

# Parents Plus parenting programme for parents of adolescents with intellectual disabilities: A cluster randomised controlled trial

Suzanne M. McMahon<sup>1</sup> | Charlotte E. Wilson<sup>2</sup>  | John Sharry<sup>3</sup>

<sup>1</sup>Department of Clinical Psychology, School of Psychology, Aras an Phiarsaigh, Trinity College Dublin, Dublin 2, Ireland

<sup>2</sup>School of Psychology, Aras an Phiarsaigh, Trinity College Dublin, Dublin 2, Ireland

<sup>3</sup>Parents Plus, Mater Hospital, Dublin 7, Ireland

## Correspondence

Suzanne M. McMahon, Department of Clinical Psychology, School of Psychology, Aras an Phiarsaigh, Trinity College Dublin, Dublin 2, Ireland.

Email: [mcmahosu@tcd.ie](mailto:mcmahosu@tcd.ie)

## Abstract

**Objective:** This study evaluated the effectiveness of the Parents Plus Special Needs (PPSN) programme, a seven-week parenting group intervention for parents of adolescents with intellectual disabilities.

**Method:** In a cluster randomised controlled trial, 24 intellectual disability services supporting families of adolescents with an intellectual disability were assigned to PPSN (12 services; 141 parents) or waitlist control group (12 services; 136 parents). Primary outcomes were parent-reported parenting practices, family adjustment, problem behaviours, emotional problems, and prosocial behaviours. Secondary outcomes were parental satisfaction, parental self-efficacy, and goal attainment.

**Results:** Compared to the waitlist group, participants in the PPSN group reported improvements in parenting practices, problem behaviours, parental satisfaction, parental self-efficacy and goal attainment, which were retained at 3-month follow-up. There were additional gains for family adjustment at follow-up.

**Conclusion:** The PPSN is effective in improving parenting behaviour, family relationships, and problem behaviours in adolescents, but not in improving emotional difficulties.

## KEYWORDS

adolescence, emotional problems, parental satisfaction, parenting practices, parenting Programme, problem Behaviours

## 1 | INTRODUCTION

People with intellectual disabilities make up between 1% and 2.5% of the population of western countries (American Psychiatric Association, 2013). It is estimated therefore, that between 2% and 5% of families globally will have at least one child with an intellectual disability (IASSIDD SIRG, 2014). Having a child with an intellectual disability places extra demands on parents, and this is exacerbated in the adolescent developmental period. During adolescence young people

must negotiate a range of transitions relating to education, employment, financial independence, and living independently. Young people with intellectual disabilities encounter significant difficulties in many of these transitions (Austin et al., 2018). They also experience significant social difficulties (Taheri et al., 2016), mental health disorders (Wallander et al., 2003), and emotional and behaviour problems (Dekker et al., 2002) at greater levels during adolescence in comparison to typically developing peers. Parents are important in the adolescent period for all young people, but their importance is enhanced when their adolescent has an intellectual disability (Hogan et al., 2007).

Trial register: ISRCTN, Trial registration: ISRCTN31917713.

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Perhaps due to the enhanced need their adolescents have for support, parents of adolescents with intellectual disabilities have additional support needs. Recent research has indicated that, in comparison to parents of typically developing adolescents, these parents experience higher levels of distress, increased risk of mental health problems, less life satisfaction, and increased financial worries (Baker et al., 2021; Lin et al., 2009; Povee et al., 2012; Staunton et al., 2020). However, these difficulties may not be related to the intellectual disability; recent studies and reviews have found that parental stress is more associated with child behaviour problems than the intellectual disability itself (Biswas et al., 2015). Furthermore, parents may need additional support to manage their adolescent's behaviour as they report that behaviour strategies that worked well when their child was younger do not continue to be effective when their child progresses to adolescence. Moreover, parents also report that while they were well supported in their child's early years, support tapered off as their child aged (Hamilton et al., 2015; Kerr et al., 2022). This is an area of concern as problem behaviours not only impact on parental stress, but also impact on whole family functioning (Povee et al., 2012). Hamilton et al. (2015) highlighted challenging behaviour as a key area with which these parents need greater support.

Raising an adolescent with an intellectual disability negatively impacts relationships and social supports. Parents experience higher rates of divorce, high levels of social isolation, stigmatisation, and caregiver burden (Al-Krenawi et al., 2011). In this context, a significant challenge for parents of adolescents with intellectual disability is having adequate time to tend to their own needs. Often parents do not have time for self-care which leaves them with depleted resources to care for their child. This can create a cycle of negative impacts as lack of self-care needs are associated with increased stress, poor social support, poor psychological wellbeing, and burnout (Al-Krenawi et al., 2011; Hamilton et al., 2015).

As parents are the primary care givers to these adolescents with complex needs, it is essential that resources are available to help alleviate parental stress and carer burnout. Parents with effective resources and support may feel empowered to cope with and adapt to their situations, thus lessening their risk of mental health issues, as well as strengthening the family unit as a whole. The literature indicates that parents often feel misunderstood, unsupported and devalued (Kerr et al., 2022; Wodehouse & McGill, 2009). Clinicians working in disability services have highlighted the importance of enabling parents to make connections with other parents who share similar experiences as they can empathise with their struggles. Parents have reported that developing connections with other parents is important as they serve as a source of advice, encouragement, empathy and compassion (Hamilton et al., 2015), and may buffer parental stress (Smith et al., 2001). Parenting programmes delivered in a group format meet all these needs. They have been shown to positively impact behavioural difficulties in children with and without disabilities, and to improve adolescent behaviour. They also impact on parenting and provide the opportunity for parents to build up a social support system (Carr et al., 2017; Mazzucchelli, Jenkins, & Sofronoff, 2018; Sanders, Kirby, et al., 2014; Sandler et al., 2011). Reviews of parenting programmes for children with intellectual disability, particularly the

Triple P Stepping Stones programme, have demonstrated the impact they have on parental self-efficacy (Hohlfeld et al., 2018), child behaviour problems, child observed behaviour, parental style and parent adjustment (Ruane & Carr, 2019; Tellegen & Sanders, 2013). However, these programmes have offered parenting interventions for parents of children with intellectual and developmental disabilities, rather than to parents of adolescents.

There is a dearth of literature on specific parenting programmes for adolescents with intellectual disability. Hudson, Reece, Cameron, and Matthews evaluated the effectiveness of the Signposts parenting programme that aimed to improve challenging behaviour in children aged 3–16 years with an intellectual disability (Hudson et al., 2009). The Signposts programme adopts a behavioural approach and focuses on measuring behaviour, replacing behaviours, planning for better behaviours, and developing more skills in your child. The programme can be delivered via telephone, in person in a group, in person individually, or it can be self-directed. According to Hudson et al. (2008), the programme was delivered in all four modalities with participants attending just one delivery method. The programme was delivered over six sessions during a 12-week period. The results indicated favourable outcomes across all age groups; however, there was a smaller effect size ( $d = 0.03$ ) for children in the age range 13–18 years than for younger children. Mazzucchelli et al. assessed the effectiveness of the Building Bridges Triple P programme for adolescents with autism, without intellectual disability, and reported benefits for parents (Mazzucchelli, Jenkins, & Sofronoff, 2018). The programme was delivered over eight sessions consisting of five group sessions and three sessions delivered via phone. This programme also adopts a behavioural approach and focuses on understanding teenager's behaviour, encouraging and teaching appropriate behaviour, managing problem behaviour, and getting teenagers connected. These results are promising in terms of meeting the needs of parents of adolescents with autism, however it also highlights the need for an effective parenting programme that specifically targets the complex difficulties associated with parenting an adolescent with an intellectual disability.

Parents Plus, an Irish charity, have developed and evaluated seven evidence-based programmes based on a social learning paradigm, and utilising a solution-focused ethos. In response to local need Parents Plus developed a Special Needs programme (PPSN), in collaboration with parents and disability service professionals (Sharry et al., 2019). To our knowledge, this is the first tailor-made programme for parents of adolescents with intellectual disabilities. The programme is delivered over 7 weeks and comprises three strands each week, including topics around supporting families, supporting children and parent self-care. It differs from previous programmes due to its focus on intellectual disabilities alongside providing support for the wider family and supporting and encouraging parental self-care. It is not solely a behavioural intervention but instead focuses on different aspects within the family and is, therefore, a family intervention. This is also reflected in the goals of the programme, with a focus on strengthening the parents' resources for parenting their adolescent, as well as reducing any problem behaviours. Sessions are delivered within a group setting by two professionals trained in the Parents Plus Special Needs programme.

The objective of the current study is to evaluate the effectiveness of the Parents Plus Special Needs programme in reducing emotional and behaviour problems and improving prosocial skills of adolescents, increasing positive parenting practices, satisfaction and self-efficacy, family adjustment, and attaining specific parent-set goals.

We hypothesised that the programme would have a positive impact on the primary outcomes of reducing adolescent problem behaviours and emotional difficulties, whilst strengthening parenting behaviour, family adjustment and adolescent pro-social behaviour as rated by the parents. We also hypothesised that the programme would have a positive impact on the secondary outcomes of parenting satisfaction and parenting confidence and would empower the parents to achieve their goals for taking part, both in terms of what they wanted for themselves and also what they wanted for their adolescent. Primary and secondary outcomes were discussed and agreed between the research and clinical teams to identify the key aims and objectives of the programme as aligned with the mission statement of Parents Plus and with the content and focus of the programme, and the secondary aims and objectives which were important within the wider literature, but not part of the focus of the programme.

## 2 | METHOD

### 2.1 | Study design

The study utilised a cluster randomised controlled trial design, in which 24 disability services/clusters were randomly assigned to one of two conditions: the Parents Plus Special Needs Programme (PPSN) or a wait-list control (WL). As all the participants were engaged with services at the start of the trial, the participants in the wait-list control group were also receiving their usual support. One service dropped out of the project resulting in 23 services completing the trial. The intervention group were offered the programme in Autumn of 2019 and the WL group were offered the programme after completion of the first groups in Winter 2019/20. Data was collected at three points from the PPSN group; pre- post- and follow-up, and at four time points from the WL group; baseline, pre-, post-, and follow-up.<sup>1</sup> However, only the first two time points for the WL group are used in this study. Time 1 data for each group were collected in Autumn 2019 and Time 2 data were collected post-intervention, 7 weeks later. Time 3 follow-up data were collected from the PPSN group's 3 months after programme completion.

### 2.2 | Procedure

This randomised controlled trial was an initial evaluation of a new Parents Plus programme that was specifically developed with and for parents of adolescents with disabilities (see <https://www.parentsplus.ie/parents-plus-programmes/the-special-needs-programme-training-for-professionals/>). The aim was to evaluate the programme as it would be run in services usually and therefore services were encouraged to use

their usual procedures for recruitment and retention of parents. A call for service interest in participating in the trial was advertised to disability services via the Parents Plus newsletter and website. Twenty-seven services across the Republic of Ireland and Northern Ireland expressed an interest in the pilot. Twenty-four of these services were deemed appropriate based on population (they worked with adolescents with intellectual disabilities, rather than solely physical or learning disabilities) and resources available (they were willing to release two practitioners for both the training and for running the programme once trained, and they had a physical location in which a group could be run). One cluster subsequently dropped out due to a lack of programme uptake.

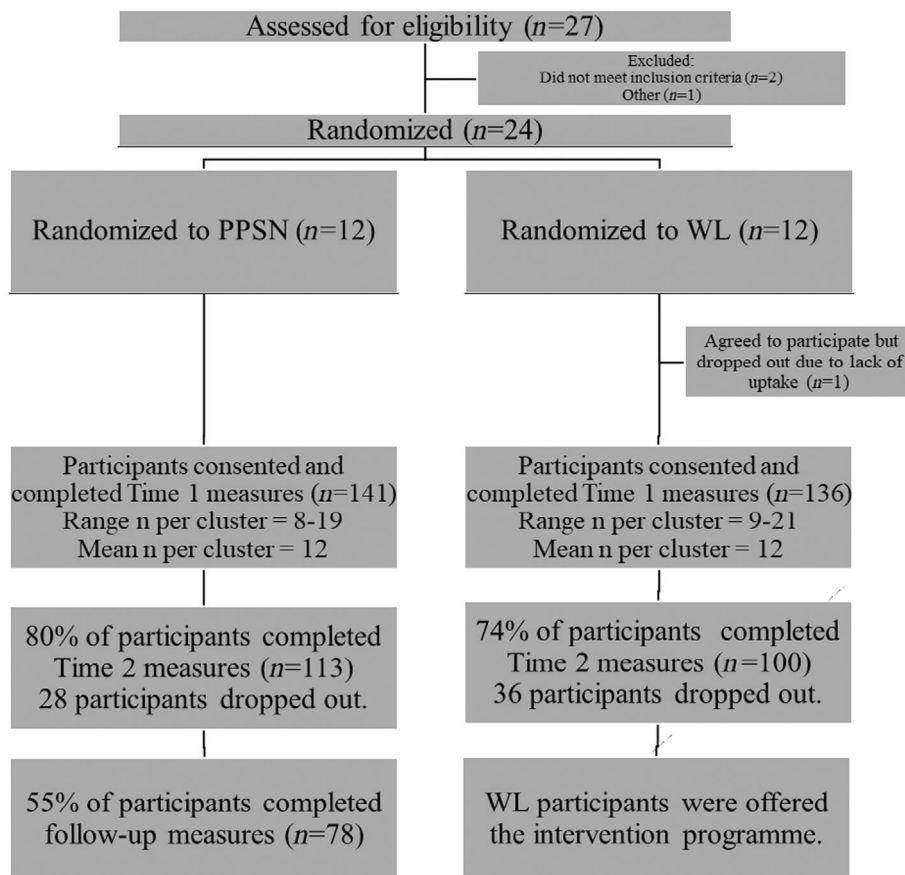
The cluster inclusion criteria were; (i) the service provides clinical support to adolescents with an intellectual disability and their families and (ii) the service had adequate resources in terms of staffing and space to facilitate group sessions. A minimum of two allied healthcare professionals per service received training in the PPSN programme. The trained facilitators were provided with recruitment posters and research packs which included all the measures and the research and quality protocol. Thus, all measures were distributed by programme facilitators to the parents at each time-point. Parents completed the measures and put them in enclosed envelopes, returned them to the programme facilitator, who sent them on to the research team. There were variations in how this was done in each service, with some programme facilitators distributing the packs to parents in the 1st group session, others distributing them in individual pre-programme meetings, and others sending them via post. Programme facilitators were instructed to send on the completed questionnaires to the research team without looking at them. However, as this was done on site there could be no independent verification of this. Data were collected between September 2019 and March 2020. The study received ethical approval from the School of Psychology Research Ethics Committee, Trinity College Dublin and from all relevant local and regional ethics committees. Written informed consent was obtained from all participants prior to data collection.

### 2.3 | Participants

The services recruited parents of adolescents with a formal diagnosis of an intellectual disability. The inclusion criteria for participants were; (i) parents of an adolescent with an intellectual disability and (ii) parents were registered service users of the disability service that recruited them. Exclusion criteria for participants was; (i) parents of an adolescent with a developmental disability in the absence of an intellectual disability. A power calculation was run after recruitment of the services when it was clear that there were significant numbers of services interested. The most relevant study to date; Mazzucchelli, Hodges, et al. (2018) and Mazzucchelli, Jenkins, and Sofronoff (2018), found effect sizes from  $d = .49$ – $1.23$  for their key child and parent outcomes. Therefore, we conducted the power analysis based on  $d = .5$  to ensure sufficient power for smaller effects. With a  $p$ -value of .05, 95% power and a two-tailed test, this indicated a total sample size of 210 parents.

In total, 277 parents eligible to participate were recruited by services. Based on service randomization, 141 parents were allocated to

<sup>1</sup>WL data collection at Time 3 and Time 4 was significantly disrupted by COVID-19.



**FIGURE 1** CONSORT diagram of trial flow

the Parents Plus Special Needs (PPSN) intervention and 136 to the treatment as usual (WL) control. At Time 2, 113 parents in PPSN group and 100 in WL group remained in the study. Figure 1 outlines a CONSORT diagram of flow through the trial. The 64 parents who dropped out were included in the primary intention-to-treat analysis. A *t*-test analysis comparing the participants who dropped out with those who remained in the study indicated no significant differences between the groups. Table 1 outlines the demographic characteristics of families, including those lost to follow-up.

The PPSN programme was designed for adolescents. Facilitators were instructed to recruit parents who had an adolescent (aged 12–19 years) with an intellectual disability. Some facilitators found that there were parents in their services that would potentially benefit from the programme, even though their child fell outside the inclusion criteria age range. As this is a pragmatic effectiveness study, it was decided that it would be most appropriate to include the data from these participants. The age range of adolescents was 9–25 years; 17% were aged 9–11 years, 59% aged 12–15 years, 21% aged 16–18 years, and 3% 19 years or over.

## 2.4 | Intervention programme

A minimum of eight parents enrolled across each of the 23 sites. The manual-based programme was conducted for seven consecutive weeks in autumn 2019. Each group session lasted two to two and a

**TABLE 1** Family demographics of participants

	PPSN n (%)	WL n (%)	Total sample n (%)
Father	18 (13%)	11 (8%)	29 (11%)
Mother	122 (87%)	125 (92%)	247 (89%)
Child male	96 (70%)	93 (68%)	189 (69%)
Child female	41 (30%)	43 (32%)	84 (31%)
No comorbidity	21 (15%)	23 (17%)	44 (16%)
Autism	78 (56%)	78 (58%)	156 (57%)
Down syndrome	33 (24%)	38 (28%)	71 (26%)
Other comorbidity <sup>a</sup>	22 (16%)	21 (16%)	43 (16%)
Mild	40 (35%)	57 (46%)	97 (40%)
Moderate	55 (48%)	58 (46%)	113 (47%)
Severe/profound	20 (17%)	10 (8%)	30 (13%)
	Mean (SD)	Mean (SD)	Mean (SD)
Parent age	47.01 (6.68)	47.98 (6.68)	47.49 (6.68)
Child age	13.48 (2.63)	14.45 (2.24)	13.97 (2.49)

<sup>a</sup>Other includes attention deficit hyperactivity disorder, Cerebral Palsy, Fragile X, Epilepsy, Wolf-Hirschhorn syndrome, Angelman syndrome, Cri-du-chat, Kabuki syndrome, Prader Willi syndrome.

half hours. Parents were also invited to a follow-up group session 3 months after course completion. Each group was facilitated by two trained facilitators. Throughout the 7-week programme facilitators

**TABLE 2** Outline of the Parents Plus special needs programme

	Supporting families	Supporting children	Parent self-care
Session 1	Raising a child with special needs.	'Tuning In' to your adolescent.	Breathing exercise.
Session 2	An emotional journey.	Positive communication and rules.	Mindfulness.
Session 3	Supporting parents' relationships.	Establishing routines.	Mindfulness.
Session 4	Supporting siblings.	Managing challenging behaviours.	Visualisation.
Session 5	Personal coping and life balance.	Friendships and socialising, sex and relationships.	Relaxation.
Session 6	Planning for the future.	Talking about special needs, self-esteem, preparing for adulthood.	Mindfulness.
Session 7	Coping in the long term.	Managing transitions.	Compassion exercise.

received two supervision sessions from a trained Parents Plus supervisor/trainer and were also invited to one group supervision. Facilitators received 2 days intensive training that included didactic teaching, role-playing and active practice of facilitating as well as question and answer sessions. Facilitators were provided with a comprehensive programme manual.<sup>2</sup> Ad hoc supervision was available on request. Facilitators consisted of professionally qualified multi-disciplinary team members working in the disability sector such as psychologists, social workers, behaviour therapists, support workers, nurses, occupational therapists, speech and language therapists, physiotherapists, family service managers and advocacy workers. Facilitators were required to complete session review forms and return to the Parents Plus supervisors as a part of the quality protocol. Given that different services rolled out the programme across the initial and waitlist time-points, there may have been some differences in how the programme was run. However, the training, the materials, the supervision and support were identical for all programme facilitators.

The programme focuses on three pillars; supporting families, supporting children, and parent self-care. See Table 2 for an overview of the programme contents and the topics addressed in each session. Every parent was provided with a parent book that included key learning principles, strategies, worksheets, and exercises. Topics were discussed among the group, with parents having the opportunity to engage in discussions with clinicians and other parents. Discussions included what it is like to raise a child with special needs, when do you best connect with your child, what is the best way to communicate with your child, the impact of child's disability on parent relationship, establishing routines, and the impact on siblings. Parents participated in individual tasks during the group such as completing targeted worksheets and engaging in a mindfulness or relaxation exercise. Parents were encouraged to practice the newly learned techniques and strategies at home between sessions.

## 2.5 | Measures

The *Parenting and Family Adjustment Scale* (PAFAS) is a 30-item measure that assesses both parental practices and family adjustment

(Mazzucchelli, Hodges, et al., 2018; Sanders, Morawska, et al., 2014). However, one item (I smack my child when they misbehave) was removed from the measure for this study due to ethical issues which may arise surrounding the mandatory reporting of smacking a child in Ireland (TUSLA, 2017). The Parenting Practices scale consists of four subscales: Parental Consistency, Coercive Parenting, Positive Encouragement, and Parent-Child Relationship. The Family Adjustment scale consists of three subscales: Parental Adjustment, Family Relationships, and Parental Teamwork. Parents rate each item from 0 ('Not true of me at all') to 3 ('Very much true of me'). Higher scores indicate higher dysfunction. A validation study has indicated good internal consistency ranging from .70 to .87, satisfactory construct and predictive validity, and Cronbach's alpha ranging from .59 to .82.

The *Child Adjustment and Parent Efficacy Scale-Developmental Disability* (CAPES-DD) consists of 30 items which assess child emotional and behavioural problems as well as parents' confidence in being able to manage these problems (Emser et al., 2016). The Intensity scale consists of several subscales; Behaviour Problems, Emotional Problems, and Prosocial Behaviours, which focus on the child, asks parents to rate their child's difficulties and strengths over the past 4 weeks. Parents rate each item from 0 ('Not true of my child at all') to 3 ('True of my child very much, or most of the time'). The Self-Efficacy scale requires parents to rate their confidence in managing the difficulty from 1 ('Certain I cannot manage it') to 10 ('Certain I can manage it'). In the current study, an average self-efficacy score across all 16 items, with a possible range of 0-10, was calculated for each participant. Emser et al. reported good internal consistency ranging from .67 to .94 across scales.

The *Kansas Parental Satisfaction Scale* (KPSS) is a three item self-report measure of parental satisfaction (James et al., 1985). Parents rate each item on a 7-point Likert scale which are summed to give an overall satisfaction score. Higher scores indicate greater satisfaction. Previous studies have indicated good reliability and validity with a Cronbach's alpha of .72 (Mazzucchelli, Jenkins, & Sofronoff, 2018).

The *Parent Plus Goal Form* (PPGF) used in this study has been used in several previously published Parents Plus studies. The PPGF evaluates attainment of target behaviours that are scored and measured across different time points. Parents identify two goals (e.g., increasing independence and reducing challenging behaviour) for their child and two personal goals (e.g., improved stress management skills and increased confidence in parenting skills) to work toward

<sup>2</sup>The manual can be obtained by requesting access from the third author.



during the intervention. The goals are rated on a visual analogue scale (i.e., 0 = not very close to achieving goal and 10 = have reached the goal). A mean goal score is calculated, again ranging from 0 to 10.

## 2.6 | Randomization and masking

Allocation in this study was blind and was by cluster randomization. The unit of randomization were disability services. The researcher responsible for randomization (CW) was blind to the services that were recruited for the study, therefore removing allocation bias. A list of computer-generated random codes was used to allocate each service to either treatment or control. Each code corresponded with a number which corresponded with a service. The blinded researcher was given a number, she then read out which group this number was allocated to, and the non-blinded researcher noted this allocation by each service. This was done at one single time-point. No further blinding was utilised in the study. It was not possible to blind the facilitator however; it is worth noting that data was completed by parents and returned to Parents Plus therefore minimising bias as facilitators should not have had access to the data. None of the facilitators were involved in processing or analysing the data.

## 2.7 | Statistical strategy

We carried out an intention-to-treat analysis on Time 1 and Time 2 data. As 64 participants dropped out, missing data (23%) was inputted, assuming no change from baseline. Analyses including 3-month follow-up data for PPSN was not an intention-to treat analysis. Given that 78 participants completed data at all three timepoints for the PPSN, a completer analysis was conducted. The primary outcomes were: Parenting Practices; Family Adjustment; Child Problem Behaviour; Child Emotional Problems; and Child Prosocial Behaviour. Secondary outcome measures were: Parental Satisfaction; Parental Self-efficacy; Parent Goal Attainment; and Child Goal Attainment. Data were analysed using SPSS (V. 26; IBM Corp.; Armonk, N.Y.). The difference between the PPSN and WL groups on parent and child demographics were tested using independent samples *t*-tests and Chi square tests; an alpha value of .007 was set in line with the Bonferroni correction. The data was subjected to mixed within-between analyses of covariance and analyses of variance. The necessary assumptions were investigated and considered to be met. Significant interaction results were followed up with *t*-tests to determine the nature of the significance. The analysis was completed by the first author with support from the second author in order to maintain independence from the Parents Plus organisation. Individual participants were the unit of analysis.

## 3 | RESULTS

Preliminary analysis indicated that there was one significant difference between the PPSN and WL demographic characteristics; child

age. Therefore, child age was included in the initial analysis as a covariate. Comparison of the results form an ANCOVA and an ANOVA indicated that the covariate did not have an impact on main group effects therefore the results of the ANOVA are reported as recommended by Gilmore (2007).

Mixed between-within subjects analyses of variances were conducted to assess the impact of intervention by comparing the intervention and waitlist control groups on the nine outcomes measures across two time points: pre-intervention and post-intervention. An alpha level of .019 was set in line with the Benjamini-Hochberg correction and a false discovery rate of 25%.

There was a significant interaction effect between time and group for three of the primary outcome measures: parenting practices [ $F(1, 276) = 20.56, p < .001, \eta_p^2 = .07$ ], problem behaviours [ $F(1, 275) = 5.60, p < .02, \eta_p^2 = .02$ ], and prosocial behaviour [ $F(1, 265) = 6.30, p < .02, \eta_p^2 = .02$ ]. Two-tailed paired sample *t*-tests of simple effects indicated that parenting practices [ $t(141) = 4.88, p < .001, d = 0.4$ ] and problem behaviours [ $t(141) = 4.17, p < .001, d = 0.4$ ] improved significantly for the PPSN group, both with moderate effect sizes, and remained the same for the WL group. There were no statistically significant changes for either group on prosocial behaviour, family adjustment, or emotional difficulties (Table 3).

On the secondary outcome measures, there was a significant interaction effect between time and group for parental satisfaction [ $F(1, 276) = 25.00, p < .001, \eta_p^2 = .08$ ], self-efficacy [ $F(1, 235) = 11.70, p < .005, \eta_p^2 = .05$ ], child goals [ $F(1, 264) = 127.00, p < .001, \eta_p^2 = .24$ ] and parent goals [ $F(1, 258) = 144.45, p < .001, \eta_p^2 = .27$ ]. Two-tailed paired sample *t*-tests of simple effects indicated that parent satisfaction [ $t(128) = -3.21, p < .003, d = 0.4$ ] and self-efficacy [ $t(128) = -12.78, p < .001, d = 0.3$ ] improved significantly for the PPSN group but remained the same for the WL group. Parents in the PPSN group moved significantly closer to achieving their parenting goals [ $t(141) = -4.71, p < .001, d = 1.1$ ], the WL remained the same. For child goals, both PPSN [ $t(132) = -12.60, p < .001, d = 1.1$ ] and WL [ $t(132) = -3.36, p < .003, d = 0.3$ ] moved significantly closer to achieving the goal however, PPSN had a large effect size whereas WL had a small effect size. While the examples of the parenting goals described here within use individual parent's own words, these goals were common across the group with some variation in wording; 'to take time out for myself', 'to learn from other parents', 'to manage stress', 'to get a bit of life back again', 'to be confident talking of sex' and 'to know how to help her through puberty'. As with the parent goals, common themes within the child goals emerged, such as; 'to be more independent', 'how to have friendships', 'to understand sexual relationships', 'to understand the impact of puberty' and 'to prepare for adulthood'.

One-way analyses of variance were conducted to compare scores on the outcome variables at Time 1 (pre), Time 2 (post), and Time 3 (3-month follow-up) for the active treatment group (Table 4). Given the multiple comparisons, an alpha level of .004 was set in line with the Benjamini-Hochberg correction and a false discovery rate of 25%. There was a statistically significant effect for time on parenting practices [ $F(2, 75) = 12.78, p < .001, \eta_p^2 = .25$ ], family adjustment [ $F(2, 68) = 5.90, p < .005, \eta_p^2 = .15$ ], problem behaviours [ $F(2, 75)$

**TABLE 3** Mean and standard deviations of PPSN and WL groups across Time 1 and Time 2

	Mean (SD)			
	Intervention (n = 141)		Control (n = 136)	
Primary measures	Pre	Post	Pre	Post
PAFAS parenting practices	13.61 (5.96) <sup>a</sup>	11.83 (4.82) <sup>a</sup>	12.98 (5.14)	13.36 (5.28)
PAFAS family adjustment	11.28 (4.37)	11.32 (4.77)	11.58 (5.18)	11.66 (5.32)
CAPES-DD problem behaviour	12.82 (6.52) <sup>a</sup>	11.55 (6.51) <sup>a</sup>	10.89 (5.86)	10.69 (5.69)
CAPES-DD emotion problems	2.52 (1.93)	2.46 (1.95)	2.24 (1.70)	2.26 (1.71)
CAPES-DD prosocial behaviour	13.22 (4.48)	13.82 (4.40)	15.11 (3.97)	14.76 (4.22)
Secondary measures				
KPSS	14.66 (3.13) <sup>a</sup>	15.51 (2.83) <sup>a</sup>	15.74 (2.81)	15.40 (2.94)
CAPES-DD self-efficacy	7.03 (1.81) <sup>a</sup>	7.48 (1.69) <sup>a</sup>	7.62 (1.56)	7.31 (1.84)
Parent Goals	2.78 (1.85) <sup>a</sup>	5.20 (2.41) <sup>a</sup>	2.85 (1.80)	3.17 (1.87)
Child Goals	2.5 (1.59) <sup>a</sup>	4.81 (4.42) <sup>a</sup>	2.60 (1.65) <sup>a</sup>	2.95 (1.84) <sup>a</sup>

Abbreviations: CAPES-DD, Child Adjustment and Parent Efficacy Scale-Developmental Disability; KPSS, Kansas Parental Satisfaction Scale; PAFAS, Parenting and Family Adjustment Scale.

<sup>a</sup>Denotes a statistically significant difference at an alpha level of .003 in line with Bonferonni adjustment.

**TABLE 4** Mean, standard deviations, and significant changes of PPSN group across Time 1–Time 3

	Mean (SD)		
	Intervention (n = 77)		
Primary measures	Time 1	Time 2	Time 3
PAFAS parenting practices <sup>a,b</sup>	13.98 (6.41)	11.33 (4.85)	10.60 (5.03)
PAFAS family adjustment <sup>c</sup>	11.38 (4.66)	11.36 (4.71)	9.97 (4.85)
CAPES-DD problem behaviours <sup>a,b</sup>	12.28 (6.36)	10.48 (6.16)	9.82 (5.96)
CAPES-DD emotion problems	2.45 (1.85)	2.45 (1.91)	2.25 (1.74)
CAPES-DD prosocial behaviour	12.49 (4.20)	13.56 (4.65)	13.52 (4.01)
Secondary measures			
KPSS <sup>a</sup>	14.51 (3.26)	15.66 (2.87)	15.47 (2.91)
CAPES-DD self-efficacy	7.14 (1.71)	7.65 (1.46)	7.64 (1.80)
Parent goals <sup>a,b,c</sup>	2.76 (1.83)	5.80 (2.03)	6.46 (2.11)
Child goals <sup>a,b,c</sup>	2.48 (1.61)	5.57 (2.18)	6.13 (2.19)

Abbreviations: CAPES-DD, Child Adjustment and Parent Efficacy Scale-Developmental Disability; KPSS, Kansas Parental Satisfaction Scale; PAFAS, Parenting and Family Adjustment Scale.

<sup>a</sup>Denotes a significant change between Time 1 and Time 2 at  $p < .005$ .

<sup>b</sup>Denotes a significant change between Time 1 and Time 3 at  $p < .005$ .

<sup>c</sup>Denotes a significant change between Time 2 and Time 3 at  $p < .005$ .

= 13.49,  $p < .001$ ,  $\eta_p^2 = .27$ ], parent satisfaction [ $F(2, 74) = 7.67$ ,  $p < .005$ ,  $\eta_p^2 = .17$ ], parent goals [ $F(2, 71) = 116.11$ ,  $p < .001$ ,  $\eta_p^2 = .77$ ] and child goals [ $F(2, 69) = 111$ ,  $p < .001$ ,  $\eta_p^2 = .76$ ]. All these outcomes demonstrated a large effect size. There were no statistically significant differences for emotional problems [ $F(2, 75) = .634$ ,  $p = .533$ ,  $\eta_p^2 = .02$ ], prosocial behaviours [ $F(2, 72) = 3.06$ ,  $p = .053$ ,  $\eta_p^2 = .08$ ], or self-efficacy [ $F(2, 51) = 2.73$ ,  $p = .075$ ,  $\eta_p^2 = .10$ ].

Further examination of the main effect of time was conducted using two-tailed paired sample  $t$ -tests applying the Bonferonni correction (Table 4). Parenting practices, problem behaviour, and parental satisfaction, significantly improved after PPSN completion and improvements were maintained at follow-up. There was no improvement in family adjustment post-intervention however, there was a statistically significant improvement in family adjustment at follow-up

which indicates that family adjustment improved after programme completion. Parents moved significantly closer to attaining their self-nominated child and parent goals at programme completion and significant additional gains were observed at follow-up.

Parents were not routinely asked explicitly about harms or unintended effects, but rather were asked for feedback on the group more generally. These did not reveal unintended effects, but as these were not asked about explicitly, we cannot rule out that these occurred.

## 4 | DISCUSSION

The results indicated that the PPSN intervention is effective in several domains. The intervention had a moderate effect on improving

parenting practices. Parents also reported improved problem behaviours and prosocial skills of their adolescents. The PPSN group had a moderate effect in improving parental satisfaction and parental self-efficacy. There was a large effect on goal attainment; parents in the PPSN group came significantly closer to attaining their child and parent goals than the WL group. As these goals were set by the parents, they are likely to be meaningful and important to them, therefore change in this area is important. The WL group remained the same on all outcome measures except child goals, which significantly improved, albeit by less than the intervention group. As the child goals are set by the parents, it is likely that they naturally began to work toward them during the trial period, although the gains appear to be much less than the PPSN group. The PPSN programme did not appear to have an effect on emotional problems in the adolescents, this outcome may be expected given that the programme does not specifically target adolescent emotional problems.

The analysis of the PPSN group over the three time points indicated significant improvement post-intervention and maintenance at 3-month follow-up for parenting practices, problem behaviours, parental satisfaction, parent goals, and child goals. There was no significant improvement in family adjustment post-intervention. However, significant improvements were observed at follow-up. This suggests that things improved for the parents after programme completion. There appears to be an effect by which the factors focused on in the programme change first, and then these positive changes have additional impacts on the family. Given the attrition however, it is important to replicate this finding before drawing firm conclusions from this result. There was no significant improvement in parental self-efficacy across the three timepoints.

The literature indicates that child problem behaviour has a significant impact on parental wellbeing and stress (Witt et al., 2003). Furthermore, it has been reported to impact on whole family functioning (Biswas et al., 2015). Parents have highlighted that child behavioural difficulties are a key area in which they need more support (Hamilton et al., 2015; Kerr et al., 2022). The current study's results indicate that the PPSN programme was effective in reducing child behavioural problems which may impact on parental wellbeing and family functioning. The results indicate that family adjustment improved at 3-month follow-up, this improvement may be associated with the reduction in problem behaviours.

These findings have important clinical implications. Studies have indicated that these parents reported feeling neglected and let down by disability services (Kerr et al., 2022; Wodehouse & McGill, 2009). The current study has identified an effective evidence-based programme that could be implemented in disability services as an efficient way of supporting parents. Due to the group nature of the programme, it is economical and efficient in terms of supporting a large amount of service users with limited staff and time. Furthermore, some of the benefits of the programme might appear a while after the programme has been completed. Disability services may therefore be in a good position to offer such a programme as their support to parents of children and young people with intellectual disabilities is often ongoing and

they will be able to monitor which parents benefit and which require additional support.

To our knowledge, there are no other studies that have investigated the effectiveness of a tailor-made programme for parents of adolescents with an intellectual disability. Mazzucchelli, Jenkins, and Sofronoff (2018) examined the effects of a tailored parenting programme for parents of adolescents with autism and reported similar effects on outcomes such as parenting practices and self-efficacy. Almost two-thirds of our sample had comorbid autism which indicates that the PPSN programme is effective in supporting parents of an adolescent with an intellectual disability and comorbid autism. Future research should examine the specific impact the PPSN programme has on adolescents with comorbid autism as this was not a focus in the current study.

A strength of this study is the use of disability specific validated measures. We focused on important outcomes which have been highlighted in the literature as areas of concern for these parents. Previous studies assessing the effectiveness of a programme for parents of children with an intellectual disability struggled to include fathers in their data analysis however, fathers made up 11% of the sample size in the current study. The use of existing disability services permitted us to carry out an ethically sound study as the waiting list continued to have access to their usual service while waiting for the intervention.

The pragmatism that was core to the study ensured that there was good external validity to the results and we are confident that a variety of disability services will be able to achieve similar results in the future. However, this may be at the cost of internal validity. There are certainly limitations associated with the pragmatic nature of this trial; the research team exerted little control over how the programme was conducted and how data was collected, and the age criterion was interpreted widely which resulted in the recruitment of parents outside of the optimal age range. Furthermore, while the facilitators were provided with a research and quality protocol, this study did not use a treatment fidelity measure. Other key limitations of this study include the use of parent report for all measures, the non-blinding of participants and facilitators, and the lack of explicit data on unintended effects or harms.

Despite the study limitations, this study provides evidence on the effectiveness of this tailored, manualised parenting programme for parents of adolescents with an intellectual disability. The results indicate the programme is effective in improving parenting practices, parental self-efficacy, parental satisfaction, and child behaviour problems. It is also effective in supporting parents to reach their set goals for both their child and themselves as parents. The goals that the parents achieved themselves were mainly in relation to improving parent self-care, managing stress, and being comfortable speaking about puberty and sexual relations with their child. The goals that their children moved toward were related to becoming more independent, understanding puberty and sexual relations, improving social skills and friendships, and preparing for adulthood. Given that parents of adolescents with an intellectual disability experience many complex difficulties, an evidence-based intervention such as the PPSN programme, that address and successfully improves some of these difficulties and



helps them to reach goals, is an important addition to disability services. A limitation of this study is that the focus was placed on the entire group. Future research could review differences between groups based on the severity of disability to analyse the changes between groups based on disability severity. As this study is based in a real-world setting, it provides professionals and future facilitators information on possible outcomes for parents following engagement with the intervention. Some changes may take longer than was given within this study, and future research could look at a follow-up 6 or 12 months after the intervention. As the intervention outcomes may take some time to become visible, professionals and parents need to consider ongoing reviews when delivering the programme as opposed to parents receiving instant positive outcomes.

As the current study is the initial investigation of the effectiveness of the PPSN programme, the scope did not include investigation of the specific patterns and mechanisms of change. It would be beneficial therefore to conduct further studies investigating this, which could influence further development and revisions of the programme. Qualitative studies of the programme are currently underway which will provide further information on the efficacy of the programme from a qualitative perspective. The current study did not measure parental wellbeing or quality of life. However, inclusion of these distal outcomes in future studies may assist in understanding the characteristics of parents who did show improvements over time.

## ACKNOWLEDGEMENTS

This study was supported by several others: Prof David Hevey, Trinity College Dublin, who provided statistical support. Ciara Ni Raghallaigh, Parents Plus, who provided support in project coordination. Aoife O'Leary, Parents Plus, who provided support in service recruitment. Lesley Lally, Parents Plus, who provided support in editing the manuscript.

## CONFLICT OF INTEREST STATEMENT

Dr Sharry is CEO of Parents Plus charity and thus received a salary for his work for them. Dr Wilson is a board member of Parents Plus charity. She does not receive any financial rewards from the charity for this. Dr McMahon declares no conflicts of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request. Ethical review of proposed use will be required.

## ORCID

Charlotte E. Wilson  <https://orcid.org/0000-0002-0800-153X>

## REFERENCES

- Al-Krenawi, A., Graham, J. R., & Al Gharaibeh, F. (2011). The impact of intellectual disability, caregiver burden, family functioning, marital quality, and sense of coherence. *Disability & Society, 26*(2), 139–150. <https://doi.org/10.1080/09687599.2011.543861>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders—DSM-5* (5th ed.). American Psychiatric Association Publishing.
- Austin, K. L., Hunter, M., Gallagher, E., & Campbell, L. E. (2018). Depression and anxiety symptoms during the transition to early adulthood for people with intellectual disabilities. *Journal of Intellectual Disability Research, 62*(5), 407–421. <https://doi.org/10.1111/jir.12478>
- Baker, K., Devine, R. T., Ng-Cordell, E., Raymond, F. L., IMAGINE-ID consortium, & Hughes, C. (2021). Childhood intellectual disability and parents' mental health: Integrating social, psychological and genetic influences. *The British Journal of Psychiatry, 218*(6), 315–322. <https://doi.org/10.1192/bjp.2020.38>
- Biswas, S., Moghaddam, N., & Tickle, A. (2015). What are the factors that influence parental stress when caring for a child with an intellectual disability? A critical literature review. *International Journal of Developmental Disabilities, 61*(3), 127–146. <https://doi.org/10.1179/2047387714Y.0000000043>
- Carr, A., Hartnett, D., Brosnan, E., & Sharry, J. (2017). Parents plus systemic, solution-focused parent training programmes: Description, review of the evidence base, and meta-analysis. *Family Process, 56*(3), 652–668. <https://doi.org/10.1111/famp.12225>
- Dekker, M. C., Koot, H. M., Van Der Ende, J., & Verhulst, F. C. (2002). Emotional and behavioral problems in children and adolescents with and without intellectual disability. *Journal of Child Psychology and Psychiatry, 43*(8), 1087–1098. <https://doi.org/10.1111/1469-7610.00235>
- Emser, T. S., Mazzucchelli, T. G., Christiansen, H., & Sanders, M. R. (2016). Child adjustment and parent efficacy scale-developmental disability (CAPES-DD): First psychometric evaluation of a new child and parenting assessment tool for children with a developmental disability. *Research in Developmental Disabilities, 53–54*, 158–177. <https://doi.org/10.1016/j.ridd.2015.09.006>
- Gilmore, G. (2007). Inappropriate use of covariate analysis renders meaningless results. *Journal of the International Neuropsychological Society: JINS, 13*, 370; author reply 371. <https://doi.org/10.1017/S1355617707070464>
- Hamilton, A., Mazzucchelli, T. G., & Sanders, M. R. (2015). Parental and practitioner perspectives on raising an adolescent with a disability: A focus group study. *Disability and Rehabilitation, 37*(18), 1664–1673. <https://doi.org/10.3109/09638288.2014.973969>
- Hogan, D. P., Shandra, C. L., & Msall, M. E. (2007). Family developmental risk factors among adolescents with disabilities and children of parents with disabilities. *Journal of Adolescence, 30*(6), 1001–1019. <https://doi.org/10.1016/j.adolescence.2007.02.004>
- Hohlfeld, A. S. J., Harty, M., & Engel, M. E. (2018). Parents of children with disabilities: A systematic review of parenting interventions and self-efficacy. *African Journal of Disability, 7*, 1–12. <https://doi.org/10.4102/ajod.v7i0.437>
- Hudson, A., Cameron, C., & Matthews, J. (2008). The widescale implementation of a support program for parents of children with an intellectual disability and difficult behaviour. *Journal of Intellectual & Developmental Disability, 33*, 117–126.
- Hudson, A., Reece, J., Cameron, C., & Matthews, J. (2009). Effects of child characteristics on the outcomes of a parent support programme. *Journal of Intellectual & Developmental Disability, 34*(2), 123–132. <https://doi.org/10.1080/13668250902850426>
- IASSIDD SIRG. (2014). Families supporting a child with intellectual or developmental disabilities: The current state of knowledge. *Journal of Applied Research in Intellectual Disabilities, 27*(5), 420–430. <https://doi.org/10.1111/jar.12078>
- James, D. E., Schumm, W. R., Kennedy, C. E., Grigsby, C. C., Shectman, K. L., & Nichols, C. W. (1985). Characteristics of the Kansas parental satisfaction scale among two samples of married parents. *Psychological Reports, 57*(1), 163–169.

- Kerr, J., Sharry, J., & Wilson, C. (2022). Parents' experiences of raising adolescents with intellectual or developmental disabilities. *Journal of Intellectual & Developmental Disability*, 47, 1–9. <https://doi.org/10.3109/13668250.2022.2057843>
- Lin, J.-D., Hu, J., Yen, C.-F., Hsu, S.-W., Lin, L.-P., Loh, C.-H., Chen, M.-H., Wu, S.-R., Chu, C. M., & Wu, J.-L. (2009). Quality of life in caregivers of children and adolescents with intellectual disabilities: Use of WHOQOL-BREF survey. *Research in Developmental Disabilities*, 30(6), 1448–1458. <https://doi.org/10.1016/j.ridd.2009.07.005>
- Mazzucchelli, T. G., Hodges, J., Kane, R. T., Sofronoff, K., Sanders, M. R., Einfeld, S., Tonge, B., & Gray, K. M. (2018). Parenting and family adjustment scales (PAFAS): Validation of a brief parent-report measure for use with families who have a child with a developmental disability. *Research in Developmental Disabilities*, 72, 140–151. <https://doi.org/10.1016/j.ridd.2017.10.011>
- Mazzucchelli, T. G., Jenkins, M., & Sofronoff, K. (2018). Building bridges triple P: Pilot study of a behavioural family intervention for adolescents with autism spectrum disorder. *Research in Developmental Disabilities*, 76, 46–55. <https://doi.org/10.1016/j.ridd.2018.02.018>
- Povee, K., Roberts, L., Bourke, J., & Leonard, H. (2012). Family functioning in families with a child with Down syndrome: A mixed methods approach. *Journal of Intellectual Disability Research*, 56(10), 961–973. <https://doi.org/10.1111/j.1365-2788.2012.01561.x>
- Ruane, A., & Carr, A. (2019). Systematic review and meta-analysis of stepping stones triple P for parents of children with disabilities. *Family Process*, 58(1), 232–246. <https://doi.org/10.1111/famp.12352>
- Sanders, M. R., Kirby, J. N., Tellegen, C. L., & Day, J. J. (2014). The triple P-positive parenting programme: A systematic review and meta-analysis of a multi-level system of parenting support. *Clinical Psychology Review*, 34(4), 337–357. <https://doi.org/10.1016/j.cpr.2014.04.003>
- Sanders, M. R., Morawska, A., Haslam, D. M., Filus, A., & Fletcher, R. (2014). Parenting and family adjustment scales (PAFAS): Validation of a brief parent-report measure for use in assessment of parenting skills and family relationships. *Child Psychiatry & Human Development*, 45(3), 255–272. <https://doi.org/10.1007/s10578-013-0397-3>
- Sandler, I. N., Schoenfelder, E. N., Wolchik, S. A., & MacKinnon, D. P. (2011). Long-term impact of prevention programmes to promote effective parenting: Lasting effects but uncertain processes. *Annual Review of Psychology*, 62(1), 299–329. <https://doi.org/10.1146/annurev.psych.121208.131619>
- Sharry, J., O'Leary, A., & Hampson, G. (2019). *Parents plus special needs Programme*. Parents Plus.
- Smith, T. B., Oliver, M. N. I., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry*, 71(2), 257–261. <https://doi.org/10.1037/0002-9432.71.2.257>
- Staunton, E., Kehoe, C., & Sharkey, L. (2020). Families under pressure: Stress and quality of life in parents of children with an intellectual disability. *Irish Journal of Psychological Medicine*, 1–8, 1–8. <https://doi.org/10.1017/ipm.2020.4>
- Taheri, A., Perry, A., & Minnes, P. (2016). Examining the social participation of children and adolescents with intellectual disabilities and autism spectrum disorder in relation to peers. *Journal of Intellectual Disability Research*, 60(5), 435–443. <https://doi.org/10.1111/jir.12289>
- Tellegen, C. L., & Sanders, M. R. (2013). Stepping stones triple P-positive parenting program for children with disability: A systematic review and meta-analysis. *Research in Developmental Disabilities*, 34(5), 1556–1571. <https://doi.org/10.1016/j.ridd.2013.01.022>
- TUSLA. (2017). Children first National Guidance for the protection and welfare of children.
- Wallander, J. L., Dekker, M. C., & Koot, H. M. (2003). Psychopathology in children and adolescents with intellectual disability: Measurement, prevalence, course, and risk. In *International review of research in mental retardation* (Vol. 26, pp. 93–134). Elsevier. [https://doi.org/10.1016/S0074-7750\(03\)01003-6](https://doi.org/10.1016/S0074-7750(03)01003-6)
- Witt, W. P., Riley, A. W., & Coiro, M. J. (2003). Childhood functional status, family stressors, and psychosocial adjustment among school-aged children with disabilities in the United States. *Archives of Pediatric Adolescent Medicine*, 157(7), 687–695.
- Wodehouse, G., & McGill, P. (2009). Support for family carers of children and young people with developmental disabilities and challenging behaviour: What stops it being helpful? *Journal of Intellectual Disability Research*, 53(7), 644–653. <https://doi.org/10.1111/j.1365-2788.2009.01163.x>

**How to cite this article:** McMahon, S. M., Wilson, C. E., & Sharry, J. (2023). Parents Plus parenting programme for parents of adolescents with intellectual disabilities: A cluster randomised controlled trial. *Journal of Applied Research in Intellectual Disabilities*, 1–10. <https://doi.org/10.1111/jar.13105>