

INDEPENDENT LIVING AND EMPLOYMENT SERVICES: EQUAL PATHS TO COMMUNITY INTEGRATION

by: Susan Webb

◆ OVERVIEW OF FEDERAL LAWS THAT SUPPORT COMMUNITY INTEGRATION

For many persons with significant disability, the availability of Personal Assistance Services is the most critical factor for determining whether an individual lives in an institution or in the community. Even in communities where PAS is available to enable an individual to live in his or her own home or apartment, the cost is often so prohibitive that institutionalization is the only option. Clearly, employment that leads to economic independence is the primary key to community integration for people with significant disabilities. Unfortunately, public policy has been slow to offer programs that encourage employment for people with significant disabilities who need PAS. During the past two decades, however, public policy changes are helping people with even the most significant needs become employed without fear of losing their safety net of social supports.

Paving the way for these system changes was the Rehabilitation Act of 1973. This Act established a new, more aggressive national system of Vocational Rehabilitation. The main thrust of this program was employment for persons with significant disabilities. Few people worked in the Vocational Rehabilitation system, however, who personally experienced a significant disability of their own. Consequently, many individuals with significant disabilities were “deemed” to be unemployable by virtue of the severity of their disability.

A small group of advocates from Berkeley, California is generally credited with beginning what became the “Independent Living Movement”. Frustrated by a feeling of powerlessness and limited choice in Vocational Rehabilitation, this small group started the first Center for Independent Living (CIL) in Berkeley, California. In 1978, when the Rehabilitation Act came before Congress for reauthorization, Title VII was added to establish a number of Independent Living Programs designed around the theory that if people became more independent, they would become more employable.

Today, there are more than 450 such Centers around the country with staffs and Boards of Directors where individuals with significant disabilities hold the majority of board seats. The 1978 Rehabilitation Act

Building upon the concepts embodied, debated and upheld in the Rehabilitation Act, the ADA extended civil rights protections to persons with a disability against discriminatory treatment by the private sector.

Amendments required these Centers to be community-based non-profit corporations offering four core services: 1) Individual and Systems Advocacy; 2) Information and Referral; 3) Independent Living Skills Instruction and; 4) Peer Mentoring and Support. In addition to the four core services, CILs are involved in additional programs to meet local consumer needs such as Personal Assistance Services. Some CILs offer PAS directly through the Center. Others provide consumer training and referral for using PAS. A menu of related services include such offerings as: 1) accessible housing search and/or home modifications; 2) advocacy services to mentor individuals living in nursing homes to move into community living arrangements; 3) job training, placement and accommodations; and 4) transportation services including bus training, van modifications and, carpool matches. Consistent with the consumer control and choice philosophy embodied by the Rehabilitation Act, advocacy has emerged as perhaps the most important element of programs offered by CILs in changing public policy toward empowerment.

In addition to Title VII, the Rehabilitation Act Amendments added Sections 501-504. These short but powerful provisions opened a whole new world of civil rights protections for individuals with disabilities. Section 504 in particular prohibited discrimination by any Federally funded program and required these programs to deliver services and programs to persons with disabilities in the most integrated setting. Universities, court rooms, employers receiving federal contracts, even prisons, were required to ensure that persons with disabilities have access to participation. For the next decade, these civil rights protections enhanced awareness of persons with disabilities as equal citizens.

On July 26, 1990, President George Bush signed into law perhaps the most historic civil rights legislation ever enacted on behalf of persons with disabilities: The Americans with Disabilities Act of 1990 (ADA). Building upon the concepts embodied, debated and upheld in the Rehabilitation Act, the ADA extended civil rights protections to persons with a disability against discriminatory treatment by the private sector. The ADA protects qualified individuals with disabilities from discrimination in employment, public programs, public and private transportation, public accommodations (e.g. banks, theaters, hotels, restaurants, retail stores, etc.) and communications. Title I of the ADA delineates the requirements for employers to ensure non-discrimination in recruiting, hiring, testing, placing, retaining and promoting qualified individuals with disabilities who, with or without a reasonable accommodation, can perform the essential functions of the job.

Ten years post-ADA, the unemployment rate among people with disabilities remains a staggering 70%. As comprehensive as the ADA provisions are, there is still one major element missing: healthcare coverage, including prescription drugs and PAS. Healthcare coverage for approximately 10 million Americans with disabilities is currently linked to remaining on public assistance, primarily Medicare and Medicaid. Under current public policy, an individual with a disability who leaves cash entitlements also eventually loses healthcare coverage. When an employer provides healthcare coverage to its employees with disabilities, the ADA requires that the insurance be provided equally to employees with disabilities.¹ However, private health insurance does not include PAS as a covered benefit.²

In 1996, recognizing that many individuals with disabilities need healthcare coverage, including PAS, to be able to work, a grassroots movement emerged to change the Social Security Disability system. Massive amounts of research by the National Academy of Social Insurance, the General Accounting Office, the Social Security Administration, the National Council on Disability and various universities provided the data taken to Congress and the White House to develop legislation to remove the disincentives that so pervasively discouraged work. Concurrently, another group worked to introduce legislation to change the long term care system so that PAS would be available nationally to all who need it to be independent, including in employment.

In December, 1999 the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) was signed into law by President Clinton. This new initiative changes the Social Security Disability program to encourage beneficiaries to return to work. TWWIIA extends Medicare coverage for up to eight years post-employment regardless of income and allows states to implement a Medicaid Buy-In on a premium share basis. SSDI/SSI beneficiaries will be given a “ticket” to deposit with an employment services provider of his or her choice for help in preparing for, finding and retaining employment. Benefits planning and

¹ One notable inequity that exists is the issue of mental health parity. The ADA requires employers who provide health insurance to provide the same insurance to employees with disabilities. However, there is no requirement that the coverage provided to all employees is adequate for all employees' health care needs. Many employer-provided health plans significantly limit coverage for mental health services. The ADA does not prohibit this type of underwriting, even though it has been challenged many times in the courts.

² Many employers offer Long Term Care Insurance coverage. However, such coverage is offered separate from health insurance and refers to employees who typically can no longer work. Individuals with pre-existing conditions, even those with disabilities who do not use PAS at the time of the application for coverage, are usually denied coverage by the insurance carrier.

assistance counselors will be established nationally to ensure that beneficiaries have accurate and timely information on how to use the work incentives. Other provisions allow for work attempts without triggering a Continuing Disability Review and expedited re-entry if a work attempt fails. The new law also requires the Social Security Administration (SSA) to conduct demonstration projects to determine whether the SSDI program will encourage work more if beneficiaries could lose \$1 in cash benefits for each \$2 earned.³

The TWWIIA Medicaid Buy-In, in those states that opt to implement it, would allow individuals who are significantly disabled and utilize PAS to work without fear of an inordinate amount of his or her income being used to pay for PAS services. However, some states have limited PAS availability to many of its citizens. A grassroots movement to introduce and pass legislation to guarantee PAS availability is currently making its way through Congress.⁴

◆ INDEPENDENT LIVING & EMPLOYMENT SERVICE PROVIDERS AS PARTNERS

The Ticket to Work and Work Incentives Improvement Act of 1999 promises to return millions of Americans to the work force by offering consumers with disabilities a “ticket” to deposit with approved employment services providers. These providers will be part of an employment network or series of networks designed specifically to assist Social Security Disability (SSD) beneficiaries. Centers for Independent Living can either partner with these employment services providers or can become providers themselves. The TWWIIA legislation is very broad and comprehensive in encouraging providers who offer an array of services to apply to the SSA as a “ticket-taker”. Employers themselves can actually become ticket takers if they provide job skills training and other supports for SSD beneficiaries. There are a number of ways these partnerships can work. The following examples are not an exhaustive list. As the regulations are developed for implementing TWWIIA, additional creative solutions are expected to emerge.

³ Current law allows an SSA beneficiary to earn up to \$700 per month (more for individuals who are blind) without losing cash benefits. This is sometimes referred to as the “earnings cliff.” It is widely known that many individuals limit work to keep earnings below this level. The “2 for 1 offset” demonstration projects are designed to evaluate whether such a plan would increase employment by offering a “ramp” off benefits instead of the earnings cliff.

⁴ The Medicaid Community Attendant Services and Supports Act (MiCASSA) has been introduced in the U.S. Senate as S. 1935 by Senators Harkins and Specter.

1. **CILs as Providers** -- A CIL may apply directly to the SSA to be an employment services provider. Many CILs offer services beyond the four core services⁵. By virtue of being community-based, CILs must be responsive to local community needs. For that reason, some CILs provide PAS directly while others provide information and referral to other agencies who provide PAS. Likewise, some CILs offer employment services and/or benefits counseling. It is rare that a CIL is not in collaborative relationships with other organizations. An individual CIL could conceivably become an employment network to coordinate and subcontract to other providers of service. Multiple CILs within the same state could join together as an employment network to provide statewide, urban, and rural employment services.
2. **CILs and State Vocational Rehabilitation** -- Many CILs are contracted by their state Vocational Rehabilitation Department to provide independent living and employment services. Under the current system, VR is reimbursed from the Social Security Trust Fund for whatever expenditures they invest in an SSDI beneficiary who returns to work. In some states, those trust fund reimbursements are used to establish and maintain CILs who are not funded with Federal Title VII funds. Under the new TWWIIA, state VR systems have a choice of whether to continue the current reimbursement payment system or to shift to an outcome and/or milestone payment structure. The new payment options under TWWIIA have potential to increase Trust Funds coming into a state; however, the new shift to milestone/outcome-based payments could conceivably force CILs currently funded by VR Trust Fund reimbursements to reconsider and become a ticket taker themselves to maintain or increase their base funding.
3. **CILs and Projects with Industry** -- Projects With Industry (PWI) are community-based employment services providers established by Title VI of the Rehabilitation Act. Although, PWI providers are generally separate entities, some CILs have PWI programs. A partnership opportunity exists with the CIL offering consumers services such as peer mentoring, independent living skills instruction (bus training, budgeting, etc.), self-advocacy training, benefits counseling, home modifications, and PAS. After a consumer achieves his or her goals for independence, PWI providers can then effectively provide job readiness, skills training, job development, job placement, etc. that are typically not provided by CILs.
4. **CILs and DD Providers** -- Partnerships between CILs and those who provide services to individuals with developmental disabilities (DD) are emerging as the DD community begins to adopt such concepts as “self-determination” and “People First”. Sheltered workshops

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⁵Core services required by Title VII of the Rehabilitation Act are 1) Information & Referral; 2) Individual & Systems Advocacy; 3) Peer Mentoring & Support; 4) Independent Living Skills Instruction.

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group homes and institutions of the past are giving way to programs that offer greater opportunity for community integration. Individuals with developmental disabilities are more likely to find work in non-segregated settings, often with on-the-job supports such as job coaching, mentoring and PAS. Partnerships between CILs and Parent Training and Information Centers (PTIs) are effective in transitioning young people with disabilities from school to work. CILs can offer advocacy services to help families resolve conflicts with schools and other social systems.

5. **CILs and One-Stop Career Centers** -- One-Stop Career Centers were established as part of the Workforce Investment Act. They are designed to provide comprehensive job readiness, search, and placement services to individuals who may qualify for one or more training and employment programs. Anyone can drop in to a One-Stop and independently use the resources located there. Counseling and comprehensive job search assistance is available to those who need it. The Vocational Rehabilitation system is now incorporated into the Workforce Investment Act. Partnerships between VR and other one-stop programs are being developed so that individuals with disabilities are served equally by such centers. CILs can be effective advocates by: 1) ensuring that the one-stop centers know about services available through CILs; 2) encouraging consumers with disabilities to be appointed to the state and local Workforce Investment Boards; 3) referring/accompanying consumers to the one-stop centers to use their resources; and 4) monitoring the one-stops to be certain they are offering individuals with disabilities appropriate and integrated services.
6. **CILs and Employers/Staffing Agencies** -- Employers and staffing agencies are finding it increasingly challenging to recruit employees with the necessary skills and work ethic. The expanding job pool and shrinking workforce have left a significant void in the available pool of potential employees. Recent economic expansion and global competition only exacerbate the problem of finding enough people to get the job done. CILs can offer qualified individuals with disabilities to expand the labor force. By establishing relationships with employers and staffing agencies, CILs also increase their credibility when advocating for improved access and when garnering support for changes in public policy. Possible funding sources to operate a job placement program can be contracts with State VR, United Way, Projects with Industry, Division of Developmental Disability, and eventually the Ticket to Work program. The Society for Human Resource Management and the American Staffing Association are excellent national resources for CILs to obtain contact information to join local chapters.
7. **CILs and Long-Term Disability Insurance Carriers** -- More than 40% of individuals applying for Social Security Disability benefits

are doing so as a requirement for receiving cash payments from an employer's long-term disability policy. Back injury, stress disorder and repetitive motion syndrome are conditions that result in employees leaving work on disability benefits. Larger insurance carriers have aggressive return-to-work programs; however, they are often based upon the "medical model" that focuses on incapacity rather than capacity. Beneficiaries who ultimately receive Social Security Disability benefits generally never return to work. Consequently, employees with disabilities who have excellent skills, good work ethics and want to work are relegated to lower standards of living and become trapped by entitlements. CILs can establish relationships with Long-term Disability insurance carriers to use the independent living model for return to work supports. CILs can charge an hourly fee-for-service to build upon capacity and accommodation of these valuable employees rather than incapacity and public benefit programs. Such fee-for-service programs can generate unrestricted funding for CILs to use for advocacy activity or anything needed to strengthen its programs and operation.

8. **CILs and Welfare-to-Work Programs:** According the recent statistics from the University of Kansas, 55% of families receiving Temporary Assistance to Needy Families (TANF) have disabilities.⁶ Often, these are mild mental retardation or learning disabilities that are not even identified. These families frequently feel frustrated by continual failure when, in fact, a cognitive limitation could be the reason for their failure. The comprehensive, holistic methods used by CILs to enhance quality of life and independence can be very effective in working with these families toward self-sufficiency. Partnerships between the CILs, welfare agencies and the one-stop career centers can be a truly dynamic opportunity to change people's lives. The CIL's peer mentoring and advocacy programs are proving to be effective supports for families who may have limited self-advocacy skills and self-esteem.

◆ EMPOWERING CONSUMERS TO NAVIGATE FEDERAL REGULATIONS

USE OF THE INTERNET

The advent of the internet has brought significant empowerment to the desktop of consumers with disabilities. Historically, the lack of transportation and accessible, affordable communications have restricted the ability of people with disabilities to congregate sufficiently to influence public policy to the same extent as other stakeholders within the

⁶National Technical Assist Center on Welfare Reform (Winter, 1999). Welfare policy and disability. 1(2): University of Kansas, Lawrence, KS.

community. Grass roots organizations such as ADAPT⁷ have expended significant effort just accumulating the donations necessary to travel to Washington, D.C. or other places across the nation to advocate for available in-home personal assistance services. Organizations such as ADAPT are even more effective today with the availability of e-mail as a vehicle for communicating and organizing their cause.

The internet is valuable in increasing the numbers of grass roots advocates and improving their knowledge and advocacy skills. New regulations published in the *Federal Register* literally appear on computer listserves within minutes of their announcement. Proposed rules open for public comment are disseminated the same way. Organizations such as National Council on Independent Living (NCIL), Disability Rights Education and Defense Fund (DREDF), National Parent Network (NPND) and other interest groups not only disseminate the rules and proposed rules, but also their recommended responses to the rules. As such, Federal agencies responsible for promulgating rules receive more and better comments from a more diverse public than ever before.

Another important aspect of internet communications is that it engenders solidarity and self-confidence. A consumer who may have been isolated in the past, believing he or she is the only one experiencing a given situation, finds through the internet that many, others are having the same problem. The internet lends a new opportunity for effective peer mentoring and support, a core service of Centers for Independent Living. People with disabilities in rural communities or belonging to certain minority groups can communicate effectively and experience camaraderie through the internet, even though they may have never met face-to-face.

WHAT TO DO WITH THE INFORMATION

Once consumers have the information, they need to know how to use it. CILs and Protection and Advocacy (P&A) organizations typically offer courses in self-advocacy. These courses often include information about how a bill becomes law and the subsequent regulatory process. However, it is difficult to effectively use this information without hands-on practice. Reading laws and regulations is not very exciting work; generally the text of laws and regulations are best used as references when searching for some particular information about an issue.

⁷ Americans Disabled for Attendant Programs Today (formerly Americans Disabled for Accessible Public Transportation) has long been recognized as a "militant" group of grass roots advocates who "climb" the stairs of the Capitol, chain themselves to buses and routinely get arrested for civil disobedience to increase awareness of disability oppression.

Navigating a law or regulation can be challenging without help, no matter how skilled and experienced a consumer becomes. Federal regulations are promulgated by the Federal agency responsible for its implementation and enforcement. Usually these agencies have websites and/or toll-free numbers to request interpretive guidance on a particular regulation. For example, a consumer who needs information on the Social Security Work Incentives can go to the internet at www.ssa.gov to get information on the regulations

USING LAWS AND REGULATIONS FOR PROBLEM

Unfortunately, disability culture has a long way to go to become credible in the eyes of “professionals”. American culture still has a great deal of paternalism deeply entrenched relative to disability. Non-disabled people, especially those with limited experience around people with disabilities, often want to take care of individuals with disabilities and believe they are being helpful and compassionate in doing so.⁸ Even as more people with disabilities enter the professions, acceptance as equals is difficult to achieve. For this reason, using laws and regulations is often a “buddy” process. Effective advocacy using laws and regulations takes more than one person; usually a group is needed to be taken seriously. For this reason, it is often faster and easier to take a personal issue to a formal or informal support group to resolve it.

For example, several years ago a consumer who uses crutches visited a Motor Vehicle Division (MVD) office on his lunch hour to renew his expiring driver’s license. The clerk informed him that it would be necessary for him to take the written test and a road test for his renewal. When he questioned why this was the case as he had a safe record and nothing had changed since his last renewal, the clerk told him it was because he was “not normal” and the state regulations required such tests. He left without renewing his license and asked for help from his local CIL. The CIL director, incensed about such a clearly discriminatory policy, called one of the MVD’s attorneys and explained this to be a violation of Title II of the ADA. The attorney argued that the MVD had a responsibility under state law to ensure that only safe drivers receive driver’s licenses. Of course, the assumption that a driver with a disability has a greater burden of proof than a non-disabled driver, was clearly the flaw in the attorney’s logic. What ensued was nearly two years and

⁸One of the most recent chronicles of the history of the civil rights movement as it relates to disability culture is a book by Joseph P. Shapiro, *No Pity*. Shapiro examines various pockets of disability culture and how advocates struggle to achieve equality within a society that still sees disability as a pitiable circumstance.

the work of 43 advocacy agencies and individuals to get the state regulations changed to eliminate this discriminatory practice. Had the individual consumer simply succumbed to the discriminatory policy, no changes would have taken place and others would have continued to be subjected to the practice. However, because this consumer had some sense of his civil rights and where to go for peer support, the landscape improved not only for him but for those others who would also seek the same public service.

Recent shifts in public policy toward empowerment and consumer choice have opened significantly improved opportunities for people with even the most significant disabilities to enjoy life more than ever. The ADA borrowed from the history of the Rehabilitation Act to ensure equal access to all facets of community life, including employment. More recently, the Workforce Investment Act, the Ticket to Work and Work Incentives Improvement Act, and appointment of individuals with disabilities to key policy making positions within the Federal government, have all served to bring greater hope for a bright future for millions of disempowered and discouraged Americans. With a strong economy and a renewed sophistication within the disability culture, no American with a disability should be left out in pursuit of the American dream.

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