



# Advocacy

## Spanning a Lifetime

*MARY FUNK*



Simple Truth...

*...ss someone like you cares a whole awful lot, nothing is going  
to get better. It's not.*

*Dr. Seuss, The Lorax*

# According to Webster's Dictionary

- ▶ Advocacy...the act of advocating, or speaking or writing in support (of something).
- ▶ Expounding on this definition, Advocacy is action to create positive change.

# Why we advocate...

- ▶ To enhance the quality of life.
- ▶ To promote and expand opportunities.
- ▶ For adequate funding necessary to ensure quality services.
- ▶ For support and information.

# Advocacy is not...

- ▶ Limited to any specific area of a person's life, but encompasses a concern for the **total** person, his or her abilities, and needs.
- ▶ Limited in time to a specific crisis or specific age.

# Advocacy is never-ending...

- ▶ Infant and Toddler Stage
- ▶ School Years
- ▶ Adulthood
- ▶ After you are no longer here

*And the greatest gift you can give your child is to  
pass on the torch!*

# Speak Up!

- ▶ Speak up as an individual. Voice wants and needs, whether for school, work, housing or any other areas of life.
- ▶ Speak up in collaboration with support agencies and government agencies to ensure seamless access to services.
- ▶ Speak up at the local, state and national levels to push for change in legislation, provide training and change systems to remove barriers people face.



# Advocacy Actions...

- ▶ Educational Action
  - ★ Educating Ourselves
  - ★ Educating Others
  - ★ Changing Attitudes



# Advocacy Actions...

## ► Political Actions

- ★ Addressing policy-makers
- ★ Addressing law-makers
- ★ Addressing public officials
- ★ Addressing social and community service providers

# Advocacy Actions...

## ► Legal Action

- ★ Creating new laws
- ★ Repealing negative laws
- ★ Working to implement disability rights laws

# Remember the “WH questions”...

- ▶ What?
- ▶ Who?
- ▶ When?
- ▶ Where?
- ▶ Why and/or how?

# Advocacy Successes...

- ▶ PL94-142
- ▶ Waiting List Initiative
- ▶ Alcohol Tax
- ▶ Closing of Great Oaks Institution
- ▶ The Arc name change
- ▶ Companion Classes to LRE/CRI
- ▶ Rosa's Law
- ▶ Autism Waiver
- ▶ SECACs
- ▶ Personal Wins

# Characteristics of a Successful Advocate

- ▶ Attitude!
- ▶ Flexible
- ▶ Fair
- ▶ Organized
- ▶ Informed
- ▶ Evidential
- ▶ Published

# Top Eight Ways to Advocate...

- ▶ Learn all you can about your child's special needs.
- ▶ Ask lots of questions and listen to answers.
- ▶ Become a “pseudo-lawyer”.
- ▶ Always avoid the blame game.
- ▶ Be a problem-solver, not a problem-maker.

## Top Eight Ways (continued) ...

- ▶ Think long-term and become a futurist
- ▶ Become a master planner
- ▶ Really get to know the provider (school system, adult provider)



## And the obvious...

- ▶ Be effective on the phone.
- ▶ Put it in writing.
- ▶ Get information and decisions in writing.
- ▶ Use the chain of command.
- ▶ Follow up and say “Thank You”.

# The 4P Rule

- ▶ Prior Planning Prevents Problems!

# Passing the torch...

- ▶ Because they know their own circumstances best, people with intellectual and/or developmental disabilities, as individuals and as groups, have the right to self-advocate. This means they have the right to speak or act on their own behalf or on the behalf of other people with disabilities, whether the issues be personal or related to public policy. All entities, public and private, must recognize and respect these rights.

The Arc, Position Statement on Self-Advocacy

# Ways to help your child become an effective self-advocate...

- ▶ Ensure your child knows his/her rights, and the responsibilities that go along with those rights.
- ▶ Provide the opportunity for your child to make day-to-day decisions about his/her life.
- ▶ Encourage your child to speak up at his/her IEP, IP, community meetings, social outings.
- ▶ Encourage your child to participate in self-advocacy organizations.

## Ways to help (continued)...

- ▶ Ensure the availability of accommodations and supports necessary for your child to speak up and participate in meetings.
- ▶ Encourage schools to support self-advocacy efforts.
- ▶ Provide a variety of opportunities for your child to practice self-advocacy skills.
- ▶ Encourage self-disclosure.

# Never ending Advocacy...

- ▶ Letter of Intent
- ▶ Special Needs Trust
- ▶ Solicit assistance from siblings, relatives, friends
- ▶ Utilize Service Coordinators
- ▶ Engage services of personal advocate