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ABSTRACT

The report summarizes 27 research studies which examined the attitudes and perspectives of parents of currently or formerly institutionalized people with mental retardation concerning movement from institutional to community placements. Several trends were evident. Parents whose offspring were living in institutions at the time of the survey were overwhelmingly (90%) satisfied. Parents whose offspring had moved from institutions to small community settings were very positive (over 80%) about the new community settings. Finally, the mean level of satisfaction with the institution for retrospective studies (after movement to the community) was only 52.3%. Results are summarized in seven tables: (1) parent attitudes about residential placement--parents surveyed during institutional placement; (2) parent attitudes about residential placement--parents surveyed during community placement; (3) parent attitudes about residential placements--parents sampled during institutional and community placement; (4) reasons for parental opposition to deinstitutionalization; (5) continuing concerns about community settings; (6) positive outcomes related to community placements; and (7) ways to facilitate parental satisfaction with the deinstitutionalization process. (35 references) (DB)

Policy Research Brief

A summary of research on policy issues affecting persons with developmental disabilities.

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Parent Attitudes About Their Daughter's or Son's Residential Placement Before and After Deinstitutionalization

Deinstitutionalization as a public policy led to a reduction of nearly 40% (about 57,000 individuals) in the population of state mental retardation institutions between fiscal years 1977 and 1987 (White, Lakin, Hill, Wright & Bruininks, 1988). Only about 15% of these individuals returned to live with a parent or relative, and only about 12% were transferred to another state facility (Scheerenberger, 1988). In other words, over this ten year period about 42,000 individuals and their relatives faced the changes and uncertainties of moving from large state operated facilities to a wide range of alternative, predominantly community-based residential settings. The trends in the last ten years show continued depopulation of state institutions at an average rate of about 4% per year (White et al., 1988). This means that tens of thousands of parents and other family members will be affected by continuation of deinstitutionalization in coming years.

Parents have been intensely involved in the deinstitutionalization process, both individually and collectively, in many different ways. Parents, often with the assistance and support of professionals, provided a large part of the early momentum for deinstitutionalization and had a primary influence on federal and state legislative and administrative initiatives that fueled this major social change (Frohboese & Sales, 1980). But, parents have played other roles as well, including passive observer and adamant foe.

Finding and maintaining a safe, caring, respectful, and permanent living place for family members who have mental retardation is one of the major concerns and challenges parents face. Not surprisingly, then, parental responses to the prospect of deinstitutionalization vary considerably depending on the extent to which they perceive the qualities they seek in long-term housing to be available to their family members in institutional versus available community-based settings. Many parents publicly and privately resist deinstitutionalization on the basis of these perceptions, causing considerable polarization of sentiment among groups of parents and other concerned people. On one side of the broad issue of deinstitutionalization are the largest national professional and parent organizations-- such as the Association for Retarded Citizens, the Association for Persons with Severe Handicaps, and the United Cerebral Palsy Association -- each supporting continued deinstitutionalization of all people with mental retardation and related conditions. On the other side are much smaller but often extremely active groups of parents and professionals committed to keeping institutions open. These groups include the Congress of Advocates for the Retarded and the Voice of the Retarded, both of which strongly oppose actions that will reduce institution populations and/or eventually close state operated institutions.

Whatever an individual's or group's position with respect to the general issue of depopulating large public institutions, it is abundantly clear that individual families whose members with mental retardation face movement from institutions to community-based settings experience strong feelings of uncertainty, and often experience feelings of fear and betrayal (Conroy, 1985; Mitchell, 1988). Those whose policies and programs create these feelings must acknowledge and respond to them. Clearly the attitudes and perspectives of families who have members living in institutions should be an important factor in planning and providing services and supports in a continuing era of deinstitutionalization.

This review examines all available research on the attitudes and perspectives of parents of currently or formerly institutionalized people regarding movement from institutional to community placements. The review attends in particular to the changes in attitudes about deinstitutionalization associated with experience with the deinstitutionalization process. It also examines the specific concerns underlying these opinions as they have been voiced by parents, as well as ways that professionals and policy makers can respond to the feelings and needs of parents.

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Research Selected for Review

Three general types of research were examined for this review of literature on the attitudes of families regarding the deinstitutionalization of a family member. One type of study surveyed parents of persons who were currently living in public institutions. In these studies, parents were simply asked how satisfied they were with the current institutional living arrangement and, in most instances, how they would feel about having their daughter or son moved to a community-based residential setting. A second type of study surveyed parents whose formerly institutionalized daughters or sons were currently living in community settings. These parents were asked how satisfied they were with the current community-based residence, retrospectively how satisfied they had been with the institutions when their children lived in them, and retrospectively how they had felt about their children moving to the community. A third type of study surveyed parents at two points in time: first, while their children were still living in institutions, and later after these same daughters or sons had moved to the community. These parents were questioned about their level of satisfaction with their children's institutional and community placements while their children were actually in those settings. These studies also asked parents before and/or after the move about their opinion regarding the move.

Research of the three types described above was identified by four basic means. First, a computer search was conducted of the Psychological Abstracts and ERIC databases from 1974 to 1988 using appropriate descriptors. Second, requests were made to all State Planning Councils on Developmental Disabilities for relevant studies on these topics conducted in their states. At the time of this review, most of these agencies were preparing their Congressionally mandated studies of "consumer satisfaction" as required in the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987, and were, therefore, considered a good source of information on research conducted within their states. Third, the "ancestry approach" was used to identify additional studies from the reference lists of previously identified studies. Fourth, a manual review was conducted of all articles published in the American Journal of Mental Retardation, Education and Training of the Mentally Retarded, Mental Retardation, and Journal of the Association for Persons with Severe Handicaps from 1980 to 1988. All studies identified as possibly meeting the standards described above were obtained and reviewed, including dissertations, theses, and unpublished manuscripts. More than 35 studies were identified and reviewed for inclusion in this report. Of the 23 studies actually tabled for this summary, 4 were published in professional journals, one was indexed in Dissertations Abstract International and was obtained from University Microfilms, and 18 were unpublished or were published in limited number by a state mental retardation/developmental disabilities or other governmental organization.

The persons whose responses were studied were overwhelmingly parents, though small numbers of other relatives (e.g., siblings, grandparents) were sometimes included in the studies and could not be separated in the data summaries. Because the vast majority were parents, all respondents in this review are referred to as *parents*. While the majority of the people who moved were adults, this review often refers to them as *children* in reference to their relationship to their parents.

To summarize 23 different surveys of parent satisfaction with present placements or attitudes about movement to community settings, it was necessary to collapse the different scales reporting parental attitudes into a common set of simple categories: positive, neutral, or negative. The results of each study were summarized as the percentage of all parents reporting positive, neutral or negative satisfaction. If a particular study included non-response or missing data in its tables, percentages were recalculated using only positive, neutral, or negative categories of response. The summary statistics computed for the overall findings of the reviewed research were the simple percentages reported in these studies of all parents who were satisfied, neutral, or dissatisfied, weighted by the total number of parents surveyed in each study.

Several decision rules were used in summarizing the findings of these studies. First, with respect to the parents' attitudes about deinstitutionalization, when a question about deinstitutionalization was asked specifically (e.g., "How do you feel about deinstitutionalizing your daughter/son?") the response could be directly interpreted. However, some studies asked about deinstitutionalization indirectly (e.g., "Where would your daughter/son best be served?"). In such instances it was inferred that parents who considered their family member better served in an institution had a negative opinion regarding their deinstitutionalization. Conversely, if the parents responded that a community setting would be the best in their opinion, their attitude about deinstitutionalization was coded as positive. In a few related instances parents were asked their opinions about the best residential option for their daughter/son now, as well as later/in the future. The parental responses coded in these instances were those reflecting their attitudes about movement at the present time (i.e., "now"). Second, when parental attitudes following movement to a community setting were measured on more than one occasion, the responses with the longest interval after deinstitutionalization were recorded. Third, when a study reported attitudes of parents whose children moved to nursing homes or large private institutions, and it was possible to separate these responses from the responses of parents whose children moved to community-based facilities of 15 or fewer residents, the responses of parents whose children moved to nursing homes or private institutions were excluded from the summary.

The intent of this review was originally to summarize all available quantitative reports of parents' attitudes about the deinstitutionalization of their children, both before and after movement to community settings. However, review of these studies revealed rich sources of observations by parents regarding factors affecting their attitudes, and regarding efforts that were or might have been made to make the deinstitutionalization process less stressful and more positive for them and other family members. These observations are conveyed in this report without quantitative ordering, except that responses reported for only one individual are so marked. They are reported largely verbatim from the various reports except for minor editing that combined similar statements or abbreviated lengthy comments.

Results

Table A-1 (see page 5) summarizes studies that surveyed parents of currently institutionalized individuals. These studies asked parents about their satisfaction with the public institution in which their daughter or son resided, and about their feelings regarding moving their daughter or son from the institution to a community-based residential setting. Table A-1 shows high levels of satisfaction with institutional settings/services with a weighted average of 91.0% of the parents indicating that they were satisfied (from somewhat to very satisfied) with the institutional setting, while a mean of 4.8% of the parents were dissatisfied. When asked their opinion about deinstitutionalization of their children, 74.6% of these parents had negative reactions (from somewhat to very opposed). Only 20.3% of the parents were positive about such a move.

Table A-2 (see page 6) summarizes the findings of studies where parents were surveyed after their daughter or son moved to the community. These studies asked parents about their satisfaction with the community living setting/services in which their daughter or son currently resided and about their overall opinion about the benefits of the move. An average of 87.6% of the parents were satisfied (from somewhat to very satisfied) with the community setting/services. The only study that found a satisfaction rating lower than 84% was a 1980 study in which the "community" facilities into which people had been moved averaged 22 residents and some were as large as 88 residents (Landesman-Dwyer et. al., 1980). That report did not provide data in a manner that permitted separation of the responses of parents of individuals who lived in small (15 or fewer bed) facilities from parents of those living in larger facilities.

Table A-2 also summarizes the retrospective views parents reported about their satisfaction with the institutional setting in which their child had previously lived, and their initial opinions about the plan to deinstitutionalize their son or daughter. When satisfaction with the institution was reported retrospectively, an average of 52.3% of the parents said they had been satisfied with the institution, while 31.5% said they had not been satisfied when their family member was living there. When these parents were asked retrospectively about their initial opinion regarding the proposed move, an average of 56.1% of the parents reported having initially positive opinions while only 25.7% reported initial negative feelings.

Table A-3 (see page 7) shows the results of studies whose designs included surveying parents both before and after the move. In each of these studies, most of the parents included were surveyed both before and after the move, but none of these studies reported pre- and post-move responses for exactly the same group. All of the studies summarized in Table A-3 found high levels of parent satisfaction in both institutional (85.4%) and community (89.0%) settings. Three of the four studies in this category reported higher proportions of satisfied parents for the community living arrangements than for the institutional setting. The fourth study (Eastwood, 1985) found a lower percentage of parents satisfied with the community setting than had been satisfied with the institutional placement. For the studies on Table A-3, an average of 14.9% of the parents had positive opinions about a proposed move to the community when asked prior to their child's move to a community setting. Conversely, when asked retrospectively about their initial opinions of the move, 61.8% of the parents reported they had had positive opinions (a statistic close to the 56.1% reporting retrospective satisfaction with the institutional placements in Table A-2).

Tables B-1 through B-4 (see pages 8-13) provide lists of comments offered by parents regarding the impressions and experiences underlying the general levels of and changes in parental satisfaction summarized above. These include comments made directly by parents or summarized by the authors of the 23 studies reviewed, plus 4 additional studies that reported parent attitudes and experiences with deinstitutionalization, but without specific quantative data on institutional or community placements that could be condensed into the categories used in Tables A-1 to A-3. Tables B-1 through B-4 summarize comments and perceptions of parents who have faced and/or have been through the deinstitutionalization process, and who have experienced its stresses, uncertainties, and expectations, as well as its effects on persons moving into community settings. The broad categories used in these tables were guided in part by earlier work done by Frohboese & Sales (1980).

Table B-1 (see page 8) records reasons expressed by parents for their opposition or concern about deinstitutionalization. Table B-2 (see page 10) notes concerns, often continuing concerns, that parents had about community settings after their daughter or son moved to a community-based residence. Of course, the concerns noted in Table B-2 should be evaluated with the understanding that almost 90% of all parents reported satisfaction with the community placement. Table B-3 (see page 11) records positive outcomes mentioned by parents after their sons or daughters had moved from institutions to community settings. Table B-4 (see page 12) records comments made by parents and summary comments of researchers who asked parents about ways to facilitate parental satisfaction with the deinstitutionalization process and outcome. These comments included both suggestions about ways to make deinstitutionalization less stressful for individual families, and suggestions about how policy makers can make the service delivery systems more responsive to the needs of all families.

Discussion

Several trends were evident across the studies reviewed. Parents whose offspring were living in institutions at the time of the survey were overwhelmingly satisfied (90% of the respondents shown in Tables A-1 and A-3 were somewhat or very satisfied with the institutional placement). Despite the considerable criticism of institutional settings in contemporary scholarly writing and court opinions, parents of institutionalized residents still feel that institutions serve their children well. In most of the studies (11 of 12) reported on Tables A-1 and A-3, 50% or more of the parents of currently institutionalized people were opposed to moving their offspring from an institution to a small community setting. These trends have remained quite constant across time and are still evident in the studies conducted in the late 1980's.

Another trend seen in these studies is that parents whose offspring have moved from institutions to small community settings were very positive about the new community settings. Ten of the 11 studies that surveyed parents about community settings found over 80% of the parents were satisfied. The only study showing rates of satisfaction lower than 80% (Landesman-Dwyer, 1980) were based on the responses of parents whose children for the most part were moved to smaller institutions (average size was 22 residents) rather than moving to small family size community-based residences.

The studies that asked parents to look retrospectively at their satisfaction with institutions were particularly interesting. There was a significant discrepancy between parents' reported satisfaction with institutional settings when they were asked prospectively (before movement from the institution) versus parents' reported satisfaction with institutional settings when asked retrospectively (after movement to the community). The mean level of satisfaction with the institution for retrospective studies (Table A-2) was 52.3% while the mean level of satisfaction with insitutional placements when asked during the institutional placement was 90.1% (Tables A-1 and A-3). One possible explanation for this difference is that parents who have had the opportunity to see their family member in a small community living arrangement have a different frame of reference and a new perspective about the adequacy of the institution. Once having seen the nature of the community residences, the institution may not look as good as it once did.

The retrospective views of parents about opposition to the move obtained after community placement also differed from the views of parents who were asked while their offspring were still institutionalized. Of those who were surveyed during the institutionalization (from Tables A-1 and A-3) an average of 19.5% had positive opinions about the move. Of the parents who were asked retrospectively (from Tables A-2 and A-3), an average of 57.3% reported initial positive opinions. Again, this rather dramatic difference seems quite possibly related to a change in perspective once a family member has moved to the community, and perhaps relatedly, to the parents' need to reflect their current feelings of satisfaction regarding the community setting with their reported attitudes about the initial move.

The summary of quantitative data on parent attitudes about residential placement shows clearly that for the vast majority of families, prior general satisfaction with institutional care and reservations about community care in time turns into overwhelming satisfaction with community settings. The summary of family observations about the process of deinstitutionalization also shows clearly that there are many ways that this process can be improved to better respond to the concerns and needs of families as they and their family members with mental retardation face a new way of living in community-based settings.

Parents are opposed to deinstitutionalization for a variety of reasons, but these reasons should be examined with research-based findings on the impact of deinstitutionalization in mind. For example, there is substantial evidence that for persons with all levels of mental retardation, moving from an institution to a small community setting is associated with a number of positive outcomes, such as improved adaptive behavior (Larson & Lakin, 1989), and increased social participation (Conroy & Bradley, 1985; Hill & Bruininks, 1981; Horner, Stoner & Ferguson, 1988). The primary implication of these findings may be that professionals must identify and implement strategies that assist parents through information, assurances and first hand experiences in developing as early as possible the positive, less stressful attitudes about deinstitutionalization and community living that almost all of them eventually come to feel. Tables B-1 through B-4 provide directly stated or easily inferred ways of approaching such a result. •

Table A-1
Parent Attitudes About Residential Placement:
Parents Surveyed During Institutional Placement

Authors (Date)	State	Number	Residence[1] Instit	Comm	Satisfied w/institution Pos	Neut	Neg	Opinion re: move Pos	Neut	Neg
Brockmeier (1974)	NE	754	X		94	3	3	9	6	85[2]
Conroy et al. (1985, 1987)	CT	223	X[3]		77	10	14	32	22	46
Conroy et al. (1987a)	GA	308	X[3]		72[4]		1[4]			
David et al. (1983)	MN	322	X		88	6	6	22	0	78[5]
Kjos (1981)	MN	223	X		92	7	1	18	2	80[5]
Marsh (1984)	NC	464	X		95	0	5	28	0	72[5]
Meyer (1980)	PA	273	X		79	15	5	14	0	86[5]
Spartz (1986)	MN	349	X		98	0	2	30	0	70
Spreat et al. (1987)	USA	284	X		93	0	7	23	17	60
Vitello et al. (1985)	NJ	152	X		91	-	-	-	-	67
Weighted Mean%[6]			X		91.0	4.2	4.8	20.3	5.1	74.6

[1] This column indicates whether the person with mental retardation was living in a public institution or a community-based setting at the time the parents were surveyed.

[2] This survey asked if the respondent prefers that the relative remain in the institution.

[3] These studies asked how satisfied the respondent was with the place his/her relative was living, while all of the other studies on this chart asked about satisfaction with the level of care/programming/services.

[4] These numbers represent only those who were very satisfied or very dissatisfied and were not included in calculations.

[5] These percentages were in response to a question that asked where should your son or daughter live.

[6] The Conroy et al. (1987a) and the Vitello et al. (1985) studies were not included in the calculation of the weighted means because the information was incomplete.

Table A-2
Parent Attitudes About Residential Placements: Parents Surveyed During Community Placement

Authors (Date)	State	Number	Residence[1] Instit	Comm	Satisfied w/institution Pos	Neut	Neg	Opinion re: move Pos	Neut	Neg	Satisfied w/community Pos	Neut	Neg
Bradley et al. (1986)	NH	102[2]		X	38	8	55			10	84	5	11
Welsch Monitor (1988)	MN	110		X[3]	61	16	22	68	10	22	90	6	5
Horner et al. (1988)	OR	31		X	74[4]	20	6	23	58	16	90[4]	10	0
Landesman-Dwyer et al. (1980)	WA	50[5]		X				26	12	62	68	23	10[6]
Rudie et al. (1984)	MN	74[4]		X	53	21	26	55	21	24	91	8	1
Wisconsin Policy (1986)	WI	63		X[7]				79	7	15	93	5	2
		29		X[8]							96	0	4
Wisconsin (1989)	WI	197		X							89	2	9
Weighted mean %[9]				X	52.3	14.8	31.5	56.1	17.2	25.7	87.6	6.0	6.5

[1] This column indicates whether the person with mental retardation was living in a public institution or a community-based setting at the time the parents were surveyed.

[2] Sixty-four of the subjects had been institutionalized the others had not.

[3] These studies asked how satisfied are you with the care/programming/services in the place your relative lives while all other studies in this set asked about satisfaction with the setting.

[4] This question was how satisfied are you with the service setting and support.

[5] Some of these people moved to larger community facilities

[6] Only the 31 families who had actually visited the community homes were asked this question.

[7] This was the response after 2 months in the community.

[8] This was the response after 12 months in the community.

[9] The Bradley et al. (1986) "Opinion re: move" response was not included in the calculations of the weighted mean.

Table A-3
Parent Attitudes About Residential Placements:
Parents Sampled During Institutional and Community Placement

Authors			Residence[1]		Satisfied w/institution			Opinion re: move			Satisfied w/comm		
(Date)	State	Number	Instit	Comm	Pos	Neut	Neg	Pos	Neut	Neg	Pos	Neut	Neg
Conroy et al. (1985)	PA	472	X		83	11	7	14	14	72			
(1987)		369		X							88	6	6
Eastwood (1985)	MA	32[2]	X		92	3	5	32	18	50			
		38		X				88	6	6	84	6	9
Feinstein et al.	LA	11	X[3]		70	30	0						
(1986)		53		X[3]				43	28	29	81	19	0
Heller et al.	IL	184	X		93	-	7	25	-	75			
(1986)		126		X							97	-	3
Weighted mean % A[4]			X		85.4	10.9	6.8	14.9	14.2	71.8			
Weighted mean % B[5]				X				61.8	18.8	19.4	89.0	7.5	5.6

[1] This column indicates whether the person with mental retardation was living in a public institution or a community-based setting at the time the parents were surveyed.

[2] This study used a institutional contrast group that was not the same as the community group.

[3] These studies asked how satisfied the respondent was with his/her relative's residence, while the others in this set asked about satisfaction with the care/programming/services.

[4] These means reflect opinions of parents surveyed during institutionalization.

[5] These means reflect opinions of parents surveyed during community placement.

Table B-1
Reasons for Parental Opposition to Deinstitutionalization

Parents have expressed a number of reasons for opposition to deinstitutionalization. Those reasons fall into the four broad categories shown below. The research studies that are the sources of parental comments in each section are referred to by the numbers in parentheses after each of the four items. Those numbers are cross-referenced to the references list on page 14.

I. Some parents believe that institutions are better environments for some people. (5, 6, 10, 11, 14, 16, 19, 21, 22, 24, 25, 27)

- Parents believe that mental retardation experts, special resources, and services are more readily accessible in the institution.
- Parents believe that staff in the institution are caring and loving.
- Parents believe that institutional residents have more freedom to walk on grounds.
- Parents believe that the family member would be happier with "their own kind"/ in the institution.
- Parents believe that the family member needs an institutional level of care, protection, security and 24 hour constant supervision because of their level of mental retardation, medical needs, or behavioral needs.
- Parents view the institution as a permanent home for this person.
- Parents believe that the person is too vulnerable or is otherwise "not qualified" to move to the community.
- Parents believe that the family member will never achieve the level of independence needed for community living.
- Parents believe that the family member has no potential for further educational or psychological development.
- Parents believe that the family member has mental retardation, and is not and can never be normal. Therefore, they should not be treated as such.
- The family member previously failed in a community setting.

II. Some parents prefer the institution because they perceive currently available community-based settings as undesirable or inappropriate. (1, 5, 6, 11, 12, 14, 18, 20, 21, 22, 24, 25, 27)

Environmental safety

- Parents are concerned about coed settings. They fear that sexual activity would be permitted indiscriminately.
- Parents are concerned about the compatibility of people within the house and the appropriateness of groupings.
- Parents fear exploitation or inadequate supervision to protect the safety and health of their family member in community settings.
- Parents are concerned about the safety of the physical structure, cleanliness, physical layout, maintenance, fire safety, and age.

Quality of Services

- Parents are concerned that needed experts or services are not as available or are insufficient in community settings (especially in rural areas).
- Parents fear that there is an absence of supportive services in the community, particularly for severe medical or behavioral problems.
- Parents fear that smaller may mean less: facilities, equipment, activities, and care.
- Parents are concerned that program quality and comprehensiveness will be less than in the institution.
- Parents perceive that community residences don't provide proper care.

Effect on the person

- Parents fear that moving would cause physical and mental stress, or that the person could not adjust to community living.
- Parents fear that the relative would be harmed by changes in relationships with staff and other residents.

Community reactions

- Parents are concerned about negative neighbor and public reactions or rejection by the community.
- Parents sense that society would not tolerate integration of persons with mental retardation.

Stability/permanence/financing

- Parents are concerned that funding for specialized services and staff will not be available in community settings.
- Parents are concerned about the financial instability of community programs in general.
- Parents are concerned about the stability of specific community providers (opening and closing facilities) because their future viability and reliability is unknown.
- Parents fear the unknown (they worry about moving their family member from a stable to an unknown environment).
- Parents worry about the stability of the placement especially over the very long term. Older parents especially want a permanent place for their daughter/son to live.
- Parents worry that the client will be pushed into yet another more independent setting.

Administrative structure

- Parents perceive administrative and systemic shortcomings in community systems and policy implementation practices.

- Parents have more faith in state supervision than in local supervision of services.

Staffing problems

- Parents believe that the quality, number, comprehensiveness, expertise and type of staff are not as good in the community.
- Parents feel that community staff provide inadequate supervision
- Parents believe that community facilities cannot attract and keep a sufficient number of qualified personnel.

III. Some parents are opposed to deinstitutionalization because the process itself is seen as injudicious. (11,14)

- Parents fear that the person will be "dumped" into an inappropriate placement.
- Parents feel that decisions about who and how many people should move are not made based on individual needs.
- Parents fear the loss of parental control and decision making authority over residency and service decisions.

IV. Some parents are opposed to deinstitutionalization because they feel that it will have an adverse impact on the parents or family members other than the person with mental retardation. (5,6,11,14,16,21)

- Parents thought that the original decision to institutionalize was final and permanent but it is now being renounced.
- Parents fear they may have an increased burden of care.
- Parents fear possible strains on family harmony and functioning.
- Parents fear the potential financial impact on the family.
- Parents are concerned about their ability to meet the physical and emotional demands of those who are deinstitutionalized.
- Emotional stresses including guilt related to institutionalization, anger, confusion, fear of the unknown, and embarrassment resurfaced during the consideration of deinstitutionalization.
- Parents feel that deinstitutionalizing some will have negative funding ramifications for the institution.

Table B-2
Continuing Concerns About Community Settings

Even though the overwhelming majority of parents were satisfied with the community setting, they raised a variety of ongoing concerns about community settings. Concerns that were mentioned by only one parent are marked with a [1].

I. The person who moved was considered to have changed for the worse. (8, 12, 15, 20)

- The person gained a significant amount of weight.
- The person's appearance, hygiene, or attire was perceived as worsening.
- The person appeared more belligerent, rude, or hostile.
- The person was less happy - was shuttled off to a different (respite) home on weekends.[1]

II. The environment of the community setting was not satisfactory. (8, 18, 20)

- The physical conditions or upkeep of the home were poor.
- The parents were concerned that we are developing a lot of mini-institutions.
- The person's clothing disappeared.
- Other resident's behavior problems negatively affected the family member's life.
- The home was crowded and not homelike. It did not provide recreation activities. (This facility was closed).[1]
- The home was coed, too small, and had too many people per room.[1]
- Too many clients were in bedroom during family visits. The staff didn't control other residents during the visit.[1]

III. There were perceived problems with the administration or structure of the community service system. (1 ,6, 7, 8, 11, 12, 15, 18, 20)

- Funding for community programs was considered inadequate.
- The parents had a lack of faith in the continuation of funding for community services.
- Parents were concerned about burial funds and handling of individual finances.
- There was considered to be inadequate monitoring and outside supervision.
- Parents were apprehensive about future relocation and transfers and preferred the status quo.
- The person was moved or reinstitutionalized due to behavioral or other problems.
- Parents worried that the person would be reinstitutionalized if the community setting fails.
- The parents noticed problems with case management.
- There was a lack of acceptance of the family member by the community.
- The ICF-MR model was judged too medically oriented to structure community services well.[1]
- The agency was considered grossly negligent; supervision was lacking.[1]
- Parents were concerned about the timeliness of communication between the providers about seizure medication.[1]

IV. The programs or services available in the community were considered inappropriate or inadequate. (1, 3, 8, 11, 12, 15, 20, 26)

- Needed services in areas such as recreation, transportation, dental, communication, day program, job training, education, psychology, health services, medicine, and behavior were not available on the premises, were inadequate, or were inappropriate.
- There was a need for additional training and better supervision for residents.
- The parents were concerned about the safety of, and the level of supervision for the person in the residence and in the community.
- Parents were uncertain about the permanence of community programs.
- The family member needed more to do, and a greater chance to get out.
- There was a perceived absence of meaningful training activities in the day programs.
- The day program was not integrated into the community.
- The day program was too demanding.[1]
- The necessity for the person to awaken very early concerned the parent.[1]
- The residence was teaching things that the person was considered unable to handle (e.g., sex education).[1]

V. There were staff related problems identified in the community setting. (1, 3, 6, 8, 11, 15, 20, 26)

- The setting had high staff turnover rates.
- There was inconsistency among staff related to turnover.
- Staff was poorly paid, too young, or inadequately trained.
- The resident was not getting enough attention.
- More staff members were needed to allow community interaction.
- The staff did not show good common sense.[1]
- The staff/agency was not able to adequately respond to emergency or behavioral outbursts.[1]

VI. The deinstitutionalization was seen as having had a negative impact on the family. (1,6,7,8,12,15,20,26)

- There was inadequate communication between care providers and guardians.
- Parents felt they were not able to have a say in what happened to their family member.
- There was a limit on the number of days the person could be away from the residence to be with family.
- The resident now lived farther away from the family.
- Parents wanted to be, but were not, consulted about major events (e.g., going horseback riding).[1]
- The parent wanted to treat her daughter as a child but the community provider was treating her like an adult.[1]

Table B-3
Positive Outcomes Related to Community Placements

Parents whose daughter or son moved to a small community setting reported five areas in which the move had a positive impact on them or their family member. Comments noted by only one parent are noted with a [1].

I. The person who moved to the community was considered to have changed for the better. (1, 6, 8, 9, 11, 12, 13, 15, 18, 20).

- The person became happier, more communicative, more aware, and more relaxed.
- The person showed increased warmth, affection, and self-esteem.
- The person showed improved emotional development.
- The person developed more social relationships.
- The person became more independent and responsible.
- The family member had a positive attitude about returning to the community residence after a home visit.
- The family member was reported to be clean and well cared for, and showed better hygiene and appearance.
- The family member was acquiring skills through his/her daily activities.
- The family member was considered to be showing positive behavioral changes and skill development in areas such as daily living, communication, and behavior problems.

II. The qualities of the environment in the community setting were judged to be better than the institution. (1, 6, 8, 11, 12, 15, 20).

- The location was considered better (closer to family members, resources, etc.).
- The community environment was considered more stable and relaxed than the institution.
- There was an everyday appearance of family life.
- The setting allowed a more normal lifestyle.
- The setting was warmer, smaller, and more homelike.
- The setting was seen as more comfortable.
- The smaller size allowed increased individual attention.
- The community setting was considered the best place this family member had ever lived.

III. The services available in the community setting were seen as better than those available in the institution. (1, 3, 6, 7, 8, 11,1 2, 18)

- The services were considered of higher quality in the community.
- All needed services were reported to be currently available, including behavioral, medical, vision, OT/PT, speech, self-care, independent living, etc.
- More one to one personal attention was reported to be available.
- The house was judged to be well managed.
- Enjoyable activities, and recreation opportunities were available.
- The day program was seen as enjoyable and doing a good job.
- There were reported to be more opportunities to learn, experience new things, and make friends in the community.

IV. The staff where the person lived was considered to be having a positive impact on the person. (1, 3, 6, 7, 8, 11, 18, 20)

- Staff provided personalized attention and interest.
- The residence had good quality staff who are knowledgeable, capable and skillful.
- The staff of the community facility showed respect for residents.
- The staff encouraged residents to learn new things, to talk more, and to be more social.
- The residence was perceived to have good staff/client ratios.

V. The move was reported to have a positive impact on the parents and family. (1, 3, 6, 8, 11, 12, 15)

- The move was reported to have improved the relationship between the child, the staff, and the parents.
- The relative now lived closer to parents and family.
- The parent enjoyed visits to the community setting.
- Siblings now felt more comfortable visiting.
- The move allowed for an increase in the frequency of visits.
- The lives of the individual and of the family had changed for the better.
- The parent was more aware of daily life events of the family member.
- Parents said they were more able to give suggestions about care.
- The move resulted in more positive attitudes about the benefits of deinstitutionalization.
- A parent related that if the person had a community-based residence from the beginning instead of being institutionalized, having a family member with mental retardation would have been less traumatic for the family.[1]
- The parent and the family members now felt better, happier, and are more at peace about the living situation.
- Parents reported increased expectations for the developmental potential of their family member following movement to a community-based residence.

Table B-4
Ways to Facilitate Parental Satisfaction with the Deinstitutionalization Process

The authors of the studies reviewed made suggestions in five areas about how professionals and service providers can change the deinstitutionalization process to be more sensitive to parents needs.

I. Attend and respond to the perceptions, needs and concerns of family members. (1, 6, 10, 14, 15, 20, 21, 22, 24, 25, 27)

- Professionals should recognize that families have information and experiences which create legitimate concerns about community settings.
- Professionals should acknowledge the extent to which unresolved concerns and philosophical disagreements between parents and professionals can be detrimental to successful community reintegration and habilitation.
- Professionals and policy makers should create support services for families going through the process to respond to the needs and concerns parents have.
- Professionals should make referrals to support groups of parents who have or who are now going through the deinstitutionalization process.
- Professionals should minimize conflict with parents.
- Professionals and planners should provide a formal forum through which parents can express their feelings and fears.
- Professionals should provide specific counseling, training, and education to help families develop realistic expectations, fears, and motivations.
- Service providers and other professionals should establish ongoing means to actively listen, address and resolve individual parent concerns.
- Service providers and other professionals should provide accurate written and visual information about alternatives to institutional care, and about the ability of persons with disabilities to learn and grow.
- Professionals should counsel, train, and inform families about the capacity of community group homes to provide services.

II. Facilitate participation of the person and his or her family in the decision making process related to deinstitutionalization. (2, 6, 14, 15, 18, 20, 22, 24, 25, 27)

- Professionals should individually inform the family about impending moves in ways intended to reduce anxiety and build support necessary for a smooth transition.
- Professionals should encourage increased involvement by the family in the transition process to help them arrive at realistic expectations, fears, and motivation, as well as to provide a sense of control over their child's well being.
- Professionals should provide formal and structured hearings designed to treat family concerns with dignity.
- Service providers and other professionals should consider and utilize families as a valuable resource in planning for the successful placement of their relatives into the community.
- Service providers and other professionals should invite parents to team meetings where possible moves will be discussed and follow-up with families after the meetings.
- Professionals should provide an opportunity to chose knowledgeably between community and institution setting if both are available.
- Professionals should inform parents about the details of community facilities in which their relative may be placed as soon as they are available.
- Professionals should consult with parents throughout the decision-making and placement process.
- Professionals and policy makers should provide for parental control and consent in the placement decision.
- Professionals should take enough time to make sure the transition process is done right in the minds of the families.

III. Arrange opportunities for family members to learn about and visit potential community sites. (1, 6, 7, 15, 20, 27)

- Professionals should arrange for parents who have been through deinstitutionalization to provide input to professionals during preliminary planning and implementation phases.
- Professionals should arrange to have parents who have been through deinstitutionalization meet with the institution parent association, small groups or individual parents.
- Professionals should share the positive feelings of parents who have been through the process in written or audiovisual forms.
- Professionals should provide parents opportunities to contact parents of previously deinstitutionalized persons, including matching families whose members have similar experiences or needs.
- Professionals should provide opportunities for parents to visit good community settings.
- Service providers and other professionals should arrange informational sessions and schedule open houses at the new residence prior to the move.

IV. Establish and maintain effective communication links between community providers and family members. (1, 6, 7, 15, 20, 27)

- Professionals should provide information about the type of community residence a particular person will be moving to.
- Service providers and other professionals should maintain contact with and involvement of parents by sharing information regularly about their residents adjustment to

the placement, the habilitation plan, and the availability of community services.

- Service providers and other professionals should inform parents when there are placement problems.
- Planners should use placements as close as possible to the family.
- Service providers and other professionals should involve parents when there is a breakdown that jeopardizes a placement or which necessitates movement to a new setting.
- Professionals and policy makers should conduct ongoing periodic family surveys to evaluate satisfaction and obtain other feedback.
- Professionals and policy makers should continually address ongoing problems in community services and communicate [illegible] families about those efforts.

V. Provide federal, state, and local support to ensure that quality community-based options are available and have long-term viability. (1, 4, 7, 8, 14, 15, 21, 22, 24, 25, 27)

- Policy makers and professionals should develop needed service structures to ensure an adequate level of services in community settings and communicate to families about those efforts.
- Policy makers and professionals should develop community resources that demonstrate the ability to provide quality programming consistently over time.
- Policy makers and professionals should promote and publicize efforts that enhance the image of permanence for community settings.
- Policy makers and professionals should continue to work to increase state and federal commitment to the development of support for additional and more specialized community alternatives.
- Policy makers and professionals should include the family in the formal structure of the quality assurance system for each individual.
- Policy makers and professionals should establish permanent systems to monitor and evaluate quality of community services effectively and educate parents about these efforts.
- Policy makers and professionals should involve families in local and state policy planning related to deinstitutionalization and the development of community service.
- Researchers, policy makers, and professionals should research, demonstrate, and communicate about deinstitutionalization from the perspective of the citizen moving to the community as the consumer.

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