



Overview of Some Adult Disability Services for People with Autism

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There is growing anecdotal evidence of a lack of awareness within the autism community of valuable adult services (including vocational rehabilitation) available to people on the spectrum. Among those who do know about these services, there is also evidence of some misinformation and skepticism.

This report will briefly review two key networks of adult supports – vocational rehabilitation (VR) and centers for independent living (CILs).

Many of the principles and priorities advanced by AFAA are similar to the principles and priorities of both of these networks.

It is also important to note that, like all service networks, these two networks are not perfect and do not always achieve their own ideals, priorities and commitment, despite their best efforts.

The MU office of Disability Policy & Studies hopes AFAA can provide assistance and support to both of the networks, helping them better achieve their goals for services to adults with autism.

Vocational Rehabilitation

Vocational rehabilitation is a nationwide network of state agencies whose goal is to help individuals with physical or mental disabilities achieve career-oriented jobs (with competitive pay) and live independently in their community. These agencies provide or coordinate supports including counseling, medical and psychological services, job coaching, higher education, job training, job placement and other individualized services – anything to help the individual get and maintain employment. Research has consistently shown that for every dollar spent helping people with disabilities get employed and live independently, federal, state, and local governments get back \$7 in taxes and savings on other disability services.

Each state has at least one state VR agency (some have separate agencies for people with blindness and/or for Native Americans). Most cities and towns have at least one office of trained VR counselors and staff. Nationally, VR agencies employ more than 9,000 staff. These offices, in turn, pay for contracted support services from local community rehabilitation service providers ("community partners") to achieve the goal of helping people with disabilities get jobs.

There are at least 8,000 of these community partners nationwide, employing an estimated 160,000 staff. Each year the national federal/state voc rehab system helps more than 200,000 people with disabilities find jobs.

This network is overseen by the Rehabilitation Services Administration, within the U.S. Department of Education, which monitors, advises, and partially funds the agencies.

The legislative basis for the VR system is the Rehabilitation Act of 1973. The Rehabilitation Act stands, with the ADA and Individuals with Disabilities Act (IDEA), as a cornerstone of U.S. federal policy toward people with disability. In particular, the Rehabilitation Act states, in part:

"Disability is a natural part of the human experience and in no way diminishes the right of individuals to live independently; enjoy self-determination; make choices; contribute to society; pursue meaningful careers; and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society"

"The goals of the Nation properly include the goal of providing individuals with disabilities with the tools necessary to make informed choices and decisions; and achieve equality of opportunity, full inclusion and integration in society, employment, independent living, and economic and social self-sufficiency, for such individuals."

It is the policy of RSA and VR that

- 1) All individuals with disabilities are presumed to be able to work, no matter how significant their disability. It is a matter of having appropriate supports.
- 2) The appropriate outcome for a person with a disability is employment in a career-oriented job; matching the person's interests and abilities, in a community setting, with non-disabled co-workers, and with competitive pay. Anything less is not considered a successful VR service outcome.

An Overview of How the Vocational Rehabilitation Process Works

- 1. Eligibility.** VR services are available to any U.S. citizen with a significant disability who wants to work but finds opportunities limited because of his or her disability and who requires VR services to become employed. The diagnosis of a significant disability is determined by a medical professional or psychologist. A significant disability is one which impedes activities of daily life and creates employment barriers. If the counselor feels there has been a misdiagnosis or needs further details, he or she can arrange for further medical evaluation, paid for by VR.
- 2. Vocational Counseling and Guidance.** Each person with a disability ("client") is paired with a vocational counselor. Together they identify a career goal for the person. RSA regulations require that this goal be a community-based job (preferably

career-oriented), job with a competitive salary, in a setting working with people without disabilities. The VR system does not believe that sheltered workshops are acceptable employment outcomes.

Based on the career goal, the counselor and client select the services the client needs to reach this goal. To determine what services the client needs, the counselor talks with the client to get an understanding of the client's knowledge, abilities, interests, past experiences, concerns, and accommodation needs. Medical and other documentation are important, but the key source of information is conversations with the client and/or client's family.

In some instances, the person's career goal may change as he or she conducts "career exploration". This is considered a normal part of the vocational counseling process.

3. **VR Services.** Together the client and counselor decide supports and services the client needs to reach his or her career goal. The specific services a client receives will vary widely, depending on the client's career goal and personal support needs. The chosen services and the career goal make up the Individualized Plan for Employment (IPE). The IPE is not complete until the client signs his or her name to indicate that she or he 1) was an active participant in its creation and 2) agrees with the services, responsibilities, and goal listed in the plan. This insures that clients have a central and determining voice in the type of services they receive. In addition, the IPE is a working document which can be revised later if necessary.

Types of VR Services VR services are broadly defined as any goods or services needed to help the client find employment. As mentioned, services can vary widely depending on individual circumstances, community resources, and career preferences.

Services can include, but are not limited to:

- **Assessment Services** These assessments focus on a person's abilities and support needs, not on barriers, and may include medical, psychiatric, social or psychological evaluation. This is NOT a qualifying assessment for services, but a clarifying assessment. This is also NOT a career filtering tool – assessment results usually do not rule out a particular career choice: they identify and clarify the support needs a particular career choice might require.
- **Vocational Assessment** identifies a client's interests, readiness for work, skills, and local job opportunities. Ideally, these assessments include an "in context" community-based assessment in addition to (or in place of) a clinical assessments.
- **Counseling and Guidance** This is the ongoing relationship between the client and counselor. As a team they review evaluation results and develop a realistic employment plan.
- **Medical Services.** In some instances, specific medical treatment (such as surgery or counseling) may increase a person's career potential. This is NOT a health care

plan for ongoing medical needs, but a focused intervention to improve employment options.

- **Job Training and Education** This covers skill acquisition, including post-secondary education to improve employment potential. It can include specific vocational training courses, classroom training, and on-the-job training among other things.
- **Other Support Services** This addresses secondary needs key to job retention, including development of transportation options, buying tools or equipment, or support for independent living.
- **Job Placement** These are services to help a client locate job opportunities and become hired. Job placement can include specific job hunting skills (such as interviewing and resume writing), but can also include services from job placement specialists who directly market a client to networks of local employers.
- **Supported Employment including job coaching** (see discussion below)
- **Independent Living Services** This includes referral to local community resources, help with self advocacy, help with money management, etc.
- **Assistive Technology Services.** Some clients need a specific device or piece of equipment to improve employment options. Assistive technology assessments can identify appropriate technology for a specific client and VR can often purchase it for the client.

Further Discussion of VR Services

- **Supported Employment.** This is one of the newer services for the VR system. Ideally, supported employment (the use of an on-site job coach to help a client navigate job tasks and responsibilities) should be a temporary transitional support which can be faded out. However, there are individuals who need supported employment on a long-term semi-permanent basis. Because the goal of VR services is the achievement of employment, there must be a cut-off point at which the client is determined to be securely employed and services are complete (usually 90 days after employment). **FUNDING FOR SUPPORTED EMPLOYMENT SERVICES IS TIME LIMITED** and long term job support must be provided by another funding source.

Ideally, the counselor and client will address this issue during the planning stage and identify other social service sources who can provide supported employment on a longer term basis. However, this is not always successful. This is an ongoing area of attention from RSA and its network of technical assistance providers for state agencies.

- **Training and Education.** Training and education are some of the most common VR services and deserve further elaboration. There is **NO TIME LIMIT** on how long the training may take, as long as reasonable progress is being made toward a client's employment goal. Training options include:

- **Short-Term Vocational Training.** Depending on the person's characteristics (disability features, past experience, etc.) and employment goal, this training may last only a few hours or one or two years. This may include training at a local vocational technical college, or at a local specialized disability vocational training service. VR frequently covers the cost of the training and a basic living stipend, including housing costs if any.
- **College Education.** Some career goals require a college degree. It is up to the client and the counselor to decide if he or she is willing and able to complete the degree and then find employment based upon that degree. VR will often contribute funding for the degree, but only after the client has first applied for any available financial aid. VR will usually contribute toward some or all of tuition, school supplies, housing, and basic living costs. The counselor and client will usually agree in advance on a timeline and course load for the degree. It is not an open-ended scholarship, but it is also on a flexible time scale as long as activities are focused on the career goal.
- **Self-Employment Services.** There is a lot of interest within the disability community in self-employment career options. There are several subtypes of self-employment, including small business owner, contract worker, and equipment ownership. VR can provide help and training with, among other things:
 - Feasibility studies and market research
 - Advice from business and marketing consultants
 - Seeking start-up funds from local banks
 - Initial equipment purchase
- **Transition Services.** One of the major categories of new clients for VR agencies is young adults completing their high school education. All VR agencies have extensive outreach efforts for transition planning and services. On a national level, there are several funded research and assistance centers on vocational rehabilitation and transition.

Centers for Independent Living

Funded under Title VII of the Rehabilitation Act, the national network of CILs includes approximately 800 community-based organizations promoting independent, community-based living and working for people with disabilities. Regulations mandate that 51% of the staff and boards of directors of these centers be people with significant disabilities.

IL Centers provide a wide range of services, depending on the needs of the local community, but regulations require that, at a minimum, they provide the core services of

- **Information and referral** (connections to service providers and funding resources in the community)

- **Independent living skills training** (training to address an individual's challenges with activities of daily living, local transportation, etc.)
- **Peer counseling** (mentoring connections with other adults living in the community with similar disabilities)
- **Individual and systems advocacy** (awareness training, advocacy for improved accessibility, assistance in transitioning from residential facilities to independent living in the community)

The specific additional services provided vary from center to center. Most centers are also actively involved in one or more of the following activities:

- community planning and decision making
- school-based peer counseling, role modeling, and skills training
- working with local governments and employers to open and facilitate employment opportunities
- interacting with local, state, and federal legislators
- and staging recreational events that integrate individuals with disabilities with their nondisabled peers

Each state has a Statewide Independent Living Council (SILC – pronounced "silk") which coordinates and monitors the state's CILs that are funded through RSA or the state. Each year the council develops a State Plan for Independent Living in collaboration with the state vocational rehabilitation agency. These plans, along with performance data, are submitted to RSA annually.

In general, the centers focus on civil rights, the independent living philosophy, and community inclusion for people with significant disabilities. They are an outgrowth of the disability rights and independent living movement of the 1970s & 1980s (although the movement is still quite active today!).

CILs and SILC are served by a national training and technical assistance center, also funded by RSA. The center is the Independent Living Research Utilization (ILRU) program in Houston, Texas.

On a national level, the CILs are represented by a professional organization called the National Council on Independent Living, or "nickel" (NCIL). NCIL states that Centers for Independent Living:

"embody the values of disability culture and serve as the organizational backbone of grassroots initiatives for the civil and human rights of people with disabilities. Centers for Independent Living vest power in people with disabilities by ensuring they control the services, management and direction of the organization.

"Centers for Independent Living envision a society in which people with disabilities are valued equally and participate fully. In order to accomplish this vision, they advocate for individuals facing discrimination in employment,

education, housing, transportation, and healthcare to ensure equal opportunity for people with disabilities as citizens of our democratic nation.

"CILs base their priorities and actions on the belief that people with disabilities have the right to decide how to live, work, and participate in their communities and that we must organize for social change, so that we may as a society do away with the biases that will support a cure, but often not an accommodation that would allow us to participate on an equal basis. In practice, creating an organization for people with disabilities run by people with disabilities changes the value system, the implementation, and the direction of an organization overall.

"Ten Principles of Independent Living"

Developed by the Statewide Independent Living Council of Illinois

- **Civil Rights** - equal rights and opportunities for all; no segregation by disability type or stereotype.
- **Consumerism** - a person ("consumer" or "customer") using or buying a service or product decides what is best for him/herself.
- **De-institutionalization** - no person should be institutionalized (formally by a building, program, or family) on the basis of a disability.
- **De-medicalization** - individuals with disabilities are not "sick", as prescribed by the assumptions of the medical model and do not require help from certified medical professionals for daily living.
- **Self-help** - people learn and grow from discussing their needs, concerns, and issues with people who have had similar experiences; "professionals" are not the source of help provided.
- **Advocacy** - systemic, systematic, long-term, and community-wide change activities are needed to ensure that people with disabilities benefit from all that society has to offer.
- **Barrier-removal** - in order for civil rights, consumerism, de-institutionalization, de-medicalization, and self-help to occur, architectural, communication and attitudinal barriers must be removed.
- **Consumer control** - the organizations best suited to support and assist individuals with disabilities are governed, managed, staffed and operated by individuals with disabilities.
- **Peer role models** - leadership for independent living and disability rights is vested in individuals with disabilities (not parents, service providers or other representatives).
- **Cross-disability** - activities designed to achieve the first five principles must be cross-disability in approach, meaning that the work to be done must be carried out by people with different types of disabilities for the benefit of all persons with disabilities.

Further Sources on Centers for Independent Living

- ILRU (Independent Living Research Utilization (<http://www.ilru.org>)
- US Department of Education, Office of Special Education and Rehabilitative Services (OSERS) (www.ed.gov)
- National Council on Independent Living (NCIL) (<http://www.ncil.org>)

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