# **Changing times, changing attitudes**



By Grace Segran

On my arrival at the headquarters of Independence Care Systems (ICS) on Park Avenue, the first person I encounter is receptionist Marilyn McDowell, in a wheelchair behind the counter. While waiting for my appointment, Marty Sesmer rolls by in his wheelchair to drop off some documents to McDowell.

"About 10 per cent (of 150) of our staff are people with physical disabilities," says Rick Surpin, founder and president of ICS. "It is intentional - as a reflection of our values and beliefs about the ability of people with disabilities to participate fully in community life and our desire to foster quality employment opportunities for them."

After a decade of listening to consumers, many of whom were disabled, discuss their frustrations and experience in the Medicaid system in the US, which provides healthcare to low-income individuals and families, Surpin saw that people with disabilities were treated as though they were 'invisible', just like their carers. They were viewed as having unusual problems that could not be easily addressed, and many of their basic needs were ignored.

"There might as well have been a neon sign at the front of the healthcare system saying 'Adults with physical disabilities are not welcome here -- you take too much of our time and resources and do not count enough for us to do anything different'," he argues.

Adults with physical disabilities generally face severe constraints in terms of available health and social services. ICS, a Medicaid-based organisation, coordinates disability care in New York that allows many New Yorkers with physical disabilities to live independently.

Some 25 years ago, Surpin, then a community development worker, noticed that home healthcare aides were treated as second-class citizens. Most tend to work part-time, earn minimum pay, have no benefits such as sick days or health insurance, and receive only minimum training as required by regulation. He figured that if they were treated better, it would have an impact on the care they provided. So, in 1985, he started Cooperative Home Care Associates (CHCA) in the South Bronx of New York City.

He also felt that it was important that the workers should own the home care provider, making decisions on a one-person, one-vote basis. "CHCA 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 organisational culture must be marked by respect and fairness."

Today, this for-profit cooperative has 1600 employees -- virtually all black and Latina women, and revenues of \$30 million. Wages and benefits are 20 per cent higher than industry average and the turnover rate is 20 per cent, half the industry average. It has several innovative programmes including a guaranteed-hours programme, with incentives to get more women to be employed. It also provides entry-level and in-service training.

Surpin also felt that people with disabilities needed to be treated better so that they can get what they most value in life. And the best guarantee for this to happen is if they were regarded as 'customers.' So in 2000, ICS began operations to move higher on the healthcare 'value chain' by infusing those values into a managed care framework that went against the grain of the prevailing industry -- as CHCA had done 15 years earlier in home care.

"With ICS, it is as though we took the sign down and replaced it with another one that says that adults with disabilities are welcome here. Our challenge is

to continually improve our knowledge, skills and resources so that we enable adults with physical disabilities to feel safe and understood and to flourish, while preventing costly avoidable medical complications," he adds.

ICS was also an attempt to protect and expand the market for CHCA. Ten years on, ICS brings in \$86 million in revenue and has 1,400 consumers on managed long-term home care, 90 per cent of whom are Latino or African-American. ICS and CHCA are affiliated organisations which share board members but have separate balance sheets.

# A new approach

"Unlike the healthcare system, ICS includes care coordination and flexibility, and does not leave the consumer to 'free fall' wherever they may land," says Surpin.

Wilfred, a paraplegic in his late 50s had a pressure sore on his lower back a couple of years ago, which would not heal and became infected.

A stay in hospital transitioned into rehabilitation at a nursing home. Two years later, ICS worked with him to move him out of the nursing home into his own apartment with the appropriate support and services he needed. He says that saved his life by giving him "a sense that there is a future" for him.

Sesmer, whom we met earlier, has a vascular disease, which resulted in his leg being amputated. He is in his 60s and weighs more than 400 pounds. One evening, he had an accident in his wheelchair and was severely injured. After being in hospital for several weeks, he was told he would have to go into a nursing home. He was devastated -- his greatest fear was that he would never get out again and that he would lose his independence.

ICS fought for him to go into acute rehabilitation and in just three weeks, Marty was home and resuming his highly active community life.

### Alignments and a little bit of luck

"It is easy to have a good concept but it is very difficult to make it happen, especially when you are breaking new ground and/or going against the prevailing worldview of the 'right' or 'necessary' way to do something," Surpin told INSEAD Knowledge.

He says they were able to obtain resources and entry into the market "because the ideas resonated with some people, and there was enough dissatisfaction with the service."

"After that, we had to prove ourselves ... We learned what we could do and what we couldn't at each stage of development -- adapted, took our gains and our losses and moved on," he adds. "Persistence was a huge part of how we got here and may be the biggest. We have also been very good at aligning our business strategy with our social goals, and to keep on making adjustments to keep the alignment."

Surpin feels that they entered the market relatively early and there was plenty of space to establish a presence before it consolidated. "Good timing is, I believe, always a mix of luck and good planning (more luck with CHCA, more planning with ICS)."

The reasons for his companies' success are not much different from innovative businesses in general, says Surpin. However, the double bottom line -- financial and social -- adds a level of complexity and limits the amount of available capital and the pool of management talent.

# A long and winding road

Surpin likens the work at CHCA and ICS to "a very long journey involving periods of intense struggle, some victories, some defeats and expanses of time and work in between." Everything is experienced at two levels -- the health and viability of the enterprises and the impact on the larger industry in terms of creating good jobs and providing person-centred care.

"There is no mountain to climb, although (there are) many hills to climb or go around. I have come to liken it to a 'thirty-year war' and I am a grizzled veteran," he muses.

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