

Literature Review on Autism, Ageing and Life-Expectancy

Call for Proposals

# 1. Introduction

The National Disability Authority (NDA) is the independent statutory body with a duty to provide information and evidence-informed advice to Government on disability policy and practice and to promote Universal Design.

The NDA is inviting proposals for a **Literature Review on Autism, Ageing and Life-Expectancy** from organisations, institutions and individuals who have a strong track record in research.

This literature review will contribute to Action 81[[1]](#footnote-1) of the [Autism Innovation Strategy](https://www.gov.ie/en/publication/c5835-autism-innovation-strategy/) (AIS) that was launched on 26th August 2024. The Strategy aims to address the bespoke challenges and barriers facing autistic people.

Action 81:

To improve our understanding of the key health challenges facing autistic people, and their associated impact on life expectancy, we will invest in research that informs policy and practice around appropriate health and social care services and supports for autistic people. This research will include a review of international literature and will be in line with the priorities of autistic people.

This literature review topic was identified by autistic people during consultation on the strategy as being an under researched area. The aim of this literature review is to outline 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 adult and their access to quality health care.

# 2. Context and gaps

In response to an historic framing of autism as a childhood condition there has been a significant rise in research focused on autistic adults such as understanding trends in their morbidity and mortality.

Reviews and studies over the last 15 years have suggested that autistic people have higher rates of mortality than the general population.[[2]](#footnote-2) Moreover, research focused on health inequalities and co-occurring conditions suggested autistic adults have a higher likelihood of having many physical and mental health conditions when compared to non-autistic people.[[3]](#footnote-3) That said, there are many methodological challenges involved in exploring knowledge in this area. Understanding these challenges is key to informing policy and practice around appropriate health and social care services and supports for autistic adults.

There is a key debate about methodological approaches in influential studies that underpin discourse on mortality rate differences. [[4]](#footnote-4) For example, few people over the age of 65 who may be autistic will have been diagnosed or recognised as being autistic so, as a consequence, studies examining autism in older people may be biased if those with a diagnosis have particular similarities, for example, belonging to a higher socio-economic group. Autism research is also influenced by wider competing perspectives about how autism is understood such as viewing morbidity and mortality through a lens of biological vulnerabilities or structural inequalities.

Accordingly, there is a diverse literature on areas such as supporting autistic adults as they age, healthy aging, older age autism, quality of life, diagnoses in later life, and interactions with health care professionals. Importantly, over the last few years there have been an increase in calls for co-produced community-based research initiatives designed to empower autistic people and influence social change in the context of ageing and life-expectancy.[[5]](#footnote-5)

Against this backdrop, there is a need for a review of research across this diverse and rapidly expanding field. We therefore require an examination of international literature to:

* Outline the methodological challenges in ascertaining differences in mortality and morbidity in autistic adults and autistic older adults.
* Review the evidence related to differences in life-expectancy between autistic and non-autistic people using internationally accepted methodology for determining life-expectancy.
* 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 (a full listing of co-occurring conditions is not necessary).
* Report if there are modifiable determinants of health that influence morbidity and mortality among autistic adults.
* Outline modifiable barriers in accessing quality health and social care that impact on the morbidity and mortality of autistic adults.
* 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.

The review should situate knowledge within wider perspectives such as the cross over between autism and neurodiversity.

Applicants are requested to outline their approach to the literature review in less than 1,500 words (see application form for more details). In addition to an examination of academic literature the review should include research and evaluations from grey literature where appropriate.

# 3. Deliverables

Successful applicants will be required to

* Deliver a literature review of a maximum of 50 pages excluding references and appendices that:
* meets Quality Guidelines for NDA Research (Appendix A)
* is of a publishable standard and accessible (guidance on making documents accessible will be provided)
* is in the following format:
* Executive Summary - a short section setting out the key findings
* Introduction - including a clear rationale for the literature review
* Methodology - including search terms, scope and sources for literature review
* Main findings - summarises the key arguments and theories and evidence related to this topic
* Conclusion
* References
* Deliver a seminar on the findings (via webinar or in-person) if requested

The NDA requires that autistic people are involved in the review.[[6]](#footnote-6) The researchers can decide the level and format of involvement but may see value in autistic people shaping the specifics of questions, advising on terminology, or supporting interpretation of literature. NDA supports the publication of work in academic journals but will not delay publication for such purposes. We strongly encourage publication in open access journals.

# 4. Selection Criteria

The NDA will evaluate the eligible research proposals on the basis of the following selection criteria:

* Experience and qualifications of research team and appropriate supervisory arrangements (30%)
* Quality and relevance of approach and methodology proposed (30%)
* Cost (30%)
* Accessibility and involvement of autistic people (10%)

Only projects which reach a pass mark (50%) under each of the above criteria (excluding costs) will be further considered.

## More information in relation to the requirements under each of these is included in the application form. Short listing

Following initial assessment, the NDA may create a shortlist of applicants to interview should a second assessment stage be deemed necessary.

## Rights reserved

The NDA reserves the right not to award any funding. Reaching the interview stage, if conducted, is not a guarantee that funding will be awarded.

## Payments

Payment will be made in three tranches

* One third on acceptance of the work and when a contract is signed.
* One third on receipt of a **satisfactory** draft literature review (a satisfactory draft is one that requires only minor further editing).
* One third on satisfactory completion of the final literature review.

The budget available for this literature review is between €24,000 and €28,000 inclusive of VAT if applicable.

# 5. Applications

Applications for funding are required to use the attached application form. The table below outlines the key milestones in the application process:

| Stage: | Date/Time: |
| --- | --- |
| Call for applications | Week starting 10th March 2025 |
| Deadline for completed applications | Tuesday 22nd Aril 2025 (12 noon) |
| Interviewing of short-listed applicants (if necessary) | Week starting Monday 28th April 2025 |
| Successful applicants notified | Week starting Monday 5th May 2025 |
| First draft report for review | Mid-September 2025 |
| Round 1 feedback from NDA | End of September 2025 |
| Second draft report received | Mid-October 2025 |
| Round 2 external peer review | End of October 2025 |
| Final report received | Mid-November 2025 |
| Approval by NDA board | End of November 2025 |
| Accessibility checks completed by NDA | December 2025 |

Applicants should note that the Board of the NDA are the final approvers of the review and may provide some feedback. Further work may need to be completed if the report does not pass accessibility checks.

### Tax clearance certificate

Successful applicants will be required to provide Tax Clearance Certificates to the NDA; otherwise funding cannot be provided. Organisations should ensure these are in order before submitting their application to avoid unnecessary delay in allocating funding.

Completed applications should be returned by: **12 noon on Tuesday 22nd April 2025**. Applications received after this time and date will not be processed.

Applications should be marked **Literature Review** and submitted by email to:[**research@nda.ie**](mailto:research@nda.ie)**.** Please address any queries you have to Damian Haslett.

Appendix A

# Quality Guidelines for NDA Research

## 1. Overall Research Design

* The research has been scoped out following engagement with the external and internal stakeholders as appropriate (e.g. officials from relevant policy area of Govt Dept and other NDA staff as appropriate) to ensure it will cover all relevant issues. A first step is to ensure that the research conforms with NDA's mission and strategy, adds value and does not duplicate work elsewhere.
* The research has value for policy makers and, where appropriate, practitioners. A key goal for NDA research is to guide policymakers and practitioners in the achievement of an inclusive, accessible Irish society in which people with disabilities enjoy equal rights and opportunities to participate in economic, social and cultural life.
* The report contains a clear and comprehensive statement of the aims of the research.
* The research design is appropriate for answering the policy questions which have been developed in consultation with customers and end users of the research, both internal and external to NDA.
* There are no major gaps in the report. It does not omit key data sources, key relevant literature, or key issues.
* The research contributes to our knowledge/understanding of a given field.
* The research conforms to ethical principles and has obtained ethical approval as appropriate.

## 2. The Research Report

* For contracted reports, the research aligns fully with all the specifications contained in the contract. The research is completed within agreed timescales and budget.
* The report is presented in a logical structure (e.g. executive summary, context, relevant literature, aims and objectives, methods, findings, discussion of findings, conclusions). The report includes a title page, executive summary, contents page, lists of tables and charts, acknowledgements, glossary of specialist terms, list of abbreviations and acronyms, list of references, relevant appendices. Contracted work includes the appropriate disclaimer.
* The report includes a concise review of the methodology employed in the research within the body of the report with a more technical description (e.g. search methods and terms for literature) outlined in the appendix.
* The report contains appropriate signposting that guides the reader through the commentary, with key messages being highlighted or summarised throughout the report.
* The report is accurate with regard to quotations, data, references, etc., and has been proof read for spelling, grammar and syntax.
* The writing style is clear, focused and to the point, taking account of the target audience. It is temperate in tone, not emotive. Authors refrain from personal opinion/editorial and focus on the evidence. Technical terms when used are adequately explained.
* The report is rigorously objective and factual. The report contains no plagiarism. Direct quotations are labelled as such and duly referenced.
* The report contains no libellous or abusive comments.
* All tables give the original source and show appropriate units of measurement.

## 3. Literature Review

* There is evidence of a systematic approach to the review of literature which should summarise and evaluate the knowledge base to date.
* Databases and search terms are clearly outlined to allow for replication of literature searches.
* The report sets out clearly the size of samples used in studies reviewed and any conclusions are appropriate to the limitations or otherwise of same.
* The report distinguishes empirical findings from opinion.

## 4. Methodology

* The research methodology is appropriate to address the research question.
* The methodological choices are discussed within the report and the limitations of the methodology are acknowledged. The value of the evidence is weighed by reference to the methodology used and size of sample.
* The methodology is valid, reliable, replicable and (as appropriate) generalisable.
* A description is provided of any formalised appraisal criteria used to support the methodology.
* Any modifications made to the methodology during the course of the research are explained and justified.
* All necessary details of the methodology are outlined (e.g. research instruments used, number of participants, size of sample, response rates, tests of significance). Where a sample has been taken for the study, the number of respondents should be shown in any tables using the data.
* The selection criteria of the sample are detailed and justified and any difference between planned and actual sample (e.g. non-participation) explained.
* Informed consent has been given by research participants and management of confidentiality/anonymity is documented.
* The safety of participants and researchers has been assured and potential risks explained.
* Data collection methods are appropriate for the type of data required and are clear and replicable.

## 5. Data Analysis

* A rationale is provided for the data analysis methods chosen (quantitative, qualitative, mixed methods, etc.).
* Data analysis is clear and valid, and synthesised to make sense of data.
* Evidence of how descriptive categories, classes, labels, and coding frames were constructed is provided for qualitative analysis.
* Analysis involving the comparison of data (e.g. international data) includes a determination as to whether extraneous variables (e.g. policy, legal or contextual differences) allow a fair comparison to be made.
* Storage and protection of data, according to established protocols and legislation, is referenced in the report.

## 6. Interpretation of Findings

* The findings are clearly linked to the aims of study.
* Clear links are identified between data, interpretation and conclusions such that others can follow a coherent, convincing and objective 'decision trail'.
* There is a synthesis and analysis of data, in such a way that conclusions clearly emerge for the reader.
* Findings have a coherent logic, 'make sense' and are resonant with other knowledge.
* Areas where findings concur or differ from those in the literature are noted.
* There is convincing discussion of the generalisability of findings and limitations of findings relating to aims & objectives (e.g. certain groups not represented etc.) and what remains unknown.
* There is a credible and clear discussion as to how findings contribute to knowledge/understanding and their applicability to current and/or new policy developments, practice.

1. This is a research action connected to Pillar 4 of the AIS - Building capacity. [↑](#footnote-ref-1)
2. [Premature mortality in autism spectrum disorder](https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/premature-mortality-in-autism-spectrum-disorder/4C9260DB64DFC29AF945D32D1C15E8F2) [↑](#footnote-ref-2)
3. [The health status of adults on the autism spectrum](https://pubmed.ncbi.nlm.nih.gov/25911091/) [↑](#footnote-ref-3)
4. [Citation Context Analysis of Autism Mortality and Suicide Findings From Hirvikoski’s Landmark Study](https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2830153) [↑](#footnote-ref-4)
5. [How healthcare systems are experienced by autistic adults in the United Kingdom: A meta-ethnography](https://journals.sagepub.com/doi/full/10.1177/13623613241235531) [↑](#footnote-ref-5)
6. [Collaborative research with disabled people: Guidance for researchers](https://nda.ie/uploads/publications/NDA-Collaborative-Research-Report_final.pdf) [↑](#footnote-ref-6)