

Reading Families' Forum

A voice for families of children and young people with special educational needs and/or disabilities

COFFEE MORNING 3rd March 2022 VIA Zoom

Nina Crispin, Information & Engagement Officer, and Katie Badger, Trainee Public Health Programme Officer, from Reading Borough Council, joined 7 parent carers at our coffee morning to gather families' views about what the new Reading all age Autism Strategy should include.

Diagnosis

It was agreed that there was a long wait for an autism assessment. A lot of effort goes into getting a diagnosis but you then still have to fight for services. What comes afterwards is key.

The Clinical Commissioning Group have been funding Autism Berkshire to run the Autism and ADHD service since January 2020 alongside Parenting Special Children. This provides support before and after diagnosis.

<https://www.autismberkshire.org.uk/berkshire-west-autism-adhd-support-service/>

They offer a helpline 01189 594 594, early bird sessions for primary school children, social skills groups for older children and young people and benefit advice.

Some parents' children had the support of nursery and/or school in recognising their child's needs and seeking support. Addington School have been brilliant as was the Dingley Child Development Centre.

Education

One child had to wait 18 months to get a special school and was only able to attend just 2/3 hours per day in mainstream while waiting. There needs to be more special school places. The Oak Tree has been delayed but is now being built.

It is hard to get an EP assessment of a child with schools saying that their child is not one of the neediest to get an assessment. (Schools have to pay for EP assessments.)

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Parent carers would like the process simpler. If mainstream can't meet needs a child gets a resource unit place, or a special school place if they need more than a resource unit. It shouldn't be a battle.

Reading Information Advice and Support Service for SEND is available <https://www.readingiass.org> for support.

Health

It took one parent 2 years to get an appointment for this child with an Occupational Therapist.

Autism Berkshire and Reading Families' Forum have seen an increase in mental health difficulties for autistic children and young people.

The Community Mental Health Team (CMHT) have refused to see someone because he is autistic, despite being seen in a neighbouring Local Authority in the past and being prescribed drugs for his mental health. The GP is unable to prescribe so the CMHT are prescribing since the person moved to Reading, but not seeing the person. This means that the person can't ask questions about his medication and is reluctant to take them, therefore. A number of other young autistic adults have had difficulty getting mental health support.

In Oxfordshire there are mental health supports if you are an autistic adult, pushed for by the Oxon Autism Partnership Board. This is a huge gap in services in Reading.

The Crisis Response Team (Crisis Resolution and Home Treatment Team) has refused to see an autistic adult, unless the person is suicidal, asking the person if they are feeling this way. This is again a huge gap in services for autistic adults and children, who have the same experience.

Parent carers advised that many health staff, including dentists, GPs and children's ward staff, lack understanding of autism.

A parent carer whose autistic daughter and herself had been subject to domestic violence has struggled to get support for her autistic daughter's mental wellbeing.

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The child has difficulty eating and sleeping and will fall. The parent carer has acted to protect them both by moving to a refuge and then locally. She has talked to the school about her daughter's experiences and the impact of boys' behaviour at school but the school has taken little action. She has also asked the GP who has not recommended any action. PACT can't offer support till September. Jane Stanford - Beale gave the details of Berkshire Women's Aid and Ramona Bridgman will find out what other supports are available.

Activities

Families would like more activities that are accessible to autistic children. Autism Berkshire have sessions at the Thames Valley Adventure Playground and will also be using Prospect Park when the new centre opens next month. Camp Mohawk, Reading Museum and the Museum of English Rural Life have accessible sessions: <https://merl.reading.ac.uk>

Families would also like more support for autistic adults where they can meet others who are autistic and intelligent, such as a daily drop in. Activities such as swimming, bowling, pub visits would be welcome.

Make Sense Theatre is great but some children need daily support in the holidays. Parents are happy to contribute.

Autism Board

The Reading Families' Forum attend on behalf of parents of children and young people up to 25 years but there are no representatives for parent carers of older autistic people. This needs to be addressed. Nina to feed back to Autism Board.

Next Steps

Nina and Katie will return to another coffee morning to hear feedback on the draft Autism Strategy when written. The strategy needs to include who will be held accountable for various actions and how will it be funded.

RB 09/03/21

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