King's Fund

# Carers Impact Project in Hertfordshire

Report on the focus groups and interviews conducted with carers in June - July 1997

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# 1 Introduction

## 1 a) Who we spoke to

Sixty carers were involved in the project in Hertfordshire, caring for a total of sixty-one people. Twenty-five of these carers came to one of three focus groups (one in Hitchin and two in Hemel Hempstead); seventeen carers were interviewed in the Hitchin area and eighteen in and around Hemel Hempstead.

One third of the people cared for (20) were children under 18, with a physical or learning disability, or both. Less than a third (16) were people over 65; of these, six had a mental health problems, and four had problems both with mental health and physical disability. Four of the older people had physical disabilities but no mental health problems. The remaining people cared for were adults with physical disabilities, learning disabilities and mental health problems, sometimes alone or in combination.

*More details of the characteristics of the carers and the people they cared for can be found in appendix 1.*

## 1 b) (i) The interviews

The individual interviews were carried out with the aid of a semi-structured schedule. This was divided into five main sections:

- The history of the caring relationship and the nature of the current caring task
- Pathways to services - how the carers found out what was available and which had proved to be the most useful sources of information
- Carers' experiences of assessment and the implications for support
- Their experience of services
- The impact of services on carers' lives and any gaps identified

On average the interviews took one-and-a quarter hours to complete. The actual time varied according to the complexity of the caring history and the range of services currently received.

## 1b) (ii) The Groups

A simple format was adopted for the groups, comprising:

- in two of the groups, a warm-up exercise based upon a written 'cameo', a fictional account of a carer incorporating some common dilemmas and problems*. The carer's GP featured in the cameo as a potential source of information and support. Breaking into smaller groups, the carers were invited to consider the kinds of action that the GP might have taken to improve the situation and also to discuss their own views about the improvements needed. They then fed back their points to the whole group and these were recorded on a flip chart. Previous experience with cameos in a focus group setting had shown that this exercise was helpful in enabling carers to put their own experience into a broader context and to develop a more general perspective on preferred outcomes.
- Individual feed-back from the group members on similar lines but drawing explicitly upon their personal experience. Their replies were recorded on a flip chart.
- A brainstorming exercise around the question, "*If you could improve the situation for carers like you in Hertfordshire, what would you change?*" Ideas were listed on the flip-chart.

## 1 c) Presenting the findings

In presenting the findings, we have broadly followed the structure adopted for the interviews. Thus we consider in turn the carers' backgrounds, their experiences of access to services, with special reference to the assessment process, and their views about services currently received. The analysis is based upon the interview data, amplified with material from the focus groups. The 'Key Messages' section at the end summarises the carers' views about desirable outcomes and the factors in their situations which help or prevent these being achieved. Some issues specific to current service provision in Hertfordshire are then outlined along with the carers' suggestions for needed improvements.

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* *The content of the cameo was considered less appropriate for the carers of mental health service users in the third group. In this group, we proceeded directly to the second stage, the exploration of individual experiences.*

# 2 What the carers told us

## 2 a) Caring background

### 2 a) (i) Length of time caring

The length of time the carers had been caring varied from little more than a year to over 30 years. Just under a third of those interviewed had been caring for less than five years, and a slightly larger proportion had been caring for over 15 years. For many carers the start of the caring role had been a gradual process, as it was for a woman in her sixties who had always lived with her mother, now aged 96. For others the start of caring was the result of an accident, a decision to adopt, or the birth of a child with disabilities.

For many carers, the time since they had begun to see themselves as "a carer" corresponded to the length of time caring. However, there were several who had been unaware of the term "carer" at the outset but had acquired that identity through their contacts with professionals or others in a similar situation. For some people, a specific event or a worsening in the condition of the person cared for had changed their perception of their own role. For example, a man whose wife had had MS for 30 years said that he only began to see himself as a carer 17 years before when she lost her mobility and transferred permanently to a wheelchair. In contrast, one carer said that her sense of herself as a carer pre-dated her current caring role, as she had had caring responsibilities since a teenager.

Parents of younger children were most likely to express ambivalence about seeing themselves as carers because they saw caring as a normal and substantial part of the parenting task. One was particularly assertive about her dislike of being called "a carer"; on the other hand, several said that they had begun to see themselves as carers when they first realised the extent of the child's difficulties and the scale of the extra care required.

Almost all the people interviewed saw themselves as the main carer but most had some help from members of the family. Sometimes this amounted to little more than occasional visits and sitting but there were examples of family members looking after the cared for person in order to provide the carer with a holiday break or providing regular support during the week. The partners of the parent carers were usually heavily involved in the caring task and had often taken complete responsibility for lifting and carrying as the child had grown older. One carer of an adult son with mental health problems considered that she shared the burden of care equally with her husband.

## 2 a) (ii) Caring tasks

Carers were providing help with a great range of caring tasks, the nature and frequency depending on the kinds of disabilities of the person cared for and the carers' own capacities, for example to lift. Several children with profound physical disabilities had to be helped with every possible personal care task, including feeding milk feeds through a tube, physiotherapy, giving medication, regular suctioning to clear airways, and re-positioning at night. Continuous night-time care was less likely to be required by younger adults and older people with physical disabilities but many needed intensive personal and nursing care during the day.

Supervision was a key part of the carers' role in caring for both children and adults, and most carers felt that meeting the social and emotional needs of the person cared for was as important as providing personal care. Some of the children needed help with mobility, and some adults had to be lifted on and off the toilet or commode. All the children needed activities to be organised, and some of the older children and young adults needed help with transport and arrangements in order to lead a social life. Constant supervision was sometimes required by older people with mental health problems in order to prevent self-harm through wandering or accidents in the home.

For the carers of people with mental health problems, the care tasks varied as the state of health of the person cared for fluctuated from episodes of acute illness to periods of relative stability. Key caring tasks were giving emotional support, monitoring the person's condition in order to identify any deterioration, and encouraging them to perform their own personal care tasks at times when they found these difficult. Most of these carers were living apart from the person cared for and had taken on responsibility for housing and financial matters which were a particular source of stress.

## 2 a) (iii) Demands changing over time

There was no standard pattern to the change in demands on the carers over time: for some carers the demands had got easier, for others more difficult, and for others still, particularly the carers of people with mental health problems, there was a cyclical pattern.

Some carers felt that the stress had eased over time, not because the circumstances had changed but because they had adapted to a different life style and expectations, and they had services in place. For others the passage of time contributed to a great weariness, erosion of energy and enthusiasm, particularly when they had broken nights. Carers of older people with physical disabilities and/or mental health problems were most likely to identify an increasing burden of physical care combined with growing restrictions on their personal freedom.

The parent carers often commented that things were easier as the child grew older apart from the increasing weight and size of the child and consequently increasing difficulties with mobility. This was partly for practical reasons, such as a decline in the number of hospital admissions as the child's condition stabilised or the introduction of a gastrostomy tube to overcome feeding problems, but also because the parent had gradually come to terms with the situation. Conflicting feelings might, however, re-emerge later on as the parents reached a stage in life where they would normally expect to be free of day-to-day responsibility for their children. Thus a mother of a much-loved child in her late teens expressed her frustration that there was no prospect of moving on and beginning to live a life of her own.

## 2 a) (iv) What got them down

The carers were honest about the things that got them down, and only four said that they had no negative feelings about caring. The constant and unremitting responsibility for another person, with its associated feelings of tiredness, resentment and frustration, engendered considerable stress. To this were added financial pressures in many cases and the frustration of trying to keep up with the routine chores and commitments of daily life. There was often, too, an underlying sense of sadness at seeing the cared-for person deteriorate or observing the increasing gap between a child's development and that of other children.

Some carers expressed resentment about their caring role. One said that her life was totally governed by having to look after her son, and another said that she did not want to be a carer, she wanted to be a wife. Several carers were frustrated at not being able to seek paid employment. Another carer who had given up full time employment to care was not frustrated but said that he missed the interaction with other people.

In many cases, the caring responsibilities were seen to put pressure on other members of the family. The attention devoted to one child meant that the other children missed out on activities or on their parents' time and attention. Some clearly longed to able to have family holidays and for the whole family to join in activities together in a way that was denied them.

The lack of recognition and acknowledgement of the carers' role was a source of pain. One carer described it as being a very lonely role, and that nobody was looking after the carers. Echoing this, someone else said, *"There's nobody there for me. Nobody asks how you're coping"*.

Frustration and anger at being unable to get adequate services, or to have services of poor quality that were subject to sudden changes got the carers down. They found their circumstances and daily routine stressful enough without having the added burden of arguing over entitlements and getting access to the services they wanted. One said that dealing with agencies caused more problems than it solved.

## 2 a) (v) What they enjoyed

Seven of the carers found nothing to enjoy in their caring role, but most were able to identify some positive aspect even if this required a moment's thought. Most carers found their main reward in the relationship with the person cared for. This was expressed particularly strongly by the parent carers who pointed to the affection they received back and the enjoyment they felt when their child improved. The quality of the caring relationship was similarly important to the carers of adults. Caring was easier when there was mutual enjoyment of each other's company, and this often reflected the quality of the relationship before caring began.

Many carers enjoyed practical aspects of caring. They liked to ensure that the cared-for person was clean and well-dressed, well-fed and comfortable. Several treasured compliments from professionals about the quality of care they provided, although one man added wryly that this was something of a two-edged sword since, *"the more they think you can do, the more they leave you to do".* There was widespread sense of satisfaction in knowing that they were enabling the cared-for person to enjoy the best possible quality of life.

A few carers pointed to personal skills and mental resources which they had acquired through caring. For example, one carer said that he loved to cook while another observed that her circumstances had taught her to be patient and open to new challenges.

## 2 b) Access and assessment

## 2 b) (i) First contacts

At the beginning of their caring careers, only four of the carers interviewed claimed to have had any idea of the help they or the person they cared for would need. When asked a slightly different question about their knowledge of services available, slightly more said that they had some general information through their own professional life or voluntary activities. The majority experience, however, was of feeling isolated with the problem and ignorant of sources of help. This was summed up by one carer who said, *"We were on our own. We knew nothing and we had no reason to know".*

For the parent carers of children with disabilities the first contact was often with the paediatrician at the hospital where the child was born. This in turn led to contacts with the hospital social worker and physiotherapist who provided a critical link with community services. If the child's difficulties were not evident at birth, the GP or the health visitor was usually the first point of contact slightly later on. Several parents, particularly, in Hemel Hempstead, cited contacts made with other parents, either individually or through a support group, as a lifeline in the early stages.

Carers of adults and older people were most likely to get in touch with their GP first. Often this contact led to the involvement of the community nurse who became a mainstay in the support system and who activated other services. Only four carers turned to Social Services in the first instance, and two approached voluntary organisations.

The carers experience of their first contacts covered a wide spectrum. At best they had received sympathetic, prompt and practical advice; at worst they had had an unhelpful and distressing encounter, perhaps the worst example of which was a consultant advising new parents to leave their child in hospital and forget that she had been born. Most had found the contacts useful to a certain extent but a widespread comment was that more information could have been volunteered. Professionals tended to respond to specific queries or focus on their own area of expertise, and were often unable to see the situation in the round. Assumptions were also made about carers having more information than they actually possessed. For these reasons, fellow carers sometimes provided more comprehensive and up to date information than professionals, particularly about equipment and benefits. They were able to approach the situation from the carer's own perspective and bring their accumulated experience of similar problems to bear.

Many carers found it difficult to say whether their first contact had encouraged them to make use of services. While fellow carers were quite likely to tell them to "go for it", professionals tended to be more restrained, identifying and arranging services rather than offering explicit encouragement. However, there were examples of professionals persuading carers of the benefits of services, including a GP who pleaded with one man to make use of respite care for his own benefit. This worked out well but there were other instances where carers felt that they had been pushed inappropriately into using services.

Carers were asked whether they had sought help for themselves (in addition to help in obtaining services for the person cared for). Almost half (17) had not done so. Some had been able to work things out within the family but others said that it had not occurred to them to seek help for themselves, or that there had been nobody to turn to. Of those who had sought help, most had turned to their GP for support. Five carers had had counselling, five of them gaining access directly, and one through the GP. Two had sought help from carers organisations and one from a voluntary service agency.

## 2 b) (ii) Social Services Assessments

The people interviewed were asked if anyone from the Social Services Department had been to see them in the past two years to talk to them about the help they needed. Almost all the carers interviewed (31 out of 35) had had some contact. In most cases, this had taken the form of a home visit but there were examples of meetings held at day centres and Social Services offices. The carers were not always clear about the status of the meeting but their replies indicate three main categories: a formal assessment as the precursor to organising a care package; intermediate reviews/discussions in order to fine-tune the existing support system, perhaps adding a new element; and practical assessments by the occupational therapist of the need for aids and adaptations in the home.

For the purposes of the following discussion, the term assessment is used generically to cover the three types.

There was a mixed picture of the context in which the assessments had taken place. Roughly a third had taken place within a pattern of regular contact and a programme of regular assessments, a third had been the result of a referral by health services (hospital and GP), and the other third had been at the carer's request, with varying degrees of urgency and desperation. One carer said that the social worker had turned up out of the blue.

Most carers were seen separately from the person cared for during the assessment process. Often this was because the person cared for was at school, college or day care. Where both were seen together this was because the circumstances dictated it, for example because the person cared for was heavily sedated. It was not apparent that carers had been offered an explicit choice about being seen separately, and most did not see this as an issue. However, one carer commented that all the professionals she had had dealings with had respected her need to be seen separately from the person she cared for, except the hospital consultant.

Those who had carried out the assessment were usually rated highly for their attitude and approach. Comments *included "excellent", "brilliant" "really good, the best we've seen",* and *"friendly and helpful".* There were, however, several examples of less positive experiences. One carer was particularly unhappy, commenting that the social workers were dismissive of her knowledge and were not interested in her ideas. Five were rather milder in their criticism. One of these was rather cynical because the social worker had been unhelpful to her at the beginning, only to change her mind after the intervention of a senior manager. Two others considered that the social worker had pre-judged the situation and had come in with a fixed idea about what to offer.

Where the person cared for underwent frequent assessments or reviews, continuity of the personnel involved was important to the carer but was not always achieved.

> *One carer of an adult with mental health problems recollected a stream of sympathetic and likeable people who had subsequently left or been promoted, and a parent carer who had lost an established social worker through retirement had experienced an eight-month gap without any contact, followed by three social workers in quick succession, the latest of whom was about to leave. In such circumstances, agreed plans and actions tended to lapse and the carer's sense of isolation increased.*

The practice of making a written record of the needs of the person cared for and giving the carer a copy was not universally adhered to. Only a minority of the carers (13) had received copies. One carer had been told that she would be sent a copy but it had not arrived yet; and another said that the social worker had made notes but she did not know what they were for.

It was even less common for a written record to be made of the carer's needs and for the carer to receive a copy. Only four carers had received a copy and one of these was so poor that the carer had complained about its quality. Another carer had been told that she would receive a copy but had not done so. Two carers who had specifically asked for their needs to be assessed and a record made received a negative response; one of these commented that the person contacted did not seem to know how to carry out such an assessment; the other had been told by an occupational therapist that there was no point. This poor picture of record keeping about carer's needs does not of course imply that carer's needs were not being implicitly taken into account, for example in the provision of respite care. It was the explicit recognition that was missing.

For most carers there were no differences between what they would like for the person cared for and what that person would like for themselves. Some of the children with disabilities were unable to communicate and so the parents had to interpret what they wanted, but all of the parents felt that they knew when the child was happy and settled. In the few cases where there were differences, they were around the use of respite facilities. The carers needed respite in order to continue caring, but the people cared for were reluctant to make use of it, or as much as the carer would have liked.

However satisfactory the assessment process had been in itself, carers were disillusioned if it failed to produce a tangible outcome. Only a minority of carers reported that the assessment had resulted in extra support, and in many cases this was a small increment to an existing service such as homecare, or another item of equipment.

*There were instances of promised support which had failed to arrive - for example, a special spoon to help a disabled child eat - and of services being provided only to be withdrawn soon afterwards. Others had had modest requests turned down on the grounds that no funding was available, and one carer was annoyed that an application to the Family Fund had been made on her behalf, which she felt would preclude her from applying herself in the future. Other carers felt that they had got nothing out of the process.*

## 2 c) Carers' experience of services

### 2 c) (i) The range of support received

The carers were asked about the support they currently received. Interviewees were prompted with a written checklist while focus group members were invited to describe their circumstances to the rest of the group.

Most interviewees were caring for people with complex needs, including severe physical disabilities. The services they received reflected this complexity and typically involved several providers at any one time. Carers of adults might thus be in touch with local health trusts and primary care, Social Services, independent care organisations and charitable bodies. Parent carers were in an even more intricate web since provision for their child included educational services and, in some cases, hospice and hospital care provided outside the county. Some carers had organised private care services in addition to the statutory services, thus increasing the complexity of their service networks.

Carers of older people with mental health problems (Alzheimer's disease) and associated physical disabilities featured strongly in the interview group. Holiday respite, homecare, district nursing, chiropody, day care, aids and adaptations were staple elements of their support system and there seemed to be reasonable comparability of provision between carers, although individual components varied. There was less consistency in the level of support from social workers, community psychiatric nurses and GPs, with some carers reporting regular contact while others had minimal or no support.

The pattern of services received by parent carers and their children also had key components which recurred from family to family. In most cases the children were of school age and attended special schools where physiotherapy, occupational therapy and speech therapy were provided. For younger children in the Hemel Hempstead area, these therapies were co-ordinated through the Child Development Centre. Respite care, both for regular relief throughout the year and holiday breaks, were an indispensable aid to coping for nearly all parents. Most of the Hemel Hempstead group used the Midway Centre, and some had negotiated additional hospice care. One very young child with particularly profound needs received care at home through a hospice-at-home scheme, night nursing and a homecare service in addition to regular weekly respite at Midway and holiday respite in a hospice. The parent carers around Hitchin used shared care, where an informal carer - in one case a friend of the family - was paid to provide respite care in their own home, on a similar model to childminding services. Saturday clubs and holiday playschemes were welcome sources of stimulation for children and brief respite for carers in the Hitchin area.

The main variable for parent carers was the extent to which they received support with the physical care of their children at home. Some managed on their own, with the help of their partner, while others had chosen to use homecare on a regular basis, sometimes to help with specific tasks such as bathing. The parent carers did not receive a great deal of "hands on" care from the community paediatric nurses service but relied on them instead for essential supplies and advice. Support was also provided by Health Visitors and Occupational Therapists.

Carers of younger adults with physical disabilities were fewer in number than either of the previous two groups but more diverse in their level of support. At one extreme was a man who took care of all his wife's physical needs, day and night, plus the household chores, relying on service providers only for aids and adaptations. This reflected their shared personal choice and pride in coping alone. Others had opted for more intensive support.

> *For example a different couple in a similar situation were receiving homecare, regular weekly visits from the district nurse to change dressings and check the care plan, a Social Services day centre twice a week, regular contact with an occupational therapist, several adaptations and items of equipment in the home, quarterly visits from a chiropodist, regular eye tests and a vehicle provided through Motability. They reported, however, that their GP was "harder to find than money".*

Most of the adults with mental health problems received low levels of support, but had in the past received more intensive support at home and in-patient care. Most of the people cared for had contact with the community psychiatric nurse, and community support workers provided valued help with social skills and activities. Few carers received support for themselves, and most would have liked more support for the person cared for then they were getting. For nearly all these carers there was constant anxiety about the health of the person they cared for and little to bridge the gap in services between low intensity community support and an admission to a hospital Accident and Emergency Department.

Many carers in the focus groups resembled the interviewees in terms of the range and level of services received. However, the overall composition of the focus groups differed in important ways from the interview group and resulted in some variation in service patterns. In particular, there were:

- *more carers of adults with mental health problems. One focus group was composed of members of a support group for carers of people with mental health problems. The majority experience was of a very low level of practical support in day-to-day living for the person concerned and virtually none for the carer.*

- *more carers of adults and children with learning disabilities, sometimes linked to severe behavioural problems. Day care (through day centre and college) and respite care were the main forms of support, and additional therapies were generally provided through day care. Evening clubs and activities were also available in some cases. The carers coped without help in the home, except for supplies of incontinence pads in one or two cases.*

## 2 c) (ii) Help from the GP

The role of the GP in providing support and information to carers was a special focus of the study in Hertfordshire. As might be expected, carers' experiences varied. Most commonly, they had found their GP sympathetic and pleasant when contacted but not especially forthcoming with either support or information. For some carers, a health visitor or community nurse within the primary health care team had been better sources of information.

*Many carers felt that their GP could do more to support them in caring, for example by recognising signs of exhaustion and being more proactive in activating referrals to other services.*

Difficulties in making prompt appointments and in ensuring that the same GP was seen each time were frequently noted. A lack of specialist knowledge by the GP of the cared-for person's condition was a further drawback experienced particularly by parent carers and carers of adults with mental health problems. One carer recalled how she had been told by her GP to look up her child's condition in the library.

If a child was seeing a paediatrician at regular intervals or attending a hospital out-patient clinic, the GP played a relatively minor role in the family's support system. For example, the adoptive mother of two young Downs children said that while her doctor provided good care during their frequent colds, she turned to Child Development Centre for expert information and advice about their progress and to the heart clinics which the children both attended for up-dates on their condition. She was unaware of any liaison between the GP and these specialist units.

Similarly, where the person cared for was an adult with acute mental health problems, the carer tended not to see the GP as a primary source of support. This was either because carer and cared-for had separate doctors, so that the carer's own GP had no direct experience of the case, or because the main responsibility for medication and ongoing care had been assumed by the Community Mental Health Team.

*In contrast to this generally low-key picture of GP involvement, there were some outstanding examples of good practice. Several of the parent carers in Hemel Hempstead belonged to the same health centre and were united in their praise for the service they received. This was based upon their doctors' genuine interest in the family as a whole, continuity of care and accumulated knowledge of the needs of the cared-for child.*

In addition, practical steps had been taken to improve the carers' access to medical care by issuing them with "best care" cards which enabled them to jump the queue for appointments and also to see their own GP. A separate waiting room would be provided when the child was fitting, and the GP made home visits readily if the child was not well enough to attend. One mother said that her doctor was prepared to issue prescriptions on her own diagnosis in some circumstances. The GPs were also active in supporting parents' access to needed services and in reinforcing their complaints when poor care was experienced.

## 2 c) (iii) Choosing the right combination of services?

A small majority of carers in the interview group said that they had been able to choose the right combination of services to help them cope. However, several qualified their answer by questioning the extent of the choice involved.

> *One carer spoke for several when he said that although the services broadly met the needs of his situation, he had more or less accepted what had been offered. These carers were resigned to the fact that the most appropriate services were not available, and they had to settle for second best.*

> *Others pointed out that choice depended on good information. Without a complete picture of the services available, it was difficult for carers to make informed decisions about the mix of services they needed*

Those carers who were confident that they had been able to take the initiative in planning the right mix of services formed a small minority and, in some cases, they acknowledged that their circumstances were exceptional. One had received a substantial court settlement for her child's birth injuries, enabling her to buy in additional care; and another had spent large sums of his own money on specialist residential and paramedical services that were not available locally. Others felt that their own assertiveness and ability to articulate the needs of the person cared for had enabled them to extend the choices open to them, but recognised that many carers might find this difficult.

Several carers felt that although they had exercised some choice and had acquired a reasonable combination of services, in practice the impact was limited by a low level of provision and by poor co-ordination. This was frequently the experience of parent carers who complained about inadequate amounts of physiotherapy for their children, the closure of several key services during holiday periods, and the decision to run additional physiotherapy sessions in the summer holiday over the same period as a

Mencap playscheme, thus denying their children the opportunity to benefit from both. Lack of practical and nursing help in the home was another issue. One mother said, *"The services are there but only just enough to keep you quiet".*

Those carers who were unequivocal in believing that they had *not* been able to choose the right mix of services considered either that the range of provision offered was too small to allow choice or that the necessary services were simply not available. The latter view was strongly expressed by carers of adults with mental health problems in both the interviews and the focus groups, with particular reference to a lack of provision for support in the home and in-patient emergency care. This view was also expressed by a number of parent carers particularly in relation to education, and, less forcefully, respite care. One carer said: *"I don't feel you get a choice, you're told what you can have and it's just too bad if you don't agree".*

In one instance, where a carer was caring for a person with physical disabilities at home, they both had to exercise choice quite assertively when they felt that they were being pressurised to consider residential care which they were sure they did not want.

## 2 c) (iv) Choice of alternative providers

When carers were offered a service such as homecare or respite care, it was unusual to be offered a choice of providers. Only three in Hemel Hempstead remembered such a choice being available. Two were parent carers who had been encouraged to visit more than one special school, and one was the carer of an older person who had visited more than one respite care centre before opting for the one attached to the day centre with which his wife was already familiar. In the Hitchin area two parent carers were offered a choice over the person providing shared care; and one other person had been offered a choice between respite accommodation in a health service facility or provided through Social Services.

On the whole, having this kind of choice was not a central issue for the carers so long as the service offered was satisfactory. They were more concerned about having the right level of overall support tailored to their specific needs. Thus, for example, it was more important to them to be able to choose the right level of homecare and to have it provided at convenient times than to choose between different homecare providers.

Where the service received proved unsatisfactory, the opportunity to choose between alternatives became important and it was often only at this point that the carer realised there was a choice of providers.

*One carer who had received 16 different homecare workers in 14 months finally snapped when one appeared on the doorstep in Stetson and cowboy outfit. His complaints led to a change of homecare agency and a dramatic improvement in the continuity of the service.*

*Another example was provided by the parent of an adult with learning disabilities who had been concerned about his neglected appearance after a spell in respite care. In this case, the immediate effect of her complaints was a reduction in the amount of respite offered until a social worker joined battle on her behalf and eventually was able to make a satisfactory arrangement with another provider. The carer had thus been able to exercise choice but at some cost to herself and her son, and only with expert help.*

*One household had had the misfortune to have a change of domiciliary care agency forced upon them at short notice. They had established a good relationship with the paid carer from the first agency but were informed that the agency would be changed. This happened at a time when their paid carer was on holiday and they had no opportunity to say goodbye. They experienced problems over the quality of the new service to such an extent that the person cared for had to be admitted to hospital. The carer felt extremely angry at the treatment she and her husband had received, and the unnecessary suffering that the change had caused.*

## 2 c) (v) Choice for the person cared for

Most carers considered that they made the key choices about services on behalf of the cared-for person, particularly where there were severe communication or memory problems, or where they were caring for a young child. In these circumstances, they felt that it was impossible for the cared-for person to exercise choice in any formal sense. On the other hand, they reported that their own decisions about care had been influenced by the reactions of the person concerned. Thus one mother of a profoundly disabled teenager said, *"She will let us know if it's not right for her. She'll cry and be unwell".* Using such signals, the carers would seek to adjust their support arrangements - for example, by increasing or reducing the level of respite - in order to reach a new compromise between their own needs and those of the cared-for person.

In contrast, adults with physical disabilities but no learning impairments were reported to play an active part, on an equal basis with the carer, in the decisions made about support, and generally took the lead in the fine-tuning of services from day-to-day. One carer reported that his wife had agreed to try out a day centre but had decided not to go again when she had found no-one on her own wavelength. Another said that his wife had identified the need for additional homecare to cope with ironing and showering and had pursued this herself.

In such cases, the cared-for person's right to exercise choice was accepted by the carer, although there were minor examples of conflict of interests, as illustrated by one man who talked of his frustration when homecare workers ignored his instructions about tasks to be done if his wife suggested that they could be left.

Choice for the person cared for was a markedly more contentious matter where serious mental health problems were involved. Carers reported being sidelined by mental health professionals who emphasised the right-to-choose of the service user but who failed to take follow-up action to support the choices made. This meant that the carer had to pick up the pieces when things went wrong.

*One example reported was of a young man who had chosen to live independently in a flat but was unable to keep it clean, cook for himself or pay the bills. In the absence of other support, his parents had had to take on these tasks and also looked after his flat during emergency hospital admissions.*

Decisions made by the cared-for person to alter or discontinue their medication were another source of conflict for carers who felt that they were left to cope with any behavioural problems which might result; and sometimes more seriously, decisions about hospital admissions did not always take into account the carers capacity to cope at home.

## 2 c) (vi) Current problems with services

### ➡ *Insufficient amounts of support*

As noted earlier, the value of services was diminished when they were not provided in sufficient amounts to make the required impact. The example of physiotherapy for children with disabilities has already been given. Here the parents' concerns were that the treatments were not sufficiently intensive or continuous to maximise the benefit to the child. Problems with physiotherapy were also noted by some carers of adults, including one man whose wife had received excellent treatment following a stroke only for it suddenly to be withdrawn because of financial restrictions.

Similar concerns were expressed about occupational therapy for both children and adults where the intervention had been too superficial and short-lived to make a lasting difference. And the community paediatric nursing service, while a valued resource, was said to be seriously short-staffed and described as "just limping along" instead of providing the intensive support which parents felt that they needed. One result was that more and more routine nursing tasks were being devolved to the parents, including the change of catheters and gastrostomy tubes.

The amount of provision was also an issue in relation to respite care, particularly for children with complex needs. For several Hemel Hempstead parents, the recent overhaul of the allocation system at the Midway Centre, had resulted in a welcome increase in the annual provision of respite nights but they were still restricted in the number of nights which could be taken as a block during the summer holiday or for special occasions during the year. It was specifically in order to fill this gap that some had sought additional hospice care.

Carers of adults with learning disabilities also relied upon respite as a source of continuous support during the year. The amount allocated appeared to be significantly lower than for children and most carers would have welcomed more, particularly where the cared-for person had behavioural problems which created high levels of stress from day to day.

Other carers of adults tended to use respite care exclusively for holiday breaks. Providing a suitable place could be found, the amount of respite taken was more likely to be governed by a combination of needs and cost than by a fixed allocation by the provider.

Carers of adults with mental health problems wanted more emotional and practical support from community psychiatric nurses, social workers and community support workers. The mental health services were described as inadequate in the intensity of the support they provided in both Hitchin and Hemel Hempstead.

## ➡ *Lack of flexibility*

Lack of flexibility was a complaint frequently levelled at respite care provision for children. Although parents could now request some specific dates during the year, they had no guarantee of receiving them and otherwise had to accept what they were offered six months in advance. Nights lost through the child's illness could not be replaced, and there was no emergency cover. One mother commented that she would need to book her breakdown well in advance.

Inflexible timetables for homecare also posed problems on occasion. Once the service was in place it proved difficult to change the arrangement in order to provide cover for emergencies or special appointments. This meant that, wherever possible, carers had to arrange their commitments to fit into the homecare schedule.

*In rural areas there was a problem over the timing of the bedtime call. One carer was told that the latest time her husband could be put to bed was 7.30 p.m., which deprived them both of their evenings together.*

A number of carers had problems over the inflexibility of transport arrangements made by the service providers.

*One carer's mother attended a hospital day centre for which transport was provided but the time of arrival and return was irregular. The mother suffered from dementia and her confusion and anxiety was increased by the uncertainty about when the bus would arrive. One of the parent carers had had long-standing problems over school transport. Her son spent a considerable time on the bus, and sometimes this led to him "fitting" in hot weather. The carer had complained on numerous occasions, and asked them to change the bus route, but to no avail.*

### ➡ *Issues of quality*

Concerns about quality of service were most frequently raised in relation to respite care and homecare.

Although the majority of carers were satisfied with the respite care and home care they received, and indeed saw them as central elements of the coping routine, others had experienced problems. Lack of continuity of care staff was the key issue for homecare. An extreme example has already been given and were repeated, somewhat less dramatically, in the accounts of other carers.

*One man related that when the Homecare agency first arrived, they supplied two regular care workers. Everything was satisfactory until they left, since when there had been no continuity. Five different care workers had arrived during one week, and the carer said that he never knew who was coming in. This introduced an unwelcome uncertainty into his caring routine and undermined the value of the support since he had to explain and demonstrate the necessary tasks to new staff. A complaint to the agency had at first been rebuffed but a compromise was now being worked out with the help of Social Services.*

Another issue was that homecare staff did not always stick to a timetable. Not knowing when they would arrive further complicated life for the carer, especially in the evening when the preparation of a meal had to be fitted around the other tasks to be done. Particular problems arose when two carers were needed for lifting. If one of them was poor at timekeeping, as was the experience of one carer, the whole care regime was thrown out.

Problems with respite centred upon the quality of personal care provided. Although standards were often excellent, several instances were reported of clothes going astray and of the cared-for person being found in a dirty and neglected state at the end of the stay. Carers of adults with learning disabilities seemed most likely to have encountered these upsetting experiences but examples were also given by parent carers. Once confidence in respite care was undermined it was difficult to rebuild and some carers gave up respite altogether.

### ➡ *Gaps in provision*

Sometimes the over-riding problem was the lack of a suitable service to meet the need. Examples which arose in the course of the study were:

- *no suitable local respite care for deaf-blind people;*
- *a shortage of respite for children with severe behavioural problems;*
- *more generally, poor quality and quantity of respite care for children in North Herts;*
- *a lack of practical support for day-to-day living for people with mental health problems in independent accommodation, including help with managing finances and paying bills;*
- *an absence of local in-patient facilities providing crisis care for adults with mental health problems;*
- *a lack of positive programmes to give adults with mental health problems opportunities for education, leisure and a social life;*
- *suitable educational provision to meet the individual needs of all children with disabilities, including adequate support for children with special needs in mainstream schools;*
- *respite care for children and adults that were conveniently located i.e. a network of provision throughout all parts of the county; a night sitting service for adults with mental health* problems;
- *long-term supported accommodation for adults with mental health problems and learning disabilities.*

### ➡ *Problems of access and co-ordination*

The exhaustion experienced by many carers was exacerbated by the continuous need to find out about services and how to access them; and then, when they did have them, to keep in touch with providers, check that necessary arrangements were in place, monitor the supply of aids and equipment, and chase up agreed action. Thus a whole layer of management and administrative responsibility was superimposed upon the care itself. This additional burden was greatest for those carers looking after people with the most complex needs because of the number of services involved.

*One carer of a profoundly disabled child said, "I spend more time being a nurse, secretary, teacher and co-ordinator than actually being his mother. Constantly being on professionals' backs is more wearing than actually looking after the child".*

Carers like this longed for someone to share the organisation of care as well as the practical tasks. They needed a co-ordinator who would investigate and complain on their behalf and ensure that the whole service package was functioning properly, including the connections between services, such as transport.

➡ ***Problems in personal communication***

Carers had experienced problems in personal communication at all stages in their dealings with statutory agencies. There were many examples of good practice, but the examples of poor communication were remembered by carers over very long periods and often caused them to feel hurt and angry.

*One carer had been treated dismissively by medical staff in hospital after the birth of a child with disabilities; and another carer had experienced paid carers from a domiciliary care agency treating her husband without sensitivity. Carers of adults with mental health problems found the consultants hard to communicate with, and wanted their role to be acknowledged, and given its due importance.*

For a number of carers accessing services was not just a question of finding out what was available but of having to fight assertively for what they wanted. One carer described facing obstruction and being deliberately kept in the dark by the Social Services Department.

➡ ***Cost***

Some carers found the cost of services high and ,in at least one case, too high, resulting in a decision not to make use of day care for an older person. Respite care for adults was found to be expensive, and one carer complained that every time his wife had respite care he had a long negotiation with the Benefits Agency over the payment for it.

## 2 c) (vii) Liaison between services

Most carers in the interview group were sceptical about whether the different services involved in their own situation communicated independently with each other. Doubts were most frequently raised about the capacity of Health and Social Services to liaise and work out common solutions.

> *A specific illustration, given by several parent carers in Hemel Hempstead, revolved around a new NHS regulation requiring the use of a sling within NHS respite facilities for lifting children above a certain weight. Parents were asked to supply a sling when sending their child into respite care but upon approaching Social Services for financial assistance with its purchase were told that funding was unlikely to be available because it was a Health matter. One parent had purchased a sling which had subsequently gone astray in the course of a respite visit.*

At a more routine level, contact between GPs and Social Services was considered minimal and usually prompted by the carers themselves. Although regular reviews were sometimes used as a mechanism for bringing services together, their efficacy could be undermined by poor attenders. Even where reviews were well-attended, carers felt that there was not sufficient liaison and follow through between each one.

Communication problems often beset the provision of aids and equipment.

> *One couple had experienced persistent problems (still unresolved) in finding the right cushions for the wife's wheelchair. Whereas they had formerly been able to contact the Occupational Therapist who had organised assessments on their behalf, this link no longer worked. Making direct contact with the wheelchair clinic had proved much less satisfactory since home visits were not offered and they spoke to a different person each time. Other carers described duplication of equipment (for example, three bath chairs being sent) or the delivery of items with the wrong specifications (such as a hoist with the wrong kind of sling).*

Carers were most confident about liaison between services where they were provided from a common base, such as a special school, the Child Development Centre in Hemel Hempstead or a day centre for adults with learning disabilities. They believed that proximity encouraged informal communication as well as the sharing of written reports.

They also believed that communication was good between the purchasers and providers of specific services, notably Social Services and the independent Homecare agencies. However, where more than one agency was coming into the home (for example, for morning and evening care), there was little evidence of liaison between them.

## 2 d) The impact of services

### 2d) (i) More time for themselves?

The carers found it quite difficult to decide whether the services they received allowed more time for themselves. Holiday respite certainly did provide a much-needed break during which they could relax and spend time with other members of the family. However, most carers considered that a minimum of two weeks was needed and not all were able to arrange this. As noted earlier, there were particular restrictions on the length of holiday respite for parent carers. From the evidence of the study, it is difficult to overstate the importance of the complete break. It is perhaps best summed up by a carer who said: *"It keeps me sane. Without respite care, it would be very hard to cope. I would have nothing to look forward to".*

The impact of ongoing weekly support was less certain. Time freed through help in the home or day care was generally crammed with chores, appointments and shopping. Three carers relied upon regular support in order to maintain their part-time jobs. Finding time for personal interests or relaxation was often impossible. One man whose wife required constant supervision described how he had to rush home before the homecare staff left on his "free" mornings in order to take a bath since this was his only opportunity to do so. Even those carers who had regular weekly respite found it difficult to unwind. One parent whose child required 24-hour physical care said that she used her weekly break mainly to catch up on sleep, and another reported that she had to devote several hours to arranging medication and preparing equipment ready for her child's return.

### 2 d) (ii) Impact on the person cared for

Almost all the carers believed that the person cared for benefited from the services received. In some cases there was an improvement in the standard of physical care, for example through regular bathing which could not always be managed by the carer alone. However, carers were more likely to emphasise the social and emotional benefits of contacts with a wider range of people. Parent carers were particularly keen for their children to spend time away from home, enabling them to meet other children and to gain confidence in different care-givers. The stimulus of extra activities and outings was seen as another bonus. Similar benefits were identified by carers of adults and older people who received day care or domiciliary care.

Even where the care was largely provided in the home, regular contact with service personnel brought benefits over and above the care received. It widened the social circle of the person cared for and gave a sense of being in touch with the outside world. Care staff and nurses were often light-hearted in their approach and lifted the atmosphere within the home. One man commented that it gave his wife the only chance to chat in a relaxed way to other women. Another related how his wife's face lit up when one of her regular care workers arrived.

Benefits to the cared for person were identified in a few cases as the indirect result of expert advice received by the carer. An illustration was provided by the mother of two young children with Downs Syndrome whose regular support from staff at the Child Development Centre at Hemel Hempstead had given her a greater insight into their development and had underlined for her the importance of positive stimulation and one-to-one play. While this had resulted in less time for herself, it had increased the rewards of caring for them and given her clearer goals.

Some of the people caring for adults with mental health problems doubted the positive impact of services on the cared-for person . They saw the support available as a basic safety net which mostly ensured survival but which did not offer the chance of a satisfying life. Social isolation and lack of personal motivation were repeatedly identified as issues which services had failed to address. Those who did see services as having a positive impact saw this as a slight amelioration rather than a qualitative difference. The chance for the cared-for person to have greater independence from the carer was among the benefits noted.

## 2 d) (iii) Impact upon the relationship of the carer and the cared-for person

The separate benefits to the carer and cared-for person from the support received usually enhanced their relationship. Thus time spent apart through day care or respite care relieved mutual boredom and irritation, while practical help in the home improved relations by lifting some of the stress from the carer. Several carers reported that they had become more patient and tolerant and that this had affected the outlook of the cared-for person. In some cases, the cared-for person had acquired a greater degree of independence and this in turn had lessened the emotional strain for the carer.

> *A recurrent theme was the importance of space within the relationship. One carer summed this up well in explaining the value of the help she received: "It enables me to stand back, get my breath and feel refreshed so that I can start again".*

Once again the carers of adults with mental health problems were less likely than other carers to identify positive effects. In part this was because several were living separately from the person cared for and were therefore not deriving immediate benefits from shared care. Some felt that services were driving a wedge between carer and cared-for by making inappropriate decisions about treatment and failing to take the carer's views and wishes into account. Others found benefits in, for example, the privacy the person cared for derived from having paid carers help with personal care tasks during acute episodes of illness.

# 3 Key Messages

## 3 a) Desired outcomes

Factors which help and hinder achieving positive outcomes (some of the factors are entered under more than one heading)

| Desired Outcome | Factors which hinder | Factors which help |
|---|---|---|
| *Easy access to services* | Phone calls not returned<br>No one comes to you you've got to go to them<br>Inequality in service provision - it depends how pushy you are<br>Carer being expected to cope<br>Funding constraints on services. | Being pushy and aggressive, "in your face"<br>Finding out what your rights are<br>People to listen to the carer<br>Legal advice if solutions offered are inappropriate<br>It is sometimes necessary to go to the top e.g. Chief Executive<br>"Best care" |
| *Good access to information* | Nobody tells you what is available<br>You have to fight for everything you get<br>Carers have to go out and find the information | Somewhere to go for advice and action better still, someone coming to you<br>Better information for parents about diagnosis<br>Computerised system to tell us about services<br>Contact with other carers who know the system. |

| Desired Outcome | Factors which hinder | Factors which help |
|---|---|---|
| *Emotional support* | Isolation<br>Guilt<br>Feeling that your problems are unique. | Moving to be near family<br>Friendship networks<br>Having somebody to talk to, eg. through counselling<br>Contact with other carers. |
| *Having a life of your own* | Poor health of the carer<br>Person cared for unwilling to let go<br>Carer's guilt | Permission to enjoy your own life. |
| *Time off* | Person cared for reluctant to use respite<br>Having to wait for carer's health to break down before being offered respite<br>Inflexible respite allocation. | Flexible, local and good quality respite facilities. |
| *A decent income* | Additional costs of care and transport<br>Difficulties in finding and keeping employment | Paying carers a better rate<br>Flexible services which allow you to keep a job<br>Advice about benefits. |
| *Reliable and appropriate services of acceptable quality* | Contract home care - sometimes not caring or compassionate, displaying no common sense.<br>Lack of stimulation in residential care<br>Lack of appropriate services for people with communication problems<br>Staff not properly trained<br>Crisis management not long-term planning | Continuity of paid carer.<br>Residential care for children in the county - better use of resources, more convenient for parents<br>Local respite services.<br>Extra support in a family crisis |

| Desired Outcome | Factors which hinder | Factors which help |
|---|---|---|
| *Opportunities for the person cared for to have a good quality of life* | Poor public transport services makes visiting people in residential care difficult<br>Few activities in the school holidays | Opportunities for stimulating activities in residential care<br>Children with disabilities integrated into mainstream schools |
| *Recognition of the carer's role* | Carers of adults with mental health problems excluded from meetings | Acceptance of carer as part of the team caring.<br>Carers able to talk to consultants about the treatment of the person cared for |
| *Better public attitudes towards people with disabilities or illness* | People making unhelpful comments | Campaigning against negative attitudes<br>More education for the public about mental illness |

## 3 b) Carers views on improvements needed in Hertfordshire

## 3 b) (i) General points

### ➡ *A more imaginative and outgoing approach to information giving*

Carers wanted more comprehensive written information geared to their particular caring situation, whether as carers of older people with Alzheimer's Disease or parent carers of children with disabilities. But they saw this as only part of the solution. More fundamentally, they identified a need for a more open approach among services to the sharing of information, particularly where there were cost implications. This needed to be reinforced by a practical commitment to taking the information to the carer wherever possible, for example by providing both information pack and an experienced person to help interpret it.

### ➡ *More attention to the location of services and transport links*

In a large rural county such as Hertfordshire, geography and transport were important to carers in determining the availability of services. In particular, carers wanted respite services to be local, for their own convenience and to minimise uncomfortable journeys for the person cared for. Nonetheless, a number had to rely on out-of-county services for respite and, in some cases, for permanent residential care. They wanted to see the full range of appropriate provision within the county.

For those without their own cars, inconvenient and infrequent public transport compounded the difficulties of reaching services. It also decreased the quality of life for people with disabilities by denying them independent access to social and leisure activities.

### ➧ *Quality of home care services*

Homecare services were the subject of considerable comment from the carers. There were examples of very good care, where everything was working well and reliably. However, there was room for improvement in a number of cases. The issues arising were to do with the continuity of the care staff, since the relationship that was built up with the cared for person was seen as extremely important; the hours of the service particularly in rural areas, where the bedtime calls were too early; and the paid carers too often being poorly motivated and trained, and unreliable in their time keeping.

More specific suggestions for improvements were uniforms for homecare staff, a written statement of their duties and boundaries and insurance for carers in case care workers had an accident on their premises.

### ➧ *Consistency in the assessment process*

Carers of people who needed regular assessment because of frequent changes in their condition were frustrated when the assessment procedure was managed by a series of different professionals. They felt that this militated against good planning and consistent care. This was a point made especially forcibly by carers of adults with mental health problems but was raised by other carers too.

### ➧ *A renewed commitment to a needs-led care system*

Frustration and anger were widespread among carers in the study about the way in which the provision of services increasingly seemed to be determined by financial resources rather than by a true assessment of need. They felt that lack of money was being used as a blanket excuse for not providing necessary support, even though their individual requests for help were specific and modest. Beneath their anger was a growing perception that services were fragile and precarious, and could be withdrawn at any time, with ominous consequences for themselves and people in similar circumstances in the future.

Several carers attributed a reluctance on the part of Social Services personnel to divulge information about available services to a funding shortage, and a desire to ration resources by being economical with information about them.

## 3 b) (ii) Issues for parent carers

### ➡ *More respite care places for children with disabilities and more flexibility in existing provision*

Experiences of respite care for children with disabilities differed between the two sites. Interviewees in Hitchin pointed to the lack of suitable facilities for residential care and family-based care in the north of the county, and their complaints were echoed by members of the Hitchin focus group. Hemel Hempstead parents were generally satisfied with the amount of respite they had been allocated, particularly following a review of entitlement at the Midway unit, but were concerned about the inflexibility of the allocation process which allowed them only limited opportunities to choose their dates and prevented them from taking an extended summer break.

### ➡ *Better communication between Health, Education and Social Services*

Carers wanted service provision to be co-ordinated so as to maximise their child's opportunities to benefit, for example through the better timing of activities and services during the summer holidays. They also wanted the different sectors to work together to solve practical problems (for example, the provision of slings for children attending respite care) and not to off-load them onto the family.

### ➡ *More input into the home*

Parent carers had a particularly heavy burden of physical care but generally received little support through homecare or sitting. They also felt that more and more practical nursing tasks were being left to them by the overstretched community paediatric nursing service. They wanted more practical help in the home and regular sitters who got to know the child.

### ➡ *Support in co-ordinating the care received*

The managerial components of caring - keeping in touch with services, ordering equipment, making special arrangements for transport, planning respite care and chasing up agreed action - amounted to a heavy additional workload which bore especially heavily upon parent carers because of the complexity of the service system with which they were engaged. They wanted a key worker who would share this organisational burden and, if necessary, confront services on their behalf.

➡ ***Better communication by hospital staff with parents of children with disabilities***

Some parents had had distressing experiences in hospital at the birth of the child with disabilities. They had been treated unsympathetically, given no information about the diagnosis, management of the disability, or what to expect in the future. They felt unsupported and rejected. The early experiences of the carer can make a great difference to their own confidence and capacity to cope with stress.

## 3 b) (iii) Issues for carers of adults with mental health problems

➡ ***Improved quality and quantity of in-patient psychiatric services***

Carers wanted an improvement in both the quality and quantity of in-patient psychiatric services. Following the closure of Hill End Hospital and the collapse of the plan to provide a more streamlined in-patient hospital with crisis beds, carers in the west of the county were deeply concerned about the absence of local emergency support. They felt that a facility offering 8 - 10 secure beds was urgently needed. Carers in both sites wanted to see improvements in the quality of care offered in both hospital and group home settings, with better qualified staff in the latter and more attention in both to structuring the person's day, providing stimulating activities and reintegrating the person into a normal environment.

➡ ***Flexible access to services for carers of people with mental health problems***

People with mental health problems often have needs for services that are episodic rather than continuous. The carers' experience was that services had to be reactivated after each successive crisis. They wanted to be allocated a `bank' of services which they could draw upon as the condition of the cared-for person changed.

➡ ***Acceptance of the carer as part of the care team***

A frequent complaint among carers of adults with mental health problems was that professionals did not acknowledge their expert knowledge of the person cared for. They wanted an accepted role within the mental health support team, with access to information about medication and an input into care plans. They also sought regular, direct communication with the consultant in order to discuss treatment plus a mechanism for alerting the medical services about any sudden deterioration in the person's condition, so that preventive measures could be taken.

➡ ***More practical support for independent living***

Carers of adults with mental health problems who were living in independent accommodation were often heavily involved in providing practical support with laundry, housework, correspondence and bills in order to prevent a breakdown of the situation. They felt that the mental health services were reluctant to acknowledge the need for this level of daily support, with a consequent increase of the burden on the carer. More supported housing in staffed group homes was one of the solutions advocated.

## 3 b) (iv) Issues for carers of people with learning disabilities

➡ ***Activities and stimulation in residential care facilities for people with learning disabilities***

Several of those caring for children or adults with learning disabilities had concerns about the regimes in residential care facilities providing respite care or, in one or two instances, a permanent home. They wanted more stimulating and imaginative activities to prevent boredom and frustration.

➡ ***Better availability of respite care for people with learning disabilities and associated behavioural problems***

Where the person cared for exhibited behavioural problems in addition to learning disabilities, the strain on the carer was compounded by a lack of appropriate respite care facilities. If such a facility was identified, the *amount* of care offered was sometimes insufficient to give the carer a proper break.

# Appenedix 1:  Summary of Characteristics

## Carer

| | Gender | | Age | | | | | Ethnic Origin | | Marital Status | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Male | Female | under 30 | 30 to 44 | 45 to 59 | 60 to 74 | 75+ | White/ British | Prefer to leave blank | Married | Separated | Widow/ widower | Divorced | Partners | Single |
| Focus Group Totals | 5 | 20 | 0 | 4 | 7 | 14 | 0 | 21 | 4 | 17 | 0 | 4 | 1 | 0 | 3 |
| Hitchin interview Totals | 3 | 14 | 1 | 7 | 6 | 3 | 0 | 17 | 0 | 12 | 0 | 0 | 1 | 3 | 1 |
| Hemel interview Totals | 8 | 10 | 0 | 7 | 2 | 7 | 2 | 18 | 0 | 16 | 1 | 0 | 0 | 0 | 1 |
| **Grand Total** | **16** | **44** | **1** | **18** | **15** | **24** | **2** | **56** | **4** | **45** | **1** | **4** | **2** | **3** | **5** |

## Person(s) Cared For

| | Relationship | | | | | | | Gender | | Age | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Parent | Grand-parent | Brother/ Sister | Spouse | Son/ Daughter | Partner | Other | Male | Female | under 18 | 18 to 30 | 30 to 44 | 45 to 59 | 60 to 74 | 75+ |
| Focus Group Totals | 4 | 0 | 1 | 5 | 16 | 0 | 1 | 17 | 10 | 4 | 4 | 8 | 2 | 4 | 4 |
| Hitchin interview totals | 2 | 0 | 0 | 5 | 9 | 1 | 0 | 9 | 8 | 7 | 2 | 2 | 2 | 0 | 4 |
| Hemel interview totals | 0 | 0 | 0 | 8 | 11 | 0 | 0 | 6 | 13 | 9 | 0 | 2 | 1 | 5 | 2 |
| **Grand Total** | **6** | **0** | **1** | **18** | **36** | **1** | **1** | **32** | **31** | **20** | **6** | **12** | **5** | **9** | **10** |

## Client Group

| | Older People (over 65) | People with physical disabilities | People with HIV/AIDS | People with learning disabilities | People with alcohol and drugs problems | People with mental health problems | Older People with Physical disabilities | Older Peope with Mental Health problems | Older People with physical disabilities and mental health problems |
|---|---|---|---|---|---|---|---|---|---|
| Focus Group Totals | 8 | 6 | 0 | 10 | 1 | 12 | 4 | 4 | 2 |
| Hitchin interview totals | 4 | 9 | 0 | 8 | 1 | 5 | 1 | 3 | 0 |
| Hemel interview totals | 4 | 14 | 0 | 10 | 0 | 4 | 3 | 3 | 2 |
| **Grand Total** | **16** | **29** | **0** | **28** | **2** | **21** | **8** | **10** | **4** |

## Share same household

| | Yes | No | Sometimes |
|---|---|---|---|
| Focus Group Totals | 19 | 4 | 2 |
| Hitchin interview totals | 15 | 2 | 0 |
| Hemel interview totals | 18 | 1 | 0 |
| **Grand Total** | **52** | **7** | **2** |