Agenda for Full Participation in America

On September 22 and 23, 2005, in the midst of urgent natural disasters and war, 2,400 Americans who live with lifelong disabilities, their family members, and the people who work along side them, came together in partnership to participate in a ground breaking event. Sponsored by eleven national organizations, the Alliance for Full Participation’s 2005 Summit’s purpose was to bring together many voices from every state and every walk of life and to conclude the meeting with one vision:

We want dignity and respect for all. We want full participation for all.

Self Advocates Becoming Empowered (SABE) challenged us and together we rose to their challenge.

This is what was heard from the attendees at the Summit: People with developmental disabilities want our fellow Americans to know that we have much to contribute and we want some things from American society:

- We are Americans too! We want to be included in all communities in our great nation and to have all the rights and responsibilities of full citizenship. We need to be safe and free at the same time. We know how to do this. Few American communities are listening.

- We belong in schools, neighborhoods, businesses, government and churches, synagogues and mosques.

- We do not belong in segregated institutions, sheltered workshops, special schools or nursing homes. Those places must close, to be replaced by houses, apartments and condos in regular neighborhoods, and neighborhood schools that have the tools they need to include us. We can all live, work and learn in the community. We invite our fellow citizens to support the Community Imperative with us. It says that no one should live in an institution because of disability. http://thechp.syr.edu/community_imperative.htm.
• We can work in worthwhile jobs. We know how to help each other do this. It is being done in some places, just not all places. We hope to be welcomed to work for the American dream alongside other Americans.

Here is what the diverse group of American leaders at the Summit believes must happen to make our vision a reality:

• For states that still fund public and private institutions, we want to see a plan to close them over the next few years, and people with lifelong disabilities helped to live in communities, in regular houses and regular neighborhoods. Starting today we expect all states to stop placing children in institutions and segregated residential schools.

• People want real jobs with real pay, real businesses and volunteer opportunities, not sheltered workshops and day programs. Just because a person has a disability does not mean that person cannot contribute to our communities.

• Families with sons and daughters with lifelong disabilities often need some support to have equal access to full and rich family lives. Having a child (who may be an adult now) with a disability must not force a family into poverty or constant, lifelong worry. While some have support to lead decent lives, others have not and are isolated and feel abandoned by America. Everyone who needs it must get the support they need.

• People with disabilities must be part of all planning, governance, leadership and implementation of the programs that affect us. As SABE has so aptly stated, “Nothing about us without us.”

• The term mental retardation has become hurtful. Stop using it! Words hurt and labels limit human potential. It is un-American. Try calling people by their name.

• Public funds expended on behalf of people with developmental disabilities must be under their control and direction and, for children and others who need it, their families and trusted friends.

• People who have chosen to work in this field directly with people with developmental disabilities should be paid a decent wage with benefits; they should not have to work two or three jobs just to support their families. This is important work that must be respected.

• Medicaid is the vital lifeline for people with developmental disabilities. Medicaid reform must protect access to this program, promote inclusion for people in their communities and empower citizens to control the funds spent on their behalf.

• Inclusive communities are part of the solution. Inclusive communities support all people, and make limited public funds go farther, to help those in need.
• America is changing and becoming more diverse. We must understand and honor this diversity, and include all people in planning, governing and participating in communities.

• Poverty limits human potential. Jobs, opportunities to start businesses, build assets, and be a part of communities, help all Americans.

• People with intellectual and developmental disabilities and their families are often pitted against people with other severe, chronic and lifelong disabilities in American politics at all levels. We want to work toward the same ends as other people with disabilities. Together. We speak for ourselves and welcome positive coalitions with others.

Teams are working in each state to implement our vision and goals. Citizens, governors, state legislators and policymakers must help all of us reach this vision. If you want to join with us to create a more inclusive America, we welcome you at:

www.AllianceForFullParticipation.org

It’s time to get it done!