

# *Family Matters*

*Counting Families In*

*March 2001*



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# Preface by the Department of Health

Cally Ward wrote *Family Matters ... Counting Families In* in May 2000 following her consultations with carers in different parts of England and a review of the literature on the subject. This was one of several projects commissioned by the Department of Health to help develop a new learning disability strategy.

Cally's report makes many of the points that carers made when the Department was putting together the National Carers' Strategy. The big difference is that we are now increasingly able to show the progress made in improving services that affect all carers, including carers of people with learning disabilities.

There is a new Act of Parliament, the Carers and Disabled Children Act 2000. From April 2001 for the first time carers can request an assessment of their needs as a carer, even if the person they care for refuses an assessment. Also for the first time local councils can offer services direct to carers, not just services for the person they care for.

The policy and practice guidance on the new legislation contains clear messages about the need for local councils to pay attention to the additional impact on the carer of a caring responsibility, that is sustained or even life-long.

The Carers' Grant, which will amount to £325 million over the next three years, is now in its second year of operation. Carers of people with learning disabilities are clearly already benefiting from this money which local councils get to improve the range and flexibility of their short term breaks services. Analysis shows that at least 10% of the £20 million spent in the first year of the new grant went on breaks for this group.

The Department is about to provide new guidance on the grant, encouraging local councils to put more time and effort into identifying older carers and carers from minority ethnic communities because of the additional problems, as Cally's report points out, they often face.

In addition, carers will gain from a package of £500 million over three years to improve carers' benefits significantly.

We also now have a carers' website at [www.carers.gov.uk](http://www.carers.gov.uk) to help carers find the information they need and UKONLINE, the government's citizen portal, will soon improve access to carers' information still further.

But we know there is much still to do. We welcome this thorough and helpful report. The Department is listening to carers and knows it needs to keep on doing so.

## Acknowledgements

I would like to thank the Department of Health for offering families the opportunity to contribute to the process of thinking about the way services for men and women with learning disabilities should be shaped in the future.

There are many people to thank. I would like to thank all the parents and families that gave up their valuable time, overcoming what some described as '*consultation fatigue*', to contribute to the process. I would particularly like to thank the family carers I meet with in Cornwall, Wolverhampton and Sheffield. All of whom so forcefully expressed their opinions and aspirations for the future.

I would also like to thank all the family carers, who wrote letters, spoke to me on the phone, or communicated via email.

The group of people who worked with me as part of the Family Carers Sub Group (See Annex 1) gave their time, energy and commitment and were, for me, an invaluable resource. The group, which included family carers and professionals, modelled what working together can achieve.

I would like to thank Jacqui Mulragh from the Surrey Users & Carers Network, for her illustrations.

Finally, I would like to say thank you to Michael, my son. Michael has a learning disability but he has taught his old mum so much, along with all the laughter and love we have shared over the last thirty years.

Cally Ward  
March 2001

## Illustrations by

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# Family Carers Sub Group

*'In the same way that it is emphasised that adults with intellectual disabilities are **people first**, so caregivers must be considered **people first** and consideration given to their full identity and multiple roles'.*

IASSID & WHO January 2000

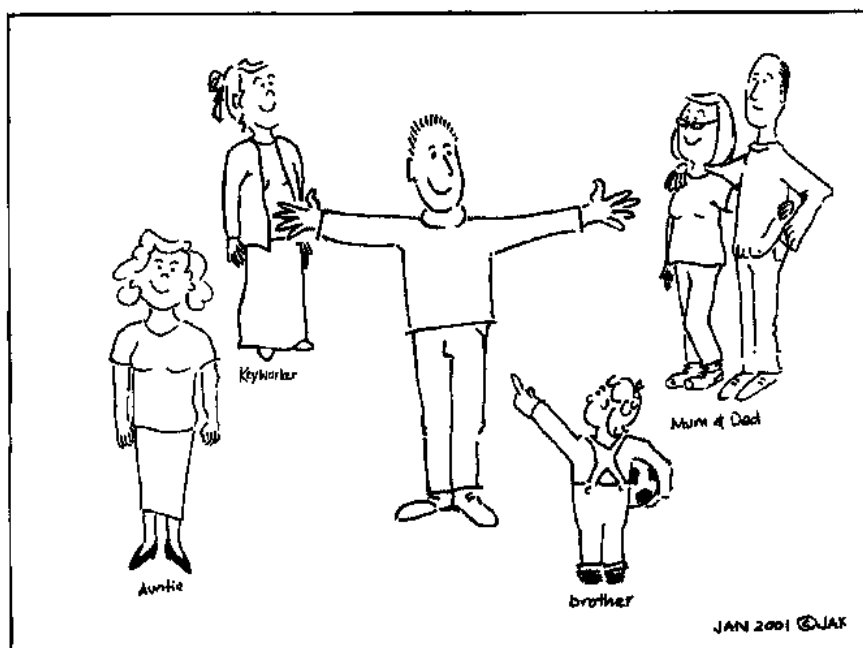
The Family Carers Sub Group welcome the opportunity afforded by the national strategy to make a difference in the lives of men and women with learning disabilities and their family carers. If the strategy is to have any credibility it will need to be seen make a difference, at a local level, in the lives of individuals.

# 1. Introduction

- This report seeks to highlight the perspectives of family carers within the development of a national strategy for people with learning disabilities. The report represents a synthesis of a broad range of views, collected through consultation workshops, correspondence, conversations with family carers, and a review of the relevant literature.
- Families have an important and unique contribution to the discussion of the future direction of services for men and women with learning disabilities. They are the only people who will have a continuous relationship with the person with a learning disability from childhood to adulthood. This contribution needs to be acknowledged, valued, listened to, and acted upon.
- We all live interdependent lives. People with learning disabilities are no different from anyone else in this respect. Individual men and women with learning disabilities need to be seen in the context of their;
  - Family relationships
  - Local communities
  - Ethnicity and culture.

At the heart of good person centred planning is this sense of the broader context of the person's life and their relationships. This is accepted good practice in relation to working with individuals from minority ethnic and black communities and should be generalised to the rest of the population.

- In many services a culture has developed that sees families as a problem and difficult to work with. The caricature of family carers acting as the barrier to the greater independence of their relative with learning disabilities oversimplifies complex family relationships and underestimates the very real contribution which family carers make throughout their relatives' lives. The reality is that services need to find constructive and positive ways to work with families in the best interests of people with learning disabilities.
- Historically, families have played a crucial role campaigning at a national and local level for the rights of people with learning disabilities and for an improvement in services. Families continue to take on this role and are at the forefront of some of the most innovative service developments for people with learning disabilities today.
- Families provide the bulk of support for men and women with learning disabilities in this country. Carers are pivotal in maintaining people with learning disabilities in the community. In many ways *care in the community* is family care. It is estimated that 60% of adults with learning disabilities are living with their family, with a third of these living with a carer over 70 years old. (Mencap 2000) However, it is only relatively recently that carers have been formally placed in the policy arena in their own right with the Carers Recognition and Services Act 1995 and more recently the Carers Strategy (DoH 1999).



"At the heart of good person centred planning..."

## 1.1. Defining Family Carers: Caring for people – caring about people

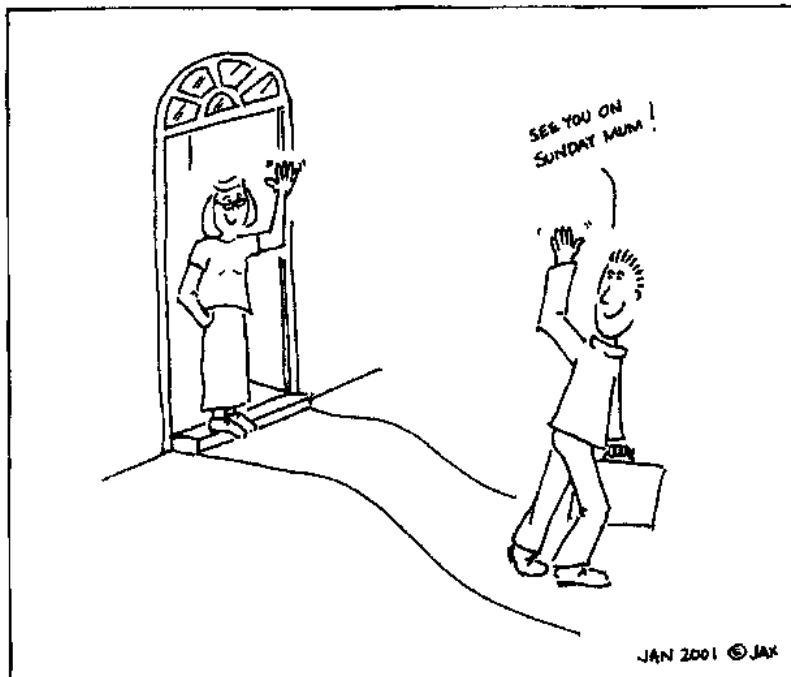
*Families don't see themselves as carers. They see themselves as family members looking after their own.*

Janicki (1996)

- This report focuses predominately on the experience and needs of carers of adults with learning disability. The reason for doing this is that parents of children with learning disabilities have clearly specified parental rights and duties in legislation under the Children Act. The situation is less clear for families supporting or caring for an adult. From being 'parents in partnership' they become 'carers' with few if any legal rights embodied in statute law in relation to decision making and the person with the learning disability. For many families this is a source of great frustration when they perceive things to be going wrong.
- The term 'carer' does not always feel comfortable for many family carers of people with learning disabilities. There are probably a number of reasons for this, some of which are discussed in more detail below. An important consideration is that the term is a relatively new addition to the language, and for many people connotes caring for an older person, either a parent or partner. *I just don't see myself as a carer; I'm his Mum.*
- This report uses the term '*family carer*' to take into account the fact that the people we talked to wanted to emphasise the family relationship they had with the person with the learning disability. We incorporate the term carer in acknowledgement of the considerable amount of primary caring that families undertake which makes them eligible for a carer's assessment under the 1995 Act and subsequent inclusion as carers under the 1999 Carers Strategy.

- For the purpose of this report a family carer is defined as a person who has personal experience of caring for one or more persons with a learning disability who is a family member. A family carer has personal contact with a family member who has a learning disability; even though that individual may have chosen to have moved away from home, or been supported in moving away from the family home, or has needed to move away from home. A family carer is a person who is *not paid* to have a personal, continuous relationship with a person with a learning disability. (We recognise that not all carers will necessarily be related by blood but that some people may choose to support a person with a learning disability in the way described above).

*Just cos someone leaves leave home doesn't mean they leave the family!*



*"Just because people leave home  
doesn't mean they leave the  
family ..."*

## 2. Mapping needs

### 2.1 Numbers of family carers

- Carer's organisations estimate that there are 6 million carers in this country, saving the public purse £34 billion pounds. (Princess Royal Trust 1998). Family carers are obviously only a percentage of this grand total. We currently have no national figures to estimate the number of family carers supporting a person with learning disabilities. Rough estimates might be hypothesised from prevalence rates and demographic patterns of the learning disability population. The Special Interest Group of Learning Disability Registers continue in their efforts to obtain national guidelines for common data sets to improve information on people with learning disabilities and their family carers.
- Much of our current understanding comes from local research studies or areas, which have developed good management information systems. The success of the Sharing Caring Project in Sheffield has been built on the excellent information available through a comprehensively maintained Register of people with learning disabilities and their family carers. Other support services have not been so lucky and have to collect their own information on the local population.
- The local collection of information to help plan and resource adult services is vital. The audit commission recently criticised one local authority for failing to identify and plan for the needs of older carers of people with learning disabilities. ( Audit commission/SSI 1999) As Eric Emerson has argued: *many of the recent changes in health, social care and educational policy have drawn our attention to the importance of targeting resources on the basis of the assessed needs of communities. Population based needs assessment has...to be taken seriously.*
- It is difficult to ascertain how successful the Carer's strategy special grant has been in relation to family carers of people with learning disabilities because of the lack of specific information gathered by Local Authorities.

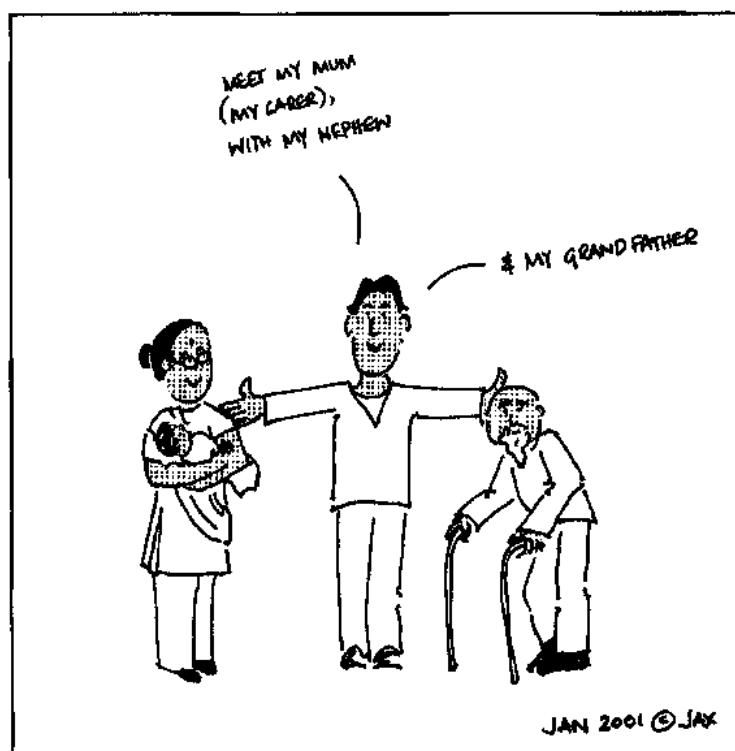
#### 2.1.1 Understanding the nature of the caring relationship

- Family needs are diverse and complex. Anyone can have a learning disabled child so there can never be a typical family experience or single family carer's perspective. All families need to be respected for their unique qualities. It also needs to be recognised that not all carers will want or be able to join a 'carers' group. This should be respected and attention taken to not ignore their contribution to any consultation process undertaken.
- Caring within a family context is also complex. The nature of the caring relationship has been variously conceptualised along a stress versus altruism axis. Evandrou (1999). Walmsley (in Williams & Robinson 1999) recognises that the caring situation is a complex one involving at least two people within the family, who will occasionally be taking reciprocal caring roles. This reciprocity is an important feature of the relationship between carers and their adult children, especially as the carer becomes older.



"Reciprocity in caring relationship as people age..."

- In relation to family carers of people with learning disabilities the relationship between the cared for and the caring is further complicated by the life long nature of the commitment and experience of caring. Many family carers feel they are caught in the role of 'perpetual parenthood' (Todd and Shearn 1995) even into the adulthood of the person with the learning disability.
- The sheer length of time that families care is important and is a unique feature of this group of carers. Research on the population of all carers indicates that the time spent caring in terms of years is not always that long. A decade would be deemed a significant span. Between 1988 and 1991 only 48% of those identified as caring in 1988 were still doing so by 1991. Yet significant numbers of family carers of adults with learning disabilities are over the age of 70. Local studies reveal many people who are in their 80s and 90s who have cared for their son and daughter all their life! (Shropshire Rural Council – personal correspondence and the Sharing Caring Project – Sheffield).
- Little research has been conducted on the role of family involvement when the person with a learning disability leaves home. This issue is neglected even though family involvement has been shown in the past to be correlated with residential and employment success. (Schalock & Lilley cited in Seltzer et al. 1993). Limited evidence from research in the US seems to indicate that the continued involvement of family in the lives of the person with learning disabilities enhances quality of life. Baker and Blacher have argued 'placement out of the home need not mean placement out of the family' (in Sutton et al. 1993).
- Research (Robinson & Williams 1999) has highlighted that many family carers of people with learning disabilities are caring for more than one person. These multiple caring roles include caring for ageing and frail parents and grandchildren.



"... multiple caring roles in the family..."

- Grant and Ramcharan (DOH 2000) have argued that despite the considerable body of research about the views of family carers and people with learning disabilities there is no research which explores *how* people with learning disabilities perceive the experience of living at home with family carers.

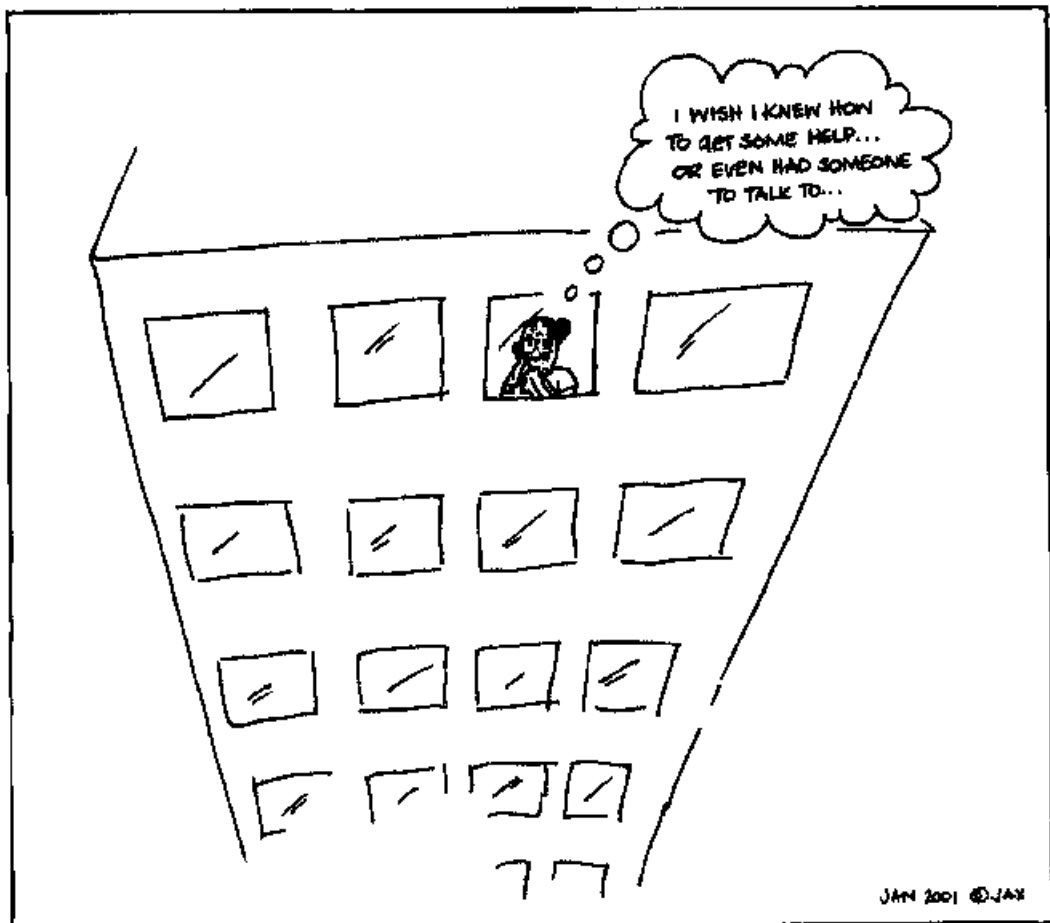
## 2.2 Disadvantage and discrimination faced by family carers

- As well as the many positive aspects of caring, research has highlighted the ways that families can be disadvantaged: (Beresford 1995)

These include:

- High levels of stress
- Finances
- Health
- Isolation
- Housing
- Marital breakdown.

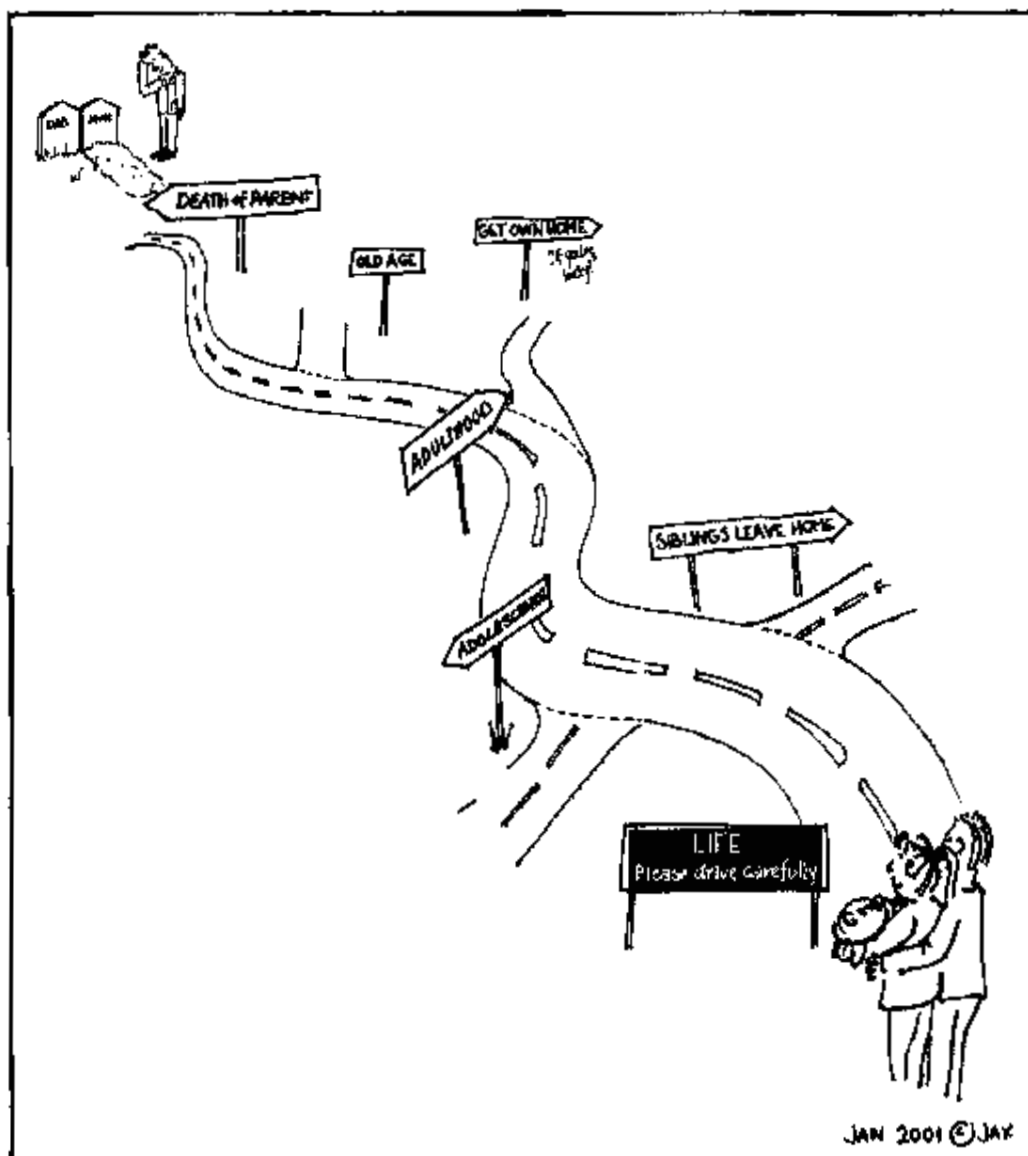
- Within the family, many parents feel that they are constantly balancing the needs of all their children. The specific experience and needs of the siblings of people with learning disabilities are often inadequately addressed. At all points of the life cycle these relationships are important to consider and appropriate support on offer. This ranges to the impact on the sibling's childhood experience and opportunities as *young carers*, to the role of brothers and sisters in later life when the parents are unable to care any longer.
- These are descriptions of findings in the *general* population. Research also shows clearly that if the situation is difficult for white family carers, the experience of minority ethnic and black families is qualitatively *worse* in relation to a number of key indicators. (Baxter et al. 1999, Nocon. DoH 2000, Chambara et al 1990). These include;
  - High levels of unmet need
  - Poverty
  - Poor housing
  - Social isolation and lack of support ;lack of information lack of culturally appropriate services



"Disadvantages of black & ethnic minority families..."

The issues of social exclusion go far beyond the fact that the family are caring for a person with a learning disability and the strategies to support these families need to be comprehensive.

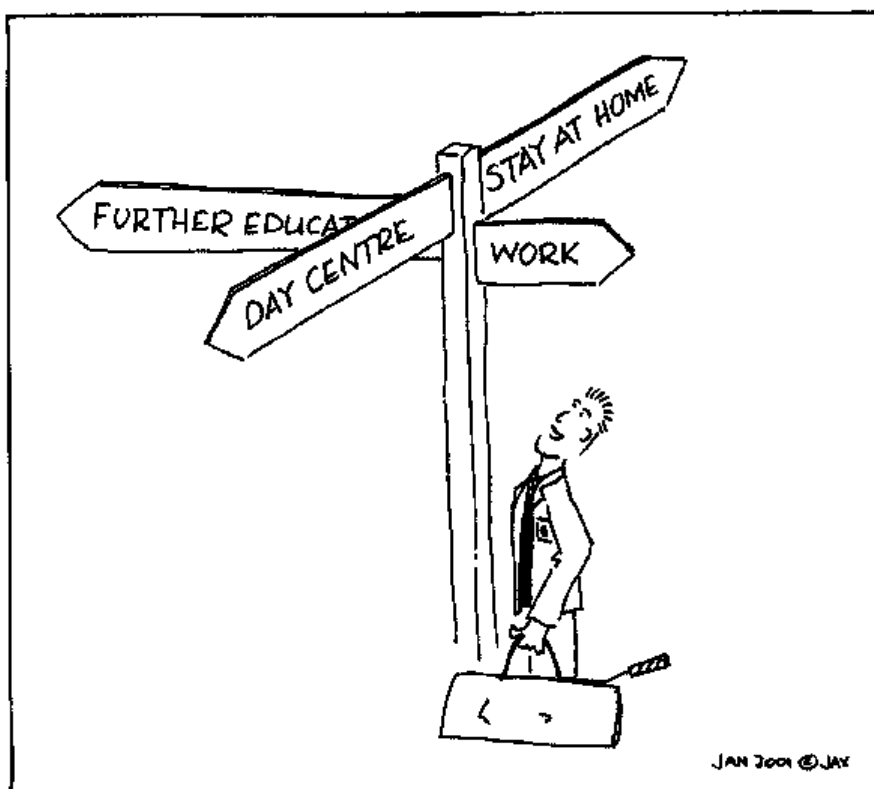
## 2.3 A lifelong commitment – facing transitions in the caring relationship



"The Road map of Life...  
... for people with learning disabilities"

- Life long carers have to cope and adjust to a number of different challenges in transitions in their 'caring career'. These include:
- Being told their child has a learning disability
- When the child reaches school age – making choices and decisions about what sort of educational opportunities would be right for their child
- Adolescence and the move from children's to adult services
- When the son or daughter leaves home – in adulthood
- Growing older together

- When health and illness (or bereavement) makes it difficult and then impossible to care.
- All these transitions can be difficult to manage and services have an important role to play in minimising the stress and anxiety that people experience. Because all of these transitions are an inevitable part of the life course and human relationships, it is vital services take a more long-term view of planning with and for people with learning disabilities.
- All *transitions* can be difficult to manage. Currently our concern focuses on two as a priority for services.



"...Leaving school - what next?..."

1. **From children to adult services.** Many parents describe this period as *the great unknown*, 'falling off the cliff into a great chasm' or the 'great abyss'. Many parents feel that they have not been adequately prepared for this transition and the change comes as a profound and unwelcome shock.

There is real lack of choice for young people with learning disabilities leaving the education system. For many young people there may be nothing suitable available and this is the time people become 'lost' to services.

*'We are a new generation of parents and we want more for our children than is on offer. A lot of our children have been to mainstream school and they want the same things as anybody else. The transition to so called adult services has been a real shock'*

Mother and Founder member of the recently formed  
Getting A life in Cornwall Group (GAL).

Young people with very complex or profound disabilities are particularly discriminated against in terms of provision. Many young people with complex health care needs are being supported at home by their families because of the lack of suitable places available to meet their needs.

At this time parents find they have become 'carers' and are not necessarily consulted because of the adult status of their son or daughter. It is this perceived *exclusion* from the decision making process that many families most resent as they continue to see themselves playing a key role in the life of the person with learning disability. This is particularly important when the person with learning disabilities has little or no verbal communication and their ability to advocate on their own behalf is limited.

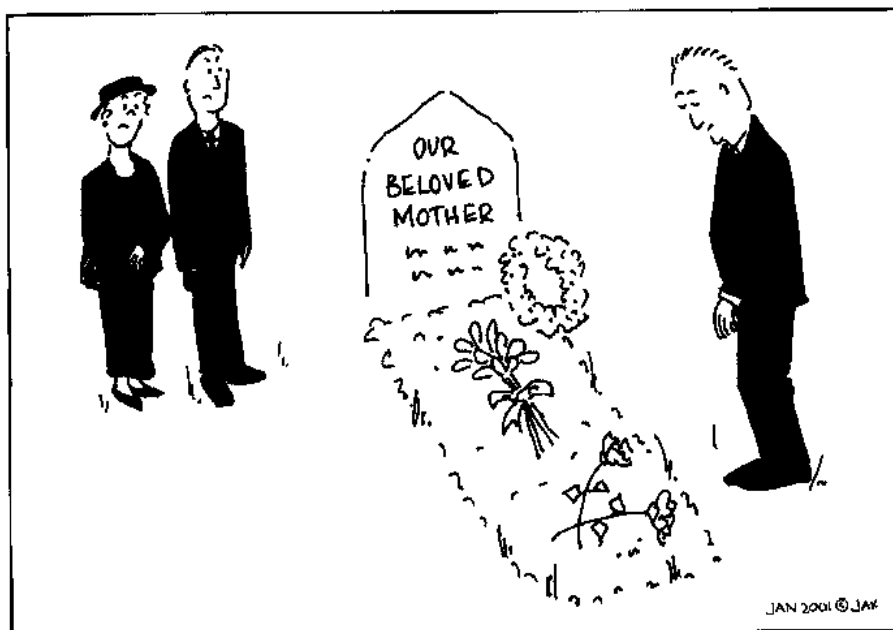
2. **Older Family carers.** In the light of demographic trends of an ageing population, the plight of older family carers needs to be urgently addressed. *Although older carers share many characteristics with their younger counterparts, there are also important differences, which have an impact on their need for services and support.* (Walker & Walker 1998)

*These include:*

- They are continuing to care and getting older at the same time
- They are more likely to be caring alone
- More likely to have reduced networks as spouse, friends die
- The relationship with their son or daughter is very important and this can develop in to mutual dependency and very strong bonds
- They have had a different experience of services than younger family carers
- They are less likely to ask for help just at the time they might need more

There is some evidence from research, both in the UK and the USA that indicates that up to 25% of people with learning disabilities do not become known to services till later in life. Often this is because their family carer is no longer able to care for them due to ill health or death. (Moss et al 1992. Janicki 1998).

*In just one day Peter lost his Mum, home and his dog. There had been no preparation and the effect was devastating.*



"... the death of a parent... what plans are in place?..."

- Research by Walker et al (1995) has also alerted us to the fact that people with learning disabilities, living with older carers, are discriminated against because they are less likely to have had their needs assessed. They are less likely to have an individualised support plan in comparison to people living in residential provision who have been part of a hospital re-provision programme.
- Another consequence of this ageing profile of family carers is a recognition that whilst they still see themselves as 'responsible' for their son or daughter (Robinson and Williams 1999) that increasing mutual dependence develops both in terms of practical tasks and emotions. In many instances the person with a learning disability becomes a carer without this necessarily being recognised or supported.

**Looking after yourself and others training:** The North Tyneside Carers Centre has developed a training course which is designed to help people with learning disabilities in their own role as carers. A maximum of five people are identified for each training course. They are then visited at home and the purpose of the course explained to them and their families or carer. The training consists of 5 weekly sessions:

- Session 1. To define the term carer and to distinguish between formal and informal care
- Session 2. To determine the sort of task that a carer might do, and how being a carer can affect a person's life
- Session 3. To determine the most common accidents/emergencies one might come across as a carer, what causes them and what to do
- Session 4. To identify the stresses and strains of caring, how we feel when under stress and ways to deal with it.
- Session 5. To identify the sources of help for carers in a variety of situations.

Literacy skills are not a requirement as all the exercises are interactive, using pictures, drawings, relaxation exercises, 'spot the danger pictures' and lots of discussion.

For further information contact:

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Wallsend,  
Tyne and Wear NE28 6DG  
Email – nt.carers@virgin.net

## 2.4 What families say is important to them

*'If you're not searching for it, it probably won't find you'*

Linda Llewelyn – Umbrella Group – Derby

- Although family carers do not constitute a homogenous group and there are clear generational and cultural differences, both in expectations and experiences, some general issues can be identified.
- In research conducted by Grant and Whittell (1999) family carers had clear views about what they valued and found the most helpful from services. These include:
  - A proactive approach
  - Flexibility
  - Consistency
  - Accessibility

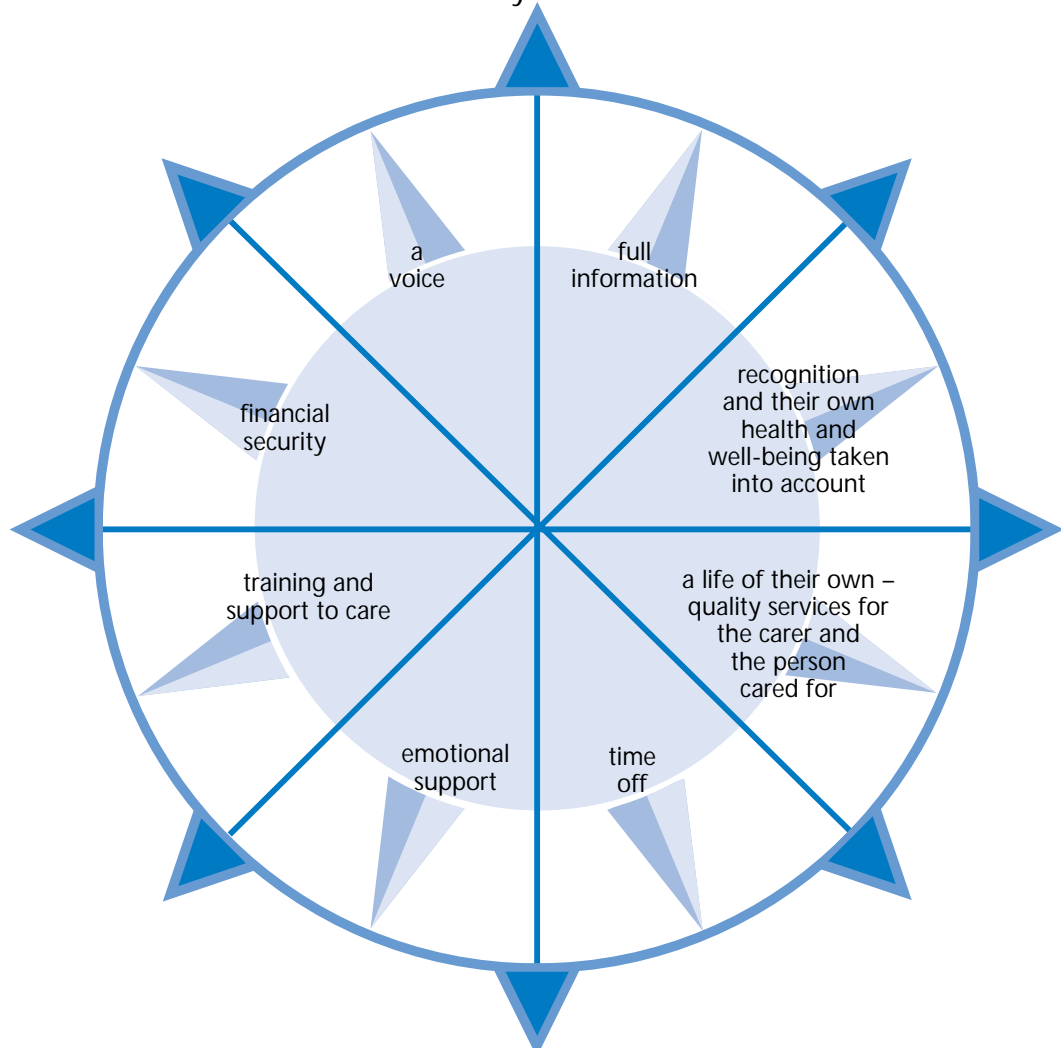
- Availability
- Reliability

They also value honesty and respect towards their opinions, expertise, and experience as carers.

- This is clearly not the experience of many family carers. In their research, Williams and Robinson (2000) concluded; *stress is caused more often by trying to deal with the service system than by any particular characteristics of the person with a learning disability*.
- The language that families often used to describe their relations with services is full of the symbols and images of war. 'We've been battling for years'. The language is one of conflict rather than conciliation and working together.
- Far-reaching consultations with carers conducted by the Kings Fund Centre have led to the development of the Carer's Compass (1998). The Compass is a useful tool to help services understand the eight key areas that carers have identified as important to them. These eight areas are discussed below in relation to the specific needs of family carers of people with learning disabilities.

**Carers want a good quality of life for the person they care for and control of their own life.**

They want:



**Are you heading in the right direction . . . ?**

by courtesy of Kings Fund

## 2.5 The Carers Compass from a learning disability carer's perspective

### 2.5.1 Life of their own – quality services

- *'We were asked to speak about family carers issues but as parents we feel we've got to talk about services for people with learning disabilities. These are the things that really effect us.'* Graduate of the NW Partnership in Policymaking programme at the regional consultation event. March 2000.
- There is almost unanimous agreement from family carers that their primary concern is the well being of the person with learning disabilities that they support. *'Get it right for people with learning disabilities and you sort our problems'*. **Nearly all the consultations with individual families or groups, written or in meetings stressed the service issues rather than the carers issues, which were seen as important, but secondary.**
- Many families have a clear sense of the 'rights' of people with learning disabilities to good quality services. This is reflected in the recommendations set out below for the strategy in relation to service developments.
- Family carers are concerned about the quality of the daytime opportunities for people with learning disabilities. Family carers are also particularly concerned that proposals to modernise day services might really be cost cutting exercises that will result in additional restrictions on their own lives.
- Family carers are concerned about the lack of housing or residential options for people with learning disabilities. Families are often accused of 'hanging on' to people and not letting them leave home. Whilst this might be true in some instances, the reality for many families is that they are keen to promote the independence of the person with a learning disability. It is the lack of residential or supported living options in an area that acts as a barrier to people leaving home. *There are just not enough places for people to leave home even when they want to.*

*I'm worried that I'm going to become an older carer before my daughter gets the chance to leave home!*

Family sub group member

- Family carers are often keen to talk about their very difficult experiences of getting appropriate health care for their relative with a learning disability. These include problems of attitudes and communications encountered in the GP's surgery, to the closure of specialist health care provision and the lack of support to use mainstream services. There is tremendous concern about how people with learning disabilities are treated in hospital and the majority of family carers say they have been unable to leave the person unattended at any time. There is also a concern about rationing of services *because* people have a disability.

## 2.5.2 Time off

- Respite care or the opportunity to have a break from caring is one of the things that family carers say they value most. Not only is it recognised that a break can help the carer but a break can be beneficial for the person with a learning disability in terms of their own needs to establish a broader range of relationships and opportunities.
- This dual function of respite – short breaks has led some family carers to say that it should be an entitlement for all learning disabled people and their carers if they should want it.
- It needs to be recognised that the nature of caring is changing (i.e. Adults with learning disabilities are less likely to go into full time residential care than in the past) and therefore many family carers will need appropriate day care in order to work.
- It is estimated that demand outstrips supply, and there is considerable unmet need. Research by the Carers National Association suggests that a third of all carers assessed under the Carers Recognition and Services Act 1995 do not get a break. (CNA 2000) Mencap estimates that at least 60% of family carers of people with learning disabilities do not get a break The question of the lack of clear guidelines around eligibility for respite- short breaks, and lack of local provision, were issues identified again and again during the consultation.
- The Carers strategy (1999) targeted the issue of breaks for carers and made available £140 million over 3 years to enable local authorities to provide more short breaks to carers. Although the grant has helped to promote the issues of local carers needs there have been problems with implementation. Under half of the local authorities managed to meet the targets set for direct spending on breaks.
- The number of family carers of people with learning disabilities who have benefited from the first year of the grant is difficult to ascertain as the majority of authorities have not specified how they have divided up the grant to different care groups. Anecdotal evidence from the consultations is that many authorities did not involve learning disability organisations in the consultation process to find out about local needs.
- The question of unmet need is further complicated by the fact that many carers are not getting the break they need because the respite services on offer to them do not meet the needs of themselves or the person with learning disabilities that they support. This is particularly pertinent for families from minority ethnic communities who would need services to reflect their cultural and religious needs.
- When family carers were asked to identify the services they most needed in their area (C.N.A.2000). They highlighted:
  - Services provided within the home
  - Increasing services which are available out of hours
  - Making services more tailored to people's needs, for example more culturally appropriate
  - Breaks of less than 3 hours.

People wanted flexible services that were tailored to their individual needs and circumstances.

- In the Kings Fund's review of Local Authorities response to carers' needs for breaks, only 6 out of 142 authorities had developed a voucher scheme which allowed individual families to have more control over when they got the break they needed. Although 32% indicated that a scheme was in the pipeline, but at a very embryonic stage.
- Direct payments were seen as a potentially valuable resource but people felt they needed further clarification on the implications for family carers. The feedback from coming from families was mixed. Many families could see the benefits but others were worried that they would effectively mean yet more work for the family.
- Many carers have to work and might have need for respite arrangements for them to do so. Research (Williams & Robinson 1999) has highlighted that family carers feel that services do not view this side of their life as important. Analysis of carer assessments has shown that people's working commitments were not discussed as a part of their carer's assessment.
- Clearly changes in the world of work, with employers paying more attention to the needs of employees caring role, is beyond the remit of the strategy but does link with the current Government agenda; Changing Working Life. Nevertheless, services should be paying more attention to how they can support family carers who need and have to work.

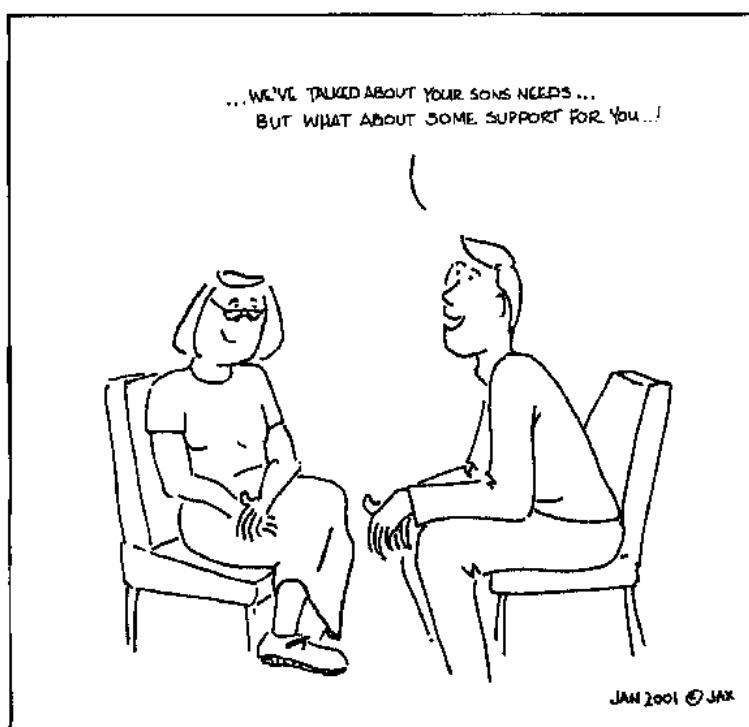
### 2.5.3 Emotional support

- So often the psychological demands of caring are underestimated in comparison with the tasks of physical care. The emotional needs of all the members of the caring family need to be recognised and supported.
- In particular, the emotional needs of siblings have been neglected and young carer's projects tend to focus on the needs of those caring for a parent. The long-term consequences of having a sibling who has a learning disability need to be explored and appropriate support offered.
- Research has indicated that family carers can be vulnerable to feeling a sense of isolation and low esteem.
- Many family carers receive their emotional support from friends and family. Some groups are more vulnerable to social isolation and lack of support from their family and community.
- Many older carers support networks diminish over time due to ill health and bereavement. Single carers are particularly vulnerable.
- The emotional needs of individual carers from minority ethnic and black communities can sometimes be overlooked because of stereotypical assumptions about the role of family in these communities. Research has shown those particular groups from minority ethnic and black communities are particularly prone to isolation and receive less support from family and friends than usually recognised. ( Chambara 1999 & Nocon et al. 2000)
- Family carers clearly value the support they receive from carer support groups and projects, but not everyone will be willing, or able to join one because of their caring responsibilities. Some areas have invested in carer support posts that can provide the one on one support that some family carers prefer and this plays a key role in offering emotional support to carers.

## Barnet Social Services – Carers Development Worker, Learning Disabilities.

Working as an integral part of the Community Learning Disability Team the role of the Carers Development worker has been to identify the family carers in the Borough supporting an adult with learning disabilities and ascertain their needs. The development worker has gone on to develop a range of different support services. This has included establishing carer support groups, (including a specific group for Asian Carers); undertaking home visits; ensuring access to Carers Assessments; offering training workshops on issues identified by the carers.

Contact:  
Nichola Whitehead,  
Carers Development Worker,  
Learning Disabilities Team,  
Barnet Social Service Department,  
Sapphire House,  
22 East Barnet Road,  
New Barnet,  
Herts EN4 8RQ 0208 8359 5477



"... we want dedicated family carer support..."

### 2.5.4 Training and support to care

- Families represent the single biggest provider of care and support to people with learning disabilities yet how much is invested in training and supporting them to undertake their caring role more effectively and safely compared to *paid* carers?

- The remit for training family carers is potentially wide. It is not just about providing training on the physical care, like lifting and moving or medication, but a broader range of issues to do with understanding learning disability and empowering family carers themselves, as individuals and in their caring role.
- Some authorities not only offer places to family carers on all their learning disability training but also include them at the point of developing the local training needs analysis and authority wide training strategy. Not only should family carers be the recipients of training they should also be involved as paid trainers of waged staff and volunteers.
- In some areas specialist workshops are on offer to family carers and people with learning disabilities to both provide information and help people plan for the future in a more informed way. There are examples of Transition workshops and Future Options targeted at older carers, which carers find very beneficial.

### Sharing the Challenge: A course for parents of disabled adults and self-advocates.

*Sharing the challenge* is a newly designed leadership training and development course for parents of disabled adults and self-advocates. Underpinned by a strong value base of inclusion and equality, the course provides information, training, and skills building so that the participants gain the knowledge they need to campaign and advocate for themselves, for others and for a better future for disabled people in our society.

The course is run over five sessions, designed to fit into the carers' day, and includes the following topics:

- Understanding why things are the way they are
- Exclusion and inclusion
- Getting the right support and employment and training
- Making change happen locally – making changes at a national level
- Person centred planning.

The course has grown out of the experience of running the **Partners in Policy Making** programme.

For more information contact:  
Lynne Elwell,  
Northwest Training and Development Team,  
Calderstones,  
Whalley,  
Clitheroe BB7 9PE.  
01254 821334

- There are now several parts of the country that have run a Partners in Policy making programme for people with learning disabilities and family carers. Graduates are equipped and empowered to take a more informed role in local planning and decision making.

- As part of the Lifelong Learners agenda family carers should have the opportunity to develop interests outside their caring role. The NIACE has been offering Carers Learners Awards for several years and has documented the benefits for family carers. (ref). Local Learning Skills Councils need to ensure that they include carers learning in their plans.

### Life long Learning and support – opportunities for family carers.

Managed by Lancashire College, Lancashire Adult Education 'Carers project' has been at the forefront of creating positive learning opportunities for carers and is funded through a partnership between Health, Social Service, and Education money. The college offers a wide range of learning opportunities for carers including; short residential courses, '*Taking Care of the carers: a recharge for mind and body*'; local groups tailor made for the participants; and courses that range from stress management to wine tasting. The college has two Carers Project workers and a co-ordinator to develop a comprehensive programme of carer support and learning.

Contact:

Donna Galway,  
Carers Project Co-ordinator,  
Lancashire College,  
Southport Road,  
Chorley, PR7 1NB  
Carers Team direct 01257 516083

Also of interest:

NIACE, the national organisation for adult learning, has produced a book about access to learning for carers – Access and Inclusion: Developing education for carers across agencies. It is available from:

NIACE,  
21 De Montfort Street,  
Leicester LE1 7GE

The Princess Royal Trust for Carers runs an educational bursary scheme for carers who want to learn. Carers need to apply through a Princess Royal Trust Carer's Centre. To find your local centre contact:

The Princess Royal Trust,  
142 Minories,  
London EC3N 1LB  
020 7480 7788  
Website: [www.carers.org](http://www.carers.org)

### 2.5.5 Financial security

- Carers are disadvantaged financially in their caring role. The long term effects of caring impact on lifetime living standards and include:
  - the carer's employment status

- their level of earnings,
- savings
- Pensions.

Maria Evandrou argues that *'it is questionable whether existing welfare benefit system, specially the receipt of ICA, compensate carers financial position sufficiently to place them on par with their non caring counter parts'*.

- The ICA 'the wage for caring' is considerably lower than the basic pension but it is lost to carers at retirement age, which causes resentment from older carers. *Im still doing the job after all!*
- The costs of caring are high and family carers of adults do not have access to non-means tested resources like the Family Fund for Disabled Children to help with key items like washing machines and general household wear and tear. People's access to aids and adaptations can take time and often families find themselves purchasing vital pieces of equipment because they cannot afford to wait.
- The Benefit system can act as a perverse incentive and trap people into dependency and restrict opportunities to take up paid employment. This is true for both the family carer and the person with learning disabilities.

### 2.5.6 A voice

*Listen to what families have to say, be there when they need help, and don't promise what you can't deliver.*

- For family carers, having a voice and being listened to is part of a broader partnership agenda.
- Family carers want their opinions and expertise about their individual family member recognised and valued. *'We are the experts, we know her so well'*. They want to be consulted and involved in the decision making process around a person's life, and recorded as part of an individual planning process.
- Family carers have valuable opinions and experiences of being at the receiving end of services and have a contribution to make in evaluating how effective services are. Family carer opinion should be regularly sought as part of ongoing monitoring of service effectiveness.
- Family carers have an important role to play in helping shape the direction and priorities of local services. They are in a position to think through the implications of any planned changes for people with learning disabilities and family carers. Families are concerned that changes in services often mean they find their caring role extended.
- Local authorities have got to find ways of hearing the voice of those 'hidden carers' who do not join organised groups. One of the criticisms to emerge from an analysis of the Carers Strategy consultations carried out in 1999 was that they were over reliant on consulting well-established groups and projects.

- The 'Give Us A Break' report, (C.N.A. 2000), concluded that carers *projects* must 'resist becoming a spokesperson for carers and concentrate on enabling carers to have a voice'. This is because the report found that Local Authorities tended to focus their consultation efforts at known groups. Too little attention was given to trying to develop methods to reach those carers who do not join groups.
- There is evidence to suggest that authorities have a poor record for feeding back on the actions arising out of the consultation process. This can lead to 'consultation fatigue'. *We are fed up being asked what we think and then nothing ever happens*. Feeding back the results of any consultation process is important.
- It has to be recognised that differences of opinion can occur between services and family carers. Some families might need the support of an advocate to speak up. What is lacking in adult services is a clear framework for resolving conflicts or difference of opinion through conciliation or mediation as there is in children services. All families are left with is Complaints procedures, the Ombudsman or in extreme cases judicial review. The lack of a clear legal framework around decision making in learning disabilities requires further consideration.

### 2.5.7 Full information

*No one ever told us that we were entitled to benefits.* Older family carer Sheffield

- Family carers say that they value having a key worker with whom they liaise with directly and get information.
- Paid staff and professionals need to be able to give up to the minute information to family carers and people with learning disabilities. Research indicates that one of the things family carers are looking for from services is expert advice and opinion. Staff need to be regularly updated. Training is just one dimension of the need to keep carers and paid staff informed.
- If family carers are to be considered valued partners, what Robinson and Williams call 'co-professionals' they need to access information that equips them to make informed choices.
- Family carers have highlighted how difficult it is to find out about key things such as what people with learning disabilities are entitled to in terms of benefits and services. They need to know how to access them and understand the different processes and procedures that authorities use, including eligibility criteria and funding.
- Many family carers say that a single point of access to information in the form of a one-stop shop would be helpful. A place where people know where they can go and get the up to date information they require.
- Information needs to be accessible. It needs to be disseminated through a range of different outlets, including libraries, GP surgeries, the local media, and voluntary organisations. Ranges of different methods of communication need to be developed. Not just written leaflets but also audiotapes, videos, and CD's in range of different languages. Special priority should be given to connecting with and ensuring information is getting to minority ethnic and black family carers.

## 2.5.8 Recognition of their own health and well being taken into account (assessment)

- One of the few entitlements that a family carer, (as defined under the Carers Recognition and services Act 1995), is to have an assessment of their own needs. Yet there is anecdotal evidence from the consultation groups that carers are often unaware of this, or have not been offered one. In some cases people said they had been refused one. The picture is one of general confusion.
- Robinson and Williams made a study of the impact of the Carers Act on family carers of people with learning disabilities. The research, undertaken in 5 Local Authority areas, found that only 35 family carers of people with learning disabilities had been offered an assessment in a one-year period.
- Those who had received an assessment of their needs generally appreciated it but approximately one-year later only 18 out of 42 services that were discussed at the assessment had been delivered.
- This led the researchers to conclude: *'Carers of people with learning disabilities are not being well served by the Carers Act.'* Whilst they would be keen to endorse the value of a properly conducted assessment they suggest, *'Assessments themselves are not necessarily a good use of resources if they do not lead to change.'* They are, after all, a means to an end, not an end in themselves.



"... assessment... let's get beyond 'tick this, tick that...'"

- One of the key problems is that many people with a learning disability have no regular or direct contact with care management or social work teams. The triggers for assessments are therefore not in place and an assessment is usually precipitated by a crisis, or if people are going through a major transition.

- The researchers conclude that carers would be better supported, and have easier access to assessments, if the process was kept closer to learning disability services. They advocate the development of dedicated carer support officers attached to day services or respite provision. They also recommend that a useful way of keeping a track of carer's needs could be by linking a review of their needs to the annual review or IPP of the person with a learning disability. Although the focus of review should still remain focused on the person with the learning disability it provides an opportunity to link this in with a review of the carer's situation. This is in line with the Mental Health National Service Framework that recommends that carers have their own plan and that it is annually reviewed.

### **Shropshire Community Council: Link officer for carers of adults with learning disabilities.**

The link officer for carers of adult of learning disabilities has played a crucial part in developing awareness of carer's needs in the county. The link officer has helped identify a number of hidden carers as well as establishing links with carers who are known to local services. The Link Officer advocates for individuals but also seeks to influence the way local services respond to the needs of family carers.

Ongoing consultation has highlighted priority areas for family carers and these are reflected in the work of the post. Particularly important are work on communication and information, respite and emotional support.

Initiatives involve:

- The Link Officer has developed a 'grab' sheet to ensure vital information about the person with learning disabilities is available in an emergency if the family carer is not present and they have to go to hospital.
- Profiling Carers Needs: Carers are supported to request a Carers Assessment and are offered a pre-meeting to ensure they maximise the benefit of having the statutory assessment.
- The training needs of staff have been highlighted and the Link Officer is involved in training across the county and has made a training video about three family carer experiences; 'Could you do what I do?'

Contact:

Flick Pennel,  
Link Officer for carers of adults with learning disabilities,  
Community Council of Shropshire,  
Ivy House,  
Upper Church street,  
Oswestry,  
Shropshire SY11 2AA  
01691 680255

- The Robinson and William's study also highlighted that a number of the family carers had their own health problems and in some cases, impairments. They found that in the carer's assessments that were undertaken, the carer's health was not discussed. There is evidence that the highest correlation between poor health status of the carer is linked to caring for someone with mental and physical impairments. (Evandrou 1999) the role of the GP in alerting the carer to their entitlement to an assessment is a crucial lynch pin in carers support.
- Other areas not covered in assessment were the carer's employment status and multiple caring roles. Many family carers are not only caring for a person with a learning disability but elderly parents and other children or grandchildren. The broader contexts of people's family lives were not properly addressed within the assessment that focused myopically on the caring role in relation to the person with the learning disability only.
- The new Carers and Disabled Children Act will take forward the policy agenda for carers. The proposed Bill develops the carers rights to both assessment in their own right, even if the cared for person refuses, and some service provision. The lessons learnt from the first year of implementing the Carers Special Grant is that Local Authorities will need clear guidance and monitoring.
- The new act proposes to give powers to Local Authority to charge carers for services provided. Many family carers are particularly concerned about the lack of a nationally agreed charging policy framework.
- One of the disappointing findings to emerge from the analysis of local carers plans has been the failure of local authorities to devise effective systems for collating any meaningful information from the carer assessments already undertaken to illuminate local needs of family carers. (Banks 2000).

## 2.6 To summarise

It is clear that family carers have a broad range of concerns as evidenced from the above discussion of the Carers Compass. For the purposes of this report we cluster these concerns under three key themes.

These Are:

- **Learning disability service development**
- **Partnership and participation**
- **Supporting Family carers.**

The report also highlights three groups of carers who have priority needs that require particular attention and the development of targeted support. These three groups are:

- Older Carers
- Family carers from minority ethnic and black families
- Families supporting a young person through the transition from children to adult services.

Outlined in the sections below are proposals for changes that need to happen at both a local and a national level if the strategy is to address the three key themes and priority groups effectively.

# 3. Values and visions

*Family carers have rights, to rights of their own, just as people with learning disabilities do.*

## 3.1 The value base

The underlying value base of this report is that men and women with learning disabilities have:

- *the same basic human rights and entitlements as any other citizen of this country and;*
- *The right to get the support they need to maximise their full potential and access a full range of opportunities.*

Similarly, the value base of this report is that family carers have rights. Family carers should be able to:

- *access the support they need to enable them to undertake their caring role effectively and with minimum stress and disadvantage;*
- *Be seen as people in their own right.*

## 3.2 What the strategy needs to achieve on behalf of family carers

### 3.2.1 Service development

Family carers would like to see:

- More opportunities, greater choice and better services for people with learning disabilities;
- Greater clarity of what sort of options should be available in any given area to overcome the postcode lottery and ensure greater equity across national provision.
- All people with a learning disability entitled to an individual plan which helps them and their carers to plan for the future and well as the present.
- People with learning disabilities supported by paid staff who have access to high quality training

### 3.2.2 Developing partnerships and encouraging participation

Family carers would like to see:

- A change in the culture of services that currently causes them so much stress and often labels them as the 'problem' rather than seeing them as important allies in the support of a particular person with learning disabilities.
- The formal development and support of partnership and participation working at a local level as a way of constructively channelling energy, expertise and commitment.
- A move toward mediation and conciliation when differences or conflict of opinions arise between families and services rather than the culture of conflict and antagonism inherent in complaints systems.

### 3.2.3 Carer support

Family carers would like to see:

- Greater clarity about their rights and entitlements as carers
- Better support for family carers of people with learning disabilities
- More effective targeting and monitoring of mainstream initiatives around carers to maximise benefits for this group
- A single point of access for support and information
- Dedicated carer support staff or services for family carers of people with learning disabilities

### 3.2.4 Priorities

- Local identification, support and planning with older carers. (Defined in this report as being 70 years and older).
- Local identification, support, and planning with family carers from minority ethnic and black communities to develop a range of more culturally appropriate services and combat unmet need in these populations.
- Supporting families of a young person going through the transition process from children to adult services.

## 4. Government Objectives

- The themes and priorities identified by the family cares sub group fit well within wider governmental objectives. The concern to enhance and improve services to adults with learning disabilities fits within the modernising agenda outlined in the White Paper, Modernising Social Services (DoH 1998), with the focus on **promoting independence, improving protection and raising standards**. The emphasis on **partnership**, inter agency co-operation, and service user involvement is also emphasised and codified in statute with **the Health Act** (1999). Other areas of relevance to this report are the questions of **equity and social inclusion, support to carers and changing working life, in a broader context of promoting policies to help sustain and support family life**.

# 5. Recommendations: Implementing change at local level

The strategy needs to make a difference, at a local level, to the lives of individual. These are some of the things that need to happen to help make these changes a reality.

## 5.1. Learning Disabilities Service issues

At a local level there needs to be:

- 5.1.1 A requirement on authorities to offer, and publicise a range of services to people with learning disabilities** that need to be on offer if people are to have a real choice in the sort of provision they have access to. (This models requirements under section 17 of the Children Act):
- 5.1.2 A Requirement to develop and publish and implement a multi agency Learning Disability Plan.** This plan needs to build on the work of the Joint Investment Plan ( JIP) between health and social services and include a broader group of partners. It should involve housing agencies; employment services; Learning Skills Councils; Education and Recreation and Leisure Departments. The plan would also need to specify *how* people with learning disabilities and family carers had been consulted and involved in the process of developing the plan.

As part of the plan, there will have to be clarification about what local agencies mean by the term 'learning disability' and the implications this has for interagency working. Agencies also need to clarify and make transparent their eligibility criteria for services.

As well as being involved in the development of the Learning disability plan other agencies will need to demonstrate and specify how they include people with leaning disabilities in their provision or service in line with government guidance.

- 5.1.3. One lead agency** specified which is accountable for co-ordinating, ensuring implementation and delivering and monitoring the plan.
- 5.1.4. The establishment of a single co-ordinated database and management information system** to assist planning and targeting resources most effectively. There are good examples of Registers and Information Projects that have helped to identify local population needs. Local systems should work to nationally agreed criteria to be useful in building up a clear national picture. There is evidence that local authorities have poorly developed systems for using information from Carers Assessments to influence strategic planning. (Banks 2000.) GP's have been identified, as having a key role in picking up on the unmet need of family carers and primary health care will need to involve in local data collection.
- 5.1.5. The development of a co-ordinated information strategy** to disseminate *information* to people with people with learning disabilities, family carers and professionals. This might include the 'one stop shop' idea but extends beyond that to the very methods of information dissemination local agencies use. This has particular relevance to getting information to hidden carers especially those from minority ethnic communities. Not only is language a barrier but written material might not always be the most appropriate form. Family carers from these communities

have indicated that face to face verbal information is valued. A more creative use of the local media is also to be encouraged as well as audiotapes, CDs, videos and the Internet.

**5.1.6** A real commitment to delivering high quality **training opportunities**. This should include:

- nationally recognised accredited training for staff who are working with people with learning disabilities and their family carers;
- All staff working in services for people with learning disabilities undertake a 'Working with Families' training workshop as a part of their core training. This should include working with diversity and cultural difference ;
- Preparation workshops on 'making the transition from children to adult services' for young people with learning disabilities, their families and staff from both services.
- Workshops for older family carers and their sons and daughters on 'planning for the future'.
- All mainstream training in learning disability services should be on offer to family carers. In some areas a certain number of free places are allocated for carers.
- Family carers and people with learning disabilities should be employed to deliver relevant training.

**5.1.7** More investment in independent advocacy or brokerage for both people with learning disabilities and their family carers. This needs to operate within a clear national standards framework.

**5.1.8** Development of direct payments and voucher schemes that create greater flexibility and control for both people with learning disabilities and family carers. There needs to be clearer guidance on how this can practically implemented by families and people with learning disabilities.

**5.1.9** Specific service issues of urgent concern to family carers include:

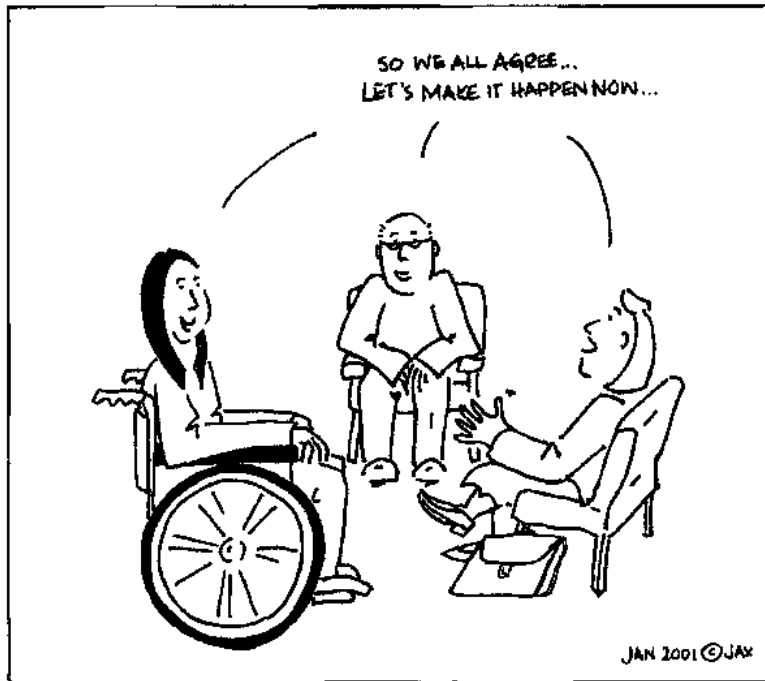
**5.1.9.1** Combating the shortfall in residential provision. There is a need to develop a local strategic approach to increasing the range and number of alternative accommodation places for people with learning disabilities over a five-year period.

**5.1.9.2** Expanding the range and developing the quality of day opportunities for people with learning disabilities. Family carers should not be expected to have their caring responsibility increased if local arrangements for day services are changed.

**5.1.9.3** Developing a range of imaginative, person centred and flexible respite or short term breaks.

**5.1.9.4** The development of protocols for health service providers to ensure that people with learning disabilities access appropriate support and treatment. The poor service people with learning disabilities receive as hospital patients is of particular concern.

**5.1.9.5** The inclusion of people with profound and complex needs. Service opportunities for people with profound and complex needs must be expanded. There is evidence that these groups of people are currently poorly served in all areas. Social care providers have to be equipped to meet health care needs.



"...working in partnership  
with families ..."

## Success in Shared Care: developing partnerships between families and professionals.

Success in Shared Care is a training organisation set up by two parents to promote shared training between professional providers and families, arising as a result of their own experiences of working in partnership with service agencies over many years. The philosophy of the organisation is:

*"By working together with providers of services we hope to encourage the ongoing development of co-operation and mutual respect in all aspects of shared care."*

Training workshops include:

- Letting Go – A parents dilemma
- Are we hearing each other?
- Communication and understanding.

Workshops have been delivered to a range of staff and parents and within a variety of different service settings, including; Social Services, NHS Trusts, and Mencap.

Contact:

Jan Webb and Joan Barnard,  
Success In Shared Care,  
'Rose Cottage',  
Bridge Street,  
Great Kimble,  
Aylesbury, Buckinghamshire HP17 9TN  
01844 345256

## 5.2 Developing opportunities for partnership working with family carers

**5.2.1** The strategy needs to promote a change in service culture that recognises that the relationship between family and professional is a crucial aspect of service effectiveness.

Some of the things that might act as levers to bring about a change in service culture have been identified already and include; **training; better dissemination of information; advocacy.**

The development of a culture of partnership needs to operate at three different levels described below. These are:

- On a one by one basis in the life of the family member
- Operational service delivery
- Strategic planning

Currently adult services are failing to build on the more constructive partnership model that underpins relationships between parents and professionals in children services. A major trigger for change in the future may come from a generation of parents who have experienced working in partnership as a right. But the fact remains that family carers of adults have no mandatory rights to be included in decision making.

Many family carers of adults feel strongly that the lack of a clear legal framework around decision-making and people with learning disabilities acts as a barrier to proper partnership working.

### **5.2.2 One to one – individual planning**

For the majority of most family carers the really important priority is being involved in the planning of support to their family member with a learning disability.

It should be a requirement that all people with a learning disability should have the right to their own individual plan. This plan should not just focus on setting short-term goals but provide an opportunity to 'map' future aspirations and needs as the person gets older and moves through the lifecourse. Family carers have a valuable role to play in this process.

As people get older it is appropriate those personal histories or life maps are developed so that valuable information about the person is not lost. Families have a key role in this process.

Good practice guidelines should be prepared to facilitate family involvement. It should be standard practice that the family carers perspective and opinion is *formally* recorded as part of a planning or review

The reality is that Care management has not always served people with learning disabilities and their families well. The majority of people with learning disabilities are not in regular or continuous contact with a care manger or social worker. A recurring comment during the consultation was '*what's a social worker then?*' *Haven't seen a social worker in years.*

Access to care management needs to be reviewed and local systems put in place to ensure that families in need are identified before a crisis develops.

## **The Sharing Caring Project is part of Sheffield Mencap & Gateway**

The Sharing Caring Project currently supports family carers over the age of 55 years. The project was funded in response to sustained pressure from ageing carers, and research by the Sheffield Case Register which revealed that most older carers were unsure about how to plan for the future and what sort of options were available to them and their relatives. The SCP works in partnership with Sheffield Citizen Advocacy to ensure that the voices of both older carers and the people they support are heard..

The project has produced a report of its initial findings: 'Crisis Approaching! The Situation Facing Sheffield's Elderly Carers of People with Learning Disabilities'. Responding to the needs identified within the report the Sharing Caring Project has been instrumental in developing initiatives that include:

- **Older Carers Support Scheme (OCSS)**

A scheme managed by Community Health Sheffield NHS Trust, developed in partnership with Sharing Caring Project & Sheffield Social Services. It offers regular contact to older carers and assists them to access a range of additional preventative supports that may be useful for them or the people they care for.

- **Life Books**

Winner of the Community Care Magazine 'Voluntary Sector Innovation Award, the Life Books the books are completed and held by the person with learning disabilities and people have the option of returning a single page to Social Services in case of an emergency. 600 were distributed free to people living with carers over 55 in Sheffield.

- **Information Packs for Carers.**

The packs have been developed in partnership with Community Health Sheffield and Sheffield Social Services. Besides outlining services and resources available in Sheffield, the pack focuses on issues specific to older carers around planning for the future.

- **'Thinking Ahead' Video Pack**

The video pack acts as a starting point for families and workers to discuss possibilities for future accommodation and support. The video outlines the planning processes, the links between funding and assessment, and different types of accommodation.

- The project has recently developed a partnership with the **Asian Disability Project** to support the needs of older Asian family carers

Contact:

Dalia Magrill (SCP Co-ordinator),  
Sharing Caring Project,  
Norfolk Lodge,  
Park Grange Road,  
Sheffield, S2 3QF  
Tel: 0114 2758879

## Older Carers Support Scheme (OCSS)

### Background Information

The Older Carers Support Scheme (OCSS) is an innovative new partnership scheme to support the most vulnerable older carers of people with learning disabilities who told the Sharing Caring Project (SCP) that they want more contact with statutory services. The project is managed by Community Health Sheffield NHS Trust (CHS), and is steered by a partnership group that includes carers, the SCP, CHS and Sheffield Social Services. The project has enabled strong links to be established between older peoples services and learning disabilities services throughout the city.

Two OCSS Support Visitors work within CHS alongside their Case Register, who already collect information about children and adults with learning disabilities throughout the city. The workers visit carers over 70 years on an annual basis and then keep in touch through monthly telephone calls. They collect information and offer advice about different services available for carers, older people and people with learning disabilities around Sheffield, and help carers to access appropriate support. The overall aim of the OCSS is to enable older carers to build up positive partnerships with statutory services so that problems can be dealt with before they turn into a crisis.

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### 5.2.3 Involving family carers in operational service delivery

Services need to demonstrate how they are involving people with learning disabilities and family carers in evaluating the effectiveness of the service that they receive. This should be done through formal review meetings; questionnaires; one to one meetings and group consultations. Particular attention needs to be paid to how they are going to ensure that the voice of hidden carers is heard alongside more vocal individuals within organised groups.

Services need to demonstrate how they involve family carers as well as people with learning disabilities in service reviews.

Services should invest in encouraging and supporting family carer support groups. All learning disability services should have a dedicated carer support worker who liases and supports family carers.

## **HFT Carer Support Service:**

HFT is a national organisation providing a range of services for adults with learning disabilities. The charity was established in 1962 by parents wishing to secure satisfactory residential opportunities for their sons and daughters as they left full time education and moved on into adulthood away from the family home. By the early 1990's 1700 families had registered an interest in the provision HFT might be able to offer a learning disabled relative. Aware that HFT would not be able to offer sufficient accommodation to match families' aspirations the Trust sought other ways of assisting them.

Research undertaken by HFT confirmed that parents who have a son or daughter with a learning disability:

- *Experience difficulties in obtaining information about the services they need*
- *Are frequently unaware of their rights and resources available*
- *Are further stressed by the uncertainties they face when considering the future.*

HFT's Carer Support Service provides:

### **Information:**

- Regular digests of national carer related news featuring examples of good practice
- Targeted mailings about local services and events
- Specific response to individual requests

### **Support:**

- Through a rolling programme of workshops for parents carers, including transitional planning from children to adult service and supporting older family carers.
- Training events for staff and carers
- Personal contact by phone or letter

**Networking and service development and research:** in partnership with other organisations innovative work in developing ways of effectively and engaging families and research into the transition between children's and adult services.

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As part of the Charter on Long Term Care a local protocol should be developed in conjunction with family carers about 'working with families of people of learning disabilities who live in residential accommodation'.

#### **5.2.4 Involving family carers in planning and decision making at a strategic level**

As part of the local Learning disability Plan a Participation And Partnership strategy should be drawn up to provide a coherent plan for consulting people with learning disabilities and family carers. This should include the following:

- How they propose to involve family carers at an individual level and a collective level;
- How they propose to involve parents and family carers at different 'ages and stages';
- How they propose to ensure that the 'hard to reach or hidden family carers are identified and given a voice;
- What partnerships they have established with local voluntary organisations;
- How consultation on service planning, development and review will be managed (e.g. Newsletters, joint working groups, use of voluntary organisations or more formally constituted Local Action Groups or Carers representatives).

A dedicated senior manager should have responsibility for developing and implementing the participation plan.

There needs to be financial investment in supporting family carers and people with learning disabilities to participate in strategic planning and decision making in an informed way. This involves funding training for carers on programmes like Partners in Policymaking, paying for them to attend relevant conferences, and covering caring, travelling and administration costs.

At a local level as part of any consultation process contributors should always receive feedback on the action taken

## **Essex County Council – Participation and Development Manager: Learning Disabilities**

Working across the whole of the county, and in partnership with a range of agencies, the Participation and Development manager's role is to ensure that both people with learning disabilities and family carers are actively involved in planning, monitoring and reviewing services from individual packages of care to strategic forums.

The Manager also takes a lead in commissioning advocacy services; the spending of the Prevention Grant as well as service development and taking a lead on staff development across Learning Disability services. All areas that are key to successfully advancing the participation agenda.

The post has helped engender a culture where senior management in the Directorate engage in meaningful consultation with people that use services and their carers. This has led to a county wide user and carer participation policy, with the provision for reimbursing user and carer expenses. Also, a network of 12 Local Action Groups have been successfully established, all of which have a strong user and carer presence and have been actively involved in shaping the priorities for the county's Joint Investment Plan and service development.

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### **5.2.5 Supporting carers in their own right**

Many of the things identified above are relevant to supporting carers by making them feel more involved in the important decision making processes that effect their lives. But there are some specific things that need to be achieved at a local level that will support them in relation to their caring role.

**5.2.5.1** These include being made aware of their entitlement to a Carers Assessment and the way the Carers and Disabled Children's Bill proposes to extend those rights. Local Authorities will need to monitor the number of Carers Assessments undertaken for this group of carers in their area, and monitor the outcomes. Assessment is not an end in itself but a means to help meet peoples needs.

**5.2.5.2** The triggers for assessment for people with learning disabilities and their carers are usually at the point of a major transition or a crisis. The majority of people with a learning disability and their carers do not have contact with a social work or care management team. Identification of carers who would benefit from an assessment needs to be triggered in other ways, as recommended below.

- 5.2.5.3** Carers identification is part of the National Priority Guidance and is being measured from April 2000. GP's are the most frequently visited professional group and have a crucial role to play in the identification and support of family carers. Identifying and supporting carers is effective for GP's as it can save them both money and valuable time. Supporting carers through GP practices is effective for carer support groups because it can help them identify hidden carers and target their support. Liaison with GP's is therefore essential.
- 5.2.5.4** Carer's contact with the Learning disability services that their family member uses is also an important point of potential support. Robinson and Williams (1999) have argued that the annual review or Individual Personal Planning meeting for the person with learning disabilities, could provide an opportunity to review the family carer's situation as well. Whilst the focus of the meeting would clearly remain on the person with the learning disability a pre meeting to focus on the carers situation could be important. A carer's plan should be recorded in conjunction with the main review. The carer's situation should be reviewed annually. Any concerns about the carer could then be referred for a formal Carers assessment if appropriate.
- 5.2.5.5** At a local service level, the role of a dedicated carer support post for this group of carers has been most effective in a number of different areas. The dedicated role and focus of this post is more important than the location of the post. Successful posts have been located in a Rural Council, a local Mencap, and generic Carer's Centres. It has also recommended that all Learning Disability services have a staff member with a carers support post (Williams & Robinson 1999).

### **Asian carers of people with learning disabilities: The Adhar Project**

The Adhar Project is a voluntary organisation based in the city of Leicester, and funded by the local Social Service Department. The project seeks to provide specific support for Asian family carers of people with learning disabilities. The project runs several locally based support groups, which provide information and advice on relevant topics as well as mutual support in a culturally appropriate environment. As well as supporting these groups the Service Co-ordinator undertakes home visits and offers one to one support when required. Where necessary the project will refer people on for assessment for support from mainstream services.

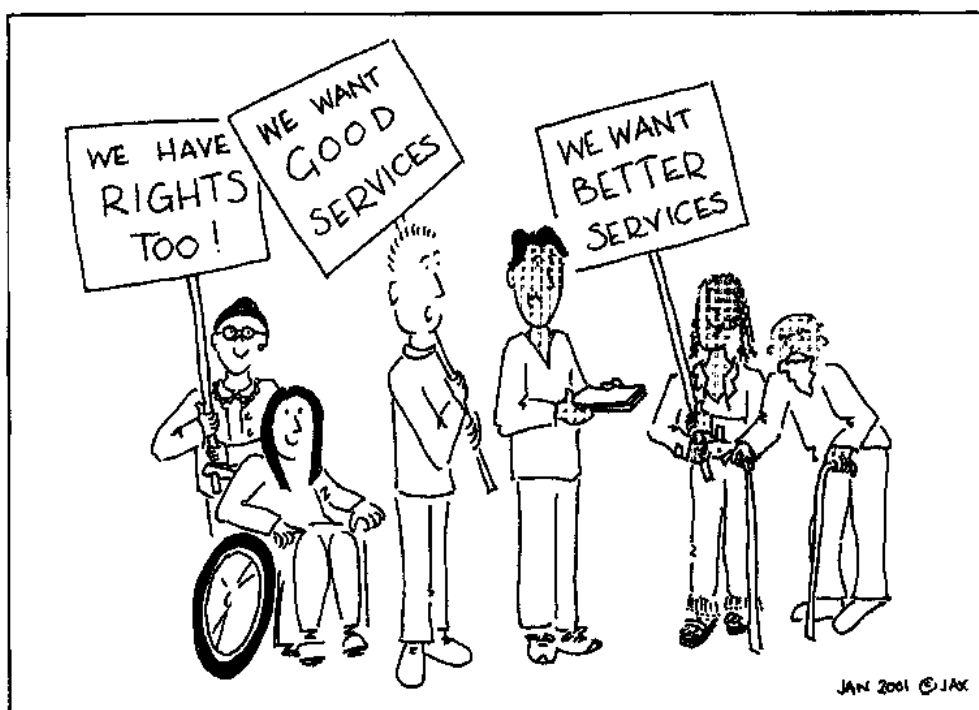
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- 5.2.5.6** Statutory agencies need to fund carer support groups in their area and recognise the need for dedicated focus on family carers of people with learning disabilities.

**5.2.5.7** It is an important development that 10% of the years Short Breaks money is channelled through the voluntary sector. Voluntary agencies have an important role to play in the support of all carers but particularly families from minority ethnic and black communities who might relate less well to statutory agencies. However, the voluntary sector will need sufficient planned and long term funding if it is to develop and sustain a range of new short term breaks and leisure activities for people with learning disabilities.

**5.2.5.8** There needs to be a more co-ordinated approach to respite care that meets the range of different needs that people have for a break. Voucher schemes, which give people more control and flexibility, should be developed.

Local Authorities will need to monitor the number of family carers of people with learning disabilities that benefit from the Carers Break initiative in it's second and third year.



"...families in campaigning role..."

## 6. National Support for local action

How can national policy support change at a local level? Family carers might not always agree on the details or the priorities of the changes they would like to see but on one point there is certainly a common voice. They want Local Authorities to be compelled to introduce changes.

*'It's alright giving Local Authorities powers to do something, lets give them a few more duties'*

*'Lets have less shall do's and more must do's please!'*

Sheffield Carer

There are a number of ways that national directed change can help bring about some of the changes needed to improve the quality of services for people with learning disabilities and support their family carers better. These should include the use of Section 7 Guidance and the use of a performance management.

### 6.1 The duties of Local Authorities – Section Seven Guidance:

- A general duty on Local Authorities to offer a range of specified services to people with learning disabilities in their area;
- A general duty on all statutory authorities to develop and implement a multi agency Learning Disability Plan to build on the work of the JIP's;
- Specification of the lead agency in terms of co-ordination and accountability.
- A duty to co-ordinate an individual plan for any person with a learning disability who wants it. (This duty could be delegated out to an independent organisation as appropriate) but the statutory authorities would be performance monitored on the number of people with learning disabilities in their area who had an individual plan, and the annual review.
- A general duty to establish data sets and management information systems that meet nationally agreed criteria that will assist comparison of performance with other authorities.
- The need to establish a National Charging Policy. The need to standardise charging polices to end local variations will be particularly important in the light of the proposal of the 'The Carers and Disabled Children's Bill' to charge carers for the services they provided.

## Performance monitoring.

Local statutory authorities need to be able to demonstrate that they are making change in clearly specified performance areas. The table below sets out some of the areas that family carers have identified as important with suggestions for performance indicators to monitor success.

## 6.2 Monitoring local performance

Performance area	Performance indicator or other evidence
<p><b>Service development:</b></p> <ul style="list-style-type: none"> <li>• Development of Multi agency Learning Disability Plan. To include:</li> <li>• Review Respite and short term breaks</li> <li>• expand residential and accommodation opportunities</li> <li>• create range of day time opportunities</li> <li>• Establish Data base and management information system to nationally agreed criteria</li> <li>• Development of Direct Payments schemes</li> <li>• Advocacy and Mediation</li> <li>• Staff training on family support</li> <li>• Access to secondary health services</li> </ul>	<ul style="list-style-type: none"> <li>• No of families supported and how often on an annual basis</li> <li>• No of different options made available in a year: overnight. Domiciliary and day time opportunities</li> <li>• No of extra placements and supported living places created annually working to a 5 –10 year strategy</li> <li>• No of people in supported employment?</li> <li>• No of people in vocational training schemes?</li> <li>• No of people excluded from day services because of complex health needs or challenging behaviour?</li> <li>• Total day service sessions available calculated as an average against the local learning disability population</li> <li>• Annual publication of demographic profile, service priorities and planning</li> <li>• no of people in receipt of direct payments</li> <li>• Money allocated and no of people supported</li> <li>• Recorded outcomes of mediation</li> <li>• Nos. of Working with Family training days and no of staff attended</li> <li>• Levels of staff with accredited training</li> <li>• Protocols established with local acute trust with regard to admission and support in hospital</li> </ul>
<p><b>Partnership and participation:</b></p> <ul style="list-style-type: none"> <li>• Development of participation and partnership strategy</li> <li>• Charter on Long Term Care</li> </ul>	<ul style="list-style-type: none"> <li>• Establishment of dedicated post to co-ordinate implementation of plan</li> <li>• Clear plan to demonstrate range of consultations and methods used</li> <li>• Formal ways family carers involved in decision making ( e.g. Essex model or local Action Groups and Lincolnshire's elected representatives)</li> <li>• Protocols developed for working with families of people in residential carer</li> </ul>

Performance area	Performance indicator or other evidence
<p><b>Supporting Carers:</b></p> <ul style="list-style-type: none"> <li>• assessing family carers needs</li> <li>• carer's support services</li> <li>• training opportunities</li> </ul>	<ul style="list-style-type: none"> <li>• nos. of carers identified as being eligible for an assessment under Carers Recognition Act</li> <li>• no of carers assessed under Carers Act 1995</li> <li>• no of carers with their own carer's plan</li> <li>• creation of a dedicated carers support post</li> <li>• nos. of family carers of people with learning disabilities benefiting from the Short Term Breaks grant</li> <li>• nos. of families benefiting from respite services</li> <li>• range of carer support services including a single point of access for information and support</li> <li>• nos. of targeted carer training days</li> <li>• nos. of carers benefiting</li> </ul>
<p><b>Priority groups:</b></p> <ul style="list-style-type: none"> <li>• supporting older carers</li> <li>• supporting people through the transition from children to adult service</li> <li>• Support to people with learning disabilities and their family cares from minority ethnic and black communities. <i>Recognise that commissioned work will add more focused performance areas and targets</i></li> </ul>	<ul style="list-style-type: none"> <li>• identification of older carers over 70</li> <li>• prevention plans in place – number of people in contact with the service</li> <li>• no carers plans</li> <li>• future plans of the person with a learning disability established</li> <li>• nos. of future planning workshops</li> <li>• nos of young people moving into and out of the borough/county at transition</li> <li>• identification of all young people with learning disabilities going through the transition process</li> <li>• nos. of people with learning disabilities and their carers supported through Transition Workshops</li> <li>• identification of individuals</li> <li>• assessment of unmet need</li> <li>• ways people are involved in any consultation process</li> <li>• how many families benefiting from short term break or respite</li> <li>• no of culturally appropriate service on offer</li> </ul>

## 6.3 In conclusion: Building the Bigger Picture

This report is one component in the process of developing a comprehensive national strategy. It has sought to identify the key issues for family carers. Both in terms of promoting better services and life opportunities for men and women with learning disabilities, as well as identifying the importance of family carer partnership and support.

Cally Ward  
June 2000.

## 6.4 References

Banks, P. (1998) *The Carers Compass*. Kings Fund.

Banks, P & Roberts, E. (2000) *A break for Carers? An analysis of local authority plans to use the Carers Special Grant*. Kings Fund.

Backer and Blacher in Sutton (1993) *Older Adults with Development Disabilities*. Paul Brookes.

Baxter, C. et al. (1990) *Double Discrimination*. Kings Fund.

Beresford, B. (1995) *Expert Opinions: A national survey of parents caring for a severely disabled child*. The Policy Press.

The Carers (Recognition and Services) Act .1995. HMSO.

*Caring about Carers: A national strategy for Carers* (1999) DoH.

Carers National Association: (2000) *Give Us A Break: A study of the impact of the Carers Special Grant in the North of England*.

Chambers, R. et al. (1999) *on the edge: Minority ethnic families caring for a severely disabled child*. Policy Press & JRF.

Department of Health (1999) *Mental Health National Service Framework*, Department of Health.

Evandrou, M. 'Unpaid work, carers and health' in Blane, D. et al (eds) (1999) *Health and social organisation*. Routledge.

Grant, G & Ramcharan, P. (1999) *Views and experiences of users and carers*. University of Sheffield.

Grant, G. & Whittell, B. (1999) *Family Care of People with Learning disabilities: Support for Family Coping*. University of Wales.

Hogg, J. et al. (2000) *Healthy ageing- Adults with Intellectual Disabilities: Ageing and Social Policy*. Geneva: World Health Organisation.

Mencap – correspondence with Brian McGinnis 2000-06-20.

Moss, S. et al. (1992) *Demographic characteristics of a population of people with moderate, severe and profound intellectual disability over 50 years of age*. *Journal of Intellectual Disability* Vol. 36.

Nocon, R. et al. (2000) Scoping exercise on the needs of minority ethnic and black people with learning disabilities. DoH.

Princess Royal Trust For Carers. (1998) Eight hours a day and taken for granted?

Robinson, V. & Williams, C. (1999) In their own right. Norah Fry Centre. Bristol.

Robinson, V. & Williams, C. (2000) In their own right one year on. Norah Fry Centre. Bristol.

Schalock & Lilley cited in Selzter, G. . et al in Sutton (1993) Older Adults with Development Disabilities. Paul Brookes.

Todd, S. & Todd, S (1997) Parental work: an account of the day to day activities of parents of adults with learning disabilities. Journal of Intellectual Disability Research. Vol.41.

Walker, C. & Walker, A. (1998) Uncertain futures. Pavilion Press & JRF.

Walker, C. & Walker, A. (1995) Fair shares For All. Pavilion Press & JRF.

Walmsley, J. (1993). Contradictions in caring: reciprocity and interdependence. Disability, Handicap and society, Vol. 8.

# Annex A Family Carers sub-group

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