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Process Evaluation of a Parenting Intervention for Pre-schoolers with Intellectual Disabilities Who Display Behaviours that Challenge in the UK

Abstract

Background Stepping Stones Triple P (SSTP) is a complex parent-mediated intervention aimed to reduce behaviours that challenge in children with moderate to severe intellectual disabilities, aged 30-59 months.

Methods To formulate a comprehensive understanding of SSTP implementation in the UK, we conducted a process evaluation collecting stakeholder views and considering intervention fidelity, dose, reach, delivery adaptations, and acceptability.

Results Fidelity and quality of delivery ratings were high. Parents perceived SSTP as valuable, reporting increased parental confidence and understanding of the child's behaviours. However, only 30% of families received an adequate dose of the intervention. Parents who only received treatment as usual described feeling abandoned by current services. Service managers emphasised the importance of availability of resources and therapist training for successful intervention delivery.

Conclusions SSTP supports effective management of early-onset behaviours that challenge. Further work is needed to ensure equitable access to the intervention across health and social care services.

Trial Registration: NCT03086876

<https://www.clinicaltrials.gov/ct2/show/NCT03086876?term=Hassiotis+Angela&draw=1&rank=1>

Key words: Intellectual Disabilities, Children, Randomised Controlled Trial, Parenting Intervention, Process Evaluation, Challenging Behaviour, Stepping Stones Triple P

Lay Summary

- This study looked at how a parent programme called Stepping Stones Triple P (SSTP) was delivered during a research trial. The research trial looked at how well SSTP worked to reduce behaviours that challenge in young children with learning disabilities.
- Parents felt the SSTP intervention offers a good balance between group therapy whilst also allowing for individualised support.
- Some of the barriers to the intervention working well include a lack of money, training and resources within NHS services. Location and timing of sessions, and the need to achieve a certain group size to deliver the intervention, were additional issues.
- Understanding what works well and does not work well in the delivery of the SSTP intervention can help us improve NHS services and the support we provide to families with children with learning disabilities who present with behaviours that challenge in the UK.

Introduction

Intellectual disability is a lifelong condition with an onset during the first 18 years of life, impairing an individual's cognitive and adaptive functioning (*American Psychiatric Association, 2013*). This can cause difficulties in communicating, understanding new information and learning adaptive behaviours. Children with moderate to severe intellectual disabilities often have additional physical or sensory impairments and co-occurring conditions, which can contribute to the diversity of needs. In an attempt to communicate unmet need, physical pain or psychological distress, children with intellectual disabilities may display behaviours that challenge (Absoud et al., 2019). Behaviours that challenge are behaviours that are considered dangerous or that interfere with community or education participation and can significantly reduce the individual's quality of life (Emerson et al., 2001, Emerson & Einfeld, 2011). Behaviours that challenge occur in approximately 10-45% in children with intellectual disabilities (Cooper et al., 2009; Davies & Oliver, 2013; Emerson et al., 2001; Lundqvist, 2013; Molteno et al., 2001; Parmenter et al., 1998). These behaviours include self-injury, aggression, destructiveness, and stereotypical behaviours (Bowring et al., 2017; Emerson et al., 2014; Hastings et al., 2013; Nicholls et al., 2020). It can be difficult to understand the underlying reasons behind such behaviours, making it hard for parents to manage them effectively (Griffith & Hastings, 2014).

Stepping Stones Triple P

The National Institute of Health and Care Excellence (NICE) recommends early intervention to increase parents' efficacy in managing behaviours that challenge, leading to improved long-term outcomes (Roberts et al., 2006). Level 4 Stepping Stones Triple P (SSTP; Sanders et al., 2004) is an early intervention tailored to parents of children with intellectual disabilities aged 2 to 8 years. It consists of six face-to-face group sessions (2.5 hours) and three

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individual telephone calls (30 minutes) delivered over nine weeks by trained therapists. SSTP teaches psycho-educational and behavioural strategies, aiming to improve parental confidence and behavioural management skills and promote a positive parent-child relationship. The theoretical basis of the SSTP lies in the social learning model, which emphasises the reciprocal nature of parent-child interactions relating to behaviours that challenge (Patterson, 2002). In light of the evidence for its efficacy, implementing SSTP in routine care may benefit families in the UK healthcare context who report difficulties accessing early intervention and lack regular and reliable support (Redmond & Richardson, 2003; Whittingham et al., 2006; Roux et al., 2013; Tellegen & Sanders, 2014; Ruane et al., 2019; Kasperzack et al., 2020; Sapiets et al., 2021). To achieve a successful wide-scale community-based implementation of SSTP, we need further understanding from pragmatic studies providing perspectives from the target population and stakeholders involved in therapy delivery.

EPICC-ID Study

The EPICC-ID study is the first large-scale randomised controlled trial investigating the clinical and cost-effectiveness of level 4 SSTP in England (Farris et al., 2020). Two hundred and sixty-one child-parent dyads participated across four sites (London: n=2, Northeast England: n=1, Northwest England: n=1) from September 2017 to December 2021. Participants were randomised at a 3:2 ratio to receive the SSTP intervention alongside treatment as usual (SSTP arm) or treatment as usual (TAU arm) alone. Treatment as usual was defined as any support received from charities, support groups, organisations or local services (e.g., help from occupational therapists, clinical psychologists, paediatricians, family health visitors). The main objective was to assess whether SSTP reduces the display of behaviours that challenge in children with moderate to severe intellectual disabilities aged 3-5 years at a 12-month follow-up (Farris et al., 2020).

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Process Evaluation

Whilst the trial itself explored the effectiveness of SSTP on a pre-specified outcome measure, this alone fails to answer crucial questions on how and why it may or may not work in practice (Oakley et al., 2006). A process evaluation supports the interpretation of a trial's outcomes and offers insight into the factors necessary for successful intervention implementation. This can inform practitioners and policy makers about how to replicate interventions and ensure effective delivery (Moore et al., 2015). This paper explores an in-depth process evaluation conducted as part of the EPICC-ID trial to examine the implementation of the SSTP intervention in UK community paediatric and child mental health services. We followed the Medical Research Council framework (MRC; Skivington et al., 2021) to formulate a comprehensive understanding of the impact of SSTP, taking into account stakeholder experiences.

Method

We investigated the training and delivery of SSTP through analysis of 1) fidelity (i.e., the extent to which SSTP was delivered as intended), 2) dose (i.e., how much of SSTP was delivered), 3) reach (i.e., the number of participants who received SSTP), 4) adaptations (i.e., the extent to which SSTP was tailored to participants), and 5) acceptability (i.e., how was the intervention perceived by stakeholders). Figure 1 presents the main functions of the current process evaluation following the model provided by the MRC (Moore et al., 2015).

[Insert Figure 1 here]

Figure 1 Core functions of the process evaluation of SSTP delivered in the EPICC-ID trial

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Intervention logic model

The logic model was adapted from the original Triple P model (Figure 2). Inputs included appropriate therapist training and supervision, ensuring access to resources, and fidelity assessments to check implementation quality relevant to the UK context. The process and outputs predominantly focused on the therapists delivering the intervention as intended and the participants implementing skills outside sessions, e.g., homework tasks. Anticipated outcomes included a reduction in behaviours that challenge, improved parental well-being and reduced service use. These were collected as 4- and 12-months post-randomisation.

[Insert Figure 2 here]

Figure 2 Logic model of the SSTP intervention adapted for the EPICC-ID trial

Fidelity

Eleven therapists completed the Training and Accreditation programme (3 training days and a half-day accreditation workshop). Therapists were social workers, specialist health visitors, assistant psychologists, specialist nurses, occupational therapists, and clinical psychologists. Therapists spent on average 37.5 hours delivering the intervention to each family, including preparation, reporting and supervision. Therapist competence was reviewed through video-recorded sessions, stored in the secure online platform Data Safe Haven. 10% of sessions (n=13) were randomly selected for fidelity coding by an independent assessor trained in SSTP, ensuring a spread of site, group, and session number.

The fidelity checklist was adapted from the i-Basis Intervention Fidelity rating scale (Green et al., 2010). The checklist included group procedures, interpersonal effectiveness, session-specific criteria, deviations from the manual, video, and sound quality. Each section

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included items scored as '0' for No, '1' for Yes or N/A. These scores were summed to give a total fidelity score (max score = 10). An additional quality score was given on a rating of 1 to 5 (poor – excellent).

Dose and Reach

The minimum acceptable dose of the intervention was pre-specified to be four group sessions and two individual sessions. Reasons for non-attendance were recorded by therapists. Participants were recruited through participating NHS healthcare services (including primary care) and parent support groups and online multimedia channels through the charity Contact. Most participants were recruited through Child Development Centres and out-patient clinics provided by child and adolescent mental health services.

Adaptations

Adaptations were recorded through therapist supervision meetings (8 2-hour sessions with an SSTP trainer and bi-monthly meetings with an SSTP trained co-applicant). Meetings were video-recorded and minutes were taken. Any changes to the intervention throughout the trial period were also recorded by the trial manager and through protocol deviations and ethics amendments.

Mechanisms of impact

We interviewed stakeholders to maximise our understanding of the implementation of the SSTP intervention. We interviewed three service managers and one therapist and examined discussions from the therapist supervision meetings. The topic guide for professionals consisted of eight questions related to the implementation of SSTP, such as views on the need

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for funding and resources, facilities to accommodate the therapy, and therapist recruitment and training.

Eighteen parents consented to take part in individual interviews about their participation in the EPICC-ID trial. These parents were randomly selected, and these were conducted in-person or online. Informed consent was written or audio-recorded and stored securely on Data Safe Haven. Separate interview topic guides were used for each trial arm, and participants in the TAU arm were interviewed once the Covid-19 pandemic had started. Parents from the SSTP arm were asked about attendance and the perceived impact of SSTP on their child's behaviours and their parenting. Parents from the TAU arm discussed their experiences of usual care and any previous group intervention participation. All parents were given vouchers for their time. Topic guides were developed and discussed with a parent advisory group, consisting of three parents with lived experience.

Parents in the SSTP arm were also asked to complete a Client Satisfaction Questionnaire after 4 months to explore their satisfaction with the intervention.

Analysis of stakeholder interviews

Interviews were audio-recorded, transcribed verbatim by a professional company, pseudo-anonymised and entered into NVivo[®] (2020). The parent and service manager interviews were analysed using thematic analysis (Braun & Clarke, 2006), involving the development of codes and themes driven by the data and the literature as well as participant experience. The analysis process allowed us to work in a series of interconnected stages, moving back and forth across the dataset until coherent themes emerged. After familiarisation with the data, two researchers created an initial code list and developed a provisional coding framework, which was extended and refined with the coding of subsequent transcripts. All coding was inductive and data-driven, whereby equal attention was given to each data item.

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The transcripts were then re-read and the code categories were grouped to form initial themes. These themes for the parent interviews were presented to the parent advisory group for review and for their added interpretation. These were then organised into three domains depending on treatment arm allocation. Due to the small number of therapist interviews, the findings alongside feedback from supervision meetings have been descriptively summarised.

Results

Intervention effectiveness

The trial did not find a significant effect of the SSTP intervention to reduce behaviours that challenge in preschool children with moderate to severe intellectual disabilities, although sensitivity analyses indicated that SSTP may be beneficial for those receiving the intended intervention dose (Ondruskova et al., *in press*). There were also no significant effects of the intervention for parental outcomes such as stress, competence and wellbeing.

Fidelity

Eleven therapists were trained and delivered SSTP and a total of 25 groups were run across the four sites [Site 1 ($N = 6$); Site 2 ($N = 4$); Site 3 ($N = 7$); Site 4 ($N = 7$); combined group from all sites ($N = 1$)]. Group sizes ranged from 1 to 8 (mean = 3.64, SD = 1.66).

Thirteen randomly selected video-recorded sessions were scored for fidelity and were given high scores on the fidelity checklist, ranging from 7 to 10 ($M = 9.38$, $SD = 0.96$) indicating high levels of treatment adherence. For quality, two sessions were given rating of 3 (adequate quality) and the remaining 11 sessions were rated as 4 (good quality).

Dose and Reach

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Out of 261 participants, 155 parents were allocated to the SSTP group and were invited to attend sessions. 91 (59%) parents attended at least one session and 64 (41%) people did not attend any. Only 30% of the intervention arm (n=50) received the minimum acceptable dose of the intervention (i.e., completers). Common reasons for non-attendance included parent or child illness (n=25), other commitments (n=15), transport or access difficulties (n=13), no childcare (n=11), child behaviour (n= 7), unforeseen circumstances (n=7). In many instances, no reasons were provided for non-attendance (n=51).

The time between the baseline assessment and the first SSTP session differed for each participating family due to logistic and organisational reasons (e.g., therapists having to wait to have enough parents to start a new group). Table 1 provides information on the days between the baseline assessment and the first session, presenting data separately for completers and those who completed less than the pre-specified number of sessions (i.e., non-completers) (see Table 1).

[Insert Table 1 here]

It was not possible to keep a structured record of the total number of potential participants approached due to the number of Participant Identification Centres (PIC) and clinicians supporting the project, however expressions of interest forms were obtained for 583 families. A complete record was available for one of the PIC sites (see Figure 3). A total of 79 participants were approached at this PIC site and 54% expressed an interest in taking part in the study, with 17 (22%) being randomised into the study. Based on these figures, we can approximate the reach of the trial may have been to around 1100-1300 children and their families.

Figure 3 An example of parents approached and reasons for exclusions from the Site 3 PIC

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Adaptations

During supervision meetings, therapists discussed adaptations that supported parents to attend sessions. For instance, it was agreed that parents could bring young babies to sessions to support with childcare. To boost the number attending group sessions, the study received approval to include parents who had been screened for the study but were ineligible due to their child's level of intellectual disability or age. Therapists also offered one catch-up session per participant to explain the session content as per manual guidance when someone was unable to attend.

From 16th March 2020, SSTP sessions and research assessments were remotely delivered due to the Covid-19 pandemic. Although there were no online versions of SSTP available at the time, a seminar from the intervention developers on how to manage this was attended by members of the study team in July 2020. Five groups (out of 25) were delivered remotely [Site 2 ($N = 1$), Site 3 ($N = 2$), Site 4 ($N = 1$), combined group from all sites ($N = 1$)]. TAU was also disrupted and the majority of services were paused as the UK went into national lockdowns.

Mechanisms of impact

Service Manager Views

Three service managers were interviewed, and the interview themes formed four domains on the barriers and facilitators of SSTP delivery, 1) How is SSTP different to other therapies, 2) costs and resources, 3) practical considerations and 4) therapist training (Table 2). Overall, the service managers saw the utility of the intervention but had concerns about implementation, particularly with regards to funding, availability of therapists and resources.

[Insert Table 2 here]

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Therapist Views

One therapist felt the positive impact of SSTP depended on the parents' comprehension and ability to apply skills, which was particularly challenging for non-native English speakers.

“It is a lot of material and so the demand on the parent is quite large in terms of their ability to follow along, to understand and to be coached. It requires that both the person administering it has confidence in their coaching skills and that the parent is coachable.” (Therapist 1, Interview)

Increasing flexibility in the number of group sessions offered would have allowed the therapists to work at a pace more suitable for parents who struggled to understand the material:

“I would like to have more flexibility to gear the program to each particular group, i.e., to be able to add in an extra week if we weren't getting through the sessions as quickly as we had hoped.” (Therapist 1, Interview)

However, the flexibility of delivery was further restricted by therapists' working hours, which often did not suit parents who preferred different weekday, evening or weekend sessions:

“In most sites the therapists are only employed for 1 day and have other commitments so they cannot be flexible in offering differing days of the week.” (Therapist supervision meeting)

At the start of the pandemic, most people were unfamiliar with telehealth use and were working from home with competing commitments, e.g., home schooling. Both therapists and

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parents experienced on-line connectivity issues, which interrupted the flow of the session and wasted valuable session time. Even so, remote delivery allowed for more flexibility with timing and session length, which was appreciated by parents, boosted attendance, and enabled additional caregivers to join the sessions.

“More parents have been able to attend, however some have been more distracted. Some of them have their child at home so there were situations where parents had to step away to manage something. I experienced better attendance and great opportunities by delivering remotely but this was balanced by distraction.” (Therapist 1, Interview)

Parent views

Of the 18 parents interviewed, 17 were mothers (95%), and 14 were of white ethnicity (78%). Children were aged between 2 to 5.11 years. Most children were male (n=15; 83%), of white ethnicity (N=11; 61%) and had additional diagnoses (e.g., autism (n=9; 50%), ADHD (n=2; 11%), epilepsy (n=3; 17%), etc.). Parents were recruited from the four study sites (North London (n=6; 33%), South London (n=5; 28%), Northwest England (n=3; 17%), and Northeast England (n=4; 22%). Participant demographic characteristics are shown in Table 3.

[Insert Table 3 here]

The themes from the interviews were organised into three domains, depending on treatment arm (see Table 4).

[Insert Table 4 here]

1. SSTP Arm

1.1. Tools for managing the child’s behaviours: “We see the tantrum coming”

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Parents felt the therapy provided valuable techniques for managing behaviours that challenge. Parents appreciated the use of resources, such as watching the intervention videos, which made it easier to comprehend the content and apply what they had learnt in practice. Learning to anticipate and distract the child's attention during a 'meltdown' was helpful:

"We can deal with all sorts of different situations now. We see the tantrum coming and we sort of steer the attention to something else and it stops a lot of the meltdown"
(Parent 11, SSTP arm)

Other useful techniques included planning activities, using reward charts to encourage positive behaviours and setting house rules using symbols or timetables, which made it easier for the child to move from one activity to the next. These techniques led to perceived positive changes in the children's communication and behaviours:

"The techniques that were learnt brought him out of himself, he makes a lot more eye contact, he communicates a lot more in his own way, he's a lot less demanding, he's at the request stage" (Parent 11, SSTP arm)

1.2. Gaining confidence in the parenting role: "You don't look at it as naughty behaviour"

SSTP sessions boosted parent's confidence, helped them to be more open-minded, adjust their parenting styles, and learn how their own behaviours and responses influence their child's actions. Overall, parents expressed better understanding and acceptance of their child's behaviours. One parent described that: "The course opened my eyes to know what I can and can't do with my child" and that "autism got better explained to me" (Parent 10, SSTP arm)

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“You see things differently and don’t go back to the old way of thinking. You don’t look at it as naughty behaviour, but you know you should look for a reason behind it”

(Parent 14, SSTP arm)

1.3. Peer-to-peer support: “First time I’ve met parents with the same situation”

The group format created an opportunity for parents to meet others with similar difficulties, to learn from others’ experiences and exchange valuable information. This made people feel less marginalised and allowed them to form support networks. However, in some cases, differences in the child’s level of ability or types of difficulties meant that parents were less able to relate to one another.

“It was nice to speak to people who understood what I was saying, and this is the first time I’ve met parents with the same situation” (Parent 11, SSTP arm)

The advice from others in the group was seen as incredibly valuable and often described as comparable to the advice given by the therapist.

“Group sessions were better than the one-to-one sessions because you have all the other parents’ experiences as well and that’s helpful, it’s almost as helpful as the advice given in the group because of being through it” (Parent 18, SSTP arm)

1.4. The role of the therapist

Parents viewed therapists positively, describing them as knowledgeable, professional, and non-judgemental. They appreciated the possibility of receiving feedback from the therapist

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who guided and supported them. Despite SSTP being delivered in a group setting, many parents praised the emphasis on individual contact with the therapist.

“Having a mix of that phone calls and that was actually really helpful. That would be a way of supporting people to talk through some of the issues that have come up that week or fortnight.” (Parent 16, SSTP arm)

Parents expressed a desire for further opportunities to speak to professionals or to have a one-to-one session in the home setting:

“I think it would be really helpful, maybe, if you swapped one of the telephone interviews if the person could come to your house and do a one-to-one session with your child. I think that would be really fantastic.” (Parent 12, SSTP arm)

Whilst most parents reported positive experiences, one parent was critical of the therapist’s teaching style due to “constantly reading from the book.” (Parent 18, SSTP arm)

2. TAU Arm

2.1. Feeling abandoned: “You are left to your own devices”

Most parents described dissatisfaction with the TAU provided to their families. The support available was dependent on the family’s location, good signposting, and the family’s energy to ‘fight’ for help. Support was generally perceived to be insufficient to meet their needs, and many were deemed too infrequent or short-lived to see improvements in the child’s behaviour. A lack of communication and signposting of available services left parents feeling isolated and marginalised:

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“...there should be better signposting to parents, maybe at schools, maybe at GP surgeries, places that parents would go. Because you feel very alone when you have a child that has needs and you don't know what to do as a parent, you don't know what's available, what services are available to you.” (Parent 3, TAU arm)

Most parents wanted further support and said they would welcome anything that could help their child, particularly in relation to behaviours that challenge:

“I think it's a very lonely experience having a child with special needs or with behavioural issues. They feel very marginalised and misunderstood, so I imagine parents just want all the help they can get. Especially with behavioural management...” (Parent 2, TAU arm)

2.2. The role of parents: “Constant battle”

Parents felt ill-equipped to get the right support for their child due to a lack of skills and understanding about their child's behaviour. A lack of service provision left parents feeling their child's progress was dependent on their own efforts to provide everyday support, which was exhausting and time-consuming.

“Getting any sort of help has been a constant battle. Um, getting the health care plan in place, getting him into a specialist provision, everything is a battle. And it's a really, really hard fight.” (Parent 9, TAU arm)

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Parents felt supported by help through schools, family, and friends. Special needs schools provided a much-needed route to professionals and therapies, and teaching assistants offered individual support which facilitated learning.

“My (child) goes to a special needs school, so we managed this afterwards. So, I felt like a lot of the pressure came off me at that point, to try and support her, to try and provide her with a range of therapies or input outside of school, now that it’s embedded in her school day.” (Parent 2, TAU arm)

Family and friends were described as a ‘sounding board’, providing emotional support and respite. However, support was limited by family and friend’s skills and their understanding of the complexity of the child’s health needs.

“As my son gets older, it gets more difficult... to get parents or our parental support or grandparents’ support. You know, they just can't handle it. And, he has epilepsy seizures, quite a big risk, and obviously, you need more skill and confidence in dealing with that.” (Parent 4, TAU arm)

2.3. TAU and the Covid-19 pandemic

Parents described the time during the Covid-19 pandemic as incredibly difficult and reported higher levels of behaviours that challenge due to a lack of routine and school/nursery closures. Many parents were trying to balance working from home with caring for their children, with no additional support from services. Parents reported feeling even more abandoned during this time when they felt they needed the most support.

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“The behaviour during the three months of lockdown took its toll. It escalated to where it was, like, unmanageable most days. Um, but there wasn't a lot we could do about that.” (Parent 9, TAU arm)

“One of the biggest challenges I've ever had to face is being in three months lockdown with a child with needs... It was really, really unfair to do I think, what they had done originally, was said children who have Early Education and Childcare Places plans would be taken care of. We'd be taken into consideration, the needs, and it wasn't.” (Parent 9, TAU arm)

3. Parents in both trial arms

3.1. Relevance of the group intervention

Parents in both trial arms reported being more likely to attend interventions if the content of the sessions was relevant to them. Parents valued learning about practical tasks (e.g., toileting, hygiene, dressing), exploring new techniques for managing behaviours, and strategies to boost the child's concentration or using different learning methods that would suit their child. Several parents said they would like to have their children present in the session to practice the tasks directly with their child under specialist supervision:

“It would be just someone else to observe your child and then, give you some ideas or things that they had tried. So then, rather than just describing what they do or how they behave, then somebody else can see it too. Then, might have an idea for you to try.” (Parent 7, TAU arm)

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Many parents felt it was beneficial to be in a group with parents of children at the same developmental level:

“I think it’s not necessarily the same age. It is the same cognitive ability or the same disability. Obviously, autism is a spectrum and there’s another mum whose son is at the more extreme end of the spectrum, like my (child). So, we have quite a lot in common, even though her boy is 10. We can relate, based on disability.” (Parent 7, TAU arm)

A few parents suggested the utility of being part of a group with parents of older children as they can offer insights on what the future might look like for their child. Seeing others in a more difficult situation helped some parents to re-evaluate their own situation and realise their own difficulties were manageable:

“All the other children had much more severe diagnoses, with more difficulties in daily life... which in a way made me happy because always at home I kept telling my husband ‘I think we are lucky to have (child)...’.” (Parent 15, SSTP arm)

One parent who had previous experience with a group intervention, valued techniques that boost parental well-being, such as meditation or relaxation to improve parents’ self-care.

“It is just as important to take care of myself as it is to take care of the children... I can’t care for him if I don’t care for me so that was a big focus like what are you doing for yourself, what support do you have in place for yourself” (Parent 12, SSTP arm)

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Another factor seen to boost outcomes from group sessions was to include an additional family member:

“Because I think there’s nothing worse in the home than non-continuity. You’re doing one thing, one way and your husband’s doing it another way... It just causes yet more problems than it sometimes solves. I just think it would be really useful if they could attend some of the sessions, or at least, have some kind of input with it.” (Parent 12, SSTP arm)

3.2. Contextual factors that affect accessibility

Parents in both trial arms described four factors that affected the perceived accessibility of group interventions, timing, group size, transport, and setting (see Table 5).

[Insert Table 5 here]

Parent Intervention Satisfaction

Forty-nine participants from the SSTP group provided feedback on the Client Satisfaction Questionnaire on the ease of use of intervention materials, format, and helpfulness, with the average score of 27.6 points (SD = 3.0; Median = 29, maximum score = 32). This indicates most participants were satisfied with the SSTP intervention.

Discussion

The current process evaluation explores the implementation of the Level 4 SSTP intervention during the EPICC-ID trial for UK parents of children with behaviours that challenge and moderate to severe intellectual disabilities. Since the trial found a non-significant

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effect in reducing behaviours that challenge and other parental outcomes, it was particularly important to explore whether the main trial findings were a result of intervention ineffectiveness or due to challenges with implementation. This study highlights essential insights into the implementation challenges of the SSTP group parenting programme in the UK context.

The SSTP was delivered with high fidelity and reached a large number of parents, with the trial successfully reaching its recruitment target. Adaptations were made to the intervention, particularly in response to the Covid-19 pandemic, and this ensured the continuity and contextual fit of the intervention. Despite these encouraging and positive findings, only a small percentage of the SSTP trial arm received the pre-determined sufficient dose of the intervention, highlighting a significant challenge for implementation. Low participation is common in other group parenting programmes with this population and may be difficult to overcome (Hodgetts et al., 2013; Ingoldsby, 2010; Mytton et al., 2014; Smith et al., 2015b). Whilst parents may have had the best intentions to attend sessions, caring responsibilities, other commitments (e.g., medical appointments) or unexpected events and limited resources may have inhibited attendance and engagement. Therefore, whilst early intervention may be recommended to prevent the escalation and persistence of behaviours that challenge (Roberts et al., 2006), this does not take into account whether families have the capacity or resources to successfully benefit from it.

This study considered perspectives of multiple interacting factors and stakeholders in intervention implementation, highlighting the complexity and challenges with the provision of effective support for families with children who have intellectual disabilities and display behaviours that challenge. Interviews with service managers highlighted the perceived value of SSTP in teaching about the management of behaviours that challenge in more depth than other therapies generally offered. However, these interviews also offered insights on pragmatic

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factors to consider when implementing SSTP in NHS services, such as costs and resources, competition with other therapies, and therapist training. The way that NHS and social care services operate in the UK may be a further barrier to group therapy attendance, suggesting the need for service changes that will make interventions more accessible to families.

The therapists reflected that the success of interventions may rely on the skills and abilities of participants (i.e., the comprehension abilities of parents). This has the danger of asserting responsibility and blame onto parents for failing to engage, when in fact, structured interventions often fail to account for individual and cultural differences that may impact a person's ability to benefit from an intervention (Clements & Aiello, 2021). Whilst resources for SSTP are available in multiple languages, the therapy in this trial was delivered in English and future intervention work should consider further tailoring and personalisation to support the needs of each family.

Overall, parents perceived the SSTP therapy as beneficial and were satisfied with the service they received. They reported the intervention equipped them with tools to manage behaviours that challenge, increased their confidence and provided them with the opportunity to speak to a professional about their child in both individualised and group contexts. Parents also appreciated the peer support they received from other members of the group. This is consistent with previous studies reporting that parents of children with disabilities can greatly benefit from group therapies, as it enables them to meet others with relatable experiences and this facilitates discussion and makes them feel valued (Smith et al., 2015b).

Due to the onset of the Covid-19 pandemic, the intervention and research assessments were moved to remote delivery. This introduced challenges such as digital poverty (i.e., problems with internet access, connectivity and digital literacy) (Seah, 2020), competing commitments (e.g., childcare, working from home, homeschooling) and the increased likelihood of illness leading to missed sessions. However, the move to online therapy also had

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the benefit of improving accessibility for families to receive therapy in the comfort of their own home, reducing travel time and expenses and allowing for more flexibility in the timings of sessions (Hinton et al., 2017). It also enabled additional family members to attend, and this was highlighted in the study as important for ensuring a consistent approach in response to behaviours that challenge. The flexibility that remote delivery offered improved accessibility for many families, although hindered others from more deprived backgrounds. It could be that services need to offer both approaches to tailor the mode of delivery to best suit the family.

The TAU arm reported limited support and feelings of abandonment by services. The feelings of fighting a constant battle are echoed across other studies exploring service provision, availability and accessibility for children with intellectual disability in the UK (Griffith & Hastings, 2014; Wodehouse & McGill, 2009). Such feelings were likely to be exacerbated further due to the pandemic, whereby access to services were significantly reduced and many people did not receive any support during the period (Flynn & Hatton, 2021). Continued reports of ineffective provision highlights the need to identify interventions that work for these families and the importance of effectively implementing them through services.

Strengths and Limitations

This study provides a comprehensive process evaluation of the EPICC-ID trial and provides insight into implementation challenges that can be addressed in future studies. We were able to consider multiple perspectives and achieved a varied sample of parents of young children with a range of comorbid conditions. These families are representative of the population for which SSTP was developed, including parents from diverse ethnic backgrounds who spoke English as a second language.

However, the study also has limitations. As the parent interviews were carried out at the completion of the 12-month follow-up, we could not investigate the experiences and views

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of parents who left the study earlier. Only one father took part in the interviews and this low representation matches the participant demographic and is consistent with other family research, where fathers are in the minority (Sanders et al., 2014). Fathers may feel marginalised and silenced in parenting groups where mothers are usually the majority attendees and so, collecting views of the fathers should be prioritised in future research (Batchelor et al., 2021). The interviews for the two trial arms were conducted a year apart, with the TAU group interviews being conducted during the first wave of the Covid-19 pandemic. This was a time of increased parental stress, limited access to services and an increase in child's problem behaviours (Jeste et al., 2020; Paulauskaite et al., 2021). This may have influenced participants' responses and, likely, the reports of negative parent experiences relating to TAU service provision. We were also unable to provide full data on the reach of the intervention due to the large number of PIC sites and number of clinicians involved with recruiting to the study.

Implications

This study shows the importance of conducting process evaluations to support with the interpretation of trials evaluating the effectiveness of interventions. It has also demonstrated that interventions may not be useful if uptake and adherence is low. The future development of interventions should prioritise the views and perspectives of those with lived experience and should consider the use of meaningful co-production techniques to successfully develop and implement interventions that are suitable, relevant and appropriate to meet parent's needs and that encourage attendance and engagement. Different interventions and approaches may need to be chosen or tailored to suit the individual to improve engagement and outcomes (i.e., some people benefit from the peer support provided in group settings whilst others may need more individualised support). There also needs to be flexibility in the timings of interventions to improve accessibility.

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Conclusion

This study highlights the need for appropriate resources, therapist training, accessibility and parental buy-in to effectively deliver parenting interventions to parents of children with intellectual disabilities in the UK. A more flexible approach needs to be considered that accounts for the high levels of demands on parents and that provides additional support and adaptations to facilitate meaningful ongoing engagement. Whilst we show that level 4 SSTP is acceptable and can be delivered with high fidelity, these issues around implementation and parental attendance and engagement would need to be resolved to achieve the desired outcomes and before determining whether SSTP should be available at scale as a public health preventive strategy.

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Tables

Table 1 Difference in days between the first session and baseline and 4-month assessment for completer and non-completers

	N	Median (days)	Range (days)
		Baseline	
Completers	48	51	(0, 291)
Non-completers	29	58	(13, 308)
		4 months	
Completers	46	68	(-16, 187)
Non-completers	26	65	(-198, 120)

Table 2 Facilitators and barriers of SSTP delivery described by the service managers

Theme	Description	Example Quote
How is SSTP different from other therapies	The value and necessity of the SSTP was recognised as it addresses behaviours that challenge in more depth than others.	“I was slightly concerned that we already offer quite a lot of interventions for families that meet the criteria anyway. So, I wasn’t sure about the difference between the intervention group and the control group.” (Service Manager 1)
	However, managers reported that they offered alternative parenting group therapies, such as Early Bird or My Child Programme, which could reduce parents’ interest in the SSTP.	“Behaviour is a very big issue and one that comes up from parents quite a lot. So, the idea of doing this enhanced Triple P seems like a very good thing to be able to offer them.” (Service Manager 3)
Costs and resources	Concerns about costs of the therapy and funding available for a long-term implementation in the services.	“We might mainstream the skills, but as with everything I really would struggle to fund it.” (Service Manager 1)
Practical considerations	Running the sessions smoothly required careful and time-consuming preparation, including finding the right venue with appropriate equipment and setting up the room before sessions.	“And that’s been tight in terms of getting rooms that are large enough to accommodate all of this that also provide the audio-visual facilities to play the videos, you know, which is what the therapy requires. So that’s caused a lot of challenges.” (Service Manager 2)

		<p>“My only concern would be that our experience of running groups and I think in particular with this research project is that it does take quite a lot of man hours to set up and run the groups. Also, some families that we work with really struggle to participate in the group setting so they would be my two caveats really...” (Service Manager 1)</p>
Therapist training	<p>The value of having trained therapists with a variety of skills was reported.</p> <p>However, difficulties with finding therapists to be trained in delivering the SSTP was seen as a service barrier.</p>	<p>“The people that we did recruit, we were particular pleased that they both were embedded in our local specialist schools, so we thought would be a good link and also once they were trained that they maybe would be able to continue using those skills, so it’s all skill development.” (Service Manager 1)</p> <p>“We had quite a lot of difficulty recruiting because we did have some people in the borough who are already trained, which we hoped we would be able to link with, but we actually weren’t able to do that because the service they were local authority employed and that service were not keen to give up their skills.” (Service Manager 2)</p>

Table 3 Demographic characteristics of the interviewed parents

Variables	Intervention arm (SSTP) (N=9)	Treatment as usual arm (TAU) (N=9)	Total (N=18)
	Mean (SD)	Mean (SD)	Mean (SD)
Parent characteristics			
Sex			
Female	8 (89%)	9 (100%)	17 (95%)
Ethnicity			
White	9 (100%)	5 (56%)	14 (78%)
Black or Black	0 (0%)	3 (33%)	3 (17%)
British	0 (0%)	1 (11%)	1 (5%)
Other			
Trial site			
North London	3 (33%)	3 (33%)	6 (33%)
South London	2 (22%)	3 (33%)	5 (28%)

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Northeast England	2 (22%)	2 (22%)	3 (17%)
Northwest England	2 (22%)	1 (11%)	4 (22%)

Notes. Data are presented as Means and Standard Deviations (SD) for continuous variables, and number of participants (N) with percentages (%) for categorical variables.

Table 4 Themes and subthemes of the interviews

SSTP Group
<ol style="list-style-type: none"> 1. Does the SSTP meet parents' needs? <ol style="list-style-type: none"> 1.1. Tools for managing the child's behaviours 1.2. Improved parenting 1.3. Peer-to-peer support 1.4. Therapist's input
TAU Group
<ol style="list-style-type: none"> 2. Need for intervention <ol style="list-style-type: none"> 2.1. Feeling of abandonment: "You are left to your own devices" 2.2. The role of parents: "Constant battle" 2.3. TAU and the Covid-19 pandemic
All parents (both SSTP and TAU group)
<ol style="list-style-type: none"> 3. What are families generally looking for in a group intervention? <ol style="list-style-type: none"> 3.1. Relevance of the group sessions 3.2. Accessibility of the groups

Table 5 All parents reported factors affecting the accessibility of the group interventions

Factor	Description	Quotes
Timing	Each family has a different preference for the timing of the group (e.g., during school times or after work). Offering regular appointments would allow more flexibility for parents to choose when to attend.	"The only thing is I work full time and none of it happens out of working hours [laughs]... it's generally in the middle of the day and I just can't make those kinds of things, so I think that really makes it difficult for our family, you know." (Parent 4, TAU arm)
Group Size	Big groups offer more chance to network and find	"Generally, you can chat about whatever you want to chat about but there are some people

<p>someone to relate to and learn from more parents.</p>	<p>that go there, that talk a lot and hijack it, sometimes. Then, you don't really get a chance to say anything." (Parent 7, TAU arm)</p>
<p>Small groups allow more space to talk and discuss child-specific difficulties.</p>	<p>"It was a small group we were able to go through things more quickly. But at the same time, if it was a bigger group, it would've been interesting to share more personal experiences" (Parent 14, SSTP arm)</p> <p>"Her child was adopted and had very severe disabilities so didn't have much in common in that sense with her. If it was a bigger group there would've been more opportunity to swap stories and stay in touch with" (Parent 12, SSTP arm)</p>
<p>Transport Choosing accessible locations would facilitate attendance. Offering travel reimbursement or providing free parking facilities would also reduce additional expenses for parents.</p>	<p>"It was our local walk-in centre, so it was a health clinic with all sorts of things, there was parking and stuff, so it was a nice place" (Parent 11, SSTP arm)</p> <p>"It was £15 in a taxi to get there and I was thinking that even if my mum was able to drop us, it would've been a bit of a trek. If it had been more local to me that would've been better" (Parent 17, SSTP arm)</p>
<p>Setting A more relaxed setting creates open atmosphere to share and bond with others. This can be boosted by hospitality, such as having tea and coffee before the session to allow parents to interact informally.</p>	<p>"I don't know... whether if it would work in some less formal setting. I mean we were sitting behind a table and of course it was a video, but maybe somewhere where you can... just kind of... relax maybe more?" (Parent 14, SSTP arm)</p> <p>"There was teas and coffees and biscuits, yes... Yes, I mean it's really nice to have. Yes, particularly as it was in the morning, and we were all a bit tired. It made us laugh, about the coffee because we tend to have some coffee try to stay awake. So yeah, that was good." (Parent 12, SSTP arm)</p>