

Information submitted by Autism Suffolk for circulation with other materials for the meeting of the Great Yarmouth and Waveney Joint Health Scrutiny Committee on Friday July 15<sup>th</sup> 2016

## **Autism Suffolk:**

### **Our Service:**

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Autism Suffolk is part of the National Autistic Society. We support families who have a child with a confirmed diagnosis of an autism spectrum condition (e.g. autism or Asperger syndrome). For families with children between 2 and 14 years of age we offer:-

- An initial consultation and registration to our services from one of our specialist Family Support Workers;
- Comprehensive information;
- Ongoing telephone support;
- A National Autistic Society (NAS) programme for parents. (Family Seminars on Understanding Autism, Sensory issues and Managing Behaviour );
- Monthly parent and carer support sessions;
- Use of our well-stocked lending library for books and sensory equipment.
- A closed, confidential Facebook group which supports and advises its members providing a protected, supportive community of parents and carers who have a child diagnosed with autism.

We also support professionals. We frequently support family support practitioners from Parenting teams, the Early Help Teams and Integrated Care teams and professionals in education. We are currently partnered and funded by Suffolk County Council and private donations until March 2017.

Our service is currently delivered to the whole of Suffolk by 3 family support workers, one of whom is responsible for supporting families in the Waveney area, an administrator and 3 volunteers.

Reported compiled by Elizabeth Bethell, Autism Suffolk, 30<sup>th</sup> June 2016

**Information and figures relevant to the Great Yarmouth and Waveney CCG.**

1. We currently are Suffolk based and as a consequence support the area of Waveney.
2. We have 564 families registered with us, living within the Waveney area, 50% of which are in and around the area of Lowestoft,, the balance of the families are predominantly from Halesworth, Beccles, Bungay and Southwold.
3. We have one family support worker, Elizabeth Bethell who is responsible for supporting families in the Waveney area.
4. The number of families who are registering with our service increases weekly but we are supporting many more families who we cannot officially register who are seeking help prior to receiving a formal diagnosis.
5. It is not uncommon for families to be in the process of formal assessment for 2 years before receiving a formal diagnosis. The longer this takes, the longer the families are left unable to access specialist support or have the appropriate information with which to understand their child's needs and how to best help them. This delay has ramifications for the well-being of the child, the parents and carers, the siblings, relationships with extended family and friends and relationships with the child school regarding teachers, teaching assistants and peer relationships.
6. After diagnosis health professionals refer families to Autism Suffolk as part of a pathway that offers post diagnostic support. But as a service we are not funded by health, or social care or education.
7. The reality for many families is that, after a long period of assessment and eventual diagnosis, nothing actually changes. Many families having struggled for potentially years in the hope that they will have some answers, understanding and most of all, support and help for them as a family and their child at home and school. But, the reality is that there is little in the way of post diagnostic help and ongoing support through the varying developmental stages their child will go through and the challenges these present to an autistic child and their family.
8. Frequently school has been a significant challenge. The child post diagnosis is entitled to be referred to County Inclusive Resource in order for the school and/or child to receive additional specialist advice and support. But this needs the school to submit a referral that highlights the various strategies that have been implemented up until that point to address any particular needs and which now warrant more specialist advice and support. This in itself can take several terms as the diagnosis enables staff to address issues in a particular way, in light of the new information and then following a referral, which can only be made at three points in the year, if the child is accepted then some support may be given. This in itself can take over a year to be in place and given the increased demand on this service the individual support will become less and less frequent and more and more unlikely.

9. On a daily basis we are talking with parents, carers and professionals and know that the very existence of a service that is there to support can provide a way of families not feeling isolated, being able to manage more effectively and hopefully and improve well-being and build up resilience. There is a drive to provide early intervention, for short periods of support, whereby individuals and professionals work for short periods of time and then withdraw. The strength of our organization is that we can do this with particular families as and when they need that, but not all families are at the same stage or have the same degree of need at the same time. But the continuous presence of a specialist support service that a family can draw on, seek advice from, gain support from, contact via any means that is accessible to the individual, ie phone, email, Facebook and drop ins, as and when is needed provides, not just practical but a significant emotional and psychological support.

#### Questions and concerns Autism Suffolk would like to raise with the CCG

- a. The concern cannot only be with reducing the waiting times but with the whole process from initial concern to post diagnostic support. If the CCG achieves its goal to improve the diagnostic pathway and reduce waiting times, it is likely that it will be accelerating the arrival of increasing numbers of families into a situation where there is a lack of service provision.
- b. Currently the parents and carers of children who are diagnosed with an Autism Spectrum condition are referred to Autism Suffolk as part of their post diagnostic support. Does the CCG have any plans to support both practically and financially the future work of the Family Support Worker, within Autism Suffolk, for Waveney post March 2017 when the current contract to work in Waveney will come to an end?
- c. Autism Suffolk is interested in understanding along with GY &W- CCG, what are the current arrangements for early intervention.

