Taking Place

Standing Up and Speaking Out about Living in Our Communities

Self-Advocates Becoming Empowered

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Year **2000**

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Introduction

People from across the United States have united for the purpose of forming a national self-advocacy organization, Self-Advocates Becoming Empowered. Since 1991 the Steering Committee members, who represented regions, have devoted our energies to achieving our goals.

To design our organization, we have met "face-to-face" to learn how to make some of our own decisions. As we struggled through this process it made us stronger as a team and has given us more confidence in ourselves. This is what empowerment is all about.

Things are taking place.

We hear alot of different definitions about what self-advocacy is and isn't.

What does self-advocacy mean to us as a national organization? Self-Advocacy is about independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It teaches us about our rights, but along with learning about our rights we learn responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other gain confidence in ourselves so we can speak out for what we believe in.

Things are taking place.

One of the things we believe is that people should live in their own communities.....

We believe that people with disabilities should be treated as equals. That means that people should be given the same decisions, choices, rights, responsibilties and chances to speak up to empower themselves as well as to make new friendships and renew old friendships just like everyone else.

They should also be able to learn from their mistakes like everyone else.

Self-Advocates Becoming Empowered

Mission Statement

Community Living is a very important issue to self-advocates across the country. Over the past 20 years we have been involved on state and local levels to help people make their own choices about their own lives.

Things are taking place.

Community $oldsymbol{L}$ iving is important to us for these reasons:

- People should not be put away
- •To learn to become independent
- •People can contribute to the community by work, projects, friendships, voting, paying taxes, etc.
- ◆To help people have self-esteem
- To make different friendships with people
- •To teach others how to work with people with disabilities
- •So people can learn how to communicate with people
- •To learn to share ideas and support each other
- •So other people can learn about people with disabilities
- •To show people who we are and what we can do

Through Community Living, we are each Taking Place.

Taking Place By:

Having a Home,

Being Respected,

Experiencing Relationships

Being Leaders

What have we learned?

- Get people out of institutions, help them to be independent
- •Mixed feelings about staff. Seems like staff are against self-advocacy. They want to pull people away. Staff are afraid that people are going to become independent and stand up to them.
- •ICFMR's are worth ____
- •I like my own apartment better
- Sometimes staff don't believe you
- I can do whatever I want. I don't have to eat at the same time everyday
- •Staff changes alot. This is hard and it makes me mad. I worry about what the next staff person is going to be like.

What are ways people hurt us?

- •By swearing at you
- Calling you "retard"
- •"You're not capable."
- •Keep you in one place all your life (workshop)
- •Fighting with you physically and verbally
- •Pulling out illegal weapons to threaten you with
- Nitpicking...taking you apart piece by piece and each piece gets more painful
- •Pull you different ways
- Tell you that you can't do something because they think you can't



What are ways people help us?

- •A social worker helped me and my husband get out and get married.
- People come by and see if I need anything
- •Follow-along people after they come out of the institutions
- •Have resources available
- People take time to explain things to you so you can understand and make decisions (doctors, social workers)

ving A Home

What do we want?

- *Ain't nothing I need.
- *Still come by and check on me
- Home of my own
- •Friends you can trust
- Choices in where to be
- •Get people registered to vote that's where the power come from
- •People need different services
- Own place
- •Safe place to live
- •Transportation for work and fun
- Do not use people for testing
- Close institutions to let people live in their own communities

A Piece of Advice?

- •Be careful
- •Beware of the wolves
- *Look at all your choices
- *Don't let people rush you
- Think about what you want to get into
- •Be careful about where you talk about private things
- Plan ahead. Get on services waiting list as soon as possible.
- •Get an education or vocational training as soon as you can
- The better job you have, the better choices you have
- Learn as many independent living skills as possible while you're at home
- •If you drive, be careful
- •Get help when you need it
- •If you want to get married, go through counseling.

What have we learned?

- Listening to people shows respect
- •When people make fun of me, I get up and walk away
- •If you are disabled and a minority, you get even less respect
- When you learn more about self-advocacy, people expect more of you, sometimes too much
- •We have a lot of work to do to changes labelling
- Others often have low expectations of people with disabilities
- *Staff are often the people who label most
- •People are labelled by "files"
- •We should be able to make mistakes like everyone else
- You are likely to be hurt by others when you are not respected

What are ways people hurt us?

- Calling us names
- •Testing us and giving us I.Q. scores
- Being physically attacked
- •By not listening to us
- *By focusing on what is wrong with us



What are ways people can help us?

- Staff can help create a positive image
- Staff should teach people with value and respect
- People can volunteer to help self-advocacy groups
- Advocacy organizations should hire people with disabilities
- •Treat people thier own age
- •Make building and programs accessible
- Self-advocacy groups should get to know their policy makers
- •Educate people about lableling

What do we want?

- •Respect
- •Everything!

A piece of advice!

- Stand up for yourself
- *Find someone who will support you
- •Always talk about things and get them off you chest
- *"Everything is a person too" Radar on MASH
- •Laws give you respect. You are entitled to respect
- •Respect people the way you want to be respected

ng Respected

Experiencing Re

What have we learned?

- •Hard
- *Takes 2 people
- Communication is important. There are alot of ways to communicate (don't have to be able to talk)
- Difficult to work with people
- Working with friends is good because of common interest
- •Easier to set boundaries with friends
- •Important to support friends and be honest
- •Important to give criticism without it sounding like critcism
- •Relationships are give and take
- •We make the decision about who we date because we have to live with it
- *It is important to date someone who understands our disability
- •Just like everyone else...we want to date, get married, have opportunities to meet people
- •People give us bad messages, like.... only date people with disabilities, date only people who "function" at the same "level" as you.
- *It is hard to date, talk about sex and have sex when you live at home with your parents

What are ways people can help?

- Parents talk about sex
- Access to sex education through others
- •Give people support if they decide to have sex before or after marriage
- •Counseling should be available
- Choice of partners is ours
- Access to birth control and condoms
- Talk about values
- •Access to transportation to meet people and date
- •Help people to communicate
- •Take time to listen to us
- •Help people feel safe and that you can be trusted so that they can confide if they need to
- Check service providers' background
- Create opportunities to meet people

lationships

What are ways people hurt us?

- Words
- •Thoughtlessness.."You can't have a relationship with someone who can't talk".
- Rushing us
- Not giving us information...like at risk for AIDS and VD, unplanned pregnancy, abuse
- Not believing us when we say we are being abused
- Not paying attention to the other people in our lives
- Not paying attention to the changes in our behaviors or moods
- Not believing in us
- Others believing the labels
- •Not giving us proper medical care or routine tests
- •Abuse....mental, physical, sexual and educational

What do we want?

- To be believed
- •To be treated like everyone else.
- *People see us as people
- We feel safe wherever we go
- More protection
- Don't be put into boxes

A Piece of Advice!

- Don't be intimidated
- *Learn your rights and responsibilities
- Understand consequences to our relationships
- Believe in yourself and others
- •Don't put people in boxes
- Protect yourself
- •You have the right to say "No."
- Decide what YOU want
- •Choose your own friends
- Always be honest with one another
- Demand opportunities to be with people without disabilities

Vhat have we learned?

learned that it's real important to step down and give other people an opportunity. People assume because I'm a leader, I'll do it. But if they don't do it how will they ever learn?

If I was a leader I would try to listen, guide and help people learn what they want. I learned to listen to their ideas, and follow their ideas. Sometimes I didn't think it would work but I'd give it a shot.

I gave other people the opportunity to be a leader. I learned how to give support. I learned to figure out how much I can do but how to get other people involved.

Stepping down...It hurt's some inside because it's hard to let go of something you helped start

It's hard to get new leaders and communicate with them...It's hard to get a new set of bosses every year

It's hard to deal with elections...I want to do it, but I can't always get people to support me.

People really use good judgment to elect the right people. We should support people to be on other organizations but we should make sure they re-connected with a self-advocacy group.

People are going to grow out of independent living programs

People just need a little help to see how things are going

What about putting the shelters on the job...the work shelters will be right where the job is.

It's hard to get the people who aren't disabled to let go of the power and control

In order to be a leader, people need to listen to the grassroots, just listen to roots. Be willing to let regions elect new members. That was how it was when we first started. If we don't we're breaking away from the grassroots.

What are ways people can help us?

- •To know that it's good when self-advocates ask for help.
 To let people know it's okay to ask for help and they shouldn't have to struggle
- •Help write, type, and present information to the board
- To be there when we have a meeting
- To invite us to important meetings
- To help us work through big problems
- •To help us write grants
- To have one place, a headquarters
- To get new ideas for the group. Each time our goals get bigger and better
- To let us do things on our own, let us make mistakes and learn. To just be there/Well ask for help when we need it

Being Lea

What are ways people hurt us?

- •Ignore us
- *Label us
- Until I die I'm going to be out there speaking for people's rights. Teaching another generation what's going to happen
- The only way we're going to teach other people is when our anger blows across their face.

A Piece of Advice!

- •It takes hard work, not all glamorous
- Have to keep your mind on it...when you're eating out dinner you still have your mind on it
- •Sometimes you pull your hair out!
- Welcome people and encourage them to come and be a part of self-advocacy
- Invite the people from the institutions.
 Us visiting the institutions and looking inside
- Stand up for things that are wrong
- Know what you're talking about
- Gather information so you can show what is wrong and what should be done
- Stick to the issues.
- •What we want is fair treatment

What do we want?

- Opportunities to have good leaders as role models
- •Supports so our voices can be heard and understood
- •Recognition for the importance and difficulty of the work the leaders do by other people, parents and professionals
- Ownership of the labels. We decide what we want to be called

THE PEOPLE SHOULD LEAD!

- People accept who we are; respect and know what we stand for...to be strong and have a voice to where no intolerance stands in the way
- •Get more people involved
- Get leaders to accept our feelings, show the group how we feel
- •Someone in Washington...a national leader with a disability in a high official position. People are saying we have a voice but we really don't.
- Someone at the "holy table" meeting on Thursday mornings
- For people in local groups to see that they have the opportunity to come and learn

ders

What would we like to see happen in our communities by the year 2000, that are not happening now?

- •A person with a disability as mayor
- •A service system where the money follows the person and where the person gets what they say they need (not others say they need)
- For hospitals not to discriminate against people with disabilities
- •For this group to have no other work to do, because we worked ourselves out of a job!
- To have no waiting lists for services, anywhere.
- ◆To eliminate the word "retarded"
- Fully integrated communities, without prejudice and discrimination
- •Supported employment and real jobs for everyone...no more sheltered workshops!
- •To have everyone learn about self-advocacy, to eliminate the hate war and violence so the world would be a better place to live
- •To have transportation for everyone who needs it
- To see people believe in disability unity, and work to sustain the disability community
- •To have children with disabilities included in regular classes
- •To have young people included in the self-advocacy movement
- To have professionals get their act together by the year 2000, so they'd actually be supportive
- That people with disabilities are accepted in their communities.
- •To have people with disabilities improve the postal service
- To draft a proposal for the country on how to treat and speak or write about people with disabilities
- •To have universal health care

Things are Taking Place.



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