



**CLOSE THE DOORS
CAMPAIGN FOR FREEDOM PACKET**

Self-Advocates Becoming Empowered



Position Statement on Closing Institutions

We believe that all institutions,
both private and public should be closed.
All people regardless of the severity of their
disability should live
in the community with the support they need.

by Self-Advocates Becoming Empowered
Adopted April, 1995

CLOSE THE DOORS: CAMPAIGN FOR FREEDOM HELPING PEOPLE LEAVE AN INSTITUTION

How to help people while they are in the institution:

1. Help people get used to moving a little bit at a time.
2. Get people moral support, training, someone to talk with, and help from case managers.
3. People First members can help by:



- a. get people to come to a local chapter
- b. visiting people in the institution—meet people in institutions before they move, be a friend to people, take them places, i.e. your home, churches, show them what the community looks like
- c. start chapters in institutions—help people learn how to speak up for themselves and learn about moving, make visits, talk about living in the community
- d. make presentations to people in the institution about advocacy and independence and living in the community



How to help people after they move out of the institution:



1. Visit people in their new places and check on them to be sure they are o.k.
2. Call them on the phone.
3. Help them join a People First Chapter. Take them to a local chapter and help them learn for themselves and become more independent.
4. People should be able to learn from their own mistakes.

**CLOSE THE DOORS: CAMPAIGN FOR FREEDOM
OUTLINE OF PRESENTATION AND SUGGESTED MATERIALS AND
TIPS TO BE USED IN MAKING THE PRESENTATION**

1. INTRODUCTION OF YOURSELF

2. PURPOSE OF THE CLOSE THE DOORS CAMPAIGN

- Overhead: Position Paper

3. VIDEO/VISUAL PRESENTATION OF AN INSTITUTION THAT HAS CLOSED

- Laconia Video or Pictures
- Tell About the Video
- Ask the Group to Think About the Following: Would they live in some type of institution where they have no control? Would you choose this?
- Overhead/Fact Sheets: Answers To Top 10 Arguments of Why People Think Institutions Should Not Be Closed

4. STORIES OF LIVING IN INSTITUTIONS

- Panel members or participants in the group will tell their stories or read stories about their friends or other self-advocates who live or have lived in institutions.

5. STORIES OF LIVING IN THE COMMUNITY

- Panel members or participants in the group will tell their stories about living in the community.
- You may want to talk about freedom, choices, jobs, friends, and living in your own place.
- You need to talk about the types of support and services you and your friends receive.
- Tell stories for your friends who cannot tell their own stories.
- A video may be used to tell a story of a friend who cannot tell his or her own story.
- Overheads/Fact Sheets: Community for All
 Stories of How People Who Have Lots of
 Needs for Support Can Live in
 Communities

CLOSE THE DOORS: CAMPAIGN FOR FREEDOM SUGGESTED THINGS STATE CHAPTERS CAN DO

1. Be educated on the issues
2. Talk to your Governor
3. Support local efforts: create a help-line for local chapters to call, provide emotional support to local chapters
4. Develop a formal policy or position paper
5. Make sure the state president is supported by national and local people
6. Find out ways to state your position to State Government
7. Bring the powers that be together to tell them what is your position and host roundtables or coalition building
8. Identify people who lived in institutions to help write letters about what it was like
9. Attend your state's Arc conferences and talk about community living and closing institutions
10. Use yellow ribbons, buttons, friendship bracelets, keys, t-shirts or other items to show your support
11. Demand Department of DD and Governor to develop a plan to close institutions
12. Put CTD articles and success stories in your newsletters
13. Get information about inspections and surveys (i.e., Justice Department or HCFA reports)
14. Have Close the Doors training for local chapters
15. Talk about which institution(s) to focus on
16. Get your DD Council, State Arc and P&A to adopt a closure position
17. Learn about direct action and lawsuits
18. Have a state leadership retreat to come up with a plan on how your state chapter will work on this goal

CLOSE THE DOORS: CAMPAIGN FOR FREEDOM SUGGESTED IDEAS FOR LOCAL CHAPTERS TO DO

1. Recruit members from institutions
2. Visit people who live in institutions to get to know them; get to know the individuals who live at the institutions on a personal level and develop friendships
3. Learn about the issue of closing institutions
4. Get people who have lived in institutions to tell their stories
5. Get people who are experts to come to talk to the group
6. Ask administrators of institutions pointed questions about how the institutions work, why do people live there, what kind of choices/decisions are they allowed to make, do they get to be included in the community
7. Visit institutions, ask to come unannounced, ask to eat with the people who live there
8. Help people who live in institutions to learn how to speak up for themselves
9. Volunteer to help people who live there
10. Local chapters could approach local Arcs, Student CEC, TASH, AAMR, Civitans, civic groups, other professional groups about closing down institutions and get them to support the movement
11. Local media coverage
12. Talk with local community providers of services and supports to enlist their support
13. Celebrate successes for people
14. Have local Close the Doors Training for members
15. Local chapters meet with the local politician in his/her office or home
16. Use videos that show personal stories to educate local members and others what is going on in institutions
17. Group act on rights issues (i.e., staff reading and not giving out people's mail in institutions)
18. Start a scrapbook about institutions in your area
19. Have members wear buttons, ribbons, friendship bracelets, or other things to show they are working on this goal

**CLOSE THE DOORS: CAMPAIGN FOR FREEDOM
TOP TEN ARGUMENTS YOU WILL HEAR
AGAINST CLOSING INSTITUTIONS**

1. They won't make it in the community because they have too many disabilities and can't take care of themselves.

If they have the supports and services in the community, they can move. They can make it. The state should be responsible to do this.

2. Institutions should be a choice: people like living in the institutions.

Nobody has had the option to live other places with the supports they really need. How can they make a choice without experience? Would you choose to live there?

3. People will end up on the streets.

We don't want anyone to move until we are sure that the supports and services are in place for them.

4. The people are perpetual children, they only have minds of two year olds.

Since when do we lock up our two year olds?

5. Parents and families don't want them to move.

Research shows that families who are against people moving change their minds afterwards because they see the real good positive things that can happen.

6. This is a good institution, everything they need is right there, like doctors and nurses in case of an emergency.

You can get the same things in the community. The community has good medical and other services for people.

7. The community system isn't ready and won't be accountable for what happens.

As more people move, the community system will have more resources to help people. People will have more people in their lives to look out for them.

8. There's no guarantee the money will be there.

People have been living in good community services for many years. The same funds that pay for the institutions can pay for the community.

9. Society isn't ready, they'll be made fun of and won't have friends.

There will be more opportunities for people to make friends because research shows people go more places and do more things.

10. The employees will lose their jobs and it will hurt the community where the institution is.

It's the state's responsibility to plan what will happen to the employees. Experience shows that state employees get other jobs in state agencies.

THE BOTTOM LINE: This is a human rights and constitutional rights issue. People have the right to live in the community.

**Close the Doors: Campaign for Freedom
Community for All!!!!**

**EVERYBODY WHO LIVES IN INSTITUTIONS TODAY
CAN LIVE IN THE COMMUNITY
WITH THE SUPPORTS THEY NEED
NO ONE SHOULD BE LEFT BEHIND**

HOW DO YOU MAKE THIS HAPPEN?

Supports must be in place that are individualized and flexible.

WHAT ARE THE SUPPORTS THAT NEED TO BE IN PLACE?

Supports that need to be in place are:

- Communication Supports to help encourage people's own ways of communicating. This includes assistive devices, interpreters, and other communications assistance devices.
- Supports To Get Around in our communities. This includes wheelchairs designed for the person, accessible transportation and access to transportation to get to recreation, leisure, work, school and medical appointments.
- Educational and Personal Growth Supports that assist people in learning new things, such as how to manage our money, use computers, take care of our home, and cook our meals.
- Personal Care Assistance to help people get up in the morning, bathe and get out of the house.
- Homemaking Assistance that help people take care of their home.
- Employment Supports that include career planning and job coaches.
- Supports That Connect Us with our communities through circles of friends, personal friendships, self-advocacy groups, churches, recreational and civic groups.

- Housing that is affordable, safe and accessible.
- Advocacy Supports that promote learning to make decisions, assertiveness and protection of rights. These supports can be provided through self-advocacy groups, as well as personal and legal advocacy.
- Access to Medical, Health and Other Specialized Supports.

HOW DO YOU MAKE SURE THESE SUPPORTS ARE PROVIDED?

A Case Manager or Service Coordinator assists in coordinating these supports. This person makes sure a person gets the supports needed and teaches a person to coordinate their own supports.



CLOSE THE DOORS: CAMPAIGN FOR FREEDOM USING THE COURTS TO HELP PEOPLE MOVE OUT

What kinds of lawsuits are there? There are two kinds of institution lawsuits. There are lawsuits brought by the U.S. Justice Department and there are lawsuits brought by advocates. Sometimes these lawsuits are joined together but sometimes they are separate.



What laws are involved? The first “claims” that are used in lawsuits are violations of people’s rights under the U.S. Constitution. Other laws that are brought up include the Americans with Disabilities Act, IDEA, Section 504 and the Social Security Act.

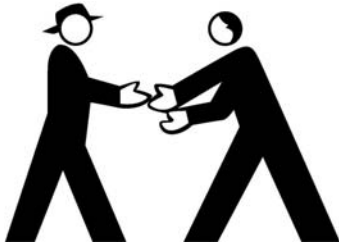
How will we get a lawyer? We can ask other states who are involved in lawsuits to recommend a lawyer to see. Ask organizations like The Arc, Protection and Advocacy or Legal Aid.

What’s involved in a lawsuit? You will need to make sure everyone in your group wants to do it. You will need information about the bad things that are happening to people at the institution. You will need to work closely with your lawyers to talk about what papers to file at the courthouse. You will need to go to the courthouse for hearings, trials and other meetings. You will need people to testify about what has happened and what needs to be done. You will need ways to support each other and keep people interested in what is happening. You will need to use the media to help state your position.



Should we go to state or federal court? When the Constitution and Federal Laws are violated, you go to federal court to file your “claims” and ask for relief.

Who should be involved? Members, people on the inside, family members who agree with you, and other disability organizations who believe in this issue.



Who can we trust? In a lawsuit everything between you and your attorney is confidential. Sometimes things need to be a surprise so the other side will not be able to come up with a defense for what they are doing. For example, if you are going to talk about somebody's abuse, you don't want the other side to know and maybe put pressure on that person to not talk about it with you. You need to make sure that everyone involved can be trusted to keep things confidential. It is really true that people's lives can depend on trust in institution lawsuits.

How will people react? State government, family members, legislators, employees and other people might be really angry when you file a lawsuit. You might get ugly remarks, phone calls, and mail. People might try to retaliate against you for taking a stand. You will need to let your lawyers know about this if it happens. Also, you will need to help your members know what to do when they get negative feedback. People who were your friends or even members might quit and not talk to you anymore.



How much does it cost and how long will it take? It depends on the agreement you have with your attorney. Some attorneys will not charge you and will ask the court for attorney fees if you win. But, you will still need some money to pay for things like getting people to the courthouse, faxes, phone calls, media campaigns, etc. Lawsuits can take a very long time. It can take anywhere from 3 to 10 years to resolve problems in court.

Where can we get more information? You can get more information about lawsuits self-advocates have filed from:

People First of Tennessee, Inc. (615) 256-8002
People First of Connecticut, Inc. (203) 792-3540

CLOSE THE DOORS: CAMPAIGN FOR FREEDOM PARENT ATTITUDES TOWARDS CLOSING INSTITUTIONS

Many parents who have children living in institutions are happy to see their family members moving out of these places. Others are concerned about them moving to the community. Common questions that they ask include the following: “Will my son or daughter be safe in the community?,” “Will they have friends?,” “Will I be able to visit them in the community?,” “Will they always have a home to live in?”

A lot of professionals asked parents what they thought about their sons and daughters before and after they moved. Two of these professionals (Larson and Lakin, 1991) reviewed 21 studies that looked at parental attitudes and expectations about their children moving out of institutions. From these studies, the following conclusions were made:

- **The vast majority of parents were satisfied (secure, content, and comfortable) with their family member living in an institution.**

Eleven of the studies asked parents questions before their son or daughter moved. Ninety-one percent said they were somewhat or very satisfied with the institution. Only 21% of the parents supported the idea of having their son or daughter move to the community.

- **The vast majority of parents changed their attitudes about community placement after their family member moved.**

Four studies surveyed parents before and after their family member moved. Only 15% of these parents had a positive reaction about their son or daughter moving before the move. After the move, 62% of the parents expressed a positive opinion about the move to the community.

Before the move, 83% of the parents reported satisfaction with the institution. After the move, 87% were satisfied with the community.

- **After experiencing community services, parents viewed the institution less positively than they did when their family member lived there.**

Seven studies interviewed parents whose sons or daughters had moved into the community about their satisfaction with the institution, the community, and their opinion of the move. Only 51% said they had a positive reaction about their family member moving to a community home before it happened. This compares with a 83% pre-discharged rate of satisfaction with the institution and a 15% rate of support for the move. The same parents reported an 88% rate of satisfaction with their children's community living experience.

- **Parents observed improved quality of life and relationships for their family members after the move.**

In five studies, more than 65% of the parents reported after the move that their family member was happier, that relationships between their son or daughter and other people improved, that needed services were available, and that staff members in the home were fine. Fewer than 12% reported negative changes in these areas.

SOURCE: Larson, S. A., & Lakin, K. C. (1991). Parent attitudes about residential placement before and after deinstitutionalization: A research synthesis. *JASH*, 16(1), 25-38.