

Self-Advocates of Washington

Planning Meeting on Helping People Who Live in Institutions

Self-Advocates of Washington held a planning meeting on Saturday, 30 August 1998 to come up with ideas for helping people who still live in state institutions. John O'Brien and Connie Lyle O'Brien facilitated the meeting and made this record from the notes they took and checked with people at the meeting. People in the meeting made all of the points in the record; John and Connie made the points into sentences and arranged them.

The membership and the board will talk about all of these ideas at the annual meeting in November; and the board will talk about some of the ideas at its next meeting.

We think that...

- The people who live in institutions now...
 - ... have exactly the same rights as any other citizen
 - ... have the very same right as the people who have moved out of institutions in past years to move into community living with the individual support they need to be safe and successful
- We, and the many other people who work to make communities better, now know a lot about how to help people succeed outside institutions. No one has to live in an institution just because of their disability if they get the help they need.
 - The only way to be successful in helping people move out of institutions is to work with one person at a time.
 - It is important to make sure that there is a good plan that covers both the move itself and what the person will need in the community. People need a good place to live, a job or something meaningful to do during the day, and chances to make friends and have fun. People need assistance with everyday living, medical care, help getting and keeping their benefits, transportation. Sometimes people have serious problems they need help with or good changes they want to make in their lives that they need help with.

- The services in the plan need to be there as soon as the person needs them and the staff who provide the services need to be ready to change things to fit the person better when things change.
- No matter what disability the person has, the person and others who care about the person need to be involved every step of the way. The harder it is to communicate with people, the more important it is to find ways to include them.
- No matter how good the plans look, it is important that somebody monitors to make sure that each individual plan really works for each person. (Some SAW members have already had experience helping people move and monitoring people's plans and others are interested in helping out in this way.)
- People don't lose their rights because they have guardians. Guardians are there to make sure that people's rights are respected. If the court says people need guardians to make some decisions for them, people have the right to guardians who...
 - ... spend time with them and know and respect them as people
 - ... recognize their human rights
 - ... work to educate themselves and the people they are guardians for about people's rights and about what is possible if people have good services
 - ... advocate for what is best for the person's growth
- There is still a long way to go to make community services as good as they should be for everyone. People with disabilities still sometimes face discrimination. Some people have moved out of institutions and had serious problems, usually because they didn't get enough of the right kind of help. These are good reasons to make community services better. They are not good reasons to keep people in institutions.
- It can be hard to leave an institution. People with disabilities can offer people good help in learning about their rights and their options, making their plans, and feeling more welcome in their community.
- No organization or group can speak for an individual in making the choice to leave an institution. This includes Self-Advocates of Washington. Organizations and groups can say what they think about laws and policies. Organizations and groups can invite people to learn about the pluses and minuses of their decisions. Organizations can invite people to discuss their plans. But groups and organizations go way too far if they take over an individual's right to choose or stand in the way of people learning about their opportunities (unless the person is convicted of a crime).
- People's rights make institutions wrong if the institution (or people who support the institution) ...

- ...takes away people's choice to leave the institution
- ...uses up much more money per day for a person in the institution than the same person can get for the services they really need in their community (because this means that people who need a lot of help because of the severity of their disability might be stuck in the institution without a choice to move out).^{*}
- ...keeps people inside the institution from getting to know other people with disabilities who live in the community, learning about their rights, finding out what people can do if they have good services
- ...tries to keep people and groups who disagree about institutions from making their voices heard in public discussions
- Some people think that leaving people in the institution is the only way to get the legislature and the governor to come up with money to serve people with disabilities who are waiting for help. We have two concerns about this...
 - ...we wonder if the money will really be there to help very many of the big number of people waiting for services or better services; if it isn't really there, people will have lost chances to move on to a better life for no reason
 - ... we don't think its fair for powerful institution supporters to take opportunities away from the real human beings who live in institutions as the price of their help in improving community services

We are concerned

Washington now has a law that says that...

- ...the state will continue to pay for 1,250 institution places for the next five years (unless the governor or the legislature changes the budget or unless people have to move out to keep federal money for the institutions or to settle a legal case).
- ...families of people with severe disabilities who get funds for services during this time have to be given a choice between institutional services and community service

^{*} People who recently moved out of institutions get only about half as much per day for community services as the institution got to keep them on the day they left. This works for some people, but it means that community staff make less money and have less benefits than institution staff. It means that some people may not get what they need in the community. One reason the institution costs so much more is that the buildings and some of the staff costs stay when the people leave. Having buildings and staff is not a good enough reason to keep people in institutions.

... the group of people who figured out this law, called the stakeholder group, will make a plan that will tell the legislature how much money is needed to deal with the waiting list for services

We know that some people who support institutions say that everyone now has to support this law and that some people who disagree with the law have taken some heat. If the law means that DDD no longer provides community services with the money to keep helping people, one at a time, to make the choice to move out into community life with the help they need, we think it is a bad law, and we are ready to take the heat for disagreeing and working to change it.

How would we know if the law takes away people's choice to leave the institution?

- Look at how much money there is in the budget to help people move. If the amount of money is based on keeping 1,250 people in institutions, the law takes away choice. (The state probably won't pay for places that no one is using, so paying for 1,250 places probably means keeping or putting people into them.)
- Reach out to people who live in the institution to educate them about their rights and about what is possible for them. If members of Self-Advocates of Washington have trouble contacting and working with people in the institution because of what the institution does, the law takes away choice.
- Monitor the plans that the stakeholder group makes for DDD. If their plans say that the state will keep paying for a set number of institution places after this law expires, the law takes away choice.
- Find out what is happening to people in the institution whose individual plans have recommended a move to the community. If the system isn't moving to follow those recommendations, the law takes away choice. (This might also be against the rules that the state has to follow to keep federal money.)
- Monitor the way people and families who get services under the law are educated about what community services can do. It wouldn't be right if case managers put a person from the community in every time somebody moves out just to keep the institution numbers up. If people and families don't have a fair chance to make a plan that says exactly what they need (not just an institution bed) and then explore how community services could help, the law takes away choice.
- If families and guardians use the law as an excuse to take away their responsibility to educate themselves about how to better respect the rights of people with disabilities and how people can be best served, the law takes away choice.

Some people are afraid of people moving out of the institution. Some staff may be afraid that they will lose their jobs or their benefits. Some families worry that a person's leaving might cause problems for them. These are understandable worries. They are harder to talk about than to say that moving out of institutions will be unsafe or bad for people with disabilities. We think that one reason that institution supporters want to keep 1,250 people in institutions is so that the per person cost of keeping people in institutions won't get so high that legislators will decide that the institutions are no longer affordable.* So sometimes people may talk more about people with disabilities than about their own concerns. It is easy to push people with disabilities under the rug instead of facing all the problems. We have to speak out to get the problems in the open air where people can work together to solve them.

We know that many, maybe even most, of the people left in institutions have guardians. We have heard that people who support institutions have looked for guardians who either support institutions or don't know anything about what community life can offer. Some of these guardians are organizations (this is called "corporate guardianship"), maybe even local civic groups. It's important that guardians who don't know much about institutions and community services educate themselves. Members of SAW could be important educators.

We have ideas

- People who support institutions focus a lot of attention on problems in community services. We can do two things about this:
 - We can invite them to join in with us and other allies to make community services better.
 - We can help people who have made it out successfully, and people who have had problems and worked things out to tell their stories. More people are doing ok or doing well than are having serious problems.

* Every time a person moves out, the cost of keeping the rest of the people in the institution goes up because the institution doesn't have a good plan for closing parts that are no longer needed, probably because this would mean laying off staff. Even though the institution costs a lot already, the institutions have trouble staying in compliance with the rules they have to follow to keep federal money. And the US Department of Justice is beginning an investigation of possible violations of people's civil rights in both Rainier School and Frances Haddon Morgan. When inspections and investigations turn up problems, the institution budget almost always goes up.

- We can involve people at Rainier and Francis Haddon Morgan in SAW. There are two ways we could start to do this...
 - ... we could activate the SAW Chapter at Rainier School
 - ... we could involve more people who live in the institution in the Puyallup Chapter.
 - and four big problems we would have to solve...
 - ... transportation
 - ... getting to people in the institution and getting them the support they need to participate
 - ... finding advisers who would be accountable to the people not to the institution (we think this would be very hard for institution staff)
 - ... we probably will have to figure out ways to adjust to make it possible for some people to participate
- We can go into the institutions and do training and organizing with people who live there.
 - It's not enough to just talk. We have to figure out ways to help people see and feel how people with disabilities live in the community. We need to reach out to people and really discuss with them, not at them. Lots of people who support institutions may not believe that people in institutions could participate; we have to figure out how to make it happen.
 - As part of the settlement of a suit, the state agreed to give people trained by the P&A system access to people in the institution for training and advocacy. We could make an alliance with the P&A system and have some SAW members and advisers go through their training as a way to set up our work.
 - We need a careful plan about how we are going to do this.
- We can find out who the corporate guardians are and meet with them to educate them about what we know. If there are local groups (like Rotary) that have taken responsibility for some people, we can ask to be on their program for a meeting. We can invite guardians to visit us and other people who have moved out of institutions to learn how people can live.
- We can help find guardians who have an open mind about community services; SAW could be a corporate guardian.
- We can ask DDD for funds to support people making plans to move, advocating for the services they need, and monitoring what happens.

- We can tell our legislators that we don't like a law that takes away the ability to keep planning with and moving people one person at a time.
 - We can attend meetings with legislators who are running in the election and tell them our position.
 - We can ask to be on the agenda of the Parent Coalition Legislative Forum and in their newsletter. It's true some family members don't agree with us, but we have as much reason as anyone to make our case for changing what we believe is a bad law.
 - We need to think long and hard about exactly what we want legislators to think about. We need a careful plan.
 - Because the elections will happen before the annual meeting, the board will talk more about this idea at its next meeting and decide what to do.
- We can look for, join with, and be allies with other groups that want to work for better community services and a chance for anyone who can be better served outside the institution to move out.
 - People First
 - The P&A system
 - WA-TASH