



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Getting Involved in Research and Training: A Guide for Persons with Intellectual Disabilities

Written and Developed by:

***Tamar Heller, Ph.D.***

University of Illinois at Chicago, Dept. of Disability and Human Development (UCEDD)

***Tia Nelis***

University of Illinois at Chicago, Dept. of Disability and Human Development (UCEDD)

***Sheila Collins***

University of Illinois at Chicago, Dept. of Disability and Human Development (UCEDD)

***Esther Lee Pederson, M.Ed.***

ELP Consulting



*~ in conjunction with ~*

### UCEDD Leadership Consortium

**Carl F. Calkins, Ph.D., Co-PI**

University of Missouri Kansas City  
Institute for Human Development (UCEDD)

**Michael Wehmeyer, Ph.D., Co-PI**

Kansas University Center on Developmental Disabilities (UCEDD)  
at the University of Kansas

**Andy Bacon, Ph.D.**

Westchester Institute for Human Development (UCEDD)  
at New York Medical College

**Tamar Heller, Ph.D.**

University of Illinois Chicago  
Dept of Disability and Human Development (UCEDD)

**Hill Walker, Ph.D.**

University of Oregon  
Center on Human Development (UCEDD)

# Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

## The National Gateway to Self-Determination

The National Gateway to Self-Determination (SD) is a consortium of University Centers for Excellence in Developmental Disabilities (Missouri, Kansas, Oregon, New York, Illinois) in partnership with a National Self-Determination Alliance (including self-advocates, families, and numerous national partners). The overall goal of this project is *“to establish a sustainable, evidence-based training system that enhances self-determination training programs that lead to quality of life outcomes for individuals with developmental disabilities throughout the lifespan.”*

## The Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function

The Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function (RRTCADD) seeks to enhance the health, function, and full community participation of adults with intellectual and developmental disabilities (I/DD) across the lifespan and bolster family caregiving capacity through a coordinated set of research, training in evidence-based practice, and dissemination activities. For articles from the Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function, please visit the website:

<http://www.rrtcadd.org/>

A National Gateway to Self-Determination is funded by US Department of Health and Human Services, Administration on Developmental Disabilities grant # 90-DD-0659. The Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function is funded by the US Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research, Grant #H133B080009.

---

## About the Authors

**Tamar Heller**, Ph.D, Professor, is Head of the Department of Disability and Human Development, University of Illinois at Chicago and director of its Institute on Disability and Human Development and the Rehabilitation Research and Training Center (RRTC) on Aging with Developmental Disabilities.

**Tia Nelis** is a Self-Advocacy Specialist at the RRTC on Aging with Developmental Disabilities, Institute on Disability and Human Development, University of Illinois at Chicago. She also is the past chairperson of the national organization Self-Advocates Becoming Empowered.

**Sheila Collins** is a master's student in Disability and Human Development at the University of Illinois at Chicago. She has lived and worked as an assistant in the Seattle L'Arche community.

**Esther Lee Pederson**, M. Ed, director of ELP consulting, consults on self-advocacy, board development, and leadership of people with developmental disabilities.

# Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

## **Table of Contents**

### **Introduction, 1**

- What is research?, 1
- What is training?, 1
- How can people with disabilities be involved in research and training projects?, 1

### **Research & Training, 2**

- Things you can do to help with a research project, 2
- Examples of ways people with disabilities have been involved in research and training activities, 4
  - Research, 4
  - Training, 5
- Things you can do on a training project, 5
- Why would you want to work on a research or training project?, 5

### **Preparation & Support, 7**

- What should you know before you work on a research or training project?, 7
- Getting the support you need, 7
- What is a support person?, 7
- Getting too much or too little support, 8
- Feeling ignored or uncomfortable, 8
- Other Issues, 9
  - Transportation, 9
  - Access to Buildings, 10
  - Getting Paid for Time Lost at Work, 10
- Difficulty Understanding Professionals, 10
- What is informed consent?, 11

References, 12

# Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

## Introduction

The self-advocacy movement is growing rapidly. As a result, professionals and people with intellectual disabilities are **working together** more and more. Professionals often seek persons with disabilities to help with their research and training projects so that those professionals can learn more about working with persons with disabilities. This is a guide to help persons with disabilities get involved in research and training activities.



*Geoffrey Caldwell (left) and George Jesien discuss the importance of self-advocacy.*

**What is research?** Research projects are done to **help people understand** how something works. For example, a research project might help people understand how different services help persons with disabilities. A researcher is the person who does the project.

**What is training?** Training projects are done to **teach people new information** that they do not know about. For example, a person might train persons with disabilities about how to make choices in their life. A trainer is the person who talks to people and teaches them new information.

**How can people with disabilities be involved in research and training?** There are lots of ways a person with a disability can help professionals with research and training projects. We spoke with people with disabilities and gathered information about what it is like for persons with disabilities to be involved in research and training projects. This guide will tell you about what we learned.

# Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

## Research & Training



*Jessica Kramer (left) collaborates with participants in a community-based participatory research project.*

### Things you can do to help with a research project!

1. **Give information** to professionals that will help them understand persons with disabilities and do research that helps persons with disabilities. For example, at a research meeting you can tell researchers about what it is like to have a disability and the types of research that are important to you.
2. **Be a subject** in a research study. This means that you would answer questions or provide other information that researchers can use to better understand the lives of persons with disabilities.
3. **Help design** research studies or research materials. For example, you can help researchers decide what kinds of questions to ask in an interview. You can also help researchers make sure that the research study is important and helps persons with disabilities.
4. **Help researchers** to better understand the information they find from research. For example, if researchers found that adults with disabilities have problems getting jobs or finding a good place to live, you can help offer reasons why persons with disabilities may have these difficulties.

## Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

5. **Write papers** with researchers about the new information that is learned from the research project. For example, if you find out about ways to help persons with disabilities who live in the community, you can write about it. Then other people can learn about your research and how to help persons with disabilities so they can live in the community.
6. **Help teach** information that is learned from the research project to other people with disabilities, service providers, professionals, parents, and other community members. For example, if you learn information about how to help persons with disabilities make choices, you might want to give a talk to tell this information to persons with disabilities.
7. **Help decide** who will receive information discovered in the research project. For example, if you learn information about helping people with disabilities do well in school, you might work with researchers to decide who should be told about this information. In this case, you might want to tell persons with disabilities, teachers, and parents about the information learned.

# Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011



*Tia Nelis leading a session at the Advanced Leadership Academy.*

## Examples

Here are some examples of ways people with disabilities have been involved in research and training activities.

### Research:

- In one study<sup>1</sup>, researchers worked with people with disabilities on a project using community-based participatory research, also known as participatory action research. This type of research values the input and involvement of participants through every step of the research process, from designing the study to leading focus groups and collecting results. In this study, researchers worked with members of a self-advocacy group to learn about ways to expand the group's ability to do advocacy work. During the entire study, researchers valued the perspectives of people with disabilities and relied on their expertise during the study.
- A lot of the information in this guide comes from another research project<sup>2</sup> where we interviewed 22 people with disabilities and asked them about their experiences in research and training activities. Learning from people with disabilities about their experiences has helped researchers to improve their practices and the ways that they work with people with disabilities.

# Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

## Training:

- One self-advocate ***worked with professionals*** to develop training activities in advanced leadership for people with disabilities. This training was designed for people who wanted to advance their leadership skills and have fun in the process. Twelve leaders attended the week-long training, where they developed skills around leadership, employment, and volunteering.

## Things you can do on a training project:

1. ***Be a trainer*** who teaches other people new information.  
For example, you can train persons with disabilities about how to make choices or about their rights and responsibilities. You can also teach professionals to understand that persons with disabilities have strengths and capabilities.
2. ***Help decide*** what goes in the training materials. For example, you can help decide what a trainer will teach his or her audience.
3. ***Teach audiences*** like self-advocacy groups, professionals, parents, or other community members about the strengths of persons with disabilities or new information that is learned on research projects.



*“It is important to educate people ... because sometimes people think since we have a disability, we can’t do anything – which is wrong.” Kelly*

## Why would you want to work on a research or training project?

Here is a list of some of the good things about working on research and training projects.

1. ***Showing other people*** that you have strengths and capabilities
2. ***Learning*** new information



## Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

3. **Helping professionals** so they can understand the needs and interests of persons with disabilities better
4. **Gaining new skills** like how to speak to an audience
5. **Meeting new people** and making new friends
6. **Traveling** to different places
7. **Helping** other persons who have disabilities

Many of the people we talked to had good research and training experiences. Here are some of the things they said about their experiences.

- “It feels good when people listen to me; when I can give talks to groups and something is being done, when people have faith in me.”
- “To see job coaches say ‘I didn’t think of that’ or just to thank me for being there and to see me for who I am. For old friends to see me doing things they never thought of me doing.”
- “I love travelling to Chicago, Washington. I like to hear what’s going on and getting involved. I’ve learned a lot.”
- “I enjoy learning how to answer audience questions without being nervous when I give presentations and help organizations by giving them information.”

# Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

## 〔 Preparation & Support 〕



*Self-advocate (right) taking survey on iPad with assistance (if needed) from Jana Peterson.*

### **What should you know before you work on a research or training project?**

Some of the people that we talked to had some problems when they worked on research and training projects. We will tell you about these problems and give you ideas about how to deal with them.

〔 Getting the support you need 〕 Sometimes people with disabilities find it helpful to have a support person to help them work on research and training projects.

〔 What is a support person? 〕 A support person is someone with or without a disability who helps a person with a disability. For example, a support person might help a person with a disability understand difficult information at a meeting or get transportation to go to meetings. If you feel that you need or want a support person, make sure it is someone who you like and feel comfortable with. You should always decide who your support person is. Don't let other people choose your support person for you.

## Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

**Getting too much or too little support** Some of the people we talked to had support persons who helped them too much or too little. Some of the people we talked to told us that their support persons talked too much at meetings and did not give the persons they were supporting enough chances to talk. Support persons who do this may be trying to help you but do not understand that they are keeping you from taking part in meetings. Other people said that they had support persons who were not helpful. For example, some support persons did not give help at meetings when the person they were supporting needed it.

1. **Talk to your support person** about how you feel. Remember that your support person may think he/she is helping you and not understand that he/she is giving you too much or too little support. Talking to your support person about it in a nice way may help you improve the problem.
2. If you talk to your support person but the problem does not go away, **try talking to him or her again**. If the problem still does not go away, you might talk to the professionals you are working with, your family, and/or friends about getting a new support person.

**Feeling ignored or uncomfortable** Some of the people we talked to told us that they sometimes felt ignored by professionals. Some people told us that they felt that professionals did not listen to their opinions. Other people told us that they did not feel comfortable speaking up at meetings or in front of an audience. What can you do to deal with this problem?

1. **Tell your support person** how you feel. Ask your support person to help you think of ways to deal with this problem.
2. **Tell professionals** how you feel and remind them that you have capabilities and opinions that can help professionals doing research and training projects.

## Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

3. **Go over things** you would like to say at meetings with your support person, friends, or family so that you learn to feel more comfortable speaking up at meetings or in front of audiences.
4. **Remember** that some professionals have never worked with a person with a disability before. While you need to learn how to work with professionals, professionals need to learn how to work with you. For example, professionals might need to be reminded that they need to listen to you or to speak slowly so you can understand them. But you should tell them to do these things in a nice way. Remember, they are learning too.

### [ Other Issues! ]

#### **Transportation, access to buildings, and getting paid for lost time at work:**

Some of the people we interviewed told us that it is important to make sure that you have transportation to get to meetings and that meetings are held in accessible buildings. For example, people who use wheelchairs told us it is important to make sure that the building has wheelchair ramps and elevators. Some of the people we talked to also told us that research and training meetings often occur during the day when they usually work. This means that you might lose hours at work and lose money. What can you do to deal with this problem?

#### **Transportation**

1. **Talk to your support person** or professionals about how you will get to meetings. If you need special transportation, like a van that is wheelchair accessible, make sure you tell your support person or the professionals you will be working with.
2. **Make sure** that you will have transportation to and from each meeting you attend and that you know where the meeting is and what time you need to be there.

## Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

### **Access to Buildings**

1. **Call professionals** or talk to your support person before a meeting to make sure the building where meetings will be held is accessible to persons with disabilities.
2. If you will need extra help getting in the building, using the elevators, or finding meeting rooms, **make sure you tell** your support person or a professional that you will need help.

### **Getting Paid for Time Lost at Work**

1. Before you agree to work on a research or training project, **find out** if you will need to miss work in order to work on the project. If you will need to miss work, find out if you will get paid for the missed hours. If you cannot afford to miss work, it is important that you ask professionals about getting paid for the hours you are at research or training meetings. Make sure you ask professionals about this and agree on how much you will be paid before you agree to work on a research or training project.

**Difficulty understanding professionals** Sometimes professionals use words related to their work that other people do not understand. This may make it hard for persons with disabilities to work well on a research or training project. What can you do to deal with this problem?

1. **Ask** professionals to use words that are easier to understand.
2. Get a support person who will help explain things to you. If you have a support person, **tell him or her that you are having difficulty** understanding things.
3. Ask for something in writing, on audiotape, or on videotape that will explain what will go on in a meeting **before** you meet with professionals. This may help you understand what goes on in the meeting better.

## Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

**What is informed consent?**

Informed consent has to do with being a subject in research. Remember, being a subject in research means that you might be asked to answer questions or provide other information. Informed consent means that you understand the information below:

1. **What** the research project is about.
2. If there are any **risks** involved in being a research subject.
3. That you can **stop** being a subject in the research at any time, by your own choice.
4. That your name will not be used in the research. This is called **confidentiality**. This means that only the researchers will know what you do or say as a subject in research. They will not tell anyone what you said. For example, if you were asked to talk about whether you liked your job, no one would tell your supervisor or anyone else at work what you said.

If you do not understand these things then you **should not agree** to be a subject in research.

**REMEMBER:** You **do not** have to participate in anything that you do not want to. **This is your right**. Do not feel pressured to participate in a research or training project. **It is your choice**. If you are not sure what to do, talk it over with friends, family, and/or your support person. **The information in this paper can help persons with disabilities who want to work on research and training projects**. Remember, working on research and training projects is a chance for persons with disabilities to make a real contribution to other people. You can help other people understand what it is like to have a disability, show that you have strengths and capabilities, and help improve the lives of persons with disabilities. As one person with a disability said, “When I see I make a difference in another person’s life with a disability that’s my biggest reward. That’s why I get involved.”

# Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities

---

2011

## References

- <sup>1</sup> Garcia-Iriarte, E., Kramer, J.C., Kramer, J.M., & Hammel, J. (2009). 'Who did what?': A Participatory action research project to increase group capacity for advocacy. *Journal of Applied Research in Intellectual Disabilities, 22*, 10-22.
- <sup>2</sup>Heller, T., Pederson, E.L., & Miller, A.B. (1996). Guidelines from the consumer: Improving consumer involvement in research and training for persons with mental retardation. *Mental Retardation, 34 (3)*, 141-148.