

A Population Health Management Approach to Supporting People with Intellectual and Developmental Disability and Behavioral Challenges

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The Issue

In an effort to effectively bring services to vulnerable populations and groups that experience health and other disparities resulting from factors relating to social and economic inequities and/or severe medical, behavioral, or other conditions, health and human service organizations and providers have started integrating services across sectors that have historically operated independent of one another. An example of this is the increasing integration of behavioral health services into primary care settings. Despite the growing need for a comprehensive service model, integrating services is a slow process. The incremental progression is a result of the challenge of “de-siloing” of policies, regulations, and systems for payment across disparate sectors.

The need for service integration is greatest with the most vulnerable populations such as the intellectual and developmental disability (IDD) community. The needs of people with IDD transcend age and other factors related to the social determinants of health, as well as all life domains. These include housing, health care, food and nutrition, education, employment, social connections, and transportation. Bringing all of these services together for people with IDD and significant behavioral, mental health, genetic complexities, and medical conditions requires a new approach in order to remove barriers that this population routinely experiences in their efforts to access health care and other critical services. Many organizations provide a subset of services needed, while facing challenges to integrate or to coordinate services across sectors and the organization.

Meeting the Needs of People with Intellectual and Developmental Disabilities

According to the Centers for Disease Control, there are 4.5 million people in the U.S. with IDD. While many people with IDD live independently and with few or no supports, a subset of people with IDD have multiple severe conditions that require highly specialized supports, increased access to primary and specialized healthcare, and careful care coordination. Coordination of services often must span the sectors described above -- healthcare, housing, transportation, education, food and nutrition, and

employment. This population experiences significant barriers to accessing healthcare and other services. Unlike the cursory physical exams which most people are accustomed, primary care visits for people with IDD average 45 minutes to an hour, because of the complexity of their medical, emotional, and behavioral conditions (Ervin, Hennen, Merrick & Morad, 2014). Most private physician practices do not accept Medicaid, the primary insurer of adults with IDD because of the low reimbursement rates. It is not financially practical for these practices to care for this population, with the perceived risks and complexities that require more time for visits, significant accommodations and flexibility in conducting patient visits, the need for alternative methods of communication using pictures and technology, the need for more space and specialized equipment in exam rooms, and the frequent need for information-gathering from families and direct care staff for patients with communication barriers (2014). The barriers to primary care access lead to a marked health disparity between persons with IDD and those without IDD (National Core Indicators, 2014). These disparities result in people with IDD being more likely to live with poorly managed complex health conditions and chronic disease, overlooked necessary cancer screenings, and undetected poor vision (2014). The life expectancy for people with severe disabilities is much lower than that of the general population -- mid-50's for people with severe disabilities or Down's syndrome (Ervin & Merrick, 2014).

The costs of caring for this special population are astronomical. In Pennsylvania alone, \$2.4 billion is spent in Medicaid-funded services for people with IDD -- 76.7 percent of all home and community-based services through Medicaid waivers in PA is for people with IDD. Visits by clients of Woods, because of the complexity of their conditions, now account for approximately \$2.5 million in costs for emergency room visits and hospitalizations a year.

A population health management model of care is the key to meeting the complex and costly needs of the IDD community. Woods Services is such a population health management organization, meeting the total population health needs of people with IDD across its programs and those of its affiliate organizations.

Population Health Management

Population health management can be defined as interventions focused on the overall health needs of specific populations. It is an interdisciplinary approach to health that aims to improve the overall health of an entire human population taking into consideration the large-scale social, economic, and environmental issues that impact health outcomes for specific groups of people.

A population health management approach has several advantages, including allowing for:

- a systems perspective to address such issues as shortages of primary care providers in the health care sector, or of direct support professionals in the IDD sector;
- a lifespan approach which links and coordinates services across sectors and systems over time;
- addressing “upstream” issues to prevent health disparities and barriers to access; and
- using data to inform the need for services in a particular geography and for a particular population.

Consider the challenge of meeting the needs of children who have been successfully served through early intervention from birth to entry into school, and who then benefit from the myriad services mandated through the education and available through health systems until age 21. At this stage, many people with IDD and significant behavioral challenges experience a reduction in the availability of both funding and services as they enter the adult systems and desire to access services they need in community-based settings to the extent possible. It’s not surprising that many families describe this transition as “the cliff.”

A New Approach

Woods and its family of affiliate organizations have a long history of providing a broad range of services for people with IDD and significant behavioral challenges -- in the case of Woods alone, more than 100 years of experience.

The extremely vulnerable population that Woods and its affiliates serves grapples with conditions in addition to IDD such as cerebral palsy, seizure disorder, Prader-Willi Syndrome, autism, multiple congenital anomalies, Angelman's Syndrome, Cornelia de Lange Syndrome, and muscular dystrophy. When intellectual or developmental disabilities are linked to a variety of genetic disorders, the medical challenges may significantly exceed those of persons without such genetic anomalies. For instance, there is a documented association of heart disease and early onset dementia in persons who have Down syndrome, early mortality experienced by persons with Rett Syndrome or Duchene's muscular dystrophy, and weight-induced medical problems experienced by persons with Prader-Willi Syndrome. In addition to having other medical issues, more than one-third of people served by Woods have some form of eye condition or vision impairment such as blindness, cataracts, atrophy, glaucoma, and retina detachments, with over 90 percent of the people with traumatic brain injury being followed for eye conditions.

Woods Services, Inc. ("Woods") has developed a new approach in order to address the needs of the special population of people with IDD and significant behavioral and medical challenges and to address a fragmented service system -- population health management.

Woods and its affiliate organizations, which are in relative geographic proximity to one another and to the

populations they serve, are population health management organizations offering and coordinating services that address many life domains across the whole lifespan. These include early intervention, education, food and nutrition services, behavioral supports, vocational and transition services, housing, employment, health care, mental health services, and community engagement -- and transportation in order to be able to access each of these services. Each organization has developed programs within a highly-regulated and siloed set of funding agencies (those addressing housing, education, and developmental disability) which are not well-integrated with the health care sector. Frequently, these regulatory and funding parameters in which the services are offered often serve as barriers to truly effective service delivery.

The Medical Center at Woods -- An Innovative Expansive of the Population Health Management Model

To break down these barriers, Woods and its affiliate organizations are expanding their population health management approach through the expansion of Woods' health care services. The Medical Center at Woods ("Medical Center") will serve as a model for integrated primary and behavioral health care for people with intellectual disability and behavioral challenges, reducing the costs of care. The Medical Center will serve as an

anchor for the additional population health services which Woods and its affiliates provide. This model, the first of its kind, will provide primary care and coordination of specialty care for people with intellectual and developmental disability, as well as significant behavioral and medical challenges, using an advanced practice provider-led interdisciplinary population health management approach. The patient population served experiences many barriers to accessing primary care, given the need for specialized exam room equipment, extra time for medical visits, and accommodations for communications challenges. Building on Woods' current health services which utilizes the services of 120 health care staff (70 nurses, 30 medication trained staff, physicians, and others), the Medical Center will be overseen by a health center administrator, and will include nurse practitioners as well as primary care physicians and specialists in pediatric and adult neurology, ophthalmology, podiatry, orthopedics, and dentistry. The Medical Center will have extended hours and will have on-call availability to address evening and weekend hours, which have typically experienced high incidences of emergency calls requiring transport to the ER. Currently Woods staff and clinicians accompany clients to hospital visits in order to provide health history and status information and to assist with communication barriers, and Woods will continue this practice.

From a systems perspective, Woods will address the

shortage of health care providers who are experienced and knowledgeable in serving this special population by deepening its existing partnerships with area hospital and health systems in order to enhance medical and nursing education programs and provide needed hands-on experience to build the skills of students in serving people with IDD.

From a service delivery perspective, Woods will be able to link additional in-home care and social services from its health center to not only clients of Woods and its affiliates, many of whom reside in close enough proximity to the health center to easily access services, but also to the wider community of people with IDD who have struggled to find providers who take their insurance or will take them on as patients.

Policy Implications & Recommendations

Taking a population health management approach requires a number of policy changes. One recommendation which will help to improve service delivery for people with IDD is to obtain a special populations designation for this vulnerable group of people who face enormous challenges to accessing care. Woods is currently seeking this designation in order to be able to better address the needs of a relatively small population which has very high -- and very costly -- needs.

A second policy recommendation is to increase reimbursement rates for health services for this special population. As described earlier, people with IDD and behavioral challenges face barriers to accessing primary and specialty care, given the need for special training among health care providers to serve people with IDD and behavioral issues -- and given how few providers have this special training and experience, the need for longer patient visits, and the need for specialized equipment and accessible medical office space.

A final policy recommendation is for organizations such as Woods and its affiliates to partner with medical and nursing education programs to help train the next generation of health care providers who do not currently gain experience in providing care to people with IDD and behavioral challenges.

In today's world of financial and health reform uncertainty, it is crucial that the most vulnerable populations, including those with IDD, have protections in place to maximize access to, and availability of, comprehensive services. The expansion of the innovative population health management model of Woods integrates services for people with IDD, increases access to care, and builds the healthcare and human services workforce with the ultimate goal of improving patient outcomes and the quality of life for the people they currently serve and will serve in the future.

About Woods and its affiliate organizations

Woods Services, Inc. ("Woods") is a nonprofit population health management organization based in Langhorne, PA, providing residential and community-based health and human services in New Jersey and Pennsylvania. In its Langhorne program, Woods serves nearly 700 children and adults with intellectual and developmental disabilities. With its affiliate partner agencies in New Jersey and Pennsylvania, Allies, Inc., Archway Programs, Brian's House, and Tabor Services, Woods delivers comprehensive wraparound support services including residential and community supports, K-12 education and vocational training, day habilitation, and comprehensive primary care, dental, and behavioral health services for approximately 4,000 children and adults in PA and NJ. The mission of Woods is to support children and adults with disabilities or challenges to achieve their highest potential and independence through innovative and individualized approaches that promote learning and personal fulfillment.

Woods provides the appropriate level of care that ranges from personal assistance to highly skilled nursing and complex medical care that can only be delivered by disability-trained professionals. Woods and its affiliate partners (non-profit membership corporations with Woods as the sole member) primarily serve individuals from Pennsylvania, New Jersey, and New York, but has a

national reach given its expertise in serving people who are medically and behaviorally frail and vulnerable. Over the past decade, Woods has expanded its mission and reach by affiliating and partnering with like-minded compassionate nonprofits, such as Brian's House and Tabor Services in Pennsylvania and Allies and Archway Programs in New Jersey.

Allies, Inc. ("Allies") founded in 1999, is a not for profit provider agency, serving more than 360 people in 19 counties in New Jersey. Initially conceived as a mission to provide a better way for people with disabilities to live and work in the community, Allies' has evolved into an Agency that guides the course for new technologies and practices. As an affiliate of Woods Services and in partnership with the other Woods affiliates, Allies' harnesses the ability to pave the way to better services throughout the Northeastern United States. Best exemplified by the organizational mission -- It is our responsibility to our wide range of customers to ensure that the most current technologies and practices are available, and that outmoded technologies and systems are laid to rest.

Archway Programs, Inc. ("Archway Programs") is a not-for-profit corporation that operates adolescent, juvenile, and adult treatment and educational facilities serving 1,500 people a year. Archway's programs include early intervention and child care, broad-based special education in a large school setting, at-risk adolescent

treatment, group homes, adolescents and adult mental health counseling, senior citizen day care, summer camp, and professional staff development. Archway Programs was founded in 1965 and is based in Atco, New Jersey.

Brian's House, founded in 1976, is a nonprofit organization which provides group homes in Chester, Delaware, and Bucks counties, as well as life skills development, vocational training, job coaching, supported employment, job placement, adult day programming, and community engagement opportunities. Brian's House serves more than 100 people annually.

Tabor Children's Services is a nonprofit community-based child welfare organization that secures supports, resources, and permanent connections for children and youth within their own community and culture so they can overcome life's challenges and reach their full potential. Tabor is a true "family of services" as it provides a comprehensive range of programs that ensure children, youth, and families are safe and secure in their homes and in their communities.

Providing services to approximately 850 children and families annually throughout Bucks County, Philadelphia, and the Lehigh Valley, Tabor is one of the few agencies with dedicated programs for both children who have endured abuse and neglect, and young adults who are "aging out" of the child welfare system.

Founded 1907 as an orphanage, Tabor's vision has led to a rich history of serving children and families in need and now serves as a multi-service community-based organization providing in-home familial support services, foster care, adoption, adolescent life skill programs, and mentoring.

Author Bios

Dawn Diamond, MS, is Senior Vice President of Strategy and Infrastructure at Woods Services. She is responsible for leading several mission-critical projects and partnership development around new and emerging business opportunities. She is the project lead for the Woods Health Center and other strategic initiatives.

Liz Hayden, MPH and MS Ed, is Strategy Development Director at Woods Services. She is responsible for providing strategic guidance in program and resource development to Woods and its family of affiliate organizations, identifying funding opportunities and writing grants, concept papers, and policy papers. She brings 24 years of program development and management in social services, public health, adult literacy, ESL, intergenerational programming, and higher education to her role.

Sarah Rosenberg, Esq. is the Director of Strategic Initiatives and Assistant General Counsel at Woods Services. She is instrumental with strategic planning,

project management, and implementation of key organizational initiatives. As Assistant General Counsel, Sarah provides support to the General Counsel with all legal affairs on behalf of Woods.