

Events

Parent Carer Forum



together improving services

for children and young people with disabilities and additional needs

Community

Activities

How we have engaged

- ❑ **5 Surveys**
 - ❑ Your Say x 2
 - ❑ PINS
 - ❑ SEND Transport (Home – School)
 - ❑ Carers Needs
- ❑ **7 Family Based Activities** *(utilising feedback forms, parent carer commentary)*
 - ❑ 4 Coach Trips
 - ❑ 2 Activity World sessions
 - ❑ 1 Summer BBQ
- ❑ **22 Parent Carer Support Sessions**
 - ❑ 2 Parent Carer meals
 - ❑ 2 Seldom heard specific sessions
 - ❑ 7 Hubs/ Training Sessions (EPS, SENDIASS, Emotion Coaching, Behaviours)
 - ❑ 11 coffee meetings (Julaybib, Sanctuary)
- ❑ **181 Signposting contacts**

How many parents we have heard from

1st April to 31st October 2024

- Over **278** known individual parent carers have engaged on more than one occasion at some level
- **181** Parent Carers have requested signposting
- **710** Parent carers have engaged through family activities, coffee mornings, hub sessions and information stands
- **292** parent carers have attended school (setting) based sessions
- **682** parent carers have participated across 5 online surveys.

Yearly Comparison

Time period - 1st April to 31st October

	2023	2024	Increase
Known individuals who have engaged on more than one occasion	234	278	44
Signposting requests	118	181	63
Engaged through family activities, coffee mornings, hub sessions and CDC information stands	688	710	22
Attended school (setting) based sessions	83	292	209
Participated across online surveys (Five in 2023 and Five in 2024)	142	682	540

What Parent Carers Tell Us

- ❑ Concerns over housing
 - ✓ Suitability – often too small/ lack of bedrooms
 - ✓ Evictions/ Homelessness
- ❑ Concerns over Finances
 - ✓ Benefits – especially UC
 - ✓ Food poverty
 - ✓ Extra costs associated with SEND CYP
- ❑ Concerns over Education
 - ✓ School based anxiety is high, where there are concerns that a child's needs will not be supported
 - ✓ Lack of reasonable adjustments
 - ✓ Poor or lack of communication
 - ✓ Part Time Timetables
- ❑ Health access concerns
 - ✓ Lack of access to Dentist's and GP's
 - ✓ Waiting too long for ASD/ ADHD assessments
 - ✓ Issues with Wheelchair Services
 - ✓ Lack of reasonable adjustments at health appointments
- ❑ Lack of short break access and/or provision
- ❑ Struggling to apply for an EHCp's
- ❑ SEND Transport Issues (Home to School/ Hospital)
- ❑ Not being seen as a carer – feeling like part of the problem/ poor parenting

What Parent Carers Tell Us

I need help, advice, support and really anything you can give me. My daughter (5yrs) has been diagnosed with ASD, has an EHCP in place and as of November 2023 is being home schooled. I am pulling my hair out as she is a big ball of energy, curiosity and emotions all rolled into one, and I feel stuck and lost on where to go and what to do for her education and growth. I care full time for both her and my partner (her father). He is registered as disabled and cannot do much due to the level of pain and discomfort he is in, as well as suffering with mental health issues.

We are stuck on the housing list (currently been on for 4 years) and we currently reside in a one bedroom house with one bathroom which is upstairs. I need to update my housing application with my daughter and partners disabilities, we need something that meets both their needs.

We receive benefits, apparently because I care for both of them I am supposed to get carers allowance also, but again I have no time or energy to fill in the forms.

Sorry this is a long message, but I feel so alone and have no idea where to start or look for help, so I am hoping that yourselves may be a place to do so. Thank you in advance.

What Parent Carers Tell Us

You have to be out of a job & claiming benefits & then you will get help and support, not if your working v hard paying your way, making ends meet and trying your best to work when your child is on holiday and there is no holiday clubs suitable for your child because of needs and social care - not interested - will be if you sent them in with the same clothes all week or not changed underwear.

Short breaks funding was so so long to get arranged. Due to delay, after delay after delay took us more than 6 months from start to finish.

Struggled at primary school as school was not very supportive as it apíll only looking at the academic side of things and not other abilities.

Support for navigating new diagnosis and available support, Support with navigating meltdown behaviors, how to de-escalate. Ways that we can aid Fox with routine changes and and new experiences.

Had to pull son out to home educate him due to school not having funding to provide 1 to 1 support he needed

What Parent Carers Tell Us

Constantly trying to juggle work, and the needs for my children. Then the housework. I feel constantly exhausted. Because my daughter is high functioning I feel like we are forgotten about as she is “fine” academically and “fine/quiet” in public. Feels like we are forgotten about as she isn’t bad enough. I feel like I am letting her down constantly

It tires me out so much. And constantly fighting for what my child is entitled too is worse than looking after my child

Challenging and exhausting, isolating and alot of self neglect

It is very stressful and draining, especially having to deal with 2. Their needs & difficulties and different from each other & can often cause them to argue/fight, meaning I also need to manage this.

Mentally exhausting having to be aware of their every action and having to constantly fill out paperwork

Unsure who I am anymore, feel like I’ve lost my sense of self

I have very little belief in my ability to parent currently. It had a massive negative affect on my mental health and I became unwell myself fighting for my kids

What Parent Carers Tell Us

The mental load is intense. As well as all 'normal' parenting needs such as finding playgroups, childcare, applying for school, doctor and dentists, there are also many areas I feel unsupported in and have only found help with since his autism diagnosis.

We now have appointments coming from different services as and when they can fit us in, having to make childcare arrangements for my other child around these as normally other child cannot attend.

I am always thinking through what I could have done differently in the day to help my child and what we can do better tomorrow to make it a better day. I feel judged when out and about, I abandon many (expensive) activities that do not go well with my child not following the activities rules.

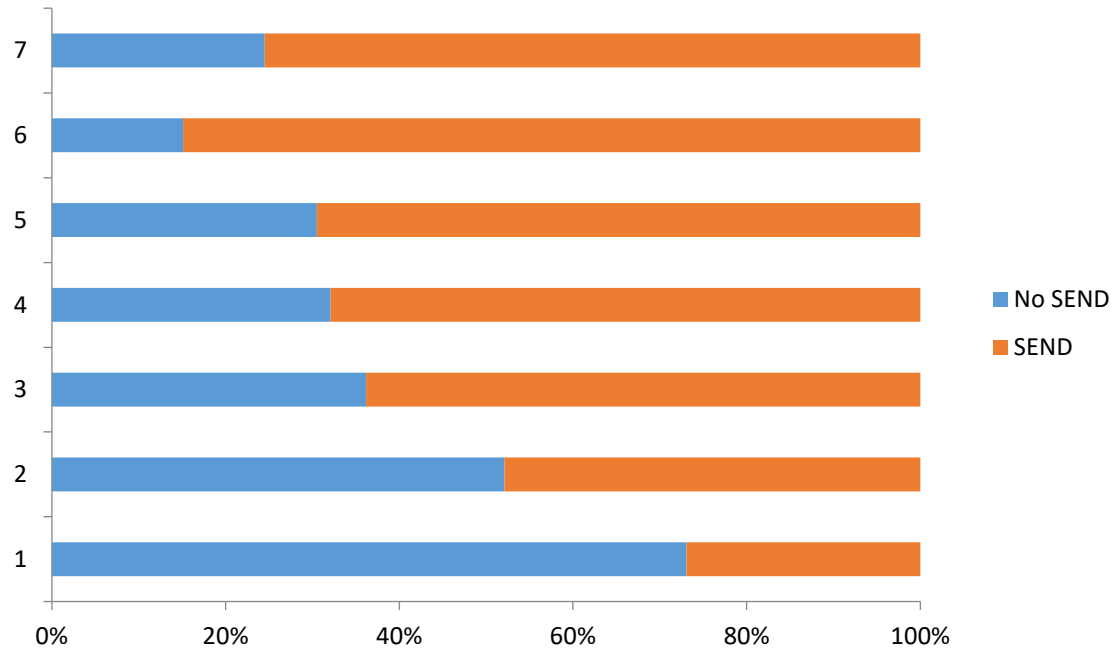
I am exhausted from a long and drawn out bedtime routine, only for my child to be awake for half the night too. This does not take into account any activities or time for myself, time with my husband or 'nice' family time.

What We Are Seeing

- ❑ **Lack of awareness/ understanding of the Parent Carer Community**
 - ✓ Parents are not just parenting but also caring
 - ✓ The system and parents themselves do not see the caring that parents do for SEND CYP
 - ✓ Providing Care is work, but the wider system expects Parent Carers to be in formal paid employment, which makes engaging with the SEND system more difficult
- ❑ **Marked decrease in Parent Carer Mental Wellbeing and Resilience**
 - ✓ Parent Carers report being overwhelmed, isolated, exhausted
 - ✓ Parent Carers presenting with multiple concerns many of which overlap when requesting signposting
- ❑ **A system that focuses on the CYP rather than the household**
 - ✓ Parent Carers reporting 'Sandwich Caring' that is not being seen
 - ✓ More than one CYP with SEND per household – disconnect when they are in different settings
 - ✓ Parent Carers with their own health needs being ignored/ neglected
- ❑ **A System that is creating Trauma**
 - ✓ Multiple appointments
 - ✓ Multiple form filling
 - ✓ Multiple and conflicting demands
 - Must be in work, but must also engage with SEND services
 - Must ensure CYP in school, must also attend health appointments

What We Are Seeing

Do you ever feel worried or anxious about your child whilst they are in school in relation to their additional needs? (1 Not at all worried - 7 Very worried)



The impact of caring for a child with SEND

