



NCDDR

2001 Survey Report:

Highlights of Findings

April 2002



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Foreword

The National Center for the Dissemination of Disability Research (NCDDR) engages in an annual survey activity to help increase the knowledge base in the National Institute on Disability and Rehabilitation Research (NIDRR) community regarding dissemination and utilization (D & U) of disability research findings. The survey focuses on obtaining information across major groups invested in disability research. A key component of the survey activity is to gain knowledge about what kinds of disability-related research are important to consumers, how consumers prefer to receive disability research information, and how the use of computers and the Internet/Web are helping consumers' search for information. The knowledge gained helps to inform researchers from the NIDRR community concerning how consumers with disabilities and their families obtain and use disability research information.

During its pilot project phase (1995-1999) the NCDDR conducted several national surveys to establish a baseline about consumers' interest in disability research information and their ability to access such information. In 2000 and 2001 the foci were expanded to learn about consumers' and stakeholders' interests in specific disability research areas, preferences on ways to obtain information, identification of easily accessible sources, and ways that consumers from different racial and ethnic backgrounds prefer to access disability research information.

In this report, major findings are highlighted based on consumer, stakeholder, and NIDRR grantee feedback.¹ Findings from the annual NCDDR investigations are reported to provide D & U insights and suggestions that the NCDDR and other NIDRR grantees can most effectively and efficiently employ in conducting D & U to consumers and targeted groups.

¹ Additional information and complete *NCDDR 2001 Survey Report* findings are available upon request from the NCDDR.

General Information, 2001

Three major groups were surveyed in order to obtain different perspectives about D & U of disability research information. The groups included:

- *Consumers* (individuals with disabilities and their families),
- *Stakeholders* (key audiences including direct disability service providers, representatives from consumer-oriented organizations, health care providers, journalists, and staff from advocacy groups), and
- *Researchers* (NIDRR grantees).

The *consumer* group was the largest group surveyed (n=1,028). This group consisted of individuals with disabilities and their families who participate in Independent Living Centers (ILC) across the country.

- Administrators of ILCs were contacted by NCDDR staff and invited to participate in the research activity by distributing the survey to at least five individuals with disabilities who participate in their ILC.
- Spanish and alternate format surveys were available and sent upon request.
- Responses were received from 175 ILCs, or 47% of the 374 centers contacted.

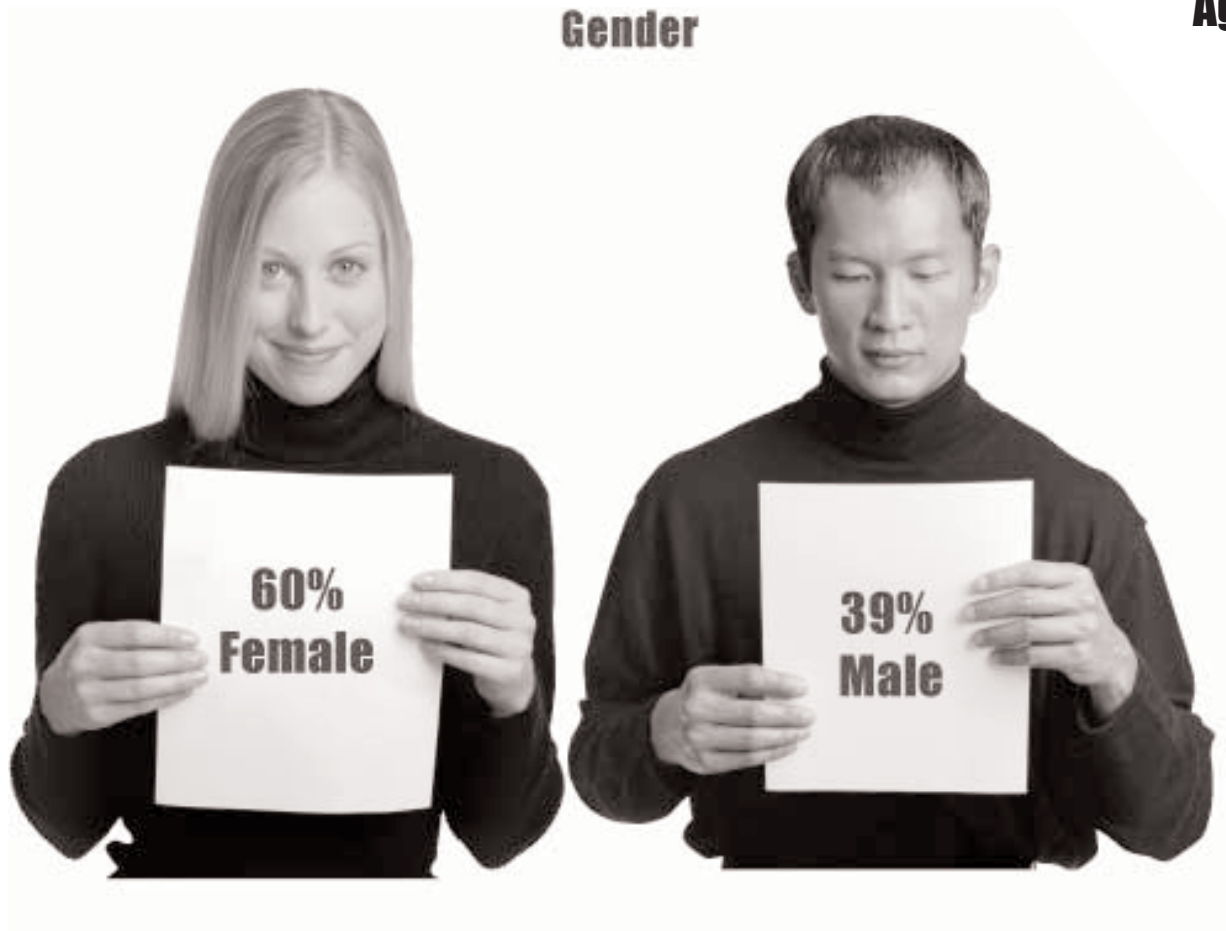
Stakeholders were the second largest group surveyed (n=340). This group consisted of representatives from various organizations that focus on more direct consumer contact. Representative groups were chosen from the following categories and sent a survey to complete.

- Staff from advocacy groups or organizations
- Staff from local and state committees on employment
- Representatives from consumer organizations
- Direct disability service providers
- Health care providers
- Journalists (mainstream and disability media)
- State directors of special education
- State vocational rehabilitation agency directors

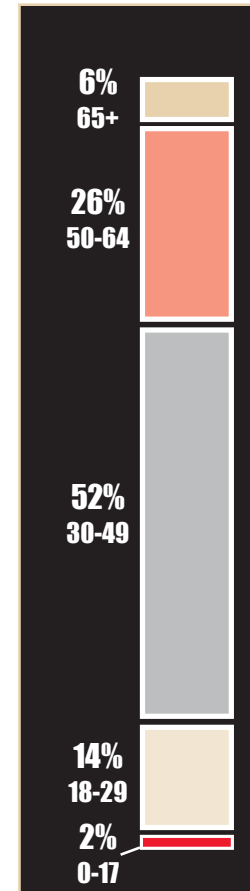
Researchers were the third largest group surveyed and consisted of NIDRR grantees (n=166). Because a key focus of the survey activity is to provide knowledge to the NIDRR community on how their perspective of D & U might differ from that of the *consumers'* perspective, only NIDRR-funded *researchers* were included in the *researchers* category.

Responses were received from 166 NIDRR grantees, or 48% of the 346 grantees invited to participate.

Who are the consumers?



Age in years (male and female)



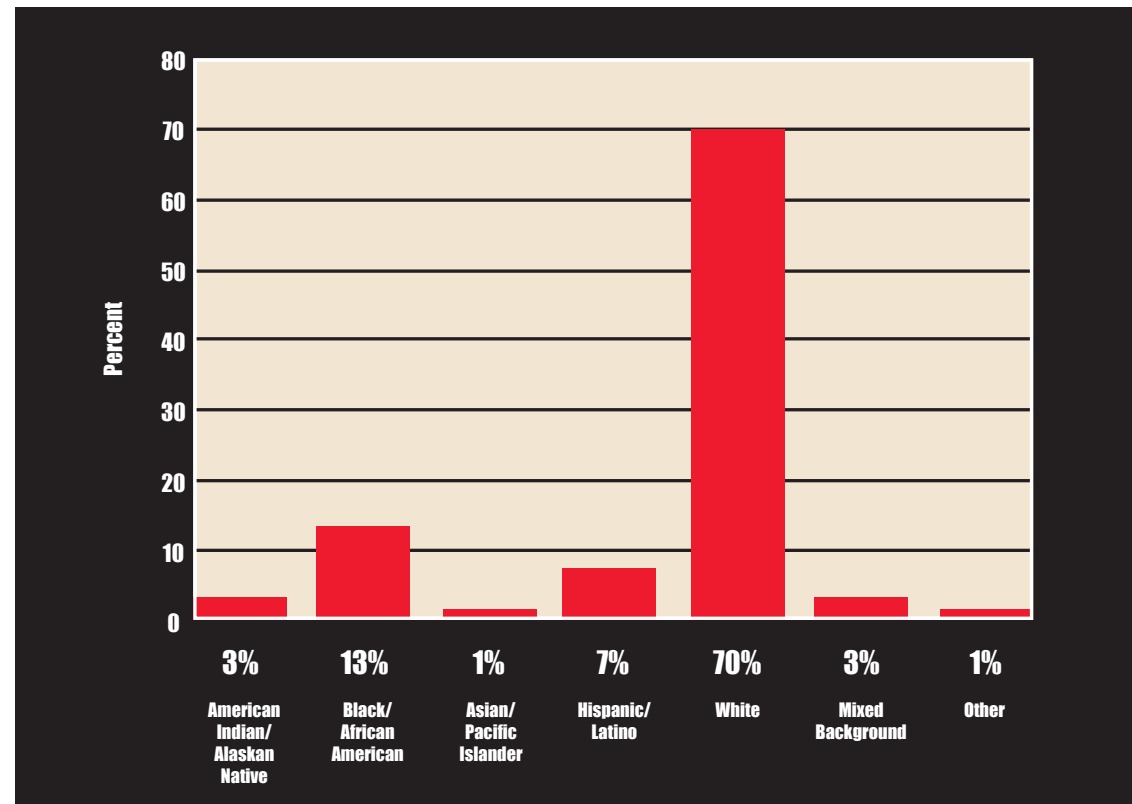
Basic demographic data, including gender, age, racial or ethnic category, disability category, geographic locale, and current employment status, were provided by the *consumers*. The majority of the *consumers* were female, and 52 percent of the *consumers* reported they were 30-49 years old.

Who are the consumers?

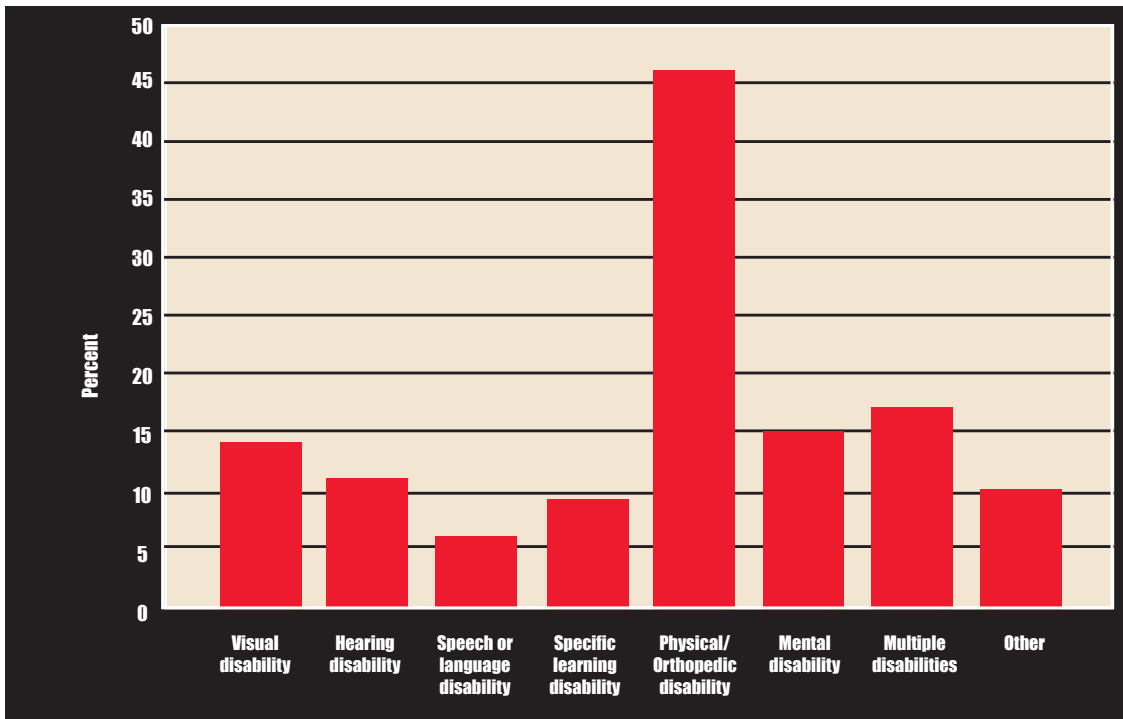
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Data were gathered to learn more about the information needs of *consumers* with disabilities from different racial or ethnic backgrounds. The respondents were asked to self-identify from five major racial or ethnic categories as well as “mixed background” and “other.” The majority of respondents selected a discrete category for self-identification. Of the few who selected “mixed background” and “other,” most indicated a mixed category consisting of “White” and “American Indian/Alaskan Native,” “Black/African American,” or “Hispanic/Latino.”

Racial or ethnic category



Disability category

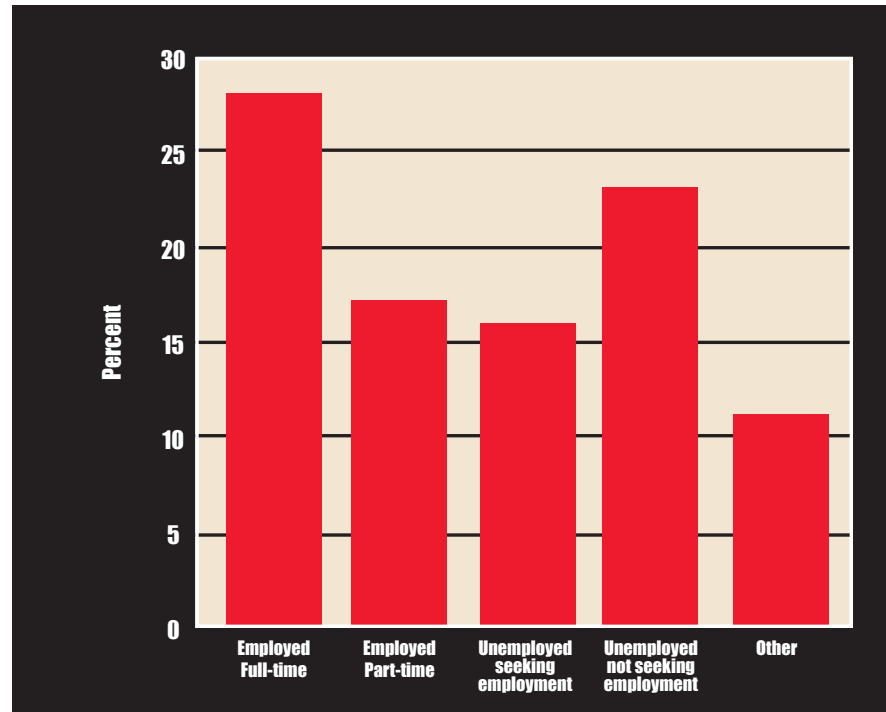


Consumers were asked to indicate which category best describes their disability. Of seven major categories provided, the majority indicated “physical/orthopedic disability,” while six percent indicated “speech or language disability.” Responses for “other” disability varied and some examples of the responses included diabetes, epilepsy, cancer, lupus, depression, cerebral palsy, and fibromyalgia.

Geographic locale



Employment status

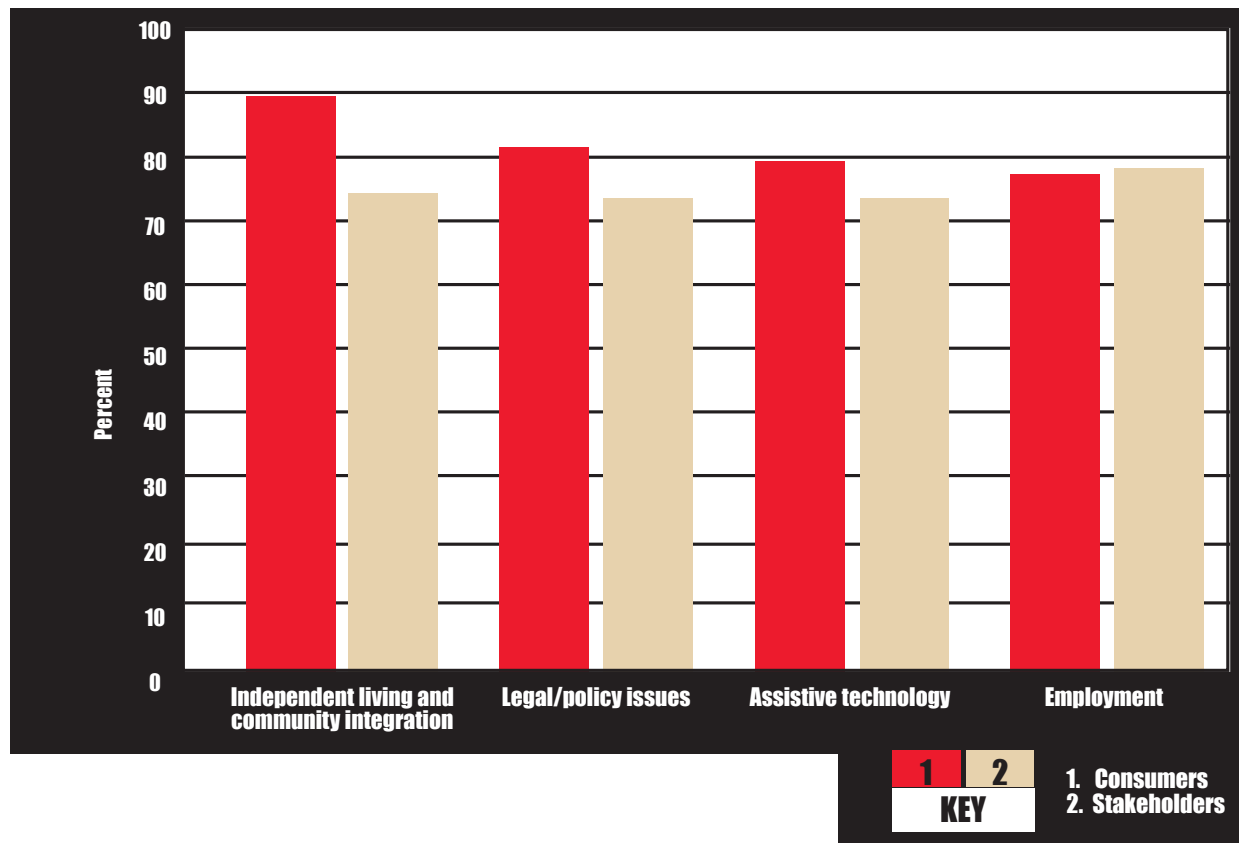


The majority of *consumers* were from “urban/suburban” areas. Twenty-eight percent of the *consumers* reported they were “employed full-time,” while 23% reported they were “unemployed and not seeking employment.” Written in responses for the “other” employment status included full-time student; receiving Social Security (SS), Supplemental Security Income (SSI), or Social Security Disability Insurance (SSDI); disabled and unable to work; retired; self-employed; and stay-at-home parent of a child with a disability.

What disability research areas are most important to consumers? to stakeholders?

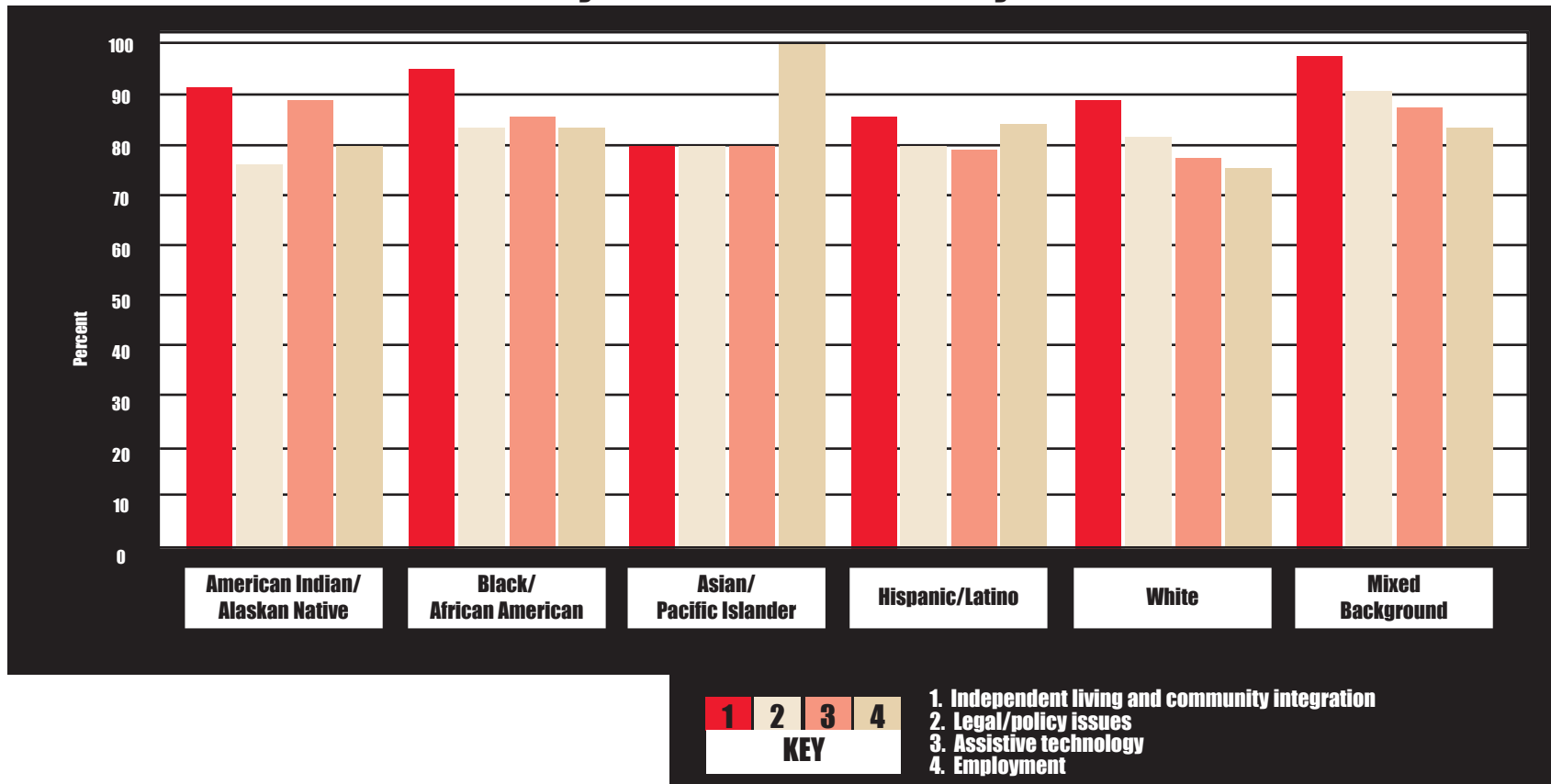
To learn more about *consumers'* and *stakeholders'* research area interests, both groups were asked to indicate the research areas they deemed most important. Out of seven research areas listed, both the *consumers* and the *stakeholders* selected the same four areas as most important: independent living and community integration, legal/policy issues, assistive technology, and employment. While the *consumers* indicated that “independent living and community integration” was the most important area, the *stakeholders* believed that “employment” was a more important research area.

Disability research areas of most importance



What disability research areas are most important to consumers? to stakeholders?
continued

Disability research areas of most importance by consumer race and ethnicity

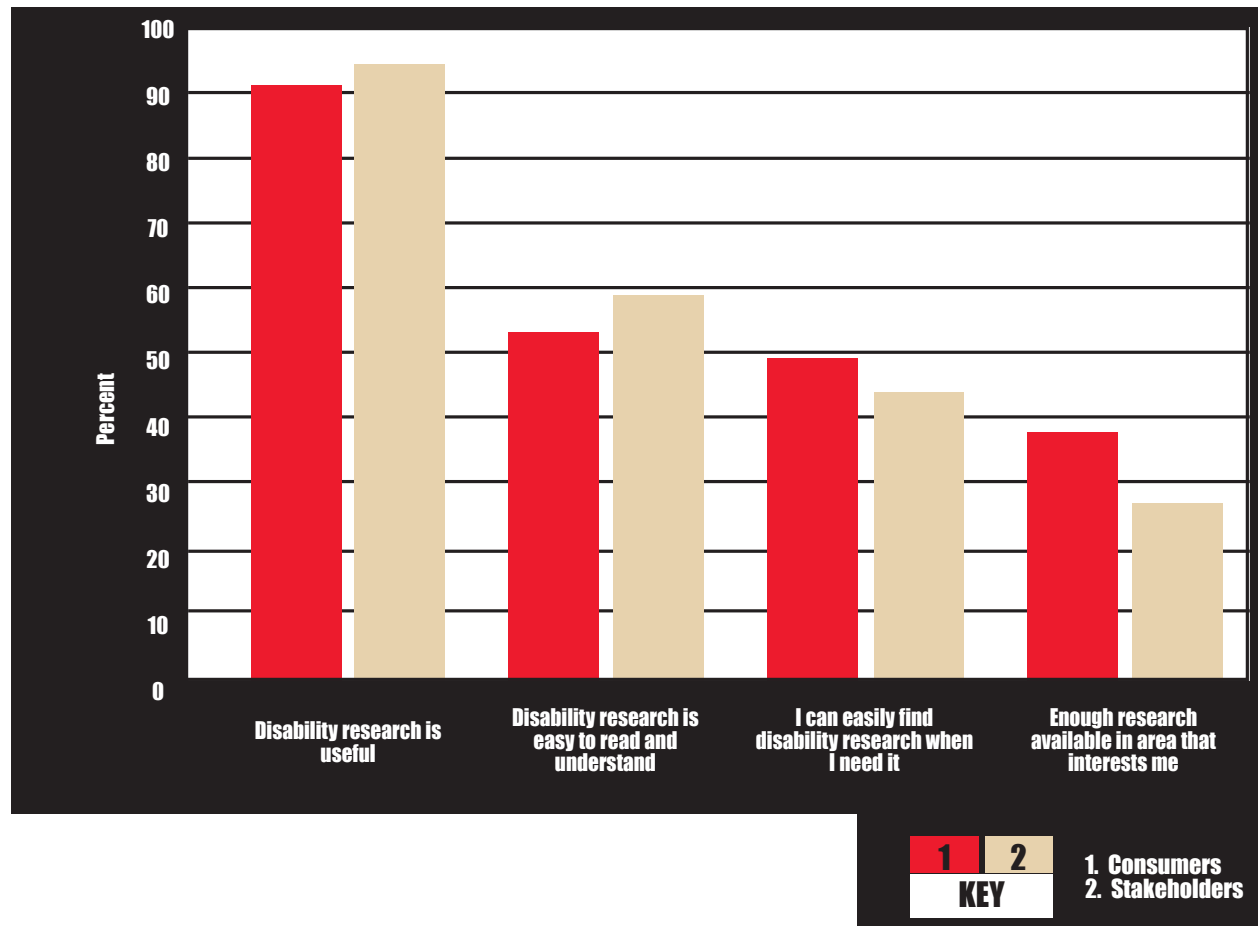


When comparing *consumers* by racial and ethnic backgrounds, “independent living and community integration” was reported as the most important research area. However, the Asian/Pacific Islander group differed in this response and indicated “employment” as the research area of most importance.

What do consumers and stakeholders think about disability research?

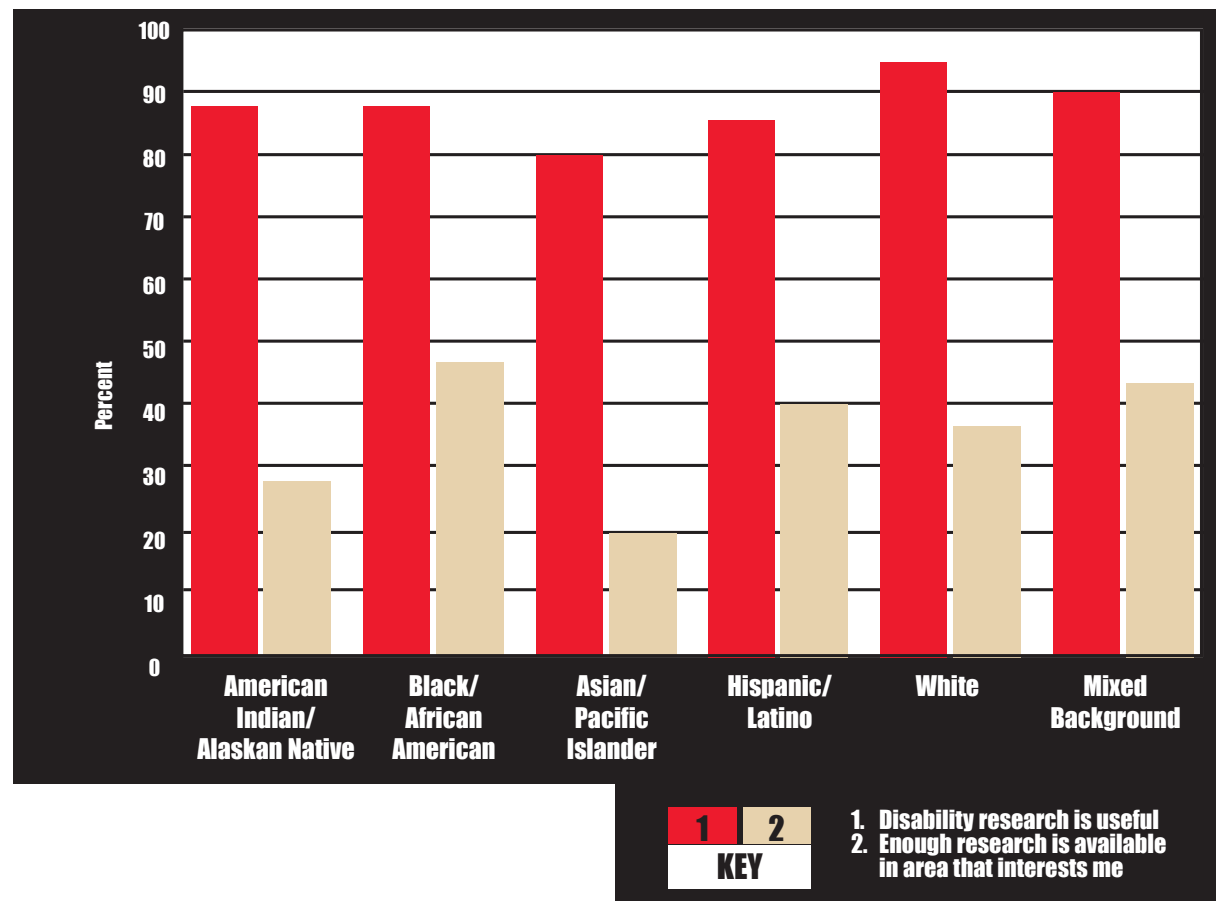
Ninety-one percent of the *consumers* and 94% of the *stakeholders* believed that “disability research is useful.” In contrast, both *consumers* (38%) and *stakeholders* (27%) indicated limited agreement with the statement “there is enough disability research available in the area that interests me most.” *Consumers* indicated limited agreement with other statements including “disability research is easy to read and understand” (53%); and “I can easily find disability research when I need it” (49%).

What consumers and stakeholders think about disability research



Across all racial and ethnic groups sampled, *consumers* believed that “disability research is useful” at a rate of 80% or higher. There was less agreement with the statement “there is enough disability research available in the area that interests me most.” Forty-six percent of the Black/African American group agreed with this statement, while 40% of the Hispanic/Latino group, 36% of the White group, 27% of the American Indian/Alaskan Native group, and 20% of the Asian/Pacific Islander group agreed with this statement.

What consumers from different racial and ethnic backgrounds think about disability research



When looking for disability research information, what approaches do consumers use most often?

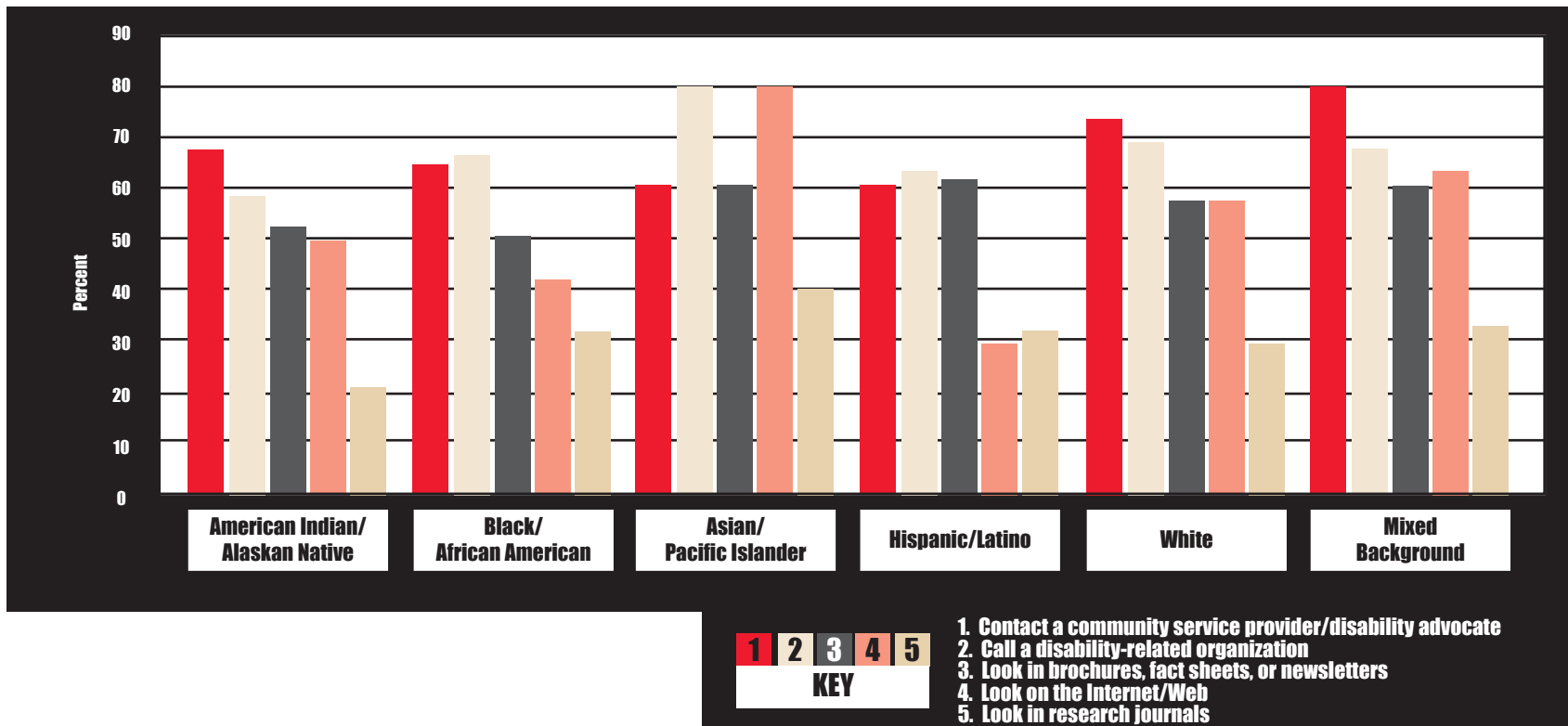


Approaches used by consumers to obtain disability research

Out of 10 response choices, four approaches were selected by more *consumers* as ways to obtain disability research. Fewer *consumers* selected the approach of “looking for it in research journals.” Responses indicated that 70% of the *consumers* selected “contacting a service provider,” while 68% selected “calling an organization,” 56% selected “looking in brochures,” and 54% selected “looking on the Internet/Web” as approaches to obtain disability research. Obtaining disability research by “looking for it in research journals” was selected by 30% of the *consumers*.

When looking for disability research information, what approaches do consumers use most often?
continued

Approaches used to obtain disability research by consumer race and ethnicity

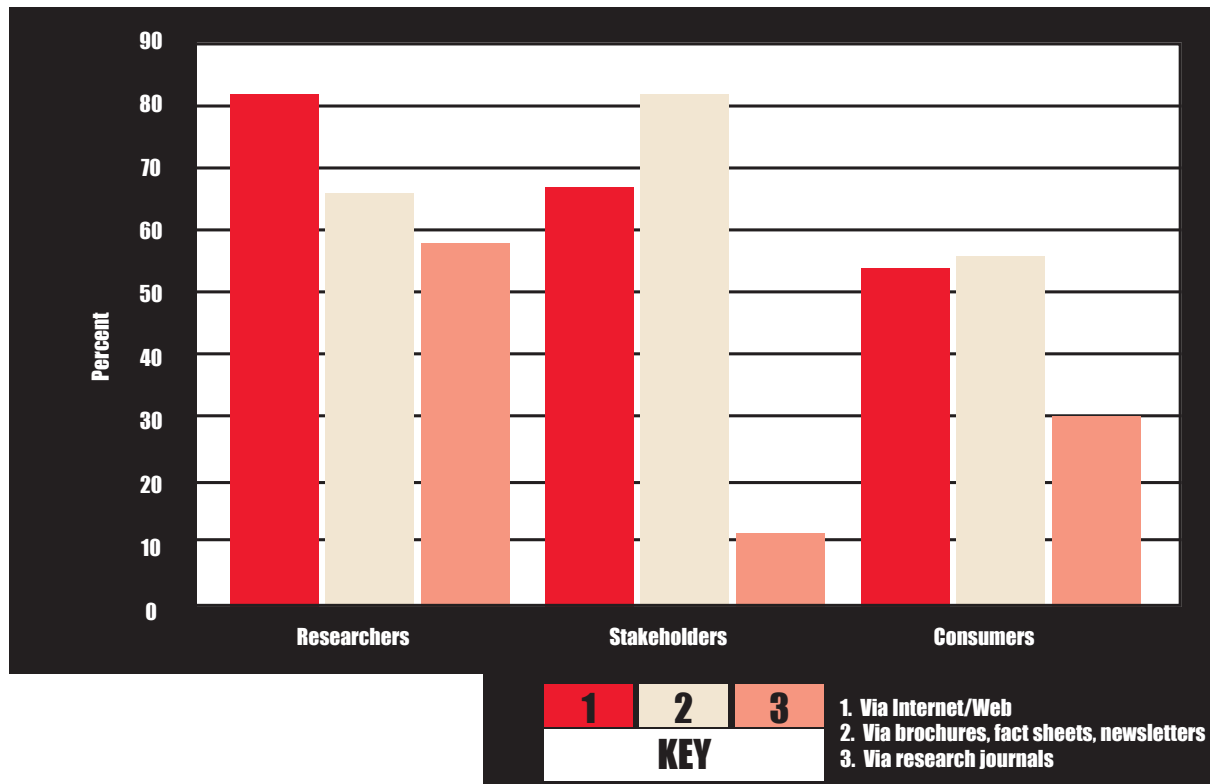


In contrast, more Black/African American, Asian/Pacific Islander, and Hispanic/Latino *consumers* indicated they used “calling a disability-related organization,” while fewer reported “contacting a community service provider.” Fewer *consumers* from all groups, except the Hispanic/Latino group, reported they obtained disability research by “looking for it in research journals.”

How do the approaches that consumers use most often compare with how often stakeholders and researchers use these strategies to disseminate disability research information to consumers?

From the approaches used by *consumers* to obtain disability research, three were directly comparable to *researchers'* and *stakeholders'* use of dissemination strategies. Eighty-two percent of *researchers* indicated they used the Internet/Web, 66% used brochures, and 58% used research journals to disseminate disability research findings; overall *consumers* used these approaches less frequently to obtain disability research information.

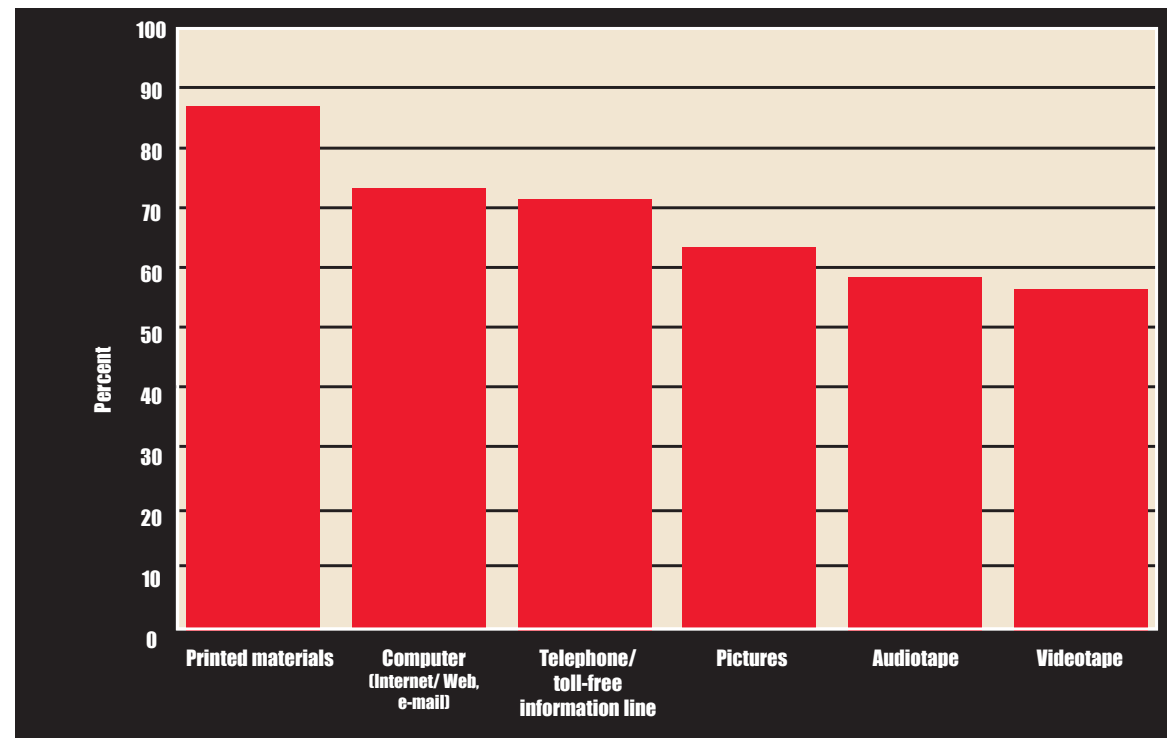
Comparison of consumers' approaches to obtain disability research and researchers'/stakeholders' dissemination strategies



How do consumers prefer receiving disability research information?

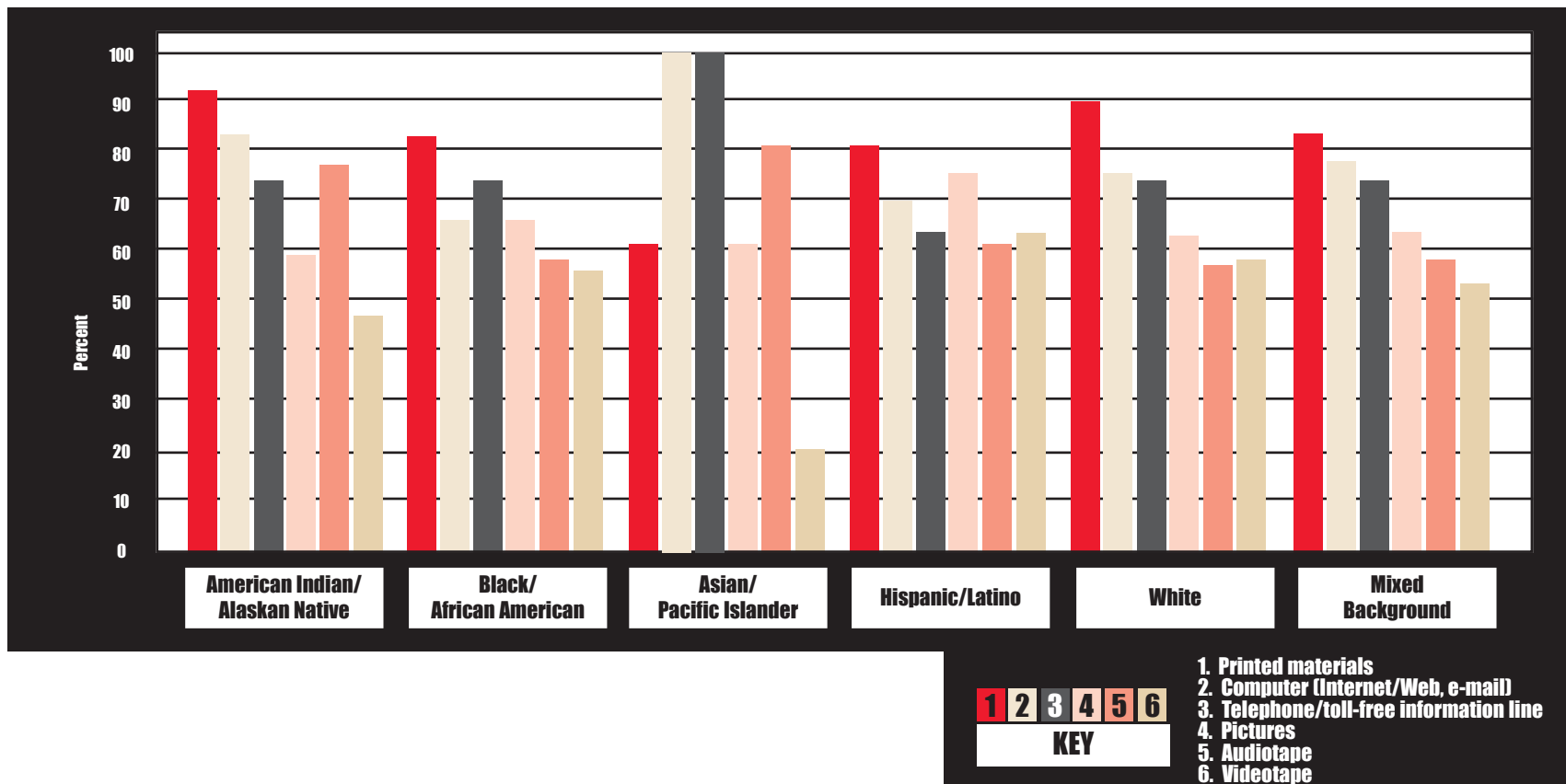
Eighty-seven percent of consumers indicated they preferred receiving disability information via “printed materials.” Other preferred formats of consumers included the “computer” (73%) and the “telephone/toll-free line” (71%). “Pictures,” “audiotape,” and “videotape” were alternate formats indicated as desirable formats by over 50% of the consumers.

Formats preferred by consumers when receiving disability research information



More consumers from different racial and ethnic backgrounds reported “printed materials” as a preferred format except for the Asian/Pacific Islander group. More Asian/Pacific Islander consumers reported “computer” and “telephone/toll-free information line” as preferred formats. “Computers” was selected as a preferred format by 69% of the Hispanic/Latino group.

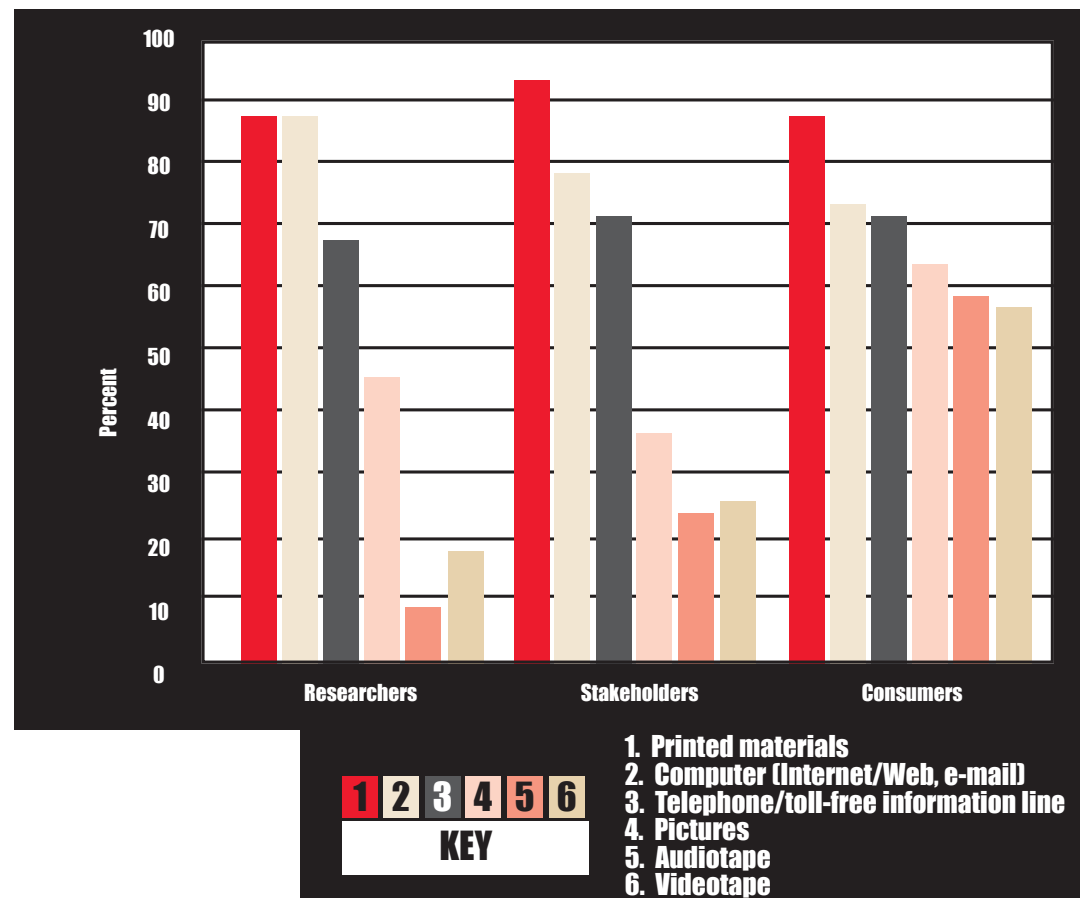
Preferred formats for receiving disability research information by consumer race and ethnicity



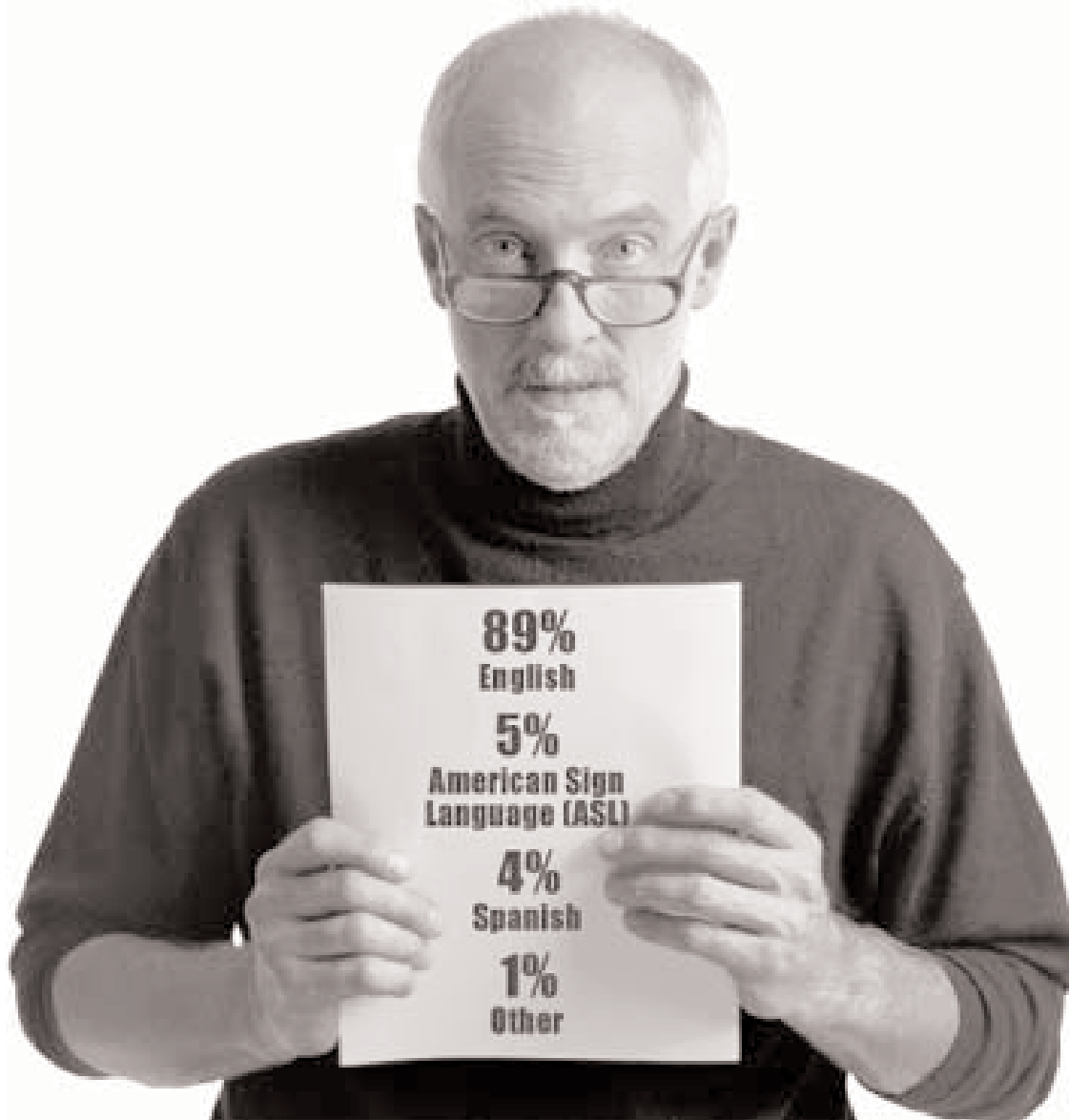
How do the consumers' preferred formats compare with how often stakeholders and researchers use these formats to get disability research information to consumers?

A comparison of *consumers'* six most preferred formats to how often *researchers* and *stakeholders* use these formats to disseminate information indicated that discrepancies exist between what *consumers* prefer and what *researchers* do. "Printed materials" was equally preferred by both *consumers* and *researchers* as a format. Survey results suggest *researchers* may be under-utilizing the dissemination strategies of pictures, audiotapes, and videotapes when targeting *consumers*.

Comparison of consumers' preferred formats and researchers' and stakeholders' use of these formats to disseminate disability research



What language do consumers most often prefer when receiving disability research information?



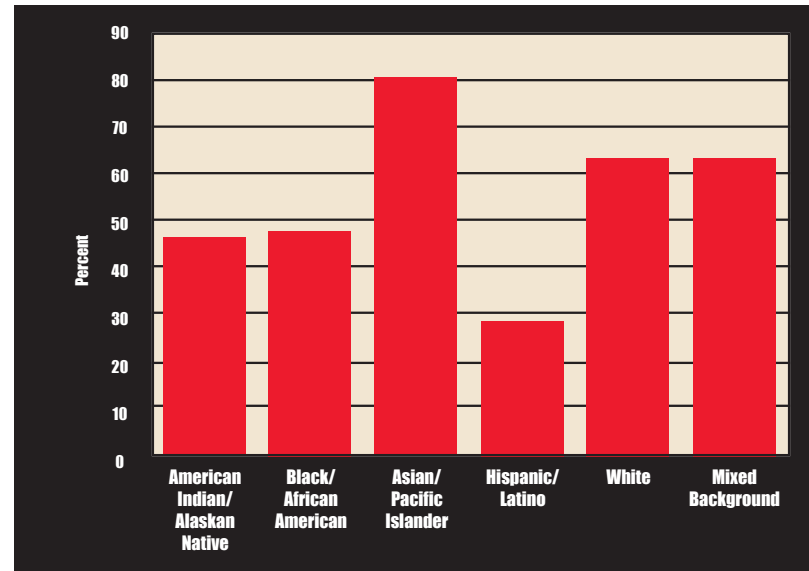
Consumers overall preferred English as the language for receiving disability research information. Among the racial and ethnic groups, all consumers indicated a preference for English, except for the Hispanic/Latino group. Fifty-one percent of this group preferred English, while 41% indicated Spanish as a preference.

Do consumers have a computer in their home that is available for their use?

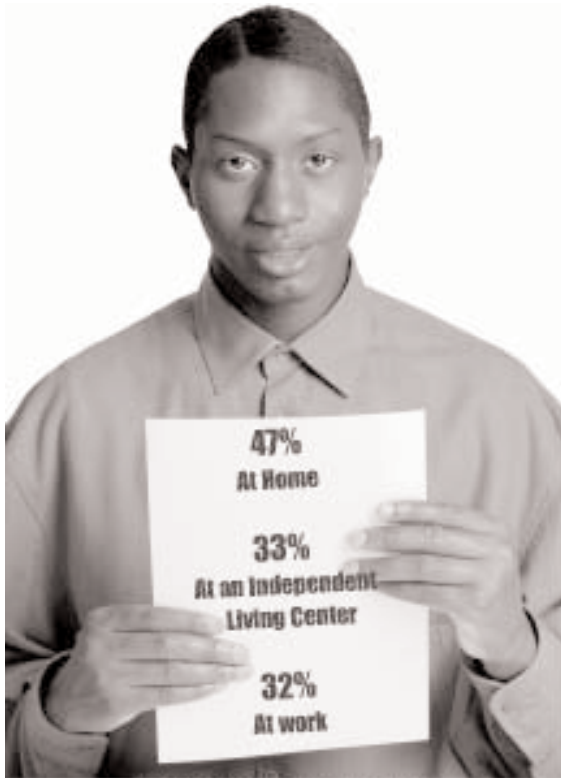
While the majority of *consumers* (58%) reported they have a computer at home, access differed across racial and ethnic groups. The group with the least access to a home computer was the Hispanic/Latino group. Twenty-eight percent of the Hispanic/Latino group indicated access to a home computer, while 46% of the American Indian/Alaskan Native group and 47% of the Black/African American group reported access to a home computer.



Computer access at home by consumer race and ethnicity

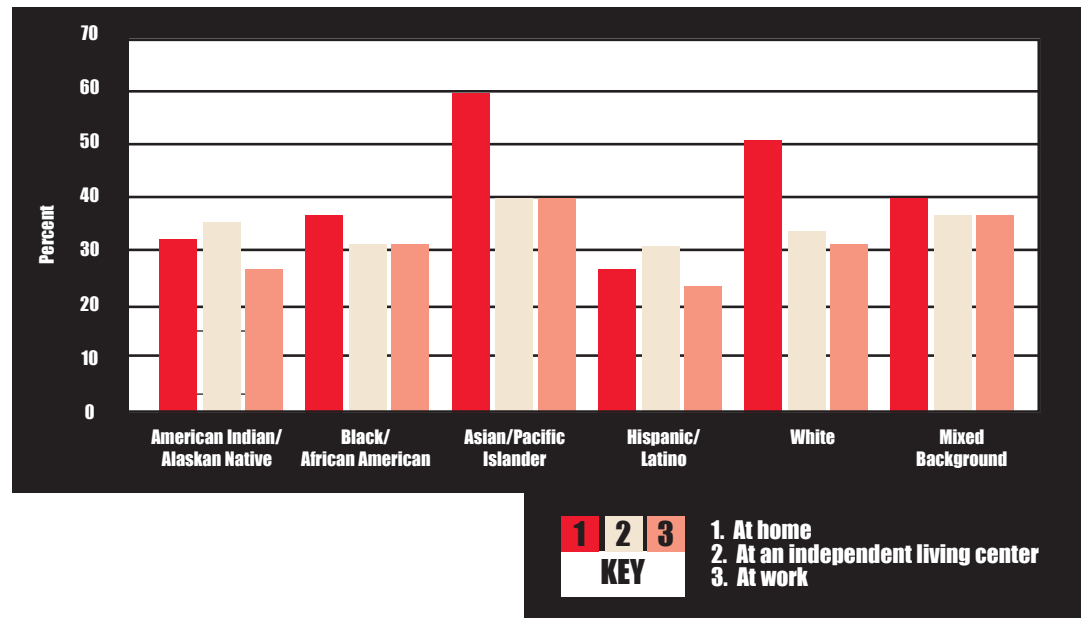


Where do consumers use the Internet/Web?



All consumers

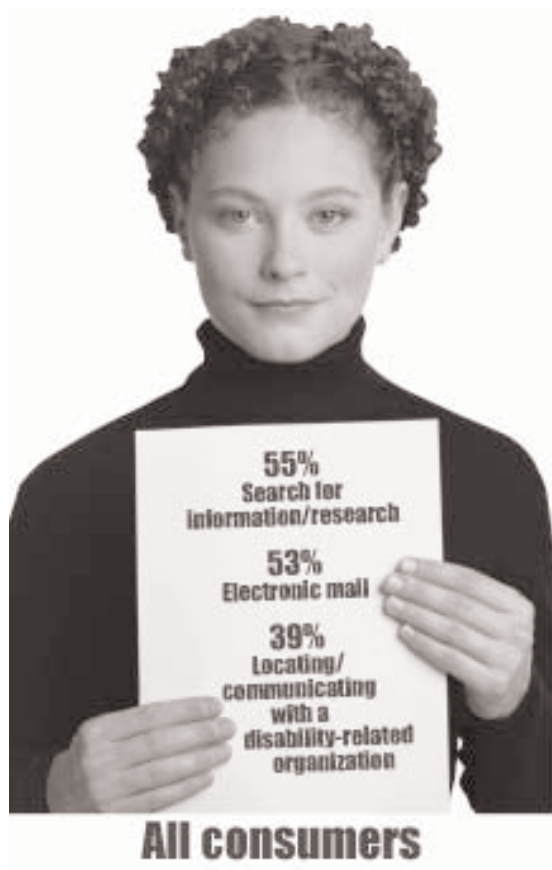
Where the Internet/Web is used by consumer race and ethnicity



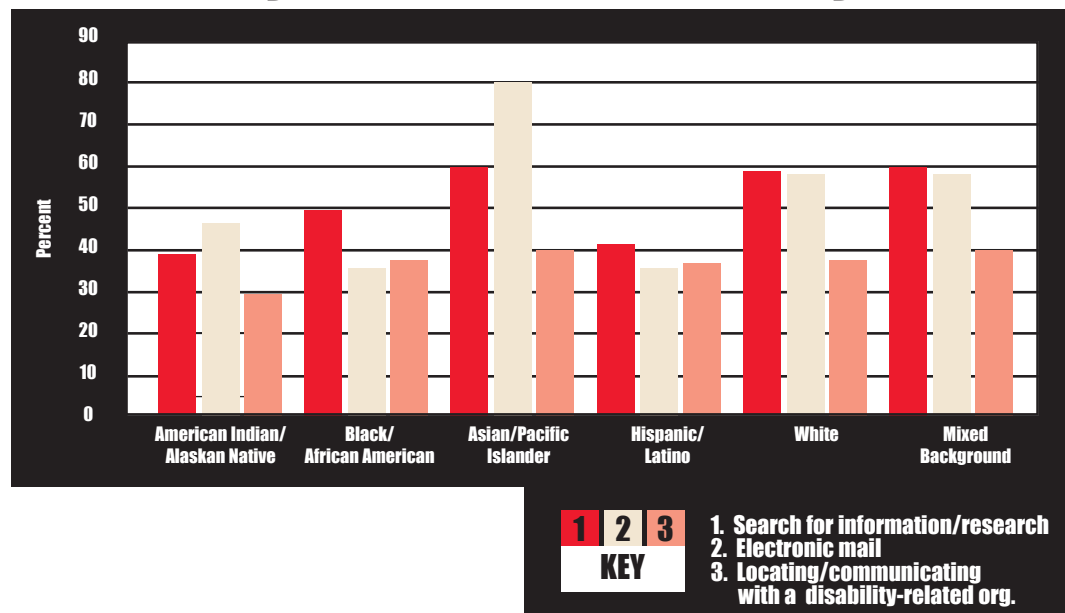
The Internet/Web was accessed most frequently at three places by *consumers* overall. More *consumers* (47%) reported using the Internet/Web at home. Across all racial and ethnic groups sampled, over 50% of the White and Asian/Pacific Islander groups used the Internet/Web at home. More Hispanic/Latino (32%) and American Indian/Alaskan Native (36%) *consumers* reported using the Internet/Web at an Independent Living Center.

Why do consumers use the Internet/Web?

Consumers who use the Internet/Web reported three main reasons for use. “Searching for information/research” was reported by 55%, while 53% reported “e-mail” and 39% reported “communicating with a disability-related organization.” Among the racial and ethnic groups, 46% of the American Indian/Alaskan Native group and 80% of the Asian/Pacific Islander group reported using the Internet/Web for “e-mail,” while 49% of the Black/African American group and 41% of the Hispanic/Latino group reported using the Internet/Web for “searching for information/research.”

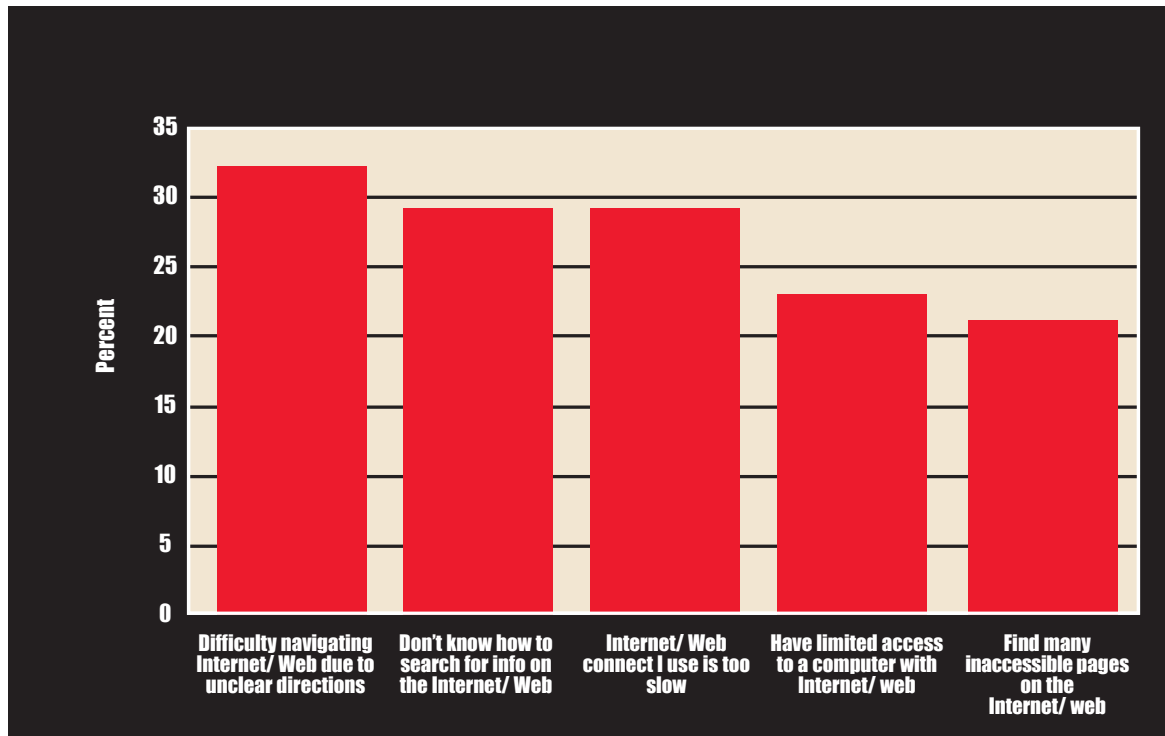


Why the Internet/Web is used by consumer race and ethnicity



What barriers do consumers encounter when seeking disability research information from the Internet/Web?

Barriers to Internet/Web use encountered by consumers

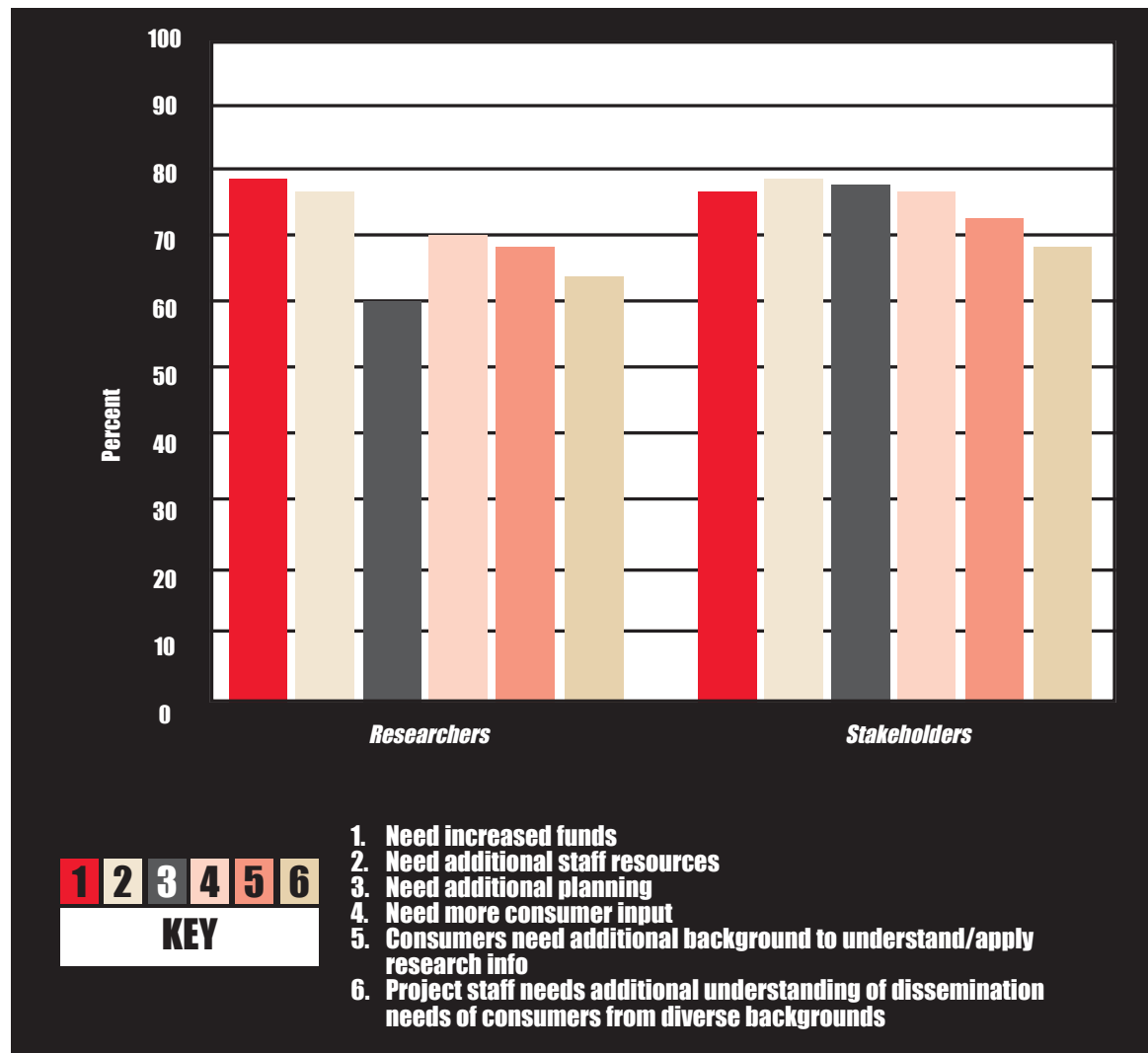


Out of eight response choices, five were selected by more consumers as barriers to Internet/Web use. Thirty-two percent of the consumers reported “difficulty navigating the Internet/Web due to unclear directions,” while 29% reported “don’t know how to search for info” and “connection I use is too slow” as barriers; 23% reported “have limited access to computer with Internet/Web” and 21% reported “find many inaccessible pages on the Internet/Web.” Write-in responses for “other” barriers included: general confusion over too much information, lack of training, lack of time, lack of adaptive devices, and too costly.

What difficulties do researchers and stakeholders experience in the dissemination of disability research information to consumers?

Both *researchers* and *stakeholders* indicated similar concerns that impact their dissemination of disability research information. Seventy-nine percent of *researchers* and 77% of *stakeholders* reported the “need for increased funds,” while 77% of *researchers* and 79% of *stakeholders* reported “need additional staff resources” as difficulties impacting dissemination. “Need more consumer input” was a concern for 70% of the *researchers*, while 75% of the *stakeholders* indicated this as a difficulty to dissemination activities.

Difficulties that impact dissemination activities



Summary and Conclusion

- The typical responding *consumer* was female, 30-49 years old, White, had a physical/orthopedic disability, and was from an urban/suburban area.
- Overall, the *consumer* group indicated a preference for English. Approximately one-half of the Hispanic/Latino group reported they preferred Spanish.
- *Consumers* were most concerned with research in the areas of independent living and community integration; legal/policy issues; assistive technology; and employment.
- Independent living and community integration was an area indicated as important to most American Indian/Alaskan Native, Black/African American, and Hispanic/Latino *consumers*.
- More Asian/Pacific Islander *consumers* reported employment as an important research area.
- Overall, the majority of *consumers* and *stakeholders* believed that disability research is useful, but fewer reported that there is enough research available in areas of interest to them.
- *Consumers* reported using different approaches to obtain disability research. They contacted community service providers; called disability-related organizations; looked in brochures, fact sheets, or newsletters; and looked on the Internet/Web. However, a smaller percentage of *consumers* looked in research journals for disability research findings. This was true for *consumers* from all racial and ethnic groups.
- Over one-half of the *researchers* reported they used the Internet/Web, brochures, and research journals to disseminate disability research findings; overall, *consumers* used these approaches less frequently to obtain disability research information.
- *Consumers* reported a preference for receiving disability research results via printed materials, computer, telephone, pictures, audiotape, and videotape formats. Over one-half of the *consumers* of all racial and ethnic backgrounds indicated that receiving information via pictures and audiotape was a preferred format.
- More Asian/Pacific Islander *consumers* reported computers and telephone/toll-free information line as preferred formats for receiving disability research information.
- A comparison of *consumers*' six most preferred formats for receiving disability research results to how often *researchers* and *stakeholders* use these formats to disseminate information indicated that *researchers* and *stakeholders* may be under-utilizing the dissemination strategies of pictures, audiotapes, and videotapes when targeting *consumers*.

- Less American Indian/Alaskan Native, Black/African American, and Hispanic/Latino *consumers* reported access to a computer at home than did all the other racial and ethnic groups.
- The group with the least access to a home computer was the Hispanic/Latino group. However, computers were selected as a preferred format by more than one-half of the Hispanic/Latino *consumers*.
- While the majority of *consumers* indicated they use the Internet/Web at home, more Hispanic/Latino and American Indian/Alaskan Native *consumers* indicated they use the Internet/Web at an Independent Living Center.
- More Black/African American *consumers* reported use of the Internet/Web at home and use of the Internet/Web to search for information and research.
- More *consumers* identified having difficulty navigating the Internet/Web due to unclear directions. Lack of knowledge on use, slow connections, limited access to the Internet/Web, and inaccessible pages on the Internet/Web were other barriers identified by *consumers*.

Results from the *NCDDR 2001 Survey Report: Highlights of Findings* provide information regarding ways consumers with disabilities find and access disability research information. Findings can be helpful in understanding the complexity of consumers' information needs characteristics. Although the results are based on relatively small samples, these highlights suggest that consumers with disabilities who are also from diverse racial and ethnic backgrounds do use a variety of sources and formats to access disability research information.



Shaping Excellence through Research

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NCDDR 2001 Survey Report Acknowledgements

The following groups of individuals were invited to provide responses to the survey. The NCDDR staff wishes to thank them for their participation in this research project.

- Consumers (individuals with disabilities and their families) from Independent Living Centers across the country,
- Administrators and staff of Independent Living Centers for their assistance in distributing the survey to consumers,
- Stakeholders (representatives from organizations that have consumer contact), and
- NIDRR Grantees (NIDRR-funded researchers).

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<http://www.ncddr.org/du/products/survey2001.html>





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The NCDDR assists, through information and technical assistance, National Institute on Disability and Rehabilitation Research grantees with identifying and crafting dissemination strategies. These strategies are designed to meet the needs of a grantee's unique target audience. NCDDR also analyzes and reports on dissemination trends relevant to disability research.



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