

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 the provision of therapies
and equipment in the Royal Borough of Kingston.

THERAPIES.

All parents and carers had had experience of the provision of speech therapy, occupational therapy, physiotherapy or a combination of these therapies. All expressed the view that the therapy offered was too infrequent and did not address their child's needs sufficiently. One child with complex health needs had received one appointment for occupational therapy in 11 months. Therapy is often in a group setting and feels institutionalised.

Parents feel that the focus is on assessment and not treatment and that many parents are having to deliver the therapies to their children - *"They are relying on parents to do it"*. They say that they feel they are in a *"tick box"* system which is process, and not outcome, centred.

Waiting Lists.

Waiting lists for therapies post diagnosis are wholly unacceptable. Parents cited having to wait between 21 and 30 months for occupational therapy. All parents feel that early therapeutic intervention for their children is critical and can really help them. *"It all takes time we haven't got"*. As a direct result of these waiting times those who can afford it have resorted to paying privately for therapies to help their children and quoted costs of £60 per hour. They stated that *"Only parents who pay get the service"*, *"Our only hope was to go private"*. Those who receive therapy privately have experienced difficulties as there is then no crossover with the NHS. There is a lack of transparency regarding eligibility for therapy and it is assumed that it is budget, not need, driven.

Those who have received therapy such as occupational therapy have received only six sessions before being signed off. What happens then? There needs to be flexibility in terms of review. Some children have needed more than six sessions and then have had to go back on to the waiting list for further help. Targets need to be set and reviewed.

Maple Centre.

Many said that there has been a marked deterioration in the services provided by the Maple Centre in the past twelve months. Hydrotherapy, music & movement and swimming have all been discontinued.

Resourcing is regarded as *“diabolical”*. Significant numbers of staff have left and have not been replaced. Specialist health visitors have also not been provided. Parents perceive that the Maple Centre is being completely run down and that it is affecting the health of their children. *“Windows of opportunity are being shut for a whole generation of children.”*

Transitional Period.

The transitional period of two years for the integration of services has gone on for far too long. There seems to be no plan for delivery of services and a lack of management. Parents feel that officials are hiding behind this transition as an excuse for not providing services. They feel that the lack of progress is having an adverse affect upon the health of their children. Present infrastructure is not being properly used.

Portage.

Those parents who receive the portage service have nothing but praise for it and for the experienced staff who deliver it. It is an excellent, family centred service. They would like to see the same quality of service provided regarding therapies.

Staff are genuinely interested in children’s needs and have their best interests at heart. They are creative and flexible and act as advocates for the whole family. They know the children. They are regarded as key workers and tailor information to the individual child and provide it at the right time.

“They want what’s best for the child”. *“They open doors”*. *“It is the only consistent therapy that we have had.”*

EQUIPMENT.

Delivery.

Parents feel that as they are not seeing the relevant therapist it is extremely difficult to know what equipment is needed by their child let alone how best to use it.

The system is regarded as inefficient and needs overhauling. Equipment no longer needed by families is not passed on to benefit other families.

Parents would like to donate items that they have purchased and no longer require.

Equipment needs to be in a central location such as Warren Park or the centre in Chessington (when it opens). It needs to have extended opening hours in the evenings or at weekends for those parents who are in full time employment to be able to access it.

Parents suggested that items such as walkers, peanut butter balls and trip trap chairs should be available for loan.

Piedro Boots.

Children who wear Piedro boots do not have their feet checked on a regular enough basis. Children's feet should be measured approximately once every eight weeks. Children who wear Piedro boots often go for as long as six months between checks. One family waited 4 years to get some special inserts for their child's boots.

Special Needs Toy Library.

Parents feel that the toy library should be incorporated into the DCIAS and extended. It was suggested that it should be mobile so that it could visit Warren Park, the Chessington centre, Norbiton Children's Centre, Surbiton Children's Centre at times when these centres are being accessed by parents and their children. Parents are happy to donate toys, puzzles and games that their children have outgrown but which could be of use to other families.

Equipment in the Home.

Some parents feel that they are discriminated against because they are earning. They feel it is unjust to expect them to pay for a hoist system and monitors.

Sometimes equipment is offered but declined by the parents because they feel that it is not suitable for incorporation in their home. Where this happens parents would like to receive a financial contribution equivalent to the cost of the declined equipment. They could then use this money towards the cost of the equipment, which they deem suitable to address their child's needs.

Information.

Many parents feel overwhelmed by information packs and prefer to receive information that is relevant to their child at particular times (see note on Portage service). Information is welcomed and parents would like to be able to access it via a website which could be the modern equivalent of the "Yellow Book". They like to hear about organisations such as Cycling Companions.

Miscellaneous.

Parents also expressed concerns that:

- There is a lack of music therapy at Dysart School.
- The Jump Ahead programme should be extended through school.
- There should be access to playgroups with 1:1 support for disabled children.
- Disability Challengers should be extended to the borough.
- Session 5 is being scrapped.

One parent was told by a member of staff at Kingston Hospital that there would always be a struggle for funding for disabled children as they will not be able to pay back society when they are adults.

Partnership.

Despite feeling somewhat beleaguered, parents still want to work in partnership with the professionals involved in the health and wellbeing of their families. Many feel angry and for some there is a lack of trust. Many feel a lack of support.

CONCLUSION AND RECOMMENDATIONS.

Parents feel that there is a lack of basic care for their children and that services have deteriorated to such an extent that their children are being failed. They would like to see an interim action plan which will affect their children now and not just affect children in the future. They feel that early therapeutic intervention is paramount. The transition period must not be allowed to drift on any longer as it is having a detrimental effect on their children.

The Portage Service is universally applauded and parents would like to see this successful blueprint applied to therapeutic and equipment services.