

Center for Medicare and Medicaid (CMS) Listens to Ohioans

The Ohio Self Determination Association recently held their annual conference, **“What People Really Want.”** It was held September 16 and 17, 2008, in Columbus, Ohio. Over 320 people attended this year’s conference. Susan Hill, Senior Policy Advisor with CMS conducted a session on “Self Determination and the Center for Medicare and Medicaid Services: The Role of the Federal Government.” Much of her session was devoted to listening to individuals and family members about what they really want in service and support provision. The session was broken into discussion groups in five (5) areas. The areas were:

Planning/Support Brokers -- I have the support I need to find services and pursue the things that are important to me.

Inclusion - I have friendships and feel connected to my community.

Individual Budgets - I have the support I need to take as much control as I choose for how my service money is spent.

Housing - I determine where and with whom I live.

Work and Transportation - I have the supports I need to work and participate fully in my community.

People were asked to discuss: “What do you really want and what stands in the way as it relates to the areas listed. Below is a compilation of what people had to say.

What Ohioans with Developmental Disabilities Really Want

- I want freedom.
- I want to be seen as a person and to be listened to.
- I want respect. I want people to speak to me, not my staff.
- I want to be included in my community.
- I need the support of my family and friends.
- I want help from outside the disability world.
- I want control over all aspects of my life.
- I want to be treated like an adult, NOT a child.
- I want the power to move into my own space and choose my roommate.
- I want affordable, accessible, safe housing.
- I want to own my own home.
- I want a real job in the community.
- I need to be paid the same amount as others do for the same job.
- I need job coaching.
- I want help finding a trusted person to rely on who can give me unbiased support to help me make choices and control my own budget.
- I need to know how much my bills are, including how much I pay my providers.
- I want the right to make choices of my providers, including the ability to interview, hire and fire people.

- I want an individual budget.
- I need support to work and earn money.
- I want be able to choose to work and not risk losing my benefits.
- I do not want to be stuck in a sheltered workshop.
- I want more friends and a way to socialize with them.
- I want the requirements for services to be simplified.
- I want better health care and less medical bills.
- I want the “money to follow the person”.
- I want access to more waiver dollars to help me do more things.
- I need information about waiver services.
- I need services to support me while I wait for waiver services.
- I want a help in buying start-up stuff when I move out into the community.
- We need to establish reasonable funding caps for waiver services that fairly balance natural and all public supports.
- I need available, affordable and accessible transportation that takes me where I want to go.
- I need people in the system that can help me to advocate for myself.
- I need help in asking the right questions so that I get the answers I need.
- I need access to my personal records so that I can direct my supports.
- I need skills training to increase my independence.
- I need to be encouraged to take risks.
- I need to build my confidence and expand my circle of supports.
- I need good support staff who are knowledgeable about disability.
- I want to choose my support staff.
- I need quality providers who take Medicaid.
- We need better training for providers.
- I need assistance to learn problem solving and communications skills.
- We need to develop advocates and natural supports in the community.
- We need to deregulate and make the rules easier to understand and implement.
- We need to weave together formal and informal supports.
- We need to build an educational system that has real transition planning.
- We need to promote community awareness through training and education.
- We need training on self determination for professionals working with people with disabilities.
- We need a system of accountability to ensure that professionals utilize the principles of self-determination.
- I need to have medications that work instead of cheaper generics.
- I need help access to technology, internet resources and computers.
- I need access for wheelchairs and scooters in the community.
- I need adaptive equipment in communities to get in and out of vehicles.
- I need to be able to communicate with the person who transports me.
- We need support for more creative transportation options, including car pooling.
- We need representation on the local transportation authority boards.