



Evaluation of the Resources and Training to Support Children & Young People with FASD Project

A partnership project between Seashell and National FASD, funded by the Department of Health and Social Care (DHSC)



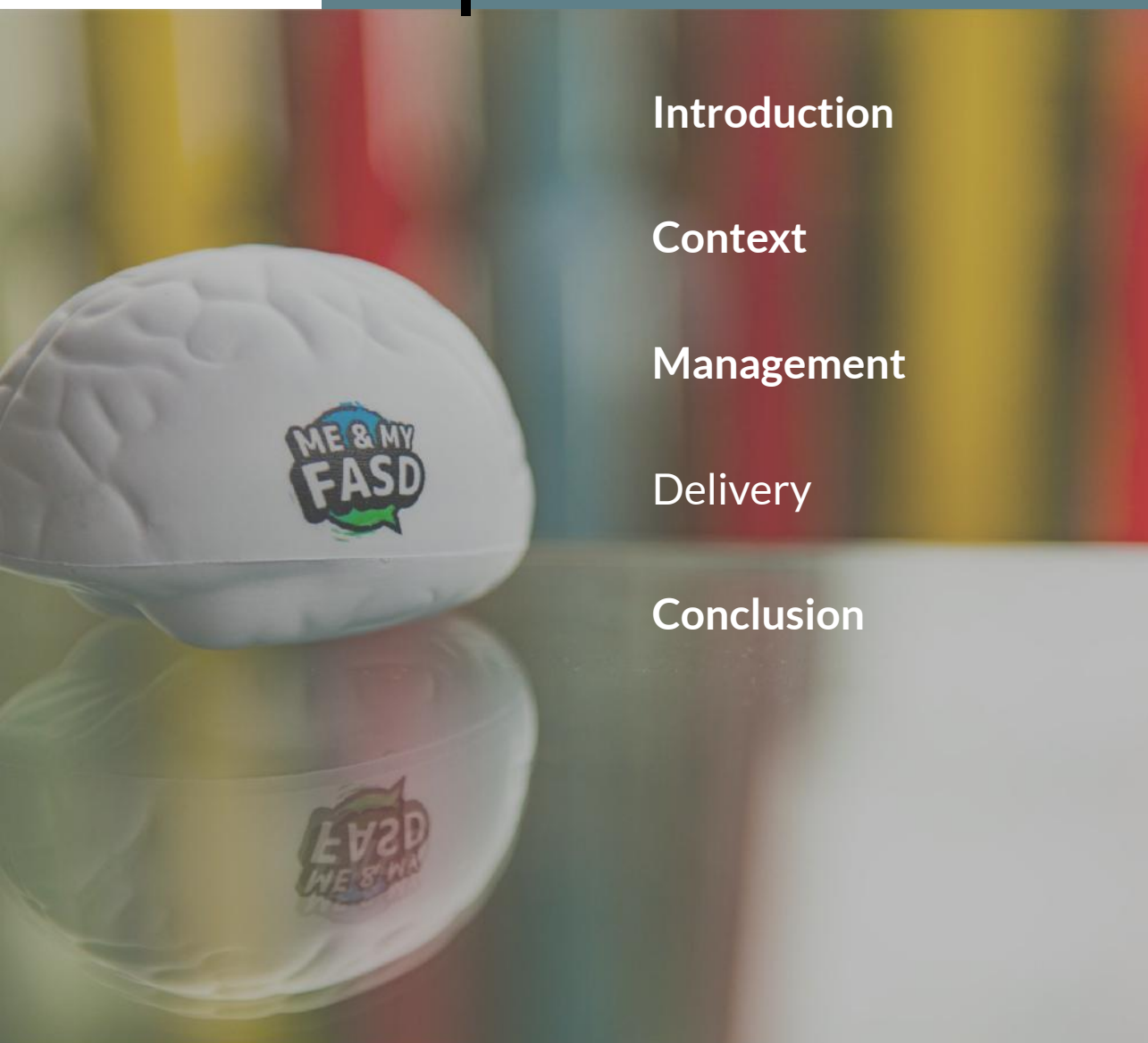
INDEPENDENT EVALUATION

Submitted to: Seashell and the National
Organisation for FASD (Formerly NOFAS-UK)

By: Rachel Flood, Director

Date: April 2021

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“

Thank you ever so much for posting the link (to the website). I emailed it to my two, I didn't tell them about it. I wanted them to open and look at it on their own. Eldest has looked through it and all I could hear was, 'OMG that's me, yep, yep, OMG do I do that, oh hell yes, I do that, and that' etc etc. Youngest hasn't looked yet but she doesn't look at her emails daily. I got a hug from eldest last night. Not one of those I suppose I had better give you a hug, or a real meaningless hug. It was a hug that felt full of love. Thank you.

”

*A Parent of children
with FASD*





Section 1: Introduction



Purpose of Report

This report provides the findings of an independent evaluation of the training programme, and associated resources, developed to support professionals working with children, young people, and their families, to better understand and manage their FASD diagnosis. Undertaken by Rachel Flood Associates Ltd., the evaluation ran from September 2020 to March 2021.

The project was delivered in partnership by Seashell and the National Organisation for FASD (formerly NOFAS-UK), with funding from the Department of Health and Social Care (DHSC) and Department for Work and Pensions (DWP) through the the Children of Alcohol Dependent Parents (CADeP) programme. This report is intended to provide an overview of the programme, its roll-out, delivery and management, and to assess how well it met its stated aims and objectives. It reviews feedback gathered from a number of stakeholders to explore key questions such as the impact the training and resources have had on their awareness, knowledge and practice, and the extent that it has improved outcomes for children and young people with FASD and their families.

Our approach to the evaluation

Following an inception meeting, and the production of a framework for the evaluation (see Logic Chain at Fig 1.), it was agreed that the evaluation aims would focus on the following:

- Assessing the impact of the training (and associated resources) on improving awareness and understanding of FASD amongst key stakeholders
- Capturing stakeholder perspectives on the effectiveness of the training and its associated resources
- Understanding the impact of the training on improving the confidence of practitioners to better support children and young people, and their families, with FASD
- Assessing the impact the resources have had on supporting children and young people with FASD, and their families, to better understand their diagnosis (specifically the "Me and My FASD" website)
- Establishing the extent of co-production (from key stakeholders, including birth mothers and the families of children with FASD) in the development of the resources, and the direction and content of the training
- Identifying any improvements in how the training and its associated resources can be delivered going forward

This report provides an evaluation of the training programme and resources developed for professionals supporting children and young people with FASD, and their families, to improve their understanding and management of the condition

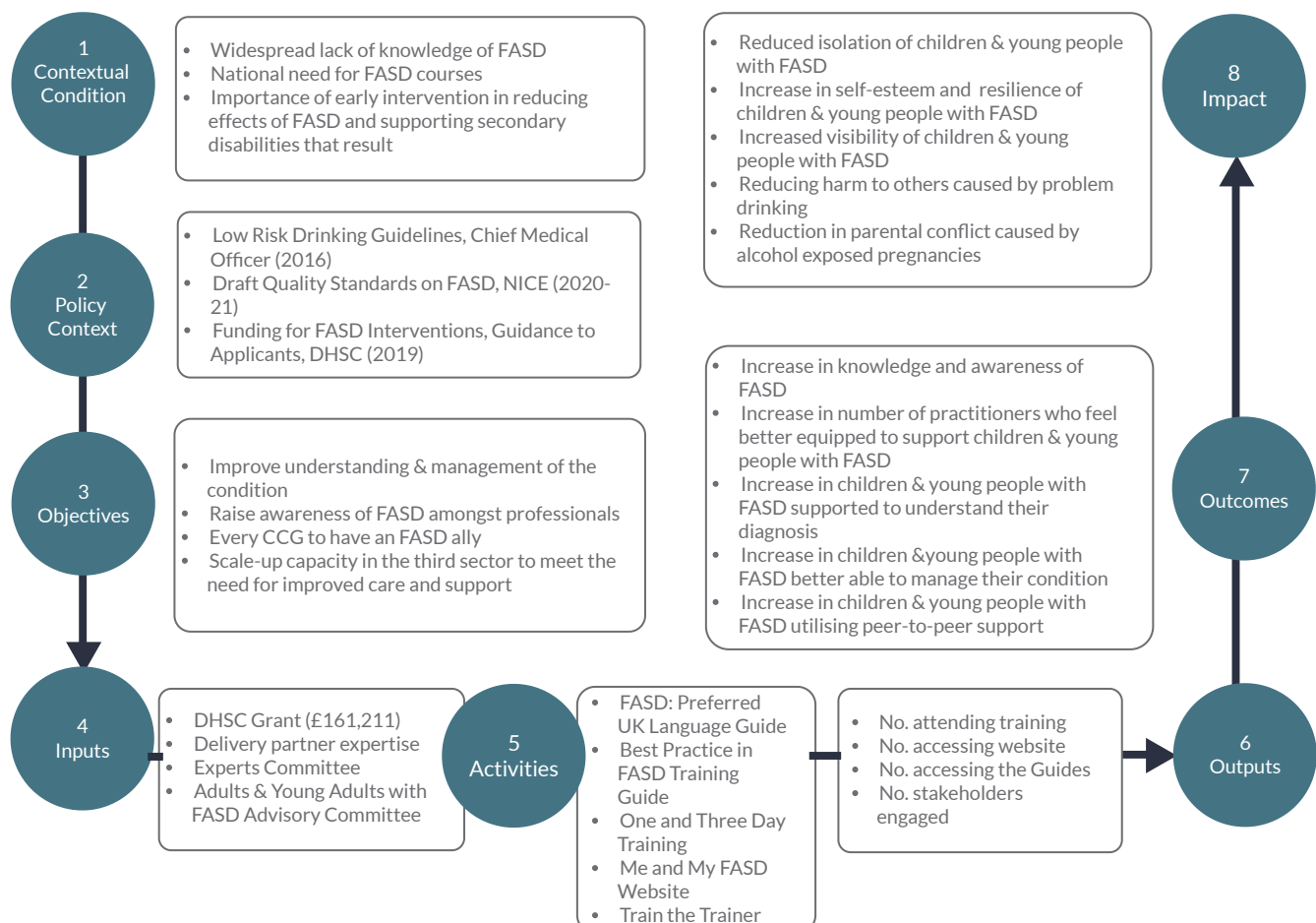
Quotes are also interspersed throughout the report as a means of bringing to life the significant impact the resources have made to children, their families, and professionals.



Logic model

The first stage of our work involved agreeing the detailed scope of the evaluation to better understand how the programme was developed and implemented. The Logic Model developed for the Training and Resources to Support Children and Young People with FASD Programme can be seen in Fig 1 below. This helped to identify our main focus and the approach to evidence gathering and data collection and was reviewed throughout the evaluation to ensure flexibility.

Fig 1: Logic Chain





Methodology

This report draws on a variety of data sources to reflect achievements and learning from the activities delivered through the project to date, including:

- 1-2-1 interviews with key stakeholders (training participants, as well as professionals and families who supported the development of the programme)
- A review of Seashell and National FASD held data (numbers attending each session, as well as anonymised evaluations from the training sessions delivered between September 2020 and April 2021)
- Analysis of an on-line questionnaire developed for the independent evaluation and shared with training participants following completion of the one or three-day programme
- Website data (analytics and survey)
- Regular client liaison meetings to discuss emerging findings and establish an understanding of how the project has been managed / delivered

Report Structure

The remainder of this report is structured as follows:

01 Context	An overview of the project and how it was developed
02 Management	Outlining of the programme management, including budget issues/amendments to the programme
03 Delivery	An overview of the different elements of the programme and analysis of monitoring data, survey results and outcomes
05 Conclusion	A summary of the main findings, lessons learnt and recommendations

This report provides an evaluation of the training programme and resources developed for professionals supporting children and young people with FASD, and their families, to improve their understanding and management of the condition.



Section 2: Context



Background to the Project

Excess alcohol consumption has a significant impact on people's health and the health and care system, and is estimated to cost the NHS £3.5bn. Public Health England (PHE) estimate that there are 595,000 adults in need of assessment and treatment for alcohol dependency, and approximately 200,000 children are living with parents suffering from alcohol dependency. Furthermore, the UK has the fourth highest level of prenatal alcohol use in the world, and alcohol exposed pregnancies present a significant public health. Foetal Alcohol Spectrum Disorder (FASD) is an increasingly recognised condition resulting from pre-natal alcohol exposure (an umbrella term that covers a range of diagnoses).

In April 2018, the Department of Health and Social Care (DHSC) and the Department for Work and Pensions (DWP) announced a jointly funded £6m package of measures to identify evidence based approaches to address this problem. This funding complemented work already underway through the Children of Alcohol Dependent Parents (CAdEP) programme and was designed to engage the voluntary sector, recognising the vital role they play in raising awareness of FASD and providing support and education to those affected.

Seashell and National FASD (formerly NOFAS-UK) are two leading UK charities with extensive experience of supporting professionals, parents, and children and young people with profound and complex needs. The project was developed in partnership to provide training for professionals from a range of backgrounds to better meet the needs of children and young people with FASD.

The project three key aims were to:



Seashell and National FASD are experts in their fields. Seashell brings many years of work in the field of special educational needs and disability, while National FASD brings considerable knowledge and expertise on FASD nationally and internationally, as well as experience of supporting children and their families with FASD. Together, they have created a formidable partnership that has successfully raised the national profile of FASD, whilst up-skilling the workforce and improving their confidence in working with children and young people with FASD.



Project Outputs

The project secured funding to deliver these three aims through the development of a toolkit of support, which included::

- ✓ A one day **"Introduction to Supporting Children and Young People with FASD"** for professionals across Health, Education and Social Care who want to improve their awareness of FASD. The course is based on the two Best Practices Guides (see below) and covers causes of FASD, its prevalence and terminology; identification of signs and symptoms across the lifespan that a person with FASD may display; how to get a diagnosis; strategies for supporting a person with FASD, including vices from the FASD community.
- ✓ A 3-day **"Me and my FASD" course** for those practitioners supporting a young person to understand their FASD diagnosis: the course is targeted at practitioners working with young people with FASD. The course shares the "Me and My FASD" toolkit - a range of practical materials designed specifically for those with FASD and offers access to supplementary versions of the toolkit for direct use with children and young people with FASD.
- ✓ **Two Guides:** The Best practice in FASD Training Guide and FASD: UK Preferred Language Guide.
- ✓ **Me and My FASD Toolkit** featuring video, audio and downloadable resources, including www.FASD.me, a website designed to support children, young people and their families to manage and understand their diagnosis and featuring peer-to-peer resources.

Key milestones

- Survey to secure stakeholder input into developing the training, guides and Me and Mt FASD Toolkit
- Hold Best Practices Workshop with leading experts in the field of FASD
- Hold a peer-to-peer workshop
- Establish an Experts Committee and Adults and Young Adults Advisory Committee
- Design website and create a number of short films
- Pilot and roll out training in 4-6 locations across England

The grant has facilitated the development of a formidable partnership that has blended their expertise, supported the cross-fertilisation of ideas, knowledge and approaches, and resulted in the production of a toolkit (training, resources, website) that is *'world class'*. There is simply nothing like this, in relation to FASD, anywhere in the world, and the feedback from children, young people, their families, and professionals, is testament to this.



Section 3: Management



Management

Overall management of the project was undertaken by Seashell, who were also responsible for:

- Day-to-day administration and logistics in relation to the project
- Organisation of the training courses including managing attendance, emailing Zoom links, collecting and reviewing evaluations, producing certificates of attendance
- Managing and monitoring the budget and spend
- Quality assurance of the training sessions through Seashell's Open College Network (OCN) Licence, and reviewing evaluations to identify if any amendments needed to the course design/content

The National FASD took the lead on the following aspects of the project:

- Me and My FASD Toolkit which was co-produced with individuals with FASD and other key stakeholders
- Organising and delivering the Peer to Peer Workshops to trial and create toolkit materials, and the Brain Base: FASD Wellbeing Summer Fun Day
- Facilitating the work of the Experts Committee and the Adults and Young Adults Advisory Committee

Partnership Working

"Together we are creating a project that is stronger than either organisation could create on it's own"

(DHSC Bid Document submitted by Seashell Trust and NOFAS-UK, Nov 2019)

The partnership between Seashell and National FASD has worked incredibly well, and their expertise in different areas (Seashell's limited knowledge of FASD but vast experience of training and delivery within the Special Educational Needs and Disability (SEND) field, whereas National FASD are leading experts in the country on FASD, but have less experience of delivering three day, accredited training programmes). As a result, the formation of the partnership combined this expertise seamlessly, to create more than the sum of its parts.

Overall management of the project was led by Seashell and their Data Governance Lead was involved from the outset to ensure compliance with GDPR when contacting participants and sharing information. A data sharing agreement was also put in place between Seashell and National FASD



Many of the participants interviewed reflected on this element, and how working together has been *"really important, as we've all benefitted from each others knowledge, which was similar but also poles apart, and actually we've got something that's much greater than if one side had gone on its own"*. This point was further reflected by the CEO of National FASD who stated that:

"The partnership has taken both organisations out of our comfort zones at times, and that's a good thing, as we have all learned from each other professionally and the products speak for themselves".

The success of the partnership between the two organisations is perhaps best reflected in their decision to continue to develop their working relationship at the end of the DHSC contract. Agreement has now been reached to continue to jointly deliver the training courses designed for this project, for a minimum of two further years, which can only be to the benefit of those children and young people with FASD and the families and professionals supporting them.

Budget

Covid also impacted upon the budget position as venue hire, travel, hotels and refreshments were no longer required for the trainers/experts. However, following agreement with DHSC it was agreed to redistribute this underspend in Quarter 4 (£20k) to develop additional resources (see page 33 for further details), to complement the toolkit, which were not factored into the original bid, including:

- The Break it Down Boards
- Misunderstood Game
- Calming Cards

These will be offered, free of charge, to all delegates attending the three day on-line training sessions. They will also be offered free of charge to participants in future Brain Bases. In addition, the resources developed through the DHSC grant above, are adding value to a further grant (secured as part of the Government's £750 Charities package) which has enabled the Programme to share these packages with 300 children and young people in England. The feedback upon receipt of these has been nothing short of phenomenal, and just a few of the comments received are highlighted on pages 35-36 with one quote contained within the sidebar of this page

Enforced changes, as a result of COVID, meant that a budget shortfall could be reallocated towards the production of additional resources, not previously planned for. Specifically, the funding was reallocated towards further developing the website and a range of additional tools which have been distributed as resource packs (free of charge due to a Covid related national grant) to over 300 children

We heard them talking, "Mummy told us the truth, we are not the only ones with this". The pack is amazing and has helped us to learn a lot (Parent)



Marketing and Promotion

Both Seashell and National FASD designed the flyers and content used to promote the training sessions, and these were then jointly marketed across their social media platforms. Pre-Covid, the intention was to deliver the sessions on a regional basis and to utilise a network of local support groups to assist with the promotion of the programme. However, with Covid, this was no longer a viable option, and meant that Seashell and National FASD needed to utilise their own networks and communication channels. This has had a direct impact on numbers attending, and both Seashell and National FASD recognise that more work needs to be done going forward if they are to work to the scale needed to ensure that awareness of FASD is more embedded across the multi-agency workforce.

Sustainability

The Project made the decision at the outset that it would not offer a 'free course', but that a charge would be attached. This meant an element of sustainability was built-in, and forward dates for courses are planned. This is important, particularly in light of the Covid restrictions which hampered attendance and delivery, that opportunities remain to continue to deliver and target those key audiences who may have missed the first round of sessions.



Without this, the end of the funding period could have stalled the roll-out of the training, as attempts were made to secure additional funding. However, as a result of the in-built sustainability approach, plans can now continue apace and this vital piece of work can continue post March 2021

Marketing and promotion of the training programme, and the toolkit resources, were developed jointly between Seashell and National FASD. However, with an incredibly strong brand in the "Me and My FASD" logo (designed by Crackerjac), opportunities were missed to embed this in promotional materials. A revised marketing and communications plan should look to develop a more consistent approach to the branding of future training programmes in particular.



Co-production

As part of the project development, an Experts Committee (including several with lived experience), and an Adults and Young Adults with FASD Advisory Committee were established to contribute to the toolkit's development and to act as an ongoing sounding board throughout the project. See page 17 for further details on the Committee Membership. This co-production approach was built in from the outset, and while Covid affected the project's ability to deliver some elements, notably the Peer-to-Peer workshop and Brain Base: FASD Wellbeing Summer Fun Days to secure input from people with FASD on what they thought was important for the project and to trial the material; the project flexed to ensure the voices of people with FASD were continually heard. The involvement of a birth mum in the training sessions was also particularly powerful and was referenced by many participants

Lived experience

The Project was able to ensure that the lived experience of people with FASD was still captured, despite the limitations around Covid. In particular, through the FASD Adults/Young Adults Advisory Committee. Membership of this committee was drawn from the existing National FASD Advisory Committee, plus some additional members were recruited for a total of nine. To support the Committee's input and views on the materials/website being developed, members were provided with an iPad, which also supported their engagement in on-line meetings to discuss the project.

Throughout the 1-2-1 interviews with key stakeholders, the level of involvement in the design and delivery of the project (from the resources to the training) was mentioned time and time again. All felt as if the level of involvement was right, and that the vision for a co-produced toolkit had been achieved. Training participants were particularly complimentary about the involvement of birth mums and children with FASD in the delivery of the sessions. This was a particularly powerful experience with participants commenting on the impact of this on their thinking and practice. Examples of feedback on this element of the approach to the training can be seen below.

"Hearing from Jan and Rossi very much enriched the learning and has left a lasting impact on me"

"Comprehensive overview that expanded upon my existing knowledge of FASD, including some incredibly valuable opportunities to listen to a mother and son share their experiences was particularly edifying and inspiring"

Co-production was a key principle underpinning the programme, and service users, families and professionals were involved in designing, developing and delivering the programme, with an emphasis on peer-to-peer support.

"Overall it was humbling to hear the personal accounts and the real difference you are making for your children. Rest assured that today has made a difference for the pupils at Pinewood School, whom you don't know, but who we will be using our learning from today to help tomorrow"



Experts Committee

The Experts Committee, and the Adults and Young Adults with FASD Advisory committee of nine young adults with FASD, have been integral to the development of the toolkit and additional resources developed as part of this project. In particular, they have informed and influenced:

- the trialling and creation of materials
- the content of the two Best Practice Guides
- the session design and delivery of the one and three day training programmes
- a myth buster to help people to have answers to the commonly misunderstood issues around FASD

As with other elements of the project, the intention was to hold a series of face-to-face workshops/meetings with the Committee to develop specific elements of the programme and to create footage for the website. While this was not achievable given the restrictions around Covid, the input from the group has clearly driven the content and direction of the project. Seashell and the National FASD worked hard to maintain contact with the committee throughout this period, holding regular meetings and other conversations them, which has influenced everything from the choice of logos, colours, content, and design, further demonstrating the project's commitment to meaningful co-production - see selection of quotes below from members of the Adults/Young Adults with FASD Advisory Committee:

"Incredible. Makes me cry with happy tears"

"You need to be able to understand your own needs so you can explain to other people how they'd be able to help you"

"People just simply didn't know about [FASD] and that's why I want to bring awareness to it so that other kids can benefit from the knowledge"

"I came up with the idea of the board game... I thought it would be a nice good fun way to get professionals and parents to understand the young children's needs and... also for the kids to understand their condition and how they can use different strategies to help them"

Seashell

Guided by experts

Including advisory committee of those with FASD

Dr Carolyn Blackburn, Education Specialist, Birmingham City University

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

Sandra Butcher, National Organisation for FASD, mum to teen with FASD

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

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

Dr Cassie Jackson, Psychologist, Centre for FASD

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

Michelle Jones, Seashell Trust

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

Dr Raja Mukherjee, Psychiatrist, National FASD Clinic

Dr Inyang Takon, Paediatrician, E. Herts NHS

ANDY, **RAILIE**, **CLAIRE**, **GEORGIA**, **LEE**, **NYRENE**, **RACHEL**, **ROSE**, **TOLKA**

NATIONAL ORGANISATION FOR FASD



Covid-19

The impact of Covid on the delivery of the project cannot be under-estimated. It meant that workshops scheduled at the start of the programme to bring experts and advisors together to develop the materials, as well as peer-to-peer workshops and summer fun days involving individuals with FASD and their families, could not go ahead. These sessions were a key element, underpinning the project's co-production approach, that were to be used to trial toolkit materials and to film content for the website. However, resources initially allocated to these activities were diverted towards the website and three new hands-on resources that grew out of stakeholder consultation and the co-production process (see page 14 for budget information). In addition, the training courses, originally designed for face-to-face delivery on a regional basis, needed to be quickly amended for a national Zoom audience. This brought its own challenges (participants turning off cameras, internet connections dropping out, interruptions as a result of being at home, a lack of interaction etc.)

While the training was still very well received, numerous comments did relate to the online nature of the programme, how it was difficult to maintain focus for a full day, particularly given the detailed content, and the relative inexperience of trainers and participants to Zoom and how it can be used effectively. From a training perspective, Zoom also meant that some of the softer skills around engagement / interaction / understanding, were much harder for the trainers to establish and gauge. However, Covid also meant that people could attend that maybe wouldn't have been able to previously because of time/location constraints. Therefore, while the impact can be seen as being both 'positive' and negative, the delivery of the programme undoubtedly suffered as a result of the pandemic and the inability of the trainers to establish relationships, build rapport, and facilitate partnership working and the sharing of experiences amongst participants, to the level that would have been achieved through face-to-face delivery.

However, one area where Covid had more of a 'positive' impact, was on the development of the Me and My FASD Toolkit, including the website, which is the key platform from which the toolkit's resources are shared with children and young people, and professionals. Because of the Covid restrictions, more time was spent on developing these on-line elements of the toolkit and three additional hands-on resources, and the rewards for this are now being reaped in relation to the excellent feedback that has been received.

Covid has clearly affected the programme and its stated aims and objectives. However, through the excellent partnership working in place, the ability to pivot, get resources and delivery on-line, has meant that its impact has been limited. It has also provided the project team with the time and space to review and update training and website content, to ensure that this is fit for purpose and providing a much needed resource for those with FASD, and those supporting them.



Section 4: Delivery



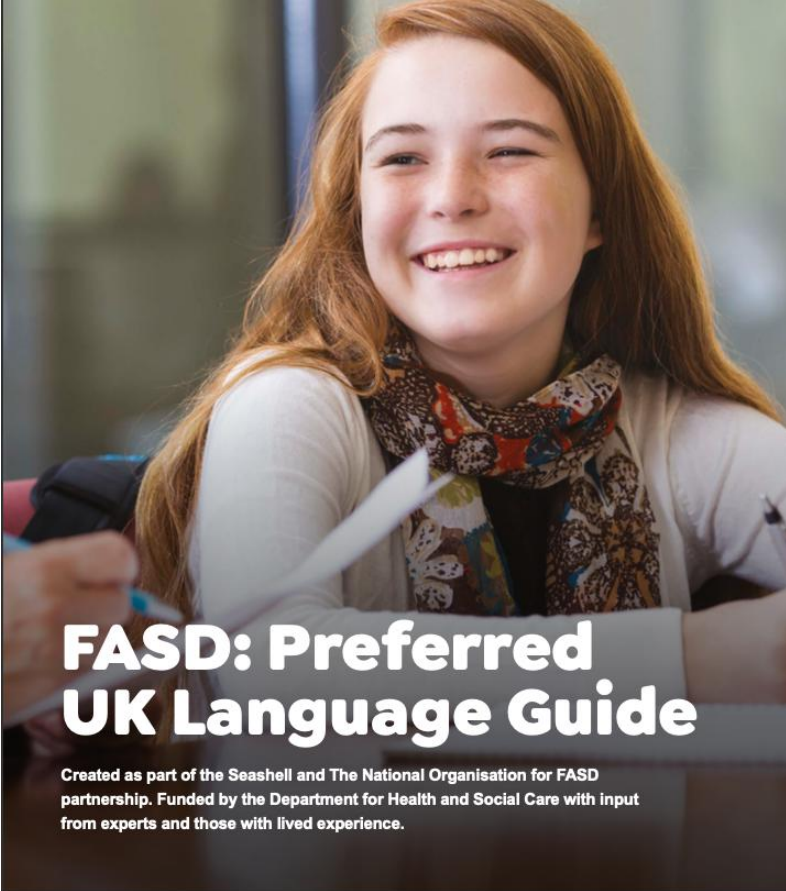
Overview

This next section of the report provides more detailed information on the specific aspects of the project including:



The partnership between Seashell and the National FASD, and the resources they have developed, reinforce the Department of Health and Social Care (DHSC) statement that *"early intervention services can help to reduce some of the effects of FASD and support some of the secondary disabilities that result"*.

Throughout this evaluation, the dedication, commitment and flexibility of those working on the project to deliver it to time and budget, in the face of a many challenges and obstacles to their original plans, whilst still securing significant impacts, should be applauded.



FASD: Preferred UK Language Guide

Created as part of the Seashell and The National Organisation for FASD partnership. Funded by the Department for Health and Social Care with input from experts and those with lived experience.



Best practice in FASD training

Created as part of the Seashell and The National Organisation for FASD partnership, funded by the Department for Health and Social Care with input from experts and those with lived experience.



BEST PRACTICE GUIDES

The project was responsible for creating the UK's first best practice in FASD training guide. In line with its principle of co-production, this involved bringing together as many of the country's leading FASD trainers, and Seashell staff, to develop the guide. Originally intended to run as a one day workshop in April 2020, an online session was developed which resulted in 36 pages of responses which were analysed to develop the two guides.

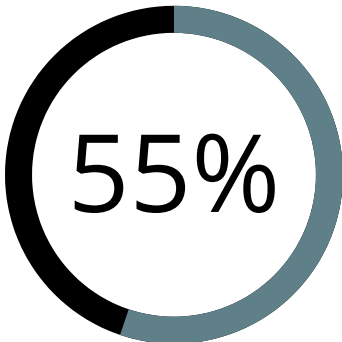
Best Practice in FASD Training Guide

- the outline topics that any training on FASD should include as standard
- a myth buster to help people to have answers to the commonly misunderstood issues around FASD
- the gold standard principles of FASD support
- emphasis the importance of involving those with lived experience

FASD: Preferred UK Language Guide

It quickly became apparent, as the Training Guide was being developed, that including a stigma/blame free language section was so important that it would need its own separate Guide, The FASD: Preferred UK Language Guide was therefore developed, and included input from those attending the one-day session above, as well as the Experts Committee and adult/young adult advisors, and over 130 responses to a SurveyMonkey request.

The guides were not only the foundation for the development of the training programme and the Me and My FASD toolkit, but they were also established to help set a benchmark for others when engaging or creating training. The two guides have also been sent to every Clinical Commissioning Group (CCG) across the country, as well as being made available through a range of social media platforms. The end result has been the production of two guides, one that represents consensus, across a wide range of stakeholders (individuals with FASD, their families, and professionals) around language, and the other which was instrumental in the development of the one and three day training programmes delivered as part of this project.



55% of survey respondents stated that they had accessed the Best Practice Guides.



TRAINING

FASD is the leading preventable disability. It is more common than autism, and the difference it can make, if the children's workforce can be supported to recognise the condition, and wider awareness of the condition is increased, is huge.

Participants could attend either a one-day (Introduction to Supporting Children with FASD) or a three-day (Me and My FASD: Supporting a Young Person to Understand their FASD diagnosis) course. To date, there have been 6, one-day training programmes delivered via Zoom (including the pilot in September 2020) and 1, three day programme. In total 73 people have attended the sessions, and a further 21 attended the pilot one day session.

Delivery and Attendance

Again, the impact of Covid on the number of training sessions, number of participants, and distribution of attendees across the different sectors needs to be recognised, as it clearly hampered the roll-out and directly affected the numbers attending.

1

NUMBER OF SESSIONS

The intention was to run 5, one day sessions: a pilot session in Manchester in September, 2020 followed by four other regional events during October and November. These were then to be followed up with 1-2 courses per month in various regional locations. To date, just 5, one day sessions have been delivered (via Zoom) and the 1-2 sessions per region has not progressed.

2

NUMBERS ATTENDING

The project envisaged reaching 30-50 participants per session. However, to date, the 5, one day sessions have been attended by 56 people in total (an average of 11 people per session); and the 1, three-day session was attended by 17 participants. This is clearly way below the numbers anticipated and further reflects the impact of Covid with people going through lockdowns, home schooling and many other pressures. It also further reflects the issue around marketing and promotion within Seashell and National FASD as well as being unable to utilise their networks of local support as effectively as they would have liked.

3

SECTOR REPRESENTATION

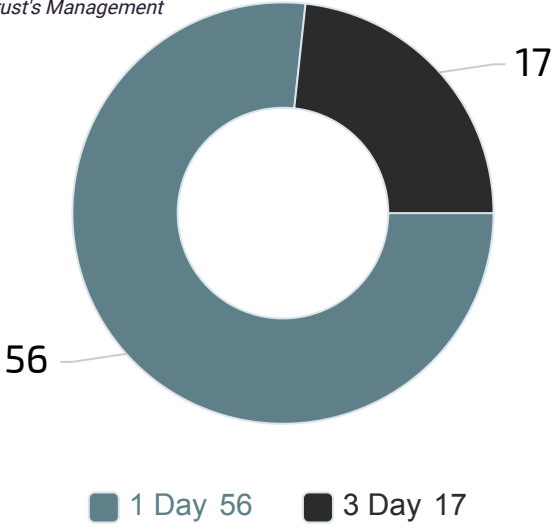
With the programme not reaching the numbers envisaged (pre-pandemic), or delivering the number of sessions anticipated, it is no surprise that there has been a knock-on effect in terms of representation from across the different sectors. Health (for obvious reasons) have not attended in the numbers that were expected. Whereas, other sectors, particularly education, have attended in significantly higher numbers. The pandemic has also impacted on the programme's ability to effectively engage with Clinical Commissioning Groups (CCG's) in any meaningful way, particularly with regards to the creation of an FASD ally in each CCG



TRAINING

This section draws on monitoring data (from the sessions) and responses to the independent survey. It provides an overview of which sectors participants were from; their reasons for attending the training; their views on how they have benefitted from the training; and the outcomes and impacts on professionals, children and young people, and their families.

Fig 2: Numbers drawn from Seashell Trust's Management Data



Attendees

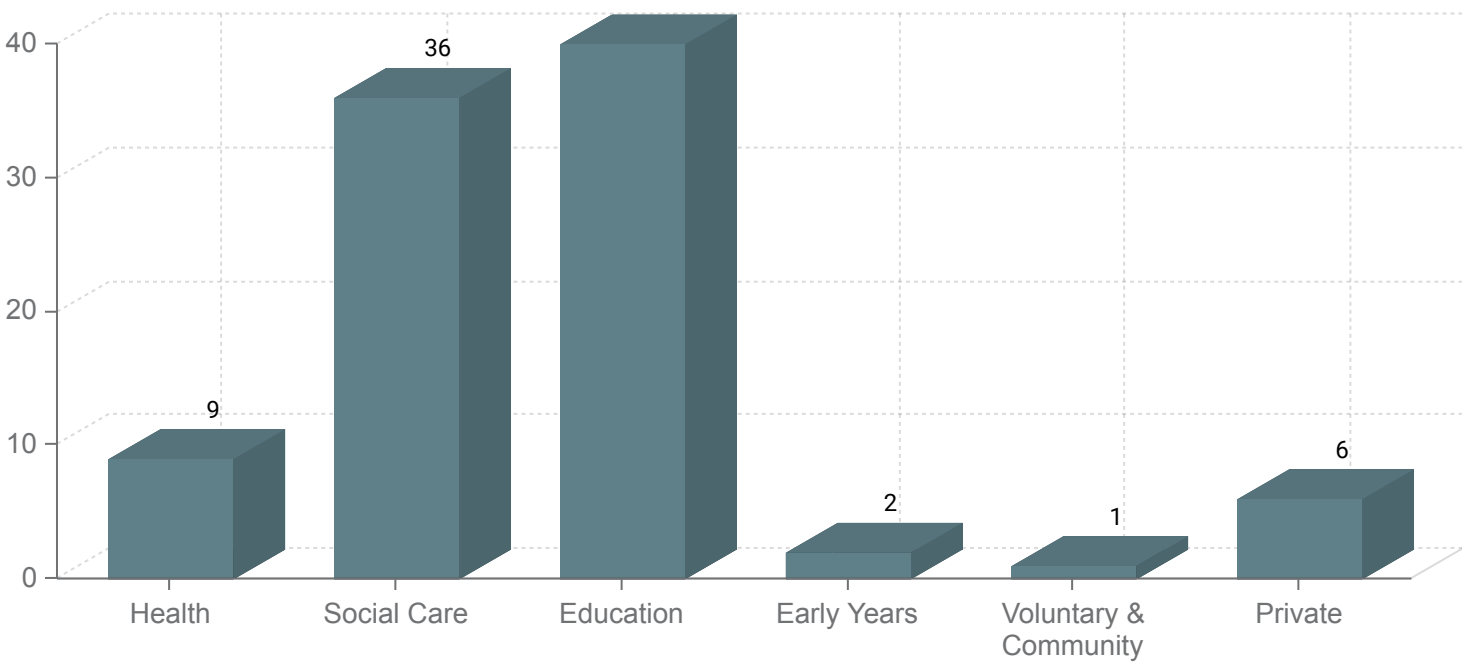


Fig 3: Sector Representation drawn from Seashell Trust's Management Data

One Day Training: introduction to FASD

“

The training exceeded my expectations and also provided food for thought

”

Seashell, in their management of the training programme, were responsible for securing session evaluations from those who attended the training. Of the 73 attendees at the one and three day training programmes, a total of 33 evaluations were returned. The findings of the session evaluations very much reflect those of the survey conducted by the independent evaluator, and a summary of the key headings is summarised below:

One Day Training: Introduction to FASD

☆☆☆☆☆☆☆☆☆☆ 9 out of 10

Understanding of FASD following the training (1 being the lowest, and 10 highest)

"I enjoyed hearing the lived experience from the trainers which helped add authenticity to the training. There is so much to learn and cover, that clearly a day was never going to be enough, however, it was enough to make me thirsty for more and a great foundation to build on"

- Overview of the forthcoming NICE guidelines on FASD were useful as supported attendees to better understand their responsibilities
- Potential for future courses (once the basics of FASD, what it is, how to identify etc. have been developed) to focus on how to have difficult conversations with parents/carers to secure effective disclosures and develop action plans
- Training needs to be rolled out at scale and pace (in line with emerging NICE guidelines) to ensure the multi-agency workforce have an understanding and knowledge of FASD
- Multi-agency backgrounds was very well received by participants who benefitted from hearing more about each other's roles and responsibilities and learning from each other



Three Day Training: Me and My FASD

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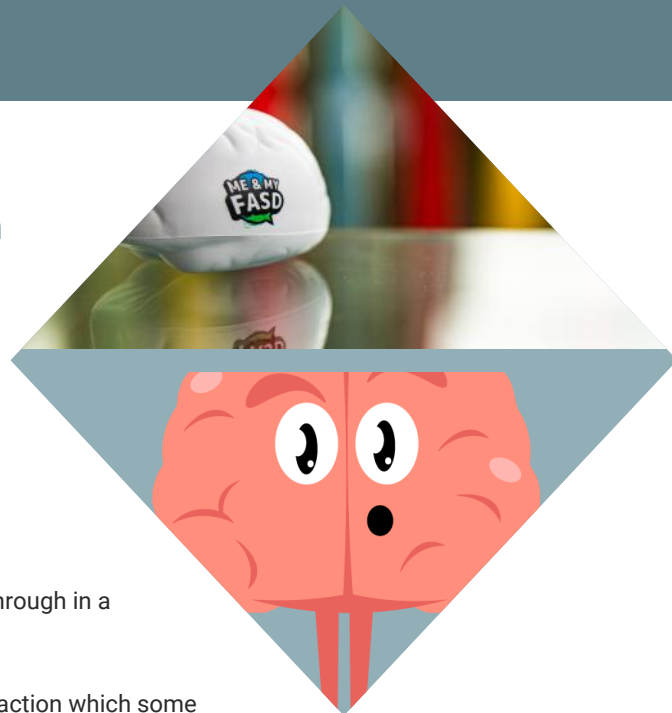
This training is the most child-centred that I have come across for FASD... confidence boosting

”

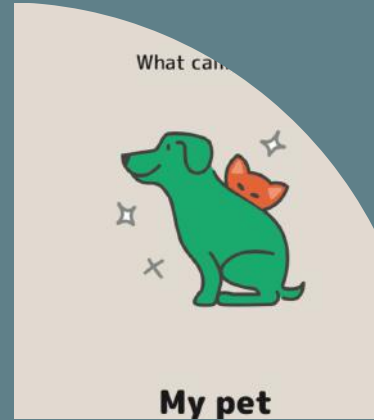
Three Day Training (pilot): Me and My FASD: A Course for Practitioners Supporting a Young Person to Understand Their FASD Diagnosis

This unique course is for practitioners working with young people with FASD. It introduces the "Me and My FASD toolkit" - a range of practical, hands-on materials specifically designed for those with FASD. The materials were developed after extensive consultation with the experts committee and the adults and young adults with FASD advisory committee, many of whom provided videos and participated in the pilot. Key headlines from the session evaluations included:

- Going through the website 'live' would support participants to follow this through in a practical fashion - this session could benefit from a rework
 - Review some content as was quite 'heavy', lots of talking and limited interaction which some attendees struggled with - potential for more discussion/break-out groups
 - Strategies to support practitioners (when back in the workplace) to challenge the systems they operate in to accept the existence of, and promote the support of FASD
 - Sensory processing section particularly useful
 - Diversity of cards/images to be revisited to better reflect black and ethnic minorities
 - Provide opportunities (when face-to-face training is allowed) to practice using the resources with other attendees
- Avoid generalisations - some professionals from an education background felt targeted as lacking knowledge and understanding of FASD. Important for trainers to remember and recognise the multi-agency backgrounds, and the expertise "in the room" that participants bring, as these are opportunities for us all to learn from each other
- Suggestion that the Education Health Care Plan (EHCP) section was not needed in the three day programme
- Specific feedback from a participant who was disappointed by the response to their ideas of what they would do with the learning from the three days, could provide an opportunity for Seashell/National FASD to bring all trainers together to reflect on the project to date and what has worked well/less well - see recommendations section



Evaluation Survey Results

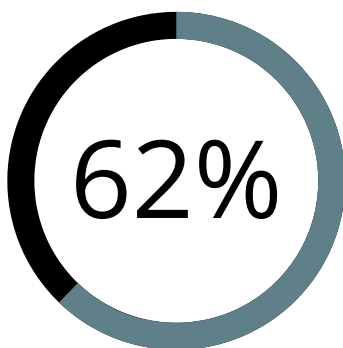


Survey Feedback

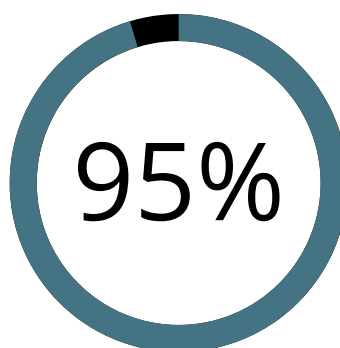
A SurveyMonkey link, as part of this evaluation process, was sent out to all participants (excluding the pilot). Of this, 23 people completed the survey, representing a return of 34%. While the overwhelming majority of respondents felt the course met their expectations, the one exception to this was due to a lack of pre-course information, with the participant stating that: *"there was no support information or documents provided. Short of writing everything down (and not then engaging in the course) there is no way you can remember even half of the information."* (participant at one day session)

The lack of pre-course information (particularly for a Zoom audience) was referenced a number of times, and is picked up in the emerging lessons/findings section.

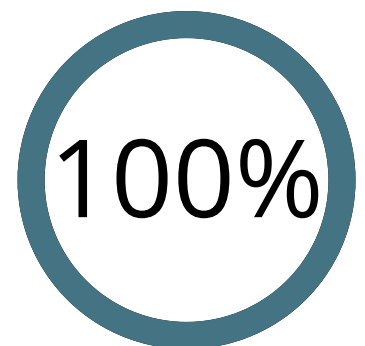
Views about the training courses and resources



Were surprised by what they had learnt on the training



Of survey participants stated that the course met their expectations



Of survey participants stated that they had learned something new

Survey Results

9 out of 10



Average score given by participants

“

I came with very little knowledge and learned a lot

”

Overall the feedback on the content, delivery and resources was incredibly positive, as shown throughout this report. Clearly Covid, and the lack of face-to-face interaction with participants, which was referenced on a number of occasions, being one of the few downsides. The vast majority of respondents to the survey found the training to be incredibly useful. However, as with any programme, it wasn't for everyone and there were a small number of comments which did not reflect the overall feeling or impacts highlighted by the majority of participants.

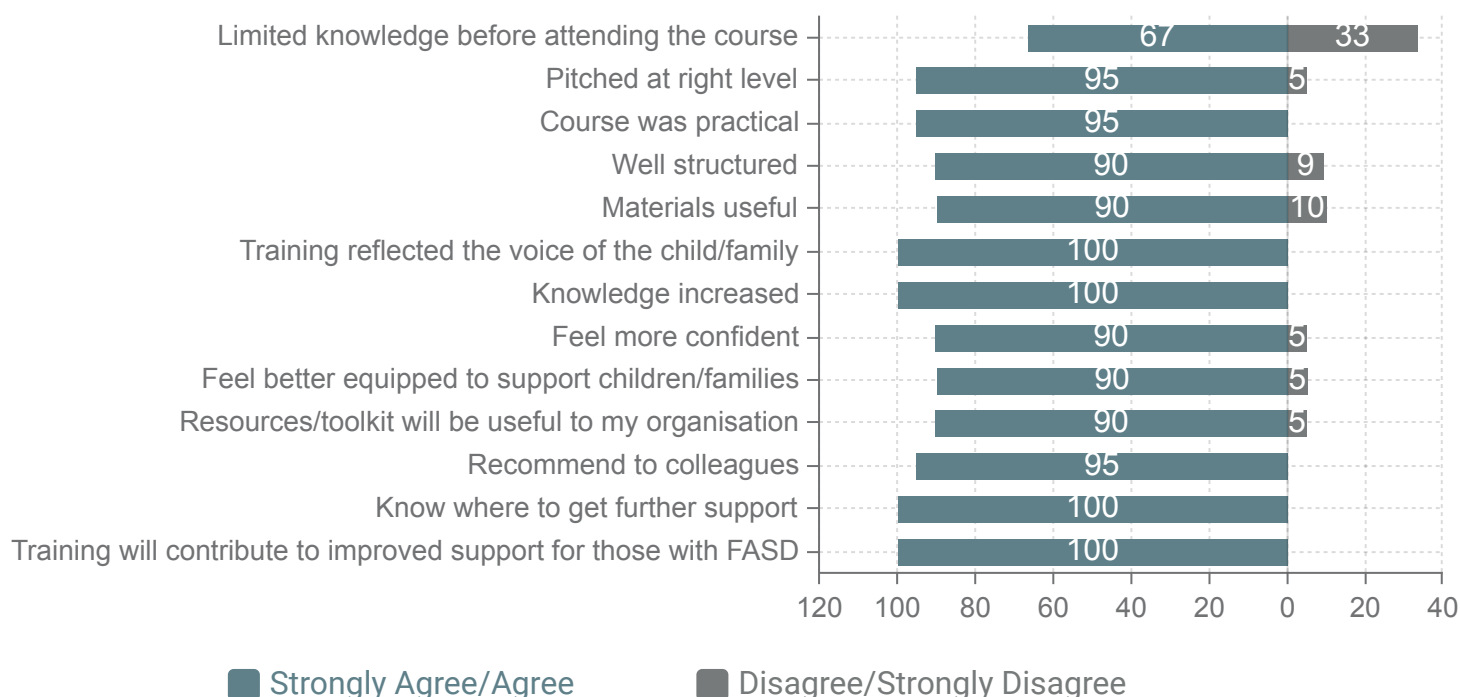


Survey Results

In response to a series of statements, figure 4 below demonstrates the % that either strongly agreed/agreed, or disagreed/strongly disagreed.

Fig 4: FASD Training Survey

Agree/disagree with the following statements



Survey respondents indicated a number of areas where the training programme had supported an improvement in their knowledge, awareness and practice, and these are summarised below



Better equipped/confident to recognise and identify FASD (signs and symptoms)



More capable of supporting children and young people to take ownership of their diagnosis



Improved understanding of the different presentations, and similarities, with other diagnosis



Increased awareness and knowledge of FASD and its impacts (latest thinking, NICE Quality Standard, myth busting etc.)



Increased knowledge of the importance of prevention and early intervention and making others more aware of FASD



More awareness around how to communicate effectively with children and young people with FASD

Quotes about the training



"Overall, I enjoyed the day and feel for nursery / teachers it is a MUST."

Practitioner

"The training exceeded expectations and has also provided food for thought. It would be great for more professionals to receive this training."

Practitioner

"I look forward to researching further about FASD and am excited to be part of what feels like the start of a revolution!"

Practitioner

ME AND MY FASD TOOLKIT

The groundbreaking Me and My FASD Toolkit meets a national need to develop and share resources to help individuals with FASD, their families and professionals to understand their diagnosis. As with all other elements of the programme, the toolkit has been co-produced with individuals with FASD and other stakeholders and features video, audio and downloadable resources, which are made freely available via the website www.fasd.me, while others are available on social media channels such as YouTube.

“

Wow the packs are great, it was an opportunity to chat about FASD with our son and working through the [break it down] board was a great strategy. We will explore the other items one at a time

”



The Me and MY FASD toolkit includes a range of innovative and unique resources. It is a mix of video and printable resources, the majority of which can be accessed via the newly created "Me and My FASD" website (fasd.me). Examples of the resources, along with feedback, are shared across these next pages, including a number of additional hands-on resources - not initially factored into the original bid - which were developed as Covid started to impact upon direct the original aims of the project and funding was redirected.



Website

A specialist website designed for children and adolescents with FASD



Calming Cards

A set of illustrated cards with suggestions on ways to stay calm



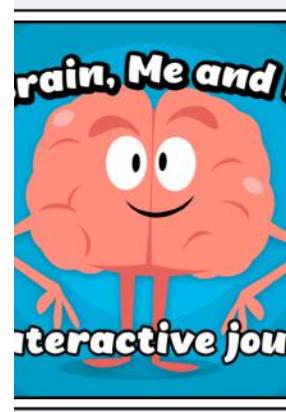
Break it Down Board

A visual tool to help people with FASD to work through situations



The Misunderstood

A fun, interactive game to support children and young people to better understand their condition



FASD Comic

An interactive comic for children and young people with FASD



THE WEBSITE

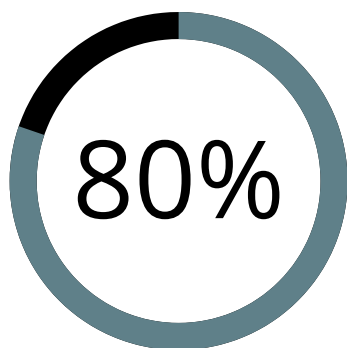


It is a fantastic website! I have sent the link to the family I am working with. The website is easy to navigate around and the 'comic book' of FASD is fabulous for young people. I love how the website was designed by young people with FASD and they are heavily featured within it. For a young person it makes is so much easier to relate to.



While Covid had a negative impact on the delivery of the training in terms of attendance; the same cannot be said for the development of the Me and My FASD toolkit. The website and graphics, designed by Crackerjac, were incredibly well received, across the board. Interview respondents stated that Covid gave people the time and space to revisit the plans for the website and develop something that has been referenced on numerous occasions, as "world class". To put it simply, there isn't anything to compare it with nationally or internationally - it is a unique resource that is plugging a much needed gap for children and young people with FASD, their families, and the professionals supporting them.

Launched in November 2020, what the website has been able to deliver is a place where children, young people, their families, and the professionals supporting them, can go to access resources to help them to explain their diagnosis and to empower them to feel more confident in their diagnosis. This has created a massive impact in terms of reducing isolation and supporting children and young people with FASD to feel less alone. This is reflected in the statistics (covering the period Sept 20 to March 2021) which shows over 9,777 visits to the site, and over 1,400 people have accessed the interactive comic (see next page).



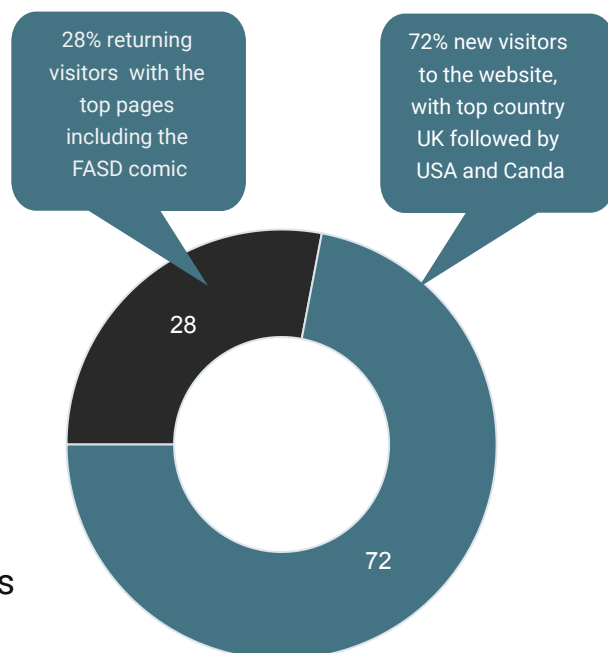
80% of survey respondents stated that they had accessed the website, demonstrating how useful this resource has been for practitioners and those they are supporting.



Website Data

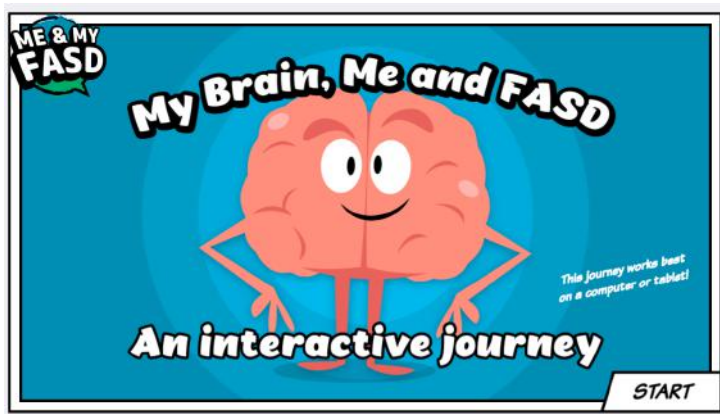
- 24,941 page views
- 9,777 unique sessions

Data to 31 March 2021



EXAMPLES OF WEBSITE PAGES AND RESOURCES

The Website features a Me and My FASD section which is a place to learn about FASD and includes a series of coping resources (see My Brain, Me and FASD for example); a FunZone with interactive elements, containing music, games and activities (such as the Walk Along With Me song - see below) and a 'merch' shop (requested by the Adults and Young Adults with FASD Committee); and a "We are Awesome" section, which features the accomplishments of those with FASD (big and small) - such as Josh and his street art below.

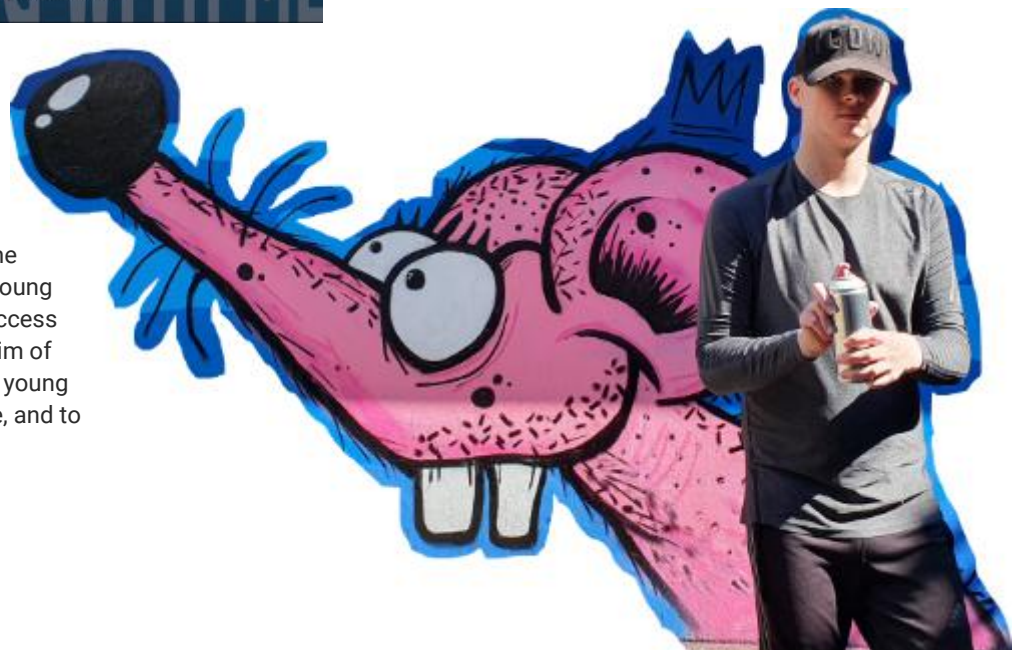


The interactive comic "My Brain, Me and FASD" was designed in partnership with Little Man Project, one of the country's leading specialists in e-learning. Feedback from parents, carers and professionals on its impact (demonstrated throughout this evaluation) shows how it has actively contributed to one of the programmes key aims of supporting children and young people to better understand their diagnosis, and to feel less alone.



The Me and My FASD Toolkit features video, audio and downloadable resources, which are made freely available via the website www.fasd.me, while others are available on social media channels such as YouTube. The song, "Walk Along With Me" for example, was created with input from more than 70 young people with FASD from the UK, and performed by musicians with FASD. It has had over 11,000 views on Facebook alone.

The We Are Awesome section of the website encourages children and young people with FASD to share their success stories. It forms a key part of the aim of the project to support children and young people with FASD to feel less alone, and to better understand their diagnosis.



ADDITIONAL TOOLKIT RESOURCES

As mentioned on Page 14, a budget underspend meant that the Programme Team could reinvest this money into producing a number additional resources for the toolkit. These resources, which grew out the consultation process with stakeholders, are shown below. These further evidence the importance the partnership placed on co-production. These additional items are being made available to practitioners who attend the Me and My FASD three-day training, and families who attend future Brain Bases. They are also downloadable from the website and available for purchase from the merch section of the website



CALMING CARDS

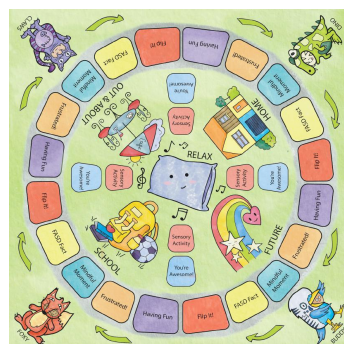
Following overwhelming feedback on the "Walk Along With Me" song, the programme team developed the idea for the Calming Cards. The Calming Cards are a set of 50 illustrated visual cards with suggestions from more than 70 people with FASD about what helps them to stay calm.

BREAK IT DOWN BOARD

This is a new visual tool to help people with FASD to work through situations and identify different strategies and strengths that can help them. The idea came from Susan McGrail, a parent, and the name came from Nyrene Cox, a member of the Adults and Young Adults with FASD Advisory Committee, who encourages others to “break it down” when things are overwhelming or hard to understand. The Break it Down board was reviewed by the Experts Committee and the Adults and Young Adults with FASD Committee, and developed in cooperation with www.OurBoards.co.uk. The board has received acclaim from around the world (see quotes about the toolkit on pages 34 to 36)

THE MISUNDERSTOODS

The Misunderstood Game was suggested by Andy Jackson. The game has several different elements to help explore different areas: fact cards; flip it cards (designed to help change the young person's self-perception); frustrated cards (emphasising coping strategies); sensory activities ideas; and other activities designed to encourage discussion about life with FASD. There is nothing like this available anywhere else in the world.



Quotes

about the toolkit



"Very happy girl! She really needed this to own her diagnosis"

"I think the Break it Down Board might be a game changer"

Parents

"(The comic) encourages professionals to work interactively with young people. It's a unique way of working that allows young people to take ownership of their own conditions and realise that although they are different, there are lots of similarities there - I've never seen anything quite like that"

Practitioner

"She lights up every time she goes to the website... which is often. You can see how empowering it is! You hit a void for sure... for the FASD world"

Response from Canada

Quotes

about the toolkit



"FASD.me is such a great resource. We now routinely recommend it to families at our FASD clinic"

Leading International Researcher

"This is the first resource we have ever had specifically for our young person with FASD. We use a lot of ASD resources but to have something that acknowledges her condition and know that others are like her can only help her feelings of belonging and not being alone in this"

Parent

This is awesome! My whole team thanks you. We have a lot of resources but this one (the Me and MY FASD Break it Down Board) is pretty cool and seems like a great way to engage families and clients. We will be sharing this with our caregivers and workers throughout our region!

Response from Canada

Quotes

about the toolkit



"The board is absolutely fantastic! Not only has it been integral in pulling my daughter up out of her meltdowns but it empowers her during the process. A truly incredible and essential piece of kit for anybody with FASD"

Parent

"Wow the packs are great, it was an opportunity to chat about FASD with our son and working through the board was a great strategy, we will explore the other items one at a time"

Parent

"My daughter took her FASD&Me bag to school with her to show her teacher today. Her teacher was so impressed with the break it down board, she wants to order some for the school. My daughter had a massive falling out with a friend and was able to use the board to help her to talk about her feelings and the impact FASD has on this"

Parent

POTENTIAL IMPROVEMENTS



While feedback gathered during the course of the evaluation, and through a review of Seashell and National FASD data, has been hugely supportive of the work the project has delivered to date (the website, training, two best practice guides, and the additional toolkit resources). All of which effectively demonstrate that the project has tapped into an unmet need for more information and awareness of FASD, there remain a number of areas where improvements could be made as the project and the partnership between Seashell and the National FASD develops. Below are a number of areas where participants on the training and/or stakeholders who have used the toolkit resources, have suggested areas where improvements could be made including:

MANAGEMENT OF THE PROGRAMME

- Differences in operating models (size/structure) of the two organisations brought some challenges, and impacted upon the speed of decision-making. Going forward, clearer terms of reference/roles and responsibilities could be strengthened to support this.
- Develop a standardised approach to the collection of evaluation forms at the end of the one and three-day training programmes, as this will provide a valuable source of intelligence on the training and its delivery and will ensure continuous improvement
- Review existing marketing and communications channel to assess effectiveness and identify mechanisms to target under-represented sectors in future training programmes

TRAINING PROGRAMME

A number of improvements to course content / delivery were identified by participants who responded to the survey, including:

- Reviewing the section on sensory improvements, felt to be less engaging than other aspects of the session
- Include more on early years, in particular, it was suggested that the Education Health Care (EHC) Plan was less useful and could be skipped for the three-day training
- Review the PowerPoint Slides as the text was consistently small
- Provide copies of the presentation (through the post to arrive before the session) if continuing or need to go back to Zoom delivery, but definitely to be made available on the day as a lot of information to process
- Include the voices of the siblings of children with FASD

TOOLKIT

Building on the brand recognition of the Me and My FASD website will be key going forward, and while the overwhelming response to the website has been nothing but positive, some suggestions have been made where improvements could be made, including:

- Develop more of a social aspect to the website to give children with FASD (who are often "social butterflies" but have difficulty in managing social interaction) the opportunity to connect with each other, and to build that peer-to-peer aspect. However, National FASD have pointed out that this can't be done due to safeguarding issues.
- Create some content for older children, as currently the focus is on younger children.



"If we get it right, our kids can fly"

Section 5: Conclusion



Conclusion

This report has provided the main findings of an evaluation of the "Resources and Training to Support Children and Young People with FASD" project that is being delivered by Seashell and National FASD. The evaluation focussed on period April 2020 to March 2021. The main findings are as follows.



73 people attended 6 sessions (five, 1 day sessions and one, 3 day session) during this period which was well below the anticipated numbers pre-Covid



Feedback from the independent survey was overwhelmingly positive and the majority of participants found the content incredibly useful and powerful



The Me and My FASD toolkit, including the website and other resources such as the Break it Down Board, has been a very positive, and has become a widely used tool for both professionals who can now signpost families to a dedicated, world-class resource, but also for children and young people with FASD to help them to feel less alone and better understand their diagnosis



The Train the Trainer element was not taken forward and more needs to be done to establish if this is the most appropriate model given the expertise needed to confidently deliver within the emerging national awareness of FASD amongst the multi-agency workforce. Whilst there is some merit in this approach, perhaps building on the idea of CCG allies/Champions would be a better focus. This would build in an element of sustainability but maintain programme integrity



100% of attendees on the programme stated that they had learnt something new about FASD, whilst the majority (95%) stated that they would recommend the course to a colleague, with a further 100% stating that the programme would directly contributing to improved support for those with FASD



The project set out to increase awareness and understanding of FASD amongst the workforce and to develop a suite of resources that would support professionals, families and children and young people. The evaluation has found that these aims have been achieved, despite Covid.

Under difficult circumstances, that could not be planned for, the project has clearly made an impact on the lives of those living with FASD, and for those supporting people with FASD.



RECOMMENDATIONS



Establish an agreed marketing and communications plan for the next stage of delivery to ensure key personnel are targeted and attendance at future sessions of 30-50 people can be realised. This will also ensure that the Best Practice in FASD Training and FASD: Preferred UK Language Guides are better promoted, given that this was the least well known/used resource from the toolkit



Contact all attendees of the sessions to date, with option to attend a regional 'mop-up' session. This will ensure that the opportunity is not lost to develop strong regional networks of contacts/professional practice networks to promote awareness of FASD and the training and toolkit



As a minimum, ensure participants receive a summary of the slides before the session (if Zoom delivery) or on the day for face-to-face events. However, if resources allow, explore options to develop a course workbook to include key details of the sessions (as opposed to every PowerPoint slide) with space for participants to write notes and ideas for how to take forward in their own practice



Create a "How to Zoom" Guide for all participants which can be shared prior to any online training sessions to support full participation. Trainers could also benefit from developing a deeper understanding of how to use breakout rooms, polls, interactive content etc.



RECOMMENDATIONS



Content (training and website) currently child focused. Therefore, opportunities to develop more content for young adults, and better engage with the Adult Workforce given that children with FASD will become adults with FASD



Routinely programme in trainer reflection sessions to review content and delivery, to ensure consistency of key messages and pick up any issues in relation to session feedback



Low number of evaluations returned following the completion of the sessions has been an ongoing issue. Recommended that certificates of attendance are "withheld" until participants return a completed evaluation, to ensure that this important element of the programme's continuous improvement is embedded



Further develop, for the three-day programme, an approach within the session that supports professionals to reflect and identify an action plan of how they intend to take forward some of their thinking/knowledge following the session. This will contribute to the continued growth of FASD awareness and understanding across the workforce



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