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1. This guide

This guide is the third in a series of three 'How-to' guides for Crossroads Care providers and The Princess Royal Trust for Carers' Centres supporting family carers of people with learning disabilities as well as, increasingly, giving people with learning disabilities a break from their caring role. It looks at ways of finding out about and promoting services and support to 'seldom heard' groups of carers of people with learning disabilities.

2. 'Seldom-heard' groups

By 'seldom heard' groups, we mean those who may not come into contact with services. This might be because:

- They do not know what is available
- They have a mistrust or previously negative experience of services
- Services do not meet their needs.

Carers who fall into this category might include:

- Older carers
- 'Mutual' carers, including family carers who have learning disabilities
- Rural or geographically isolated carers
- Young carers with parents who have learning disabilities
- Family carers from BME and minority communities
- Family carers of people with complex needs

Most of these groups are highlighted as a priority in Valuing People Now (2009)¹ and local development plans should show how they are going to meet their needs. There are a number of key themes that should underpin work with any of these marginalised groups:

- Providing information about existing services and how to access them
- Developing appropriate and flexible services in partnership with family carers and people with learning disabilities
- Ensuring services value the role of family carers and respect their views and experience
- Focussing on preventive work to help families plan for the future

Even if they have no contact with learning disability services, these groups of carers will use other local services that might include:

- GPs and community health services
- Hospitals
- Schools
- Libraries
- Dentists
- Opticians

They may also have links into community groups and organisations and with faith groups or churches.

All of these could be supporting family carers in different ways but may not identify the support they need for their caring role. People within these organisations can be useful 'gatekeepers' to link with family carers and pass on information about services and support.

Another way of building relationships with marginalised carers is to involve them in discussions about what services *should* be like (far less threatening than asking what

¹ The Department of Health (2009); *Valuing People Now: a new three-year strategy for people with learning disabilities*. Various documents are available at <http://tinyurl.com/vpnow>.

services they need!) or in working with you to develop clear and appropriate information for carers. The second guide in this series has suggestions for working with people to develop information that meets their needs.

It is also important to understand the more specific services, support or information that different groups might need and these are discussed in more detail below.

3. Older carers

Many people with learning disabilities who live with older family carers will not be known to services until there is a crisis and the carer can no longer cope. Those family carers might be parents but could also be siblings or other relatives. Although the White Paper, *Valuing People* (2001)² identified people living with older carers as a priority for long-term planning, many will still remain invisible until there is a change in their family circumstances.

The Foundation for People with Learning Disabilities wants to make sure that older families of people with learning disabilities get the right support. They have recently published the findings of a project about people with learning disabilities who are living at home with their parents or other relatives who are getting older now. It helped local organisations find better ways of helping older families of people with learning disabilities. More information is available at <http://tinyurl.com/olderfams>.

Services and support have changed from the days when families were presented with either the choice to place their son or daughter into institutional care, or take them home and cope on their own. However, many older carers seem unaware of this or have a mistrust of paid services, because of negative experiences in the past. Families may have many years of experience with different services and workers who come and go and this can make them reluctant to engage with services. Older family carers are also more likely to be sole carers with smaller support networks and can be reluctant to seek help perhaps because, with this, comes the acknowledgement that they can no longer cope alone.

Key issues when thinking about services or support for older family carers are:

- Making sure people have good, accurate information about what is available – in particular about preventative services that support them in their caring role.
- Support that will help them to maintain the caring relationship and give them more certainty about what will happen in the future.
- Services that work together with older family carers and treat them as equal partners in caring for their relative.
- External support that can act as a safety net in an emergency but also offer longer term solutions if there is a permanent change in the family circumstances.

² The Department of Health (2001); *Valuing People: A New Strategy for Learning Disability for the 21st Century*.

In many cases, simple practical support – for example with bathing or shopping can help meet the carer’s own needs and also alleviate some of the stress of caring for their relative.

There is a real role for organisations offering breaks to build older carers’ confidence in services and offer a safety net. Perhaps starting with just an hour or so at a time and being clear that this is a partnership with the carer, rather than a suggestion that they cannot cope.

Even if they have no contact with learning disability services, older family carers will use other local services that are useful starting points to identify carers or to promote services.

Another way of reaching people might be via peer support from other older family carers. They might be aware of and concerned about their peers who are not known to services.

4. ‘Mutual’ carers, including family carers who have learning disabilities

Many people with a learning disability are still living at home with their family; others have moved out and may be living with a friend or partner. As family carers start to need more support themselves, the older person and the person with learning disabilities can sometimes end up looking after each other. Partners or friends might also need more support from each other as they grow older. This is called ‘mutual’ caring. The Foundation for People with Learning Disabilities has published a helpful range of material supporting older families who are looking after each other, available at <http://tinyurl.com/mcaring>.

Without this type of support, there are many cases where neither person would be able to stay living independently in their own home and community.

There are a number of reasons why these carers remain hidden and can be difficult to reach:

- Fear of being separated if the level of care or support they need is discovered
- Lack of information that is accessible and easy to understand about peoples' rights as a carer or support that might be available to them
- Lack of practical support that could make a big difference. Things like getting to appointments or a benefits check to make sure they are getting everything they are entitled to
- Not seeing themselves as carers or not being recognised by others as carers
- Not being aware of the different choices about how care and support can be provided to support the caring relationship.

Some people with a learning disability might feel proud of what they do and value the independence that comes with the change in roles. This could make them reluctant to ask for help in case it is seen as not being able to cope with the responsibility.

Services and support will need to acknowledge and respect the role played by each carer and the inter-dependent relationship with their relative or friend.

Again, there is a role for organisations offering breaks to build mutual carers' confidence in services by offering sensitive and appropriate support.

You may be able to identify mutual carers with a learning disability through learning disability services or through other local health or community services. Advocates might be supporting people who do not know what support they can get as carers. Make sure the advocacy service has information about what is available and perhaps go along and talk to workers at a team meeting. This approach is also useful with other community services that might be aware of people's needs but not necessarily make the link and refer them on to services that offer breaks.

5. Rural or geographically isolated carers

Many young people move away from rural areas to live and work and this can have real implications for older people living in isolated locations away from services and support. This can impact on family carers of all ages.

Families are now much more fragmented and geographically dispersed which means there is often little or no support from siblings or other relatives. The increase in the elderly population, coupled with the number of people with a learning disability who are living longer and remaining with their families, means that many of these carers are coping alone. Younger carers who are trying to balance work with caring, can find this much more difficult when there is a lack of transport, local support networks and services within a rural area.

Carers' breaks services are increasingly focussing on community provision and promoting inclusion but this can be difficult if people live in isolated areas where community facilities and networks are shrinking. It will be important to identify which communities and activities are important to the person and plan how to support them to access these.

In the same way, support offered in the home to give the carer a break needs to be flexible enough to meet the needs of those in more rural areas. Three hours might be plenty of time to allow a carer who lives in town or on a regular bus route to go shopping. However, if buses only run a few times a day and the journey to town is over an hour, this might not meet the carer's needs.

A key role for breaks services is to look at the issues affecting geographically isolated carers in their area and identify ways of working with them to strengthen local support networks and build opportunities for peer support.

Clearly central, building-based services are more difficult for these carers to access and some areas have developed a 'virtual' carers' centre using telephone and internet contact and home visits. Different organisations supporting carers work

together to avoid duplication and make the best use of their resources in rural areas. This might mean setting up a single point of contact for all enquiries, each providing drop-in or outreach services in just one or two locations or linking carers into other community support services.

Individual carer support budgets are one way to ensure that any carer gets a break that meets their needs and might be particularly appropriate for geographically isolated carers where traditional support might not be flexible enough.

6. Young carers with parents who have learning disabilities

Although there is now better recognition of young carers, both by services and in legislation, only a small number are identified or assessed for support. Reasons for this include:

- Blurred boundaries of responsibility between adult and children's services
- Lack of awareness in professionals about the needs of young carers
- Young carers who do not see themselves as carers at all
- Young carers' lack of awareness of the support available to them
- Young carers' reluctance to seek help, for example, in case it results in them being removed from the family home

Research shows that young carers can experience physical, emotional or social problems that affect their schooling and relationships with others outside the home. Although studies focus on young people who are in touch with support networks or groups, it is probably safe to assume that the same issues are true for young carers who are harder to reach.

Young carers' projects seem to have a lot of success in valuing and understanding young carers' experiences and problems by valuing non-intrusive support. Services can support young carers with parents who have learning disabilities by:

- Recognising that they might be isolated and stigmatised by their parent's disability
- Understanding why they might be afraid of outside interference
- Recognising that they often do not want to stop caring completely but do want to share the burden so they have the same opportunities for education, socialising and employment as other young people

Because the concept of parents with learning disabilities is still challenging for many people, services must raise awareness of and recognition for the role of their young carers. Services must not be designed on the assumption that young carers will continue to carry out the caring role but must acknowledge the complexity of the relationship. With this, comes support to plan for the future when the young person might want to move away from the family home.

Social workers and teachers would appear to be the people most able to identify young carers and signpost them to services and support. However, the potential stigma associated with having a parent with learning disabilities can mean that young people are often reluctant to confide in others.

Again, a general acknowledgement of the existence and needs of this group and sharing information through other community networks, statutory services, schools and health services might help you identify young carers who need support. The most successful projects have involved young carers in designing support that meets their needs.

7. Families from BME and minority communities

Studies have shown that families from black and minority ethnic communities are less likely than white families to access a whole range of services. In particular, there seem to be a number of barriers to the uptake of carer support and breaks.

Many families do not know what is available because:

- Information does not get to them through word of mouth or printed materials in appropriate languages
- Some workers believe South Asian families from certain communities in particular want to 'look after their own' so may not signpost them to services
- There may be no interpreter available to explain services or an interpreter might find it difficult to explain this accurately. For example, in some languages there is no word for 'learning disabilities'
- Families may not understand the idea of carer breaks and believe that this indicates they cannot cope and could result in their relative being permanently removed from the home
- There may be reluctance to accept what is seen as charity

There are also issues about the appropriateness and flexibility of services to meet carers' needs. Services need to demonstrate that they:

- Will respect family values and preferences
- Can recruit more workers and volunteers from a range of communities so they can be more flexible in offering ethically matched placements or support
- Look at how to support more specific family needs. For example, families might not want their relative to stay away overnight on a regular basis but might need a longer placement while they visit family abroad for a few weeks each year

Schemes that want to include and support black and minority ethnic carers must see their work in the context of the local community. Mapping the local community and

building good relationships with existing groups and leaders is an essential part of this and should enable you to:

- Build up a good knowledge of the communities
- Start to become more visible as a service provider amongst black and minority ethnic families and organisations
- Learn about the ethnic make-up of the population and identify who might need your services or support
- Show that you are including families from the start – rather than as an afterthought
- Identify any gaps in your staff team or knowledge

It is important for this community development and outreach work to be carried out by people who are trusted within the community and it can be useful to recruit volunteers or staff from within the community or co-work with existing groups.

8. Family carers of people with complex needs

Families have consistently argued that government plans should include more support for people with a learning disability and complex needs and their carers. During the consultation on the white paper 'refresh', Valuing People Now (2009)³ lots of families said they did not think change was happening fast enough for people with complex needs. As a result, it is now one of the priority areas for the delivery plan.

Family carers of people with complex needs should not be seen as a separate and distinct group. Improved healthcare and changes in government policies have led to an increase in the number of older people with complex needs living with their families in the community. This means that an increasing number of carers of people with complex needs are older people who will face all the issues previously discussed for this group of carers. Others will be part of a black or minority ethnic family and/or living in isolated rural areas. This means the carers already face significant issues, with the additional responsibility of caring for a relative who needs a very high level of support with everyday tasks. Caring for someone who needs this level of support can in itself be isolating and the lack of appropriate services and support can further marginalise carers.

Good community support and carer breaks can mean that people with complex needs who would otherwise need residential or nursing care can remain in their own homes. However, as with all other groups, this should be planned as a creative partnership with family carers, using existing networks to build their confidence and trust and to identify what is needed.

³ The Department of Health (2009); *Valuing People Now: a new three-year strategy for people with learning disabilities*. <http://tinyurl.com/valpeople>

9. References and contact details

The Department of Health (2001); *Valuing People: A New Strategy for Learning Disability for the 21st Century*. Various documents are available at <http://tinyurl.com/vpnow>

The Department of Health (2009); *Valuing People Now: a new three-year strategy for people with learning disabilities*. <http://tinyurl.com/valpeople>

Further information can be found on The Princess Royal Trust for Carers' three websites www.carers.org, www.carers.org/professionals and www.youngcarers.net, and on Crossroads Care's website, www.crossroads.org.uk, or by contacting Cath Baker, Policy and Development Officer (Learning Disabilities), telephone 01568 760027, email cbaker@carers.org.

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