Gloucestershire Safety & Quality Improvement Academy

Gloucestershire Hospitals NHS
NHS Foundation Trust

Pilot study of neurodevelopmental diagnostic clinic model in school aged children, for whom diagnostic conclusions have been difficult to reach in Gloucestershire

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1. Background

In Gloucestershire, neurodevelopmental assessment of primary school aged children with social communication difficulties usually involves collation of educational reports and screening questionnaires followed by assessment with a paediatrician. The aim is to reach a diagnostic conclusion as to whether there are difficulties consistent with a diagnosis of ASD. For some, this model of working can lead to a delay in diagnostic conclusions due to complexities with the child and, as a result, the child may remain under review for a prolonged period of time without clear conclusions. It is recognised that clear diagnostic conclusions are helpful to the child, as they direct recommendations for support within the home, community and education.

This pilot was a model of multi-professional working between a paediatrician and clinical psychologist using two structured assessments—the Diagnostic Interview for Social and Communication Disorders (DISCO) and the Autism Diagnostic Observation Schedule (ADOS) assessment.

2. Aims

The aims were to pilot a neurodevelopmental clinical model of joint working between a paediatrician and psychologist. Data would be collected regarding the clinician and patient experience, time from referral to diagnosis, and the advantages and difficulties of this method of working, and to provide information for the MDT reviewing the primary school aged pathway for ASD diagnosis.

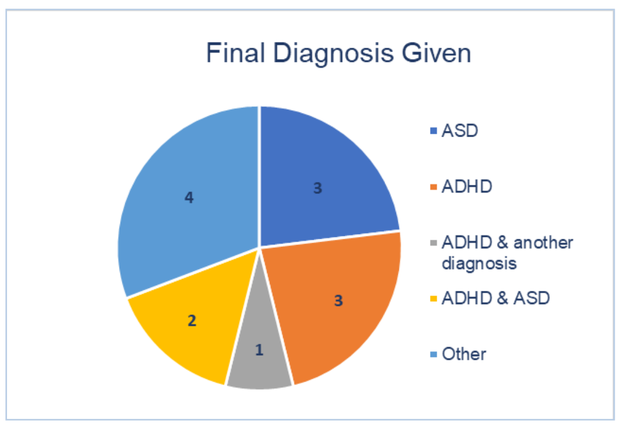
3. Methods

The paediatrician selected patients for whom reaching diagnostic conclusions had been challenging. Data collected included demographic details, presenting problem, time to diagnosis from referral and parent completed questionnaires detailing their experience of the process. ADOS and DISCO assessments were carried out with a follow-up meeting between the clinicians, the parents and members of educational staff to go through the results and to make recommendations for support.

4. Results:

Data was collected on thirteen children overall, with an age range of five years and nine months at their initial assessment, to eleven years and two months (median age: nine years, four months). There were eleven male participants and two female participants.

Data collected included time from first referral to Community Paediatrics to diagnosis made. Many children were referred several times but the referrals were declined pending further action in the community. Six parents returned a questionnaire about their experience of the process.



The spectrum of diagnoses made after joint testing, and the number of children assigned these diagnoses.

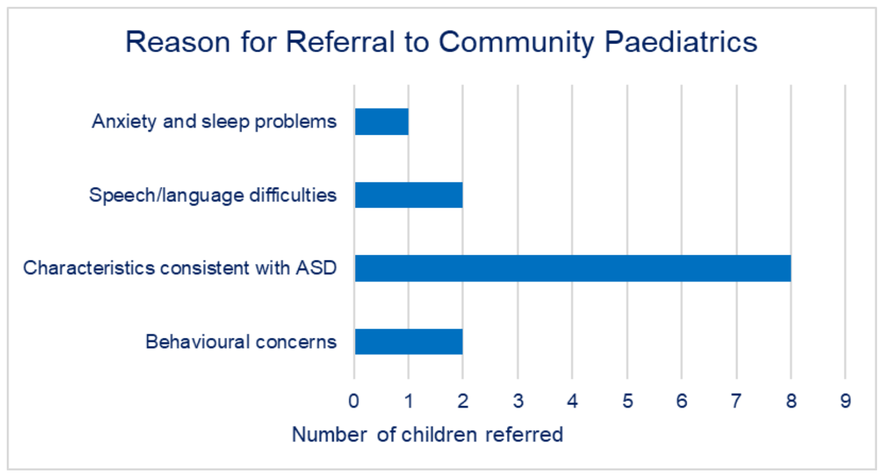
Question Asked in Parent Feedback Questionnaire	Difference in Rating Given Before and After Assessments (Median Value)
How much did you feel you understand your child's difficulties?	2 point increase
How much do you feel other professionals understood your child's difficulties?	2 point increase
How much do you understand why your child behaves as she or he does?	3 point increase
How confident do you feel that there was an appropriate plan in place to support your child?	2 point increase
How much do you feel school understands your child's difficulties?	2 point increase

Positive Feedback from Parents:

- One appointment meant not repeating and missing information
- The clinic offered an "easy diagnostic process" and "runs very smoothly"
- The clinic made us feel as though we are not alone in seeing [their child's] difficulties
- The clinicians were very clear about the whole process
- We felt we were being taken seriously that [our child] has difficulties

Areas for Improvement:

- There were limited opportunities to follow up with the clinicians involved
- We would value a similar process further down the line as and when we can get [the child] back in school.
- Need more focus on how to support [their child] moving forward
- We would have liked more time to process and reach deeper into areas and ideas



The reason for referral to Community Paediatrics grouped by the GP's main concern

Time to Diagnosis from Initial Referral to Community Paediatrics (days)			Time to Diagnosis from Referral Prompting Joint Clinic (days)		
Minimum	Maximum	Median	Minimum	Maximum	Median
142	1715	610	59	519	185

Table detailing the time for a patient referred to Community Paediatrics to reach a diagnosis.

Feedback from Clinicians:

- Parents seemed to find it helpful to understand their child in this way
- Improved ability to reach professional conclusions in challenging situations
- Prevented the duplication of clinician time and increased professional satisfaction and enjoyment
- Useful to have MDT feedback session and learn from other professionals
- Ability to communicate effectively between clinicians was valuable in ensuring the correct outcome

5. Discussion

The clinicians felt the process was beneficial, resulted in improved clinician satisfaction and produced increased diagnostic accuracy in a complex patient group. This process resulted in positive patient experience and is likely to shorten time to diagnosis using a model of working that is closer to NICE guidance. This model of working does not fit the commissioned model of assessment, but could be very valuable, both to enable diagnostic certainty for the more complex cases and to decrease the overall number of non-conclusive visits to the paediatric clinic.

Conflicts of Interest:

VT (psychologist) is working on developing a School aged pathway

CM (paediatrician) utilised the pilot to increase experience of DISCO interview and therefore trialled different ways of using the interview and report writing as the pilot progressed. Whilst CM was trained and had used the interview prior to the start of the pilot, experience increased as pilot progressed.