



**Autism
Anglia**

Registered Charity No. 1063717

**Obtaining a diagnosis of autism for children living
within East Norfolk CCG**

**A report to Great Yarmouth & Suffolk Health Overview & Scrutiny Committee
July 2016**

Contact person in relation to this paper:

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Background:

This report has been compiled from information gathered by Autism Anglia with the help of Sunbeams Play based in Great Yarmouth. It comes as a result of both organisations finding that parents inform them that they are unhappy with the length of time it is taking / has taken for their son or daughter to be diagnosed with autism which has an effect on what support and services the child and their family receives. Whilst it is accepted and acknowledged that support for any child should be based on the individual child's needs and not diagnostic label, in reality services and support are not forthcoming without the diagnosis, and even then these can be patchy and difficult to obtain.

This report shows the experiences of just some parents. However these are consistent with what Autism Anglia and Sunbeams too frequently hear from other parents who are concerned about the time it is taking to assess and diagnose their son or daughter. It is clear from the information provided that in many cases the start of the assessment process for diagnosis is not starting within 3 months of the referral being made. See survey responses on pages 2 - 4 of this report.

**Survey June 2016 by Autism Anglia – Parental experiences of obtaining a
diagnosis of autism for their son or daughter.**

With the help of Sunbeams Play in Great Yarmouth, a survey was undertaken to gather the experiences of parents who had received a diagnosis for their son or daughter in the past 3 years or who are currently seeking a diagnosis of autism for their child.

Survey Results

The survey was completed by 20 parents. Of these during the past 3 years:

- 12 had received a diagnosis of autism for their son or daughter
- 8 are seeking a diagnosis of autism for their son or daughter

Responses from those who have already obtained a diagnosis said the following relating to their experiences of getting the diagnosis for their child.

A. Who referred for diagnosis:

Who referred	Number of parents
GP	7
Parents	1
Parents & Nursery	1
Speech & Language Therapist	1
Psychologist	1
School & NCC specialist	1

B. How long it took before the child was seen by a paediatrician following the referral being made (start of the diagnostic assessment):

Time taken	Number of parents
2 months	1
3 months	3
4 months	1
5 months	1
6 months	2
9 months	2
Not stated	1
Other: "Went to CATS team on private insurance to avoid year-long queues. Still haven't seen a paediatrician under ECCHC".	1

C. After seeing the paediatrician how long parent had to wait for the actual diagnosis:

Time taken	Number of parents
1 year	2
13 months	1
18 months	1
2 years	2
Around 2.5 years – 3 years	1
4 years	2
13 years	1

Did not state	1
Not applicable as went private	1

D. How the diagnosis was given?

Method	Number of parents
Face to face by paediatrician and in a letter	2 (one parent added that she had to chase to get the letter)
Letter only	4
Face to face by the paediatrician	4
Face to face by CAMHS	1
MDA meeting	1

Other comments parents made about the diagnostic process:

- Always chasing lost paperwork between school and Newberry clinic. Long wait for assessments by educational psychologist, speech & language therapist and ASD specialist.
- Initial visits to paediatrician at Newberry clinic lead me to being told there was nothing wrong and son 'normal', yet now diagnosed with ASD, ADHD and epilepsy.
- Was appalling service and something we would never want to repeat!

Responses from those who are currently seeking a diagnosis said the following relating to their experiences to date of getting the diagnosis for their child.**A. Who referred for diagnosis:**

Who referred	Number of parents
GP	3
GP & Health Visitor	1
Health Visitor	1
ADHD Nurse specialist	1
School, parent, family support worker	1
Sunbeams	1

Since referral:

- **4 parents** said they **have not yet seen a paediatrician**;
One parent was referred in July 2015 and whilst her son has been discussed at the Waveney Diagnostic Group for Autism in October 2015 her son has not yet been seen by a paediatrician. He has though had a speech and language assessment in December 2015 and was discussed at the Forum in January 2016.

Another parent was referred in October 2015 and has not yet heard anything.

One parent said she is still waiting to see a paediatrician despite first going to her GP 2.5 years ago.

2 parents said they **have not yet got an appointment date to see paediatrician.**

- **4 parents** said they **have seen a paediatrician.**

1 parent said that the appointment was about 2 months following the referral before she saw a paediatrician.

1 parent saw paediatrician 3 months after referral was made. Whereas another parent said it was 6 months after referral which was made about 2 years ago but has not yet received a diagnosis.

1 parent's child was referred in May 2015 and seen by paediatrician in July 2015 however no diagnosis has yet been provided.

- **All 8 parents** said they **have not been given a timescale for when a decision about diagnosis will be made.**

Other comments:

- *We have not been taken seriously. Communication has been shocking. Timescales are shocking waiting for appointments. Professionals not agreeing with each other preventing my child from getting the help needed.*
- *Extremely disappointed at the times between appointment and have now come to the end, I can't give or provide any further evidence, the professionals have it all. My son's education is suffering whilst we wait for a decision on his diagnosis.*
- *We had an appointment in July 2015 then the next one in September was cancelled. We have now gone for a private diagnosis as we felt this was the only way we could get any help. His diagnosis is still ongoing and next appointment at Newberry clinic is end July 2016.*
- *I had 3 referrals declined was then passed onto the point one mental health team I had to wait a year for a diagnosis of ADHD despite observations, nursery reports and lots of evidence backing this up I am still waiting for an autism diagnosis and I still haven't seen a paediatrician he was diagnosed with ADHD and medicated by a psychologist.*
- *I've been told it's a long journey to getting the autism diagnosis.*

Supplementary Information:

In 2014 NICE quality standard [QS51] was published.¹

This quality standard covers autism in children, young people and adults, and lists 8 quality statements covering various aspects.

¹ <https://www.nice.org.uk/guidance/qs51/chapter/List-of-quality-statements>

Statement 1 says: People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.

The “Autism: recognition, referral and diagnosis of children and young people on the autism spectrum (NICE clinical guideline 128)”, gives a number of recommendations which we feel are pertinent to this report and survey findings.

1.5 Autism diagnostic assessment for children and young people

1.5.1 states: *Start the autism diagnostic assessment within 3 months of the referral to the autism team*

1.5.2 states: A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment.

1.5.3 states: The autism case coordinator should:

- act as a single point of contact for the parents or carers and, if appropriate, the child or young person being assessed, through whom they can communicate with the rest of the autism team
- keep parents or carers and, if appropriate, the child or young person, up-to-date about the likely time and sequence of assessments
- arrange the provision of information and support for parents, carers, children and young people as directed by the autism team

1.8 Communicating the results from the autism diagnostic assessment

1.8.1 After the autism diagnostic assessment discuss the findings, including the profile, sensitively, in person and without delay with the parents or carers and, if appropriate, the child or young person. Explain the basis of conclusions even if the diagnosis of autism was not reached.

1.8.2 Use recognised good practice when sharing a diagnosis with parents, carers, children and young people.

1.8.3 For children and young people with a diagnosis of autism, discuss and share information with parents or carers and, if appropriate, the child or young person, to explain:

- what autism is
- how autism is likely to affect the child or young person's development and function.

1.8.4 Provide parents or carers and, if appropriate, the child or young person, with a written report of the autism diagnostic assessment. This should explain the findings of the assessment and the reasons for the conclusions drawn.

1.8.8 For children and young people with a diagnosis of autism, offer a follow-up appointment with an appropriate member of the autism team within 6 weeks of the end of the autism assessment for further discussion (for example about the conclusions of the assessment and the implications for the child or young person).

About autism

Autism affects approx. 1 in 100 people in the UK, with no cure and is lifelong. It is a spectrum condition which means that while all people with autism share certain difficulties, the condition affects each person differently.

Autism affects the way a person communicates with and relates to others and how they make sense of the world around them.

People with autism may also experience some form of sensory sensitivity or a lack of sensitivity.

On its own autism is not a learning disability or a mental health problem; however some people with autism have an accompanying learning difficulty or mental health problem.

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