

Qualitative analysis of two exemplar sites for Autism diagnostic assessment change: An NHSE-funded study

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1. AIMS

1. This study aims to examine existing models of Autism diagnostic service delivery.
2. To inform NHSE about solutions to autism service delivery.

2. OBJECTIVES

To investigate which approaches offer **the most timely, cost-effective, high quality** and child and family friendly solutions, and in line with realist thinking, to identify what works well, for whom, under what circumstances and at what cost in children's Autism diagnostic and support services.

3. METHODS

Two sites in the South East were interrogated to understand **who, how, and at what cost** do families and children get involved in diagnostic pathways. The qualitative analysis conducted is part four of five national packages of work. The focus is on a thematic analysis of key innovations and experiences of professionals (including Speech and Language Therapists, Clinical Psychologists, Health Visitors), as well parents and children and young people with Autism as they go through diagnostic pathways.

Realist methodology requires reading and interrogating data to track and isolate emerging themes of relevance.

The author has conducted 35 interviews and read 625 transcribed pages from said interviews, with the following themes emerging so far:

Themes
Needs-led vs diagnosis led services
Assessment as a process vs single event
Core team vs staff brought in when needed
Passive vs proactive waiting list management

THEMES

Quotes from professionals highlighting the four key themes:

Passive vs proactive waiting list management

"we're getting screening questionnaires completed at the point of referral rather than waiting on for... rather than waiting for a specialist to become free" (CAMHS Operational Lead)

Assessment as a process vs single event

With screening appointments being completed first, parents are aware of the assessment as a process from the start **"because we've moved it to the start parents and schools are really clear "yeah, we have to do this as part of the assessment process"** (CAMHS Operational Lead)

Core team vs staff brought in

"I'd probably say there's about 7 of us but we often kind of rotate in terms of who's kind of doing the assessments." (Speech and Language Therapist)

"I think we got a little pot of COVID money to do some extra, to get extra workers for a limited period, so we've tried to double-up on the assessments we're doing every week." (Consultant Psychiatrist)

"I think, we've had to increase like the, we used to have one day's clinic but we've increased our clinic as well so we now have two days." (Clinical Psychologist)

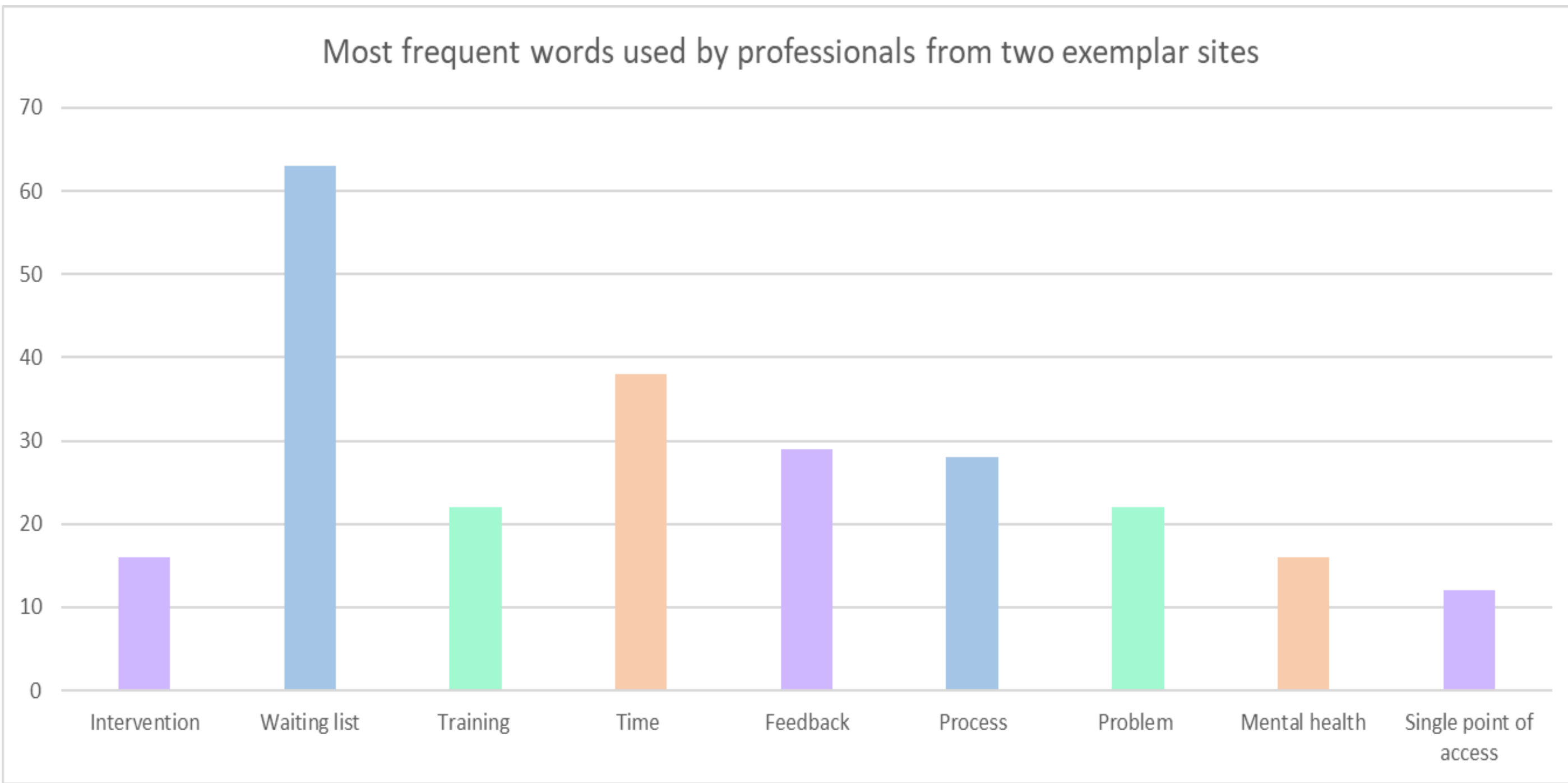
Needs led vs diagnosis led

"we see the children as, or offer the support as in when the parent require it and on need basis" (SEND Health Visitor)

4. FINDINGS

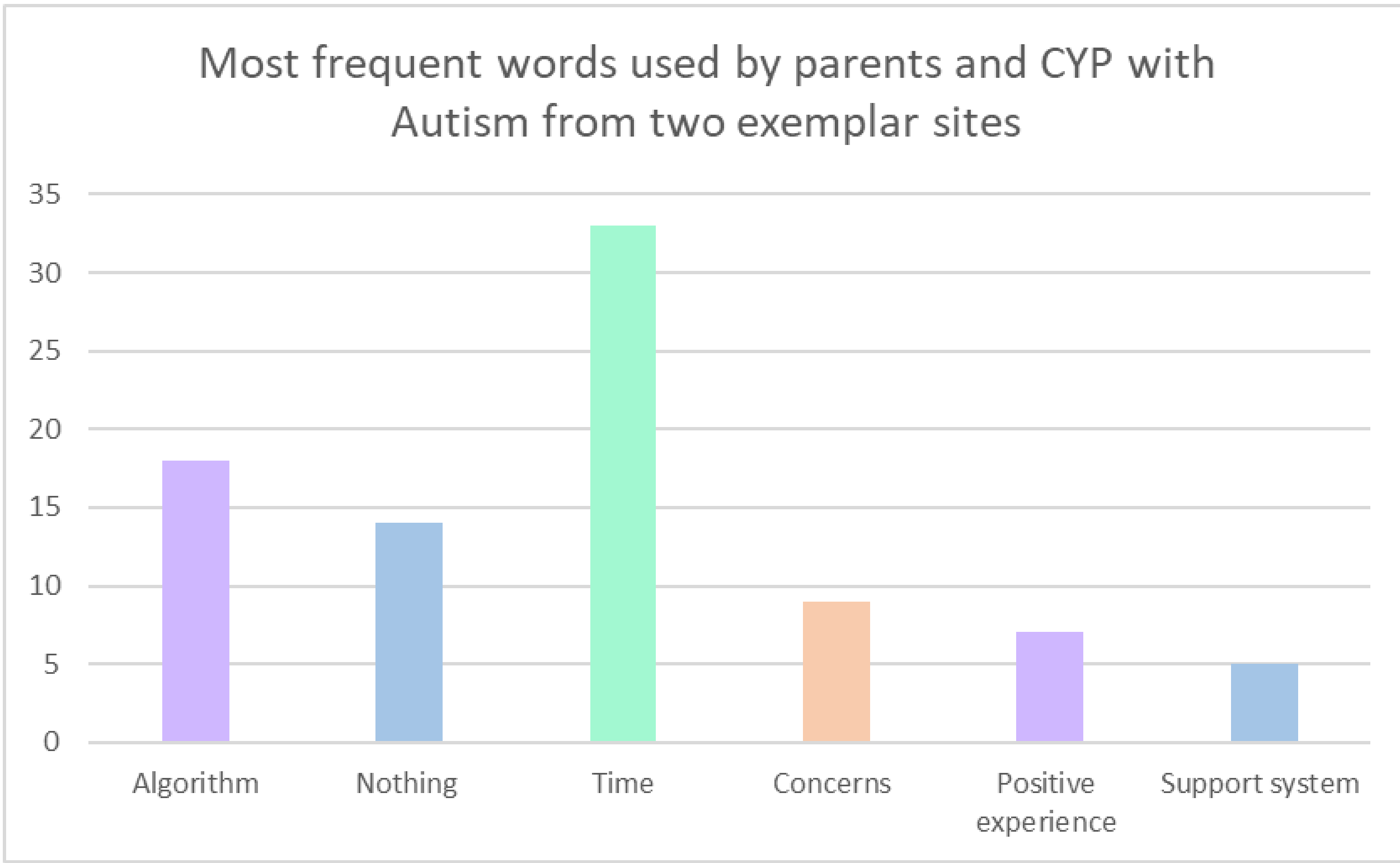
WORDS

The first graph shows the most frequently used words from professionals:



The most frequent phrase used by professionals from both sites was **waiting list**, which was mentioned 63 times.

This graph shows the most frequently used words from parents and children and young people with Autism:



The most frequent phrase used by families from both sites was **time**, which was mentioned 33 times.

5. CONCLUSIONS

- Waiting lists are a concern from professionals at both sites, hence the strategies that are being trialled in these sites to tackle waiting lists.
- Frequency of the word 'process' links in with the theme of the assessment being seen as a process vs a single event, showing that being on an Autism pathway is seen as a process.
- Many of the frequent words throughout the interviews are reflective of the current themes emerging, such as having a 'single point' of access, whether that be to access support, finding out information about the process and waiting list management.

6. WHAT I'VE LEARNT

- Process of informed consent and good clinical practice
- Conducting focus groups and interviews with CYP with neurodisability
- Liaising with NHS clinical staff, service managers and navigating the NHS
- Liaising with PCIE groups, for example third sector charities (Autistica) and volunteering groups
- Co-producing results – probing, finding touch points and pressure points of diagnostic assessment

7. WHAT HAS EXCITED ME

- Being able to contribute to a study that has important implications for NHSE
- Using university knowledge in a real-world setting
- Developing research skills in a specialist area of interest

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