

## Parent Network Meetings – October 2015

### Parent Feedback on Communication with Health Services

#### Overview

The topic for these parent 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. Then parents had a chance to talk individually with each other and service providers over refreshments.

56 parents attended across the five meetings in Cambridgeshire's five districts. We also received feedback from 10 parents online. Each meeting was well attended by service providers from health, education and social care. Notes from the individual meetings have been recorded and can be reviewed separately on the Pinpoint website under <http://www.pinpoint-cambs.org.uk/get-involved/the-pinpoint-network/for-parents-of-disabled-children>. This is a summary of parents' comments on communication with health services from all five meetings and the online feedback.

#### Parent Feedback

In groups and with service providers, parents were asked to answer the following three questions on communication with health services:

1. Stop – What communication methods with health services **do not work**?
2. Keep – What current ways and forms of communication **work well** with health?
3. Start – What **new methods** would like health services to use when communicating with you?

The feedback has been collated and grouped into categories as shown below. Numbers in brackets indicate that a similar comment has been made more than once.

#### Method of communication

Stop:

- Letter / postage (optional)
- Getting addresses wrong – letters, medicine
- Incorrect information on letters
- Not by email unless agreed / preferred
- Automated phone messages about appointments
- Leaving things out of reports/letters if it has been discussed
- Having to tell same story over and over again, even letters not read in advance, or names and details wrong on letter

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- Having to repeat diagnosis 100's of times
- Communication via a third party. leaving voicemails as they are often not clear
- Taking forever to write up reports and send out

Keep:

- Texts reminder for appointments (x 8)
- Phone call reminder for appointments (x 3)
- Email communications (x 4)
- Post / letter for appointments (x 2)
- CCing into letters and emails
- Hospital passport (x2)
- Posters in community places
- Talking to us, listening to us, involving my daughter, some are very aware of this
- Enough time to talk (2 hour appointment with consultant psychiatrist and paediatrician)

Start:

- Increase use of technology (e.g. videos)
- Web-based signposting and FAQ's...Apps
- Options for reminders: text, email, letter, what suits each person? (x 3)
- Start texts to remind re: appointment for services not doing it (x 3)
- Texting would be useful, better than voicemail. Stop assuming someone else has kept parent informed
- Email or people making phone calls rather than automated
- Accessible 'choose & book' system
- Notice if appointments cancelled
- For planned discharge, get a letter with planned date
- Follow up letters after all meetings/consultations
- Respond by referring to the matter for which help is being sought rather than sending a generic and unrelated response
- Using healthcare passport
- Finding some way of using the hospital passport in the electronic system. Our daughter's used to always be on the front of the nursing notes and the medical notes when she was in hospital so it was always 'right in front of their noses'. People looked at it and paid attention to it. It has been scanned into her electronic record but now nobody seems to look at it. I think it's because they would have to actively look for it rather than it being there.

### Information Sharing

Stop:

- Working in isolation
- Not involving me in communication with each other. Producing reports and circulating them without talking to us or even sharing with us beforehand.
- When we have tried to get help from the health services we have been repeatedly deflected and have had to make numerous follow up calls, then find that the referral has been lost. I think tracking their own communications and exchanging information with other parts of the same service should be fairly straightforward in this day and age!

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**Keep:**

- Patient summary – all about me page – shared with other relevant professionals
- Communication of best practice – share e.g. GP surgeries phoning families, costs nothing
- Record of visits e.g. teacher for deaf children and educational psychologist

**Start:**

- Facilitate seamless working and referrals
- More joined up working between services
- Openness and transparency from all

What Information?

**Stop:**

- Producing leaflets in numerous different languages for seldom used services e.g. How to complain....
- Jargon and abbreviations
- Leaving families with no report or follow up letter
- Leaving families with 'Bombshells' and nothing tangible to have or read at home

**Start:**

- 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.
- Being clearer about the thresholds and age ranges
- Communicating plans and follow up for our children
- Letting families know what is available from all services so they can be accessed
- Training within services – EHC, autism, other special needs information

In Schools

**Stop:**

- [Having] no linkage between school and health services (especially move to secondary school – making us feel isolated)
- Is access to services too based on school performance (of child), if okay in school no access to health services?
- For complex needs, don't leave it up to the school (even special school) to address needs, keep CAMHS and therapies engaged throughout, issues come out during assessment
- Assuming school has adequate provision, not necessarily equipped to know there's an issue (lack awareness, training)
- Too quick to discharge (therapies), passing onto school
- Not having nurses based in special schools (new from September)

**Keep:**

- Being able to access health service through special school / independent school
- SENCo's knowing therapists and other health providers
- Attendance at IEP reviews - joint working with education service.

**Start:**

- Mainstream school to communicate child's health needs to school nurse
- 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
- Even better coordination with education services e.g. more multi-disciplinary meetings around the child.

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### Access to services

#### Stop:

- Being 9-5, Mon – Fri, make booking system available for phone calls / appointments
- Out of hours – if have crisis, it's not responsive, needs re-assessing
- How to get in touch - confusing

#### Keep:

- CAF but explain why it's important to fill it in properly – gateway to services
- Supporting letters from professionals to access funding / equipment from other charities (if not available from NHS), need to share this more

#### Start:

- Services who contact about waiting lists need to know how long before they need to question....approximate time frame
- To consider chronic needs as important as acute
- 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

### Transitions between services

#### Stop:

- Dropping us off at certain ages e.g. early support to starting school, with no apparent reason / plan
- No paediatrician coordinates move to adult services so dealing with GP who can't truly understand needs and overworked

#### Start:

- No carry across from children to adult services – start over, need to chase

### Specific Services

#### Stop:

- GP stop being 'clueless', need to be able to refer and help – more trained, listen to parents more
- GP services being so disjointed in many cases
- Changing / taking away medication w/out consulting parents (paediatrician)
- Discharging before communicating this with parent, notify of intentions e.g. SLT
- Long replacement process for therapists – bureaucracy
- Automated message that require a response from Addenbrooke's

#### Keep:

- Community Nursing Service (but delay in getting supplier)
- Early Support positive – works well, knows who to contact to get appropriate staff
- Clinic 9 Addenbrooke's good service from appointment request
- Addenbrooke's staff were well-informed at A&E
- GP that listens to me, has holistic approach and proactive, family centred
- Trying to create more capacity among therapies and let parents know so they can campaign / help

#### Start:

- Autism Team – sharing / communication
- Need more cohesive appointment system in hospital services
- LEAD PROFESSIONAL

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- Lead professional – needs to be respected
- New role for 'lead co-ordinator' please
- Getting GPs more informed
- Wheelchair service needs to be more proactive, parents have to chase all the time

#### General

##### Stop:

- Difficult to communicate with right individuals
- Assuming you know our child (because you have a degree), parent is expert in child
- No understanding of who is the lead when your child has complex needs
- Reactive approach, think ahead, not just in crisis
- Withdrawing service that meets identified needs
- One cap fits all policy. See children as individuals to meet their specific needs
- Shutting out wider family in care plan discussions

##### Keep:

- Workshops and problem solving together (parents and professionals)
- Working with parents and groups like Pinpoint – give parents a voice
- Self-supporting / self-help groups – supported by NHS (e.g. breast feeding)
- Facilitating challenge from families and responding positively
- CAF – extend its use in practice (TAC support)
- Transparency in NHS

##### Start:

- Join up more with parents in developing services
- Continuity and consistency in approach and information (also in Information)
- Clinical feedback more important than admin
- Keep communication open so parents kept up to date
- Need to improve communication between parents e.g. groups
- Improved training to include use of equipment i.e. syringes used for seven days, etc. for carers (schools)
- Come to annual review meetings, give lots of notice (could location be flexible?)
- Minute annual review meetings and share with everyone before final
- For annual review meetings, recommend parent to take a friend / partner with them, give lots of notice
- Acknowledging that mistakes can happen
- Viewing every child as an individual
- Managing expectations. What services do offer and what they don't, waiting times etc.
- NHS commissioners and providers to reflect on government policy and promises
- Listening and including parent's knowledge of their children in planning and care provision
- Listen and record views of parents and children
- Listening to the children
- Being more open about who is seeing which children for which diagnosis
- Mould care and support around the child's individual needs.
- Essential to have social stories (?) offered for every appointment as a matter of routine.

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### Summary

Some specific themes that can be highlighted include:

- Use text to remind about appointments, but give parents the option of how they would like to communicate e.g. via text, phone, email, letter
- Pay careful attention to detail in all correspondence
- Work closely with schools regarding provision and communication of what's provided
- Promote the use of the hospital or healthcare passport <http://www.pinpoint-cambs.org.uk/information/healthpassports>
- Improve information sharing between services
- Improve transition from children to adult services
- Keep and expand parent involvement in problem solving and support, both at the individual level and collective level
- Use an individualised approach

It is recommended that this feedback is shared with service providers and commissioners within Cambridgeshire Community Services, local hospitals and GP's, the Cambridgeshire and Peterborough Clinical Commissioning Group and Cambridgeshire County Council. And that any changes made to services as a result is shared with parents via Pinpoint.