

Independent Living Working Group Recommendations

Executive Summary



**RESEARCH AND
TRAINING CENTER ON
INDEPENDENT LIVING**

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People with disabilities want to be employed, educated, and participating citizens living in the community. In today's global new economy, America must be able to draw on the talents and creativity of all its citizens.

From the introduction to the New Freedom Initiative

Pooling the expertise and ideas of colleagues in independent living, governmental, and research sectors to develop and document priorities in disability research, practices, policies, and funding initiatives, the Research and Training Center on Independent Living sponsored a working group to identify specific, actionable recommendations with a 5-10 year horizon, with measurable outcomes, that will increase full participation for Americans with disabilities in community life.

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This report presents our prioritized recommendations for disability research, practices, policies, and funding initiatives and was produced by a grant to the Research and Training Center on Independent Living at the University of Kansas from the National Institute on Disability Rehabilitation Research (H133B000500). The views expressed in this report are those of the participants and are not necessarily those of the funding agency. Core areas addressed were transportation, long-term care, employment, health care, and center for independent living resources.

TRANSPORTATION

Transportation, a vital link to jobs, education, health care services, and the community at large, can be a life-altering challenge for people lacking vehicle access because of disabilities or age. In 1979, grants began to be given for transit programs for the elderly and disabled in Section 5310 program, now the central source of transit assistance for senior services and local disability programs across the country. Lessons learned show program-by-program coordination, though a step in the right direction, has its drawbacks. Our recommendation is to:

1. Build a national comprehensive plan for universal accessible transportation

Likely to increase exponentially as baby boomers age, a significant number of people with disabilities don't have access to transportation, in part, because current transportation funding is disconnected from the existing transportation infrastructure — both public and private. Thus, isolated service systems do not permit a seamless, comprehensive transportation system.

A coordinated, integrated system from the national to the local level would support community participation for all citizens and would ensure that all existing public transportation (this includes infrastructure, architecture, vehicles, capital, etc.) and service (public, private, non-profit, for profit) is accessible without exception (including non-key stations) within three to five years and maintained. Confusing and manipulated “carve outs” and equivalent services should be eliminated.

Requiring collaboration between transportation planners, disability access specialists, vehicle manufacturers, GIS companies, elected and appointed officials, and constituent groups, this system would build on the New Freedom Initiative of “United We Ride.”

It would be implemented by the Federal Transit Authority and private transportation providers and further freedom, elimination of institutional living, and empowerment (“real voice”) for persons with disabilities of all ages. Supporting this initiative would be mobility planning and training for individuals with disabilities and a proposal for a set of standards for international travel.

Future research should address identifying best practices and models, assessing the consequences of lack of transportation on security and safety, and identifying the demographics of the 1100 counties not served by public transit.

Long-Term Services and Support

Current life-time services and supports are overly complex, inefficient, and costly, do not deliver quality care, and do not meet consumer needs for choice and control. Although Social Security and Medicare provide a system of income and health support, our nation lacks a system in respect to long-term care not necessarily of a medical nature such as help with activities of daily living, a crucial need as our population ages.

Issues to consider include the population served, the whole age spectrum, location of the services provided or received, integration of public and private financing, commonality of issues or needs of population served not by age or disability, personal choice over time in models, delivery system mechanisms, the role of centers for independent living in delivery, coordination of support services and housing settings, and coordination of support services within a geographic area. Our recommendation is to:

2.

Establish a system of community-based lifetime services and supports defined by these components:

- Provides accessible, integrated housing for persons across ages and incomes
- Integrates public and private financing
- Bases eligibility or use on functional need
- Permits personal choice over time
- Draws from a range of service models that emphasize consumer choice and control
- Has a range of delivery mechanisms that emphasize consumer control and choice

This system would be achieved through legislative, financing, and policy changes at federal and state levels supported by a universally accessible social insurance model. Federal and state agencies that provide services to persons with disabilities and older Americans and community-based organizations both public and private such as centers for independent living and Area Agencies on Aging would implement it.

With the elimination of biased financing and service models not supportive of community participation and quality of life, healthier and more productive people can participate more fully in community activities such as employment, social engagement, and family life.

Future research to support this recommendation should support cost analysis of models of community and institutional services, the impact of cost shifting in different

service delivery models, and comparison of the economic status and resource base of younger adult users of PAS compared to older adult users of PAS.

Employment

Access to health care and work supports has become extremely complex for many potential users, negatively impacting their health and well-being. The system needs to change in order to promote maximum employment and productive community involvement for citizens with disabilities. Our recommendation is to:

3. Transform current Social Security, state and private disability income insurance, health care and long-term services programs into a universal work insurance model created by and for all U.S. citizens. Work and work re-entry, early intervention, disability competence training, vocational training, health care, community-based long-term services, benefits program planning, and other supports are presumed and inherent, and available as needed.

Employers today provide private health coverage and pay taxes into Medicare and Social Security, a disproportionate burden that can be reduced with this recommendation. There is a need for a new wage replacement insurance model to fit the goal of employment as a presumptive outcome for people with disabilities. To fund this system, all citizens would pay payroll taxes (similar to F.I.C.A.) into the universal work insurance model trust fund for services offered through the new program overseen by the agencies that administer provisions of the Social Security Act.

This recommendation will transform the eligibility, financing and universality of social, health, and vocational supports and services and will need sustained long-term financing. Besides measurably increasing the wages and employment outcomes of Americans with disabilities, all Americans would have access to needed health care and work insurance, which would result in improved outcomes for health, well being, community living, and employment.

Future research to address these issues should include: an economic analysis to compare the cost/benefits of work supports versus SSDI; and conducting a cost analysis of tax credits and other incentives for employees with disabilities to sustain current employment. In addition, researchers should conduct a thorough study of all financing options that could support the goal of this recommendation.

Health Care

Historically, people with disabilities have been served by a fragmented system that increases their risk for poor health and results in higher health care costs and lower quality of life. Civil rights must include health promotion as an essential life skill. All

should have access to quality health care integrated as a system, informed by medical need, inclusive of trained medical personnel responsive to people with disabilities, and funded adequately. Also, the health care system must include improved transitional health promotion and access for young adults with disabilities through mentoring, better trained providers, a seamless system, and open communication. Our recommendation is to:

4. Create an empirically-tested, cost-effective, reimbursable consumer-controlled, community-based program that integrates systems (such as health care, personal assistance services, transportation) to promote improved health across ages and across disabilities.

There are numerous ways to establish this program, but possible steps could be characterizing the extent and dimensions of the problem; identifying, developing, and testing potential interventions; disseminating the intervention; identifying costs and potential cost savings of the intervention; and identifying individual/group health and health promotion outcomes.

Centers for independent living and other community-based consumer-directed organizations such as Area Agencies on Aging could implement the program. However, because the current service system is disconnected, inefficient, and difficult for consumers with disabilities to negotiate, current providers would need to cooperate to provide better, more seamless services with better outcomes.

The goals of the recommendation would be met when consumers participating in the new system would have improved health outcomes and express increased satisfaction with their health care services. Long-term, the average cost for health care will decrease while levels of community participation will increase.

Future research might explore whether an interactive, robust training program of medical personnel serving people with disabilities increases access to health care. Additional research should investigate how an integrated health care system prompts people with disabilities to take initiative for their own health care.

Centers for Independent Living: Role and Resource

The role of centers for independent living, an existing network of human service agencies designed to help people with disabilities live more independently and contribute to their communities, has evolved since 1972 when disability activists in Berkeley, California, rejected institutional living and set up a program that provided support services for people with disabilities who wanted more control over their lives. These centers are defined by their board, staff, consumer population served, and funding. In recent years, centers have become more active in supporting people with disabilities to transition from institutional residences to community living. Our recommendation is to:

5.

Establish funding initiatives to support prevention of institutionalization of people with disabilities.

Sub-recommendations include:

- Investigate the economic and social effects of Centers for Independent Living interventions to help people with disabilities transition from home into participation in community.
- Investigate the economic and social effects of Centers for Independent Living interventions to transition people with disabilities from institutional settings to community settings.
- Recommend that Centers for Medicare and Medicaid Services amend its Minimum Data Set data collection to capture data on causation of institutionalization.

Under the present system consumers with disabilities have little choice regarding where they want to live when reliant on Medicare and Medicaid funding. In addition to institutional options, aging Americans and those with disabilities should be provided with opportunities to live independently and participate in their communities.

Examples of research activities might include but not be limited to:

- Developing an instrument to assist CILs to identify consumers at risk for institutionalization with a subsequent plan for retention in the community.
- Conducting a randomized study to analyze and compare the economic savings between:
 - a) preventing people with disabilities from entering long-term care institutions
 - b) allowing people to enter institutions and then assisting them to transition back to community living.
- Conducting an analysis of the economic and social benefits of moving aging Americans and those with disabilities from long-term care institutions to community-based housing with appropriate supports.