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OUR VOICE

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CRISIS IN NY NURSING HOMES

Arnie Abrams, Contributing Editor

COVID-19 has provided us with both a tragic wakeup call and an opportunity to reimagine long-term care solutions in ways that replace facilities with communities, nursing homes with real homes and segregated approaches to care with fully integrated assistance shaped by the needs and preferences of those being served.

Each year, families throughout the Hudson Valley become caught up in the whirlwind of facts, fantasies and uncertainties that too often occurs when a close relative unexpectedly becomes disabled and requires long-term care. While there are a number of viable long-term care solutions, the option that clearly dominates most long-term care thinking and decision-making continues to be placement in nursing homes based upon the institutionally biased belief that congregate care facilities are the 'safest' choice. Ironically, assumptions made about the safest option have been deeply challenged as thousands of nursing home residents have needlessly lost their lives during the current pandemic.

Clearly, we have been traveling down the wrong path. In the 21st Century, institution-based services are neither our ONLY option nor our BEST option for ensuring the safety and wellbeing of our most vulnerable citizens. Despite continuing efforts to improve congregate care standards and to revise policies and protocols to minimize risk, conditions in nursing homes today are very much the same as they were when ILI was founded, over 30-years ago.

It is time to adopt a new vision, one that embraces the right of all individuals to actively participate in decisions that affect the care they receive and to live with dignity in least restrictive settings. And... it is time to systematically phase-out the last vestiges of a broken system that has too long been the status quo throughout New York State. Our fundamental right to live with dignity and to participate in the management of the care we receive, exists without precondition or a designated endpoint. It must be cherished and protected at every stage of our lives. Authentically inclusive, supportive, barrier-free communities are not just an ideal to which we aspire, but a moral imperative that determines our goals, defines our actions and serves as the final measure of our progress.



"The best level of health care you can get is home care."
NYS Assemblymember Aileen Gunther

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Help Us Close Gaps & Build Bridges to Equity & Inclusion



Fair Pay 4 Home Care

It's time to recognize our home care workers who are not only essential, but critically important to the quality of life for older adults and people with disabilities. Rachel May, chair of the Senate Committee on Aging is sponsoring the Fair Pay for Home Care Act. This bill will raise the base pay rate for home-care workers to 150% of minimum wage, while making sure that the whole system of how we support this sector is made more sustainable. Sign the petition at actionnetwork.org/petitions/callingforhomecare/. Be heard!

NY Project Hope
Coping with COVID

Emotional Support Helpline: 845-762-2275

Transformation: A Balance of Challenges and Opportunities:

Now is the time to Reimagine the Long-Term Care System



Doug Hovey

The nursing home crisis didn't begin with COVID-19 and will not end unless we embrace the necessity for fundamentally changing our approach to long-term care. It's time take immediate steps to ensure the front door closure of all congregate care nursing facilities New York State! The fact is, these institutions, no matter how well-managed, embody a core cultural bias about age and disability that has denied many of our most vulnerable and tenured citizens the opportunity to maintain connections with community, to be seen as people and not patients, and to be recognized as being capable participating in, and meaningfully contribute to mainstream society when given the opportunity.

This transformation action will involve: 1. an uncompromising commitment by state and local government to the orchestration of long term care services; 2. a dedicated initiative to make foundational improvements to the home care system -- pass the Fair Pay 4 Home Care Act and expand other long-term care supports such as the Access to Home (ATH), Open Doors and Long Term Care Ombudsman programs; 3. a substantial and sustained effort to develop alternative housing models for nursing home eligible individuals that are equitable in scale with mental health and DD housing, and finally; 4. an earnest pledge to ending long-term care referrals to a failed model of institutional support.

Self Direction 101

Mental Health Self-Directed Care (SDC) is a groundbreaking program, that provides an alternate path to recovery for individuals living with serious mental illness.

SDC demonstrates the efficacy of providing service participants with the opportunity to personally shape the services they receive in ways that most effectively address the social determinants of health and wellness that are fundamental to sustainable recovery.

SDC is the only NYSOMH program that has ever offered service recipients full control over the content and character of their individualized care plans. As one of two agencies that originally piloted SDC in New York State, Independent Living Inc. (ILI) provided the tools for self-direction and witnessed their success.

SDC shares its inherent strength with consumer-directed approaches that have proven successful with other disability groups including people with development disabilities and frail elderly and disabled individuals seeking a long-term care alternative to segregated placement in congregate care facilities.

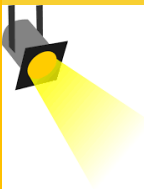
Consistent with ILI's unwavering focus on

helping individuals with mental health and substance use disorders transition from chronic service dependence to independence, SDC uses public dollars to support people's fundamental right to choose the mental health care solutions that are best matched with their personal needs and preferences. ILI's experience with this initiative provides clear evidence as to how New York State's pioneering leadership in promulgating this approach over the past three years has profoundly changed the lives of hundreds of people living with mental illness.

SDC services have yielded positive results in housing, employment, quality of life, self-esteem, and other measures of well-being, and often at the same or lower cost than traditional services.

SDC reshapes how people view their lives and their futures, provides opportunities for meaningful engagement and social connectedness, leads to improvements in personal environmental conditions, self-care, and wellness, and has resulted in an enhanced mental health outlook key to achieving a sustainable recovery. New York State should be proud of its investment in SDC, and of the numerous individuals whose lives have been improved because of it!

IN THE SPOTLIGHT



Kudos to the **Rotary Club of Greater Newburgh** and the **Thorpe Charitable Founda-**

tion for their generous donation and support of several families of people with disabilities that have been financially impacted by COVID-19. The club has been very active in assisting the local community. Through ILI they donated \$2000 to families in need.



K is a 40-year-old Newburgh resident, a single mother of a 10-year-old daughter, and until recently, was the primary caretaker of her elderly mother. A current recipient of ILI's peer and benefits counseling services K. is unemployed - having lost her job due to the pandemic - and as her family's sole provider, is struggling day-to-day to make ends meet.

While actively looking for new employment opportunities, K. has been emotionally devastated by the pandemic and now worries about losing her housing (having fallen behind in her rental payments). To further complicate matters, her daughter recently tested positive for COVID-19 (the same dreadful illness that recently claimed her mother's life).

Thanks to the generous donation of \$400 made by the Rotary Club of Newburgh, K. and her daughter feel "more confident" that her family will be okay. With all that she and her daughter have been through in the past few months, this special gift provides both needed support and a ray of hope for "better times ahead."

One-Million Masks

Helping to keep our communities safe



On January 15, District 7210 Rotary held an event at Dutchess Stadium aimed at keeping local people and communities safe during the pandemic. The second part of their "Million Mask Challenge," an estimated 175,000 masks – including 150,000 adult surgical masks, between 18,000 and 20,000 children's masks and 5,000 KN95s – were provided to 35 local Rotary clubs responsible for distributing them to local small businesses, not-for-profit organizations, first responders, fire departments, EMS providers, community centers, food banks, homeless shelters in support of the community's most vulnerable residents.

According to the CDC, adults with disabilities are more likely to have underlying medical conditions that may put them at increased risk of severe illness from COVID-19 including, heart disease, stroke, diabetes, chronic kidney disease, cancer, high blood pressure, and obesity. In addition, having a disability may make it harder to practice social distancing and exercise other precautions. We applaud the "Million Mask Challenge," which has made stops in Dutchess County, New York City, Connecticut, New Hampshire and Maine. A third tour is planned, but the specifics haven't yet been announced.

A Perfect Storm

Each year, ILI participates in the New York Association on Independent Living (NYAIL)/Consumer Directed Personal Assistance Association of New York State (CDPAANYS) sponsored Legislative Budget Advocacy Day held in the State Capital with the goal of educating our Assembly Members and Senators about the crucial role played by Independent Living Centers in supporting New Yorkers with disabilities. Due to the continuing threat posed by the COVID-19 pandemic, this year's event was conducted virtually, during the week of February 8.

ILI President and CEO Doug Hovey, Board Chair Joe Ranni, Board Member Andy Weyant and Systems Advocate John Harper met via ZOOM with 6 State Lawmakers including Senators Skoufis (D) and Martucci (R) and Assembly Members Gunther (D), Schmitt (R), Jacobson (D) and Brabenec (R). Doug's "cut to the chase" agenda focused on the current nursing home crisis, embracing both budgetary and legislative actions aimed at ensuring community livability, promoting housing accessibility and guaranteeing fair pay for home care workers. Our overarching goal was to encourage and accelerate the movement of individuals with disabilities

from 'out-of-sight-out-of-mind" nursing homes and other congregate care facilities to safe, fully integrated community settings offering greater independence and an improved quality of life.

As the event proceeded it became increasingly clear that the perfect storm of 2020 had revealed fundamental cracks in the foundation of institutional care and inspired a seismic shift in our elected officials' acknowledgement of, and appreciation for the critically important role played by peer organizations during catastrophic circumstances, as well as the value of their collective insight into identifying flaws and shaping transformative solutions leading to a highly evolved model of community-based long-term care.



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Teaching people to fish...

Lori, a 40-year-old single woman with 2 children was able to secure a job in a Nursing Home as a CNA while trying to re-establish her nursing career. Unfortunately, she contracted COVID-19. During her struggle with the virus, the Self-Directed Care (SDC) program assisted her with food, cleaning supplies and personal care items. When she returned to work, Lori was determined to regain her independence, enduring long hours that included night and occasionally overnight shifts. Thanks to her unwavering commitment and with the support of SDC, Lori's journey forward has continued. She now has private insurance through her job and has been able to finance a new car.

On February 25th of this year, Mary L. a 43-year-old single mother living with a mental illness and Opioid Use Disorder celebrated 3-years of sobriety. This was a special milestone marking the longest period of sobriety that she has experienced during her adult life. She attributes her success to the support she has received through treatment, therapy, and self-help groups, but MOST significantly to the assistance provided through IL's Self-Directed Care (SDC) program.

As she describes it, SDC enabled her to focus on her physical and mental health and well-being in ways that she was never able to accomplish prior to her enrollment in the program. From her own perspective, during her years of active addiction, she had neglected many aspects of her life. She ate poorly and did not exercise, did not practice adequate self-care, and lost sight of many of her dreams. SDC has allowed her to focus on goals such as weight loss and pain reduction through personal training, chiropractic medicine, and even small kitchen appliances that have enabled her to prepare nutritious meals. Support from her SDC Broker has motivated her and helped to keep her grounded with yoga classes, meditation, and massage—activities she would otherwise have been unable to afford. Moreover, SDC has allowed her to pursue her educational and career goals by assisting with getting the necessary study materials and enrolling in licensure examinations. Over the past 3 years, Mary has avoided the revolving door of treatment programs, detoxes, and encounters with the criminal justice systems which plagued her life in the past.



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