The Role of Technology Use by a Person with Intellectual or Developmental Disabilities as a Family Support[*]

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A nationwide survey of family members of people with intellectual and developmental disabilities was conducted to update the knowledge base concerning technology use by people with intellectual and developmental disabilities. Survey responses provided information about use of technology for mobility, hearing and vision, communication, independent living, and in the area of computer use. In addition, survey items queried the use of electronic and information technology devices such as use of e-mail, mobile telephones, and digital cameras. This study analyzed the technology needed and/or used by people with intellectual and developmental disabilities who lived at home with their family members and considered findings in terms of family supports.

Keywords*: technology, intellectual disability, information technology.*

There is now sufficient evidence that technology use has considerable promise to promote a better quality of life and better life outcomes for people with disabilities, including people with intellectual and developmental disabilities (Braddock, Rizzolo, Thompson, & Bell, 2004; Wehmeyer, Palmer, Williams-Diehm, Shogren, Davies, & Stock, in press). And yet, evidence over the past decade suggests that people with intellectual and developmental disabilities too often have limited access to technology and that technology is underutilized by this population for a variety of reasons (Wehmeyer, 1998; 1999; Wehmeyer, Smith, Palmer, Davies, & Stock, 2004; Wehmeyer et al., 2008; Wehmeyer, Palmer, Smith, Parent, Davies, and Stock, 2006). Weh-

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meyer (1998; 1999) found that across device use areas (technology for mobility, hearing/vision, independent living, communication) and for computer use in school and work settings, except in the area of mobility, there were more respondents (family members of students and adults with intellectual disability) who indicated that their family member could benefit from technology but did not have access such technology than there were people who actually had access to the technology. Carey, Friedman and Bryen (2005) surveyed 83 adults with intellectual disability about their use of electronic technologies and found that use of such technology was well below the percentage of the general population using such devices.

This literature has, appropriately, approached the role of technology use from the perspective of quality of life outcomes for the user. It is equally true, however, that technology designed to support people with intellectual and developmental disabilities themselves will also serve as a support to that person's family, given that family members too often have to assume care and support roles even as their son or daughter move into adulthood. When there is underutilization of technology by people with disabilities, there are likely additional roles and responsibilities for support assumed by parents and family members. Unfortunately, the literature is clear that, for many reasons, people with intellectual and developmental disabilities do not use or have access to technology. Recently, Tanis, Palmer, Wehmeyer, Davies, Stock, et al. (in press) revisited the issue of technology use by people with intellectual disability, surveying 180 adults with intellectual and developmental disabilities to determine their technology use. Despite some progress, this study confirmed that technology devices are still underutilized by this population.

The reasons for underutilization of technology by people with intellectual and developmental disabilities vary (Alper & Raharinirina, 2006). Some of the frequently identified barriers include device cost, availability, maintenance, and training (Wehmeyer, 1998; 1999). Another important factor involves the design of technology devices themselves. Electronic, information, and assistive technologies are often too complex for people with cognitive disabilities to use and fail to include universal design features that would enable cognitive access (Friedman & Bryen, 2007; Wehmeyer et al., 2004; 2006). This is despite the fact that there is preliminary evidence that people with intellectual and developmental disabilities who use technology do benefit from such use. Wehmeyer et al. (2008) conducted a single subject design meta-analysis of studies that reported on the efficacy of technology use by people with intellectual disability. That analysis determined that, overall, technology use by people with intellectual disability resulted in 'Fair' effects. Among classes or types of technology, palmtop computers or smartphones had the highest effectiveness, followed by auditory/prompting devices, electronic and information technologies, video devices, and augmentative communication devices. All of these rated 'Fair' and above on the effectiveness rubric used (percent nonoverlapping data), though only palmtop computers rated as

highly effective. Studies in which people with intellectual disability utilized computers, home appliances, voice recognition software, and switches fell below the rating of Fair effects.

Wehmeyer and colleagues (2008) suggested that at least one reason that some technology use seemed to have such limited effectiveness was, as mentioned, very few devices evaluated actually incorporated features of universal design to ensure cognitive access. Among all studies reviewed in the Wehmeyer et al. meta-analysis, there were 456 participants with intellectual disability involved. From among those 456 participants, only 8% (n = 36) of the devices provided some means of equitable use, 26% (n = 121) described some flexible use feature, and 8% (n=35) incorporated some simple and intuitive use feature. Among the remaining UD features (perceptible information, tolerance for error, low physical/cognitive effort), only 3% (n = 15), 5% (n = 26), and 1% (n = 4) of devices reported such features.

Since these surveys were conducted, the number of reports of technology devices designed with features for cognitive access has expanded. Evaluations have been conducted of the efficacy of cognitively-accessible information, communication, and electronic technologies across life domains, including the use of an accessible audio reader (Davies, Stock, King & Wehmeyer, 2008), navigation within and between environments (Lancioni, O'Reilly et al., 2009; Lancioni, Singh et al., 2010), prompting systems using palmtop computers and PDAs (Davies, Stock & Wehmeyer, 2002a, 2002b, 2002c; Riffel et al., 2005; Stock, Davies, Davies, & Wehmeyer, 2006), ATM use (Davies, Stock & Wehmeyer, 2003a); dressing skills (Lancioni, O'Reilly, et al., 2007), money management (Davies, Stock & Wehmeyer, 2003b), and independent cell phone use (Stock, Davies, Wehmeyer & Palmer, 2008). Parette, Wojcik, Peterson-Karlan, and Hourcade (2005) have detailed the potential for technology to both gain access to the general education curriculum and to enhance social acceptance for students with disabilities.

The purpose of this article is to report findings from a survey of family members with regard to the technology use by their family member with intellectual or developmental disabilities (Palmer, Wehmeyer, Davies, & Stock, in press) and to consider this data in light of family support needs. Specifically, we examined the technology use of family members with intellectual or developmental disabilities who lived with a family member, typically in the family home.

Method

Participants

Surveys were mailed to 5,917 households from a listing of members of The Arc of the United States. Completed surveys numbered 1,651 (return rate of

28%), but 24 of the surveys were not usable due to excessive missing or conflicting information. An additional 10 surveys lacked the age of the person being described and were eliminated from the analyses, which used a total of 1,617 surveys. From the total set of 1,617 surveys, 1,025 reported data for a family member residing in a family home. From among those 1,025 surveys, parents completed the majority (*n* = 932, 90.9%). Other respondents included siblings (*n* = 49, 4.8%), other relatives (*n* = 34, 3.3%), friends (*n* = 2, 0.2%), guardians (*n* = 6, 0.6%), and direct support staff (*n* = 2, 0.2%).

The gender of the person with intellectual disability for whom responses were provided included 592 (57.8%) male and 433 (42.2%) female family members. For purposes of analyses, we grouped responses together by the family member's age, with people with intellectual disability ranging in age from 1 to 17 years (*n* = 374, 36.5%) constituting one group, ages 18 to 21 years (*n* = 139, 13.6%) constituting a second, ages 22 to 39 years (*n* = 342, 33.4%) constituting a third group, and 40 years and above (*n* = 170, 16.6%) constituting the fourth and final group.

Table 1 provides information on areas of support need for family members with intellectual disability across age groups.

Table 1. Areas of Support Speech

Age:	1-17 yrs.	18-21 yrs.	22-39 yrs.	40 + yrs.	Totals Support Need
Area:					
Mobility?	113	40	100	50	302
Speech?	111	39	63	29	242
Fine Motor?	158	46	102	36	342
Learning?	283	105	249	121	758
Memory?	242	90	199	91	622
Sensory?	115	44	98	48	305

Survey Instrument

The survey used was adapted from the survey used by Wehmeyer (1998, 1999). There were 11 questions soliciting demographic information, and then a series of questions related to five domains in which technology is frequently used, including for mobility, hearing or vision, communication, and independent living. The survey also queried about computer use, which of course crosses domains. The last questions queried respondents about the use of electronic and information technology such as e-mail, digital cameras, cellular telephones, or personal data assistants. Finally, a question about computer or technology training was included. Each section (four domains plus the computer use section) asked if the family member with an intellectual disability used technology as a support in that domain or not. If

the person did use technology, follow up questions queried respondents about which devices were used; what training was available and who provided that training; what problems the family member might have using the device and, if problems exist; what supports exist to address those problems; and what maintenance issues might exist. If the respondent answered "no" to the question as to whether their family member used technology as a support in the domain area, then a follow up question determined if they (the respondent) thought that their family member with a disability might benefit from technology support in that area. If the respondent answered no to this query, he or she was directed to go to the next domain area. If the respondent answer "yes", he or she was directed to an additional 5 questions pertaining to what device might be useful, and what barriers existed to limit such access at the moment, including cost, knowledge about the device, assessment, or device complexity.

The electronic and information technology section consisted of five questions asking if the family member with intellectual disability used email, a digital camera, a smartphone, a PDA, and whether the family member with disability had ever received training with regard to these devices. The survey closed with a final, open ended question providing family members the opportunity to elaborate on benefits, barriers, and supports with regard to technology use by their family member with intellectual or developmental disability.

To ensure that we could compare results from the present survey with the responses from Wehmeyer (1998, 1999), the items from the original survey were retained with a few exceptions. A section on the use of common household appliances from the original survey was eliminated from the current survey and replaced with the items pertaining to the use of more recent electronic and information technologies.

Procedure

A membership mailing list was obtained from The Arc of the United States and the survey and a postage-paid, self-addressed envelope were mailed to all usable addresses with a cover letter requesting recipients to complete and return the survey. Upon receipt at the project office, surveys were assigned an independent identification number, any identifying information was redacted, and data for each response section were coded by research personnel and entered into an SPSS database for analysis.

Statistical analyses were descriptive in nature, mainly reporting frequencies and cross-tabulations to identify the number of people and percentage of use/need for items. In the case of several questions that involved information provided in words and phrases, a content analysis (Johnson & LaMontagne, 1993) of answers for each question was conducted, and responses were grouped accordingly in order to describe these open-ended answers and provide further results of the survey.

Results

Survey results were described specifically for each area of technology use: mobility, hearing and vision, communication, independent living, and computers. Table 2 provides data about frequency of use and percentage of respondents who indicated that their family member used technology as a function of the number of respondents who indicated their family member had support needs in the related functional area across technology use type and age groups. Percentage use data were calculated based upon support need data for mobility, speech/communication device, and sensory areas for those frequencies, and across the sample as a whole for use of independent living and computer technologies, the latter because it is clear that IL and computer technologies can provide support to virtually all people with intellectual and developmental disabilities.

Discussion

The analysis of technology use by people who live with their families provides information about the role of technology as a support for the family. Prior to discussing the findings, though, it is important to note limitations to this study that should be considered. First, we were not able to make more than one request for responses to surveys, and thus we were not able to make multiple mailings. This almost certainly limited the response rate, but also limited our ability to examine non-response bias. Second, it could be argued that members of The Arc of the United States are better informed and more likely to be aware of supports such as technology, and as such, the findings probably represent a best-case scenario.

We focus our discussion on findings represented in Table 2, which provide the frequency of people with intellectual disability using technology by age group and device function and, importantly, the percentage of users as a function of the total number of people who needed support in a given area. Previous surveys (Wehmeyer, 1998; 1999) have shown that device use as a function of need varies across ages and device type, and that is true in this analysis as well, with some notable exceptions. In the previous surveys, the highest percentages of people who actually need devices and use them occurred in the mobility and communication areas and among school-age children. The explanations for this seem fairly straightforward: mobility and communication devices are accepted as durable medical devices, and thus covered by insurance, and schools focus heavily on communication needs. Overall, this trend continued in the current study, with mobility need/use the highest (64%) and communication also high (60%). What is different in this sample is that the use of computers (in this case percentage use is calculated as a function of the entire sample, and not just a particular support need area) was high 62 percent of the respondents used a computer at school, work, or

home. This reflects, certainly, the ubiquity of computer-based technology and the need to ensure that people with cognitive disabilities can use such technology.

Table 2. Types of Technology Use by Age Range (Number of Persons and Percent of Total Needing Support in Related Area).

	Technology Types				
Age Range	Mobility	Sensory	Communication	Independent	Living*
1-17 yrs.	77 (68%)	29 (25%)	94 (85%)	20 (2%)	315 (31%)
18-21 yrs.	28 (70%)	15 (35%)	26 (67%)	8 (1%)	113 (11%)
22-39 yrs.	65 (65%)	26 (26%)	21 (33%)	17 (2%)	172 (17%)
40 + yrs.	23 (46%)	12 (25%)	4 (14%)	6 (1%)	35 (3%)
Total	193 (64%)	82 (28%)	145 (60%)	51 (5%)	635 (62%)

*Used complete sample (n = 1,025) to calculate percent use.

Unlike mobility device use, however, communication device use showed considerable variability as a function of age group, with 85% of respondents of school age children who had speech difficulties indicating they had access to a technology device, dwindling down to only 14% of people 40 and over. One presumes that the influence of schools is at work here, but with augmentative communication devices now inexpensively available as apps on devices like the iPad (e.g., Verbally app, etc.), there is no compelling reason adults with intellectual and developmental disabilities who have communication limitations cannot have technology support. Unfortunately, the age effect was also at work in the computer use area, with those in the oldest age group least likely to use computers, including tablet computers such as the iPad. The two least frequently used device areas, sensory and independent living, differed somewhat in their trends. The percentage of people who identified sensory issues as an area of support need and who actually had a sensory device was fairly consistent across age groups, from 25% to 35%. One is struck by how low this usage percentage is and illustrates an area of needed focus independent of age group.

The low usage of devices for independent living was consistent and even more striking than the sensory area. Across the sample, only 5% of the family members of respondents indicated any technology use to support independent living. This is despite the fact that one of the growing segments of the general electronic and information technology segment involves devices serving this purpose for people without disabilities, from devices providing directions through global positioning satellite (GPS) data to applications assisting in everything from healthy eating to transportation. Stock, Davies, Wehmeyer and Lachapelle (2011) overviewed emerging practices in technology to support independent community access for people with intellectual and cognitive disabilities, highlighting available devices to

assist people with cognitive disabilities in navigating one's community, fixed-route bus systems, and community-access information as well as to support independent leisure activities (Davies, Stock, King, Woodard, & Wehmeyer, 2008). The gap between what is available to support people and what is utilized in this area is striking, indicating, most likely, a need to education people with disabilities and their families about what technology options are available

Overall, although there has been progress in the past decade with regard to technology use by people with intellectual and developmental disabilities who could benefit from such support, there are still far too many people who do not have access to potentially beneficial technologies, particularly for areas such as independent living support and computer use. Inevitably, parents and family members are support providers to their sons or daughters or siblings who live in the family home, as did the participants in this sample, and those supports that are not provided by traditional disability support systems, which of course in many cases have been cut considerably in current economic circumstances, or technology, must be provided by the family or not at all. In the latter case, this results in additional time commitments on the part of family members.

Previous research has indicated training and ongoing support for the use of technology is provided by direct support staff and family members (Wehmeyer, 1998). Our survey does not identify how much these two populations know about the technology they are providing supports for people to use, but it seems likely that this is an area that needs attention. With the emergence of relatively inexpensive and ubiquitous technology support solutions provided through computer or tablet/iPad technologies, smartphone technologies, and the increasing availability of Smarthome types of technologies that assist in everyday activities like cooking or security (Stock et al. 2011), there is a need to educate families about their options, train families and people with disabilities how to use such supports, and ensure that technology is designed to be usable by all people, including people with cognitive disabilities.

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