

# Reading Families' Forum

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

## **COFFEE AFTERNOON 25<sup>th</sup> May 2022 via Zoom**

Nina Crispin, Information & Engagement Officer, and Amanda Nyeke, Public Health and Wellbeing Manager, from Reading Borough Council, joined us.

Two parent carers and Autism Berkshire attended to discuss the draft Reading all age Autism Strategy priorities and suggested actions. 4 other parent carers emailed their views and a 7<sup>th</sup> had to leave due to internet connection issues.

### **Vision Statements**

Agreed all draft statements are good.

One parent said "For all autistic people in Reading to feel supported, included, integrated and to be enabled to live their best and healthiest lives through awareness and support across the life course" was most important and another felt that "An understanding and supportive society to empower autistic children, young people and adults to live fulfilling lives" was the most important to her.

Autism Berkshire suggested a vision statement for each priority.

### **Priorities**

Agreed all the priorities are appropriate. Agreed that there should be a way to measure the progress with the priorities, otherwise it is difficult to see if progress is being made.

Autism Berks felt that 4 and 5 could be combined. This depends on the evidence of whether autistic people are ending up in inpatient care due to health and care inequalities or poor housing and support for independent living or both. RFF know young people in mental health beds who have not had sufficient access to mental health support previously. Autism Berkshire have seen this due to poor support with independent living.

One parent felt that priorities 1 and 2 were most important. Another felt that 4 was the most urgent – the wait for a diagnosis is years. (The Autism and ADHD team has had more funding but there has been an increase in referrals recently.)

A third parent said that the priorities were in line with what had been discussed before. Short term, the parent's priorities were 2,3,1 and 6. Longer term, the parent's priorities were 4, 7, 5 and 8.

Two other parents emailed to say that they agreed with the priorities and for their son, the greatest priorities were 3,4,5 and 6 with the focus on the short term on 4 and 5.

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A sixth parent emailed to say that they agreed with all the priorities and that their main priorities were 3, 4, 5 and 6 with short term priorities being 5 and 6.

## Priority 1 Actions – Improving Awareness, Understanding and Acceptance of Autism

Autism Berks advised that improving transitions from education was vital.

One parent said that speech and language needed to be more accessible. Private therapies are very expensive and not always covered by health insurance. There are blocks to getting support all the time; you get to the top of a waiting list then are told that your child doesn't need the support.

Transport is vital to ensure that autistic people can access social experiences. Transport needs to be inclusive and accepting.

One parent said that there was little communication with the Autism and ADHD team (formally part of CAMHS). Parents have to chase for updates. During Covid, another parent received electronic information but, when you followed one link and then another, it was easy to get lost. The family knew about Parenting Special Children but not Autism Berks. It has helped parents if the Autism and ADHD team make the referrals – it helped when they asked the Autism Advisor Jenna to contact the family.

**Autism Berks is funded by the NHS for pre and post diagnosis support. This includes Early Years specialists, courses, activities and help applying for benefits. They will tell the Autism and ADHD team again that they need to seek parents' permission so that they can contact families.**

[Introducing the Berkshire West Autism & ADHD Support Service - Autism Berkshire](#)

One family had a 2 year wait for their child to be diagnosed with autism and had to pay for speech and language therapy privately. Their child was denied an Education, Health and Care Plan after diagnosis. Their child was not talking at 3 years old. They were referred and given advice but there were not enough staff to show the child's parents or visit them at home and there was no response to emails.

Parents said that when they are new and worried parents, action is really important.

## Priority 2 actions -Improving Support and Access to Early Years, Education, Supporting Positive Transition and Preparing for Adulthood.

Some schools can be really helpful but you ask for support, but you have to ask. There has been a lot of staff absence due to Covid which has made things more difficult. A lot depends on the SENCo.

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Some parents have also had to go to their GP several times to get support.

Schools should know about Autism Berkshire's support above.

**Priority 3 – Increasing Employment etc not relevant to those at meeting.**

**Priority 4 Better Lives for Autistic People – Tackling Health and Care Inequalities**

Vaccinations are really difficult – it is hard to get reasonable adjustments such as a quiet space for Covid vaccinations.

Reasonable adjustments are also important for other health appointments. Parents can feel that they are drowning in all the appointments and services they have to find out about and navigate.

Two parents emailed that the strategy should state clearly that access to services should be based on need. For example, mental health support is available at the Community Team for People with Learning Disabilities if an adult has a learning disability and are autistic but not otherwise. The meeting also heard that autistic children without a learning disability are seen at CAMHS but there is no mental health support for children with a learning disability.

**Priority 5 Actions – Building the Right Support in the Community and Supporting People in In-Patient Care**

Zero tolerance for bullying is vital.

Knowing about inclusive activities is also really important such as inclusive swimming sessions. (One parent only found this out at a library group for young children.) See below for details.

**Priority 6 and 7 – Independent Living and Youth Justice not relevant to those at meeting**

**Priority 8 Actions – Supporting Families and Carers of Autistic People**

For some families it is early days and they are still finding out about what is available. Link to Local Offer with lots of information below.

It would be helpful to know about opportunities to meet other parent carers and their children. RFF recommend:

Fifi's Vision [Fifi's Vision, SEND Parents Support Group | Reading Services Guide](#)

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Camp Mohawk [Home](#) | [Camp Mohawk](#)

Autism Berkshire – link above

Museums My Way [Museums, My Way](#) | [Reading Museum](#)

## Other Support Available

Autistic children often have slower processing speed even if they have no other learning difficulties, and can be entitled to extra time in exams, including Year 6 SATS. They can also do their exams in a separate room so that they can make use of their extra time.

Autistic young people are entitled to a Disabled Students Allowance at University.

The Local Offer has lots of information about services for autistic children and young people and their families. The Reading Services Guide covers support for autistic adults and their carers 25 years +

[Reading Services Guide](#)



SEND Local Offer

✉ [localoffer@reading.gov.uk](mailto:localoffer@reading.gov.uk)

📘 [www.facebook.com/readinglocaloffer](https://www.facebook.com/readinglocaloffer)

☎ 0118 937 3777 OPTION 2

Brighter Futures for Children

Reading SEND LOCAL OFFER

The Local Offer includes a list of activities for children with special educational needs and disabilities (known as short breaks). These include activities with workers who specialise in working with children with additional needs such as Autism Berkshire, Make Sense Theatre, Chance to Dance and Multisport at RFC Community Trust

[SEND Short Breaks](#) | [Reading Services Guide](#)

**Any other feedback** – please email Fran Morgan [fran.morgan.rff@gmail.com](mailto:fran.morgan.rff@gmail.com)

Next Coffee Morning to be confirmed.

RB 5<sup>th</sup> June 22