



Confronting a Looming Crisis

People with learning disabilities and/or autism and their carers getting older

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“Many years ago Valuing People identified the need to plan to support individuals with learning disabilities into old age, and also to support family carers to plan positively for the future. This report highlights that it is a priority to identify older carers and to plan with them, to ensure that not only are the needs of their relatives met, but their own needs are met too.”

Vivien Cooper, OBE
CEO, The Challenging Behaviour Foundation

Executive summary

Increased longevity means that an increasing proportion of people living with a learning disability are aged 45 and over and are transitioning into older age/retirement. It also means that ageing family members are increasingly playing an extended caregiving role into later life. A small scale study was carried out in the New Forest, Hampshire during 2018-19. Twenty-one older carers (5 were male) were interviewed about their experiences of caring for their older adult family members with learning disabilities and/or autism. The average age of the carers was 75 though 20% of the sample were over 80 years old.

Key findings:

Older carers are struggling to continue to care for their loved ones. Four main themes described their struggles:

1. Transition to retirement was felt to be a misnomer in the face of continuing responsibilities and duties to care and/or manage care. Little respite was available to take a break, take stock, or just do the things that most other 'retired people' do.
2. The Care Act 2014, despite its laudable goals, is yet to be applied sufficiently well to make a difference to the lives of people with learning disabilities and/or autism or their carers who took part in this study.
3. Challenges with social service provision including lack of continuity of social worker input, variable and declining levels of expertise, and pejorative attitudes towards carers appears to be worsening. That said, carers are understanding of the pressures on health and social care and are willing to work with them to improve the situation.
4. Carers' fears for the future as they contemplate who will care for their loved one once they are no longer able to care for them.

There is a need for age-appropriate housing, weekend activities for people with learning disabilities, and respite for carers. Transformational change which includes trust-building and co-production between health and social services and carers is needed to improve relationships between the parties. Meaningful partnerships between social workers and carers will reduce the problem of the frequent need of carers to urge social services to provide adequate care and support.

Information on options for people with learning disabilities transitioning into old age as well as practical support will help reduce the risk of crisis situations happening when older carers can no longer care.

Recommendations for practice, policy and research

Clinical and professional practice:

1. An integrated system whereby more precise figures of people with learning disabilities and their carers are logged and shared between the local authority and health service, and which are also shared with designated charities such as Mencap - to target those who have health and social care needs.
2. Clearer remit of the roles and responsibility of social care managers and support workers and their relationship to health provision, including direct tasks - to help ease the burden of the family carer's role.
3. Co-ordinated and appropriate respite, to enable carer's to have a 'night off' and/or longer stretches of time to rest, and enable life goals to be realised - putting carers on a more equal footing with non-carers who are enjoying retirement.
4. Combined carer and cared-for assessments which acknowledge mutuality and interdependence, and which are more family-oriented in approach; with assessors who understand and consider the ageing process.
5. Greater and more varied 'appropriate' specialist housing options with on-going updates of availability as part of a wider information sharing and communication strategy.
6. A way of organising designated social workers which allows for social care relationship continuity.
7. A family approach to assessing the need for and provision of adaptations including the use of appropriate technology to address changing needs of both people with learning disabilities and their carers to ease the growing older phases of their lives.

Policy recommendations:

8. More emphasis and clear guidance for family members on the duty of the local authority to undertake comprehensive needs assessments (under s5 of the act) - with plans co-produced in terms of a whole family approach. This should include planning for future needs - to pre-empt crises

Research recommendations :

9. A larger, more comprehensive UK-wide study which qualitatively interviews the experiences of both older people with learning disabilities, their older family carers, and practitioners specifically in relation to the Care Act 2014.

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