

Caring Conversations

Caring, Coping and Mutual Caring

Older family carers of people with learning disabilities

Whilst fearing for the future, many older family carers are not always ready, may sometimes be unwilling or may lack confidence in the available options or assume or hope other family or friends will resolve matters when they occur. In opening this conversation we are also aiming to encourage adults with learning disabilities who are carers to have their needs, wishes and feelings better taken into account.

In some families the older person, usually a parent, would not be able to remain living independently in their own home without the support of their relative, usually an adult son or daughter, with learning disabilities. Mutual caring can develop gradually and may not be noticed by agencies. Sometimes, there may also be risks to well-being to consider.

As part of arrangements for taking forward the refreshed national strategy for carers[1] this “Conversations” paper aims to encourage Directors, Councils, Learning Disability Partnership Boards, local carers, people with learning disabilities and local communities to talk about the issues it outlines and to see how we can improve understanding and outcomes for all those involved.

Older family carers – Some Facts

<p>Location Despite the growth in independent living most people with a learning disability still live in the family home.</p> <p>Most older family carers and their adult children with learning disabilities have lived in their local community all their lives.</p> <p>Commissioning The needs of an older carer/parent and an older adult with a learning disability will be different and commissioning should reflect this. Commissioning needs to be joined up across older people and people with learning disabilities.</p> <p>Social Context Many adults with learning disabilities are unwaged. As family carers get older they are more likely to be sole carers, have smaller support networks, have had negative service experiences and be reluctant to receive support.</p>	<p>Demography The number of adults with a learning disability and life expectancy will both increase over the next 10 years. Numbers are expected to increase in real terms by around 2% each year and need to be built into local needs assessments.</p> <p>More people with learning disabilities will outlive their parents in the future than has been the case: parents have often relied on the fact that they will outlive their son or daughter.</p> <p>General Practice Many older carers of adult children with learning disabilities will be known to health and social care. Some, however, may remain hidden and isolated. For some this will be a conscious decision.</p> <p>GP practices often have an early opportunity to identify mutual caring and support needs.</p>
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Directors, Learning Disability Partnerships, service user and carers’ organisations will bring a wealth of local experience to this topic. A lot of good work is going on. Quite a few councils have dedicated services in this area. We hope the material in this paper will support local conversations on this topic. The most valuable resource, however, will be local experience and feedback of family carers, people with learning disabilities, health and social care professionals, providers and third sector partners. Do celebrate what works well, talk about what matters and would make a real difference to individual outcomes locally: Listen, Learn and Lead.

Some conversation points

Have we identified all adults with a learning disability who live with family carers aged 65 and over?	How well do we co-ordinate services between agencies and providers of personalised care and support?
Do we understand the needs, hopes and fears of older family carers and adults with learning disabilities living with elderly carers?	How far are we using opportunities for joined up budgets for older families and flexible ways of supporting them?
Are adults with learning disabilities, who are carers, getting carers assessments?	How available and accessible are local independent advice and advocacy services for older family carers and adults with learning disabilities?
Are person-centred planning and whole family approaches used to assess sustainability and promote greater choice, control and certainty about current and future arrangements?	How far do we allow for the time and consistency needed for building trusting relationships with families?
What do older family carers and adults with learning disabilities expect about support, care and accommodation?	How much do we know about “mutual caring” in the locality?
Have we reflected those needs and views in local commissioning and local joint accommodation strategies?	Are risks to safety and well-being identified and managed in a person-centred and proportionate way?
What is in place for older family carers to keep in contact with agencies?	Is the Joint Position Statement on Carers with Learning Disabilities [2] reflected in what we do?
How many older family carers/families have a plan in place for emergencies?	

Needs - Older Family Carers

Valuing Older Families Now [2010] [3] sets out some consistent needs of older carers which we can all use. Feeling confident that the person they have given a lifetime commitment to will be *happy, safe and able to speak up when older family carers are no longer able to support them.* [p5] is a common theme. This includes:

- being in contact **before** a crisis.
- having the information needed for informed choices and control
- having person centred support with planning for emergencies and the longer term
- being able to stay together for as long as they want
- being treated as partners in caring
- having information to guide decision making
- having a timely and real say about making changes

Awareness of levels of inter-dependency within families by health and social care professionals varies. Early identification may be problematic. Issues around inter-dependency within families may be misunderstood. Intelligence to inform strategies and commissioning may be limited or not integrated across agencies.

Older family carers speaking

Around a quarter of older family carers in a recent survey [4] cared for an adult with a learning disability. Here are some of the things they said:

“Anxiety – worrying about the future...”

“Who will look after him if I or my wife becomes unable to do so – or if we die?”

“I am now 72 and worry about my son’s future care if I were ill or worse”

“Will I be able to look after my son as I get older and he gets older?”

“Lifting my daughter becomes more difficult as we get older”

“How can I ensure he will have the same quality of life when I am gone?”

“Our concerns are... about ... accommodation and support when we are no longer around.”

“I am always busy caring ... so you forget about your own health.”

“My son is an only child with no other surviving family members. As I get older how will he manage by himself?”

Older family carers - What helps

- Raising awareness and engaging with older carers and adults with learning disabilities.
- Enabling older family carers and adults with learning disabilities to recognise they may be “carers”.
- Accepting time is needed to build relationships to discuss options with both parties and meet fears of “interference”.
- Using person centred and *whole family* approaches - local protocols.
- Building a robust evidence base on numbers, needs and expected care outcomes for commissioning
- Including data on older family carers within local joint strategic needs assessments [JSNA]
- Promoting information and support to enable older family carers to work with others to make plans for the future.
- Considering carer support worker roles for this group and getting the right people to do this.
- Co-producing emergency support plans with families so adults with learning disabilities have choices about the future.
- Trying to reduce social isolation and strengthening support networks around the family
- Showing we are listening and learning.
- Developing a better understanding of *mutual caring* involving adults with learning disabilities and what it involves.
- Enabling families to identify risks and empowering them to explore ways forward of meeting them so they feel safe and in control of their lives.

About Mutual Caring

Mutual caring is where an adult with a learning disability and their relative are supporting each other to remain living together. In older families this usually happens when a family carer needs more support. The family develops routines and ways of coping that result in both the older person, often a parent, and the person with learning disabilities are looking after each other. Every mutual caring situation is different. Issues we need to think about include:

- People with learning disabilities:
 - not realising they are carers
 - not being recognised or supported as “carers”
 - missing out on work and social opportunities
- Families becoming isolated or at risk
- Feelings of anxiety and worry about being separated and about the future
- How to facilitate planning for the future
- Greater awareness about mutual caring by professionals across all local agencies and within mainstream services such as general practice.
- The value of practical support and joined up working
- The value of carers’ assessments being carried out with people with learning disabilities^{[5][6]}

If we are to move forward the starting point is to identify more completely the number of people with learning disabilities living with older family carers and finding the best ways to support them.

Mutual Carers Speaking

People with a learning disability are becoming more aware of themselves as carers. These are some of the voices of people who provide care to an elderly parent [6]:

“I am a carer for my mum and that means a lot to me and that’s what I like to do”
(Michael, aged 61, caring for his mum aged 90 who has dementia)

“I do all the washing and cooking, I help mum to get in and out of bed and help her up in the middle of the night” (Michael, as above)

“Carers with a learning disability don’t get treated right - professionals should listen to us and take us seriously” (Andrew, aged 47 caring for his mum aged 80+)

“I started doing more for my mum when her eyesight started to go and it helped when I had a carers’ assessment” (Andrew, as above)

“The carers’ assessment has given me greater freedom - I can do more things now” (Michael, as above)

“I came home one day and found my mum on the floor - I called an ambulance and she was in hospital for 6 weeks” (Janet, in her sixties caring for her mum aged 80+)

“Having a circle of support has given me time to talk about what I need - people helped me to plan a holiday to have a break from caring” (Janet, as above)

References:

[1] Recognised, Valued and Supported: next steps for the Carers Strategy, Department of Health

[2] Carers with Learning Disabilities Network
www.crossroads.org.uk/_downloads/_publications/JointPositionStatementCarersWithLD.pdf

[3] Valuing Older Families Now
www.valuingpeoplenow.dh.gov.uk/webfm_send/324

[4] Always on Call, Always Concerned [2011]
www.carers.org/sites/default/files/always_on_call_always_concerned.pdf

[5] Being a carer and having a carers’ assessment www.learningdisabilities.org.uk/being-a-carer

[6] The Foundation for Learning Disabilities Mutual Caring Project provides an invaluable range of resources. See: www.learningdisabilities.org.uk/our-work/family-friends-community/mutual-caring/ and: www.learningdisabilities.org.uk/olderfamiliesresources

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