



Systems Advocacy

Systems Advocacy services include activities that affect public policy change, including staff and volunteer contacts with elected officials and policymakers and reviews of current service delivery. This type of advocacy involves monitoring public policy and funding decisions at the local, state, and national levels that will affect the lives of people with developmental disabilities and their families. Staff and volunteers involved in systems advocacy represent the interests of people with developmental disabilities and their families on a number of local boards, committees and councils. Arc staff and volunteers also monitor policy and funding issues through Wake County Human Services, inform people with developmental disabilities and their families about decisions that will impact their lives, and notify them about opportunities for input. We depend on The Arc of North Carolina and The Arc of the United States to help us keep up with relevant state and national issues.

Individual Advocacy (advocating on behalf of someone else)

The Arc may provide individual advocacy assistance to people with developmental disabilities and their families in response to their request for the assistance to address an issue, problem, or concern. Most of our individual advocacy requests for assistance are related to school issues. Other requests include help in negotiating a problem with a residential or vocational service provider or a guardian, trouble accessing services and supports and/or appeal of a decision regarding eligibility for services.

Self Advocacy

Self advocacy is teaching an individual with developmental disabilities to advocate for her/himself by making choices and communicating those choices to her/his family, peers, and people in their community. The Arc of Wake County provides the supports to people with developmental disabilities so that they can learn to use self-empowerment to communicate their choices and decisions.

Self advocacy works to increase the services and opportunities available to people with developmental disabilities by empowering them to access needed services and exercise their rights to participate fully in community life.

It is important to understand the barriers that self-advocates face: discrimination, lower expectations, condescension, patronization, marginalization, disenfranchisement, and ignorance.

Systems Advocacy

How to Influence Policymakers and the Policymaking Process

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1. Understand Historical and Policy Context

- Research treatment of persons with disabilities (such as exclusion, segregation, and automatic referral by generic system to disability system).
- Become knowledgeable about current policy framework and its strengths and inadequacies.
- Use understanding of historical and policy context to explain why change is necessary and the nature and scope of needed changes to current policy.
- Recognize intensity of feelings by persons with disabilities regarding why critical to develop new or modify existing policy based on historical treatment.

2. Articulate Values, Principles, and Goals of Disability Policy

- Recognize the difference between the old v. new paradigm of disability policy (old paradigm--need to "fix" "defective" disabled person v. new paradigm--recognize that disability is a natural part of the human experience and the responsibility of society to fix the natural, build, social and political environment by providing necessary supports, services, and accommodations (civil rights model).
- Recognize the goals of disability policy--equality of opportunity, full participation, independent living, and economic self-sufficiency.
- Equality of opportunity (individualization, inclusion, meaningful opportunity).
- Full participation (empowerment, self-determination, informed choice at individual and systems level).
- Independent living (skills, services, and supports).
- Economic self-sufficiency (training, education, assistance and supports).

3. Understand That Policy is Made In a Political Context

- Public policy is proposed, debated, modified and adopted in a political environment, include use of:
 - Politics
 - Self Interest
 - Power
 - Compromise of Positions, Not Principles

4. Understand the Needs of Policymakers

- Self-Interest (re-election, power, status among peers and interest groups).
- Balancing priorities (Time pressures).
- Political Implications.
- Dependent on others for advice.

5. Understand the Needs of Staff

- Promote and protect boss.
- Help in sorting through avalanche of inputs to determine what is real and what is posturing.
- Help develop assumptions and present fiscal and program estimates.
- Help in identifying key players.
- Help in developing viable policy options, drafting bills, report language, floor statements, speeches.
- Help in developing political strategy.

6. Understand the Need for and Role of An Organized Coalition in Exercising Power Over

the Policymaking Process

- Need for a coalition (policymakers demand it, source of power, and helps provide support/assistance to policymakers and their staff).
- Composition of the coalition (cross-disability consumers and providers and nontraditional groups).
- Cohesion (keep the disability community together).
- Synergy.
- Skilled individuals performing varied tasks working together.
- Leadership (policy entrepreneur).
- Responsibility (carrying out agreed on tasks).

7. Understand the Need for A Strategic Plan

- Planned spontaneity (need to think strategically; act on basis of a plan; importance of pre-meetings).
- Reality Check (macro issues, past advocacy efforts and why change now possible, *constraints on achieving success, capacities of coalition, and degree of opposition*).
- Identify the prize (focus on principles and major concerns, not positions).
- Decide on overall strategy:
- Determine the nature and degree of controversy/opposition.
- Decide on appropriate vehicle such as modifying a statute, regulation, or guideline.
- Identify key policymakers who will assume leadership roles. Frame the issue; decide on the message.
- Control the dynamics of the debate to create an aura of inevitability.
- Determine how a particular tactic (such as direct action or a meeting with a policymaker) fits in.
 - Develop favorable program and fiscal estimates.
 - Present viable policy options based on research and program and fiscal estimates.
- Assess effectiveness of strategies.

8. Understand the Power of Personal Stories Tied to Policy Objectives

- Telling personal stories in isolation doesn't work.
- Need to decide policy objective and how to frame the issue and then tie personal story to policy objectives and policy options.
- Best personal stories demonstrate positive impact of proposed intervention/change in policy (describe circumstances before and after intervention).

9. Understand the Importance of Long-Term Relationships and That Who Delivers the Message Is Often More Important Than the Message

- Develop long-term trust relationships to maximize influence.
- Strategically select the spokespersons who will have maximum influence over policymakers.
- Ensure that message is presented in manner that recognizes the needs of particular policymakers/staff.

10. Recognize Your Strengths and Limitations

- Keep your eye on the prize--put ego aside.
- Don't agree to a policy option when not fully knowledgeable.
- Don't agree to a policy option on behalf of others who you don't represent.

5 Steps to Becoming Your Child's BEST Advocate!

1 Start with the assumption that you are an *equal partner* in your child' education.

2 Deal with your perceptions or feelings about yourself as a parent of a child with special needs.

3 **Acquire knowledge!**
You don't have to memorize or know everything but be aware and ask questions. And don't be intimidated!

1. Know about IDEA 2004 (Individuals with Disabilities Education Improvement Act of 2004)
2. Know that not all issues are controlled by the local school system.
3. Know how "the system" operates.
4. Know the people.

4 **Improve your skills!**

1. Communication
2. Documentation and Letter Writin
3. Record Keeping

5 **Participate!**
This is the **most** important thing you can do for your child!

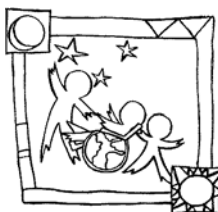
Participate in:

1. The development of your child's IEP (Individualized Education Program)
 - share your ideas
 - attend all meetings!
2. Teacher conferences
3. Parent Group meetings
4. School functions



Remember...

You are an equal partner in your child's education!



exceptional children's assistance center

North Carolina's Parent Training & Information Center (PTI)

907 Barra Row, Suites 102/103

Davidson, NC 28036

800-962-6817 • www.ecac-parentcenter.org

Ten Steps to Becoming an Effective Self-Advocate:

Step 1: Accept your disability:

Before you can advocate for yourself, you have to admit to yourself that you really do have a learning disability. You aren't dumb. You aren't lazy. You have probably worked very hard to hide your learning problems (even from yourself). Now is the time to admit to yourself that you have some difficulties and may need some special help in order to be successful.

Step 2: Admit your disability to others:

You cannot be a successful self-advocate if you continue to hide your difficulties from others. Naturally, you can't expect teachers to provide appropriate accommodations if they don't know about your disability. But it is just as important to be able to admit your difficulties to your friends. When you can really be honest about your learning disability, you will find that you no longer feel so ashamed and embarrassed about your learning difficulties. You will be able to relax a bit more in school and spend more energy learning than hiding.

Step 3: Understand your learning style:

Hopefully, you now have a pretty good understanding of how your brain works and how your processing difficulty interferes with your education. School psychologists and teachers can offer you some ideas that they have about your learning disability, but only you can decide what makes the most sense to you. If the ideas offered in this course don't make sense, ask for help in understanding better. Or ask for other ideas about information processing that might "fit" you better. If you don't understand how you learn, you can't ask for accommodations that you really need.

Step 4: Realize how "other issues" might interfere with your self-advocacy:

You have learned about the common effects of a learning disability including low self-esteem, communication difficulties, and attentional problems. Think about how these issues might interfere with your ability to advocate for yourself. Are you too shy and withdrawn to ask for help? Do you get angry and aggressive when embarrassed or frustrated? Are you able to communicate your needs or do you need to ask someone (teacher, parent, friend) to help you ask for accommodations? Are you impulsive and tend to say or do things that you later regret? As with your learning disability, you need to be open and honest about any of these related problems before you can be an effective self-advocate.

Step 5: Know what you need:

Do the accommodations listed in this course meet all of your possible needs? Which ones do you think will be the most useful for you? Can you think of other accommodations that may be better? It is not possible to anticipate all of the needs which your learning disability will cause for you. You will need to constantly rethink the accommodations and possibly come up with some ideas of your own.

Step 6: Anticipate your needs in each class:

Don't wait until the final exam to start thinking about accommodations. Right from the start of each class you should be thinking about how you might be able to learn the material better. Maybe the teacher has a style that confuses you. Maybe there are too many distractions in the room. Maybe assignments aren't presented clearly. Begin talking with your teachers about accommodations as

Step 7: Know your rights and responsibilities:

You have learned about your legal rights to an appropriate education and appropriate accommodations to meet your needs. But are you really prepared to argue your rights with a teacher that may be "reluctant" to provide appropriate accommodations? Do you know where to turn for support when your needs are not being met? And remember, accommodations are intended to counteract the negative effects of your learning disability, not just make school easy for you. Don't take advantage of your right to accommodations by requesting things you don't really "need".

Step 8: Be willing to compromise:

Some teachers will bend over backwards to "accommodate" for your special learning needs. Others will be less "flexible". Be ready to compromise in order to get at least some accommodation. You may also need to "prove" to some teachers that you really need help and are not just being "lazy". Maybe make a "deal" or "contract" with a teacher. If you do this, be sure to follow-through with everything you have agreed to do. This helps to build trust.

Step 9: Know where to go for support:

Sometimes even an effective self-advocate needs support. Maybe to help with a "difficult" teacher. Maybe to provide advice when you get "stuck". Or maybe just so you don't feel isolated and alone. Find someone who understands your learning disability and can provide support (or can even advocate for you) when needed.

Step 10: Plan for the future:

Many LD students just try to survive one day at a time and don't think too much about long-term goals. But to really advocate for yourself you need to think about where you want to be in one, two, five, or ten years. What kind of work do you want to do after your education? Do you want to go to college? When you have a very clear plan for the future, you will be better able to see the reason for your education today.

Here are a few tips when using these steps:

1. Have a very good idea of what you want and why you want it.
2. Rehearse what you will say, maybe with a friend or parent.
3. Speak clearly.
4. Maintain eye contact (as much as possible).
5. Take your time when talking and ask for time to think if you need it.
6. Rephrase what you hear to be sure you really understand.
7. Be respectful.
8. Be careful of your body language (do you look or act angry, impatient, etc.?).
9. Be flexible and ready to compromise.
10. Make it very clear what you are willing to do in return for the accommodation (get assignments done faster, pay more attention in class, improve effort, etc.).
11. If there is resistance, ask to have a follow up meeting with a support person (case-manager, other teacher, parent, etc.).
12. Be very appreciative of any accommodation given (Say, "thank you.")