

Meeting with Facebook parents' group

4th April 2017, 10am-1pm, at St Mary's

In attendance: Parents (Shelley Eggleston, Clare Jones, Joanna Zukowska, Jonathan Marsden, Melissa Simmonds, Joanne Ferguson, Natalie Brownell, Sally Toland), Jayne Ludlam (Executive Director Children Young People and Families), Dawn Walton (Interim Director, Inclusion and Learning Service & CCU), Sapphire Wright (Programme Lead - Paediatric Neurodisability Project, Sheffield Children's Hospital), Heather Burns (Senior Commissioning Manager NHS Sheffield CCG), Tim Armstrong (Head of 0-25 SEND Team), Dr Christopher Rittey (Consultant Paediatric Neurologist/Clinical Director), Katie Monette (SPCF Chair), Anne Snowdon (SPCF Development Worker), Eva Juusola (SPCF Participation Coordinator, notes), Edmund Cross (facilitator)

1. Hopes and concerns for the meeting (from flipchart notes)

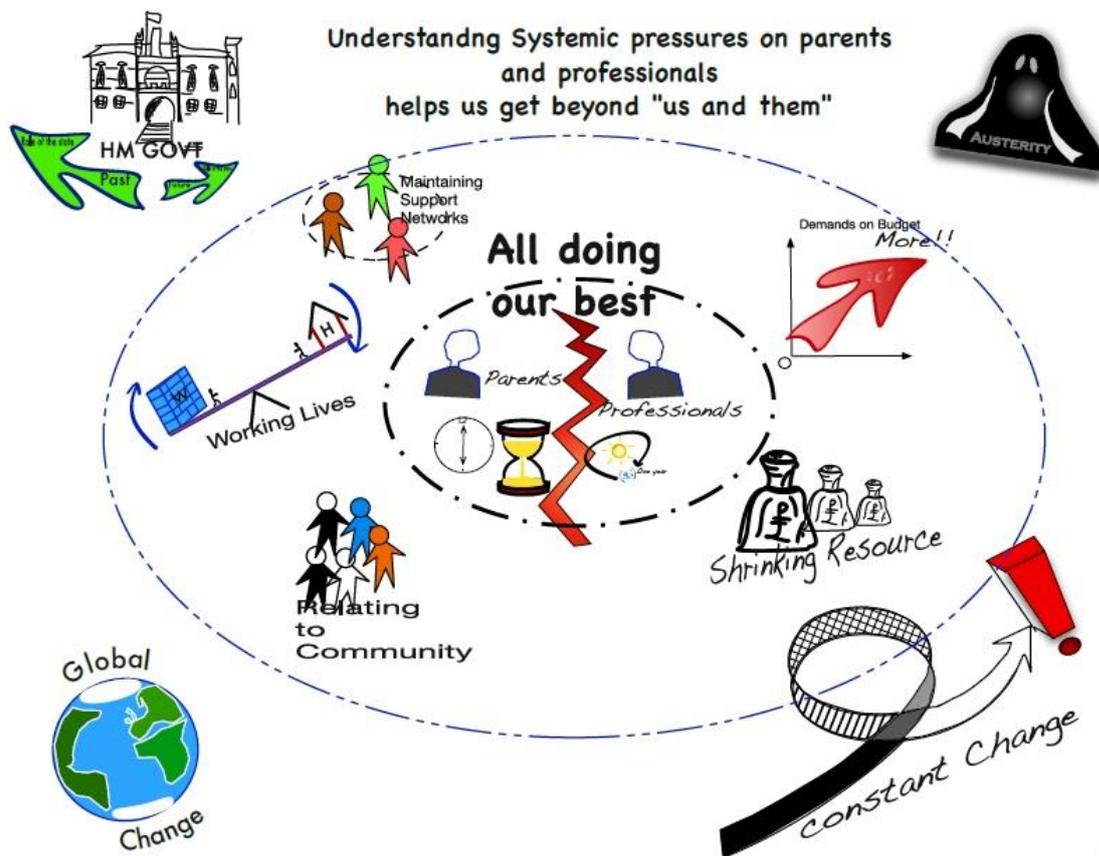
Hopes

- Ongoing and improved communication
- Right signpost
- Parent outreach in mainstream schools
- Increase awareness of disability
- Co-production
- Listening to parents
- Genuine change
- Today to be restart –thinking of ways of working together
- Joint commissioning
- SPCF to be used more productively (wealth of knowledge)
- Involve jointly from the beginning
- Simple adjustments to make big differences
- Identify what works well and what doesn't
- Working together and communication
- Build trust
- Listening
- Move forwards towards a change culture, a stop to "Us and them"
- More family-centred approach
- Promises to be kept/followed through
- Successful working = less stress for everyone

- Removal of barriers
- Hope for better outcomes
- Greater transparency
- More effective use of resources – more accurate plans

Concerns

- Added to a list and left
- Isolation
- Not enough awareness in mainstream
- Funding budget
- Community divide
- Known issues but no resolution
- No action
- Budgets
- Statutory processes
- No trust
- Changes in IR and the lack of communication
- Nothing will change despite good intentions
- Different success criteria: needs vs budgets
- Box-ticking exercise
- Acknowledge good intentions
- Lack of resources / austerity



2. Education, Health and Care Plans

What can we observe?

- When EHC needs assessment requests are turned down, the reasons are not well explained to parents. Parents are told that their child is making good progress and their needs can be met from the school's budget, but parents may disagree with this view. Parents feel that the evidence they have submitted is being disregarded, and that evidence from professionals is being used selectively to support the refusal to assess. Parents feel that there is a lack of transparency, as they don't know who makes the decisions, and on what basis. Sometimes decisions appear to be made too quickly, e.g. before a panel has had time to meet.
- Statement-to-EHCP transfers take a long time. Parents report that they are often cut-and-paste jobs from the statement.
- There are issues with the content and quality of EHCPs, e.g. social care sections left blank despite accessing overnight respite. Woolly wording (e.g. "access to", "opportunities for") is used in the provision sections, which leaves the plan open to interpretation by schools. As schools' attitudes to inclusion vary, parents feel that they need the legal protection of a well-written plan. Parents report they get a better plan if they write it themselves. Disputes about the content of plans prolong the process.
- Frequent changes in personnel mean that there is a lack of continuity.
- There is too much focus on the process, and people lose sight of the principles of person-centred planning.

- There are issues around the input from professionals. Health professionals rarely come to meetings, often because meetings are arranged with little notice, or because they have not been invited. The quality of reports submitted by professionals is crucial, as it affects the quality of EHCPs.
- It can be difficult for parents to get hold of their caseworker.

How does this make us feel?

Parents: physical symptoms (e.g. sleep problems, exhaustion, needing medication for depression), failing my child, resentment towards other parents who have it easier, guilt, frustration, anger, sadness, feeling alone, sense of injustice, rollercoaster of emotions, feeling unprepared, personal development (e.g. becoming defiant, growing a thick skin)

Professionals: frustration, disappointment, sense of injustice, battle-weary, anxiety, withdrawal, tension, sad, how in the earth are we going to do this?

We discussed whether anyone asks parents how they are feeling. Parents reported that this was rather hit and miss. Sometimes the GP will ask them, sometimes staff at CAMHS or Ryegate reviews. Some services have a whole-family approach. However, most parents would just say they were “fine” even if they are not. Some feel that they do not have time to go to the GP.

Services and families have different success criteria and different agendas. It is the system that lets parents down.

3. Health services

As some Health representatives were only able to attend for part of the meeting, the group prioritised a discussion about issues with Health services and possible solutions:

- Health services need to consider the whole child and the whole family. Specialists usually focus on their area of expertise, but everything is connected.
- Confusion about access routes, e.g. parents are told that their child can't access CAMHS because they are under Ryegate, or that they can't access a cycling programme because they are under the “wrong” consultant. Professionals don't always understand the different pathways, either. Access to services should be based on need, not on the consultant that the child is under.
- Waiting times for services vary considerably, and it isn't clear why.
- The role of GPs needs to be developed.
- Families don't get a service while they are on a waiting list. This can lead to a deterioration of the child's condition and have an impact on the whole family. Parents should have access to workshops, and schools should be given generic advice while the child is on a waiting list. The screening system should prioritise cases where there is a significant impact on the child and/or the family (e.g. if a mental health condition means that the child is no longer accessing an education).
- There are different service offers and criteria for children's and adult services.

- Services are not proactive enough. Parents should be told about red flags (e.g. non-verbal and severe learning difficulties = likelihood of challenging behaviour) early on, so they can be prepared and access help at the point of first challenge.
- Parent training should to be accessible without a diagnosis and at an earlier point.
- There needs to be earlier signposting to support groups.

4. Immediate solutions

- Draw up an EHCP exemplar and share with plan writers, schools and parents
- Improve the local offer website. Include information from SPCF's new SEN booklet and Transitions Guide, improve the search facility, implement changes requested by the working group in 2016. Send out local offer leaflets – where are they? Rebecca Mason to contact SPCF to arrange meeting after Easter, and draw up an action plan.
- Improve communication between the SEN Team and parents: acknowledge all emails and phone calls, log them, and respond within a reasonable time frame. Make explicit what the expectation is (service standards). Tell parents when part-time workers are in the office. Tim Armstrong to draw up an action plan.

5. Next steps

There was general agreement that further meetings were needed to discuss specific issues in more detail. Jayne Ludlam, Dr Rittey and Heather Burns offered to meet with parents three or four times per year. These meetings should be themed and attended by the same people, but able to pull in others as needed. Possible topics: EHC plans, Health services, locality model, MyPlans, SEN Support Grid. Eva Juusola to liaise with attendees and agree a set of meeting dates.