Oregon Office on Disability and Health

# Community Action Guide Access to Health Care Version 3.0


Original Authors
Versions 1.0 and 2.0

Charles E. Drum
Marilyn Berardinelli
Patty Pickett-Cooper
Gloria Krahn
Willi Horner-Johnson
Brian Ritacco
Rania Wasfi

Revision Authors
Version 3.0:

Angela Weaver
Amy Sharer
Jessica London

Institute on Development and Disability
Oregon Health & Science University

Community Action Guide
Version 3.0
Community Engagement Initiative for Disability Access to Health Care

© Oregon Office on Disability and Health
Institute on Development and Disability
Oregon Health & Science University
707 SW Gaines Street
Portland, OR 97239

Copyright 2015 OHSU Institute on Development and Disability (IDD). ALL RIGHTS RESERVED. No part of this copyrighted work may be modified, reproduced, or used in any form or by any means -- graphic, electronic, or mechanical, including photocopying, recording, taping, web distribution or information storage and retrieval systems -- without the written permission of the IDD.

For permission to use material, submit a request to oodh@ohsu.edu.

This publication was supported by Grant/Cooperative Agreement Number U59/DD00094203 from the Centers for Disease Control and Prevention (CDC) Disability and Health Program. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of NIDRR or the CDC.

## Contents


About the Oregon Office on Disability and Health (OODH) ..... 1

Recommended Citation: ..... 2

Introduction ..... 3

Inside this Guide ..... 5

Benefits of CEI ..... 5

What is Community Engagement? ..... 6

Overview ..... 6

Principles of Community Engagement ..... 6

The Three Phases of the Community Engagement Initiative ..... 8

Phase 1: Town Hall Meetings ..... 9

Action Steps ..... 9

Suggested Strategies for Implementing a Successful Town Hall Meeting ..... 10

Phase 2: Community Infrastructure Meeting ..... 11

Action Steps ..... 12

Suggested Strategies for Implementing a Successful Community Infrastructure Meeting ..... 12

Phase 3: Community Resource Mobilization ..... 13

Suggested Strategies for Successful Resource Mobilization: ..... 14

Tools ..... 17

To Organize CEI ..... 17

Checklist of Practical Strategies for Implementation of CEI ..... 18

*Three Months Prior to Phases 1 and 2 of CEI* ..... 18

PHASE 1: Town Hall Meeting ..... 19

*Two Months Prior to the Town Hall Meeting* ..... 19

PHASE 2: Community Infrastructure Meeting ..... 20

FACILITATOR'S GUIDE: Implementation of Phase 1-The Town Hall Meeting ..... 21
General Suggestions to Ensure a Successful Town Hall Meeting: ..... 21
Suggestions for Guiding the Discussion: ..... 22
FACILITATOR'S GUIDE: Implementation of Phase 2- Community Infrastructure Meeting ..... 23
General Suggestions for a Successful Community Infrastructure Meeting: ..... 23
Suggestions for Guiding the Discussion: ..... 24
Use of the Slideshow Presentation ..... 26
ADA Tool to Measure Access ..... 37
The Accessibility Checklist for Medical Clinics and Facilities in Oregon ..... 37
Conclusion ..... 37

## Appendixes

Appendix A: Bibliography ..... 38
Appendix B: Planning Materials ..... 42
CEI Planning Checklist ..... 43
Appendix C: Town Hall Materials ..... 46
Demographics Survey ..... 47
Town Hall Meeting Flyer ..... 49
Meeting Sign In Sheet ..... 51
**Infrastructure Sample Agenda** ..... 52
Definitions for Town Hall Meeting (backside of agenda) ..... 53
Town Hall Facilitation Outline ..... 54
Satisfaction Survey ..... 59
Appendix D: Infrastructure Meeting Materials ..... 60

Infrastructure Invite Letter ..... 61
Infrastructure Meeting Flyer ..... 62
**Infrastructure Sample Agenda** ..... 63
Definition of Disability (backside of agenda) ..... 64
Infrastructure Facilitation Outline ..... 67
Satisfaction Survey ..... 72

# About the Oregon Office on Disability and Health (OODH)

The Oregon Office on Disability and Health (OODH) is one of the programs under the Oregon Institute on Disability & Development (IDD) that is housed at the Oregon Health & Science University (OHSU). The mission of the OODH is to improve the health and wellness of people living with disabilities through health promotion, training, data analysis, education, community engagement, dissemination of information, and policy development that address health disparities and secondary conditions.

The original version of the Community Action Guide[1] was developed with the assistance of the Oregon Office on Disability & Health's Community Living Work Group and the Oregon Disabilities Commission's (ODC) Local Concerns Task Force. The Local Concerns Task Force was established to develop strategies to increase accessibility for Oregonians with disabilities living in rural areas and to inform the ODC about rural concerns and issues through local Town Hall meetings.

The second edition, Community Action Guide 2.0, was a reiteration of the original guide with modifications and edits that primarily reflected lessons learned through implementation. In addition, a chapter was added, "An Alternative Approach to CEI", that details the process of providing mini-grants to communities for access projects.

The third edition, Community Action Guide 3.0, was created in response to the CDC's Disability and Health Branch's change in funding priorities, from a broad all-encompassing community access focus, to a more specific focus that only included "access to health care" and its three related subtopic areas: transportation, physical access, and providers' attitudes and communication. Beginning in 2012, OODH partnered with the NW ADA Center Region X on the implementation of the Community Engagement process and would like to acknowledge them for their invaluable contributions.

---

[1] Authors: Drum, C., Goff, T., Horner-Johnson, W., Pobutsky, A., Ritacco, B., Weaver, A

For more information or to request the Community Action Guide 3.0 in alternate format, please contact:

Oregon Office on Disability and Health
Institute on Development and Disability
Oregon Health & Science University
707 SW Gaines Street
Portland, OR 97239
Phone: 503-494-1205
oodh@ohsu.edu
http://www.oodh.org/

## Recommended Citation:

Weaver, A., Sharer, A., Mood, C. (2014). Community Action Guide: Access to Health Care, Version 3.0. Portland, OR: Oregon Office on Disability and Health, Institute on Development and Disability, Oregon Health & Science University.

# Introduction

> *"Knowledge which is unable to support action is not genuine."*
>
> *–Rudolph Virchow, 1879*

The concept of community has a wide range of meanings. Community may be defined as people living, working, and playing in a shared place. In addition, community could alternatively be described as a social unit of varying size whose members share common values, standards, and experiences.

In order to create programs to enhance health in a particular community, collaborators tap into the community's expertise and willingness to help facilitate action. The health of a community depends on all of their members and the members' ability to participate in, and be integrated into, the community. The ability for individuals to partake in their community, contributes to their individual physical, emotional, and spiritual well-being.

Participation in a community happens at many different levels. It happens when a family goes shopping or to the movies. It happens when a person who is sick goes to see his/her doctor. It happens when a student gets on the city bus to take a class at the community college. It happens when a worker heads off to the office in the morning and home again in the evening, and it happens when a group of concerned citizens attend a neighborhood meeting to voice their concerns.

Among people with disabilities, involvement in community life is often a very different, more difficult, experience. Due to various access issues, people with disabilities have fewer opportunities to be involved in their

communities. Even when they do participate, they report less satisfaction when compared to people without disabilities.[2]

People with disabilities often have less access in several key areas of community life. They may encounter barriers to a variety of public places, such as restaurants, stores, and movie theaters, as well as obstacles to transportation, employment, education, housing, recreation, and health care. This reduced access results in greater levels of social isolation and restricted community involvement.[3]

The Community Action Guide: Access to Health Care (Version 3.0) was developed by the Oregon Office on Disability and Health (OODH) and describes a process to include people with disabilities in community planning as it relates to accessing heath care. The process is called the "Community Engagement Initiative," or CEI. CEI engages representatives of the disability community and members of the community infrastructure to work together to improve access to health care for people with disabilities.

> ***Community Participation:*** *A process that involves community members as active representatives in both the decision-making and policy development processes of their society. Participation promotes action, which may lead to change (CDC, 1997).*

[2] Kinne, Patrick, & Doyle, 2004; US DHHS, 2001; NOD/Harris, 1994,2000.

[3] NOD/Harris, 2000, 2002, 2004; Diab & Johnston, 2004; Cardinal & Spaziani, 2003; Downs, Wile, Krahn & Turner, 2004.

## Inside this Guide

This guide was designed for use by a variety of groups interested in creating effective strategies for improving access to health care for people living with disabilities. The Community Action Guide outlines the principles underlying community engagement and strategies for successful engagement that can be employed by various groups, including grassroots organizations, advocates, community leaders, health care professionals, and representatives of state or local agencies. It's a practical, hands-on guide that includes step-by-step descriptions of the community engagement process, checklists for conducting successful events, tools for assessing the access of health care facilities/clinics, and examples of how the CEI process has been applied.

## Benefits of CEI

Bringing together people from the disability community and community leaders provides opportunities for new relationships and ongoing dialogue. New working relationships can lead to changes that benefit everybody. This action guide offers strategies for working together to strengthen that shared community.

> ***Community Engagement:*** *The process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations with respect to issues affecting their well-being (CDC, 1997).*

# What is Community Engagement?

## Overview

The community engagement process or CEI, described in this guide is a method to increase accessibility to health care for people living with disabilities. This guide provides strategies and tools to aid people in identifying their community's strengths and needs, as well as suggestions on addressing issues of local concern. CEI may also serve as a general model that can be adapted to address other social issues of community importance. Individuals from grassroots organizations and leaders in the community may use this model to provide a structure for collaborative work to promote change within their community.

## Principles of Community Engagement

The Centers for Disease Control and Prevention (CDC) define community engagement as the process of working with groups of people related by location, interest, or similar issues that affect their well-being. Community engagement is also called community development and the CDC has offered guiding principles to those involved in the community engagement process.

The CDC explains that before a community engagement effort begins, organizers should do the following:

- Define the purposes or goals of the engagement effort and the populations and/or communities to be engaged.
- Become knowledgeable about the community where the engagement will occur.

Learn about the community's economy, political structures, cultural influences, demographic trends, history, and experience with and perception of past engagement efforts.

The CDC identifies the important elements of a successful community engagement. Organizers should:

- Develop community support by building trust, establishing relationships, and gaining commitment to the engagement process.
- Respect the community's right and responsibility to identify both the issues and the strategies for addressing those issues.

The CDC outlines principles to guide a successful community engagement. They include the following:

- It is necessary to have a mutual and equal partnership with the community in order to create positive change.
- Community engagement is more effective in an environment of respect for diversity.
- Bringing together and using community assets and building capacity are important to sustaining effort.
- The individual or organization engaging the community must be flexible enough to meet the changing needs of the community and be prepared to give the community the power to determine the direction.
- Collaboration between the engaging organization and the community is a long-term commitment.
- Community engagement efforts should address multiple levels of the social environment, rather than only individual behaviors, to bring about desired changes.

Oregon Office on Disability and Health (OODH) incorporated these principles in developing the CEI process. They serve as a sound basis to meet the needs of diverse community members and to build healthier communities.

> ***Collaboration:*** *to cooperate or work together to remove the barriers to participation in the community.*

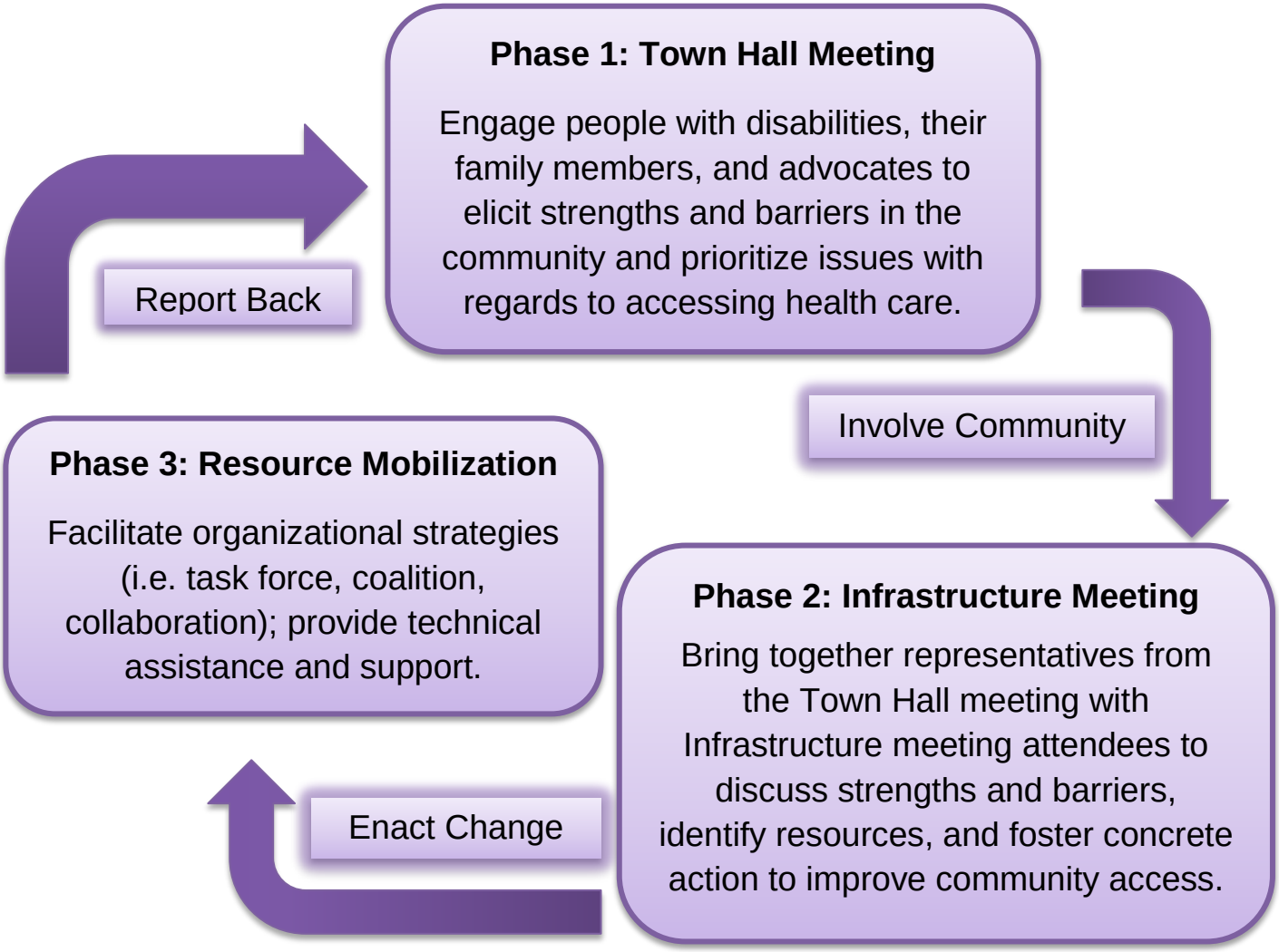
## The Three Phases of the Community Engagement Initiative

This guide's community engagement method consists of three phases and their supporting activities. The phases may take place within a community as separate activities or may be integrated with one another.

The three phases are:

1. A Town Hall Meeting
2. A Community Infrastructure Meeting
3. Community Resource Mobilization

Each of the phases is described in greater detail below:



## Phase 1: Town Hall Meetings

The first phase is conducting the Town Hall meeting. The purpose of the Town Hall meeting is not only to provide people with disabilities who are experiencing health care accessibility issues, but also their family members, advocates, disability service providers, and others who support them, with an opportunity to:

- Identify their community's strengths in accessing health care.
- Identify the physical and attitudinal access barriers to health care that exist within their community.
- Prioritize health care access issues to be addressed.

### Action Steps

The Town Hall meeting begins with a brief introduction of the purpose of the meeting and a review of the agenda.

Through a facilitated discussion, the participants first identify community strengths and resources, and then the community's needs and gaps in regards to three key areas of health care access:

- Provider Knowledge, Communication and Attitude
- Transportation
- Facility Access and Services

After identifying the health care access issues within these key areas, the participants then prioritize their top three issues within each topic area. Careful notes are taken throughout the process. Later, the nine prioritized issues are organized and presented for discussion during the second phase of CEI – the Community Infrastructure meeting.

To ensure a local perspective throughout the process, it is beneficial to identify 2 to 4 attendees of the Town Hall meeting to attend both the Community Infrastructure meeting and follow-up mobilization activities.

## Suggested Strategies for Implementing a Successful Town Hall Meeting

Organizing a Town Hall meeting involves a number of steps from identifying and recruiting participants to facilitating the discussion. The following list includes key elements involved in planning a Town Hall meeting:

- Carefully plan outreach efforts. Identify agencies and organizations that serve community members with disabilities. These may include centers for independent living (CILs), senior centers, parent groups, residential service providers, vocational providers, veterans' programs, and assisted living facilities.
- Recruit participants by disseminating meeting notices or flyers to disability service organizations for posting, newsletters, or listservs; contact local media (radio and/or television); and/or post flyers in locations frequented by persons with disabilities.
- Reimbursing participants for transportation costs may aid recruitment.
- Scheduling one Town Hall meeting on Friday and one on Saturday bridges the gap between those who can attend as part of their jobs and those who can only attend when they are not working. Results from each meeting can be combined.
- Schedule meetings for 3.5 to 4 hours. Try to balance sufficient time for discussion while avoiding fatigue among participants.
- Provide refreshments along with lunch if you have the meeting over the lunch hour.
- Choose meeting locations for physical accessibility, central location, and proximity to public transportation.
- Choose facilitators who are knowledgeable of and comfortable discussing health care access issues for people with disabilities. Facilitators should be familiar with the community engagement model and have an understanding of classifying access issues as structural, attitudinal or policy barriers in an effort to help participants understand the complexity of certain obstacles. An attitudinal barrier may be more difficult to address than a structural barrier, such as lack of a curb ramp from the parking lot to the sidewalk.

- Ask questions to determine specifics of community assets and barriers, such as location, frequency, etc. Maps may be useful for plotting assets and barriers.
- Always start with identifying community assets.
- Ask probing questions to determine if the community has current or previously planned activities to address local health care barriers.
- Facilitators who have knowledge about available resources may help to build the capacity of the participants to address barriers.
- Prioritize the issues. What is most important to the community? What should be addressed first?
- Identify participants who can provide local perspective to serve as representatives in the Infrastructure meeting.

## Phase 2: Community Infrastructure Meeting

The purpose of the Community Infrastructure meeting is to increase participants' awareness of health care access barriers encountered by people with disabilities. It is also an opportunity for community leaders to confirm the issues and/or to provide a more detailed perspective. By developing a shared understanding of the barriers and discussing ways to improve them, the Community Infrastructure attendees are better able to address them.

The Community Infrastructure meeting is made up of elected officials, business leaders, service providers, city planners, health care representatives and providers, and others, including invited members from the Town Hall meeting.

The three objectives of this meeting are:

1. Describe and discuss the barriers identified during the Town Hall meeting.
2. Identify possible resources to improve access to health care for people living with disabilities.
3. Promote action on identified barriers.

## Action Steps

Recruit community leaders from private and public transportation, hospitals and other health care facilities or clinic representatives, coordinated care organization (CCO) representatives, city planners, disability service providers, and representatives from the educational institutions (high schools, colleges, etc.). Invite representatives from the Town Hall meeting to share local perspective on the community's strengths and barriers. The meeting should follow a standard format with sign-in, introductions, a brief description of the Community Engagement Initiative, review of the agenda, and a slideshow presentation.

The slideshow presentation serves to frame the discussion. It includes a disability community profile and the strengths and barriers identified at the Town Hall meeting. An example of a slideshow presentation is available in Appendix D. During the meeting, the discussion is guided toward identifying possible community resources available to resolve the issues prioritized during the Town Hall meeting. At the end of the meeting, participants are asked to form workgroups to address the issues. Workgroups may join existing networks, if available, or create new alliances, task forces, coalitions, or action committees.

The results of the Community Infrastructure meeting are summarized and sent to all attendees of the Community Infrastructure and Town Hall meetings. The summary should include the following for each identified barrier:

1. Agreement that the barrier exists.
2. Refinement or modification of the barrier, if needed.
3. Identification of community members and resources to resolve the issue or an agreement to resolve/solve the issue.
4. Provide contact information of all the members of each workgroups or task forces and an initial plan outlining next steps.

## Suggested Strategies for Implementing a Successful Community Infrastructure Meeting

The following list includes suggestions for planning a Community Infrastructure meeting:

- Conduct the meeting two to three weeks following the Town Hall meeting, if possible. Otherwise, conducting the Community Infrastructure meeting within one to three days after the Town Hall meeting has worked out as well.
- A weekday meeting, which includes a catered working lunch, has proven successful.
- Allocate 3 to 4 hours for the meeting.
- Extend personal invitations to governmental and service change agent representatives and decision makers including mayors, city planners, transportation providers, health care representatives and disability service providers. Offering to prominently display attendees' sponsorship on flyers and other meeting materials may increase participation.
- Use governmental and service directories and websites to obtain contact information.
- Incorporating current data on the disability prevalence, health status, and health disparities including access to health care into the slideshow presentation helps build content. (See Appendix D.)
- Incorporating photographs and maps into the presentation lends a sense of reality to the issues.
- Physical access barriers are easier to represent visually in the presentation than policy and attitudinal barriers.
- For some Community Infrastructure members, the meeting is their first exposure to disability and related health care access issues. Thus the PowerPoint and personal stories from community members may help set the context for the issues.

The Community Infrastructure meeting serves as a natural process for confirming, refuting, or reframing issues and concerns. For example, it was common for one or more barriers, which were at first thought to be physical barriers to be reframed as a lack of communication about the available resource.

## Phase 3: Community Resource Mobilization

The purpose of the community resource mobilization process is to bring together networks of community members to:

1. Develop solutions to address the identified barriers.
2. Take action to remove or change those barriers.

Providing technical assistance and support to the emerging groups is important to sustaining the effort.

## Suggested Strategies for Successful Resource Mobilization:

We provide these suggestions to mobilize community resources.

- Get commitments on the spot!
- Create a reasonable time frame to complete the overall goal.
- Identify existing resources and help community members connect with them.
- Break the goals into manageable parts.
- Identify a specific person responsible for each part. This helps sustain momentum.
- Determine where jurisdiction falls for each issue. For example, if there are physical access issues for people with disabilities accessing health care, understanding who has jurisdiction over funding (e.g. the city, county, or state) will allow the appropriate agency to be involved.
- Establish new groups or committees within existing organizations to accomplish goals.
- Designate volunteer field coordinators, including representatives of both the Town Hall and Infrastructure meetings, to help sustain momentum and encourage ongoing dialogue.
- Establish new grassroots organizations to accomplish goals.
- Provide regular follow up with the key disability organization to support their oversight and coordination efforts.

Sharing information with the community contributes to a sense of individual

empowerment and community competency, so identifying ways to keep community members informed throughout the process is valuable.

*The strategies suggested here provide the basis for implementing the CEI process smoothly. Some may find that modifications are helpful, depending upon the particular community. With sufficient planning throughout each phase, organizers will find that the CEI method allows communities to plan for real action and change.*

# Tools

There are many tools available via the Internet for use in the community engagement process.

The Oregon Office on Disability and Health has found the following tools to be helpful and beneficial when implementing the CEI process.

The tools (found below) include the following:

- Checklist of Practical Strategies for Implementation of the Community Engagement Initiative (covers the Town Hall meeting and Community Infrastructure meeting)
- Facilitators' Guide for the Town Hall meeting
- Facilitators' Guide for the Community Infrastructure meeting
- Organizational Strategies
- Use of the Slide Presentation
- ADA Tool to Measure Access

## To Organize CEI

The Checklist of Practical Strategies is a handy tool planners may use to organize the phases of the Community Engagement Initiative (CEI). It is organized in chronological order to provide a framework of the tasks leading up to each meeting.

The Facilitators' Guide for the Town Hall meeting and the Facilitators' Guide for the Community Infrastructure meeting include general suggestions for ensuring successful meetings and suggestions for guiding the discussions.

Each of the tools is described in greater detail in this section.

## Checklist of Practical Strategies for Implementation of CEI

This checklist is designed to assist with each phase when planning a community engagement event.

### ***Three Months*** *Prior to Phases 1 and 2 of CEI*

- ☐ Identify and contact the primary disability organization that will serve as your liaison between your organization and the targeted community's disability community. The organization maybe a Center for Independent Living, Arc, or other disability advocacy organization. Depending on your organization's budget, you may want to contract with the agency and pay them for their staff's time and effort.
- ☐ Set date and time for each event.
- ☐ Select and reserve accessible meeting sites close to public transportations; set up contract, if necessary.
- ☐ Recruit facilitators for both meetings.
- ☐ Identify catering services and obtain price quotes.
- ☐ Identify potential sign language interpreters, real time captioning (RTC) services, Braille services, and providers of assisted listening devices.
- ☐ With the help of the primary disability organization, begin to create two invite lists: one for Town Hall meeting attendees, and one for Infrastructure meeting attendees.

  **Town Hall attendees may include:**
  - o Local and county government disability service providers
  - o Disability family advocacy organizations
  - o Centers for Independent Living
  - o Special Olympics and other recreational services such as local parks and recreation

  **Infrastructure meeting attendees may include:**
  - o Public and private transportation
  - o Hospital administration
  - o Local health care providers
  - o Local, county and state disability service providers
  - o Veterans' Services

## PHASE 1: Town Hall Meeting

### *Two Months Prior to the Town Hall Meeting*

- ☐ Post flyers announcing event and identifying procedures to RSVP and to request accommodations, if needed (e.g. alternate formats)
- ☐ Publicize meeting through local media and local disability organization listservs
- ☐ Meet with facilitators (orientation)
- ☐ Gather relevant disability data and other information

### *One Month Prior to the Town Hall Meeting*

- ☐ Arrange for note takers
- ☐ Prepare any maps and visuals that will be used
- ☐ Order food for event
- ☐ Arrange services for sign language interpreters and real time captioners, if needed
- ☐ Place orders for Braille or assisted listening devices, if needed
- ☐ Provide for other accommodations, if needed
- ☐ Develop the agenda
- ☐ Gather (purchase if necessary) two flip charts, two easels, and markers

### *One Week Prior to the Town Hall Meeting*

- ☐ Call participants as a reminder (if applicable)
- ☐ Prepare registration table materials, agenda, and flashcards (labeled 1-2-3) for ranking barriers
- ☐ Meet with facilitators to prepare for meeting
- ☐ Confirm catering and provide final number of attendees

### *Meeting Day*

- ☐ Set up registration table with sign-in sheet, pens, and nametags
- ☐ Laptop computer, or tablets and pens, for note takers (1 or 2)
- ☐ Arrange room for meeting and lunch
- ☐ Place signs to direct participants to meeting room
- ☐ Set up flip charts and easels

## PHASE 2: Community Infrastructure Meeting

### *Two Months Prior to the Community Infrastructure Meeting*

- ☐ Create an invite letter, both email and hardcopy versions, and include key partners' logo and/or signatures
- ☐ Create one page flyer with key meeting details to include with the letter
- ☐ Create meeting agenda to include with letter
- ☐ Utilizing listservs, email and personal phone calls, invite representatives from local and county government, service providers, public and private transportation, hospital administration, local health care providers, and service organizations (see previous list above)
- ☐ Call invitees who do not RSVP

### *One Month Prior to the Community Infrastructure Meeting*

- ☐ Begin to summarize information from Town Hall meeting and create template for slideshow presentation
- ☐ Take photos of areas of need identified in the Town Hall meeting for slideshow presentation

### *One Week Prior to the Community Infrastructure Meeting*

- ☐ Confirm attendance with phone calls or emails
- ☐ Order lunch for meeting
- ☐ Arrange for note takers
- ☐ Meet with facilitators to prepare for meeting
- ☐ Meet with facilitators to review and finalize slideshow presentation
- ☐ Finalize accommodations

### *Meeting Day*

- ☐ Set up registration table with sign-in sheet, pens, nametags
- ☐ Laptop computer, or tablets and pens, for note takers (2)
- ☐ Arrange room for meeting and lunch
- ☐ Place signs to direct participants to meeting room
- ☐ Set up two flip charts and two easels

## FACILITATOR'S GUIDE: Implementation of Phase 1-The Town Hall Meeting

## General Suggestions to Ensure a Successful Town Hall Meeting:

- Before the event, participate in development of the agenda and questions needed to guide the discussion. Use the opportunity to determine ground rules, questions to be used to identify very specific barriers, and how the attendees will prioritize the barriers (e.g. simple majority vs. using stickers or flashcards numbered 1-2-3 to identify barriers important to each individual).
- During the event, encourage and maintain a supportive environment for participation by community members who may not be used to speaking in public settings. Look around the room and leave enough time for people who may be hesitant to speak up before moving on. Use reflective listening to help draw people out and to clarify the point they are trying to make if it seems unclear.
- Observe the representation or over-representation of people with particular types of disabilities. Encourage participation from all attendees to ensure a broad representation from all disability groups.
- Keep the discussion focused on local issues. Be prepared for people to bring up broader state and federal issues, and try to localize these to a level where the project can have more of an impact. For example, Medicaid reform is often discussed as a problem for people with disabilities. The facilitators could shift this discussion to inquiries about willingness of local physicians to accept Medicaid/reimbursement rate.
- If the discussion gets off topic, redirect to the topic at hand, or ask the person to hold onto that idea if it pertains to a later portion of the agenda. It may be useful to use the "parking lot" strategy- display a piece of paper on the board with the words "parking lot" written on the top; write down the subjects that are off topic that may be discussed with any remaining time or following the meeting.
- Be mindful of the time constraints and politely remind people of the need to move on when people get into too much detail, without diminishing

the validity of the person's contribution. You might say, "You seem to be really interested in [particular issue being discussed]. Would you be willing to stick around a few minutes after the meeting to discuss this further? Let's get some other input on [current issue] now."

## Suggestions for Guiding the Discussion:

- Introduce the facilitators, participants, and purpose of the meeting.
- Communicate logistics including location of the restrooms, scheduled breaks, lunch or refreshments, or other pertinent information.
- Introduce the ground rules for the discussion.
- Frame the discussion. Talk about what participants at other Town Hall meetings have identified, and share statistics. Post and describe the three key areas of improving access to health care, e.g. transportation, facility access, and attitudes and communication.
- Guide the discussion to identify the best things about the community.
- A substantive list of positives from the community may be the tone for a positive and constructive meeting. Here are examples of questions that may be used to get information about the community in relation to health care access.
    - What do you like about your community?
    - What works in your community?
    - What are the best things about accessing health care in your community?
- Guide the discussion to identify specific barriers in each of the three access domains. See facilitation guide:
    - Do you have any difficulties getting into and around your doctor's office or other health care facilities?
    - Do you have any difficulties with accessibility of examination tables or other health care equipment?
    - Have you had any problems with policies and/or communicating with your health care provider?
    - Have you found that the level of accessibility varies in different types of health care services you access: routine, chronic, or emergency care?
- Guide the prioritization of the barriers.

- Community engagement is most effective when facilitators are able to shift the focus from state or national concerns to issues of local concern.
- There may be over-representation of one or more type of disability that appears to experience a large number of barriers to health care. Facilitators who encourage participation from people experiencing less-represented disabilities may obtain valuable information about a community's strengths and barriers.
- Facilitators who encourage participation by community members not used to speaking in public settings increase the effectiveness of the community engagement effort.
- Facilitators who can promote a sense of empowerment are effective in engaging participants.
- Summarize the meeting: "This is what you told us." Identify solutions to the barriers. Here are some examples:
    - What ideas do you have for ways to work with health care providers?
    - What responsibility does the patient have?
    - What responsibility does the provider have?
- Share closing remarks, including next steps, announcements, or other opportunities to share information or get involved.

## FACILITATOR'S GUIDE: Implementation of Phase 2-Community Infrastructure Meeting

### General Suggestions for a Successful Community Infrastructure Meeting:

Framing the discussion around a slide presentation, which has been prepared ahead of time, provides structure to the meeting. For more information about the content of the slide presentation, see slide presentation tool in Appendix D.

## Suggestions for Guiding the Discussion:

- Introduce facilitators, participants, representatives of the Town Hall meeting, purpose of meeting, and hopes for accomplishments.
- Communicate logistics including location of restrooms, scheduled breaks, availability of refreshments, and other pertinent information.
- Present demographic information.
- Present the best aspects of health care accessibility in the community as identified by the participants of the Town Hall meeting.
- Present identified barriers in each of the three topic areas.
- Provide opportunity for the community infrastructure to provide more information on the existence of barriers.
- Ask probing questions to get more information about perceived barriers. Examples include:
    - Are you currently addressing the identified barrier? Are there resources already in place? If yes, who is the contact?
    - Are there plans to address the barrier? Has it been budgeted?
    - If there are no plans to address the barrier, why not?
    - Are there opportunities to form or join work groups or committees?
    - Where does a citizen bring concerns regarding this issue? How does a citizen get involved in the process of change?
- Summarize the meeting.
- Discuss next steps.

## Use of the Slideshow Presentation

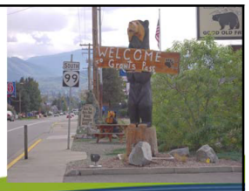
A slideshow presentation is a valuable tool for use during the Community Infrastructure meeting. It can provide context on community issues and presents the information synthesized from the Town Hall meeting in a concise and organized manner. It also serves to focus the discussion around identified strengths and barriers in a specific community.

The presentation may also be helpful in presenting a snapshot of the community members with disabilities including the prevalence of disability, education and employment rates, as well as information on relevant health status.

Including direct quotes from Town Hall attendees, which capture the core of both the strengths and barriers is very powerful strategy and may be added as bullet points under each of the key topic areas.

Find a sample slide show presentation in Appendix D.

> *The slide presentation should capture the core of a community's strengths and barriers.*




# Community Infrastructure Meeting
# Grants Pass
# Health Care Access
# for People with Disabilities

## Welcome and Introductions

- HASL, Center for Independent Living
- NW ADA Center
- Oregon Office on Disability and Health, OHSU
- AllCare
- Primary Health of Josephine County

2

## Meeting Objectives

- Increase Knowledge of Disability Prevalence and Health Status
- Review Results from Grants Pass Town Hall Meeting on Health Care Access
- Identify Ways to Increase Health Care Access
- Create Partnerships with the Disability Community

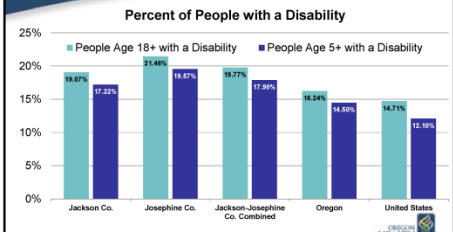
3

## Meeting Materials

- Meeting Agenda
- Definitions of Disability
- Disability Demographics
- Workbook
- Satisfaction Survey

4

## Disability Demographics: Grants Pass & Beyond




Source: 2011 American Community Survey 1-year Estimates, www.census.gov

5

## Local Demographics

**Snapshot of Jackson County, Oregon**

| | |
|---|---|
| **Total population 5+ yrs old** | **Median Age** |
| 192,383 | 41.6 |
| **People 5+ yrs. old w/ Disability** | **Percent 5+ yrs old w/ Disability** |
| 33,121 | 17.22% |

Source: 2011 American Community Survey 1-year Estimates www.census.gov

6

## Local Demographics

**Snapshot of Josephine County, Oregon**

**Total population 5+ yrs old**
77,891

**Median Age**
47.2

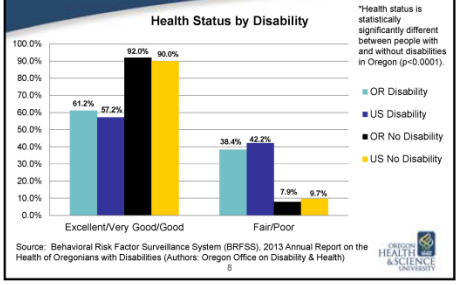
**People 5+ yrs. old w/ Disability**
15,245

**Percent 5+ yrs old w/ Disability**
19.57%

Source: 2011 American Community Survey 1-year Estimates www.census.gov

7

## Self-Reported Health Status




Source: Behavioral Risk Factor Surveillance System (BRFSS), 2013 Annual Report on the Health of Oregonians with Disabilities (Authors: Oregon Office on Disability & Health)

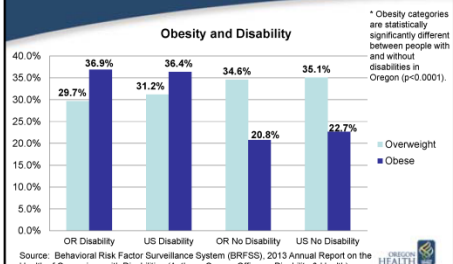
8

## Primary Health Risk Factors

- Obesity
- Smoking
- Anxiety & Depression
- Cardiovascular Events

9

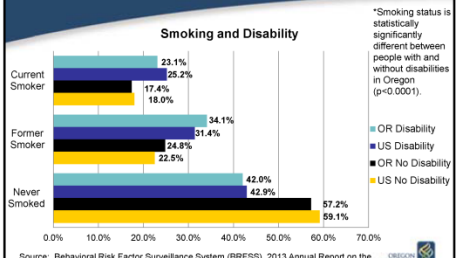
## Obesity




Source: Behavioral Risk Factor Surveillance System (BRFSS), 2013 Annual Report on the Health of Oregonians with Disabilities (Authors: Oregon Office on Disability & Health)

10

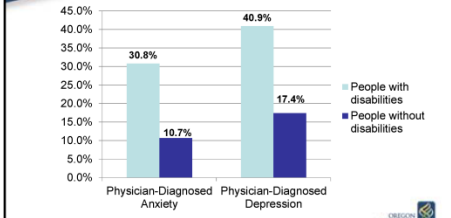
## Smoking




Source: Behavioral Risk Factor Surveillance System (BRFSS), 2013 Annual Report on the Health of Oregonians with Disabilities (Authors: Oregon Office on Disability & Health)

11

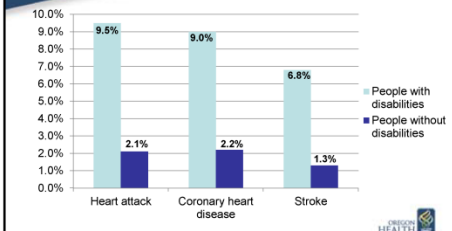
## Anxiety and Depression




Source: 2011 Oregon BRFSS

12

## Cardiovascular Events




Source: 2011 Oregon BRFSS

13

## But….

- This doesn't mean that people with disability should be considered sick or ill
- People with disabilities can be healthy
- Disability itself is not necessarily the cause of health disparities but environmental and social factors.

14

## Improving Access to Health Care

Community Engagement Initiative

Step 1. Town Hall Meetings
Step 2. Infrastructure Meetings
Step 3. Mobilization
Step 4. Follow Up

15

OREGON HEALTH & SCIENCE UNIVERSITY

**What happened at the Town Hall meeting yesterday?**

## Grants Pass Town Hall Meeting

- Held yesterday - Thursday
- Approximately 12 attendees
- Included people with cognitive, sensory, mental and mobility impairments, parents/personal care attendants, and service providers
- Not intended to be a representative sample

17

## Grants Pass Town Hall Meeting (cont.)

Facilitated Process with Active Participation:

- Focus on local issues
- Identified Best Things in Health Care in Grants Pass
- Identified Barriers
- Prioritized Barriers
- Discussed Potential Solutions

18

## Best Health Care Practices

- Dentist offices that work with Voc Rehab clients work well with the clients and ensuring they have a positive experience.
- Josephine Community Transit listens to their customers and makes improvements.

19

## Best Health Care Practices

- ER staff at the Three Rivers Hospital are overall very respectful and take the time to get to know their patients.

"Once the people at the hospital knew me they didn't try and put me in a wheelchair. I have worked really hard to get out of a wheelchair."

20

## Best Health Care Practices

- Most service counters in both clinics and hospitals were accommodating for people who use wheelchairs, etc.
- Some PT and OT providers meet the individual needs of their clients, and they are well respected. One PT has an adjustable table. (easy transfers)

21

## Best Health Care Practices

- Good detailed explanations from pharmacy staff and some providers.

*"The doctors explained everything to me and didn't use a lot of medical language that I couldn't understand."*

22

## Best Health Care Practices

- Medical durable equipment
  - HASL has a DME loan program
    - Fills the gap between the time it is prescribed and received
    - Recently donated 15 power chairs to the community (fund raiser with local businesses)

23

## Barriers to Accessing Health Care

1. Transportation
2. Facility access and services/ policies
3. Provider attitudes, communication and disability knowledge

24

## Prioritized Barriers to Transportation

- Grants Pass Transit
  - Communication with riders/customers
  - Limited hours and days
- Bus stops
- Crosswalks and curb cuts

25

## Prioritized Barriers to Transportation

**Communication between bus drivers and disability community:**

- People first language – basic respect

One bus driver has repeated said, *"Why do I have to always help you just because you are retarded."*

26

## Prioritized Barriers to Transportation

**Bus stops**

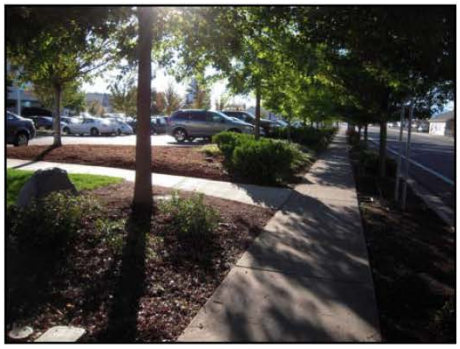
- Not convenient to medical site (Siskiyou and Three Rivers Hospital)
- Not all shelters are not wheelchair friendly

27

## Prioritized Barriers to Transportation

- *"When I get off the bus [at Three Rivers Hospital] there are no signs to show me how to get to the entrance (of the hospital). There's just no signs."*

32



## Prioritized Barriers to Transportation

**Cross Walks and Curb Cuts**

- Bus stop on opposite side of the street from the clinic and there is no cross walk.
- On some side walk routes there are not curb cuts.

34

## Prioritized Barriers to Transportation

**Cross Walks**

- The timing of the traffic lights does not give enough time to cross the street.
- For someone who is blind there are no audio cues that indicate it is ok to cross.

36

## Town Hall Solutions

- Disability and Etiquette Training for drivers.
- Develop partnerships within the community to identify transportation needs. "Listen to the community."
- Consider prioritizing sidewalk routes from bus stops to health care facilities/clinics.

37

## Transportation Solutions

38

## Prioritized Barriers in Facility Access & Services

**Exams rooms**:

- Exam tables too high, difficult to transfer
- Lack of accessible scales

*"I haven't been weighted in like two year because I can't get on the scale. There's nothing to hold on to."*

39

## Prioritized Barriers in Facility Access & Services

**Waiting areas:**

- Path of travel is obstructed and it is too crowded… no consideration for a person who uses wheelchair.

**General information:**

- Asking for help, directions, bus info.

40

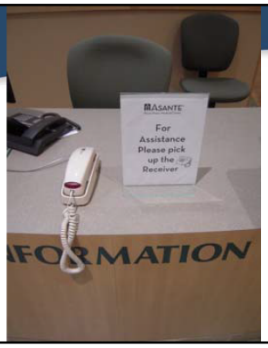
## Prioritized Barriers in Facility Access & Services

**General Information and Accessibility:**

- Asking for help, directions, bus info.

*"Sometimes they (doctors' offices) don't know where the closest bus stop and they can't give me instructions on how to get to there."*

41



## Prioritized Barriers in Facility Access & Services

**Physical access:**

- Pharmacy and other building difficult to get into:
  - No ramps
  - Heavy doors
  - Narrow doorways

43

## Prioritized Barriers in Facility Access & Services

**Parking Areas:**

- Accessible parking at Three Rivers Hospital is not completely correct.
- Not enough spaces (always full)
- Incline grade too steep

47

## Town Hall Solutions

- Designated accessible exam rooms that have the adjustable tables
- Accessible scales
- Additional disabled parking spaces to meet demand not just ADA requirement

50

## Solutions: Facility Access & Services

51

## Prioritized Barriers to Communication & Attitudes

**Disability awareness and responsibility:**

- Providing necessary accommodations
  - American Sign Language Interpreters
  - Lack of understanding of rights and obligations

52

## Prioritized Barriers to Communication & Attitudes

**Disability awareness and responsibility:**

- Providing necessary accommodations
  - Health promotion materials and forms in accessible formats, i.e., large print

*"I have low vision and I can't read handouts. Why don't they have large print ones? They just say, our office can't do that."*

53

## Prioritized Barriers to Communication & Attitudes

**Disability awareness and responsibility:**

- Respectful communication:
  - Private clinics and hospital volunteers

*"I can't see over the counter and the staff won't come around and talk me. I have to yell or write on a piece of paper."*

54

## Town Hall Solutions

- Disability awareness training for medical and front end staff
- Educational materials (1 page fact sheets: Effectively serving patients with disabilities
- Accessibility surveys to highlight barriers

55

## Solutions: Barriers to Communication & Attitudes

56

OREGON HEALTH & SCIENCE UNIVERSITY

**Review of who is working on which issue(s)**

## Next Steps

- HASL will maintain monthly contact with infrastructure key leaders and work groups
- NW ADA Center will provide technical assistance and requested supports

58

## For further information or technical assistance

Contact:

NW ADA Center
1-800-949-4232
www.nwadacenter.org

HASL
Randy Samuelson
541-479-4275
www.haslonline.org
randy_hasl@yahoo.com

59

## Questions?

Thank You for Attending!!

60

## ADA Tool to Measure Access

### The Accessibility Checklist for Medical Clinics and Facilities in Oregon

The checklist was developed by the NW ADA Center at the University of Washington. The tool is designed to be convenient and user-friendly tool for identifying architectural and communication barriers that may be encountered by people with disabilities in public and private buildings. The checklist was created using the 2010 ADA Standards for Accessible Design: Oregon State Building Code and allows one to access the path of travel from the parking lot, through the building, to the exam room.

**The checklist is *not* a substitute for federal accessibility standards or the appropriate state and local building codes.**

# Conclusion

The purpose of the Community Action Guide is to share information that can help communities use a community engagement process themselves. The goal is to provide a blueprint for communities to empower themselves for change.

We have found this guide to be an effective tool for facilitating networking and encouraging action around health care access issues in Oregon. Some of the outcomes of the community engagement process to date include:

1. Expanded public transportation routes into more rural areas to ensure access to medical appointment for those living outside the original bus routes.
2. Development of hospital staff trainings on appropriate disability communication and etiquette, and accessibility issues to be incorporated into their new employee orientation.
3. Restriping of hospital parking lots to include appropriate number of van accessible parking spots.

These are simply a few examples of ways in which communities have responded to the needs raised in Town Hall meetings and applied the resources identified through Community Infrastructure meetings.

Oregon communities have a long-standing tradition of responding to issues and allocating resources on a local basis. Historically, these processes have sometimes overlooked the needs of citizens living with disabilities. The overall goals of the community engagement process described in the Community Action Guide are to increase awareness in communities about disability issues and facilitate local action that increases the accessibility of health care for people living with disabilities.

We believe communities must work locally to meet the needs of all citizens. The difficulty in realizing that vision increases the challenge; it should not cause us to close our eyes to where we need to go.

## Appendix A:

Adaptive Environments (1995). Checklist for Existing Facilities, Version 2.1. Checklist for readily achievable barrier removal. Retrieved 27 December 2005 from http://www.adaptenv.org/publications/checklist-pdf.pdf

Bracht, N. and Gleason, J. (1990). Strategies and structures for citizen partnerships. In Neil Bracht (Ed.), Health promotion at the level. Sage Sourcebooks for the human services series, Vol. 15. (pp. 109 -124). Newbury Park, CA: Sage Publications.

Bricout, J. C. & Gray, D. B. (2006). Community receptivity: The ecology of disabled persons' participation in the physical, political and social environments. Scandinavian Journal of Disability Research, 8(1), 1-21.

Burroughs, C. & Wood, F. (2000). Measuring the difference: Guide to planning and evaluating health information outreach. University of Washington: National Network of Libraries of Medicine, Pacific Northwest Region.

Cardinal, B.J. & Spaziani, M.D. (2003). ADA compliance and the accessibility of physical activity facilities in western Oregon. American Journal of Health Promotion, 17, 197-201.

Center on Community Accessibility at Oregon Health & Science University. (2007). Center on Community Accessibility [entire website]. Retrieved from http://cdrc.ohsu.edu/oodh/index.html

Centers for Disease Control and Prevention. (2004). Community engagement: Definitions and organizing concepts from the literature. Retrieved 17 February 2006, from http://www.phppo.cdc.gov/dphsdr/FaithBase/PCE/part1.asp

Centers for Disease Control and Prevention/Agency for Toxic Substances and Disease Registry, Committee on Community Engagement. (1997). Principles of Community Engagement. Atlanta, GA: Centers for Disease Control and Prevention.

The Community Access Monitor Program of the Massachusetts Office on Disability. Retrieved 27 February 2005 from http://www.mass.gov/mod/camprogram.html

Committee for Community Engagement, U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 1998.

Community in participation in DAIS. http://www.dais.sa.gov.au/webdata/resources/files/CommunityParticipation.doc Retrieved 21 July 2006.

Diab, M.E. & Johnston, M.V. (2004). Relationships between level of disability and receipt of preventive health services. Archive of Physical Medicine and Rehabilitation Disabilities. Washington, DC: Louis Harris and Associates.

Diab, M.E. & Johnston, M.V. (2004). Relationships between level of disability and receipt of preventive health services. Archive of Physical Medicine and Rehabilitation. 85(5), 749-57.

Drum, C.E., Berardinelli, M., & Davis, C.E. (2007). Outpatient Health Care Usability Profile. Portland, OR: RRTC on Health and Wellness, Oregon Health & Science University.

Drum, C.E., Goff, T., Horner-Johnson, W., Pobutsky, A., Ritacco, B., & Weaver, A. (2002). Community Action Guide: A Process for Improved Community Accessibility. Portland, OR: Center on Community Accessibility, Oregon Institute on Disability and Development, Oregon Health & Science University.

Drum, C., Krahn, G., Horner-Johnson, W., Ritacco, B., Berardinelli, M., Wasfi, R., & Pickett-Cooper, P. (2007). The Oregon Community Engagement Initiative: Case studies of a coalition development process. Oregon Health & Science University. Manuscript submitted for publication.

The Institute for Community Research. Community Research Organization. Retrieved 28 February 2005 from http://www.incommunityresearch.org/research/research.htm

Luke, D. (2005). Getting the big picture in community science: Methods that capture context. American Journal of Community Psychology, 35(3/4), 85-200.

National Organization on Disability. (2000). 2000 NOD/Harris Survey of Community Participation. New York, NY: National Organization on Disability and Harris Interactive, Inc.

National Organization on Disability. (2002). N.O.D. Harris Survey of Americans with Disabilities. New York, NY: National Organization on Disability & Harris Interactive, Inc.

NC: University of North Carolina at Chapel Hill. Retrieved 27 December 2005 from http://www.fpg.unc.edu/%7Encodh/pubs.htm.

Nod/Harris. (2004). Detailed Results from the 2004 N.O.D./Harris Survey of Americans with Disabilities. New York, NY: National Organization on Disability & Harris Interactive, Inc.

North Carolina Office on Disability and Health. Removing Barriers to Healthcare: A Guide for Professionals. Chapel Hill, NC: University of North Carolina at Chapel Hill. Retrieved 27 December 2005 from http://www.fpg.unc.edu/%7Encodh/pubs.htm.

North Carolina Office on Disability and Health (2005). Removing Barriers: Planning meetings that are accessible to all participants. Chapel Hill, NC: University of North Carolina at Chapel Hill. Retrieved 27 December 2005 from http://www.fpg.unc.edu/%7Encodh/pubs.htm.

North Carolina Office on Disability and Health (2001). Removing Barriers to Health Clubs and Fitness Facilities: A Guide for Accommodating All Members, Including People with Disabilities and Older Adults. Chapel Hill,

North Carolina Office on Disability and Health (2002). Removing Barriers: Tips and Strategies to Promote Accessible Communication. Chapel Hill, NC: University of North Carolina at Chapel Hill. Retrieved 27 December 2005 from http://www.fpg.unc.edu/%7Encodh/pubs.htm.

The Northwest ADA & IT Center, one of 10 regional Disability and Business Technical Assistance Centers funded by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education. Retrieved 12-27-05. NW ADA Center & IT Phone: 1-800-949-4232 (V/TTY ) http://www.nwada.org/

Rappaport, J. (1981). In praise of paradox: A social policy of empowerment over prevention. American Journal of Community Psychology, 9(1), 1-25.

Stark, S., Hollingsworth, H.H., Morgan, K.A., & Gray, D.B. (2007). Development of a measure of receptivity of the physical environment. Disability & Rehabilitation, 29(2), 123-37.

Suarez, Y., Balcazar, R., and Keys, C. (1999). A Self-Help Guide Community Needs Assessment and Action Planning. Institute on Disability and Human Development, University of Illinois at Chicago.

U.S. Department of Health and Human Services. (2001). Healthy People 2010. Washington, DC: United States Government Printing Office.

U.S. Geological Survey, Geographic Information Systems http://erg.usgs.gov/isb/pubs/gis_poster/

University of Washington School of Public Health. (2005). Center for Community Based Research. Retrieved 29 February 2005 from http://sphcm.washington.edu/research/community.asp.

What is community participation? http://www.swsahs.nsw.gov.au/areaser/CommunityRep/participation.asp Retrieved 7-21-06.

The Work Group on Health Promotion and Community Development at the University of Kansas. (2007). Community Tool Box [electronic database]. Lawrence, Kansas: University of Kansas. Retrieved from http://ctb.ku.edu/about/en/

World Health Organization. Social mobilization, advocacy and community participation. Retrieved 21 July 2006 from http://www.who.int/docstore/hiv/Core/Chapter_6.html

## Appendix B: Planning Materials

CEI Planning Checklist.....43

## Planning Checklist

Community Engagement [Your town here]: [Date of event here]

[Month(s)] [Year]

| Activity | Meeting Type | Date to be completed | Person responsible | Notes |
|---|---|---|---|---|
| **Set a date & time for each event** | "Town Hall or Infrastructure" | | | |
| **Identify & reserve accessible location for meetings** | | | | |
| **Identify partners** | | | | |
| **Meet with facilitators** | | | | |
| **Gather background information from community** | | | | |
| **Identify Disability Agencies / Organizations (spreadsheets)** | | | | |
| **Identify Infrastructure Attendees (spreadsheets)** | | | | |
| **Publicize meeting through local media and local disability organization listservs** | "Town Hall or Infrastructure" | | | |
| **Post flyers announcing event and identifying procedure for requesting accommodations** | | | | |
| **Order food for event** | | | | |

| Activity | Meeting Type | Date to be completed | Person responsible | Notes |
|---|---|---|---|---|
| Arrange services of sign language interpreters, if needed | | | | |
| Place orders for Braille or assisted listening devices, if needed | | | | |
| Order meeting Materials (Folders, Nametags, Flipcharts) | | | | |
| Arrange for note takers (Real Time Captioning) | | | | |
| Invite representatives: local and county government, service providers and service organizations; utilize listservs, email + personal phone calls - include agenda | | | | |
| Confirm attendance with phone calls | | | | |

**Tasks prior/after the meetings:**

| Activity | Meeting Type | Date to be completed | Person responsible | Notes |
|---|---|---|---|---|
| Take photos of areas of need identified in the Town Hall meeting | | | | |
| Develop slide presentation for meeting using summary and photos | | | | |
| Meet with facilitators to go over presentations and materials | | | | |
| [Add your own] | | | | |

**Tasks 1 Week Before meeting:**

| Activity | Meeting Type | Date to be completed | Person Responsible | Notes |
|---|---|---|---|---|
| [Add your own] | | | | |
| [Add your own] | | | | |

# Appendix C: Town Hall Materials

Appendix C: Town Hall Materials ..... 46
Demographics Survey ..... 47
Town Hall Meeting Flyer ..... 49
Meeting Sign In Sheet ..... 51
Sample Town Hall Agenda ..... **Error! Bookmark not defined.**
Definitions for Town Hall Meeting (backside of agenda) ..... 53
Town Hall Facilitation Outline ..... 54
Voting Cards ..... **Error! Bookmark not defined.**
Satisfaction Survey ..... 59

## Demographics Survey

1. What is your **age**? _____

2. What is your **gender**? ❑ Male ❑ Female

3. What is your **race/ethnicity**? **(Check all that apply.)**

   ❑ American Indian/Alaska Native

   ❑ Asian

   ❑ Black/African American

   ❑ Native Hawaiian/Other Pacific Islander

   ❑ White

   ❑ Other (specify) _____

4. Are you of **Hispanic** or **Latino** origin? ❑ Yes ❑ No

5. What is the **highest grade** or year of school you have **completed**?

   ❑ Never attended school or only kindergarten

   ❑ Grades 1 through 11

   ❑ Grade 12 or GED (high school graduate)

   ❑ College 1 year to 3 years (including trade school)

   ❑ College 4 years or more (college graduate)

6. Do you **live with others**? ❑ *Yes* ❑ *No*

**Please turn the page! ☺**

7. Do you represent:

- ❑ Residential program
- ❑ Vocational services program
- ❑ Brokerage
- ❑ A Person with a disability
- ❑ County or State employee
- ❑ Transportation Industry
- ❑ Health Care Representative
- ❑ Other (please specify): _____

8. **Are you CURRENTLY covered by any of the following types of health insurance or health coverage plans?** (Check all that apply)

- ❑ Your employer
- ❑ Someone else's employer
- ❑ A plan that you or someone else buys on your own
- ❑ Medicaid or Medical Assistance [or substitute state program name]
- ❑ Medicare
- ❑ The military, CHAMPUS, or the VA [or CHAMP-VA]
- ❑ The Indian Health Service [or the Alaska Native Health Service]
- ❑ Some other source
- ❑ No health insurance coverage

## Thank you!

# Do You Have a Disability?
# Share Your Experiences in Accessing Health Care Services in [Your town here]

## Town Hall meeting
## [Day of week]
## [Month] [Day], [Year]
## [Time]
**at**
**[Location]**
**[Address]**

- Discuss access barriers to health care
- Explore perceptions of health care professionals
- Examine city infrastructure and transportation needs

**Please RSVP if you plan to attend!**

Call [local community group] at 888-888-8888
or email _____

**Lunch will be provided**

Accommodations provided with 1-week advance notice

Northwest ADA Center

Primary Health of Josephine County
Your Community Health Plan

AllCare Health Plan

Oregon Health & Science University

Sponsored by: [Your List of Sponsors Here]

**[Your Town Here] CEI Sign In Sheet – Town Hall** **Duplicate this sign in sheet as needed**

| Name | Organization Name | Phone | Email |
|---|---|---|---|
| **1.** | | (  )_____-_____ | |
| **2.** | | (  )_____- _____ | |
| **3.** | | (  )_____- _____ | |
| **4.** | | (  )_____- _____ | |
| **5.** | | (  )_____- _____ | |
| **6.** | | (  )_____- _____ | |
| **7.** | | (  )_____- _____ | |

# Health Care Access:

# Community Engagement Initiative

## [Your town here] Town Hall Meeting Agenda

## [Date] & [Time]

Welcome and Introductions: ..... 11:30am-12:00pm

Working Lunch

- Meeting Overview .....12:00-12:30pm
- Best things about health care? .....12:30-1:15pm

BREAK ..... 1:15-1:30pm

Identifying Barriers to Accessing Health Care ..... 1:30-2:30pm

- Physical Access
    - Signage
    - Communication (written materials)
- Transportation
- Health Care Providers' Attitudes

Review and Prioritize Barriers ..... 2:30-2:50pm

Brainstorm Solutions ..... 2:50-3:15pm

Evaluation Forms ..... 3:15-3:30pm

## Definitions

**Accessibility** can refer to the ease in which something is available to you, your ability to easily move around in a place, or ability to participate in an activity (e.g., the doorway being wide enough for your wheelchair).

**Accommodation** can refer to modifications or adjustments made to meet someone's needs.

**Barriers** are things that inhibit or prevent you from getting what you need. For example, stairs can be a barrier for someone using a mobility device.

**Emergency care** means you are seriously injured or extremely sick and need medical care right away.

**Routine care** includes preventive and chronic care. By routine care we mean the type of care you get when you visit your health care provider on a regular basis during which you may receive preventive screenings, exams, and lab/blood tests. During routine visits your health care provider may help you manage any ongoing health care conditions (e.g., diabetes, high blood pressure) you may have.

**Urgent care** means needing to see a doctor right away because you are injured or sick.

# Town Hall Facilitation Outline

## I. Welcome

**A. Introductions of facilitators**

**B. This meeting is part of Community Engagement Initiative -** a process developed by OODH at OHSU and made possible to do in [Your town here] through funding provided by [List funder(s) here]

**C. Give a special call out to our community partner(s) -** [List community partner(s) here]

**D. Provide History and Experience Here -** (Example: We have partnered with over 20 communities throughout Oregon)

1. To identify the health care access concerns of the disability community.
2. To mobilize the community to address issues and improve health care access and quality of life for individuals with disabilities.

**E. CEI has four parts**

1. **Town Hall**
   - **a)** We are here to hear from you
   - **b)** What is working well in your community (access to health care)
   - **c)** Barriers to health care (prioritize them)
   - **d)** Begin to gather solutions
2. **Community Infrastructure meeting**
   - **a)** Meet with health care providers/administrators
   - **b)** Community leaders and service providers
   - **c)** Discuss barriers
   - **d)** Strategize solutions
3. **Community Mobilization**
   - **a)** Working together with community leaders to address change, remove barriers, and make things better for community members like yourself who face barriers to accessing health care.

     ***** Some of these changes will occur quickly while others may take more time and effort.

**4. Follow Up**

**a)** [**Key Disability Organization**] will be touching base and will provide technical assistance as needed for the next _____ months. **[Your community organization here]** is also a valuable resource.

## II. Meeting Overview

**A. Logistics -** Bathrooms, agenda, break (approximately 1:15PM– feel free to get up if you need to)

**B. Ground rules:**

1. Raise hands
2. One person speaks at a time (so we can all hear you)
3. Say your name when you speak
4. Limit time so everyone can speak and we can get through the agenda
5. Parking lot (off topic ideas)
6. Don't debate or criticize others. Everyone's views are valid
7. Write it down if you don't feel comfortable saying it

## III. Introduction to discussion

**A.** We used a variety of resources to prepare for this meeting which include:

1. Issues brought up at previous Town Hall meeting(s)
2. Results of related surveys conducted with disability communities
3. Reviewed articles by researchers on health care access

**What we have found is - Overall people with disabilities:**

**a)** Experience poorer health than the general population (mainly due to environmental and social factors – not necessarily the disability itself).

**b)** Have more unmet health care needs and receive fewer preventative services (cancer screenings/dental checkups) than general population.

**All this info brings us to our meeting goal today, which is to identify barriers contributing to individual's ability to *access health care/services in our community*:**

**B. Today we will be discussing how individuals access health care in the following ways:**

**1.** Transportation to get to health care provider

**2.** Facility access and services/policies of health care settings (Doorways, exam tables, parking, signage, printed materials/forms as well as accessibility of services - interpreter services, assistance filling out forms, large print, etc.)

**3.** Provider knowledge, attitude & communication

**4.** We know national issues are important/financial (hot issue)

**5.** Focus on local issues where we can make a difference

## IV. The best things about health care in [Your town here]:

**A.** Before we start talking about barriers, let's talk about what works.

**B.** What do you think are some of the best things about accessing health care in your community?

**C.** What do health providers do that make it easy?

## V. Identifying barriers to accessing health care:

**A.** Please hold off on solutions until we have identified all the barriers

**B.** After we identify the barriers we will then vote and prioritize

**C.** The last part of the meeting we will discuss possible solutions to:

**1.** Specific barriers

**2.** Names of specific hospitals or clinics where there have been access issues

***** Not too deep into personal stories so that everyone has enough time to share

**D. Transportation:**

**1.** Do you have trouble getting to your doctor's office or other places where you get health care, specialty therapy services, fill your prescriptions, etc.? What makes it difficult?

**E. Facility Access & Services (hallways, parking, signage, exam tables, brochures):**

1. Do you have any difficulties getting into and around your doctor's office or other health care facilities? (Think about your path of travel; what do you need to access quality care?)
2. Have you had any problems with the procedures of your health care providers? (Service animals)
3. Is it hard to obtain the reasonable accommodations you need to access health care services? (Assistance with transferring, communicating, etc.)
4. How easy or hard is it to communicate with doctors or health care office staff and/or get information (prescriptions, health information, etc.)?

**F. Provider knowledge, attitude and communication**

5. What has your experience been with trying to find providers who understand your disability?
6. Have you had any problems with negative attitudes or lack of respect from your doctors or other health care providers and support staff?
7. How easy or hard is it to communicate with doctors or health care office staff?
8. Has your doctor provided you with health information materials about your medical conditions or other health and wellness issues? Have these materials been provided in accessible and understandable formats?

## VI. BREAK

## VII. Review and Prioritize Barriers

**A.** Use your numbered 1-2-3 flashcards to vote for your top three barriers you think are most important

**B.** Read list of barriers

**C.** Count cards

**D.** Each person gets three votes per topic (transportation, access, attitudes)

**E.** “Vote on what you think are the 3 most important issues or priorities.”

**F.** “Vote for the top 3 issues that you also think are the most likely to change.”

## VIII. Brainstorm Solutions

**A.** Read top three barriers for each topic

**B.** Brainstorm solutions for these prioritized issues

**C.** Tie to local resources

**D.** Resource table

## IX. Closing Remarks

**A.** Explain next steps – Infrastructure meeting

**B.** Also looking for a few volunteers who would be willing to represent the attendees at today’s meeting

**C.** Sign in sheet – so we can contact you

**D.** Have people sign photo release forms

## X. Evaluation Forms

**COMMUNITY ENGAGEMENT: TOWN HALL**
**SATISFACTION SURVEY**

Your feedback is very helpful to us. Please answer the following questions:

**Which of the following best reflects your overall level of satisfaction with the Community Engagement Town Hall meeting?**

- ☐ Highly satisfied
- ☐ Satisfied
- ☐ Satisfied somewhat
- ☐ Not at all satisfied

**How would you rate your satisfaction with how the meeting was conducted?**

- ☐ Highly satisfied
- ☐ Satisfied
- ☐ Satisfied somewhat
- ☐ Not at all satisfied

**How would you rate the usefulness of the meeting?**

- ☐ Highly useful
- ☐ Useful
- ☐ Somewhat Useful
- ☐ Not at all useful

**What was your level of participation?**

- ☐ Very High
- ☐ High
- ☐ Neither High nor Low
- ☐ Low
- ☐ Very Low

**Do you have other comments on this meeting? Please write them here:**

**Today's Date: _____ Location: [Your town here]**

**THANK YOU!!**

# Appendix D: Community Infrastructure Meeting Materials

Appendix D: Community Infrastructure Meeting Materials ..... 60
Community Infrastructure Invite Letter ..... 61
Community Infrastructure Meeting Flyer ..... 62
Community Infrastructure Sample Agenda ..... 63
Definition of Disability (backside of agenda) ..... 64
Community Infrastructure Facilitation Outline ..... 67
Satisfaction Survey ..... 72

# Community Infrastructure Meeting Invite Letter

[Letterhead of your organization]

[Date]

Dear _____,

We would like to invite representation from your organization to attend a Community Infrastructure meeting in [Your town here] focusing on health care access issues for people living with disabilities. The meeting is being sponsored by [name of your agency here and any other key sponsors] and [other sponsors]. The meeting will be held on [Day of week], [Month] [Day] at [Your address here] from [Time here]. Lunch will be provided.

The primary objective of this Community Infrastructure meeting is to bring together community leaders from [Your town here] to discuss health care access barriers facing people with disabilities. These barriers will have been identified by people with disabilities during a Town Hall meeting we're also hosting in [Your town here] on [Day of week] [Month] [Day].

The second objective of the Community Infrastructure meeting is to facilitate the identification of resources and supports in [Your town here] and the surrounding communities to help improve access and remove access barriers. Our office, along with the other sponsors of this event, will also provide technical assistance regarding the implantation of solutions that are related to our agencies' overall areas of expertise.

We hope you, or a representative from your organization, will be able to join us for this important meeting as your participation can help facilitate change for improved community access.

Additionally, we will be providing a limited number of accessibility assessments for health care facilitates. If you are affiliated with a clinic or health care facility, and would like us to conduct an assessment of your facility's usability for people with mobility, sensory, and/or cognitive disabilities, please let us know. We will be happy to schedule an assessment with you. Results and recommendations will be provided.

Sign language interpreters, individual listening devices and materials in alternative format will be provided with one week's advance notice. We look forward to seeing you and ask that you please RSVP by [Day of week] [Month] [Day], to [your agency] at (888) 888-8888 or at [email address]. Also, please feel free to contact [our agency] if you have any further questions or need additional assistance.

Sincerely

[Your name]

On behalf of all the sponsors:

[List sponsors here; include logos if appropriate

# [Your town here] Community Leaders Meeting to Discuss Health Care Access for People with Disabilities

## [Day of week]
## [Month] [Day], [Year]
## [Time]

**[Location]**
[Address]

- Discuss access barriers to health care
- Explore perceptions of health care professionals
- Examine city infrastructure and transportation needs

**Please RSVP if you plan to attend!**

Call [your agency] at 888-888-8888 or email _____

**Lunch will be provided**

Accommodations provided with 1-week advance notice

Northwest ADA Center

PrimaryHealth of Josephine County
Your Community Health Plan

AllCare HEALTH PLAN

OREGON HEALTH & SCIENCE UNIVERSITY
OHSU

Sponsored by: [Your Sponsors Here]

# Health Care Access:

# Community Engagement Initiative

## [Your town here] Community Infrastructure Meeting Agenda

## [Date] & [Time]

Welcome and Introductions ..... 11:30am-12:00pm

Working Lunch

- Meeting Objectives ..... 12:00-12:15pm
- Disability Demographics and Data ..... 12:15-12:30pm
- Best Things About Health Care?..... 12:30-1:00pm

BREAK ..... 1:00-1:15pm

Increasing Health Care Access in [Your city here] ..... 1:15-2:15pm

Next Steps ..... 2:15-2:40pm

Closing Remarks and Evaluation ..... 2:40-3:00pm

We all thank you for your participation!

[List of Sponsors; consider adding logos]

# Definitions of Disability

## BRFSS

*People are considered to have a disability if they answer "yes" to one or both of the following questions*:

1. Are you limited in any way in any activities because of physical, mental, or emotional problems?
2. Do you now have any health problem that requires you to use specific equipment, such as a cane, wheelchair, special bed, or special telephone?
3. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
4. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (respondents 5 years or older)
5. Do you have serious difficulty walking or climbing stairs? (respondents 5 years or older)
6. Do you have difficulty dressing or bathing? (respondents 5 years or older)
7. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a physician's office or shopping? (respondents 15 years or older)

## US Census

a. Does this person have a physical, mental, or other health condition that has lasted for 6 or more months and which -
    i. a. Limits the kind or amount of work this person can do at a job?
    ii. b. Prevents this person from working at a job?
b. Because of a health condition that has lasted for 6 or more months, does this person have any difficulty -
    i. a. Going outside the home alone, for example, to shop or visit a doctor's office?
    ii. b. Taking care of his/her own personal needs, such as bathing, dressing, or getting around inside the home?
c. Does this person have any of the following long-lasting conditions:
    i. a. Blindness, Deafness, or severe vision or hearing impairments?
    ii. b. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?
d. Because of a physical, mental or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities:
    i. a. Learning, remembering, or concentrating?
    ii. b. Dressing, bathing, or getting around inside the home?

## American Community Survey

- **Sensory Disability** - Conditions that include blindness, deafness, or a severe vision or hearing impairment.
- **Physical Disability** - Conditions that substantially limit one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying.
- **Mental Disability** - Because of a physical, mental, or emotional condition lasting 6 months or more, the person has difficulty learning, remembering or concentrating.

- **Self-care Disability** - Because of a physical, mental, or emotional condition lasting 6 months or more, the person has difficulty dressing, bathing, or getting around inside the home.
- **Go-outside-home Disability** - Because of a physical, mental, or emotional condition lasting 6 months or more, the person has difficulty going outside the home alone to shop or visit a doctor's office.
- **Employment Disability** - Because of a physical, mental, or emotional condition lasting 6 months or more, the person has difficulty working at a job or business.

# Community Infrastructure Facilitation Outline

**I) Welcome**

**A)** Introductions of facilitators and everyone attending

***Slide***

**B)** This meeting is part of Community Engagement Initiative - a process developed by OODH at OHSU and made possible to do in [Your town here] through funding by the [Name of organizations here] and by the Centers of Disease Control and Prevention that funds our office, OODH.

**1)** Since 1999 - Our office has partnered with over 20 communities throughout Oregon (Pendleton/Corvallis/Bend most recently)

**(a)** To identify the concerns of the disability community.

**(b)** Worked together to address issues and improve community accessibility and quality of life.

**II) Meeting Overview**

**A)** Logistics, bathroom, breaks

**B)** Ground Rules:

**1)** Raising hands

**2)** One person speaks at a time

**3)** Say your name when you speak

**4)** Big agenda: Limit time so everyone can speak and we can get through the agenda

**5)** Parking lot (off topic ideas)

**6)** You are here to work together as a group so we are not here to debate, criticize, or point fingers. Everyone's views are valid.

**7)** Write it down if you do not feel comfortable saying it.

**8)** Evaluation forms - feel free to leave additional comments.

## III) Introduction to Discussion

**A)** Variety of sources to prepare for this meeting:

**1)** Issues brought up at other Town Hall meeting(s)

**2)** Surveys we have conducted

**3)** Articles by researchers on health care access

**(a)** People living with disabilities report having more unmet health care needs

**(b)** People with disabilities receive fewer preventative services such as cancer screenings/dental services

**1.** We asked people with disabilities about their experiences

***Slide***

**B)** Meeting Objectives

**1)** Looking at disability demographics in [list relevant counties here]

**2)** Review Town Hall meeting results

**3)** Start to identify ways to increase and improve disability access to health services

***Slide***

**C)** Meeting Materials

**1)** Meeting Agenda

**2)** Definitions of Disability

**3)** Disability Demographics

**4)** Workbook

**5)** Satisfaction Survey

***Slide***

## IV) Present Community Demographic Information

**A)** Demographics

**1)** Disability prevalence

**(a)** Newport - 19.1% of total population is disabled

**(b)** Lincoln Co - 24.6%

**(c)** Oregon - 16.4%

**(d)** US - 14.9%

**B)** Health status of people with disabilities

**1)** Higher rates of obesity, smoking, anxiety, depression, and cardiovascular events.

***Slide***

## V) Community Engagement Initiative

**A)** CEI has four parts:

**1)** Town Hall

**(a)** We are here to hear from you

**(b)** What is working well in your community (access to health care)

**(c)** Barriers to health care (prioritize them)

**(d)** Begin to gather solutions

**2)** Community Infrastructure Meeting

**(a)** Meet with health care providers/administrators

**(b)** Community leaders and service providers

**(c)** Discuss barriers

**(d)** Strategize about solutions

**3)** Community Mobilization

**(a)** Working together with community leaders to address change, remove barriers, and make things better for community members who face barriers to accessing health care.

***** Some of these changes will occur quickly while other may take more time and effort.

**4)** Follow up

***Slide***

## VI) [Your town here] Town Hall meeting topics

**A)** Transportation to get to health care provider

**B)** Accessibility of health care settings

**C)** Provider knowledge, attitude, and communication

**D)** We know national issues are important (financial/insurance reimbursement) but today we are only looking at issues you can control as a community

**E)** Lastly, we will begin to identify ways to increase accessibility

## VII) The best things about health care in [Your town here]

**A)** Before we start talking about barriers, let's talk about what works.

**B)** Present best things about health care access from Town hall meeting

**C)** Do you have anything to add?

## VIII) Present Barriers to Accessing Health Care

**A)** Let's talk about barriers that people with disabilities have experienced when accessing health care.

**B)** Read top three barriers in each area

**C)** We asked people with disabilities questions in each of these areas; Transportation, Physical Access, Health Provider Attitudes

**1)** Transportation

**(a)** Do you have trouble getting to your doctor's office or other places where you get health care? What makes it difficult?

**2)** Physical Accessibility

**(a)** Do you have any difficulties getting into and around your doctor's office or other health care facilities?

**(b)** Have you had any problems with the procedures of your health care providers? (Service animals)

**(c)** Is it hard to obtain the reasonable accommodations you need to access health care services?

**3)** Provider knowledge, attitude, and communication

**(a)** What has your experience been like with trying to find providers who understand your disability?

**(b)** Have you had any problems with negative attitudes or lack of respect from your doctors or other health care providers and support staff?

**(c)** How easy or hard is it to communicate with doctors or health care office staff?

**(d)** Has your doctor provided you with health information materials about your medical conditions or other health and wellness issues? Have these materials been provided in accessible and understandable formats?

**IX) Break**

**X) Closing Remarks**

**A)** Explain next steps

**B)** Extend invitations for further participation on workgroups

**C)** Sign-in sheet

**XI)** Evaluation Form

**COMMUNITY ENGAGEMENT: INFRASTRUCTURE MEETING SATISFACTION SURVEY**

Your feedback is very helpful to us. Please answer the following questions:

**Which of the following best reflects your overall level of satisfaction with the Community Engagement Infrastructure meeting?**

- ☐ Highly satisfied
- ☐ Satisfied
- ☐ Satisfied somewhat
- ☐ Not at all satisfied

**How would you rate your satisfaction with how the meeting was conducted?**

- ☐ Highly satisfied
- ☐ Satisfied
- ☐ Satisfied somewhat
- ☐ Not at all satisfied

**How would you rate the usefulness of the meeting?**

- ☐ Highly useful
- ☐ Useful
- ☐ Somewhat Useful
- ☐ Not at all useful

**What was your level of participation?**

- ☐ Very High
- ☐ High
- ☐ Neither High nor Low
- ☐ Low
- ☐ Very Low

**Do you have other comments on this meeting? Please write them here:**

**Today's Date: _____** **Location: [Your town here]**

**THANK YOU!**

**If you would like to receive this information in an alternative format (computer disk, large print, audio, or Braille) –**

**Please Contact:**

**Oregon Office on Disability and Health**

**Institute on Development and Disability**

**Oregon Health & Science University**

**707 SW Gaines Street**

**Portland, OR 97239**

**Phone: 503-494-1205**

**TTY: 7-1-1**

**oodh@ohsu.edu**

**http://www.oodh.org/**

Copyright 2015 by OHSU Institute on Development and Disability (IDD). ALL RIGHTS RESERVED. No part of this copyrighted work may be modified, reproduced, or used in any form or by any means -- graphic, electronic, or mechanical, including photocopying, recording, taping, web distribution or information storage and retrieval systems -- without the written permission of the IDD.

For permission to use material, submit a request to oodh@ohsu.edu

This publication was supported by Grant/Cooperative Agreement Number U59/DD00094203 from the Centers for Disease Control and Prevention (CDC) Disability and Health Program. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of NIDRR or the CDC.