



VR Research in Brief

A Partnership in Career Development for People with Disabilities: Collaboration Between Vocational Rehabilitation Counselors and Families

Around 37 percent of the nation's people with disabilities are employed, while the same is true for 80 percent of their peers without disabilities (U.S. Census Bureau, 2005). This is in spite of the fact that, according to recent Harris Polls, almost 70 percent of adults with disabilities who are not currently working say they would like to be employed.

Much research has been done on ways to improve employment approaches and options for people with disabilities. Many of these studies focus on the work of the local and federal programs whose mandate it is to help youths and adults with disabilities find jobs. A great deal less research has emphasized the family's role and influence in the job-acquisition process. This research brief highlights studies that speak to the role of the family and addresses employment-related topics given priority by family members and the individuals they are supporting.

Families strive to find work environments and opportunities that are in their loved one's best interests. However, they often feel overwhelmed by the multiple service providers they must access and the various qualifications they must meet even to begin the employment-seeking process. This brief will summarize studies that provide suggestions of ways families can navigate the system and utilize the resources available to them through state entities such as Vocational Rehabilitation (VR). It ends with additional resources and suggestions to VR counselors of ways to make the best possible allies of families when working with their clients to develop career paths. The information provided here aims to serve as a thread that unites these key players—individuals, their families, and VR counselors—because this connection is critical if people with disabilities are to succeed in developing positive professional lives.

Scouting the Research Landscape

This document draws its information from studies done at universities, institutes, and technical assistance (TA) centers and reported on in the published and grey literatures.

Research that specifically focuses on family members' roles in job definition and acquisition is limited other than a well-known study done in 2000 by a Prime Study Group for the 26th Institute on Rehabilitation Issues (IRI): *The Family as a Critical Partner in the Achievement of a Successful Employment Outcome*. The fact that this study continues to be cited although it was done based on 1990s information shows that there

is a need for current research to further explore the roles families can play in career development.

The 2000 IRI document gives a detailed examination of the family and VR interaction using a broad definition of the term "family." It states the importance of understanding how systems and cultures work so as to reach employment goals. It identifies the benefits of a partnering approach and lists specific gains to program administrators, the VR professional, the individual "consumer," and the employer. It points out that the professional tools counselors already have in hand, such as their knowledge about how

to coordinate among systems, is an important skill they can share with families. Finally, this in-depth study offers training options, case studies, and specific tools that emphasize a person-centered planning concept that involves families.

Although current studies that deal more indirectly with the family and VR interaction comment on the importance of the role of families, the 2000 IRI study is unique in that it also describes some of the downsides of having families involved. Some VR clients do not have positive (and may even have had abusive) relationships with their families. Others seeking employment may have achieved more self-sufficiency than their families feel comfortable with, while the individuals feel that maintaining this independence is key. Some families even have lower expectations than the VR counselor, with this “low bar” sometimes stemming from a lack of knowledge about training options, successful models of disability leaders, or supportive laws and programs. Finally, and most importantly, many families fear the loss of Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits, which they think may well occur when wages are earned. The negative impact of such legitimate concerns on career planning is upheld in many VR studies; for example, the Rehabilitation Services Administration’s (RSA’s) report *An Assessment of Transition Policies and Practices in State Vocational Rehabilitation Agencies* cited this fear as one of the most significant barriers to achieving family involvement in career planning efforts (The Study Group Inc., 2007). By understanding these potential “downsides,” the VR counselor can find ways still to bring families constructively to the table. The Social Security Administration’s (SSA’s) *Youth Transition Demonstration (YTD)* will also provide valuable resources in this area when it concludes in 2012; that study will generate, based on both process and random-assignment evaluations, empirical evidence on the impacts of SSI work incentive waivers and on the enhanced transition services for youths with disabilities including family supports and access to VR services (Luecking and Wittenburg, 2009).

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In the latter part of the 20th century a shift occurred in perceptions of disabilities, and the medical model of disability has since been in good part replaced by a social model that recognizes disability as a natural part of a person’s life. The social model embraces the concept of

interdependence—a recognition of the benefit to be gained by team effort and an approach through which families and individuals alike have the ability to work with service providers as team players.

Family and Community Players. When it comes to individuals with disabilities making career decisions, family members are influential forces, both directly and indirectly. The following sections of the brief emphasize family assumptions as well as actions that may help—or hinder—their family member’s efforts to find employment.

The study “Transition to Employment: Role of the Family in Career Development” (Lindstrom, Doren, Metheny, Johnson, and Zane, 2007) points out that most families say that they want their children to “live outside of the home, work in the community, and earn at least minimum wage—yet significantly fewer of the families studied imagine that these outcomes [will] actually occur.” Less than two-thirds of the parents in this study expected that their children would transition into postsecondary education.

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of postsecondary education and career planning must begin early in the lives of young people with disabilities. Through Individual Education Plans (IEPs) and Individualized Plans for Employment (IPEs), specific strategies can be adopted as early as middle school to help young people and their families begin to explore the career world through volunteering, interning, and job shadowing.

It is of utmost importance to emphasize that studies in this field consistently report that parents' general attitudes toward their children's capabilities are greatly influential. Parents' attitudes "influence adolescent vocational identity development, which includes interests, goals, and values related to career planning" (Lindstrom et al., 2007). Such a position is also upheld in the National Alliance for Secondary Education and Transition's (NASET's) 2005 literature review *National Standards and Quality Indicators: Transition Toolkit for Systems Improvement*, and so much so that "family involvement" is designated as one of that study's five key areas.

It is also important to note that most parents are first exposed to the medical model of disability, because their child's disability most often was first addressed by working with physicians. As often as not, a child with a disability has grown up without his or her family making connections with the disability community, and therefore without being exposed to the broad opportunities that community makes available. The 2007 Lindstrom study quotes one mother who confessed her view of her daughter's limitations: "She talked about going to college, but I didn't think it was going to be feasible for her because I knew she had a disability." These limitations could have been diminished or eradicated if that mother had known the options available to her and her daughter.

Though the Institute of Education Science's (IES's) *The National Longitudinal Transition Study-2*, a study that will offer the first national picture of the involvement of families in the educational development of their secondary-age children with disabilities, has not yet been completed, already its raw data supports the

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central message of this brief: family members and community allies are vital to employment planning. They bring resourcefulness, creativity, motivation, and advocacy skills to the table. The studies described in the following

section of this brief focus on person-centered planning, "customized employment," and youth transitions, all of which—as basic assumptions—include family and community members as active members in both planning and action.

Hasnain and colleagues' publication "Person-Centered Planning: A Gateway to Improving Vocational Rehabilitation Services for Culturally Diverse Individuals with Disabilities" and Griffin and colleagues' "Customized Employment: Where We Are; Where We're Headed" both assume the importance of families in the definition of career paths.

Planning for one's future is like putting together a puzzle: there are several pieces and all of them have to fit together in order for the final picture to be complete. Person-centered planning gets to the core of an individual's goals and how community, state, and federal resources can be pulled together to empower an individual to make choices about his or her life. This approach to planning puts to work the concept of interdependence. Team members from all realms of a person's life, including family and community members, become equally contributing partners as the individual crafts goals around career, community participation, leisure interests, independent living arrangements, personal relationships, and more. Hasnain and colleagues' study points out that VR offers a variety of employment services and supports: vocational evaluation, preliminary vocational training, postsecondary education, transportation, interpreters, adaptive equipment, "on-the-job training, supported

employment, adjustment counseling, independent living skills development, job exploration, and placement services” (Hasnain, Sotnik, and Ghiloni, 2003). However, choosing *which* of these supports work for an individual is more easily achieved with the insight of family and friends.

Person-centered planning includes the option of “customized employment.” Customized employment (CE), an approach being tested and researched since 2001 through the Department of Labor’s Office of Disability Employment Policy (ODEP), focuses on *individualization and negotiation* to address the needs both of the job seeker and the employer. The CE process begins with an “exploration” phase during which the job seeker invites family, friends, and colleagues to share their perspectives and connections about potential employment opportunities. CE focuses this broad group on the creation of a “blueprint” for that person’s job search by linking services from Workforce Investment Centers (One-Stops or Career Centers), VR, Medicaid, Community Rehabilitation Programs (CRPs), Schools, Social Security, families, and friends. Bringing together the services and supports provided by multiple state agencies is a feat unto itself. The support VR counselors provide may be exactly what an individual and a family is looking for.

What Families Need to Know About Federal and State Options

When people with disabilities set career goals, VR professionals play the roles of facilitators, resource consultants, expert witnesses, and individual allies. The following study focuses on ways in which VR counselors can most strategically unite key players to assure successful employment and career outcomes, while figuring out “the system.”

StateData: The National Report on Employment Services and Outcomes (Butterworth, Smith, Hall, Migliore, and Winsor, 2008) argues that setting a “simple” career goal usually requires services and supports that stem from multiple state and federal providers. Therefore, a VR counselor’s understanding of services offered by various

departments is essential. For example, the SSA offers:

special provisions that limit the impact of work on Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits. These financially oriented work incentives include the Plan to Achieve Self-Support (PASS), Impairment-Related Work Expenses (IRWE), and Blind Work Expenses (BWE). PASS, IRWE, and BWE allow individuals to set aside money, resources, and expenses to be excluded from total earned income calculations (Butterworth, et al., 2008).

Helping individuals and families understand how benefits and earnings interact most constructively is a critical element in creating a successful career development plan for any individual.

Of course, as is highlighted in the National Council on Disability’s (NCD) 2008 study *The Rehabilitation Act: Outcomes for Transition-Age Youth*, VR practitioners encounter many disincentives to applying best practices in serving transition-age youths. VR counselors are currently not able to report and “capture” as service units their attendance at IEP meetings, career exploration activities with students prior to eligibility, meeting with family members to explain VR services, or consultations with teachers and other IEP team members. The NCD study authors recommend that RSA and state VR agencies recognize such transition services provided by VR counselors and, in addition, allocate additional staff resources to meet the needs of transition-age youths, which would include working with families. As it is reported in *An Assessment of Transition Policies and Practices in State Vocational Rehabilitation Agencies*, the integration of VR and transition services can be confusing; practitioners need to start career planning and partnering with families early. Projects in SSA’s Youth Transition Demonstration, which began evaluation in 2003 and will continue through 2012, build on the findings in the previously referenced *National Standards and Quality Indicators* report

and do what practitioners find so difficult: connect youths to VR while including family supports.

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ports, and service providers at private, state, and federal levels—has a portion of the responsibility when exploring the role that employment will have in a person’s life. This interdependence requires individuals “to act themselves and also to inform, guide, and manage the actions of supportive others” (Powers, 2005). Therefore, the final section of this research summary emphasizes the maxim of self-determination.

L.E. Powers’ publication “Self-Determination by Individuals with Severe Disabilities: Limitations or Excuses?” and Lindstrom and colleagues’ publication “Transition to Employment: Role of the Family in Career Development” explore the centrality of the individual in this concept of interdependence further. “Self-determination is owned by an individual; it is not a program, and strategies such as person-centered planning” (Powers, 2005) make personal successes possible. Studies show that progress begins by “infusing self-determination opportunities within transition preparation, particularly for employment” (Powers, 2005). The Powers study consisted of 400 students with disabilities who reportedly had transition plans included in their IEPs, yet

Self-Determination

At the heart of the VR process is the individual. Having the person with a disability provide him- or herself with information, support, choice, decision making, and empowerment is key to employment-related planning. Everyone—family members, friends, community sup-

“only 40 percent of students with intellectual disabilities were present for their IEP meeting. Only 10.4 percent of students with intellectual disabilities had employment goal(s) listed on their transition plan.” Of these employment goals, many individuals end up being “limited to disability stereotypic areas such as food service, maintenance, landscaping, and stocking, to name a few.”

A child’s capability is largely dependent on what a parent teaches. This includes believing in oneself, respecting oneself, and setting goals that do not have to parallel social presumptions. “Parents of children in special education generally reported allowing their children fewer opportunities for participation in activities and daily decision making, and these parents express greater intent to control their children’s future careers” (Powers, 2005). For some parents, seeking broad horizons for their child may seem risky, but self-advocates attest to the fact that it is a risk worth taking. Family members serve as role models, and it is up to them to reserve a “place at the table” for the person they are representing. Parents may have doubts, but providing an individual with an opportunity to contribute to his or her own life is imperative. VR counselors can play a crucial role in helping families’ views of what is possible expand.

“Led by people with disabilities and their family members and professional allies, advocacy efforts for advancing self-determination remain strong.[...]Further attention also is needed on the social marketing of self-determination as not only a revered value, but also a vehicle for individuals to advance their quality of life and effectively use supports and services” (Powers, 2005). This process can begin by espousing a team approach when working toward self-determination in such a basic life decision as employment.

Recommendations for Practitioners

The following recommendations may serve as general guidelines for service providers working with youths with disabilities to set career development goals:

- *Involve Individuals and Families.* Include individuals and families in school-to-work transition planning beginning in middle school. Encourage families, even then, to begin exposing their youths to career options through volunteering, internships, and job shadowing.
- *Define “Family” Broadly.* Recognize that many people (neighbors, a friend, a teacher) can provide different contributions to individuals’ career planning, thus expanding both the VR counselor’s and the family’s reach.
- *Consider Cultural Attitudes.* Look for cultural attitudes that might help or hinder a family’s willingness or ability to work in partnership with counselors. Involve good language translators and cultural interpreters.
- *Recognize That Unfamiliarity with Disability Models and Program Systems Can Limit Family Expectations.* Help expand family members’ view of possibilities by exposing them to models of people with disabilities who are successfully employed. Educate them about rights, program options, and service systems as a way of expanding their view of what is possible in terms of jobs and careers.
- *Recognize That Families May Be Protective.* They may under- or over-estimate their relative’s capabilities. They may also have fears stemming from prior interactions with government agencies. For families to become partners, these concerns must be identified and addressed.
- *Be Aware That the Fear of Losing Benefits Can Be a Career-limiting Factor.* Help family members understand how best to work with SSA and its waivers and programs to limit the effect of wages on benefits so as to retain the maximum supports,

both financial and medical, that the individual and family need to make everyday life possible.

- *Help Families Understand What Professional-level Training Is Available.* Provide information about professional-level jobs for people with disabilities so that they gain the skills to work at their most productive level.
- *Utilize Person-centered Planning Practices, Including Customized Employment.* These strategies bring together teams of people, including members of the broader family and community who know the individual, to set goals based on the individual’s interests, capabilities, and cultural identities.
- *Help Families Navigate Among Federal and State Agencies.* Help families connect programs and resources that support career planning, job retention, and the ability to maintain supports while working.
- *Understand That Self-Determination Is a Key Element in Successful Career Exploration and Job Acquisition.* This is most easily achieved when interdependence among multiple players—the individual, their support people (family included), and the VR and other systems—is the chosen route.

Resources

Both the RSA and the Office of Special Education (OSEP) fund training programs offering parents technical assistance to aid them in encouraging their children with disabilities to plan for careers and independent adult-hoods. The RSA currently funds seven Parent Information and Training Programs serving 10 states. These programs help parents better understand VR and independent living programs and services, communicate more effectively with transition and rehabilitation personnel

and other relevant professionals, develop an individualized plan for employment, and understand relevant sections of the *Rehabilitation Act*. The OSEP Parent Training and Information (PTI) Centers offer IDEA-focused training on transition planning in over 100 Parent Centers throughout the United States, with at least one in each state. Each VR agency is required to have a PTI representative on their State Rehabilitation Councils. Information on the RSA programs can be found at this link: <http://www.pacer.org/tatra/rsa.asp>; information on the OSEP Parent Centers can be found here: <http://www.taalliance.org/>.

The National Secondary Transition Technical Assistance Center (NSTTAC) has also compiled an annotated bibliography of studies focusing on what families need to know about transition, as well as what the professionals who work with them need to know and do to work effectively with families. That bibliography can be accessed at the following website: http://www.nsttac.org/products_and_resources/ParentInvolvementAnnotatedBibliography.aspx

New Editions wishes to thank Deborah Leuchovius of the PACER Center for her review of and contributions to this brief.

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This report has been funded at least in part with federal funds from the United States Department of Education under contract number ED060062/003. The content of this publication does not necessarily reflect the policies of, nor imply endorsement by, the United States Government.