Independent Living Research Utilization

Key Components of Systems Change

First of Three Papers on
Unlocking the code of effective Systems Change

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Table of Contents

Acknowledgements

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[1] A list of participants can be found at http://www.ilru.org/html/projects/CMS/colloquiumindex.htm

I. Introduction

Over the past several years, staff members and partners of the Independent Living Research Utilization (ILRU) team have provided technical assistance, training, publications, and other support to the Real Choice Systems Change initiative of the Centers for Medicare & Medicaid Services. As we conducted this important work, we began to observe there were clear distinctions between those programs that achieved (or showed real promise for) enduring change and those programs that failed to realize their full potential. In 2004, after almost four years of working with Real Choice grantees, we took the step of looking much more closely at how to foster meaningful, sustainable changes in the social services systems that support people with disabilities of any age. We identified six outstanding projects that had received Real Choice Systems Change grants; each of these projects initiated significant and beneficial change in their respective states (Arkansas, Connecticut, New Hampshire, New York, Oklahoma, and West Virginia). The chosen projects were diverse in many respects, including --

- the scale, scope, and character of the service systems in place,

- the people and needs that were the focus of the changes,

- the types of participants involved in the change process,

- the changes being pursued, and

- the history and duration of the change process.

We asked representatives of these projects to reflect on their experiences and share lessons they learned about systems change. We interviewed project staff and consumer leaders. We wanted to know whether there were common factors that are central to achieving people-friendly systems change.

In January 2005, ILRU continued its investigation by inviting representatives from the six projects and other key Real Choice Systems Change leaders to a colloquium to discuss key elements of meaningful and sustainable systems change.[2] The group spent 2 1/2 days in Houston in active dialogue focused on three topics:

- Key components of systems change

- Features of a high-quality community service system

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[2] Readers interested in the original three papers used as catalysts to stimulate dialogue at the colloquium may access them at http://www.ilru.org/html/projects/CMS/colloquiumindex.htm

- The promotion of self-direction and consumer control in service programs and systems

From our study of successful programs and the recommendations and guidance of the colloquium participants, we have developed three papers that address these central aspects of the creation of enduring change.

> In this paper, the first in the series, *Key Components of Systems Change*, we attempt to create an overall framework for the discussion of systems change and to give a summary of the concepts discussed in all three papers. In addition, this paper includes several specific recommendations that can be applied now by any grantee, state, or program to enhance prospects of achieving enduring change in home- and community-based services.

> The second paper in the series, *Features of High-Quality Community-Based Services*, identifies the features of high-quality integrated community services and the systems that support them. It serves as foundation work for additional exploration and discussion of what constitutes effective community services. The paper will undergo continuing development in discussions with representatives of projects and consumer leaders in states. The authors believe the paper, in its current form, will augment assessment of existing systems and planning of new or improved systems and, after refinement, it will become an even more useful tool for those involved in systems transformation.

> The third paper in the series, *Promoting Self-Direction and Consumer Control in Home- and Community-Based Service Systems*, examines what contemporary social service systems can do to promote consumer-directed services. We identify different features that make a service "self-directed," and we identify characteristics of successful consumer direction and self-determination. As with the second paper, in its present form, it serves as foundation work for additional dialogue and will also undergo continuing development in discussions with representatives of projects and consumer leaders in states.

II. Challenges in Describing and Creating Systems Change

A. Context for Change

In many current disability support systems, people with disabilities, including older adults, struggle with the difference between what the systems allow them to do and their actual needs and potential. Many people involved in the current

systems – including care providers, family members, and the users of the services themselves – long for systems that are more responsive to the needs of people with disabilities. The *New Freedom Initiative*, which spawned the Real Choice Systems Change program, was created to answer this need. Real Choice Systems Change projects aim to change disability support services in ways both large and small, so that users of these services have real, empowering choices to make about the types of care they receive.

Real Choice Systems Change can seem a daunting undertaking when the "system" is put forward as something that has a life of its own with power over people and communities. But systems are inanimate entities that are designed by, acted upon, and used by people. It is people—individuals and people working in concert—who bring change into the environments and communities of which they are part. It is their will to change that begins the processes of mobilizing constituencies for change. These changes can range from the miniscule and invisible to ones that are prominent and far-reaching.

Idealists may presume that support service systems ought to change simply because it is the right thing to do. Unfortunately, these systems do not exist solely to benefit the people dependent upon them. They also have to contend with the needs, pressures, and vested interests of many other parties. Changes centered on individual needs often compete with the needs and priorities of outside parties who may be more entrenched, more powerful, and difficult to persuade about the merits of systems change.

This observation does not mean that systems cannot uphold the people they support in an honorable and beneficial way. Some already do. But there are many difficulties in creating or protecting people-friendly aspects of systems if those aspects collide with other priorities and preferences. People-friendly outcomes may require systems that are very different from those with less people-centered outcomes. Discovering how to create and sustain people-friendly support services is the focus of our research.

B. What Do We Mean By "Systems Change?"

The term "systems change" is difficult to define precisely. Human service and community systems rarely take the form of a single unified organization. Rather, they are composed of many interconnected systems and subsystems, such as hospitals, social workers, home care providers, community service organizations, and even individual families. These groups are not always directly connected to one another. For example, families and other informal caregivers are often the backbone of any care system – yet many families remain remote and disengaged from the formal service systems designed to assist them. When we refer to the systems involved in "systems change," we are talking about all these system levels, both formal and informal.

In describing systems change, it is often easier to focus on formal systems and structures. However, descriptions of formal systems based mainly on hierarchies and regulations may overlook the powerful roles that individuals and informal relationships play within these systems. The values, attitudes, and relationships of these individuals are especially important. In some cases, the conduct of officials within the systems may contradict the stated goal of the systems. For instance, officials may offer services that are little more than custodial maintenance, when the services were meant to be empowering to recipients.

Even without a precise definition, we can still name and describe many types of intentional systems changes. For example, some systems have been gradually *de-institutionalized*, becoming more community based, more individualized, more granting of individual control and direction, and better integrated with other systems. This type of shorthand definition may not be precise enough for every purpose, but it offers an adequate definition for people to use in discussing and organizing systems change projects.

C. Considering the Scope of Systems Changes

Because formal systems can be quite complex, any discussion of systems change should distinguish between "whole system" changes and changes focused on a single component of the system. Changes at both levels can be substantial and beneficial. The choice of where to begin a systems change project depends largely on timing, opportunity, and the leverage of the people initiating the change.

Systems change projects may focus on anything from minor system components to major system components; they may also start with small subsystems and then become gradually more comprehensive in scope. Additionally, while some people involved in systems change may not be in a position to effect large-scale changes, they may have leverage to effect changes in smaller systems components. For example, in helping patients to make productive transitions between acute inpatient care and community living, systems change advocates might conceivably leave the overall hospital system largely intact. However, considerable changes would be made in the specific hospital subsystems related to discharge planning, and changes would also be required in the coordinating, planning, and financing practices of local agencies that offer community-based services.

We must not assume, however, that small component or subsystem changes are easier to make due to their scale. Even small components may have well-entrenched defenders and interest groups holding them in place. It may not be any more difficult to make a large systems change than a small change if the timing is right and the parties involved are well positioned.

D. Systems Change Cannot Be Completely Predicted or Controlled

In planning a systems change, it's tempting to imagine that social service systems are a type of apparatus that responds to rational external engineering much in the way that a machine would. If this were true, talented agents of change could foresee and guide all aspects of change. The resulting changes would be largely predictable and would turn out exactly as intended.

In fact, however, systems are composed of both rational and non-rational elements. In real life, intentions and logic compete with non-rational factors such as vested interests, attitudes, habits, and expedience. As a result, real change processes are complex, nuanced, and not entirely predictable.

People who expect systems changes to be easily managed may be caught by surprise when changes unfold in unforeseen ways. This does not mean that all aspects of change are unforeseeable or that change cannot be steered to some degree with logic and rationality. It does mean, however, that changes to complex systems involve a measure of uncertainty and risk. Not every attempt at change will succeed.

Even problems with obvious solutions may not be fixable if the conditions needed to effect the change are missing. People within the system must possess the underlying will and values to overcome resistance to the proposed change. There may be moral, cultural, and political factors in a community that prevent change. At a given time, people and communities may be unwilling to endorse feasible solutions that collide with the prevailing view of what is proper and needed. Only if these dominant community views change can system changes be successful. Thus, it is extremely important to stress community and constituency education strategies in any systems change plan.

E. The Prospect of People-Centered System Changes

Change does not appear simply because it is needed. Nor will simply setting people-centered goals and using people-centered vocabulary bring about change. Real change requires both a vision of what might be possible and needed, and people willing to do the difficult work of bringing these visions into reality. In some cases, these struggles for change are multi-generational in duration and may involve periodic setbacks and revisions of approach as conditions change. They all are dependent on mobilizing people to engage themselves in a committed way to make progress on key issues.

Realists recognize that many demanding challenges must be addressed before beneficial changes can take place. These challenges are only partially foreseeable at the outset or while a project is underway. So what must occur for systems to meet the varied demands and to become or remain people-centered?

To answer this question, we need to know which theories and assumptions about people-centered systems change are valid, and which others are misleading or

incorrect. What follows in this paper are some of the key factors repeatedly identified by practitioners in the change process as being significant for them.

They suggest some common investments that can help facilitate change at the local, state or national level. The effect of these can be catalytic and synergistic, particularly when a number are simultaneously present.

III. Key Ingredients of Systems Change

Colloquium participants identified four key components of meaningful systems change:

1. leadership at all levels

2. inclusion of stakeholders

3. equalization of knowledge

4. sustainability

This list of components is not intended to end discussion, but rather to inform further work on our collective understanding of meaningful and sustainable systems change.

A. The Right Leadership at All Levels

1. Essential Qualities for Systems Change Leaders

Leadership is central in mobilizing and influencing people. Effective systems change requires experienced, realistic, and skillful leaders who can cooperate effectively to spark progress and vision. The colloquium participants described several qualities that are essential for leaders of Real Choice Systems Change.

Different types of leaders are needed (such as bureaucratic, technical, and advocacy leaders), and leadership must occur at all organizational levels. No single leader can embody all the knowledge and skills needed for systems change in a single package. Leaders can and should come from various sectors – not just from government offices, as some might presume. They can include consumers, families, advocates, community providers, neighbors, employers, academics, technical consultants, and progressive professionals. Having the right kind of governmental leadership can be a significant advantage, however, because government systems can exert substantial influence toward change.

Leaders from different institutions and areas of expertise should work together for change through leadership alliances. Leadership

alliances are loose networks where people share ties such as values, ideology, beliefs, common interests, personal relationships, and relationship networks. These commonalities can be quite influential in both what gets done and how it is done. Such networks usually start with existing relationships where there is some measure of trust already. Over time, newcomers can establish themselves as valued members of these informal alliances as well, and over time, as valued members of the larger community.

Leaders need practical operational skills as well as vision. Vision is of course a key component of leadership, but it takes practical skills to turn visions into reality. Colloquium participants noted that effective leaders must also be competent, realistic, decisive, and able to get along with people. A certain "political savvy" is required, because systems change leaders must not only be adept at preparing and planning for change, but they must also navigate a maze of personal and institutional relationships to put their plans into action. Leaders must be able to exercise caution and discretion; they must be careful to avoid conflicts of interest. They must be credible when speaking about the content of proposed changes, and they must be prepared to meet the numerous challenges that will arise throughout the change-making process.

Leaders must prepare for continuity in leadership. They do this both in the ways they interact with governmental systems and other types of leaders, and in the way they pave the way for their own successors. In the case of dealing with governmental systems, it is critical that systems change leaders operate in a non-partisan way as much as possible. Turnover in state administration and legislative branches can be deadly to emerging shifts in policy and service delivery if players on all sides have not been educated or persuaded about the value of the changes – or if political enemies have been made by appealing more heavily to one side than to another. This education and inclusion process should also be extended to new people within the systems change movement; these individuals will carry efforts forward when current leaders leave their positions. The loss of informed staff, volunteers, consultants, and advisors weakens and fragments corporate knowledge.

2. Strategies for Recruiting and Developing Leaders

Of course, leaders with the range of skills described above do not always appear on the systems-change scene fully formed. Leadership recruitment and development are essential activities, part of a continuous process within social institutions and movements to generate a pool of leaders who can meet the

challenges involved in change. Our colloquium participants offered a diverse range of strategies for investing in leadership development.

Strategy #1: Add to and strengthen the leadership pool

When groups deliberately work to add new people to their leadership and to provide all their leaders with opportunities to develop their skills, chances for success increase. One example of this type of development is the well-known "Partners in Policy Making" program supported by state Planning Councils on Developmental Disabilities. States participating in this program learn how to identify consumers and families interested in leadership, and then provide them with training, peers, and mentors to strengthen their potential leadership contribution. In many states, this program has been in effect for over a decade and represents a comparatively long-term investment.

Many states, including Massachusetts, provide similar intentional training and support not only to consumer and family leaders, but also to staff, professionals, board members, and others. They offer this training through a specially designed regional- and state-level program sponsored by the State Department of Mental Retardation.

North Carolina developed a consumer and family training program on leadership and advocacy through a partnership between the state's Consumer Empowerment Division, the North Carolina Planning Council on Developmental Disabilities, and the North Carolina Council of Community Programs. This project was undertaken in conjunction with the state's introduction of Consumer and Family Advisory Councils as part of broader state reforms of the mental health, substance abuse, and developmental disabilities system.

The key is to invest in developing leaders who will create positive changes by exercising personal and collective leadership. Although there are many different models for recruiting and developing leaders, any effective leadership training program must:

- target emergent leaders and localities

- institute a deliberate recruitment process

- implement a specific leadership development curriculum relevant to the particular issues to be addressed

- establish necessary sponsorship and financing mechanisms

- implement measures to ensure continuity, follow up on training after it has been delivered, and evaluate the overall effectiveness and impact of the training program

Strategy #2: Develop leadership within state agencies and community organizations

Systems change advocates should capitalize on potential leaders already available within the agencies and organizations that may implement home- and community-based services. But new programs and heightened expectations require expanded leadership development. Many state agencies and community organizations have leadership development programs; however, few include training on how to collaborate with constituent groups to implement new approaches associated with modern home- and community-based services.

Executives of state agencies and community organizations should offer leadership training programs (or enrich existing programs) that incorporate constituent involvement and consumer direction. Some business models of customer-oriented quality management support this approach. However, training must go further to help leaders embrace the kind of shared leadership that fosters truly successful service programs.

To help members of state agencies and community organizations learn the unique skills required for consumer-directed systems, staff development training should include these topics (along with more traditional leadership topics):

- Shared vision: Work with broad-based constituencies as they create, test, and continually validate a conceptual framework for service programs.

- Values identification and clarification: Support identification of the principles, standards, and qualities a group considers essential in program design and implementation.

- Constituent partnerships: Involve the "right" constituencies and people, determining the desired background, skills, and qualities of those from the community who should play leadership roles, ensuring they are fully oriented to the programs in which they will be involved and that they continue to be fully informed of the issues they are expected to address. This area also involves knowledge of disability and techniques for facilitating full involvement of all, including persons with cognitive disabilities. Leaders should also have an understanding of the different organizational structures that can be used in partnerships: boards, task forces, advisory councils, etc.

- Working in partnership: Alter philosophical perspectives to create openness to shared power as well as learn the techniques that facilitate true partnership processes.

- Strategic planning, implementation, and evaluation in a power-sharing environment: Engage in group planning and process techniques that ensure constituents are continuously and fully informed of and involved in planning and implementation. This includes reporting to and securing guidance from constituent partners.

Strategy #3: Promote shared leadership through regular leadership meetings

When leaders meet together to resolve an important matter, their collective energies, resources, and constituencies can be unified into a single focus. They are also able to talk directly with one another to create a shared understanding. These two factors allow consensus to emerge so that leaders can then take joint action.

Getting to joint action is not automatic. Joint meetings help create the desired conditions for change, but they do not compel or assure change. According to the West Virginia Real Choice grantees, this type of shared leadership is important because it shows a deliberate attempt to get many key leaders from as many stakeholder groups as possible in the room together to prepare a common statewide change agenda. Their experience with this strategy was not utopian in its results, but it brought many stakeholder leaders into greater agreement and alignment on important issues and provided a kind of "social capital asset" that will serve as the foundation of future change. (For additional details about the West Virginia group's experience, see their report at http://www.hcbs.org/files/40/1979/findcomground-1.pdf.)

One way to effectively convene leaders to establish and implement a common agenda involves these steps:

- Involve leaders from all stakeholder groups in planning the process for the meeting so that there is investment and ownership up front.

- Use a neutral facilitator who is familiar with long-term care and community living concepts to keep the discussion going and assist the group in finding common themes.

- Use a process of "appreciative inquiry" in which you ask, "What's working well, what can we learn from what's working well, and how can those lessons be applied to other areas?"

- Use a visioning process that enables the group to identify the current status of the issues, the future goal and action steps for reaching the goal, and the priorities of the action steps.

- Have a follow up plan with assignments to specific people, and then actually follow up.

B. Stakeholder Involvement

1. Diversity of Stakeholder Involvement

Having key people involved from all stakeholder sectors is the next essential ingredient that our colloquium participants agreed upon. Stakeholders include:

- service recipients

- family members

- advocates

- state agencies and government representatives (including politicians) who represent not just disability funding and services, but also community planning and development, transportation and housing services

- business people

- anyone affected by the inclusion or exclusion of people with disabilities and older people from the community

2. Full Inclusion in the Change Process

Colloquium participants argued that change can and should be negotiated across many groups, and that leaving people out of that negotiation process can be costly. Including diverse stakeholders makes it easier to reach consensus and develop vision – key processes for solidifying disparate elements into functional alliances. These stakeholder alliances enable people to act collectively to unite their efforts, energies, and purposes. Stakeholder discussion groups are valuable for formulating credible and persuasive answers to questions that are raised about systems change; the involvement of diverse participants allows people to test and modify positions in front of the group, so that the questions of many people are answered, rather than those of just a few. Finally, the shared consensus and vision generated by these groups also reduces the risk of losing momentum when leaders leave. The vision takes on its own life and no longer depends on any one person's presence.

In order to forge stakeholder alliances, change agents must first identify who the stakeholder parties are, then identify what will bring these groups to the table and keep them there. In the case of stakeholders who may have an agenda that conflicts with the

purpose of Real Choice Systems Change (for example, nursing home administrators who may see community-based services as threatening to their purpose and income), it may be necessary to invest additional time into developing a relationship and educating those representatives before actually including them at the table.

By engaging key stakeholders, several states generated support for systems change efforts that led to a workable mandate. One state, West Virginia, held an inclusive conference that brought a wide range of stakeholders together to gradually build a shared vision and consensus. That state's spokespersons reported that this event was a high-water mark in terms of recent systems change developments. In Connecticut and New Hampshire, two small towns marshaled an impressive range of initiatives affecting people with disabilities. Subsequent efforts brought in new supporters and stakeholders to the collective network and generated considerable good will and momentum. In these instances, there were actually many discussion tables rather than a single table, but the principle of having the right people at the right table flourished and expanded.

3. **Strategies for Creating Meaningful Stakeholder Roles**

Once stakeholders are identified and included in systems change discussions, they must be involved in the change process in authentic, substantive ways. Stakeholders must be active at all levels of change (policy development, program development and implementation, service delivery, monitoring and evaluation), and each group must have real (not token) roles to play.

By attending to the voice of consumers, families, and communities, leaders are more likely to develop support systems consistent with what these groups actually want and need. In one state, a long-term care agency sought consumer input so seriously and with such systematic quality that it persuaded even doubting consumers to have faith in the state's system change agenda and to take an active role. The active ingredient is not that participation by consumers occurs, but that leaders respect the voice of consumers and unmistakably use consumer feedback to inform policy decisions and directions.

Colloquium participants suggested two main strategies for encouraging stakeholders to voice their opinions and contribute substantively to change projects.

Strategy #1: Help people form social networks

People with social supports tend to function better than those who are socially isolated. As witnessed in the peer support movements

in mental health and independent living, there is something about solidarity with others who face the same challenges and concerns that strengthens, encourages, and gives practical assistance to "fellow travelers."

Networking and solidarity can help people in many other ways, including the following:

Learning about resources	Being able to sound people out
Hearing other perspectives	Getting advice and counsel
Drawing strength in numbers	Being able to assist others
Validating arguments and getting clearer information about what works and what doesn't	Creating pathways for joint action

People are much more likely to pursue and stay with demanding change agendas when they are well supported in their efforts by like-minded allies. An investment in such networking may be more fruitful than first meets the eye, because it can help create a "base" for change through the making of a unified and mutually supportive constituency.

There are many ways to help people find, start, and nourish change-oriented networks. The key is simply to help people with common interests find each other. Here are ways that you can enable service recipients, families, and other stakeholders to share perspectives, learn from each other, and support needed system changes:

- Start networks by connecting people you know who have some of the knowledge, interest and investment in the relevant issues.

- Make resources available such as a place to meet, staff to answer questions, and other resources.

- Give advice when asked.

- Take their opinions seriously by taking feedback from the networks to your formal advisory board and policymakers.

Strategy #2: Encourage stakeholder discussion groups to imagine and design groundbreaking initiatives

Once social networks are formed, the next step in innovation is to provide a forum where stakeholders can describe the groundbreaking changes they need. For instance, stakeholders may form miniature "think tanks" in which they examine particularly vexing problems and generate proposals for change. These

brainstorming sessions are often focused on specific challenges such as social inclusion, individualization, home ownership, or empowerment. Admittedly, not all such "think tanks" are equally successful, but by the same token not all problems are equally easy to resolve.

In Oklahoma, a key state advisory group consisting of consumers and families was formed to look deeply into many issues and brainstorm ways forward. The group was given extensive support to encourage their thinking and imaginative process. For example, in this project --

- Participants were treated as partners in the systems change process; this raises the value of their participation.

- Participants were given reading, research and reporting assignments to support and facilitate the process of creative thinking.

- Small group activities were used to help participants analyze for themselves the pros and cons of a policy, service, or procedure.

- Each participant was specifically asked for his or her opinion about the problems and proposed solutions; this technique ensured that everyone participated, and it gave quieter participants an opportunity to speak without having to fight for the floor. People need multiple options for offering input so that they can feel comfortable participating.

As stakeholder groups help to develop new initiatives, it's important to remember that they do not have to invent projects that change the world all at once. Small-scale projects can also challenge established, conventional, and institutionalized practices. These experimental demonstration projects take ideas from the drawing board into the real world, where they can serve as instructive examples of what could someday occur on a larger scale. They can elevate the "state of the art" in social services by modifying and updating old practices, and move ideas that are "gems in the rough" into more polished and advanced approaches. When the results are persuasive and compelling, others will more easily adopt and disseminate them. The Cash & Counseling Demonstration programs in Arkansas, Florida, and New Jersey are good examples of this type of innovation.

4. **Individual Roles and Group Dynamics**

Finally, our colloquium participants noted that change leaders must attend to individual roles and group dynamics if stakeholder networks are to succeed over the long term. Without such attention, some groups lose focus; other groups develop good ideas, but have trouble putting them into action because it isn't clear who is

supposed to do what. Some key strategies for keeping groups on track include:

- defining what type of coordination is optimal

- creating clear priorities and strategies

- eliminating confusion about who is doing what by asking people to clarify various roles in the change process

- directing potential supporters to appropriate entry points and entry roles for newcomers to the work of change.

These steps can help eliminate questions about who has or will take central responsibility for shaping the change process and who will assist with various stages of implementing the changes.

By following the steps modeled by our colloquium participants and other effective programs, change leaders have a good chance of enabling consumers, families, and other stakeholders to develop worthwhile initiatives.

C. Equalization of Knowledge

If leaders make a genuine effort to involve the diverse range of stakeholders we've described above, they must recognize that the people in these networks will bring disparate levels of knowledge and understanding of issues to the table.

This can be seen as a barrier or an opportunity. If it is seen as a barrier, it may be used as a reason to exclude certain people or groups from participating. Our participants, however, believe that this situation offers an opportunity for conveners to practice articulating the questions and issues more clearly.

1. Value of Equalizing Knowledge

Why is such practice valuable? Readiness for change, in both the cultural and political sense, does not occur until enough people in enough constituencies achieve consensus to prevail over the dissenters. The process of achieving consensus and swaying dissenter opinions takes both time and serious educational and persuasive effort. Unanimous agreement is not required, but most colloquium participants agreed that there must be sufficient consensus among key constituencies to create a mandate for action. Gaining this mandate is easier when much work has already been done to raise consciousness and issues, dissect and evaluate the arguments and proposals, and engage large numbers of people in some kind of thinking, discussion, and deliberative process.

Just as importantly, equalizing knowledge is not a one-way conduit from conveners to participants. Relationships among network

members are strengthened when participants are allowed to name their issues, discuss them extensively, and eventually describe remedies that seem to offer the most hope for progress. While the conveners share their knowledge of the issues with the constituents, the constituents educate the conveners about their own wishes and experiences. This mutual education process can take a great deal of time, but it may be the only way that diverse constituencies can get to a point where they understand the nuances of the issues well enough to substantively pursue changes to the system.

State agencies have an important role to play as well. Knowledge is power, so if states are serious about empowering consumers and families to have more control over their lives and a higher quality of life – and if states are serious about empowering communities to alter their infrastructures to be more inclusive – then they, too, must work to equalize knowledge. Because states know more about the policies, programs, and services within their vast range of control, they can be valuable educators for stakeholder networks.

2. **Strategies for Equalizing Knowledge**

Knowledge can be imparted through a number of means, including trainings, meetings, social occasions, conferences, special project work, websites, and printed material. The key is meaningful and on-going communication, in whatever form is best for a given issue.

Strategy #1: Prepare people to better understand key issues and to apply critical thinking

To understand abstract, multi-sided issues, people need more than a "broad stroke" picture of those issues – they need to know and understand the details. When people are "in the dark" about the details of issues, they are less likely to be able to act; when they do act, they are less likely to act with finesse and discipline. When they are well informed, they can better participate in public issues because they know what is at stake. Detailed information can be helpful for advocates, politicians, activists, consumers, families, and many others. In fact, in special education circles, family advocates are regularly given instructive briefings on special education laws and regulations to make their advocacy more effective.

Once people understand and master background facts, they can then analyze the information and apply it. The analysis is often what leads people to favor or to oppose change. For instance, although institutional care is currently among the dominant support systems for the elderly and for people with disabilities, many people realize that not all these individuals need institutionalization. What they don't realize is that there are viable alternatives that can

substitute other forms of support for institutional care. If a substitute support system were made available, people who now rely on institutional models of care might instead choose an effective community-based model of support. Only after this sort of analysis do people question why institutional care should be given a monopoly or preferential bias among the options for support. Institutional bias is well known to people who understand today's system, but it is clearly not well understood by many others. Education can change this.

Such briefings can go a long way to demystify systems, claims, and slogans that have heretofore been baffling or impenetrable. In the process, these briefings also clear up misconceptions, offer people a better sense of their options, and help people see where change might be possible. Educational investments empower members of the public to play a role in the personal and public affairs that shape their lives.

To help people understand issues better and to apply critical thinking to solutions --

- Plan and budget up front for the resources required for educational activities.

- Survey stakeholders to find out what their misconceptions are.

- Develop and offer materials, briefings, trainings, forums, and other activities that share detailed information about systems change issues.

Strategy #2: Create opportunities for values-based engagement and training

Much of what we call "change" involves shifts in beliefs, attitudes, and even deeper values – because these are usually very significant in motivating people to take collective action. If these value shifts are to occur, we must provide opportunities for people to try out different perspectives and evaluate their relevance and value.

Sometimes this "trying out" of perspectives and values can come about informally simply by creating the networking and dialogue opportunities in which people can share and discuss such issues. In a more formal context, forums and training sessions can have considerable values content; these can be designed to sharpen people's appreciation of differing values and the consequences that may flow from their adoption. For example, adoption of a value that addresses safety by simply stipulating that safety of service recipients is paramount could fail to allow for levels of informed risk-taking on the part of service recipients. Training on the many

aspects of risk management could have great value for stakeholders as they establish a common value around safety and risk.

Strategy #3: Expose people to excellence

Many people have correctly noted that "vision building" is a key component of the change process. Such vision only takes hold in people when they are exposed to examples that help them revise their sense of what is both good and desirable. One way to achieve this is by bringing stakeholders into contact with other people, examples, and activities that exemplify excellence and help others to expand their vision.

For example, the Alliance for Full Participation Conference represents a single event to strengthen vision and to motivate people to change. Another example is the annual Ellensburg Conference in Washington State, which is an ongoing investment that for well over a decade has exposed Washington residents and others to national best practices in the field.[3] In local instances, such as the Model Communities initiative sponsored by the Real Choice Systems Change project in New Hampshire, leaders have created deliberate training events and conferences that are intended both to inspire and build vision.

The essential steps in exposing people to excellence are the same, although target groups will vary according to location and interests. The steps are as follows:

- Identify promising examples of excellence (best practices and evidence based practices).

- Create learning opportunities in which people are exposed to examples of excellence to stimulate their thinking about how programs could be improved.

- Reinforce vision building by exposing more and more groups to create a cumulative impact.

D. Systems Changes Must Be Sustainable

Colloquium participants noted that not all Real Choice Systems Change projects were initiated with a plan for sustainability, and to them that was a contradiction

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[3] For more information about these two projects, see the Alliance for Full Participation website at http://www.allianceforfullparticipation.org/public and the Ellensburg Conference website at http://www.communityinclusion.org.

in terms. If a state system or subsystem authentically changes, they reasoned, the change should continue beyond the term of a federal grant.

1. **Barriers to Sustainability**

   Colloquium participants agreed, however, that there are often serious barriers to sustainability, including --

   - lack of a clear vision about what should be sustained

   - lack of adequate documentation that a service works effectively and should be sustained

   - lack of a way (including funding) to sustain the change

2. **Strategies for Sustaining Systems Change**

   States that have instituted enduring systems changes seem to have several things in common. Their strategies are described below.

   Strategy #1: Allow leaders to work across conventional boundaries

   The first ingredient in sustainability takes us back to the leadership (at all levels) component earlier put forth as a key to systems change itself. When diverse people who cross over multiple boundaries "own" the vision, they invest time, energy, and personal passion that will carry the vision forward beyond the limits of a finite grant. Of course, this requires a change in culture within the state system that allows leaders to think and act outside the confines of their own institutions. Operating in "silos" – such as single-project, single-agency, or single-disability modes – can be a serious barrier to systems change in general and the capacity to sustain that change.

   Strategy #2: Affirm, recognize, and celebrate valuable actions, initiatives, and leadership

   It can be a thankless and taxing exercise to labor alone and unappreciated on changing systems and communities for the better. Such work can be discouraging and even punishing, and some people might easily give up on the exercise. Fortunately, much of this burden can be lifted for people if you show respect, appreciation and validation of their efforts. Such reinforcement can help people stick to difficult tasks and find renewed resolve to persevere. It is helpful when those concerned about change parcel out some energies and time to pay homage to hardworking persons and groups. Simply being thanked can go a long way to helping people endure.

There are other reasons to give such trailblazers and committed actors the recognition they deserve. Their work can be very instructive for others who are similarly engaged because they have accumulated insights and lessons that might be lost if they were not identified as being important. Additionally, such recognition validates the actions of others. Their role modeling represents more than a singular investment: it contributes momentum to others throughout the broader systems change movement.

Strategy #3: Use the media to build your profile and develop a relationship with the public

In modern times, achieving any major shift in public perception always involves a consistent, clear, and credible message put forward through the media. More importantly, however, the message must be relevant to the listener. The public does not yet widely know, for example, that there can be options other than nursing home care when a family member reaches a certain level of infirmity. Thus, people may not ask for what they don't know is possible. A relationship built over time with the newspapers and television and radio stations can reap huge rewards in raising the consciousness of the public to the next level, giving immeasurable support to an agency seeking passage of new laws or new funding.

We must invest in helping change groups shape, communicate, and get out their message more successfully. We must not assume that everyone is equally equipped in this regard or that the media chosen and the content to be shared are going to be similar in different places or situations. This process of "message making" may need to be repeated with considerable regularity so more people can benefit from your assistance and support.

Strategy #4: Change regulations to provide a framework for future action

Regulations provide an institutional bridge between past and future leaders. New staff, consultants, and advisors gain immediate exposure to what the requirements are under the current paradigm of services. They in turn will continue to refine and change regulations for the next generation of leaders. Sometimes, policy makers change regulations to force issues that are stymied within a state. Other times, the revisions in policy will be an outgrowth of changes in processes and procedures that occur naturally over time. It can, and often does, happen either way.

Strategy #5: Collect data that will prove the effectiveness of system changes

Change advocates need concrete evidence that new service approaches enhance lives and are more cost-effective (or at least cost-neutral). Without such data, it may be extremely difficult to persuade legislatures and federal funding agencies to change laws and policies or to better fund certain services. In order to collect the right data, leaders must establish a data collection process at the beginning of a project. One New England group that was awarded a Nursing Facility Transition systems change grant so effectively collected and reported information from moving people out of nursing homes that they easily won funding from their state legislature to continue the service beyond their grant period. If they had not implemented an effectual data collection method early on, they would have had inadequate proof with which to make a case.

Strategy #6: Find additional sources of funding for change projects

Finally, and clearly, there is the need for continued funding for those services that prove to be effective and satisfactory for service recipients. The previous five items build the foundation that makes future funding much more possible. With these in place, the systems change leader will be able to articulate the larger vision and the workable outcomes from that vision to win needed financing with a large base of support.

IV. Conclusion

This paper illustrates that potentially effective catalysts are available to people trying to bring about needed changes in their community or state. These catalysts can be very beneficial if used with discretion and wise application. However, they are not a panacea. They do not guarantee success, but they sometimes produce powerful results. We hope that the principles and examples discussed in this paper will help systems change leaders across the country to recognize some catalysts that might suit their particular change challenges.

Obviously there are more catalysts for change than those presented as examples here. Our understanding of the key components of meaningful and sustainable systems change continues to grow as we collectively gain experience through the Real Choice Systems Change Grant initiatives. We expect this paper and others in the series to facilitate further discussion and discovery among all stakeholders who work to transform the social support systems serving people with disabilities of all ages.

V. Reading List

This list, which is common to all three systems change papers produced by ILRU, contains the two publications which were referenced in the second and third papers, but primarily is offered as a reading list for those wishing to read more about improving service systems to make them more responsive to people with disabilities, the users of those systems. The list draws from many fields, not just human services. Not all materials are still in print, but the reader should be able to locate all these references in most large libraries.

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