

Myths

A Review of the Past

Historically, society has tended to isolate and segregate individuals with disabilities in large facilities and institutions. Despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.

In June 1999, the Supreme Court ruled in *L.C. & E.W. vs. Olmstead* that it is a violation of the Americans with Disabilities Act for states to discriminate against people with disabilities by providing services in institutions when the individual could be served more appropriately in a community-based setting.

Specifically, the Court ruled that people with disabilities have a right to receive services in the most integrated setting appropriate if (1) the person with a disability so consents, (2) the person's treatment team agrees that the person would benefit from treatment in this setting, and (3) such treatment does not unduly affect the state's ability to provide treatment to other people with a disability.

This ruling applies to people with disabilities who (1) currently reside in state-operated and/or funded habilitation centers, nursing homes and psychiatric hospitals, and (2) people with disabilities who are at risk of being placed in such facilities. The Supreme Court has stated that it is unconstitutional to segregate people because they have a disability.

In Missouri, there continues to be a strong institutional orientation regarding where people with developmental disabilities live. A significant portion of residential resources are spent on relatively few people who live in institutional settings.

In Missouri, we know that:

- **There are over 100,000 individuals with developmental disabilities;¹**
- **21,405 of the individuals served by MR/DD live in their own home or with their family;²**
- **15,017 of these individuals receive case management only;²**
- **5,269 individuals receive placement supports in supported living arrangements or group homes;²**
- **1,144 individuals live in a state habilitation center (on campus, habilitation center);³**
- **Costs of supporting a person in a habilitation center averages \$283 per day;⁴ and**
- **There are 2,579 individuals waiting for community services and 491 individuals waiting for residential services.³**

Shattering

"All Relevant Research Supports..."

All relevant research supports the fact that community settings result in improved quality of life in areas such as: opportunities for integration and social participation, participation in employment, opportunities for choice-making and self-determination, quality and duration of services received, contact with friends and relatives, adaptive behavior, and other indicators of quality of life (American Association on Mental Retardation, The Arc, The Council on Quality and Leadership, Center on Human Policy, National Association for Councils on Developmental Disabilities, Research and Training Center on Community Living, & TASH, 2004).

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The most recent research (Gardner, 2003) establishes the fact that there are no increased risks related to health and wellness, abuse, or safety when community affiliation, choice, and self-determination are increased. We recognize and acknowledge that much can be done to further enhance the quality of community-based services and supports in Missouri. To address this need, we recommend the following:

- Continue development of alternative safety nets and crisis response systems for individuals living in the community;
- Increase capacity for high quality individualized supports and services in the community;
- Develop methods to use the skilled and trained workforce in the habilitation centers to assist in providing community supports;

- Promote and raise the level of competency, respect, and compensation for direct care workers who provide community supports and services; and
- Provide training and develop resources that support our community provider network to more effectively support individuals in the community.

As Missouri continues to shift towards an improved system of community supports, a number of questions have been raised in relation to this movement.

...Community Settings Result in Improved Quality of Life"

It is NOT reasonable to segregate people in institutions when experience and research prove that even people with significant disabilities and intensive needs can be supported in the community.

It is NOT reasonable to continue to invest scarce public dollars in operating large, congregate settings.

It is NOT reasonable to deny even one person the right to live among us in the community, where services and supports can be provided.

Myths

Q) Can everyone with a developmental disability be served in the community?

A) Yes. Missourians, even those with significant medical needs, can be supported in the community with proper planning and supports. Individuals with complex medical needs requiring 24-hour supports are being successfully served in the community everyday all across Missouri.

Nine states, plus the District of Columbia, have closed ALL state institutions: Alaska, Hawaii, Maine, Minnesota, New Hampshire, New Mexico, Rhode Island, Vermont and West Virginia. Missouri has successfully transitioned 86 individuals from Habilitation Centers to the community between January 2004 and March 2005.⁵

Community programs, including staff training, are designed around the needs of the person and are more likely to address their unique needs and preferences than larger institutions.

Q) Has moving from institutions to the community been successful? Are outcomes for people better in the community?

A) Yes. Research demonstrates that moving people from institutions to the community has been extremely successful and that outcomes for people in the community are better than for individuals segregated in institutions.

Recent research has also found this to be true of people with very serious challenges. Stancliffe and Lakin (1998) reported the following information: "Individuals who left institutions used significantly more community places, engaged in significantly more social activities,

experienced significantly more personal integration, had significantly more family contacts and made significantly more choices at an adjusted expenditure that was 66% of that of their counterparts who remained in institutions."

Summaries of current research noted that, "Overall, adaptive behavior was almost always found to improve with movement to community settings from institutions, and that parents who were often as a group initially opposed to deinstitutionalization were almost always satisfied with the results of the move to the community after it occurred" (Larson & Lakin, 1989, 1991).

Q) Do people living in institutions have more challenging and complex needs than people living in the community?

A) No. While many people remaining in institutions do have multiple disabilities and extensive support needs, there are people with similar disabilities and more intensive needs who are living with their families or being supported in community programs throughout Missouri.

Q) Are community physicians, dentists, and health care providers able to provide care to persons with intensive needs in the community?

A) Yes. Community health care providers are very capable of providing care to individuals with developmental disabilities. Sometimes, additional training or coordination is needed, but with proper supports in place, this coordination and training can occur when needed. The result of these collaborative efforts is access to quality medical, dental and behavioral health care for individuals with disabilities with complex medical needs in communities all across Missouri.

Q) Is there widespread abuse in community programs? Are institutions safer?

A) No. Institutions and community programs are licensed and certified by the same state and federal agencies. Community programs require licensure/certification or other accreditation such as CARF or the Council on Quality and Leadership for Persons with Developmental Disabilities, in addition to other requirements.

The Centers for Medicare and Medicaid Services requires states to monitor the delivery of home and community-based services to ensure the health and safety of individuals receiving these services.

When people live in the community, neighbors, friends, and the public can see and report any abuse - something less likely to happen for an individual living in an isolated setting.

A recent study found allegations of abuse actually decreased after community placement (Conroy, Garrow, Fullerton, Brown, & Vasile, 2003). In 2004, 5,102 persons were served in community-based settings with 1,009 allegations of abuse/neglect incidents. Additionally, 1,365 persons were served in habilitation centers in 2004 with 469 allegations of abuse/neglect incidents.⁶

¹ Using 1.8% per Gollay Study

² MRDD Data Book, Division Census FY04

³ MRDD Data Book 4/05

⁴ Medicaid per diem 4/05, DMH Administration, Reimbursements Section

⁵ MRDD, Monthly On-Campus Census Report

⁶ DMH, Consumer Abuse/Neglect Allegations and Substantiations

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