

# EnhanceAble

## Report

### The Aiming High For Disabled Children Parents Consultation Day 07.02.09

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## Report

### The Aiming High For Disabled Children Parents Consultation Day 07.02.09

Report prepared by Julie Hagarty – CEO - EnhanceAble &  
Caroline Baxter – Manager Disabled Children’s Information  
and Advice Service - EnhanceAble

#### Context

EnhanceAble was invited by Mike Corrigan, Manager, Integrated Services for Children with Disabilities and Complex Needs, Royal Borough of Kingston (RBK), to bid for funding from Together for Disabled Children to deliver the parental consultation element of Kingston’s Aiming High For Disabled Children’s Agenda (AHDC).

Working in partnership with RBK, voluntary sector colleagues and local parent support groups a bid was crafted and delivered to Together for Disabled Children in November 2008. **(Please see appendix 1 for a copy of the bid)**. The bid was successful and a grant of £3,300 was awarded in December 2008.

A working group consisting of staff from the Disabled Children’s Info and Advice Service, Enhanceable’s CEO, a local parents group (MAPS) and a local community action group (YORDA Adventures) worked together to deliver the consultation event in line with the plans in the bid.

The bid consisted of a plan to hold a one-day parent consultation event in the form of 16 workshops to give parents and carers of Kingston’s disabled children a forum to express their view and wishes

about the future of services and how the Aiming High money should be spent.

One hundred and fifty spaces were available for parents and carers of children with disabilities or complex and additional needs to attend the consultation event. Parents and carers had the opportunity to hear about the AHDC agenda and to attend workshops on different topics. This provided them with a platform to give feedback to RBK and the Kingston Primary Care Trust (KPCT) on local services for disabled children as they stand currently and, in keeping with the grant remit, recommendations for the kinds of services they would like to see developed in the future.

Over 700 addressed invitations were sent out and posters and further invitations were sent for publicity and distribution to:

- All GP practices in the borough
- Schools
- Libraries
- Faith Centres
- Hospital
- Social Services offices
- Children's Centres

The event was also publicised in local newspapers, on the RBK website and on the local radio station, Radio Jackie.

Parents and carers were offered the opportunity to attend either a morning or afternoon session, or both. Lunch, free childcare and transport were offered to those who required support to attend the event.

Yorda Adventures, a local community action group dedicated to delivering high quality childcare/short breaks to disabled children and young people, provided the childcare and EnhanceAble the transport.

Eighty-one applications to attend the day were received. Twelve parents requested and utilised the childcare, and five parents took up the offer of the door-to-door transport.

On the day, fifty-eight delegates attended, forty-six attended the morning session and thirty-nine attended the afternoon session.

Fifty one percent of delegates were parents or carers with children on the Autistic Spectrum. Many other disabilities were also represented. These figures are comparable with data statistics from the Kingston

Register for Disabled Children and the Disabled Children's Information and Advice Service figures.

**Please see appendix 2 for the statistics in respect of delegates.**

Both sessions commenced with an introductory speech from Julie Hagarty, CEO of Enhanceable and a presentation from Mike Corrigan, Manager, Integrated Services for Children with Disabilities and Complex Needs, on the Aiming High for Disabled Children's Agenda.

**Please see appendix 3 for a copy of Mike Corrigan's presentation.**

Delegates had been offered the opportunity to sign up for workshops on the following topics to allow for detailed discussion and debate as to how best to move the AHDC agenda forward, with the aim to improve and enhance services in Kingston.

The workshops available were:

1. Childcare
2. Play and Leisure Activities
3. Short Breaks
4. After School Activities
5. Meetings and Reviews
6. Working with schools
7. Access to the Community
8. Therapies and Equipment

Each workshop was led by a facilitator and had a scribe. The workshops each lasted for an hour.

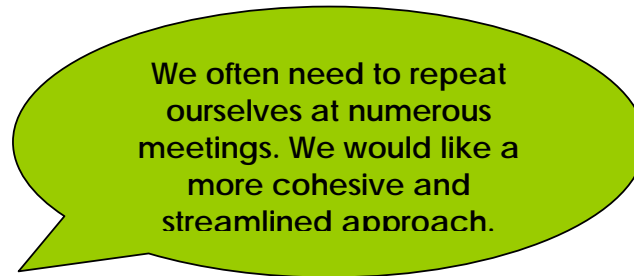
Each workshop group prepared a consensus conclusion to feedback to the rest of the delegates at the end of morning and afternoon sessions. The summaries below show **only** the issues highlighted in consensus conclusions.

A full record of each workshop is appended to this report. In order to draw valid conclusions from the consultation event these appendices and their implications must be fully considered

**Please see appendix 4 for the reports from the individual workshops.**

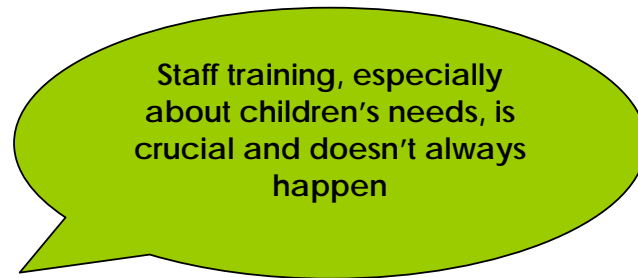
The conclusions fed back to the whole group from the morning sessions were as follows:

## Community Access



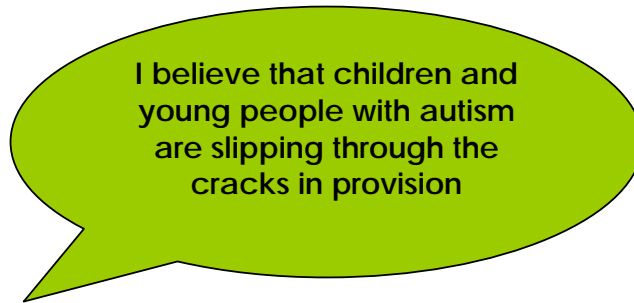
- Parents wanted to know who was in charge of their case, with regard to whichever agency they are working with. Parents also expressed a wish to have clarity as the lead agency/professional for their child.
- Parents felt that they often needed to repeat themselves at numerous meetings and would like a more cohesive and streamlined approach.
- Parents felt that the amount of paperwork and the complexity of it was a heavy burden. They would like printed material to be simpler and more concise.
- There was a strong feeling that there was not enough information sharing with parents. Parents want to have more information about their individual case and about services in general.
- Key times were identified when extra support is required:
  1. Diagnosis
  2. Early Years
  3. Transition between schools
  4. Transition to Adult Services

## Play and Leisure



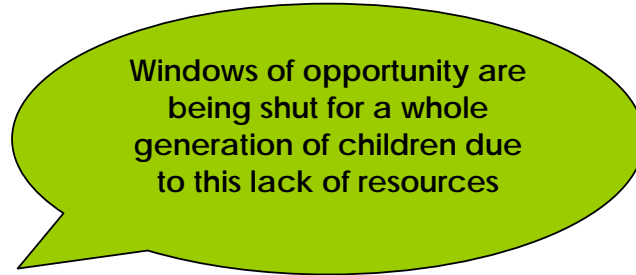
- A need for frequent and regular sport, drama and music clubs was highlighted for children of all ages and needs.
- Parents highlighted missing provision for children and young people with moderate learning disabilities, specifically those with Asperger's and high functioning autistic spectrum disorder.
- Parents do want their children to access mainstream activities where possible but it has to be a child centred decision not a fiscal one.
- Some suggestions were made that mainstream children could act as "Buddies". This would give valuable life experience to both groups.
- All parents felt very strongly that staff training in all areas and most especially awareness of the children's needs was crucial and a need that is not always currently met.
- There was general consensus that a child centred approach was key to the delivery of services
- This group of parents wanted more information readily available, and could highlight occasions when the DCIAS had not been informed of new groups or leisure opportunities and could not, therefore, pass on the information.

## Working with Schools



- A number of issues were highlighted concerning the needs and provision for children and young people with ASD.
- Concern as to the very delayed times for diagnosis particularly for children with ASD
- Parents believe that children and young people with ASD are “slipping through the cracks” in provision.
- Parents want access to an ASD expert available for every school and for all school staff to have specific training.
- Levels of school staff training and understanding of disability is inconsistent from school to school and within individual schools. Parents also highlighted a need for non-teaching staff to receive more training to alleviate problems at break times.
- Parents want there to be more training for all school staff about disability issues and inclusive practices.
- Parents feel that due to an extreme shortage of therapy staff teaching assistants have to deliver the prescribed packages of therapies and support. Parents do not want this to continue.
- Parents reported that communication styles, speed and modes of communication needed to be standardised for all children in RBK on the SEN register. Parents gave the following examples of poor practice: unavailable personnel, lost letters, unreturned phone calls. Parents did remark that some schools are handling communication well, whereas others are failing.
- Whilst the role of the SENCO’s is valued and important, parents believe that they require greater support and training.
- Some parents perceive that there is an inconsistency as to who receives services. Some parents also felt that it is now harder to obtain a statement.

## Therapies and Equipment



Other parents' whole-heartedly agreed with this statement.

Both groups stated that the health and development of the children is being adversely affected by the lack of therapy services

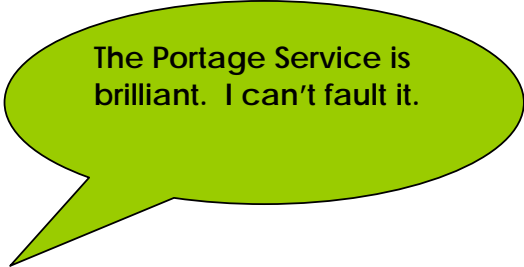
All the parents and carers who attended these groups had experience of accessing local provision. All expressed the view that the therapy offered was too infrequent and did not address their child's needs sufficiently. One parent of a child with complex health needs reported only having received one appointment to Occupational Therapy in eleven months.

Parents feel that the focus is on assessment and not treatment and that many parents are forced to deliver therapies themselves to their children.

- Parents felt that the shortage of Physiotherapy, Occupational Therapy and Speech & Language Therapy available was due to lack of staffing and an apparently poor recruitment and retention policy.
- Waiting lists were highlighted as being wholly unacceptable. Parents cited having to wait from between 21 and 30 months for OT. (This refers to OT's who are providing clinical treatment).
- All parents were in agreement that early therapeutic intervention was critical – many were being forced to pay for therapies to ensure the best care and best possible outcomes were achieved. Parents reported often having to pay up to £60 per hour for therapies. This was felt to be discriminatory.
- Parents identified a need for transparency in eligibility criteria and would like to know about budgets for therapies.
- Parents expressed great concern at the severe deterioration of services at the Maple Children's Centre and reported

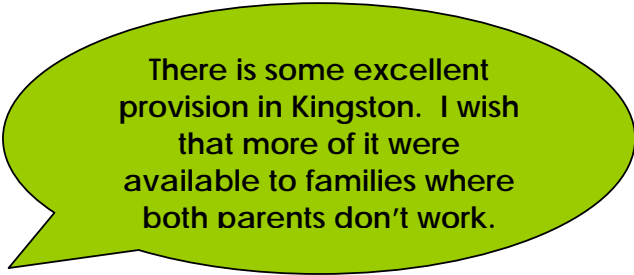
acceleration in this deterioration of services over the last 12 months.

- Parents expressed concerns about the drop in quality of services during the transition to the Integrated Services model. They have been told that this is an interim period but strongly feel that an urgent action plan needs to be in place to ensure that children do not suffer.
- Parents very much want to work in partnership with the borough to improve services
- The Portage Service was singled out as being accessible and – “Excellent” by both groups
- Keyworkers to support families were seen as a crucial step to improve communication and confidence.
- As there is such a deficit of therapy, parents believe they are not being made aware of what equipment is available to their children
- Where parents had been advised to use equipment they questioned how they could be expected to use said equipment if they are not being shown how or given specific guidance.
- Specialist footwear is not being checked, as it should, due to lack of staff –this is of great concern to parents. Parents cited their non-disabled children having footwear checks every 6 weeks but their disabled child cannot.
- Parents wished to know why the Specialist Health Visitors had not been replaced.
- A loan equipment service is required.
- Parents wish to see an extension of the SEN toy library



**The Portage Service is brilliant. I can't fault it.**

## After School, Short Breaks and Childcare



**There is some excellent provision in Kingston. I wish that more of it were available to families where both parents don't work.**

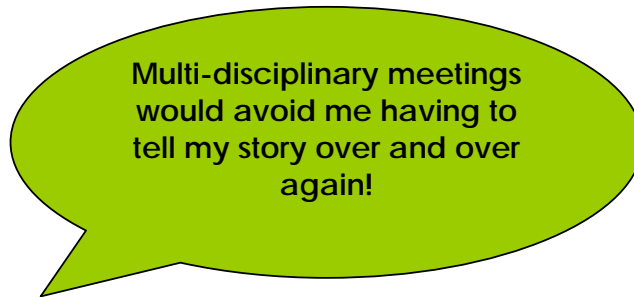
- Parents were keen to praise good provision such as “Yorda Adventures (After school club at Dysart), and felt strongly that this type of provision must be extended and must be more flexible and accessible – i.e. not just for working parents
- “Working Parent” plays schemes need to be extended beyond those currently available.
- The Kingston Holiday Club was recognised as a very high quality provision but was only available to working parents of disabled children.
- Parents reported the disappointment that nothing is available currently after school for Bedelsford and St Philips pupils
- Affordable access to mainstream activities is seen as both equitable and vital.
- Support to access mainstream activities is seen as key to the development of young people with disabilities and their successful integration into the mainstream world.
- Parents highlighted the deficit to access to short breaks for under 8’s since the facilities at the Maple Children’s Centre have been closed.
- Parents were passionate to ensure that their ability to work is seen & understood as crucial.
- Affordable and appropriate short breaks must be made available to a wider group than presently supported.
- More specialist Family Support must be made available to ensure families do not break down under the pressure of supporting a disabled young person
- The groups perceived that specialist services are in fact being reduced and eligibility criteria tightening
- Parents wish for a dedicated internet forum to share ideas and peer support
- More play and leisure equipment is required in all areas of the borough

- There is a need to make existing facilities in the borough more accessible. With more available trained support staff disabled children would be more able to access mainstream facilities.
- Parents would like to see the voluntary sector more involved in the provision of these activities and services. These should include more non-sporting opportunities
- For children to be able to take full advantage of opportunities transport provision needs to be more flexible and available.
- Some parents felt that it would be very helpful if lists given out for private childminders and babysitter contained more details about specialist provision available.



**Kingston Holiday Club and  
Yorda Adventures are  
fantastic.**

## Meetings and Reviews



Parents felt that meetings and reviews should be very positive experiences that empower them and the professionals who support their children to deliver the best services and care packages. Their experiences, however, have often been far removed from this ideal.

- Parents unanimously supported the suggestion that it would be helpful if meetings were "Multidisciplinary" to reduce the number of meetings that parents have to attend and avoid repetition.
- Parents remarked that as health, social services and schools all use similar information, but in different formats, they are often repetitive. It would be better if standardised documentation were used.
- Parents expressed serious concern about the lack of preparation for meetings. They would like papers and agendas to reach them within the prescribed timescales and for professionals to be up to date, having read papers and completed tasks (set in previous meetings) before attending. Plain English must be used in all reports, without over use of jargon and acronyms.
- Professionals need to respect and act upon the views of parents.
- Key Workers were recognised as being vital in ensuring actions are followed after meetings and that meetings are streamlined.
- Independent Chairs need to be available for some meetings, for example when there is a multidisciplinary meeting and/or strong conflict within the group.
- The majority of parents believed that financial issues, and not the child's needs, are the first priority.
- The PCT are perceived to being the weak link, not attending meetings or acting on decisions made at meetings. GPs regularly refuse to attend key meetings.
- Some parents requested a transparency in decision-making and eligibility criteria. All parents feel criteria's are tightening.

- Information on why specific decisions were made and who made them, this, it was felt, would allow an easier route for right of reply for parents.
- Parents felt it was very important to have access to advocacy, particularly for families with English as a second language, literacy issues or learning difficulties.
- The groups perceived and wanted reported a significant “decline in services since the Making it Happen event”.

## **Focus Groups**

At the close of each session parents and carers were asked whether they would be interested in becoming members of focus groups to help move the agenda forward. The response was strongly positive.

Parents were keen to support the development of services and two areas of particular interest were highlighted. The need to have an information website and parents forum and an education focus group.

## **Action**

- EnhanceAble has already begun investigations into the cost of the website and will be organising a meeting of the focus group within the next few weeks.
- The education focus group will be discussed with the Support for Learning team to ascertain the best way to support parents in this group.
- Parents wish to see an improvement in the provision of therapies and equipment and want to be involved in the planning of this increased provision

## Conclusion

Parents and Carers were adamant that consultation, while valuable, must result in positive action. The perception of many of the delegates was that services, particularly therapies and respite/short breaks, have reached such critical levels that immediate action is required.

Services such as Portage, Kingston Holiday Club and Yorda Adventures were very highly praised by parents, as were individual therapists.

The issue is access to services. Parents reported that, due to funding and staff shortage, access is severely limited. The levels of parental frustration due to the length of waiting lists, and the perceived tightening of eligibility criteria for access to services, was extremely high.

As a result of all the feedback parents and carers are hoping to see a structured plan of service development in the very near future, particularly as they reported feeling extremely frustrated by the elongated period of transition to an integrated service, as shown by the quote:

**“Windows of opportunity are being shut for a whole generation of children due to this lack of resources”**

The consultation event was very well received by those who attended, and provided a strong array of opinion that opens up potential for positive and constructive debate.

**There were numerous suggestions for how the Aiming High money could be spent, and all of these suggestions are in the body of this report.**

Parents see it as vital that the statutory services make a strong, coherent and prompt response to the suggestions they have put forward in this report, to avoid the development of further anger and frustration.

Feedback from the delegates who attended has been excellent and EnhanceAble have already received requests to run further and similar events in the future. Parents and carers affirmed their desire to feel involved in the development of services that meet disabled children's needs in a timely and proactive fashion.

EnhanceAble will be preparing a bid for the second tranche of grant money to facilitate parent consultation on the Aiming High Agenda in

the coming months; questionnaires and small outreach meetings will be used to further broaden the range of opinion and suggestion.

EnhanceAble has been keen to demonstrate its commitment to AHDC and is pleased that the dialogue generated by this event has mapped out paths of opportunity for all partners to **Aim Higher** for disabled children and young people in Kingston.

## Appendix 2 Data Statistics

## Appendix 3 Presentation by Mike Corrigan

## Appendix 4 **Feedback Reports**

1. Access to the Community
2. Childcare, Short breaks, After School Activities
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