Research Findings on Community-Based Versus Institutional Settings for People with Significant Disabilities

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Over the past several decades, researchers have been studying how people with disabilities react to living in different types of settings. Some research compares people who live in institutions with people who have moved to community-based settings. Other studies look at the same people over time to see how they adapt to living in the community. The studies cited in this paper are published in journals that are reviewed by editors to ensure that researchers followed proper methodology. Studies on this topic focus in one or more of the following areas: 1) mortality, 2) quality of life, and 3) satisfaction.

Mortality

One common myth is that people are at greater risk of dying in community-based settings. To test this claim, there were several studies that looked at mortality rates in community settings compared to institutions. The most recent studies (Lerman, Apgar & Jordan, 2003, and O'Brien & Zaharia, 1998) found that there was no difference between the two settings. Earlier studies had mixed results. Researchers in California (Strass, Ehman & Grossman, 1996) found a higher risk in the community, while researchers in Pennsylvania (Conroy, 1995) discovered less risk in the community. Taken together, the studies show that community-based settings and institutions are similar in mortality rates. Community living does not pose a greater risk to the lives of people with disabilities.

Quality of Life

While it is important to assess risk, it is just as vital to study benefits. Many studies have looked at the quality of life of people with disabilities in the two settings to see if one has an advantage over the other. There are many aspects of quality of life, and the following studies show significant support for community-based settings.

One major area of quality of life is the ability to learn new skills and/or adaptive behaviors. Overwhelmingly, studies found that individuals in community-based settings were more able to learn adaptive behaviors than residents of institutions. In a summary of many studies, Lynch and his colleagues (1997) found that self-care and domestic skills had the most improvements when people were placed in the community. Researchers at the University of Minnesota compiled thirty-three studies and learned that most found significant improvements in the community. Among the studies that compared community-based settings to institutions, community settings were better for academic skills, community living skills, language and communication skills, motor skills, self-care and domestic skills, social skills and vocational skills (Kim, Larson, & Lakin, 2001). They conclude, "In 19 of 21 studies reporting statistically significant changes in adaptive behavior, statistically significant improvements in adaptive behavior were found to be associated with movement to community settings" (p. 44).

Additional studies found community-based settings to be beneficial in other areas of life. In Oregon, Knobbe et al (1995) found that those who moved to the community had better social networks, more opportunities for integration, and higher income. Stancliffe & Avery (1997) discovered that people had increased self-determination and autonomy in the community.

Results are consistent in Illinois, as shown in a study of over 300 people, some who stayed in nursing homes and some who moved to the community. The researchers (Heller, Factor, Hsieh & Hahn, 1998) report, "Our main finding was that moving out of a nursing home resulted in positive health and community functioning outcomes for adults with developmental disabilities age 30 years and older over a 3-year period" (p. 242).

Clearly, these studies show that people benefited from moving to a community setting by learning new skills and having greater opportunity to direct their lives.

Satisfaction

The final area of research is satisfaction. Though attainment of skills is important, happiness is vital. Studies have looked at both the satisfaction of the person with a disability and the family. In a study by two researchers in the Northeast (Wehmeyer & Bolding, 1999), they matched people in community settings with someone of a similar IQ in an institution. They report, "The findings show that people who lived or worked in community-based settings were more self-determined, had higher autonomy, had more choices, and were more satisfied than were IQ and age-matched peers living or working in community-based congregate settings or noncommunity-based congregate settings" (p. 356).

Similar findings are reported by Eliason (1998), who, after looking at data from Oklahoma interviews, concludes, "Individuals living in the community were more satisfied than those in institutional settings. Individuals in the community also experienced three and one-half times as many social integrating activities when compared to individuals in institutions, and also spent more time engaged in productive activities related to work and school" (p. 166).

Additional studies report greater satisfaction in the community (Lerman, Apgar & Jordan, 2003, Conroy 1998), and no studies found people who stayed in institutions to be more satisfied than those who moved into the community. The results are conclusive.

Finally, it is important to note how parents respond to community settings. In a review of several studies, Larson & Lakin (1989, 1991) found that "parents who were initially opposed to deinstitutionalization were almost always satisfied with the results of the move to the community after it occurred" (p. 36).

Conclusion

As shown above, research overwhelmingly supports community-based services over institutions. Community living does not pose a greater risk of mortality for people with disabilities, but improves quality of life and satisfaction.

References

- Conroy, J. W. (1998). Are people better off? Outcomes of the closure of Winfield State Hospital. Report submitted to the Kansas Council on Developmental Disabilities. Rosemont, PA: Center for Outcomes Analysis.
- Conroy, J. (1995). *Mortality among Pennhurst class members: 1978-1989*. Ardmore, PA: The Center for Outcome Analysis.
- Eliason, S. L. (1998). Social integration and satisfaction among individuals with developmental disabilities: a sociological perspective. *Education and Training in Mental Retardation and Developmental Disabilities*, 33(2), 162-167.
- Heller, T., Factor, A. R., Hsieh, K., & Hahn, J. E. (1998). Impact of age and transitions out of nursing homes for adults with developmental disabilities. *American Journal on Mental Retardation*, 103 (3), 236-248.
- Kim, S., Larson, S. A., & Lakin, K. C. (2001). Behavioural outcomes of deinstitutionalization for people with intellectual disability: a review of US studies conducted between 1980 and 1999. *Journal of Intellectual & Developmental Disability*, 26 (1), 35-50.
- Knobbe, C. A., Carey, S. P., Rhodes, L., & Horner, R. H. (1995). Benefit-cost analysis of community residential versus institutional services for adults with severe mental retardation and challenging behaviors. *American Journal on Mental Retardation*, 99(5), 533-541.
- Larson, S. A. & Lakin, K. C. (1989). Deinstitutionalization of persons with mental retardation: behavioral outcomes. *Journal of the Association for Persons with Severe Handicaps*, *14*(4), 324-332.
- Larson, S. A. & Lakin, K. C. (1991). Parental attitudes about residential placement before and after deinstitutionalization: a research synthesis. *Journal of the Association for Persons with Severe Handicaps*, 16(1), 25-38.
- Lerman, P., Apgar, D.H., & Jordan, T. (2003). Deinstitutionalization and mortality: findings of a controlled research design in New Jersey. *Mental Retardation*, 41(4), 225-236.
- Lynch, P. S., Kellow, J. T., & Willson, V. L. (1997). The impact of deinstitutionalization on the adaptive behavior of adults with mental retardation: a research synthesis. *Education and Training in Mental Retardation and Developmental Disabilities*, 32, 255-261.
- O'Brien, K. F. & Zaharia, E. S. (1998). Recent mortality patterns in California. *Mental Retardation*, 36 (5), 372-379.

- Stancliffe, R. & Avery, B. (1997). Longitudinal study of deinstitutionalization and the exercise of choice. *Mental Retardation*, *35*, 159-169.
- Strauss, D., Eyman. R. K., & Grossman, H. J. (1996). Predictors of mortality in children with severe mental retardation: the effect of placement. *American Journal of Public Health*, 86 (10), 1422-1429.
- Wehmeyer, M. L. & Bolding, N. (1999). Self-determination across living and working environments: a matched-samples study of adults with mental retardation. *Mental Retardation*, *37*(5), 353-363.