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Early positive approaches to support (E-PAtS): Qualitative experiences of a new support programme for family caregivers of young children with intellectual and developmental disabilities

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Abstract

Background: Early Positive Approaches to Support (E-PAtS) is a co-produced and co-facilitated group programme that aims to provide early years support to family caregivers of children with Intellectual and Developmental Disabilities.

Method: Thirty-five caregivers who had attended E-PAtS groups took part in individual interviews or focus groups. Caregiver experiences concerning attendance of E-PAtS were explored, in relation to process variables and perceived outcomes. Interviews were thematically analysed.

Results: Three major themes were identified: our group, evolving emotions, and positive approaches. Being with and being supported by other families was very important to caregivers. Families reported increased confidence and greater realisation of the need for self-care. Children were reported to show fewer behaviours that challenge and increases in adaptive skills. Findings corresponded to mechanisms and outcomes in the E-PAtS logic model.

Conclusion: E-PAtS shows promise as one way families and children with Intellectual and Developmental Disabilities can access early years support.

KEYWORDS
early intervention, family carers, intellectual and developmental disabilities, positive approaches, wellbeing

1 | INTRODUCTION

Family caregivers provide rich accounts of positive gains associated with raising a child with Intellectual and Developmental Disabilities but are also known to be at high risk of stress and emotional difficulties (Hastings, 2016), even when their child is under 5-year-old (Totsika et al., 2011). Many caregivers feel ill-equipped to support the developmental needs of children with intellectual disability through typical parenting approaches alone and without additional support (Douglas et al., 2017; Plant & Sanders, 2007; Willingham-Storr, 2014). Early concerns for caregivers commonly relate to communication needs (Carr & O'Reilly, 2016; Chadwick et al., 2019) and supporting their child to sleep (affecting the wellbeing and functioning of both child and caregiver: Priday et al., 2017; Kirkpatrick et al., 2019).

Behaviour problems of children with intellectual and developmental disability also affect parent and family systems and can in turn be affected by family context and parenting practices and relationships (e.g., Totsika et al., 2020).

The dynamic interplay between systems of support, caregiver and child emotions and behaviour can be understood with reference to The Developmental Systems Model (DSM) (Guralnick, 2001, 2005a), which provides a framework to guide early intervention for children with and without Intellectual and Developmental Disabilities (Guralnick, 2005b, 2017). Within the DSM, and consistent with thinking that underpins Family Systems Theory (Trivette et al., 2010), interactions between family members, both those concerning parents and those concerning parents and children, are considered the central processes that determine developmental outcomes for children, and wellbeing for children and families. The nature and quality of interactions between family members is further influenced by both family level characteristics (e.g., caregiver stress) and characteristics of the child (e.g., needs of a child) paralleling broader literature concerning coercive caregiver-child interactions (Eddy et al., 2001) and corresponding applications within the field (e.g., Ho et al., 2021; Totsika et al., 2014).

Given the particular range and cumulative nature of risks and challenges facing both children with Intellectual and Developmental Disabilities and their caregivers, provision of proactive supports at a family-systems level appears critical and is increasingly advocated for (e.g., Local Government Association & NHS England, 2014). The needs of this group of families remain marginalised, with access to specialist services a challenge (Sapiets et al., 2021). Families of children with Intellectual and Developmental Disabilities are often left "battling" against the system (Griffith & Hastings, 2014).

There is evidently a gap, therefore, in support that takes a systems-approach, bespoke to families of children with Intellectual and Developmental Disabilities, in the pre-school period; the access to which is not contingent on the prior development of behaviour problems or a particular diagnosis. The Early-Positive Approaches to Support (E-PAtS) group programme has been purposefully designed in this context through a co-production model (led by Gore and Bradshaw) to provide a first offer for services to meet the specific and broader needs of families raising a child with Intellectual and Developmental Disabilities aged 0–5 years. E-PAtS is a fully manualised, non-commercial programme, underpinned by the DSM (Guralnick, 2001, 2005a) in combination with other positive psychological approaches (see below) that is routinely co-facilitated by a trained family caregiver and practitioner, building on prior research attesting to the strengths of partnership working in group delivery (e.g., Dodds & Singer, 2017; Gore & Umizawa, 2011).

E-PAtS comprises eight, 2.5 h sessions (Table 1) delivered to groups (generally 4–8 families, with provision for two adult caregivers per family to attend). All sessions include a blend of practical exercises, group discussions and information giving. Facilitators share responsibility for delivering programme content and

TABLE 1 Description of E-PAtS sessions

Session	Topic	Example content
Session One	Working together (group formation and access to support services)	Establishing a safe space; Sharing information on locally available services; developing assertiveness skills
Session Two	Looking after you and your family (focussed support for caregiver wellbeing)	Sharing and normalising difficult emotional experiences; identifying and planning for values-based, wellbeing strategies
Session Three	Supporting sleep (sleep for children)	Understanding sleep stages; developing bedtime routines; supporting better sleep for children
Session Four	Interaction and communication (communication for children)	Exploring a communication partnership model; identifying how children communicate key needs
Session Five	Supporting active development (development of adaptive skills)	Maximising engagement in everyday activities; task analysis, prompting and positive reinforcement
Session Six	Supporting challenges 1 (supporting behaviours that challenge)	A functional model of behaviours that challenge; choice making, predicating the world and sensory needs
Session Seven	Supporting challenges 2 (supporting behaviours that challenge)	Using knowledge of the arousal curve to guide support; developing proactive interventions
Session Eight	Bringing it altogether (final integrative session)	Planning for the future; celebrating successes and achievements

supporting group members, drawing on both lived and professional experience. Sessions aim to support access to appropriate services and proactively address areas of developmental and behavioural difficulty for children (sleep, communication, adaptive behaviour and behaviours that challenge) through evidence-based practices (e.g., Gore et al., 2014; Ho et al., 2021; Priday et al., 2017). Critically, E-PAtS is also designed to bolster emotional resilience for families in accordance with third-wave psychological therapy models and an empowering approach (Prevedini et al., 2020). The E-PAtS logic model is presented in Figure 1. This summarises the contextual considerations, theoretical assumptions, aims and mechanisms of the programme, linked to predicted outcomes and six (design) principles that specify conceptual, practical, and values-based inputs to the programme.

The current study concerned an initial evaluation of E-PAtS groups delivered in the United Kingdom. As a first study, a qualitative approach was taken to allow a detailed investigation of caregivers'

CONTEXT AND ASSUMPTIONS:
- Young children with IDD are at risk of developmental difficulties and behavioural problems, associated with poor wellbeing, reduced quality of life and high long-term costs. Parents and families of children with IDD are at risk of isolation and emotional difficulties and routinely report difficulties accessing services.
- There is a bidirectional relationship between parent/caregiver wellbeing and the development and behaviour problems of children with IDD.
- There is a need for a family-focused intervention in the early years that targets parental / caregiver well-being, confidence / skills and knowledge.

AIMS AND MECHANISMS
- E-PAtS fosters the resilience, wellbeing, knowledge and skills of parents/family caregivers who have a child with IDD in the early years and increases access to social and professional support.
- This provides a basis for improving parent/caregiver-child transactions, family-orchestrated child experiences, and children's health and safety.
- Positive changes in these areas improve the development, behaviour and wellbeing of children with ID, which further improves outcomes for parents/caregivers and reduces support costs over the long term.

OUTCOMES

SHORT TERM (Post-intervention)
Group process and knowledge acquired from programme curriculum leads to:

Parents / family caregivers:
- Increased confidence, emotional wellbeing and resilience
- Increased partnership working between family members
- Increased knowledge/skills regarding child development, and management of emotional and behavioural problems

Family Support System:
- Increased knowledge and engagement regarding professional /financial support services

Child:
- Improved child-caregiver relationship / positive perception of child

MEDIUM TERM (approx. 6-months)
Implementation of skills acquired from programme, building on prior outcomes leads to:

Parents / family caregivers:
- Further increased confidence, emotional wellbeing and resilience; increased partnership working between family members
- Improved patterns of family interaction (caregiver-child transactions; family orchestrated child experiences and children's health and safety)

Family Support System:
- Increased access to appropriate professional and 'financial' support services
- Increased system of social support

Child:
- Improved child-caregiver relationship / positive perception of child
- Improved development and adaptive skill acquisition
- Initial reductions in emotional and behavioural problems

LONG TERM (12 months+)
Further implementation of skills and interaction of prior outcomes leads to:

Parents / Family caregivers:
- Maintained confidence, emotional wellbeing and resilience; increased partnership working between family members
- Continued positive patterns of family interaction
- Improved family quality of life

Family Support System:
- Reduced need for specialist professional/service utilisation
- Maintained system of social support

Child:
- Maintained child-caregiver relationship / positive perception of child
- Further improved development and adaptive skill acquisition for child
- Further reduced emotional and behavioural problems

EXTERNAL FACTORS
- Availability of local services and supports for families to access following the programme
- Competing demands on time and availability of family caregivers to attend programme

INPUTS

Principle 1: Early Targeted Support
- Specifically for IDD population (broadly defined)
- No formal diagnoses for child required
- Support for families with children aged 0-5 years
- Proactive support to address current needs, reduce risk of crisis, and prompt future support strategies

Principle 2: Evidence Based Practices
- Commitment to use of evidence based principles and strategies in each session
- Amenable to evaluation with clear research plan to support development and evaluation

Principle 3: A Positive Approach
- Recognises and builds on joys of raising a child with IDD/supports positive aspirations
- Employs mechanisms to motivate, engage and empower caregivers
- Founded upon a constructive approach to behaviour change
- Builds resource to reduce risk of emotional and behavioural difficulties (resilience)

Principle 4: Partnership Working
- Developed through ongoing co-production between caregivers and professionals
- Co-facilitated delivery via caregiver and professional dyads
- Mechanisms and strategies to support peer-to-peer learning and a supportive group context

Principle 5: Emotional and Social Wellbeing
- Recognition of caregiver vulnerability to emotional difficulties and social isolation within the context of child wellbeing and behaviour
- Provides a specific dedicated session to support caregiver wellbeing and resilience
- Wellbeing and emotional needs of caregivers reflected throughout all sessions

Principle 6: Contextualised Systems Support
- Supports low cost delivery in multiple settings
- Flexible and adaptive approach to delivery
- Targets direct support for at least 2 adult family caregivers
- Supports proactive service access for families

E-PAtS Materials and Curriculum
- 2 x primary sessions on empowering families and supporting caregiver resilience and wellbeing (with further coverage of both areas in all additional sessions)
- 5 x sessions on supporting development and reducing emotional and behavioural problems for children and increasing the skills / capacity of family caregivers. One final integration session including planning beyond the group programme
- Curriculum structure and mechanisms to supports flexible attendance for primary and second caregiver
- Work book, resources and tools given to each group member
- Implementation manual, process and related resources. Facilitator training and supervision programme

PROCESSES

Building Family Resource
- Social and emotional peer support to build confidence, increase resilience and support wellbeing for family caregivers.
- Increased caregiver skills and strategies to support own emotional wellbeing and resilience.
- Collaboration for 2+ caregivers (i.e., mother and father) to develop shared knowledge and approach for supporting child.
- Individualisation that responds to the varied needs and circumstances of children and families.
- Increased caregiver skills and knowledge to support development, emotional and behavioural difficulties for children with IDD
- Strategies and Knowledge to support proactive engagement with local services and professionals.
- Facilitation of a socially and emotionally supportive peer group context.

FIGURE 1 The early positive approaches to support logic model

Early Positive Approaches to Support (E-PAtS) Programme Logic Model

views, and to support further development of the programme. The study had the following main aims: 1. To explore family caregivers' overall experiences of attending an E-PAtS group and associated outcomes for themselves and their family; and 2. To investigate processes and mechanisms that operated in E-PAtS groups from the accounts of family caregivers.

2 | METHOD

2.1 | Ethics statement

Ethical approval for this study was gained from the Tizard Centre Ethics Committee. Families were provided with information sheets and given opportunities to ask questions before consenting to take part.

2.2 | Intervention

Interventions (hosted by a charitable support organisation) were delivered at two sites (site one in Northern Ireland and site two in the north of England), by trained E-PAtS facilitators (caregivers and practitioner dyads), utilising E-PAtS manuals and materials. Whilst host organisations also provided other interventions, E-PAtS was offered to families in the context of a first or early line of support. Facilitators were trained to deliver E-PAtS by the first two authors using a manualised 5-day programme and supervised by programme developers to ensure integrity of programme delivery. A total of 46 caregivers from 37 families were recruited across five E-PAtS groups in Northern Ireland and 17 caregivers from 16 families across two E-PAtS groups in England with all families offered free child-care support. Retention was high. Only four caregivers from three families who started the course dropped out in Northern Ireland, largely due to child illness or new/competing work commitments. Three caregivers dropped out in England (one of whom did not attend the first session).

2.3 | Participants

All families recruited to programmes were invited to interview, with 35 caregivers consenting to take part (Northern Ireland, $n = 25$; England $n = 10$). The majority were female (96% in Northern Ireland and 80% in England), White British or White Irish (96% in Northern Ireland and 90% in England) and birth parents or grandparents (94% overall) (with one foster parent and one adult sibling also taking part). Mean age of participants was similar across sites (Northern Ireland 36.9 years, range 26–44 years: England, 38.8 years, range 26–50 years).

The focal child for whom participants were attending E-PAtS, based on available data, was most commonly male in both Northern Ireland (72%) and England (70%) and with similar mean ages (England 40 months, range 26–50 months; Northern Ireland 37 months, range 2–42 months). Children had a variety of learning, physical and communication needs and diagnoses which most commonly included Global Developmental Delay (32% in Northern Ireland and 60% in England), Down Syndrome (32% in Northern Ireland and 40% in England), Autism (20% in Northern Ireland and 30% in England) or another genetic condition (16% in Northern Ireland and 10% in England). A small proportion of children had no formal diagnosis (16% in Northern Ireland and 10% in England). Key characteristics of participants largely reflected available demographics of the wider pool of families attending E-PAtS at both sites with regards gender and ethnicity of caregivers and age and gender of their children (see Table 2). All participants completed the E-PAtS programme, attending at least six out of eight sessions.

2.4 | Interviews

Participants took part in 45–60 min focus groups (Northern Ireland $n = 19$ across four groups; England $n = 6$, in one group) or individual interviews (Northern Ireland $n = 6$; England $n = 4$) as best suited their preferences within two-months of completing E-PAtS. A semi-structured format was used to explore experiences of the group and experiences following attendance.

Interviews were conducted by the second author who had supported development of the programme and trained group facilitators in one site, but had no prior contact with group members or participants.

2.5 | Analysis

A thematic analysis was conducted based on the six steps described by Braun and Clarke (2006). This was considered appropriate given the relatively early stage of intervention development and supported exploration of detailed personal accounts. Combining individual and focus group data can enhance the trustworthiness of findings (Lambert & Loiselle, 2008). Given roles in programme development and facilitator training, we recognised the potential for interviewer bias and adopted a collaborative approach to analysis. The first two authors independently scrutinised transcripts and applied initial codes, with emerging themes derived by consensus following multiple rounds of analysis and reflective discussions to support reflexivity. Team-based approaches to qualitative analysis have received increased attention during recent years (e.g., Cascio et al., 2019) and build upon the concept of 'Dependability' (i.e., consistency of judgement), considered a critical component of thematic analysis by Boyatzis (1998).

3 | RESULTS

3.1 | Overview

Three major themes were identified ('Our Group'; 'Evolving Emotions', and 'Positive Approaches'), each with further sub-themes that captured

TABLE 2 Participant characteristics and demographics of families taking part in E-PAtS groups at each site

	Northern Ireland intervention (*n* = 46)	Northern Ireland evaluation (*n* = 25)	England intervention (*n* = 17)	England evaluation (*n* = 10)
Female carers (%)	97	96	76	80
White British or White Irish carers (%)	97	96	80	90
Child average age (months)	34	37	40	39
Male children (%)	62	72	62	70

the social and emotional experiences, learning and outcomes reported by participants. Quotations are referenced by location (L1 for Northern Ireland or L2 for England), by number where an individual interview (e.g., PC1) and with the code 'FG' where from a focus group, and the number of the FG where there was more than one (e.g., FG1).

3.2 | Our group

The first theme concerned experiences of being in a group with other family carers. Social dynamics, a safe group and processes of engagement and co-creation were reported as a foundation for learning and emotional support.

3.3 | Feeling normal

The value of spending time with other family carers was emphasised, with reference to how infrequent opportunities to do this had been in the past.

> You never get a chance to meet with other parents and the fact that you are actually in a room with other parents for that length of time was good, erm and bringing together (PC8 L1)

Being with other carers of children with Intellectual and Developmental Disabilities in particular was seen as critical. Participants reported a sense of belonging and feeling normal; that this was a group for them:

> That's what I like about the whole thing, as everyone was in the same position (FG L2)

> I found the camaraderie in the sense of, you belonged, you know, your group, and everybody (FG2 L1)

> It makes you feel normal (FG3 L1)

3.4 | Saying the unsayable

Sharing experiences helped participants feel secure and express themselves openly. Participants described being able to say how they really

felt during sessions and reflected on the importance of talking to people with lived experience who 'just get it,' without worrying about their reactions:

> I can't say these things to my mum or my friends because they would be worried about me (PC1 L2)

> People understand you, you don't have to explain yourself. It is nice to come to and be with a group of people who get you (FG1 L1)

3.5 | Experts by experience

The strengths of co-facilitation were highlighted throughout interviews. Family-carer facilitators were viewed as having high expertise and unique insights regarding what works in practice, with sessions consequently seen as relevant and genuine:

> Legitimacy and authenticity, if you haven't lived it, you don't have a clue. Having someone that is in the trenches, you pay more attention to someone who has been through it. (FG4 L1)

In a similar way, peer-to-peer discussion was seen as the main means through which information was accessed and new knowledge generated. Participants spoke about being motivated and empowered by both giving and receiving information grounded in lived experience, to co-create support strategies:

> You can always give that wee bit of advice to someone, maybe it's turned a lightbulb on. Where no matter what condition your child has or developmental or any of that, everybody was able to take that wee bit of advice from each other, or give. (FG1 L1)

3.6 | Evolving emotions

The second major theme centralised on emotional experiences, concerning how caregivers gained confidence, established supports they needed, and prioritised personal wellbeing within the context of raising a child with additional needs.

3.7 | Doing a good job

Participants described how their self-perceptions of caregiving expertise evolved throughout sessions. Being able to speak openly in a supportive group, and share experiences without judgement seemed to confirm to participants they were doing the right things and to feel confident about their parenting abilities:

> It was more for me that, because you beat yourself up so much with having a child with an additional needs thinking, can I do more can I, is there anything I am doing wrong? So, just going to it really give me that confidence that I am not doing anything wrong. (FG2 L1)

> It's helped me understand that I'm actually a good mum. It's given me that confidence you know? When you used to think, oh my god, you are in melt down, thinking I'm doing an awful job and I have then days when I think I wish I could help them more, I wish I could do more for my children. But this has helped me get that, that confidence. I am really doing a good job. (PC3 L2)

3.8 | Building support

For many, E-PAtS had helped increase appreciation and acceptance of the need to access support for their family. In the context of a supportive peer group, seeking support was seen as both OK and necessary:

> I am like [child]'s main sort of carer, but sort of just gave me that perspective to sort of just stand back and go right hang on a minute, maybe I don't need to do so much, maybe I need to go and speak to people that help (FG4 L1)

Participants reported having gained practical knowledge about local services and how best to access these. A need to be assertive was emphasised, with group membership bolstering this attitude. Participants expressed confidence in raising issues and persisting in the face of set-backs:

> There is other parents in the same position and they have opened their mouths and you learn. You learn if you don't fight, you don't get really, and it actually is the way it is in the community. (PC1 L1)

> Probably give me more confidence to speak up for him you know and to go you know this isn't right, he should be getting this, he should be getting that you know (PC1 L1)

3.9 | Caring for myself to care for others

Participants reported having not prioritised their wellbeing in the past but recognising, increasingly, the need to look after themselves having attended E-PAtS. Participants described how session activities and discussions helped them realise how little they did for themselves, explore beliefs that underpinned this, and come to see self-care as a further essential act.

> What the session taught me is two things, one is I have to look after myself, coz who is going to look after [name of child], it isn't about just me soldiering on I actually have to look after myself coz I have got somebody else to look after as well and for your own mental wellbeing you've got to (PC2 L2)

Participants recognised the need to make changes to support their own wellbeing amidst the challenges and complexities of their life and caregiving demands. For some this process had just begun:

> I feel like I've got no help, no support with my children at all. It's just me and my children at all times...I think I need some kind of stress release, something to make me feel good about myself...I am just trying to find a way. (PC1 L2)

Participants also frequently described ways they had started to carve out small opportunities to rest, socialise and relax in ways that connected to their needs, interests and circumstances.

> Just wanting a bit of me time, and I felt that was brilliant... even just painting my toe nails or just having a half hour nap and chilling time, and I wouldn't have even thought if doing that if I hadn't have been on that course (FG1 L1)

> So I went for a night out with my niece and the whole night I didn't think about you know going back, and you know, waking up early with kids, you know about owt like that. I just thought, I am having a really good time (FG L2)

Both a stance towards self-care and finding practical ways to commit to opportunities to support oneself in daily life was associated with positive outcomes for participant's wellbeing and sense of self:

> Not just [name of child's] mum or the person with the kid who constantly cries so I felt like me. It were really good (FG L2)

3.10 | Positive approaches

The final major theme concerned understanding, knowledge and strategies participants gained through attendance of E-PAtS and utilised in family life to support positive developments and outcomes.

3.11 | Opening another window

Multiple examples of new knowledge related to evidence-based approaches were reported, building on caregiver's prior skills and expertise and connecting to areas of concern. Participants described how attending E-PAtS had helped them better understand their child's needs, abilities and reasons for behaviour:

> I learnt about when they are chatting gibberish that they are trying to communicate something (FG4 L1)

> I like the functions, I swear by them now so I do and being the detective…it just opens another window for you, you know, something you never knew about, like why is he behaving like this, and if you can't remember then you just go back to page of the functions (FG3 L1)

Steps to share knowledge gained with family members were commonly described by participants, helping others to understand more about their child and fostering better relations and systems of support:

> I have spoken to my husband about this and all the course and everything I have learnt so yes. I go home and do that every day so that he has that information as well (PC3 L2)

> I showed my mum and dad because they have an awful hard time so they are…They still think it's down to behaviour and I am like no it isn't, there is the answers to you. You don't look at them, and this is why he is behaving like this and they understand more now (FG1 L1)

Participants appeared enthusiastic when describing ways they had used knowledge and insights to support their child, with detailed examples of proactive strategies across developmental and behavioural domains outlined.

> I have learnt now you know, give him a see-through cup with milk and water in it you know? I am going 'do you want milk or do you want water?' And [name of child] actually going and choosing what he wants, whereas before he didn't have a choice, I'd just given

him it… I have been able to communicate a lot better with him by choices (PC1 L1)

Descriptions were both attuned to the complexities of family life and recognised interplay between caregiver's own behaviour and that of their child. Personal agency and the need to safeguard and support personal emotions was emphasised:

> I have got four children, in the morning you are busy, so just up and you get the kids ready yourself. I just put the breakfast in his mouth but now, where now, I actually decide to say 'let's put one sock on and you do the other sock.' So I have started doing that so that's really helpful. Even feeding him, I will load the spoon but get him to put it in his mouth. I tried to calm down, break things in small pieces, small bits so that he can understand more. So yes the kids noticed, he's noticed, definitely (PC3 L2)

> The challenging behaviour definitively. Its, I have had to change the way I was dealing with it… that's where. I was so close to the kids going 'right come on' and I was getting myself so worked up and then he was getting more worked. After the course I was like you know what, take a deep breath, calm, speak to him in a low voice, get down on his level. And I see the tantrums, they have lessened (FG1 L1)

3.12 | Over the moon

Utilising new strategies and safeguarding personal wellbeing during family interactions was associated with a variety of positive outcomes for caregivers and their children. Participants spoke of joy in witnessing small steps their children had been able to take and reductions in CB:

> She can now do it completely on her own…that's brilliant, absolutely brilliant to see her, you know, picking up a cup and drinking and putting it down (PC1 L2)

> He has hardly any meltdowns now, it's like communicating more with him (FG3 L1)

Participants reported satisfaction, pride and esteem for both their child and self at the surprise of what had been achieved:

> You can see he's enjoying it. You know he's enjoying the fact that he can, he can make his own choices now. He's looking at me going are you serious? I get to choose here you know? He is actually really loving it. (PC4 L1)

> The reaching. He taking the actual spoon and if I hold his hand he would never have done this. And put

yogurt, he putting it up to his mouth, so it the first time I swear, I am like over the moon (FG2 L1)

4 | DISCUSSION

This evaluation explored experiences and outcomes for caregivers who attended E-PAtS programmes together with processes and mechanisms that operated in groups. As a first study, there were some limitations. Whilst relatively large and with representative demographics with regards families who accessed E-PAtS within the charitable organisations, the sample was a subset of those who attended programmes (with possible recruitment bias therefore), we did not gather data on other programmes accessed, and a purely qualitative method was used. Furthermore, the current data did not permit us to explore how particular dimensions of family context and socioeconomic situation related to engagement and experience of E-PAtS. The approach taken was considered acceptable given the early stage of intervention development but meant data were self-reported, with potential for bias with regards recall and social desirability (see for example, Smith, 2015) and several questions remain with regards feasibility and utility of E-PAtS (discussed below). It was, however, notable that the vast majority of families overall completed the E-PAtS programme and so positive accounts from those interviewed may not be unrepresentative of those families who accessed E-PAtS via these charitable organisations. Dropout rates in parenting programmes are often much higher, with up to 50% of parents typically not completing the full intervention (Rostad et al., 2018).

Consistent with the DSM (Guralnick, 2001, 2005a) and the reciprocal nature of parent–child transactions (e.g., Lucyshyn et al., 2015), the E-PAtS logic model identifies a number of positive outcomes over time. Primary outcome areas referenced for family caregivers were apparent across themes with some suggestion of temporal developments and sequences as depicted by the model. It should be noted that interviews were conducted within 2 months following attendance meaning longer term outcomes were not wholly appraised. Firstly, families reported increased confidence both in terms of caregiving and assertiveness to seek and secure service supports. Given difficulties families of children with Intellectual and Developmental Disabilities face accessing services (Galpin et al., 2018; James, 2012) and that increased confidence or perceived competence has often been taken as a key outcome in parenting interventions, this was an important finding (George et al., 2014).

Participants also described gaining greater realisation of the need for self-care and a commitment towards this as part of E-PAtS sessions, reflecting concepts of resilience building (Gavidia-Payne et al., 2015). This included reports from participants who, following sessions, had found small but meaningful new ways to support personal wellbeing, with resulting positive changes to mood and self-perception. Again, these findings connect with outcomes reported by programmes including, or focused solely on, emotional functioning for parents (Borek et al., 2018; Dykens et al., 2014; Singer et al., 2007)

and in the context of high rates of emotional difficulties amongst parents of young children with Intellectual and Developmental Disabilities, are a priority outcome within E-PAtS.

Whilst the reports of participants typically surrounded positive experiences and outcomes, the evaluation also prompted an opportunity to improve the utility of programme mechanisms. Here, it was notable that though many carers had been able to establish further ways to support their own wellbeing (be it carving out time for themselves or a particular activity with others), some, though motivated, had not yet found a concrete way to do this. One programme addition prompted by this finding therefore, regards the inclusion of additional coping strategies for caregivers to utilise in the immediate term, in addition to supporting development of longer-term strategies that support resilience.

Positive outcomes for children are hypothesised to emerge during the medium term following attendance of E-PAtS. Whilst E-PAtS does not set 'homework' tasks, a variety of positive outcomes were reported for children, even at 2 months, that included reductions in dimensions of behaviours that challenge, and increases in adaptive skills. Parenting programmes focussed particularly on specific dimensions of child behaviour have reported similar outcomes (e.g., Priday et al., 2017; Tellegen & Sanders, 2013), but in the current case, families attended a group for a variety of reasons, at a relatively early stage and engaged with curriculum that covered multiple domains. Supporting change across this breadth of areas, with time dedicated to specific areas being relatively brief was, therefore, encouraging. Furthermore, the joy, hope and increased confidence this entailed for families was very apparent, indicating both social validity and the longer term additional wellbeing outcomes for carers hypothesised in the logic model.

E-PAtS programme principles, mechanisms and processes as depicted in the logic model, were also evidenced across interviews, often operating in dynamic ways that connected to caregiver outcomes. Whilst several connections were suggested, some key findings were notable. In particular, theme one highlighted how a sense of belonging, non-judgement and shared experience appeared critical to helping establish a socially and emotionally supportive group context.

Both peer-to-peer discussions and the sensitivity and insight of facilitators with lived experience was central to supporting positive working relationships, and fostering key dimensions of partnership working. These interpersonal variables are known to be valued by caregivers (Brotherson et al., 2010; Dunst et al., 1994) and to mediate interactions between service provision, family quality of life (Summers et al., 2007) and caregiver stress (Dempsey et al., 2009). Participants felt able to speak openly and discuss intimate areas of concern. These experiences resonated with reports from families who have accessed other specialist programmes and systems of peer-support (e.g., Borek et al., 2018; Dew et al., 2019; Dodds & Singer, 2017; Gore & Umizawa, 2011; Shilling et al., 2013) and were referenced in relation to engagement, learning and emotional support throughout sessions.

E-PAtS is underpinned by a family systems approach (Guralnick, 2001, 2005a; Trivette et al., 2010) and participants also provided clear

illustrations of ways they had shared information with other family members (at a couple-subsystem level) and come to better recognise and appreciate the interplay between their own emotions and behaviour and that of their child (a parent–child-subsystem level). These reports detailed bespoke solutions developed within the ecologies of family life that connected to processes described in caregiver stress interventions (Neece, 2014; Reid et al., 2015) and broader family quality of life outcomes (Summers et al., 2005, 2007).

The positive findings and limitations of this study, suggest the need for future research, particularly with regard longer-term follow up of families who have attended groups and careful exploration of implementation issues through methods of process evaluation (see Moore et al., 2015). The experiences of caregivers, as captured in this study, have prompted exploration of quantitative outcomes and feasibility testing to inform an effectiveness trial of E-PAtS (see Coulman et al., 2020; Coulman et al., 2021). It will also be important to explore processes associated with E-PAtS delivery further, through detailed investigation of group dynamics and programme mechanisms and to explore the experiences of facilitators themselves. Here, it may be possible to identify aspects of E-PAtS that can inform the development of other programmes and interventions in different contexts. A critical issue concerns the potential for E-PAtS to support families who are living in poverty.

Findings from this study also have implications for practice, with E-PAtS offering good potential for future service-delivery to support families raising a child with Intellectual and Developmental Disabilities within the contexts explored in the current study. E-PAtS is intended to be low cost and deliverable across community, health, education and social care settings following relatively brief training to families supporting children with a broad range of additional developmental needs (though economic evaluation and delivery across a breadth of implementation contexts remains an area for future research). E-PAtS is not intended to serve as a complete system of support in and of itself and (whilst flexible and accommodating) may not provide the right match for all families. Rather, E-PAtS has been designed as one further element of what might be required as part of a pathway of support, providing general support as a foundation for families with a range of needs relating to their child. Choice is important in any system of support and additional, specialised, intensive or alternative interventions are very likely to be required for some families throughout their child's lifetime. E-PAtS does however, hold promise as one further form of support for families and children with Intellectual and Developmental Disabilities as part of a pathway of interventions and systems.

DATA AVAILABILITY STATEMENT

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