

# **Strengthening Communities Initiative Pilot Project**

**January 2004 through June 2005**

**Executive Summary for the  
DHHS Office of Physical and Cognitive Disabilities**

## **Introduction**

This report is a review of the activities and outcomes of the Strengthening Communities Initiative Pilot Project. This is one of a number of initiatives sponsored by the DHHS Office of Physical and Cognitive Disabilities designed to improve the quality of life for adults with developmental disabilities living in Maine.

This report contains several sections. The Executive Summary outlines overall goals and objectives with statewide themes and recommendations. Sections follow this on: critical factors for success, the three individual agency reports, and an evaluation report.

Project staff, Lisa Sturtevant of DHHS and Mary Kelley of Muskie, appreciate the support of the DHHS Office of Cognitive and Physical Disabilities, including Jane Gallivan, Bill Hughes, Paul Tabor, Bob Kennelly, Peter Alexander and Brian Scanlon, along with the support of Muskie Center for Learning Director Nadine Edris and Administrative Assistant Elaine Ecker, Evaluators Michel Lahti and Al Sheehy, and the consultation work of John Walker of the Northeast Asset Based Leadership Project.

We are grateful for dedication to quality improvement shown by the three agencies that participated in the project: Community Partners, Inc, the Progress Center, and the Charlotte White Center. We also appreciate the guidance and support offered to us by people whose work we embraced as the foundation of the Pilot Project, Beth Mount, and John McKnight, John O'Brien, Connie Lyle O'Brien, Pam Walker.

## OVERVIEW

Service delivery systems in mental retardation services have undergone dramatic changes in the move from institutional services to community services. As community services have strengthened and grown, sometimes people who receive services become unintentionally isolated from community life. The National Core Indicators Quality of Life Survey conducted in Maine of adults with mental retardation showed that many individuals with mental retardation have few relationships outside of paid caretakers which can lead to loneliness and isolation.

The Strengthening Community Initiatives assumes that communities are healthier when all people contribute according to their strengths, and that individuals enjoy a better quality of life when they are well connected to strong social networks. Our definition of inclusion is that people with disabilities form genuine relationships when they participate in meaningful activities in their communities. The project is a partnership of DHHS, Muskie School Center for Learning, and three community provider agencies.

Implementing this project, staff of DHHS Office of Physical and Cognitive Disabilities and Muskie Center for Learning supported agencies through training events and technical assistance, and consumers through planning and training events.

The full process included:

- Development of an agency-specific plan.
- Orientation of agency and state staff to the work of the pilot project.
- Staff training in Community Inclusion and Asset Based Community Development.
- Person Center Planning with identified consumers and teams.
- Staff development through support and training for lead persons and inclusion coordinators.
- Community Building forums.
- Staff retreat with Connie Lyle O'Brien and John O'Brien.
- Development of Agency specific recommendations for sustainability.
- DHHS recommendations.

## OUTCOMES and EVALUATION

During the course of the pilot project, we heard many stories of improvement in individual's lives. One woman became reunited with her brothers and her extended family; another woman's team helped her to organize supervised visits with her children. Some people found employment. One man attended the NASCAR races in Florida with a friend. A woman found a friend in her apartment complex to have dinner with and watch the nightly game shows and another woman acted as a model in a local fashion show. While to some observers these outcomes may seem modest, they exemplify the kinds of results we are looking for: helping people with disabilities become involved with ordinary people, in ordinary settings, doing ordinary things. Lessons can be drawn from their successes, and attention needs to be paid to some others who've not yet begun to make meaningful connections.

Muskie evaluation staff tracked project outcomes using various methods, one of which was a phone survey during which agency staff were asked a series of follow up questions. Survey results showed that by participating in the pilot project:

- 56 % of Direct Support Professionals increased their knowledge of the person.
- 56% of staff surveyed said they feel more effective in their role.
- 61% of staff surveyed said their experiences have positively influenced their work in other areas.
- 83 % of staff surveyed said that they are identifying more community supports.
- 69 % of staff surveyed said that they dialogued with a community member about the gifts of a person that they support.
- 60 % of people surveyed routinely have used new knowledge gained through pilot with others they support.
- 50% of staff surveyed said that consumers they work with are more connected to their family and to their friends as a result of this process.
- 81% of people surveyed said they feel more hopeful and better about their future.

In addition, some staff expressed concerns about their agencies' ability to sustain efforts without ongoing technical support from the project staff. Additionally the survey showed that the process of Futures Planning itself in the pilot may be cumbersome and may not be well integrated with other planning processes.

It is clear that there is general support for further implementation of this pilot, but this should not be misconstrued as demonstrated effectiveness of the pilot project. The complete evaluation of the project is attached.

## **THEMES FROM AROUND THE STATE**

Project staff collected data on each of the personal futures planning meetings as well as follow up meetings, training meetings and organizational and community forum meetings. This documentation has been summarized into statewide themes that are listed here below.

**DHHS direction is strong for developing and strengthening inclusion initiatives for people receiving services; however constituents sometimes hear varying messages on implementation.**

- DHHS provided funding, motivation, and guidance to develop the pilot project to look in depth at community inclusion.
- Regional managers made initial connections and supported the three provider agencies involvement.
- Individual Support Coordinators (ISC's) support of, participation in and follow up on outcomes varied based on individual caseworker. Reasons for the varied participation rate are unclear and may benefit from further study.

**Program structures (day/residential) unintentionally can isolate people in our services.**

- Staffing ratios of 1:3 or 4 can make it difficult to connect a person based on their individual capacity.
- Facility based programs looked internally for “activities” versus to the community for connections and membership.
- The need to focus first on health and safety limits staff time spent in intentionally working on community membership actions.
- Some Direct Support Professionals have been hired to “care for” people and are now being asked to connect people to others and think about peoples gifts and capacities.
- Structured hours of 9-2 in Day Services hinder connecting, for people who live at home, to community places or events that happen on nights and weekends.
- Consistent management/supervisory support for Direct Support Professionals is essential for continued brainstorming and problem solving to reduce and eliminate barriers.
- Ability to look at new ways of supporting people can conflict with current agency structure and services causing uncertainty.

**Inclusion definition was clarified by project participants as a result of participation and during the Inclusion Retreat.**

- Participants learned to understand inclusion differently; as more than just presence and participation but about relationships and belonging.
- Participation in project challenged staff, ISC’s and agencies who thought that they “were already doing it” to see things differently.
- Solidified that all people have gifts that can be given freely within their communities. This is a pre-requisite for effective inclusion work.
- Understood that development of relationships with community members is at the core of inclusion.
- Discussed that Inclusion is not a program or something you do to a person, but is a way of life.

**The Person Centered Planning Process within the Pilot Project encouraged people to spend time listening, brainstorming and developing actions focused on connecting someone to their community.**

- When new connections did occur, people served and their Support Staff expressed joy, happiness and enthusiasm.
- All (#23) Individuals wanted to increase their connections to other people in their life and their community when asked.
- All (#23) people had gifts and capacities that could be shared within their community in a valued way.
- Limited unpaid friends were evident for 18 out of 23 of participants when a relationship map was completed and or discussions about having people to spend time with occurred.

- Strengthening of family ties was identified as a desirable outcome for 7 of 23 people involved.
- Use of graphic facilitation assisted teams with understanding and visualizing someone's circle of relationships.

**All three Communities hold a wealth of clubs, groups, associations and members interested in discussions; but, intentional connections and sharing of networks with people served by the agencies was limited.**

- At community forums, community members said they did not know their neighbors with disabilities.
- Community Provider Agencies are seen as the professionals whose job it is to care for this group of people.
- Community members stated they “did not know there was a problem with loneliness”; and that if they had known they felt they would need to be given permission to become involved with people who receive services.
- Direct Support Professionals (DSP's) vary in their knowledge of a given community.
- Staff and consumers used the community mapping tools to learn what is available in their communities, a necessary step for making inclusive connections.
- Community is sometimes seen as scary and unsafe by staff.
- The (mis)understanding of confidentiality creates staff fear of introducing a person with a disability to a community member.
- Encouragement of the use of safe, personal networks can lead to wonderful new relationships.

**There is a body of knowledge and practice that supports inclusion work.**

- See section on Key Elements of Success. These are some of the patterns of work which we observed people doing within the agencies that helped people to make meaningful connections.

**There are barriers to the work identified by agencies.**

- See section on Barriers. Agencies identified barriers which made inclusion work difficult despite good intentions.

## **Recommendations:**

The closure of the state institution and the development of the community system are huge accomplishments of DHHS. The next phase of the work is that of helping people with mental retardation become full community members. There are pockets within the state where people with disabilities are in roles of employee, volunteer, friend, church member, romantic partner, health club member, bird watcher and many others. But,

many people we met remain isolated and lonely and have roles exclusively as clients and consumers of our system.

Community Inclusion is about being in a place where all people are valued for their unique gifts and talents and everyone feels welcome in places where people know your name and care about you. This report is an attempt to further the work of helping communities to welcome all citizens back into the fabric of community life.

These recommendations are based on the work within the Pilot, which was limited in scope and size but represented three geographic areas of Maine and twenty-three unique individuals.

### **1. Assist people who receive services to build relationships:**

- Working to connect people to others is the key to people who receive services obtaining community membership. Support must be provided at many levels.
  - Agency/State level; support and direction to all staff, as well as time and resources to make connections; forums to discuss and eliminate barriers,
  - DSP level; use training to improve skills, utilize relationship tools in planning, explore personal networks for potential connections,
  - Community level; Public education events such as Public Service Announcements. Occasions of hospitality, such as community dinners and forums where introductions of people with disabilities to their non-disabled peers can occur naturally (especially those already available to everyone such as congregations, service groups, etc.)

### **2. Operationalize Community Inclusion within all levels of the Department:**

- State led direction supports the work of connecting people to their communities. Currently there is some disconnect between the mission and service delivery as evidenced by the consumer's disclosure of lack of unpaid friends and connections to their communities.
- Clarify definition of inclusion.
- Determine role of case managers within the planning process, and as supporters of community membership. Are they drivers of the process; or monitors of the outcomes?

- Similar questions could be asked of all positions within the department.

**3. State wide systematic support for on going inclusion efforts providing support for brainstorming and creativity in implementation:**

- Continue the support to the three agencies as they have requested and assist them with sharing their knowledge.
- Continue to provide agency trainings on Inclusion and Community Mapping to any Provider who requests it.
- Pursue Quality Outcomes work around inclusion and Development of Quality Network proposal.
- Development of communities of practice where people can learn together and support one another.

**4. Develop incentives for programs to embrace inclusion work:**

- Consider providing financial rate incentives for agencies with more community based supports which encourage development of meaningful roles within community settings and support genuine relationships. (Similar to higher rate of pay for supported employment vs. sheltered employment).
- Monitor how all services are provided to encourage community inclusion. Ensure agencies connect overall agency planning to individual person centered plans.
- Because day habilitation is an entitlement program, special attention should be directed to enabling day habilitation programming to be provided in ways that enhance community inclusion.
- Recognize success through opportunities to share success stories and effective strategies.

**5. Assist in the identifying of barriers with agencies in order to work together to find solutions and clarify any misinformation:**

- Develop forums to discuss and eliminate barriers with agency and state stakeholders. Possible frameworks include: solution circles, brainstorming discussions and training.
- Ensure Executive Directors provide clear direction to their staff about inclusion work, to support for good decision-making.
- Consider providing consultation to managers regarding risk management that supports inclusion, such as Lynn Seagel to discuss risk management with agency Executive Directors.

**6. Person Centered Planning need to be re-energized and re-focused on the person, their relationships, their capacities and their community:**

- As work is done to look at how person centered planning occurs the role of people on the team will be key to ensuring outcomes for people. The team make up must include people who know the person well: family, friends, and long-term staff.
- Facilitators need skills in bringing together the right people (those who know the person well), listening well and using creative tools to gather information. The team as a whole can identify members to follow up on action plans and monitor the progress of the plan.
- Provide systemic support for improving quality of planning process, implementation, outcome monitoring and quality assurance.

**7. Continue and expand incentives and recognition for Community Inclusion work:**

- On going delivery of David C. Gregory Community Inclusion award.
- Sharing of success stories of people who are involved in their community through multiple forums.
- Expand the Department web site on inclusion.

**8. Track outcomes of Community Inclusion Pilot Project work as to effects and quality:**

- A pilot test of measures to track indicators that relate to other state agency reporting systems.
- More intensive coaching and accountability mechanisms to more closely monitor application of the process.
- Documentation of the ways in which this planning process is either more efficient or more effective, or both, for the consumer – staff person – and agency

## Barriers to Inclusion

Through out the pilot project in all three agencies real and perceived barriers to connecting someone to their community were brought up on a regular basis. In some instances a barrier would derail any actions until it was discussed and a plan for overcoming it decided upon. In other cases there continue to be barriers that hinder a person becoming included within their community. Intentional work by Direct Support Professionals toward reaching desired actions was hindered by perceived and real barriers.

### Agency Identified Barriers to Community Inclusion

- **Confidentiality.** With the advent of HIPPA, concern about confidentiality issues has become paramount. Many staff think they can no longer introduce someone who they support to people they know in the community. This makes the work of connecting people to community members quite improbable. However, some managers think about how to prepare staff to introduce a person based on their capacities and talents, which enhances connection and does not violate confidentiality.
- **Liability:** Agency staff have been told they cannot pursue certain interests with consumers due to potential liability. Example cited was staff couldn't take consumers horseback riding because the agency will be held liable if a horse hurts a staff person. Some staff report employers are unwilling to hire consumers due to potential liability, others report volunteer sites which cannot consider taking on a consumer due to liability
- **Transportation:** Many areas of the state do not have public transportation. As most people with mental retardation do not drive, transportation is a huge issue. Worries about "allowing" someone to go in a community members car hindered car pooling to community events.
- **Licensing;** issues arose for people who receive support in a Medicaid program and are said to need "24 hour-eyes on" supervision.
- **Staff turnover;** in one agency 50% of the people involved had 100% staff turnover in their life in a one-year period. The ability to keep good staff and excite them to great work is difficult. One agency commented that the process of connecting someone and seeing the benefits made their job better. It may be important to assist staff with ongoing development and also exciting them about the day-to-day opportunities they have to do good work. New staff may or may not know the community and the assets in it so good communication and transfer of information is needed to keep the small connections occurring.

- **Lack of understanding;** both community, agencies and state staff struggled with understanding community inclusion. Community members will benefit most from getting to know a person and their gifts and not just “what is community inclusion?” Agencies will benefit from continued work about what does it look like and what are the stories we can tell about inclusion.
- **Communication:** sharing of information about what was happening was a constant struggle and varied in different agencies. Systems change work requires new ways to keep people in the loop.