

# *Autism Survey Report*



*November 2014*

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## Introduction and Background

Following routine engagement with a number of support groups of parents of children with Autism, Asperger's and similar conditions, it became clear that a number of issues were recurring amongst these groups. This particularly included issues around access to paediatricians and Children's and Adolescent Mental Health Services (CAMHS), especially for children and young people with autism. Healthwatch Lincolnshire had also received prior intelligence about a shortage of paediatricians.

A brief study was carried out in partnership with some of the groups so we could gather peoples' views of these services and, in particular, waiting times to access services.

Due to the limited number of responses to the survey it is difficult to come up with any conclusive recommendations. However, some suggestions have been drawn out from the responses received.

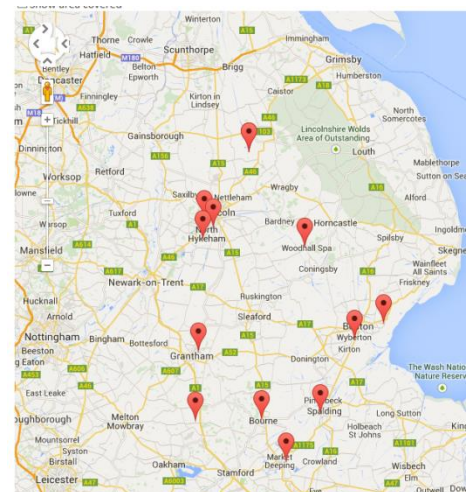
## Methodology

A survey was sent out to the lead individual within the groups previously engaged with. Some were sent to individuals who had agreed to take part and it was sent to other professionals to distribute on our behalf. This included several contacts within Children's Services at Lincolnshire County Council. It was also sent out to special schools to distribute to parents. Tim Barzycki, Social Care Community Engagement Officer with Healthwatch Lincolnshire also attended the showcase event at the Epic Centre in November and a carers rights day event organised by Parent Carer Forum. A copy of the survey can be found at Appendix 2.

## Profiles

We had 9 responses. Every person completing the forms was a parent with at least one child with Autism and almost all the children did not have additional disabilities. As might be expected, most were primary or secondary school age and attended either mainstream or special schools. Interestingly, none said their child was home educated which could imply this group of parents are unintentionally excluded when it comes to receiving information. Only one parent had other caring responsibilities eg an aged parent.

We asked for a postcode of the respondent in order to measure the geographical spread of information received and the adjacent map shows a large part of the county was included in this process.



## Health Care

Despite half the respondents having to wait 6 - 12 months to see a paediatrician, most were satisfied or fairly satisfied with the outcome and waiting time, with only 2 being not at all satisfied and one of those had waited 4 - 6 months.

Similarly, only one of 3 respondents who had to wait over 12 months thought it not at all satisfactory. Conversely one respondent who had to wait 1 - 2 months for a health assessment for their child also thought it was not at all satisfactory. A comment received was 'Waited 4-6 months to see paediatrician and saw different one each time, so had to start all over again from the beginning each time'.

## Social Care

Few had had a social work assessment of their child's needs and most of those that had were at least fairly satisfied with the outcome and time scales with only one not at all satisfied and even fewer had a social work assessment of their own's needs.

What isn't clear is whether a social work assessment was offered but not taken up by the parent. However, this is something that could be taken up with the children's services team.

Worryingly a third of all respondents were not aware they were entitled to a carers assessment, whilst a quarter had to wait between 4 and 12 months. Only 3 respondents received a carers assessment within 3 months.

## Education

Almost half of respondents had to wait over 6 months to have an educational assessment of their child's needs and of those who received an assessment, only about a third were satisfied or very satisfied. Whilst it is not always going to be possible to satisfy everyone, especially where a child's education is involved, more work needs to be done in schools to improve assessments and parental satisfaction.

## CAMHS

Of those who received a service from CAMHS most had to wait between 6 - 12 months or over 12 months to receive a service with only 2 receiving a service in under 6 months. All the ones who had to wait over 12 months to receive a service were dissatisfied. This could imply that the frustrations of waiting to receive a service leads to a more critical appraisal when it is eventually provided.

## Specialist Services

All of those who said they used specialist services used a specialist dentist, with most also needing optician services, were generally satisfied with the services provided. However, one person using a specialist play therapist was not at all satisfied.

## Individual Budgets

Only one person received an individual budget to support them with care provision. Other respondents said no or were not aware. These findings would suggest there is an opportunity to raise awareness of individual budgets within this client group.

The main points from the comments received are:

- Schools dragging their feet.
- Waiting time to see paediatrician.
- Lack of consistency in seeing same person so had to repeat history each time causing delay in diagnosis.
- We were not taken seriously and had to change surgeries to get a referral.
- Poor assessments - unsatisfactory results.
- Autism is still ignored or pushed aside.
- Always having to wait past appointment time due to services running late x 2.
- Paediatrician appointment always late x 2.
- School transport - new since September - boys not happy.
- Social worker now leaving - will have to have someone else who is only on a six month contract.
- GP blocking Autism assessments.
- Nobody wants to pay for the services out of their budgets and you get sent round in circles till they hope you get so disheartened that you give up.
- My experience of transition from mainstream to special needs school couldn't have gone any better. My son is like a different child... great head teacher.

Further comments are listed in Appendix 1.

## Most Valued Services

- Statement, advice and guidance for Educational Psychologist.
- Direct payment support worker is a great help with my sons.
- Direct payments - helps me a lot as I can get support worker to help with boys.

## Quotes

- There is nothing positive to say about my Health and Social care experience. They are likely to send people down the route of suicide even quicker.
- Always kept waiting at Dentist and Doctors. Always running late is their excuse.
- Waited 1 - 2 months for educational assessment and was very satisfied.
- CAMHS don't appear interested.
- There has been little or no follow through.
- It was a long process to get (son) diagnosed by the paediatrician.
- Better signposting from health care would have been appreciated.
- Doctors need to learn to listen to parents - we know our children.

## Issues and Recommendations

- Whilst there is no correlation between waiting times and satisfaction levels, the frustrations of waiting to receive a service can possibly lead to a greater chance of a perceived negative experience when it is eventually provided. More work is needed to understand why parents and children have such long waits and a better understanding of what work is being done to address this.
- Work required to reduce waiting times to receive an appointment with a paediatrician or relevant professional.
- Additionally more work needs to be done to ensure waiting times are kept to a minimum once the child has an appointment as a number of comments referred to appointment always running late including Paediatrician, dentists and doctors.
- Ensure that all parents of children with disabilities, including autism, ADHD and similar conditions and especially those in home education receive appropriate and timely information about available services.
- To recruit and retain paediatricians in order to reduce the waiting times for appointments and maintain continuing of service for those parents and children already in the system.
- Greater awareness by GPs of relevant conditions and a production of a simple referral pathway.
- To ensure a process is in place to routinely offer a social work assessment to the child and the parent(s).

- Similarly a process needs to be in place where parents are routinely offered a carers assessment at initial contact with services and perhaps incorporated into the Make Every Contact Count (MECC) criteria.
- Whilst we acknowledge that Healthwatch Lincolnshire has no jurisdiction in schools and education, it would appear more work needs to be done in schools to improve assessments and parental satisfaction, especially with the new Special Educational Needs and Disability reforms and Education Health and Care plans introduced in the Children and Families Act 2014.
- Review referral process into CAMHS and provision of mental health advice required especially if not accepted as a referral by CAMHS.
- More information about individual budgets needs to be routinely provided

**AUTISM SURVEY**  
**FOR PARENTS OF CHILDREN AND YOUNG PEOPLE WITH AUTISM**

The following are comments made by parents recorded from the survey.

- We have been advised my son will not get an EHIC as supposedly his needs are not that great. School have been dragging their feet. Since in only one day a week very hard to get any information.
- Waited 4-6 months to see paediatrician and saw different one each time, so had to start all over again from the beginning each time.
- Educational assessment 1-2 months and very satisfied.
- No individual budget for the child.
- We saw signs of our child's eventual diagnosis when he was 30 months old.
- We were not taken seriously and had to change doctor's surgeries to get a referral.
- He wasn't diagnosed until age 5, year one, due to having a different paediatrician each time and delays in appointments and constant cancellations.
- Excellent GP. Dentist keeps changing.
- Have to inform all care about ASD.
- Waited 1 - 2 months for educational assessment and was very satisfied.
- **Service least valued.** Doctors who need to learn and listen to parents. We might not have a medical degree but we know our children.
- **Additional services needed.** Mental health advice.

Parents with children who have other Disabilities.

- Attended special school but no longer in education. From survey the family had poor assessments and were not satisfied with results.
- 'We have a very negative viewpoint of all these services when dealing with our sons - Autism is still ignored or pushed aside.'



- **Service most valued.** None.
- **Service least valued.** Social Services because nobody wants to pay for the services out of their budgets and you get sent round in circles till they hope you get so disheartened that you give up.
- **Additional services needed.** Emotional support for both my 26 year old and me as a disabled carer, and practical support for my son to live some semblance of an existence which he does not have now.
- **Regarding Experiences.** There is nothing positive to say about my Health and Social care experience. They are likely to send people down the route of suicide even quicker. But then of course that would save dipping into the budget.

#### Parents with Children attending Special Schools.

- No health assessment.
- Always having to wait past appointment time due to GP, Dentist, Hospital running late.
- Always kept waiting at Dentist and Doctors. Always running late is their excuse.
- Have to go to GP for heart/BP checks before they would dispense more medicines.
- Appointment still not come.
- GP blocking Autism assessments. Given basics like allergy testing.
- **Service most valued:**
  - Direct payment support worker is a great help with my sons.
  - Direct payments. Helps me a lot as I can get support worker to help with boys.
- **Service least valued:**
  - School transport - new since September - boys not happy.
  - GP and CAMHS as they don't appear interested.
- **Regarding experiences.**
  - Paediatrician appointment always late.

- Social worker now leaving - will have to have someone else who is only on a six month contract.
- Appointments late with community paediatrician, again supposed to be 3- monthly due to ADHS needs.
- ONCE, my son was assessed. There has been little or no follow through. Very disappointing

## AUTISM SURVEY

### For parents of children and young people with autism

Healthwatch Lincolnshire wants to gather the views of parents and carers of children and young people and, of young people with autism and similar conditions eg Asperger's. We have produced this survey with the support of a number of parent support groups and their members in order for you to give us your feedback. We would therefore appreciate your cooperation in answering the following questions. If you have more than one child with this condition please complete a separate form for each child.

The results of this survey will be shared with local authorities and other relevant health and care commissioners and service providers to help influence improvements in children's services in Lincolnshire.

Thank you for taking the opportunity to share your views with Healthwatch Lincolnshire by taking the time to complete this survey. Any feedback you provide will be anonymous and information received remains confidential within Healthwatch Lincolnshire.

#### About You

1 Postcode .....

2 Are you completing this survey as

A parent  a grandparent  Other family member  foster carer   
 other paid carer  other unpaid carer  Young person with a relevant condition

3 This survey has been completed in respect of a child who is

Pre school age  Primary age  Secondary age   
 16 -18  19-25

4 How many disabled children are there in your household (including the one this survey is about)

\_\_\_\_\_

5 Does this child have any other disabilities or long term conditions (eg physical disabilities, diabetes, epilepsy etc) YES  NO

6 Do you look after any other family member eg ageing parent? YES  NO

7 Which type of school does this child attend?

Mainstream  Special school  College   
 home educated  other

please state \_\_\_\_\_

## HEALTH AND CARE

### 8 Paediatrician

How long did you have to wait to see a paediatrician? (Please tick one only)

Less than a month  1-2 months  2-3 months  4-6 months  6-12 months   
Over 12 months  Not applicable

9 How satisfied were you with the outcome of the assessment including waiting times?

Not at all satisfied  Fairly satisfied  Satisfied   
Very satisfied  Not applicable

### 10 Health

How long did you have to wait for a health assessment? (Please tick one only)

Less than a month  1-2 months  2-3 months  4-6 months   
6-12 months  Over 12 months  Not applicable

11 How satisfied were you with the outcome of the assessment including waiting times?

Not at all satisfied  Fairly satisfied  Satisfied   
Very satisfied  Not applicable

### 12 Social Worker

How long did you have to wait to have a Social Work assessment of your child's needs? (Please tick one only)

Less than a month  1-2 months  2-3 months  4-6 months   
6-12 months  Over 12 months  Not applicable

13 How satisfied were you with the outcome of the assessment including waiting times?

Not at all satisfied  Fairly satisfied  Satisfied   
Very satisfied  Not applicable

14 How long did you have to wait to have a Social Work assessment of your own needs? (Please tick one only)

Less than a month  1-2 months  2-3 months  4-6 months   
6-12 months  Over 12 months  Not applicable

15 How satisfied were you with the outcome of the assessment including waiting times?

Not at all satisfied  Fairly satisfied  Satisfied   
Very satisfied  Not applicable

**16 Carer Assessment**

How long did you have to wait to have a Carers assessment? (Please tick one only)

Less than a month  1-2 months  2-3 months  4-6 months   
6-12 months  Over 12 months  Not aware I was entitled

17 How satisfied were you with the outcome of the assessment including waiting times?

Not at all satisfied  Fairly satisfied  Satisfied   
Very satisfied  Not applicable

**18 Education**

How long did you have to wait to have an Educational assessment of your child's needs? (Please tick one only)

Less than a month  1-2 months  2-3 months  4-6 months   
6-12 months  Over 12 months  Not applicable

19 How satisfied were you with the outcome of the assessment including waiting times?

Not at all satisfied  Fairly satisfied  Satisfied   
Very satisfied  Not applicable

**20 CAMHS**

How long did you have to wait for a CAMHS assessment? (Please tick one only)

Less than a month  1-2 months  2-3 months  4-6 months   
6-12 months  Over 12 months  Not applicable

21 How satisfied were you with the outcome of the assessment including waiting times?

Not at all satisfied  Fairly satisfied  Satisfied   
Very satisfied  Not applicable

**22 Specialist Services**

Do you use any of the following specialist services? YES  NO   
(Please tick all that apply)  
opticians  dentists  play therapist  social worker   
other

please state \_\_\_\_\_

23 How satisfied were you with these specialist services including waiting times?

Not at all satisfied  Fairly satisfied  Satisfied   
Very satisfied  Not applicable

**GENERAL**

24 Do you receive an individual budget for this child YES  NO   
Which service(s) do you use it for and what difference this makes to you and your child?

25 Please tell us about any issues (positive or negative) around health care eg GP; hospital; dentist; optician; because of your child's condition

26 Please state which service you most value and why?

27 Please state which service you least value and why?

28 Are there any additional services you would like to receive?

29 Please tell us anything else, positive or negative, about your health and social care experiences and where it took place.

Completed forms should be forwarded to Healthwatch Lincolnshire, Unit 1, 1 - 2 North End, Swineshead, BOSTON PE20 3LR. Closing date is 30 NOVEMBER 2014.

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