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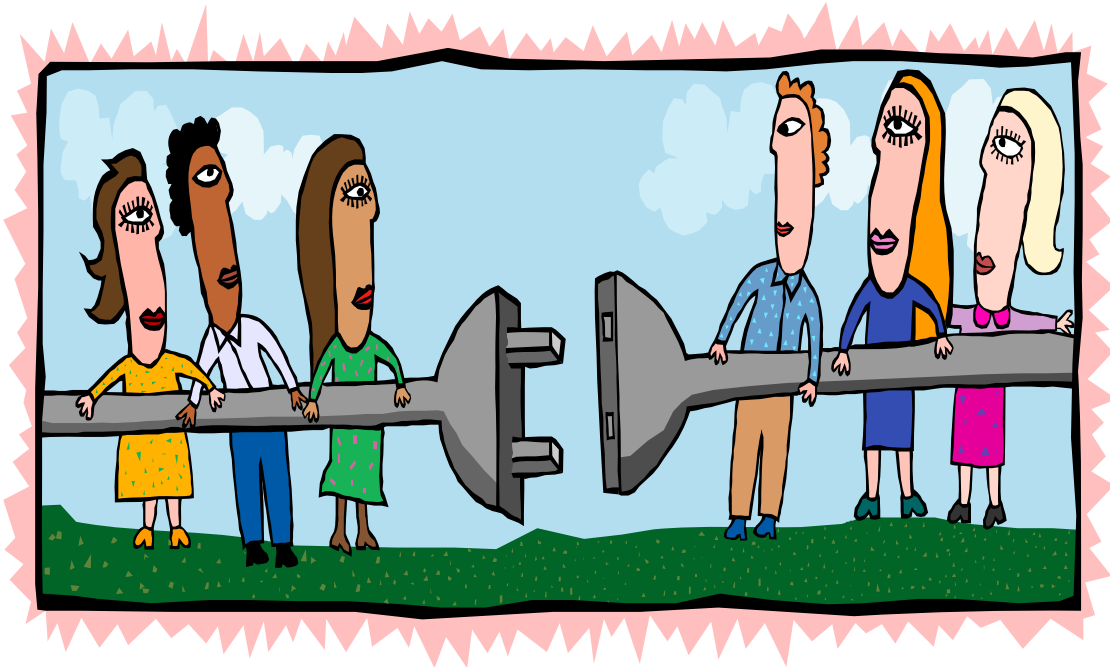
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*Empowered Parents: Educated, Engaged, Effective!*

# A Guide to The Role of Parent Centers In Systems Change



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## **THE ROLE OF PARENT CENTERS IN SYSTEMS CHANGE**

### **What is “Systems Change”?**

“*Systems change*” in special education is about making positive changes in the lives of children and youth with disabilities and their families, not just one child and family at a time, but by changing laws, policies, procedures, and attitudes that impact many children with disabilities and their families. Systems change is important for parents and parent centers because it helps to improve systems in ways that keep families from needing our individual assistance in the first place. It makes systems more responsive to the needs of children and youth with disabilities and their families, and thus improves the experiences of and outcomes for children and families. It encourages us to “go upstream” to fix what’s making so many children end up in the river, instead of waiting downstream to fish out a handful of the many children that are drowning.

### **Legislative Support for the Parent Center Role in Systems Change**

Congressional findings for the reauthorization of the Individuals with Disabilities Education Act (IDEA) in 2004 note that parent training and information activities assist parents by supporting the roles of such parents as participants within partnerships *seeking to improve early intervention, educational, and transitional services and results*. These findings are reflected in the provisions of IDEA regarding the role of parent centers, which includes providing parents with information and training to help them participate effectively in school reform activities and enable their children to reach challenging academic standards established for all children – a goal that definitely requires significant changes in our educational systems!

### **Administrative Support for the Parent Center Role in Systems Change**

Especially since 1997, the U.S. Department of Education has focused significant attention on the critical role of federally-funded parent centers in systems change activities. For example, states receiving State Improvement Grants (SIGs) were required to contract with parent centers in order to receive funding, providing clear evidence to states that parent centers were to be seen as systems change and improvement partners. To receive a new State Personnel Development Grant, states “must award contracts or subgrants to...parent training and information centers or community parent resource centers...to carry out the State plan.”

The U.S. Department of Education also sent a clear message to states that parent centers should be included in state stakeholder groups, such as the State Performance Plan (SPP) team. While this was not a *mandate*, it was *strongly* recommended.

The U.S. Department of Education’s commitment to the critical role of parent centers as partners in systems change and improvement is also demonstrated by the inclusion of the National and Regional Parent Technical Assistance Centers in all activities of their Technical Assistance and Dissemination Network (TA&D Network), including the TA Communities of Practice ([www.tacomunities.org](http://www.tacomunities.org)), conference calls on the review of SPPs and APRs, and planning committees for national and regional OSEP conferences (such as Project Directors, OSEP Leadership, and Regional IDEA Implementation Meetings). *We are now at the table!*

## **Key Systems Change Opportunities**

In the world of special education, there are many opportunities for parent centers to engage in systems change, including but not limited to:

- Providing input into federal and state laws, regulations, and policies (remember that we cannot use government funds to lobby on particular legislation, such as the Individuals with Disabilities Education Act. Check out Independent Sector's tools and materials for more information at [http://www.independentsector.org/programs/gr/advocacy\\_fact\\_sheet.htm](http://www.independentsector.org/programs/gr/advocacy_fact_sheet.htm));
- Participating in our state's State Performance Plan and Annual Performance Report planning, implementation, and evaluation, and engaging diverse families directly or through sharing their experiences and perspectives in the process;
- Participating on our State Special Education Advisory Council; if we are not represented, attending meetings and sharing information during public portions of meetings, and encouraging children and youth with disabilities and their families to participate;
- Participating on state monitoring teams, and/or training and supporting parents of children and youth with disabilities on state monitoring teams; and
- Helping diverse families become more involved in district self-assessment, monitoring, and self-improvement activities, by providing training and technical assistance, sharing information with families about how to get involved, and working with our state to make their involvement a more significant part of the process.

## ***Participation in State Performance Plan/Annual Performance Report Processes***

One of the most important roles for parent centers today is in developing, implementing, and evaluating the impact of State Performance Plans. Parent centers can play key roles in every stage of the SPP and APR, including:

- Analyzing our own data collected from families regarding strengths and needs of the state's special education system and feeding it into the SPP and APR process, either formally (incorporating it directly into the SPP and APR) or informally (sharing the information to help guide the stakeholder and state assessment process);
- Sharing strategies and approaches for improvement, including identifying a role for the parent center in all indicators, not just parent involvement (Indicator 8);
- Disseminating information about the SPP and APR, including the U.S. Department of Education's determination letters about the state (meets requirements, needs intervention, needs substantial intervention) through our websites, newsletters, and statewide and district-level workshops; and
- Helping to disseminate and encourage families to complete parent surveys and helping to analyze the results and recommend strategies to get broader and more diverse parent participation in the survey process as well as to improve parent supports.

Parent centers can also review the letters from the U.S. Department of Education to states regarding their SPPs and APRs identifying noncompliance and data collection deficiencies, and contact the lead agency for Part B (ages 3-21) and Part C (early intervention, 0-3) to discuss how the areas will be addressed and what the parent center's role will be.

A detailed parent center guide to participation in the SPP, [Parent Centers and State Lead Agencies: Partners in Improving Outcomes through Development and Implementation of State Performance Plans and Annual Performance Reports: A Parent Center Guide](http://www.spannj.org/publications/), can be found at <http://www.spannj.org/publications/>.

### ***Participation in State IDEA Implementation***

Most states adopt their own statute, regulations, or code provisions regarding special education. These state rules govern special education in addition to the provisions of IDEA, and often provide additional protections to children and youth with disabilities and their families. For example, some states have retained the provision requiring short-term benchmarks or objectives for all students with disabilities, not just those who take alternate assessments as is the case under IDEA. As parent centers, we can play a critical role in helping our state legislators, Board of Education, and education agency make important decisions about how special education should be organized in our state.

For example, parent centers in some states have partnered with their state education agency to hold regional public hearings and focus groups to garner input to shape their policies. In other states, legislators have put together stakeholder groups to try to come to consensus about recommendations for state legislation. In states where there are not as many formal opportunities to provide parental input, some parent centers have partnered with other disability and parent organizations, such as their Council on Developmental Disabilities, Protection and Advocacy agency, University Center of Excellence on Developmental Disabilities, cross-disability coalitions, and disability-specific organizations, to hold public hearings and focus groups, collect written testimony, and gather information through on-line and hard copy surveys, feeding this information into the decision-making process.

Once rules are finalized, parent centers can play an invaluable role in working with state education agencies to ensure that all stakeholders, parent and professionals, are aware of the new rules and procedures and implement them appropriately. Parent centers have joined with their state education agency to conduct train the trainer sessions for key stakeholders; facilitate or sponsor county or regional parent-professional workshops on the changes; and develop parents' rights brochures or guides and parent-friendly forms (such as IEP forms and forms requesting a hearing, mediation, or complaint resolution). If state lead agencies are not willing to partner with their parent center(s) on these initiatives, parent centers can take the lead by conducting in-person workshops, teleconferences, and web-based training. There are potential funding sources for these initiatives. For example, most states have an Interest on Lawyer Account/Interest on Lawyer Trust Account fund at their state Bar Foundation. Depending on the state, IOLTA dollars go to support civil legal assistance for poor people, efforts to improve the administration of justice by our courts, scholarships and clinical instruction for law students, and *initiatives to educate the public about legal issues*. Changes in major laws such as IDEA provide an attractive opportunity for Bar Foundations to finance meaningful education of parents of children and youth with disabilities (a high-profile issue!) For a directory of Interest on Lawyer Trust Account Programs, go to the American Bar Association website at <http://www.abanet.org/legalservices/iolta/>.

## Systems Change in the Context of your Everyday Activities

For many parent centers, the idea of participating in “systems change” activities can seem intimidating and overwhelming, raising questions such as, “How can I fund systems change work?”, “How can I take on one more activity?,” and “How do I go about it?” The reality is that parent centers already undertake many activities that are an essential part of systems change work. Some of the activities that we already do that relate to systems change are:

- *Providing training and technical assistance to families and professionals:* Every parent center already provides training and technical assistance to families. We can use our training and TA activities to support systems change in a variety of ways, from incorporating best practices and information on federally-funded Technical Assistance and Dissemination Centers (<http://www.federalresourcecenter.org/frc/oseptad.htm>) into our training and TA, to developing and conducting specialized workshops on topics such as The Parent’s Role in Student Achievement; Parent Participation in Self-Assessment and Monitoring; and NCLB/IDEA, among others. If we incorporate information about post-school outcomes, effective secondary transition practices, and youth self-advocacy into our Transition to Adult Life workshops, we are encouraging families to have higher expectations and giving them tools to identify the effectiveness of the approaches that are being used with their own children. If we include information about the types of questions that parents will be asked in the parent survey in our Basic Rights trainings, we are letting parents know what schools are expected to do to support them in their roles as active, engaged parents and to welcome and include students with disabilities into school life. If we develop workshops on our state’s standards and assessments, and accountability provisions of IDEA and NCLB, we are letting parents know that students with disabilities can learn and achieve. We can also share information on our websites, in our newsletters, and through trainings and TA with families about opportunities to participate in systems change and improvement activities, such as meetings of SPP/APR Stakeholders and the Special Education Advisory Council, public hearings and focus groups, and federal monitoring visits.
- *Collecting, analyzing, and sharing data:* As parent centers, we already collect information on the families who call us and their concerns. We have demographic information (race, age of child, type of disability) as well as geographic location and category of issue they are facing. We can collect, analyze, and share this data with our state education agency, Board of Education, governor and legislature, other disability and parent groups, and the media, to help them better understand the problems with special education in our state and their scope. We can also feature this information on our websites.
- *Representing the parent voice in policy:* As a parent center, we know about the issues that are impacting families, what’s working and what’s not, and how to make things better. Our active participation on stakeholder groups and at public hearings, as well as in individual meetings with policy makers, can go a long way toward ensuring that the experiences and perspectives of families are considered. Letting parents know about upcoming opportunities to share their voice, and helping to build their capacity through workshops and TA, will also expand the network of active parents. We can also offer workshops and TA to local special education parent advisory councils and support groups, the PTA, and disability organizations, to facilitate their participation in these conversations so that ours is not the only parent voice. *Building capacity to engage in systems change is critical!*

## **Parent Centers as Leaders and Agents of Change**

As parent centers, we know that we need to advocate for larger change that improves the lives of children and youth with disabilities and their families. We are “*change agents*.” “Change agents” may:

- Advocate on an individual basis (i.e., go to an IEP meeting or mediation with a family).
- Act as a catalyst for new ideas.
- Think about systems that affect children and youth with disabilities and their families and how they fit and work together.
- Help others understand how change happens.
- Coordinate activities aimed at making change.
- Help others work as a team.
- Facilitate the sharing of information with decision-makers.

“Change agents” also *listen, learn, respond, advocate, pursue, intervene, team* and *facilitate*. We *listen* to families, children and youth, staff and administrators of government agencies, legislators and other policy makers, and other organizations and advocates. We *learn* about social, economic, political, historical, and other factors that affect children and youth with disabilities and their families. We *respond* to important questions and needs. We *advocate* for child and family concerns. We *pursue* multiple channels for change. We *intervene* at the system level, not just in individual cases. We *team* with others interested in change. We *facilitate* needed discussions and actions. We help *build the consensus and momentum needed for change*.

## **Engaging Families in Systems Change in Special Education**

Systems change in special education is not just about directly impacting policies and practices, but also about making sure that the people –the families and the children and youth themselves - who are directly affected are part of the process of change. As parent centers seeking to make systems more responsive to the needs of children with disabilities and their families, we strive to reflect the kind of society we are working for. We draw our strength from and are accountable to our members, constituencies, and affected groups. We work to gain access and voice for children and youth with disabilities and their families in institutions such as schools, helping to change the power dynamic to a more collaborative process and providing the support that families need to be effective partners. And we model that collaboration in our relationships with state agencies, districts, schools, local parent organizations, and our partners.

Finally, we hold ourselves to high standards. Are we changing the public debate? Are we bringing new voices in? Do our solutions work? Are we improving the lives of children and families? Are systems becoming more just and accountable? If not, what else must we change?

## **The Stages of Systems Change**

In today’s world, improving systems doesn’t happen just based on a vision, goals, or even passion. We must also understand *how change happens* and *who makes it happen*.

As Frederick Douglas said, “Power concedes nothing without a *demand*. It never has and never will.” The status quo is like a huge rock that will never be set in motion without a push. Even after the demand for change has been made, virtually all institutions typically go through a series of stages aimed at avoiding or minimizing change.

The first stage is usually *denial* of the need for change. “If I wait long enough, the demand for this change will go away.”

The second stage is *resistance* to the change. Resistance can take many forms, but it can include attacking the people who are suggesting the change, and blaming the people who would benefit from the change for their own problems.

The third stage, which only happens if enough pressure has been put on decision-makers, is *exploration*. *Exploration* involves asking questions about how to make change within the confines of existing government budgets; whether and how specific laws or regulations will need to be revised; and the best way to build wider public support for the change.

Policy-makers often also seek to *manage* the change. This can involve trying to limit the extent to which the change really affects the root causes of the problem(s). It can also mean trying to limit the structural changes that have to be made in affected government agencies (the number or roles of staff, etc.), the laws or regulations that will have to be rewritten, and/or the number of people who will be “adversely” affected by the change.

The final stage is *collaboration, compromise, and maintaining momentum*. Once we have persuaded the policy-makers that change is needed and inevitable, we work closely with them to help shape the new policy, rules, and structures. We may find ourselves collaborating with the very people and institutions we were pushing at earlier stages of your campaign. This stage also involves *compromise*, which can be very difficult, especially when the end result is not as positive and far-reaching as our vision, but which is essential to move forward.

This is why it’s so important that the final stage also focus on *maintaining momentum*. We may have succeeded in implementing key improvements, and it’s important to recognize the improvements that will be made. But it’s also essential to keep an eye on the prize, to regroup, and to figure out what our next step is to keep you moving toward our vision. If we don’t, we run the risk of losing everything we have accomplished as others work to undermine or reverse the changes. *Effective systems change advocates never rest on our laurels!*

## **Your Strategic Plan for Systems Change**

Once we understand how the change process works, we can begin to develop a *strategic plan* to make the changes we want. Our strategic plan helps us identify the resources we have, the resources we need, and what we hope to accomplish. It helps us establish priorities for our limited resources. It ensures that everyone in our group is “on the same page.” It creates a focus that directs, motivates, and inspires everyone involved.

## **The Process of Developing our Strategic Plan**

It is important to involve as many key people and organizations as we can when we are developing our strategic plan. We need to keep in mind that:

- No one person can have a complete handle on the whole strategy. We need to make sure that each person gets a chance to add their piece to the jigsaw puzzle.
- Group process in strategy development must allow frank criticism of ideas without personal attacks or defensiveness. The important thing is to develop a strategy that works. Building trust is essential for an effective group process.
- Strategic planning is most effective when people can learn to think long-term as well as short-term; can see the whole picture as well as the individual pieces; and work collaboratively, instead of in isolation.

There are several important tools we can use to get broad input into our strategic plan. For example, people can “*brainstorm*” in small groups or in the group as a whole. When brainstorming, it’s important to record *all* ideas, encourage *everyone* to provide input, and accept *all* ideas without debate. When people “shoot down” things that other people say, they cut off access to valuable information and ideas. As Roger Van Oech said, “There are precious few Einsteins among us. Most brilliance arises from ordinary people working together in extraordinary ways.” It usually takes the insight, experiences, expertise and creativity of lots of people to make a group extraordinary!

Another approach is for each person to write down their ideas, and then discuss them in a small group. The ideas from the small group are then “reported out” to the larger group for discussion. This provides an opportunity for participation for people who dislike speaking in large groups. It also gives people a chance to “try out” their ideas in a safer, smaller “community” before exposing them to the entire group.

If there are or may be strong differences among people, it is a good idea to have the strategic planning session(s) facilitated.

### **Strategic Planning Format**

One effective tool for developing a strategic plan is the following model that asks ten important questions.

#### *1. What do we want?*

This question asks us to identify our “objectives.” What’s wrong with the current situation, and why? What do we want to happen differently as a result of our work? How do we want the lives of children with disabilities and their families to change? This question involves both *content* and *process* goals. *Process goals* might include getting more families actively involved, demystifying the decision-making process, and changing the way the media reports on special education. Our *content* or *policy goal* is the outcome that we want. For example, our content goal might be to improve the capacity of teachers to work effectively with families and to include children with disabilities in their general education classroom.

## 2. *Who can deliver it?*

This question asks us to consider the *audiences* we will be working with, the “targets” of our systems change advocacy. Who has formal authority to make the decisions we want? Who can influence those with formal authority? For example, the governor, the legislature, and our State education agency are *formal authority*. There are many individuals and institutions that can influence them. Children and youth with disabilities and their families, voters, the media, businesses, churches, banks, unions, service providers, all can impact the decisions of the people with formal authority.

Who are the groups and individuals who oppose the key changes that are needed? Be specific. What key individuals have the power to give us critical changes on which our activities focus? What are our key activities for using the mass media (TV, newspapers, radio)? What are our key activities for using our own media? (Reports, newsletters, websites, etc.)

## 3. *What do they need to hear?*

This question focuses on the message(s) we will deliver to different audiences. To be effective, our message must contain relevant facts, and be delivered in a way that touches and moves the people we want to reach. It’s important to focus on *self-interest* as well as *public interest* arguments. What does each of our audiences care about? How do we need to talk to them to make them care about our issue, and support our solution? To answer this question, we need to find out information about how policy-makers have acted in the past. What kinds of laws have they sponsored or opposed? We also need to find out information about the individuals and institutions that can influence them. Is our issue related to any of their priorities? Are they already working on the same issue, either for or against us? What is their mission and vision? These answers will help us shape our message to have the best chance of reaching each audience.

## 4. *Who do they need to hear it from?*

Our message needs messengers to deliver it. Different messengers are more effective with different audiences. A doctor may have more credibility with the medical association. When we think about messengers, we must consider both “*expert*” and “*authentic*” voices. “*Experts*” are people that the larger society sees as having special knowledge in an area. An “*authentic*” voice is someone directly affected by the issue. For example, we may want to show that children with disabilities are not being educated in the general curriculum. A university researcher could be an “*expert voice*” on what’s happening – or not happening – in the classroom, and the subsequent poor outcomes for children. A parent of a child with a disability struggling to do his or her homework would be an “*authentic voice*” on what her child actually is or isn’t learning. Both of these voices are important. The voice of the university researcher provides necessary facts, but might be dry and unemotional. The voice of the mother will touch the hearts of the policymaker or the general public.

It’s also important to include “*authentic voices*” because of the myth that parents and youth cannot speak for themselves. Long-term change in how policymakers view parents and students with disabilities will only happen if the faces and voices of families and children and youth with disabilities, speaking for themselves, become a part of the public discussion.

5. *How do we get them to hear it?*

This question focuses on the means of delivery of our message. We need a good balance of *persuasion* and *pressure*. We use facts, research and reports, human-interest stories, and ideas to *persuade* people that our issue is important and our solution will work. (See [The Savvy Guide to Media](#) for helpful hints on using the media to persuade those with formal authority and the general public). We use coalitions, organizing, mobilizing, lobbying, etc. to *pressure* decision-makers to change policies for the better. Participation in our State Performance Plan and Annual Performance Report stakeholders' process is an excellent opportunity to share our messages and the messages and perspectives of families and their children.

6. *What do we have to build on?*

This question asks us to consider the tools we already have for systems change. When we consider this part of the strategic plan, we should be sure to include:

- *Leadership:* What resources do we have available in terms of spokespeople, staff, knowledgeable and committed volunteers? What are our key strengths and areas for improvement regarding our own advocacy leadership?
- *Supporters:* Who are our current supporters? What authentic and expert voices, decision-makers, and decision-influencers are already on our side? What individuals and organizations are part of our initial core team? Consider the following potential supporters: children and families affected by the policy you want to change, administrators, community based organizations and advocacy groups, national, state, and local officials, community institutions (churches, schools, etc.) that serve constituencies affected by the policy, and other professionals who work at family-serving private or government agencies.
- *Information:* What are our key priorities and activities for documenting problems and solutions related to the improvements we seek? What are our key priorities and activities for analyzing the levels of the system(s) we are trying to change? What information do we need and how will we obtain it? There are many different kinds of information we may need, from existing research, facts, documentation from many sources, including the people directly affected as well as universities, government reports, etc. Sharing anecdotes, stories of how current policy affects real people, can be very powerful. But anecdotes alone will not help us understand the full scope of the problem or what the most effective solutions will be. We need to gather, catalog, and examine existing data. We may also want to conduct a formal assessment, using surveys, interviews, government reports, and research studies. We may use "action research," which is a way to get affected communities directly involved in documenting the problems, their impact on real people, and proposed solutions.
- *Resources:* Resources include people, money, space, and access to equipment like copiers, phones, etc.
- *Tools:* Tools include existing laws and regulations that support our vision or goals, committees or task forces that are charged with investigating the issue and developing recommendations, constituency groups that have formal consultation and advisory roles, children and youth with disabilities and their families that we have helped, etc.
- *Access* (to media, to decision-makers, to influential people, etc.)
- *Messages* (to the public, the media, supporters and potential supporters, decision-makers and those with influence over them, etc.)

### 7. *What do we need to develop?*

We must also identify the gaps in people, information, expertise, infrastructure, support, etc. Who else do we need to involve? How can we get access to that critical information and expertise? How can we build your organizational infrastructure so it can support systems change efforts? Who can help us?

What specific groups or individuals are already dedicated to making the key changes? Who are potential supporters? What specific groups or individuals do we want to build into a support network that can provide various kinds of help? What activities are we carrying out to build a committed constituency and/or a support network? What success are we experiencing in supporting those who want to participate in systems change efforts?

There is nothing more frustrating for an organization, or for the people it is helping, than to have to abandon a systems change activity before it has really gotten off the ground. That's what happens when we try to make change without making sure that we have what we need to be successful. Unsuccessful systems change efforts contribute to a sense of defeatism and hopelessness by the very people they intended to help.

### 8. *How do we begin?*

An ancient Chinese proverb says, "A journey of a thousand miles starts with a single step." In your systems change work, we have your long-term vision. But we also have shorter-term goals that build toward our vision. For an effective systems change effort, we want to identify a first effort that is big enough to matter, but small enough to achieve. It lays the groundwork for future action. It is symbolic. It builds our base. It engages the public. It gives our members and supporters a sense that change is possible. It encourages and renews us. And it makes policymakers sit up and pay attention! Think of the State Performance Plan, which has a six-year goal with annual increments of change expressed in yearly targets. This is a good example of shorter-term goals that build toward a longer-term outcome.

### 9. *How do we know it's working?*

Evaluation is important to systems change. If we wanted our landlord to clean up the fire escape, we would know we were successful only if the fire escape actually got cleaned up. We have to constantly evaluate our efforts to make sure that we are moving in the right direction; we can't wait until the effort is over to check out our progress. We might need a mid-course correction. Ongoing evaluation is also important to boost morale. We can celebrate small measurable victories along the way. Our evaluation needs to look at implementation of our strategy, and the effectiveness of our strategy in actually making change happen. If things aren't going the way we planned them, we need a way to find out whether our planned strategy was wrong, our implementation was faulty, or our goal is not reachable at this time. *We have to be flexible in letting go if we need to.*

When evaluating our systems change efforts, we must consider whether we have actually *implemented your plan*. Have we created the training and organizational materials? Have we successfully reached out to families that we want to involve? Have we built a strong coalition? Did we get the 100 parents to come to state focus groups that we projected?

We must also consider whether our efforts have led to any *increase in engagement* of the children, youth and families directly affected. Are we building, expanding, strengthening diverse family leadership? Are more “authentic (and diverse) voices” part of policy discussions?

Successful systems change also leads to *changes in policies and practices*. Did the law change? Were the regulations strengthened? Is the agency providing stronger enforcement? The bottom line is changes in outcomes and quality of life for affected children and families. Was our proposed solution a good one? Now that it’s been implemented, are things better?

*10. Where do we go from here?*

What are the next steps? How are we going to make the next improvements a reality? Change in and of itself is not always a good thing. It’s only when change is directed at improving the experiences and quality of life for children and families that it makes sense. So when working for systems change, it’s critical that we identify solutions that will be meaningful and effective, that will improve outcomes, increase involvement and participation, and have a lasting impact. If we keep these key questions in mind, we will never lose sight of our goal, and our systems change efforts will be more likely to improve the quality of life and outcomes for children and youth with disabilities and their families.

## **Getting and Keeping Families & Youth Involved in Changes that Impacts their Lives**

We often hear, “It’s hard to get parents involved.” Life today can be hard. Parents get to spend little enough time with their families. Many parents have two jobs, or work long hours. Sometimes parents are exhausted by the daily grind. Some parents feel hopeless. Our work has to help them deal with their practical realities, as well as encouraging and supporting their participation in broader efforts for more systemic change.

There are some very successful ways to increase engagement in the hard work of improving systems. Parents will *get involved* if they believe that the issue is important to them and their family; they have something to contribute; they will be listened to and their contributions will be respected; and their participation will make a difference. Parents will *stay involved* if there are multiple opportunities for engagement, from a small contribution of time and effort to progressively larger contributions of time and effort, and if the level of participation can vary depending on their life circumstances. Parents will also stay involved if they receive sufficient advance notice of opportunities for engagement, if their engagement is facilitated by the provision of supports such as child care, transportation, and dinner, and if they get the support they need to fully understand the issues. Once families are at the table, or in the meeting, they will only stay involved if they are listened to and they can see that their ideas are supported and respected. It is important that there be no retribution for their participation, but if there is retribution, then there must be support for them and a forum and mechanism to address that retribution. Finally, they will stay involved if they see that they are making a difference.

There are many ways that parents can contribute to systems change. They can give permission to share their stories with policy makers verbally or in writing, talk about their stories in a small group (like a focus group), tell their stories directly to policy makers at a public hearing or a forum that we organize as a parent center or in partnership with our state education agency.

As families become more involved, they can play an important role in reaching out to encourage participation of others. They can assist in the collection of documentation. For example, they can go to their school or district Special Education Parent Advisory Council or PTA. They can help analyze the information that we receive. And they can help spread the word, to other parents, to their neighbors, their schools, their friends, newspapers, etc. *If we help them find their voice, they'll help us!*

There are many ways to reach families directly impacted by the issues we care about. We can go to the places parents routinely go, such as back to school nights or PAC or PTA meetings. We can go to the meetings of other groups that involve families, such as the local Arc or other disability-specific parent support group meeting, Parent to Parent, Family Voices, Family to Family Health Information Resource Center, or Federation of Families for Children's Mental Health chapter. We can reach out using media that our constituency reads or listens to. We can ask "mediating institutions" (like schools) to disseminate information about our group and our interest in reaching people who are affected by that issue. We can speak at public forums attended by families and the broader public.

Our outreach must provide *information and education* to those we are trying to engage, in ways that are tailored to meet the various interests of the families we are trying to motivate to action. What is it we are trying to get parents involved in? Why is it important to them and their family? What's the current problem, what's a possible solution, why will these efforts help move toward the solution? Who else is involved? The level of detail required will vary depending on the relationship of that person or group to our issue.

We also need to know the realities of their lives and needs, so that we can identify obstacles to their participation. We may need to convince them that they don't have to be afraid to participate. We may need to provide orientation or training so that they feel more comfortable and prepared to engage. We may need to provide child care, a place to meet, transportation, travel reimbursement, translators, sample letters, etc. We need to demonstrate that the activity is likely to lead to something positive.

The effectiveness of particular outreach and engagement tactics vary in different communities and with different constituencies, based on issues like poverty, culture, language, immigrant status/documented vs. undocumented, women vs. men, age differences, etc. In some communities it's ineffective to do an outreach campaign based solely on notifying people by phone or mail. Many families in these communities have mailboxes that are constantly broken into, don't have telephones, and/or have very low literacy. When trying to engage immigrant communities, we may have to overcome a cultural barrier of non-participation, based on real-life experiences of harsh punishment for engagement in advocacy, as well as fear of getting involved because of the Immigration & Naturalization Service. Our group may be composed of people from the communities we are targeting; if not, we need to rely on help from community organizations serving those communities, who understand the barriers, and who know the outreach and engagement tactics that work ("cultural brokers.") (The National Center for Cultural Competence at Georgetown University has an excellent guide on using cultural brokers in working with diverse families, which can be found on their website for free downloading at <http://www.II.georgetown.edu/research/gucchd/nccc/resources/brokering.html>.)

## **Building New Leadership**

We can't fall into the trap of thinking that new leadership will just arise naturally. We have to nurture it. We have to develop a plan to identify new leadership and build their capacity. We must make space for people interested in leadership to demonstrate their interest, and we must provide support and leadership development to help them be effective. We should neither assume that someone has no knowledge or skills, nor that they are immediately ready to jump into leadership positions. Remember that we all made mistakes along the way; sometimes those mistakes were our most valuable teachers. Having opportunities to practice leadership in real situations is the only way that new leadership is developed.

To build new leadership, we have to meet and talk with families, sharing information, listening carefully to their strengths, needs and concerns. During meetings, we have to specifically recognize the value of their participation and contributions. We have to make sure that there is space for everyone to contribute. And we have to do all this while respecting the differing methods that people have of coping and adjusting to difficult situations, as well as all their other obligations to their families and to survival.

We will build new leadership if we provide the supports that people need to participate fully. Have meetings at times and places that are convenient for families and potential leaders. If we can, we compensate people for their time, expertise, and expenses. At a minimum, we provide stipends, travel expenses, and child care. Clearly identify a primary contact, someone they can get to know and feel comfortable with. Match veteran group members with inexperienced ones for support and to share ideas. If we want new members to speak up at public meetings, we ensure that they have the information they need before the meeting. Give them chances to ask questions and talk issues over before they are expected to speak in public. Provide orientations to new members about the issues, key people, and the process for participation.

It's also important to be ready to hear what new and diverse parents say, about the issues, about our group, and about the work we've done so far. This may be difficult, because we've invested a lot of time and energy, and we believe we are doing the right thing. But often the "outsider's" perspective is invaluable, because it can be more objective. And we must respect the passion that people who are directly impacted by a problem have for change. We may feel that we have awakened a sleeping tiger, but we must be ready to deal with the passion for change that we inspire when we help people feel that change is possible.

## **Key Leadership Qualities**

Sometimes we have a very narrow idea of "leadership," thinking that leaders must be dynamic people who are motivational speakers. But there are many different ways to lead:

- Challenging the process
- Inspiring a shared vision
- Enabling others to act
- Modeling the way
- Encouraging the heart.

Leadership in systems change simply means inspiring and helping people to work toward a shared goal. It doesn't have to mean taking charge. As leaders, we need to help grow new leadership from our constituents and members. Systems change leaders can be:

- *Role models and mentors*;
- *Visionaries* who think long-term;
- *Strategists* who choose the part of the vision that is attainable;
- *Historians* who know the history and collect stories;
- *Resource mobilizers* who bring everyone's resources together;
- *Statespersons* who embody credibility and authority;
- *Communicators* who use symbols and metaphors to serve as public educators;
- *Outside sparkplugs* who raise the stakes;
- *Inside negotiators* who use their knowledge of the system to apply pressure; and
- *Generalists* who bring multi-layers years of experience to any effort.

**Communicators:** Effective leaders in systems change are good *communicators*, both verbally and in writing. Although not every leader has to be strong in every area, it's important that every group have leaders who can *write effectively*, and who can *speak effectively* one-on-one, in small and large groups, to the media, and to decision-makers. All effective leaders must be *good listeners*, and aware of how their unspoken communication (their tone of voice, body language, mannerisms, etc.) affects the people around them.

**Team Players:** Effective systems change leaders also help *develop team spirit and cohesiveness*. They *recognize the accomplishments of others* and *provide constructive criticism* when needed. They provide *encouragement and motivation*. They facilitate resolution of differences. They *seek to involve everyone*. They *delegate and build the leadership skills of others*. Effective leaders *accept responsibility for getting things done*. They take initiative, but they *also leave room and space for others to take initiative*. They offer help and information, and set a good example by seeking help and information when they need it. They make things happen, and they *stand aside to let positive things happen when others take action*. And they *keep their eye on the prize* – improving systems and outcomes for children and their families.

**Problem-Solvers:** Systems change is all about solving problems. So effective leaders use a *step-by-step approach to problem solving*. They help others:

- State the problem as simply and clearly as possible;
- Gather and organize all relevant information and available resources;
- List as many ideas or solutions they and their group can think of;
- Evaluate each idea or solution and choose the best one
- Design an implementation plan, with a timetable, assigned roles and resources; and
- Evaluate outcomes and readjust as necessary.

**Self-Aware:** Effective leaders know themselves (who am I? What am I doing here? What are my goals, purposes, expectations, motivations, and how do they fit into the group? What strengths or challenges do I bring? How can I use and improve my leadership capacity?) They know their own strengths and limitations, and make space for other leaders with advocacy and organizational skills and expertise they lack.

## Stages of Systems Change Leadership Development

**Individual Advocacy:** Effective systems change organizations know how to move constituents from addressing their individual needs to working for a larger vision. Many families come to our organizations initially seeking to improve their capacity for *individual advocacy*. They are looking for special knowledge about their rights and the processes that are available to secure those rights. It is usually only when families receive the support they need to solve their immediate concerns that they are then ready to become involved in wider arenas.

**Peer Advocacy:** As they begin to experience success in their self-advocacy, some see the plight of those “in the same boat” and want to provide *peer advocacy*. In addition to the knowledge and skills of individual advocates, peer advocates also need to have strong listening skills and empathy. They need to learn how to avoid substituting their judgment for the judgment of their peers who they are trying to help. And they need to learn how to collaborate with others – their peers, the individuals and agencies that might be able to provide help and support, and the institutions with which they are advocating.

**Systems Change Advocacy:** The next key stage of leadership development is *systems change advocacy*. Many families never reach this level of advocacy because they are consumed with the struggles of their daily lives – putting food on the table, working, taking care of their children, dealing with the obstacles placed in their way by the institutions that they deal with on a daily basis. But there are many parents with whom we work who will want to participate in systems change advocacy. They will need our support to learn:

- How service systems work, and their interrelated nature;
- The key decision-makers in the legislative, regulatory, and administrative arenas;
- Formal and informal decision-making processes: How is a law or state regulation written, introduced, and passed/adopted? What is the role of lobbyists?;
- A clear knowledge of the facts about the issue(s), including barriers to change and solutions. They must understand more than how the current policies affect them;
- The qualities and components of effective systems, institutions, and services;
- The state and community resources that are available to assist families and children.

They also need support to develop effective advocacy skills, including:

- Critical reading, thinking, and writing;
- How and when to compromise (i.e., when compromise moves the issue forward);
- Networking, team-building, consensus-building, problem-solving, and conflict resolution;
- How to train others, make presentations and engage in public speaking aimed at a variety of audiences;
- How to conduct a meeting;
- How to participate effectively in strategic planning, advocacy research, and development of reports;
- How to maximize stakeholder participation in planning and decision-making;
- Outreach and organizing skills; and
- How to grow new leadership.

What kind of systems change leader are you? What kind of leadership exists in your group or organization? Where are your leadership gaps? What are you doing to build new leadership, to bring in new ideas, fill leadership gaps, maintain momentum, and sustain your organization and larger systems change efforts?

## **Conclusion**

In our work, we are always guided by the words of Margaret Mead. “Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.” Small groups of committed individuals succeeded in passing the Voting Rights Act and the Civil Rights Act of 1964, got the vote for women, established Social Security, public schools, and labor rights, and passed the first and every subsequent law guaranteeing the right to a free, appropriate public education for children with disabilities. We know that democracy is not a spectator sport, that systems change cannot be made by sitting on the sidelines. Engaging children and youth with disabilities and their families in making a difference is its own victory, because it strengthens our democracy and continues to build the networks of committed individuals needed to improve the lives of the children, youth and families we serve.