

Concepts Of Independence

BY WARREN SHAW

Anyone who has ever experienced difficulty with “activities of daily living” – anything from getting out of bed to getting out the front door, and everything in between – understands the need for personal assistance.

But who is in charge of the assistance rendered, and the assistants who render it? Those are the issues addressed by the consumer-directed homecare movement.

Consumer-directed homecare is perhaps not an immediately familiar concept. But it is uniquely pertinent for many people with disabilities, and can be a primary bulwark against life in a medical institution.

The origins of the consumer-directed homecare movement lie in the mid-1970s, the era of the City’s Fiscal Crisis. An existing City system



Concepts’ Pres. Sandra Schnur and Vice Pres. Ira Holland sitting front row with Client Coordinator Ellen Fried, middle row. Joining them, back row, left to right, are Asst. Dir. Jacob Mathieu, Program Dir. Edward Litcher and Timekeeper Jean Dominique.

had provided homecare through direct payments to home attendants, who were selected by the aid recipient (the “consumer”). According to Edward Litcher, one of the movement’s founders, the City’s program treated home attendants as independent contractors.

This setup came under challenge when the New York State Medicaid Program concluded that the City’s homecare program did not provide for the supervision, training or replacement of home attendants or provide an overall mechanism for ensuring the delivery of quality services.

This determination threatened the loss of Medicaid payments, which the financially strapped City was in no position to absorb. Nor could it handle the increased costs of designating home attendants as municipal employees.

So the City moved to privatize homecare services instead. That is, it planned to offer contracts to several large not-for-profit agencies. They were to manage the City-wide provision of and payroll for home attendants, a plan that became known as “vendorization” after the government’s term “vendor” for firms that furnish goods and services through public/private contracts.

The problem with vendorization was that it put decisions regarding selection and supervision of home attendants entirely in the vendor’s hands. The consumer was reduced to a mere object of care.

That may have been acceptable to people who were very frail or otherwise diminished. But for the so-called “younger disabled,” – that is, people who needed home health care, but wanted to live independently and make their own way in the world – care-object status was a real impediment. Home health care is a very intimate relationship, involving contact up to 24 hours a day between the attendant and the consumer. To have a stranger involuntarily thrust upon you was a slap in the face.

In response, in 1977 a group on Roosevelt Island (largely comprised of former patients at Goldwater Hospital), led by Victoria and Ira Holland, along with Ed Litcher and others, formed a corporation called Concepts of Independence for the Disabled, with the intention of developing a more self-directed alternative to vendorized home health care. Victoria Holland was the first president. But she passed away soon after, and the corporation became essentially inactive.

Until Sandra Schnur got involved.

Schnur was practically the archetype for self-directed homecare. A polio quadriplegic, she needed help with basics like getting dressed.



But she was also among the City’s most determined citizens. Fastidious in her appearance, with a taste for fashion and an enthusiasm for the City’s restaurants, museums and concerts, starting in 1958 she self-published a regularly-updated “Guide to Enjoyment for the Handicapped in New York City” (later renamed “New York With Ease”).

Her brochures included scores, if not hundreds, of points of interest around town, with reviews of the locations’ accessibility – doors, steps, bathrooms and the like. To my knowledge, nothing like it had ever been seen before.

By the mid-Seventies Schnur had completed a stint of employment at the Mayor’s Office for the Handicapped. Known within City government as a capable and reliable figure, she was serving as Director of the Department of Social Services’ half-fare program for people with disabilities when the consumer directed care problem emerged. As a homecare consumer herself, Schnur became a leader in the fight, and helped form a task force comprised of City officials and homecare consumers.

In 1979, the task force voted in favor of a trial program under which consumers themselves would assume responsibility for hiring, training, supervising and discharging their own home attendants. Vendors would only be needed to process payroll and interact with Medicaid and other governmental matters. They would neither screen nor recommend potential employees. Those choices (and risks) would lie with the consumers.

To run the program the Hollands’ inactive corporation was revived, with new officers and a new board of directors, all consumers. Schnur became the new president, and Litcher the first program director. By the end of the first year of operation they had met and exceeded the trial period’s condition of enrolling one hundred consumers.

In 1983, Concepts changed its name to Concepts of Independence, Inc. Changes to the program since that time include 1992 amendments to state regulations that allow consumer-directed personal care assistants to perform high-level health services that would otherwise have to be furnished by registered nurses.

In more recent years, litigation and statutory amendments have



Concepts’ letterhead, with a congratulatory message, taken from the Home Care Council of New York City’s 1990 Annual Awards Dinner Journal.

allowed Concepts to broaden the potential pool of consumers through so-called “surrogates” (trusted friends or family members) to assist with the executive and administrative burdens of self-directed homecare and to expand the pool of potential assistants to include family members.

The burdens of running your own home care service program can be significant. As explained by T.K. Small, formerly director of policy at Concepts, and a longtime home health care consumer, “Managing my care properly is life or death for me. Without home assistants I would need skilled nursing 24/7, if I could afford it, or I’d have to go into an institution. But with them I’ve been able to build and maintain a career as an attorney, as a radio broadcaster and as a political advocate.

“I have someone who’s been with me 21 years; another who does two to three nights a week who has a child and a small business; and another who does one night a week. My team is five or six people altogether. It takes quite a bit of work coordinating and scheduling everything, let alone finding a new person, training them, and deciding whether they’ll work out.”

The program now has nearly 4000 participants. And similar programs have proliferated throughout New York State.

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For more of Warren Shaw’s work in disability history, one may visit www.DisabilityHistoryNYC.com