

RRTC-ILDP Issue Brief: Applying Independent Living Principles to State Health Care Programs for People with Disabilities

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What independent living principles should apply to state health programs serving people with disabilities? Are principles such as consumer control more important than others such as cross-disability inclusion and equity? What criteria should be used to measure how well state health care programs perform with respect to disabled people? How do these programs address the principles? Is it fair to apply all principles to all programs?

To help clarify principles which could and should guide our health care, this Issue Brief looks at how state health care programs targeted at people with disabilities achieve independent living objectives. As numerous states develop managed care programs targeted at SSI and SSDI beneficiaries, it is important to focus attention on health care reform at the state level. This brief identifies which principles are most important and then applies them to evaluate six selected state Medicaid 1115 waiver programs which are unusual in that they are specifically aimed at adults and children with disabilities: (1) Arizona Long Term Care System (ALTCS/DD) and the Arizona Health Care Cost Containment System (AHCCCS), (2) Wisconsin Independent Care Program (I Care), (3) Ohio Accessing Better Care (ABC), (4) Oregon Health Care Plan, (5) Massachusetts Community Medical Alliance (CMA), and (6) Washington, D.C., Health Services for Children with Special Needs, Inc. (HSCNS).

The key principle of the independent living movement in the United States is consumer sovereignty—the idea that disabled persons, not professionals, should choose which services best fulfill the needs and interests of the individual (DeJong, 1979). The movement also embraces self-reliance—the idea, in direct opposition to the medical model’s “sick role,” that disabled people must rely on their own resources to acquire their rights and benefits. Other features of independent living include community integration, cross-disability emphasis (inclusion of people with all types of disability), community-based and community responsive approaches, peer role modeling, provision of a wide range of services, a community advocacy orientation, and open and ongoing access to services (Lachat, 1988).

During the last decade, organizations representing the health care concerns of people with disabilities have derived additional principles from the independent living movement, including: non-discrimination policies which aim to ensure that people with disabilities of all ages and their families have the opportunity to participate fully in the system; and comprehensiveness which expands the definition of “health” to include prevention services, rehabilitation therapies, assistive technology, and ongoing health-related maintenance. Health care should provide an array of health, rehabilitation, personal, and other support services. Finally, the principle of equity ensures that no group of individuals in society bears a disproportionate burden.

Selected findings

Consumer Control. It is a mark, perhaps, of the consumer age in health care and the impact of the disability movement, that all of the health care programs in this study have implemented numerous strategies to involve consumers (members) in medical necessity (clinical) decision-making, quality assurance, and program governance. Most programs allow their members to select their primary care physicians (PCPs) during enrollment. However, choice can be limited by such factors as the reluctance of specialists to act as PCPs, plan problems in “managing” reluctant specialists who are not trained to be PCPs, and credentialing and licensing issues. This problem seemed most pronounced in the Washington, D.C. program for children with severe mental and physical disabilities. While almost one third of the target population have primary diagnoses of severe mental illness, most psychiatrists are not qualified to provide early periodic screening, diagnosis and treatment as required by law. Because they lack this qualification, these psychiatrists cannot be primary care physicians. As much as the planners would like to offer greater choice, practical problems such as these are an ongoing impediment.

Other sample research findings include:

- **Consumer roles in administration**—Several programs developed innovative strategies to enhance the consumer’s role in the organization and provision of health care services. Access to Independence in Madison Wisconsin, conducted a community needs assessment. A group of leaders evolved from their research focus groups and survey sample who will soon incorporate as the HMO itself. This will give people with disabilities ultimate authority over their health care delivery system. The needs assessment also identified each respondent’s favorite practitioners in the area and plan organizers recruited these individuals for the new network.
- **Grievance processes**—The six Medicaid 1115 waiver programs have implemented a variety of formal mechanisms to enhance consumer control internally through plan member service departments, and externally through existing state Medicaid agency grievance and appeal structures. Depending on the program, these entailed as many as four avenues of appeal: the HMO’s informal and formal grievance process and the states’ informal and formal process which may include an ombudsman. Programs such as that in Oregon, which has a statewide Ombudsman program, and HSCNS permit members to pursue all avenues simultaneously. To date, few grievances have been filed in these still relatively new programs, those that have been filed have been promptly resolved. Thus, it is unclear whether allowing so many different ways to pursue a complaint has any measurable impact on consumer control.

- **Ethics committees**—The programs involve members in numerous ways in quality assurance programs and governance. One such way is participation on formal advisory committees which meet periodically and for which minutes are filed. One interesting strategy has been developed in Wisconsin. Here each of three Independent Living Center projects has formed an Ethics Committee composed of professionals and consumers to review medical necessity and other ethical issues such as confidentiality and equity. In the early stages of the statewide programs (there are only 71 enrollees, statewide), the three committees have “pooled” their experiences in order to share learning. One challenging issue, currently before the committee, is how to insure confidentiality during peer (consumer) review of clinical decisions.

Non-Discrimination. To the extent that state Medicaid law permits and enrollment limits allow, the six 1115 waiver programs have sought to include people with all disabilities in their systems. However, The Oregon Health Plan uses medical necessity criteria that may exclude individuals who need certain medical procedures. In 1995, disability rights advocates accused the architects of the plan of violating the Americans with Disabilities Act by excluding some procedures that are frequently required by people with disabilities. In response, Oregon amended its plan by expanding the number of allowable procedures. As a result of this precedent, some disability advocates question whether other programs such as HSCNS in Washington, D.C., can legally include some groups (e.g., children and youth under age 16 with severe mental health, developmental, and physical disabilities) while excluding other groups (e.g., older children, children with both mental health and mental retardation, children requiring kidney dialysis) (Robert Griss, personal communication, 1995). According to HSCSN and other program officials, no such legal challenge has ever been made.

Other findings include:

- **Volume of health care use**—All six 1115 waiver programs include high volume health care users, and we found no reported complaints filed regarding coverage limitations (annual and lifetime maximums) imposed on enrollees. In fact, most are designed to screen out individuals who are less likely to need care. Massachusetts’ CMA program, ABC in Ohio, and I-Care in Wisconsin restrict eligibility to people with severe physical disabilities and chronic illnesses. ALTCS/DD and I-Care use a level-of-care screening instrument based on Activities of Daily Living (ADL) functioning levels.
- **Levels of coverage**—The functional assessment screening protocol used in Arizona was recently revised to effectively screen out almost 1,300 people with developmental disabilities who had previously qualified for coverage. These individuals were reclassified to “Transitional” status. Individuals in “Transitional” status continue to receive the same level of coverage as before. However, developmental disability program officials could not predict whether this “distinction without a difference” will continue.
- **Long term care**—Personal assistance services (PAS) and respite care is restricted in each program by “medical necessity” criteria. While spokespersons from every program acknowledge the need for flexibility, some programs appeared to have more flexible approaches than others. The most flexible approach is implemented in Wisconsin. Supported by the state long-term care agency, Access for Independence’s medical guidelines do not make a firm distinction between acute and long-term care needs. Thus,

decisions about care for each member are made on an individual basis, and program officials have resisted pressure to impose rigid standards. In the more medically oriented Massachusetts program, guidelines required members to have clearly documented medical needs before being authorized to receive personal care. Initially, ALTCS/DD in Arizona imposed strict medical guidelines in authorizing personal assistance and respite care. However, when prior authorization decisions were decentralized to regional teams, care coordinators became more flexible in their decisions. According to each of the program representatives in our study, the key issue in setting limitations in personal assistance and respite care services was the capitation rate. The higher the rate, the more flexibility in the medical necessity guidelines for personal assistance and respite care.

Comprehensiveness. Because benefit packages in these programs are designed for people with disabilities, a wide range of services are provided. However, most programs are very limited in covering personal assistance services (PAS) and respite care. Typically, Medical necessity criteria cut off PAS when the medical situation stabilizes. In Massachusetts and Washington, D.C., care coordinators are responsible for arranging PAS for non-medical problems if the plan itself has not authorized such coverage. In Madison, Wisconsin, where members have a large collective role in deciding how much PAS to authorize, the community appears to continuously debate the issues of the adequacy and equity of PAS benefits. Risk management issues, conflicting community norms of entitlement and self-reliance, and the strong support of the Wisconsin long-term care authority frame this debate. Interestingly, because of the extensive involvement of the disability community in the governance of the program, and because of a strong long-term care tradition in the state, Access to Independence officials are confident that appropriate PAS needs of its members will be mostly accommodated in the new managed care system.

Except for the children's program in Washington, DC., mental health and substance abuse treatment services are not provided. This pattern reflects a trend in private and public managed care to "carve out" behavioral health care from the medical care benefit. In Wisconsin, Ohio, and Massachusetts, the separation is accomplished by making Medicaid/SSI beneficiaries with a primary disability of mental health or substance abuse ineligible for coverage in these programs and setting up a distinct managed behavioral health care network for this population.

Equity. In as much as all Section 1115 waiver programs are Medicaid based, out-of-pocket expenses, cost sharing, and eligibility based on income level do not affect enrollees. Unfortunately, the limited number of enrollees in many of the sample programs is too small to determine if providers are complaining about reimbursement rates. Moreover, qualified providers are forbidden from billing their patients for costs over and above the approved Medicaid rate. Thus, few, if any, enrollees bear a disproportionate share of the burden.

Recommendations

Independent living policy development should focus on principles that are appropriate to state health programs with limited means that target individuals with specific disabilities. All programs include specific target populations and exclude others. Advocates and policy makers should recognize the constraints of state programs and develop criteria related to consumer

control, non-discrimination, comprehensiveness, and equity that these programs can reasonably achieve given their mandate and their resources.

Given that consumer sovereignty is generally regarded as the cornerstone of the independent living movement, consumer control should be ranked highest when rating health care programs. The data presented here suggests that consumer control at all levels of the health care organization (clinical decision-making, quality assurance, and governance) is the key to meeting other important standards such as equity, efficiency, non-discrimination, and comprehensiveness. Without consumer control, other principles are very difficult to achieve.

Independent living policy development should focus on identifying a comprehensive set of criteria for each key principle and also develop criteria that distinguishes one principle from another. Our analysis suggests that criteria listed under one principle are related closely to criteria listed under other principles. Additional policy work is needed to clarify the underlying concepts, develop more precise measures of program performance, and arrive at a commonly-agreed upon set of principles and measures.

References

DeJong, G., (1979), *The Movement for Independent Living: Origins, Ideology and Implications for Disability Research*, East Lansing, MI: Michigan State University.

Lachat, M., (1988), *The Independent Living Service Model: Historical Roots, Core Elements and Current Practice*. Hampton, N.H.: Center for Resource Management.

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The RRTC-ILDLP is charged with conducting research and disseminating findings about policy issues that impact the lives of disabled people and the progress of the independent living disability rights movement. Specifically, the RRTC examines policy barriers to independent living goals in the areas of health care, housing, transportation, and employment. The Center seeks to demonstrate and facilitate collaborations between Centers for Independent Living, other community groups, and governments in forming and implementing public policies that respond to the needs of disabled people and improve the health of communities for all residents.

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