As learning disability institutions close, care in the community must improve

A new job role of care practitioner is needed to support adults with severe and complex learning disabilities

My 31-year-old daughter, who has Down’s syndrome, lives in her own home with two other people. She receives support from her care provider and I see for myself how this helps her lead a fulfilling and busy life. Society now takes a more enlightened, community-based approach for people like my daughter. Thirty years ago she might well have spent her adult life in an institution of some variety.

And rightly so we are seeing a similar drive for home-based support to replace institutionalised care for adults with more complex needs or challenging behaviour, often those diagnosed with autism or spectrum disorders.

An NHS England and council leaders’ plan from October 2015 includes the complete shut down of some institutions for people with “severe” learning disabilities, to be replaced by supported housing schemes. This move is particularly urgent as there is an ever-increasing number of people with complex learning disabilities. Improved medical intervention means more people with disabilities are living to adulthood. In 2000, only around 13,500 babies born prematurely survived to adulthood. By 2015, the figure was around 50,000, and many had very complex profiles of disability. This trend will continue.

For adults with complex learning disabilities, health and social care services have traditionally provided two options long, expensive stays in hospitals (as Sir Stephen Bubb highlighted) or social care focused around tick-box activities that often have little to do with personal care. People with learning disabilities have ended up in a distressing revolving door between hospital and this old-style community care.

As an estimated 1,300 people with severe learning disabilities get transferred from outdated assessment and treatment units and similar institutions, we need a new group of specialised professionals to help support them. The issue is structural. If someone with learning disabilities living in supported housing becomes ill, the current model would mean a care worker contacting the team nurse, who may have to involve a social worker, make an assessment, and arrange medical care. They may end up back in hospital. Frequently, it’s a sledgehammer to crack a nut.

This new cohort of people - I call them care practitioners - must be, through experience or training, better suited to work with this client group.

Care practitioners need to be equipped to provide personalised and engaging support to people with learning disabilities, many of whom may have mental health issues, and support them with everyday activities. The particular skills that such care practitioners require are, for example, knowing exactly what triggers cause anxiety for an individual, and how to manage that behaviour to preserve the person’s dignity.

Leverage these care practitioners, with salaries in the £20,000-£30,000 range, to be a careers option for nurses, social workers and care workers with solid experience. Occupational therapists or psychology graduates would also be potential recruits.

The model would have its own career progression - from assistant, to care practitioner, to senior practitioner. Their background in thinking holistically about the whole person rather than as a collection of medical or social problems would make them the first line of care.

For the last two years I’ve been the chair of the advisory board of MyLife, a community support service in Hartlepool. The service was set up specifically to provide support for people with severe learning disabilities. Here I’ve been fortunate to put my vision into practice, leading to MyLife exclusively recruiting care practitioners.

I’ve seen the difference in service users who, previously held in inappropriate institutions or going from one service to another, have become more integrated into the community. We give them a solid foundation; a home. Young people at MyLife’s four bungalows are supported by teams of three to make the most of the opportunities for education, work and personal development.

When my daughter was a child I had to fight hard to secure every thing, and every service, that was best for her. Now she’s an adult I still do the same, but she’s fortunate to have quality personalised support in her own shared home.

People with severe learning disabilities should expect the same - and avoid what Bubb called the “serious shortcomings” of institutional care. But to deliver this new vision we need a new professional, a care practitioner.

Barry Carpenter is chair and adviser to MyLife, and a member of Health Education England’s learning disabilities expert reference group.

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