



## **Independent Living Research Utilization**

# **Facilitating Consumer Partnerships in State Policy and Program Design**

### **PARTNERS**

INDEPENDENT LIVING  
RESEARCH UTILIZATION  
(ILRU)

BOSTON COLLEGE GRADUATE  
SCHOOL OF SOCIAL WORK

FAMILY VOICES, INC.

HUMAN SERVICES  
RESEARCH INSTITUTE

INSTITUTE FOR  
DISABILITY ACCESS

THE MEDSTAT GROUP, INC.

NATIONAL ASSOCIATION  
OF STATE UNITS ON AGING

CHANCE  
INSTITUTE ON DISABILITY  
UNIVERSITY OF  
NEW HAMPSHIRE

UTAH STATE UNIVERSITY  
(CENTER FOR PERSONS  
WITH DISABILITIES)

### **Prepared by:**

**Judith Holt, Ph.D.**  
**Darrell L. Jones, M.A.**  
**Richard E. Petty, M.B.A.**  
**Suzanne Crisp, B.A.**  
**Helen Roth, M.A.**  
**Sara Galantowicz, M.P.H.**

**October 2007**

ILRU Community Living Partnership  
National State-to-State Technical Assistance Center  
A National Technical Assistance Program  
at Independent Living Research Utilization

© October 2007

ILRU Program  
2323 S. Shepherd, Suite 1000  
Houston, TX 77019  
713.520.0232 (Voice and TTY)  
713.520.5785 (Fax)  
<http://www.ilru.org>

Lex Frieden  
ILRU Director

Richard Petty  
Director  
ILRU Community Living Partnership

Darrell Jones  
Project Manager  
ILRU Community Living Partnership

Editor: Darrell Jones  
Publications Staff: Marisa Demaya and Sharon Finney

Permission is granted for duplication of any portion of this publication, providing that the authors and ILRU are credited:

Holt, J., Jones, D. Petty, R., Crisp, S., Roth, H., Galantowicz, S. (Authors). (2007). *Facilitating Consumer Partnerships in State Policy and Program Design: A Guide for Implementation Strategies*. Houston, Texas: ILRU.

ILRU supports community independence for people with disabilities through education, consulting, and publications. ILRU is a program of Memorial Hermann|TIRR (The Institute for Rehabilitation and Research). TIRR is a nationally recognized rehabilitation facility for persons with physical disabilities.

This paper was developed under Grant Nos. 11-P-92574/6-01 and 18-P-91554/6-01 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS). The contents do not necessarily represent the official position of CMS and no endorsement should be inferred.

# Table of Contents

Acknowledgements .....	iv
<b>Introduction .....</b>	<b>1</b>
<b>Part One: Preparing State Agencies to Become True Partners with Consumers 3</b>	<b>3</b>
Strategies to Facilitate Consumer Partnerships at the Organizational Level.....	4
Avenues and Arenas for Consumer Leadership.....	6
<b>Part Two: Laying the Groundwork for Effective Partnerships .....</b>	<b>8</b>
Recruiting and Identifying Consumer Partners.....	8
Defining the Responsibilities and Authority of Consumer Partners.....	9
Conducting a Reality Check .....	10
Supporting Adult Learning .....	12
<b>Part Three: Using Facilitators to Enhance Collaboration .....</b>	<b>14</b>
Traits of an Effective Facilitator .....	14
Facilitator Responsibilities.....	14
Suggestions and Cautions .....	15
<b>Part Four: Conducting Effective Partnership Meetings .....</b>	<b>16</b>
Getting Started .....	16
Ensuring the Environment and Materials are Accessible .....	19
Ensuring and Sustaining Attendance and Participation .....	22
<b>Part Five: Strengthening and Expanding the Partnership.....</b>	<b>24</b>
Support Information and Education.....	24
Promote Leadership Development.....	25
<b>Part Six: Evaluating Effectiveness of the Consumer Partnership .....</b>	<b>27</b>
Spread the Concept of Sustainability .....	28
<b>Conclusion.....</b>	<b>29</b>
<b>References .....</b>	<b>30</b>
<b>Additional Resources .....</b>	<b>31</b>

## **Acknowledgements**

The guide is based on the lived experiences of consumers who participated in uncharted waters with States during the Real Choice Systems Change initiative. It was written to demonstrate that partnerships can and do work effectively. The development of this guide was truly a team effort involving not only the six authors but also a number of other individuals who assisted with conceptualization, sharing lessons learned from their states, and/or reviewing drafts and providing valuable suggestions for its improvement. We wish to thank the following:

Michelle Hoffman of the Long Term Care Authority of Tulsa

Tracy Warren of the Idaho Council on Developmental Disabilities

Lee Bezanson of Boston College Graduate School of Social Work

Erin McGaffigan of the University of Massachusetts Medical School Center for Health Policy and Research

We also want to particularly acknowledge the insights gained from the Oklahoma Partnership and the Massachusetts Consumer Planning and Implementation Group's publications which are referenced in the guide.

# Facilitating Consumer Partnerships in State Policy and Program Design

## Introduction

Individuals with disabilities have first-hand knowledge of the supports they need to live meaningful lives in their communities and the barriers to obtaining them. At the same time, those who design, fund, and administer home- and community-based services (HCBS) understand the statutory and regulatory requirements and budget realities which govern them. As states move towards real systems transformation, it is imperative that these two groups work together in leveraging their experience and expertise. Currently, state service-delivery systems face considerable challenges in conceptualizing and creating sustainable programs that maximize the independence, real choices, rights, and integration of people with disabilities. Collaborative partnerships between consumers, policymakers, and program administrators are an essential part of the strategy for addressing these challenges.

Partnerships involve more than just substituting old vocabulary (safety, security, supervision) for new (self-determination, choice, community participation) or increasing the number of people with disabilities who serve on various advisory committees or workgroups. Authentic partnerships can fundamentally change the roles and relationships of service systems and service users in the process of system transformation. Authentic partnerships involve consumers at each point of the system continuum, including program design, implementation, and evaluation. In a true partnership, consumers are respected as leaders as well as service recipients.

The purpose of this guide is to provide state agencies with an array of practical guidelines, recommendations, and techniques to create and sustain partnerships with individuals with disabilities. To work together, each partner must learn how to communicate with, respect, and trust the other. The ultimate goal of such partnerships is an efficient, responsive service system that promotes the independence, freedom, rights, and integration of individuals with disabilities.

The guide is written primarily for executives, managers, and staffs of state agencies involved in planning, administering, and delivering home- and community-based services. In many instances, this group has already demonstrated its commitment to expanding and enhancing HCBS programs. The guide encourages greater collaboration in the pursuit of system transformation, through power-sharing within organizations, and the involvement of new consumer partners as full participants in the process.

Full participation of consumers in HCBS systems translates into meaningful consumer involvement in all facets of program planning, implementation and evaluation. Meaningful implies that consumers are not token representatives of the disability community but rather have real power and authority in the decisions that are made, and that they have multiple avenues for becoming involved.

Within this guide, the term “consumer” is used to denote individuals with disabilities who currently “use” the services from an agency. Although there are differing views on the appropriateness of the term, it is still in wide use. The authors suggest that each state agency, in collaboration with its service users, decide what term is most acceptable and functional within

the specific state context. Other critical partners may include individuals with disabilities who are advocates, but are not currently receiving services, as well as family members of individuals with disabilities. Although each of these groups brings valuable perspectives, it is essential to have those receiving the services as full partners. Only with their perspective can states effectively drive system transformation.

The guide is presented in six Parts:

- Part One: Preparing State Agencies to Become True Partners with Consumers
- Part Two: Laying the Groundwork for Effective Partnerships
- Part Three: Using Facilitators to Enhance Collaboration
- Part Four: Conducting Effective Partnership Meetings
- Part Five: Strengthening and Expanding the Partnership
- Part Six: Evaluating Effectiveness of the Consumer Partnership

Although the guide focuses on practical strategies that can be used to enhance and support partnerships with consumers, strategies are not the key point of the paper. The strategies are the “nuts and bolts,” but the overarching principle is to share real power with consumers. If an agency does not share power, then all of the accessible meetings with consumers are essentially window-dressing to business as usual. Power sharing is complex and challenging. However, it is a fundamental precept of systemic change and this guide.

## **Part One: Preparing State Agencies to Become True Partners with Consumers**

### **Partnering in New Hampshire for Medicaid Buy-In**

*While bringing everyone to the table and working to reach consensus on many difficult and sensitive issues took a lot of time, the outcome was much greater than ever could have been achieved if this collaborative partnership did not exist. --Susan Fox, Former Director, NH Division of Developmental Services*

*Our partnership was critical to the Buy-In itself and to its consumer-enabling design. Perhaps equally important it laid the groundwork for future collaborations on issues important to the disability community. --David Robar, Granite State Independent Living*

People who work within the constraints of state government often fail to appreciate the fact that sharing power can enhance one's power to achieve laudable goals. The passage of the New Hampshire Medicaid Buy-In program illustrates this phenomenon.

When the Ticket to Work and Work Incentives Improvement Act (TWWIIA) was enacted in 1999 it offered states new options to enhance the opportunities for individuals with disabilities to work; one of these options authorized the development of a Medicaid Buy-In to allow individuals with disabilities to purchase their Medicaid benefits, including long term supports, if they entered or returned to the workforce.

In New Hampshire the Governor convened a group of key stakeholders, including consumers, advocates, and state policymakers, to identify guiding principles for all state TWWIIA initiatives and to make the many TWWIIA opportunities a reality in the state.

One outcome of that convention was a partnership between the state and consumers to complete the design (already underway) of a Medicaid Buy-In program and get it enacted with assistance from a Medicaid Infrastructure grant (MIG). The state and Granite State Independent Living (GSIL) jointly developed the grant. At the time the state was struggling with its budget and new programs were not under consideration no matter how worthy. Nonetheless the partnership moved forward with a common vision that a Buy-In program was in the public interest but would require massive education of legislators and the public if a program was to reach fruition.

The grant provided funds to launch this educational campaign from the disability community itself. While the state was the named grantee and retained ultimate sign-off authority, it partnered with GSIL as the fiscal agent for the grant. This achieved several important outcomes.

First, the partners had to reach consensus to authorize any actual expenditures.

Second, it kept both the state and the disability community tightly focused on the goal of enacting a Buy-In.

Third, devolving the funds to a private community agency eliminated reams of red tape and permitted swift and effective action by the partners.

The partners chose and utilized multiple strategies including press releases, letters to the press, media spots, and bipartisan sponsorship of the Buy-In legislation and the development of a video given to each legislator. These educational strategies were strengthened by the mobilization of the disability community to make personal contact with each and every legislator to explain the importance of the program if individuals with disabilities were to contribute fully to the state by participating in the workforce.

The New Hampshire Medicaid Buy-In passed with overwhelming bipartisan support despite a difficult budget session. The Buy-In was shaped by consumers and advocates and reflects their insistence on generous eligibility requirements. There were secondary gains as well. The educational effort raised awareness of disability issues in the state and created an environment in which other disability issues could be heard.

The partnership of trust has grown from the seeds planted during the Buy-In effort. The partnership succeeded in a climate where neither partner could have succeeded alone. The partnership proved to be far greater than the sum of its parts.

--Lee Bezanson, Boston College Graduate School of Social Work

There is a growing trend in business and the public sector to improve the quality of the goods and services they deliver by gaining better and clearer perspectives on the needs and preferences of those who use them. Paying attention to what consumers want often not only increases revenues and brand loyalty, but improves customer satisfaction as well. Listening to customers—truly listening to, hearing them, and acting on what they say—has been credited in corporate turnarounds such as Continental Airlines, DYNegy Midstream, General Electric, and others.

Home- and community-based service programs face challenges not unlike many businesses: they can benefit from the involvement of constituents, especially those who receive services, as they design and improve programs. As service systems undergo significant changes driven by changing demographics, funding trends, and pressure from more traditional institutional service systems, home- and community-based service programs will need the backing and strong support of constituents in state legislative processes. That strong support is more likely to occur if consumers have been fully engaged in program design and implementation as full partners.

### ***Strategies to Facilitate Consumer Partnerships at the Organizational Level***

Although there are no silver bullets that magically create effective consumer partnerships, there are many strategies that, if combined and pursued with some determination, will make a measurable difference. The following are some steps that can be taken to create a foundation for

effective consumer partnerships. They are described briefly here, not as a comprehensive treatment of the subject, but rather as suggestions for getting practical results.

**A. Make Partnerships with Consumers a Central Organizational Goal**

Articulate a goal of meaningful consumer partnerships throughout the agency, including the top level of agency management. Managers at even a single level of the agency can do much to advance such a goal. Systems not designed with people-centered goals generally fail to promote consumer involvement. Faithful and conscientious work toward such a goal, however, usually results in progress.

**B. Provide Opportunities for Executives, Administrators, Staff, and Others to Learn More about Consumer Partnerships**

Be intentional about the creation of "vision and people building" experiences to help all involved "stretch" their sense of the potential of consumer partnerships in service systems. Raising the bar can foster positive change. People respond to inspiring examples of what is possible - but they cannot implement visions that they have not yet had.

**C. Use Examples in a Positive Way to Foster Expansion of Consumer Partnerships**

Use examples of success stories to show other leaders and legislators what might be possible with enhanced consumer collaboration. As authentic involvement of consumers advances within a given state, more and more examples of success will emerge. These stories will help to re-orient the thinking of leaders who focus only on the challenges of such partnerships.

**D. Select Managers and Service Leaders Who Are Committed to Enhancing Their Own Competencies in Partnering with Consumers**

Know, practice, and impart competencies in a shared leadership model throughout the organization. Incorporate training into staff development activities that will help leaders and staff at all levels of the agency to develop these competencies. Appoint individuals who have these skills to key leadership roles. Naturally, service users will have their own insights about who the most committed service leaders might be, so include users in the selection and supervision process. The following items are examples of these competencies.

1. Promoting Collaborative Leadership Approaches

Choose leaders who are capable of and willing to work in a collaborative framework, involving stakeholders within and outside their organizations. They can do much to advance consumer partnerships. Working collaboratively and in teams requires different skills from traditional "top down" management approaches. Relinquishing paternalism in favor of welcoming the contributions of others is significantly more enabling. Select leaders with this competency and support leaders in acquiring it through training and adoption of team oriented management approaches throughout the agency. Include performance expectations for all levels of leadership regarding language and behavior that supports empowerment of consumers. A key indicator of a leader's commitment to collaborative philosophies is the demonstration of empowering language and behavior.

2. Sharing Control and Authority

Establish a board or task force that includes a substantial number of service users who then have authentic power to influence policy, service delivery, and evaluation of

services. Share control by learning to become more aware of how agency personnel may unconsciously and unintentionally monopolize control, power, and authority.

3. Having a Level of Comfort with the Messiness of Participatory Processes

Allow others to shape their experience and to make their own unique contributions by relaxing and accepting a more open-ended approach to how participation might take place. Once you open the door to participation, you begin to share the public space with others who may do things differently than you do. People do not usually fit easily into someone else's preferences and notions of how participation ought to unfold. In having open, candid discussions, dissension should be valued.

4. Restraining Vested Interests That Might Limit Service Users' Potentials

Look for opportunities to defend, expand, and enrich the interests of people who are the recipients of the services. When service users have an authentic role in directing the systems that affect their lives, it is much more likely that the focus will remain on what is in the best interest of all concerned. In any service system, there are opportunities and temptations for those involved to indulge their own vested interests, whether those interests are power, misguided paternalism, reputation, wealth, or control of information.

5. Employing People with Disabilities

Hire individuals with disabilities as one means of creating a more empowering system. Employees with disabilities have experienced social and physical barriers and have thoughtful perspectives that can strengthen an agency's approach to service delivery. Although an employee may have some concerns about differing with their employer, their insights are valuable. Employing individuals with disabilities also sends a strong message to consumers that the agency views people with disabilities as equals.

## ***Avenues and Arenas for Consumer Leadership***

Consumer leadership at the state systems level is the next logical step in the evolution of systems. Every time a state agency engages in planning activities, proposes service configurations, reviews the status of services provided, monitors the effectiveness of the services, and evaluates programs and systems, the agency should ask the question: "Have consumers been engaged in a purposeful and meaningful way?" Does the activity genuinely reflect their input and preferences?

One way to ensure that consumer voices are heard at all levels of agency operations is to seek consumer feedback through a wide variety of processes, products, and goals including:

- Proposals
- Policies
- Programs and services
- Progress measures
- Barrier identification
- Consumer outcomes

- Analysis of consumer satisfaction data
- Board, task force, or focus group operations

The next step is to make sure that consumer partners are involved in multiple settings. Although agencies generally operate through boards, committees, and workgroups, this does not imply that this type of partnership is the only method, nor the best method. The strategies to support boards and committees can be readily applied to other methods of partnering with consumers at the state level. Below is a list of some of the ways state agencies can and do receive input and feedback from consumers.

- Planning and implementation boards
- Strategic planning or visioning meetings<sup>1</sup>
- Task forces focused on specific, sometimes time-limited, issues
- Focus groups that are conducted, following accepted procedures
- Roundtables at regional/national conferences
- Opinion surveys (something other than service satisfaction surveys such as: is communication sent out by a state agency to the public clear?)
- Formal consulting roles

---

<sup>1</sup> These typically would involve a broader array of constituencies than a board. See <http://www.hcbs.org/files/40/1979/findcomground-1.pdf> for an example of an inclusive visioning meeting.

## Part Two: Laying the Groundwork for Effective Partnerships

*You can never change things by fighting the existing reality. To change something, build a new model that makes the existing model obsolete*

--Buckminster Fuller

The effort, time, and expense involved to build lasting, productive relationships should not be underestimated. If consumer partners are to become more than token members, both the state and consumer partners will have to recognize the value of full partnerships and be willing to commit to the process of developing and nurturing the partnership. Such institutional commitment must include development of supportive state level policies, training of state personnel, implementation of necessary procedures, and funding sufficient to support ongoing collaboration. This institutional commitment ensures that as state leadership positions change, the collaborative partnership and process is an accepted and expected part of how the agency does business.

### ***Recruiting and Identifying Consumer Partners***

Recruit and identify consumer partners in a thoughtful and systematic manner. Do so in consultation with the disability community. *The overriding consideration for identifying consumer partners is their current use of services and willingness to fully participate.* Although family members of individuals with disabilities, advocates for people with disabilities, and provider/state agency staff who have disabilities all bring important and useful perspectives to the state-level decision making process, they generally do not reflect the daily insights of a service user. The participation of those individuals is valuable, but to initiate change, make sure that those who are directly and immediately impacted by the system have a voice and role in the change process. Below are additional suggestions for the recruitment process.

- Recognize the importance of cross-disability, elders, and cultural/racial/ethnic diversity. In an increasingly diverse society, these voices need to be heard.
- Include representatives from diverse geographic areas. Often rural perspectives are neglected due to travel constraints.
- Include consumers who are new to partnership with a state agency as well as previous or current leaders who have valuable prior experience.
- Look for consumers who have specific interests and/or new perspectives. It is important to seek out new faces with fresh ideas. Frequently, the same consumers are recruited to serve on many different committees for multiple terms or to participate in other feedback loops. Often new consumer partners shed new light on problems or offer new ideas to solve those problems. They may also help identify problems not previously known.

- Form a nominating or selection committee of consumers and consumer advocates to recruit and select the consumers to serve.<sup>2</sup>
- Provide an orientation to recruits about the project and encourage them to ask questions about their role. Expectations for participation should be specified (e.g., committees, focus group, reviewer). Request a brief written or oral statement from the recruit that indicates their interest and relevant experience. If easier for the consumer, use an informal interview process

### ***Defining the Responsibilities and Authority of Consumer Partners***

It is critical that consumer partners are members of groups, committees, subcommittees, or taskforces that have *actual authority* to change elements of the system. If the group has limited or token authority, then the voices of consumer partners are of limited value. If input is essentially meaningless, consumers may quit coming to meetings or end any relationship with the state agency.

In the same sense, if consumer input has been obtained through focus groups, opinion surveys, roundtables at conferences, or other means, the agency should make a strong commitment to take the recommendations seriously and to communicate back to the participants the results of their input.

When the group has a specific charge to improve an aspect of the system and the authority to do so, then each member, including consumer partners, has a responsibility to assist in achieving this task. There are several key expectations for all group members, including consumer partners, such as:

- *Attendance* at meetings (Strategies for supporting this will be discussed in the next section);
- Willingness to *participate* in meetings;
- *Listening* to other group members and their perspectives;
- *Contributing* to the group discussion;
- *Cooperating* with other members;
- *Compromising* – the hallmark of groups; and
- *Collaborating* to reach common goals.

As the group reaches decisions on an issue, the consumer partners must have the same responsibilities for achieving the group's task as any other member and should recognize and respect this responsibility.

States should acknowledge that consumer partners may have previously had adversarial interactions with the agency. The state can then take proactive steps to discuss their intent to work in an open and collaborative manner with the consumer partners. In a similar vein, the state agency personnel must be willing to recognize that the voices of strong advocates can only help

---

<sup>2</sup>Read about the experience of the Massachusetts' Real Choice grant at <http://www.hcbs.org/files/108/5357/CPIGS.pdf>, p. 7. (Accessed September 24, 2007)

the system transformation process. Don't rule out such consumers as participants simply because they have made waves in the past.

To reinforce the role and responsibilities of consumer partners as well as those of the agency, it is sometimes useful to have a letter of understanding that specifies what both parties have committed to and the decision-making responsibilities of the group. Below are some suggested areas to be discussed and agreed upon prior to beginning the work of the committee, task force, etc. whether in person or in writing:

State agencies can:

- Specify the desired outcome of the group process, such as developing a new policy for using state funds for supported employment; revising the income limits for the Medicaid Work Incentive (buy-in); or developing compliance procedures for home- and community-based services.
- Explicitly state the type and amount of reimbursement that will be provided to the consumer for travel arrangements, lodging, and meals.
- Provide cash incentives or stipends for consumers.
- Link the consumer to a benefits counselor to assess the possible impact of such income on their benefits, if income is available to consumer partners.
- Determine if the consumer has ready access to a computer with an Internet connection and, if not, how this can be provided by the agency.
- Agree to have decision-makers at the table (no random assignment-of-the-day representatives.)
- Provide support such as meeting space and/or a telephone conference line for the consumer partners to meet separately when needed so they can better understand each other's disability perspective, discuss approaches, or develop consensus on recommendations.

In a partnership process, the state agency should also clearly define their expectations for participation of the consumer partners:

- Attend all committee meetings and any subcommittee meetings assigned. It is understood that there may be some occasions when attendance is not possible due to illness or family concerns.
- Participate in the committee and provide input into the decisions.
- Read materials or conduct assigned research and be prepared to discuss the content.
- Specify what accommodations are required.

### ***Conducting a Reality Check***

Developing a trusting relationship is the basis for a successful partnership. However, there are several serious considerations that need to be explicitly addressed. A framework for better understanding the concerns of consumers as partners is articulated in the findings of the

Oklahoma Real Choice System Change and CDPASS grants.<sup>3</sup> Based on their successful efforts, consumer partners and state agency staff have determined that “...consumer partners often lack the skills, knowledge, tools, and financial resources to perform effectively.” They go on to conclude –

“Public policy that is created out of groups involving consumers is often ineffectual because:

- *Financial resources are limited.* The lack of resources is the single biggest challenge facing consumer representatives. It is often difficult to find money and support for representatives who wish to participate fully in public policy development. Often, professional members can be involved as part of their job function, therefore receiving financial support for participation. The lack of resources for consumer representation has a direct effect on the availability and performance of consumer stakeholders and the development of informed and empowered consumers.
- *There is a lack of system knowledge.* Most public policy involves complex system knowledge. It is a challenge for some consumer partners to communicate their viewpoint in this environment, as they may not have the full range of knowledge required to understand service system interrelatedness, terms, and complexity.
- *Information exchange is limited among all stakeholders.* The group processes used must commit to careful thought and sufficient time and resources to support learning, and meaningful exchange of information and ideas. When each person considers varied perspectives and engages in insightful dialogue, then new ideas emerge and build on one another, creating a powerful synergy.”

Funding strategies for consumer participation could include the lead agency providing stipends from a line item in their budget. Community or advocacy groups might share the costs of participation or provide a co-share, or financial support for a group scholarship fund. A legislative mandate could strengthen the financial support to convene and sustain participation in a formal sense. Also, the legislature could provide direct funding as a separate line item. Another approach would be to utilize the HCBS Medicaid Waiver as a support for these partnerships through effective utilization of the mandated consumer input and involvement at the systems level. There are a number of potential solutions to providing a payment for the services of consumers, but what is most important is an open and candid discussion with the consumer partners so that creative solutions may emerge. For some consumers, coverage of travel and associated costs (including personal assistance services) is sufficient. For others, a benefit analysis can indicate the amount of income that an individual consumer can earn without jeopardizing their benefits.

Strategies to address all of the above points include ongoing open communication between and among the different constituencies with an appreciation and understanding of differing perspectives around an issue. This communication should take place in a meaningful discussion of service system issues. If the discussions are to be relevant, then the use of resources is at their heart. Whether the resources are to be used to support the consumer partners or to fund services, it is important to have a discussion about resources.

---

<sup>3</sup> Long Term Care Authority of Tulsa (2003).

The process must be interactive and iterative. Solutions are rarely identified through a linear process, but rather through a process that strengthens as it proceeds through enhanced trust and collaboration. This kind of process can take longer and may sometimes be circuitous, but can be valuable in strengthening the partnership and its work.

### ***Supporting Adult Learning***

As the partnership develops, it is critical to integrate established adult learning principles throughout the process. Each member of the partnership (whether agency personnel or consumer partners) is both a teacher and a learner and as such the principles of adult learning can benefit and strengthen the partnership. Here are a few of those principles that may be particularly important:

- Create learning environments for adults that are “safe.” If adults feel threatened or embarrassed, the learning process is damaged. The collaborative partnership must be a safe process, where no member feels marginalized or their expertise devalued.
- Respect adult learners as decision-makers. If decisions made by the group are not honored, then the partnership is a paper charade and the members’ contributions are negated.
- Focus on feelings as well as ideas and actions. If the group process focuses exclusively on ideas, then the feelings may serve to undermine the process. Feelings must be acknowledged and respected. In the same sense, the group must develop a sense of action so that their work will result in actual positive change.
- Sequence and reinforce learning activities. Break down new knowledge into small steps that logically lead to the big picture.
- Give ample time and opportunity to reflect on new knowledge and to question and consider how the knowledge applies to the learner. Group discussions and constructive criticism of new materials are useful strategies.
- Accept that adults need to develop relationships with and “use” other learners in the learning context as well as to feel they are contributing to others’ learning. This is probably the most critical application of the adult learning principles to the group process. If this occurs, then each member grows from and contributes to the process in a meaningful way.<sup>4</sup>

---

<sup>4</sup> Vella (1994).

**Massachusetts Real Choice Grant: Consumer Planning and Implementation Group  
(CPIG)**

***Building Trust***

One of our biggest lessons learned was the importance of transparency. There was a lot of distrust given the years of budget cuts and apparent distance in philosophy. It was not until people sat in one room and shared their concerns, interests, and goals that people really began to see the potential for collaboration. To build the trust, the consumer community needed to know the true limitations that policymakers face. Policymakers needed to see direct, first hand how this change in policy could directly impact people's lives. An important step for us to achieve transparency was creating consistent methods of communication that were clear, straight to the point, and reliable. After each meeting of the Collaborative Team (our group of five CPIG members and five policy partners that provided direction to the grant), a "hot topics" email was mailed to CPIG members within a predetermined time frame so everyone could be aware of our progress and share comments.

The time required to build trust must not be underestimated, and the importance of it cannot be ignored. The delayed start of consumer involvement in our grant led consumers to want a chance to catch up. Early on, they voiced a desire to have a couple of meetings without grant staff to learn from each other and to discuss their desired grant outcomes. We had met so many times without them, they wanted their turn. We could have said that grant funds were being used to provide accommodations and stipends. We could have said that we did not think that would be constructive, and that we wanted to be more collaborative. However, these approaches would not have built trust. The first leap of faith was expressing to the consumer community that we valued their input and that we trusted that their meeting would lead to good for the grant.

From there, history was formed. The CPIG was influential in all aspects of the grant, making recommendations that were ultimately accepted by the Collaborative Team. Today, the work of this grant influences the very nature in which the consumer advocacy community works with state policymakers to make true systems change.

--Erin McGaffigan, MSW LSW, Massachusetts Real Choice Grant

## **Part Three: Using Facilitators to Enhance Collaboration**

Selecting facilitators with the capacity to foster effective meetings and group processes can be important to the success of partnerships. Facilitators can help build and maintain smooth and productive partnerships between multiple collaborators. The facilitator has two primary roles: first is to support the group as they work to achieve a stated purpose; second is to ensure that the voices of each member are heard so that various perspectives are discussed and addressed in the decision-making process. The facilitator's primary role is to attend to the group process and not to any single person or persons in the group.

Using a facilitator to guide the group's meetings is one way of demonstrating a real commitment to making the process equitable and inclusive. Successful partnerships take time and effort, and there are numerous opportunities for misunderstandings to occur. Having a facilitator, acceptable to all parties, sends a powerful message that the agency is taking this process seriously and is also being responsive to the perceptions of the consumer partners. And finally, a facilitator can be extremely useful to keep the group on topic and accomplish its task in a timely and effective manner.

### ***Traits of an Effective Facilitator***

In considering candidates for the role of facilitator, choose someone who has the following key qualities:

- Training in facilitating group meetings with a successful track record as a facilitator
- Acceptance by all members of the group, including the consumer partners
- Skills to cope with a variety of personalities
- Ability to control dominating group members and bring quiet members out in a non-intimidating manner thus establishing a sense of fairness of participation
- A general knowledge of the content, including political issues and sensitive areas
- Availability over a period of time--at least one year
- No vested interest in the outcome of the group's decisions or strong alliances with an individual group member or members

Individuals from a variety of backgrounds can fulfill this role, including university faculty, individuals from the business sector or a nonprofit director. The facilitator should have received training, have experience in human services, and not be affected by or benefit from the group's decisions. The facilitator should not be the state agency's administrator or staff, to preclude any perception of bias in the issues being discussed.

### ***Facilitator Responsibilities***

A facilitator does not make decisions during the meeting for the group but rather helps each member of the group to recognize that they have a pivotal role in the group and ensure that each member is "heard" by other members. "Heard" implies not just the actual words spoken by a group member, but also that their perspectives and insights regarding the topic of discussion are

not ignored by other group members. Often the group member to be “heard” may be a consumer partner and their opinions can be set aside as the more vocal members express their opinions. A skilled facilitator can come back to members’ comments as the discussion continues so they are not lost. In addition, the facilitator can provide a summary of all comments as part of the review process before moving to another topic, not just the prevailing opinion.

A facilitator can be an effective catalyst in the trust-building process. Through impartiality and sensitivity to both verbal and nonverbal concerns, each participant can feel valued and secure. Trust does not happen quickly, and for group members who have previously had adversarial relationships, the ability to hear and to be heard may be a tentative process. However, with a facilitator-intermediary, this process can be less formidable and more transparent.

In addition, when selecting the facilitator, choose someone who can be attentive to both verbal statements (side conversations, members who interrupt, etc.) as well as body language, facial expressions, and the energy level and mood of the group.

Keeping the pace of the meeting deliberate, not rushed, and being able to stop for members to catch-up is crucial. It can also be effective for the facilitator to state what they have observed and possibly suggest appropriate responses.

In addition to facilitating the actual meetings, facilitators should:

- Assist with the preparation of the agenda to ensure both continuity and neutrality in how items are phrased.
- Conduct a quick evaluation at the end of each meeting to determine what worked and what didn’t in the process. (Do not evaluate the topic itself.)
- Spend additional time before and/or after the meeting, if appropriate, to assist consumer partners in understanding the meeting process, any pre-meeting information, or post-meeting responsibilities.

### ***Suggestions and Cautions***

In some instances, a facilitator may, over time, form an alliance with some members of the groups or may clearly prefer one position over another position. If this occurs, the group members should meet with the facilitator and discuss the concerns. If the facilitator cannot remain neutral, a new facilitator needs to be identified.

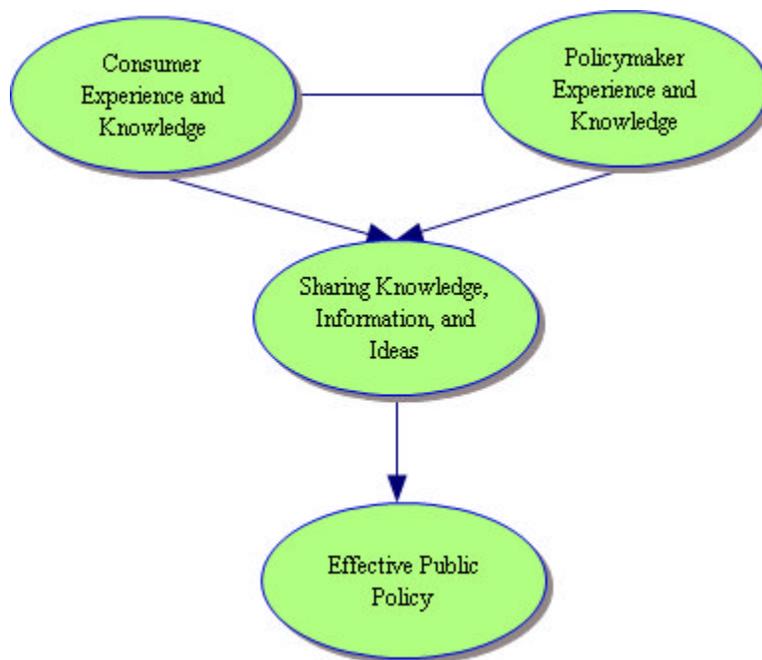
Given their possible inexperience, a consumer may not feel comfortable with making decisions in the group and may defer instead to the opinions of agency personnel. A facilitator can address this by having consumers discuss an issue from their perspective prior to the full group discussion or providing opportunities for the consumer to discuss their perspectives during a pre-meeting orientation.

## Part Four: Conducting Effective Partnership Meetings

Much of the collaborative work between consumers and agency staff occurs in the context of meetings. To be effective and worthwhile, these meetings should follow a structure that is consistent, engaging and predictable, be accessible to all participants, and benefit from sustained attendance and participation of every member. Suggestions for achieving each of these goals are discussed below.

### *Getting Started*

The following graphic is a simple description of a rather complex process. It is good to keep this in mind as you are getting started in the collaborative process.



The process of conducting an effective meeting can begin long before the actual meeting itself is scheduled to start. Below are some suggestions for pre-meeting activities, as well as effective meeting techniques.

*Advance meetings* – Allow consumer partners to meet separately without state agency staff if requested. This may be especially useful if the consumer partners are individuals with different disabilities. Having cross-disability consumer partners is valuable due to the breadth and depth of the cumulative experiences, but it also necessitates that the consumer partners have ample opportunity to understand the varying perspectives. Since individuals with physical disabilities have often been the most visible advocates, it is important that all consumer partners are comfortable expressing their opinions both to other consumer partners and state agency staff. With this foundation, consumer partners are more likely to feel comfortable engaging state agency staff in group discussions.

*Expectation setting* – Clarify in advance the process to be used and the extent of authority the group has been given. This is especially important for consumer partners who may have past experience as a token member of a committee or in a group with no real decision-making authority (sometimes referred to as “punch and cookie” groups). Often individuals with disabilities are hesitant to commit their time and effort to a process that has generally not worked. Don’t overstate the power of the group, but describe it accurately. A well-articulated expectation for the final product will also serve to assist members of the group with their own individual expectations.

*Vision and mission* – Make time for the whole group to identify the vision and mission for the group. The agency’s vision and mission statement may not be relevant and/or appropriate to the consumer partners in the group. In that case, empower the group members to either develop their own statements for the group and/or add language to the agency’s statements. The vision and mission statements are critical since they articulate the group’s goal and purpose. Buy-in at this point is essential. If any member of the group can’t accept the statements in the vision and mission statement, discussion should continue until consensus is reached. Ground rules, established using the consensus method during the first meetings, are essential and should be published.

Place the vision and mission statements on a poster to be available during each meeting and refer to them in times of disagreement. Use the statements as the group touchstone. Meaningful vision and mission statements will enhance the group’s work and keep the group focused on their specific assignment. During the process of developing or adapting a vision and mission statement, the expectations of the group members will probably emerge. If not, make this a specific activity prior to beginning the work of the group. Facilitate the process by specifying what a final product would look like. A vision and group mission, identified group expectations, and a defined end product form the foundation for the essential group activities.

*Guiding principles* – These need to be stated explicitly. The group may develop the organizing principles based on those established by other successful collaborative groups. For example, the Oklahoma Partnership laid out these principles for their Real Choice System Change and CDPASS grants<sup>5</sup>:

- “Effective public policy is born when it is created by a diverse group of stakeholders who: are committed to a shared vision, share knowledge, and become informed and active participants.
- Effective public policy considers and incorporates each stakeholder’s experiences.
- Resources must be targeted to support and facilitate full participation and continual learning.”

*Decision-making process* – Carefully discuss what the process will be, especially since some consumer partners may have had experiences in which an agency already knew what they were going to do and the group process was merely rubberstamping the decision. It is important to discuss how decisions/recommendations will be made and to whom, including whether the process is one of democratic consensus, and the extent to which the membership will influence

---

<sup>5</sup> Long Term Care Authority of Tulsa (2003).

decisions and issue recommendations. Again, both advocates and agencies will need to look to the broader good rather than perpetuating old battles and defeats.

It is also critical to understand the political climate of the situation. Looking at issues in the context of a budget surplus is frequently not the same as examining the same issue in the context of a budget deficit or a court order. The group must determine if it is willing to examine the issue in the light of both vision/mission and the political climate.

*Structuring effective meetings* – It is best to have the group (or a specific subgroup) develop the agenda prior to the meeting. A call for agenda items should be made days or weeks before the meeting and the agenda should be finalized and sent to each member along with directions to the meeting location, time, and estimated time to adjourn.

Begin the meeting with a summary of the last meeting (even when minutes are available). This will serve to refresh everyone’s memory and update those who could not attend. The next step is to read the agenda and ask for additions. Specify the amount of time to be spent on each topic alongside the agenda item. If more time is needed, negotiate this with the entire group or table until next time. It is preferable to address thoroughly a small number of items than try to push through a packed agenda with little time for real discussion. Also indicate on the agenda the person responsible for leading the discussion about that time.

*Active participation* – To facilitate participation, arrange the meeting room in a welcoming manner – one that invites interaction. Circles are the best, but an open square or horseshoe shape can be effective as well. Have note cards available for those who prefer to relay their comments or questions in writing. This is extremely important when individuals in the group are hesitant about making comments or posing questions to the entire group. Using mentors is another helpful technique. Have a mentor available to a group member to facilitate individual discussion and provide additional clarifications. The mentor might be useful to relay questions or areas of confusion. Have the mentor available to the individual member during breaks and lunch, if appropriate, to review the material discussed to ensure that the individual has 1) understood all that has transpired, and 2) relay the opinions or recommendations to the facilitator that they were uncomfortable discussing in group.

Often participation in meetings decreases over time, for a variety of reasons. Sometimes, if the group or sponsoring agency considers recommendations only from certain members of the group, or reinforces only one approach to solving a problem, individuals can be discouraged from participating. In reality, there is rarely one solution to a problem. Encourage participants to be open to explore other options, even non-traditional ones. Debate and disagreement are part of a democratic process—encourage them, but always consider the common goal/vision that may be referred to on a flip chart during each meeting. Always have a flip chart available for “parking lot” issues that will need to be brought up again. If you reach an impasse, take a break or table the issue until next meeting.

Finally, there are other techniques that can encourage participation and keep all members engaged in the process. For example, use examples and stories to convey important issues. Consumer partners may be more comfortable with this format, and find it more interesting and engaging. In the same vein, provide relevant, well-produced, and accessible audio-video presentations as one effective means of holding the attention of the group members.

*Speakers* – If speakers are invited, make sure they know who the audience will be and what the audience expects. Be sure that invited speakers are knowledgeable about current best practice elements of the topic. Nothing can quell enthusiasm more than a speaker who is not in synch with the audience or is describing approaches that are a decade old. During question and answer period, be sure the presenter repeats the question in the simplest terms possible. Remember speakers and guests may need accommodations also.

*Effective closings* - How a meeting is closed can either renew the energy of the group or reinforce the concept that nothing will ever change. There are several strategies that can be used effectively including:

- At the end of the meeting, summarize what the meeting did and did not accomplish and have an open discussion on the agenda for the next meeting.
- Determine if homework assignments would be beneficial. Typically, agency staff are assigned follow-up activities, but consumer partners should also utilize their skills and contact networks to obtain useful information to further the process at the next meeting.
- Be sure to discuss the next meeting time (beginning and ending) and location.
- Ask participants to evaluate at the end of each meeting. The evaluation should be simple and quick, but provide a way of checking on where group members are in this process.
- Read evaluation results (either individually or summarized) at the beginning of the next meeting. This reinforces with each of the group members that their input is valued.
- End each meeting on an optimistic note, indicating how the progress came closer to meeting the vision.

### ***Ensuring the Environment and Materials are Accessible***

The goal of meeting and materials accessibility is to ensure that everyone is on equal footing. Unequal access is one of the primary reasons why consumer partners often begin the meeting process in a secondary position. Although there are a number of accessibility concerns, the immediate physical environment and the materials used are two critical components.

*Environment* - Prior to the meeting, take some time to visit the room where the meetings will be held to ascertain if it will meet the needs of your consumer partners. (Note: The consumers should have identified these needs as the Letter of Understanding is developed.) The checklists below, adapted from *Checklist for Enhancing the Participation and Input of People with Disabilities* (Roth, 2006), can assist in determining if the environment is truly accessible to all participants.

### **Environmental Questions to Consider: Getting to the Room**

- Is the location of the meeting easily accessed by public transportation?
- Is the location in a consumer-controlled location such as an Independent Living Center or an advocacy group?
- Is the location one at which consumers are comfortable attending meetings?
- Is adequate accessible parking available?
- Is the meeting room easily located within the building?
- Once inside the building, are there large signs available to direct people?
- Are the entrances to the room accessible?
- Have you disseminated readily understandable maps of the location of the building and the room?
- Do all contact information and directions include TTY or relay information?
- Are the restrooms accessible?

### **The Meeting Room**

- Is the room well ventilated, free of odors, and maintained at a comfortable temperature?
- Have meeting attendees been asked to refrain from the use of perfumes, hair sprays and other chemicals prior to the meeting?
- Has the room been cleaned with unscented products for at least 4 days prior to the meeting?
- Does the room have good acoustics?
- Is the room large enough for the group members and any additional staff, the facilitator, interpreters, service animals, and personal assistants or companions?
- Does the room have good lighting?
- Is carpeting low pile?
- Does the size and arrangement of space for meetings accommodate the stationing and flow of expected wheelchair users?
- Are additional chairs and tables removed from the room to allow wheelchair access?
- Are the tables and chairs in the room comfortable?
- Is the room large enough to arrange the tables and chairs in a configuration that encourages participation?
- Is there a room nearby that is quiet if consumer partners need a break?
- Does the room have a flip chart, microphones, and a screen for PowerPoints?
- Are visual or auditory distractions minimized?
- Are support staff available, friendly, and identified with different colored nametags or other means?

*Materials* – To assure accessibility, give serious consideration to the preparation of meeting materials. Not having print materials available in the appropriate format for consumer partners undermines their role as authentic partners. Give the same level of consideration to ensuring that the materials are understandable. Since each consumer partner will have individualized needs, visit with each consumer partner prior to the meeting to determine what type of alternate formats are preferred. It is inappropriate, for example, to assume that all individuals who are blind want materials on a disk or that all individuals who are deaf prefer an ASL interpreter.

### **Materials & Other Considerations**

- Are materials available, as needed, in Braille, large print, on discs, or on audio tape?
- Are items written on a flip chart or projected as they are developed by the group read aloud?
- Are videos that will be used captioned?
- Do videos that will be used have an audio description?
- Are assistive listening devices and qualified interpreters available?
- Are graphs, charts, tables, PowerPoints in accessible format?
- Are personal assistance services provided by your agency (if requested) or do you reimburse the participant's own personal assistant?
- Are speech translators available for those whose speech is difficult to understand?
- Are the materials for all partners written in clear, easily understood language?
- Are the materials free of acronyms?
- Do the materials have phrases that may be readily understood by the agency representatives, but not by the consumer partners? For instance, many consumer partners will understand the phrase "institutional bias of Medicaid," but may not understand "deficit reduction act."
- Are materials culturally responsive? For instance, the term "undocumented immigrants" is less negative than "illegal immigrants."
- Do you have name-tags and tent cards printed in large readable letters?
- If food is to be served, have you checked for special diets and utensils?
- Are refreshments reachable from a wheelchair?
- Are straws located at each table?

*Other accommodations to consider* – Always provide individualized supports. Generally, accommodations have focused on individuals with physical or sensory impairments. However, consumer partners may have a variety of other impairments including traumatic brain injury, intellectual disabilities, mental illness, and neurological disorders. As noted above, even

individuals with the same type of disability can have different individual needs and preferences for accommodations. It is important to always ask the consumer partner what *his/her* needs are several days prior to the meeting to ensure that appropriate accommodations are made. Many of the suggested accommodations listed below may be useful for all of the group members. These suggestions are not intended to be comprehensive, but may be considered as you plan accessible meetings.

### **Other Accommodations**

#### ***Environment***

- Preferential seating—possibly near a door
- Consumer partner may participate in meetings by phone if needed
- Have stress reliever toys available on the table for individuals who want to use them during the meeting

#### ***Before and during the meeting***

- Prearranged or frequent breaks
- Option for note takers or tape recorders
- Advance copies of materials to be discussed
- Recognize that changes in room, routine, or personnel may be difficult and address them as early as possible

Also consider that some consumer partners may have had experiences with state agencies where requests for accommodations were either ignored or addressed minimally. For instance, a consumer partner who is blind and requires written information on a disk may have been told in the middle of a meeting that, “We will send you these handouts later” or “We will tell you the main points on the handout.” Due to this history, consumer partners may not be initially satisfied with the accommodations and request additional ones or “fine-tuning” of current ones. The issue of having appropriate individualized accommodations is much more than just accessibility; it is an indication of the level of respect and attention given to meeting each member’s needs.

This section discussed environmental and materials accessibility in the context of group meetings. However, these suggestions are relevant for other types of consumer partnership activities. Whether engaging consumers in a group or individual setting, always give consideration to both environmental and materials accessibility.

### ***Ensuring and Sustaining Attendance and Participation***

Perhaps no other characteristic so defines a strong group member as regular attendance at meetings. In some instances, state agency members may be inconsistent in attendance, depending upon other duties, reassignment, or resignation. In other cases, consumers, facing transportation and personal assistance barriers, may be unable to attend regularly. Regardless, each time a

group member leaves or a new one joins, the overall process is interrupted – trust has to be rebuilt and energy has to be spent on bringing the group “together again.”

When regular attendance is challenging for consumer partners, here are some strategies that can be employed to address the barriers. Discuss the barriers to attendance with individual members and clarify the issues. Don’t assume that you can intuitively guess what the problem is.

Although the cost of attendance—transportation, meals, lodging, and personal assistant services may be the problem, other challenges may be equally significant. Often a significant barrier is that consumer partners have the sense that the partnership is not genuine and that the purpose of the group is more cosmetic than real.

- *Computer capacity* - To ensure an equal playing field, your agency may want to provide computers for consumer partners.<sup>6</sup> Participation implies more than providing input at meetings. It also means that each member has access to equipment to respond to email, access online documents, and enter into listserv conversations. Many consumer partners may not have readily available computer access and accessing computers at a local library, in many instances, is neither reasonable nor feasible. Providing the needed equipment may be difficult due to agency rules, but it may be critical to have full consumer participation. Paper and a printer may also be needed.
- *Maintaining continuity* - If a consumer partner misses meetings, it is important to provide them not only with the minutes of the meetings but also have a follow-up discussion with them to ensure that they can continue to be an active partner in the process.

---

<sup>6</sup> Read how the Long Term Care Authority of Tulsa created and funded a cost-effective technology component for their Partnership activities at [http://www.hcbs.org/files/122/6092/Eff\\_PP\\_Publication.pdf](http://www.hcbs.org/files/122/6092/Eff_PP_Publication.pdf) (Accessed September 24, 2007).

## Part Five: Strengthening and Expanding the Partnership

Real collaborative leadership between consumers and agency staff requires ongoing investment and commitment to the partnership. To create strong partnerships, provide information and education, and promote leadership development. Each of these is discussed in greater detail below.

### *Support Information and Education*

Consumers will not necessarily always understand the policy or guidelines that underlie a service. Their perspective may be based on what agency/provider staff or other service users have told them. State agency staff may not realize how policies are being interpreted or misinterpreted in the field, and consumers may lack important information about how and why certain policies are implemented. Communicate about differing perspectives and provide information and education where appropriate. It will strengthen the partnership in the long term.

A common assumption is that everyone in a group or everyone who has similar interests (e.g. disability services) also has similar knowledge and understanding of, and experience with the issues under consideration. In fact, this assumption often derails best efforts to partner with consumers. Acknowledge the differences. Consumers and state agencies each have a perspective of “reality” that is critical if system transformation is to occur in a meaningful way.

The purpose of information/education sessions is to provide individuals with the tools and resources they need to understand issues, develop strategies, and fully participate in the group. In providing background and ongoing information and education, remember that no one can assimilate all the relevant information about the topic in a single setting. Frequently, agency staff may believe that providing a single orientation session for consumer partners is all that is required. However, for effective education and information sharing, provide orientation activities that are both incremental and interactive. All adult learners better remember what they hear if they can discuss it, get clarification, and pose questions about what they have learned. Therefore, make orientation an ongoing process of providing information to consumer partners as needed. In fact, even those who initially say that an orientation is not needed, may often be open to education/information sharing sessions if asked again after a few months.

Listed below are several potential topics for inclusion in any education activities. In developing and presenting these topics, always use principles of adult learning.

- **Basic information about the political structure, system processes, funding sources, state organization, providers, and advocacy groups relevant to the group’s charge and authority.** Provide only information that is directly relevant to the subject and provide it in an impartial manner. Information for the sake of information is not beneficial.
- **Standard terminology.** Agree on standard terms that will be used consistently. For instance, the term “consumer-direction” is frequently used, but has multiple meanings. It could mean that a consumer can select from a set menu of services, determine the frequency of a particular service, decide whether to use a self-directed or agency model for personal assistance services, or direct a care provider about what the individual would

prefer to do that day. By clarifying the meaning of the term, it will save time, confusion, and backtracking by the group.

- **Enhanced understanding of the concept of consumer partnerships.** Explain and discuss the concept of collaborating with consumers as partners as it applies to state policy, procedures, and regulations that guide the services and supports for individuals with disabilities.
- **The nature of the policy change process.** Discuss policy to identify what can be changed and what cannot, and consider carefully those policies that can't be changed. Sometimes things can be changed if the state is willing to consider innovative alternatives. If a policy cannot be changed, look for other options. Invariably there are some things that cannot be changed at this time. Accepting that fact will also facilitate the group process.
- **State and federal commitments of accountability and responsibility.** Identify state and federal commitments of accountability and responsibility as public stewards. These should clearly reflect the intent of federal and state policy.
- **Relevant resources.** Provide lists of relevant resources – people, services, websites, etc.

In addition to education, agencies should take steps to strengthen the group process over time. Selected techniques for doing so are listed below.

- Provide a glossary of commonly used terms, phrases and definitions, and a list of acronyms and what they mean.
- Provide the group with a participant list that includes a “humanized” bio for each participant as well as contact information. “Humanized” bios focus on the person more than academic achievements of organizational status.
- Create a level playing field through the exchange of information. It is important to learn and respect each other’s languages. This facilitates a shared leaning experience. Story telling (reflecting the personal approach) is an excellent way to establish these personal understandings.
- Include strategies to enhance the development of personal skills in group settings.
- Dedicate time to training as a protected part of each meeting and/or at another time. Education is an ongoing process that cannot be compressed into a one-time activity.

Other types of training that might be offered to various group members include how to advocate effectively, skills training on communication, and the sociopolitical concept of disabilities. Provide both agency personnel and consumers these ongoing opportunities to support improved communication, understanding, and group work. In this new, shared environment, everyone has a steep learning curve!

### ***Promote Leadership Development***

One of the critical elements of achieving successful partnerships is state-level leadership, often in the form of a person with decision-making power in a position to influence others. The leader must clearly articulate a stated commitment to support meaningful collaboration. Leaders

must understand the importance of the group process and pass it down as an expected behavior and an organization goal throughout the agency. Meaningful participation becomes the intended outcome. Leaders set the atmosphere, ensure the group vision is attainable and provide the resources to make involvement possible. Leaders make the decision for inclusion to happen.

As consumer partners are full members of decision-making groups and their experiences and insights are valued, they will continue to develop the skills and knowledge to become increasingly strong leaders. Other aspects of leadership development that occurs in the context of shared decision-making at the state level for consumer partners include:

- Improved understanding of cross-disability issues
- Strategies for partnering across disabilities
- Improved understanding of the state's rules and constraints
- Better understanding of the complexity of developing state policy—what rules are real (explicitly mandated by state or federal rule) and what may actually be changed

## Part Six: Evaluating Effectiveness of the Consumer Partnership

Evaluating the effectiveness of consumer partnerships can be conceptualized in several different ways. Some of the methods may be formal and others more informal. No single method of evaluation provides a complete picture. In addition, effectiveness needs to be considered across points in time. Effectiveness measured at the conclusion of a project may look quite different when measured 12 months after the project's conclusion.

“Effectiveness” of partnerships may also be defined in several ways. Given all these variables – point in time of evaluation and definition of effectiveness, and the measurement strategies – formal and/or informal and point of view; the methods described below may serve as a starting point in conceptualizing both the evaluation questions and the methodology.

*Informal* - Sometimes the best evaluation of effectiveness is to examine the working relationship of state agency staff and consumer partners and advocates six months to a year after the conclusion of a specific project that had collaborative leadership (consumer partners and state agency staff). One might examine

- The consistency of participation including, both attendance and contribution to doing research, homework, reports, etc., on the part of the members, both consumer partners and state agency staff.
- The number of collaborative presentations made at the state or national level with consumer partners. Are consumer partners brought along for “show” or are they an integral part of the presentation?
- The type of interactions between consumer partners and state agency staff in public meetings. Does there appear to be a greater understanding of each party's perspectives? Has the state agency continued to support a collaborative process in the development of policy and programs?
- Whether the recommendations from the group have been implemented.

*Formal* - Formal evaluation methods generally include written surveys or structured interviews conducted in person, on the phone, by mail, or email/internet. Typically all members of collaborative groups participate with an external (independent) evaluator. The use of an external evaluator generally leads to more candid responses and impartial findings. Questions (whether structured interview or survey) generally examine one or more of the following:

- How did the consumer involvement process differ from other boards, work groups, committees, task forces, etc., which you had previously been a member of? What worked? What did not work? What have you learned? What would you change about the process?
- Was this a cross-disability initiative? Have you been involved in cross-disability initiatives previously? How did this compare? What are the reasons to create cross-disability policy? What are the reasons not to? How could it have been done better?
- What was the recruitment and selection process for the consumer partners? Who did it represent? Who was left out? What could have been done differently? Did your experience change over time? What was your experience with accessibility?

- Was this model of collaboration different? What were start-up challenges? What were barriers to progress? What are some lessons learned?

Another approach would be to use some of the questions presented previously and rephrase them for responses on a Likert scale. If you need quantitative information, this approach may be useful.

The use of focus groups often provides very rich information. As one member of the group responds to a question, others will expand and deepen the response. A caution on focus groups is the composition of the group. Consider carefully whether the group should be a mixed group or a group of only consumers or only state agency staff.

*Systemic* - Another way of evaluating effectiveness of partnerships with consumers is to track changes in the state agency. The changes may be at the policy level, the program level, in the way the state agency does business, or in perceptions of consumers of their services.

- Have recent system decisions on policy showed the impact of consumer involvement and perceptions?
- Are state programs making changes that support consumer collaboration?
- Is the state funding increasing for community supports?
- Are consumer partnerships becoming an accepted part of the agency's policies and programs?
- Do consumers and advocates see positive progress in the state's policies and programs?
- Has the state continued to partner with consumers in ongoing as well as time-limited committees, taskforces, work groups, etc.?
- Is a quality management system in place that heavily relies on a quality committee to provide feedback and recommendations to the entire quality management system?
- Has a means of evaluating the community service experience been developed that utilized consumers and service users? Is there a baseline by which to evaluate progress toward satisfaction, access, and services?

### ***Spread the Concept of Sustainability***

A successful partnership of state agency staff and consumers forms the foundation for the state agency to consistently change how they do business. All members of the collaborative group should be dedicated to letting other constituencies (at both the state and community level) know about the process. State agencies can continue to use the same approach in multiple contexts and settings. By repeatedly developing policies, procedures, and program guidelines with the full participation from consumer partners during the entire process, the state agency will be modeling the collaborative process for other state entities as well as community providers. A state agency that feels strongly about the efficacy and value of this collaborative partnership model can also strongly encourage (or even mandate) that community providers use the model.

A practical method to sustain and spread the model of authentic consumer partnerships with state and community providers is preparing a guidebook that describes the process with replicable steps. The guidebook will be most relevant and acceptable if all members of the group

assist in the development, review, and approval process. By pairing the guidebook with training and technical assistance across the state for provider agencies and consumers and advocacy groups, the concept and practice of partnerships will become an *expectation* rather an *exception*.

There is an additional critical sustainability activity that is both informal and effective. With the success of the partnership, consumer partners should be willing to inform consumer groups and other advocates about the partnership by describing both their responsibilities as well as what they learned about supporting an interactive learning process. It is important for state agencies to spread the word and continue to use the model, but consumer partners also have a responsibility to assist others in better understanding how they can be a contributing partner in this type of group. Being a partner in state level policy development requires all partners to learn, adjust, and adapt to a collegial model of joint responsibility.

Just as the voices of the service users must be heard to help shape the transformed system, these voices can become valuable advocates with legislative bodies, the general public, and broader disability communities. Where state agency staff may be limited in their public discourse by lobbying constraints, advocates can step forward to educate, rebut, and push forward the vision of system transformation.

## Conclusion

This guide reflects the opportunities and subsequent learning experiences afforded grantees and consumers through the Real Choice Systems Change initiative to form expanded partnerships at multiple levels. It reflects both lessons learned and aspirations yet to be fully realized. The guide is not a recipe to be followed exactly, but rather each section of the guide is intended as a starting point for discussion and deliberation within state agencies and with consumer partners.

In order to maximize the usefulness of the guide, it should be reviewed thoughtfully with the intent to understand the next logical steps in the paradigm shift that disability services are currently experiencing. The underlying concept of “we” rather than “I” in the decision-making process at the state level, while deceptively straightforward, requires time, commitment, and effort. The time to begin the process is now. And, since it is a process, the journey will have detours and delays as well as valuable insights and strengths. Just as 50 years ago, individuals with disabilities began to talk of their dreams and aspirations as full productive citizens, state agencies have the challenge to assist in furthering these dreams to fruition by partnering with those who best know their lives and needs.

## References

- Long Term Care Authority of Tulsa. (2003). *Effective public policy through shared vision, shared knowledge, and full participation of all stakeholders*. Tulsa, Oklahoma. Available at [http://www.hcbs.org/files/122/6092/Eff\\_PP\\_Publication.pdf](http://www.hcbs.org/files/122/6092/Eff_PP_Publication.pdf) (Accessed September 24, 2007).
- Roth, H. (2006, July). *Checklist for enhancing the participation and input of people with disabilities*. Houston, Texas: Independent Living Research Utilization in collaboration with The MEDSTAT Group, Inc. Available at [http://www.hcbs.org/files/96/4767/ILRU\\_ACCESS\\_CHECKLIST.pdf](http://www.hcbs.org/files/96/4767/ILRU_ACCESS_CHECKLIST.pdf) (Accessed September 24, 2007).
- Lomerson, N., McGaffigan, E., O'Connor, D., & Wamback, K. (2007, February). *When CPIGs fly: Meaningful consumer involvement in systems change*. Shrewsbury, Massachusetts: University of Massachusetts Medical School, Center for Health Policy and Research. Available at <http://www.hcbs.org/files/108/5357/CPIGS.pdf> (Accessed September 1, 2007.)
- Vella, J. (1994). *Learning to listen, learning to teach: The power of dialogue in educating adults*. San Francisco, CA: Jossey-Bass.

## Additional Resources

Lakey, B. (1975, April). *Meeting facilitation—the no magic method*. Accessed September 24, 2007 at <http://www.reclaiming.org/resources/consensus/blakey.html>

Siebenaler, K., Tornatore, D., O’Keeffe, J. (2002, September). *Partnership development activities: Comparative analysis of FY 2001 Systems Change Grantees*. Research Triangle Park, North Carolina: RTI. Available at [http://www.hcbs.org/files/35/1723/SystemChangePartnershipEval\\_rti.pdf](http://www.hcbs.org/files/35/1723/SystemChangePartnershipEval_rti.pdf) (Accessed September 1, 2007).

University of Massachusetts, Center for Health Policy and Research. (2006, November). *CPIGs Fly: Consumer involvement within the Massachusetts Real Choice and Independence Plus Grants* [Final Report]. Available at [http://www.hcbs.org/files/101/5012/CPIGs\\_Fly\\_Consumer\\_Involvement.pdf](http://www.hcbs.org/files/101/5012/CPIGs_Fly_Consumer_Involvement.pdf) (Accessed September 1, 2007.)