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The Pursuit of Equity for Individuals with Intellectual and Developmental Disabilities and Autism: A 10-Step Plan

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Abstract

People with intellectual and developmental disabilities and autism (ID/A) are not equitably served by our healthcare, education, housing, and economic systems. As a result, this group is left powerless, often misunderstood, underserved, and at a heightened risk of poor health outcomes and elevated healthcare costs. The pursuit of health equity requires innovative approaches that engage a broad array of decision-makers, advocates, health and human service providers, and, most importantly, the voices of individuals with ID/A, their caregivers, and allies. Through collaborative efforts across systems, institutions, and agencies, the Woods System of Care aims to catalyze action that leads to health equity that addresses the complexity of care from birth to the end of life for people with ID/A.

Introduction

Individuals with intellectual and developmental disabilities and autism (ID/A) experience significant barriers to accessing healthcare, resulting in poor health outcomes and elevated costs. There is a solution: A healthcare system that ensures health equity will improve health outcomes, quality of life, and cost-effectiveness for all patients, including those with ID/A. A staggering 7.39 million people with intellectual and developmental disabilities and autism (ID/A) are not equitably served by our healthcare, education, housing, and economic systems. As a result, this group is left powerless, often misunderstood, underserved, and at a heightened risk of poor health outcomes. Adults with both intellectual or developmental disabilities and autism spectrum disorder spend five times more annually on healthcare than the general population.[2] Over the course of a lifespan, the cost of care is $2.4 million for individuals with co-occurring intellectual disability and autism, compared with $1.4 million for individuals with only autism and $188,000 for the general population.[2] However, for people with intellectual disability and complex co-occurring medical and psychiatric needs, such as the population that Woods serves, the lifetime cost of care is closer to $6,000,000, conservatively assuming a life expectancy of 60 years, based on internal agency data.

Avoidable disparities[3] extend beyond the health differences caused by primary disabling conditions.[4] The intersection of disabilities like ID/A with limiting social conditions and inaccessible social health networks, biased institutional cultures, and discriminatory health and social policies and structures exacerbates barriers to care and health inequities. Improving health equity is critical to delivering high-quality care in a cost-effective manner.

Promoting Solutions

The pursuit of health equity requires an innovative and tailored ID/A framework with mutually supportive approaches that activate a broad array of decision-makers, advocates, health and human service providers, and, most importantly, the voices of individuals with ID/A, their caregivers, and allies. Through collaborative efforts across health systems, payers, disability justice advocates, social sector, and community-based providers, the Woods System of Care aims to catalyze action that leads to health equity that addresses the complexity of care from birth to the end of life for people with ID/A.

Woods draws on more than 110 years of experience in the field of ID/A. Our health equity guiding principles serve as the cornerstone of our mission to promote health, reduce health disparities, lower healthcare costs, and improve the quality of life for all children, adolescents, and adults with ID/A. Woods has developed a strategic health equity framework consisting of five core components: 1) policy reform, 2) stakeholder engagement, 3) quality performance & analytics across the lifespan, 4) integrated service delivery models, and 5) organizational effectiveness & accountability. These five components mutually support our proposed 10 broad health equity recommendations to address individual risk factors, community social determinants, and societal structural determinants by addressing systemic and policy barriers that impede health equity for individuals with ID/A.

Recommendation 1: Establish a National ID/A Health Equity Advocacy Coalition

We encourage the development of a national ID/A health equity coalition that is concerned with health equity and quality of care and life for people with ID/A and that advocates for the recognition that ID/A services are a form of healthcare rather than an outgrowth of special education. Based on what we know from the general population, sample goals for this coalition to consider are to:

- Collect empirical data to quantify inequities and identify where/when they occur;
- Lead and implement health equity policy recommendations;
- Establish and engage a diverse stakeholder group (diverse people with lived experiences, community providers, and representatives from government, managed care organizations, and health systems, etc.) to serve as the voice and advocacy body for fair, just, and inclusive health equity rights for optimal health and well-being of individuals with ID/A.

Recommendation 2: Support the Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population Act (HR 2417 - The HEADs Up Act)

People with disabilities are deemed as an underserved community according to the definition of equity that supports Executive Order 13985[1] of Jan 20, 2021: Advancing Racial Equity and Support for Underserved Communities Through the Federal Government. However, the Health Resources and Services Administration (HRSA) does not designate people with disabilities or subgroups of the population, such as people with ID/A and complex conditions, as part of a medically underserved population (MUP). We advocate for a MUP designation for all people with disabilities. A MUP designation can help advance health equity[5] and open up opportunities for healthcare providers who provide healthcare services for a significant number of patients with disabilities in their practices to apply for federal student loan forgiveness. Additionally, this recommendation supports Federally Qualified Health Center (FQHC) Look-alike designations specifically for people with ID/A.

Recommendation 3: Build Value-based Care into a Newly Established ID/A Health Equity Investment Fund

Public-private investment partnerships can allocate resources to address the historic failure to invest sufficiently, justly, and equitably across the lifespan of people with ID/A. Examples of possible investments include:

- *Investments in new health plan benefit designs* that impact ID/A health disparities through new cost-sharing models, customized services and benefits for people with ID/A, standardization of services, cultural humility and competency training, utilization management across the lifespan, and new medication management policies.
- *Use data-driven analysis to identify and stratify health disparities to shape ID/A programs, services, and policies:* The complexity of care for people with ID/A is equally complicated with limited availability of ID/A data and stratification across race, ethnicity, socioeconomic status, etc. Investments in cross-sector data sharing and integration enabling the transformation of individual-level information into actionable intelligence can be used to understand urgent and long-term community needs, improve services, systems, and practices, develop innovative policies and interventions, and, ultimately, build stronger community support. Additionally, investments in the standardization of identified value-based health equity metrics should be established to measure outcomes, outputs, and processes.
- *Create a business case for value-based ID/A health equity:* Return on investment must also include quality of care, social adjustments, and the costs associated with timeframes when using a life-cycle management approach for people with ID/A.
- *Examine and enhance billing services provided for people with ID/A to adequately meet their needs*: People with ID/A require increased time to properly assess and treat beyond the standard billing of 15 minutes, which causes a significant barrier to getting adequate healthcare services.

Recommendation 4: Advance Disability Justice

Disability justice builds on the disability rights movement while taking a more comprehensive approach to help secure rights for disabled people by recognizing the intersectionality of disabled people who belong to additional marginalized communities. It recognizes how diverse systems of oppression interact and reinforce each other. There is a pressing need to raise awareness of stereotypes towards and discrimination against people with intellectual disabilities through advocacy and education and to facilitate positive encounters. Policies and practices must remove barriers to access due to racial and economic disparities in healthcare, like mistrust of healthcare systems, stigmas, stereotyping, lack of respect for patients, improper diagnosis and treatment, and communication and financial barriers.

Recommendation 5: Pilot ID/A Health Equity-focused Demonstration Projects in Community-based Healthcare Settings

With ongoing attention to value-based care to manage and improve population health, healthcare organizations must focus on the value of improving health inequities through partnerships with others outside of the traditional healthcare system. They must collectively determine the value and cost of care for social risk factors for high-need and high-cost groups with complex health conditions. People with ID/A are a prime group to pilot community-based healthcare services, FQHC-Look-Alike models, or adaptations of the PACE model and emerging alternative payment models focusing on customized care. This unique, community-based approach to healthcare must engage players who are dedicated to sharing a fundamental principle of culturally person-centered care to truly meet the health and social needs of people with ID/A, linking value-based payment and delivery reform to identified health inequities.

All players in the ID/A ecosystem must also use advanced technology and comprehensive data models across organizations and systems to tackle the root cause of health inequities among people with ID/A. This requires new healthcare financing and service-delivery models to ensure adequate coverage for all people with ID/A, not just those receiving services in group home settings or congregate care environments. Community-based healthcare services must address the myriad challenges that include engaging and reaching hard-to-reach people with ID/A complexities by addressing health-related social needs within the community. Community-based healthcare services provide localization and a better opportunity to identify barriers, personalization, and impact through a shared or collective partnership.

Recommendation 6: Train, Educate, and Build a Healthcare Workforce to Ensure Fair, Just, and Culturally Appropriate Quality of Care for People with ID/A

Ableism and attitudinal barriers are present even in healthcare settings and physician perceptions. The pervasive absence of professional training and the lack of disability competency and awareness among healthcare providers are among the most significant and fundamental barriers preventing people with disabilities from receiving quality healthcare.[5] A culturally appropriate and skilled healthcare professional workforce is essential to reducing health disparities and improving the quality of life for people with ID/A. Knowledgeable, culturally competent, sensitive, and respectful healthcare providers can provide high-quality holistic and preventive services and decrease healthcare spending by reducing hospitalization. Increasing HRSA funding for CME education for nursing and other health professionals to provide training, education, and resources to healthcare professionals would better equip them to provide high-quality, competent care for individuals with ID/A and thus advance health equity by reducing health disparities and improving health outcomes.

Recommendation 7: Provide Technical Assistance, Supports, and Services to Minimize Negative Consequences from Law Enforcement and Criminal Justice Systems Against People Who Have ID/A

Problems related to the interactions between police and individuals with ID/A arise because police often misunderstand the responses of individuals who have an intellectual disability. Furthermore, the individuals with disabilities themselves may misunderstand the situation in which they find themselves. This often presents challenges in access to medication and healthcare services while interacting with inexperienced law enforcement personnel. Providing supports and eliminating waiting lists should reduce the number of people with intellectual disability in prison. Individuals with intellectual disabilities often fall victim to the justice system because they don't understand the ground rules. It is critical to advocate for the legal rights of these individuals who have been arrested or unfairly treated. Police need training in how to interview and collect reasonably accurate information from individuals who have an intellectual disability.

Recommendation 8: Designate People with Disabilities as a Health Disparity Population Under the Minority Health and Health Disparities Research and Education Act

Inclusion of people with disabilities in the health disparity population would enable their participation in health and healthcare disparities research, program development, professional training, health promotion, and clinical interventions conducted and supported by the National Center on Minority Health and Health Disparities. We recommend that the formal definition should be amended to include "populations for which there is a significant disparity in the quality, outcomes, cost, or use of health care services or access to or satisfaction with such services as compared to the general population."

Recommendation 9: Establish Regulatory Policies and Equity Standards that Strengthen Inclusive, Friendly, Safe, and Healthy ID/A Environments

Community living and participation for people with ID/A require policies, practices, and initiatives that are culturally person-centered. It's important to distinguish that there are individuals with ID/A who require minimal support and those in need of greater support who await the availability of services. This recommendation aims to address both distinct groups with all-inclusive and tailored regulatory policies and equity standards. Examples of such requirements include requiring the use of accessible medical and diagnostic equipment to ensure safe and accessible access. This means improving the health, education, social, and economic well-being of all people with ID/A, empowering their families/caregivers, and creating safe communities. Equitable communities mean that people are not held back from reaching their potential because of social conditions, systems, and policies that make it difficult to live good lives. Communities that are equitable strive to put into place the social conditions, systems, and policies that address these harms to allow everyone to contribute to their full potential and help the whole community to flourish.[6]

Recommendation 10: Strengthen Public Health Infrastructure

Health equity and emergency preparedness shape the level of community resilience. People with ID/A are already at a disadvantage as a disparate population that experiences social, economic, racial, and health inequities. When public emergencies occur, such as the pandemic, our public health infrastructure, as it exists now, is not equipped to respond adequately to this population's safety and protection. Future public health emergencies will continue to exacerbate existing health inequities if no changes are made. ID/A ecosystem partners can begin to address improvement in the following areas:

- Improved data collection concerning healthcare for people with disabilities across the lifespan;
- Investments in public health data systems to address gaps in data collection and analysis;
- Tailored and more timely and accurate communication and resource distribution for individuals with ID/A, families, and all participants in the ID/A ecosystem;
- Increased training for community resource workers (aka community health workers) to support people with ID/A, their families, and caregivers;
- Identification of high-quality indicators of health equity with particular attention to public health emergency preparedness at the state level.

Conclusion

The Woods System of Care Health Equity Framework and its 10 recommendations for advancing health equity for people with intellectual and developmental disabilities and autism disorder can pave the way for dismantling health inequities using tailored approaches that accurately assess and use data to identify and reduce or eliminate disparities. Furthermore, the Woods System of Care can pilot value-based contract mechanisms, policies, and stakeholder engagement to encourage health plans and health systems to advance health equity at various levels. This includes addressing individual risk factors and prevention interventions that improve health outcomes; developing community health and social networks interventions that address members' social, cultural, economic, and environmental needs to remove barriers to health-related social conditions; elevating ID/A voices in decision-making that lead to the co-design of integrated service delivery models and policy reform; and developing system-level interventions that address culturally competency training and regulatory standards for ID/A-safe environments. The framework sets the stage for structural policies that foster coordination among key stakeholders, including people with lived ID/A experiences and their advocates; community-based and social service providers; local, state, and federal policymakers; health plans; health systems; and others.

Woods System of Care recommendations are intended to address the commonplace discrimination and health disparities faced by people with ID/A in the healthcare system and work towards achieving health equity.

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