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Abstract

This paper reviews studies of parental attitudes on the deinstitutionalisation of a family member. It shows parents were very satisfied with institutional placement before their family member moved into the community. When family members had moved into the community, parents showed a higher level of satisfaction with the community setting. It also summarises parental concerns of deinstitutionalisation, their continuing concerns about their children's community placement and their perceptions of positive outcomes of community living. **Keyword: Accommodation**

Parent Attitudes About Residential Placement Before and After Deinstitutionalization: A Research Synthesis[1]

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This paper reviews 27 studies of parental attitudes on the deinstitutionalization of a family member. In 12 of the studies, the family member was institutionalized. Those studies showed overwhelming satisfaction with the institutional placement and general opposition to deinstitutionalization. In seven studies, the family member had already moved from an institution to the community. Those parents retrospectively reported lower levels of satisfaction with the earlier institutional placement, lower levels of opposition to deinstitutionalization, and high levels of satisfaction with community settings. The three studies in which parental attitudes were sampled both before and after deinstitutionalization mirrored the other studies, showing high levels of general satisfaction with institutional placements before deinstitutionalization and high levels of satisfaction with community placements after deinstitutionalization. Also summarized are parental concerns about deinstitutionalization, their continuing concerns about their children's community placement, their perceptions of the positive outcomes of community living, and ways to facilitate parental satisfaction with deinstitutionalization.

Descriptors: community integration, community services, deinstitutionalization, developmental disabilities, families, group home, institutionalization, mental retardation, parents, residential

Deinstitutionalization as a public policy led to a reduction of over 60,000 residents of state mental retardation institutions between 1977 and 1988 (White, Lakin, & Bruininks, 1989). About 15% of these indi-

viduals returned to live with a parent or relative and about 12% were transferred to another state facility (Scheerenberger, 1988), whereas more than 44,000 individuals and their families faced the changes and uncertainties of moving from large, state-operated facilities to a wide range of alternative, predominantly small, community-based residential settings. The trends in the last 10 years show continued depopulation of state institutions at an average rate of about 4% per year (White, Lakin, Hill, Wright, & Bruininks, 1988). At that rate, tens of thousands of families in coming years will be affected by continuing deinstitutionalization.

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 fueling this major social change (Frohboese & Sales, 1980). However, parents have also played other roles, including passive observer and adamant foe.

Finding and maintaining a safe, caring, respectful, and permanent place to live for family members who have mental retardation and who are living away from home is one of the major concerns and challenges that parents face. Not surprisingly, then, parental responses to the prospect of deinstitutionalization vary considerably, depending on the extent to which parents perceive these qualities in long-term housing for their family members in institutional versus alternative community-based settings. Many parents publicly and privately resist deinstitutionalization on the basis of negative perceptions, causing considerable polarization of sentiment among groups of parents and other concerned people (Frohboese & Sales, 1980; Landesman-Dwyer et al., 1980; Payne, 1976). 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 As-

sociations, which support continued deinstitutionaliza-
tion of all people with mental retardation and related
conditions. On the other side, are much smaller, but
often extremely active, groups of parents and profes-
sionals committed to keeping institutions open, includ-
ing the Congress of Advocates for the Retarded and the
Voice of the Retarded.

Whatever an individual's or group's position with
respect to the general issue of depopulating large public
institutions, it is clear that many families whose mem-
bers face movement from institutions to community-
based settings can experience strong feelings of uncer-
tainty, fear, betrayal, and/or guilt (Conroy, 1985;
Mitchell, 1988). Attention to parental attitudes and
perspectives should be an important feature in planning
and providing services and supports for deinstitution-
alization programs.

During the last 10 years, two comprehensive reviews
have been published on parental responses to deinsti-
tutionalization. The first, by Frohboese and Sales
(1980), reviewed the historical context of parental op-
position to deinstitutionalization. This study examined
archival, public testimony, and interview data to delin-
eate in great detail concerns expressed by Nebraska
parents regarding the impeding deinstitutionalization
of their sons or daughters. In addition, the authors
analyzed possible reasons for those concerns, and po-
tential strategies to address them. The second, by Con-
roy (1985), reviewed theoretical and applied research
published between 1957 and 1983 on parent responses
to deinstitutionalization, and possible psychological
reasons for those responses. Conroy identified four ma-
jor gaps in the literature on parental responses to dein-
stitutionalization, including (a) the lack of a represent-
ative national sample of families of persons who are
institutionalized, (b) limited understanding of the rea-
sons for parental opposition, (c) the lack of pre-test/
post-test studies of changes in parental attitudes, and
(d) potential unexamined differences between parents
of adults versus parents of children who are to be
deinstitutionalized.

This review extends these earlier summaries of re-
search on parental attitudes by summarizing all identi-
fiable studies on the attitudes and perspectives of par-
ents of currently or formerly institutionalized family
members regarding movement from institutional to
community placements. Particular attention is paid to
changes in attitudes associated with the experience of
deinstitutionalization and to addressing the gaps noted
by Conroy (1985). It also examines the specific concerns
underlying parental opposition to deinstitutionaliza-
tion, examines parental evaluations of the positive out-
comes of deinstitutionalization and continuing con-
cerns about community settings, and identifies strate-
gies to address parental concerns and to facilitate
parental satisfaction with deinstitutionalization.

Method

Three general types of research were examined for
this review. One type surveyed parents of persons who
were currently living in public institutions. In those
studies, parents were simply asked about their satisfac-
tion with the current institutional living arrangement,
and in most instances how they would feel about having
their son or daughter moved to a community-based
residential setting. A second type of study surveyed
parents whose formerly institutionalized sons or daugh-
ters were currently living in community settings. Those
parents were asked about their satisfaction with the
current community-based residence, how satisfied they
had been with the institution when their son or daughter
was living in it, and how they had felt about their child
moving into the community. A third type surveyed
parents twice: first, while their son or daughter was still
institutionalized, and later after he/she had moved to a
home in the community. Those parents were ques-
tioned about their satisfaction with each type of place-
ment while their children were actually there and about
their opinion on the deinstitutionalization of their child.

The three types of research described above were
identified by five basic means. First, a computer search
was conducted of the *Psychological Abstracts* and *ERIC*
databases from 1974 to 1988 using appropriate descrip-
tors. Second, requests for studies on these topics were
made of all State Planning Councils on Developmental
Disabilities which, at the time, were preparing their
Congressionally mandated studies of "consumer satis-
faction" (as required in the Developmental Disabilities
Assistance and Bill of Rights Act Amendments of 1987).
Third, additional studies were located in the reference
lists of previously identified studies. Fourth, a manual
review was conducted of articles published between
1978 and 1989 in 27 journals, including the *American
Journal of Mental Retardation*, *Education and Training
of the Mentally Retarded*, *Journal of the Association for
Persons with Severe Handicaps*, and *Mental Retarda-
tion*. Finally, persons known to be involved in or knowl-
edgeable about investigations of this type were con-
tacted to obtain unpublished or informally published
research, including dissertations, theses, and unpub-
lished manuscripts. More than 35 studies were identi-
fied and reviewed for this report. Of the 23 studies
reporting quantitative information, four were published
in professional journals, one was indexed in *Disserta-
tions Abstract International* and was obtained from
University Microfilms, and 18 were unpublished or had
limited publication by a state mental retardation/de-
velopmental disabilities unit or other governmental or-
ganization.

Twenty-three of the studies were summarized by
creating a simple scale that grouped parental attitudes
into three categories: positive, neutral, or negative. For
each study, the percentage of all parents reporting pos-

itive, neutral, or negative satisfaction was recorded. If a particular study included nonresponse or missing data, percentages were recalculated using only positive, neutral, or negative answers. Simple mean percentages were computed and weighted by the total number of parents surveyed in each study.

Several rules were developed for summarizing the findings. First, when a question about deinstitutionalization was asked directly (e.g., "How do you feel about deinstitutionalizing your son or daughter?") the response was coded directly. However, when parents were asked about deinstitutionalization indirectly (e.g., "Where would your son/daughter best be served?"), a negative opinion about deinstitutionalization was inferred if parents considered their family member better served in an institution. Conversely, if the parents responded that a community setting would be the best, their attitude about deinstitutionalization was coded as positive. In the few instances in which parents were asked their opinion about the best residential option for their son/daughter both now and in the future, responses reflecting attitudes at the present time (i.e., "now") were coded. Second, when parental attitudes after movement to a community setting were measured on more than one occasion, the responses with the longest interval after deinstitutionalization were recorded. Third, when it was possible to separate the attitudes of parents whose son-or daughter had moved to a nursing home or large private institution from those whose son or daughter had moved to a community-based facility, only the parents whose sons or daughters moved to community-based facilities were included. Finally, the vast majority of persons whose responses were studied were parents. However, small numbers of other relatives (e.g., siblings, grandparents) were sometimes included and could not be separated in the data summaries.

Review of the identified studies also revealed many observations by parents regarding factors affecting their attitudes, both before and after deinstitutionalization. There were three basic types of observations: direct open-ended comments of parents, open-ended comments that were categorized and/or summarized by researchers, and parent opinions solicited through closed-ended questions. Qualitative observations from all 27 studies are listed without quantitative ordering. No effort was made to quantify the number or proportion of parents expressing each view, or to suggest that these are universally or even widely held views. Rather, all views expressed by two or more parents were included in the summaries to reflect, in a broad qualitative way, parental experiences and perceptions. The number of parents holding these views, therefore, may vary considerably from item to item.

The process for identifying and categorizing parental comments involved several steps. First, each study was

reviewed and parental observations were listed. Lengthy and complex comments were edited into one or more one-sentence comments. Each successive comment was compared with those already listed. Comments that were identical or essentially the same were not added to the list but existing comments were sometimes modified to include the subtle expansion of an idea. For example, Feinstein, Lemanowicz, Spreat, & Conroy (1986) quoted one parent as saying "I am happy for him. He is doing great at Fernwood. He is more alert and happy." They quoted another parent as saying "I think it was the best move ever made for our son. He is happier and more content." In this case, one of the resulting combined statements was "The person became happier, more communicative, more aware, more content, and more relaxed." After the complete list of comments had been generated, each study was reviewed again to confirm that all comments were included.

The second step involved classification. Broad categories were defined by separating comments made before the move from those made afterward. The latter were further divided into positive and negative comments. Comments made by parents and researchers about how the deinstitutionalization process could or should be improved were also isolated. Next, individual parent statements were categorized based on the headings developed by Frohboese and Sales (1980), summary statements made by other researchers or parents, and subcategories developed by the authors. One author then classified all the comments by heading and the other author reviewed the classification decisions. Joint decisions were made about comments that were in question. Each study was then reviewed a third time to ensure that all specific comments had been included and that those made by only one parent in one study were specifically identified.

The final step in creating the qualitative tables involved making minor editorial changes to express all comments in each table in a consistent format, such as making noun usage uniform (e.g., son/daughter, him/her, he/she became "the person"), and generalizing references to specific sites, such as to "the institution" or "the setting", etc., depending on the context. Once all of these editorial changes were completed, the studies were reviewed a final time to check whether the core content of all comments were included on the tables. Comments made by only one parent were eliminated.

In addition to this qualitative listing, 10 studies provided quantifiable parental observations on specific positive or negative aspects of the move. A summary table was constructed of the quantifiable observations reported in two or more independent studies. A mean of the study means was computed for studies reporting the percentage of parents who noted positive, neutral, or negative responses to each item. Another mean of

the study was computed for studies that reported mean scores for all parents on a 5-point Likert-type scale.

Findings

Table 1 summarizes the responses of parents of currently institutionalized individuals. These studies asked parents about their satisfaction with the public institution in which their son or daughter resided, and about their feelings regarding moving their son or daughter from the institution to a community setting. Table 1 shows high levels of satisfaction with institutional settings/services, with a weighted average of 91.1% of the parents indicating that they were satisfied (from somewhat to very satisfied) with the institutional setting, whereas a mean of 4.9% of the parents were dissatisfied. When asked their opinion about deinstitutionalization of their son or daughter, 74.2% of these parents had negative reactions (from somewhat to very opposed). Only 20.6% of the parents were positive about such a move.

Table 2 summarizes the findings of studies in which parents were surveyed after their son or daughter moved to the community. These studies asked parents about their satisfaction with the community living setting/ services where their son or daughter currently resided and retrospectively about their initial opinion of the move. The length of time between deinstitutionalization and the measurement of parental satisfaction with the community setting ranged from 2 months to 2 years (three studies) to 5 to 7 years (three studies). An average of 88.0% of parents were satisfied (from somewhat to

very satisfied) with the community setting/services. Interestingly, the only study that found a satisfaction rate lower than 84% (68% satisfied) was the earliest of the post-release studies in which the "community placements" averaged 22 residents, a typical pattern of the mid-to-late 1970s. When the parents in these studies were questioned retrospectively about their satisfaction with the institution in which their son or daughter had once lived, an average of 52.3% of the parents said they had been satisfied with the institution, whereas 31.5% said they had not been satisfied during the time their family member was living there. When these parents were asked retrospectively about their initial opinion regarding the proposed move, an average of 56.5% of the parents reported initial positive opinions, whereas only 26.6% reported initial negative feelings.

Table 3 shows the results of studies that surveyed parents both before and after the move. In each of these studies, most of the parents were surveyed both before and after the move, but none of these studies reported pre- and post-move responses for exactly the same group. These studies measured parent satisfaction with the community a median of 1 year after the move, with a range of 6 months to 4 years. Each of these studies found high levels of parent satisfaction with both institutional (83.3%) and community (86.9%) settings. Two of the three studies reported higher proportions of parents satisfied with the community living arrangements than with the institutional setting. Among the three pre/post-move studies, an average of 15.1% of the parents reported positive opinions about a proposed

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

Authors (Date)	State	No.	Residence[a]		Satisfied w/Institution			Opinion re: Move		
			Institution	Community	Positive	Neutral	Negative	Positive	Neutral	Negative
Brockmeier (1974)	NE	754	X		94	3	3	9	6	85[b]
Conroy & Feinstein (1985)[c]	CT	223	X[d]		77	10	14	32	22	46
Conroy & Feinstein (1987a)	GA	308	X[d]		72[e]		1[e]			
David et al. (1983)	MN	322	X		88	6	6	22	0	78[f]
Heller et al. (1986)[g]	IL	184	X		93	—	7	25	—	75
Kjos (1981)	MN	223	X		92	7	1	18	2	80[f]
Marsh (1984)	NC	464	X		95	0	5	28	0	72[f]
Meyer (1980)	PA	273	X		79	15	5	14	0	86[f]
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%[h]			X		91.1	4.2	4.9	20.6	5.1	74.2

[a] 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.
[b] This survey asked if the respondent prefers that the relative remain in the institution.
[c] Parents of those in or moving to nursing homes were excluded.
[d] These studies asked how satisfied the respondent was with the place his or her relative was living, while all of the other studies asked about satisfaction with the level of care/programming/services.
[e] These numbers represent only those who were very satisfied or very dissatisfied and were not included in calculations.
[f] These percentages were in response to a question that asked where should your son or daughter live.
[g] The people in this study moved from a larger state institution to a smaller regional institution.
[h] 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 2
Parent Attitudes About Residential Placement: Parents Surveyed During Community Placement

Authors (Date)	State	No.	Residence		Satisfied w/Institution[c]			Opinion re: Move			Satisfied w/Community[c]		
			Institution	Community	Positive	Neutral	Negative	Positive	Neutral	Negative	Positive	Neutral	Negative
Bradley et al. (1986)	NH	102[b]		X[a]	38	8	55	79	7	10	84	5	11
Bureau of Evaluation (1986)	WI	63		X[a,d]						15	93	5	2
Feinstein et al. (1988)	MN	29		X[a,e]	61	16	22	68	10	22	96	0	4
Horner et al. (1988)	OR	110		X[c]	74	20	6	23	58	16	90	6	0
Landesman-Dwyer et al. (1980)	WA	31[f]		X[c]				26	12	62	90	10	0
		50[f]		X[c]							68	23	10
Rudie & Reid 9 1984)	MN	74		X	53	21	26	55	21	24	91	8	1
State of Wisconsin (1989)	WI	197		X[g]							89	2	9
Weighted mean %					52.3	14.8	31.5	56.5	16.7	26.6[h]	88.0	5.8	6.5

cm* 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.
b Sixty-four of the subjects had been institutionalized; the others had not.
c These studies asked how satisfied the respondent was with the place his or her relative was living, while all of the other studies asked about satisfaction with the level of care/programming/services.
d This was the response after 2 months in the community and was used in the calculation of mean satisfaction with the community.
e This was the response after 12 months in the community and was not used in the calculation of mean satisfaction with the community.
f The community facilities in this study ranged in size from 1 to 88 residents with an average of 22.
g Only the 31 families who had actually visited the community homes were asked this question.
h The Bradley et al. (1986) "Opinion re: move" response was not included in the calculations of the weighted mean.

move to the community when asked prior to the move. However, when asked *after* the move about their initial opinion, 61.8% of the parents reported they had had positive opinions (similar to the 56.5% reporting retrospective positive opinions regarding the move in the post-move-only studies).

Qualitative comments of parents on their concerns, observations, and suggestions about deinstitutionalization, and specifically about parental involvement, were included in the 23 studies reviewed, and in four additional studies that examined parent attitudes and experiences with deinstitutionalization but that did not contain measures of satisfaction that could be expressed quantitatively. Tables 4 through 7 categorize these comments and provide examples of the observations and experiences of parents that underlie the parent attitudes reported in Tables 1, 2, and 3. The suggestions made by parents and/or researchers regarding efforts that were, or might have been, made to make the deinstitutionalization process less stressful and more positive for parents were also summarized.

Table 4 records 51 reasons expressed by two or more parents for their opposition or concern about deinstitutionalization. In general, the parents were concerned because of (a) their perception of the superiority of the institutional environment, (b) the potential or existing problems in community settings, (c) the perceived problems with the deinstitutionalization process, and (d) the potential negative implications for the family of deinstitutionalization. Table 5 notes 40 concerns, often continuing concerns, that parents had about community settings after their son or daughter moved to a community-based residence. Major categories of concern included (a) negative changes in the person who moved, (b) unsatisfactory conditions in some community settings, (c) inadequacies in the programs or services available in some communities, (d) staffing problems, such as high turnover in the community settings, (e) perceived problems with the administration of the community services, and (f) negative impacts of the deinstitutionalization process on some families. Table 6 records 45 positive outcomes noted by parents after a move from institutional to community settings. Categories of positive outcomes included (a) positive changes in the person, such as increased happiness, (b) positive environmental features, such as a more home-like setting, (c) improved services, including higher quality of services, (d) positive staff characteristics, such as being respectful and encouraging, and (e) positive family impacts, such as increased enjoyment in visiting. Finally, Table 7 records 41 recommendations made primarily by the researchers who conducted these studies, but also by some parents, concerning ways to facilitate parental satisfaction with the process and outcomes of deinstitutionalization, ways to make deinstitutionalization less stressful for individual families, and

Table 3

Parent Attitudes About Residential Placement: Parents Sampled During Institutional and Community Placement

Authors (Date)	State	No.	Residence[a]		Satisfied w/Institution			Opinion re: Move			Satisfied w/Community		
			Insti-tution	Com-munity	Positive	Neutral	Neg-ative	Positive	Neutral	Neg-ative	Positive	Neutral	Neg-ative
Conroy & Bradley (1985)	PA	472	X		83	11	7	14	14	72			
Conroy et al. (1987)	PA	369		X							88	6	6
Eastwood (1985)	MA	32[b]	X		92	3	5	32	18	50			
		38		X				88	6	6	84	6	9
Feinstein et al. (1986)	LA	11	X[c]		70	30	0						
		53		X[c]				43	28	29	81	19	0
Weighted mean %[d]			X		83.3	10.9	6.7	15.1	14.3	70.6			
Weighted mean %[e]				X				61.8	18.8	19.4	86.9	7.5	5.6

[a] 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.
[b] This study used an institutional contrast group that was not the same as the community group.
[c] These studies asked how satisfied the respondent was the place where his or her relative was living, while all of the other studies asked about satisfaction with the level of care/programming/services.
[d] These means reflect opinions of parents surveyed during institutionalization.
[e] These means reflect opinions of parents surveyed during community placement.

ways that the service delivery system could be more responsive to family needs. Four of the five categories of suggestions related to ways of encouraging and involving parents in the deinstitutionalization process. The fifth category included changes in the service delivery system that would address parental concerns.

In addition to noting the broad range of comments summarized in Tables 4 through 7, several studies asked parents specific questions. A review of those reports revealed six items that appeared in at least two independent studies. These items noted parental responses to questions regarding changes resulting from deinstitutionalization. Some studies reported the mean response of parents on a scale of 1 to 5 (1 = very satisfied, or substantial positive change in their family member; 5 = very negative, or substantial negative changes). Other studies reported the percent of parents reporting positive, neutral (no change), or negative change in the area listed. As shown in Table 8, most parents in these studies reported positive changes in their son's or daughter's happiness and relationships with others after the move to the community. Most also reported satisfaction with the availability/adequacy of needed services, and the competence of staff in community settings. Parents reported that no change in their own relationships with their sons or daughters was associated with the move. However, only 43.7% of the parents reported positive feelings about the security of funding for community residences.

Discussion

As previously noted, Conroy (1985) identified four major gaps in the literature on parental responses to deinstitutionalization: (a) the lack of an adequately representative national sample of families of persons

who are institutionalized, (b) limited understanding of the reasons for parental opposition, (c) the lack of pre-test/ post-test studies of changes in parental attitudes, and (d) potential unexamined differences between parents of adults versus parents of children who are to be deinstitutionalized. The studies reviewed here respond to at least three of these four gaps.

The first gap was partially addressed in the study by Spreat, Telles, Conroy, Feinstein, & Colombatto (1987), which included a representative national sample of 284 parents of institutionalized persons. More impressively, the state and local studies reviewed here surveyed over 4,000 parents from fourteen different states, including five from the Northeast Census region, four from the Midwest, three from the South, and two from the West. All reported similar findings.

The gap in understanding parents' reasons for opposing deinstitutionalization was addressed to some extent in the summaries of parent perceptions in Table 4. Although the comments noted were not ranked in terms of frequency or the strength of the perceptions, all came from more than one parent and most were mentioned in more than one study. Table 4 represents the diversity of reasons for parental opposition to deinstitutionalization. Further study is needed to determine which reasons are most frequent among parents of people in institutions.

The third gap, an absence of pre-release/post-release investigations, was not adequately addressed by any of these studies. Although three studies attempted to measure parent attitudes at two or more points in time, one used completely different groups, and the other two used overlapping but not identical groups. This area remains a major limitation of the data base on changes in parent attitudes related to deinstitutionalization. On

Table 4
Reasons for Parental Opposition to Deinstitutionalization

I. **Some parents believe that institutions are better environments for some people.** (4, 7, 10, 11, 14, 16, 19, 21, 22, 24, 25, 27)
- Parents feel that mental retardation experts, special resources and services are more readily accessible in a centralized institution.
- Parents believe that staff in the institution are caring and loving.
- Parents think that institutional residents have more freedom to walk on grounds.
- Parents feel that the family member would be happier and more satisfied with "their own kind" in the institution.
- Parents believe the family member needs an institutional level of care, protection, security, and 24-hr supervision because of their level of mental retardation, medical needs, or behavioral needs.
- Parents view the institution as a permanent home for their family member.
- Parents felt the person would die if he/she had to leave the institution.
- Parents consider the person too vulnerable or 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 feel 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 made normal. Therefore, they should not be treated as such.
- Parents are concerned because the family member previously failed in a community setting.
- Parents felt that normalization, the developmental model, least restrictive environments, and dignity of risk were inappropriate concepts for persons with mental retardation.

II. **Some parents prefer the institution because they perceive currently available community-based settings as undesirable or inappropriate.** (1, 4, 7, 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 (especially medical and behavioral services) are not as available or are insufficient in community settings (particularly in rural areas).
- Parents fear there is an absence of supportive services in the community, particularly for those with 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.
- Parents fear the move will have a negative effect on the person's relationship with family members.

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.

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 and monitoring 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.
- Parents are concerned about turnover in community settings.

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 (i.e., opening and closing facilities) because their future viability and reliability is unknown.
- Parents fear the unknown (i.e., 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 son/daughter to live.
- Parents worry that the client will be pushed into yet another more independent setting.

III. **Some parents are opposed to deinstitutionalization because the process itself is seen as injudicious.** (11, 14)
- Parents feel that decisions about who and how many people should move are not made based on individual needs.
- Parents fear that the person will be "dumped" into an inappropriate placement.
- 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.** (4, 7, 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 are concerned about their ability to meet the physical and emotional demands of those who are deinstitutionalized.
- Parents fear the potential financial impact on the family.
- Parents fear an increased burden in terms of their social life, job, recreation/vacation opportunities, or time spent alone or with their spouse.
- Parents fear possible strains on family harmony and functioning.
- Parents feel that deinstitutionalizing some will have negative funding ramifications for the institution.
- Parents feel that emotional stresses including guilt related to institutionalization, anger, confusion, fear of the unknown, and embarrassment resurfaced during the consideration of deinstitutionalization.
- Parents were concerned that the person would move farther away.

Note. The sources for the comments in each major section are indicated by the numbers in parentheses. The numbers refer to entries in the reference list.

Table 5
Continuing Concerns about Community Settings

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 appeared more belligerent, rude, or hostile.
- The person's appearance, hygiene, or attire was perceived as worse.

II. The environment of the community setting was not satisfactory. (8, 18, 20)
- The physical conditions or upkeep of the home was 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 in the community home.
- The home was crowded/too small.

III. 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.
- The day program was not integrated into the community.
- The person moved before the facilities were ready.
- The person had to move again because of another person's behavior problems.
- The person doesn't like his/her job.
- Parents were uncertain about the permanence of community programs.
- The family member needed more to do, a greater chance to get out, and more integrated experiences.
- There was perceived to be an absence of meaningful training activities in the day programs.
- Parents were concerned about services for persons who were aging.

IV. There were staff-related problems in the community setting. (1, 3, 4, 8, 11, 15, 20, 26)
- The setting had high staff turnover rates.
- There was inconsistency related to turnover.
- The staff members were poorly paid, too young, or inadequately trained.
- The resident was not getting enough attention.
- Staff members had to do too much paperwork.
- No funds were available for increased staff for a person who had behavioral or medical emergencies.
- Communication between staff and parents was not good.
- More staff members were needed for community activities.

V. There were perceived problems with the administration or structure of the community service system. (1, 4, 5, 8, 11, 12, 15, 18, 20)
- The 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.
- The parents noticed problems with case management.
- Parents were apprehensive about future relocation and transfers and prefer the status quo.
- The person was moved or reinstitutionalized due to behavioral or other problems.
- Parents worried that the person will be reinstitutionalized if the community setting fails.
- There was a lack of acceptance of the family member by the community.

VI. The deinstitutionalization process was seen as having a negative impact on the family. (1, 4, 5, 8, 12, 15, 20, 26)
- There was inadequate communication between care providers and guardians.
- Parents 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.

Note. The sources for the comments in each major section are indicated by the numbers in parentheses. The numbers refer to entries in the reference list.

a more positive note, the findings of the three studies that did sample groups of parents at more than one point in time had results that were very similar to those of both the pre- and post-release studies.

The final gap perceived by Conroy (1985), understanding the differences that may exist between parents of children and youth and parents of adults, was addressed only indirectly in three studies. Marsh (1984) reported a small, but statistically significant, difference in the mean age of residents whose parents opposed and those whose parents supported community placement ($M = 33.38$ and $M = 29.41$, respectively, $t = 3.61$, $df = 332.7$, $p < .001$). Spartz (1986) also reported that

the age of the son or daughter was related to parental opposition to community placement ($\chi^2 = 6.562$, $df = 2$, $p = .038$, $N = 319$), but again the magnitude of differences was small. Finally, Meyer (1980) reported that younger respondents were more likely to prefer community placement both in the present and in the future. Although differences in attitudes as related to the age (and other characteristics) of the parents of institution residents remains an important issue, practically speaking, the number of children and youth in institutions is decreasing rapidly. Children and youth (0 to 21 years) comprised only 10.6% of all residents of public facilities in 1989, with children aged 0 to 14

Table 6
Positive Outcomes Related to Community Placements

I. **The person who moved to the community was considered to have changed for the better.** (1, 4, 8, 9, 11, 12, 13, 15, 18, 20)
* The person became happier, more communicative, more aware, more content, and more relaxed.
* The person showed increased warmth, affection, and self-esteem.
* The person showed improved emotional development.
* The person developed more social relationships with other people.
* The family member had a positive attitude about returning to the community residence after a home visit.
* The person became more confident, independent, and responsible.
* The person's quality of life improved.
* The family member was clean and well cared for and showed better hygiene and appearance.
* The family member was acquiring skills through 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.
* The family member is living well now whereas at the institution he merely existed.

II. **The qualities of the environment in the community setting were judged to be better than those of the institution.** (1, 4, 8, 11, 12, 15, 20)
* The location was considered better (closer to family members, resources, etc.).
* The environment was considered more stable and relaxed than the institution.
* There was an every day 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 for increased individual attention.
* The community setting was considered the best place this family member has ever lived.
* The home is clean and well cared for.

III. **The services available in the community setting were seen as better than what was available in the institution.** (1, 3, 4, 5, 8, 11, 12, 18)
* The services were considered higher quality in the community.
* All needed services were currently available, including behavioral, medical, vision, OT/PT, speech, self-care, independent living, etc.
* More one-to-one personal attention was available.
* The house was judged to be well managed, efficient, and intelligently run.
* Enjoyable activities, and recreation opportunities were available.
* The day program was felt to be enjoyable and doing a good job.
* There were more opportunities to learn, experience new environments and activities, and make friends in the community.

IV. **The staff were considered as having a positive impact on the person.** (1, 3, 4, 5, 8, 11, 18, 20)
* Staff provided personalized attention and interest.
* The residence had good quality staff who were sincere, knowledgeable, capable, and skillful.
* The staff of the community facility showed respect for residents.
* The staff do a good job.
* 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, 4, 8, 11, 12, 15)
* The move was reported to have improved the relationship between the person, 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 their brother or sister.
* 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.
* The move allowed an increase in the frequency of visits.
* Parents were more able to give suggestions about care.
* Parents want the person to continue living in the home.
* The move resulted in positive attitudes about the benefits of deinstitutionalization.
* The parent and the family members now felt better, happier, and were more at peace about the living situation.
* Parents now have increased expectations for the development potential of their family member.

Note. The sources for the comments in each major section are indicated by the numbers in parentheses. The numbers refer to entries in the reference list.

years old constituting 2.7% of all residents and 4.7% of all releases, and youth 15 to 21 years old constituting 11% of all discharges (Scheerenberger, 1990).

Although these studies produced a wealth of information, certain methodological limitations were evident. First, there are questions about the reliability and validity of the survey instruments. The majority of these studies used unpublished instruments with untested reliability, although the use of satisfaction scales is commonplace. The results may also have been influenced by a response bias. Heal & Fujiura (1984) noted that attitudinal variables, such as parental satisfaction, are susceptible to differences in the way the survey was administered, to the characteristics of the investigator administering the surveys, and to the characteristics and roles of the respondents. The David, Morris, and Suom-

Table 7
Ways to Facilitate Parental Satisfaction with the Deinstitutionalization Process

I. Attend and respond to the perceptions, needs, and concerns of family members. (1, 4, 10, 14, 15, 20, 21, 22, 24, 25, 27)
- Professionals should recognize that families have information and experiences that 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 of parents.
- Professionals should make referrals to support groups of parents who have gone or who are now going through the process of deinstitutionalization.
- 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 listen actively, address, and resolve additional 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, 4, 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.
- Professionals should consult with parents throughout the decision-making and placement process.
- 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 institutional settings 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 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, 4, 5, 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 that parents who have been through deinstitutionalization can 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.
- Before the move, service providers and other professionals should arrange informational sessions and schedule open houses at the new residence.

IV. Establish and maintain effective communication links between community providers and family members. (1, 4, 5, 15, 20, 27)
- Professionals should provide information about the type of community residence to which a particular person will be moving.
- Service providers and other professionals should maintain contact with, and involvement of, parents by sharing information regularly about their resident's 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 that 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 to 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, 5, 6, 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.

Table 7—*Continued*

- 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 establish permanent systems to monitor and evaluate quality of community services effectively and educate parents about these efforts.
- Policy makers and professionals should promote and publicize efforts that enhance the image of permanence for community settings.
- 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 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 consumer, the citizen moving to the community.

Note. The sources for the comments in each major section are indicated by the numbers in parentheses. The numbers refer to entries in the reference list.

Table 8
Quantitative Summary of Parental Comments Regarding Changes Resulting from Deinstitutionalization

Parental Opinions After Deinstitutionalization	No. of Studies	No. of Parents	Mean Score[a]	Mean Percent Reporting[b]		
				Positive	Neutral	Negative
Change in son's or daughter's happiness after	3	161		74.7	18.6	6.7
the move	2	166	1.74			
Parental feeling that needed services are avail-	1	27		74	15	11
able/adequate in the community setting	2	166	1.86			
Change in relationships between son or	1	25		68	24	8
daughter and other people after the move	3	198	1.86			
Parental satisfaction with the competence of	5	713		77.1	(12.9)[c]	(10.5)[c]
the community staff	3	198	2.39			
Change in relationship between parents and	1	102		25	75	0
son or daughter after the move	3	198	2.48			
Parental feeling that the funding for com-	3	499		43.7	(27.5)[c]	(31)[c]
munity residences is secure	3	198	2.57			

[a] These studies reported results as a mean score on a scale of 1 to 5. All of the means have been coverted so that a score of 1 means very satisfied or much change for the better, whereas a score of 5 means very dissatisfied or much change for the worse.
[b] These studies reported the simple mean percentage of parents who reported each level of satisfaction.
[c] The percentages listed in parentheses were based on a smaller number of studies than the positive rating. This happened when one or more study reported only the percent of parents who reported positive answers.

ala study (1983) addressed the possibility that different investigating agencies may induce differential responding by sending half of the surveys on the letterhead of an institution, and the other half on the letterhead of the Governor's Planning Council on Developmental Disabilities. However, they found no statistically significant differences in the responses of the two groups.

Second, questions can be raised about the representativeness of the findings. The state and regional studies reviewed here had response rates ranging from 50% to 84.4%, with a median of 63%. The lone national study (Spreat et al., 1987) reported a considerably lower response rate of 35.5%. The question of whether the responders varied systematically from nonresponders was addressed by Conroy & Bradley (1985), who noted no significant differences between these groups on a subset of the most critical items. The issue of representativeness also applies to whether the characteristics of persons moving to community settings whose families reported satisfaction were comparable to the characteristics of those who remained in the institutions, whose families' eventual satisfaction after deinstitutionalization we may wish to infer. As deinstitutionalization

has progressed, the people remaining in institutions typically have more severe impairments than those moving to community settings (White, Lakin & Bruininks, 1989). However, in the five studies (c.f. Tables 2 and 3) reporting the level of retardation, a mean of 56% of those who were deinstitutionalized had severe or profound mental retardation.

Finally, the majority of the studies of post-deinstitutionalization attitudes used retrospective data rather than pre/post data. While this practice afforded the opportunity to examine the differences between retrospective and prospective attitudes, it also demonstrated that this approach is not adequate for determining what would have actually been said in a pre/post survey. Clearly, future research that seeks to examine accurately changes in attitudes must measure these attitudes both before and after the intervention.

This review revealed several patterns in the results of parent attitude studies. Across the different types of studies, parents whose offspring were living in institutions at the time of the survey were overwhelmingly satisfied with the institutions (90.0%). Despite the considerable criticism of institutional settings in contem-

porary scholarly writing and court opinions (Haney, 1988; Heal, 1988; Scheerenberger, 1983), parents of institutionalized adults and children still feel that institutions serve their son or daughter well. In most studies (10 of 12), 60% or more of the parents of currently institutionalized people were opposed to moving their offspring from an institution to a community setting. This pattern has remained quite constant across time and is still evident in the studies conducted in the late 1980s.

The studies that asked parents to look retrospectively at their satisfaction with institutions were particularly interesting. There was a substantial discrepancy between parents' reported satisfaction with institutional settings when they were asked prospectively (i.e., before movement from the institution) versus parents' reported satisfaction about institutional settings when asked retrospectively (i.e., after movement to the community). The mean level of satisfaction with the institution for retrospective studies was 52.3%. However, when questions were asked during institutional placement, the mean level of satisfaction across all types of studies was 90.0%. In addition, across all types of studies an average of 19.9% of parents surveyed during their child's institutionalization reported positive opinions about a move to the community, but retrospectively, an average of 57.7% of parents reported initial positive opinions.

These findings raise an important question about why parental responses change so dramatically. It may be 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 on institutional living. Once having seen the nature of the community residences, the institution may not look as good as it once did. This in turn may have affected their recollection of past satisfaction. An alternate possibility was suggested by Conroy (1985). He explored the possibility that changes observed in parental responses after deinstitutionalization can be explained by dissonance theory. Basically, his explanation was that the decision to place a child in an institution, despite the negative consequences of such a decision for the child, could create a state of high post-decisional dissonance. This dissonance is reduced over time as parents come to adopt a position that the institution is what the relative needs. Placement into a community setting provides strong evidence that the institution was less appropriate than the parents once believed. This then results in a change in attitudes about both the institution, and about the appropriateness of the community setting.

The summary of quantitative data on parental attitudes about residential placement shows clearly that prior satisfaction with institutional care and reservations about community care in time turns into satisfac-

tion with community settings for the majority of families. Nine of the 10 studies that surveyed parents about community settings found that over 80% of the parents were satisfied. The summary of family comments about the process of deinstitutionalization, however, clearly shows there are many ways this process can be improved to respond better to the concerns and needs of families. Parents are concerned about deinstitutionalization and community placement for a variety of reasons. Some of the reasons for resistance to deinstitutionalization turn out to be contradicted by the realities of community living. For example, there is strong evidence that moving from an institution to a small community setting is associated with positive outcomes for persons with all levels of mental retardation. Some of these positive outcomes are improved adaptive behavior (Larson & Lakin, 1989) and increased social participation (Conroy & Bradley, 1985; Hill & Bruininks, 1981; Horner, Stoner & Ferguson, 1988; Molony & Taplin, 1988). Furthermore, more parents in the studies summarized in Table 8 reported increased happiness and improved social relationships among persons who moved, and a wide variety of other positive outcomes were noted by parents in the studies summarized in Table 6. Finally, concerns expressed before the move about the availability and adequacy of services, and the competency of staff turned out not to be concerns for most parents after the move. When such evidence is available to counter concerns noted by parents, professionals have an obligation to provide in a respectful manner information to facilitate the reduction of parental anxiety. This will require establishing and maintaining effective communication links between providers and family members. Responding to parental uncertainty about their son or daughter's future lifestyle by arranging opportunities to learn about and visit community sites and talk with parents of persons who previously moved to the community also appear to be helpful.

On the other hand, some of the concerns raised by parents before deinstitutionalization turn out to be continuing concerns after deinstitutionalization. These continuing concerns underline the importance of attending and responding to the perceptions and concerns of family members before, during, and after their child moves from an institution to a community setting. The importance of responding to parental concerns and encouraging their participation in the deinstitutionalization process was also confirmed by Stoneman and Crapps (1990), who found that the amount of parental involvement in the deinstitutionalization process appears to be a strong predictor of future involvement by parents. Acknowledging parental concerns before the move, facilitating parental participation in the deinstitutionalization process, and involving parents in ongoing quality assurance efforts to address concerns such

as those noted in Table 5 requires only the commitment to do so. Responding to parents' concern about the stability of funding for community settings and other systemic matters requires broader attention to federal, state, and local policies as they affect and assure long range support for community services.

However, the clearest message in these studies is that the overwhelming majority of parents become satisfied with community settings once their son or daughter has moved from the institution, despite general predispositions to the contrary. The primary implication that may be drawn is that professionals, policy makers, and advocacy groups still have much to do in implementing programs that will assist parents in developing as early as possible the positive, less stressful attitudes about deinstitutionalization and community living that eventually almost all parents come to feel.

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