

Healthwatch Lincolnshire

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| Statement regarding: | Children and Young Peoples Autism Services in Lincolnshire |
| In response to: | Family Experiences around access to assessment and diagnosis for Autism and Dyspraxia |
| Statement prepared: | 19 September 2018 |
| Statement circulation: For Action | Four Lincolnshire Clinical Commissioning Groups - Federated Mental Health, Learning Disabilities and Autism Spectrum Disorder Commissioning Team |
| For Information | Lincolnshire Health Scrutiny Committee; Lincolnshire Health and Wellbeing Board; United Lincolnshire Hospitals Trust (ULHT); Lincolnshire Community Health Services; Lincolnshire County Council Children's Services; NHSE; Healthwatch England and East Midlands |

Why is Healthwatch Lincolnshire bringing this to your attention?

Since our inception in 2013 Healthwatch Lincolnshire has been aware of inequalities in service provision for the people of Lincolnshire requiring assessment and diagnosis for some conditions. However at this current time we are experiencing an increase in concerns raised with us by families and professionals around the challenges and often distressing inability to access assessment and diagnosis of conditions within county specifically autism and dyspraxia. We recognise that services are not always commissioned or available in county and that patients may need to travel. However in this instance feedback is that access is also not available out of county meaning that patients, families and professionals are not getting the best outcome.

We are aware that CAMHS excludes the **diagnosis**/treatment of Autism Spectrum Disorder (ASD), Tourettes Syndrome, Dyslexia, Dyspraxia and other neurodevelopmental disorders of childhood, but does not clarify what is the appropriate pathway.

Also we note that LCHS states that currently the Occupational Therapy Service is not commissioned to see children who have a diagnosis of Developmental Co-Ordination Disorder (DCD, also known as Dyspraxia) **or to assess for this condition**, but does not clarify what is the appropriate pathway.

We are aware of the good work emerging around the services offered post assessment and diagnosis, however the concerns within the escalation paper are specific to the needs of families and patients needing assessment and diagnosis.

How does Healthwatch Lincolnshire feel this affects patients?

Healthwatch Lincolnshire is concerned that:

- Trusts are providing messages that clarify that they do not commission or provide assessment and diagnosis of the conditions mentioned however do not provide a clear pathway for families and professionals.
- Patients and families are receiving messages that it is not possible to receive an assessment and diagnosis within county.
- Patients and families are receiving messages that it is not possible to receive a referral for assessment and diagnosis *outside* of county.
- Families and professionals (GP's and Education) can find it difficult to provide the help and support needed because of the lack of knowledge of pathways to get a formal assessment and diagnosis.
- Families are strained, exhausted and frustrated at the complex routes and lack of access, thus creating stresses with their caring role.
- Patients at the centre are not receiving equity and equality of access or process in their young lives which could have long and far reaching consequences.

What we have been told:

These are just some of the examples of what we have heard.

"We see a paediatrician but have been told that they cannot do the diagnosis and no-one in Lincolnshire has been commissioned to do this".

"We have been told that it is the function of the Occupational Health/Therapist to carry out the dyspraxia assessment."

"There is no paediatric NHS OT in Lincolnshire, we've just had to pay for a private assessment. Best money we've ever spent though!"

"Our GP has tried everywhere to refer the child but to no avail. Even tried out of county but they will not take 'out of county'. How does a child get the diagnosis as it will help with the EHC plan and they cannot go forward with the EHC plan until the diagnosis has been given?"

"The Care Quality Commission have signposted us to you (Healthwatch) to raise the concerns."

What actions are in place to improve the situation?

We are aware that the autism strategy has been in place for a number of years, in which we as a Healthwatch contributed to patient and family voice. However the practical application of this strategy appears not to address the wider needs of local people which could and potentially will impact their whole lives if not addressed early and may also prevent equity and equality of access and use of, services including education.

As a Healthwatch we do recognise the positive work done in this area such as the developments around an autism passport, however without the ability to access assessment and diagnosis this will not be fully utilised.

We have also heard recently from LPFT who talked of the success in gaining the autism reasonable adjustments standard mark.

Next steps

Healthwatch Lincolnshire on behalf of Lincolnshire residents and professionals impacted by the inability to obtain assessment and diagnosis, are keen to escalate these concerns to the following bodies and ask specifically what the pathways are for children and families to get an assessment for autism and dyspraxia in a timely manner? And, what are the current challenges to this type of provision and what action is being taken in the best interest of our children?

- **Lincolnshire Health and Wellbeing Board and Lincolnshire Health Scrutiny Committee to ask for their support to investigate this matter in more depth.**
- **All 4 Lincolnshire Clinical Commissioning Groups, for response as to their actions in place to improve the situation via the Federated Mental Health, Learning Disabilities and Autism Spectrum Disorder Commissioning Team**
- **All other organisations listed for circulation in this report for information and where appropriate comment or escalation.**

This statement has been prepared on behalf of Healthwatch Lincolnshire Public Experience Committee by:

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