

The impact of assistive technology and environmental interventions on function and living situation status with people who are ageing with developmental disabilities

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Abstract

Purpose: A longitudinal study of 109 people with developmental disabilities, 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.

Method: Functional status were measured at two times (Time 1 baseline and Time 2 an average of three years post intervention) on 32 functional activities under two conditions: without AT (person only) and with AT (environment adjusted). 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.

Results: 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 better 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. Additional quantitative and qualitative data on AT-EI use, needs, and barriers and supports to its integration into everyday activities are reported.

Conclusions: Results suggest a beneficial impact of later life AT-EI assessment and programming for people who are ageing with developmental disabilities, 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.

Background and literature review

Assistive technology and environmental interventions, referred to as AT-EI, have been used by people with disabilities to enhance function, and as supportive resource tools for community living and participation. According to the definitions used within the Developmental Disabilities Assistance and Bill of Rights Act (1994, currently undergoing reauthorization), and based upon those used in other similar legislation, assistive technology (AT) is 'any item, piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with developmental disabilities'. AT commonly includes seating and mobility, communication, access, environmental control and daily living technologies. Although not specified in the legislation, environmental modifications such as grab bars, ramps, lifts, and modifications to building interiors and exteriors also target the same goals and are often delivered in conjunction with AT. Although an increasing number of studies examine the impact of AT-EI few have included or focused upon people with developmental disabilities who are ageing.

There are an estimated 526 000 people over age 60 with mental retardation and other developmental disabilities in the United States. This number is predicted to double by the year 2030.¹ Research suggests that people with life-long developmental disabilities may experience age-related changes in motor, perceptual and sensory abilities earlier than the non-disabled population, potentially as

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early as age 30–45 depending on specific diagnoses and co-existing conditions.^{2–4} The combined effects of disability, ageing, changes in physical environments and social support systems also impact upon community living status and choices. Family and others who provide assistance to people with developmental disabilities also are ageing, experiencing threats to their own function. They express concerns about future living decisions for themselves and for the individuals they support.⁵

At the community and societal levels, legislation and social activism movements have resulted in widespread deinstitutionalization of people with developmental disabilities. This movement has also established the right to live in the community and to receive supportive resources to do so, including assistive technology and environmental modifications.^{6–8} The majority of persons with developmental disabilities in the US live in the community (57% with family members or in homes with 1–6 people; 7% in community group homes or supported living situations with 7–15 people). However, 8% continue to live in nursing homes, 22% in settings of 16 or more people, such as public or private institutions, and 6% in intermediate care facilities of 7–15.⁹

In Illinois, the relatively high rate of nursing home placement, coupled with the level of resources available to support transitions to community living, were contested within a class action lawsuit brought on behalf of individuals with developmental disabilities who were living in nursing homes and institutions.^{10,11} The state was legally mandated to address this issue and provide resources as indicated, including AT-EI, to enable transitions to community living. The Home and Community-based Waiver programme also was instituted nationally to meet the same mandate of providing community living options and resources to people with disabilities.

It is argued that AT-EI may serve as a supportive resource for community living and participation, and that there is a need for proactive, later life AT-EI assessments and programming to identify and address potential issues and needs early. However, there are few studies examining the impact of later life AT-EI with people who are ageing with developmental disabilities.^{1,11–13}

Mann and colleagues have conducted several relevant AT-EI outcome studies with frail elders.^{14–16} In a randomized controlled trial of 104 frail older adults, Mann *et al.*¹⁴ found that subjects who received functionally-based AT-EI showed significantly less functional decline, and reported lower levels of pain before versus after treatment. Although subjects in the treatment group spent more money on AT-EI products and services, those in the control group had significantly more costly expenditures for in-home nursing and case manager visits, and

subsequent institutional care. This study suggests that AT-EI attenuated frail older adults' functional decline.

In a study of older adults with cognitive impairments, primarily due to Alzheimer's Disease, results showed that subjects had low average scores for basic and instrumental activities of daily living (ADLs).¹⁵ They used fewer devices and were less satisfied with the devices when compared to older adults without cognitive impairments. A follow-up study found that devices to accommodate physical impairments were more readily accepted and used than those for cognitive impairments (e.g. memory aids, safety assists) among seniors with cognitive impairments. However, once used, people were more satisfied with the cognitive devices.¹⁶

Gitlin and Corcoran^{17–19} conducted a series of studies to test a home environmental intervention programme for older adults with Alzheimer's Disease and their caregivers. The intervention focused upon enabling the caregiver and client to solve functional and behavioural problems via changing the social and physical environmental press (e.g. simplifying tasks, adjusting environmental stimuli, removing dangerous objects, using AT-EI as indicated). Findings of the most recent randomized clinical trial suggest that this environmental approach positively impacted on both the caregiver and the person with dementia by slowing the rate of functional decline, and enhancing caregiver self-efficacy.¹⁹

Despite the potential benefits of AT-EI, results from need surveys indicate that only a small percentage of adults with mental retardation use AT-EI. They and their family members expressed the greatest unmet AT-EI needs in the areas of communication (10% using, 12.5% need), mobility (9% using, 7.5% need), and independent living/environmental control (7% using, 16.25% need).^{20,21} A large percentage reported that individuals with mental retardation were not using basic household appliances like can openers (44%), toasters (38%), VCRs (34%), radio/stereos (28%), or televisions (18%). These findings support the need for further research to examine why people with mental retardation are not using AT in everyday life, and what its impact may be upon their function if considered and applied within later life programming.

In a pilot study of 35 persons with cerebral palsy and mental retardation, subjects received medical and functional screenings with referrals to AT-EI services as indicated.¹³ Results showed functional improvement or maintenance over time when subjects were rated with AT, with greater functional decline when rated without AT.

In a related study of 80 adults and older adults with developmental disabilities, subjects in nursing homes

were found to use less AT to address a greater number of functional limitations than those living in the community.¹⁵ The greatest unmet needs for AT-EI were wheelchairs and seating systems, followed by communication and daily living equipment. A larger study of community living transitions in general, not specific to AT-EI, also showed that the greater level of functional impairment, the less likely people were to leave the nursing home.²²

In summary, there are few outcome studies that examine the impact of AT-EI over time with people with developmental disabilities, particularly persons who are ageing and who are transitioning to or trying to remain living in the community. To examine whether AT-EI serves as a supportive resource for function and community living, additional studies are needed. This study aimed to examine the functional and living situation outcomes of a sample of 109 people with developmental disabilities who received later life AT-EI assessments, services and products. Functional ratings were compared with AT and without AT over time. Differences between people who lived in nursing homes as compared to community settings were also examined. Finally, the study qualitatively explored how AT-EI is perceived and used as a supportive resource by people with developmental disabilities and others in their lives.

Research questions

- (1) How does functional status differ over time and between conditions (with AT, without AT) for people with developmental disabilities who receive a later life AT-EI intervention?
- (2) How does functional status, with and without AT, differ for people living in institutional settings as compared to community settings?
- (3) Qualitatively, how do people who are ageing with developmental disabilities and others in their lives (e.g. family, social supports, agency staff and people who provide functional assistance) describe the impact of AT-EI on their everyday lives?
- (4) Qualitatively, what are the barriers and supports to using AT-EI within functional routines in community and institutional settings over time?

Methods

DESIGN

The Rehabilitation Research and Training Centre (RRTC) on Ageing with Developmental Disability has been studying transitions to the community, and factors

influencing that process and outcomes over time as people with developmental disabilities age. This longitudinal outcome study focused on the influence of AT-EI on functional and living situation status. Given that all subjects had experienced developmental disability from birth or early in childhood, all had some familiarity with AT-EI and had been using it to varying degrees prior to this study. This study then examined the additive impact of AT-EI newly provided as part of a targeted later life intervention to address functional and community living issues identified by people with developmental disabilities. All of the subjects were attempting to transition to community-based settings, and received AT-EI as a supportive resource to do so. A longitudinal research design was used to study the processes and outcomes over time and across conditions, both quantitatively and qualitatively.

SAMPLE

The sample consisted of 109 subjects who received AT-EI services based on functional needs in the areas of activities of daily living (ADL), communication, social, leisure, community living and/or participation activities. The average age of the subjects was 50.52 (range 35–89, S.D. 12.49). Subjects as early as age 35 were included given previous research showing early age and disability related functional changes. Forty-eight percent were men and 52% were women. Eighty-eight percent (80.7%) were Caucasian and 21 were African American (19.3%). The majority of the clients had a diagnosis of mental retardation: 13 mild (11.9%); 19 moderate (17.4%); 28 severe (25.7%); and 46 profound (46%). Only two subjects did not have a diagnosis of mental retardation (2.8%); however, were identified as having 'other mental retardation'. Of this sample, 40 (36.7%) had coexisting cerebral palsy. Over 60% reported some level of communication impairment, 35.8% reported upper extremity limitations, and 51.3% reported lower extremity limitations. In regard to living situation at end of the study, 58.2% were living in community settings (e.g. family, group homes, other community) and 51.8% in institutional settings (e.g. nursing homes, state institutions, and intermediate care facilities of 16 beds or more). All were living in urban or suburban areas in and surrounding Chicago.

INTERVENTION DESCRIPTION

All subjects were initially screened by case managers at the Assistive Technology Unit (ATU), a community-based centre located at the University of Illinois

at Chicago, for functional issues that would indicate a need for an AT-EI. A screening form developed by assistive technology specialists contained a series of questions about function in activities of daily living, communication, seating and mobility, and access to products and the environment. Those subjects who identified at least one need in any of these areas were referred for comprehensive assessment and services.

Subjects received specialized AT-EI assessments, follow-up services, and products through the ATU. Specific AT-EI ordered included seating, positioning and mobility; augmentative and alternative communication (AAC); technology and environmental access and control; daily living equipment; and environmental modifications of the person's living situation or day programme worksite. Services were delivered by a team of AT specialists including occupational and physical therapists, speech and language pathologists, rehabilitation engineers, and technicians as indicated per case. Services included initial AT-EI assessment in the individual's environment; selecting, ordering and procuring AT-EI; installing, fitting, customizing, and adapting AT-EI as needed; and providing training or technical assistance with the consumer and others involved in using the AT-EI. Specialized AT-EI assessments took an average of two hours (range 60 minutes to 4 hours), and subjects were seen for an average of three visits per client during the three year period (range 1–12 visits). Funding for services was provided through multiple sources. These included funding via the state class action lawsuit to provide resources to transition out of nursing homes to the community, and traditional sources such as Medicaid, Medicare, Office of Rehabilitation Services, and others as indicated by case.

DATA COLLECTION

At the time of referral for specialized AT-EI assessment, subjects and legal guardians were contacted to participate in this research study, were informed of their rights, and, if interested, completed informed consent procedures. Upon entry to the study, data were collected via interviews within the subject's current living situation by trained interviewers who were not a part of the

intervention delivery team or individual's living situation. Interviews included one faculty member and three advanced graduate students in occupational therapy and/or disability studies with functional assessment experience and training by the study principal investigators.

To the extent possible, the subjects themselves were interviewed, with accommodations as needed such as communication devices, signing or other alternative strategies (see table 1). However, in situations where the person was not able to participate with accommodations, such as with individuals with severe and profound mental retardation, a proxy was identified by the subject and/or primary family, guardian or case manager as the person most familiar with the subject's everyday function and routines (e.g. primary person providing functional assistance) in that setting (institution or community). For individuals living in group/communal living situations or institutional settings, more than one proxy was used depending on familiarity with daily living activities within and outside the living situation (e.g. day programme, work programme). Regardless of proxy use, the subjects were included in interviews to the extent possible, and their input, including nonverbal gesturing, was recorded as data.

Demographic information was collected using the Inventory for Client and Agency Planning (ICAP), an assessment completed annually with all people with developmental disabilities receiving services.²³ Functional status and AT use were assessed at Time 1 (baseline at time of receiving AT services) and Time 2 (an average 3 years post intervention) using an adapted version of OT FACT, a functional assessment tool.²⁴ A total of 32 functional tasks reflecting basic and instrumental activities of daily living, community participation, leisure, and social activities were chosen from the extensive pool of available items to represent a range of activities related to community living and participation (see results for item listing). For each item, respondents were also asked to describe the type of AT-EI used and any unmet needs.

Functional status was assessed using a 3-point scale: 2= independent (person does task by self); 1= person participates in the activity and requires some level of

Table 1 Subject and proxy involvement in interviews

	<i>Subject only informant</i>	<i>Subject primary informant with proxy input as needed per activity</i>	<i>Proxy primary informant with subject input as possible</i>
# of subjects	8	45	56

assistance (partial independence); and 0 = dependent (another person performs the task for the person). Each subject was rated under two conditions: (1) without AT, and (2) with AT at Time 1 and 2 for each item. The without AT rating reflects the performance of the person, while the with AT rating reflects an environment-adjusted rating to study the specific influence of AT-EI. A 'don't know' option was also given if the person did not have the opportunity to perform that activity in that setting. In addition to function, subjects were also asked to report the type of AT-EI used for each activity, and any unmet AT-EI needs.

Additionally, the interviews asked open-ended qualitative questions about problems, issues and concerns related to performing everyday activities with and without AT, and how the AT-EI influenced their living situation and overall participation over time.

ANALYSIS

Descriptive analyses (frequency counts, averages, ranges, etc) of AT-EI use and needs were computed using SPSS, Version 10.²⁵ Rasch analysis was performed, using the BigSteps programme,²⁶ to transform the ordinal scores from the three-point functional scale to Rasch-derived, equal interval linear measures. While often ignored in the analysis of survey data, equal-interval data is fundamental for even the most basic mathematical manipulation of scores.^{27, 28} Using SPSS, 95% confidence intervals were then computed from the Rasch-derived functional scores and their standard errors of measurement to compare significant differences across conditions (with AT and without AT), and over time (from Time 1 to Time 2) in relation to functional status. To perform comparisons, a stable reference point was set, Time 1 without AT, since this represented the person-only score without environmental adjustments of AT-EI. A t-test was done to compare functional levels between the community living and institution-based groups.

The qualitative data from open-ended questions was analysed by two of the interviewers by coding for emerging patterns or themes that supported quantitative findings, added additional details to further illuminate them, introduced new findings not elicited in the quantitative portion, or challenged the findings in some way.^{29, 30} Direct quotes from respondents, including participants with developmental disabilities and proxies from the community or institutional settings, are provided to illustrate these themes.

Quantitative and qualitative data were then compared by the authors to triangulate, or synthesize, the multiple

sources of data, and to provide a broader understanding of the results from multiple perspectives.²⁹

Results

DESCRIPTIVE RESULTS

Table 2 shows the 32 functional items assessed, frequency of people using AT-EI to support that activity, and frequency of people who reported a need for new or additional AT-EI specific to that activity. A total of 1390 AT-EI products were used across the 32 activities, averaging approximately 12.8 devices per subject. The number of people reporting AT-EI used per activity varied, ranging from a low of three people reporting AT-EI use for reading to a high of 74 using AT-EI to move around outside. An average of 44 AT-EI products were used per task.

As shown in table 2, subjects were using the AT-EI across a wide spread of activities, including community participation, social, and leisure activities, beyond the basic activities of daily living assessed in many functional assessments. Such activities included going on community outings, social activities, entertaining self, and religious activity. Of note, only 41 out of 109 subjects were using AT-EI for operating basic appliances (e.g. TV, VCR), a small number given the range of inexpensive environmental control devices available to enable participation in these everyday tasks.

CONDITION COMPARISON RESULTS

Figures 1–4 show the results of comparisons of functional status of subjects across different conditions. The solid line represents the 45° identity line, and dashed lines represent the 95% confidence intervals, which were determined from Rasch-derived functional scores and their standard errors of measurement. The upper left half of the figure represents subjects who showed better or higher functional performance (as indicated as outside the 95% confidence interval) while the right lower half represents subjects who showed worse or lower functional performance. Subjects who were between the two dashed lines (inside the 95% confidence interval) did not show significant differences in functional performance under the two conditions compared.

When comparing AT conditions at Time 1 (baseline), 70.2% had higher functional scores with AT, 20.2% had the same or maintained scores, and 9.6% had worse scores with AT versus without AT (see figure 1) (n = 94 with 15 missing data points). At Time 2 (average three years post), 73.5% had higher function with AT,

Table 2 Descriptive results of AT use and need at the end of study (% using adds to more than 100% given that subjects reported using the same technology for more than 1 activity)

Activity	# using AT-EI (%)	# need more AT-EI (%)
Move outside 2 blocks	74 (67.88%)	6 (6.54%)
Move in room	70 (64.22%)	9 (8.26%)
Go shopping	69 (63.30%)	2 (1.83%)
In/out tub/shower	68 (62.39%)	6 (6.54%)
Community outings	65 (59.63%)	6 (6.54%)
Get around work/day programme	64 (58.72%)	2 (1.83%)
Social activities	64 (58.72%)	2 (1.83%)
Entertain self/leisure alone	62 (56.88%)	6 (6.54%)
Get in/out home	60 (55.05%)	2 (1.83%)
Move throughout house	59 (54.13%)	4 (3.67%)
Get in/out vehicle	58 (54.13%)	3 (2.75%)
Transfer chair/bed	58 (54.13%)	1 (0.92%)
Wash body/hair	56 (51.38%)	5 (5.45%)
Get dressed	53 (48.62%)	4 (3.67%)
Religious activity	53 (48.62%)	3 (2.75%)
Communicate	47 (43.12%)	10 (9.17%)
Eat	47 (43.12%)	4 (3.67%)
Emergency contact	45 (41.28%)	2 (1.83%)
Toilet transfer	45 (41.28%)	2 (1.83%)
Wash hands/face	45 (41.28%)	2 (1.83%)
Brush teeth	43 (39.45%)	2 (1.83%)
Operate appliances	41 (37.61%)	9 (8.26%)
Sports activities	39 (35.78%)	3 (2.75%)
Participate in work/day programme activities	36 (33.03%)	2 (1.83%)
Weight shifts/pressure reliefs	36 (33.03%)	1 (0.92%)
Put on shoes/socks	25 (22.94%)	3 (2.75%)
Use phone	21 (19.27%)	3 (2.75%)
Clean home	19 (17.43%)	2 (1.83%)
Cook (prepare simple meal)	16 (14.68%)	3 (2.75%)
Laundry (wash & dry)	12 (11.01%)	2 (1.83%)
Write/type	11 (10.09%)	6 (6.54%)
Read short book	3 (03.75%)	2 (1.83%)

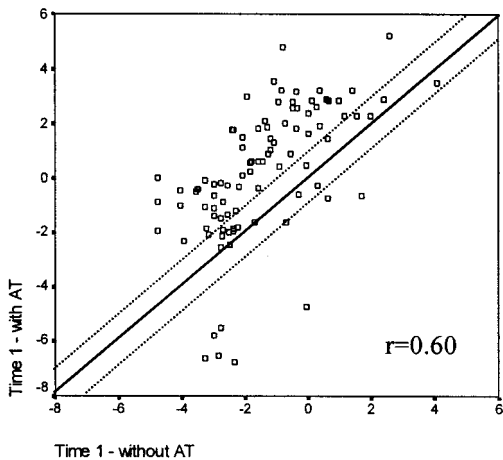


Figure 1 Time 1 functional comparisons, With versus Without AT.

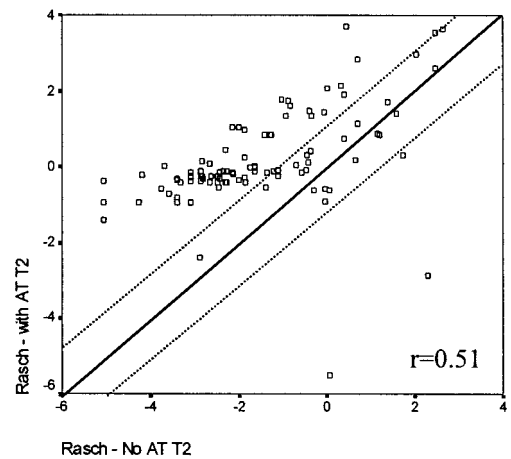


Figure 2 Time 2 comparisons, With versus Without AT.

23.5% had no change/maintained, and 3.1% had worse function with AT versus without (see figure 2) (n=98 with 11 missing data points).

When comparing change over time without AT, all subjects (109) showed no change, neither improving nor declining under this condition (see figure 3). When rated with AT, 13.6% had improved functional scores at Time 2, 81.8% had no change/maintained, and 4.5% had worse function at Time 2 versus Time 1 (see figure 4) (n=88 with 21 missing data points).

COMPARISON OF LIVING SITUATION AND FUNCTIONAL STATUS

T-tests were done to compare the group of subjects who lived in the community to those who stayed in or

transitioned back to the nursing home or institutional setting. Subjects who lived in the community had significantly higher functional independence levels than those who lived in institutional settings at Time 2, regardless of AT rating condition: $t_{96} = 2.78$, $p < 0.01$ in the 'with AT' condition; $t_{107} = 5.39$, $p < 0.001$ in the 'without AT' condition.

QUANTITATIVE RESULTS

The qualitative data collected helped to further describe the 'bigger picture' of life for these individuals, and the role of AT-EI as a functional and community living tool. These data also illuminated additional issues and outcome patterns that were not identified through the quantitative data. The following themes emerged, and are highlighted by direct quotes from participants with developmental disabilities and proxies from the community and institutional settings. The quotes reflect raw data with original spelling and grammar, including communications constructed via augmentative communication devices.

Participants validated that they operated differently 'with' and 'without AT', and that AT-EI made them a 'different person'. This was especially true for seating, mobility and communication technologies, which often made the difference between function and no function for one or more activities. For example, when asked to talk about how the person did an activity with and without AT-EI, people replied:

Simple. I talk (referring to AAC device). I need it. When broke, I no talk.
(participant in the community using an AAC device to answer)

He's all over the place with his new chair (received a power wheelchair and new seating system). Before that, he never left his room unless someone had the time to roll him over to another room. Now he's whizzing down the hall and around the block. I can't keep track of him sometimes... One day they were tearing up the sidewalk outside the house and he couldn't use the new chair. It was like he was a different person again—dependent on people to move him everywhere. It's kind of amazing to think about—with it he moves, without it he's dependent on me.
(community proxy)

Several people discussed the cross-activity impact of AT-EI; that is, how AT-EI ordered for one activity

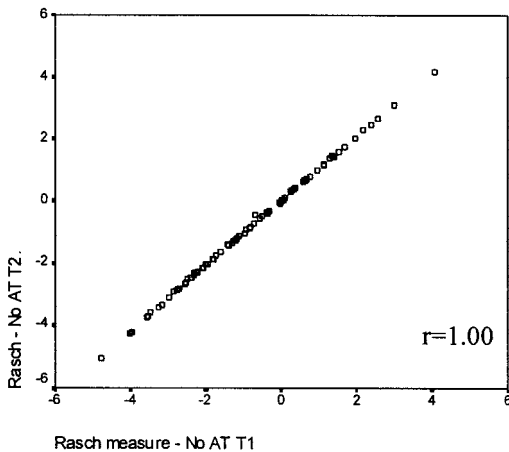


Figure 3 Without AT functional comparisons, Time 1 to Time 2.

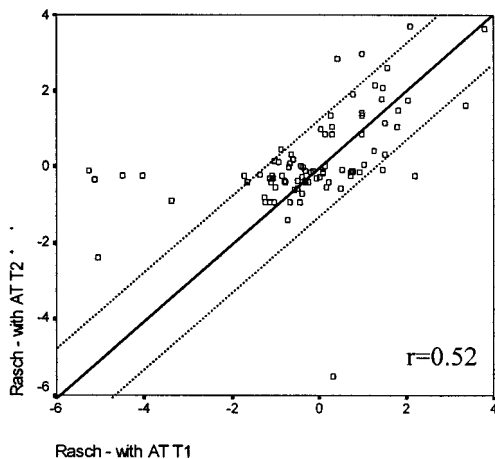


Figure 4 With AT comparisons, Time 1 to Time 2.

was then utilized across several activities throughout the day and across settings:

I got this (points to new wheelchair and seating system). I fly. I go to see people; they my friends. I go outside...I sit up...I see things...I eat lunch (pats wheelchair)
(participant in the community)

We go more places than we used to before, do new things. It's kind of a hassle to get him in the van sometimes, but he's going out a lot more... With the new seat, he can sit up better and doesn't seem to be in as much pain. It (points to seating system) helps him sit up so he can eat some finger foods by himself...It's easier to transfer him to the toilet... I think he sees things better cause he's sitting up and not falling to the side as much. I put all kinds of things on his laptray all the time for him to touch and play with—from the house, the store, wherever we are. He picks them up and brings them to his face to feel. He holds them. He shakes them to see if they make a noise and smiles when they do and does it again. Before, he didn't notice things—I think it opens the world more to him.
(community proxy)

Many people commented on the influence of the AT-EI even though functional scores did not reflect a change. People identified outcomes other than functional performance, such as control, power and choice:

I tell you (what) I want. I like (points to different choices on the AAC device). Happy.
(participant in the community)

Since he got that device (communication system), he tells me what he wants. He makes me wait until he's finished before I start doing something. He interrupts me all the time (laughs). He tells me when I'm doing something the wrong way or when something hurts or is bothering him. He tells me when he's mad or unhappy about something.
(community proxy)

It's like she's more in control of things now. More assertive about getting my attention or getting me to help quicker. It's like she wants to get in that

chair and get her communication stuff set up faster than we can move, especially at the start of the day. She starts pointing at things right away so I can tell what she wants to do first.
(community proxy)

People who provided assistance commented upon the impact of the AT-EI on their own lives, particularly those who were providing physical assistance to individuals with severe and profound mental retardation:

Sometimes all the tech is a blessing and sometimes a curse. When it works, it makes things a lot of easier for me. I don't have to lift as much—it's saved my back. I can get her in the van easier so go out more. I don't have to guess what she's trying to tell me... It makes me feel good to see her doing things for herself. I don't think too much about this until something breaks and the tech isn't there, or we're waiting for some new tech.
(community proxy)

You know I still help but it's a different kind of help. Some things are easier, like getting him up in the morning and taking care of everything before he goes to his day program. Some things take less time. Some take more time cause I have to set things up, but it makes me feel good to see him doing things that I never thought he would do. I feel better about him... I'm getting older you know so anything that helps me or saves my back is worth it. If I'm not around some day, God forbid, I'd like to think this stuff (referring to AT-EI received) will help him keep going and maybe keep him in the community. With all the new stuff coming out, maybe things will get even better for him.
(community proxy)

Within the nursing home and other institutional settings, a primary reason for choosing to use AT-EI was related to how much the AT-EI decreased the staff's burden of care, as reflected in quotes from nursing home proxies:

I use the tech that helps me or saves me time and energy, like the transfer aids or the grab bars and the ramps and the wheelchair. You know, the stuff that makes it safer for her too so we don't drop her or she doesn't hurt herself. That other stuff, like the thing she uses to communicate, takes a lot of time to set-up and needs to be just so to

work for her. Some people will do it if they've got the time that day, or maybe the therapist when she visits, but a lot of times it never gets put on her tray so I guess she doesn't use it that much. In fact, I'm not even sure what happened to that thing—haven't seen it in a long time.
(nursing home proxy)

Whatever makes it easier, mostly for us cause we're the ones getting him up and out of bed every day. If it's hard to set-up or takes a lot of time, chances are that's the stuff that won't be used too much or gets put in a closet and never comes out again. It's just too much of a hassle to do, and with all the staff change over, it gets lost in the shuffle a lot.
(nursing home proxy)

A number of people identified how the living situation and environment the person operated in significantly influenced the person's function and use of AT-EI, positively and negatively. Many respondents choose a 'don't know' answer to functional items, discussing how these activities, or the technology to support them, were not considered in that setting:

I've never done that (referring to cooking and laundry) here. They do it for me. I'd like to try.
(participant in nursing home)

We do all that stuff for him (cooking, laundry). We wouldn't let him near those facilities, and we don't have the time, people or resources to do any of that on the ward. We do almost everything for him. Who's got the time? Yeah, sometimes I wish we did but we don't. He's lucky if he can get in his chair every day—we're so short staffed. And some of those people don't know what they're doing. I see his cushion put in every which way but right—sometimes he's on it upside down or it's not there at all. Or he's falling out of the chair or something's falling off his chair and dragging on the floor. It depends who's working with him that day and if they know anything about him or how to set up things for him.
(nursing home proxy)

We had to spend a lot of time with him when he moved here (group home in the community). He

didn't do anything, probably didn't have the chance to before. There's only a couple of us working here so we pretty much have it down to a science on how to set him up so he can do things. We get him involved in everything. Doesn't matter if he can do stuff by himself, it's more just being a part of what's going on around him. The tech's been helpful in that. Now that we've got some, I have other ideas for more tech too—who do I talk to about that?
(community proxy)

Before (in nursing home) I never did that (attend church). Now I go every week cause of this (puts hand on wheelchair). I like it. I see my friends.
(participant in the community)

Many people were prompted by the functional activity questions to think about unexplored opportunities:

You know, I didn't even think of that before (referring to using the phone and having an emergency system to call for help). You're right, he doesn't really have any way to connect with other people outside this place (nursing home). He has a call ball to get us, and we worked to put that in a place where he could get to that but sometimes people don't position it there so he can't reach it. Same with the TV, we usually control it for him.
(nursing home proxy)

Until you brought that up (control TV and other appliances), I hadn't thought about it. Some people in the home are able to do that on their own but it would be good to try some kind of tech to give access to that if someone can't use a regular remote. That would be great to try—how do we do that?
(community proxy)

She could really use some more leisure things to do, especially after she gets back from the day program when there's not much to do. Some things to interact with the other people who live here. Could tech help her do that? Maybe something with a switch or something. I'm not even sure about the phone or how to do that. There's a computer at her day programme, but I don't think she's ever worked with it. If she can operate that device

(points to communication device) I'm guessing she could do other stuff too. How do we get that kind of thing covered?
(community proxy)

Still, when asked about the decisions related to living in the community or an institutional setting, issues related to severity of disability, and level of social support or advocacy, were discussed as reasons for not transitioning out of, or returning to, nursing home placement, as reflected by proxies:

He's here (nursing home) because he's so severely disabled. He's dependent on us to do everything for him. The tech only helps a little, probably us more than him. He doesn't have family to go to, and group homes don't want someone that disabled.
(nursing home proxy)

It's a lot easier to get someone out to the community if they can do more for themselves. Then they don't need as much help from people like us. You know, someone could give a wheelchair to and then they'd be able to move around without help. Most of the people here (nursing homes) can't do that. We have to help them with everything.
(nursing home proxy)

I think a lot of it has to do with two things: how disabled the person is, and who's fighting for them to get out. And, who's there to help them once they get out cause, it's not easy to stay in the community after that, especially when someone's pretty disabled and needs a lot of support. It takes a lot of time and effort to get a placement in the community for someone who is pretty disabled, especially if they can't toilet themselves. There's long waiting lists for places and by the time they come up for someone they're pretty set where they are or have lost function and the place won't accept them anymore. Still, if someone's fighting for them or with them, that'll help cause the squeaky wheels gets the grease. The tech is great and I've seen it help people a lot no matter where they live so I guess that's good. But there's a lot more to thinking about transitioning to the community than the tech. Without the right supports and the perfect timing, it's a tough move to make, and easy to land up back in the nursing home if the

supports aren't there. (case manager proxy who works on transitioning planning)

Discussion

Functional comparisons by time and by condition (with versus without AT ratings) suggest a beneficial impact of the later life AT-EI for this sample; however, there are some nuances in the results that may be related to the nature and severity of disability within the sample studied and/or the nature of the items used to measure function. At specific time points (baseline or follow-up three years post), subjects consistently rated their functional performance better under the environment-adjusted condition (with AT) as compared to person-only performance (without AT). Over 70% rated better performance with AT, with a small increase in percentage at Time 2 (73%), suggesting it is useful to assess function under both conditions to try to tease out the impact of AT for a given person rather than combining AT and human assistance under the same category of 'assistance'.

Almost 10% rated their performance as worse with AT versus without AT at Time 1, suggesting that for a notable portion, the AT hindered rather than enhanced function. When asked about this effect qualitatively, respondents acknowledged that some AT, such as specialized mobility, communication or daily living equipment that needed to be set-up very carefully, became barriers rather than supports. This occurred when assistants did not know how to use the AT-EI properly or did not have the time to ensure set-up accuracy. This was a particularly difficult problem if these assistants varied across the day, which was the case for many subjects, especially those living in nursing homes and intermediate care facilities.

In some cases, AT-EI designed to address one issue, such as a custom seating system to address issues of tone and posture, interfered with other activities, such as ability to get from bed to wheelchair or to transfer smoothly from surface to surface without having to lift above or around the seating system. However, there was a decrease in this negative effect by Time 2 (from 10% at Time 1 to 3% at Time 2). This may be due to later life needs assessments to determine how prior technology was or was not working for the person as he/she aged, updated technology and more choices of solutions to better match the person's needs, and/or more careful attention across activities by the specialized service delivery team. These results point to the need for careful attention to assessing functional needs within the

context of the social world, and within the broader picture of the person's routines across the day.

When comparing function across time under the same condition, the results are less clear. When rated without AT, there was a perfect correlation with no significant differences between Time 1 and 2. This finding was surprising in that one would expect to see some levels of functional decline over time when rating person-only performance. This could be due to the severity of disability among this sample, other changes in the living environment that might mediate functional decline, or, a lack of sensitivity of the rating scale or items to this population in distinguishing among finer levels of functional change. Separate analyses of the measurement properties of the rating scale and items are being performed to further examine these issues. The finding of no change is worth exploring in more detail to see if it was specific to this sample or not, and/or to the methods of reporting and measuring function.

When rated with AT, however, there was a wider distribution of function, with over 13% showing better scores at Time 2 than Time 1, and 4.5% showing worse scores at Time 2. The higher function result is worth noting given this sample, and does support a potential beneficial role of the later life AT-EI, particularly among subjects operating at lower functional levels (figure 4). This suggests that for this sample, which included a large number of people with moderate to profound mental retardation and other coexisting impairments, that AT may be more beneficial in helping people to go from completely dependent to performing activities with some assistance, rather than enabling complete independence.

In regard to living situation and the role of AT-EI, results confirmed earlier findings that overall, individuals living in the community had higher levels of function than those in institutions.^{11, 22} Despite the legislation and class action lawsuit to provide supportive resources to transition to community living regardless of severity of functional impairments, only 58% of this group were living in the community at Time 2, and this group reflected people with less disability as defined by level of functional independence. When taken into consideration with the earlier findings that the AT-EI appeared to most benefit people at the lower to middle functional ranges, it would appear that factors other than AT-EI were influencing living situation outcomes, including severity of disability and issues related to policies regarding placement decisions.

As reflected in the qualitative results, respondents discussed that it is easier to transition a person with more function to the community given the need for

fewer resources and greater expectations on the part of transition and support staff. The qualitative results showed a pattern in that the longer the person stayed in an institutional setting (e.g. nursing home, intermediate care facility), the greater the likelihood of dependent treatment by staff and lower expectations of functional AT-EI needs and potential to benefit from its use. Staff described that they tended to utilize AT-EI that made life easier for them, such as mobility equipment, or that was needed to prevent or mitigate medical complications, such as a seating system for pressure sores. However, other AT-EI that required set-up and involved more time to use even though it offered increased control to the person using it, such as communication devices and daily living equipment, were perceived as more optional. For this equipment, setup and implementation was more inconsistent and depended on individual staff motivation, interest, training and available time. Over time, this technology was more often reported as misplaced, stored out of sight, or abandoned.

Staff in institutional settings also described many unrealized functional opportunities that could benefit from AT-EI use, ranging from very basic activities such as turning on a TV or calling for help, to those that required more time or resources to go beyond the confines of the room, such as attending a religious service or sporting event. In some cases, certain activities, such as participating in cooking or cleaning, were not allowed in the institutional setting regardless of AT-EI impact.

Despite the unrealized potential, respondents in institutional settings repeatedly described more benefits to AT-EI than drawbacks. They described a 'surprise effect' when they personally observed the individual with a developmental disability able to participate in activities not done before, such as independently moving even for short distances, communicating, and being able to set in a position so he/she could interact with the world and items in front of him/her. Although staff did not talk about this effect causing them to pursue new activities or supportive AT-EI to enhance opportunities, in comparison to many who described this phenomena in community settings, it did serve to challenge institutional care staff's perceptions of people with developmental disabilities and their potential.

In comparison, people in the community, whether it be participants with developmental disabilities or people who were providing assistance to them, spoke of integrating AT-EI in everyday life in more ways, and repeatedly stated an interest in learning more about how to do so even more. Many discussed developing AT-EI set up

strategies until they 'had it down to a science'. They had thought about trying new activities and finding AT-EI to support that, such as accessible controls for the TV, radio or other appliances. They spoke of a shared goal of enabling control and enhancing choice through AT-EI. This included using AT as a tool to enable the person to participate in a social or communal activity, such as meal preparation, regardless of whether he/she was completely independent or used assistance. In essence, they viewed AT-EI as a tool to promote mutual interdependence and engagement in a social context.

However, people in the community also spoke of barriers to AT integration. In some cases, it related to lack of information and resources to obtain more AT-EI as people aged and encountered new needs or changes in function. For this sample, such mid- to later life follow-up assessments and programming were important and frequently requested. People with developmental disabilities and proxies who provided assistance both spoke of needing time to even accept and learn how to use the AT at first, especially with technology that was more advanced or represented a new skill area, such as a new communication device or wheelchair. It wasn't until months later that they were ready to learn new ways to incorporate the AT-EI into more activities, to identify ways to adapt the technology or the environment to fit their needs better, or to consider adding additional technology given success with what they previously received. However, many identified problems in finding such later-life AT-EI programs, and securing funding to deliver them after the transition to the community was completed and the person was now seeking ways to stay in the community over time.

Conclusions

Results of this study suggest a beneficial impact of later life assistive technology and environmental assessments and interventions for people with developmental disabilities living in the community and institutional settings. The AT-EI appeared to impact upon everyday functional activities related to basic daily living, leisure, social and community participation. However, the impact was relatively small over time, a finding that may be due to the sample studied, and/or to the sensitivity of the items used in the functional assessment. Additional analysis of the measurement properties of the functional scale and items used are needed. Results indicate that measuring function with and without AT, to separate its influence from human assistance, is valuable in distinguishing AT influence, and merits further examination of how to assess function given AT influence.

Qualitative results suggest that severity of disability coupled with environmental supports and expectations, may have a greater influence on living situation than AT-EI products. Even within the setting, issues related to staff/assistance training, consistency, interest, time, and beliefs about the person and his/her competence and needs affected whether certain activities were even considered for the person, and whether the AT-EI was perceived as a supportive resource or as an added burden. In comparison to people in institutional settings, people in the community spoke of integrating the AT-EI into everyday activities and routines more, viewed the AT-EI as a supportive resource, and actively sought out additional opportunities to explore new activities and technology. They also spoke of the impact of AT-EI on choice, control, and quality of life, regardless of functional scores. These areas need to be better addressed within assessments and outcomes studies of AT-EI.

The study is limited in that it represents a longitudinal descriptive study of a heterogeneous sample of people with developmental disabilities who all received AT-EI interventions. Although significant in following a sizable sample, including individuals with severe and profound mental retardation, over a three year time period, the study results need to be expanded upon within randomized intervention trials with control and treatment groups in order to generalize findings and examine the specific influence of AT-EI. Additional qualitative studies would help to illuminate how AT-EI influences individual choice, control, and quality of life, and the social and sociopolitical supports and barriers to obtaining it as a supportive resource for community living. Additionally, studies related to policies related to resource allocation, particularly to adults and older adults with disabilities who want to transition to and/or maintain living in the community long term, are needed since these issues were indicated as highly influential in determining living situation, regardless of AT-EI.

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