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



Research Digest: December 2022

Welcome to the final edition of our planned quarterly research digests for 2022. In this edition we bring you a selction of 10 papers covering a wide range of topics relevant to the needs of people with a learning disability, care providers and NHS commissioners to give an overview of the current research landscape, with a focus on diabetes. Going forward, each of our quarterly digests will have a main focus on a topic of importance to people with a learning disability and autistic people, as well as including updates on the general scope of current research. As always, for each paper we have provided a summary of 1) the population, 2) the setting and 3) the rating of the level of evidence provided, based on the 5 point rating summary provided here, where 1 is the best level of study and 5 an expert review. Please feel free to reach out with any questions or feedback on the format of these digests.

In this edition Focus on Diabetes

- 1. A Systematic Review of Health Promotion Programs to Improve **Nutrition for People with Intellectual Disability**
- 2. Prevalence of Diabetes in People with Intellectual Disabilities and Age and Gender Matched Controls: A Meta-analysis
- 3. Respiratory-associated deaths in people with intellectual disabilities: a systematic review and meta-analysis
- 4. A systematic review of in-patient psychiatric care for people with intellectual disabilities and/or autism: effectiveness, patient safety and experience.
- 5. Diabetes and Obesity in Down Syndrome Across the Lifespan: A Retrospective Cohort Study Using U.K. Electronic Health Records

- 6. Disparities in diabetes-related avoidable hospitalization (DRAH) among diabetes patients with a disability using a nationwide cohort study
- 7. A systematic review of the barriers and facilitators influencing the cancer screening behaviour among people with intellectual disabilities
- 8. Constipation in autistic people and people with learning disabilities
- 9. A systematic review of systematic reviews of secondary health conditions, health promotion, and employment of people with intellectual disabilities
- 10. Antidepressant prescribing for adult people with an intellectual disability living in England







 Sample: 44 studies with people with a learning disability as participants
 Setting: Varied (mainly smaller studies)
 A level of evidence: 3

A Systematic Review of Health Promotion Programs to Improve Nutrition for People with Intellectual Disability

Dean, S., et al., (2021)

DOI: https://doi.org/10.1007/s13668-021-00382-0

10th December 2021

The effect of health promotion interventions on nutrition outcomes for people with a learning disability was investigated with a systematic review of 44 studies. The authors found that health promotion interventions strongly rely on addressing the attitudes, beliefs, knowledge, skills and behaviours of people with a learning disability with mixed outcomes. They suggested that researchers and clinicians should also consider interventions which focus on social environments (e.g. family, friends, peers), and physical environments (e.g. home, school, community residences), whilst also increasing the emphasis of health eating in policies.



Sample: 405 adults over 40 years old compared with 499 adults over 18 years old but under 40 years old.
 Setting: Analysis of a 10-site retrospective cohort study.
 3) Level of evidence: 3

Prevalence of Diabetes in People with Intellectual Disabilities and Age and Gender Matched Controls: A Meta-analysis

Vancampfort, D., et al., (2021)
DOI: https://doi.org/10.1111/jar.12949
17th October 2021

This meta-analysis aimed to find out how common diabetes is in people with a learning disability, whilst comparing the results to groups of people from the general population. They found that 8.5% of people with a learning disability in their sample had diabetes and that someone with a learning disability was nearly 2.5x more likely to have diabetes in comparison to someone from the general population. The factors which were most commonly associated with diabetes were older age, having Prada-Willi syndrome, smoking, co-morbid depression, anxiety, and hypertension. Being male or female was not associated with having diabetes. The authors argued that diabetic screening should begin at 30 years of age in people with a learning disability which is 10 years below the screening age for the general population. They also suggested that people who have a learning disability and a diagnosis of anxiety or depression should be screened for diabetes, whilst people who have a diagnosis of diabetes should be screened for the presence of depression or anxiety.



1) Sample: People with a learning disability and/or autism, from 106 studies.
2) Setting: Systematic review of studies evaluating admissions to psychiatric inpatient services. Varied in size.
3) Level of evidence: 2

Respiratory-associated deaths in people with intellectual disabilities: a systematic review and meta-analysis

Truesdale, M., et al., (2021)

DOI: https://doi.org/10.1136/bmjopen-2020-043658

14th July 2021

The authors of this article performed a systematic review and meta-analysis on respiratory-associated deaths in people with a learning disability. They found that respiratory-associated deaths are almost 11 times higher in people with a learning disability compared to the general population. Pneumonia contributed to a large portion of these deaths. Respiratory disorders are potentially avoidable with improved public health initiatives and equal access to quality care. The authors recommended that people with a learning disability should be identified as a high-risk group and efforts should be made to increase the uptake of flu and COVID-19 vaccinations, and there should be a development of prognostic guidance and risk management tools for this population group.





Sample: 982 adults aged 50 or over with a learning disability.
 Setting: general hospital, primary care, own homes etc.
 3) Level of evidence: 2

A systematic review of in-patient psychiatric care for people with intellectual disabilities and/or autism: effectiveness, patient safety and experience.

Melvin, C, L., et al., (2022) DOI: <u>https://doi.org/10.1192/bjo.2022.571</u> 21st October 2022

This systematic review evaluated the effectiveness of psychiatric in-patient treatment for children, adolescents and adults with a learning disability and/or autism by considering treatment effect (e.g. length of stay, clinical outcome, readmission), patient safety (e.g. restrictive practices) and patient experience (e.g. patient or family satisfaction). Improvements in mental health, social functioning, behaviour and forensic risk were found with admission to in-patient services across the 106 included studies. Patients admitted to specialist service had greater complexity, but were less likely to be secluded or discharged out-of-area.



A comparison cohort of 38,266 people from the general population.

2) Setting: UK primary care services

3) Level of evidence: 2

Diabetes and Obesity in Down Syndrome Across the Lifespan: A Retrospective Cohort Study Using U.K. Electronic Health Records

Aslam, A, A., et al., 2022

DOI: https://doi.org/10.2337/dc22-0482

30th September 2022

Diabetes was almost 3.7 times more common in people with Down syndrome than people from the general population. The average age of receiving a diagnosis of diabetes was 15 years younger for the group with Down syndrome compared to the general population. Type 2 diabetes rates were higher for people with Down syndrome in all age groups from 5-34 years. The peak BMI for people with Down syndrome was higher and achieved at a younger age (males 31.2 kg/m2 at age 31 years; females 32.1 kg/m2 at 43 years) in comparison to the peak BMIs for the group of people from the general population (males 29.5 kg/m2 at 54 years; females 29.2 kg/m2 at 51 years). Obesity was also associated with type 2 diabetes. The results of this study provide strong evidence that at younger age, people with Down syndrome are more susceptible to diabetes and obesity. The management of diabetes in people with Down syndrome should be altered to allow for earlier identification and close monitoring of the condition. Health promotion initiatives and efforts to increase the uptake of annual health checks for children with Down syndrome should be prioritised to reduce the incidence of diabetes in people with Down syndrome.



Sample: 49,411 diabetes patients, of which
 313 were registered as having an intellectual disability.
 2) Setting: Korean based population cohort study
 3) Level of evidence: 2

Disparities in diabetes-related avoidable hospitalization (DRAH) among diabetes patients with a disability using a nationwide cohort study

Youn, H, M., et al., (2022) DOI: <u>https://doi.org/10.1038/s41598-022-05557-5</u> 2nd February 2022

The findings of this South Korean study report that disability severity was significantly associated with higher risks for DRAH, where severely disabled diabetes patients showed the highest hazard ratio of 2.24 (95% CI 1.80–2.79). Among three DRAH indicators, severely disabled diabetes patients showed increased risks for long-term and uncontrolled DRAH. In addition, intellectual and mental disability showed higher risks than other types of disability. In conclusion, diabetes patients with disability are at higher risk for DRAH compared to those without disabilities, and those with intellectual and mental disabilities were more likely to experience DRAH compared to those with physical or other types of disability.





1) Sample: 16 studies, systematic review 2) Setting: Systematic review, varying size 3) Level of evidence: 2

A systematic review of the barriers and facilitators influencing the cancer screening behaviour among people with intellectual disabilities

Chan, N, S, D., et al., (2021)

DOI: https://doi.org/10.1016/j.canep.2021.102084

15th December 2021

The facilitators and barriers to cancer screening utilization in people with a learning disability were investigated with a systematic review of 16 studies. The authors identified the following key barriers to cancer screening among people with a learning disability: (1) fear of screening (2) a belief that screening is distressing (3) previous negative interactions with healthcare professionals; (4) a sense of being singled out, embarrassed, or unprepared (5) a lack of knowledge of cancer screening and the details of the procedure (6) mobility issues (7) a high severity of ID (8) a lack of capacity to provide consent and (9) a lack of ability to communicate verbally. The facilitators the authors identified were: living in a supervised setting, prior use of other healthcare services, being educated about screening via social media platforms and having an accompanying carer during the screening. The authors suggested that strategies should be developed to overcome the barriers to cancer screening among people with a learning disability, such as the provision of appropriate training and support to healthcare professionals in the administration of cancer screening procedures.



1) Sample: People with a learning disability and/or autism 2) Setting: Primary care 3) Level of evidence: 2

Constipation in autistic people and people with learning disabilities

Maslen, C., et al., (2022)

DOI: https://doi.org/10.3399/bjgp22X720077

30th June 2022

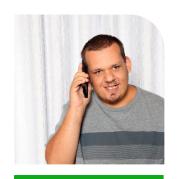
This article provides an overview of constipation and related concerns in people with a learning disability and/or autistic people. The authors found that the prevalence of constipation and related GI issues is significantly higher in people with LDs and/or autistic people when compared to the general population, a result which was consistent nationally and internationally. A second finding was that constipation and other GI problems are one of the key causes of avoidable emergency admissions to hospital in people with a learning disability and/or autism. The authors made several recommendations for primary care. The authors recommended that primary healthcare professionals working with people with a learning disability and/or autism:

- Pay close attention to bowel issues during annual health checks.
- Carefully consider any long-term use of laxatives and interventions aiming to promote appropriate laxative use.
- Regularly review medications which contribute to anticholinergic burden and consideration of their impact on bowel issues.
- Provide proactive lifestyle plans including: healthy bowel management plans; diet reviews; activity reviews; and fluid intake reviews
- Consciously avoid diagnostic overshadowing and arrange specialist referral for detailed evaluation when needed.
- Education and training of the patient, their family, and carers should be accessible and person centred. Communicate any relevant information in a manner the individual can understand









Sample: 25 systematic reviews
 Setting: Systematic review of systematic reviews, varying sample sizes in each.
 Slevel of evidence: 1

A systematic review of systematic reviews of secondary health conditions, health promotion, and employment of people with intellectual disabilities

Kanako, I., et al., (2021) DOI: <u>https://doi.org/10.1017/jrc.2021.2</u> <u>14th May 2021</u>

The authors of this paper systematically reviewed 25 systematic review articles concerning secondary health conditions, health promotion interventions and employment of people with a learning disability. First, they found clear evidence that people with a learning disability experience a higher rate of secondary health conditions. Second, physical activity interventions alone were found not to be sufficient in reducing body weight for people with a learning disability and they should be paired with healthy eating. Third, there was good evidence to support the effectiveness of self-management and adaptive functioning training. Competitive employment and supported employment were found to improve the physical and mental health of people with a learning disability. The authors recommended that disability service providers should consider adding health promotion interventions to improve the likelihood of their clients with a learning disability gaining employment.



Sample: Literature review
 Setting: NHS England data
 Setting: Of evidence: 5

Antidepressant prescribing for adult people with an intellectual disability living in England

Branford, D., and Shankar, R. (2022) DOI: <u>https://doi.org/10.1192/bjp.2022.34</u> 7th March 2022

In 2021 the number of people with a learning disability (including children) who were treated with antidepressants was 20.7% compared to 10.3% for those without a learning disability. Depression rates are however roughly comparable between people with a learning disability (around 17%) and those without (16.8%). Antidepressants have replaced antipsychotics as the most widely prescribed psychotropic medication. The authors suggest that this is most likely because antidepressants are being prescribed for issues other than depression and that they are increasingly being used for longer after symptoms have passed. The authors suggest that where recognised indicators of depression are no longer present in a person with a learning disability, there should be a review to withdraw the use of the medication as soon as possible. Also, carers should be made aware of the maximum amount of time the treatment is expected to last at the start of the treatment. The authors also call for more work to be done to test deprescribing programmes for people with a learning disability, and for there to be an urgent need to understand whether the change to antidepressants as the most widely prescribed psychotropic in England actually reflects the use of evidence-based use of the medications. This is in addition to the current NHS England STOMP programme, which seeks to reduce inappropriate psychotropic prescribing for people with a learning disability.



