

Aiming High for Disabled Children Consultation Day
Saturday 7th February 2009.

Report regarding the views and perceptions expressed in two workshops
of parents and carers of disabled children on Meetings and Reviews in the
Royal Borough of Kingston.

Over the two sessions eleven parents attended. We had four fathers and two BME parents amongst the group.

Seven of the parents had children with ASD, three parents had children with complex needs and one parent had a child with Dyspraxia.

All the parents and carers who attended the groups had direct experience of a variety of different types of meetings.

Annual Education Reviews
Looked After Children Reviews
Case Reviews
Health Reviews – Joint and Individual
Multi Disciplinary
Hospital Reviews
Disagreement resolution meetings with the Local Authority
Continuing Care meetings with the PCT

There was both positive and negative feedback about the meetings.

Parents felt that meetings and reviews should be a very positive experience that would empower them and the professionals who support their children to deliver the best services and care packages. The reality however is often very far removed from this ideal.

Support for parents in this area was perceived to be crucial. All the parents who attended the workshops were extremely keen to see the Keyworker system be implemented as soon as possible.

There was a consensus that disability criteria within Kingston had become more prescriptive and was denying children and families' access to much needed services and this was felt to be a "backward step". Parents reported having no option but to purchase services from the private sector, which was seen to be unfair and clearly discriminatory to those on lower incomes.

Parents reported being exhausted by the amount of meetings they are expected to attend and wish to see a more sensible and joined up approach. It was hoped that the new Integrated Service would allow for this improvement.

Education:

Parents felt that generally the education-based meetings were well run and informative. Annual reviews were reported by some parents to be a meeting to be “dreaded” and “feared” particularly if they are informed prior to the meeting that a representative from the LA is to be present. This was recognised not to necessarily be a portent of doom but was perceived by many that it could be. Unexpected changes to provision and or statements are presumed if an LA rep is going to be present.

Other parents felt that the Annual Reviews although hard work to prepare for could be a very positive experience that celebrated the achievements of their children.

Some of the parents have a perception that decisions around their children’s educational provision are made on a fiscal and not child centred model.

Another area of concern re education reviews is that each school seems to run an individualised meeting programme and parents can feel confused by differing methods and meeting organisation. Another area of concern is that many times they will arrive at a school for an annual or interim review without being given sight of crucial reports before hand, which is the prescribed practice but oftentimes does not happen. This puts parents on the back foot particularly if the report contains unexpected information and does not allow them time to prepare a considered response.

Parents also were uncomfortable about the many meetings that Educational Psychologists are asked to attend but cannot, as there are not enough school purchased hours for them to go to meetings as well as carry out their assessments.

Looked After Reviews

These reviews were felt to be useful and informative particularly as they are chaired by an independent chairperson but also very litigious and

irrelevant for a disabled child who only spends one or two nights a week in respite. The documentation is more geared toward children who are in more permanent care. Parents wished for this paperwork to be reflected upon and made more appropriate.

Case Reviews/Hospital/ Multi Disciplinary Reviews/ Continuing Care meetings with the PCT (Health)

Parents covet these meetings particularly those with children with significant physical or health needs but report struggling to get access to them. One parent reported that his daughter three years ago met the eligibility criteria for a case review but even though his daughter's condition had not changed significantly he was told that she did not now meet the criteria for a case review.

Parents expressed concern at the perceived tightening of eligibility criteria and wished to know why this was the case.

Multi Disciplinary reviews are much coveted as parents feel this is a way to lessen the huge amount of meetings that they need to attend and feel if a great deal could be covered in "one hit" it would make their lives a great deal less complicated.

One parent was very keen that a document be drafted for parents and professionals to complete prior to a review to cover recent changes and developments in a child. This document would also allow room for the parent to express their expectations for the child's care and development over the next few months.

Parents also reported that Social Workers are extremely loathe to attend any meetings that are perceived to be Health led which causes anxiety and anger as parents would like to have their input.

The PCT representatives came in for a great deal of criticism in this area. Parents were extremely angry and perplexed as to the lack of willingness of GP's to attend meetings. Parents feel that as the primary care giver and now purchaser of services for their children it was crucial that GP's or at the very least Health Visitors were required to attend.

Parents reported being very unhappy with the lack of professionalism shown by some professionals who attend these meetings and felt a more "corporate approach" would be better. Parents gave examples of

meetings where professional did not know who should chair meetings, agendas not being available and no minutes of previous meetings or action plans.

Parents often have to take the lead at these meetings, which is far from ideal.

It was strongly recommended that independent chairs, advocates for parents and keyworkers to coordinate the meetings would be a big step forward.

It was also recognised that when the Integrated Services for Disabled children are sited in one building these meetings could well improve.

Conclusions and recommendations:

Parents are very keen to be actively involved in meetings regarding their children and wish that they could feel more empowered by them. The parents who attended the workshops recommended the following suggestions that they feel would make the system better for all involved:

- More multi disciplinary meetings
- Better preparation by professionals before meetings
- Statutory service level agreements to ensure that any actions decided upon within meetings are followed thorough and apportioning accountability
- Professionals must listen to parents
- Agendas provided in advance
- Individualising Care
- Key workers
- Independent Meeting Chairs
- Training and guidance must be available to parents
- Standardised documentation
- Advocacy to be made more available – particularly for parents who have English as a second language, have learning difficulties and or literacy issues
- Clear criteria for eligibility re accessing services
- GP's must attend meetings when invited or send representation
- Use of plain English
- Transparency as by whom and why decisions have been made about provision to allow parents a right to reply
- Transparency in eligibility criteria for access to services