD etc. Giving any other diagnosis (because it's more comfortable to the professional) is not supporting the individual, misleading and in the long term has the potential to cause more harm."

28. Challenges of ramping up services are further complicated as FASD is a complex condition to address because it involves both a prevention angle as well as a diagnosis/support angle for those affected which leads to further decisions needed as to which part of FASD to focus upon – prevention, recognition/diagnosis/support or whether or not to approach these simultaneously.

29. How a local area answers these questions will determine how they move forward in terms of who to involve and how to get started.

30. The presentations about progress in Greater Manchester and Sheffield highlighted two different approaches to ramping up FASD services:

    a. Building a funded programme first and incorporating awareness-raising into the project

    b. Raising awareness first to create a base of interest and then launching a programme

31. Greater Manchester built an Alcohol-Exposed Pregnancies programme (backed with £1.6 million of non-recurrent transformation funding) as a 'proof of concept' project on reducing Alcohol-Exposed Pregnancies and

working toward ending new cases of FASD. They incorporated into the project training across GM to raise awareness of the risks of alcohol-free pregnancy and FASD in addition to "Drymester," a public awareness raising campaign via social media and in schools.

> **Getting started must involve a consensus about the terms of reference/language to use in professional settings and NOT talking about money but instead 'un-met need'"**

32. Sheffield focused initially on a massive local FASD-awareness campaign that involved what became a national FASD conference that reached 725 registrants - with 270 local stakeholders across services in addition to 290 national participants tuning into the webinar on the day.

33. Further information about the GM and Sheffield examples is provided below.

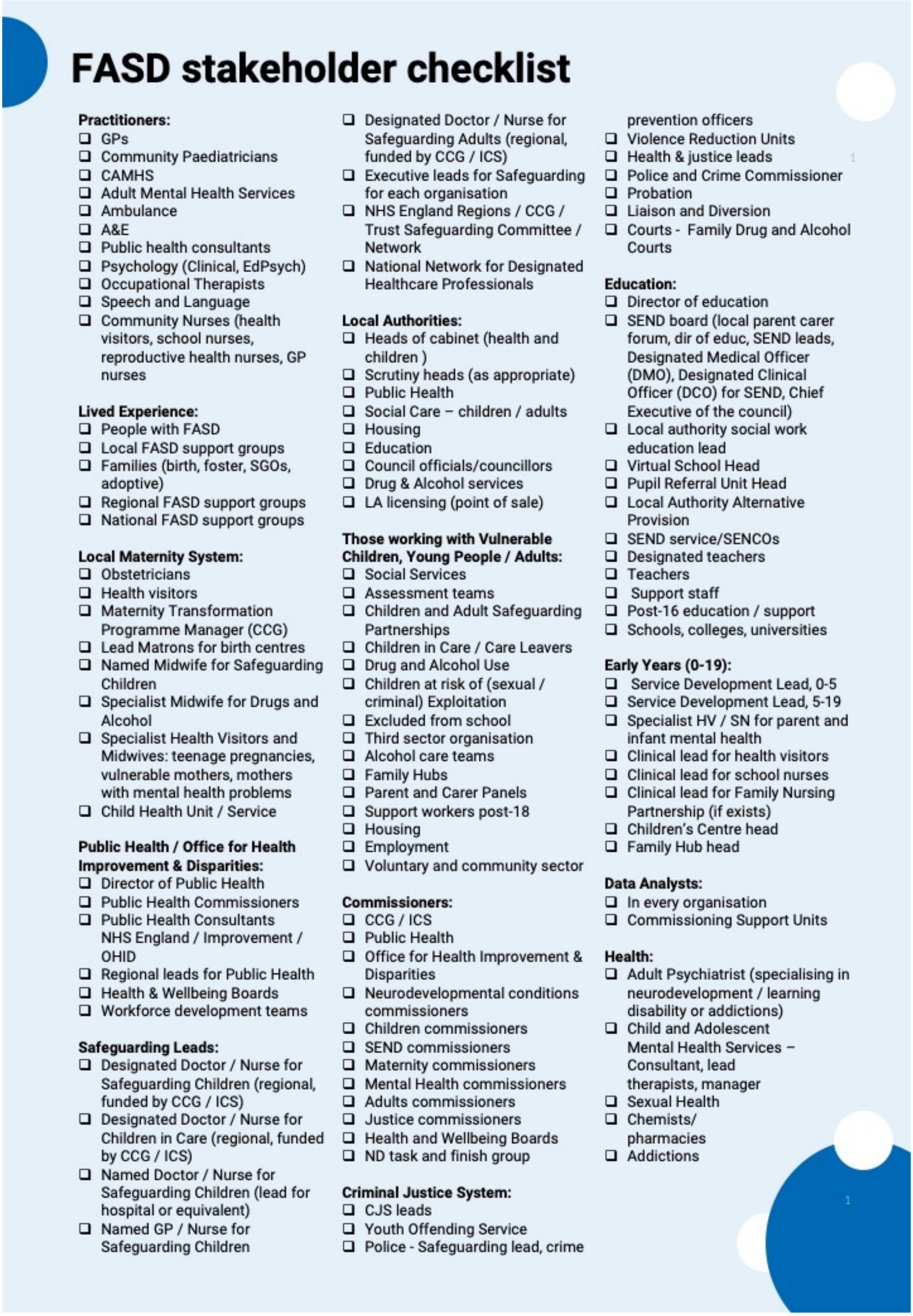
Who to involve? "How do we get the stone rolling?"

34. Launching any project involves considering who will be the key people who can help facilitate attaining that goal. Someone said, "Like much of life, the key can be found in building and sustaining positive, two-way relationships."

35. When asked 'who to involve in ramping up FASD services', participants provided a wide range of suggestions. The following checklist is obviously extensive. We provide this list as a way to help local areas begin to think of the possible wide range of allies to bring into discussions. The more collaborative the work, the stronger the outcome will be. As one participant said, to tackle FASD "NHS and all other partners must work together".

> **Be persistent"**

> **Start small and build!"**



FASD stakeholder checklist

Practitioners:
- ☐ GPs
- ☐ Community Paediatricians
- ☐ CAMHS
- ☐ Adult Mental Health Services
- ☐ Ambulance
- ☐ A&E
- ☐ Public health consultants
- ☐ Psychology (Clinical, EdPsych)
- ☐ Occupational Therapists
- ☐ Speech and Language
- ☐ Community Nurses (health visitors, school nurses, reproductive health nurses, GP nurses

Lived Experience:
- ☐ People with FASD
- ☐ Local FASD support groups
- ☐ Families (birth, foster, SGOs, adoptive)
- ☐ Regional FASD support groups
- ☐ National FASD support groups

Local Maternity System:
- ☐ Obstetricians
- ☐ Health visitors
- ☐ Maternity Transformation Programme Manager (CCG)
- ☐ Lead Matrons for birth centres
- ☐ Named Midwife for Safeguarding Children
- ☐ Specialist Midwife for Drugs and Alcohol
- ☐ Specialist Health Visitors and Midwives: teenage pregnancies, vulnerable mothers, mothers with mental health problems
- ☐ Child Health Unit / Service

Public Health / Office for Health Improvement & Disparities:
- ☐ Director of Public Health
- ☐ Public Health Commissioners
- ☐ Public Health Consultants NHS England / Improvement / OHID
- ☐ Regional leads for Public Health
- ☐ Health & Wellbeing Boards
- ☐ Workforce development teams

Safeguarding Leads:
- ☐ Designated Doctor / Nurse for Safeguarding Children (regional, funded by CCG / ICS)
- ☐ Designated Doctor / Nurse for Children in Care (regional, funded by CCG / ICS)
- ☐ Named Doctor / Nurse for Safeguarding Children (lead for hospital or equivalent)
- ☐ Named GP / Nurse for Safeguarding Children
- ☐ Designated Doctor / Nurse for Safeguarding Adults (regional, funded by CCG / ICS)
- ☐ Executive leads for Safeguarding for each organisation
- ☐ NHS England Regions / CCG / Trust Safeguarding Committee / Network
- ☐ National Network for Designated Healthcare Professionals

Local Authorities:
- ☐ Heads of cabinet (health and children)
- ☐ Scrutiny heads (as appropriate)
- ☐ Public Health
- ☐ Social Care – children / adults
- ☐ Housing
- ☐ Education
- ☐ Council officials/councillors
- ☐ Drug & Alcohol services
- ☐ LA licensing (point of sale)

Those working with Vulnerable Children, Young People / Adults:
- ☐ Social Services
- ☐ Assessment teams
- ☐ Children and Adult Safeguarding Partnerships
- ☐ Children in Care / Care Leavers
- ☐ Drug and Alcohol Use
- ☐ Children at risk of (sexual / criminal) Exploitation
- ☐ Excluded from school
- ☐ Third sector organisation
- ☐ Alcohol care teams
- ☐ Family Hubs
- ☐ Parent and Carer Panels
- ☐ Support workers post-18
- ☐ Housing
- ☐ Employment
- ☐ Voluntary and community sector

Commissioners:
- ☐ CCG / ICS
- ☐ Public Health
- ☐ Office for Health Improvement & Disparities
- ☐ Neurodevelopmental conditions commissioners
- ☐ Children commissioners
- ☐ SEND commissioners
- ☐ Maternity commissioners
- ☐ Mental Health commissioners
- ☐ Adults commissioners
- ☐ Justice commissioners
- ☐ Health and Wellbeing Boards
- ☐ ND task and finish group

Criminal Justice System:
- ☐ CJS leads
- ☐ Youth Offending Service
- ☐ Police - Safeguarding lead, crime prevention officers
- ☐ Violence Reduction Units
- ☐ Health & justice leads
- ☐ Police and Crime Commissioner
- ☐ Probation
- ☐ Liaison and Diversion
- ☐ Courts - Family Drug and Alcohol Courts

Education:
- ☐ Director of education
- ☐ SEND board (local parent carer forum, dir of educ, SEND leads, Designated Medical Officer (DMO), Designated Clinical Officer (DCO) for SEND, Chief Executive of the council)
- ☐ Local authority social work education lead
- ☐ Virtual School Head
- ☐ Pupil Referral Unit Head
- ☐ Local Authority Alternative Provision
- ☐ SEND service/SENCOs
- ☐ Designated teachers
- ☐ Teachers
- ☐ Support staff
- ☐ Post-16 education / support
- ☐ Schools, colleges, universities

Early Years (0-19):
- ☐ Service Development Lead, 0-5
- ☐ Service Development Lead, 5-19
- ☐ Specialist HV / SN for parent and infant mental health
- ☐ Clinical lead for health visitors
- ☐ Clinical lead for school nurses
- ☐ Clinical lead for Family Nursing Partnership (if exists)
- ☐ Children's Centre head
- ☐ Family Hub head

Data Analysts:
- ☐ In every organisation
- ☐ Commissioning Support Units

Health:
- ☐ Adult Psychiatrist (specialising in neurodevelopment / learning disability or addictions)
- ☐ Child and Adolescent Mental Health Services – Consultant, lead therapists, manager
- ☐ Sexual Health
- ☐ Chemists/ pharmacies
- ☐ Addictions

Figure: FASD stakeholder checklist

36. One participant summarised the range of people who will be important to engage: “Basically anybody who interfaces with women of childbearing age and those children and young people who are in higher prevalence groups. Developmentally delayed children, those in groups known to have higher prevalence, e.g. Looked After Children and those in the judicial systems. CAMHS colleagues should be open to the possibility that children they are treating may be in the incorrect diagnostic group, and that prenatal alcohol may not have been appropriately considered. Third Sector colleagues working with vulnerable groups need to be alert to the possibility of FASD.”

37. Someone said, “Those involved in the planning need to be wider and outside the NHS/ Health system. Input from those with lived experience in the specific local area is critical. Expertise from education, social services, criminal justice and housing would really see true differences being made to individuals lives. This would ensure that an FASD diagnosis is really truly more than a ‘label’, but has the ability to support and change the direction of an individual’s life with all areas of that individual and their family being supported.”

38. It was noted that “Few public sector practitioners recognise FASD as an organic brain injury and therefore, a neurological impairment. Few also recognise the implications of FASD presentations with coping skills/ managing anxiety/ impact on the carers. Getting started must involve a consensus about the terms of reference/ language to use in professional settings and NOT talking about money but instead un-met need. We have been engaging with the ICS leads for a year now and they accept FASD as a neurodevelopmental condition.”

39. Not all of these will need to be involved initially, and careful thought should go to developing a core group - perhaps through the use of “champions”. One participant reinforced the importance of bringing key people on board early: “Champions are local and regional leaders and influencers who are respected, trusted and already have at least a basic understanding of FASD prevention, identification and services/ support. They are most important initially - and can then spark and facilitate broad participation by all stakeholders, including diverse professionals, parents/ carers, people with lived experience and key policymakers.”

Find champions

- ☐ Consultant community paediatrician with an interest in neurodevelopment / FASD
- ☐ Consultant paediatrician leading the Child Development Centre
- ☐ Clinical Director of Child Health Unit / Service
- ☐ Lead Matron & operational manager for department
- ☐ Divisional Leads (doctor / nurse / manager) for business cases / new services
- ☐ Lead for Allied Health Therapists
- ☐ Lead for neurodevelopmental pathways (may be ASD / ADHD)
- ☐ Clinical Geneticists (role according to SIGN 156)
- ☐ Designated professionals for looked after children

“Champions are local and regional leaders and influencers who are respected, trusted and already have at least a basic understanding of FASD prevention, identification and services/support.

They are most important initially - and can then spark and facilitate broad participation by all stakeholders, including diverse professionals, parents/carers, people with lived experience and key policymakers.”

Figure: Find champions

40. Another participant highlighted the need to engage service users early. “Service users should include both parent/ carer perspectives and also those of any charity/ Third Sector organisations who are currently or will be in the future providing support to families before, during and/or after a diagnosis of FASD. Representation from the widest group is critical, with wider consultation and feeding in from interested groups both professionals and those affected by FASD.” Other participants highlighted the need to ensure that charities and Third Sector organisations are FASD-informed as there are examples where those who have experience with Autism or other conditions are not necessarily able to meet the needs of those with FASD and will need additional training.

41. Another participant noted the importance of ensuring thought is given from the outset for adults with FASD as his family has experienced first-hand the challenges of trying to wrap support around adults with FASD: “My 5 adopted children are siblings with Prenatal Alcohol Exposure and all have FASD – but only 2 officially diagnosed – and I am a GP – they are now aged 20-30 and adult services in my area are ‘not commissioned for FASD’.”

42. National FASD as part of its 2020-21 DHSC funded partnership with Seashell created the Best Practice in FASD Training and FASD: Preferred UK Language guides here: https://nationalfasd.org.uk/learn-more/resources/publications/.

Getting started

43. One participant highlighted the fundamental importance of enabling local families affected by FASD to inform official decision-making. This is covered further below in the section on meaningful engagement with those with lived experience.

44. Someone highlighted the need to ensure in planning that programmes are not dependent on just one or two people but are built into the system and self-sustaining.

45. As an example of the need for sustainability, it was pointed out that in the North East a Health Needs Analysis[1] by all health directors was pushed by the alcohol framework, but as soon as a key person retired it “fell through the cracks”. This highlights the need for involvement of more than just one key person and for responsibility to be built into organisational structures.

46. As one participant said, “It doesn’t matter where it sits as long as someone takes ownership/ strategic lead and a budget.”

47. That said, another participant highlighted the need to ensure the positioning still allows for the full range of those affected to be addressed. For example, the 2020-21 DHSC FASD grants were from the Children of Alcohol Dependent Parents Programme and if not carefully handled this could give the impression across the workforce that FASD only affects those who are alcohol-dependent. SIGN 156 and the NICE Quality Standard are focused exclusively on children and young people, so care is needed to ensure that services don’t drop off for those who are adults.

48. Someone noted the “SEND Board should have the relevant people in the room. Local Parent carer forums should have access to these meetings. Director of Education, SEND leads, Designated Medical Officer (DMO) and/or Designated Clinical Officer (DCO) for SEND, Chief Executive of the council. One participant with lived experience noted, “The lack of understanding in education has the biggest impact on our family.”

49. From a practical perspective, participants emphasised the importance of the following elements:

    a. Clear plans

    b. Timescales

    c. Looking at evidence of what good practice should offer and learning from examples of areas in the country that may have offered this.

    d. A team who will support the management and implementation of these needs to be in place to ensure the establishment of embedding FASD assessment, diagnosis and support within services is implemented in a timely and effective way.

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[1] Healthcare Needs Assessment: Fetal Alcohol Spectrum Disorders in the North East of England, Dr Zoe Greaves, August 2016.

e. Having regional and national interest groups and to share practice and increase confidence of those involved in diagnosis is critical.

f. There is a need for closed professional conversations to be able to take place in safe environments. There should be acknowledgment that working with and supporting families affected by FASD can be in itself trauma triggering. Within any good service model clinical supervision support should be built in.

g. Clear goals: "Ensure that all services and the workforce are aware of what the aim is – from the chief executive to the frontline practitioners, statutory and Third Sector services. Get FASD discussed on as many agendas as possible. Hold a conference or learning event and invite representatives from the whole city including commissioners."

h. Create a 'safety net' by covering all services and creating a framework for the client group which stops people with FASD and their carers slipping through multi-agency communication gaps

How to get the attention of commissioners

50. (Please note this will also be covered in the next section on 'building a case.')

51. Participants highlighted the importance of creativity in engaging commissioners and noted it's possible to raise interest of commissioners from a number of mechanisms, i.e. via direct conversation and enquiries and also as a result of complaints and investigations.

52. One participant said, "There are potentially many ways to involve commissioners - one way is to invite them to meet and talk to people with FASD and their carers. Another is to invite them to observe professionals who are experienced in assessing FASD e.g., National FASD Clinic. Another way might be to hold a training forum specifically for commissioners, including local health, education, social care and charity commissioners (e.g., CCGs) as well as national commissioners involved in steering training etc (e.g, professional body leads)."

53. Someone else said, "Focus on real stories and simple stats". It's "key to involve local authority heads of cabinet (health and children) as well as potentially scrutiny heads."

54. Another said that in their area, "Coproduction has been easier with children's commissioners but there is a start to introduce all age strategies which should help and FASD is on our next joint commissioning meeting. This is a good place to start as many services are across different sets of funding and all the relevant commissioners will be in attendance."

55. Someone else pointed it it's possible to "raise awareness within the workforce and include commissioners within all the training, ensure FASD is discussed in all meetings which involve commissioning, mental health (adult and CAMHS), midwifery, substance misuse, youth justice, probation, neurodevelopment commissioners."

> **"From my experience local areas are not aware of where to start and what they need to do in relation to FASD, so it would be good to learn from those who have done it already and those with lived experience, so we can help local areas to offer the best systems they can and hopefully avoid a postcode lottery of support for those with FASD."**

SECTION 3: “What about the business case/ financing?”

56. Roundtable 3 explored key items to consider when making the business case for ramping up FASD services. It involved presentations from a commissioner who is also a service user as parent to a young person with FASD who highlighted key areas that will need to be addressed for commissioners. Another presentation featured an overview of the recent University of Salford prevalence study and how this can be used when presenting the case for local FASD services. These presentations were followed by a Q & A period.

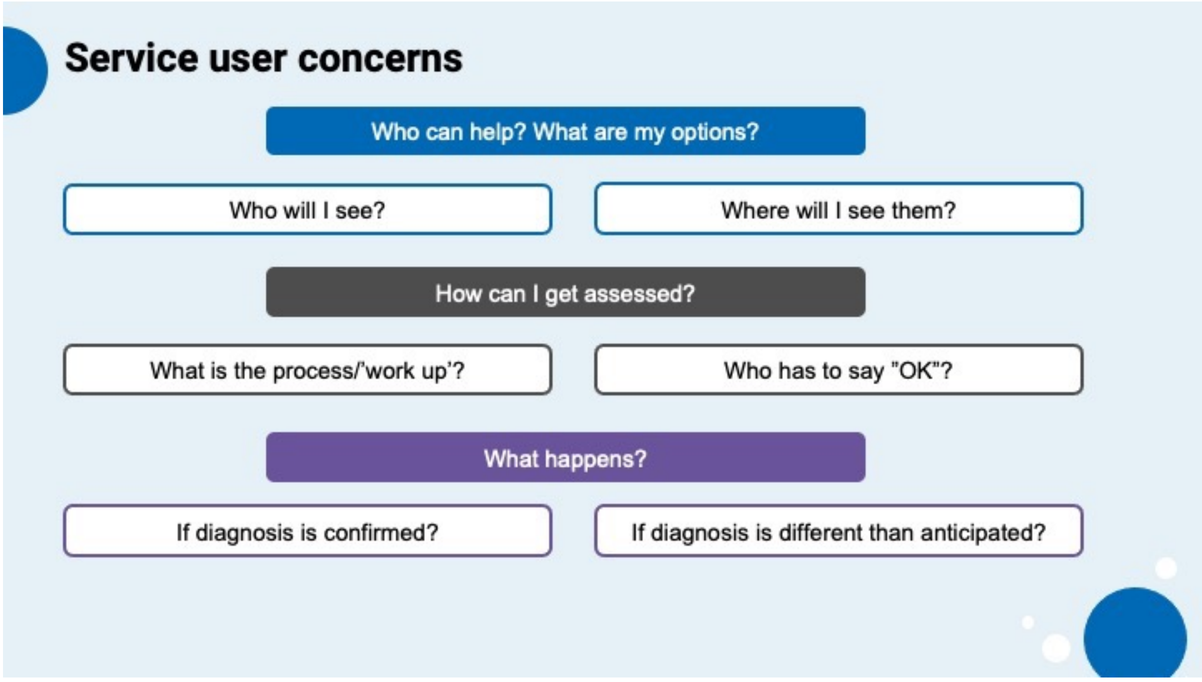
The importance of the service user perspective

57. The session opened with the perspective of a parent having sought diagnosis and support for a loved one.

58. It is critical to include this perspective in local planning, because while commissioners must think about healthcare management and management of resources, they also consider service user experience. As someone said, “While we must consider the commissioner take on this, the voice of the child / family and their journey must be part of developing a plan.”

59. The speaker discussed the service user concerns as outlined in the following chart. They boil down to a few key questions: “Who can help?” “What are my options?” “How can I get assessed?” “What happens after the diagnosis?”

60. He highlighted that, “As a parent you’re worried about what you will find in the process. It’s a benefit to know whether or not it is FASD or something else to consider.” The same is true for adults seeking FASD diagnostic assessment.



Service user concerns

Who can help? What are my options?

Who will I see?

Where will I see them?

How can I get assessed?

What is the process/'work up'?

Who has to say "OK"?

What happens?

If diagnosis is confirmed?

If diagnosis is different than anticipated?

Figure: Service user concerns

61. It’s important to think early on how families can give experience into planning, to develop case studies – perhaps contrasting someone with diagnosis and without.

Considerations for commissioners

62. Participants then heard his perspective as a commissioner, focused on the key considerations any commissioner will have to explore when ramping up FASD services.

63. The core questions are:
    a. Do we know how many have this care need?
        i. What is the prevalence? How can we determine that?
    b. What is the assessment and care management pathway?
        i. How to "work smart" in the system e.g. links to other schemes or services: Pregnancy advice; diabetes, COVID; Autism/ Neurodevelopmental conditions
    c. What are the preventative options? "A good commissioner should think of preventative options"
        i. Prevent FASD
        ii. Reduce adverse outcomes; benefits of early intervention
    d. What is the investment and its pay-back? (Value for money: whole-life costs vs. system costs now)
        i. Health AND Social Care (Mental Health, alcohol/ drugs misuse)
        ii. Education
        iii. Criminal Justice System

64. Demonstrating "improvement over time" is also important. The NICE Quality Standard on FASD has some measurables which may help with this.

65. While "choice" is important, it was highlighted that now the buzzword in commissioning is "integration". This fits well with the framework needed for FASD recognition, diagnosis and support.

66. The business case is about investment and payback, which is difficult to determine for health. Some changes are about thinking how to link whole system and exploring what are the knock-on effects of change and importantly, unintended impacts (Does it impact adoptions? Are there inequalities in the scale of need, etc?).

67. A longer list of key questions for commissioners was compiled with participant feedback, see below.

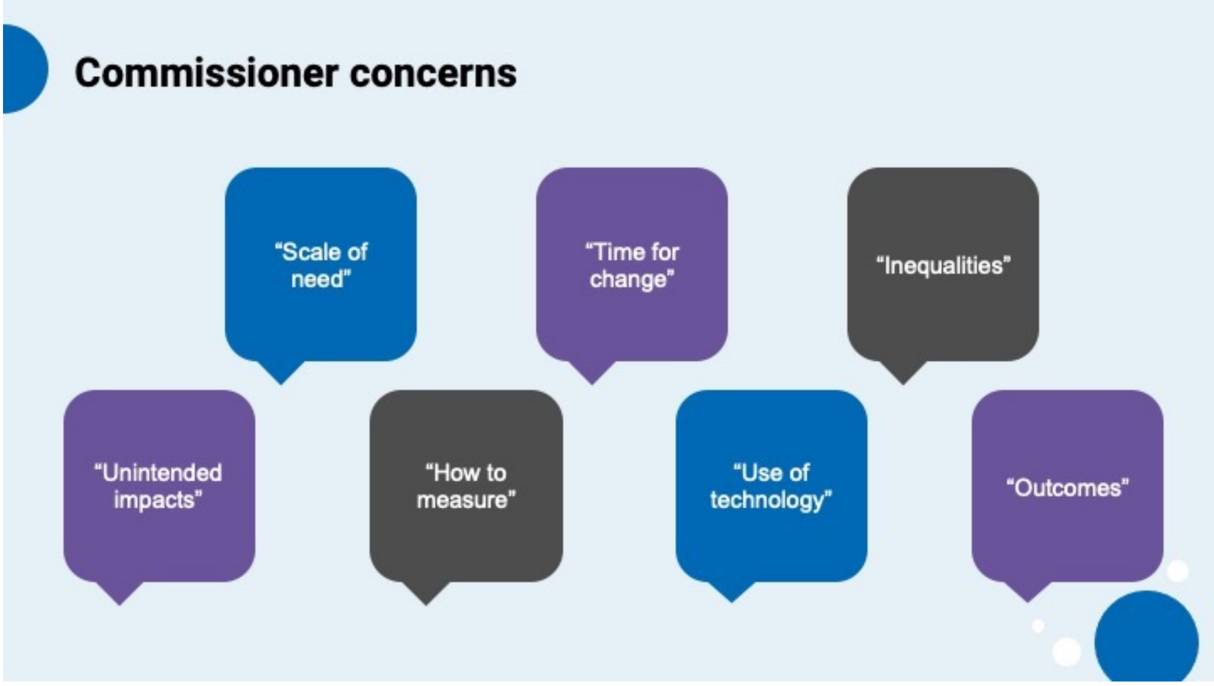
68. It is also important to consider the impetus for considering ramping up services. This could be a range of reasons, from very local situations to the changing national landscape:
    a. A local death/ serious incident/ media coverage/ public campaign/ questions from MP
    b. New guidance (SIGN 156 / DHSC FASD Health Needs Assessment/ NICE Quality Standard)
    c. Innovation funding (e.g. Best Start for Life)
    d. Local/ regional/ national data shows clear need/ unwarranted variation/ inequality

69. A participant said, "It's important that any business case must align with priorities of those with power and strategic objectives." Someone suggested it's important to "start where they are at (which may be far from where we want to be)." "Use their language and align with their strategic objectives." The presentation included key phrases and considerations, included here in boxes.

Key words for commissioners

"Quality"
"Pathway"
"Access"
"~~Choice~~" "Integration"
"Care Plan"
"Outcomes"

Figure: Keywords for commissioners



Commissioner concerns

"Scale of need"
"Time for change"
"Inequalities"
"Unintended impacts"
"How to measure"
"Use of technology"
"Outcomes"

Figure: Commissioner concerns

70. The importance of raising awareness system-wide was reemphasised. In one area where a pilot has been underway, they are still coming across senior leaders who don't understand FASD. In another area, where work has been ongoing for years there has never been a concerted approach to bring together interdepartmental leaders to discuss FASD. Someone said, "Their support is needed before you can start with commissioning prevalence studies, services or anything."

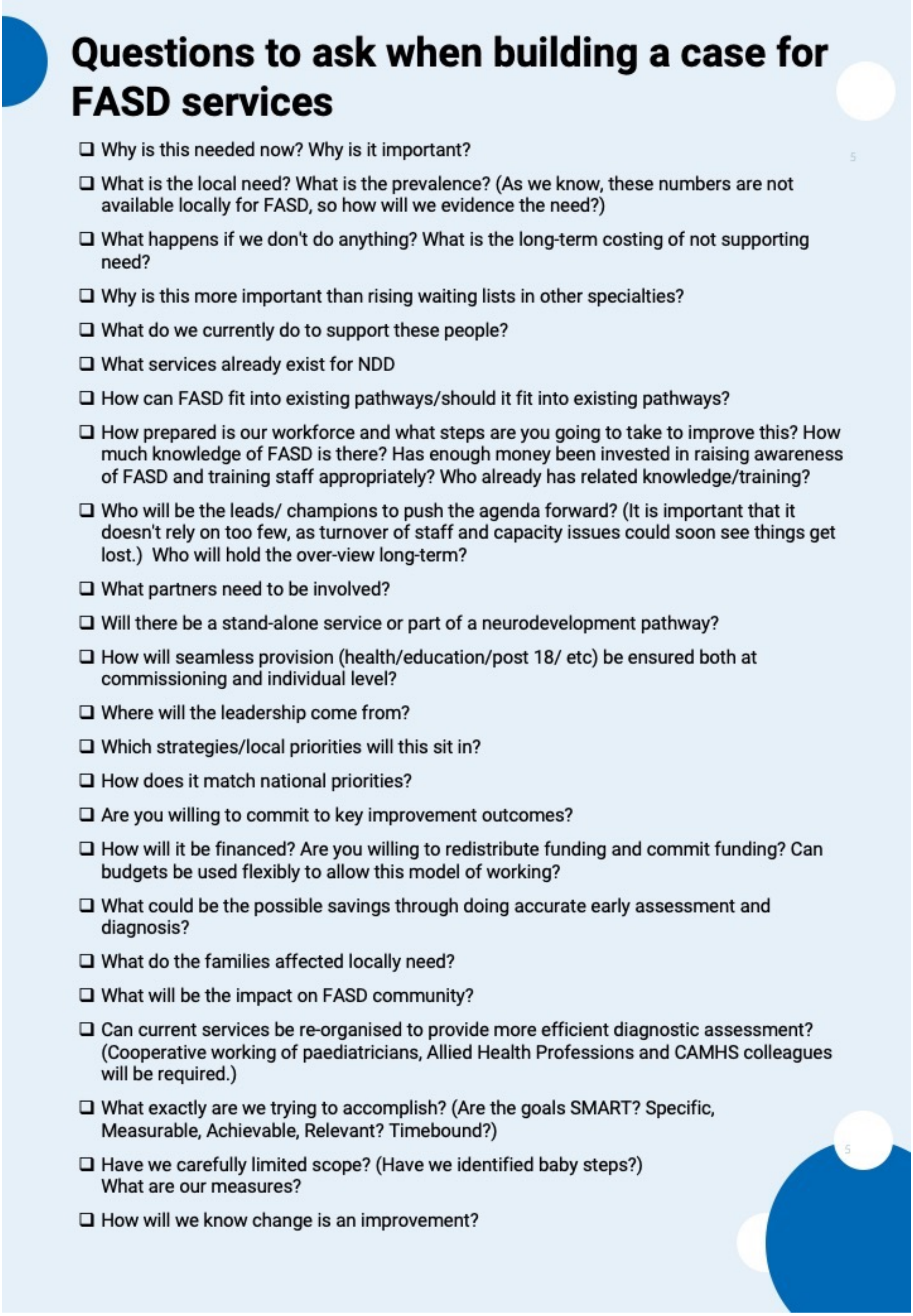
   a. If you have someone in the ND pathway who is FASD informed and participating in meetings, one participant said, "then you are fine, as commissioners will ask me what's needed. In areas where the expertise doesn't exist then it will be much harder and it leads to a postcode lottery…Many are not convinced despite two decades of UK work, papers, etc. We need to work out how we change that. Clinicians need this in core training. Not knowing enough is a hindrance."

b. Someone else pointed out that there may be a deeper systemic problem. They said, in Scotland SIGN 156 exists. The clinical expertise exists. Training exists. But still they need to overcome barriers of senior clinicians to believe in this as a diagnosis and stop saying it's not their job to diagnose. CAMHS is seen as a big problem by many with lived experience as anecdotally many families supporting people with FASD have a negative experience with CAMHS. This participant said, "Paediatricians are good at looking at the overall history, but not what's happening in the brain." They struggle to determine if a person meets the standard deviation criteria regarding three brain domains needed in SIGN. Scotland has a long way to go. This person was fearful FASD will be bottom of the pile not alongside other neurodevelopmental conditions.

71. Again, the importance of using patient stories (ideally delivered by the patient/ family) is key. Someone highlighted the power of using infographics to show the patient journey.

72. Someone suggested it's important to make "small tests of change" using the model: "Plan, Do, Study, Act". They noted it's important to track measures in real time to show impact (and make changes accordingly).

73. A participant suggested it's helpful to use local data, even if extrapolated from elsewhere, and compare no action vs medium action vs full implementation. More about prevalence is included below.



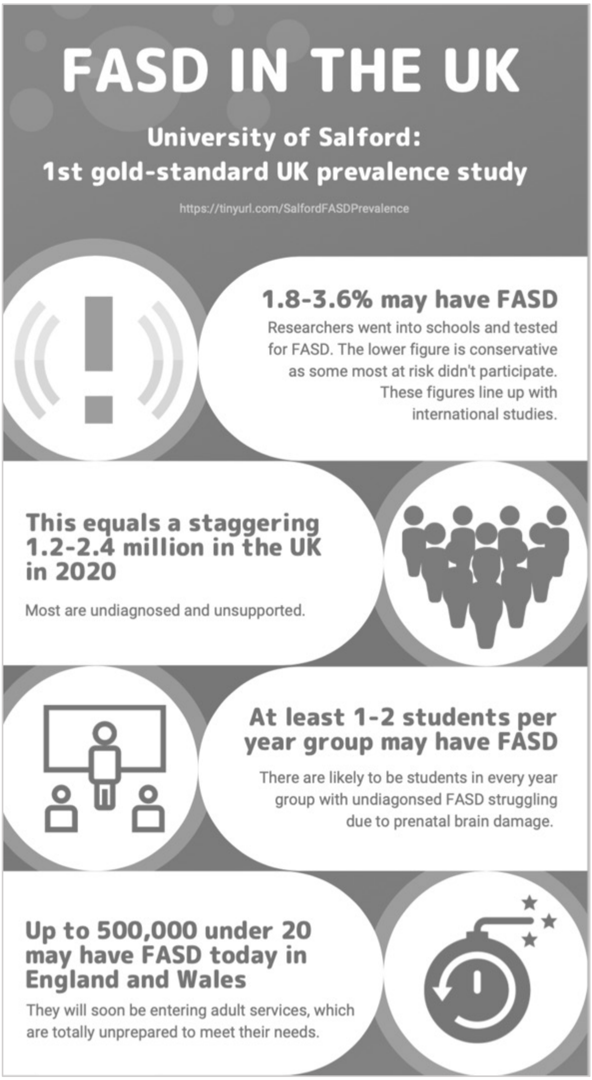
Questions to ask when building a case for FASD services

- ☐ Why is this needed now? Why is it important?
- ☐ What is the local need? What is the prevalence? (As we know, these numbers are not available locally for FASD, so how will we evidence the need?)
- ☐ What happens if we don't do anything? What is the long-term costing of not supporting need?
- ☐ Why is this more important than rising waiting lists in other specialties?
- ☐ What do we currently do to support these people?
- ☐ What services already exist for NDD
- ☐ How can FASD fit into existing pathways/should it fit into existing pathways?
- ☐ How prepared is our workforce and what steps are you going to take to improve this? How much knowledge of FASD is there? Has enough money been invested in raising awareness of FASD and training staff appropriately? Who already has related knowledge/training?
- ☐ Who will be the leads/ champions to push the agenda forward? (It is important that it doesn't rely on too few, as turnover of staff and capacity issues could soon see things get lost.) Who will hold the over-view long-term?
- ☐ What partners need to be involved?
- ☐ Will there be a stand-alone service or part of a neurodevelopment pathway?
- ☐ How will seamless provision (health/education/post 18/ etc) be ensured both at commissioning and individual level?
- ☐ Where will the leadership come from?
- ☐ Which strategies/local priorities will this sit in?
- ☐ How does it match national priorities?
- ☐ Are you willing to commit to key improvement outcomes?
- ☐ How will it be financed? Are you willing to redistribute funding and commit funding? Can budgets be used flexibly to allow this model of working?
- ☐ What could be the possible savings through doing accurate early assessment and diagnosis?
- ☐ What do the families affected locally need?
- ☐ What will be the impact on FASD community?
- ☐ Can current services be re-organised to provide more efficient diagnostic assessment? (Cooperative working of paediatricians, Allied Health Professions and CAMHS colleagues will be required.)
- ☐ What exactly are we trying to accomplish? (Are the goals SMART? Specific, Measurable, Achievable, Relevant? Timebound?)
- ☐ Have we carefully limited scope? (Have we identified baby steps?) What are our measures?
- ☐ How will we know change is an improvement?

Figure: Questions to ask when building a case for FASD services

Proving local need – prevalence

74. Participants received an overview of what is known about FASD prevalence in the UK, featuring results from the recent University of Salford prevalence study.



FASD IN THE UK

University of Salford:
1st gold-standard UK prevalence study

https://tinyurl.com/SalfordFASDPrevalence

1.8-3.6% may have FASD

Researchers went into schools and tested for FASD. The lower figure is conservative as some most at risk didn't participate. These figures line up with international studies.

This equals a staggering 1.2-2.4 million in the UK in 2020

Most are undiagnosed and unsupported.

At least 1-2 students per year group may have FASD

There are likely to be students in every year group with undiagonsed FASD struggling due to prenatal brain damage.

Up to 500,000 under 20 may have FASD today in England and Wales

They will soon be entering adult services, which are totally unprepared to meet their needs.

Figure: Salford prevalence study

75. For decades there have been calls for more details regarding FASD prevalence in the UK. This "cuts both ways". Inaction has been justified because it's alternately considered:

    a. Too big a problem to deal with, and

    b. Too rare to bother with

76. The historical excuse for inaction was that we don't know how widescale a problem FASD is. Following the Salford study, we no longer have that excuse.

77. Typical passive surveillance techniques are a 'bad' way of determining FASD prevalence, because this just shows how much FASD is not being recognised. FASD is not being diagnosed so therefore it's not being recorded. Some of the passive surveillance figures that do exist show only those with "Fetal Alcohol Syndrome" (now called "FASD with sentinel facial features") – which represents less than 10% of those with FASD.

78. The challenge is distinguishing what is the exposure risk and FASD. The outcome is not a direct correlation. It's a challenge to see how many alcohol-exposed births lead to FASD. The most recent screening prevalence study by Cheryl McQuire et al (2019) showed at least 6%, but that data starts in 90s when drinking in pregnancy was much more prevalent.

79. The gold standard for determining FASD prevalence is via an active-case ascertainment study. Internationally these studies were done on a large scale and showed FASD rates between 1-5% (see for example P. May et al, 2018.) The Greater Manchester Alcohol-Exposed Pregnancy project included funding for a small-scale active-case ascertainment study – a UK first.

80. The 2021 Salford study was a pilot involving a team experienced with FASD.

81. The Salford results showed 2-4% prevalence with 3% as the ballpark figure. (This matches the 3.2% estimated in SIGN 156 and referenced in the 2019 NICE briefing paper.)

82. This study proved a need to do an active-case ascertainment study on a bigger scale with proper funding. It should cover different areas and sub-populations.

83. However, this does NOT mean that each local area needs to wait for local prevalence figures. As the speaker said, "We don't need lots of small-scale projects, but need to take the experience from Salford and scale up. Doing it piece meal would be more expensive."

84. Participants believed that the Salford study has confirmed that action is necessary in local areas. Someone said, "It doesn't help to wait for a prevalence study in every area."

85. It's important to note that the Salford data is considered a low estimate as students with EHCPs in specialist schools weren't included. There were some students in the schools that were part of the study identified by their teachers as likely to be at risk, but researchers weren't given access to those students for various reasons. COVID also impaired access.

86. The Salford study gives a ballpark figure that proves FASD is not a rare disorder. The prevalence is likely higher than Salford shows.

87. One participant said, “It is particularly important to co-produce the dataset that will make visible the demand / unmet need and show impact / outcomes and (social) return on investment. This will be fundamental as we enter the era of data-driven population health.” The Salford study is an important step toward that aim.

Showing possible costs/savings

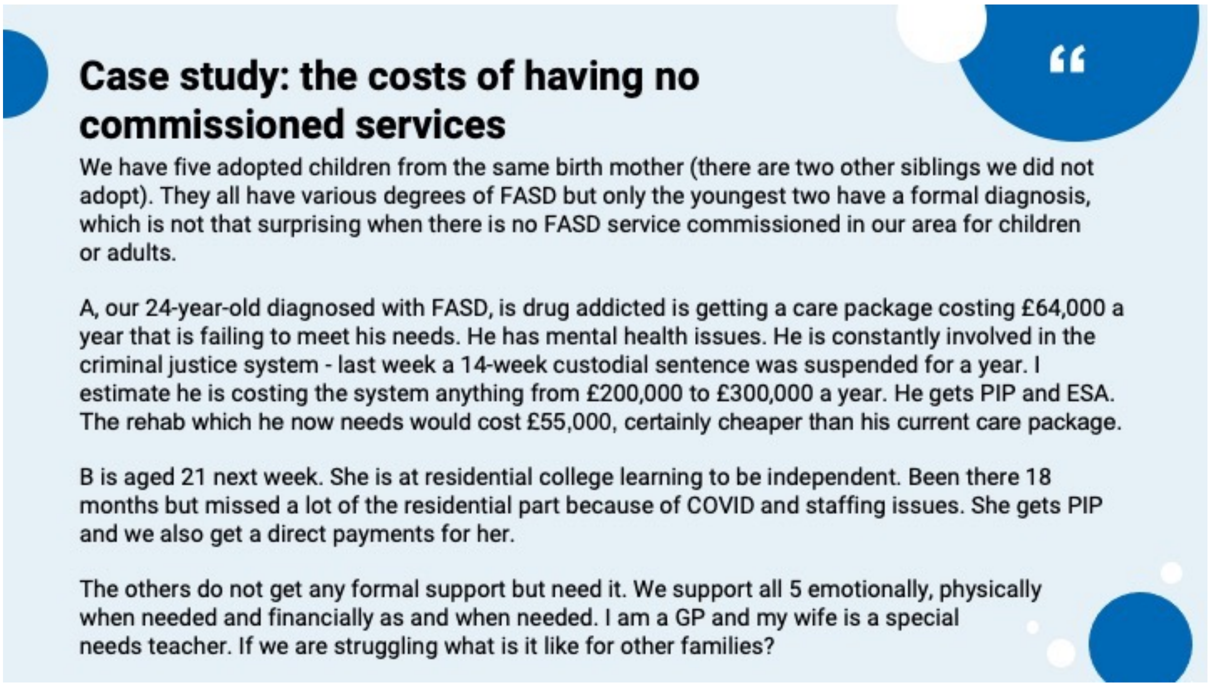
88. Business cases also have to address funding and cost issues. In the current climate, one participant noted that funding anywhere across the NHS is “a huge barrier” at the moment.

89. Someone pointed out that with FASD services there is a significant return on investment, but it is long-term. Preventing children being born with FASD doesn’t have a readily visible return on investment. If you prevent a child being born with FASD, you don’t see the money you can then spend, but it is there. Similarly, you can’t see outright the savings from early diagnosis and support, but they are there. For example, it costs £80,000 per year if someone ends up in prison.

90. According to one participant, “Diagnostic FASD services will save cost overall. Many children with FASD are being seen in multiple clinics for several years before they are given a diagnosis. The centralisation of the diagnostic process will limit this fragmentation and reduce cost overall.”

91. One participant said, “We need to prove the case that the costs involved in ramping up the services can lead to better management, opportunity and reduced costs later in life. While many know there is a need, when so many of those with the condition ‘look normal’ it is easy for it to be overlooked and ignored. So, what is the compelling case to recognise it and provide services?” Someone said, “At the moment, there is very little to guide us on how best to support children (and even less for adults).” But, as someone else said based on their lived experience: “Many times the lack of not knowing what works for those with FASD is used as an excuse to do nothing.” There are projects seeking funding to evaluate and assess projects, e.g. the University of Salford SPECIFIC FASD parenting course, or National FASD’s “Me and My FASD Toolkit”. But again, the lack of funding for FASD services is a barrier.

92. A first step in providing a tool to estimate the costs of FASD was published by the DHSC published in 2021, as part of its “Parents



Case study: the costs of having no commissioned services

We have five adopted children from the same birth mother (there are two other siblings we did not adopt). They all have various degrees of FASD but only the youngest two have a formal diagnosis, which is not that surprising when there is no FASD service commissioned in our area for children or adults.

A, our 24-year-old diagnosed with FASD, is drug addicted is getting a care package costing £64,000 a year that is failing to meet his needs. He has mental health issues. He is constantly involved in the criminal justice system - last week a 14-week custodial sentence was suspended for a year. I estimate he is costing the system anything from £200,000 to £300,000 a year. He gets PIP and ESA. The rehab which he now needs would cost £55,000, certainly cheaper than his current care package.

B is aged 21 next week. She is at residential college learning to be independent. Been there 18 months but missed a lot of the residential part because of COVID and staffing issues. She gets PIP and we also get a direct payments for her.

The others do not get any formal support but need it. We support all 5 emotionally, physically when needed and financially as and when needed. I am a GP and my wife is a special needs teacher. If we are struggling what is it like for other families?

Figure: Case study: the costs of no commissioned services with alcohol and drug problems: support resources." (The DHSC defines this to include 'dependent and non-dependent problematic use'.) It states, "Collaborative assessment, information sharing and clear pathways between systems and services are vital to identifying families affected by drug and alcohol problems and ensuring they receive appropriate support early."

93. Based on international data, the DHSC workbook estimates the cost per child with FASD to be £18,100, of which £17,200 are direct costs to the LA, NHS, CJS.

94. Some felt that as this is an estimate based on international data it may not accurately capture the full range of the costs involved with FASD in the UK. For example, costs of special educational education here in the UK is likely to be significantly higher. More work needs to be done to develop the economic costs.

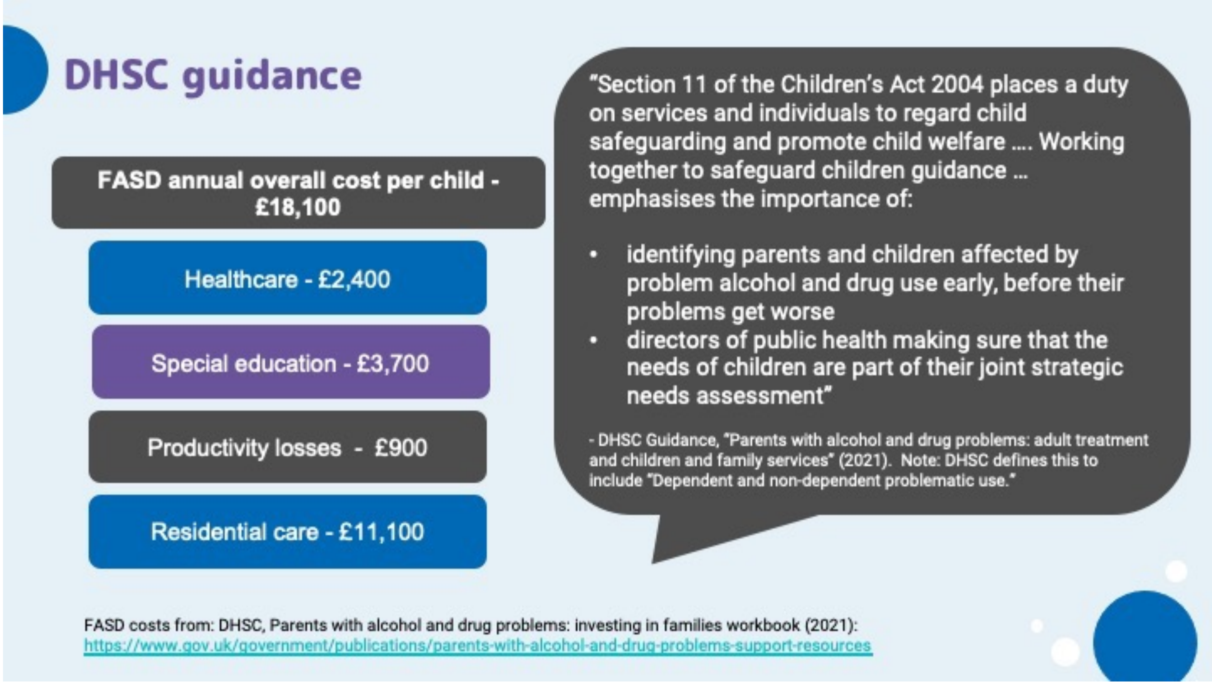
95. One GP who has five adopted children with FASD urged the costs savings are key to consider. These costs aren't showing any cost to FASD because there is no service. The care package for one child is £64,000. One child is a 'frequent flyer' in health, justice and other systems at a minimum cost of £300,000 across the system. The rehab which he now needs would cost £50,000. Integrated care would show this total cost which is currently not showing when looking just at health costs.

96. Another parent said that the cost of his son's specialist school is £21,500 per year. These types of costs are not covered in the DHSC workbook tool.

97. These DHSC estimates also don't include lost productivity costs when a parent/carer is unable to work due to having to be available to support loved ones who are not otherwise supported in the system and need someone on hand during the day to help scaffold them.

98. Someone suggested it would help to find someone with a complex series of diagnoses and look along a timeline of their cost to the healthcare system.

99. A UK study on cost saving of early diagnosis could prove helpful.



DHSC guidance

FASD annual overall cost per child - £18,100

- Healthcare - £2,400
- Special education - £3,700
- Productivity losses - £900
- Residential care - £11,100

"Section 11 of the Children's Act 2004 places a duty on services and individuals to regard child safeguarding and promote child welfare .... Working together to safeguard children guidance ... emphasises the importance of:

- identifying parents and children affected by problem alcohol and drug use early, before their problems get worse
- directors of public health making sure that the needs of children are part of their joint strategic needs assessment"

- DHSC Guidance, "Parents with alcohol and drug problems: adult treatment and children and family services" (2021). Note: DHSC defines this to include "Dependent and non-dependent problematic use."

FASD costs from: DHSC, Parents with alcohol and drug problems: investing in families workbook (2021): https://www.gov.uk/government/publications/parents-with-alcohol-and-drug-problems-support-resources

Figure: DHSC guidance and FASD costs

Identifying possible outcomes in a business case for FASD services

100. Up to now provision of FASD services has been a post-code lottery. As one participant said, there is a “very mixed approach in CCGs, some accept and will refer but many others, the majority will not, and most will not fund. The question that is always asked is what difference does it make? That is fundamentally wrong, and we know there are now bespoke interventions that can make a difference.”

101. “The way it has been up to now is not the way it will be in future,” said one participant. “All the major public health bodies have recognised FASD as a full spectrum, with lifelong consequences. The importance of recognition, diagnosis and support is no longer debatable.”

102. That said, a business case will have to identify anticipated outcomes. The following list of possible outcomes was compiled from participants as a starting point:

    a. A family to have had the benefit of a clear and completed assessment

    b. Diagnosis with support system behind the assessment

    c. Once a full assessment is conducted, discharge possible from the assessment service

    d. If a future referral is needed (e.g. mental health) you would not need to repeat previous work

    e. Positive family feedback to the trust

    f. Parent/ carers, children/ young person, school have better understanding of the child’s difficulties

    g. Avoiding children/ young people spending time bouncing from one service to another being assessed several times with no conclusion or appropriate help

    h. Promoting positive outcomes with support (e.g., meaningful activities and relationships) and avoiding poorer outcomes (e.g., criminal justice) that too often occur without support.

    i. Avoiding the added cost saving from multiple, unproductive referrals to different services

    j. Prenatal advice and support to reduce alcohol exposed pregnancies

    k. Invest to save, “huge amounts of money could be saved if early diagnosis pathways are in place”

> **The way it has been up to now is not the way it will be in future. All the major public health bodies have recognised FASD as a full spectrum, with lifelong consequences. The importance of recognition, diagnosis and support is no longer debatable.”**

Pilots can be useful to start things rolling

103. It’s possible to start with a pilot programme in a local area. This has proven successful for example in Greater Manchester.

104. It’s important however to ensure that there is a mechanism built in for continuing funding as there have been examples over the years of FASD work being dependent on one or two key figures in various areas. The work has faded when they moved on because it was not built into the system.

105. On a larger scale, the hope is that NHS England or another funding entity can support a pilot to lead to scaling up of FASD services, as was done in Scotland . One model is that a national centre can support regions. The Greater Manchester example of funding from alcohol prevention gives vision of how to integrate pathways and move forward. Future sections will address these and other possible pathways.

106. Participants suggested options for pilot projects:

    a. “We can possibly place a timeframe of an initial two years of a multidisciplinary diagnostic clinic for FASD and then review outcomes (should be decided by team).”

    b. A pilot study could be via questions to schools: 1) Have you concerns that you have C/YP at school who could have FASD, 2) If there was an assessment pathway would you consider referring? 3) At the present time how many children have you that attend your school that you are likely to make a referral for?

    c. “When we set up our local pathway we did an audit looking at children seen before and after the pathway and we found an improvement in the time to reach a diagnosis and in the number of children where there was clear outcome to assessment. We didn’t have any funding from CCG and our pathway is not what we would like it to be. I would be interested in piloting an improved pathway with more psychology time, some dedicated specialist S&LT time, and some post diagnostic support. Outcomes would be feedback from parents, carers and children, time to reach diagnosis. One drawback to a pilot is identifying professionals who are willing/ able to accept a time limited contract/ additional hours.”

    d. “I have experience in COPD pilot that demonstrated huge savings of time and money from unnecessary AE attendance to reducing unnecessary driving to patients by community matron - focus was on cost savings but ultimately great for the patients as in control and looked after remotely - matrons able to focus on those that were unwell and needed more care.”

    e. The GM project which started with seed funding is a useful model to allow business case development. Funding came through transformation money in the GM system as part of a wider prevention programme. There was always going to be phase two as strong willingness to continue with transformation money that hasn’t yet come about. That said, the ‘ideal’ would be working prevention and diagnosis alongside each other.

    f. In Sheffield there is a pathway for Autism and ADHD. They have now added FASD into the pathway. Referrals are being made from social care, and they are keeping numbers so we can demonstrate there is a local problem. The first clinic was expected in February. (Pathways will be further discussed in a separate section.)

What about the coming Integrated Care Systems?

107. Participants noted the commissioning landscape in England is changing from CCGs to Integrated Care Systems (ICS) and Provider Collaboratives. These will need to be the targets of commissioning. It will be the role of the ICS to plug commissioning gaps.

108. This could be helpful in theory as we move to greater integration with social care and public health. Though there may also be drawbacks.

109. The transitions to ICSs could be a challenge but could also be an opportunity to have FASD pathways embedded within new work streams.

110. The ICSs will be told to focus on neurodevelopmental disorders (albeit operationalised within the NHS long term plan as “Learning Disabilities and Autism Spectrum Disorders”).

111. One participant noted: “The argument to broaden out the Autism and LD ICS is a strong one and makes logical sense due to the similarities of skills required for assessment and support. In addition, I think the structure of the FASD assessment framework has a lot to offer other neurodevelopmental assessments such as Autism and LD. For example, in FASD, part of the assessment involves assessing 10 central nervous system domains using a standardized approach where possible, with clear clinical threshold criteria. Whilst potentially more work at the assessment stage, as it can require a multidisciplinary approach, this depth of assessment is vital for ensuring accurate formulations and care plans that are tailored

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[2] See for example, Scotland’s Alcohol Framework, 2018, sections 115-118, pp 39-40

to provide appropriate support. Furthermore, in FASD it is acknowledged that, whilst the cause of difficulties in different domains may be theoretically linked, it is possible to have multiple diagnoses/ difficulties such as FASD, LD, and Autism. As such, if there was a 'neurodevelopmental' approach which included FASD, ASD and LD, there will be less fragmentation between services where people are moved between services. In summary, having worked in ASD, LD, and CAMHS services prior to working in FASD, not only will it benefit people with FASD to have FASD included in an ICS, the structured holistic approach of a broad assessment and formulation in FASD could also ultimately have a positive influence on Autism and LD services." This pros and cons of this will be further discussed in the section focused on pathways.

112. One participant pointed out that the ICS will allow greater opportunity to appoint clinical champions. Again, these are supposed to champion Autism and Learning Disabilities. It should be explored with urgency, can we insert FASD into this structure?

113. Some argued that while we ought to be able to benefit from the change in system, it is important to be patient as disruption of change will make things hard in the short term.

114. One participant pointed out that "The ICSs will be pre-occupied and focused on pandemic strategies. Small populations will lose out for five years or more. The stress is in social care and care of the elderly. FASD advocates need to be strategic in approach to gain resources."

115. There has been at least one positive example already of the new ICS working proactively on FASD. The Northeast and North Cumbria ICS mental health work stream fully adopted FASD on a neurodevelopmental pathway to galvanise system development.

116. One participant pointed out that the action with regard to ICSs is not only on the local level: "There will be local ICSs which can include representatives for FASD, however it will also be important to try and influence the statutory ICS body which oversees the whole system."

How can the DHSC FASD Health Needs Assessment, the NICE Quality Standard and other documents from PHE/ OHID and SIGN help when creating a business case?

117. The recent policy developments from SIGN, DHSC, NICE, PHE/ OHID can be presented as political drivers that previously didn't exist and give a benchmark to CCGs and ICSs. "Evidence is a driver for change," said one participant and unlike any time previously, now the official entities are on record. Collectively, these documents show best practice and what should and could be done.

118. Another participant provided a note of caution however, "It is important to recognise that documents like these are received by leaders every day and those on the frontline rarely see them or are aware of them. Even if boards ask or expect frontline to implement them, effectiveness is very variable."

> **It is important to recognise that documents like these are received by leaders every day and those on the frontline rarely see them or are aware of them."**

119. The roundtable occurred before the announcement of the publication of the NICE Quality Standard. Many felt at the time that there is "No need to delay waiting for NICE Quality Standard". Someone said, there is "No need to delay as [SIGN] 156 can be used." From this perspective, the NICE QS will give extra weight to proposals, but shouldn't be the deciding factor. Someone else said, "I don't think areas should wait for the NICE QS, we should be using the draft standards to commence change." The NICE QS will enable auditing of success. "Our service at present does not have a clear pathway for assessment and diagnosis despite knowledge and recognition of cases - NICE QS once published should ensure we can request a pathway is commissioned".

120. Others felt that the delay in publishing the NICE Quality Standard has had significant impact. One participant said, "It has proven to be difficult to move forward without the NICE QS as this is the standard that will be used to inform commissioners of the need for a service to be funded. Training to raise awareness locally has been very successful however there is a frustration on how to take

this forward. A draft plan has been started within our paediatric/ neurodevelopment service to consider what we shall need - we need to pull in other agencies along with this to formulate a business plan for the future."

121. One participant said, "If people feel it is best to wait, workforce development can start in preparation to NICE QS and mapping of the local area's current offer. Links can be made within regional areas to look at the wider offer. All this can be done so when it is released we are ready to start. We already have the health needs assessment and many have already been waiting with no diagnosis and no support. Should they really have to wait any longer?"

122. The importance of lived experience was recognised by one participant, "These documents need bringing to life with really case studies where people have struggled to get a diagnosis, support and the effects, also positive case studies where someone getting a diagnosis and support and the positive impact it has had."

123. Prevention work via maternity services can start now utilising the PHE High Impact use of alcohol in pregnancy document.

124. The DHSC health needs assessment can be used to engage stakeholders across both children and adult services.

125. A participant said, "Co-ordinated team assessment approaches could already be developed. This approach is "advantageous to any type of ND problem. Specific FASD training for practitioners should be being put in place now."

126. Someone else noted that thinking differently about FASD needs "a big push to move from a psychosocial model of disorder to a biopsychosocial version, -not least in psychological and educational services. All this requires time, receptiveness and funds."

127. A basic premise of these roundtables was that it's important to start planning now to ramp up FASD services.

What else can help – future projects?

128. Participants offered some thoughts about projects that might strengthen the business case:

    a. "A child and family experience survey will be useful."

    b. "Would be great if someone was willing to share the business case they have used as it is an onerous task and although needs localizing the basic format and information will likely be very similar?"

    c. A mapping exercise could prove useful and will also help look at how all the services link together.

    d. A UK study on cost saving of early diagnosis?

    e. The need for funding for a national active-case ascertainment prevalence study was highlighted repeatedly.

Conclusion

129. Some commissioners participating thought there is enough data here for commissioners to act now. The Salford prevalence study could be used as the basis for estimating local prevalence. It was also pointed out that COVID and COVID recovery are the "major headaches in commissioning now", so getting a response on a prevalence study request might not be met.

130. One commissioner said, "There's enough fair and reasonable prevalence material to make a first move, probably in a pilot fashion - not necessarily launching into massive new project, but pilot." Some felt that piloted action including education, health, social care etc is needed, but that a lot of small prevalence studies are not needed.

131. One participant said, "A good commissioner can pick this up and do something."

132. Times have changed, and the opportunities with the new ICSs may be helpful. One commissioner said, "Three years ago if I included costs of social care I would have had a strong push back from healthcare colleagues, this is now not the case. I don't

feel there is a prevalence issue, although others have had resistance on this. Communications around outcomes and big ticket costs due to inappropriate services will help development of business cases."

133. Another participant urged people to focus on business cases using the 'invest and save' model. "Changes in trajectories will save money massively in the long term. Business cases will be crucial to the outcomes."

134. Families of those with FASD urged action now as the lives of those with FASD are being impacted daily by continued inaction, even now when progress on ramping up FASD services seems more possible than ever before.

Who should be involved, including perspectives of those with lived experience

135. Participants heard a presentation from the mother of a teen with FASD who also runs a local support group and is a member of the local parent carer forum.

136. Contact has created Quality Indicators for Co-production and Inclusive Practice to "help groups, organisations and partnerships identify and develop good practice in how they work together in co-production."

    a. According to Contact: "Good quality co-production and participation is required by the Children's & Families Act 2014 and subsequent SEND Legislation. Quality indicators help organisations and partnerships identify and develop good practice in how they work together in co-production. Evidence shows that when local area partners actively work towards these quality indicators together, a culture of inclusion and co-production begins to thrive, trust strengthens, relationships flourish and better outcomes are generated for all."

137. How to find local families with lived experience?

    a. Families will currently be using all the different services across Health, Education and Social Care, but the service may not hold this information as it might not be included in the list of diagnosis or the family are struggling to access a diagnosis, so you may need to change your paperwork or put out a call for those willing to help.

    b. Parent carer forums may also have members who are raising a child with FASD, they also already work in co-production with the Local Authority and Health, so they have the connections and knowledge needed.

    c. Local support groups are a great source of knowledge, as they will understand the local needs of the families that attend. The FASD UK Alliance is a coalition of independent FASD groups across the country: https://fasd-uk.net/. Local support groups may not have the set up or knowledge about the systems on their own, so linking in together with the parent carer forum might be a good source of support and help them to develop their skills. If a group doesn't want to do this, it is important that they should still be able to contribute. Each initiative might want to have their own participation policy for these circumstances.

    d. In areas without a support group, it is also possible to contact paediatricians who might be supporting people with a diagnosis.

138. Some difficulties they may have in enabling them to participate are:

    a. Understanding of procedures

    b. Training in attending meetings is good practice. This should cover confidentiality. It might include shadowing an experienced rep until they feel ready to attend on their own.

    c. Funding - groups may not receive any funding so therefore this may cause barriers as they don't have the setup, may not have laptops, etc.

    d. A participation agreement might be useful, this will help all to think about some of the barriers:

    i. Times of meetings

    ii. How long you give for a response

    iii. Expenses

    iv. Which meetings are best for them to

attend as they may not have capacity to attend them all, remembering that they are often unpaid volunteers raising a family member with FASD.

e. Learn together, be open and honest.

139. To engage people with FASD, check with the local support groups. If your area has a young people forum, they may be supported by the parent carer forum or they might know if one exists in your area. They may have young people with FASD who are used to participation. It is also important that you make adjustments for their involvement. (Young people in care also often have a group.)

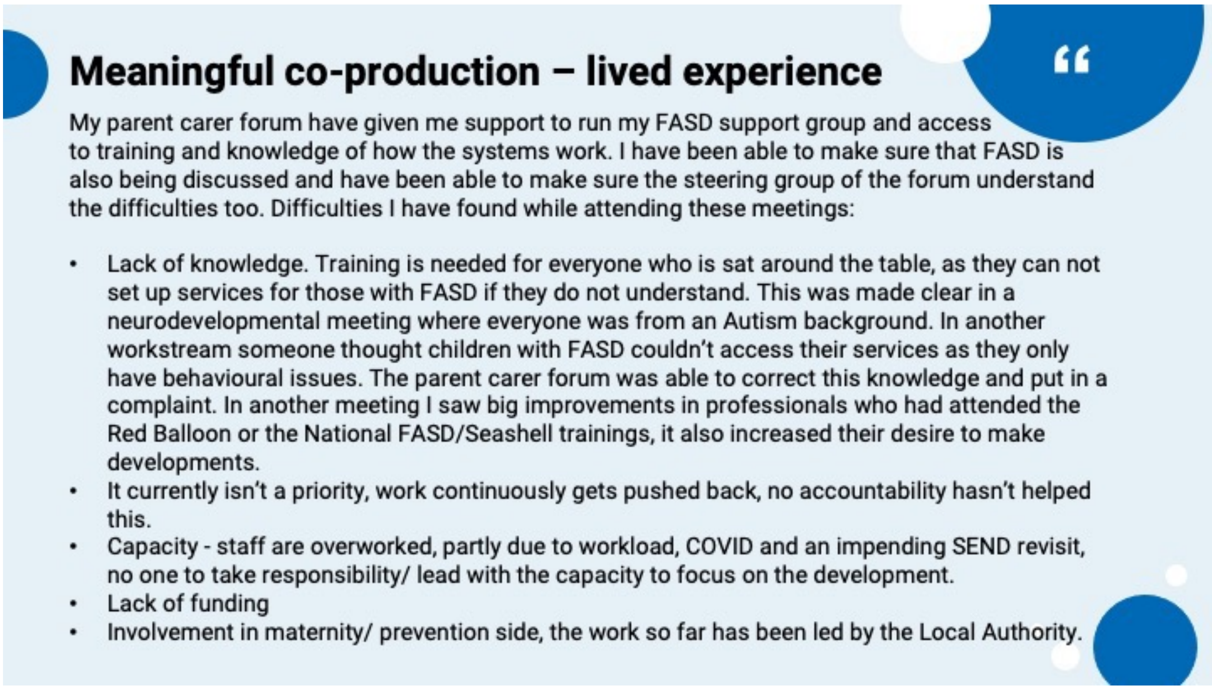
140. If parent carers also feed in their experience or join in the work of the parent carer forums, this will make sure their experiences/ needs are shared across all the workstream in the local area, not just those about FASD, this combined with the work on FASD will have a greater impact on improving the services and outcomes of those with FASD and their families.

141. One participant emphasised “keeping very clear very focused and intentionally reaching groups that may not see themselves as influencers.”

142. Another said stakeholders “are often separated into categories of parents, service users and professionals which then creates a pecking order. Be mutually respectful of all participants views and acknowledge all fully if reports are created or services created. If meetings are taking place all professionals will be funded so ensure that other attendees are acknowledged for their time and efforts. “

143. Someone else said, “Listen to people with lived experience about what they think will help change current practice ensure they are part of all discussion of proposals for future practice.”

144. Another suggested: “Ask people to liaise with local FASD specific groups if they exist in a locality rather than starting to address it themselves and then simply consult a FASD family or a FASD organisation after the fact.”



Meaningful co-production – lived experience

My parent carer forum have given me support to run my FASD support group and access to training and knowledge of how the systems work. I have been able to make sure that FASD is also being discussed and have been able to make sure the steering group of the forum understand the difficulties too. Difficulties I have found while attending these meetings:

- Lack of knowledge. Training is needed for everyone who is sat around the table, as they can not set up services for those with FASD if they do not understand. This was made clear in a neurodevelopmental meeting where everyone was from an Autism background. In another workstream someone thought children with FASD couldn’t access their services as they only have behavioural issues. The parent carer forum was able to correct this knowledge and put in a complaint. In another meeting I saw big improvements in professionals who had attended the Red Balloon or the National FASD/Seashell trainings, it also increased their desire to make developments.
- It currently isn’t a priority, work continuously gets pushed back, no accountability hasn’t helped this.
- Capacity - staff are overworked, partly due to workload, COVID and an impending SEND revisit, no one to take responsibility/ lead with the capacity to focus on the development.
- Lack of funding
- Involvement in maternity/ prevention side, the work so far has been led by the Local Authority.

Figure: Meaningful co-production

Case study: Greater Manchester

145. Participants received an overview of the Greater Manchester Health and Social Care Alcohol-Free Pregnancies Project as an example of good practice with a prevention programme.

146. The activities in Greater Manchester were funded in 2018 by non-recurrent transformation funding and driven by the Head of Population Health. It was a pilot programme, targeting 4/10 of Greater Manchester localities, with dedicated resources and leads.

147. An implementation group, including public health leads, CCG leads, Head of Midwifery, academic colleagues, was an important part of the process and took time to 'get right'.

148. Having people with full time role on this was considered very important.

149. Those involved in planning the project 'took time to learn' before going ahead as there was a huge learning curve. They pulled together work already being done to adapt to their programme by liaising with FASD specialists and existing networks both within the area and out of area.

150. They consulted with people with lived experience and involved them in decision-making, e.g. families sat on procurement panels, etc. and had a voice.

151. The following intended impact areas were identified:

Impact 1: Fewer alcohol exposed pregnancies within pilot areas

Impact 2: Alcohol screening in pregnancy as standard across pilot area maternity services

Impact 3: Clear and consistent messaging from professionals regarding alcohol and pregnancy in pilot areas

Impact 4: Increased public understanding and awareness of the risk of alcohol use in pregnancy and FASD as a hidden disability

Impact 5: Families affected by FASD in GM having more support

Impact 6: Increased understanding of the prevalence of FASD in Greater Manchester

152. GM's programme focused specifically on prevention. However, it also provided a vehicle to increase awareness of FASD as it's not possible to talk about prevention without talking about FASD. A public awareness campaign (Drymester) wasn't initially in the plan, but came from strategic advisors and families that it was vital.

153. They included a public consultation via independent market research company.

154. Understanding across Manchester was very low, so the training component also was important. The programme engaged Red Balloon Training, to provide training for more than 900 staff in the pilot areas across services, with a focus on midwives. All involved, including for example the theatre group, participated in the bespoke training. GM also asked National FASD to develop an Introduction to FASD e-learning module that is being provided to 300 across GM. This training was developed so that it is also available to other areas.

155. The GM project yielded the first UK active-case ascertainment prevalence study. This study is also an aid to other areas across the country who might not have capacity to do a full prevalence study of their own as it lines up with international data (more about this will be covered in future roundtables).

156. GM have expanded into all pilot areas, and even into some areas they didn't pilot. The next stage is to get ownership to promote awareness/diagnosis. They now are working with the remaining GM maternity providers to implement the same pathways.

157. Enablers for the GM Alcohol-Exposed Pregnancies Programme were:

a. GM is a devolved health and social care partnership

b. Personnel

c. Finance (though this also had disadvantages)

d. Bespoke training

e. Support with data capture and analysis

f. Awareness campaign and social media presence

g. Prevalence study

158. Barriers included:

    a. Personnel
    b. Capacity within localities
    c. No national strategy
    d. No buy in from certain strategic networks
    e. Lack of ownership beyond pilot and next steps
    f. Non- recurrent funding
    g. COVID

159. An evaluation of the GMHSCP Alcohol-free Pregnancies Programme is available here. As one example of the impact, between July 2019 to February 2021, over 1,000 people were identified as being at risk of an AEP, with 67% going on to engage with a prevention intervention, with 18% reducing alcohol intake.

160. Participants discussed how having a budget had advantages and disadvantages as some time was lost in areas that waited for the money to be in place before getting started. Following the end of the initial funding, other areas are now being asked to do things without funding that other areas did with funding. Having funding to put in place a local project manager obviously facilitated things in one area.

161. One participant said that while "we're all using Drymester now" (Sheffield is using it straight out of the box), the question is how do we ensure it doesn't stop? They highlighted the need for a sustainable service, not a capital fund for 2-3 years which then stops. This highlights again the earlier points raised about the need to plan from the start to build sustainable services.

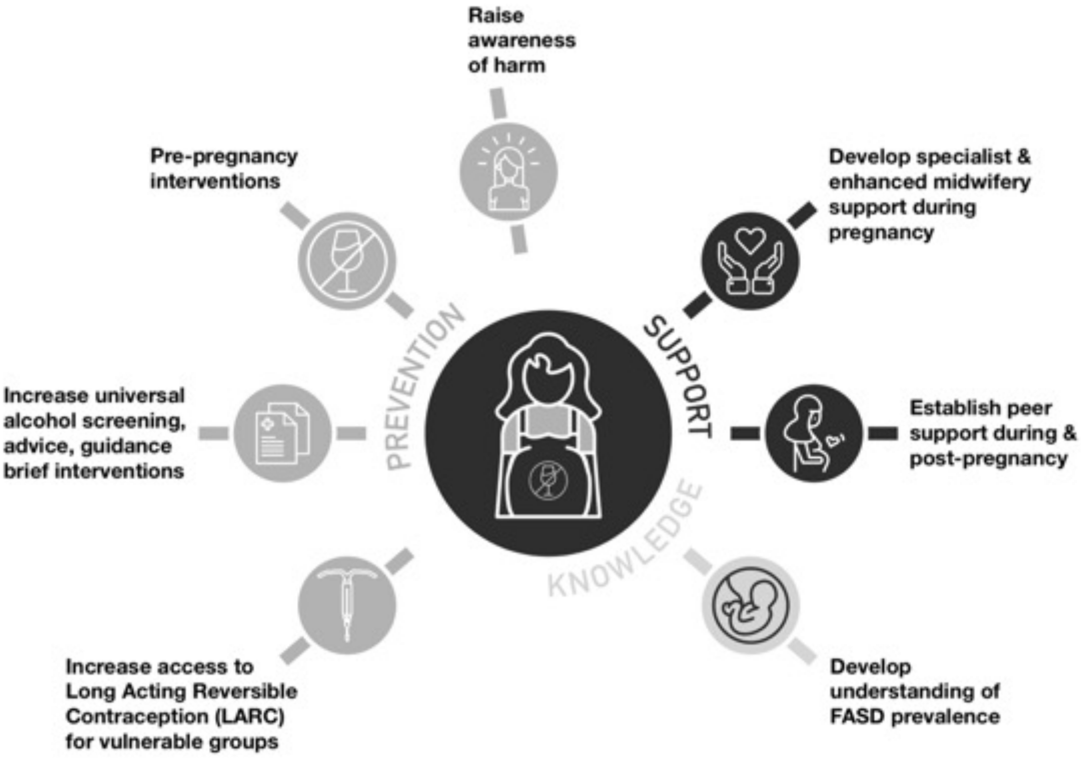


Figure 1: The Approach

From: Greater Manchester Alcohol-Exposed Pregnancy Programme Evaluation, 2021

Figure: Greater Manchester AEP Programme

Case study: Sheffield

162. Participants also heard a presentation based on Sheffield's work. Sheffield is at the early stages of the process of ramping up FASD services.

163. There have been efforts in Sheffield to get FASD recognised in Sheffield since 2007. Initial groundwork included:

    a. The Multi-Agency Pregnancy Liaison and Assessment Group (MAPLAG) is a Sheffield Children Safeguarding Partnership meeting. MAPLAG meetings take place fortnightly to discuss issues around women who experience difficulties with drug or alcohol use in pregnancy. These multi-agency pregnancy discussion meetings have been held since 2000.

    b. A small-scale audit was conducted in 2017.

    c. A Learning Brief written and disseminated.

    d. FASD training has been delivered in partnership with a Sheffield grandmother.

    e. The Lifestyle Screening and Referral Tool includes Alcohol. Frontline practitioners across Sheffield use an electronic tool to assess and refer service users to the alcohol service.

    f. Hidden Harm – covers drug and alcohol use, mental ill health, domestic abuse and harmful gambling.

    g. Learning Lesson Reviews - involve ALL partner agencies. Circulate learning briefs. Deliver in multi-agency training events. Promote discussion.

    h. They have been using existing networks involving the key decision makers to get the message heard, including:

        i. Children and Adult Safeguarding Partnerships

        ii. Health and Well Being Board

        iii. Drug and Alcohol Strategic Board

        iv. CCG/ ICS

        v. Director of Public Health

        vi. They have reached out to the overall Autism/ Learning Disability service through All Age Committee which makes it a bit easier to do services for all.

164. Sheffield chose to prioritise a major learning event/conference first to kickstart their efforts to ramp up services. They started with a big conference on 9 September (International FASD Awareness Day). Video & audio clips and presentation slides from the conference are available here: https://www.safeguardingsheffieldchildren.org/sscb/campaigns/fasd-fetal-alcohol-spectrum-disorder-awareness.

    a. Planning started with listening to the speakers' ideas and include people with lived experience from the start.

    b. Participants – they circulated invitations to ALL services through senior leadership meetings with the expectation that the leaders will nominate people and also attend. Included commissioners, foster carers, parent and carer forums and local universities, and more.

    c. The conference had 725 registrants, with 560 on the day (270 local stakeholders across services in addition to 290 national participants). They teamed up with external organisations (including National FASD) as co-sponsors to create a national-level conference at which the DHSC released its FASD Health Needs Assessment during a special meeting of the All-Party Parliamentary Group on FASD.

    d. Format was a webinar – they were able to reach more people, and people don't need to travel (especially important due to COVID but may still be useful model in future).

    e. Feedback provided has identified further needs, resources, training. They included options for whether participants would like further information about FASD, be a champion for FASD in their service area.

    f. Website – now presentations, audio recordings and videos all on the Sheffield Safeguarding Children Partnership website, keeping the conversation going.

165. Post-conference, Sheffield are keeping the momentum going:

    a. Enthusiastic participants have been feeding back on conference to network meetings. This really encouraged buy in. FASD has moved from being "any other business" to a standing agenda item for all future meetings. This has brought FASD into the "single door" approach. Before this FASD was only AOB, now on equal footing with Autism/ ADHD.

   b. They have set up an All Age FASD Steering Group which feeds into Hidden Harm meetings.

   c. FASD is a part of neurodevelopmental pathway task and finish group – to provide a coordinated approach and help secure funding – with a small-scale clinic starting February 2022.

   d. City-wide training is being arranged for the Sheffield workforce (children, adults and families).

   e. The online tool has normalised discussion of alcohol with pregnant mums. Sheffield are developing an electronic Audit PC tool that calculates the units (included in paper form – while the electronic version has more forms of alcohol), and produces a brief information sheet for service user explaining the impact the alcohol is having on them physically and mentally - they are adding FASD to this part too, and can be used in agreement with service user to refer into the Sheffield alcohol service.

166. Sheffield has launched the Drymester Campaign to increase public awareness around the harm that can be caused by drinking alcohol during pregnancy.

   a. 40-week campaign from 1st January 2022.

   b. Statutory and Third Sector services showing Drymester videos and messages across their social media sites.

   c. Videos playing in all GP surgery waiting areas.

   d. Banners, posters and videos in main areas including hospitals, libraries, market.

   e. Dentists, pharmacists, optometrists, midwives across Yorkshire and Humber delivering the Drymester message.

   f. Posters in pubs, night clubs, supermarkets, sport clubs, swimming pools and gyms – displayed on back of loo doors, behind bars, and at reception.

   g. Videos playing during half time on main video screens at Sheffield Wednesday and Sheffield United FC.

Data collection

167. A question was raised as to whether the Manchester or Sheffield initiatives led to implementing discussion/collection of data about alcohol consumption in all pregnancies by maternity services and recording that as routine – as smoking – or increased referral to alcohol services within pregnancy?

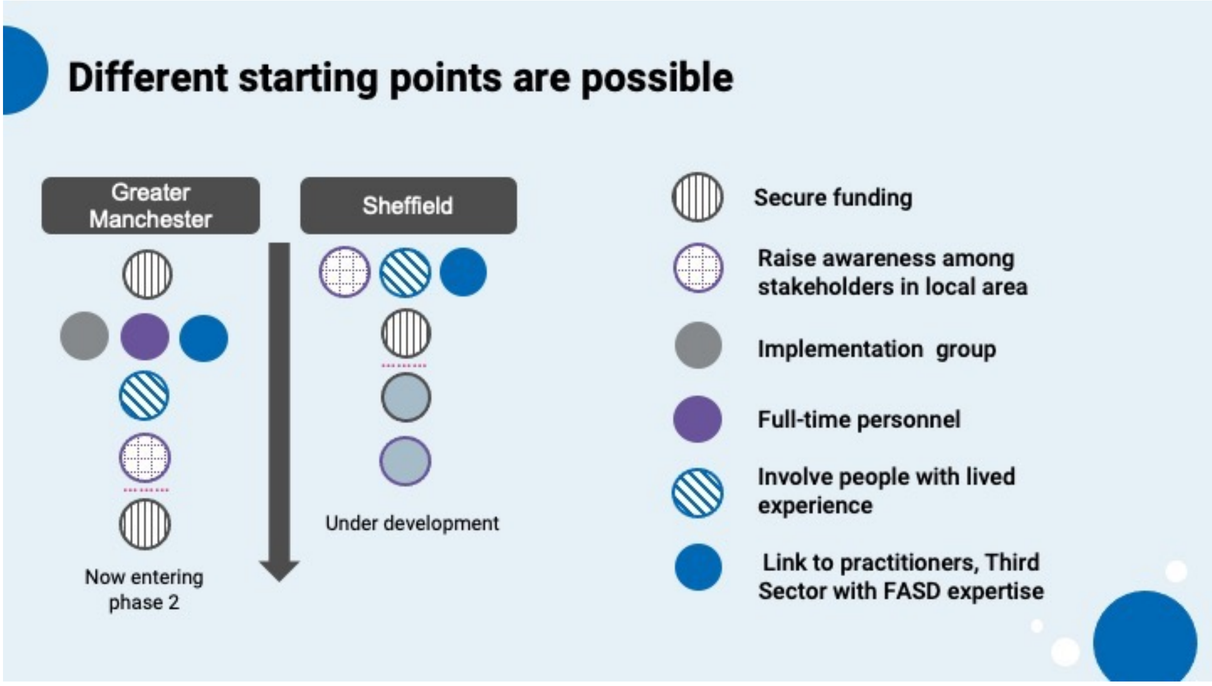
   a. GM pilot maternity services routinely screen for alcohol and document at 3 intervals during pregnancy and provide enhanced support and work in partnership with SMS services when required. One of the lessons learned was that data was vital and it was key to start data early, as it takes a while to get going and to get right.

   b. Sheffield are using the alcohol screening tool to collect data both about screening and also referral to alcohol services. It is based on Audit PC and can be accessed at www.alcoholscreeningsheffield.co.uk. It is currently being expanded and updated to include drug screening, smoking cessation and harmful gambling. It is mandatory for all children social care to use it in assessments.

168. Participants asked if there a role for NHSE in implementing alcohol recording.

Shared learning

169. “GM and Sheffield meet regularly to share learning. It’s so valuable.”



Different starting points are possible

Secure funding

Raise awareness among stakeholders in local area

Implementation group

Full-time personnel

Involve people with lived experience

Link to practitioners, Third Sector with FASD expertise

Figure: Different starting points - funding vs. awareness

Other examples

170. Derbyshire is in the midst of ramping up FASD services as a result of a tragic death of a young adult with FASD. Derbyshire started by giving trainings on CMO guidance. Then took to senior leaders and slotted FASD into pathway. It became a formal process that went to ICS board. The Children’s Commissioner in the CCG said this is a system priority in one meeting. Leader of safeguarding adult board has begun to push it forward. Lessons from Derbyshire include:

    a. Teach to raise awareness

    b. Start where individuals are at (many do not recognise the problem, do not know the guidelines, are too busy and believe there are no more resources)

    c. Focus on a serious incident/ death/ complaint/ family asking for an assessment

    d. Work with champions

    e. Collect data to make FASD visible

    f. Find a way to get the problem raised at a committee and for them to agree to action (even baby steps)

    g. Engage senior leaders to support you

    h. Keep measuring data and teaching more people

    i. Collect patient stories

    j. Steal shamelessly from others (with due credit of course!)

    k. Collaborate across boundaries and with networks

    l. Build a social movement and business case for change.

    m. Listen to people where they are at. It takes time to get them to understand.

    n. Reach senior leaders.

SECTION 4:
Understanding elements of the diagnostic process

171. Roundtable 4 explored elements of the diagnostic process for FASD. It started with a case study of a 48-year-old woman who fought for 8 years for her right to diagnosis, exploring the impact that delay had on her life but also the inefficient use of NHS resources in the decades where she was not properly diagnosed. There was a presentation about the SIGN 156 diagnostic guidelines which is now in effect throughout the UK. Discussion focused on the types of practitioners and resources needed to conduct the multi-disciplinary assessments called for in SIGN. This section is closely related to the following section on pathways.

Importance of diagnosis – a case study

172. The roundtable began with a video of Nyrene, an adult with then-suspected FASD[3] who had an 8-year battle as an adult to get access to an FASD diagnosis. The video showed her speaking in Parliament on 19 May 2019 about why a diagnosis is so important to her.

173. In the video Nyrene said, "Every single day is very, very hard. I don't want to be a normal statistic not working because I have children. I want them to know yes, it is difficult. I want to prove that I am able to do things. Without a diagnosis it is hard at work because they just take on the Asperger's side, they won't acknowledge the FASD. Until anything's concrete, their hands are tied. When I first joined the job, I had an amazing support team and then I got moved into the cafe which was an absolute nightmare and I had numerous meetings … I thought I'm not going to lose another job. I've lost so many jobs over 12 years of working. I've been disciplined so many times and I've took them to tribunals, and I've won every single time but I shouldn't have to keep doing that. It's not fair. It can be a bit crap out there. If you don't make it what it is if you don't stand up for what you know you're entitled to and what you should be getting, who else is going to listen to you? I make enough noise in Greenwich. No one listens to me but you know by coming to these meetings and being that older woman of nearly 46 still undiagnosed eventually I might be diagnosed before I earn a pension. It's not going to help me, it will help the other adults you know that are next in line that have gone under the radar because no one acknowledged it. It's unfair … it's just a bit crap and I would like to be diagnosed. I have every right to be diagnosed, just so I can say you know what I've done it, finally done, it's done. I can move on now. I can stay in this job until I retire."

174. With her permission an update was given on her recent experiences. In the time since the Parliamentary talk, she has been sent for various assessments, including at one of the country's top psychiatric hospitals, and was made to sit through an MRI that was extremely challenging and traumatic for her. None of the professionals, including some very eminent and experienced practitioners, felt confident in making an FASD diagnosis. (One more junior practitioner outright rejected the relevance of an FASD diagnosis, causing great distress).

> **Without a diagnosis it is hard at work because … they won't acknowledge the FASD. Until anything's concrete, their hands are tied. … I've lost so many jobs over 12 years of working. I've been disciplined so many times and I've took them to tribunals, and I've won every single time but I shouldn't have to keep doing that. It's not fair. …. I would like to be diagnosed. I have every right to be diagnosed, just so I can say you know what I've done it, finally done, it's done. I can move on now. I can stay in this job until I retire."**

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[3] Nyrene Cox is a member of the National FASD Adults/Young Adults with FASD Advisory Committee.

175. She eventually finally secured CCG funding to go to the National FASD Clinic where she was given an FASD diagnosis at the age of 48.

176. Participants heard an analysis of her situation from one of the practitioners involved (again, this was with her permission). For decades she had been bouncing around the NHS, while none of the practitioners involved took a multi-disciplinary view. She went to many clinics and all missed the FASD diagnosis as they didn't have the overview. "Complex cases, like this one, need a broader approach," said this participant. It was pointed out that a full FASD assessment revealed that she has real strengths and weaknesses. "It's easy to look only at her confident presentation and you don't see someone with problems. This is because her cognition isn't an issue, but her executive functioning is." She failed all tests with time pressure. Her expressive language was in the average range, but underneath that, "the understanding was not there". Abstract reasoning is a major challenge. Self-organising is a real problem. She needs lots of supports. Working in café with lots of decisions to be made quickly is something she just can't do. She needs a great deal of scaffolding and support. This had been missed multiple times by the NHS. She needed the full range of assessments of all domains to be understood to get the diagnosis. Hopefully, now she'll be able to use this to get the support she needs at work."

> **Complex cases, like this one, need a broader approach…It's easy to look only at Nyrene's confident presentation and you don't see someone with problems. This is because her cognition isn't an issue, but her executive functioning is…. She needed the full range of assessments of all domains to be understood to get the diagnosis. Hopefully, now she'll be able to use this to get the support she needs at work."**

Key points about FASD diagnosis

177. Next, participants received an overview of the key elements of SIGN 156 diagnosis. This was again presented via video.

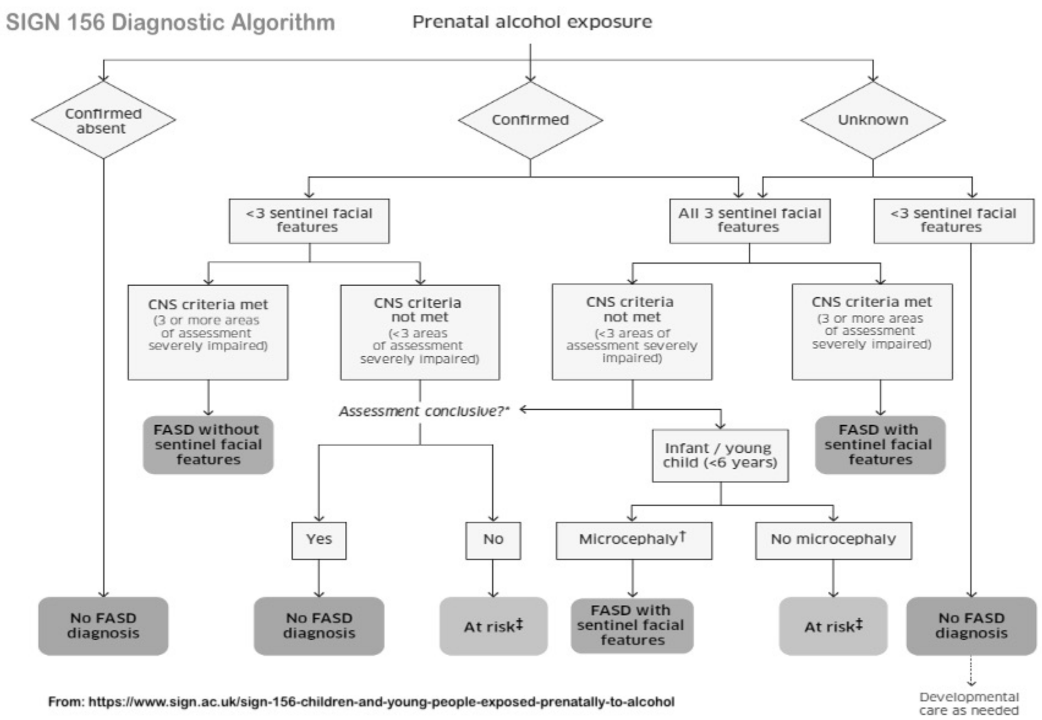
178. Three key elements are part of any FASD assessment:

    a. Alcohol exposure
        i. Confirmed
        ii. Confirmed Absent
        iii. Unknown
    b. Facial Features
    c. CNS areas of assessment or domains

179. The SIGN 156 diagnostic algorithm simplifies the possible outcomes to four diagnoses:

    a. FASD with sentinel facial features
    b. FASD without sentinel facial features
    c. At risk from neurodevelopmental delay related to prenatal alcohol exposure
    d. No FASD diagnosis (though still need a support plan)

> My response to people who say there is ‘no point in diagnosis’ is to ask if they would also refuse to diagnose Downs Syndrome and say there is no benefit. If they will make a Downs Syndrome diagnosis, FASD is just as important. It’s just that it is harder to diagnose... People are saying we won’t make the diagnosis because it is hard not because it is not important.”



From: https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol

Figure: SIGN 156 Diagnositic Algorithm

180. The SIGN 156 guideline is now effective throughout most of the UK (clarification is needed about Northern Ireland).

181. Benefits of using the SIGN 156 guideline include:

    a. It provides a standardised approach for clinicians. (Previously there were a possible 256 diagnostic codes and 22 categories. The DSM update is expected in March will include FASD as a neurobehavioural syndrome.)

    b. The terminology used now mirrors Canadian Guidelines, and those used in Australia, New Zealand and S. Africa (all Commonwealth countries)

    c. SIGN 156 will allow consistency in information gathering internationally, as data collection will be key to evidencing improved outcomes

    d. It enables evaluation of the post diagnosis benefits possible for this patient group especially educationally, and in relation to prevention of secondary mental health problems

    e. It identified the need for research in this area of work

182. FASD requires multidisciplinary assessment (further information is provided below about this point).

183. FASD is a whole-body diagnosis, and can affect the:

    a. Brain

    b. Central Nervous System, and

    c. Physical development

184. Key features of FASD include:

a. A ‘patchy’ cognitive profile with a ‘disorganised’ brain

b. The person needs 3 or more affected brain areas of assessment/domains indicating ‘severe impairment’ – which is defined as >2 standard deviations below the mean

c. There is a high variability from individual to individual

185. Since SIGN 156 has been adopted by NICE, it will be used generally across the UK. However, it should be noted, said one participant, that it is taken from Canadian guidance and not everyone agrees with that. There is an international consensus statement group trying to bring together international standards for the diagnostic process.

SIGN 156 now applies across Scotland, England, and Wales

“The diagnostic/ descriptive criteria for FASD are the same for adults as for younger individuals.”

“Prenatal alcohol exposure should be actively considered as a possible underlying cause for neurodevelopmental delay, or an unexplained departure from a typical developmental profile.”

Figure: SIGN 156 key quotes

Proof of prenatal alcohol exposure

186. The only time when FASD can’t be considered is when prenatal alcohol is confirmed absent. There doesn’t absolutely have to be a positive intake history to make the diagnosis. It’s possible a practitioner could still feel they had a circumstantial history, or they could put the patient into the ‘at risk’ of FASD group.

187. According to SIGN 156, confirmation of PAE requires documentation that the biological mother consumed alcohol during the index pregnancy based on:

    a. Reliable clinical observation

    b. Self-report or reports by a reliable source

    c. Medical records documenting positive blood alcohol concentrations, or

    d. Alcohol treatment or other social, legal or medical problems related to drinking during the pregnancy

188. As one practitioner highlighted, “Information about risk factors is needed and that comes down to system change and recording information per the coming NICE Quality Standard statement. Asking the question is key, as is taking a developmental history from pre- pregnancy not just post-birth.” Another person pointed out, “History of pre- and post- heavy drinking, with gap, unless pregnancy planned, is something to use in assessment.”

> **The only time when FASD can’t be considered is when prenatal alcohol is confirmed absent.**

189. Having advice and tools on how to do this will be key, as another participant highlighted, “Sharing of antenatal knowledge was identified as a challenge, particularly for children taken into care as mother’s alcohol intake is often recorded in her records and there is no set process in place to ensure they are routinely shared.”

190. Another practitioner said “Prenatal alcohol exposure evidence is probably one of the biggest hurdles for individuals to overcome. This is not restricted to those who are parenting care experienced individuals. I’m aware of biological parents who have not had their own declaration accepted as part of their child’s assessment for FASD.”

191. A screening tool to collect PAE history has been developed in Fife - the Fife Neurodevelopmental Questionnaire (FNDQ)[4] with extensive input from Scotland’s Fetal Alcohol Advisory Support and Training service.

   a. FNDQ is a 38-page history-taking tool for assessment done jointly with parents

   b. It is planned to be rolled out across Scotland

   c. It is used in CAMHS teams, community paediatrics, Speech and Language, epilepsy teams and it’s part of the Fife ND pathways

   d. There is a PDF digital form that can be typed into and they are exploring possibilities for making this an online tool

   e. The FND-Q normalises asking about alcohol use

      i. It emphasises that this is the parents’ information to disclose and the conversation needs to be based on trust

      ii. It provides a structure to ask questions in a sensitive way, understanding the broader context of birth mum’s experience

      iii. It also emphasises the positive actions – what birth mum did change rather than what she didn’t/couldn’t change

192. Someone pointed out that education and awareness about how to have these discussions is critical and practitioners and educators (who often are on the frontline) do not want to stigmatise and blame the birth mother and also often must overcome objections from social workers to raise these issues.

Who should be involved in FASD diagnosis?

193. SIGN 156 identifies the following team members across the lifespan:

   a. Neonatologist/ paediatrician/physician with competency in assessment of FASD

   b. Child development specialists with the skillset to conduct physical and functional assessments (e.g. speech and language therapist, occupational therapist, clinical psychologist, educational psychologist)

   c. Further individuals who can provide valuable input into the diagnostic process may include:

      - parents and carers
      - advocates
      - childcare workers
      - clinical geneticists
      - cultural interpreters
      - family therapists
      - general practitioners
      - learning support
      - mental health professionals
      - mentors
      - nurses (e.g. school, learning disability, etc)
      - neuropsychologists
      - probation officers
      - psychiatrists
      - social workers
      - substance misuse service staff
      - teachers
      - vocational counsellors

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[4] This was presented at the Collaborative FASD conference held virtually in February 2021, you can view the conference on the FASD Hub Scotland YouTube channel. The session starts at 1:41:00).

What tools are needed for an FASD assessment?

194. 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”:

    a. Motor skills
    b. Cognition
    c. Memory
    d. Neuroanatomy/ neurophysiology
    e. Academic achievement
    f. Language
    g. Attention
    h. Executive function, including impulse control and hyperactivity
    i. Affect regulation
    j. Adaptive behaviour, social skills or social communication

195. SIGN 156 states: “The diagnostic/ descriptive criteria for FASD are the same for adults as for younger individuals.”

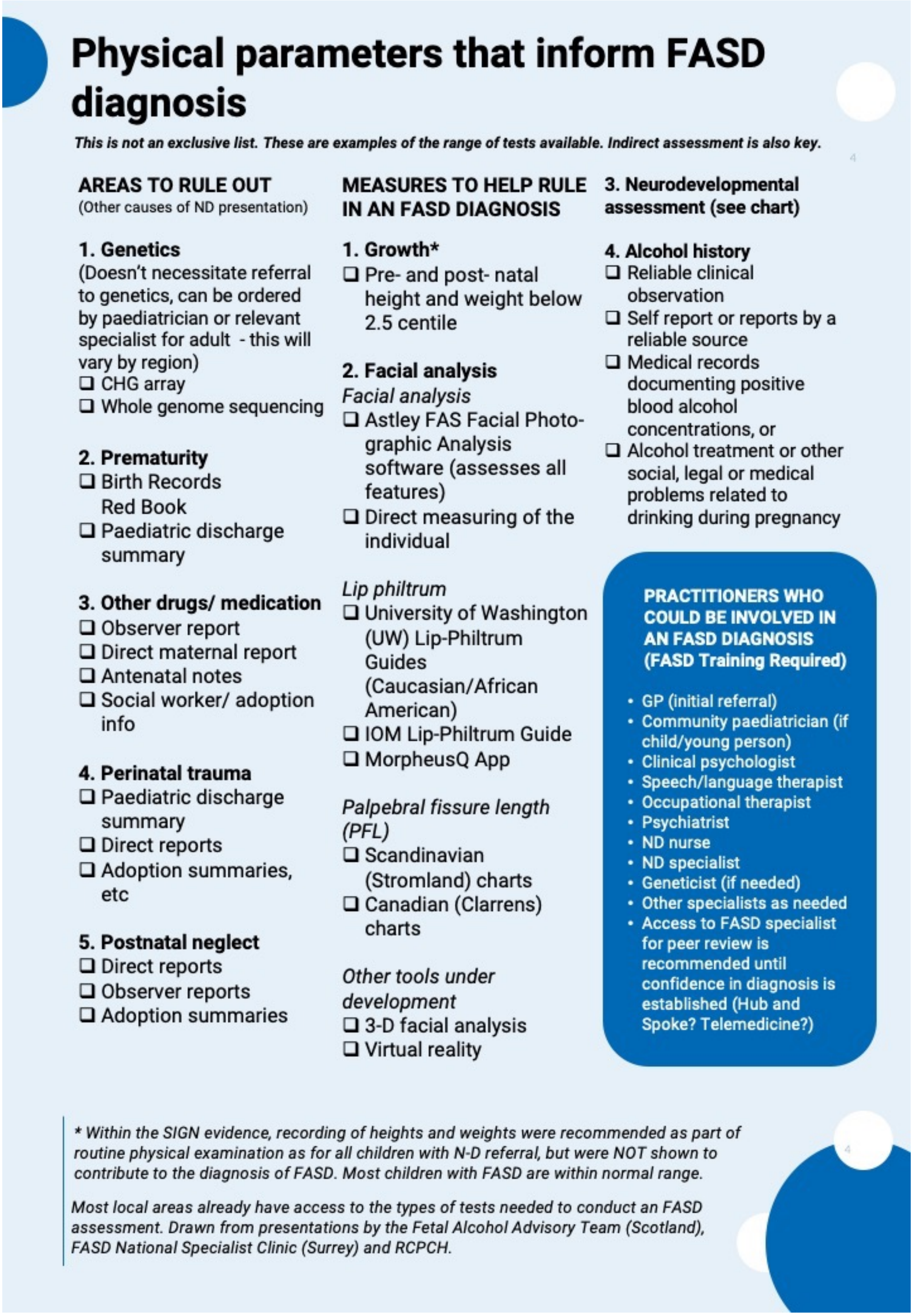
196. The aim is to get something that tests each of the domains if possible. Though not exhaustive, the included chart shows the various tests that can be used.

197. Many consider this need to do these neuropsychological assessments potentially problematic when thinking about ramping up FASD services. Challenges highlighted include:

    a. Neuropsychology is rarely available in child health services
    b. Families are being told that CAMHS do not have these tools as standard practice
    c. There is still stigma about the diagnosis, with some professionals saying they do not want to ‘label’ people with the diagnosis

198. One participant said that in Scotland, “The cognitive assessment of FASD seems to be putting some barriers in place for some families where CAMHs do not have these tools as standard practise in their service. Some areas have it together. Other areas have taken a step back and people have to wait 2 years+ as the tools aren’t available. People are being told that that’s OK, as then CAMHS will have the tools they need. [One person] has been told the tools don’t exist in her CAMHS, that the tools simply aren’t there as they wouldn’t normally be used. If an area is in special measures, it gets even worse.”

199. Another participant pointed out the sea-change this may require. “We are expecting in many places professionals who have had expertise for years in ASD and ADHD to suddenly become experts in FASD. The significant difference between diagnosis of ASD/ ADHD and FASD is the use of standardised assessment tools. I think this makes professionals uncomfortable. They appear to be not used to using them in level 3 CAMHs services, or certainly not those that are listed in the neurodevelopmental pathway, and maybe this feeds into the ‘labelling’ discourse we then hear parents reporting. There is still stigma associated with FASD. I’ve heard of one clinical psychologist say to a parent, ‘well if they do meet the criteria, we would have to consider carefully if we would tell them about this diagnosis as it could do more harm than good.’ The parent was very clear that there was no way they would not tell their child about an FASD diagnosis. They would only ever see a diagnosis as being a positive for them to understand themselves better, own their strengths and talents and embrace their challenges so together they could work on strategies that would support them to be successful. But when parents/ carers are faced with professionals who just do not ‘get’ FASD it is very difficult.”



Physical parameters that inform FASD diagnosis

This is not an exclusive list. These are examples of the range of tests available. Indirect assessment is also key.

AREAS TO RULE OUT
(Other causes of ND presentation)

1. Genetics
(Doesn't necessitate referral to genetics, can be ordered by paediatrician or relevant specialist for adult - this will vary by region)
- ☐ CHG array
- ☐ Whole genome sequencing

2. Prematurity
- ☐ Birth Records
  Red Book
- ☐ Paediatric discharge summary

3. Other drugs/ medication
- ☐ Observer report
- ☐ Direct maternal report
- ☐ Antenatal notes
- ☐ Social worker/ adoption info

4. Perinatal trauma
- ☐ Paediatric discharge summary
- ☐ Direct reports
- ☐ Adoption summaries, etc

5. Postnatal neglect
- ☐ Direct reports
- ☐ Observer reports
- ☐ Adoption summaries

MEASURES TO HELP RULE IN AN FASD DIAGNOSIS

1. Growth*
- ☐ Pre- and post- natal height and weight below 2.5 centile

2. Facial analysis

Facial analysis
- ☐ Astley FAS Facial Photographic Analysis software (assesses all features)
- ☐ Direct measuring of the individual

Lip philtrum
- ☐ University of Washington (UW) Lip-Philtrum Guides (Caucasian/African American)
- ☐ IOM Lip-Philtrum Guide
- ☐ MorpheusQ App

Palpebral fissure length (PFL)
- ☐ Scandinavian (Stromland) charts
- ☐ Canadian (Clarrens) charts

Other tools under development
- ☐ 3-D facial analysis
- ☐ Virtual reality

3. Neurodevelopmental assessment (see chart)

4. Alcohol history
- ☐ Reliable clinical observation
- ☐ Self report or reports by a reliable source
- ☐ Medical records documenting positive blood alcohol concentrations, or
- ☐ Alcohol treatment or other social, legal or medical problems related to drinking during pregnancy

PRACTITIONERS WHO COULD BE INVOLVED IN AN FASD DIAGNOSIS (FASD Training Required)

- GP (initial referral)
- Community paediatrician (if child/young person)
- Clinical psychologist
- Speech/language therapist
- Occupational therapist
- Psychiatrist
- ND nurse
- ND specialist
- Geneticist (if needed)
- Other specialists as needed
- Access to FASD specialist for peer review is recommended until confidence in diagnosis is established (Hub and Spoke? Telemedicine?)

** Within the SIGN evidence, recording of heights and weights were recommended as part of routine physical examination as for all children with N-D referral, but were NOT shown to contribute to the diagnosis of FASD. Most children with FASD are within normal range.*

Most local areas already have access to the types of tests needed to conduct an FASD assessment. Drawn from presentations by the Fetal Alcohol Advisory Team (Scotland), FASD National Specialist Clinic (Surrey) and RCPCH.

Figure: Physical parameters that inform FASD diagnosis

Example of tests used in FASD diagnosis neurodevelopmental assessment

Neuroanatomy/ neurophysiology
- ☐ Paediatric assessments
- ☐ Head circumference
- ☐ MRI (if clinically indicated)
- ☐ EEG (if clinically indicated)

Academic Achievement
- ☐ School reports
- ☐ WIAT (Wechsler Individual Achievement Test)

Sensory and motor
- ☐ Bruininks Oseretsky Test of Motor Proficiency (gross and fine motor)
- ☐ Movement ABC
- ☐ Beery Visual Motor Integration and Sensory Profile Measure
- ☐ Short Sensory Profile
- ☐ Sensory Processing Measure
- ☐ Adult and Child Sensory Profiles (W. Dunn)

Executive function, including impulse control, hyperactivity
- ☐ BADS (Behaviour Assessment of Dysexecutive Syndrome, Children)
- ☐ D-KEFS (Delis-Kaplan Executive Function System)
- ☐ BRIEF (Behaviour Rating Inventory of Executive Functioning)
- ☐ NEPSY-II

Memory
- ☐ Children's Memory Scale
- ☐ Rivermead Behavioural Memory Scale
- ☐ NEPSY-II
- ☐ Rey Complex Figure Test and Recognition Trial

Language
- ☐ CELF (Clinical Evaluation of Language Fundamentals – core, receptive, expressive)
- ☐ Communication Checklist for Children
- ☐ Communication Checklist for Adults

Cognition
- ☐ WISC (Weschler Intelligence Scale for Children)
- ☐ WAIS (Weschler Adult Intelligence Scale
- ☐ WPPSI (Weschler Preschool and Primary Scale of Intelligence)

Attention
- ☐ TEA-CH2 (Test of Everyday Attention Children)
- ☐ Delis-Kaplan Trail Making or Colour-Word Reference
- ☐ Conners Inattention Scale (Children and Adults)
- ☐ SDQ (Inattention Scale)
- ☐ Formal co-morbid ADHD diagnosis (indirect assessment)

Affect regulation
- ☐ Self Report Questionnaires (such as Child Depression Inventory)
- ☐ SDQ (Overall Score)
- ☐ Child Behaviour Checklist

Adaptive behaviour, social skills or social communication
- ☐ ABAS (Adaptive Behaviour Assessment System)
- ☐ The Social Language Development Test (Elementary and Adolescent)
- ☐ Vineland Adaptive Behaviour Scales-II
- ☐ Children's Communication Checklist
- ☐ SCQ (Social Communication Questionnaire)
- ☐ Formal co-morbid ASD diagnosis (indirect assessment)

Helpful for very young children
(multi-domain - motor, language, social skills and to some extent cognition)
- ☐ Griffiths Developmental Scales
- ☐ Bayleys Scales of Infant and Toddler Development

> ***This is not an exclusive list.***
> *These are examples of the range of tests that are available.*
> *Indirect assessment is also key.*
> *Most local areas already have access to the types of tests needed to conduct an FASD assessment.*
>
> *Drawn from presentations by the Fetal Alcohol Advisory Team (Scotland), National Clinic for FASD (Surrey) and RCPCH.*

Figure: Examples of tests used in FASD diagnosis neurodevelopmental assessment

Multidisciplinary teams versus multidisciplinary assessments

200. SIGN 156 calls for a multidisciplinary team: “Because of the complexity of the outcomes related to PAE, a multidisciplinary team is essential for an accurate and comprehensive assessment and subsequent management recommendations. The multidisciplinary assessment team can be local, central or virtual; satellite clinics and telemedicine may be used to meet the needs of referrals from remote and rural locations. The team will vary according to the specific context and the age of the individuals being assessed. The team members should possess the necessary expertise to conduct all aspects of the assessment and have updated knowledge about FASD. New members of the team must receive appropriate training.”

201. The public draft of the NICE Quality Standard (20 August 2020) available at the time of writing calls for “Evidence of local pathways that allow children and young people with probable prenatal alcohol exposure to be referred to a healthcare professional with expertise in FASD.” It calls for service providers to “establish multidisciplinary teams with expertise in FASD and have pathways for GPs to refer children and young people for assessment.” It also says: “Commissioners (such as clinical commissioning groups) commission services for the diagnosis of FASD that include neurodevelopmental assessments. Children and young people who are known to have had exposure to alcohol before birth or have all 3 facial features suggesting this have a more detailed assessment if there are concerns. People from different professional backgrounds may be involved in assessing their motor skills (movement), language, cognition (thinking and reasoning) and the ability to manage emotions.” This should be checked against the final version. But it is clear that NICE intends for commissioners to plan to improve the quality of care for people with FASD based on measurable indicators.

202. There are ways to balance the demands that arise. As one participant said, practitioners “need to be able to manage as far as possible as single or small team not always having access to full multidisciplinary team.”

203. One participant pointed out there is a difference between a “multidisciplinary team” and the a “multi-disciplinary assessment”. This point causes confusion and needs to be understood.

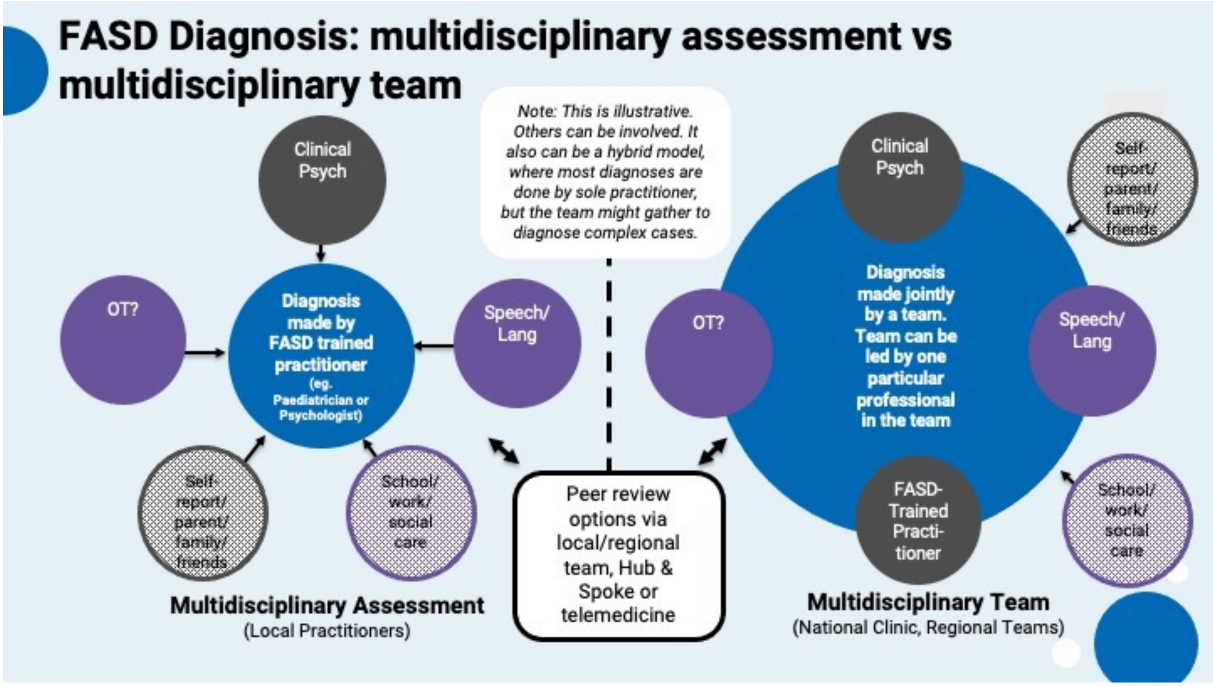


Figure: FASD diagnosis: multidisciplinary assessment vs multidisciplinary team

204. The National FASD Clinic, where all assessments are done face to face by one team is the gold standard. Most agree that this model should be used only for complex cases as it is not affordable for all nor even needed. Only the more complex group will need to go from indirect assessment to direct face to face.

205. To help with the demands on local services and to help with ramping up services more cohesively and rapidly, some have proposed a "Hub and Spoke" model that can help clinics needing guidance and support.[5] This is what is being done currently in Surrey and Kent. Elements of the Hub and Spoke model include:

   a. National clinic leads on FASD services, sees the most complex cases, provides clinical advice

   b. Regional clinics around the country diagnose more straightforward cases, perhaps provide peer review

   c. Local services manage most cases locally, escalating as needed.

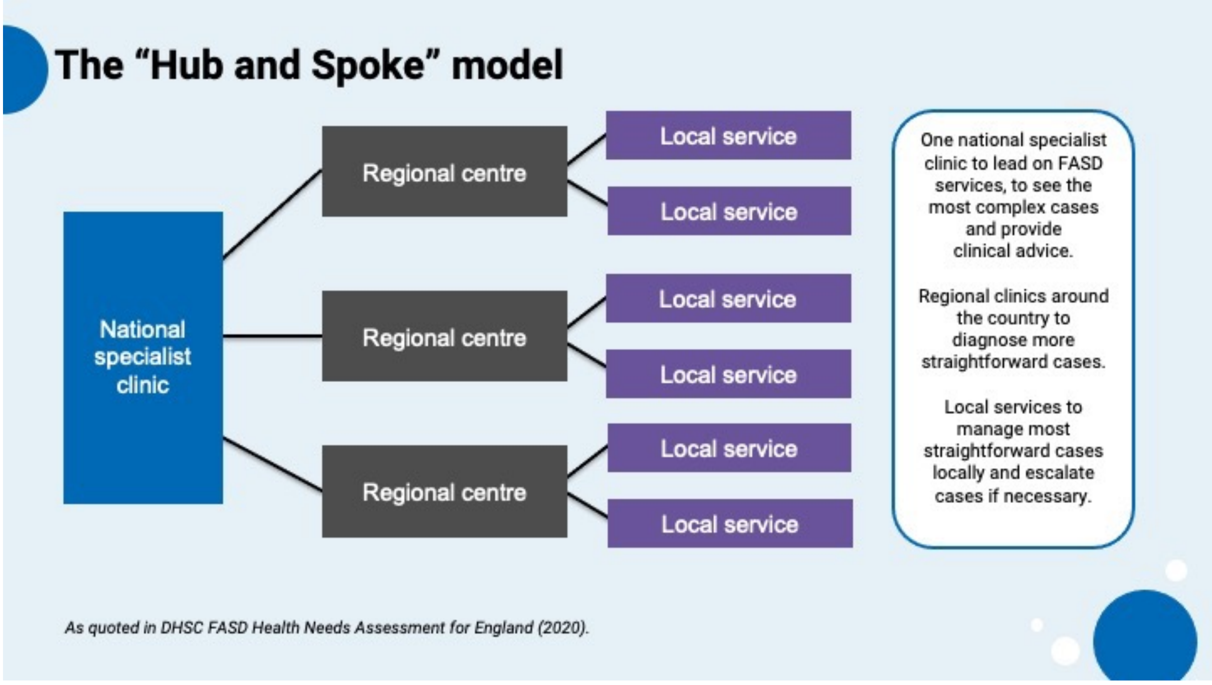


Figure: Hub and Spoke model

206. Others say that ramping up FASD diagnostic capacity does not need the Hub and Spoke Model. They say that it's possible to develop local and regional expertise, so long as there are peer review panels in place that can help build confidence of those new to diagnosis. There are areas such as the North East where this has been ongoing for many years.

207. A participant with lived experience said, "Having someone who can hold together the different assessments and has FASD knowledge is essential. Assessments by CAMHS units aren't working in a way or with access to tools that are identified as being needed. One person was told that that don't do executive functioning tests because they 'only do that for brain injury'. Parents have to chase information from specialist to specialist, doing subject access requests can be very hard. Input from school is very important. If not demanding help from CAMHS, then won't take parents seriously as they don't have 'triangulation'".

208. The next section will continue to explore issues related to pathways.

209. Other challenges with multidisciplinary teams include:

   a. Some question whether people need the full assessment.

   b. Some suggest stopping assessment when criteria have been met in three domains.

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[5] This is quoted in the DHSC FASD Health Needs Assessment for England (2020.) For more information, see Mukherjee R. Consensus Statement Regarding the Recognition and Diagnosis of Foetal Alcohol Spectrum Disorders Across the Lifespan in the UK: Development of proposed UK Clinical pathways. UK FASD Professionals Network Meeting; Oxford. 2013.

c. Others say if you don't test all areas, a diagnosis may be missed. Referring back to the example of the case study, Nyrene, if they had done only a cognitive assessment not including sensory assessment, then she would not have met the criteria.

d. Someone else noted, "The time to score is the pain, not the interpretation of the collated scores."

e. It also was noted that "multiple visits to hospitals, clinics, and different people can be extremely stressful for kids."

f. Some identified the capacity/ access to the clinical psychologists as a problem, which results in the executive functioning tests that are needed are not accessible. A question was raised, "How do we deal with that backlog?"

g. Who will coordinate this process? Some have queried if specialist nurses might be able to assist? For example: One participant noted: "One of the ideas from the FAAST project also was that a nurse practitioner with appropriate skills who collated all the pre-clinic information and sourced information about existing assessments that the child had had was a really good investment."

h. There can be a division and lack of communication between services.

i. "It can mean taking same developmental history multiple times. However, if rely on others' histories, don't know what they have asked. This can be a challenge for FASD if no one has asked about whether or not it was alcohol-exposed pregnancy."

j. "Everyone involved in the process has a clear structure to follow that must be multidisciplinary. We need to have something robust in place to allow mental health services and trusts to work alongside medical."

k. "One of the barriers is the 'tendency' for colleagues in psychology/ psychiatry to favour the psychosocial model and attribute presenting complaints to issues such as ACEs (Adverse Childhood Experiences), rather than taking extra time and trouble to carry out a full assessment, incorporating exploring the domains that need to be recognised as important."

l. Another participant said, "It has to be recognised that there are still many clinical colleagues both medical and psychiatry/ psychology who are not confident with FASD diagnosis or may still be sceptical of its existence."

m. While access to standardised assessments for the Central Nervous System and neurodevelopmental areas was flagged as an issue, one participant said, "More importantly, a pragmatic consideration for when other clinical judgements or indirect assessments may help contribute to diagnostic assessment."

n. "We need to go in very strong and very confident from the get-go about the myth surrounding the absolute need for facial features and diagnosis."

o. There needs to be a way to communicate more directly between provisions and professionals, this is especially important as pathway to assessment is messy and information gets lost or re-interpreted along the way.

p. Difficulties in children with multiple ACEs likely to be seen as psychological/ behavioural and not referred on.

Brighton experience

210. Brighton has taken steps over the years to increase diagnostic provision. Paediatricians found that patients were bouncing between CAMHS and them; people were coming in and out of the services. In Brighton they do have a clinical psychologist and an OT who are both interested. Practitioners did the University of Washington training on the 4-digit code. They thought about setting up a clinic but with no resources from commissioners that was not possible. Instead, they decided to assemble all assessments from different services (e.g. some had S&L, some Ed Psych, etc). They couldn't get all people into the room but could get the clinical psychologist to read the assessments and the paediatricians to look things over and do a multidisciplinary assessment from that model. (More about Brighton will be discussed in next section.)

Commissioning challenges call for creative approaches

211. While at first glance some think the changes required for a full FASD assessment model are too great, there are hidden costs that this can help prevent. As one person said, "It is difficult to know whether to go for gold or bronze, but actually many of the children are being over tested and re-referred because we aren't doing things in a good way in the first place." This leads to money 'wasted' in the system because of this.

212. Challenges highlighted include:

    a. "Services are really tight and the diagnosis process for FASD appears to be intensive. How do we square this?"

    b. In Scotland, one participant highlighted, it's proving challenging to get health board areas to "provide time and resources to allow assessments of referred children."

    c. One participant summarised the "the main challenge" in ramping up FASD services "is the massive increase in capacity for diagnosis that will be required - together with a lot of groundwork to raise professionals' awareness, develop training etc."

    d. In many cases the main barrier is getting people "through the door" in the first place - most people aren't aware of the huge prevalence of FASD and the traits are mistaken for other, more well-known neurodevelopmental conditions.

    e. Thorough assessment may be more difficult in younger children who all develop at their own pace, delaying diagnosis, and as the children get older we may not be able to find an accurate history of pre-natal alcohol exposure (or lack thereof).

    f. To ensure that both individuals & families receive the relevant information & support/to stop misdiagnosis.

    g. It's often not possible to get the full range of assessments because of the way things are commissioned. Working across trust boundaries is an obstacle. For example, in one area they lacked access to Speech and Language. The person couldn't do cooperative work as they are based in a different Trust. This can lead individual practitioners having to do a great deal on their own to make assessment possible without help or buy in from other services.

    h. One participant said, "This has to be resolved. We don't need a specialist service, we need to bring interested professionals together to do assessment. Ideally in one room, but if not then by sharing information. I can't diagnose without assessments to show the deficit."

    i. Making clear the process is important: "Parents/ carers contact us mostly about diagnosis and not knowing how to go about it, they also say GPs are not aware of the process."

    j. Other problems involve doctors dismissing the request asking why you want to label a child.

    k. "People have also said when on the ASD pathway they told the doctor that they drank and it was dismissed. When these difficulties arise a parent's only option it to either fund it themselves, try the Adoption Support Fund or often they go on another pathway ADHD/ ASD."

213. Someone asked if increased screening is an ambition and how would it be targeted? This would need some idea of size of at-risk population to target screening.

214. What can help:

   a. "NICE Quality Standards may give more leverage to demand investment in service development for FASD diagnosis and support."

   b. Adequate training in place to be able to build clinical teams who are empowered to make a diagnosis.

   c. Establishing local/ regional FASD special interest group or forum where professionals can meet to discuss difficult cases to support and empower local teams.

   d. Continuing work to make sure that FASD becomes embedded as a potential diagnosis in diagnostic pathways for neurodevelopmental and behavioural problems.

   e. "There needs to be a local offer for diagnosis. [Information on FASD is not on some local offers at all.] Families should not need to travel too far unless it is a complex case that needs to. The local offer should be supported by a regional/ area team who can give advice, while skills are developed, they can also then see more complicated cases. The regional/ area team should then be supported by the national clinic in the same way and only refer complex cases. This would make diagnosis more available, while building up skills. workforce development needs to be planned including teams that will be a part of the pathway."

   f. Parent/ carers/ adults should be signposted to support and information from the GP/ paediatrician when they first enquire.

   g. Outdated information also causes problems as many of our families have been told they cannot get a diagnosis as their child does not have FAS (now called FASD with sentinel facial features). Some information still only mentions FAS. (While welcomed, the NHS website only changed their webpage from Fetal Alcohol Syndrome to Fetal Alcohol Spectrum Disorder in March 2022).

   h. Often those with FASD struggle to access assessments as they as their difficulties are not seen by those that don't understand/ have no training.

   i. Availability of staff that that do assessments that are required is also an issue.

   j. Other pathways need to be also trained to understand FASD/ overlaps, so they don't miss comorbidities or leave a family with no support if they do not meet the criteria for a diagnosis of ADHD/ ASD.

   k. "Allay potential commissioning fears about opening a potential 'floodgate' of new diagnoses, by explaining that these children are almost certainly reaching attention "in the system" (educational or health) because of difficulties which have already been recognised, but they are almost certainly taking up additional resources because they have not received the correct diagnosis, and therefore the help and support which is best suited. This is inefficient as well as being unhelpful to individuals and families."

   l. Need for acknowledgment/ awareness of the issue at a senior within professional organisations (e.g. teaching, Royal Colleges, psychology, etc). This would support the development of professional training and awareness (a future roundtable will discuss training).

> **Allay potential commissioning fears about opening a potential 'floodgate' of new diagnoses by explaining that these children are almost certainly reaching attention 'in the system' (educational or health) because of difficulties which have already been recognised, but they are almost certainly taking up additional resources because they have not received the correct diagnosis...This is inefficient as well as being unhelpful to individuals and families."**

Need to avoid young people falling through the cracks

215. Meanwhile, it is critical to consider those areas where people might fall through the cracks. This includes:

    a. Getting services “to take ownership” of kids who are 15, 16, 17 and older.

    b. Implementing the statutory requirement for FASD to be considered in Looked After Children’s medical assessments. (One participant noted that when his daughter became an adult, they had to go for exceptional needs funding, even with her LAC experience. He said that “Even with babies there is a reticence to suggest that assessment is necessary, even where there is evidence.” He said, “Absence of evidence is taken by professionals as evidence of absence. That’s a serious lack. Even in child protection proceedings that happens.” This particularly relevant when considering whether or not the young person was exposed to alcohol in pregnancy.)

    c. Another parent said, “Kids who aren’t causing trouble in school won’t get the assessment as they are no one’s priority. The Adoption Support Fund is hard to access and some families are scared of getting some services involved.”

    d. Another participant said that it can be challenging to obtain “an objective and truthful assessment of behaviour and progress in school” as is ensuring “school support teams and educational psychologists are ready to accept and act on objective diagnostic data rather than being over reliant on observational assessment.” It was pointed out that “providing the necessary support and environment in school can be pivotal in promoting self-esteem/ reliance, social skills and educational outcomes.”

    e. “Social services need to include enquiry and documentation of pregnancy and pre-pregnancy lifestyles, and not assume that early childhood deprivation accounts for presenting behaviours and psychological profiles.

    f. Homeschoolers are often left out of the picture. We need to be sure there is a way to feed in their information, and to recognise that schools aren’t the only source of triangulation information.

    g. Some of the assessment tools are more difficult to use where there isn’t school input. This would apply to home schooling, but equally to those children and young people with FASD who cannot access education in a conventional setting as well as those young people and adults who are no longer in education, but in employment.

    h. A practitioner noted the importance of thinking about children at risk and said we are at risk of creating diagnostic group where nothing is done for them. This is especially problematic for kids in alcohol dependent families. This is a “real problem” as he has had to ask courts in some cases to order that information is added to records.

    i. It is important to ensure that adults with possible FASD are adequately supported throughout the diagnostic process so that they are able to access all materials, contribute to the assessment fully and understand the diagnosis. The process itself should not be designed to be so confusing they can’t participate.

216. One participant noted that there are often families with lived experience who can assist much earlier in the process. “Local FASD support groups could work alongside their local clinic offering information, support, advice, training, sign-posting & advocacy to provide families a knowledgeable base/ prevent them from seeking further medical referral where advice such as sleep clinics could suffice.”

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[6] See section 44, p. 17. The reference to “Fetal Alcohol Syndrome” needs to be updated to reflect SIGN 156. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/413368/Promoting_the_health_and_well-being_of_looked-after_children.pdf

SECTION 5: Pathways - options & possible unintended consequences

217. Roundtable 5 explored various ways in which pathways for diagnosis of FASD might be developed. Participants first heard about a pathway that was created due to perseverance of local practitioners without additional funding via a Child Development Centre. They then heard a presentation about the “Hub and Spoke” model in which local areas could rely on a regional centre and a national clinic to support them. The pros and cons of using a new or existing neurodevelopmental pathway for FASD diagnosis were discussed. Areas of concern were explored, including: access to clinical psychologists, how to ensure the very young and those over 18 are not missed in planning, and importantly the impact on the lives of those with lived experience was highlighted, since even in an area such as Scotland where on paper things appear to be in place, expected changes following guidance are not trickling through to families as of yet.

Overview

218. A diagnostic pathway outlines the route that leads from a patient presenting their symptoms to a clinician to receiving a diagnosis.

219. For FASD diagnosis, there are various ways pathways can evolve and this document outlines some of the considerations without any attempt to achieve consensus on which is best. As one participant said, “Any pathway must be achievable in a local area - they do not all have to look the same.” They also can start one way and evolve over time as the local area experience and expertise develops and funding is made available.

220. As one person said, “Pathways have to be workable and realistic. Pathways have to hold at the centre the needs of those they aim to serve (the patient and their parent/ carer). They are not there as a bureaucratic tool. Pathways should be based on equality for all. Pathways have to accommodate the needs of those with neurodevelopmental disabilities. This becomes especially important when moving into adulthood and individuals may not have as many supporters around them to help scaffold appointments, transitions, responding to requests etc. The end user is often the last person to be considered. In the same way as support groups for those with learning disabilities and Autism have been engaged in developing services, support groups and those with lived experience must be included in developing pathways and services for those with prenatal alcohol exposure/ FASD.”

> **Every delay is such a long time in the life of someone with FASD especially if supports are not yet in place.”**

221. The pathways need to be efficient and timely to take into account the needs of those being assessed. One person said, “It’s so common to hear from carers during training that they are just being sent from pillar to post causing huge stress and getting nowhere fast. Another parent said, “Every delay is such a long time in the life of someone with FASD especially if supports are not yet in place.”

222. Following are examples of pathways to illustrate this point. The examples given are not the only options. More consideration could be done on a national level to help local areas ramp up FASD diagnostic services by providing examples of best practice.

223. Some have suggested pilots might be funded through “cost to save” model of investment by the NHS.

Brighton FASD Clinical Pathway

224. Participants received a presentation about the clinical pathway in Brighton and Hove. This was presented as an example of what is possible even in an area where no funding has been made available yet for FASD diagnosis.

225. Some working in adoption and fostering were aware of the need to improve services for those prenatally exposed to alcohol. They came up with a clinical pathway which one participant said, “is not perfect but improves things for children within our catchment area”. They are working to further expand upon this and hope the coming NICE Quality Standard may help with further improving local services.

226. Their pathway involves the Child Development Centre which includes a multi-disciplinary team with occupational therapists, clinical psychologists, paediatricians, and speech and language therapists (who are from outside the Child Development Centre). That said, it was noted that not all areas have access to such a team.

227. Patients come through a general referral pathway. Prenatal alcohol exposure might be known, but might not. This underscores the importance of having all paediatricians aware of the risk. From the start the local team knew that not all referrers would be aware of the risks, so they also have done training and awareness work locally.

228. Referrals come from social workers, health visitors, SENCOs health workers, school nurses.

229. If a child has been looked after or adopted, then there might be more information. If adopted in Brighton and Hove they would have a permanence report which hopefully would mention prenatal alcohol exposure. PAE might be known before or it might only come up at initial development assessment by the clinician.

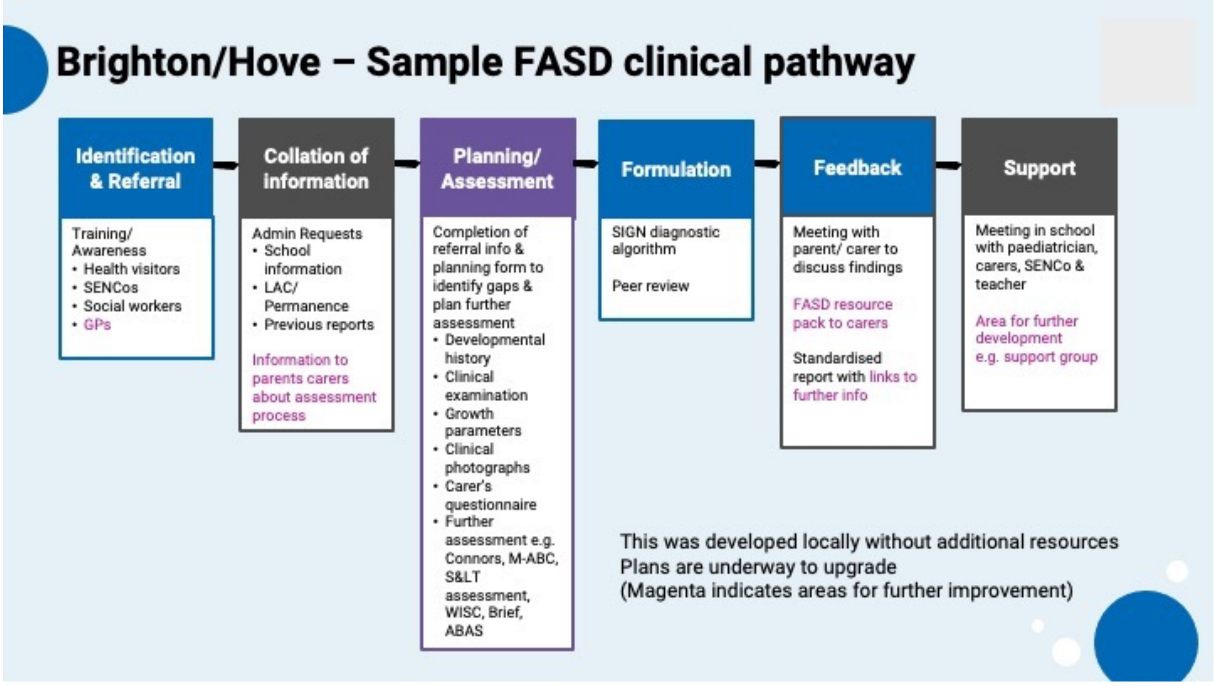
230. There is a school referral form which is not specific for FASD, that is used for all referred children. It has sections looking at different areas of development and gets as much information as possible from the school before a clinician sees them.

231. They ask parent/ carer what assessments have already been done. For example, they might have been to CAMHS and had some assessments done. They then plan whatever assessments are still needed. There may be a gap that have to refer out for, e.g. speech and language assessment. They wait until all info is available then go through the SIGN 156 diagnostic algorithm.

232. Then they feed back to parent/ carers. They provide an FASD information pack. They have a standardised report especially with links to further info. (Some of these items need updating.)

233. While they used to go into the schools following the diagnosis, they can no longer do this because of capacity but send full information to schools. Online meeting with SENCOs is easier.

234. They currently have no pos-diagnosis support available locally, but have been talking with parents who are developing a local FASD support group.



Brighton/Hove – Sample FASD clinical pathway

Identification & Referral

Training/ Awareness
- Health visitors
- SENCos
- Social workers
- GPs

Collation of information

Admin Requests
- School information
- LAC/ Permanence
- Previous reports

Information to parents carers about assessment process

Planning/ Assessment

Completion of referral info & planning form to identify gaps & plan further assessment
- Developmental history
- Clinical examination
- Growth parameters
- Clinical photographs
- Carer's questionnaire
- Further assessment e.g. Connors, M-ABC, S&LT assessment, WISC, Brief, ABAS

Formulation

SIGN diagnostic algorithm

Peer review

Feedback

Meeting with parent/ carer to discuss findings

FASD resource pack to carers

Standardised report with links to further info

Support

Meeting in school with paediatrician, carers, SENCo & teacher

Area for further development e.g. support group

This was developed locally without additional resources
Plans are underway to upgrade
(Magenta indicates areas for further improvement)

Figure: Brighton and Hove pathway

Hub and Spoke model

235. Participants then heard a presentation about the "Hub and Spoke" model – a way to structure services so that there is regional and national support available for local services.

236. The Hub and Spoke model of service delivery already exists in many other parts of the NHS (an example was given for urology). The concept mixes local support with expertise and resources to help supplement local services. One participant said, "Hub and Spoke works well for paediatric epilepsy in my experience and seems to me a sensible model."

237. The preference is for people to be seen locally where possible. But when people start a local pathway on an unfamiliar area such as FASD, they need help, support, advice and guidance. The National Clinic has 20 years' experience and tremendous resources in the multi-disciplinary team which most areas don't have yet.

238. The Hub and Spoke model would link local services to regional ones with more experience and resources. Regional centres through supervision of local services gatekeep which cases need access to more complex assessment at a regional level.

239. Regions needs to be defined and may change as demand increases. For example, the National Clinic also currently serves as a regional centre for the region including Kent and Surrey. It may eventually need to be just Surrey if demand increases. Demand isn't there now but may evolve as more and more become aware of FASD. Training has been done with clinicians before they start work to get a certain level of expertise. Then, they are given a resource pack and information on what to collate.

240. With this model, some cases will stay local, others will be regional and if established more widely, some other complex cases will go to the National Clinic. Those that stay local will have access to management and support people regionally and/or nationally as needed.

241. When asked what defines a "complex case" a practitioner replied, "That's where supervision comes in. The type of thing we would look for, you need to have more resources, where the information gathered from tools available in a local setting, where you lack information from parents, where there are lots of comorbidities going on drugs, alcohol, genetics etc, where you need more assessments, where everything has to be pulled apart, that's a complex case. It's hard to define specifically, but it is clear from the full presentation. Where PAE is known, information is available, then you stay local, get support locally. That is better for the individual and the family."

242. Even in areas where the Hub and Spoke systems are set up, there is still a challenge accessing services. As one participant with lived experience said, "This is sadly the case in Surrey too. Even though we have the Surrey and Borders, in local CAMHS parents are told FASD is not covered."

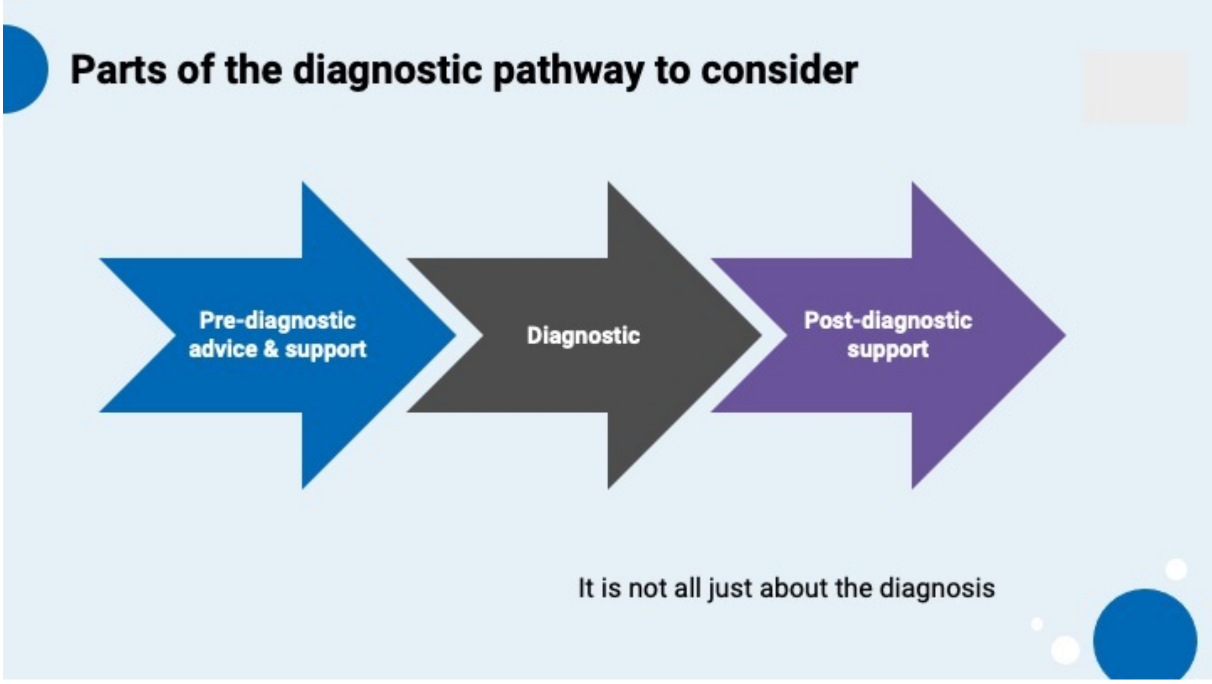
Pre- and post- diagnostic pathways are important too

243. It's important to note that the diagnosis is just one part of the pathway. Pre-diagnosis advice and support is needed. In Surrey there is a small local training course and they also recommend the Seashell/ National FASD courses.

244. One parent noted, "Providing support and strategies pre-diagnosis would have been so important for us, but it wasn't available."

245. Post-diagnostic support requires more attention. The NICE Quality Standard calls for a care management plan so post-diagnostic support will need to be considered more thoroughly moving forward.

246. For example, a parenting course is under development with the University of Salford. The Salford Parents and carers Education Course for Improvements in FASD outcomes In Children (SPECIFIC) is a 2-hour by 7-week training programme to teach caregivers about the FASD brain, sensory processing, self-regulation, communication, language, abstract reasoning, routine, and social relationships. It teaches a brain-based perspective with a focus on practical strategies for fostering an environment where a child with FASD can achieve their potential. The goal is for people to have access to that nationally.



Parts of the diagnostic pathway to consider

Pre-diagnostic advice & support

Diagnostic

Post-diagnostic support

It is not all just about the diagnosis

Figure: Parts of the FASD diagnostic pathway to consider

Scottish lived experience using the new neurodevelopmental pathway

247. Scottish lived experience shows the needs of those with FASD are still unmet, even where policy is ahead of other areas. Lessons from Scotland can help inform commissioners and others who are considering ramping up FASD services in other parts of the UK.

248. As noted previously, Scotland in many ways is years ahead of and leading the rest of the UK when it comes to FASD. They have made significant developments based on years of work that has gone into these developments:

    a. SIGN 156 was released in 2019 after a multi-year process gathering evidence.

    b. The Fetal Alcohol Advisory Support and Training Team (FAAST) is funded by the Scottish Government with a national remit. It provides and facilitates training, consultation and research to “enhance the capacity, knowledge and confidence of Scotland’s health and social care workforce in their work with those affected by FASD.”

    c. FASD Hub Scotland (funded by the Scottish Government) provide a tiered support service for parents/carers (adoptive and biological parents, foster carers, kinship carers and step parents) across Scotland who live with children, young people and young adults who have a history of prenatal alcohol exposure (PAE), with or without an FASD diagnosis. The service extends to provide a point of reference and training for professionals who work with and support these families (social work, education and other Third Sector organisations/charities) within Scotland. The support model enables information, advice, support, training, resources, and signposting to be provided through a variety of direct and indirect contact points. One of the core features of the model is one-to-one peer support provided by paid staff – parent partners – who come alongside families to provide support, guidance, information and signposting focused on the specific needs of the individual family, for a period up to six months. The one-to-one Family Support is managed through a robust case management system, overseen by a clinical psychologist and project managers which allows for further enhanced therapeutic interventions to meet the needs of individual families.

    d. There also is an FASD E-Learning Tool led by clinical experts and educational experts. This has been modified specifically for GPs in Scotland for a GP E-Learning FASD module (accessed through RCGP).

   e. Their new "Children's Neurodevelopmental Pathway Practice Framework" guidance (2021) says: "There is now greater recognition of FASD and rather than start a new pathway, it makes more sense for this to be considered as part of existing or new neurodevelopmental pathways."

249. While all acknowledged this focus in Scotland is welcome, participants heard a presentation based on feedback provided to the FASD Hub Scotland. This feedback indicates that many families in Scotland are still struggling to access diagnosis and support.

250. Families report inconsistency across the country in relation to:

   a. Timescales

   b. Assessment teams

   c. Assessment tools

   d. Considering FASD alongside other neurodevelopmental conditions

   e. Prenatal alcohol exposure history

   f. FASD assessment criteria are still not understood

   g. As difficult as the process is for children and young people, it is much more challenging for adults

251. One participant said in Scotland they are "yet to see the outcomes of the ND pathway guidance."

252. Another participant noted that SIGN 156 is guidance whereas the NICE Quality Standard will be something against which Trusts can be judged. In Scotland it's left to individual Health Boards to decide how or whether to follow guidance and no funding is given to support that. "Scotland is in a much better place than the rest of the UK but guidelines without compulsion compete for all sorts of resources."

253. Another practitioner noted that in other parts of the UK, "The NICE Quality Standard will help as commissioners will have to take notice."

254. On the positive side, there are further steps happening that lead to hope for further progress in Scotland:

   a. They are now building a national steering group and reference group

   b. There is increased awareness about FASD across health, education, social work and criminal justice (training has been provided to more than 2000 people)

   c. FASD support services are being developed, along with a national support network

   d. Research is taking place in Scotland

   e. Profession networking is increasing

   f. QNIS has launched the "Healthier Pregnancies, Better Lives Programme" focussed on prevention

   g. Growing focus within health boards to include FASD in workstreams and ND pathways are being developed

255. Someone said, "There have been two Parliamentary debates in Scotland on FASD and it hasn't made a huge difference but is a step in the right direction. People have heard about FASD… but like climate change, hearing about it doesn't create action."

256. In Scotland it was pointed out that there are still areas where policy needs to be joined up. "There's a disconnect between Scotland's neurological framework and action plan which excludes children and young people, largely excludes prevention, and largely excludes anything ND – and the development of a Scottish ND pathway. These two haven't been reconciled but it'll be happier day when they are."

257. Recurring themes that cause concern are being reported in Scotland from parents/carers, in particular with relation to CAMHS:

   a. For example, one family went to the paediatrician with a young child whose symptoms looked like Autism but PAE was confirmed present. The paediatrician didn't know whether it was Autism or FASD, so sent the child to CAMHS who dismissed them and said come back when they have "real problems". The family has had struggles. The FASD Hub Scotland has worked with them to think about the neurobehavioural approach and provided strategies and helped them to scaffold their child. They now have a different paediatrician who has had FAAST training. Everyone agrees prenatal alcohol exposure is present and probably the diagnosis is FASD. However, they are now on a 3-4 year waiting list for CAMHS to get all the assessments needed. The child will be 11 before being assessed, after the first referral at age 4.

b. There are reports that CAMHS aren't doing the full range of assessments necessary. Many in CAMHS still don't understand FASD. One family were told their child "couldn't have executive functioning tests as only kids with brain damage can get that". This showed they did not understand that FASD is caused by organic brain damage.

c. There are Inconsistent access to assessments and wait times for assessments. An OT might do basic work but might not understand sensory integration.

d. They often see FASD considered only as a last resort, not alongside other conditions, and prenatal alcohol exposure is overlooked.

258. The lived experience presented from Scotland is similar in other parts of the UK. One participant noted the referral letters and background information seen in the National FASD Clinic in Surrey are full of similar examples.

259. Someone pointed out, "On a more hopeful note, there are also paediatric and CAHMS colleagues who are increasingly recognising and referring for FASD (often with a lot of input from parents to guide but also sometimes professionals are aware and have informed themselves about FASD)."

Which type of pathway?

260. There are at least three options for creating pathways:

a. Adding on FASD to an existing neurodevelopmental pathway (this has challenges of its own given the lack of FASD understanding and the long waitlists).

b. Creating a new neurodevelopmental pathway that includes FASD (some say this might be easier). One commissioner said, "We do not have a pathway that includes FASD currently but there are discussions taking place to create new ND pathways and I feel following discussions today that FASD should be included at the start – I will be going back to the lead to see if this can be considered now."

c. Others say things move faster when there is no neurodevelopmental pathway to follow, leaving the diagnosis for children and young people with paediatricians via an FASD-specific pathway.

Why a neurodevelopmental pathway?

261. Some have long said that this FASD diagnosis works best when it fits into a pathway that neurodevelopmental practitioners understand.

262. One clinician noted the importance of looking at the whole child, "I think that for children, it makes sense that there is a holistic initial appointment before more targeted assessments happen (to look into all possible causes for the developmental problems and plan appropriate support). In our area all children referred into the Child Development Centre are offered an initial developmental assessment whatever the presentation and following that more targeted assessment is planned."

263. Another practitioner noted FASD should be integrated into neurodevelopmental pathways only "with a clear guideline for what additional assessments would be needed for children with suspected FASD - in addition to what is available for ASD and ADHD."

264. As one practitioner said, "That's what I do, when not working with FASD. I work with ADHD and Autism. If you understand wider neurodevelopmental presentations, you can understand how this fits into that context, the principles are the same."

265. However, as one person with lived experience said, "Adding to ND pathway is only great if the pathway is great."

266. Someone else noted, “I think it’s important that we don’t get competitive with other diagnostic ND disorders. We need better funding for all, but recognition that we are way behind with recognising those with FASD.”

> **Adding to the neurodevelopmental pathway is only great if the pathway is great.”**

267. Having FASD included in the ND pathway might support getting social care agencies (especially adoption and fostering) on board.

268. Someone advised, “Don’t try and fit a new ND pathway into what you already have. Include all areas - health, education, criminal justice and social care so you are truly supporting the individual throughout their life. Include Third Sector organisations who will be able to provide the peer support, including support before and after a diagnosis, and parenting strategies. Work alongside the professionals. Have those with lived experience key to forming the pathways. They are the ones who are experiencing the pathway. Do with, not do to! Make sure the pathway is focused on the full lifespan - adult services must be included.”

Examples of areas with FASD in the ND pathway

269. As mentioned, Scotland has developed a new national neurodevelopmental pathway. As one participant said, in Scotland, the hope was that the ND pathway would give a totally new approach to:

    a. See what the child’s strengths and weaknesses are

    b. Explore what their challenges are

    c. Then out of that, the diagnosis would follow

270. With the Scottish model, “The diagnosis (FASD, ADHD, etc) is secondary to getting a really good idea about the child…The Scottish national pathway is to establish what are the issues for the child and their family, not just get a diagnosis. Getting people to work that way is totally different. We’re only six months in, we have to keep pushing.”

> **It’s important that we don’t get competitive with other diagnostic neurodevelopmental disorders. We need better funding for all, but recognition that we are way behind with recognising those with FASD.”**

271. To aid this the Fife Neurodevelopmental Questionnaire (FNDQ) under development looks at gathering information about the child in a consistent way and then work towards a diagnosis. “When you first see it people think it will take a long time to go through, but then find a lot of information already exists.”

272. Someone else noted that in Scotland the issue has been that “diagnosis and assessment process stops at first diagnosis. The issue is that someone with one ND condition is likely to have more than one [co-existing condition]. Must recognise conditions are all possibilities and need to reduce sub-surface fighting between single condition groups. In Scotland, after April, responsibility for FASD moves from children and families government section to ND conditions, this will help with adults with FASD.”

273. A parent commented that this stopping at first diagnosis also happens in England. “For our son whose first diagnosis was ADHD, followed by ASD a couple of years later, followed by FASD years after that, this broad assessment at first would have been very important. It would have speeded things up and saved a great deal of anguish and trauma for our son who was not appropriately supported in school and at home until the FASD diagnosis was made, giving us the missing part of the puzzle, an understanding of his underlying lifelong organic brain damage.”

274. The Northeast and North Cumbria ICS mental health work stream have fully adopted FASD on a neurodevelopmental pathway to galvanise system development.

275. In Derbyshire work is underway to include FASD as part of ND pathway. ICS have “bolted FASD on” after the ND pathway (following death inquiry of a young adult with FASD).

276. In Kent a system partnership group has been set up including a variety of leading professionals that have a connection with neurodisability and FASD. These are focussing on prevention, comms and engagement, and workforce mapping and training programs. This is to support the Hub and Spoke model connected with the National FASD Clinic.

277. The Kent and Surrey pathways are both embedded into neurodevelopmental pathways but they are newly established pathways that look broadly at ND and FASD is part of that. Someone noted, “It can be harder to put in where there are already established separate ADHD and ASD pathways not a ND pathway.”

278. In Kent and Surrey, “We are getting away from the idea that ND is only about one thing or another. We know that FASD and ADHD overlap. We know etiological disorders are there. It can be a bit of Tourette’s, a bit of epilepsy, all things that fit together instead of thinking about narrow single pathway approaches. Children’s services are starting to set up pathways around that.”

279. Many other areas are beginning work on this and would be aided by national joined-up thinking on how to ramp up services to be able to begin to tackle the priorities identified in the DHSC FASD Health Needs Assessment, to implement SIGN 156 guidance, address the areas for improving the quality of care identified in the NICE Quality Standard on FASD.

280. Someone noted, “Regardless of the pathway, you need professionals within the system in the who understand FASD and professionals who are leading, championing and responsible for the training of other professionals. You need a named individual who is responsible for the final ND assessment/diagnosis outcome - whatever that might be. You need a professional with an expertise in FASD diagnosis who is involved from the triage stage. You need agreement between paeds and CAMHs in respect of who has responsibility, but also that when paeds make a request for neurodevelopmental assessments to feed into a potential FASD diagnosis or anything else they will do this, and not just see a child presentation as not ASD, not ADHD, not LD, because that is what they are ‘used to seeing’ and therefore reject with limited assessment and not provide the detailed reporting against >2SD (spikey profile) which would demonstrate an FASD profile. The problem is the paediatrics and CAMHs clinicians do not work for the same employers, same budget holders and to the same objectives. One cannot ask the other to do work. The ND pathway risks the above requirements being missed. The Hub and Spoke model looks like a much better way of doing things, even if this is the starting point with the objective of over time smoothing out to only the very complex cases being seen in the Hub. I believe this was the model that was originally used in Scotland for Autism many years ago. Now ASD is embedded within all local services. There has to be recognition of clinical reluctance to diagnose and people not feeling confident. Alongside still lots of misunderstanding, misconceptions and misinformation.”

Cons of neurodevelopmental pathways

281. Multiple practitioners highlight concerns that in a neurodevelopmental pathway “diagnoses stop at first diagnosis” which is a problem as FASD is “all about co-occurring disorders”. Comments included:
    a. If ADHD is diagnosed, then practitioners don’t look further
    b. Conversely, if referred for ADHD, some don’t quite make the criteria so get discharged
    c. “Equally, if a practitioner is of the mind that it is Autism, then that is the path you will be sent.” One parent whose child was first given an ASD diagnosis said, “I feel the Autism pathway…does not cater for the neuro differences. This is the gap that needs closing”

d. The problem is that people proceed based on first diagnosis and almost never proceed to a FASD diagnosis

e. For those with FASD, the "broad brush approach associated with a neurodevelopment pathway inserts a risk of being diverted into an alternative diagnosis creating delay and worsening long term outcomes"

f. "Discharge is popular when people can't look at the bigger/ whole picture"

282. "I believe the pathway should be separate as existing professionals and pathways are not used to making FASD diagnosis. This leads to misdiagnosis or possibly favouring towards particular diagnosis such as ASD. Some 'old school' clinicians are reluctant to change their current beliefs/ ways of working/ clinics."

283. Neurodevelopmental experts are not all trained in FASD nor understand some of the basics. One family said, "Our boys had full facial features but FASD was still not diagnosed at Great Ormond Street Hospital 6 years ago; facial features are not always considered." This was backed up by another family whose child went to GOSH and was told FASD was ruled out when it later was determined at the National FASD Clinic that their son also had full facial features. The misunderstanding led to delays of years for these families in getting their children into the right schools and putting in place the right supports at home, with a major impact on the lives of the young people and their families.

284. Someone else noted, "The best forum in Scotland has been the multiagency work in developing a national pathway for assessment of those with any neurodevelopmental issue. It has prompted the discussion about how health professionals share skills to contribute to assessment processes. Unfortunately, flexible budgets to support this collaborative cross department working have been more difficult to negotiate."

285. Someone else noted, "In many ways this is a 'false' issue: it's not either/ or - it's both! FASD does HAVE to be part of the diagnostic consideration for any child who presents with neurodevelopmental or neurobehavioural problems. However there also needs to be a distinct FASD pathway which outlines the process once FASD is being considered as a possibility, or if that is the primary question - just as there is for ASD, for example."

Waitlists and funding are interlinked

286. In areas where paediatricians are diagnosing outside neurodevelopmental pathways, the wait times are much shorter than where people with possible FASD are being added at the end of the neurodevelopmental waitlists which can often be quite long. "FASD diagnosis in some instances is faster than an ADHD or ASD as the others go down the commissioned neurodevelopmental pathway that has 2 year waiting lists. FASD goes through the paediatric pathway so diagnosis can be done in 2 visits or 6 months if all the assessments have been available for the paediatrician to use."

287. Another practitioner said, "ASD and ADHD now have such enormous waitlists that the NHSE are keen to shorten the process so adding in sorting out comorbidity is going to be a challenge."

288. Delays can follow while waiting for development of new ND pathways. "Implementing the neurodevelopmental pathway on the ground in some areas [in Scotland] has been to make the diagnosis process of FASD more complicated. In one are we have anecdotical evidence from families that there has been a step backwards with services almost being halted while people are waiting for the pathway to be implemented. Waiting times for CAMHs services and COVID has also played into this."

289. Another participant said, "Families all across the UK are in crisis. Waitlists, if they are lucky enough to get on them, are too long. This is made worse by the announcement of the April 2022 closure of the Centre for FASD. The timelines are too long. Families and their loved ones are in crisis. It's devastating to families to hear there will be a three or four year wait while their child is spiralling and not appropriately supported in school, college and/ or work."

Funding is a distinct question from the ND pathway waitlists

290. Participants were cautioned not to let the neurodevelopmental pathways waitlist get confused with bureaucratic issues, such as funding, which can and need to be sorted.

291. Someone said, "Funding needs to follow creation of the pathway."

292. Another person said, "Rolling out neurodevelopmental pathways is going to be problematic, because from my knowledge and experience although there are suggested frameworks that clearly include FASD there is not additional funding and resources being provided (this certainly is the case in Scotland) and therefore services are being asked to squeeze and restructure already over-stretched services. I'm sure with time and space it would be possible for services to restructure and successful create multi-disciplinary teams. I think where we are seeing things work well is in the smaller geographical areas or lesser populated areas. In the larger inner-city areas or larger geographical areas where visiting clinicians may only be present every 8 weeks it is a greater challenge."

> **In our area there are 7,000 people on neurodevelopmental waiting lists. Some have been waiting 5 years. It's not about the pathway being wrong, it's a different discussion. It's about undercommissioning and under resourcing. It's about Commissioners saying we'll give you £100,000 when you need £1m. That's what happens. You ask for a number, you get one tenth and that causes long waits."**

293. "Waiting times are as much to do with under-resourcing and should not in itself say what is the right approach. I get the pragmatic reason to be soon but there should also be something about people funding and seeing the importance of ND pathways generally."

294. One practitioner said that "In our area there are 7,000 people on neurodevelopmental waiting lists. Some have been waiting 5 years. It's not about the pathway being wrong, it's a different discussion, it's about under-commissioning and under resourcing. It's about commissioners saying we'll give you £100,000 when you need £1m. That's what happens. You ask for a number, you get one tenth and that causes long waits."

295. Another participant said, "With FASD, we're at a point before things have been commissioned so now's the time to make sure this is funded properly. This will in the long-term lead to saving money. Let's not forget that point. It's also the right thing to do to help some of the most vulnerable members of our society."

296. Someone pointed out it would be helpful if there was a cost established for taking people through the whole FASD diagnostic process. "If we don't know how much it costs it is hard to talk with commissioners about specific contracting."

297. One researcher said, "We did some work exploring existing neurodevelopmental pathways a while back, in practice they were all 'Autism and ADHD' which is frustrating - again this was often down to funding and commissioning, the team had to create this minimum pathway to prove it's feasible/more effective before being allowed to expand."

If starting to diagnose without an ND pathway

298. One practitioner advised, "If starting from new - ensure capacity for numbers. You may have to start small but have scope to increase as cases come forwards be clear where which part of an assessment will fall within the pathway."

299. The importance of updated training and awareness throughout the system was emphasised. (Training will be covered in a separate section).

300. It's important to bring together everyone around the table at the earliest possible opportunity. "Think outside the box."

301. One issue is that many areas are commissioning separate services for individual potential diagnoses - e.g. ADHD or ASD - and a child may have to join different

pathways often by different services - for e.g. CAMHS versus child health. “We have moved away from an integrated approach with good differential diagnosis and contributory factors to presentation.”

Psychologists are key but in high demand, how to meet the need?

302. As SIGN 156 and the NICE Quality Standard outline, the person needs to be assessed. This means the psychologist needs to have the skills to do so. In different areas many are being told that they do not have clinical psychologists available. As someone said, “We will have to be creative to find a way round the gaps”. Suggestions include:

   a. Explore sharing a resource within another area - regional support. Professionals should be made available to neighbouring areas

   b. Look at where else you may obtain information needed, access specific SALT assessment and explore academic assessments through schools

   c. Involve local university students in final year to support an assessment service whilst being mentored by a more experienced clinician?

   d. “Are local educational psychologists able to contribute or (for adopted children)? Could this be commissioned through the Adoption Support Fund? (Although we do have clinical psychology, we are also exploring this option with the head of the regional adoption agency to give us some more capacity.)”

   e. A local awareness raising event inviting the relevant commissioners to highlight the gap could also be helpful

   f. More professionals should receive relevant training

   g. A ‘provisional diagnosis’ could be introduced in cases where prenatal alcohol exposure is proven, facial features are obvious and behavioural or intellectual effects have been noted by professionals, enabling families to access support immediately

   h. Look at what assessment have already been completed in the child’s file / history. Many children have already been involved in CAMHs services previously and could well have already completed assessments which could feed into an FASD assessment for the central nervous system/ brain domains. Could assessments from other psychologists such as educational psychs also provide similar / the same input. For example, are they able to carry out a WISC-5, ABAS-3, BADS?

   i. “Does it have to be a clinical psychologist who undertakes assessments - could other trained health professionals carry these standardised assessments out? Like they do already for OT and S&L. The sessions could be video recorded so the psychologist could review any areas that were of particular interest/ concern to them. This would allow for their professional judgement to be maintained within the process/ assessment but reduce direct time input, and enable them to still have full oversight”

   j. Prioritising cases to maximise use of scarce psychological time

   k. Improve awareness among CAMHS. “During the FASD training for clinicians in Scotland the most sceptical attendees were invariably within CAMHS and clinical psychology. In practice such folk may contribute to barriers to progressing along a route to assessment/ diagnosis”

   l. Need more engagement from the Royal College of Psychiatrists. It was noted that some in RCPscyh are trying to increase awareness via the college. This can be helped with joint input from RCPCH or other colleges. Similarly, there are people trying to raise awareness and profile of FASD in the Royal College of Psychiatrists.

Peer review and champions – ways to help areas ramp up services while training is underway

303. Options exist to help a local area without FASD expertise and experience to move forward. Providing structural access to peer review is one way to help.

304. One person noted, "I think we should set up regional peer review meetings via Teams with experienced clinicians available to support those new in this area - local peer review can be done more frequently - add bite-sized training at each session - e.g. cover one chosen aspect for 15 minutes."

305. Someone noted, "The supervision of a selected number of cases seems to be the best approach - identification of others nationally to support the demand as other areas increase services." "We need a Community of Practice for clinicians dealing with FASD." (Note: at the time of printing this idea was being explored.)

306. With remote working it has become easy to link up clinicians from different trusts. As someone noted, "There does need to be appropriate consent and clinical governance processes in place but this is not difficult to set up. Locally we have extended our peer review to include two neighbouring areas and this has been very successful. Our peer review meetings happen monthly for one hour over teams. I would suggest that centres where they have developed some confidence and experience link up to areas where clinicians may be working in isolation or have not yet developed confidence."

307. There can be a dedicated person with FASD expertise in each CCG/ ICS. Someone noted, "I think we should make use of the people undergoing training and encourage the development of FASD 'champions'. This could be facilitated/ encouraged by annual 'study days' (?run/ hosted with aid of National FASD), and also they can be invited to the UK FASD research collaborative network."

308. Regional clinical confidential peer support groups might be an option, using the model that has been established for safeguarding. "There used to be a national clinical FASD forum in Scotland, I believe this was well attended and had the opportunity for clinical discussions in the second half of the day. The first half was more open and provided opportunity for visiting speakers and wider learning. I think this is a miss. With online opportunities there could be lots more done to connect people together virtually which would not need people to be travelling great distances, is more time and cost effective. But would bring big advantages in connecting clinical colleagues together."

309. Encourage people to become champions in each service.

310. One practitioner said, "With the Royal College of Paediatrics and Child Health trying to increase awareness with community paediatricians, we want to make sure all is commissioned properly. To ensure these we need awareness and local people raising issues locally. This needs to happen with Ed Psychs and in all multi-disciplinary ways."

Family support is often missing from pathways or inappropriate for FASD

311. As previously mentioned, pre- and post-diagnostic pathways are important too. An essential part of this is understanding that the individual and family experience of using those pathways is important and they must be involved as core stakeholders as these pathways are being developed.

312. Clear details of the expected pathway should be made available to care givers.

313. Ongoing support is recognised by DHSC and NICE as being important for those with FASD. However, most pathways if they exist don't have a solution for this, specifically for linking to or creating local family support networks.

314. The Greater Manchester model set in place local support while raising awareness, ahead of putting in place the diagnostic pathway. This requires a commitment to continuing services. The answer is not necessarily to add FASD to existing support networks that are not FASD-informed as is happening in some areas. Someone said, "I fear that there will be organisations that will seek to become involved in FASD without the knowledge required. One of the DHSC Section 64

grants in part went to form a localised FASD pathway. There is absolutely no information on that organisations website that refers to FASD."

315. One researcher said, "Lots in the Salford study were flagged as having issues and flagged as problems but no support was included. Few with EHCPs joined as [it was perceived that] there was no benefit from being in the study."

316. Someone noted that in their area "There is a children with disability register that we encourage families to register on to make the need visible. Is there an equivalent for adults to self-refer to so that adults with FASD can be located more easily and the scale of need can be considered?"

317. Lived experience: "As much as Surrey do have pathway…those diagnosed FASD are often forwarded to ASD pathways where FASD can overlap but the nuances are of the spikes profile is not supported."

The very young at risk for FASD are being missed by existing pathways

318. The very young known to be prenatally exposed to alcohol are being missed. One practitioner said, "When thinking about babies being referred in, there's a fundamental problem that we have which is that most ND pathways are not commissioned to accept referrals for children that do not have a defined ND problem. That's a big issue. I want to refer children on to a paediatrician for onward review. The intermittent follow up for children at risk of significant ND impairment is embedded in the framework of neonatology. We follow up kids with problems relating to birth and prematurity. I identify kids with prenatal alcohol exposure and without a defined problem there's nowhere for them to go. Those children and the significant information gleaned at that time gets lost and with it the ability to make early diagnosis. It's important that this is not forgotten in commissioning."

319. Another practitioner shared the frustration expressed. "We have to flag these children to the health visitors and say please make an early referral. I don't write the rules and we aren't able to do what my colleague says. We can say this is a child with prenatally alcohol exposure, if you have any concerns refer back and mention alcohol exposure in your referral."

320. The question then is the ability to accept referral for children identified as 'at risk' for FASD/ neurodevelopmental challenges. One practitioner said, "I have significant concern that as pathways begin to get commissioned (hopefully) it is important that commissioned services are able to accept referrals of children "at risk of FASD" identified during pregnancy and the newborn period who do not YET have evidence of a neurodevelopmental problem. Otherwise, these children (and the relevant background information) is frequently lost to follow-up, and early identification."

321. Others say those at-risk children are often being monitored through health visiting and or portage services who can refer to early assessments (if they have understanding of the risks associated with alcohol-exposed pregnancies).

322. One person said, "In Scotland, in the red book we are asking Health Visitors to record any prenatal alcohol exposure, so that this information will lead to early referral if they have neurodevelopmental delay. Others said that "red books do not always follow children/ young people who are unable to live with their first family. These are often withheld/ lost. Therefore, information within them is also lost." Others said, "At least it may be a start to normalise this information being important to children's health."

Adults are also being missed in existing pathways

323. Most of the discussion about pathways talks only about children and young people. There needs to be consideration of the adult pathways.

324. The National Organisation for FASD reports they are receiving increasing numbers of calls from adults seeking diagnosis and sadly there is little to tell these people who already find the systems hard to navigate.

> **We acknowledge it affects adults, we acknowledge it's a lifelong condition, but we're not doing anything."**

325. "The part we're not talking about is the adult side. It gets mentioned, but if there are adult pathways that anyone takes seriously [including in Scotland], I'm not aware of them. It's hard…to get people to pay attention when you don't know what the problem is but when you have clear examples of people in the criminal justice system in their 20s, 30s and 40s it's all there but not diagnosed. If you require knowledge of PAE that's very hard for a 38-year-old. We acknowledge it affects adults, we acknowledge it's a lifelong condition, but we're not doing anything including for parents suspected of FASD and now have kids suspected of FASD."

326. As one person said, "The real struggle is diagnosis of adults over 16. Scotland plan is all about action on adults, but "adult services see word 'fetal' and think is nothing to do with them. Don't have a good answer."

327. Another practitioner said, "Adult pathways are really important. I - not infrequently - identify pregnant women in my substance misuse clinic who I think are very likely to have FASD." There is no information on pathways for adults with FASD who may be pregnant.

328. Someone said, "The adult pathway is again along the lines of the Autism diagnosis. Here in Surrey we are lucky to have the National FASD clinic, but elsewhere the Autism pathway is what we have. This pathway is not helpful."

329. Another person said, "Something we hear time and time again across neurodevelopmental conditions – we are told to watch and wait until they're older and then they're too old!"

330. Someone with lived experience suggested, "Most of our adults who didn't get childhood FASD diagnosis get a Borderline Personality Disorder diagnosis because the signs look similar. Someone suggested studies should been done in the BPD population to see how many were 'missed FASD'."

> **Something we hear time and time again across neurodevelopmental conditions – we are told to watch and wait until they're older and then they're too old!"**

Reassessment is needed and is often not covered in pathways

331. FASD is a lifelong condition and as the person develops there is a need to reassess them. As one person said, "It is so important we consider the pathway for adult diagnosis and route for reassessment of neuro psychological challenges.

332. This often can be an issue as well if a child was given an early FASD diagnosis without full assessments. One person with lived experience said, "The difficulties we hear all the time about access to assessments is a major issue. Our personal experience was diagnosis at 6 months and no assessments until 15."

333. Someone else noted, "I am interested at how a pathway might work for adults. In Sheffield they are going to be seen through an ND pathway which is great but ... a young man, a CLA (Child Looked After), with the old Alcohol-Related Neurodevelopmental Disorder (ARND) diagnosis started to have significant difficulties. The social worker had no FASD training. The foster carer had had FASD training, prompted him to put forward the young man for diagnosis. But he'd never had a mental capacity assessment because he had no psych assessment. So they had no paperwork on how to keep him safe. He died because, in part, he had no appropriate

support. The social worker couldn't get adaptive behaviour assessment, speech and language, etc. so they tried to put him through the learning disability service to get the assessments but he was rejected as he had IQ in the normal range. Tried to go through the community mental health team and was turned down. So where do you place people? With an ND route, who would be the physician who would oversee that? We know there's a training issue, is there a commissioning issue? How do you get neuropsychological assessments reassessed? Children who could be assessed at 8 or 14 and then especially for CLAs they need to be reassessed if being moved into independence so that the social worker can make appropriate provision for housing and adult needs. They aren't being picked up, leading to homelessness, hunger, mental health issues, and worse." This comment resonated among those with lived experience.

334. Another person noted, "One thing it is important to be aware in adults is that some areas see it as an addiction issue. Whilst that is part of this, it is the neurodevelopmental aspects that the individual needs help with. Those pathways are developing but not everywhere do integrated joint approaches."

335. The other major area where pathways fail is in looking at how to identify and support those with FASD in the Criminal Justice System. In NE/Tees Valley, "we have an assurance that MoJ and CJS will include FASD on service and inmate reviews of neurodevelopmental conditions". However, this is exceptional and not present in most areas.

336. A practitioner noted, "FASD doesn't go away when you become an adult. We have an adult pathway in Surrey. I run this service. It is possible. What we don't have is how to get those reassessments. We've had between 6 and 12 people we had to reassess. The presentation changes, somethings get better, others get worse. It's very much about relooking and see where this fits. I am doing a court case and the individual expresses themselves well but really struggles in other areas. There's a separation between vulnerability and capacity. If I struggle with it, a lot of people will. Long term follow up to determine need is important. As are adequate resources so you can be seen promptly and don't have a long wait. Also, they must be seen by people who understand FASD and need to understand FASD in the wider context. They can't do generic approaches. This can be embedded but needs to be differentiated for those with FASD."

Case study: early diagnosis but no assessments

My son was diagnosed early as a baby at six months old with Fetal Alcohol Syndrome (now called FASD with sentinel facial features). He then had no assessments throughout the next 14 years other than for his sensory needs. He had no support when starting nursery school or throughout infant school, he was not supported by portage services and had no assessments of his needs. The primary school he was in refused to put him on SEN support, yet he was struggling at school and his difficulties increased throughout his time there, so much I had to ask post adoption support for help. Post adoption also didn't do any assessments of his needs, even though he had regressed in some skills, headaches due to stress and increasingly dysregulated after school, which impacted massively on home life so much that In the end I made the very difficult decision to move schools at the start of year three.

This change was really difficult for him and he struggled to start with attachment and security, he had to make new friends all of which is especially difficult for adopted children, once he was settled the support was much better. The consultant paediatrician said he needed to see the educational psychologist, but due to him not presenting any behaviours difficulties at school they said he was at the bottom of the list. His difficulties increased over time again, including self-harm and still no assessments from school or post adoption. Things became so difficulty that post adopted said we were at risk of adoption breakdown. When picking a high school, we only had the choice of one, as our local school said they couldn't support without an EHCP and we couldn't get any help with transport. The high school pressured the primary school to apply for an EHCP, so he saw the educational psychologist in year 6. They didn't do a full assessment; they just looked a couple of things and they didn't have an understanding of FASD so didn't understand his difficulties and only suggested sensory respite which didn't happen.

The EHCP arrived just after he started high school, they didn't undertake any assessments as part of the process, so the detail in the EHCP wasn't SMART as there was no reports to use. He didn't get the same transition as those on an EHCP did, even though they knew about transition difficulties, so he had a very difficult start. After this things went well for a while, mainly due to consistent support from his teaching assistant who provided emotional support. Difficulties again have increased, he started to self-harm again and he is now showing signs in school with behaviour and is school refusing feeling ill with headaches and dizziness. They are expecting more from him but the gap with his peers has increased and he is struggling with some of the curriculum. School also didn't do the assessments they said they would, he still hasn't seen the educational psychologist or had the dyslexia assessment. He has just started the speech and language assessment now in year ten. The new post adoption social worker attended FASD training and her support was much better after, she then applied for the Adoption Support Fund for the assessment I had been trying to get for some time with the Centre for FASD, so we could understand his strengths and weaknesses.

So, we will soon have two assessment 15 years after his diagnosis and we are awaiting the amendments to his EHCP, if he had the assessments sooner, he would have had better access and support throughout his education, better transitions, resulting in better outcomes. As schools didn't understand where his weaknesses are, they are reluctant to make any reasonable adjustments that he needs and find it hard to understand the safeguarding risks while he is in school, which make him extremely vulnerable. If he was less stressed at school, he may have had been able to continue with the activities he enjoyed in his community, he used to really enjoy football at the after-school club and swimming as a part of the local team, instead of being isolated. It would have also reduced the unnecessary stress, extremely difficult time on the family and wouldn't have impacted on my work and health. If he had had the assessments needed at the relevant times, he would not have regressed, Impacted on his health, especially his mental health. He may have received the EHCP earlier which would have not only enabled better support but also a more holistic approach with education, health and social care all working together for the best outcomes for my amazing son. Could you imagine what the next step towards adulthood would have been like if we were still trying to access the assessments? You can understand why the startling statics for adults with FASD are what they are.

Figure: Case study: early diagnosis no assessment

SECTION SIX: Prevention

337. Roundtable 6 explored prevention services. It included an overall update on the Greater Manchester Alcohol Exposed Pregnancies Programme, a more specific presentation on efforts to engage midwives in GM and a presentation featuring a dialogue with a birth mother who emphasised the importance of having these conversations with women. Participants shared further views about targeted versus universal prevention campaigns, the importance of sharing information about the risks of alcohol-exposed pregnancies via schools to those who are not yet considering pregnancy, and other related topics.

338. As one person said, "Not only is it important to respond to FASD, it's also important to go to the root cause."

Lessons from Greater Manchester's experience

339. Participants first heard some personal reflections on the Greater Manchester Alcohol-Exposed Pregnancy/FASD pathfinder work.

340. The Greater Manchester programme has focused on two questions:

   a. Is it possible to identify people who are at risk of alcohol-exposed pregnancies?

   b. Is it possible to intervene in a way that makes a difference?

341. From the outset, they provided "academic scaffolding" through Salford to have credible academic colleagues providing a basis for their programmes. They wanted to test new ways of working, discover prevalence and test what works. They were confident that benefits would outweigh costs.

342. Their interventions were loosely based on the CHOICES model from US but work on the ground dictated it needed to be adapted for GM.

343. They have been on what one participant called "an innovative journey over the past four years". The project:

   a. Secured £1.6 million of investment to test new ways of working.

   b. Provided CPD-accredited training for 390 health and social care staff, rated as 'excellent' or 'very good' by 96% of attendees.

   c. Embedded pre-pregnancy interventions which have identified over 1,100 women as 'at risk' of an alcohol exposed pregnancy, more than two-thirds of whom engaged in support subsequently offered.

   d. Established routine alcohol screening at first contact, booking and 36-week maternity appointments. Over 15,000 women have taken part, with enhanced support being provided to those continuing to use alcohol while pregnant.

   e. Trained specialist midwives to fit long-acting reversible contraception, resulting in 252 women at risk of an alcohol exposed pregnancy receiving this as their preferred contraception.

   f. Commissioned GM's first ever FASD prevalence study.

   g. Distributed Voluntary, Community and Social Enterprise (VCSE) grants to develop new GM peer support networks and resources for families/ carers of people with FASD.

   h. Developed the award-winning #Drymester digital behaviour change campaign, whose content has been viewed over 10.5 million times.

   i. Produced a drama performance and educational workshop ("Birthday"), which engaged over 5000 young people and has since been adapted into a film and lesson plans for use across schools and colleges. The Birthday piece was for young people at the beginning of their sexual awakening.

   j. Co-produce the first ever NICE Quality Standards for FASD and other national guidance.

344. It was noted that "When we did our cost benefit analysis the single biggest benefit fell to Speech and Language in the early stages and Criminal Justice in the later stages, we had to reach out to those partners as part of this."

Lessons shared from the Greater Manchester experience

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.*

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.*

Figure: Lessons shared from the Greater Manchester experience

345. When discussing what's next for the GM programme, the goals outlined included:

    a. Maintain momentum

    b. Embed as business as usual, "so we're not relying on non-reoccurring special funding"

    c. Scale up across Greater Manchester

    d. Implement national guidelines

    e. Improve diagnosis, treatment and support (these were not the primary focus initially, as the choice was made to start with prevention)

346. Participants received another presentation focused on the GM maternity pathways.

347. The FASD/ AEP staff training included specialist/ lead midwives attending Red Balloon Training. Following this an

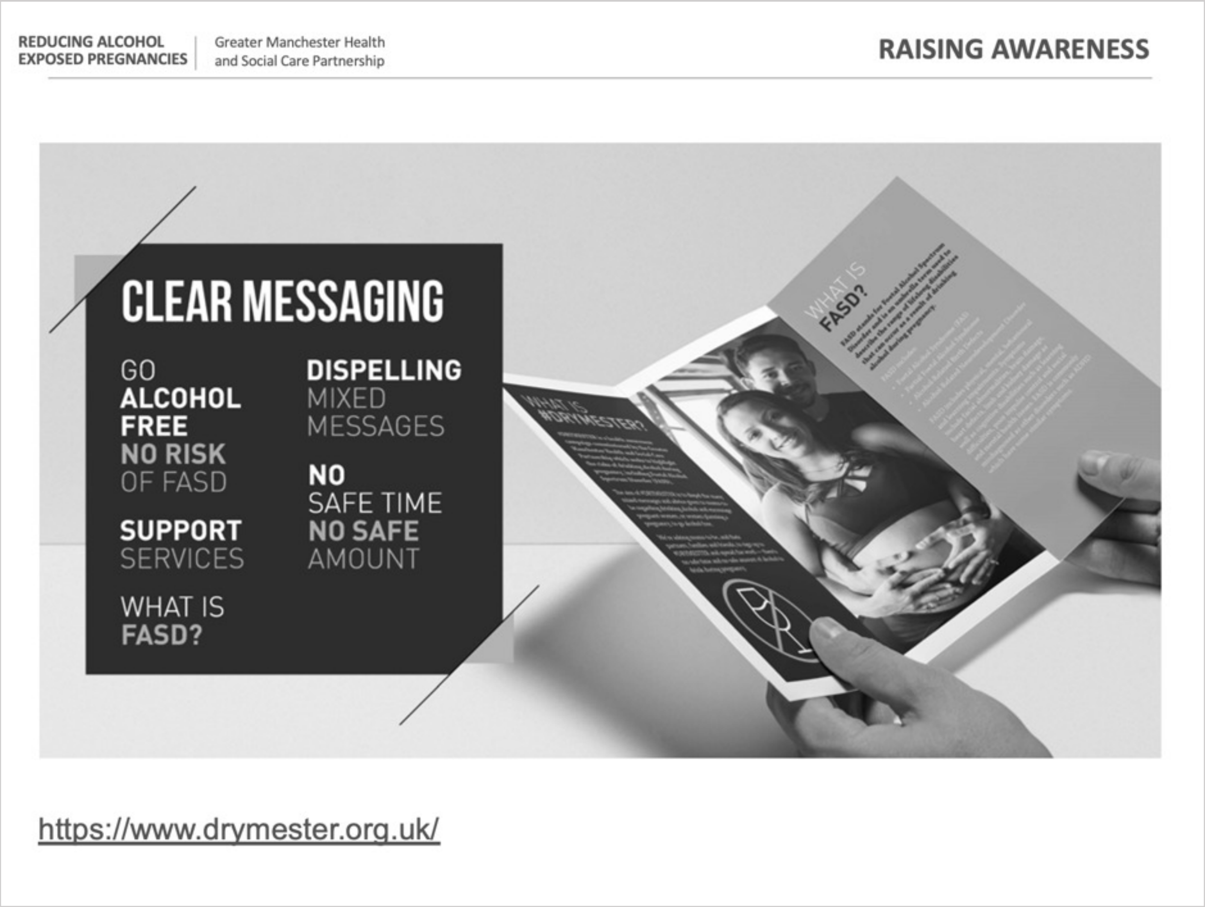
    a. Interactive bespoke 2-hour session was developed for midwives that was inclusive of local pathways. This was Initially delivered to all community and antenatal clinic staff.

    b. It was then later delivered to rotational and core staff within the hospital setting

    c. This was followed up by walk round sessions comprising of bitesize ward-based training.

    d. FASD/ AEP training is now mandatory in induction for all staff and included on maternity annual public study day.

348. The Drymester project focused on clear messaging.



REDUCING ALCOHOL EXPOSED PREGNANCIES | Greater Manchester Health and Social Care Partnership

RAISING AWARENESS

CLEAR MESSAGING

GO ALCOHOL FREE NO RISK OF FASD

SUPPORT SERVICES

WHAT IS FASD?

DISPELLING MIXED MESSAGES

NO SAFE TIME NO SAFE AMOUNT

https://www.drymester.org.uk/

Figure: Example of Drymester messaging

349. The initial plan was to use TWEAK for the Northern Care Alliance AEP pathway as this was the tool in use at Tameside and Glossop. Instead, the midwives opted for Audit C as this was used throughout the trust and was deemed more sensitive in identifying an AEP.

350. Long Active Reversible Contraceptives (LARCs) were a key part of the maternity pathways with specialist midwives trained to fit the implant. This was offered on the postnatal ward prior to discharge and in additional clinics in the postnatal period. In addition to preventing future AEP, this offers enabled women to access LARC who had previously not accessed via community services for different complex reasons. Discussion is on-going about how to expand across all maternity providers in GM.

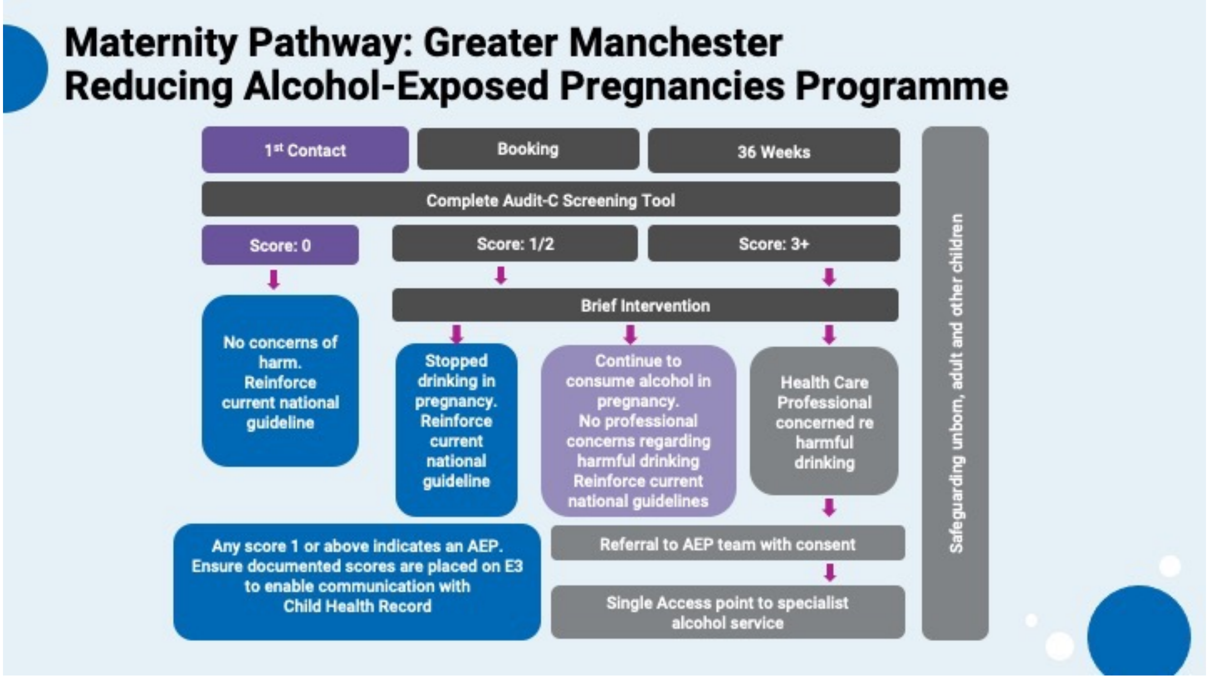
351. In GM, prevention interventions all include pathways to sexual health services for LARCs.

352. One practitioner from another area said, “We have found in our substance misuse clinic that those at the highest risk are the hardest to reach as far as LARC is concerned. They may agree with or want it, but making it happen is a second issue… we try to make sure this is offered prior to discharge from hospital.”

353. Some queried if there might be benefit in delivery by nursing colleagues and perhaps in Family Planning/ sexual health clinic settings. In GM this is part of a wider discussion in the review of sexual health services.

354. In GM It was noted that “It was a real challenge getting midwives into training.” University of Salford research some positive results. Quotes from the study included, “… because we’ve got really clear pathways for additional support now, I think midwives feel a lot more confident” and “now with a bit more knowledge, I understand why I’m asking those questions”. All midwives are involved in screening and support but there are specialist teams that provide enhanced support for those who need it:

   a. Midwives demonstrated a commitment to universal screening without prejudgement



Maternity Pathway: Greater Manchester Reducing Alcohol-Exposed Pregnancies Programme

1st Contact

Booking

36 Weeks

Complete Audit-C Screening Tool

Score: 0

Score: 1/2

Score: 3+

No concerns of harm. Reinforce current national guideline

Brief Intervention

Stopped drinking in pregnancy. Reinforce current national guideline

Continue to consume alcohol in pregnancy. No professional concerns regarding harmful drinking Reinforce current national guidelines

Health Care Professional concerned re harmful drinking

Any score 1 or above indicates an AEP. Ensure documented scores are placed on E3 to enable communication with Child Health Record

Referral to AEP team with consent

Single Access point to specialist alcohol service

Safeguarding unborn, adult and other children

Figure: Maternity Pathway GM

b. Training had led to increased confidence and a better awareness of the rationale for screening

c. All participants were aware of the CMOs' abstinence recommendation and said this was their usual advice

d. Having a clear referral pathway enabled midwives to screen because they knew how to respond to disclosures.

355. The GM Alcohol-Exposed Pregnancy Maternity pathways include:

a. Northern Care Alliance midwifery staff trained in AEP/ FASD. Routine alcohol screening using Audit C at first contact, booking and 36 weeks, midwives fitting LARC

b. Tameside and Glossop Integrated Health Care Trust: midwifery staff trained in AEP/ FASD. Routine alcohol screening Using TWEAK at first contact, booking and 36 weeks, consultants fitting LARC

c. Stockport: midwifery staff trained in AEP/ FASD, implementing AEP Pathway, strong partnership approach, midwives fitting LARC

d. Manchester University Foundation Trust early implementation

e. Wigan and Bolton scoping current offer

f. GM/ East Cheshire AEP Working Group established to share good practice, identify opportunities for innovation and embed pathways across GM Maternity Providers

356. Midwives fed back that having a pathway is key as they are much more likely to have conversations, much more comfortable if they know what supports are available and what the next steps would be for a woman and her partner.

357. Lessons learned from the work with midwives included:

a. Commence engagement with local midwifery services at earliest opportunity

b. Requires defined midwifery leadership – not an 'add on'

c. Utilise diversity of skills; midwives and maternity support workers as this enhances the scope and ability to embed the pathway

d. Training: make it mandatory and be explicit re role of alcohol brief interventions

e. Data collection: engage Trust business intelligence colleagues

f. Wider partnerships are key to support and prevention

g. Audit pathways after early implementation

PHE Maternity High Impact Area (2020)

Reducing the incidence of harms caused by alcohol in pregnancy

Commissioners:

- Commission services to deliver interventions to women who are not pregnant but at risk of an alcohol exposed pregnancy, i.e. using alcohol and not using effective contraception….
- Commission services for pregnant women and partners who are continuing to drink but are not alcohol dependent
- Commission services supporting pregnant women who are alcohol dependent
- Monitor the rate of alcohol exposed pregnancies
- Monitor services for pregnant women through local key performance indicators
- Work across the system to support integrated systems/ staff knowledge

"Drinking any alcohol can cause difficulties in pregnancy and can result in Foetal Alcohol Spectrum Disorder (FASD), causing lifelong disabilities for children. There is no safe time or safe amount of alcohol to drink during pregnancy."

Public Health England

Figure: PHE Maternity High Impact Area

358. Challenges included:

    a. Not highlighted as a priority area in Saving Babies Lives or NHS Long Term Plan – therefore no direct funding or national reporting requirements

    b. Perception that this is an additional ask of midwives

    c. Absence of AEP/ FASD workforce training and therefore lack of knowledge and confidence

    d. Impact of COVID on maternity workforce

359. Opportunities have been provided by some recent changes on a national level:

    a. FASD prevalence findings

    b. PHE Maternity High Impact Area: Reducing the Harms Caused by Alcohol in Pregnancy

    c. DHSC FASD Health Needs Assessment

    d. NICE Antenatal Care Guideline (2021) – Discuss alcohol and CMO Guidance

    e. NICE Quality Standard – Statements 1 and 2

    f. NHS Equity and equality: guidance for local maternity systems – local action planning

360. Additional next steps for the work with midwives in GM include:

    a. Co-produce GM AEP Guideline and implementation across all providers

    b. Continue to facilitate GM AEP Maternity Working Group

    c. Include AEP prevention pathways in the GM Maternity Equity and Equality Action Plan

    d. Continue to engage local maternity services in scaling up and proving leadership

Q&A with a birth mum

361. Participants then heard a dialogue between a birth mum and participants with experience in training on FASD prevention. Following are the questions and a paraphrase of the answers.

362. *Were you aware before being pregnant of public health campaigns on alcohol and pregnancy?* "No. None whatsoever, before my son I had two other children and I knew about eggs, cheese, smoking but regarding alcohol, no. I thought a pint of Guinness was a good thing. With my other kids I was so poorly I didn't drink anyway and I was never a big drinker.

363. *Did any medical professional ever talk to you about PAE risks?* "Well, first I had gone through menopause and couldn't get pregnant, and then they couldn't work out how far along I was and said it wasn't a viable pregnancy. They did genetic tests, thought he had awful diseases because he wasn't growing. They worried about smoking or toxoplasmosis from a cat. It was all because he wasn't growing. My partner and I nearly split up over my demanding that my son's dad got rid of the cat. Alcohol never came up. The doctor said with all the worries I could have sleeping tablets to help with that. I didn't want to do that because it would be bad for the baby. I wanted to be as healthy as possible. He said the only other option was to have a tot of brandy of an evening to help relax, so I tried that. Tried that for stress because stress isn't good. I tried it and after 2 or 3 nights I stopped because I didn't like it and thought I'd rather be awake, but that was the only thing mentioned about alcohol."

364. *Did they mention smoking?* "Yes, they kept telling me off for smoking. They said he'd be small for his age. I did cut down a lot, I didn't stop but did cut down."

365. *Some professionals say they daren't ask women about drinking in pregnancy, do you think you'd have been upset if anyone asked you about your drinking?* "I don't think so. It's difficult to say now, but looking back, I so wish that they had. But, the question in the TWEAK – How much do you drink? It's slightly aggressive. If someone is drinking in pregnancy, that question will make them sit back, a bit like when you get told off about smoking. But, if I had been told about the damage it can do, the evidence around that, then it would have given me a choice. I would have been making a choice about whether or not to harm the baby. At that point I would have been making a choice. If I had had those facts and been making that choice I would have gone 'Oh My God' and stopped. I don't have a problem with alcohol, or drugs which usually means drinking as well. But if they were giving that information and women with that addiction were given the choice, they might opt for the support, they might think about it and you might be on a win if they were given the facts. I wish that's how it had been. My son's outcome might have been different, I wouldn't have had the Guinness or the brandy."

366. *What kind of support do you think a woman who is a social drinker, not addicted, but social, what sort of support do you think she might need?* "I don't know that a woman like me would need support per se, but would want the facts, the evidence, this is what can happen, here's something to look at. Light drinkers, social drinkers, the 70% of FASD birth mothers who are intelligent, good jobs, stable environment etc they need the facts. And the facts might help those who do need the support, the addicted ones, might take the support."

367. *We know your experience dates back a couple of decades, but we know women are still hearing the same messages, the same lack of information and that there are objections from some communities out there who deny women want or should have the information. So your experience is important.* "It's important that money is found for a huge campaign like for smoking so everyone really knows the evidence."

> **If I had been told about the damage it can do, the evidence around that, then it would have given me a choice. I would have been making a choice about whether or not to harm the baby."**

368. *Your pregnancy was unplanned and we know some say that talking about FASD to women who might have been drinking in an unplanned pregnancy, not knowing what was going on, might cause distress. Would it have helped if people had told you what to look out for because you had an alcohol exposed pregnancy. Would that have helped?* "Yes it would. And with the unplanned pregnancy. I was a builder, I was down the pub after work drinking pints. If I'd been told I would have been super worried. They did tell me it was not a viable pregnancy, they asked if I wanted it taken away. Had I known about the alcohol worries, knowing me I would have carried on and hoped that nothing was wrong. But if that information was given out, when the first signs appear, usually in toddlerhood, then we could find out if it was FASD and get support. Ultimately if they have support from the get go then you'll get the best out of that person, even they always need some support, and be a good member of society."

369. Another participant said, "I was told about risks of being an older mum, I was offered tests, for all sorts of things and they would not shy away from telling me the risks and options. But not with alcohol. People know how to have those conversations, but they don't when it comes to alcohol."

How the conversations happen is most important of all

370. The NICE Quality Standard mentions that women should be given verbal and written advice about the Chief Medical Officers' guidance that the safest approach is to avoid alcohol in pregnancy.

371. Participants explored various ways to raise these topics in a supportive and non-stigmatising way. As one practitioner said, "How you develop that relationship and ask those questions is really important. Remember it is always better to stop once you know, so the conversation is always important". Another participant said, "The language should be honest, factual, and kind." Someone else said, "A big part of our learning is that the way in which a midwife approaches this with someone is more important than the questions themselves. These questions delivered badly can be harmful." Someone else said, "It's not what you ask it's the way that you ask it. That's the bit you miss out on. The worst thing about DSM [Diagnostic and Statistical Manual of Mental Disorders] and ICD [International Classification of Diseases] was bullet points rather than looking at the complexity of relationships. If you have the relationship, you have a start and can go forward." Another pointed out, "What is needed is a supportive discussion that may mean they disclose alcohol use but also all sorts of other things that can lead to a healthy pregnancy."

372. This is a conversation to be had with all who are pregnant. One practitioner said, "We often think of women who continue to drink as dependent, that's wrong, often it's about coping strategies and we need to deal with that." Someone else said "We have stereotypical views about youngish women with complex and hazardous lives. But the majority are the older women in professional jobs who are the ones most likely to drink in pregnancy to harmful levels."

373. It doesn't help to ignore the risks involved when having these conversations. One participant said, "Colleagues of mine were told they couldn't get pregnant and had a boozy Christmas holiday, then found out the woman was pregnant. They were very worried about outcomes, but were just told by midwives not to worry, there was no problem. They had to come to me for information. All was alright in the end, but they should have been able to have this conversation with their midwife."

374. The pre-pregnancy phase is important too and not covered in the NICE Quality Standard. One participant highlighted, "It is worth remembering that it is not just women with unplanned pregnancy who are at risk of AEP but a significant proportion of women who consciously plan pregnancy do not reduce/quit drinking until the pregnancy is confirmed."

375. "In Sheffield we have the alcohol screening tool but we are encouraging midwives to start the conversation with providing information about drinking in pregnancy before they consider the use of the screening tool. Health visitors and GPs also use the screening tool but again we have asked that they try and raise the awareness of the pregnant woman and her partner/ family so they can make informed choices and to use the screening tool if they want to access support from the alcohol service - early days still."

376. Kent and Medway have completed a series of task and finish groups involving the CCG midwifery team in Kent and Medway. These groups were set up to discuss the maintenance of the midwife/ mother relationship. Discussions around the rewording of questions approaching a lifestyle before discovering they were pregnant, and then how to find out about drinking habits, then finally finding out when they discovered they were pregnant. This was believed to gain the essential information on if they consumed alcohol during any stage of pregnancy, without asking the question outright and risking a relationship breakdown. Also, in the Kent and Medway FASD System Partnership group they are focusing on public prevention and education of practitioners and have linked up with Greater Manchester to tie in good practices.

> **Even if the GP etc has somehow heard of FASD, if you say you drank during pregnancy they are often adamant that x amount would not be harmful. So you are sent away again.”**

377. There is a need for more national thinking about this topic or more information about the range of tools/ techniques available. Someone pointed out: “Midwifery also need a joined-up process - consider which audit tool should be adopted nationally for simplicity (Audit C seems very user friendly and is already in use in some areas).” Others prefer other more open-ended discussion techniques especially before using validated screening tools. For example, using motivational interviewing techniques or asking about single binge drinking have been proven effective.

378. Further research is needed. One researcher said, “When we looked at evidence for the ‘best’ way to ask alcohol questions in the SIGN process we couldn’t show evidence of which current ones worked best...We need to look at this area from a research perspective.”

379. National FASD is developing a Midwives Toolkit that will be available in spring 2022, working with an advisory committee of midwives and the Experts Committee. This is based on earlier work that reached some 16,000 midwives.

380. In Australia, they evaluated the impact of an online training module for midwives and nurses: https://www.publish.csiro.au/py/PY21026.

Examples of open-ended questions for determining alcohol-exposed pregnancies

Some clinicians prefer the more conversational approach:
- Do you remember how many weeks you were when you knew you were pregnant?
- Before you were pregnant how much would you drink during the week/the weekend?
- Were there times when you drank more and times when you drank less?
- How many drinks would you usually have in a day? a week? a month?
- What about drugs and/or smoking?
- Did you drink alcohol during a previous pregnancy?
- How much did you drink per week prior to this current pregnancy?
- Have you consumed any alcohol in the last three months?
- How many units are you drinking now?*

Others prefer the one question screen, which research suggests is as accurate as one of the screening tools:
- When was your last drink of alcohol?

This question has also been shown to be useful:
- Have you had any special occasions or difficult times?

**The first group of questions are excerpted from the Scottish e-learning: https://learn.nes.nhs.scot/Scorm/Launch/21391*

Figure: Examples of open-ended questions to determine AEP

Targeted interventions

381. There are a range of people who drink alcohol in pregnancy. It affects all levels of society and all kinds of people. Some research highlights the need for targeted interventions, see for example the BMA, 2007.

382. One positive example is in GM: “The alcohol service, specialist midwives and GPs are promoting the Drymester campaign and are using the resources to have discussions with women whether they are pregnant or not.”

383. The CICA (Alcohol Health Champions) programme in Greater Manchester is targeted at social drinkers. The training for the champions does not particularly cover FASD, but one participant suggested that “something like this could be tweaked. The evaluation shows that alcohol health champions can be confident in providing brief advice about alcohol. I wonder whether this could be modified for FASD prevention?”

384. One participant said, “It’s important to consistently convey two-sided prevention message - and do so with the full range of women who are trying, thinking about or likely to become pregnant in the foreseeable future, including regular ‘social’ drinkers among well-educated, higher socio-economic status (SES) women.”

Time for a national universal prevention campaign?

385. Participants discussed the benefits of a national universal campaign.

386. On 13 October 2021 Government stated in a written answer in Parliament that “No specific public health messaging on fetal alcohol spectrum disorder (FASD) has been undertaken in the last five years.” This confirms that since the 2016 change to the Chief Medical Officers’ guidance there has been no attempt to ensure the population is aware of this messaging.

> **No specific public health messaging on fetal alcohol spectrum disorder (FASD) has been undertaken in the last five years.”**
>
> --Parliamentary Undersecretary for Health and Social Care Maggie Throup, 13 October 2021

387. Someone said, “I think there most definitely is a need for a national campaign and as we discussed in the roundtable, I think it should be based on the two very positive affirmations. If you are drinking be mindful to have something in place so that you don’t become pregnant and if you are pregnant me mindful of the dangers of drinking.” Or, as someone said, “Clear messaging: “If you drink, don’t get pregnant. If you are pregnant don’t drink”. “We have had good luck with the drink driving campaign in public health. It’s a two-sided message. FASD is almost always one sided – no alcohol no risk. Driving was ‘If you drive, don’t drink; if you drink, don’t drive.’ It’s a choice. FASD can be prevented by no alcohol and no pregnancy, and both should be pushed as some still want to drink. They need options from both sides.”

388. One person pointed out “That is the point of the CHOICES model in GM. The CHOICES model identifies young women who are sexually active - if they are AND they drink, then the contraception should be secure.”

389. Another said, “Yes I think there should be a campaign to raise awareness nationally - this could be aimed at all groups that come across women who may be drinking and not just midwives.”

390. “A national public health messaging programme is the best approach (also less costly I would think): TV - Instagram and other social platforms, as well as being part of school education and PHSE type work. “

391. Someone said, “There needs to be posters in pubs - On backs of doors in library - children centres - football clubs etc anywhere where young people may go - it can’t just be a female responsibility.”

392. Another participant said, “The Drymester campaign is very good and appeals to people. I think if a prominent person like Kate Middleton put her weight behind supporting the clear messages and linking it with her

Early Years work it would be accepted by the newspapers and they would spread the word."

393. On the other hand, one participant said, "Straightforward provision of information is not the most effective way to induce change in population level behaviour, since it is well known that people continue to do things that are bad for them. Having said that, people do need information, and basic knowledge is very low in the UK. Could the Greater Manchester Drymester resources/ media techniques be scaled up?"

394. A participant commented that we need "Two-sided message that explains why in a compelling, emotionally-resonant way - not just another boring or authoritarian message along the lines of Nancy Reagan's Ill-fated campaign of Just Say No to Drugs. See NES eLearning resource on FASD (Scotland) and this terrific Danish bike helmet PSA on an entirely different health topic."

395. In Kent and Medway: "We have found short films and video clips have been the most effective way of getting to a wider audience. We have been working on an online portal to use technology to create an interactive portal to give the public and professionals a basic real life understanding of FASD, with expert commentary and signposting to regional organisations for further training, support and advice."

396. "It's a delicate balancing act because we need to get the message over but not unduly scare people who are pregnant or know that they drank while pregnant. It needs to be consistent and multi-dimensional. So through GPs, but also in libraries pharmacies and main stream shops like Boots. Schools have a role, but the fail point is that there aren't enough people with a working knowledge to make things work so there has to be a programme of awareness raising with interested professionals."

397. Someone highlighted it's important to engage GPs to understand FASD and have the discussion with all pregnant women. In Sheffield, they "use Drymester and the videos are played in many of the GP surgery waiting rooms and the sexual health clinics."

398. One participant said, "I do think that we should try to lobby for universal alcohol harm prevention campaigns. A society that was less obsessed with alcohol would be good for everyone, not just pregnant women. We should be campaigning for minimum unit price. If we could shift society's behaviour as a whole, it would be less unusual to choose to drink soft drinks on a night out (for example). A lesson can be learned from the anti-smoking public health efforts, which gained traction because of the impacts on passive smokers, not because of the impact on the individual smoker. In the same way, a fetus is a 'passive drinker', and this should be a powerful argument to carry out a population level intervention, like minimum unit price. Minimum unit price or similar policies that increase the price of alcohol are recognised to be the most effective way of reducing alcohol harm in the population. Lange et al. (2017), in their global prevalence of FASD study, found that '1 of every 13 pregnant women who consumed alcohol during pregnancy is estimated to have had a child with FASD'. In other words, for every 13 passive drinkers, one will end up with a very significant life-long condition. I don't know what the equivalent figures for illness are for children who are passive smokers, but surely the figure of 1 in 13 is persuasive."

399. Someone else said, "Video clips are very useful in supporting health messages and providing information particularly to young people - whatever is put out needs to be accessible to everyone - diversity and disability considerations."

400. Lessons can be learned from other campaigns. Someone commented, "The message about smoking and pregnancy is generally accepted even if it is sometimes ignored. We need a national message about alcohol and pregnancy with the same national drive behind it. It can't all be left to schools."

401. Another person said, "We have learned how to deal with smoking, we are beginning to learn how to deal with domestic violence/ relationship conflict, and hopefully the same will develop with alcohol gradually. It took 30 years from when we knew risks of smoking until that translated into societal norms and absence of smoking in public places."

402. However, it also was pointed out that comparisons to smoking campaigns have limits. With smoking campaigns, "We have passed a tipping point, the vast majority of people don't smoke. It's much easier to say it's better not to smoke. Most people do drink. It's hard for medical professionals to tell people not to do something they do themselves."

Examples of universal campaigns

403. In January the North England North Cumbria ICS Alcohol Clinical Network steering group received a briefing from Blackpool Best Start about the Blackpool 'Superbabies' campaign supporting an alcohol-free pregnancy.

404. Sheffield have adopted the Drymester campaign to raise public awareness. Leaders from the GM programme attended a recent All Age FASD Steering Group in Sheffield to share developments regarding progressing the Drymester Campaign including getting a national figure to support it. Red Balloon training is also delivering training to raise professionals awareness. One participant said in Sheffield they are now "told by clinicians / social workers / health visitors that it is working as people are now actively querying the FASD diagnosis in children the problem is that we do not have a system for diagnosing them yet, though the discussions are happening on the clinical model and pathway."

405. In November 2021, Australia launched the "Every Moment Matters" campaign with government funding and supported by leading Third Sector organisations. The tagline is, "The moment you start trying is the moment to stop drinking." This is part of a $37 million investment in FASD diagnosis and prevention.

406. For more information, CANFASD publishes an annual bibliography of articles related to FASD prevention.

The importance of engaging other healthcare professionals

407. Someone asked, "Do you not think we need to shift the focus from midwives to reaching health colleagues who will discuss alcohol in a preconception situation? how do we achieve that?" Others who could be involved include: pharmacists, health visitors, dentists, primary care staff, social care, family planning/ contraception/ sexual health nurses.

408. In Greater Manchester, prevention interventions were delivered by 'life-style' services, women's centres, early years, drugs and alcohol and they are now looking to expand to universal services

409. In Sheffield, "We have discussed it with pharmacist, optometrist and dentists. All have agreed to promote the No Safe Time and No Safe Amount message. Pharmacists have agreed to display Drymester posters from March and have invited me to a PLI to speak about FASD and reducing alcohol exposed pregnancies. The training Red Balloon is delivered through the SCSP so is targeting a wide range of professionals from all services in Sheffield."

410. Someone pointed out, "There will be relatively few healthcare professionals, especially in health visiting, primary care, education, sexual/ reproductive health, looked after CYP, justice system and other community settings who do NOT ever encounter people affected by FASD. The goal should be to recognise this reality (including among adults) not solely to create/ isolate specialist FASD practitioners."

411. Someone commented that "We have developed a system with Kent and Medway CCG Comms department to work with their local network in drawing greater awareness of FASD. We are also linking with GP surgeries through the same network to get involved in podcasts, team meetings and training. This we hope to roll out to other departments and healthcare professionals. Videos from our #BeAware campaign have been shared alongside articles to all healthcare professionals through the CCG email and Comms department."

412. Someone else said, "Our GP and local pharmacy still use and have on offer FASD information produced for the Rosie Maternity unit in Cambridge by the FASD Trust [editor note: the FASD Trust is no longer in operation]. The message is still as it should be but contact details to find anything else is no longer available. Maybe any resource for the public has more than one source of further information."

Engaging with schools

413. Participants also discussed the importance of raising awareness among young people before they are planning a pregnancy. As one person said, “Education and schools is where it’s at.” As someone else noted, waiting until there is “midwife involvement might be too late.”

414. Some noted that in some areas it’s already being addressed in schools but it’s patchy. “It has been in education but in very limited areas. Health & Social Care and also in post 16 PSHE but if the teachers don’t know/understand then it’s missed there is so much to cover.”

415. If we focus on “education in schools … we catch the next generation who are at a point of starting their journeys with alcohol and sex - may be more open to hearing about risks.”

416. Some resources are available for younger people not intending a pregnancy imminently:

417. Birthday is a play from Greater Manchester that has also been made into a film with accompanying teacher materials. The 500+ young people who saw ‘Birthday’ were so engaged and demonstrated changes in knowledge and intent for future behaviours. Birthday can be used by anyone and has detailed lesson plans https://oldhamtheatre-workshop.co.uk/birthday-access/.

418. For the younger primary aged children FASD Hub have created the FASD Makes Me, Me animation which can be accessed at www.fasdhub.scot, along with some resources for teachers.

419. National FASD have a project for 15–25-year-olds, available at https://preventfasd.info. This includes:

    a. An award-winning film, RISK and materials for classroom or group leaders to use for discussions;

    b. Comics designed by university students called The Conceivables; and

    c. NOments - a lifestyle campaign involving a reality tv star in dialogue with a practitioner encouraging people to ‘celebrate the #NOments.”

> **[It’s important to embed prevention] into education from a very young age so the ‘no alcohol no risk’ message starts to change the generations of the future. I remember speaking to a colleague who is from the US and she was shocked that I didn’t get taught this at school, she just thought it was normal.”**

SECTION 7: FASD care management plans

420. Roundtable 7 explored care management plans. The NICE Quality Standard includes mention that people diagnosed with FASD should have care management plans. This topic is quite important but often overlooked. Most places – even those with pathways – haven't yet considered what the care management plans should look like and what is best practice. Participants heard a presentation about and discussed elements of care management plans. TRIGGER WARNING. Participants also heard a presentation based on the tragic story of a young man who was failed by the system after he left care and who sadly died.

General principles of a care management plan

421. Participants received a presentation from a practitioner outlining principles of care management for those with FASD based on relevant research.

422. The core point is that positive support matters. "From the limited research available, people with FASD can learn skills through positive behaviour support interventions when approaches are appropriately adapted to their unique neurodevelopmental profile (i.e. impairments in central nervous system). These are outlined in Petrenko (2015)[7]."

423. The speaker emphasised there is evidence for positive outcome for approaches that:

   a. Adapt the environment to facilitate learning and enhance a person's quality of life where the focus is creating an environment where a person's needs are met

   b. Build skills following targeted scaffolded learning experiences

   c. Specifically, there is some evidence for interventions that target underlying deficits in attention and self-regulation in children

424. There is a caveat on how much targets can be generalised and how long-term the effects are. Evidence is limited, but there are some good outcomes with targeted interventions and more approaches to adapt the environment.

> **Provision of services should involve promoting hope, use of family expertise, and building knowledge and skill."**

425. Reid et al[8] suggest that provision of services should involve promoting hope, use of family expertise, and building knowledge and skill. This can take place within the wider family and socioeconomic context and involve consideration of a range of risk and protective factors and strengths. "Building skills on a basis of hope and targeted family intervention are part of a whole."

426. The speaker noted some additional considerations are important. It's key to:

   a. Make adaptations based on the unique CNS profile

   b. Take the burden of planning off the individual themselves, provide structure

   c. Plan targeted interventions engaging interests as leverage

   d. Consider how do we get the voice of the individual into their care plan – e.g. by asking questions like "what do you find calming"?

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[7] Petrenko (2015) Positive Behavioural Interventions and Family Support for Fetal Alcohol Spectrum Disorders; Current Developmental Disorders Report, September; 2(3): 199–209. doi:10.1007/s40474-015-0052-8.

[8] Proposed integrated theoretical framework for provision of services for children with FASD. Reid, Crawford, Petrenko, Kable, Carmichael & Olson, 2021. Vol: (089) https://doi.org/10.1007/s40474-021-00241-1.

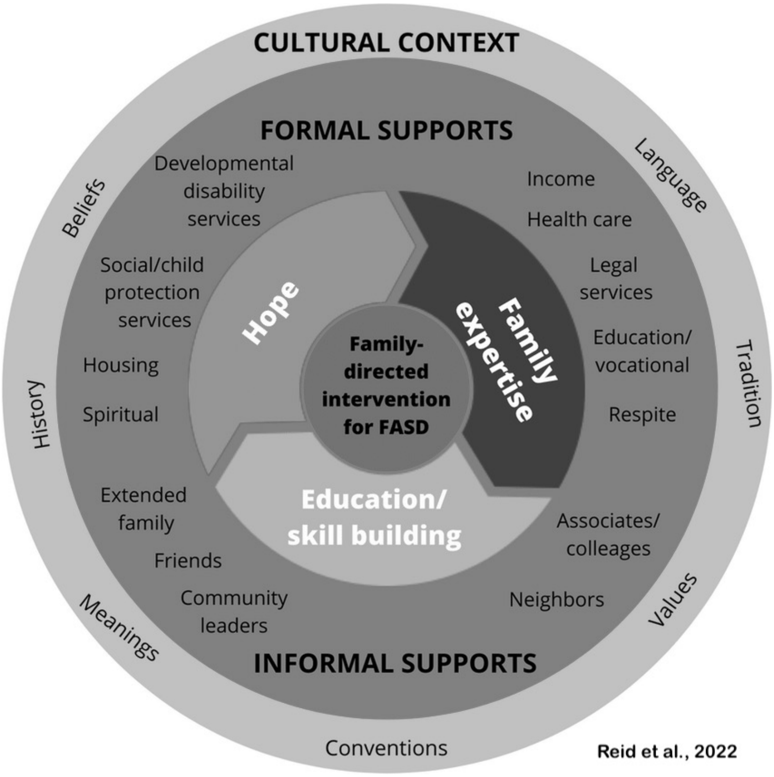

Figure: Family-directed intervention for FASD[9]

Speaking for one who can't speak for himself because for him it's too late – Aaron's story

427. Participants next heard a presentation about a young man who sadly died as result of the lack of joined up thinking about how to support him. This story is included at length because it so clearly shows the importance of a proper care management plan for those with FASD especially as they transition to adult services. The young man here is referred to as Aaron (not his real name). Derbyshire conducted a multi-agency learning review and are taking steps that have been mentioned elsewhere in this report to address the shortcomings identified here.

428. After attending an FASD training course commissioned by their independent foster care agency, Aaron's foster carers recognised he showed symptoms of FASD. At 17-years-old they were trying to get him diagnosed before he turned 18, as they had been advised on their training course that it was more difficult after 18. He was diagnosed aged 18 by a compassionate paediatrician. He loved music and was very sociable, but was unable to pick up cues or know when he was being manipulated.

429. The Leaving Care team asked what he would like and said he could live independently. They had undertaken no FASD training. They ignored warnings from his carers about potential difficulties caused by FASD. They took answers from him about his capacity at face value.

430. He moved to semi-independent living, with a staff member who could be asked for help but only between 10-4. It also required him asking for help, not the staff recognising his needs and offering support. He was anxious about living with others which led to a deterioration in his daily living skills.

431. Normally he liked to shower, but that stopped. His foster carer spoke to him about it and ascertained the problem was a lack of towels. He had been unable to improvise, ask staff for a towel, nor purchase one. Despite the fact he could arrange some things – getting a tattoo for example, but despite knowing he needed a towel and having the money for one and knowing he could ask for one, he couldn't put all that together and make it happen without

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[9] "A Family-Directed Approach for Supporting Individuals with Fetal Alcohol Spectrum Disorders", Current Developmental Disorders Reports, 9(10):1-10, DOI:10.1007/s40474-021-00241-1.

assistance and that was leading to him being unclean.

432. He started to spend all his money in the first week of the month, spending lots on other people then having no money for food for three weeks. Living with others made him anxious which made him dysregulated. He started missing GP and orthodontic appointments once living independently. More significantly he started missing mental health appointments unless someone actually took him. Adult mental health services just recorded him as DNA (did not attend) and closed his case for failure to engage. He needed someone to take him to each appointment. If the social worker did this he would go, otherwise not.

433. Aaron was having huge difficulties. Because of all of this he trashed his room. The house staff with no FASD training and no understanding of his situation saw this as deliberate behaviour and he was evicted.

434. Now homeless, he had a social worker who initially did not understand FASD because they had never had FASD training. Despite being given information from the carer, the social worker just didn't get it because Aaron presented as able, and not understanding this is typical of FASD the social worker didn't make allowances.

435. The social worker contacted an expert in FASD and had several consultations and she recommended psychological and speech and language assessments. However, accessing these proved to be impossible. The social worker contacted the learning disability service who wouldn't help because his IQ was 70 and contacted mental health services who said they don't do those kinds of psychological assessments. The social worker could not get the assessments which were essential to get an understanding of Aaron's strengths and areas he would need additional support, such as where he could live.

436. He moved in with someone who he thought was his boyfriend, where he experienced mate crime, sexual exploitation and modern slavery.

437. He started drinking problematically, which he hadn't done when living with his carers. He would put himself at risk whilst drunk and then refuse healthcare.

438. He had other finance problems. He got other benefits as well as PIP. He would go to the benefits office, they would take him through what he needed to do for benefits, he would sign a paper and come away with no idea of what he had just agreed to. He struggled to understand number value in context.

439. He was very suggestible and 'friends' would get him to engage in risky behaviours for their own entertainment.

440. A Vulnerable Adults Risk Management (VARM) multi-agency process was held. These manage high risk where the person makes informed choices (MCA) that could put them at significant risk of harm.

441. Aaron had never had a mental capacity assessment. They presumed capacity. They didn't even understand he might need one and assumed all his choices were informed. They assumed all unwise decisions were things he was choosing to do. At end of the meeting they did conclude he was at high risk of everything, including death.

442. He died 3 months later. Nothing had changed. His foster carers are devastated. He was very much loved.

443. Changes that are being made now have to mean that people like Aaron are put on a better path.

444. As one parent said, "That was a hard listen. Any one of those things could happen to our son. It's so important that practitioners and commissioners think about these things now. It's up to all of us to ensure that the NICE Quality Standard statement on care management plans is implemented moving forward." Another parent said, "It is sadly such a thin line between safe and in danger."

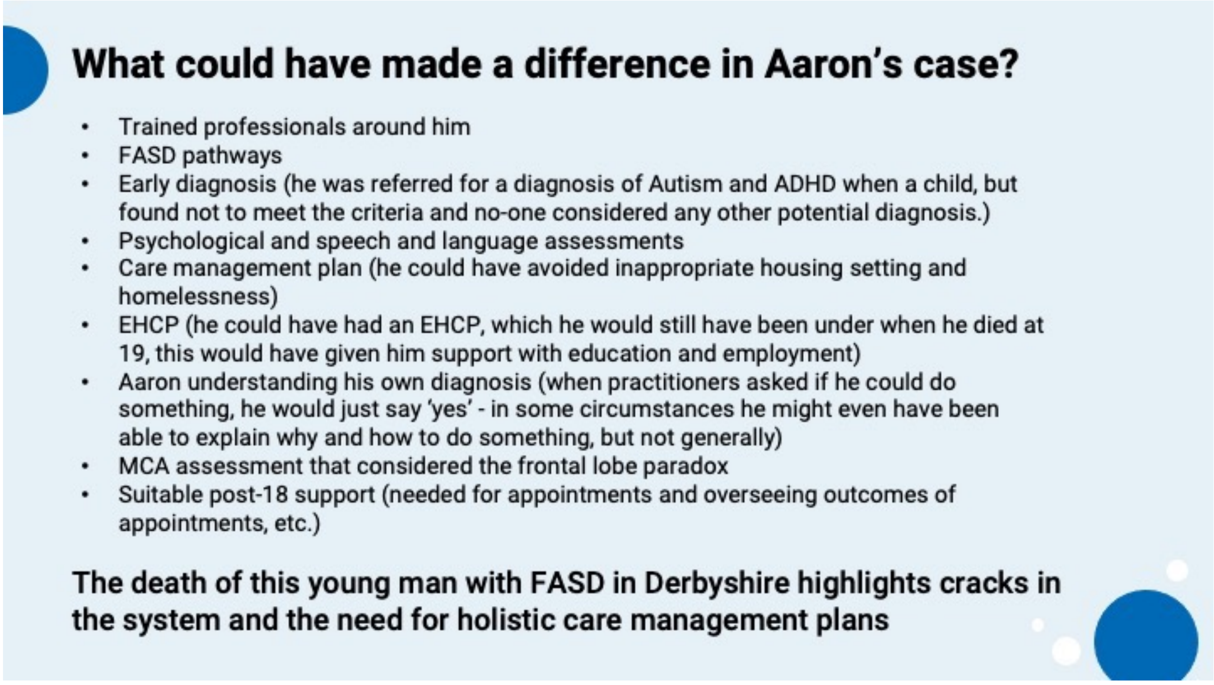
445. One practitioner said, "Aaron's story is tragic but not unique. I can give you a dozen other stories where I've heard very similar presentations where needs are not met, a person gets into difficulties and people die. It is tragic. We must look at the individual's, family and carer needs. There's something about the transition from childhood. Kids don't stay 18 and often become adults with no support. They have transition needs and need to look at what life as an adult will be – they don't stop growing, their developmental strategy is shallower. They continue to grow and learn but at a slower pace. There is a lack of understanding of an individual as a whole.…The profiling that people do as part of FASD diagnosis can feed into understanding their individual profile, their strengths and weaknesses. We can scaffold weaknesses

and build on strengths. Understanding the spiky profile allows for a care plan that can allow for support but also independence. Individuals with FASD want that, they see the world around them and want to be part of that. When calm, you can state what you are thinking about but can't do that in the long-term. Understanding this needs to be part of adolescent and adult care plan. Also, we have to think about how the adult understands their own situation. As they get older, we see with all ND conditions, if you don't understand your own condition and where you have to ask for help, the things described become evident. We have to know how to empower people to ask for help, to keep themselves safe and that starts in childhood. This is part of getting the best quality of life you can get. The start has to be the assessment, understanding individual needs and looking at long term provisions."

446. In other words, "We need diagnosis to open the door to all the other help you need. Having no care plan leaves people hanging. We need appropriate care for the child, and then reassessment and appropriate care as they get older. This would avoid Aaron's situation. Get better quality of life for all in this situation and the care management plan is key to that."

447. Another participant said, "There's often so much focus on diagnosis (completely understandable when even that is so hard to get!), but that should be the beginning of the story, not the end. Without more detailed needs assessments, and then the right support to actually meet those needs, it's not enough."

448. Someone else said, "Aaron's story is representing the faults in the system. For many of our adults we have ticks in the positive good practice action boxes but it is lack of communication between mental health, social care, education, disability services, housing, justice, addictions, employment services, exploitation teams etc that means they fall through the gaps."



What could have made a difference in Aaron's case?

- Trained professionals around him
- FASD pathways
- Early diagnosis (he was referred for a diagnosis of Autism and ADHD when a child, but found not to meet the criteria and no-one considered any other potential diagnosis.)
- Psychological and speech and language assessments
- Care management plan (he could have avoided inappropriate housing setting and homelessness)
- EHCP (he could have had an EHCP, which he would still have been under when he died at 19, this would have given him support with education and employment)
- Aaron understanding his own diagnosis (when practitioners asked if he could do something, he would just say 'yes' - in some circumstances he might even have been able to explain why and how to do something, but not generally)
- MCA assessment that considered the frontal lobe paradox
- Suitable post-18 support (needed for appointments and overseeing outcomes of appointments, etc.)

The death of this young man with FASD in Derbyshire highlights cracks in the system and the need for holistic care management plans

FIgure: What could have made a different in Aaron's case?

Further general thoughts about care management plans

449. Participants discussed general elements of care management. As one person said, "How we frame things matters." "'Care management' sounds very medical. For the child and young person needs are often more around neurodisability and behaviour. Perhaps renaming it to 'long-term support, care and management plan'?"

450. One person said, "Strong management plans are those that centre around the needs of the individual, involve both the individual, their voice and views, and those of the parents/ carers as the primary agents of support and often change."

451. Participants highlighted other elements of good care management plans:

    a. Should be carried out by someone or a collective body with understanding of and specialising in FASD

    b. Supported by a neutral party also understanding FASD

    c. For most it must be multidisciplinary

    d. Focus on educational need, health need, and social/ care needs

    e. Must be realistic and adapted to the services in the area

    f. Different services may provide the required support in different areas.

    g. Must be practical, reflective of what the young person and their family sees as important, what goal they wish to achieve

    h. Must be adequately funded for success

    i. Families need more information on what to do "when things go wrong". "Quite often they are left floundering without solid ideas for where to seek timely support when difficulties arise"

    j. Should be individualised

    k. SMART/ outcome focused

    l. Holistic

    m. Include input from the child and their parent/ carer

    n. "We need to ensure that information given to families is standard across medical professionals"

    o. Ensure that future diagnosis comes with sufficient sign posting or support plan

    p. "Carers should be encouraged to share diagnosis with educational setting at earliest opportunity with a school information package"

    q. Advice is given regarding medication if ever needed in the future (for ADHD/ sleep etc.)

    r. Community awareness is needed to support the care plan. One person said, "Spread awareness to local police, solicitors, judges, housing organisations, GP surgeries, community groups to treat those with FASD within a level playing field"

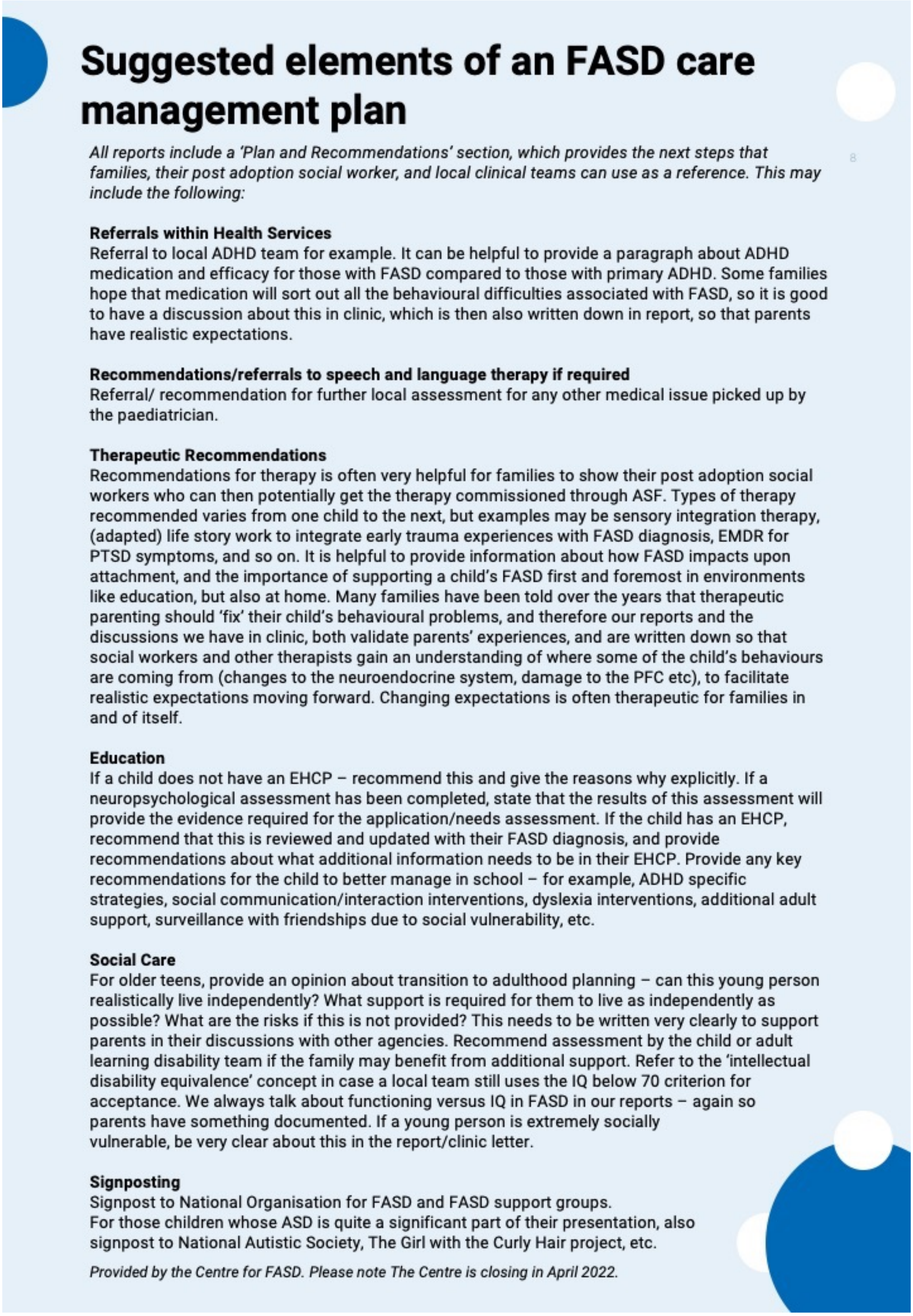
452. One person with lived experience shared a sobering perspective that shows creative thinking is needed to meet the needs of those with FASD, "I have no experience of a care management plan because there was no support after FASD diagnosis for our children. A good care management plan would be excellent but knowledge of neurodevelopmental conditions is still very poor and needs to improve massively for care management plans to be implemented and to be useful."

453. A care plan can save money in the longer-term. As one parent said, "My son has a 30k assessment but nothing coming forward due to support for FASD is not there." A practitioner replied, "That's the sort of information we ned to gather. What a waste."

454. One participant thought it would be helpful to have more work done on models of what a care management plan could look like for those with FASD. SIGN 156 has a form for this, which could be a guide. But this person thought it would be possible to assemble a more detailed guide.

455. Someone queried, "I wonder if ICSs - with their system-wider thinking in principle - may help here to ensure that there is better coordination?"

456. The Centre for FASD includes elements of care management in all its reports. These are outlined in the following box.



Suggested elements of an FASD care management plan

All reports include a 'Plan and Recommendations' section, which provides the next steps that families, their post adoption social worker, and local clinical teams can use as a reference. This may include the following:

Referrals within Health Services
Referral to local ADHD team for example. It can be helpful to provide a paragraph about ADHD medication and efficacy for those with FASD compared to those with primary ADHD. Some families hope that medication will sort out all the behavioural difficulties associated with FASD, so it is good to have a discussion about this in clinic, which is then also written down in report, so that parents have realistic expectations.

Recommendations/referrals to speech and language therapy if required
Referral/ recommendation for further local assessment for any other medical issue picked up by the paediatrician.

Therapeutic Recommendations
Recommendations for therapy is often very helpful for families to show their post adoption social workers who can then potentially get the therapy commissioned through ASF. Types of therapy recommended varies from one child to the next, but examples may be sensory integration therapy, (adapted) life story work to integrate early trauma experiences with FASD diagnosis, EMDR for PTSD symptoms, and so on. It is helpful to provide information about how FASD impacts upon attachment, and the importance of supporting a child's FASD first and foremost in environments like education, but also at home. Many families have been told over the years that therapeutic parenting should 'fix' their child's behavioural problems, and therefore our reports and the discussions we have in clinic, both validate parents' experiences, and are written down so that social workers and other therapists gain an understanding of where some of the child's behaviours are coming from (changes to the neuroendocrine system, damage to the PFC etc), to facilitate realistic expectations moving forward. Changing expectations is often therapeutic for families in and of itself.

Education
If a child does not have an EHCP – recommend this and give the reasons why explicitly. If a neuropsychological assessment has been completed, state that the results of this assessment will provide the evidence required for the application/needs assessment. If the child has an EHCP, recommend that this is reviewed and updated with their FASD diagnosis, and provide recommendations about what additional information needs to be in their EHCP. Provide any key recommendations for the child to better manage in school – for example, ADHD specific strategies, social communication/interaction interventions, dyslexia interventions, additional adult support, surveillance with friendships due to social vulnerability, etc.

Social Care
For older teens, provide an opinion about transition to adulthood planning – can this young person realistically live independently? What support is required for them to live as independently as possible? What are the risks if this is not provided? This needs to be written very clearly to support parents in their discussions with other agencies. Recommend assessment by the child or adult learning disability team if the family may benefit from additional support. Refer to the 'intellectual disability equivalence' concept in case a local team still uses the IQ below 70 criterion for acceptance. We always talk about functioning versus IQ in FASD in our reports – again so parents have something documented. If a young person is extremely socially vulnerable, be very clear about this in the report/clinic letter.

Signposting
Signpost to National Organisation for FASD and FASD support groups.
For those children whose ASD is quite a significant part of their presentation, also signpost to National Autistic Society, The Girl with the Curly Hair project, etc.

Provided by the Centre for FASD. Please note The Centre is closing in April 2022.

Figure: Suggested elements of an FASD care management plan

Strong care management plan elements for under 18

457. Another person said, “There must be a multi-agency, whole family approach that can reduce the impact of stress on parent carers at having to negotiate with several people that simply do not understand what their day-to-day life looks like.” Or as another person said, “The plan should cross over between, home, education, health and social needs.” Specifically, “The plan MUST link education and health/ care. This is the only way it can support the young person.” Someone else said, “There need to be clear mechanisms for multi-agency working. Crossing boundaries between those employed by CAMHS, paediatric services, voluntary sector to facilitate assessment and support.”

458. Someone else noted that, “Care management plans are generally created by the young person and their family focusing on what they value and consider important.” With FASD this may take some creative approaches to meetings and utilisation of items such as the resources available via National FASD’s Me and My FASD toolkit (www.fasd.me).

459. Participants share a range of additional thoughts on care management plans for those under 18:

    a. A standard plan is needed to enable all to be treated equally and fairly
    b. Tailored specifically for each child
    c. Goals and supports should run across ALL areas of life using the same language.
    d. Guided by knowledge of FASD
    e. Someone asked, “Should it be outcome focused? Stockport have an outcomes framework that way the young person is at centre”
    f. A standard pack of FASD information should be provided for families to digest and share as required Information, including signposting and access to relevant services including FASD support groups
    g. Advice and well-being for carers is a key element, including a safe space for them to share concerns
    h. Benefits advice
    i. Respite provision
    j. Literature on coping strategies and parenting tips / training where possible
    k. A designated professional contact
    l. Access to home support workers to support carers within the home environment
    m. Relevant therapy services
    n. Reflective meetings within education to ensure needs are met/ are flexible
    o. Plans could be laid out at diagnosis by paediatrician in standard packs
    p. A support worker could concentrate on life skills
    q. A parent advisor along with diagnosing clinician and support worker should be involved
    r. All other agencies directly involved or potentially involved should be represented on the plan
    s. Designation of lead agency at the time of diagnosis (this may be education, health (child development centre), CAMHS, or social care
    t. Minimum requirement of annual monitoring and review of progress
    u. “In teenage years those with an EHCP should have an annual review that looks are preparing for independence and what that means. They should also consider PIP, personal payments, housing, support needs, etc. I would follow the EHCP template and not try and create a new system - it will not get funding, traction, etc.”
    v. Encouragement of partnership with voluntary support organisations (local or national)
    w. Another participant said, “It is critical that care plans and information about elements of the FASD diagnosis are presented in Easy-Read format or shared via video so that people with FASD are better able to access the full import of their diagnosis and the type of care they are entitled to”

460. Education is clearly an important element of the care plan for those under 18. Someone suggested, "I think it would be ok to ask in the plan, 'Do they have an EHCP?' If not, ask 'Is the current support working, why/ why not and when to review, that way it would highlight the importance of the correct support and give parents a chance to voice if it isn't working." Someone else said, "Schools say they don't have money for integrated management. Schools know, but can't act at the moment. There will be a tsunami of cases." Another said, "Following diagnosis support in schools is obviously essential in order to optimise progress and reduce stress etc. What links to education/ educational psychology are feasible and likely to ensure that support and monitoring are in place and continue beyond transition to school leaving etc?" "Children should have an EHCP which sets out to cover these areas with the plan extending beyond 18 years."

Who has responsibility for oversight for care plans for those under 18?

461. There are a range of views on who should have oversight for care management plans for those under 18 and we have included below an array of responses. Any plan should make clear to the family who the lead contact is following diagnosis:

   a. One participant suggested, "The responsibility for care pathways should be GP + CAMHS + education until the age of 18." Another said, "Our colleagues in Norway have a model of a multi-disciplinary meeting following assessment to feedback results and develop positive support plan - involving GP, social work, and schools as well as the individual and wider family - e.g. grandparents. This is a regional service."

   b. Others thought it could sit within education if this is the area of most need. From this perspective, community paediatrics and neurodevelopment services in CAMHS will have a role but not necessarily as the key professionals.

   c. Someone else noted, "Ultimately it will be the carers (and child) who have the key role in managing the plan."

   d. Another participant said, "Our area have just done a keyworker pilot, we are just waiting for the report. The key person might sit in different teams for different people, this approach might work, it needs someone to coordinate it who has the time to follow it up."

   e. "The question of who holds responsibility for devising and managing the plan is challenging. Probably the most obvious is within education as this will be the most consistent and constant (other than parents/carers) input throughout the individual's life up to the age of 18. However, in saying this there needs to be in place clear expectations, standards and understanding that Health will and need to engage in the process, review and implementation of the plan, and where appropriate social care/ services. Within Scotland all those in education aged 12-15 with additional support needs are able to have their own independent advocate to ensure their voice is heard. This is paid for by the SG. This is extremely powerful for young people: My Rights My Say (https://myrightsmysay.scot/). In Scotland, at 16 this becomes their legal right. The age of 12 is the point at which capacity is deemed. Something similar could be adopted and built into this process in England."

   f. "If the family need the support (some may feel they manage okay), they should be able to access a social worker and not have to fight because they don't fit the criteria for a social worker on any of the social work teams. It absolutely is the role of the children with disabilities team."

   g. "Under 18, initially I'd suggest the clinical team responsible for giving the FASD diagnosis should be the accountable holder for setting up the plan and all key stakeholders currently involved in the individuals care, including parents/ carers and where appropriate the young person themselves, should be included in devising the plan. Assuming that most young people up to at least the age of 16 will be engaged in some form of education the education organisation should be then responsible for the management of the plan. For those educated outside state-run education, the private institution should also be responsible. For those who are home educated I'd suggest their paediatrician, GP, possibly disability social worker I think this should be done in consultation and with agreement of the parents/carers as the education providers for the young person. For those over 18 same at the point of diagnosis being given (hoping we get to the point where it's more simple for those over 18 to gain an diagnosis). If still engaged in education, then the educational institution. Otherwise, a significant specialist or key worker involved in supporting the individual such as disability social worker, care provider, probation where appropriate, medical professional such as psychologist or psychiatrist, etc. Ensuring 'buy-in' from across service sectors will require wide understanding of both FASD and the needs of the individual. Work will need to be done at a high level initially to gain 'buy-in'. I expect there are already legislations that could be used to underpin the need for cooperation across sectors for the welfare and benefit of the individual."

h. "This question is unlikely to get individual agreement. I think we should try and make if part of the EHCP process. I think it is reasonable to argue that FASD creates a hidden learning need so all with a diagnosis should have an EHCP - if that is the case, they will have to have an annual review - which is statutory as far as I am aware - and can go to age 25 - assuming their learning need is still there. Thereafter it will depend on the severity of their problem as to whether longer term follow up is required but it might need then to be an annual disability review - it is after all a hidden disability which we need to have exposed. We will not get purchase or resources for a separate process."

i. "Frankly it should be one named responsible person who knows the child young person well or gets to know them and has an informed wide knowledge of the local support networks available to communities. This may not be a medical professional, but could be. I would guard against setting a role in stone that would fail to yield the best possible outcome for individuals. I suspect that I would rather see a role description rather than a specific person. In terms of buy in I think that there should be an effective challenge to the EHCP process so that it is used as intended and not just having educational interventions. For those who do not need an EHCP then there is likely to be one professional working with the family who would take the role."

j. "In Scotland the GIRFEC (Getting It Right For Every Child) suggests a lead professional dependant on the age and needs of the child. So below five the health visitor may be responsible, but school age the teacher may have lead role to coordinate services. There should be a multiagency plan with an appropriate person for the age, stage and needs of the child or young person. This is more difficult to identify post-18."

How to ensure transition to adulthood goes smoothly?

462. The pre-18 care plans also must begin to plan for the transition to adulthood where all too often people with FASD drop off the radar, with tragic outcomes later, as in the case of Aaron.

463. One parent said, "I strongly believe that there is a window during maturation of those living with FASD. If we manage the support during these extremely vulnerable years 16 - 25 I think we stand a good chance of helping people like my son to keep safe and grow safely."

464. Someone else noted: "There is very little help for under 18s and none for adults. Going from waiting list for children's services to waiting list for adult services should not mean going back to the bottom of the list."

465. "We should consider appropriate transition planning as we do for a physical disability - for instance this is an opportunity to bring other professionals into the discussion which may include youth services/ justice/ voluntary sector/ charities." Someone suggested, "The final two care team review meetings are a great opportunity to plan well for transition and insist on a final array of assessments."

> **I strongly believe that there is a window during maturation of those living with FASD. If we manage the support during these extremely vulnerable years 16 - 25 I think we stand a good chance of helping people like my son to keep safe and grow safely.”**

466. “EHCPs continue till age 25 as long as there is an ‘educational need’ - it is this issue we need to get background proof on from experts in the neurocognitive delays caused by FASD. We do not want each individual to have to prove their educational need each year as the system will default to say they do not have one and so drop the work/ cost/ etc.” One practitioner noted, “Kids will be seen as not having enough difficulty to get an EHCP. They should have one because difficulties get more. Must talk explicitly in there about transition and support up to 25 embedded in EHCP. Need this as commissioners won’t do anything without money. Support workers and key workers can be allocated but it has to be there.” A practitioner commented, “EHCPs are great but limited. We need more, from social care or elsewhere. Executive functioning difficulties have to be recognised. The need for support has to be recognised and this is missing.” Another said, “Having read many EHCPs they are variable in how far they go in terms of incorporating information and how much this relates to the specific recommendations - they are education focused i.e. what will help develop the next level of skill in relation to academic learning, and they may not consider the longer term needs and level of support as an adult.”

> **The system that currently works best is if you have a learning disability (LD) and live in an area that has a cradle to grave LD nursing service. Most young people with FASD are not currently accepted into the LD service as often they do not meet the IQ level criteria that is imposed.”**

467. “I remain very concerned about this as it appears that the transition of those with special educational needs is ineffective. This has to be something that we look to influence policy on, but in reality it is much more than just an FASD issue.” Someone else said, “I think this is very challenging for children/ young people with any long-term condition. Often there is an expectation that the GP will take on care and refer appropriately for any services. The system that currently works best is if you have a learning disability and live in an area that has a cradle to grave LD nursing service. Most young people with FASD are not currently accepted into the LD service as often they do not meet the IQ level criteria that is imposed. A long-term condition approach with ongoing support into adult years works is best model. Cystic Fibrosis service has developed this way and care for those with muscle disorders.” One participant noted these frustrations also happen for those with other conditions including ASD, “Honestly what we see is very similar, you get diagnosis and are sent on your way. At least there is diagnosis and a base awareness, but there is very little in the way of formal support. Often can’t even get EHCP. For adults there is very little. An Autism diagnosis means the person is entitled to social care assessment but often that doesn’t happen. The goal for 2030 is a post-diagnostic care pathway for autistic people. This is relevant to FASD - e.g. continued link for later life difficulty. The system doesn’t exist for later support.”

468. The Autistica Support Plan was suggested as an example that may also be relevant for FASD.

469. Someone else noted, "There needs to be services for these individuals where it is not dependent on IQ. We are trying to develop that now."

470. Someone else commented, "The Government supported the development of education leads in ASD within schools. We should aim for the same in FASD."

Elements of care management plans for over 18s

471. One person said, "If the care management plan is done well pre-18 then the young person and their supporters should now feel able to continue articulating their needs and goals post-18."

472. The elements of a care management plan for those over 18 will be different in some ways. The reality is that all too often even less is done to support adults with FASD and this is perceived by families as a time fraught with possible dangers for their loved ones. As someone with lived experience noted, "Sadly there is a cliff edge from child to adult services".

473. Another person, a GP with five adopted children who were all prenatally exposed to alcohol, said he's spent 20 years trying to engage with services. "Now they are all adults and there are no commissioned services for adults. We've been in court three times in recent months with one, and can't get help. Young adults need lives improved now. It will be better in 20-30 years, but help is needed now."

474. Participants provided the following suggestions for possible elements of a care plan that can be considered for those over 18:

    a. A holistic approach is needed - as with those under 18, the individual needs to be at the centre and their parent/ carer/ elected supporter (this maybe a spouse or significant other as the individual ages). Parent/ carer involved along with FASD-aware diagnosing team

    b. Ensure engagement with individual and that they are listened to – this requires information to be presented in Easy-Read format and may need to be restated at each meeting. Support likely will be required to help the individual plan for and attend meetings

    c. A standard plan could help ensure that all are treated equally and fairly. Ideally the plans should be recognised and used across a wide spectrum of services including police, general health, education, employment

    d. Separate information packs for caregivers and those with FASD (in a format accessible for those with FASD)

    e. A designated support person will likely be required, perhaps a personal assistant

    f. Multi-disciplinary input - learning disability services, mental health services or social services will likely need to be involved. As one person described it, "Collaborative work with a network of support"

    g. Benefits and careers advice

    h. Issues about capacity need consideration, certainly in making medical decisions

    i. Risk assessments need to be included and preventative measures in place to avoid breakdown and Criminal Justice System interventions

    j. "There could be a role for a 'navigator/ co-ordinator' similar to those for people with dementia - this should be an employed role based within statutory services so it has 'teeth' to make things happen and access funds."

    k. Flexible support plans are needed due to fluctuating capacity (needs can change over time)

    l. Supported living

    m. Life skills

    n. Occupational therapy

o. An annual review might be needed ("though not to take away benefits or supports as scaffolding for someone with FASD is lifelong, but to see if further needs arise")

p. Someone with lived experience suggested, "Find funding to have trained FASD support workers/ personal assistants – so that a young adult living with FASD has a support worker who is aware that FASD is not ASD."

q. Some with FASD are parents themselves and will need additional support with their parenting. Too often the children are separated without an FASD-informed assessment[10]. Some parents may need diagnostic assessment themselves, "I see several mothers each year in my substance misuse clinic for pregnant women who I believe are very likely to have FASD, but it is even more difficult to know where to refer to be able to get a diagnosis… which might result in better support for the future."

475. Other things to consider when formulating a care plan for those over 18:

a. Recognise that adults with FASD, including care leavers, will need support in the community

b. "Ensure those with FASD receive the right scaffolding to stop them making wrong decisions leading them to the justice system, becoming homeless or taking their own lives. This will save money"

c. We have to "stop the isolation that FASD can bring to individuals/ families"

d. Reassessment may be needed. "Adults keep needing to be reassessed because they have a high level of service need. Redo assessments that were done when young child. Especially social care often misses the high level of need. Nothing changes magically at 18."

e. The care management plan needs a section where meanings of each individual element is explained, not only for families but for all professionals. "It must spell out individual needs"

f. One practitioner said, "It would be useful to have a meeting for all professionals supporting the child. When one hands child off to another then understanding is lost. Have the child at the centre, make everyone appreciate their needs. Don't just develop a plan, but make sure child's needs are understood – e.g. mental health don't understand FASD and this is a real problem. Health, housing and all other agencies need to be in a meeting to really understand the individual"

g. "The adult learning disability (LD) support service can work well for those with FASD, but many adults with FASD don't qualify as their IQs are too high so there is a model that can help if it can be extended to more people"

476. One participant said that in Kent & Medway they are seeing more and more cases of individuals falling through the gaps as they transition from children's services into adult services. The wrap around care plans and support that has scaffolded those individuals through childhood seems to disappear when they transition into adult services. Due to the extreme vulnerability and desire to accommodate others, they are becoming prey to county lines gangs, and getting involved in the Criminal Justice System (CJS). Their support groups and 1-2-1 family clinics are trying to engage with these individuals and prevent involvement within the CJS and suicidal tendencies. They are working with commissioners in Kent and Medway, and their newly formed FASD System Partnership Group, to explore transitions into adulthood with bespoke rolling management of a support package using the Individual Service Fund model that was created through the 2014 Care Act.

477. One participant suggested the original Refocusing the Care Program Approach for mental health could provide some insights into best practice. They said, "I feel the wholistic nature of the approach has been largely lost as mental health services have come under more pressure with fewer resources so it is now more of a crisis management and resource sifting process (my experience may not be representative and I suspect services for people with LD may do it better than adult mental health)."

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[10] See: National FASD, "Parents who have FASD," (2017): https://nationalfasd.org.uk/documents/Parents%20Who%20Have%20FASD.pdf.

Who should be responsible to oversee post-18?

478. The issue of who has responsibility for oversight of care management plans for those with FASD over 18 is also confused/ confusing. Someone noted: “The care management plan is often documented by health but health seems to be least involved or least accessible especially in adulthood and community services are most involved. We need to see it as a fully holistic plan cutting across all sectors including the voluntary and community sector groups.”

> **There are significant risks that individuals may fall between services and therefore end up being unsupported with no one taking responsibility.”**

479. Another participant said, “The question of who should be responsible is probably not straight forward as it is for the under-18s. If the individual is still engaged in education perhaps the responsibility could continue with education. However, as many may not be in that situation, and adult services are recognised to be disparate, there are significant risks that individuals may fall between services and therefore end up being unsupported with no one taking responsibility. Also remembering that FASD is a lifelong condition individuals may need higher levels of support as different points/ periods during their life. Could overall responsibility for adults lay with the GP as the key lifelong professional in an individual’s life? If this was the case, would they have the power, resources, tools and knowledge to be able to access all the individual would need? Alternatively, if an individual is engaged in services such as CAMHs at transition to/ from young person to adult there needs to be a much clearer coherent pathway to enable support and management plans to transfer and continue.”

480. Someone said, the question of who should be responsible to oversee care management plans post-18 “is less clear to me and needs discussion as services need to develop. At this point I don’t think GPs would have knowledge or capacity - it will fall to the young person/ adult and their carers / support key professionals.”

481. One participant suggested, “The ‘named’ individual could be any of the following: - a clinical lead - including GP, psychologist, psychiatrist - an educator/ institution - disability social worker.” Someone else said, “GP + social care + mental health will be needed to plan future needs and liaise with other services.”

Preparing parents to help support a young person

482. How to teach people with FASD how to support themselves is a core part of post-diagnostic support. This job falls primarily to parent/ carers/ guardians who themselves likely have a limited understanding of how to support someone with FASD.

483. The University of Salford, as previously mentioned, has developed a parenting course: the Salford Parents and carers Education Course for Improvements in FASD outcomes In Children (SPECIFIC).

484. One of the researchers noted that the idea of the SPECIFIC parenting course, developed with input from many others including those with lived experience, is to be the first stage in a family journey of understanding management and support for their child, how to help them advocate for their child. The goal is for this to be the first port of call after a diagnosis and could be included in care management plans in the future when the course is rolled out nationally. They are testing it at the moment in children of primary age. The course is taught in groups for three hours per week for seven weeks. They are hoping to get funding shortly for a proper trial.

485. A practitioner summarised, “The basic premise of the course is that those supporting people with FASD need to know about the underlying needs of that person and how to help them achieve the best quality of life and think about the neurological impacts on quality of life. If you don’t understand the vulnerabilities, you can’t understand the impacts. We’re trying to talk people through prevention of mental illness, prevention of harm to avoid mental health harm, prison,

sexual difficulties etc. We can't prevent it all but can minimise it in this case by educating families to give right level of support."

486. One parent noted, "The same day we were told our child has lifelong brain damage we were told there is 'no post-diagnostic protocol'. We need to empower parents post-diagnosis, not leave them devastated, the parenting course would have made a huge difference and possible avoided the mild depression I went into at a time when I should have been gearing up to learn better how to support my child."

> **We need to empower parents post-diagnosis, not leave them devastated."**

The importance of people with FASD understanding the diagnosis – new resources that can help

487. Helping young people understand their diagnosis is a key step in any care management plan for other conditions and it should be no different for FASD.

488. National FASD and Seashell have created materials to help with this as part of their partnership funded by the DHSC in 2020-2021. The "Me and My FASD toolkit" involves a website (www.fasd.me) with a wide range of peer-to-peer coping strategies, an interactive "My Brain, Me and FASD" interactive comic and booklet, hands-on materials including the Break it Down Board, Calming Cards, and The Misunderstoods: Living FASD game. National FASD has piloted a "Me and My FASD Club" featuring a new magazine "Living FASD" and other materials. They have created a 3-day training for practitioners such as learning disability nurses, SENCOs and others to help them work with young people to understand and own the diagnosis. This project grew out lived experience, when families were faced with a void in getting professionals to help their loved ones understand the diagnosis. These materials were created with input from the National FASD experts committee and the Adults and Young Adults with FASD Advisory Committee and can be purchased in bulk by local services seeking to support those with FASD.

The Me and My FASD Toolkit is designed to help children and young people with FASD understand and own the diagnosis.

The Me and My FASD Toolkit was created under a partnership between Seashell and National FASD, funded by the Department of Health and Social Care.

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Figure: Example of materials in the Me and My FASD Toolkit available from www.fasd.me

The need for research to see what works

489. It was noted that statistics from the 1990s by Streissguth are often presented to show the vulnerability of those with FASD as they enter adulthood. That research was done at a time when not as much was understood about how to support someone with FASD. One participant noted, “We need funding for research to replace the Streissguth statistics that are always quoted. Instinctively it’s logical to believe if supports are in place then these negative outcomes won’t happen, at least not to that extent. We need research to prove that. National FASD’s materials to help support individuals with FASD to understand their diagnosis, need a research overlay to see if they work. Our friends at the University of Salford have agreed to help us research the impact, but there’s no funding.”

490. Another participant highlighted, “The importance of research quantifying the prevalence of FASD (national and local level) as well as qualitative research relating to FASD and pregnancy in society/ health systems/ education settings/ etc. to better understand the experiences of those with FASD and their close contacts and therefore we can best prevent and service these populations (applying the research to policy development and programme implementation with the expertise of those with lived experience).”

491. At the end of the day, better research can increase understanding of what can help people with FASD and will inform more effective care management plans. For this to happen, funding streams need to be available and currently they are not.

> **There is no call for interventions specifically for FASD from the big funding schemes, hence we are forced to do research piecemeal.”**

> **As a researcher, the main barrier is funding. FASD projects have rarely been funded in the UK. We need to evaluate interventions, to work out which ones work, and to get evidence of cost effectiveness.”**

SECTION 8: How to train up locally and nationally

492. This roundtable explored issues related to how to meet the need for FASD training that exists and which will be further intensified with the NICE Quality Standard. Participants heard a presentation summarising two case studies: training done in Scotland and new trainings offered by the Royal College of Paediatrics and Child Health. They also heard a presentation about the need for best practices in training and preferred language as new actors enter the field. They also heard a presentation about the critical importance of engaging those with lived experience in training.

Overview

493. The workforce has not received adequate education either in their training or continuing professional development on the risks of alcohol in pregnancy nor how to recognise, diagnose or support those with FASD.

494. Currently across the UK there are only a limited (though growing) number of experienced FASD-informed trainers, support groups and organisations that have been conducting training. While some have been doing this for decades and have deep expertise to share, there is nowhere near the capacity needed to meet the coming demand for training. Attention is needed on how to scale up training.

495. With the current increased focus on FASD and related issues across all the major public health bodies, Commissioners will need to explore how staff can be quickly trained in FASD across multiple specialities. The number of those trained are among the measurable indicators in the NICE Quality Standard. It's also important that the quality of training is addressed in some way.

496. Participants heard a presentation from a specialist practitioner who said that during his training he had been taught that prenatal alcohol exposure (PAE) was "really rare." He said he then realised that six months into his position that he had seen more babies with PAE than were then estimated to be in the whole of Scotland, so he "knew something was wrong with the statistics".

497. The speaker provided details about the Scottish experience. It is useful, as mentioned previously, to learn from the experiences there as Scotland is ahead of the rest of the UK in this area. Scotland's work on FASD training has developed over several years and included:

   a. Early identification of problem needing action (public health and other senior paediatricians)

   b. Report and case made to Scottish Government

   c. Established workshops/ information sessions, conferences (with lived experience input and supported by Royal College of Paediatrics and Child Health Scotland and Royal College of Physicians Edinburgh)

   d. Scottish SIGN 156 guidelines through Health Improvement Scotland

   e. Multidisciplinary input

   f. Multidisciplinary training from Canada (2019)

   g. Establishment of Fetal Alcohol Advisory Support & Training Service (FAAST) team

   h. FASD support meetings: education/ case discussions

498. While this work (summarised more fully in the box below) was groundbreaking, someone noted that these efforts were the start of a longer process, "Despite investment early on in relation to education by Scottish Government, this requires sustained revisiting of education to clinicians." In a previous roundtable, another participant pointed out that people with lived experience are reporting they still regularly encounter practitioners in Scotland who lack understanding of FASD, so even there much work is yet to be done.

499. England and other parts of the UK are seriously behind Scotland. However, there are some positive steps including progress made with the Royal College of Paediatrics and Child Health. Participants heard an overview of the RCPCH steps as a case study. This work has involved action over recent years, including:

   a. Presentation at Annual meetings

      i. 2017 – Establishing a specialist clinic for children with FASD - Bond/ Aiton/ Bennet

      ii. 2018 - After initial refusal they were given slot at "rare diseases" conference day (Aiton/ Steer/ Johnson)

    iii. 2019 - Presentation of SIGN guidelines via a workshop (Jackson Mactier, Shields, Steer, Brown)

b. Letters to successive RCPCH Presidents:

    i. 2020 - Following Report of Commission on Alcohol Harm

    ii. 2021 - Following publication of DHSC FASD health needs assessment

c. Invited to deliver FASD workshops at BACCH conferences 2018 and 2019

    i. Aiton, Bond, Carter, Gregory, Takon

    ii. Asking questions, facial features, growth, disability assessment

    iii. Massively oversubscribed

d. A blog on the College website – Jackson

e. 2021 - Agreement to progress College-supported study day (through connections with College training through safeguarding – Dr J Carter)

f. RCPCH training days - excellent feedback

    i. Nov 2021 and Feb 2022

    ii. 2 further planned this year – July and October (TBA)

g. Article agreed for 'Milestones' – quarterly newsletter

h. Further conversations ongoing regarding:

    i. Policy development (related to alcohol)

    ii. Possibility of online training

    iii. 'RCPCH and Us'

    iv. Curriculum

i. General Progress+ curriculum (core syllabus) - modules welcomed and submitted

j. Specialist - SPIN module - later this year (equipping a specialist community paediatrician to lead a multidisciplinary team for FASD)

k. Information sessions for paediatric neurodisability and CCH Trainees

500. RCPCH courses are evaluated against their planned outcomes and CPD credits are given. The current courses evaluate well in meeting their proposed aims for attendees. It also was noted that input of lived experience from National FASD has been very well received and regarded in the RCPCH trainings.

501. The response to the RCPCH trainings shows that there is great appetite from some practitioners for training. The workshops sell out very quickly – each has 80 people and there is a waiting list of more than 200 for future meetings. But the speaker warned, "We are still preaching to the choir to some extent."

502. The speaker identified some barriers to further progress regarding training more broadly:

    a. 'Expected' reasons & attitudes, e.g. too difficult, no point as nothing can be done anyway, etc.

    b. Wariness of single-diagnostic groups

    c. Re-establishing a 'ballooning' curriculum

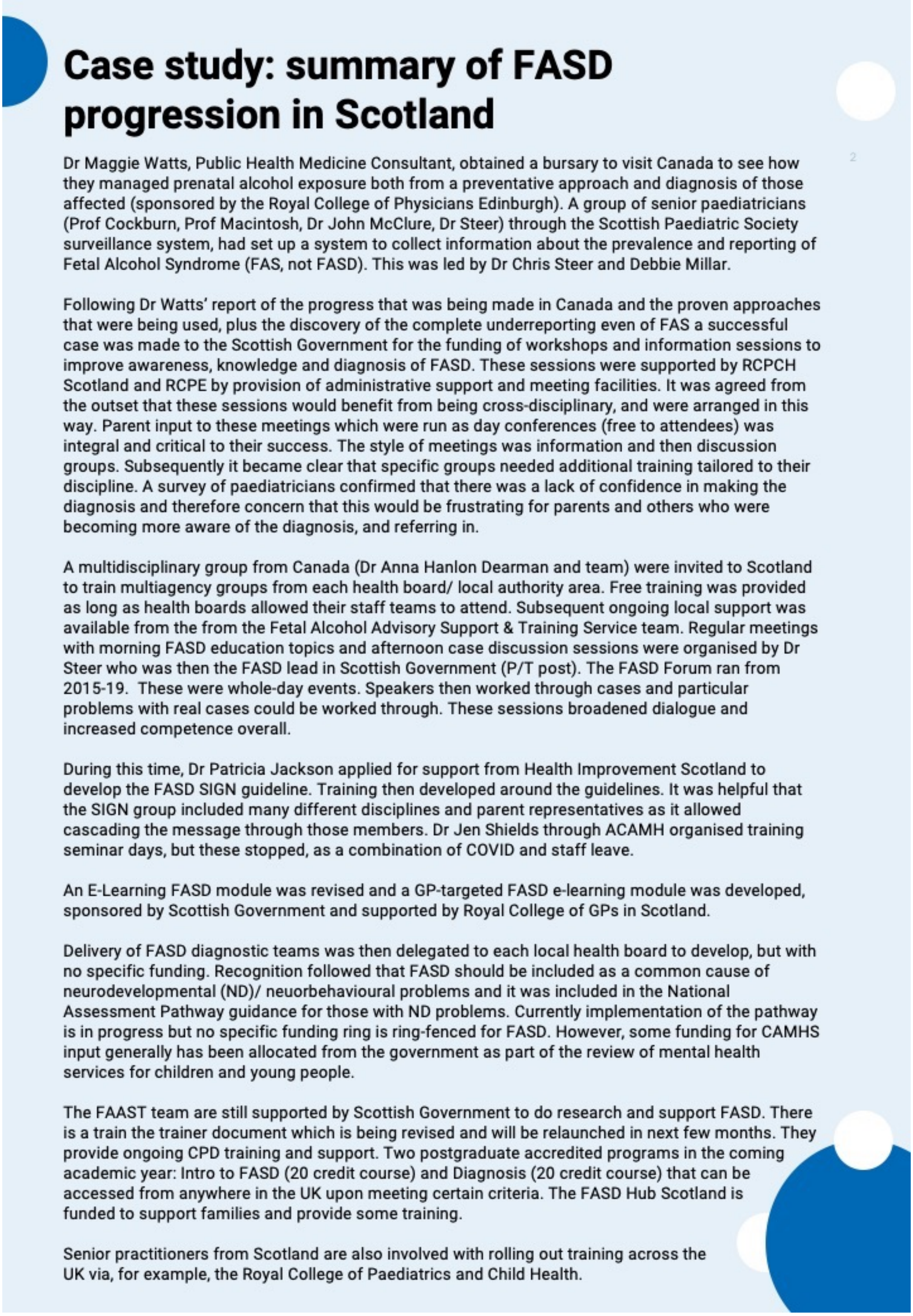
503. Someone else noted, "It is helpful for paediatricians that the College have taken on board that colleagues need to be trained. Need to integrate information into curriculum for new colleagues in training. Can't just roll out a few courses and think everything is done, it'll take much more than that."

504. The speaker said that to keep momentum going a sustained effort will be needed that looks at:

    a. Bottom-up and top-down change

    b. Support network for practitioners (some have previously suggested a national multidisciplinary Community of Practice in addition to local and sector-specific COPs)

    c. There are some real challenges for multi-disciplinary involvement that require further attention, including the need for further thoughts on how to ensure the neuropsychology assessment/ practice interaction between paediatric and CAMHS services, engaging GPs and interventions, etc.



Case study: summary of FASD progression in Scotland

Dr Maggie Watts, Public Health Medicine Consultant, obtained a bursary to visit Canada to see how they managed prenatal alcohol exposure both from a preventative approach and diagnosis of those affected (sponsored by the Royal College of Physicians Edinburgh). A group of senior paediatricians (Prof Cockburn, Prof Macintosh, Dr John McClure, Dr Steer) through the Scottish Paediatric Society surveillance system, had set up a system to collect information about the prevalence and reporting of Fetal Alcohol Syndrome (FAS, not FASD). This was led by Dr Chris Steer and Debbie Millar.

Following Dr Watts' report of the progress that was being made in Canada and the proven approaches that were being used, plus the discovery of the complete underreporting even of FAS a successful case was made to the Scottish Government for the funding of workshops and information sessions to improve awareness, knowledge and diagnosis of FASD. These sessions were supported by RCPCH Scotland and RCPE by provision of administrative support and meeting facilities. It was agreed from the outset that these sessions would benefit from being cross-disciplinary, and were arranged in this way. Parent input to these meetings which were run as day conferences (free to attendees) was integral and critical to their success. The style of meetings was information and then discussion groups. Subsequently it became clear that specific groups needed additional training tailored to their discipline. A survey of paediatricians confirmed that there was a lack of confidence in making the diagnosis and therefore concern that this would be frustrating for parents and others who were becoming more aware of the diagnosis, and referring in.

A multidisciplinary group from Canada (Dr Anna Hanlon Dearman and team) were invited to Scotland to train multiagency groups from each health board/ local authority area. Free training was provided as long as health boards allowed their staff teams to attend. Subsequent ongoing local support was available from the from the Fetal Alcohol Advisory Support & Training Service team. Regular meetings with morning FASD education topics and afternoon case discussion sessions were organised by Dr Steer who was then the FASD lead in Scottish Government (P/T post). The FASD Forum ran from 2015-19. These were whole-day events. Speakers then worked through cases and particular problems with real cases could be worked through. These sessions broadened dialogue and increased competence overall.

During this time, Dr Patricia Jackson applied for support from Health Improvement Scotland to develop the FASD SIGN guideline. Training then developed around the guidelines. It was helpful that the SIGN group included many different disciplines and parent representatives as it allowed cascading the message through those members. Dr Jen Shields through ACAMH organised training seminar days, but these stopped, as a combination of COVID and staff leave.

An E-Learning FASD module was revised and a GP-targeted FASD e-learning module was developed, sponsored by Scottish Government and supported by Royal College of GPs in Scotland.

Delivery of FASD diagnostic teams was then delegated to each local health board to develop, but with no specific funding. Recognition followed that FASD should be included as a common cause of neurodevelopmental (ND)/ neuorbehavioural problems and it was included in the National Assessment Pathway guidance for those with ND problems. Currently implementation of the pathway is in progress but no specific funding ring is ring-fenced for FASD. However, some funding for CAMHS input generally has been allocated from the government as part of the review of mental health services for children and young people.

The FAAST team are still supported by Scottish Government to do research and support FASD. There is a train the trainer document which is being revised and will be relaunched in next few months. They provide ongoing CPD training and support. Two postgraduate accredited programs in the coming academic year: Intro to FASD (20 credit course) and Diagnosis (20 credit course) that can be accessed from anywhere in the UK upon meeting certain criteria. The FASD Hub Scotland is funded to support families and provide some training.

Senior practitioners from Scotland are also involved with rolling out training across the UK via, for example, the Royal College of Paediatrics and Child Health.

Figure: FASD Progression in Scotland

Best practice in FASD training and preferred language

505. Participants then heard a presentation about the need for standards in training, using as case studies the Best Practice in FASD Training and FASD: Preferred UK Language guides, produced by Seashell and The National Organisation for FASD as part of "Resources and Training to Support Children and Young People with FASD," funded by the Department of Health in 2020-21.

506. The presenter, who has been delivering training on FASD for nearly two decades, noted that the language we use to talk about alcohol in pregnancy and FASD has changed. Some of these changes are due to the SIGN 156 terms, but others ensure the move away from blaming and shaming and to affirm the individual.

507. The FASD: Preferred UK Language Guide, states, "This is a guide. The goal is to avoid stigmatising or blaming language. Usage is highly personal - above all we respect how individuals with FASD choose to identify themselves." It includes:

    a. Terms that are stigma-free and blame-free

    b. A common description of FASD

    c. Additional terms that should be used with caution

    d. Sample sentences using the preferred language

    e. A glossary of frequently used terms

508. The language guide was created with input from the National FASD Experts Committee, the Adults and Young Adults with FASD Advisory Committee, as well as with input from other experts who participated in a special workshop exploring the issues. In addition, 136 people from across the UK provided input via an online survey. It encourages avoiding terms like "FASD sufferer".

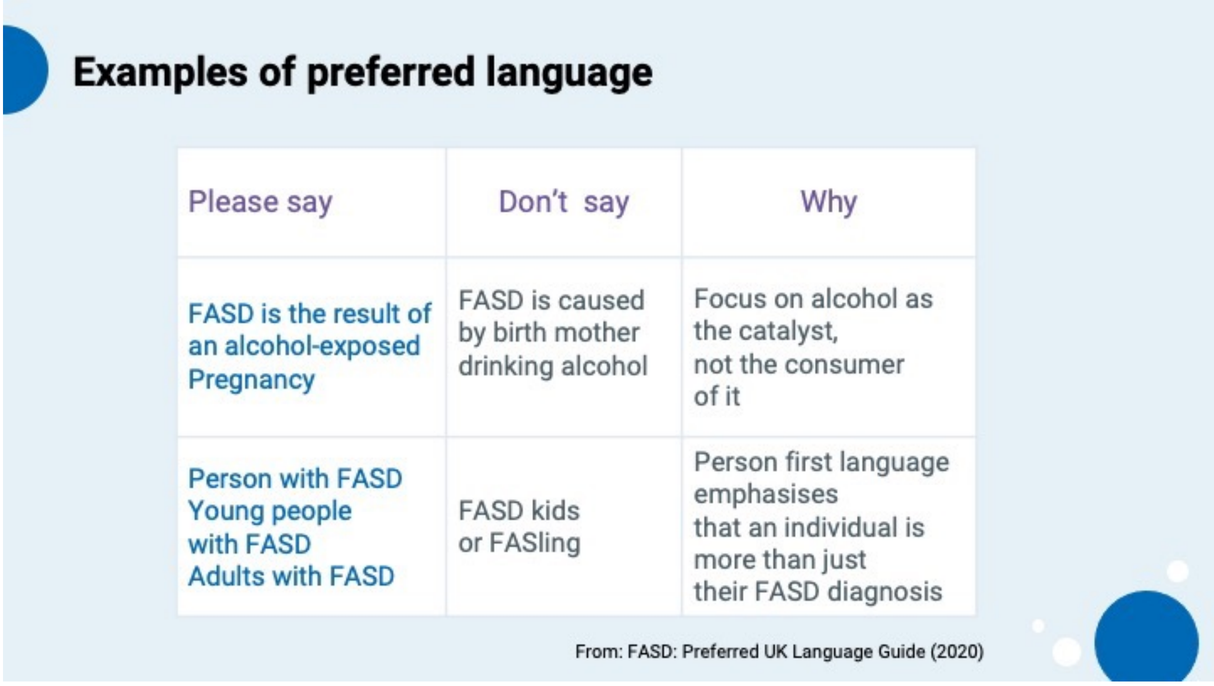
509. Participants also received an overview of the Best Practice in FASD Training Guide. The guide emphasises that "Training should be non-judgemental and delivered to promote dignity and to advocate for people with FASD". The guide was created with input from The National FASD Experts committee as well as with input from other experts who participated in a special workshop exploring the issues. It includes:

    a. A checklist for FASD training

    b. An overview of best practice in FASD training

    c. Essential content for an introduction to FASD training course

    d. A fact and fiction section, debunking myths about FASD



Examples of preferred language

Please say	Don't say	Why
FASD is the result of an alcohol-exposed Pregnancy	FASD is caused by birth mother drinking alcohol	Focus on alcohol as the catalyst, not the consumer of it
Person with FASD Young people with FASD Adults with FASD	FASD kids or FASling	Person first language emphasises that an individual is more than just their FASD diagnosis

From: FASD: Preferred UK Language Guide (2020)

Figure: Examples of preferred language

510. The guide is not meant as a template for training. It is meant to highlight best practice for consideration when engaging or creating training in the field. It has a checklist commissioners can use when commissioning training to see if the training is meeting minimum standards.

511. It focuses on the fact that FASD is a complex neurodevelopmental disorder and that "due to the nature of its origin the courses need to be delivered by or in conjunction with a trainer with FASD experience and appropriate training skills."

512. It emphasises the importance of the trainer's experience:

    a. Trainer has 3+ years' experience working in the field/ living with people with FASD or presents in conjunction with someone who has

    b. Trainer regularly updates own knowledge and skills advice

513. It sets out the following principles for any training:

    a. Reflects current UK Governmental guidance and latest scientific understanding

    b. Adheres to 'no-blame, no shame' and non-judgmental ethos as described

    c. Follows the FASD: Preferred Language Guide

514. The guide recommends that all training should include a sensitive content warning. Often someone in the middle of training will recognise that they have known someone with FASD or either they or a loved one may have had alcohol in pregnancy. It's not uncommon for people to get sad or angry in a training. It's essential to signpost to places for support or to offer to speak to anyone privately if needed.

515. Ensuring good quality training when commissioning training is most important. There is a great deal of out-of-date and negative terminology. Given the nature of the topic, all training must include hopeful notes and advice for help.

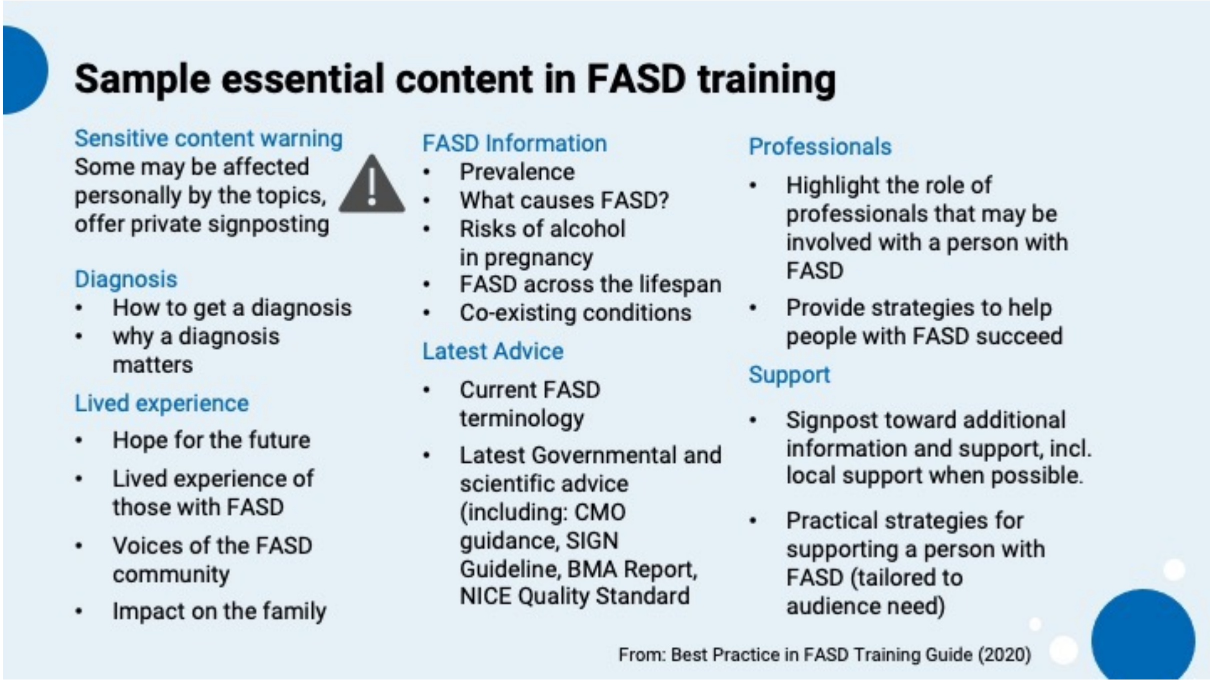
516. Someone noted that Local Authorities, health and social care could promote the Best Practice in FASD Training guide. They also could "ask any training they commission to confirm they follow the guide and it should be recorded. If we offer training for those with lived experience that would also help if they co-deliver with someone that isn't delivering correctly, they can feed that back to the commissioners. A label 'we have used the best practice guide' could be designed. A list of minimum training for different roles could be put together."

517. It was noted that where organisations are forced by financial limitations to develop internal training, just doing this by googling will never work as they will find out of date, inappropriate and decontextualised material and will produce "awful" training that can have a negative impact. It is essential to engage with people who are FASD-informed when creating training.

> **Where people are forced by financial limitations to develop internal training, just doing this by googling will never work as they will find out of date, inappropriate and decontextualised material. It is essential to engage with people who are FASD-informed when creating training."**

518. "Training should not be a tick-box exercise," said one participant. Another said, "We also must guard against people having 1 x 1 hour training and thinking they know all they need to know."

519. It is important care is given as to the content and delivery of FASD, as it's a new era and increasingly new Third Sector organisations are engaging with little prior experience with FASD. Someone else agreed that new providers are "jumping on the opportunity or are being commissioned to do it as they are a registered preferred provider for other courses."



Sample essential content in FASD training

Sensitive content warning

Some may be affected personally by the topics, offer private signposting

Diagnosis

- How to get a diagnosis
- why a diagnosis matters

Lived experience

- Hope for the future
- Lived experience of those with FASD
- Voices of the FASD community
- Impact on the family

FASD Information

- Prevalence
- What causes FASD?
- Risks of alcohol in pregnancy
- FASD across the lifespan
- Co-existing conditions

Latest Advice

- Current FASD terminology
- Latest Governmental and scientific advice (including: CMO guidance, SIGN Guideline, BMA Report, NICE Quality Standard

Professionals

- Highlight the role of professionals that may be involved with a person with FASD
- Provide strategies to help people with FASD succeed

Support

- Signpost toward additional information and support, incl. local support when possible.
- Practical strategies for supporting a person with FASD (tailored to audience need)

From: Best Practice in FASD Training Guide (2020)

Figure: Sample essential content in FASD training

The importance of including lived experience in FASD training

520. Participants next heard a presentation about the importance of including lived experience in training from someone with extensive professional experience doing FASD training and who is also a foster carer and guardian. "I did an early GP training for med students and had daughter, 8 at the time, join to talk about what living with FASD was like." (She is now nearly 20.)

521. He said that if those providing training care and want to make a positive difference to the lives of those with FASD, "We need to be able to listen to the voices of those with lived experience. The authentic voice of those who know needs to be heard, understood and above all valued."

522. He noted that often those that have the most to gain from having experienced and expert teams in organisations around them are side lined. "Things are done to them and for them rather than with them. This cannot be best practice. Increasingly the best practice in training will need to harness this experience and use it to frame the learning." With all the changes happening at the moment with FASD policy, he said, "Professionals with lived experience are particularly important at this time."

523. The Best Practice in FASD Training guide emphasises the importance of involving those with lived experience in training. It states, "It is important that the voice of the FASD community is heard within the training. It is recommended that the training include people with FASD where possible, or videos including people with FASD and quotes from people with FASD."

524. It isn't always easy to include lived experience, he commented, but "without that perspective any training can become unbalanced, and its value diminished".

525. Those with lived experience fall into two camps:

    a. The parents, guardians, relatives, siblings and carers that the children with FASD live with

    b. The children and young people with FASD themselves

526. Care must given about how to include the voices of people with lived experience:

    a. Young people and adults with FASD will need additional support on many levels to contribute to training

    b. Birth mums also need support on how to share their stories and how to speak publicly about it, too often they are stigmatised

527. The presenter noted that we have to overcome the bias that exists - medical professionals often believe that those with lived experience have nothing relevant to

say. "It's a sad reflection that very often the families of children and young people with FASD have needed to become experts in the condition. Their detailed experience is vital in understanding the strengths of people with FASD and the challenges that they face. This is vital in a condition that shows such wide individual variation"

528. The presenter gave the inclusion of those with lived experience in recent work by National FASD and Seashell as an example as it's a core element of all National FASD/ Seashell trainings. "The families where children and young people live have had the opportunity to contribute to each project that National FASD and Seashell have developed as part of the DHSC project. This runs through all of the resources, and we have ensured that a broad sweep of parents are trainers delivering the content. Adults and young people with FASD have been the driving force behind the development of the Me & My FASD Toolkit (www.fasd.me), including suggesting resources that were not part of the intial planning. Over 100 have contributed in different ways and nine young people and adults are part of the National FASD Adults and Young Adults with FASD Advisory Committee with ages stretching from 16 to 45+. In addition to being available via the website, the materials and videos they helped to co-produce are featured in the Seashell/ National FASD trainings and the 3-day training is based entirely on these materials. It was described by one person who took part in the pilot as being "the most child-centred I have come across for FASD".

> **"The most authentic and important voice comes from those who live with FASD each and every minute of the day."**

529. There are challenges with engaging lived experience in training. "Working with any children and young people to allow them to give their voices on issues and topics that affected them is never easy. Ensuring that real emphasis is placed on their lived experience is even harder," said one person. Challenges include:

    a. Very few families have experience being asked about or in presenting their lived experience

    b. The demands of living with someone with FASD can mean that at times the capacity to make the contributions can vary in the moment and means some might need to cancel at short notice (recordings of lived experience can often help)

    c. Many with FASD might not be able to contribute to virtual or face-to-face meetings and when they do they may need significant scaffolding and creative presentation styles (for example a Q & A format versus a set presentation can help). Budgets will be needed to help with travel for them and a supporter, and care must be taken to ensure they are able to participate in the discussion and are not only there in a token way

    d. With FASD, behaviours at home compared to other 'official' places can be quite different and therefore we need to ensure that what parents, carers, siblings and even partners say is perceived as real experience rather than professionals dismissing it and assuming that it is being embellished or fabricated

    e. "To allow them real voice, every communication and report needs to be accessible to those with FASD. This is not yet done, even by National FASD, though we are committed to doing this better. Without this level of real inclusion their hugely valuable contributions will be limited." The presenter said, "I'm not going to pretend it is easy to get input from those with FASD, it's not. Pre-COVID, we had intended to have a series of face-to-face meetings and workshops to obtain this lived experience. With lockdowns, we tried to engage people with FASD in Zoom team meetings, but this too was a challenge too far. To help overcome some of the obstacles, National FASD:

        i. Provided iPads to all advisors with FASD

        ii. Invested time on individual discussions

        iii. Organised COVID secure meetings with family bubbles

        iv. Dedicated significant time to make it happen, this was vital and made it possible to understand what was needed and the best way to allow people with FASD engage

v. Built flexibility into the planning

vi. Budgeted for the added costs and helped funders to appreciate these costs are necessary for true co-production.

530. Someone commented, “The big worry is that people aren’t willing to pay for good training that incorporates (at a certain expense) the voices of those with FASD.”

531. It must be noted that not everyone values lived experience. The presenter (a former headteacher) said, “From my personal experience and by no means is this isolated, my contributions on FASD have been dismissed as I have no medical qualifications. Yet we know FASD demands a multi-agency approach that includes those with the condition and those who live with them. My 15 + years of FASD experience and training have been described as ‘research’ in official reports by the adoption service only last year. Also, when supporting my then foster son regarding his care plan, social services have looked for alternative advice about FASD, because they didn’t regard my experience as valid. This being the same Local Authority that was commissioning my services to support other children with FASD elsewhere. This is not isolated, a family friend who has a child with FASD who has presented nationally about the topic has been told in no uncertain terms not to mention that they live with someone with FASD because if the audience knows that the message given will be devalued. So, we need to create a training environment that engages with the parents and carers of children and young people with FASD and values their contribution.”

532. However, he warned, it’s also critical to understand the limitations of the voice of parents and carers. “As parents and carers, we don’t really know what it is like to live with FASD. The most authentic and important voice comes from those who have FASD and who live with FASD each and every minute of the day.”

> **Including people with lived experience has always been the most powerful teaching tool at any FASD conference or training forum I have attended.”**

533. He noted the good news is that there is an ever-growing group of children, young people and adults with FASD in the UK who want to make a difference to the lives of others with FASD. In the past some have sat in front of the All-Party Parliamentary Group on FASD and other official bodies and have spoken about having FASD, the good and the not-so-good. Others have appeared on national and local TV and radio and in the printed media. “Significantly they have guided the National FASD/ Seashell preferred language guide that outlines how they wish to be portrayed as people with FASD in national discussions. “

> **“Properly co-produced, co-led training is vital for excellence.”**

534. These considerations matter. As someone commented, “Including people with lived experience has always been the most powerful teaching tool at any FASD conference or training forum I have attended.”

535. Someone noted that “Properly co-produced, co-led training is vital for excellence.” Another said, “Don’t undersell training that includes lived experience.”

How to ensure training is fit for purpose

536. Participants considered ways to ensure training is fit for purpose. One participant said, “We need people with proper training and expertise to deliver trainings.” That said, there is no one-size-fits all.

537. Several participants highlighted that the length of training matters. “Half days don’t do it. It gives a flavour but is only a starting point. Even a three-day training is a start of a cycle of training for a true expert.” Several participants said that two hours (a commonly requested session length) is “not enough”. One thought that Initial training could be two hours to

cover the basics, but further training would be needed on specific aspects, including how to obtain information from birth family about alcohol use in pregnancy and how to explain the implications of alcohol exposure/ risk of FASD to prospective and current foster and adoptive parents, for example. Someone noted, "Two hours isn't long enough for staff to disengage from all their ongoing work concerns and focus on a subject which is emotive and asks them to revise their current practice."

538. Someone else thought that while "Two hours training is not adequate, it might be better than nothing. Main issue is how qualified the trainers are. Can The National Organisation for FASD maybe try for some kind of accrediting courses [for those that are not accredited otherwise]?"

539. Another participant said that different levels of training will be appropriate for different professional roles. "For example, two hours may be appropriate for some staff but inappropriate for the social workers in your example. Training should be mapped onto professional roles, not only by discipline but also their current post, and subject to accreditation, albeit that will be hard to implement and monitor."

540. Someone else said, "Some kind of national audit of quality of services would be useful, measuring against SIGN or NICE guidelines."

541. Another person said, "Training is best delivered in my opinion under the auspices of recognised organisations/ sponsors with experienced and recognised presenters. Scottish Government sponsorship ensured accountability and employed experienced folk; presumably the RCPCH did something the same. RCPsychiatry needs some training days and so does the RCGP. Any training exercise needs IMO to be followed up by feedback analysis of acceptability and effectiveness."

542. Someone else noted the importance of what happens post training and commented that professionals who have recently accessed training need access to supervision and support following the training.

543. Another practitioner said, "Although the DHSC FASD Health Needs Assessment clearly set out a need for training professionals, if regulators like HCPC (who are the professional regulatory organisation approving training courses for clinical psychologists, educational psychologists, occupational therapists, physiotherapists) are not willing to consider conditions-specific training, then how do we ensure newly qualified health professionals have adequate training?"

544. Someone noted that it's not enough to think about training for professionals. It's also important to train families and individuals. "People with FASD must own their own FASD so they can understand themselves – this is the way they can be part of the world is to understand." (Please see the prior section for more information about this.)

> **“It's not enough to think about training for professionals. It's also important to train families and individuals.”**

545. There is a need to identify short-term and long-term training goals nationally and locally, according to another participant. "It's key to embed FASD into multiple Colleges training, so in ten years' time everyone will have a basic level of understanding. With Autism there are different levels 1, 2, and 3 – with 3 being real experts." There may be some areas that will need to be prioritised in the shorter-term. Someone said, "We need to be looking at where screening will occur and how we skill up the screeners."

546. The importance of engaging with local experts when possible was emphasised, "Flying in and flying out after short training can be bad, a locality-based element to training can be very valuable. If people doing training are also supporting families in an ongoing way then it is seen as more solid and reliable. A deep dive into an area can be massively important."

547. Someone noted, "Best practice should also be based in the full understanding of the locality. Generic courses are popping up which may or may not be good quality but without knowing the exact commissioning in localities they fall short of being suitable. Attendees come out with general awareness of FASD and the theoretical mechanisms rather than being able to immediately apply the local routes and pathways to diagnosis and support for families. One area is not like another and what resources are in one are not in another. Local trainers with lived experience who

understand local resources as well as having expertise in FASD have considerable impact which must not be underestimated."

548. Equally, it was noted that it's important to do the training involving local people sensitively. Those doing it must be sensitive and engaged. Bringing people with lived experience into a room with the same professionals have who have previously failed families can sometimes cause challenges and be triggering for both the families and professionals. It was noted that it can also work that professionals are outraged that work they have done for a family has been wasted/ ineffective due to systemic lack of understanding of FASD and can sometimes lead to change.

549. Another participant said, "It's great to see examples of best practice, it would be good to have a generic/ centralised package training day that can be used and is user-friendly so that people can offer training in local areas. Obviously having been trained first!"

550. Someone else suggested FASD trainer practitioner accreditation should be developed.

551. It was noted that two postgraduate accredited programs are in development at the University of Edinburgh and will be rolled out in the coming academic year: Intro to FASD (20 credit course) and Diagnosis (20 credit course) that can be accessed from anywhere in the UK upon meeting certain criteria.

> **"FASD is so prevalent that it should be included in all health professional basic training."**

552. One person noted, "FASD is so prevalent that it should be included in all health professional basic training." Other suggestions for training included:

    a. Break down training and offer in multiple sessions

    b. A modular approach with points towards a final certificate once all competencies are completed.

    c. Make it accredited training

    d. Develop themed training on FASD for different audiences i.e. families, teachers, social workers, safeguarding, disability services, substance misuse, midwives, etc.

    e. Include issues such as values/ beliefs of the trainees to get them to explore their own biases which may get in the way of helping people

    f. Listening skills are also vital in developing relationships with parents, carers and people with FASD

    g. Offer refresher training

    h. Training must be ongoing and sustained:

    i. Integrate training about FASD at the earliest possible stage for all health staff

    j. Multi/ interdisciplinary training among all those who can contribute to assessments and support plans should be encouraged

    k. Training must be properly funded

    l. "Tailor training to the level of the courses. For example, not everyone needs trained in diagnosis as only certain professions will be recognised as qualified to do this but all health professionals should know what its needed to diagnose so that any referrals they make will be recognised"

    m. Funding must be made available. One participant noted, "CCG are saying they won't keep paying for one off training"

    n. Using keen 'early adopters' at the courses to consider becoming 'local champions' and helping to foster and support ongoing local network development (this of course is something which takes time as well as resources)

Vehicles to meet future training needs

553. One participant said this increased emphasis on FASD across public health bodies, while welcome, necessitates a focus on how to develop training to meet the need, “Awareness might be raised to the point where existing structures and experts cannot meet the training need.”

> **Awareness might be raised to the point where existing structures and experts cannot meet the training need.”**

554. To meet the coming need for training, there needs to be more buy-in throughout the system. One person suggested, “Health Education England needs to be engaged in training approaches. HEE needs to have FASD in post-graduate curricula.”

555. Broader training for a wider group of professionals is critical. Someone noted, “This should be included at a basic level in undergraduate training and not just post grad. “ Another said, “The drip-drip feed of ongoing lobbying to encourage practitioners is vital. The Royal College Psychiatrists has been very slow. There has to be a progressive approach.” Other professional bodies/ fields who need to consider FASD training include:

    a. RCGP
    b. RCPhysicians
    c. RCPsych
    d. RCPCH (continued progress)
    e. Speech and Language
    f. The Royal College of Nursing (RCN)
    g. The Royal College of Obstetricians and Gynaecologists
    h. Royal College of Midwives
    i. OT/ Physio
    j. Educational Psychologists and specialist teachers
    k. Engagement with social work staff working with children and young people in assessment process
    l. Other voluntary sector colleagues
    m. “Work with trainees - all trainees need to be assessed for competency in FASD”
    n. Lawyers (including disability and SEND lawyers) and the Criminal Justice System
    o. Pharmacists
    p. Sexual health clinics

556. Some have suggested cross-seeding across colleges. Someone said, “The more joint/ collaborative work the better - like the intercollegiate document which governs safeguarding training for each role.” Another said, “I think a joint paper from RCPsych and RCPCH emphasising the multiplicity of problems that a young person might have would be good.” There are some indications this is moving forward following these roundtables.

557. Someone noted, “This is all about training health professionals and social workers. What about training all school staff - teachers, learning support assistants, dinner supervisors, receptionists, caretakers, etc.? Also, educational psychologists, speech and language therapists, occupational therapists and physiotherapists need to understand FASD and how to assess individuals with FASD. Just doing the medical staff will not be enough.”

    Someone else said, “Educational needs could potentially be the topic of an entire series of roundtables,” one person said. Ideas for reaching education colleagues include:

    i. Virtual school heads/ designated teachers/ and post-adoption support
    ii. Link training need to pupil premium plus funding
    iii. SENCO networks could also be utilized

558. Participants identified others who can help with widening out training:

    a. Local parent carer forums should be involved with workforce development meetings within the local area, these should be good for covering basic awareness/ introduction to FASD. Training for parent carers forums themselves could be useful. “There is a national parent carer forum every year, it would be good to deliver to every parent carer forum in one go and then they can go back to their local area and see what is happening and have a better understanding of the needs of the families”

b. The LA workforce development should draw up an action plan of how it intends to roll out training, to essential staff and who they are, timescales etc.

c. Health watch could get involved

d. “In Scotland we have training for Children’s Panel members (children’s judicial system) Same could be done for Juvenile courts in England and the police should also be trained/ have basic awareness and knowledge”

e. “ICS seem as though they will be a better approach for the high level of training needed for health care professional and that will fit with the Hub and Spoke model”

f. “It is also important to think of the wider community and voluntary groups who often have a local area voluntary sector forum, which would be a good way to filter training out into the community”

g. “The holiday activity fund (HAF) and short break also use local community resources so by training going to these groups that would also spread into the community”

h. “Support groups will be ideally placed to train families once the training is developed as long as they have access to training themselves”

i. “Over the years we have engaged with the training programme leads in different settings and have been invited to do sessions for them. In addition, we deliver ad hoc sessions with teams i.e. paed training days where we are asked to do a session as part of that. It doesn’t then feel extra, just simply part of what needs to be offered”

j. Embed within local safeguarding boards free training offer

k. Make FASD training compulsory as part of key partners induction programmes and core training

l. “Food tec teachers cover diet in pregnancy we need to make sure alcohol is included in their training”

m. “Both local and national training have advantages; providing nationally developed training can help ensure quality and consistency of message whereas speaking to the local context can engage participants and speak to local systems and issues”

559. One participant highlighted that Scotland has used different models over time, and it included ensuring those involved with deciding the process themselves had refresher training on FASD:

a. From 2013 – 2019 they held whole day (or two day) trainings with introduction and basics, then worked examples, followed by mentored group tasks to assess understanding and potential competence in real world situations. Funded by the Scottish Government, this involved three visits by a multidisciplinary team from Winnipeg, Manitoba to share expertise in a collegiate and supportive setting. Teams were invited from all Health Board regions. Feedback regarding acceptability and usefulness was positive.

b. The Scottish Government also funded and supported the biennial FASD Clinical Forum from 2015-2019, with guest speakers and presentations followed by worked examples and problem-solving sessions where clinicians were able to present their own cases and seek feedback from the group and expert panel. These formats, particularly the formal training days, invited active learning and participation. They were enjoyable and avoid a ‘tick box’ exercise. Folk who may be struggling with definitions and concepts were supported and it was possible to include some friendly rivalry between different groups during Q/ A sessions too.

E-learning – prospects and limitations

560. E-learning is an increasingly flexible way to do training on a wider level, though it too has some limitations.

561. One participant gave a summary of the development of FASD e-learning in Scotland as a case-study. Scotland developed its first e-learning module in 2013. This “atrophied over time” and they did a “refresh” in 2019. Originally, it used to be more discursive and was for a social work audience. It includes self-tests and takes a couple of hours. It was clearly noted that this training is “not enough to actively work on the topic or teach colleagues.” It should be seen as a primer for further learning. The most recent e-learning resource has some self-testing sections to assess knowledge, although it is quite broad brush in order to suit a wide ‘health and social care’ grouping. The Scottish e-learning is accessible to everybody. “It’s a primer, an introduction and personal involvement, investment is necessary. It’s not a panacea.” It was noted that it helped to “get silos of rivalry between health boards, friendly rivalry, on self-improvement.”

562. One participant from the University of Hull noted they have “early agreement in principle from eLearning for health for an alcohol in pregnancy for midwives and maternity service user module. Health improvement in practice are also developing a module covering smoking, alcohol, and obesity management in pregnancy for midwives. So, some overlap between these but we are liaising to share resources and knowledge.”

563. National FASD has a new e-school featuring an introduction to FASD CPD-accredited course (3.5 hours) with plans to further develop the school with free e-learning for midwives, a mix of smaller free modules on a range of topics and more in-depth and focused courses for various sectors.

564. Someone suggested it would be useful to embed within GP/ paediatric e-learning service providers to mandate training requirements. Other discussions are ongoing to see if it might be possible within the e-learning for health framework.

> **E-learning may represent a good start point for many as preparation for attending ‘live’ training.”**

565. One person said, “I think that the e-learning resources are likely to be less effective, although they may represent a good start point for many as preparation for attending ‘live’ training.”

566. Someone else said, “Online is great if staff group have access to computers for suitable length of time - many don’t. Evidence indicates training teams together results in greater retention and better implementation. Hard copy resources are useful as it’s often a while between training and putting into practice. Planned updates and a way to catch new staff are important.”

567. Someone else said, “I’ve joined quite a few online courses - they are very variable in quality. Many of them seemed to be orphaned i.e. set up but not maintained or updated.”

Sample educational and training resources

568. Below are some links to educational and training resources. Please note the list below is not exhaustive, it is just a starting point to direct toward solid information. There are many other links provided throughout this report:

    a. FASD: Preferred UK Language Guide (Seashell/National FASD) – https://nationalfasd.org.uk/bestpracticefasdtrainingguide/

    b. Best Practice in FASD Training Guide (Seashell/National FASD) - https://nationalfasd.org.uk/bestpracticefasdtrainingguide/

    c. SIGN 156: Children and young people exposed prenatally to alcohol (the website had additional resources) - https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol

d. FASD: Parent and carer information booklet, Health Improvement Scotland/ SIGN, https://www.sign.ac.uk/assets/pat156_fasd.pdf

e. The FASD e-Learning module (anyone can create a TURAS account to access this) https://learn.nes.nhs.scot/ to improve their knowledge

f. Fetal Alcohol Advisory Support Team (https://www.faast.ed.ac.uk) - funded by Scottish Government with a national remit to provide and facilitate training, consultation and research in order to enhance the capacity, knowledge and confidence of Scotland's health and social care workforce in their work with those affected by Fetal Alcohol Spectrum Disorders (FASD)

g. The National Organisation for FASD (https://nationalfasd.org.uk/) – Their website is a source of information and resources. National FASD provides 1-day and 3-day trainings developed as part of their partnership with Seashell, funded by a DHSC grant in 2020-21. National FASD also has an e-school (https://eschool.nationalfasd.org.uk) which features an interactive introduction to FASD e-course that was created with funding from Greater Manchester Health and Social Care Partnership and which can be purchased in bulk by local authorities. A free midwives e-course is coming soon, funded by Diageo

h. FASD Hub Scotland (https://www.adoptionuk.org/fasd-hub) - information service, advice, support, and training for all parents/ carers (adoptive, biological, foster and kinship) of children, young people, and young adults with a history of prenatal alcohol exposure (PAE), with or without a formal diagnosis of Fetal Alcohol Spectrum Disorders (FASD).

i. RCGP FASD e-learning course for GPs (need to sign up for free RCGPaccount) - https://elearning.rcgp.org.uk/course/info.php?id=483

j. Department of Health and Social Care: FASD Health Needs Assessment - https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment/fetal-alcohol-spectrum-disorder-health-needs-assessment

k. Drymester - Alcohol-Free Pregnancy https://www.drymester.org.uk/

l. FASD and Sleep Courses for Paediatricians and Sleep counsellors. Developed by Sleep Scotland with support funding from Scottish Government. Available online to anywhere in the UK - https://sleepscotland.org/

m. FASD Network UK – provides training, support and commissioned services primarily in 15 areas in the North East but also nationally - http://www.fasdnetwork.org

n. FASD UK Alliance – this is an informal coalition of groups and organisations across the UK who provide training (most of these trainings will include lived experience) and who can be contacted for people to involve in trainings to add lived experience - https://fasd-uk.net

o. FASD at Salford – provides some of the latest information about research. https://hub.salford.ac.uk/fasd/

p. Foetal Alcohol Spectrum Disorder: unlocking minds and opening doors, Open Door Learning Tools, Neuro Key (Tees Valley, Durham and North Yorkshire Neurological Alliance), December 2020. https://www.na-tvdny.org.uk/wp-content/uploads/2020/12/NeuroKey-FASD_Brochure-2020.pdf

ANNEX 1: Participants list

Please note all participants took part in their individual capacities and not as representatives of their organisations. Affiliations are listed for identification purposes only. There was no attempt to achieve consensus. This report is the sole responsibility of the co-chairs. This is the full list of participants who participated, not everyone was at every roundtable. The co-chairs would like to once again thank everyone who participated for sharing their time, insights and expertise.

Sandra Butcher (co-chair)
Chief Executive, National Organisation for FASD; Member National FASD Experts Committee; Specialist Committee Member, NICE Quality Standard on FASD (lay member)

Prof Raja Mukherjee (co-chair)
Consultant Psychiatrist, Clinical Lead Adult NDD & FASD, CCIO-PLD, Foetal Alcohol Spectrum Disorder Service, National FASD Clinic, Honorary Professor University of Salford; Member National FASD Experts Committee; Specialist Committee Member, NICE Quality Standard on FASD

Dr Neil Aiton
Consultant Neonatologist, University Hospitals Sussex NHS Foundation Trust, Honorary Senior Lecturer, Brighton & Sussex Medical School, Specialist Committee Member, NICE Quality Standard on FASD

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

Prof Gillian Baird
Professor of Paediatric Neurodisability, Honorary Fellowship of Royal College of Speech Therapists, Honorary Fellowship of Royal College of Paediatrics and Child Health, Vice President of the National Autistic Society; Vice Chair, NICE QS on FASD Committee

Dr Carolyn Blackburn
Reader in Interdisciplinary Practice and Research with Families, Birmingham City University; SEND Consultancy; Member National FASD Experts Committee

Dr Michelle Bond
Consultant Paediatrician, Sussex Community NHS Foundation Trust, Medical Adviser for Adoption & Fostering - Brighton & Hove, Named Dr for Children in Care – Brighton & Hove

Dave Boulger
Head of Population Health, Greater Manchester Health and Social Care Partnership

Aliy Brown
Project Manager, FASD Hub Scotland and FASD Lead for Adoption UK

Joanna Buckard
Director of Innovation, National Organisation for FASD; Director Red Balloon Training & Consultancy; Member National FASD Experts Committee

Martin Butcher
Herts FASD Support Network Chair

Dr Alexandra Carlisle
FASD Clinic Lead, Neurodevelopmental Specialist Clinician and Chartered Clinical Psychologist, Fetal Alcohol Spectrum Disorder Service, National FASD Clinic, Surrey and Borders Partnership Trust

Dr Peter Carpenter
Chair Neurodevelopmental Specialist Interest Group, Royal College of Psychiatrists

Dr Jamie Carter
Consultant Paediatrician, Designated Doctor for Safeguarding Children (Brighton & Hove & West Sussex) & Designated Paediatrician for Child Deaths, Sussex, Honorary Clinical Senior Lecturer BSMS

Maria Catterick
Founder/ Director, FASD Network UK

Maria Chase
Practice Support Consultant, Fostering Network

Richard Clements
Primary Care Manager – Primary Care Transformation, NHS North East London Clinical Commissioning Group

JoanneCole
Head of Operations, Neuro Key

Prof Penny Cook
Professor of Public Health, School of Health and Society, University of Salford

Dr Ken Courtnay
Chair of the Intellectual Disability Faculty of Royal College of Psychiatrists

Mandy Craig
SCSP Vulnerabilities Manager, Sheffield Children Safeguarding Partnership (SCSP)

Monica Davison
National Maternity Programme Manager, Maternity & Change, Early Years, Children & Family Directorate, Office for Health Improvement and Disparities (OHID)

Clare Devanney-Glynn
Spotlight on FASD; Specialist Committee Member, NICE Quality Standard on FASD (lay member)

Dr Avani Devkaran
GP Lead for Integrated Paediatrics, Herts and West Essex ICS

Angela Dillon
Designated Nurse Looked After Children and Care Leavers, Leeds, Leeds Community Healthcare NHS Trust, Safeguarding and Looked After Children's Team

Dr Ges Gregory
Consultant Neurodevelopmental Paediatrician, Lead Paediatrician for Children in Care, Children, Young People and Families Directorate Cambridgeshire and Peterborough NHS Foundation Trust

Jan Griffin
Birth Mum and Son; Member National FASD Experts Committee

Georgia Harper
Embracing Complexity Lead

Katie Hewitt
Workforce Development Manager, Sheffield Children Safeguarding Partnership

Dr Cassie Jackson
Director and Clinical Lead, Centre for FASD; Member National FASD Experts Committee (unable to attend roundtables but contributed input)

Dr Patricia Jackson
Honorary Fellow University of Edinburgh Department of Child Life and Health, Co-Chair SIGN 156 Guideline Group: Children and Young People Exposed Prenatally to Alcohol

Michelle Jones
Head of Sensory Support Service (Seashell), Seashell; Member National FASD Experts Committee

Andrew Keeping
CEO, FASD Awareness

Dr Ashley Liew
Consultant Child and Adolescent Psychiatrist, Learning Disabilities Service, Forward Thinking Birmingham, Consultant Paediatric Neuropsychiatrist, Birmingham Children's Hospital

Adelle Lynch
Senior Policy Manager - Alcohol, Office for Health Improvement and Disparities, Department of Health and Social Care

Susan McGrail
FASD Greater Manchester; Member National FASD Experts Committee

Rachael Nielson
Alcohol Exposed Pregnancies Project Manager Population Health Team - Greater Manchester Health & Social Care Partnership

Dr Frank O'Kelly
General Practitioner, Amicus Health, Vice Chair EPCCB, Member Armed Forces CRG

Dr Suzanne O'Rourke
Fetal Alcohol Advisory Support and Training Service

Rob Owens
Caseworker for Bill Esterson MP

Jo Pennell
Independent Paediatric Occupational Therapist, Treetangle Occupational Therapy, former Consultant Occupational Therapist and Clinical Lead Post Order Service, Surrey and Borders Partnership NHS Foundation Trust

Prof Moira Plant
Emerita Professor of Alcohol Studies, University of the West of England

Melanie Powell
Commissioner, NHS East and North Hertfordshire and Herts Valleys Clinical Commissioning Group

Dr Alan Price
Lecturer in Psychology, Liverpool John Moore University, Research Fellow FASD Salford, University of Salford

Miranda Reid
Executive Assistant/ Office Manager, National Organisation for FASD

Roisin Reynolds
Senior Advisor, Alcohol Exposed Pregnancies, Greater Manchester Health & Social Care Partnership; National FASD Trustee; Specialist Committee Member, NICE Quality Standard on FASD

Brian Roberts
Field of Enterprise Training, Consultant, National FASD; Member National FASD Experts Committee

Dr Jonathan Sher
Senior Fellow & Programme Lead, Healthier Pregnancies, Better Lives, Queens Nursing Institute Scotland

Sue Sharp
Hertfordshire FASD Support Network; Member National FASD Experts Committee

Casey Sharpe
Senior Alcohol and Gambling Research Officer, Office for Health Improvement and Disparities

Jasmin Shepherd
Team Leader, Alcohol Population Health, Department of Health and Social Care

Anya Sizer
Councillor for Hoxton East and Shoreditch, Regional Organiser for the Fertility Network UK

Maxine Smeaton
Chief executive Epilepsy Research UK (formerly Mencap)

Prof Lesley Smith
Professor in Women's Public Health, The University of Hull

Cecilia Stevens
Deputy Designated Nurse for Looked After Children and Care Leavers, NHS East and North Hertfordshire and Herts Valleys Clinical Commissioning Groups

Dr Christopher Steer
Recently retired neurodevelopmental paediatrician; co-author of SG/NES E-Learning Course on FASD

Oliver Susoy
Policy Manager, Alcohol, Healthy Behaviours Team - Prevention, Community and Social Care Group, Department of Health and Social Care

Dr Inyang Takon
Consultant Paediatrician, Queen Elizabeth II Hospital, East and North Hertfordshire NHS Trust; Member National FASD Experts Committee; Specialist Committee Member, NICE Quality Standard on FASD

Henry Wright
Policy and Alliance Coordinator, Learning Disability England

Jane Young
Director, Sylvia Adams Charitable Trust

Dr Sebastian Yuen
Consultant Paediatrician, Chesterfield Royal Hospital, Designated Doctor for Safeguarding Children (Derbyshire)

ANNEX 2: The NICE Quality Standard

This section is provided to give a quick overview of the NICE Quality Standard on FASD, which was published on 16 March 2022 as this report went to press.

The NICE Quality Standard includes details about what it means for different audiences, including service providers, healthcare professionals, commissioners, pregnant women and children and young people with FASD and should be read in full. It also includes details on how improvement can be measured. Quality Standards are not mandatory but "when exercising their judgement, professionals and practitioners are expected to take this quality standard into account, alongside the individual needs, preferences and values of their patients or the people using their service."

For related information see SECTION 1: Why the time is now, p. 13, SECTION 2: Who to involve in planning, p. 21 and SECTION 3: Business case, p. 29.

Please see the full Quality Standard here: https://www.nice.org.uk/guidance/qs204

QUALITY STATEMENT 1: Advice on avoiding alcohol in pregnancy

Pregnant women are given advice throughout pregnancy not to drink alcohol.

For related information see SECTION 6: Prevention, p. 83

Rationale: "Drinking alcohol during pregnancy increases the risk of harm to the baby. There is no known safe level of alcohol consumption during pregnancy and the UK Chief Medical Officers' low-risk drinking guidelines state that the safest approach is to avoid alcohol altogether to minimise risks to the baby. Midwives and other healthcare professionals should give women clear and consistent advice on avoiding alcohol throughout pregnancy, and explain the benefits of this, including preventing fetal alcohol spectrum disorder (FASD) and reducing the risks of low birth weight, preterm birth and the baby being small for gestational age."

Quality Measures:

a) "Evidence of local arrangements to ensure that midwives and other healthcare professionals carrying out antenatal appointments are aware of the risks of drinking alcohol in pregnancy, including FASD, and the advice in the UK Chief Medical Officers' low-risk drinking guidelines on alcohol consumption in pregnancy."

b) "Evidence of local arrangements to ensure that antenatal appointments include discussion of the risks of drinking alcohol in pregnancy and the advice in the UK Chief Medical Officers' low-risk drinking guidelines."

Outcome: Rate of alcohol-exposed pregnancies.

Other selected points:

- Healthcare professionals have training on FASD awareness and alcohol brief interventions.
- Verbal and written advice is provided to pregnant women.
- A non-judgemental approach is used, discussing any concerns and providing support according to the woman's needs, which may include a structured conversation, help to stop drinking through a brief intervention and signposting, or referral to specialist services.
- Commissioners commission maternity services that give advice at antenatal appointments about not drinking alcohol during pregnancy. They commission services for pregnant women who continue to drink but are not alcohol dependent and for those who are alcohol dependent.
- If pregnant women are worried about already having drunk alcohol during pregnancy or want support to stop drinking, they are reassured and offered further help.

QUALITY STATEMENT 2: Fetal Alcohol Exposure

Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded.

For related information see SECTION 6: Prevention, p. 83

Rationale: "Talking about and recording alcohol consumption during pregnancy allows personalised discussions about the risks of alcohol use as part of routine healthcare throughout pregnancy. It also gives opportunities to offer tailored support and interventions if the woman wishes to cut down or stop drinking. This may reduce risks and improve outcomes for the mother and baby. Women should be asked about their alcohol consumption in a sensitive, non-judgemental way. Women who wish to discuss their alcohol use should be asked about the quantity, frequency and pattern of drinking, and this should be documented in their maternity records. This information may also help support early diagnosis and treatment for children with fetal alcohol spectrum disorder (FASD)."

Quality Measures:

- "Evidence of local arrangements to ensure that antenatal appointments include discussion about drinking alcohol in pregnancy."
- "Proportion of routine antenatal appointments attended in which alcohol consumption is recorded."

Outcome: Diagnosis rates for FASD.

Other selected points:

- Midwives have training on FASD awareness and alcohol brief interventions.
- Healthcare professionals discuss any concerns and provide support according to the woman's needs.
- They record information on a woman's alcohol consumption during pregnancy in her maternity records at antenatal appointments, including the number and types of alcoholic drinks consumed, as well as the pattern and frequency of drinking.
- Services are commissioned for pregnant women who continue to drink but are not alcohol dependent and for those who are alcohol dependent.

QUALITY STATEMENT 3: Referral for assessment

Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment.

For related information see SECTION 4: Diagnosis, p. 49 and SECTION 5: Pathways, p. 65

Rationale: "When children and young people present with developmental problems, prenatal alcohol exposure is often not considered as a possible cause, especially if they do not have the characteristic facial features of prenatal alcohol exposure. This results in inconsistency in referring children and in the assessments they are offered. Referral for assessment can lead to different investigations and a range of outcomes including diagnosis of fetal alcohol spectrum disorder (FASD) or another neurodevelopmental disorder, or identification of an impairment not associated with any specific diagnosis."

Quality measures:

a) "Evidence of local pathways that refer children and young people with probable prenatal alcohol exposure to a healthcare professional with additional training in FASD."

b) "Evidence of local arrangements to increase awareness of FASD among healthcare professionals."

c) "Evidence of local services with healthcare professionals who have additional training in FASD."

Outcome:

a) Average time to diagnosis of FASD.

b) Diagnosis rates for FASD.

Other selected points:

- Primary care services give training to GPs to raise awareness of prenatal alcohol exposure as a possible cause of neurodevelopmental disorders.
- Community paediatric services, child development centres, and child and adolescent mental health services have training on assessing and diagnosing FASD.
- They establish multidisciplinary teams and multidisciplinary approaches, and develop referral pathways for assessment.
- Referral is to community paediatric services, child development centres or child and adolescent mental health services for assessment by a healthcare professional with additional training in FASD.
- They discuss the need for referral with sensitivity, recognising the need to avoid anxiety and stigma.
- Commissioners develop pathways for referring children and young people to healthcare professionals with additional training in FASD.

QUALITY STATEMENT 4: Neurodevelopmental assessment

Children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure have a neurodevelopmental assessment if there are clinical concerns.

For related information see SECTION 4: Diagnosis, p. 49 and SECTION 5: Pathways, p. 65

Rationale: "Fetal alcohol spectrum disorder (FASD) is one possibility when prenatal alcohol exposure is being considered as a cause of neurodevelopmental disorder. A neurodevelopmental assessment is needed to confirm, or rule out, a diagnosis of FASD. The neurodevelopmental issues associated with FASD are complex and varied, so the specific aspects of the assessment and the professionals involved will vary. Confirmation of a diagnosis of FASD (or risk of FASD) ensures the child or young person receives the right treatment, care and support while plans for longer-term management are being made."

Quality measures:

- "Evidence of local services with healthcare professionals with expertise in neurodevelopmental assessment who have had additional training in FASD."

Outcome: Diagnosis rate for FASD.

Other selected points:

- Healthcare professionals with expertise in neurodevelopmental assessments have additional training in FASD.
- Multidisciplinary teams are set up that may be local, central or virtual.
- The assessment covers the areas of brain function known to be affected by prenatal alcohol exposure with the aim of making a diagnosis and developing a management plan.
- When diagnosing FASD, healthcare professionals should create an environment that supports all those affected, and avoid blaming, stigmatising and inducing feelings of guilt in the parents.
- Commissioners commission services for neurodevelopmental assessments that consider FASD as a diagnosis.
- Different healthcare professionals may be involved in assessing motor skills (movement), language, cognition (thinking and reasoning) and their ability to manage emotions.

QUALITY STATEMENT 5: Management plan

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

For related information see SECTION 7: Care management, p. 97

Rationale: "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. 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. The plan helps to coordinate care across a range of healthcare professionals, as well as education and social services, and improves outcomes."

Quality measures:

a) "Evidence of local frameworks for managing FASD that ensure healthcare professionals coordinate care across disciplines and organisations."

b) "Evidence of local arrangements for communicating and sharing management plans between providers of health, education and social services."

Outcome: Health-related quality of life for people diagnosed with FASD.

> **Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to."**

Other selected points:

- Frameworks for managing FASD that allow healthcare professionals to work across disciplines and organisations
- Provide information on the effects of FASD to education and social services.
- Healthcare professionals develop a management plan for children and young people diagnosed with FASD.
- They discuss with the children, young people and their families their priorities and goals to be included in the plan, and who the plan should be shared with.
- They identify interventions and support to address the particular needs of the child or young person, including further referrals and education support.
- Children and young people with FASD and their parents or carers develop a management plan with the team who carried out the assessments before their diagnosis. They discuss what the plan should cover, their priorities and goals, and who the plan should be shared with.

> **NICE guidance and Quality Standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive."**

NATIONAL ORGANISATION FOR FASD

nationalfasd.org.uk

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