

pinpoint Network Meeting – 6th March 2014 – Cambridge

The meeting was held at the Fields Children's Centre in Cambridge and was attended by 12 parents and 12 providers.

It ran from 10 – 1.30 pm and had two sessions.

Session 1 Summary

The session focus was on the support parent carers need from pinpoint currently and in the future.

Questions

What are the biggest challenges facing you as a parent carer ?

- Keeping going
- Me time
- Inconsistent knowledge base of professionals
- Skilled help with behaviour
- Getting a skilled, joined up approach
- Holiday activities
- Transitions
- Social exclusion
- Bullying
- Stigma
- Accessing respite
- Accessing support
- Accessing short breaks
- Activities for children
- Service gaps for child with medical needs but no learning disability
- Finding out about entitlements post 18
- Information
- Emotional roller coaster
- Lack of a break
- Adult mental health services availability
- Transition within health – no longer having a consultant

What support would be helpful from pinpoint to help you overcome these challenges ?

- Focused support for families with children with medical needs but no LD
- Support with transition from child to adult services
- Develop the use of on-line forums for families who cannot attend events
- Sexual Health Training
- Help in building local support networks

- Help in accessing higher level people in CCC
- Advocacy Services

Not all parents attend Network Meetings – what do you see as the barriers stopping people participating ?

- People may lack confidence and be put off by round robin introductions

Existing Services which were identified to meet Parents Needs

- Short breaks Team
- pinpoint website and facebook
- On-line forum facilitated by Rachel Allen looking at SEND issues
- Transitions team
- Mayhem Event – 29th March

Actions Noted

- pinpoint to consider forming a focus group to look at the needs of parent carers with a child with medical needs but no learning disability
- pinpoint to consider the further development of online forums
- pinpoint to use local rooms to hold surgeries with parents to bring the service closer to them
- pinpoint to look at offering further Sexual Health Training
- pinpoint to consider facilitating a group for parents going through the transitions process with their child

Session 2

12 service providers joined the session and worked in groups with parents looking at the implementation of the single plan in Cambridgeshire. The group work was led by the STAR Team and a report will be produced on this work.

Service providers and parents were facilitated to have some time to discuss individual issues.