

# Parental Attitudes Toward Deinstitutionalization

by Lynda Anderson and Sheryl A. Larson

With the growing number of state institution closures, many parents are concerned about finding and maintaining a safe, caring, respectful, and permanent home in the community for their sons and daughters who have mental retardation. The possibilities and uncertainty of the move away from institutions have stimulated parental responses ranging from ardent support for deinstitutionalization to adamant opposition. Many studies have examined parental attitudes and expectations related to deinstitutionalization. Twenty-one such studies reviewed by Larson and Lakin (1991) reported on observations by parents regarding the move from institutions to the community, and offered suggestions for families and individuals in making the transition. From these studies, the following conclusions emerged about parent attitudes toward their son's and daughter's lives in institutions and in the community:

- **The vast majority of parents were satisfied (secure, content, and comfortable) with their family member's public institution placement.** Eleven of the studies surveyed parents while their family members lived at the institution on their opinion about moving to a community setting. Ninety-one per cent of the parents were somewhat or very satisfied with the institution. Only 21% of the parents supported the idea of having their son or daughter move to a community setting.
- **The vast majority of parents changed their attitudes about community placement after their family member had moved to the community.** Four studies surveyed parents before and after their family member moved to a community setting from the institution. Only 15% of these parents had a positive reaction to their family member moving before the move occurred; after the move, 62% of the parents expressed a positive opinion about the move to the community. Before the move, 83% of the parents reported satisfaction with the institution; after the move 87% were satisfied with the community setting.
- **After experiencing community services, parents viewed the institution less positively than they did when their family member lived there.** Seven studies interviewed parents whose sons or daughters had moved from an institution to a community home about their satisfaction with the institution, the community setting, and their opinion of the move. Only 52% of these parents expressed satisfaction with the institution, and 56% of the parents reported they had a positive reaction about their family member moving to a community home before it happened. This compares with an 83% pre-discharge rate of satisfaction with the institution and a 15% rate of support for the

move. The same parents reported an 88% rate of satisfaction with their children's community living experiences.

- **Parents observed improved quality of life and relationships for their family member after the move.** In five studies, more than 65% of the parents reported after the move that their family member was happier, that relationships between their son or daughter and other people improved, that needed services were available, and that staff members in the homes were competent. Fewer than 12% reported negative changes in these areas. The only area in which parents reported considerable uncertainty was the 31% who felt that community funding was less secure than institutional funding.

Those parents initially opposed to their child's move to the community offered a number of reasons for their attitude. In open-ended responses in 16 studies, parents said they were initially opposed to the move because they felt that the institutions were better than community homes at responding to the specific characteristics or needs of their children; available homes were inadequate in terms of safety, service quality or staffing; the process involved in the decision to move people was unfair, improper or disrespectful; or they felt movement to the community would increase the caregiving responsibilities of the family members. While most parents were ultimately satisfied with the community placement, many offered recommendations for lessening the fear about the move. They suggested those planning for people's moving must acknowledge as legitimate the fears and wishes of the family and respond to them as well as they can. They must include the person who is going to move and the family members in decisions related to the move. Visits should be arranged for family members to potential community sites, and parents who have been involved in previous moves should act as guides in these visits and/or be available in other ways to parents. Government agencies should assist in establishing communication between families and community providers. Finally, they emphasized the importance of public articulation of government commitments to funding and other policies to ensure the viability, continuity, and quality of community settings.

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**Reference:** Larson, S.A. & Lakin, K.C. (1991). Parents attitudes about residential placement before and after deinstitutionalization: A research synthesis. *Journal of the Association for Persons with Severe Handicaps*, 16(1), 25-38.