

pinpoint Network Meeting – 4th March 2014 – St Neots

The meeting was held at the Bargroves Centre in St Neots and was attended by 11 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 ?

- Support with medical issues within school
- Sharing of information within school
- Consistent action within school
- Holiday activities
- Bullying
- Sibling support
- Isolation – particularly in the holidays
- Getting support to continue into the teenage years
- Exclusion from social activities
- Relationships
- Transition from child to adult services
- Uneducated staff and SENCO within school
- Fighting for what my child needs
- Exhaustion
- Time
- Knowledge – not knowing where to go

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

- To look at why Camplay is no longer accessible to some parents
- SEN advice
- Information about childcare/clubs/holiday clubs
- Information on autism friendly activities
- Help on finding the right school
- Helping identify support for children with medical needs and no learning disability
- Support during diagnosis – pre and post

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

- Fear of the unknown
- Lack of confidence
- Expense
- Travel
- Time
- Not considering yourself as a parent of “disabled” child
- Venue
- Needing to be “on call” for children
- Transport
- Lack of awareness

What is the one thing you would like pinpoint to do to support you in the future?

- Continue to operate
- Network Meetings
- Make it clear how pinpoint differs from other organisations eg pps
- Keep bringing parents/professionals together
- Offer advice on courses/activities
- Continue to give parents a break – coming together to socialise
- Allow parents to meet decision makers

Existing Services which were identified to meet Parents Needs

- Parent Partnership Service can assist with school placements/SEN advice
- START Team can advise on meeting a child’s medical needs within a school setting
- There is an Empowering Parents Course offered through Home-Start for children aged 0-5 with a new diagnosis or undergoing diagnosis
- Transition Team and Mayhem Event will provide advice and support for parents and children going through transition from child to adult services

Actions Noted

- pinpoint will move forward with the exploration of a “buddy” system to bring to allow parents to support each other with particular activities /help with transport to meetings and also raise confidence
- pinpoint will look at the way meetings are promoted to ensure it is clear that there can be help with transport
- pinpoint will rotate venues to make them more local to participants across the area
- pinpoint will look at the promotional material/website to ensure there are clear messages about the unique services it offers and differences to other organisations
- Consider the following areas for future network meetings:
 - Activities for children –sharing parental experiences
 - Childcare for children
 - Bullying
 - Educating staff/parents in school settings to raise awareness of additional needs
 - Sibling Support
 - Holiday survival plans

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.

At lunchtime service providers and parents had time to network and also to discuss individual issues.