



***Independence Care System:
A Pioneering Model of Long-Term Care for
Adults with Physical Disabilities***

“Having a significant disability means that my life is different, and most people don’t understand how I can be independent...a lot of medical professionals just see me as a failure. People at ICS don’t. ICS allows people to be autonomous... We are respected as people...ICS should be a model in how health care for people with severe disabilities is delivered.”

Barbara Bobbi Linn, ICS Member, Bronx, NY

Rick Surpin, President
Independence Care System

surpin@icsny.org

(212) 584-2580

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EXECUTIVE SUMMARY

For a decade now, Independence Care System (ICS) has operated a nonprofit Medicaid Managed Long-Term Care (MLTC) plan in New York City whose motto is: “People with Physical Disabilities Welcome Here.”

When ICS opened our doors in 2000, the needs of low-income adults struggling to maintain their independence with significant physical disabilities or chronic illnesses were not only unmet in existing long-term programs; they were invisible. In fact, no long-term care program in New York State focused on their needs.

In response to this situation, ICS instituted a pioneering program of social and health care services specifically designed to assist Medicaid- and nursing home-eligible adults with physical disabilities to live independently and participate fully in community life. Our 1,500 members represent a greatly underserved population: all are low-income, nearly 90% are people of color, nearly two-thirds are women, and many live in the City’s most blighted neighborhoods. Approximately 50% of our members are also eligible for Medicare. Unlike other MLTC programs that serve mainly the elderly, 80% of ICS’s members are between the ages of 18 and 65. Those over 65 have similar conditions and disabilities as our younger members.

The services provided to our members—which make up the ICS Disability and Chronic Care Coordination model—include:

- **Person-centered care coordination**, the “driver” of the ICS program model, which ensures that each member’s needs are comprehensively assessed; that members participate in the development of their care plans; that referrals are made to vetted, accessible providers; and that members are followed from home to hospital or nursing facility back home again, to ensure the speediest return.
- **Enhanced care management**, currently focused on people with Spinal Cord Injury and Multiple Sclerosis; this led the National MS Society to designate ICS one of three “Centers of Excellence in Long-Term Care” --the first long-term care provider of home-based services ever to receive this designation.
- **Home care services**, including both agency home care providers and Consumer-Directed Personal Assistance--making ICS the *only* NYC agency providing this choice. Consumer Directed Care enables ICS members to select their own caregivers, who have broader latitude to help than agency caregivers—a crucial factor for the independence of members with very high needs (e.g., catheterization, suctioning).
- **12-24 hours of personal care**, which in contrast to agencies that refuse to accept people who need extensive care, is given to over 20% of ICS members. This is similar to the percentage in NYC’s personal care program, demonstrating ICS’ commitment to meeting the full needs of our population and preventing unnecessary institutionalization of people with disabilities.

- **Behavioral health program**, including home visits, crisis intervention, supportive counseling and collaboration with community providers to address the complex behavioral issues faced by 60% of ICS members.
- **Expert wheelchair fitting, purchase, maintenance and repair**, including professional evaluation, home assessment, skilled wheelchair technicians, three vans for pick-up and delivery, timely repairs (in the home and in ICS' repair shop), training, demonstration and loaner chairs, and self-help workshops in wheelchair maintenance.
- **Specialists in pressure ulcer prevention and intervention**, who assess all ICS members to identify those at risk (nearly 60%) and coordinate care. This program has reduced the percentage of ICS members who developed a pressure ulcer in the last year while in our program to 5%, compared to the average national pressure-ulcer prevalence rate for individuals requiring long-term care/home care of 28%.
- **Social/educational/artistic activities to combat isolation**, which have proven to be a first step for many members to becoming socially involved in activities beyond ICS.
- **Transportation services**, including ambulette companies found by ICS to have the safest equipment, best on-time records and greatest sensitivity to the needs of people with physical disabilities, and car services.

The ICS program of services has resulted in improved health care outcomes, including prevention of potentially avoidable medical complications, reduced emergency room visits, fewer and shorter hospitalizations, and success at keeping our members out of nursing homes and living independent lives, in the language of the landmark Supreme Court *Olmstead* decision, in the “least restrictive environment.”

Yet, the ICS model is largely unrecognized. Indeed, the needs of people who have multiple disabilities and conditions and who are eligible for a nursing home level of care, but live at home have barely been discussed, let alone addressed, in the current health care debate. This paper is intended to describe the ICS approach and to present our arguments for health policy that builds on the ICS experience and encourages the development of similar models to meet the long-term care needs of a greatly underserved population—low-income adults, especially younger, more active adults—with physical disabilities and chronic illnesses.

ADULTS WITH PHYSICAL DISABILITIES: NEEDS AND CHALLENGES

The special long-term care needs of adults with disabilities pose an ongoing challenge to the State's home and community-based service system. This has been particularly so since the U. S. Supreme Court ruled in *Olmstead vs. L.C.* (1999) that the *Americans with Disabilities Act* prohibits the unnecessary institutionalization of individuals in long-term medical facilities. In the intervening years, a series of reports by the Institute of Medicine have documented the lack of progress in meeting the needs of people with disabilities—most recently, the 2007 publication, *The Future of Disability in America*.

A primary reason for this lack of progress is that the needs and critical issues faced by adults with physical disabilities are substantially different from those faced by the elderly, yet they are treated as if they are the same. In a striking dissimilarity, many people with physical disabilities have had functional limitations from a very young age. They grow with those limitations, striving to manage them and live happy, productive lives. They seek to work and contribute to society; to study, worship, play sports, volunteer and create art; to raise families. No matter when the disability appears, they will, in all likelihood, have to live with its implications for the rest of their lives. As they get older, their disabilities and secondary conditions will become even more limiting and complex.

Given this predictable trajectory, adults with physical disabilities need a service system that blends social supports and medical services and that coordinates and provides those supports and services on a dependable, ongoing basis. Supportive services such as personal care, wheelchair repair and transportation are critical to daily living for people with physical disabilities. Their need for medical services occurs periodically, when illness or medical conditions threaten their health.

Unfortunately, the health care system in general was, and remains, anything but welcoming. Many offices are not fully accessible: doorways and halls are too narrow; bathrooms, dressing rooms and exam rooms are too small, and adaptive equipment such as height-adjustable exam tables are unavailable. Many providers lack the knowledge or comfort level to treat people with physical disabilities in a sensitive, welcoming way. Many are discouraged by the extra uncompensated time or additional staff required to treat a person with a significant disability.

In addition, most people with physical disabilities have more than one physician, and too many of those physicians are reluctant to spend the time and lack the mindset to work with non-physician providers to coordinate care. The result is people with physical disabilities consulting many different providers, who do not communicate with one another; the overuse of emergency rooms; fragmented care; and most importantly, a failure at prevention and early intervention, thereby driving up costs and greatly compromising the person's health.

Another problem in terms of meeting the needs of people with physical disabilities is that the current home care system is largely defined by Medicare. In addition to focusing on serving the elderly, Medicare uses an acute care medical model. Federal law prohibits Medicare from paying for services other than those considered necessary for the diagnosis or treatment of illness or injury or restoration of function. It also requires that a beneficiary “be confined to the home” or homebound in order to receive home health benefits and that the home care have a clear end point.

Many adults with physical disabilities use motorized wheelchairs, which allow them to leave their home, but they still need home care services. Because both the statute and regulations are unclear on this issue, people with disabilities using wheelchairs are often considered ineligible for home care. The focus on “in-the-home” status for a Medicare beneficiary also has resulted in a highly restrictive assistive technology policy. An individual who needs a power wheelchair for mobility outside the home but can use a manual chair inside the home will be unable to obtain the power wheelchair from Medicare. This results in the person being confined to his or her home and profoundly isolated.

Because of the high level of Medicare restrictions, adults with physical disabilities are largely dependent on Medicaid for their services, particularly for home and community-based care. Medicaid uses a broader “medical necessity” regulatory frame and covers long-term care services, such as personal care. However, the Medicaid fee-for-service system, which often follows Medicare regulations, can be inflexible and incapable of tailoring services to individual needs.

In this context, physically disabled adults residing in the community live within severe constraints in terms of available health and social services and access to them.¹ Because they are viewed as “problem” consumers who have unusual problems that are not easily addressed, many of their basic needs are virtually ignored.

¹ In addition to the Institute of Medicine’s report, the best analysis of the state of the service system for people with physical disabilities can be found in *Living in the Community with Disability: Service Needs, Use & Systems*, edited by Susan M. Allen and Vincent Mor (1998) and *More Than Ramps: A Guide to Increasing Health Care Quality and Access for People with Disabilities* by Lisa I. Iezzoni and Bonnie L. O’Day (2006).

ICS DISABILITY/CHRONIC CARE COORDINATION MODEL

The value of serving a distinct population is the ability to learn the particular needs and the challenges the people face in getting their needs met—an essential foundation for developing a person-centered, needs-based service delivery system. With the input of staff with physical disabilities and disability rights backgrounds, ICS learned that people with physical disabilities need and want to be involved in planning their own care, so we made fostering the engagement of members in their own care a critical element of the ICS model.

We also learned that people with physical disabilities need reliable, quality, specialized support services; preventive care to avoid unnecessary hospitalizations for conditions associated with their disabilities; medical providers who understand their needs and whose facilities are physically accessible; opportunities for social participation; advocacy with health and social service systems; and assistance for returning home as quickly as possible from hospital or nursing home stays.

In order to address these needs, ICS instituted a pioneering program of social and medical services that are essential to enabling people with physical disabilities to live independently. The broad range of services provided by ICS constitutes our Disability and Chronic Care Coordination model.² Its major features follow.

- **Person-Centered Care Coordination—Driver of ICS Program Model**

Care coordination is the “driver” of the ICS Disability and Chronic Care Coordination Model. The work begins in the member’s own home, with a health assessment by a nurse from the ICS Assessment Unit; the assessment is focused on functional strengths, limitations, and medical needs. Next comes a social work assessment focused on social support needs, such as housing, benefit eligibility, or financial management.

The ICS assessment process includes the State-mandated assessment in conjunction with additional tools, such as the Braden Scale for Pressure Ulcer Risk Assessment, and an ICS-developed “complexity scale,” which documents the complexity of our members’ needs when they begin with ICS and helps with the process of monitoring changes in condition and needs over time.

Social work care managers develop an individualized plan of care with each member, which the member signs. The plan is based on the understanding that members have the right to choose their own goals, priorities and preferences for services, in keeping with their lifestyles. It can include a host of health and social services, from home care to physical, occupational and speech therapies, medical supplies, nutrition services, respiratory therapy, transportation, wheelchair evaluation, maintenance and repair, wound care and more.

² The concept of Disability Care Coordination Organizations was developed as an extension of the Chronic Care Model by Susan E. Palsbo, Margaret F. Mastal and Lolita T. O’Donnell in “Disability Care Coordination Organizations: Improving Health and Function in People with Disabilities” in *Lippincott’s Case Management* (2006). ICS was a case example in this study.

The social worker coordinates the delivery of those services, works with the ICS service ordering staff to put services in place, monitors their quality and use, and addresses problems as they arise. Problems cover a wide range, from those related to the member's health care needs to service-related problems, such as conflict with a home care aide, a breakdown in mobility equipment, or the stress of a life transition—positive, such as having a baby or starting a job, as well as negative, such as admission to a hospital or nursing home—which can greatly affect the member's health. An important feature of the ICS approach is that our care managers have the ability to make quick adjustments—e.g., put in place extra home care hours for a member who suddenly has a job interview. They also have the freedom to try several interventions in order to find the most effective one for that individual member.

ICS's care coordination model is consistent with the definition developed by the National Coalition on Care Coordination. The Coalition was formed in 2008 by leading social, health care and professional organizations; its definition reads: "Care coordination is a person-centered, assessment-based interdisciplinary approach to integrating health care and social support services in which a care coordinator manages and monitors an individual's needs, goals and preferences based on a comprehensive plan."³ That is precisely the approach ICS has taken successfully with our targeted population.

- **Enhanced Care Management**

Since ICS began, we have monitored the common conditions and issues faced by our members, nearly one-third of whom have two major diagnoses: Multiple Sclerosis and Spinal Cord Injury. MS is a chronic, progressive disease that attacks the central nervous system and causes the progression of disability over time, most often beginning in people under the age of 50. SCI causes loss of feeling and muscular control, is often concurrent with Traumatic Brain Injury, and typically afflicts active young men.

Both members with MS and those with a SCI have great difficulty finding health care providers who are well informed about their conditions, knowledgeable about available resources and how to access them, and sensitive to their special medical, emotional and physical needs. Both also have very high rates of hospitalization due to two potentially avoidable medical complications: urinary tract infections (UTI) and pressure wounds.

In fact, the most common secondary diagnosis for these members is neurogenic bladder, and UTIs are among the most frequent complications of that condition. Yet, people with MS and SCI miss the usual cues, from burning and discomfort to increased frequency of urination, because they are incontinent and lack sensation. Undetected, a UTI puts the member at risk of bladder and kidney stones, widespread infection, kidney damage and for some, a life-threatening condition caused by mounting bladder pressure called *Autonomic Dysreflexia*. Pressure wounds or skin ulcers, the other major complication, (see page 12 for full description), can have dire

³ The definition of Chronic Care Coordination and an assessment of the state of the field is described in an excellent report commissioned by the *National Coalition on Care Coordination* by Robert Berenson and Julianne Howell "Structuring, Financing and Paying for Effective Chronic Care Coordination," July 2009.

consequences. In addition, mental and behavioral health problems, including depression and anxiety, are prevalent in both populations.

For all of these reasons, ICS created an enhanced care management program currently geared to the special needs of members with MS or a SCI. The major goal is to improve the member's quality of life by assisting with symptom management while preventing and minimizing complications, especially the number of emergency room visits and hospitalizations for those complications.

- **ICS' enhanced care management program has as its main features:**

- Supplementing the regular nursing assessment with additional assessments specific to the disease or injury as well as a Quality of Life Inventory.
- Developing an individualized care plan with an emphasis on educating members and their caregivers about the disease or injury, its potential complications, and self-management techniques.
- Providing additional staff training, including special training for home care workers on the specific disease or injury.
- Intense engagement with members, especially in terms of communicating with and coordinating care with each members' multiple physicians.
- Special emphasis on preventing urinary tract infections (UTI), including individualized training for members and their caregivers on bladder management, early identification of a UTI, and the best methods of symptom management, as well as home visits as needed by a urology nurse who provides training (e.g., in catheterization) and assists with urinary problems.
- Focus on the prevention of and early intervention for pressure ulcers, which particularly plague people with a SCI who must sit or lie on a surface at all times; people with a SCI have an 80% chance of developing a pressure ulcer during their lifetime, and a 30% chance of developing more than one.
- Special attention to mobility needs, particularly for members with a SCI who frequently encounter shoulder problems linked to long-term manual wheelchair use.
- Customized home exercise regimens for ICS members with MS—including visits by a physical therapist to train the member and his or her caregivers so that the member can perform the exercises regularly and independently—this in recognition of the MS member's vulnerability to falls, contractures, and extreme fatigue.
- Collaboration with community-based services, including making referrals to and accompanying members to medical appointments at MS Centers, which are staffed by clinicians who specialize in MS, and working with Mount Sinai Medical Center's SCI

Model System (one of 16 federally funded programs) to facilitate the transition from hospital to home for people with a SCI and to put ICS's long-term care services in place.

- Monitoring to identify mental and behavioral health problems, including depression and anxiety, common in both populations.

ICS is proud to note that our enhanced care management program has gained recognition from the Multiple Sclerosis Society. The New York City Chapter named ICS "*Community Partner of the Year*" in 2007 and the National Society designated ICS as one of three "*Centers of Excellence in Long-Term Care.*" ICS is the first long-term care provider of home-based services ever to receive this award.

In addition, since beginning to provide enhanced care management services to members with MS in 2006, ICS has succeeded in decreasing hospitalizations and emergency room visits for members with MS by 15%. Similar data is as yet unavailable for our SCI members, who have been receiving enhanced care management services for less than one year.

- **Home Care Services: Agency And Consumer-Directed Models**

Paraprofessional home care services are widely regarded by our members as their "lifeline" or primary support. ICS offers two kinds of aide services: the agency model and the consumer-directed model. We are the only agency in New York City that offers this choice. ICS also provides services to approximately 25 members at any one time who reside at Barrier Free Living, the City's only transitional homeless facility for people with physical disabilities. In contrast to many long-term care organizations that do not enroll people who need extensive care, ICS also provides 12 to 24 hours of care when appropriate. Such care is available for over 20% of our members, which is similar to the percentage in NYC's personal care program, thereby demonstrating ICS' commitment to meeting our members' real needs and preventing unnecessary institutionalization.

Agency Model

Approximately 80% of our members use personal care aide services through an agency with which we contract. Our largest contractor, with 35% of our service volume, is Cooperative Home Care Associates (CHCA), which is also ICS's sponsoring agency and an affiliate.⁴ CHCA is a 24-year-old, worker-owned home care agency, based in the South Bronx. It was conceived on two basic premises, which have proven to be true: that home health care clients receive a higher quality of care if home care aides have higher quality jobs, and that when workers own

⁴ In addition to CHCA, ICS is also affiliated with PHI. An 18-year-old nonprofit organization based in the South Bronx, PHI combines policy and practice activities in several states, including New York, and nationwide to promote the use of the "better care through better jobs" model for direct care workers in both the home care and nursing home sectors. All three sister organizations—CHCA, PHI and ICS—were founded by Rick Surpin.

the company on a one-person, one-vote basis, they create the best possible jobs for themselves. With 1,600 home care aides today, CHCA has been widely recognized for the quality of its training, its jobs, and its business model.

All aides working with ICS members must be willing to support our members' needs and interests, including accompanying them to work or school. Finding the right match between an aide and a member is particularly important in what we expect to be a long-term relationship. This focus on the right match and promoting a good long-term relationship is in marked contrast to prevailing practices in most home care agencies, which change workers when the relationship is perceived as becoming "too close."

Consumer-Directed Model

Approximately 20% of ICS members use Consumer-Directed Personal Assistance Services (CD-PAS), in which they hire and supervise their own personal assistants through a contracted fiscal intermediary. The core functions for members in this model are to recruit, hire and train Personal Assistants; establish work schedules and determine required tasks; supervise the Assistants in the performance of their duties; and evaluate and discipline, including discharge, the Assistant as necessary. The Personal Assistant is acting as the extender of the consumer and follows his or her directions. State regulations allow consumer-directed caregivers broader latitude in tasks they perform than agency caregivers—a crucial factor for the independence of members with very high needs (e.g., the administration of medications, catheterization, and suctioning tracheotomies).

Members who use CD-PAS value highly the sense of autonomy and control they exercise over a critical service. At the same time, autonomy entails considerable responsibility, which can be overwhelming and exceedingly difficult to manage. This can be especially true for the member who is just beginning to use Personal Assistants. In response, ICS has initiated additional support services, including training for the member on recruitment, hiring and supervision of Personal Assistants and Personal Assistants on their role and responsibilities.

- **Behavioral Health**

The most complex and time-consuming issues in care management are those involving members with co-existing physical disabilities and behavioral health, brain injury and mental health issues. Approximately 60% of our members have behavioral health issues, primarily depression, anxiety and personality disorders. They can play out in a variety of ways, including verbal and physical abuse or unrealistic expectations of caregivers, which result in unstable personal care services; poor adherence to medical and medication regimes; and frequent crises. Such behaviors put the member at risk of a loss of services or even disenrollment.

The typical intervention for adults with behavioral health issues is to link them with community-based mental health providers with the expectation that the person will have the ability and willingness to go to the provider on a consistent basis. However, many members are unwilling to go or to stay engaged. Many providers are not knowledgeable about the interplay of

medical issues related to physical disabilities and behavioral health conditions (e.g., traumatic brain injury and substance abuse); their facilities are physically inaccessible to wheelchair users; and they have long waiting lists and cannot respond to crisis situations.

The ICS Behavioral Health Program was developed to provide more expertise and staff capacity to deal with these issues. A Behavioral Health screening tool—based on the *New York State Office of Mental Health’s Single Point of Access Intensive Care Management Program* screening tool, adapted by ICS—is used as the basis for determining the level of support required and appropriate interventions.

Specific services delivered by the ICS behavioral health staff include:

- Home visits to conduct behavioral assessments;
- Crisis intervention;
- Short-term supportive counseling;
- Linking members with a mental health agencies, whenever possible with those that specialize in working with people with co-existing conditions;
- Advocating with providers, particularly those unfamiliar with how disability-related medical issues and mental health issues interact in the person’s day-to-day life, which ICS staff is in the position to observe; and
- Supporting the member’s engagement in the treatment process.

• **Wheelchair Purchase and Repair Program**

From the beginning, ICS has recognized that wheeled mobility is perhaps the most critical need people with physical disabilities have. It means the difference between isolation and independence. In response, ICS made developing a Community-Based Wheelchair Purchase and Repair Program a major organizational priority. Being a managed care organization helped because ICS did not need to obtain prior approval for repairs or to purchase a new chair, which significantly reduced red tape, hurdles and delays. In fact, in the fee-for-service system, wheelchair users can be housebound for weeks and months, awaiting authorization, when their chair needs repair or replacement.

With a staff of rehabilitation and occupational therapists and trained wheelchair technicians, ICS’ Community-Based Wheelchair Repair and Maintenance Program has the following major features.

Expert Wheelchair Evaluation

At ICS, each member who has a wheelchair or needs one is professionally fitted by a physical or occupational therapist, along with a certified rehabilitation technology supplier. The member’s mobility needs are assessed. Members are listened to carefully about how they live, their level of activity, and what they need to maintain that level. Every effort is made to give members the opportunity to use demonstration equipment to try out the recommended chair—indoors and out—before it is ordered.

A home inspection is done to ensure that the appropriate chair will fit through the doors, hallways and elevators of the member's home, a procedure not done in fee-for-service Medicaid or Medicare. Therapists offer ways to increase accessibility with such items as portable metal outdoor ramps. The order specifications are drafted with the member, therapist and supplier. Wheelchairs are purchased based on functional needs, related to intended use, the realities of the home environment, and cost, not only at the time of purchase, but over the chair's life cycle. When their new chair arrives, each member is trained in its operation.

Maintenance and Repair Services

After the member has received his or her chair, ongoing attention will be required to keep the chair in good working order. Tires, castors, brakes, wheels, axles, upholstery, joy sticks (driving mechanisms), leg and arm rests, batteries and motors are just some of the items that can need adjustment, repair or replacement. ICS technicians tend to all of these matters, not only extending the life of the member's chair but also saving money. While a new chair can cost up to ten times as much as a repair, repairs are often forgone or denied by fee-for-service Medicaid or Medicare, in part because of the cumbersome process of approving and arranging such repairs.

When a chair breaks down, ICS members have access to an "on the road" technician, traveling in an ICS van, who can evaluate the problem with the member's chair in their home, sometimes solving it on the spot, or pick up the chair for an in-shop assessment and repair. This service is crucial for ICS members. They are poor, nearly all lack vehicles to transport a broken wheelchair, and many have no space to store a back-up chair, which they would need to use to deliver their broken chair to a repair location. "Bringing it into the shop" for our members is typically not an option.

If the chair cannot be repaired in the member's home, an ICS repair technician takes it into our repair shop, where every effort is made to complete the repair and return it within one week. Committed to the principle that a person dependent on mobility equipment to get out of bed at all, much less to live their lives, must have a working chair at all times, ICS operates a wheelchair loaner program. Every effort is made to give ICS members who do not have a back-up chair a loaner chair to use while their primary chair is being repaired. Every attempt is made to deliver a loaner chair within 24 hours so that no member is ever stranded at home without a chair. ICS also operates a toll-free hotline that members experiencing a problem with their chairs can call for prompt attention and for help in emergency situations.

Member Self-Help Workshops

ICS is committed to ensuring that our members are as comfortable, knowledgeable and safe as possible in using their equipment. To that end, ICS holds regular weekly workshops where members are encouraged to bring their chairs for preventive maintenance or small repairs. ICS staff teach members how to do preventive maintenance themselves, if they can (such as cleaning the chair, lubricating wheels, tightening nuts and bolts, monitoring battery capacity). Such teaching also takes place on a one-to-one basis, in the member's home.

Program Expansion

Today, 60% of ICS' 1,500 members rely on some type of wheeled mobility device. As the number of our members has grown, so has the need to expand our program. In 2008, ICS relocated the wheelchair program to our new Brooklyn Center. The space includes a wheelchair evaluation room with a versatile power ceiling lift to provide maximum safety and support to members transferring in and out of their wheelchairs for fittings and repairs; a dedicated wheelchair repair and maintenance shop; an oversized shower room where wheelchair users have the opportunity to have their chairs cleaned; and storage for new and repaired member chairs and loaner chairs.

Nothing in the fee-for-service system resembles the level of attention and resources that ICS has devoted to our Community-based Wheelchair Repair and Maintenance Program. It remains unique among long-term care service organizations in New York City.

• **Pressure Ulcer Prevention and Wound Management Program**

Pressure ulcers represent a significant health care threat to adults with restricted mobility. This is especially true for individuals who use wheelchairs and are seated or lying on a surface at all times, which is true of the vast majority of ICS members. Pressure ulcers can have a profound impact on a person's personal, social and financial life as well as on his or her health; they cause extraordinary skin damage, pain, systemic infection, amputations, and even death.

Since the majority of ICS members have a diagnosis that affects their mobility, ICS created a Pressure Ulcer Prevention and Comprehensive Wound Management Program in 2003. The focus of the program is not only on healing the wound in the shortest period of time, but also on preventing skin breakdown in the first place. ICS chose to perform this service as a care management function because of the need among our members and also because the providers with whom ICS contracts, based on their practice in fee-for service, focus on acute interventions rather than on prevention and ongoing intervention.

As stated previously all ICS members are assessed for pressure ulcer risk, using the Braden Assessment, when they enroll; this assessment is administered again, every 180 days. Based on these assessments, 60% of our members have been determined to be at risk for pressure ulcer development. Those members receive a range of preventive interventions, including:

- pressure-relieving mattresses;
- wheelchair seating evaluations with pressure mapping;
- physical or occupational therapy;
- nutritional consultation; and
- education of the member, family and caregivers.

For the 10% of ICS members with open wounds, the focus is on comprehensive wound management. The registered nurses on the ICS Wound Care Team coordinate a wide spectrum of services for our members, including wound assessment as well as coordination of treatment plans with physicians, clinics and skilled nursing agencies.

Members with wounds often have frequent hospitalizations for wound infection, osteomyelitis, surgical debridement and flap surgery. During such hospitalizations, ICS nurses specializing in wound care maintain continuous contact with the member, all physicians involved and the discharge planner. During hospitalization, they advocate for such items as specialized mattresses or beds and such services as VAC therapy; they arrange for such equipment and services to be provided at the member's home upon discharge. This ability and commitment to work across settings result in better health outcomes and significant improvements in the quality of life for our members.

The ICS Wound Prevention and Intervention Program has had notable results. While pressure ulcer prevalence rates for individuals requiring long-term care/homecare average 28% nationally, at ICS, in 2008, only 5% of ICS members developed a new pressure ulcer while in our program. Our members also avoided extremely costly hospitalizations (\$43,180, on average, per pressure ulcer-related hospital stay, according to the Centers for Medicare and Medicaid Services); the ICS wound-related hospitalization rate in the last year was a very low 5%.

- **Social Activities**

Adults with physical disabilities have very limited opportunities to connect with other people. The only time many people leave their home is for medical appointments. Their isolation is often because they do not feel comfortable as the only person with a disability in larger social settings, especially when they are newly disabled. The number of medical and social model day care centers for the elderly have grown significantly over the last ten years. In contrast, there are very few centers that will serve younger disabled adults. In response, ICS offers a rich array of social, educational, and artistic activities, as well as support groups, to ICS members. Participation in any one of the activities often leads to increased social participation in general.

- **Transportation**

Many ICS members rely on ambulette services for transportation to their medical providers. In the fee-for-service system, they would be unable to identify a transportation company that consistently arrives on a timely basis, is appropriately equipped with safety equipment for a variety of wheelchairs, and has experienced, sensitive drivers.

By contrast, ICS contracts with several transportation companies based on their commitment and ability to arrive on time, use the proper safety equipment, and employment of experienced and sensitive drivers. While it will always be a difficult for ambulettes in New York City to consistently arrive on a timely basis due to traffic conditions and multiple riders, ICS works daily at achieving this goal. ICS also contracts for car services for those members who can use one, for the same cost and with more ability to arrive on time, an option that is not available in fee-for-service.

A MODEL FOR THE FUTURE

The ICS Disability and Chronic Care Coordination model is a new model of care that has proven effective in determining, responding to, and meeting the long-term care needs of Medicaid and nursing-home eligible adults with physical disabilities who want and are able to live at home.

The overall features of the model are consistent with the “triple aim” model proposed by Donald Berwick, president and CEO of the Institute for Healthcare Improvement.⁵ Berwick argues that improving the U.S. health care system requires pursuing three aims: improving the experience of care, improving the health of an identified population, and reducing per capita costs. He also calls for “integrator” organizations that work to achieve those aims. ICS, such an integrator organization, has pursued these aims by:

- Serving an identified population—low-income, nursing home eligible people with physical disabilities and chronic illnesses.
- Making creative use of a capitated payment system and a global budget by leveraging our payor role to meet the needs of a population that includes high cost and high need members, while preventing avoidable medical complications as well as frequent and protracted hospitalizations.
- Working to improve the experience of care by treating those we serve as members or customers instead of passive patients, as people capable of taking on primary responsibility for planning their own care, in collaboration with ICS’ care coordinators.
- Recognizing that support for independent living for this population must include both medical and social services, tailored to the needs of each member and the demands of their lifestyle (e.g., parenting, working, studying, volunteering, etc.).
- Supporting the whole person in between physician visits and hospitalizations, maintaining contact and coordinating care with the member’s multiple physicians—primary care and specialists—and other caregivers, including nurses, therapists, home care aides, and providers of equipment and supplies.

The ICS model would be considerably strengthened by enabling appropriate physicians, group practices and health centers to enter into a formal collaborative arrangement to function as medical homes for our members. They would be paid a quality-based, care management fee above their usual payment for medical treatment. This enhanced rate would recognize their willingness to become more skilled at caring for people with physical disabilities, to make their facilities and equipment as accessible as possible, and to commit to providing the extra time and extra personnel sometimes required to care for people with the most significant physical disabilities.

⁵“The Triple Aim: Care, Health, and Cost,” by Donald M. Berwick, Thomas W. Nolan, John Whittington, *Health Affairs*, Volume 27, Number 1 (May/June 2008).

The combination of a community-based care coordination program with a primary care medical home network is similar to two model programs—Community Care of North Carolina and Vermont Blueprint for Health Integrated Health Program. It is a combination that merits further attention.

Beyond these specifics, the ICS model embodies the promise of *Olmstead*—the 10-year-old U.S. Supreme Court decision *Olmstead v. L.C. and E.W.*, which prohibited the unnecessary institutionalization of people with disabilities and guaranteed them the right to live in the “least restrictive environment.” It also is in keeping with President Barack Obama’s recent declaration of the “Year of Community Living,” with a promise to increase access for Americans with disabilities to the services they need to live in their own communities. And it is a harbinger of the type of service system that must be in place if America is to keep an aging, physically challenged but active citizenry out of nursing homes.