

Strategies for Coordinating Housing and Assistance

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“Quality is never an accident. It is always the result of intelligent effort. There must be the will to produce a superior thing” . - John Ruskin

Over the past fifty years, people in the United States with disabilities and those working on their behalf have conquered daunting legal, attitudinal, and societal barriers to community living. The recent past has provided compelling examples of people with disabilities living in their own homes, controlling their own lives, and receiving the assistance they need to live as valued members of their communities. Family members, policy makers, individuals with disabilities, and service providers are working hard to listen to people with disabilities, to accompany them on their personal journeys, and to learn how to assist them in their efforts toward a rich and rewarding life. From their experiences it has become evident that, if every person with a disability is to achieve a desirable future, we must begin by assisting people to choose and control their homes and supports.

COMMITMENT TO CHANGE: PRINCIPLES AND STRATEGIES

To accomplish this, communities must embrace and include all of their members, regardless of disability or differences. Individuals who require more assistance than others to fully belong, participate, learn, work, recreate, and have meaningful relationships must be able to rely on their communities, their families, and friends for that assistance, not solely on agencies or service providers. This goal is realistic and attainable if: (a) people with disabilities and their families guide the process; (b) friends, service providers, and others become competent listeners and are willing to let go of old assumptions and habits; and (c) energy and resources are directed at implementing worthwhile goals.

This article defines and describes the fundamental principles and associated practices that are essential if positive change is to occur. First, we will look at seven key principles which state that people with disabilities should be in charge of managing how their personal assistance is provided; relationships with others are a key element for everyone, regardless of disability; public assistance and other funds must be used creatively and effectively; services should be designed for and based on the needs and desires of the person; opportunities for learning can occur in a wide variety of settings; we must maximize all available technology and make it affordable; and that we must build on the capacity of communities to include all members. Secondly, we will see how these principles and practices led to the fulfillment of one man's dream. Lastly, we will examine some practical strategies for moving forward.

People Must Have Control Over Their Personal Assistance

In order to provide the most effective assistance to people with disabilities, we need to ensure that individuals receive and have control over the assistance they need. This includes helping people to design and plan for assistance based on their individual needs and desires; recruit, interview, hire, train, manage, compensate fairly, and schedule the individuals who will assist; and solicit assistance from unpaid individuals in their communities and neighborhoods.

Historically, we have relied on system solutions to concerns and problems. This tactic has left a wealth of potential resources untapped. One key to future success is to request assistance from everyone who is willing and able to help. Often the simplest solutions are overlooked. For example, a stay-at-home mother who lives next door may be quite willing to stop by or call once a day to help a person take medicine or change positions. This type of arrangement has two benefits: first, it eliminates the need for scheduling another paid contact; and second, it creates an opportunity for a relationship to develop between neighbors.

It is not necessary for experts and professionals to determine what people with disabilities need. Those individuals who are closest to the person with a disability are in the best position to help the person achieve a life that is considered desirable. This does not mean that professional assistance is unnecessary; rather, those experts should be called upon for consultation, training, and advice on areas related to living in the community.

Learning is more likely to happen in situations where assistance is based on the person's changing schedule, interests, and needs, not on a program's. Individuals must receive assistance where, when, how, and with whom it is needed. Flexibility must be maintained to increase, decrease, or change the amount and type of assistance a person receives as their needs and desires change.

Personal Relationships Must be Promoted and Supported

People do not need or want to be congregated or segregated based on their disabilities, the availability of funding, or staffing patterns. Friendships must be nurtured based on common interests and mutual fondness; therefore, people must be assisted to spend time in places and to engage in activities that offer the greatest chance for relationships to begin. If a person chooses to share his or her living space, he or she decides with whom to live based on relationship.

If people are to have full, rich lives, experiences that lead to romance, love, and intimacy must occur. The children of present and future generations will have role models for intimate relationships, beginning with their parents, and typical interactions with friends of both genders. These factors give weight to the expectation that people with disabilities will have a future that includes love, marriage, and parenting experiences. As people enter into relationships, become sexually active, or decide to become parents, we have a responsibility to provide the assistance and education that will give people with disabilities the greatest chance of success and happiness.

Resources Must be Flexible

This principle pertains to the flexibility of available funds and other resources. People with disabilities and their families must have access to, and control over, subsidies, benefits, and financing options. This flexibility and control will allow people to purchase and design the services they need from agencies, service providers, or individuals. “Package deals” that force people to live in a certain building in order to receive the assistance they need are not an option; rather, services must be available “a la carte”. This flexibility is not limited to the person’s home, but should also allow people to purchase appropriate assistance in the workplace, the classroom, the community, as parents, and as homeowners.

People with disabilities must have opportunities to raise their standard of living above the poverty level by accumulating cash in savings, earning competitive wages, purchasing homes, obtaining quality education, developing credit histories, investing money, and traveling. By earning money, becoming consumers, contributing to their local economies, and saving and investing money, people with disabilities will gain status and become less vulnerable.

Services Must Meet the Needs of Individuals

The design and delivery of services is a critical factor as we strive to meet the needs of people with disabilities. Living situations that put people at risk of being lonely, isolated, poor, victimized, or without medical and health assistance are unacceptable. Viable solutions cannot be reached by limiting the services that people with disabilities receive. Health care and long-term support must not limit opportunities for people with disabilities; rather, they must ensure that all individuals live in homes that they control and receive the assistance they need, regardless of the type or severity of their disability or medical needs. People with disabilities, their families, and those working on their behalf must remain knowledgeable and actively involved in policy and planning issues that will affect future generations.

If the service system is to continue to play a role in the lives of people with disabilities, it must become an entity that offers an array of effective, useful, and affordable services based on market needs. This can be achieved if small, locally-managed agencies are encouraged and supported to deliver high quality assistance that is tailored to individuals, and if people with disabilities and their families have the power to collaborate with the service system to create policies and influence practices affecting their lives.

Learning Must Occur Naturally

Because adults with disabilities are increasingly included in all aspects of everyday life, there are greater opportunities to learn in typical ways (i.e., in the classroom, from their parents and peers, and from role models). Everyday experiences allow learning to occur naturally: financial planning skills are gained by paying bills, having a bank account, and budgeting; knowledge is obtained and opinions formed through reading, conversing with others, having real-life experiences, taking lessons, and attending classes. Interpersonal skills are developed as people spend time with others in social situations and learning from parents and mentors develops relationships.

Lifelong education and training should focus on gaining skills, building capacity by enhancing talents and gifts, and developing and broadening interests. The focus must remain on discovering what people can and want to do, providing assistance for things people cannot do, and creating opportunities for learning to occur in typical settings. Employment opportunities must be expanded beyond low-paying, unskilled food service and janitorial positions. We must structure public benefits to allow individuals to pursue employment opportunities without fear of losing income for personal assistance and health care.

Assistive Technology must be Available and Affordable

Technology is a valuable form of assistance for people with disabilities. The increasing availability and affordability of power chairs and lifts will make it easier for people with disabilities to move about; computers, automation, and other forms of technology make it possible for many people to communicate, live on their own, maintain jobs, and participate in their communities.

A voice-activated computer can be programmed to dial the phone in case of emergency; a lighted doorbell or telephone can be used by a person who does not hear; a trained dog can open and close doors or retrieve items; a roll-in shower or power lift can make bathing an independent task; and textured floor and wall surfaces can assist a person who does not see to move about more easily in his or her home. The Internet can assist people to locate and research available resources; to gain knowledge and information about a wealth of topics; and to exchange information, using a variety of mediums, with people throughout the world.

Communities Must be Strengthened to Support the Needs of All Citizens

Finally, our focus must shift from the shortcomings of communities or their individual members to recognizing the capacities and gifts of each person and the richness of resources that result when such gifts are considered collectively. The needs of people with disabilities must not be added to the list of items needing money and attention, such as rising crime, increasing drug use, parental apathy, unemployment, a lack of local control, and other modern social problems. When all of a community's people are valued equally for their unique talents and contributions, and supported equally in their struggles, then no single member is viewed as more or less valuable than the next. When the competencies of each person are pooled, they complement and build upon one another to create far greater possibilities than if they stood alone.

BUTCH'S STORY

When we first met Butch Gagnon, he was living in a group home on Ansell Street in Salem, New Hampshire. He had been there for seven years. For six of those years he had been saying he wanted to live somewhere else. It took another 26 months, a number of false starts, and a tenacious team of stalwart supporters, but finally, on April 12, 1996, at age 61, Butch moved into the first home that he had ever been able to call his own.

Butch's story chronicles the early stages of a profound change in the way in which people with disabilities are supported to live in their communities: through control of personal assistance and the development of relationships on many levels. This is not merely a shift or a shuffle, but a true metamorphosis that is taking place in assisting people to have control over their own lives. It is a change that requires the debunking of myths, the reengineering of bureaucracies, and the rethinking of priorities and values. It is a growing movement that can be understood best through the personal experiences of the individuals who are the champions of this change--the people with disabilities and those who assist them.

"I was just about to open a beer, Butch. Would you join me?"
Butch's neighbor

Just One of the Neighbors

After the death of his parents in the late 1950s, Butch was moved into a state hospital at the age of 23. He spent his early and middle-aged adulthood, from his mid-twenties to his early fifties, in hospitals and nursing homes. In 1987 he was the first resident to be moved into the group home on Ansell Street, in Salem, New Hampshire. Butch's first impression was that the group home was a great improvement over his experience in a large institution. But in less than a year, he began to voice his growing dissatisfaction with his living situation. What he wanted was not a "small institution," but a home more like the one he remembered from his youth--a home with a living room, a home of his own.

A support team formed that was composed of Butch, his service coordinator and other representatives of the agency, and individuals from the agencies that provided his residential and vocational assistance. Butch's first planning session was held at the end of January 1994. The team discussed his ideal home, neighborhood, and assistance. They covered everything from the color scheme Butch imagined for his new home, to his desire for a fireplace and a neighborhood with children and low traffic. Because Butch used a wheelchair, he needed an accessible home and a live-in personal care attendant strong enough to lift him.

When asked about any other needs he might have, Butch named three items: new shoes, a motorized wheelchair, and, because of the lack of accessible public transportation in his rural community, a van. These items may not seem directly relevant to a homebuyer's planning process. However, the fact is that for most people, moving into a home of one's own involves much more than simply the right real estate. It requires a system of assistance and resources that ensure a person's safety, health, and comfort.

It took two years of searching for the right combination of things for Butch to make his move out of the group home and into his own home. Separating his finances from those of the other three people who lived at the same group home was not the least of these challenges. Once Butch's budget was separated and clearly delineated, planning and progress were possible. The financial manager for the residential assistance agency informed Butch of the amount of money they currently received on his behalf for his living expenses in the group home. The agency agreed to reallocate those dollars to

Butch for his monthly mortgage payments and personal living expenses. Also during that two-year process, other important progress was made. First, with public funds, Butch was able to acquire both a motorized wheelchair and new orthopedic shoes; second, members of his support team helped Butch to obtain a grant to buy a used van.

Butch and his team discovered many new ways of working together and in concert with other individuals and agencies. One specific example of creative collaboration involved Butch's negotiation with his employment support agency. In exchange for needed repairs and upkeep, Butch granted the agency use of his van on a temporary basis. This arrangement essentially expanded their motorpool at minimal cost. The agency was able to use the van to transport Butch and others to and from work and on job searches until Butch moved into his home and needed the van for himself.

This win-win exchange is typical of the new type of collaboration that people around the world are discovering is an essential element of their success in finding homes of their own. They are redefining the relationship that traditionally existed between an agency and the individuals it served. People are coming together as individuals with a common goal of helping one of them to find and settle into a home of their own choosing. Such collaboration results in a new urgency and a new enthusiasm for creative allocation of resources, and a renewed sense of purpose that benefits all.

A big challenge for Butch, exacerbated by the length of time it took to find the right house, was finding someone to share that house with him. "Julie's little, but she's mighty," Butch smiles when he refers to the young woman who, with her three-year-old daughter, shares his home. "She used to work at the group home, so she knows me. That's important. When she heard I was looking for a new home and a housemate to be my personal care assistant, she said 'What about me?' Once we decided to go for it, she really took the bull by the horns."

With Butch's permission, Julie spent weekends and evenings scouring the neighborhoods in search of FOR SALE signs, following up on promising leads in the newspaper classifieds, and checking out referrals from friends and acquaintances. She would call Butch and tell him about a place, and he would instruct the van driver to cruise past the address for a drive-by assessment on their way home from Butch's job at a local retail store. If the house looked like a possibility, Butch would ask Julie or George, his service coordinator, to make an appointment and arrange for a ramp to be set up, if necessary, so he could look around inside. Butch finally found a small home which met his budget needs and his definition of an ideal neighborhood. An additional benefit was the minimal amount of renovation that would be necessary in order to meet his accessibility needs.

Within the first few weeks of moving into their new home, Butch and Julie had met their three closest neighbors. One man just down the street had done some of the renovation work and his wife invited them over to pick some flowers from her garden to brighten their living room.

"When we got there," Julie says with a smile in her voice, "her husband invited Butch onto the porch to show him around. He said, 'I was just going to open a beer, Butch. Would you like to join me?' Butch's smile lit up the whole neighborhood. For the first

time in his life, a neighbor invited him over for a beer. That never happened in the group home. Finally, he is what he always wanted to be -- just a regular neighbor." An effective change in the way we approach community living requires that we dramatically change our approach to personal assistance and the management of related resources. For the first time in his life, Butch chose the person who would help him with his basic and personal needs, such as getting in and out of bed and getting dressed. He also chose Julie as his housemate.

As Butch's story illustrates, an effective change in the way we approach community living requires that we dramatically change our approach to personal assistance and the management of related resources. Some specific strategies that may be useful in facilitating changes include:

Begin With a Pilot Program

This approach offers policymakers and service providers an opportunity to test the program on a limited basis, for a defined number of people, and under "safe" conditions. A pilot program may be appealing due to the short-term nature of the commitment. Once community living has been demonstrated successfully, formerly reluctant stakeholders may be more amenable to commit their resources on a long-term basis.

Involve Key Partners from the Beginning

People with disabilities and their families, independent living centers, community development organizations, disabilities rights organizations /advocates, people first organizations, and service agencies must be included.

Develop Personal Relationships with Individuals

Nurture relationships with policy-making and service organizations or institutions. Such relationships offer both parties an opportunity to learn about common interests, visions, and goals, and facilitate collaboration.

Involve Everyone

Ensure that people have a vested interest in the success of the program by giving them "a piece of the pie." For example, invite all agency heads to serve on the program's steering committee and meet quarterly over lunch. Through the composition of the committee and decision-making authority of the group, assure that there is a compelling reason to attend.

Build Incentives

Learn what motivates people and build these incentives into the collaborative process (e.g., positive publicity for the agency/organization).

Butch's story is a good illustration of the multiple layers and connections, affiliations and partnerships, collaborations and negotiations that are involved in the process of

individuals obtaining control over their homes and assistance. This successful venture requires the collaboration of state, federal, and local agencies; the alliance of private and public entities; and the partnership of individuals, their personal assistants, bureaucrats, service providers, family, and friends. On both an institutional level and a personal level, champions of change emerge. These champions are individuals with and without disabilities who are willing to take a risk and agencies that are willing to bend the rules. Everyone is willing to do whatever it takes to support person-controlled assistance and to insure true community living. They are willing to try something new and different, to defy the obstacles, and to succeed.

Afternote: This article is dedicated to Butch Gagnon who, on April 12, 1996, moved into a home he owned after 38 years of living in a variety of institutions, nursing homes, and group homes. On June 21, 1997 Butch had a massive heart attack from which he never recovered. Butch's vision of living in his community and his life will hopefully inspire many more individuals to reach their dreams.

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