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The True Costs and Benefits of Self-Directed Care

Living with Independence, Freedom, and Equality (LIFE) Account Feasibility Study & Implementation Plan

By: Kathleen Bates

This article explores the benefits and challenges associated with self directed services and how LIFE Accounts would complement social participation opportunities for persons with disabilities.

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**Prepared for the Living with Independence, Freedom, and Equality (LIFE)
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The American Dream is “*that dream of a land in which life should be better and richer and fuller for everyone, with opportunity for each according to ability or achievement.*”

-James Truslow Adams

I know James Truslow Adams was not talking about me, or the other 20% of the population in the United States who have disabilities, when he first wrote this statement in his book, *Epic of America*, in 1931. Back then, people who had disabilities were condemned to a life of misery and isolation, forced to live in institutions apart from the community.

With legislation and policy changes such as the Americans with Disabilities Act, the Olmstead Act and President Bush’s New Freedom Initiative, community-based supports and the Independent Living philosophy have come to the forefront and made the American Dream possible for all citizens. The door of opportunity has been opened, but as a society we have to be willing to value all human potential, especially for people who live with disabilities. The issue of community supports should be important to everyone because disability does not discriminate; it is a part of every society and every culture. Any one of us could sustain a disability at any point in our lives.

My dreams are very ordinary. I want a life that includes a job that makes me happy, owning my own home, and having family and friends to share with. I want to have enough money to pay my bills, take a real vacation once in a while, and to be able to retire and still live comfortably. Most importantly, I want to be able to choose my own path. This can be difficult for anyone but it’s especially challenging when you have to rely on the assistance of Personal Care Workers for your most basic needs, such as getting out of bed, showering and dressing.

Despite my disability, I do not believe in the concept of independent living. More accurately, I believe in “interdependent living.” Each one of us depends on someone else to succeed. It takes a lot of support to live successfully in the community. Support comes in many forms. Natural support is the neighbor who gets your mail or the brother who plows your driveway in the winter. Agency-driven support is the nurse from the home-health care agency who checks in on you and takes your blood pressure. Consumer-directed support allows the individual to interview and hire his/her own Personal Care Workers. For many people, one kind of support is not adequate. Some individuals may require a combination of services. Currently I don’t know of any formal backup systems in place, so it is up to the individual to develop his/her own backup plan when other support systems fail.

This article explores the challenges people who have disabilities experience when managing their personal care programs. It also examines the positive aspects of choosing self-directed care.

Long-term care options

When we think of long-term personal care options, we should imagine a spectrum. At one end of the spectrum is institutional care, such as a nursing home. An individual's personal care might be guaranteed, but when and how it is given is not really up to the individual. At the other end of the spectrum is a fully consumer-directed program. In such a program, a person is completely in charge of their care. In between are several other programs, all having similarities to each other, with varying degrees of consumer choice and control. The philosophy behind consumer-directed personal care is that the person who experiences the disability is the expert about that disability and his or her own life and unique needs, therefore making them the most qualified to manage their own personal care programs.

The Personal Care Attendant (PCA) program is run solely by Granite State Independent Living center. In order to access this program, an individual must be eligible for New Hampshire Medicaid. A person must have a severe physical disability, including requiring the use of a wheelchair for mobility. He or she must need at least two hours of hands-on personal care a day. This includes activities such as showering, dressing, using the bathroom, or range of motion exercises. Participants must be at least 18 years of age and their own legal guardians, and be able to self-direct their own care.

Individuals can become eligible for consumer-directed personal care services through the home and community-based care waiver (HCBC). This waiver allows individuals to remain in the community rather than in an institutional setting. The Personal Care Service program (PCSP) is very similar to the PCA program, except services can also be provided in the community and not just in the home. For example, a PCSP worker can drive an individual to work or take them grocery shopping. If a person is not able to self-direct their own care they may have an authorized personal care service representative who assists them in directing their care. Several agencies around the state have been certified to provide PCSP services. Services can also be provided to children. In this case, the parents are hiring PCSP workers for their children with disabilities. Children who are eligible for the Developmental Disabilities waiver may obtain PCSP services.

Agency-directed care is similar to consumer-directed care with some key differences. For admission into either an agency-directed or consumer-directed program, a medical assessment must be done by a nurse. As part of this assessment a list of services needed and the length of time to accomplish them is established as part of a service plan. In both agency-directed care and consumer-directed care, a 60-day check-in is required, and a report is written and sent to the individual's doctor to certify the need for personal care supports. With traditional home health care services, the home health aides must be licensed nursing assistants. This is not true for agency or consumer-directed care, which might increase the hiring pool. With agency-directed care, the individual does not get to hire the person who comes to his or her home and oftentimes does not get to meet them before personal care services are provided. Not everyone wants to manage their own personal care programs because it can be very stressful and a lot of

responsibility. Those individuals who do choose consumer-directed care do so because they want choice and control over who will come into their home and provide services.

I use four different types of personal care services. I am a co-employer with Granite State Independent Living Center. I use both the PCA and PCSP programs. I place ads in the paper, interview, and hire my personal care workers. GSIL handles all of the legalities for my employees such as worker's compensation, background checks, and tax information. I use Smart Care, another PCSP program which is also a consumer-directed program. I get to choose who works for me and I participate in the development of my care plan. Initially the applicants have already been hired and interviewed. It is difficult to hire personal care workers for my afternoon needs because I don't need them for very long. I receive assistance from a traditional home health care agency in the afternoon to help me with lunch and using the bathroom. I would not advocate for one service over the other. I think it is wonderful that I have so many personal care options available to me, and I need them all to live successfully in the community. Even with all of these options, I still at times need to call on my friends and family for backup.

Daniel has to get to work

It's 6:00 am and Daniel's personal care attendant has just called in. She says her car has broken down on the highway and she won't be able to come in and help him with his morning routine. When Daniel, who has a spinal cord injury, does not have the help he needs to get out of bed, "It throws a whole monkey wrench into it," he says.

Daniel continues, "For health reasons, this can cause some serious problems. If I don't get out of bed, that can cause respiratory problems. If I don't get moved, that can cause pressure problems with my skin. And I miss work, so it affects my income. It throws off basically the whole day. It could throw off the whole week."

There have been occasions when Daniel has had to enlist the help of friends or family members to assist him with his personal care needs. He has a good backup system but it can stress a relationship. "That affects someone else's life and that can cause a whole host of other problems."

Daniel feels one of the biggest challenges to managing his personal care program is recruiting, because the pay is very low and there are no benefits. He competes with other low-paying employers like Wal-Mart, where there isn't so much responsibility. A Personal Care job is also a stepping stone to other jobs in the medical field. For example, a nursing student might work as a personal care attendant while in school, but would likely move on to a higher paying position after graduation.

Daniel spends about five to ten hours a week doing timesheets, recruiting and payroll. He feels that self-directed care is a great option for people since it offers greater flexibility and can be combined with agency-driven care or used independently.

Since traditional home health care does not offer the same flexibility as self-directed care, Daniel relies on agency care only on the days he is not working. He uses attendant care at work for assistance with lunch, using the bathroom and administrative assistance throughout the day. “This allows me to function and hold down a job – just like everyone else. When the system works, it works very well.”

Priscilla’s Rent is Going Up

Priscilla is 92 years young. She lives in an assisted living community. Her apartment is decorated with beautiful paintings and sculptures that *she* created. The rent is going up and she is worried she will have to move to a facility that accepts Medicaid. With a little smile and a gleam in her eye, Priscilla emphatically states, “I hope I run out of me before I run out of money.”

Last fall Priscilla became gravely ill. Her doctor suggested that hospice come in and help her with her care. Priscilla says, “My workers were so nice, but I improved instead of dying, so they decided to graduate me.” Hospice care was discontinued, but Priscilla had grown accustomed to the extra help and companionship. A friend told her about Emily, a woman who could help her out. The two met and really liked each other. Emily began working for Priscilla. “She is a good companion, she’s a good worker,” Priscilla says. “I consider her my friend.” Priscilla decides how she spends her days, and because she can afford to employ Emily with her own money, she enjoys many freedoms that her neighbors do not. “She takes me in her car to my doctor’s appointments or to my dental appointments,” Priscilla says. “Sometimes we go to an art show or do something else I really want to do. She liberates me.”

Annie wants to be more involved with her community

Annie is 43 years old. She is very friendly and loves to interact with her neighbors when she is out doing her errands. She has a degree in Behavioral Science and was employed for a short time as a Peer Facilitator. She has had a few opportunities to volunteer for organizations that focus solely on disability issues. Annie really wants to be more involved with her hometown community’s Main Street program. Annie says with a bit of frustration in her voice, “I know it is hard for people with disabilities to get jobs but I am just as concerned with making a commitment I can’t keep, if my personal care attendant can’t get me out of bed.”

Self-directed care is important to Annie because it allows her to have a say in who works for her and who does not. She wants the people who work for her to understand that she relies on them to accomplish her goals. “My goals are pretty simple: to be a productive citizen in my community whether I get paid or not. I would love to get paid like any other person, but sometimes I have to prove to people I am smart and able to work with people.”

There are many reasons why employment is a tough issue for people who have disabilities. One of the main reasons is that people are afraid that they will let potential employers down if they are unable to get to work. It is not at all like calling in sick, because you're not. You just cannot get out of bed. It's frustrating. In Annie's case, paid employment is not the issue. She wants a fulfilling life doing something that is meaningful to her. Working or volunteering in the city she has lived in for 42 years would be important to her, but it is impossible without reliable personal care. "Knowing I have reliable PCA's is a win-win situation," Annie says. "If I am happy with the work they do, they in turn are happy also. They help me to be able to go out in my community and show the outside world that I am just as important like any other member of society."

Life Is Complicated

Mary, a mother of eleven-year-old triplets, isn't sleeping well. She's lying in bed, listening for Amy. If Amy rolls over, she may get her head stuck between the mattress and the wall. Without her body jacket, Amy has no neck control and rolling over like this could be life-threatening. Amy is non-verbal but she can make enough noise to let Mary know she needs her. Then Mary will go in and re-position her. Afterward, she settles back into bed. A while later, Mary's son Jacob, who is also disabled, crawls into the room. Mary gets up again to help him to the bathroom. Any other sleep she gets will be brief and restless.

Mary's children are typical in all the ways that matter. They each have their own friends and their interests vary. Amy loves books, plays and musicals. Jacob likes action movies. Alice loves hip-hop music and dancing.

Five days a week, an LNA comes in to help Amy and Jacob get ready for school. Both children have Cerebral Palsy and use power wheelchairs to get around. Both need body jackets for support and correction of scoliosis. Amy uses a feeding tube because she has difficulty swallowing. Jacob can feed himself, but uses a feeding tube when he is ill. Neither child can dress or groom themselves independently. Each child has to take numerous medications. Mary does not have enough nursing support so she must prepare them herself. On Thursday and Friday mornings, Mary has no support at all, and she "gets nothing else done. I am there totally as a caregiver. I'm not really even a Mom." Mary also has to make sure that her third child, Alice, who has ADHD, is up and ready for school.

Hiring support staff for the children is another challenge. Mary relies on a healthcare staffing agency to place ads in local newspapers and take care of all the other requirements for employment such as worker's compensation and background checks. Ultimately, she is responsible for all the interviewing, hiring and managing of Amy and Jacob's caregivers. She spends about six hours a week scheduling and communicating with support staff. "I want them to really be there and look at us as a family." If Jacob says he needs to use the bathroom then they need to be able to get Amy settled and take

Jacob to the bathroom. “We are on number forty-two for staff; my husband just numbers them now. We’ve gone through about thirty others that just couldn’t handle it.”

Raising three children is expensive by anyone’s standards, but there are a lot of additional expenses when those children require special care. When Mary and her husband attend a family support conference for the weekend, they have to use some of their own money in combination with respite and agency funds. “I don’t know anyone who doesn’t spend some of their own money,” she says. “People who are qualified cost more money.”

Some costs are not so obvious. When her children were in the second grade, Mary tried to enroll them into religious education classes so that they could make their first communion. Three different churches refused to allow Amy and Jacob to participate in the classes because of their disabilities. Mary was devastated, but eventually found a church that welcomed them with open arms. The children made their first communion. In fact, a special needs class was created to accommodate several other kids who attend the church. “Father Bob really put his neck on the line for us,” Mary says. “He was told by the Bishop that he could lose his job if he did this. He did it anyway.”

Mary was stressed out, not sleeping and felt it was impossible to be a good employee. “I was diagnosed with Post-Traumatic Stress Disorder five years ago. I was withdrawn,” Mary says. “I was still functioning and getting my kids out the door, but I didn’t want to do anything else beyond that.” Mary is on medication and is doing much better. She is now self-employed as a special education advocate.

Despite the numerous challenges involved in organizing Amy and Jacob’s care, Mary will continue to manage their care until they can do it themselves. “The more visible my kids are, the more accepted they will be,” she says. “We want to be recognized as a family first, not as the family with the disabled kids. That’s only part of who we are, but that’s not all that we are.”

“They Work for Me Because They Like Me.”

Lucy is self-employed. She is a teacher and an advocate. She leads an active life despite needing a wheelchair to get around. “The hardest part about living on your own,” she says, “is hiring personal care attendants.”

Last year Lucy spent \$340 on ads she put in the paper for personal care attendants. “Sometimes no one answers ads for weeks and you have to hire the first person who comes to the door even if your gut tells you that it is not going to work out,” she says.

Lucy offers an example of things not working out: “My care attendant failed to show up for her evening shift. I had to go to my neighbor, who was a complete stranger at that point, and ask for help. I had not been able to go to the bathroom for 12 hours and I would not have been able to go to bed. I was lucky enough that she had some experience

in personal care assistance and was able to help me. This was not the only time that something like this has happened to me.”

Two weeks later, Lucy offered her neighbor a job, and her neighbor accepted. That could only happen because Lucy self-directs her own care and can choose who she hires. This is not possible with agency care. Lucy says, “Self-direction is really hard sometimes, but on the other hand I have met some incredible people that ended up working for me because they like me, not because an agency told them they had to work for me.”

What Should be Done?

During the course of these interviews several themes emerged. Inevitably, if you have a disability, you naturally lose some freedom and choice. For this reason, self-directed care gives you back some of that choice. Managing your own personal care is sometimes very difficult and complicated, but individuals want to do it. Even though people choose to self-direct their care, the system is not foolproof, and sometimes it fails.

“Community-based care is a great option,” Daniel says, “I think the state should look hard at investing in the (Medicaid) infrastructure because it’s a cost effective way to provide services. It’s just another option for folks – gives people more choice.” Generally, community-based supports are less costly than institutional care. At the heart of quality community supports is people. People who, in many cases, are not paid a livable wage or given health care benefits. Part of investing in community-based care is investing in the workforce. Higher wages, training and benefits would make being a direct support worker a respected profession and a viable career choice. We currently have a system in which those who provide direct support to individuals with disabilities may also need public assistance. For example, 30 to 35 percent of all nursing home and home health aides who are single parents receive food stamps.¹

Full participation in the community is everyone’s right. We must continue to bring the issues of community-based supports and self-direction to the forefront. One of the best ways to do this is to advocate for ourselves and our families by educating our representatives. Mary says, “I had a legislative coffee. My representatives have met the kids. I discussed with them the fact that I am *expected* to be a caregiver because my children have disabilities. This is something I can’t get paid for. The way the system is set up now my children will never leave.” She has also written many letters and testified at legislative hearings about the lack of nursing care in the state. Mary would like her children to be able to live as independently or interdependently as possible like other young adults who leave home. With the right supports she feels they can succeed.

The lack of adequate back-up support was an issue that came up frequently in the interviews. Lucy says, “New Hampshire needs a statewide back-up system for direct

¹ William J. Scanlon, *GAO Testimony: Nursing workforce: Recruitment and retention of nurses and nurse aides is a growing concern* (Washington, DC: General Accounting Office, May 2001).

supports, some place that people who have disabilities can call if their support worker fails to show up. It would be a dream come true to have all the organizations that provide direct support come to the table to figure out this vital issue. We need to create a system where you could call a toll free number and talk with a real person who could help you connect with someone in your community who would provide direct support when it is needed. A provider network that is similar to New Hampshire's transportation collaborative could be the solution. It would be good for everyone; workers could get more hours and people with disabilities would get their needs met."

With advances in medicine and technology, people are living longer, thus needing supports and services longer. As we move away from the medical model and the inevitable nursing home placement of older adults and individuals with disabilities, quality in-home supports and services will become more important for everyone. All people deserve quality lifespan care regardless of their income.

How can LIFE Accounts Help?

Living with Independence, Freedom and Equality (LIFE) Savings Account Program was proposed in 2004 by President George W. Bush as part of his New Freedom Initiative. In support of this idea, the Centers for Medicare and Medicaid Services, or CMS, put out a request for proposals to the states to develop LIFE Account models. New Hampshire and Wisconsin were awarded three-year grants to develop LIFE Account feasibility plans. In such a program, an individual with a disability would be allowed to build financial resources and keep them in a savings account. In order to be eligible for a LIFE Account program, individuals must live in the community and self-direct their own personal care program. The final requirement would be that an individual would have to manage their own Medicaid service budget, and have the ability to make decisions about how the money is spent. The money saved in a LIFE Account would not exclude any one from other programs in the future such as, Medicaid or Supplemental Security Income. If any money is saved at the end of the year, one-half would be placed in the participant's LIFE Account, and the other half would go back to the state. An example of how savings could be generated would be if an individual had a neighbor who volunteered to provide rides to work, and in the past the individual had been paying someone to provide that service.

The catch is, right now in New Hampshire, only some people with disabilities have the authorization to oversee their own service budgets. For example, children and adults with developmental disabilities have the option to participate in Consolidated Services provisions. This allows adults with developmental disabilities, and parents and legal guards who support their minor children to oversee individual service budgets, and make purchasing and staffing decisions in accordance with Individual Service Plans. In this case, there is a dollar value attached and it may be possible for an individual or family to realize savings based on the spending decisions that are made.

However, other people with disabilities, including people who qualify for the Elderly and Chronically Ill Waiver and state-only Medicaid for Personal Assistance Services, are only able to make staffing decisions based on the number of hours they are eligible to receive by Department of Health and Human Services. In this case, there is no service budget, per se, only a time budget – the number of hours that people can either have performed by a home health agency, or to hire staff using the personal assistance service option. Therefore, time may be realized, but no dollars would be realized in savings based on how the program is currently structured.

In other states, however, programs exist that do allow people with disabilities to manage their own Medicaid service budgets. One such program that has worked successfully in several other states is “Cash and Counseling.” This approach allows participants a flexible monthly allowance they can use to make choices about the kind of services they need. Financial counseling and money management are also an integral part of this innovative program (need citation). The LIFE Account program goes one step further by allowing individuals to not only manage their service budget, but also to keep half of any of unspent resources for items or services needed to improve their wellbeing and social participation.²

When someone saves money, they usually do so with a purpose. There has to be some incentive to save. People who are disabled and receive Medicaid are often the poorest in society and very often have difficulty meeting their basic needs (She, P. & Livermore, G., 2006). In many cases, people with disabilities live on such a low income that they are already experts in saving money.

By the year 2030, a full 20 percent of the U.S. population will be over 65. An aging population means shrinking service dollars. Agencies and organizations are already competing for fewer resources. A greater number of people will need services, which will be more expensive. The need to save money will become increasingly important.

It cost money to fully participate in the community; to secure flexible, accessible transportation, or pay for items that would significantly enhance participation, but that are not covered by the traditional Medicaid program. Extra money that is saved in a LIFE Account could give an individual more choice and freedom, and begin to improve the quality of life for people with disabilities. Currently, people are afraid to increase resources from earned income for fear of losing their benefits.

Saving money is hard work. The money that is saved in a LIFE Account belongs to the person that saved it. In order to save money, an individual will have to either go without a service or find a less expensive way to obtain it. The current thinking is that the money saved should be spent on something that would increase independence in the community. If we are really talking about *living with independence, freedom and equality*, then perhaps there should not be any restrictions on how assets can be used.

² According to the Centers for Medicare and Medicaid Services (CMS), one of the uses of the LIFE Account as conceived by the department is to “replace the need for human assistance”.

Some of the individuals interviewed for this project had very interesting ideas on how they might use the money saved in their LIFE Accounts to improve the quality of their lives. “A LIFE Account would help tremendously,” Mary says, “The money could be used for things that are not readily available to my children now; such as computers, a track system for transfers, or a little extra money for fun.” When Annie was asked how she would spend extra money that she had saved in a LIFE Account, she had a very difficult time answering. She said, “I have no idea because I never have extra money.” After thinking about it for awhile, she added, “It would be really great to save for a van because I get tired of waiting for the bus all the time.” When Lucy was asked the same question, she replied “I would use the extra money to cover the cost of having my Personal Care Assistant accompany me to advocacy conferences.” These are just a few examples of how LIFE Accounts could help people with disabilities accomplish their goals.

Conclusion

People with disabilities are the experts about their own lives. For this reason, we are the most qualified to choose what kind of services we need and who will provide them. Self-directed personal care programs, the ability to manage service budgets and LIFE Accounts are all programs that give us more choice and control. The idea is that these programs will increase access to the community and improve the quality of life for people who have disabilities. In order to make this work, we need to invest in the work force. While some people are simply not suited for personal care work, many others would not even consider it because of the low pay and the lack of benefits. Our communities are stronger when everyone is involved. Some people just need more support than others to be involved. Community is each of us helping each other in our individual quests to succeed.

President Clinton said it best in his speech to UNH graduates of 2007, he spoke about the power of the African concept of *ubuntu*, or “I am because you are”. It means, he said, “We do not exist alone; therefore for us to ignore one another’s problems is a travesty.” He also noted the practice among people in the central African highlands who, when greeted, respond, simply, “I see you.” “All problems can be solved if we just see each other,” he said. “There is nothing beyond the reach of our common endeavor. All we have to do is remember it is our *common* endeavor.”