MODEL COMMUNITIES
The national discussion continues
Hosted by the Community Living Exchange Collaborative at ILRU
Baltimore: Model communities discussion continues

On March 1, 2004, about 30 people gathered in Baltimore, Maryland, to continue a discussion that began in that city one year earlier. That first conversation occurred at a national conference—*Living and Working in the Community 2003*—sponsored by the Centers for Medicare and Medicaid Services (CMS). Conferees from a few states discovered that they share a mutual interest. Specifically, they are focusing on their respective *Real Choice Systems Change Initiative* grants on innovative ways to create “model communities” in which all citizens can participate equally.

**Shared Interests**

The group had an impromptu meeting with Jay Klein, director of the Center for Housing and New Community Economics (CHANCE*). They asked whether it was possible to have a separate meeting focused exclusively on strategies for building model inclusive communities. Klein’s organization is a managing partner of the Community Living Exchange Collaborative at ILRU (the Exchange), an information clearinghouse and direct technical assistance provider to *Systems Change Grants for Community Living* grantees.

To accommodate the group’s request, the Exchange arranged a two-day model communities discussion in Denver, Colorado, in July 2003. Klein facilitated the meeting of *Systems Change* grantees from six states, a CMS official and several Exchange partners. (*Note: A full report of that meeting is available online at www.hcbs.org —search for “model communities.”*)

The Denver discussion was so productive that participants asked to meet on a regular basis—at least a couple of times a year. Because many of them planned to attend CMS’ March 2004 national conference in Baltimore, the Exchange scheduled the next discussion as a preconference session.

In the months between meetings, the Exchange partners worked with Denver participants to develop a list of topics to discuss in Baltimore. This report covers the major themes and conversations of the day-long gathering.

*CHANCE is part of the Institute on Disability at the University of New Hampshire.
The Systems Change Initiative—A Review

The Systems Change Initiative—which is part of the current Administration's New Freedom Initiative—was launched in federal Fiscal Year 2001. According to CMS, the overall goal of the initiative is: “To foster systemic changes to enable children and adults of any age who have a disability or long term illness to:

- Live in the most integrated community setting appropriate to their individual support requirements and their preferences;
- Exercise meaningful choices about their living environments, the providers of services they receive, the types of supports they use and the manner by which services are provided; and
- Obtain quality services in a manner as consistent as possible with their community living preferences and priorities.”

To date, CMS has issued approximately $158 million to grantees in all 50 states and two U.S. territories for work in the following areas:

- **Nursing Facility Transition**: To help states transition eligible individuals from nursing facilities to the community.
- **Community-Integrated Personal Assistance Services and Supports**: To improve personal assistance services that are consumer-directed and/or offer maximum individual control.
- **Real Choice Systems Change**: For effective and enduring improvements in community long-term support systems to enable people with disabilities or long-term illnesses to live and participate in their communities.
- **Quality Assurance and Quality Improvement in Home and Community-Based Services**: To assure the health and welfare of people participating in home and community-based waiver programs.
- **“Money Follows the Person” Initiative**: To permit funding to “follow the person” to the most appropriate and preferred community setting.
- **Independence Plus Initiative**: To give people with disabilities more control over such long-term care services as personal assistance services.
- **Family-to-Family Health Care Information and Education Centers**: To create a national network of information centers to support families.
- **Community-Based Treatment Alternatives for Children**: To help states provide community-based mental health services through Medicaid for children with serious emotional disturbances.
- **Technical Assistance for Consumer Task Forces**: To provide expanded support to Real Choice advisory panels.
- **Respite Care for Adults**: To explore respite for caregivers of adults with disabilities through Medicaid or other funding streams.
Of the wide variety of topics discussed during the 2003 Denver meeting, four major themes emerged as issues participants wanted to talk more about in Baltimore:

- Sustaining enduring systems change within communities.
- Increasing community participation of people with disabilities in communities.
- Research within communities.
- Coordinating several different systems change initiatives in communities.

At Klein’s suggestion, participants formed discussion groups around these topics to focus on opportunities and things that are going well with their respective efforts, obstacles and things that could be going better, and recommendations for removing obstacles.

**Group Report: Sustaining enduring systems change within communities**

**Opportunities**

- The number and variety of states exploring the concept of model communities is akin to an experiment. The diversity in factors such as the size and demographics of the various communities offers a chance to compare notes on how different tactics fare in different circumstances. What works in one place might not work in another, but common themes begin to surface.

“We have a deep commitment to change and looking at things anew. We are thinking about what makes a community in new and different ways. This is exciting—and challenging—given all the other changes that are taking place in society today. There are many things to consider and many opportunities for positive change.”

~ Richard Petty, ILRU Program Director
A State’s Choice

States have a great deal of leeway in deciding how best to use Real Choice Systems Change grant dollars. CMS has provided a general framework, but it is left up to each state agency receiving the funding—to work closely with a mandatory consumer task force—to decide the best way to address the state’s unique needs. There’s no specific charge to “develop a model community” in the grant guidelines. It just happens to be the approach that a few states—many of which have participated in the discussions thus far—determined best for their Real Choice projects. In general, it’s fair to say that these states consider “the community” an important partner in changing systems to assure that people with disabilities of all ages can be independent and productive—wherever and however they choose to live their lives.

There seems to be good leadership fueling and sustaining the work.

There are many other groups in the community that have interests similar to ours. Some of them have been involved in community development work longer than we have. We can learn from them and should seek them out.

Barriers

- Attitudes. The “doors” may be open, but people with disabilities don’t really have equal access to the community.
- Grantees lack knowledge about what’s available in the community.
- Our culture seems to be moving in the direction of more isolation and less a sense of community.

Recommendations

- Infiltrate existing groups in the community. Make sure people with disabilities are represented in these groups. Look for ways to embed the disability/community inclusion perspective in a variety of community discussions and activities.
- Assure that people with disabilities have numerous and genuine opportunities to be leaders in the community.
- Look at rebalancing resources so that people with disabilities moving from institutions to the community have sufficient control over their circumstances to participate in a meaningful way.
- Work with the federal government to explore ideas for generating additional funds from the community at large—not just from the service system.

Group Report: Increasing community participation

Opportunities

- There are a number of innovative programs/projects already underway that could support people with disabilities and others who want to be involved in community activities but may not have sufficient financial resources. Time Dollar USA, an organization that promotes the concept of “banking” volunteer service (one hour service = one time dollar), was mentioned as an example of this concept. (Note: More information about Time Dollar USA is available online at www.timedollar.org).
- Community development block grants (CDBG) offer people with disabilities opportunities to be involved in their communities. For instance, in Morgantown, West Virginia, people with disabilities were asked to participate in CDBG planning. This provided opportunities to infuse disability issues into general
discussions about the community. The same could happen with such things as housing initiatives and similar community development activities.

- Rather than spending money to create special programs for people with disabilities, there are opportunities to use that money to support people with disabilities in programs that already exist.
- Communities should focus money and other resources on supporting individuals—not creating segregated programs and services.

**Obstacles**

- “Special” programs designed just for people with disabilities keep them apart from the rest of the community.
- Program specialization is another barrier—there needs to be more comprehensive programs working together to meet the needs of a diverse array of people.

**Group Report: Research within communities**

**Challenges**

- With multiple grants and the nature of the *Systems Change Initiative*, it can be difficult to know if an action has an effect.
- With the wide variety of issues the projects are dealing with, there’s a need to collect different kinds of data (i.e., quantitative statistics as well as stories reflecting how people are experiencing the systems change).
- It’s important to quickly deliver information gleaned from research to a wide variety of audiences for decision making. This can be a special challenge for states doing participatory research.
- There is a need for information and research to be driven by citizen needs.

**Barriers**

- Information collected by different programs or states is not comparable because they are not working with the same definitions, research questions or methods.
- There’s a feeling that the wrong kind of data is collected and that too often it doesn’t result in useful information. A lot of the data is based on the medical model or is program driven, as opposed to community driven.
- It is not always easy to know about existing data that may be useful.
- Confidentiality issues and “turfism” hinder data collection.

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When people with disabilities are included in community life, their issues become community issues. That brings problem solving to a whole new, inclusive level. The states participating in these ongoing discussions are making the connection. They are leading the nation to a new way of defining “community.”

~Jay Klein, Moderator
Recommendations

- Projects can get around the difficulty of getting hard data by using qualitative and quantitative research methods.
- CMS could help by providing “data minders” to set standards for data collection and by pointing to research that may already exist.
- All research-related information should be accessible to people with disabilities.

Group Report: Coordinate multiple system change initiatives

Opportunities

- The number and variety of grants some states have secured is a catalyst for bringing about change at multiple levels.
- Multiple initiatives result in more agencies and organizations being involved, which is good. Working together, they are often able to solve problems such as budget constraints.

Barriers

- There are people on waiting lists as well as people who don’t get services at all because of disability-specific funding mechanisms.
- There is some degree of fragmentation among the Systems Change Initiative grants—probably due to the diversity of grantees and their respective missions, histories and structures.

Recommendations

- The grants should be used to inform state legislators and policymakers about how to remove obstacles such as strict funding and eligibility criteria.
- States with multiple grants should consider establishing a collaborative entity that has some oversight of the various grants to avoid confusion and frustration.
- The different grant projects should share information with each other to contribute to the sustainability of the systems change.
Small groups raise recurring themes

Although the initial topics were different, the small group discussions surfaced a few common themes:

- Programmatic “silos” (distinct programs that have little to no interaction with other programs) and fragmentation get in the way of building community. While this is usually thought of as a barrier, some states are approaching it as an opportunity to look at the big picture and bring disparate parts together. This collaboration can bring about sustainable change beyond the limited life of the Real Choice grants.

- We need to look at what other organizations and people are doing to make their communities tick. There are efforts beyond the disability world from which we could learn.

- Infiltrating community development initiatives could advance the cause of people with disabilities in the community. For instance, getting involved with a group planning to create a new community center would be an opportunity to introduce disability interests to a general issue.

- People with disabilities much have access to information if they are to have choice and control in their lives. We must consider how to best use research and information to answer their questions.

“...when we were closing the institution, I thought it was a bunch of hogwash. I’ve become such a true believer, it’s like I got religion. There’s a role that’s very different than the role we had in the past.”
Instead of continuing to work in small groups, participants opted to flesh out those common themes in the large group. The first topic they tackled was leadership and the importance of promoting people with disabilities into leadership roles in the community. Representatives from several states shared their own efforts to prepare and promote people into community leadership roles. For example:

- In West Virginia, the mental health consumer organization already had a large training program and was willing to partner with the Real Choice project to provide training on a variety of topics.
- The Arkansas Real Choice grant sponsors a leadership academy and requires participants to implement leadership activities in their own communities.
- In Florida, an intensive, four-day advocacy training targets grassroots consumers who are committed to creating change in their communities.
- The Real Choice project in New Hampshire is working with *Democracy Works*, a Connecticut-based organization devoted to strengthening democratic processes and citizen participation in communities. One focus of the collaboration is to incorporate information about disabilities and aging in community surveys and profiles.
- In some states, existing *Partners in Policymaking* programs provide ready-made leadership and skill building training opportunities for the Real Choice projects.
- Some states are exploring whether there are opportunities to build relationships with local human rights commissions (required in cities that receive community development block grant funds), Workforce Investment Act councils, state independent living councils, Olmstead advisory teams and community citizen advisory committees.

**Overcoming fear**

When a discussion participant suggested that people must “find their own voices” before they can begin to think about being community leaders, the conversation took a turn. Participants generally agreed that people with disabilities who are entering the community for the first time—people leaving institutions, for instance—must learn to articulate their own desires and needs.

That prompted more than one participant to bring up the “f” word—“fear.” People dependent on institutions and/or the health and human services system, they said, are wary of expressing themselves for fear of retaliation from providers. While a few possible solutions were tossed around, introduction of the “fear factor” seemed to have a chilling effect on the discussion’s energy.
To get things moving again, facilitator Dave Hasbury offered a personal observation about what it means to really be part of a community. “Being in the community is not the same as being part of the community,” he said. “If you want to be part of the community, you’ve got to bring something to it.”

When we approach community from the “rights” angle (e.g., people have the right to live in the community, the right to services) the problem belongs to people with disabilities and those who advocate for them. It’s about how to enforce rights—how people can access what they believe they are entitled to. That’s not particularly a community problem or issue.

The fact that there are people who are disenfranchised and unable to contribute what they have to offer is an issue for the community. And, Hasbury suggested, it is an opportunity for Real Choice projects to infiltrate existing community systems to show what people with disabilities have to offer and how the community can be more inclusive. Hasbury asked, “How does the way we support people shift from what we’ve done in the past to make it possible for them not to be isolated?”

**Finding community allies**

Hasbury’s comments seemed to strike a chord with participants, and the discussion turned to strategies to learn about and tap into existing community development efforts.

As a starting point for finding prospective community development allies, three questions were suggested:

- Who are we?
- What do we care about?
- Who else cares about what we care about?

The answers to those questions will likely lead Real Choice projects to community organizations that share similar values and goals—organizations that will recognize the value of including people with disabilities in their visions of community. Other ideas for existing citizen-driven groups included local emergency preparedness committees, environmental groups and healthy community organizations.

Several participants suggested that there are a lot of opportunities to infiltrate the community through boards, committees and organizations that are unrelated to the disability and human services world. Garden clubs, civic groups and recreational organizations—to name just a few—are all part of the community fabric, and present opportunities for people with disabilities to be involved.

Participants agreed the Internet is a great place to find out about these opportunities. Other prospects include community bulletin boards hosted by the news media, the Chamber of Commerce, community centers and other resources for local information.
Silos: Distinct programs that have little to no interaction with other programs—even when they serve overlapping populations.

“Over the years, we taught the community that we needed special programs for people with disabilities. Now we’re trying to undo that.”

“A need for useful information”

A number of participants reported they are struggling to find examples of good qualitative and/or quantitative information that documents community change. In search of information they can use to promote change in other places, researchers in the group noted that the little information they do come across is often sketchy or inaccurate.

As a result, some states are trying to get creative in their search for useful information. Suggestions included political organizations (e.g., League of Women Voters, public policy watch groups), “healthy communities” organizations, environmental groups and groups that have formed to resolve specific community problems such as health and safety issues). In addition to yielding information, alliances with groups such as these provide opportunities to promote inclusion of information about people with disabilities in their information gathering and distribution. In one state, the Systems Change project is exploring working with a local university to establish a “science shop” through which researchers and students set up research in the community.

“Collaboration to break down “silos””

The states represented in Baltimore are addressing the challenge of building model communities in a lot of different ways—and with varying degrees of success. When describing what’s happening in their respective states, participants use one word frequently—“collaboration.” Whether it’s the accomplishment they are most proud of, the story of an unexpected alliance or still an elusive goal, almost every model community project seems to list collaboration with others as a top priority.

Most often, collaboration is mentioned as a solution to one of the projects’ most persistent headaches—programmatic, financial and social “silos” that tend to categorize and isolate some people in the community.

Some of the silos have existed for so long that they’re community institutions—and seemingly impossible to penetrate. Some of them were even constructed by people with disabilities, when it seemed like a good idea to build separate (some said “special”) systems.

Whatever their origin, many Real Choice projects share a common belief that collaboration is critical to breaking down—or at least connecting—silos. A few states gathered in Baltimore shared examples of their collaborative efforts thus far:

- In Connecticut, the good collaboration among statewide steering committee members is spreading to the three towns participating in model community projects. In each town, groups comprised of private citizens and municipal leaders are working together to plan activities and determine how to best spend their limited funds. They’ve generated enough enthusiasm that the towns are coming up with their own money to supplement project funds. Now the
three towns are starting to collaborate with one another, and they are considering ways to share what they are learning with communities not funded by the project.

The steering committee also hosted a two-day event to bring together experienced community integration advocates with people with disabilities, family members and others who were less familiar with the prospects of inclusion, choice and control. A video produced during the meeting illustrates strong collaboration and sharing at the meeting.

- **In Idaho**, a collaborative effort has grown up around implementing the 214 recommendations developed several years ago by the state’s Olmstead Committee. The Real Choice project is working with the committee to secure grant funding to implement the recommendations and provide some overall structure to the effort. There have been some stops and starts along the way and the groups have found some “mid-course corrections” necessary. Nonetheless, they remain optimistic and have chosen not to be discouraged by setback.

- “Out of sheer desperation,” the Real Choice project in **Arkansas** “broke into” the housing silo—a move that is resulting in new collaboration. “Instead of making those silos go away, sometimes you just have to break into them.”

- The **New Hampshire** project’s cross-disability advisory council has evolved to a point that it may start to advise the state’s long-term care system. Project representatives say territorial issues don’t arise in council meetings because of the cross-disability focus. A growing relationship with elder organizations is a welcome by-product of the collaborative effort.

**Until we meet again**

At day’s end, facilitators asked participants for ways the Exchange could better support their efforts. Suggestions from the group included:

- Arrange a meeting or training session with some of the experts in community development and citizen driven initiatives who are frequently mentioned in these model community discussions (John McKnight, for example).

- Assist with the issues and concerns raised by researchers including determining what information is useful in meeting reporting requirements and telling what’s really happening in communities.

- Continue a dialogue with CMS and encourage more long-term funding as opposed to small pilot grants.

**What are you taking home from this meeting?**

“I’m interested in a community integrated planning institute that in an ongoing way creates learning activities for communities so they can learn that what we taught them 20 years ago was wrong (in terms of people with disabilities being special).”

~Connecticut participant

“We will continue to try to put money into small community advancements. We’ve found that communities are making entire cakes out of the ‘crumbs’ of funding we’re able to give them.”

~West Virginia participant

“One of our learning issues is to stay focused on the community and quality of life as opposed to specific issues such as silos of information, transportation and funding.”

~Florida participant

“I will work on keeping the balance shifted to positive things. It is easy to get caught up in the day-to-day problems so that it’s hard to focus on thing that might make real change. We will also learn more about community development.”

~New Hampshire participant
Meeting Support Team

Moderator:
Jay Klein  
Director, Center for Housing and New Community Economics (CHANCE)  
Institute on Disability  
University of New Hampshire

Community Living Exchange Collaborative at ILRU
Representatives:
Richard Petty  
Program Director  
ILRU  
Houston, TX

Lee Bezanson  
National Project Coordinator  
Home & Community-Based Services Resource Network  
Laconia, NH

Darrell Jones  
Program Training Coordinator  
ILRU  
Houston, TX

Graphics Facilitator:
Dave Hasbury  
Dave Hasbury & Associates  
Toronto, ON

Proceedings Report:
Kaye Beneke  
Freelance Business Writer  
Austin, TX

For More Information
The Community Living Exchange Collaborative at ILRU  
2323 S. Shepherd, #1000  
Houston, TX 77019  
713-520-0232 (v/tty)  
E-mail: sfinney@ilru.org  
Website: www.hcbs.org

Clearinghouse for the Community Living Resource Network  
www.hcbs.org
This is the official website for The Community Living Exchange Collaborative and includes a broad range of topics and tools.

Centers for Medicare and Medicaid Services (CMS)  
www.cms.hhs.gov/newfreedom
For comprehensive information about the New Freedom and Real Choice Systems Change initiatives.