Protocol for a Scoping Review of National Autism Strategies: Considering Autism Policy within the framework of the United Nations Convention on the Rights of Persons with Disabilities

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ABSTRACT

Introduction: The emergence of national autism strategies is changing how autism is perceived across the world and creating opportunities to set priorities that can improve the health, inclusion, and well-being of Autistic people and protect their human rights. The development of national autism strategies across North America, Europe, and Australia provides an important opportunity to examine, compare, and learn from different countries' approaches. A scoping review will be conducted to identify all national autism policies in countries that have signed or ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The research team will identify major themes, strengths, and opportunities of these strategies to help inform the development of future autism strategies. Areas of alignment with the Convention's articles will also be highlighted.

Methods and analysis: This study will follow the guidance of the JBI (formerly Joanna Briggs Institute) for scoping reviews. An Internet search on the Google search engine international grey literature (non-academic literature such as government and non-profit organization reports) will locate documents pertaining to national autism strategies. Screening for inclusion and data abstraction will be conducted by two independent reviewers. A third reviewer will resolve discrepancies. The research team will include quantitative aggregate summaries of key descriptive and summary statistics (e.g., number of countries, number of ministries involved). A deductive approach to qualitative content analysis will be used to identify gaps and opportunities based on the alignment of policies with the UNCRPD.

Ethics and dissemination: Research ethics approval is not required for this scoping review. An integrated knowledge translation approach will be used, and end users (persons with lived experience, professionals, and policymakers) will be involved throughout the research process. This will ensure results directly inform advocacy efforts, future initiatives, and policy development. The results will also be disseminated through conference presentations, peer-reviewed publications, accessible-language summaries, and a policy brief for government decision-makers.

INTRODUCTION

Autism leads to differences in how a person perceives, communicates, and interacts with people and their environment.[1] It is estimated that 61-78 million are Autistic globally, equating to a prevalence of 1-2%.[2–4] Autistic people often experience a range of developmental, behavioural, and mental health challenges, with variations in characteristics and support needs among individuals.[5]

There are varying perspectives on the definition of autism, including the contrasts between biomedical and social science approaches.[6] The biomedical model classifies autism based on the diagnostic criteria from the Diagnostic and Statistical Manual (5th edition),[7] and the International Classification of Diseases (11th edition), focusing on deficits and impairments.[8] Critics argue this approach overemphasizes a behaviourally defined diagnosis[9].

In contrast, social science perspectives, including the neurodiversity paradigm and the social model of disability, view neurological differences as part of identity and disability as the result of societal and environmental barriers (i.e., living in a society designed for non-Autistic people).[10,11]

Many countries lack sufficient access to diagnosis, health care, education, employment, financial support, and social care and supports.[12,13] Without access to necessary systems of care and support, Autistic people often experience barriers that lead to poorer outcomes in health, education, work, and community participation.[1]

National strategies align government priorities and resources to achieve improved outcomes and a better quality of life for groups experiencing inequities.[14] However, in many countries, public and broader disability policies lack tailored approaches that address the unique cognitive, social, and sensory needs and profiles of Autistic people. The lack of targeted support contributes to disparities in healthcare, education, employment, housing, justice, social services, as well as barriers to community participation and social and inclusion. These Inequities are further exacerbated in underserved populations and geographic regions.[15] Over the past several years, many countries have been developing and implementing national strategies and policies specifically aimed at supporting the rights of Autistic people and addressing inequities.[16,17] International policy development provides valuable lessons for countries developing rights-based policies to address barriers faced by Autistic individuals.

To the best of the authors' knowledge, this is the first comprehensive scoping review that will be conducted summarising current national-level autism policies. The scoping review will identify countries with national-level autism strategies and examine the major themes of these policies.

The review will use the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as a framework to analyze themes of national autism strategies, identify areas of strength in upholding the human rights of Autistic people, and identify areas where policy can be strengthened to protect the human rights of Autistic people.

The UNCRPD is an international human rights treaty that focuses on protecting and promoting the rights and dignity of persons with disabilities.[18] Signing the convention as a state party means that a country agrees to be bound by the obligations outlined in the treaty and commits to ensuring the rights of persons with disabilities within its territory. The convention consists of an overarching set of principles and 50 Articles that cover a wide range of rights and issues pertaining to persons with disabilities, alongside procedural matters.[19] For example, Article 5 (equality and non-discrimination) emphasizes that persons with disabilities should not be subject to discrimination and should enjoy equal opportunities in various domains of life, such as health, education, employment, and access to services.[18] Since its adoption by the United Nations General Assembly in 2006, the UNCRPD has been ratified or acceded to by 191 Member States, while four Member States have signed the Convention without having yet proceeded to ratification. It was also signed and formally confirmed (acceded to) by the European Union, in its capacity to do so as a regional integration organization. By signing, States Parties show intention to take steps to be bound by (ratify) the treaty at a later date, creating an obligation to refrain from acts that would define the purpose of the treaty.[18,19]

The findings of this review offer critical insights for policymakers, researchers, service providers, self-advocates, educators, support persons and caregivers worldwide, who are working to implement best practices and advance the development of comprehensive, autism policies that are fully aligned with the rights-based framework of the UNCRPD.

Research Questions

This scoping review aims to address the following research questions:

1. Which UNCRPD signatory countries have established national autism policies and strategies?
2. To what extent do the national autism policies and strategies of these countries align with the articles of the UNCRPD?
3. What are the key priority themes, strengths, and opportunities for developing national policies and strategies that uphold the human rights and inclusion of Autistic people?

Terminology used in this paper

Autism

As outlined earlier, differing perspectives exist as to the definition of autism, primarily the ongoing debate between biomedical and social science approaches. This review adopts a human rights-based approach, aligned with the social model of disability and the articles of the UNCRPD.[20] Accordingly, the authors use “autism” instead of “Autism Spectrum Disorder”, and “Autistic person” rather than “person with autism” reflecting strengths-based and identity-first language, which has been documented in the research literature as preferred by self-advocates.[21,22]

Persons with Lived Experience

This review follows guidelines that use the term “patient and public involvement,” however, the term “patient” may not be appropriate in the context of consideration of people with disabilities outside of a healthcare setting. Therefore, this review will use the term “persons with lived/living experience (PWLE) involvement” in the discussion, which will generally refer to the engagement of Autistic people, families, supporters and caregivers. These groups, however, will be referred to separately when necessary.

Policy

Policy is defined as “a law, regulation, procedure, administrative action, incentive or voluntary practice of governments and other institutions”,[23] while strategies outline the specific actions taken to achieve changes over time.[24] In this review, the terms “policy” and “strategy” will be used interchangeably to refer to the legislation, plans, and national strategies adopted by governments to address autism within their respective countries.

METHODS AND ANALYSIS

Study Design

Scoping review methodology will be used to systematically identify and map the evidence, irrespective of source.[25] This protocol follows the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 Checklist,[26] as modified by the JBI Scoping Review Methodology Group’s “Best practice guidance and reporting items for the development of scoping review protocols.”[27] The final review will be reported using the PRISMA extension for Scoping Reviews (PRISMA-ScR).[28] Any modifications made over the course of the scoping review will be transparently reported in the final published paper.

Eligibility criteria

The eligibility criteria were established using the PCC (Population/Concept/Context) framework, as recommended in the JBI guide to Scoping Reviews.[29]

- *Population:* Autistic people of all ages. Only documents specifically related to autism (i.e., containing "autism" in the title) will be included. Documents focused more broadly on neurodiversity, neurodevelopmental disabilities, or all disabilities will be excluded.
- *Concept:* National autism policies. Documents will be considered for inclusion if: (1) they are national level in scope; (2) they constitute a policy, strategy, action plan, framework, or legislation; and (3) they were published prior to January 2025. All available policy documents will be retrieved, but only the most recent versions of documents will be included during the screening process). Exclusions include: (1) clinical care guidelines; (2) regional-, state-, or provincial-level documents; (3) non-government publications; (4) and documents with a more recent version.
- *Context:* Only documents from countries that are signatories or parties to the UNCRPD will be included, as those countries have committed to promoting the rights of persons with disabilities.

Information sources

Grey literature, which includes reports and information outside of the academic literature by entities such as governments, will be the primary source of information, as the required information is most likely to be found in these types of documents. Sources will be appropriately cited. The Google search engine will be the primary "database" searched to locate national autism strategies. If a document is found but not publicly available, the government agency for the country will be contacted with one original and one follow-up email before excluding the country. The search will cover documents produced up to the end of 2024.

Search Strategy

A targeted grey literature search will identify national government autism policies. The following is an example search strategy to locate relevant documentation for each country.

Step 1: For each UNCRPD nation-state, a Google search will be carried out in English with the following consistent search terms:

Table 1: Search Terms

National **Search Terms**	***Autism*** **Search Terms**	***Strategy*** **Search Terms**	***Country*** **Search Terms**
National Federal	Autism Autism spectrum disorder Autistic ASC ASD	Strategy Policy Plan “Action plan” “Master plan” Guidelines Law Legislation Act Bill	Country name

The search will be used to identify countries with existing autism policies by locating the policy or finding information that references the existing policy. For countries where documents cannot be identified in English, the search terms will be translated into the official language of that country.

Step 2: In Step 2, policies from countries with existing autism policies identified in Step 1 will be retrieved using the same English search terms. These will be uploaded to a secure Google Drive folder. In addition to the search terms used in Step 1, related reviews, evaluations, progress reports, and consultation reports will be searched. For documents in a language other than English or French, attempts will be made to obtain English versions by contacting the relevant institution. All publicly accessible documents or those obtained through follow-up will be uploaded to country-specific folders in the secured Google Drive, with access restricted to the research team.

Step 3: Documents in languages other than English or French (the native languages of research team members) will be translated by a certified translator.

Selection of sources of evidence

Two reviewers independently working in pairs will screen policies against predefined eligibility criteria to identify national autism strategies. A pilot test on 10% of the document titles and summaries will ensure reviewer agreement throughout the screening process. Once sufficiently high agreement is observed (>70%), full screening will commence. A third reviewer will resolve discrepancies.

Reasons for exclusion will be recorded in an electronic screening form stored on Google Drive. The full research team will discuss any unclear inclusion/exclusion decisions. A PRISMA flow diagram will track the selection process, including reasons for exclusion.[30]

Data charting process

The UNCRPD articles will guide the development of the data abstraction form, which will be refined through iterative discussion during screening and pilot testing. Paired reviewers will use Google Forms to chart data independently. A pilot test of 10% of the included documents will assess consistency in data extraction across reviewers. Adjustments to the form may be made as needed. Disagreement between reviewers will be resolved by a third reviewer and, if necessary, further escalated to the full research team for discussion. Final decisions on which policy documents to use for data extraction (e.g., the core strategy, annexes, related implementation plans or legislation) will be made collectively based on initial results from pilot testing and feasibility considerations.

Data items

The information to be extracted is organized into seven sections:

1. **General information:** Title, country, publication year, and document type (e.g., act, bill, strategy).
2. **Financial Information**: Funding details, allocation, and expected distribution year and currency.
3. **Consultation processes**: Stakeholder involvement in the development of each document (e.g., persons with lived experience, members of the autism community, and service providers)
4. **Ownership and mandate:** Accountable for the policy and its monitoring.
5. **Evaluation:** Measurable metrics, implementation plans, indices, indicators, or targets included in the document and lessons learned.
6. **Perspective and Population:** Focus on specific populations (e.g., children, adults), autism definitions, language (person- or identity-first), and disability model (social/human rights or biomedical).
7. **Sector/Right-Specific:** Relevance to every UNCRPD article.

Modifications may be made during data extraction, and the final version will be included in the full review.

Critical Appraisal

This scoping review aims to provide an overview of government-developed autism policies, which were not developed in accordance with academic guidelines, therefore we will not conduct an assessment of methodological quality or risk of bias, which is typical for a scoping review.[29] Additionally, this scoping review is intended to include all published autism policies, regardless of rigour, to assess the strengths and weaknesses of the policies. Thus, conducting a critical appraisal is not relevant to the objectives of this paper.

Synthesis of results

Results will be synthesized using descriptive statistics (e.g., frequencies and percentages) as well as a high-level content analysis, aligned with the structure of the data abstraction form. Descriptive statistics will summarise variables from each of the seven sections, presented in either tables or graphs. Qualitative data (e.g., the definition of autism) will be analyzed through content analysis to highlight key elements and context. Combining quantitative and qualitative results will provide a comprehensive understanding, with input from Autistic PWLE, to contextualize results and determine the presentation format.

Patient and public involvement statement

PWLE are core members of the research team, ensuring their active involvement throughout the research process. The team includes three Autistic self-advocates and two family members. A plan for PWLE involvement was co-designed using the Saskatchewan Centre for Patient-Oriented Research's Project Planning Tool.[31] Participation was made accessible based on individual needs and abilities. PWLE have contributed to study design, protocol drafting, data interpretation, and advising on result dissemination, and will co-author final outputs, review summaries, and evaluate the research process.

This engagement ensures the study prioritizes the needs and experiences of Autistic people and their supporters, placing their voices at the forefront of the scoping review and its findings.

DISCUSSION

To the authors' knowledge, this is the first empirical paper to summarise international autism policies from a human-rights perspective. By analyzing policies through the lens of the UNCRPD, we provide a critical opportunity for countries developing, implementing, or revising national autism strategies to integrate essential human rights considerations.[32]

Currently, while many countries are starting to develop new autism national strategies and revise existing strategies, there are many other countries still lacking autism or even disability national strategies. The development of autism-specific strategies provides a mechanism for enhancing services and supports for and upholding the human rights of Autistic people worldwide. The World Health Organization recognized autism as a global health priority in 2014, urging coordinated efforts to address significant gaps in autism care and support to address major global shortcomings.[33] Autism national strategies provide an opportunity for each country to outline key priorities and approaches within the context of that country's culture and existing disability laws and policies that can provide the services, supports, and opportunities needed to help Autistic people thrive.

Global advocacy has underscored the need for government-led national strategies to improve the health and well-being of Autistic people and support their families and caregivers.[34] National strategies can play a crucial role in streamlining national leadership, fostering cross-ministerial/departmental collaboration, and ensuring access to appropriate and tailored services and supports across the lifespan.[6]

Several countries, including England,[16] Malta,[17] and the United States,[35] already have national strategies in place, some of which have been revised several times since their inception. These countries have seen improvements in healthcare, education, employment, social services, community integration, , and societal inclusion and acceptance of Autistic people.[34]

The findings of this review will be valuable for policymakers and advocates working to develop, implement, and evaluate national autism strategies worldwide. By using the UNCRPD as a framework to guide data extraction and contextualize results, this review provides a rights-based approach to policy analysis that can help advance inclusive disability policies. This scoping review can inform future autism policies by highlighting current practices, promising approaches, and areas for improvement.

Additionally, our review will serve as a key evidence-based resource for the global autism community. An accompanying lay summary is provided for increased accessibility of this information including descriptions of policy tools designed to address the inequities relevant to the autism community. Developed with and for PWLE, this resource can be used by Autistic people and families/caregivers to advocate for their own rights.

Strengths and limitations

To the best of the authors' knowledge, this is the first comprehensive review of international autism strategies and policies. The results aim to support inclusive policy design and systemic change. Framed by the UNCRPD, the findings can support future policy development, strengthen the rights of people with disabilities, and enhance the implementation of the UN CPRD by state parties.[36–38]

The scoping review will follow JBI's rigorous methodology, including a targeted grey literature search. A key strength of this study is the effort made to locate autism policies that have been identified but cannot be found, or are unavailable, in English. Policies in languages other than English or French will be translated by certified translators.

Importantly, PWLE are involved as members of the research team and co-authors of the manuscript, ensuring their voices are central to the study, from data analysis, and contextualization of results, to knowledge dissemination.

Despite these strengths, there are several limitations. Policy documents not publicly available or inaccessible through direct government contact may be missed. Language barriers may also limit the identification of policies not in English or French, and translation inaccuracies could affect the quality of extracted information.

ETHICS AND DISSEMINATION

As this scoping review uses publicly available documents and does not involve human subjects, ethical approval of the research is not required. Adopting an integrated knowledge translation approach, the research team will engage end knowledge users (i.e., Autistic people, families/supporters/caregivers, researchers, service providers, and policymakers) throughout the research process, ensuring recommendations are directly applicable to practice and policy.[39] Results will be shared with Kids Brain Health Network; Autism Alliance of Canada; Autism Europe; the Office of National Autism Coordination/ National Institute of Mental Health/ National Institutes of Health and the Interagency Autism Coordinating Committee in the United States; the Autism Advisory Council of the Government of Malta; and the Public Health Agency of Canada; as well as being presented at national and international autism and disability conferences. Autistic research team members will help develop accessible knowledge translation products and disseminate them through their own networks.

AUTHORS’ CONTRIBUTIONS

DS and DP wrote the first draft of the protocol; all authors participated in content contribution and editing. AM, CR, and PK developed the data extraction form and conducted pilot testing. DS, DP, AM, CR, PK, JDZ contributed to the development of the search strategy and inclusion/exclusion criteria. DS, JDZ, and ACT supervised and reviewed the design of the protocol. SE, YS, AG, SD, HTN, and JL provided input on the study objectives, design, and dissemination plan. All authors read and revised/contributed to the final protocol before submission.

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COMPETING INTERESTS STATEMENT

The authors declare no competing interests.

OPEN SCIENCE FRAMEWORK REGISTRATION

This protocol is registered with Open Science Framework (OSF): Singal, D., Schor, M., Pearlston, D., Minuk, A., Roth, C. G., Kar, P., ... Zwicker, J. (2025, February 18). Scoping Review of National Autism Strategies: Considering Autism Policy within the framework of the United Nations Convention on the Rights of Persons with Disabilities. Retrieved from [osf.io/729cb](osf.io/729cb)

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