

ILRU Exchange

Community Living Briefs

A publication of the Community Living Exchange Collaborative at ILRU.

“Community Living Briefs” is a resource for Real Choice Systems Change Grants for Community Living grantees and their stakeholders, which provides practical tools and strategies to facilitate the full integration of people with disabilities into the mainstream community.

Beyond Incremental Change—the Challenge of Inclusion

by Lee Bezanson

“Today, there are over 54 million Americans with disabilities, a full 20 percent of the U.S. population. Almost half of these citizens have a severe disability, affecting their ability to see, hear, walk, or perform other basic functions of life. In addition, there are over 25 million family caregivers and millions more who provide aid and assistance to people with disabilities.”

New Freedom Initiative, Executive Summary.

From Medical Model to Civil Rights

The states, territories and the District of Columbia are engaged in efforts to provide new and enhanced community living opportunities to citizens of all ages who experience disabilities and chronic illnesses. Real Choice Systems Change Grants for Community Living are enabling states to make changes to their social service programs to achieve these enhanced community living opportunities. Efforts focus on eliminating the institutional bias inherent in publicly funded programs and creating community-



based options with increased control residing in the citizens that are using services. These efforts are beginning to bear fruit by moving citizens from institutional settings to the community and by offering them broader community-based choices of both services and providers. However, these efforts all focus on the social service world and particularly the social service worlds of Medicaid and

programs administered by the Social Security Administration (SSA). This narrow focus limits results to incremental changes in social programs. While these changes are positive they represent only the first steps of the long journey to equality and inclusion for all citizens. This paper speaks to the imperative of that larger journey.

The Early Years

Medicaid was born in 1965 well before Ed Roberts and his peers at Berkeley formed the Rolling Quads and started the independent living movement. At the time of Medicaid's birth, it was generally believed that institutional care was the best alternative for people with significant disabilities. Society regarded disability as a medical problem that needed to be fixed.ⁱ As Mary Johnson notes in her book, *Make Them Go Away*, attitudes about disability reach deep into personal prejudices and national values.ⁱⁱ The very notion of inclusive and accessible communities had not yet emerged. Yet in spite of this dismal cultural environment the Medicaid crafters showed remarkable foresight. The enabling statute authorized states to furnish to families and individuals with disabilities “rehabilitation and other services to help such families and individuals attain or retain capability for independence of self-care.” [emphasis added]ⁱⁱⁱ States, perhaps reflecting the larger cultural landscape, ignored this language and initially built Medicaid programs that viewed the world through a medical lens, strengthened institutional bias and drew upon health care professionals as the only acceptable deliverer of long term supports. The resulting system-administered program models were predictably unsatisfactory to those who used

the services. Medical insurances would pay for a rehabilitation counselor to teach someone with quadriplegia to dress herself, an activity that could encompass four hours each day. She, however, prefers to have a personal care attendant for one hour so that she can get going and head off to her job in her adapted van. Medical insurance didn't cover that—it was neither rehabilitation nor medical.

The earliest models for Medicaid programs for long-term supports for citizens with disabilities and chronic illnesses evinced bureaucratic control and medicalization. For the most part in the early years state Medicaid programs ignored the statutory mandate to promote independence of self-care. The Medicaid agency, with direction from the federal government, created the menu of services, defined disability as a medical issue, created all



the rules of the game and expended its resources to pay medical providers of services whether they were institutions (MR/DD facilities and nursing facilities) or community-based agencies (primarily home health agencies).^{iv} Those in control of the institutions and the community-based services were deeply entrenched in their own cultures of self-interest. Rarely, if ever, did the Medicaid agency involve the users of services or even the providers in the design, implementation or evaluation of its programs. Rather, the user of services served as the means through which the dollars passed from government to the providers. One Connecticut individual commented, "... I feel like a conduit through which the government is using me to pass dollars to the social service providers."^v These providers collectively constituted the social services network and came to feel entitled to their Medicaid revenues; Medicaid staffers came to call this provider-entitlement. If an individual wanted services he had to fit himself into the mold created by this network and Medicaid regardless of what his needs and preferences were.

This translated into several unwelcome results. Citizens had to eschew full time work to maintain the low-income eligibility requirements of Medicaid and they had to accept the services and providers recognized by Medicaid, the vast majority of which were medical in nature. A senior who wanted a daily shower at 6 A.M., a life-long habit, might have to settle for a twice-weekly afternoon bathing arrangement because that was when the approved provider agency had staff available.

Frequently, before the states built community-based infrastructures, the only provider that offered sufficient services

was an institution so the system effectively coerced citizens that needed significant services to live in institutions. While the social service network was a part of the larger community, it functioned as a discrete enterprise and not as an integral part of the whole.

Users were pretty much on their own when it came to participating in mainstream community life. This was true for all citizens but it was exacerbated for citizens with disabilities who faced both physical and attitudinal community barriers to participation. One New England citizen set out to do some Christmas shopping for his wife. When he tried to pull into the single "handicap" parking space in his town, he discovered that the plowmen had piled all the snow there. Sometime later he tracked them down and asked why they had put the snow in the "handicap" spot. Their reply, "We didn't think you people came out in this weather."^{vi}

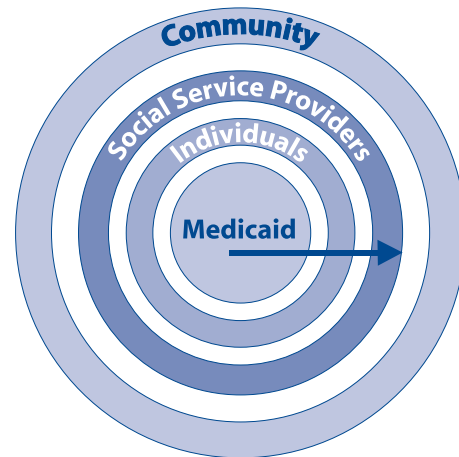


Figure 1

Figure 1 represents this early model graphically. The four concentric circles show Medicaid (government) in the middle directing the show, the second circle is the users of services, the third is the provider network and the fourth is the broader community. The arrow runs from the Center outward only to the edge of the provider network circle; the broader community is excluded. Note too the separation between the circles, depicted here by white to reflect how little collaboration was happening among the various stakeholders.

Over time, as the larger society began to change in response to the disability rights movement(s), Medicaid began to adapt some of its programs to accommodate the expressed desires of the citizens and families being served by the programs. Beginning in 1981, states were permitted to develop home and community-based waiver programs that

supported citizens with services in their homes and communities. The early waiver programs maintained a medical model approach but gradually states expanded the array of services offered and provided more individualized options. Nonetheless states continued to expend the majority of their long-term care Medicaid dollars on institutions rather than on community-based options^{vii} despite the fact that the overwhelming majority of citizens and families that use long-term supports prefer home and community-based options and deplore institutions.^{viii}

While the states were expanding home and community-based options during the 1980s, advocates were moving for a strong federal legislative agenda. These efforts culminated in the passage of the Americans with Disabilities Act of 1990 (ADA). While the ADA led to many positive changes it had little impact on Medicaid. To the extent states continued to expand home and community-based programs their motivation was based on the demands of citizens and families and on the fiscal reality that home and community-based programs were generally more cost effective than institutional programs. That civil rights were at stake rarely entered into the discussion.

In 1999 the Supreme Court issued the Olmstead decision which ruled that unnecessary institutionalization of citizens with disabilities who could live in the community was discrimination under the ADA.^{ix} Advocates renewed their efforts to end institutionalization by staging a series of demonstrations.

Also in 1999 Congress passed the Ticket to Work and Work Incentives Improvement Act (TWWIIA) with little debate. TWWIIA was designed to strengthen work incentives for citizens with disabilities. Under TWWIIA citizens with disabilities could return to work without losing access to critical services like health insurance and long-term supports. With the passage of TWWIIA, Congress established the Medicaid Infrastructure Grant Program to effect systemic change in programs to enable citizens with disabilities to work.



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Medicaid (CMS) Services to offer grants to states to effect permanent and sustainable changes to their programs in support of citizens with disabilities and chronic illnesses. These funds were in addition to the funds made available under Medicaid Infrastructure Grants. The combined stimulus of these two funding efforts set the states into renewed activities to overhaul their long-term care/supports systems and to support citizens with disabilities and chronic illnesses to return to or remain in work.

Under these grants, both Systems Change Grants for Community Living and Medicaid Infrastructure Grants, many states are changing their program models as well as their old approaches to design, implementation and evaluation. In the current iteration the model (at its best) creates collaboration between the Medicaid agency and the users of services.



Program design, implementation and evaluation flow from the collaboration. The resulting programs increasingly empower individual users to make choices about the services they need, when the services are needed, where the services will be provided and by whom. In these models citizens live in the community and as they require services they reach into the social services network to access services.

Increasingly states are adopting a consumer-direction or self-determination approach that puts citizens and families in the driver’s seat instead of providers. *Independence Plus* waivers and the Cash and Counseling demonstrations have been the more popular of these models. Citizens remain in their homes and reach into Medicaid as their need for supports arises. The social service network providers are still available as a choice to users of services but these users have additional options of their own choosing; many choose to train family and friends as their personal assistants. In the Arkansas Cash and Counseling Demonstration one participant put it this way: “I am quadriplegic and when you are in a situation like this, you need someone that you can trust to be there, you know, someone that isn’t going to be talking your business all out in public...”^x While these new program models yield high satisfaction ratings from those who participate in them, the programs continue to be separate from the larger communities in which people live. The focus continues to be on the programs themselves as if they exist in isolation from everything else around them. The discussion is still about the social service system rather than the community at large.

A New Systems View

Whether the national climate, the advocacy or the Olmstead decision deserves the credit, in 2001 Congress appropriated new funds that enabled the Centers for Medicare and

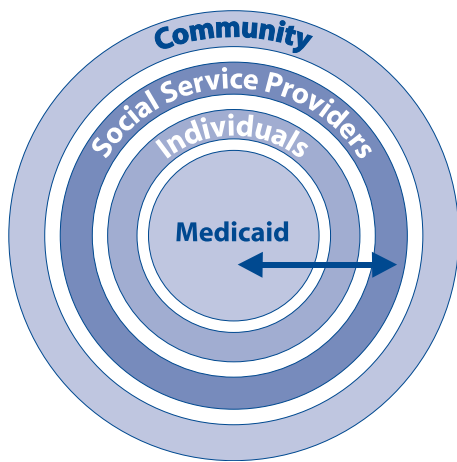


Figure 2

Figure 2 represents this model graphically. The four concentric circles show Medicaid (government) in the middle, the second circle is the users of service, the third circle is the provider network including new providers chosen by the users of services and their families, and the fourth is the broader community. The arrow runs from the consumer into the center and from the consumer into the provider network. The broader community does not participate actively. The white spacing between the circles is thinner to reflect the increased collaboration among the stakeholders.

Beyond Systems Change— A New Model

A few states have begun to develop a new model that moves beyond the social service provider networks to incorporate the full local community. The full local community means everyone and everything in the community: the religious institutions, the schools, law enforcement, clubs, informal associations and everyone who is resident there. Most call these efforts “model community” approaches. Their reasons for moving to model community are several.

First, these states have seen the shortcomings of older models; they have listened to families for many years and partnered with them to create more responsive programs. Yet citizens in these programs often live in their communities without being an integral part of them. Thus, their supports may be excellent and freely chosen but they continue to live in a world that continues to define them as “other” or “special.” In an effort to move from an “us” and “them” world to

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a “we are all us” world, a world with full inclusion for everyone, it seems imperative to engage the broader community. This view is similar to Mary Johnson’s “accessible society” discussion in *Make Them Go Away*. It also resonates with John McKnight’s *community vision* which sees its goal “as ‘recommunalization’ of exiled and labeled individuals.”^{xvi} These states recognize that the public at large needs education to overcome stereotypical beliefs that linger in society from earlier times. One New Hampshire citizen, who is quadriplegic, worked part time at an Independent Living Center. One day as part of his job he drove in his van to a meeting with the state Medicaid agency; he was part of a committee developing a Medicaid Buy-in program shortly after the passage of Medicaid Infrastructure Grants. In the course of the meeting after he explained that this would allow him to work full time without losing his Medicaid, one of the Medicaid nurses looked across the table at him and said, “You can’t work!”

Second, these states believe that everyone benefits from a society in which everyone contributes and gets to participate. African lore in Botswana holds that the giraffe, with its liquid eyes gives its tears to the women who make Botswanan baskets and they weave them into the basket design. Why does the giraffe give its tears? “...it means that we can all give something.”^{xvii} Under this view, it is important to find ways to support all citizens to contribute to their communities and to the collective solutions for problems and challenges in those communities. Under this approach citizenship becomes an inherent part of the equation.

Third, these states have studied the demographic changes that predict increasing demand for home and community-based supports in the coming years as society ages and the numbers of citizens with disabilities increases. “The...problem with programs based upon the typical social policy map is that the sum of their costs can be greater than the wealth of the nation.”^{xviii} Medicaid and other social programs cannot continue to shoulder these growing demands alone. The broader community will need to leverage its resources as well. It will take a collective effort.

Fourth, with the de-linking of poverty and disability new opportunities for community economic development arise. Citizens with disabilities who work will contribute new resources to their communities; these resources are greatly needed by the new businesses, growth for existing businesses or new ideas for solutions to community issues.

In model community states, Medicaid and others are reaching out to the larger community and inviting it to engage in making itself inclusive of everyone. The focus is on the community environment not any group of citizens. Communities have always adapted themselves to accommodate the perceived needs of their citizens. They have been making reasonable accommodations from the beginning of time. Libraries, sewage treatment plants, pedestrian crosswalks, and biking lanes are but a few of these accommodations. (The date may not be far away when we will be lengthening the time for crossing these crosswalks to insure that elders have sufficient time to negotiate safely!) Some of these community accommodations have been designed for a specific group. Curb cuts were designed to give wheelchair access to the sidewalks. Yet the benefit accrues to everyone. Local retailers have new customers, families with strollers have a new convenience and shoppers pushing carts have an easier trip to their cars. Unfortunately, with some of the community accommodations that have been made, design flaws have precluded some citizens with disabilities from enjoying the benefits. Libraries that are not wheelchair accessible are one example. Model communities work to end these discrepancies and develop the relationships that enable them to do so.

In the model community approach states' resources are being committed to engaging local communities to become fully accessible and inclusive. Medicaid and the social service network of providers and advocates are at the table but so too are citizens with disabilities, the Town Selectmen, the Superintendent of schools, the religious institutions, the Rotary Club, Kiwanis. The dialogue is inclusive of everyone. And from these new dialogues new local initiatives emerge: accessible meetings with accessible materials, accessible voting places, city councils and task forces with members who have disabilities, public education on the need for universal design in new buildings, a Hoyer lift at the town pool—the list is endless. An acknowledgement of our interdependence is growing. Model communities are into caring, not care. Enthusiasm grows with each accomplishment.

While no single model seems to have emerged from these efforts its core principles are depicted in Figure 3.

In Figure 3 everyone, user and non-user of services alike, is out in the broader community. The broader community includes the social service network as part of itself rather than something “other.” Medicaid is still in the center (because the focus of this paper is Medicaid’s role in providing supports for citizens with disabilities) but the dynamic of

the arrow has changed. In Figure 3 the community member when he/she finds a need for some services above and beyond what his community offers everyone, simply reaches out and gets resources from Medicaid or other programs and then brings those resources back to the local community where he spends them. And each individual is free to enjoy all the natural relationships and supports in his community; new relationships create new thinking about possibilities.

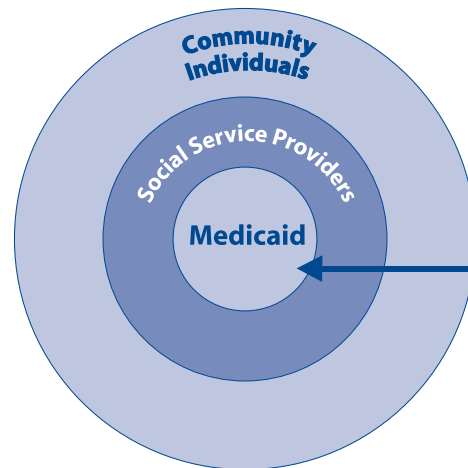


Figure 3

Figure 3 graphically represents this model. The four concentric circles are now three. The users of services are now all out in the broader community—even if in an institution—(all of which must become part of the community). Medicaid (government) in the middle, the second circle is the providers of service; the users network, including new providers chosen by the users of services and their families, is in the broader community. The arrow runs from the consumer into the center and from the consumer into the provider network. The broader community participates actively. There is no longer a need for white spacing between the circles.

Because this approach is built on enhanced informal supports from the community-at-large, most people need to reach into Medicaid less frequently than in the past. Citizens and communities benefit both in terms of a stronger social fabric and in terms of economic development.

One promising practice in model community states is the “dream catcher.” The dream catcher works in the community and works on helping citizens build new community relationships to enhance the pursuit of their dreams. One such person with dreams was Melanie. Melanie loved two

things above all others—painting people's nails and making cookies. When the dream catcher first met Melanie she was somewhat isolated and had no real outlet for either her cookie making or her nail painting. The dream catcher had a hundred community connections so she soon found a Senior Center that was delighted to have Melanie bring them cookies once a week. Soon Melanie was also doing nails for some of the ladies at the Center. The dream catcher also introduced Melanie to her hairdresser. The hairdresser and Melanie have since become friends. Melanie now works for her part time as a receptionist. Melanie is now studying hard in her free time because she plans to go school and get certified to do people's nails professionally.

One theme that runs through all of these model community initiatives is the importance of relationships. Local action arises from relationships. In one New England town a group of citizens noticed that James always walked from his home to town every day. They also knew that James lived on a meager SSI check every month and ran out of money ten days after the check arrived. James often forgot his coat even during the cold winter months. These citizens did not refer James to the social service providers. Instead they made and currently make it a point to carry an extra coat during the winter months. It's fairly easy to stop the car and offer James a warm coat, or hat, or gloves. And they create frozen dinners each month that they deliver to James just as his check money is running out. They call it "helping James." It is not a program.

Model Communities understand that the disability rights movement is about the most fundamental of civil rights. They offer promise that we will yet fulfill the vision of the founding fathers that "...all men are created equal, that they

are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness." There was no exclusion for citizens with disabilities. Our journey will not be complete until we have created a social fabric that supports everyone's unalienable rights by eliminating our penchant for labeling and segregating certain groups. To date, model communities offer a promising approach for achieving this goal. And Medicaid supports can be tailored to be an important part of that promise.

About the Author

Lee Bezanson is Associate Research Professor at the Boston College Graduate School of Social Work, the Director of the Community Living Exchange Collaborative: A National Technical Assistance Program Clearinghouse, and a member of the management team for the Exchange at ILRU. She provides technical assistance to state and Independent Living Center Systems Change Grants for Community Living grantees with a focus on consumer-directed initiatives and model community approaches to systemic change in the delivery of supports to individuals with disabilities and chronic illnesses. Ms. Bezanson is a co-author of the three-part series, "Making Accessibility Real: A Guide for Planning Meetings, Conferences and Gatherings." Ms. Bezanson was formerly the National Project Director of the HCBS Resource Network and served as Co-Chair of the HCBS Resource Network Board. She was a faculty member for the national Olmstead trainings sponsored by ILRU. Ms. Bezanson is a former Medicaid Director for the State of New Hampshire. As Director of Long Term Care in New Hampshire, she directed New Hampshire's Medicare/Medicaid Integration Program for dual eligibles.



"Each community boasts a unique combination of assets upon which to build its future. A thorough map of those assets would begin with an inventory of the gifts, skills and capacities of the community's residents. Household by household, building by building, block by block, the capacity mapmakers will discover a vast and often surprising array of individual talents and productive skills, few of which are being mobilized for community-building purposes. This basic truth about the "giftedness" of every individual is particularly important to apply to persons who often find themselves marginalized by communities. It is essential to recognize the capacities, for example, of those who have been labeled mentally handicapped or disabled, or of those who are marginalized because they are too old, or too young, or too poor. In a community whose assets are being fully recognized and mobilized, these people too will be part of the action, not as clients or recipients of aid, but as full contributors to the community-building process."

John L. McKnight and John P. Kretzmann
Building Communities from the Inside Out

ⁱGerbon DeJong, “Independent Living From Social Movement to Analytic Paradigm,” Archives of Physical Medicine and Rehabilitation 60, October 1979.

ⁱⁱMary Johnson, Make Them Go Away (The Advocado Press, Inc., 2003).

ⁱⁱⁱ42 U.S.C. 1396.

^{iv}Policy direction from the federal government came not only from the Health Care Financing Administration but also from the Social Security Administration through its SSI and SSDI policies.

^vComment at a Hartford, Connecticut meeting between HCFA and the New England States Consortium on Dual Eligibles.

^{vi}JD, Keene New Hampshire 1997.

^{vii}Burwell, “Medicaid Long Term Care Expenditures in FFY 2000,” May 7, 2001.

^{viii}“These Four Walls...Americans 45+ Talk About Home and Community,” AARP, May 2003.

^{ix}Olmstead v. L. C. 527 U.S. 581 (1999).

^xEckert, J.K., et.al., The Cash and Counseling Qualitative Study: Stories from the Independent Choices program in Arkansas, January 2001, p. 91.

^{xi}John McKnight, The Careless Society (Basic Books, 1995) at 169.

^{xii}Alexander McCall Smith, Tears of the Giraffe, (Anchor Books 2000) at 227.

^{xiii}McKnight, 163.

Community Living Exchange Collaborative at ILRU

On September 28, 2001, the Centers for Medicare and Medicaid Services (CMS) awarded two grants for the implementation of the National Technical Assistance Exchange for Community Living, one to Independent Living Research Utilization (ILRU), a program of The Institute for Rehabilitation and Research, the other to the Center for State Health Policy (CSHP) at Rutgers University. The goal of the grants is to provide, in collaboration, a program of technical assistance for grantees implementing programs under the

CMS National Community Living Initiative. The views expressed in this publication do not necessarily represent the position of the funder.

Community Living Exchange Collaborative at ILRU directs its support toward systemic changes to enable children and adults of any age who have a disability or long-term illness to live as fully integrated as possible in the community, to exercise meaningful choices about any and all aspects of their lives, and to obtain quality services consistent with their preferences.





For More Information

Sharon Finney, Information and Communications Manager
sfinney@ilru.org

Community Living Exchange Collaborative at ILRU

Independent Living Research Utilization

2323 South Shepherd, Suite 1000

Houston, Texas 77019

(713) 520-0232 (voice)

(713) 520-5136 (TTY)

(713) 520-5785 (fax)

http://www.hcbs.org/ilru_team.htm

Richard Petty, Project Director

repetty@compuserve.com

Darrell Jones, Program Training Coordinator

dljones@bcm.tmc.edu

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