

# Managing epilepsy in people with intellectual disabilities – creating capable communities<sup>†</sup>

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## SUMMARY

Almost a quarter of people with intellectual disabilities have epilepsy. This life-long condition adversely affects their health, safety and well-being and carries an increased risk of sudden unexpected death in epilepsy (SUDEP) in this population. This commentary considers what not only health and social services but also communities and people with intellectual disabilities themselves can do to improve outcomes.

## KEYWORDS

Intellectual disability; developmental disorders; epilepsy; epilepsy mortality; sudden unexpected death in epilepsy.

Nearly a quarter (22.5%) of people with intellectual disabilities have epilepsy, compared with less than 1% of the general population. For many, these seizures are pharmaco-resistant and lifelong. The additional diagnosis of ‘epilepsy’ appears to be a bellwether for greater levels of cognitive deficit, increased polypharmacy, multimorbidity and poorer life outcomes (Sun 2020). People with intellectual disabilities have five times higher rates of preventable emergency department attendance, with the most common reason being seizures. Of the 63% of people with intellectual disabilities who die before 65 years of age, around 40% have a comorbid epilepsy diagnosis. Sudden unexpected death in epilepsy (SUDEP), which is considered a major cause of preventable mortality in those with epilepsy, is at least three times higher in people with intellectual disabilities (Young 2015). Other concerns arise in those aged being over 40 and in relation to the long-term impact of anti-seizure medications and their side-effects, for example, on bone health. For a minority at risk of life-threatening seizures, there is a poor administration of risk counselling, essential epilepsy training and emergency care plans (Sun 2020).

The reasons for the challenges in supporting people with intellectual disabilities are multifactorial (Watkins 2022). They range from not having a

single service (given the range of biopsychosocial needs) to problems with communication and advocacy. In the UK, there is no national care pathway encompassing the various care needs of people with intellectual disabilities and epilepsy. This is further influenced by the lack of clear prescribing guidance for this population (Watkins 2020). The complex challenges require a multi-tiered proactive holistic response to mitigate harm in this vulnerable population. Potential solutions need to be diverse but cost-effective to bring about rapid positive change and enable swift dissemination.

## What should be done to improve outcomes?

### *The present*

Kerr et al (2023, *this issue*) argue strongly and rightly for a range of improvements, including better informed psychiatric services and rapid implementation of reliable validated technology such as the EpSMon (an epilepsy self-monitoring app). However, although a focus on psychiatric services and other important healthcare stakeholders, such as epilepsy specialist nurses and neurologists, is important and essential, it can only be the start of the improvement narrative. To improve outcomes across the lifespan for this complex vulnerable group there is a need to create capable and informed communities. These would stretch beyond the usual health-linked settings to all social and community settings to which people with intellectual disabilities have access. They would range from schools, colleges, residential homes, supported living and respite care to social places such as swimming pools. Such communities require knowledge, awareness and basic training in epilepsy-related risks in general and those affecting people with intellectual disabilities in particular. E-training modules such as those as offered by the Epilepsy Nurses Association ([esna-online.org](https://esna-online.org)) and Epilepsy Action ([www.epilepsy.org.uk](https://www.epilepsy.org.uk)) are easy and cost-effective source for various stakeholders to become epilepsy aware.

At a patient level, SUDEP Action ([sudep.org](https://sudep.org)) offers a range of patient leaflets to improve awareness of epilepsy-related risks. Work is ongoing

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with experts by experience to provide a more person-centred and interactive approach to risk management in people with intellectual disabilities and epilepsy, including consideration of making EpSMon more easily accessible for the intellectual disability community.

Clinician-level tools focused on seizure risk, such as the SUDEP and Seizure Safety Checklist, are discussed comprehensively by Kerr et al (2023). This checklist is a validated international tool for communication and discussion of epilepsy risk. However, it is important to make all stakeholders, especially non-clinical carers, aware of the importance of SUDEP and seizure safety. It is now recognised that risk communication for people with epilepsy, particularly those with intellectual disabilities, is an important part of mitigating harm, given the chronic nature of the problems. Such risk communication needs to be embedded into epilepsy essential training, thus widening the ‘safety net’ for people with intellectual disabilities and epilepsy (Shankar 2017).

It is imperative that the focus is not just on epilepsy care but on the wider health and social needs of people with intellectual disabilities. Clear benefits of annual health checks and their need to be introduced early have been established. However, making these person-centred and getting people with intellectual disabilities and epilepsy to engage can be challenging. It is also important to focus on ensuring that any pathway provides assurance on key healthcare factors that significantly influence epilepsy care and over all well-being. This includes polypharmacy, particularly of psychotropics and anti-seizure medications specific to this population. Associated problems, such as constipation, which in general is overrepresented in people with intellectual disabilities, are more likely given the concerns of polypharmacy and genetic syndromes (Maslen 2022).

In the creation of capable communities, attention needs to be given to stress in families and carers and the support they require over time. There is little literature on this. Newly introduced tools such as the evidence-based Step Together (Purple Light) Toolkit (Shankar 2020) can help address gaps in local systems and communities to improve visibility on social matters for people with intellectual disabilities and epilepsy (Shankar 2020).

### *The future*

A major challenge has been the scant bespoke research on people with intellectual disabilities and epilepsy, and this needs addressing (Shankar 2018). Improving communication between the different systems, particularly primary care, to ensure improved health monitoring could be easily attainable.

The future can be promising for people with intellectual disabilities and epilepsy if the four pillars of excellence – co-production, furthering genetic understanding, using big data and implementing high-quality technology – are harnessed in a systematic and meaningful manner.

There are developments in creating frameworks for digital care in epilepsy, such as digital healthcare platforms to provide rapid advice and treatment when needed as opposed to traditional appointments (Page 2018). This could provide person-centred epilepsy care as needed, when needed. Similar developments using artificial intelligence are raising real possibilities to improve diagnostic predictability, understanding of the course of seizures and nocturnal monitoring; examples include BioEP ([www.neuronostics.com](http://www.neuronostics.com)), the 24/7 EEG™ SubQ device ([www.uneeg.com](http://www.uneeg.com)) and NELLI® ([www.neuroeventlabs.com](http://www.neuroeventlabs.com)). These have the potential to give better, objective, consistent, sustainable and regular insights into how the lives of people with intellectual disabilities and their care providers are influenced by seizures. However, there needs to be an understanding of the possible difficulties with implementing technological advances with some people with intellectual disabilities. For example, factors such as sensory sensitivities could prevent easy adoption of generic technological developments. It could be that future developments in artificial intelligence will provide person-centred approaches.

Until these developments are fully evidenced and implemented, the continued need would be to ensure that current best practice as outlined by Kerr et al (2023) is followed and to focus on creating capable communities to support this vulnerable population.

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### **Declaration of interest**

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