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**Pinpoint Forums Participation Group**

**Meeting Note 12 July 2024**

**Attendees:** Emma Harkin, CCC Head of SEND; Lisa Belton, Pinpoint; Greg, Living Sport; Kathryn Goose, ICS Commissioning, Celia Enderle and Sue Berry, Cambridge Rare Disease Network

**Apologies:** Fran Cox, Assistant Director CCC; Michelle King Little Miracles; Claudia Holmes Cambridgeshire Downs Syndrome Group; Cambridgeshire Dyspraxia Group; Sharon Allen, Arthur Rank; Safe Soulmates; Justin Heron, Spectrum; Brian Roberts, FASD Support Group; National Autistic Society Cambridge; Janet Dullaghan, Pinpoint; Karlene Allen, ICS Commissioning; Salmon Rebecca, Strategic Improvement Manager SEND CCC

1. **Welcome**

Sarah welcomed everyone to the meeting and reminded everyone about the Terms of Reference for the meeting.

1. **Feedback (what’s working well, better if, urgent issues)and a wider discussion on current issues:**

We discussed how children with SEND can find it difficult to access out-of-school activities. It was noted that whilst football is a prevailing offer, it is not always inclusive, and those preferring alternative opportunities will find it hard to find other activities. Whilst some SEND-targeted activities exist, parent carers and children/young people can find getting back out after school rather challenging. Pinpoint reminded colleagues that we can help share opportunities through our website and social media comms. CamRare (cricket) and Living Sport (summer activities) will also promote Pinpoint to their families.

A single website with a list of accessible sports opportunities, such as swimming, and facilities like ‘changing places’ would be possible. Pinpoint has offered to help facilitate this.

We discussed Health's work to provide more information to parent carers through a single website, which was welcomed.

It was noted that travel training had made a significant difference to those who could access it before it ceased—it provides considerable independence for those who can travel on buses independently. There was a desire to see more commissioned in the future. The Cambridgeshire and Peterborough Combined Authority is currently commissioning buses—Sarah suggested that this could be raised as something the CPCA might take forward with CCC.

CamRare is taking the opportunity of their regular surveys to provide feedback to the Pinpoint so we can ensure that it helps raise parent carer voices – this is most welcome.

There is genuine concern about parent carer resilience—parents report exhaustion, lack of sleep (theirs and their children's), and a lack of respite. While some parent caregivers successfully access short break funding, they are too tired/stressed and find it too difficult to find a suitable PA to employ. It was felt that help with a list of appropriately vetted staff might be very welcome.

There are concerns that children are still waiting for suitable school places and that there are increasing reports of schools saying they cannot meet children’s needs (when it was felt that previously, they may have been more likely to say yes, and the children would have remained in the mainstream rather than special schools).

Medical care services seem to be better, but there are still significant concerns about waiting times for diagnostic services.

It was noted that information is available (on the internet) is ypu know what to search for (which vocabulary to use). We discussed whether AI, flowcharts and charts may help parent carers find what they need more readily.

There is a real concern that SENDIASS is overwhelmed and does not have the resources to meet the surge in demand from parents and carers who need legal advice and advocacy support. There was a desire to see a greater provision of independent support for families. There was a discussion about how parent carers could access free, high-quality advocacy.