

Parent Network Meeting – Communication

Cambridge, 19 October 2015 (daytime)

Ross Street Community Centre, Cambridge

Attendees

Parents: 17

Service Providers: Emma Cannon, Julie McLean, Leah Moors, Michelle Docking, Peter Dawson, Sally Hamilton, Sasha Long, Siobhan Macbean, Louise Silver, Holly Poynter, Samantha Lucier, Amelia Williamson

Pinpoint: Eve Redgrave, Lenja Bell

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 lunch. After lunch, Eve Redgrave ran a mini training session on communication with parents.

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

- False promises! Frustration when school says they will do something and then don't

Health

- Ignoring parents' concerns – GP's, Nursery Nurses, etc.
- Automated message that require a response from Addenbrooke's
- GP services being so disjointed in many cases
- Having to repeat diagnosis 100's of times

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- No understanding of who is the lead when your child has complex needs
- Jargon and abbreviations
- How to get in touch - confusing

Social Care

- Communicating amongst professional without involving parents
- Don't assume parents older children have all the information
- Be more transparent and honest about social care's level of involvement and what level of need is covered by locality, etc.
- Improve communication between the agencies
- Prevention is better than cure – too much firefighting
- Stop parents feeling like they are constantly at war with professionals and that everything is a fight
- Do not leave messages late in the day
- Ensure the message is clear and there is a timely way to contact you back (named person)
- Simplify the language on the website – too 'professional-language heavy'
- Wasted appointments due to a lack of information being delivered
- Paperwork can be too impersonal
- Do not assume emails are regularly checked
- Overwhelming families with too frequent visits

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

Education

- Interventions from other services e.g. SENDIASS + START to help families with school issue
- Email contact is very helpful
- MDT meetings very important
- Keep communication book but make sure info is updated for parent i.e. on issues, explanations, etc., not just smiley faces
- Email contact with school / SENCo, regular updates
- Weekly update email from school is good
- More information in communication book when young person is not verbal
- Phone calls from school
- Open door policy with school
- Opportunity to establish parents' preferred communication method with LA professionals – this may vary / be flexible

Health

- Texting to remind of appointments – option to opt out
- Early Support positive – works well, knows who to contact to get appropriate staff
- Clinic 9 Addenbrooke's good service from appointment request
- Service to keep or start text reminders for appointments
- Patient summary – all about me page – shared with other relevant professionals
- Addenbrooke's staff were well-informed at A&E

Social Care

- Ensure families know about the reasons for referrals
- Keep sharing information and have a system to check parents have received meeting minutes
- Keep Short Breaks
- Emails are good – establish preferences. Opt in/out & letter confirmation
- Just keep communicating!
- Local offer information
- Face to face communication
- Signposting to alternative services
- Texting / using mobile telephones
- Having a consistent social worker

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

Education

- Schools to be clearer with how funding is used in terms of TA time and support to parents
- Website to show the conversion funding table i.e. what hours = in £
- Parents have opportunity to attend START panel meetings when decisions are being made about future provision / placement of child. Evidence is critical of these meetings and parents are in a strong position to answer / respond. It will also reduce time in extra admin and gaining further evidence as and if required.
- Honest communication about time. If we need to write short emails. Be concise about what they need.
- When arranging meeting dates / times include parents in email chain
- Schools to provide SEND information, easily accessible – near entrance ideally

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- That SENCo's have up to date information
- SENCo's to have more time to dedicate to individual pupils
- Communication book as above (Keep) – discretely re: the child / young person and ask young person what they want
- Make sure schools send all information to one another (i.e. primary to secondary) in a timely way. And that they read it.
- Accountability of different services.
- Consistency of knowledge and message across all professionals (and with schools variable)
- More integration in community for special school pupils (in primary)
- Home to school book to also have medical info i.e. make more specific (inhaler / medication / seizures)
- Clearer information as to when parents will receive information re: secondary transfer, panels, etc. = timelines
- Website / local offer not necessarily clear re: feedback
- Communication with START – parents need frustration to be diffused, not have angry response from START office

Health

- Send invitations to all professional involved
- Lead professional – needs to be respected
- More individualised information and support
- Consent to share
- Support (guidance) to enable parents to put health information into EHC Plan – what is relevant
- Training within services – EHC, autism, other special needs information
- Improved training to include use of equipment i.e. syringes used for seven days, etc. for carers (schools)
- Services who contact about waiting lists need to know how long before they need to question....approximate time frame
- Everybody who needs to now gets to know, consent to share extended and implemented properly between services
- Autism Team – sharing / communication
- Need more cohesive appointment system in hospital services
- Notice if appointments cancelled
- Transition from children's services / paediatric service and adult. When system does work it is because staff are working outside their remit.
- Need to be able to opt out of mobile texts for appointment reminders
- LEAD PROFESSIONAL
- Transition to adult services more straight forward and co-ordinated

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- Reminders for appointments (emails, texts)
- More joined up working
- Changing details (address, etc.) with one person
- New role for 'lead co-ordinator' please
- Using healthcare passport

Social Care

- Social care to contact agencies to raise awareness of our roles
- Guest speakers from social care to attend school events and reduce stigma
- Establish circles of support to improve communication / understanding of child's needs
- Better guidance about available services
- Better sharing of information between services, but particularly health – facts, not opinions
- Be honest and include why social care are not involved
- Early stage communication / explanation to be clearer
- Re-introduce family support workers to get to know the families and help you navigate the system
- Include families more in the understanding the process
- Send out meeting minutes in draft for comments
- Ensure parents are aware they can access records
- Information about the average waiting times for service e.g. Saturday clubs
- All services to get better at communicating what options are available from all services
- Training for professionals on improved communication, the experiences of parents in attending meetings / receiving information and coming prepared to discuss options / alternatives
- Someone to help parents / carers 'form fill' - drop in centre
- Ask what the preferred method of communication is
- Talk to parents about gaps in services so this can be addressed
- When parents call in, ensure they are called back
- Appreciate crisis calls are a last resort – response from emergency duty team needed
- Focus on the needs of the family as a whole
- Be clear about what is available for parents
- Offer alternatives when services are not accessible
- Be clear about who to contact, how to contact and how often you will be contacted

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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.