



Social Inclusion Meeting 22/09/2010

Apologies: Liz Carroll (inclusion worker North Devon) Jo Evans (parent) Nicky Jeffery (parent) Mike Hurley (parent) Margaret Ladbury (parent) Jude Odell (Inclusion Team Manager, Plymouth) Gwen Pearson (Children and Young Persons Commissioning Lead)

Attended by: Chris Morris (Chair) Kim Antonio (parent), Donna Beswick (parent) Tony and Marian Gilbert (parents), Becky Hart (parent), Bobbie Potter (parent), Sheri Ostler (parent), Mark Tarrant (PCMD), Jess Oliver (Cerebra Research Unit), Val Shilling (Cerebra Research Unit)

Summary:

This was a very well attended meeting during which parents shared their experiences, good and not so good, around inclusion. We have summarised the discussion into what seemed to be the key topics to come out of our meeting; things that we need to consider when developing the research. We then detail some of the research opportunities and ideas that came out of our discussion.

- Inclusion is about **being able to choose** to take part. Sometimes the barriers to this can be physical such as lack of changing facilities or proper wheelchair access. Sometimes the barriers are emotional, such as not feeling welcome. Sometimes parents become 'programmed' to think that things can't be done and they stop trying.
- **Practical barriers** can include financial (services aren't integrated and often accessing charity money can be difficult if you don't have a firm diagnosis you don't fit their box), time (particularly when families often have a number of hospital appointments) and the differences between accessing social groups and activities in rural and city areas.
- **Attendance is not inclusion** – unless activities are structured so that everyone can be involved and children are encouraged to play together, simple 'attendance' can in fact be a negative experience. Families sometimes feel that their children are allowed to attend under sufferance. It is not necessarily the case that people want to exclude, they just don't know how to go about inclusion or sometimes even how to talk about it. **Real inclusion is about embracing difference not trying to pretend it doesn't exist.**
- It can be difficult for parents to 'make a fuss' when things are done badly as many organisations such as Scouts are led by volunteers. Families have had good experiences when group leaders themselves have more experience – **the education of adults running clubs and groups is critical to the success of inclusion.**
- Attitudes are the root of difficulties – **if we can measure attitudes and change them for the better then inclusion should follow naturally.** The long term effects of interventions to change attitudes may take time to take hold but would be setting the scene for future generations.
- **Fear of the unknown** – public views about what it means to be disabled have to be changed. People are often ignorant of disability but this doesn't necessarily mean that that

don't want to understand. Families themselves can help with understanding by encouraging and answering questions. The limitations are that attitudes are changed on a very small scale and not all parents have reached a point where they are happy to have such conversations.

- **Personal contact changes attitudes and experiences.**
- **Education at an early age is critical** – children growing up together is the best way to develop understanding. Breaking long held attitudes is much more difficult. Overcoming physical barriers to inclusion is much more straightforward than overcoming attitudinal ones.
- **Personal Journeys.** A very important part of our discussion was around families' own personal journeys. Parents and their families need time to adjust to their child's disabilities. Some parents described how, before their own children, they too had little understanding or interest in disability. If parents, siblings and grandparents have to go through a long process of coming to terms with disability – is it realistic to expect people who have had no exposure to disability to change their attitudes overnight?

Actions:

1. **CM to arrange a meeting with inclusion teams from Devon, Torbay and Plymouth with the parents in the social inclusion group.**
2. **CM to refine the options regarding the direction of research and send to the social inclusion group for discussion at the next meeting (see below)**
3. **Group to meet again end of November beginning of December**

POTENTIAL RESEARCH OPPORTUNITIES & IDEAS

Mapping social networks of disabled children

This would be a way of seeing how many and what types of people children come into contact with. I think there has been some previous research on this topic showing that disabled children tend to have more contact with adults than other children.

Measuring social inclusion using questionnaires

We could develop a questionnaire to measure inclusion by asking child &/or parents whether they perceive they have the opportunity to be included in key life situations. The key 'opportunities' would be identified in a process led by children and families.

Whether children and young people actually do take part is determined partly by the child's choice of wanting to take part, hence measuring the 'opportunity'.

Based on our discussion, an example question for children might be:

- Can you take part in existing local organised groups and clubs for young people if you want to? *Organised groups might be cubs or brownies, or scouts or guides but might include other types of group activities.*

Response options might be along the lines of:

- I can take part in all the group activities I want
- I can take part in most of the group activities I want
- I can take part in very few of the group activities I want
- I have no opportunity to take part in group activities

Measuring peoples attitudes towards disabled children & people

These could be completed by children, professionals working with children (such as teachers, health professionals etc), or general population. The answers to the questions are used to calculate scores indicating attitudes. There are some existing questionnaires that people complete asking about their feelings towards disabled people.

Some examples taken from an existing measure for children are below.

- I would be happy to have a handicapped child for a special friend.
- I would feel good doing a school project with a handicapped child.
- I would be pleased if a handicapped child invited me to his house.
- I would not go to a handicapped child's house to play.

Measuring families of disabled children's experience of attitudes towards them

This is about how children, siblings and parents perceive people they meet are acting and behaving towards them. A family-completed questionnaire would be developed based on positive and negative events that families have experienced. The scores derived from the questionnaire would measure the extent to which the people they meet are enabling or barriers to inclusion.

School-based studies

Once we have a way of measuring attitudes we could undertake research studies in and around schools.

These could compare attitudes in different schools, such as inclusive mainstream schools where there are lots of disabled children, mainstream schools where there are very few or no disabled children, and perhaps also private schools. This would seek to confirm the hypothesis that increasing contact with disabled children is associated with more positive attitudes towards disabled children.

Following on from that, we could undertake research to see whether attitudes can be modified/improved through a controlled intervention that includes contact with disabled children and families and providing information to foster understanding and reduce fear.

Both of these projects are dependent on refining ways to measure attitudes.