

Using a Rights-Based Approach to Look at Autism Strategies Around the World

Panel Presentation | April 18th, 2023

**How many countries
in the world do you
think have a
national autism
strategy?**



**Why should we
include persons
with lived
experience in
research?**

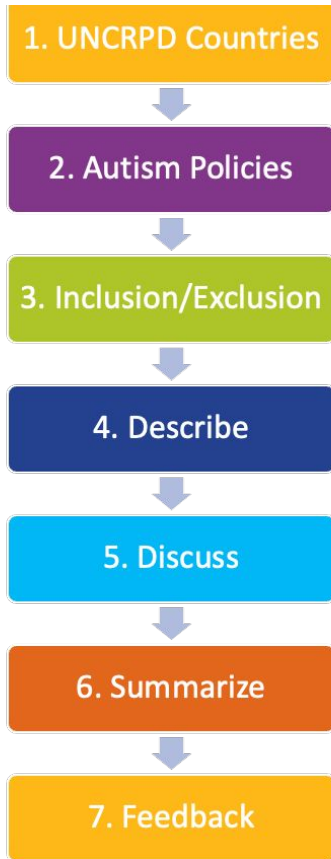


The Framework

Why is the United Nations Convention on the Rights of Persons with Disabilities a useful framework for this analysis?



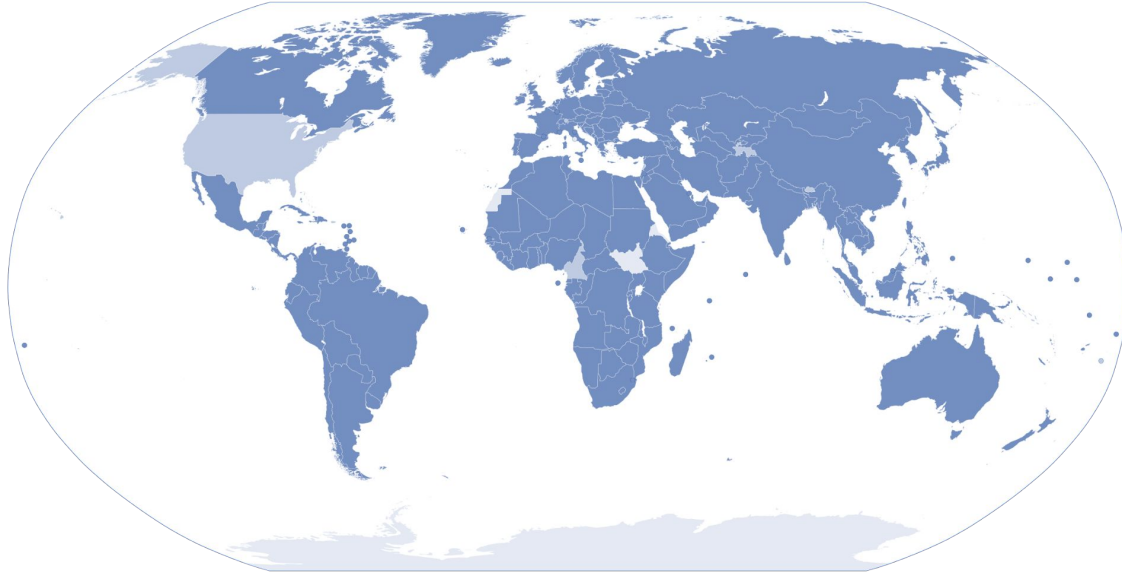
CONVENTION
ON THE RIGHTS
OF PERSONS
WITH DISABILITIES



The Process

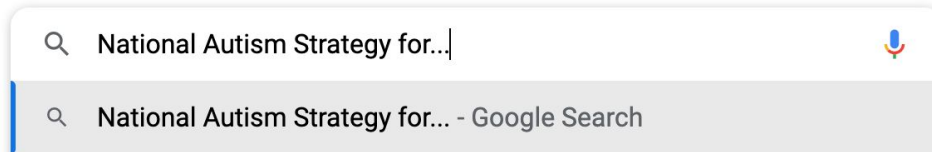
How did you identify countries with national autism policies and approach analysis?

The Process



Step 1: Identifying countries that have **committed** to the **UNCRC**

The Process



Step 2: Searching for autism strategies from those countries

The Process

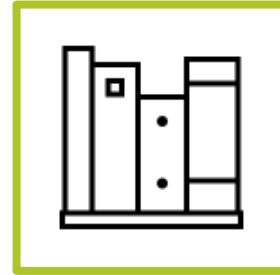
Step 3b: Strategies to **exclude**



Clinical care
guideline



For a **region**
in a country



Previous version



Non-government
group

The Process

Step 4: Describing the strategies

Document Details

Country name:

Choose ▾

⋮

Does the document address Article 24: Education?

Yes

No

Unclear

What type of document is it?

Strategy

Policy

Act/bill/law

If so, which aspects of Article 24 does it address?

inclusive education/general classroom placement (Art 24.1)

educational accommodations (e.g., access to assistive technology; Art 24.2 (c))

The Process

Step 5: Team members **discuss information**



The Process

Step 6: Summarizing the information

	Quantitative	Qualitative
Example	<i>50% of countries include a definition of autism in their strategy</i>	<i>Definitions of autism included in the strategies had the following elements...</i>

The Process

Step 7: Feedback from persons with lived experience



The Panelists

- Preeti Kar
- Alexandra Minuk
- Christiane Roth
- Yvonne Spicer



The Findings

**What we learned from
autism policies around the
world**

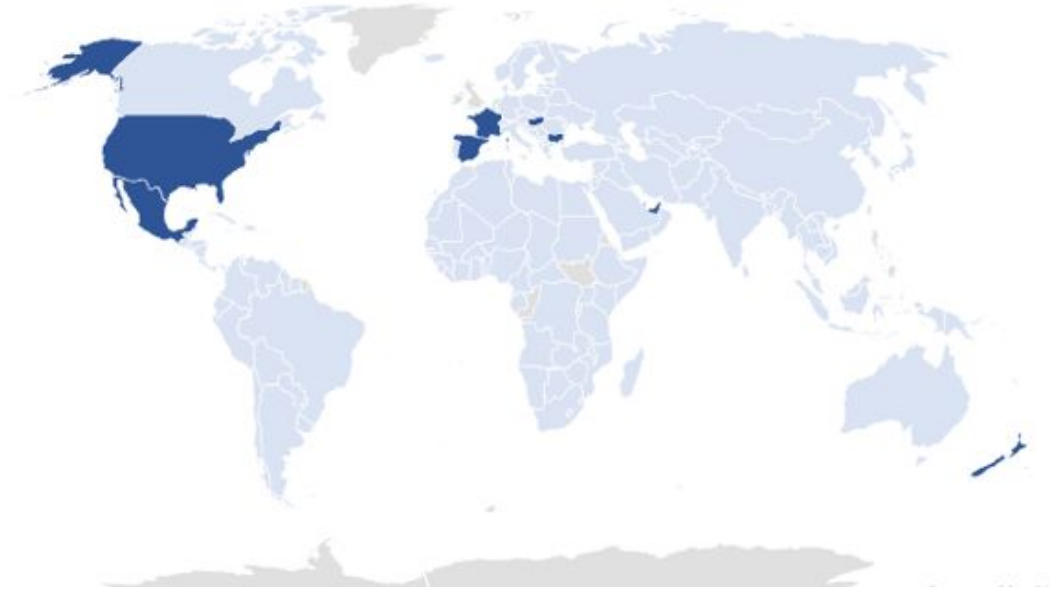
13 UNCRPD Countries with an Autism Policy

England
Wales
Northern Ireland
Scotland
Spain
Malta
Hungary
Bulgaria
France

USA
Mexico

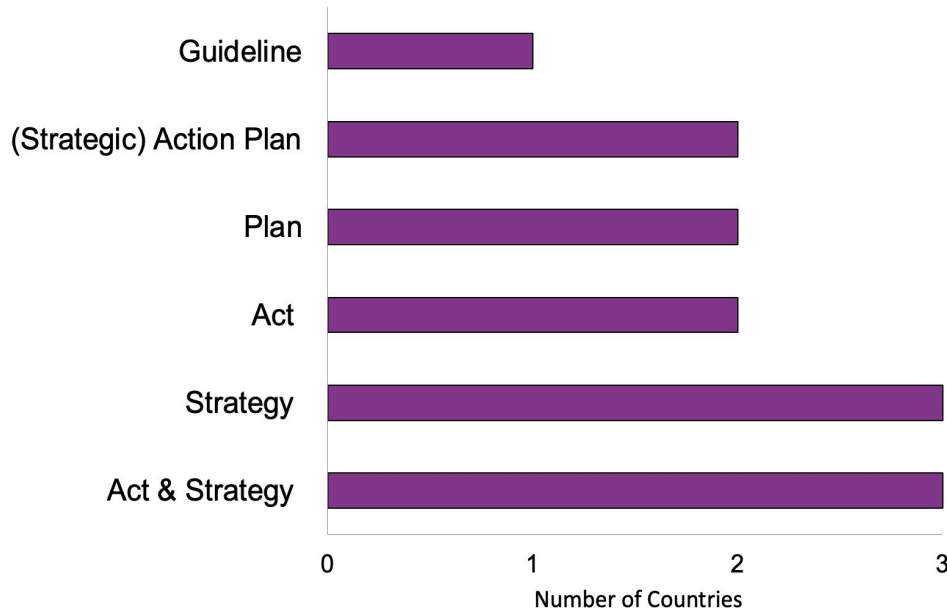
Qatar

New Zealand

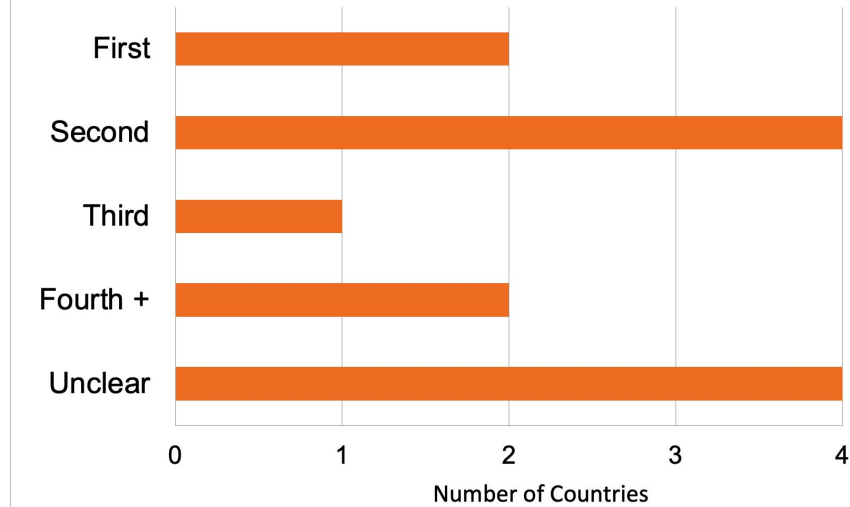


How do countries approach autism policy-making?

Policy Instrument or Type

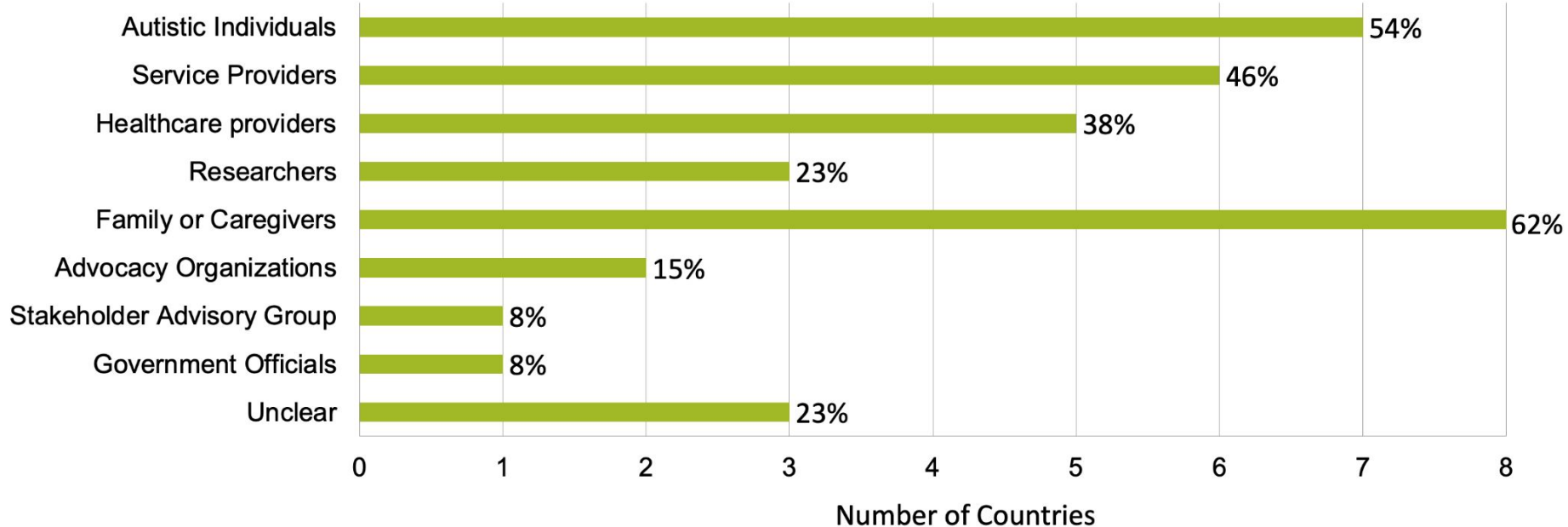


Version of Autism Policies

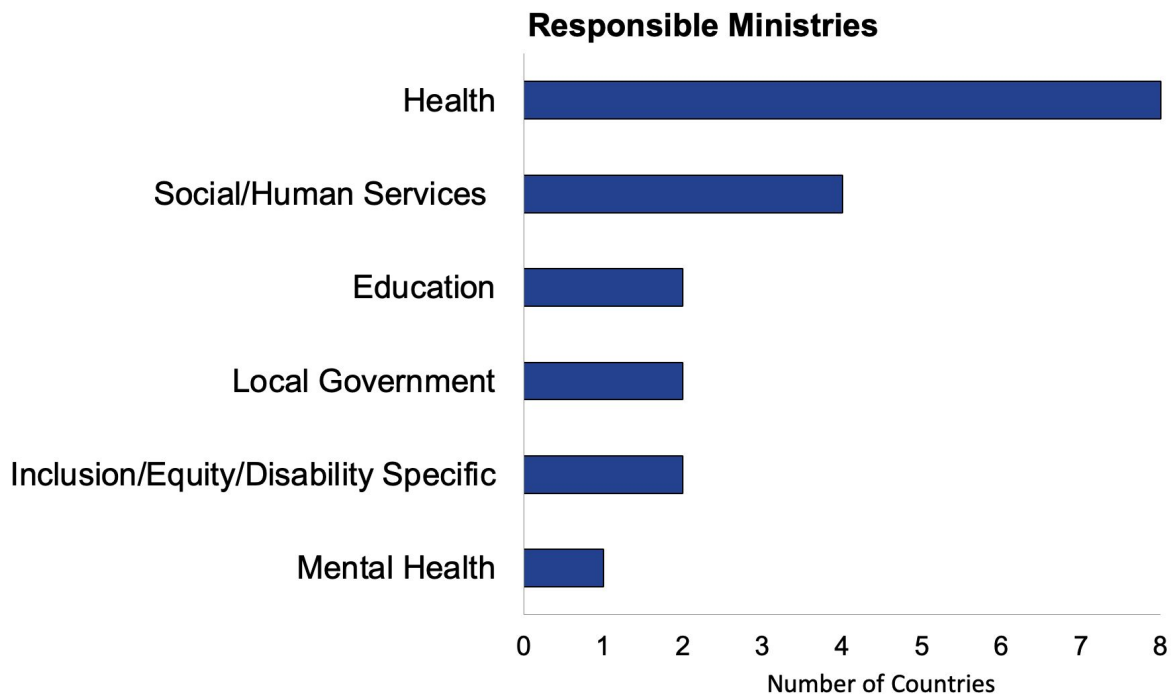


Who was included in the policy-making process?

Stakeholders Informing Autism Policies



Who is responsible for autism policies?



"need for greater focus on ensuring coordination and collaboration across Departments." - Northern Ireland

How is implementation ensured?

Country	Cross Sectoral Governance Structure for Policy Implementation
England	Cross-sectoral Executive Group with Task and Finish Groups
Malta	Cross-sectoral Council
Scotland	prev. ASD Reference Group
Wales	National Autism Team / Integrated Autism Service
USA	Interagency Autism Coordinating Committee
Northern Ireland	Cross-Departmental Autism Stakeholder Forum
Mexico	Inter-Secretarial Commission
France	Steering structure with ministries and bodies at national and regional level and advocacy groups.
Qatar	Cross-sectoral task force

What impact has been achieved?

Best Practice Example (France)

LISTE DES MESURES

AMBITION 1 :

CONSTRUIRE UNE SOCIÉTÉ INCLUSIVE POUR TOUTES LES PERSONNES AUTISTES À TOUS LES ÂGES DE LEUR VIE

Lesson Learned:

*"It was **hard to assess its impact because of a lack of clear outcome measures** (Wales Strategy)*

N°	Fiche	Mesure	Ministère Pilote	Calendrier	Indicateurs de suivi
		Accès aux apprentissages			
1	3	Création de 180 nouvelles UEMA	Education nationale	A partir de 2019	Nombre d'unités créées Nombre d'enfants scolarisés Modalités de sortie après UEMA Satisfaction des familles
2	3	Création de 45 unités d'enseignement en élémentaire	Education nationale	A partir de 2018	Nombre d'unités créées Nombre d'enfants scolarisés Modalités de sortie après UEMA Satisfaction des familles
3	3	Ouverture d'ULIS généralistes en école élémentaire	Education nationale	A partir de 2018	Nombre d'élèves avec TSA scolarisés

Women &
Children

Awareness
raising

Accessibility

Participation
Public Life &
Politics

Education

Health

Habilitation &
Rehabilitation

Mobility

Risk &
Emergencies

Participation
Culture &
Recreation

Access to
Justice

Research,
Stats, Data

Employment

Civil Rights &
Freedoms

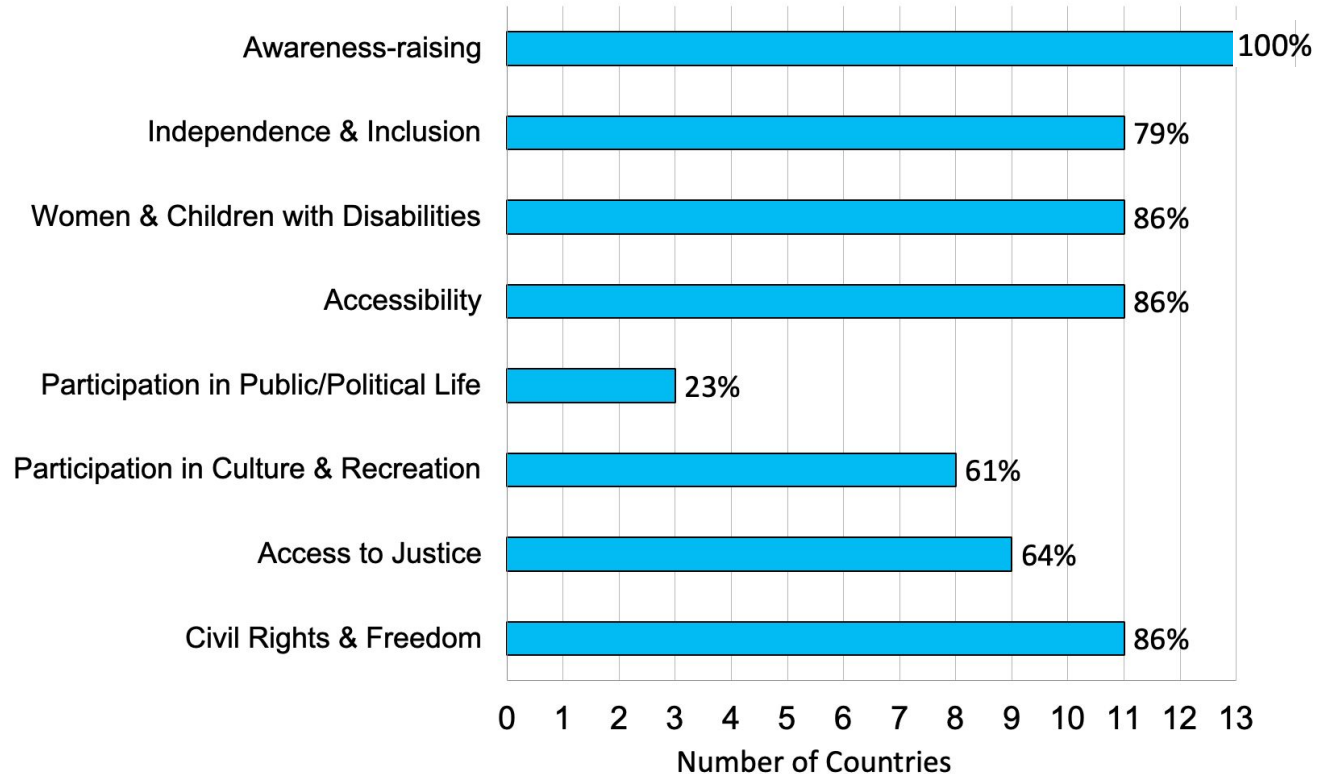
Independence
& Inclusion

Social
Protection

**What topics did
autism policies
include?**

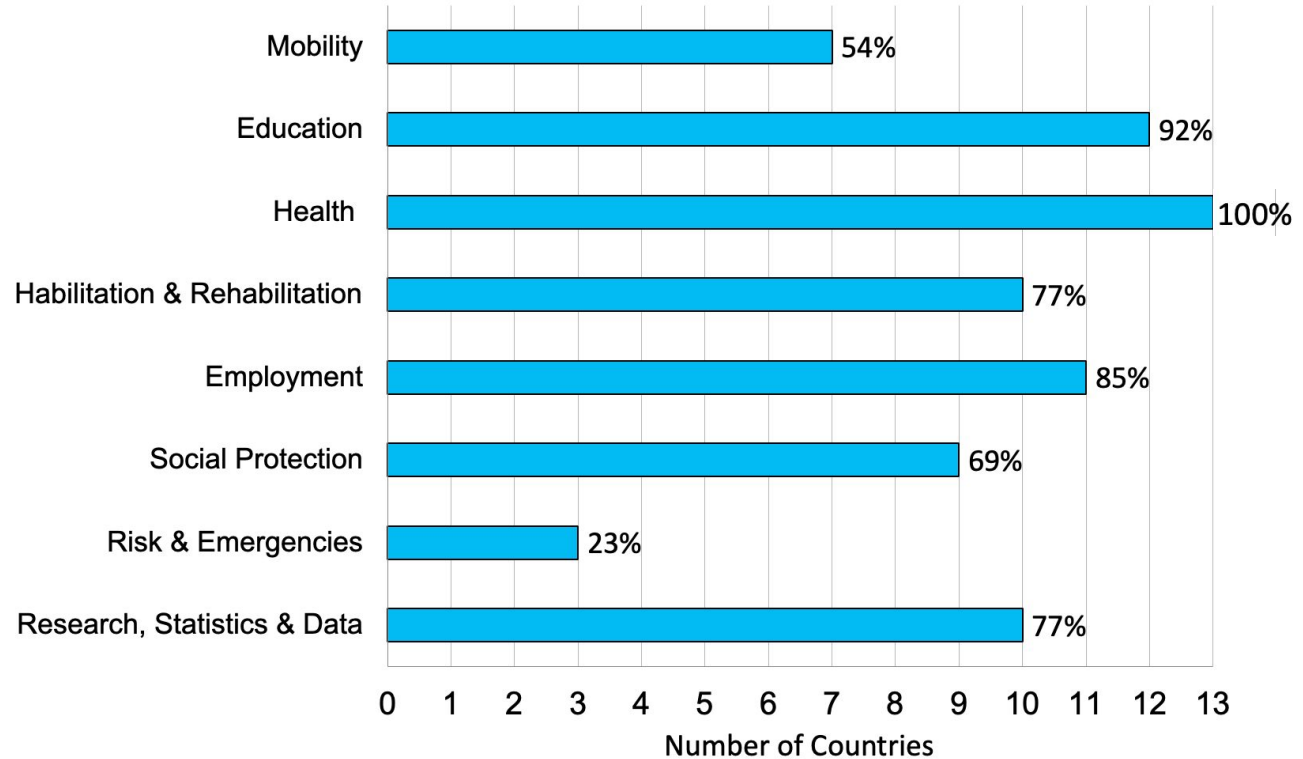
Findings:

UNCRPD Themes in Autism Policies



Findings:

UNCRPD Themes in Autism Policies



The Findings: *Awareness-raising*

✓ national public awareness campaigns

✓ bullying prevention and public acceptance

✗ representation in media, recognition of capabilities/contributions



“Prevention of stigma and discrimination and change of negative attitudes by raising autism awareness” -Mexico’s autism policy

The Findings: *Health*

✓ early identification and intervention

✓ high quality of care from trained professionals

✗ healthcare coverage or senior care



“Establish **mobile ASD specialist teams** of health and education professionals to go to nurseries and schools as required, to provide advice and support.” - *Qatar's autism policy*

The Findings: *Habilitation, Rehabilitation, Social Protection*

✓ multidisciplinary assessments

✓ housing support

✓ advocating for full physical, mental, social & vocational ability

✗ retirement

✓ high quality of care from trained professionals

✓ early identification and intervention

The Findings: *Education*

✓ Inclusive classroom placement

✓ Access to general, tertiary, and vocational education

✗ Staff training/evidence-based practices, individualized academic & social supports



*“We want more teachers and educational staff to understand the **specific needs of their autistic pupils**, ensuring that more **school placements can be Sustained.**” - England*

The Findings: *Research, Statistics, Data*

✓ Improve Health System Data and general statistics

✓ Invest in research and innovation

✗ More data collection (especially longitudinal)



“US 2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy”

The Findings: *Intersectionality*

✓ sexual and reproductive health

✓ safe relationships, abuse and violence prevention

✗ intersectionality

*“Respect for the development of the personality of persons with disability and, in particular, of children with disabilities and their **right to preserve their identity**” - Spain*

The Findings: *Political Participation*

✓ Participation in autism policy and decision making

✗ Increasing general political participation

✗ Voting, or running public for offices



Measures need to “facilitate the **integration** of people with ASD and the enjoyment of a life as autonomous as possible” Including ‘education, health, employment, social benefits, **political participation**, leisure and free time, etc.”

Limitations

- General disability laws may cover topics but these were not included in our search
- What is included in these policies doesn't necessarily reflect everything available in that country
- Discussions with stakeholders are critical in ensuring understanding of the policy environment

Concluding Thoughts

- There are a number of examples Canada can look to in developing a national autism strategy
- It is important to adopt a strengths-based approach in highlighting examples of positive practices
- It is essential to draw on diverse perspectives and especially those of persons with lived experience

Q&A Time

Question for Allie: In what ways are UNCRPD countries progressing toward their goal of achieving full inclusion in education for children with ASD?

Response:

- 92% of countries addressed inclusive education in their strategies, though this was not necessarily defined in terms of full physical, academic, and social inclusion. So while some progress is being made, it is difficult to measure and make meaningful comparisons.
- Students around the world continue to access their education in separate, specialized settings. Without addressing the components of Article 24 (e.g., social supports) other than classroom placement, we cannot achieve full inclusion.

*“We want more teachers and educational staff to **understand the specific needs** of their autistic pupils, ensuring that **more school placements can be sustained.**” - England*

*“Although children with ASD require certain areas of the curriculum to be emphasised with more intense teaching and learning opportunities, it is important that the activities and methods chosen are **developmentally appropriate**” - New Zealand*

Question for Christiane: Based on your review, what is important for the Canadian autism policy to be successful/impactful from a policy development perspective?

Response:

- Including people with lived experience in the process
- Learning from other countries
- Having well thought out structures to ensure implementation of the strategies, such as a coordinating council or dedicated office
- Have measures
- Funding allocations (9 out of 13 policies included specific funding allocations)

2. Assessment and Analysis

“We committed to a **review** of the existing autism strategy Think Autism to ensure it is still fit for purpose. We launched a public **call for evidence** [...] involving autistic people, their families and carers, professionals and voluntary organisations. This [...] **shaped our understanding of the issues autistic people and their families face across their lives** [...] and **shaped the focus and actions we are taking in this strategy.**” - *England*

Question for Preeti: What are some unique themes you learned about that are relevant for the drafting the Canadian autism strategy?

- It will also be important to include themes that others didn't! Participation in Public/Political Life so discussing voting, and including strategies for situations of risks and emergencies as vulnerability may be increased. Some strategies discussed the impacts of the COVID-19 pandemic but few discussed a plan for other humanitarian emergencies.

“This **vulnerability is increased** in situations of risk and humanitarian emergencies, in the face of possible cruel, inhuman or degrading treatment, and in the face of exploitation, violence and abuse...” - *Spain*

“Progress must be made in the recognition and effective exercise of the **right to sexual and reproductive health** of all women, especially **women with ASD**” - *Spain*

Question for Yvonne

What do you think other countries can learn from this information?