Technical Report – Clinical Service Program Databases (Version 1.0)

Todd Schwanke, MSE, ATP & Roger O. Smith, PhD, OTR
May 17, 2004

Introduction (Clinical Databases)

Analysis of existing clinical and national databases was one of the major components of the needs assessment phase of the ATOMS Project. Overall, the project's needs assessment phase analyzed existing resources and knowledge sources to determine and isolate research and development needs to be addressed in developing the next generation assistive technology (AT) outcomes data collection and analysis system.

Existing assistive technology clinical databases were chosen for analysis both for their potential to provide a status report of AT outcomes in current systems and to guide future development. First, the design and content of existing systems provide us with the ability to look at what is currently collected, how it is currently analyzed, and how it could be analyzed for AT outcomes. Second, analysis of the results from the first portion could then be used to identify existing systems and strategies that might be beneficial to carry through into the development of a national system.

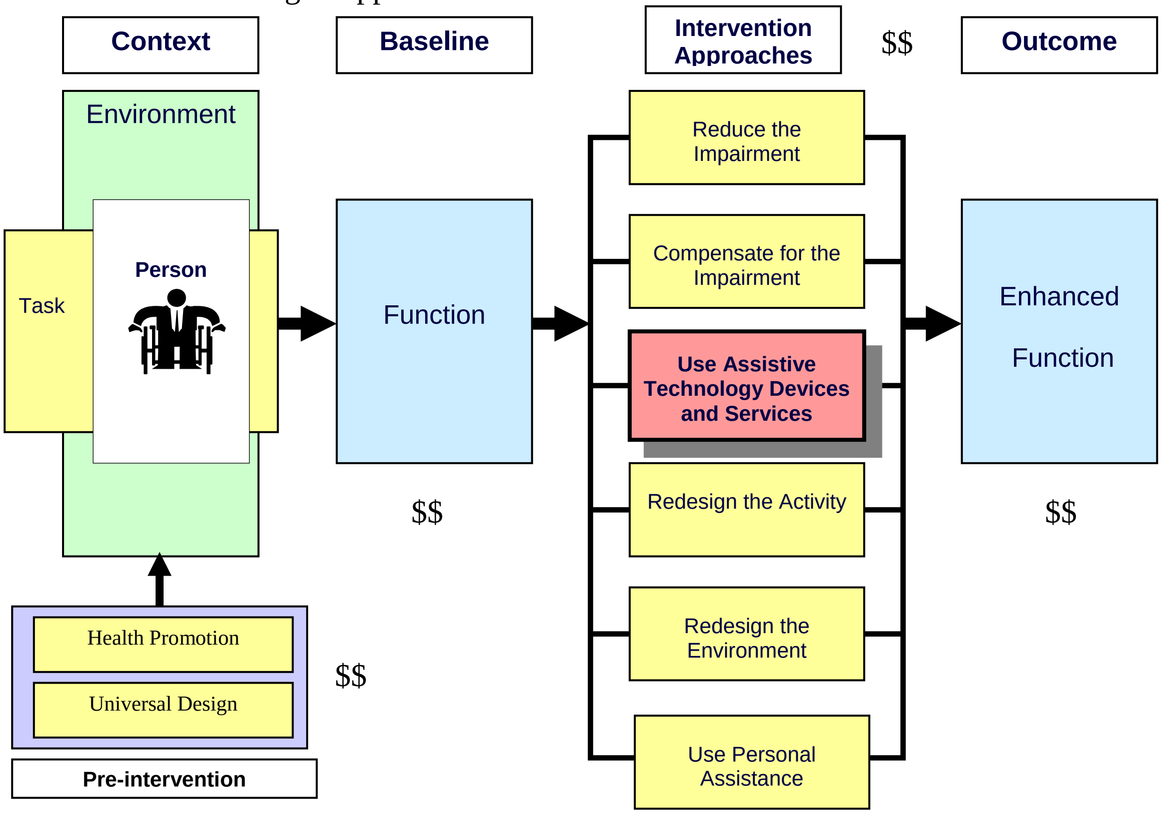
This analysis began by examining service program records from five AT service programs from Eastern, Midwestern and Western United States. Data fields were extracted from these records and compiled to compare the data across programs and to analyze what potential data might be available for use as "ingo" or "outcome" data.

The following excerpt (and subsequent sections) pull discussions from Schwanke and Smith, (submitted) First we describe the ATOMS Project perspective of the two primary types of data required for an outcomes system. It also explains the theoretical framework surrounding how these data types relate to outcomes information.

> "The ATOMS Project revolves around a few key concepts that relate to this investigation. One is that a successful outcome data collection effort requires two major classifications of data. Thus, when we explore employment related data we must look at both types. The first data type is that that describes the intervention(s) provided. If we do not document the intervention carefully, then we would not know what caused any particular outcome. The second type of data is that which describes the outcome. Obviously, even if we knew the details of the intervention provided, if we did not measure the outcomes, we would not know what effect the intervention had. Oldridge (1996) said this simply. Outcomes research determines "what works". Consequently, it is necessary to identify the "what" and to measure how well it "works". Smith (2002) used the terms "outcomes" and "ingos" as two essential types of data for understanding outcomes. The key to remember is that no outcomes measurement system will function without both of these essential types of data.
>
> "A second ATOMS Project key concept is that outcomes data and variables relate to each other in a theoretical framework (Smith, 2002). Figure 1 depicts these variables and highlights the relationships. Particularly important in

this chart is its motion from the left to the right that shows the "ingo" data, including a) the description of the individual, b) the activities they perform and c) the environment/context for which they perform the activities. This demographic class of variables describes the ingredients to create a specific functional baseline. A comprehensive outcomes system would document this baseline function. This baseline function can be assumed to reside below the desired level. Obviously, if no functional issues were present, no intervention would be necessary."

FIGURE 1: Eight Approaches to Intervention



"Subsequent to the identification and clarification of the baseline needs, interventions can be designed. The assumption in the ATOMS model is that interventions are created for the individual and their individual situation. Thus, they are customized and range from remediation to compensation to personal or attendant services provided by someone else. Clearly, assistive technology devices and services poise a primary potential intervention. Following these interventions, we assume that the initial baseline function would be improved. This would be measured as outcomes subsequent to the intervention. Figure 1 also highlights that our model includes pre-interventions such as universal design and health promotion activities. By definition, a successful pre-intervention would result in an elevated baseline function, so a lower intensity or omission of a later intervention would be possible."

Below, we summarize the methods, experiences, and findings from the analysis of clinical databases of assistive technology service providers. We also discuss the implications of these findings to future ATOMS Project efforts.

Methods and Findings

> "The ATOMS Project attempted to evaluate what assistive technology outcomes variables might be currently available in assistive technology service programs and in vocational rehabilitation services. To do this the research team took two major approaches.
>
> "First, service program records were collected from five AT service programs from Eastern, Midwestern and Western United States. Data fields were extracted from these records and compiled to compare the data across programs and to analyze what potential data might be available for use as "ingo" or "outcome" data.
>
> "Second, analysis of individual service program data and comparisons across programs revealed that insufficient data were available for outcomes analyses."
>
> "ATOMS Project service program partners each submitted five complete service program records to the project coordinator. These records included complete client files and documentation used by the program. All unique identifiers in the documentation were omitted from records and only client data fields were compiled as a part of this study. The study team examined these sample service records, documentation, and databases to determine what types of data were being collected, how they were collected, and how they might be incorporated into a larger measurement scheme that examined outcomes.
>
> "The study coordinator created a list of record fields representing the program and client data. Due to the large numbers of unique forms, the possible number of fields and their values/options the list did not exhaustively include the indigenous data field names. Similar types of information were compiled and labeled using a generic data field title. Consequently, the coordinator interpreted data fields to identify those of similar nature. This resulted in a catalog of data fields bridging both paper and electronic sources (even if they did not have a formal data field label), categorization of information so it could feasibly fit in a record with a common name, and selection of a common field name to represent generic data (e.g. gender versus sex versus male/female resolved to gender.) Following the creation of the initial list of data fields and coding of each set of service records into the list, each of the service programs was provided an opportunity to review the list and how their records were coded and to suggest edits that led to a revised set.
>
> "Three specific steps were implemented to compile and revise the data fields from the five programs.
>
> 1. The records were first inspected for possible sample fields. All records for a particular service program were inspected before proceeding to the next service program.

2. Items identified as fields were marked with an “F” and options/values for fields were marked with a “V”.
3. New fields were added to a list in a Microsoft Excel spreadsheet file as they were identified. Categories and sub-categories of data fields represented themes identified from the raw service records. Five columns documented the presence of a field in a service program’s records.
    a) “Yes/No” – ‘Yes’ indicated the field was present.
    b) “Field Name” – The field name used by the particular service program, if available.
    c) “Form Name” – The form or screen name that the field was found on, if available.
    d) “Electronic/Hard Copy” – Indication of whether the service organization stores the field electronically or on paper.

A summary of the data fields acquired from this process are listed in the following tables.”

Table 1

Major Categories of Fields Identified

- Background
    - Demographic fields
    - Environment fields
    - Disability fields
    - Referral fields
- Evaluation & Services
    - Evaluation fields
    - Service fields
    - Tasks fields
    - Device fields
    - Billing fields
    - Team Members & Responsibilities fields
    - Report (Fields in report documents not appearing elsewhere) fields
- Outcomes
    - Performance fields
    - Satisfaction fields
    - Quality of life fields

Table 2

Demographic Fields

IDNum
Name
Address
City
State
Zip code
County

Demographic Fields

- Phone
- Date of birth
- Age
- SS#
- Disability
  - value: Blind
  - value: Low Vision
  - value: etc.
- Job title
- Gender/Sex
- Race
- Last grade completed
- Tested grade level in reading
- Tested grade level in arithmetic
- Number of previous jobs
- Total years of work history
- School/job/career goals
- School Attending
- Computer experience
- College of University
- Major

Discussion

The analysis confirmed suspicions and experience that no current systematic methodology exists to collect outcomes related data consistently within or across assistive technology service programs. The data collected by these programs are idiosyncratic and colloquial to particular institutions and tend and to be very limited in what types of data and for what purposes they are compiled. This is not surprising given that there are few known service delivery systems that collect data specifically for outcomes analysis, other than for program evaluation.

The ATOMS Project analysis of existing assistive technology service delivery programs suggests that there is some valuable data in these service delivery databases, even though the data is not collected specifically for outcomes. However, this data is not complete enough to fully satisfy the “ingo” and “outcome” data type requirements.

During this investigation, the ATOMS Project staff encountered the vocational rehabilitation (VR) systems’ electronic record systems and the federally mandated RSA-911 reports that are required annually of each state’s VR system. These systems contain data fields that are more representative of the “outcome” data type and that are collected pre and post-intervention. This has provided optimism that there is other existing data that could be linked with that from the service delivery programs to provide a more complete set of data that could be analyzed to produce useful outcomes information.

While a linkage of existing data systems that have not been designed for AT outcomes may not represent the ideal solution for AT outcomes data collection and analysis, it presents a couple opportunities. First, it gives the ATOMS Project the chance to practice with large, diverse data sets that will provide essential experience in developing recommendations for a large-scale, national system. Second, it will require piloting of linking data from multiple sources, which will necessitate resolution of issues related to privacy, data quality, and data interchange. Successful linkage of this specific could answer numerous questions about AT outcomes that are of interest to many stakeholders of AT services and devices. These include the AT service administrator for program evaluation, the State Vocational Rehabilitation Agency for evaluating agency access and effectiveness, the AT consumer for examining the success rates and potential of AT devices and services, and the AT practitioner who wants to know what types of service and devices work best under what conditions and what has worked for others in similar situations. Though this represents only one (vocation) of the four service area settings (vocation, education, independent, medical) that the ATOMS Project is considering, it would be a large step forward.

The challenge is clear given that current data collection and management systems are not designed specifically with assistive technology outcomes in mind and they do not currently communicate, making them insufficient to assess AT outcomes. This hampers the rapid development of any future system. However, it is also clear that key pieces of a system might already exist.

The ATOMS Project currently is working with two of its partners to establish protocols to extract selected service delivery data and link it to data from state vocational rehabilitation records in a single database. While both systems will be sources of “ingo” and “outcome” data, the AT service delivery systems will be the primary source of “ingo” data and the vocational rehabilitation system will be the primary source of “outcome” data. The database will then be analyzed with targeted outcomes questions to determine its capability to provide useful answers to those questions.

References

Oldridge, N. B. (1996). Outcomes measurement: Health-related quality of life. *Assistive Technology, 8,* 82-93.

Schwanke, T. D. & Smith, R.O. (2004). *Assistive technology outcomes in work settings.* Manuscript submitted for publication.

Smith, R. O. (2002). Assistive technology outcome assessment prototype measuring "ingo" variables of "outcomes". *RESNA 25th International Conference on Technology and Disability: Research, Design, Practice and Policy*, 239-241.