Development and pre-feasibility testing of SPECIFiC: A psychoeducation program for caregivers of children with fetal alcohol spectrum disorder (FASD)

Abstract

A growing number of evidence-based services are available for fetal alcohol spectrum disorder (FASD), but few focus on caregiver psychoeducation. Despite new guidance in the UK requiring FASD services, the evidence base for effective interventions is currently lacking. An FASD caregiver training program would be a novel and valuable addition to service provision. SPECIFiC (Salford parents and carers education course for improvements in FASD outcomes in children) was developed using an evidence-based logic model with input from clinicians, families, and the charity sector. The course was delivered online to a small number (*n* = 9) of families in a mixed-methods, exploratory pre-feasibility study. Families were represented by either one or two caregivers, all of whom were adoptive parents or special guardians of a child with FASD. Parent perceptions were assessed using semi-structured interviews. The performance of proposed outcome measures (stress, psychological functioning, parenting self-efficacy, knowledge of FASD, and child behavioral difficulties) was evaluated. Pre- and post-measures were acceptable and showed promise as outcome measures for a future trial. Participants spoke positively about the course, welcomed the opportunity to discuss their own situations with other FASD caregivers, found the advice to be immediately useful, and described the course as therapeutic. Suggestions for improvements tended to focus on timing and technical issues. Based on a small sample, SPECIFiC was shown to be an acceptable and feasible psychoeducation program. Further evidence from a randomized controlled trial is needed to evaluate whether SPECIFiC can lead to reduced stress in parents, improved parenting self-efficacy, and ultimately a reduction in children’s behavioral difficulties.

Keywords**:** FASD; parenting; psychoeducation, intervention development; mixed methods

Highlights

- New psychoeducation program for caregivers of children with FASD
- Dual delivery by professional trainer and experienced caregiver
- Small pre-feasibility study (*n* = 9) suggests the program is acceptable and feasible
- Participants responded positively to the program

Development and Pre-Feasibility Testing of SPECIFiC: A Psychoeducation Program for Caregivers of Children with Fetal Alcohol Spectrum Disorder (FASD)

Fetal alcohol spectrum disorder (FASD) is a common neurodevelopmental disorder caused by prenatal alcohol exposure. Current estimates show an international prevalence of around 1%, and a UK prevalence of between 1.8% and 3.6% (Lange et al., 2017; McCarthy et al., 2021). FASD is characterized by difficulties in motor skills, cognition, language, academic achievement, memory, attention, executive function, affect regulation, adaptive behavior, and social communication (Cook et al., 2016), and around 10% of cases also have distinctive craniofacial dysmorphia (May et al., 2018). FASD is a lifespan diagnosis but with recognition and appropriate support, especially from an early age, life outcomes including social and occupational functioning can be improved (Alex & Feldmann, 2012; Streissguth et al., 2004).

Evidence-based interventions for individuals and families affected by FASD have shown some evidence of efficacy. Cognitive and behavioral interventions for children with FASD have led to some improvements in motor skills, mathematics, attention, executive functioning, adaptive functioning, impulsivity, and social skills, although more high-quality evidence from randomized controlled trials is needed (Ordenewitz et al., 2021). Interventions for families have typically shown better treatment effects than interventions directed only at children (Ordenewitz et al., 2021). Interventions for families tend to include separate caregiver and child components, where the caregiver sessions act as an adjunct to the primary component of child cognitive or behavioral training (Ordenewitz et al., 2021). This method appears to improve on the design of child-only intervention. However, less is known about the impact of caregiver-focused or caregiver-only interventions. A small number of such studies have shown that long-term support and advocacy along with training in FASD and a child component can be effective. For example, the Parents under Pressure program, originally designed for a non-FASD population but adapted for families affected by FASD, involves developing a tailored, individual case plan including child cognitive skills training, caregiver psychoeducation, and consultation with the child’s school (Reid et al., 2017). Similar programs include Families on Track (Petrenko et al., 2019), Strongest Families (Hundert et al., 2016), Families Moving Forward (Bertrand, 2009) and SEEDS (Hajal et al., 2019), all of which involve some form of long-term and/or personalized support.

FASD interventions that focus solely on parent training are almost absent from the literature; only one appears to have been published. The Dunedin Parent Training Course (Gibbs, 2018) was a two-hour by seven-week FASD caregiver training course in New Zealand. It was based on empowerment and advocacy and was delivered by the author who was an academic as well as being the adoptive parent of children with FASD. The course was evaluated qualitatively, and participants reported that they gained useful knowledge and skills that were relevant to caring for children with FASD. They especially valued the opportunity to learn from someone with real-life experience, and to discuss the subject matter and their own situations with the trainer and the other participants. Caregiver training programs like this may be a resource-efficient method of upskilling, empowering and providing peer support to caregivers of children with FASD.

Caregivers of children with FASD in the UK have been shown to have very high, even clinically significant, levels of stress related to caring for their children (Mohamed et al., 2020). Adoptive parents of children with FASD in the UK have reported being offered training courses on trauma and attachment issues, Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD) and associated conditions or difficulties but having no access to any form of support or training specifically designed for families of children with FASD (Price, 2019). An FASD caregivers' training course should help to reduce stress in parents and may also help caregivers to support their children more effectively, leading to improved functioning. Since the only published FASD intervention that is specifically and solely a caregiver training course (Gibbs, 2018) is yet to be subject to a formal, definitive evaluation, it is timely and appropriate to assess the impact of such a course on caregiver stress, child behavioral functioning and related outcomes using validated psychometric instruments.

At a time when healthcare services are under pressure in terms of resources (Sokol, 2021) and with few FASD-specific services available in the UK (Schölin et al., 2021), an FASD caregiver training program that can be delivered by a range of professionals and organizations, including non-governmental organizations, may be an apt and timely intervention. In the UK, two national public health bodies are currently recommending increased attention and support for FASD. The National Institute for Health and Care Excellence (NICE) has recently published the first ever UK quality standard for FASD, which recommends that management plans are available for all people diagnosed with FASD (NICE, 2022). SIGN 156, on which the NICE quality standard on FASD is based, has been Scottish guidance since 2019 (SIGN, 2019). The Department of Health and Social Care's latest Health Care Needs Assessment for England also concludes that there is a need to develop innovative approaches for supporting people living with FASD and their families (DHSC, 2021). Since services that are specific to FASD in the UK are minimal, there is an urgent need for evidence-based intervention development here. The situation is similar across the world, with groups in several countries reporting that increased services are needed for FASD (Petrenko & Davis, 2017).

This report describes the development and feasibility testing of the 'Salford parents and carers education course for improvements in FASD outcomes in children' (SPECIFiC); the first published report of an FASD caregivers' training course in the UK, and one of the first internationally. The program aims to improve caregivers' stress levels, psychological functioning, parenting self-efficacy, health-related quality of life and knowledge of FASD, as well as children's behavioral difficulties. The aims of the study reported here are: firstly, to describe the development of the program and its underpinning logic model; and secondly to present the results of a small, exploratory pre-feasibility assessment of the program to evaluate participants' perceptions of and engagement with the course, and the performance of proposed outcome measures. These findings will inform a future randomized controlled trial.

Method

Program Development

In the first stage of development, a review of both peer-reviewed and grey literature (documents published by governments, NGOs, charities and other non-commercial organizations) was conducted to establish any current evidence on parenting programs for FASD, other neurodevelopmental disorders and generic parenting programs. Only one published FASD parent/caregiver training program was identified (Gibbs, 2018), a useful conclusion from which was adopted for SPECIFiC: namely, that participants valued learning from a trainer with real-world FASD caregiving experience. Several other FASD interventions had parent-training components (Bertrand, 2009; Coles et al., 2018; Hajal et al., 2019; Hundert et al., 2016; Leenaars et al., 2012; Petrenko et al., 2019; Reid et al., 2017), although these were usually focused on specific aspects of FASD rather than general FASD training. A number of effective parenting programs exist for generic parenting skills (Pidano & Allen, 2015; Sanders, 2008) and other disorders or difficulties, such as Autism (McConachie et al., 2005)) and externalizing behavioral difficulties (Timmer et al., 2019), but not for FASD. Families affected by FASD have expressed the need for programs specifically designed for them and that the generic or wider neurodevelopmental parenting advice they had received was unhelpful (Price, 2019). A search of the grey literature identified resources and strategies produced by charities and public health organizations, which contained advice based largely on clinical experience. Alongside this review, meetings were held with families affected by FASD to explore their needs and what kind of advice they thought would be useful for families of children with FASD. Three meetings were held, in the form of unstructured focus groups, where between four and ten caregivers of children with FASD discussed what they would like to see in a training program. Outcomes tended to take the form of specific practical advice, such as the use of wall planners at home with pictures to help children to understand and visualize what their day will look like, and the use of fiddle toys for children with attention and hyperactivity difficulties. Using evidence from these sources, a logic model was compiled as a framework for the development of the program (See Figure 1). The key assumptions of the logic model were: FASD caregivers want more support including FASD-specific training (Mukherjee et al., 2013; Price, 2019); FASD caregivers can be trained to care differently for their children, leading to reductions in stress and behavioral difficulties (Bertrand, 2009); and FASD caregivers who attribute their child's difficulties to brain differences are more likely to use antecedent strategies and feel more confident in managing their child's behavior compared to caregivers who see their child's difficulties as willful disobedience (Petrenko et al., 2016).

Based on these assumptions, a 10-session outline program was designed to be tailored specifically for caregivers of children with FASD, emphasizing a brain-based approach with strategies for changing the environment around the child. The outline course was presented to a steering committee composed of caregivers of children with FASD, national and international clinical experts, researchers, and FASD charity sector leaders at a 3-day event in December 2019. The steering committee provided feedback on the outline course, which was revised into a 7-session format to be delivered by two facilitators – one professional trainer and one experienced caregiver of a child with FASD. The manual was written in accordance with the Preferred UK Language Guide for FASD (National FASD & Seashell Trust, 2020).

The seven-session program was written up as a delivery manual by AP alongside DT and AW. The program was originally designed for face-to-face delivery but was converted for delivery via video conferencing due to the Covid-19 pandemic.

The SPECIFiC Program

SPECIFiC is a seven-session psychoeducation course for parents or carers of children aged 5-10 years recently diagnosed with FASD, with each session lasting two hours. Its aim is to deliver information about FASD, how FASD can present, and strategies for providing effective support for children with FASD. It is built around a neurobehavioral model, where the behavioral challenges associated with FASD are viewed as products of atypical brain development rather than deliberate actions on the part of the individual with FASD. This first version of SPECIFiC was delivered online via video conferencing by two facilitators: one experienced parent of a child with FASD and one person with relevant professional experience (having previously delivered training, teaching and/or therapy), but not necessarily related to FASD. Each group consisted of up to six families, each family with either one or two adult members present. The sessions were delivered during school hours in term time in order to maximize any time parents had with children out of the home.

As shown in Table 1, following an introductory session, the remaining six sessions focused on: sensory processing; self-regulation; communication, speech and language; abstract and concrete reasoning; routine, structure and consistency; and social relationships. Effective advocacy, self-care and accessing support and services were recurring themes. Participants were advised to keep records of strategies that were and were not effective to help them develop their own tailored support strategy and identify triggering stimuli in order to avoid them. They were advised to focus on positives with their children, using immediate social rewards rather than slower or more negative forms of reinforcement. They were advised to identify their children's strengths and interests, and to encourage and support these as a source of self-esteem and potential vocations in adulthood. The sessions typically involved: two or three presentations of information by the facilitators, followed by time for group discussion; videos featuring experienced FASD caregivers and/or young adults with FASD talking about the topic of that session (which were recorded especially for the program); and activities designed to consolidate learning or prompt further discussion. At the end of each session, participants were asked to put into practice at home something they had learned in that session, and report back at the beginning of the following session. All participants were provided with a carefully curated reading list including websites, online PDFs, books and podcasts, and were encouraged to keep learning about FASD after this introductory course. They were advised to keep in touch with other families affected by FASD both online and in-person (when possible) to provide ongoing peer-to-peer support.

Design

This was an exploratory pre-feasibility study of a manualized psychoeducation course for caregivers of children aged 5-10 years with FASD, delivered and assessed remotely using video conferencing. The course was assessed using a before-after design with no control group. Testing in trial format with a control group and larger sample will be conducted in the future; this preliminary stage of testing is designed to assess the acceptability and feasibility of the program as well as the assessment methods. The age range of 5-10 years was chosen because children in the UK typically attend primary school aged 5-11 years, but the transition year (age 11) can be a difficult time for children with FASD. Assessment was mixed methods, with qualitative thematic analysis of post-course semi-structured interviews, and quantitative analysis of pre- and post-course psychometric questionnaires and session evaluation forms (which were completed after each session).

Participants

Nine families were purposefully recruited by email via FASD clinics, families' groups, and a UK FASD prevalence study ongoing at the time (McCarthy et al., 2021). For inclusion in the study, families met the following criteria: at least one child aged 5-10 years; child diagnosed with FASD or has probable FASD; no previous FASD training; and suitable computer equipment and internet connection to attend the online sessions. The category of 'probable FASD' was included to allow the participation of families who have been told by a healthcare professional that their child likely has FASD, but that diagnosis is not available in their area. Families were asked for their preference of morning or afternoon sessions; four joined the morning group, and five joined the afternoon group. All caregivers in each family were invited to join the sessions; one of the families was represented by two caregivers whilst the other eight families were represented by one caregiver. In one case, this was because the family was a single-parent family, and in all other cases this was due to work commitments from the other caregiver. The study was open to adoptive parents, foster carers, special guardians and birth parents, however only adoptive parents and special guardian families were recruited. In families with more than one child meeting criteria, one index child was nominated to be the subject of informant-report psychometrics. Likewise, one index parent per family was nominated to complete all measures, although their partners were also invited to participate in the interviews. Table 2 shows the sample characteristics.

Procedure

Ethical approval for the study was granted by the University of Salford Health Research Ethics Committee in March 2020 (reference: HSR1920-053). Two of the program developers (AP and AW) facilitated the afternoon sessions, and two recruited facilitators (one professional trainer and one parent of children with FASD) took the morning group. The two recruited facilitators were included in the study to assess whether the course could be acceptably delivered by facilitators who were not previously familiar with the manual. They were given two weeks to read the manual, then all four facilitators met by video conferencing for three training sessions, which included discussions and role-play of delivery.

The sessions were originally planned to be delivered once weekly but were held twice weekly for three and a half weeks in order to make use of the school term during November and December 2020. Families were provided with full study information and provided consent to take part electronically.

Measures

Session Evaluation Forms and Fidelity Checks

After each session, participants were asked to complete a session evaluation form electronically by rating aspects of the session on a three-point scale as either unhelpful, helpful or very helpful. The same form was used after each session and the aspects rated were content, delivery, discussions, videos, activities and Q&A sessions. In order to assess the fidelity of delivery, the research fellow (AP) was present at all sessions, both morning and afternoon, to evaluate whether the training was delivered according to the program manual.

Caregiver-Report Questionnaires

Informant-report psychometric questionnaires and a project-developed FASD knowledge questionnaire based on the course content were administered to the index participants before and after the course via video conferencing. All measures except for the EQ-5D-5L, CORE-OM, and the FASD Knowledge Questionnaire, were selected based on their suitability for intervention testing in neurodevelopmental disorders, and for their validity and reliability. The EQ-5D-5L was chosen as the preferred measure of health-related quality of life for intervention studies and its use will inform the health economics assessment in the feasibility trial and full randomized controlled trial. The CORE-OM was chosen as a measure of change following psychological interventions, and the FASD Knowledge Questionnaire was designed especially for this study as a measure of knowledge improvement.

The Parenting Stress Index Short Form (PSI-4-SF) (Abidin, 2012) is a 36-item questionnaire for caregivers of children aged one month to twelve years, which provides a total stress score and three subscales: parental distress, parent-child dysfunctional relationship, and difficult child. Statements related to parenting stress are responded to on a five-point scale from strongly disagree to strongly agree, with higher scores indicating higher stress levels. Outcomes can be described in terms of raw scores and percentiles, with the normal range between the 16th and 84th percentiles, and the clinically significant cut-off at the 90th percentile. Internal consistency for the PSI-SF is good to excellent, with Cronbach's alpha scores of .90 for the parental distress subscale, .89 for the parent-child dysfunctional relationship subscale, .88 for the difficult child subscale, and .95 for the total stress score (Abidin, 2012).

The Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) is a 25-item questionnaire for caregivers or teachers of children aged 4-17 years. There are five subscales covering conduct, hyperactivity, emotional problems, peer problems, and prosocial behavior as well as an overall difficulties score. Participants respond to statements relating to their children's behavior on a three-point scale from not true to certainly true. Higher scores indicate more severe difficulties, except for the prosocial behavior scale, where higher scores indicate more prosocial behavior. The SDQ total difficulties scale has good internal consistency, with a Cronbach's alpha of .82 when scored by parents (Goodman, 2001).

The Eyberg Child Behavior Inventory (ECBI) (Boggs et al., 1990) is a 36-item questionnaire for caregivers of children aged 2-16 years. Statements related to children's behavioral difficulties are rated on two scales: a seven-point scale from never to always to produce an intensity score, and by a yes or no option that determines the problem score. Higher scores indicate higher levels of problems on both scales. Both the problem and intensity scales of the ECBI have excellent internal consistency, each with a Cronbach's alpha score of .98 (Boggs et al., 1990).

The Tool to Measure Parenting Self-Efficacy (TOPSE) is a 48-item caregiver-report questionnaire designed to assess the impact of parent-related interventions on caregivers' sense of their own parenting self-efficacy (Kendall & Bloomfield, 2005). Caregivers respond to statements on emotion and affection, play and enjoyment, empathy and understanding, control, discipline and setting boundaries, pressures, self-acceptance, and learning and knowledge on a 10-point scale from (0) completely disagree to (10) completely agree. Higher scores indicate higher levels of parenting self-efficacy. The full scale has excellent internal consistency, with a Cronbach's alpha of .95 (Kendall & Bloomfield, 2005).

The EQ-5D-5L is a 26-item adult self-report measure of health-related quality of life. It is formed of five subscales related to mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, in which participants indicate to what extent they have difficulties with those issues on a five-point scale from (1) no problems to (5) severe problems. The five scales can be combined to calculate a composite index value. Higher scores indicate better health. A recent systematic review (Feng et al., 2021) found high rates of test-retest reliability and convergent validity have been demonstrated across clinical and non-clinical populations, not including FASD.

The CORE-OM is a 34-item self-report instrument, designed to measure the effectiveness and efficacy of psychological therapies. Participants respond to statements about subjective wellbeing, mental health symptoms, function, and risk to self and others on a 5-point scale from (0) not at all, to (4) most or all of the time. Higher scores indicate more severe problems. Its internal consistency has been shown to be excellent, with a Cronbach's alpha of .94 in both clinical and non-clinical populations (Evans et al., 2002).

The FASD Knowledge Questionnaire was designed for this project as a tool to assess improvements in participants' knowledge of FASD. Participants responded to 25 multiple-choice questions based on course content, each with four possible answers. The questions were designed by the research fellow and were based on information provided in the sessions. For example, participants were asked, "The brain area most associated with executive functioning is a) the temporal lobe, b) the parietal lobe, c) the frontal lobe, or d) the occipital lobe". Two questions had two correct answers, giving a maximum score of 27.

Participant Interviews

After the course, semi-structured interviews were held with each family (*n* = 9) over secure video conferencing (meaning that the meetings can only be accessed by invitees). The interviews were conducted by the research fellow (AP), who was familiar with the participants, the content, and the progression of the course, having recruited the participants, collected other data, and facilitated the afternoon sessions. The research fellow was a male post-doctoral researcher who had experience of conducting and analyzing interview data using thematic analysis. Two parents were present for one interview, while the other eight were attended only by the researcher and the index parents. Participants were asked about the content and delivery of the sessions, practical aspects such as timing and group size, whether they felt that the sessions had been useful and enjoyable, whether the information they had learned had made any difference at home, session components such as videos and activities, technical aspects such as the experience of using video conferencing, and whether they had any suggestions for improvements.

Data Analysis

Session Evaluation Forms and Fidelity

The evaluation forms for each session were described in terms of frequencies and percentages of each possible answer (unhelpful, helpful and very helpful). Some fields (e.g., videos, discussions) were not applicable to all sessions, and not all participants gave a response for each field. Total scores were calculated by first adding the total number of responses for each field across all seven sessions, then by adding together all the responses by possible answer (not helpful, helpful, or very helpful). Sessions were considered to have adequate fidelity if all session components were delivered.

Caregiver-Report Questionnaires

Each of the questionnaires was scored according to the authors' instructions. Scores from the pre- and post-course questionnaires were compared in a repeated measures design using paired t-tests with Cohen's *d* as a measure of effect size. Given the small sample size, results were interpreted based on effect sizes with 95% confidence intervals rather than statistical significance in accordance with guidelines provided by Lancaster and colleagues (2004). In this preliminary research stage, these quantitative measures were conducted primarily as part of the process evaluation rather than as a reliable measure of improvement. Analysis was conducted using IBM SPSS version 27.

Participant Interviews

Participant interviews were video recorded, transcribed verbatim and subjected to thematic analysis using Braun and Clarke's (2006) guidelines. Passages in the transcripts were converted into codes, which were then organised into themes. The Braun and Clarke method of thematic analysis allows some variation according to different research questions and assumptions. In this study, the aim was to describe participants' actual experiences and their descriptions were assumed to accurately depict those experiences. It was therefore conducted according to an essentialist, rather than constructionist, paradigm; and themes were identified at the semantic, rather than latent, level. The study was exploratory, so no thematic framework was developed prior to analysis. Rather, the themes were identified from within the dataset in order to generate theory. Methodological details and results of the qualitative analysis are presented in accordance with the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007).

Results

The attendance of the sessions was 97%. Eight out of the nine families attended every session, while one family (consisting of one caregiver) was unable to join two sessions due to work commitments.

Session Evaluation Forms and Fidelity

Session evaluation forms were sent to all nine families after each session, and the number of completed forms returned for each session ranged from three to eight. Figure 2 shows that participants generally indicated that aspects of the program were helpful or very helpful. Aspects of the course were unhelpful 4.7% of the time, helpful 34.1% of the time, and very helpful 61.1% of the time. Discussions were indicated as being helpful or very helpful 100% of the time, and the content and delivery of the sessions were each indicated to be helpful or very helpful 97.5% of the time. The activities (97.2%), Q&A sessions (92.9%), and videos (82.1%), were indicated as being helpful or very helpful most of the time. In both groups, all session components were delivered correctly according to the treatment manual.

Caregiver-Report Questionnaires

Table 3 shows the pre- and post-course scores for all outcome measures. Cohen's effect sizes are reported with 95% confidence intervals. Paired t-tests showed movement in the direction of improvement on all measures and on all subscales. The effect sizes for parenting self-efficacy (d = 1.59), knowledge of FASD (d = 1.16), and parental stress – difficult child (d = .85) were high or very high. Effect sizes were in the medium range for all other scales with the exception of health-related quality of life (d = .40) and parental stress – parent child dysfunctional interaction (d = .03), which were small. The 95% confidence intervals around these effect sizes tended to be wide, usually with the lower end in the small or very small range. One exception to this was parenting self-efficacy, whose confidence intervals ranged from medium (.57) to extremely large (2.58), indicating a higher degree of confidence of a large effect, albeit from this limited sample.

Participant Interviews

Participant interviews lasted between 20 minutes and 65 minutes. Thematic analysis of the participant interviews identified five broad themes. Overall, the participants spoke very positively about the course in terms of the content and delivery. They were glad of the opportunity to discuss the content of the course amongst the group and described the sessions as being part training and part support-group, commenting that this was a helpful format. The advice that was delivered was described as immediately beneficial in terms of improving their understanding of their children's needs, and strategies for supporting them. They spoke about a lack of support for families with FASD and were pleased to see that this course was being developed. Some suggestions for improvement were noted, especially in terms of timing and technical difficulties. In this analysis, quotes are labelled by family number and whether that family attended the morning or afternoon sessions (AM or PM).

Theme 1: Two Hours is Not Enough

One of the first observations to become apparent during delivery was that two hours was not sufficient time for these sessions. This was noted by the facilitators during the course and was discussed in the participant interviews. Interestingly, the morning sessions were allowed to run long and frequently lasted for around three hours. This was convenient for the morning participants, but the afternoon participants were unable to stay past the advertised time, so those sessions were limited to two hours. Some participants in the afternoon group expressed that they would gladly attend for longer if it meant they had more time to reflect and discuss during the sessions. "…the other thing is that it would be good to [have] more time per session to discuss things" (family 7, PM). Since the morning sessions were advertised as two hours, the subject of overrunning was mentioned in the interviews. This was not seen as a big problem by participants, but they would have liked to have a clear timetable. "there's so much content that the sessions are obviously running to a much longer time, but that's ok because we want the content" (family 6, AM).

Related to this, there was a preference for the sessions to be held once per week rather than twice a week. The four to six hours of delivery per week was a major commitment for some people, while some participants also described how the gap between sessions was insufficient for reflection and instigating any changes and strategies at home. "…for me personally I found four hours [per week] a massive commitment" (family 9, PM).

> "…we haven't been able to initiate some of the things because we only had a gap of three days, I think that's when you have a session on a Friday and then you've got the one on Tuesday there's not many days in between" (family 3, AM).

Theme 2: Part Training, Part Support Group

Participants described the sessions as part training, part support group and attached great value to the opportunity to discuss the content and their own situations with the facilitators and other families. The discussions amongst the groups served to bring the content to life, by transforming the abstract information and strategies into real-life situations. The course was designed to feature plenty of discussion time but had not been conceptualized as a hybrid training and support group. This was something that emerged organically, and the participants were unanimous and emphatic in their praise for that aspect of the course. "…apart from the actual training element itself actually the sharing of all the stuff that people have experienced is kind of the key thing that you get out of it" (family 6, AM)**.** Similarly, several participants noted the value of talking to other people in a similar situation. There was a feeling of isolation among many of the families, especially in terms of interaction with other FASD caregivers. Some of them felt criticized by outsiders who did not understand FASD, and it was therapeutic to know that other people were in the same situation and understood. "I cannot tell you, and I may cry now, what it's like being able to just talk to another parent who gets it, who knows what you're going through, and who shares your worries and concerns" (family 2, AM).

Theme 3: Praise and Gratitude

Overall, the participants were glad to have the opportunity to take part in this course. They praised the course as a whole and described how it was better than they had expected and that it had had a positive effect on their lives.

> "…the only thing I wanted to say is don't change it because it's great and it really gets you thinking just enough to put things in place to just make your life a little bit less stressful. I found it really helpful so I'm just really glad you've let me come on it that's all so thank you" (family 8, AM).

Participants liked the informal and open atmosphere and reacted positively to the duo of facilitators, especially in terms of the balance of professional and real-life experience.

> "I thought the balance between [the facilitators] was good. I thought the handoffs were non-clunky but not super slick like you were some sort of New York advertising

> consultancy, you know, it was genuine, it was honest, it was factual, it was beneficial" (family 1, PM).

Some participants noted the lack of support available for families with FASD and described how a course like this is desperately needed. They reported a lack of understanding among professionals, and that this kind of service was preferable to those they had received previously.

> "…you're just on your own really with FASD, the social workers don't understand it, the pediatricians Google it, even CAMHS didn't want us to go for the FASD assessment because if she has FASD but doesn't have ADHD you'll never be able to medicate, but for me it wasn't about medicating it was about finding out what is going on" (family 5, PM).

When asked about the size of the group, participants consistently reported that it was about right and that adding many more people could upset the dynamics of the group. The length of the sessions, the length of the course, the fact that delivery was online, and the mix of participants' personalities were seen as factors affecting group size. Some participants noted the individual differences of participants in terms of their willingness to share or join in, and that since some people tend to speak more than others, session time would have to increase again to accommodate this. Some felt that a larger group could also deter some quieter people from joining in.

> "I think maybe half a dozen, you wouldn't want it to be too big because I think it's important that people are able to join in and I know sort of there was a lady on our course and she was quite shy, and it took a while to get her out of her shell" (family 2, AM).

Theme 4: Advice Was Immediately Beneficial

One of the strongest themes to emerge from the interviews was that the information, advice and strategies discussed in the sessions had an immediate positive effect on the participants' state of mind, and sometimes on aspects of their children's functioning. Often, participants reported that the course helped them to understand their children's needs better, which was reassuring and helped them to feel more effective as parents. Sometimes, this was in relation to misunderstood behaviors – a better understanding of the causes of behaviors was beneficial to the whole family. Sometimes, an improved understanding of their children's difficulties had an impact on their attachment relationship or led to increased respect for their child.

> “It was an absolute revelation for me that [son] has this habit of dumping whole boxes and rummaging through toys and to realize that that's possibly a sensory thing, I never knew, I just thought it was him and he's got too many toys” (family 7, PM).

The experience of being on the course, discussing the topic with people in a similar situation, knowing that people were experiencing similar challenges, and the discussions around the importance of self-care, were beneficial and even therapeutic for some participants.

> “I was able to come in [to the session] and discuss how the incident with my child has haunted me for years and was partly the reason why we moved schools, and that sort of preyed on my mind, and to have another parent discuss it, I've been able to sort of lay that ghost to rest, it's been a massive weight off” (family 2, AM).

Specific strategies for handling relationships with the child that were discussed in the sessions, such as allowing a wait of up to 40 seconds for a response after asking a question, spotting triggers, and dealing with heightened emotional states, often led to improvements in children’s everyday functioning. “There's a definite improvement in him at the minute … we can definitely bring him down a lot quicker than we used to be able to and de-escalate it and just to know what's actually going on with him” (family 2, AM).

Theme 5: Suggestions for Improvement

Participants were asked to describe any problems, difficulties or suggestions for improvement of the course. Many of the afternoon participants suggested that the sessions should be longer and participants from both groups would have preferred one session per week. These issues were considered fundamental and therefore were the subject of theme one. Related to the issue of timing however, some participants also suggested that December could be an inconvenient time of year for parents of children with FASD due to the changes in routine and environment associated with Christmas.

> “…and also avoid December because December is a killer, we are on our knees anyway because it's the hardest term but our kids … they’re over sensitized [from doing] stuff at school or they're not doing stuff at school, but you know, all the lights and everything...” (family 4, PM).

There were some technical problems associated with the use of video conferencing. The most common complaint was that the videos played in the sessions were too quiet and it was difficult to hear what was said. Sometimes, participants' microphones, camera and/or sound failed to activate, and they had to log out and log back in again, which usually solved the problem.

> "There was a couple of times when we were watching videos where you couldn't hear very well but I think you did manage to change that, some of the voices were sometimes out of sync with the mouth moving which was a bit weird" (family 9, PM).

Participants also gave some constructive feedback on specific aspects of the content and delivery. The topic of self-care was discussed during session one and was considered an important aspect of the course, but at least one participant pointed out that this is such an important topic that it should be discussed throughout the course, perhaps briefly in every session, to help emphasize the importance of self-care in a population of caregivers known to have high stress levels. "I think self-care should go through every single session and in a much more valued way … because without regulated parents and carers we don't get regulated kids and for me that's the most important thing" (family 4, PM).

During session seven there was a roleplay exercise in which participants were asked to play the role of a parent and child engaging in a social roleplay situation. This was the only roleplay exercise in the course and the feeling from facilitators was that participants were not very enthusiastic about acting out a scene. In the afternoon session there were no volunteers, so the facilitators demonstrated the roleplay themselves. One morning participant suggested that the concept might be better delivered as a demonstration.

> "I didn't mind the roleplay, but a lot of people couldn't really seem to get into it as they are so self-conscious, so I think there was probably an element of maybe just demonstrating it and then people might take more in rather than just worrying about how they're coming across" (family 2, AM).

Discussion

The SPECIFiC program was designed to deliver psychoeducational training and advice to caregivers of children with FASD, and this exploratory pre-feasibility study was designed to assess the acceptability, feasibility and initial signal of efficacy of the program based on delivery to small number of participants. Two complete programs were delivered by two pairs of facilitators; one pair of facilitators was involved in the development of the program and the other was not. The program, in terms of its content and delivery, appears to be acceptable and feasible. When comparing before and after scores, measures tended to show movement in the direction of improvement in functioning and there was no evidence of any movement in the opposite direction. Participants were generally very grateful and complimentary, and some useful feedback will help to improve the program before the next stage of evaluation, which will be a randomized controlled feasibility trial. The session evaluation forms showed that participants generally found the sessions helpful or very helpful. In terms of fidelity, the delivery of the course was found to be consistent across both groups, with all sessions being delivered according to the treatment manual.

The results of the psychometric measures in this study should be interpreted with caution. The sample size was very small and there was no control group, which leaves these data vulnerable to confounding variables such as the placebo effect and regression to the mean. Findings are interpreted here as an initial signal, which will be tested in trial format in a future study. Nevertheless, there was some evidence of improvements on quantitative caregiver-report measures, with strong effect sizes for most aspects of stress, child behavioral difficulties, knowledge of FASD, caregivers' psychological functioning, and especially parenting self-efficacy. The FASD knowledge questionnaire was developed for this evaluation based on the content of the course. The improved scores suggest that the content of the course was understood and retained. The Parenting Stress Index was considered *a priori* as a potential primary outcome for the randomized controlled trial, and its performance reported here suggests that it would be a good choice. Parents' stress levels are important for two reasons: they may be a mechanism for child behavioral change; and secondly, they may be an important outcome of child behavioral change. As noted by one of the participants, "*without regulated parents and carers, we don't get regulated kids*". Since parents of children with FASD have high levels of stress related to caring for their children (Mohamed et al., 2020), improvements in child behavioral difficulties should also lead to reductions in those stress levels.

There was a strong improvement in parenting self-efficacy (as measured by TOPSE), which may have been linked to an improved understanding of children's needs, knowledge of effective strategies, and a perspective that emphasizes that difficulties are brain-based rather than deliberate misbehavior, all of which were central to this program as shown in the logic model. As highlighted by the logic model, previous studies have shown that FASD caregivers who attribute their child's difficulties to brain differences rather than willful disobedience are more likely to feel confident in their parenting abilities (Petrenko et al., 2016). Caregivers also raised this point in the interviews, saying that they felt more effective and confident having learned more about their children's needs and received some useful advice for supporting them.

Improvements in children's behavioral difficulties were suggested by both the SDQ and the ECBI. The decrease in difficulties makes sense in the context of the improvements in caregivers' stress and parenting self-efficacy. Further, these tentative encouraging findings from the quantitative measures are supported by findings from the participant interviews. Caregivers reported improved states of mind especially in relation to the support-group aspects of the course. They were relieved to be able to discuss their situations with people who understood. They talked about improved levels of understanding of their children's needs and how that made them feel better and gave them confidence that they were providing effective and appropriate support for their children. They gave examples of improvements in their children's everyday functioning and even described improvements in their relationships with their children. The therapeutic nature of the course was further supported by the improved mental health (CORE-OM) scores. The CORE-OM is designed to assess the efficacy of psychological therapies in terms of psychological wellbeing and functioning. If improvements are also shown in a bigger trial, this would suggest a therapeutic benefit to SPECIFiC as well as the intended outcomes of reducing parenting-related stress levels and improving child functioning. Health-related quality of life (as measured by the EQ-5D-5L) also showed some movement in the direction of improvement. This tool was chosen because it is useful in the evaluation of the cost effectiveness of an intervention since it can be used to calculate quality-adjusted life years (QALYs). Crucially, it is the preferred NICE measure of QALYs and was chosen for this reason. However, it is based mostly on physical health characteristics such as movement and pain, which would not be expected to improve substantially due to a psychoeducational program, even one with therapeutic effects. The Parent-Child Dysfunctional Interaction subscale of the PSI-SF had the smallest improvement. This subscale is designed to measure a negative parent-child relationship, especially from the perspective of the parent (Abidin, 2012). There was no indication that the caregivers in this study had negative feelings toward their children. In fact, many participants described a positive relationship characterized by feelings of warmth. The stress experienced by FASD caregivers is not related to a negative opinion of their children but is typically related to difficulties with executive functioning or adaptive functioning (Paley et al., 2006), exacerbated by a lack of support and infrastructure in society (Mukherjee et al., 2013; Price, 2019). It is therefore not surprising that there was little change on this subscale.

Participants reported that the opportunity to learn from and talk with other families affected by FASD was an important aspect of the course. The decision to use real-life experienced facilitators was inspired in part by the findings of Gibbs (2018), whose participants also reported valuing that kind of delivery. This was also encouraged by advisors in steering group meetings. The opportunity to hear from not only facilitators but also other participants with experience of caring for children with FASD may have led to the therapeutic effect seen in the improved mental health (CORE-OM) scores. Although group discussion was seen as an important aspect of the course during the development stage, the next iteration will emphasize this more, and will allow more time for extended group discussions. The praise and gratitude offered by participants in relation to the course suggests that the program is acceptable and feasible, and that additionally they found it both enjoyable and helpful. Participants' descriptions of immediate benefits, including those relating to state of mind and child functioning, alongside the improvements in psychometric scores, suggest a signal of efficacy which will be assessed further in trial-format studies.

The fidelity checks showed that the two recruited facilitators were just as able to deliver the course as those who developed the manual. This is crucial for the potential future large-scale delivery of SPECIFiC, since the facilitators were not specialists, and the training was relatively inexpensive. The facilitators were chosen based on experience of caring for a child with FASD (one facilitator per group), and some professional experience relevant to training delivery (one facilitator per group). If shown to be effective and well received in a subsequent randomized controlled trial, SPECIFiC could therefore be delivered to large numbers of families throughout the UK at relatively little cost to the NHS. Training for facilitators, fidelity checks, and manual revisions can be conducted by the original developers. SPECIFiC potentially could also be adapted for use in other countries, although this would require further development involving researchers, facilitators and people with lived experience in those countries.

Limitations

This was a small-scale pre-feasibility study on a purposively selected sample, and as such, assessments of likely rates of recruitment and retention were not assessed. Further, larger studies will be needed to assess this, and the efficacy of the program. The planned randomized controlled feasibility trial will include a control group as well as the treatment group who receive the SPECIFiC program. The sample in this pre-feasibility study was unlikely to be representative; the group featured adoptive and special guardianship families, but not birth families or foster carers. The sample also contained one single parent family and only one family was represented by two parents in the sessions. The feasibility trial will take steps to ensure a representative sample of FASD families, although birth families are still likely to be underrepresented, as they are less likely to be diagnosed (Mukherjee et al., 2019).

One aspect of the sessions, the videos of caregivers and young adults with FASD that were recorded especially for the program, received a higher proportion of 'unhelpful' responses than any other, with 17.9% of participants indicating that at least one of the videos was unhelpful. Although participants valued the content of the videos, there were some problems with the audio quality that meant it was sometimes difficult to hear the speakers. This was reported by both facilitators (anecdotally) and participants during the sessions. For the next iteration of the program, technical advice will be sought, and videos may be re-recorded professionally. Other aspects that will be addressed in the revision of the manual include a greater emphasis on self-care and use of demonstrations in preference to participant roleplay activities.

Restrictions associated with the Covid-19 pandemic had a major impact on the delivery of this program. SPECIFiC had originally been conceived as a face-to-face group program, but social distancing rules made this unrealistic. It was therefore converted to remote online delivery via video conferencing and this format appeared to work well. There was good group cohesion evidenced by lengthy discussions, a relaxed atmosphere where participants spoked candidly about their own experiences with one another, and spontaneous swapping of contact information between participants at the end of the course. Moreover, online delivery meant that participants could be recruited from across the UK. Remote delivery bypassed any difficulties related to travel such as the time and financial cost as well as difficulties relating to provision of care for children with FASD. Online delivery of SPECIFiC appears to have many advantages over face-to-face delivery, especially when the country is affected by the Covid-19 pandemic. Both online and face to face delivery formats are options for future iterations of SPECIFiC.

Research Fellow AP conducted the participant interviews and analyzed their content and was also involved in the development and delivery of SPECIFiC. We therefore acknowledge that researcher bias is a potential limitation to the qualitative part of this study. AP may have felt a sense of ownership of SPECIFiC and could therefore be biased to emphasize positive aspects of interview content, and participants may have been more likely to respond positively to him, knowing his role in developing the intervention. In order to improve on this in the next stage of the project (i.e., in the feasibility trial), interviews will be conducted by a researcher who is independent of design and delivery. Coding and identifying of themes will be conducted by two researchers working independently.

The timing of the course was not optimal due to delays in the project caused by the pandemic and constraints in the duration of funding, leading to a compressed version of the course (three and a half weeks instead of seven weeks) taking place during November and December 2020. The interviews showed that participants would have preferred longer, less frequent sessions. In the morning sessions, participants were able and willing to stay later and often these sessions lasted for up to three hours, while the afternoon participants tended to have other commitments which prevented an extension. Although this was unplanned, it served as a useful demonstration that a three-hour session was acceptable, and even preferable, providing that the sessions were scheduled to fit in with participants' other commitments. The time between sessions was important for reflection, discussion with partners, and for implementing new strategies. December was also seen as a difficult month for a course. The next revision of the manual will suggest that SPECIFiC should be delivered in three-hour sessions once per week, and that school holiday periods should be avoided. Finally, the session evaluation forms were not completed anonymously and therefore could have been impacted by a social desirability bias or demand effects. During the next stages of the project, it will be important to ensure anonymous data collection for all measures.

Future Directions

The next stage of this project will be a feasibility study using a randomized controlled trial design. The trial is registered here: https://www.isrctn.com/ISRCTN14483801 and will use a waitlist design, where 60 families will take part in SPECIFiC with data collection before and after, whilst a control group of 60 further families will be tested before and after receiving treatment as usual, which is written information about FASD and self-support. After data collection, the control group will also receive SPECIFiC. This feasibility trial will primarily aim to estimate recruitment and retention rates, and to demonstrate a signal of efficacy to justify progression to a larger, definitive randomized controlled trial.

Conclusion

The SPECIFiC program was designed to provide FASD-specific advice and guidance and was fully manualized with that aim that it could be readily adopted and delivered by a variety of professionals. Based on feedback from this small sample, the program appears to be acceptable and feasible, and fidelity was high when delivered by newly trained facilitators. The proposed outcome measures for a future, definitive trial showed a signal of efficacy, especially in terms of reducing parenting-related stress levels and improving parenting self-efficacy and caregivers' knowledge of FASD. Participant feedback was highly positive overall, and participants especially valued the opportunity to discuss the content of the course in the context of the real-life experiences of the group and facilitators. Some suggestions will help to improve the program, especially in terms of timing and some technical difficulties, in preparation for a randomized controlled feasibility trial.

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Table 1

Overview of the seven program sessions

Session	Topic	Key features
1	Introduction to FASD and SPECIFiC	Overview of the course Icebreaker Discussion: What do we hope to get out of the course Top tips for raising a child with FASD The neurobehavioral model – seeing behavioral problems as symptoms rather than willful misbehavior The importance of self-care
2	Sensory processing	Introduction to sensory processing Sensory difficulties in children with FASD and how this can impact behavior Video: Mother and teenage daughter with FASD discussing sensory difficulties and strategies Strategies for supporting a child with sensory needs
3	Self-regulation	Introduction to self-regulation The stress response system; fight, flight and freeze Identifying triggers Keeping a diary of strategies and results Video: Parent talking about self-regulation
4	Communication, speech and language	Introduction to common communication difficulties in children with FASD Video: Mother of a teenage boy with FASD talking about how they have learned to communicate with him Strategies for supporting children with communication difficulties
5	Abstract and concrete thinking	Introduction to abstract and concrete thinking in children with FASD Introduction to executive functioning Strategies for supporting children with abstract thinking difficulties Using pictures and charts at home
6	Routine, structure and consistency	Difficulties with predicting the future in children with FASD – the need for routine and consistency Video: Parent of child with FASD talking about the importance of structure Supporting children with FASD by using routine, structure and consistency Sleep problems in children with FASD and how to help
7	Social relationships	Children with FASD and social relationships School and EHCPs Video: Young adult with FASD reflecting on his childhood Social support for parents and caregivers

Table 2

Sample characteristics

Family number	Session	Caregiver type	Caregiver gender	Child diagnosis	Child age (years)	Child gender
1	Afternoon	Adoptive parent	Male	Probable FASD	9	Male
2	Morning	Adoptive parent	Female	FASD without SFF	9	Male
3	Morning	Adoptive parent	Female	FASD without SFF	7	Male
4	Afternoon	Adoptive parent	Female	Fetal Alcohol Syndrome	6	Male
5	Afternoon	Special Guardian	Female	Fetal Alcohol Syndrome	7	Female
6	Morning	Adoptive parent	Male	FASD with SFF	5	Male
7	Afternoon	Special Guardian	Female	FASD with SFF	6	Male
8	Morning	Adoptive parent	Female	Probable FASD	5	Male
9	Afternoon	Adoptive parent	Female	Probable FASD	5	Female

Note. SFF = Sentinel Facial Features

Table 3

Results of paired t-tests for each questionnaire with Cohen's effect sizes

	Pre-intervention		Post-intervention		Effect size	95% CI of effect size	
	Mean	**SD**	**Mean**	**SD**	**d**	**Lower**	**Upper**
PSI-SF PD	32.11	11.07	28.44	11.63	0.67	-0.08	1.38
PSI-SF PCDI	30.56	8.58	30.44	8.76	0.03	-0.63	0.68
PSI-SF DC	41.89	9.37	36.89	9.804	0.85	0.06	1.61
PSI-SF TS	104.56	26.92	96.00	28.77	0.61	-0.12	1.32
SDQ	22.11	5.37	19.00	7.91	0.77	0.00	1.50
ECBI–I	70.63	10.17	65.88	9.70	0.51	-0.24	1.24
ECBI-P	64.25	8.80	57.63	5.55	0.62	-0.16	1.37
TOPSE*	371.78	48.55	406.22	36.31	-1.59	-2.58	-0.57
EQ-5D-5L*	0.77	0.20	0.84	0.14	-0.40	-1.07	0.29
CORE-OM	0.79	0.62	0.38	0.38	0.75	-0.02	1.47
FASD KQ*	21.44	3.50	25.67	1.58	-1.16	-2.00	-0.28

* Increase in score indicates improvement (for all other metrics, decrease in score indicates improvement)

Note. PSI-SF = Parenting Stress Index Short Form; PD = Parental Distress; PCDI = Parent-Child Dysfunctional Interaction; DC = Difficult Child; TS = Total Stress; SDQ = Strengths and Difficulties Questionnaire; ECBI-I = Eyberg Child Behavior Inventory Intensity scale; ECBI-P = Eyberg Child Behavior Inventory Problem scale; TOPSE = Tool Of Parenting Self-Efficacy; EQ-5D-5L = EuroQol 5 Dimension 5 level; CORE-OM = Clinical Outcomes in Routine Evaluation Outcome Measure; FASD KQ = FASD Knowledge Questionnaire.

Figure 1

SPECIFiC Logic model

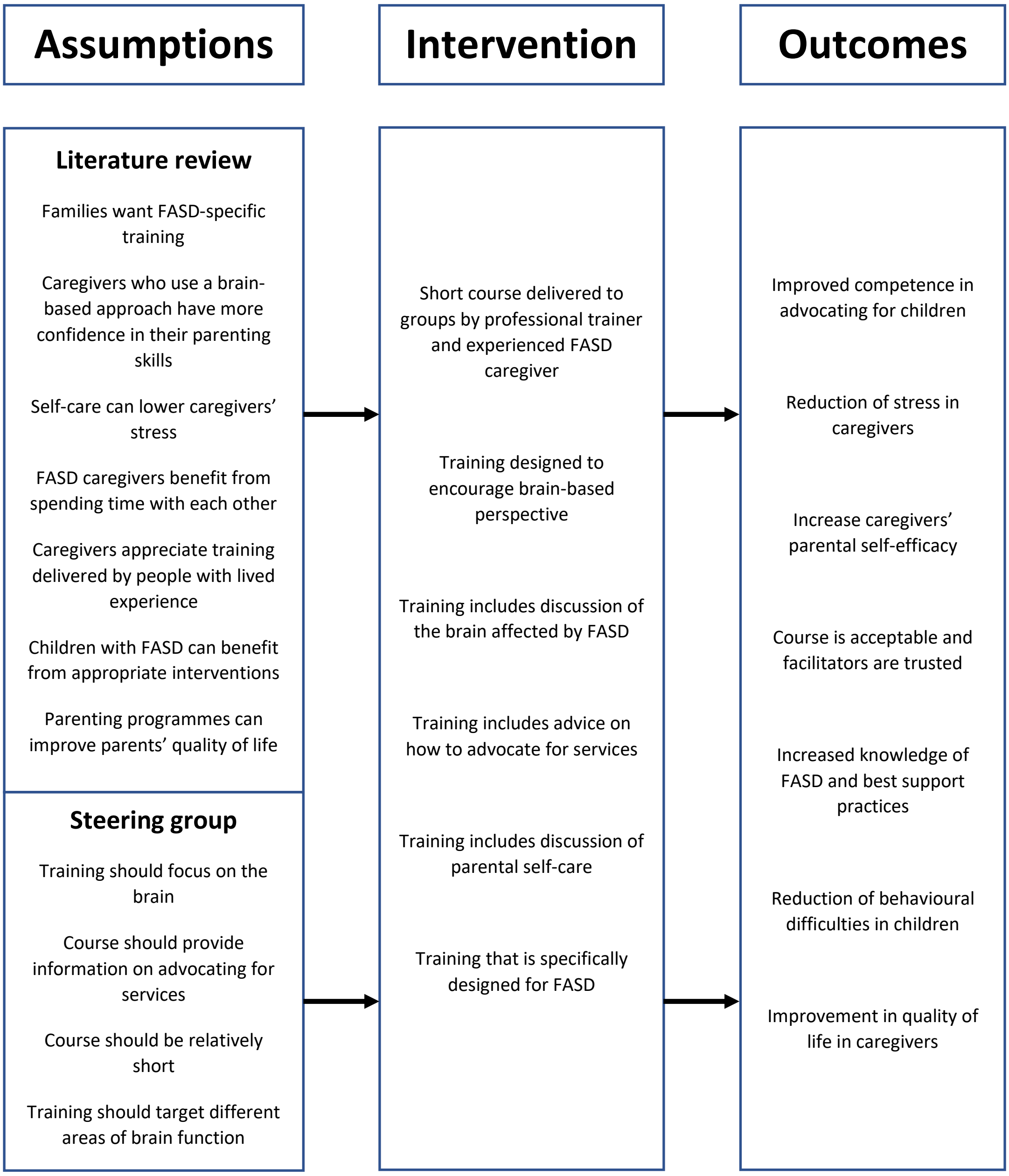

Figure 2

Responses to session evaluation questionnaires (as percentage of total responses)