ETHICAL ISSUES IN THE EVALUATION AND SELECTION OF
ASSISTIVE TECHNOLOGY

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I
INTRODUCTION

Assistive technologies (AT) are meant to help people in their primary functional tasks. Wheelchairs, scooters, walkers, and canes are assistive technologies for mobility and related mobility products include driver-adapted vehicles, lifts on vehicles and portable ramps. More people use assistive technologies related to mobility (6.4 million) than any other general type of assistive technology. While AT for mobility is the largest single group of AT products, there are many other types of products as well. There are environmental aids to daily living as well as technologies for personal, car and household management, augmentative communication devices, and technologies to compensate for sensory (e.g., hearing, eyesight) loss. As of July 2001, ABLEDATA (www.abledata.com) lists 27,000 assistive technology products where over 18,000 items are available presently. The small market size for individual AT products leads to small profits and limited investment, which in-turn limits the availability of AT products. This is proven by the fact that one-third of AT products listed in ABLEDATA are no longer available.

In spite of the assistance and promise of independence offered by many technologies and the growth in AT options, the rate of AT non-use, abandonment and non-compliance remains high. Studies of abandonment reveal that on average, about one-third of all devices provided to consumers end up stored in the closet, basement or drawer. While many AT products go into disuse because they are no longer needed, a lack of consumer involvement in selection is regarded by consumers themselves as an important reason devices are not used. This issue can be addressed appropriately in a
comprehensive evaluation process. Individuals with disabilities, who are involved in the decision in a meaningful way, generally will be more satisfied with AT services overall.\textsuperscript{6}

II

KEY ETHICAL ISSUES

Consumers require a comprehensive assessment by a qualified person

Training dollars and time need to be devoted to educating professionals about available technologies and strategies to assess with consumers the most appropriate technologies for their use. This education has to be at the pre-service, field, and in-service levels. It also needs to be across different disciplines to include health care (in-patient and out-patient), social, education and vocational services.

AT practitioners require a means of determining consumer preferences and priorities and having consumer input guide AT selection and targeted outcomes. Providers need to assess and document the outcomes and impact of the AT services they provide to consumers in terms of social participation and quality of life. Outcomes result from interventions and examples of outcomes can be performance in education or employment, performance of activities of daily living, and consumer satisfaction or subjective quality of life.\textsuperscript{7} The latter encompasses the person's sense of well-being, health, comfort, happiness and satisfaction with such specific areas of functioning as work, social relationships, and finances.

Professionals in the AT field recognized the need for credentialing practitioners or providing certificates of specialty in AT. A professional society, RESNA, has established an AT credentialing exam for AT practitioners and one for AT Suppliers for the vendors and product trainers who provide and service AT products.\textsuperscript{8} Several
universities (e.g., CSUN) offers certificate training in AT service delivery. Other AT professionals have called for AT practitioners to support the need for and routine use of outcome measures in AT products and service delivery. The problem has been that there has not been good agreement on terminology or on what outcomes are important to measure. The NIDRR announcement Final Funding Priorities for FY 2001-2003, June 26, 2001, called for a Disability and Rehabilitation Research Project on AT Outcomes and Impact. The NIDRR Announcement defines “Outcomes indicators are measures of the amount and frequency of those occurrences, and include service quality. Within this perspective, some analysts use the word “impacts” to distinguish between long-term or end results that occur on a societal versus an individual level. Still others use the term “impact” more strictly to refer to estimates of the extent to which the program actually “caused” particular outcomes.”

The background statement of this announcement also provides an excellent overview of the issues and needs for AT Outcome Measurements. The NIDRR Background relates that there is no one AT Outcomes instrument that has good acceptance. The NIDRR project is to develop “stakeholder” support for AT Outcomes, developing methods for evaluating existing instruments and promoting instruments that interact with the consumer and the other stakeholders.

One consensus building process is based on gathering agreement all of the people involved or who has a “stake” in the process. These people are called “stakeholders” in the consensus building process. In the AT process, the primary stakeholders are consumers or AT users, AT service practitioners and health care providers (including, physicians, nurses, therapists and allied health professionals). Secondary stakeholders...
are family members or caregivers for AT users, provider agencies (medical, educational or vocational rehabilitation agencies), third-party payers (Federal and state agencies and public and private insurers) and AT vendors and manufacturers.

One means of assessing a consumer’s perspective is to have the individual prioritize his or her desired outcomes and then rate over time progress in achieving them. This is the system used in the Matching Person & Technology (MPT) process,\textsuperscript{12} as well as Goal Attainment Scaling and the COPM.\textsuperscript{13} In this way, outcomes are measured in terms of changes in the person's satisfaction in being able to get to where they want to go, whether by walking or some other means, rather than just by the functional capability to do so. This is an idiographic (the person is the unit of analysis and serves as his or her own control) versus normative (person is compared to a group standard) approach and one which best captures a consumer-directed and social model perspective of outcomes assessment.\textsuperscript{14}

Consumers have the right to choose the technologies they receive and use.

People will select their assistive technologies based, first, on how well they satisfy their needs and preferences, then according to their attractiveness and appeal.\textsuperscript{15} If the device meets the person's performance expectations and is easy and comfortable to use, then a good match of person and technology has been achieved. The perspective of the user increasingly will be the driving force in device selection, not which technology is most affordable or quickest to obtain. Thus, it is not acceptable to point to technological solutions before the prospective user’s goals are fully defined and the individual’s needs and preferences are apparent.
The real message is consumers want ‘a voice in the choice.’ For example, a person being discharged with a recent SCI will still be adjusting and may be indecisive about what wheelchair, what cushion, or what home or vehicle modifications are being offered. However, six months to a year later, this same consumer is likely to be very vocal about what satisfies them or what “works” and doesn’t “work” for them personally. This is the point where the dialogue can be extended and, without being contentious, can allow for different points of view between all of the stakeholders.

AT practitioners and health care professionals must acknowledge that people develop and change perspectives over time. A consumer who is not ready for technology use now may be ready in a few months. Professionals must raise the topic of technology again, when it appears that are more receptive to alternative approaches.

A technology must be adapted to user needs and preferences; consumers should not have to adapt to a technology’s features.

Until the past 15 years or so, it was common to have, for example, one style of wheelchair prescribed for many people. Options and choices in wheelchairs and other assistive technologies, if they existed at all, certainly were not vast. Manufacturers of products or devices did not think it worth their while or cost-effective to uniquely shape devices or craft them to fit individual needs and preferences, particularly in the wheelchair industry. An example of this apparent mind set was in the late 1980s, a new wheelchair company became established quickly because it offered a range of colors in light-weight models instead of the bulky, chrome-plated models from the two major manufacturers. The consumer's choice of colors, styling, lighter weight and durability literally took a major market share away from the bigger, slower to change former market
leaders. This change in market dynamics demonstrates the power and influence of consumer choice.

The wheelchair industry in North America is estimated to be $750 Million per year market in CY 2000 and growing at about 10% per year.\textsuperscript{18} On the other end of the spectrum, Sonic Pathfinder, an ultrasonic electronic travel aid for the blind, is manufactured in Australia and has world wide sales of less than 12 units a year.\textsuperscript{19} The Sonic Pathfinder is kept on the market by a concerned and caring person, without profit. The same can be said of many other small manufacturers and vendors of AT products. Unfortunately, good works alone will not keep a marginal product on the market. There are many AT products that breakdown too often and cost too much to repair. Just as this paper urges quality performance measures for the AT practitioners, it will also urge AT manufacturers and their associated vendors to apply quality performance measures to reduce the cost and improve the reliability and durability of their AT products.

Differing consumer-professional perspectives and priorities need to be openly discussed

Professionals have tended to define outcomes of their services, or goals achieved (e.g. independence), in terms of physical functioning whereas consumers more often equate independence with social and personal freedoms\textsuperscript{6,7,20} A social model of rehabilitation measures outcomes in terms of changes in, for example, the person's satisfaction in being able to get to where they want to go, whether by walking or some other means, rather than by the mere functional capability to do so.\textsuperscript{21} This social model of rehabilitation views it as essential to define the consumer's perspectives of the most desired outcomes.\textsuperscript{7,22} Thus, outcome instruments need to be oriented toward the consumer's perspective if it is to gain the support of the primary stakeholders.
However, there also is a need to evaluate the AT service delivery process and its costs, efficiency and effectiveness. Different stakeholders have different needs, which may be a reason no existing outcomes instrument has good acceptance by stakeholders. The availability of outcome instruments with different methodologies yielding different data from the same events will be discussed later in the paper.

**Professionals should not impose their view of what is best.**

Services for people with disabilities and chronic health conditions are for the most part delivered by medical and healthcare professionals. These professionals, in keeping with their training, often tend to view disability against the normal curve of the state of the mass population’s health and, thus, as a health problem that requires treatment and cure.23

Consumers with disabilities, such as in the independent living movement, have become strong advocates for their own rights and self-determination. These consumers have changed the focus from people with disabilities as belonging in the lower tail of the normal curve and requiring treatment and segregation, to the person with a disability and how obstacles to living in the middle (or higher) of the normal curve can be eliminated or minimized. AT products should be refined to conform to varied preferences and needs of the individual who will use them. It is precisely this need for the availability of varied choices in technology features that has led to the existence of 18,000 different products.

Most professionals who provide services for people with disabilities are adjusting to increasing consumer preference into every aspect of service delivery. The more enlightened professionals have recognized that the consumer understands their own disability very well and have valuable insights into what will satisfy or “work” for them
and what doesn’t. For this dialogue to most effective, the practitioner and the consumer must have time to communicate and reach an understanding and consensus. The need for consumer agreement has been included in Rehab Act amendments as a requirement for “informed consumer choice.” In today’s time-managed programs, whether managed clinical care or agency case management, time is limited, and yet it is a critical element of effective service delivery. The lack of time (and funds) to provide full service frustrates all the parties involved, although each for a different reason. Many practitioners do not have the flexibility to take the time to establish rapport and to listen the underlying concerns of their patients (clients). The ethical issue for AT practitioners of having the time necessary to interact with the consumer is the identical issue facing others in health care service delivery, whether the consumer is a person with a disability or not.

Cost of a technology should not be the deciding factor in which technology a consumer selects and receives.

Cost issues are not unique to serving people with disabilities. Cost is a question for any person in the health care system, and frequently, it is a life or death issue. In AT, these discussions must move beyond “pity” because the person is disabled or that they are “deserving” because they are disabled. The process should look beyond judgements about the perceived role or value of this person in society and should not be focused just on employment. However, there must be some cost-containment, and achieving the balance between “unfettered choice” and “informed choice” required in the Rehab Act has yet to be accomplished.

The passage of the ADA legislation over 10 years ago has set the tone that people with disabilities are an equal part of American society, and have the right to equal access
to public areas and services. The recent amendments to the Rehab Act\textsuperscript{25} include
electronic accessibility, which is to include items as simple as access to cell phones,
Automatic Teller Machines, automated information kiosks and the Internet.

The American society as a whole has affirmed the right of people with disabilities
to have public access to places, spaces and information. The question for society is now
that people with disabilities have a right to access, will society pay for the means (i.e.,
AT) to allow them to use it?

A word of caution is needed when painting with such broad brushstrokes. ADA
accommodations fall on the owners of public access places, spaces and information. This
is the difference between publicly available systems (e.g., assisted listening devices at the
symphony hall) versus private use devices (e.g., hearing aids). Although, the hearing
impaired person must have a recent model hearing aid to benefit from most of the public
accommodation systems.

At present these are separate issues, however, it is clear that these issues are
connected and that giving a person the right to access does not give them equally the
means to access. This is not to imply every person with a disability is given a “wish list”
of every item available. It does say we think there should be a process where a person
with a disability can apply to receive the AT that will allow them that public and
electronic access that American society has made available.

Another ethical issue to consider with cost is the quality of the AT services. The
typical response of some government and managed care systems is ‘we have so many
patients (clients, consumers) waiting for service that we have to limit the time (or cost) to
serve them all.’ It appears as though what is being said by some of these organizations is
‘it is better to treat 100% of the patients in a cavalier manner, than to treat only 75% (in the same time/cost) in a controlled, quality manner.’ The managers of such service delivery organizations and the third-party payers will vigorously deny this allegation; however, careful review of the evidence of poor AT services belies their contentions. An example of poor services are state-funded counselors, in numerous states, report case loads of 150 to 250 clients. Does anyone really believe counselors with these burdens have time to deliver quality services to all of their clients, let alone try to stay abreast of new technologies and AT services available for their clients.

Managers of AT service delivery programs and administrators of funding agencies (both public and private) have limited resources compared to the need, which makes all the more critical that their programs are cost-effective and efficient. The stakeholders in the AT process must work together to balance the consumers need, with quality service delivery and cost containment as three legs of a stool (AT process) - shorten any one leg and the stool is unstable. It would be ideal if an outcome instruments process could measure each of these efforts and lead to a balanced, cost-effective AT service system.

If there is an effort to improve quality by reducing the caseload, it must be recognized that this means there is always a backlog of people waiting for service, so that another form of the question is ‘is expediency a justification for poor service delivery?’ In the case of AT for people with disabilities, the AT is not ‘life-supporting, life-sustaining.’ Just as there is triage in an emergency room for order of selection to the patient in most urgent need, there should be a process for order of selection in AT service delivery. Those with a most critical need are served immediately, while those with a less
critical need are served in turn. In this case, the agency providing the service (or paying the costs) determines the order of selection as part of a quality assurance program, which includes AT outcome measures. For example, the order of selection process could use a priority list with an additional drop-in clinic time as one approach.

**Failure to follow-up is, indeed, a failure.**

A common term today is “feedback.” Technically, it means to return information about the output back into the input; i.e., to feedback. A simplified example is a commercial aircraft flying across the ocean in bad weather and without visual reference can stay on course with feedback about the wind, weather, fuel and ground surface variations. Without the feedback for course correction, the aircraft may never reach its destination. Another term used to describe this process is “closing the loop.” This refers to small course corrections (or error signals) fed back to the input to correct the output and each small, corrected output is looped back to the input to stay on course. The same feedback process is true in AT service delivery; there must be information (i.e., feedback) given to the provider (i.e., input) on how well an intervention worked (i.e., output) in order to arrive at the desired result (i.e., performance).

Follow-up in AT service delivery is the feedback that closes the loop for achieving the desired result. Without the feedback (follow-up), the AT practitioner could miss the target, and the consumer (patient, client, AT user) suffers. Worse yet, the whole effort of the intervention may have been wasted, as it has a high probability of not meeting the consumer’s need and of being abandoned or not used. The amount of time for follow-up is small (as in the feedback example) when compared to the original time
expend on the assessment and initial evaluation of the AT products provided. The other waste in the service delivery system is the cost of the services and the AT products provided. As noted earlier regarding “comprehensive assessment,” there should be a continuum of AT services from the initial referral until the completion or release as agreed to by the consumer. Follow-up must be an integral part of the process.

In summary, the primary stakeholder regarding AT outcomes is the person who uses (or is expected to use) a particular AT. Other primary stakeholders are the AT practitioner and health care providers need outcome measures for assure quality and cost-effective service delivery. Family members and caregivers are secondary stakeholders, as are provider agencies, third party payers, and AT manufacturers and vendors. From one point of view, it is important that AT outcomes focus on the person individually, and not numbers of people. This view, looking at qualitative measures, promotes the achievement of individual participatory preferences and priorities, not solely functional standards. It would also provide quality measures of AT service delivery. An alternative view would look at quantitative measures; the aggregate of a variety of consumers. These data would be more predictive for the secondary stakeholders. These AT outcomes would evaluate the service delivery process and it’s effectiveness, which may include cost-effectiveness.

III
IMPLICATIONS FOR PRACTICE

The ideal AT service delivery system is one that provides a continuum of AT care from the initial referral for AT services by the primary provider to discharge. In such an
The ideal system, the AT service provider meets a pre-determined standard of knowledge and skills in AT service delivery (e.g., credentialing). This AT service provider follows an assessment guide that encourages consumer (i.e., patient, client) interaction, choice and agreement with the recommended AT devices and services. An initial AT outcome instrument should be completed during this stage of the process. The objectives of the AT plan are approved and supported by all of the stakeholders, with appropriate funding. As AT devices and services are provided, appropriate training should be provided for its use. After the AT intervention is completed, there should be at least one planned follow-up evaluation by the AT service provider. Any adjustments or changes are reported and implemented. A final AT outcomes instrument is completed at the conclusion of the AT service delivery process.

Unfortunately this rarely, if ever, occurs. There are few institutions with the AT service delivery staff to fulfill the need. Further, there are limited resources to provide the recommended AT, and few agencies or institutions use any form of assessment guide or outcome measurement. This means that, in spite of the best intentions and efforts of the institution or agency managers, there is little documentation to support the effectiveness or impact of AT service delivery. While management may implement some limited quality assurance programs, these programs are ineffective in providing useful outcomes data that leads to improved services and devices.

The cost of programs for AT service delivery continues to grow as new services are added or existing services are expanded to include AT. At present, there is scant information about the impact of AT service delivery being used to justify the cost. A process must be developed in conjunction with all the stakeholders to assure that AT
services are not denied because there is no standard or agreed upon method to evaluate outcomes and impact.

IV
IMPLICATIONS FOR RESEARCH

While there is not general acceptance of an AT outcomes instrument, there are several researchers in the North America and Europe working to develop such instruments. There is support in the professional societies for using outcome measures. One task that researcher's face is teaching the stakeholders in the AT service delivery process how to apply and interpret the data from the instrument and use data from an outcomes instrument to improve the process for AT users and other stakeholders.

An area many AT researchers have struggled with is scientific methods for data collection and analysis; that is developing randomized clinical trials. Most AT research tends to be “evidence-based” or qualitative data, whereas the research community at large prefers quantitative methods such as the classical randomized trials. As research in the AT field matures it is growing beyond single-subject case studies. A good example of a randomized controlled trial on the effectiveness of AT in maintaining independence and reducing home-care costs in the elderly by Dr. William Mann, et. al.

A European consortium has preliminary results defining the cost-effectiveness of AT service delivery. There have been at least three outcomes instruments under development. First was CERTAIN (Cost-Effective Rehabilitation Technology through Appropriate INdicators), developed in the mid 1990s by the European Commission – DGXII. CERTAIN led to the development of EATS: Efficiency of Assistive
Technology and Services, which now undergoing validation and reliability studies. At the same time EATS was under development, the Italian member of the consortium, SIVA, was developing the SIVA Cost Analysis Instrument. SIVA, which stands for Assistive Technology Research and Information Service (Servizio Informazioni Valutazione Ausili) in the Don Carlo Gnocchi Foundation in Milano, Italy. EATS information is available on the SIVA website as part of their contribution to the European Commission consortium. (www.siva.it/research/eats/index.htm)

The ability to measure the cost-effectiveness of AT service delivery intrigues agency and institution managers, for obvious reasons. The interest in cost-containment should not be considered obstructive; rather, it is prudent fiscal responsibility on the part of all stakeholders. It is the ethical responsibility of all the stakeholders to assure the Outcomes Measurement process is used responsibly to provide the appropriate level of AT services as needed without discrimination or unnecessary and avoidable limitations.

V
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