

CHAPTER 8

Tips For Being an Effective Disability Policy Change Agent

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As a congressional committee staffer for more than a decade (1985-1997), I played a role in the enactment of over 20 bills related to disability policy. The process of making policy includes formulating solutions to problems of general concern and transforming these solutions into policy. Disability policy includes those policies specially targeted to addressing the needs of persons with disabilities and generic policies that address issues and concerns affecting non-disabled persons as well as persons with disabilities. There is a need for people to get involved in the policy-making process, becoming disability policy change agents — to ensure that our policies foster the inclusion, independence and empowerment of people with disabilities.

Changing policy is not an easy task. There are certain lessons that I've learned over time in how to maximize the likelihood that you will be successful. This paper describes ten tips for disability policy change agents on how to influence policymakers.

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Understand Historical and Policy Context

The first tip is to “understand the historical and policy context in which you are operating. You need to be able to describe the nature of the problem you are trying to fix.” If you believe there is something inappropriate, illegal, or unfair that needs to be changed, you just don’t say it’s bad and expect that it will be changed. You must be able to justify why change is necessary. This process requires research and surveys. For example, you may want to research the treatment of persons with disabilities (e.g., data on the numbers of persons with disabilities employed in nursing-related positions or accepted into nursing schools; possible reasons explaining the data, such as the use of criteria or methods of administration that have the effect of excluding or denying effective opportunities to qualified applicants with disabilities).

The second point is the importance of understanding current policy (e.g., model policies developed by associations or governing boards, state laws or regulations). Start with current policy, not with the policy you are trying to get adopted. A key aspect of serving as a change agent is to possess as much knowledge about current policy as those who developed it. It is important to understand why and how current policy was developed; the extent to which specific efforts were made to include policies relating to people with disabilities, good and bad; what issues and concerns did the policymakers attempt to address; what were the basic precepts that formed the basis for the policy. In sum, when you want to bring about change in policy, a key strategy is to explain why change is necessary and the nature and scope of the change that you’re trying to bring about.

Values, Principles, and Goals of Disability Policy

Tip number two. Change agents’ actions must be guided by a set of agreed-upon principles. The guiding principles are the values that underpin what it is you’re trying to accomplish. Too often change agents are overly anxious to start negotiations over what changes to policy must be made. As a change agent, you must be able to articulate the principles that will guide your actions. For the disability community, it is important to understand the old and the new

paradigms of disability policy. The old paradigm views people with disabilities as “defective and in need of fixing,” “incompetent,” “vulnerable,” and “dependent.” People with disabilities are patients who need professionals to tell them what they need.

The new paradigm of disability policy rejects this old approach; instead, it views disability as a natural and normal part of the human experience that in no way diminishes a person’s right to fully participate in all aspects of society, commensurate with his or her abilities and disabilities. The focus should be on fixing the environment, rather than on “fixing” the person.

There are four goals of disability policy:

- 1) Equality of opportunity;
- 2) Full participation;
- 3) Independent living; and
- 4) Economic self-sufficiency.

Equality of Opportunity

There are three aspects of “equality of opportunity.” First, treat a person as an individual based on facts, objective evidence, and science. Do not treat a person based on presumptions, stereotypes, fear, ignorance and prejudice.

Second, ensure each person an effective and meaningful opportunity to participate. For the “average” employer this may mean, for example, providing a computer with certain software, a desk, a chair, lights, physical access to and from the work site. For the “average” nursing student this might entail the provision of seats in the lecture hall, a lighted room, and amplification. These are all reasonable accommodations and auxiliary aids and services provided to the “average” person (although we rarely, if ever, refer to these goods and services as such). Similarly, people with disabilities are also entitled to effective and meaningful opportunity. But what works for the “average” person may not work for a person with a disability. It may be necessary to provide reasonable accommodations, auxiliary aids and services or make reasonable modifications to policies, practices and procedures that are unique to the individual. Third, people with disabilities should participate in the most integrated setting appropriate — it is

unacceptable to unnecessarily isolate and segregate people based on disability.

Full Participation

The second goal of disability policy is the concept of full participation. What this means, as noted by disability activists, is "Nothing about us without us." That says a lot. If you are going to be making policy, people with disabilities must be at the table as active participants. There is nothing better than having people with disabilities at the table, in order to avoid the adoption of policy that has the unintended consequence of denying equal opportunity to all. The disability community describes the goal of full participation in terms of "self-determination," "empowerment," and "self-advocacy."

Independent Living and Economic Self-Sufficiency

The third goal of disability policy is independent living. The fourth goal is economic self-sufficiency. The promotion of independent living and employment is a legitimate outcome of policy.

In sum, these four goals of disability policy can serve as the guiding principles for the disability policy change agents. These guiding principles can be used to help change agents determine when to compromise and when to persist in their advocacy.

Policy is Made In a "Political" Context

The third tip is to understand that policy is made in a political context. I am not just talking about bills enacted by the legislative branch or regulations promulgated by executive agencies. Whether you're talking about universities, admissions criteria, or licensure, policy is made in a political context, in a political environment. If you are a change agent, you need to understand the tools of the trade — politics, power, self-interest, and compromise. **Politics** is not a dirty word; it is defined in the dictionary as the art of governing. **Power** sounds bad. Well, it is bad when you don't have it. It's good when you do. Power is what you need to effect change. **Self-interest** is also very

important. Finding and realizing a policymaker's self interest is key to affecting change. We **compromise** positions all the time. But we try not to compromise principles.

Needs of Policy Makers and Staff

Tips four and five consist of understanding the needs of policy makers and the needs of staff. And here is where understanding a person's self-interest is really important. The discussion yesterday was about altruism — doing the right thing for the right reasons. We heard quotes from Martin Luther King, Jr., and quotes about "glory" and "love." As a change agent I don't focus on whether or not the policymaker I am trying to influence has lofty ideals. What I care about is identifying somebody's self-interest, because at the end of the day altruism does not control a person's behavior. That's just a hard reality. If you find someone who is with you based on altruism on Monday and they find it is not in their self-interest on Tuesday, they won't be with you in the end. They will find an excuse or rationale or justification to change their minds.

It is also important to understand that policymakers and their staff need help in carrying out their various responsibilities associated with adopting policy. They are dependent on others for information. That's where change agents come in. Change agents can provide data, they can provide information, and they can provide anecdotes. Additionally, they can help do the research and help develop the policies. In sum, policymakers and staff need input. The better and the more effective your input, the better chance of success.

Organized Coalitions in Exercising Power over the Policymaking Process

The sixth tip requires an understanding of the need for and role of organized coalitions. In my opinion, nothing happens in terms of change unless there is an effective coalition and the broader the coalition, the better. And, if coalition members can "duke it out" behind closed doors and then go public with a unified, cohesive message, you have a better chance of winning in the end. Again, the broader the coalition the better.

Let me highlight some of the key aspects of an effective coalition. The first point is leadership. Sometimes in the literature we call leaders in the policy context “policy entrepreneurs.” We can also call them brigadier generals. Without a leader, an idea usually goes nowhere. Because it is hard work, starting by identifying a problem, then getting on the policy agenda for consideration, and finally actually securing positive action. It may require someone working on the issue seven days a week, eighteen hours a day. This is what it takes to effect significant change. Change does not happen because it's the right thing to do. Without a leader, somebody who is saying, “This is my mission,” it's just not going to happen.

Another important aspect of a coalition is synergy — the bringing together of a number of persons who together can perform the functions essential to bring about change. Any significant change effort will need persons competent in performing such roles as visionaries, researchers, fiscal analysts, drafters, political strategists, lobbyists, grass roots advocates and media experts.

Strategic Plan

Tip number seven addresses the need for a strategic plan. I call this “planned spontaneity.” The more spontaneous an action appears, the better. But the best spontaneous action is the result of exhaustive planning. That's the reality in terms of change and politics.

One key aspect of a strategic plan is carrying out a reality check. When we worked to enact the Americans with Disabilities Act, I was the staff director and chief counsel of the Senate Subcommittee on Disability Policy. I insisted on behalf of Senators Tom Harkin and Ted Kennedy that the disability community come up with answers to the following 250 hardest issues and questions we thought others might raise and ask. We played devil's advocate, we asked the hardest questions you could imagine.

If you are a change agent, you have to know the current law and you have to be able to anticipate what policymakers and opponents are saying and why. And, you have to develop answers to those issues and

concerns that you know will be raised. This process is not simple, but it pays dividends in the end.

This leads to the next set of issues: How do we frame the issue and what is the message? How you frame an issue can be the difference between winning and losing.

How do you frame the issue so that you are going to maximize the likelihood that, at the end of the day, you will be able to foster a consensus and move things in the right direction? As an example of the difference between one message versus another, if you are trying to get more community-based services and support for people with disabilities, one way of doing it is to say "Free our people, close institutions." Another way is to say, "People with disabilities should have choice, the opportunity to live and work and pray with their families. Let's keep families together." If you are trying to organize the disability community, "Free our people" is perfectly appropriate. But if you are trying to convince policymakers, market-based solutions, real choice, keeping families together is a whole lot more powerful message to policy makers. How you frame your message depends on who is the audience. Moreover, when you are developing viable solutions, they need to be based on research. They have to be able to withstand scrutiny.

The Power of Personal Stories Tied to Policy Objectives

The eighth tip is realizing the power of personal stories tied to policy objectives. Personal stories themselves do not really resonate when it comes to bringing about change. Figure out the policy objective. For example, I'm a nurse, I'm working, and I'm effective. That's the message and you have personal stories tied to that policy objective. Personal stories are extraordinarily powerful, because we know that policymakers are bombarded with issues and they can't focus on everything. However, if you can get to their heart first, to their soul, so they understand deeply what this is all about, then all of a sudden the mind opens up to information. That is why personal stories tied to policies are so critical.

Long-Term Relationships and Who Delivers the Message

Tip nine addresses the importance of long-term relationships, along with the idea that who delivers the message is more important than the message itself. Points one through eight are insignificant in comparison to tip nine. If you do not have a relationship with the policy makers, if you do not have trust, if you do not have the right people who are in the policy-making position with you, or the right people to convince the policy makers, it doesn't matter what you do, you will not win.

Finding the right person to deliver the message is almost always the difference between success and failure. Developing trust relationships is the difference between winning and losing. It is as simple as that. No matter what you do otherwise, if those two are not there —if you do not find the right people and develop a trusting relationships — you will not win.

Strengths and Limitations

The last point is tip number ten, know your strengths and limitations. Do not speak for people whom you don't represent, don't give answers when you don't know what you are talking about. Be willing to say I will get back to you, I need to do more research, I need more information.

Mr. Silverstein's Handouts Follow.

Handouts

Tips for Disability Policy Change Agents on How to Influence Policymakers

1. Understand Historical and Policy Context

- Research treatment of persons with disabilities (such as use of criteria or methods of administration that have the effect of excluding or denying effective opportunity to qualified applicants with disabilities).
- Become knowledgeable about current policy and its strengths and inadequacies from a disability perspective.
- Use understanding of historical and policy context to explain why change is necessary and the nature and scope of needed changes to current policy.

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

- Recognize the difference between the old versus the new paradigm of disability policy (old paradigm -- need to "fix" "defective" disabled person versus new paradigm — recognize that disability is a natural part of the human experience and the responsibility of society to fix the natural, built, social and political environment by providing necessary supports, services, and accommodations).
- 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

- Policy is proposed, debated, modified and adopted in a "political" environment (whether the focus is public policy or policy governing a profession or organization).
- Tools of the trade include use of:
 - Politics
 - Power
 - Self-interest
 - Compromise of Positions, Not Principles

4. Understand the Needs of Policymakers

- Self-interest (re-election/appointment, power/status among peers or interest groups).
- Balancing priorities (Time pressures).
- Dependent on others for advice.

5. Understand the Needs of Staff

- Help in sorting through avalanche of inputs to determine what is real and what is posturing.
- Help develop assumptions and present implications (fiscal and program).
- Help in identifying key players.
- Help in researching and crafting viable policy options.
- Help in developing strategy for effecting desired change.

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

- Need for a coalition (source of power, and helps provide support/assistance to policymakers and their staff).
- Composition of the coalition (include as many stakeholders as possible).
- Cohesion (power of consensus).
- Leadership (policy entrepreneur).
- Synergy.
- Responsibility (carrying out agreed-on tasks).

7. Understand the Need for A Strategic Plan

- Planned spontaneity (need to think strategically and act on basis of a plan).
- 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 policy, practice, or procedure.
 - Identify the key policymakers who will assume leadership roles.
 - Frame the issue and 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 policy maker) 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 whom you don't represent.

Audience Participation

Marca Bristo. My question comes up more than any other issue in all the work I have done with change. Illustrate the difference between a principle and a position. Give an example if you want.

Bobby Silverstein. Let me paraphrase the question - "What IS the difference between a principle and a position?" For example, one of the issues was in a psychiatric situation. One of the necessary skills was to get away quickly. One needs to be able to move quickly, along with being able to walk to do this. We need to ask what is the principle, that is, what is the issue and concern in the discussion? In this situation, the principle, which is what we are talking about, is safety, the safety of and concern for others in the environment. Now, the position would be ultimately whether you had to be able to walk.

Or the question is: Are there different ways in which we could address the issue? A change agent may insist that certain words used in a position are unacceptable. The issue consists of what is the concern, what is the issue, and what is the principle? Moreover, can we find different ways of addressing that issue or concern? So, the critical importance is not that the focus be on walking. The critical importance is to say: What is the purpose, and issue, and function, and concern of walking? Make sure that when you articulate those, the answers are based on a set of values. Then together you can try to come up with a solution.

What is the purpose and function or the concern that is driving you? When you ask WHY, you find out that you often share the same principle and concern. In turn, you are more likely to have a better sense of what the real issues are and to reach a consensus. Typically, in negotiation that is why we discuss principle versus position. Typically you look to split differences and things like that rather than truly find out what is behind it. What is the purpose, what is the function, what is the issue?

When you are challenging current policy, ask WHY over and over again. If you have a common set of principles in the negotiation, you're more apt to get to "yes" at the end of the day. My experience in negotiation is that when you sit down and focus on values, there are a lot of shared values. And in this group — no matter what your positions were that we talked about yesterday (day 1 of symposium), I know that in 45 minutes we could come up with a set of principles that everybody would agree on.

When we deal with walking versus getting away quickly, I know we could reach a consensus on a position. I think the point I am trying to make is that it's the shared values that you have to achieve. You have to get to those shared values. You share the value of safety and I share the value of safety. You might say in the beginning, well I value escaping on foot. And I say, I value just escaping. But the reality is, the value is safety. That is exactly the point! With change, take the time to start off with trying to find those shared values. Don't skip that step.

Thank you and good luck for the rest of your day.