



Social Inclusion Working Group: meeting notes

Thursday 19th January, 2012

Apologies: Sarah Lacey (parent), Jude Odell (Inclusion Team Manager, Plymouth), Gwen Pearson (Children and Young Persons Commissioning Lead).

Attended by: Chris Morris (Chair) Mary Fredlund (parent), Bel MacDonald (parent and Face2Face coordinator), Megan MacMillan (PhD student), Liz Carroll (Out of School Inclusion, Devon), Ellen Williams (parent), Mark Tarrant (PCMD), Antonia East (parent), Hannah Thompson (Torbay Inclusion Project), Kim Antonio (parent), Jo Evans (parent and head teacher), Camilla McHugh (PenCRU).

This was another well attended and exciting discussion to develop our programme of work around social inclusion. We covered a broad range of topics including:

1. Measuring social inclusion

Discussion around measuring inclusion as research continues, with pros and cons. The group felt this was worth pursuing as it would have impact on the NHS in a number of various ways as well as on children & families well being. Comments were made around awareness that children can't self report always and reflected on problem of parents filling in the questionnaires on their behalf, as well as variability of disabilities.

Action: PenCRU to continue to seek funding for identifying key life opportunities that should be available to young people as the first stage of developing a measure.

Parent's feelings of stigma were also discussed. Measurement of issues related to social inclusion need to take into account parents attitudes, mental health and not focus exclusively on children.

Action: PenCRU to re-circulate previous research proposal 'Understanding caregiver' experiences of disability discrimination'.

An email that PenCRU received highlighted how important friendship was to children's inclusion, and the group agreed. There was discussion of the conflicting needs of mixing with all children, but also the need to have contact with children with similar needs and the benefits of sharing their experiences.

There was discussion about how the complexity of the issues could be assessed through measurement. A separate but related option is to carry out qualitative interviews about children's and/or families' experience to provide a richer description.

Action: PenCRU to circulate ESRC paper 'Life as a disabled child' as an example of this work.

2. 'Promoting positive attitudes' Megan MacMillan PhD work

Megan introduced two parts of her plan of work, a systematic review and a cross sectional survey of children in mainstream schools. Megan asked for feedback on the definition of disability used at the start of the survey. There was discussion as to how to access schools in the area; recommendations included contacting the learning communities; SENCO groups; Devon association of heads, primary (DAPH) and secondary (DASH) and Special Heads Association Devon, SHAD.

Action: Megan to send documents to PenCRU to circulate to Family Faculty, and draft news item for PenCRU website. Megan will be in contact to involve members of the group in designing her survey.

3. Update from inclusion services

Hannah gave an update on what was happening in Torbay. There is an allocation of £500 per child, the service provided is tailored to the individual's needs and clearly has a huge impact. However there is an ongoing need for inclusion services to demonstrate the benefits in order to secure funding.

Action: PenCRU to put Hannah in contact with DCC independent travel trainer.

4. Future direction of the group:

There was discussion about how the group wanted to work in the coming year and to set an agenda.

The group is keen to support Megan in her PhD, as well as pursuing the ideas for measuring inclusion, qualitative research to describe children's & families' experiences and to evaluate inclusion services. Chris described an idea for a 'cohort study' following up the experiences of families with disabled children over a couple of years, assessing how changes to the NHS and social care affect their lives.

The idea of applying for 'programme grant' was raised; such grants allow for 3-4 inter-related stream of research on a topic. Certainly there's plenty of ideas and work for the group.

The group agreed to meet six monthly. A date in June 2012 TBC