



Systems Change Advocacy Works



Systems change in terms of disability

- An organized effort to improve the way things are currently done by educating and influencing policymakers to make changes that are positive and more responsive to people with disabilities and their families.

Why does it work?

- Large numbers of people deliver the same message to the same target within an established time frame
- A unified message is stronger and has a good chance of seeing desired results



Individual vs. Systems Change Advocacy

- Systems change advocacy differs from individual advocacy in that individual advocacy focuses on changing the situation of one person, while systems change advocacy focuses on changing laws and policies that affect large groups of people.

“WE or US not I”

- **“SYSTEMS CHANGE** is..
the big picture of making change for all individuals with disabilities not just for personal gain.



Why is systems change advocacy necessary?

- Policy changes will effect tens of thousands of individuals.
- Policy makers do not necessarily know what is needed unless you tell them.
- There is power in numbers.



Micro vs. Macro

- **Micro** - the person with a disability is thought to have a problem or issue that needs to be addressed, either through therapy, medicine, or treatment. The start point of this notion is that the person has some deficiencies brought on by their disability, and these must be lessened or fixed.
- **Macro** - the effort is to change the perceptions, assumptions, or attitudes of the people around the person with a disability.

Micro vs. Macro continued

“**Obviously**, a good disability advocate understands both approaches, but in the end, it is the macro effort that will produce a better, more open, and accepting world.” – [Al Condeluci](#)



Qualities of a effective systems change advocate

- Remaining neutral
- Understanding the issue
- Open and flexible
- Respectful
- Patient
- Focuses on big picture
- Tough as nails



Common Concerns of Parents

- It's scary – Legislators/policymakers are important people. I can't do this!
- I shouldn't speak up. They might retaliate against my child
- No one will listen to me.
- I don't know enough to advocate.
- I'm busy. I don't have time to advocate.
- My speaking up won't make a difference. What's the point?

Common Concerns of Self Advocates

- It's scary or intimidating
- Does **MY** voice matter
- I shouldn't speak up. I may make someone mad.
- I need help knowing who to contact
- I don't know enough to advocate.



Connecting with others

Local

- Disability Specific Organizations
- Chambers of Commerce
- City Council Meetings
- School Boards
- Non-Profits
- Local chapters of The Arc

State

- Department of Health
- Department of Education (SEAP)
- DD Council
- Protection and Advocacy
- UCEDD
- People First - SABE
- Disability Specific Organizations

Connecting with others continued

National/Federal

- The Arc US
- Association of University Centers on Disability
- American Association on Intellectual and Developmental Disabilities
- National Association of Councils on Developmental Disabilities
- Disability Specific Organizations
- ANCHOR

More than just telling your story

- Legislative Process
- Rule Making
- Joining Boards and Commissions
- Participating in Stakeholder Groups
- Connecting with other advocates
- Partners in Policymaking



Removing emotions from advocacy

- **Self pity.** If you find yourself asking, “Why does it have to be so hard?” or “Why can’t things be different?” you are falling into the self-pity trap.
- **Resistance.** If you use passive aggressive behavior to defeat them, you also defeat yourself.
- **Anger.** If you blow up, you prove that they were right about you!
- **Shutting down.**

Removing emotions from advocacy continued

- **Attitude.**
- **Quitting.** OK, you quit. Now what?

To be an effective advocate, you must control your emotions and use them as a source of energy.

Just remember, anger is always your enemy. You must keep your emotions in check. The moment you lose control of them, you lose the fight every time.

How to utilize social media

- Liz's twitter experience – Broadwater
- Post pics
- Give shout outs
- Always remain positive
- Hashtags
- Birthdays other events
- Follow social media pages to stay up to date
- Join FB Live events



Strengthening personal relationships

- Outside of the legislature
- Keeping in touch year round
- Send Birthday/Holiday cards
- Acknowledging their success
- Be aware of their other bills
- Nominate for awards



You become their go to

- Become their disability expert
- Nothing but the facts
- Additional resources
- Examples



Louisiana Acts passed to change the lives of students with disabilities

- Act 328 – Restraints and Seclusion
 - Act 522 – Created the Advisory Council on Student Behavior and Discipline
- Act 833 – Alternative Pathway for promotion and a high school diploma
 - Act 303 – Retroactive petition for high school diploma

Louisiana Acts passed to change the lives of students with disabilities continued

- Act 696 - Provides for access to behavioral health service providers in schools including ABA
- Act 274 – Created Special Education Advisory Committees (SEAC) in local districts
- Act 456 – Camera Bill

Louisiana Acts passed to improve health outcomes for individuals with disabilities

- Act 258 – Supported Decision Making
- Act 57 – Evie’s Law
- Act 450 – Dental Bill
- Act 648 – Insurance coverage for Applied Behavioral Analysis (ABA)
- Act 421 – TEFRA

Acts passed to improve the lives of individuals with disabilities

- Act 117 – Tax exemption for business who employ individuals with disabilities
- Act 223 – Accessible parking included on drivers test
- Act 74 – Drivers License
- Act 811 – End the R Word
- Act 93 – Louisiana ABLE Act

Question and Answers



Thank you for attending

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