

Looming crisis for family carers

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aging parents providing informal care for older children living with conditions such as Down syndrome must be better supported if we are to avoid a looming crisis in social care, according to the findings of an interim findings released this week.

The findings, a collaboration between a researcher at the University of Bath with New Forest Mencap, highlight the strains an aging population has placed on informal, unpaid carers and suggests that increasing numbers of older [parents](#) (some in their 80s and 90s) who are providing care to loved ones with severe learning disabilities (some in their 50s and 60s) are struggling to cope.

Presenting findings at Westminster Health Forum on Learning Disabilities, the author, Professor Rachel Forrester-Jones, call on healthcare policy-makers to tackle the looming 'iceberg' ahead by including older parent carers at all levels of planning in the NHS's Long Term Plan.

According to the National Institute for Health and Care Excellence (NICE), two-thirds of adults with learning disabilities and / or autism live with their families—mainly parents. Yet whereas in the late 1940s life expectancy of people with Down syndrome was just 12 years old; nowadays it is more like 65—66 years old—a huge 450% increase.

The economic value of care provided by the nation's unpaid carers is estimated to be worth £132 billion a year and the report authors suggest much more needs to be done to properly support those providing care. This could include increased respite care for the carers themselves, but also better systems and processes to make the lives of carers easier when it comes to dealing with bureaucracy, they suggest.

For the study, Bath Professor Rachel Forrester-Jones interviewed 20 older carers whose average age was 75 in order to uncover more about their day-to-day experiences of providing care to loved ones with learning disabilities and / or autism. Her study focused on rural Hampshire, seen as particularly significant given it has seen a disproportionate increase in the number of older residents in comparison with other age groups.

The findings suggest that challenges for older carers include finding appropriate support for loved ones who themselves are getting older and frailer; facing challenges in access and support from [social services](#); as well as financial challenges exacerbated by austerity and the closure of certain specialist day centres. Most starkly, it also highlights a collective fear faced by older parents centred on what happens to their disabled loved one if parents are to die first.

Professor Forrester-Jones, of the University of Bath's Department of Social & Policy Sciences and keynote speaker at this week's Westminster Health Forum event, explained: "The issue of increasingly older parents, specifically those providing care to their [older children](#) with conditions such as Down syndrome has gone unnoticed and under the radar for too long. With an aging population this iceberg issue will reach breaking point if it isn't tackled.

"For this study I spoke to parents who reported how they have been caring for their—now older—adult children over a lifetime. Some are dealing with their older children slowing down either because they have reached a plateau of skill acquisition, or because they are declining in health and skills, or because they are locked into their older parents' slower pace of life. Others are having to deal with increasing and various forms of challenging behaviour whilst at the same time experiencing frailty and ill health themselves. Yet, they don't feel they are partners or co-producers of services with professionals and they don't feel they have agency. Rather, they are still fighting with the authorities to gain benefits and formal care, and, in the face of depleted and disappearing daily activities and other services due to austerity cuts, they end up organising everything themselves.

"We need to find a way to comprehensively register the number of older people with learning disabilities and or / autism, as well as their older carers to find out who needs support. This must include greater

cooperation between GPs and Adult Services but also a plan of action which is pro-active in providing information and support to assist older carers. A key first step is to include older parent carers at all levels of planning in the NHS's Long Term Plan and the Core Capabilities Framework for Supporting Autistic People."

Liz Rolfs, of New Forest Mencap who commissioned the study, added: "There are too many instances of elderly parents appealing for help. It is usually, but not always, an elderly mother who says that they have cared for their own mother, they have cared for their husband and they are still having to care for their adult son or daughter. They are tired. Respite care that is suitable is hard to get, so it is difficult to take a break. They would like the right to retire and want to be able to go to their grave knowing that their child is healthy, happy, active and secure. The insult is that once a parent is in receipt of a state pension, they lose the Carer's Allowance.

"Sadly we are all aware that cuts in Adult Services are being imposed on Councils nationwide and the government must take responsibility. But we also feel that Councils need to consider how they prioritize their spending. Learning disability must not be allowed to be the Cinderella service."

A detailed report about this work will be released in September 2019.

Provided by University of Bath

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