

**Parent Panel Consultation Event
20 November 2010**

Report

**Collated and written on behalf of and in consultation with the
Parent Panel**

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The Kingston Parent Panel was reactivated with support from EnhanceAble Children's Services via the Aiming High for Disabled Children's Parent Participation Grant in the summer of 2010.

Parents from across the borough were invited to join the panel. In September after the new membership was settled and updated terms of reference agreed it was decided that to offer a true perspective of parent and carer views the Panel would host a consultation event. Those who would attend the event would have the opportunity to participate in workshops and then be able to question the professionals who would be present.

It was felt that it was important to hold the event at the Moor Lane Centre as this would offer parents the opportunity to see the facilities that were available at the Centre.

Three key areas of concern were highlighted for more forensic discussion:

- Therapies
- Education for children and young people on the Autistic Spectrum
- Transition to Adult Services

Invitations to the event were sent to all parents who have a child on the I-Count register of children with disabilities; local libraries; all schools; doctors' surgeries and local children's centres. Over 50 parents accepted the offer to attend.

Childcare was offered free of charge for up to 25 children whose parents attended the event. Yadapa a local charity who support young people with disabilities to access art, drama and music activities supported by the Home and Community support team provided the childcare and all the available places were allocated and utilised.

The day was run in two sessions allowing delegates the opportunity to attend for the whole day or choose either one of the sessions.

At the commencement of each session Caroline Baxter, Manager EnhanceAble Children's Services, Grahame Snelling Head of Prevention and Integration, Sarah Quibell – Parent Panel member spoke to those present to provide:

- Information on the day
- Provide an assurance that The Royal Borough of Kingston was keen to listen to the views of parents
- Outline of what was hoped to be achieved from the event
- To offer an explanation of what the Parent Panel is and what it hopes to achieve in the future.

The other professionals who were present were:

Christine Cleveland	-Strategic Manager of Integrated Services for Disabled Children
Wendy Jenkins	- Manager – Moving Forward Team
Carol Nelson	- Team Manager – Disabled Children's Team
Angela Firth	- Team Manager – Disabled Children's Team
Joy Iruo	- Transition
Vivienne Overton	- Social worker from the Adult Services Team
Julie Hagarty	- CEO EnhanceAble
Diane Lacey	- Web Forum Moderator – EnhanceAble Children's Services
Stella Tomkins	- Information Officer – EnhanceAble Children's Services

Parents selected the appropriate workshops for them. After the group discussions took place each group fed back their views to all those present and then took the opportunity where appropriate to ask questions of the relevant professionals.

Professionals attended the workshops as well to hear the views of the parents and carers.

Feedback from the workshops and questions were as follows:

Education for children and young people on the Autistic Spectrum

Facilitators: Emily Davey and Diane Lacey – Parent Panel Members

The parents who attended the sessions had children right through the age range so the feedback covers both primary and secondary school education and support.

What is working well?

- Many SENCO's were seen as "good". A good SENCO was seen as the key to good communication and success for a child/young person
- Early Bird and Early Bird Plus Courses
- Parent Partnership/EnhanceAble
- Portage
- The Kite Group/EnhanceAble
- Targeted Advisor for Asperger's – Ben Swift
- Early diagnosis is seen as key and very useful
- Support in Nursery Schools reported to be good
- Good LSA's – crucial to ensuring a good school experience
- Children's Centres – highlighted as good and supportive
- Specialist Leisure Activities – Tolworth Gym, Surbiton Tennis Club

What is not working well?

- Obtaining a statements is reported to be very difficult
- Statement/Statutory Assessment process is too slow
- Lack of access to therapists so that children can be assessed properly
- Some parents reported that the Local Authority refused to assess child so they were forced to have private assessments at great expense – children were subsequently statemented.
- Too much jargon used by professionals
- Not enough feedback on academic progress
- Lack of information on senior/secondary schools with expertise re Autistic Spectrum Disorder
- Young people displaying challenging or difficult behaviour are treated with negativity and lack of understanding
- Therapy and other provisions highlighted on statements are often not provided/implemented
- The PCT is seen as the main barrier to therapy provision
- Year 5 seems to be the time that support for children seems to start to decrease

- Lists of schools that are provided by the Local Authority come with no details which can prove to be very time consuming
- Staff at schools are reported to often make inappropriate comments or remarks about children and young people due to a lack of understanding of Autism

Recommendations from parents and carers:

- Children and young people presenting with Autism not to be seen as problems by the school
- Coordinated support services
- Fewer delays in delivery of therapies and other services
- An academic secondary provision which recognises the social needs of young people on the spectrum
- Let School Action plus give access to senior/secondary school choice rather than force parents to do battle to get a statement
- Monthly academic reports from schools
- Further independent advice on statementing
- Increased information given by SENCO's or Key workers as you move through the system
- Secondary school lists to be given with much more information about provision available at each school
- Teaching assistants to be in the classroom all day

Transition to Adult Services

Facilitator Sam Manning – Parent Panel Member

What is working?

- Transition Fair
- Moving Forward staff team
- New Transition Pack
- Targeted Advisor for young people with Asperger's Syndrome
- Good support for young people who have serious health issues

What is not working?

- Lack of joint working between Children and Adult Services
- Young people without a statement but with a disability have no clear support pathway
- No clear set of "Trigger Dates" re processes for transition
- Transition is too narrowly defined
- Not enough information available

- Left up to parents to do all the work and research
- Late diagnosis – a real gap is services for these young people
- Large cohort of young people who are not known to specific support services seen as “falling off the radar”
- No clear pathway
- Legal and money advice not available
- No advice seen as available to those under 16
- Clarification required on statements and how they progress past 16
- How to access further education for a statemented young person
- Medical advice post 18. No clear handover or pathway
- Young people are being asked to sign forms and make decisions that they do not understand, without sufficient support

What Agencies need to be proactively involved in the process?

- Social Services – both Children and Adult teams
- Schools
- Connexions
- Moving Forward Team
- Health Services both Paediatric and Adult teams
- Befriending Service
- Targeted Advisor teams
- Advocates for young people and their families

What is needed?

- Adult and Children’s Services to work together with families
- A clear pathway for young people and their families
- Safety net for non statemented young people
- Education for parents re transition - Guidance for parents to realise that transition is not just when education finishes but is on going
- Parents Stories need to be put in the Moving Forward Pack
- Re look at the eligibility criteria for services
- Information for young people who do not meet the criteria
- More Transition Fairs
- Local Authority to provide more general information via talks and events etc
- Multi Agency work to include health services
- Clear signposting to services
- Advice available for under 16’s
- More Targeted Advisors
- More information on EnhanceAble and other voluntary sector organisations to be made available
- Clarification about further education and the support available
- Advocates for young people

Therapies

Facilitator Sarah Quibell – Parent Panel Member

Concerns:

LACK OF INFORMATION:

- Parents should be given information at the point of diagnosis
- Parents are having to surf the internet to get information
- Information provided by the hospital is out of date
- Parents want the right sort of valuable information
- Parents want the information to be in an accessible, simplified format.
- Health visitor input is really lacking
- A key worker should be appointed on diagnosis
- Reading lists should be provided
- Parents should have support in fact finding
- All reports should be comprehensible and parent friendly

SPEECH AND LANGUAGE THERAPY:

- There is a major gap in this service as there is no permanent therapist.

WHO DOES A PARENT GO TO ?

- If you do not have a firm diagnosis for your child, who can give you assistance?
- Who is actually responsible for the clinical care and development of your child?
- Who monitors the quality of care received?
- Who should a parent target for sending letters or emails about their child's care?
- It feels like there is no-one coordinating the services.
- Your child does not become disabled until they are 3 years old. Services are geared towards older children.
- Navigating the system is difficult
- Information should be treated sensitively
- Information should be integrated
- Parents do not want to have to repeat the life story again and again
- Parents want a tool which is easy
- Support groups and anecdotal information are helping parents rather than information from the professionals as this is not being obtained

- There is only so much a parent can cope with
- There should be a flow chart and code of practice for parents to access

LACK OF THERAPY PROVISION:

- Therapy should be on an individual needs basis
- Therapy is not proportionate to need
- Provision is governed by finances and not by the actual needs of the child
- You just get your quota
- Deeply frustrating for parents
- Parents pay privately because there is no other option
- Many parents pay for private therapy sessions but for many this is simply not sustainable financially in the long term and then they feel that they are not doing the best for their child.
- Many parents are willing to do OT exercises at home with their child but this cannot be achieved because they do not have the relevant equipment such as swings available to them.
- There must be some means by which the gap can be bridged between private and NHS provision.
- Lack of therapy impacts on family life as a whole, particularly when sensory needs need to be under control and the only way of doing so is via therapies.
- Once it has started, the quality of therapy is generally good but there is just not enough of it
- There is a lack of transparency between what professionals would like to provide and the resources they have available
- It is difficult for working parents to access therapies
- Parents should be given tactics and information to use at home
- There is a waiting list for baby massage, by the time some parents were offered a course the baby was too old. Massage should be given to disabled babies first.
- A group could be run to show parents how to massage and stretch.
- Resources are wasted
- A quota of OT sessions is completed but then you have to return to your GP for referral for further sessions

LACK OF FLEXIBILITY IN THERAPY PROVISION:

- A child's needs change or fluctuate. This is particularly true of sensory issues

- Sometimes a child can be on a level but then need help with a sensory issue but cannot access this help.
- Parents would welcome access to therapy equipment in a supervised environment like a drop in centre such as is provided in the adult physiotherapy clinic at Kingston Hospital.
- People could be trained to support therapists and supplement their sessions
- Give parents the tools to do the job
- There is a huge waiting list for a communication group but a child can only attend for one year. This is down to resources and the loss of the group is very hard for autistic children to cope with.

STATEMENTING:

- There is too much delay between diagnosis and assessment for a statement
- Parents feel that there is a “push back” against providing a statement- “if you don’t push, they won’t give it to you “.
- If you do not have a statement you cannot get therapies in nursery school
- There is a lack of help in accessing early years education

THERAPY IN SCHOOL:

- Parents reported that their children are not receiving therapy in school, even though it is part of their statement.
- Services provided in school are dependent on the SENCO when your child is in school so is thus dependent on how good the SENCO is
- There should be a system for complaining about SENCOs
- SENCOs can be” like brick walls”
- Statemented children are not getting OT and SLT
- Schools can’t get therapists into school
- There should be better training for SENCOs
- There could be an education programme in schools so that a bigger pool of resources can be developed from school leavers upwards

EARLY SUPPORT PROGRAMME:

- Some parents liked the idea of a programme designed for families with children aged 0 -5 involving a key worker

PHYSIOTHERAPY.

- One hour every two weeks is not sufficient if child is going to mainstream school

MOOR LANE CENTRE

- There is nobody at Moor Lane
- What is the point of Moor Lane if you have to write to Graham Snelling to get services
- Parents are not told things as if they are they will expect more from Moor Lane
- Key workers were mooted years ago
- Integration of services is not making the lives of parents easier
- Professionals attend meetings when they do not have regular contact with the child
- Each team works in isolation although they are in the same building
- There is still no IT link

What is working?

PORTAGE SERVICE.

- Greatly appreciated and admired
- “Fantastic”, “wonderful”, “they go the extra mile”, “it’s what everyone else should be doing”.
- They are well prepared
- They take notes and keep records
- They attend other groups
- They pick up everyone else’s jobs
- They have a planned approach
- They support the whole family
- Families feel bereft when the child goes to school and they lose that support

After each of the workshop session’s feedback was provided to the whole group by the individual facilitators.

It was highlighted during the question and answer sessions that the lack of representation from the Education Service was a real gap but there were understandable reasons for this due to staffing issues. Grahame Snelling

stated that he would feedback to his education colleagues and agreed that it would be looked into as to whether a more education targeted event could be arranged in the New Year. Grahame will liaise with colleagues in the Education Service, the Parent Panel and EnhanceAble Children's Services to try to organise a mutually convenient date if appropriate.

The Primary Care Trust had also been invited to attend the event but was unable to field a representative and this was seen as a great disappointment by the parents who attended. The provision of therapies and equipment plays such a key role in the support of children and young people's development and parents were keen to meet with PCT representation.

Parents and carers were asked to complete an evaluation document on the day and 17.24% responded. 90% responded very positively and wished for more events of this nature.

Parents were asked as to what parts of the day they found most useful:

Meeting with professionals	20%
Meeting members of the Parent Panel	40%
Meeting with other parents and carers	70%
Attending the Workshops	70%

Attendees were asked as to what topics they would wish to discuss at similar events in the future:

- Definition of criteria for accessing pathways to specific services
- Pre-school educational opportunities
- Advocates for children and young people
- After school activities for young people over 16
- Childcare for over 16's
- Specialist support services for children with social communication difficulties

Parents were asked for any other comments on the day:

"The event was very useful and well organised. Thank you to the Parent Panel, the catering and facilities were very good".

"I fully enjoyed and learned a lot from today. It is the 1st time I have visited the Moor Lane Centre and will certainly be interested in future participation. Yadapa provided excellent activities for the children so I could fully concentrate on the workshops".

"It was great to be asked to be involved"

"Social care pathways tailored to individual needs and memory therapy. How to deal with change and issues out of context. More help when needed"

“Think you should put special needs therapies on the curriculum for crèche/nursery assistants to develop a greater pool of skills resource”

“My son does not seem to “fit” any of the criteria for existing services. I am sure he is not the only young person in this category and wonder if there is a way we can work together to overcome this sense of isolation”

There were also three parents who requested to join the Parent Panel.

The Parent Panel will meet again in early January 2011 and decide on the next step re consultation with other parents and carers.

Conclusion:

The results and feedback from the workshops show that there are still some areas of real concern but offered some solutions and guidance as how all the services can be improved. Parents were keen to highlight the areas that needed to be targeted to improve services and to make them more effective and accessible.

Parents provided powerful examples and evidence of how early intervention could have saved money in the long run.

Parents are keen to have an ongoing dialogue with professionals the borough, schools, health and from other support organisations locally to ensure that their concerns and priorities are understood when it comes to commissioning services.

The Parent Panel will be key to this dialogue and will continue to work with professionals and the wider parent body to ensure that a communication is proactive and is effective.