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**Pinpoint Forums’ Participation Group**

**Attendee organisations:** Rare Disease Network, Living Sport, Little Miracles, Safe Soulmates, Local Authority, Pinpoint

**Apologies:** Downs Syndrome Group, Spectrum, FASD Support Group, Cambridgeshire Dyspraxia Group

**Other invitees:** NAS Cambridge, Dreamdrops, Arthur Rank Hospices

1. **Welcome and Terms of Reference**

Pinpoint welcomed everyone to the meeting, introductions were made and everyone confirmed they were content with the Terms of Reference, which had been circulated with the meeting invite. The session ensures we hear all voices, as not every parent carer will access Pinpoint, and we all reach different families. We want to hear all those voices.

1. **Feedback (what’s working well, better if and urgent issues to be addressed)**

* **The EHCP process still seems to daunt everyone** – it feels like a battle or a fight; even those close to the system find it hard. You don't always know who is going to turn up – ypu are not able to control what happens.  It adds a lot of stress to the process. The SENCO sat in the middle of this.
* **Transition points are stressful** – where to look for information and not knowing what to look for makes it hard to find! Signposting needs to be better. Transitions are patchy and haphazard.

*IDEA: could we have an infographic that shows what should happen and who should do it…with spaces so you can add dates and names? Then, put it on your fridge to check back on. Could set out the role of parents / expect from it.  What is within the gift of the process, and what isn't?  What is the role of health?*

* **Mainstream families need more help** – struggle to get schools to understand their needs. What are the options and choices? Process hard to understand.
* **Autism diagnosis – the length of time it now takes to get a referral and the time on a waiting list is long.**
* **Parenting courses** – some parents cannot access the courses as they are not available or they do the course but it's not recent enough to count (it expires) and they have to do it again. An example was given of a family doing a parenting course for a child when they were three and again when they were 4. They were then asked to do it again when they were nine, pre-diagnosed.  This child is out of school until year 8, so the diagnosis is out of school.  The same family has then been asked to take a parenting course for a second child - autism and ADHD.  So that’s four courses so far! The irony is that the parent is a trainer for parenting courses!  Parenting courses make children and parents feel guilty as they don't work to resolve the behaviour.
* **EHCP myths persist** – parents are being given the wrong information – child must be two years behind.
* **Mental health services for autism** **are problematic** – some children's needs are greater than the threshold for Centre 33 and YoUnited Support but not severe enough to meet the CAMH thresholds, so children get bounced between services with no access to support.
* **Alternative Provision / Education Other Than At School shouldn’t be needed** – increased demand, but the needs shouldn’t have got to this stage (earlier intervention)
* **Respite – disparate offers were considered divisive and are driving competitive behaviour** amongst those accessing support but have left many families angry with each other and the system.
* **Families of children with complex health needs are not getting the support they need** – it feels worse at present, and more families are expressing their anger. Symptom management rather than palliative care.

*ACTION: The LA would welcome some examples from individuals on the call– anonymised but with sufficient detail so that officers can look at when it doesn’t work to establish what more could be done to resolve issues.*

* **The diagnosis route for ADHD doesn’t work!** The current route is to go to the GP, only to be told it’s a long waiting list, and in between, you are given a link to a site to follow for behavioural support.  The behaviour can be challenging to address without access to medication, which can support the behaviour.  A change is needed in how ASD /ADHA diagnosis happens - could it be more flexible? Can it be diagnosed differently to access support earlier? Do we hear the GP's perspective on this? The private process was not helpful and was very costly, £1k-£2k. £80 plus on private medication.  Those with a private diagnosis cannot access an NHS prescription – it needs an NHS diagnosis.

*ACTION: The LA will follow up on parenting courses – name, content, delivery points, etc.*

* **How do we do “waiting well”?**

*INVITATION: would this group be interested in co-producing some of the waiting healthy advice and support with the LA? (YES!)*

* **Pupils are struggling during the academic year (outside of an Annual Review process) and cannot keep up, leading to more dropping out in Years 7 and 8.** Do we know how many? Can we do more to support these children and their families? Can we have a more inclusive curriculum? *[to note, an inclusive curriculum is an expectation of every school]*. Growth in emergency reviews - is it causing more issues?
* **More are dropping out of school and into Elective Home Education**. Some are being lost to the system as there is no way of tracking these children – the DfE does not have a national database, as set out in the Government’s Green Paper.

*IDEA: Can we do more to support year 8 and 9 parent carers - what should happen? What is a reasonable adjustment? What should a worried parent carer do? [to note, the LA are addressing this with heads and SENCOs]*

* **Secondary schools don't know how to deal with ‘nagging mums’ (and Dads), seen as threatening, and come down heavy-handed on this behaviour**.  Can we offer support for teachers on how to build confidence in having challenging conversations with parent carers? Pastoral leads in secondary schools work full-time teaching hours and manage pastoral roles in addition. The job is difficult. How do we help everyone stand in each other shoes when communicating? Is there a link to the mental health support teams now in most secondary schools?

*ACTION: LA will seek ways to promote Pinpoint’s offer directly to parent carers.*

1. **A topic-based discussion for our next meeting**

The LA proposed that we co-produce a framework for individual participation at a child/young adult level. This was agreed.

1. **Other burning issues/updates**

* Pinpoint is developing training for school staff to roll out in the Spring Term to support the Neuro Diversity Booklet.
* The new Head of SEND at the LA is Emma Harking, who started in the role this week.