



The Identification and Evaluation of Best Practice Assistive Technology and Universal Design Solutions and Services for Older Adults with Intellectual and Developmental Disabilities

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Many older adults opt to remain at home and are increasingly utilizing assistive technology and environmental interventions (AT-EI) to do so (AARP, 1997; Heller, 1998; LaPlante, Hendershot & Moss, 1992). However, there are few studies of AT-EI usage and long term impact with people aging with developmental disabilities (DD) that would provide implications for effective service delivery.

AT has been shown to address mobility and sensory impairments among older adults in general (Mann et al., 1993) and with Alzheimer's Disease (Yang, Mann, Nochajski, & Tomita, 1997; Gitlin, 2001). However, older adults with DD are a heterogeneous group, with varied cognitive, mobility, communication, and sensory issues that affect function and community living status (Hammel, Heller & Ying, 1998; Mendelson, Heller & Factor, 1997). At the activity level (WHO, 2002), surveys of adults with I/DD and their caregivers have identified unmet needs for communication, environmental control, self-care, and home adaptation technologies (Wehmeyer, 1998; Parette & VanBiervliet, 1992). They also note that the primary barriers to getting AT included funding and lack of information and training. This fact points to the need for functionally-based, long-term support interventions.

The challenges to the field still lie in making these technologies accessible to and usable by people aging with I/DD.

The Nursing Home Transition study (Mendelson et al, 1997), sponsored by the RRTC, followed over 150 people with I/DD who resided in nursing homes and transitioned to the community, and the impact of AT on their functional performance over time. The Cerebral Palsy Clinic project involved functional screenings of 35 people with cerebral palsy and I/DD with referrals to AT services. Functional outcome and long-term technology use and need data showed significant functional improvements over time “with technology” versus “without” (Hammel, et al, 1998), and provide a basis for future clinical trials.

At the societal participation level (WHO, 2003), a survey by the National Council on Disability (1994)

reported that older adults used AT to reduce their dependency on others and avoid institutionalization. Studies also show high rates of AT abandonment that

can be attributed to societal barriers that include funding, lack of consumer involvement, lack of access to information and social supports, AT unavailability, AT break down and complexity, and general physical inaccessibility (Gitlin & Burgh, 1995; LaPlante et al., 1992; Mann, et al, 1993; Philips & Zhao, 1993).

As caregivers of older adults with I/DD age themselves, we can anticipate even greater difficulty in maintaining and supporting the use of AT over time. Studies have demonstrated that intervention targeted toward building the competence of caregivers and individuals with Alzheimer's Disease collectively had mutually beneficial effects on both groups (Corcoran & Gitlin, 1992; Gitlin et al, 2001). A similar person- social support-environmental model approach to AT competence and use may also be beneficial to people aging with I/DD.

Study Purpose/Objectives

Aim 1: Identify AT/UD needs, issues and barriers to effective service delivery and support specific to people aging with I/DD and people in their social worlds who support them.

- What AT/UD products, services and supports are most needed by people aging with I/DD and their social supports?
- What specific disability and environmental issues are affecting consumers, family and staff from using AT/UD in everyday activities in home, work, and community environments?
- What are the impairment, functional performance and social participation level outcomes of standard AT services? How satisfied are consumers and families with AT/UD current services and solutions?

Aim 2: Provide training on aging, disability and AT strategies to social supports to enable them to support consumers in identifying issues, needs, and resources.

- Does training on aging with I/DD and AT/UD strategies help family, staff, and case managers better identify and support consumer needs?

Aim 3: Design, implement and pilot test a AT long term support and advocacy (ATLAS) intervention in a clinical trial. Target audience: consumers, family/caregivers, agency community agency staff.

- What are the outcomes of an Assistive Technology Long term Support and Advocacy (ATLAS) intervention in meeting long-term functional and participation goals identified by consumers and social supports in their lives? Are outcomes maintained over time? How does this compare to outcomes gained through standard AT services?
- What is the cost-effectiveness of ATLAS in relation to resources needed and benefits gained versus existing standard practices?



Aim 1: Identify AT/UD needs, issues, and barriers to effective service delivery and support specific to people aging with I/DD and people in their social worlds who support them.

Sample Population and Methodology

Data from two outcome studies were used to examine these questions: 1) a study of people transitioning out of nursing homes to the community and 2) an ongoing outcome study of community-based people aging with I/DD that receive standard AT services to address age-related functional issues at two sites: Chicago, IL. and Buffalo, NY. Following is a summary of the first analysis. The second study used additional measures across the ICF schema (e.g., ADL & IADL functional status, community living and participation, environmental barriers, caregiver status, quality of life, and AT service delivery satisfaction and unmet needs) and is currently in process.

A longitudinal study of 109 people with I/DD, age 35 and older, was done to study the additive impact of mid to later life assistive technology and environmental interventions (AT-EI) on function and living situation status. All subjects were trying to transition out of institutional settings to community settings.



Data Collection and Measures

Functional status was measured at two times (Time 1 baseline and Time 2, an average of 3 years post intervention) on 32 functional and social participation activities via OT FACT under two conditions: without AT (person only) and with AT (environment adjusted).

Data Analysis

Rasch analysis was performed to convert ordinal functional scores to equal interval measures, with 95% confidence intervals computed to compare differences in function, with and without AT, across time. Qualitative interviews and observations were conducted with consumers and social supports in their lives to describe their experiences, needs, and interactions surrounding AT use in everyday life.

Findings

Results indicated that over 70% of subjects had better function with AT versus without AT at both time points. Over time, function did not change when rated without AT; however, when rated with AT, 13.6% had improved function at Time 2. Subjects living in the community at Time 2 had significantly higher functional scores as compared to subjects in institutions, regardless of AT condition.

Social supports had a strong influence upon whether AT-EI was even considered, and, if available, whether it was setup consistently on a daily basis to enable functional use or not by the person. Thus AT either became a support or a barrier in large part due to the influence of the social supports and caregivers. Issues of time, lack of knowledge or training on how to address needs or setup of AT, perceptions about the person's potential to benefit or not from the AT, and turnover and burnout of staff negatively influenced use of AT beyond those activities in which the AT made the task easier for the caregiver, such as transferring or mobility. AT was identified as underutilized in social, recreational, spiritual, and community participation

activities. Greatest unmet AT needs were reported in the areas of: communication, operating basic appliances (e.g., TV, VCR, radio), mobility in room and in neighborhood/community, community outings, leisure/entertainment, and taking a bath/shower.

Aim 2: Provide training on aging, disability and AT strategies to social supports to enable them to support consumers in identifying issues, needs, and resources.

Sample Population and Methodology

A series of workshops were held at community sites throughout Illinois and New York addressing the need for information by care providers pertaining to normative age related changes and accelerated aging with disability trends, the impact of these changes on function, community living, societal participation, and the use of assistive technology and environmental interventions as supportive strategies. Training modules in six content areas, Seating and Positioning, Cognition and Learning, Communication, Sensory Functions, Upper Extremity Function, and Funding and Service Provision, were developed and used during the workshops. Training included introductory lectures, PowerPoint slides, video case studies, interactive learning activities, and a hands-on opportunity to try out various technologies.

Data Collection and Measures

Ninety seven participants in the workshops were asked to complete a 20-item Pre and Post survey that included questions on both general knowledge and the application of knowledge. Participants included family members, consumers, case managers, and staff from community group home and day programs. Results indicated that the workshops were highly effective.

Data Analysis

McNemar's test on individual test items was used.

Findings

Preliminary analysis of the data indicated significant differences ($F = 33.22$; $p < .001$) in the overall mean between the pre (Mean = 12.70; S.D. = 3.53) and post test (Mean = 16.58; S.D. = 2.75).

Results from the McNemar's tests on individual test items indicated that the participants' greatest improvements were found in knowledge questions pertaining to communication, seating and mobility systems, and the normative changes associated with aging ($p < .001$). While improvement was also significant in items pertaining to the application of knowledge, the participants' ability to apply knowledge remained low even after the workshops.

Aim 3: Design, implement, and pilot test a AT long term support and advocacy (ATLAS) intervention in a clinical trial. Target audience: consumers, family/caregivers, and community agency staff.

Sample Population and Methodology

Sixty subjects from the second study described in Aim 1 are randomly assigned to participate in the ATLAS intervention group or a control group receiving existing services. The clinical trial took place over 2.5 years (years 3.5-5) at Chicago, IL. and Buffalo, NY. Based on needs identified in Aim 1 & 2, ATLAS involved the development of long term support teams of consumers who use or need AT, their family and caregivers, and key community staff. Given support from Drs. Gitlin and Corcoran, the intervention adapts their caregiver-client functional problem solving approach used with people with Alzheimer's Disease,

and applies the Competence-Environment Press framework to people aging with I/DD and their social supports in community-based settings. Additionally, an advocacy and social networking component has been added to link consumers and caregivers with information resources and disability groups where they can trade strategies with other AT users.

The intervention involves five 2 hour sessions primarily focused in the home and surrounding neighborhood. Consumers and social supports work with an OT for 4 sessions to identify issues they are facing related to community living and participation, and to problem solve how to address these issues through environmental strategies (physical modifications, technology, social environment changes, information access, etc.). In the 5th visit, a disability advocate works with the team to link them to information, resources and social support networks in the community and through Internet.

Data Collection and Measures

Qualitative and quantitative data is gathered at each visit, following the protocols used by Gitlin and Corcoran in their randomized trials. Function (e.g., independence, safety, and difficulty) in basic and instrumental ADLs, leisure and community living activities is measured via self report and observation using the C-CAP tool validated by Gitlin. Additionally, occupational goals (e.g., importance and satisfaction ratings), environmental barriers and strategies tried, and readiness to learn/change are assessed at baseline, and again at 3 months post (end of intervention) and 9 months post to see change over time.

Data Analysis

General estimated equation model (GEE) is being used to analyze changes over time within a repeated



measures design that accounts for a heterogeneous sample. The impact of the intervention on functional and societal participation performance, goal fulfillment and satisfaction is being analyzed, and in Phase 3, compared between treatment and control groups. A comparison of the AT/UD delivery process, long-term AT use/abandonment rates, and cost effectiveness of the standard versus BEST-AT intervention is being examined.

Findings

We have noted that by targeting this intervention beyond the individual to the social environment has already resulted in environmental changes that have affected many people. For example, two participants seen in separate group homes both identified issues with bathing and bathroom access. The group home managers were linked to community agencies that performed home modification assessments; they in turn took the detailed plans and used community contractors who donated their time to modify the entire bathroom at both homes. Because of this, all home members have noted improved access and function.

Implications for Research and Practice

The results from Aim 1 suggest a beneficial impact of later life AT-EI assessment and programming for people who are aging with DD, and qualitatively point to the influence of the social and physical living context upon AT-EI use and relationship to community living decisions long term.

The results from Aim 2 indicate a need for more long term support in AT in real life scenarios that require identification of needs and problem solving strategies to address these needs. A workshop or training materials alone are not adequate for applying

knowledge to complex situations. The information obtained in this study has been helpful in providing direction for the ATLAS intervention trial. Additionally, the training modules were combined into an interactive educational package that is available through the RRTC Clearinghouse for use in community-based settings.

Targeting this intervention beyond the individual to the social environment has already resulted in environmental changes that have affected many people. Thus, we hypothesize that the strength of the intervention, and its success if shown, will rely on how effectively the social environment can be brought into the collaborative problem solving team to integrate AT-EI into everyday contexts.

Furthermore, a new area of research and development has been identified through our state of the science symposium, which recommended designing and building access-ready and age-friendly

communities that integrate people with I/DD into all aspects of participation. The symposium that consisted of a round table of consumers, therapists, architects, engineers, anthropologists and space planners has provided detailed ideas for future development and research in this area.



Publications and Products

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