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WHAT WE WANT FROM RESIDENTIAL PROGRAMS
- A PRESENTATION BY -

PEOPLE FIRST OF WASHINGTON
AND

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This presentation is based on two seminars conducted by John O'Brien and Connie Lyle with People First members and other self-advocates. The first seminar, entitled 'Evaluating Programs' was held on August 6, 1983, with twenty-one People First of Washington Members. The second seminar, entitled Speaking Up and Speaking Out To Make Services Better, was held on July 25, 1984, with one hundred self-advocates who were attending the International Self-Advocacy Leadership Conference in Tacoma, Washington.

The results of these two seminars have been shared with and endorsed by People First Members across Washington State.

You will notice that most of the things that People First
What We Want From Residential Programs
Members want from residential programs do not require more money, new laws rules or regulations.

The things that People First Members want from residential programs require that DDD, and residential program administrators and staff see people with disabilities as valuable and competent people. The things that People First Members want from residential programs require that DDD and and residential program staff assist people with disabilities with respect and dignity and in a way that promotes and encourages individual choices. The things that People First Members want from residential programs requires that DDD and residential staff assist people with disabilities to have a wide variety of experiences to learn from in developing independence. The things that People First Members want from residential programs requires that people with disabilities are present and participate in the community and in all parts of the decisions that affect their lives and the lives of others.

The seminars conducted by John O'Brien and Connie Lyle had five parts.

(1) The first part was identifying the things that 'help' in service programs.

(2) The second part was identifying the things that 'hurt' in service programs.

(3) The third part was identifying the 'common experiences', the things that often happen to people with disabilities.

(4) The fourth part was identifying why it was that people with disabilities have the experiences they currently have.

(5) The fifth part was identifying ways to make service programs better...identifying the things that People First Members want from service programs.
This is how residential programs can HELP us.....

* by helping us get out more into the community
* by teaching us how to do things on our own, like cooking, how to protect ourselves
* by treating us with respect....like adults
* by helping us to have and use good transportation so we can go places
* by listening to us and what we want to learn...what we want to do...how to best help us...
* by creating accessibility
* by letting me make plans for my future that I want

* by having an IPP/ISP with goals I want
* by letting parents and others know that we can make it on our own
* getting parents and relatives to work side by side with us

* by helping us to understand benefits, and pay and deductions...it helps to have a clear explanation
* by helping us to educate ourselves and the public...
* by helping us to learn how to help each other, including staff

* by helping us to be a part of a support group like People First....encouraging us to speak up and speak out
* by cooperation...I try to see the staff's point of view and it helps when they try to see my point of view...teamwork is what it takes
This is how residential programs can HURT us...

* by treating us like children
* by making us go to bed at 10:00 on Saturday night
* by not letting us do the things that other people do
* by not believing that we are adults...men...women

* by making us get 'permission' to do things
* by not believing us...they thought I was joking...it was serious
* when the staff get treated better than us...this is our home...where we live...
* by not listening to us...turning us 'off'
* by the staff being afraid of us becoming self-advocates

* by giving us drugs and making us wait instead of helping us with problems
* by the staff 'staying in their offices', making us wait...sending us away if we get their early
* the good staff get fired because others want to control us

* by locking the doors to the kitchen at night...I can't get a snack
* by making me feel that asking for help is a bother to the staff...I sometimes get afraid the staff will think I'm a troublemaker for asking for what I need
* being told 'you can't' when you want to try something new
* when the staff won't explain things or talk things out with us
* by not having enough residential choices so we can't choose how we want to live
Our Common Experiences......

These are some of the common experiences that we as people with developmental disabilities face in our lives....

* rejection...people make fun of us

* we are at risk of being mugged...stolem from....over medicated

* we are poor...we don't have much money...

* loneliness...having to live with lots of other people....you can still be lonely when you live with lots of other people....you are lonely when there is no one who really cares about you

* lots of programs don't give us very many choices....we don't have much of a say in what goes on....

* we have few chances for different experiences or choices in life...

* we are confused about what a 'handicap' or 'disability' is...we seem to be treated different than other people...why is this...

* we spend alot of wasted time....

* we're moved around alot

* people treat us like children and think they are doing the right thing....
Why it is that people with disabilities have the experiences that they have......

Things that happen to people with disabilities because of the way other people think about us...

All people are different...'nature makes differences'...
People with disabilities are different in that:
- I may have seizures
- I may learn more slowly
- I may use crutches

People in the community (and many people who provide services for people with disabilities) have a lot of 'myths' and wrong ideas about my differences. It's as if all they look at is my differences. It's like they see me through 'dark glasses'. Many people think that my differences make me crazy, dangerous, pitiful and childish.

Sometimes the service programs that are supposed to assist me treat me as if I was childish. I can get caught in a crazy circle...
Because of my differences and the way that a lot of people see and think about my differences:

- people notice little things about me... and make a big deal of them...
- people are scared of me for no reason
- people treat me like a child and think they are doing good....
- I can get stuck in programs where there is a crazy circle that keeps me 'helpless' and 'childish'....

Making Things Better....

To change the ways that people think about us and to break out of the crazy circle that keeps me down, there are five things that we want from residential programs:

(1) programs that help us get out in the community
(2) programs that let us (and helps us) to make good choices
(3) programs that help us develop independence
(4) programs that treat us with respect and dignity
(5) programs that help us to meet other citizens in the community
Community
part of our neighbourhood and
programs that help us to be a
and activities we have been to
so we can remember the places
together pictures and stories
programs that help us to put

We live
things outside of the place where
programs that encourage us to do

to do in the community
all the different choices and things
programs that help us to understand
vacations and other recreation
programs that help people to have
and not in large groups
programs that take people places I to I

and help us to use transportation
programs that are close to transportation

programs of places
programs that take us to a wide variety
programs that are accessible

experience as other people.
community so we can have the same
programs that help us get out into the
(1) Programs that are residential programs
What we want from residential programs

(2) Programs that let us and help us to make good choices and be responsible.

* programs that allow and expect people to make their own decisions, be responsible and look after themselves

* programs that give people choices about where they live and how many people they live with

* programs that encourage and expect people to set goals in their IPP/ISP meetings that they want...programs that see people as the best 'expert' about themselves

* programs that allow and encourage the residents to be a part of the hiring and evaluation of the staff

* programs that allow people to make their own choices about marriage and sexual matters

* programs that value and try out the residents suggestions

* programs that encourage people to try new things and make new choices and not be self-conscious about failing or making a mistake the first time

* programs that encourage and assist people to vote

* programs that encourage and assist people to be on boards of directors and other decision making bodies
What we want from residential programs

(3) Programs that encourage and assist us in developing independence

* programs that give people a wide variety of experiences to learn from

* programs that teach the things that are really important and that you really need to know to be independent

* programs that teach us how to deal with and solve problems

* programs that help us to get adult education

* programs that teach us new things and not the same old thing over and over again

* programs that treat people like 'you can!' and not like 'you can't'

* programs that teach people how to make choices and be responsible

* programs that teach us how to get the help we need and what to do in an emergency

* programs that teach us how to be respectful and disagree at the same time

* programs that involve us in training the staff or our attendants
What we want from residential programs

(4) RESPECT

Respect and dignity are very important. Without respect, dignity and a value for people none of these other things will work.

* programs that treat us like adults and expect us to be adults
* programs that listen to us and what we want
* programs that give us privacy and where the staff knock on our door and ask to come into our rooms
* programs that give us straight answers
* programs that help us to dress well for what we do
* programs that let us decide about activities, bedtime, etc.
* programs that treat us respectfully and take us seriously
* programs that have staff that talk and write about us to others in a positive and adult way
* programs where the residents and staff are working together as a team
* programs that don't have places that are 'off limits' or 'staff only'
* programs that respect our feelings and our ideas
* programs that let us disagree without being afraid of getting in trouble
* programs that are for the residents convenience and not just staff convenience
What we want from residential programs

(5) A chance to meet and know a wide variety of people

* programs that help us to make and be friends
* programs that help us to meet people who are not developmentally disabled
* programs that help us get together with others in the community

* programs that help us to meet and spend time with relatives and our families
* programs that help us to have a friend we can call if we need them or are feeling sad or blue
* programs that help us not to be afraid to talk to people
* programs that have staff who introduce us to their friends and families
* programs that have staff who include us in the things they like to do, to be a part of their community

* programs that introduce us to the neighbors and help us to feel a part of the neighborhood and the community
* programs that encourage us to join community groups and help other people
* programs that help us not to be discouraged when we meet new people
* programs that help us to meet people