

AUTISM

A GLOBAL FRAMEWORK FOR ACTION

Report of the WISH Autism Forum 2016

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FOREWORD

While the staggering increase in the prevalence of autism spectrum disorder (ASD) over the past 30 years is cause for concern, we have made significant strides in increasing awareness of the condition and developing innovative ways to improve the lives of children, young people and adults with ASD.

In 2007, the United Nations (UN) representative from Qatar – Her Highness Sheikha Mozah bint Nasser Al Missned, wife of His Highness Sheikh Hammad Bin Khalifa Al Thani – successfully proposed a UN General Assembly resolution, creating World Autism Awareness Day. This day, recognized on 2 April every year, encourages all member states to take measures to raise awareness about ASD across the world.¹ Further, on World Autism Awareness Day in 2016, the UN General Assembly convened an expert panel that emphasized that children and adults with ASD and other neurodevelopmental disorders have a special place at the heart of the UN Sustainable Development Agenda and in the implementation of the Sustainable Development Goals.²

However, our work is not done. There are still large gaps in the evidence base for effective treatment and also in the epidemiological studies investigating the causes and prevalence of the condition. We also struggle to provide families with adequate support and ensure that children with ASD have access to public education and services.

This report explores these challenges and offers three overarching policy recommendations aimed at improving support for children with ASD, their families and communities. Importantly, we acknowledge that ASD cannot be effectively addressed by the health sector alone. Successful national policies require collaboration across health, education and social sectors. Only by breaking down these barriers can we hope to succeed.



A handwritten signature in black ink, appearing to read 'A. V. Darzi'.

**Professor the Lord Darzi of Denham,
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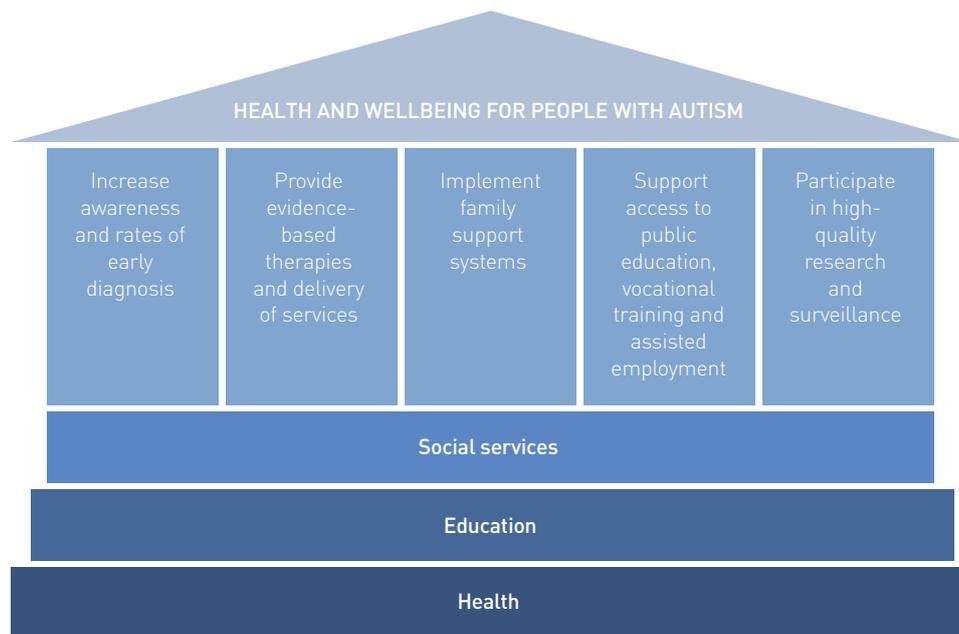
EXECUTIVE SUMMARY

Autism spectrum disorder (ASD) represents a group of lifelong neurodevelopmental disorders emerging during early childhood and interfering with a person’s ability to socially relate to and interact with others.

As of 2010, there were an estimated 52 million cases of ASD worldwide, representing a substantial increase over the past 40 years.³ Meanwhile, the economic impact of ASD in the United States (US) alone – based on direct medical, direct non-medical and productivity costs – reached an estimated \$268 billion in 2015, a figure that is expected to rise to \$461 billion by 2025.⁴ ASD and other neurodevelopmental disorders also affect the quality of life of those with the conditions, as well as of their families and caregivers.

This report provides an overview of ASD and the challenges we face globally in supporting and caring for those with the condition. In proposing recommendations for the future, we emphasize five primary areas of action, as shown in Figure 1.

Figure 1: Framework for action



To accomplish these goals, policymakers must:

- increase awareness of ASD and encourage early detection and diagnosis, allowing children to access services as early as possible;
- ensure that children with ASD have access to evidence-based therapies by providing additional training to parents, teachers and clinicians around the most effective interventions;
- provide those with ASD and neurodevelopmental disorders access to public education, with the goal of inclusion;

- ensure that families of those with ASD and neurodevelopmental disorders have the appropriate support and information to care for their family members; and
- encourage participation in high-quality research and health surveillance to obtain a full and accurate picture of the challenges we face in treating ASD and neurodevelopmental disorders.

The WISH Autism Forum has developed three primary policy recommendations to address ASD and other neurodevelopmental disorders globally. These recommendations, aimed at policymakers, support a multi-sector response to ASD that includes health, education and social services. We believe this guidance will help governments to improve the lives of those with ASD and neurodevelopmental disorders, as well as their families and communities.

Recommendation 1

Create an interagency co-ordinating commission to address ASD nationally.

We recommend the establishment of an independent governmental agency, such as a national Interagency Co-ordinating Commission or a Division of Autism and Neurodevelopmental Disorders, to provide guidance to national governments on issues related to ASD and neurodevelopmental disorders.

- **Membership of the Commission or Division** should include representatives from health, education, social services, employment, family members of those with ASD, self-advocates, service providers, public stakeholders and national non-government organizations (NGOs), as well as researchers and universities representing a variety of perspectives from within the ASD and neurodevelopmental disorders community.
- **The vision of the Commission** should be to provide ultimate independence, productivity and community inclusion as key components, and to address wide-ranging issues and challenges faced by people with ASD and neurodevelopmental disorders and their families.
- **Shared and collaborative leadership** should be constituted under the Department of Public Health, Education and Social Services (as chairperson and co-chairs) with government authorization to develop and update national strategic plans, programs and policies for ASD and neurodevelopmental disorders, and to monitor national, regional and international activities in research, training and advocacy for ASD and neurodevelopmental disorders.
- **Guidance and government oversight** should be provided on broader concerns related to ASD and neurodevelopmental disorders to accelerate and enhance the development of services across the person's lifespan.

Recommendation 2

Establish interdisciplinary training and research centers for excellence in ASD and neurodevelopmental disorders across the lifespan. We recommend the establishment of national or regional training centers (based on size of catchment) with core funding and oversight by interagency co-ordinating commissions to:

- **Provide interdisciplinary education and training** in multiple disciplines at undergraduate, graduate and post-graduate levels regarding ASD and neurodevelopmental disorders across the lifespan.
- **Provide cutting-edge research, evaluation and policy analysis** in areas of importance to the field of ASD and neurodevelopmental disorders.
- **Communicate, disseminate and share information and research findings** with a broad constituency.
- **Direct services and support** to persons with ASD and neurodevelopmental disorders of all ages, and their families, to minimize disparities in healthcare, enhance educational opportunities, develop work skills, enrich daily living and promote community inclusion.
- **Use emerging technologies to bolster learning, employment and community participation** for all persons with ASD and neurodevelopmental disorders.
- **Work with schools as well as vocational and employment settings** to deliver evidence-based programs in inclusive settings.
- **Engage with policymakers who are charged with setting future policy** to put research into practice and evaluate the impact of services and policies.
- **Support individuals and families as they engage in self-advocacy and self-determination.**

Recommendation 3

Establish a global partnership framework to address ASD and neurodevelopmental disorders across the lifespan. To address the significant gaps in the care of persons with ASD and neurodevelopmental disorders at a global scale, we recommend the formation of a global partnership framework involving member governments from high-income countries (HICs) and low- and middle-income countries (LMICs), as well as the private sector and civil society. This partnership will help to coordinate a sustainable response for each region in terms of policy reform, service development and delivery, research and dissemination of evidence-based practice. Such a partnership framework will provide checks and balances for appropriate use of resources and assist in allocating funds to meet specific regional and national needs. Key activities should include:

- **Setting global research priorities and a research capacity development agenda.** This group should collaboratively set comprehensive research priorities and a research capacity development agenda on ASD and neurodevelopmental disorders, in line with the UN Sustainable Development Goals (SDGs). Efforts in LMICs in particular should enhance cost-effective and culturally appropriate methods to reliably estimate the prevalence of ASD and neurodevelopmental disorders to inform and help with the design and equitable distribution of basic services in health, education and social care.
- **Facilitating global and regional collaborations in piloting new, or scaling up existing, evidence-based interventions.** The global effort should leverage and share regional resources to support public and private sector programs in enhancing services, training and research. The partnership framework should be aware of potential asymmetries, prioritize local needs and integrate measures of program effectiveness and costs.
- **Establishing a global minimum standard of services.** The global partnership framework agenda should work toward developing a minimum standard of inclusive health, education and social services available across the lifespan for children, young people and adults with ASD and neurodevelopmental disorders.

SECTION 1: OVERVIEW OF THE GLOBAL IMPACT OF AUTISM SPECTRUM DISORDER

Definition

ASD represents a group of lifelong, complex neurodevelopmental disorders emerging during early childhood and interfering with a person's ability to socially relate to and interact with others. According to the American Psychiatric Association Diagnostic and Statistical Manual, Fifth Revision (DSM-5), the current diagnostic criteria for ASD include deficits in: (a) social interaction and nonverbal communication; and (b) restricted, repetitive movements, behaviors and interests.⁵

An alternative classification by the World Health Organization (WHO) International Classification of Diseases, Tenth Edition (ICD-10), defines ASD as characterized by impairments in three core areas: social interaction; communication; and restricted repetitive behaviors.⁶ The ICD-10 also includes:

- Asperger's syndrome: characterized by typical language development with deficits only in social communication and restricted repetitive behaviors.
- Atypical autism: broader spectrum of social difficulties that do not fit the classic definitions of ASD or Asperger's syndrome.

However, these disorders have been incorporated into the broader definition of ASD in the DSM-5.^{7,8} The ICD-11, scheduled for release in 2017, is also likely to follow suit with the new ASD nosology.⁹

An important challenge to the categorical diagnosis is that features of ASD are continuously (and not discretely) distributed in the general population and often shared with other neurodevelopmental and neuropsychiatric conditions.¹⁰ According to this quantitative trait model, ASD represents the severe end of a continuous distribution of social communication disabilities in the population. Such a conceptualization of ASD represents important implications for personalized therapies in relation to specific causes of ASD.¹¹

Causation

The causes of ASD are not clear-cut, but evidence suggests that a number of environmental and genetic factors are at play. Research on identical twins first suggested that genes may have an important role in ASD.^{12,13} A recent genetic analysis that combined several large population-based sources (more than 38,000 subjects) found genetic links between ASD and typical variations in social behavior and adaptive functioning. This suggests that multiple types of genetic risk factors for ASD influence the continuum of behavioral and developmental characteristics, with the extreme end of the continuum resulting in ASD.¹⁴ Insights into genomic variability and biology of ASD are increasingly being uncovered, and we continue to make progress in establishing a correspondence between behaviorally defined clinical symptoms of ASD and genetic causation.^{15, 16} However, finding the genetic variations and understanding their meaning are equally important. Using maps of protein–protein interactions throughout cells, for example, can identify protein networks affected by many different gene mutations that lead to similar brain dysfunction.¹⁷

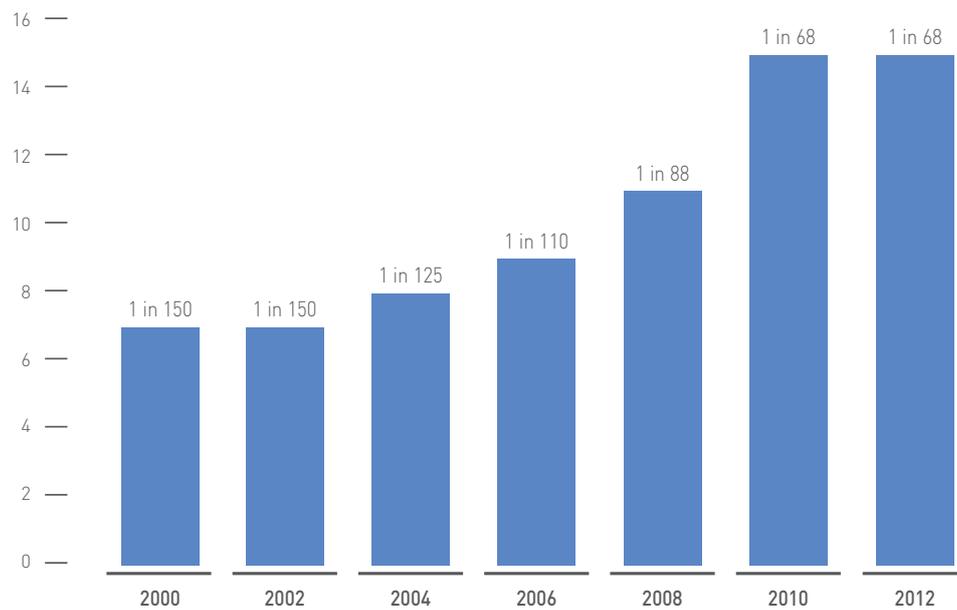
Also, there is recent support for a ‘female protective effect’ as an explanation for males being four to five times more likely to have the disorder. More mutations are observed in females than males with ASD, suggesting that, in girls, the number of mutations present in the same genes must reach a higher threshold for ASD to be expressed.^{18, 19}

A number of environmental factors are also thought to be potential contributors, including prenatal exposure to drugs, organophosphate insecticides, agricultural pesticides,²⁰ viruses, air pollution and complications at birth.²¹ There is also a suggestion that differences in synaptic connectivity patterns in ASD may, in part, reflect the result of each person’s unique interaction with his or her environment.²²

Prevalence

In 2010, there were approximately 52 million people living with ASD worldwide.^{23, 24} This figure represents a substantial increase compared to previous decades. In the US alone, the estimated prevalence of ASD has risen from one in 2,000 eight-year-old children in 1988, to one in 68 in 2010, representing a more than tenfold increase during this period.²⁵ The prevalence figure for surveillance years 2010 and 2012 remained unchanged (see Figure 2).²⁶

Figure 2: Prevalence of ASD in the US per 1,000 among eight-year-olds, by surveillance year

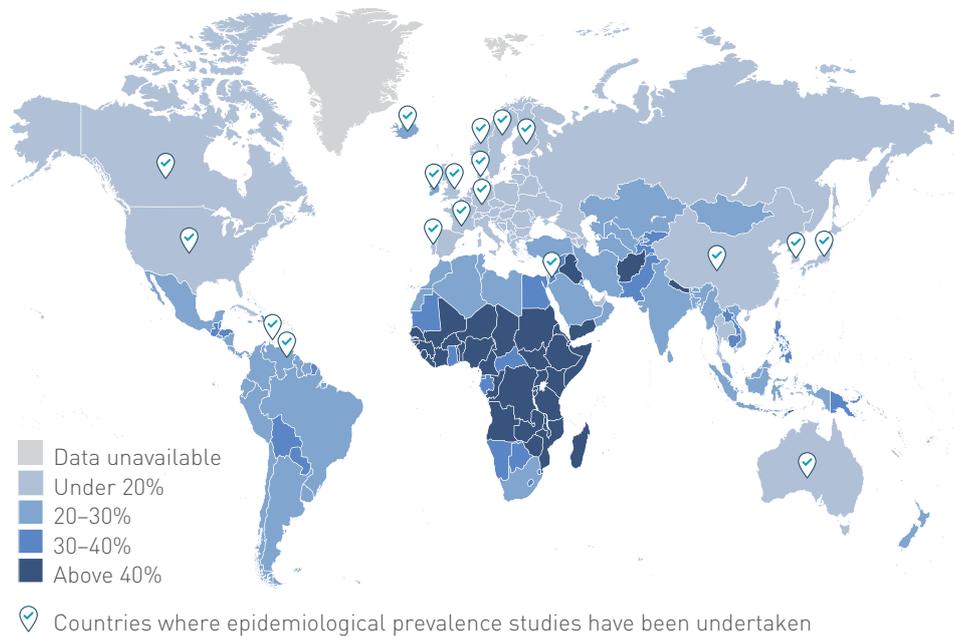


Source: Adapted from CDC (2014)²⁷

Some attribute this increase to greater awareness of ASD in HICs, use of broader diagnostic criteria and better identification of children who were previously classified as having an intellectual disability or intellectual developmental disorder (ID/IDD).^{28,29} However, it is clear that the increase in diagnoses is cause for global concern.

To date, 86.5 percent of all cases of ASD have been reported in HICs, where only 20 percent of the world population resides.^{30,31} With the exception of China, few population-based studies have been conducted in LMICs. As demonstrated in Figure 3, many LMICs have young populations, resulting in higher levels of potential diagnoses of ASD. As such, the lack of studies in these countries may well underrepresent the impact of ASD.

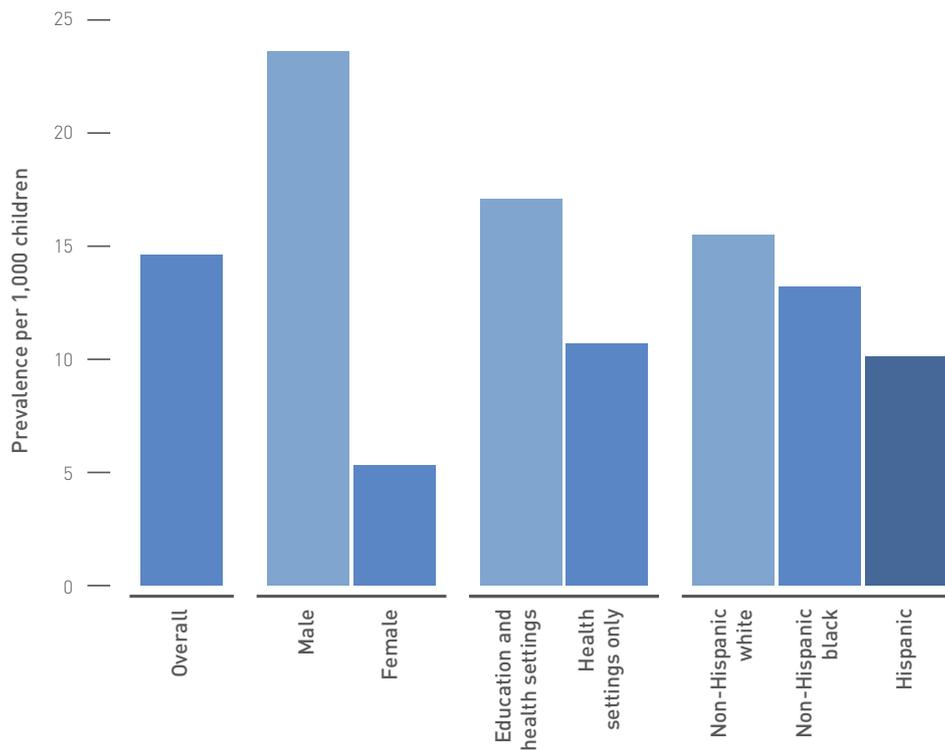
Figure 3: Percentage of population under age 15 by country and locations of ASD prevalence studies



Sources: United Nations (2015)³², Elsabbagh et al. (2012)³³

Unfortunately, there are also difficulties in measuring the prevalence of ASD, stemming from population awareness, selection of studies and diagnostic capabilities, as well as cross-cultural appropriateness and comparability of ASD screening, measurement and epidemiological data.³⁴ The positive relationship between ASD and higher socio-economic status in studies reported from the US, for example, is now thought to reflect a bias in reduced case ascertainment in low-resource settings.³⁵ These uneven rates of diagnosis have also led to a variation in ASD prevalence by race and ethnicity, with prevalence among white, non-Hispanic children significantly greater than among black and Hispanic children (see Figure 4). This underscores that some children may not be receiving appropriate services and support.^{36,37}

Figure 4: Autism prevalence estimates in eight-year-olds in the US, 2012



Source: Christensen et al. (2016)³⁸

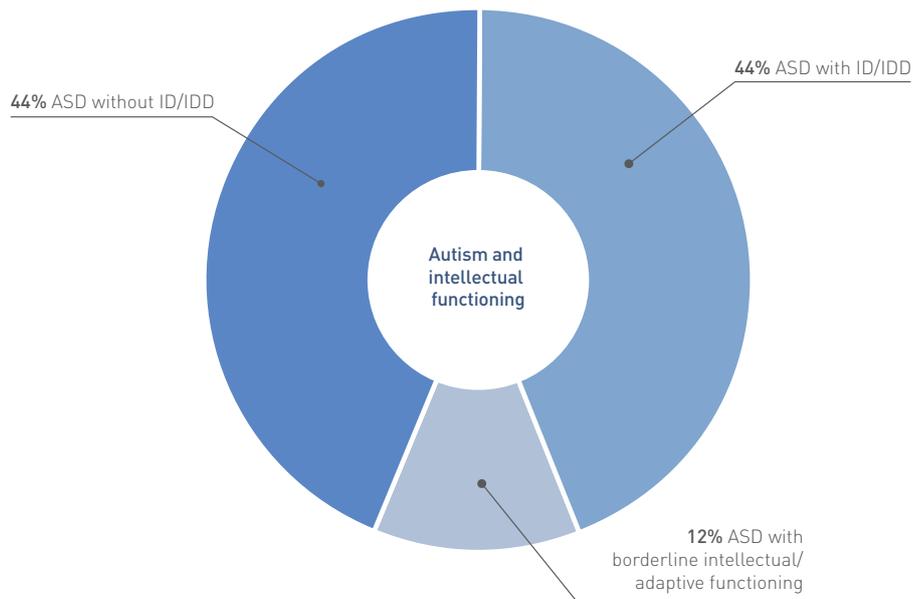
Co-occurrence

While much research focuses on ASD independently, almost half (44 percent) of subjects with ASD have co-occurring ID/IDD (see Figure 5).³⁹ The current definition of ID/IDD emphasizes deficits in the affected person's adaptive, as well as cognitive, functioning.^{40, 41} This includes deficits in general mental abilities such as reasoning, problem solving, abstract thinking, judgment, academic learning and learning from experience.⁴² An additional group of people with ASD perform in the borderline intellectual cognitive and adaptive functioning range⁴³ – while a quarter of people with ASD are non-verbal. At the higher functioning end of the spectrum, many people with ASD have average or high intelligence and can live normal lives.

The overall prevalence of ID/IDD has been reported to be as low as 0.7 percent in HICs, but can be as high as 3 percent in LMICs due to adverse pregnancy and delivery as well as postnatal factors, including trauma, infection, social deprivation, toxic and metabolic conditions, and seizures.^{44, 45} When ASD and ID/IDD co-occur, they may be indistinguishable in toddlers and attributed to developmental delay. Therefore, from a clinical, evidenced-based (as well as ethical) perspective, early intervention and early education services should target both populations.

ASD also commonly co-occurs with other neurodevelopmental, psychiatric, neurologic, chromosomal and genetic diagnoses in up to 83 percent of cases.⁴⁶ As ASD often does not occur as a single presenting condition, the 'bridging' between ASD and other neurodevelopmental disorders using a joint strategy for assessing young children is highly important given the size of the problem, potential health gains and burden reduction.⁴⁷

Figure 5: Autism and intellectual functioning



Source: Baxter et al. (2015)⁴⁸

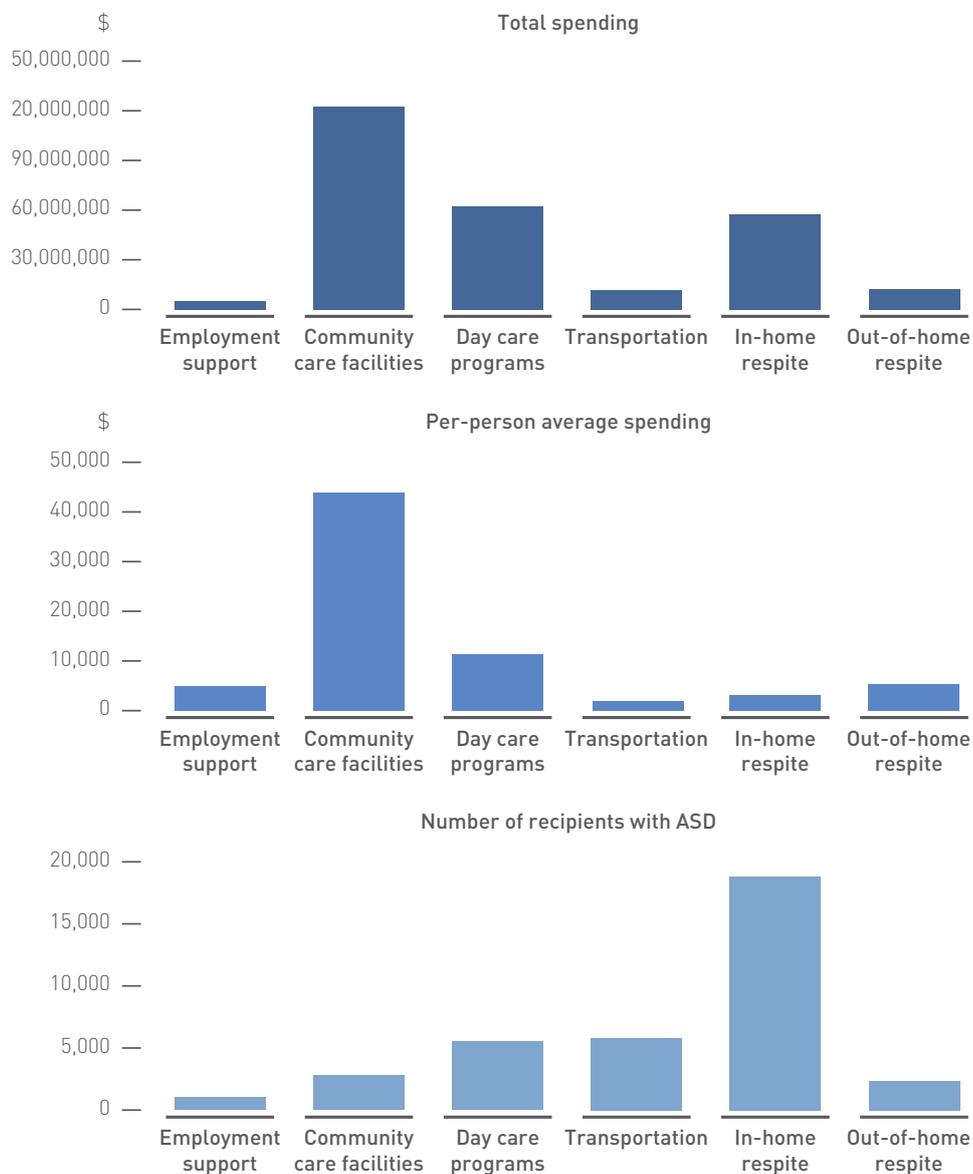
Costs and quality of life

The economic impact associated with ASD is substantial and includes direct medical, direct non-medical and indirect productivity costs.⁴⁹ Studies estimate the lifetime cost of caring for an individual with ASD and ID/IDD to be \$2.2 million in the US, and £1.5 million in the United Kingdom (UK); though the figures drop to \$1.4 million in the US and £0.92 million in the UK for ASD without co-morbid ID/IDD.⁵⁰ Also, if unrecognized or untreated, ASD can contribute to poor educational attainment and difficulty with employment, leading to negative economic implications.

Recent estimates of the total economic impact of ASD in the US in 2015, based on direct medical, non-medical and productivity costs combined, totalled \$268 billion – ranging from 0.9 to 2 percent of gross domestic product (GDP). This figure is expected to rise to \$461 billion (ranging from 0.99 to 3.6 percent of GDP) by 2025.⁵¹ These figures are on par with recent estimates for diabetes and exceed the costs of stroke and hypertension. However, what sets ASD apart from other non-communicable diseases – such as heart disease, cancer, stroke and hypertension – are the significantly higher non-medical costs when compared to direct medical costs.^{52, 53}

Figure 6 displays non-medical spending for ASD in California; however, these costs are often not uniform across groups. According to a recent study in California – where it is estimated that services are provided to 75 to 80 percent of persons diagnosed with ASD – there were no significant differences in terms of per-person spending between males and females. Yet there were dramatic disparities by race and ethnicity, as well as age.⁵⁴ White, non-Hispanics received the highest per-person spending, and Hispanics among the least, across all age groups. The average spend per-person for ages 18 and above was 2.6 times greater than that for children and adolescents aged three to 17 years, yet the total costs for all children and adolescents with ASD were significantly higher than those for adults. This can be explained by the lower overall number of individuals receiving services in older age groups.⁵⁵ However, as the current cohort of children and adolescents with ASD move into adulthood, the expenditure for this group is likely to increase dramatically.

Figure 6: Non-medical spending on ASD by California Department of Developmental Services



Source: Adapted from Leigh et al. (2016)⁵⁶

In addition to the cost associated with ASD, the condition can affect the quality of life for those with ASD as well as their families. Although some people with ASD and neurodevelopmental disorders can lead independent lives, for many, the impact of these conditions is severe. The disorder interferes with the quality of their lives and the quality of life and productivity of their parents,⁵⁷ who may experience increased anxiety and depression, and may need to decrease hours worked outside of the home due to their child's diagnosis.⁵⁸ As such, evaluating the effects of ASD is a complex exercise that should include investigation of the effects on family members and caregivers as well as on those people with the condition.

Global initiatives

There have been several initiatives across the globe designed to raise awareness of ASD and improve care for those people with the condition. In 2008, Autism Speaks – a US-based leading advocacy organization – launched the Global Autism Public Health (GAPH) initiative to enhance global ASD awareness and promote research, training and service delivery.⁵⁹ Subsequently, numerous international grants have been funded due to the interest in global research on ASD at the International Society for Autism Research (INSAR) meetings.

In April 2013, a WHO Executive Board resolution (EB133/4 – see Appendix 1) focused on co-ordinated efforts for the management of ASD. Across Europe and North America, a number of parents' advocacy groups have become highly influential. In September 2015, the Autism Europe initiative led the European Parliament to officially adopt the Written Declaration on Autism⁶⁰ (see Appendix 2). The document called on all European Union (EU) policymakers to adopt a combined holistic approach that responds to the urgent needs of 5 million EU citizens affected by ASD and to tackle the discrimination and challenges faced by them and their families throughout their lives.

Outside HICs, public health initiatives concerning the impact of ASD and other neurodevelopmental conditions remain poorly implemented, despite major advances in the control and treatment of infectious diseases.^{61, 62} The knowledge gap between evidence and action in the care of individuals with ASD and neurodevelopmental disorders in LMICs has remained considerably wide.^{63–66}

In response, in 2014, international child neurology associations jointly held a global workshop with the participation of 14 African countries. A major outcome of this gathering was the establishment of a virtual ASD network for Africa entitled Global Research in Autism and Neurodevelopment (GRAND).⁶⁷ GRAND has been funded by the Shirley Foundation in the UK to support pioneering projects in ASD research such as the Global Mapping Project for ASD and neurodevelopmental disorders.

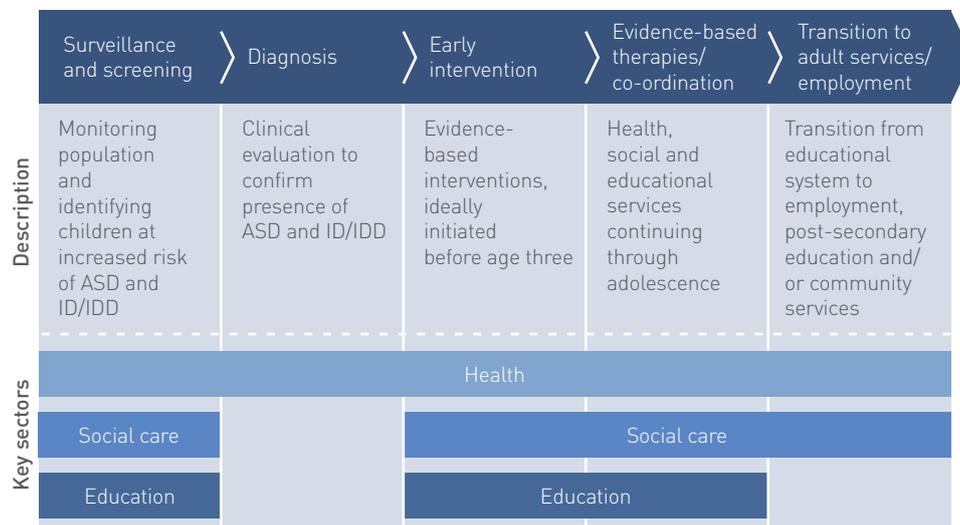
In July 2014, a WHO Technical Working Group meeting on parent skills training for caregivers of children with developmental disorders met in Geneva, Switzerland, supported by Autism Speaks. Subsequent meetings were held during INSAR gatherings to enrich research and services in low-resource settings. These efforts also linked the ASD and neurodevelopmental disorders agenda with goals related to confronting stigma, inequality and neglect of vulnerable individuals.

There are also a number of promising ASD initiatives underway in Qatar. In 2015, a National Autism Working Group was created within the Ministry of Public Health. This group encompasses stakeholders from around the country, including child psychiatrists, developmental pediatricians, speech therapists, occupational therapists, psychologists, educators, administrators and, most importantly, family members. This group is charged with creating a National Autism Plan based on six pillars: awareness; early recognition and screening; diagnosis and assessment; interventions; school services; and transition to adulthood. The WHO has collaborated closely with this group in finalizing the National Autism Plan, which will be launched at the end of 2016. Qatar Foundation for Education, Science and Community Development is also planning to open a state-of-the-art school, the Renad Academy, for children with ASD, and the Qatar Biomedical Research Institute (QBRI) is currently undertaking the first ASD prevalence study in Qatar to better identify service needs in the country.⁶⁸

ASD journey

Currently there is no cure for autism. The aim of current interventions is to affect developmental trajectories positively and to lead children toward a more neurotypical outcome. While some children and adolescents may grow into adults for whom the label is no longer appropriate – due to an apparent reduction of symptoms or improvements from treatment – ASD is primarily a lifelong condition requiring a co-ordinated set of services across health, education and social sectors (see Figure 7).⁶⁹

Figure 7: Autism and intellectual developmental disorders journey



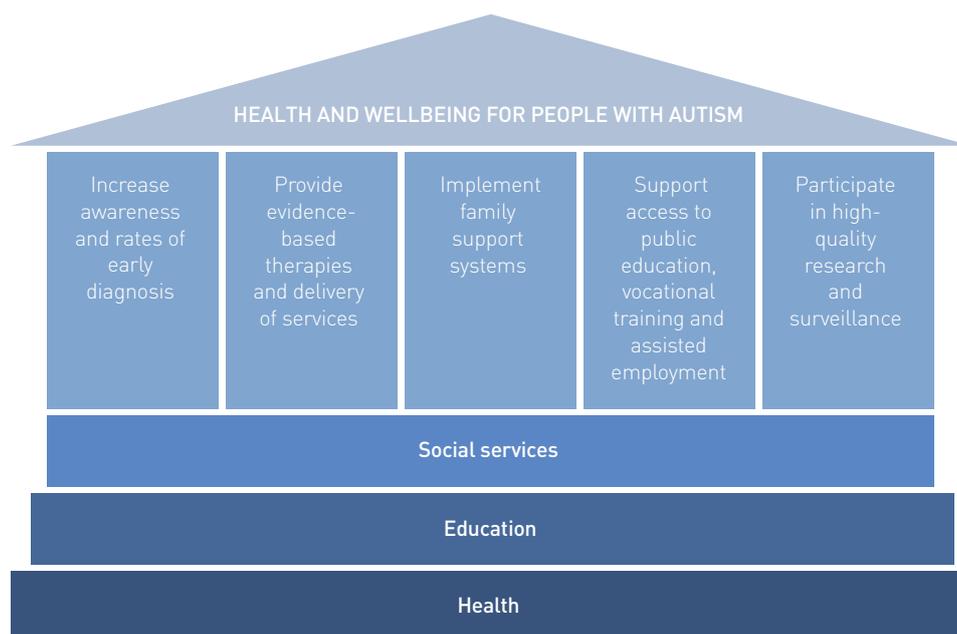
Source: Fein et al. (2013)⁷⁰

While we are hopeful that precision medicine builds person-centered information and potentially guides effective behavioral and biological treatments – such as novel drug discovery targeting core symptoms – in the future, it is imperative for policymakers to focus on implementing cross-cutting policies that encourage support across the life journey of ASD.

SECTION 2: GOALS, CHALLENGES AND OPPORTUNITIES FOR ACTION

There is growing momentum globally around recognizing ASD and neurodevelopmental disorders and advocating for the needs and rights of affected children and their families. Based on the evidence available, we believe there are five key areas where policymakers can affect substantive change (see Figure 8).

Figure 8: Framework for action



Though the social services, education and health sectors contribute in varying ways across each of these five areas, we believe it is imperative for these domains to work together to improve the quality of care and services provided to people with ASD.

Goal 1: Increase awareness and rates of early diagnosis

Challenges

The early identification and diagnosis of ASD is essential to ensure that children can access evidence-based interventions and optimize long-term outcomes. Although there is increasing consensus that early signs of ASD can be detected during infancy by experimenting with new technologies such as brain responses⁷¹ and eye tracking,⁷² early detection of ASD and neurodevelopmental disorders at a global level remains a major challenge. Recent evidence suggests that 38 percent of children with

ASD were not identified in HICs until after four years of age, despite the fact that 87 percent of these children had noted developmental concerns before age three.⁷³ This is partly due to the many steps needed to identify children with ASD – from surveillance and screening to evaluation and diagnosis.

A major issue in general population screening for ASD is that it does not fit the usual biomedical model, as it is a behaviorally defined and broad spectrum condition.⁷⁴ A child with ASD can only be evaluated by behavioral symptoms, not by means of a scan or a blood test. In the future, it may be possible to detect ASD before symptoms emerge, but such measures are at least a decade away, even in HICs.^{75,76} The limited surveillance and screening of developmental delays in the home, primary healthcare and education settings reflect challenges in awareness, resources and training that include:

- **Limited knowledge among parents about ASD and neurodevelopmental disorders:** This is particularly so in LMICs and low-resource settings, where many parents are not mindful of the appropriate timing for certain developmental skills such as speech and language.^{77,78} As a result, parents may not be aware that developmental delays are present. Further, when parents do have developmental concerns, many may not reach out to healthcare providers.
- **Cultural stigma:** In many countries, the stigma around ASD and other neurodevelopmental disorders, as for mental illness in general, may discourage parents from seeking attention when a concern arises, or delay further evaluation or treatment even when suggested by a medical professional.⁷⁹
- **Lack of knowledge among educators and primary care clinicians about ASD and the benefits of therapies:** Training in the care of patients with acute illness is more emphasized in LMICs; many primary care clinicians in these countries lack awareness of developmental milestones and how to assess them. Therefore, developmental delays may go unnoticed and children may not be referred for evaluation. Many teachers lack training and knowledge about ASD and neurodevelopmental disorders and therefore do not pick up on early signs in their classrooms.⁸⁰
- **Lack of trained clinicians to perform targeted screenings and evaluations:** There are a limited number of clinical providers in pediatrics, psychiatry, neurology and psychology that have the expertise to appropriately diagnose children with ASD and neurodevelopmental disorders, particularly in some low-resource and rural settings.⁸¹
- **Challenges in widespread use of standardized assessment tools in LMICs:** Popular diagnostic instruments used in HICs can be very expensive, require extensive and costly training, and be lengthy to administer.⁸² Nearly all of the leading tools are published by Western Psychological Services (WPS) and any WPS translations have to be authorized by WPS on a fee basis with all rights reserved. The 'gold standard' diagnostic instruments, such as the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2),⁸³ and the Autism Diagnostic Interview, Revised (ADI-R),⁸⁴ were primarily developed for research purposes. They are not suitable for standard clinical or research use in LMICs due to purchasing and training costs, which can reach thousands of dollars per trainee.⁸⁵

Opportunities for action

To increase rates of early diagnosis, there must first be improved awareness of developmental delays and increased surveillance in the home, community, healthcare and education settings. Awareness campaigns have been successful in educating parents about ASD in many parts of the world.^{86,87} In India, posters about early warning signs of ASD displayed in waiting rooms of pediatric offices or health clinics helped to increase understanding of diagnoses.⁸⁸ The internet resource 'Learn the Signs. Act Early.', has helped educate parents with downloadable materials.⁸⁹ There are also several examples of LMIC community health workers being trained to monitor child development and educate families as part of outreach goals. For instance, community health volunteers called Accredited Social Health Activists (ASHAs) in India have provided a link between the community and the health system,⁹⁰ particularly in rural areas. ASHAs educate families about typical child development, maternal healthcare delivery and infectious diseases, and monitor them during their interactions with their children. ASHAs also facilitate consultations for children who have suspected developmental delays.⁹¹ Another potential opportunity in India is the training of grassroots workers, called Anganwadi workers, who are responsible for immunization, nutrition and preschool day care services under the Integrated Child Development Services. Anganwadi workers can assist in developmental screening and simple techniques of early intervention.

There is a critical need within the healthcare system to provide training and education to all clinicians, while also developing additional specialized training programs for targeted screenings and evaluations for ASD and neurodevelopmental disorders. At the primary care level, rates of diagnoses can be increased by providing information to pediatricians, nurses and community health workers about developmental milestones as well as signs of ASD and neurodevelopmental disorders.

ASD has provided an impetus for developing standards for integrated care of all children with neurodevelopmental disorders and for a global training strategy suited to varying resource and cultural contexts. A recent Grand Challenges Canada-funded study involved two-stage assessments:

- Stage 1: Screening of children for neurodevelopmental delays in immunizations clinics at primary healthcare centers in Lagos State, Nigeria.
- Stage 2: Clinical evaluation and follow-up interventions for children who screened positive.

Similar methods could be successfully incorporated into training of community health workers for general developmental surveillance during immunization visits.⁹²

Training must include screening and diagnostic tools that can be equitably and cost-effectively delivered in low-resource settings. These may include general measures of neurodevelopment – such as Infant Development Inventory,⁹³ Child Development Review,⁹⁴ Centers for Disease Control and Prevention (CDC) Milestone Moments⁹⁵ and WHO Growth Standard Charts⁹⁶ – as well as specific ASD screening tools such as the Modified Checklist for Autism in Toddlers (M-CHAT),⁹⁷ a 23-item questionnaire for

parents about the symptoms of ASD or developmental delay, which has been translated into more than 40 languages, available as an open source assessment tool. The majority of children who score high on M-CHAT have developmental delay and/or neurodevelopmental concerns.⁹⁸

Alternatively, a Three-item Direct Observation Screen (TIDOS) for ASD involves an observational screening completed by pediatric primary healthcare workers with assessment of joint attention, eye contact, and responsiveness to name. When combined with ASD checklists, such as the Social Communication Questionnaire, this method has led to significantly improved identification of children with ASD.⁹⁹

In the educational context, teachers are an invaluable resource, as they work closely with children, are familiar with major developmental milestones and are a trusted source of information for parents.¹⁰⁰ Checklists exist, such as the Teacher's Observation Guide, to help identify developmental milestones as well as the presence of ASD and various neurodevelopmental disorders. These can easily be disseminated to educators, even in low-resource settings.^{101, 102} We must further integrate and create partnerships between healthcare professionals, teachers and schools if we are to achieve substantive improved outcomes.¹⁰³

Goal 2: Provide evidence-based therapies and delivery of services

Challenges

Young children with ASD require interventions that target language and communication skills, joint attention, social imitation, pointing, socio-emotional reciprocity and self-help skills – and these services should begin as early as possible. Early interventions initiated before the age of three have the greatest positive impact on outcomes.¹⁰⁴ Evidence-based therapies, such as Applied Behavior Analysis, can lessen the impact of core symptoms of ASD and are potentially adaptable to the LMIC context.¹⁰⁵ However, current programs have cost limitations for families and professionals (including certification and training of trainers). This is not a challenge unique to LMICs, but also applies to many HICs. For example, the implementation of the Early Start Denver Model (an effective and relevant intervention for toddlers at risk of ASD and other neurodevelopmental disorders)¹⁰⁶ used in France has been difficult due to limited training opportunities and high training costs.¹⁰⁷

Some children and adolescents with ASD and neurodevelopmental disorders experience auditory, visual and tactile hypersensitivities and respond to them with acute distress and may also engage in self-injury.¹⁰⁸ Such unsafe behavior limits participation in family, school and community life. There are also significant disparities in access to services, driven by barriers including:

- **Lack of trained professionals to provide co-ordinated and evidence-based therapies:** Deficits in ASD-specific knowledge contribute to the current disparities in the timing and quality of ASD services delivered globally.¹⁰⁹ The situation is further complicated by the fragmented nature of many treatment and support systems, which can lead to inefficiencies if insufficient attention is paid to co-ordination and co-operation.¹¹⁰ In low-resource settings, treatment of acute illness is often prioritized by professionals over conditions such as ASD. The parents of children with ASD in Kenya, for example, often resort to coping strategies such as dietary management, respite care and seeking relief in supernatural powers, prayers and spiritual healing, due in part to a lack of trained professionals.¹¹¹
- **Uneven distribution and variable quality of services:** Children and families living in rural areas often have limited access to therapeutic services provided in urban settings. This is a widespread disparity in HICs – as noted by the CDC Autism and Developmental Disabilities Monitoring (ADDM) Network’s data in the US¹¹² – yet the greatest disparity exists in LMICs, where most people with ASD live in areas with minimal available services.^{113, 114, 115}
- **High cost of service:** Many families throughout the world do not have health insurance to pay for resource-intensive services that are recommended for ASD and neurodevelopmental disorders. Also, there is limited adaptation of early intensive behavioral interventions, such as the Early Start Denver Model, that can be provided at a lower cost to children and families.

Opportunities for action

Countries need to adopt a multi-stage approach to increase their capacity to provide services to children with ASD and neurodevelopmental disorders. First, formal training programs are needed for health professionals to develop expertise in evidence-based services. High-intensity interventions commonly available in HICs should also be adapted to be less resource-intensive and more affordable in LMICs. For services provided by health professionals, quality control mechanisms, such as certification for training and licensing for programs, are necessary to ensure adequate quality.

Providing healthcare coverage to children with ASD and neurodevelopmental disorders is also essential to help alleviate the burden of care costs. Chile was one of the first Latin American countries to introduce a National Mental Health Plan in its public health system. The plan includes public funding for ID/IDD.¹¹⁶ However, people with neurodevelopmental disorders without ID/IDD were excluded. Likewise, in most parts of Nigeria, children and young people with infectious diseases, such as HIV, malaria and sickle cell, receive healthcare coverage.¹¹⁷ Expanding existing programs that provide healthcare coverage for infectious diseases may be a starting point for providing coverage for a larger range of services focused on chronic and mental illness, including ASD.

In addition to increasing healthcare capacity, there is an opportunity to train parents to provide services directly to their children with ASD (see Case study 1). Training parents can result in favorable outcomes, including improved social behavior, increased language skills and decreased inappropriate disruptive behaviors.¹¹⁸ A promising parenting program is the Stepping Stones Triple P (Positive Parenting Program) that has been evaluated as part of a randomized clinical trial with parents of children with ASD.¹¹⁹

Joint Attention, Symbolic Play, Engagement and Regulation (JASPER) is another treatment approach based on a combination of developmental and behavioral principles targeting social communication.¹²⁰ JASPER has been empirically tested in randomized clinical trials involving children between the ages of one and eight. The program can be implemented by parents, teachers, clinicians and other trained service providers, as well as incorporated into inclusion and special education classrooms. JASPER has been useful in both HIC and LMIC settings and was recently recommended by the National Institute for Health and Care Excellence (NICE) guidelines.¹²¹

Importantly, we need to align services to provide evidence-based therapies for young people with ASD¹²² and extend support to teens and adults transitioning into adult-based services that aid in developing coping strategies and accessing community services. This should include developing skills to access in-home and out-of-home respite services, transportation, employment and leisure. The timing of transition to adult services may vary locally and individually, but should usually be completed by 18 years of age. People with ASD and their families and caregivers should be involved in the planning of adult services and receive information on available health, employment and social services.¹²³

Case study 1: World Health Organization Parent Skills Training Package for caregivers of children with developmental disorders¹²⁴

Previous research suggests that parent skills training programs can be effectively delivered by non-specialists in community settings and may have beneficial effects for families of children with developmental disorders.¹²⁵ The benefits to the child include improved developmental outcomes and reduced problem behaviors.^{126, 127} Based on available evidence, WHO developed a parent skills training program for caregivers of children between two and nine years old with a developmental delay or disorder, including ASD. The WHO Parent Skills Training program aims to promote children's engagement, communication and adaptive behaviors through play and home routines, leading to improved overall child and family functioning. A package of materials is currently Available at WHO for pilot testing in countries, and evidence about its effectiveness is currently being investigated with a randomized controlled trial in Pakistan.¹²⁸

(Case study 1 continued)

Lessons learned

- The WHO Parent Skills Training program can be delivered by a range of non-specialist providers, including social workers, community volunteers, community-based rehabilitation workers, nurses, primary care doctors, teachers, caregivers and parents, in community-based facilities and schools.¹²⁹
- Pilot projects conducted showed that these training materials are acceptable and scalable in low-resource settings.

Goal 3: Implement family support systems

Challenges

It is well-known that families whose children are perceived as different feel isolated, alone and stigmatized, and too often take on self-blame.¹³⁰ This is especially true for parents whose children carry an ASD or neurodevelopmental disorder diagnosis.

Families of children with ASD often struggle to deal with their child's disorder in the home setting or in the community¹³¹ and may not know anyone to reach out to for help. The lack of knowledge and lack of available role models also limits opportunities to learn how their child is best taught and responded to.

Many parents of children with disorders and disabilities also experience diminished opportunities for employment and advancement.¹³² They often lack adequate financial resources to pursue formal instruction on how to cope with their child's special needs, and support for formal systems remains underfunded.^{133, 134}

Families' feelings of isolation, self-doubt, stigma and general sense of loss of control can be traced to the following:

- **Lack of connection to other families:** Families gain enormously from connecting to others who have experienced what they are going through and can help guide them in their quest to support their children. However, these connections are not common in all areas.^{135, 136, 137}
- **Few programs to support their children:** The scarcity of programs that support children with ASD and other neurodevelopmental disorders reduces children's ability to benefit from early treatment.^{138, 139}
- **Lack of continuity of services:** Children with ASD require a lifespan approach that sustains them and supports them as they grow, develop and strive to be included in their communities. However, services are often disjointed and lack integration.^{140, 141, 142}

Opportunities for action

To improve the quality of life for families of those with ASD, policymakers, government organizations and NGOs need to work collaboratively to create and offer services that provide appropriate support. The most effective community and governmental efforts to do so include the family voice, which allows families themselves to become part of the national policy discussion and contribute direct feedback about their experiences.¹⁴³ This can result in adjustments to services that improve support. A three-pronged approach to effective service design would include:

- connecting families to information and to other parents;
- developing programs to support children; and
- ensuring that services are sustained across the lifespan of the person with the disorder.

Connecting families to each other and to policymakers to share up-to-date information are the most important elements that families have identified for support.¹⁴⁴ Family-led organizations and coalitions have shown to be an effective and low-cost way to supply information about ASD.^{145, 146} For example, Qatar's National Autism Working Group involves family members in facilitating:

- awareness;
- early detection;
- diagnosis;
- interventions;
- school services; and
- transition to adulthood.

Policy and program directors can enhance these efforts by initiating and sustaining structures (for example, developing support groups, family events and activities) that allow families to connect to others. In situations where the internet is available, connections can be formed online for families to communicate with each other about their concerns.¹⁴⁷ This communication strategy is especially effective in rural areas and less developed countries, where face-to-face meetings can be challenging.¹⁴⁸

Finally, connecting families and family leaders to government initiatives is critical to create effective programs. Truly responsive programs can only be developed by integrating the family point of view. Family Voices in the US has been particularly successful in doing so, as their founder has enlisted legislators in the quest for home-based service options.¹⁴⁹

Programs should also be implemented to educate families about the conditions that impact their children. These educational programs can be made readily available by using online training. Training opportunities should range in complexity, from developing skills for interacting with the affected family member to parental coping mechanisms. These types of skills assist in children's development and also help to reduce parental stress. Importantly, inviting families to be part of the decision-making process makes such programs more likely to be successful (see Case study 2).

Although early diagnosis and treatment have been shown to increase the adaptability and skill levels of children with ASD, support for the growing child and family must be sustained over time. The developmental trajectory brings about new challenges and changing needs. Programs need to be created that assist people with ASD to reach their full potential throughout their lifespan. The emphasis should be on supporting their independence, self-advocacy and as much full inclusion as possible in their communities.¹⁵⁰

Case study 2: French response to assisting children with ASD and their families – education thérapeutique du patient (ETP)¹⁵¹

France uses a model of support systems for families coping with chronic diseases, including ASD, called ETP (therapeutic education). This is a national program that includes autism resource centers, experts and families, and is interconnected with the Third National Autism Plan, which was enacted in 2013. The governance of the plan involves regular discussions between the government, relevant family associations, researchers and professionals. The program has an allocated budget (around € 17,000 per year) and is implemented in several French catchment areas by autism resource centers in partnership with local family associations. Autism resource centers have ASD trainers for two types of training: unspecific (that is, information dissemination); and specific (for example, educational approach), using weekly or monthly sessions totaling eight hours across one or five months. Programs are evaluated using clinical outcomes, such as quality of life, stress level and parental satisfaction. The corresponding intervention has three dimensions:

1. Improving knowledge about the disorder and its treatment.
2. Enhancing parental skills in interacting with their children.
3. Decreasing parental stress levels and improving coping skills.

Lessons learned

- This plan consolidates and integrates the health, education and social sectors.
- A national working group (including families) evaluates the guidelines containing the main points of the plan.
- The program is effective when publicly funded and set up by the government in regional autism resource centers.
- Challenges include regional variations, as well as disparities between urban and rural regions and sustaining support over the long term.

Goal 4: Support access to public education, vocational training and assisted employment

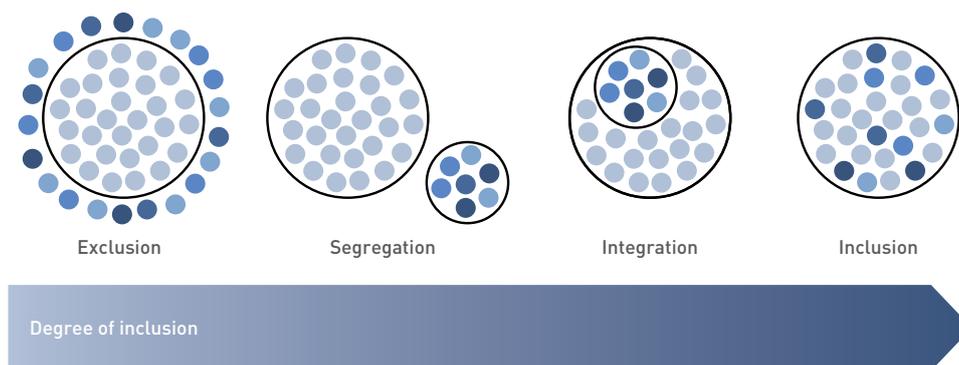
Challenges

Education is globally recognized as a basic human right.¹⁵² This perspective is reflected in a number of international policies, including the UN Convention on the Rights of the Child, the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the International Covenant on Economic, Social and Cultural Rights.¹⁵³ In particular, the UNCRPD represents an important shift in awareness and advocacy, with an emphasis on considering people with disabilities as empowered individuals with important rights. These include the right to an “inclusive, quality and free primary and secondary education on an equal basis with others in the communities in which they live”. (UNCRPD Article 24 – ‘The right to inclusive education’ is reproduced in Appendix 3).¹⁵⁴

Despite this policy and its current adoption by 162 member states (as of 22 March 2016), children with ASD and neurodevelopmental disorders continue to face barriers accessing an inclusive public education in many places in the world. In fact, about one-third of the more than 60 million children still excluded from public schools worldwide are children with disabilities.¹⁵⁵

The goal of providing children with an inclusive education in mainstream public (government-funded) schools is an important one. The path from exclusion to inclusion is a continuum (see Figure 9), and many communities fall somewhere in between, with their current practices also varying based on the severity of the child’s disability.

Figure 9: Exclusion to inclusion continuum



Source: Adapted from Michigan Alliance for Families¹⁵⁶

Children with more severe forms of ASD, with concurrent ID/IDD, are at highest risk of being excluded from the mainstream education system. Educating children with ASD and neurodevelopmental disorders in segregated schools can increase prejudice and stigma in societies, especially if these schools are under-resourced and further perpetuate discrimination.¹⁵⁷ Integration has been an important stepping-stone for many countries as they move toward the goal of inclusion. However, inclusion – even

in LMIC settings – must include proper resources and support services for children with ASD to achieve the model learning environment, as evidence shows it can help all students reach their full potential.¹⁵⁸ Inclusion brings the disability and non-disability communities together and facilitates a common sense of citizenship and equality.

The lack of enforcement of existing policies that guarantee children with ASD and other neurodevelopmental disorders the right to an equal, inclusive education is often due to a shortage of:

- **Properly trained teachers:** Many teacher training programs do not provide special education training, or provide general education teachers with training on how to accommodate a child with a disorder or disability in their classroom.
- **Appropriate school curriculum and other educational modifications:** Many school systems do not have the resources to develop their own learning programs and materials for children with ASD and other neurodevelopmental disorders and do not have a system for accommodating them in a regular classroom.
- **Educational data:** Many countries do not collect data on the educational outcomes of children with and without disabilities. Tracking these metrics could improve accountability across schools.¹⁵⁹

Opportunities for action

There is a critical need to provide a broader set of training programs and certifications to teachers that would facilitate the inclusion of children with disabilities into mainstream public schools. Ideally, these programs should be structured to provide special education training to a group of educators as well as give general education teachers the skills that would allow them to knowledgeably accommodate children with disorders such as ASD in inclusive classes. There is also an opportunity to train special education teachers, giving them the skills to carry out interventions that would improve their work with children with ASD specifically, including Applied Behavior Analysis practices and peer-mediated interventions.¹⁶⁰

In parallel to these training programs, there is a need to provide special education teaching and learning resources that can be adapted by individual school systems. For children with ASD and moderate to severe ID/IDD, there may be a need to create a separate core curriculum based on the general needs of this group. Children with ASD who do not have ID/IDD may follow a general education with added support and modifications based on their specific therapeutic and learning needs.¹⁶¹ The National Foundation for Educational Research (NFER) has published an assessment and related educational policy about the inclusion of children with ASD in mainstream schools.¹⁶²

Efforts should also be made to tailor special education goals to the specific needs of each child. A common strategy for doing this in higher resource settings is to create individual education plans for each child that take into account their specific needs and goals, with regularly scheduled meetings with parents and advocates, if requested. Such personalized plans can include special measurable arrangements

for learning tasks and exams, allowing for exemptions for assignments and assessments, extra time for learning tasks and tests, and adaptation of the conditions or the format of the task.¹⁶³

Systematically collected data is central to monitoring educational goals for children with ASD and other neurodevelopmental disorders. As part of this, governments need to provide a system and infrastructure that enables school systems to collect and report data on children's progress in the school environment, usually through annual assessments.

To prioritize and act on these goals, countries should develop an action plan with clear targets and a timetable for implementation. This action plan should be overseen by a core group of administrators within the Ministry of Education or an Interagency Commission on Autism and Neurodevelopmental Disorders that is held accountable for reaching targets by pre-specified deadlines.

These goals also create a parallel need for community awareness and education about the benefits of including children with ASD and other neurodevelopmental disorders in mainstream schools. These advocacy efforts are often best accomplished by building partnerships between schools, parents, other stakeholders and specialized multidisciplinary therapy and support centers.¹⁶⁴

It should also be noted that, when full inclusion does not seem feasible for a given country or region, integration of children with ASD and other disabilities into the mainstream school through co-locating general education and special education programs can be an important step to full inclusion.

In summary, we need to promote enrollment in inclusive education with in-classroom support. We should increase funding to train both specialist and mainstream teachers (see, for example, Case study 3) to support the growing numbers of children and young people with ASD. We must also promote greater capacity to implement individualized education plans (IEPs) with the active participation of parents and family caregivers.

Case study 3: Special education teacher training and certification program in India¹⁶⁵

India, like many other LMICs, has struggled with an inadequate number of special education teachers for children with ASD and other disorders. Advocacy efforts to develop a certification program for special education, with a focus in ASD, were spearheaded by Action for Autism in the mid-1990s. This advocacy campaign succeeded in 2003, in part because of the efforts of families of children with ASD.

(Case study 3 continued)

Since that time, a two-year training program has been implemented that provides education to student teachers on the theoretical and practical aspects of working with children with ASD. Each year, a maximum of 25 students enroll in Action for Autism's training program, costing about INR 800,000 (or \$12,000) per trainee.¹⁶⁶ Through various modules, including workshops, classroom lectures and school training, students learn to screen, assess and teach children with ASD. On graduation, certified teachers work in specialized schools, mainstream schools, or NGOs focused on providing services to children with ASD.

Lessons learned

- Build advocacy based on a country's existing laws and regulations that guarantee children's rights.
- Use a multi-sector approach to develop a curriculum for teacher training by including medical professionals, teachers, administrators and parents.
- Prioritize inclusion training as part of any program; the ultimate goal should be for teachers to work with children with ASD in mainstream schools.
- Emphasize high quality by requiring certification of trainers as programs are expanded.

Goal 5: Participate in high-quality research and surveillance

Challenges

Despite the fact that the greatest number of children with ASD and neurodevelopmental disorders live in LMICs, little research has been conducted in these settings.¹⁶⁷ Studies on important topics related to ASD and neurodevelopmental disorders have mainly been conducted in HICs and therefore provide an incomplete and biased view of the global impact of ASD and neurodevelopmental disorders and the challenges facing this community worldwide.

There is a critical gap in quality epidemiological research to describe the prevalence of ASD and neurodevelopmental disorders across the globe. Proper epidemiological studies involve the use of validated research tools for systematic clinical screening and diagnosis. Cost-of-illness studies are needed to help governments understand the true economic impact of ASD in their country. There is also a lack of research to evaluate the effectiveness and cost-effectiveness of interventions delivered to children with ASD. These types of studies are important for planning and advocacy purposes, resource allocation and to justify developing provider and researcher training programs and service provision.

There are a number of barriers to quality research related to ASD and neurodevelopmental disorders, including:¹⁶⁸

- **No national research agenda:** Many countries, in particular LMICs, do not prioritize the research questions, including those related to ASD and neurodevelopmental disorders, that could maximize health, education and societal gains. As a result, there is a risk that research funding and national health goals will not be consistent with the country's actual needs.¹⁶⁹
- **No link between research and policy:** Research, including that which is focused on ASD and neurodevelopmental disorders, is often not prioritized because it rarely informs policy development in the local context.¹⁷⁰
- **Lack of research capacity:** Too few health researchers, particularly within LMICs, are trained in rigorous standardized methods, including responsible conduct of research. Researchers without proper training may produce studies that are poor quality and have biased research results. Some researchers may not have adequate English language skills to co-ordinate applications in peer-reviewed journals.
- **Underdeveloped research environments:** ASD research programs often lack adequate administrative infrastructures and appropriate policies to facilitate research activities.
- **Lack of research networks within LMICs and between HICs and LMICs:** Too few partnerships limit opportunities for collaboration within and between countries. In addition, when partnerships do exist between countries, these research partnerships are often asymmetric between HICs and LMICs.

Opportunities for action

Co-ordinating research at the national level is key to maximizing the benefits of research for ASD and other conditions. The US Interagency Autism Coordinating Committee (IACC), with a broad membership of stakeholders, families of people with ASD, service providers and researchers, is a model national committee that coordinates research activities and provides advice to the U.S. Secretary of Health and Human Services (Ministry of Health in the US). The IACC annually publishes advances in biomedical and services research, with an increasing emphasis on lifespan and consumer-based concerns. WHO has also urged member countries to improve research frameworks and information systems to better record data on ASD, ID/IDD and other neurodevelopmental disorders.¹⁷¹

Research questions should not be set solely by research funders; they should prioritize local and national needs. WHO's Mental Health Gap Action Programme (mhGAP) and the IACC models are innovative examples of agencies that facilitate the coordination of a research agenda based on local factors and focused on developing priorities for national dynamic action plans. There are varying methods to develop consensus on national research priorities and the optimal approach depends on the context. A three-step approach with nine common areas for best practices in priority setting emerged in the literature and was summarized by researchers at WHO in 2010¹⁷² (this is listed in Appendix 4).

Advocacy organizations can also play a role, particularly in co-ordinating across countries and contributing to funding. The European Autism Interventions – A Multicentre Study for Developing New Medications (EU-AIMS), for example, is now the largest single grant for ASD in the world and the largest study of any mental health disorder in Europe. EU-AIMS-funded researchers collaborate with other groups, including the European Babysibs Autism Research Network (Eurosibs) and the Autism Spectrum Disorders in Europe (ASDEU) project.

After setting research priorities, it is important to have qualified personnel to implement the action plan. To increase the number of training opportunities in LMICs, governments should partner with HIC governments and universities to train ASD researchers in high-quality research methods. The Fogarty International Center at the US National Institutes of Health is an example of an international partnership program that includes research training and career development awards for junior researchers in LMICs.¹⁷³

It is also important to strengthen mental health training opportunities in schools of public health and medicine.¹⁷⁴ This should include training in public health research methods, knowledge diffusion, leadership, mentorship and advocacy.¹⁷⁵ As this capacity is being developed, the ASD and neurodevelopmental research environment needs to be strengthened. Critical components include:

- appropriate research policies, including procedures to monitor and review the ethical aspects of human subject research;
- a basic infrastructure in research centers that includes administrative support to oversee research contracts, finance, equipment and supplies; and
- access to resources, such as published literature.¹⁷⁶

To help researchers from LMICs with this last goal, in 2002, WHO developed the Health Inter-Network Access to Research Initiative, in collaboration with major publishers, to enable researchers from resource-poor countries to access health research literature. Today, about 15,000 journals (in 30 different languages) are available to health institutions in more than 100 LMICs.¹⁷⁷

While the development of a stable research environment requires upfront investment, benefits accrue over time through easier administrative access to research funds and stronger partnerships with funded research programs. Integrating with the health research systems that are already in place, such as those for infectious diseases, can also enhance synergies and create a more sustainable national research platform for the future. Strong research partnerships between academic groups, NGOs and governmental entities also create more stable administrative environments. Case study 4 details an example of research capacity building in Sub-Saharan Africa.

Case study 4: Building research capacity in Sub-Saharan Africa¹⁷⁸

As with many LMICs, there has been a lack of mental health research in most African countries, leading to a lack of evidence-based practice for diagnosing and treating many mental health disorders, including ASD. Between 2005 and 2010, the UK government partnered with local stakeholders in Ghana, South Africa, Uganda and Zambia to assist in the development, implementation and evaluation of priority strategies for making mental healthcare accessible to poor communities.¹⁷⁹

One of the four objectives of the program was research capacity development, and local partners were trained to develop a process to identify their needs. Research mentoring and postgraduate study were included in all phases to help develop qualitative and quantitative skills. Following the project completion, additional training was provided in academic writing and publication of papers in peer-reviewed academic journals. Specific efforts were made to support all mentees to publish as first authors and to increase publication opportunities, such as special journal issues.

To support ongoing capacity development, this program also developed the Alan J Flisher Centre for Public Mental Health at the University of Cape Town, South Africa, which has subsequently offered a Master of Philosophy in Public Mental Health and registered 39 Masters students from eight African countries between 2012 and 2016.¹⁸⁰

Lessons learned

- Provide training to junior and senior LMIC investigators, as senior staff may have gaps in their knowledge.
- Include capacity development activities that are specific to extending the skills of senior, mid-level and junior investigators.
- Use diverse methods for communication, including email, teleconferences, Skype and face-to-face meetings.
- Adopt 'train the trainer' approaches so that local individuals can provide ongoing training and support to other team members.

SECTION 3: POLICY RECOMMENDATIONS

There is a critical need to strengthen national capacities in caring for children, young people and adults with ASD and other neurodevelopmental disorders. To accomplish this objective, policymakers should address a variety of areas. We must:

- increase awareness of ASD and encourage early detection and diagnosis, allowing children to access services as early as possible;
- ensure that children with ASD have access to evidence-based therapies by providing additional training to parents, teachers and clinicians around the most effective interventions;
- provide those with ASD and neurodevelopmental disorders access to public education, with the goal of inclusion;
- ensure that families of those with ASD and neurodevelopmental disorders have the appropriate support and information to care for their family members; and
- encourage participation in high-quality research and health surveillance to obtain a full and accurate picture of the challenges we face in treating ASD and neurodevelopmental disorders.

We offer three key recommendations for policymakers to co-ordinate the response to ASD and neurodevelopmental disorders. While specific initiatives will differ in countries and regions, we believe that these recommendations will promote collaboration between disciplines and encourage global partnerships between nations and world regions. It is our hope that governments will support the implementation of a multi-sector response to ASD that includes health, education and social services, and ultimately improves the lives of those with ASD and neurodevelopmental disorders, as well as their families and communities.

Recommendation 1

Create an interagency co-ordinating commission to address ASD nationally.

We recommend the establishment of an independent governmental agency, such as a national Interagency Co-ordinating Commission or a Division of Autism and Neurodevelopmental Disorders, to provide guidance to national governments on issues related to ASD and neurodevelopmental disorders.

- **Membership of the Commission or Division** should include representatives from health, education, social services, employment, family members of those with ASD, self-advocates, service providers, public stakeholders and national NGOs, as well as researchers and universities representing a variety of perspectives from within the ASD and neurodevelopmental disorders community.

- **The vision of the Commission** should be to provide ultimate independence, productivity and community inclusion as key components, and to address wide-ranging issues and challenges faced by people with ASD and neurodevelopmental disorders and their families.
- **Shared and collaborative leadership** should be constituted under the Department of Public Health, Education and Social Services (as chairperson and co-chairs) with government authorization to develop and update national strategic plans, programs and policies for ASD and neurodevelopmental disorders, and to monitor national, regional and international activities in research, training and advocacy for ASD and neurodevelopmental disorders.
- **Guidance and government oversight** should be provided on broader concerns related to ASD and neurodevelopmental disorders to accelerate and enhance the development of services across the person's lifespan.

Recommendation 2

Establish interdisciplinary training and research centers for excellence in ASD and neurodevelopmental disorders across the lifespan. We recommend the establishment of national or regional training centers (based on size of catchment) with core funding and oversight by interagency co-ordinating commissions to:

- **Provide interdisciplinary education and training** in multiple disciplines at undergraduate, graduate and post-graduate levels regarding ASD and neurodevelopmental disorders across the lifespan.
- **Provide cutting-edge research, evaluation and policy analysis** in areas of importance to the field of ASD and neurodevelopmental disorders.
- **Communicate, disseminate and share information and research findings** with a broad constituency.
- **Direct services and support** to persons with ASD and neurodevelopmental disorders of all ages, and their families, to minimize disparities in healthcare, enhance educational opportunities, develop work skills, enrich daily living and promote community inclusion.
- **Use emerging technologies to bolster learning, employment and community participation** for all persons with ASD and neurodevelopmental disorders.
- **Work with schools as well as vocational and employment settings** to deliver evidence-based programs in inclusive settings.
- **Engage with policymakers who are charged with setting future policy** to put research into practice and evaluate the impact of services and policies.
- **Support individuals and families as they engage in self-advocacy and self-determination.**

Recommendation 3

Establish a global partnership framework to address ASD and neurodevelopmental disorders across the lifespan.

To address the significant gaps in the care of persons with ASD and neurodevelopmental disorders at a global scale, we recommend the formation of a global partnership framework involving member governments from HICs and LMICs, as well as the private sector and civil society. This partnership will help to co-ordinate a sustainable response for each region in terms of policy reform, service development and delivery, research and dissemination of evidence-based practice. Such a partnership framework will provide checks and balances for appropriate use of resources and assist in allocating funds to meet specific regional and national needs. Key activities should include:

- **Setting global research priorities and a research capacity development agenda.** This group should collaboratively set comprehensive research priorities and a research capacity development agenda on ASD and neurodevelopmental disorders, in line with the UN SDGs. Efforts in LMICs in particular should enhance cost-effective and culturally appropriate methods to reliably estimate the prevalence of ASD and neurodevelopmental disorders to inform and help with the design and equitable distribution of basic services in health, education and social care.
- **Facilitating global and regional collaborations in piloting new, or scaling up existing, evidence-based interventions.** The global effort should leverage and share regional resources to support public and private sector programs in enhancing services, training and research. The partnership framework should be aware of potential asymmetries, prioritize local needs and integrate measures of program effectiveness and costs.
- **Establishing a global minimum standard of services.** The global partnership framework agenda should work toward developing a minimum standard of inclusive health, education and social services available across the lifespan for children, young people and adults with ASD and neurodevelopmental disorders.

APPENDIX 1: WHO RESOLUTION EXECUTIVE BOARD EB133/4 – AGENDA ITEM 6.1, 30 MAY 2013, 133RD SESSION EB133.R1 COMPREHENSIVE AND COORDINATED EFFORTS FOR THE MANAGEMENT OF AUTISM SPECTRUM DISORDERS

The Executive Board,

Having considered the report on the comprehensive and coordinated efforts for the management of autism spectrum disorders,

RECOMMENDS to the Sixty-seventh World Health Assembly the adoption of the following resolution:

The Sixty-seventh World Health Assembly,

Recalling the Universal Declaration of Human Rights [1948]; the Convention on the Rights of the Child [1989]; the Convention on the Rights of Persons with Disabilities [2007]; United Nations General Assembly resolution 62/139 declaring 2 April as World Autism Awareness Day; and United Nations General Assembly resolution 67/82 on addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities;

Further recalling, as appropriate, resolution WHA65.4 on the global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level and resolution WHA66.9 on disability; resolution SEA/RC65/R7 adopted by the Regional Committee for South-East Asia on comprehensive and coordinated efforts for the management of autism spectrum disorders (ASDs) and developmental disabilities; resolution EUR/RC61/R5 adopted by the Regional Committee for Europe on the WHO European Declaration and Action Plan on the Health of Children and Young People with Intellectual Disabilities and their Families; resolution EM/RC57/R.3 adopted by the Regional Committee for the Eastern Mediterranean on maternal, child and adolescent mental health: challenges and strategic directions 2010–2015, all of which emphasize a strong response to the needs of persons with developmental disorders including autism spectrum disorders and other developmental disorders;

Reiterating commitments to safeguard citizens from discrimination and social exclusion on the grounds of disability irrespective of the underlying impairment whether physical, mental, intellectual or sensory according to the Convention on the Rights of Persons with Disabilities; and promoting all persons' basic necessities of life, education, health care and social security, as well as ensuring attention to vulnerable persons;

Noting that globally, an increasing number of children are being diagnosed with autism spectrum disorders and other developmental disorders and that it is likely that still more persons remain unidentified or incorrectly identified in society and in health facilities;

Highlighting that there is no valid scientific evidence that childhood vaccination leads to autism spectrum disorders;

Understanding that autism spectrum disorders are lifelong developmental disorders and are characterized by the presence of markedly abnormal or impaired development in social interaction and communication and a significantly restricted repertoire of activity and interest; manifestations of the disorder vary greatly depending on the developmental level and chronological age of the individual;

Further noting that persons with autism spectrum disorders continue to face barriers in their participation as equal members of the society, and reaffirming that discrimination against any person on the basis of disability is inconsistent with human dignity;

Deeply concerned about the rising number of identified individuals with autism spectrum disorders and other developmental disorders, that individuals with autism spectrum disorders and their families face major challenges including social stigma, isolation and discrimination, and that children and families in need, especially in low resource contexts, often have poor access to appropriate support and services;

Acknowledging the comprehensive mental health action plan 2013–2020 and, as appropriate, the policy measures that are recommended in resolution WHA66.9 on disability, which can be particularly instrumental for developing countries in the scaling-up of care for autism spectrum disorders and other developmental disorders;

Recognizing the need to create or strengthen, as appropriate, health systems that support all persons with disabilities, mental health and developmental disorders, without discrimination;

1. URGES Member States:

(1) to give appropriate recognition to the special needs of the individuals affected by autism spectrum disorders and other developmental disorders in policies and programmes related to early childhood and adolescent development, as part of a comprehensive approach to address child and adolescent mental health and developmental disorders;

(2) to develop or update and implement relevant policies, legislation, and multi-sectoral plans as appropriate, in line with resolution WHA65.4, supported by sufficient human, financial and technical resources to address issues related to autism spectrum disorders and other developmental disorders, as part of a comprehensive approach to supporting all persons living with mental health issues or disabilities;

(3) to support research and public awareness-raising and stigma-removal campaigns consistent with the Convention on the Rights of Persons with Disabilities;

(4) to increase the capacity of health and social care systems, as appropriate, to provide services for individuals and families with autism spectrum disorders and other developmental disorders;

(5) to mainstream into primary health care services the promotion and monitoring of child and adolescent development in order to ensure timely detection and management of autism spectrum disorders and other developmental disorders according to national circumstances;

(6) to shift systematically the focus of care away from long-stay health facilities towards community-based, non-residential services;

(7) to strengthen different levels of infrastructure for comprehensive management of autism spectrum disorders and other developmental disorders, as appropriate, including care, education, support, intervention, services and rehabilitation;

(8) to promote sharing of best practices and knowledge about autism spectrum disorders and other developmental disorders;

(9) to promote sharing of technology to assist developing countries in the diagnosis and treatment of autism spectrum disorders and other developmental disorders;

(10) to provide social and psychological support and care to families affected by autism spectrum disorders and to include persons with autism spectrum disorders and developmental disorders and their families in disability benefit schemes, where available and as appropriate;

(11) to recognize the contribution of adults living with autism spectrum disorders in the workforce, continuing to support workforce participation in partnership with the private sector;

(12) to identify and address disparities in access to services for persons with autism spectrum disorders and other developmental disorders;

(13) to improve health information and surveillance systems that capture data on autism spectrum disorders and other developmental disorders, conducting national level needs assessment as part of the process;

(14) to promote context-specific research on the public health and service delivery aspects of autism spectrum disorders and other developmental disorders; strengthening international research collaboration to identify causes and treatments;

2. REQUESTS the Director-General:

(1) to collaborate with Member States and partner agencies in order to provide support, and to strengthen national capacities to address autism spectrum disorders and other developmental disorders, as part of a well-balanced approach that strengthens systems addressing mental health and disability and is in line with existing, related action plans and initiatives;

(2) to engage with autism-related networks, and other regional initiatives, as appropriate, supporting networking with other international stakeholders for autism spectrum disorders and other developmental disorders;

(3) to work with Member States, facilitating resource mobilization in different regions and particularly in resource-poor countries, in line with the approved programme budget, which addresses autism spectrum disorders and other developmental disorders;

(4) to implement resolution WHA66.8 on the comprehensive mental health action plan 2013–2020, as well as resolution WHA66.9 on disability, in order to scale up care for individuals with autism spectrum disorders and other developmental disorders, as applicable, and as an integrated component of the scale-up of care for all mental health needs;

(5) to monitor the global situation of autism spectrum disorders and other developmental disorders, evaluating the progress made in different initiatives and programmes in collaboration with international partners as part of the existing monitoring efforts embedded in related action plans and initiatives;

(6) to report on progress made with regard to autism spectrum disorders, in a manner that is synchronized with the reporting cycle on the comprehensive mental health action plan 2013–2020, to the Sixty-eighth, Seventy-first and Seventy-fourth World Health Assemblies.

(Third meeting, 30 May 2013)

APPENDIX 2: EUROPEAN PARLIAMENT WRITTEN DECLARATION SUBMITTED UNDER RULE 136 OF THE RULES OF PROCEDURE, ON AUTISM* 27 APRIL 2015 (0018/2015)

1. Autism is a lifelong complex brain disorder that appears during early childhood, it affects around 1 per cent of the population. Autism can range from mild to severe impairments in a person's ability to understand everyday information, communicate and interact socially with other people. The causes of autism are still being investigated.
2. There is currently no cure for autism, but it is demonstrated that early and intensive intervention can help overcome the symptoms of autism and significantly improve the level of independence of people with autism.
3. Despite the importance of early diagnosis to provide adequate support and education, early detection is still lacking across Europe.
4. The Commission and the Council are called upon to support accurate detection and diagnosis of children and adults with autism. It should be achieved through the harmonization of evidence-based approaches across Europe.
5. The Commission and the Council are also called upon to adopt a strategic and holistic approach to respond to the challenges faced by people with autism throughout their lifetime. A European strategy should aim at encouraging research on autism, prevalence studies and exchange of best practices regarding evidence-based interventions for children with autism as well as support and habilitation services for adults.
6. This declaration, together with the names of the signatories, is forwarded to the Council and the Commission.

* In accordance with Rule 136(4) and (5) of Parliament's Rules of Procedure, when the declaration is signed by a majority of Parliament's component Members, it shall be published in the minutes with the names of its signatories and forwarded to the addressees, without however binding Parliament.

APPENDIX 3: UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES – ARTICLE 24, EDUCATION

- 1.** States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:
 - a)** The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
 - b)** The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
 - c)** Enabling persons with disabilities to participate effectively in a free society.

- 2.** In realizing this right, States Parties shall ensure that:
 - a)** Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
 - b)** Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
 - c)** Reasonable accommodation of the individual's requirements is provided;
 - d)** Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
 - e)** Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

- 3.** States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:
 - a)** Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
 - b)** Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;

- c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.
- 4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.
- 5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

APPENDIX 4: CHECKLIST OF BEST PRACTICES FOR HEALTH RESEARCH PRIORITY SETTING*

STEP 1: Preparatory work

1. Determine context	Determine what resources are available for the research, what the broad goal of the research will be, the population it will serve, and what the health, research and political environment is where the research will take place.
2. Pick an approach	There are several established consensus-building approaches for establishing research priorities. Determine whether you will use one of these recognized approaches or whether there is sufficient reason to develop a new approach.
3. Be inclusive	Determine who should be involved in setting a research agenda and why. Strive to include a broad representation of stakeholders from health and other sectors, from different regions of the country.
4. Gather information	Determine what information is needed to inform the priority setting. Such information can include qualitative data on broader stakeholder views, as well as quantitative data on impact of disease, effectiveness data, economic evaluations and impact analyses of previous priority setting work.
5. Develop an implementation plan	Establish plans to turn research evidence into practice and determine who will be responsible for this process.

STEP 2: Decide on priorities

6. Determine criteria	Determine the factors that will be considered in the priority setting process (that is, the magnitude of the health problem, the likelihood of available approaches to reducing disease or economic impact, and so on).
7. Carry out priority building exercise	This should follow the approach selected during the planning phase.

STEP 3: Post-prioritization wrap-up

8. Evaluation	Decide on how and when an impact analysis of the priority setting exercise will take place and who will conduct this analysis.
9. Transparency	Write a report detailing how the priorities were set and who was included in the process.

* Adapted from Viergever et al. (2010) ¹⁸¹

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