

LeDeR

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



Research Digest: March 2023

Welcome to the first 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 autism. Particular attention is applied to suicidality as this is shown to be a prominent cause of death for autistic people.

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 these digests.

In this edition Focus on Autism

1. Autism and autistic traits in those who died by suicide in England
2. Premature mortality in a population-based cohort of autistic adults in Canada
3. Mortality in Persons With Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder: A Systematic Review and Meta-analysis
4. Epilepsy related multimorbidity, polypharmacy and risks in adults with intellectual disabilities: a national study
5. Rates, causes and predictors of all-cause and avoidable mortality in 163 686 children and young people with and without intellectual disabilities: a record linkage national cohort study
6. Suicidality in autistic youth: A systematic review and meta-analysis
7. Mortality rate, risk factors, and causes of death in people with epilepsy and intellectual disability
8. Autism: making reasonable adjustments in healthcare
9. Benefits and harms of interventions to improve anxiety, depression, and other mental health outcomes for autistic people: A systematic review and network meta-analysis of randomised controlled trials
10. Loneliness in autistic adults: A systematic review



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Autism and autistic traits in those who died by suicide in England

Cassidy, S., et al., (2022)

DOI: <https://doi.org/doi:10.1192/bjp.2022.21>

15th February 2022

In a sample of 372 coroners inquest reports from two areas of England, there is evidence of autism in 41.4% of the adults who died by suicide, which is significantly higher than the 1.1% of people in the UK general alive population believed to be autistic. Aside from autistic traits, the characteristics of those people who died were similar between those with or without autistic traits. This suggests that autistic traits are significantly over-represented in those who die by suicide in England.

- 1.) Sample: 372 coroners reports of adults in 2 regions of England who died by suicide.
- 2. Setting: 2 NHS England regions.
- 3. Level of evidence: 2



Premature mortality in a population-based cohort of autistic adults in Canada

Lunsky, Y., et al., (2022)

DOI: <https://doi.org/10.1002/aur.2741>

28th May 2022

This study looked at how many autistic men and women died over 6 years (2010-2016), along with how they died, and compared this to adults who did not have autism living in Ontario, Canada. It found that autistic men and women were more than three times as likely to die as people of the same age who did not have a developmental disability. However, adults with other developmental disabilities besides autism were even more likely to die than autistic adults. This means that we have to pay more attention and invest in better social and health care for autistic people, along with people who have other types of developmental disabilities.

- 1) Sample: 42,607 adults from the general population, 10,646 autistic adults and 10,614 adults with a learning disability.
- 2) Setting: Administrative health and social services population in Ontario, Canada.
- 3) Level of evidence: 2



Mortality in Persons With Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder: A Systematic Review and Meta-analysis

Catalá-López, F, et al., (2022),

DOI: <https://doi.org/10.1001/jamapediatrics.2021.6401>

14th February 2022

In this systematic review of 27 studies, including a total of 642,260 people, autistic people were found to be significantly more likely to die from both natural and unnatural causes compared to the general population and compared to people with ADHD. People with ADHD were not found to have a significant increase in deaths from natural causes than the general population but were more likely to die from unnatural causes (e.g. suicide, accidental deaths) than the general population.

- 1) Sample: 642,260 people of all ages
- 2) Setting: Systematic review and meta-analysis of 27 studies, varied sizes, mainly mid sized.
- 3) Level of evidence: 2



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Epilepsy related multimorbidity, polypharmacy and risks in adults with intellectual disabilities: a national study

Sun, J., et al., (2022)

DOI: <https://doi.org/10.1192/bjo.2022.571>

24th January 2022

About a quarter of people in the UK who have epilepsy also have a learning disability compared to only 0.6% of the general population. Epilepsy is also associated with about two-fifths of all deaths related to polypharmacy and multi-morbidity. This study of 904 adult deaths across 10 centres in the UK found that the average age of death from epilepsy was 39.9 years, with over 50% of these people having multiple physical health conditions, a third had a psychiatric co-condition and a fifth had an underlying genetic disorder. Of autistic people, 37% also had epilepsy.

- 1) Sample: 904 adults
- 2) Setting: 10 hospitals across the UK
- 3) Level of evidence: 3



Rates, causes and predictors of all-cause and avoidable mortality in 163 686 children and young people with and without intellectual disabilities: a record linkage national cohort study

Hughes-McCromack, L. A., et al., (2022)

DOI: <https://doi.org/10.1136/bmjopen-2022-061636>

16th September 2022

Children with a learning disability were found to be significantly more likely to die from avoidable, treatable and preventable causes of death than children without a learning disability. Children with a learning disability who were aged 5-9 years were the most likely to die from avoidable, treatable and preventable causes than the general population peers. The authors propose a number of improvements to health care management for children with a learning disability including improved epilepsy management and risk assessments and coordinated multidisciplinary actions to reduce aspiration/reflux/choking and respiratory infection.

- 1) Sample: 7,247 children and young people with a learning disability living in Scotland, aged 5-24 years old, and 156,439 age matched comparison groups.
- 2) Setting: Retrospective health records data in Scotland from 2011 to 2020
- 3) Level of evidence: 3



Suicidality in autistic youth: A systematic review and meta-analysis

O'Halloran, L., et al., (2022)

DOI: <https://doi.org/10.1016/j.cpr.2022.102144>

12th March 2022

The systematic review and meta-analysis aimed to study the incidence of, and risk/protective factors for suicidality in people with autism aged under 26. Suicidal ideation was found to be present in one in four young people with autism. 8.3% of young people with autism had made an attempt at suicide and 0.2% died by suicide. Negative childhood experiences were found to be strong risk factor for death by suicide in this sample. The authors concluded that risk-assessment, early intervention, and resilience promotion should therefore be prioritised in healthcare to reduce suicidality in young people with autism.

- 1) Sample: 29 papers were included in the meta-analysis, whilst 37 were included in the narrative synthesis.
- 2) Setting: Systematic review and meta-analysis, varied sample sizes.
- 3) Level of evidence: 2



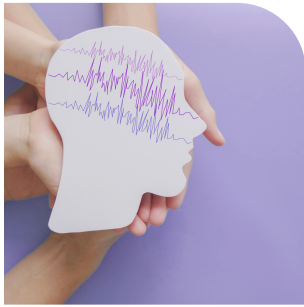
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1) Sample: 28,500 people diagnosed with epilepsy admitted to hospital from 2005-2015, 6,029 of which also had a learning disability
2) Setting: Hospitals in New South Wales, Australia
3) Level of evidence: 3

Mortality rate, risk factors, and causes of death in people with epilepsy and intellectual disability

Liao, P., et al., (2022)

DOI: <https://doi.org/10.1016/j.seizure.2022.07.012>

27th July 2022

The mortality rates in people with a learning disability and epilepsy were compared to the mortality rates in people that did not have a learning disability but did have a diagnosis of epilepsy. The risk factors and causes of death were also compared. Mortality rates in children and young adults with epilepsy and a learning disability were higher in comparison to the rates in people with epilepsy without a learning disability. Neurological, respiratory, endocrine and nutritional, and metabolic disorders were overrepresented causes of death in people with a learning disability. Several comorbid conditions were identified as risk factors for mortality, highlighting that efforts should be made to improve the management of epilepsy and comorbid conditions in people with a learning disability in order to reduce the amount of early deaths.



1) Sample: Expert review
2) Setting: NHS England
3) Level of evidence: 5

Autism: making reasonable adjustments in healthcare

Haydon, C., et al., (2021)

DOI: <https://doi.org/10.12968/hmed.2021.0314>

8th December 2021

This expert review sets out why it is important to identify autistic people and the negative consequences of not recognising or understanding autism, including people developing more severe illness and even experiencing premature death. This article sets out what clinicians can do to help reduce those negative consequences by making 'reasonable adjustments' in any healthcare service in which they work. This key points include:

- When clinicians recognise that someone might be autistic, they should ask about preferences and reasonable adjustments.
- If autistic people have a positive experience of accessing health interventions, they are more likely to access health services in the future when needed.
- Autistic people have high rates of co-occurring health conditions and are at increased risk of premature mortality from preventable and treatable illness.
- Owing to difficulties accessing health services autistic people are less likely to receive early or preventative interventions resulting in greater acuity, more emergencies and more hospitalisations.
- Recognising autism and making adjustments for autistic people in healthcare settings can reduce barriers and delays in getting appropriate treatment thus improving health outcomes and reducing health inequalities for autistic people.



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- 1) Sample: 71 studies including a total of 3,530 participants
- 2) Setting: Systematic review, varied sizes and samples.
- 3) Level of evidence: 2

Benefits and harms of interventions to improve anxiety, depression, and other mental health outcomes for autistic people: A systematic review and network meta-analysis of randomised controlled trials

Linden, A., et al., (2022)

DOI: <https://doi.org/10.1177/13623613221117931>

11th August 2022

This systematic review and network meta-analysis of randomized controlled trials aimed to determine the most effective interventions to improve anxiety and depression in people with autism. 71 studies were included in the analysis, despite the authors conclusions that all trials had a high risk of bias as samples often excluded participants with a learning disability. They found evidence that mental health interventions available to non-autistic people lower symptoms in autistic people. This included some support for cognitive behavioural therapy and mindfulness. Medications targeting the core features of autism did not lower mental health symptoms. The authors recommend that until higher quality evidence exists, autistic people should be given access to the mental health interventions administered to the general population, with consideration of each individual's preferences. Research should focus on determining mental health interventions that are effective in people with autism and a learning disability.



- 1) Sample: 34 studies systematic review
- 2) Setting: Systematic review, varied, mainly small scale studies.
- 3) Level of evidence: 3

Loneliness in autistic adults: A systematic review

Umagami, K., et al., (2022)

DOI: <https://doi.org/10.1177/13623613221077721>

8th March 2022

This systematic review of 34 studies exploring loneliness in adults with autism. The authors showed:

1. Only a small amount of research has asked people with autism to describe their experiences of loneliness (e.g. what it is like to feel lonely as a person with autism).
2. When questionnaires were used, they often were not adapted to autistic adults.
3. Collective loneliness (e.g. the extent to which a person feels they 'fit in' with society) seemed important to autistic adults but studies investigating other aspects of loneliness (e.g. loneliness in relation to romantic relationships or friendships) are much more common.
4. Anxiety and depression, and a lack of understanding of autism might increase loneliness in autistic adults
5. Having relationships and accepting oneself may decrease feelings of loneliness in adults with autism.

The authors concluded that it is important that clinicians detect when people with autism experience loneliness and promote social activity in order to prevent negative outcomes including depression and suicide. One limitation of this study was that people with a co-occurring learning disability were underrepresented.



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