Self-Advocacy: Past & Present

Valerie Bradley
Stephanie Giordano
Yoshi Kardell
Human Services Research Institute
What We Will Cover

- A Brief History of the Self-Advocacy Movement
- Current State of Self-Advocacy in Georgia
- Future of Self-Advocacy Nationally and Locally?
- Ways to Facilitate Participation in Self-Advocacy?
What did you believe, and when did you believe it?

1960
“Label jars, not people!”

Choice
“Who’s in charge?”

Self-Determination
“Nothing about me without me”

Self-Direction

Supported Decision making
“Thank you, but what you built we don’t want”

Self-Advocacy!

Developmental Model

Normalization

Continuum Trap

People First Language

Supports!

Families!

Person-Centered

Integrated Supports

Dignity of Risk
• Beginning in the 1970’s people with developmental disabilities began organizing and speaking up for equal rights
• In 1974, the first People First Convention was held in Oregon
• Self-advocacy groups began to formalize around the nation throughout the 80’s
• Self-advocate leaders emerged and helped shape the direction of the movement, pushing for people with disabilities to have the right to live a life like anyone else
A Look Back

- Self Advocates Becoming Empowered (SABE), a national self-advocacy organization, was formed in 1992 (http://www.sabeusa.org)
- By 1993, the majority of states had statewide self-advocacy organizations, some with a network of local chapters
- Many focused on building peer supports among people with disabilities, teaching self-advocacy skills, and ending the segregation of people with disabilities and closing institutions
A Look Back

Locally, many self-advocacy groups received support from provider organizations, or other supporters, through grant funding, staff support, or in-kind contributions and were often focused on:

- Providing social activities for people with disabilities
- Drawing attention to local issues such as accessibility of public places, access to supports and services, and inclusion in community
- Connecting with larger statewide efforts such as speaking with policy makers about specific issues
In recent years, other national disability groups formed around specific issues:

- National Youth Leadership Network (NYLN) (no longer active)

- Autistic Self Advocacy Network (ASAN) ([http://autisticadvocacy.org](http://autisticadvocacy.org))

- Association for Successful Parenting (TASP) ([http://achancetoparent.net](http://achancetoparent.net))
Self-Advocacy organizations face challenges – some that are common to other organizations and some that are not, including:

- Identifying skilled support and facilitation that is not intrusive but assists people to find their voices
- Recruiting and maintaining membership
- Developing activities that add value to their member
- Securing stable funding
- Organizing around a common cause
What Are Self-Advocacy Priorities

Currently, these tend to be top issues that self-advocates talk about:

• Real jobs for real pay
• Living my good life
• Making my own decisions
• Managing my supports
• Belonging to community
• Right to friendships & romantic relationships
• Right to make mistakes
What’s Next for Self-Advocacy?

How is the voice of people with disabilities represented in other prominent social justice movements of our time?

- Me Too
- Black Lives Matter
- Voting Rights
- Access to Health Care
- Guardianship
- Universal Design
- Political representation
- Interdependence
Self-Advocacy in Georgia

People First of Georgia (http://www.peoplefirstofga.com)
- Statewide self-advocacy organization
- Local chapters across the state
- Goals
  - Free people from nursing homes and institutions,
  - Increase choice and control in the lives of people with disabilities, and
  - Create positive social attitudes toward people with disabilities

Autistic Self-Advocacy Network Chapter
Georgia Council on Developmental Disabilities (https://gcdd.org/
What Does National Core Indicator (NCI) Data Say About People Who Attend Self-Advocacy Events?
Adult Consumer Survey (2016-2017)

- Respondents: Individuals who receive at least one service beyond case management from the IDD agency
- Face-to-face survey with the person receiving services
- Survey includes three main parts:
  - Background information – largely collected from state records
  - Section I – Subjective questions *only* the person can answer
  - Section II – Objective questions can be answered by a proxy when needed
- Georgia response rate: 64% valid Section I; 100% valid Section II; 462 total survey complete
Topics Addressed in Adult Consumer Survey

- Individual Outcomes
- Health, Welfare and Rights
- System Performance
Respondents Who Attended a Self-Advocacy Event

- Yes: 11%
- Had the opportunity, but chose not to: 4%
- No: 85%
### Who Attended Self-Advocacy Event?

#### Gender
- 57% male
- 43% female

#### Age
- 35% under 35
- 50% 35-54
- 16% 55 and older

#### Primary Means of Communication
- **Verbal**
  - 88%
- **Gestures or Body Language**
  - 13%
Who Attended Self-Advocacy Event?

Type of Residence

- 16% group setting
- 18% foster or host home
- 24% own home
- 42% parent or relative home
63% of those who attended a self-advocacy event also voted in a local, state or federal election.
What Can You Do To Facilitate Participation of People in Self-Advocacy?
Steps You Can Take

- Bring up possible involvement in self advocacy organization during planning meetings
- Volunteer to be a supporter/facilitator at a local self-advocacy group
- Work with families to help them understand the value of involvement in self-advocacy organizations (only 5 Georgia respondents with guardians attended a self-advocacy meeting)
- Make sure that Individuals understand their rights including the right to vote, to contact their legislators, etc.
- Collect materials from self-advocacy organizations
Sangha Unity Network, Inc.
www.sanghaunitynetwork.org
770-849-8716

Molly Tucker
Community Services Specialist
Center for Leadership in Disability
mtucker17@gsu.edu
404-413-1427
Questions and Feedback
Thank you

For Georgia Collaborative ASO general inquiry or questions please email:

GACollaborativepr@beaconhealthoptions.com