

**Appendix**

**A Report on**  
**Respite Services for**  
**Adults with a Learning Disability**  
**In Herefordshire**

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## **TERMS OF REFERENCE**

The report was compiled using the following terms of reference

- i) Establish the current usage of respite services
- ii) Establish the amount of service cancelled
- iii) Look outside of Herefordshire to see how others provide services
- iv) Collect views from carers on current provision
- v) Consult with carers on respite needs for the future
- vi) Make recommendations to improve the provision of respite services

## **SCOPE**

The report was compiled from June to September 2004. The data collection for the amounts of service received began early in this process and centred on service used from April 2003 to March 2004. All figures given within section 5, relate to that financial year, unless otherwise stated.

The collecting and compiling of views within section 6 "Carers' Perspective", was provided by Carers Support and is there based on the views of Carers who are known to them.

## **EXECUTIVE SUMMARY**

- Herefordshire provides a high level of residential respite care compared to other authorities within the West Midlands (Review and development of Learning Disability services, Kathy McAteer, 2000)
- The level of respite currently being offered is sufficient to meet the current demand. However it is not being offered in a consistent way, which supports carers.
- The respite service received is highly valued by unpaid carers, despite the uncertainty and cancellation of planned service.
- The service cancelled 15% of planned respite care within in-house respite services
- There are currently 8 people residing long-term within in-house respite units. This represents 5 beds or 40% of our internal respite capacity + the three emergency beds
- Carers who have received services for a number of years appear are reluctant to have other forms of respite other than the traditional building based services
- Carers who have recently began receiving services or carers of teenagers are more willing to consider alternatives to building based services
- Respite services are often seen in the context of services for carers rather than services for the people who attend them
- Services for people with additional mobility issues are less available than for those without

## **INTRODUCTION**

There are currently 147 adults with a learning disability living with (unpaid) family carers in Herefordshire.

The 1995 Carers Recognition Act gives carers of people with learning disabilities the right to request an assessment of their needs including the need for short breaks.

The term 'short break' (also known as short term care or respite care) is where a person with a learning disability spends time away from the family. The most traditional form of this is through the use of registered residential respite care units.

Traditionally local authorities and the NHS have provided these services. Increasingly they are also provided through the independent sector.

There are other ways of providing respite to carers. This can include support in their own home, support to enable people to access community facilities, or through the use of day services.

## **CURRENT SITUATION**

Herefordshire Council learning disability services (including the PCT) currently spends just over £540,000 (net) on in house residential respite provision and emergency beds and an additional £48,000 on the purchase of residential respite in the independent sector.

The money used in the independent sector funds some services for people with profound and multiple disabilities, adult placements and additional support through residential colleges where individuals cannot return home during holidays. It does not include the purchase of community-based alternatives, which are provided as part of someone's whole care package.

This figure does also not include the cost of transport for individuals where Social Care have to arrange this. There is also additional money being spent on alternative respite provision such as community support, day care and direct payments.

The in-house provision of residential respite care consists of 12/13 respite beds and 3 emergency beds. 4 respite beds + 1 emergency bed at Ivy Close, Hereford, 4 respite beds + 1 emergency bed at Windsor Place, Leominster and 4/5 respite beds + 1 emergency bed at Southbank Close, Hereford.

Within the West Midlands, Herefordshire provides the third highest provision of respite care per capita. The lowest allocation was 10 bed nights per thousand rising to 260 bed nights per thousand (excluding Birmingham) Herefordshire has 232 beds nights per thousand. This is especially relevant given the small percentage of people living with family carers compared to other authorities (1/4 in Herefordshire compared to  $\frac{3}{4}$  in other authorities)

The current allocation of respite care to individuals is between 20 nights and 136 nights per year. People who are newer to the service tend to have a lower allocation of nights. The average allocation of nights is around 70 nights per year.

The majority of people who receive respite care also receive other services. This is mainly either day opportunities, or home support.

## **IN-HOUSE PROVISION**

Herefordshire currently provides 12/3 respite beds and 3 emergency beds across three separate units.

### **Ivy Close (Hereford)**

Number of beds = 4 + 1

Net Cost = £130,000

Ivy Close is a purpose built site comprising four houses. Three of the houses are used as long-stay accommodation for adults with a learning disability. The remaining house is used as respite resource and has five beds, four of which are allocated for planned respite and one for emergency accommodation.

From April 2003 to March 2004 Ivy Close accommodated 19 people on a planned basis. The number of nights allocated for each person is agreed following a Community Care Assessment and ranged from 20 to 108 nights per year. The number of allocated nights for the whole year totalled 930, which is 65% of the total availability.

The average allocation was 49 nights. Two people are allocated twice that amount and a further two are allocated nearly 50% more than average. Five people are allocated approximately 50% less than the average.

#### **Emergency Placements**

The number of nights allocated to provide emergency placements at Ivy Close, based on the current structure, is 365 nights. During 2003/4 nine people accessed this service plus an additional two people who also received planned respite at Ivy Close. The total number of emergency nights used during the year was 574 or 157% of the allocated nights.

This increase in the amount of emergency provision resulted in a reduction of service for those in receipt of planned respite services. This was exacerbated by a number of emergencies occurring at the same time. February to March was a particularly difficult period of time with 55 respite nights being cancelled during the two-month period.

#### **Cancellations**

- Approximately 66 nights were cancelled by families themselves
- Ivy Close cancelled 138 nights due to planned respite beds being blocked by emergency admissions.
- The cancellation, by the service, represents 15% of the allocated service.

## **Southbank Close (Hereford)**

Number of beds = 4/5 + 1

Net Cost = £220,000

Southbank Close is a purpose built site comprising three bungalows. Two of the bungalows are used as long-stay accommodation for adults with a learning disability. The remaining bungalow is used as a respite resource and has five bedrooms, one of which is occasionally used as a double room, for certain service users only. Four bedrooms are allocated for planned respite and one for emergency accommodation

From April 2003 to March 2004 Southbank Close accommodated 14 people on a planned basis. Only the most recent of those using the service have received an allocation based on a Community Care Assessment. Those who began using the service when Southbank was classed as a part of the hospital received higher amounts of respite based on the then higher availability. This higher allocation was reduced approximately three years ago as pressures mounted on the service. It is the new lower allocation for these families that has been included in the report. The number of nights allocated now for each person ranged from 36 to 107 nights per year. The number of allocated nights for the whole year totalled 1117 nights. This is 74% of total respite availability.

The average allocation was 75 nights. Two people are allocated approximately 50% less than this average, with most others receiving slightly more than this average

### **Emergency Placements**

The number of nights allocated to provide emergency placements at Southbank Close, based on the current structure is 365. Seven people during 2003/4 accessed this service. Three of these are people who received planned respite at Southbank Close, received additional emergency provision. The total number of emergency nights used during the year was 267 or 73% of the allocated nights.

Southbank Close has, unfortunately, had two of its respite beds allocated to two long-stay clients for many years. This has had significant impacted of the levels of respite. The amount of long-stay usage and emergency combined equates to 997 nights or 273% of the emergency allocated bed spaces.

### **Cancellations**

- Approximately 30 nights were cancelled by families themselves
- Southbank Close cancelled 232 nights due to planned respite beds being blocked by emergency admissions.
- The cancellation, by the service, represents 21% of the allocated service.

## **Windsor Place**

Number of beds = 4 + 1

Net Cost = £190,000

This building has five beds, four of which are allocated for planned respite and one for emergency accommodation. The service does not offer planned respite over the Christmas/New Year break, as the service has previously not been requested. Based on this, the total number of respite nights available during the year is 1,400 beds.

From April 2003 to March 2004 Windsor Place accommodated 14 people on a planned basis. The number of nights was allocated for each person following a Community Care Assessment and ranged from 36 to 136 nights per year. The number of allocated nights for the whole year totalled 897 nights. This is 64% of the total availability.

The average allocation was 75 nights. Four people out of the fourteen using the service were allocated nearly twice that amount, one of which has since moved into supported accommodation and no longer uses the service. Four people are allocated approximately 50% less than the average.

A further six people access the service at Windsor Place on an "as and when" basis. This is to cover short-breaks for the carers. Another 70 nights of respite were provided in total.

### **Emergency Placements**

The number of nights allocated to provide emergency placements at Windsor Place, based on the current structure, is 354 nights. During 2003/04, six people accessed this service. The total number of emergency nights used during the year was 314 or 88% of the allocated nights.

However, several of the emergencies occurred during the same period. Two beds were filled by emergency placements during the majority of October to January. This meant a reduction in planned respite services.

### **Cancellations**

- Approximately 30 nights were cancelled by families themselves
- Windsor Place cancelled 73 nights due to respite beds being blocked by emergency admissions.
- The cancellation, by the service, represents 8% of the allocated service.

### **Allocation of respite across in-house services**

With the 12 beds we are able to offer a total of 4200 nights respite per year. (All services are closed over the Christmas New year period) This figure can be slightly increased as Southbank Close do have the potential of offering one of their rooms as a double. However this is only for specific named individuals and therefore is somewhat limited in use but does raise the total to 4306 nights.

From March 2003 to April 2004 the 12/13 beds supported a total of 47 people on a planned basis. For 2003/4 this represents on average 67% of respite potential

being allocated to the 47 individuals. The biggest demand for all respite care is at the weekend with nights during the week being less requested.

The total number of emergency bed nights available is 1084 per year across the service.

During 2003/4 the actual number of emergency bed nights used was 1155 with the extra pressure being at Ivy Close and Southbank Close. As well as this two beds at Southbank Close were being blocked by long- term residents who were unable to move on to the other bungalows because of personality incompatibility (one has since moved) These means the actual emergency blocked bed total is 1885 bed nights per year.

The first two months of this Financial Year have proved difficult for all of the internal respite providers. Ivy Close began with three emergency placements, which has now been reduced to two.

Southbank Close had three long stay/emergency residents blocking respite beds. In July this reduced to two but then increased to three again the following week.

Windsor Place had two emergency placements. Another was admitted the same day one person moved on and a third bed was taken up in August. Originally this was intended for two weeks. There is currently no known date for this latest person to move on.

### **Comparison of Allocated Respite Nights across services**

Service	Number of users	Number of beds	Total bed nights	Number of nights allocated	% usage	Weekend bed nights	Number of nights allocated	% usage
Ivy Close	19	4	1400	930	65%	192	168	88%
Southbank Close	14	4/5	1506	1117	74%	204	168	82%
Windsor Place	14	4	1400	897	64%	192	144	75%

### **ONGOING ISSUES WITH IN-HOUSE SERVICES**

Currently there are 8 people residing in respite care units. This means that on top of the 3 emergency beds, 5 of the 12/13 respite beds are blocked leaving only 7/8 beds available for planned respite. If there are further emergency situations further respite beds may need to be used to accommodate these individuals.

For people who use the current respite provision it is probably appropriate for them to receive emergency care provision within that unit. However, currently the respite units provide respite to all people within the learning disability service, wherever their previous placement was.

The eight individuals who are currently blocking the beds came from a range of previous placements. Five were living in their own homes or with a family carer, one was living in supported lodgings, one in a family placement and one is a long-term resident who moved into the unit from another home within the site.

Last year the service cancelled 15% of planned respite across its three services. This was higher at Southbank Close than other services.

Some individuals receive very high levels of service. However families have become used to this level and reductions in current allocation could result in family breakdowns, which ultimately will result in increased blocked beds.

The Commission for Social Care Inspection (CSCI) who are responsible for registration and inspection of the three services have stressed that we must not provide respite care and long-term provision within the same house. This will mean that we will have to look at moving people on from emergency beds within an agreed period of time.

To totally unblock the respite and emergency beds. Would require additional revenue of over £250k. This money is not currently available within the service.

Although people who are new to the service are willing to consider newer more innovative ways of providing support and respite care, older carers do not want to consider alternatives to residential respite provision.

Because all of the resources are tied up in the current building based services it is not possible to fund alternatives even if carers were willing to consider them.

## **CARERS VIEWS**

Herefordshire Carers Support worked with the learning disability carers network to establish their views on:

- The types of respite care/short breaks that are available now
- What works and what doesn't work – the issues around this provision
- What, if anything, could be different

Although the learning disability carers network is small and therefore cannot be seen as representative of the 47 carers who currently use respite care, or the 148 people currently living with family carers, it nevertheless provides useful information on the views of carers.

The full report from Carers Support can be seen as appendix 1. However the key results are as follows.

None of the carer's involved used alternatives to building based respite. Overall parents who have been caring longer do not want to consider alternatives to building based respite, (although they wanted the service to be more reliable) whereas those with younger adults or teenage children were prepared to consider alternative ways of providing respite.

Carers within the group valued the break they got because:

1. They knew where their son/daughter was and were confident about the care they were receiving from staff who had got to know them. They felt that routine had become important to them as carers and to their dependants
2. The respite gave them the chance to re-charge their batteries and continue in their caring role (most said they caught up on sleep) For parent-carers this period did give them the chance to give time to other children in the family

The main problems they identified with the current situation was:

1. Late cancellations of respite is a real problem. Carers never felt 100% secure that they could plan anything e.g. a weekend away in case the respite was cancelled at the last minute. Respite is usually disrupted because of emergencies, this is problematic for both carers and dependants as the routine element is disturbed and often the carers have a behavioural backlash to cope with
2. Some emergencies cause bed blocking which cuts down on the number of respite beds available.
3. Some establishments did not provide good facilities for people with profound disabilities, e.g. easy wheelchair access. It was felt that it sometimes took a long period of time for carers to build up a relationship of trust with care staff, especially when working with people with profound disabilities, so that they felt confident about the quality of care offered.

The Carers Network felt that things could be improved by:

1. That the situation in residential establishments is sorted out so that respite beds are not used for emergencies and that once respite is booked it is honoured
2. That more flexible options are available to those carers who want this – expand Direct Payments (tying in with the Direct Payments LIG); consider a Voucher Scheme; greater investment in 'short breaks'
3. Link up with more parents of younger children, particularly those at transition (the SEN Consortium are considering Respite Care Provision as a priority topic)

## **THE NATIONAL PICTURE**

The following section will attempt to give an up to date view of respite services across England for adults with learning disabilities.

Information is taken from varying sources including, newspapers and specialist magazines, the Internet and a one to one interview with a service manager from another authority.

According to research completed by the National Development Team:

- The most common form of respite care provided is in residential units.
- Social Services departments and adults with learning disabilities have different views about what constitutes a valued respite service.
- The noteworthy elements of the innovative respite services visited are that they:
  - Involve people with learning disabilities in planning.
  - Development of befriending services and friendships.
  - Create new opportunities for people.
  - Seek to promote safety through partnerships.
  - Offer training which seeks to improve services.
  - Promote choice, by learning from people with learning difficulties.
- Most of the services visited were uncertain about their future, not least because of their fragile financial position.
- There is a dearth of information about the cost effectiveness of different forms of respite care services.
- The numbers of respite places available in England or of adults using these in a single year are unknown, because of inadequacies in social services ICT systems.

Respite services are often aimed at carers rather than service users. Many things follow from the way that respite care is defined; traditionally it has been associated with relieving the 'care burden.' An idea which is alive and well in many recent policy documents. The community care White Paper tells us "the government recognises that many need help to be able to manage what can become a heavy burden."

This notion is now being challenged by services which are increasingly service user focused, who see the individual with learning disabilities as the primary consumer of respite services.

In Liverpool, the charity Natural Breaks provides an example of a respite service in which the user perspective formed the basis of service planning and development. This is a voluntary sector service to provide opportunities for people with learning disabilities to use ordinary social and leisure facilities in the community. Service users are matched with support workers on a one to one basis for weekly evening breaks and sometimes for longer breaks.

## The Statistics

In 2000, a research project supported by the Joseph Rowntree Foundation asked questions of all social services departments and district health authorities along with NHS trusts and voluntary organisations in England, their aim, to build up a national picture of respite provision for adults with learning disabilities, explore the barriers and identify innovative respite services. The most complete set of data came from social services departments; it is those returns which form the basis of the findings.

Some 63% of local authorities referred to the benefits for carers, with 45% mentioning the provision of some kind of break. By contrast, only 44% of local authorities referred to benefits for users, with just 27% mentioning a break for them.

Many of the authorities mentioned plan to review their services. There appeared a desire to move away from the traditional methods of providing respite care, either in residential units or hospital based units towards more innovative ways of working.

Although the government acknowledges the role of respite provision, "to enable people to achieve maximum independence and control over their lives, numerous studies report high level of unmet need throughout the country.

The survey revealed that the main forms of respite care available to adults with learning disabilities were:

- Residential provision combined with other services ( 92% of local authorities)
- Family based respite (79%)
- Day services ( 80% )
- Residential units dedicated to respite. (70%)
- Hospital provision (70%)
- Volunteering or befriending schemes (74%)
- Holiday respite (65%) and
- Domiciliary services (60%)

Some caution is needed when comparing these findings with those of previous studies, although the range of services appears quite comprehensive, there is a definite bias towards residential services due to the quantity of places available as compared with family based respite services the number of which is typically small.

Furthermore it was found that in 90% of authorities a residential option was most likely to be offered on a planned basis, in 89% of authorities on an emergency basis. This is in direct contradiction of the government's key objective to target home based services.

Studies of the users and non-users of respite care have provided an insight into which groups of people are most likely to be excluded.

69% said that they targeted one or more groups. Those with complex service needs (60%) and those with challenging behaviour (52%) were most commonly targeted.

However, only 13% of those people from black or ethnic minority groups were targeted.

Regardless of the range of respite services available and the desire to shift the emphasis away from traditional provision, the predominance of residential respite care provision means that consumer choice is limited by what is available.

A study in 2003 from Breaking Point says that 6 out of 10 families are either receiving no short term service or one that is so minimal it does not meet their needs. 1 in 3 families have had their respite breaks reduced in number during the past year and 6 out of 10 families are on awaiting list for at least 6 months.

## **Waiting Times**

Due to the lack of efficiency in Social Services departments' information technology,

Information on waiting times to access services was lacking. Of those who provided data on average waiting times, it appears that immediate access to either home based or residential units is more often or not a remote possibility.

## **Innovative Respite Services**

According to the study supported by the Joseph Rowntree Foundation. The questionnaire did not define 'innovative respite schemes', yet 32 social services departments identified them.

Some 8 services visited had innovative schemes which,

- Clearly stated that their aims and service philosophies were developed from the ideas, preferences and experiences of people with learning disabilities and their families.
- Emphasised the importance of person-to-person support and of building new relationships for people which extended beyond their immediate families.
- Recognised that sharing leisure activities as part of the respite service can realise additional advantages and opportunities for adults with learning disabilities and, in turn, their families.

One of those services which was once defined as innovative had to be subsequently re-cast as it's original philosophy of being 'on demand' at it's conception had been progressively compromised by fewer qualified staff and an increase in the number of service users, but no increase in either the staffing complement or the budget for the day to day running of the unit. Although still held up by senior managers as a 'model' service it had become inflexible and narrow in terms of its capacity.

Using the views of people with learning disabilities and their families, the research concluded that a valued respite service should:

- Enable people to have control.
- Offer good experiences and personal advantages.
- Sustain feelings of personal worth and esteem.
- Be small scale and separate from accommodation offered to people on a long-term basis.
- Promote individual support as a result of individual planning.
- Sustain significant relationships and make links with their lives, particularly their diverse roles in their families.
- Be local, even in emergencies.
- Be responsive to the ideas and concerns of service users.
- End its association with the dispiriting features, (such as, lost clothes, inattention to essential medication, unfamiliarity to people's routines and preferences) associated with unit- based respite services.

These ideals were not reflected in the working definitions of respite services many of which only referred to the benefits of respite for people's families or carers.

The most popular innovative form of respite service being developed in the country at the moment is the shared care scheme. There are currently 400 of these schemes which link individuals with learning disabilities with families, couples or individuals who offer them short breaks. The majority are run by local authorities, the remainder by voluntary organisations.

Research shows that shared care can provide a valuable and flexible service to families. Individuals can receive a high standard of personal care in the context of real caring relationships and the support carer's can often become family friends. Some schemes also provide sitting services, befriending and escorts to holiday placements.

Shared care schemes are seen as a service provided to meet, primarily, users needs. The benefits to their family, when examined, are definitely a secondary consideration.

Short breaks, however, do provide a highly valuable support to families or long-term carers. Described by a service user as "a mini- break for me and a mini-break for my family", the schemes are a valuable service on many levels providing, much needed respite from caring for the families and a positive, life enhancing experience for the user.

Support carers- known as sort term carers, shared carers, link carers, and respite or short term foster carers- mainly provide care in or from their own home. In the 202 schemes surveyed by The Shared Care Network there were 7,844 carers for children compared to 1,386 carers for adults. They are usually reimbursed for their expenses.

In the 202 schemes surveyed the numbers of adults taking short breaks were 2,021.

These supportive services are in demand and waiting lists are growing, an equivalent to one quarter of adults receiving services at present is on waiting lists. Others are not referred because it is known that their needs cannot be met.

While many schemes are starting to provide services for users with challenging behaviours, physical impairments and complex health care needs, such users are most likely to be on waiting lists.

The main reason for this, a shortage of support carers and of staff to recruit support carers and a lack of funding to reimburse carers, lengthening waiting lists, low status within social services departments.

Currently, provision, assessment, support and payments to support carers also require attention.

## **A specific example - Luton Social Services**

Luton Social Services department were happy to share their ideas for the management of respite services.

Up until 3 years ago Luton faced similar problems as most of the country with little or no choice or availability in respite provision. There was only residential respite provision where most beds were blocked by those individuals needing emergency accommodation.

In the last 3 years a lot of work and resources have been dedicated to developing the service and today the authority has much more to offer.

### **(a) Volunteers**

A type of family based respite provision has been developed, whereby, volunteers are recruited and go through a thorough screening process including CRB checks for the entire family, questioning by social workers as their opinions on religion, disciplining etc.

These families or individuals then accept individuals with a learning disability into their homes for short breaks. There has to be a limit on the number of nights per year that they provide accommodation as more than 28 nights would lead them to having to be registered under the CSCI. These individuals can get expenses reimbursed.

### **(b) APS Respite**

Adult placement schemes are also used for short-term breaks. These schemes have already gone through a rigorous screening process and can be used in an emergency.

### **(c) Residential Units**

This area of provision is still used for planned breaks. The authority bought an old building that was renovated and then registered for the sole purpose of providing respite care. The issue of 'bed blocking' was tackled utilising the help of the local CSCI that put a limit of one month on the length of time any individual was allowed to stay at the home. This did put extra pressure on social workers to find placements for individuals who couldn't return home but the system works. The home is run on a rota type basis with individuals assessed and individual planning in place to work towards fairness and compatibility of client mix at the unit.

#### **(d) Supported Living**

This part of the respite provision is combined with individuals making the transition from being home based to leading a more independent lifestyle in their own home.

An individual is assessed for receiving Supporting People funding. If eligible, and the individual is lucky enough to find suitable accommodation, the moving out phase is prolonged with the individual spending a short time at their new home each week and the rest of the time at home with their families. The length of time they spend living independently over weeks and months increases as skills and confidence increase until the amount of time they go home for is equal to any young person who has just left home for the first time.

On investigation, Luton predominantly provides services for people with learning disabilities who are physically quite able and without challenging behaviour.

Their sister authority, Dunstable, provides services for those people who have more complex needs, although they are currently working on developing services for individuals with more complex needs. This practice of sharing services with neighbouring authorities is not unusual throughout the country.

The department in Luton have a similar amount of people to which they must provide services. They also have transition workers, reviewing officers, senior practitioners, and six social workers. Even with this, they still perceive that they have a long way to go.

### **CONCLUSIONS ON THE NATIONAL PICTURE**

There appears to be a lack of quality respite provision for adults with learning disabilities throughout the country with no area better placed than any other.

Residential services are still the most popular; there still remains a great amount of loyalty to the familiar model of 2 respite beds in a 24-bed hostel. Resistance to considering options beyond such known and established services is one factor in keeping these types of services going.

Lack of resources, financial, time and human being the main obstacles to change.

### **CONCLUSION**

The level of respite currently being offered is sufficient to meet the current demand. However it is not being offered in a consistent way which supports carers.

Many carers have been using building based respite for a long time and although they are unhappy with the uncertainty of the current situation they would prefer to keep this form of respite provision.

Carers who are have been using the service for less time of those who are not currently using the service (including those supporting teenagers) would be more prepared to consider alternative forms of respite care.

There are other ways of providing respite care to people; some other authorities are more advanced in offering these. Herefordshire offers some alternatives to building based respite but these are limited.

## **RECOMMENDATIONS**

### **1. Review of in-house respite care**

It is necessary to ensure that in-house respite provision is able to offer a consistent service. Given that 8 of the beds are currently blocked this may involve an overall reduction in the amount of respite care beds available, but would result in a more stable service. The review should also consider the potential of externalising this service.

### **2. To continue to review in-house services**

To ensure that over time we continue to have the correct level of residential respite to meet demand. This will enable us to adjust the level of resource so that we are able to meet the demand for new types of service provision

### **3. Emergency Placements**

That we look at alternative ways of providing emergency placements to people who are not current users of the respite provision. However that we do recognise that for users of the respite provision the unit is probably the most appropriate place for them to receive emergency care.

### **4. Alternative services**

That we develop a range of alternative services to support and provide respite for carers. This could include the development of longer hours within day opportunities, the development of community support, and non-registered respite for individuals without care needs.

### **5. Direct Payments**

That we promote direct payments as an alternative to respite services especially (but not exclusively) for people who are new to the service. This will include the development of information packs including video's that can be left with carers.

### **6. Allocation of services**

It is recognised that many of the people who are in receipt of high levels of service have been using respite for many years and have become used to that level of service. However it is important to ensure that people have equal access to services which meet their needs and that we can accommodate new people into the service. It will therefore be necessary to complete reassessments to ensure that this happens.

## **References**

- Review and Development of Learning Disability Services
- Community Care Magazine. Issues Dated From 1996- 2003
- The Joseph Rowntree Foundation Website.
- The Foundation For People With Learning Disabilities Website.
- Medway Council.
- Bromley Social Services.
- Laura Kennedy, Development Officer, Luton Social Services.

# **Complete Report on Carers Feedback**

## **Carers' Perspective**

### **a. Introduction**

This section of the report was compiled following discussions with carers who attend the Carer Network meetings and the Parent-carer Support Group.

We looked at the provision of respite care and short breaks from the carer's point of view. The points we covered were:

- The types of respite care/short breaks that are available now
- What works and what doesn't work – the issues around this provision
- What, if anything, could be different

### **b. Carers' Perspective of The Current Provision**

The current provision seems to be in 'bricks and mortar' – Southbank Close, Ivy Close, Windsor Place and for the under 18s, 1 Ledbury Road.

No one in the group used any other form of respite, although one person whose son had ILF did use this occasionally to pay for an alternative carer for a few hours, which gave her a break.

The provision at the residential establishments was in the form of periods of respite, overnights and days, sometimes at the weekend or sometimes being tied in with going from day care, staying overnight and coming home after day care the following day. As this was the pattern that has been established over time, this was accepted as the norm and on the whole carers found it difficult to consider that there might be other options. They felt that both they and the service user had become accustomed to this routine and would not want to do anything else.

'Short Breaks' – i.e. shorter sessions of alternative care which gave the carer a break, e.g. an evening off or time out at a weekend had not really been offered or considered as an option.

Direct Payments does not appear to have been 'sold' as an option either to the person with a learning disability or to the carers as an option to consider in their own right. There is a distinct lack of knowledge about this among, not only carers but also social workers, as to how the system works and could be developed.

However, it should be noted that most of the carers coming to the network meetings have been in the system for many years, have argued for this provision and feel worn down through the constant challenges they have faced over the years.

Carers coming to the Network meetings, whose dependants are 20-30ish or the parent-carers whose children are under 18, do have a different approach. They are much more open to other ideas and willing to consider other options which would allow for quality 'family' time as opposed to one member of the family having to go

away to give the others a break. They were also more positive about 'short breaks' to work in conjunction with periods of 'respite'.

### **c. What Works and What Doesn't**

Carers coming to the Network meetings felt that the positives about respite provision were:

1. They knew where their son/daughter was and were confident about the care they were receiving from staff who had got to know them.
2. They felt that routine had become important to them as carers and to their dependants
3. They felt that their sons/daughters had made friends with the particular group, were comfortable with them and the activities they might pursue during the period of respite
4. For them as carers this period gave them the chance to re-charge their batteries and continue in their caring role (most said they caught up on sleep)
5. For parent-carers this period did give them the chance to give time to other children in the family

The negatives were:

1. Too often planned respite is disrupted because of emergencies, this is problematic for both carers and dependants as the routine element is disturbed and often the carers have a behavioural backlash to cope with
2. Some emergencies cause bed blocking which cuts down on the number of respite beds available.
3. Late cancellations of respite is a real problem. Carers never felt 100% secure that they could plan anything e.g. a weekend away in case the respite was cancelled at the last minute
4. It was felt that it sometimes took a long period of time for carers to build up a relationship of trust with care staff, especially when working with people with profound disabilities, so that they felt confident about the quality of care offered.
5. Some establishments did not provide good facilities for people with profound disabilities, e.g. easy wheelchair access.
6. Parent carers were much more open to suggestions about other options – shared care, shorter but regular breaks, Direct Payments or a voucher scheme. They wanted to be able to have more flexibility about arrangements and to feel more in control.

#### **d. What Could Be Different:**

Most of the older carers felt that on the whole they did not want things to be different except to be more reliable i.e. no last minute cancellations – security that respite beds would not be used for emergencies and that what was planned would be honoured. It is also important to remember that these are the carers who have been most instrumental in getting the service provision that is available and, for all its faults, works for them.

However, some younger carers, especially the parents of the under 18s felt that there should be more options and that flexibility was the key. Suggestions of how respite/short breaks would work for them were:

- To have Direct Payments or a voucher scheme to be able to sort out their own arrangements.
- To expand the Shared-care scheme so that children did not have to go into residential establishments.
- To have regular short breaks to complement longer periods of respite
- To have options like 'an extra pair of hands' so that family outings or holidays can be made more relaxing for the carers

I think it is very important to take into account the views of the parent-carers because although their children are not in the adult services bracket yet, many of them are in the transition stage and so there will be implications in the next few years, as carers want different service provision.

#### **e. Recommendations**

1. That the situation in residential establishments is sorted out so that respite beds are not used for emergencies and that once respite is booked it is honoured
2. That more flexible options are available to those carers who want this – expand Direct Payments (tying in with the Direct Payments LIG); consider a Voucher Scheme; greater investment in 'short breaks'
3. Link up with more parents of younger children, particularly those at transition (the SEN Consortium are considering Respite Care Provision as a priority topic)