

The use of assistive technology by people with mental retardation and barriers to this outcome: A pilot study

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Abstract

While it is generally acknowledged that people with mental retardation do not utilize assistive technology to the degree warranted, there has been little empirical evidence to support this assumption. This article reports findings from a pilot study that evaluated the use of assistive technology by people with mental retardation and examined barriers to this outcome. A national survey found that people with mental retardation under-utilized assistive devices. The survey identified several barriers to technology use, including cost, a lack of information, device complexity and a lack of training and support.

Keywords: Assistive technology; Mental retardation; Survey; Device utilization; Barriers

1. Introduction

Historically, it was assumed that people with mental retardation could not learn to work productively, live independently or participate in the community. Mental retardation was more closely associated with incompetence and protection than with independence and self-sufficiency. These beliefs are changing as research and practice show that, with adequate support, people with even the most severe cognitive impairments can learn skills that enable them to live in, work in and contribute to their communities. A key element in this support is the availability and use of assistive technology devices. The use of such technology should enable people with mental retardation to

overcome barriers to independence and inclusion (Parette, 1991).

Unfortunately, it is generally acknowledged, though not empirically validated, that assistive technology devices are under-utilized by people with mental retardation (The Arc, 1993). There are a number of reasons for this assumption. The development of assistive devices has, by and large, primarily addressed the needs of people with physical and sensory impairments. Few devices have been developed to address the barriers introduced by cognitive impairments. This is partly because the potential market for devices developed exclusively for a cognitive impairment is limited. This limited market removes financial incentives to undertake the expensive research,

development and manufacturing process necessary to make a device available to consumers. A second factor is that accommodating for limitations associated with cognitive impairments, including ineffective learning and problem-solving strategies, difficulties generalizing learned skills, impaired memory and higher-order thinking skills and social/behavioral difficulties, is a much more complex process than developing devices that enable, for example, physical access.

However, many devices designed for individuals with other disabilities and for elderly people can also benefit people with mental retardation. For example, people with mental retardation who have limited verbal skills can access a variety of communication devices to use as either an alternative to speech or to augment their existing communication abilities. Devices to control the environment are important to people with severe or multiple disabilities and/or cognitive impairments whose ability to move about in the environment and access a variety of electronic appliances is severely curtailed. Such devices allow an individual with mental retardation to control home electrical devices, audio/video equipment like home entertainment systems or do simple tasks like locking and unlocking doors. Certainly some people with mental retardation have limited mobility and can benefit from existing mobility devices. Likewise, a person with mental retardation who cannot complete everyday tasks of self-care without support may benefit from devices like an automated dining device, or computer programs that write checks and pay bills. Currently available assistive technology devices can increase access to education, employment, and social activities.

Even when devices exist, barriers remain to their use by people with mental retardation. Not only are such devices frequently not designed to address barriers created primarily by cognitive impairments, they are also rarely designed and manufactured with the unique needs of people with mental retardation in mind. As such, devices are often too complex to operate and lack detailed training procedures and follow-up to ensure the satisfaction and success of users with mental retardation (The Arc, 1993).

Several factors further complicate this situation. Despite the movement toward inclusion, far too many people with mental retardation go to school, live and work in settings where they are almost exclusively in the company of other people with mental retardation (Davis, 1992; 1993). Direct care staff or paraprofessionals with limited training and experience with people with mental retardation are often responsible for providing on-going care and the supports necessary for a person to live, work or learn independently. While a supportive, well trained paraprofessional can provide the support people with mental retardation need to successfully use assistive devices, this outcome is too rarely achieved. Paraprofessionals (and professionals) do not receive adequate training to use and maintain the device. Consequently, devices remain unused or fall into disrepair. When people live in congregate settings, assistive devices are often picked up by other residents or classmates and may become damaged through misuse, abuse and overuse. One solution is to keep devices in a secure area, which, in turn, undermines the opportunity for the user to implement the device as a part of his or her daily routine. Finally, enabling a person with mental retardation to engage in an activity using a device may prolong that activity. Consequently, the staff person may elect not to use the device, but instead do the activity for the person.

Since many children and adults with mental retardation live with parents and family members, these care providers become the gateway for access to assistive technology. Several barriers are relevant in these circumstances. Many times family members are uninformed about the availability of specific assistive devices. If a device is not recommended through a school, work or recreation program, the family is not aware of the potential benefits. Centers funded through the Technology-Related Assistance for Individuals with Disabilities Act (P.L. 103-218) (Technology-Related Assistance, 1994), and Parent Training and Information Centers funded through the Individuals with Disabilities Education Act (IDEA) have implemented educational programs to remedy this situation and make families aware of existing technology. However, these

efforts vary state by state, and the flow of information to families (as well as consumers) remains a problem (Hayward, Tashjian, Wine and Curtin, 1992).

Assessment and funding issues are also barriers for family members and people with mental retardation. If parents identify a specific need for their child, there is rarely a clear course of action to obtain the necessary assessment information. When adequate assessment information is secured, funding the device becomes the next hurdle. In the absence of physical or sensory impairments, insurance providers and other third party funders are frequently reluctant to pay for devices. Despite the fact that these and other issues have been identified by practitioners and advocates alike (The Arc, 1993; Perlman, 1993), there have been very few alterations to the *status quo*, and the potential benefits of assistive technology for people with mental retardation remain largely unrealized.

2. Technology use by individuals with mental retardation

The existing research on assistive technology and people with mental retardation has focused mainly on (a) teaching individuals with mental retardation to use specific devices, (b) evaluating the efficacy of using assistive devices compared with other procedures, or (c) using technology to assess functional needs (Datillo, 1987; Realon et al., 1988; Realon et al., 1989). Little research empirically evaluates the degree to which people with mental retardation utilize assistive technology and existing barriers to this outcome.

Perlman (1993) reported the findings of a series of focus groups conducted with consumers with mental retardation or learning disabilities and their caregivers. The focus groups discussed the specific needs and concerns of assistive technology users with cognitive impairments and their families. Twenty-four individuals with mental retardation participated in three different focus group meetings. These participants ranged in age from 18 to 60 years and were recruited from activity centers or programs for people with developmental disabilities. Three focus group partic-

ipants worked competitively through a supported employment program, and one-third were involved in volunteer activities. Two-thirds of these participants lived at home with family members; the remainder lived in group homes for people with mental retardation. Three additional focus meetings involved 18 caregivers for people with mental retardation. Perlman (1993) also included three focus groups for adults with learning disabilities.

Perlman (1993) identified several common concerns that emerged across all focus groups as well as concerns unique to the various groups. There was a common need for simpler instructions and for assistive devices and services to be made easier to use. People with mental retardation consistently expressed the desire to operate devices more independently and frustration that they were unable to achieve this outcome. Caregivers for people with mental retardation voiced concern over the safety of various devices, as well as the difficulty of allowing greater risk-taking through device use. When the discussions centered on home and recreational products, like electronic appliances, audio/visual devices and recreation and leisure devices, individuals expressed common frustrations with the complexity of products and the difficulty of instructions. People with mental retardation frequently identified an additional individual limitation, like poor motor coordination or dexterity, as a factor that made it difficult for them to use these products independently. Additionally, all participants identified high costs for the device when compared with the added convenience as a barrier to access.

Perlman's (1993) findings also provided evidence that knowledge about the availability of devices remains a barrier for people with mental retardation and their caregivers. He cited an example of a man who, when asked to identify products he would like to see developed, described a television he could access without getting up from a chair. This man was obviously unfamiliar with remote control devices. Other wish lists provided similar examples and also illustrated the types of accommodations to benefit people with mental retardation. One participant

wished for a device to lift a person out of a bathtub, while another wanted a talking clock. Both devices are currently available. Other participants wished for devices that were not as readily available, such as a microwave with easy to use buttons, a voice activated VCR, or an easy to use copier with clear directions.

2.1. Purpose of the study

Given that assistive technology has the potential to benefit people with mental retardation and improve their quality of life, it is important to increase the use of assistive devices by this population. The first step is to better understand the extent to which assistive devices are currently used by people with mental retardation, and to document the existing barriers to further usage. The present study is part of a project conducted by The Arc, a national organization on mental retardation. This study was conducted to achieve this outcome and report the findings from a pilot study to evaluate the utility of the survey instrument.

3. Method

3.1. Procedures

Project staff conducted an extensive review of the literature to identify a survey instrument that had been used to evaluate technology usage by individuals with disabilities. Although this search yielded some unpublished studies reporting the use of surveys to examine technology usage by people with mental retardation (Parette and Van-Biervliet, 1990; Perlman, 1993), there were no extant surveys identified that met the needs of the research activity. Consequently, project personnel constructed a survey instrument (described in detail below) that examined technology use in the areas of mobility, hearing and vision, communication, home adaptation, environmental control and independent living, as well as the use of common household appliances, electronics and computers.

Because many people with mental retardation might have difficulties responding to detailed

questions about technology use, including issues related to funding, device availability, training and device complexity, we determined that the most reliable informant would be the parent or caregiver of an individual. We selected a random sample of 250 members of The Arc, a non-profit national advocacy organization focusing on mental retardation. These members had identified themselves as being the family member of a person with mental retardation. These members received the survey with a cover letter explaining the intent of the project and a stamped return envelope. Only one mailing was conducted.

3.2. Sample

A total of 80 surveys were returned, for a response rate of 32%. Surveys were returned from 31 states. In all cases but one the respondent (parent or caregiver) lived in the same state as the family member with mental retardation. The majority of respondents identified themselves as the parent of a son or daughter with mental retardation, although two respondents were grandparents and one was a sibling. The individuals for whom the respondent reported information ranged in age from 2 to 55 years. The mean age of this group was 25.7 (S.D. = 12.54) with 29% being school age (21 and under) and the remainder adults. Forty-two percent of the people in the sample were working for pay, with 36% unemployed and the remainder exclusively in school. Sixty-two percent of the sample was male ($n = 50$) and 38% female ($n = 30$). Seventy-four percent of the individuals with mental retardation lived with a family member ($n = 59$) and 26% lived elsewhere ($n = 21$). The majority of people living outside the family home resided in group homes.

3.3. Instrumentation

The survey consisted of five areas of questions focusing on the use of technology for a specific purpose (mobility, hearing and vision, communication, home adaptation and access, environmental control and independent living) and two areas

focusing on the use of specific devices (common household appliances/electronics and computers). The five use-specific areas consisted of the same questions specific to that purpose. For example, respondents were first asked if their family member used a mobility technology device. If they responded yes, they were directed to a question asking them to check device(s) used (crutch, cane or walking stick, walker, wheelchair, other) and a follow-up question on funding for the device (private insurance, personal funds, charitable donation, school/agency program, SSI, Medicaid or other government program, other). In addition, the survey asked if the family member received adequate assessment or evaluation services before purchasing the device and information about how to appropriately and effectively use the device. Respondents were then asked 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 did not use a mobility technology device, they skipped to a question that asked if they could potentially benefit from such a device. If they responded yes to this question, they were asked to check which devices (listed previously) their family member could use. Finally, these respondents were asked to check all relevant barriers to their family member using or benefiting from a mobility device. These barriers were:

- lack of funding or high cost
- little information about the product
- assessment or evaluation not available
- product unavailable
- device too complex for person to use
- inadequate training for person to learn device
- other.

The other four use-specific areas used the same questions, substituting the relevant domain area and available devices in that area. The questions identifying usage of common household appliances or electronics provided information on the availability and use of such devices by people with mental retardation, and also provided a means of evaluating the degree to which survey respondents answered potential use and benefit ques-

tions negatively due to a lack of knowledge or understanding about assistive devices. This section required the respondent to first check which common appliances and electronic devices were available to their family member (television, stereo/radio, VCR, microwave, oven/stove, blender, coffee maker, can opener, toaster, dishwasher). Secondly, respondents identified whether their family member used each device independently, with assistance or not at all. Finally, they identified what prohibited the family member from using devices:

- the person does not understand the use of the device
- the device is too complex to operate
- the person cannot physically operate the device
- safety factors
- the person does not choose to use the device
- other.

The survey results in the area of environmental control and independent living could be examined based both on the respondent's perception and understanding of their family member's need and potential benefit, and by the degree to which the family member actually utilized common appliances and electronic devices.

The final area examined computer use. Respondents identified if there was a computer in their home and if so, whether it was purchased specifically for the family member. If respondents indicated it was purchased specifically for the family member, they were asked to identify how it was purchased (e.g., private insurance, personal funds, etc.). The survey then asked if their family member had access to a computer in any environment, and if so which environment (family home, recreational and leisure environment, living residence other than home, day activity program or school, place of employment or other). If the respondent indicated yes, they were asked to identify how their family member used the computer (educational activities, finance and budgeting, recreational and leisure activities, work related activities, communication, other). If respondents indicated that their family member did not

Table 1

Frequency and percentage of respondents who indicated their family member used technology or who did not use, but would benefit from, technology by purpose-specific areas ($n = 80$)

Device purpose	Device use and need			
	Frequency use	Percent use	Frequency need	Percent need
Mobility	9	11.3	6	7.5
Hearing and vision	5	6.3	10	12.5
Communication	10	12.5	10	12.5
Home adaptation and accessibility	6	7.5	7	8.75
Environmental control and independent living	7	8.75	13	16.25

have access to a computer in any environment, they were asked if the family member could benefit from such access and asked to check relevant barriers to computer access (lack of funding, little information, etc.).

3.4. Analyses

Surveys were scored by project personnel and data entered and analyzed using SPSS for Windows (Norusis, 1992). Responses to each question were analyzed using a crosstab procedure that provided frequency counts. Results are presented in narrative and tabular form below.

4. Results

4.1. Purpose-based questions

4.1.1. Device use

Table 1 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 utilize such technology but would benefit if they did. Actual device use was low across all areas. The most frequently used device area was communication (12.5% of respondents). The percent of respondents who reported that their family

Table 2

Frequency of responses to barriers to assistive technology use by area and total

Barriers	Device purpose					
	Mobility	Hearing and vision	Communication	Home adaptation	Independent living	All areas
Cost or lack of funds	3	8	8	5	5	29
Lack of information	1	5	10	2	11	29
Lack of assessment	2	4	8	2	4	20
Product unavailable	0	1	4	1	2	8
Device complexity	1	2	3	2	4	12
Inadequate training	3	4	6	1	4	18

Table 3

Frequency of responses to funding sources for assistive technology use by area and total

Barriers	Device purpose					
	Mobility	Hearing and vision	Communication	Home adaptation	Independent living	All areas
Private insurance	5	0	2	1	1	9
Personal funds	3	3	3	4	4	17
Charitable donation	0	0	0	0	0	0
School or agency	2	1	4	0	0	7
Government	0	1	3	2	2	8

member did not currently use, but could benefit from, assistive devices was higher than the percent of respondents who identified such devices currently in use in three of the five areas (hearing and vision, home adaptation and environmental control). In the communication area, the same number of respondents indicated they needed devices as respondents who indicated their family member used a device. Only in the mobility area was the number of people using a device greater than people who were not using a device but needed one.

4.1.2. Barriers to device use

Table 2 presents the number of barriers identified for each area and the total number of times a given barrier was recorded. Respondents selected all barriers that applied in their circumstance, so the total number of barriers identified is greater than the total number of users of technology. The

most frequently identified barriers to technology use were the cost of devices and the lack of information about devices. Limited assessment and evaluation information ranked next, followed by inadequate training for the individual to benefit from a device.

4.1.3. Purchase of devices

Table 3 summarizes the funding mechanisms used by individuals with mental retardation and their family members to pay for technology devices. Once again, respondents were encouraged to identify all that applied. The most frequently checked funding source for assistive devices was personal funds. Private insurance funded most mobility devices, the bulk of which were wheelchairs (seven of nine). School and agency programs were the leading funding source for communication devices, although government programs (Medicaid, SSI) and personal funds were

Table 4

Frequency of assessment and information availability prior to device purchase

Device purpose	Assessment available			Information availability		
	Yes	No	NR ^a	Yes	No	NR ^a
Mobility	4	2	3	5	2	2
Hearing and vision	4	1	0	2	1	2
Communication	7	3	0	7	3	0
Home adaptation and accessibility	3	2	1	4	1	1
Environmental control and independent living	4	2	1	5	2	0

^aNR = no response

frequently used as well. Table 4 summarizes the number of respondents who did or did not receive adequate assessment and information before purchasing a device.

4.1.4. Device satisfaction

Mean satisfaction scores (1 = not satisfied, 5 = very satisfied) from current users of technology ranged from 2.89 for mobility devices to 4.4 for home adaptation devices. Users were generally satisfied with devices. Hearing, vision, independent living and home adaptation devices all averaged above 4.0 (satisfied). Satisfaction with communication devices was 3.6 (between neutral and satisfied). There was a great deal of variability between respondents, with 'not satisfied' ratings (1.0) reported in four of the five areas.

4.2. Device-based questions

4.2.1. Common household appliances and electronic devices

Table 5 summarizes findings regarding the use of common electronic devices by people with mental retardation. With six of the ten devices, the percentage of people with mental retardation who didn't use the appliance was greater than the percentage of those who used it independently. Television was the appliance most likely to be used independently. Three of the four appliances

whose independent use was greater than lack of use were recreational and leisure items (TV, VCR, radio or stereo). Even in these categories, however, a noteworthy percentage of people with mental retardation either did not use the item or needed someone else's assistance to do so. The most frequently identified barriers to device use were safety and a lack of understanding about the device's intent on the part of the individual with mental retardation (both $n = 35$). Thirty respondents identified the complexity of the device as the major barrier.

4.3. Computer use

The final area examined the use of computers by people with mental retardation. Forty-five percent ($n = 36$) of the respondents indicated there was a computer in their home. Only six of these respondents indicated they had purchased that computer specifically for their family member with mental retardation. Thirty-five percent ($n = 28$) indicated that their family member accessed a computer in any environment (including the home). Sixteen respondents indicated that their family member used a computer at school or a day program, 3 at the individual's employment setting, and 17 at the person's home. The most frequent use for a computer identified was for recreational purposes ($n = 23$), followed by edu-

Table 5
Percent of respondents indicating availability and independent use of devices by type of device

Device	Availability of device			Independence of device use			
	Available	Not available	No response	Use independently	Uses with assistants	Does not use	NA/NR ^a
Blender	84	9	7	10	14	59	16
Can opener	74	19	7	18	12	44	26
Coffee maker	84	9	7	13	14	57	16
Dishwasher	73	16	11	15	25	32	28
Microwave oven	91	4	5	28	26	37	9
Oven/range	96	0	4	11	30	55	4
Radio/stereo	95	0	5	55	10	28	7
Toaster	95	1	4	44	12	38	6
Television	96	0	4	68	10	18	4
VCR	90	4	6	36	20	34	10

^aNA/NR not applicable or no response

cational purposes ($n = 21$), communication ($n = 5$), and financial or budgeting purposes ($n = 1$).

Of respondents who indicated that their family member did not have access to a computer ($n = 40$), 19 people (48%) indicated they thought their family member would benefit from a computer. The complexity of computers, lack of training and cost were the three biggest barriers identified ($n = 10$ each). Information about computers was the next most frequent barrier ($n = 6$).

5. Discussion

Although assistive technology promises to provide people with mental retardation part of the support necessary for increased independence, integration and productivity in many areas, this pilot study's results support the observation that this promise remains largely unfulfilled. Across all areas, technology use was limited. In the majority of the areas the number of people who needed technology devices exceeded the number of people who actually used devices. This is probably a conservative estimate of need since it relied upon parents and other family members to estimate potential benefits for their family member with mental retardation. Examining the use of common household appliances and electronic devices, it is evident that a greater proportion of people could benefit from devices that enable them to use these items independently than was indicated when respondents were asked if their family member would benefit from environmental control and independent living devices.

The cost of devices and a lack of information about devices were both frequently identified barriers to the use of assistive technology. Family members were primarily reliant upon personal funds to purchase devices. Private insurance was really only a viable source for the purchase of wheelchairs, confirming anecdotal reports from users that insurance is only useful for funding devices with a specific medical intent. Communication devices, on the other hand, were most likely to be funded by a school or agency program, although this still accounted for only one-

third of the funding sources identified for communication devices.

In addition to funding and information issues, difficulties in obtaining assessments and inadequate training to use devices were barriers frequently identified by respondents whose family members did not use, but could benefit from, assistive devices. Device complexity was not as frequently identified as a barrier by these respondents, but emerged, along with safety factors and a lack of understanding of devices, as one of the primary barriers to the use of specific electronic devices and appliances. The number of respondents whose family member used technology who reported they had access to adequate assessment and information was greater in all areas than those who did not have such access. The importance of adequate assessment, therefore, was confirmed by the fact that technology users had access to assessment and those who did not use technology but could benefit did not have such access. Generally, most users were satisfied with technology, although there was considerable variability.

Perhaps the most promising technological advances that could benefit people with mental retardation have been in the area of personal computers. Computers are finally emerging as the ubiquitous household device promised a decade ago when the first personal computers were introduced. Computers have innumerable potential uses that can simplify complex tasks, from budgeting and keeping financial records to word processing packages that receive voice input. Computers can enable people with mental retardation to be more independent. However, only 35% of the respondents reported that their family member had access to a computer in any environment. The most frequent environments in which people with mental retardation accessed computers were school settings and the family home. Not surprisingly, the most frequent use of computers were for educational and recreational purposes. Only one respondent indicated that their family member used a computer for budgeting or bill paying purposes. Once again, the potential benefit of computers to improve the quality of life of people with mental retardation was largely unrealized.

Unlike other areas, however, the potential benefit of computers was readily recognized by parents and family members, almost half of whom indicated that although their family member did not use a computer, they would benefit if they did.

This study attempts to empirically examine the degree to which people with mental retardation use assistive technology. The generalization of the results is limited by several factors, particularly sample size. Although 80 respondents do not provide a complete picture of the use of technology, because this sample included parents and family members from a large number of states, the findings are widespread. Future research might provide additional information by examining technology use by other disability groups compare with usage by people with mental retardation.

These findings provide impetus for action in a number of areas. While there is an ongoing need to advocate for the development of technological devices that will specifically accommodate for limitations related to cognitive impairments, ongoing efforts should overcome barriers not related to device availability. Cost and information are among the most prevalent of these needs and are closely related. There is a continued need to make information about assistive technology devices, their utility and sources of funding available to people with mental retardation and their family members. Secondly, technology consumers need access to assessment information, either from device manufacturers, assistive technology professionals, or, in the case of simple to use technologies, self-evaluation procedures.

Training is also an area of continued need. Users of technology with mental retardation need ongoing training in device use and follow-up services to ensure that devices are used correctly and safely. Manufacturers of electronic devices, home appliances and assistive technology would probably increase usage across a number of populations if devices were designed to be cognitively accessible. In addition, documentation accompanying devices needs to be clear and understandable. Professionals and paraprofessionals who work with people with mental retardation need to receive training in device use, maintenance and availability so that they can provide the support

needed by the individual to successfully use a device. Improvements in these areas will bring the promise of assistive technology closer to fulfillment for people with mental retardation.

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