

Parent-led video feedback therapy: communication interventions for young autistic children

Document Audience	Commissioners and providers of services for pre-school and school-age children on the autism spectrum.
Document Purpose	To summarise the latest evidence on parent-led video feedback therapy, a form of communication intervention for young children with autism.
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Author	Autistica, the UK's autism research charity
Recommendation	<p>Local health economies should provide parent-led video therapies as an early intervention for young children with autism, when clinically appropriate.</p> <p>The Pre-school Autism Communication Therapy (PACT) is the only well-evidenced intervention of this type available in the UK. All local areas should have healthcare professionals accredited to deliver PACT.</p>

What is parent-led video therapy?

1. Parent-led video therapy is a form of intervention to improve the social communication skills of young children on the autism spectrum, particularly those who speak few or no words.
2. The therapy is non-invasive: it involves videoing a child on the spectrum as they play and then using the footage to feed back to parents to support them to recognise and respond to their child's alternative communication patterns. The therapy focuses on behaviours such as eye-gaze, sharing, showing and giving.
3. The Pre-school Autism Communication Therapy (PACT) is the only well-evidenced intervention of this type available in the UK.
4. Since late 2017 a training programme has become available to certify health and care professionals in the use of PACT in clinical practice.
5. These types of interventions aim to help parents and young children who might naturally communicate in very different ways to interact more effectively and improve the whole family's wellbeing. The intention is not to 'teach parenting skills' or 'cure' autism. The intervention empowers parents to maximise their support of their autistic child, enabling them to develop their own communications skills and ultimately advocate for themselves.

The need

6. One of the best predictors of an autistic person's life chances is their language and communication ability at a young age.¹
7. Currently one in four autistic people speak few or no words throughout their life.²
8. Language and communication skills have a significant impact on an autistic person's ability to convey their mental and physical health needs and are recognised as a key factor underlying behaviour that challenges.^{3,4,5} These skills are likely to affect an autistic person's mental and physical health outcomes, their likelihood of social exclusion, their educational attainment and chances of finding employment.^{6,7,8,9}

9. Parent-led video therapies are distinct from other interventions for autistic children. Existing interventions can help prepare children on the autism spectrum for social situations or enable them to functionally communicate their needs. However, PACT is the only well-evidenced therapy that has the potential to improve a child's social communication skills in a sustained way as they develop and therefore alter their longer-term trajectory in life.
10. Autistic people and their families identified *effective interventions to develop communication and language skills* as their second highest priority for autism research during an extensive priority setting partnership led by Autistica in 2016.¹⁰

The benefit and evidence

PACT

11. PACT has been shown to significantly improve the social communication skills of children on the autism spectrum and reduce restrictive repetitive behaviours for over six years after the therapy was delivered. It is the first therapy to demonstrate these outcomes and the only intervention of this type to have long-term evidence of its effectiveness.
12. PACT is the only social communication intervention of this type in the UK to have been rigorously tested in a Randomised Control Trial (RCT). Trials into PACT were funded by the Medical Research Council and the (then) Department for Children, Schools and Families (now the Department for Education).
13. The RCT was completed in 2010 involving 152 autistic children, aged from two years to four years and 11 months. A follow-up study was completed in 2016, when the children were aged between 7 and 11 years old, showing that the improvements had persisted six years after PACT was delivered. The results of both studies were published in *The Lancet*.^{11,12}
14. PACT is a relatively non-intensive intervention and is now ready to be used in clinical practice. Information about accredited training and the estimated cost of delivering PACT are provided below.

iBASIS

15. In 2015, another parent-led video-aided therapy, similar to PACT, was developed as an early intervention for autistic infants under the age of two. This intervention, known as iBASIS (Intervention within the British Autism Study of Infant Siblings), was tested in an RCT of 54 families with children between nine and 12 months old in Manchester and London.
16. Although the evidence around iBASIS is not yet as robust as it is for PACT, the initial results of the study were promising. The families receiving the adapted PACT intervention had improved interactions between parent and infant over the course of the study and in follow-up assessments when the children were three years old.¹³
17. Another study, the Australian Infant Communication and Engagement Study (AICES), is underway to see whether the results from iBASIS can be replicated in one-year-old infants.¹⁴

PASS

18. PACT has also been adapted for use in low and middle income countries. In 2016, an RCT was completed on 65 autistic children, aged two to nine years, in India and Pakistan, with similar improvements in their communication ability.¹⁵

JASPER

19. In America, a play-based intervention called JASPER has also been found to produce improvements in the social communication ability of school age children on the spectrum, although this intervention takes less advantage of video-interaction feedback.
20. In 2014 a pilot trial of JASPER was completed with 61 minimally verbal autistic children aged five to eight years. The study found significant increases in the children's use of spontaneous language and new words following parent-led play sessions.¹⁶
21. A follow-up study published in 2018 found that children's communication ability still improved when parents applied most but not all of the techniques from the therapy.¹⁷
22. There is currently no accredited training for this intervention available in the UK.

The costs

23. Indicative training costs	£1,100 (per professional) <i>or</i> £1,600	<ul style="list-style-type: none">▪ PACT accredited training for NHS staff, with supervised post-course fidelity and support.▪ PACT 'train the trainer' certified course, with post-course fidelity.
24. Indicative delivery cost	£268.60 ¹⁸ (per child for a full therapy course)	<ul style="list-style-type: none">▪ 18 contact hours (12x 90 minute sessions) with a trained speech and language therapist, occupational therapist or specialist nurse at salary band 5 (<i>average of £25,181.50 per annum, with annual leave and public holidays</i>).
25. Other costs	£0	<ul style="list-style-type: none">▪ Existing ADOS equipment or smartphone cameras can be used for video feedback.▪ Existing toys or household objects can be used for play interaction.

26. The only significant costs in providing PACT are the one-off costs of training health and care staff and the salary costs of those staff delivering the therapy course.

27. The cost of providing PACT will largely depend on the arrangement of local NHS personnel. A range of different health and care professionals from NHS pay band 5 upwards can be trained to deliver PACT including: speech and language therapists, psychiatrists, psychologists, occupational therapists and specialist nurses.

28. In the trial, the cost of a PACT session was estimated at £264, which compares favourably to the £296 cost of a similar outpatient appointment with Children and Adolescent Mental Health Services (CAMHS).

29. In trial conditions the total cost of delivering the intervention was £4105 per child, with an average of 16 sessions per family. However, the subsequent PASS trials found similar results with a reduced number of 12 sessions.

Accredited training for PACT

30. The intellectual property rights for PACT are held by a not-for-profit social enterprise (Community Interest Company) called IMPACT that was established for that purpose.

31. Accredited training is now available from the team in Manchester that developed and tested the intervention. A 'train the trainer' programme is also available. Further information about PACT can be found online at: www.research.bmh.manchester.ac.uk/PACT/trainingPACT

32. Training for local health and care professionals can be arranged by contacting Dr Catherine Aldred, Consultant Speech and Language Therapist at craldred@tiscali.co.uk.

33. Alternative rates are available for charities and special groups. The training programme is currently being piloted with teaching assistants to enable the delivery of PACT in educational settings.

National recognition and guidance

34. PACT was recently added to the recommended curriculum for the Children and Young People's Improving Access to Psychological Treatment (IAPT) programme, overseen by NHS England and Health Education England.¹⁹

35. In February 2017 the National Institute for Health Research (NIHR) featured PACT in its NIHR Signals programme, which summaries "the most important research" for decision makers.²⁰

36. NICE Clinical Guideline 170 *Autism spectrum disorder in under 19s: support and management* was published in 2013 before the latest evidence about PACT became available. However, in section 1.3 the guidelines recommend that play-based social-communication interventions which use video-interaction feedback are considered for supporting pre-school and school-aged children.²¹

About Autistica

37. Autistica is the UK's autism research charity and the largest independent funder of autism research in Europe. We operate Discover, the UK's national network for autism research, connecting autistic people and their families with autism researchers, local charities, support groups and NHS Trusts. Our vision is a world where all autistic people and their families live a long, healthy, happy life. Our funding priorities are determined by the autism community and can be read in full in our recent [Research Strategy](#). We are determined to involve autistic people in everything that we do and have published that commitment in [our Involvement Promise](#).
38. Autistica did not fund research into the development of PACT and has no financial interest in the adoption of parent-led video feedback therapies within the NHS. We did support the testing of an adapted communication intervention as part of the iBASIS trial.

¹ Magiati I, et al (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. *Clin Psychol Rev.* 2014 Feb;34(1):73-86

² Wallace S, Parr J, and Hardy A. (2013). *One in a Hundred: putting families at the heart of autism research*. London: Autistica.

³ NICE (2015). NG11 Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.

⁴ Chiang H (2008). Expressive communication of children with autism: the use of challenging behaviour. *J Intellect Disabil Res.*52(11):966-72 .

⁵ McClintock K, et al (2003). Risk markers associated with challenging behaviours in people with intellectual disabilities: a meta-analytic study. *J Intellect Disabil Res.* 2003 Sep;47(6):405-16.

⁶ Pickard H, et al (2017). Are Social and Communication Difficulties a Risk Factor for the Development of Social Anxiety? *J Am Acad Child Adolesc Psychiatry.* 56(4):344-351

⁷ Paul R and Cohen D (1984). Outcomes of severe disorders of language acquisition. *J Autism Dev Disord.*14(4):405-21.

⁸ Howlin P, et al (2014). Cognitive and language skills in adults with autism: a 40-year follow-up. *J Child Psychol Psychiatry.*55(1):49-58

⁹ Howlin P, et al (2005). An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. *Autism.* Vol 9 (5): 533-549.

¹⁰ Autistica and the James Lind Alliance (2016). *Your questions: shaping future autism research*.

¹¹ Green J, et al. (2010). Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial. *Lancet*; 375: 2152-60.

¹² Pickles A, et al. (2016). Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial. *Lancet [Online]*.

¹³ Green J, et al. (2017). Randomised trial of a parent-mediated intervention for infants at high risk for autism: longitudinal outcomes to age 3 years. *J Child Psychol Psychiatry.* 58: 1330-1340.

¹⁴ Telethon Kids Institute (2018). *Australian Infant Communication and Engagement Study (AICES)* [webpage].

¹⁵ Rahman A, et al. (2016). Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in south Asia in India and Pakistan (PASS): a randomised controlled trial. *The Lancet Psychiatry.* Vol 3(2), 128 – 136.

¹⁶ Kasari C, et al. (2014). Communication interventions for minimally verbal children with autism: a sequential multiple assignment randomized trial. *J Am Acad Child Adolesc Psychiatry.* 53(6):635-46.

¹⁷ Shire S, et al. (2018). Brief Report: Caregiver Strategy Implementation-Advancing Spoken Communication in Children Who are Minimally Verbal. *J Autism Dev Disord* [Epub].

¹⁸ *The indicative cost of delivering PACT to one child was estimated as 18 hours time (12x 90 minute sessions) of a band 5 NHS employee, working 37.5 hours a week with 27 days of annual leave and 8 public holidays. The average annual band 5 salary was taken as the mean of the pay points available, according to the Agenda for Change pay spine points for 2017 published by NHS Employers.*

¹⁹ NHS England (2017). *Children and Young People's Improving Access to Psychological Therapies Programme > Learning Collaboratives and Training Offer* [webpage].

²⁰ NIHR (2017). *NIHR Signal: Parent-focused therapy has some long-term benefits for children with autism.*

²¹ NICE (2013). CG170 Autism spectrum disorder in under 19s: support and management.