

Forging Strategic Alliances with Disability Advocates

National Adult Protective
Services Association (NAPSA)

2019 Conference

Panelists

Carol Stamatakis, Executive Director, Senior Solutions, Council on Aging for Southeastern Vermont, Inc.

Nancy Alterio, Executive Director, Massachusetts Disabled Persons Protection Commission.

Kathy Bates, Facilitator, NH Self-Advocates Leadership Team (SALT) and Wings and Wheels Consulting

Patty Quatieri, Peer Support Leader, Massachusetts Disabled Persons Protection Commission.

Benefits of Strategic Alliances



- ▶ More resources for Adult Protective Services, statutory or systemic improvements
- ▶ State agencies are limited in their ability to directly engage in legislative advocacy
- ▶ People with disabilities are better served

Abuse of Persons with Disabilities



Abuse of Persons with Disabilities

- ▶ Rate of serious violent crime **two to three times higher** than for persons without disabilities
- ▶ Higher percentage of violence committed by persons the victims knew
- ▶ Persons with cognitive disabilities had the highest rates of violent crime among types of disabilities

U.S. Department of Justice, Bureau of Justice Statistics, 2017

Abuse of Persons with Disabilities Challenges

- ▶ Law enforcement is less likely to respond to reports and victims are less likely to access the justice system
- ▶ Shelters and programs for victims of domestic violence are often not accessible
- ▶ Isolation and dependency compound vulnerability.

PUBLIC POLICY



History and Values of the Disability Rights Movement

History



- ▶ Widespread institutionalization, often from birth or early childhood to death
- ▶ No right to public education, access to employment or other basic civil rights
- ▶ Rampant human rights violations

Historically

- ▶ Persons with disabilities have been devalued
- ▶ Seen as less able to make meaningful contributions to society
- ▶ Seen as less credible in their ability to relay accurate information
- ▶ Persons with disabilities first group experimented on and systematically executed by the Nazis before targeting Jews, homosexuals and others whom they considered to be inferior (Gallagher, 1990)

Not surprising - persons with disabilities are more likely than others to be abused

VALUES of the Disability Rights Movement

- ▶ De-Medicalization of Disability
- ▶ Autonomy, choice, self-determination
- ▶ Community integration
- ▶ Civil rights and equal treatment under the law
- ▶ Educational and employment opportunities

Public Policy Achievements

- ▶ Rehabilitation Act (1973)
- ▶ Medicaid Home and Community-Based Care (1981)
- ▶ The Individuals with Disabilities Education Act (IDEA) (1971)
- ▶ Americans with Disabilities Act (1990)
- ▶ State laws - De-Institutionalization, Guardianship Reform, Independent Living

Self-Advocacy

People with developmental disabilities
advocating for respect and inclusion

Sharing stories to challenge stereotypes and
change attitudes

Educating elected officials, government staff,
health professionals, service providers,
employers, schools, city leaders, transit, people
with disabilities and families

“I am the Expert on Me”

My Journey To Self-Advocacy



- ▶ About 40 years ago, I worked a full- time job at St. Elizabeth's Hospital.
- ▶ I took a bus to work on my own every day
- ▶ At the age of 25 years old, I was held against my will, and sexually assaulted by a man I knew.
- ▶ I survived the assault.
- ▶ After the assault, I lost my job. I did not take the bus anymore, and had no money.
- ▶ My control was gone. My choices were gone.

And So It Began....

- ▶ First visit to the State House in Massachusetts was to advocate for housing.
- ▶ “Nice to meet you Senator Robert Havern! My name is Patty Quatieri and can you please help me?”
- ▶ I would check in at the front desk. I would say, “Hi everyone, is Senator Havern there?” The woman at the front desk would say, “Oh, Patty what do you need again?”
- ▶ By going to the State House often, I built strong relationships with the Senators and Representatives.
- ▶ First Self-Advocate to join the Central Massachusetts DDS Board.
- ▶ First Chairperson with a Developmental Disability.

Prevention and Protection through Empowerment

Education and Advocacy by and for
People with Disabilities

- Sex education
- Recognizing abuse
- Know the law

Awareness and Action Training
Peer Support Leadership (Massachusetts)



The key to staying safe is knowing
your rights . . . Unlock your power!

Building Relationships



Government Agencies
and Disability Advocates

Advisory Boards

Representation of People with Disabilities

- ▶ Be selective in recruiting - avoid tokenism
- ▶ Considerations:
 - Identifies as a person with a disability
 - Experience as a disability advocate
 - Cross-disability awareness
 - Knowledge of the subject matter
 - Meets criteria applicable to other members

Welcoming and Accessible Boards and Meetings

- Preparation
- Orientation
- Support during meetings
- Mentoring
- Compensation for participation
- ADA Compliance

Federal Laws

- ▶ American with Disabilities Act of 1990
 - Title II applies to state and local government
- ▶ Section 504 of the Rehabilitation Act of 1973
 - Applies to recipients of federal financial assistance - including grants
- ▶ Both require that victims with disabilities benefit from and participate in all programs, services and activities and must provide for equally effective communication

Cultivating Legislative Champions



Build and Maintain Relationships with Legislators

- Make a personal connection BEFORE there is an issue to discuss
 - Tell the story of what you do and why
 - Introduce the agency, staff and programs
- Any bill (positive or negative) can be an opportunity to educate
- Connect legislators with local resources and contacts in their district

State House “Frequent Flyer”



- Joined Massachusetts Advocates Standing Strong Organization.
- Visited State House often with a group of self-advocates.
- We never stopped. We were persistent.
- About 13 years later, we made our mark.
- We changed the name of The Department of Mental Retardation to The Department of Developmental Services.

State House Advocacy

- Worked with Massachusetts Advocates Standing Strong to advocate for the DDS budget
- Trained peers to use their own voices and advocate for themselves and others
- Asked senators and representatives to support bills that help all persons with disabilities
- Advocated for an increase in The Disabled Persons Protection Commission budget - DPPC increased number of staff



Be a Resource

- Ask what you can do to help
- Information, data, and statistics are of great value to legislators
- Be credible, reliable and responsive
- Provide summaries or “talking points”
- Concede areas of challenge in your programs
- Admit when you don’t know an answer – and offer to find out

Powerful Partnerships in Advancing Public Policy



State Councils (Developmental Disabilities,
Vocational Rehabilitation, Independent Living)

Protection and Advocacy

Self-Advocacy Groups

Other Stakeholders, Community Partners

Abuse of Persons with Disabilities Promising New Directions

- ▶ Vulnerability and risk reframed to focus on responsiveness of systems rather than personal attributes of persons with disabilities
- ▶ Empowerment of persons with disabilities - peer support and self-advocacy programs

Abuse of Persons with Disabilities Promising New Directions

- ▶ Funding agency held domestic violence and rape crisis centers accountable for physical and program accessibility



Sexual Assault Response Unit (SARU)



- Created in 2017 with VOCA funding
- Provides sexual assault survivors who have disabilities with peer support, information, and resources.
- Works with individuals with disabilities, families, and their care-providers.
- Offer free and confidential sexual assault information; peer support; and assistance in accessing trauma services.

Patty

The Peer Support Leader



- I share my story and train other professionals on how to work with people with disabilities (Rape Crisis Center, DDS, Clinicians, Law Enforcement)

- I engage in peer-to-peer support with sexual assault survivors with disabilities.
- Creator of the "Peer Support Press"



Public Policy Successes



NH Self-Advocacy Leadership Team (SALT)

- Funding for APS and abuse prevention
- Central registry legislation
- Changed “incapacitated” to “vulnerable” in APS statute.

Partners in Advocacy

- Nancy and I created a strong working relationship. We shared the same passion for advocacy for all persons with disabilities.
- Met with Commissioners and agency heads to share my views.
- Testified in Washington DC about abuse of persons with disabilities and elders.
- Participated in the Department of Public Health (DPH) focus group to change how rape crisis centers are funded to increase accessibility.
- Active member of the ACL Grant funded Advisory Committee to create accessibility guidelines for rape crisis centers.
- Testified at public hearings so that VOCA funds could be used to create a Sexual Assault Response Unit at DPPC.
- I am currently involved in a project with Worcester Polytechnic Institute (WPI) that is creating technology to increase accessibility for reporting abuse.

Advocacy Today



- We are in the process of changing the name of the DPPC to the Commission for the Protection of Persons with Disabilities (CPPD).

➤ I am working with Kecia Weller, another self-advocate from California to help create a national peer support network for survivors of sexual abuse that have disabilities



Resources

The National Domestic Violence Hotline; Domestic Violence & People with Disabilities,

<https://www.thehotline.org/is-this-abuse/domestic-violence-disabilities/>

Nancy M. Fitzsimons, Justice for Crime Victims with Disabilities in the Criminal Justice System: An Examination of Barriers and Impetus for Change, 13 U. St. Thomas L.J. 33 (2016).

<https://ir.stthomas.edu/cgi/viewcontent.cgi?article=1380&context=ustlj>

Get on Board and Make a Difference! Effective Practices for Including People with Developmental Disabilities and New Members on Boards and Committees

http://www.gmsavt.org/wp-content/uploads/2010/12/get_on_board_and_make_a_difference_v.2.pdf

Self Advocacy Resource and Technical Assistance Center (SARTAC)

<https://selfadvocacyinfo.org/>

Thank You!

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