Alliance for Full Participation

Participating Organizations

- American Network of Community Options and Resources, Alexandria, VA
- The Arc of the United States, Washington, DC
- The Council on Quality and Leadership, Towson, MD
- American Association on Intellectual and Developmental Disabilities, Washington, DC
- National Association of State Directors of Developmental Disabilities Services, Alexandria, VA
- Association of University Centers on Disabilities, Silver Spring, MD
- National Association of Councils on Developmental Disabilities, Washington, DC
- United Cerebral Palsy, Washington, DC
- National Association of Direct Support Workers, Minneapolis, MN
- APSE: The Network On Employment, Richmond, VA
- AUCD, Silver Spring, MD
- Autism Society of America, Bethesda, MD
- National Association of Councils on Developmental Disabilities, Washington, DC
- NISH, Vienna, VA
- Self Advocates Becoming Empowered, Kansas City, MO
- TASH, Washington, DC

Please note that all data below was derived from the collaboration's nomination for the Collaboration Prize. None of the submitted data were independently verified for accuracy.

Formation
Type of Collaboration:

- Joint Programming to launch and manage one or more programs
- An alliance or similar collaborative structure through which members retain structural autonomy and have defined roles and responsibilities to achieve specific social goals or purposes

Geographic Scope: National

Collaboration Focus Area:

- Civil Rights
- Human Services
- Other

Population Served: People with Disabilities

Year Collaboration was Established: 2003

Goals Sought Through Collaboration:

- Develop a stronger / more effective "voice"
- Expand reach and/or range of services / programs
- Improve programmatic outcomes

Reasons Prompting Collaboration:

- Advancement of a shared goal
- Response to a community need

Who Initiated Collaboration: Executive Director(s) / CEO(s) / President(s)

Number of Participating Organizations: >10

Were Partners Added or Dropped?: Yes

Consultant Role: To draft the governing agreement or provide other legal advice
AFP was created by the leaders of non-profits serving the intellectual and developmental disabilities (IDD) fields who came together to set clear, measurable goals to improve the lives of people with IDD. While in theory all the member organizations agreed on common goals; in practice, prior to the creation of AFP, they often spent more time pointing fingers at one another than in working together.

AFP was created in response to negative press regarding the service provided to people with IDD living in the community. Each entity in the AFP coalition represents a different facet of the IDD population, including people with IDD, state agencies, family members, policy makers, service providers, and direct support workers. Members knew it was critical they stop focusing on differences in their approaches and band together to promote the positive impact of community integration, so that progress made since the passage of the Americans with Disabilities Act would not be lost.

AFP's coalition-building approach created a sense of purpose and action within the IDD community. State teams mirror the national collaboration, increasing program effectiveness on the local level. AFP's recently announced challenge goal to double employment for people with IDD by the year 2015 is the first of its kind since the 1980s.

Several things have been critical to AFP’s success:

- Defining who should be at the table: In its early stages, there was a lot of discussion around whether AFP should focus on serving ALL people with disabilities, (“the Big D”) or just those with intellectual and developmental disabilities (IDD). The decision to target just the IDD community was critical. AFP is an action-oriented entity, not a discussion forum. The size of the Board had to be manageable, the group, while diverse, had to have enough similarity in purpose and mission to allow for consensus building. It’s not that integration for all people with disabilities isn’t important, it’s that AFP can only credibly focus on the IDD subset of this population.
- Selling AFP to the volunteer leadership: AFP was initially the brainstorm of the staff leadership of the membership organizations. To engage volunteers, AFP held a two-day retreat with top volunteers of the member organizations. This was critical in strengthening the strategic planning and ensuring buy-in.
- Defining mission-critical principles: There are some employment models, such as sheltered workshops and employment enclaves, which might technically fit a definition of employment, but which do not constitute model practices. A continual debate on what does or doesn’t constitute employment would consume valuable board time and hamper progress. Launching its employment initiative, AFP created a competitive employment definition that represented what it considers model practice and required prospective members to endorse the definition.
- Setting specific, measurable goals and defining activities: Without clear direction, discussions at the Board level floundered, and meetings were sidetracked with discussions that were tangential, but not critical, to AFP’s mission. With specific goals in front of them, tactics to reach those goals, a timeline and a set of accountabilities, the Board is able to focus their activity very effectively.
- Aligning support and resources: To speak as a credible voice for change, AFP assembled an Advisory Council of the leading thinkers to guide and support resource development, advise on goal development and strategy. The Council ensures that the practices being promoted are rooted in solid research and outcome measurements, and provides an objective endorsement of AFP’s work.

Management

Management Structure: Jointly managed by the Executive Directors of the partner organizations

AFP's Board consists of the executive directors of all member organizations. From the outset, AFP made a conscious decision to function as a working board, not an oversight committee. AFP was not looking to create another bureaucratic entity, but rather a dynamic organization that focused members’ efforts on very specific challenges. AFP is a very lean organization. Staffing consists of two contractors, with Board members, committees and borrowed staff providing the additional manpower.

This ‘lean and mean’ approach is critical. AFP is not a threat to its members. Its activities don’t compete with other education or training efforts. Instead, AFP provides a national focus and collective voice for initiatives, leverages work being done by members, and promotes leading practices across multiple channels.

Challenges

Challenges to Making the Collaboration Work:

- Defining and measuring success
- Addressing lack of staff or allocation of staff resources
- Achieving shared vision
- Raising funds or integrating fund development to support the collaboration
The biggest current challenge facing AFP is operational capacity. Economic challenges have left Board members with less time to commit to AFP as they focus on the operating capacity of their own entities. At the same time, AFP’s work in employment is critical and with its success, AFP is being called on to provide additional information and technical support to state teams.

**Impact**

**Internal Efficiencies and Effectiveness:**

- Fund development - Access to new / more sources of funding
- Greater ability for each partner to focus on core competency - Greater ability to allocate resources to areas of need
- Improved marketing and communications, public relations and outreach - Improved marketing and communications, public relations and outreach

**Community Impact:**

- Stronger / more effective "voice"
- Improved programmatic outcomes

AFP has impacted the IDD community by:

- Creating a movement: AFP’s 2005 Summit, “Many Voices, One Vision”, attended by over 2400 people, resulted in a nationwide Agenda for Full Participation, a series of action goals embraced by all founding organizations and integrated into each organization’s strategic plan. AFP energized the various segments of the industry to work together for change.
- Increasing federal awareness. AFP demonstrates to federal agencies the willingness of IDD organizations to work together to increase effectiveness, and strengthens the voice of the IDD community.
- Educating the general public about the importance of integrating people with developmental disabilities into their communities.
- Developing a network of state teams working together to move policy and practice forward on the local level. State teams evaluate current employment policies and practices, set benchmarks and implement strategies for doubling employment.
- Creating educational webinars to highlight leading practices, developed a quarterly newsletter, launched a major employment Summit, developed an interactive web site, and provided technical assistance to AFP’s state teams to support its employment challenge goal.

Measuring the impact of AFP’s work is critical. After the success of the 2005 Summit, the Board decided future AFP efforts needed to be tied to specific, measurable goals. Our employment initiative is tied to benchmarks within each state, and states are completing a scorecard to establish the baseline against which progress will be measured. Practices which are promoted will be rooted in outcomes-based research, and AFP’s progress towards its employment goal will be measured and celebrated.

**Model**

AFP’s model is easily replicable in fields in which diverse constituent groups share common goals, but offer different approaches or perspectives on how to achieve those goals. It offers a low-cost, low-barrier entry point for creating effective collaboration, unifying efforts, and strengthening a collective voice.

**Efficiencies Achieved**

The greatest efficiencies achieved through the AFP collaboration have been through the work of our state teams and have come in the area of program delivery. Prior to AFP’s collaboration, several groups were working on increasing employment opportunities for people with intellectual and developmental disabilities (IDD), but the initiatives were not linked across multiple stakeholder groups, targeted participation from specific groups, or lacked specific measurement goals. AFP created a very specific, measurable goal: to double employment for people with IDD by the year 2015, and put in place the network to link together all those populations invested in achieving this goal. It’s a bold, ambitious goal, particularly in the current economy. Because employment policy and practice is set largely on the state level, rather than one national goal, it is essentially 50 smaller goals, with each state taking the larger goal and applying it to the context of their state.

Measuring Success: AFP’s advisory council, comprised of leaders in the IDD field, developed a scorecard that each state team uses to establish current benchmarks in employment policy and practice. This scorecard and rating system are
rooted in established leading practices, proven to increase employment outcomes. Because the way that various populations are measured varies from state to state, even establishing the number of people currently served by various programs, or establishing a current employment rate can be challenging. Coaching state teams to think about tangible employment goals, rather than vague goals of ‘improving employment’ provides results that are specific and measurable. Once a state has determined their current employment statistics and evaluated their practices using the scorecard, they have a roadmap for specific strategies that will lead to improved outcomes in their state. By encouraging all states to use the same scorecard, AFP is creating a framework for a national conversation on employment and establishing uniform ways of measuring outcomes.

AFP’s scorecard offers very specific measurements relating to employment:
• What percentage of people with IDD are being served in integrated employment?
• What percentage of the state’s budget is allocated to support individualized, integrated and competitive employment?
• What are admission trends for segregated employment?

The scorecard measures states on their implementation of:
• Employment first policies
• Practices relating to employment data collection and dissemination.
• Statewide coalitions (both informal and formal) to support integrated employment.
• Programs and services to transition youth from school to employment.
• Specific programs to support innovation in employment service delivery.

The implementation of the AFP scorecard, and the strategic planning that each state conducts results in specific, quantifiable results for employers and for people with IDD within the state.

Achieving Efficiency: In many states, there are already coalitions working on some element of employment for people with disabilities such as Employment First coalitions, Medicaid Infrastructure Grant entities, and NTAR leadership centers. If a viable employment coalition already exists, AFP does not want to create another bureaucratic entity. Instead, AFP works within the construct of the existing employment coalition to provide resources, support and technical assistance to move states forward in employment outcomes. AFP provides access to a national network of information, resources and training regarding employment programs and information that will support the state teams, whatever heading they are organized under, in reaching improved employment outcomes in the state. Increasing the efficiency of all groups working on employment is critical to AFP’s success—while spending on disability-related services has increased over the past decade, fewer resources go to employment for people with the most significant disabilities, the IDD population. AFP’s role in highlighting emerging best practices and policies is critical in ensuring what resources are available are being channeled into effective activities.

Building New Collaborations: AFP also reaches beyond its traditional barriers to establish new opportunities for collaboration. AFP has joined with Rutgers NTAR Leadership Centers to provide technical assistance and support to states working on employment and to connect AFP and NTAR’s teams together in networking. In addition, through a grant from the Social Security Administration, AFP is using its state team scorecard research to identify, investigate and promote transition-aged employment policies and provide SSA with research that will help shape future employment programs.

Quantitative Measures: People with intellectual and developmental disabilities want what we all want—to experience economic freedom and the opportunity to connect with the society around them. The majority of people with disabilities are unemployed or underemployed, despite their ability, desire and willingness to engage in meaningful work. It is estimated that only 22 percent of working-age adults with developmental disabilities are employed, compared with 74 percent of adults without disabilities. Developmental disabilities impact one-two percent of the US population, impacting approximately 5 million Americans directly, and countless other family, friends and supporters of people with disabilities. AFP’s goal of doubling employment by the year 2015 means that nearly 1 million more people with IDD will be able to experienced the dignity of having a job and contributing to society. In addition to the benefits to people with IDD, people with disabilities represent a tremendous opportunity for businesses as well.

With significantly higher unemployment than the general population, people with disabilities are one of the last untapped labor sources in the country. Robert Cimera of Kent State University has found that each person in supported employment results in an average sayings of $133.10 per month to taxpayers. Beyond the social good that is created when people with IDD are able to experience the joys, risks, financial and emotional rewards of an integrated life in the community, AFP’s employment goal provides taxpayers, businesses, and communities as a whole with specific, measurable cost-efficiencies.
Evolution

Early Years: The Alliance for Full Participation is now in its sixth year as a formal coalition, but its evolution began in the late 1990s through a series of informal relationships. Initially, the American Association on Intellectual and Developmental Disabilities hosted a series of brown bag lunches in its DC office to allow CEOs to share information and resources concerning association management and emerging trends in the field of IDD. In 1999, a series of articles about the deplorable condition of services for people with IDD created concern that poor service quality might impede the growth of community services and reinforce support for institutional systems. A coalition was created to address public issues relating to quality and availability of public services for people with IDD, and through funding from the Administration on Developmental Disabilities, a national conference called Wingspread was held to discuss public awareness, self determination, workforce development, and quality management. This early efforts at organizing proved two things: there was the ability to create a broad consensus within the DD community; and the CEOs and leadership of the organizations had a mutual commitment to work together to achieve goals. From this informal coalition, the formal entity AFP was created.

Management Structure: Building on the trust that was established in the early years, in 2003, the participating groups decided to move beyond discussion forums and focus on specific actions to advance their joint missions. AFP created a limited liability partnership, to formalize the collaboration and to provide each member organization with a ‘buy-in’ and sense of ownership in the coalition. AFP formed a working board, adopted a vision and mission to support improved quality of life for people with IDD and began to plan and implement specific projects that would lead to this outcome. AFP organized a large Summit meeting in 2005 in Washington, DC attracting over 2400 people to create a national agenda to facilitate the full inclusion of people with IDD in mainstream community living.

In 2005, the Summit focused on making the national coalition tangible on a local basis, and state level coalitions were created to take AFP’s action agenda and inform states and practice to make it a reality. In 2009, AFP officially became a 501c3, to enable it to more easily take advantage of funding opportunities. Also in 2009, AFP announced its campaign to double employment for people with IDD by the year 2015. This goal was very carefully selected. AFP’s Board realized that they had a tremendous amount of momentum following the 2005 event. They wanted to select a specific, measurable goal, and one which had the most opportunity to impact the quality of life for people with IDD, on which to focus their efforts. If you can solve employment for people with IDD, alleviating issues of poverty, isolation, and housing follows. AFP’s management structure has evolved carefully and slowly. AFP’s initial start as an informal coalition allowed members to establish trust in each others motives; and early successes such as the Wingspread conference built confidence among members that larger initiatives would be successful.

It was very important that AFP not be seen as another non-profit in an already crowded field serving the IDD population. AFP’s organizational structure, management focus and staffing are all designed to create an entity that can focus and leverage the collective goals of each member organizations, rather than an entity that might compete for program dollars or resources. AFP’s success requires a high level of involvement by member organizations. Each Founding group put up $7,500 in seed money to establish AFP and each Board member and member organization is required to take a very active role in the leadership and implementation of programs, directing programs and lending staff as needed for implementation. This ‘skin in the game’ is critical to ensuring that AFP retains its action oriented focus.

Challenges: Initially, AFP struggled with defining its scope and role. Particularly following the success of the 2005 Summit, many organizations wanted to join the collaboration. Within the membership, differences in populations served (some groups served the entire disability population, others focused specifically on the IDD community), led to conversations about “Who exactly, should be at the table.” Additional discussions focused on how to define employment, as within the IDD community, there are some practices, such as sheltered workshops or enclaves, which do not fit AFP’s mission of integrated, competitive employment. AFP learned quickly that it was important to allow discussion on controversial issues, then force a board vote, make a decision, and move on. AFP’s lean staffing structure has also created capacity challenges. Current economic realities mean that most member organizations have very little excess staffing capacity. As members’ staff are less available or less able to respond quickly to responds for information and assistance, AFP has had to be creative to ensure it is able to meet its program goals.

Benefits of Collaboration: As is typical in the non-profit world, each AFP member group serves a very specific segment of the IDD population: people with disabilities, their families, providers, policy makers, State Developmental Disability Councils, specific IDD populations such as Autism or Cerebral Palsy, direct support workers, etc. AFP’s current employment initiative requires each group to move beyond their specific IDD population’s interests and look for ways to collectively prioritize, strategize and move forward an agenda results in definitive action. Benefits of this collaboration include:

- Increased effectiveness of member organizations: AFP members move beyond talking to committing to specific actions that increase employment outcomes. The visibility and peer accountability of being part of a national coalition has increased employment focus among each organization.
- Increased collaboration and access to resources: AFP creates a national dialog on employment, rather than 14 separate conversations. AFP’s Advisory Council provides access to resources not individually available to member organizations.
- Bigger voice: AFP’s members working together has led to a bigger and louder voice focusing on employment, generating broader awareness among community, business, state and federal leaders.
- Economic efficiencies: AFP’s employment initiatives result in very specific, tangible benefits to taxpayers, businesses and communities. Leveraging resources also helps each organization o meet its individual missions more effectively.

Why Us?
Too often, an industry’s non-profit landscape is littered with silos—professional or trade associations focused on narrow
segments of an industry. AFP’s model of collaboration offers a readily replicable, transferable model for non-profits to break through their silos to create purposeful, coordinated action that leverages and multiplies the individual actions of each separate group. AFP’s national collaboration, begun in 2003, and ignited by its national Summit in 2005, has sparked a movement both national and local in scope, which is resulting in direct, measurable improvements in employment outcomes for people with IDD.