



# **“Getting on With It”: A Course by Caregivers, for Caregivers – Pilot Overview and Evaluation Report**

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**Preface** – NOFASD Australia acknowledges and pays respect to the past, present and future Traditional Custodians and Elders of this nation and the continuation of cultural, spiritual and educational practices of Aboriginal and Torres Strait Islanders.

NOFASD Australia works to support families living with FASD and prevent harms caused by alcohol.

Tēnā koutou katoa,  
Ko Dartmoor te Maunga  
Ko Exe te Awa  
No Ingarangi ahau  
Engari kei Otepoti taku kainga  
Ko Anita Gibbs tōku ingoa

Greetings to you all  
Dartmoor is the (my) mountain  
Exeter is the (my) river  
I am from England  
But Dunedin is my current home  
Anita Gibbs is my name

Warm greetings to you all.

## Introduction

In 2017, Associate Professor Anita Gibbs, a caregiver of two children living with FASD, as well as a registered social worker and long-time educator at the University of Otago, undertook an extensive piece of work to design and deliver an evidence-based caregiver course ‘Getting on with it’ – in her home town of Dunedin, New Zealand. After running and evaluating this initial ‘pilot’ (Gibbs, 2019)<sup>1</sup> she, with her co-facilitators, broadened the course to both a one-day version and a digital collaboration with NOFASD.

This report outlines the development of the digital online Getting on with it (GOWI) pilot between NOFASD and Dr Anita Gibbs over the course of 2019, and includes a combined evaluation report of an internal brief survey as well as an external telephone-based evaluation undertaken in early 2020 by an independent, external contractor

The idea of calling the course ‘Getting on with it’ (GOWI for short), was born out of Anita and other caregiver’s general frustrations of waiting for implementation of FASD action plans and interventions and supports, which never seemed to quite appear. For example, NZ’s first action plan has recently ended (2014-2019) with virtually no ongoing financial or other support for caregivers and those with FASD. Additionally, GOWI in Australia was specifically initiated to provide FASD-specific online peer-to-peer mentoring, support and advocacy, of an ongoing nature, which we knew was not available in either NZ or Australia.

This report will discuss how the pilot came about, the recruitment of participants, the current course aims and content overview, the course process and philosophy overview, the evaluation reports (combined internal and external evaluations), and the next steps for the future of GOWI in Australia.

## Background to the pilot

Anita Gibbs presented an outline of the course Getting on with it: A Course by Caregivers for Caregivers at the 2<sup>nd</sup> Australasian FASD conference in Perth, in 2018.<sup>2</sup> Louise Gray CEO of NOFASD suggested a potential collaboration and a digital online pilot for a group of Australian caregivers/parents. After several months of ZOOM meetings, a team for the pilot was formed and a small amount of money was donated to assist with the work.

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<sup>1</sup> Gibbs, A. (2019). An evidence-based training and support course for caregivers of children with foetal alcohol spectrum disorder (FASD) in New Zealand. *Advances in Dual Diagnosis*, 12(1/2), 73-84. doi: 10.1108/ADD-10-2018-0013

<sup>2</sup> Gibbs, A. (2018, November). *A training and support course for parents and caregivers of children and youth with FASD*. Verbal presentation at the 2nd Australian Fetal Alcohol Spectrum Disorder (FASD) Conference: Our Science Our Stories, Perth, Australia.

The team comprised Anita Gibbs, Louise Gray, Sophie Harrington, Cheryl Dedman and Christine Brooks. Extensive planning, initially between Anita and Louise led to the appointment of a practical facilitator Sophie, who co-ordinated all administrative aspects of the day-to-day implementation of the pilot – advertising, recruitment, selection, contacting participants, answering questions, digital platform setup, recording sessions, and general communications in between weekly sessions.

Two caregivers with substantial experience of parenting children with FASD - Christine and Cheryl - were approached and agreed to help Anita co-facilitate specific components of GOWI, as well as, provide peer to peer parent support for the entire group of parents and, or caregivers who participate in the pilot. The co-facilitators acted as contributing parents as well as co-facilitators, at times they were learners seeking new knowledge, at other times due to their own wealth of lived expertise, they offered new insights and experiences that helped all the participants in the pilot. Both co-facilitators had many years of professional and personal experience in and around FASD.

The main idea of co-facilitators was so that they could get to grips with the material and group process and take a lead in future online GOWI groups. Anita was keen for others to take these groups forward (a *train-it-forward* approach), as having co-facilitators who could eventually do that would ultimately be better for each new online course and would avoid ‘burn out’ for Anita. She signalled her keenness right at the outset to share material and content and is keen to promote ongoing support initiatives for caregivers and parents in Australia and New Zealand.

Anita Gibbs drew on the material developed in her 7-week course in Dunedin, New Zealand (Gibbs, 2019), and she adapted it for 6 weeks instead of 7 weeks, and for 90-minute online delivery instead of 2-hour face-to-face delivery. She made weekly adjustments to aspects of the original course in response to the similar but different contexts of the pilot GOWI online course. As it was a pilot, Anita invited suggestions and comments from Sophie, Cheryl and Christine as the course progressed, as well as providing most of the evaluation questions to the evaluator (see page 13 onwards).

### **Recruitment and participants**

As mentioned in the evaluation report, pilot participants were recruited using social media advertising on Facebook, LinkedIn and using the NOFASD Australia website (Appendix 3). Interest was expressed from all parts of Australia (and further afield) but an ideal number of participants from the Perth area of Western Australia led to a decision to pilot the first online course with most parents from WA, and the course co-facilitators were from Victoria. Anita was based in NZ, hence three time zones were in operation for the pilot.

In this initial pilot the criteria for selection was willingness to commit to participate for 6 weeks from November 12 to December 17, 2019; to have access to technology that could use ZOOM meetings, and to be able to connect to Wi-Fi; and be wanting to participate in caregiver training around parenting children with a FASD diagnosis or suspected to have FASD. We also, because of the family make-up of the final group of participants, skewed some of the material to caregiving children and youth over 10 years of age – but participants agreed to this focus before training was delivered. The original GOWI course in Dunedin recruited self-selecting volunteers with children aged 6 to those with adult children who had FASD. More details are provided regarding participant demographics in the evaluation (page 14).

### **Current Course aims and content overview**

The GOWI training aimed to assist parents and carers with children with Fetal Alcohol Spectrum Disorder (FASD) or suspected FASD, to develop greater resilience and strategies to help their families live successfully with impairments in a disabling society.

Objectives of this training were to have participants:

1. Achieve an increased knowledge of FASD, and its impacts and challenges across the lifespan.
2. Be better equipped in knowledge of successful strategies and interventions that can be used to help families where FASD is an issue.
3. Become aware of helpful and successful strategies and approaches to apply to their own unique family environment, as well as, to the systems in their environment, such as health, welfare, education and justice.
4. Fostering peer-support relationships with others who share the lived-experience of FASD.

The six sessions of 90 minutes covered the following topics:

1. What is FASD? Understanding the impact of prenatal alcohol exposure on the brain.
2. FASD across the lifespan and FASD Lived Experience.
3. Self-care, parental survival, managing stress, building family strengths and resilience.
4. Interventions and strategies that work for individuals and families where FASD is an issue
5. As above.
6. Dealing with systems of education, health, welfare and justice. Accessing supports and getting on with professionals

Each session using the ZOOM platform included mini lectures with PowerPoint slides by Anita, use of audio-visual on some occasions, open discussion of session topic, question and answer time, and a take home task which was then reflected upon at the start of each new session. After each session material and handouts were sent to participants as well as PowerPoint notes or additional information as a result of requests or questions from participants. The practical facilitator made herself the point of contact for all participants and the facilitators.

From the original course in Dunedin some changes of content were made to account for the Australian context, for example the Australian diagnosis guidelines were referred to and the NDIS scheme was referred to as well as Australian resources to help families. Additionally, more up to date readings and handouts were provided, and more reference was made to indigenous and Aboriginal perspectives on FASD, and models in use to help indigenous and Aboriginal people than the original Dunedin course.

### **Course philosophy and process overview.**

The course itself was viewed as necessary for a range of reasons –

- Parents and caregivers of children with FASD have challenges obtaining assessment, diagnosis, interventions, respite, or even acknowledgement that they are parenting a child with a neuro-disability.
- Parent and caregivers often feel isolated, excluded and misunderstood.
- Parents and caregivers can experience high levels of exhaustion, grief, loss, and burnout.
- They can also be frustrated about being denied access to help or funding, and agencies turning them down or telling them they just need to change their parenting approaches.
- Parents and caregivers can sometimes end up involved with too many agencies, undergo repeated family assessments but receive no assistance.
- But parents and caregivers also want to use positive strategies to help support their children's success and they proactively look for opportunities to upskill their knowledge and skills.
- Parents and caregivers are their children's strongest advocates and supporters and they know what's best for their children, but they often need help to ensure their children flourish.

Hence the course design was an attempt to address some of these concerns and wishes from parents and caregivers to receive FASD-specific online peer-to-peer mentoring, support and advocacy, of an ongoing nature. We knew this provision was limited in both NZ or Australia.

The course that Anita Gibbs designed incorporated well known best evidence frameworks for FASD and disability, those drawing on brain-based approaches, eco-systems and disability human rights' perspectives (Gibbs, 2019). The brain-based or neuro-developmental approaches tell us that the brain (and whole body) is impacted by pre-natal alcohol exposure (PAE) and this leads to a range of brain-based functional impairments that are in need of accommodations across the life course of an individual living with FASD. It is therefore essential to help caregivers understand the primary impacts and challenges of FASD, as well as the secondary ones, which lead to stigma and discrimination and exclusion from services.

A brain-based approach ensures brain domains and functioning are fully assessed and this can lead to a positive change in the many environments around the child. An eco-systems approach views FASD within eco-systems, family systems and the person-in-environment lenses to understand the impacts and challenges of all systems interacting with a child and their families. This approach also includes using systems to help build resilience and strengths for the person and their teams of helpers.

Systemic approaches include Communities of Practice, Wraparound, Keyworker and Case Management. There is a focus on changing systems and ensuring team around the family

approaches are implemented with clear roles, boundaries, lines of accountability and transparency. Thirdly, disability human rights' perspectives posit that children with FASD are born with a lifelong disability like any other disability, and that children should not be denied services, or excluded, or stigmatised for having impairments. Children should have rights to participate and be fully 'human' like anyone else, that is they should have the same human rights as anyone else. Children with FASD should be accepted as being neuro diverse as well as different in some areas of functioning.

Children with FASD as a Disability are the 'same but different', they are both Dis and Abled – hence DisAbled (a recent term adopted by critical disability researchers and others with a disability). This framework ensures work and interventions are challenging the barriers that DisAbled people with FASD face, as well as advocating for inclusion and participation, and promoting the voice of those with FASD across all policy and practice initiatives.

Without going into detail the GOWI course drew on key concepts as well as processes in the design and operation of the course. These included educational goals to give caregivers information; peer support by caregivers for caregivers – this was a part of the recruitment information and seemed to reassure participants that facilitators could be trusted to share their lived experience knowledge. Mentoring, and or coaching were relevant to each session in terms of practical examples of how to deal with issues faced by parents or who to ask for support when help seeking in the future. In addition, the use of advocacy and empowerment were a feature of the original Dunedin GOWI course, in terms of helping caregivers appreciate their own capacity to advocate for their children as well as to advocate for each other.

A deep desire of the training was to focus on helping families find time to flourish in spite of deep challenges. The concept of 'Pay it Forward', was that parents and caregivers might build enough trust in each other and confidence to keep meeting on a regular basis to exchange ideas and support each other once the initial training had been completed. In both the Dunedin and Australia GOWI courses this has been achieved.

## **Group Etiquette**

The practical facilitator tested out the use of ZOOM with a couple of the participants and developed a detailed Group Etiquette procedure see (Appendix 2) and this was used throughout to ensure participants could get a chance to speak and feel included. The caregivers views on whether they felt the digital space worked for them are considered in the combined evaluation report (page 12 onwards).

There were a few times when the internet connections cut out for some participants during the sessions, due to the instability of their connection but mostly participants were able to log out and sign back in and restart their attendance at the ZOOM session. On one occasion, the course facilitator could not change the PowerPoints while she was speaking. This potential situation had been planned for and the practical facilitator was able to share the PowerPoint with the participants whilst the co-facilitators continued with discussions whilst the course facilitator logged back in. The group easily adapted to the circumstances of the technology available to them. On completion of the course a certificate of completion was awarded (Appendix 4).

## **Group facilitators' reflections -**

Anita – This pilot was a rewarding experience and I was pleasantly surprised it worked so well. I was always slightly concerned about how to include everyone and enable the quieter ones to feel included even when they preferred to stay quiet during the sessions. Participants were a little shy to begin with but then opened up over the six sessions. Sometimes it was hard to hear people and people cut in and cut out with the WIFI, at the same time this was also good for flexibility – people liked joining and leaving at different times and also being in different locations and sometimes the kids waved at us too which was lovely.

The evaluation feedback will give more detail on people's views, overall they seem to have felt comfortable with the digital platform and style of group process. Giving them all an optional task each week seemed to keep them connected to the group and participants were often able to share something that had worked or that they had tried differently the week after each session. Sometimes, I felt getting through the pre-prepared material was a bit of a rush, sometimes I felt I ran out of time. We all shared some of our personal stories, usually to illustrate a point or to respond to someone's specific question. We did review some material for FASD across the lifespan, but the group predominantly had children aged 10 and up so we did not have a younger child focus. Next time around we could be age specific.

GOWI was at least six to nine months in the making – many hours of planning and meeting were required to get this pilot underway – it relied on mostly volunteer hours from everyone involved, with a small amount of funding from a donation to cover some of the work. Larger funds would need to be obtained if more online training and groups were established. Finally, without kindness and humour as essential ingredients this pilot would not have been the success it appears to have been.

Sophie Harrington – The interest from parents, carers and organisations to be participants for the pilot course, was overwhelming. If the staff and financial resource could have been cloned, the number of interested parties would have created enough demand to run four courses.

Participants were provided with the opportunity to trial the online platform in advance and the group etiquette was shared ahead of time, with participants encouraged to comment on the etiquette if they had any concerns about the suggested approach. These factors, along with the involvement of a practical facilitator to manage the administration of the course, were all key components which ensured the course ran smoothly.

Participant feedback was insightful and will assist the facilitators to reflect on ways to improve the GOWI program for future participants, particularly to encourage Aboriginal participants. Overall, it was a pleasure to be a part of this pilot program and incredibly rewarding to listen to, learn from and support parents and caregivers, throughout this enriching process.

Christine Brooks – It was a privilege to be invited to join GOWI as a co-facilitator. I found the experience to be both rewarding and informative.

It was rewarding to see a group of mostly strangers bond and learn together as well as grow in confidence and knowledge as the weeks passed. Although not immediate, through Anita's humour and down to earth manner and Sophie's warmth, the participants relaxed and gradually started to share their experiences, ask questions and offer each other suggestions. By outlining the group protocol from the beginning which included confidentiality within the group and the understanding that we are all here for the same reasons, a safe environment was provided to express very personal emotions and ask for help when needed.

GOWI was informative for me personally and from the feedback I was not alone in gaining a wealth of knowledge from Anita (a professional) as well as each of the participants as they shared their lived experiences, strategies and latest research. The weekly information part of the sessions provided valuable up-to-date material, which was much appreciated by each participant.

As a pilot program we can learn and reflect before moving forward with the next GOWI. Aspects like time-zone differences, children's age range, fitting the material into the session time and providing a detailed program manual need to be considered and streamlined so that each program is the best that can be offered. The concept of extending the groups beyond the program so that they become self-run support groups means ongoing scaffolding for many families.

Cheryl Dedman - I felt privileged to be asked to be a co-facilitator of the GOWI on-line program. The concept of being able to reach FASD families in remote areas was a fantastic idea, as was the idea to be able to reach busy families who for various reasons, find it difficult to attend a similar face-to-face program.

I felt that the team of Anita, Sophie, Chris and myself, worked well together to utilise each other's experience and expertise to produce a realistic, genuine and down-to-earth program. Whilst some of the content related to older children with FASD, which may have been beyond the ages of the children of many participants, I felt that this too was critical to provide information for parents/carers to plan for the future.

As with any pilot, there were lots of learning opportunities for those delivering the program, but all of these opportunities will enable the program to develop even further. There were no problems that could not be overcome, and this was often seamless, which I think is testimony to the great communication and preparation by the program team

## **“Getting on With It”: A Course by Caregivers, for Caregivers (Pilot) – Combined Evaluation Report**

### Introduction

Getting on With It – A Course by Caregivers, For Caregivers (GOWI) is a newly developed online training program facilitated in partnership with NOFASD Australia (NOFASD) and Associate Professor Anita Gibbs from University of Otago (Dunedin, New Zealand). The first GOWI pilot commenced in November 2019. This paper outlines the evaluation data from this pilot course.

The GOWI course was facilitated via video streaming software Zoom. The training consisted of six modules over a period of six weeks. Each module session was 90 minutes. The training was conducted at 4.30pm AWST every Tuesday evening from 12<sup>th</sup> November 2019 to 17<sup>th</sup> December 2019. The course was facilitated by Professor Anita Gibbs but with support from NOFASD. Parents and carers involved with NOFASD were key support people involved in the training, while a NOFASD employee supported the training as a practical facilitator. The practical facilitator was responsible for setting up the training, making introductions, recording training sessions and fielding online questions during the training. The practical facilitator was also responsible for general communications, digital platform setup and participant recruitment.

The GOWI training aimed to assist parents and carers with children with Fetal Alcohol Spectrum Disorder (FASD) or suspected FASD, to develop greater resilience and strategies to help their families live successfully with impairments in a disabling society.

Objectives of this training were to have participants;

- a) leave with an increased knowledge of FASD, and its impacts and challenges across the lifespan,
- b) be equipped in knowledge of successful strategies and interventions that can be used to help families where FASD is an issue,
- c) have considered helpful and successful strategies and approaches to apply to their own unique family environment, as well as, to the systems in their environment, such as health, welfare, education and justice, and
- d) have fostered peer-support relationships with others who share the lived experience of FASD.

### Participants

Participants were recruited using social media advertising on Facebook, LinkedIn and using the NOFASD Australia website. A total of 59 individuals expressed interest in participating in the GOWI training using these recruitment methods and, as a result, applications for the training were closed after ten days. NOFASD Australia selected twelve participants out of the

59 expressions of interest based on the ability of individuals to attend the allocated time slot and who had the required technology to support the online training.

A total of 12 individuals were enrolled in the GOWI course and all participants (100%) completed the training. Two participants were not able to attend two sessions and three sessions, respectively.

Participant demographics are listed in Table 1.

	<b>n</b>
<b>Sex</b>	
Male	2
Female	10
<b>Location</b>	
Western Australia	
Perth Metropolitan	3
South Regional	3
North Regional	3
East Regional	1
Interstate	2

Table 1: Participant demographics

All participants were parents or carers of children who had been diagnosed with FASD or who had suspected FASD. On average, each participant had two children with FASD, however, this ranged from one child to five children. Participants had 29 children combined. Children were aged from between 0-4 years to 19+ years old.

#### Data Collection

Data was collected using a two-stage process. Stage one involved the use of an online survey by Survey Monkey. This survey consisted of eight questions using a combination of quantitative and qualitative questions. The expected time for completion of the survey was six minutes. Participants completed the survey anonymously, however, participant IP addresses were collected. The aims of stage one were to ascertain the effectiveness of the training and to get an overview of participant satisfaction of the training. All responses were received within two weeks of the last training session.

The second stage consisted of a follow-up telephone interview using an external evaluator. The aims of the stage two evaluation were to; a) determine to what extent participants implemented strategies discussed in the training, b) determine how successful these strategies were, c) to gather more in-depth and rich qualitative data about the training and d) to provide further feedback on how the training could be improved. Participants were asked for their permission

to be contacted before the external evaluator interviewed them. Only when consent was given were participant contact details passed onto the external evaluator.

## Results

**Response rate.** A total of 12 participants completed the online survey, resulting in a response rate of 100%. The average number of training sessions attended was five, resulting in an attendance rate of 83%. This attendance rate was higher than expected given that many participants had numerous personal, parenting and professional commitments.

A total of 11 participants completed the telephone interview with the external contractor, resulting in a response rate of 92%. One participant was not able to be contacted despite efforts to contact them on three occasions. On average, it took two contact attempts before each telephone interview could be conducted. Interviews were between five and 40 minutes in duration.

**Motivation.** Participants listed differing reasons for their motivation to enrol in the GOWI training. The most popular reason why participants were attracted to the course was their desire to connect with other ‘FASD parents’. The second most common reason for enrolling in the training was to gain information from other carers, as well as professionals:

*“I am involved with NOFASD and have a foster daughter with FASD. I always want to increase my knowledge. I like the idea of a support group that will also provide information.”*  
*“To gain information from somebody with an academic and caregivers background and hear from other parents and carers about their experiences and approaches.”*

All participants reported that the course was successful in meeting their needs and expectations.

**Satisfaction.** The overall level of satisfaction of the training was measured by asking participants to what extent they would recommend the GOWI training to other parents and carers in a similar position to them. All participants (100%) strongly agreed or agreed that they would recommend the training to others.

**Need.** Participants were asked about how much the GOWI training was needed in their community. Responses to this question indicated a strong need, with 83% of participants strongly agreeing and 17% agreeing that more FASD-related training was necessary in their local area. Given that participants were in metropolitan and rural areas across Australia, these findings suggest that there is a need for the GOWI course nationwide.

**Content.** Participants were asked to comment on the training content in two separate questions. First, participants were asked to rate how up-to-date and relevant they felt the training content was. Second, participants were asked to rate how much they liked the approach taken by the trainers. All participants (100%) strongly agreed or agreed that the training content was up-to-

date and relevant and all participants (100%) strongly agreed or agreed that the approach taken was appropriate. One participant highlighted the approach as an important positive aspect of the training:

*“I found [the training] very beneficial. I liked the friendly relaxed approach and the non-judgmental environment.”*

**Training effectiveness.** The majority (83%) of participants stated that they strongly agreed or agreed that they had a better understanding of how to support their child after completing the training. Participants were asked if they felt their time was well-invested in the training. All participants (100%) strongly agreed or agreed that the GOWI training was worth their time. These findings suggest that participants not only felt better prepared to support their child or children after completing the training but found overall value in the training to the extent that they felt their time was invested well.

Effectiveness of the GOWI course was explored further in the external evaluation. The course effectiveness was measured by the extent to which participants gained knowledge and learnt new strategies and/or interventions. Almost all participants reported having improved their knowledge, but in different ways:

*“Yes, I definitely learnt some more about FASD...because to me it was like another world that opened up. I didn't know much about FASD beforehand.”*

*“It gave me a better understanding about how people cope and manage their lives with multiple children with FASD and just how different it is for everyone.”*

Participants were encouraged to identify any strategies that they had tried as a result of the course and whether they had been successful. Most participants reported learning various new strategies or interventions to assist their children with FASD:

*“Yes [I learnt new strategies] specifically around money - you know, how people with FASD handle money and strategies to support them. Each week there was something little I picked up.”*

*“Yes, I did [learn new strategies]. I think for us I was looking at the physical side of trying to regulate...trying parkour. He's absolutely loving it. It's really nice to see something that's so natural for him, and this is very self-led, it's a lot less structured. It still satisfies him from a sensory side of things. We've started doing it since the course.”*

Some participants reported not learning any new strategies or interventions from the program. This could be due to some participants having a high baseline of knowledge and experience of

implementing strategies. Despite this, participants reported learning self-care and self-management strategies to assist them to cope with their children's behaviours:

*"I think [the course] has made me a lot less frustrated, a bit more realistic and a lot more of an advocate [for my child] because I have a lot more knowledge."*

*"I'm in awe of everyone's resilience and this inspires each other when you see people in these situations. [Other participants] gave me strategies to get on with day to day living without getting caught up in every situation."*

**Peer Support Relationships.** Participants were asked about the extent to which they developed supportive peer relationships during the course. Information was gathered from a series of open-ended questions at the end of the survey and again in the external evaluation stage. Three themes were identified including; a) the connection, empathy and emotional support with other 'FASD parents', b) learning from experiences from other participants and c) learning information and strategies from the course facilitators.

Theme one was demonstrated by comments that the training helped participants feel less isolated and more supported. Comments included "feeling valued and not alone" and "meeting other carers and feeling that I was not alone". Theme two demonstrated the power of experiential learning through comments such as "learning through common experiences and being able to relate to others" and "learning so much with people that are walking through this like me". This theme was also depicted in the following comment:

*"Being with others who "get it" which is so important for me. It also gave me a valuable realisation that my son's behaviours were not normal and that normal responses were not the right way to deal with them."*

The external evaluation demonstrated differences to the internal evaluation, as some participants reported that they built peer-support relationships and found this helpful, whereas others felt that they did not. It is noted previously that some participants did not wish to build peer support relationships, which could account for this difference. Alternatively, the online format and the personalities of participants may have prevented peer support relationships from developing:

*"I thought it was slow to get started and I think everyone was a little hesitant and when you're communicating via screen, it doesn't help, but [the facilitators] really did make a difference and really helped put everyone at ease so everyone was more willing to join in. But the format with everyone spread out across the place it makes it difficult to form a relationship."*

*“I’m a bit standoffish, it takes a lot to sort of connect or click with people, I found them all to be very nice or very knowledgeable and very FASD-savvy, and because they all had FASD children, it was a relief to hear their stories and connect in that sense.”*

To determine the feasibility of an ongoing parent/carer support group, participants were asked if they planned on engaging with the online group post-training. Responses to this question were varied, with 58% stating that they would continue, 33% were unsure and 8% stating that they would not continue with the support group. For participants who reported 'maybe' or 'no', all stated that they could not commit to continued support group engagement due to being time-poor.

**Training format.** Participants were asked four questions about the format of the training, including what they thought about the online format, duration of each session, overall course length and the facilitators. All participants reported that the online format of the training was not only suitable for the course but provided them with the convenience to engage in the course while attending to their parenting tasks:

*“I think that [online] is the best way to reach people who are unable to get to a face to face group, not only that, the fact that they could still go about their business by caring for their young people was fabulous. So they could put into the group what they could.”*

Participants advised that the Zoom video conferencing software was suitable and easy to use, although some participants questioned whether this type of software would be suitable for different participant cohorts:

*“I think for some people, the average person, I think [online] could be a bit hard. It’s very easy flowing but at the same time, it could be a bit difficult... for people like myself (as an Aboriginal person). We’re used to sitting face-to-face and talking... [also] older people might also find it a bit difficult. I would have preferred [the course] to be face-to-face but it was not a realistic thing so online was ok. If you could mix it up and do a bit of both that would work.”*

Participants commented on the duration of each session (90 minutes) and the overall length of the course (six sessions). Results were mostly positive, however, some participants recommended a change in the course structure. Although these suggestions are helpful, some suggestions conflicted, indicating a difference in opinion:

*“I thought [the duration] was good. I didn’t think it was too long, it could have maybe gone for a couple more weeks maybe, but it was definitely not too long.”*

*“I think like most people I think it could have kept going and a lot more could have been discussed. I think it could have been an ongoing course and it gives people time to think. Maybe shorter [sessions] and over a longer timeframe.”*

All participants had positive feedback about the facilitators of the training, indicating that the approach taken by the facilitators was suitable and desirable. Participants used a range of words to describe the facilitators including “brilliant”, “supportive”, “approachable”, “down-to-earth”, “organised”, “respectful”, “lovely”, “awesome”, “fantastic” and “practical”.

**Areas of improvement.** Participants were encouraged to provide feedback as to how the GOWI training could be improved. Although some participants stated that no improvements were needed or could be made, other participants provided constructive recommendations. Three themes emerged during the internal evaluation. First, many participants stated that more space or more prompting could be used to engage quieter participants:

*“I found the training excellent, but one comment I would make is, being that I am not a strong public speaker, I found it hard to “butt” in. It would have been awesome if there was a button that could be pressed if a person wanted to say something then the co-ordinator opens up the microphone. This would be good especially taking into account the lagging on most services.”*

The second theme to emerge was the difficulty in attending the training at the timeslot of 4.30pm (AWST). One participant stated that “the time slot was a bit hard when juggling four kids” while another stated, “it would be easier for some if everyone was in the same time zone”. Given that participants were located across Australia, the allocated time may have been more suitable to some participants than others.

The third theme to emerge from responses to this question is a general desire for more information. One participant asked for “more examples of therapies people have used and discussion about specific therapies”, while another suggested “more topic studies [and] training/resource aids”. Two participants also suggested that they would benefit from in-person training, however, as the online format was highly regarded by other participants, it may be that in-person training may only suit a certain cohort.

During the external evaluation, one participant provided constructive feedback about how participants with younger children may perceive the approach by the facilitators.

*“The actual facilitator had too much input about their own experiences and her own children. Her children were 18 at the end of the scale and some people were only just getting into the system. She needs to be more mindful about those at the start of the journey. I felt that we needed to be more mindful of the newer ones coming in and how overwhelming it is when all these services come in. [She] spoke about a lot about the unlawful activity which may be*

*overwhelming for those with younger children. There needs to be range but wondering if it needs to be 0-18 years.* (Note: Facilitator's children were 15 and 16 at time of pilot not 18).

## Discussion

The findings from the two-stage evaluation process are outlined below:

1. Participants were satisfied with the course, indicated that the course was worth their time investment and was needed in participants' local communities.
2. Some participants enrolled in the course to connect with other parents, while others wanted to learn more information and strategies/interventions only. Differences in motivation likely influenced what participants got out of the course.
3. All participants reported improvements in knowledge, but only some participants reported learning new parenting strategies and even fewer implemented them. Despite this, participants reported improved parenting due to learning self-management and self-care strategies.
4. Some participants developed peer support relationships, while others did not. Motivation for enrolment in the course, the online format and participant personalities were identified as barriers to forming peer support relationships. Better management of group dynamics could be helpful to engage quieter participants and to support the building of peer support relationships.
5. Participants enjoyed the practicality of the online video software, however, some participants reported that this format may not suit some participant cohorts.
6. Aboriginal and Torres Strait Islander populations and/or older populations may find it difficult to navigate the online training format. Some participants wanted a face-to-face module.
7. Participants indicated that the 4.30pm (AWST) timeslot was difficult to manage, although the online video format assisted to maintain high engagement and attendance.
8. There were differences in how the session format was received. Some participants wanted more time for discussion, whereas others wanted to complete the course content with less discussion time. Despite this, the duration of each module and the course length were deemed suitable.
9. All participants praised the facilitators and the overall seamless running of the course.

## Recommendations

**Recommendation 1: Maintain using an online video format, but consider alternatives for specific participant cohorts, such as Aboriginal and Torres Strait Islander people and/or older parents and carers.**

The video format and the Zoom videoconferencing software was highly regarded by course participants, however, some participants raised concerns regarding the suitability of this format for other participant cohorts. Participants recommended that a quick Zoom tutorial prior to the first session could assist those with minimal technology skills. Alternatively, a face-to-face session or course could be beneficial for some participant cohorts.

**Recommendation 2: Include self-care and self-management strategies specifically for parents and carers.**

Feedback from the evaluation process indicates that most parents/carers had already developed strategies to support their children with FASD, however, almost all participants reported gaining new self-care and self-management strategies. Participants reported improved parenting of their children with FASD due to having an improved awareness of their coping skills and limitations. For future GOWI courses, it is recommended that there be a greater focus on self-care and self-management strategies for parents/carers, rather than behavioural strategies focused on their children. Incorporating self-care and self-management strategies into the course could be done using the information from Eileen Devine’s NOFASD carer resilience webinars.

**Recommendation 3: Review the current course objectives and consider amending the session structure.**

Given the feedback provided, it is important to consider the purpose and objectives of the GOWI course. It is important to clarify if the GOWI course aims to provide information to participants or is primarily a support group. Feedback indicates that some participants wanted to build peer support relationships, whereas others wanted to learn information. Once the course objectives have been clarified, the session structure could be reviewed to reflect any changes. Although it is unnecessary and unsuitable to implement a strict structure given the nature of the course, understanding whether to prioritise discussion or completion of the PowerPoint presentation will assist in running of the program and managing participant expectations, which will ultimately improve satisfaction.

**Recommendation 4: Consider age-specific and location-specific courses.**

Feedback from the evaluation process indicates that the GOWI program could benefit from age-specific and location-specific versions. Some participants raised that parents and carers with younger children could feel overwhelmed when discussions centred on the issues faced by adolescents and young adults with FASD. Age-specific courses could assist to reduce any feelings of overwhelm, and this could be done by dividing the current GOWI course into two types. For example, a course for children eight years and younger could focus on supporting children at home and school, as well as a greater focus on diagnosis, whereas a course for children aged over eight years could focus on supporting children as they move into adolescence and adulthood. If parents/carers had children in more than one age group, they could choose which course was most suited for them.

Facilitation of the GOWI course by state or territory could assist in planning an appropriate timeslot, maintaining engagement and attendance and encouraging the development of peer support relationships outside of the course. This could be easily achieved given the advancements in social media advertising which allows for people in specific locations to be targeted with relevant promotional material.

**Recommendation 5: Consider standardising the course, including the development of a program manual.**

One participant recommended developing a training manual to allow multiple Getting on With It courses to be delivered Australia-wide. Development of a training manual could also enable to delivery of a train-it-forward (TiF) program model which could empower parents and carers to deliver the training in their local community. A TiF model could also assist parents/carers to feel supported regardless of where they live and allow for the provision of face-to-face support for those participant groups who may not suit the online video format.

**Conclusion**

This report highlights the findings from both the internal (stage one) and external (stage two) evaluation reports. Findings demonstrate the suitability, desirability and need for the course amongst parents and carers with children with FASD. The course was effective at meeting its objectives, however, the recommendations in this report will assist in developing the course further. Overall, this GOWI course offers considerable promise in its ability to support parents and carers throughout Australia, which will have numerous positive flow-on effects to the children involved and the wider community.

## Final reflections post-evaluation feedback –

In the original course held in Dunedin, New Zealand it was noted that:

“Parents and caregivers overwhelmingly valued both the content and process of the training course. They highlighted that strength of the training was the delivery by experienced, professionally trained caregivers of children with FASD. They valued the opportunity to spend time with peers in similar circumstances who understood the challenges of parenting a child with FASD. They enjoyed the ‘safe’ atmosphere created by the group leaders and were able to comfortably share difficult material with their peers.” (Gibbs, 2019: 80).

The digital pilot reported on here mirrors the feedback from the face-to-face group. Participants of the NOFASD and University of Otago online GOWI training resoundingly noted that they were satisfied the course had met its aims and offered caregivers the chance to learn and share in a safe non-judgemental setting that could fit in with their busy lives and geographical locations.

A real strength of GOWI is its valuing of the ‘lived expertise’ of all caregivers of children with FASD or suspected to have FASD. Caregivers valued being viewed as experts themselves being able to share safely with other caregivers, as well as to glean useful information from one another. All participants said they would recommend this course to others. In addition, having lead key facilitators who themselves have expertise in parenting children with FASD, and also are grounded in up to date knowledge of FASD, including best practices, definitely assisted the success of this pilot.

The extensive evaluation feedback contained within this overall document had some important suggestions and we plan to draw upon these suggestions as we move forward. It is our intention to offer further GOWI courses via the online medium incorporating this feedback to some of the structure, materials, age groups, timing, locations and efforts to encourage increased participation from quieter members, as well as meet the needs of Aboriginal caregivers and their families.

The current GOWI offers the chance for caregivers to take the GOWI model forward themselves and continue to offer their peer to peer support to one another, post the initial 6-week education and facilitator-led course. The ‘pay it forward’ model of training co-facilitators, enables experienced individuals to take on new groups or to support an existing group to continue. This is vital in a climate of few resources to support caregivers. A core aim is *both* education and support, it is this twin track approach that is unique in digital caregiving training for FASD and not either, or. Caregivers need core and accurate and up to date information but they also need to know they are not alone in what is an extremely challenging journey at times. Caregivers value peer to peer support and often surprise themselves that they too are able to offer something to someone.

## Appendix 1: Online Advert

### **FREE 6-week, evidence-based online training course for parents and carers – commencing 12th November 2019**

*Getting On With It: Training for parents/caregivers supporting someone with diagnosed or suspected Fetal Alcohol Spectrum Disorder (FASD)*

NOFASD Australia, in conjunction with Associate Professor Anita Gibbs (PhD) from the University of Otago, are providing training for parents and caregivers supporting individuals with diagnosed or suspected Fetal Alcohol Spectrum Disorder (FASD). Anita is an adoptive parent, social worker, and university academic. She has both lived experience and research knowledge of FASD.

This 6-week, evidence-based training course will be facilitated online from 6 pm to 7.30 pm AEST, commencing on Tuesday 12th November and concluding on Tuesday 17th December 2019. Participants are required to commit to all 6 sessions in order to get full value from the training. A certificate of completion will be sent at the conclusion of the course.

To find out more and to register your interest, please contact the NOFASD Helpline on 1800 860 613

This is a no blame, no shame course run by professionally qualified parents who have experience of FASD.

**\*This course is only available to families living in Australia.** Our apologies for the confusion regarding NZ residents.

## Appendix 2: Online Group Etiquette

### Getting on with it – online FASD training and support group for parents and carers 2019

#### Meeting time:

4.30 pm to 6 pm (AWST Australian Western Standard Time)

#### Meeting dates:

SESSION 1: Tuesday 12<sup>th</sup> November

SESSION 2: Tuesday 19<sup>th</sup> November

SESSION 3: Tuesday 26<sup>th</sup> November

SESSION 4: Tuesday 3<sup>rd</sup> December

SESSION 5: Tuesday 10<sup>th</sup> December

SESSION 6: Tuesday 17<sup>th</sup> December

#### Meeting Facilitators:

Anita Gibbs – *Lead Facilitator*

Sophie Harrington – *Course Coordinator*

Cheryl Dedman – *Co-Facilitator*

Christine Brooks – *Co-Facilitator*

#### Group etiquette for the best online shared experience

- **START THE MEETING:** You will receive an email invite from Sophie. Accept the Zoom invite in the email by clicking on the link. Please join the meeting 5 minutes prior to the 4.30 pm AWST start time.
- **MUTE YOUR MICROPHONE:** When you join the group and you are welcomed by the facilitators, please give your first name and click the mute button on your Zoom screen to ensure the group can't hear background noises. To mute your Zoom microphone, hover over the lower left corner of your screen and you will see a microphone, when you click on it, a line will appear over the microphone symbol. **REMEMBER** to unmute your microphone when we ask you to introduce yourself.
- **HEADPHONES:** You may wish to use headphones for the session to help block out any noises from your environment.
- **CONFIDENTIAL SPACE:** The group is a safe, non-judgemental and confidential space. All participants are parents and/or carers of children with FASD.
- **SUPPORT GROUP:** The purpose of the online training is to upskill parents and carers, share thoughts, experiences and knowledge and with the intent to build connections to establish a support group to enable an ongoing group if participants would like this, after the 6 week program has finished.
- **SESSION RECORDING:** The sessions will be recorded for NOFASD staff training purposes only. Session content will not be distributed outside of the organisation and will be treated as confidential material.

- **ZOOM CHAT FUNCTION:** Zoom provides a ‘chat’ option, which allows participants to share messages with one named individual or the whole group. If you have any questions/comments/feedback during the training, please could we ask you to send all messages to Sophie Harrington. If you would like to speak to Anita/Cheryl/Christine, please say so in your message and Sophie will forward the correspondence in real time. To access the chat option, hover over the lower part of your Zoom screen, the tool bar will appear at the bottom of the screen.
- **NO QUESTION IS A SILLY QUESTION:** remember, there are no silly questions, send your questions to Sophie, if you’re thinking, you can be sure somebody else will be too.
- **EQUAL TIME FOR ALL:** Please be mindful throughout the 1.5 hour session, we need to provide equal opportunities for everyone to participate if they would like, we can’t allow one participant to hold the floor for too long.
- **MOST IMPORTANT!** Ask anything you would like to know via the chat option during the training, or by email to [Sophie.harrington@nofasd.org.au](mailto:Sophie.harrington@nofasd.org.au) after the session. And ENJOY, this is your time, to get out of the training, what you would like to know.

### Appendix 3: Program Flyer

# FASD

Training for parents/caregivers supporting someone with diagnosed or suspected Fetal Alcohol Spectrum Disorder (FASD)



#### SESSIONS WILL COVER:

What is FASD?  
Understanding the impact of prenatal alcohol exposure on the brain.

FASD across the lifespan.  
Interventions and strategies that work with individuals and families where FASD is an issue

Self-care, parental survival, managing stress, building family strengths and resilience

Dealing with systems of education, health, welfare and justice

#### LOCATION, TIME & DATE:

**Where:**  
An online Zoom©, 6 session course, delivered over 6 weeks.

**Dates:**  
Tuesday 12<sup>th</sup> November to Tuesday 17<sup>th</sup> December inclusive.

**Time:**  
6 pm – 7.30 pm AEST

**Contact: 1800 860 613 to register your interest.**

**This is a free course.**

#### COURSE LEADERS:

Anita Gibbs (PhD) is an adoptive parent, social worker, and University academic. She has both lived experience and research knowledge of FASD.

Christine, a foster parent, seeking to understand and share the complexities of this challenging condition.

Sophie Harrington is a national community educator for NOFASD Australia.

A NO blame, NO shame course run by professionally qualified parents who have experience of FASD.

## Appendix 4: Training Completion Certificate



# CERTIFICATE of COMPLETION

THIS ACKNOWLEDGES THAT

*Cheryl Dedman*

SUCCESSFULLY COMPLETED THE SIX SESSION ONLINE FASD TRAINING COURSE

Getting on with it, an online FASD training and support group for parents and caregivers supporting someone with diagnosed or suspected fetal alcohol spectrum disorder (FASD)

*S.Harrington*

Sophie Harrington  
National Community Educator  
National Organisation for Fetal Alcohol Spectrum  
Disorder Australia

*A.Gibbs*

Associate Professor Anita Gibbs  
Coordinator - Social Work Continuing Education  
University of Otago