

**Advancing Global Healthcare for Neurodivergent Populations (Including Intellectual and Developmental Disabilities (IDD), Autism Spectrum Disorder (ASD), and Mental Health Conditions) Through the Mollie Woods Hare Global Center of Excellence at the Woods System of Care (WSOC)**

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**Abstract**

The Mollie Woods Hare Global Center of Excellence at the Woods System of Care (WSOC) represents a pioneering initiative aimed at improving the care and support for individuals with intellectual disabilities (IDD), autism, and mental health conditions worldwide. This center, in collaboration with international organizations like the World Health Organization (WHO) and The Network: Towards Unity for Health (TUFH), strives to share suggestions to improve global standards of care for these complex populations. The center's core objectives focus on developing a clearinghouse for clinical practice standards and guidelines tailored to complex populations, providing training for current and future healthcare providers and systems, and conducting research to disseminate the best practices, including the WSOC's Patient-Centered Integrated Care Model, through hosting global conferences, publishing research, and fostering cross-sector partnerships. Additionally, it advocates for policy reforms both in the U.S. and globally, aiming to improve health equity, reduce disparities, and expand access to healthcare for neurodivergent populations. This article provides insight into the center's efforts, driven by its Community of Practice (CoP), which plays a crucial role in advancing its mission to drive innovation and build a more equitable healthcare system for neurodivergent individuals worldwide.

**Introduction: The Global Crisis of Neurodivergence**

Imagine a world in which millions of people with Intellectual and Developmental Disabilities (IDD), Autism Spectrum Disorder (ASD), and mental health conditions are denied basic opportunities. A world in which families struggle to find the adequate support they need, where specialized healthcare is scarce, and in which delays in diagnosis mean critical years of development are lost. Unfortunately, this world isn't hypothetical. It's the current reality for countless families across the globe. Limited awareness and resources lead to delayed diagnoses, while stigma isolates this population from education, employment, and social inclusion. And fragmented support systems, along with widespread discrimination, further marginalize these individuals, leaving them at risk for poorer health and shorter lives. Hence, this isn't just a healthcare gap; it's a pressing crisis in human rights and equity, demanding urgent attention and a unified call for change.

The statistics surrounding autism and intellectual disabilities are both striking and revealing. In the United States alone, approximately 1 in 36 children are diagnosed with autism, as reported by the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. Furthermore, data gathered from 2009 to 2017 indicates that about 1 in 6 children aged 3–17 years has been diagnosed with a developmental disability.<sup>i</sup> These numbers highlight a growing recognition of neurodivergent conditions in the U.S., yet the picture is even more complex on a global scale. The World Health Organization estimates that 1 in 100 children worldwide have autism, though some well-controlled studies indicate even higher prevalence rates. In many low- and middle-income countries, however, the true extent of autism remains largely unknown.<sup>ii</sup> Additionally, nearly 200 million people globally are estimated to live with intellectual disabilities, a number that is expected to rise.<sup>iii</sup>

In addition, individuals with IDD and autism also face unique and significant challenges related to healthcare utilization, comorbidities, and mortality rates. Research shows that adults with IDD are nearly four times more likely to incur high healthcare costs than those without IDD, primarily due to psychiatric hospitalizations, ongoing care, and medications, as noted in a Canadian study.<sup>iv</sup> Similarly, children with both autism and intellectual disabilities have healthcare costs 2.7 times higher than those with autism alone.<sup>v</sup> These high costs are further compounded by the presence of multiple comorbidities. Individuals with IDD often experience comorbidities such as anxiety, depression, epilepsy, gastrointestinal issues, obesity, cardiovascular diseases, diabetes, and sensory impairments.<sup>vi</sup> Those with autism may also face gastrointestinal problems, immune function disorders, metabolic issues, and sleep disturbances, in addition to common conditions like anxiety, depression, and epilepsy.<sup>vii</sup> These complexities require personalized healthcare management to meet the unique needs of each individual, which are often fragmented and scarce. A combination of such health challenges, limited access to healthcare, and other factors contribute to significantly higher mortality rates in individuals with IDD and autism compared to the general population. A 20-year study of 406 adolescents and adults with ASD found that 6.4% died at an average age of 39, with causes of death ranging from chronic conditions like cancer and heart disease to accidents, such as choking and poisoning, and complications from medications.<sup>viii</sup> Similarly, research conducted in England estimates that individuals with IDD are 3 to 18 times more likely to die prematurely than their peers without disabilities.<sup>ix</sup>

### **Woods System of Care (WSOC): A Legacy of Care and Support**

The urgency for a unified, global response to the neurodivergence crisis is clear. To address this, Woods System of Care (WSOC), a U.S.-based leading population health management organization dedicated to providing comprehensive, life-cycle care for individuals with intellectual disabilities and autism (ID/A), acquired brain injuries, as well as mental and behavioral health challenges, has launched the *Mollie Woods Hare Global Center of Excellence on Neurodivergence (Intellectual Disability and Autism) and Mental Health*. The center is an innovative initiative that serves as a hub for research, training, and international collaboration focused on improving the care of individuals with intellectual disabilities, autism, and related mental health conditions worldwide.

Founded in 1913 by American educator Mollie Woods Hare, Woods System of Care (WSOC) currently serves over 52,000 children, adolescents, and adults through its expansive network of

providers and partners in Pennsylvania and New Jersey. With 12 affiliated organizations, WSOC operates across key locations in these two states, delivering essential services to individuals in need. The organization's extensive referral network spans 175 school districts and 23 states, underscoring the trust communities place in WSOC's ability to provide high-quality, specialized care. Supported by a dedicated workforce of around 8,000 employees within the Woods Network, WSOC remains steadfast in its mission of offering comprehensive care and support tailored to meet the unique needs of each individual it serves. By launching the *Mollie Woods Hare Global Center of Excellence*, WSOC is now expanding its reach beyond regional borders, reinforcing its commitment to improving the lives of neurodivergent populations worldwide and advancing a more inclusive, equitable healthcare system on a global scale.

### **The Mollie Woods Hare Global Center of Excellence: A Global Response**

The Global Center of Excellence at the WSOC, in partnership with leading international organizations such as The Network: Towards Unity for Health (TUFH) and the World Health Organization (WHO), was established to address the complex healthcare needs of neurodivergent populations, including those with IDD, autism, and mental health conditions. A key priority of the center is to research and develop a comprehensive clearinghouse for existing clinical practice standards and guidelines tailored to neurodivergent populations, providing healthcare providers with easy access to up-to-date, evidence-based tools to enhance care delivery. In addition, the center is dedicated to training both current and future healthcare professionals globally through targeted educational training programs, workshops, and collaborations with medical institutions. The center also aims to disseminate the best practices, including the WSOC's Patient-Centered Integrated Care Model, through hosting global conferences, publishing research, and fostering cross-sector global partnerships. Additionally, it advocates for policy reforms both in the U.S. and internationally, aiming to improve health equity, reduce disparities, and expand access to healthcare for neurodivergent populations. Through these initiatives and more to follow, the Global Center of Excellence at WSOC is dedicated to fostering a more inclusive and equitable healthcare system that prioritizes the well-being of individuals with neurodivergence worldwide.

### **Community of Practice (CoP): Collaborative Global Solutions**

At the heart of the Global Center of Excellence is its *Community of Practice (CoP)*, a collective of experts from various backgrounds, such as healthcare, social services, research, policy, and advocacy, working together to tackle the most pressing challenges faced by individuals with IDD, autism, and mental health conditions. These experts come from across the globe, representing diverse cultures, regions, and perspectives to ensure that the suggestions generated by the center are truly global in nature and adaptable to the unique needs of different communities. The CoP is currently immersed in a comprehensive, multi-step process that aims to identify both the strengths and the gaps in the support and care provided to individuals with intellectual and developmental disabilities (IDD), autism, and mental health conditions.

### **Review of Global Resources and Best Practices in Neurodivergent Care**

A key initial effort of this group has been an in-depth review of diverse existing global resources, guidelines, tools, and case studies from reputable sources such as the World Health Organization

(WHO), academic journals, and government health agencies. While this review is still ongoing, it has already shed light on many valuable best practices and highlighted key challenges faced by healthcare systems worldwide in supporting this underserved population.

The insights from several existing guidelines reviewed so far emphasize a holistic, person-centered approach, combining empirical research, patient experiences, and professional training. They stress the importance of effective communication in involving individuals, families, and caregivers in decision-making and highlight tailored health assessments for disease prevention and early detection. Guidelines also address crucial areas such as family engagement, abuse prevention, life transition planning, and regular health screenings. They offer tools for assessing support needs, promoting independence, and providing ethical frameworks for professionals. Training for caregivers and healthcare providers includes communication, crisis management, and cultural sensitivity, while resources for family caregivers focus on managing stress and improving well-being.

### **Identifying and Addressing Global Gaps in Neurodivergent Care**

Despite the strengths of these guidelines, significant gaps remain when viewed through a global perspective and the lens of inclusion. Key challenges include the lack of centralized resources, which makes it difficult for families and healthcare providers to access up-to-date, comprehensive information. Many guidelines are also not easily accessible or affordable, and complex language can be a barrier, especially when translations are unavailable. While they promote evidence-based practices, the guidelines are often not updated to reflect the latest research and innovations. Additionally, most guidelines are designed with high-income countries in mind, making them less applicable in regions with different healthcare contexts and challenges. They also often overlook the perspectives and unique needs of low- and middle-income nations. Furthermore, while cultural adaptation is acknowledged in the guidelines, there is a clear gap in providing concrete, actionable strategies for implementing culturally sensitive care.

Hence, the gap analysis conducted by the CoP is crucial as it highlights key challenges in the current literature and underscores the need for continuous refinement of guidelines and resources to effectively address the healthcare, support, and inclusion needs of individuals with IDD, autism, and related mental health challenges worldwide. Furthermore, based on the gaps identified, the CoP is actively developing targeted suggestions to address these issues. These suggestions are designed to offer practical, region-specific solutions that consider the unique needs and challenges of different local contexts. The focus is on ensuring these solutions are culturally sensitive and feasible for implementation, considering the realities healthcare providers face on the ground. Additionally, the suggestions aim to align local healthcare practices with global standards, such as those established by the WHO,<sup>x</sup> ensuring that improvements are both sustainable and consistent with internationally recognized best practices.

### **Global Workforce Analysis and Training Development for Healthcare Providers**

In parallel with this review, CoP is also conducting a global analysis of workforce competencies to better understand how healthcare providers are equipped to meet the needs of individuals with IDD, autism, and mental health conditions. Through thematic analysis, the CoP is uncovering

regional disparities and common challenges and identifying areas where healthcare systems excel or fall short. These findings are crucial for developing targeted training modules aimed at health and social care professionals, including family physicians, primary healthcare practitioners, and those working with the mentioned population. The goal is to enhance informed decision-making and person-centered practices when working with individuals with disabilities and their caregivers.

The training modules are rooted in WHO's Primary Health Care approach<sup>xi</sup> that emphasizes humane, patient-centered care that is accessible, affordable, and integrated into communities. This approach empowers individuals to take charge of their own health while ensuring healthcare systems are resilient and responsive to community needs. Guided by the values of "all teach, all learn" and "learning by doing," the course combines theory, lectures, and practical application. Participants are encouraged to reflect on how the knowledge gained can be applied within their own local environments, fostering inclusive care practices and improving the quality of services for individuals with I/DD and other disabilities.

### **A Unified Call for Change**

The Mollie Woods Hare Global Center of Excellence at the WSOC is leading transformative efforts to improve the lives of individuals with intellectual disabilities, autism, and mental health challenges. By fostering collaboration through its Community of Practice (CoP), the center is driving positive changes in global healthcare systems and influencing public policies to create better outcomes for neurodivergent populations worldwide. Although this initiative is in its early stages, its potential for driving lasting, transformative change is immense. Realizing this vision requires the collective efforts of healthcare providers, researchers, policymakers, and advocates, all working together toward a common goal. Only through collective action can we break down barriers, challenge inequalities, and create a future where every neurodivergent person is recognized, supported, and given the opportunity to reach their full potential.

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<sup>i</sup>Centers for Disease Control and Prevention. *Data and statistics on autism spectrum disorder*. <https://www.cdc.gov/autism/data-research/index.html>

<sup>ii</sup>World Health Organization. *Autism spectrum disorders*. <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>

<sup>iii</sup>World Bank & World Health Organization. (2011). *World report on disability 2011*. World Bank. <https://documents1.worldbank.org/curated/ar/665131468331271288/pdf/627830WP0World00PUBLIC00BOX361491B0.pdf>

<sup>iv</sup>High health care costs among adults with intellectual and developmental disabilities: A population-based study. (2018). <https://pubmed.ncbi.nlm.nih.gov/30381849/>

<sup>v</sup>Contributing factors to healthcare costs in individuals with autism spectrum disorder: A systematic review. (2022). <https://pmc.ncbi.nlm.nih.gov/articles/PMC9074281/#:~:text=Included%20studies%20suggest%20lack%20of,expenditure%20in%20individuals%20with%20ASD>

<sup>vi</sup>Intellectual disability and psychiatric comorbidity: Challenges and clinical issues. (2015, May 26). *Psychiatric Times*. <https://www.psychiatrictimes.com/view/intellectual-disability-and-psychiatric-comorbidity-challenges-and-clinical-issues>

<sup>vii</sup>Co-occurring conditions and autism. Autism Research Institute. <https://autism.org/comorbidities-of-autism/>

<sup>viii</sup>Mortality in individuals with autism spectrum disorder: Predictors over a 20-year period. (2019, February 28). <https://pmc.ncbi.nlm.nih.gov/articles/PMC6713622/>

<sup>ix</sup>Mortality among adults with intellectual disability in England: Comparisons with the general population. (2016, August). <https://pmc.ncbi.nlm.nih.gov/articles/PMC4940652/#:~:text=Studies%20have%20reported%20that%20people,those%20of%20the%20general%20population>

<sup>x</sup>World Health Organization. (n.d.). Training for caregivers of children with developmental disabilities, including autism. World Health Organization. <https://www.who.int/teams/mental-health-and-substance-use/treatment-care/who-caregivers-skills-training-for-families-of-children-with-developmental-delays-and-disorders>

<sup>xi</sup>World Health Organization. (2020). *Implementing the primary health care approach: A primer* (ISBN 9789240090583). World Health Organization. <https://www.who.int/publications/i/item/9789240090583>