

# Meeting of the Interagency Autism Coordinating Committee

April 17, 2024; 10:00 a.m. - 5:00 p.m. ET



**Susan A. Daniels, Ph.D.**

HHS National Autism Coordinator  
Director, Office of National Autism Coordination, NIMH  
Executive Secretary, IACC

**Joshua Gordon, M.D., Ph.D.**

Director, National Institute of Mental Health (NIMH)  
And Chair, IACC

# Welcome, Roll Call, and Announcements



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# Global Autism Activities at the World Health Organization (WHO)





- Chiara Servili, MD, MPH, PhD
  - Introduction by: Leonardo Cubillos, MD, MPH

Chiara Servili Department of Mental Health and Substance Use WHO

# Improving health, well-being and participation for persons with developmental disabilities



# Pathways to transforming environments and health systems for persons with neurodevelopmental conditions

<p>DEEPEN VALUE AND COMMITMENT</p>	<ul style="list-style-type: none"><li>• Why transforming?</li><li>• Today's opportunities</li></ul>
<p>RESHAPE ENVIRONMENTS</p>	<ul style="list-style-type: none"><li>• Approaches to achieve inclusion and equal participation</li><li>• Policy, advocacy, education and community action</li></ul>
<p>STRENGTHEN SYSTEMS AND SERVICES</p>	<ul style="list-style-type: none"><li>• Build competencies at all levels and enhance role of non-specialists</li><li>• Monitor performance and outcomes</li></ul>



# Why do we need change?



**317 million** children and adolescents have a **developmental disability**



0.01 speech therapists & **0.02 occupational therapists** per 100 000 population



**Institutionalization**, human right deprivation, poorer quality of care



Countries spend just **2% of their health budget** on mental health



**Children with ASD are 1.4x more at risk of obesity**  
Young people with developmental disabilities are **51% more likely to consider themselves unhappy**



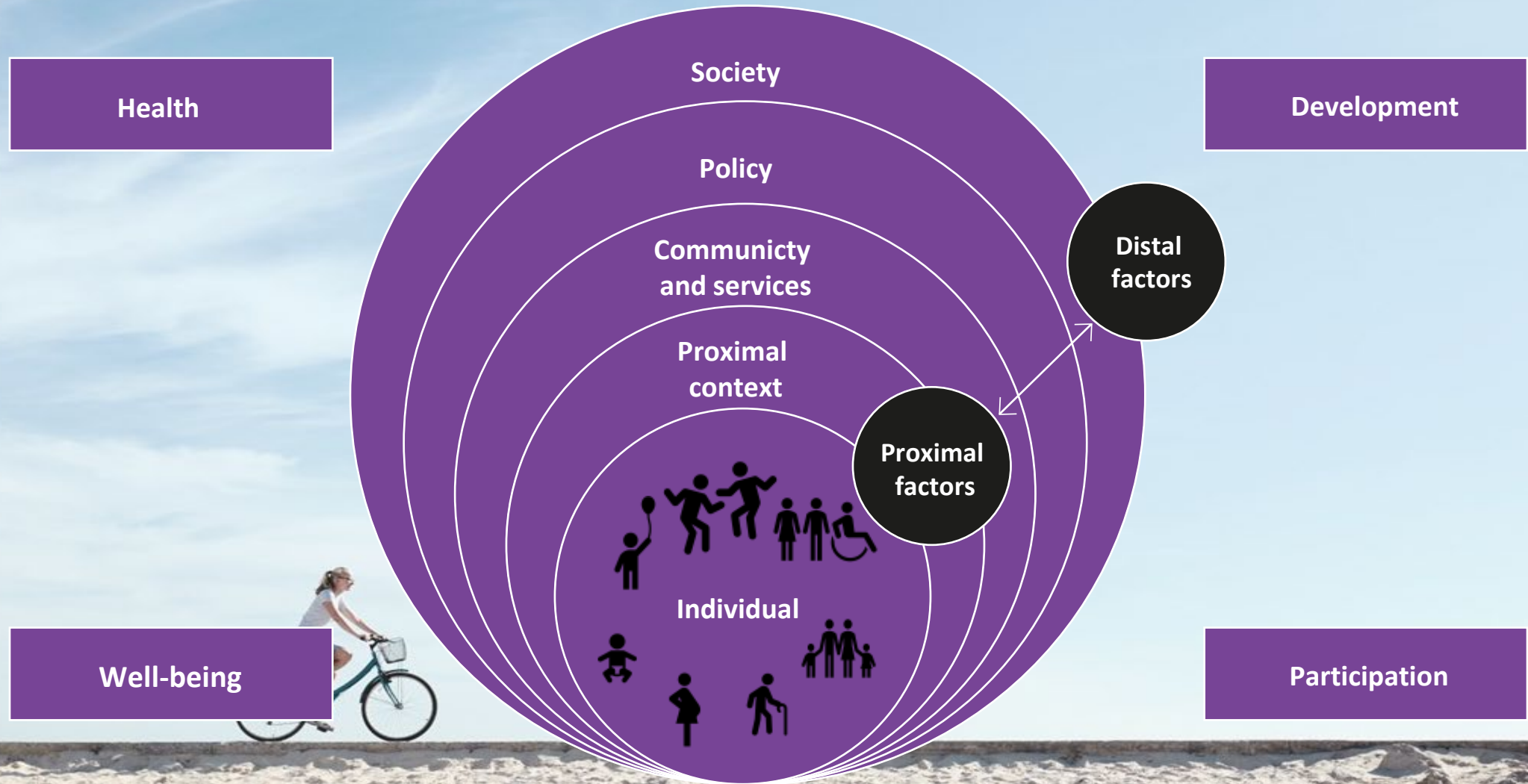
Higher risk of **premature mortality**

# Inequalities in health and opportunities to thrive





# An ecological approach to optimizing health trajectories



# Opportunities

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- International commitments (SDG, CRPD)
- Countries' demands and readiness to take action
- Strong voice of disability and neurodiversity advocates
- Much increased attention to mental health

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# Why a global report on children and young people with developmental disabilities?

→ To accelerate changes towards enabling environments and responsive health care



→ To provide a framework for action

## Who is it for?

Decision-makers, policy-makers and service-planners in health and other sectors

Other global and national stakeholders including those representing youth and persons with lived experiences

# 10 priority action areas



**Strengthen  
coordination  
and accountability**



**Deepen  
commitment  
at all levels**



**Promote  
participation  
in advocacy, leadership,  
policy, programming  
and monitoring**



**Address the social  
determinants  
of health, well-being  
and participation**



**Strengthen  
multisectoral  
policy-making  
to address inequities  
in healthcare**



**Strengthen  
services for inclusive  
and people-centred  
evidence-based  
care**



**Address  
stigmatization  
and foster inclusive  
enabling  
environments**



**Inform,  
empower  
and support  
caregivers**



**Strengthen  
data and  
research**

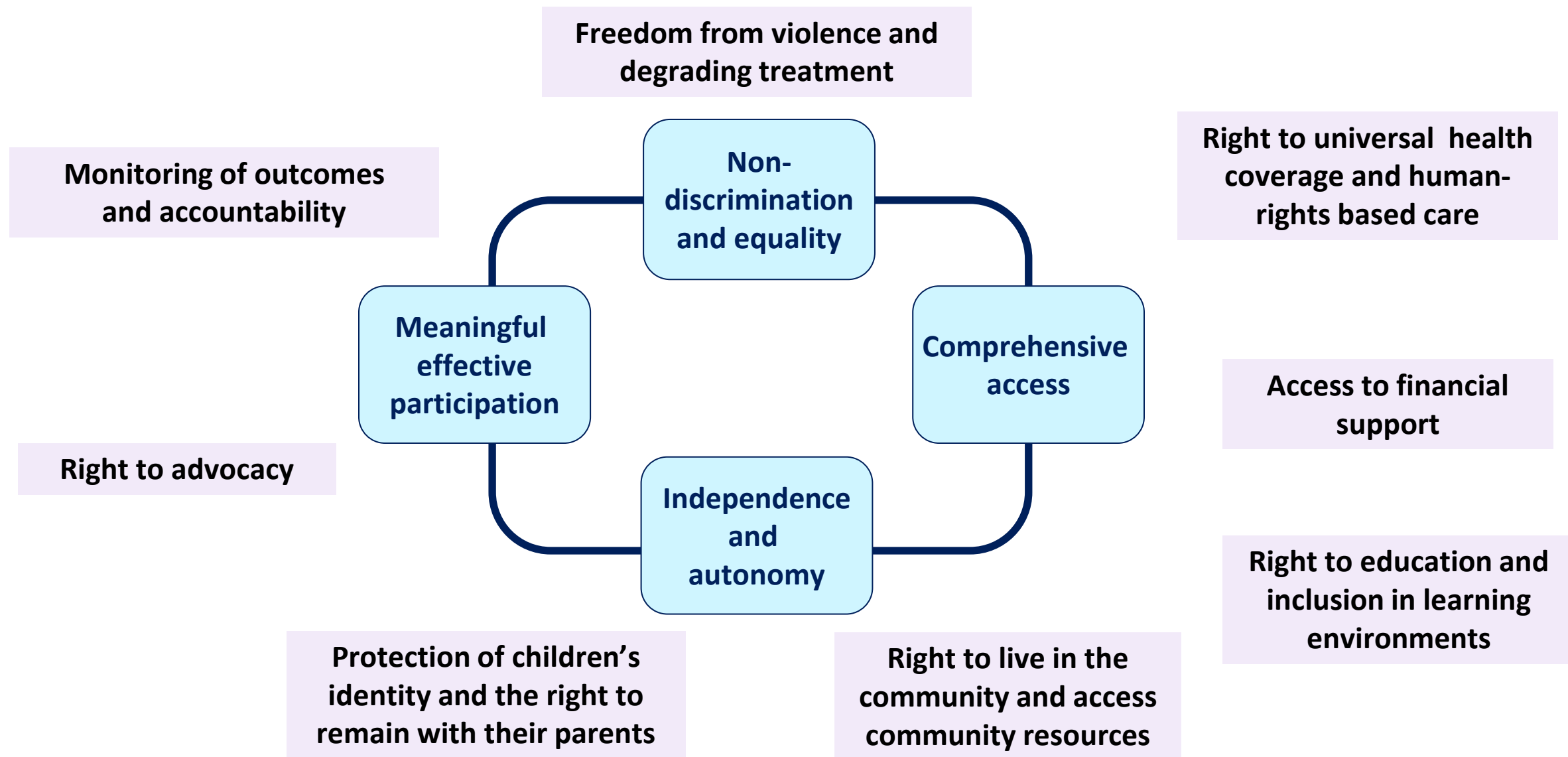


**Develop inclusive  
plans and protocols  
for health emergency  
preparedness and  
response**



**Beyond commitments:  
implementing legal and policy  
changes**

# Right-based approach to promotion of health and inclusion for persons with developmental disabilities



# Gaps in policies, barriers to change and opportunities

## Lack of coherence in policy

- Low access to care/waiting lists
- Inadequate support during transitions

- ✓ National plans and programmes to reduce health inequalities

## Inadequate enforcement of legislations and monitoring of implementation of policies

- Human-rights violation
- Low coverage of services

- ✓ Legal requirement for health and social care providers registered with the Care Quality Commission to provide employees with training on autism and learning disabilities

## Inadequate investments in community-based systems

- Inappropriate use of residential care and long-stay facilities

In spite of focused efforts, In February 2023, there were 2045 people with a learning disability and autistic people receiving inpatient care, of whom over half (56%) had a total stay of two years or longer

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# Conditions and approaches to policy making

- ✓ Local government structures
- ✓ Intersectoral coordination
- ✓ Enactment and regular updating of laws and policies on disability and inclusion
- ✓ Policy provisions explicitly addressing children with DD
- ✓ Awareness raising
- ✓ Adequate budgetary allocations
- ✓ Adequate monitoring and accountability



## Twin-track approach

- mainstream inclusion in services and
- targeted provisions for empowerment, care and support

## Health in All Policies

health considerations for children with DD into decision-making across sectors

## Reflecting real life concerns

Active involvement of young people and their families





**Transforming  
care systems and services**

## Principles for organizing and delivering care:

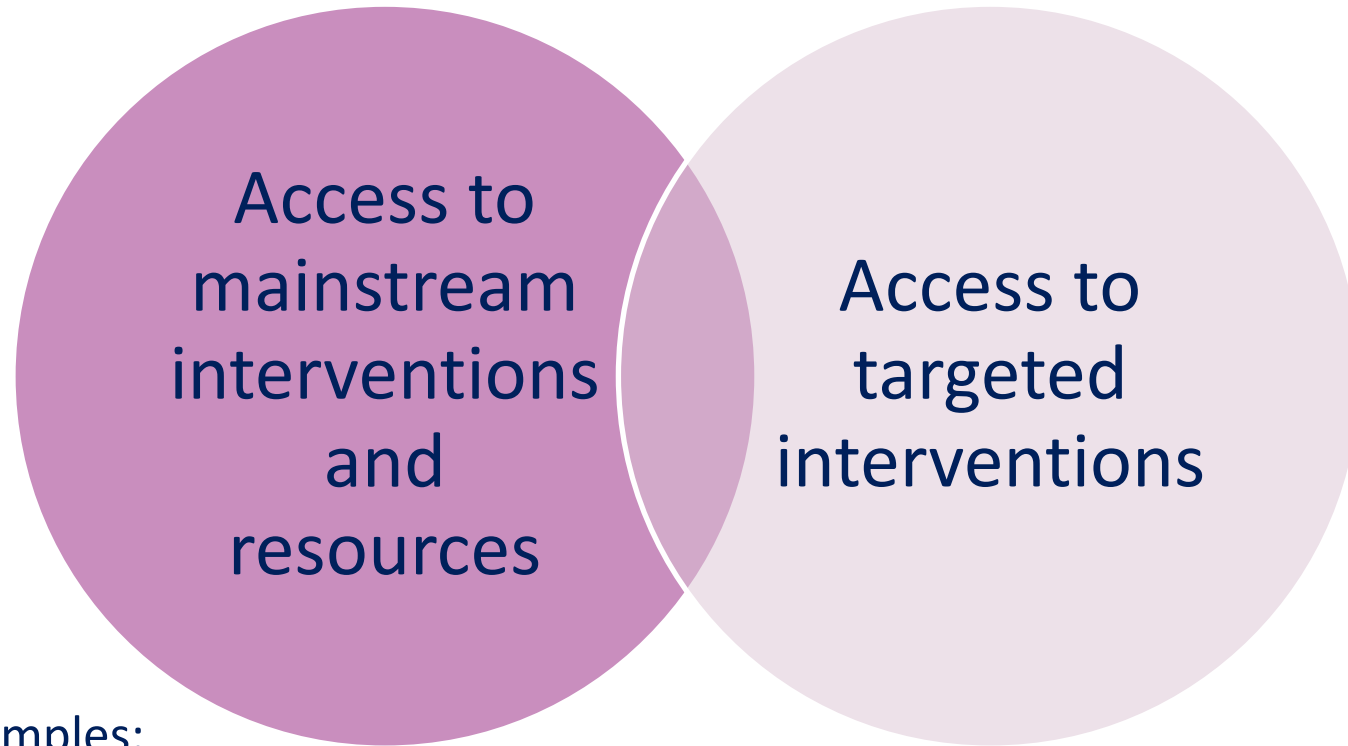
Interventions focus on:

- promoting health capital, functioning and skills (social skills, vocational training, prevention of other health conditions)
- removing barriers and promoting access to resources

Services embrace person-centred and family-centred care



# Principles for organizing and delivering care: A twin-track approach to care



## Examples:

- Annual health checks
- Improve access to sex education for adolescents through adapted learning strategies and accommodations
- Outreach parenting

## Examples:

- Build continuous surveillance and early identification
- Embed interventions into health, developmental, educational and social support services (e.g, well-care services, monitoring for high-risk children, school health services, one-stop health services)
- Develop integrated community-based service network
- Eliminate long-term institutional care

## Principles for organizing and delivering care:

A stepped approach to building tiered care systems

- To reduce costs to systems and families
- Care options at various levels of intensity linked through care pathways
- Flexible, informed by choices, preferences and evolving needs

Connect care pathways between sectors and agencies

E.g. individualized service plans



# More likely to be exposed to harmful care practices

## Involuntary care and restraint measures

Common elements of good practices include:

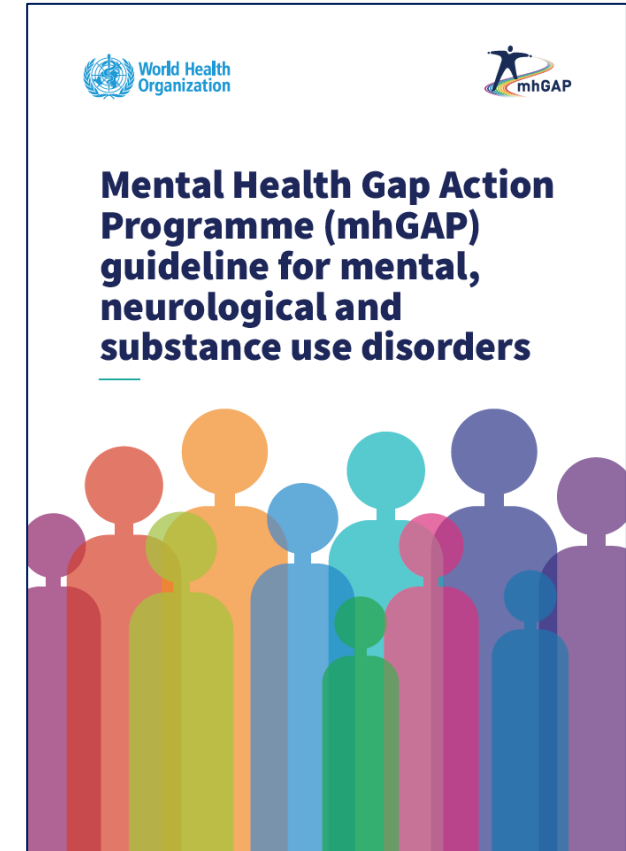
- strong leadership in care facilities based on national policy
- strict monitoring systems
- staff trained on management of difficult behaviours
- restraints being identified as human rights violation and treatment failure

## Inappropriate prescribing of medications

- Inappropriate use of antipsychotic medication for behavioural difficulties
- As substitute of unavailable psychosocial interventions
- No monitoring of clinical response, side effects, dose, adherence

# mhGAP new recommendations for children and adolescents with developmental disabilities

- 3.1 Psychosocial interventions focused on social skills training and developmental behavioural approaches for children and adolescents with autism.
- 3.2 Cognitive behavioural therapy (CBT) for children and adolescents with autism and anxiety.
- 3.4 Beginning-to-read interventions for children with disorders of intellectual development
- 3.5 Early communication interventions for children with developmental speech disorders
- 3.6 Psychosocial interventions using cognitive learning techniques for children and adolescents with neurodevelopmental disabilities
- 3.7 Structured physical exercise to improve development, including social and communication development, and functioning in children and adolescents with autism.



# WHO Caregiver Skills Training for families of children with developmental delays or disabilities

## Italy

- Ministry of Health has promoted implementation in the National Health Service
- CST offered in 12 Italian regions through Child Neuropsychiatry Services
- The intervention is for families of children up to 6 years of age, with neurodevelopmental delays and autism

## Peru

- CST delivered through Community Mental Health Centres (CAPS)





**Promoting  
participation**



# Strengthening participation

## Policies

Inclusive education

Disability allowances and financial support

## Community

Community-based inclusive development

Supported employment programmes

Awareness raising

Inclusion in sports and recreational activities

## Services

Care providers competences

Engagement of users in planning and monitoring

## Family

Caregivers empowerment and training

Caregivers' mental health and support

## Individual

Skills training (including job skills, digital literacy)

Assistive technology



**ADDRESS BARRIERS**



**DEVELOP OPPORTUNITIES FOR PARTICIPATION**



**Public health  
monitoring**

# Priority areas for monitoring

## IMPACT

Every person with a developmental disability can reach their full potential and optimal health, well-being and participation

## OUTCOMES

Improved access to health care	Health inequities are reduced	Safety and security are improved	Inclusion in education and recreational activities
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## OUTPUTS

Improved environments (physical environment, socioeconomic determinants, quality of caregiving and family functioning)	Strengthened health care services, systems, and capacity
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## INPUTS

Leadership, governance, legal and policy processes and frameworks	Inclusion of people with developmental disabilities in leadership, planning and evaluation	Advocacy, civil society and multisectoral engagement	Investing and financing for health care, education, socioeconomic inclusion and support	Care workforce and care service development	Monitoring and health information systems
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**Research priorities**

# Research priorities

- Interventions to **optimize functioning, participation, health and well-being, beyond childhood**
- Understanding of the core social determinants of **health inequalities**
- Approaches to monitor **system performance** and changes towards inclusive health and education
- Strategies to improve transition services, and on addressing barriers to accessing **life-long services** for health promotion.
- Inclusive approaches when **testing ECD and mental health interventions**

# Research priorities

- Research to inform person-centred and **individualized approaches**: which component of an intervention or strategy, and its frequency, intensity and timing, benefits which group of children and caregivers
- Research on models for **scaling up** services that meet standards of high-quality care
- Role of **digital technology**
- Strategy to improve **participation in research**



**Promoting action in  
countries**

 <p><b>Strengthen leadership, governance and advocacy</b></p> <p>An increased number of countries implement multi-sectoral and multi-stakeholder strategies and actions for mental health and psychosocial well-being for children and adolescents.</p>	 <p><b>Strengthen service delivery and care systems</b></p> <p>An increased number of countries are able to offer improved access to quality care services (across health, education and social services / child protection services) for children and adolescents with mental health conditions, and their caregivers.</p>
 <p><b>Promotion and prevention in mental health</b></p> <p>An increased number of countries are able to offer nurturing, supportive environments for children and adolescents and opportunities for them to strengthen cognitive and socioemotional skills.</p>	 <p><b>Strengthen information systems, evidence and research</b></p> <p>An increased number of countries are able to generate and use quality data and evidence to inform multi-sectoral actions and policies for mental health and psychosocial well-being and development of children and adolescents.</p>

# Mental Health and Psychosocial Well-being and Development of Children and Adolescents

## UNICEF and WHO Joint Programme



### Child and adolescent mental health high on agenda in 3 countries in Europe

2023 News release | Reading time: 2 min (315 words)

Albania, North Macedonia, and Serbia have joined a programme run by WHO and UNICEF to improve mental health and psychosocial well-being and development among children and adolescents in the target countries by 2030. The programme is part of the WHO European Region to participate in the programme, which aims to build and sustain a health system change. The WHO/UNICEF Joint Programme on Mental Health and Psychosocial Well-being also supports Bhutan, Colombia, Egypt, Guyana, Maldives, and Mozambique.





WHO and UNICEF to jointly work together to strengthen child and adolescent mental health and psychosocial well-being. Dr. João Breda, Head of the Athens Office on Mental Health, WHO Regional Office for Europe, and Dr. ...

#### Related

[Pan-European Mental Health Coalition](#)  
[WHO Office on Quality of Care and Patient Safety](#)  
[WHO/UNICEF Joint Programme on Mental Health and Psychosocial Well-being](#)

- Albania, North Macedonia, Serbia
- Colombia, Guyana
- Cote D'Ivoire, Mozambique
- Bhutan, Maldives
- Egypt, Jordan
- Malaysia, Papua New Guinea



	Outcome area	Approaches and examples
	Strengthen leadership, governance and advocacy	<p><u>Strengthened cross-sector coordination</u> for CAMBH through formal mechanisms</p> <p><b>Cote d'Ivoire:</b> multistakeholder policy dialogue on care pathways for neurodevelopmental conditions, engagement of 10 regional centres of health excellence</p>
	Strengthen service delivery and care systems	<p>Over 3150 health care staff, teachers and community workers have been trained to facilitate integration of interventions for mental health and neurodevelopmental conditions into primary health care and community settings</p> <p><b>Colombia:</b> 681 health care staff in areas affected by armed conflict were trained on CAMBH</p>
	Promotion of well-being, development and mental health	<p>Focus on reduction of risk behaviours and the prevention on mental and neurological conditions in schools, homes and communities.</p> <p><b>Papua New Guinea:</b> school-based prevention programmes, supporting development of school-based counselling guide, training of family support workers from 15 provinces on CAMBH</p> <p><b>North Macedonia:</b> 4 municipalities organized CAMBH awareness campaigns training for female community leaders</p>
	Strengthen information systems, evidence and research	<p>Focus on generation and dissemination on knowledge on evidence-based practices and interventions for children, caregivers and families.</p> <p><b>Mapping of services and systems performance analysis</b></p> <p><b>Maldives:</b> engaging in CAMBH data landscaping activity</p>

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Thanks

[servilic@who.int](mailto:servilic@who.int)



# Global burden of conditions affecting the nervous system

Conditions affecting the central nervous system are the number-one leading cause of disease burden worldwide

In 2021, around **3.40 billion individuals** had conditions affecting the nervous system, equivalent to...

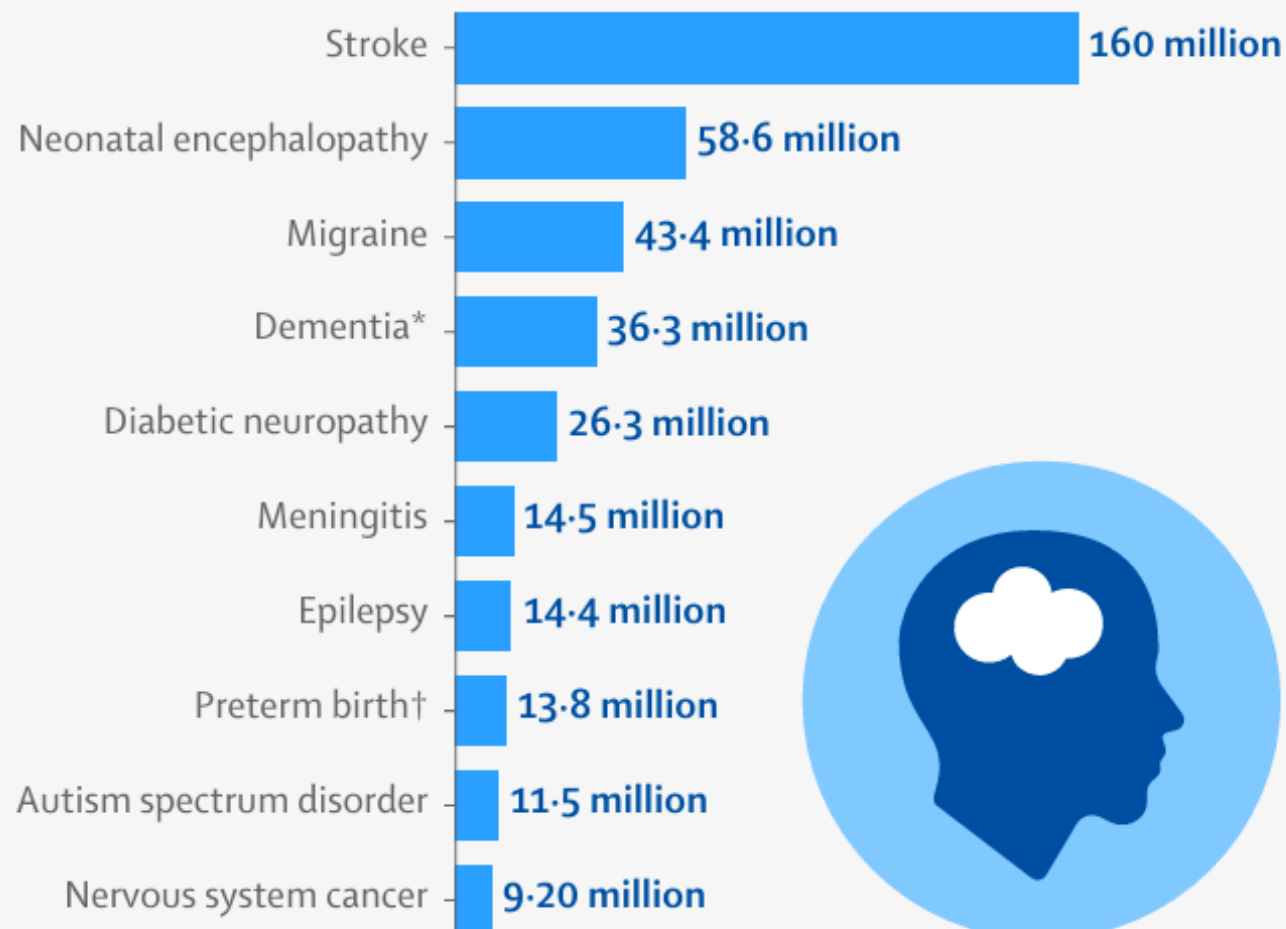


These conditions contributed to...

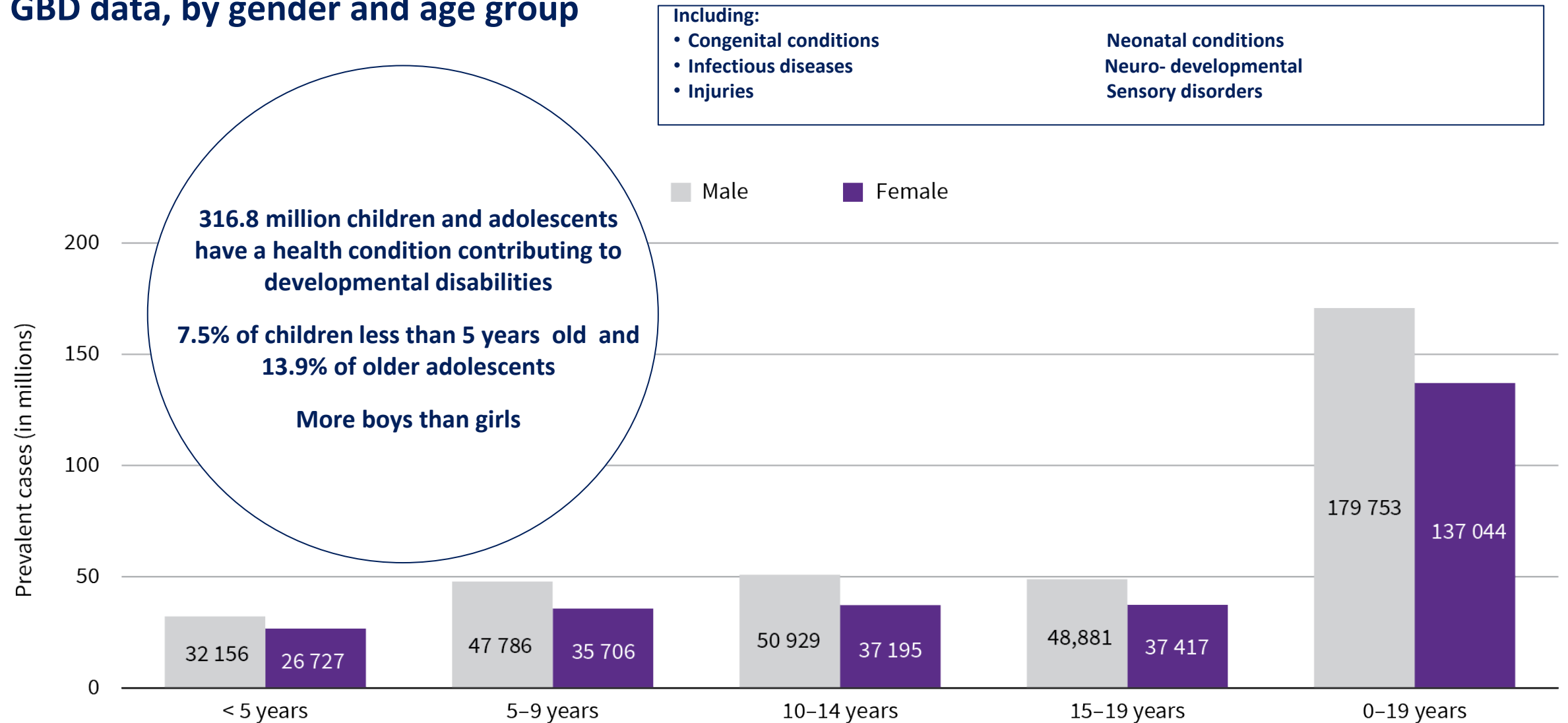


... making them the leading cause of disease burden worldwide.

The ten neurological conditions that accounted for the greatest DALYs in 2021 were...



# Global prevalence of conditions that contribute to developmental disability based on 2019 GBD data, by gender and age group



**Break**



# National Autism Coordinator Update

IACC Full Committee Meeting  
April 17, 2024

**Susan A. Daniels, Ph.D.**

HHS National Autism Coordinator

Executive Secretary, IACC

Director, Office of National Autism Coordination



# Overview

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- Autism Acceptance Month Updates
- FY 2019-2023 Report to Congress on Federal Autism Activities
- White House Updates
- Federal Committee Updates
- Federal Department and Agency Updates
- Non-Governmental Activities and Updates
- Legislative Updates

More information about these updates can be found in the meeting materials:

[https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/april17/nac\\_update.pdf](https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/april17/nac_update.pdf)

## National Autism Coordinator Update

# Autism Acceptance Month Updates

- On April 1, 2024, **President Biden** issued a Proclamation on **World Autism Acceptance Day**. [Read full Proclamation here](#).
- HHS has officially changed its designation of April to **National Autism Acceptance Month**.
- On April 2, 2024, the **United Nations** held a virtual observance event titled “*Moving from Surviving to Thriving: Autistic individuals share regional perspectives.*” [View event details here](#).
- On April 2, 2024, **Indian Health Service** posted a message celebrating Autism Acceptance Month. Additionally, IHS held a webinar titled *Applied Behavior Analysis: Love It, or Hate It, but First Understand It* on April 5, 2024. [View the message here](#).
- On April 11, 2024, **National Institute for Environmental Health Sciences** held an event featuring Eric Garcia, author of *We’re Not Broken: Changing the Autism Conversation*. [View event details here](#).



Additional AAM news and events found on IACC website:  
<https://iacc.hhs.gov/meetings/autism-awareness-month/2024/>



## National Autism Coordinator Update

# NIMH Director's Blog for Autism Acceptance Month

- Dr. Joshua Gordon and Dr. Susan Daniels co-authored a blog post for Autism Acceptance Month.
- The blog post highlighted the importance of incorporating lived experience perspectives in shaping federal autism research, services, and policy.
- [View the blog post here.](#)

About the Director

Director's Messages

Dr. Gordon in the News

Congressional Testimonies

NIMH Directors

Messages by Year

2024 2023 2022 2021 2020 2019

Messages by Topic

**HEALTH TOPICS**

Anxiety Disorders

Autism Spectrum Disorder (ASD)

Bipolar Disorder

Borderline Personality Disorder

COVID-19

Depression

Eating Disorders

HIV/AIDS

Obsessive-Compulsive Disorder (OCD)

Post-Traumatic Stress Disorder (PTSD)

Psychosis

Schizophrenia

Substance Use

Suicide

Traumatic Events

**POPULATIONS**

Children and Adolescents

### The Importance of Lived Experience Perspectives – Insights From the IACC

*Joshua A. Gordon, M.D., Ph.D., and Susan Daniels, Ph.D., HHS National Autism Coordinator and Director of the NIMH Office of National Autism Coordination*


April 4, 2024

Follow the NIMH Director on X

During National Autism Acceptance Month, NIMH and the NIMH Office of National Autism Coordination celebrate the important contributions of autistic people in our families and our society, and we reaffirm our support for their acceptance, inclusion, and full participation in all aspects of community life. This April, we would like to highlight NIMH's unique role in federal autism coordination efforts and reflect on how the lived experiences of autistic people and their families have shaped federal autism research, services, and policy.

We have the privilege of serving as the Chair and Executive Secretary of the Interagency Autism Coordinating Committee (IACC). The IACC is a federal advisory committee established by Congress and currently authorized under the Autism CARES Act of 2019. The committee includes federal officials from agencies that support autism research and vital services for people with disabilities, as well as public members, including autistic adults, family members, advocates, researchers, and service providers from diverse communities around the country.

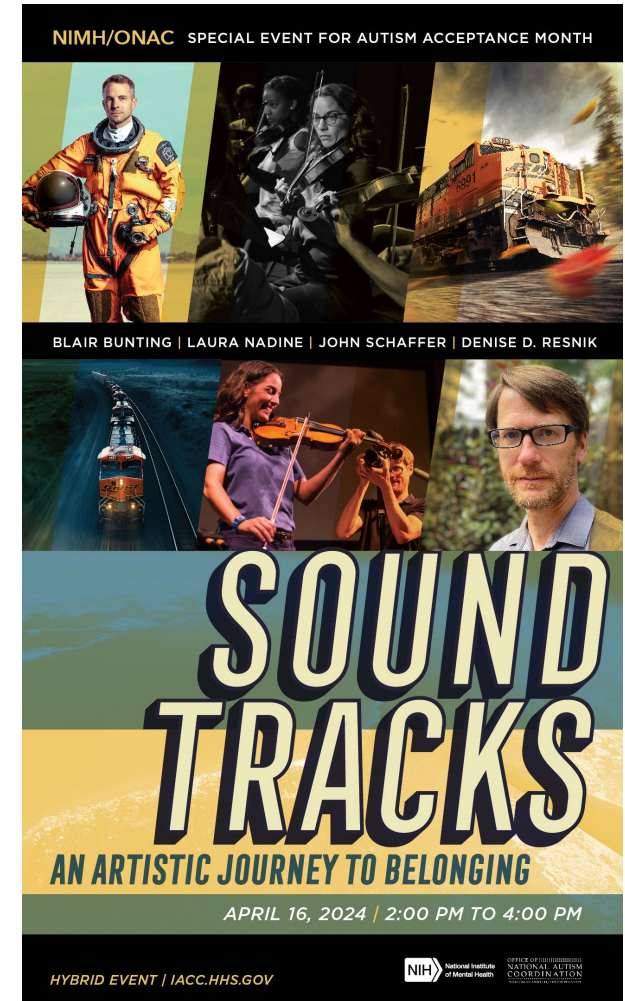
The IACC serves as a forum for community engagement



Dr. Gordon (left) and Dr. Daniels (right) at the January 2024 IACC meeting.

# NIMH/ONAC Special Event for Autism Acceptance Month

- On April 16, 2024, **NIMH** and **ONAC** hosted a special event titled, *Sound Tracks: An Artistic Journey to Belonging*.
- Hybrid event featured autistic photographer Blair Bunting, autistic violinist Laura Nadine, and neurodivergent filmmaker John Schaffer.
- The event included a showing of the film *Sound Tracks* as well as Q&A with the artists and remarks from Denise Resnik of First Place AZ, the non-profit organization that sponsored the film
- The recording will be posted on the IACC website for public access.
- [View Event Web Page.](#)



## National Autism Coordinator Update

# FY 2019-2023 Report to Congress on Federal Autism Activities

- Describes the autism-related activities of **over 25 federal departments, agencies, divisions, and offices** in FY 2019-2023.
- Includes descriptions of federal programs on biomedical and services **research, education, health, employment, housing, disability benefits, justice, and disability services.**
- Provides **updates on progress** made in implementing the provisions of the Autism CARES Act of 2019.
- Includes information on the **incidence and prevalence** of autism, average **age of diagnosis and intervention, effectiveness** of new and existing **interventions**, and home and community-based services (**HCBS**).
- Previously submitted to Congress, as required by the **Autism CARES Act of 2019.**
- **Expected public release: Spring 2024**



# White House Updates

- President Biden used his State of the Union address to urge Congress to add funding for Medicaid home and community-based services. His budget request for the 2025 fiscal year also includes funding for special education services and provider training. [View the remarks here.](#)
- President Biden recently signed an Executive Order which will help create more Registered Apprenticeship (RA) programs in the federal workforce. [View Executive Order here.](#)



# Federal Committee Updates

- **Interagency Committee for Disability Research (ICDR)**
- National Council on Disability (NCD)
- Federal Partners in Transition (FPT)
- Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)
- Disability Advisory Committee (DAC)
- President's Committee for People with Intellectual Disabilities (PCPID)
- Children's Interagency Coordinating Council (CICC)

Updates on these committees can be found in the meeting materials:

[https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/april17/nac\\_update.pdf](https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/april17/nac_update.pdf)

# Interagency Committee on Disability Research ([ICDR](#))

- Managed by the Administration for Community Living (ACL)
- Scope: Disability, independent living, and rehabilitation research programs
- Recent activities include:
  - Launch of the Interagency Rehabilitation and Disability (IRAD) [Research Portfolio](#). The IRAD Research Portfolio is a searchable, government-wide inventory of disability, independent living, and rehabilitation research. The Research Portfolio currently features data from five federal agencies [National Institutes of Health (NIH), National Science Foundation (NSF), Veterans Affairs (VA), Administration for Community Living (ACL), and the Centers for Disease Control (CDC)]. [Read more here](#).
  - ICDR released a [new toolkit on participatory action research](#).
  - ICDR released a new toolkit [Surveying the Landscape of Disability Data and Statistics: A Toolkit for Interagency Collaboration](#).

## Federal Department and Agency Updates

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- **Food and Drug Administration (FDA)** proposes new ban on electrical stimulation devices. [Read press release here.](#)
- **Government Accountability Office (GAO)** released a report on strengthening autism interagency coordination. [View report here.](#)
- **Census Bureau** announces next steps on the American Community Survey (ACS) disability questions. [View statement here.](#)

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# Non-Governmental Activities and Updates

- [INSAR 2024 Annual Meeting](#): May 15-18, 2024
- [Autism Science Foundation Day of Learning](#): April 4, 2024
- [Profound Autism Summit](#): April 5, 2024
- [AIR-P Webinar: Introduction to Plain Language Writing for Academics and Researchers](#)
- [National Coalition Sets Roadmap To Improve Health Care For Those With IDD](#)
- Report: [The Case for Inclusion: Transforming Temporary Progress into Long-Term Sustainability](#)

Full text of updates can be found in the meeting materials:

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## National Autism Coordinator Update

# Legislative Updates

- **Legislative Hearing to Support Patients and Caregivers** (February 14, 2024; House Energy and Commerce Committee, Subcommittee on Health). View the [hearing recording here](#).
  - Among the legislation discussed, the subcommittee discussed [H.R. 7213](#), Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024 (co-sponsored by Reps. C. Smith and H. Cuellar).
- **Legislative Hearing on Disability Employment** (February 29, 2024; Senate Special Committee on Aging). View the [hearing recording here](#).
- **Legislative Hearing to Support Entrepreneurs and Employees with Disabilities** (January 30, 2024; House Committee on Small Business). View the [hearing recording here](#).



Full text of updates can be found in the meeting materials:

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# Additional Updates

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- A National Autism Coordinator Updates Document outlining additional White House activities, Federal committees, news, events, and legislative updates can be accessed in the April 17, 2024 IACC Meeting Materials:
  - [National Autism Coordinator Updates – April 2024](#)

# IACC Committee Business

IACC Full Committee Meeting  
April 17, 2024



**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC

HHS National Autism Coordinator

Director, Office of National Autism Coordination, NIMH

# Committee Business Overview



- ONAC Staff Updates
- 2019-2020 IACC Portfolio Analysis Report – Available Now!
- International Portfolio Analysis Report
- 2023 IACC Summary of Advances status
- *2024 IACC Summary of Advances* discussion
- 2024 Strategic Plan Update status
  - Analysis of Request for Public Comments on Co-Occurring Conditions

# ONAC Staff Updates



- Oni Celestin, Ph.D. has been appointed as the Deputy Director of ONAC. She will assist with the overall management of the office.



# 2019-2020 Autism Research Portfolio Analysis Report Available Now!



- This report provides comprehensive information about autism research funding among federal agencies and private research organizations in the United States.
- This edition represents the **12<sup>th</sup>** and **13<sup>th</sup>** years of data collected and the **9<sup>th</sup>** comprehensive report of U.S. autism research funding.
- The report presents trends in autism research funding from **2008 to 2020** and alignment of research projects with the **Objectives of the 2016-2017 IACC Strategic Plan**.
- The report also includes analysis of the Cross-Cutting Objective on **autism in girls and women** and an examination of autism projects focused on addressing racial, ethnic, geographic, and socioeconomic **disparities**.
- View the **full report** and accompanying **At-a-Glance summary**:  
<https://iacc.hhs.gov/publications/portfolio-analysis/2020/>



# Funders Included in the 2019-2020 Autism Research Portfolio Analysis Report



- The time and efforts of all funders who contributed to the portfolio analysis are greatly appreciated by the IACC and ONAC.
- **14** federal departments and agencies and **16** private organizations contributed their autism research funding information for the *2019-2020 Portfolio Analysis Report*.
- **5** federal funders and **4** private organizations were newly added to this year's report, reflecting the expanding landscape of autism research in the United States.

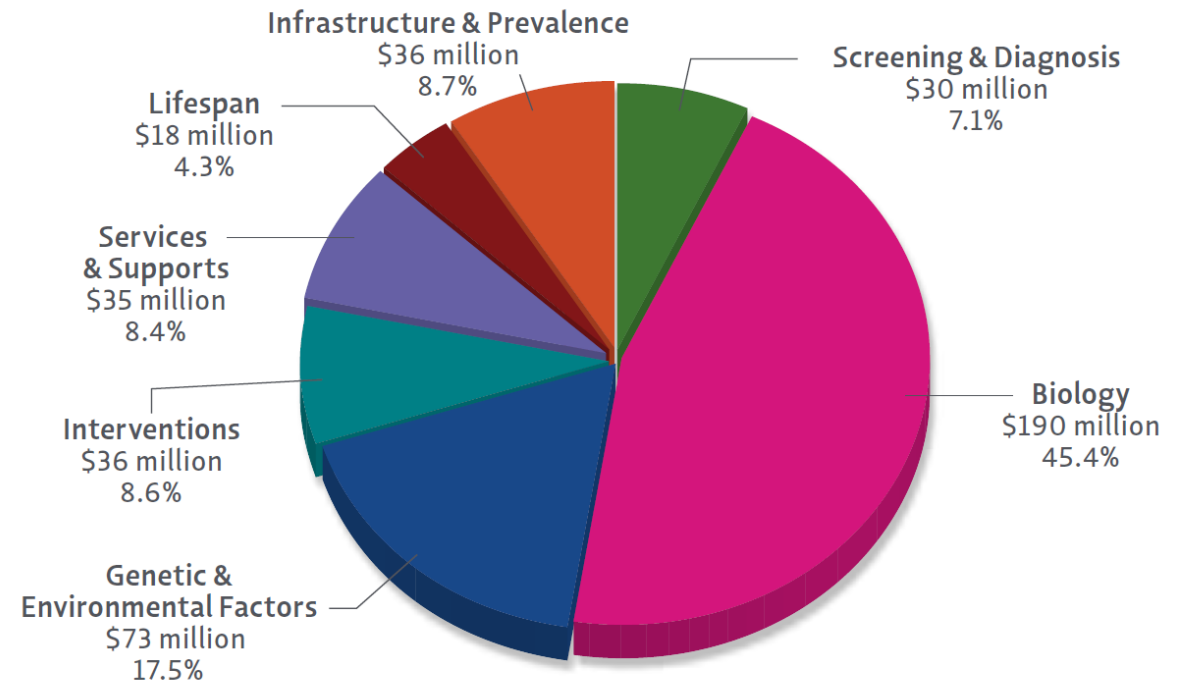


# Research Funding Aligned to IACC Strategic Plan Question Areas



- In **2020**, total U.S. autism research funding was estimated to be **\$418.9 million**, spanning **1,573 projects**.
- The largest portion of funding addressed the underlying **Biology** of autism (Question 2).
- Funding for research in the areas of **Services and Supports** (Question 5) and **Lifespan** (Question 6) has increased in recent years (approximately doubling since 2016).

## 2020 Autism Research Funding by IACC Strategic Plan Question Area



*Distribution of 2020 autism research funding by IACC Strategic Plan Question. 2019 proportions were similar.*



# IACC Portfolio Analysis Report

## Next Steps



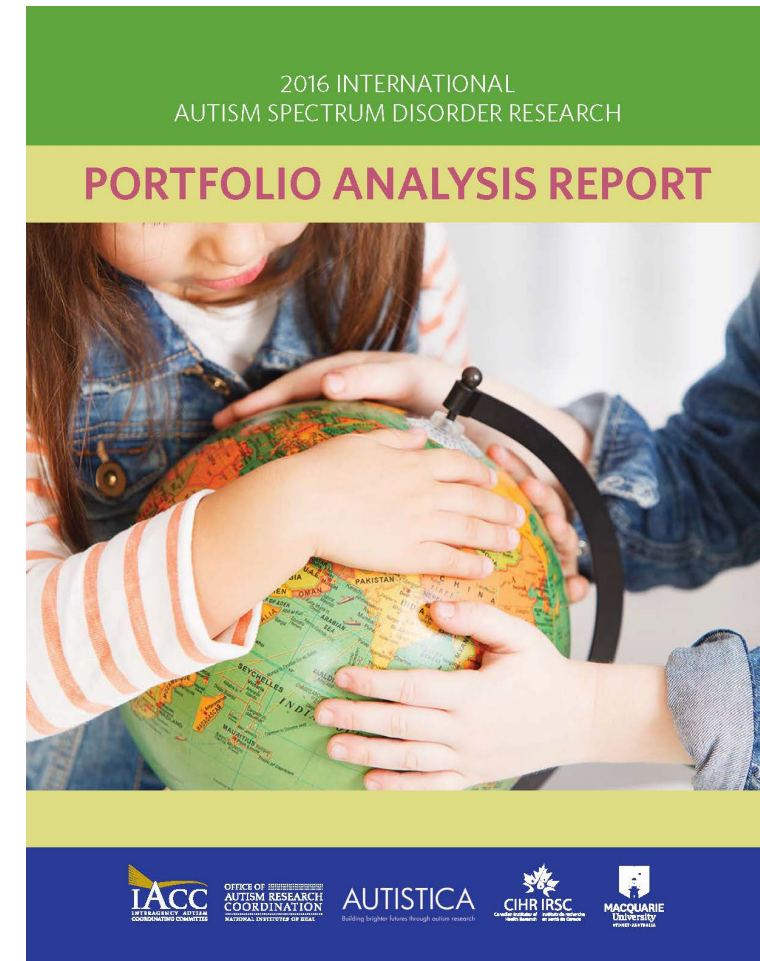
- ONAC is currently working on the 2021 and 2022 *IACC Portfolio Analysis Reports*
- ONAC will continue to identify additional U.S. autism research funders for inclusion in the Reports.
- The next iteration of the Report will evaluate research progress using the updated Recommendations of the *2021-2023 IACC Strategic Plan*.



# International Portfolio Analysis Report



- The first *2016 International Portfolio Analysis Report* collected autism research funding data from four countries: United States (IACC/OARC), United Kingdom (Autistica), Canada (CIHR), and Australia (Macquarie University).
- The comparison of portfolios revealed areas of emphasis, similarities, differences, and gaps across the portfolios.
- The analysis fostered international collaboration and identified global trends in autism research funding.
- <https://iacc.hhs.gov/publications/international-portfolio-analysis/2016/>



# International Portfolio Analysis Report



- During the Committee hiatus, ONAC would like to start work on a new edition of the International Portfolio Analysis Report
- This edition will focus on **2023** autism research funding.
- In addition to Canada, United Kingdom, and Australia, ONAC will also reach out to other international collaborators to expand the scope of the report.



# 2023 IACC Summary of Advances Status



- ✓ IACC members nominate articles (January 2023 – January 2024)
- ✓ IACC members discuss nominations at committee meetings (April 2023 - January 2024)
- ✓ IACC members vote on top 20 articles (January-February 2024)
- ONAC prepares article summaries and draft publication (Winter-Spring 2024)
- IACC members preview/comment on draft (Spring 2024)
- ONAC prepares final publication (Spring-Summer 2024)

# 2024 IACC Summary of Advances Status



IACC members nominate articles (January-December 2024)

**TODAY:** IACC members discuss nominations at committee meetings (April-July 2024)

IACC members vote on top 20 articles (January-February 2025)

ONAC prepares article summaries and draft publication (Winter-Spring 2025)

IACC members preview/comment on draft (Spring 2025)

ONAC prepares final publication (Spring-Summer 2025)

# 2024 Summary of Advances Nominations



**Joshua Gordon, M.D., Ph.D.**

Director, National Institute of Mental Health  
(NIMH) and Chair, IACC

**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC  
HHS National Autism Coordinator  
Director, Office of National Autism Coordination, NIMH

# Summary of Advances discussion guidelines



- Goal of today's discussion: review the list of 18 nominated articles
- Selected articles should represent **significant advances or progress** in understanding of autism, across the 7 topic areas of the *IACC Strategic Plan*
- During the discussion:
  - Are there nominated articles you find particularly noteworthy?
  - Are there any articles that should potentially be removed, including any in the following categories?
    - Study too preliminary
    - Small sample size
    - Review article
    - Commentary
    - Workgroup recommendations



# Question 1: Screening and Diagnosis



- 1. Community testing practices for autism within the autism and developmental disabilities monitoring network.**

Robinson Williams et al. *Paediatr Perinat Epidemiol*.

- 2. Role of Primary Care Clinician Concern During Screening for Early Identification of Autism.**

Wieckowski et al. *J Dev Behav Pediatr*.



## Question 2: Biology



### **3. Motor Control Adherence to the Two-thirds Power Law Differs in Autistic Development.**

Fourie et al. *J Autism Dev Disord*.

### **4. Social Anhedonia Accounts for Greater Variance in Internalizing Symptoms than Autism Symptoms in Autistic and Non-Autistic Youth.**

Gerber et al. *J Autism Dev Disord*.

### **5. The developmental timing of spinal touch processing alterations predicts behavioral changes in genetic mouse models of autism spectrum disorders.**

Tasnim et al. *Nat Neurosci*.

## Question 2: Biology



- 6. Role of autonomic, nociceptive, and limbic brainstem nuclei in core autism features.**  
Travers et al. *Autism Res.*
  
- 7. Risk factors and clinical correlates of sensory dysfunction in preschool children with and without autism spectrum disorder.**  
Wiggins et al. *Autism Res.*
  
- 8. Infants who develop autism show smaller inventories of deictic and symbolic gestures at 12 months of age.**  
Wu et al. *Autism Res.*

# Question 3: Genetic and Environmental Factors



## **9. Pregnancy Planning and its Association with Autism Spectrum Disorder: Findings from the Study to Explore Early Development.**

Harris et al. *Matern Child Health J.*

## **10. Risk of Autism after Prenatal Topiramate, Valproate, or Lamotrigine Exposure.**

Hernández-Díaz et al. *N Engl J Med.*

# Question 4: Interventions



*There were no nominations covering this topic from January - April 2024.*

# Question 5: Services and Supports



## **11. Feasibility of the Autism Navigator® JumpStart to Coaching in Everyday Activities course in South Africa.**

Chambers N, de Vries PJ, Wetherby AM. *Autism*.

## **12. Health and Education Services During the COVID-19 Pandemic Among Young Children with Autism Spectrum Disorder and Other Developmental Disabilities.**

Pazol et al. *J Dev Behav Pediatr*.

## Question 5: Services and Supports



**13. Implementing school-based cognitive behavior therapy for anxiety in students with autism or suspected autism via a train-the-trainer approach: Results from a clustered randomized trial.**

Reaven et al. *Autism*.

**14. Foster Care Involvement Among Youth With Intellectual and Developmental Disabilities.**

Shea et al. *JAMA Pediatr*.

# Question 6: Lifespan



## **15. Health Conditions, Education Services, and Transition Planning for Adolescents With Autism.**

Hughes et al. *Pediatrics*.

## **16. Perspectives on Employer-Initiated Terminations Among Young Adults on the Autism Spectrum.**

Pezzimenti et al. *J Autism Dev Disord*.

## **17. Economic impacts of the COVID-19 pandemic on families of children with autism and other developmental disabilities.**

Pokoski et al. *Front Psychiatry*.

# Question 7: Infrastructure and Prevalence



## **18. Racial and ethnic disparities in the co-occurrence of intellectual disability and autism: Impact of incorporating measures of adaptive functioning.**

Furnier et al. *Autism Res.*



# 2024 IACC Summary of Advances: Next Steps



- Continue sending article nominations to ONAC staff
- We will discuss the next round of nominations at the July IACC meeting

# *2024 IACC Strategic Plan Update*

## Request for Public Comments on Co-Occurring Conditions in Autism



**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC

HHS National Autism Coordinator

Director, Office of National Autism Coordination, NIMH

**Oni Celestin, Ph.D.**

Deputy Director, Office of National Autism Coordination,  
NIMH

# 2024 IACC Strategic Plan Update: Co-Occurring Conditions



- In October 2023, the IACC voted to focus on **co-occurring physical and mental health conditions** and their impacts on health outcomes for the *2024 IACC Strategic Plan Update*.
- A draft report on co-occurring conditions was initiated by the previous committee and will be used as the foundation for this report.
- ONAC is currently updating the draft report.



# Request for Public Comments on Co-Occurring Conditions



- On behalf of the IACC, ONAC released a Request for Public Comments to assist the IACC in identifying priorities related to physical and mental health conditions, and other related conditions that commonly co-occur with autism
- Comment period: January 3 – February 14, 2024
- The announcement was posted on the Federal Register, IACC website, and cross-posted by other federal agencies and advocacy organizations.

# Request for Public Comments on Co-Occurring Conditions: Questions



1. What are the most significant challenges caused by co-occurring **physical health conditions** in autistic people?
2. What are the most significant challenges caused by co-occurring **mental health conditions** in autistic people?
3. What are the most significant challenges caused by **other conditions** that co-occur with autism?
4. What additional **research** is needed to help address co-occurring conditions for autistic people?



# Request for Public Comments on Co-Occurring Conditions: Questions



5. What could be improved in autism **services and supports** to help address co-occurring conditions for autistic people?
6. What **lasting impact** has **COVID-19 infection and illness** had on co-occurring physical and/or mental health conditions for autistic people?
7. What lasting **positive or negative impacts** have **societal changes** due to the COVID-19 pandemic had on physical or mental health for autistic people?



# Request for Public Comments on Co-Occurring Conditions: Responses



- **1,254 responses received!**
- The complete text of all responses is posted on the [IACC website](#).  
*Note: This document contains reference to sensitive topics that may be triggering for some individuals.*
- The ONAC Team read and reviewed all responses.
- Preliminary analysis of responses will be presented today.



# Analysis Framework



Responses were sorted into 6 categories:

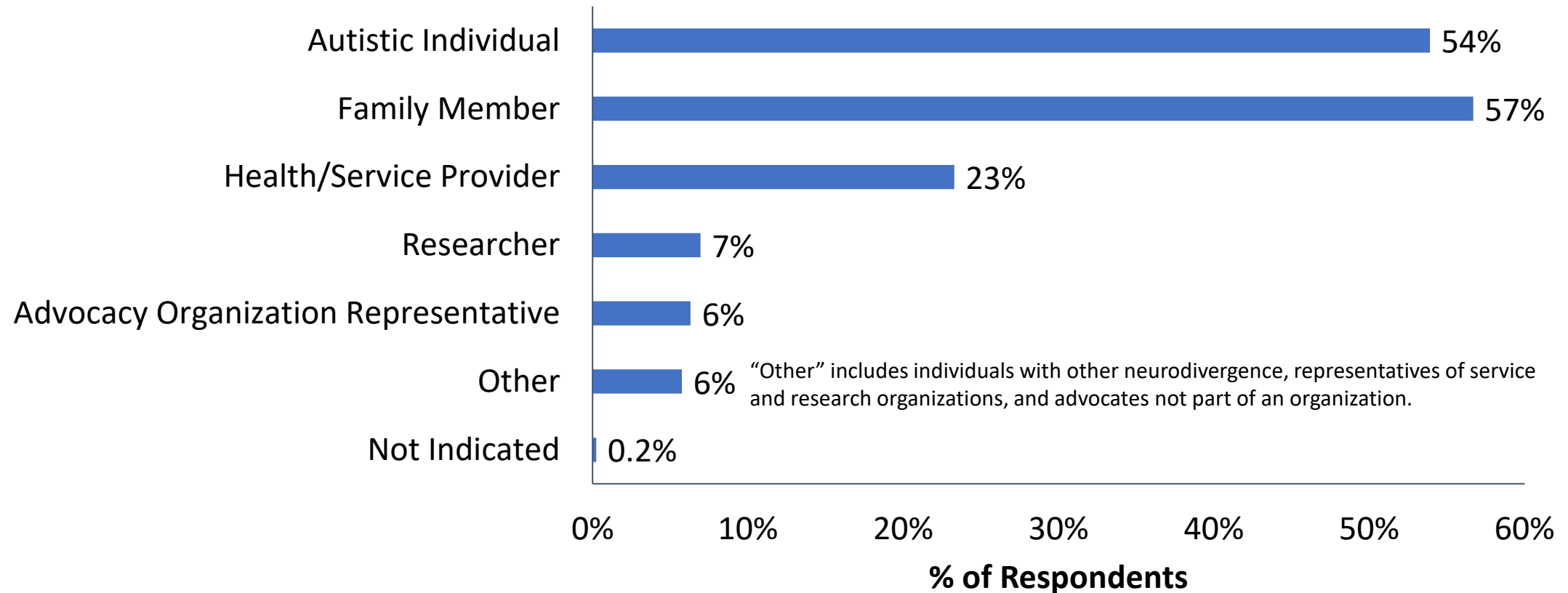
- **Demographic of Respondents**
  - Examples: Autistic individual, family member, service provider
- **Types of co-occurring conditions described**
  - Examples: GI issues, sleep disturbances, anxiety, depression
- **Impact of co-occurring conditions**
  - Examples: Emotional challenges, difficulty finding appropriate providers, bias/stigma, stress
- **Research needs**
  - Examples: Research on gender differences, research that includes autistic lived experience
- **Services needs**
  - Examples: Accessibility of services, insurance coverage, provider training
- **Impact of COVID-19 pandemic**
  - Examples: Exacerbated health conditions, disruptions in services, increased remote work and school



# Demographics of Respondents



- The 1,254 respondents identified as:



- 484 respondents (39%) identified as members of multiple groups

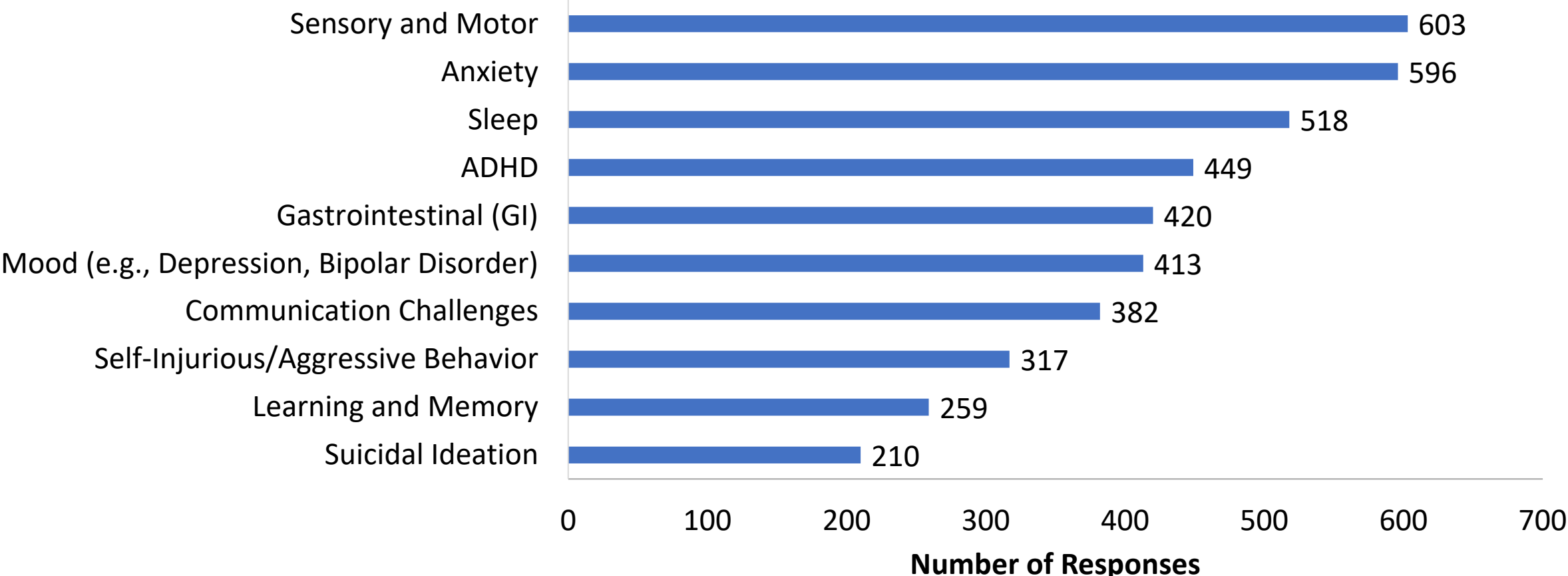
# Co-Occurring Conditions Described



# Co-Occurring Conditions Described



Respondents identified many co-occurring conditions that impact physical and mental health and well-being. The top 10 conditions identified were related to:



# Impact of Co-Occurring Conditions



The most significant challenge is **finding medical providers who believe us**. Most of my medical needs are not met.

She **masks extensively at school** and her teachers say she is “fine”, but she **comes home broken**. Many days she is not able to go at all, and she spends those days huddled on the couch with a blanket over her head.

Co-occurring physical health conditions can cause **pain**, but pain can be **difficult for autistic people to communicate**, which often results in **delays in care and delays in intervention**.

Professionals often do **not see beyond the autism diagnosis** to consider any other medical condition/issue that the person may be experiencing.

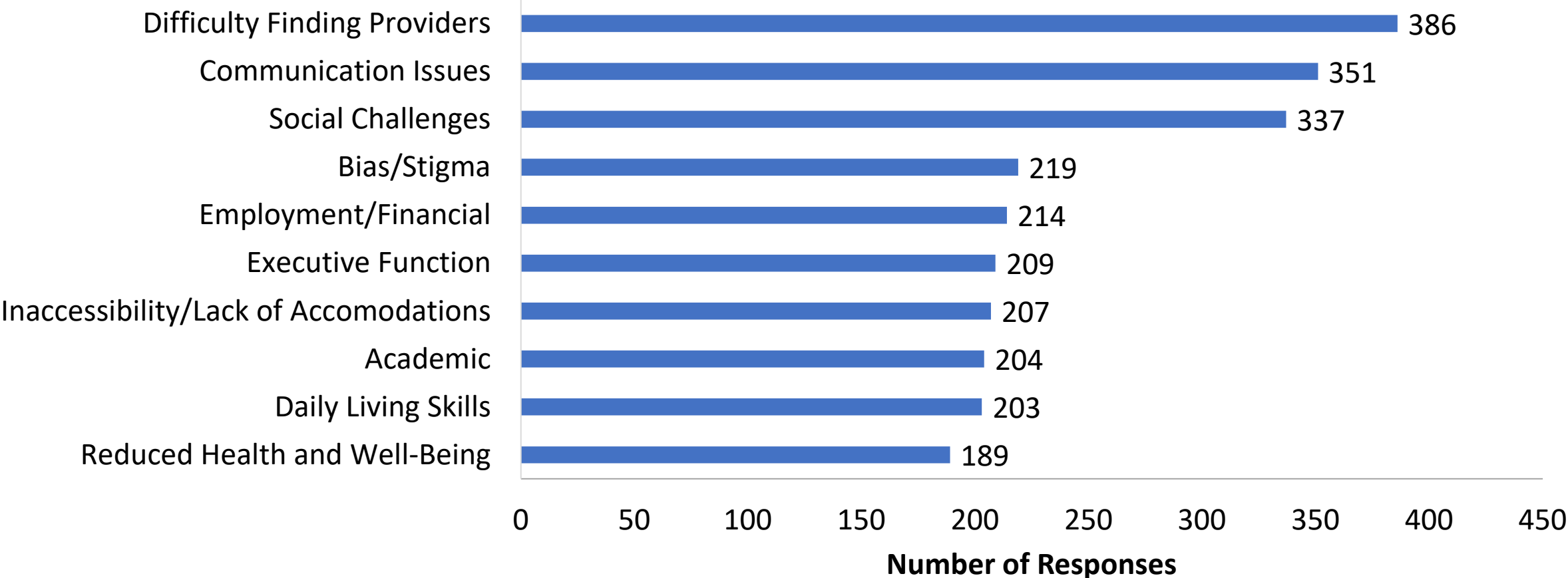
When I **can't remember or focus on my daily routine**, I get more **stressed out and more dysfunctional**. When all of this accumulates into an **autistic meltdown or shutdown**, I inevitably wind up **completely drained of energy and burnt out**, which triggers a severe depressive episode.

If he has not had good sleep or feels off at all it affects his entire day. Which means he does not get anything out of his therapy or school for that day. **If he doesn't sleep, I as his caregiver [don't sleep] and it means we both have a hard day.**

# Impact of Co-Occurring Conditions



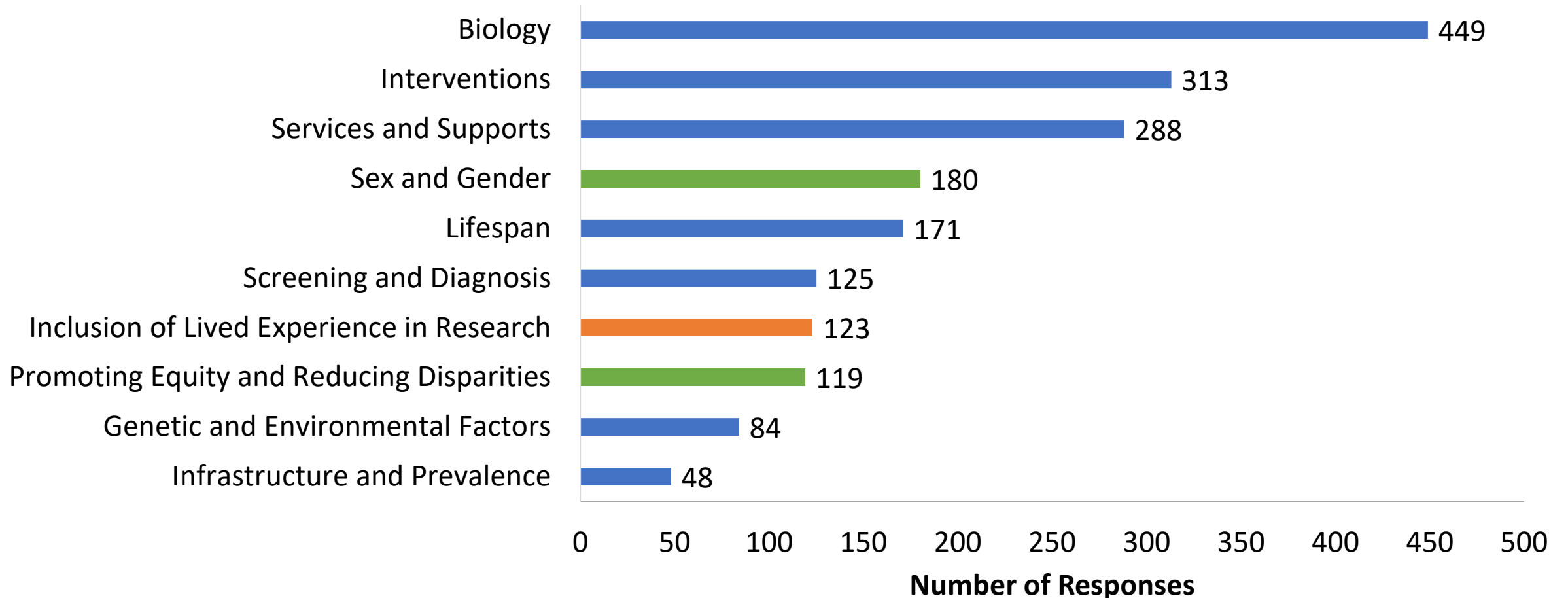
Respondents identified multiple ways in which co-occurring conditions impacted autistic individuals and their interactions with others. The top 10 impacts identified were:



# Research Needs



Responses were aligned with the **7 Questions areas of the Strategic Plan**, the **2 Cross-Cutting Topics**, and an additional category for **Inclusion of Lived Experience in Research**.



# Services Needs



A **care manager or navigator** to help with access to health and housing services is needed badly. I am afraid we are going to see autistic adults become homeless when their parents die. **There is no support system in place for them. They graduate high school and there is nothing for them.**

More doctors, dental, and psychological/psychiatric professionals need to receive **mandatory training on how to work with autistic patients.**

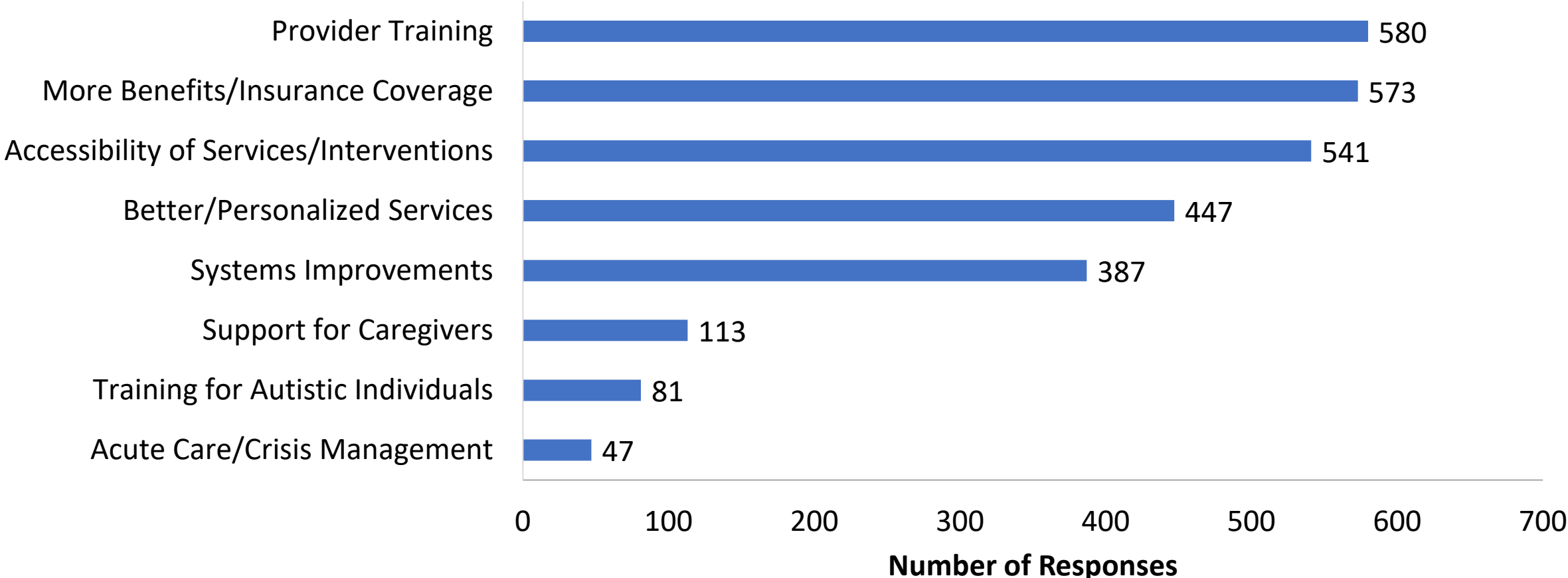
My son has significant mental health problems yet the department has denied services since he has autism! **The departments will not work with each other to serve this comorbid population.**

Any **state sponsored insurance requires a daunting amount of paperwork** that those of us with ADHD will often avoid. These are lifetime diagnoses. Regardless of whether we have more or less income and stability we should receive continual medical coverage.

# Services Needs



Respondents described multiple areas for improvement in services and supports to help address co-occurring conditions for autistic people:





# Impact of the COVID-19 Pandemic



Increased remote work and healthcare has been the **single best thing** that has ever happened to my mental and physical health as an autistic person.

Before Covid-19 we had an incredible support system of providers in our home that walked alongside us and supported our family holistically. **We lost those providers** due to in-person services being suspended and we **have yet been able to find replacements.**

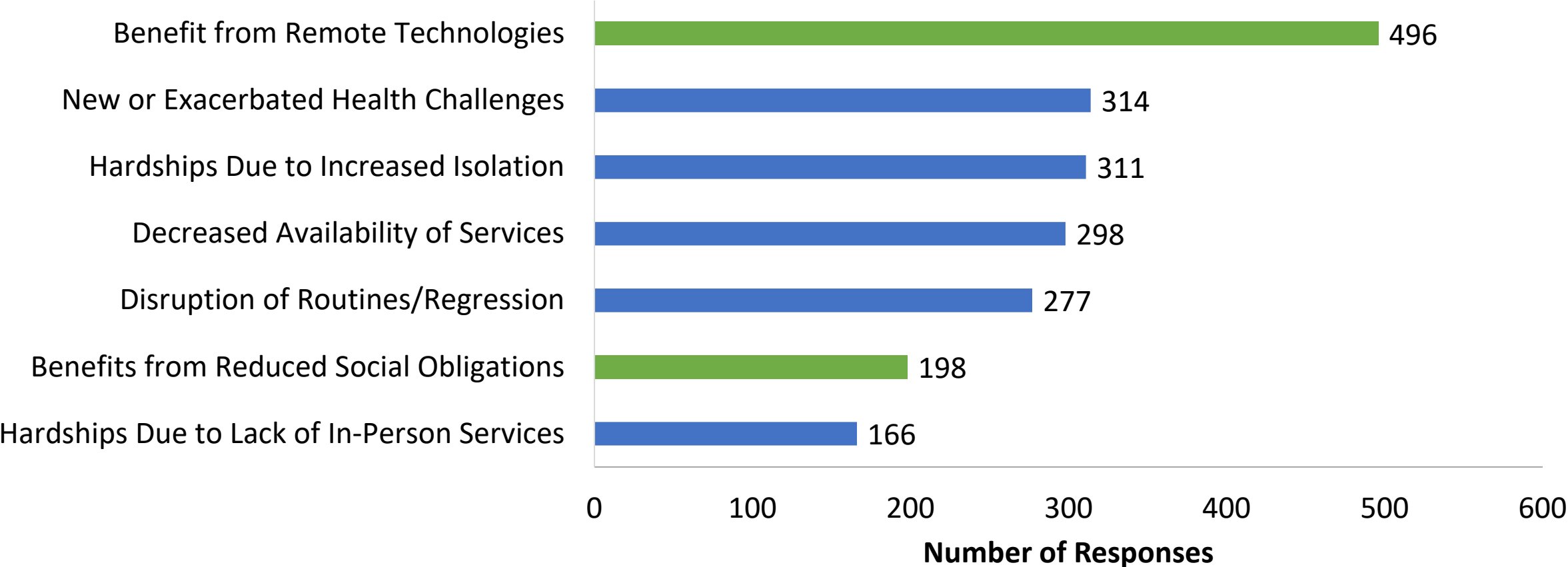
My son was a happy child, playing soccer, scoring well on speech tests, taking swimming lessons, having a routine helped him. Then **he was isolated.** All the media, fear, his **anxiety increased,** his therapist could not see him for months so he lost treatment for his **OCD which became debilitating.** He is not the same child he was before.

It's scary because we are now **seen and treated as second class citizens** because we're considered disabled. I don't want to be the last person in the hospital to be seen because I have so many comorbidities someone thinks I'm better off dead.

# Impact of the COVID-19 Pandemic



Respondents identified several **positive** and **negative** impacts of the COVID-19 pandemic on physical and mental health and well-being. The top 7 impacts identified were:



# 2024 IACC Strategic Plan Update

## Next Steps



- Currently: ONAC staff updating the content of the report drafted by the Working Group of the previous IACC
  - Full RFI analysis will be included in the new draft
- Late Spring 2024: Draft shared with Committee, feedback requested via survey
- July IACC Meeting: Committee discussion of draft
- Late Summer/Early Fall 2024:
  - 2<sup>nd</sup> draft shared with Committee
  - Additional feedback gathered and incorporated
  - Committee approval via email or virtual meeting
- December 2024: Anticipated publication



# Round Robin Updates

**Joshua Gordon, M.D., Ph.D.**

Director, National Institute of Mental Health  
(NIMH) and Chair, IACC

**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC  
HHS National Autism Coordinator  
Director, Office of National Autism Coordination, NIMH



# Lunch Break



Please scan the lunch option QR code on the printed agenda for additional lunch options

# Public Comment Session



**Joshua Gordon, M.D., Ph.D.**

Director, National Institute of Mental Health  
(NIMH) and Chair, IACC

**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC  
HHS National Autism Coordinator  
Director, Office of National Autism Coordination, NIMH

# Oral Public Comments



- Sharief Taraman, M.D.

**Full text** of public comments available at:

# Summary of Written Public Comments



9 written public comments were submitted on topics below by the following individuals:

***Research and Service Needs, Resources, and Policy Implications – 3 comments***

- Mackenzie Purcell
- John Poulos, Autistic Self Advocacy Network
- Nicole Corrado

***Mental Health Research, Services, and Treatment – 2 comments***

- Lisa Morgan, M.Ed., C.A.S.
- Fran Stanley

***The Role of the IACC and the Federal Government – 2 comments***

- Anthony Tucci, L.L.M., Esq., C.P.A.
- Jinny Davis

***Addressing the Needs of Autistic Individuals with High Support Needs – 1 comment***

- Tiffanie Smith

***Inclusion of Autistic Perspectives in Research – 1 comment***

- Tosha Brothers

Full text of public comments available at: [https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/april17/public\\_comments.pdf](https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/april17/public_comments.pdf)



**Break**



# Global Autism Leadership Through Advocacy and Government



# Global Autism Leadership Through Advocacy and Government



- Andy Shih, PhD
- Pru McPherson, LL.B.
- Mark Nafekh
- Menan Abd El-Maksoud, MD

# Update: Global Autism Public Health Initiative (2010-2024)

Meeting of the Interagency Autism Coordinating Committee

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Andy Shih, PhD

Chief Science Officer

April 17<sup>th</sup>, 2024



# Global Autism Public Health Initiative (GAPH)

*Support local leaders to address local priorities, using locally-customized solutions*

## Research

Prevalence studies (Mexico, South Korea, China, Qatar)

Family Needs Assessment Questionnaire (Canada, Serbia, Brazil, Bulgaria)

Open Source Screening & Diagnostic Tools (NASQ)

Caregiver-mediated intervention (PACT)

## Policy

National action plans (Bangladesh, Egypt, Aruba)

Clinical Practice Guidelines (Malaysia, Serbia)

Global Report on Children with Developmental Disabilities

## Capacity Building

Albania, Ethiopia, Saudi Arabia, China, Kazakhstan

WHO Caregiver Skills Training (CST)

## Advocacy

Advocacy Leadership Network (ALN)

Chinese American Association for Autistic Community

African Research Consortium for Neurodevelopmental Disabilities

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## Advocacy

**Advocacy Leadership Network (ALN)**

Chinese American Association for Autistic Community

African Research Consortium for Neurodevelopmental Disabilities

## Team (2008 – Present)



Pamela Dixon



Lucia Murillo Chacko



Michael Rosanoff



Amy Daniels



# WHO Caregiver Skills Training Program

- Empowers caregivers with skills they can use in daily routines to promote development (social communication, daily living, positive behavior)
- Implemented in more than 35 countries



# Scope of WHO Caregiver Skills Training (CST)

---

## For whom

Caregivers of children aged 2–9 years who have developmental delays or disabilities with a specific focus on caregivers of children with **delays or impairments in social and communication domains**



## Aims

Increase caregivers' skills to promote their children's development and well-being through joint engagement in play and home routines.



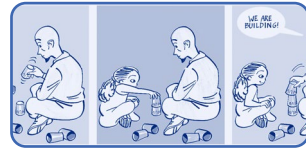
# Structure and Content



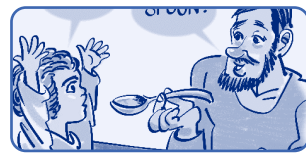
9 Group sessions



3 Home visits



Engaging children in everyday activities and games



Understanding and promoting children's communication



Understanding behaviour and helping the child show more positive behaviour



Teaching skills for everyday life



Caregiver wellbeing & problem-solving

# Content

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- Naturalistic/Developmental behavioural approaches for promoting shared engagement and communication
  - JASPER (Joint Attention Symbolic Play Engagement Regulation)
  - PRT (Pivotal Response Treatment) – behavioural intervention
- Positive parenting approaches for promoting positive child behaviour/management of challenging behaviour
- Promotion of caregiver problem solving & well-being

# eLearning CST (eCST)

- Self-directed eLearning for caregivers
- Based on WHO CST skills and strategies
- Total 8 hours, self-paced
- Supports low bandwidth, suitable for mobile devices
- Currently being translated in Arabic, Chinese, Spanish, Hindi, Marathi, Yoruba, and Portuguese
- Also used to support hybrid delivery of CST

**To access eCST:**

<https://openwho.org/courses/caregiver-skills-training>

Lesson 4: Communication

 **Key Message**

These are some of the ways children communicate:

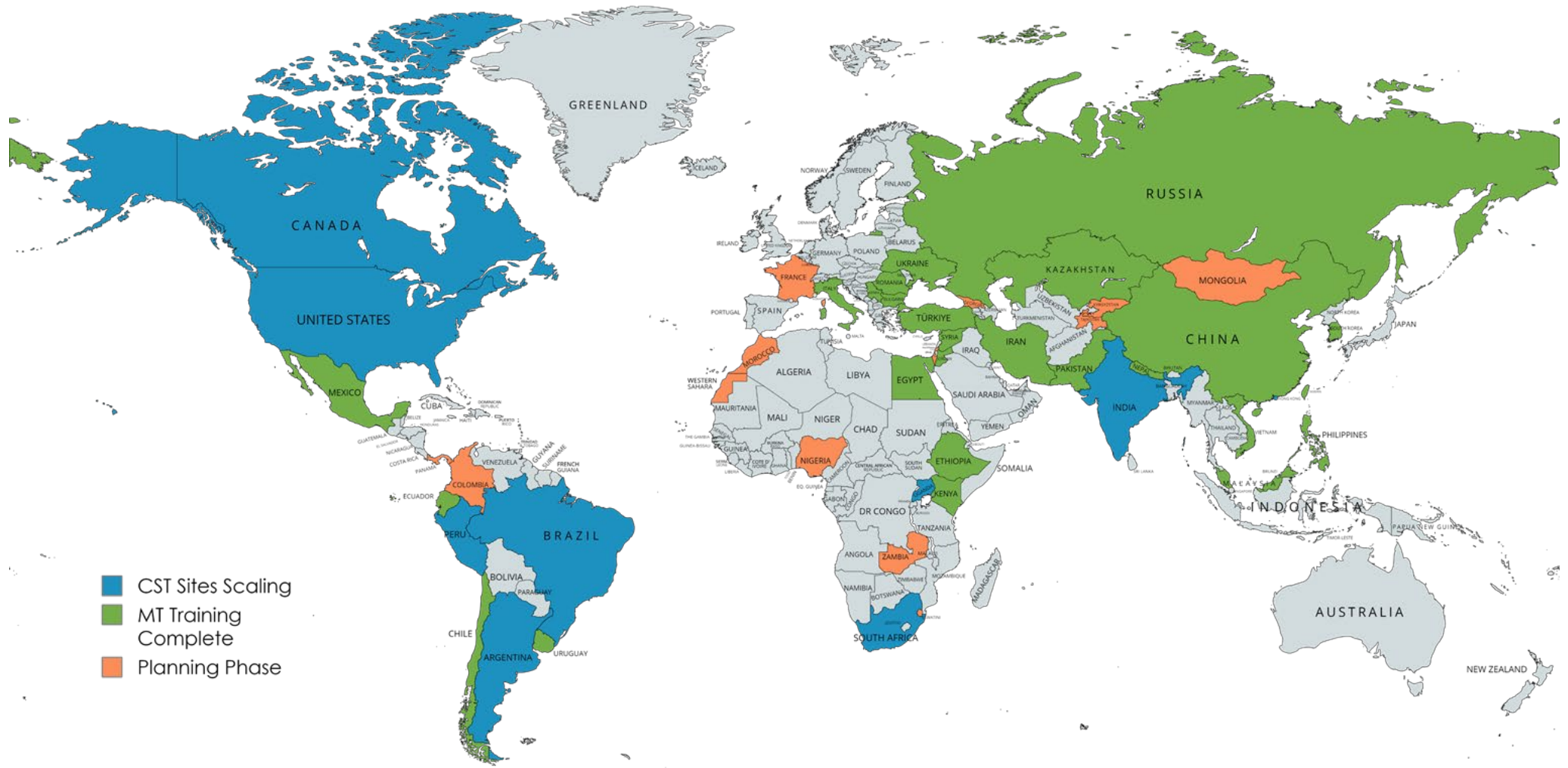


**BODY:** Turning or moving towards something, taking someone's hand to put it on an object (to get help), pulling someone by the hand, turning or nodding the head, gesturing with the head

**HANDS:** Pointing to something, showing or giving an object to someone, reaching, grabbing or pushing something away



# CST Sites Worldwide (2016-2024)

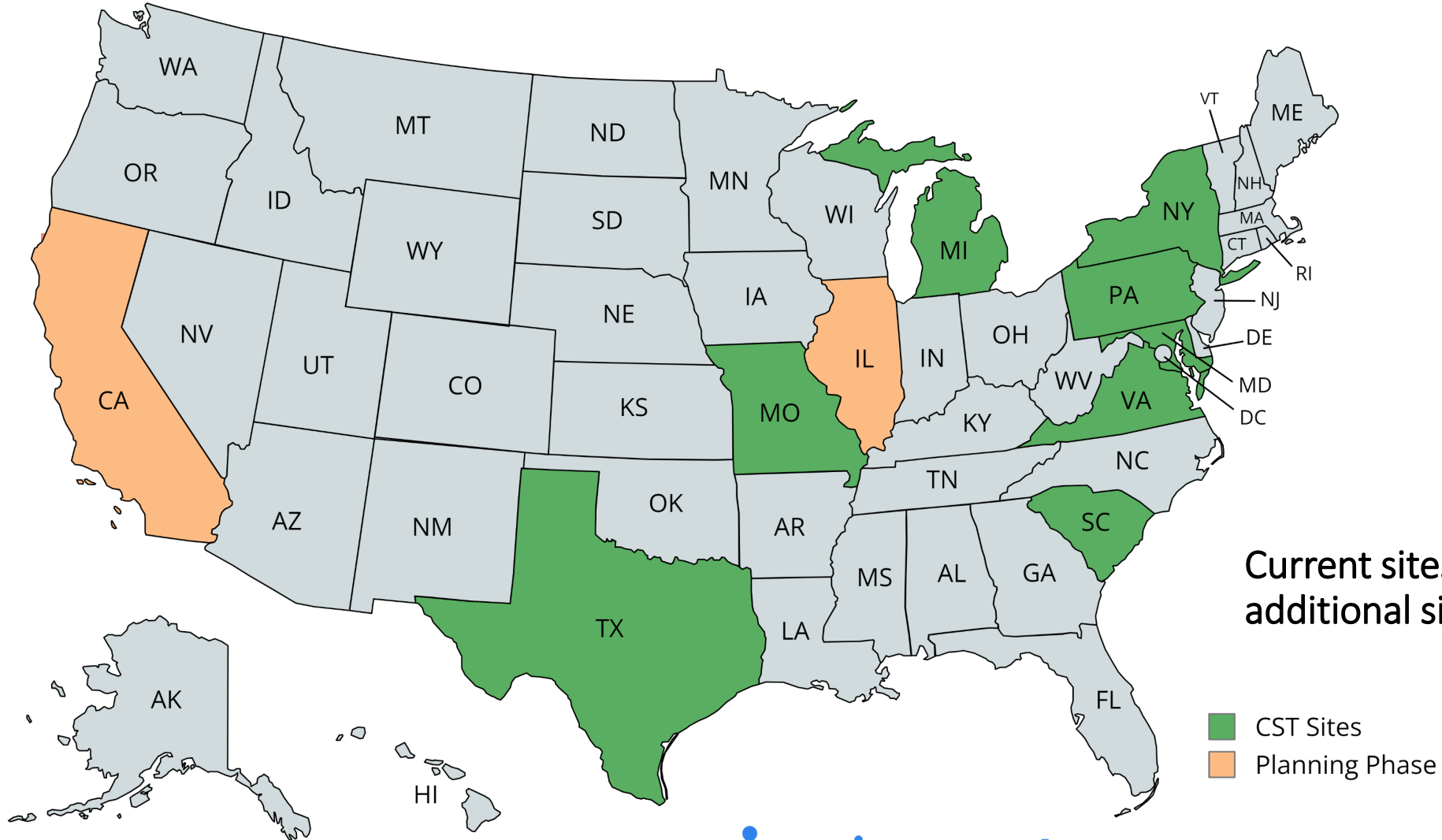


- CST Sites Scaling
- MT Training Complete
- Planning Phase



- Implemented in >35 countries
- Trained ~250 Master Trainers

# CST U.S. Sites



Current sites: 8 states with additional sites in planning phase

# Learnings from field testing (in HIC and LMIC)

## High levels of feasibility of implementation

- facilitators' fidelity in interaction with child
- caregivers' adherence to home practice
- viability of delivery

## Excellent acceptability to caregivers

## Can be adapted for remote-delivery

## Improves:

- caregiver skills in interaction
- caregiver self-efficacy and stress
- child communicative gestures (predictor of language development)
- parent-reported child behavior
- daily living skills

Original Article


## Adapting and pre-testing the World Health Organization's Caregiver Skills Training programme for autism and other developmental disorders in a very low-resource setting: Findings from Ethiopia

Bethlehem Tekola<sup>1</sup>, Fikirte Girma<sup>2</sup>, Mersha Kinfe<sup>2</sup>, Rehana Abdurahman<sup>3</sup>, Markos Tesfaye<sup>4</sup>, Zemi Yenus<sup>5</sup>, WHO CST Team<sup>6</sup>, Erica Salomone<sup>6,7</sup> , Laura Pacione<sup>6</sup>, Abebaw Fekadu<sup>1,2</sup>, Chiara Servili<sup>6</sup>, Charlotte Hanlon<sup>1,2</sup>, and Rosa A Hoekstra<sup>1</sup> 

Journal of Autism and Developmental Disorders  
<https://doi.org/10.1007/s10803-021-05367-0>

ORIGINAL PAPER


## World Health Organisation-Caregiver Skills Training (WHO-CST) Program: Feasibility of Delivery by Non-Specialist Providers in Real-world Urban Settings in India

Koyeli Sengupta<sup>1</sup> , Henal Shah<sup>2</sup>, Subharati Ghosh<sup>3</sup>, Disha Sanghvi<sup>1</sup>, Sanchita Mahadik<sup>1</sup>, Allauki Dani<sup>2</sup>, Oshin Deshmukh<sup>1</sup>, Laura Pacione<sup>4,7</sup>, Pamela Dixon<sup>5</sup>, Erica Salomone<sup>6,7</sup>, WHO-CST team<sup>7</sup>, Chiara Servili<sup>7</sup>



Journal of Autism and Developmental Disorders  
<https://doi.org/10.1007/s10803-021-05297-x>

ARTICLE

## Pilot Randomized Controlled Trial of the WHO Caregiver Skills Training in Public Health Services in Italy

Erica Salomone<sup>1,2</sup> , Michele Settanni<sup>3</sup>, Helen McConachie<sup>4</sup>, Katharine Suma<sup>5</sup>, Federica Ferrara<sup>3</sup>, Giulia Foletti<sup>3</sup>, Arianna Salandin<sup>3</sup>, WHO CST Team, Chiara Servili<sup>2</sup>, Lauren B. Adamson<sup>6</sup>



Autism  
1–13  
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DOI: 10.1177/1362361319848532  
[journals.sagepub.com/home/aut](https://journals.sagepub.com/home/aut)  


updates



# Goals for Scaling up CST

Near/long-term goals for the scaling up CST in the **U.S.** and **worldwide**

Near-term	Long-term
<ul style="list-style-type: none"><li>➤ Explore incorporation of CST into US programs and systems (<i>e.g. Head Start, Part C Early Intervention, PTICs, HMOs</i>)</li></ul>	<ul style="list-style-type: none"><li>➤ Broad nation-wide accessibility</li></ul>
<ul style="list-style-type: none"><li>➤ Increase the number of communities and countries implementing CST globally via broad, multistakeholder collaborations</li></ul>	<ul style="list-style-type: none"><li>➤ Facilitate, enhance and sustain global CST accessibility, implementation, and innovation through an online community of practice</li></ul>



 **autism speaks<sup>®</sup>**  
**advocacy leadership  
network**





# advocacy leadership network



- Accomplished international leaders
- Self-advocates, families, professionals, policy makers
- Social media-facilitated real-time community engagement. Biennial in-person meetings and virtual working groups to facilitate knowledge exchange and collaboration
- Focus on advocacy, dissemination, implementation and research
- High impact network collaboration
  - UN/WHA resolutions
  - Caregiver Skills Training (CST)
  - Global Report for Children with Developmental Disabilities





Inaugural meeting (New York City, 2010)





Biennial (Washington DC, 2016)

# 第四届自闭症倡导领袖联盟双年会

THE 4<sup>TH</sup> BIENNIAL MEETING OF AUTISM ADVOCACY LEADERSHIP NETWORK

November 10<sup>th</sup> 11<sup>th</sup>, 2018  
2018年11月10日-11日

Xiamen, China  
中国·厦门



ALN/CST Technical Consultation (Xiamen, 2018)



Africa Regional (Addis Ababa, 2020)





Biennial (Long Island City, 2023)







# ALN - Near Term Goals

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**advocacy  
leadership  
network**



- Advocacy Training Package – by and for Autistic Adults
- Launch African Research Consortium for Neurodevelopmental Disabilities
  - Quarterly webinars
- Biennial Meeting 2025



Thank you!!!





Australian Government

# National Autism Strategy

Help shape the change.

**U.S. Interagency Autism Coordinating Committee Meeting**  
**17 April 2024**

Pru McPherson  
Director  
Autism Policy  
Email: [pru.mcpherson@dss.gov.au](mailto:pru.mcpherson@dss.gov.au)

The Australian Government acknowledges Aboriginal and Torres Strait Islander peoples throughout Australia and their continuing connection to land, water, culture and community.

I am privileged to be standing on the ancestral lands of the Nacotchtank and the Piscataway People and pay respects to their elders past and present.




*The Australian Government and the National Autism Strategy Oversight Council acknowledge Autistic people, their families, carers and support networks, representative organisations and the Autistic and autism community who have worked tirelessly and campaigned long and hard for the establishment of an National Autism Strategy.*

## Statement on Language

People use different words to talk about autism, and each person will have their own way of talking about autism and about themselves. Some people in the Autistic community like to use 'Autistic person' (identity-first language), some like to say 'person with autism' (person-first language), and some are fine with using either. The Australian Government is using identity-first language to talk about the National Autism Strategy. This means that we will usually use the term Autistic person or Autistic people.

# Agenda Overview

1. Phase 1 - Building Evidence & Governance
  2. Phase 2 - Consultation and Development of the Draft
  3. Release of the Draft National Autism Strategy
  4. The National Autism Strategy – Context, Vision & Goal
  5. Phase 3 – Implementation
  6. Next Steps
  7. Discussion and Q & A
- 

# Background

- In November 2019 the Australian Parliament's Senate Select Committee on Autism was established to inquire into services, support and life outcomes for Autistic people in Australia.
- In 2021, Australia's national policy framework for disability, was launched: **Australia's Disability Strategy 2021-31** (the ADS).
- In 2022, the Australian Government **committed to development of the National Autism Strategy** (the Strategy) led by the Department of Social Services, reporting to the **Minister for Social Services the Hon Amanda Rishworth MP**
- The Australian Government also **committed to development of the National Roadmap to improve the health and mental health of autistic people** (the Roadmap) led by the Department of Health and Aged Care, reporting to the **Minister for Health and Aged Care, the Hon Mark Butler MP**



# Context Setting: National Autism Strategy



Australia's  
Disability  
Strategy

National  
Autism  
Strategy

Supports &  
Services

Autistic  
Individuals

The National Autism Strategy is expected to:

- be a **whole-of-life** plan for all Autistic Australians
- build on the **understanding and recognition** of autism
- support **improved service integration and coordination** between all levels of government
- make education, employment and health **services** for Autistic people more **inclusive and accessible**
- provide **better support** for parents and carers of Autistic people, and
- establish a national autism **research agenda**.

# A Phased Approach

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- Development of the Strategy is being **undertaken in three phases.**
  - **Phase one: Evidence base Development stage from October 2022 to July 2023**
  - **Phase two: National Consultation from August 2023 to May 2024**
  - **Phase three: Agreement and Launch by end of 2024**

# The National Autism Strategy

Phase 1 – Building Evidence & Governance



# Phase 1



## Building an Evidence Base

Key issues facing **First Nations autistic people**, prepared by First Peoples Disability Network

The experiences of **autistic women and girls**, prepared by Women with Disabilities Australia

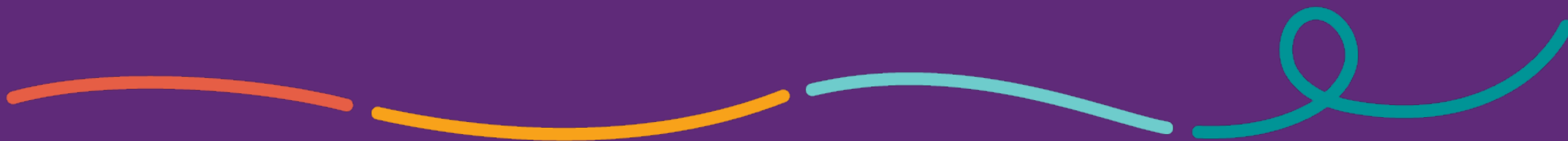
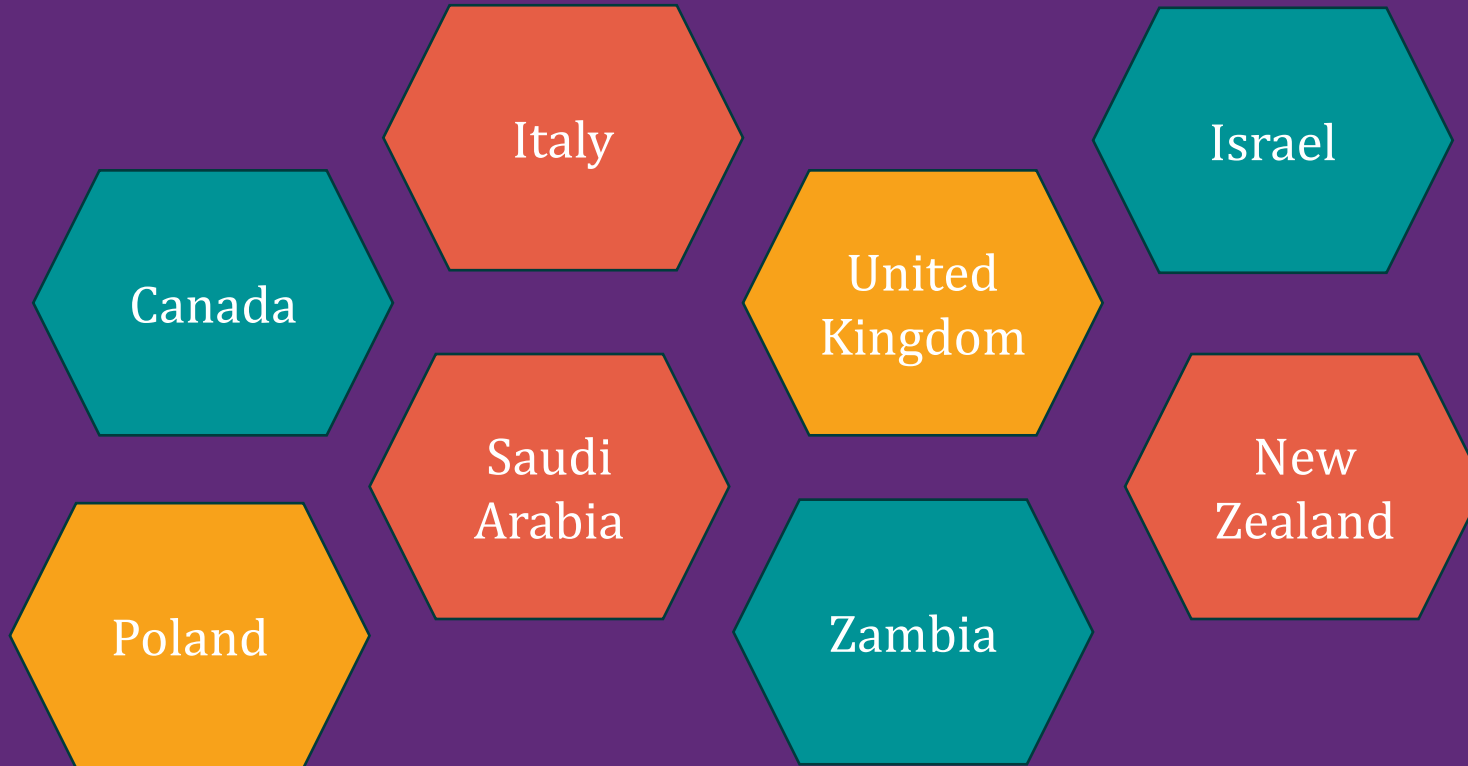
Engaging with **autistic people with an intellectual disability**, prepared by Inclusion Australia

**Lessons learnt** for a National Autism Strategy, prepared by Autism Aspergers Advocacy Australia

**Community insights and unheard perspectives:** Recommendations for inclusive community engagement in the National Autism Strategy, prepared by Autism CRC.

Research evidence, policy, and **landscape mapping** to inform the national Autism Strategy, prepared by Autism CRC

# International Consultations



# Phase 1



# Governance Arrangements








# Governance, Research & Reporting

## The Oversight Council

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-  **8 Autistic community & sector members**
  -  **2 research & professional sector members**
  -  **6 Australian government members**
-

# The National Autism Strategy

Phase 2 – Consultation and Development of the Draft





# Phase 2



## National Consultation Process



# Targeted Activities

First Nations Autistic People

Autistic people from culturally and linguistically diverse communities

Autistic women and girls

Autistic people that identify as LGBTQIA+

Autistic children and young adults

Older Autistic people

Autistic people with additional an / or complex support needs

Autistic people with common co-occurring neurotypes and conditions

# What can be done to better support Autistic people?

**A person-centred and individualised approach** to ensuring there is better support for autistic people.

**Funding and support** for Autistic people from different population groups.

**Training and education** for a wide range of **services and workers** who are supporting Autistic people.

**Improved support from health services** that is responsive to the specific needs of Autistic people from diverse population groups.

**Better support** for Autistic children **within school settings**

**Awareness, education and public promotion of autism** and the lived experience of diverse population groups.

# Themes from Consultations



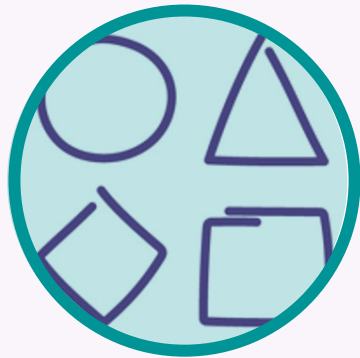
**Inclusion**



**Acceptance**



**Recognising  
Autistic strengths**



**Recognition of  
individual diversity & capacity**



**Better quality of life**

# The Draft National Autism Strategy

Released on April 2nd, 2024 – World Autism Awareness Day



# Our Vision and Goal

The National Autism Strategy's **vision** is for a **safe** and **inclusive society**, where all Autistic people can fully participate in all aspects of life, in line with international human rights.

The **goal** of the National Autism Strategy's is to **improve life outcomes** for all Autistic people.



# Our Guiding Principles

1. In partnership - Nothing about us, without us

2. Accessible based on Universal Design

3. Self Determination and Autonomy

4. Aligned and Accountable Outcomes

5. Acceptance and Inclusivity

6. Rights

7. Individualised and Holistic



# Social Inclusion

1. Improve understanding of, and change attitudes towards, Autistic people across all of society, through:

---

- a. Greater public education and awareness including a better understanding of autism within workplaces, and with a focus on health, education and the criminal justice system.
- b. Increasing visibility and representation of Autistic people in the media, sports and the arts.
- c. Increasing accessible and sensory-friendly public and online spaces.
- d. Increasing the capability of advocates and advocacy organisations to challenge and reduce stigma of autism.





## Social Inclusion continued

2. Increase opportunities for social connections and peer support.
3. Improve Australian Government service delivery, communication, and information to meet the needs of Autistic people.
4. Ensure consideration of the needs of Autistic people in future amendments to or reviews of the *Disability Discrimination Act 1992* (Cth) and associated disability standards.
5. Improve the safety and welfare of Autistic people through the reduction of all forms of discrimination, violence, abuse, bullying, vilification, and exploitation.



# Economic Inclusion

**6.** Increase meaningful employment opportunities (including business ownership, self-employment, entrepreneurship and social enterprise) for Autistic people.

---

**7.** Support employers to hire and retain Autistic employees through improving the accessibility of recruitment processes and fostering workplace environments that are safe and inclusive for all Autistic people

---

**8.** Improve the supports and services available to Autistic people to ensure they have choice and control over their education and careers.



# Economic Inclusion continued

**9.** Increase representation of Autistic people in senior and board positions to promote people as visible role models.

---

**10.** Improve inclusive practices and the quality and accessibility of advocacy resources for Autistic students across all education settings, and their families, carers and support networks.

---

**11.** Build on commitment 5 *Improve the safety and welfare of Autistic people through the reduction of all forms of discrimination, violence, abuse, bullying, vilification and exploitation* to specifically focus on Autistic students in all levels of education.



# Diagnosis

**12.** Consider the use and consistency of current identification screening, outcome and diagnostic tools. Work with relevant professional bodies to develop a set of standardised co-designed training/professional development and resource materials to support professionals involved in the identification, assessment and diagnosis of autism to improve the experience, and quality of this process for Autistic people and their families and carers.

---

**13.** Develop a set of best practice resources to support Autistic people and their families, carers and support networks through the identification, assessment and diagnosis process.



## Diagnosis continued

**14.** Explore ways to improve access to primary care, including through the Medicare Benefits Schedule (MBS), to:

- a. improve quality health and mental health services for Autistic people, with focus on continuity of care, and
- b. explore ways to make Autism diagnosis and assessment processes more timely and accessible.\*

---

**15.** Consider early screening and identification arrangements, and improved access to health professionals.



# Services & Supports

**16.** Improve access to quality, timely, neurodiversity-affirming and equitable supports and services for Autistic people, including for people living in rural, regional and remote areas.

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**17.** Encourage greater representation of people with lived experience in delivering supports and services to Autistic people.

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**18.** Develop a set of best practice training and resource materials for people providing services and supports to Autistic people.

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**19.** Explore the feasibility of a decision-making tool to empower Autistic people to make informed decisions about all areas of their life.

---

**20.** Work with states and territories to improve service integration between the NDIS, foundational supports and mainstream services.



# Governance, Research and Evidence, Evaluation & Reporting

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**21.** Develop a governance framework to support:

- a.** strong accountability mechanisms,
  - b.** co-leadership and active involvement of Autistic people, as well as parents and carers, and professionals within the autism sector, and
  - c.** whole-of-government, cross-sectoral and coordinated approaches to implementation.
- 

**22.** Explore how autism research can best be fostered and applied to policy and service delivery and underpinned by the Strategy's Guiding Principles

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**23.** Develop a National Autism Strategy Evidence Framework, including a Theory of Change, Program Logic, Outcomes Framework, and Evaluation Framework.

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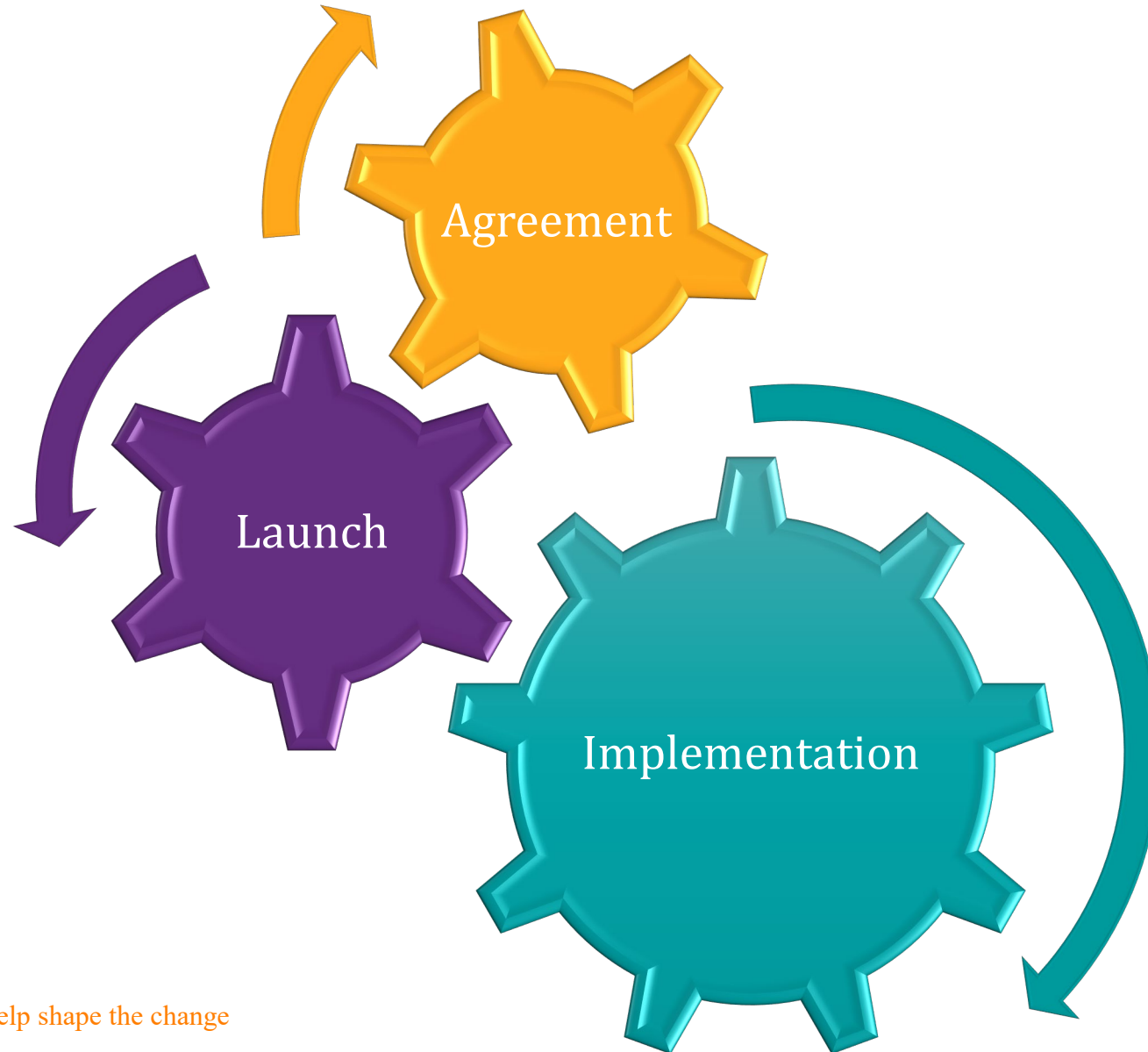
**24.** Develop a robust Evaluation Plan and reporting mechanism, co-led by Autistic people and the autism community, for the National Autism Strategy.

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# Phase 3



## The National Autism Strategy





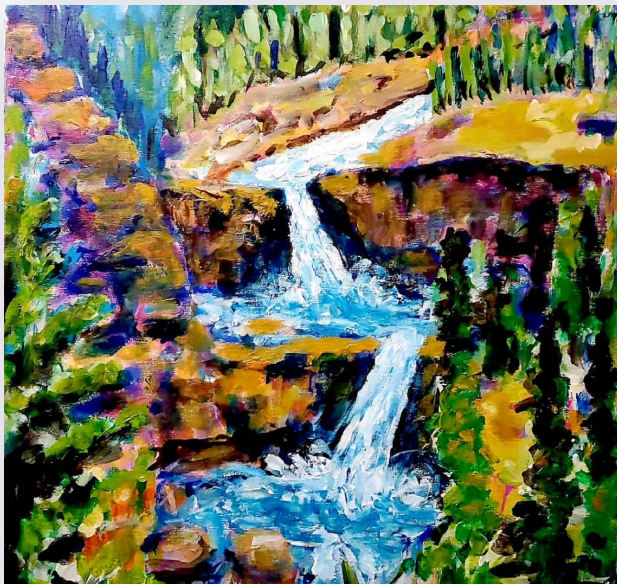
Thank you.

Q&A



# Canada's Autism STRATEGY

The strategy outlines federal actions that aim to address 5 priority areas.



Artwork by Raymund Gabriel

## Priority 1: Screening, diagnosis and services

- Provide up-to-date professional training on autism.
- Develop national guidelines for screening, diagnosis and services for adolescents and adults.
- Assess the pathways and obstacles to hiring neurodiverse professionals in healthcare and allied health professions.

## Priority 2: Financial support

- Improve the key factors contributing to the financial stability and security of Autistic people in Canada and their families, such as:
  - tax measures and benefits
  - employment
  - financial literacy and planning
  - appropriate housing

## Priority 3: Data collection, public health surveillance and research

- Develop inclusive research guidelines.
- Promote Autistic participation in research.
- Include diverse demographics and co-occurring conditions across all age groups and regions when collecting data.

## Priority 4: Public awareness, understanding and acceptance

- Develop autism education and training programs.
- Support continued engagement with the Autistic community.
- Foster inclusivity through increased public knowledge, understanding and acceptance of autism.
- Make communities and workplaces more accessible for people with disabilities.

## Priority 5: Tools and resources

- Enhance access to diverse, evidence-based tools and resources, including:
  - translation
  - Improved navigation
  - best practices guides
  - culturally relevant online platforms





**Enhancing support for Autistic Children in Egypt**  
**Prof.Menan Abdelmaksoud**  
**Secretary General Mental Health and Addiction Treatment**  
**Ministry is Health and Population**

# Vision



Child and adolescent services with quality and  
without stigma all over Egypt



- 15 child and adolescent psychiatric units

Activati  
Go to Set

2012



# Autism

Abbassia

Mamoura

Assiut

Port- Saied



# Autism awareness campaigns





# legislative frameworks including autism in national law of people with disability



# Caregivers Skills Training Programme 2016



World Health Organization



# CST Road Map



Translation  
and  
adaptation

CST  
Training of  
master  
trainers

Practice with  
families

Training of  
facilitators



# 2020 CST Training of master trainers

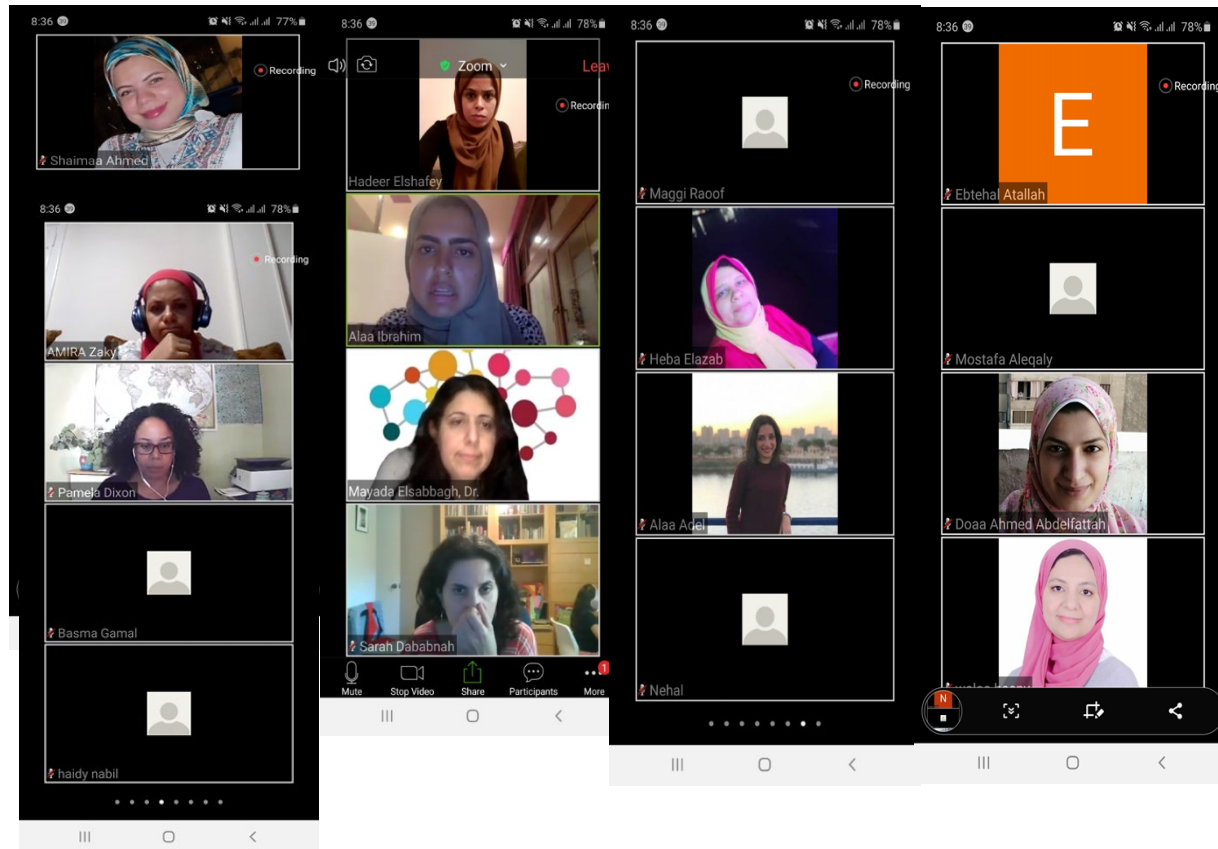


# Practice with families

- Cairo
- Alexandria
- Assuit

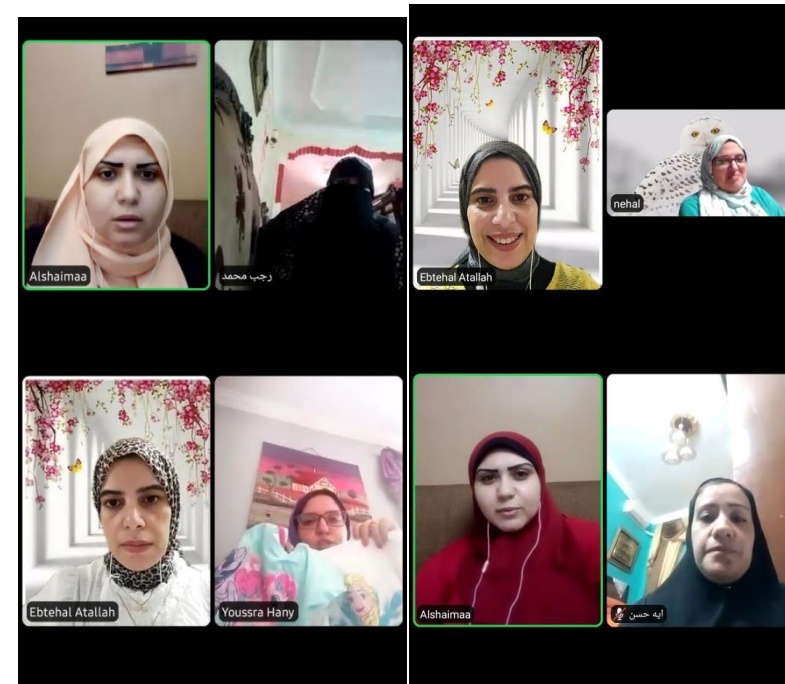


# ONLINE TRAINING 2020



# COVID 19 and online adaptation

the WHO Caregiver Skills Training for Online Delivery Supporting Caregivers for Children With Developmental Disabilities With the WHO





رئاسة مجلس الوزراء المصري

Apr 28

بيان صادر عن وزارة الصحة والسكان:

في كلمته خلال مؤتمر المكتب الرئيسي لمنظمة الصحة العالمية  
بجنيف..  
القائم بأعمال وزير الصحة يعلن دراسة إطلاق مبادرة للكشف المبكر  
عن مرض التوحد

أعلن الدكتور خالد عبدالغفار وزير التعليم العالي والبحث العلمي والقائم  
بأعمال وزير الصحة والسكان، بدء وزارة الصحة في دراسة تدشين  
مبادرة للكشف المبكر عن مرض التوحد في الأطفال من عمر عامين.

جاء ذلك في كلمة الدكتور خالد عبدالغفار، خلال المؤتمر الافتراضي  
الذي عقده المكتب الرئيسي لمنظمة الصحة العالمية بجنيف اليوم  
الخميس، حول التدريب على مهارات مقدمي الرعاية لعائلات الأطفال  
الذين يعانون من التأخر النمائي أو الإعاقات.

وأكد القائم بأعمال وزير الصحة والسكان، اهتمام الرئيس عبدالفتاح  
السيسي، بأصحاب الهمم، حيث شارك مرات عديدة في احتفالية  
«قادرون باختلاف» والتي تقام في ديسمبر من كل عام بمناسبة اليوم  
العالمي للأشخاص ذوي الإعاقات، ليؤكد التزام الدولة برعاية مختلف  
الفئات وأصحاب الاحتياجات.

وأشار الدكتور خالد عبدالغفار، أن نسب الأطفال الذين يعانون من  
صعوبات في الفهم والتواصل تبلغ نحو 2.7% من الأطفال في الفئة  
العمرية 5 أعوام فأكثر، مؤكداً أن مصر لها تجارب رائدة في برامج  
الكشف المبكر ورعاية الأطفال المصابين بالتأخر النمائي والإعاقات،  
ومنها البرامج التي تتبناها المراكز التابعة للأمانة العامة للصحة النفسية  
لعلاج التوحد والتأخر الذهني النمائي عند الأطفال، إلى جانب العديد  
من البرامج التي تنفذها الإدارة



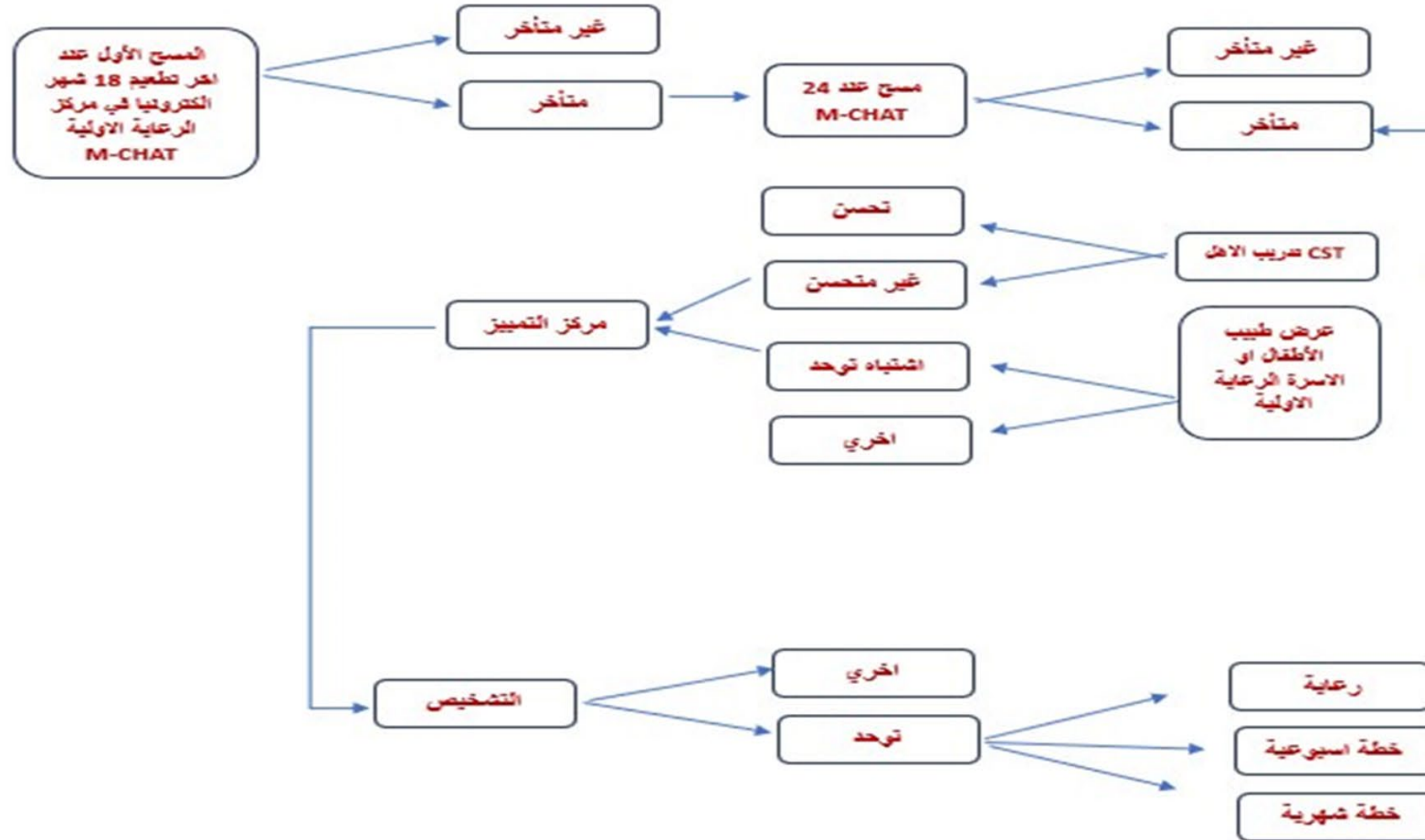






**Training of 37 of  
PHC staff for  
piloting the  
screening 2023**

# Referral pathway



# Building codes





2024

H.E. Minister of Health  
& Population  
accompanied by H.E.  
minister of Social  
Solidarity  
launching Abbassia  
Autism Center, in  
preparation for the  
Presidential Initiative  
For Prevention & Early  
Detection Of Autism

# International Autism Day 2024



**8th International Mental Health Conference**  
**3rd Child & Adolescent International M.H Conference**  
**2nd Pan African Congress on autism**



**Autism**  
**THE ROAD MAP**  
Detection intervention care

**2024**  
**18/20**  
**April**

Alexandria  
Bibliotheca

Under the patronage of H. E.  
Minister of Health & Population  
**Prof. Khaled Abdel Ghaffar**

Conference President  
Secretary General Of Mental Health  
and Addiction Treatment  
**Prof. Menan AbdElmaksoud**

# Challenges



- 1. Building Capacity: This includes training professionals in diagnosis, therapy, and support services.
- 2. Efficient Supervision System: This involves monitoring and regulating service providers to maintain standards of care and support.
- 3. Continuous Learning: Keeping up with advancements in research, therapies, and interventions is essential for providing up-to-date and effective support for professionals and caregivers to enhance service quality.
- 4. Establishing Effective Partnerships: To ensure resources are effectively utilized and services are accessible to all who need them.





Thanks



# Discussion



- Moderated by: Joshua Gordon, MD, PhD
- Andy Shih, PhD
- Pru McPherson, LL.B.
- Mark Nafekh
- Menan Abd El-Maksoud, MD

**Break**



# International Autism Research and Advocacy Panel Discussion



**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC

HHS National Autism Coordinator

Director, Office of National Autism Coordination, NIMH

**Karen D. Bopp, PhD**

Co-Chair

Autism Alliance of Canada Board of Directors



## Panelists:

- James Cusack, PhD
- Gauri Divan, PhD
- Liliana Mayo, PhD
- Amina Abubakar, PhD
- Clare Gibellini

# Closing Remarks

**Joshua Gordon, M.D., Ph.D.**

Director, National Institute of Mental Health  
(NIMH) and Chair, IACC

**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC  
HHS National Autism Coordinator  
Director, Office of National Autism Coordination, NIMH



# Thank you to the ONAC Staff and Meeting Support Team!



**Susan Daniels, Ph.D.**  
HHS National Autism  
Coordinator and  
Director, ONAC



**Oni Celestin, Ph.D.**  
Deputy Director



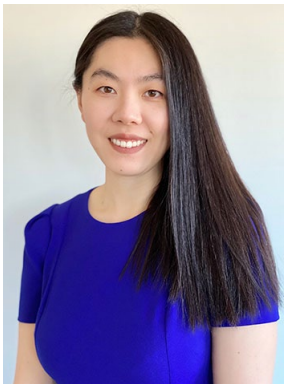
**Ana Cappuccio, LL.B.**  
Operations Coordinator



**Katrina Ferrara, Ph.D.**  
Science Policy Analyst



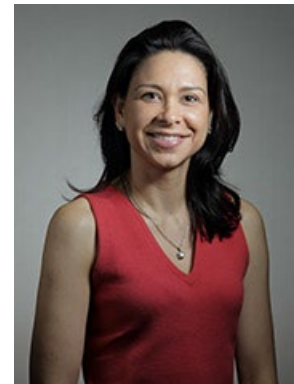
**Steven Isaacson, L.M.S.W.**  
Neurodiversity Liaison



**Tianlu Ma, Ph.D.**  
Science Policy Analyst



**Rebecca Martin, M.P.H.**  
Public Health Analyst



**Angelice Mitrakas, B.A.**  
Management Analyst



**Luis Valdez-Lopez, M.P.H.**  
Science Policy Analyst



**Jeffrey Wiegand, B.S.**  
Web Development and  
Digital Outreach Manager



# Next IACC Meeting



## IACC Full Committee Meeting (hybrid)

July 10, 2024

Check the IACC website for meeting information and updates.

<https://iacc.hhs.gov>