

Reading Families' Forum

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

COFFEE AFTERNOON 18th May 2023 via Zoom

Health Care and Delivering Better Value programme that Brighter Futures for Children are applying for.

Miranda Walcott, Designated Clinical Officer for Special Educational Needs and Disabilities for the BOB Integrated Care Board (ICB) attended our online session. Fran Morgan and Ramona Bridgman from Reading Families' Forum also attended with seven other parent carers.

The BOB ICB covers the Buckinghamshire, Oxfordshire and Berkshire West (Reading, West Berkshire and Wokingham). It commissions health care and has 2 providers in Reading – the Berkshire Health Foundation Trust that provides CAMHS, therapies such as physio and assessments for ADHD and autism, and the Royal Berkshire Hospital.

The ICB has commissioned a new Keyworking Team which provides support to young people who are autistic and/or have a learning disability, if they are at risk of being admitted to a mental health unit. They have a Dynamic Support Register (DSR) of young people at risk in this way.

The ICB is new and takes over from the Clinical Commissioning Group or CCG. The ICB has a number of priorities such as ensuring therapists such as physio and Occupational Therapists, attend panels to decide if a child needs an Education, Health and Care Plan. They are also making training in special educational needs and disabilities a priority and promoting annual health checks for young people aged 14+ with a learning disability. If your young person has a learning disability, they are entitled to a health check with their GP every year. Ask your GP surgery to put your young person on their Learning Disability Register and your young person will be invited to these checks.

A new CAMHS service for children with a learning disability 0 – 18 years is being set up, hopefully by the end of the year.

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Feedback from parent carers:

- There are very few college places for young people with complex physical and health needs. Miranda said that they are looking at how they can train college staff, but the college place is usually funded by the Local Authority.
- Miranda is also clarifying how Continuing Health Care and the Local Authority should work together when a young person transitions to adulthood.
- Referrals from the children's to adult ADHD team aren't always clear.
- It is difficult to get support when an autistic child is showing difficult behaviours. Family Support Workers have not always been helpful, especially if they have not observed the behaviour. Parenting Special Children and Autism Berkshire are funded by the ICB to provide support to families including with managing difficult or distressed behaviours. [Introducing the Berkshire West Autism & ADHD Support Service - Autism Berkshire](#). Newbold Hope, run by a parent carer, is a national organisation supporting families whose children have difficult or dangerous behaviours. [Home - Newbold Hope](#) A GP or school nurse can also refer a child to CAMHS for psychological support.
- Some families had been told by CAMHS that they couldn't offer trauma or psychological support to autistic children. Miranda advised that a review of CAMHS therapies is being undertaken.
- One young person had been very aggressive and this led to them being cared for outside the home. The family had lots of different Social Workers and the young person had not been referred to the Keyworking Team. Miranda will contact them.
- A school had said there was no money to get an Educational Psychologist to assess a child until the Children's Action Team had got involved. If schools meet the needs of young people who are autistic or neurodiverse, all children benefit.

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- It was noted that there was a long wait for autism assessments. Families that can afford to, can go private and get the autism team to endorse the assessment. However, this is not possible for families on lower incomes.
- Another family had frequent changes of Social Worker (3 in one month) and found some unhelpful e.g. using sarcasm/humour with a traumatised autistic child. Several families had been referred to Triple P parenting which doesn't work for autistic children.
- Families noted a very long wait (7 years) for an autism assessment for adults. When a child is diagnosed as autistic, it can lead to parents realising that they may be autistic too. AutAngel in Reading can support adults who are diagnosed as autistic or think they might be autistic.
- Being a parent carer and balancing work and home life is hard. It can be exhausting to manage your child(ren)'s additional needs. It is also difficult to find an understanding employer and the cost of living makes harder to work reduced hours.

Rani Mehta for Newton Europe joined the coffee afternoon. Newton Europe are helping Brighter Futures for Children to apply for the national Delivering Better Value programme. If they are successful, they will get £1 million to improve special educational provision in Reading.

The parent carer survey revealed some themes and Rani wanted to ask parent carers about the survey findings. Parent carers on the call filled in an online poll. Rani will send out the questions for those not able to access the poll.

Families said:

- Some children had been out of school for 3 years. Support needs to be put in to special school children experiencing this as well as mainstream children. Some special school children are getting as little as 2 x 45 min sessions per week.
- There needs to be more provision for young people post 16 e.g. when refused school because of an incident(s). There is little to reengage young people.

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There is also insufficient college provision for young people with complex physical and medical needs aged 19 plus after special school

- Additional support put in place at school needs to be reflected in support during tests and exams to make them accessible.
- Teachers need training in meeting additional needs in the classroom including when there are 30 in a class with several different additional needs in the class. They need to understand stimming and masking.
- Schools need more than a notional £6,000 to meet children's needs without an EHCP.

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