

Early-Positive Approaches to Support

The development of a new family carer support programme.

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Background

- Challenging behaviour has a significant negative impact on people with learning disabilities and those who support them.
- Challenging behaviour often starts in childhood and without intervention endures into adulthood.
- Early support in childhood may prevent challenging behaviour from developing and improve outcomes for people with LD, and their families.

Why a family carer programme?

- Brief and low cost.
- Sustainable and empowering for family carers.
- Well evidence-based.
- Family carers are best placed to offer support and often the most motivated to do this.

Why a new programme?

- There are many programmes for family carers of typically developing children however these rarely meet the additional needs of family carers of children with LD.
- Programmes for family carers of children with LD do exist – Confident Parenting, Stepping Stones Triple P, Incredible Years etc.
- These existing programmes are well evidenced however they are designed to provide support *after* challenging behaviour has developed.

Developing the group

- 1. Deciding on the content areas**
 - Based on principles of positive behaviour support.
 - Risk factors for development of challenging behaviour.
 - Known areas of difficulty for children with LD.
 - Advice from other professionals.
- 2. Initial working party meeting**
 - Attended by a range of professionals who were experts in at least one of the topic areas, and a family carer.
 - Discussed what should go in each session, extra resources, how to run the group.
- 3. Developing the session content**
 - Using feedback from the focus group and the literature.
- 4. Family carer focus group**
 - Invited 7 family carers to offer advice on the format and content looking back on what would have been useful for them.
- 5. Specific feedback on sessions and resources from working party and focus group.**

The E-PAtS programme

- For family carers with a child aged 0-5 where developmental delay/LD has been suggested.
- 8 x 2.5 hour sessions, facilitated by a professional and family carer.

- 1 Working together** - Introduction, accessing services
- 2 Looking after yourself (1)** - importance of looking after yourself
- 3 Looking after yourself (2)** - a mindfulness approach
- 4 Sleep** - How to help your child sleep well.
- 5 Communication** - supporting your child to communicate
- 6 Fostering life skills through active development** - developing skills and independence
- 7 Responding to challenges** - responding to challenging behaviour
- 8 The next steps** - tying it all together

The workbook

- *The passport* – specific information about the child in relation to session content to be shared with others.
- *Top tips* from other family carers.
- *Service directory & additional resources.*

The proposed pilot

- **Participants** - two groups of family carers (n=24) of children aged 0-5 – delayed start for one group to serve as a control.
- **Recruitment** - local family carer groups/other contacts.
- **Measures** -
 - *Quantitative* - parental confidence, challenging behaviour, sleep habits, challenging behaviour knowledge, adaptive behaviour.
 - *Qualitative* - interviews with family carers.

The next steps

- *Larger trials* of the programme around the UK.
- *PhD* - tailoring the programme to children with specific syndromes.

