Outcome Measures in Assistive Technology
EQUAL Research Network Workshop
June 25 2003

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Collaborators

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- Marcus Fuhrer  NIH (Emeritus)
- Jeffrey Jutai  Univ. of Western Ontario
- Marcia Scherer  IMPT*
- Hy Day  York University

* Director of the Institute for Matching Person & Technology http://members.aol.com/IMPT97/MPT.html
Declaration of biases

- Work in a Canadian context.
- Come from a research background.
- Close collaborative links with the CATOR project (www.ATOutcomes.com)
- Work in AT mostly conducted with the QUEST tool.
Recognizing the power of AT.

“Independence is independence. Failure to acknowledge, in our outcome measures and conceptual frameworks, the extent of the freedom that good AT provides can lead to significant underestimation of what rehabilitation can do.”

R Lee Kirby, 2002
Vocabulary

- Outcomes:
  "AT outcomes encompass any changes in users’ lives or their environment that are causally attributable to use of a device." (Fuhrer, 2003)

- Outcome measurement:
  "A process for examining how well something has worked." (Jutai, in preparation)

- Outcome measures:
  "Measurement instruments (questionnaires, scales, tests) applied to variables identified as having changed as a consequence of using AT."
Why does it matter?

- Technology has grown tremendously in the last few decades.
- Technology now has considerable implications for adults and older persons with disabilities.
- There is no time and money available for trial and error approach.
- We need to demonstrate that AT is effective and meaningful.
An essential ingredient to decision-making

- Users, family members, friends, and co-workers
- Practitioners
- Program administrators
- Payers
- Policy-makers
- Researchers
- Product developers

- To gauge the value of using and providing AT.
- To determine the cost effectiveness of services.
- To select the best AT from an array of choices.
- To develop new products.
A creative picture…

“The presentation of outcomes data can be tremendously empowering to those with an appreciation of its impact. Like the colors on the artist’s palette, data can be used to create a picture that will inspire, persuade, inflame, or call the viewer to action. …Like the completed painting, when presented well, data invite the viewer to participate in interpretation.”

Nolan & Mock, 2000
A huge challenge

- Number of available products.
  - Commercially developed & customized.
  - Can we measure them all in the same way?
- AT is part of rehabilitation.
  - How can we isolate AT from other interventions?
- Multiple dimensions of outcomes
  - No generally accepted taxonomy.
  - What are we to measure and how?
A huge challenge (cont.)

- Influence of other variables.
  - Personal & environmental.
  - How can we control for these variables?
- Obtain outcomes in the natural environment.
  - What settings are more valid?
- Observe outcomes over time.
  - At what time intervals and for how long?
Why is AT lagging behind?

- Conceptual issues.
- Methodological issues.
Needs fulfillment (H. Day, work in progress)

- Premise: AT can impact the consumer in different ways, depending on his (her) needs and the type of device.
- Analogy with Maslow’s hierarchy of needs.
Needs fulfillment (H.Day)

Maslow’s Hierarchy of Needs

- Physiological
- Safety & Security
- Belongingness
- Esteem
- Self Actualization

Levels of impact of AT

- Prolongation of Life
- Standard of Life
- Quality of Life
A framework for the conceptual modeling of assistive technology outcomes (Fuhrer et al. 2003)

- Outcomes are viewed as a result from an interaction among:
  - characteristics of an intervention
  - the recipients of that intervention (the users)
  - their environment.

- Overarching framework to develop eventually more device-specific models for the measurement of outcomes.
What about a taxonomy?

- Need for a classification system for the various outcomes that might be measured.
Proximal outcome dimensions
(Jutai, work in progress)

- Proximal outcomes are those for which the device is designed (engineered) to make a significant impact.
- These will vary according to the device (specific).
An example

<table>
<thead>
<tr>
<th>Category</th>
<th>Type</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Static lounge chair</td>
<td>Comfort</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Posture</td>
</tr>
<tr>
<td></td>
<td>Wheelchair</td>
<td>Ease of propulsion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ease of transfer</td>
</tr>
<tr>
<td></td>
<td>Geriatric chair</td>
<td>Safe transfer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Support</td>
</tr>
</tbody>
</table>
Distal outcomes dimensions

- Distal outcomes are those that are affected by factors other than the technical features of the device.
- They are pertinent for all major categories of assistive technology (generic).
An example

- Distal outcome dimension
- Use and discontinued use
- Device satisfaction
- Subjective well-being
- Quality of life
- Costs
- Functional capability
- Community participation
A starting point…

“Assistive technology not only promotes personal independence and increases quality of life, it helps prevent costs to society by reducing risks of secondary conditions and reduces caregiver costs. Assistive technology is cost effective in that appropriate devices can increase the capacity of both children and adults with disabilities in the home, workplace and community.”

Galvin, 1997
From outcome dimensions to outcome measures

- Within the scope of all these proximal and distal outcomes, there is considerable room for innovative thinking and research.
- The PIADS and the QUEST are two promising measurement instruments for the quality of life and satisfaction outcome dimensions.
The Psychosocial Impact of Assistive Devices Scales (Version 4.2)

A tool for evaluating the psychological benefits of rehabilitation technologies

Hy Day, & Jeffrey Jutai, 2002

e-mail: jjutai@julian.uwo.ca
General Description

- Goal: Assess the effects of an assistive device on functional independence, well-being, and quality of life.
- Targeted age groups: Adults, Older adults, Teens.
- Concept definition: Captures through 3 subscales, the concepts of:
  - Competence: feelings of competence and efficiency
  - Adaptability: willingness to try out new things and take risks
  - Self-esteem: feelings of emotional health and happiness.
PIADS Items

- Competence
  - Independence
  - Adequacy
  - Confusion
  - Efficiency
  - Productivity
  - Usefulness
  - Expertise
  - Skillfulness
  - Capability
  - Quality of Life
  - Sense of Power

- Adaptability
  - Well-being
  - Willingness to take chances
  - Ability to participate
  - Eagerness to try new things
  - Ability to adapt to the activities of daily living
  - Ability to take advantage of opportunities

- Self-Esteem
  - Happiness
  - Self-esteem
  - Security
  - Frustration
  - Self-confidence
  - Sense of power
  - Sense of control
  - Embarrassment
PIADS Evaluation Procedures

- Self-report (glossary of terms)
  - Individually with paper & pencil
  - In a group
  - Over the phone (modified set of instructions)
  - Individually with Palm Platform (under development)
- Duration: 5-10 minutes
- Scoring:
  - Individual items: Scores can range from -3 (maximum negative impact) to +3 (maximum positive impact)
  - Total scores: Competence, Adaptability, and Self-esteem obtained by averaging across responses.
# PIADS version 4.2

## PIADS SCORING SHEET

<table>
<thead>
<tr>
<th>Client ID#:</th>
<th>Item</th>
<th>Competence</th>
<th>Adaptability</th>
<th>Self-Esteem</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.</td>
<td>Happiness</td>
<td>2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Independence</td>
<td>3.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Confusion*</td>
<td>5.*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Self-esteem</td>
<td>7.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Frustration*</td>
<td>10.*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Usefulness</td>
<td>11.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>Self-confidence</td>
<td>12.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Well-being</td>
<td>15.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Quality of life</td>
<td>17.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>Willingness to take chances</td>
<td>22.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>Ability to participate</td>
<td>23.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>Ability to adapt to the activities of daily living</td>
<td>25.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(A) Sum of subscale column: 12
(B) Number of items in subscale: 6, 8

Subscale score: (A) * (B)
Psychometric Properties

- **Reliability**: A reliable OM is one that produces the same result each time.
  - Test-retest stability
  - Internal consistency
  - Reliability of caregiver proxy

- **Validity**: A valid OM is one that measures what it is intended to measure.
  - Sensitivity to user condition and device features
  - Responsiveness to device intervention
  - Content validity
  - Factorial validity
Psychosocial Impact of Electronic Aids to Daily Living

Bloorview MacMillan Centre, Toronto, Canada

QUALITY OF LIFE IMPACT OF ASSISTIVE TECHNOLOGY
Jeffrey Jutai, Ph.D., C. Psych.
Research Department, Bloorview MacMillan Centre, Toronto, Ontario

ABSTRACT
There has been no systematic research to evaluate the quality of life impact of assistive technology. The Psychosocial Impact of Assistive Devices Scale (PIADS) is a 26-item self-reporting scale designed to fill the measurement gap in this area. This paper will summarize the results available to date which suggest how outcome measurement research using the PIADS can improve the prescription and delivery of assistive technology.

The need for measurement
It is generally assumed that assistive technology offers a comprehensive measure of quality of life. However, the extent to which this assumption is true is not well understood. The Psychosocial Impact of Assistive Devices Scale (PIADS) is a 26-item self-reporting scale designed to fill the measurement gap in this area. This paper will summarize the results available to date which suggest how outcome measurement research using the PIADS can improve the prescription and delivery of assistive technology.

Measuring the Psychosocial Impact of Assistive Devices: the PIADS*

Hy Day, Ph.D., C.Psych and Jeffrey Jutai, Ph.D., C.Psych

Assistive devices (ADs) are considered essential to the health and well-being of all people but especially people with sensory or physical disabilities. These include such products as wheelchairs, low vision aids, prosthetic limbs, and hearing aids. Since current quality of life measures are inadequate for assessing the impact of ADs, a questionnaire to measure the psychosocial impact of ADs on users was developed and standardized. Factor analysis yielded three factors. This led to the creation of three subscales that measure the impact along the domains of experience, adaptability, and self-esteem. The results show that the scales have good reliability. To examine utility, the scales were used to compare two competing ADs: eyeglasses and contact lenses. These results show that the subscales have good validity. Clinical studies are in progress.

The predictability of retention and discontinuation of contact lenses

Jeffrey Jutai, Ph.D., C.Psych,* Hy Day, Ph.D., C.Psych,* William Woolrich, B.S.W.,* and Graham Strong, O.D.*

*University of Western Ontario, London, Canada; York University, Toronto, Canada; and University of Victoria, Victoria, Canada

[The text continues with additional research on the predictability of retention and discontinuation of contact lenses.]
The Quebec User Evaluation of Satisfaction with assistive Technology (QUEST 2.0)

Louise Demers, Rhoda Weiss-Lambrou, & Bernadette Ska, 2000

Website: http://members.aol.com/IMPT97/MPT.html
General Description

- **Goal:** Evaluate a person’s satisfaction with a wide range of AT.
  - **Clinical tool**
    - to document the real-life benefits of AT
    - to justify the needs for these devices
  - **Research tool**
    - compare satisfaction data with other outcome results
    - compare satisfaction data across user groups and settings
- **Targeted age groups:** Adults, Older adults, Teens.
- **Concept definition:**
  - Satisfaction is defined as a person’s critical evaluation of several aspects of an AT.
    - This evaluation is believed to be influenced by one’s expectations, attitudes and personal values.
Specific Objectives

1. Assess degree of satisfaction
   - 8 Device items

2. Identify sources of user satisfaction-dissatisfaction
   - 4 Services items

3. Identify 3 most important items
QUEST Items

- Comfort
- Weight
- Durability
- Adjustments
- Simplicity of Use
- Dimensions
- Effectiveness
- Safety

Device

- Service Delivery
- Professional Services
- Follow-up Services
- Repairs & Servicing

Services
QUEST Evaluation Procedures

- **Self-report:**
  - Individually with paper & pencil
  - Interview: optional material (list of 12 items in large font, enlarged rating scale)
  - Individually with Tablet PC Platform (under development)

- **Duration:** 10-15 minutes

- **Scoring:**
  - Individual items: 5-point rating scale (“not satisfied at all” to “very satisfied”)
  - Total scores: Device, Services and Total scores obtained by averaging across valid responses.
# QUEST version 2.0

**Quebec User Evaluation of Satisfaction with Assistive Technology**

**QUEST (Version 2.0)**

Technology device: ____________________________

User name: _________________________________

Date of assessment : _______________________

The purpose of the QUEST questionnaire is to evaluate how satisfied you are with your assistive device and the related services you experienced. The questionnaire consists of 12 satisfaction items.

- For each of the 12 items, rate your satisfaction with your assistive device and the related services you experienced by using the following scale of 1 to 5.

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not satisfied at all</td>
<td>Not very satisfied</td>
<td>More or less satisfied</td>
<td>Quite Satisfied</td>
<td>Very satisfied</td>
<td></td>
</tr>
</tbody>
</table>

- Please circle or mark the **one number** that best describes your degree of satisfaction with each of the 12 items.
- Do not leave any question unanswered.
- For any item that you were not "very satisfied", please comment in the section **comments**.

Thank you for completing the QUEST questionnaire.

© J. Demers, R. Weiss-Lambrou & B. Shi, 2000

## ASSISTIVE DEVICE

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>How satisfied are you with,</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>1. the <strong>dimensions</strong> (size, height, length, width) of your assistive device?</td>
<td></td>
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<tr>
<td>Comments:</td>
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<tr>
<td>2. the <strong>weight</strong> of your assistive device?</td>
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<tr>
<td>Comments:</td>
<td></td>
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<tr>
<td>3. the <strong>ease in adjusting</strong> (fixing, fastening) the parts of your assistive device?</td>
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<tr>
<td>Comments:</td>
<td></td>
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<tr>
<td>4. how <strong>safe and secure</strong> your assistive device is?</td>
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<tr>
<td>Comments:</td>
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<tr>
<td>5. the <strong>durability</strong> (endurance, resistance to wear) of your assistive device?</td>
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<tr>
<td>Comments:</td>
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<tr>
<td>6. how <strong>easy</strong> it is to use your assistive device?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Comments:</td>
<td></td>
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<tr>
<td>7. how <strong>comfortable</strong> your assistive device is?</td>
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<tr>
<td>Comments:</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>8. how <strong>effective</strong> your assistive device is (the degree to which your device meets your needs)?</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

© J. Demers, R. Weiss-Lambrou & B. Shi, 2000
Quebec User Evaluation of Satisfaction with Assisting Technology

Technology Device: 

User Name: 

Date of Assessment: 

The purpose of the Quest questionnaire is to evaluate how satisfied you are with your assistive device and the related services you experienced. The questionnaire consists of 12 satisfaction items.

- For each of the 12 items, rate your satisfaction with your assistive device and the related services you experienced by using the following scale of 1 to 5.

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<td>Not Satisfied at all</td>
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<td>More or less Satisfied</td>
<td>Quite Satisfied</td>
<td>Very Satisfied</td>
</tr>
</tbody>
</table>

- For each of the 12 items, rate your satisfaction with your assistive device and the related services you experienced by using the following scale of 1 to 5.

- Do not leave any question unanswered.

- For any item that you were not "very satisfied", please comment in the section "comments".

How satisfied are you with:

1. the dimensions (size, height, length, width) of your assistive device?

Comment:
Psychometric Properties

- **Reliability:**
  - Test-retest stability
  - Alternate form equivalence
  - Internal consistency

- **Validity:**
  - Content validity
  - Construct
  - Factorial validity

- Responsiveness to change?
## QUEST translated/adapted versions

- **Dutch:** Luc Witte, Hoensbroek
- **Norwegian:** Øjvind Lorentsen, Tomter
- **Danish:** Åse Brandt, Aarhus
- **Swedish:** Kersti Samuelsson, Linkoping
- **Japanese:** Takenobu Inoue, Tokorozawa
- **Finland:** Petra Järnström, Helsinki
- **England:** Lynn Goodacre, Preston
- **Italian:** Renzo Andrich, Milan
- **Chinese:** Fung Alexandra
- **Portuguese:** Silvia Rodrigues, Coimbra
- **Afghan:** Francesca Flumeri, Rome
Studies using QUEST

Assistive devices as an early childhood intervention: evaluating outcomes

Ruth E. Benedet, John P. Lee, Shannon R. Marmo and Anita M. Fuerel
Department of Human and Child Health, School of Public Health, Prosthetics and Orthotics International, 2001, 23, 114–125

Clinical results of an investigation of paediatric upper limb myoelectric prostheses fitting at the Quebec Rehabilitation Institute

F. ROUTHIER***, C. VINCENT***, M. J. MORISSETTE*** and L. DESAULNIERS***
*Centre for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRISS), Quebec Rehabilitation Institute, Quebec City, Canada
**Department of Rehabilitation, Laval University, Quebec City, Canada
***Quebec Rehabilitation Institute, Quebec City, Canada

Assistive devices as an early childhood intervention: evaluating outcomes

M. SHONE STICKEL†, S. RYAN‡, P. J. RIGBY‡ and J. W. Dorevitch MacMillan Centre, Toronto, ON, Canada
Department of Occupational Therapy, Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada
School of Occupational Therapy, The University of Western Ontario, London, ON, Canada

Assistive devices as an early childhood intervention: evaluating outcomes

Abstract

Toward a comprehensive evaluation of the impact of electronic aids to daily living: evaluation of consumer satisfaction

M. SHONE STICKEL†, S. RYAN‡, P. J. RIGBY‡ and J. W. Dorevitch

Abstract

Purpose: It is generally accepted that electronic aids to daily living (EADLs) play an important role in the lives of many people with severe disabilities by providing the means to assist and control devices for daily living activities. This study used a device (ATD) targeted to young children to assess the needs and preferences of children using an ATD. The primary purpose of this study was to explore consumer satisfaction with the ATD.

Background

Electronic aids to daily living (EADLs) play an important role in the lives of many people with physical disabilities, by enhancing their autonomy to participate in daily activities. These technologies provide the means for persons with limited movement to access and control devices for home security, communication and

ASSISTIVE TECHNOLOGY

Satisfaction with rollators among community-living users: a follow-up study

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† Duxin Centre for Technical Aids for Rehabilitation and Education, Aarhus, Denmark
‡ Department of Clinical Neurology, Division of Occupational Therapy, Lund University, Sweden
§ Department of Technology and Society, Division of Traffic Planning, Lund University, Sweden

Abstract

Purpose: Rollators are used in order to make walking possible for people with reduced walking ability. The use of rollators is increasing, but little is known about outcomes. The aim of this study was to investigate users’ satisfaction with rollators. Methods: A follow-up study was carried out in seven Danish municipalities, 6 months after the patients’ choice of rollator. The sample consisted of 122 patients with stroke, multiple sclerosis, rheumatoid arthritis, or other chronic conditions. Three months after the first interview, a second interview took place and data from the 94 most available follow-up was analysed.

Reliability and validity of the Dutch version of QUEST 2.0 with users of various types of assistive devices


REHABILITATION IN PRACTICE

Client satisfaction with service delivery of assistive technology for outdoor mobility

S. JEDELOO*, L. P. DE WITTE†, B. A. J. LINSEN‡ and A. J. P. SCHRIJVERS§
*Julius Centre for General Practice and Patient Oriented Research University Medical Center, UMC Utrecht, D 3585 CS, PO Box 85080, 3508 GA Utrecht, The Netherlands
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Assistive devices as an early childhood intervention: evaluating outcomes

Disability and Rehabilitation, 2003, vol. 25, no. 6, 267–272

Reliability and validity of the Dutch version of QUEST 2.0 with users of various types of assistive devices


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Observations

BAD
Nobody uses the QUEST exactly as it was meant to be used.
- Addition of items
- Variation in procedures
- Unexpected respondents
- Analyses

GOOD
QUEST appears to produce useful results.
- Various AT
- Different research goals
- Different languages and settings
Conclusion

- ATs are powerful rehabilitation interventions.
- AT outcome measures do matter.
- Although the challenge is huge, important progress has been made.
- Conceptual models are being developed.
- Work on a taxonomy is going on.
- Specific AT tools are being implemented.
- Most of all, there is an international interest and commitment to AT outcomes.
Closing …

“The process of outcomes management is similar to investments in stock market portfolio in which the value becomes much apparent over time.”

Edward A. Dobrykowsik, 1999
Editor, J Rehab Outcomes Measurement
Thank you!

Montreal, Canada