

## Charting Impact Report \* Prepared 05.17.2011

This report represents The Arc of the US's responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.



### The Arc of the US

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#### Mission:

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

- CEO Reviewed
- Board Chair Reviewed
- Not yet stakeholder reviewed

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## 1. What are we aiming to accomplish?

#### **MISSION**

The Arc's mission is to promote and protect the human rights of people with intellectual and developmental disabilities and to actively support their full inclusion and participation in the community throughout their lifetimes.

#### THE PEOPLE WE SERVE

The Arc is "for people with intellectual and developmental disabilities" and is the only national organization that serves people with Intellectual Disability, Down syndrome, Autism Spectrum Disorder, Fetal Alcohol Syndrome and many, many other diagnoses, throughout their lifetimes in communities across the United States. The Arc also serves and support the entire family, including parents, siblings, grandparents and other family members, as well as supporting professionals in the field. There are more than 7 million people with I/DD in the U.S.

#### LONG TERM GOALS

The Arc's goals over the ten year period, 2010 – 2019, are to assure that:

- 1. Infants, children and youth with intellectual and developmental disabilities (I/DD) have access to the supports and services they need to live in their family homes, to succeed in school and to partake in all of the experiences of childhood.
- 2. Adults with I/DD have the opportunity to lead lives of their own choosing, free from poverty, to be employed, to reside in the community, and to live independently with ready access to whatever services and supports they need.
- 3. People with I/DD have the opportunity to participate in civic activities, volunteerism and community service, religion, arts, culture and recreation alongside their peers without disabilities.
- Individual members of the public value, respect and accept people with I/DD as equal members of society.
- 5. Quality health education, health promotion and health care are widely available and accessible, enabling individuals to avoid known environmental causes of I/DD and to prevent secondary health problems for people with I/DD.

# 2. What are our strategies for making this happen?

The Arc's 700+ chapters serve more than 1 million people with intellectual and developmental disabilities (I/DD) and their families. The following are The Arc's strategies for getting there:

### Goal 1 – Strategies for Infants, Children and Youth with I/DD.

- Increase the availability of early intervention services in naturally occurring environments.
- Increase the full inclusion of students with I/DD in schools.
- Promote best practices in school-to-community transition.
- Eliminate the use of seclusion and non-emergency restraint in schools.
- Increase student involvement in developing their own Individualized Education Program(IEP).
- Increase access to advocates to support people with I/DD, including parent advocates and youth self-advocates.

### Goal 2 – Strategies for Adults with I/DD.

- Increase opportunities for integrated employment at fair wages, and self-employment.
- Build the capacity of businesses to employee people with I/DD...
- Identify and promote best practices in services and supports for people with I/DD relating to housing, employment and

### Charting Impact Report \* Prepared 05.17.2011

### community participation.

- Increase the availability of affordable, accessible rental housing and home-ownership, as well as supported and independent living
- Increase access to personal supports.
- Replace state institutions with community based services and supports.
- Support self-determination and self-advocacy.
- Rebalance the Medicaid program so that home and community based services and family support are readily available.
- Improve basic income support systems to reduce the incidence of poverty.

### Goal 3 – Strategies to Promote Civic Participation for People with I/DD.

- Build the capacity of civic, religious, and other organizations to include people with I/DD in their programs and activities.
- Increase voting and participation in the political process.
- Increase the availability of family support and respite services.

### Goal 4 – Strategies to Promote Acceptance and Respect for People with I/DD.

- Publicize incidents of bigotry, discrimination, and victimization of people with IDD.
- Engage in testing to identify discriminatory practices in housing and employment
- Increased public awareness of people with I/DD, their needs issues and concerns, and showcase their positive role and contributions.
- Monitor the media and promote more accurate, respectful and positive coverage.
- Educate of legal and law enforcement officials, teachers, clergy, and others to well serve people with I/DD.
- Educate people with I/DD and their families about how to protect their civil rights.

### Goal 5 - Strategies for Health Promotion for People with I/DD

- Educate the public to avoid environmental agents known to cause I/DD.
- Increase access to medical, dental, and mental health care, including making health insurance universally available.
- Build the capacity of health care professionals to serve people with I/DD.

# 3. What are our organization's capabilities for doing this?

The 700+ chapters of The Arc provide the means to achieve our mission of service for people with intellectual and developmental disabilities (I/DD) and their families. Local chapters are on the front lines providing individual advocacy, programs, services and supports. Their work touches on all aspects of community life, including education, employment, health care, housing, recreation and more. The Arc serves more than 1 million people with I/DD and their families at more than 2,300 locations, while also advocating on behalf of the entire universe of more than 7 million people with I/DD in the U.S.

### **Promoting Best Practices**

The Arc is the nation's largest provider of services and supports for people with I/DD, including advocacy services. Each chapter is a separate 501(c)(3) tax-exempt nonprofit. The national office advances their work by promoting best practices in programs, services and supports for people with I/DD, as well as in nonprofit governance and management. Support is provided online through websites, blogs and social media, as well as through conferences, meetings,

### Charting Impact Report \* Prepared 05.17.2011

conventions, webinars and one-to-one technical assistance.

### Federal Public Policy Advocacy

The Arc's federal public policy advocacy protects and promotes the rights of people with I/DD and provides the resources they need to fully participate in community life. The Arc has a detailed Public Policy Agenda to guide our work on federal policy issues. In addition to influencing policy developments within the executive and legislative branches of government, The Arc participates in court cases when needed as a "friend of the court."

### State Public Policy Advocacy

State and local chapters of The Arc engage in both individual advocacy and public policy advocacy at the state and local level. The national office supports their work by building a knowledgebase and sharing information among and between chapters, coordinating national strategies for state policy reforms, informing chapter leaders about the latest policy developments, and training chapter volunteers and staff leaders.

#### Research and Innovation

The Arc also works to translate theory and knowledge into practice through cooperative working relationships with individual researchers and research institutions, including the university centers on disability. The Arc marshalls data, information and research from available sources, and supports or sponsors additional research where needed to fill gaps or further inform strategy and action.

### Communications and Public Education

The Arc educates the public about the needs, issues and concerns of people with I/DD and their families. We provide timely, credible and accessible information to opinion leaders, decisionmakers and members of the public through websites, social networking sites, radio, television, print and other media, as well as through the communications channels of our extensive network of state and local chapters.

# 4. How will we know if we're making progress?

The Goals and Strategies, listed above, are excerpted from the Strategic Framework for the Future of The Arc, 2010 – 2019. The full plan may be found on The Arc's website, www.thearc.org. Based on this long-term plan, The Arc prioritizes among the multiple goals and strategies and develops two-year operational plans to guide the work of the national organization. State and local chapters are free to develop their own priorities, drawing on the nationally established goals and strategies, as well as to develop additional goals and strategies that are consistent with the unique needs within their own local communities.

Near-term objectives and indicators vary depending on the particular goal and strategy, as well as the methods and tactics employed in pursuit of the particular strategy.

Overall Impact is gauged by measureable changes in the residential status, employment and other life circumstances of people with intellectual and developmental disabilities, as well as by monitoring the level and adequacy of funding for the programs, supports and services that assist them in being included in society. Data sources include independent research by academics and other third parties, surveys and information collected from chapters of The Arc, individuals with I/DD and their family member, public opinion surveying and other market research.

As described in response to question 3, identifying and promoting the replication of best practices in services and

### Charting Impact Report \* Prepared 05.17.2011

supports for people with I/DD by chapters of The Arc is a method used to pursue numerous of the goals and strategies. Typically, this method involves "near term objectives" and "indicators" such as:

- Identifying evidence-based, best practices in a specific area of program service delivery;
- Supporting demonstration or pilot programs engaged in promising practices;
- Establishing learning communities for practitioners interested in the specific program area;
- Attaining meaningful program evaluation and outcome data regarding the pilot projects;
- Disseminating knowledge attained about what works;
- Replication of programs, services and supports that have been demonstrated to work at additional sites.

Federal and state public policy advocacy are additional methods used to pursue many of the goals and strategies. With advocacy "near term objectives" and "indicators" include:

- Obtaining congressional staff interest in addressing the particular issue;
- Obtaining congressional member commitment to introduce legislation;
- Introduction of the legislation;
- Sign-on of additional sponsors for legislation;
- Successful hearing presentation regarding proposed legislation;
- Favorable consideration of legislation in committee of legislative body;
- Favorable consideration of legislation by full legislative body;
- · Signature by Executive;
- · Successful implementation.

# 5. What have and haven't we accomplished so far?

The following are specific accomplishments during the period January 2010 - March 31, 2011.

Goal I – Accomplishments for Infants, Children and Youth with I/DD.

- Successfully advocated for passage of the:
- Teacher Jobs and State Fiscal Relief Act of 2010, providing \$26.1 billion to avoid substantial budget cuts in Medicaid and school system funded programs, services and supports.
- Social Security Applicants Access to Representation Act of 2010, improving access to non-attorney advocates for claimant in social security cases.
- Launched Walmart Foundation School-to-Community transition project, piloting promising practices in youth transition to employment and community living at 50 sites nationwide.
- Advanced proposed legislation to limit the use of seclusion and restraint in schools through two houses of Congress; final passage unsuccessful.
- Launched Autism NOW: National Autism Resource and Information Center.
- Launched new website and blog, new quarterly print newsletter, Empower, and a new quarterly e-newsletter, The Arc's e-Newsletter, Twitter and Facebook presence to reach broader audience.

### Goal 2 – Accomplishments for Adults with I/DD.

- Successfully advocated for:
- o creation of a voluntary insurance program for long term support and services,
- o financial incentives for states to expand home and community based services.
- o expanded affordable housing options for people with disabilities...

### Charting Impact Report \* Prepared 05.17.2011

• Provided educational programs for chapters on transitioning from operating group homes to supported housing and from operating segregated employment programs to supporting integrated community employment.

### Goal 3 – Accomplishments Promoting Civic Participation for People with I/DD.

• Successfully advocated for passage of The Twenty-First Century Communications and Video Accessibility Act of 2010, ensuring that Americans with disabilities can more fully participate in all that new technologies have to offer.

### Goal 4 – Accomplishments Promoting Acceptance and Respect for people with I/DD

- Successfully advocated for passage of Rosa's law, eliminating the terms "mentally retarded" and "mental retardation" from federal health, employment and labor laws.
- Engaged social media and traditional media to respond to incidents of derogatory treatment of people with I/DD by celebrities.
- Conducted first comprehensive survey of Family and Individual Needs for Disability Supports (FINDS) (report due for release 6/14/11)
- Awarded The Arc's 1st Image and Inclusion Award to Lauren Potter and Robin Trocki of the hit show, "Glee."

### Goal 5 – Accomplishments Promoting Health for People with I/DD.

Successfully advocated for Affordable Care Act that expands insurance coverage for people with disabilities, prevents denials of coverage for pre-existing conditions, prohibits annual and lifetime caps on coverage, prohibits discrimination on the basis of health status, expands Medicaid eligibility and provides support for training of medical professionals.