

LeDeR

Learning from lives and deaths – People with a learning disability and autistic people



Research Digest: Summer 2024

Welcome to the summer edition of our planned quarterly research digests for 2024. In this edition, we bring you a selection of 10 papers covering general care themes for people with a learning disability. This digest, limited to work in 2024, highlights some of the most recent work regarding some of the most important issues facing people with a learning disability. In this issue we also highlight two recent studies that have arisen from the LeDeR data, the use of specialist learning disability nurses (study 9) and the prevalence of constipation for people with a learning disability (study 10).

For each paper we have provided a summary of 1) the country of focus, 2) the type of study, and 3) the rating of the level of evidence provided, based on the 5 point rating summary [provided here](#), where 1 is highest level of evidence and 5 is expert opinion. Please feel free to reach out with any questions or feedback on these digests.

In this edition

General issues edition

1. The experiences of caring for someone with dementia and a learning disability: A qualitative systematic review

2. How are medical students learning to care for patients with intellectual disabilities? A scoping review

3. Sleep in people with and without intellectual disabilities: a systematic review and meta-analysis

4. People with intellectual disability and their risk of exposure to violence: Identification and prevention - a literature review

5. Cervical screening participation and access facilitators and barriers for people with intellectual disability: a systematic review and meta-analysis

6. EMDR treatment for people with intellectual disabilities: a systematic review about difficulties and adaptations

7. The views of psychiatrists on proposed changes to the England and Wales Mental Health Act 1983 legislation for people with intellectual disability: A national study

8. Definition, assessment and management of frailty for people with intellectual disabilities: A scoping review

9. Specialist intellectual disability liaison nurses in general hospitals in England: cohort study using a large mortality dataset

10. Constipation prevalence and risk from prescribed medications in people with intellectual disability: Findings from an English mortality programme



@Aliveleder



leder@kcl.ac.uk



<https://www.kcl.ac.uk/research/leder>



The experiences of caring for someone with dementia and a learning disability: A qualitative systematic review

Hughes et al. (2024)

DOI: 10.1177/14713012231225797

As the life expectancy of people with a learning disability increases so too does the risk of a person developing dementia. The onset of dementia poses new challenges for families and carers of people with a learning disability. This systematic review examined the needs of families and formal carers when caring for people with a learning disability and dementia. The review noted that specific training and support needs are required for all carers, and that care plan considerations should factor in the support in place for the carers, the economic and environmental barriers experienced by the carers.

- 1) Country: UK (predominantly)
- 2) Type: Systematic review. 7 studies in the UK, 2 in Australia, 4 in the USA and 1 in Ireland.
- 3) Level of evidence: 3



How are medical students learning to care for patients with intellectual disabilities? A scoping review

Anderson and Studer (2024)

DOI: 10.1111/jar.13290

Of the 27 medical training programmes reviewed, 24 programmes involved individuals with intellectual disabilities in some capacities. To assess programme effectiveness, 19 programmes measured changes in affective traits, 8 programmes measured knowledge gain, and 9 programmes assessed improvement in skills required for patient management. As a framework for evaluating the programmes' coverage of intellectual disability content, the study applied the Core Competencies on Disability for Health Care Education (Havercamp et al., 2021). This revealed gaps in the coverage of the six core competencies. They conclude that designing learning objectives and instructional content based on this framework will bring consistency and greater strength into the intellectual disability curricula for medical students.

- 1) Country: UK
- 2) Type: Scoping review of 27 articles describing intellectual disability education programmes for medical students in the UK.
- 3) Level of evidence: 3



Sleep in people with and without intellectual disabilities: a systematic review and meta-analysis

Browne et al. (2024)

DOI: 10.1111/jir.13093

Sleep problems are regularly reported in people with a learning disability. Recent years have seen a substantial increase in studies comparing sleep in people with a learning disability to the people without. People with a learning disability are generally found to have poorer sleep than those without. In addition, evidence suggests that the quality and duration of sleep is associated with a genetic syndrome or neurodevelopmental condition, and that those with these sleep for less time and with less quality than those with other types of learning disability. People with a learning disability of heterogeneous origin showed no difference in sleep time to the general population, but still generally had poorer sleep quality. The authors suggest that further work is needed to differentiate between common and distinct mechanisms which cause these sleep differences across different types of learning disability.

- 1) Country: UK
- 2) Type: Systematic review
- 3) Level of evidence: 2



@Aliveleder



leder@kcl.ac.uk



<https://www.kcl.ac.uk/research/leder>



People with intellectual disability and their risk of exposure to violence: Identification and prevention - a literature review

Starke et al. (2024)

DOI: 7:17446295241252472

Through a literature review of 26 articles, from various countries (UK, USA, Canada, Australia, Brazil, Sweden, Israel, South Africa, and Hong Kong) the authors noted that violence against people with a learning disability is known to be an issue worldwide, and that this is a continuous risk throughout their lives. There was less research concluded on violence against youths and elderly people, and this is a gap in our knowledge. The authors also noted that there appears to be a gap of knowledge between professionals who work with people with a learning disability and those who are work with people exposed to violence. The authors stress that further collaboration between professionals of different specialisms is needed to increase awareness of the risk of violence towards people with a learning disability. In addition, there was a noted need to educate people with a learning disability about the risks of violence, and how to report it safely.

1 Country: Sweden

2) Type: Literature review

3) Level of evidence: 3



Cervical screening participation and access facilitators and barriers for people with intellectual disability: a systematic review and meta-analysis

Power et al. (2024)

DOI: 10.3389/fpsy.2024.1379497

Cervical screening for people with a learning disability is around 35%, although this varied depending on study and region, with up to 63% found in North America, the highest region. Overall, the rates of cervical screening for women with a learning disability was found to be low, and lower than for the general population. Barriers to uptake were noted as fear, a lack of awareness about what a screening was for or how it would be done, and a lack of awareness regarding the need for women with a learning disability to have a cervical screen. The authors also discuss how people with a learning disability may find themselves excluded from sexual healthcare and education, and that awareness of these issues needs to incorporate an inclusive education for both people with a learning disability and their caregivers.

1) Country: 31 studies from North America, 21 from Europe, 7 from Asia, and 4 from Oceania.

2) Type: Systematic review of 63 studies.

3) Level of evidence: 2



EMDR treatment for people with intellectual disabilities: a systematic review about difficulties and adaptations

Schipper-Eindhoven et al. (2024)

DOI: 10.3389/fpsy.2023.1328310

People with a learning disability are at an increased risk of developing post traumatic stress disorder (PTSD). Eye movement desensitization and reprocessing (EMDR) therapy has been demonstrated to be effective in the treatment of PTSD, however communication difficulties, cognitive capabilities, and issues with stress regulation have made some clinicians cautious about using EMDR for people with a learning disability. This review noted 13 articles where therapists have adapted EMDR protocols to better adjust to the needs of the person with a learning disability. These include simplified language, the involvement of family or caregivers in the delivery, decreased pace, and increased time. EMDR was shown to be able to be reasonably adjusted for treatment, and showed efficacy in helping people with a learning disability who also had PTSD when these adjustments were suitable and appropriate.

1) Sample: Netherlands

2) Type: Systematic review of 13 studies

3) Level of evidence: 2



@Aliveleder



leder@kcl.ac.uk



<https://www.kcl.ac.uk/research/leder>



The views of psychiatrists on proposed changes to the England and Wales Mental Health Act 1983 legislation for people with intellectual disability: A national study

Tromans et al. (2024)

DOI: [10.1177/00207640231212112](https://doi.org/10.1177/00207640231212112).

- 1) Country: UK
- 2) Type: Survey analysis
- 3) Level of evidence: 4

The Draft Mental Health Bill proposes removal of both intellectual disability and autism from Section 3 of the Mental Health Act for England and Wales (MHA). A key change is that people with a learning disability and/or autistic people could not be detained beyond 28 days, in the absence of diagnosed co-occurring mental illness. A total of 82 psychiatrists (33%) from approximately 250 eligible completed the survey. Nearly two-thirds (64%) reported good awareness of the proposed changes, with over half (55%) reporting disagreement with the changes. Psychiatrists working in inpatient settings for people with a learning disability reported increased awareness of the changes, less agreement with the reforms, and increased expectations of the reforms having negative unintended consequences, compared to their peers working exclusively in the community. Consultants reported greater disagreement with the changes compared to their non-consultant peers. Qualitative analysis identified five main themes: impact on diagnosis and treatment, seeking alternative options, introducing inequities, resources, and meeting holistic care goals through the Care, Education and Treatment Reviews (CETR) process. Psychiatrists working with people with a learning disability reported widespread disagreement with the proposed changes to the MHA, with greater levels of disagreement among those working in inpatient services. Caution with respect to the proposed changes, and monitoring of the impact of the changes if implemented, is therefore advised.



Definition, assessment and management of frailty for people with intellectual disabilities: A scoping review

Grohmann et al. (2024)

DOI: [10.1111/jar.13219](https://doi.org/10.1111/jar.13219)

- 1) Country: UK
- 2) Type: 20 studies from a scoping review
- 3) Level of evidence: 3

People with a learning disability may experience frailty earlier than the general population. This scoping review aimed to investigate how frailty is defined, assessed, and managed in adults with a learning disability, what factors are associated with frailty, and the potential impact of COVID-19 on frailty identification and management for people with a learning disability. Frailty prevalence varied between 9% and 84% for people with a learning disability, with greater severity of a learning disability, the presence of Down syndrome, older age, polypharmacy, and group home living being associated with frailty. The study noted that multiagency working and provision of evidence-based information may be beneficial in frailty management.



@Aliveleder



leder@kcl.ac.uk



<https://www.kcl.ac.uk/research/leder>



Specialist intellectual disability liaison nurses in general hospitals in England: cohort study using a large mortality dataset

Sheehan et al. (2024)

DOI: 10.1136/bmjopen-2023-077124

- 1) Country: England
- 2) Type: LeDeR data for NHS England between 2016 and 2021
- 3) Level of evidence: 3

Learning disability liaison nurses (LDLN) in general hospitals may enhance access to high-quality, adapted healthcare and help improve outcomes for people with a learning disability. This study explored associations between the input of LDLN and the quality of care in people with a learning disability who are admitted to hospital. One-third of people with a learning disability who died in hospital in England between 2016 and 2021 had input from a LDLN. LDLN input was however found to not be evenly distributed across England and was more common in those who died of cancer. Having an LDLN involved in an individual's care was associated with increased likelihood of reasonable adjustments being made to care and of best practice being identified but was not associated with a rating of overall quality of care received. LDLN however currently see only a minority of people with a learning disability who are admitted to hospital in England. Increasing the availability of LDLNs could improve care for this disadvantaged group.



Constipation prevalence and risk from prescribed medications in people with intellectual disability: Findings from an English mortality programme

Roberts and Ding et al. (2024)

DOI: 10.1177/17446295241267085

- 1) Country: England
- 2) Type: LeDeR data for NHS England in 2021
- 3) Level of evidence: 3

Constipation is common in people with a learning disability, with associated risk of death. Risk factors include lifestyle factors (such as mobility or diet), health conditions, and certain medications. In this study the authors explored constipation in a sample of people with learning disability who died in 2021 and whose deaths were reviewed by LeDeR. Forty-eight percent of the sample had constipation and half of the sample were prescribed at least two medications that are commonly associated with side effects of constipation. There were high rates of antipsychotic (30%) and laxative (40%) drug prescription. Five people in 2021 with a history of constipation died of causes of death associated with constipation. This study highlights the risk of secondary constipation due to prescribed medication and the seriousness of the condition in people with a learning disability.



@Aliveleder



leder@kcl.ac.uk



<https://www.kcl.ac.uk/research/leder>