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

Research Digest: Autumn 2023

Welcome to the autumn edition of our planned quarterly research digests for 2023. In this edition, we bring you a selection of 10 papers covering a wide range of topics relevant to the needs of people with a learning disability and autistic people (or service users), care providers and NHS commissioners to give an overview of the current research landscape, this time with a focus on pneumonia. Pneumonia is one of the top 5 causes of death for people with a learning disability, and in the 2022 LeDeR national report it was found to be second only to COVID-19. In this digest we will look at the latest work into this avoidable cause of death. A new addition to this digital edition is that all study titles are now hyperlinks directly to the papers.

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 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

Focus on: Pneumonia

1. Incidence and clinical outcomes of pneumonia in persons with down syndrome in the United States

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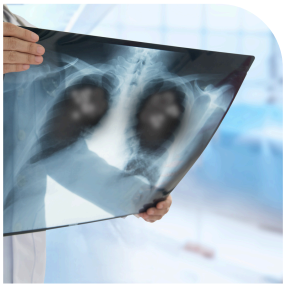
9. Use of psychotropic medications in adults with intellectual disability: A systematic review and meta-analysis

10. Ideal models of good inpatient care for adults with intellectual disability: Lessons from England



1) Sample: 33,796 people with Down syndrome and 135,184 without Down syndrome.

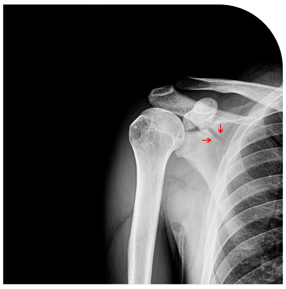
2) Setting: retrospective matched cohort study using persons who had made healthcare claims in the United States. Follow ups made 1 year later.

3) Level of evidence: 2

Incidence and clinical outcomes of pneumonia in persons with down syndrome in the United States

Janoff et al. (2023)
DOI:10.1016/j.vaccine.2023.05.063

For people with Down syndrome and pneumonia there was no difference of mortality when compared with the sample of people without Down syndrome at 30 days. However, 1 year later there was a significant increase likelihood of a person with Down syndrome being hospitalised due to pneumonia compared to those who did not have Down syndrome (39.4% vs 13.9%). In addtion, admissions to intensive care were also higher 1 year later for people with Down syndrome (16.8% vs 4.8%). Finally, mortality was also shown to be higher for those with Down syndrome than those without, 1 year later (5.7% vs 2.4%). The authors concluded that greater long term care awareness of the risks of pneumonia for people with Down syndrome in the first year after getting sick is important, and that Down syndrome should be considered an independent risk condition for pneumonia.



1) Sample: 6,183 adults (over 18) with a learning disability and 67,842 with no learning disability.

2) Setting: Retrospective cohort study of American nationwide claims for medicare assistance from 01/01/2011-12/31/2016.

3) Level of evidence: 2

High cardiorespiratory disease burden following a fracture among adults with intellectual disabilities

Whitney et al. (2023)
DOI:10.1016/j.bone.2023.116784

This study examined the association between fragility fractures and an increased 2-year rate of cardiorespiratory diseases among adults with intellectual disabilities and found that fractures at the vertebral column, hip, non-proximal femur, tibia/fibula, and multiple sites had an elevated hazard ratio (HR) for pneumonia, respiratory failure, heart failure, and cerebrovascular disease compared to those without fractures. Humerus and radius/ulna fracture were associated with an elevated HR for congestive heart failure and cerebrovascular disease. The study highlights the importance of addressing fragility fractures in the care of adults with intellectual disabilities to prevent further health declines, and highlights the link between bone fractures and a subsequent risk of cardiorespiratory disease.

1) Sample: 10,204 people with Down syndrome, 39,814 general population controls, 69,150 people with intellectual disabilities.
2) Setting: UK electronic health records (1990-2020)
3) Level of evidence: 2

Cause of death in adults with intellectual disability in the United States

Landes et al. (2023)
DOI: 10.1111/jir.12789

This study examines the cause of death patterns of adults with intellectual disability (ID) in the US. Data from the National Vital Statistics System 2005-2017 US Multiple Cause-of-Death Mortality files was used to identify more common causes of death for ID-identified adults. The study found that heart disease was the leading cause of death for adults with and without ID, while those with ID had a higher risk of death from pneumonitis, influenza/pneumonia, and choking. Adults with mild/moderate ID also had a higher risk of death from diabetes mellitus. Differences in cause of death trends were associated with biological sex and race-ethnicity. The study concludes that efforts to reduce premature mortality for ID should consider risk factors for general causes of death, such as heart disease and cancer, but also consider the increased risk of death from choking among all ID adults and diabetes among mild/moderate ID adults. Further research is needed to better understand the factors determining lower rates of death from neoplasms and demographic differences in causes of death among ID adults.

1) Sample: 56 autistic children and 139 not autistic children (ages 2-17)
2) Setting: Children's hospital in the USA
3) Level of evidence: 2

Relationship between daily swallowing frequency and pneumonia in patients with severe cerebral palsy

Tanaka et al (2022)
DOI: doi.org/10.1186/s12887-022-03547-0

This study investigated the relationship between swallowing frequency and the history of pneumonia in patients with severe cerebral palsy. Swallowing frequency is crucial for preventing aspiration and entry into the trachea, and it may be correlated with the incidence of pneumonia. The results showed that swallowing frequency was constant within individuals, with frequencies per hour being 12.2 ± 12.2 for those with pneumonia and 27.0 ± 20.4 for those without pnuemonia. Swallowing frequency was also shown to be significantly associated with the incidence of pneumonia in the previous year. The study concluded that swallowing frequency could be used as an index for assessing the risk of dysphagia and pneumonia in patients with severe cerebral palsy.

Parental home-based pulse oximetry monitoring for adults with intellectual disabilities at risk of serious respiratory problems including COVID-19: a brief report

Finlayson et al. (2023)
DOI: doi.org/10.1111/jir.13030

1) Sample: 9 adults with a learning disability, mean age of 34 years old.
2) Setting: Homes of people with a learning disability in Scotland.
3) Level of evidence: 3

The COVID-19 pandemic increased the risk of respiratory health issues in people with a learning disability, leading to serious consequences and even death. Home-based oxygen saturation monitoring is recommended for people with a learning disability, but there is limited evidence on its feasibility. This study conducted in Scotland found that baseline mean readings for eight adults with a learning disability were within the normal range, and for another one, 94%. Fluctuations were experienced by six of these individuals, but these were within limits that are not dangerous. The parents who completed the evaluation found home-based pulse oximetry monitoring to be easy and effective. Home-based pulse oximetry monitoring appears to be safe and not difficult for parents to perform. Further research is needed to promote home-based respiratory health monitoring more widely for people with a learning disability.

Experiences of people with intellectual disability and dementia: A systematic review

Jacobs et al. (2023)
DOI: https://doi.org/10.1111/jar.13063

1) Sample: 308 autistic children, 110 with co-occurring intellectual disability
2) Setting: Specialist clinic for autistic children in the USA (2010-2019)
3) Level of evidence: 2

This systematic review of 88 studies involving people with intellectual disability and dementia aims to understand their experiences of dementia. The findings reveal changes in individual functioning, a narrowing of social worlds, and how people make sense of these changes despite often having no knowledge of their dementia diagnosis. The review also discusses how people's experiences are shaped by their environments. It acknowledges the complexities of communicating with people with intellectual disability about dementia, challenges views that they cannot be involved in research, and recommends supporting inclusion in future studies.

1) Sample: 68 published papers between 2000 and 2020 from 6 countries.
2) Setting: 27 qualitative, 18 descriptive, 12 quantitative, 9 mixed-methods and 2 literature reviews
3) Level of evidence: 1

The value and contribution of intellectual disability nurses/nurses caring for people with intellectual disability in intellectual disability settings: A scoping review

Doody et al. (2023)
DOI: https://doi.org/10.1111/jocn.16289

A systematic scoping review of literature on intellectual disability nursing found that there is limited knowledge about the assessment and intervention strategies employed by these professionals. Despite the extensive literature on the role of intellectual disability nurses in healthcare, there is a lack of understanding about their unique contributions to client care, service delivery, policy, and ultimately to the art and science of nursing. The review aimed to identify relevant literature from seven academic databases and found that the literature supports a biopsychosocial-educational approach to addressing the physical, mental, and social needs of clients with intellectual disability across the care continuum.

1) Sample: 24 published articles.
2) Setting: Global studies, reported in English.
3) Level of evidence: 1

Use of psychotropic medications in adults with intellectual disability: A systematic review and meta-analysis

Song et al. (2023)
DOI: doi.org/10.1177/00048674221149864

This study examines the use of psychotropic medications by adults with intellectual disabilities. A search of 24 articles revealed a pooled prevalence of 41% of psychotropic medications, with antipsychotics being the most common. Subclasses included antidepressants, anxiolytics, hypnotics/sedatives, and psychostimulants. Heterogeneity was considerable between studies, except for psychostimulants. There was no significant association between assessed characteristics and variability in prevalence estimates. The study concludes that two-fifths of adults with intellectual disabilities are prescribed psychotropic medications, with antipsychotics and antidepressants used by one-third and one-seventh of adults, respectively. Further investigation is needed to determine the source of variability and ensure appropriate use of these medications.

1.) Sample: 23 published studies.
2) Setting: Studies from the UK and countries deemed similar to the UK.
3) Level of evidence: 2

Ideal models of good inpatient care for adults with intellectual disability: Lessons from England

Burrows et al. (2023)

DOI: https://doi.org/10.1177/00207640221140

The de-commissioned inpatient facilities for people with a learning disability and/or autism in England have led to challenges in follow-up, community care, and interventions. This has caused patient trauma, family distress, and discharge difficulties. The study aimed to evaluate the utility of inpatient models for people with a learning disability and outline best clinical practice. A rapid review of 23 papers was conducted, and key data related to in-patient models of care was extracted. Four broad models/frameworks/approaches were identified, with evidence primarily based on locally developed and implemented models. The study recommends the best clinical practice and standards, emphasizing the need for clinical service providers and policymakers to be aware of the specific needs of individuals with a learning disability and/or autism.

1) Sample: 17,130 autistic people without a learning disability and 6,450 autistic people with a learning disability.
2) Setting: A matched retrospective cohort study.
3) Level of evidence: 2

Estimating life expectancy and years of life lost for autistic people in the UK: a matched cohort study

O'Nions et al. (2023)

DOI: doi.org/10.1016/j.lanepe.2023.100776

This study conducted in the UK aimed to estimate life expectancy and years of life lost experienced by autistic people. The study involved a cohort of 17,130 people diagnosed with autism without a learning disability and 6,450 people diagnosed with autism and a learning disability. The results showed that people diagnosed with autism but not a learning disability had 1.71 times the mortality rate of those without these diagnoses, while those diagnosed with autism and a learning disability had 2.83 times the mortality rate. The reduction in life expectancy for those diagnosed with autism but not a learning disability was 6.14 years for men and 6.45 years for women, while those diagnosed with autism and a learning disability had 7.28 years for men and 14.59 years for women. The findings suggest that the widely reported statistic that autistic people live 16 years less on average is likely incorrect.