Principles for Community Healthcare Report

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Mission: Orchard Village partners with families and communities to optimize personal outcomes for individuals with developmental disabilities through a community-integrated approach.

I. Introduction and target audience

Approximately 200 million people throughout the world, including six and half million Americans and 200,000 Illinois residents, have intellectual or developmental disabilities (I/DD). Broadly defined as developmental disabilities (I/DD), diagnoses such as Autism, Down syndrome and Cerebral Palsy are included in this category. Individuals with I/DD often suffer co-occurring issues such as seizure disorders as well as chronic and pervasive mental health issues such as depression or bi-polar conditions. Additionally, due to metabolic and genetic reasons, people with developmental disabilities also experience a high rate of secondary medical problems as compared to mainstream Americans. For example, the obesity rate for people with I/DD is estimated to be 50%, significantly higher than the normalized population[1]. Similarly, diabetes and hypertension rates for this population also exceeds by a wide margin that experienced by average citizens.

Not all of the incidence rate differential can be explained the diagnosis of developmental disabilities. CDC and NIH data continue to reinforce the inverse relationship between education and obesity rates. The average educational level of people with I/DD (and Orchard Village participants) is between first and sixth grade. There is also a corollary relationship between income level and obesity rates – the lower the income level, the higher the incidence of obesity and other medical conditions. With unemployment rates approaching 70% for people with developmental disabilities (making this group the poorest minority in the country), it is not surprising that people with disabilities experience high rates of obesity. Like others with I/DD, individuals at Orchard Village have an income level that is significantly below the poverty level – approximately $7,000 per year.

Additionally, inadequate primary care also jeopardizes appropriate health care and satisfaction with health services. The combination of poverty and the diagnosis of a developmental disability qualifies consumers for Medicaid. Because of the low rate of reimbursement, I/DD care is often provided by clinic residents who turnover on a yearly basis, resulting in a lack of continuity of care and limited interest in the long-term health of the individual. In addition, because people with I/DD only constitute small percentage of a clinic-based physician's case load, there is limited opportunity for the physicians to learn about the nuances of health care of people with I/DD. Combined with a void of widely available specific health care tactics and strategies that physicians and people with I/DD can use to increase their health outcomes, leads clinic based physicians to dispense generalized information about how people can ameliorate secondary conditions. "Eat less" or Exercise more" are typical comments, with many physicians concentrating on shorter term health issues. Little surprise that this lack of involvement and interest has led to people with I/DD consuming 9% of Medicaid health expenses while only constituting 2% of the Medicaid caseload[2].

Individuals with a long term relationship with a physician typically receive better continuity of care and experience better health outcomes. There are a limited number of doctors that specialize in supporting people with Down syndrome and other conditions. But the majority of general practice doctors also suffer from the same lack of action-oriented specific advice for people with I/DD trying to surmount obesity and other issues such as diabetes. Doctors often rationalize their vague directives indicating to our customers and staff: "I can't get mainstream individuals to change their behaviors to reduce obesity and other issues. How can a person with limited cognitive ability achieve this goal?" This is not an isolated example for people with I/DD. State and Local Data confirm much of the data previously detailed. The rate of obesity among group home residents in Illinois is 42%; and the incidence rate is 45% at Orchard Village.

Individuals with I/DD are at risk for negative health outcomes such as prescription cascading, which is when patients experience a side effect from a medication they are already taken, and are prescribed a new medication for that side effect. According to an article by Isha Patel et al., "Prescription cascading is associated with risky medications prescribed for conditions such as dementia, hypertension, insomnia, pain management, epilepsy, nausea, and bacterial infections. Developmentally disabled individuals have a high prevalence of chronic disease conditions, including some of the above stated conditions. In addition due to patients' limited mobility and cognition, they may not be able to communicate their symptoms[3]." Orchard Village staff works closely with the individuals in our care, and because they spend much more time with them than their doctors, they are able to help communicate any symptoms to the prescribing doctor so that appropriate actions can be taken.

Another important issue is medication adherence. In a Pharmacy Times article, author Erik Hefti explains that individuals with I/DD do not necessarily understand the impact and side effects of the medications they're taking, which can have a profound effect on how condition(s) are treated, especially for chronic conditions. Hefti also states that "Patients with intellectual disabilities can also have various living situations, which can impart more challenges to medication therapy and adherence. These living arrangements can range from total independence to residing in group homes. It was found that patients with intellectual disabilities living in group homes had higher adherence rates compared with those who lived independently or in a family home[4]."

To reduce negative health outcomes and provide more support for the relationship between doctors and their patients with I/DD, our staff is responsible for frequent contact with the community-based doctors treating the individuals we serve. Residential Program Management staff keeps up this communication to ensure medication and dietary orders are updated within our system and relays it to our direct support staff. This helps us to attain good health outcomes by ensuring medication is given to residents as prescribed by their doctor, certain conditions such as diabetes and epilepsy are monitored (and treated when necessary) appropriately and that residents have their basic assurances provided to them. Our RN trains staff members working directly with residents to ensure they are fully informed about each individual's medical conditions, are on the lookout for early warning signs of problems and encourage good practices and preventative behaviors. Such preventative health measures promote a happier, healthier life for our residents, which is one of our guiding principles as an organization.

After determining that there were many structural impediments to increased health of people with I/DD, we decided to develop our own materials to tailor health and nutrition curricula specifically to individuals with I/DD. An example would be our information about the interactions of certain food with pharmaceuticals that people with I/DD utilize. Additionally, we also determined that the cookbooks that consumers utilize to learn or practice cooking were woefully inadequate. People with I/DD most effectively learn when utilizing materials that are produced in a task analyzed and presented in a pictorial fashion. No cookbook incorporated these best practices.

Orchard Village is also working toward implementing an Electronic Medication Administration Record (eMar) to streamline and automate the medication administration process. eMar is a server-based electronic medication administration system designed for use in institutional pharmacies, assisted living, long-term care and rehab facilities. The software automates the process of distributing, tracking and re-ordering medications and treatments safely and efficiently for both facilities and pharmacies. We are moving from a paper system to an eMar for a variety of reasons including:

- Less emphasis on paperwork and more time spent with the individuals, which increases efficiency;
- Fewer administrative errors, with changes being recorded instantly;
- More accurate documentation of an individual's vital signs, problem lists, pain scales and other information;
- More accurate medication records and other health history, using medication and other barcodes for quick scanning and reporting options;
- Integration with our electronic case management system for a more collaborative approach;
- A friendly interface that multiple staff users can feel comfortable using;
- Modifications and settings that each user can change to accommodate their own industries and preferences;
- Availability on wired and wireless networks and in several hardware options, such as desktop computers, laptops and handheld devices with touch screens to work comfortably in all settings (at home, at the doctor's office, on-the-go);
- Easier and more efficient reporting to supervisors.

In a study led by Richard. D. Paoletti and assoc., researchers collected data on medication errors (based on a direct observation process) on 2 cardiac telemetry units and a medical-surgical unit. During the first phase of the study, all three units participated in the average manual Medication Administration Record (MAR).After implementing an eMar system, researchers observed a 54% reduction of medication errors overall[5]. Further, research by Eric G. Poon and assoc., states that "the bar-code eMar system is more likely to prevent errors associated with memory lapses or mental slips in executing a therapeutic plan… the prevention of many potential adverse drug events could be attributed to the reduction in documentation errors[6]."

The decision to move to an eMar was made so that we can not only improve the lives of the individuals we support, but the community at large. When people with I/DD live in the community (as the individuals we serve do), they are intrinsically a part of that community. The healthier and happier these individuals are, the better they are able to interact with and integrate into the community in which they reside. In everything we do, we work to increase community integration. Our Orchard Academy students and InnOVations program participants go to job internship sites in the community. Our Employment Services department listens to individuals' desires and skillsets and places them in jobs in the community. Our residential homes (called Community Integrated Living Arrangements) are houses in neighborhoods throughout the Skokie area and residents have neighbors and other people they see regularly (e.g. mail carriers, grocery store cashiers, library clerks) who they can talk to. We seek to not only give the individuals we serve a vibrant, active life in the community, but to increase community understanding, admiration, tolerance and support of their co-citizens with developmental disabilities as well.

II. Promoting overall health in the community

Orchard Village currently serves 300 individuals (children through mature adults) in a variety of community-based settings: family residences, small group homes, community apartments, job sites, and classrooms, primarily in north and northwest suburban Chicagoland. The communities we participate in include but are not limited to: Arlington Heights, Chicago, Des Plaines, Evanston, Glencoe, Glenview, Highland Park, Lake Forest, Lincolnwood, Lisle, Morton Grove, Mount Prospect, Niles, Northbrook, Park Ridge, Rolling Meadows, Skokie, Wheeling, Wilmette and Winnetka. Orchard Village believes health is a broad conglomerate and encompasses many aspects of a person's life. That's why we offer many varied services to individuals with developmental and other disabilities, with the goal of improving lives overall, not just in one area. The services we offer include:

Residential Services: Helps people realize their dream to live in a home in the community, whether a 24-hour supervised group home or in their own apartment. Our staff actively works with our residents to ensure that they are involved in their environments, are connected to family and friends and are meaningfully engaged with their communities.

Employment Services: Facilitates an individual's desire for employment, either supported or competitive. Employment staff listen to the needs and desires of the individuals we serve and assess their skill sets. Comprehensive training ranges from resume development to career advancement. With individualized attention and ongoing support at the work site, participants are successful in their chosen careers in the community.

InnOVations: Trains participants for a paid job in the community. Individuals participate in work internships, job training, skill building and therapeutic recreation. Programming and services are client-driven, and curriculum and activities are adjusted to adapt to the changing interests and skills of the participants.

Home-Based Support Services: Provides attentive service facilitation to clients living at home with their families or on their own in the community. As a unique complement, Orchard Village can provide its own trained Personal Support Workers for families who require reliable in-home care for a loved one. We also offer the services of our expert Behavior Analysts for individuals wishing to improve their behaviors or increase skills.

Orchard Academy: Teaches the independent living, vocational and social skills necessary for 17 through 22 year olds in special education to transition successfully into adult life. Students find success in securing and retaining employment, learning to navigate public transportation, being involved in social activities, living on a budget, planning a daily menu, caring for their home and other skills essential to living on their own in the community.

For many individuals, a more comprehensive and continuous "case management" approach to health maintenance is called for, including frequent contact between our nursing professionals and the community-based doctor(s) treating an individual client's various symptoms/conditions. We currently employ 1 FTE Registered Nurse (RN), 6 FTE Case Managers and 85 front line staff (called Direct Support Professions or DSPs), who work in the homes. In addition to administering medications, our DSPs are responsible for meal preparation and supporting our clients to make good exercise and food choices. We are hoping to further improve by training staff to use USDA MyPlate nutrition guidelines and portion sizes, help individuals with diabetes test their blood sugars, make better food choices, take prescribed medication and administer insulin when necessary. Staff will also be trained on using BMI trackers to keep track of individual's health.

III. Community partnerships promoting a continuity of health care for high risk/underserved and disadvantaged populations

Orchard Village is a member of the Intersect for Ability network, a collaborative of 10 agencies serving individuals with developmental disabilities in the greater Chicago Metropolitan area. Intersect for Ability was created to address the unmet needs of the developmental disability population. Orchard Village is also a member of the Skokie Valley Rotary Club and the Skokie Chamber of Commerce. Allison Stark, President & CEO and Jennifer Gentile, VP of Programs are members of the Skokie IPLAN (Illinois Project for Local Assessment of Needs) Community Health Advisory Committee.

Allison Stark is a Co-Chair of The Intellectual/Developmental Disabilities Committee and the Board of Directors of the Illinois Association of Rehabilitation Services. Ms. Stark regularly attends Arc of Illinois and other conferences, and recently presented on a panel for Successes & Challenges in Competitive Integrated Employment at the Illinois Association of Rehabilitation Facilities & Illinois Association for Behavior Health Conference.

Orchard Village is also affiliated with the Institute on Public Policy for People with Disabilities, and is accredited by the Illinois Department of Human Services Division of Developmental Disabilities (Bureau of

Accreditation, Licensure and Certification & Bureau of Quality Management); the Illinois Department of Human Services Division of Rehabilitation Services; and CARF Accreditation award for Administration and Employment Services. State Representatives often visit Orchard Village to learn more about individuals with developmental disabilities and the political issues involving disability and support in Illinois.

For Employment Services, Orchard Village partners with over 80 different employers to create job opportunities for individuals with disabilities. In addition, Orchard Village partners with over 10 different local organizations for volunteer internship sites (for example, Niles Food Pantry, Emily Oakes Nature Center & Marshall's. Orchard Academy also partners with several internship sites in the community (such as Sunrise Senior Living) to build students' soft skills and improve socialization.

Many local high schools and workplaces partner with us as well to support the individuals we serve. For example, Lake Forest Academy (LFA) recently partnered with us to host a fundraiser for our Special Olympics team at the Track & Field Invitational. Our athletes competed in a variety of races alongside the other high school athletes that competed in the invitational. This event would not have been possible without the help of the staff and students from LFA. The LFA athletes helped work with our athletes one on one and showed them proper stretching and form to get them ready for their race. Many other students helped sell pizzas and raffles tickets on our behalf. This event not only served as a way to build more awareness and raise funds but to help continue our efforts to integrate our clients into the community.

Footnotes

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2. United Cerebral Palsy “A Case for Inclusion: An Analysis of Medicaid and Americans with Mental Retardation and Developmental Disabilities” 2006: pg. 3

3. Patel I, Trinh S, Phan T, and Johnson M. “Prescription cascading in developmentally disabled individuals” May-June 2016, *Indian Journal of Pharmacology,* Volume 48, Issue 3, 334-335, http://www.ijp-online.com/article.asp?issn=0253-7613;year=2016;volume=48;issue=3;spage=334;epage=335;aulast=Patel

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5. Paoletti M, Suess T, Lesko M, Feroli A, Kennel J, Mahler J, and Sauder T. “Using Bar-Code Technology and medication observation methodology for safer medication administration” March 2007, *American Journal of Health-System Pharmacy,* Volume 64, Issue 5, 536–543, https://doi.org/10.2146/ajhp060140

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