Literature Review on Autism, Ageing and Life Expectancy

April 2026

An Roinn Leanaí, Míchumais agus Comhionannais
Department of Children, Disability and Equality

Údarás Náisiúnta Míchumais
National Disability Authority

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Acknowledgments

This scoping review is an original piece of work funded by the Department of Children, Disability and Equality (DCDE) and contributes to the Autism Innovation Strategy (AIS) and does not duplicate work elsewhere. This review was commissioned, managed and administered by the National Disability Authority (NDA).

The research team would like to give their heartfelt thanks to the Public and Patient Involvement (PPI) contributors and Gheel Autism Services for their time and valued insights on autism and ageing. Lastly, the research team would like to thank the academic advisory committee for their valued inputs and the HSE as the external reviewer.

Disclaimer

DCDE has funded this research and the NDA coordinated it. Responsibility for the research (including any errors or omissions) remains with the Research Team at Trinity College Dublin. The views and opinions contained in this report are those of the authors and do not necessarily reflect the views or opinions of DCDE or the NDA.

Research Team

Dr Louise Lynch

Principal Investigator

Trinity College Dublin

Dr Kristian Mallon

Research Assistant

Trinity College Dublin

Dr Darren McCausland

Co-principal investigator

Trinity College Dublin

Ms Jessica Eustance-Cook

Subject Librarian

Trinity College Dublin

Professor Eilish Burke

Trinity College Dublin

Dr Martin McMahon

Trinity College Dublin

Contributor Roles Taxonomy (CRediT) Statement

Louise Lynch: Conceptualisation, methodology, validation, analysis, original draft, review and editing, visualisation, supervision. **Kristian Mallon:** Validation, analysis, original draft, review and editing. **Jessica Eustance-Cook:** Methodology. **Darren McCausland:** Conceptualisation, methodology, validation, analysis, original draft, review and editing, visualisation. **Eilish Burke:** Review and editing. **Martin McMahon:** Review and editing

Contents

List of acronyms

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DALY	Disability Adjusted Life Year
DCDE	Department of Children, Disability and Equality
GBD	Global Burden of Disease
GI	Gastrointestinal
GP	General Practitioner
GRADE	Grading of Recommendations Assessment, Development and Evaluation
HSE	Health Service Executive
ID	Intellectual Disability
IQ	Intelligence Quotient
NASS	National Ability Supports System
NDA	National Disability Authority
NGO	Non-Governmental Organization
NHS	National Health Service
OCD	Obsessive Compulsive Disorder
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
Prisma-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping review
QoL	Quality of Life
SD	Standard Deviation
SMRs	Standardised Mortality Rates
TCAID	Trinity Centre for Ageing and the Life Course in Intellectual Disability
UK	United Kingdom
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organisation
YLD	Years Lived with Disability

Glossary of key terms

Mortality

A prominent measure in epidemiological studies is mortality, which can be defined as the number of deaths in a certain group of people in a certain period of time (1). Mortality is commonly presented as a rate per 1,000 or 100,000 individuals, also called the death rate.

Morbidity

Morbidity is defined as having a disease or a symptom of disease, or to the amount of disease within a population (2).

Standardised mortality rate

The standardised mortality rate (SMR) is another commonly used measure of mortality. The SMR compares the rates of death of a cohort of interest (e.g. autistic people) with another known population (3).

Life expectancy

Whilst life expectancy is generally considered to reflect differences in mortality (4) it is important to note the distinction between the two. Life expectancy is defined as the mean number of years a cohort of people might expect to live according to the current age-specific mortality rates. Life expectancy is presented in the form of life tables. These measures are often used in epidemiological studies investigating mortality and ageing in autistic people.

Prevalence

Prevalence is defined as the proportion of a population who have a specific characteristic in a given time period (5).

Incidence

Incidence is the rate of new cases identified within a specific time period (6)

Years lived with disability

Years lived with disability (YLDs) is defined as years of life lived in less than ideal health (7). YLD in the context of autism tell us how many years people in a population have had their diagnosis for.

Disability adjusted life years

Disability adjusted life years (DALYs) represent healthy life lost due to premature mortality, illness or disability and are collated across large samples to determine a population rate per 100,000. One DALY represents the loss of the equivalent of one year of full health or no disability (8). DALYs combine YLD with years of life lost. In the context of autism, a high DALY indicates earlier access to diagnosis, on average, for a population and a low DALY indicates later access to diagnosis.

Language use and terminology

Throughout this review, person-first language (e.g., person with autism) and identity-first language (e.g., autistic person) were adopted, accounting for preferences reported in the autistic community and contemporary literature (9). As the literature demonstrated that there is not universally accepted terminology, a mixture of person first and identity first language was employed (10–12). The official diagnostic category name, Autism Spectrum Disorder, as used in ICD-11 and the World Health Organisation (WHO), was used to introduce autism initially. This report endeavours to use sensitive and respectful language. As a result, standard epidemiological terms have been tweaked e.g., burden of disease.

Executive summary

Under Pillar 4 (Building Capacity) of the Autism Innovation Strategy, launched in August 2024, Action 81 outlines the key aim to 'improve our understanding of the key health challenges facing autistic people, and their associated impact on life expectancy'. This included a commitment to conduct research aligned with the priorities of autistic people, led by the National Disability Authority (NDA). This scoping review aims to summarise the current evidence base on Autism Spectrum Disorder (hereafter referred to as autism), ageing and life expectancy, and seeks to:

- Identify the methodological challenges in understanding morbidity and mortality in autistic adults,
- Examine differences in life expectancies and the consequences of frequently occurring health conditions in autistic adults, and
- Identify modifiable factors to improve the health of autistic adults and their access to quality health care.

A scoping review was undertaken, following the Arksey and O'Malley (2005) framework and guided by the PRISMA Extension for Scoping Review checklist. A search of published papers including grey literature identified 4,188 studies for screening, with 115 being eligible for inclusion in the final review. Data extraction and analysis identified four key themes across the studies included in the review: epidemiology (22 studies); health and healthcare through the life course (14 studies); mental health (35 studies) and quality-of-life (46 studies).

Epidemiology

Data from a 2019 epidemiological study shows that the global prevalence of autism has increased from 20.3 million cases in 1990 to 28.3 million cases in 2019. From 1995 to 2010, incidence rates for autism increased from 9.0 to 38.6 per 100,000 person-years. Findings from cohort studies reported mean age of death for autistic people ranging from 67 to 77 years and estimated life expectancy to be approximately 68 years. However, the reported age of death should not be interpreted as life expectancy for important methodological reasons, including study samples skewed towards younger cohorts due to under-diagnosis in adulthood and later life, and difficulties comparing samples across countries due to diagnosis and other differences such as data quality and case ascertainment methods. Hence, the average age of death is not an appropriate summation of life expectancy for this population. Similarly, estimates of life expectancy are likely biased by under-representation of older cohorts and/or over-representation of autistic people presenting with poorer health and increased support needs. Therefore, reported age of death and estimated life expectancies are likely lower than would be the case if a truly representative sample of all autistic people were used, and should be treated with caution.

An increased risk of all-cause mortality for autistic people and higher overall standardised mortality rates compared with the general population have also been identified in studies. As people with autism aged, studies showed that their years lived with disability (YLD), a measure reflecting the average time spent with an autism diagnosis, decreased from 431.8 per 100,000 at age 20-24 years to 5.8 per 100,000 at age 90-94 years. This pattern likely reflects the smaller number of autistic individuals represented in older age groups, likely due to underdiagnosis. Disability-Adjusted Life Years (DALYs) for autistic adults saw 10-fold disparities in results across studies, ranging from approximately 30 to 383 per 100,000, due to methodology variations.

Inconsistencies in the measurement of prevalence of autism and DALYs may be due to differences in assessment techniques or measurement errors. Epidemiological findings on the prevalence and incidence of autism, as well as the impacts on quality-of-life as indicated by decreased mortality rates, increased DALYs, and YLDs, highlight the significant global impact presented by autism. An earlier autism diagnosis means higher YLDs and DALYs. The fact that autism, a lifelong condition and diagnosis, may not be identified until later in life means that measures such as YLD and DALYS are not the most accurate way or informative way to describe disability associated with autism because an autism diagnosis does not always equate to the onset of disabling difficulties.

A small number of studies (n=3) highlighted differences between autistic people with and without co-occurring intellectual disability. One study highlighted a significant increased risk of having a mental health condition or physical disability with co-occurring intellectual disability while other studies reported increased healthcare and support needs. Although estimates of life expectancy are likely biased by under-representation of older cohorts and/or over-representation of autistic people presenting with poorer health and increased support needs, the presence of a co-occurring intellectual disability appears to be associated with a reduction in life expectancy.

Methodological challenges in understanding morbidity and mortality in autistic adults

The review highlighted several potential methodological challenges in understanding morbidity and mortality in the autistic population. A change in the definition of autism in the Diagnostic and Statistical Manual in 2013, as well as a lack of comprehensive population-level data, means that the numbers of those with autism are predominantly based on cohort studies. These cohort studies differ in their sampling methods, diagnostic procedures, and data collection processes, which can lead to uncertainty or variation in estimates. Poor awareness and lack of accommodations within healthcare environments impact healthcare, with consequences for morbidity and mortality of autistic people. Another key challenge highlighted by studies is the underdiagnosis of autism in older adults, which may lead to underreporting biases in mortality and morbidity figures. Further challenges may arise when researchers do not provide appropriate support for autistic people to report their physical and mental health experiences, potentially leading to misinterpretation or inaccurate responses.

Health and healthcare through the life course

Autistic adults have unmet health needs. To optimise healthcare provision for autistic adults, healthcare practitioners need a more thorough understanding of common co-occurring health conditions including anxiety, depression and attention deficit hyperactivity disorder (ADHD). Disconnected healthcare, being misunderstood by healthcare professionals, and difficult individual access issues for autistic people are compounded by stigma, sensory sensitivity, lack of understanding of needs, communication issues, and a shortage of services, which potentially lead to an increase in chronic health conditions. Increased barriers to healthcare access have been shown to predict poorer mental and physical well-being among autistic people. Approaches to improve healthcare access were highlighted, including more individualised communication and support, better empathy and understanding, and simple accommodations within healthcare settings, for example a quiet place to wait.

Mental health

Mental health issues, especially depression and anxiety, are more prevalent in autistic adults than non-autistic adults and contribute to reduced overall well-being. Lifetime anxiety disorders were very common in autistic people, ranging from approximately 40-70%, which declined with age. Other psychiatric disorders including bipolar disorder are more common in autistic people than the general population. Suicidal ideation and suicide attempts are highly prevalent in autistic people, especially adults, with over twice the risk of dying by suicide reported. Previous trauma was linked with suicidality. Other studies associated older age with increased likelihood of psychiatric comorbidity, with one study highlighting increased comorbidity associated with later-age autism diagnosis. Findings indicate a clear need for the provision of mental health screening services for autistic people, with a specific focus on critical transition periods such as adolescence to adulthood.

Quality of life

Several studies reported the negative impact of restricted social integration on mental well-being and quality-of-life for autistic adults. This may be associated with exclusion, bullying, social impairment and loneliness. Inadequate social support was associated with lower self-esteem and quality-of-life, while widespread exclusion from, and difficulties with employment further impacted quality-of-life for many autistic adults. Studies reported that compared to their general population peers, autistic women had significantly poorer well-being, were more prone to cognitive decline and heightened menopause symptoms such as emotion regulation and mental difficulties. Findings suggest a need for enhanced social support networks to mitigate the effects of restricted social integration. The complex communication and sensory needs of autistic people is a critical consideration in developing any such initiatives and the inclusion of autistic voices is vital. To achieve this, education of healthcare professionals requires a much greater focus on autism.

Promising interventions, practices, policies and programmes

The review highlighted several recent interventions, policies, and programmes that show promise for autistic adults. For example, a major review of 972 articles published between 1990 and 2017, synthesized evidence on 28 interventions for young autistic adults, and suggested effectiveness across various areas, including social, communication, and mental health outcomes. Another review of 19 interventions published between 2007 and 2018 found positive outcomes for cognitive behavioral approaches and mindfulness techniques for reducing psychiatric conditions, including anxiety in both children and adults in this population who did not have an intellectual disability. An earlier systematic review of 13 psychosocial interventions for adults with autism published between 1950 and 2011, highlighted how such interventions may also improve sociability domains. The use of computer-assisted technology in the application of social cognition training produced positive outcomes including improvements in communication and social skills. However, recent evidence suggests that mental health outcomes remain an area in which evidence-based interventions remain lacking.

Introduction

Autism spectrum disorder (ASD) (hereafter referred to as autism) is a neurodevelopmental condition, whereby people present with social and communication difficulties and repetitive behaviour (13,14). Autism is a lifelong developmental condition which can be diagnosed at any age although early signs generally appear in the first two years of life (15). It relates to how a person communicates and interacts with others, and how they experience the world around them (16). Autism exists on a spectrum, which means it affects people in different ways, at different times, in different situations. The current International system for the Classification of Diseases 11th Revision (ICD-11) diagnostic requirements state that to receive a classification of autism, a person's behaviour should be characterised by several essential features, which include: "Persistent deficits in initiating and sustaining social communication and reciprocal social interactions", "a range of restricted, repetitive, and inflexible patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual's age and sociocultural context", and "symptoms which result in significant impairment in personal, family, social, educational, occupational or other important areas of functioning" (17).

Autism often co-occurs with intellectual disability (ID). Population-based estimates generally report co-occurrence rates of around 30%, although earlier studies have reported figures as high as 70% (15). From a global perspective, a 2021 review (18) found that around 61.8 million individuals (around one in every 127 people) were on the autism spectrum. In Ireland, the lack of reliable and consolidated data sources for autism prevalence remains a challenge. Recent evidence (19) indicates prevalence estimates of 1.2% for adults aged 18 years and over, with a further 4.5% suspecting they have undiagnosed autism. The 2024 Irish Health Survey (19) reported that almost 19% of Irish adults (>18 years) identified as being neurodivergent, which includes autism and other diagnoses.

Comorbidities are common in autistic people and include epilepsy, obesity, insomnia, constipation, seizures, diabetes, gastrointestinal (GI) problems, sleep disorders, and mental health conditions like depression, anxiety, obsessive-compulsive disorders and suicides (20,21). Alongside presenting with many complex health issues, autistic adults also report receiving lower-quality healthcare and increased difficulties accessing healthcare (22). Furthermore, autistic adults report an overall lower mental and physical quality-of-life compared to the general population, potentially attributable to having less social support structures, less coping strategies, more comorbidities and the nature of autism itself (23–25).

In August 2024, the Department of Children, Disability and Equality published the Autism Innovation Strategy (26). This document was the result of two public consultations convened in April 2022 and February 2024 which sought the views of over 370 organisations and stakeholders including representatives from the autistic community and their supporters. The Autism Innovation Strategy consists of four pillars and 83 actions. Action 81 of the Autism Innovation Strategy, which falls under Pillar 4: Building capacity, outlines the aim to:

'Improve our understanding of the key health challenges facing autistic people, and their associated impact on life expectancy', through investing in research that informs policy and practice around appropriate health, and social care services and supports for autistic people. A primary element of this research includes a review of international literature which will be in line with the priorities of autistic people, led by the National Disability Authority (NDA).

Consequently, the aim of this review is to summarise the current evidence base on autism, ageing and life expectancy. This broad scoping review aims to establish the state of the science on the health of autistic people, which will give insight into how to improve their health and access to quality health care. The specific research question guiding the review is:

'What are the methodological challenges in understanding morbidity and mortality in autistic adults, to examine differences in life expectancies, examine the causes and consequences of frequently occurring health conditions in autistic adults, and modifiable factors to improve the health of autistic adults and their access to quality health care?'

Within this, a number of objectives are addressed in the research:

1. Identifying and outlining methodological challenges in understanding morbidity and mortality in autistic adults
2. Examining differences in life expectancies for autistic adults, including comparisons with the general population
3. Examining the causes and consequences of frequently occurring health conditions in autistic adults, and modifiable factors
4. Review the evidence related to differences in morbidity between autistic and non-autistic people and summarise the epidemiology of key health conditions that occur more frequently in autistic people than non-autistic people
5. Report if there are modifiable determinants of health that influence morbidity and mortality among autistic adults.
6. Outline modifiable barriers in accessing quality health and social care that impact on the morbidity and mortality of autistic adults.
7. Summarise promising interventions, practices, policies, or programmes to support autistic adults improve their health or improve access to health services, and how effective they are.

Methodology

This section outlines the methodological approach used to answer the stated research question and meet the key objectives.

Design

A scoping review methodology was deemed the most appropriate approach to address the research objectives. This was based on the ability of scoping reviews to map the extent, range, and nature of the literature, as well as to identify possible gaps in the literature on a specific topic (27). Arksey and O'Malley's (2005) scoping review framework was used (28). This approach involved six key steps:

1. Identifying the research question
2. Identifying relevant studies
3. Study selection
4. Charting the data
5. Collating, summarising, and reporting results
6. Optional step: Consulting stakeholders.

Guided by this framework, relevant literature was identified, and the extracted data were synthesised using a thematic approach that was relevant to the research question.

1. Identifying the research question

The specific research question was pre-defined by the NDA request for proposals, being guided by the information needs identified by the Autism Innovation Strategy.

2. Identifying relevant studies

A comprehensive search strategy was developed to identify relevant studies to address the research question. The research team, in collaboration with the subject librarian, developed the search terminology using a combination of index terms and keywords. To ensure a comprehensive review of research in the field, all databases were searched from inception. Database searches were in English but results from all languages were included and screened to the full text screening stage where possible. Google translate was used to translate non-English articles. Articles that could not be translated were excluded. Five databases were searched: CINAHL Ultimate (EBSCO), MEDLINE (EBSCO), EMBASE (Elsevier), Global Index Medicus (WHO) and Web of Science (Clarivate). Additional searches were run on Grey Literature sources i.e. Google Scholar, OCLC, Stella Catalogue, LENUS, RIAN, OPENAire, BASE, ProQuest Dissertations & Theses and Overton, as well as NGOs, NHS, HSE, NDA, AsIAm and Autistica websites. See **Appendix 1** for the Search Strategy.

Keywords were determined according to the main concepts identified within the review question: 1. ASD/Autism and 2. Life Expectancy. A proximity operator was applied for the second concept to bring in nuance around the terminology used to capture longevity of life and life expectancy challenges.

3. Study selection

The inclusion and exclusion criteria were designed using the Joanna Briggs manual of scoping review methodology, consisting of Population, Concept, Context, and Study Design (29). If eligibility was inconclusive from the title and abstract, the full text of the article was assessed.

Any articles that did not match the inclusion criteria were excluded. See Tables 1 and 2 for inclusion and exclusion criteria.

Table 1. Inclusion criteria

Criteria	Description
Population	The population of interest are autistic people.
Concept	The concept of interest is 'life expectancy' and/or 'ageing'.
Context	The context is that many people with autism experience health challenges. The associated impact of these challenges on life expectancy and ageing needs understanding, especially around appropriate health and social care services and support for autistic people.
Study design	Study designs for inclusion are review articles, editorials, guidelines, all quantitative and qualitative research designs and grey literature e.g. reports and documents published but not subject to peer review.
Settings	No restrictions on settings applied.
Language	No language limits applied.
Year	No date restrictions.
Publication status	There will be no restrictions applied based on publication status.

Table 2. Exclusion criteria

Criteria	**Description**
Population	People who do not have autism, or where autism is not specified in the article.
Concept	No reference to health, health conditions, mortality, morbidity, ageing or life expectancy.

4. Charting the data

All results (including grey literature) were exported to the Covidence software platform (30) which was used to review and eliminate articles using the inclusion and exclusion criteria. The screening was a two-step process involving title and abstract screening in the first instance. A secondary full-text screening was applied to the remaining papers to determine their relevance for inclusion in the final review. Full text data was extracted by a researcher (KM) and oversaw by a second researcher to ensure that the appropriate data was extracted. All screening was done by two independent reviewers (KM/LL), and any conflicts were resolved by a third team member (DMcC). The results of the search and the study inclusion process are reported in full in the final scoping review and presented in a PRISMA flow diagram, see Figure 1.

5. Collating, summarising and reporting results

Key results from all included literature (addressing the research objectives) were extracted by KM & DMcC and oversaw by LL. Key data relating to the research objectives were pooled within a data extraction form in Microsoft Office Excel. This enabled relevant article data to be collected consistently by the research team. An initial thematic analysis of this data was performed by categorising recurrent concepts identified in the literature to determine important themes. Next, studies were grouped within the four broad themes identified as important to addressing the research question:

- Theme 1: Epidemiology
- Theme 2: Health and healthcare through the life course
- Theme 3: Mental health
- Theme 4: Quality of life

The inclusion of studies under the quality-of-life theme followed discussion and agreement with the NDA on a broad definition of ‘health’ prior to undertaking literature searches. This facilitated the inclusion of studies which, while not having direct implications for life expectancy and mortality, nonetheless addressed important aspects of quality-of-life, which contribute to overall health and well-being, and which provide important context for the ageing of people with autism.

An in-depth analysis of studies within these four themes was conducted to identify important findings, structured by sub-themes which emerged within each section. Reporting of results to address the research question was structured according to these themes.

6. Stakeholder consultation

As a final recommended step in the Arskey and O’Malley (2005) framework (28), aimed at enhancing the validity and relevance of the findings, initial results from the scoping review were reported to the NDA for ongoing consultation. This step provided additional insights and identified missing literature and has informed the final presentation of the scoping review. In addition, a number of individuals with lived experience of autism were consulted.

Public and patient involvement

Public and patient involvement (PPI) is critical to ensure that research is carried out with and for the people it is to benefit, to make it more relevant and meaningful. Involving individuals with lived experience of autism provided insights that helped shape the research, improved study design, and ensured that findings addressed real-world needs.

The research team spoke to four people with lived experience of autism, two adults with autism, an adult with a co-occurring mild-moderate intellectual disability and a carer for an adult with a co-occurring severe intellectual disability. Each person was given a unique identification number. The interview with the person with intellectual disability was in person while the remaining three discussions took place over the phone.

PPI participants were consulted at the mid-stage of the project to provide guidance prior to analysis and to validate key findings and themes in accordance with their lived experience of autism. These PPI participants shared their experiences of autism through individual interviews and presented diverse experiences with autism across their lifespan. The participants highlighted challenges they encountered with mental health, difficulties accessing healthcare and the importance of appropriate support, in line with the findings of this review. Overall, the life experiences of these participants underscore the importance of personalised support, improved healthcare accessibility, and greater societal understanding of autistic adults' needs.

To ensure a comprehensive approach, the review was guided by the PRISMA Extension for Scoping Review checklist (PRISMA-ScR), which supports methodological rigour and reporting of the key elements of a scoping review according to acceptable standards (31). See Appendix 2 for the completed PRISMA-ScR checklist.

Ethical issues

There were no perceived ethical issues in undertaking this review. To limit bias, two reviewers screened studies with a third to mediate in the event of any conflicts. At the time of writing this final report all applicants declare that they have no conflict of interest.

Overall quality control and review management

To ensure this review was comprehensive, rigorous, and transparent, the Arksey and O'Malley scoping review framework and PRISMA Extension for Scoping Review checklist were followed (28). The search strategy was defined, documented, and reproducible with an audit trail, by the Subject Librarian. Storage and data management processes and version control procedures were followed in line with TCD guidelines. All records were held electronically. Data were stored and backed up daily on the TCD Server.

Summary tables, charts, and diagrams were used to map the characteristics of '*life expectancy and ageing'* for people with autism and to visualise the scope of the data. The final publication will adhere to the PRISMA-ScR reporting framework (32).

To ensure methodological rigor and transparency in the review the following strategies were incorporated:

1. Team based approach.
2. Intentionally leveraged expertise from a subject librarian whose expertise contributed to developing a comprehensive and reproducible search strategy.
3. Audited to ensure traceability across all stages for the review.
4. Ensured team members were proficient in review management and screening software.
5. Clear resolution strategy.
6. Clear data storage and management to document any limitations or iterations during the whole process.
7. Weekly team meetings to review the process for credibility, reproducibility, and trustworthiness.

Results

There were 6,832 articles from the five databases searched, inclusive of 43 found in grey literature, of which 2,644 were duplicates and removed automatically by Covidence. After title and abstract screening 4,188 articles met the eligibility criteria, with 308 deemed suitable for full text review. The exclusion reasons for 193 articles included having a paediatric or youth population focus, wrong outcome or setting (i.e. not focused on autism), no full-text available, and duplicate articles. The final number of studies/articles included in the review was 115. Figure 1 shows the Prisma diagram of the search process. Appendix 3 shows all the studies included in the review.

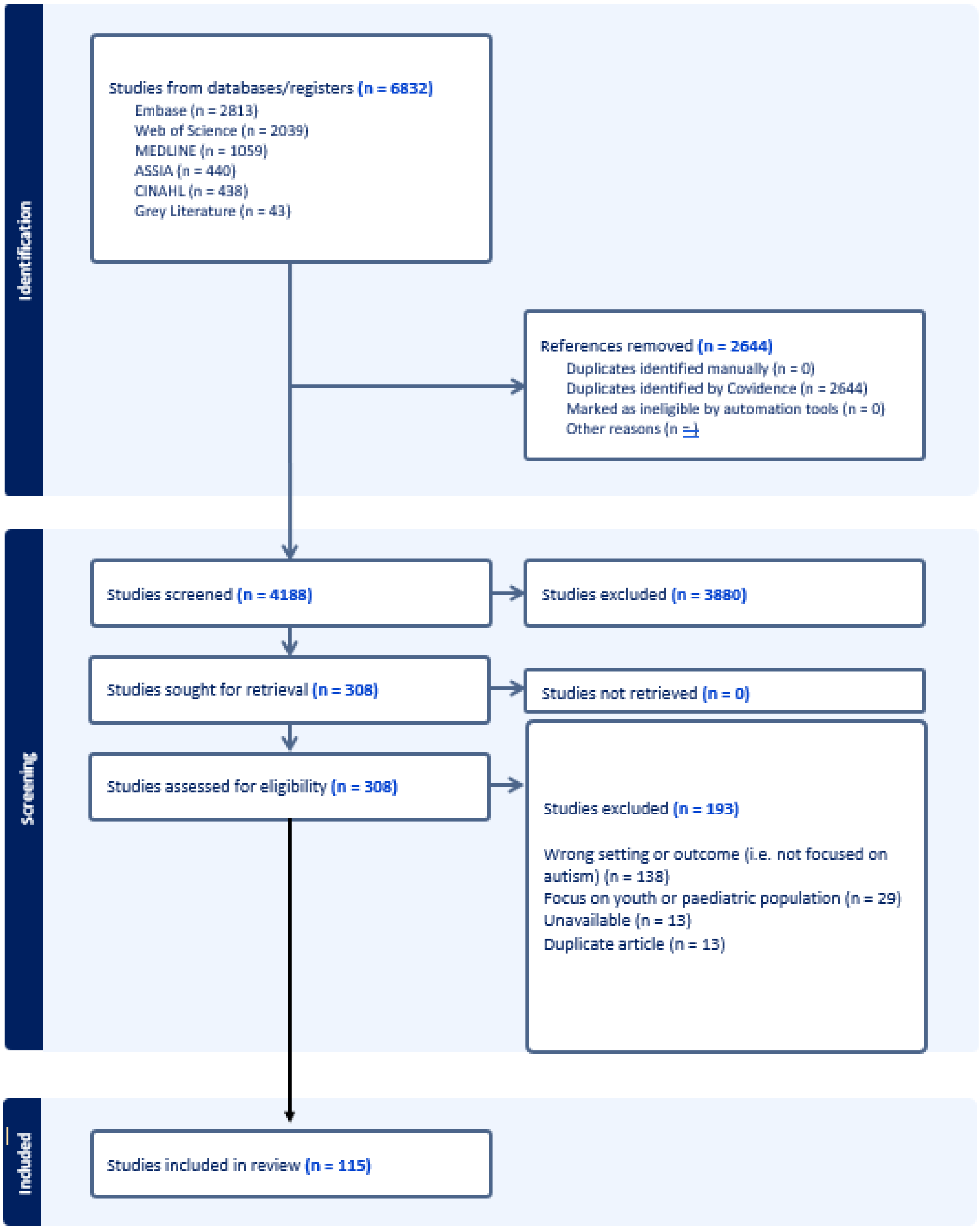
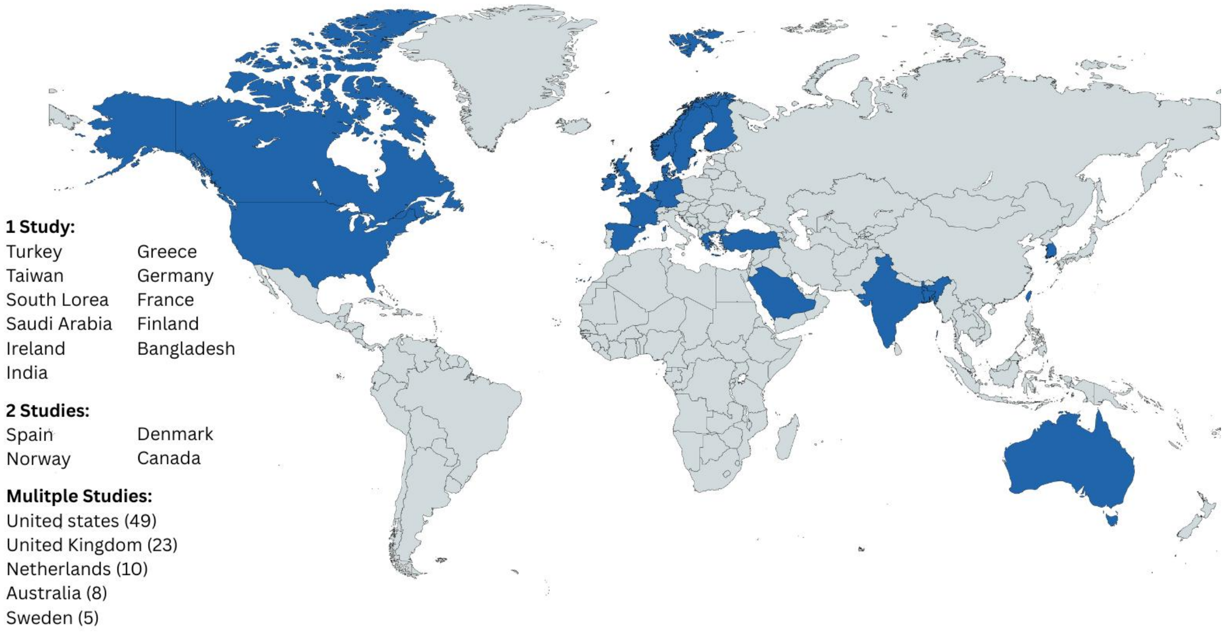


Figure 1. Prisma diagram of the search process for the autism literature review

The included studies had worldwide representation spanning 20 individual countries i.e. US (n=49), UK (n=23), Netherlands (n=10), Australia (n=8), Sweden (n=5), Spain, Norway, Denmark, Canada each had two studies while Turkey, Taiwan, South Korea, Saudi Arabia, Ireland, India, Greece, Germany, France, Finland and Bangladesh had one study included. See Figure 2. Multiple studies included cross-country collaboration (n=18). A multitude of study types were identified including cross-sectional (n=43), cohorts (n=25), reviews (n=22) and meta-analysis (n=5), longitudinal (n=12) and qualitative studies (n=9). The study's publication years range from 2001 to 2025. In total, almost 1.2M autistic adults were represented in the final studies.



Multiple studies included cross-country collaboration (18).

Figure 2. Countries represented in the final studies in literature review

After thematic analysis, four broad themes were identified, into which the studies could be allocated to i.e. Epidemiology, Health and healthcare through the life course, Mental health, and Quality of life. These overarching themes aligned with the original review objectives as shown in Figure 3, where each colour coded theme line denotes a link to one of the seven study objectives.

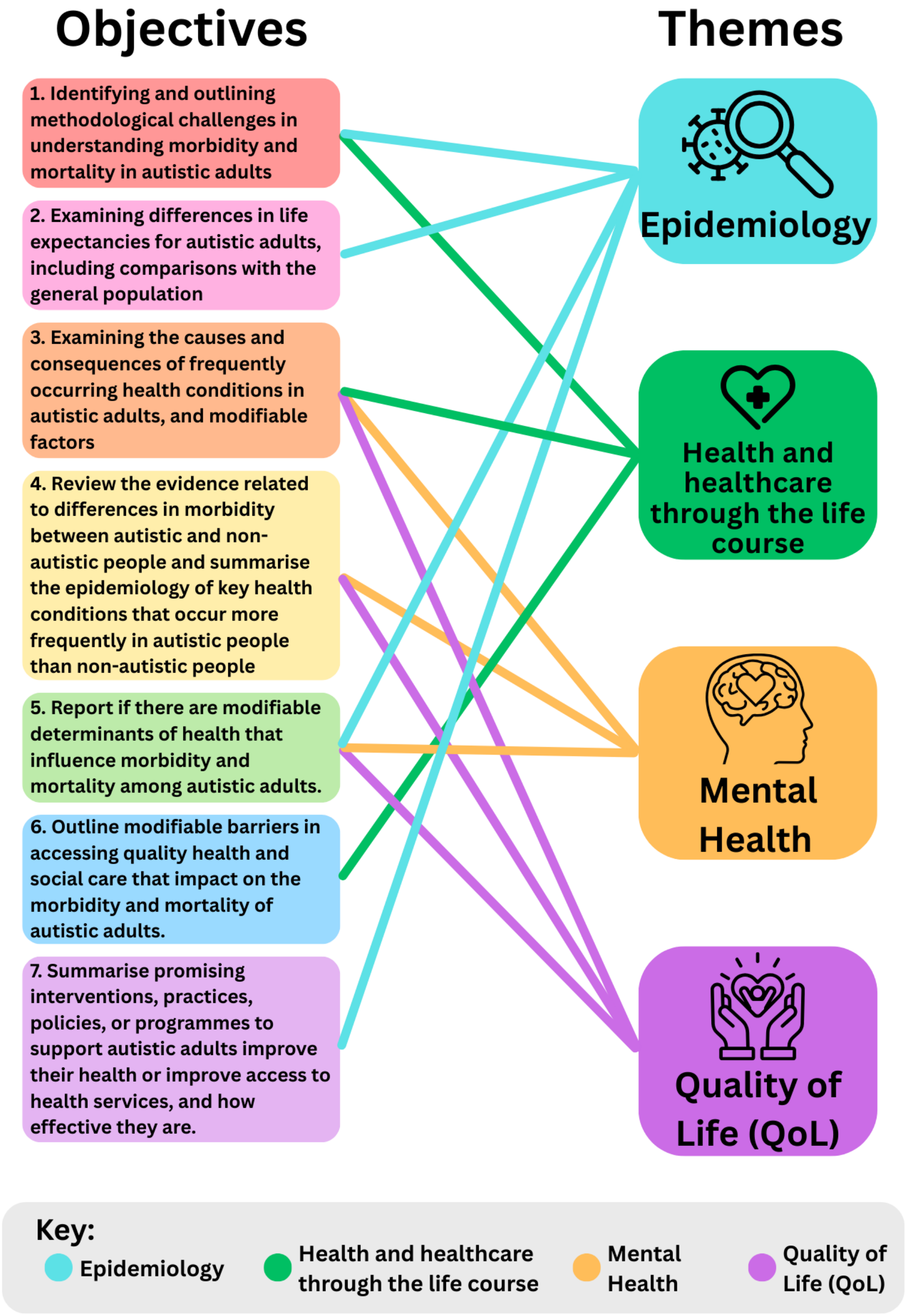


Figure 3. Literature review broad themes and their alignment to study objectives

1. Epidemiology

A total of 22 studies (19%) were included in the epidemiology theme, covering prevalence, incidence, mortality, years lived with disability (YLDs), disability-adjusted life years (DALYs), life expectancy, and morbidity. Each of these individual measures provides a better understanding of how autistic people age despite inherent methodological issues with studying life expectancy in this population. However, estimates of prevalence and incidence are likely biased by the under-representation of older cohorts. Therefore, reported levels are likely lower than would be the case if a truly representative sample of all autistic people were used, and should be treated with caution.

1.1 Prevalence

An estimated 61.8 million individuals (788.3 per 100,000) were diagnosed with autism globally in 2021 (18). Li et al. (33) examined the prevalence of autism, between 1990 and 2019, where 28.3 million cases of autism in 2019 (369.4 per 100,000) were identified compared to 20.3 million in 1990 (372.8 per 100,000). In Ireland, the prevalence was 607.3 per 100,000. Li et al. (33) also reported declines in prevalence with increased age, likely due to underdiagnosis. Solmi et al. (34) reported similar findings, identifying over 28 million autistic individuals in 2019, with steady decreases in autism prevalence as age increased.

1.2 Incidence

Building on these prevalence estimates that highlight the age-related patterns of autism, incidence trends also highlight how diagnosis rates have developed over time and across different age groups. A retrospective cohort study (37) investigated time trends and associated factors of incidence rates of autism diagnoses across the lifespan from 1995 to 2010, using data from the Danish Psychiatric Central Research Registry. Results showed that the autism incidence rates per 100,000 per year rose from 9.0 to 38.6. Overall, incidence rates were lower for the older age groups (21–39 and 40–65 years) than for those found in children, adolescents and young adults.

1.3 Mortality and cause of death

Multiple cohort studies and systematic reviews indicate a consistent pattern of elevated all-cause mortality for autistic people. A South Korean cohort study (38) investigated socio-demographic characteristics and compared mortality and life expectancy among people with disabilities to the general population from 2008 to 2017. Age Standardised Mortality Rates (SMRs) for autism were 1,378.3 per 100,000 compared with 412.4 per 100,000 for the general population.

This elevated mortality risk is further evidenced in a systematic review (39) assessing mortality risk among persons with autism or attention deficit hyperactivity disorder (ADHD) and their first-degree relatives, encompassing 642,260 individuals. All-cause mortality (death from any cause) was over two times higher for autistic people. Similarly, Bishop-Fitzpatrick et al. (40) reported that descendants of autistic people had significantly higher rates of many conditions versus controls, including coagulopathy, deficiency anaemia, hypothyroidism, metastatic cancer, neurological disorders, paralysis, and valvular disease.

Evidence from cohort studies across different countries reinforces these findings, where the increased risk of all-cause mortality ranged from 2.1 to 7.9 for autistic adults. For example, an Australian population-based cohort study (41) examined mortality rates among autistic people. When compared with the general population, mortality rates for autistic people were 2.06 times higher. Mouridsen et al. (37) conducted a retrospective cohort study comparing mortality among 341 Danish autistic people followed up from 1960–93, reported that mortality risk among those with autism was nearly twice that of the general population. Similarly, a retrospective, population-based cohort study in Taiwan (42) reported that autistic adults had a 2.9-fold increased risk of all-cause mortality when compared with non-autistic controls, and these elevations were consistent across age groups. Autistic people aged 15–29 years had a 4.1-fold increased risk of all-cause mortality, and those aged >30 years had a 2.6-fold increased risk. In autistic adults aged >30 years, a higher mortality rate was found in most risk factor categories except cancer and suicide, including infection and urogenital categories, in which mortality rates were not increased in the other age groups.

An earlier retrospective cohort study by Shavelle et al. (2001) (43) carried out over 12 years (1983-1997) in the US reported similar patterns. This study reported about twice the overall risk of death compared with the general population. Deaths due to seizures were more than 30-times higher, while deaths due to circulatory issues were twice as high and cancer deaths over 1.5-times higher. More recent evidence from a longitudinal US study (44) of adolescents and adults with autism followed over a 20-year period (1998 – 2018) identified cardiac arrest and cancer as the most common cause of death.

Vos et al. (2017) (35) modelled YLDs for autism across age groups, reporting declines from 431.8 per 100,000 at ages 20–24 to 5.8 at ages 90-94 to 1.2 per 100,000 in those ≥95 years. Whiteford et al. (2015) (36) highlighted the widespread impact of autism, including YLDs and DALYs, from 1990 to 2010, including variation by gender. The age-standardised DALYs per 100,000 of population attributable to autism in 1990 and 2010 were approximately 85 in males and 29 in females. Differences in DALYs for autistic adults saw 10-fold discrepancies in different study results, which ranged from approximately 30 to 383 per 100,000.

1.4 Life expectancy

Bahk et al. (2022) (38) reported that the average life expectancy for autistic people was 67.6 years compared to 82.8 years in the general population. Similar patterns in a 2024 UK matched-cohort study (45) found a reduction in life expectancy of over six years for autistic people, over seven years for autistic men with intellectual disability and almost 15 years for autistic women with intellectual disability. However, estimates of life expectancy are likely biased by under-representation of older cohorts and/or over-representation of autistic people presenting with poorer health and increased support needs. Therefore, reported age of death and estimated life expectancies are likely lower than if a truly representative sample of all autistic people were used, and should be interpreted with caution.

1.5 Morbidity

A cross-sectional retrospective cohort study from the US, by Hand et al (2020) (46) compared the prevalence of physical and mental health conditions in a national sample of autistic older adults (N=4,685) to a matched general population comparison cohort (N=46,850). This study found that autistic older adults had significantly greater odds of nearly all physical health conditions compared to the general population, including an almost 20-times greater likelihood of epilepsy, six-times greater likelihood of Parkinson’s disease and five-times greater likelihood of GI conditions. Health conditions commonly associated with advanced age in the general population (e.g. osteoporosis, cognitive disorders, heart disease, cancer, cerebrovascular disease, osteoarthritis) were also significantly more common among autistic older adults. These findings align with those of Micai et al. (2023) (47), whose systematic review and meta-analysis found a significantly increased prevalence of motor problems (36% vs 68%), GI disorder (12% vs 37%), depressive disorder (14% vs 34%), epilepsy (13% vs 23%), hearing disorder (1% vs 11%), and neurocutaneous disorder (0% vs 3%) in studies comparing autistic adults to autistic children/adolescents. Additionally, A US-Australian cross-sectional study (48) discovered the prevalence of parkinsonism (i.e. Parkinson’s-like motor signs) in middle-aged and older adults with autism was 26.8%. Over 84% multimorbidity, combining immune dysfunction, GI disorders, neurological, and joint diseases was identified in a group of autistic adults which was significantly associated with age (49).

1.6 Methodological issues in measuring outcomes in older adults with autism

Whilst the current literature provides insight into the prevalence, morbidity, mortality and life expectancy of autistic people, several methodological issues exist. Alongside the changing dynamics of autism incidence and prevalence, these constraints have implications for the interpretation of outcomes in older autistic adults and can complicate the understanding of life expectancy in this population. Methodological issues included the broadening of diagnostic criteria and the inclusion of more autistic people with no intellectual disability, increasing diagnostic and service availability, increasing awareness of autism among health professionals, and increasing trends toward diagnosing autism in very young children (50).

Although there is an evident increase in autism incidence rates, it is unclear if these increased rates reflect true changes or if they are due to methodological issues. Given changes in diagnostic parameters and practices over the years, older autistic adults may be under-represented in longitudinal studies, and thus incidence, life-expectancy and mortality rates may not reflect the true picture (6).

Epidemiological summary

In summary, studies included under the epidemiological theme identified increasing prevalence and incidence of autism globally. In 2021, approximately one in every 127 people was on the autism spectrum. This is estimated to be higher in Ireland with an estimated prevalence of between 1-1.5%, equating to approximately 1 in 83 (6). Autistic people tended to have higher rates of all-cause mortality when compared with the general population, including mortality from cancer, seizures and circulatory issues. Studies also reported that autistic people appeared to have higher rates of various other conditions when compared with the general population. Findings highlighted a decrease in life expectancy for people diagnosed with autism compared to the general population, which ranged from 6.1 years to 14 years. However, it is important to consider the methodological constraints inherent with the epidemiological data on autism, including changes and increasing coverage of diagnostic criteria and reporting standards, which may potentially skew true prevalence findings.

2. Health and healthcare through the life course

Fourteen studies included in the review (12%) focused on aspects of health and healthcare for adults with autism, and the impacts these may have on health outcomes, healthy ageing, and life expectancy. This included studies of unmet health needs, the transition to adulthood, ageing, and barriers to healthcare access for autistic adults. Understanding these issues may provide important contextual information on ageing, mortality, and life expectancy.

2.1 Difficulties accessing and engaging with healthcare services

Several studies identified specific health issues prevalent among adults with autism and highlighted some of the critical healthcare issues and implications associated with these. Autistic adults are more likely to have chronic health conditions, exacerbated by poorer access to healthcare, anxiety, sensory sensitivity and what some authors described as ‘meltdowns’ (22). They were 4-7 times more likely to have a ‘meltdown’ in a common healthcare scenario than a non-autistic adult. Bradshaw and colleagues’ (51) review identified many co-occurring health conditions including anxiety, depression, ADHD, epilepsy, eating disorders, and obsessive-compulsive disorders. The review was designed to empower GPs to recognise undiagnosed autistic adults and to understand co-occurring conditions, thus providing more meaningful support. Findings from this review revealed that many GPs may have undiagnosed autistic patients within their practice.

A review to identify gaps in service needs for adults with autism highlighted needs across several health and social care areas, including psychological, medical and sexual health; care and support; instrumental/activities of daily living; communication; and housing (52). Specifically, this review reported that autistic adults receive less support as they age and face recurring unmet needs in transportation and engagement in social and recreational activities. Caregivers report concerns about future living arrangements, financial strain, barriers to meaningful relationships, and inadequate employment and recreational opportunities for adults with autism. Communication barriers, limited provider training and high staff turnover rates further compound these difficulties.

Autistic adults reported barriers to GP access including communication difficulties, difficulty making appointments over the phone and an unsuitable waiting room environment. Accommodations would include the ability to email the doctor beforehand, having an appointment when it is quiet and having a quiet place to wait (53). A separate review examining co-occurring mental health conditions for autistic individuals highlighted issues with a lack of community-implementable interventions, limited workforce capacity, disconnected service systems, and disparities in accessibility and quality of services (54). Similarly, Malik-Soni and colleagues showed barriers to healthcare access for autistic people, including shortage and cost of services, physician awareness, stigma, limited screening and diagnosis, unclear referral pathways, insufficient transition services, suboptimal physician awareness of healthcare needs, shortage of services, limited insurance, communication difficulties with physicians, and limited awareness of healthcare needs of ageing adults (55). Shaw and colleagues identified similar challenges including communication mismatch, lack of belief in oneself, helplessness, fear and healthcare avoidance (56).

Maljaars and colleagues (57) examined healthcare needs, barriers and facilitators, and access to services for autistic adults qualitatively. Identified themes included a lifetime of being misunderstood, falling between the gaps, processing autism diagnosis in later life, impersonal services, concerns about service pressures and scarce resources, lack of continuity of care, empathy and understanding, healthcare access challenges and concerns for the future. Another qualitative study of communication and support needs among autistic adults highlighted the necessity for personalised communication using different methods. It highlighted a need for more tolerance and understanding, emphasising the far-reaching consequences of inappropriate or miscommunication including vulnerability and ultimately a withdrawal from society (58).

2.2 Changing needs through the life course

Several studies examined health needs of adults with autism across the life course, highlighting different and changing support needs evolving from early adulthood to later life. A consensus Delphi study with clinicians on autism and ageing and found that cognitive differences, life events, and co-occurring conditions influence the symptomatology of autism changes during the ageing process. while differences in cognitive ageing may be explained by the fact that the brains of autistic older adults are less able to adapt, because the cognitive reserves are already in use (59). Furthermore, a longitudinal study found that most autism symptoms followed an inverted U-shape curve, with most symptoms improving from adolescence to mid-life and then deteriorating from late mid-life to older age (60) (although variations emerged depending on language level and intellectual ability) (61). However, the absence of an intellectual disability appeared to show worse physical health and repetitive behaviours.

Similarly, Perkins and Berkman (2012) (62) found that the characteristics of autism change across the lifespan, and that comorbidities like epilepsy and mental health issues can reduce quality-of-life. In addition, results showed that over 80% suffered from some form of mental illness and mortality rates were almost six-times higher than those of the general population adults. Song and colleagues (2022) (63) identified that unmet needs of autistic people changed across the lifespan, with young adults (22-30 years) reporting more unmet needs than adolescents and transition-age adults (adolescence moving to full adulthood), but transition-age adults received less services like speech and language, occupational therapy, one-to-one support and social skills training than adolescents.

A systematic review by Wright and colleagues (2013) (64) highlighted predictors of better outcomes for autistic adults included having a higher childhood IQ and early language ability, but many autistic adults experience difficulties in social integration, employment and independent living. While symptom severity appeared to reduce with age, support services for adults are inadequate, and gaps in healthcare, social support and research persist. Conversely, in Waldron and colleagues' study (2021) (65) older autistic adults (50+) described health benefits from participating in physical activity, e.g., improved mobility and better mood, routines, socialisation and engagement with autism organisations or community groups, as key areas for self-care practice and emotional fulfilment.

Health and healthcare through the life course summary

In summary, studies included under the health and healthcare through the life course theme identified a higher risk of chronic health conditions associated with autism, including increased risk of multimorbidity. Mental health difficulties and diagnoses were common with several studies highlighting associations with depression, anxiety, and other conditions. Several studies also highlighted the impact that communication difficulties associated with autism have on the health of autistic adults, including misunderstanding of health needs by clinicians, barriers to healthcare settings, and consequent failure to address health needs. These issues provide a critical context for understanding health outcomes for adults with autism, and how these change over the life course to impact ageing and life expectancy. However, the scope of this literature exhibits considerable variability in study focus, sample sizes, and participant profiles, which limits the overall interpretability and generalisability of findings.

3. Mental health

A total of 33 studies (29%) focused on the mental health of autistic adults. The most emergent topics related to mental health included depression, anxiety, and suicidal thoughts, ideation and behaviour. Hand et al (2020) (46), in a retrospective matched-cohort study showed that most mental health conditions were approximately 25-times more common among autistic older adults, including schizophrenia and psychotic disorders, attention deficit disorder (ADD) and personality disorders, while suicidality or self-inflicted injury was 11-times more common in autistic older adults when compared with age-matched non-autistic people. A cohort study (66) examining the prevalence of co-occurring psychiatric disorders in 129 adults with autism, reported that 73 participants (56.6%) met criteria for a current psychiatric disorder, whilst 89 participants (69.0%) met lifetime criteria for a psychiatric disorder.

High rates of psychotropic medication use have been observed among autistic adults. A longitudinal cohort study found that 55% of autistic adults took at least one neuropsychiatric medication, 27% took antipsychotics, and 35% took antidepressants (66). Similarly, a review which followed a group of autistic people over thirty years found that 55% of participants took neuropsychiatric medication (67). These findings indicate high rates of mental and emotional wellbeing difficulties, as well as cognitive issues. These difficulties may potentially underlie the increased use of psychotropic medications in this group.

3.1 Anxiety

Reported anxiety levels among autistic people ranged from approximately 22% to 65%. Amongst all psychiatric disorders reported in this study, anxiety disorder had the highest current and lifetime prevalence (39.5% and 52.7 %, respectively). Dow et al. 2021 (68) reported high rates of anxiety in adults with autism of around 63%. A cross-sectional study by Lever et al. (2016) (69) reported differing rates of lifetime anxiety disorders according to age, with rates decreasing across the age spectrum from 65.2% in younger adults to 42.2% in older autistic adults. Similarly, findings from the SPARK cohort (70) which included 2,917 autistic adults, reported anxiety disorders in up to 41% of individuals with autism. Relatively comparable rates (38-46%) of anxiety disorders were reported in two other cross-sectional studies (71,72). Underwood et al. (2023) (73) and Karabulut et al. (2015) (74) also reported the occurrence of anxiety disorders, albeit slightly lower than other studies (22% and 9%, respectively).

3.2 Depression

Depression rates for autistic adults ranged from 16-46% in studies. A large-scale systematic review and meta-analysis of 35 studies examining the rates of anxiety and depression in adults with autism reported the current and lifetime prevalence were 27% and 42% for any anxiety disorder, and 23% and 37% for depressive disorder (75), where current prevalence refers to diagnoses present at the time of reporting, while lifetime prevalence refers to whether the individual has ever been diagnosed with the condition. Another meta-analysis (76) of 66 studies assessing the prevalence of depressive disorders in adults with autism reported similar findings, with pooled lifetime and current prevalence rates of 14.4% and 12.3%, respectively.

At an individual study level, a cross-sectional study (68) of 98 autistic adults highlighted that over half of all respondents self-reported suffering from depression. Another cross-sectional study (77) reported that when compared to the general population, young adults aged 18–29 years with autism had a significantly higher prevalence of depression (16.4 % vs. 6.4 %). A UK study (78) exploring psychiatric comorbidity profiles between those who are diagnosed versus those not diagnosed with autism, reported higher rates of depression in the autism group (35% and 28%, respectively). Another comparative study (79) matching adults with autism to adults without autism, showed the autistic group had significantly higher lifetime major depressive disorders. In terms of the severity of depressive symptoms in adults with autism, one UK cross-sectional study highlighted that 37% of adults with autism reported levels of symptoms that reflected moderate depression and 46% reported symptoms indicative of severe (80). Two other cross-sectional studies assessing the co-occurrence of psychiatric disorders in adults with autism found that depression was among the most frequently identified comorbidities reported in almost 30% of those with autism. A longitudinal study (81) also identified that depression symptoms in adults with autism were related to reduced psychological well-being overall.

Only one study reported alternative findings; a retrospective cohort study which found that the relative risk (RR) for depression was significantly lower for individuals with autism compared to those without (RR: 0.20) (82).

3.3 Suicidal behaviour

The prevalence of suicidal behaviour, including suicidal ideation and suicidal attempts in autistic adults is high. A meta-analysis (83) of 52 studies encompassing a total of 88,509 autistic individuals found that pooled prevalence estimates of lifetime suicidal ideation and suicidal attempts were 37.2% and 15.3% respectively. When compared with youth, prevalence estimates of suicidal ideation were significantly higher in adults (48.9% vs. 20.7%). A Finnish cohort (84) reported that autistic adults were at an increased risk of premature mortality with a mean age of early death of 18.1 years. When examining the cause of death, autistic participants had an over 2-fold increased risk of death due to suicide. A recent analysis of data (85) from autistic adults in the UK and Australia reported high levels of suicidal thoughts and behaviour indicative of elevated suicide risk. Among the potential correlates of suicidality in autistic adults, previous trauma has been identified as having a direct effect (86).

3.4 Other conditions

Beyond some of the most frequently reported comorbid psychiatric conditions reported in autistic adults, such as anxiety and depression, those with autism present with various other comorbid conditions, diagnoses, and psychiatric and psychosocial problems. A US cohort (87) identified that the number of conditions diagnosed by a professional was high, with an average of 1.7 (SD = 2.0) medical or developmental, and 3.0 (SD = 2.3) psychiatric conditions reported across a sample of 4,657 adults with autism. A retrospective analysis (67) of 33 autistic adults presenting for care at a tertiary care neuropsychiatric hospital, found that 31 (94%) of participants had at least one type of prominent psychiatric manifestation, with obsessive compulsive disorder (OCD) identified as the most common lifetime psychiatric diagnosis (48.4%), followed by bipolar affective disorder (39.3%). A UK case-control study (88) reported that almost three-quarters of adult autistic males reporting to psychiatric services had psychiatric comorbidity, most commonly schizophrenia. Another systematic review and meta-analysis by Rong et al. (2021) (89) found the prevalence of ADHD in autism in those aged 18+ was 22.4% and lifetime prevalence was 44.4%. Other commonly reported comorbid conditions included mood disorders, reported in 53% of all autistic Swedish adults (90). Another Swedish-based retrospective cohort study (91) reported that 25% of all older autistic adults (55 to 96 years) had inpatient psychiatric care at some point. Adults with autism also appear to exhibit higher levels of distress and event-related stress when compared with their non-autistic counterparts (92).

Mental health summary

Mental health problems are common among autistic adults, especially depression, anxiety, and suicidal thoughts or behaviours. Many studies report that about half of autistic adults experience depression or anxiety at some point in their life, and suicide risk is higher compared to the general population. Autistic adults are also frequently diagnosed with other mental health conditions, such as schizophrenia, OCD, bipolar affective disorder and ADHD. More than half of autistic adults take psychiatric medications, and many are overweight or obese. Autistic adults often live with multiple mental health and medical conditions at the same time. Common co-occurring conditions include OCD, bipolar disorder, and schizophrenia, and many experience ongoing distress or stress. Overall, the evidence highlights that mental health needs among autistic adults are widespread and require better understanding and support.

4. Quality of life

For the purposes of this review, quality-of-life encompassed the broad thematic areas of physical wellbeing, emotional and mental wellbeing, social inclusion and support, adapted from Schalock's model of quality-of-life. Gender differences were also considered in assessing quality-of-life (93). The largest number of studies in this review, 40% (n=46), had a focus on quality-of-life for autistic adults.

Autistic people generally report lower quality-of-life across the life course when compared to non-autistic people. Physical wellbeing in autistic adults appears to be affected, with autistic people reporting increased medical conditions, lower levels of physical activity and frequent occurrence of somatic symptoms including fatigue, sleep difficulties, musculoskeletal pain, nausea and GI issues. Autistic adults also appear to experience higher rates of mental health issues, including stress, worry, and lower emotional wellbeing compared to non-autistic adults, potentially influenced by factors such as social difficulties, employment status and camouflaging. Gender differences also exist with autistic women reporting lower wellbeing and greater challenges in areas such as relationships, security and life achievement, while autistic men without ID partake more in social activities than autistic women and men with ID.

4.1 Physical wellbeing

Across the lifespan, autistic people reported a lower quality-of-life compared to those without autism (94). Autistic people of all ages have reported poorer quality-of-life and outcomes in areas related to well-being, relationships, emotional distress and health in adulthood (95). A recent review underscores these findings, reporting that outcomes in autistic older adults are generally poor, marked by low quality-of-life, increased medical conditions, limited physical activity, low adaptive skills, elevated risk of cognitive decline, high rates of mental health conditions and reduced social or community participation (96). Autistic adults report worse sleep quality compared to non-autistic adults, and this was associated with lower quality-of-life for participants in a study where higher perceived stress further exacerbated the relationship between poorer sleep quality and lower quality-of-life (97).

Compared to German non-autistic people, autistic people reported reduced mental and physical quality-of-life, where an increased number of barriers to healthcare was a significant and negative predictor of both, followed by the number of mental comorbidities (98). A Saudia Arabian study using an adapted version of the World Health Organisation (WHO) quality-of-life short form to assess quality-of-life found that autistic young adults had lower quality-of-life in all areas compared to their non-autistic peers and proposed that early intervention and diagnosis could result in overall quality-of-life improvements (99).

4.2 Emotional wellbeing, mental health, and cognitive decline

Autistic adults experienced negative assumptions regarding their abilities and found they were often the target of adverse attitudes and biases (100). Camouflaging and masking (i.e. trying to actively disguise and compensate for autistic features in social contexts) in autistic adults had negative associations with mental health, including feelings of insufficiency and exhaustion, while it also had positive aspects in that it allowed people to interact socially and build resilience (101). A diagnosis of autism in childhood was predictive of reduced quality-of-life in emerging adulthood, the period of life between adolescence and young adulthood (i.e., late teens to mid to late 20s). This is mediated by internalising problems (subscales of anxiety/depression, withdrawn/depression and somatic complaints) in adolescence (102).

Being employed was associated with better mental quality-of-life while higher educational attainment was a predictor of better physical quality-of-life. A longitudinal cohort study found that when compared to non-autistic adults, physical quality-of-life and living independently were associated with better psychological quality-of-life in autistic adults (103).

According to a UK review, autistic people suffer from higher rates of mood disorders than the general population due to lived experiences of autism, including increased vulnerability for chronic stress, often related to social-communication difficulties, bullying and sensory sensitivities, which contribute to a reduced and increased suicide rates (81). Autistic participants experienced more stressors over the lifespan than their non-autistic counterparts with perceived additional stresses in work, housing, marital/partner relationships, legal/crime, life-threatening situations, possessions, treatment/health, and friend and familial relationships (85). Better outcomes were observed for those autistic adults who had higher childhood IQ and early language ability but while modest improvements in social reciprocity, verbal IQ, repetitive behaviours and communication were seen in adulthood, most adults remain dependent on parents or residential services, with very low rates of competitive employment, marriage, or independent living (104). Psychiatric conditions (especially depression) and epilepsy often worsened prognosis, meaning they were often associated with poorer long-term outcomes and reduced quality of life

One review reported that ADHD and autism are distinct disorders and the co-occurrence of these conditions was coincidental (105). A twin study deemed that ADHD and autism were both linked to lower quality-of-life scores in young autistic adults, while autism was linked to social impairment and reduced risk-taking (106). A cohort follow-up study showed that autistic adults were less satisfied with their quality-of-life than adults with other psychiatric disorders and that autistic adults had greater levels of worry, stress, anxiety and depression compared to non-autistic adults (107,108).

Cognitive ageing in autistic adults aged 24-85 years showed no significant difference compared to non-autistic adults, with rates of decline highest on visual/verbal memory but self-perceived cognitive decline or difficulties in autistic adults was significantly associated with depression (109,110). Older high-functioning autistic adults were found to experience deficits in attention, working memory and fluency equivalent to controls from the general population and no statistically different results were observed in executive functioning declines between older late-diagnosed autistic males and aged-matched peers (111,112). Similarly, a review showed that declines in cognitive skills associated with ageing were similar in ageing autistic adults and the general population, but quality-of-life was less affected by ageing in the autistic group (113). Conversely, Klein and colleagues (2023) (96) deduced that high rates of cognitive decline were present in autistic adults and that autistic women were more prone to cognitive decline than males. A systematic review deduced that the effects of ageing in autism were heterogeneous, with cognitive function showing some declines (e.g. processing speed, memory) with older age while generally co-occurring difficulties (medical, psychiatric) tended to increase with age (114).

4.3 Social inclusion and support

The absence or presence of close persons significantly impacted quality-of-life regarding social relationships in autistic adults, which highlights the importance of addressing improving social networks (115). Subjective social support (i.e. a person's self-perceived sense of social support, including the quality of their close relationships) was found to significantly contribute to all aspects of quality-of-life for middle-aged and older autistic adults. Social interactions contributed to the models for physical and psychological quality-of-life, whereas instrumental support (i.e. social support which encompasses actions such as help with personal care, medical care and transportation) contributed to models for social, environmental and autism-specific quality-of-life (116).

Lower reported self-efficacy and self-esteem in a group of autistic adults, were associated with stigma in the form of exclusion or isolation and the majority also experienced verbal bullying (117). Many of the negative interactions came from educators, peers, and family members and these interactions directly contributed to decreased social satisfaction, diminished self-efficacy, and lowered self-esteem. Qualitative interviews exploring quality-of-life in everyday lives identified the importance of connections to family and peers, social interactions, being understood by professionals, being in control of situations, interests, passions, and future plans as perceived determinants of improved quality-of-life (118). A group of autistic adults independent of cognitive ability rated themselves as having predominately 'fair' social functioning capability, limited dating experience and the majority were unemployed (119). Social integration and adaptive functioning appeared to decline over time, and adaptive skills and language processing declined over time or remained stable depending on individual factors. A late autistic diagnosis gave people an insight into past events, where they understood why they felt different to their peers and used camouflaging to fit in. This facilitated a greater level of self-acceptance and understanding, but most participants perceived themselves to be isolated and experienced a subjective sense of loneliness (90). Young adults (aged 19-25) also purported to having high levels of loneliness, with highest levels observed in those who were 25 years of age (91).

4.4 Gender differences

Autistic women showed significantly lower wellbeing rates than matched controls in the domains of life achievement, future security, safety and relationships, where an autism diagnosis was a significant contributor to the results. Menopausal awareness was often poor, and inadequate support was apparent in the lived experiences of many autistic women, where additional menopausal difficulties specifically related to autism included major deterioration in everyday function, communicative ability, extant relationships, emotion regulation, and mental health, specifically increased suicide risk (85).

An investigation into gender differences in social interactions for autistic people with and without an intellectual disability found that men with autism and no intellectual disability participated in a higher ratio of activities than both autistic women and men with an intellectual disability (63).

Quality of life summary

Studies included under the quality-of-life theme identified difficulties related to physical wellbeing, mental and emotional wellbeing, social inclusion and support, and gender-related differences. Autistic people tended to report lower quality-of-life across the lifespan when compared to non-autistic people. Physical wellbeing difficulties in autistic adults appears to be compounded by increased medical conditions, lower levels of physical activity and increased levels of somatic symptoms. Autistic adults also reported high rates of mental and emotional wellbeing issues. Gender differences were observed, with autistic women reporting lower wellbeing in general, while autistic men were more likely to partake in social activities.

It is important to consider the methodological limitations inherent in quality-of-life-related data, particularly when observing autistic people. Many studies reporting on health-related quality-of-life in autistic adults used cross-sectional designs. Thus, findings should be interpreted as associative rather than causative. As cross-sectional data captures information from only one point in time, the ability to assess quality-of-life in autistic adults longitudinally or at multiple time points is limited. Additionally, generic health-related quality-of-life measurement tools are often not tailored for autistic people and fail to account for differences in communication preferences or styles, whilst also relying on self-report data, which may introduce recall bias.

Discussion

This literature review on autism, ageing and life expectancy yielded results that present a complex arena for autistic people to navigate. Through the four primary themes of epidemiology, health and healthcare through the life course, mental health and quality-of-life, the results highlight the importance of appropriate communication, social interaction and more understanding of autism to improve quality-of-life and health outcomes in adults with autism. Indeed, autism is not a one-size-fits-all categorisation. Autism has a wide spectrum of capabilities, ranging from high functioning people with IQs above 140 to being non-verbal with more limited capabilities (120). Thus, a more individualised approach to care and services is required.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was published in 2006 'To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity' (121). This charter certifies that all people with disabilities are viewed as equal members of society, and individual countries are tasked with executing and protecting these rights. The Department of Children, Disability and Equality (DCDE) Priority Areas of Research Interest 2025, which address five primary thematic areas, will be used to direct and inform the Governmental disability strategy and will guide this review's interpretation (122). Results from this review focus primarily on the areas falling under overarching themes, disability and equality for adults with autism, with some reference to childhood experiences where applicable.

Epidemiology

It is essential to understand the proportion of autistic people in society to be able to accommodate additional needs, ensure sufficient services are provided and inform public policy (123). The prevalence and incidence of autism have increased as awareness has increased, and diagnostic procedures have evolved. However, inconsistencies in numbers prevail. Incidence rates for Danish autism diagnoses across the lifespan increased from nine to 38.6 over a fifteen-year timeframe (1995 to 2010), with men continuing to have significantly more incidences of autism than women (50). In 2021, globally one in 127 people had autism with almost twice as many males than females while a 1990-2019 epidemiological study showed that 1 in 271 people had autism (124). Global epidemiological evidence estimates autism prevalence rates of over 28 million in 2019 alone. The age-standardised DALYs attributable to autism was approximately 85 for males and less than 30 for females (34,36). The lower DALY reported for autistic women is due to later diagnosis in females (125,126). A 2017 study showed that years lived with disability (YLD) attributable to autism decreased as people aged from 431.8 per 100,000 of the population at aged 20-24 years to 5.8 at 90-94 years (35). This reduction in YLD reflects the smaller number of autistic individuals represented in older age groups rather than a reduction in autism among older adults. Furthermore, autism is a lifelong condition which may not be identified until later in life. This means that measures such as YLD and DALYS are not the most accurate way to describe morbidity in this population because an autism diagnosis does not necessarily equate to a disability and an earlier autism diagnosis will mean higher YLD and DALY numbers.

The inconsistencies in the measurement of the prevalence of autism and DALYs may be due to differences in assessment techniques or measurement errors. Moreover, these discrepancies in numbers highlight a lack of understanding of autism prevalence and the needs of the autism population, making it difficult to accurately plan for service and healthcare requirements such as appropriate mental health services (55,127).

Recent studies showed the average life expectancy of autistic people was approximately 67 years (37,38,41,128). A 2024 UK-based study found that the life expectancy of autistic women and men was approximately five years less than the general population, at almost 77 and 75 years, respectively for those without an intellectual disability (45). Findings from cohort studies reported mean age of death for autistic people ranging from 67 to 77 years, and studies have estimated life expectancy in a similar range. Critically, however, age of death reported should not be interpreted as life expectancy for important methodological reasons, including study samples skewed towards younger cohorts due to under-diagnosis in adulthood and later life, and difficulties comparing samples across countries due to diagnosis and other differences. As such, average age of death is not an appropriate summation of life expectancy for this population.

Similarly, estimates of life expectancy are likely biased by under-representation of older cohorts and/or over-representation of autistic people presenting with poorer health and increased support needs. Therefore, reported age of death and estimated life expectancy are likely lower than would be the case if a truly representative sample of all autistic people were used, and should be treated with caution. For example, a recent UK study published in the Lancet (45) reported using an improved approach to estimating life expectancy (the life table method used by the UK Office for National Statistics) but still cautioned about reported estimates. Findings, they warned, “are likely to be subject to exposure misclassification biases: very few autistic adults and older adults have been diagnosed, meaning that only a fraction of the total autistic population could be studied. Those who have been diagnosed may well be those with greater support needs and more co-occurring health conditions than autistic people on average”. Given these challenges, it may be concluded that some autistic people may experience a shorter lifespan, and this in itself “represents an inequity that could be reduced by alterations in health and social policy that improve support for and inclusion of autistic people”.

Overall, studies observed an almost threefold increased risk of all-cause mortality (42) and over two-times the standardised mortality rates for autistic people compared with the general population (43). However, this perceived reduced life-expectancy in autistic adults may be due to methodological discrepancies or increased comorbidities.

Even with the inherent methodological challenges, these epidemiological findings on the prevalence and incidence of autism, as well as the impacts on quality-of-life as indicated by decreased mortality rates, increased DALYs, and YLDs, highlight the significant impact presented by autism globally. They also evidence how the broader determinants of health reported, such as quality-of-life, mental health and comorbid diagnoses, collectively influence the life-course trajectory of those living with autism and the importance of appropriate interventions and raising awareness of these interconnected outcomes.

Methodological challenges in understanding the morbidity and mortality in autistic adults

This literature review has demonstrated a lack of overall public awareness of autism, and a lack of accommodations in healthcare settings and research environments (22,51,54,55,118). Healthcare providers, including GPs and researchers need to be educated on the specific needs of people with autism, so they are not excluded from services and research. More autism-focused organisations need to be made available to the autistic community, where a personalised approach assists people with autism in their everyday lives. Underdiagnosis of autism in older adults has also been identified (51), potentially leading to autism not being accurately reflected in data on mortality and morbidity. As noted, estimates of life expectancy may be similarly unreliable given under-representation of older adults and/or over-representation of individuals with poorer health and higher support needs who are diagnosed at a younger age. Additional challenges may exist in the self-reporting of physical and mental health issues by some people with autism; communication, social skills, or sensory issues may result in inaccurate or misinterpreted answers (53,56).

Health and healthcare through the life course

In line with DCDE's focus on emerging needs in autism services and support, research on health and healthcare access across the life course needs to be more fully understood. Unmet health needs were a recurring theme with some studies focusing on helping healthcare practitioners optimise the experience for autistic adults by understanding their co-occurring health conditions e.g. anxiety, depression and ADHD. Other studies found that quality issues, disconnected and inaccessible services, as well as autistic people being misunderstood by professionals, inhibited service access (51,54,118). To provide more meaningful support, GPs and healthcare providers need a better understanding of autism and the specific needs of autistic people. Stigma, sensory sensitivity, lack of understanding of needs, communication issues and shortage of services compounded already difficult access issues for autistic people, which potentially led to a deterioration in existing health conditions or delayed or missed diagnoses (22,55). To facilitate full, appropriate access to healthcare for autistic people, appropriate individualised communication to include empathy and understanding and some accommodations e.g. quiet place to wait, are required (53,57,58). Increased barriers to healthcare access were found to be predictors of reduced mental and physical quality-of-life for autistic people, who were found to have 84% multimorbidity (49,98).

Inequalities in service provision were reported in the transition from adolescence to adulthood for autistic people, with many reporting receiving less and often inadequate services, which persisted throughout adulthood (63,64). It is proposed that earlier intervention and earlier detection of autism would result in increased quality-of-life for autistic adults (55).

Mental health

This review showed that mental health issues, especially anxiety and depression, as well as psychiatric disorders e.g. bipolar and mood disorders, are very common in adults with autism compared to those without autism and that they contributed to reduced overall well-being (57,64,65,68,69). Those diagnosed with autism at later ages (≥21 years) were shown to have a higher number of lifetime psychiatric comorbidities compared to those diagnosed earlier in life (<21 years) (87). When considering the future implications for care from these findings and their potential to inform service provision, it is important to gain a better understanding of why increased prevalence rates of many of these comorbid mental health conditions and diagnoses are seen. Older age is a key determinant of psychiatric comorbidity in those with autism, with depressive symptoms shown to be positively associated with age (72). Furthermore, poorer physical health and somatic symptoms also appear to be contributing factors to poorer mental health and comorbid conditions (129), including anxiety and depression (81,130).

Of deep concern is the fact that people with autism, especially adults, have an over two-times risk of dying by suicide (83,84,131). Previous trauma has been linked with suicidality (86). These findings indicate an urgent need for the provision of mental health screening services for those with autism, with a specific focus on transition periods such as adolescence to adulthood. The implementation of potential interventions and programmes involving early behavioural health screening should be considered at these crucial transition periods as well as in older adulthood, and as soon as mental health diagnoses or symptoms are detected. Such proactive preventative approaches may enable timely detection and potentially reduce long-term psychological burden and associated complications.

Quality of life

According to Verdugo and colleagues (2012) (132) a good quality-of-life, as determined by a person's perceived existence shaped by their personal experiences, is intricately linked to the UNCRPD. Restricted social integration of autistic adults heightens mental stress and can lead to exclusion, bullying, social impairment and loneliness, while inadequate social support was associated with lower self-esteem and quality-of-life (81,106,115–117,133,134). Research on the employment of autistic people, which falls under workforce dynamics in DCDE's Overarching Themes, portrays a challenging environment. Although employment was associated with better quality-of-life, many autistic adults experienced difficulty, low rates in employment and restricted employment opportunities (52,62,64,103,104,113,119). Similarly, an employed PPI participant reported an increased quality-of-life, although another PPI contributor reported a decreased quality-of-life due to bullying at work. A project to enhance employment readiness for young adults with autism as they transition from education has been established by Autistica in the UK, with a target of improving employment rates (135).

A limited number of studies investigated sex differences in autistic people. However, those that did showed that autistic women had significantly lower wellbeing rates, were more prone to cognitive decline, had an increased suicide risk and heightened issues due to the menopause compared to peers in the general population (63,85). The diagnostic challenges for women with autism combined with increased camouflaging warrant further investigation.

These findings suggest the need for enhanced social support networks to mitigate the effects of restricted social integration. Peer support initiatives providing autistic adults with the opportunity to connect and share lived experiences can foster belonging, mutual understanding and empowerment which can ultimately improve quality-of-life (136). Integrating peer-led support initiatives within various settings including the community, educational and workplace settings align with the aims set out by the UNCPRD to ensure equality and inclusivity for all persons with disabilities. Moreover, developing gender-specific or tailored interventions for autistic women alongside peer-based initiatives may increase awareness and address disparities related to gender-based issues such as menopause, cognitive decline and suicide. Considering the complex communication and sensory needs of some individuals with autism, it is important that the provision of such initiatives is user-friendly and tailored accordingly. To achieve this, healthcare education requires an increased focus on autism such as the HSE developed autism training (137).

Other

Limited studies investigated differences between autistic people with and without intellectual disability, however one study determined that autistic children and adults with co-occurring intellectual disability had lower quality-of-life scores in the areas of interpersonal relationships, social inclusion and physical wellbeing, compared to neurotypical people (138). In addition, the co-occurrence of autism and intellectual disability showed a significantly increased risk of having a mental health condition or physical disability while the absence of an intellectual disability seemed to show worse repetitive behaviours and physical health in autistic adults (60,139). A Chinese lifetime costing study showed that having a co-occurrence of intellectual disability with autism would cost almost two-times more than autism alone for health and lost working time, with annual nationwide costs associated with autism estimated at over $40billion (140). Similarly, a US study (141) estimated that one in three autistic children has a co-occurring intellectual disability, which had increased associations with impairments and resultant higher support requirements and costs. In general, autistic adults had a higher prevalence of most mental and physical health conditions than the general population, except for Parkinson’s disease (46–48). Although ADHD and autism are recognised as distinct conditions, one study reported up to 44% lifetime prevalence of ADHD in those aged 18+ with autism (89). The associated increased costs of autism with and without co-occurring conditions warrant focus on a more thorough understanding of the condition and considerations of impacts on service provision and care.

Limitations

While this scoping literature review is broad and exploratory in nature, individual study quality is not assessed, and all relevant literature may not be included due to time constraints.

References

1. Definition of mortality - NCI Dictionary of Cancer Terms - NCI [nciAppModulePage] [Internet]. 2011 [cited 2025 Dec 4]. Located at: nciglobal,ncienterprise. Available from: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/mortality

2. Definition of morbidity - NCI Dictionary of Cancer Terms - NCI [nciAppModulePage] [Internet]. 2011 [cited 2025 Dec 4]. Located at: nciglobal,ncienterprise. Available from: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/morbidity

3. Johnson JC, Thaul S, Page WF, Crawford H, Test I of M (US) C on the CN. Standardized Mortality Ratios. In: Mortality of Veteran Participants in the Crossroads Nuclear Test [Internet]. National Academies Press (US); 1996 [cited 2025 Oct 24]. Available from: https://www.ncbi.nlm.nih.gov/books/NBK233196/

4. Music Milanović S, Ivičević Uhernik A, Mihel S, Pristaš I, Stanić A, Stevanović R. Life Expectancy and Mortality Differences between Populations on Croatian Islands and the Mainland. Croat Med J. 2006 Aug;47(4):611–8. PubMed PMID: 16909459; PubMed Central PMCID: PMC2080454.

5. What is Prevalence? - National Institute of Mental Health (NIMH) [Internet]. [cited 2025 Dec 4]. Available from: https://www.nimh.nih.gov/health/statistics/what-is-prevalence

6. Estimating Autism Prevaelce in Ireland: Challenges and Opportunites. National Disability Authority. September 2025. Report.

7. Vos T, Flaxman AD, Naghavi M, Lozano R, Michaud C, Ezzati M, et al. Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. The Lancet. 2012 Dec 15;380(9859):2163–96. doi:10.1016/S0140-6736(12)61729-2 PubMed PMID: 23245607.

8. Leading causes of DALYs [Internet]. [cited 2025 Dec 4]. Available from: https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates/global-health-estimates-leading-causes-of-dalys

9. Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, Hand BN. Avoiding Ableist Language: Suggestions for Autism Researchers. Autism Adulthood. 2021 Mar 1;3(1):18–29. doi:10.1089/aut.2020.0014 PubMed PMID: 36601265; PubMed Central PMCID: PMC8992888.

10. Robertson ZS, Stockwell KM, Lampi AJ, Jaswal VK. Autism Terminology Preferences Among Autistic and Non-Autistic Adults in North America. Autism in Adulthood. 2025 Feb 3. doi:10.1089/aut.2023.0175

11. Neurodiversity Movement Identification and Perceived Appropriateness of Terms Used to Describe Autism | Autism in Adulthood [Internet]. [cited 2026 Feb 19]. Available from: https://www.liebertpub.com/doi/abs/10.1089/aut.2024.0297

12. ‘Autistic person’ or ‘person with autism’? Person-first language preference in Dutch adults with autism and parents - Riley Buijsman, Sander Begeer, Anke M Scheeren, 2023 [Internet]. [cited 2026 Feb 19]. Available from: https://journals.sagepub.com/doi/10.1177/13623613221117914

13. American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. American psychiatric association; 2013. [Internet]. [cited 2025 Jul 2]. Available from: https://scholar.google.com/scholar_lookup?publication_year=2013&journal=Diagnostic+and+Statistical+Manual+of+Mental+Disorders:+DSM-5&

14. Lord C, Charman T, Havdahl A, Carbone P, Anagnostou E, Boyd B, et al. The Lancet Commission on the future of care and clinical research in autism. The Lancet. 2022 Jan 15;399(10321):271–334. doi:10.1016/S0140-6736(21)01541-5/ASSET/6659FA11-6E81-48F1-A71B-E62DBADBDF81/MAIN.ASSETS/GR6.JPG PubMed PMID: 34883054.

15. White SW, Maddox BB, Mazefsky CA. The Oxford handbook of autism and co-occurring psychiatric conditions [Internet]. Oxford University Press; 2020 [cited 2025 Jul 11]. Available from: https://books.google.com/books?hl=en&lr=&id=g5TgDwAAQBAJ&oi=fnd&pg=PP1&dq=The+Oxford+Handbook+of+Autism+and+Co-Occurring+Psychiatric+Conditions&ots=ZSQfcm7Fz5&sig=IAOviOnPQIlDVyb78miIZuHShgs

16. As I Am | Ireland’s Autism Charity | What is Autism? [Internet]. [cited 2025 Dec 4]. Available from: https://asiam.ie/advice-guidance/what-is-autism

17. ICD-11 for Mortality and Morbidity Statistics [Internet]. [cited 2025 Oct 31]. Available from: https://icd.who.int/browse/2025-01/mms/en#437815624

18. Santomauro DF, Erskine HE, Herrera AMM, Miller PA, Shadid J, Hagins H, et al. The global epidemiology and health burden of the autism spectrum: findings from the Global Burden of Disease Study 2021. The Lancet Psychiatry. 2025 Feb 1;12(2):111–21. doi:10.1016/S2215-0366(24)00363-8 PubMed PMID: 39709974.

19. Data Irish Health Survey 2024 - Main Results - Central Statistics Office [Internet]. CSO; 2025 [cited 2025 Oct 31]. Available from: https://www.cso.ie/en/releasesandpublications/ep/p-ihsmr/irishhealthsurvey2024-mainresults/data/

20. Forde J, Bonilla PM, Mannion A, Coyne R, Haverty R, Leader G. Health Status of Adults with Autism Spectrum Disorder. Rev J Autism Dev Disord. 2022 Sep 1;9(3):427–37. doi:10.1007/s40489-021-00267-6

21. Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, et al. The health status of adults on the autism spectrum. Autism. 2015 Oct;19(7):814–23. doi:10.1177/1362361315577517 PubMed PMID: 25911091.

22. Weir E, Allison C, Baron-Cohen S. Autistic adults have poorer quality healthcare and worse health based on self-report data. Molecular Autism. 2022 May 26;13(1):23. doi:10.1186/s13229-022-00501-w

23. Rydzewska E, Hughes-McCormack LA, Gillberg C, Henderson A, MacIntyre C, Rintoul J, et al. Prevalence of long-term health conditions in adults with autism: observational study of a whole country population. BMJ Open. 2018 Sep 1;8(8):e023945. doi:10.1136/bmjopen-2018-023945 PubMed PMID: 30173164; PubMed Central PMCID: PMC6120653.

24. Rydzewska E, Hughes-McCormack LA, Gillberg C, Henderson A, MacIntyre C, Rintoul J, et al. General health of adults with autism spectrum disorders – A whole country population cross-sectional study. Research in Autism Spectrum Disorders. 2019 Apr 1;60:59–66. doi:10.1016/j.rasd.2019.01.004

25. Khanna R, Jariwala-Parikh K, West-Strum D, Mahabaleshwarkar R. Health-related quality of life and its determinants among adults with autism. Research in Autism Spectrum Disorders. 2014 Mar 1;8(3):157–67. doi:10.1016/j.rasd.2013.11.003

26. Autism Innovation Strategy [Internet]. [cited 2025 Jul 2]. Available from: https://www.gov.ie/en/department-of-children-disability-and-equality/publications/autism-innovation-strategy/

27. Mak S, Thomas A. Steps for Conducting a Scoping Review. J Grad Med Educ. 2022 Oct;14(5):565–7. doi:10.4300/JGME-D-22-00621.1 PubMed PMID: 36274762; PubMed Central PMCID: PMC9580325.

28. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. International Journal of Social Research Methodology. 2005 Feb 1;8(1):19–32. doi:10.1080/1364557032000119616

29. Peters MDJ, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. JBI Evidence Implementation. 2015 Sep;13(3):141. doi:10.1097/XEB.0000000000000050

30. Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia. Available at www.covidence.org. (2025).

31. A scoping review on the conduct and reporting of scoping reviews | BMC Medical Research Methodology | Full Text [Internet]. [cited 2025 Oct 6]. Available from: https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/s12874-016-0116-4

32. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med. 2018 Oct 2;169(7):467–73. doi:10.7326/M18-0850 PubMed PMID: 30178033.

33. Li YA, Chen ZJ, Li XD, Gu MH, Xia N, Gong C, et al. Epidemiology of autism spectrum disorders: Global burden of disease 2019 and bibliometric analysis of risk factors. Front

Pediatr. 2022;10:972809. doi:10.3389/fped.2022.972809 PubMed PMID: 36545666; PubMed Central PMCID: PMC9760802.

34. Solmi M, Song M, Yon DK, Lee SW, Fombonne E, Kim MS, et al. Incidence, prevalence, and global burden of autism spectrum disorder from 1990 to 2019 across 204 countries. Mol Psychiatry. 2022 Oct;27(10):4172–80. doi:10.1038/s41380-022-01630-7 PubMed PMID: 35768640.

35. Vos T, Abajobir AA, Abate KH, Abbafati C, Abbas KM, Abd-Allah F, et al. Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. The Lancet. 2017 Sep 16;390(10100):1211–59. doi:10.1016/S0140-6736(17)32154-2 PubMed PMID: 28919117.

36. Whiteford HA, Ferrari AJ, Degenhardt L, Feigin V, Vos T. The Global Burden of Mental, Neurological and Substance Use Disorders: An Analysis from the Global Burden of Disease Study 2010. PLoS One. 2015 Feb 6;10(2):e0116820. doi:10.1371/journal.pone.0116820 PubMed PMID: 25658103; PubMed Central PMCID: PMC4320057.

37. Mouridsen SE, Brønnum-Hansen H, Rich B, Isager T. Mortality and causes of death in autism spectrum disorders: an update. Autism. 2008 Jul;12(4):403–14. doi:10.1177/1362361308091653 PubMed PMID: 18579647.

38. Bahk J, Kang HY, Khang YH. Disability type-specific mortality patterns and life expectancy among disabled people in South Korea using 10-year combined data between 2008 and 2017. Prev Med Rep. 2022 Oct;29:101958. doi:10.1016/j.pmedr.2022.101958 PubMed PMID: 36161125; PubMed Central PMCID: PMC9501987.

39. Barkley RA, Dawson G. Higher Risk of Mortality for Individuals Diagnosed With Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder Demands a Public Health Prevention Strategy. JAMA Pediatr. 2022 Apr 1;176(4):e216398. doi:10.1001/jamapediatrics.2021.6398 PubMed PMID: 35157011; PubMed Central PMCID: PMC10072169.

40. Bishop-Fitzpatrick L, Rubenstein E. The Physical and Mental Health of Middle Aged and Older Adults on the Autism Spectrum and the Impact of Intellectual Disability. Res Autism Spectr Disord. 2019 Jul;63:34–41. doi:10.1016/j.rasd.2019.01.001 PubMed PMID: 31768189; PubMed Central PMCID: PMC6876625.

41. Hwang YIJ, Srasuebkul P, Foley KR, Arnold S, Trollor JN. Mortality and cause of death of Australians on the autism spectrum. Autism Res. 2019 May;12(5):806–15. doi:10.1002/aur.2086 PubMed PMID: 30802364.

42. Wu CS, Tsai HJ, Chien YL, Gau SSF. All-Cause Mortality and Specific Causes of Death in Autism: A Nationwide Analysis. Autism in Adulthood. 2025 Feb;7(1):81–92. doi:10.1089/aut.2023.0103

43. Shavelle RM, Strauss DJ, Pickett J. Causes of death in autism. J Autism Dev Disord. 2001 Dec;31(6):569–76. doi:10.1023/a:1013247011483 PubMed PMID: 11814268.

44. Smith DaWalt L, Hong J, Greenberg JS, Mailick MR. Mortality in Individuals with Autism Spectrum Disorder: Predictors over a 20-Year Period. Autism. 2019 Oct;23(7):1732–9. doi:10.1177/1362361319827412 PubMed PMID: 30818975; PubMed Central PMCID: PMC6713622.

45. O'Nions E, Lewer D, Petersen I, Brown J, Buckman JEJ, Charlton R, et al. Estimating life expectancy and years of life lost for autistic people in the UK: a matched cohort study. The Lancet Regional Health - Europe. 2024 Jan 1;36:100776. doi:10.1016/j.lanepe.2023.100776

46. Hand BN, Angell AM, Harris L, Carpenter LA. Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults. Autism. 2020 Apr;24(3):755–64. doi:10.1177/1362361319890793 PubMed PMID: 31773968; PubMed Central PMCID: PMC7433648.

47. Micai M, Fatta LM, Gila L, Caruso A, Salvitti T, Fulceri F, et al. Prevalence of co-occurring conditions in children and adults with autism spectrum disorder: A systematic review and meta-analysis. Neurosci Biobehav Rev. 2023 Dec;155:105436. doi:10.1016/j.neubiorev.2023.105436 PubMed PMID: 37913872.

48. Starkstein S, Gellar S, Parlier M, Payne L, Piven J. High rates of parkinsonism in adults with autism. J Neurodev Disord. 2015;7(1):29. doi:10.1186/s11689-015-9125-6 PubMed PMID: 26322138; PubMed Central PMCID: PMC4553212.

49. Miot S, Chancel R, Peries M, Crepiat S, Couderc S, Pernon E, et al. Multimorbidity patterns and subgroups among autistic adults with intellectual disability: Results from the EFAAR study. Autism. 2023 Apr;27(3):762–77. doi:10.1177/13623613221121623 PubMed PMID: 36056616.

50. Jensen CM, Steinhausen HC, Lauritsen MB. Time trends over 16 years in incidence-rates of autism spectrum disorders across the lifespan based on nationwide Danish register data. J Autism Dev Disord. 2014 Aug;44(8):1808–18. doi:10.1007/s10803-014-2053-6 PubMed PMID: 24554161.

51. Bradshaw P, Pickett C, van Driel ML, Brooker K, Urbanowicz A. Recognising, supporting and understanding Autistic adults in general practice settings. Aust J Gen Pract. 2021 Mar;50(3):126–30. doi:10.31128/AJGP-11-20-5722 PubMed PMID: 33634275.

52. Burke SL, Wagner E, Marolda H, Quintana JE, Maddux M. Gap analysis of service needs for adults with neurodevelopmental disorders. J Intellect Disabil. 2019 Mar;23(1):97–116. doi:10.1177/1744629517726209 PubMed PMID: 28847208.

53. Doherty M, Neilson S, O'Sullivan J, Carravallah L, Johnson M, Cullen W, et al. Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study [Internet]. 2022 Feb 1. doi:10.1136/bmjopen-2021-056904

54. Maddox BB, Dickson KS, Stadnick NA, Mandell DS, Brookman-Frazee L. Mental Health Services for Autistic Individuals Across the Lifespan: Recent Advances and Current Gaps. Curr Psychiatry Rep. 2021 Aug 17;23(10):66. doi:10.1007/s11920-021-01278-0 PubMed PMID: 34402984; PubMed Central PMCID: PMC8961310.

55. Malik-Soni N, Shaker A, Luck H, Mullin AE, Wiley RE, Lewis MES, et al. Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. Pediatr Res. 2022;91(5):1028–35. doi:10.1038/s41390-021-01465-y PubMed PMID: 33767375; PubMed Central PMCID: PMC7993081.

56. Shaw SC, Carravallah L, Johnson M, O'Sullivan J, Chown N, Neilson S, et al. Barriers to healthcare and a 'triple empathy problem' may lead to adverse outcomes for autistic adults: A qualitative study. Autism. 2024 Jul;28(7):1746–57. doi:10.1177/13623613231205629 PubMed PMID: 37846479; PubMed Central PMCID: PMC11191657.

57. Maljaars J, Gijbels E, Evers K, Spain D, Rumball F, Happé F, et al. Impact of the COVID-19 Pandemic on Daily Life: Diverse Experiences for Autistic Adults. J Autism Dev Disord. 2023;53(1):319–31. doi:10.1007/s10803-022-05437-x PubMed PMID: 35076831; PubMed Central PMCID: PMC8788399.

58. Cummins C, Pellicano E, Crane L. Autistic adults' views of their communication skills and needs. International Journal of Language & Communication Disorders. 2020;55(5):678–89. doi:10.1111/1460-6984.12552

59. Heijnen-Kohl SMJ, Hitzert B, Schmidt R, Geurts HM, van Alphen SPJ. Features and Needs of Autistic Older Adults: A Delphi Study of Clinical Experiences. Clin Gerontol. 2025;48(1):110–20. doi:10.1080/07317115.2022.2060157 PubMed PMID: 35426768.

60. Hong J, DaWalt LS, Taylor JL, Haider A, Mailick M. Autism through midlife: trajectories of symptoms, behavioral functioning, and health. J Neurodev Disord. 2023 Nov 3;15(1):36. doi:10.1186/s11689-023-09505-w PubMed PMID: 37919643; PubMed Central PMCID: PMC10623813.

61. Elias R, Lord C. Diagnostic stability in individuals with autism spectrum disorder: insights from a longitudinal follow-up study. Journal of Child Psychology and Psychiatry. 2022;63(9):973–83. doi:10.1111/jcpp.13551

62. Perkins EA, Berkman KA. Into the unknown: aging with autism spectrum disorders. Am J Intellect Dev Disabil. 2012 Nov;117(6):478–96. doi:10.1352/1944-7558-117.6.478 PubMed PMID: 23167487.

63. Song W, Salzer MS, Nonnemacher SL, Shea L. Lifespan service receipt and unmet needs among individuals on the autism spectrum. Adm Policy Ment Health. 2022 Jul 1;49(4):694–705. doi:10.1007/s10488-022-01192-4

64. Wright SD, Brooks DE, Grandin T. The challenge and promise of autism spectrum disorders in adulthood and aging: A systematic review of the literature (1990-2013). Autism Insights. 2013;5:21.

65. Waldron DA, Coyle C, Kramer J. Aging on the Autism Spectrum: Self-care Practices and Reported Impact on Well-Being. J Autism Dev Disord. 2022 Aug;52(8):3512–22. doi:10.1007/s10803-021-05229-9 PubMed PMID: 34379240.

66. Buck TR, Viskochil J, Farley M, Coon H, McMahon WM, Morgan J, et al. Psychiatric comorbidity and medication use in adults with autism spectrum disorder. J Autism Dev Disord. 2014 Dec;44(12):3063–71. doi:10.1007/s10803-014-2170-2 PubMed PMID: 24958436; PubMed Central PMCID: PMC4355011.

67. Nahar A, Thippeswamy H, Shanker Reddy MS, Kishore MT, Chaturvedi SK. Psychiatric comorbidity in persons with high-functioning autism spectrum disorders: Findings from a tertiary care neuropsychiatric hospital. Asian J Psychiatr. 2019 Mar;41:50–3. doi:10.1016/j.ajp.2018.09.008 PubMed PMID: 30316630.

68. Dow D, Morgan L, Hooker JL, Michaels MS, Joiner TE, Woods J, et al. Anxiety, Depression, and the Interpersonal Theory of Suicide in a Community Sample of Adults with Autism Spectrum Disorder. Arch Suicide Res. 2021;25(2):297–314. doi:10.1080/13811118.2019.1678537 PubMed PMID: 31656121.

69. Lever AG, Geurts HM. Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder. J Autism Dev Disord. 2016 Jun;46(6):1916–30. doi:10.1007/s10803-016-2722-8 PubMed PMID: 26861713; PubMed Central PMCID: PMC4860203.

70. Psychiatric and Medical Profiles of Autistic Adults in the SPARK Cohort | Journal of Autism and Developmental Disorders [Internet]. [cited 2025 Oct 6]. Available from: https://link.springer.com/article/10.1007/s10803-020-04414-6

71. Smith IC, Ollendick TH, White SW. Anxiety moderates the influence of ASD severity on quality of life in adults with ASD. Research in Autism Spectrum Disorders. 2019 Jun 1;62:39–47. doi:10.1016/j.rasd.2019.03.001

72. Uljarević M, Hedley D, Rose-Foley K, Magiati I, Cai RY, Dissanayake C, et al. Anxiety and Depression from Adolescence to Old Age in Autism Spectrum Disorder. J Autism Dev Disord. 2020 Sep;50(9):3155–65. doi:10.1007/s10803-019-04084-z PubMed PMID: 31190198.

73. Underwood JFG, DelPozo-Banos M, Frizzati A, Rai D, John A, Hall J. Neurological and psychiatric disorders among autistic adults: a population healthcare record study. Psychol Med. 2023 Sep;53(12):5663–73. doi:10.1017/S0033291722002884 PubMed PMID: 36189783; PubMed Central PMCID: PMC10482712.

74. Sociodemographic characteristics of patients with adult autism spectrum disorder [Internet]. [cited 2025 Oct 6]. Available from: http://psychiatry-psychopharmacology.com/en/sociodemographic-characteristics-of-patients-with-adult-autism-spectrum-disorder-13729

75. Hollocks MJ, Lerh JW, Magiati I, Meiser-Stedman R, Brugha TS. Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis.

Psychol Med. 2019 Mar;49(4):559–72. doi:10.1017/S0033291718002283 PubMed PMID: 30178724.

76. Hudson CC, Hall L, Harkness KL. Prevalence of Depressive Disorders in Individuals with Autism Spectrum Disorder: a Meta-Analysis. J Abnorm Child Psychol. 2019 Jan;47(1):165–75. doi:10.1007/s10802-018-0402-1 PubMed PMID: 29497980.

77. Fortuna RJ, Robinson L, Smith TH, Meccarello J, Bullen B, Nobis K, et al. Health Conditions and Functional Status in Adults with Autism: A Cross-Sectional Evaluation. J Gen Intern Med. 2016 Jan;31(1):77–84. doi:10.1007/s11606-015-3509-x PubMed PMID: 26361965; PubMed Central PMCID: PMC4700008.

78. Happé FG, Mansour H, Barrett P, Brown T, Abbott P, Charlton RA. Demographic and Cognitive Profile of Individuals Seeking a Diagnosis of Autism Spectrum Disorder in Adulthood. J Autism Dev Disord. 2016 Nov;46(11):3469–80. doi:10.1007/s10803-016-2886-2 PubMed PMID: 27549589.

79. Joshi G, Wozniak J, Petty C, Martelon MK, Fried R, Bolfek A, et al. Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: a comparative study. J Autism Dev Disord. 2013 Jun;43(6):1314–25. doi:10.1007/s10803-012-1679-5 PubMed PMID: 23076506.

80. Murray C, Kovshoff H, Brown A, Abbott P, Hadwin JA. Exploring the anxiety and depression profile in individuals diagnosed with an autism spectrum disorder in adulthood. Research in Autism Spectrum Disorders. 2019 Feb 1;58:1–8. doi:10.1016/j.rasd.2018.11.002

81. Oakley B, Loth E, Murphy DG. Autism and mood disorders. Int Rev Psychiatry. 2021 May;33(3):280–99. doi:10.1080/09540261.2021.1872506 PubMed PMID: 33648430.

82. McDermott S, Moran R, Platt T, Issac T, Wood H, Dasari S. Depression in adults with disabilities, in primary care. Disabil Rehabil. 2005 Feb 4;27(3):117–23. doi:10.1080/09638280400007380 PubMed PMID: 15823993.

83. Huntjens A, Landlust A, Wissenburg S, van der Gaag M. The Prevalence of Suicidal Behavior in Autism Spectrum Disorder. Crisis. 2024 Mar;45(2):144–53. doi:10.1027/0227-5910/a000922 PubMed PMID: 37668055.

84. Jokiranta-Olkoniemi E, Gyllenberg D, Sucksdorff D, Suominen A, Kronström K, Chudal R, et al. Risk for Premature Mortality and Intentional Self-harm in Autism Spectrum Disorders. J Autism Dev Disord. 2021 Sep;51(9):3098–108. doi:10.1007/s10803-020-04768-x PubMed PMID: 33140146; PubMed Central PMCID: PMC8349316.

85. Moseley RL, Turner-Cobb JM, Spahr CM, Shields GS, Slavich GM. Lifetime and perceived stress, social support, loneliness, and health in autistic adults. Health Psychol. 2021 Aug;40(8):556–68. doi:10.1037/hea0001108 PubMed PMID: 34618502; PubMed Central PMCID: PMC8513810.

86. Pelton MK, Crawford H, Robertson AE, Rodgers J, Baron-Cohen S, Cassidy S. Understanding Suicide Risk in Autistic Adults: Comparing the Interpersonal Theory of Suicide in Autistic and Non-autistic Samples. J Autism Dev Disord. 2020 Oct;50(10):3620–37. doi:10.1007/s10803-020-04393-8 PubMed PMID: 32125567.

87. Jadav N, Bal VH. Associations between co-occurring conditions and age of autism diagnosis: Implications for mental health training and adult autism research. Autism Res. 2022 Nov;15(11):2112–25. doi:10.1002/aur.2808 PubMed PMID: 36054777; PubMed Central PMCID: PMC9637770.

88. Haw C, Radley J, Cooke L. Characteristics of male autistic spectrum patients in low security: are they different from non-autistic low secure patients? Chaplin E, McCarthy J, editors. Journal of Intellectual Disabilities and Offending Behaviour. 2013 Jan 1;4(1–2):24–32. doi:10.1108/JIDOB-03-2013-0006

89. Rong Y, Yang CJ, Jin Y, Wang Y. Prevalence of attention-deficit/hyperactivity disorder in individuals with autism spectrum disorder: A meta-analysis. Research in Autism Spectrum Disorders. 2021 May 1;83:101759. doi:10.1016/j.rasd.2021.101759

90. Hofvander B, Delorme R, Chaste P, Nydén A, Wentz E, Ståhlberg O, et al. Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. BMC Psychiatry. 2009 Jun 10;9(1):35. doi:10.1186/1471-244X-9-35

91. Nylander L, Axmon A, Björne P, Ahlström G, Gillberg C. Older Adults with Autism Spectrum Disorders in Sweden: A Register Study of Diagnoses, Psychiatric Care Utilization and Psychotropic Medication of 601 Individuals. J Autism Dev Disord. 2018;48(9):3076–85. doi:10.1007/s10803-018-3567-0 PubMed PMID: 29663191; PubMed Central PMCID: PMC6096790.

92. van der Linden K, Simons C, van Amelsvoort T, Marcelis M. Lifetime and Momentary Psychotic Experiences in Adult Males and Females With an Autism Spectrum Disorder. Front Psychiatry. 2020 Aug 3;11. doi:10.3389/fpsyt.2020.00766

93. Schalock RL, Brown I, Brown R, Cummins RA, Felce D, Matikka L, et al. Conceptualization, Measurement, and Application of Quality of Life for Persons With Intellectual Disabilities: Report of an International Panel of Experts. Ment Retard. 2002 Dec 1;40(6):457–70. doi:10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2

94. van Heijst BFC, Geurts HM. Quality of life in autism across the lifespan: a meta-analysis. Autism. 2015 Feb;19(2):158–67. doi:10.1177/1362361313517053 PubMed PMID: 24443331.

95. Graham Holmes L, Zampella CJ, Clements C, McCleery JP, Maddox BB, Parish-Morris J, et al. A Lifespan Approach to Patient-Reported Outcomes and Quality of Life for People on the Autism Spectrum. Autism Res. 2020 Jun;13(6):970–87. doi:10.1002/aur.2275 PubMed PMID: 32154664.

96. Klein CB, Klinger LG. Aging Well and Autism: A Narrative Review and Recommendations for Future Research. Healthcare (Basel). 2024 Jun 17;12(12):1207.

doi:10.3390/healthcare12121207 PubMed PMID: 38921321; PubMed Central PMCID: PMC11203987.

97. McLean KJ, Eack SM, Bishop L. The Impact of Sleep Quality on Quality of Life for Autistic Adults. Res Autism Spectr Disord. 2021 Oct;88:101849. doi:10.1016/j.rasd.2021.101849 PubMed PMID: 34539812; PubMed Central PMCID: PMC8442542.

98. Grove R, Clapham H, Moodie T, Gurrin S, Hall G. ‘Living in a world that’s not about us’: The impact of everyday life on the health and wellbeing of autistic women and gender diverse people. Womens Health (Lond). 2023 Sep 20;19:17455057231189542. doi:10.1177/17455057231189542 PubMed PMID: 37727115; PubMed Central PMCID: PMC10515546.

99. Algazlan AS, Alsharidi TR, Alqady BS, Alghamdi MF, Alhazmi MI, Babelli NI, et al. Living with autism: Quality of life assessment for young adults with autism in Saudi Arabia. International Journal of Advanced and Applied Sciences. 2024 May 9;11(3):102–8. doi:10.21833/ijaas.2024.03.011

100. Ghanouni P, Quirke S. Resilience and Coping Strategies in Adults with Autism Spectrum Disorder. J Autism Dev Disord. 2023;53(1):456–67. doi:10.1007/s10803-022-05436-y PubMed PMID: 35079928; PubMed Central PMCID: PMC8788904.

101. Bradley L, Shaw R, Baron-Cohen S, Cassidy S. Autistic Adults’ Experiences of Camouflaging and Its Perceived Impact on Mental Health. Autism Adulthood. 2021 Dec 1;3(4):320–9. doi:10.1089/aut.2020.0071 PubMed PMID: 36601637; PubMed Central PMCID: PMC8992917.

102. Andersen PN, Orm S, Fossum IN, Øie MG, Skogli EW. Adolescence internalizing problems as a mediator between autism diagnosis in childhood and quality of life in emerging adults with and without autism: a 10-year longitudinal study. BMC Psychiatry. 2023 Mar 9;23(1):149. doi:10.1186/s12888-023-04635-w

103. Lawson LP, Richdale AL, Haschek A, Flower RL, Vartuli J, Arnold SR, et al. Cross-sectional and longitudinal predictors of quality of life in autistic individuals from adolescence to adulthood: The role of mental health and sleep quality. Autism. 2020 May;24(4):954–67. doi:10.1177/1362361320908107 PubMed PMID: 32169010.

104. Seltzer MM, Shattuck P, Abbeduto L, Greenberg JS. Trajectory of development in adolescents and adults with autism. Mental Retardation and Developmental Disabilities Research Reviews. 2004;10(4):234–47. doi:10.1002/mrdd.20038

105. Antshel KM, Russo N. Autism Spectrum Disorders and ADHD: Overlapping Phenomenology, Diagnostic Issues, and Treatment Considerations. Curr Psychiatry Rep. 2019 Mar 22;21(5):34. doi:10.1007/s11920-019-1020-5 PubMed PMID: 30903299.

106. Aydin Ü, Capp SJ, Tye C, Colvert E, Lau-Zhu A, Rijsdijk F, et al. Quality of life, functional impairment and continuous performance task event-related potentials (ERPs) in young adults with ADHD and autism: A twin study. JCPP Adv. 2022 Jul 10;2(3):e12090.

doi:10.1002/jcv2.12090 PubMed PMID: 37431386; PubMed Central PMCID: PMC10242939.

107. Barneveld PS, Swaab H, Fagel S, van Engeland H, de Sonneville LMJ. Quality of life: A case-controlled long-term follow-up study, comparing young high-functioning adults with autism spectrum disorders with adults with other psychiatric disorders diagnosed in childhood. Comprehensive Psychiatry. 2014 Feb 1;55(2):302–10. doi:10.1016/j.comppsych.2013.08.001

108. Black MH, Greenwood DL, Hwa JCC, Pivac J, Tang J, Clarke PJF. What Are You Worried About? Content and Extent of Worry in Autistic Adults. J Autism Dev Disord. 2024;54(5):2040–54. doi:10.1007/s10803-023-05963-2 PubMed PMID: 36988767; PubMed Central PMCID: PMC10052250.

109. Torenvliet C, Groenman AP, Radhoe TA, Agelink van Rentergem JA, Van der Putten WJ, Geurts HM. A longitudinal study on cognitive aging in autism. Psychiatry Res. 2023 Mar;321:115063. doi:10.1016/j.psychres.2023.115063 PubMed PMID: 36709700.

110. Torenvliet C, Groenman AP, Agelink van Rentergem JA, Radhoe TA, Geurts HM. When mind and measurement diverge; the interplay between subjective cognitive complaints (SCCs), objective cognition, age, and depression in autistic adults. Psychiatry Research. 2024 Mar 1;333:115759. doi:10.1016/j.psychres.2024.115759

111. Geurts HM, Vissers ME. Elderly with autism: executive functions and memory. J Autism Dev Disord. 2012 May;42(5):665–75. doi:10.1007/s10803-011-1291-0 PubMed PMID: 21656030; PubMed Central PMCID: PMC3324697.

112. Geurts HM, Pol SE, Lobbestael J, Simons CJP. Executive Functioning in 60+ Autistic Males: The Discrepancy Between Experienced Challenges and Cognitive Performance. J Autism Dev Disord. 2020 Apr;50(4):1380–90. doi:10.1007/s10803-020-04368-9 PubMed PMID: 31953573; PubMed Central PMCID: PMC7101290.

113. Howlin P, Magiati I. Autism spectrum disorder: outcomes in adulthood. Curr Opin Psychiatry. 2017 Mar;30(2):69–76. doi:10.1097/YCO.0000000000000308 PubMed PMID: 28067726.

114. Tse VWS, Lei J, Crabtree J, Mandy W, Stott J. Characteristics of Older Autistic Adults: a Systematic Review of Literature. Rev J Autism Dev Disord. 2022 Jun 1;9(2):184–207. doi:10.1007/s40489-021-00238-x

115. van den Heuvel RM, Teunisse JP, Radhoe TA, van der Putten WJ, Torenvliet C, Wen S, et al. Social Network Types in Autistic Adults and Its Associations with Mastery, Quality of Life, and Autism Characteristics. J Autism Dev Disord. 2025 Jan 27. doi:10.1007/s10803-025-06722-1 PubMed PMID: 39871022.

116. Charlton RA, McQuaid GA, Wallace GL. Social support and links to quality of life among middle-aged and older autistic adults. Autism. 2023 Jan;27(1):92–104. doi:10.1177/13623613221081917 PubMed PMID: 35362329; PubMed Central PMCID: PMC9806477.

117. Marion A, Bowman K, Thomas G, Harrison AJ. A mixed method examination: how stigma experienced by autistic adults relates to metrics of social identity and social functioning. Front Psychiatry. 2023;14:1243618. doi:10.3389/fpsyt.2023.1243618 PubMed PMID: 37965369; PubMed Central PMCID: PMC10640997.

118. Øverland E, Hauge ÅL, Orm S, Øie MG, Skogli EW, Pellicano E, et al. 'I have to charge my social battery': Perspectives from autistic young adults on Quality of Life. Autism. 2024 Jun;28(6):1369–81. doi:10.1177/13623613241245578 PubMed PMID: 38629698; PubMed Central PMCID: PMC11457465.

119. Farley M, Cottle KJ, Bilder D, Viskochil J, Coon H, McMahon W. Mid-life social outcomes for a population-based sample of adults with ASD. Autism Res. 2018 Jan;11(1):142–52. doi:10.1002/aur.1897 PubMed PMID: 29266823; PubMed Central PMCID: PMC5924705.

120. It's time to embrace 'profound autism'. The Transmitter: Neuroscience News and Perspectives [Internet]. 2022 Oct 27 [cited 2025 Oct 6]. Available from: https://www.thetransmitter.org/spectrum/its-time-to-embrace-profound-autism/

121. United Nations, 2006. https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf [Internet]. [cited 2025 Oct 6]. Available from: https://www.google.com/search?q=126.+United+Nations%2C+2006.+https%3A%2F%2Fwww.un.org%2Fdisabilities%2Fdocuments%2Fconvention%2Fconvoptprot-e.pdf&rlz=1C1GCEA_enIE1022IE1022&oq=126.+United+Nations%2C+2006.+https%3A%2F%2Fwww.un.org%2Fdisabilities%2Fdocuments%2Fconvention%2Fconvoptprot-e.pdf&gs_lcrp=EgZjaHJvbWUyBggAEEUYOdIBBzI1N2owajSoAgCwAgE&sourceid=chrome&ie=UTF-8

122. Department of Children, Disability and Equality: Priority Areas of Research Interest 2025 [Internet]. Report. Available from: https://assets.gov.ie/static/documents/20250515_DCEDIY_Research_Priorities.pdf

123. Zeidan J, Fombonne E, Scorah J, Ibrahim A, Durkin MS, Saxena S, et al. Global prevalence of autism: A systematic review update. Autism Res. 2022 May;15(5):778–90. doi:10.1002/aur.2696 PubMed PMID: 35238171; PubMed Central PMCID: PMC9310578.

124. Global, regional, and national burden of 12 mental disorders in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. The Lancet Psychiatry. 2022 Feb 1;9(2):137–50. doi:10.1016/S2215-0366(21)00395-3 PubMed PMID: 35026139.

125. Mc L, Mv L, An R, B C, B A, P S, et al. Quantifying and exploring camouflaging in men and women with autism. Autism: the international journal of research and practice. 2017 Aug;21(6). doi:10.1177/1362361316671012 PubMed PMID: 27899710.

126. Schepman P, Robinson R, Blakeman KH, Wilhelm S, Beck C, Hallberg S, et al. Factors influencing quality of life in patients with osteoarthritis: analyses from the BISCUITS study. Scand J Pain. 2023 Jan 27;23(1):139–48. doi:10.1515/sjpain-2021-0213

127. Maenner MJ, Rice CE, Arneson CL, Cunniff C, Schieve LA, Carpenter LA, et al. Potential Impact of DSM-5 Criteria on Autism Spectrum Disorder Prevalence Estimates. JAMA Psychiatry. 2014 Mar;71(3):292–300. doi:10.1001/jamapsychiatry.2013.3893 PubMed PMID: 24452504; PubMed Central PMCID: PMC4041577.

128. Bishop-Fitzpatrick L, Movaghar A, Greenberg JS, Page D, DaWalt LS, Brilliant MH, et al. Using machine learning to identify patterns of lifetime health problems in decedents with autism spectrum disorder. Autism Res. 2018 Aug;11(8):1120–8. doi:10.1002/aur.1960 PubMed PMID: 29734508; PubMed Central PMCID: PMC6203659.

129. Browne K, Lawson W, McGarry S, Scott M, Girdler S, Milbourn B. “Consistent Support Is Good for My Mental Health”—Exploring the Lived Experience of Autistic Mental Health. Autism in Adulthood. 2024 Oct 10. doi:10.1089/aut.2024.0141

130. Huang WL, Leventhal B, Lin CC, Chien YL. Health anxiety and somatic symptoms in adults on the autism spectrum. Psychiatry Res. 2025 Aug;350:116550. doi:10.1016/j.psychres.2025.116550 PubMed PMID: 40398191.

131. Moseley RL, Hedley D, Gamble-Turner JM, Uljarević M, Bury SM, Shields GS, et al. Lifetime stressor exposure is related to suicidality in autistic adults: A multinational study. Autism. 2025 May;29(5):1184–208. doi:10.1177/13623613241299872 PubMed PMID: 39655441; PubMed Central PMCID: PMC12038079.

132. Verdugo MA, Navas P, Gómez LE, Schalock RL. The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. J Intellect Disabil Res. 2012 Nov;56(11):1036–45. doi:10.1111/j.1365-2788.2012.01585.x PubMed PMID: 22672317.

133. Schiltz H, Gohari D, Park J, Lord C. A longitudinal study of loneliness in autism and other neurodevelopmental disabilities: Coping with loneliness from childhood through adulthood. Autism. 2024 Jun;28(6):1471–86. doi:10.1177/13623613231217337 PubMed PMID: 38153097; PubMed Central PMCID: PMC11132953.

134. Hickey A, Crabtree J, Stott J. ‘Suddenly the first fifty years of my life made sense’: Experiences of older people with autism. Autism. 2018 Apr;22(3):357–67. doi:10.1177/1362361316680914 PubMed PMID: 29153003.

135. Autistica, 2024. Creating an employment readiness programme for autistic young people`. [Internet]. Report. Available from: https://www.autistica.org.uk/our-research/research-projects/employment-readiness

136. Weldele M. Peer Support in Autism. Autism Research Institute [Internet]. 2025 Mar 14 [cited 2025 Oct 7]. Available from: https://autism.org/peer-support-in-autism/

137. Health Service Executive. Autism Awareness training. [Internet]. Report. Available from: https://healthservice.hse.ie/staff/training-and-development/autism-awareness-training/

138. Does Quality of Life Differ for Children With Autism Spectrum Disorder and Intellectual Disability Compared to Peers Without Autism? | Journal of Autism and Developmental Disorders [Internet]. [cited 2025 Oct 7]. Available from: https://link.springer.com/article/10.1007/s10803-017-3289-8

139. Dunn K, Rydzewska E, MacIntyre C, Rintoul J, Cooper SA. The prevalence and general health status of people with intellectual disabilities and autism co-occurring together: a total population study. J Intellect Disabil Res. 2019 Apr;63(4):277–85. doi:10.1111/jir.12573 PubMed PMID: 30488508.

140. Zhao Y, Lu F, Wang X, Luo Y, Zhang R, He P, et al. The economic burden of autism spectrum disorder with and without intellectual disability in China: A nationwide cost-of-illness study. Asian Journal of Psychiatry. 2024 Feb 1;92:103877. doi:10.1016/j.ajp.2023.103877

141. Shenouda J, Barrett E, Davidow AL, Sidwell K, Lescott C, Halperin W, et al. Prevalence and Disparities in the Detection of Autism Without Intellectual Disability. Pediatrics. 2023 Feb 1;151(2):e2022056594. doi:10.1542/peds.2022-056594 PubMed PMID: 36700335.

Appendix 1: Search strategy

Search Strategy

Concept 1: Autism

EMBASE: 'autism'/exp

Keywords: autistic* OR autism* OR asperger* OR audhd OR asperger* OR ASD

Concept 2: Life span/expectancy

EMBASE: 'life expectancy'/exp OR 'survival'/exp

Keywords on title and abstract in EBSCO databases (Life* N3 (span* OR expect* OR limit* OR length* OR time* OR long* OR short* OR impact* OR reduc* OR extend*OR course* OR line OR plan* OR duration*)) OR longevity OR mortality

Keywords on title and abstract in EMBASE databases (Life NEAR/3 (span* OR expect* OR limit* OR length* OR time OR long* OR short* OR impact* OR reduc* OR extend* OR course* OR line OR plan* OR duration*)) OR longevity OR mortality

Table 3. Search Terms in EMBASE (Elsevier)

Number	Search term
1	'autism'/exp
2	**autistic***:ab,ti OR **autism***:ab,ti OR **audhd**:ab,ti OR **asperger***:ab,ti OR **asd**:ab,ti OR **aspie**:ab,ti
3	#1 OR #2
4	((life NEAR/3 (span* OR expect* OR limit* OR length* OR time OR long* OR short* OR impact* OR reduc* OR extend* OR course* OR line OR plan* OR duration*)):ab,ti) OR longevity:ab,ti OR mortality:ab,ti
5	'life expectancy'/exp OR 'survival'/exp
6	#4 OR #5
7	#3 AND #6

Appendix 2: PRISMA-ScR checklist

Table 4. Details of PRISMA-ScR Checklist

Section	Item	PRISMA-ScR Checklist item description	Reported on page #
Title	1	Identify the report as a scoping review.	2,8,13
Structured summary	2	Provide a structured summary that includes (as applicable) background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	8
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	11
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	12
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	NA
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status) and provide a rationale.	14
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	13
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	13
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	14
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in	15

		duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	15
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	14,15,18
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	14,15,18
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	17
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	41
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	NA
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	17-32
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	19
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	33-40
Limitations	20	Discuss the limitations of the scoping review process.	39
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	40
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	2

An Roinn Leanaí, Míchumais agus Comhionannais
Department of Children, Disability and Equality

NDA
Údarás Náisiúnta Míchumais
National Disability Authority

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin