

COMMENTARY: ADDRESSING HEALTH DISPARITIES IN ADULTS WITH DEVELOPMENTAL DISABILITIES

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Adults with developmental disabilities are a growing population that experiences significant health disparities due to unmet health care and social needs. Few standardized health care guidelines are available or broadly accepted as best practices for this population. The Adult Disability Medical Healthcare (ADMH) is a community-based clinic that provides a unique multidisciplinary team-based approach to addressing the social and health care needs of adults with developmental disabilities within the framework of a Patient Centered Medical Home model. ADMH is developing the necessary research infrastructure and obtaining input from individuals with developmental disabilities, their families, and community stakeholders and is performing foundational analysis to inform the development of guidelines for evidence-based best practices for the care of adults with developmental disabilities. This will set the stage for future research evaluating the impact of these guidelines on health outcomes and the reduction of health disparities in this population. This commentary highlights a process for development of evidence-based guidelines and best practices for care of adults with developmental disabilities. *Ethn Dis.* 2019;29(Suppl 2):355-358. doi:10.18865/ed.29.S2.355

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INTRODUCTION

Adults with developmental disabilities are a growing population that experiences significant health disparities due to unmet health care and social needs. Despite these recognized gaps, few standardized models or guidelines^{1,2} currently exist for the care of this population. The Adult Disability Medical Healthcare (ADMH) was developed as a replicable health care model for patients with developmental disabilities, within the context of a Patient Centered Medical Home. This model is designed to provide comprehensive, compassionate, coordinated, and continuous care that is both accessible and patient- and family-centered. Through the assessment of care needs and the collection of meaningful and relevant clinical data, ADMH is working to develop evidence-based guidelines for the care of adults with developmental disabilities. This commentary describes our approach to providing care for adults with developmental disabilities.

BACKGROUND

Adults with developmental disabilities are living longer, healthier,

more meaningful lives and are increasingly served in community settings.^{3,4} Persons with Down syndrome have experienced significant increases in life expectancy over the past few decades, owing to reduced institutionalization and improved access to medical care, such as surgical intervention for congenital heart defects.⁵ The average lifespan for people with Down syndrome has increased from age 30 to age 60 over the past 25 years. The number of adults with intellectual and developmental disabilities aged >60 years is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030.⁶ According to a study by the Centers for Disease Control and Prevention published in 2015, one in 20 adults in the United States has a disability, with the highest percentage living in the southeastern United States.⁷ Advances in medicine, technology, public policy changes (including implementation of the Americans with Disabilities Act), and a societal push for inclusion, have given health care providers the opportunity to play a pivotal role in promoting, managing, and delivering care that supports a high quality of life for adults with developmental disabilities.

Biologic factors related to syn-

dromes, multiple co-morbidities, limited access to high quality health care, and environmental factors all contribute to increased risk for people with developmental disabilities developing chronic health conditions at younger ages.⁸ These adults also experience higher rates of obesity, sedentary behavior, and poor nutritional habits compared with the general population.⁹ The importance of recognizing adults with disabilities as a “disparity” population is justified based on their “population-level differences in health outcomes that are related to a history of wide-ranging disadvantages, which are avoidable and not primarily caused by the underlying disability.”¹⁰ Dr. Camara Jones has drawn powerful parallels between racism and ableism, indicating that both lead to health disparities.¹¹ These health disparities are amenable to both policy and health care delivery interventions that address system- and practice-level barriers for individuals with disabilities.

Lack of adequate systems of care is an important factor underlying disparities in access to services and high-quality care for patients with disabilities.⁸ This gap is particularly significant for those transitioning from pediatric to adult health care service providers. While there are well-established guidelines for the care of children with developmental disabilities,¹² there are few standardized guidelines for adults. There is also a lack of formal training for health care providers¹³; therefore, providers for adult patients are often left making medical decisions based on standards for the general population without the support of evidence-based guide-

lines tailored to those with disabilities.

Common barriers to comprehensive health care services for individuals with developmental disabilities transitioning to adult care include a lack of available providers, inadequate practice infrastructure, and fragmented, uncoordinated care.¹⁴ Additional barriers to successful transition and optimal health care outcomes include: 1) Low expectations and social isolation of individuals with developmental disabilities – (most significant factor)¹⁴; 2) Difficulty identifying adult primary care and subspecialty providers¹⁴; 3) Adolescent and family resistance to transitioning to adult providers¹⁴; and 4) Lack of provider time to address important transition issues.¹⁵

ADULT DISABILITY MEDICAL HEALTH CARE—A NEW APPROACH

In response to the challenges outlined above, the Adult Disability Medical Healthcare (ADMH) was established in Atlanta, Georgia in December 2014. ADMH is a community-based medical practice that provides a multidisciplinary team-based approach to addressing the social and health care needs of teens and adults with developmental disabilities within the framework of a patient centered medical home model. The patient centered medical home (PCMH) is a model for strengthening primary care through the reorganization of existing processes and systems to provide patient-centered, comprehensive, coordinated, and accessible care that is continuously improved through

a systems-based approach to quality and safety.¹⁶ Studies have shown that patients with disabilities and more complex health care needs use health and related services more frequently than patients without disabilities, and have more unmet health needs.¹⁷ They are also less likely to receive care within a medical home model. A collaborative approach has been shown to be more successful for providing health care for adults with intellectual and developmental disabilities.¹¹

ADMH provides an environment that is adapted to be more appropriate for individuals with developmental and intellectual disabilities and their families. Staff training, streamlined process of obtaining vitals and getting patients into the exam rooms quickly, use of local anesthetic cream for blood draws, soft music as needed are a few of the approaches used to create a space and experience appropriate for this population. ADMH accepts most health insurance payers, including Medicaid and Medicare, and provides two formats of service for patients and their families: 1) a primary care medical home in which patients and their families/caregivers are seen and receive comprehensive care; or 2) consultative coordinating care, in which patients and their families/caregivers are referred to ADMH for consultation and comprehensive assessments, and return to their local primary care providers or specialty physicians. For younger patients, this may also include coordination with their pediatrician and development of a transition plan to adult medical care.

Approximately 65% of the ADMH patients are from metropolitan Atlanta, 25% from rural Georgia and

10% from other neighboring states or are individuals moving to Georgia. Patients' ages range from early teens to those beginning to show loss of functioning in their late 30s and 40s, with the oldest patient to date at age 73. The most common comorbidities identified in patients with Down syndrome include hypothyroidism, skin disorders and cardiac abnormalities. The most common co-morbidities identified in patients with other disabilities include seizure disorders, skin disorders, cardiac abnormalities, cerumen impaction and hypothyroidism. As the population of people living with developmental disabilities ages and lives longer, more inclusive lives, it is essential that we ensure access to comprehensive evidence-based care that meets their evolving medical and social needs. The ADMH team has begun to perform foundational research and develop critical infrastructure to both develop and pilot evidence-based best practices for the health care of teens and adults with developmental disabilities.

KEY PARTNERSHIPS AND STAKEHOLDER-INFORMED APPROACHES

A partnership with the Transdisciplinary Collaborative Center at Morehouse School of Medicine provided resources that allowed ADMH to improve the quality of care, including training and access to REDCap (a standardized Research Electronic Data Capture database system), access to their institutional review board, and other ongoing support and collaboration. This has enabled

ADMH to pursue the goal of addressing disparities in care for patients living with developmental disabilities.

Partnership with the Center for Leadership in Disability at Georgia State University and a team of students from the Georgia Leadership Education in Neurodevelopmental Disabilities (Ga LEND) training program helped with the design and execution of two focus groups to assess the most critical health and non-health related issues and needs for this population of patients. The focus groups targeted input about community stakeholders as well as patients and their caregivers about the supports needed to optimally transition from pediatric to adult care.

The first focus group included key community stakeholders from organizations engaged in supporting the needs of individuals with disabilities. This session focused on the ideal services and goals for a community-based organization providing care for individuals with developmental disabilities. Topics of discussion included overcoming barriers to access, such as lack of provider acceptance of Medicaid and Medicare, an inadequate number of providers with the expertise or interest in serving patients with disabilities (especially in rural areas), and insufficient services with long waiting periods before getting appointments. Participants mentioned other barriers including: inadequate guidelines for the care of adults with disabilities; limited insurance formularies – especially with respect to psychiatric medications; and the lack of access to information about obtaining waivers for care. Participants emphasized the need to include patients in their care and decision-making. This included the

need for open lines of communication with families and the need to educate families about their choices, including how to navigate the system of care and its multitude of resources. Participants also commented that greater knowledge was needed among care providers regarding health needs specific to certain developmental disabilities, while also acknowledging that universal, developmentally appropriate preventive and treatment interventions were necessary for this population.

The second focus group included participants who were ADMH patients, patient family members, or other caregivers. This group helped assess strengths and weaknesses of current care models, focusing on meeting patient and caregiver needs through improved and/or expanded services. Focus group participants highlighted the need for extending the clinical team to include a nutritionist and a psychiatrist. They emphasized the need to have more community resources available, compiled in book form and/or housed on the ADMH website. They also noted the need for more information about mental health and sexual and reproductive health at visits, and for coordinating follow up appointments and care between visits. They also expressed an interest in forming a support group for patients and caregivers of ADMH patients.

NEXT STEPS, LESSONS LEARNED AND RECOMMENDATIONS

As a result of the work to date, the ADMH plans to implement a patient and caregiver survey, informed

by the focus groups, to further assess key elements of the clinical experience, opportunities for improvement, and existing gaps in care. Input from these surveys will help inform the development of more comprehensive systems of care and evidence-based guidelines. ADMH also plans to develop a practice-based database utilizing REDCap to capture key health care data and outcomes. Development of a customized database is crucial for capturing and measuring the impact of evidence-based guidelines. It will also be leveraged for future research aimed at evaluating the impact of guideline-based care.

CONCLUSION

Adults with developmental disabilities are a growing population that experiences significant health disparities due to unmet health care and social needs. ADMH is working to inform and develop appropriate evidence-based guidelines for the care of adults with developmental disabilities. Our developing data infrastructure, capturing both clinically relevant and patient-, family-, and community-relevant measures, will help identify common themes as well as specific medical and social needs within this population. These data will help inform guidelines for patient- and family-centered care to promote and support improved health and social inclusion for individuals and families with developmental disabilities throughout all stages of life. It is our hope that this comprehensive model of care will be replicated in primary care settings to improve the

health of individuals with developmental disabilities in all communities.

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CONFLICT OF INTEREST

No conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Research concept and design: Videlefsky, Nodvin, Heiman; Acquisition of data: Videlefsky, Reznik; Data analysis and interpretation: Videlefsky, Nodvin; Manuscript draft: Videlefsky, Reznik, Nodvin, Heiman; Acquisition of funding: Videlefsky, Nodvin; Administrative: Videlefsky, Reznik, Nodvin, Heiman; Supervision: Videlefsky, Nodvin

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