



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

COFFEE EVENING 17th December 2019

Children with Special Educational Needs and/or Disabilities (SEND) and social care

Claire Lewis (Service Manager for the Children and Young People's Disability Team plus 2 Family Intervention Teams in Brighter Futures for Children) joined 16 parent carers to discuss children's social care in Reading.

From 2nd Jan, Claire will manage a **new Children and Young People with Disability Service (0- 18 yrs) in BFFC**. This will include CYPDT, Cressingham and Pincroft and short breaks commissioners. This will mean that all the services that support children with SEND are in one place and there can be more co-production with families. Claire also sits on the Transition to Adult Social Care panel and the SEND panel which decides whether to approve Education, Health and Care Plans.

EHCPs

Claire advised the SEND panel turns down EHCPs if there is a lack of evidence. Reports to panel need to be well written.

One family's child who has been diagnosed with autism has only made progress with a high level of support by the family which is unlikely to be replicated when the child attends school. However, they are struggling to get an assessment for an EHCP. Another family were told by the school that their child did not qualify for an EHCP because the child wasn't aggressive, even though the child was diagnosed at 2 and isn't meeting milestones. A third family's child has been diagnosed with autism although the school had previously doubted this. There can be little communication between parents and school.

Despite the difficulties getting the SEN team to agree to assess for an EHCP, schools have told some parents that they need to apply for an EHCP so that their child gets the support it needs. Many parents felt caught between schools and the SEN team.

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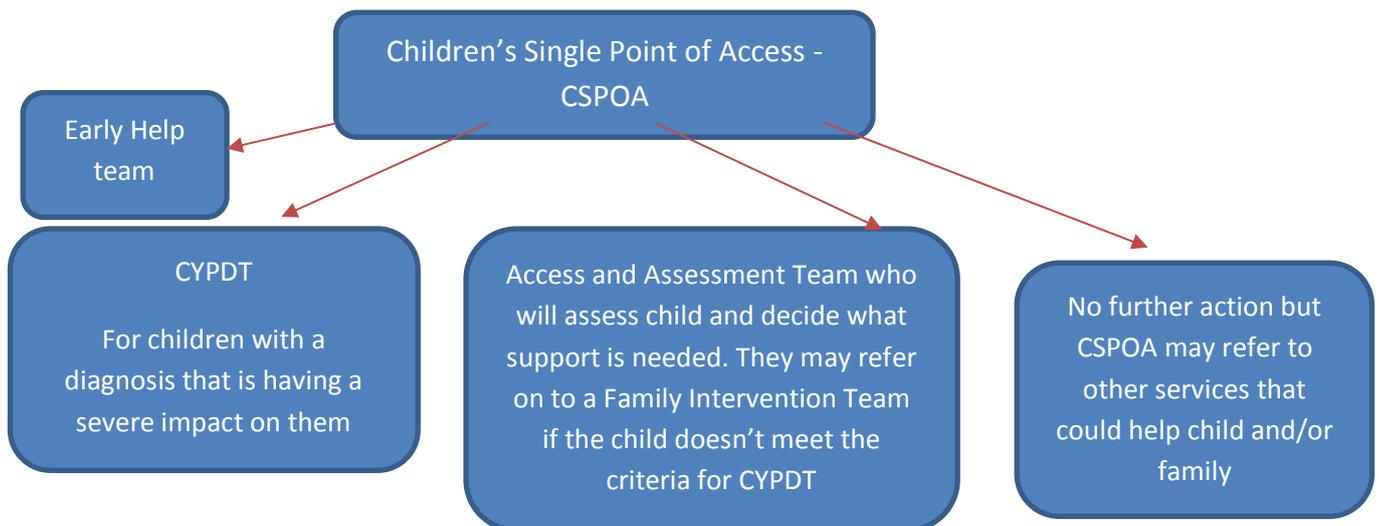
A fourth family's child had an EHCP, but the school did not provide the support in the EHCP and the child is now at special school. RFF will invite the SEN Team Manager to a coffee evening to discuss the above challenges.

Accessing short breaks and support to take children with SEND out to activities

Some parents were not sure how to access short breaks, although their children had been diagnosed by CAMHs and/or their child had an EHCP.

Some short breaks clubs can be accessed directly without contacting Brighter Futures (BFFC). Parents advised that there was nowhere in Reading to take children with disabilities – Swings and Smiles in West Berks is getting very full.

The short breaks team commission services such as Thumbs Up Club and Mencap Saturday Club. Family or professionals can also contact BFFC for support, including direct payments. The route is as follows



All children with a disability qualify for an assessment for support under Section 17 of the Children Act 1989.

Parents agreed that the system for getting support was complicated and confusing; some just haven't been told what is available. One parent

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phoned and spoke to a SW, when the parent phoned again, they had no record of who she spoke to and this happened again. That parent tried for 10 years to find out who their child's SW was and eventually gave up.

It is hard to find out all the information yourself if you are also caring for a disabled child/child.

One parent said that they struggled to take their 2 disabled children out and has had little information about what support is available. Other parents echoed this frustration. The school referred to family to BFFC who allocated them to the Early Help team. The Family Support Worker visited the children and took the non-disabled child to the park once. This can sometimes be helpful, but this family wanted help to take their disabled children out to activities. The FSW did not appear to have training about autism. The FSW referred the family on to Home Start that the children were not the right age for; it would have been helpful if the family were referred to CYPDT for an assessment as they meet the criteria. Claire recommended this family ask the school to help them refer the family to CSPOA again making it clear that they wanted a referral to CYPDT.

Another family contacted CSPOA but were told they didn't qualify for support as their child was in mainstream. Claire was clear that a child doesn't need to attend a special school or have an ECHP to qualify as a child in need under Section 17 of the Children Act 1989

Claire agreed that training and support was needed for CSPOA staff.

Children and Young People's Disability Team (CYPDT)

Claire is keen that packages of support are reviewed as children's needs may change. 2 families at the meeting had been contacted by a SW asking to see their child that week; it would be preferred if more notice was given ideally at the previous visit.

Some SWs are good in CYPDT. Some families not present had advised the Forum that they had many changes of SW, so it has taken time to get the right support in place. Others have found SWs more difficult to get hold of than the Family Support Workers that they used to have. Claire advised

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that she is replacing agency staff with permanent staff. Another permanent SW is due to start at the beginning of January.

CYPDT have 167 children open to them plus more open just to the Occupational Therapist. SWs have between 26 – 28 cases although some can include families just needing Direct Payments.

The criteria for CYPDT is that a child has a diagnosis and is severely affected by their disability. Claire advised that she is looking at updating this and will co-produce this with families.

Autism

One family advised that their child was newly diagnosed and was very worried about a lack of support. The family are having to fight hard to get an EHCP assessment and for a Carers' Assessment. There is also only one autism advisor for the whole of Reading.

The Clinical Commissioning Group (CCG) fund Parenting Special Children and Autism Berkshire to support families while waiting for a diagnosis and afterwards.

Claire advised that the govt are requiring that employers must ensure that all health and care staff receive learning disability and autism training appropriate to their role by Dec 2022. Brighter Futures want to ensure Social Workers have training in this area.

Carers' Assessments

The new agreed procedure is that parent carers should approach the Carers' Hub who will undertake a Carers' Assessment. They will then refer to CSPOA above if needed. BFFC have started paying them to do this and the information about this is will Adult Social Care to agree the final wording. Most families – except Forum trustees – were unaware of this and it is not on the Local Offer, Carer's Hub website or newsletter or BFFC website. SWs have been informed by email several weeks ago. One SW told a family that they had been holding on to their carers' assessment application waiting for information about the new procedure. Another family had been told in August by the Carers' Hub that they weren't doing carers' assessments, so the parent had not had an assessment. A parent

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queried the Carers' Hub's Capacity as they appear to be losing 2 members of staff.

Another family had struggled to get support and advice from CSPOA following abuse to their child.

ACTIONS

1. Forum will send copy of the coffee evening write up to Steve Devlin, SEN team manager and invite him to our next coffee evening.
2. Forum will also feed back to CAMHS and SEN team about the need to inform families about short breaks and social care.
3. Claire to feed back to SWs the need for advanced notice of visits.
4. Brighter Futures is setting up training in autism for Social Workers and Claire will look at training and support for CSPOA
5. Claire will be looking at criteria for referral to CYPDT and co-produce this with families

RB 06/01/2020.

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