

Identifying the employment and vocational rehabilitation concerns of people with traditional and emerging disabilities

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Abstract. *Objective:* This study was conducted a) to examine the concerns of people with disabilities regarding their participation in independent living and in society and b) to explore whether people from “emerging” disability groups and those from “traditional” disability groups prioritize issues related to these concerns similarly.

Study design: National survey using the “Concerns Report Method for Citizens with Disabilities” (CRM), an agenda-setting instrument, which involves people with disabilities in the research process. The CRM was administered to a national sample of people with a variety of disabilities.

Results: Survey items related to employment and vocational rehabilitation are typically rated as “problems” by the entire group of respondents as well as by respondents from specific disability groups. One employment-related item pertaining to adequate salary and benefits emerged as one of the top three issues selected by the entire group and by respondents in specific disability groups.

Conclusion(s): Despite progress in many areas of disability policy and quality of life, people with a variety of disabilities remained concerned about employment and vocational rehabilitation issues. The chronically high national unemployment rate of people with disabilities highlights the need for increased attention to programs and policies to address this need.

Keywords: Independent living, people with disabilities, Concerns Report Method, participation, employment, vocational rehabilitation

1. Introduction

The ‘Disabled Citizens’ Concerns Report Method (CRM) [10] was developed in 1980 as a community agenda-setting tool for constituent groups to collaborate with researchers in identifying socially important issues [2]. The CRM exemplifies participatory action research (PAR) because it involves representatives of the population being studied, as key informants, survey respondents, and/or conference participants throughout the research process.

By 1989, when Congress was considering the ADA, the CRM had been used in over 30 different projects

with surveys completed by over 20,000 people across 18 different states by the Research and Training Center (RTC/IL) on Independent Living at the University of Kansas. RTC/IL staff organized and summarized the archived results and published them for use as testimony in support of the ADA, mailing the information to all senators and congressional representatives [2].

The CRM has been used by researchers interested in building consumer-generated research agendas with various disability groups, including individuals with mental retardation [14], individuals with traumatic brain injury [15], individuals with psychiatric disabilities [12], and Peruvians with disabilities [13].

To implement preferred “person first” language recommendations, the CRM is now called the “Concerns

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Report Method for Citizens with Disabilities.” This change also recognizes that state and federal legislation and programs greatly influence the lives of people with disabilities beyond the boundaries of traditional communities [2]. “Community” is no longer assumed to be a city or neighborhood, or even a county, but rather an area as large as necessary to examine specific issues of interest, such as housing, personal assistance, or employment for people with disabilities.

The purpose of this study was to identify and prioritize the concerns of people with disabilities across the United States regarding their ability to fully participate in their communities and in society. This CRM was selected as a method for two reasons. First, by using a consumer-driven survey methodology, researchers could involve independent living experts and consumers in exploring the issues. Second, by focusing on participation, researchers could gather data from experts on one of the most important “products” of independent living – full participation. Participants in the study included individuals with a variety of disabilities, including “emerging disabilities,” such as Multiple Chemical Sensitivity Syndrome (MCSS) and Chronic Fatigue Syndrome (CFS), as well as individuals with what are considered more “traditional disabilities,” such as spinal cord injury and blindness. Persons representing emerging disability groups have been identified by the National Institute on Disability and Rehabilitation Research (NIDRR) as underserved groups who would likely benefit from independent living services and philosophy [7]. The Research and Training Center on Full Participation in Independent Living (RTC/FPIL), was charged by NIDRR to examine the definition of independent living and to assess its relevance for those from emerging disability groups, as well as for those who are traditionally served by centers for independent living (CILs). To do this, RTC/FPIL researchers sought to examine whether there was a convergence of important disability-related issues among the various groups.

This paper will provide a description of the CRM process. The results of the national survey on Full Participation in Independent Living will be reported, and finally, implications of this survey for consumers and researchers will be discussed.

2. Method

2.1. *The CRM process*

There are 4 steps to the CRM process: 1) a working group of key informants is assembled to recommend

items and actively contribute to creation of the survey; 2) the survey is disseminated as broadly as possible to identified respondents; 3) the survey results are compiled, analyzed and reported; and 4) a “town meeting” is convened to discuss the results of the survey and identify steps for further action to address concerns. Each of these 4 steps will be discussed.

2.1.1. *Survey creation*

Key informants were selected by inviting two national organizations promoting independent living, the Association of Programs in Rural Independent Living (APRIL) and the National Council on Independent Living (NCIL), to select representatives. Additionally, representatives of “emerging” disability groups, as well as several other consumers not representing large organizations were included. The 14 key informants (e.g., CIL administrators and staff, executive directors of APRIL and NCIL, and consumers) attending represented 12 states, four racial/ethnic groups, both urban and rural service areas, and a variety of disability groups, including those with cerebral palsy, muscular dystrophy, chronic fatigue syndrome, multiple chemical sensitivity syndrome, traumatic brain injury, and diabetes. The group met to review and select items for the Full Participation in Independent Living national survey. To provide preliminary information for working meeting participants, researchers provided an index of approximately 300 possible disability-related concerns divided into categories such as assistive technology, employment, housing, education, and transportation. Participants were divided into breakout groups, assigned a category, and asked to select several items, either from the list or from their own experiences and work, to best represent the most important and current issues in that category. Items from the index could be selected “as is”, rewritten, or combined. New items could also be identified and inserted. When all participants were convened in a plenary session, a representative from each breakout group presented its recommendations to the larger group for discussion and selection by consensus of the group. Limiting survey items to a manageable number was a requirement for reaching consensus. Selected items were assembled in a list and the group again used discussion and a consensual process to eliminate some items and combine others to shorten the list. The group also recommended demographic questions, as well as specific wording ensuring accuracy and comprehension for both issue and demographic questions. For example, the group recommended using the combination term “disability/chronic health condition” to

avoid deterring potential respondents not choosing to identify themselves as “disabled.” After the meeting, research staff compiled and formatted the list and sent it out to the work group participants for their approval. Based on incorporation of either assent or feedback from half of the participants who responded, a 48-item CRM survey was finalized. Items representing 19 categories of issues were included in the survey. Categories with the most questions included equality (7); health care (4); community services (4); vocational rehabilitation (4), assistive technology (3), and employment (3). All other categories had only one or two questions.

Each of the 48 items selected by the key informants was paired with two Likert-type rating scales for importance (0 = low to 4 = high) and satisfaction (0 = low to 4 = high). Respondents would be asked to assign both an importance and satisfaction score for an issue using the 0 to 4 scale. These scores would then be analyzed for each item and ranked.

The final survey also included an 18 item demographic section with questions on education, employment, income, disability type, and zip code. The survey was loaded onto the RTC/FPIL website for online completion, and produced on survey forms for pencil and paper completion. Additionally, key informants were also asked for strategies and potential sources through which to disseminate the survey.

2.1.2. *Survey dissemination*

The next step was to broadly disseminate information about the survey to potential respondents across the USA. The CRM does not use scientific sampling since the goal is to involve as many persons with disabilities as possible in the agenda-building process. For this reason, a “canvass” approach was used.

For this study, paper survey packets were disseminated containing a cover letter, the survey, a postage paid envelope, a brailled card inviting persons who are blind to request the survey in an alternate format, and information about an incentive available to respondents. Similar information was available with the online version of the survey. A cover letter explained the purpose of the survey, invited responses, and offered a free copy of an advocacy tool, the “Guidelines for Writing and Reporting about People with Disabilities” [9], as an incentive. Respondents requesting the incentive provided necessary information to receive the guidelines separate from the survey itself.

The survey was disseminated in a variety of ways. Emailed invitations to participate were distributed via two national disability organizations (ILRU and Uni-

versity of Montana RTC/Rural national list serve) with extensive mailing lists that include both disability organizations and individual consumers. These invitations encouraged potential participants to respond online or to call a toll-free number to have a paper survey mailed to them. Both APRIL and NCIL provided a link to the online survey on their websites, and encouraged member CILs to do the same. RTC/FPIL staff attending several regional and national conferences distributed surveys to attendees at exhibit tables. Several national disability organizations, including those representing Deaf persons and persons with Chronic Fatigue Syndrome, disseminated survey invitations via their newsletters, listservs, and websites. Additionally, approximately one dozen chat rooms and moderated discussion groups serving persons from emerging disability groups agreed to post survey invitations, to ensure that these groups were informed. Approximately 800 of the paper surveys were mailed to disability organizations, or to individual respondents upon request. It is impossible to determine how many electronic contacts were made.

2.1.3. *Compilation and analysis of responses*

Online survey responses were automatically added to an SPSS database. Scannable paper surveys were entered into the same database. Additionally, emailed surveys received from respondents who were blind were transcribed on a scannable survey form, randomly checked for reliability, and then added to the database. These data were then analyzed for the importance and satisfaction of each item. Next, a weighted differential score was calculated for each item that reflected the combination of relative importance and relative satisfaction. For example, a weighted mean score for question 1 was 98% for importance and 77% for satisfaction. The weighted differential score between these scores was 21% (e.g., 98% minus 77% = 21%). This difference or “differential score” was used to sort the items into one of three standard CRM categories: (1) low importance (so satisfaction level is irrelevant), (2) high importance and high satisfaction, and (3) high importance and low satisfaction. Items that were found to be of high importance but with low satisfaction were identified as problems that require further discussion and improvement. This focus of this paper is survey-identified problems related to employment and vocational rehabilitation.

2.1.4. CRM national town meeting

Typically the CRM is conducted in community or state settings where town meetings can be conducted at an identified place and time. These meetings are usually convened so that consumers and others concerned with these issues can attend and obtain the prepared concerns report with concerns and strengths highlighted, and participate in action planning to address the identified problems. The research team realized that conducting a town meeting at the national level would be prohibitively expensive, and would not be likely to provide a representative audience of stakeholders. To reach a broader audience to react to the CRM, we conducted outreach in multiple ways. Staff members presented results at the Association of Programs for Rural Independent Living (APRIL) national conference, the National Council on Independent Living (NCIL) national conference, and through a national web cast sponsored by the Research and Training Center on Independent Living at the University of Kansas, and the Independent Living Research Utilization (ILRU) group at The Institute for Rehabilitation and Research (TIRR) in Houston, Texas. These presentations provided opportunities for a broad cross-section of persons with various disabilities to obtain and discuss the results of the survey.

3. Results

3.1. Responses received

A total of 1367 survey responses were received. The majority of the responses were received online; paper and emailed responses comprised 23% of the total. Due to the use of electronic dissemination methods, it was not possible to calculate a response rate.

3.2. Demographics of respondents

Seventy-two percent of the respondents were female. Forty-one percent reported being married, 33% single, and 20% divorced. While persons with disabilities aged 18 and over were eligible to participate, 77% of the respondents reported ages between 31 and 60 years. Three percent of respondents reported Hispanic ethnicity. Eighty-seven percent chose "White" as one of their races, although respondents were allowed to choose multiple racial categories. As a group, respondents had high education levels with 26% reporting they earned at least a four-year college degree, while

22% indicated they held graduate degrees. Thirty-eight percent of respondents reported not working, 40% reported working full or part-time, and 8% reported being self-employed. Respondents could choose multiple responses to the employment question, including homemaker, retired, or student, so the categories were not mutually exclusive. Fourteen percent of respondents reported that they earned less than the federal minimum wage of \$5.15 per hour. Twenty percent of the respondents reported an individual gross monthly income of less than \$550. Twenty-five percent reported monthly incomes of \$550–\$1000. Only 11% reported a monthly income of \$4000 or more.

Thirty-nine percent of respondents reported receiving income from Social Security Disability Insurance (SSDI) and 14% reported receiving Supplemental Security Income (SSI). Smaller numbers of participants reported receiving benefits from other programs such as public assistance (5%), food stamps (11%), publicly-funded PAS (4%) and Section 8 housing funds (9%). Again, these categories were not mutually exclusive. Seventy-nine percent of respondents reported living in their own homes or apartments; 10% reported living in the home of a parent or other relative. Less than 1% of the responders reported living in each of the following settings – developmental centers, group homes, nursing homes, or outdoors in a car, truck or porch.

3.2.1. Disabilities of respondents

Respondents reported experiencing over 29 different disabilities; more than 50% reported having 3 or more disabilities. Twenty-two percent declined to identify a primary disability. The most frequently reported disabilities were asthma (27%), learning disabilities (23%), multiple chemical or electrical sensitivities (32%), and post-polio syndrome (24%). Because respondents were allowed to select all of the disabilities that they experienced, these responses were not mutually exclusive.

3.2.2. Geographic distribution of respondents

Responses were received from all fifty states plus the District of Columbia. Four states accounted for 29% of the responses (California-125; Kansas-102; Georgia-84; and New York-83).

3.3. Problems identified

In analyzing the survey issues identified by respondents as problems (i.e., having high importance and low satisfaction ratings), there was no clear cut-off of

differential means to separate “problems” from “unimportant issues” (low importance ratings) or “strengths” (high importance and high satisfaction ratings). For example, for the entire group of respondents, the range of differential scores (difference between mean importance and mean satisfaction ratings) extended from a high of 58.98 for item number 45 to a low of 17.23 for item number 3. There were no significant breaks in this incremental sequence of means.

However in comparing the items that rated high enough to be included in the top twelve for the entire group of respondents as well as for respondents with specific disabilities, the results showed that items relating to vocational rehabilitation and employment re-occurred frequently. There were 19 categories of disability items in the survey with a total of 48 items across these categories. Of these, four questions related to vocational rehabilitation and three related to employment. Table 1 shows the actual text for these 7 questions. The entire group of respondents, as well as three specific “traditional” disability groups and three “emerging” groups, all included at least five, and more typically six or seven, of the employment and vocational rehabilitation items in their top twelve identified problems. Traditional groups included persons designating blindness ($n = 246$), post-polio ($n = 325$) or muscular dystrophy ($n = 180$) as a disability they experienced. Emerging groups included persons designating arthritis/autoimmune disorders ($n = 132$), chronic fatigue syndrome (CFS) ($n = 142$) or multiple chemical sensitivity syndrome (MCSS) ($n = 432$) as a disability they experienced.

Additionally, one of the employment questions (#45) related to adequate salary and benefits from employment to meet living needs emerged as one of the top three items, out of 48 items, for the entire group of respondents and for the six disability-specific groups described.

3.4. *Town meeting*

The researchers convened town meetings at two national independent living conferences and obtained general feedback on the identified concerns. Additionally, since many consumers cannot travel to these conferences, researchers also conducted a web cast on November 20, 2002 to share the results of the survey and to solicit questions or comments about the CRM. This nationalized approach to conducting a town meeting did not yield a specific list of action plans for addressing the identified problems to full participation. The multiple presentations created the opportunity for a discussion that focused more on the findings.

4. Discussion

Results from this survey confirm that issues related to vocational rehabilitation and employment are serious concerns for many people with a variety of disabilities across the nation. These data are aligned with the findings of other studies, such as those of the National Council on Disability [6]; the National Organization on Disability/Harris Interactive [8], and Disability Rights Advocates [1], that have identified a significant ongoing disparity between unemployment rates of non-disabled adults and adults with disabilities in this nation. For example, the unemployment rate for non-disabled adults was 6.1% in August of 2003 (US Department of Labor, 2003), up from a more typical rate of 4–5%. However, the unemployment rate for disabled Americans is frequently reported at 60% or higher [5]. Results indicate that both unemployment and underemployment are concerns since the survey item most frequently selected as the top problem concerns the ability to earn enough in salary and benefits to live on.

4.1. *Study strengths*

As a consumer-involved study, this application of the CRM validates the seriousness of the employment and vocational rehabilitation concerns of people with disabilities. This is supported by the fact that of 48 items selected by key informants to be included in the survey, seven items (15%) were related to these issues.

While the CRM does not include scientific sampling of the population under study, the high education levels of respondents together with their high unemployment rates and low-income levels indicate that respondents are likely experiencing life situations that are too often the norm for people with disabilities in the US. Clearly, there are valid reasons for concern about employment and vocational rehabilitation issues among this population. One fifth of the survey respondents reported income falling below the 2003 Federal Poverty Guidelines of \$8,980 per year for a family of one. One quarter of the respondents reported monthly income just above the poverty line. These data are similar to findings of the Center on Emergent Disability that approximately 37% of Americans with a disability lived in poverty in 2002 and that 47% of workers with disabilities lived at or below poverty in that year [3]. It appears that people with disabilities as a group did not benefit from the prosperous decade of the 1990's. These individuals very likely experience greater barriers to full com-

Table 1
Text of CRM questions related to vocational rehabilitation and employment

Question number	Category	Text
41.	VR	Programs are available to assist you in your transition to employment and community living.
42.	VR	You have the service and support you need to obtain and succeed in employment.
43.	Employment	You are given the same opportunities as non-disabled job applicants.
44.	Employment	You have the same chances for advancement and promotion as non-disabled employees.
45.	Employment	You can make enough in salary and benefits in your employment to meet your living needs.
46.	VR	The service you receive (or have received) from the state vocational rehabilitation agency helps you get the job or training that you wanted.
47.	VR	Vocational rehabilitation counselors are supportive of your self-employment goals.

Note. VR refers to Vocational Rehabilitation.

munity participation during economic downturns than their non-disabled counterparts.

Despite passage of ground-breaking civil rights legislation, such as the Americans with Disabilities Act in 1990 and public policy aimed at reducing employment barriers for people with disabilities, such as the Reauthorization of the Rehabilitation Act in 2003, there remain substantial barriers to the ability of persons with a variety of disabilities to engage in substantial, gainful employment. While the independent living movement has contributed to significant improvements in the lives of people with disabilities, problems related to employment and access to resources remain severe. As Litvak and Martin [4] note below, many people with disabilities continue to live in poverty:

The independent living movement has come a long way toward increasing consumer control of the institutions that serve disabled people. But we remain among the poorest in this country and continue to have very high unemployment and underemployment rates. The challenge for the Movement and its leaders who are in power now is to continue the revolution so that it truly meets the needs of those at the bottom of the disability ladder, not just the “talented 10% (p. 51).

4.2. Study limitations

Despite the validation of CRM as a survey method, it is difficult to identify with certainty the most serious problems experienced by any specific disability group from these data for several reasons. Most respondents reported experiencing more than one disability and over 50% reported experiencing three or more conditions. Twenty-two percent of respondents declined to designate a primary disability. Therefore, there were insufficient responses from those who solely identified as having a specific disability to analyze results by primary disability with a high degree of confidence. An-

other study limitation was the limited success of the town hall meeting concept at a national level. One of the concerns we had was representativeness of those at the town hall meeting in identifying specific solutions and action plans to address stated barriers to full participation in the community. Taking the town meeting model to the national level was not as successful as we had hoped. However, as a group of people with a variety of disabilities, the top problems identified have a theme that is similar to other studies identifying issues important to people with disabilities.

5. Conclusion

This study raises awareness of problems related to unemployment and underemployment for persons with both traditional and emerging disabilities. It confirms that employment and vocational rehabilitation services, and related quality of life issues, continue to be critical concerns of persons with both traditional and emerging disabilities. These data indicate the need for increased collaboration between those working in employment services, vocational rehabilitation, and independent living to improve employment opportunities for people with disabilities and to ensure that all Americans with disabilities have the same opportunities for full participation as non-disabled people living in this nation.

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