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**Model Communities Discussion
July 16-17, 2003
Adam's Mark Hotel
Denver, Colorado**

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**See Appendix A for a complete participant list.*

About The Exchange

In September 2001, the Centers for Medicare and Medicaid Services (CMS) awarded two grants for the implementation of the National Technical Assistance Exchange for Community Living, one to Independent Living Research Utilization (ILRU), a program of The Institute for Rehabilitation and Research, the other to the Center for State Health Policy (CSHP) at Rutgers University. The resulting project, Community Living Exchange Collaborative, provides a program of technical assistance for grantees implementing Systems Change Grants for Community Living under the CMS National Community Living Initiative. The views expressed in this publication do not necessarily represent the position of CMS.

The Community Living Exchange Collaborative at ILRU directs its training and technical support toward systemic changes to enable children and adults of any age who have a disability or long-term illness to be as fully integrated into the community as possible, to exercise meaningful choices about any and all aspects of their lives, and to obtain quality services consistent with their preferences.

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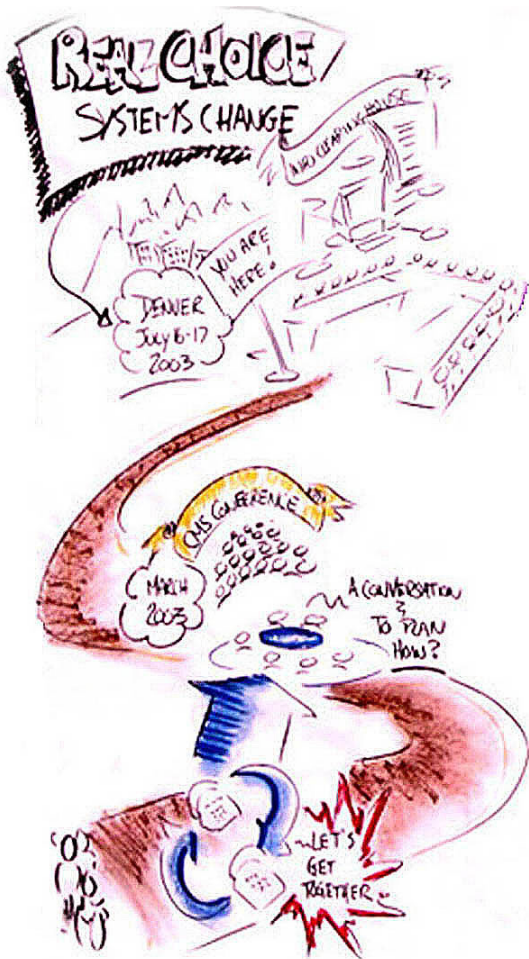
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Overview: Model Communities Discussion



About the Discussion

On July 16 and 17, 2003, representatives from a diverse assortment of states came together in Denver, Colorado, to share information, learn from one another and explore ways to help each other achieve an important, mutual goal: **to build better and stronger communities in which people with disabilities are readily and routinely part of the fabric of everyday life.**

The people at the meeting hailed from six states: Colorado, Connecticut, Florida, Idaho, New Hampshire and Texas. There are some notable differences in everything from population to geography to political environment among the states represented, but they do have a number of things in common:

- ▶ Over the past two years, each received significant funding—in the form of a *Real Choice Systems Change* grant under the Systems Change Grants for Community Living initiative of the Centers for Medicare and Medicaid Services (CMS).
- ▶ Each state has made a specific choice to use at least part of its *Real Choice* grant funds to incorporate the community at large into the vision of the long-term care services and supports “system” they are working to change.
- ▶ Each is committed to creating “enduring” systems change—not just a quick, temporary fix—in keeping with the vision and intent of the *Systems Change Grants for Community Living*.

A Network in the Making

The Denver meeting grew out of a few seeds of conversation started several months earlier at a CMS-sponsored national conference, *Living and Working in the Community 2003*. Special interest networks often have their roots in large gatherings such as this—people with similar interests and concerns “find” each other and begin to share experiences and ideas.

Discussion Overview

And so it was at the CMS conference in Baltimore, Maryland. A few *Systems Change* grantees who are working to create “model communities” in their own states started an informal dialogue—one they weren’t ready to conclude when the conference ended. Fortunately, they didn’t have to.

The Community Living Exchange Collaborative at ILRU (The Exchange) serves as an information clearinghouse and direct technical assistance provider to *Systems Change Grants for Community Living* grantees.

Jay Klein, director of the Center for Housing and New Community Economics (CHANCE)—one of The Exchange’s managing partners—sought input from the state grantees who had expressed interest in gathering to share ideas and strategies for assisting people with disabilities to be included in communities. Using their suggestions as a framework, The Exchange coordinated the logistics and developed an agenda to advance the discussion that started in Baltimore.

A Quick Review

To better understand how the attendees fit into the *Systems Change* initiative, a quick review may help. 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.”

In Fiscal Years 2001 and 2002, CMS issued \$125 million to grantees throughout the nation for work in one of three major 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:** To help design and implement effective and enduring improvements in community long term support systems to enable children and adults of any age who have a disability or long-term illness to live and participate in their communities.

The six states that participated in the **Model Communities** meeting in Denver are among the 48 states, District of Columbia and two U.S. Territories that have received *Systems Change* grants. Some also get funding from one or more of the other community living grant projects—or they are working closely with local and/or state organizations and agencies that do.

A State's Choice

It's important to note that states have a great deal of leeway in deciding how best to use *Systems Change* grant dollars. CMS has provided a general framework, but it is left up to each state agency receiving the funding—working closely with a mandatory consumer task force—to decide the best approaches to address their 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—most of which participated in the Denver meeting—determined best for their *Real Choice* projects. Their individual reasons will become more evident in the state reports later in this document. In general, it's fair to say that these states consider "the community" to be an integral part of the systems they are trying to change to assure that people with disabilities of all ages can be independent and productive—wherever and however they choose to live their lives.

High Points

- ▶ **CMS Participation**—As director of CMS' Division for Community Systems Improvements Disabled and Elderly Health Programs Group, Steven Lutzky, Ph.D., has a different vantage point of the *Systems Change* initiatives than others at the discussion table. The fact that Dr. Lutzky was at the table for the first full day of the meeting was—as more than one participant put it—"really cool." He punctuated the day's conversation with a number of ideas and answers that many in the group found helpful and thought-provoking. Some of his comments are included as the *CMS Feedback* on page 19 of this report.
- ▶ **Graphic Facilitation**—The announcement that Dave Hasbury would be facilitating by "drawing the meeting" generated a few puzzled looks among participants. Mr. Hasbury combines graphic arts with excellent listening and facilitation skills to create a real-time picture of the discussion as it's unfolding. The puzzled looks turned to pleased amazement as it became apparent what a good job the artist/facilitator did in capturing the essence of the discussion. The illustrations featured in this report are Hasbury's drawings from Denver.

Discussion Overview

Back to Denver

The two-day meeting in Denver was billed as a “discussion” and was guided by a flexible agenda. Beyond the participants themselves, there were no guest speakers or fancy presentations. Anyone who wanted to share documents or presentation materials with the group submitted them in advance for inclusion on a CD in the meeting packets.

Before the meeting, the planning group had suggested five possible discussion areas, based on interests expressed at the Baltimore meeting:

- ▶ model and inclusive communities;
- ▶ access to community services;
- ▶ money following the individual;
- ▶ community mapping; and
- ▶ frameworks for evaluation design.

At the beginning of the meeting, the discussion group agreed to keep things flexible and to let the discussion drive the two-day agenda.

To start things rolling and get a feel for “who’s doing what,” participants spent the better part of the first day of the meeting sharing information about the *Systems Change* projects, including the *Real Choice* projects, in their respective states. From there, it became easier to identify mutual goals, challenges, problems, pitfalls and other issues associated with trying to build model inclusive communities.

Jay Klein, moderator, and Dave Hasbury, graphic facilitator, supported the discussion by keeping track of key points, new ideas, shared concerns and recurring themes—and finding ways to incorporate them into the next level of the group’s discussion. By the end of the meeting, several concrete ideas and activities had risen to the surface and the group was planning next steps—individually and collectively.

About This Report

This report documents the high points of a wide-ranging, two-day long conversation between approximately 30 people. In an effort to organize information without losing the give and take of the discussion (one of the best parts of the meeting), the publication is built around the four main discussion topics/activities:

- ▶ state overviews;
- ▶ CMS feedback;
- ▶ shared interests; and
- ▶ next steps.

Texas: Testing “System Navigators”

Changes & Challenges

The Texas delegation noted that the Texas Legislature’s 2003 session resulted in massive changes to the health and human services system. HHSC is overseeing the consolidation of 11 agencies into five, as well as merging their separate administrative functions into HHSC. In addition, HHSC now has responsibility for determining eligibility for all health and human services, as well as policy-making responsibility for the Temporary Assistance for Needy Families program.

As one representative put it, “Our state is undergoing critical changes that make it more important than ever to have an effective initiative like the *Real Choice* grant to help consumers get services.”

Two communities were selected. A collaborative in Sherman, located in the Texoma region of north Texas, is demonstrating a “single point of access” model. In Central Texas, two regions (Waco and Belton) have joined forces to test a “multiple points of access” model.

Sherman: Single Point of Access

In the nearly 30 years she has worked in the human services arena, Janis Thompson says she has seen too many planning initiatives that ended up as documents collecting dust on a bookshelf. As she and other human services professionals started working on a local access plan for the Sherman/Texoma region, they were determined that this time it would be different. Says Thompson, director of the Area Agency on Aging of Texoma, “If we wrote another plan, it wasn’t going on a shelf!”

Thanks to the convergence of a number of factors, Thompson says, the local access plan is alive and well—and the rural three-county region is beginning to reap the rewards of the planning effort.

Thompson describes the development of the local access plan as a true collaborative effort involving human services professionals, people with disabilities, disability advocates and others. Among other things, they worked together to:

- ▶ create stronger linkages between the human services programs scattered throughout the region,
- ▶ organize people with disabilities and advocates to assure their ongoing involvement and input (which lead to the creation of the Texoma Independent Living Center), and
- ▶ address problems specific to their rural area—particularly lack of transportation to access services.

The creation of a 2-1-1 Area Information Center (where callers can find information about all community services available to them) helped the Texoma region’s coordination efforts gain momentum. Things really took off, though, with the completion of a methodically developed regional access plan that attracted a number of small grants and strengthened the community’s capacity to test the use of system navigators through a single access point. That single point is the Texoma Area Information and Access Center. Says Thompson, “Persons of any age with any disability can easily get their hands on a lot of resources and, if necessary, get the personal assistance of a navigator.”

Heart of Central Texas Real Choice Project: Multiple Points of Access

The *Heart of Central Texas Real Choice Project* involves 13 counties located in two of Texas' human service regions. Six of the counties are in the Waco region in which Don Smith serves as the Area Agency on Aging (AAA) director. Seven are in the Belton/Temple/Killeen area in which Richard McGhee is director of the Central Texas AAA. Other major partners to the project include the Heart of Texas Independent Living Center and the 2-1-1 Area Information Center located in Waco.

Smith and McGhee say the local access planning effort benefited from significant stakeholder involvement and an impressive number of agencies and organizations have committed staff and resources to the effort. Planners made a concerted effort to involve the broadest range of services and service populations possible. From the beginning, the plan was created around three desired outcomes: 1) no wrong door (people are directed to appropriate services no matter where they enter the system), 2) a single point of access to services and 3) a technological infrastructure for service agencies to share information.

The Heart of Central Texas Real Choice Project has three major components:

- ▶ **Real Choice Aging and Disability Resource Centers (ADRCs):** Integrated with the 2-1-1 Area Information Center, the ADRCs employ resource specialists who answer the telephones and refer callers to appropriate service agencies. Persons with complex, unmet needs that may require more specialized assistance are linked up with "system navigators." Smith and McGhee call these navigators—who are experts at navigating a complicated system—"barrier busters." The system navigators are supervised by the project director who, in turn, reports to the project's leadership team.
- ▶ **"Super" Community Resource Coordination Group (Super CRCG):** Some 35 agencies and organizations have committed key staff to serve as liaisons to the ADRC system navigators. What makes this unique among coordination groups they've worked with in the past, according to Smith and McGhee, is the liaisons' ability to assign their respective agencies' staff and resources to a particular case "on the spot." This, they say, is a departure from the more usual case staffing meetings, where agency personnel do not have the authority to commit any resources to a problem.
- ▶ **Virtual Community Resource Coordination Group (Virtual CRCG):** A 13-county, high security Internet system enables *Real Choice* project participants to exchange consumer information online with other organizations. Smith and McGhee say this is

Next Steps

Terry Childress, HHSC's program administrator for long-term care services and supports, says Texas' current *Systems Change* projects are laying the groundwork for systems access models that can be duplicated across the state. And, he says, they tie in nicely to the state's *Promoting Independence* initiative which is demonstrating the success of the "money follows the person" concept, where dollars that supported a person in a nursing facility pay for his or her community services. Texas is seeking additional funding in the next round of *Systems Change* grants.

Texas: Testing “System Navigators”

the “accountability” piece of the project. The Virtual CRCG also has a public component in the form of an online database and referral questionnaire. In addition to helping people with disabilities locate appropriate services, the information collected allows the project to measure needs that are not being met, information that can be used to document future funding and service needs at the local and state level.

While the project is off to a great start, Smith and McGhee say the leadership is focusing on fine tuning and streamlining several system components. For instance, because this is a joint effort covering two large regions, project personnel are working to clarify issues around lines of authority and responsibility. And, because participating agencies have their own electronic data collection/reporting systems, their usage of the Virtual CRCG is not as widespread as the project leadership had hoped it would be. Finally, as a result of the state’s budget cutbacks and the consolidation of health and human service agencies, many seasoned workers are leaving or losing jobs. That’s resulting in a big loss of expertise within the system.

New Hampshire: Rethinking Community

The advisory council has identified the New Hampshire legislature as one group of leaders to educate. Collier reports they've created a series of workshops for legislators that will take place over the next three years.

Educating its own members—with the goal of sustaining their interest and involvement for the life of the grant period—has been an important part of the advisory council's work to date. A lot of different groups are at the table, Collier says, including people who work in various parts of "the system" and individuals who get support from it. They are learning a lot from each other, Collier says, "and that's exciting."

Littleton: A Town's Involvement

A significant portion of New Hampshire's *Real Choice* dollars are going to model community activities in Littleton. Fox says one reason the town's proposal was so exciting was the way it tied in to community improvement efforts that were already underway. Littleton was already involved in improving energy efficiency, downtown revitalization and making the community more accessible to encourage citizen involvement at all levels.

Alexandra Evans, the project manager, works out of the town office. That's tangible proof, Fox says, of Littleton's conviction that it's important for all people to have choice and to be integrated into the community.

Further evidence of the town's commitment to becoming more inclusive, Project Manager Evans says, is the number and type of people who came together to work on the grant application. Nearly 30 people were involved—including private citizens; school, social services and health care workers; people with disabilities; family members; small businesses; and community leaders.

In the seven months since it received the grant, Evans says, Littleton leaders have focused on getting better educated about disability issues. Other early activities include:

- ▶ Developing a mission statement and goals that the whole community can embrace.
- ▶ Working with the Governor's Commission on Disability to develop a plan to remove physical, informational and other access barriers; and
- ▶ Addressing employment issues (a meeting for local employers, professionals and civic leaders to promote hiring people with disabilities is in the planning stages).

Evans stresses that the Town of Littleton is taking the lead in these activities—a fact that lends credibility and accountability to the effort.

Collaborative Research

Christine Tappan is a research associate with the Institute on Disability. Her work will contribute to the ongoing development of the *Real Choice* project's activities. Unlike the traditional research approach—which usually occurs after the fact to determine what did or didn't work—Tappan will use a collaborative "participatory action model" that will provide continual feedback throughout the project.

Tappan describes it as "community-based action research" in which the researcher serves as a catalyst for an effort that involves a lot of different people performing a variety of research-related activities.

The first phase of research has already started, with Tappan and advisory council members collecting information about "how the Littleton community currently perceives the elderly and people with disabilities." Through semi-structured interviews, document research and real life observation using "ethnographic techniques" (audio/video tape, photos, etc.), the research will help the advisory council develop plans in accordance with community perceptions and attitudes, Tappan says.

"It's a challenge for folks to move away from the traditional paradigm of research," Tappan says. "It's challenging to be learning collectively and to learn about our various roles as we go along."

Florida: A Multifaceted Approach

Reporting for Florida:

Lloyd Tribley

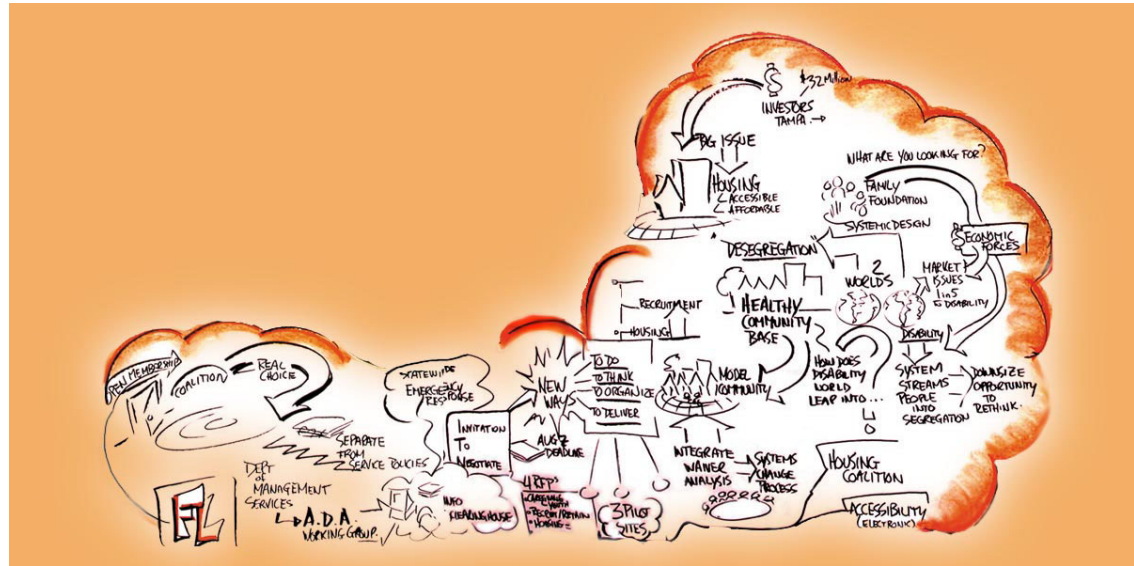
Program Director
Governor's Working Group on the
Americans with Disabilities Act
Real Choice Partnership Project
Tallahassee, FL

Thomas Nurse

Project Director
Family Network on Disabilities of Florida
Clearwater, FL

Wendi Herzman

Executive Director
Deaf Services Bureau
of West Central Florida
Hudson, FL



In Florida, the Governor's Working Group on the Americans with Disabilities Act is spearheading the *Real Choice Partnership Project (RCP)*, the state's Olmstead Systems Change program. Established by executive order, the group reports directly to the governor on policy issues. Operationally, it's part of the Department of Management Services, which is less vested in the systems the ADA Working Group is attempting to change.

Lloyd Tribley, RCP program director, describes the RCP as a loose coalition— anyone who is interested can participate. In addition to input from its membership, the group relies on feedback from its cross-disability advocacy organizations and information garnered from public hearings as the foundation for its activities.

In general the ADA Working Group's mission is to create healthy communities in terms of the overall quality of life for all citizens. A piece of that is to integrate the knowledge and achievements the disability community has gained over the years with community efforts. Some of the activities underway include:

Florida: A Multi-Faceted Approach

- ▶ **Clearinghouse on Disability Information:** The Clearinghouse is Florida's single point of entry for disability information. It is mandated by the executive order and is one of the RCP's major goals. Supported by a toll-free/TTY call center, the Clearinghouse meets national information and referral standards. A supporting Web site (abilityforum.com) is in development.
- ▶ **Invitation to Negotiate (ITN):** An ITN is a flexible variation of a request for proposals, allowing for consolidation of best practices between the funding organization and potential grantees. The ADA Working Group has developed an ITN to develop three pilot projects to establish comprehensive long-term care networks. The ITN emphasizes innovation with the hope that communities that respond to it will focus on new ideas and community partnerships to break down barriers to accessing systems. Among other things, organizations responding to the ITN are asked to address care giving and recruitment/retention issues, new ways of addressing affordable housing and an analysis of how Medicaid waivers could relate to systems change and help move persons with disabilities from institutions to community settings.
- ▶ **Requests for Proposals (RFPs):** To support the pilot sites, the ADA Working Group is developing RFPs to fund initiatives related to personal assistance (including focusing on young people as care givers and personal assistant recruitment and retention issues) and affordable housing. It is also partnering with the University of Florida Shimberg Center on Affordable Housing to support elements of a statewide research agenda on affordable and accessible housing developed in concert with several housing coalitions.
- ▶ **Accessible Public Information:** Florida's governor and the ADA Working Group are committed to fully accessible information to support citizens and healthy communities. The state has launched a campaign to make government agencies, documents and websites accessible to people with disabilities. The effort was recently honored with a Systems Change Leadership Award from the *Florida Alliance for Assistive Services and Technology*.

Thomas Nurse, project director for the Family Network on Disabilities of Florida, maintains close ties with the ADA Working Group and is determined that its systems change activities will reflect the importance of people with disabilities and their families as a major and recurring theme.

"The term inclusion is too soft a word," Nurse says. "It's really an issue of desegregation. Currently, there is segregation by systems. And there is a phenomenal disconnect between systems."

"Communities are built around families," says Nurse. "We are part of the solution."

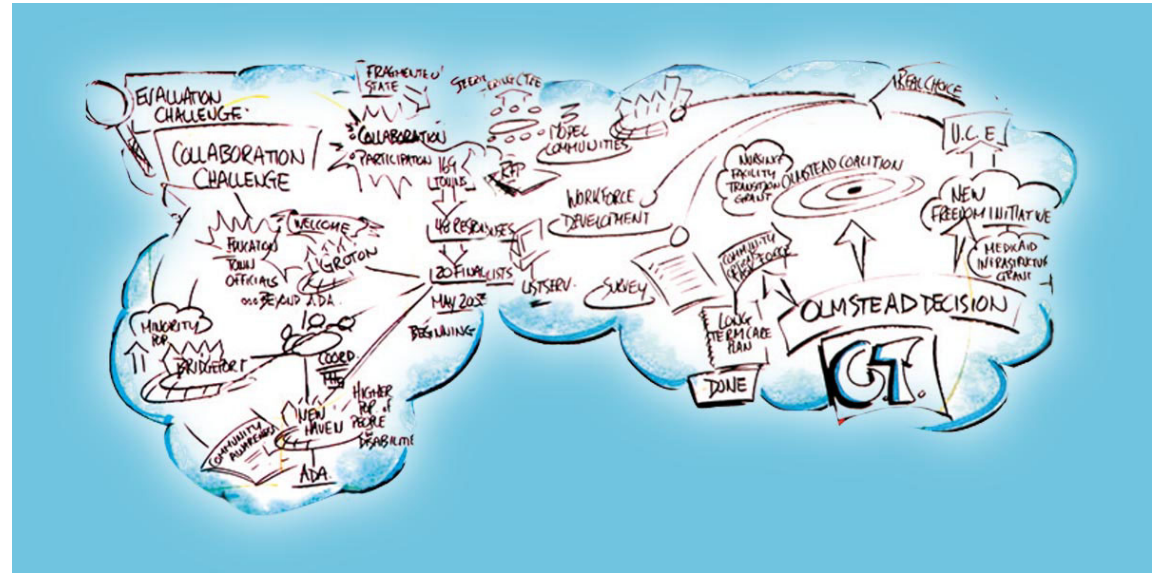
Connecticut: Collaborative Relationships

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Connecticut's *Real Choice* model community project has roots in a number of collaborative efforts that had already formed around other community integration activities—many of them stemming from the Supreme Court's *Olmstead* Decision and the current Administration's *New Freedom Initiative*. The partnerships developed around long-term care and community living issues were a significant result of those activities.

The state's Department of Social Services (DSS) received a *Medicaid Infrastructure* grant and *Nursing Facility Transition* funds in the first round of CMS grants, and the *Real Choice Systems Change* grant in the second round. For two of the three projects, DSS subcontracted with organizations with expertise in disability issues. The University of Connecticut's Center for Excellence (UCE) is implementing the *Real Choice Systems Change* project and the Connecticut Association of Centers for Independent Living (CACIL) received the *Nursing Facility Transition* funds. With so much going on, Project Coordinator Christine Gaynor says the collaborative relationships established around earlier activities are really paying off.

Connecticut: Collaborative Relationships

Connecticut's *Real Choice* project is focusing on three major areas:

- ▶ demonstrating three model communities;
- ▶ workforce development, and
- ▶ assessing people with disabilities' perceptions of how they are included in their communities.

Much of the project's activity to date has been devoted to selecting the three model communities. One challenge in that regard, Gaynor says, is the fact that the state is "fragmented in a lot of ways." There are 169 towns in Connecticut and each one has its own way of doing things. There is no county system and there are a number of different state agencies that provide services without centralized coordination.

Believing it was important for each town to have the opportunity to apply for grant funding, the project sent a request for proposals to each town manager. Twenty towns applied. Of them, a selection committee chose three:

- ▶ **Groton:** A small community that will focus its *Real Choice* efforts on the town government's role in making the community more accessible and livable.
- ▶ **New Haven:** A community claiming a slightly higher per capita proportion of people with disabilities than other

Connecticut towns. New Haven plans to concentrate on public awareness about ADA access.

- ▶ **Bridgeport:** One of the state's larger communities with a large percentage of minority residents. This town is currently paring down the number of objectives they started with and will likely focus on community education and awareness.

As the model communities gear up, Gaynor says the project staff is trying to build on the momentum the RFP process started. Communities that wanted to apply for the grants were required to have task forces in place when they applied. Now that they have them, she says, it's an opportunity to keep them involved as a grassroots network focused on healthy and inclusive communities.

"We're trying to get a blueprint here," Gaynor says. "In the third year, we plan to have a statewide conference where the grantees and others who are interested can get together and share lessons learned."

Lessons Learned:

Connecticut's first attempt to obtain a *Real Choice Systems Change* grant didn't succeed. Looking back, Christine Gaynor, project coordinator, thinks it was because the grant proposal was trying to do too many things at once. For instance, it proposed establishing 15 model communities. After receiving their grant in the second round of funding the plan was scaled down to focus on three communities.

Idaho: Model Communities on the Frontier



Reporting for Idaho:

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It's worth noting that Idaho's *Real Choice* model communities project is housed at Idaho State University's Institute on Rural Health. That makes sense for a state where the largest city (Boise) has less than 200,000 residents and the rest of the 1.1 million citizens are scattered in rural communities throughout the state.

Leigh Cellucci, project manager, says the project is a dual effort of the Institute on Rural Health and Idaho's Department of Health and Welfare—the actual *Real Choice* grant recipient. One of the partnership's primary goals is to develop a model that can be used by communities throughout the state.

The Community Integration Committee (CIC) is another important part of the effort. The state-wide group includes representatives from the advocacy, service provider, business and other interested communities. Cellucci says the CIC has been a vital advisor to the Institute of Rural Health throughout the project.

Idaho: Model Communities on the Frontier

Cellucci says the project's first significant activity was an assessment to determine people's needs, and where and how to channel grant dollars and energy for the model community effort. The CIC was instrumental in assisting with a survey of people with disabilities, service providers and others who could provide good input.

The result of that effort was a request for proposals that led to a grant to a three-county area surrounding the Idaho Falls community. Cellucci says there is a lot of local support for the effort—starting with the town's mayor and city planner. Beyond that, she says there is "a lot of involvement from people and organizations who are not the 'usual players.'" People from real estate businesses, faith-based groups and the business and construction community are on board.

From here, the project will proceed in three phases:

- ▶ Assessing various aspects of quality of life in the community;
- ▶ Initiating a community development project based on the results of the assessment; and
- ▶ Following up with an effectiveness study focused on the effort's impact on individuals.

Regarding the effectiveness study, Cellucci says "we want to effect change; but we also want to see that all of the domains that we

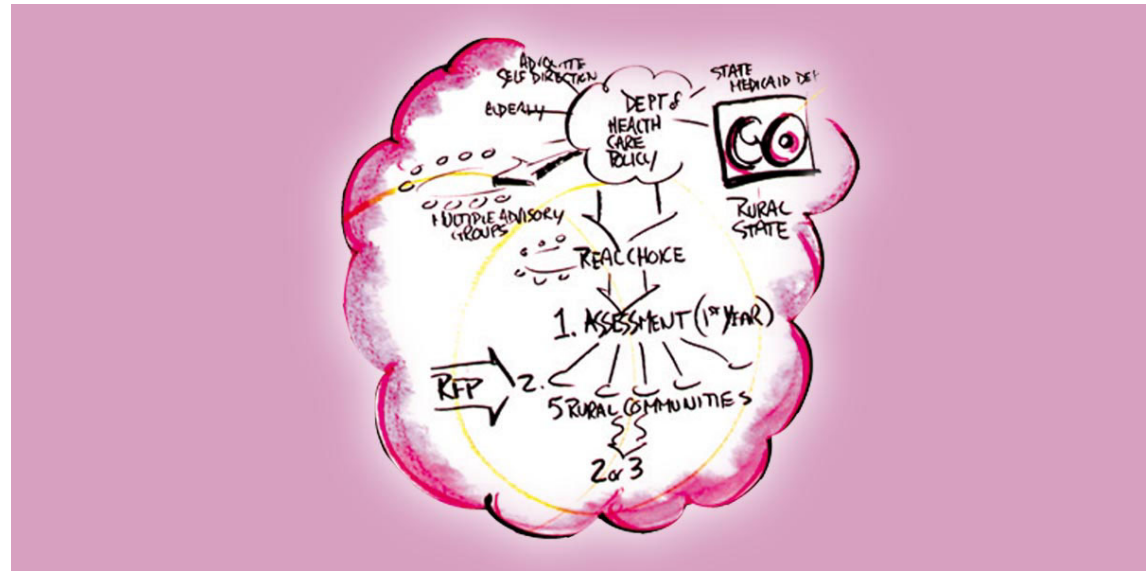
think will be impacted *are* impacted." Also, she says, the project plans to conduct long-term follow-up to evaluate the overall impact and sustainability of improvements the community achieves.

In terms of the people who are integrated into the community through the project, Cellucci says, "We'll be looking at their physical *and* emotional health. We want to make sure the changes we perceive to be happening are, in fact, happening."

Finally, Cellucci says the project will emphasize the individual person with a disability's responsibilities in making a transition to the community. "People have to buy into the notion of wanting to get back into the community," she says.

She adds that those associated with the project will take care not to put success ahead of people with disabilities' goals and needs. "This is a person-centered project," she says.

Colorado: Filling in the Gaps



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Colorado's *Real Choice Systems Change* grant is managed with three other community living projects in the Systems Change Section of the state's Medicaid agency—the Department of Health Care Policy and Financing. Even before receiving the *Real Choice* dollars, the unit had initiated three different consumer-directed programs in which some 49 people with disabilities are currently participating. A new program to serve the elderly population is in the works.

With so much already in the mill, the project staff decided to identify unmet needs or gaps that the *Real Choice* dollars might be used to address. The first year of funding has been devoted to that assessment.

In the second year, the project will offer grants to five rural communities to address unmet needs they identify as barriers to including all citizens. The project's advisory committee is currently deciding what should be included in the requests for proposals, expected to be issued in January 2004.

CMS Feedback

Reporting for CMS:

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Baltimore, MD

By all accounts, one of the high points of the first day of the discussion was the opportunity to share with—and learn from—Steven Lutzky, Ph.D., director of the Division for Community Systems Improvements Disabled and Elderly Health Programs Group at the Centers for Medicare and Medicaid Services (CMS). If they expected a bureaucratic government official, participants were pleasantly surprised by Dr. Lutzky. He was an attentive listener and responded to participants' questions and concerns with straightforward and practical insight. Most of his input came in the form of responses to questions or comments.

The following is a collection of thoughts and ideas Dr. Lutzky offered during the course of the day, categorized by major theme:

▶ **Paradigm Shift**

The money follows the person—this is the paradigm shift. CMS is no longer thinking in terms of money following the building or a service. It's a philosophy of consumer control and community involvement—and taking that philosophy and applying it to one's own community. It's not that prescriptive and should look different from place to place. The commonality is putting people with disabilities in control ... empowering them ... empowering the community. It's about building communities as opposed to building alternative communities.

▶ **Leadership**

When the leadership is motivated, things happen. The mantle that grantees have taken up is a key component. Don't underestimate the role that grantees play. Individuals who have kept going despite all the difficulties make a tremendous difference. Get "religion" and keep up the momentum.

▶ **Research**

CMS strongly supports having researchers in the overall approach to building model communities and creating systems change. Having ongoing research integrated within

the project is something CMS is quite interested in and strongly approves of. CMS strongly encourages grantees to look at change from the system's perspective. States need to incorporate research into the design of the system to allow for data driven program improvement and to help make the case that these grant funds have been well used and that further funding is justified.

▶ **Budget Matters**

(In response to the participants who feel stymied by state requirements to be "budget neutral.") Get to know the budget people and learn how they develop cost assumptions. Learn from them to build programs and experiences that inform the budget process—and help them understand the services and issues. Make sure they have the in-depth information they need to make accurate costs analyses. CMS is aware that expenditures in states that are providing extensive community-based services (like Oregon and Washington) haven't been "over the edge."

▶ **State-Driven Change**

CMS recognizes it has limited ability to change things as the real work goes on at the state level. CMS does have the ability to help by removing some of the barriers, and can provide some

technical assistance and seed funds. Beyond that, CMS is willing to work with grantees to address issues they may have with the state Medicaid agency.

▶ **Perceptions and Flexibility**

(Responding to comments about barriers imposed by Medicaid rules, CMS requirements, etc.) Not to say there aren't barriers, but it's important to make sure they are real. A lot of times it's a perception. There is a lot more flexibility and authority under Medicaid state plan options and 1915(c) HCBS waivers than people may realize.

▶ **Need for Feedback**

CMS welcomes positive and constructive feedback and guidance on the kinds of things for which grantees would like assistance. The agency would also like to know if there are things that aren't working well, if there are special areas of technical assistance grantees are interested in to overcome particular barriers, or if they have ideas for specific language to include as terms and conditions in the grant contracts.

For More Information

Centers for Medicare and Medicaid Services(CMS)

www.cms.gov

For comprehensive information about the *New Freedom* and *Real Choice Systems Change* initiatives. Select the *New Freedom* tab from the *Topics* on the left side of the CMS home page

Home & Community-Based Services Resource Network (HCBS)

www.hcbs.org

This is the official website for The Community Living Exchange Collaborative and includes a broad range of topics and tools. The HCBS *Clearinghouse*—a searchable, comprehensive information database—appears in the menu on the left side of the home page

Shared Interests

Recurring Themes

These are best described as a “condensed compilation of comments” offered by enough participants enough times during the meeting to suggest they should be captured in this report:

- ▶ The system operates from the “we can’t possibly meet all those needs” position to minimize the “out of the woodwork” effect of people overwhelming a system that is easily accessible.
- ▶ From the system’s point of view, people with disabilities and families are always going to take. The truth is, they have a lot to contribute. We must stop talking about “the disability community” and start talking about “the community that includes some people with disabilities.”
- ▶ Good public policy and political reality are at odds with each other. States are saying they want to create better access to systems; but, in many cases, budget limitations result in decisions that make it harder for people to get or keep services they need.

The Next Level

With such a diverse collection of states at the table, it comes as no surprise that no two model community efforts are the same. Different states—different needs. In the course of the discussion, though, it was clear there were a few issues and concerns of collective interest—regardless of a state’s individual goals and activities. Many of the participants considered the opportunity to discuss and work on these “shared interests” to be the main reason for coming to Denver in the first place.

Building on the foundation laid by the state overviews, discussion participants turned to the task of identifying their shared interests and deciding if and how they could address them as a group. Working together in several small groups, they identified nearly a dozen such issues to start with. A bit more discussion about how the issues relate to one another resulted in three broad categories of shared interest topics:

- ▶ Community “buy in” and involvement in systems change;
- ▶ Research (and how its role is changing); and
- ▶ Defining “access” to community services and how it relates to systems change.

Defining the Issues

Discussion participants spent most of the remainder of the meeting in shared-interest focus groups to:

- ▶ define/clarify the issue (if needed);
- ▶ discuss what kinds of things they would like to do to advance the issue (what can we learn, what can we do, how can we help each other in this area?); and
- ▶ suggest what, if anything, the full discussion group needs to do to follow up (suggestions to CMS, requests for technical assistance, etc.).

With only a couple of hours of meeting time left, the small work groups couldn't fully develop their topic areas. But, they did offer some initial thoughts and starting points when they reported back to the full group, as summarized below.

Community Involvement:

- ▶ The entire community—citizens, political and agency leaders and others—must “buy in” to systems change and must be included and involved in creating a model inclusive community.
- ▶ The systems we've developed have been driven by the language we've been using. To change the system, we need to change the language. Over time, words like “disability,” “model,” and “services” have become empty—or they have negative and/or bureaucratic implications. They marginalize the vision of “supporting people”—providing things they need to function—in “inclusive, livable communities.”
- ▶ Instead of trying to “fix” parts of the system and/or community, we need to “rebalance” and “transform” them using a “holistic” approach. This includes such things as integrating funding streams, moving away from thinking of the community as “subgroups” of people, and building connectivity into the tools and relationships that people rely on to access the system.

- ▶ The trend toward individual isolation in today's society needs to be factored in when planning ways to connect people in the community.

The (Changing) Role of Research:

- ▶ In evaluating change, it's important to include *both* the change process AND the outcomes for individuals. You can't just look at change in the community without looking at outcomes for people—and vice versa.
- ▶ Research and evaluation must go beyond “yes and no” questions about change. We need questions around “how, why and what changed.”
- ▶ Research and evaluation must be ongoing through the change process—and the results “fed back” into the process for continuous quality improvement. Decisions about how to do this (and who will do it) should be made early.
- ▶ There are a lot of people/organizations doing healthy community work. We need to be at their “tables” to be sure people with disabilities and elders are included in their thinking. We don't need to create a new table.

Access to Community Services:

Access means:

- ▶ It is possible for all people to live in the community of their choice with whatever supports they need. (People shouldn't have to move away from family

and friends just to get a service). This includes creating reliable methods by which people can articulate their preferences and needs—and feel comfortable doing so.

- ▶ There is a network of resources and a force of knowledgeable humans (no voice mail or telephone menus) who can get you to the right place based on what your needs are (as opposed to your income, disability, etc.)
- ▶ There are coordinated resources that support individuals and their families in the community.
- ▶ There is an ongoing “conversation” about the needs and goals of individuals and families.

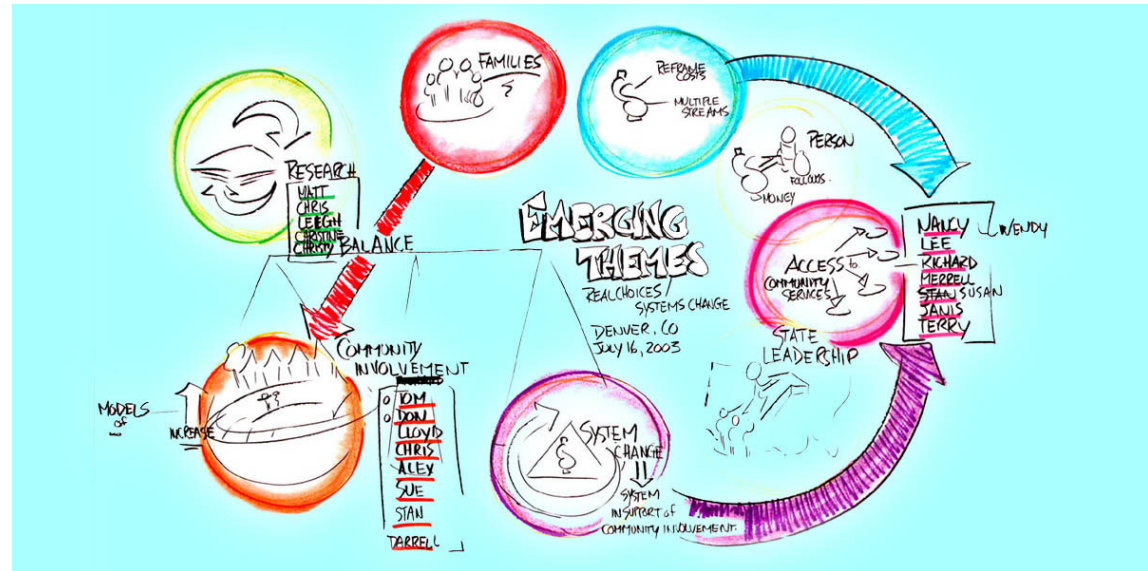
Barriers to access include:

- ▶ Underestimating a person's potential.
- ▶ Lack of policy leadership.
- ▶ Fragmentation and gaps in services—with no continuum of services when a person's needs change.
- ▶ Complex eligibility criteria and turf battles. Services are system driven—not person driven. People need more empowerment to guide their own needs and desires.
- ▶ The medical model dominates the system—still!
- ▶ Individuals and families lack information about how to navigate the system.

Next Steps

More Recurring Themes

- ▶ Leadership from the state level is important to local efforts. At the same time, people working at the community level need to guard against letting their own perceptions of what the state will (or won't) allow or support hold them back in trying new things.
- ▶ The *Systems Change* grants are intended to result in enduring, sustainable change. We can measure change—whether or not something happened. But we need to think about how we can measure if a change will last and grow.
- ▶ When we're talking to policy-makers and others about the advantages of coordinated and inclusive programs and services, we need to make sure they understand what the current chaotic system is costing the community. We need to develop the facts and figures that demonstrate a more efficient system is a more cost effective system.



Just as the conversation about shared interests was gearing up and getting good, the meeting clock was winding down. In their last hour together, participants talked about if and how they would like to continue the discussion beyond Denver.

Participants plan to stay connected via Internet bulletin boards, e-mails and phone calls to share news, ideas and general feedback. Beyond that, there was strong consensus in support of meeting again—twice a year, if possible. Based on this input, The Exchange will pursue the prospect of arranging one meeting in conjunction with CMS' annual *Real Choice Systems Change* meeting, and another at a central location.

Grantees had a few ideas on which to focus future activities, including:

- ▶ Linking up with other healthy community and systems change efforts to learn from them—and vice versa.
- ▶ More discussion specific to sustainability and long-term outcomes for *Real Choice* initiatives, as well as ideas to gain legislative support for achieving sustainability.

- ▶ Strengthening methods to share information between discussion group participants as well as individuals, organizations and agencies we work with at the national, state and community levels.

Feedback for CMS

Following up on the shared interests they talked about earlier in the meeting, discussion participants recommended a few issues they would like to bring to CMS' attention for the federal agency's action or further discussion:

- ▶ Support ongoing research in the area of model communities so that people who want to effect good policy will have reliable and useful information to work with.
- ▶ Support ongoing model community work. It's important. Help us find ways to make stronger connections with Medicaid and other federal programs that will help communities be more willing to be more inclusive.
- ▶ The information you share with state Medicaid directors is important, but it doesn't always get circulated beyond that group. Share it with a broader group of people and organizations.
- ▶ CMS' vision for model inclusive communities needs to be shared with a broader group of stakeholders, too.
- ▶ Increase opportunities for dialogue with stakeholders—especially those who can

help promote and advance CMS' model communities agenda.

- ▶ Translate complex government policies into plain language.
- ▶ Sponsor a full-day pre-conference (in advance of the next CMS grantees conference) on topics pertinent to the grantees and others working on model inclusive community projects.

Technical Assistance, Please

Before they headed for home, the group's last order of business was to list a few areas in which The Exchange can provide additional technical support:

- ▶ Maintain the good communication that was started with CMS through Steve Lutzky at this meeting. Try to set up an ongoing electronic question and answer session with him via the Home & Community-Based Services Resource Network (HCBS) website (www.hcbs.org).
- ▶ Be the conduit for the recommendations to CMS discussed earlier in the meeting.
- ▶ Provide information, training and tools to help grantees and community advocates impact change on the local and state levels.
- ▶ Put information about the community action research methods (as discussed during the New Hampshire and Idaho presentations) on the HCBS Network's website.
- ▶ Distribute the report of this event for use in our work at home and future work together.

Closing Thoughts

With the *Systems Change* initiative, the Department of Health and Human Services (HHS) and Centers for Medicare and Medicaid Services (CMS) have launched an unprecedented opportunity to create real, sustainable, positive change for people with disabilities. For community living advocates, *Systems Change* signifies there is growing recognition of the fact that people with disabilities will not realize meaningful change in their lives until they are full-fledged, participating members of their communities.

What is significant to me about the discussion in Denver is the participants' shared commitment to find innovative ways to involve communities in their efforts to create systems change. So many past efforts have targeted human services systems *alone*—with little focus on how they relate to or rely upon the communities in which they exist.

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 represented in Denver are among the first to make this connection. They are leading the nation to a new way of defining "community."

Jay Klein, Moderator

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