



READING FAMILIES' FORUM PARENT CARER SURVEY 2023 – 2024

Introduction

106 Reading parent carers completed our annual survey between 29th Sept 2023 and 18th Jan 2024. It was promoted through the Local Offer, closed Facebook groups and our members.

A wide range of families completed the survey.

Many families had positive support from services. The key themes were the importance of school in whether things were going well for the child or not, together with the importance of communication and coproduction with individual families.

Some children were receiving some good short breaks. However, many families were not either receiving any or not enough short breaks (primarily in the 3 – 5 and 8- 11 age groups).

Improvements were needed in terms of long waits for some health care services especially the Autism and ADHD assessments, CAMHS and wheelchair services.

Our Survey Reach

The children had a spread of ages from 0-2 to 18 – 25 years.

Parent who completed the survey had a broad range of racial origins, but we did not reach quite as many black and mixed origin families as we might expect:

- 18% Asian compared with 18% in the 2021 Census
- 6% Black cf 11% in the census
- 2% Mixed origins cf 5 %
- 1% Other cf 3%
- 71% White cf 67%
- 3% Chose not to disclose the information

Economic status: 43% of families were entitled to free school meals and 11% were not sure. The 2021 Census records Readings as having 17% of the population being in relative poverty; we know that families of disabled children have a higher proportion due to the impact of caring for a disabled child on employment. However, it is clear that we reached a range of families.

We asked parent carers what is going well for their child

11 said their children's needs were being met in school. Individual services were singled out including Make Sense Theatre, Dingley Child Development Centre and particular family support and youth workers, particular schools, individual PAs (Personal Assistant) and the Local Offer.

Sadly, 4 parents could not think of anything that was going well for their child.

We also asked what would improve things for their children

While some were individual to the family, there were several themes:

Communication

Families wanted professionals to talk to each other,

Families also wanted more meetings with the school and SENCOs and for Brighter Futures for Children to respond to calls and emails.

One Mum said what several families have: “I want to feel more relaxed and supported as a parent.” Another said, “I want schools to listen and acting on suggestions from family when a child is struggling.”

Health

Waiting times for autism and ADHD assessments was the biggest area of improvement families wanted in health care. They described the impact of struggling to manage their child’s behaviour and getting support without a diagnosis. One said that their child was not getting the correct meds and diagnosis from CAMHS, and this was having a significant impact on their child. Others talked about waiting for counselling, and tier 4 support. Another asked that CAMHS to allow trauma work.

While few mentioned dentists, waiting times for dentist was mentioned for the first time with the Reading Families’ Forum.

Better support in school

Several children were being home schooled because of a lack of support in school and another was missing a lot of lessons as found the noise and behaviour of others in class challenging.

Many families wanted more help for teachers to recognise masking, autism, and neurodiversity in general. They wanted a more positive, understanding school environment, a chill out zone so children can decompress and movement breaks.

A number wanted more support from school with their child’s communication and social interaction and opportunities to practice this in real life situations.

Other issues families wanted to improve were a full-time rather than part-time education in special school, getting support without an EHCP, teaching more tailored to the individual child, and extra time to complete work and exams.

A couple of families wanted schools to recognise and assess physical needs.

Children’s Social Care

Most families did not have an allocated worker in social care. 15 families had a Social Worker, 4 had a short breaks worker or other youth worker, three were being assessed in children's social care and 75 did not have a Social Worker.

The wait for a social worker varied with some waiting days /weeks and some waiting over 6 months. There were 22 families who had a social work assessment and could remember how long they waited. For some it was a matter of hours or days. 1 waited 6 months and 2 waited over a year for a children's social worker. assessment. Several said that bad experiences in the past had put them off seeking help.

Children's Care Plans

Only one family had a care plan (children's social care) but said that they were not receiving all the help that was agreed despite contacting the Social Worker.

Five families did not have a care plan although they had a children's social worker or short breaks worker. (This included two 17 – 18-year-olds.)

Four families had a written care plan but found it difficult to understand: one to a children's social worker and 3 to short breaks workers.

One family wanted overnight respite but there was no suitable service being commissioned, despite a need being assessed. Another wanted more care hours, another more youth workers.

One family said that school holiday care needed to be longer than a few hours to enable them to work.

Social workers needed to read up past history so that they could be more sensitive about certain issues during visits (1)

Short Breaks

Twenty five 0 – 17-year-olds had no short breaks. They were all ages from 0- 2 to 15 –16 age ranges. The two biggest age groups were:

- Four 3- 4-year-olds in mainstream early years setting, resource unit and home educated.
- Eleven 8 – 11-year-olds: 7 in mainstream settings and 3 in special schools.

Some families said that they were unable to afford to send their children to mainstream clubs and some could not find a suitable mainstream or SEND club.

Direct Payments

33 families had short breaks and another 3 had theirs stopped suddenly or at short notice and with little communication and one had DPs refused as they were home educating their child.

- 15 families were clear what they could spend the direct payments on.
- 9 were unclear what they could spend the money on – all for children.
- 9 had not been able to find a Personal Assistant (PA) - children and young adults.
- One parent carer said, “I have to pay a higher wage to recruit PAs meaning I won't have enough money to pay for all the hours we are awarded.”

Families spoke of several things that would make direct payments easier. The most common concerns were:

- Hourly rate insufficient to recruit a PA, especially if a child has complex needs.
- Help with recruiting
- Managing paperwork, tax, and employment insurance too much
- Clarity and consistency as to what families can spend direct payments on.

Families are having to have spare income to make direct payments work: many were topping up the PA hourly rate or paying while waiting for money to come into the managed bank account. Families who are not able to do this are likely to suffer – some could not afford mainstream activities.

Several said that they were now using care agencies via Brighter Futures for Children to get the support they need as they could not get PAs.

Preparing for Adulthood

Several families wanted better transition to 18+ services and help to decide between post 16 options and access supported living.

One family waited over a year for adult social care. Two families relied on duty social workers from adult social care, and one was struggling to get access to ASC.

One family were open to adult social care without an allocated worker and no written care plan. Two had a care plan but found this difficult to understand.

Four 18 – 25-year-olds had no activities outside of college and work – these include one in mainstream college, one in special college and 2 working. One family specifically mentioned a lack of clubs for adult women with additional needs.

Complaints

33/106 families had made a formal complaint to at least one service in the last 3 years. Some had complained to more than one service, but the majority were to Brighter Futures for Children and schools. Key areas of complaint were support being changed without consultation and reasonable adjustments such as fidget aids being refused.

10 had gone to a Stage 2 complaint and 9 to an external complaint e.g. LGO

Of the complaints that had been completed, 7 parents were happy with the outcome, 6 not and 4 partially. The key issues that families raised were communication, a clearly defined process with timescales and a solution focussed approach. When professionals were defensive or used their power to intimate, families felt the situation had not been resolved. “There is no help my daughter is still facing issues at school.”

Mediation

10 families had gone through mediation in the last 3 years. Most (8) saw it as positive, with improved communication being highlighted. One felt that the mediators did not understand their child’s condition sufficiently.

SENDIST Tribunals

This has been an issue raised to us in the last 2 years, with families experiencing a very adversarial approach and data protection being a real concern.

8 families in the survey applied for tribunal. 4 were resolved by a consent order before going to tribunal. Those that did go to tribunal were less happy with the outcome with the length of time until the hearing, an unequal time to present evidence, bias and the tribunal not understanding complex conditions being areas that families wanted to improve. All were represented by a solicitor, independent advocates, or an agency.

Visiting Schools and seeing SENCo before a move

Families have contacted the Forum in the last year with difficulty visiting new schools.

Within the last 3 years, 35/47 families surveyed were able to at least talk to the SENCo on an open day before a move.

2 families were not able to see the school because the school wanted more information from the LA, school names were not given but this was for one mainstream and one special school.

2 were not able to talk to the SENCo because there were no appointments, both children are currently home schooled.

Other reasons for not being able to visit school and talk to SENCo were Covid (2), a confusing college open day (1), emergency moves (2), a newly opened school (1) and personal reasons (1).

Wheelchairs

13 families had a child who used a wheelchair. 3 families were happy with their child’s wheelchair, but most (10) were not.

- 3 had to fund the chair themselves or through a grant

- 2 had been waiting over 3 months for a reassessment and one was still waiting.
- 3 had been waiting for an assessment about additional parts e.g. a more comfortable cushion.
- 2 had been waiting more than a month for repairs.
- 1 had been refused another wheelchair although the family felt that the chair was no longer suitable.

Summary and Conclusions

Many families had positive support from services. The key themes were the importance of school in whether things were going well for the child or not together with the importance of communication and coproduction with individual families.

Areas for development are:

1. Communication and coproduction in schools
2. Schools' ability to meet the needs of pupils
3. More short breaks especially for the 3 – 5 and 8- 11 age groups, including support for those unable to afford mainstream activities for their SEND children. Lack of clubs and hobby opportunities for those with additional needs, can affect them later in life.
4. Tackling waiting lists for Autism and ADHD assessments and CAMHS as well
5. Reducing waiting lists for wheelchair assessment and reassessments as well as repairs.
6. Ensuring that families open to children's social care have a written care plan that they find easier to understand.
7. Making managing direct payments and recruiting PAs easier for families.
8. Ensuring that families have more support in moving to adult services and get the help they need.
9. Ensuring those open to adult social care have a clear care plan and know how to contact someone in the team.

We anticipate that the new RISE team will address points 1 and 2 and look forward to working with Local Authority and health colleagues to find ways to address the other points raised by families.

Recommendations:

1. Waiting times for assessments (especially ADHD, autism, and social work) or other support systems when children are not yet diagnosed. Propose advice leaflets on what to do if your child is waiting on an assessment including not just the Berkshire West Autism and ADHD service but what help you can get in the home and education setting so parents don't feel like they have been 'abandoned'.

2. Teachers need to be better educated on neurodiversity to ensure that children are comfortable and supported when carers are not there and that children are as ready for their future as any other pupil. Service providers also need to be better educated to meet and understand the families' needs as a whole. We expect that the RISE team and PINS project will greatly assist with this.
3. Lack of help received even with a social care plan, and jargon used in the plan. Simplify care plans so that families can understand.
4. Short breaks and Direct payments are not as accessible to everyone, especially those in the younger age range and those who may have to 'top-up' the DP's (excludes those who cannot afford this) or cannot find PAs. To make direct payments clearer for families, once they have been awarded them, send out the joint Brighter Futures for Children and RFF leaflet or create a website with some examples of what DPs could include and how to find a PA, including phone numbers, websites, etc.
5. Better transition to adulthood services: more staff and funding could help. Also, if parents are told about all of the services and advised where to look, the transition might be more streamlined.
6. Improve wheelchair services (funding, assessment, repairs), tackle waitlists for these.

RFF

24/03/2024