

The Lincolnshire Autistic Society [LAS] is aware of the urgent need to address autism related issues in County and raise them with the Lincolnshire Partnership Board, the Local Authority and the 4 CCGs who have ultimate responsibility to provide much needed services for autistic children and adults. This is already something which LAS has been doing for a number of years but as a result of our recent Networking Workshop it became clear from the attendees that our work in this area isn't well known by the support groups. The LAS are looking to give the support groups a greater say and an effective voice so that together we can make a difference for autistic people. As we have committee members who sit on the Lincolnshire Autism Partnership Board and many of the working groups associated with that Board, as well as working closely with the other decision making bodies the LAS are in a position to be an even stronger and more effective voice when we combine with the Lincolnshire support groups. Would you help us collect information on the important issues which concern families and people with autism so that we can raise these with the relevant authority?

We aware that two of the main areas of concern at present are:-

1. Education Health Care Plans
2. Children's diagnostic pathway.

We would be grateful if you could ask your members to provide you with information on both these issues outlining their experience, good or bad, with obtaining, or otherwise, either of these.

Please cover for each:-

- how they were made aware of the EHCP/Diagnostic Assessment process
- what information they received to start the process
- was it helpful/easy to understand
- how difficult was it to provide the evidence needed
- the length of time the process took
- how difficult it was to speak to the right person
- what obstacles faced them in the process
- how relevant the process was to their child
- how successful they were
- what feedback did they get from the professionals involved in the process if unsuccessful.

It would be helpful if parents were willing to include their names with this information. We would not need to add the name to the data but if asked for further evidence from the authorities then we have the names to back up the data. If you provide us with this information we would then be able to simply collate this under the relevant headings of EHCP or Children's Diagnostic Pathway and amalgamate it with the evidence from other support groups like yourselves. We will then be able to analyse this information, compare it with national statistics if relevant, and then make a formal report to the relevant body and ask them to provide a response. Once a response is received we would obviously share this with you.

All raw data collected will be held securely and anonymised for processing, and therefore, all processed data will be non-identifiable. We will hold all data that makes any persons identifiable, such as names, on a secure database which only members of the LAS committee will be able to view. This information will only be used for the LAS committee to be able to contact individuals should any data analysis suggest that it would be beneficial to do so, and will be deleted/destroyed once full processing of the data is complete. Updates of analysis will be provided through the Lincolnshire support groups. If identifiable data such as names is required for any other purposes, then you will be contacted, informed of the proposed use of the data and you will be asked for permission to process the data in a new way.

We would appreciate it if you could let us have this information by the end of March 2019.

We would like to do this with other issues as they arise but feel that in order to provide the right information to the relevant parties we need to pick one or two topics only at a time otherwise the process would become unmanageable and ineffective. However, please let us know of any other major issues of concern your groups may have so that we can begin to build a picture of the issues within Lincolnshire for autistic people.

If you would like us to come to one of your meetings to discuss this or talk to your members we would welcome the opportunity to do so. I shall look forward to hearing from you.

Yours sincerely  
Elizabeth Elvidge  
Chairman, Lincolnshire Autistic Society.