



## INDEPENDENCE CARE SYSTEM

BY WARREN SHAW

Perhaps most widely known for its longtime star executives Anna Fay and Marilyn Saviola, two of our movement's stalwarts (sadly no longer with us), Independence Care System, or ICS, used to be a hybrid of a Medicaid long-term managed care plan and health service provider, focused on the needs of New Yorkers with physical disabilities.

### Founder Rick Surpin

ICS was founded in the year 2000 by Rick Surpin, who is himself a sort of hybrid. On one hand, he is an expert in urban policy and former director of the Center for Community Economic Development at the Community Services Society, which worked to create jobs for low income New Yorkers. On the other, Rick was deeply influenced by what he observed as a teenager in the late 1960s while delivering wholesale fruit and produce for his father's company. On his delivery schedule was a most infamous client – the Willowbrook State School. The chaotic and abusive scenes he witnessed there instilled an abiding interest in people with disabilities.

Beginning in 1985, he persuaded the Community Services Society to support an experiment – a worker-owned co-operative home care service, which he logically dubbed Cooperative Home Care Associates (CHCA). Since a cooperatively run business means that the workers control the board and make policy decisions, it was Rick's hope that CHCA would mean higher quality employment, wages and benefits in what is typically a fairly low-paying and low profit margin industry.

CHCA met Rick's hopes. In the course of running that organization,



Rick Surpin, third from right, is shown with ICS members, left to right, Sasha Quinones, Shirley Seth, Michaline Branker, Azzlee Blackwood, Louise Washington, and Rose Marie Ocasio.

he came to understand that people with disabilities cared more than other consumers about the job satisfaction of their personal assistants and aides. People with disabilities frequently need longer work hours than, say, the elderly, and they need stable assistance. So they get to know their people very well, and their assistant's or aide's morale is singularly important to them.

### Building A Community

That understanding led, in turn, to an ambition to combine the idea of higher-quality work for home care staff with higher-quality services for people with disabilities. Just as Cooperative Home Care had built a community of workers, he hoped to build a community of people with disabilities who related to home care workers as allies. ICS came out of this ambition.

The organization was initially authorized by the state as a chronic care demonstration program. ICS became one of the state's first managed long-term care plans – that is, an entity that manages the care and supports on a long-term basis for people with chronic conditions who live independently and are eligible for Medicaid. So while CHCA supplied the home care staffing at the higher weekly hours that ICS' physically disabled members tended to require, ICS coordinated their Medicare and Medicaid insurance needs and developed a variety of other services, including unique services not available elsewhere – most importantly, out-of-warranty wheelchair repair.

Power wheelchairs are complex pieces of machinery that periodically require skilled maintenance and repair, but once they are out of warranty Medicaid and Medicare either do not cover that work or pay too little for it to actually get done. The upshot all too often is that wheelchair users wind up immobilized for substantial periods of time.

ICS developed an in-house service which greatly reduced that problem. It also provided coordination and management of different forms of care and services to ensure that consumers' needs were optimized.

As Rick put it, "say you have a member who gets homecare, gets wheelchair maintenance and belongs to the social adult day program – that's three different services right there, and it takes deliberate fo-

cus to make sure that they are all in place; that they work well with each other; and are there for the member in an orderly and effective way."

### Leaders

Marilyn Saviola was involved with ICS from the very beginning. An experienced homecare executive and longtime homecare consumer, Marilyn was also a member of the consumer-oriented Homecare Coalition and, of course, was one of the City's longest-serving and most dedicated activists. Marilyn was immediately interested in ICS' potential, and Rick leaped at the opportunity to hire her. As he put it, "nothing could give ICS more legitimacy than having someone like Marilyn in senior management." She became Vice President for Advocacy.

Anna Fay was working as an administrator of the rehabilitation department of Mt. Sinai Hospital when ICS began operations. She soon became a member of ICS' Board of Directors. Five years later, when ICS tried starting its own consumer directed personal assistance program Anne joined in, that effort and later became an ICS Vice President.

By 2007, ICS had some 3000 members. With offices on the second floor of 257 Park Ave. South (where portions of the DIA Singers' first CD were recorded), ICS had grown into a large and unique combination of provider and insurer.

It would be misleading, though, to infer that all was well. ICS was one of New York State's first managed long-term care companies, but as managed long-term care evolved it quickly became a vehicle for controlling costs. The state's Department of Health increasingly expected managed long-term care plans to provide as few service hours as possible. Most other managed long-term care plans did so, in response to payment plans that were continually reduced.

ICS, with its unique consumer base and its members' specialized needs for 12-and 24-hour-a-day home health services, simply could not conform to that model, yet the pressure to do so continued to grow.

The state's Department of Health almost succeeded in shutting ICS down in 2008. Although that effort was beaten back, the Department's ongoing refusal to pay for 30 percent of members needing high hours of personal care led to chronic deficits and in 2018 the Department declared ICS' managed care plan insolvent and directed it to close. The plan shut down at the end of March 2019.

### Fighting Shutdown

The shutdown did not come without a fight. ICS' physically disabled members formed an advocacy group dubbed "The Civics League." Demonstrations and a petition drive led to meetings with top level Department of Health personnel. As a result, ICS became authorized to reconfigure itself as a Medicaid "Health Home" – that is, an entity that provides care management and coordination, but does not directly authorize services.

In a confusing and awkward structure, to actually obtain services members have to join a separate long-term health plan.

For ICS, the impact of this change was dramatic. Membership fell from 7000 to 3000, and staff went from 400 to 100. ICS retained its downtown Brooklyn offices, where it now shares space with the Brooklyn Center for Independence of the Disabled. It also shares space in the Bronx with CHCA.

As anyone who attended ICS' December 2019 memorial for Marilyn could see, first hand it still has a vibrant community of members and staff, but between its April 2019 transformation and the subsequent COVID pandemic, ICS is still adapting. Today ICS' Pres. and CEO is Regina Martinez-Estela, a long term ICS executive, formerly with Eastern Paralyzed Veterans Association.

At age 73, Rick is semi-retired. He takes considerable pride in his singular creation. "ICS provided a distinctive blend of services and a real community that a lot of members cherished.

Of course, there is a level of romantic aspiration about the fusion of interests between home health staff and consumer, but I think we succeeded in enhancing cooperation and alignment.

That is immensely gratifying. And the spirit of what we tried to do is still there."

More of Warren Shaw's work in disability history can be found at [www.DisabilityHistoryNYC.com](http://www.DisabilityHistoryNYC.com).