PROMISING PRACTICES IN HOME AND COMMUNITY-BASED SERVICES

Massachusetts -- Facilitating Culturally Competent Self-Determination

Issue: Development of Local, Ethnic Community Governing Boards

Summary

The State of Massachusetts established community governing boards to manage service delivery as a part of a self-determination initiative for people with developmental disabilities. The governing boards – elected by people with disabilities and their families – reflect the Boston area's ethnic neighborhoods and serve people with similar ethnic and cultural backgrounds. State staff report this approach takes advantage of relationships and cultural linkages to improve services for people with developmental disabilities in their own communities.

Introduction

People with developmental disabilities are gaining the skills to direct and control the supports they receive through self-determination initiatives in over 25 states across the country. The majority of these projects offer support in relatively homogeneous suburban and rural communities. Only one initiative, in the Greater Boston area, supports self-determination in ethnically diverse urban areas.

Local governing boards manage services offered to individuals within their ethnic communities.

The Massachusetts Self-Determination Project draws strength from local ethnic communities by building upon existing personal, family, and cultural relationships. Rather than relying on existing state agencies or private service providers to carry out the project's objectives, the Boston initiative supported the establishment of local governing boards to allocate resources and manage services offered to individuals within their own ethnic communities who have disabilities and are eligible to receive support. The governing boards are comprised of people with developmental disabilities, their families and members of the local community.

This report briefly describes the structure and functioning of the initiative, its current status and some of the outcomes that have been achieved. The information presented is based on, (a) a review of initiative documents both during implementation and at the conclusion of the four-year start-up grant period and, (b) interviews with the initiative coordinator and other relevant staff.

Background

In 1997, the Robert Wood Johnson Foundation (RWJF) awarded grants to 29 states to extend the concept of self-directed services to state developmental disability service systems. This approach was based on research demonstrating increases in satisfaction and decreases in cost when: (a) people directed their own services and, (b) control over the nature, extent, and duration of services was shifted from professional provider organizations to the people receiving support. These changes in authority give individuals the power to direct the funds allocated on their behalf, the freedom to choose among all eligible providers, and the support necessary to accomplish the goals they have identified.

Many people in these communities were underserved or not served by the traditional system.

Intervention

The initiative applies the principles of self-determination to the organization and delivery of supports to persons with developmental disabilities who reside in the urban, ethnically

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diverse neighborhoods within the Boston area. Many people in these areas were underserved by the traditional system of services from provider agencies, or were not receiving services. The initiative reflects the recognition that people with disabilities, like people without disabilities, need assistance and support of different intensities at different times of their lives; and that the support offered is frequently more welcome and more effective when it comes from families, close friends, and familiar members of the community.

The Massachusetts initiative began in 1997, based on the assumption that lasting change in the power structure of the developmental disability service system cannot be achieved unless the individuals receiving support are recognized as full members of their communities and of the local culture. Focusing on the individual as an integral member of the social context brings a broader perspective to the meaning of self-determination and system change. For example, social patterns and expectations may vary between ethnic communities. As a result, the role and definition of the "self" in self-determination may differ greatly between one community that places a high value on self-reliance and independent action, and another that defines the role of the individual by the nature of his or her relationships with extended networks of family and friends.

People receiving support are recognized as full members of their communities.

Community governing boards were given the authority to operate and the resources to make funding decisions by the State Department of Mental Retardation (DMR). Shifting the authority for decision making to the governing boards means that control over resource allocation transfers from the centralized state bureaucracy to local community groups. For the first time, people with disabilities, their families, and members of their own communities were given the responsibility and the means for organizing the delivery of services in their communities.

The governing boards collectively control group budgets for state-funded services for approximately 600 individuals and families. Flexibility is a key aspect of the process of allocating funding. Although it has rarely happened, disagreements may occur over a particular decision the board has made. In this situation, the person or the family can take their funding to a provider agency that is independent of the local governing board.

Local boards have been established in the Haitian, Latino, African-American, Jewish, Asian, and other communities to provide access to funding for people with disabilities within their communities. Additional boards have been set up to support people with particular conditions such as autism. All boards meet together on a regular basis to discuss mutual issues and concerns, identify problems, and seek solutions. The boards have also created a multicultural alliance to advocate for local issues that benefit all people with disabilities.

Implementation

Implementation began with an RWJF self-determination grant of $100,000 over three years to support a community organizer to assist in the development of the local boards. DMR provided $25,000 for each board to cover the initial costs of recruiting support workers. All board members are volunteers. The funding that was made available was used to support services rather than administration. Board budgets have increased as the number of families grew and as responsibilities of the board members expanded.

Working primarily through existing ethnic community organizations and local leaders, governing boards were established over a period of months, one at a time, beginning in the Haitian community. The process of development was different for each group. Sometimes DMR worked with a local agency connected to an ethnic community to facilitate outreach to people with disabilities and families, to organize meetings, and to support collaborative problem solving. Organizations that filled this role had to promise not to become a provider of services.

In the African-American community, for example, families already receiving support were brought together to form a new governing board to take on responsibility for overseeing service

provision. Members of the Jewish community began their process of becoming organized with the placement of a single article in a local Jewish newspaper asking for interested people to respond. In every case, once a small group of families was formed, natural leaders came to the surface. Families became the backbone of the process, helping connect the boards with the larger community.

Impact

The initiative has grown steadily in numbers and confidence since it began. Families report a high level of satisfaction to state staff, although the state has not formally measured satisfaction. The boards have created an array of innovative approaches to help communities help people with disabilities. The Latino Governing Board, for example, coordinated an employment support fair for providers to present to families, in Spanish, the support alternatives they could offer. A monthly school-to-work group was formed by members of the Latino, Asian, and Haitian boards to work with DMR, the state Rehabilitation Commission and local schools on the development of new alternatives for community employment. A Vietnamese Family Group representing ten families pooled their resources to jointly fund the provision of community and employment supports. Finally, the Haitian board focused on the development of an effective school-to-work transition process and the need to provide residential support.

The boards have created an array of innovative approaches to help people with disabilities.

The self-determination initiative has had a powerful impact on the nature and provision of services and supports to people with disabilities in the urban Boston area. As a result, the locus of control and decision-making has begun to shift from state staff and providers to individuals with disabilities and their families.

Discussion Questions:

What are the advantages and risks of starting the governing boards with small budgets and expanding the boards' responsibilities as they develop?

Could similar governing boards be effective in rural areas?

Contact Information

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Charles Moseley, Ed. D., wrote this report, one of a series of reports by Medstat for the U.S. Centers for Medicare & Medicaid Services (CMS) highlighting promising practices in home and community-based services. The entire series is available online at CMS' web site, http://www.cms.gov. This report is intended to share information about different approaches to offering home and community-based services. This report is not an endorsement of any practice.