Editorial

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Transforming care in England

When the National Health Service in the UK was set up in 1948, the colonies or institutions which were built originally in the nineteenth century to segregate people with learning disabilities from the rest of society, became “hospitals” in which people were “nursed” and their problems defined in medical terms. We now know how damaging institutional life was for many people. Because of their size, location and regimented routines, institutional services made people dependent, powerless and lacking in choice, privacy or social networks. They were often treated inhumanely, and sometimes with deliberate cruelty or abuse (Sperlinger, 1997). Although since the 1980s many long-stay institutions have closed with a move to new community service provision, many of the attitudes and behaviours and some practices remain as legacies of the past.

Much has advanced in public health, in the management and prevention of infectious diseases, in the delivery of antenatal, prenatal and postnatal care. Premature and low birth weight babies have a significantly higher survival rate, and society now cares for children with multiple disabilities and complex needs. The average life expectancy for an adult with learning disabilities has also risen although we know they die on average 13–20 years earlier than someone without learning disabilities, often from causes that are preventable and avoidable. “Transforming Care” is a three-year NHS England funded programme (2016–2019), in response to the perceived slow pace of change following the exposé of abusive practices at a non-NHS assessment and treatment unit (Winterbourne View) for people with learning disabilities and/or autism. “A hospital is not a home”. At the heart of the Transforming Care Programme is co-production, giving people with learning disabilities (and those with autism) and their families a voice that is listened to, addressing health inequalities through a rights-based approach and building capacity and person-centred support in the community to reduce reliance on inappropriate inpatient provision.

This special issue is a collection of papers, written by clinicians, practitioners, commissioners and others who are working at a national level, alongside experts by experience and family carers, to transform care. It may not be of the same style as previous issues, but it captures the uniqueness of our journal, with its original focus on translating policy into practice and sharing practice-based evidence. NHS England uses the term “learning disabilities” rather than “intellectual disabilities”, so we have allowed for this terminology to be interchangeable in this special issue. Whaley and colleagues remind us that the words we choose to use can either oppress and diminish or empower and humanise. They present a framework for looking at the power of, and around, people with learning disabilities who have mental health issues or display behaviour that can challenge services. Sanderson, in his paper, describes the potential a personalised approach and personal health budgets could have in promoting choice and control over one’s care. He argues they can not only improve health and care outcomes but reduce the total spend across the system.

In October NHS England (2015) published a new national service model (Building the Right Support) and signalled its intention to close the last remaining free-standing learning disability hospital in the country. Turner’s case study in this special issue comes from the North East of the country and illustrates the culture change and local leadership required to make things happen: how every aspect of the jigsaw can come together if we work in partnership, as one team, to create the conditions within which the person can be discharged from a mental health or specialist learning disability hospital, and supported to have and live an ordinary life in the community.

DOI 10.1108/AMHID-01-2019-070

There is understandable anxiety given the current financial austerity and particularly the funding challenges in social care. It is precisely at such times that we need to innovate, hear what people with learning disabilities and their families want, and make the best use of the resources we have in a creative way that achieves meaningful outcomes and healthier lives.

Public Health England's analysis show 17 per cent of adults with learning disabilities known to primary care services and living in the community, will be receiving antipsychotic medication, and this compares to less than 1 per cent of the population without learning disabilities. This is a shocking statistic and an issue known about for decades. Two papers by Branford and colleagues on Stop Overmedicating People gives us the background and implementation of a national call to action. It is an approach that has galvanised people with learning disabilities, family carers and voluntary organisations as well as healthcare professionals and researchers. Whether this will result in a meaningful reduction in use or better-informed reviews, or improvements in quality of life and patient safety, remains to be evaluated.

The NHS marked its 70th birthday in June 2018, and it was important we celebrated its many successes and the incredible achievements in public health, basic sciences, neuro-imaging and translational research. It was a time to reiterate its universality and commitment to free healthcare at the point of need. It is also right we recognise the experiences of the past, health inequalities, the legacy of institutions and "forgotten lives". Deb's review of Professor Nick Bouras' memoires (a psychiatrist's chronical from deinstitutionalisation to community care) charts the dramatic changes that have occurred in our recent past; the clinical developments, research challenges, successes and frustrations working within systems that may not at times even have a shared vision. Our challenge now is to shift the balance of power from hospital to community, from clinician to patient, from executive boards to front-line staff and from engagement to co-production. But it is not just a health issue. We have a long way to go as a society if we are to truly support people with learning disabilities to have a life rather than a service. Ultimately that is what Transforming Care is all about.

Post-script: Since this special issue was commissioned and submitted for publication, the National Health Service has developed and published its Long Term (10 year) Plan, making "learning disabilities and autism" one of its clinical priority areas (2019). Available at: www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf and an easy-read version; www.longtermplan.nhs.uk/wp-content/uploads/2019/01/easy-read-long-term-plan.pdf

References

NHS England (2015), "Building the right support", available at: www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf (accessed 22 February 2018).

Sperlinger, A (1997), "Introduction", in O'Hara, J and Sperlinger, A. (Eds), Chapter 1, *Adults with Learning Disabilities: A Practical Approach for Health Professionals*, Wiley Publishers, p. 8.

Further reading

Heslop, P., Peter, S, Blair, P.S., Fleming, P., Hoghton, M., Marriott, A. and Russ, L. (2013), "The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study", *The Lancet*, Vol. 383 No. 9920, pp. 889-95, doi: 10.1016/S0140-6736(13)62026-7.

About the Editor

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