



MODEL COMMUNITIES FORUM MAY 25, 2004

A Sharing of Ideas on Community Inclusion for People with Disabilities

This forum was funded under a Real Choice Systems Change Grant (#18-P-91541/1) from the U.S. Department of Health and Human Services to the Connecticut Department of Social Services and the University of Connecticut A.J. Pappanikou Center for Developmental Disabilities.



University of
Connecticut

A.J. Pappanikou Center for Developmental Disabilities

A University Center for Excellence in Developmental Disabilities Education, Research and Service



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Introduction

On May 25, 2004 representatives from seven Connecticut towns gathered at the University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities (UCEDD) in Farmington to share ideas and experiences related to the inclusion of people with disabilities in the life of their communities. Three of the towns - Bridgeport, Groton and New Haven - were Model Communities, having been selected in 2003 from a list of twenty towns that submitted applications to receive a grant from the Center. The four other community representatives were from municipalities that had submitted proposals but were not selected for funding.

The Model Communities initiative is one part of a Real Choice Systems Change Grant funded by the Centers for Medicare and Medicaid Services (CMS), a division of the U.S. Department of Health and Human Services. The grant was awarded to the Connecticut Department of Social Services in October of 2002, and is being administered by the A.J. Pappanikou Center for Excellence in Developmental Disabilities, a division of the University of Connecticut Health Center.

In addition to representatives from the seven municipalities, attendees at the May forum included members of the Real Choice steering committee (a cross section of members from state agencies and representatives of consumers) and UCEDD staff who have an interest in community inclusion. The forum offered participants an opportunity to share experiences, talk about community inclusion barriers in their town, and offer strategies that are being employed to overcome barriers. In addition to the three Model Communities, representatives from Danbury, Old Lyme, Southbury and New Britain attended the workshop.

Invited to present at the May 25th meeting was special guest Nicole LaPointe, Manager of the Model Community Project for the Town of Littleton, New Hampshire. Her focus on “Lessons Learned” in Littleton offered much fodder for discussion.

Experiences with Community Inclusion:

Personal Perspectives

A video filmed at the two day Interroburst 2003 conference held in October of 2003 was shown to serve as a starting point for discussion of community inclusion. The Interroburst event had been organized to bring together people with a wide variety of disabilities to discuss their feelings of isolation or exclusion within their community. Participants included both individuals who have lived in the community for some time and those who recently transitioned into the community from institutional settings such as nursing facilities. Parents and family members were also in attendance. The video is being used as a learning tool to promote awareness and to encourage a dialogue with state and private agencies working toward the goal of community inclusion.

During the course of the May 25th event the following themes were identified and discussed by Forum attendees:

Barriers:

- Devaluation: People often have the feeling they don't belong in their community, that they are viewed more as the disability label that they have rather than as a person first. Several people commented that for them the stigma attached to being disabled is more of a handicap than the disability itself. There was also some discussion of how sometimes people with disabilities view themselves as victims, and how it is difficult to advocate for yourself if do not believe you can contribute something of value to the community.
- Attitude: A part of this issue is the lack of knowledge and exposure 1) between people with disabilities and typical citizens, and 2) within the disability communities themselves. One of the best ways to break down barriers is to put people with different backgrounds and experiences into face-to-face contact. One of the most interesting things about the Interroburst 2003 gathering was that many attendees

gained an understanding for the first time about disabilities that were different than theirs.

- Transportation: a tremendous barrier to inclusion. If you live in a city or town that has public transportation, you at least have some options (a fixed route service and a comparable Para-transit system). But if you live in a suburban or rural area, there is often next to nothing. There is a crucial need to make more transportation options available to more people.
- Genuine inclusion: We must give the same attention to assisting people in making a real connection to their community as we do in obtaining housing vouchers and personal assistance support services. A relevant quote from the Interroburst video: “Sometimes it seems we are just parachuting people into the community”.
- Competition between disability groups: Some disability groups focus exclusively on the needs of their constituency, preventing more substantive systems change that will enhance the lives of all people with disabilities. We are all in this together and more focus needs to be placed on supporting each other and working together on mutual goals.
- Education: In spite of the settlement in the P.J., et al v. State of Connecticut, Board of Education litigation our public schools are still lagging behind in implementing inclusion practices. Students with disabilities may be physically present in our public schools but are still isolated and excluded for too much of the time.
- Dis-empowered parents: Parents in wealthier towns are able to hire advocates and even lawyers to address IDEA violations, but they are by far in the minority (and access to attorneys doesn’t mean the local school system is able to properly include students). Typical parents in less well-off communities, while caring, cannot match the strategies developed by local school systems to support their claim that they are providing a free, appropriate public education.

- Transition services: There is a need for better transition services for youth moving from a school setting to adulthood in the community. IEPs should begin including plans for making the school to career transition early on in a student's high school years - as required by law - but many local school districts have not yet developed the best practices needed to making the transition process work more effectively for students with disabilities.

Strategies:

- Start small. As one attendee said: "Many of these problems can be really overwhelming and have existed for a long time. I think the idea as far as solutions are concerned is almost like painting a broad picture of reality, and then trying to grab a piece or a couple of pieces at the community level to try to make a change." Pick a couple of things that are more relevant to your community or where there are more opportunities in the community. Go where there is least resistance. Some of the things talked about at the Interburst conference were:
 - ❖ an updated type of welcome wagon to support people who are new to a community, local support groups for people with disabilities,
 - ❖ the promotion of universal design strategy that encourages accessibility for all throughout the lifespan,
 - ❖ awareness training for police departments and other city agencies,
 - ❖ advocacy at all levels, and
 - ❖ mentoring.
- Create opportunities to develop relationships between people with and without disabilities. As one of the Forum participants said: "I see people with disabilities getting together all the time, but it's with other people with disabilities. How much can we demand from others when we don't take the initiative to take advantage of what is already available to us?" While those with disabilities should take more responsibility to reach out and participate in their community, communities must come up with new strategies to include all its citizens in community life.

- Develop mentoring programs. Create a pool of mentors - people with disabilities who are succeeding in their quest to be included - to reach out and help someone else as a way of giving back something for the opportunities they have been provided.
- Part of the P.J., et al v. State of Connecticut, Board of Education class action settlement requires that the state provide training for parents who have children with disabilities. Informed parents increase the likelihood that appropriate services will be provided to children who need a non-traditional education program. The UConn UCEDD is spearheading training for parents through the Understanding Special Education (USE) project.
- Dispel the myth that people with disabilities are only interested in disability issues: create opportunities at the local level for people to become involved in task forces, committees, and study groups that do not focus specifically on disability concerns.

Connecticut's Model Communities

All three of the towns selected as Model Communities (Bridgeport, New Haven and Groton) have developed Task Forces to work on activities that promote inclusion; however, each Task Force is structured differently. The role of New Haven's Task Force is primarily advisory, and the City's Office of Persons with Disabilities is providing leadership and direction for the project. The group meets on a quarterly basis, and comprises representatives from a variety of organizations and agencies, including the local Independent Living Center. In Bridgeport, the 35 member Task Force meets every other month and does most of its activity through workgroups. These currently include Public Attitudes, Housing, Addressing the Resource Gap, and Infrastructure Reform. In Groton, the Task Force meets twice a month, using part of the meeting time to work on specific projects. An update of specific activities is included in the Appendix to this report, and Task Force minutes and project updates can also be accessed through the UCEDD website at <http://www.uconnucedd.org/Projects/RCSC/default.htm>.

Other towns spoke of task forces and commissions existing in their communities, with varying degrees of effectiveness. For example, Old Lyme created a task force specifically to develop a proposal for the Model Communities grant application process. A number of task force members are still linked together. While they have no formal meetings, members are on distribution lists for information regarding community inclusion. They are considering making a proposal to the Board of Selectman to reactivate the task force and to begin writing additional grants.

Southbury's grant writing task force had limited resources and was not able to sustain its momentum. Danbury's task force was formed for grant application purposes and has since disbanded. However, they have the municipal Commission on Persons with Disabilities which works to identify issues in more of an advisory capacity.

By ordinance, New Britain has a Commission on Persons with Disabilities that sets disability policy and is advisory as well. They make recommendations to the Mayor and the town's ADA coordinator. One result: numerous curb ramps have been installed throughout the city. The state Department of Children and Families has allocated funding under their Kid Care Program to help integrate services for youth with behavioral health disabilities and developmental or other diagnosed psychiatric disabilities. The New Britain Park and Recreation Department offers programs and services for children with disabilities (e.g., therapeutic horseback riding component).

A member of the Steering Committee that oversees the Model Communities Project contributed that her home town of Windsor has been active in several ways. On their website they list all of the vacancies on town boards and commissions. In this way, residents with disabilities may access a process for getting involved with town government. Bridgeport is also planning to do the same on their City website. Windsor has had Community Conversations on Race, a program of The National Conference for Community and Justice (NCCJ) initially sponsored in Windsor by the advocacy organization Democracy Works. Bridgeport is also working with Democracy Works on training people with disabilities to serve on municipal Boards and Commissions.

A review of the various grant proposals submitted by towns revealed a number of common themes that would enhance community integration. These included:

- ❖ dissemination of information regarding disability issues to residents with disabilities;
- ❖ identifying resources for residents with disabilities (e.g., developing a resource directory);
- ❖ increasing community participation by people with disabilities;
- ❖ promoting self-advocacy;
- ❖ conducting accessibility surveys within the municipality; and
- ❖ promoting disability awareness.

Next Steps

At the end of the Forum, a participant survey was distributed. The majority of people who attended the gathering found that the sharing of information and ideas was very helpful, as was the opportunity to meet people from other parts of the state and other municipalities. The idea of taking the lessons learned in the model communities and hosting regional meetings was introduced during the meeting; both the survey and ensuing emails indicated a shared enthusiasm for the idea. A group of towns in Fairfield County had previously expressed interest in hosting a meeting in their area, as did several of the towns attending the Forum from the Southeastern part of the state (Groton, Old Lyme). The Interburst video was seen as a valuable tool that could be used in a variety of places, including Town Commissions, with some type of a study guide to stimulate dialog to educate the community. Further topics were requested for regional meetings, which will begin in early fall 2004.

The Real Choice grant staff welcomes the opportunity to make our expertise and resources available to other communities that believe our model community project can be a resource.

Appendix

The Littleton, New Hampshire model community project:

Nicole LaPointe, Project Manager of the New Hampshire model community of Littleton, presented information about activities in that community. Littleton is a town of 6,000 people located in Northern New Hampshire. It saw the Real Choice grant as an opportunity to enhance its long-standing history of inclusive activities. Project sub-groups have focused on the following areas:

I. Access to Town Government. This group works with the town manager and the department heads of the Town of Littleton to enhance the accessibility of public buildings, public information, and public programs, including voting.

II. Collaboration with the “Committee for Public Transportation in the North Country”. The Model Community Project, in addition to participating on this committee of transportation providers and others, has offered to produce and distribute a survey for the public that identifies barriers and gaps in the transportation system.

III. The Incentive Grant Program. This program is promoting the use of universal design by Littleton businesses by providing technical assistance and small matching grants to local merchants and property owners who want to improve the accessibility of their businesses or property.

IV. Accessibility Survey. This group’s aim is to promote accessible businesses, sites, and attractions in Littleton and the surrounding area, and to educate the community about the economic and social benefits of universal design.

V. Access to Employment. This group is working to identify, integrate and harness available resources, and to advocate for new means of increasing work opportunities for all citizens.

VI. Model Community Public Relations. This group works to promote the Model Community Project, its educational information, and its project pieces. The members consider a variety of media, including the Model Community web site, local papers, local television, radio, and statewide sources to convey information.

VII. The Littleton Time Dollar Network. This sub-group is planning to create a Time Dollar Network in Littleton, get it up and running for at least a year and then find a home for it to be sustained in the community. Time Dollars are a tax-exempt kind of currency system measured in hours of service that empowers people to help others and building social and community connections. Under this system, an hour helping another person earns one Time Dollar.

This last topic was of particular interest to many of the Forum attendees.

Littleton's website www.golittleton.com/modelcommunity .

Lessons Learned

Nicole spent time presenting some overall "lessons learned" from the project as a whole. These are as follows:

Identify Community Assets

Have the local task force make a list of community assets. Talk to the people named on that list. Bring your ideas about system change and approaches. Add to the list their ideas.

Reach out, follow-up, have conversations. Have the members with the best connections make the contact or set up and introduction.

1. *Lesson learned*: Identify work already in process and ask, what can we contribute?
2. *Lesson learned*: Look for Community Champions, support their innovations, and let them take leadership in the project direction.

3. *Lesson Learned:* Some of the most fruitful ideas have been generated through one-on-one conversations.

Maintain and Support an Effective Task Force

Practice inclusivity (go through a checklist, challenge yourselves to think how you communicate information).

Invite people to participate and **thank them** for their contribution.

Find the best fit for people. Sometimes someone can't come to the meeting, but will be a resource and an ally. Value their contribution, too, and keep them in the loop.

1. *Lesson Learned:* It's okay to change horses in midstream if the horse you're on isn't going anywhere. Knowing what doesn't work is important, too. Challenge your community group to state and restate their values (in our case: 1) universality of design, 2) honoring choice and valuing gifts, and 3) sustainability, survivability). Encourage each other to measure every program or policy choice against these standards.
2. *Lesson Learned:* Don't pigeon hole your natural leaders, support them and let them go.
3. *Lesson Learned:* Having 'leadership development' as part of the original project scope provided a lot of room for various kinds of activity.
4. *Lesson Being Learned:* Know the limits of your resources / energy, *and* be flexible enough to let indigenous leaders take initiative even if it means adding or changing direction.

Sustaining the Project beyond Grant Funding

We **ask ourselves** at every juncture—if we pursue this idea, how will we sustain it?

Engage the people and organizations who have a natural fit with the particular activity. Explore possibilities of mutual benefit. How would it help them (e.g., volunteer recruitment, client engagement, members' satisfaction) if they took this on? It might

take a while for them to see the benefit, so keep them in the loop. Get them involved with the planning and development of the program idea whenever possible.

If the activity itself is not sustainable (e.g., research) ask how the outcomes are going to **make a sustaining contribution** to the community (How will the results be disseminated? Who will they benefit?).

Be clear about your goals and role in the program, and the parts that are truly important to sustain.

1. *Lesson Learned:* Your volunteers will be the ones who are still walking the walk after the funding goes away, so give them the tools, mentorship, and connections they need to make the changes they want to see, even if it's not part of the project scope.
2. *Lesson learned:* When contracting, look for value-added opportunities, and for synergies.
3. *Lesson Learned:* Resist the urge to re-invent! Join forces with other groups, put your weight behind an idea that is already in motion. Support other good ideas in your community by recognizing natural synergy and encouraging the components you care about.
4. *Lesson Learned:* We have not been working to sustain the coordinators position, but rather focusing on how the individual project pieces can be absorbed into the fabric of how business gets done.

Evaluation Strategies

Process: Keep notes from meetings and one-on-one conversation. Take time to consider the 'big picture' as well as the daily tasks and deliverables. Think of success in terms of peoples' connections to one another and the way communication has developed. Reflect often with the task force about what has been done to date.

Products: Bear in mind that each document and instrument, evaluation tool, promotional piece that can be recycled and reused by another community group is a valuable accomplishment. Share freely, and track who you share with!

Outcomes: We use the **Logic Model** (resources, activities, outputs, outcomes) to get at our goals and objectives. This guides thinking to “What is it we really want to know about what we’ve accomplished?” Keep your methods simple. Key informant interviews, forums, postcard surveys. Find out what tools are already out there that you can modify, or what research is being done that you could tack a question onto (in exchange for contributing to the cost of copying, for example).

Lesson learned: Apply the same values to your research strategy that you do to the project activities.