

March 2008

Independent Consultation in
Tower Hamlets with children and
young people with complex needs;
experiences of personal care
packages.

Reporting to Tower Hamlets
Integrated Services for children with
disabilities.

Marisa Tighe

Background

In 2005, Tower Hamlets Integrated Services consulted disabled children and young people about their experiences of local services (Triangle report; 'Shape it up a bit').

Subsequently, it was decided that another area required exploration through consultation: the personal care of children and young people with complex needs. Therefore, in January 2008, Tighe Independent Consultation Services was commissioned by Khalida Khan, Disabled Children's Integrated Service Manager in Tower Hamlets, to meet with children, young people and their families and to report on their perceptions of their personal care packages. In particular, it focussed on discovering what aspects of the care they were:

1. Satisfied with.
2. Dissatisfied with.
3. What changes they would like to see implemented in the future.

Aims

The findings will inform the integrated service plan for children with disabilities, the future commissioning of third sector services and personal care contracts. It is hoped that reporting the results of this consultation will help to improve the quality of the everyday experiences of children and their families in Tower Hamlets. It may influence the way personal carers actually implement support while taking into consideration the 'Every Child Matters' Legislation and working with the 'Every Disabled Child Matters' campaign.

The Children and Young People

The 14 children and young people consulted were between the ages of six and 19 and lived in Tower Hamlets. Most attended the special schools: Stephen Hawking (7), Beatrice Tate (4) and Phoenix (1), but two were at mainstream primary school. Five were girls and nine were boys. Nine were Asian or Asian British, four White British and one Black British: African. The children and young people included had a wide range of impairments, some multiple: Cerebral Palsy, Martsolf Syndrome, Severe Developmental and Learning Disability, Epilepsy, Autistic Spectrum, Cranifacial Abnormalities, Visual and Hearing Impairment and Cystic Fibrosis (as described in the Integrated Service list of families with personal care packages). Most, but not all, were non-verbal.

Methodology

The children were consulted at home and/or at school. Within the limits of the cohort of children every attempt was made to ensure there was a balance of ages, gender, race and range of impairments. Information was gathered in semi-structured interviews through both open-ended and closed questioning. In order to make questioning interactive and less potentially threatening, most children were asked to select symbolised words in response to questions. Due to their very differing abilities to comprehend and answer questions, it was necessary to frame questions carefully and flexibly using a variety of augmentative communication aids such as signing, symbols and objects of reference tailored to individual needs. Towards the end of the interview, the children and young people were also given the opportunity to make any other comments they wished regarding the personal care they had been receiving. Questions were staged. The first type of question required a simple yes/no response; for example, is your carer good at feeding you? If the response was 'no' then a process of elimination was used in order to discover the reason for this response; e.g. is he/she too fast, too slow, too rough, gives you no choice, too much choice?

Different methods of eliciting information from children and young people with multiple disabilities were considered through the reading of an article entitled 'The participation of children with multi-sensory impairment in person-centred planning' by Kim Taylor (2007). The methods used in this consultation were closely related to the 'Talking Mats' method of indicating preferences (Brewster, 2004 Cameron & Murphy 2002 and Germain 2004).

Due to the particular communication difficulties of many of these children and young people, it was necessary to check for accuracy in interpretations of responses, either with their family members or school staff who knew them well. The author's extensive experience as a special needs teacher with knowledge of inclusion issues, speech, language, communication difficulties and complex needs was also used to analyse the findings. The conclusions drawn are her's alone. The author has approximately 15 years experience of working in Tower Hamlets and a Psychology degree from University College, London.

Parents were given a different interview schedule and all asked the same questions. Some questions were closed, some used rating scales and some were open-ended. They were also encouraged to make any comment they wished regarding their personal care packages and to make suggestions regarding improvements that could be made to the service. The use of a translator was necessary in some cases.

Some participant observation was used to draw conclusions, where appropriate, with consent and due respect to privacy and dignity. Other ethical issues were given careful consideration such as reassuring families

about confidentiality and obtaining consent to visit children, young people and their families.

By working hard to consult disabled young people, this report acknowledges its responsibility to include the views of disabled people with regard to the Disability Discrimination Act 1995 and other governmental guidance and legislation such as 'Valuing People' DoH 2001 and DFES 2004 'Every Child Matters'.

Findings

Limitations of and Influences on Findings

Only half the young people and children visited appeared to have the cognitive ability to communicate a yes/no response even when supported by people they knew very well and using such support strategies as objects, signs and symbols. Of those seven, three were able to answer consistently across all questions. Four were able to answer some questions but not others. Interviews with families and school staff, who knew them well, were, therefore, essential in helping to interpret or confirm responses and providing further insights and information. The current research suggests that there is still much to be discovered about validating and facilitating meaningful consultation with people with intellectual and complex physical disabilities (Kim Taylor 2007). For example, children with short-term memory difficulties often have a tendency to overly focus on the last thing mentioned when responding to lengthy questions. There is also always the possibility of children answering questions as they think they 'ought to', rather than as they really feel, particularly with someone they do not know and trust yet.

It was not possible to ask all children exactly the same number and type of questions. This was due to individual differences in cognitive ability, speech language and communication skills, social and emotional maturity and varying care packages. Both qualitative and quantitative information was gathered and analysed but as Kim Taylor (2007) and Ware (2003, 2004) point out, these responses need to be taken as individual expressions of feelings in the 'here and now' and assumptions should not be made that these are expressions of the future also. For that sort of information interviews would need to be repeated over a much longer period of time to confirm findings.

Quantitative Results

What children and young people were happy about

Of those children and young people who were able to respond consistently to the particular question:

- All said that they **liked** their carer.
- 73% (5 of 7) were happy with the **gender** of carer they had. Most had a female carer and preferred that.
- 75% (3 of 4) were happy with how they were **dressed**.
- 66% (2 of 3) said they were happy with how they were **washed** (the one who was not happy was unable to explain why but, possibly may have been struggling with feelings of embarrassment e.g. one young woman said she did not like 'being helped in the bathroom' but was happy being helped everywhere else.
- Of the incontinent children, who were able to respond, both felt safe and happy with the way they were **changed** by their carer.
- Only one child was both helped at **mealtimes** and able to respond about how they were helped. He was happy with the help he received.
- All (4) said they were happy about the time of day at which the carers came.

What children and young people were not happy about

Of those children and young people who were able to respond consistently to the particular question:

- None were satisfied with the **frequency of visits** from carers. 75% (3 of 4) wanted them to come more often and 25% (one child) less often: 'so I learn how to do things myself'.
- Two of seven young people wanted to change the **volume** of their carer's **speech**.
- 50% (2 of 4) said they would prefer a **young** carer and 50% said it didn't matter.
- Children and young people suggested that carers should:

'Play with us more and make it more fun'.

Keep own emotions under control, e.g. 'When I was naughty, when I calmed down and said sorry they were still moody. That made me worse.'

'Talk less' - child on the autistic spectrum

'Talk more'

'Help me in the evening as well, to get me dressed and have a bath'

'Take me onto the school bus'

Making reference to the 'Every Child Matters' The ideal Carer

Being healthy: enjoying good physical and mental health and living a healthy lifestyle.

Children and young people described an ideal carer as someone whom:

- 'let's me choose what to eat'

Staying safe: being protected from harm and neglect.

Children and young people described an ideal carer as someone whom:

- 'stays with you and doesn't let anyone take you'
- 'doesn't hurt you'
- 'tells me what's going to happen next'
- 'is young or old, but not too old'
- 'I have seen before' - one child gave a score of 10 out of 10 for this for importance.

Enjoying and achieving: getting the most out of life and developing the skills for adulthood.

Children and young people described an ideal carer as someone whom:

- 'plays with me'
- 'has fun with me'
- 'chatty'
- 'talks slowly and quietly'

Making a positive contribution: being involved with the community and society and not engaging in anti-social or offending behaviour.

Children and young people described an ideal carer as someone whom:

- ‘gives me choices’

Economic well being: not being prevented by economic disadvantage from achieving their full potential in life.

Children and young people described an ideal carer as someone whom:

- ‘gives me less help so I learn to do things for myself’

Summary

All children liked their carers and the time of day they came. Most were happy with their gender, the way they dressed, washed, fed and changed them.

The main changes to the care packages most requested by children and young people were:

1. To improve to the way the carers communicated and played with them
2. To increase the frequency of visits from the carers.

What Parents were happy with:

- The **time of day** at which the carer came to help - all were happy with this.
- The **number of carers** that came for each session.
- 65% (6 of 9) were happy to use **respite** care facilities (2 were unsure what it was or if they were able to get it).
- All were happy with the **language skills of the carers** they had at present. Of the 10 families where English was their second language, 40% considered it extremely important for the carer to speak their first language; giving it a score of between 8 and 10 out of 10 on a rating scale.
- 43% (6 of 14) said they thought all carers were **trained** properly. 14% (2 families) said some were, some weren't.
- All were happy with the **gender** of carer but one would have preferred a man if there had been a man available with appropriate training. However, most preferred a woman even for the older young men cared for. This appeared to be more of an issue for the Asian families and may,

perhaps, be linked to feeling uncomfortable with having men other than family in the home due to religious/cultural expectations.

- Where **special equipment** was available to use carers used it appropriately.
- 50% (7 of 14) of parents said that they were happy with the carers punctuality.
- 99% (10 of 11) were clear about whom to contact to lodge a complaint or **express their concerns** about a carer.

What Parents were not happy with and Want to change:

- 43% (6 of 14) of parents were happy with the number of visits per week but wanted to increase **how long** the carers stayed on each visit.
- 57% (8 of 14) of parents wanted to increase the **number of times** the carer **visited** throughout the week.
- All were happy with how many carers were sent to them for each session, but 22% (3 of 14) were not happy with the **number of carers known to them**. Due to the serious medical needs of their children, they felt they would benefit from the setting up of a 'team' of carers trained in the needs of their particular child and who share the weekly sessions. This would enable them to perhaps swap shifts and cover when the regular carer is ill or on leave instead of a stranger covering.
- 33% (3 of 9) of families were unhappy with the quality of **respite** care available to them and therefore unwilling to make use of it.
- 43% (6 of 14) said they did not think all carers were **trained** properly. 14% (2) said some were, some weren't.
- 59% (7 of 12) said they did not get a **replacement** when their carer was off sick.
- Four families complained that they were: not always informed on the same day when a carer was going to be ill; were informed at the last moment; or were given conflicting reasons for a change in carer or agency. This appeared to cause them distress and to encourage a lack of trust. Some preferred not to have a replacement as the change caused their child to become anxious and it was almost easier to do temporarily without. One family said they just didn't send their child to school if the carer did not arrive. Two families said **unknown replacements** were not appropriate due to specific training being necessary before starting work with their child.

- 50% (7 of 14) said they were unhappy with the carer's **punctuality**. Two families said the carers offered to make up the time, which was acceptable with one family, but not the other.
- 45% (5 of 14) were clear about whom to contact to lodge a complaint or express their concerns about a carer but were unhappy with the **way their concerns were dealt with**. Some of the comments were:
 - ‘I don't have time to keep ringing’
 - ‘We have no faith in the social worker’
 - ‘We would like a key-worker at the agency so that we can talk to the same person each time’
 - ‘Agencies don't help with interpersonal issues between families and carers’
 - ‘The issues are - lack of information, poor communication and contactability’
 - ‘You get passed on to one person after another’
 - ‘We get told to ring more and more people’
 - ‘My social worker is too hard to contact, he doesn't even have a mobile phone’
 - ‘The school helps more than the social workers’
- Other complaints about carers ranged from making long-distance telephone calls abroad from their telephone, arriving sleepy and eating the family's food. **See Appendix 1e.**

Parents also wanted:

- Two parents would like **help with housework** due to mothers' ill health caused by strain of lifting disabled child.
- One wanted **overnight respite** during week.
- Four parents wanted carers with **medical training**, e.g. knowledge of administering medication, using gastrostomies, suction equipment, and shunts.
- Carers with training in and **experience of autism** **See Appendix 1a.**
- One parent wanted more opportunities to get **respite**.
- Four families wanted **quicker responses to changing circumstances**, e.g. due to hospital stays/ill-health, pregnancy and one reported it had taken them 11 months to get care sorted out despite guidance saying it should take 35 days.
- Four wanted **weekend help**. Three said it was to take the child out and one said it was to baby-sit so mum could go out.

- Five families wanted extra help in the **school holidays**. Some of the consultations took place in the half term holidays. One family had four children under seven: one severely disabled, one on the autistic spectrum, a baby and a toddler all in a very small flat. Four out of the five wanted help to take their child on outings.
- Two families wanted carers to be able to be left with **sole care** of their child for short periods.
- Help with **siblings** who often lacked sufficient attention from parents or who also had special needs - three parents.
- Three parents mentioned wanting helpers to be able to take their child out to the **school bus**.
- Eight parents wanted carers to be able to take the child on **outings**.
- One parent wanted **evening help** as well as morning help.
- One parent wanted more **advice about the benefit** systems, how to get a disability badge and information about where they could get discounts for outings such as the cinema.
- Two families wanted help to **adapt their homes** to their child's needs

Summary

The changes to the care packages most requested by parents were:

1. Increased frequency and length of carer visits.
2. New systems for covering for carer sickness or holidays and number of carers known to the children and young people
3. Improvements to grievance procedures.
4. Improvements to carer training and monitoring.
5. More advice on benefits for disabled children.
6. For carers to be able to take children and young people out and onto the school bus.
7. Holiday and weekend help.
8. Improved quality of respite care - appropriateness and frequency.
9. Improvements in punctuality.
10. Improved cultural matching of family and carer. Several families mentioned that when a close match was found it made life easier.

Qualitative Findings

1. Families had some concerns about the specific **training** and experience of carers. One family was also concerned about how they made use of the training they had received and how agencies monitored this. They were not aware of carers being observed 'on the job' as part of professional development or monitoring.

- It appears that agencies have difficulties finding staff who have been trained in the slightly more **medical** duties such as administering epileptic drugs, using gastrostomies and suction machines which meant that families often experience long periods of time without a carer until someone suitable has been found. This also had implications for not being able to leave a carer in sole care of the child or young person in order to briefly visit a shop or attend meetings about their child.
 - Several parents felt carers needed training in dealing with **the emotional and behavioural needs** of the child as well as the physical needs. Five parents also mentioned that they might need support to deal with their own feelings in such an emotionally demanding job. **See Appendix 1b**
 - Training in understanding the very particular anxieties, behaviour and communication difficulties of children on the **autistic spectrum** were found lacking.
 - Training on the issues related to **cultural differences**, e.g. one white mother reported that she was very happy with her Asian carer, but the carer complained that she felt treated 'like a slave'. Two other parents reported that sometimes the carers treated their children as if they were their own instead of respecting the families rules. **See Appendix 1a**
2. There was an additional, persistent issue that kept emerging during discussions. It seems that the appropriate **attitude** of the carer was the characteristic they valued most. One parent said 'maybe the agencies could get to know the staff better. We have had some very unusual characters and unsuitable choices for carers sent to us'. Another said 'I'd rather have someone with the right personality and less experience than someone with lots of training and a less suitable personality'. **See Appendix 1c**
 3. Another key issue raised by parents, children and young people was **consistency** in carers. This issue came up time and again and as one parent said 'they change carers like clothes'. Another said 'we get a lot of change.' Parents reported that it is hard to have to explain all the details of the child's personal care needs over and over to a new carers and many of the children and young people with such complex needs find change much harder to deal with than the average child. They often find the concept of time a challenge and need warning that change is coming in order to feel safe and relaxed. This is apparently very much an issue when carers are off sick and a complete stranger visits the home as a replacement. When an agency stopped operating one family had to wait seven weeks before a new agency was found and their child became unused to carers helping. Many other families experienced long periods without care. **See Appendix 1d.**

4. The way **changes in circumstances** were dealt with was another issue raised by families. With complex needs visits to hospital are often very much part of the family's lives and when this happened care provision stops. It appears that sometimes there is a long delay in reinstating the care or in adjusting the care package to reflect new and perhaps temporary, needs. This can have very detrimental effects on the family and child or young person and can also be an issue when carers go on holiday or there is a pregnancy/ birth of a sibling. **See Appendix 1d.**
5. Although not an intended focus for this consultation, an interesting observation was made during planning that of the families contacted only white families had a **direct payment scheme** as a personal care package. One parent told me 'I had to fight hard for it' and 'you have to learn a lot about employing people but the direct payment department is very helpful'.
6. Finally the need for **honesty** from service providers was raised. Two very different families said the following:

'If only they would be honest with us about what they can provide. They talk about considering the needs of the whole child but then come up with, what appear to be excuses for what they can't provide. Why don't they just say 'we are sorry we can not provide everything you need but this is due to governmental budget restrictions'

'They just pass the buck'

Families used the following descriptions to describe an **ideal carer**:

- emotionally strong
- not easily offended
- young and flexible
- lives locally so they can arrive on time
- punctual
- without families of their own so they don't have to take time off for their own children
- willing to get further training
- eager to learn
- sensitive to the cultural ethos of the families rather than just treating the children as they would their own
- sensitive to the needs of both parents and children e.g. when moving around the home being respectful of the parents privacy
- reliable
- enthusiastic about the job rather than 'going through the motions'
- considerate
- conscientious

- know my child's physical, and emotional/spiritual needs
- tidy
- Not too old and physically fit enough to cope with the high physical demands of the job

Conclusions

This consultation was undertaken to discover what aspects of the personal care packages children and young people were satisfied or dissatisfied with, and what changes they would like to see implemented in the future.

There appeared to be general satisfaction amongst this group of children/young people in Tower Hamlets regarding the functional aspects of personal care such as the way they were dressed, washed, changed and fed. However, they identified two main areas of improvement. The first was the way the carers communicated with them. They wanted them to chat and play with them more and to involve them in what was going to be done next. The second change they wanted to see was an increase in the frequency of carer visits and consistency of staff as it can take a long time to get used to and trust a new person caring for them.

Parents generally confirmed these findings but also emphasised the need for more carers with an enthusiastic attitude enabled by good training and an appropriate personality. More help in the school holidays and weekends, especially with outings, was often requested. There appeared to be wide variation in parent beliefs regarding disability, respite and about what could be expected of a carer, e.g. whether they could and should be left in sole charge, play or chat with the children, take them on outings or to/from the school bus. It seems possible that this could have been due to carer job descriptions not being communicated effectively to families and or to differing cultural and individual expectations. There was some dissatisfaction about grievance procedures and the carer agencies' lack of monitoring carers' everyday practise. This has implications for the accountability of agencies' contracts with Tower Hamlets Integrated Services for Disabled People.

Recommendations

Further work exploring:

- How to consult meaningfully with children and young people with complex needs about their personal care. Exploring the use of video with families and carers, over time, (with due regard to ethical issues) may be of interest.
- Cross cultural understandings of disability and expectations of carers.
- The use of key workers in carer employment agencies and making links with Lead Professionals assigned to the families.

- How to support agencies in training and monitoring carers' performance.

Appendix 1

Additional comments made by parents:

- a) One family reported that a carer had smacked their autistic child. Another carer lost him when they had taken him on an outing. This meant that she felt the need to 'chaperone' the carer, which of course, defeated the object of getting help. Another carer used a very loud voice, which caused her child anxiety, as children on the autistic spectrum can be hyper sensitive to sound. He was also very frightened when a new carer arrived in a full hijab without warning, which he was not familiar with, and so could not stop screaming.
- b) One family reported that the carer was too scared to look after their son alone. Two parents of children with Cystic Fibrosis said carers often dropped out after the initial training period because they didn't feel able to cope. One also said they felt the carers needed help to deal with their child objectively when they were being behaviourally challenging.
- c) One family told me they had a carer get down on their knees while on duty to pray and preach to them and that they could 'write a book about the inappropriate behaviours of carers' they had had.
- d) One family had been waiting four months for an agency to find an appropriate carer. Three other families had gaps of 2-3 weeks without care due to carers going on holiday or care arrangements changing after a hospital visit.
- e) One family said money had gone missing while a particular carer was with them. Another reported carers talking on their mobile too much when working.
- f) 'What will happen to him after he is 19?'

Appendix 2

Children and young people's interview - sample questions:

First Stage

- Do you like your carer?
- Is your carer good at...
 - Washing you?
 - Dressing you?
 - Feeding you?
 - Moving you?

Changing you?
Talking to you?

- Would you like them to come more often?
- Why? To do what?
- What is good - a man carer or a woman carer?
- young carer or an older carer?

Second Stage

If 'no' to any of the questions above:

- Are they too loud, too quiet, too rough, too fast, too slow...?

Plus 'What is a good carer? Then one at a time - Someone who is young, old, man, woman, gentle, gives you choices, who tells you what to do, speaks slowly, quickly, quietly, loudly, lots, a little.

Appendix 3

Interview with parents - Name..... Date

<p>What do you get help with?</p> <p>Are you happy with the care you get for each of the following -</p> <p>feeding, changing, moving, bathing/washing dressing</p>	<p>feeding, changing, moving, bathing/washing dressing</p> <p>Yes No Yes No Yes No Yes No Yes No</p>
<p>When do you get help? Respite for a week...</p> <p>Is this often enough? How happy are you with this amount of help?</p>	<p>Yes No Not happy Very Happy 1 2 3 4 5 6 7 8 9 10</p>
<p>Is care provided at the most useful times?</p>	<p>Yes No</p>
<p>What else do you want help with?</p>	
<p>How many different carers are there? Is this ok?</p>	<p>Not ok Ok Good</p>

Do the helpers speak your first language?	Yes	No
How important is this to you?	A little	Very Extremely
	1 2 3 4 5 6 7 8 9 10	
Do you think they are trained well enough? Trained to feed? Manual handling?	Yes	No
Do you meet them before they start working with you?	Yes	No
Do you prefer Male female? What choice are you given? Is this ok?		

Interview with parents continued

What happens if the carer is ill? Do you get a replacement? Do you know them?	Yes Yes	No No
Equipment - do they use the right equipment? Do you have a hoist?	Yes	No
Are they punctual and stay the correct time?	Yes	Mostly No
If there was a problem do you know whom you can talk to regarding concerns about the carers?	Yes	No
What changes would you like to see?		

This is a fair record of our discussion	
Signed	date

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