

## Full Participation in Independent Living Concerns Report Survey

**Background:** Recent discussion regarding the “new paradigm” of independent living is due in part to the phenomenon that increasingly diverse groups of people with disabilities — people with different types of disabilities, as well as people from ethnic, racial and cultural minorities — are and could be benefiting from independent living services. Believing that independent living is a philosophy to be lived and used to change the community, more information is needed as to the composition of people who are termed as having disabilities, especially those with “emerging” disabilities, such as multiple chemical sensitivity syndrome and chronic fatigue syndrome.

### Research questions:

1. What concerns do people with disabilities have about their own independent living and participation in society?
2. Do people from emerging disability groups and those from traditional disability groups prioritize concerns similarly?

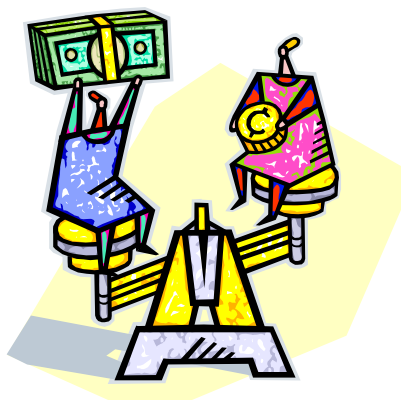
**Purpose and anticipated benefits:** Understanding how people with disabilities regard their participation in independent living and in society and whether people from “emerging” disability groups and those from “traditional” disability groups prioritize issues similarly can be used to address fair representation in policy decisions.



**Who:** Glen White and Dot Nary, (as viewed in photographs to the left) with the assistance of University of Kansas researchers Jim Budde and Hoang Yen Vo and funded by the National Institute on Disability and Rehabilitation Research worked with 14 representatives from the Association of Programs in Rural Independent Living and National Council on Independent Living, representatives of emerging disability groups, and other consumers who selected survey items from 300 suggestions. A total of 1,367 respondents returned the final survey. Of the respondents, 72% were female, 41% married, 20% divorced, 87% white, and 40% full- or part-time employees with an additional 8% self employed. Twenty-five percent reported \$550 to \$1,000 monthly incomes; 39% depended on SSDI. They reported 29 different disabilities with 50% having three or more disabilities. Multiple chemical sensitivity (32%) was the most frequently indicated disability.

**When:** 2001-2002

**Method:** Using the Consumer Concerns Report Method in which a working group of independent living experts was convened to choose disability concern survey items, the 48-item Full Participation in Independent Living National Survey with an additional 18 demographic questions addressed topics of concern, including consumer control, housing, health care, advocacy, community services and access, transportation, parenting, the media, personal assistance services, recreation, voting, assistive technology, peer counseling, education, employment, vocational rehabilitation, and center for independent living services. Item ratings were based on the highest and lowest percent of difference between importance and satisfaction. This survey was distributed throughout the nation by disability groups, mailing lists, chat rooms, websites, and conference exhibit tables. Responses were solicited on paper using Scantron forms and accompanied by a Braille card (with a toll-free number to call for assistance), online, and by email. Upon request, both an email and paper and pencil version of the survey in Spanish were made available. While dissemination of this Spanish version did not result in the receipt of any responses, the request provided valuable information about persons wanting to be heard, and about additional populations to include in the future. More than 1,300 responses were received with all 50 states represented, plus the District of Columbia. Presentations to solicit comments were done at two national conferences and through a national webcast.

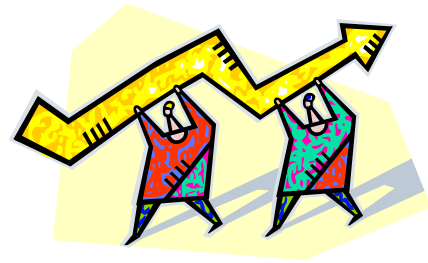


### **Results: Top 10 Problems Reported (All Respondents)**

1. Not earning enough in salary and benefits to meet living needs
2. Not getting the same employment opportunities as non-disabled applicants
3. Lacking affordable coverage for the purchase of assistive technology
4. Not being able to try a variety of assistive devices on trial basis before purchase
5. Not having the same chances for advancement and promotion as non-disabled employees
6. Not being identified fairly and accurately by the media
7. Lacking affordable comprehensive healthcare
8. Not having the service and support needed to obtain and succeed in employment
9. Getting healthcare from insensitive providers
10. Not having reasonable policies and practices related to purchase, repair, and replacement of assistive devices

### Top 10 Strength Reported (All Respondents)

1. Having available voter registration
2. Having accessible information and entertainment from the media (e.g., TV, radio, news, Internet, etc.)
3. Working with others for the rights of people with all types of disabilities/chronic health conditions
4. Making own personal decisions about life
5. Setting and pursuing own personal goals with or without help
6. Speaking up for what is needed and wanted
7. Accessing polling places in the community
8. Being accepted as members of the community
9. Having rights respected as a parent
10. Being allowed to worship and participate to the extent that you choose



**Conclusion:** Those with traditional and emerging disabilities shared similar concerns. Of all discussed concerns, employment and vocational rehabilitation were the top concerns of both groups. Adequate salary with benefits was of most concern. “The traditional and emerging disabled population continues to have high unemployment and underemployment rates. It remains among the poorest in the country,” said Dot Nary, The Research and Training Center on Full Participation in Independent Living, a division of the Research and Training Center on Independent Living at the University of Kansas. “Results indicate that there is 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,” Nary said.

**Quotation:** “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.” (p. 76) (Nary, D. E., White, G. W., Budde, J. F., & Vo, H. Y. (2004). Identifying the employment and vocational rehabilitation concerns of people with traditional and emerging disabilities. *Journal of Vocational Rehabilitation* 20, 71-77).

**Project output:** Besides a journal article — Nary, D. E., White, G. W., Budde, J. F., & Vo, H. Y. (2004). Identifying the employment and vocational rehabilitation concerns of people with traditional and emerging disabilities. *Journal of Vocational Rehabilitation* 20, 71-77— there were several presentations and two webcasts, including: presentations at 2002 National Council on Independent Living conference; “Employment for Persons with Emerging Disabilities: Barriers and Facilitators to Participation” at the 2003 national conference of the National Council on Independent Living, Washington, DC; meeting with Dave Keer, National Institute of Disability Rehabilitation Research (NIDRR) project director, Richard Johnson, NIDRR Scholar Project officer, Steven Tingus, NIDRR director, and Troy Justesen, associate director of the White House Office on Domestic Policy; September 2002 webcast conducted by the National Council on Independent Living ILNET program titled, “Full Participation in Independent Living: What Does it Mean?”; November 2002 webcast conducted by Research Information for Independent Living (a joint project of the RTCIL at the University of Kansas and the Independent Research Utilization Project at TIRR in Houston), titled “Full Participation in Independent Living: Are We Making Progress?”; meeting with seven disability service providers and activists from Korea in November 2002 on site; presentation at summit meeting in Washington, DC, sponsored by the DRRP on Emerging Disability and Employment Outcomes under the Institute on Community Inclusion; presentation titled, “Independent Living Centers as Community Change Agents” at the Great Plains ADA/IT Symposium in Kansas City in May 2003; presentation on access to health care services at the Kansas Cancer Partners’ Conference in Topeka, Ks., in March 2003.

**Additional resources:** For more information about employment and vocational rehabilitation, check out these sites:

- **Virginia Commonwealth University** “Information, resources, research, about work and disability issues” at <http://www.worksupport.com/>
- **University of Wisconsin-Stout Research and Training Center** at <http://www.rtc.uwstout.edu/>
- **Job Accommodation Network**, a free consulting service designed to increase the employability of people with disabilities, at <http://janweb.icdi.wvu.edu/>