

East Sussex parents influence autism services with new report

The parent-led autism support group iContact has published a detailed report, *The East Sussex Autism Survey*, sharing the experiences of families of autistic children, available at www.icontactautism.org/news. Already the findings have led to positive collaboration between the parent-led group and East Sussex County Council to effect change.

The report presents responses from 100 parents of autistic children across the county. Key problems raised included:

- long waits for diagnosis, often of several years
- patchy provision in schools, with some very poor experiences
- little or no support in some of the greatest areas of need: social, emotional and general life skills.

The findings reflect poor experiences nationally, where 17% of autistic children have been suspended from school, only 15% of autistic adults in full-time paid employment and high rates of suicide. (All statistics fully sourced in the report.)

But there are signs of a sea change. There is growing visibility of autism in the media and the House of Commons runs an All Party Parliamentary Group on Autism. Today there is more scope than ever before for autistic children to grow up as confident adults able to play an active role in society.

The report sets out clear recommendations. In a spirit of collaboration, iContact shared an early draft with East Sussex County Council. Their response is included in the Appendix and includes information about plans for new initiatives and a commitment to work with families to continue to improve provision.

Quote from iContact

‘The report clearly shows anger among some parents whose experiences have been far from ideal,’ says iContact. ‘But there is now a growing sense of optimism and even excitement about what we can achieve. Some schools are already delivering excellent support for children and their parents. Others are doing their best but lack resources and training. We are heartened that County are keen to incorporate the experiences of children and parents in future decision making, and to provide schools with increased support.’

Quote from Councillor Ruth O’Keeffe MBE, MA in Ed (Open) MBPsS PGCE

The East Sussex Autism Survey is a very well researched and carefully presented piece of evidence showing the state and nature of provision in East Sussex as told from the perspective of some of the least acknowledged experts in this field, those living day to day with children and young people with an autism spectrum condition, with everything that this means for family life. The struggles, aspirations, trials, triumphs and tragedies of real families are all there to be used for good.

A flavour of quotes from parents in the report

I feel I wasn’t listened to for many years. My concerns dismissed and made to feel my son’s problems were "all in my head". Finally at age 9 (we’d been with the paediatric unit since he was 20 months old!!) and with a new consultant we’d never met before, we had a diagnosis.

Often professionals can be quite curt. We were told, after waiting over two years for diagnosis "XX" has autism, he will always have it, you will just have to cope with it, we're signing him off now".... and that was it.'

The class teacher knows even less than the Senco about high-functioning autism. The lack of understanding is beyond frustrating, my views are given little or no consideration, I feel talked at and dismissed.

He is sent home between 9.30 and 12 most days because of anxiety (making it difficult for me to remain in work)'.

School 1 left him in his own excrement for extended periods and left him hiding in a Wendy house repetitively stamping through break times.

We have seen the OT once last year for a 10-minute appointment – that's it. We were given four half-hour session of speech therapy after waiting two years to be seen because there is so many children and they're short staffed – that's all we are given.

The experience left me with the impression that despite the "every child matters" slogan, in reality some children matter more than others.

[ENDS]

Notes for editors

1. Autism is a developmental condition thought to affect more than 1% of children in the UK. Autistic children can present with challenging behaviour, sleeplessness and high levels of anxiety and distress. These difficulties can be successfully overcome or managed through tailored strategies but there is often little awareness of these techniques or commitment to the resources needed to put them in place.
2. Autism is an invisible disability, which means that it may not be clear that someone has it. In children, this leads to much misunderstanding as their expressions of high anxiety or fear are often interpreted as 'naughtiness'.
3. iContact has developed positive working relationships with statutory partners and is working on a range of new projects – sign up for updates at www.icontactautism.org

About iContact

iContact is a Lewes-based parent-led group working with families and services to bring about change across East Sussex. Formerly part of Families for Autism, the organisation relaunched in October 2016 to refocus on engaging with statutory services to improve provision.

Its core activities are:

- supporting people with autism and their loved ones in Lewes and the surrounding areas
- campaigning, working with education providers and statutory services to ensure that parent voices, and those of their children, are at the heart of the decision-making process. We promote a culture of inclusion throughout the community.
- celebrating the unique qualities and strengths of each and every individual with autism and empowering people on the spectrum to reach their potential in everything they do.

For more information email us at info@icontactautism.org. Find out more, including meeting times, at www.icontactautism.org or follow us on Twitter @[@icontact-autism](https://twitter.com/icontact-autism)