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How Are We Enhancing Participation, Quality and Accountability In the Lives of Persons with Developmental Disabilities and Where Do We Go From Here?

- ❖ My name is Nicole Patterson and I am a person who receives services that are available for persons with developmental disabilities, and I also work in the system to bring a consumer voice within the Department of Developmental Services in California.
- ❖ Today I will be talking to you about the past, present, and future in five areas that are important to self-advocates. The five areas are: education; community living; working and being in charge of their own money; advocacy and having a voice; and contributing to the community.

20 years ago (1986) was a time when people with developmental disabilities had little to no voice.

Education -

- In 1986 most people with developmental disabilities were placed in special schools for reasons that may not have to do with their ability to learn, but because of the attitude that people with developmental disabilities can't learn and become productive citizens so why even deal with them. Or for other special accommodations that a

public school didn't provide at that time for example adapted P.E. or providing help with using the restroom.

Community Living –

- People with developmental disabilities were placed in, care homes, family homes, developmental centers. A very small percentage of people lived in their own homes.
- The way the system was setup, transportation was not a factor because people with disabilities did very little community travel outside of program transportation.
- Access was a problem 20 years ago because some people with disabilities could not access medical offices or go to the bathroom in public places because they were not accessible to people that used wheelchairs
- You were not seen as a person wanting or needing a personal relationship with anyone, friends at school and family was good enough.

Working and having our own money-

- Having your own money usually meant working in segregated programs where people got paid piece work at a rate of .25 per piece or lower.
- The parents or a social worker was in charge of any moneys that people might get in their name.

Advocacy and having voice-

- The voice of self-advocates were not heard. The voices of parents, teachers and doctors were heard. We had no voice.

Contributing to the Community-

- As far as contributing to the community, how can you give to a community that didn't feel you were worthy enough to be considered as person in the community?

Don't worry the present gets better

Education-

- More people with developmental disabilities are included into public schools and learn how to socialize with children that may not have disabilities.
- Teachers had to find ways to make the transition work, and they came up with special classes that may have kids without developmental disabilities, but have kids with learning disabilities and behavioral issues that are also put in these special classes so they're still segregated to a degree.

Q: But how many of us get an education

Community Living –

- More people are living in community settings or in their own places

Q: But is the living situation, were I want to be or where I was made to be.

- Thanks to ADA, transportation and access is better then before because more people with disabilities are

accessing the community for going to school, work and for fun.

Q: But the ADA Law was signed in 1990 why do we still have places in our country that are not accessible to all forms of disabilities 16 years later in 2006?

- Yes, you do hear about more people with developmental disabilities having more personal relationships in their lives.

Q: The way our system is setup in the developmental disabilities circle, does it encourage personal relationships or not?

Working and having our own money-

- Most of the people with developmental disabilities that do work, have part-time jobs at a fast-food places, department stores or at a movie theaters. A hand full of us are working in jobs and have careers that provide the services for people with developmental disabilities. These kinds of jobs were designed to give a voice from consumers before decisions are made about services for consumers; and to insure that the services meet the needs of people they serve.

Q: But is the job meaningful, am I respected as a co-worker or am I there to just make you look good?

- We may have more of us now receiving what ever monies we get in our own name and paying our own bills.

Q: But are we really in control over the services we get?

Advocacy and having a voice

- Now we have started our own self-advocacy organizations that are designed to be run by us -and for us, all over the country.

Q: But when we receive grant monies from places are we the ones that you look at to carry out the responsibilities of the contract, or are you looking at staff that may be working for the organization that may not have a disability? If so who is running the organizations?

- We went from not knowing about boards and committees that had to do with us and the services we receive, to knowing about these boards and committees; and now we have a chance to participate on boards and committees. We are one step closer to having our voice heard.

Q: But ask yourself is the voice being heard from those people, if not what is the point?

Contributing to the Community

- Consumers' ways of looking at volunteering and giving back to the community are being on local boards and committees for instance consumers typically volunteer in organizations that have advisory boards or committees that have to do with people with developmental disabilities and their services.

Q: Self-advocates if we want people to care about us and our needs, why don't more of us feel the need to give our time to, things that have nothing to do with our needs but other people's needs outside of the disabled community.

BUT, WE ARE NOT DONE YET!! Think about this for a minute, the first thing that comes to mind is , that is pretty good, it better then what it was, RIGHT? Think again....

Here comes the future

Let's answer the questions that were raised under each topic stated in the present to help give you something to think about through this conference and for our future, from an advocate's point of view.

Education-

Q: How many of us get an education.

A: Not many people with developmental disabilities get their high school diploma or go on to higher forms of education because the support is not there forms parents, case mangers. Teacher and people in general are just not trained to recognize the full capability of our population. If we can teach our children at an early age, that it's about capability not disabilities, we can encourage not discourage. I feel that if we do this with children with developmental disabilities we would have a higher rate of people with developmental disabilities getting better a education and wanting to do more.

Community Living –

Q: But is the living situation, where I want to be, or is that where I was made to be.

A: There are so many living situations that we can see ourselves living in as safe healthy, and happy individuals.

When you ask a person why they are in a care home, that may be capable of living in their own home, they say to you: I don't want to be alone. Maybe if we learn how to think outside of the box, we as people who support that individual can come up with more choices of living options besides care homes or living alone to choose from available to everyone with a developmental disability such as: rooming with friends without the live in staff; paid roommate; paid neighbor; or you the service coordinator and the consumer work together to come with living options that better meet their needs.

Q: But the ADA Law was signed in 1990 why do we still have places in our country that are not accessible to all forms of disabilities 16 years later in 2006?

A: The problem is that there are too many loop holds in this law. The law should have been written in such a way that if you where a business that was open to the public no matter how old, or where it located it needed to comply with the ADA law within 10 years. Businesses can be closed down for so many other reasons, but not for being unaccessible to people with disabilities.

Q: The way our system is setup in the developmental disabilities circle, does it encourage personal relationships or not?

A: A: The way our system is setup in the DD circle doesn't encourage personal relationships because as soon as you start talking about a relationship or getting married, instantly people start telling you what you are going to lose, and never what you can gain. So nine times out ten, you as the person with developmental disability get scared out of that relationship, or keep it a secret. Most people that work in our

field seem to think that people with developmental disabilities don't really want, nor need a partner. That's why many times people with developmental disabilities develop unhealthy relationships with their support staff.

Working and having our own money-

Q: But is the job meaningful, am I respected as a co-worker, or am I there to just make you look good?

A: If these positions have a purpose, you need to know what the purpose is before you hire the self-advocates. Allow us to do the job we were put there to do. Respect us as co-workers, not as a token.

Q: But are we really in control over the services we get?

People with developmental disabilities want to have more control over where the services come from, when they happen who the provider answers to, who paid them, and when the services begin and they stop.

Advocacy and having a voice

Q: But when we receive grant monies from places are we the ones that you look at to carry out the responsibilities of the contract? Or are you looking at staff members that may be working for the organization that may not have a disability? If so, who is running the organizations?

A: If you want the voice of self-advocates to continue, when contracting with an advocacy organization that is run by people with developmental disabilities, be sure that it is in the control of the self-advocates to carry out the mission of the contract. This would increase responsibility for our own organizations.

Q: But ask yourself, is the voice being heard from those people, if not what is the point?

A: In order to hear the voice of self advocates that are on your committees and boards these things have to happen: the materials that are sent out need to be understood by all members, you need to make sure that the self-advocates know that their voice is important to you, and you want to hear from them on things that are being discussed. Because if you give us a sense of value, it will make us want to do the job to the best of our ability.

Q: self-advocates if we want people to care about us and our needs, why don't more of us feel the need to give our time to things that have nothing to do with our needs, but other people's needs outside of the disabled community.

A: If we start getting out in the community and helping other people in need, we can show society that we are not just takers, but we are people who care about giving back.

So I say you today, as we go through this conference and back to our jobs, think about where people with developmental disabilities have been and where we are now; and help us move into a future full of our **Participation**, **Quality** of choices so that we can increase our **Accountability** in our lives as citizens.

Thank You.