Organizations in Community Living: Supporting People with Disabilities

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Abstract

This article highlights the common characteristics of organizations that promote community integration, compares these organizations on several structural dimensions, discusses emerging practices in community living and argues against the use of the model replication framework underlying many current research, training, dissemination and change strategies in the disability field. Based on an analysis of research field data collected from 31 human service organizations in 21 states, this article contributes to the growing body of literature on alternative approaches to helping people with severe disabilities live in their own homes.

The Organizations and Study Methodology

The organizations were identified through a national search, including announcements in national newsletters, reviews of professional literature and contacts with key informants in the field. The key informants ranged from university personnel to disability activists; they shared a commitment to integration and an opportunity to obtain firsthand knowledge of different agencies around the country. This approach to sampling is a variation of the snowballing technique common in qualitative research and is designed to elicit information on programs considered by key informants to be doing a good job of integrating people with severe disabilities into the community. Nominated programs were screened based upon an in-depth, semistructured telephone interview prior to the visit.

These organizations represent a purposeful sample selected to uncover new findings about how organizations can and do support people with disabilities in the community. The organizations in this sample include 10 located in the Northeast, 8 in the West and Mountain states, 7 from the Midwest and 6 from the South/mid-Atlantic regions. The organizations supported between 10 and 1,200 people in community living arrangements, 20 with local agencies and 11 with regional responsibilities. The sample included one for-profit agency, with the other local organizations designated as non-profits; regional organizations were state, county or privately operated. These organizations all identify themselves as human service organizations except for one, which considers itself an international community (i.e., people with and without disabilities who have chosen to share their lives together). While these agencies primarily serve people with developmental disabilities, many also support people with multiple disabilities, including individuals who have been given mental health diagnoses.

The purpose of the study was not to find ‘perfect’ or representative programs, but “to understand how services are organized and what daily life is like at programs that have a reputation of being exemplary. Some programs lived up to their reputations and others have not.” Although the researchers screened organizations on the basis of broad community integration criteria, the study was designed to treat concepts such as “community integration” and “good” as problematic, in order to further investigate their meaning.

The research team members each used an open-ended field guide during the on-site visits, which generally were 2 to 4 days in length. The visits typically included interviews and observations with staff members, management personnel, people supported by the organization, parents, neighbors and others.
associated with the individual people or program (e.g., board members). Generally, a tour guide accompanied the researcher on the visits, although independent contacts were made at several sites. Visits also included the review of written material, generally prepared by the organization. The research study was conducted under the direction of experienced principal investigators in national qualitative research with all researchers trained by the investigators and/or receiving doctoral training and field experience in qualitative research.

The findings presented in this article are based on the analysis of over 1,000 pages of detailed field notes, transcribed interviews and observations from these on-site visits. In addition, case studies of 20 to 60 pages were written by individual researchers highlighting agency practices, issues and dilemma. The organizational characteristics were identified and analyzed on the basis of the constant comparative methodology common in qualitative research. In contrast, the section on administrative and program characteristics begins with predetermined management categories and analyzes the data qualitatively within those categories for themes and practices.

The Nature of Organizations

While there are diverse views on the nature of organizations reflected in the literature, two major orientations predominate: a management view based primarily upon a goal-oriented, rational model of organizations and a sociological view based on the assumption that organizations are primarily social systems with histories of their own. Depending upon the orientation and underlying assumptions of the researchers, different aspects are considered important in understanding the nature of organizations. For example, the characteristics of organizations, such as shared histories, are fundamental from a sociological point of view. From a management perspective, the critical aspects of organizations often are the structural dimensions, such as size or specific mechanisms, that can lead to immediate, practical implications.

In the disability field, the heavy reliance on a management perspective of organizations underlies the strong model replication framework predominance in this field. The framework assumes that (1) models can be developed for human service organizations, (2) key components of the models (usually structural) can be identified, (3) these components can be replicated through mechanisms such as training and dissemination and (4) replicated models with the same key components will result in similar outcomes in the lives of people served. This article challenges these premises by describing how the organizations in this study have broad characteristics in common with each other but vary tremendously on the structured components considered key in most model development and replication efforts.

Organizational Characteristics

Firmly rooted in the qualitative research tradition, this study examined organizations screened for basic conformity to the following principles, which were used to operationalize community integration:

- All people with developmental disabilities belong in the community.
- People with severe disabilities should be integrated into typical neighborhoods, work environments and community settings.
- People with severe disabilities should be placed in homes and natural community settings.
- Community living arrangements should be family-scale (operationalized as six or fewer people).
- Organizations should encourage the development of social relationships between people with severe disabilities and other community members.
- Organizations should foster participation in community life and the development of community living skills.
- Organizations should involve parents and consumers in the design, operation and monitoring of services.