

THE PENNSYLVANIA SELF-ADVOCACY PROJECT

Building the knowledge of self-advocacy in Pennsylvania

The Pennsylvania Developmental Disabilities Council Funded Project

Self-Advocacy: The state-of-the-state in Pennsylvania

Final Report
March 16, 2005

Final Report Contact:

Cynthia Shima Kauffman
301-262-2956

Project Staff and Presenters:

The Council on Quality and Leadership (CQL)

Liz Obermayer
Cynthia Shima Kauffman

Speaking For Ourselves

Debbie Robinson
Steve Dorsey
Otis Hicks
Pam Kennedy

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Final Report
Executive Summary

Purpose:

The Pennsylvania Developmental Disabilities Council (Pennsylvania DDC) has funded the Pennsylvania Self-Advocacy Project to learn about the state of self-advocacy in the Commonwealth. Together, the partners of this project are to gather information and make recommendations that will help the Pennsylvania DDC to improve the support of self-advocacy efforts in Pennsylvania.

What:

The Pennsylvania Self-Advocacy Project steps were to:

- Define self-advocacy:
 - Self-advocacy as a noun: The grassroots, civil rights movement of self-advocacy, including its association and groups.
 - Self-advocacy as a verb: Speaking or advocating for yourself rather than someone speaking for you.
- Develop a survey process that focuses on whether people with disabilities are:
 - Connected to others who support their access to services, resources, and future success.
 - Empowered to control their lives.
 - Supported in self-advocacy efforts on an individual and group basis.
- Complete a survey tool based on:
 - A meeting with a statewide group of self-advocacy stakeholders.
 - Four regional focus groups with people having developmental disabilities.
 - Input from the stakeholder and focus groups.
 - Interviews of people with disabilities.
- Present results and recommendations based on the:
 - Interpretation of data.
 - Analysis of the results.
 - Written final report.
 - Presentation for the full Pennsylvania DDC.

Results

There is evidence that self-advocacy is valued by many stakeholders in Pennsylvania. There is not, however, sufficient visible action supporting self-advocacy across the state. People often do not understand what self-advocacy is. Consequently, people with disabilities are not always supported in seeking help or membership related to self-advocacy.

Recommendations

Go back to grass roots but do it differently.

- Advocate for terminology change:
- Focus on awareness for people with disabilities
- Focus on Accountability

- Promote a statewide campaign.
- Focus on outcomes and actions.
- Model behaviors.
- Identify ways to find people.
- Develop ways to promote knowledge and confidence Establish actions plans with behaviors.
 - Promote having access to information.
 - Support control and decision making on immediate issues (daily routine, choice of activities, choice of service)
 - Prioritize long term or future quality of life thinking, decision making, and control.
- Establish action plans.
- Assist in building financial and human capital.

**THE
PENNSYLVANIA
SELF-ADVOCACY
PROJECT**

Building the knowledge of self-advocacy in Pennsylvania

Self-Advocacy:

The state-of-the-state in Pennsylvania

A statewide survey of people with disabilities living in Pennsylvania, 2002-2005: Is there support in Pennsylvania for self-advocacy?

Introduction

Self-advocacy in recent years has been described as alive and well. Over the past decade, national, state, and local-based self-advocacy groups have become a presence in achieving results for people with disabilities across the United States. These accomplishments have, in general, enjoyed high-profile attention on the part of the disability community, with much interest directed toward the control and self-determination that people with developmental disabilities have achieved. It is important to take into consideration, however, that the self-advocacy movement's success may have a downside. Self-advocacy may have inadvertently created the sense that all people with disabilities know about and have access to self-advocacy at both the individual and organized group levels.

The Pennsylvania Developmental Disabilities Council (Pennsylvania DDC) funded Speaking For Ourselves and The Council on Quality and Leadership (CQL) to complete a joint project to determine the state-of-the-state in supporting self-advocacy efforts across Pennsylvania.

Overview of the Findings

Who responded to this survey as self-advocates?

- Men accounted for 38% and women for 62%. People completing the survey identified themselves as having intellectual and/or developmental disabilities (38%), physical (22%), sensory (18%), brain injury (9%) and other or unknown (13%) disabilities.
- Three hundred surveys were targeted. Project staff contacted 45 County Administrators and 17 identified stakeholder groups for help in finding people to survey. About 100 people initially agreed to participate in the survey process: 87 actually completed the interview.

Are Pennsylvanians with disabilities connected to people that can help them to be self-advocates?

- Most people have someone to talk to when information or support is needed (82%). The majority of support people identified were family or staff members.
- 33% of the people have no one to give them self-advocacy information.
- 67% have no knowledge of how to contact a legislator or elected official.

Are Pennsylvanians with disabilities supported in self-advocacy efforts?

- 67% know about self-advocacy groups, and 67% state they know how to contact a group.
- 50% said they wanted to belong to a self-advocacy group and 33% did not know who to contact.

Project staff developed a survey that focused on whether people with disabilities are:

- Connected to others who support their access to services, resources, and future success.
- Empowered to control their lives.
- Supported in self-advocacy efforts on an individual and group basis.

The information in this report is drawn from the 2004 survey data of The Pennsylvania Self-Advocacy Project. This report includes the method, results, conclusions and recommendations.

Method

The Pennsylvania Self-Advocacy Project began work in October, 2002. The Pennsylvania DDC funded Speaking For Ourselves and CQL as partners to determine if Pennsylvanians with developmental disabilities are supported in self-advocacy efforts. Speaking For Ourselves is a statewide self-advocacy organization. CQL is an international organization committed to quality of life measurement and support for people with disabilities. Four project phases were completed:

Phase One: Planning and Development

This first phase contained the project planning stage and the stakeholder workgroup development. The stakeholder group served as experts in building the self-advocacy survey tool (Attachment 1). As a pre-requisite to the stakeholder workgroup meeting, project staff defined the terms of self-advocacy. The definitions used for this project are:

- Self-advocacy as a noun: The grassroots, civil rights movement of self-advocacy including, its association and groups.
- Self-advocacy as a verb: Speaking or advocating for yourself rather than someone speaking for you.

Phase Two: Survey Tool Development

Project staff developed the survey instrument based on the stakeholder recommendations. Also, this phase incorporated focus groups of people with disabilities in Altoona, Scranton, Pittsburgh, Philadelphia, and Williamsport. Focus group information helped to further define the questions for the self-advocacy survey tool (Attachment 2). The tool is a three section interview instrument comprised of:

- Demographic questions on age, gender, disability, living situation, and legal decision making status.
- Part 1 questions focused on the degree to which people believed they have access to people who serve as supports in their lives. These questions address access to information for informed decision making, finding resources that help to solve a problem, and trusted people to serve as ongoing support.
- Part 2 questions were specific to self-advocacy. Part 2 includes two sections:

- Section A of Part 2 was for people who are not in formal self-advocacy groups. These questions focused on whether the person has the support they need to advocate on their own behalf and whether support would be available if they chose to find a self-advocacy group.
- Section B of Part 2 was for people who are members of self-advocacy groups. The questions in this section focused on whether the self-advocacy group has the support it needs to continue and whether belonging to the group is important to the person.

Phase Three: Information Gathering

The activities in this phase covered several priority areas:

- Identifying interviewers: Leaders and regional staff of Speaking For Ourselves coordinated efforts to work with people with disabilities as interviewers for the survey tool.
- Training interviewers: CQL trained eleven regional staff and self-advocacy leaders in the tool and interview process.
- Finding the people with disabilities across the state to be surveyed by phone. Two members representing The Pennsylvania DDC, the contract coordinator and the project liaison, helped the Self-Advocacy Project staff. Together, the team identified a process to target a statewide cross-section of people with disabilities to be interviewed. The following considerations and steps were taken during the interview identification process:
 - *People with the label of mental retardation are tracked through each county's Mental Health/Mental Retardation (MH/MR) system.* The Forty-five MH/MR administrators were identified as the best source for help in finding people willing to talk with interviewers.*
 - *Pennsylvania does not appear to have accessible sources for identifying its citizens with other developmental disabilities.* It was determined that the cross-disability organizations invited to the stakeholders workgroup were the best sources for identifying people with other developmental disabilities. Seventeen stakeholder groups representing most disability groups in the state were contacted to help find people willing to be interview.
 - *Concerns existed about the perceived priority of the interview.* The Pennsylvania DDC agreed to write an introduction to the letter sent by the Self-Advocacy Project. The introduction focused on the purpose of the self-advocacy project to gather information and make recommendations on how to better support self-advocacy efforts in Pennsylvania.
 - *Project staff coordinated its work with Speaking For Ourselves' regional coordinators.* During Phase Three, activities were decentralized throughout Pennsylvania to better reach as many people with disabilities as possible. County administrators and stakeholder groups were asked to identify people who would be interested in being interviewed by the Project and ask them to sign off on an interview agreement form. Those forms, then, were sent directly to the Speaking For Ourselves regional coordinator in the locality of the county or stakeholder group. Regional coordinators worked with interviewers to schedule surveys based

on the times indicated as most convenient by the interviewee. The regional coordinators also helped interviewers to complete the surveys by providing training, mentorship, and, in some cases, transportation.

***Note of clarification:** Self-advocates in Pennsylvania and elsewhere have adamantly stated for years that they find the label "mental retardation" to be hurtful and demeaning. Currently, self-advocates are requesting that when a label is necessary, the term "intellectual disability" should be used. For this report, the Self-Advocacy Project uses "mental retardation" only to refer to Pennsylvania's system of services that uses this term to define eligibility and name itself.

Results

Who responded to this survey?

Pennsylvania uses a specific database for people labeled with mental retardation. Conversely, there are no comparable lists to capture the numbers and names of people with other developmental disabilities. The project team and Pennsylvania DDC technical support staff identified the county MH/MR administrators and stakeholder group as the most comprehensive targets to solicit help in identifying people to be surveyed (Attachment 3). The target for interviews was 300 people. Eighty seven people completed the surveys.

Forty-five county MH/MR administrators and 17 stakeholder groups were contacted to help identify people to volunteer for the survey. Project staff received responses from 14 counties and none from stakeholder groups (Table 1). Roughly 100 people were identified and 87 completed the survey.

Forty-five letters were sent to County Administrators covering all 67 counties. Fourteen counties responded with names of people to interview. Seventeen letters were sent to stakeholders that had been represented on the survey development work group. No names came from the stakeholder groups.

Of the respondents, men accounted for 38% and women accounted for 62%. The mean age of the respondents was 37. Ages ranged from 20 to 68 years. People completing the survey had intellectual and developmental (38%), physical (22%), sensory (18%), brain injury (9%), and other or unknown (13%) disabilities. People surveyed lived in a variety of settings, with most at home with family (29%) or in group home settings (32%). Others lived in their own apartment or house (24%), supported living (5%), nursing home (2%), Lifesharing through Family Living (non relative) (7%), and state institution (1%).

Are Pennsylvanians with disabilities connected to people who might help them access supports, information, and resources?

Most people have someone to talk to when they need information (82%). Likewise, 83% of the time, people had someone to talk with when they needed supports or services. Most people identified for this were family or staff members. Similar results were found with other questions about access to help, finding outside resources, and finding information on jobs, transportation, or living options.

More than half the respondents (64%) stated they had access to needed equipment. People also stated they generally have others in their lives to help get what they want for their futures (84%). People believed they have friends, are connected to their community (84%), often respected (70%), and have the opportunity to help others (86%). When asked if they had people who could help find information about self-advocacy, 67% of the interviewees said they did not. When asked if they often felt lonely, 28% of the people responded yes.

Do people with disabilities think they have control in their lives?

More than 62% of the people stated they were their own legal decision makers. For the 38% who did not make their own legal decision, about one third said their parents decided, while one third had agency staff making decisions. The remaining third did not know or chose not to answer. Most

people said they make their own decisions and control their own lives (84%), 82% stated they worry they may lose the right to choose and make their own decisions. Of 83 people who responded to these questions, 86% said they want to speak for themselves.

Are Pennsylvanians with disabilities supported in self-advocacy efforts?

More than 67% of the people stated they know about self-advocacy groups and the same amount (67%) know how to contact a group. Of all 87 respondents, 45% said they did not belong to a group, however; of the remaining 55%, only half of those said they were in a group. The others chose not to or did not know the answer. The majority of people stated that if they belonged to a group, they would want to help others, and would want it to be fun, social, and about learning new things.

Of the people who belong to self-advocacy groups, (90%) stated the members support each other and had support from others outside the group to stay together. Nearly half believed they independently found the group. Almost all (99%) thought it was important for them to belong to a group. More than 90% of the respondents wanted their groups to include fun, friendships, and individual advocacy.

Feedback from the Interviewers

Was it difficult to get surveys completed?

- Some people who had signed a form agreeing to be interviewed questioned how the project got their names.
- In several situations, direct care staff refused to let interviewers speak with the person with a disability, even though the person consented to be interviewed.
- Parents sometimes chose to speak for the person, even though the person consented to be interviewed.
- In some cases, people who consented to the survey changed their minds and did not complete the process.
- The phone interviews generally did not work as well as face-to-face interviews.
- Since the interviewers were primarily people with disabilities, some of whom had intellectual disabilities, the phone interview and length of the survey posed barriers to the process.
- There was little local support to interest people in being a part of the survey process.
- The Health Insurance Portability Accountability Act (HIPAA) was sometimes used by professional and support staff as the reason for not referring people to be interviewed or allowing interviews to take place (steps to assure confidentiality during the project were a priority).

Conclusions and Considerations

Many people and organizations support the value of self-advocacy in Pennsylvania. The Pennsylvania DDC, stakeholder groups, cross-disability and advocacy organizations, families, supports coordination professionals, provider agencies, the Office on Mental Retardation, and other state-level agencies value the idea and the results of individual and/or group self-advocacy. There

are sporadic and even some statewide activities supporting organized self-advocacy. People with disabilities:

- Clearly had people or sources to contact when needing information, resources, and services related to things they knew to ask for.
- Believed they were in control of their lives but overwhelmingly stated others made decisions for them.
- Stated they feared losing the right to make their own decisions.

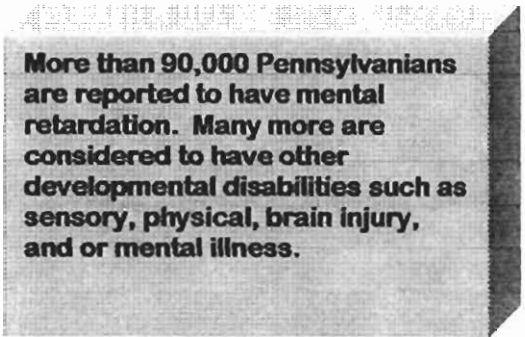
There is not, however, sufficient visible action supporting self-advocacy across the state. People interviewed:

- Had the least clear answers to the specific questions specific to self-advocacy.
- Appeared to have less understanding of the meaning of self-advocacy.
- Infrequently stated they wanted to belong to a group.
- Often stated they did not know how to contact someone about self-advocacy.

The lack of clarity about self-advocacy appears to begin with a lack of understanding of what self-advocacy is. In addition, it appears that people are not consistently supported in seeking help or membership related to self-advocacy.

The people who responded were representative of a variety of characteristics

It is estimated that more than 90,000 people in Pennsylvania have mental retardation/intellectual disabilities. Tens of thousands others are considered to have other disabilities (physical, sensory, brain injury, or mental illness). Three hundred surveys from across the state were targeted for this project. Project staff contacted 45 county MH/MR administrators and 17 identified Stakeholder groups for help in finding people to survey. About 100 people agreed to the survey and 87 completed the interview. The 87 people represented diversity in gender, age, disability, living situation, and decision-making status.



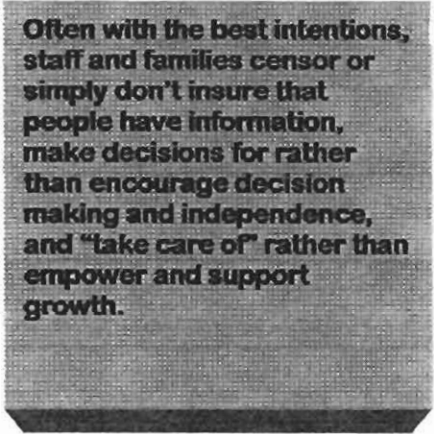
More than 90,000 Pennsylvanians are reported to have mental retardation. Many more are considered to have other developmental disabilities such as sensory, physical, brain injury, and or mental illness.

People believe they are connected to others who might help them

People reported they have others in their lives who help them get information, access resources, and connect them with supports and services. Families and paid staff are the ones relied upon to provide information, decision making support, and to find resources. Few people said they have their own abilities or use friends and advocates to access the same. Most people live with family or in group settings with paid staff. Family and paid staffs are the majority of support sources for people. For many potential respondents, professionals and families were not forthcoming with support for people to participate. In multiple situations, staff and family members stated they would answer for the person or refused to call the person to the phone, even though, the person indicated their previous interest to participate in the survey.

When asked about connections to people who help them get what they need, most respondents consistently said they had supportive people in their lives. The answers were not so clear when people reported on decision-making, controlling their lives, and their fear of losing the ability to make self-directed decisions. The survey results show conflicting information. The respondents stated that they controlled their own lives and made their own decisions, yet most respondents also stated they had family or staff members make most life decisions for them.

People with disabilities stated they make decisions and control their lives. The results show that people said they have a lot of friends. At the same time, they worried about losing control and the ability to decide for themselves. Additionally, they only connected staff and family to their sources of support and access to services. People with disabilities who responded were pleased with and appreciative of the helpful connections they have in their lives.



Often with the best intentions, staff and families censor or simply don't insure that people have information, make decisions for rather than encourage decision making and independence, and "take care of" rather than empower and support growth.

CQL has a data base of more than 5,000 interviews with people who have disabilities. The data show that people with disabilities make choices in their lives and have some control over their daily routines and preferences for immediate activities or objects. What is missing, however, is evidence that people believe they have control and decision making power over the longer term quality of their lives. As with the CQL data, the Pennsylvania Self-Advocacy Project shows the same results. People with disabilities appreciate and need the connections they have to family and paid staff. Consequently, those same connections may help perpetuate the more short term type of choice and control, such as daily routine. The project data is also consistent with CQL data in that people with disabilities are less likely to be empowered to make decisions on longer term quality of life decisions, such as where to live and work, or advocating for ones' self or others.

People with disabilities most often trust and depend on those they see as supportive and caring. Often with the best intentions, staff and families censor or simply don't ensure that people have information, make decisions for rather than encourage decision making and independence, and "take care of" rather than empower and support growth.

People who participate in self-advocacy are supported to do so; people who do not participate, do not have support

Equal numbers of people who vote also state they are their own legal decision makers. Yet, the majority of people said that staff and families make decisions for them. The responses to specific questions about self-advocacy were not consistent. People with disabilities in Pennsylvania may not:

- Fully know what self-advocacy means;
- Have information they need to make informed decisions about acting as self-advocates at the individual or group levels; and,
- Have active support for learning about and engaging in self-advocacy efforts.

More than 30% of the respondents belong to self-advocacy groups of some kind. Yet, less than one percent of people with developmental disabilities belong to formal self-advocacy groups across the state. The high number of self-advocates in the study does not, then, reflect statewide participation; it may be expected that better informed, self-directed, and more independent people have the confidence and understanding to participate in surveys of this type.

Caring providers and family members may perpetuate conditions that isolate people with disabilities. Isolation is a strong barrier to knowledge and confidence to advocate for one's self or others. People with disabilities are often "happy with what they get," and they may well increase the complacency of well-meaning providers and family members.

Inarguably, the Pennsylvania DD Council and the stakeholders involved in the planning of the survey value self-advocacy for individual as well as more formal group efforts. Project results show that even though the primary stakeholders were highly engaged in planning the survey tool and are known to promote self-advocacy efforts, there was little activity from the stakeholders in identifying people to participate.

Professionals and families voice support for self-advocacy as an important initiative, but the project results show there is low priority or incentive for action. The results of this project, like the national data on outcomes interviews, suggest that people with disabilities often have input into short term decisions about their day activities and/or routines. But it is not as likely that people have the same degree of decision making for the longer term quality of their lives. The results additionally offer no evidence that people with disabilities have access to information about self-advocacy (either as a verb or noun). Therefore, it is unlikely that they will know if self-advocacy is of personal value. Support for self-advocacy in Pennsylvania remains sketchy and in many ways, non-existent.

Recommendations for the Pennsylvania DDC

"Go back to the grass roots but do it differently"

This single statement reflects our overarching recommendation as a result of what we learned from the work of this project.

Self-advocacy by its very nature requires a person-to-person approach; thus, its support and development can happen only at the grassroots level. Efforts to support self-advocacy in the past have clearly enjoyed success; many people with disabilities in Pennsylvania see themselves as self-advocates and self-advocacy groups exist. At the same time, the great majority of people with developmental disabilities know nothing about self-advocacy or where to find supports to be a self-advocate.

The qualitative and experiential results of the interview surveys indicate that there is much more to be done. If self-advocacy is to be accessible to every Pennsylvanian with a developmental disability, then we must move beyond "first generation" strategies. It is imperative that self-advocacy be not just a noun or a verb, but both a way of thinking and a mode of action and is a systemic responsibility requiring commitment and action at the state and local levels from all stakeholders.

To cite a well-known call to action, it is important to think globally, but act locally. To that end, we recommend the following statewide strategies:

1. **Advocate for terminology change.** Self-advocates are requesting that when a label is necessary, the term "intellectual disability" should be used. Intellectual disability is quickly becoming the national and international term of choice for identifying people with cognitive limitations or difficulties.
2. **Focus on awareness for people with disabilities.** Self-advocacy will not be accessible statewide until people with disabilities know what it is and are able to decide if it is important in their lives.
 - a. Encourage all stakeholders, including self-advocacy groups, to make sure that people with disabilities know what self-advocacy is, how to get information, and who to contact for help.
 - b. Engage in joint public awareness and education activities that motivate staffs and families to encourage people with disabilities to understand and engage in self-advocacy at the individual and group levels.
 - c. Campaign aggressively at the county levels for support to all self-advocacy efforts. This should be a combination of target groups such as administrators, supports coordinators, parent/family groups, people with disabilities, and formal self-advocacy groups.
3. **Focus on accountability.** Discover ways to hold state decision makers and organizations accountable for actions that support self-advocacy.
4. **Promote a statewide campaign.** Challenge all organizations to self-assess actions and behaviors. Are professionals and other stakeholders able to say "at the end of the day, have we fully included people with disabilities as decision makers about this organization/system and the quality of their own lives?"
5. **Focus on outcomes and action.** Consider holding all funded projects responsible for actively supporting self-advocacy (individual and group) in project activities. Focus on the outcomes of the action not the statement of the value of self-advocacy.
6. **Model behaviors.** Highlight the priority for self-advocacy efforts in every request for proposal, contract, and deliverable.
7. **Identify ways to find people.** Advocate for accessible ways to reach people with all types of disabilities through data bases, key advocacy or service groups, and state systems. Include in this process people that traditionally are not connected to service systems or support groups.

8. ***Develop ways to promote knowledge and confidence.*** Consider an initiative that produces a curriculum or training package to help people with disabilities learn about and gain confidence in making decisions and having control in their futures. Success here should have a great impact on self-advocacy at the individual and group levels.
9. ***Establish actions plans.*** Encourage all key stakeholders to build and implement action plans that:
 - a. Promote access to information.
 - b. Support control and decision making on immediate issues, such as daily routine and choice of activities and services.
 - c. Prioritize long term or future quality of life thinking, decision making, and control on the part of people with developmental disabilities.
10. ***Assist in building financial and human capital.*** Help self-advocacy efforts find sufficient local, state, and federal money to enable comprehensive outreach efforts for individual and group self-advocacy efforts. Encourage all stakeholders to be ambassadors for people with disabilities to have access to information and support for making decisions about their own lives, and to advocate on their own or others behalf.

Attachment 1

Invited Members of the Stakeholder Workgroup

Pennsylvania Developmental Disabilities Council

MH/MR Program Administrator's Association of Pennsylvania

The ARC of Pennsylvania

Office of Mental Retardation

Pennsylvania Protection & Advocacy

Autism Living and Working

Pennsylvania Association of Resources for People with Mental Retardation

Pennsylvania Consumer and Family Group

PA SILC

PA TASH

Mental Health Association

Brain Injury Association

Always on Our Own

PARF

United Cerebral Palsy

Temple University-Institute on Disability

Attachment 2

The Pennsylvania Self-advocacy Project
Survey Instrument



the Self-Advocacy

Building the
knowledge

of self-advocacy in
Pennsylvania



Project

The Council on Quality and Leadership
and Speaking For Ourselves

funded by Pennsylvania Developmental
Disabilities Council

Thank you for agreeing to share your answers to help The Self-Advocacy Project.

Who Are We?

We are The Self-Advocacy Project of Pennsylvania. Some of the staff of this project are professionals who are self-advocates and some are not self-advocates.

What is the reason for this Project?

The survey is to learn about how well services help people with disabilities in Pennsylvania and what information or help and support they need in their lives.

How will the information I give help?

The information we get from people such as yourself will then help us give recommendations to the Pennsylvania Developmental Disabilities Council and other organizations. These recommendations will hopefully, help these organizations to do a better job of providing supports and information.

Will anyone know I gave these answers?

The information you give us will not be used in any way to find out who you are as an individual. It will be used with no names so that we can learn what people think and make recommendations on how to be a stronger support to people in having more control of their lives.

So, if no one will know who I am, why do you need to collect information about me?

We need your initials or some identifier to make sure that we do not get information from the same person more than once. Only the staff of The Self-Advocacy Project will see your initials.

We need information about you like your age, where you live, and other things because this helps us learn if there are differences for people in certain parts of Pennsylvania, of certain ages, abilities, gender, or whether people have guardians.

We will ask for your permission to be interviewed (if you do not fill out the survey yourself). We will also include a confidentiality statement that tells you again what we will and will not do with your information.

How will you get the information from people all over Pennsylvania when some people do not read or have telephones?

We are choosing a large number of people to help us get this information. We know that some people will need to give this information in different ways.

A few people have told us that they would like to complete a written survey that is easy to read and understand. We will send a written survey to those people.

Other people have told us that we will need to call on the phone or visit in person to get the information we need. We are going to complete some interviews by phone and some in person.

What if people want to answer the survey alone but do not understand all of the questions?

We will give you a phone number that you can call to ask for someone to help you over the phone or in person. The contact is: Otis Hicks, (610) 825-4592 x14.

How will others know what you do with the information once you group it and make recommendations to the Developmental Disabilities Council and other organizations?

You can use the same phone number [(610) 825-4592 x14] to let us know that you would like to see the report when it is done this Fall (about October, 2004). If you want, you can ask for a copy of the report from the Developmental Disabilities Council by contacting Kathy Gotts, (710) 787-6057.

Background

Help us to understand a little about who you are

Initials: _____**Gender:** Male _____ Female _____**Age:** _____**Type of Disability You Have:**☐ Intellectual☐ Developmental☐ Physical☐ Other

Describe: _____

Psychiatric/Mental Health

Describe: _____

Sensory☐ Brain Injury☐ Hearing☐ Language☐ Vision

Describe: _____

I Don't Know

Describe: _____

County where I live _____

Zip Code: _____

Circle or check the type of place that best fits where you live:

- ☐ **My Own Home or Apartment** I pay rent or a house payment and it is my home. I may or may not have staff to support me in my home.
- ☐ **Supported Living/Individual Support** I live in my own place and have staff work with me so I can be as independent as possible.
- ☐ **My Family's Home** I live with my parents, brother or sister, or other relatives in their home. I may or may not have staff to support me in our house.
- ☐ **I Share a Home with Others** I live with others and together we all pay rent or a house payment.
- ☐ **Nursing Home** I live in a place called a nursing home. Staff, including 24 hour nursing, work in this group setting.
- ☐ **Group Home/CLA** I live in a home with several people. This home belongs to my agency and it has staff that work with me and others.
- ☐ **CRR - Community Residential Rehabilitation** I live with other people with disabilities and am working toward living independently.
- ☐ **Personal Care/Boarding Home** I live in a home where I pay room and board.
- ☐ **Family Living** I live with a family that is not related to me.
- ☐ **Institution** I live with many other people in a large building or facility and have many staff that work with all of us.
- ☐ **State Center**
- ☐ **Psychiatric Hospital**
- ☐ **Jail/Prison**
- ☐ **Medical Hospital**

go to the next page if you live someplace other than those listed above

Other

Description of where I live: _____

I make my own legal decisions Yes _____ No _____

If not, who does?

☐ Parent ☐ Sister/Brother ☐ Grandparent ☐ Agency ☐ Other

Are you a registered voter? Yes _____ No _____

I vote in: *Check all that apply*

Local elections _____ State elections _____ National elections _____

I receive services or supports Yes _____ No _____

If yes, what kind? _____

Confidentiality: This information will only be used as part of the statewide data collection project. No individual information will be used to identify any person and will not be given to any source outside The Self-Advocacy Project.

“I want to build a system that responds to each person's needs, and treats each person with respect. Not one that requires spokespeople to tell me what all people need.”



part 1

Self-Advocacy:
(verb)

Speaking or ...
Advocating for
yourself instead
of someone
speaking for
you.

This section is about ACCESS to:

Partners: People in my life that help me feel connected to others. Partners may help me locate resources.

Sharing Experiences and Information: People or sources that seem to understand my experiences and need for information.

Supports: People or equipment that can provide help to do things for myself.

1. I have someone to talk with when I feel alone.

☐ No ☐ Not often ☐ Often ☐ Yes

2. That person is:

☐ No One ☐ Family ☐ Friend ☐ Professional or Staff

3. I have someone to talk with when I need to know something.

☐ No ☐ Not often ☐ Often ☐ Yes

4. That person is:

☐ No One ☐ Family ☐ Friend ☐ Professional or Staff

5. I have someone to talk with when I need help or supports in my life.

☐ No ☐ Not often ☐ Often ☐ Yes

6. That person is:

☐ No One ☐ Family ☐ Friend ☐ Professional or Staff

**7. I have people who can help me find information
I want or need about:**

Self-advocacy groups

☐ No ☐ Not often ☐ Often ☐ Yes

Services

☐ No ☐ Not often ☐ Often ☐ Yes

Job options

☐ No ☐ Not often ☐ Often ☐ Yes

Transportation

☐ No ☐ Not often ☐ Often ☐ Yes

Living options

☐ No ☐ Not often ☐ Often ☐ Yes

**8. I know where to go get help finding
resources to solve a problem for myself.**

☐ No ☐ Not often ☐ Often ☐ Yes

9. When I need help I ask:

☐ No One ☐ Family ☐ Friend ☐ Professional
or Staff

10. I have different people that understand my feelings, concerns, happiness, and experiences.

☐ No ☐ Not often ☐ Often ☐ Yes

11. I have people who can help me get information I want or need.

☐ No ☐ Not often ☐ Often ☐ Yes

12. This is who I ask to help when I need to find information on something:

☐ No One ☐ Family ☐ Friend ☐ Professional
or Staff

13. I know people that I feel comfortable with or trust to help me get the supports that I want.

☐ No ☐ Not often ☐ Often ☐ Yes

14. These are the people I feel comfortable with and trust to help me get the supports I need:

☐ No One ☐ Family ☐ Friend ☐ Professional
or Staff

15. I have all of the equipment, technology, or other help I need.

☐ No ☐ Very little ☐ Some/not all ☐ Yes

16. I know how to contact my legislator, government representatives.

☐ No ☐ Yes

**This section is about
your ABILITY to:**

Make Choices: I have control of my own choices, decisions, and access to information to make informed choices.

Be Self-Determined and Be Empowered: My life is in my control. I have support to be in control of my life. I decide how I want my life to work. I let others help me.

Live in a WORLD that has: Social Connections that help me belong, have friends, have people I can feel close to and trust. I give as much as I get in these relationships.

1. I make decisions for myself and will continue to do so.

☐ No ☐ Not often ☐ Often ☐ Yes

2. I worry that I may lose the right to choose and make decisions for myself.

☐ No ☐ Not often ☐ Often ☐ Yes

3. My family or others need to make most decisions for me.

☐ No ☐ Not often ☐ Often ☐ Yes

4. I control my own life.

☐ No ☐ Not often ☐ Often ☐ Yes

5. I have people in my life who help me control what is important to me.

☐ No ☐ Not often ☐ Often ☐ Yes

6. The people that help me control what is important to me are:

☐ No One ☐ Family ☐ Friend ☐ Professional
or Staff

7. People listen when I speak for myself.

☐ No ☐ Not often ☐ Often ☐ Yes

8. I know how to take charge of my life.

☐ No ☐ Not often ☐ Often ☐ Yes

9. I often feel lonely.

☐ No ☐ Not often ☐ Often ☐ Yes

10. People talk to me the way I want them to.

☐ No ☐ Not often ☐ Often ☐ Yes

11. I have friends that understand me and my life.

☐ No ☐ Not often ☐ Often ☐ Yes

12. I am a part of my community. I belong.

☐ No ☐ Not often ☐ Often ☐ Yes

13. People ask my opinion.

☐ No ☐ Not often ☐ Often ☐ Yes

14. I help others.

☐ No ☐ Not often ☐ Often ☐ Yes

1. One of my goals is to speak for myself.

☐ No

☐ Yes

2. I know where to go if I want to join a local group that helps to speak for all people with disabilities.

☐ No

☐ Yes

3. People in my life are helping me to get what I want for my future.

☐ No

☐ Not often

☐ Often

☐ Yes

**This section is about
having SUPPORT for:**

Goals: I have goals for my future, for what is important to me. I have support for what I want to work toward.

“When we [self-advocates] talk about leadership, we’re for everybody, and hopefully in the future these environments will be more accessible for more people to participate.”



“Empowerment is a choice... it is the individual voice.”

part 2

Self-Advocacy:
(noun)

The grass roots, civil rights movement of self-advocacy (speaking for) including its association and groups.

I belong to a group that speaks for other people with disabilities. ☐ No ☐ Yes

Comment: (what group, what do you want us to know about this group?)

IF THE ANSWER IS **NO**: ASK QUESTIONS **A**

IF THE ANSWER IS **YES**: ASK QUESTIONS **B**

**This section is about
ACCESS to:**

Partners: People in my life that help me feel connected to others. Partners may help us locate resources.

Sharing Experiences and Information: People or sources that seem to understand my experiences and need for information.

Supports: People or equipment that can provide help to do things for myself.

QUESTIONS A

1. I know about groups that speak, work hard, or advocate for better information, access, or services for people with all types of disabilities.

☐ No ☐ Yes

2. I would like to belong to some type of group.

☐ No ☐ Yes

3. I would like to belong to a group that shares information, experiences, and supports each member of the group.

☐ No ☐ Yes

4. I know how to contact a group if I want to join.

☐ No ☐ Yes

1. I would like to be a part of a group that helps people to speak for themselves.

☐ No ☐ Yes

2. If I joined a group, I would want to help others speak for themselves.

☐ No ☐ Probably not ☐ Probably ☐ Yes

3. I would like to be a part of a group that could help change laws so people with disabilities have more control over their own lives.

☐ No ☐ Yes

4. If I joined a group, I would want it to be social, fun, and have opportunities to learn new things.

☐ No ☐ Probably not ☐ Probably ☐ Yes

5. I know who to ask if I want to find one of these groups.

☐ No ☐ Yes

6. I would have support and transportation to get to group meetings.

☐ No ☐ Probably not ☐ Probably ☐ Yes

**This section is about
your ABILITY to:**

Make Choices: I have control of my own choices, decisions and access to information to make informed choices.

Be Self-Determined and Be Empowered: My life is in my control. I have support to be in control of my life. I decide how I want my life to work. I let others help me.

Live in a WORLD that has: Social Connections that help me belong, have friends, have people I can feel close to and trust. I give as much as I get in these relationships.

1. I would be interested in finding a group that helps me meet my goals and speak for myself.

☐ No ☐ Yes

2. I would like to be a part of a group that works hard to make change for all people with disabilities in the state of Pennsylvania.

☐ No ☐ Yes

3. I know where to find and join one of these groups.

☐ No ☐ Yes

**This section is about
having SUPPORT for:**

Goals: I have goals for my future, for what is important to me. I have support for what I want to work toward.

QUESTIONS B - FOR GROUP

1. I always have a way to get to the group meetings.

☐ No ☐ Not often ☐ Often ☐ Yes

2. My group has support from others to stay together.

☐ None ☐ A little ☐ Pretty much ☐ A lot

3. My group has partners that can share information and support each other.

☐ No ☐ Yes

4. I found this group by myself.

☐ No ☐ Yes

Self-Advocacy:
(noun)

The grass roots, civil rights movement of self-advocacy (speaking for) including its association and groups.

**This section is about
ACCESS to:**

Partners: People in my life that help me feel connected to others. Partners may help me locate resources.

Sharing Experiences and Information: People or sources that seem to understand my experiences and need for information.

Supports: People or equipment that can provide help to do things for myself.

1. This group helps to make changes in state policy.

☐ No ☐ Not often ☐ Often ☐ Yes

2. This group has a strong voice for all people with all types of disabilities.

☐ No ☐ Not often ☐ Often ☐ Yes

3. This group helps educate others about issues for people with disabilities.

☐ No ☐ Not often ☐ Often ☐ Yes

4. Other organizations (or people) help support this group to do its work.

☐ No ☐ Not often ☐ Often ☐ Yes

5. My group shares information and teaches me to learn new skills that help me to make new friends.

☐ No ☐ Not often ☐ Often ☐ Yes

6. This group helps members have many different experiences.

☐ No ☐ Not often ☐ Often ☐ Yes

**This section is about
your ABILITY to:**

Make Choices: I have control of my own choices, decisions, and access to information to make informed choices.

Be Self-Determined and Be Empowered: My life is in my control. I have support to be in control of my life. I decide how I want my life to work. I let others help me.

Live in a WORLD that has: Social Connections that help me belong, have friends, have people I can feel close to and trust. I live as much as I get in these relationships.

**. It is important for me to belong to the
roup.**

☐ No ☐ Sometimes ☐ Often ☐ Yes

**. Someone helps me find this group as a way
o make friends.**

☐ No ☐ Not often ☐ Often ☐ Yes

1. My group has [the money it needs] to get people to meetings, make phone calls, write letters, or other things that help meet its goals of helping make changes for people with disabilities.

☐ No ☐ Not often ☐ Often ☐ Yes

2. I wish my group did more or different things.

☐ No ☐ Not often ☐ Often ☐ Yes

3. What additional or different things would you like your group to do?

☐ Fun ☐ Individual advocacy ☐ Change laws

☐ Other

Please explain other: _____

**This section is about
having SUPPORT for:**

Goals: I have goals
my future, for
what is important to
me. I have support
for what I want to
work toward.

Interviewer Confidentiality for the Self-Advocacy Project

In the course of interviews, you will be seeing and hearing information that is confidential in nature. During this interview, you will have access to personal information. This information is confidential (staff, records, and this interview).

Because this information is confidential, you must not share it. The only people with whom this information may be shared are staff of the Self-Advocacy Project. Completed survey forms should not be left uncovered or lying around where others might happen to read them. Do not make copies of the completed forms.

Most importantly, you must never use or release the person's name or that of their parent, relative or guardian; or other identifying information about them in any conversations or in written materials with anyone other than the entities identified directly above.

Please check the boxes to indicate you have complied with the following statements:

☐ I understand and will adhere to my commitment to confidentiality during and after this interview.

☐ I explained to the person I am interviewing about the project's commitment to confidentiality of personal information. To the best of my ability, I have determined the person understands this information.

Your signature below shows your understanding and agreement to follow the rules of these statements.

Interviewer

Date

The Council on Quality and Leadership
100 West Road, Suite 406
Towson, MD 21204
410.583.0060 phone
410.583.0063 fax
www.thecouncil.org

Speaking For Ourselves
502 W. Germantown Pike
Suite 520
Plymouth Meeting, PA 19462
610.825.4592 phone
610.825.4595 fax
www.libertynet.org/speaking

**Pennsylvania Developmental
Disabilities Council**
Harrisburg Office
Room 569 Forum Building
Commonwealth Avenue
Harrisburg, PA 17120
717.787.6057
www.paddc.org

Attachment 3

Requests for Assistance in Identifying People to be Interviewed

MH/MR County Administrative Offices

Stakeholders

Sample Letters

Sample Interview Agreement Form

Allegheny
Armstrong/Indiana
Beaver
Bedford/Somerset
MH/MR County Administrative Offices
Berks
Blair
Bradford/Sullivan
Bucks
Butler
Cambria
Cameron
Carbon/Monroe/Pike
Clarion
Clearfield/Jefferson
Centre
Chester
CMSU
Crawford
Cumberland/Perry
Dauphin
Erie
Fayette
Forest/Warren
Franklin/Fulton
Greene
Huntingdon/Mifflin/Juniata
Lackawanna/Susquehanna/Wayne
Lancaster
Lawrence
Lebanon
Lehigh
Luzerne/Wyoming
Lycoming/Clinton
Mercer
Montgomery
Northampton
Northumberland
Philadelphia
Potter
Schuylkill
Tioga
Venango

Washington
Westmoreland
York/Adams

Stakeholders

Office of Mental Retardation

Pennsylvania Developmental Disabilities Council

MH/MR Program Administrator's Association of Pennsylvania

The ARC of Pennsylvania

Pennsylvania Protection & Advocacy

Autism Living and Working

Pennsylvania Association of Resources for People with Mental Retardation

Pennsylvania Consumer and Family Group

PA SILC

PA TASH

Mental Health Association

Brain Injury Association

Always on Our Own

PARF

United Cerebral Palsy

Temple University-Institute on Disability

Blindness and Visual Services

- Two people who work in sheltered or supported employment settings.
- Phone people from the area you cover that fit the above descriptions as much as possible. We believe that a higher percentage of people agree to be interviewed if they have direct contact by someone (or an entity) they know or think of as local. Please explain the purpose of our invitation to them for the interview using the description in this letter. If they agree to be interviewed, either mail them the Interview Agreement Form with a request to mail the finished form within the week or complete it on the phone with them and mail in the addressed and stamped envelope.
- If phoning people is not possible, please send our enclosed letter and Form Interview Agreement Form to **15** people that have similar characteristics to those above. It would be helpful if you attached a note of your own supporting their participation in the project.

If you or any of the Supports Coordinators have questions or concerns about the project or the interview process, please feel free to call **Otis Hicks at 610-825-4592. {you may want to include your 800 instead}** Please accept our warmest thanks and appreciation for your valuable efforts in helping this project to be successful for the Developmental Disabilities Council and people with Developmental Disabilities in Pennsylvania.

Sincerely,

Graham
Executive Director
Pennsylvania Developmental Disabilities Council and

The Self-Advocacy Project Staff

The Council on Quality and Leadership

Liz Obermayer
Cynthia Shima Kauffman

Speaking For Ourselves

Otis Hicks
Pam Kennedy
Steve Dorsey
Debbie Robinson

Draft Letter to Stakeholders:

Dear (name of Stakeholder Group Member from Pam's list):

The Pennsylvania Developmental Disabilities Council (PDDC) is currently funding the Self-Advocacy Project to learn about the state of self-advocacy in the Commonwealth. Together, the partners of this project, Speaking For Ourselves and The Council on Quality and Leadership are completing this work for the PDDC. Recommendations from the Project will help the PDDC improve its work in support of self-advocacy efforts in Pennsylvania.

A year ago, in Harrisburg, the Self-Advocacy Project staff held a meeting with multiple stakeholders. This meeting resulted in many contributions to the development of the interview tool that we will use to gather information for the Project. At that time, we determined that the success of the Project depends upon our collaboration with a variety of the stakeholders also interested in learning about the views of people with Developmental Disabilities.

We appreciate how busy each of you are. We believe that gathering information for this project will be a valuable tool in providing future support to Pennsylvanians with Developmental Disabilities and will make your efforts worthwhile.

Seeking People Agreeing to Participate in an Interview:

With your help, we need to talk to people with Developmental Disabilities, other than Mental Retardation. We are asking you to help us identify five (5) to eight (8) people (over the age of 21) who agree to be interviewed and have characteristics of the disability arena you represent (for example Brain Injury, Deaf, physical disabilities, Mental Illness, etc.). We are asking you to:

- Select people that match or come close to matching the following characteristics. We would like to interview people who are able to speak or write during the interview process (rather than having a parent, worker, or other speak for them). However, we would be happy to interview at least one person that will need help in communicating.

Additionally, it will help us to have information from people that share a variety of characteristics. If possible, please identify people with some of the following characteristics:

- At least one person (preferably two) living on their own or with housemates in their own place.
- One or two people living in residences operated by an organization.

- One person living in a boarding, foster, family care, halfway house, or other type of alternative community setting.
 - One person living in an institution (this can be a traditional institution, or nursing homes, jail, etc.).
 - One person living with parents, sister, brother, or other family members.
 - Two people who work in regular competitive jobs.
 - Two people who engage in other types of day activities such as school, clubhouses, Independent Living Centers, etc.
- Phone people from the area you cover that fit the above descriptions as much as possible. We believe that a higher percentage of people agree to be interviewed if they have direct contact by someone (or an entity) they know or think of as a connection. Please explain the purpose of our invitation to them for the interview using the description in this letter. If the person agrees to be interviewed, please mail them the Interview Agreement Form with a request to complete and mail to us within the week. ***If you wish***, you can complete the form while on the phone with them. We ask that you mail the form to us in the addressed and stamped envelope.
 - If phoning people is not possible, please send our enclosed letter and the Interview Agreement Form to **15** people that have similar characteristics to those above. It would be helpful if you attached a note of your own supporting their participation in the project.

If you have questions or concerns about the project or the interview process, please feel free to call **Otis Hicks at 610-825-4592**. Do you want the 800 # instead? Please accept our warmest thanks and appreciation for your valuable efforts in helping this project to be successful for the Developmental Disabilities Council and people with Developmental Disabilities in Pennsylvania.

Sincerely,

Graham
Executive Director
Pennsylvania Developmental Disabilities Council and

The Self-Advocacy Project Staff

The Council on Quality and Leadership

Liz Obermayer
Cynthia Shima Kauffman

Speaking For Ourselves

Otis Hicks
Pam Kennedy

Steve Dorsey
Debbie Robinson

June 1, 2004

Dear ,

The Pennsylvania Developmental Disabilities Council (PDDC) is currently funding the Self-Advocacy Project to learn about the state of self-advocacy in the Commonwealth. Together, the partners of this project, Speaking For Ourselves and The Council on Quality and Leadership are completing this work for the PDDC. Recommendations from the Project will help the PDDC improve its work in support of self-advocacy efforts in Pennsylvania.

You were chosen to be one of several hundred Pennsylvanians to be interviewed. We are asking for your time in taking a short survey that will help the Developmental Disabilities Council learn from people with disabilities in Pennsylvania about who you depend on to:

- Help you to get information you need.
- Listen and help you fix problems.
- Help you find things or people that help you live a better life
- Work hard to make changes in the way people with disabilities are supported and treated.

We really need your help in trying to answer some of these questions. The survey will take about 20-30 minutes on the phone. Please fill out the **Interview Agreement Form this week** and return it in the addressed and stamped envelope. The name and address on the envelope will be:

Otis Hicks or the name/address of the regional coordinator

Speaking for Ourselves

Suite 550 502

W. Germantown Pike

Plymouth Meeting, PA 19462

If you have any questions feel free to call **Otis Hicks at 610-825-4592** 800#?(I do think this number should remain Otis'. That way, he can track the kind of questions we get and can give consistent answers. Make sense?)

We look forward to hearing from you in the next week. Thank you so very much for helping us to collect information. ***We cannot do this project well without you.***

Sincerely,

Liz Obermayer
Cindy Kauffman

Pam Kennedy, Debbie Robinson,
Steve Dorsey & Otis Hicks

The Council on Quality & Leadership

Speaking for Ourselves

PENNSYLVANIA SELF-ADVOCACY PROJECT
Interview Agreement Form

Please circle or check the best answer for you.

_____ I choose to take part in this survey

_____ I choose not to be part of this survey

The surveys will be done by phone. If the phone will not be a good way for you, what will work best?

_____ Phone is OK

My Name and Phone Number are: _____

_____ In Person

My name, address, and phone number are: _____

_____ Mail

If the phone survey is OK with you, what is the best day/ time for us to call?

Day of the Week

Time of Day

_____ Monday

_____ in the morning

_____ Tuesday

_____ in the afternoon

_____ Wednesday

_____ in the evening

_____ Thursday

_____ Friday

_____ Saturday

If you will need someone on the phone (or with you) to help answer the survey questions, let us know, OK?

_____ I speak (write) for myself.

_____ I will speak for myself but will have someone on the phone in case I want help.

_____ I will have someone with me for the survey to can help me understand and answer the questions.

Thank you from all of the Self-Advocacy Project staff!!