How Policy Efforts for the Intellectual and Developmental Disability Community Can Foster Innovation

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Children and adults with intellectual and developmental disabilities (I/DD) need accessible, affordable, quality primary and preventive healthcare along with dental and behavioral health services. Serving the I/DD population often requires highly skilled and specialized primary medical and dental care for a population which may have medical and behavioral complications resulting from genetic or other types of conditions. Unlike the cursory physical exams most of us are accustomed to, primary care visits for people with I/DD take an average of 45 minutes to an hour, given the medical and emotional complexities of the I/DD population with medical and behavioral co-morbidities. Additionally, direct access to highly skilled care in close proximity to where the I/DD population reside is critical to prevent unnecessary emergency room visits and hospitalizations for this very vulnerable and medically compromised population.

As many traditional medical settings and providers are not

well equipped to provide care to many people with I/DD, leading to very real access challenges, innovative models of care and specialized training for providers are viable solutions to eliminating these barriers. However, without sound policy to back them, innovation efforts fall short.

The following policy efforts are being undertaken to promote innovation to increase access to affordable, high-quality primary, preventive and specialized healthcare services for people with I/DD with medical and behavioral co-morbidities. They include: 1) establishing a definition of a special population of people with I/DD and significant medical and behavioral co-morbidities; 2) establishing a special population reimbursement rate for primary care for this population; and 3) establishing a demonstration residential healthcare facility that tests a model of care that will improve outcomes for this population.

Background

According to the Special Olympics, there are 6.5 million people in the U.S. with I/DD.[1] While many people with I/DD live independently and with few or no supports, a subset of people with I/DD have multiple severe conditions that require highly specialized supports, increased access to primary care and careful care coordination. Some of these conditions include such diverse genetic or neurologic conditions as traumatic brain injury, autism spectrum disorder, muscular dystrophy, cerebral palsy, and epilepsy, in addition to mental illness, and emotional and behavioral

challenges. It is a challenge to meet the complex medical and behavioral health needs of this population in traditional settings. Despite the trend in the disability advocacy community to push for the closure of all residential facilities and to provide all services in a community-based setting, the medically compromised population of people with I/DD would not be well-served in community settings. Those individuals that are so medically fragile would be at great risk of harm if they were not able to receive the comprehensive health services of the residential model.

Innovative programs that offer specialized and primary health and dental care coupled with a home health model in which centralized and integrated medical, dental and behavioral health services are provided in a close and accessible location are essential to ensuring that the complex needs of the medically fragile and behaviorally challenged I/DD population are met. For these programs to be sustainable, policies need to be in place to provide protections and financial support.

Defining a Special Population to Increase Innovation

It is undisputed that many children and adults with I/DD tend to have multiple health issues and more complex medical issues than those without, including medical and behavioral co-morbidities and frailties such as chronic disease and behavioral health issues. Given the special

needs of this group, and the history of not being well-served by the traditional medical and behavioral health community, assigning a special population definition to this group in order to ensure that comprehensive services can continue to be provided in a way that meets their high level of need is necessary.

When intellectual or developmental disabilities are linked to a variety of genetic disorders, the medical and behavioral challenges may significantly exceed those of persons without such genetic anomalies. These individuals have the most complex medical and behavioral issues and require specialized care and supports. Consider the association of heart disease and early-onset dementia in persons who have Down Syndrome, or the early mortality experienced by persons with Rett Syndrome or Duchene's muscular dystrophy, or weight-induced medical problems experienced by persons with Prader-Willi Syndrome.

The creation of an I/DD Medically Frail and Behaviorally Challenged definition for this special population, which includes having an I/DD diagnosis, coupled with medical, genetic and/or behavioral co-morbidities and frailties, will support policies to improve access to affordable, high-quality care and foster innovative programs.

Expanding Access & Enhancing Quality Care through Special Population Rate

The special population of people with I/DD who are medically compromised as a result of a combination of genetic disorders, chronic disease and behavioral health issues requires much more time in primary care visits and an increased need for care coordination, as well as greater skills and experience with this population.

Section 330 of the Public Health Service Act provides health centers caring for special populations, such as migrants and the homeless, an enhanced reimbursement rate designed to cover the cost of caring for the uninsured and "super-utilizers" of healthcare services. Establishing an enhanced special population reimbursement rate for practices caring for vulnerable populations positions them on equal footing with other safety-net providers, extends primary care to more patients, lowers costs, and improves care quality.

According to the American Association on Intellectual and Developmental Disabilities, there is a marked health disparity between persons with I/DD and those without I/DD.[2] Evidence-based studies demonstrate that the medical needs of persons with I/DD are greater than the general population and, as a result, are more costly. Furthermore, many people with I/DD may have conditions overlooked, especially chronic diseases that are common in the general population (diabetes, asthma, obesity, dental issues, cardiovascular disease), because healthcare providers may be exclusively focused during a healthcare visit on conditions that only relate to the

person's disability. With this population, a one-size-fits-all model is not sufficient and rules, regulations and services must be sufficiently person-centered to accommodate both consumer choice and consumer need.

A Special Population federal portable adjustable reimbursement rate for the I/DD Medically Frail and Behaviorally Challenged of at least $220 per visit for primary care should be established under the Health Resources and Services Administration, and CMS would allow for expanded health services. Furthermore, it will result in increased access to primary care, improved care coordination, and a reduction in ER visits and hospitalizations among I/DD individuals with medical frailties and behavioral challenges, resulting in significant overall savings.

Residential Healthcare Facilities for when Community Care is not an Option – the Woods Case Study

Historically, the disability community, advocates and others have advocated tirelessly to promote the rights of persons with disabilities to live and receive services in home and community settings and to close residential facilities. In fact, the Americans with Disabilities Act (ADA) website uses as its motto, "Community Integration for Everyone." However, the special I/DD Medical and Behavioral Frail population described above requires multiple levels of care, which must be individually-tailored

and which may need to change throughout the lifespan as people grow, learn and change. Education and advocacy for the special population of people with I/DD who also often have genetic disorders and multiple medical and behavioral issues, which make it extremely difficult for appropriate services to be found in community-based settings, is an ongoing need. There are some individuals that are so frail that the community presents an extreme risk of harm.

Woods and other major providers of services for people with I/DD, in alignment with this philosophy, have also advocated tirelessly to improve services, to design and promote services to support community integration wherever possible, in terms of living arrangements, in the employment arena, in healthcare and in other settings. However, Woods recognizes the risk of harm posed to some people with I/DD and medical frailties by obtaining care in the community, and has provided specialized services, including on-site, residential healthcare, for more than 600 residents on its campus, who have not been able to have their needs met in community-based and home settings.

Modeled after traditional skilled nursing facilities, Woods operates an innovative model of care—a residential health facility that includes private and semi-private rooms, meals, nursing care, physical and occupational therapy, speech-language pathology services, medical-social services, medications, medical supplies, transportation

and dietary counseling, and services though health and occupational professionals who have the skills and expertise to meet the many complicated health and social needs of the most medically frail people with I/DD who would otherwise not be able to access such services on their own in the community.

Through the experience of serving hundreds of residents ages 4 – 94 who have a wide range of complex medical, behavioral and emotional needs, Woods has gained tremendous expertise in the provision of comprehensive health and other services to this very vulnerable population. Woods has designed an adaptable model of residential skilled healthcare to carry out this high level of care by compassionate and knowledgeable professionals.

A special residential healthcare facility (RHF) demonstration at select, existing residential I/DD facilities that already serve the complex needs of the I/DD population with medical and behavioral co-morbidities who require 24/7 medical support should be established through CMS. An RHF for the I/DD medical and behavioral frail population should be supported at an adjustable rate of at least $400 a day. The RHF will include skilled nursing by healthcare professionals highly experienced with the medically fragile and behaviorally challenged I/DD population and physician and specialty support, which will ensure the continued health, wellness and safety of this vulnerable population, and which will reduce ER visits and hospitalizations.

It is only through the existence of good policy that innovation is successful. By creating a Special Population Definition for the I/DD Medically Frail and Behaviorally Challenged and assigning higher portable adjustable reimbursement rates to this population, innovative models of care that increase access to primary and specialized healthcare can flourish.

References

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About the author

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