

## Creating a Training Program for Informal Personal Assistants

### Why It Matters: Filling Important Gaps

If you're a person with a disability, you may need some help with daily activities, like cooking, bathing or dressing. A paid personal assistant, or formal PA, can provide this support, which makes it possible to live in the community.

But what happens if the agency that pays this formal PA limits the services and number of hours they can provide? This often happens, and when it does, most people with disabilities turn to friends and family members to fill the gap. We call these unpaid helpers "informal" PAs.

Informal PAs are usually highly motivated and personally invested in helping the person with a disability (also called a consumer). But they express doubts about their skills and high levels of stress and anxiety about providing care.

In this project, we developed a training that gives informal PAs the same kind of information and skills that formal PAs are required to have. With this new knowledge, informal PAs can safely assist consumers in their daily lives. They can help consumers avoid disruptions in community living, like going to the hospital. Plus, they may help consumers increase their community participation.

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*"The training covers a very wide gamut of people with disabilities and potential caregivers. It also gives a common space for there to be communication back and forth between caregiver and consumer so that they are speaking the same language."*  
*- Participant with a Disability*

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In the training video for "Slide Board and Stand Pivot" (shown on left), a physical therapist demonstrates how to help a wheelchair user transfer with a slide board.

## The Training Content: Meeting Most Important Needs

This training for informal PAs is based on a training we developed previously for formal, paid PAs. Most of the skills that an informal PA needs are the same. Before we created the training, we also asked consumers which topics were most important to them when working with a friend or family member. We used their responses to select 11 topics for the training:

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*“If there is a certain thing that I am struggling with at home, I can pull up the online course very easily for a reminder or maybe review something again if I wasn’t 100% sure.”*

*- Informal Personal Assistant*

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- Personal Care
- Health and Wellness
- Secondary Conditions
- Physical Disabilities and Conditions
- Body Mechanics and Transfers
- Recognizing Abuse and Neglect
- Psychological and Emotional Conditions
- Effective Communication
- Assistive Technology
- Safety and Emergency Planning
- Transportation and Travel

### Who We Train

In this research project, we are training people in pairs (also called dyads) – the consumer and the informal PA. It’s important for consumers to learn new skills, too, so they can direct their own care in partnership with their friend or family member.

We are training a total of 50 dyads (100 people) to gain information on how well the training works for both consumers and informal PAs. In this test of the training, we are focusing on people who are newly injured or at risk for institutionalization. That way we can analyze how the training affects their community living and participation.



The “Slide Board and Stand Pivot” training video (shown on right) teaches informal personal assistants how to safely assist a consumer who uses a wheelchair.

## How We Train

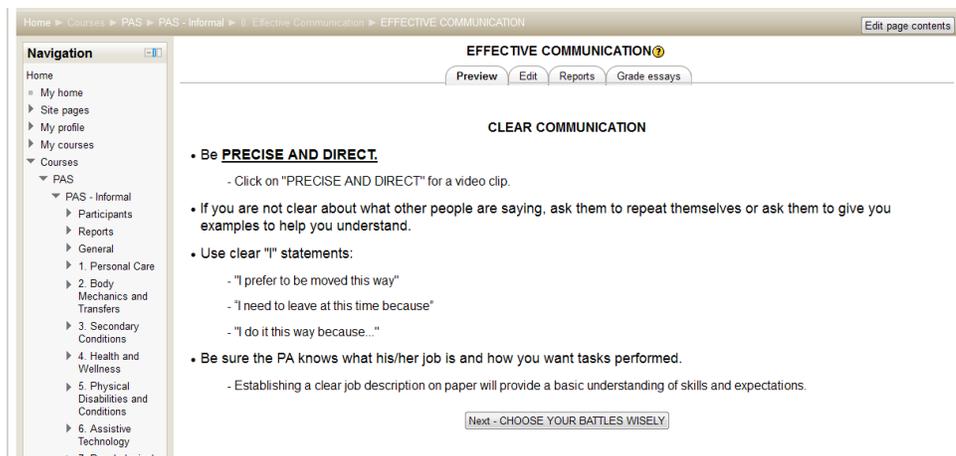
The training is conducted in small groups including consumers and their informal PAs. For each topic or “module,” the trainer presents information about the subject, gives examples, and shows videos. Training participants practice the new skills in class and take quizzes to determine what they know before and after the training.

Here’s an example of what one training module includes:

### Body Mechanics and Transfers

- Verbal instruction and handout explaining techniques
- Video: “Sliding Board and Stand Pivot”
- Hands-on practice with equipment (transfer bench, Hoyer lift, gait belt, etc.)
- Demonstrate skills with immediate feedback

The course materials are also online so people can review them at home. The example below shows the Effective Communication module.

A screenshot of a web-based course interface. The browser address bar shows the path: Home > Courses > PAS > PAS - Informal > Effective Communication > EFFECTIVE COMMUNICATION. The page title is 'EFFECTIVE COMMUNICATION'. Below the title are buttons for 'Preview', 'Edit', 'Reports', and 'Grade essays'. The main content area is titled 'CLEAR COMMUNICATION' and contains a list of bullet points:

- Be **PRECISE AND DIRECT**.
  - Click on "PRECISE AND DIRECT" for a video clip.
- If you are not clear about what other people are saying, ask them to repeat themselves or ask them to give you examples to help you understand.
- Use clear "I" statements:
  - "I prefer to be moved this way"
  - "I need to leave at this time because"
  - "I do it this way because..."
- Be sure the PA knows what his/her job is and how you want tasks performed.
  - Establishing a clear job description on paper will provide a basic understanding of skills and expectations.

At the bottom of the content area is a button that says 'Next - CHOOSE YOUR BATTLES WISELY'. On the left side, there is a 'Navigation' sidebar with a tree view showing the course structure, including 'Home', 'My home', 'Site pages', 'My profile', 'My courses', 'Courses', 'PAS', 'PAS - Informal', 'Participants', 'Reports', 'General', '1. Personal Care', '2. Body Mechanics and Transfers', '3. Secondary Conditions', '4. Health and Wellness', '5. Physical Disabilities and Conditions', '6. Assistive Technology', and '7. Deontological'.

## Next Steps

Our goal is to empower people with disabilities to participate in their communities. We will evaluate how effective this training is to make any needed revisions in the course. Then we can offer the training to people around the United States – consumers and their friends and family – who can benefit from gaining specialized skills and knowledge to provide personal assistance.

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*“It touched on everything.  
There were no gaps.”  
- Informal Personal  
Assistant*

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## The CHEC: Extra Help for Newly Injured Consumers and Their Supporters

The Informal PA training team will also offer another training for consumers who have recently acquired a disability and their informal personal assistants.

The Community Health Environment Checklist (CHEC) is a tool that this team developed for people with disabilities to find out how usable the businesses and public spaces in their communities are. Family members and friends will be offered training in how to administer CHECs at community sites to determine how usable the places are where the consumer likes to go. This could help with the consumer's community reintegration and increase participation.

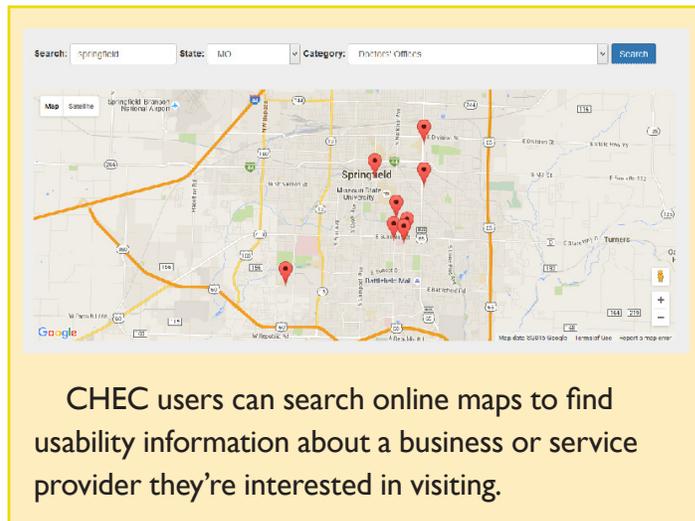
The goal of the CHEC is to provide pragmatic information for potential problems (i.e., to let people know if they can get into a certain location and participate as they wish). For that reason, the CHEC focuses on usability rather than accessibility alone. Accessibility describes the physical environment and whether or not it conforms to regulations outlined in the Americans with Disabilities Act (ADA) and section 504 of the Rehabilitation Act. By these standards, a space is either accessible or not – e.g., a doorway either provides 32” of clear space to enter or does not. Usability, however, describes how an individual interacts with his or her environment. Spaces can be usable for some people and not for others, and may depend on factors that are not covered by accessibility regulations, such as noise levels.

### Who Can Use the CHEC?

The CHEC may be used by any interested individual or group, including people with disabilities, older adults, staff members at Centers for Independent Living and other community-based organizations, rehabilitation professionals, and advocates.

Free training in how to use the CHEC is provided by the developers of the tool at Washington University in St. Louis. Three training options are available: face-to-face, online, or using a manual.

On completing a CHEC assessment (either on paper or online), users return the data to Washington University, where staff create an online Google



map and link for users to share with people in their community.

### How Does the CHEC Compare to Other Online Ratings?

Most online rating systems are crowd-sourced, which means any person who wishes to rate a business or service provider can register with the site and provide his or her opinion. Categories for rating a business are usually limited to a handful.

The CHEC, in comparison, is a valid and reliable measure of environmental usability and receptivity. Trained CHEC assessors complete a standardized evaluation for each location, answering more than 50 questions to produce a score that reflects measurable features in each site.

The CHEC thus provides a great deal of detail to people who want to make informed decisions about where they participate in their community.



Watch our video on YouTube for an introduction to the CHEC.

