

## Feasibility Study - Summary for Family Carers

### What is E-PATs?

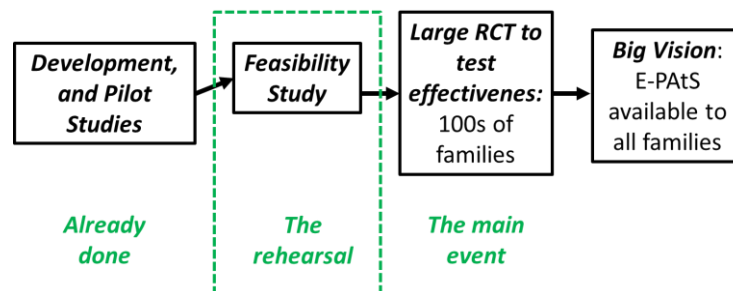
Early Positive Approaches to Support (E-PATs) is an 8-week programme for families raising a young child (five years and under) with a learning and/or developmental disability. It was developed by family carers working alongside professionals (co-produced). Sessions are run by 2 facilitators (one family carer and one professional) who both have experience of working with, or parenting, children with a learning and/or developmental disability.

Children with learning and/or developmental disabilities have a range of developmental difficulties and everyday living challenges. Family carers report that raising a child with a learning and/or developmental disability can affect their own wellbeing. There is limited existing evidence for early support approaches for these families. Those support approaches that do exist rarely involve co-production with families.

### What is the feasibility study?

A Randomised Controlled Trial (RCT) is a gold standard research design that would measure if E-PATs benefits families, compared to the support that is typically available to families of young children with learning and/or developmental disabilities.

Before this can happen, we needed to run a feasibility study to test whether a large RCT can be done in the future (like a rehearsal for a future larger research study).



In the feasibility study families were randomly placed into either the intervention group (who received E-PATs straight away) or a control group (who had the option of receiving E-PATs after the end of the study). Family carers completed questionnaires several times throughout the study period and some were interviewed.

### Key feasibility questions

The study focused on answering a number of questions to see if it would be possible to run a large RCT project later. This included checking if the research process was acceptable to families.

#### **1. Could we find organisations and facilitators who wanted to be involved?**

Yes. We identified organisations who were willing to take part. Three organisations took part, one in England and two in Northern Ireland.

#### **2. Could we recruit enough families to take part and did they stay in the study?**

Yes. We had 74 families taking part in the research (95 participants). After 12 months 72% of families completed follow-up data.

### **3. Are families happy to take part in the research?**

Yes. The experience of being recruited was positive, including the interactions with the research team.

### **4. Were the questionnaires manageable?**

Yes. The questionnaires were manageable. Participants completed questionnaires at baseline (initially), again after 3 months and then after 12 months. Generally, participants described the experience of completing the questionnaires as 'fine'.

### **5. Are people happy to take part in and deliver E-PAtS?**

Yes. Family carers were overwhelmingly positive about the groups which were felt to be informative and supportive. They were positive about the course facilitators. Participants valued family facilitators sharing past experiences and ideas and were comforted by the fact that facilitators had "walked the road themselves."

Facilitators and organisations were also positive. We recorded and assessed a number of E-PAtS sessions, which were delivered to a high standard.

Participants described improved wellbeing as a result of attending the E-PAtS sessions. It encouraged people to take time for themselves and recognise their own needs. A facilitator reported that *'one of the Daddy's said "I haven't been out on my motorbike in years and I just took myself out on my motorbike for a while."* Another family carer told us:

*"I was suffering from depression but now I've stopped taking my medication"*

As well as helping participants feel not so alone, they were able to take home strategies for assisting with living skills. They reported increased confidence in understanding and dealing with their child's behaviours as well as advocating for their child to medical professionals. Knowledge gained at the group sessions was generally shared with wider family members.

*"There are times I go on the internet just to see what can I do and everything in there is stories, stories, stories. I don't know what to do, I was just confused. So I cried, 'what do I do? A beautiful little boy, what do I do with you?' so when I went to the sessions it was so helpful, you cannot imagine".*

### **6. Do family carers attend E-PAtS sessions?**

Yes. Full attendance was classified as 5 out of the 8 sessions. Family attendance of at least 5 sessions was 76%.

### **7. What usually happens to families?**

A different group of family carers across the UK completed a survey to find out what focused support (if any) they were receiving for their child or themselves. This helped us to define what usual support looks like.

Less than one third of participants (29.3%) reported that their child or they themselves had received some focused support. Of the survey respondents 10.5% clearly named a parent training/support intervention (e.g. Stepping Stones, Triple P). This illustrates that usual support for these families rarely includes group support programmes.

### **8. Would organisations be interested in taking part in the large RCT?**

Yes. A survey distributed to organisations to find out if they would be interested in running E-PAtS received 15 responses. The majority indicated that they were somewhat or very likely to participate in a large RCT if invited.

**9. Would families be happy for the research team to access other data (e.g. data that is already collected by schools or the NHS)?**

Yes. Families who answered this question thought that this would be acceptable in a future study.

**10. Can we find measures that would be useful in the large RCT?**

Yes. We would need the large RCT to know for sure whether coming to E-PAtS results in differences in family carers' psychological wellbeing. However, the questionnaires used did seem to show what had changed for family carers in the study. For example, we did find families who attended E-PAtS reported more improvements in wellbeing than families who did not attend (the control group).

**What else did we find?**

Families and organisations were very helpful and their experiences will help us to make changes moving forwards. For example:

*Supporting attendance*

There were some difficulties for participants attending sessions for a number of reasons: childcare; illness/appointments for other family members; work patterns; practicalities of getting to the venue. Some families did 'share' attendance (with different family carers attending different sessions) at the group sessions. We propose that in a future RCT we look at ways to help with missed sessions and attendance.

*Questionnaires*

Some family carers found answering questionnaires time-consuming and off-putting. The questions around carers' stress were sometimes hard to be asked, although being asked did result in their feelings being acknowledged. Participants described how answering the questionnaires on their child made them reflect about how difficult things can be and how delayed their child's development may be. We will work out ways to provide more emotional support for carers during questionnaire completion in future research.

*Randomisation*

Those who were in the control group were given the option to be offered E-PAtS or not after the 12 months. All but one family said they would like to be offered it illustrating that the option to attend E-PAtS was the most acceptable process to participants who end up in a control group.

Disappointment was expressed by some who had to wait 12 months to attend.

*"when I first heard of the E-PAtS study I thought 'happy days, this is finally something that can help us here'...and then to find out it was being put off for a year it was hard to accept."*

**What are the next steps?**

The research team think that we are now ready to run the large RCT with an increased number of participants and training sites.

In response to family carers' feedback we will arrange sessions that fit around participants and we will use fewer questionnaires. We will continue to interview families throughout the research to learn what is most effective. A network of supervisors and trainers will need to be set up across multiple sites.

We would like to thank all of the families, facilitators and organisations who were involved.

For more information about E-PAtS see: <https://bit.ly/CBFEPAtS>



Centre for  
Trials Research

---

Canolfan  
Ymchwil Treialon



University  
of Glasgow



NUFFIELD DEPARTMENT OF  
**PRIMARY CARE**  
HEALTH SCIENCES

