

Parent Network Meeting – Communication

Fenland, 21 October 2015 (daytime)

Oasis Community Centre, Wisbech

Attendees

Parents: 7

Service Providers: Donna Sparrow, Harlee Scott, Josie Lynn, Kate Richardson, Shelley Cook, Siobhan Macbean, Susie Robertson, Abbie Ivatt, Sue Adams, Chandrasekar Rathinam, Helen Phillips

Pinpoint: Eve Redgrave, Lenja Bell, Judith Middleton

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

- Classifying SEND as one person – individuals
- Waiting for things to fail
- Maze of links
- Assumptions – professionals believing they know best!
- Delays in communication
- Presuming school are sharing information
- One size doesn't fit all
- Not a formula / robotic

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- Waiting on reports
- Being left in the dark

Health

- 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
- Assuming you know our child (because you have a degree), parent is expert in child
- Discharging before communicating this with parent, notify of intentions e.g. SLT
- Changing / taking away medication w/out consulting parents (paediatrician)
- Reactive approach, think ahead, not just in crisis
- Withdrawing service that meets identified needs
- Long replacement process for therapists - bureaucracy

Social Care

- Scare mongering re: budgets (better wait until have a plan, ask for parents' views)
- Not calling back
- Feeling of 'starting again' with new worker
- Not being tick boxy
- Raising expectations that aren't going to be met, gap for those children who will fall between services
- Having to chase for things (PAS writing notes etc. when out and about and wearing badge)

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

Education

- Inclusion (within schools)
- Regular / weekly communication (Gretton)
- Diary (Gretton)
- Phone calls
- Tailored to individual needs (Gretton)
- CAF / TAC
- Letters, but also texts and emails

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- Independent Supporters / Core Assets / SENDIASS / Pinpoint
- Telephone contact

Health

- GP that listens to me, has holistic approach and proactive, family centred
- Healthcare passport and use it! (Special Needs nurse at Hinchingsbrooke and Darlington ask for it)
- Working with parents and groups like Pinpoint – give parents a voice
- Being able to access health service through special school / independent school
- SENCo's knowing therapists and other health providers
- Trying to create more capacity among therapies and let parents know so they can campaign / help

Social Care

- Letter with contact numbers and leaflet when service changed – useful
- Good move from children to adults social work, good things to do for daughter, personal assistance 5 hours per week
- One size doesn't fit all
- Consistent person – know who to go to, contact numbers
- Always get a response – team approach, everyone knows you, unit model works, consistent, know your 'story'
- Face to face meeting – makes it easy to pick up phone
- Not always problem focused – makes it more positive, easier to sort out things when needed

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

Education

- Communicating
- Primary schools to have better communication with secondary (mainstream)
- Listen to parents
- Share details of services
- Texts
- Concise
- Knowing who your START team caseworker is
- More info prior to EHCP transfer / start
- More detailed info re: the EHCP process e.g. order / expectations
- Consistency- info from START (post) plus links

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- Concise – (timeline)
- Offer alternative communication methods – email / post / text
- More training around specific SEN diagnosis for management staff
- ‘Compulsory’ sharing of info from school
- Listening
- Initial letter include process and contact details
- Updates (email / text)
- Start communicating – email, telephone, letter
- Letter when allocated a casework officer and contact details (transfer)
- Communication after panel
- Communication between school and START (details of meetings etc.)
- Communication with all service
- Look at individual needs
- Advise where in process – let others know what is being done

Health

- For planned discharge, get a letter with planned date
- 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
- Health and education communicating more
- Telling parents when staff are ill or leaving – what happens next, who is covering
- Cross border communication between health services e.g. offer CAMHS cross border
- No carry across from children to adult services – start over , need to chase
- Information on carer when young person >18, who provider should speak to and contact
- Look at geographic placement of clinics, take into account public transport
- SLT to continue to oversee some children based on individual needs, need continuity

Social Care

- Inform parents about feedback processes
- Informing parent of what their children can get, etc. – info and someone to talk to about it
- Ask for parents’ views, they have ideas on how to be more efficient
- Where to go with issues, be clear
- Arrangement if social worker not available for some reason, someone who knows family, the basics

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- Provision where needed e.g. Fenland
- Ask what people want – tailored support, checking out it's working for all individual families
- Listen to parents
- Social worker for children who don't have complex needs
- Increase awareness of Short Breaks entitlement
- Clarify where you need to live to get various things – put something on local offer
- Need to increase awareness of social care – promote disability and other social care (it's not all child protection), leaflets in with START info, info for schools, parents to do promotion / share experiences, SENCo briefing to increase knowledge, link parents to parents (buddy scheme)
- Reduce stigma of social care

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.