TITLE:
AAC/AT OUTCOMES RESEARCH AND DATA CAPTURE TOOLS

ABSTRACT:
Presentation of framework and taxonomy for addressing AAC/AT outcomes, scenarios of device utilization based, and demonstration of platform and web-based AAC/AT outcome data capture tools.

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SUMMARY OF PROPOSAL:

The underlying goal of AAC/AT outcomes research is to understand the impact of the device upon the user. Unfortunately the field has lacked a conceptual framework and taxonomy related to device outcomes in order to adequately understand device impact.

In 2000, several individuals conducting work in the areas of AAC and AT outcomes research formed the Consortium for Assistive Technology Outcomes Research (CATOR), a multidisciplinary, international effort to carry-out multi-site research activities related to assistive technology device outcomes.

In 2001, the National Institute on Disability and Rehabilitation Research (NIDRR) announced a program to research AT device outcomes through multi-site collaboration. CATOR proposed an ambitious research and development agenda which was subsequently funded for 5 years and recently extended for an additional 3 years.

As a result of the funded work, as well as additional work conducted through CATOR, several significant contributions to the field of AAC/AT outcomes have been developed and will be presented in this paper.

One of the major early efforts of CATOR was to identify and review existing approaches to outcomes measurement, identify the barriers associated in the use of those outcome measures, and identify factors contributing to device abandonment/discontinuance. As a direct result of this work, CATOR developed a "Framework for the Conceptual Modelling of AT Device Outcomes" as well as a "Taxonomy of AT Device Outcomes". Both of these, along with recent work related to a "Framework for Modeling the Selection of AT Devices" and the identification "Psychometric and Administrative Properties of Measures Used in AT Device Outcomes Research" have been published and are beginning to be widely referenced in AAC/AT outcomes research. As a result of this work, it is possible for researchers and clinicians to examine and measure assistive device outcome vantages from both the proximal and distal outcome dimensions within the ICF framework. An overview of this work will be presented.

As a direct result of developing an underlying conceptual framework and taxonomy, a long-term, multi-site cohort study was undertaken to examine if there was a direct relationship between limitation and supportiveness with AT device use. The study explored reasons for user discontinuance and examined variations in the temporal course of AT device use. Over 200 individuals who were prescribed AT devices were followed over a 2 year period with data collection points at baseline, at 6 months, 1 year and 2 years. Short-term and long-term effects were examined using a variety of outcome instruments including SF-36, AM-PAC, ATDPA, PIADS, QUEST, etc. Diagnostic categories were evenly distributed between neurological, orthopedic, and medically complex subjects. Individuals were found to adhere to 1 of 7 scenarios of device utilization and could be grouped according to the trajectory of device targeted for evaluation at onset/baseline. The results of this study will be presented.

In addition to the conceptual work and cohort study, CATOR undertook the challenge of examining and developing alternative outcome data capture tools. Historically, most AAC/AT outcomes instruments are completed with paper/pencil. As a consequence, the process of entering data into a central database requires significant effort. It was our contention that the collection of outcomes data using web based interfaces for direct entry, and/or portable devices (such as personal digital assistants [PDAs] or tablet computers) would greatly facilitate data collection in AAC/AT field as data could easily be ported digitally into a main data collection/repository site either synchronously or asynchronously. Specifics are discussed in the following 2 paragraphs. This presentation will demonstrate via video clips a number of platform and web-based AAC/AT outcome data collection/capture tools that have been developed by CATOR.

Platform Independent AAC/AT Electronic Data Capture Instruments:
To determine feasibility of platform independent electronic data collection instruments their functionality within the clinical setting was paramount. In order to be successful, portable/mobile strategies were required to address location, software variations, and user independence. Facilitation of direct entry of AAC/AT outcomes data capture using portable devices (such as personal digital assistants [PDAs] or tablet computers) was accomplished through the use of palm, tablet, and pocket PC platforms. To date, the following portable/mobile solutions for specific AAC/AT outcome instruments have been developed and will be demonstrated: 1) Palm Platform (AT Satisfaction survey using Press-Gainey, Functional AAC Status Survey instrument, PIADS); 2) Tablet PC Platform (PIADS, QUEST, ATDPA); and 3) Pocket PC Platform (AT Satisfaction survey using Press-Gainey, PIADS, QUEST). Functionality of each of these developed platform independent AAC/AT data collection/capture tools were implemented within AAC/AT service delivery programs for beta-testing and evaluation. Video demonstration and examples of data collection reports will be presented.

Web-Based AAC/AT Outcome Data Capture Tools:
Feasibility of developed web-based AAC/AT outcome data collection tools required functionality within both the clinical and administrative environments. Success was determined when web-based data collection strategies were location, user, platform, and software independent. To address a broad potential user stakeholder group, web-based solutions addressed both “in-house reporting” within a specific clinical setting as well as “remote reporting”. In-house reporting was deemed important to facilitate ease of use by staff traveling throughout a facility such as an inpatient units within a medical center. Remote reporting was required to address not only reporting from remote locations, but also potential data entry from varying systems, the ability to enter data automatically or following portable device synchronization, and finally, the ability to observe results or reports instantaneously. Because many AAC/AT devices are web enabled and the web is an equalizer for many within the disability community, the addition of web-based data collection as a method of participation by users of AAC/AT devices was included and developed. To date, the modules for the Assistive Technology Act (ATA) Annual Performance Report, ATDPA, AT Satisfaction Survey, PIADS, and QUEST for on-line web-based reporting and will be demonstrated via video clips. Real-time web-based administration of the PIADS on a Blackberry simulator will

also be demonstrated. Included in the real-time demonstration will be how performance on the PIADS by a potential AAC device user with ALS compares to normative data for that population with respect to likelihood of success with that AAC device (see Fig 1).

Finally, this presentation will briefly highlight two current additional ongoing CATOR efforts. First, is the collaboration with the AAATE in pilot testing the web-based data entry format described above in an effort to develop an international web-based data repository for AAC/AT outcomes data that would allow data from multiple outcome instruments and afford stakeholders with a variety of cross-dimensional AAC/AT outcome reports. Secondly, update attendees on 3 current CATOR research projects that include: 1) the development of a computer adapted test instrument that measures the impact of a device on functioning, health and subjective well being; 2) the development of validated methods for measuring and classifying AAC/AT interventions; and, 3) the development of an instrument to measure the impact of AAC/AT on the user-caregiver dyad.

FIGURE 1:

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