King's Fund

Carers Impact Project in Tameside

The Picture Now

Feedback from Carers
May 1998

The Picture Now: feedback from Carers

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Improving outcomes for carers

Summary of feedback from carers

Tameside Action Plan	A Positive Difference	Issues to be Addressed
To ensure carers are better informed (which requires staff to be carer aware)	✓ Homecare workers more carer aware - but room for improvement! ✓ Carers Centre ✓ Social Events, Carers Week etc. ✓ Charter Days	Professionals do not always see carers as the experts and do not fit with carers routines. Need more advertising for the Carers Centre Problems finding hidden carers Assumptions made about young carers Carer is forgotten when the caring role ends.
To ensure good practice in assessments and care co-ordination	✓ More involvement in daughter's care plan ✓ Young carer offered assessment with educational psychologist → ✓ Carer asked about the help she needed →	Need more involvement of carers in assessment. More self recognition by carers needed But only when at the 'end of her tether' But carer filled in assessment form and never saw or heard of it again! People do not know about carers' rights to an assessment Lack of acknowledgement within private sector of the importance of needs assessment for people with learning disabilities

Tameside Action Plan	A Positive Difference	Issues to be Addressed
To involve primary healthcare teams and GPs		Problem of access and communication for deaf carer and deafblind husband at GPs Insufficient information from GP and lack of recognition by GP Greater clarity needed about who will co-ordinate routine health checks for person with learning disabilities
To strengthen the carers voice within joint planning	✓ Carers council ✓ Joint Strategy Group	
To improve continence services	✓ More discussion with carers → ✓ 'open door policy' - anyone can ring in	**but** not yet sorted Inadequate and inflexible supplies Lack of expert advice Costs of meeting the shortfall Difficult to get information about continence services No laundry service to deal with acute continence problem
To inform carers of training available		Carers need training at home Carers need specific training in handling people with behavioural problems

Tameside Action Plan	A Positive Difference	Issues to be Addressed
To inform carers of all available counselling services	✓ Hospital referred carer for counselling → ✓ Carer support groups	**but** after insensitive diagnosis giving Very little choice of counselling mainly private
To support Asian carers		Respite unit unable to cook Asian meals
To continue work in progress on respite care	✓ Carers of people with learning disabilities have confidence in respite care and regard it as an essential support ✓ Better quality of care for people with learning difficulties ✓ Good dialogue with social services about the needs of person being cared for	One carer considered there was inadequate space for wheelchairs Unit had no adapted transport for taking son on extended trips during his stay No back-up to ensure quality of day care when staff absent Cutbacks in respite allowance Rising costs of respite care
To improve homecare services	✓ Good support for carers of people with Alzheimer's disease	Inconsistency of homecare for older people Expensive service
To ensure carers have access to help in a crisis		
To progress work on housing needs of carers		
To meet the commitments of the Carers Team	✓ Well planned discharge with home visits to check facilities	

Follow-up interviews with carers in Tameside

Telephone interviews were conducted with a small number of carers in order to gain some current feed-back about continence services and about respite care for people with learning disabilities. Both these services had been identified as areas of concern for carers during the earlier round of interviews and focus groups at the outset of the Carers Impact project in Tameside.

a) Continence services

Five carers were interviewed. Three were parent carers, looking after children of school age or younger. The others were men caring for their wives, both aged over 60 years. Two of the parent carers each had two children with the same disorder (cerebral palsy in one family and a rare genetic condition in the other).

Three carers were currently receiving some support from the continence services. Another had had support in the past but this had now stopped. The fifth had experienced chronic difficulties in helping her teenage daughter to cope with her urinary incontinence but had had no contact with the continence services.

The issues identified were:

➡ *A lack of expert advice*

Support exclusively took the form of supplies of incontinence pads or `slips'. Despite the recent drive within the service towards the promotion of continence, none of the three carers receiving support had recently been offered advice on the management of incontinence or a reassessment of their needs. They considered that they had become their own experts in coping; for example, one parent said that he did his own reassessments simply by asking for larger pads as his children got older.

A carer whose wife had formerly received pads reported that they had abruptly been withdrawn two years ago on the grounds that “she no longer needed them”. In this case, the person cared for was able to get to the toilet with some difficulty but felt that she needed the pads as an extra safeguard at night and when sitting in her wheelchair during the day. The decision to withdraw the supply of pads had reportedly been taken without explanation or consultation.

The final carer had struggled for most of her 15 year old daughter’s life to cope with her urinary incontinence and also to gain recognition from others that this was a `real' problem. She felt repeatedly dismissed as an over-anxious mother by her doctor and by her daughter’s school, despite overwhelming evidence of the child’s inability to cope. This had effectively denied her access to any specialist expertise. Only after a recent diagnosis of an autistic condition had the professionals begun to take notice. Her daughter has since been referred to a psychiatrist who has recommended a consultation with an incontinence nurse. She felt that she would have greatly benefited from advice at an earlier stage when her own income was larger, enabling her to make adaptations to the bathroom facilities at home (such as the installation of a bidet) which would have helped her daughter to manage her problem more independently.

➡ *Inadequacy and inflexibility of incontinence supplies*

All three carers receiving incontinence support complained of an inadequate supply of pads. A quota of 4 per day had been set for each person, regardless of individual need. More pads were needed even when the person cared for was in good health and the number could increase dramatically in certain circumstances. One parent said that his son used considerably more after a gastrostomy which had markedly increased his fluid intake. Other carers noted that periods of illness led to heavier use. None of these factors was taken into account in deciding the quota, and the carers resented this inflexibility of approach which left them to make up the shortfall in provision from their own resources. In their view, the level of provision was determined entirely by service resources, with no regard to individual need.

The parent carers whose children were at school were particularly hard-pressed. At one time the schools had supplied their own pads but now parents were required to send them in with their children. In one case, the school had requested 4 pads per day (i.e. the whole of the day's supply) and the parent had had to negotiate with the staff to reduce the number to 2, although extra pads still had to be sent in in case of accidents. The same parent had also had to supply pads when his second child had gone into hospital a year ago; moreover, her use of pads had escalated at this time to 12 per day because of her condition.

The carers noted a marked tightening in the supply of pads over the past couple of years. A mother of two boys, aged 9 and 3, had been told that the youngest would not be eligible for free pads until he was 4, whereas her older son had received supplies at 3. In the meantime, she was continuing to cope with commercial toddler nappies which the little boy was rapidly outgrowing. Another parent said that he had formerly been able to pick up extra pads from the health clinic towards the end of the month when supplies were running low but this was no longer possible now that all pads were delivered centrally. A spouse carer said that the interval between deliveries had been extended from 6 to 8 weeks, with the same number of pads per delivery.

One carer wanted more flexibility in the kind of pads provided as well as their overall quantity. He was receiving two different kinds of pads for his wife and had found that one worked well but that the other needed to be `doubled up' in order to prevent her soaking through. This of course meant that each consignment was lasting an even shorter time. However, he met with a flat refusal when he requested that the mix should be adjusted to provide a larger proportion of the effective pads.

➡ *The costs of meeting the shortfall*

The costs of meeting the shortfall in provision of incontinence pads made serious incursions into the carers' limited budgets. In the case of the woman whose supply had been withdrawn completely, the cost of pads had to be met entirely from household resources. Actual costs varied according to the specific pads used and the amount needed. One parent was paying £12.70 per week for her younger child's commercial nappies and also buying extra packs of pads at £12.45 for her older son when supplies ran out after about 5 weeks of the 8 week interval between deliveries. Another reckoned that he was paying around £70 per month to meet his children's needs. One carer was regularly buying packs of pads for his wife and had also invested in a range of incontinence aids, such as bed-sheets, chair covers, special pants and gauze. Without her regular weekly stay in respite care each month, where incontinence supplies were provided, he considered that he would have been unable to meet the costs.

Anxiety about the costs of incontinence care were combined with feelings of injustice about having to meet them. From the carers' perspective, incontinence was a medical problem which required an appropriate and full response from the Health Service. Being told that they should use their Attendance Allowance for this purpose was a particular source of resentment. As one carer said, "It only stretches so far".

b) Respite care for people with learning disabilities

Four carers were interviewed. All were parents of young people between 17 and 22 years old with learning disabilities. One young man had associated profound physical disabilities and a young woman had a mild impairment which limited her mobility. All were currently receiving respite care, usually once a month for a 2 or 3 day stay. One young man had been placed with a family through the Family Link scheme; otherwise, they were cared for in small, community-based units.

The interviews confirmed the findings of the earlier Carers Impact research in Tameside that carers generally have confidence in respite care and regard it as an essential support for themselves and the person cared for. All the carers in this small sample felt that their son or daughter benefited from respite care. Companionship, the experience of living in a different environment, independence and new activities were the chief gains mentioned. The carers themselves benefited through having a `breather', being able to spend more time with their partners and other children, and having the opportunity to pursue personal interests. Respite care was thus admirably fulfilling its assigned purposes. There were, however, some outstanding issues:

➡ *Facilities and transport*

All the carers were happy with the level of staff support and the personal care which their young people received. The few concerns which were expressed focused on facilities and transport. One carer whose son was a wheelchair user considered that there was inadequate space in the common areas of the unit - particularly the lounge and dining room - to accommodate wheelchairs comfortably. Transport was an issue for two carers. One said that her son was usually taken to the respite unit directly from school by school transport. On the occasions that she had to transport him herself, he made a fuss because of his firm expectation that he would be taken in the bus. The other reported that the unit had no adapted transport for taking his son on extended trips during his stay at the unit; this meant that he could only be taken out in taxis or private vehicles.

➡ *Dietary needs*

An Asian carer reported that the respite unit which his son attended was unable to cook Asian meals. His son's need for at least one Asian meal a day could be met only by taking him out to a restaurant or by using a take-away. Unfortunately, this proved an expensive solution since the costs were met from his son's allowance.

➡ *Availability of holiday respite*

All the carers were satisfied with the amount of regular respite care which they received. For one carer, however, their was an unresolved issue about the availability of extended respite to cover a two-week family holiday. Whereas last year she had been offered respite for the whole period, this year she could obtain it just for one week and only then by contributing some of her regular respite nights. The new rules had been blamed upon cut-backs in Social Services. Failing a solution, the only option would be for her daughter to take a week's leave in order to look after her brother.

➡ *Cost*

The rising costs of respite care was raised as an issue by one carer who felt that an excessive proportion of her daughter's welfare benefits had to be diverted to this purpose, leaving only a small amount to spend on clothing and other personal needs.

Carers Review of Progress, 9 May 1998

The review of progress was facilitated by Carers Impact with the help of staff from the Tameside Carers Centre. It took place during a regular meeting of the Carers Forum in Tameside.

The format for the review was small group discussions, organised around key topics which had featured in the Carers Impact Action Plan for Tameside.

These were:

- **Having a voice**
- **Information and assessments**
- **Primary health care**
- **Needs of young carers**
- **Quality of services (home, day and respite care; crisis services; hospital discharge)**
- **Needs of ethnic minority carers**
- **Housing**
- **Training for carers**
- **Counselling**
- **Continence services**

The number of carers present on the day was insufficient to form a group for each topic. Topics were therefore combined and the carers were asked to join the group which interested them most.

During the discussions, the carers were asked to focus their attention on changes observed or experienced during the past year, thinking about what good things had happened and about changes which had not been so good. They were also invited to nominate their top three priorities for urgent attention. Key points were written on flip-charts by the facilitators.

The time available for discussion was limited and some issues were covered more fully than others. Carers often found it difficult to focus on changes over the defined time-scale, which was of course an arbitrary and artificial period in relation to their own experience. The points which emerged do not constitute a systematic analysis of progress from the viewpoint of carers; nonetheless, they are useful in giving an impression of current strengths and weaknesses in Tameside's response to their needs.

Group 1

Having a voice | **Information** | **Assessments**

✓ Good things identified

- Carers Council and JSG.
- More involvement in daughter's care plan - better in recent years.
- Carers Centre team.
- Carers support groups.
- Involvement of Carers Impact.
- Charter days.
- Social events - e.g. Carers Week, festive lunch.
- Homecare workers more carer aware (but still a lot of room for improvement).

✗ What is not so good

- Hidden carers and the continuing problem of how to find them.
- Insufficient advertising for facilities such as the Carers Centre.
- More self-recognition by carers needed.
- Not enough involvement of carers in the care plan.
- Problems of involving carer if living in different local authority area.
- Means-testing of carers' benefits.
- Only one allowance paid no matter how many people you care for;
- If the person you care for goes into permanent residential care, they try to remove your rights as a carer even though the emotional side of caring is increased.
- The carer is forgotten (seen as redundant) when the caring role ends.

☞ Top priorities

- At a national level, carers' benefits should be easier to get (with clearer information) and they should not be means-tested. There should be recognition of the costs of caring for more than one person.
- Clearer signposting to services, including local free paper, GP surgeries, supermarkets, shopping areas.

Group 2

Primary health care **Young carers** **Quality of services**

✓ Good things identified

- Tameside now purchasing care for people with learning/behaviour difficulties coming out of hospital and for those already in the community. Offers a better quality of service than formerly provided directly by Social Services (no agency workers, better trained staff, better managerial back-up). Good quality staffing improves the experience of users; for example, there is a greater choice of activities on offer and more encouragement to take part.
- Good dialogue with Social Services after moving to Tameside about needs of husband (deaf carer with deaf-blind husband). Offered place at a deaf club plus transport. *But* he didn't take to it and that means we are together all the time. Also invited to hearing clubs and trips. More successful.
- Good support for carers caring for people with Alzheimer's , via homecare and respite care, once they are `in the system'.
- Young carers have been offered a two month assessment with an educational psychologist, but only when they are at the end of their tether.
- Discharges from hospital seem to be well planned with home visits to check facilities.

✗ What is not so good

- Access to breast screening for daughter with learning disabilities. Poor transfer of information between Social Services, Health Trust and private sector facility where she lives. Greater clarity needed about who will co-ordinate routine health/dental checks.
- Lack of acknowledgement within private sector of the importance of needs assessment for people with learning disabilities.
- Inconsistency of homecare for older people. Service expensive too. Cost has escalated during past 6 weeks.
- Assumptions made about the capacity of young carers to cope.
- No back-up to ensure quality/continuity of day care when staff absent. More resources needed to enable activities/treatments to carry on.
- No free transport service for people living in community facilities and using day care. Free service only provided for those living in their own homes.
- Problems of physical access and communication for deaf carer and deaf-blind husband when visiting GP's surgery. Staff do not seem to understand the problems. Also difficult for deaf people to manage hospital

appointments on their own. Doctors sometimes fail to communicate clearly enough. Reception staff with signing skills needed.

👍 Top priorities

- Stability and continuity of staffing - e.g. in day care and homecare.
- Carers/supporters with signing skills for deaf-blind people.
- Communication - for example, about the availability of assessments for carers. People just don't know.

Group 3

Continence services | **Counselling** | **Training for carers**

Housing | **Needs of ethnic minority carers**

✓ Good things identified

- More discussion with carers about continence problems but not yet sorted.
- New 'open door' policy for continence support - anyone can ring in.
- Hospital has responded positively to one carer who highlighted the need for counselling after the insensitive initial handling of a diagnosis.

✗ What is not so good

- Inadequate supplies of incontinence pads; for example, children have to take 3 pads to school out of an overall allowance of 4.
- No laundry service to deal with acute incontinence problems.
- Difficult to get information about continence services before needs arise. Information urgently needed, possibly through a leaflet, including which products to buy.
- Counselling available for carers mainly private -very little choice. Too few counselling services, especially for children's needs.
- Changes needed in professional culture to increase sensitivity to carers. Professionals do not always have the experience to understand people's needs; fail to fit in with carers' routines and way of life; do not see carers as the experts.
- Carers need training at home; not always easy to get on appropriate course.
- Carers need specific training in handling people with behaviour problems. Courses do not always help.

👍 Top priorities

- Better training for carers.
- Improvements in the way carers are treated; seeing them as individuals; greater sensitivity to their needs.