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Health care and risk of early death for people with learning Disabilities

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This commentary is on the original article by Amin et al. To view this paper visit <https://doi.org/10.1111/dmcn.13352>.

Amin et al.'s¹ important paper considers the causes of mortality in individuals with tuberous sclerosis complex (TSC), and reports that those with learning disabilities are at significantly greater risk of early death compared to their peers with TSC who do not have learning needs. Patients with learning disabilities are known to be at higher risk of poor health across the lifespan compared to typically developing peers. The CIPOLD report² highlighted the risk of premature death for people with learning disabilities, following the publication of the MENCAP reports^{3,4} that identified the poor care which contributed to their deaths. Males died 13 years sooner and females 20 years sooner than their non-disabled peers. However, many of the people with learning disabilities in the study were reported to have a collection of difficulties, so it was hard to identify which specific factors led to death. Amin et al. correctly suggest that one reason for a higher death rate within the group who had a learning disability was the possible inability of clients to be able to identify symptoms indicative of disease progression and difficulties in communicating to others any changes in health. Future studies should investigate specific diseases and disorders in relation to people who have a learning disability. This could assist the medical management of a condition and direct attention towards implementing preventative intervention to maximize best health outcomes. People with learning disabilities are often dependent on others to interpret their needs and to check their health. This is important as the Department of Health (Corporate Plan)⁵ identified that health inequalities need no longer exist, although it seems that from Amin et al.'s study there are still ongoing lessons to be considered and learned. Firstly, people who have a learning disability remain a group where there is a high level of unrecognized illness, and where there remains reduced access to preventative health screening and health promotion training. Secondly, health care professionals need to consider when and how to share this information with others in education and social care who are involved in caring for someone with TSC. People with learning disabilities have specific needs: these include understanding how to communicate symptoms of poor health and dependence to a carer or other significant person, and to identify and then convey the particular problems that are occurring. Attention needs to be given to the communication styles of people with learning disabilities in relation to interpreting differing states that could be indicative of poor health. Additionally, if people use augmentative and alternative communication, health care professionals (in particular speech and language therapists) need to ensure that people with learning disabilities have been taught how to express relevant concepts related to poor health. They must also have access to advocates who can support them to access information. It is not just people who have learning disabilities who need additional support, as the median age of death of the sample was 33 years (interquartile range 26–46) highlighting the seriousness of the disease progression in people who have TSC. Information about specific acute conditions as identified in Amin et al.'s paper need also to be in accessible formats for children, young people, and those who do not have a learning disability.

REFERENCES

1. Amin S, Lux A, Calder N, Laugharne M, Osborne J, O'Callaghan F. Causes of mortality in individuals with tuberous sclerosis complex. *Dev Med Child Neurol* 2016 Dec 9; doi: 10.1111/dmcn.13352. [Epub ahead of print].
2. Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with learning disabilities in the UK: a population-based study. *Lancet* 2014; 383: 889–95.
3. Mencap. *Death by Indifference*. London: Mencap, 2007.
4. Mencap. *Death by indifference: 74 deaths and counting. A progress report 5 years on*. London: Mencap, 2012.
5. Department of Health. *Corporate Report. Department of Health Corporate Plan 2013 to 2014, 2014*. Available at: <https://www.gov.uk/government/publications/department-of-health-corporate-plan-2013-14/department-of-health-2013-14-corporate-plan> (accessed 19 December 2016).

