pinpoint
for parents by parents

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Parent Network Meeting – Communication

Huntingdon, October 2015 (evening)

The Medway Centre, Huntingdon

Attendees

Parents: 11

Service Providers: Catherine Ward, Charlotte Clark, Charlotte Maylor, Dawn Stilwell, Fiona Scarlett, Gemma Wilkinson, Jane Crittenden, Josette Kennington, Siobhan Macbean, Sian Hooban

Pinpoint: Eve Redgrave, Lenja Bell, Sue Platt

Overview

The topic for these network meetings was Communication, with an aim to gather parents' views on ways to improve communication with health, social care and education services. Parents worked in groups with providers from each service to answer three questions on communication. After the group work, each service fed back the key points which had been captured on flip chart paper and are recorded below. The parents had a chance to talk individually with each other and service providers over refreshments.

Feedback from group work

Parents and service providers were asked to answer the questions below with regard to communication methods, not about what the service provides.

1. Stop – What communication methods with Education / Health / Social Care services **do not work**?

   Education
   - Conversations in corridors at school
   - Schools intimidating parents
   - Schools making parents feel bad for wanting what their children are entitled to
   - Assuming parents know the EHCP process
   - Inviting parents to 'Annual reviews' only to find that they are EHCP transfer reviews.
   - Copying and pasting from the statement into EHCP.
   - The need to fail before help is put in place.

Pinpoint receives funding from:
Department for Education
Cambridgeshire County Council

- One cap fits all
- Schools using pictures of children and young people without consent
- Inconsistency
- Issuing final plans without agreed amendments

Health

- Not arranging follow up after diagnosis
- Leaving families with no report or follow up letter
- Leaving families with ‘Bombshells’ and nothing tangible to have or read at home
- Leaving things out of reports/letters if it has been discussed.
- One cap fits all policy. See children as individuals to meet their specific needs
- Working in isolation
- Shutting out wider family in care plan discussions
- Putting all health issues down to specific diagnosis

Social Care

- Sending letters that point out the obvious and cause parents more stress and are not helpful.
- Making assumptions.
- Assuming parents know timings of processes.
- Assuming that schools and health know all about the social care services that child receives or their needs.

2. Keep – What current ways and forms of communication **work well** with Education / Health / Social Care?

Education

- Putting information leaflets in foyers e.g. SENDIASS
- Being transparent
- Being very open to amendments
- Putting info on websites
- Replying to phone calls within 48 hours. START
- Signposting ALL pertinent information.

Health

- Email communications
- Record of visits e.g. teacher for deaf children and educational psychologist.

- CAF – extend its use in practice (TAC support)
- Transparency in NHS
- CCing into letters and emails
- Facilitating challenge from families and responding positively.
- Text messages to remind of appointments the day before.

Social Care

- Annual forms for direct payments
- Providing support in work
- Parent and family support groups
- Family support workers. IF trained. They need credibility.
- Unit clinicians.

3. Start – What **new methods** would like Education / Health / Social Care services to use when communicating with you?

Education

- Providing information packs pertinent to the parent and child's condition. Not ALL info for every condition in all information sent.
- Educating schools how to signpost
- Talking about SEN support not just EHCP. Lots of confusion in schools and amongst parents.
- Schools need to listen and evidence need.
- Taking care who you send info to
- Accepting responsibility
- Letting parents know where the papers are going to.
- Checking personal details are correct or permitted to be used.
- Answering the phone. START
- Keep parents informed even if it's just a holding call.
- All service providers put Local Offer on their signature block on emails.
- Educating all regarding the Local Offer

Health

- Making sure there are follow ups after diagnosis and keep it going
- Up to date useful information packs provided by health staff to keep people informed.
- Follow up letters after all meetings/consultations

- A consistent standard for feedback when Child or young person is seen in school etc.
- Informing parents when health professionals are seeing our children in schools
- Communicating plans and follow up for our children
- Joined up working in health with others (E.g. paediatricians and educational psychologists)
- Facilitate seamless working and referrals.
- Acknowledging that mistakes can happen
- Viewing every child as an individual
- Managing expectations. What services do or offer and what they don’t, waiting times etc.
- NHS commissioners and providers to reflect on government policy and promises
- Openness and transparency from all
- Listening and including parent’s knowledge of their children in planning and care provision.
- More joined up working between services.
- To consider chronic needs as important as acute
- Listen and record views of parents and children
- Listening to the children
- Being clearer about the thresholds and age ranges
- Having messages and appointments outside of school times
- Considering the age of the child and what is going on for them (E.g. exams) When booking appointments.
- Being more open about who is seeing which children for which diagnosis
- Mould care and support around the child’s individual needs.
- Letting families know what is available from all services so they can be accessed.
- Getting GPs more informed.

Social Care

- Phone calls. Sometimes conversations are better.
- Giving adequate notice for changes or what will be happening. More helpful for ASD children.
- Sharing possibilities for the future
- Attending meetings such as TAC. Make sure parents know the process and their rights.
- Being aware of the effect of comments.
- Being clear about service provider role and purpose.
- Ccing parents into emails about the child.

- Sharing draft minutes of meetings before they are finalised. Keep these factual and up to date.
- Clarify and publicise information sharing
- Looking at ways to deal with personality clashes with workers.
- Being aware about good and bad days for families. Families may need to off load and this could be because they were asked how they were and it is part of your role to listen.
- Communicating between different parts of social care
- Coordinating between services
- Text reminders of meetings
- Dealing with emergency situations to do with the child rather than leave it all up to the parent.
- Family intervention services are needed at crisis point. Make them available.
- Info from all areas, Health, schools and families about social care made available.

Next Steps

The feedback from the group work will be collected and analysed across the five network meetings and shared with education, health and social service managers and frontline staff. Pinpoint will update parents on how this work is taken forward.