

Interagency Committee on Disability Research (ICDR)

Focus Group Input from Individuals with Disabilities and Targeted Individuals

Implementation Plan

Prepared By:

CESSI

6858 Old Dominion Drive, Suite 200

McLean, VA 22101

(703) 448-6155

2007

The National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, under Contract No.GS10F0006M, Order No. ED-04-CO-0032, funded this report.

Contents

Section I: Implementation Plan for Focus Groups	3
Background and Overview	3
Previous Focus Group Activity (2002-2005)	3
Research Questions	5
Section II: Recruitment Strategy	6
Focus Group Selection	6
Recruitment Strategy	7
Participant Screening	8
Section III: Focus Group Planning	8
Working with Local Coordinators	8
Preparing Meeting Materials	9
Orientation and Travel Planning for Moderator(s)	9
Section IV: Conducting the Focus Groups	10
Section V: Post Focus-Group Activity	10
Data Analysis	10
Coding Scheme	10
Preparing Reports	10

Appendices:

- Appendix A: 2007 Regional Focus Group Agreement Letter
- Appendix B: 2007 Assistive Technology Regional Focus Group Fact Sheet
- Appendix C: 2007 Informed Consent Form: Audiotaped Focus Groups
- Appendix D: 2007 Assistive Technology Regional Focus Group Screening Form
- Appendix E: 2007 Assistive Technology Regional Focus Group Guide

Section I: Implementation Plan for Focus Groups

Background and Overview

The focus group activity forms part of an initiative through which the Interagency Committee on Disability Research (ICDR) conducts activities to solicit input regarding the national disability agenda and gaps in disability-related research. These activities, under funding allocated from the New Freedom Initiative to coordinate federal disability research programs, support the ICDR's charge to identify, assess, and coordinate research on assistive technology (AT) for individuals with disabilities, including technology that incorporates the principles of universal design. A specific focus of the research is to seek input from "targeted populations," including individuals with disabilities of all ages, their family members, guardians, advocates, and authorized representatives (U.S.C., Title 29, Section 16, Sec. 763).

The current set of focus groups differs from previous groups in one regard. In the set of focus groups already conducted, the emphasis of the discussion was on use of AT in general. This set of focus groups will include a general discussion of AT use, but will also ask the participants to describe their experiences with AT in preparation for, during, or following emergency situations.

For the purposes of this research we use the definition of AT given in the Assistive Technology Act of 2004 (available at: <http://www.govtrack.us/data/us/bills.text/108/h4278.pdf>, last accessed July 10, 2006):

ASSISTIVE TECHNOLOGY.—The term 'assistive technology' means technology designed to be utilized in an assistive technology device or assistive technology service.

ASSISTIVE TECHNOLOGY DEVICE.—The term 'assistive technology device' means any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.

ASSISTIVE TECHNOLOGY SERVICE.—The term 'assistive technology service' means any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device.

Previous Focus Group Activity (2002-2005)

A stated goal of the focus groups is to obtain information from individuals who do not generally provide input to governmental officials and policy makers, may not receive traditional disability services, may be considered members of an underserved disability group, or may not view themselves as part of a "disability constituency." In previous focus groups conducted between 2002 and 2005 we sought out a spectrum of individuals with disabilities and/or their representatives. The focus groups convened include:

Year 1 (2003):	Year 2 (2004):	Year 3 (2005):
<p><i>Hispanic Americans:</i></p> <ul style="list-style-type: none"> • MA (Region I) • Hispanic Youth, Florida (Region IV) <p><i>Asthma:</i></p> <ul style="list-style-type: none"> • Breathing Disorders, New York (Region II) • Respirators and Breathing Devices, via teleconference (No Region) <p><i>Psychiatric Impairment:</i></p> <ul style="list-style-type: none"> • Georgia (Region IV) • Idaho (Region X) <p><i>Sensory Impairments:</i></p> <ul style="list-style-type: none"> • Students with Hearing Disabilities, Fairfax County, VA (Region III) • Blind and Low Vision Youth, Fairfax County, VA (Region III) <p><i>Veterans:</i></p> <ul style="list-style-type: none"> • Veterans with Physical Disabilities, Dallas, TX (Region VI) • Veterans with Psychiatric Disabilities, Idaho (Region X) <p><i>Caregivers/Personal Assistants:</i></p> <ul style="list-style-type: none"> • Georgia (Region IV) • Dallas, TX (Region VI) 	<p><i>Older Americans:</i></p> <ul style="list-style-type: none"> • Ann Arbor, MI (Region V) • Seattle, WA (Region X) <p><i>Asian Americans:</i></p> <ul style="list-style-type: none"> • Ann Arbor, MI (Region V) • San Gabriel, CA (Region IX) <p><i>Native Americans:</i></p> <ul style="list-style-type: none"> • Arizona (2 groups) (Region IX) <p><i>Violence-Induced Neurological Disorder:</i></p> <ul style="list-style-type: none"> • Washington, DC (Region III) • Detroit, MI (Region V) <p><i>TBI/Head Injury:</i></p> <ul style="list-style-type: none"> • Berea, OH (Region V) • Akron, OH (Region V) <p><i>Diabetes:</i></p> <ul style="list-style-type: none"> • Kansas City, MO (2 groups) (Region VII) 	<p><i>African-Americans:</i></p> <ul style="list-style-type: none"> • Princess Anne, MD (Region III) • Anderson, SC (Region IV) <p><i>Persons with Disabilities in Transition (College to Work):</i></p> <ul style="list-style-type: none"> • Blackwood, NJ (Region II) • Stillwater, OK (Region VI) <p><i>Persons with Spinal Cord Injury:</i></p> <ul style="list-style-type: none"> • Englewood, CO (Region VIII) • Providence, RI (Region I) <p><i>Persons with Cognitive/Intellectual Disabilities:</i></p> <ul style="list-style-type: none"> • Ogden, UT (Region VIII) • Topeka, KS (Region VII) <p><i>Persons with Disabilities who are Employed:</i></p> <ul style="list-style-type: none"> • New Haven, CT (Region I) • Washington, DC (Region III) <p><i>Children with Special Health Care Needs:</i></p> <ul style="list-style-type: none"> • Sandia Park, NM (Region VI) • Huntsville, AL (Region IV)

All were either users or potential users of AT or durable medical equipment. Before fielding the focus groups, our procedures for recruiting and screening participants, conducting focus groups and protecting participant privacy were reviewed by CESSI's Institutional Review Board (IRB) and were approved by the Office of Management and Budget (OMB).

Over 300 consumers with disabilities or their caregivers participated in 36 regional focus groups. The groups produced valuable insights into the issues faced by individuals who need or want to use AT to improve their lives. The 2002-2003 groups revealed they have an enthusiasm for and interest in using AT, but they do not always have ways to identify appropriate AT or pay for it. They also have concerns about appropriate knowledge of AT among providers such as rehab specialists, counselors, teachers and medical personnel. In the 2003-2004 groups we refocused the questions to emphasize coping strategies, and we found that individuals who are connected to support groups, have access to and know how to search the Internet, or have a family member or provider to assist them tend to feel more positive about the quality of their lives than those who don't have access to such resources. The focus group participants noted that persistence and self-advocacy play an important role in obtaining desired technologies and feeling better about life.

The 2004-2005 groups provided valuable insight into the "life cycle" of AT use: seeking, obtaining, using, maintaining, and discontinuing use of AT. We found concrete examples of individuals whose disability situations were changing in such a way that they would need to modify or replace their current AT to meet their needs. For example, one young man with hearing loss who had not been strongly interested in obtaining the best possible hearing aid in high school became much more motivated to obtain a good hearing-aid when he entered college and wanted to be more competitive as a student.

The groups in each of the three years led us to develop suggestions for research, such as "Can we identify 'defining moments' in a person's life when his or her AT needs are likely to change? For example, we normally think of the time when a child begins school as one of these times, but are there other, less obvious defining moments?" We will incorporate what we learned from the previous groups into this year's questions.

Research Questions

This year's research questions are designed to prompt focus group participants to describe their experiences in using AT and to describe AT (whether existing or not-yet-designed) they do not have but would find useful. We will focus particularly on use of AT in preparation for, during, or following emergency situations.

1. What types of assistive technology and also mass-market technologies (such as cell phones) do you find useful and how have these improved your everyday life?
2. What are the steps you have followed to determine a need for AT, identify appropriate technology, and obtain it?

3. How do you overcome barriers to obtaining, using, maintaining, and upgrading your AT? What are your strategies?
4. What items of AT would you like to have? These can include either high-tech or low-tech items that currently exist, or items that have not yet been invented.
5. You live in a region where there is a risk for natural or man-made emergencies such as [earthquakes, fires, hurricanes, etc.]. How have you included AT in your planning for such emergencies?
6. In thinking about communications during an emergency, do you think there are differences between information sources in terms of how accurate, relevant, timely, and useful is the information they provide? Can we rank higher-quality sources vs. lower-quality sources? Are there sources you would have difficulty accessing? Why?
7. How have you included people (either your social network or people you don't know) in your planning for emergencies? How do you see the roles of technology and people interacting in an emergency?
8. Have you ever been in an actual emergency situation? How did AT help? In what ways was AT not useful? In what ways were people helpful or not helpful?

Section II: Recruitment Strategy

Focus Group Selection

As noted above, a specific focus of the research is to seek input from “targeted populations,” including individuals with disabilities of all ages, their family members, guardians, advocates, and authorized representatives. The ICDR seeks to include groups underrepresented because of their age, their impairment type, or their race or culture. In 2007, focus groups will reflect the current emphasis on emergency preparedness and emergency response. For these groups we will select six geographic areas subject to various kinds of natural or human-caused emergencies, and interview two groups in each area. Some potential threat zones for the 2007 focus groups have been identified with assistance from the ICDR, and are listed below:

- Earthquake (Western U.S.)
- Flood (Coastal areas and river systems)
- Hurricane (Southeast U.S.)
- Volcanic eruption (Pacific Northwest)
- Landslide (Western U.S.)
- Coastal flooding/storm surge/tsunami (Any coastal area)
- Wildfire (Western U.S.)
- Tornado (Central U.S.)
- Industrial accident (ex. Oil refineries, chemical processing plants) (Gulf Coast, various locations throughout the U.S.)
- Dam Failure (Various locations on major rivers)
- Terrorism (Medium to large cities, industrial areas, main transportation hubs)

- Civil unrest (Medium to large cities)

For these groups, we are most interested in obtaining the participation of “ordinary” individuals with disabilities and/or their representatives. We will seek individuals over the age of 21 whose disabilities or chronic health conditions interfere with major life activities. In other words, we will look for individuals over the age of 21 whose disability or health condition impacts their employment, community life, education, or household activities. These individuals are users or potential users of AT or durable medical equipment.

Recruitment Strategy

We have two goals for the recruitment strategy. The first goal is to engender trust in the research process. The second is to ensure broad access to participation among people who may not have had the opportunity to offer input into federal research and policy.

In order to meet both of these goals, we will work with local organizations representing each constituency we wish to recruit. Selected local organizations will work in concert with the CESSI Project Coordinator to identify and screen participants and host the focus groups.

We will contact rehabilitation providers, members of the ICDR subcommittees, and other researchers to obtain leads about service providers who might be interested in helping to recruit and host a focus group. We will also do a Web site search for such organizations.

The CESSI Project Coordinator will make an initial telephone contact with each identified organization to introduce the study, review the purpose of the focus groups, discuss the requirements for recruiting study participants and hosting the groups, discuss the compensation offered to participants and to the local organization, and offer additional information. The Project Coordinator will then gauge the level of interest of the organization in hosting a focus group. The Project Coordinator will follow up as needed with additional telephone and email contacts, and will answer any questions the Local Coordinator might ask.

Participant Screening

During our initial contact with each local organization, we will clearly identify the eligibility criteria for focus group members. The Project Coordinator will instruct the Local Coordinator to recruit from both within the organization and among the local community, and to seek diversity in educational, employment and socio-economic background of the participants. We will ask that each local organization recruit between 8 and 12 individuals per focus group, with a target participation of eight to ten persons. This strategy will help to ensure adequate participation if a group member drops out for any reason.

The Local Coordinator will be asked to identify potential focus group participants over the age of 21 and to contact each by telephone or in person to explain the purpose of the focus group, describe how the group will be conducted, discuss the compensation that will be offered to participants, talk about the participant's role in the group, and explain that the focus group organizers will protect their privacy in accordance with applicable laws..

The Project Coordinator will send electronic and paper copies of a participant screening form, the *2007 Assistive Technology Regional Focus Group Screening Form*, to each Local Coordinator (See Appendix D). If a potential focus group member over the age of 21 expresses interest in participating, the Local Coordinator will conduct a screening and record the participant's answers on the form. The form includes questions that ask about the person's disability or impairment, use of AT, and basic demographic information. If a potential participant indicates that he or she does not use adaptive equipment and would not find it useful, that person will be dropped from consideration, and thanked for his or her time. The Local Coordinator will be asked to fax each completed form to the Project Coordinator, who will monitor the recruitment process and make suggestions for any needed changes in recruitment strategy. The Project Coordinator will ask each Local Coordinator to call before faxing any forms so that the Project Coordinator will be able to immediately remove any incoming faxes from the fax machine.

Section III: Focus Group Planning

We will conduct three types of activity in preparation for the focus groups: working with Local Coordinators to plan the meetings, preparing meeting materials, and conducting orientation and travel planning for the Moderators.

Working with Local Coordinators

The Project Coordinator will work closely with each Local Coordinator in the meeting planning process. The Project Coordinator will conduct conference calls with the Local

Coordinator and with the Moderators to answer questions, discuss the recruitment process, and plan meeting logistics. The Project Coordinator will also assist the Local Coordinator in meeting any organizational Institutional Review Board (IRB) requirements. The Project Coordinator will offer guidance to the Local Coordinator in assisting participants in making travel or other plans for attending the meeting, and will offer guidance on information that should be provided to participants prior to the meeting.

Prior to the meeting, the Project Coordinator will send electronic and paper copies of the following documents to the Local Coordinator (See Appendices for these documents):

- 2007 Regional Focus Group Agreement Letter
- 2007 Assistive Technology Regional Focus Group Fact Sheet
- 2007 Informed Consent Form: Audiotaped Focus Groups
- 2007 Assistive Technology Regional Focus Group Screening Form
- 2007 Assistive Technology Regional Focus Group Guide

The Agreement Letter specifies details of the Local Coordinator's responsibilities. The Fact Sheet explains the rationale for the meetings and describes recruiting requirements. The Informed Consent Form is to be provided to respondents prior to or at the focus group meeting. The Screening Form is to be used by the Local Coordinator to screen potential focus group participants over the age of 21. The Focus Group Guide outlines the activities that will occur at the meeting, and lists the research questions.

Preparing Meeting Materials

The Project Coordinator will prepare an inventory of items necessary for the meeting, such as tape cassettes, name tags, and general supplies. The Project Coordinator will assemble a package of materials prior to the meeting and will send the package to the Local Coordinator shortly before the meeting date. The Project Coordinator will verify that the materials have been received prior to the meeting. Any missing shipments will be replaced.

Orientation and Travel Planning for Moderator(s)

The Primary Researcher (PR) will hold conference calls with the Moderators both prior to and after the first focus group to orient the Moderators, answer questions, and ensure consistency in the Moderators' approach, including the use of follow-up prompts. All Moderators may adapt the research questions slightly depending on the composition of the group. For example, if participants tell the Moderator they do not use AT designed for individuals with disabilities, the Moderator will attempt to focus the discussion on technologies that are most useful to that group. Although Moderators will use the Focus Group Guide to ensure that all relevant topics are addressed, they will also follow the lead of participants to explore issues they raise.

The Project Coordinator will work with the Moderators to ensure that their travel and lodging arrangements offer the most efficient itinerary. The Project Coordinator will also coordinate with the Moderators to make sure that any special needs are accommodated.

Section IV: Conducting the Focus Groups

For each focus group, a CESSI staff person will serve as the Moderator and lead the discussion, and the Local Coordinator or other representative from the host organization will serve as the co-facilitator. The Moderator and co-facilitator will use the 2007 Assistive Technology Regional Focus Group Guide as a model for the focus group activities and research questions. The focus group discussion will be audiotaped.

We will make every effort to make the focus group experience comfortable for the participants. The individuals who will serve as Moderators have disabilities and/or have substantial experience in organizing and conducting focus group research. We will provide printed materials in alternate formats, will hold the meetings in accessible locations and will make other accommodations to facilitate full participation.

Section V: Post Focus-Group Activity

Data Analysis

Each focus group meeting will be audiotaped. Immediately after each meeting, the Moderator will produce a written summary of the meeting, describing the population, summarizing the dialogue, and listing the major issues that were discussed. Following the meeting, the taped group discussion will be transcribed in preparation for data coding. Focus group transcripts will be kept in a secure location.

Coding Scheme

Individual statements made during the discussion will be coded into categories using NVivo, a software program designed to facilitate data coding. The PR and a Research Assistant will code the data using a “grounded theory” research approach that allows coding of emerging data categories.

Preparing Reports

The PR will review the coded data and will organize the respondents’ comments by theme. For example, one key theme relates to how people locate and obtain AT. Within

this theme, the PR will examine the variety of ways in which people seek and find AT. The PR will present descriptive information for each theme, as well as quantitative information wherever possible. The PR will submit a Draft and a Final Data Analysis Report of Focus Groups to the ICDR. The Report will focus primarily on information that may guide future research efforts, but will also include narrative and anecdotal information as supporting evidence. The Report will not identify individuals by name; pseudonyms will be used in all cases.

Appendix A
2007 Regional Focus Group Agreement Letter

[date]

2007 Regional Focus Group Agreement Letter

Dear Focus Group Coordinator:

This letter confirms that you have agreed to serve as a Focus Group Coordinator, assisting me or other researchers at CESSI, Inc. in conducting focus groups for the referenced study. The purpose of this study is to obtain input from individuals over the age of 21 with disabilities and/or their representatives about the kinds of adaptive equipment or assistive technology that would help them live with a disability. This set of focus groups will include a general discussion of AT use, but will also ask the participants to describe their experiences with AT in preparation for, during, or following emergency situations. This project is sponsored by the Interagency Committee on Disability Research, which is made up of representatives of different agencies throughout the federal government and funded under the Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR).

You have agreed to assist in recruiting and screening focus group participants as well as in facilitating one or more focus groups. Since this is a research study, the privacy of information obtained through the study, including during the screening process and the focus groups, must be kept protected by the research team. Accordingly, in your role as Focus Group Coordinator, you agree not to identify individual focus group participants nor will you reveal information shared by participants. In other words, you will not share any information you obtain in working on this study with anyone other than CESSI research staff members. You also agree to submit all screening forms to CESSI without retaining copies. The only information you will retain, in a secure location, is a list of focus group participants, to assist us if we need to follow up with any participant.

If you agree to the terms set forth in this letter, please sign below. Thank you very much. We look forward to working with you on this important project.

Sincerely,

Ashley Ney
Project Coordinator
(703) 448-6155, ext. 226

AGREEMENT WITH TERMS OF LETTER

Name-Signature

Name - printed

Title

Address

Telephone number

Appendix B
2007 Assistive Technology Regional Focus Group Fact Sheet

2007 Assistive Technology Regional Focus Group Fact Sheet

Purpose

The purpose of this focus group project is to obtain input from individuals over the age of 21 with disabilities, impairments or health conditions about kinds of adaptive equipment or assistive technology that helps or would help them cope with their disability. We particularly want to know about their positive experiences and successes in getting information and help with assistive technology devices. This set of focus groups will include a general discussion of AT use and will also ask the participants to describe their experiences with AT in preparation for, during, or following emergency situations.

This project is sponsored by the Interagency Committee on Disability Research (ICDR) which is made up of representatives of different agencies throughout the federal government. These agencies support research and development of new technology, and they want to make sure that the research they fund will support products that are really useful to people with disabilities of different backgrounds. We anticipate that the feedback from these meetings will be valuable to the ICDR in coordinating future research. We also expect that the information gained will help the ICDR develop strategies to improve the use of assistive technology in everyday life and in emergency situations, and promote users' independence and integration into the community.

Definition of Adaptive Equipment or Assistive Technology

By adaptive equipment or assistive technology (AT), we mean both high-tech and low-tech equipment; things like wheelchairs, walkers, computers or appliances that talk, magnification devices, or remote controls that turn on lights. We also would like to know about equipment that is not specially designed for people with disabilities, including how this equipment has been useful or whether they have had problems with these devices (for instance, computers, cell phones, remote controls, etc.).

Focus Group Requirements

A focus group is a small group of about 8-12 individuals who share a similar situation and come together to talk informally about a particular topic. We expect the group to last about two hours.

We are attempting to recruit people with a wide variety of backgrounds. We are looking for people over the age of 21 of different ages, races, educational levels, and occupational backgrounds to make sure we obtain the views of a wide variety of people.

We are particularly interested in recruiting persons with disabilities who live in geographic areas subject to various kinds of natural or human-caused emergencies. These threat zones include:

- Earthquake (Western U.S.)
- Flood (Coastal areas and river systems)
- Hurricane (Southeast U.S.)
- Volcanic eruption (Pacific Northwest)
- Landslide (Western U.S.)
- Coastal flooding/storm surge/tsunami (Any coastal area)
- Wildfire (Western U.S.)
- Tornado (Central U.S.)
- Industrial accident (ex. Oil refineries, chemical processing plants) (Gulf Coast, various locations throughout the U.S.)
- Dam Failure (Various locations on major rivers)
- Terrorism (Medium to large cities, industrial areas, main transportation hubs)
- Civil unrest (Medium to large cities)

Focus Group Logistics

The Local Coordinator will conduct a short entry interview (using a Screening Form we will provide) for each potential participant.

Either the Local Coordinator or the recruiting agency (e.g., community center, disability network organization, etc.) will be paid a fee of \$600 for administering the group. Our goal is to recruit 8-12 participants for each site.

Each focus group participant will be given an honorarium of \$50 and will be reimbursed for any reasonable expenses, such as mileage or other transportation, day care, or personal assistance services, necessary for attending the focus group meeting.

Contact Information

On behalf of the ICDR, we appreciate your collaboration on this focus group project.

If you have recommendations or questions, please contact: Ashley Ney @ 703-448-6155 Ext. 226.

This project is conducted as part of the U.S. Department of Education Contract No. GS10F0006M with CESSI. The views expressed herein do not necessarily represent the positions or policies of the Department of Education. No official endorsement by the U.S. Department of Education of any product, commodity, service or enterprise mentioned in this publication is intended or should be inferred.

Appendix C
2007 Informed Consent Form: Audiotaped Focus Groups

2007 Informed Consent Form: Audiotaped Focus Groups

****FOR CESSI USE ONLY****

Approved by the CESSI Institutional Review Board Administrator:

Date: _____

Expiration Date: _____

1. PURPOSE OF STUDY:

The purpose of this focus group is to obtain input from individuals over the age of 21 with disabilities and/or their representatives about what kinds of adaptive equipment or assistive technology would help them live with a disability. Adaptive equipment or assistive technology means both high-tech and low-tech equipment; items like wheelchairs, walkers, computers or appliances that talk, magnify or remotely control things. We also want to ask you about using equipment that is not specially designed for people with disabilities, and whether you have problems using that equipment. We are especially interested in hearing you describe your experiences with AT in preparation for, during, or following emergency situations.

This project is sponsored by the Interagency Committee on Disability Research, which is made up of representatives from different agencies throughout the federal government. These agencies do a great deal of research and development on new technology, and the agencies want to make sure that the research they fund will support products that are really useful to you and other individuals with disabilities and/or their representatives. What you say will assist them in targeting their efforts to conduct research that is the most useful. Our ultimate goal is to inform policy makers, administrators and disability leaders about where research dollars for technology and equipment for people with disabilities should be directed.

2. PROCEDURE:

We anticipate holding 12 focus groups around the country each year. The focus groups will consist of eight to twelve individuals and will last approximately 90 minutes. We will ask questions about the types of assistive technology that group members use. Specifically, we will ask about how persons with disabilities find information about assistive technology, how they acquire assistive technology devices, and what difficulties they have encountered in using them. We will ask about commonly used equipment that is not designed specifically for people with disabilities. And we will ask about experiences with AT in preparation for, during, or following emergency situations.

Individuals who participate will receive an honorarium of \$50 for their participation, as well as reimbursement for reasonable expenses related to attending the group, such as mileage or child care services.

3. RISKS AND DISCOMFORTS:

We believe there are no significant risks to the individuals who participate in this research project. Sometimes difficult issues may arise during the focus group. The facilitator is acting as a researcher, not as a qualified therapist or counselor. If necessary, you may leave the focus group at any time. We can also let you know about appropriate counseling services.

4. BENEFITS:

There are no direct or immediate benefits for participation in the focus group. We anticipate that the findings of our focus groups will be used to provide consumer input to federal agencies conducting research on assistive technology. Many federal agencies do not have a way to obtain such input from people with disabilities who use technology. This project will assist these agencies in developing their technology research agenda by providing the consumer's perspectives. Additionally, our reports will contain quotes of participants discussing problems and issues that they face on a daily basis as they attempt to live and work independently. This will provide a real-world perspective for agencies that conduct technology research. Please note that your name will never be used in a report. We will use pseudonyms (invented names) whenever we quote directly from the group, rather than real names.

5. ALTERNATIVE PROCEDURES:

There are no applicable alternatives to holding these groups.

6. PRIVACY:

Focus group participants will not be identified by name, address or any specific personal information if direct quotes are used in describing the results of this study. As a focus group participant you are notified here, and on the consent form you will be asked to sign, that you are not to repeat any specific personal information which you may hear in the focus group.

In writing about this study, the investigators will assign each focus group member a pseudonym and change small details about their lives (such as age, job or number of children), so that they are not identifiable. The audiotape of the interview will be transcribed, but the transcriber will not be given complete names, only the pseudonym that has been assigned. Identifying information contained in the screening instrument and the consent form will be kept in a locked file cabinet, accessible only to the researchers. Three years after the study is over and all the publications are finally completed, the audiotapes and all identifying information kept in the locked file cabinet

will be destroyed. The study organizers will protect your privacy in accordance with applicable laws.

7. PARTICIPATION

Your participation is completely voluntary. If you decide not to participate or you decide to leave the group before the end of the session, you will not be penalized or lose any benefits to which you are entitled. If we ask a question which you do not wish to answer, you can just skip the question.

8. COST/PAYMENT:

You will be given an honorarium of \$50 for your participation. You will also be reimbursed for any costs for transportation, day care or personal assistance you incurred by participating in the focus group. No royalty, fee or other compensation of any character shall be paid by CESSI.

9. RESEARCH INVOLVING MINORS:

Individuals must be over the age of 21 to participate in these groups.

Contact Information

If you have any questions about this research or experience any problems, you may contact Ms. Ashley Ney at 703-448-6155, Ext. 226. If you have questions regarding your rights as a research subject, you may contact Tracy Turner, CESSI's Director of Administration, at 703-448-6155, Ext. 206.

CONSENT FORM FOR INTERVIEW RESEARCH

I have read the previous page(s) of the consent form and the investigator has explained the details of the study. I understand that I am free to ask additional questions.

I understand that I have a right to privacy and that the investigators on this study protect my privacy in accordance with applicable laws. My name and any other identifying information will not appear in any presentation or publication resulting from this study. I understand that I am not to repeat any specific personal information I may hear during the focus group. My name and any other information which might identify me will not be available to any person or group other than the investigators of this study and the Institutional Review Board (IRB) at CESSI, which oversees all studies.

If I wish additional information regarding this research and my rights as a research subject, or if I believe I have been harmed by this study, I may contact Dr. Susan Daniels, chairperson of CESSI's IRB at 202-363-8970.

I understand that I may be contacted by CESSI's IRB during or after my participation in this study as part of its efforts to monitor the experience of subjects.

I understand that participation in this study is voluntary and I may refuse to participate or may discontinue participation at any time without penalty.

I acknowledge that no guarantees have been made to me regarding the results of my participation in this study, and I consent to participate in the study and have been given a copy of this form.

WITNESS

STUDY SUBJECT

DATE

The subject has been given the opportunity to read this consent form and to ask questions before signing, and has been given a copy.

INVESTIGATOR'S NAME

SIGNATURE OF
INVESTIGATOR

DATE

For any questions regarding the rights of a research subject, please contact Tracy Turner, Director of Administration at 703-448-6155, Ext. 206, or Dr. Susan Daniels at 202-363-8970.

Appendix D
2007 Assistive Technology Regional Focus Group
Screening Form

2007 Assistive Technology Regional Focus Group Screening Form

Introduction

Hello, my name is _____ and I am calling from _____. I obtained your name from _____. [*Please state how you know this person, or how you obtained this person's name.*] I am calling to tell you about a focus group on technology for people with chronic health conditions or disabilities in which you may be interested. Is this a good time?

The purpose of this focus group project is to obtain input from people over the age of 21 with disabilities, impairments, or health conditions like yourself about what kinds of adaptive equipment or AT would help you live with your disability. By adaptive equipment or AT, I mean high-tech and low-tech equipment; things like wheelchairs, walkers, computers or appliances that talk, magnification devices, or remote controls that turn on lights. We want to ask you about using equipment that is not specially designed for people with disabilities and whether you have problems using that equipment. We are especially interested in hearing you describe your experiences with AT in preparation for, during, or following emergency situations.

This project is sponsored by the Interagency Committee on Disability Research, which is made up of representatives of different agencies throughout the federal government. These agencies do a great deal of research and development of new technology, and the agencies want to make sure that the research they fund will support products that are really useful to you and other people with disabilities.

I am wondering if you would be interested in participating in a focus group on this subject. A focus group is a small group of about 10 individuals who share a similar situation who come together to talk informally about a particular topic. For this group, we are recruiting individuals from parts of the country where emergencies like hurricanes or earthquakes might happen. The group will take place [*date, time, and place*]. We expect the group to last between 90 minutes and two hours. You will be given an honorarium of \$50 for your participation and reimbursed for any reasonable expenses, such as mileage or other transportation, day care, or personal assistance services you need to attend the meeting.

All of the information you provide during the focus group or telephone screening will be kept in accordance with applicable privacy laws. We will change your name in any reports we write so that no one knows that you participated. We will provide a consent form for you to sign that details the way we keep information private when you arrive at the group. Are you interested in participating?

We are attempting to recruit people with a wide variety of backgrounds for the focus group. We are looking for people of different ages (over the age of 21), races, educational levels and occupational backgrounds to make sure we obtain the views of a

wide variety of people. We would appreciate if you would answer the following questions. If you feel uncomfortable with any question, you may just skip it. This will not disqualify you for participation in the focus group.

Local Coordinator Directions: Please complete these phone interviews as far in advance of the focus group date as possible to screen at least 10-12 participants. As soon as you complete each form, fax a copy to the CESSI Project Coordinator at 703-442-9015 for approval of the proposed participant. Procedures may vary for individual sites, so please follow recommendations from Ashley Ney, Project Coordinator. Please contact Ashley at 703-448-6155, ext. 226 immediately before faxing any forms so that she can remove them from the fax machine upon receipt.

Local Coordinator Script: Before asking any questions, please read the following statement to each potential participant: “All the information you provide during this telephone call and at the focus group meeting will be handled in accordance with applicable privacy laws. We will change your name in any reports we write so that no one knows that you participated. When you arrive at the group, we will provide a consent form for you to sign that describes the way we keep information private. Are you interested in participating?”

Please ask the respondent for the following information:

1. Last name, first name, middle initial	
2. Full mailing address, including ZIP code	
3. Home telephone number	
4. Work telephone number (if applicable)	
5. Other telephone number (if applicable)	
6. Email address (if applicable)	
7. Gender (Male or Female)	
8. Age (must be over 21 to participate)	
9. Do you consider yourself to be of Hispanic origin?	<input type="checkbox"/> Yes <input type="checkbox"/> No
10. With what racial or ethnic group(s) do you identify? (You may	<input type="checkbox"/> White

check more than one)	<input type="checkbox"/> Black or African American <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Native Hawaiian or Other Pacific Islander
11. Including yourself, how many people live in your household?	
12. What is your primary disability, impairment, or health condition?	

12. Do you have any other disabilities, impairments, or health conditions that affect your ability to perform daily activities? Yes No (Skip to Q14)

13. If yes, what other disabilities do you have?	
--	--

14. Do you use adaptive equipment or AT that helps you live with your health condition or disability? By AT or adaptive equipment, I mean things like wheelchairs, walkers, bathroom equipment, talking computers or appliances or modified remote controls to turn on appliances. Yes No (Skip to Q17)

15. If yes, what do you use?	
------------------------------	--

16. If you use AT or adaptive equipment, who usually pays for it? (Please check all that apply).

Source	<input checked="" type="checkbox"/>
Private health insurance through your employer	
Private health insurance from some other source	
Medicare	
Medicaid	
Self-pay	
Family	
Other (Please specify _____)	

If the respondent answered questions 15 and 16, skip to Q19 now.

17. If you don't use adaptive equipment, why not?	
---	--

18. If you are not using AT or adaptive equipment, would you find it useful to use in the future? Yes No

[Please note—we are interested in individuals who use adaptive equipment as well as individuals who do not use adaptive equipment but would find such equipment useful. If this person does not use adaptive equipment and would not find it useful, please terminate the interview.]

19. Are you currently employed? Yes No (Skip to Q21)

20. If yes, what is your occupation?	
--------------------------------------	--

21. What is the highest level of education you have completed? (Please check one)

Level of Education	<input checked="" type="checkbox"/>
Some high school	
High school graduate	
Some college	
College graduate	
Vocational or trade school	
Some post-graduate work	
Master's Degree (M.A., M.S., or other Master's)	
Doctoral Degree (Ph.D.)	
Other (Please specify _____)	

22. What is your marital status? (Please check one)

Marital Status	<input checked="" type="checkbox"/>
Married	
Never Married	
Widowed	
Divorced	
Other (Please specify _____)	

23. Please tell us your approximate family income, before taxes, including all sources. (Please check one)

Income	<input checked="" type="checkbox"/>
Under \$20,000	
\$20,000 – \$39,999	
\$40,000 – \$59,999	
\$60,000 – \$79,999	
Over \$80,000	

Thank you very much for your cooperation in answering these questions. We will let you know shortly whether you have been selected to participate in the focus group and, if so, when and where the focus group will be held.

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless the collection displays a valid OMB control number. The valid OMB control number for this collection is [application in process]. The time required to complete this information collection is estimated to average four hours per respondent, including the time to review instructions, travel to the focus group, gather the data needed, and complete participation in the focus group. If you have any comments concerning the accuracy of the time estimates or suggestions for improving this form, please write to U.S. Department of Education, Washington, DC 20202-4651.

Appendix E
2007 Assistive Technology Regional Focus Group Guide

2007 Assistive Technology Regional Focus Group Guide

Pre-Group Logistics

Local Coordinator: Please greet each participant, introduce yourself, and give each participant a copy of the Informed Consent form. This form describes the meeting format (taped), discusses compensation for participation, explains privacy protections, and gives the potential participant an opportunity to decline to participate. Please note: people who attend the group but do not stay until the end will receive the \$50 and reimbursement for related expenses.

After all participants have signed the Informed Consent form, hand out name tags (if used) and introduce the Moderator.

Welcome and Introductions

Moderator: Welcome the focus group participants to the discussion and explain the purpose of the focus group and standard procedures (see below).

Thank you for coming today. I know that some of you have gone out of your way to be here, and we genuinely appreciate your interest and willingness to share your experiences. I realize that technology may not be at the top of your list, but technology has tremendous potential for improving lives of people with disabilities, and we are eager to learn about how assistive and adaptive technology has benefited you as well as to hear your recommendations for improving technology supports.

Purpose of the Focus Group

The purpose of this focus group is to obtain input from people over the age of 21 with disabilities, impairments, or health conditions like yourselves about what kinds of adaptive equipment or AT would help you live with your disability. By adaptive equipment or AT, I mean things like wheelchairs, walkers, computers or appliances that talk, magnification devices, or remote controls that turn on lights. We also would like to hear about equipment that is not specially designed for people with disabilities and whether you have problems using that equipment. I want you to think about high-tech and low-tech equipment. We are also very interested in hearing you describe your experiences with AT in preparation for, during, or following emergency situations.

We also would like to learn about successful experiences you have had getting information and help with AT devices. Sharing your experiences will benefit other people in this group because they may hear useful suggestions that apply to problems that they are trying to solve.

We plan to hold 12 focus groups like this around the country each year, to talk to people like you about your experiences with AT. The results of the group discussion will be included in an annual report for the focus groups we will be conducting. These reports

will be shared with the Interagency Committee on Disability Research, which is made up of representatives of different agencies throughout the federal government. These agencies fund a great deal of research and development of new technology, and the agencies want to make sure that the research they fund will support products that are really useful to you and other people with disabilities.

We plan to prepare a report for the project each year which will be shared with ICDR members. It is important that we hear what has worked for you, what strategies have been successful—we want to identify what works so that we can create solutions based on your experiences.

Focus Group Definition and Working Procedures

This focus group is a way for us to listen to people and learn from them.

Before we begin, let me explain a little bit about how a focus group works. During our meeting I will ask you some general questions like, “What kind of AT do you currently use?” You can answer to me or you can talk to each other, discussing the questions among yourselves. We would like to ask you to please speak one at a time, so everybody in the group can hear you. You should also be aware that the discussion is being tape recorded, so that I do not have to remember everything that you have said and also, so I can listen to the tape later. I would very much appreciate it if you would state your first name the first couple of times you speak.

Just a few words about privacy: it is important that what is said during our discussion stays within the group. Also, if I use any information in the reports, I will change your name so that it will be not known who made any particular statement. If any of this makes you uncomfortable, you can decide to not be part of the group at any time.

Now, let us develop some simple rules for our discussion. First, there are no right and wrong answers, any answer is appreciated. Second, you do not have to agree with any statement, you can provide an alternative argument if you wish. Finally, we are not here to criticize things, just to make them better in the future. One of the reasons for this is that we already have a lot of information on the problems, but we need more information on what is working well.

Do you have any questions before we get started? [*Discuss logistics: people should feel free to get up if they need to; location of restrooms*]. At the end of the focus group, we will make arrangements to reimburse you for any money you paid for transportation or other costs to participate in this group.

Focus Group Agenda

Go around the group for **brief introductions**. Ask each participant to introduce himself or herself and to tell the group something about himself or herself, such as a favorite activity.

Questions

- What types of assistive technology and also mass-market technologies (such as cell phones) do you find useful and how have these improved your everyday life?
- What are the steps you have followed to determine a need for AT, identify appropriate technology, and obtain it?
- How do you overcome barriers to obtaining, using, maintaining, and upgrading your AT? What are your strategies?
- What items of AT would you like to have? These can include either high-tech or low-tech items that currently exist, or items that have not yet been invented.
- You live in a region where there is a risk for natural or man-made emergencies such as [earthquakes, fires, hurricanes, etc.]. How have you included AT in your planning for such emergencies?
- In thinking about communications during an emergency, do you think there are differences between information sources in terms of how accurate, relevant, timely, and useful is the information they provide? Can we rank higher-quality sources vs. lower-quality sources? Are there sources you would have difficulty accessing? Why?
- How have you included people (either your social network or people you don't know) in your planning for emergencies? How do you see the roles of technology and people interacting in an emergency?
- Have you ever been in an actual emergency situation? How did AT help? In what ways was AT not useful? In what ways were people helpful or not helpful?

Closing

Moderator: Thank the group for their participation.

Remind the group that this information will be handled in accordance with applicable privacy laws and individual names will not be used in any reports.

Moderator and Local Coordinator: Hand out expense reimbursement forms and assist participants in filling them out. Try to collect these before participants leave the meeting. Explain to participants and local coordinator that it may take up to two months for reimbursement checks to be received.

Verify that each participant has signed an Informed Consent form.

Local Coordinator: Make sure the Local Coordinator completes an expense reimbursement form.