

## Early Positive Approaches to Support (E-PATs):

A support programme for family caregivers of young children with additional developmental needs

Dr Nick Gore

SEND Early Years Conference: Barnet 2024



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## Overview

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- Tizard Centre University of Kent:
- Clinical Psychologist
- Researcher
- Lead on E-PATs programme and related research



## Today

1. A summary of the key features and theoretical basis for the Early Positive Approaches to Support (E-PATs) Programme (The Logic Model)
2. An overview of prior E-PATs research
3. *A little bit about our current research with E-PATs (RCT) and Barnet!*

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### The Context

#### Children with Additional Developmental Needs

- Includes those with Intellectual Disabilities and those who are Autistic and those with Global Developmental Delay
- In early years may or may not have a confirmed diagnosis
- A range of challenges in learning everyday skills, communicating, sleep, health...
- At increased risk of developing behaviours that challenge



#### Parents/Caregivers

- Report many joys associated with raising a child with additional developmental needs
- Are at increased risk of experiencing stress and other emotional difficulties (early on)
- Some of which relates to the extra needs of their child (especially behaviours that challenge)
- Some of which relates to poor support, isolation, adverse experiences with services



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### Why E-PATs? – Context and Assumptions

- Raising children brings both joys and challenges and this remains true for families who have a child with intellectual disabilities (ID) (Ferreer, et al., (2017); Hastings et al., (2005); Hastings et al., (2002))

*"It can be difficult and frustrating and heart breaking sometimes but oh my Lord, she has taught me so much. She brings absolute joy to me and her family"*

- Families of children with disabilities sometimes need some extra support to navigate through the additional challenges that relate to their child's particular needs.

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Lived experience and research has highlighted many things that can be helpful when raising a child with additional developmental needs

- Behavior that Challenges: Harvey et al., (2012); Horner et al., (2002); Durand et al., (2012)
- Communication: Snell et al., (2010)
- Sleep: Priday, Byrne & Totsika, (2017)
- Caregiver wellbeing: Lunsky et al., (2017); Neece, (2014)
- Quality Support: Guralnick, (2017)



But often this information is not made available to those who need and could use it the most (families) – when they need it

Families of children with additional developmental needs/ID often report receiving little support or only being able to access something when things get really difficult. Griffith & Hastings, (2014); Gilson et al (2017); Douglas et al., (2017)

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In practice it is very hard to change things once challenges are impacting on family life in a big way (even in the early years) and even when this is successful there may be a sense that it all came a bit too late....

*'If only we'd known this from the start – how different life might have been'*



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•Many parenting programmes exist for typically developing children. These do not always meet the requirements and are often not acceptable to families who have a child with additional needs

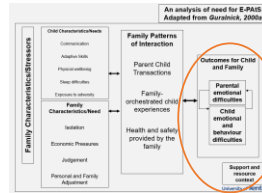
•A smaller number of parenting programmes have been developed or adapted for children who have intellectual/developmental disabilities

•There is however, a gap regarding early years support that focuses both on the wellbeing of parents and wellbeing , behaviour and development of children with additional developmental needs. This combination is important...



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•There is a bidirectional relationship between parent/caregiver wellbeing and the development and behaviour problems of children with additional developmental needs .



Family caregivers are at increased risk of experiencing stress and emotional difficulties (even when their child is very young)...

Because of the additional challenges they experience and lack of support they receive

Experiencing stress and emotional challenges makes it harder and harder for family caregivers to support their child



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•E-PATS has been designed as a UNIVERSAL programme of Support specifically for families who have a child with additional developmental needs to try to change this situation.....

•To maximise joys (quality of Life) and reduce challenges now and in the future



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OBJECTIVE AND MEASUREMENTS	IMPACTS	PROCESSES	OUTCOMES
<p><b>Objective 1: Early Targeted Support</b></p> <ul style="list-style-type: none"> <li>• Increase in E-PATS program usage</li> <li>• Increase in parent self-efficacy</li> <li>• Increase in parent confidence</li> <li>• Increase in parent knowledge</li> <li>• Increase in parent skills</li> <li>• Increase in parent support</li> <li>• Increase in parent confidence</li> <li>• Increase in parent knowledge</li> <li>• Increase in parent skills</li> <li>• Increase in parent support</li> </ul>	<p><b>Objective 2: Family Support</b></p> <ul style="list-style-type: none"> <li>• Increase in parent self-efficacy</li> <li>• Increase in parent confidence</li> <li>• Increase in parent knowledge</li> <li>• Increase in parent skills</li> <li>• Increase in parent support</li> <li>• Increase in parent confidence</li> <li>• Increase in parent knowledge</li> <li>• Increase in parent skills</li> <li>• Increase in parent support</li> </ul>	<p><b>Objective 3: Family Support</b></p> <ul style="list-style-type: none"> <li>• Increase in parent self-efficacy</li> <li>• Increase in parent confidence</li> <li>• Increase in parent knowledge</li> <li>• Increase in parent skills</li> <li>• Increase in parent support</li> <li>• Increase in parent confidence</li> <li>• Increase in parent knowledge</li> <li>• Increase in parent skills</li> <li>• Increase in parent support</li> </ul>	<p><b>Objective 4: Family Support</b></p> <ul style="list-style-type: none"> <li>• Increase in parent self-efficacy</li> <li>• Increase in parent confidence</li> <li>• Increase in parent knowledge</li> <li>• Increase in parent skills</li> <li>• Increase in parent support</li> <li>• Increase in parent confidence</li> <li>• Increase in parent knowledge</li> <li>• Increase in parent skills</li> <li>• Increase in parent support</li> </ul>

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**Early Targeted Support**



E-PATS is a group programme for families of children:

- o5 and under
- oWith additional developmental needs (thought to have an intellectual disability or to be Autistic – but without the need for formal diagnosis)

And that is basically it!

**UNIVERSAL: Supporting as many families as possible, as early as possible**



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**Why might families come to E-PATS?**

- Experiencing difficulty with an aspect of their child’s development or behaviour
- Processing what it means for them to be raising a child with additional developmental needs
- Experiencing emotional difficulties, stress, uncertainty
- Feeling isolated, alone and unsupported
- Seeking ways to plan and prepare for the future
- **Looking for ways to get the best for their child and family**

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**Inputs: Key things that make up the E-PATS programme**

- A **non-commercial** programme
- **Bespoke** (designed specifically for this group of families)
- **Evidence Based**
- **Positive/strengths based** approach to supporting caregivers and children



**PARTNERSHIP WORKING**

- Has been **co-produced** over a period of 10+ years by professionals in the child disabilities field and family caregivers **working together – led by Gore**
- Is routinely **co-facilitated** by trained family caregivers and professionals working in **partnership**

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**Why Family Caregiver Facilitators?**

**E-PATS views family caregivers as the ultimate expert on their own child and places high value on the wisdom of lived experience**

- E-PATS is **always** delivered by a trained family caregiver and professional working together.
- A **key ingredient of the programme** from the very start and is vital for each delivery.
- **Professionals** bring useful experiences and valuable knowledge to E-PATS but this is **only part of what is needed**.

Family caregivers bring a **different but highly valuable type of expertise** and knowledge, that which is **gained through direct, lived experience**.  
 Caregivers are best placed to **really understand the joys and challenges** associated with raising a child who has a disability and to **know what works best in practice**.

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Family caregivers typically feel **more at ease** when with other caregivers and **trust** support and advice from **those who have walked in similar shoes**.

So carer facilitators are **not an added extra** in E-PATS.

**They are central to making the programme work and providing the kind of support families need and deserve.**



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Delivered in **group sessions for 6-12** caregivers supporting children with a variety of needs. **1-2 caregivers from each family can attend**

1. Provides **high quality, evidence-based information and strategies** specific to the needs of families raising a child with additional developmental needs/ID
2. Supports **access to other services** and systems of support
3. Provides **emotional and social support** and attends closely to caregivers’ **emotional needs**



**8 x 2.5 hour group sessions that together cover:**

- Accessing services and supports
- Emotional wellbeing and resilience for caregivers
- Supporting sleep for children
- Supporting communication
- Supporting skills development
- Positive approaches to behaviours that challenge

*“Empowering families with practical, realistic and sensitive support”*

**All sessions include:**

- Social and emotional support
- Some information and tips
- Discussing and sharing ideas with other families
- Exercises to try in the sessions
- Some resources and guidance to take away
- Things that might help right now and / or in the future



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## E-PaTS Research



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## What families say....

*'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.'*

*'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'*

*'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'*

*'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'*



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## Feasibility

We ran a Feasibility RCT (Northern Ireland and Barnet) and know we can:

- Recruit
- Retain (and have learnt how to improve here)
- Get data (and have learnt how to improve here)
- Families are accepting of design and process
- *Promising outcomes*



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## Next steps

E-PaTS is implemented across the UK with hundreds of facilitators now trained

E-PaTS is being delivered in an area of Canada (translated into French) and two areas of Norway (in Norwegian) and we hope soon in Spain!

E-PaTS was delivered online throughout the pandemic

The UK Randomised Controlled Trial of E-PaTS has just begun



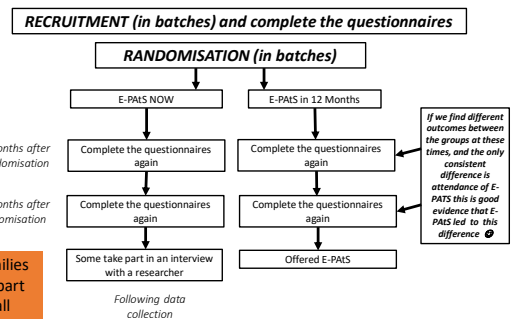
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## The Research Story

- RCT – The Main Event
- We want to test if Early Positive Approaches to Support (E-PaTS) improves wellbeing for parent/caregivers who have a child (18 months to <6 years) with Intellectual Disabilities (ID).
- The only real way to test 'does E-PaTS work' is to have lots of people participating (458 families will take part in this study)
- Families taking part in the RCT will have a 50/50 chance of attending an E-PaTS programme straight away, or 'waiting' to receive it in 12-months' time. Only by comparing what happens to the two groups can we find out if E-PaTS makes a difference to families.
- Funded by NIHR PHR



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### Main Inclusion/Exclusion Criteria:

1. Family Carer **18+** with sufficient level of **English language** enabling (verbal) completion of outcome measures
2. **Not previously accessed E-PATS** or enrolled on **another parenting programme** or programme of **personal psychological support** at baseline
3. **First carer** needs to be available to attend the E-PATS group sessions
4. **Child under 6 years** at start (and **18 months plus**)
5. Child with a diagnosis or exploring diagnosis related to global developmental delay/intellectual disability) AND scores **<80** on Vineland Adaptive Behaviour Scales
6. **No child-protection concerns** and **not in a state of crisis**

Up to 2 carers per family can participate  
 Second carer can attend if wants to/is able to

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### What families get

- An opportunity to take part in an E-PATS group (either now or in 12 months)
- Feedback and involvement in using the findings from the study to support more families in the future
- Financial 'thank you'  
 All participants (primary and secondary caregivers, including those in the intervention arm who do not attend E-PATS personally) will receive:
  - £15 voucher after completion of baseline data
  - £15 voucher after completing evaluations at 4-months.
  - £30 following completion of measures at the 12-month post-randomisation point**If 2 family members complete data at each of these times the family therefore gets: £120.**
- Those participants taking part in interviews as part of the Process Evaluation will receive a further £20 voucher.

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### Who is doing the research?

- Dr Nick Gore and Dr Jill Bradshaw at University of Kent are leading the research.
- Lots of other researchers from different universities are also involved
- There are family caregivers on the research team and an advisory group
- The research is happening in all UK countries
- Lots of organisations (including Mencap) are working together with the researchers
- The research is funded by NIHR PHR

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### The provider sites

- Northern Ireland**  
 Mencap Northern Ireland  
 Belfast & Derry City
- England**  
 Local Mencap Partners  
 Barnet, Carlisle, Croydon,  
 Local Authority & Royal Mencap Society  
 Newham Complex Needs and Dyslexia Service
- Scotland**  
 Kindred  
 Thriving Families
- Wales**  
 Local Authority  
 Newport



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### Barnet Mencap: E-PatS next groups 2024

<p><b>Group 2</b></p> <p><b>Mondays starting 4<sup>th</sup> March 2024</b>                  (for 8 sessions with breaks for Easter and a double session to account for bank holiday)</p>	<p>OR</p>	<p><b>Group 3</b></p> <p><b>Thursdays starting 9<sup>th</sup> May</b>                  (for 8 sessions with break for half term)</p>
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Both groups are face to face and held at Barnet Mencap Office, 35 Hendon Lane, Finchley Central, N3 1RT 10am till 12.30pm

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### NEXT STEPS

If you would like to find out more about the study:

Contact the research team at [LSSJEarlySupportRCT@kent.ac.uk](mailto:LSSJEarlySupportRCT@kent.ac.uk)

Or

Valerie.Lam@barnetmencap.org.uk

You can also hear more about E-PATS and the study from family carers: <https://youtu.be/cOVp5inAa70>



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Thank you for Listening

I welcome any questions and comments



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