

# Open to all

Emma Povey shares how the Newcastle Autism Team reduced health inequalities by changing their service offer to enable parents to engage with support



EMMA POVEY

The Speech and Language Therapy Autism Team at Newcastle upon Tyne Hospitals NHS Foundation Trust supports autistic children and young people. Newcastle is a city with an ethnically diverse population, and 44% of autistic children known to our service are from families with English as an additional language. 49% are from the most deprived decile.

When a child receives an autism diagnosis from our team, parents are offered three follow-up sessions including one by a specialist SLT and two by colleagues from the North East Autism Society. We diagnose between 85 and 110 children every year, and around 35-40% of our families were not accessing our post-diagnosis offer.

It is widely recognised that early intervention is recommended to support the development of speech, language and communication skills in autistic children (NHS England, 2022; Whitehouse et al., 2021).

However, we were concerned that the intervention our team offered was not accessible to all the families on our caseload due to various barriers caused by health inequalities.

To help us get started in addressing health inequalities, we decided to start delivering Paediatric Autism Communication Therapy (PACT).

We wanted to know if PACT was accessible to families experiencing multiple barriers in accessing healthcare.

## Bringing PACT to our families

**Funding** Newcastle and Gateshead Clinical Commissioning Group received some funding from NHS England which enabled three SLTs to receive training and accreditation to deliver PACT.

## Working with families

We recruited 16 families from our caseload who had been unable to access our usual offer due to barriers caused by health inequalities. Each family was offered up to thirteen PACT sessions over six months.

## What did the parents tell us about barriers they were experiencing?

Parents reported difficulties related to their child's needs, and difficulties accessing support related to factors such as childcare, travel costs and language.

These included:

- 58% reported that childcare limitations made accessing health appointments difficult. Many parents felt that they could not leave their other children with someone else to allow them to attend appointments.
- 46% reported that transport and travel costs made attending appointments difficult. Parents reported difficulties using public transport with their children, and alternatives were expensive.
- Some families reported reluctance in requesting an interpreter in case they were allocated someone from within their community.

## About PACT

Paediatric Autism Communication Therapy (PACT) is an autism-specific intervention which has been shown to be effective in the development of communication skills in the short and long term (Mozolic-Staunton et al., 2020; Alred, Green and Adams, 2004; Green et al., 2010). It uses video feedback techniques to help parents recognise their child's communicative signals and create supportive communication environments. Parents identify ways they can change their own interaction to support their child's strengths and abilities.

We chose PACT to trial as an alternative to our standard offer because the intensive nature of the approach over a six month period allows the development of a strong therapeutic relationship, promoting trust and open discussion between parent and therapist. The use of video feedback, rather than the therapist working directly with the child, allows flexible modes of delivery. This helps avoid some of the barriers to attending, with no need to travel to appointments and no need for childcare.

## How we reached our families

To ensure attendance we tailored our service in the following ways:

- Flexible offer of session locations.
- Regular and repeated use of the same interpreter.
- Some families were supported to

## Around 35-40% of our families were not accessing our post-diagnosis offer

borrow toys from the local toy library. Initially the SLT would support the family to manage the loans, gradually encouraging them to access the service themselves.

- Although parents were given an appointment letter for the sessions, they would often forget. Therapists found that a text reminder message sent to parents ahead of the session was essential to avoid missed appointments.

## What was the response to PACT?

13 out of the 16 families who took part in the project completed the PACT intervention. The average attendance for the 16 families was 77%.

Parents were asked to evaluate any changes in their ability to support their child's communication development following PACT. They told us that PACT worked for them because they enjoyed setting their own targets and practising agreed strategies. They liked watching and discussing the play session videos with the therapist, and were able to spend more time playing with their child.

- 100% of parents noticed a change in their skills.
- 100% of parents reported feeling more confident in playing and communicating with their child following PACT.
- 100% of parents reported that they allow their child to choose the toys they want to play with and they now follow their child's lead in play. One parent told us: "Before I started this programme he pushed



## REFERENCES

To see a full list of references visit: [rcslt.org/references](https://rcslt.org/references)

me away when I tried to play with him ... It's now the other way round, he wants me around and we are playing together. Now I have stopped all my social media because I want to be with my children and I am happier now". Another parent said: "I really wasn't sure about PACT at first but it's made a massive difference".

We found that some families' expectations of the therapy were based on more traditional approaches where the child is seen for 1:1 therapy with a therapist. Families also sometimes expected therapists to demonstrate or 'teach' them how to play with their child. As PACT is a different way of working, at times it was difficult shift this expectation towards parent-mediated therapy.

## Thinking about the future

This project showed us that PACT can be an effective treatment option which can be made accessible for families experiencing multiple barriers. We faced some practical challenges, such as finding suitable interpreters. Currently, there is a level of inequality as the waiting time for PACT is longer than our other treatment pathways due to the intensity of the approach, but we hope to secure additional funding to support delivery in future.

We have applied learning from the project to our other pathways, such as sending text reminders for appointments and aiming for the same interpreter for all appointments. We are also implementing coaching techniques with parents and school support staff.

We now offer PACT as pathway when it is clinically indicated for families requiring an interpreter. We also offer it to those not requiring an interpreter but who are unable for other reasons to access our alternative therapy offers such as the Hanen More than Words Parent Program. All SLTs in the Autism Team have now been trained to deliver PACT. With this support in place, we hope it might be possible to see a reduced need for longer-term input from services.

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