

# Reading Families' Forum

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

## **COFFEE AFTERNOON 14th July 2022 via Zoom**

Nicola Norris, Interim Disability Lead; Mark Hobson, Short Breaks Coordinator; Samantha Whitehouse, Cressingham Manager and Helena Baptista the Registered Home Manager of Pineroft Children's Home joined 7 parent carers. All work for Brighter Futures for Children.

Ramona Bridgman, RFF Chair, Pauline Hamilton, RFF Trustee, Fran Morgan, Participation Coordinator and Autism Berkshire also attended..

We agreed that Nicola and her team would talk about their services and then parent carers could ask questions.

Nicola manages Cressingham, Pineroft and Children and Young People's Disability Team (CYPDT). She advised the CYPDT has a new team manager Albina Brahilika. Caroline Bright is the Assistant Team Manager. Referrals to CYPDT are made through the Children's Single Point of Access (CSPOA) Tel: 0118 937 3641 (Office hours only) or email [cspoa@brighterfuturesforchildren.org](mailto:cspoa@brighterfuturesforchildren.org)

CYPDT has 2 short breaks workers managed by a Consultant Social Worker. There are also 4 Occupational Therapists managed by Tracy Allen. The OTs can assess a child for aids and adaptations in the home. Families can refer their child through CSPOA above. You don't have to have a Social Worker to have an Occupational Therapy Assessment. Helpfully, since the pandemic, Occupational Therapists can help families with behaviour management and sensory assessments.

From April 22, Pineroft has become a Shared Care service supporting a maximum of 12 families. Young people are aged 8 to 18, they will spend 3 nights at Pineroft in groups of 4 and will go home for 8 overnights. Pineroft are currently in Phase 1 where 7 children have already transitioned in and we have a further 3 referrals. Referrals are made through the Short Break Resource Panel. Young people will need to have a learning disability, physical disability and/or sensory impairment. Our children have very complex needs hence why parents need more support than the support offered in Cressingham.

Mark has been working hard with the team to set up short breaks for children such as Make Sense Theatre, Reading Football Community Trust, Reading Play and Chance to Dance. They try to listen to feedback from families. The Lego Club was set up as not all children like sport or performance.

Cressingham host the Lego Club with a kind donation from Autism Berkshire of lots of Lego! The club is now full. Parents understood that criteria had to be set to ensure public money was well spent, but questioned using DLA as a requirement to access the Lego Club – many families find the DLA form too distressing to complete as you have to list everything your child can't do. Others find

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it difficult to complete as English is not their first language. Some parents have had to go to tribunal to successfully challenge a decision not to award their child with DLA.

Parents felt that requiring DLA favours children whose parents are resilient and speak English well. A parent said that the Equality Act requires reasonable adjustments to ensure that disabled children can access services. Jane advised that Autism Berkshire can help with applying for DLA. The NHS funds them to provide support to families of children on the waiting list for an assessment and/or already diagnosed.

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

A parent said that CAMHS had refused to assess their child for autism and had referred the family to Early Help who were not qualified to assess if their child had autism. CAMHS did send them a link to a YouTube video and common Questions and Answers but this wasn't helpful. The family had to pay for a private assessment and are now in debt.

### **Other feedback from families about children's social care:**

Some parents had an assessment through CSPOA but the Social Worker didn't understand disability. Nicola said that CSPOA didn't do assessments. This would be one of the other teams like the Assessment and Action teams. One parent had not been referred to CSPOA to assess their child's needs when the Education, Health and Care Assessment took place. This delayed the child getting support for 3 years. Nicola said this was an area that her team were working on.

A parent said in the comments section that service providers try to wear parent carers down. Nicola advised that she did not feel comfortable with this. Parents said that they were sorry she felt uncomfortable. They don't blame Nicola, just want her to hear the difficulties that they have faced. Parents experience lots of gaps in services for their children and find professionals can blame parents for being too demanding. The experience can be traumatising for parents. Sometimes a trauma informed response is needed. Parents would welcome collaboration and empowerment.

Agreed that we want to work together to address problems parents have had, although not all this is within Nicola's remit. Multi-agency working addressing children's needs is helpful. Parents want to have a positive relationship with their children and enjoy family life rather than have to invest time and energy getting the services their children need.

A parent suggested that children's social care send their policies and operating procedures to the Families' Forum so that families can understand what to expect.

Ramona explained that a number of parents had contacted the Forum about issues with what happens when families go to Tribunal over a decision regarding an Education, Health and Care

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Plans. The Families' Forum has raised this with Brian Grady, the new Director of Education and interim Children's Director. Nicola would like to be involved so Ramona will send her a copy of the email.

Some parents have found it difficult to work out what short breaks are available for younger children eg less than 8 years with one to one support. Make Sense Theatre offer children with complex needs aged 5 – 9 with complex needs. Reading Football Community Trust are also doing some play sessions for 5 – 8 year olds at the Avenue School [Book Reading FC Football Courses & Soccer School Sessions \(officialsoccerschools.co.uk\)](http://officialsoccerschools.co.uk) Mark kindly agreed to contact the parent direct.

Some parents expressed distress and frustration. One parent had been waiting for 3 years for an Occupational Therapy assessment. Their non-verbal child runs off putting the child in danger. The Social Worker referred the parent to a Family Worker who has since closed the case, although the parent is still struggling to manage their child.

Another parent said that they were struggling to cope with their autistic child's behaviour. The parent has physical and mental health difficulties herself. Her child isn't sleeping either. She has contacted social services but had not got help.

### **Agreed Actions:**

Nicola kindly agreed to contact both the above parents direct.

Mark will contact the parent needing advice about short breaks for a 5 year old.

Ramona will send Nicola a copy of the email to Brian Grady

Ramona and Nicola will consider how best to address parents' concerns and who with. Several families said they would be happy to work with us.

RB 26<sup>th</sup> July 22