

Independence Care System

A Disability Care Coordination Organization in New York City

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Abstract: Adults with physical disabilities living in the community generally live within severe constraints in terms of available health and social services. Independence Care System (ICS) is a Medicaid-based disability care coordination organization in New York City that allows many New Yorkers with physical disabilities to live independently. This article summarizes our program, our experience, our impact, and our plans for further development. We are becoming a disability-competent, integrated system of care that will create unique value for our members. In the process, we will also contain costs and provide greater accountability for the State Medicaid program. **Key words:** *care coordination, home and community-based services, managed long-term care, physically disabled*

NEW YORK STATE, like many states, has increasingly relied on managed care entities as the key mechanism to contain Medicaid costs and achieve greater accountability for quality care. The elderly and adults with disabilities have been exempt from traditional managed care arrangements because of concerns about restricted access to long-term care services and providers.

However, State legislation was passed in 1997 authorizing the establishment of several managed long-term care plans to specifically serve the elderly and adults with disabilities. All of the plans that were started under this legislation focused on serving the elderly, except one—Independence Care System (ICS), a nonprofit organization in New York City. ICS coordinates and provides a wide range of health and social services for adults with physical disabilities. These services allow many New Yorkers with disabili-

ties to live independently in a community setting.

BACKGROUND

ICS began operations in April 2000 after 5 years of planning and development. It was initially conceptualized after years of listening to consumer advocates, many of whom were disabled themselves, discuss their frustrations and experience in the Medicaid fee-for-service system. It was crystallized after seeing and learning from the groundbreaking work of the Community Medical Alliance, a Medicaid managed care program for Medicaid-eligible adults and children with varying disabilities or chronic illnesses (Master, 1998; Master & Eng, 2001).

Today, ICS has more than 1000 members and we expect to double in size over the next 3 years. Our members are adults with physical disabilities due to neurologic and muscular disease or injury—for example, spinal cord injury (25%), multiple sclerosis (20%). All of our members must be at least 18 years of age, eligible for Medicaid and eligible for placement in a nursing home. Most of our members are Latinos or African American; 10% are white;

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60% are women; 50% are dually eligible for Medicare and Medicaid; and only 10% are 65 or older.

The services covered by managed long-term care plans in New York State are an extension of those available in the Medicaid fee-for-service system—for example, care management services. At the same time, we are paid by Medicaid through fixed or capitated monthly payments for each member to pay for the services we cover (Table 1). This

Table 1. Health and long-term care services covered by ICS

Care Coordination—ICS is responsible for the coordination and management of all member health and social support needs, including medical social services
Home Care Aide Services (includes home health aides, personal care aides, home attendants, and personal assistants)
Home Health Nursing, Physical, Occupational, and Speech Therapies
Nutrition Services
Medical Equipment and Supplies (including wheelchairs)
Transportation (nonemergency)
Dental Care
Optometry (eye examinations, glasses, and other vision services)
Audiology and Hearing aids (services and equipment for people with hearing impairment)
Adult Day Health Care
Social Day Care
Respiratory Therapy
Social and Environmental Supports (such as home modifications, linkage to vocational training, and referrals to Independent Living Services for skills training, help in setting up an apartment, using accessible transportation, check writing, etc)
Home Delivery of Meals
Personal Emergency Response System (PERS)
Site-based Rehabilitation Services (such as physical, speech, occupational therapies)
Nursing Home Care

payment system enables us to make more flexible service arrangements than is possible in the fee-for-service system.

Hospital and physician services are not covered in the benefit plan and are billed Medicaid fee-for-service. All Medicare covered services for the dually eligible are also billed directly. However, all care is coordinated by ICS.

SPONSORSHIP

ICS is jointly sponsored by Cooperative Home Care Associates (CHCA) and the Paraprofessional Healthcare Institute (PHI). CHCA is a 20-year-old worker-owned home care agency, based in the South Bronx, which specializes in paraprofessional care. It was conceived on the basic premise that home healthcare clients would receive a higher quality of care only if home healthcare aides were offered higher quality jobs. And, if workers owned the company on a 1-person, 1-vote basis, they would create the best possible jobs for themselves.

Today CHCA has over 1000 aides. Their wages and benefits are approximately 20% higher than industry average. It has sponsored several unique innovations, including a guaranteed hours program, and made a significant investment in entry-level and in-service training. A majority of the board of directors are controlled by elected worker-owners and an elected worker council provides a vehicle for participation in learning about and shaping management policies and practices.

CHCA has 2 customers, in effect—its workers and its contractors/clients. The company has an unusual mandate. Like all companies it must be financially viable but, at the same time, it must be worth owning from a worker’s point of view. The jobs must be good and the organizational culture must be marked by respect and fairness. A workforce that has generally been devalued and often treated as if they are replaceable parts is highly visible and at the core of CHCA’s culture.

The Paraprofessional Healthcare Institute is a 15-year-old national nonprofit organization that is affiliated with CHCA. It combines

policy and practice activities in several states and nationally to promote the use of our *better care through better jobs* model in both the home care and nursing home sectors.

Starting ICS was an attempt to protect and expand the market for CHCA both as an enterprise in New York City and as a national model of our school of thought by moving higher on the healthcare “value chain” or reimbursement ladder. We believed that we could infuse our values into a managed care framework and go “against the grain” of the prevailing norms in the industry, just as we did 20 years before in home care. We have come a long way since we began thinking about undertaking what is now ICS, but it is too early to know how successful we will be.

COMMUNITY SERVICES FOR ADULTS WITH PHYSICAL DISABILITIES

Although New York State has created an extensive home and community-based health and social service system to help people stay out of nursing homes, this system is largely oriented to the elderly. Services for the elderly have been put in place over the last 30 years through 3 major federal funding streams—Medicare and Medicaid for healthcare and the Older Americans Act for social services. As a result, there is a broad network of health and social services and fields of related practice supported by professional schools and gerontological societies available to the elderly.

However, physically disabled adults living in the community generally live within severe constraints in terms of both available health and social services and access to them. Underutilization of services by adults with physical disabilities in the fee-for-service Medicaid system is widespread and widely recognized both locally and nationally (Allen, 1998; Allen & Mor, 1998; Coughlin et al., 2000; Vladeck, 2003). Viewed as “problem” consumers who have unusual problems that are not easily addressed, many of their basic needs are virtually ignored. Access for many people with physical disabilities depends on both an adequate wheelchair and regular transportation that are not consistently available.

The lack of an appropriate service system for adults with physical disabilities plays out in a multitude of arenas:

- Primary care practitioners often have little training or knowledge about various physical disabilities (DeJong, 1997; Gans et al., 1993). There is no equivalent of a geriatric practitioner for adults with disabilities. Many adults with disabilities tend to rely on the specialty clinics of academic medical centers. These clinics are staffed by resident physicians who attend a clinic for a short time, and then rotate to a different assignment. As a result, there is no continuity of care or building of knowledge about the consumer/patient over time and often inappropriate referrals are made to other clinicians in the process.
- Virtually unattended, adults with disabilities are more vulnerable to health problems such as decubitus ulcers, urinary tract infections, respiratory tract infections, fractured bones, and contractures. These problems become serious quickly, often resulting in unscheduled hospitalizations and secondary disabilities and limitations.
- There are very few providers of preventive services, such as dentistry and mammography, who have accessible equipment for people who use wheelchairs. To the extent that there are available services at all, they often are located in agencies that specialize in serving people with developmental disabilities rather than the broader group of adults with disabilities.
- Certified Home Health Agency (CHHA) practices are primarily defined by Medicare regulations, which are oriented to a homebound elderly population. Many people with disabilities are not considered by the CHHAs to meet homebound criteria and are consigned to the largely custodial personal care program, which does not provide skilled services.
- Paraprofessional home care is widely regarded by many disabled individuals as their “lifeline” or primary support. Home care aides are the immediate link

between client/family care givers and professional service providers, particularly in terms of daily support for self-care and prevention programs, early detection of problems and changes in physical condition. Yet, paraprofessionals are rarely respected, trained, or communicated with in a way that recognizes their value.

- Medicare regulations for rehabilitation services focus on restoration of physical ability. However, people with disabilities often require maintenance therapy to prevent further deterioration that is often not considered reimbursable under either Medicare or Medicaid.
- The number of medical and social model day care centers for the elderly have grown significantly over the last 10 years. In contrast, there are only a few centers that will serve younger adults and the limited number of people with disabilities who have tried them generally find them to be too dominated by the elderly.
- The mobility needs of disabled adults are often not met appropriately. Customized fittings for wheelchairs, for example, are typically done in a hospital setting without ever visiting the consumer's home to make sure the chair fits through doors, elevators, and hallways. Motorized wheelchairs require routine maintenance and minor repairs but it is extremely difficult to find reliable service providers and to get Medicaid or Medicare to pay for it. The purchases and repairs that Medicaid and Medicare do pay for, require a relatively lengthy prior approval process that makes a timely response virtually impossible.
- Consumers are typically 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. A single trip will often take an entire day to complete.

One of our members described his immediate life before joining ICS as follows: "It's as if you're free falling through the health care system. I wasn't a person anymore." Wilfred

is a 55-year-old man who is paraplegic. When a decubitus ulcer on his lower back would not heal, and become infected, a hospital stay transitioned into rehabilitation at a nursing home. He was admitted for a stay of 2 weeks. It was 2 years later when we worked with him to move him out of the nursing home into his own apartment with appropriate supports and services. Today, he thanks our care manager who worked with him for "saving his life" by giving him a "sense that there is a future" for him.

There are many stories like Wilfred's at ICS, some more dramatic than others. There is an underlying theme to all of the stories—that adults with physical disabilities are faced with a Medicaid fee-for-service system that is often inflexible and incapable or unwilling, or both, of tailoring services to individual needs. And, it is a system that does not include care coordination or advocacy leaving the consumer to "free fall" wherever they may land, whether it is appropriate or not.

ICS PROGRAM MODEL

Our program model is based on 3 fundamental beliefs:

1. People with disabilities often can take the lead role in planning and managing their own healthcare and social supports. They typically know a great deal about their bodies and their needs. They need knowledgeable people to work with them in making the system work for them.
2. People with disabilities need a service system that blends social supports and medical services. Their daily living needs primarily require supportive services such as personal care and transportation to medical appointments. Their need for medical services typically occurs periodically when illness or medical conditions threaten their health.
3. Each individual with disabilities has unique needs and preferences, which must be recognized and addressed. What is most valuable to one person will probably not be the same for another. We

need to enable each individual to receive what they consider valuable as much as possible.

ICS uses the flexibility of managed care to put these beliefs into practice. First, we provide some services that are not available in fee-for-service such as care coordination and wheelchair maintenance. Second, we provide a range of health and social supports necessary for independent living. Third, we focus on the prevention of serious medical problems that too often result in long hospital stays.

The core of our approach is an interdisciplinary care management process with either a nurse or a social worker serving as the primary care manager. The care manager is responsible for coordinating the member's overall care, including care by primary and specialty care providers, and identifying gaps in needed services. An individualized plan of care is developed with each of the members, on the basis of their priorities and their choices about their providers—including physicians, home health aides/personal assistants, and others. If a member does not have a primary care physician, ICS staff helps to identify one. A specialist physician may serve as a primary physician as long as the physician agrees to provide preventive as well as specialized medical care. The plan of care is developed soon after enrollment, reviewed every 6 months. It is agreed to and signed by the member.

We started out 6 years ago with the belief that care management was the new and value-added service that made ICS and Medicaid managed long-term care, in general, distinct from Medicaid fee-for-service. In many ways, this has been true. At the same time, we have learned that it is essential but very difficult to establish an excellent interdisciplinary care management practice.

Nurses and social workers have very little experience with working collaboratively. They have fundamentally different mental models of their roles as care managers, what consumer participation in care planning means and how consumers or patients

should respond to their professional knowledge. Each tends to view the other as not entirely doing what needs to be done to meet the member's needs (Bowers et al., 1996). We are continuously seeking to develop effective formats and processes to inform each other, to have productive discussions, including conflicts, and blend the varied knowledge and skills of our care management staff.

We have also learned that care management needs are not necessarily related to the extent of a member's functional limitations. The need for care management, beyond arranging for and coordinating services, is generally related to 1 or any combination of 3 major factors: (1) service-related problems such as a changed relationship with home care aides or family members or breakdowns in mobility equipment; (2) critical transitions such as hospital or nursing home entrance or discharge or potential loss of housing; and (3) mental or behavioral health issues and substance abuse. Too often, the problems take an enormous amount of time and effort to address and in some cases occur again in some form.

Supportive services for independent living

In addition to care management there are 6 program areas that provide critical support services for living independently and in which we have developed distinctive skills and knowledge.

Wheelchair purchase and repair

At the beginning of our program, we recognized that wheeled mobility was at least equal to home care aides as the most critical need for adults with disabilities. Potential members of ICS described the importance of the "right chair" and the need to keep those chairs working—that is, access to timely repair service. Creating a member-responsive wheelchair service became a priority for the organization.

Members work with a therapist and a certified equipment supplier to identify his or her mobility needs. Most members have access to several "demo" products prior to selecting a specific chair. The order specifications are

drafted with the member, therapist, and supplier. Our seating evaluators work to purchase new wheelchairs on the basis of their functional need or intended use and an assessment of the member's home environment, as well as the cost over its life cycle (not only at the time of purchase).

A wheelchair repair technician visits members in their home to repair chairs as needed. Chairs are typically repaired within the home. When necessary they are repaired at a shop and usually returned within 48 hours and a loaner chair is provided. Members also have access to maintenance training and a workshop to perform preventive maintenance—for example, cleaning the chair, lubricating wheels, tightening nuts and bolts, monitoring battery capacity.

There is nothing in the fee-for-service system that resembles this level of attention and resources to enable wheelchair users to get around as if they had legs that worked. In fact, in the fee-for-service system, wheelchair users can be housebound for weeks, and sometimes months when their chair needs repair or replacement.

Pressure ulcer prevention and intervention

Pressure ulcers represent a significant healthcare threat to adults with restricted mobility or chronic disease. This is especially true for individuals who use wheelchairs, and are, therefore, on a surface virtually all of the time. Approximately 40% of our members have been determined to be at moderate to high risk for developing pressure ulcers. All of our members are assessed for risk of pressure ulcers as part of their regular nursing assessment and appropriate interventions are developed for each person at moderate to high risk. These interventions may include further assessment through use of pressure mapping; purchase of new beds/mattresses; new or modified wheelchair cushions; member/caregiver education; modifications of bowel and bladder routine; and assessment of nutritional status.

The focus on pressure ulcers in the fee-for-service system is to heal the wound(s) in

the shortest period of time during an acute episode of care. Our focus is also to heal the wound in the shortest period of time *and* to prevent skin breakdown from occurring in the future. We will often accompany members to medical appointments, and follow a member during periods of admission to the hospital or skilled nursing facility.

Members with wounds often have frequent hospitalizations for wound infection, osteomyelitis, surgical debridement, and flap surgery. Our care managers specializing in wound care maintain continuous contact with the member, all physicians involved, and the discharge planner. We frequently advocate for specialized mattresses/beds and services, such as VAC therapy, during hospitalization and arrange for them at home upon discharge. This ability and commitment to work across settings results in better health outcomes, and a significantly improved quality of life for many of our members.

Home care aide services program

Approximately 80% of our members use home care aide services (not including Consumer-Directed Personal Assistance Services). Home care aides are the primary support for most of our members. They are also the link between members/family caregivers and professional service providers.

We believe that a high-quality job for the home care aide is a prerequisite for high-quality support for our members. As an affiliate of the Paraprofessional Healthcare Institute's *Quality Care Through Quality Jobs* approach we seek to promote the 9 essential elements of a quality job: family-sustaining wages; affordable health insurance; full-time stable work; excellent training in both technical and relational skills; participation in decision making; career advancement opportunities; linkages to services to resolve barriers to work; quality support and supervision; and an organizational commitment to an ongoing quality improvement process (Dawson & Surpin, 2001). We have been working with a core group of preferred paraprofessional home care agencies who

share our commitment to implement all or most of these elements.

At the same time, the aides working with ICS members must be willing to support their needs and their interests, including going to work or school. They must be competent, reliable, and compatible with our members. Finding the right match between the aide and our member is particularly important in what we expect to be a long-term relationship. It is also difficult to achieve the first time and usually requires a few, if not several, attempts. This focus on the right match and promoting a good long-term relationship is a marked contrast to prevailing practices in most home care agencies, which change workers when the relationship is perceived as becoming "too close."

The relationship between the aide, the member, and possibly family member is an ongoing process of accommodation (Callopy et al., 1990; Surpin & Hanley, 2004). The process is made more difficult since the aide is essentially a "guest" in the member's home. When the participants are not compatible or the process breaks down, ICS staff must provide problem-solving assistance to restore stability with the service.

Finally, aides will be increasingly trained to play a valuable role in the care management process. Providing aides with information about the member's conditions and goals combined with training about what to look for and how to communicate it to the appropriate staff will increase our capacity to manage critical conditions, such as wounds, more effectively and provide for increased skill development and compensation for the aide.

Consumer-Directed Personal Assistance Services

Approximately 20% of our members use Consumer-Directed Personal Assistance Services (CD-PAS) in which they hire and supervise their own personal assistants through a contracted fiscal intermediary. ICS is the only managed long-term care plan in New York State to offer CD-PAS.

The core functions for members in this model are to recruit hire and train personal assistants; establish work schedules and deter-

mine 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. Since the assistant is exempt from the State Nursing Practice Act, he or she is able to perform all daily tasks related to a member's needs, including health-related tasks such as administration of medication, catheterizing, and suctioning tracheotomies.

Members who use CD-PAS generally value tremendously the sense of autonomy and control they exercise over a critical service. At the same time, autonomy entails considerable responsibility as well, which at times 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 this context, we have initiated additional support services including consumer training on the role and responsibilities of consumers in terms of recruiting, hiring, and supervising their personal assistants; and personal assistant training on the role and responsibilities of the assistant. A central registry of personal assistants to assist consumers in identifying potential assistants and to help assistants in finding employment is planned for implementation in 2007.

Transportation

Many of our members rely on ambulette services for transportation to their medical providers. ICS contracts with several transportation companies on the basis of their commitment and ability to arrive on time, have the proper safety equipment, and have good drivers. While it will always be a difficult for ambulettes to consistently arrive on a timely basis because of traffic conditions and multiple riders, we are consistently improving our performance.

We contract for car services for those members who can use one, for the same cost and with more ability to arrive on time. We also recently initiated a public transportation training program in small groups and through

individual coaching. This training program grew out of a recognition that buses are actually more reliable than ambulettes and enable members far greater mobility for all activities, and not just those that are medically related.

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.

In response, we have developed a variety of substitutes for adult day centers including seminars on health issues and disability culture, support groups for women, weight watchers, and affinity groups—for example, writers, movie lovers; classes in ESL/GED; painting and jewelry making; and social events. Participation in any one of the activities has often led to increased social participation in general. Members have formed mutually supportive relationships, learned new or improved existing skills, and gained critical health-related information, and several people have significantly reduced their weight.

One member, Crysenthia, describes her experience: “My kids can never get in touch with me since I became a member of ICS—before, I was always at home and now I am out and about all of the time. I am happier and they are happy for me.”

Our program model is also continuing to evolve. While we will continue to provide multiple diseases and condition management, we will also develop more expertise in areas of our member’s primary condition/disease. We will establish specialized care management programs for members with multiple sclerosis and spinal cord injury in 2007. A behavioral health program will also be established with specialists supporting care managers. A similar program for the members with diabetes will be established by the following year.

This approach will enable us to do the following over time: (1) focus on health main-

tenance and monitoring of interventions; (2) identify appropriate physicians for members and whenever possible, getting members out of hospital clinics; (3) develop collaborate relationships with physicians; (4) increase the knowledge and skill of home care aides to contribute to the care management process; and (5) increase the knowledge and skill of the member and their family to manage their own care.

THE IMPACT ON OUR MEMBERS

Marty is an ICS member who is in his sixties, weighs more than 400 lb, and has a vascular disease called Buerger’s. The disease is responsible for his leg amputation and threatens his remaining limbs while causing tremendous pain. When he gets home, his personal assistant—without whom he could not get out of bed in the morning, much less dress, cook, groom, use the bathroom, and tend to his multiple medical needs—will put hot cloths on his legs to get the circulation going. He also has had 3 heart attacks. However, Marty also works 20 hours a week and is active in several disability advocacy organizations.

One evening when Marty was out with friends he backed out of a train station elevator and the back wheels of his chair got caught on the curb. Suddenly, Marty’s chair tumbled over, and he was thrown to the ground. He struggled to right himself but found, to his horror, that he could no longer bear weight on his leg without excruciating pain.

Marty’s friends managed to get Marty back into his wheelchair, onto the train, home, and into bed. But once there, he could no longer transfer—for example, from bed to wheelchair, wheelchair to shower—which he used to do by standing on one leg, with the help of his personal assistant. His muscles and tendons were severely damaged. He had to be hospitalized. It was after being hospitalized for several weeks after his accident that Marty was told he would have to go into a nursing home.

Marty was devastated. His greatest fear was that he would never get out. “I was afraid I would lose my independence,” he says. “If

they keep me in a nursing home long enough, I could lose my services as well as my apartment." He also knew that a nursing home would mean the end of his myriad activities which he says, "keep me young, thinking and alive."

He called Marilyn Saviola, the director of advocacy at ICS, who is disabled as a result of postpolio that left her quadriplegic herself. Marty and ICS staff agreed that Marty should go into an acute rehabilitation facility, not a nursing home. But the rules of the game were against him. Rachael Stacom, his care manager and now a clinical manager, explains: If you're going into an acute rehabilitation, you'll have physical therapy and occupational therapy 6 days a week. The problem is, hospitals push our members into nursing homes because acute rehabilitation centers are supposed to be for people who are going to get better. They'll say, "Look. An amputee. He's not going to walk again. Why put him in acute rehab?"

The confrontation over Marty's fate was face-to-face. The hospital social worker and the nurse care manager responsible for discharge planning wanted to go into a conference room without Marty. Saviola said: "No. It's Marty's life. He should be here." Marty attended the meeting.

During the meeting, Marilyn and Rachael argued that Marty's functional ability was higher prior to his going in for this hospitalization. He could go from the chair to the bed and do a lot of his own activities of daily living, independently or with assistance. After he fell, he lost that ability. We needed to restore what functional capacity he had before the accident, which made him appropriate for acute rehabilitation. The hospital staff said, "But you can't restore him to the functioning of a normal person, so he belongs in a nursing home." Stacom said, "But you can restore him to his norm."

After some resistance, the hospital agreed to at least apply to several rehabilitation centers to see if they would accept Marty. ICS used its network of contacts to further advocate for Marty's admission. Several days later, the good news came: Marty would

Table 2. What adults with physical disabilities need from ICS

Support services to live independently that are reliable and good quality
Opportunities to plan and manage their own healthcare and social supports
Opportunities to participate in community life
Prevent serious medical conditions, as much as possible, that result in hospitalization
Get them out of hospitals/nursing homes, once in, as fast as possible
A sense of community—people caring about each other, both members and staff

be transferred to an acute rehabilitation facility.

Compliments of a grinding routine of daily physical therapy, Marty began to get better. He learned to transfer with assistance using a sliding board. While we have seen disabled people stranded in nursing homes for "months and months and months," Marty was out in just 3 weeks (Bonavoglia, 2004). And all of us at ICS, not just Marty, were absolutely delighted to see him come home and resume his highly active community life.

These are the kind of results or outcomes that our members need (Table 2) and have come to expect from us.

A FRAMEWORK FOR POLICY AND PRACTICE

ICS is essentially a hybrid between a managed care organization and a home and community-based service provider that focuses on the needs of adults with physical disabilities. This unique form of organization has recently been described as a disability care coordination organization. Disability care coordination organizations are characterized by 6 key elements: comprehensive medical, psychological and social assessments of members; self-directed person-centered planning; support in health visits; a centralized

medical-social record; engagement with community resources; and constant communication with members (Palsbo et al., 2006).

Further, related research has also begun to define a disability-competent health system model. This model adapts and extends the chronic care model (CCM) (Wagner et al., 2001), which has become widely used to improve the health of people with chronic illnesses such as diabetes and asthma. The CCM provided a useful framework to define elements of a disability-competent health system in 3 major areas: health system design; clinician support; and self-management support (Palsbo & Kailes, 2006).

Disability care coordination organizations, like ICS, are faced with the challenge of extending and building disability competence throughout the health and social service system our members use. Too many practitioners and agencies have developed notions of the “right way of doing things” that are based on acute care-oriented regulations and frameworks that too often have no relationship to the needs of our members.

Care coordination alone is essentially a lay over on current practice patterns and service arrangements. It can have a significant effect on an individual basis but mostly cannot address systemic issues. Our most effective interventions have been when care management is combined with a preferred provider relationship in which the provider has a commitment, financial incentives, and openness to integrating service and administrative operations. In some cases, such as our wheeled mobility program, we have started our own service for lack of a provider that could fully meet that criteria.

Disability care coordination organizations, like ICS, are also excellent sources of innovation for enhancing quality outcomes for adults with disabilities. A collaborative project among 4 organizations—AXIS Healthcare; Community Living Alliance and Community Health Partners in Wisconsin; and ICS, led by Susan Palsbo of George Mason University and Margaret Mastal of the Delmarva Foundation, is developing appropriate performance measures for disability care coordination or-

ganizations. We also are beginning to develop training and practice models to incorporate paraprofessionals as key supports in disability care coordination models. Finally, we intend to demonstrate the value and life-cycle cost of purchasing wheelchairs for use in the community and not only for use “in the home” or on a short-term basis.

ICS' FUTURE

ICS is currently based on a long-term care service approach that is mostly effective for our members. However, one of our primary goals is to reduce the frequency and duration of hospitalizations for our members. Primary healthcare is a critical element for achieving that goal and it is not currently included in our covered services and capitation payment.

Most New York City community-based primary care practitioners are unfamiliar with disability-related care. Even their offices often have narrow halls and doorways, small examination rooms, and inaccessible examination tables. Many of our members use hospital-based clinics in order to see specialists who they often are using as their primary physician. Since Medicaid physician fees in New York are relatively low for specialty care, the clinic is the only available setting.

Our medium-term goal is to identify appropriate physicians for our members who have or are capable of developing the necessary medical knowledge and using it in the context of interactions over time that respect the patient-members and allow time for them to collaborate in decisions about their care and treatment. The lack of an adequate number of physicians, who can and are willing to do this, results in consultations with many providers, reliance on less knowledgeable but amicable physicians, and/or development of the patient's/member's own expertise (Bowers et al., 2003).

This will require expanding our Medicaid-covered services to comprehensive primary, acute, and long-term care services, including mental health and substance abuse treatment. We will also have to foster the development of multispecialty physician group practices who

have the staff and physical facilities to provide the necessary expertise and care for our members (Enthoven & Tollen, 2004). These practices will function as preferred providers or affiliates.

Further, we will need an appropriate, risk-adjusted payment system that can blend primary and acute care costs with long-term care costs. Multiple rate cells or categories related to service needs and costs would provide assurance to both ICS and the State, that payment rates are commensurate with need. Risk adjustment within Medicaid will be the first stage of appropriate financing; integration of Medicare-covered services and financing will be the second.

The major cost savings in managed long-term care are in decreased hospital utilization—less frequent admissions and shorter stays. Cost savings will likely increase as disability-centric care coordination becomes more sophisticated and more integrated with physicians over time. The challenge for State policy will be whether

those increased savings will be shared by the State and ICS, to enable further development of community-based services or retained by the State alone.

Our goal is to become a disability-competent, integrated system of care that creates unique value for our members. Part of the unique value will be in the support services we provide to help people live independently, part of it will be in keeping people out of hospitals and nursing homes, as much as possible, and part of it will be connection to a community of people—other members, our staff, and our key providers. Connectedness and hope are healthy antidotes to isolation and depression. Feeling “known” and respected provides a strong foundation for positive interactions about difficult issues and problems. It is the best way that we know how to cope well with societal arrangements that were not designed with adults with physical disabilities in mind and to try to change them over time.

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