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Focus Groups on Assistive Technology Use and Outcomes: A Consumer Perspective

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Introduction

This needs assessment activity used the focus group as a qualitative research method to examine the perceived outcomes of using assistive technology (AT) by users of the technology. As a key stakeholder of AT outcomes their consumers' views are crucial. Our efforts sought to understand AT users "lived experience" and the meaning of assistive technology outcomes for consumers as they participate in their daily life activities. The focus groups took place at three sites: Milwaukee, Wisconsin, Menomonie, Wisconsin, and Seattle, Washington. We conducted the first group with a population of students with disabilities in an urban university (Group 1). The process was replicated in northern Wisconsin with a population of working age adults with disabilities who are part of a vocational rehabilitation institute located at that campus (Group 2). The third group was held in Seattle, Washington at a clinical outpatient rehabilitation facility. Participants of this group were adult clients who are currently active with the clinical and/or residential programs of the organization (Group 3). The results from each of the groups are briefly presented below, followed by summary comments.

Group 1: University Student Focus Group

Methods

Five students with varied disabilities, three women and two men between the ages of 20-50, currently enrolled in an urban university, participated in a focus group

(Appendix A) with two facilitators using a modified Nominal Group Technique (NGT) (Delbecq, Van de Ven & Gustafson, 1986; Gustafson, Cats-Baril, & Alemi, 1992) to answer five open-ended questions (Appendix B). The questions were designed to capture attitudes and cognitions about assistive technology. Data were analyzed by trained qualitative investigators in the three steps suggested by Morgan (1988): open coding; the refining of thematic categories; and finally, the thematic coding of the raw data.

Results

An extensive list of AT devices was generated by the focus group process. The tables included in Appendix C (Group1: UWM) show how the group felt about the most helpful types of AT information they had received (Appendix C, Table 1), how the group felt about their acquisition of AT information (Appendix C, Table 2), and the ways in which the group members used the information (Appendix C, Table 3) . The fourth table in Appendix C reveals the themes that evolved after expert coding. Two discoveries emerged from this data collection and analysis. First, the definition of outcomes from consumers and, secondly, the implications of how consumers view outcomes. The priority listings identified by the student research participants indicated highly idiosyncratic, disability-specific prioritization. Activities of daily living (ADL) and mobility were primary. The scope of available equipment, sources of supplies, and rehabilitation professionals' knowledge of available equipment were considered important. Equipment that increased efficiency and productivity was identified as essential.

Discussion

A key discovery emerged. In this group, the consumers' definition of "outcomes" differed from the definition of "outcomes" held by service providers and researchers. The results challenge subsequent focus groups to revise their questions to elicit necessary information related to outcomes. Similar findings emerged from the two additional focus groups conducted by ATOMS partners and were underscored by the shared insight of an ATOMS team member who has a disability himself.

Group 2: Adult Vocational Rehabilitation Focus Group

Methods

The group followed the modified Nominal Group Technique (Appendix A) format listed under the University focus group summary and used the same questions to generate data. The data from this group did not undergo the same coding as was done with the first group. The raw data is reported in Appendix D.

Participants

Adults of working age (average age 39) who are clients of a vocational rehabilitation institute participated in this group. There were six participants, two males and four females. Disabilities included paraplegia; back injury (3); mental health issues; fibromyalgia; scoliosis; severe cerebral palsy and arthritis. Two participants had multiple disabilities. Five participants were users of devices requiring low to moderate expertise to use. One person had numerous devices that required high level skills to use.

Results

Three lists of AT devices were generated but not prioritized by the participants (Appendix D). The group did not discuss outcome measures in spite of prompting to do so. They focused on process issues and their own personal experiences related to

securing their AT. The group is intelligent and experienced in using AT devices from a number of service perspectives. They had excellent verbal skills and insight. Utilization of AT and participation in this focus group had a positive impact on the group members. Transportation to the distant group site presented a barrier to participation by one member of the group. However, she was able to participate fully and successfully in the group process by using a speaker phone.

Discussion

The group had trouble grasping the researchers' definition of outcomes. Stepping back and helping consumers understand what outcome measures are will help better determine how they will be utilized. A definition of outcome measures and some examples for the group to review before participating would be helpful in future groups. The focus group methods, format and structured questions worked well.

Group 3: Adult Outpatient Rehabilitation Focus Group

Methods

As with the previous groups, this group, too, followed the modified Nominal Group Technique (Appendix A) format and used the same questions to generate data. Also, the data from this group did not undergo the same coding as was done with the first group. The raw data is reported in Appendix E.

Participants

Seven individuals participated in this group with the following demographics.

Participant #1 Age: 56
Gender: Male.
Disability: CP
AT devices participant uses:
Power W/C
Augmentative Communication
Computer with Alternate Access

Lap tray
Level of expertise of devices: Expert
Attendant, interpreter, advocate attendance at focus group: NA

Participant #2 Age: 56
Gender: Male.
Disability: CP
AT devices participant uses:
Power W/C
Augmentative Communication
Computer with Alternate Access
Lap tray
Level of expertise of devices: Expert
Attendant, interpreter, advocate attendance at focus group: NA

Participant #3 Age: 41
Gender: Male.
Disability: Post Surgical Rupture of Aorta Quadriplegic
AT devices participant uses:
Power W/C
Augmentative Communication
Computer with Alternate Access
Lap tray
Level of expertise of devices: Expert
Attendant, interpreter, advocate attendance at focus group: NA

Participant #4 Age: 41
Gender: Male.
Disability: CP
AT devices participant uses:
Power W/C
Augmentative Communication
Computer with Alternate Access
Lap tray
Level of expertise of devices: Expert
Attendant, interpreter, advocate attendance at focus group: NA

Participant #5 Age: 52

Gender: Male.
Disability: CP
AT devices participant uses:
- Power W/C
- Augmentative Communication
- Computer with Alternate Access
- Lap tray

Level of expertise of devices: Advanced
Attendant, interpreter, advocate attendance at focus group: NA

Participant #6 Age: 42
Gender: Female.
Disabilit:. Neuromuscular Disorder C-4 Quadriplegia
AT devices participant uses:
- Power W/C
- Augmentative Communication
- Computer with Alternate Access
- Lap tray
- Mouth stick
- Optical head pointer

Level of expertise of devices: Expert
Attendant, interpreter, advocate attendance at focus group: NA

Participant #7 Age: 42
Gender: Female.
Disability: CP
AT devices participant uses:
- Power W/C
- Augmentative Communication
- Computer with Alternate Access
- Lap tray
- Reacher
- Pointer stick

Level of expertise of devices: Expert
Attendant, interpreter, advocate attendance at focus group: NA

Methods

Following the group technique, raw lists were created (see Appendix E). There were no revisions. The questions were address in order with everyone having an opportunity to respond. The facilitators rotated the person who started commenting for

each question. The entire meeting was done verbally with the facilitators taking notes. At times the facilitators had to expand a little on the question by giving examples. The meeting was held in a rehabilitation facility with everyone around a large round table so they could all see each other. Several of the participants used only their A/C equipment to interact, others, because we were familiar partners, chose to speak rather than use their device.

The group was specifically selected to reflect the perspective of people with multiple disabilities. These folks often have sensory limitations as well but they were not represented in this group. The group members all had multiple disabilities, were known to each other, and were comfortable in communicating both verbally and with their A/C equipment.

Results

The participants were uniformly interested in wanting access to information about technology that would allow them to make choices, even though they may not be realistically able to acquire new equipment. The group facilitators reported that we need to address this group with a protocol that allows them to express what value AT has contributed to their lives.

In the future, we would use the same group size and configure them in a similar fashion. We would conduct the meeting the same way, however the questions should be changed to reflect outcomes, i.e. what is your technology? and what has it done for you in your life?

Summary and Discussion

Several key discoveries important to professionals working with assistive technology emerged from all three of these initial consumer focus groups. First of all, the data from all three groups clearly demonstrates that the consumers' understanding of "outcomes" is very different from the definition of "outcomes" that is held by service providers or researchers. Secondly, group members focused on the devices themselves, not outcomes or effectiveness of devices. They were more concerned with process than outcomes and the idiosyncratic utility of the device to enable them to take care of themselves independently and to participate in the lifestyle of their choosing. Members of all three groups expressed interest in continued participation in the ATOMS research projects and were pleased to be asked to provide a their perspectives as consumers of AT devices and to contribute to the development of a more effective outcomes measurement system for the future. The focus group method was agreed by all group leaders to be effective as an initial step in identifying consumer perspectives and in eliciting their perceptions, cognitions and attitudes towards assistive technology. All agreed that additional steps will be necessary to integrate the consumer stakeholder perspective into the developing AT outcomes measurement system. The results of all three groups were discussed at an ATOMS collaborators meeting and challenged the researchers to design new questions to elicit specific outcomes information for subsequent focus groups (see Appendix F). These new questions, based on the information garnered in the first round of consumer focus groups will be used in the second round with the same participants, targeted for the Fall of 2003.

References

Delbecq, A.L., Van de Ven, A.H. & Gustafson, D. H., (1986). *Group techniques for program planning: A Guide to nominal group and delphi processes*. Middleton: The Green Briar Press.

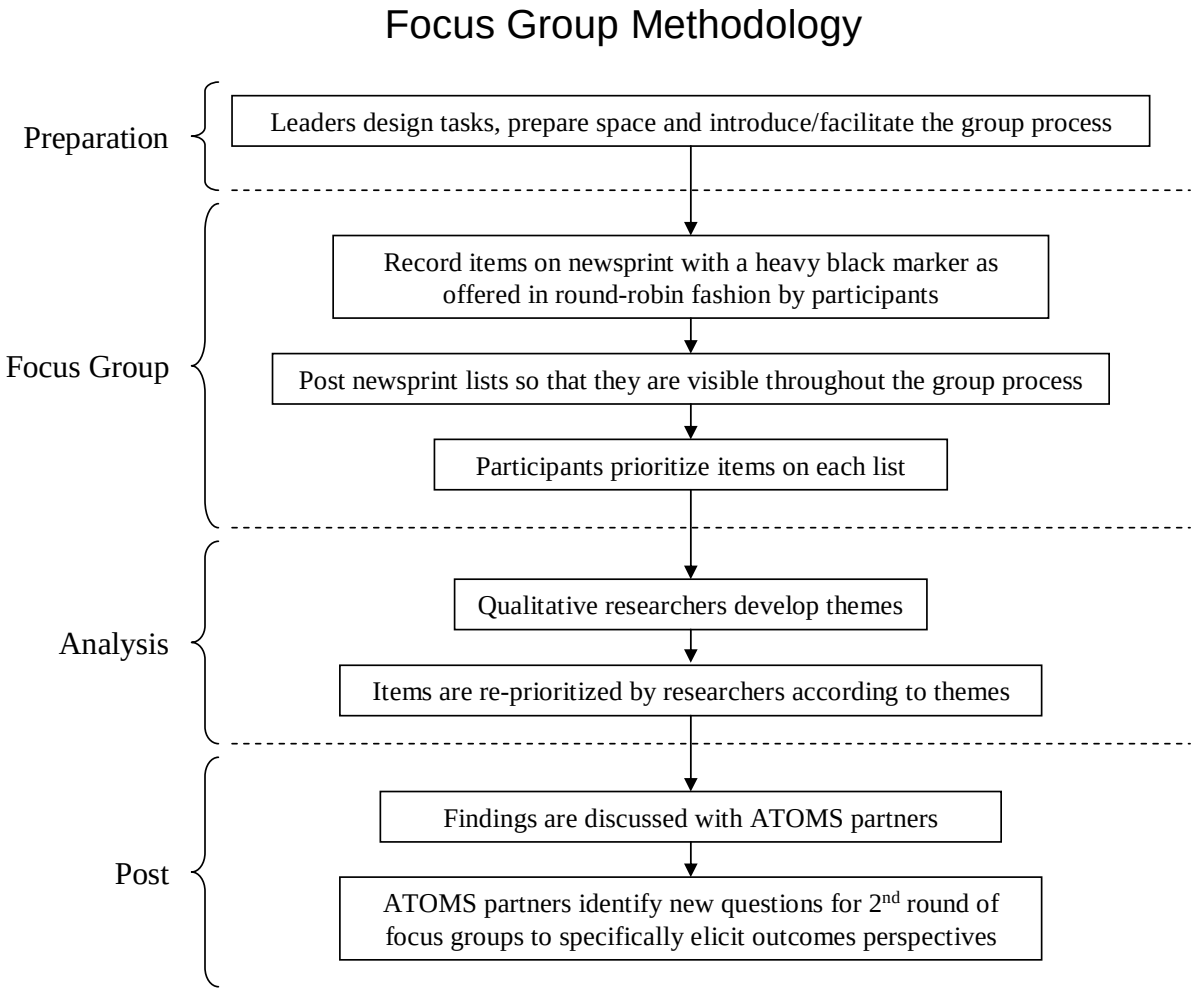
Gustafson, D.H., Cats-Baril, W.L., & Alemi, F. (1992). *Systems to support health policy analysis: Theory, models and uses*. Ann Arbor: Health Administration Press.

Morgan, D.L. (1988). *Focus groups as qualitative research*. Newbury Park: Sage Publications.

Appendices

Appendix A

Modified Focus Group Format



Appendix B

Consumer Focus Group Round #1 Questions

1A. What assistive technology devices do you use?

1B. How do you get your assistive devices?

2. What types of assistive technology would be most helpful?

3A. How would it be best for you to get this information?

3B. How could you use the information?

Appendix C - **Raw Data and Data Analysis University: Group 1**

Table 1

2: Most Helpful Types of AT Information	Number of priority votes received (max 3 per student)
Resources for out-of-pocket purchases	4
Financial aid – getting info on what consumers are entitled to or qualified for	2
What kind of devices are available for your specific disability	2
Benefits to be more clear before purchase	1
Customer comments available	1
Information on most beneficial device	1
Options available	1
Pros & cons of using technology	1
Specific listings of what is accessible and how it is accessible, so individual can decide (e.g. for an apartment complex)	1
Truth in advertising	1
Alternative ways to use certain equipment	
Educational resources about device	
List of resources to access on internet	
Measurements	
Reputable web sites	
Softer, more comfortable	
Specifics on installation	
Support line	
Total Votes	15

Table 2

2: Most Helpful Types of AT Information	Number of priority votes received (max 3 per student)
Resources for out-of-pocket purchases	4
Financial aid – getting info on what consumers are entitled to or qualified for	2
What kind of devices are available for your specific disability	2
Benefits to be more clear before purchase	1
Customer comments available	1
Information on most beneficial device	1
Options available	1
Pros & cons of using technology	1
Specific listings of what is accessible and how it is accessible, so individual can decide (e.g. for an apartment complex)	1
Truth in advertising	1
Alternative ways to use certain equipment	
Educational resources about device	
List of resources to access on internet	
Measurements	
Reputable web sites	
Softer, more comfortable	
Specifics on installation	
Support line	
Total Votes	15

Table 3

3A: Best Method of Acquisition of AT Information	Number of priority votes received (max 3 per student)
Internet	3
Primary Physicians	2
VSA-National/state organization for disabled artists	2
E-mail from specific companies	1
Friends, word of mouth	1
Independent Living Centers	1
Oncologist	1
Rehabilitation Technician	1
County social worker	
Disability focused magazines	
DVR counselors	
E-mail about updates	
Milwaukee County Office for persons with disabilities-Handy News notes	
SAC	
Total Votes	15

Table 4

Expert-Coded Themes and Number of Matching Items From Group Lists

Theme	Number of Items
Question 1A: What assistive technology devices do you use?	
Activities of Daily Living	5
Mobility	5
Communication/Personal	3
Communication/Occupational	2
Total	**15**
Question 1B: How do you get your assistive device(s)?	
Personal	7
Agency/Funding Source	6
Specialist/Professional Referral	2
Total	**15**
Question 2: What types of assistive technology information would be most helpful?	
Access	8
Educational	7
Assistance Required	
Comfort	
Descriptive	
Total	**15**
Question 3A: How would it be best for you to get this information?	
Professional	7
Independent Mode of Access	5
Organization	2
Education	1
Agency	
Total	**15**
Question 3B: How would you use the information?	
Efficiency	4
Personal Productivity	4
Quality	4
Cost	3
Funding	
Total	**15**

Appendix D

Raw Data Adult Vocational Rehabilitation: Group 2

Question 1: How could assistive technology outcomes information be helpful?

Know more about product
Could I try it first?
Understand features, functions, compatibility, etc.
Would like to try voice activated wheelchair
Adaptive software
Availability of products
I know I will have future needs, this would allow me to research things
Helps in purchasing
Brochures on services
"Different technologies"

Question 2: What types of assistive technology outcomes information would be most helpful?

Funding connections would be helpful
Have bought things and then thrown out
Word of mouth is helpful
Make more informed decisions
See equipment and try
Need info in a timely manner
Future oriented information
Information on AT other than work related
Try out new products on computer
Try and purchase
Is it cost effective?
Expo for families
Fliers
Sit and talk to one another
Help to deal with vendors

Question 3: How would it be best to get the information?

Consumers Report would be helpful
Try out is most important
Information to all people
Expo of devices
Through DVR counselors

Appendix E

Raw Data PROVAIL: Group 3

Question 1A: What Assistive Technology devices do you use?

Wheelchairs
Communicator (Liberator, Light Talker, Pathfinder, Dyna…?, Canon Alphabet Board)
Computer
Morse Code (DARCI and EZ Keys, Handi-Code)
Cell phone
Speech to Speech
Eyeglasses
Key guards
Mouthstick
Lap Tray
AFOs
Computer optical pointer
Transfer disk
Adapted telephone
Cup holder
Electric toothbrush
Hoyer lift
Adapter silverware
Rocker knife
Lip Bowl

Question 1B: How did you get your assistive devices?

DVR Counselor
Settlement
Speech pathologist
Medicaid
Company direct
Family
AT Developer
Medicare
Insurance
Assistive technology service provider
Friends
OTs
PTs

Supported Employment
Personnel agency
Person via "Sprint" and Washington State U
Wheelchair service provider
Pass plans

Question 2: How could assistive technology outcome information be helpful to you?

To interact with company to offer ideas for improving a device
To get information on products to be used as AT that you may not normally see that way
To have information as a resource for others in my life
Build awareness (advocacy)
Spread the word. The more that know how helpful it is the better

Note: One or more participants brought up the content of the following cues spontaneously without prompting. Use information to:

Decide and choose device/system and service
Compare devices/services
Identify what potential improvement I might have
Identify what independence I might achieve
Identify how my quality of life might change

Question 3: What types of Assistive Technology outcomes information would be most helpful?

Comparing devices
Better promotion of conferences for all to participate
Data base of products and services
Team approach, multidisciplinary

Note: Participants brought up the content of the following cues spontaneously without prompting.

Availability
Maintenance
Functional and performance outcomes of devices and services
Device features
Service features
Success of various funding sources for a given device or service

Question 4: How would it be best for you to get this information?

Word of mouth

Government/university resources
Trade shows
Auctions
Yard sales
Radio spots
Newspapers
Websites
Phone Hotline

Note: Participants brought up the content of the following cues spontaneously without prompting.

Friends
Neighbors
Other users
Catalogs
Therapists and rehabilitation personnel
Television and other commercial advertising
Internet

Appendix F

Focus Group Questions for Consumer Focus Groups - Round 2

1. What has assistive technology done for you?
2. Based on your experiences, what would you tell the funder of your assistive technology device to convince them to continue to increase funding support?
3. Other than funding, what were the positive or negative experiences you had with the process of getting your assistive technology?
4. What would you tell the inventor or manufacturer of your device(s) about what works or doesn't?
5. Who have you told about what works and what doesn't with your device?

Acknowledgment

The ATOMS Project and this work are supported in part by the National Institute on Disability and Rehabilitation Research (NIDRR), grant number H133A010403. The opinions contained in this publication are those of the grantee and do not necessarily reflect those of the NIDRR and the U.S. Department of Education.