

Creating Partnerships for Community:

An Agenda for Change in NYS



Summer 2005

Created by the NYS Team of the Alliance for Full Participation
September 22-23, 2005 in Washington DC.

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The *Alliance for Full Participation (AFP)* is a formal partnership of leading organizations serving the developmental disabilities field that share a common vision - to help create a better and more fulfilling quality of life for people with developmental disabilities. AFP was created in this vision and the hope that through the diversity of our many voices we can collectively achieve this goal.

Our Vision: That people with developmental disabilities and their families realize the promise of integration, productivity, independence and quality of life choices.

Our Mission: To dream, plan, work, mobilize and organize people with developmental disabilities, their families, and supporting communities and organizations to make the promise of integration, productivity, independence and quality of life a reality in policy and practice. The AFP membership is the embodiment of Many Voices, One Vision. Our member organizations have diverse histories, leadership, members and priorities, but they are ultimately working toward the same end. A 2005 Summit is the nexus of Many Voices, One Vision. For the first time in history, our organizations have come together to host a national Summit to create a social agenda and action plan for fulfilling its vision. Over two thousand individuals are expected to attend to help craft a new strategic policy and social agenda in support of full participation, and to carry forward and implement that agenda in their communities.

How Could Life Be Different? Take a look around your community. Are you aware of people with developmental disabilities? Are they involved in the everyday activities that others might take for granted? Consider the value of having the opportunities that we need in order to achieve our goals. For people with developmental disabilities, these activities play a tremendous role in how they identify themselves, how they perceive their lives, and how they are able to fulfill their ambitions. Things that many people take for granted, such as having a job, an education, and being able to live on their own, are things for which those with developmental disabilities often have to work very hard. But when they are able to achieve these goals, it makes an incredible difference in their lives and enriches our communities. Not only does full participation help us realize the value we can gain from encouraging and promoting diversity among our communities and organizations, but it makes a tremendous difference for those who otherwise might have to work for the basic opportunities that others enjoy. Full inclusion enriches communities and enhances the lives of those who are touched by these efforts, whether they have a disability themselves, care for someone with a disability, or simply know someone with a disability. We can help make this powerful difference by working together to achieve full participation in our own communities.

Realizing Full Participation: There are five key areas of importance related to full participation: housing, transportation, education, employment, and personal safety. Think about how important these issues are in life and the role they play in how we define ourselves and measure our successes. Full participation is possible and it is important. Working together, our organizations and our communities can successfully create and bring public awareness to a model that demonstrates that full participation can, and should, be achieved. With your help, we can work to make a difference by focusing on these areas and learning from the successes that many people with developmental disabilities have achieved in each area. These inspiring stories should remind us that we can make a difference, and that the differences we make—while they may seem small to us—will change people's lives in remarkable ways.

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Introduction:

As the national organizations in the field of developmental disabilities prepare to hold a September 2005 *Alliance for Full Participation Summit* in Washington DC, New York State representatives of those national organizations met to develop a State agenda for change.

As a starting point, participants agreed to use the vision statement developed by the Self-Advocacy Association on NYS (SANYS) as a focal point for our deliberations. That vision statement:

Creating Partnerships for Community Vision Statement

People with developmental disabilities, supported by Office of Mental Retardation and Developmental Disabilities (OMRDD) and provider organizations, will live where they choose in their communities with the supports they need. A wide array of options including a variety of individualized and family supports will be available to all.

People with developmental disabilities will have a broad range of opportunities for competitive and supported employment, including intensive supports if needed, as well as opportunities for self-employment. For those who choose to volunteer in their community or pursue other interests, individualized supports will be available for these activities.

People with developmental disabilities will live as fully included and contributing members of their community with the supports they need to participate in typical community events, activities, organizations and associations.

This process has validated prior work and pointed out areas where there is still critical work to be done. The partner organizations involved in this agenda setting process have all committed to work toward developing and refining policies and practices so that they are consistent with the NYS agenda priorities - - and to engage other needed community partners.

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It is generally agreed that NYS is a national leader in developmental disabilities services and supports and that our Governor and his administration have supported inclusion of individuals with disabilities in communities and other advances in the developmental disabilities service system. Our provider agencies are providing quality services to individuals and families as well as quality advocacy for those who are not strong self-advocates. With that, there is also the recognition that more needs to be done and, with it, there is a sense of urgency. Having a vision for the future will not solve immediate problems.

Common Threads

While many of the following are specifically stated in one or more areas of the NYS agenda, they are common features under all areas of concern:

- Change is hard; many stakeholders have an ingrained mindset and/or an investment in the service system that makes change difficult.
- Respect for individuals with developmental disabilities and promoting positive images of those individuals is essential.
- Build on best practices and what is already happening.
- User-friendliness is a crucial characteristic.
- Diversity is a critical aspect that should be recognized and infused throughout the DD Service system and this agenda for the future.
- Maximize involvement of individuals with developmental disabilities and their families in the developmental disabilities services system, including paid employment opportunities.
- Maintain a good working relationship amongst service system partners and recognize the strength of our self-advocate and parent organizations (regional and statewide) while maintaining consistency of message.

Pervasive Themes

Similarly, some pervasive themes emerged in the development of action steps:

- Leadership and leadership succession is essential at all levels
- Information and economics are power
- Quality is driven by best practices and customers
- Access to the bureaucracy and power structure are critical and to be maintained
- Informed decision making is the ultimate aim

The following agenda is categorized under three major foci using the nationally identified critical issues:

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- **LEADERSHIP: Where Will the Next Generation of Individual, Organizational and Community Leaders Come From?** Our ability to maintain and build upon the many successes of the past four decades depends on the availability of strong leadership. To ensure that we will always have a strong group of leaders, we must work at identifying and supporting leadership qualities of self-advocates, family members, public and private program administrators, researchers, educators, policy makers and other supporters. Many of our field's current leaders are people who started working or advocating in the disability field in the 60s and the 70s and will retire within the next few years. We must ensure that the next generation of leaders is prepared and supported and committed to the vision of full participation.

- **COMMUNITY MEMBERSHIP AND SELF DETERMINATION: Building Communities that Welcome and Support People with Disabilities.** Integration and inclusion have been the focus of the disability service system for two decades. Yet, specialization and segregation are common practice in many state and local service systems. Segregation can be seen in our continued reliance on separate early intervention, childcare, and special education schools and classrooms, sheltered workshops, other specialized adult day habilitation programs, and congregate living arrangements. Advocates for full community membership argue for system reforms that enable the individuals with disabilities and, when appropriate, their family members, to determine how public dollars are used on their behalf. Yet, we have not developed the infrastructure to facilitate community membership through self-determination.

- **ENHANCING THE QUALITY OF SUPPORTS AND SERVICES: Upgrading the Workforce and Establishing Performance Expectations.** The traditional way of measuring program quality does not focus on self-determination, individualized supports and community inclusion. Our challenge is to maximize the quality of current supports and services, while trying to change them at the same time. Our other challenge is to develop quality assurance standards that protect the health and safety of people, while letting individuals and families live their lives. Whether our goal is to improve the quality of current services and supports or to transform the existing system, we need to improve the cultural competency of service systems and enhance the capacity and competency of direct support professionals. We will need improved management and information systems to lead us in designing quality services and supports.

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Leadership:

Working Definition:

Leadership is supporting current leaders and cultivating future leaders to:

- Encourage and support the individual with developmental disabilities to satisfy their personal acquisition of choice, inclusion and empowerment,
- Encourage, support and guide organizations that serve people with developmental disabilities through services which provide full inclusion, choice and personal empowerment with quality and innovation,
- Promote and guide public policies to support individuals with developmental disabilities in their journey in personal choice, planning, inclusion and empowerment,
- Promote positive images of people with developmental disabilities as valued members of our community.

Priorities:

1. **Continue and expand opportunities for leadership recognition, training and mentoring .**

For example:

- Develop and support ongoing leadership training opportunities for people with developmental disabilities, their family members, guardians, advocates, and service provider agency administrators and staff, including the DDPC Partners in Policy Making Training Program and other basic and advanced advocacy training opportunities.
- Develop and support mentoring programs with age-appropriate activities and goals for all people with disabilities but especially for older people to keep them involved in the community, young people who need assistance doing new things, and individuals from culturally diverse and under-served communities.
- Build on Parent Resource Network efforts for encouraging establishment and maintenance of new parent leaderships, parent support groups and advocacy resources and provide regional opportunities for encouraging leadership, informational clearinghouses, and networking. This should be done both with comparable efforts for self-advocates and also separately.

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- Identify and implement strategies to encourage and enable family leaders, advocates and disability professionals to mentor a second/third generation of their own family and community members, including young people with disabilities, their siblings, friends and supporters, to become the next generation of leaders who act as advocates, self-advocates, disability professionals and policy makers.
- Recognize the influence that individuals with disabilities, who have a successful community life, have as role models for others.
- Create a resource network, modeled after the Parent Resource Network, that is controlled and directed by people with developmental disabilities.

2. Provide opportunities to effectively influence organizations at all levels.

For example:

- Continue sponsorship of public policy forums that provide opportunities to express opinions & develop strong feedback loops on how that information is used.
- Build on initiatives such as youth leadership projects and the DDPC Promoting Leadership Opportunities which provides training for self-advocates and agency board members and matches trained self-advocates to local communities agencies looking for policy and planning committees and boards in ways that assure that individuals with disabilities are active participants (not token members).
- Encourage agencies to actively recruit family members and people with developmental disabilities to assume employment roles within the disability field. This might require raising expectations as well as creating opportunities; it may also call for developing and using creative employment supports such as adjusting job responsibilities, job sharing and/or waiving credential requirements in lieu of life experiences.

3. Build the developmental disabilities workforce in a way that supports and develops leadership.

For example, engaging in and including self-advocates in activities such as:

- Outreach to high schools, colleges and universities to encourage exposure to the developmental disabilities field. Some examples include: participation in the developmental disabilities workforce like the Klarberg Fellowship Program at the University of Rochester, and the LEND inter-disciplinary fellowship programs at the three University Centers for Excellence (UCEDDs), as well as innovative low cost options, including developing pilot projects.

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- Assist in filling critical gaps in the developmental disabilities workforce.
- Encourage workshop and training programs that address leadership turnover (for example, the Support Center for Non-Profit Management leadership training for agencies serving people with developmental disabilities).
- Examine leadership across the board and look for opportunities to develop leadership in people with developmental disabilities and their family members to take advantage of employment opportunities at all levels of the workforce. An agency's consumers should also be identified, recruited and trained for existing jobs in the same manner.
- Work with other State and local agencies that interact with developmental disability organizations to find leaders from within these agencies who understand developmental disabilities. Cultivate linkages with generic agencies so they are increasingly able to serve/support individuals with developmental disabilities.

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Community Participation and Self-Determination:

Working Definitions:

Community participation occurs when people with developmental disabilities live as fully included and contributing members of their community with the supports they need to participate in typical community events, activities, organizations and associations.

Self-Determination is a philosophy and way of life for individuals with developmental disabilities that includes freedom to live a meaningful life in the community; authority over dollars needed for support; support to organize resources in ways that are life enhancing and meaningful; responsibility for the wise use of public dollars; and confirmation of self advocates as leaders in newly designed systems.

Priorities:

1. Change attitudes and perceptions about people with developmental disabilities.

For example:

- Stigma is a major obstacle which needs to be reduced and eliminated using any means available.
- Increase the willingness/decrease resistance of communities, community leaders and civic organizations to involve individuals with disabilities as members of their communities.
- Being “in the community” is still not “of the community.” People with disabilities need to be involved in community activities where others can get to know them, their likes and dislikes. However, personal contact is the most powerful education and sensitivity tool and increases the focus on “people, first” and the importance of community membership.
- Enhance and support existing Speakers Bureau, community presentations (e.g. “Baggage), and disability sensitivity activities that include people with disabilities as the presenters/trainers.
- Gather existing resources to create a tool kit for engaging communities and their leaders (with a special focus on those outside the developmental disabilities field) and include information on individuals with developmental disabilities who may

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also be difficult to work with. Make sure that all materials are available in alternate formats.

- Identify (or create) a video/DVD/film targeting and supporting community participation for persons with developmental disabilities.

2. Define, enhance and nurture system, community and individual/family responsibility.

For example:

- Engage in efforts that clarify what is the responsibility of the individual with a disability and/or their family, what assistance the system and its service providers can contribute, and what is the responsibility of the community when providing assistance in understanding the ramifications of those defined responsibilities.
- Continued support and promotion for current successful projects aimed at systems change.
- Identify barriers impeding systemic change and collaborate for solutions.
- Look at, and expand, options for people who are in secure facilities, including special needs units and people with developmental disabilities residing in nursing homes and psychiatric centers.

3. Tap into and expand the existing community “knowledge bank” and resources through statewide and regional task forces on community participation and other strategies.

For example:

- Participate with the planned OMRDD Community Participation Task Force to enhance mobilization and coordination of community partnerships. These task forces will engage community leaders, including faith-based congregational leadership, within and outside the developmental disabilities field, to create an “agenda for change” geared toward community participation for individuals with disabilities.
- Statewide leadership is necessary; however, the locus of activity should rest with key local leaders - planned strategically, possibly with multiple roles (i.e. community leader and a parent of an individual w/DD), linking with existing VESID efforts, and involving local provider agencies and their public relations staff.
- Work toward incorporating the following guiding principle of the Self-Advocacy Association of NYS - “To envision a world where consumers are viewed as typical contributing members in all communities”.

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- Improve physical and programmatic accessibility of community organizations as well as find viable resolutions to inadequate or unavailable transportation alternatives.

4. Increase the number of individuals living self-determined lives.

For example:

- Identify and remedy obstacles to living self-determined lives.
- Decrease the complexity of the self-determination process and make it user-friendly. In doing so, address the current tension between flexibility and standardization.
- Increase statewide support for and availability of knowledgeable Start up Brokers, Fiscal Intermediaries, Benefits Planners, and other necessary personnel.
- While assisting those currently developing self-determination plans, do not neglect the masses receiving services and support through the system to live more person-directed lives.
- Illustrate ways (i.e. database on staffing units and resources) that using “my money” and “self-determination money” can be combined to make use of existing and available resources.
- Develop guidelines for use of public funds and Consolidated Services and Supports (CSS) that support greater community inclusion.
- Clarify the distinction between self-determination (a philosophy and pilot program) and Consolidated Services and Supports (a funding mechanism). Consider describing self-determination as person-centered supports with person-controlled budgets.
- Seek information and assistance from individuals with expertise in Self-Determination who have a national perspective. Look at policies and practices used in other states – and reactions of individuals using self-determination - to see if they have implications for NYS.
- Explore linking websites (e.g. Self Advocacy Association and OMRDD) and using the Internet, to educate stakeholders about the process, how to use it, respond to Frequently Asked Questions (FAQs), and the like.
- Initiate collaboration, with a lead sponsor, to provide a central clearinghouse for information and/or an Internet/electronic forum to support information sharing for self determination and CSS, including a means for people to ask questions about the process and how it works and receive a response from a designated individual.
- Educate and provide information to individuals, families, community/provider agencies, and policy makers about how they can support people in Self Determination and CSS processes.

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- Review available materials on self-determination to determine how they can be modified and used more effectively.
- Develop how-to guides for people in CSS, specifically targeting housing and staff hiring issues.
- Provide more uniformity in training and roles for staff assisting with Self-Determination planning and implementation, including DDSO staff.

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Quality Services & Supports:

Working Definition:

Quality community services and supports are those that combine an emphasis on health and safety **AND** consumer satisfaction with their lives and living situations.

Priorities:

1. Ensuring that person centered principles are incorporated in the state service system culture.

For example:

- Maintain a focus on the individual and his/her needs and desires.
- Recognition that certification provides a minimum standard (quality assurance) but an elective higher standard (quality improvement) is also needed to promote excellence.
- Look at external accreditation models and expand the internal COMPASS model to further improve the measurement of quality and allow greater consumer/family input on the definition of quality.
- Individuals with disabilities and families should be encouraged to be more active in the Quality Assurance process and in the development of Individual Support Plans. Incident review teams are a good example of the former; ensuring that the family members, friends, and direct support professionals are involved in their quality circle for the individual support plans embodies the latter.
- Identify and reform state regulations and policies that conflict with individual choice and person centered principles using information from nationally recognized accrediting organizations that embody person centered principles
- Find data that validates what is being done to support efficacy/viability and how it facilitates choice as well as a feedback loop for improving quality.
- A continuum of options is necessary (preferably data supported); there is always need for new conceptions and the ability to explore available options.
- Promoting the benefits of a healthy diet, exercise and a positive lifestyle is important, as is education on self-management of health issues. However, in promoting healthy lifestyles for the individuals, take into consideration individual choice.

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- Eliminating the fear that “this is all there is” and assumptions that there are no other options so one shouldn’t look for or ask for other alternatives.

2. Recognize the importance and contribution of the Direct Support Professionals (DSP), and the Workforce in general, as crucial to improving competencies and service delivery.

For example:

- Continue to improve compensation and benefits.
- Continuation and expansion of recognition programs (e.g. Everyday Heroes).
- Better use of technology in aiding Direct Support Professionals to provide supports.
- Improve training standards and worker competencies using available (and emerging) resources such as the College of Direct Support Professionals, and/or NYS DEAL.
- Encourage providers to hire family members and people with disabilities as employees. Address attitudinal barriers that prevent use of this resource.
- Empowering Direct Support Professionals through enhanced training opportunities, to effectively advocate for individual supports in meaningful ways.
- Continued recognition of direct support professionals in the DDPC Annual Achievement Awards.

3. Maximize use of technology in assisting individuals receiving supports in their daily lives as well as in managing the service system.

For example:

- While computers, and other assistive technology, are more available to support individuals with disabilities, training on their use must be increased dramatically using lessons learned from the College for Technology in NYC and other sources.
- New software is becoming available to simplify computer use that should be shared (where appropriate).
- Envision new uses for technology to assist people with developmental disabilities and their families to participate in their communities.

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Assistance Needed from the National Perspective

While NYS has made great strides in the developmental disabilities field, we are reliant on federal assistance to maintain and expand the quality of our service system. The national politics and economics have a huge impact on disability and the ability to do our work. Thus, National-State-Community partnerships are vital. To that end, several points have been identified where assistance is required:

- Assistance in identifying best practices that we can tailor to fit our State environment.
- Assistance in enacting and maintaining policies consistent with this agenda and those needed to move ahead with this agenda.
- Tailoring a national unified agenda for change in a manner that consolidates resources and influence to support full community membership and participation for individuals with developmental disabilities and their families and caregivers.

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Participants in the NYS Agenda Setting Process

Organization Represented

NYS Participants

National Association of Councils on Developmental Disabilities (NACDD)	Sheila Carey - NYS Liaison to Alliance for Full Participation And Executive Director, NYS DDPC George Fertal – Chairperson, NYS DDPC Wendy Orzel Eric Leonard Anna Lobosco Ellen Meyers
Self-Advocates Empowered (SABE)	Becoming Chester Finn- National Chairperson, SABE Rain Rippel – President, Self-Advocacy Association of NYS Steve Holmes Daniel Borgia John Fitzgerald Janice Fitzgerald, Executive Director, Parent to Parent of NYS
National Association of State Developmental Disabilities Directors (NASDDDS)	Thomas Maul – Commissioner, NYS Office of Mental Retardation & Developmental Disabilities Gary Lind
The ARC	Marc Brandt – Executive Director, NYSARC, Inc. Nancy Cannon MaryBeth Schneider Naome Adam Ric Swierat – Executive Director, Westchester ARC Carolyn Holodak, Westchester ARC Michelle Michaels Tom Moore (Long Island NYSARC Board Officer)
National Association of Protection & Advocacy Systems (NAPAS)	Gary O’Brien – Chairperson, NYS Commission on the Quality of Care & Advocacy for Persons with Disabilities Tom Harmon
Association of University Centers on Disability (AUCD)	Ansley Bacon – Director, Westchester Institute for Human Development Barbara Levitz Mitchell Levitz Karen Edwards Jenny Overeynder - Strong Center on Developmental Disabilities Teena Fitzroy Arnold Birenbaum – Rose F. Kennedy Center Zefa Dedic

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