

The logo for Reading Families' Forum is a blue oval with the text "Reading Families' Forum" in white, stacked vertically.

Reading Families' Forum

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

CHAIR'S REPORT FOR THE AGM

SEPTEMBER 2019

INTRODUCTION

The Reading Families' Forum has been a charity since April 2016, building on our work to promote co-production between families with children with Special Educational Needs and/or Disability (SEND) and service providers for the last 16 years. (Co-production means developing services together.)

We have a membership of 216 parent carers and 547 people follow us on Facebook!

MANAGEMENT

At the last AGM in September 2019 the following trustees were voted in:

- Lynsey McDonald – secretary
- Alice Carter – treasurer
- Pauline Hamilton & Alison Ries – trustees and our longest serving forum members
- Ramona Bridgman, Chair.

We have a number of parent carers who have provided invaluable support over the past year: Ruth Pearse, Beryl Thompson, Omera Waheed, Simona Maluwe and Liang – I Yang.

We have 2 employees and 1 paid contractor:

Our Parent Participation Co-ordinator, Fran Morgan, organises our events brilliantly, minutes our meetings and is a point of contact for families and service providers alike. She also arranges speakers for groups of parent carers at schools and children's centres.

Lisa Harry is our Youth Forum administrator and does a great job of organising events for Special United.



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Tara Robb is an excellent self-employed administrator and does all our bookkeeping.

REVIEW OF OUR WORK OCT 2019 – SEPT 2020

We have held 5 Coffee Evenings attended by at least 5 - 16 parent carers each:

1. Claire Lewis, Service Manager for the new Children's Disability Service attended to discuss the service, including Children in Need assessments, parent carer needs assessments and short breaks.
2. Marie Roeton came to inform parents about the Deputy's Office and Elfi Stalmans from Me2 updated parents on Me2's expansion into Reading.
3. Deb Hunter, Service Manager for SEND, and Steve Devlin, SEN Team Manager, joined us on zoom to discuss support for our children during the lockdown and the risk assessments done to help decide whether children could attend school.
4. Deb Hunter and Maryam Makki, Family Information Service Manager, attended to discuss support available for families during the pandemic and preparation for starting/returning to school in September.
5. Claire Lewis and Gabi Dawkins, the new Team Manager for Children and Young People's Disability Team, joined us to discuss short breaks and parent carer needs assessments.

We held our first Transition Information Day in November 2019 at the Avenue School with lots of information stalls, Owen's animals, face painting/fake tattoos and hair braiding. 32 young people and parent carers attended. We helped write the information booklet for parents on preparing their young people for adulthood published in November 2019.

An information and fun day was held in March 2020 at Academy Sport. 126 children and parent carers enjoyed numerous stalls, Owen's Animals, circus skills and face painting.

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Our planned conference on Transition has been postponed at least until the new year because of Covid.

We have also obtained parent carer views by attending Brookfields coffee mornings, seeking feedback on Facebook and holding a survey on what is working and not working and what changes parent carers wanted to see in preparation for the CQC inspection – this inspection will be after January 2021 due to Covid.

Support to parent carer groups Fran has arranged speakers to attend parent carer groups to assist them in aspects of caring for a child with additional needs. We have paid for Parenting Special Children to provide 5 sessions to 3 school groups since the last AGM.

Co-Producing Improvements for children/young adults with SEND The Forum sit on the SEND strategy board and the 6 work strands that are part of the board's work: communication strategy, early intervention through to specialist provision, consistent approaches to emotional well-being, preparing for adulthood, short breaks and preparing for the CQC inspection. We also regularly review the Local Offer.

The Forum co-chair Strand 2 which is looking at improving training for school staff in autism and managing challenging behaviour to reduce exclusions and minimise children's anxiety.

We sat on the new special school bid assessment meetings for the new special school, The Oak Tree School, is due to open in September 2022 at Winnersh Farm.

We were also part of:

- the interview panel for the new Director of Children's Services (Deborah Glassbrook) and the interview panel for the SEN assistant team managers (Adeana Robinson and Nadia Trueman)
- the post 16 data panel,
- the mental health support team board which has now finished as the MHSTs are up and running,

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- the commissioning panel for the support for children and young people who at risk of being NEET (not in education, employment or training).

We attend the SEND Joint Implementation Group with Health, Social Care and Education across the 3 LA areas: Wokingham, Reading and West Berkshire and lead on the equipment task and finish group.

The Forum has had meetings with the lead councillor for culture, heritage and recreation and the council parks and leisure team. A wheelchair accessible roundabout has been installed in Portman Road and there is some new accessible equipment at Palmer Park. We are assured that the new pool at Palmer will be accessible with a changing place and pool side hoist.

We have been involved in a Berkshire wide review of what is needed for those children/young people with autism and/or learning disabilities and behaviour that challenges. We know that it has been difficult for families to get support when their children are aggressive and/or self-harming.

The Forum has contributed to a review of the Transition team for 18 – 25 year olds in the Adult Social Care team and are awaiting the results and the draft accommodation strategy for adults.

We are about to re-join the Autism Strategy Board and are awaiting the first draft of the Autism Strategy.

Getting our young people's views heard

The Special United Youth Forum has met 7 times since the last AGM.

- In November, we discussed young people's views ready for the CQC inspection
- In January we met with Claire Lewis and Helena Baptiste to discuss short breaks
- In March we took part in a Reading University research on what it is like to grow up in Reading.
- In May, we heard about the Local Offer and discussed what activities young people wanted to see during lockdown

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- In June we talked with Steve Devlin about the impact of lockdown on education and the lockdown risk assessments
- In July, Deb Hunter joined us to discuss some artwork following the terrorist attack and activities over the summer
- In August, Gabi Dawkins joined us to talk about the CYPDT and how to access support.

All young people who attend received a £10 voucher, plus free food for the first 3 face to face meet ups! The other meet ups have taken place on Zoom.

PARENT CARER VIEWS ON SERVICES AND WHAT WE ARE DOING

There are many services that families value across health, education, the LA and the voluntary sector.

However, there is real frustration with families having to fight for services for their child and feeling left without support. Clear eligibility criteria applied consistently is vital. Gatekeeping by making services hard to access disadvantages those families with less resources and knowledge to fight for their children and puts families under unnecessary stress.

Families have told us in the last 12 months about continued difficulty getting short breaks – getting through the Children’s Single Point of Access and getting into CYPDT, and a lack of PAs to use direct payments on. Short break provision for those with more complex needs and those with personal care needs has reduced in recent months from the low level it was before Covid, leaving a huge gap and families under pressure

The Children’s Disability Service Manager is very aware of the above and has arranged for autism training for the other teams in Brighter Futures. They have appointed a SEND commissioner for 6 months with the hope of extending this long-term. The SEND commissioner’s role will be to organise short breaks provision. Someone has also been identified to co-produce the direct payment policy and recruit PAs. The other good news is that Me2 is now operating in all areas of Reading.

In response to concerns about a lack of communication, we have asked the SEN team to produce clearer information on the Local Offer about all

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of its policies and procedures to ensure that families and staff are clear about what they should reasonably expect.

Families tell us that we need more changing places in Reading and that processes for assessing and adapting school buildings needs sorting. A number of children with physical disabilities in Reading struggle to access mainstream early years and schools. We need clear policies in Reading about what must be provided by schools as part of the requirements of the Equality Act, and what goes beyond 'reasonable adjustments' and must be provided through SEND funding or a local access strategy. It is vital that education is accessible for physically disabled children within Reading.

Greater access to speech and language and occupational therapy for autistic children has been requested. This needs mapping – how many autistic children, including those without EHCPs, need this in Reading compared to what is available?

Emotional support for siblings – a plan needs to be identified to develop this; it has been a longstanding gap for siblings of disabled children, which RFF has raised repeatedly with RBC/BFFC.

There is concern about a lack of clear pathways for our young people as they approach adulthood and a lack of clear information about the options. Many young people feel that their views are not taken on board. This was to be the subject of our conference on transitions and we are raising this with adult social care.

Families report a difficulty getting equipment outside the home, the right wheelchair and some equipment in the home. We are liaising with the Senior OT in Reading and with the CCG regarding these issues.

There is lots that young people like about living in Reading but they have concerns that they are not listened to and describe a lot of bullying because of their additional needs.

Parent carers are concerned about a lack of understanding about autism in some schools and young people feeling anxious as their needs are not

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met sufficiently. There are also some concerns about mental health support in a crisis for our children and young people.

Training for mainstream teachers in SEND is being looked at within Strand 2. While it is great to have the mental health support teams up and running in many schools, we are also working with the CCG to improve mental health provision in a crisis.

During Covid – risk assessments were often not seen; some schools acknowledged that in the first weeks of lockdown they were short staffed and having to do a number of risk assessments quickly.

Respite for young people aged 18 – 25 during Covid has been more difficult. Loddon Court and Chiltern have opened but Whitley Wood is still closed.

Some of our young people have been very worried about going back to school and catching Covid, and some have been worried about missing education. Most have been bored and most have found it not easy to learn at home. Few parent carers have earned high marks!

The CCG have begun a survey into the need for hydrotherapy. Hydro has been invaluable for lots of our families and we encourage all to complete the survey. The consultation document and questionnaire can be found here: www.berkshirewestccg.nhs.uk/hydrotherapy

The survey closes on 2nd October.

FUTURE EVENTS

These are our proposed plans for the next 12 months if Covid allows:

- ✚ Information and Fun Day (all ages) March 20
- ✚ 5 Coffee Evenings
- ✚ 6 Special United Events
- ✚ A transition conference in June

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Questions and areas for discussion at the AGM

- Does anyone else wish to stand as a Trustee?
- Does anyone want to stand as a Chair – I enjoy the job and am very happy to continue but have been doing it for 7 years so will understand if anyone wants to take over!
- What should our 3 main focuses be over the next 12 months?
- What topics shall we cover in our coffee evenings?

Ramona Bridgman - Chair, Reading Families' Forum

28/08/2020