

Overcoming barriers to effective working with older family carers

We have already seen in the section 'Understanding the importance of working with families' how crucial it is to appreciate the important role families play in the lives of learning disabled men and women. In this section we look more specifically at the barriers that there are to developing good working relationships between families and services; and the particular difficulties involved in developing effective work with older family carers.

The aims of this section are to:

- Identify the barriers to good working relationships, between families and services,
- Consider what barriers currently exist in your workplace or service,
- Consider ways of working to dismantle these barriers and build better relationships.

Matt Janicki (*Help For Caring For Older People Caring For An Adult With A Developmental Disability*, NYDD. 1996.), based on his extensive experience in the US of working with older family carers and their learning disabled adult children, provides the following guidelines for working with families:

Guidelines for working families – growing older together

- Build trust.
- Listen to the family (don't offer what you cannot deliver).
- Acknowledge a job well done.
- Skip jargon.

- Help and support – don't control.
- Begin with pressing concerns, but recognise deeper concerns.
- Respect cultural values and traditions, but do not stereotype.
- Work with the family.
- Ask how families make decisions.
- Values – be clear about yours and theirs.
- **Don't give up.**

Exercise 11

Ask yourself this question

“What are some of the barriers to effective working with older family carers in your opinion?”

Make a list of all the things that ‘get in the way’ of developing good working relationships with older family carers in your experience?”

Keep hold of this initial list because we will return to it later!

Barriers to working with older family carers

Many writers have identified the range of barriers to working with older family carers. (See Janicki, as above, *‘Uncertain Futures’*, Walker C. & Walker A. 1998, *‘Moving On Without Parents’*, Bigby. 2000 and *‘A Crisis Approaching’*, Magrill D. 1997)



These include:-

- **Identification** – even knowing who and where carers/families are.
- **Lack of information** – for families about what's available and how it works.
- **Lack of proactive approach** – services are currently reactive. They only get involved if there is a crisis!

a lifetime of caring – open learning materials 2.66

- **Older family carers are less likely to ask for help** because of a number of factors including:
 - A history of mistrusting services,
 - Previous bad experiences,
 - Worries their son or daughter will be ‘taken away’,
 - Don’t know who to ask.

- **Feeling their opinions are not valued or listened to** by services when it comes to planning services for their son or daughter.

- **Staff attitudes** to families and their lack of experience and knowledge – they need better information so they can pass it onto families.

- Not enough ‘joined up’ working – a **lack of joint working** between older people’s services and learning disability services.

- **Uncertainty** about the future – the way services are organised and financial resources – makes planning for the future difficult.

- **Lack of flexibility** in services – families are told what’s available not asked what they need!

Are these some of the barriers you identified? What practical things do you think we can do to dismantle them? Here are some suggestions!

Identification of older carers

Remember that research indicates that significant numbers of people with a learning disability are not known to their local learning disability service until there is a crisis in the caring situation. Identification is quite a complex task and will involve a number of different strands. Service managers and planners are the people who need to co-ordinate this bit of outreach. Staff and services, however, are in an important position to make links through existing networks of people with learning disabilities and their families. If you are wanting to provide a carer’s service, or something that will benefit the whole family, then think about advertising your service. Use the local press; contact other community groups; spread the word and written information around to GP surgeries, libraries and other community facilities. Get out there!

Lack of information about what's available and how it works – having the right sort of information is key to being able to make informed choices and decisions in your life. Often families rely on word of mouth between themselves to find out important things.

“We cared for Andrew for years and years but no one told us we were entitled to any benefits. We’ve found out now, but only because another family told us.”

There are many different ways to ensure that information gets to the right people. Relying on one method is not good enough – try various approaches. If you've got a service that would be of benefit to people, tell them about it!

Getting information out to the right people

- **Use the local media** – newspapers and radio, even television. Sometimes the best approach is a 'human interest story'. Tell a story about families' experience (good or bad) to promote what you have to offer, and spread the word on how you can help.
- **Print leaflets and posters about your service** – what's available – how to get access to it – whom to approach. Keep the language clear and jargon free. Make font sizes larger than normal (at least 18) and don't use certain colours which get harder to distinguish as you get older. For example, reading materials printed on low contrasting coloured paper like black print on red paper.
- **Produce videos and audiocassettes in a range of languages** – to reflect your local community. Topics that have been successfully developed in this way include: planning for the future; moving out of the family home; showcasing the range of local provision and health promotion.
- **Disseminate your written information widely** – get your information out to GP surgeries, community groups, supermarket notice boards, the post office. Anywhere where there is a billboard and people are likely to see it.
- **Talk to other groups** so information about your service can spread through the local community. Talk to Primary Care Groups – GP's are usually the first point of call for the majority of families. As we saw previously, with Enid and Mary, District Nurses are working out in the community and have an important role to play. Talk to community groups. This is particularly important in

making contact with families from minority ethnic and black communities. Church and other religious groups are also a useful point of contact. **Get the word out on the street in your community and use a range of different networks. Don't get locked into service networks.**

Providing people with information is the starting point. Letting them have the opportunity to think about how it connects to their life, making choices and decisions is a process services need to nurture and support.

- **People need to be in the right environment to 'hear' the information and think through what it means in their particular family circumstances.**
- **Bring people together into support groups.** This is a good forum to share information and give people support to think through what they have heard.
- **Provide one-off information giving sessions** on a particular topic. The Sharing Caring Project in Sheffield has regularly run one-off information and consultation sessions on a range of topics, where up to 100 older carers take part.
- **One-to-one advice and guidance** – some people will never feel comfortable in groups. They will need personal contact on a one on one basis. This could be provided locally in different ways through a liaison worker, family adviser, carer's support worker, independent advocate, or social worker. What is important is that they get the opportunity to hear about possible sources of support and alternative provision and get them to think it over, without having to make immediate decisions.

Many older carers say they feel pressurised into making decisions in meetings with professionals. Once they have had the time to think about it they have been known to change their minds. This can be frustrating for staff as well. *"We had it all agreed at the meeting. Everything was in the process of being set up and she (the mother) just changed her mind. I couldn't believe it!"* Of course everyone has the right to change their mind, but the real issue remains, families must not be pushed into making decisions to suit the timeframe of staff and services.

Services lack a proactive approach

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

Mother from a Derby based support group

There is a perception amongst many older carers that it is very difficult to find out what services and support are available. Services are seen as reactive and under intense financial pressure and consequently do not reach out to families.

"Nobody tells you anything!"

Father

At a local level, decisions need to be made about how to ensure that services do begin to work with older family carers and their adult children, in a more proactive way. This calls for a strategic approach from senior managers to set up a database or some method of routinely identifying older family carers and make decisions made about whether to appoint dedicated carer support workers or set up a new carer support service. But there are also things that current services can do to work in a more proactive way with families in general and older family carers in particular.

What can you do?

- Be family carer aware! Develop your understanding of what an important role families play in the lives of people with learning disabilities. Think how you can support older family carers!
- Make families feel welcome when they visit your service.
- Develop the 'named person' role required by 'Valuing People' (DoH. 2001.) to liaise with families.
- Build relationships by keeping in touch informally and formally. Talk to people on the telephone, invite people to reviews, arrange transport for them or hold it in their home, set up support groups, have a newsletter, and ask family carers to contribute.
- Be sure you know where to refer a family on for an assessment and support. You need to know what is out there and who to get in contact with.

In relation to families growing older together, make sure you are familiar with the key areas of:

- Age related health issues.
- Planning for the future – what are the options for people?
- Increasing support as needs change – needs could change very quickly as people get older. A yearly review is not enough.
- Providing leisure opportunities for the person with learning disabilities which would also provide a break for the older carer.
- Providing support for people with learning disabilities who are providing a lot of care and support to their ageing parent.

Develop a project that encourages people with learning disabilities to put together a Lifebook. Engage carers in the development of this project as people with vital information and expertise.

Older family carers are less likely to ask for help!

“Oh I couldn’t bring myself to ask the social services for any help. We’ve been coping all right for 50 years. Yes we’ve been coping all right!”

Mother in her 80’s

Sometimes it is very difficult to ask for help, even if you have a right to it in law and really deserve it! Asking for help can be a daunting prospect for any of us, let alone independent minded family carers who have been coping for decades, with a whole backlog of not very positive experiences of services.

The Helping Relationship ***Is it hard to ask for help?***

“People want to help one another, and helpers experience deep personal satisfaction through this helping process.”

‘The Helping Relationship’, Brammer L. 1998

Exercise 12

Think about a time in your life when you needed to turn to someone and ask him or her for help or support. Try to think of an example from your own non-working life.

- Who were they?
- How easy was it to approach them and ask them for help or support?
- How did it make you feel? Were you comfortable or uncomfortable asking for the help? Did you feel in control, or just a little vulnerable and exposed? Have you ever had to ask for help in your working life?

Now think about a time in your life when someone has approached you for help or support.

- Who were they?
- How did it make you feel to be asked for this help? Did it make you feel good to be asked? Were you able to help?
- Was there a difference in the emotions and feelings experienced between the two experiences? How do you think this might link the experiences of older family carers?
- Is it hard to ask for help?

If it isn't always easy for us to ask for help, then consider some of the reasons that it might be particularly hard for older family carers.

Carol Walker in her work on older family carers, (*‘Uncertain Futures’*) has suggested the following reasons why older family carers are reluctant to engage with services. These include:

- A reaction to their struggle to get help in the past.
- Rejection of assistance in the past.
- Dissatisfaction with current or past provision.
- A very deep sense of personal responsibility.
- Indicates a sign of failure on their part.

- The fear of loss of services.
- The fear they might lose control over the care of their relative, even to the extent of them being taken away from the family home.

The practical implications of this can mean that staff fail to appreciate how much a family could benefit from support as illustrated.

A carers' worker made a referral for social work support for a carer (87) and her son with learning disabilities. As part of the screening process, an interviewing officer rang the carer and asked her a series of questions. The family was then deemed ineligible for support at the time. When the decision was appealed, it turned out that the carer had replied that she could 'manage' to a series of questions, since she hadn't wanted to admit that she wasn't able to cope with things like bathing her son to a stranger on the phone. Following the appeal, an initial visit was made and a comprehensive home support package began.

What can you do to overcome some of these barriers? You need to accept that you cannot undo the damage of past history, however much we'd like to. The key to engaging older family carers is to build up their trust. To work hard at establishing relationships with them now. Relationships in which you are able to demonstrate *your* understanding and appreciation. Where you show you are *really* listening to what they have to say.

Ways to building relationships and overcome barriers

- Reach out to people – don't expect them to come to you with their problems. Ask people how things are going – show your care and concern.
- Listen to what people have to say.
- Don't dismiss what they have to say because it doesn't fit into your ideas and agenda.
- Don't assume you know best about their son or daughter.
- Try to engage families in discussions which provide an opportunity to share views.
- If families are expressing their anger and frustration, don't take it personally, try and work through to a resolution.

- Don't promise what you cannot provide, but do put families in touch with services that can provide emotional and practical support.
- Keep talking and problem solving with the family.
- Reassure families that leaving home doesn't mean leaving the family, and families haven't failed if their learning disabled member leaves home, rather they've created a new opportunity for them.
- Reassure families around their worries around abuse – respond to concerns promptly. Ensure families know about your local Vulnerable Adult procedures.
- Don't lose touch! Follow meetings up.

Feeling their opinions are not valued or listened to when it comes to planning services

“No one listened to me when I said he wasn't very well. They wrote me off as a neurotic mother, I know they did, and yet he did have problems and he would not have got the treatment he needed if I hadn't kept on and on. They should have listened to me. After all I've known my son longer than any of them.”

Mother in Derbyshire

How can we make families feel more valued in the planning process? We need to remind ourselves why it is important to include families as an integral part of the planning process.

- a) If people are living at home, families are the conduit through which the support will flow.
- b) Families have a lot of knowledge and expertise that has been built up over many years.
- c) With families growing older together the interdependence between parent and adult child demands a dual focus – many people with a learning disability value their carer's opinion and judgement, so keep people on board.

Listening

Listening to people is one of the most valuable and fruitful tasks you can undertake if you really want to engage with families. **Individual staff** need to develop good listening skills and organisations need to develop systems to ensure the voice of the people that use their services and their families are heard.

As an individual try out this next exercise to work out what sort of listener you are:

Exercise 13

How well do you listen?

Which sort of listener do you most closely resemble? It is important to know your own type and take this into consideration when listening to other types. It is easier to listen to someone who is similar to you, which means you may have to make more of an effort to listen with some people than with others.

Practical listeners

These people like to listen to factual information and then to test what they have learned by putting it to practical use. They enjoy 'hands-on' experience and look for quality allied to utility. A favourite question would be: "How does this work?"

Analytical listeners

These listeners are more interested in the ideas expressed than the sender of the message. They enjoy thinking a problem through step by step and like to fit detail into a complete concept. A favourite question would begin with: "What?"

Action listeners

These people listen for hidden messages. They like variety and change and are adaptable and flexible. Their strength is in taking action and carrying out plans. A favourite question begins: "If?"

Concept listeners

These listeners are very interested in the message sender. They are imaginative and innovative and like to work in a co-operative way. A favourite question would be: "Why does this happen?"

Complete this questionnaire overleaf, and add up the score.

When listening how often do you...?

	Always	Usually	Sometimes	Seldom	Never
Allow your attention to be distracted					
Let your personal bias take over so you become over emotional					
Listen only to facts					
Interrupt					
Forget to summarise					
Assume you know what is being said					
Criticise the speech/tone/dress of the speaker					
Decide the subject won't interest you					
Ignore body language					

Scoring

Always = 2; Usually = 4; Sometimes = 6; Seldom = 8; Never = 10

Total _____

There is no 'correct' score, but the best listeners will score between 72 ad 90 points, the worst 18 to 36 points.

**Reproduced from '20 Training Workshops for Listening Skills',
Sproston C. & Sutcliffe G. 1989**

As an organisation services need to:

- Make time to listen.
- Formalise ways of listening... make sure older family carers are involved in the planning and reviewing process in a real and meaningful way.
- Provide practical support to enable them to get to meetings and to participate.
- Think about how meetings are conducted. Don't use jargon. Be clear about why certain things are being highlighted for attention and explain any risk assessments you have undertaken.
- Record the family perspective and make sure a copy of any notes is sent on to them.
- Record if there are any differences of opinion between services and families and whether or not there are any implications. Remember it's their life too, their opinion is important, however difficult or different to your own.
- Follow things up – *"people always come and consult us, but we never hear anything about it afterwards"*.

2 Staff become a barrier to effective working relationships with older family carers

Put simply, if you don't have respect, recognition and appreciation for all the things families have contributed to the support of their son or daughter over the years, then these families will switch off and dismiss you.

"I get paid to work with people with learning disabilities not their ruddy families."

Day centre support worker on a Working with Families training day at Lewisham

Attitudinal change: Staff and services need to find a new way of working with families. Attitudes like the one expressed above have got to change. There has to be

greater respect for the contribution families make in the lives of men and women with learning disabilities. Ultimately, this will be beneficial for the person with learning disabilities, if everyone in their life is working together.

Better information and knowledge: As families grow older together, staff need to be informed about what support there is in the community:

- For the old carer as an older person ,
- For family carers,
- For the person with a learning disability in their role as carer,
- For the person with learning disability to have opportunities for an active lifestyle,
- People's rights to both carers assessments and community care assessment.

If you are working with families growing old together it is vital that you find out about the range of facilities in your local area – that cut across the service divide.

Lack of joined up working

Older family carers, many of them in their late 70's, 80's and even 90's and their middle aged children, can fall between older people's services and learning disability services.

Older people versus learning disabilities

A carers worker trying to make a referral for a person with learning disabilities and his frail elderly carer met with little success. It turned out that two referrals had to be made – one to older people's services and one to the disability service. Since the needs of both mother and son were inter-dependant, the case kept being batted from team to team with no-one able to take responsibility for taking a holistic view of the needs of both people.

A true story about eating pizza!

Mrs Peters (who is 82) lives with her 56 year old learning disabled daughter, Janis. Both receive Domiciliary Support in their own home in their own right. Every day the domiciliary worker from the elderly team arrives to cook lunch. A pizza is cut in half and prepared in the microwave for Mrs Peters lunch, which she eats when it is cooked. Three quarters of an hour later the outreach worker supporting Janis arrives and takes the second half of the pizza, cooks it and Janis has her lunch. This happens every day, though of course they do not always eat pizza!

These are perhaps two extreme examples of older peoples' and learning disability services not speaking to one another with ridiculous implications for the families involved.

Managers and planners need to develop local protocols for developing joint work between services and you need to know about them, to ensure people will not fall through the net.

Things that might help include joint training for staff from both services:

- One agency needs to provide a key worker who can take responsibility and overall accountability for the services and ensure liaison takes place.
- Emergency plans need to be developed with the family for those 'just in case situations'. Information needs to be shared so it is very clear who acts to implement the plan if there is a sudden problem or crisis.
- GP's need to be brought into the loop with the key worker or named person liaising with them, when and if appropriate.
- **Any care or support packages need to have a dual focus (whether residential or domiciliary). They need to be planned with both the parent's and their adult child's needs in mind.**

If you are concerned that services are not taking a joined up approach to supporting a family then tell your manager – try and do something about it!

Lack of flexibility in providing support

A legacy of the past is the way services have been presented and delivered to people.

The attitude has been: *“This is what we have to offer”, – not “What is it that you need?”*

‘Respite care’ is a good example of this. Traditionally respite care has been offered on an overnight basis, often in blocks, often within a dedicated respite care service. Whilst many families value the service offered, there are many more who have not felt that this is the sort of break they want or need. Consequently, the majority of families do not receive any sort of short-term break. This is true for all communities, but has real relevance for some minority ethnic communities, who would feel unhappy about overnight stay and mixed sex services for religious considerations. Our perception of ‘respite’ needs to broaden.

Short-term breaks should be flexible and benefit the older family carers and their son or daughter. A short-term break can take a variety of forms:

- A befriender takes the person with a learning disability out for a walk, the pictures or some other sort of leisure opportunity. The frail carer feels happy knowing their son or daughter is out and about having fun when perhaps they can no longer do so with them.
- Support comes into the family home whilst the family carer goes shopping, visits a friend or even visits the doctors. Home based support is something many family carers value. It is particularly valued in minority ethnic communities in the absence of any culturally appropriate single sex provision.
- Some families want to have their breaks together, here a change of environment is obviously as good as a break from caring. One Mencap group offers day trips in the summer which are well attended and much enjoyed. A weekend away could be just the break in humdrum routine that is required to restore people. This could be especially good for older carers who can’t get out as much.
- Some families wanted a form of ‘shared care’ where the transition from parental care to services takes place in an incremental and planned fashion, where the person lives a few days at home and the remainder of the week is in residential provision.

3 Uncertainty about the future – a barrier to planning

We need to listen to people and build support around their needs not our assumptions!

Within the White Paper, *'Valuing People'*, older family carers and their adult sons and daughters with learning disabilities are one of the groups targeted for priority attention. All Local Authorities will be asked to demonstrate, as part of having their performance monitored, the number of future plans that have been agreed with older family carers. It is important to identify some of the barriers to planning for older family carers.

Factors that could inhibit the development of planning for the future:

- Families, which are currently not known to services. You cannot plan with them if you don't know them!
- Planning for the future inevitably means facing your own mortality. It is sometimes difficult to be open about death and dying.

"Dare I say it? I hope I go before he does. I know it would be hard but that's what I hope."

90 year old mother from Shropshire

- Not having the information about what is available or how you go about accessing it!
- Services are constantly changing – it is hard for staff to keep up, let alone families.
- Families sometimes have little confidence in services which are currently available.
- Financial constraints have helped shape the way services respond to requests for help! ie, transitions become points of crisis, rather than an opportunity to prevent problems by planning proactively.

Christine is a learning disabled woman in her early twenties who is desperate to leave home and be more independent. She is a capable young woman who has a job in a local office which she got after leaving college with an NVQ level 1 Business Administration. Her parents, both in their late 50's, are very supportive of her aspiration to leave home and approached the local social service department on her behalf. The family was told they were a very low priority and nothing could be done unless her parents chucked her out of home and she became homeless. Then Social Services would be forced to re-house Christine. The family felt they couldn't risk this approach!

"I've asked them time and time again – what will you do when I die! Where will she go (referring to his learning disabled daughter). No one can tell me definitely. They just tell me something will be done. But what?"

Father (75) from Sheffield

Finally, David Thompson from the GOLD programme (Growing Older with Learning Disabilities) (see resource section) reminds us how the language of services can look very different from an older family perspective.

service perspective

older family carer perspective

Learning disability/ learning disabilities

The latest fashion in labels for their relative. Been through mental retardation and mental handicap.

Emphasising independence

Failing to understand the support the person with learning disabilities needs and undermining their role as a carer.

Rights, Advocacy, Empowerment	The services' way of deciding what is best for the person with learning disabilities, disregarding the view of the family.
IPP's/ISP's/Person Centred Planning	Services making plans with or without the agreement of families.
Modernising day services	Further disruption to their lives and valid fears that they will get less access to day services and it will be less reliable.

4 In conclusion:

How family friendly is your organisation?

At the beginning of this section you were asked:

"What are some of the barriers to effective working with older family carers in your opinion?"

In this section we have discussed some of the barriers that stop services engaging effectively with older family carers and begun to think about some ways that barriers might be dismantled.

How would you characterise your services relationship with older family carers? Consider the categories below and give an honest answer.

TYPES OF RELATIONSHIPS BETWEEN FAMILIES AND PROFESSIONALS

Laybourn and Hill (quoted in *'Family Matters'*, DoH. 2001) have characterised the relationship between people who use services and those that are paid to support them in the following ways:

- Collaboration – parents and professionals respect one another and recognise their respective contribution and act together as equals.
- Co-existence – do not interfere with one another.
- Confusion – relative roles unclear.
- Colonisation – professionals take over.
- Conflict – for example, contrasting objectives.

Exercise 14

- 1 On a continuum between collaboration and conflict where would you put your organisation in relation to its relationship with families?
- 2 In your opinion, what are the barriers operating in your organisation in terms of supporting older family carers?
- 3 How could your organisation identify and support older family carers better? List ways you think the service could become more family friendly.

In this section you have had the opportunity to reflect upon:

- The barriers that exist between families and services and how they stop the development of good working relationships developing between them.
- The barriers that exist in your own workplace in terms of working with older family carers.
- Ways to dismantle these barriers and build effective relationships with families.

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