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Aiming High for Children with Disabilities Short Breaks Consultation

Tower Hamlets



2 setting the scene

A great deal of recent legislation and guidance on health, education and social care highlights the need for user participation and the principle of parent participation has increasingly been accepted.

With exciting new Government proposals to transform short break provision for disabled children, young people and their families nationally comes a new opportunity to seek parent's views in ways that are meaningful to both parents and professionals. It is hoped that by using the experience and knowledge that parents have about their children, we will be more effective in developing and improving short breaks services that better meet the needs of children and their families in Tower Hamlets and ensures better outcomes.

Children's Service and their partners in Tower Hamlets were keen to inform parents about Government proposals for short breaks and what this might mean for children and their families locally. They were also keen to consult with parents for the following reasons:

- To draw on parents' expertise and knowledge about their disabled children.
- To achieve family-centred Services
- To create flexible, personalised and responsive services
- To give parents an opportunity to express views and wishes in a positive and receptive environment
- Because informed and involved parents are more likely to have realistic expectations of services and some shared ownership of choices and priorities
- To reach groups which may feel excluded and include them in service planning

3 the aims of the consultation

the consultation had three main goals:

- To give information to parents and professionals regarding the Government vision to transform Short Breaks between 2008-2011.
- To give details on what this meant for children, young people and their families in Tower Hamlets.
- And most importantly, to ascertain their views on how services should be shaped and delivered to best meet their families needs during that period.

4 the who and the how

- 30 organisations/parents groups borough wide were contacted and visited.
- Approximately 150 parents were consulted in small groups.
- Over 100 professionals were seen and their views ascertained.
- 500 questionnaires were sent out to family homes or given out by schools and local service providers.
- 50 activity questionnaires were distributed so that children and young people (with adult help where appropriate) could give information about what short breaks they might like.
- 3 public meetings were held – two on Short Breaks and one informing parents about the Parent Participation Grant and the importance of becoming involved in decision making. Approximately 55 people attended.

5 what parents said -the main themes

1. Not enough good quality respite for children with Autistic Spectrum disorders.
2. Limited opportunities for children with less severe disabilities to access any short break services.
3. Problems with transport was a constant theme amongst many parents.
4. No sitting services or outings for young people.
5. Lack of play schemes which catered for both the disabled child and their able bodied siblings.
6. Not enough 1-1 support for inclusion in mainstream clubs and play schemes.
7. Not enough specialist provision for children where inclusion in mainstream services did not meet their needs.
8. Lack of general information.
9. Poor communication between services and parents and across services generally.
10. Lack of clarity or transparency in the allocation of short breaks.
11. Not enough places at after schools and holiday schemes.
12. No specific counselling services or general parent support group/activities.
13. Lack of opportunity for 'Whole family' activities such as outings and holidays.

6 lack of information

- Many parents said that they did not receive information about services at the point of first diagnosis. This was felt to be a crucial gap and left some parents feeling totally alone at a time when they most needed support.
- Some parents wanted to be sign posted to others parents who had gone through similar experiences and had come through it with hope for the future.
- There was no one booklet that informed parents about all services available to disabled children and young people and this was also felt to be a gap.
- It was felt that information was needed in specialist areas and in age ranges:
 - Information on the range of services available for ASD children and young people.
 - Information on the range of services available for children with complex health needs.
 - Information on services for Visually and hearing impaired children and so on and so forth.
- Some parents said that they only knew about services because another parent had informed them.
- There was a general view that there should be one 'point of call' within the Local Authority where information on services could be obtained.
- Most parents consulted had no knowledge of the Local Authority web site or what information was on it.
- Parents suggested different ways in which they could be kept informed. Newsletters, emails, meetings, fun events and outings were all suggested by parents during the consultation.

7 play schemes and holiday clubs

- It was a commonly held view across the full range of disabilities that there wasn't enough after schools clubs and school holiday schemes available for children and young people with disabilities.
- Although parents felt that a limited number of children could function at mainstream provision if they were provided with adequate support, this support was sometimes not available during holidays or at after schools clubs because of the way the Educational budgets were allocated.
- Although those parents who obtained services at after schools clubs and holiday schemes were generally pleased with the quality of care and activities available, it was felt that children and young people needed more time, and families needed this respite from their caring responsibilities.
- Parents felt that places available for children and young people with severe ASD condition were extremely limited and there were often waiting lists for places at many schemes. This meant that families may only be offered a couple of days activity instead of the full week. Parents felt again that this was detrimental to their child's development and undermined previous progress.
- Some parents were extremely unhappy that they had to wait up to two years for a place at a play scheme and felt that their child had lost out on the opportunity to improve their all round developmental skills.
- Parents at Beatrice Tate school felt that it would be beneficial for their children to be able to access holiday play and activity schemes in the same way as children from Steven Hawking and Phoenix school.

8 respite for children with ASD

- Parents of ASD children felt that there was a real need for a local specialist respite centre for young people with ASD.
- Although there was some provision within the borough at Discovery Home, some parents (particularly parents at Phoenix School) felt that this was not an appropriate venue for the child. Reasons given were:
 - Lack of staff awareness to the needs of ASD young people.
 - Building more appropriate for children with complex health needs and not for ASD young people.
- Parents of ASD children felt that there may come a time when they needed overnight respite care for their children, whereas parents of children with other disabilities were less likely to require these services.
- Although Parents of ASD children felt there was a need, they also said that they would not want this service at the risk of losing other support services such as after school clubs and there was recognitions that this kind of care was extremely expensive and only services a limited no of children and their families.

9 Limited opportunities

- Parents of children with hearing and visual impairment felt that there was very limited opportunities for their children or families to experience any short break what so ever, even though their child's disabilities were complex and often had a major impact on the ability to lead 'normal' family lives.
- Professionals within this field backed that view and felt that children and parents were not treated fairly in the allocation of short breaks and hoped that this would shift with new money within the near future.
- Children with complex communication problems were also amongst those who received very few short break opportunities. A professional from AFASIC said that a specialist youth club in Tower Hamlets was much need and could be provided a relatively low cost. A similar club in redbridge had 70 young people attending.
- Some parents reported that they had been assessed for short breaks and were eligible, however they were now languishing on waiting lists for want of suitable short break services to become available. This was backed up by some professionals who recognised that they had to wait for one child to leave the service before they were able to offer a service to another. This was often through lack of funds. Many providers said they could offer more if given the appropriate funding.

10 transport

- Some parents reported that transport was a major headache and the lack of transport prevented children and their families from accessing services which would benefit their children.
- Parents reported that they were sometimes unhappy with transport services as buses were sometimes late in picking up and dropping off. This meant that their child was often not able to access the full session at a given service.
- It was felt by some parents that the issue of transport was not give enough thought when considering how children might access services. An example of this was the very good services for disabled children at the Mile End Leisure Centre. Many families said that it was impossible to get their family to the centre and so it didn't really matter that these services were provided at all.
- A few parents were unhappy with the level of training of staff who assist children and young people on the Local Authority buses, feeling that they were ill equipped to deal with children and young people with behavioural difficulties.
- Some parents felt that problems associated with transporting their disabled child meant that all children in the family were restricted and missed out on opportunities to get out and about.

11 Sitting services

- Some parents were unhappy that they had lost a sitting service which they once received. They felt that this had been a major support to the family.
- Parents felt that children had previously really enjoyed going out into the community with their sitter and this service was greatly missed by the children and young people involved.
- Some parents said that of all the services that they received they recognised this one as giving the most benefit to them and their families.
- They reported that sitting services gave the opportunity for them to have some time to themselves. It also gave time for them to spend quality time with their other children whilst knowing the their disabled child was enjoying themselves.
- Parents general felt that the lack of such a service was a major gap in service provision and one that they would very much like to see return.
- A few parents said that they had been offered an alternative sitting service, but they had to be present with their child. Most felt that this was not a short break because it gave no opportunity to get away from their caring responsibilities.

12 Play schemes for disabled children and their siblings

- Some parents felt that there was very few play schemes that catered for their disabled child and for their able bodied siblings and the ones that were running had long waiting lists. One parent who had a place at the Toy Library scheme run on a Saturday morning felt that such schemes were enormously valuable for the whole family. He reported that:
 - It was a great opportunity for the disabled child to have quality play experiences with their siblings.
 - The other children in the family benefited by being able to play with a variety of children with a range of disabilities. This made the able bodied children more aware of difference and they were more relaxed around disability.
 - It gave the parent an opportunity to play with all of the children in the family and to relax with other parents in similar circumstance.
 - This kind of scheme normalized the family dynamic because children were able to see that other children and families had similar situations.
- Professionals from Tower Hamlets Play Association felt that integrated play services for children with disabilities and their siblings was something that they could provide. They were also keen to welcome more children with disabilities and their parents and felt that they had the expertise to ensure positive experiences for disabled children in Tower Hamlets.

13 support in universal settings

- There was several parents who felt that their children would benefit from universal play schemes, but felt that children may need 1-1 support to allow them to mix successfully with other children and to make the most of their experience.
- **Befriending** - One parent felt that young people with disabilities in youth provision could be paired with peers of their own age for a period whilst the young person was new to the group. This young person could be paid for their services and would be responsible for ensuring that the disable young person is involved in all aspects of the clubs activities.
- Another parents said that her child received 1-1 support during school hours, but couldn't access after school club because this 1-1 support was not available after school. She felt this was very wrong and prevented her child from accessing a service that was available to his able bodied class mates.

14 the need for specialist provision

- Some parents reported that they had tried universal services, but this had not been a rewarding experience for their child, because they had not been able to integrate. It was felt that there needed to be a mixture of both universal services with support and specialist provision where a universal service did not meet the needs of a child.
- Some professionals reported that universal services (even with support) was not appropriate for all children and that specialist provision must be provided to ensure that the needs of all children and young people were appropriately met. Youth services and after schools clubs were examples where it was felt that some children would fair better in specialist services which were better able to meet the needs of a particular group of young people.

15 poor communication

- Some parents said that they experienced poor communication between service providers. At it's worst, this could result in a child or young person missing out on short break experiences.
- Some parent felt that communication between transport providers and parents was poor. In their experience, this often meant that children and young people were not picked up or returned home on time and again this lack of communication might result in a child missing out.
- A few parents felt that a lack of communication between service providers had resulted in a lack of awareness of their child's needs. Two example of this were at Discovery Home where there was no female staff to deal with the needs of a teenage girl and on transport where assisting staff appeared totally unaware of the manifestations of a particular condition.

16 Lack of clarity/transparency around Short Break allocation

- Parents complained that they had little knowledge about how Short Breaks were allocated.
- One parent said that she had asked for a policy on how Short Breaks were allocated, but none was provided.
- Parent reported that they felt that short breaks were allocated in a very ad hoc manner and may be dependant on the professionals that you were involved with and their knowledge of the short break system.
- Some parents felt that their child wasn't given a fair share of Short Breaks and many gave examples of families that had access to many more services than themselves.
- Parents acknowledge that the amount of Short Break services should entirely depend on the needs of the child or young person and their family. However some parents felt that a new system needed to be agreed so that parents were clear about what short breaks they were entitled to and why.

17 counselling and support for parents

- Many parents stressed the need for counselling services, particularly when their child had been newly diagnosed with a disability. Some felt this was a gap in service provision which left parents depressed and isolated during the most difficult period of their lives.
- Some parents and professionals spoke about the need to have support services for parents of disabled children which focused on their 'all round' wellbeing. A service which offered advice, support groups, counselling and relaxation techniques such as message, yoga, reflexology etc. Under one roof was thought by professional and parents to have enormous benefits for parents and the whole family.
- There are many parent support groups in Tower Hamlets doing an excellent job of supporting parents, however some parents report gaps and have not been able to find a suitable group.

18 outings and holidays

- When discussing trips and family holidays, many parents reported that they had never had a family holiday because of the difficulties posed by taking their disabled child away on a long trip.
- Generally, parents felt that it would be enormously beneficial for all the family to be able to get away for a few days, although there was acknowledgement that this may only be possible if they had assistance both physically and financially.
- Parents who had family in Bangladesh and other countries acknowledged that they may choose to go back home to visit family if they are able to do this. However the parents that were consulted said that they did not feel that such holidays should be subsidized by Short Breaks funding. Some parents however felt that they would welcome a holiday in the countryside if this were available.
- Some parents said that their disabled child had never experienced any kind of holiday. Most felt that the right kind of holiday would be a fantastic experience for their disabled child and the whole family.

19 last word

It should be remembered that there are many parents and children in Tower Hamlets that are entirely happy with the services that they receive and where significant support is provided by staff and other parents.

This consultation deliberately sort the views of parents and professionals in trying to ascertain areas where improvements could be made, both in the quality and quantity of existing services and where service gaps might be usefully reviewed in the future.

There were times when I was overwhelmed by the skills and commitment of parents who work tirelessly to ensure that their child enjoys the best possible opportunities in life. As a group, parents present as entirely sensible and fair, keen to become involved in decisions that affect the lives of their children and families. This is was also true of many of the professionals I met who were truly inspirational in their commitment to provide excellent opportunities for children and young people with disabilities to grow and develop to their full potential.

Therefore, the findings of this consultation should not be viewed as negative – rather it is an opportunity to work with parents and professionals, using their experiences to shape future services which are family centred and responsive to the needs of children, young people and their families in Tower Hamlets.