Les résultats avec les aides techniques

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Abstract

A method of measuring functional outcomes for users of assistive technology is being developed through a pilot project currently underway at a regional technology centre. The primary purpose of the project is to discover whether the provision of assistive technology results in improvement in client well-being and functioning. This information will be used to evaluate how well client needs are met by the centre, assess the impact of clinical practices on clients, and identify areas for quality improvement in the centre. A client-centred approach has been selected which will accommodate the multiple consumers of the centre's services.

Three stages of the project have been completed. In the initial stages, eight key factors were identified that centre team members believe to be important in the successful use of assistive technology. These factors were used as the basis for developing a questionnaire to be administered periodically to clients, their families, community support personnel and centre team members. The questionnaire has been used to gather preliminary data from ten clients who have received equipment recommended by the centre.

The article explores the evolution of a focus on outcomes and the decision-making process used in determining the elements selected for the outcome tool. The data from the pilot project are presented and the rationale for the next phase of the project is discussed.

Abrégé

Une méthode de mesure des résultats fonctionnels des utilisateurs d'aides techniques est élaborée dans le cadre du projet pilote d'un centre de technologie régional. Le projet vise avant tout à découvrir si les aides techniques entraînent une amélioration du bien-être et du fonctionnement des clients. Ces renseignements serviront à évaluer dans quelle mesure le centre répond aux besoins des clients, à évaluer l'incidence des pratiques cliniques chez les clients et à identifier des domaines en vue d'améliorer la qualité du centre. Une approche axée sur les clients a été choisie, et elle sera adaptée aux multiples consommateurs des services du centre.

Trois phases du projet ont pris fin. On a d'abord identifié huit facteurs-clé qui, selon les membres de l'équipe du centre, revêtent

de l'importance en vue d'une utilisation efficace des aides techniques. Ces facteurs serviront à élaborer un questionnaire qui sera rempli périodiquement par les clients, les membres de leur famille, le personnel de soutien communautaire et les membres de l'équipe du centre. Le questionnaire a servi à recueillir des données préliminaires chez dix clients qui ont reçu le matériel recommandé par le centre.

L'article se concentre sur les résultats et le processus décisionnel qui a servi à déterminer les éléments choisis en tant qu'outil de mesure des résultats. La présentation des données du projet-pilote est suivie d'une discussion sur la justification de la prochaine phase du projet.

In the rehabilitation and medical arenas, outcomes are defined as changes in status attributed to a specific intervention or treatment (Frattali & Cornett, 1994). The development of ways to measure outcomes is a complex task that can absorb much administrative and clinical time and effort. In this article we describe the reasoning behind the development of outcome measures for assistive technology including augmentative communication. We hope that this paper will promote discussion among our colleagues which will assist us in refining the concepts we discuss.

Although emphasis on outcomes has exploded in the past few years, is it just a trend that will soon disappear? Is our investment of time into the documentation of outcomes worthwhile? We believe that the increased interest in outcomes has been matched by a growing body of knowledge and sophistication about the topic. The broader area of managing quality care, of which outcomes are a part, is not a fad. It has been fuelled by a demand for accountability that will not vanish, making the investment of time not only worthwhile but necessary. If we who understand Assistive Technology do not develop appropriate outcome measures, inappropriate ones may be forced on us.

Expectations for Accountability & Demonstration of Effectiveness

Within the last decade increasing emphasis has been placed on demonstrating results, whether that be in relation to volume of sales, the competence of graduates, or the prudent investment of public funds. The need for accountability permeates all aspects of human endeavour. Society expects that we demonstrate a rational purpose behind our activities and show that what we do works.

There are several factors fueling expectations for accountability. Resources and public funding are becoming increasingly restricted. These limited funds are needed to develop the skills that society values, to recompense people for exercising those skills, and to provide the services and equipment that can improve the quality of our lives. As a result, society must make choices. The choices we make will be influenced by the calibre of evidence presented to justify a particular alternative. Documentation of relevant outcomes will help us to make informed choices, both as a society, in how we spend our money, and as professionals, in how we provide service.

Healthcare reforms are occurring throughout the western world, forcing us to question our assumption about service delivery and quality of care. Similar expectations are also found within the field of education. Healthcare providers are challenged to question whether the services they provide are appropriate, effective, and essential. The focus in dimensions of performance is on "doing the thing right" and "doing the right thing well" (JCAHO, 1994). In a changing society, Blackstone (1995) states that by measuring outcomes, we are able to influence the directions of change.

It is within such a climate that our response to our question, "Is our investment of time into the documentation of outcomes worthwhile?" must be "yes". It is imperative that we direct our energy to provide evidence to support the continuation of services that we believe to be essential for the populations with whom we work: those for whom assistive technology can, as one of our pilot project respondents commented, "open up life".

Monitoring Client Satisfaction

Client satisfaction surveys have been favoured as a technique for demonstrating that appropriate service has been provided and that clients have positive feelings about the contact they experienced. Satisfaction surveys are useful (Batavia & Hammer, 1990), but they are not sufficient as the sole determinant of the outcome. There are several reasons for this. The return rate is traditionally low, which brings into question whether the responses are representative of the whole population, or whether they represent only the extremes of "very satisfied" and "very unsatisfied" clients. Respondents may be concerned that negative comments may jeopardize their future interactions with staff at a facility. The use of client satisfaction as the sole outcome measure leaves no room for comparing the expected result with the actual result. Client or consumer satisfaction is one of six areas of outcomes management identified by Blackstone (1995). The other five are: clinical results, cost benefit, quality of life - social impact, and quality of life - educational/vocational impact.

Quality Management

Methods of demonstrating effectiveness and efficiency have changed over time. Quality assurance gave way to quality improvement, which has given way to quality management. All have consumed considerable time and a large component of the resources we have available. The title changes but the process retains many similar features, and our use of these programs has shown us the cyclical nature of looking at quality, outcomes, and satisfaction. The science of outcomes measurement has been defined as systematically measuring and analyzing outcomes and using the findings to change the way care is provided (Hicks, Benjamin, Aram, & Frattali, 1994).



Attention on Outcomes

Facilities and professional organizations are striving to provide people with the skills they need to produce evidence of successful outcomes. Some medical facilities have established interest groups, programs, and even departments charged with developing and monitoring outcomes within the facility.

Papers and presentations on the topic of outcomes and outcomes measures have proliferated (Culp, 1987; Fratalli, 1990a). Within the field of augmentative communication the first outcomes conference "Alliance '95" was held in Monterey, California (Outcomes in AAC Conference Report, February 1995). At this meeting presentations and discussion sessions were held to focus on the type of outcomes that have significance for those who use, design, or recommend augmentative communication systems. The interest in the topic was so great that it is anticipated that the conference will become an annual event.

Standardization of Outcome Measures

Is it feasible to impose research standards on an area such as the measurement of outcomes in assistive technology? The field of Assistive Technology is in its infancy and a battery of standardized tests is not yet available to measure the aspects of care in which we are interested. There are many questions about Assistive Technology that could be the focus of outcomes studies including questions that relate to service delivery or comparative effectiveness of intervention strategies that are not addressed by traditional performance indicators. For example, the Functional Independence Measure (FIM, 1990), a measure of independence in performing certain tasks, is widely used to record progress, but is inappropriate for evaluating the effectiveness of providing assistive technology because it is based on the premise of independence from using any type of aid. In the absence of standardized measures it is reasonable to select parameters that have relevance for the investigators and to collect data on those issues in a systematic manner over a period of several years so that we can begin to develop data banks on which to base future documentation of outcomes.

Elements Within Outcome Measures

In developing an outcomes tool it is imperative to decide which elements should be measured and to set up a system whereby the various elements can be triangulated into a result which balances the key factors involved. Triangulation is not a tool or a strategy of validation, but an alternative to validation (Denzin, 1989). There are four basic types of triangulation: data triangulation (the use of a variety of data sources in a study), investigator triangulation (the use of several different researchers or evaluators), theory triangulation (the use of multiple perspectives to interpret a single set of data), and methodological triangulation (the use of multiple methods to study a single problem) (Denzin, 1978). A general prescription has been to pick triangulation sources that have different biases, different strengths, so they can complement one another (Huberman & Miles, 1994).

An outcomes tool can address many aspects of client behaviors, clinical interventions and service delivery. A tool might be developed to measure specific aspects of assistive technology, for example to evaluate the appropriateness of recommendations made by the assistive technology team or to evaluate the effectiveness of treatment.

It is important that more than one aspect of outcomes is considered (DeRuyter, 1992). For example, an intervention

may be successful if judged by the client's increased ability to interact with others when it is used, or may be unsuccessful if judged by the increased amount of time required of an aide or teacher to set up the equipment. An outcomes tool should tap into the perceptions of all the people involved in using the technology on a routine basis if true effectiveness is to be judged. This highlights the question of who the client is; in the field of assistive technology, the client may include the person receiving the technology, his or her family and friends, the clinician who made the referral, the teacher, the program assistant, the funding agency, and on...(Heaton, 1992).

Tool Development

As members of the Assistive Device Service (ADS) at the Glenrose Rehabilitation Hospital in Edmonton our objective in measuring outcomes was to find out whether the assistive technology we recommended, and the training and follow up provided, resulted in qualitative improvements in client functioning. The team believed such information would be valuable in determining how accurate ADS staff were in identifying and addressing client needs, and measuring the impact of their clinical practices on clients, and thereby identifying areas for improvement in clinical practice.

Since the ADS sees approximately 120 clients of all ages on an annual basis for assistive technology needs (environmental control, computer access, power mobility, and augmentative communication), it is important that the outcome measure has equal relevance to paediatric and adult clients within a broad scope of assistive technologies. The tool must be generic enough to match this broad scope and sensitive enough to capture relevant information. An interview format with standardized questions was selected as the most reliable method of collecting data.

A data collection method was needed that would not be excessively time consuming so that it could comfortably be accommodated within routine contacts with the client, or alternatively collected outside regular client appointments. Greater internal reliability is obtained if one individual does the majority of the interviews. The possibility of using a summer student to gather information on an annual basis was proposed. If this strategy was to be viable it would be necessary to "script" the information interview very carefully so that a relatively "naive" interviewer could carry it out and not lose vital comments which would have more relevance to an experienced assistive technology clinician. The alternative would be to rotate the responsibility for interviewing clients among team members on the basis of a four month schedule. In order to determine which avenue would be practical, it was decided to run a pilot project with clients currently using assistive technology.

Identification of Key Factors and Stakeholders for this Project

Outcomes were selected that would be applicable to any age or type of disability. The key factors for the ADS outcome tool included whether the client uses the recommended device effectively and whether improved function is a result, whether adequate assistance was provided by the ADS team, whether the client has the skills needed to use the device and whether specific environment conditions influenced the use of the device.

Since the ADS consults to clinicians in the community as well as playing a primary role in evaluation and training for some clients, the relevant stakeholders were identified as the client, the caregiver(s), the external (community) clinician and the ADS clinician(s) providing the service.

Pilot Project

As a first step in verifying that the outcome tool would tap the desired information, the pilot project was developed. Ten clients were selected using the following criteria:

- clients whose needs encompassed the four areas of augmentative communication, computer access, mobility control and environmental control
- at least one client who had "abandoned" the device

All ADS team members were asked to administer the outcome tool to one client for whom they had not acted as the primary clinician. In this way we hoped to monitor the various interpretations that each interviewer perceived as the intent and scope for each question.

Table 1. Systems Surveyed and Respondents

Total # Systems Surveyed	12	Total # Respondents	26
Augmentative Communication	5	Clients	9
Computer System	4	Parent/Spouse	5
Power Mobility	2	External Aide-Clinician	6
Environmental Controls	1	ADS Clinician	6

1. The client will competently operate the device.	
a) Can the client use the relevant features?	
26 respondents replied yes	100%
b) Does the client need assistance in using any features?	
9 respondents replied yes	35%
15 respondents replied no	58%
2 respondents required more consistent help in the use of the device	ce and programming it
2. The device will be used for the purposes specified at the time of t	the recommendation
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 The device will be used for the purposes specified at the time of t 26 respondents replied yes All clients and caregivers selected purposes relevant to their system in conversation, for independent mobility, to operate things in the environ 	the recommendation 100% n use, such as for written communication, for nment, to provide more freedom and independence.
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Table 2. Continued

Examples of devices being used in other ways: an augmentative communication device used for recreational writing, resulting in improved sentence building; a computer system used to get onto bulletin boards and e-mail with the addition of a modem, and another augmentative communication device user who has programmed his communication codes onto his computer as macros.

When asked about other things users would like to do, comments showed computer system users were interested in moving beyond basic use of their computer and ranged from asking for a more extensive computer systems (modem, access to e-mail) to new/upgraded software or using their augmentative communication system for computer emulation.

3.	The client will identify improved function as a result of using the device.	
	13 respondents replied yes	93%
	1 respondent replied no	7%
	Comments included: I can say anything I want; It's a great way to communicate; The communication device has opened up her life. She enjoys coming home and telling me about the events of the day; It has increased her ability to have conversations, she talks to peers, orders food independently.	
	b) Has using the device meant a change in level/type of aide/caregiver support?	
	8 respondents replied no change	57%
	6 respondents replied less support	43%
	5 respondents indicated that they were more independent even though they still required support from an Comments included: I can talk for myself; I am more independent; I have more confidence and better con my aide in the evening to change TV channels.	n aide/caregiver. ntrol; I don't need
4. /	Adequate clinician assistance was provided to the client and caregivers.	
	11 respondents replied adequate	42%
'	4 respondents replied inadequate	15%
	b) Was the ADS clinician able to provide an adequate level of support?	
	26 respondents replied yes	100%
	c) Are there other things about the device you do not understand?	
	4 respondents replied no	29%
4	Comments showed a general desire for more support for aides and caregivers. This was particularly aides change yearly and there was no mechanism for subsequent aides to receive training.	important where
5	5. The client had the necessary skills to use the device.	
	24 respondents replied yes/teachable	92%
	1 respondent replied no	4%
	2 respondents identified poor motor skills and 2 respondents identified poor literacy skills as reaso further training. 1 family of a client who had a brain injury stated they had expected more improvement skills than actually occurred in their child.	ns for needing ent in cognitive

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6.	The environment was supportive/unsupportive.		
	23 respondents replied supportive	88%	
	b) What factors made the environment supportive?		
	Key factors identified were the support of family and friends, and accessibility of home, transportation and	d school.	
	Clients and family identified problems when systems were used at school, for example no access to maintenance at school, or the school being unable to purchase new software.		
7.	Factors affecting the abandonment/misuse of the device will be identified.		
	1 respondent replied abandoned	8%	
	11 respondents replied devices in use	92%	
	The abandoned device was identified by its former user as being slow, out-of-date, difficult to operate, and with a voice synthesizer that was hard to understand. Another device user who depends on her device for communication identified a battery problem which prevented her from using her device all day.		
8.	Client expectations		
	5 respondents replied as expected	35%	
	6 respondents replied better than expected	43%	
	3 respondents replied worse than expected	21%	
	Comments received:		
	l don't have to hover over my daughter, she can communicate and call for someone. It helps keep my husband "sane". It gives me the opportunity to talk to anyone.		
	I really did not know what to expect. I was not totally disappointed - I had higher expectations and thought she'd progress more and bene system. I expected the device would work well and it did, therefore the outcome was as expected.	fit more from the	
	It was too slow, I didn't use the voice synthesizer - the pronunciation was poor if I misspelled words.		

Interpretation of Results

Preliminary results confirmed that the questions posed provided respondents with the opportunity to talk about how they use assistive technology and the functional effects of its use. From a service delivery perspective we were able to confirm some clinical suspicions and gain clinical insights from the responses. Comparison of information from clients, their caregivers, community personnel, and ADS clinicians provided differing insights into the success (or lack thereof) of assistive technology use. We anticipate such outcomes information from all our clients will form a valuable addition to the information used to set program goals and objectives and develop educational programs. The clinicians conducting the pilot interviews provided helpful feedback which encouraged us to simplify and clarify the wording of questions and the layout of the forms used to collect data. However, the procedures envisaged originally for administering the questionnaire demanded more extensive revisions. To provide a glimpse into the process of revision, we offer the following table, Table 3, which describes the features of our initial plan, the barriers we encountered (essentially based on limited time and money) and our revised plan of action.

Table 3. Process of change in developing an outcomes measures tool

In	itial procedures	Barriers	Revised format to reduce costs and manpower
1.	Use personal interview to administer questionnaire and gather data to obtain maximum information and compliance	 Services are provided to a large geographic region and no travel budget is available to interview out- of-town clients. Varying format of data collection affects validity of information. Eliminating out-of town clients results in incomplete information. 	 Use a mail-out interview survey with follow-up telephone calls to encourage compliance.
2.	Interview all clients who receive a system recommended by ADS. (Clients include device users, their family/caregivers and community clinicians)	2. Time and cost: an estimated 0.3 FTE allotment needed to collect and analyze data	2 & 3. Reduce costs by interviewing 50% of clients who receive a system annually. Follow clients and caregivers thereafter for three years. Reevaluate after first 3-year cycle.
3.	Interviews to be conducted six months after receipt of the system to ensure client is familiar with system, and repeat interviews annually thereafter.	3. Changing data collection points to specific times of the year (e.g., every July instead of six months after receipt of equipment) results in comparison of unequal client information	
4.	To track differing clients' needs relating to augmentative communication, power mobility, computer applications and environmental controls, clients receiving more than one system will be interviewed separately about each device.	 Clients could potentially be interviewed about four different systems. 	4. Maintain as originally planned
5.	For consistent administration of the questionnaire, one interviewer will be used for all interviews	5 & 6. Identifying the most appropriate person to administer the questionnaire (coordinator, program assistant summer STEP student?)	5 & 6. Coordinator to assume responsibility for data collection. Summer university students to be considered to help with data
6.	The interviewer will be familiar with assistive technology but not clinically involved with clients.	Outcomes are not part of a clinical job description, nor is there any institutional funding for additional positions.	administration and analysis of information.
PI	an		
1.	Readminister revised questionnaire in	mail survey form to initial list of clients and	I ten new clients.

Conclusion

This article has attempted to document the decision-making process used by an assistive technology centre in developing functional methods to gather client related outcomes information. Although compromises have been made in the way data is collected, preliminary results support the view that valuable information is obtained which forms part of the cycle of quality management of care.

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Appendix: Equipment used by respondents

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E & J power chairs with joystick (2) Apple IIgs with single switch, printer Real Voice communication device Relax with single switch access Liberator with IEP+, single switch access Dynavox Vois 160 Intellikeys, 486, modem, fax Macintosh, 1 handed keyboard, printer, modem Handivois 140 Apple IIe, single switch