

# Board Orientation 2015



The Arc of Pennsylvania



# Welcome and Introductions



# History and Culture of The Arc

# History: The Founding

1930s: Informal parents groups forming around the United States.

-as many as 125 groups by 1950

1949: The Arc of PA forms

1950: Parents gather at annual AAMD (now AAIDD) meeting in Columbus, OH.

1950: Minneapolis MN organizing meeting

-23 organizations from 14 states present

-Constitution and Bylaws adopted for the National Association of

Parents and Friends of Mentally Retarded Children established

1951: Constitution/Bylaws ratified by 20 local groups

1953: National Association for Retarded Children incorporated in Tennessee.

1954: National office opened in New York, NY

1958: First report, entitled "Research in Mental Retardation: Why and

How," is released.

# History: Early Years

Name changed to National Association for Retarded Citizens

1960s:

- The Arc helps expose the link between lead poisoning and brain damage in infants and children.
- The Arc represented on the first President's Panel on Mental Retardation.
- The Arc's advocacy helps fuel creation of research funding and creation of Medicare and Medicaid.

1970s:

- The Arc's advocacy instrumental in passage of PL 94-142 Education of all Handicapped Children Act, SSI disability program, Section 8 Assisted housing program, and Developmental Disabilities Act
- Study by The Arc links under-nutrition and developmental disabilities
- Research funded by The Arc defines Fetal Alcohol Syndrome
- Conference held on "Poverty and Mental Retardation."

1973: Name changed to National Association for Retarded Citizens

# History: the 1980s and 1990s

1980s:

- The Arc advocacy fuels passage of the Civil Rights of Institutionalized Person Act, Supported Employment programs in the Rehabilitation Act, Home and Community based services options in Medicaid, extension of Education of the Handicapped Act to infants, toddlers and pre-schoolers, Work incentives in Social Security Act, Fair Housing Act bar on disability discrimination, and more.
- National prevention education initiatives launched.

1981: Name changed to Association for Retarded Citizens of the U.S.

1990s:

- The Arc's advocacy fuels passage of the Americans with Disabilities Act
- National media campaign launched focusing on danger of alcohol consumption in pregnancy.
- Fetal Alcohol Syndrome Prevention and Education Act passed.
- Publication released on "Genetic Issues in Developmental Disabilities"



1992: Name changed to The Arc of the U.S.

# History: 2000 - 2009

## 2000s:

- The Arc's advocacy prevents huge Medicaid funding cuts, increases public housing vouchers for people with disabilities, restores protections under the ADA, extends hate crimes protection to people with disabilities, creates support for post-secondary education, and more.
- The Arc participates in development of UN Convention on the Rights of People with Disabilities.
- Research report published setting "National Goals and Research for People with Intellectual and Developmental Disabilities."
- The Arc leads national protest of negative portrayal of people with intellectual and developmental disabilities in movie, Tropic Thunder.
- The Arc and UCP combine government affairs staff to form Disability Policy Collaboration
- School-to-Community Transition project; 50 projects funded in 27 states (\$3.85 million over 4.5 years; Walmart, M&S Smith Trust, AT&T)

# History: this decade

- All national staff finally under the same roof at 1825 K St NW
- The Arc's advocacy instrumental in:
  - \$16.1 billion in Federal Medicaid matching funds to prevent cuts.
  - Melville Affordable Housing Act passed to create more accessible housing
  - Health care access guaranteed for people with disabilities as pre-existing condition limits, annual/lifetime caps eliminated thru health care reform.
  - Rosa's law passed to replace "mental retardation" with "intellectual disability" in
  - Federal employment, health and labor laws
  - Won passage of Combating Autism Reauthorization Act
  - Medicaid, SSI and SSDI held harmless in BCA and Fiscal Cliff I.
- Study of "Family and Individual Needs for Disability Supports" (FINDS) and report, *Still in the Shadows with Their Future Uncertain*.
- Autism Now! National Autism Resource and Information Center project launched. (\$3.2 million over 4 years)
- The Arc CEO appointed to President's Committee for People with Intellectual

## Disabilities

- eXplore eRecycling project (\$565k over 18 months; Walmart, Alcoa)
- HealthMeet project launched (\$3 million over 3 years)

# Core Values of The Arc

- The Arc is committed to serve all persons with disabilities
- Everyone has strengths, abilities and inherent value
- Everyone must be treated with dignity and respect
- All persons with disabilities have a fundamental right to learn, live, work and play in inclusive communities
- Self-determination is paramount for persons with disabilities

# Core Values of The Arc

- Society benefits from the contributions of people with diverse personal characteristics
- Adults with disabilities deserve Employment First
- The Arc values Natural Supports in the community as much as public supports
- The Arc promotes empowerment to make informed decisions and choices

- The mission of The Arc is enhanced by collaborations and partnerships with other organizations

# The Arc is committed to ...

- Full inclusion
- Participation in the community for their lifetimes...for people with intellectual and developmental disabilities



# The Arc

## Focus on the individual

- The Arc is passionate about its cause
- The families of people with I/DD play a critical role in the leadership of The Arc
- The Arc serves all people with I/DD
- The Arc supports an increasing role for people with I/DD in the organization at all levels
- The Arc ensures that individual rights are protected and justice is served

# The Arc

## Diversity of our Chapters

- Largest grassroots organization of its kind. Chapters play a key role in the governance of The Arc and in developing positions and policies.
- Chapters of The Arc are a very diverse group
  - Nationally - Small vs. large (231 chapters with revenue less than \$100k, 113 with over \$10 million)

- Nationally - Service providers vs. advocacy only (74% services & advocacy; 22% advocacy only; 4% service only)
  - This can cause conflict on specific issues
- PA – Most provide services including residential, employment, vocational, day programs, recreational, Early Intervention, representative payee

# The Arc

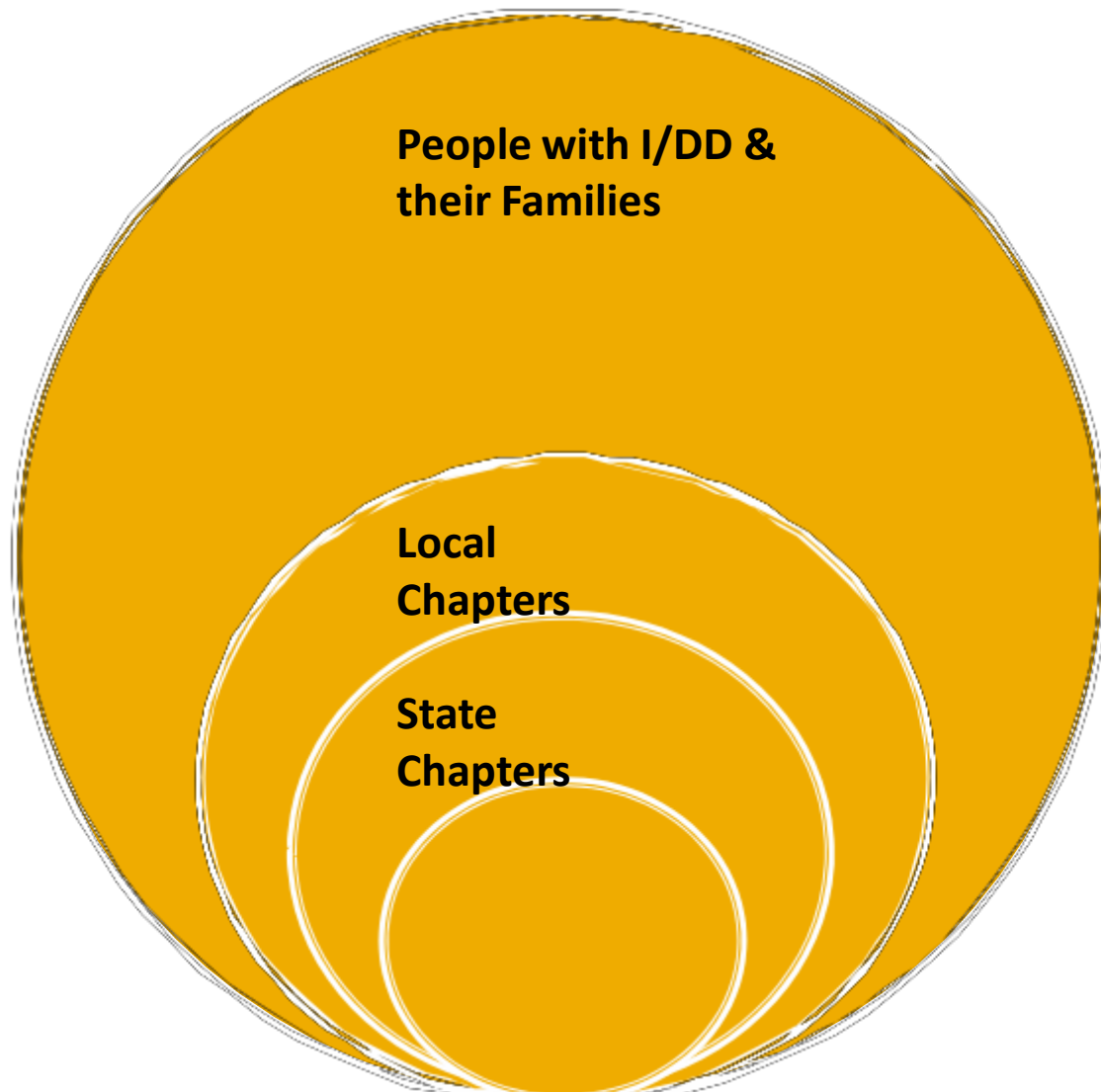
The Arc is an agent for change

- Advocating for changes to help improve people's lives
- Constantly evolving
- Need to work with a diverse group of chapters to get things done

# Organizational Structure of The Arc

- Chapters are separately incorporated, nonprofit, 501(c)(3) tax-exempt corporations
- Different because we have three levels
- National
- State
- Local

# Governance Structure



**National  
Office**

State and local chapters  
are  
corporate “members” of  
national organization.  
• Their President, VP or  
other  
designee casts their votes  
(1-23)  
at the annual meeting for:  
• Board members  
• Core values  
• Position statements  
• Resolutions  
• Bylaws amendments  
• Individual members do  
not  
have voting rights  
• Organizational members  
do

not have voting rights

# Qualifications to be a Chapter

- Nonprofit corporation
- Pledge to advance & uphold Mission, Core Values and Guiding Principles, Positions, Public Policy Agenda
- Meaningfully involves parents, family members and people with I/DD in leading & guiding
- Pays dues to national
- Prominently identifies as part of The Arc
- Provides opportunity for individual membership
- Local chapter must affiliate with both state & national



# State & Local Chapters

- Local Chapter Duties
  - Engage in advocacy
  - Provide families, media and public with information about needs issues and concerns, and about services & supports
  - Mobilize constituents in support of public policy at national and state level
- State Chapter Duties
  - Engage in state public policy advocacy
  - Mobilize constituents in support of public policy at national and state level
  - Promote public awareness

- Encourage, assist and support local chapters

# State Chapters

- 40 state chapters & 1 state office
  - Montana & Idaho – new in 2012
- Still Missing in Action
  - Alaska, Kansas, Maine, New Hampshire, Oklahoma, Rhode Island, South Dakota, Utah, Vermont
- Dues based on size of population

- Range from \$2,600 to \$11,750

# State & Local Chapters

- over 700 chapters nationally

# Board Composition

- Must have at least 19 directors and no more than 25 directors
- 6 officers (President, 1<sup>st</sup> Vice President, 2<sup>nd</sup> Vice President, Secretary, Treasurer, and Immediate Past President)
- 13-19 elected by local chapters
- Up to 3 appointed by President, approved by Board
- *ex officio* (members of Arc US board)
- Officers (2 year term), Directors (3 year term)
- 2 terms as Director, maximum 10 consecutive years

# Board Composition (continued)

- Majority must be parents, other family, or people with I/DD
- Board must have at least 3 Directors who are self-advocates
- All must be an individual member of The Arc
- Up to 25% may be staff of local chapters

# Role of the Board (Governance)

- Long-range and strategic planning
  - Mission, Vision, Goals & Strategies
- Oversight of progress toward mission
- Fiduciary oversight
- Set policy (core values, positions, legislative agenda)
- Raise financial and other resources
- Arrange for executive management



- Manage board affairs

# Role of Individual Board Members

## (Governance)

- Governance
  - Uphold mission, vision, core values, positions
  - Attend and participate in quarterly meetings
  - Stay informed and exercise independent judgment
  - Participate on committee, task force or tailored activities
  - Abide by conflict of interest policy
  - Provide advice and counsel to management on request
- Giving and Getting
  - Charitable contribution that is personally significant
  - Participate in fundraising efforts
- Chapter & Community Relations
  - Attend and participate in National Convention
  - Participate in chapter recruitment/retention
  - Serve as advocate/ambassador for people with I/DD and families

- Direct media , government contacts to Executive Director.

# How to be an Effective Board Member?

- Read the board meeting packet
- Participate in board meetings, ask questions, express views
- Serve on board committee(s)
- Learn about the work of The Arc
- Serve as the ambassador to your state/local chapters...attend your state/local Arc board meeting
- Introduce potential corporate and major individual donors to The

Arc

# Mission Statement

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

# Ten Ideas to Inform Your Leadership

1. At our core, The Arc is a human rights organization.
2. We serve people with all types of intellectual and developmental disabilities (Autism) at all stages of life (children/young families).
3. Home and community is where people should be.
4. We are committed to self-determination and self-advocacy.

# Ten Ideas to Inform Your Leadership

5. Parents, siblings and people with IDD are central to The Arc. To succeed we must embrace and involve the next generation of families

6. As the largest provider of programs, services and supports, The Arc should be leading the way as the preeminent provider of quality services that people need and want.

7. Effective system advocacy and individual advocacy are needed to get the job done.



# Ten Ideas to Inform Your Leadership

8. The Arc should be the thought of as a leader in the disability field and the preferred resource for advocacy and information.
9. The Arc is one organization, with national state and local leadership, presence and impact; together we leading and catalyzing a growing movement on behalf of people with I/DD.
10. The Arc brand must be as well known and respected as any of the other top 10 national charities.

# Regulatory Advocacy

## Examples

- Worked on draft regulations for Adult Protective Services
- Submitted comments to the Office of Developmental Programs regarding waiver regulations
- Participated in work group addressing the Special Education Chapter 14 regulations

# Legal Advocacy

The Arc of PA was the plaintiff in the case that led to the PARC Consent decree requiring all student to have access to education – led to the first national law guaranteeing rights to education for students with disabilities

We advocate in the federal courts and state supreme courts for proper interpretation of laws.

- We have served as a ‘friend of the court’ by filing briefs in cases which significantly involve and/or affect persons with developmental disabilities, such as cases involving deinstitutionalization
- We joined with the Disability Rights Network in the suit to stop the Human Services Block Grant

# Coalitions

## Examples

- Intellectual Disability and Autism Coalition
- Adult Protective Services
- Chapter 51

# Include Me

- Inclusive Education program implemented in partnership with Pennsylvania Department of Education
  - Began in 2010
- Offers technical assistance in 30 districts across Pennsylvania
  - Works with K-12 grades
- Works with Early Intervention teams to promote inclusion in Pennsylvania preschools

- Tool for connecting young parents and families with The Arc of Pennsylvania

# Communications Products and Services

- In Touch e-Newsletter
  - Regular e-mails about current policy issues and events
- Action Alerts
  - Sent via email or through Capwiz
- PA Message
  - The Arc of Pennsylvania's quarterly newsletter
- PIE
  - Alerts
  - Quarterly Slice newsletter focuses on policy issues

# Communications Products and Services

Website



Facebook



Media (including press releases and interviews)

