

National Survey of the Use of Assistive Technology by Adults With Mental Retardation

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Abstract: Although assistive technology provides a promising means to accommodate for barriers to independence and self-determination for people with mental retardation, such devices are underutilized by this population. The Arc conducted a national survey of the use of assistive technology by people with mental retardation. In four of five areas, the percentage of individuals who used a device was under 10%. In two of these areas, the percentage of individuals who might benefit from a device exceeded the percentage who used a device, and in a third area, the percentage using devices was nearly equal to those who did not use but might benefit from a device. Availability and cost were reported as primary barriers. Suggestions were made to address these issues.

In the *Findings and Purposes* section of the Technology-Related Assistance for Individuals with Disabilities Act of 1988 (e.g., Tech Act, P.L. 100-407), Congress stated that the provision of assistive technology devices and services to individuals with disabilities enables

individuals to: (A) have greater control over their own lives, (B) participate in and contribute more fully to activities in their home, school and work environments, and in their communities, (C) interact to a greater extent with non-disabled individuals, and (D) otherwise benefit from opportunities that are taken for granted by individuals who do not have disabilities. (p. 1044)

In the Tech Act (as it is frequently called) an *assistive technology device* was defined as

any device, piece of equipment, or product system, whether acquired commercially or off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. (Wallace, Flippo, Barcus, & Behrmann, 1995, p. 3)

The findings from Congress as noted in this Act illustrate the potential benefit associated with the use of assistive technology, including increased self-determination, independence, and integration. For a variety of reasons, however, assistive technology devices remain largely underutilized by people with mental retardation (Arc,

1993; Wehmeyer, 1995) and, as such, it seems likely that people with mental retardation do not fully benefit from assistive technology. There are a number of reasons for this underutilization (Parette, 1991; Perlman, 1993; Wehmeyer, 1995).

First, few devices have been developed to address the unique barriers introduced by cognitive impairments. Two contributing factors are the limited market for devices developed exclusively for people with mental retardation and the complexity and difficulty of designing devices to accommodate for cognitive impairments.

A second, related reason that people with mental retardation may not use assistive technology devices is that these mechanisms are too complex to operate. Perlman (1993) interviewed individuals with mental retardation to identify potential barriers to their use of assistive devices, and among the concerns identified across these interviews was the need for simpler instructions and devices that are easier to operate. There are a number of devices across multiple domains, from adaptive communication to home environment control devices, that could

be of benefit to people with mental retardation if they were less complex to operate.

Third, people with mental retardation may not take advantage of assistive technology because of a lack of knowledge about the availability of specific devices or support to use and maintain them. Individuals or their families may not know specific devices exist, may not know how to purchase or obtain funding for them, or may not have the training and support needed to adequately utilize the device.

Unfortunately, very little is known about the degree to which people with mental retardation need or use assistive devices or about the barriers to this outcome. Wehmeyer (1995) noted that existing research on use of assistive technology by people with mental retardation is focused primarily on teaching individuals with mental retardation to use specific devices, evaluating the efficacy of using assistive devices compared with other procedures, or using technology to assess functional needs (e.g., Datillo, 1987; Realon, Favell, & Dayvault, 1988; Realon, Favell, & Phillips, 1989). These and other studies have shown conclusively that individuals with mental retardation can use and benefit from assistive technology devices. The present study was designed to test the hypothesis that such devices are generally underutilized by people with mental retardation and to examine barriers to such use.

Method

Procedure

The Assistive Technology Use Survey (described in the Instrument section) was mailed to 5,400 members of The Arc, a national organization on mental retardation. Members were identified from the national membership list as having a family member with mental retardation. Because many people with mental retardation have difficulty responding in detail to questions about technology use, including issues related to funding, device availability, training, and device complexity, we determined that the most reliable respondent would be the parent or caregiver. As such, the survey was written to be completed by a family member or other caregiver knowledgeable about the person's assistive technology use. Survey recipients were informed that their name had been randomly selected from the membership list, and they were asked to complete the survey and return it to The Arc in an accom-

panying self-addressed stamped envelope. A total of 1,802 completed surveys were returned (a response rate of 33%). The data presented here reflect the analysis for technology use by adults with mental retardation.

Sample

The sample included 1,218 family members (or other adult knowledgeable about the assistive technology use of someone with mental retardation) from 47 states and the District of Columbia who returned completed surveys. Each respondent was asked to provide demographic information about the person to whom the responses applied. The age for these individuals with mental retardation ranged from 20 to 80 years (mean = 35.65, standard deviation [SD] = 10.42). The 651 men ranged in age from 20 to 80 years (mean = 35.41, SD = 10.36), and the 561 women ranged in age from 20 to 78 (mean = 35.87, SD = 10.49). Gender identification was not provided by 6 respondents. With regard to residence, 686 respondents indicated that the person with mental retardation lived at home with them; 518 reported that their family member lived elsewhere, including 11 with a spouse in a house or an apartment, 10 in a foster home, 287 in a supervised group home or nursing home, 27 with another relative, 31 with a friend or another person in a house or apartment, and 66 alone in a house or apartment. Eighty-six respondents indicated that their family member resided outside the family home but did not identify that location or listed "other," and 14 respondents did not indicate where their family member resided.

Instrument

Project staff conducted an extensive review of the literature to identify survey instruments designed to evaluate technology use by individuals with disabilities. Although this search yielded some unpublished studies reporting the outcome of surveys of technology use by people with mental retardation (Parette & VanBiervliet, 1990; Perlman, 1993), no extant measures were reported or available. Based on the existing literature on assistive technology, I developed a pilot-version of a survey instrument to examine technology use in the areas of mobility, hearing and vision, communication, home adaptation, and environmental control and independent living as well as the use of personal computers.

This pilot instrument was sent to a random sample of 250 members of The Arc to evaluate its utility. I used the responses to revise the survey (see Wehmeyer, 1995). The final survey consisted of five areas of questions focusing on the use of assistive technology for a specific purpose (i.e., mobility, hearing and vision, communication, home adaptation and access, environmental control, and independent living) and the use of personal computers. The five use-specific areas consisted of the same questions specific to that purpose. For example, respondents were first asked whether their family member used a mobility technology device. If they responded yes, they were directed to check which device was used (crutch, cane, or walking stick; walker, wheelchair, scooter, other) and respond to a follow-up question on funding for the device (private insurance, personal funds, charitable donation, school/agency program, Supplemental Security Income (SSI)/Plans for Achieving Self-Sufficiency (PASS) or government funding, other). In addition, they were asked whether the family member with mental retardation received adequate assessment or evaluation services before purchasing the device and information about how to appropriately and effectively use the device. They were then instructed to rank satisfaction with the device on a Likert-scale ranging from 1 (*not satisfied*) to 5 (*very satisfied*).

If respondents indicated that their family member with mental retardation did not use a mobility technology device, they skipped to a question that asked whether they could potentially benefit from such a device. If they responded yes, they were asked to identify the beneficial device and to check all relevant barriers to their family member using or benefiting from a mobility device. The barriers listed were lack of funding and/or high cost of device, little information about product, assessment/evaluation not available, product unavailable, device too complex for person to use, product upkeep too difficult, inadequate training for person to learn device, staff fail to upkeep/help use, and other.

The same questions appeared in the other four use-specific areas, with the substitution of the relevant domain area and available devices in that area. In the hearing and vision technology section, potential device choices included text reader, adapted computer keyboard, special alarm,

Braille printer, white cane, hearing aid, and other hearing or vision device. In the communication technology section, potential device choices included synthesized speech communicator, telecommunications device for the deaf/teletype (TDD/TYY), picture book, touch or point system, light- or switch-operated system, or other communication device. Choices in the home adaptations section included ramps, extra wide doors, stair lift, hand rails, raised toilet, adapted door locks, lowered counters, slip resistant floors, or other home adaptations. Finally, available choices in the environmental control and independent living section included adaptive eating device, button hooks or other dressing implements, adapted telephone, switches for leisure/play device, rocker knife, spoon/fork grip, or other adapted utensils for eating, switches for independent living, environmental control unit, or other environmental control and independent living devices.

In the final survey area personal computer use was examined. Respondents noted whether there was a computer in their home and, if so, whether it was purchased specifically for the family member. If the answer was yes, they were asked to identify how the computer was paid for (e.g., personal funds, Medicaid). The respondent then had to report whether the family member with mental retardation had access to a computer in any environment and if so, specify which environment (family home, recreational and leisure environment, living residence other than family home, day activity program or school, place of employment, other). If the respondent indicated yes, they were asked to identify how their family member used the computer (educational activities, household finances and budgeting, recreational and leisure activities, work-related activities, communication, other). If respondents indicated that their family member did not have access to a computer in any environment, they were asked whether they thought their family member could benefit from such access and instructed to check relevant barriers to computer access (e.g., lack of funding, little information) (See author's note for further information about survey.)

Analyses

Surveys were coded by project personnel, who entered and analyzed data using SPSS for

Windows (Norusis, 1992). Responses to each question were analyzed by purpose-specific or device-specific questions using a crosstab procedure that provided frequency counts.

Results

Device Use

Table I provides the number and percentage of respondents who indicated that their family member used technology in each of the five purpose-specific areas and the number and percentage who reported that their family member did not currently use an assistive device but would benefit if they did. Table 2 provides information regarding the degree to which respondents whose family member used assistive technology indicated they received adequate evaluation and training services and the degree to which these individuals and their family members were satisfied with the device.

The most frequently identified device used for mobility purposes was a wheelchair (n = 110). Users of hearing aids constituted the largest group of hearing and vision device users (n = 58), with "other" the second most common response (n = 51). The vast majority of respondents who checked "other" indicated that their family members used eye glasses to correct problems with vision. No respondents indicated use of a text reader or adapted keyboard. Of the listed commu-

nication devices, the most frequently reported in use were nonspeech touch or point systems (n = 19), picture systems (n = 18), and synthesized speech devices (n = 12). The largest number (n = 25) indicated "other," the option for communication devices that were not listed. In the home adaptation category, 40 respondents noted that they had installed extra wide doors, 59 had installed hand rails, 57 had installed a ramp, 34 indicated raised toilets were available, and 31 respondents reported that they had other home adaptations (respondents often selected multiple adaptations). From the environmental control and independent living devices listed, the most popular device was a rocker knife, spoon/fork grip or other adapted utensil (n = 26), followed by adaptive eating devices (n = 23). Most other devices received fewer than 5 responses.

Barriers to Device Use

Table 3 presents the number of barriers identified for each purpose-specific area and the total number of times a given barrier was recorded. Respondents who indicated that their family member with mental retardation could benefit from, but did not currently have, an assistive device selected all barriers that applied to their circumstance (total number of barriers identified, therefore, exceeds the total number of users of technology).

Table 1
Frequency and Percentage of Respondents Indicating Use of and Need for Assistive Device

Device purpose	Use		Need	
	Frequency	%	Frequency	%
Mobil	155	12.7	30	2.5
Hearing and Vision	107	8.9	57	5.0
Communication	59	4.9	104	9.3
Home adaptation	117	9.7	95	8.4
Environmental control	66	5.5	87	7.6

Table 2
Percentage of Respondents Reporting Adequate Evaluation for and Training on Use of Device and Satisfaction

Device purpose	Adequate			Satisfied			Dissatisfied	
	Evaluate	Training	Very	Somewhat	Neutral	Somewhat	Very	
Mobility	88	87	51	31	6	7	5	
Hearing and vision	96	92	55	18	18	8	1	
Communication	86	85	30	22	11	20	17	
Home adaptation	67	65	69	12	6	11	2	
Environmental control	75	80	54	22	13	8	3	

Table 3

Frequency of Responses to Barriers to Assistive Technology

Barrier	Device Purposes					
	Mobility	Hearing and vision	Communication	Home adaptation	Independent living	All areas
Cost	20	25	33	44	23	145
Information	13	18	47	23	53	154
Assessment	6	7	28	12	16	69
Availability	3	3	11	2	7	26
Complexity	6	7	20	2	8	43
Staff	1	5	13	1	5	25
Upkeep	2	2	2	1	0	7
Training	6	13	23	2	13	57

Purchase of Devices

Table 4 shows the funding mechanisms used to purchase technology devices. Again, respondents were encouraged to identify all that applied.

Computer-Use Questions

Thirty-three percent of the respondents (n = 399) indicated that there was a computer in their home. Of those, 56 indicated that the computer had been purchased specifically for the family member, and 48 respondents reported using personal funds to pay for them. A smaller percentage (23%, n = 284) indicated that their family member used a computer, either at home or in another environment (62 respondents did not answer this query and 872 indicated that their family member did not use a computer). Of these 284 computer users, 88 used it in a day activity program, 46 at work, 135 at home, 28 in a living situation other than home, 40 in a recreation or leisure program, and 28 in other situations (respondents checked all that applied). When asked to identify what the person with mental retardation did with the computer, 30 respondents indicated that it was used for communication, 130 for educational activities, 10 for household finances or budgeting, 183 for leisure activities, 29 for work-related activities, and 26 for other

activities (again, respondents checked all that applied).

Of the 872 respondents whose family member did not use computers either at home or elsewhere, 330 (38%) indicated that they believed that their family member could benefit from a computer. The most frequently cited barrier to computer use was the cost or lack of funds' (n = 223), followed by the lack of training available (n = 169), the complexity of the device (n = 124), the lack of assessment of technology need (n = 88), and a lack of information about what the computer could do to benefit the family member (n = 84).

Discussion

Survey results suggested that, generally, adults with mental retardation underutilize assistive technology devices. In four of the five purpose-specific areas, less than 10% of this population used a device. The only exception was the mobility area, in which nearly 13% of respondents indicated a family member used a device. The percentage who felt that their family member could benefit from a mobility device was the lowest of all categories as well (2.5%). In two of the remaining four areas (communication and environmental control) the percentage of individuals who might benefit from the

Table 4

Frequency of Response to Funding Sources for Assistive Technology

Funding	Device Purposes					
	Mobility	Hearing and vision	Communication	Home adaptation	Independent living	All areas
Insurance	37	11	6	2	1	57
Personal	44	49	19	64	35	211
Donation	3	1	4	2	2	12
Agency	8	10	11	12	8	49
Government	44	25	12	20	9	110

use of a device exceeded the percentage who actually used a device, and in a third area (home adaptation), the percentage who used devices was nearly equal to those who did not use but might benefit from a device.

The primary barriers to device use identified by respondents whose family member did not have a device but might benefit from one were information about the availability and the cost of devices. These two categories were ranked either first or second in all five purpose-use areas. The third most common barrier was the lack of availability of assessment and evaluation information and opportunities. Limited training on device use was identified as the fourth most common barrier, with device complexity as the fifth.

The lack of information about device availability is a problem that has been recognized in previous studies. For example, in their 1993 study of financing of assistive technology devices and services, the National Council on Disabilities identified the number one finding from the study as:

Information on assistive technology devices and services is difficult to find and often inconsistent from source to source. Information dissemination is fragmented and uncoordinated. The barrier of awareness precedes questions of technology funding and thus denies individuals with disabilities an effective means to increase independence, productivity, and integration. (p. 31)

The information needs of people with mental retardation and their families are important to address throughout the technology identification and selection process. First, people with mental retardation and their families need to be made aware of the "full range of assistive technology devices and related services and their potential in different environments to respond to the functional needs of users" (National Council on Disabilities, p. 31). This "information as awareness" level is, obviously, critical to the eventual selection and use of a device. In addition, however, families and individuals with mental retardation need information to enable them to compare specific devices based on performance, affordability, reliability, and other factors, information about obtaining and utilizing evaluation and training resources, information on maintenance and repair, and information on funding.

System-level initiatives, including the federal technical assistance centers funded by the

Tech Act, have been launched to address, at least in part, the problems of information dissemination, and the growing presence of assistive technology information available through electronic databases, most visibly those now available on the Internet, will further meet the information needs of consumers. Although these broad initiatives will continue to be excellent vehicles to meet the information needs of families and assistive technology users, it seems evident from the response to our survey that these alone are not sufficient. Several of the respondents to The Arc's survey indicated that their awareness of and information about devices came through interactions with a service provider or an advocacy organization, including several federally funded parent information centers. Many of these entities have established informal, and often small, information clearinghouses and, when possible, set up assistive technology lending libraries or programs that enable users to test the device or software before purchasing it. It seems likely that one way to get information into the hands of people with mental retardation and their families is to make such information available through the various services that consumers and their families access on a day-to-day basis.

Funding assistive technology is a complex problem with no simple solution. The most frequently identified funding source across all purpose-specific categories in the survey was the family's personal funds and the second, government-sponsored funding, such as Medicaid or Medicare, Social Security Disability Insurance (SSDI) or SSI, or the Vocational Rehabilitation system. The use of private insurance seemed only to be viable for mobility- and hearing-/vision-related devices, due principally to the medical nature of the specific impairment.

A comprehensive treatment of issues related to funding of assistive technology is beyond my scope in this article. However, the National Council on Disabilities (1993) has identified seven successful approaches to financing assistive technology devices and related services, and although most of these pertain to systems-level changes (e.g., changing health care service delivery programs, creating tax incentives, restructuring federal funding programs), two recommendations relate to actions that might be useful for advocates and service providers. First,

the National Council on Disabilities recommends expanding alternative financing mechanisms. Respondents to The Arc's survey were, by and large, dependent upon more traditional funding sources (government programs, agencies, insurance) and when these were not viable, depended upon personal funds. They did not, to any large extent, access alternative funding sources. The National Council on Disabilities has identified several successful alternative sources, such as the establishment of low interest loan programs and private foundations to fund assistive devices, corporation-sponsored employee accommodations programs, service clubs and charitable organizations as providers of devices, and establishing lending libraries and equipment loan programs. The latter can provide individuals with the opportunity to use a device for a time-limited period, either until funding can be identified or in order to establish the necessity of the device and, thus, make them eligible for funding through more traditional sources (e.g., SSI or Vocational Rehabilitation).

A second recommendation from the National Council on Disabilities related to funding issues is to mandate adherence to the concepts of *universal design*, which refers, quite simply, to attempts to make all products and environments accessible to all people (Moon, Hart, Komissar, & Friedlander, 1995). Adherence to principles of universal design will impact funding because resulting products will be more affordable due to the wider market for the product and because of the reduced need to adapt or customize the product. The Trace Center, a Rehabilitation Engineering Research Center in Wisconsin, has identified seven principles of universal design: (a) *equitable use*: a design is useful and marketable to any group of users; (b) *flexibility in use*: a design accommodates a wide range of individual preferences and abilities; (c) *simple and intuitive use*: use of the design is easy to understand, regardless of user's experience, knowledge, language, or cognitive skills; (d) *perceptible information*: the design communicates the information needed by the user, be it through different modes or by providing adequate contrast. (e) *tolerance for error*: the design minimizes adverse consequences of accidental or unintended actions; (f) *low physical effort*: design can be used comfortably with minimum fatigue; and (g) *size and space for approach and use appropriate*: design allows for approach, reach,

manipulation, and device use independent of user's body size, posture or mobility (Trace Center, 1995, p. 1). Adherence to these principles will go a long way toward ensuring that products and devices are both affordable for and usable by people with mental retardation.

The use of personal computers has considerable promise to enable individuals with mental retardation to accommodate for cognitive impairments that are impediments to independence and self-determination. For example, people who might not otherwise be able to maintain a checkbook because they lack the prerequisite math skills could use a computer to overcome that barrier. More respondents, however, indicated that their family member had no access to a computer but would benefit from such access ($n = 330$) than indicated that their family member used a computer in any environment ($n = 284$). From the latter computer users, the most frequently cited use was for entertainment, followed by educational purposes. Only 10 people used the computer for household financial or budgeting purposes and 29 for work purposes. Although cost of the computer was the primary reason cited, both a lack of training and the complexity of computers were both frequently identified barriers. There are very few software programs that are designed for use by adults with mental retardation. Existing software programs are often too complex, and when they are not, they are often not age-appropriate. Even when software is available, existing operating systems create a barrier for individuals with mental retardation. Accommodations for such persons to use computers will include the development of software with simple displays, provision of information in non-text-based formats (e.g., graphics, video, audio), minimization of the number and complexity of decision-making points, presentation of information sequentially, and little reliance of memory.

In summary, the results of this national survey suggest that in many cases people with mental retardation and their families are unaware of the potential benefit they could derive from assistive technology and, if aware, are not informed about the types of devices available, how to fund them, and where to obtain adequate assessment and training. Beyond awareness and information, there is a need to create alternative and more flexible sources to fund such devices and to emphasize principles of universal design to ensure that people with mental

retardation can benefit from readily available devices. With the growing emphasis on enabling people with mental retardation to assume greater control over their lives, efforts to raise awareness and increase access to assistive technology for people with mental retardation and their families seem particularly important.

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This research was funded by The Arc's National Research Committee, Mary Ann Ronski, chair. The author acknowledges the efforts of Sue Eades in data entry. A copy of the Assistive Technology Use Survey can be obtained from the author.

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