

# The Health Home: A Service Delivery Model for Autism and Intellectual Disability

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Autism spectrum disorder (ASD) and intellectual disability (ID) are lifelong conditions with profound impact on the functioning of affected individuals and their families. Optimizing developmental outcomes requires a lifelong perspective on treatment. The patient-centered health care home (health home) model is currently used to improve health outcomes and care integration in a variety of chronic general medical and psychiatric conditions. The authors propose the health home model as a new conceptual

framework from which to build systems of care for persons with ASD or ID and their families. The authors describe essential elements of a health home for these populations, which would be located in a behavioral health setting. They also describe an existing model of such a health home, the Center for Autism and Developmental Disabilities in Pennsylvania.

*Psychiatric Services* 2015; 66:1135–1137; doi: 10.1176/appi.ps.201400443

As defined in *DSM-5*, autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social communication and social interaction and by restricted, repetitive patterns of behavior, interests, or activities that manifest during the first few years of life. ASD is frequently associated with intellectual disability (ID). Individuals with ID without ASD also have delays in many domains that affect their ability to function independently. The overwhelming majority of individuals with ASD or ID require some level of lifelong support because of the severity of these conditions and the high prevalence of related comorbidities.

Over 2 million people in the United States are affected by ASD. A study released by the Centers for Disease Control and Prevention in March 2014 reported that the prevalence of ASD in eight-year-olds rose from nine per 1,000 population (1 per 110) in 2006 to 14.7 per 1,000 (1/68) in 2010 (1). The prevalence of ID in Pennsylvania in 1996 was 14 per 1,000 population among children and 6.4 per 1,000 among adults (2). By any estimate, the number of individuals affected by ASD or ID represents an enormous public health issue. ASD and ID also carry a financial and human cost. Ganz (3) reported the per capita lifetime incremental cost to society of autism at \$3.2 million. Lost productivity and adult care were the largest components of costs.

## THE CCM AND THE PATIENT-CENTERED HEALTH CARE HOME

The chronic care model (CCM) was developed by Edward Wagner and colleagues (4) at the MacColl Institute for

Healthcare Innovation in the 1990s with the goal of improving care for chronic health conditions in primary care settings. This model involves productive interactions between an informed, energized patient and family and a prepared, proactive practice team (5). The clinical team's work is supported by a care delivery system. The CCM is a framework from which the concept of the patient-centered health care home (health home) has developed. The health home model is currently used with notable success for a variety of chronic general medical and psychiatric conditions (6). Because ASD and ID are lifelong disorders involving profound impairments, application of CCM to these populations seems appropriate. However, a literature review yielded only rare descriptions of such an approach to care in the ASD and ID populations. These examples were in a primary care setting, with no description of implementation. In 2008, professionals at the Waisman Center of the University of Wisconsin–Madison described a conceptual framework to support early identification and continuous services for children with ASD and their families. This schema embeds services for children with ASD within a medical home in a primary care setting (7).

## THE HEALTH HOME FOR INDIVIDUALS WITH ASD OR ID

Implementation of a health home in a primary care setting may not be optimal for individuals with ASD or ID. A population-based national health survey of parents compared

responses to questions regarding a primary care medical home by parents of children with ASD and parents of children with other special health care needs (8). Parents of children with ASD were significantly less likely to report care consistent with the medical home elements. These results should not be a surprise because the most serious and disabling concerns for this at-risk population are social, emotional, and behavioral rather than medical. In addition, among individuals with ASD or ID, prevalence rates of comorbid psychiatric disorders range from 70% to 81% (9).

To address these concerns, we propose locating the health home for individuals with ASD or ID in a specialty behavioral health setting, with a multidisciplinary team that has expertise in treating these conditions (10). A lifelong and developmentally focused approach to the behavioral health needs of these at-risk populations may provide the greatest opportunity for maximizing independent functioning, sustaining family health, and optimizing medical care. Such a model would serve as a regional comprehensive treatment center where patients with ASD or ID (and their families) would be evaluated and receive evidence-based care and guidance over the lifespan of the family member. Furthermore, such a health home would encourage families to focus their already stretched resources on maximizing the developmental progress of the disabled family member, rather than struggling to manage the silos of care in the current system. Overall, the health home works to ensure that community resources are carefully coordinated and follow best practices to optimize both individual and population-level health.

## **ESSENTIAL ELEMENTS OF THE HEALTH HOME FOR ASD AND ID**

The primary goal of the health home team would be to energize and engage patients and families in a lifelong process of becoming more functional and independent by developing an ongoing relationship with the team. This alliance begins with longitudinal care coordination provided by highly trained ASD/ID life-care managers. These individuals would serve as the heart of the model by providing families with lifelong guidance and education and supporting effective care coordination and communication between the family, the clinical team, and community stakeholders. These bachelor's-level clinicians would function with a broad understanding of the needs of patients and families and would be supervised by master's-level clinicians from the multidisciplinary team.

Families must receive ongoing guidance to have a clear expectation of the disabled family member's current developmental goals and upcoming transitional challenges. This developmental guidance is a lifelong process and helps to highlight areas of progress and delay. To ensure consistency, we propose that this process require informed life-care managers and a "life-care manual." The manual would be organized around key developmental periods over the

lifespan, encourage a review of essential domains of functioning, and provide a template and common language for the family and clinical team. Patients and families would meet quarterly with the assigned life-care manager to discuss current and future developmental goals via a manualized review of key functioning areas, including communication, social functioning, independent living skills, problematic behaviors, comorbid mental illness, medical issues, and family functioning. Through this discussion, patients and families and the team would work collaboratively to ensure that issues are addressed proactively.

Clinical care would be delivered by a multidisciplinary team with expertise in the evidence-based treatment of the social, emotional, and behavioral needs of patients with ASD or ID. Team members' backgrounds would include psychiatry, developmental pediatrics, psychology, behavior analysis, social work, counseling, nursing, occupational therapy, physical therapy, and speech and language therapy. The team would receive extensive and ongoing training and supervision to ensure a high level of expertise in evidence-based practices. Care begins with an initial diagnostic evaluation by the multidisciplinary team; it is critical that this evaluation provide not only an accurate diagnosis and case conceptualization but also the initial plan of care. Persons with ASD or ID have evolving needs over many developmental stages. Therefore, periodic reassessment of the treatment plan is needed. In addition, ongoing patient monitoring would identify areas of decline or lack of developmental progress and would trigger targeted reassessment by team members to tailor interventions to the needs of the patient and family.

The transition to adulthood is particularly challenging for patients with ASD or ID, and a common treatment concern is the provision of educational and vocational services in silos, isolated from clinical services. The health home team would work closely with school districts, vocational training agencies, adult transition services, and sheltered workshops. The expertise of the multidisciplinary team is needed to address impairments in social functioning, communication, problematic behaviors, and comorbid mental illness. Each limitation has a negative impact on academic and vocational success.

The ASD/ID health home would also include the use of an electronic patient registry, which would expand the functionality of electronic health records by supporting patient tracking and incorporating patient and family survey instruments. Patient tracking is essential for chronic conditions to ensure that no patient is lost to follow-up. Survey instruments, completed quarterly by patients and families, would monitor the domains of functioning described above, and results would be discussed at the quarterly treatment review with the life-care manager. This information helps patients and families remain informed about developmental and treatment progress. Outcome monitoring also provides ongoing feedback to clinicians, administrators, policy makers, and researchers on the efficacy of interventions and supports

continual improvements in individual and population-level health.

Furthermore, integration of general medical services into the health home is essential in providing comprehensive care to these vulnerable patient populations. These services should include primary care, neurology, cardiology, genetics, and other subspecialties. Profound impairments in communication and common problematic behaviors are frequently driven by anxiety and misunderstanding of medical procedures and can impede access to high-quality medical care. Providing medical services within a health home has been linked to improved patient satisfaction and health outcomes (11).

Finally, improved access of community members to the expertise of the multidisciplinary team through timely consultative services is another benefit of the health home. Hospital and school personnel, physicians, pharmacists, and mental health providers would be able to contact members of the team through formal patient assessments, EHR connectivity between providers, or more informal phone or electronic communication. The community standard of care will improve as more providers are exposed to both evidence-based care and the expertise of the team.

### **CADD: A HEALTH HOME MODEL FOR ASD AND ID**

Philhaven Behavioral Health is the 13th largest behavioral U.S. health provider. The Center for Autism and Developmental Disabilities (CADD) is a Philhaven program that serves as the central Pennsylvania regional center for ASD and ID. CADD is developing an integrated health care approach for individuals with ASD or ID that is based on the health home model. CADD has a multidisciplinary team with recognized expertise in the treatment of the social, emotional, and behavioral issues affecting individuals with ASD or ID. Currently, team members' backgrounds at CADD include psychiatry, nursing, psychology, behavior analysis, social work, and counseling. Principles of the CCM have driven the philosophy of the program since its inception in 2005. Patients and families are engaged in an active partnership that involves evidence-based care delivered by a coordinated practice team. CADD provides ongoing care to approximately 1,200 individuals with ASD or ID and their families. CADD treats patients over the lifespan; patients' ages range from 12 months to 65 years and older. CADD completes approximately 500 multidisciplinary evaluations per year and provides both office-based and community-based services.

However, notable gaps exist in the full implementation of the health home model. Current third-party reimbursements do not support the life-care manager position, which is critical for true integration of care. Funding streams must offer greater flexibility to support innovative health care solutions for high-risk populations. In addition, although the model at CADD arguably has merit, the program has yet to integrate outcomes research into the clinical operations to determine the clinical effectiveness and cost-effectiveness

of this coordinated system of care for patients with ASD and ID.

### **CONCLUSIONS**

The high prevalence of ASD and ID and a greater awareness of co-occurring general medical and psychiatric conditions have led to growing appreciation of the need for lifelong care for individuals with ASD and ID. The health home can serve as a new model of integrated care for these large at-risk populations and provides a unique opportunity to develop a new approach to care that uses limited resources more effectively. We hope that this column will stimulate discussion and subsequent research regarding the improvement of outcomes for those affected by ASD and ID.

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The authors report no financial relationships with commercial interests.

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