

care

support



Time to think about...
Executive summary

trust

protect

Time to think about...

Executive summary

Shaping support for older family carers of adults

With learning disabilities in planning for the future

Context

Over the last 15-20 years, recognising and responding to the needs of carers has steadily gathered momentum, evidenced through developing legislation to give carers rights, implementing policy to benefit carers directly and through an increasing body of research to inform practice. Unpaid carers (family and/or friends) are providers of care and so the economic argument for continuing to support carers is unequivocal; both at a local and national level.

Demographic changes have also led to a specific group of carers now wanting support in their own right (older family carers of adults with learning disabilities) as for the first time in history, adults with learning disabilities are outliving parents. Paradoxically, whilst advancements in healthcare can be celebrated, older carers now worry about what will happen to their sons or daughters when they are no longer able to provide care. Securing housing as well as funding for care packages is a concern and supporting older carers to think about making plans for the future requires a very personalised, individual response. Ensuring the future housing needs of adults with a learning disability (in terms of identifying numbers and planning) continues to be a priority for South Lanarkshire Council's Local Housing Strategy.

Research aims

Building on the recommendations from independent research carried out in 2005 for South Lanarkshire Council into the needs of older family carers, a strategic approach has been developed in supporting this carer group in thinking about making plans for the future, entitled Time to Think About...A dedicated Social Worker post was created to support this work.

The approach has taken the form of offering individual visits to older carers across South Lanarkshire to explore issues in relation to future planning, to pass on information, answer carers' questions, 'signpost' onto other agencies and to record carers' wishes for the future with three key aims:

- To increase the support offered to older family carers
- To raise awareness of older carers' needs
- To influence the future planning process at South Lanarkshire Council

Research methods

An 'Action Research' approach was taken with the intention of bringing about changes as a result of carers' participation in the research and learning process. Time to Think About... ultimately seeks to shape support for older carers through identifying gaps in provision that can be evidenced and in working to then address these. The target population was older family carers in South Lanarkshire who were supporting an adult with a learning disability living in the family home. 166 visits were completed over a four year time frame (given the four year time frame, individual circumstances may have changed and practice revised during this time - these variables should be taken into account when reading the report). Carers who might benefit from this dedicated support were visited by the dedicated worker and other Social Workers within the local authority's area teams. The data collated is subjective in nature but nevertheless provides a good insight into the support older carers require for future planning and in shaping service design to meet the needs of ageing adults with learning disabilities and their families. Visits took the form of semi-structured interviews covering legal issues, housing, emergency planning, Carers' Assessments, support for carers within South Lanarkshire and carers' health issues.

Responses from carers were recorded on a proforma for later coding and analysis. An information pack was developed to accompany this piece of work. In total, 195 visits were offered, 85% of respondents agreed to take part with 166 visits completed (n=166). Carers were all aged over 50 and the vast majority were White, Scottish in ethnic origin and from rural and urban areas across the authority. Some carers were interviewed as couples.

Key findings

Time to Think About... illustrates that older family carers do want to be supported in thinking about planning for the future. This is evidenced by the high take-up rate when carers were offered the opportunity to explore options around what is for many a very sensitive subject to address. A personalised yet fairly informal approach was welcomed and this is illustrated by the high take-up rate with the visits juxtaposed with a much lower number of carers attending information workshops. Though staff were concerned about raising expectations, many carers passed on that a visit focussing on the carer as opposed to the service-user (though not in superseding the wishes of service-users) was welcomed as good practice.

Legal issues

In discussing legal rights, Time to Think About... saw an increase in the amount of carers taking a proactive approach in seeking independent legal advice, though older carers heavily involved in carers' rights were not always those who were most proactive and for some older carers, dealing with legal issues such as applying for Guardianship remains a daunting thought. Advising carers of their legal entitlement to a Carer's Assessment also saw an increase in the number of Carers' Assessments completed, reinforcing the argument that practice and timing are important factors in offering Carers' Assessments.

Housing options

Older family carers want a range of housing options on offer and welcome the opportunity to plan ahead before a crisis occurs though for some families unable to let go, crisis intervention will always be inevitable. Just over a third of carers were wanting their relative to remain in the family home but 37% of those questioned identified the need for 24 hour support for their relative and meeting the care needs of individuals (more and more with profound and multiple learning disabilities) remains a financial challenge. There is a need to look at supporting carers and service-users to 'plan' in relation to housing options as an entire generation of unpaid care decreases but in also accessing the desired option at a time of need. Thorough planning should

lead to a decrease in crisis intervention for older carers. Older carers still state they are unaware of the housing options available and how to negotiate their way through applying for housing through the local authority with a reliance on Social Workers to assist with this process. Again, through Time to Think About... some carers were keen to begin the process of supporting their relatives with a housing application and carers spoke of discussing housing options and care packages with family members where possible. Housing concerns form only a part of this report and the report focuses areas for discussion in relation to housing issues. The qualitative data retrieved is a starting point for further quantifying housing demand for people with learning disabilities.

Support

Good partnership working is central to supporting carers within South Lanarkshire and older carers continue to be well supported by South Lanarkshire Carers Network and The Princess Royal Trust Lanarkshire Carers Centre. Some older carers have benefited from a personalised, 'carer-centred' response (solution focussed) to their specific needs through the dedicated post for older carers but this intensive support is difficult to offer in larger numbers. Research suggests that carers do benefit from dedicated support (emotionally and practically) and that responses should fit around the carer and not vice versa. Carers continue to access support through a range of sources yet reliance on family members over formal carers' support is evident.

Emergency planning

A reliance on family members in an emergency remains high with almost a third of carers giving this response. Very few formal plans are in place and this is a real worry for older carers. The majority of those questioned stated they would rely on either family or Social Work Resources to 'step-in' in an emergency but the need to look at supporting older carers at a time of crisis (indeed carers across the board) remains clear. A practical approach with carers should be supported by a strategic response from health and social care partners.

Carers' health

44% of older carers described their health as 'good' but responses are subjective and almost half of those questioned have significant health issues. Carers often link their sense of wellbeing to the support offered to the person they are providing care for. It would be interesting to note whether having dedicated carer support (very much in the shape of carer advocacy) does increase a carer's overall sense of emotional and physical wellbeing and this would need further research.

Recommendations

Given the points for discussion/good practice made at the end of each section and the justification put forward for these, broad recommendations will be made here as South Lanarkshire Council should take note of the specific points made in terms of shaping service design. Recommendations are as follows, derived solely from the data analysis and emergent themes:-

- South Lanarkshire Council should continue the development work to better address the needs of older family carers.
- Findings from this report should be disseminated to staff within South Lanarkshire Council, to partners and carers.
- Consideration should be given to researching and developing a toolkit for supporting older family carers to standardise practice.
- Legal provision should broadly be addressed as part of the review process as it stands so that older carers can be supported in future planning.
- The quality of the Support Plans/Carers' Assessments offered to older carers (and other carer groups) should be monitored alongside numbers.
- Emergency planning for carers should be developed and reviewed with carers, partners and colleagues.
- Older carers' health and social care needs should be taken into account when looking at future planning and a consistent, strategic approach taken.

- Consideration should be given as to how a growth in the numbers of adults with learning disabilities requiring housing and support can be met. Work should start on collecting data in light of this report.
- Older carers should continue to receive good, up-to-date, timely information in relation to future planning.
- Consideration should be given to whether the current practice model in working with older family carers of adults with learning disabilities should be reviewed with a view to a more individualised response to working with carers.

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