SOCIAL INNOVATIONS Journal

Volume 6: 29 April, 2021

https://socialinnovationsjournal.com/index.php/sij/issue/view/77

Community Based Living as a Tool for Better Health Outcomes for the I/DD Population

Marge Conner-Levin, MSW

Abstract

Community-based group home models with high staff to individual ratios provide adaptable and replicable treatment options for individuals who have an intellectual and developmental disability (I/DD) along with a medical condition that requires daily nursing. The combination of specialized staffing, positive and open environments, and flexible interventions leads to both positive health outcomes and quality of life. Maintaining community-based living helps improve opportunities to meet both basic and enhanced needs and to provide high quality social determinants of care.

The Challenge

All individuals facing lifelong disabilities and medical conditions that require 24-hour a day supervision and nursing services also face a challenge of how to find quality of life in their living circumstances. The positive effect from high quality of life on individual health outcomes is well documented. For all human beings, meeting our basic life needs of safety, shelter, and nourishment, to meeting our more evolved needs of social interaction and connection, cohesive medical care, intellectual stimulation, physical activity, and sense of purpose, though perhaps not ranked equally, are critical to overall good health. When an individual has a disability and a chronic health condition, choices to meet one's needs are more limited and richer with obstacles.

History

In 1999 Allies, Incorporated (Allies) was founded in Hamilton, New Jersey as a grassroots provider organization dedicated to providing home-like, community-based living for individuals who have intellectual or developmental disabilities (I/DD). Allies works to provide housing that accommodates adults while simultaneously mirroring and supporting as much that would be typical of a community lifestyle as possible. This includes locating homes in residential areas not far from local commerce; decorating the homes with furniture typical of any suburban home instead of stereotypical group home décor; including individuals served in all aspects of community living such as shopping; membership in community organizations such as houses of worship, gyms, and social clubs; dining out; using public transportation; participating in local recreational events; attending college; and using community healthcare facilities for medical and dental care. Additionally, Allies prioritizes recreation and social activities as key components of care equal to the basics. Key to Allies' model is a high staff to resident ratio which creates flexibility yielding highly individualized care.

It all comes together to provide experiences that the individuals served might not have been offered had they been living in one of New Jersey's developmental centers or nursing homes. The individuals love their experiences as do their families and/or guardians. Through the 1990's, developmental centers and nursing homes continued to be the most common placement in New

Jersey. For parents and caregivers deciding where and by whom individuals are served is a tough choice. Parents know, in raising their child with a disability, that the day will come when the needs of their child may be greater than their capabilities. Costs of care are high and logistics of care are difficult to navigate especially as parents face their own inevitable aging issues.

Twenty two percent of adults diagnosed as having an I/DD also have a significant medical condition requiring around the clock (24/7) nursing supervision and specialized medical care (Hansen-Turton & Hayden 2020). Of those individuals, yet another subset is diagnosed as having a significant behavior disorder that interferes with daily functioning requiring specialized care (Hansen-Turton & Hayden 2020). Somewhat greater than the general population is the likelihood that medical conditions requiring 24/7 care will emerge as individuals with I/DD age. Unfortunately for this population, impaired communication skills, limited mobility, and negative financial pressures increase the risk for poor social determinants of health (Friedman & Carli 2020) furthering lowering quality of life and health outcomes.

The Program Model

In 2002 Allies saw success with its group home model evidenced by improved levels of functioning and quality of life amongst its residents. Allies approached the New Jersey Division of Developmental Disabilities (NJ DDD) about using its group home model to provide long term housing and treatment to individuals who had an I/DD diagnosis along with a medical condition that required 24/7 care. Allies proposed this as an alternative to nursing homes or New Jersey's state developmental centers where many of these individuals were living. Allies was especially interested in offering an alternative for young adults. Allies' call to action was born of its deeply held belief in community living despite, and with, chronic and complex challenges. NJ DDD supported Allies' proposal. This was prior to the concerted effort of NJ DDD to reduce the population in developmental centers.

Nursing homes and developmental centers are built to accommodate larger groups of individuals than group homes. Their residents to staff ratios are far less than Allies' two individuals to one staff ratio. Nursing homes and developmental centers are based on hospital and medical models of care with all care delivered on-site. Outings or experiences that mirror community-based living are minimal.

Fast forward to 2021, Allies serves 48 individuals in its 12 medical group homes spread throughout New Jersey. These homes can serve up to four individuals and are staffed 24/7 with one nurse and one community support staff. Pharmacy services are contracted to an outside pharmaceutical provider that delivers medications and medical supplies to the homes. Supplies include all medical equipment deemed medically necessary and additional equipment that contributes to quality of care. Individuals reside with Allies for as long as they and/or their families/guardians wish. Allies offers care through the end of life integrating hospice care into treatment plans as indicated. All medical services are external to the homes in the community. Adapted vans are used for transport to medical appointments. One current resident has a rare medical condition that requires regular medical appointments at a hospital in Manhattan, New

York some 45 miles from the home. Staff transport the individual in the van, maintaining a 2:1 ratio meeting the individual's parent in Manhattan. This individual can go into medical crisis quickly and the preventive care and specialized monitoring provided at this Manhattan based facility is the key factor maintaining this individual's stability.

Additionally, Allies employs a combination of regional registered nurses and licensed practical nurses to provide back-up coverage and oversight, not only to the medical homes but to all of its group homes. The regional nursing team provides a unique vantage point in the care of all individuals. As residents in non-medical group homes age and develop their own medical conditions, the regional nurses can identify when an individual's needs shift indicating a need for a higher level of care. At this point, instead of referring individuals to a nursing home, Allies engages them and their families and/or guardians in care planning that may include a transfer to one of the Allies' medical group homes.

External referrals to Allies are made by NJ DDD to an admissions team. After a review that includes treatment home staff and nurses, a preplacement meeting is held that includes nurses, treatment home staff, key NJ DDD care coordinators, family members and/or guardians, and the individual. This meeting is to help everyone assess if Allies is a good option for care. When an individual is referred from a nursing home or other congregate care environment, the nurse will go to the facility to assess the individuals' needs as well as to gain training from the facility on any specialized needs. Care coordination and thorough planning during the admission process facilitate a smooth transition and clear and open communication regarding needs and expectations.

Due to the 24/7 on-site nursing and nursing oversight available emergency department use is low. The goal of each medical home is to not only provide the required daily care but to anticipate and assess for changes. This is an especially key point when viewed through the lens of comparison to nursing home and/or developmental center care. Due to the very low staffing ratio, changes in medical status are quickly identified and addressed. Nurses operate under standardized agency-wide protocols. An extensive quality assurance program monitors care inputs and outcomes.

All the residents of Allies' medical homes are included in all trips and excursions with the other non-medical group homes. Meals are home cooked and family visitations are unrestricted.

Ongoing Challenges

The individuals served by Allies encounter the same fragmented "sick" care medical model characteristic of the United States health system. Medical providers who understand and work well with the I/DD population can be limited. This may be made worse by limited health insurance reimbursement offering fewer options for treatment. Medical appointments generally take more time due to the complexity of needs along with communication limitations posed by an individual's disability.

The worldwide pandemic has resulted in an additional level of challenge for everyone but especially for this population. Individuals cannot attend medical appointments unaccompanied and many do not understand and may refuse to wear masks. Infection control policies and procedures have been enhanced requiring additional expenses and training. Nursing shortages that existed prior to the pandemic are exacerbated.

Conclusion

Delivering medical care to individuals with an I/DD along with complex medical conditions is a work in progress for the healthcare industry. Allies' medical group home model offers features that are highly attractive, adaptive, and replicable. Chief characteristics of the model that lead to good health outcomes are the fostering of continued community connections, enhanced medical surveillance, reduced use of acute medical care, and overall improvement in quality of life all enabled by a low staff to resident ratio and positive living environments.

Works Cited

Friedman, PhD., Carli. (2020) "Social Determinants Of Health, Emergency Department Utilization, And People with Intellectual and Developmental Disabilities." Disability and Health Journal.

Hansen-Turton, Tine, and Hayden, Liz. (2020) "A Population Health Approach For People With Intellectual Disabilities Using A Patient-Centered Medical Home Model." Social Innovations Journal

Author

Marge Conner-Levin, MSW, is Senior Vice President of Health Services for Allies, Inc., a New Jersey based non-profit human services organization.