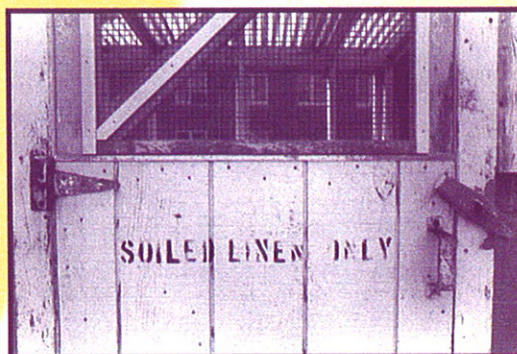
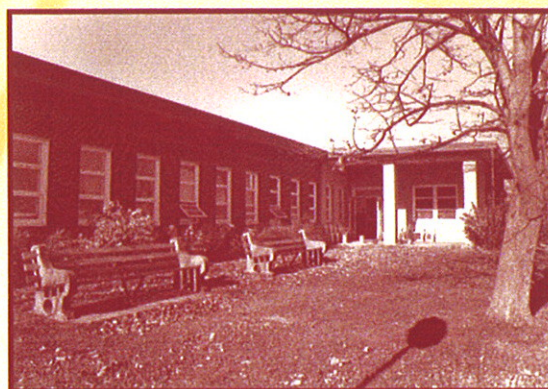
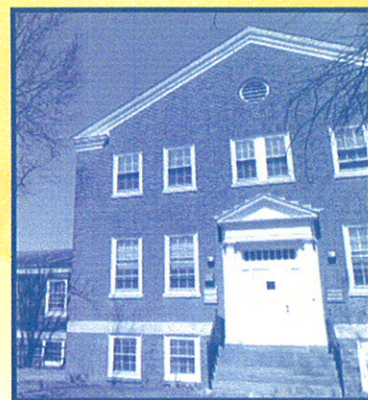


Life After North Princeton Developmental Center

Final Outcomes

A Follow-up of Former Residents



*Prepared by Staff of the
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LIFE AFTER NORTH PRINCETON DEVELOPMENTAL CENTER: FINAL OUTCOMES

A FOLLOW-UP OF FORMER RESIDENTS

NOVEMBER 2003

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The successful implementation of the Developmental Disabilities (DD) Planning Institute's research design to evaluate the closure of the North Princeton Developmental Center (NPDC) in the State of New Jersey relied on the cooperation of many persons and organizations. This cooperation occurred from the onset of the project, with staying informed of closure activities, and continued through the entire evaluation period as comprehensive information was collected on former NPDC residents and those in DD Centers. Information was gathered from consumers and their families or guardians, as well as the staff who were currently working with them. Thus, this evaluation was only possible with the cooperation and time of virtually hundreds of individuals, all of whom assisted us freely during countless hours of fieldwork.

The DD Planning Institute would specifically like to acknowledge those who were instrumental in the data-collection efforts of this progress report. These individuals are as follows:

- Consumers for their participation and critical insights into the current service delivery system for persons with developmental disabilities;
- Family members and guardians of consumers for providing their own unique and valuable perspectives; and
- Staff employed in the DD Centers and community provider agencies for coordinating necessary interviews and providing essential information.

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projects, but have also granted us the freedom to design and implement follow-up evaluation studies that strive to meet the highest standards of social science research.

All of the descriptions, statistical inferences, and conclusions drawn as part of this evaluation are solely based on the professional opinions of DD Planning Institute staff. Some material in this report may not necessarily reflect the opinions of staff employed by the State of New Jersey and their provider organizations.

Chapter I: Executive Summary and Summary of Findings

Executive Summary

This is the fourth and final report published by the DD Planning Institute which evaluates the impacts of closure of North Princeton Developmental Center (NPDC) on its former residents. Data for this final progress report were collected in 1994 and 1996 prior to the NPDC closure and 3, 15, and 27 months after consumers had left the facility. Data sources included staff, family members/guardians, and consumers themselves. The evaluation was based on following a sample of 150 consumers who left NPDC (called “movers”) and a matched sample of 150 consumers who remained in New Jersey’s other DD Centers (called “stayers”). A major goal of the evaluation was to assess the quality-of-life of persons who moved into community residences after leaving NPDC.

There is strong empirical evidence that higher community participation, family phone contacts, self-care, freedom, mental health utilization, and productivity are positively linked to community living. There is moderately strong empirical evidence that promoting autonomy, family visits, and safety are also positively linked to community living. In all evaluation domains that were assessed within the first 27 months after the NPDC closure, consumers living in the community were doing “equal to or better than” their institutional counterparts.

There is no evidence that deinstitutionalization in New Jersey is associated with increased mortality, and no other negative consequences of deinstitutionalization were found.

Despite opposition to the closure of NPDC by some family members, there is now strong support of community living by a clear majority of NPDC family members. These positive subjective assessments by the relatives of former residents – coupled with empirical

data supporting “equal to or better” quality-of-life for consumers living in the community – provide strong support for expanding and accelerating community living alternatives for many persons currently living in New Jersey’s DD Centers.

Summary of Findings

Highlights of the major findings of this evaluation study are as follows:

Implementation of Research Design and Closure Process

- ❖ The “movers” and “stayers” were statistically equivalent on key characteristics, allowing comparisons between these groups. “Movers” selected randomly were similar to all those who left NPDC – making it likely that their experiences after the closure were comparable to all former residents of NPDC after leaving.
- ❖ High response rates were obtained from staff and family members/guardians at all time periods. While staff of the DD Planning Institute met with all of the consumers in the evaluation sample, only a very small proportion were able to be interviewed about their current well-being due to their cognitive abilities.
- ❖ Analyses of person-centered plans for all “movers” revealed that successful implementation occurred only for consumer choices regarding the number of persons living in their residences.

Living Arrangements

- ❖ Most “movers” moved to group homes after leaving NPDC, with some individuals remaining in DD Centers or nursing homes. Those with lower mobility and/or swallowing problems were more likely to go to institutional placements after NPDC.
- ❖ Almost all group home settings were found to be less institutional than DD Centers or nursing homes. Comparable institutionalization ratings were found between nursing homes and DD Centers.
- ❖ Community residences were more likely to have the following features: (1) the outside of residences look like others in the neighborhood; (2) the inside of residences look like others in the neighborhood; (3) residences have a smaller number of persons residing in them; (4) consumers have more personal possessions evident; (5) staff engage in more informal interactions; (6) fewer social controls are used; and (7) domestic skills are taught.

Day Activities

- ❖ About half of “movers” and “stayers” who reside in DD Centers left their cottages for day activities while almost three-fourths of community “movers” leave their homes during the day.
- ❖ About one-third (36%) of DD Center residents and 12% of those in the community receive in-home day services. These in-home activities were predominately socialization-focused, and few were paid for their efforts. All of those compensated were paid directly by their residential providers.

Deaths at 27 Months

- ❖ A total of 35 “movers” and “stayers” had died during the evaluation period.
- ❖ Four characteristics measured in 1994 prior to the NPDC closure were the best statistical predictors of death. They included: (1) being 60 years or older in 1994; (2) having epilepsy/a seizure disorder in 1994; (3) having low self-care abilities in 1994; and (4) having one or more medical conditions in 1994.
- ❖ Persons with high-risk characteristics who moved into nursing homes had an increased chance of dying by 27 months.
- ❖ Community living had no significant independent impact on the death rates of consumers.

Competencies and Behaviors

- ❖ Community living was strongly associated with gains in self-care competencies, while institutional living was significantly related to losses in multicognitive functioning. No differences due to residence type were found for mobility.
- ❖ Increases in the behavior towards self of “movers” were associated with the prior existence and continuation of psychiatric problems and treatments, rather than with community residence per se.

Relationships with Family and Peers

- ❖ Phone contacts by family members/guardians were definitely more likely to occur if individuals were residing in community residences, regardless of their own characteristics. Family visits were also more likely to occur in community residences at 3 months. However, there were sharp decreases in visits thereafter.
- ❖ The acquisition of more peer friends is not influenced by community living at any time period. Instead, having peer friends is determined by higher levels of competencies and displaying lower rates of aggressive behaviors at different time periods.

Health Care Utilization

- ❖ Initial health utilization differences found at 3 months between community and institutional residents had dissipated by 15 and 27 months. However, residence in the community continued to predict seeing a psychiatrist (if a psychiatric diagnosis existed) at all time periods, even after considering other consumer characteristics.

Attitudes About Quality-of-Life and Consumer Choice of Residence

- ❖ Community family members were much more likely than those with relatives in institutions to think that consumer life quality in all areas (such as material well-being, productivity, personal safety, and health) was best achieved in community residences.
- ❖ Community family members/guardians believed that life overall is significantly better for consumers in the present than it was at NPDC. Institutional family members/guardians did not significantly change their views about consumers' lives overall at NPDC and at present.
- ❖ Community families were nearly unanimous in their view that it is better to live elsewhere than at NPDC. Institutional families did not feel the same way.
- ❖ Of the "movers" who were identified as reliable respondents, those living in community residences after the closure showed a positive shift in wanting to live in settings other than NPDC and in their ratings of their life quality overall.

Empirical Findings on Quality-of-Life

- ❖ There is **strong** empirical evidence that community residence is positively associated with a better quality-of-life in the following areas:
 1. Community participation;
 2. Promoting family phone contacts;
 3. Promoting self-care;
 4. Promoting freedom via lower social controls;
 5. Promoting mental health utilization; and
 6. Promoting productivity.

- ❖ There is **moderately strong** empirical evidence that community residence is positively associated with a better quality-of-life in the following areas:
 1. Promoting personal choices and autonomy;
 2. Promoting family visits; and
 3. Promoting safety from personal harm and of one's personal possessions.
- ❖ There is **weak** empirical evidence that community residence is positively associated with a better quality-of-life in the following areas:
 1. Promoting physical health care utilization; and
 2. Promoting emotional well-being.
- ❖ There is **no empirical evidence** that any of the following specific quality-of-life areas are better achieved in either community settings or DD Centers:
 1. Peer friendships;
 2. Reducing inappropriate behaviors; and
 3. Promoting material well-being.

Chapter II: Description of Research Design and Sample

Introduction

On the 19th of April 1995, the former Commissioner of the New Jersey Department of Human Services, William Waldman, issued a statement that confirmed the State's intention to close the North Princeton Development Center (NPDC), a state-operated facility for persons with developmental disabilities. While the Division of Developmental Disabilities – the branch of the Department of Human Services charged with the oversight of all of the State's services for persons with developmental disabilities – had closed another of its developmental centers in 1992, the announcement to close NPDC was extremely significant for several reasons. First, with the announcement came an unprecedented commitment by the former Director of the Division of Developmental Disabilities, Dr. Robert Nicholas, to serve all those residing at NPDC – even those with extremely intensive needs – within community settings. In previous institutional closures, only individuals who had the highest cognitive competence and skill levels were placed in community settings, while others were transferred to other institutional settings.

The commitment to community services for all persons leaving NPDC was accompanied by a promise that consumers would have placements “equal to or better” than the institution (DHS, 1995). Thus, the Division of Developmental Disabilities asked the DD Planning Institute to design and implement a research study that could evaluate the extent to which consumers' functioning, behaviors, and quality-of-life were impacted by the NPDC closure.

Another unique feature of the plans for the NPDC closure was a commitment by the Division of Developmental Disabilities to use a “person-centered” planning process. A person-centered approach was selected over a more traditional systems-centered strategy to

plan for the postclosure services of NPDC residents. This approach attempted to emphasize individual and family preferences and consumer strengths – in order to enable them to become more productive and independent (Waldman, 1995). Resources were expended to pay for the education and training of staff, families, and consumers about the person-centered process. Individual Support Plans (ISPs) were developed for all persons in order to individualize community-based placement decisions. Postclosure provider organizations were selected for individuals based upon how well they proposed to meet the preferences of, and services recommended by, consumers, family members, and concerned others as outlined in these ISP documents. While there was widespread agreement that a “person-centered” approach was an ideal philosophy in planning for persons with developmental disabilities, this effort represented the first time this approach was officially endorsed by the Division and implemented systematically with any of its clients. Using the Individual Support Planning process as the basis for designing and choosing alternative living arrangements for NPDC residents after the closure represented a departure from traditional transitional planning. The use of “person-centered” planning was perceived as constituting a major shift in the State’s decision-making processes regarding service delivery for NPDC residents (Lerman et al., 1996).

Individual Support Plans were expected to serve as documents whose implementation was deemed pivotal to positive outcomes and functioned as the “blueprints,” which providers were to use in designing alternative living arrangements and varied supportive services. Thus, the degree to which these ISPs were executed, and consumers’ choices and service needs were realized, was seen as critical to achieving ideal policy goals, enhancing the life quality of consumers, and increasing consumer and family satisfaction with new community placements. Determining the extent to which the

implementation of ISPs actually occurred, as well as examining other aspects of the deinstitutionalization process, were seen as central research tasks of the DD Planning Institute's evaluation of the NPDC closure.

Overview of Research Design and Evaluation Measures

The overall goal of our research was to evaluate whether the closure of the NPDC and the provision of care in alternative living arrangements impacted on the functioning, behaviors, and quality-of-life of its former residents. Two major aspects of the closure process were chosen for assessment: (1) the extent to which consumers' choices, services, and supports – as outlined in their Individual Support Plans – were actually executed following the closure; and (2) the degree to which specific factual knowledge about each consumer's level of functioning, medical status, and service and adaptive equipment needs was transferred to new provider agency personnel. After examining the implementation of the Individual Support Plans and the transfer of critical knowledge, the evaluation was designed to assess the impact of the closure on the lives of the former residents – using objective and subjective measures. In order to achieve these broad goals, 6 specific research objectives were identified, as discussed below.

- **Implementation of Individual Support Plans** – This study proposed to assess the extent to which services, supports, and activities desired by 150 former NPDC residents, their families, and concerned others, as outlined in their Individual Support Plans (ISPs), were provided within the first 3 months after consumers' initial moves.
- **Transfer of Knowledge About Consumers Between NPDC Personnel and New Provider Personnel** – This study aimed to assess the extent to which knowledge about 150 former NPDC residents' levels of disability, medical statuses, and adaptive equipment and medical service needs was transferred from institutional personnel to provider staff assisting consumers after the closure.
- **Documentation of New Living Arrangements After the Closure** – This study aimed to provide information about the living arrangements of 150 former NPDC residents at 3, 9, 15, and 27 month periods after their initial moves. Additionally, it was designed to

document any changes in the residential statuses of the former NPDC residents between these time periods.

- **Changes in Competencies and Behaviors** – This study aimed to report on the multicognitive functioning, self-care capabilities, mobility, and special behaviors of 150 former NPDC residents at 3, 9, 15, and 27 month periods after their initial moves. Changes in these areas from their initial institutional baseline levels would be analyzed and comparisons with similar persons who continued to reside in DD Centers would be conducted.
- **Comparisons of Quality-of-Life Measures** – This study proposed to assess the quality-of-life of 150 former NPDC residents after they left the facility. Changes in quality-of-life between 3, 9, 15, and 27 month periods after their initial moves would be examined and the quality-of-life of the 150 former NPDC residents would be compared with that of similar persons who continued to reside in DD Centers. Additionally, the abilities of consumers' competencies and behaviors, as well as environmental and programmatic features within their living environments, to explain life quality would be assessed.
- **Examination of Family Member/Guardian and Consumer Satisfaction with Closure** – This study aimed to report the retrospective feelings of 150 former NPDC residents and their family members/guardians about the care received at NPDC prior to its closure and compare it to that reported after consumers' initial moves.

In order to meet all of the evaluation objectives, data was collected from a variety of sources – including staff, family members/guardians, and consumers themselves – according to a carefully constructed research design. This design is summarized in Table II-1. As illustrated, in order to carefully monitor changes in the former NPDC residents (i.e., known as “movers”), assessments were done at the following intervals after they left NPDC – 3, 9, 15, and 27 months. By assessing individuals at 6-month intervals for the first 15 months after placement, it was hoped to determine if there were initial short-term changes in their competencies. Since there was prior evidence that persons living in institutions were unlikely to significantly change in their competencies and behaviors during a 15- to 18-month period (Lerman et al., 1995), those in the comparison sample (i.e., known as “stayers”) were assessed at intervals of 3, 15, and 27 months – or annually.

Table II-1: Overview of Research Design of NPDC Evaluation

Types of Samples	Before NPDC Closure		After NPDC Closure			
	Fall 1994	Winter 1996	Spring 1997-Summer 1998	Fall 1997-Winter 1999	Spring 1998-Summer 1999	Spring 1999-Summer 2000
	T ₁	T ₂	T ₃ (3 months)	T ₄ (9 months)	T ₅ (15 months)	T ₆ (27 months)
Former NPDC Residents ("Movers") (n=150)	Data Collected from Staff on Consumer Competencies, Behaviors, and Family Contact	Data Collected from Staff on Consumer Competencies, Behaviors, and Family Contact	Data Collected from: Staff, Consumers, and Family Members/Guardians on Consumer Competencies, Behaviors, Family Contact, Health Care Utilization, and Quality-of-life	Data Collected from: Staff, and Consumers on Consumer Competencies, Behaviors, Family Contact, Health Care Utilization, and Quality-of-life	Data Collected from: Staff, Consumers, and Family Members/Guardians on Consumer Competencies, Behaviors, Family Contact, Health Care Utilization, and Quality-of-life	Data Collected from: Staff, Consumers, and Family Members/Guardians on Consumer Competencies, Behaviors, Family Contact, Health Care Utilization, and Quality-of-life
Comparison Sample of DD Center Residents ("Stayers") (n=150)	Data Collected from Staff on Consumer Competencies, Behaviors, and Family Contact	—	Data Collected from: Staff, Consumers, and Family Members/Guardians on Consumer Competencies, Behaviors, Family Contact, Health Care Utilization, and Quality-of-life	—	Data Collected from: Staff, Consumers, and Family Members/Guardians on Consumer Competencies, Behaviors, Family Contact, Health Care Utilization, and Quality-of-life	Data Collected from: Staff, Consumers, and Family Members/Guardians on Consumer Competencies, Behaviors, Family Contact, Health Care Utilization, and Quality-of-life

A variety of data collection instruments and tools were used to obtain the necessary information at each time period. The names and brief descriptions of these instruments are summarized as follows:

- **North Princeton Evaluation Information Forms** – These survey instruments were used with current staff to obtain objective information on consumers' competencies and behaviors via modifications of the Client Assessment Form (CAF) and Medical Assessment Form (MAF). These CAF and MAF forms were originally developed and used by the DD Planning Institute in a self-administered format when baseline information on consumers was collected in 1994 and 1996. The North Princeton Information Forms were also used to measure the subjective and objective life quality of consumers, as perceived by staff. Many of the life-quality measures were identical to those asked of consumers and family members/guardians. Interviews with staff were completed in consumers' residences and generally were completed in an hour to an hour and a half. Interviewers were DD Planning Institute staff who were highly trained.
- **North Princeton Evaluation Consumer Surveys** – These interview schedules were used to elicit information and opinion directly from consumers about their life quality. Interview protocols included using FACES scales – in addition to WORDS – to verify the reliability of verbal responses and obtain the satisfaction of those who were unable or had difficulties communicating verbally. Screening interviews using WORDS and FACES were used to identify persons who could provide objective and subjective information about their life quality. Many of the life-quality questions were identical to those asked of staff and family members/guardians. Consumer interviews were conducted in their residences and ranged in duration from several minutes to an hour, depending upon respondents' communicative abilities. In order to protect consumers' confidentiality, every attempt was made to interview consumers in private without the presence of staff or other residents. Interviewers were DD Planning Institute staff who were highly trained.
- **North Princeton Evaluation Family Surveys** – These survey instruments were used to obtain family member/guardian perspectives on consumers' well-being. Family members/guardians provided their own assessments about consumer quality-of-life, whereas staff provided assessments for consumers. Many of the life-quality questions paralleled those asked of consumers and their staff. Family members or guardians were surveyed by phone by an **independent** survey research company, with an average interview length of approximately fifteen minutes. Data was collected from family members/guardians without the interviewers' knowledge of staff/caregiver and consumer responses to similar questions.
- **North Princeton Environmental Assessments** – Direct observational assessments of internal and external characteristics, individualized decorative variations, and "homelikeness" within consumers' living arrangements were made by trained DD Planning Institute personnel. Assessments also included eliciting factual information from staff, such as the distances to stores and other community amenities from these residences.

- **ISP Preferences/Supports Indicator Sheets and ISP Modification Forms** – ISP Preferences/Supports Indicator Sheets were prepared by NPDC case managers and/or other DD personnel to summarize information contained in consumers' ISPs. While ISPs were given to community and other new provider agencies to guide the individualized planning of residential and other support services, ISP Preferences/Supports Indicator Sheets were used internally by DDD personnel to make postclosure placement decisions. ISP Preferences/Supports Indicator Sheets – as well as ISPs – outlined the choices and preferences of consumers, family members, and concerned others regarding living locale, household composition, roommate desires, environmental conditions (i.e., smoking, atmosphere type, accessibility), leisure activities, and recommended levels of service for consumers (i.e., medical, psychiatric, supervision). ISP Modification Forms were completed when consumers' preferences or support needs changed prior to placement. Both consumers' ISP Preferences/Supports Indicator Sheets and ISP Modification Forms were used in conjunction with information from other instruments in order to rate the degrees of actual implementation of consumers' ISPs. Ratings were conducted by the Co-Principal Investigators.
- **Client Assessment and Medical Assessment Forms (CAFs/MAFs)** – These self-administered questionnaires measured the multicognition, self-care functioning, mobility, and special behaviors of consumers. Client Assessment Forms were completed by Habilitation Plan Coordinators (HPCs) and other knowledgeable persons and Medical Assessment Forms were filled out by nursing staff within the DD Centers prior to the time of the NPDC closure. This information was used to assess the transfer of medical and special equipment knowledge from NPDC personnel to new provider staff. Additionally, CAF and MAF data was used to provide baseline information on the entire sample and select the comparison sample against whom competency and behavioral changes in the former NPDC residents were compared over time.

Piloting and Pretesting the Instruments

The measurement instruments used in this study of the NPDC closure were piloted, pretested, and used in the DD Planning Institute's evaluation of the earlier Johnstone closure. For a detailed account of the consumer focus group used to test item wording and sample questions, as well as the pretesting of the draft instruments, see Apgar et al. (1998).

While pretesting on the initially developed instruments was conducted prior to the Johnstone evaluation, slight modifications and wording changes were made for this study based on our experiences of interviewing 155 consumers, staff, and family members/guardians as part of the Johnstone study. Thus, the final instruments used in this evaluation of the NPDC closure represent the conceptual and empirical work done for the Johnstone study, with slight improvements based on practical experiences. In addition, the final 27-month interviews of staff contained improved questions on material possessions and safety.

Interviewer Training and Reliability

With the exception of the surveys of family members/guardians, the data for this study was collected by 5 trained interviewers plus the Director/Co-Principal Investigator of the DD Planning Institute. Two of the 5 interviewers were employed by the DD Planning Institute for the evaluation of the Johnstone closure and, thus, had extensive experience in the unique challenges of obtaining reliable information from persons with developmental disabilities. The other 2 interviewers were known by DD Planning Institute personnel as being experienced, competent professionals with experience in the field of developmental disabilities. Four of the interviewers, including the DD Planning Institute Director/Co-Principal Investigator, have at least a Master's degrees in social work, psychology, and/or counseling and experience in the field of developmental or other disabilities.

After completing formal training, interviewers were required to conduct and observe field interviews until they demonstrated that they were able to reliably complete and code interviews.

Evaluation Sample

The overall “mover” sample is comprised of 136 former NPDC residents who were chosen randomly from all those living at the facility prior to its closure plus 14 former NPDC residents who were oversampled from those who were residing in medical cottages at the facility. A comparison group of 150 “stayers” for these 150 “movers” was then assembled from an earlier random sampling of persons living in New Jersey’s remaining DD Centers. Persons in the “stayer” comparison sample were matched with “movers” based on age, gender, multicognition, self-care, mobility, and behavior towards self and others.

Analyses yielded 2 important findings regarding these evaluation samples. First, the 136 persons in the “mover” sample who were randomly chosen did represent – on all of the matching characteristics – the nearly 500 persons targeted to move to community settings who were living at NPDC immediately prior to its closure. The total 150-person “mover” sample (which included the oversampled medically-frail persons) also represented this group on all, but 2 characteristics – the 150 “movers” were slightly older and less mobile than the rest of the NPDC population. Secondly, study findings revealed that the matched 150 “movers” and 150 “stayers” were statistically equivalent on all of the matching characteristics: age; gender; multicognition; self-care; mobility; and behavior towards self and others. For a detailed description of sample selection and comparability, see Appendix A of this report.

Summary of Research Design

The aims of this evaluation were to assess the impacts of deinstitutionalization on the former residents of the North Princeton Developmental Center (NPDC). In order to achieve the aims of this study, the research design relied on surveys, on-site observations, and reviews of records. Data on the “movers” and “stayers” used in the analyses for this report were based on face-to-face interviews with staff and consumers, telephone interviews with family members/guardians, and direct observations of consumer living environments.

Analyses revealed that the matched 150 “movers” (including 136 persons chosen randomly and 14 chosen to represent the medically frail) and 150 “stayers” were statistically equivalent on age, gender, multicognition, self-care, mobility, and behavior towards self and others. In addition, the 136 person random “mover” sample can be generalized with great confidence to the experiences of all former residents of NPDC who resided there immediately prior to its closure. Thus, the experiences of the random sample “movers” can represent the 27-month outcomes of the nearly 500 persons who lived at NPDC in 1996 prior to its closure. Additionally, assessments of the competencies, behaviors, and quality-of-life of “movers” can be compared with those made for “stayers,” as these 2 groups are statistically the same on age, gender, multicognition, self-care, mobility, and behavior towards self and others.

Chapter III: Sample Status and Survey Respondents

Introduction

As part of the research design, the DD Planning Institute was charged with collecting data on a total of 150 former NPDC residents who were selected from those living at the facility as of January, 1997. Since residents left NPDC on varying dates, information on consumers was collected between April 1997 and August 2000 after they left the facility. Data was obtained from 3 main sources: face-to-face interviews with consumers and staff; telephone interviews with family members/guardians; and on-site assessments by trained interviewers of the DD Planning Institute. This chapter will outline the status of the sample at all time periods and the respondents at each follow-up period.

Sample Status and Attrition

The research design, as depicted in the last chapter in Table II-1, specified that data was to be collected on NPDC residents at 2 points in time – 1994 and 1996 – **prior** to the facility closure. In addition, data on those in the comparison sample was to be collected at one point in time – 1994. These assessments were used to construct the “movers” and “stayers” samples (see Appendix A for a detailed explanation of this process) and served as baseline measures by which to assess changes after the closure.

After the NPDC closure, the 150 former residents in the “mover” sample were scheduled for follow-ups during 4 time periods – 3, 9, 15, and 27 months after they had left the facility. Additionally, the 150 consumers in the “stayer” sample were scheduled for follow-ups during 3 time periods – 3, 15, and 27 months after their “mover” matches left NPDC. Thus, there were a potential total of 300 consumer follow-ups (150 “movers” and 150 “stayers”) at 3, 15, and 27 months and only 150 consumer follow-ups (for the 150

“movers”) at 9 months. These totals and the assessments which actually occurred due to sample attrition during the evaluation period are depicted in Part A of Table III-1.

As illustrated, data was collected on all consumers scheduled for follow-ups with the exception of those 35 persons who had died. Detailed analyses were done on those who died during the evaluation period. Final findings on mortality of consumers were presented in A Year Later, the 15-month progress report (Apgar et al., 2001). However, the chapter on mortality as presented in this earlier document is reproduced in Appendix B of this report for the benefit of readers of this final report. The following sections will discuss the respondent groups at all follow-up periods as outlined in Part B of Table III-1.

Table III-1: Overview of Data Attrition and Respondent Groups in This Study

<u>Sample Group</u>	<u>1994 Preclosure</u>	<u>1996 Postclosure¹</u>	<u>3 Months Postclosure</u>	<u>9 Months Postclosure¹</u>	<u>15 Months Postclosure</u>	<u>27 Months Postclosure</u>
<u>A. SAMPLE ATTRITION</u>						
Consumers Scheduled for Follow-up	300	150	300	150	300	300
Data Collected on Consumers	300	150	291	142	277	265
Deceased	0	0	9	8	23	35
<u>B. RESPONDENT GROUPS</u>						
Duplicated Staff	300	150	290	142	276	263
Unduplicated Staff	DNA	DNA	223	108	213	207
Family Members/Guardians	N/A	N/A	264	N/A	250	222
Unduplicated Consumers	N/A	N/A	290	142	276	263

DNA = Data Not Available

N/A = Data Not Scheduled for Collection from this Respondent Group

Only data on the former NPDC residents and NOT their matches were collected at these time periods.

Staff Respondents

At the 3-month follow-ups, DD Planning Institute interviewers visited 223 different staff members who worked with the 290 consumers in the evaluation sample (see Part B). At 15 months, 213 distinct staff were interviewed about 276 consumers while at 27 months, a total of 207 unduplicated staff were questioned about 263 individuals. The characteristics of staff at these time periods were almost identical, as depicted in Table III-2.

Table III-2 provides overall data on the staff respondents, as well as comparisons of the differences between these individuals according to their work settings – community versus institution. As depicted, the average age of staff was about 39 years overall, with institutional respondents being significantly older than their community counterparts. These staff had completed slightly more than 14 years of schooling (some college), with no significant differences found between the educational backgrounds of those working in community and institutional settings. Lastly, the average DD experience of staff working in community residence – between 7.0 and 8.2 years – was significantly less than the approximate 13 years reported by those interviewed in institutional settings.

Table III-2: Demographic Characteristics of Unduplicated Staff Respondents at All Follow-ups Overall and By Institution/Community Work Settings

Staff Characteristics	Staff Respondents Employed in Community Settings	Staff Respondents Employed in Institutional Settings	T-Test Sig. Level	All Staff Respondents
<u>Years of Age (Mean)</u>				
3 Months	34	40	.00001	39
15 Months	36	41	.002	39
27 Months	36	41	.003	39
<u>Years of Education (Mean)</u>				
3 Months	14.7	14.3	NS	14.5
15 Months	14.3	14.2	NS	14.2
27 Months	14.4	14.0	NS	14.2
<u>Years of Experience Working with Persons with DD (Mean)</u>				
3 Months	7.0	13.2	.00001	11.1
15 Months	7.9	12.9	.0001	11.0
27 Months	8.2	12.2	.0004	10.7

NS = Not Significant

Family Member/Guardian Respondents

Obtaining the opinions and attitudes of family members or guardians (in instances in which no family contacts were available or known) was viewed as a critically important aim of this evaluation. Since severe or profound cognitive impairments of consumers oftentimes preclude them from providing their own in-depth evaluations of the life circumstances, it was deemed important to rely on the reports of concerned others when making such assessments. Thus, many evaluations, including this one, have relied on the input of family members when assessing the life quality of individuals with developmental disabilities (Campo et al., 1996).

As noted in Chapter II, information was obtained from family members/guardians via 15-20 minute telephone interviews conducted by an independent survey research firm. The use of an independent firm to complete and code the interviews was viewed as desirable, since it eliminated the possibility that staff/caregiver or consumer responses, which were gathered by DD Planning Institute personnel, could influence the collection and coding of family member/guardian information. All questions asked of family members/guardians were developed by the DD Planning Institute and paralleled, or were identical in wording to, those asked of staff and consumers. However, family members/guardians provided their own assessments, whereas staff provided assessments for consumers.

Table III-3 provides a breakdown of family members/guardians interviewed, and the response rates, at each of the follow-up periods. As illustrated, at all time periods, the response rates were extremely high. While family members answered questions specifically pertaining to their relatives, workers from the Bureau of Guardianship Services were interviewed about multiple consumers assigned to them. These consumers had no other

known family or they were unable to be reached. While the response rates were extremely high at all follow-up periods, reasons for incomplete interviews included language barriers, health issues of family members, lack of knowledge about new living arrangements by family members/guardians, and other reasons.

Table III-3: Family Members/Guardians Interviewed at Each Follow-up

	3 Months	15 Months	27 Months
Consumers Who Had Family Members/ Guardians Eligible to Participate	284 ¹	271 ²	251 ³
Refusals to Be Interviewed	1	3	10
Unable to Be Contacted	8	14	15 ⁴
Unable to Complete Interviews	11	4	4
Total Interviews	264 (93% Response Rate)	250 (91% Response Rate)	222 (88% Response Rate)
Total Family Member Respondents	170 (170 Unduplicated)	163 (163 Unduplicated)	157 (157 Unduplicated)
Total Guardian Respondents	94 (23 Unduplicated)	87 (22 Unduplicated)	65 (20 Unduplicated)

¹ 9 consumers were deceased by 3 months and 7 consumers had no known family and were their own guardians.

² 23 consumers were deceased at 15 months and 6 consumers had no known family and were their own guardians.

³ 35 consumers were deceased at 27 months, 1 consumer had moved out-of-state, 2 consumers died between the times of their 27-month interviews and their family members could be contacted, and 11 consumers had no known family and were their own guardians.

⁴ One BGS guardian who was assigned to 10 consumers in the sample was not able to be contacted at 27 months.

Consumer Respondents

Though consumers with a full range of official mental retardation diagnoses were included in this evaluation, the majority (67%) of “movers” were officially diagnosed as having severe or profound mental retardation prior to leaving NPDC. As “movers” were originally matched with “stayers” (i.e., the comparison group) on their multicognitive abilities, the preponderance of these individuals also had severe or profound cognitive disabilities. It was also found that most of these consumers had communicative difficulties,

since the communication by consumers was found to be strongly associated with their cognitive abilities (Lerman et al., 1995).

Table III-4 shows the abilities of consumers at 3, 15, and 27 months to communicate using a WORDS or FACES format. At the times of these interviews, only a small proportion of consumers was able to consistently complete both of our WORDS and FACES prescreening questions – meaning that they were able to verbally communicate what made them happy and unhappy (WORDS format) AND distinguish between happy and unhappy faces after being shown them (FACES format). Interestingly, the abilities of consumers to answer the prescreening questions were quite stable. Approximately 15-20% of consumers at each time period were able to provide information about what made them happy or unhappy using WORDS or FACES. These individuals were considered reliable respondents who were interviewed further about their well-being.

Table III-4: Consumers Interviewed at Each Follow-up

Passed WORDS and FACES?	3 Months	15 Months	27 Months
No	85%	82%	85%
Yes	15%	18%	15%
Totals	100% (N=290)	100% (N=276)	100% (N=263)

Summary of Findings

Since the onset of the evaluation, there was some attrition in the evaluation sample due to consumer deaths. A total of 35 “movers” and “stayers” had died by the times of their 27-month follow-ups. Prior analyses have shown that community living had no significant impact on the death rates of consumers. While staff of the DID Planning Institute met with all the consumers in the

evaluation sample (i.e., those who left NPDC and their comparisons), only a very small proportion were able to be interviewed about their current well-being. Using a prescreening tool, consumers were assessed for their reliability. Analyses revealed that the proportion of consumers who were found reliable was quite stable over time. Data collected from current staff and family members/guardians was seen as critical for the evaluation. High response rates of family members/guardians were obtained for both “movers” and “stayers.”

Chapter IV: Where Do They Live and Work Now?

Introduction

A central aim of this evaluation was to track the whereabouts of those who left NPDC (“movers”) and compare them to the residential movements of those who were institutionalized and not part of a DD Center closure (“stayers”). Also critical to the closure evaluation was documenting the day activities of “movers” once they left NPDC. This chapter will provide information on the living arrangements and day activities of consumers. It will also include in-depth analyses of decision criteria used to make placement decisions for “movers” at the time of the closure.

Living Arrangements

Throughout the evaluation, more than 70% of “movers” were residing in community settings. The preponderance of these individuals were residing in group homes, with several individuals living in supervised apartments and a skill development home (see Table IV-1).

About a quarter of “movers” remained in institutional settings after leaving NPDC. These predominately included persons residing in DD Centers and nursing homes, with a few persons residing in hospitals or other specialized congregate care facilities for persons with disabilities.

There were few changes in the types of living arrangements for “stayers” since the start of the evaluation. Almost all of the “stayers” were residing in DD Centers, with a single person moving to a nursing home, skill development, or group home.

As stated earlier, at the time when the NPDC closure was announced, and throughout the closure process, there was a public commitment by the DDD Director and administrators to provide community living arrangements for all consumers leaving the facility. This commitment included the initial resolution that placements in other DD

Centers would not be viable options for the NPDC residents and that appropriate community alternatives would be developed for all consumers, with the exception of those persons court ordered to moderate security units. However, as seen in Table IV-1, about a fourth of “movers” went to other institutions after leaving NPDC. This next section will provide in-depth analyses to determine what factors were used to make these decisions.

Table IV-1: Living Arrangements of “Movers” and “Stayers”

	3 Months		15 Months		27 Months	
	“Movers”	“Stayers”	“Movers”	“Stayers”	“Movers”	“Stayers”
Institutional Living						
Developmental Center	21	144	15	138	13	135
Nursing Home	16	1	15	1	13	0
Other	3	0	1	0	2	0
Total	40 (27%)	145 (100%)	31 (23%)	139 (99%)	28 (22%)	135 (99%)
Community Living						
Group Home	101	0	99	0	91	1
Supervised Apartment	5	0	6	0	6	0
Other	0	0	1	1	3	1
Total	106 (73%)	0 (0%)	106 (77%)	1 (1%)	100 (78%)	2 (1%)
Deceased	4	5	13	10	22	13

What Types Of “Movers” Went to Another Institution After Leaving NPDC?

As seen in Table IV-1, 40 of the initial 150 “movers” were living in other institutions (i.e., DD Centers, nursing homes, hospitals, or other specialized facilities) after leaving NPDC. At 15 months, 31 of the remaining 137 “movers” were still living in these facilities. At 27 months, there were 27 “movers” remaining in institutional placements. Since about 22-27% of the “mover” sample have not been placed in community residences at any of the time periods, it is important to identify the types of persons who were deemed to be better served in institutional settings.

It was believed that the most likely “mover” candidates for alternative institutional placements were those with a special medical problem. In order to test this hypothesis, analyses were done on the medical conditions and special medical treatments that were reported at 3 months for the “movers” placed in institutional and community residences. The 3-months period was chosen in order to maximize the number of consumers included in the analysis (due to attrition in the sample over time). Medical conditions and treatments were used as independent variables in logistic regression analyses.

Table IV-2, Part A, provides the findings for the 3 medical conditions that were most closely related to “movers” being placed in institutional facilities. Having a swallowing problem was the medical condition most likely to be associated with institutional placement ($p < .0001$). Muscle problems with the upper half of the body proved to be more closely linked to institutional placement than muscle problems with the lower half of the body ($p < .008$ and $p < .11$, respectively). It is important to note that 8 other medical conditions tested did not have a significance that was above the .15 cutoff for a likely association – including medical problems involving lungs, heart, stomach, bladder, kidneys, hormones, endocrine system, skin/hair, allergies, or Hepatitis B.

Part B provides data pertaining to 3 types of medical treatments that proved to have a statistical association with institutional placement – turning and positioning of the body ($p < .0002$), tube/liquid diet ($p < .02$), and special feeding procedures ($p < .003$). There were 3 types of treatments that were not statistically below the .15 cutoff – special bowel equipment, catheterization, and dressing/wound care.

In order to assess which of the conditions made an independent, unique, contribution to “movers” being placed in institutions, all 3 were entered into a logistic regression simultaneously. Only swallowing was found to make a unique contribution (table

not shown). A similar logistic analysis was performed with the 3 treatments. Only turning and positioning and special feeding emerged as potential unique explanatory variables for who remained in institutional care after NPDC. Finally, swallowing, turning and positioning, and special feeding were analyzed simultaneously along with the most salient matching variable – physical mobility.

Part C provides the statistical results when the medical treatments and conditions were simultaneously entered into the logistic regression analysis. Swallowing and low mobility (i.e., below the median for the entire “mover” sample) emerged as the strongest explanatory candidates. Finally, Part D provides the “best model” results when only swallowing and low mobility are entered together. The odds are 5.7:1 that a “mover” with a swallowing problem will enter an institution, compared to a “mover” who does not have this type of medical problem. In addition, “movers” with mobility capabilities below the median will have odds of 3.0:1 of being placed in an institution, compared to a “mover” with mobility capabilities above the median. Each makes an independent contribution in explaining who was likely to remain institutionalized after the closing of NPDC. However, when both conditions are present, the chances of consumers remaining in institutions after the NPDC closure increase even further.

Table IV-2: Types of Medical Conditions and Treatments Associated with Placement of “Movers” in Institutional Settings at 3 Months

**A. Medical Conditions Significantly Associated with Institutional Placement of “Movers”
(Max. n = 142)**

Medical Conditions	Institutional Living (Max. n= 40)	Community Living (Max. n= 106)	Significance
Swallowing Problem	41%	8%	p<.0001
Muscle Problem/ Upper Body	38%	17%	p<.008
Muscle Problem/ Lower Body	44%	29%	p<.11

**B. Medical Treatments Significantly Associated with Institutional Placement of “Movers”
(Max. n = 142)**

Medical Treatments	Institutional Living (Max. n= 40)	Community Living (Max. n= 106)	Significance
Turning/ Positioning	38%	10%	p<.0002
Tube/ Liquid Diet	15%	4%	p<.02
Special Feeding	31%	9%	p<.003

**C. Multivariate Analysis of Conditions and Treatments Significantly Associated
with Institutional Placement of “Movers”
(Max. n = 142)**

Variables	Significance	Odds Ratios
Swallowing Problem	p<.01	4.4:1
Turning/ Positioning	p<.53	1.5:1
Special Feeding	p<.44	1.6:1
Low Mobility	p<.08	2.4:1

**D. Best Model - Medical and Physical Conditions Significantly Associated
with Institutional Placement of “Movers”
(Max. n = 142)**

Variables	Significance	Odds Ratios
Swallowing Problem	p<.0009	5.7:1
Low Mobility	p<.02	3.0:1

Day Activities

As reported in the 3-month progress report, Closing Old Doors – Opening New Ones (Apgar et al., 1999), the lowest implementation of Individual Support Plan (ISP) preferences at 3 months was found with regard to the type of work “movers” indicated they wanted to do after leaving NPDC. Additionally, many “movers” (39%) who moved to the community were not in day activities outside their homes initially 3 months after leaving the facility. Thus, it is useful to examine the day activities of “movers” in comparison to “stayers,” as well as any changes that have occurred in the day activities of former NPDC persons over time since leaving the facility. The following sections detail the day activities of “movers” and “stayers” during the entire evaluation period.

First, it is useful to describe the day activities of those residing in DD Centers. As seen in Table IV-3, the proportion of “movers” and “stayers” who are leaving their cottages for day activities is comparable at all time periods, except at 3 months. About half of the “movers” and “stayers” in these settings leave their residential living environments during the day. The discrepancy between “movers” and “stayers” at 3 months may be attributable to the temporary placement of some “movers” in DD Centers while their community residences were waiting to open. Since these were considered transitional placements, out-of-home day activities of these “movers” may not have been pursued.

Table IV-3: Day Activities of “Movers” and “Stayers” Residing in DD Centers

	3 Months		15 Months		27 Months	
	“Movers” (N=21)	“Stayers” (N=144)	“Movers” (N=15)	“Stayers” (N=138)	“Movers” (N=13)	“Stayers” (N=135)
Out-of-Home Day Program	24%	49%	53%	51%	46%	46%
No Out-of-Home Day Program	76%	51%	47%	49%	54%	54%

Next, special attention was paid to the day activities of community “movers.” Previous progress reports highlighted the need for careful monitoring and attention by DD personnel with regard to this group. Past practices by DDD encouraged, and even required, out-of-home participation in day habilitation or vocational activities by consumers living in community residences. However, analyses revealed that only 61% of “movers” who lived in the community were in outside day activities at 3 months. Further examination indicated that the proportion of former NPDC residents living in the community who were engaged in out-of-home day activities rose slightly over time. By 9 months, 66% of “movers” who lived in the community were in outside day activities and this proportion had risen to 72% by 15 months. This proportion remained stable at 27 months with 73% of “movers” living in the community leaving their homes during the day at this time period. These figures are depicted in Table IV-4.

Table IV-4: Day Activities of “Movers” Living in the Community

	3 Months	9 Months	15 Months	27 Months
Out-of-Home Day Program	61%	66%	72%	73%
No Out-of-Home Day Program	39%	34%	28%	27%
Total N=	106	108	105	99

In-Home versus Out-of-Home Day Activities

In an effort to investigate further the day activities of those who did not leave their homes, additional questions were asked at 27 months. These questions focused on determining whether consumers were involved in day activities inside the home, the focus of these activities, and whether consumers were paid for these efforts. Analyses of in-home versus out-of-home day activities for community versus institutional residents are depicted in Table IV-5. A total of 42% of consumers living in institutions left their cottages for day programming, while 35% were engaged in some type of day activities at home. Twenty-three percent of institutional residents were in no structured activities during the day. In contrast, 73% of consumers residing in the community were in out-of-home day programs, and 12% of this group were in in-home activities. A total of 15% of community dwellers engaged in no structured day activities.

Table IV-5: Day Activities of Community and Institutional Residents at 27 Months

	A. Out-of-Home Day Programs	B. In-Home Day Programs	C. No Day Programs	Totals
A. Institutional Residents (n=162)	42%	35%	23%	100%
B. Community Residents (n=101)	73%	12%	15%	100%

Table IV-6 displays summary data on in-home versus out-of-home day activities for all consumers in the sample at 27 months. Part A indicates that equal proportions of consumers (49%) who leave their homes during the day are engaged in activities which focus on socialization and employment. A small proportion of individuals (2%) are engaged in other types of programs, such as those focused on medical or mental health problems. In contrast, the clear majority of consumers (84%) who were receiving in-home day

programming were doing socialization activities, with 12% engaged in employment tasks, and 4% receiving other services.

Part B of Table IV-6 depicts the differences in the weekly time that consumers are engaged in structured activities. This time includes lunch, but does not include travel time to and from out-of-home program sites, if applicable. The four-hour difference is statistically significant. This means that those leaving their homes during the day are spending markedly more time engaged in structured activities than those who stay at home for programming (21.9 versus 17.8 hours weekly, respectively).

Lastly, Part C depicts the compensation differences between those engaged in in-home versus out-of-home day activities. About half of consumers who leave their homes during the day are compensated for their efforts, with 54% of these individuals being directly paid by their residential provider organizations. Only 19% of those working at home are paid, but all of these individuals are compensated by their provider agencies.

Table IV-6: Summary Data on In-Home versus Out-of-Home Day Activities of All Consumers in the Evaluation Sample at 27 Months
(Includes All Consumers Who Were in Day Activities at 27 Months)
(Max. n=211)

	A. Focus			B. Weekly Time Hours (Mean)	C. Compensation	
	Socialization	Employment	Other		Paid	If Paid, Compensated by Provider Organization
Out-of-Home Day Program (N=142)	49%	49%	2%	21.9	51%	54%
In-Home Day Program (N=69)	84%	12%	4%	17.8	19%	100%
Significance	p<.0001			p<.0005	p<.0001	p<.0001

Examining Day Programming Differences by Residential Type and Location

In an attempt to better understand the differences between consumers who were receiving out-of-home services, additional analyses were undertaken. Analyses included examination of consumers' day program status according to their residential setting types and regions of residence.

As seen in Table IV-7, there are distinct differences in the day program statuses of consumers living in community versus institutional settings (i.e., nursing homes and DD Centers). While 73% of community residents left their homes for programming, none of the consumers living in nursing homes and 46% of those in DD Centers were engaged in off-site day activities. Significantly more consumers living in DD Centers than their counterparts were participating in day services within their cottages. Only 15% of nursing home residents had some structured in-home activities, with the clear majority (85%) of these residents in no such programs during the day.

Table IV-7: Summary Data on Day Activities of All Consumers at 27 Months According to Their Residential Settings

Type of Day Program	Type of Residential Setting		
	Community Residence	Nursing Home	DD Center
Out-of-Home Day Program (N=142)	73%	0%	46%
In-Home Day Program (N=69)	12%	15%	36%
No Day Program (N=52)	15%	85%	18%
Totals	100% (N=101)	100% (N=13)	100% (N=148)

Next, day programming differences of “movers” were examined according to their regions of residence – Northern, Upper Central, Lower Central, and Southern. As seen in Table IV-8, there were no significant regional fluctuations between the proportion of “movers” who left their homes for day activities. About 60% of “movers” in all of the regions were engaged in out-of-home day programs.

**Table IV-8: Summary Data on Day Activities of “Movers” at 27 Months
According to Their Regions of Residence
(n=126)**

Type of Day Program	Region of Residence			
	Northern	Upper Central	Lower Central	Southern
Out-of-Home Day Program (N=78)	61%	62%	64%	60%
In-Home or No Day Program (N=48)	39%	38%	36%	40%
Totals	100% (N=31)	100% (N=26)	100% (N=44)	100% (N=25)

Day Program Differences by Consumer Characteristics

Additional multinomial logit analyses were undertaken to determine whether consumers’ characteristics (i.e., multicognition, mobility, self-care, behavior towards self and others, age, and gender), residential setting types, and regions of residence had independent impacts on predicting the day program activities of consumers. The results are depicted in Table IV-9. Part A of this table illustrates that 2 variables – higher mobility and living in a community residence – independently distinguish those in out-of-home day programs from those who are not in structured activities. Region did not appear to significantly differentiate between these 2 groups when mobility and residential setting type were considered. Part B of Table IV-9 indicated that there are 3 factors – higher mobility, living in an institutional

setting, and residing in a region other than Southern – that independently predicted in-home day programming versus no structured day activities. Lastly, Part C of this table illustrates that 3 variables – higher mobility, living in a community residence, and residing in the Southern Region – independently predicted out-of-home day programming as opposed to in-home services.

Table IV-9: Explaining the Day Program Activities of All Consumers at 27 Months

Variables	A. Out-of-Home versus No Day Program	B. In-Home versus No Day Program	C. Out-of-Home versus In-Home Day Program
	(n=139 and 51, respectively)	(n=69 and 51, respectively)	(n=139 and 69, respectively)
Mobility	p<.0001	p<.04	p<.0001
Community Residence	p<.04	p<.01	p<.0001
Southern Region	NS	p<.0006	p<.0001

NS = Not Significant

Employment of Consumers

Additional multivariate analyses were undertaken to examine the characteristics of consumers who were more likely to engage in employment-focused day activities either inside of outside the home. These analyses revealed that 2 consumer characteristics were significant predictors – having higher mobility and higher self-care skills. Logistic analyses indicated that consumers with higher self-care skills were 7.6 times more likely to engage in employment focused activities (p<.0001), while those with higher mobility were 2.5 times more likely (table not shown).

Many consumers found to be reliable respondents commented on being dissatisfied with their current day activities. These comments included desires to pursue specific employment. For example, when asked what day activities consumers would like to do instead of those that they are engaged in now, the responses included:

“Work at McDonald’s – making french fries and cleaning tables off.”

“Crush cans or a job working at McDonald’s, Wendy’s, or Boston Markets.”

(Be a) “construction worker.”

“Be an auto mechanic.”

Many of those who did not specify specific activities indicated a desire to simply “get a job,” specifically one “on the outside,” as articulated by DD Center residents. Lastly, the desire to increase earnings from employment was expressed by other reliable consumer respondents.

Summary of Findings

The living arrangements of “movers” and “stayers” have not changed dramatically since the 3-month follow-ups. Approximately, three-fourths of “movers” resided in community settings, with the preponderance of these individuals residing in group homes. Almost all of the “stayers” remained in institutional residences.

Additional analyses were done on the “movers” to determine which consumer characteristics were associated with remaining in institutional settings after leaving NPDC. Having a swallowing problem and low mobility were significant independent predictors in explaining who was placed in institutional settings after the closure.

Higher mobility by consumers, community residence, and living in the Southern Region were significant in distinguishing between those who received out-of-home versus in-home day services.

When examining the differences between those who leave their homes and those who do not for structured day activities, marked differences were seen in the focus, time spent in activities, and compensation of these 2 groups. Most consumers in in-home

programs were engaged in socialization activities, while about half of those who leave their homes were participating in these social tasks. In addition, those leaving their homes during the day were spending significantly more time engaged in structured activities than their in-home counterparts. Only a small percentage of individuals staying home were paid for their efforts and all of these were compensated directly by their residential providers.

Chapter V: Characteristics and Correlates of Living Environments

Introduction

The 15-month report, A Year Later (Apgar et al., 2001), described the construction of 2 major indicators that were capable of distinguishing between institutional living quarters and community residences. One index, using 10 items, described characteristics associated with a “lack of institutionalization.” Some of these items were adapted and modified from earlier studies conducted by Devlin (1989), Pratt et al. (1981), and Conroy and Seiders (1994). Others were added based on findings of an earlier study of the closing of a New Jersey DD Center (Apgar et al., 1998). These types of environmental features were found to be significantly correlated with social and psychological well-being (Rotegard et al., 1981; Rapaport, 1982; Thompson et al., 1996; Apgar et al., 1998).

The 10 items that were found to be highly reliable at 3 and 15 months were as follows: (1) not having handicapped parking signs; (2) no dumpsters; (3) absence of an identification plaque; (4) lack of lighted exit signs; (5) no visitor parking; (6) no exposed fire sprinkler; (7) homelikeness of living room; (8) homelikeness of bathrooms; (9) personalization of bedrooms; and (10) staff eating with residents. (See Appendix C for a reproduction of the factor analyses of the 3- and 15-month data, as well as the 27-month data.) The index was also found to include size of residence as a factor item at all time periods, but it was not included in subsequent analyses for the sake of continuity with the earlier reports.

The second index utilized 4 items that referred to freedom from social controls. Similar items had been found in an earlier study to be associated with the lack of institutional features within the dwellings of consumers (Apgar et al., 1998). While these 4 items – plus 2 additional questions – were used to assess social controls at 3 and 15 months (Apgar et al.,

2001), it was discovered that only these 4 items could form a reliable index at all time periods. These items referred to not using: (1) room restriction or time out; (2) point systems or demerits for infractions; (3) loss of specific privileges; and (4) emergency manual or nonphysical restraints. (See Appendix D for more details.)

The purpose of this chapter is to expand the analyses to 27 months and to identify the types of social and psychological correlates associated with the 2 indices.

“Lack of Institutionalization” Index

Scores on the lack of institutionalization index were based on assigning a 1 if a feature was present and a 2 if absent. Total scores ranged from 10 to 23 at all time periods and were documented to have a Cronbach alpha – a measure of reliability – of .96 at 3, 15, and 27 months. The bar graph that was depicted in the 15-month report, A Year Later (Apgar et al., 2001), can be virtually reproduced in this report based on 27-month data with only a few minor changes (see Table V-1). For example, at 15 months, all 13 nursing homes scored under 17, as they did at 27 months. At 15 months, 77 out of 78 DD Centers had scores of less than 17, and at 27 months, 73 out of 75 were below this score. In contrast, at 15 months, all community residences (i.e., group homes) scored 17 or higher.¹ At 27 months, 62 out of 64 community residences achieved this type of rating. It is evident that ratings using the lack of institutionalization index proved to be quite stable over time.

Besides yielding quite strong reliability over time, the lack of institutionalization index also exhibited a high degree of validity, since the correlation between index scores and community residence was .93 – .94 at all 3 time periods. On the basis of this strong relationship between the environmental index and place of residence, it can be stated that

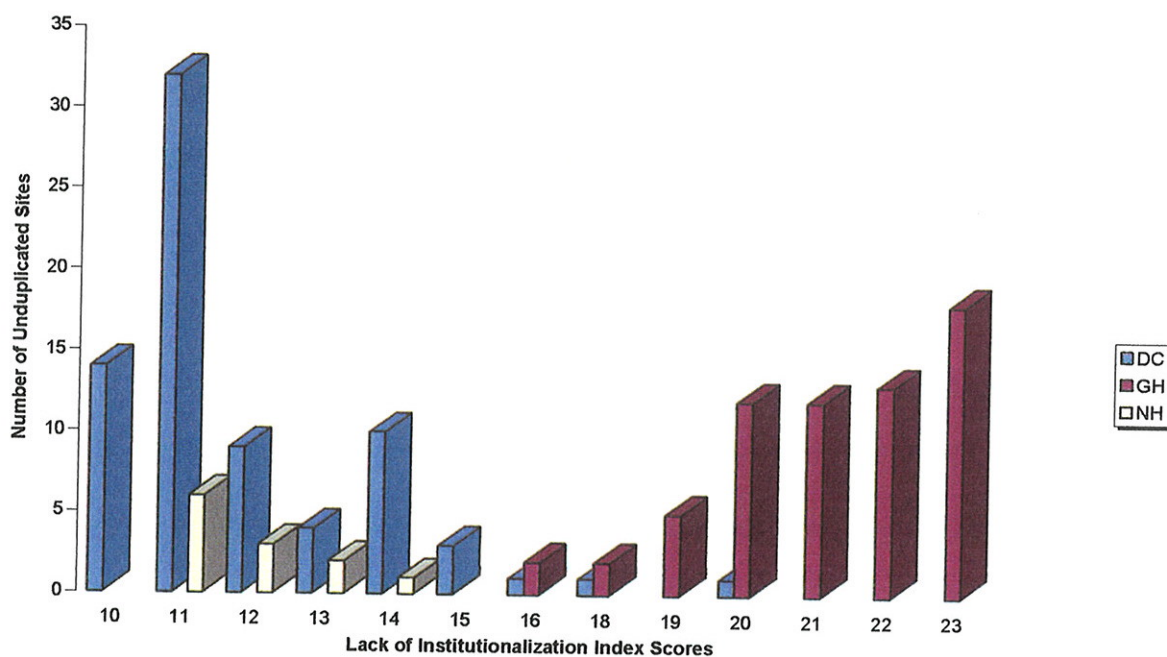
¹ Scores on the lack of institutionalization index were not given to 2 community residences visited at 15 months due to missing data.

the “movers” who were placed in community settings were living in residences with the following characteristics:

1. Those that look like others in the neighborhood (i.e., absence of lighted signs and special parking);
2. Those that look like others on the inside (i.e., homelikeness of living spaces);
3. Those with a smaller number of persons living there (i.e., strong correlation with size of residence);
4. Those with personal belongings of the inhabitants (i.e., “personalization of bedrooms”); and
5. Those with more informal relationships with staff (i.e., staff eating with residents).

The next section will identify other distinct social and individual characteristics (i.e., noninstitutional features) that are also correlated with living in community-based facilities.

Table V-1: Distribution of Scores on Lack of Institutionalization Index at 27 Months



Lower Scores Indicate Residences with MORE Institutional Features and
Higher Scores Indicate Residences with FEWER Institutional Characteristics.

Single Correlates of Community Living

Analyses of items and indices other than quality-of-life domains (reported in other chapters), revealed that there were 11 distinct correlates that had a significant association with environments that are considered less institutional (i.e., community settings) and those considered more institutional (i.e., DD Centers). The variables described below and noted in Table V-2 are linked to 3-month findings. A subsequent section will identify findings at 15 and 27 months related to these variables.

1 – Family Phone Contacts

In earlier reports, it was noted that both staff and families reported more frequent telephone contact if consumers lived in a community residence. In Table V-2, this finding is again confirmed by differentiating between community and institutional environments – or 61 to 35%, respectively. This difference is statistically significant at $p < .0001$.

2 – Leave Residence for Day Program

Earlier reports noted that not all of the “movers” or “stayers” left their living units to attend day programs. Table V-2 specifies that 61% of consumers residing in community settings left to attend day programs, whereas 42% living in institutional environments left their residences. This difference increases over time, but as early as 3 months there is a statistically significant difference in the use of outside day programs ($p < .002$).

3 – Low Social Control

The 4 items that make up this index were scored as 1 if the control was present and a 2 if it was absent. Therefore, scores ranged from 4 to 8 with the higher scores indicating residences with lower formal social controls. In Table V-2 low social controls refer to scores of 7 or 8. Eighty percent of persons residing in community settings experienced low social

controls, compared to 55% of institutional residents. This difference is statistically significant at $p < .0001$.

4 – Realizing Ideal Goals in the Community

In each of the interviews with staff and family members/guardians, interviewers asked whether the ideal goals pertaining to the quality-of-life for consumers could “best be achieved in a developmental disability center, a community residence, or equally in both of these settings.” Respondents were asked where each of 10 quality-of-life goals listed below could best be promoted:

1. Self-care and independence;
2. Choices and freedom;
3. Emotional well-being;
4. Community involvement and leisure;
5. Friendship and family ties;
6. Material well-being;
7. Personal safety;
8. Productivity;
9. Physical well-being; and
10. Appropriate behavior.

A factor analyses of all items for staff revealed that the 10 items formed a single factor at 3, 15 and 27 months. Similar results were also found for family members. The Cronbach alphas were above .90 for staff and family members at all time periods. Data in Table V-2 refer only to staff attitudes.

In Table V-2, there is strong evidence that staff are much more likely to believe that ideal goals pertaining to quality-of-life can best be achieved in community settings if they

work in these environments compared to institutional settings – 97 versus 35%, respectively ($p < .0001$)

5 and 6 – Basic and Domestic Skills Taught

Interviewers at all 3 time periods asked staff if skills such as dressing, eating, hygiene, cooking and shopping were taught to consumers, whether they lived in the community or in an institutional residence. Analyses of these items at 3 months disclosed that the first 3 items – dressing, eating, and hygiene – formed a basic skills index that was separate from the 2 items that formed a domestic skills index.

While the Cronbach alpha of the domestic skills index revealed higher reliability (.63) than the basic skills index (.56), neither one was as high as our generally accepted standard of .70. However, in the absence of any other indicators linked to improving self-care competencies, it was decided to use these 2 indices.

As indicated in Table V-2, at 3 months, both types of skills – basic and domestic – are more likely to be taught in community versus institutional settings – 52 versus 38% for basic skills and 64 versus 33% for domestic skills. Both are statistically significant, but the relationship between type of environment and the teaching of domestic skills is much stronger (i.e., $p < .0001$) compared to $p < .02$, respectively.

7, 8 and 9 – Psychiatric Diagnoses and Medication

At 3 months, consumers living in community settings were much more likely to have psychiatric diagnoses ($p < .01$) and receive antipsychotic medications ($p < .0001$). They were also much less likely to have staff respond that psychiatric medications were used to control inappropriate or undesirable behavior ($p < .05$).

In order to best understand the importance of these findings, it is useful to take advantage of our knowledge about the NPDC “movers” before the closure. In 1994, a

comparison of a random sample of NPDC residents and a random sample representing all the DD Centers, revealed that NPDC residents were much more likely to be associated with the following psychiatric indicators:

1. having psychiatric problems in 1994 (72 to 39%);
2. using antipsychotic medications in 1994 (53 to 31%); and
3. using medication to reduce behavior in 1994 (57 to 32%).

The random sample of “movers” in our evaluation study at 3 months were not matched on any of these variables, as noted in earlier progress reports. Therefore, it is not surprising that the “movers” (i.e., consumers from NPDC) who left for the community had a higher proportion of persons having psychiatric problems and requiring antipsychotic medication. Their designated psychiatric problems did not change because they moved into a community residence. However, the disposition of staff to use medication to reduce behavior by using psychotropic medications did change. Staff in community settings were significantly less likely to report using this procedure to control behaviors than their NPDC institutional counterparts at 3 months, even though there were more consumers with psychiatric problems living in these residences.

10 – Receiving Speech Therapy

The interviewers also asked staff if a consumer received speech and physical therapy. At 3 months, there was a clear difference in the report concerning the delivery of more speech therapy to institutional residents – 17 to 5% ($p < .005$). There was no difference in the receipt of physical therapy between types of environments, and is, therefore, not noted in the table.

11 – High Self-Care

Even though the “movers” and “stayers” were matched on 7 variables – including self-care – there is strong evidence that consumers with higher competencies were more likely to live in community settings. Consumers with high self-care are also more likely to have higher multicognition, but the relationship is stronger between self-care and community living ($p < .002$), and is, therefore, noted in the table.

12 – Changes in Caregiving Staff

Examination of staffing changes between 3 and 15 months indicated that 25% and 59% of consumers residing in DD Centers and community settings, respectively, had changes in their caregiving staff ($p < .0001$). Differences in staffing changes between these groups were still significant between 15 and 27 months, though slightly more moderate. Between 15 and 27 months, 30% of institutional residents experienced changes in their staff, while 48% of community dwellers experienced such changes ($p < .005$). While changes of staff may have diminished during the second year, this variable may be capable of making a unique contribution to distinguishing types of living environments at both time periods.

Summary of Analyses with Individual Variables

In summary, it is clear that community settings are operated with a lower degree of social controls, have staff who strongly believe that ideal goals are realized in noninstitutional settings, and have residents who receive more contact with family. In addition, consumers who moved into these types of environments from NPDC continue to have more psychiatric problems and higher self-care and multicognitive skills. However, it is unknown whether each variable had an independent, unique association with environment types when all of the individual variables are controlled in a multivariate analysis. The next section discusses the results of this type of statistical analysis.

Table V-2: Significant Correlates with Institutional Environments at 3 Months
(Based on the Maximum Number for Each Analysis)

	Variables	Community Residence	Institutional Residence	Significance
1	Family Phone Contact	61%	35%	p<.0001
2	Leave Residence for Day Program	61%	42%	p<.002
3	Low Social Control	80%	55%	p<.0001
4	Quality-of-Life Goal realized in Community (Staff Only)	97%	35%	p<.0001
5	Basic Skills taught	52%	38%	p<.02
6	Domestic Skills taught	64%	33%	p<.0001
7	Psychiatric Diagnosis	63%	48%	p<.01
8	Use Antipsychotic Medication	57%	32%	p<.0001
9	Use Medication to Control Behavior	38%	49%	p<.05
10	Receive Speech Therapy	5%	17%	p<.005
11	High Self-Care	55%	36%	p<.002
12	Changes in Caregiving Staff	59%	25%	p<.0001

Assessing Unique Correlates of Community Living

In order to maintain the highest maximum number of respondents, groups of variables listed in Table V-2 were examined simultaneously using multivariate logistic regression analyses. Variables that had a significance of at least .15 at 3, 15 and 27 months were retained as candidates for “best models.” Finally, the single best multivariate model was examined by controlling for self-care, the most salient matching variable. The variables that were consistently associated with community living at a significant level are depicted in Table V-3. Since self-care proved not to make a unique significant contribution in the best model – when all of the variables were simultaneously entered – it is excluded from the table.

**Table V-3: Consistent Significant Correlates of Community Living at 3, 15, and 27 Months
(Based on the Maximum Number for Each Analysis)**

Consistently Significant Variables	<u>3 Months (N=279)</u>		<u>15 Months (N=271)</u>		<u>27 Months (N=259)</u>	
	Significance	Odds Ratios	Significance	Odds Ratios	Significance	Odds Ratios
1. Quality-of-Life Goal realized in Community	p<.0001	63.1:1	p<.0001	35.2:1	p<.0001	53.8:1
2. Low Social Control	p<.0001	4.8:1	p<.0001	6.8:1	p<.0001	7.6:1
3. Use Antipsychotic Medication	p<.001	3.3:1	p<.02	2.3:1	p<.01	2.6:1
4. Domestic Skills taught	p<.0007	3.3:1	p<.0001	4.7:1	p<.0008	3.5:1

Of the 11 variables depicted in Table V-2 only 4 emerged as making consistent significant, independent, unique contributions to understanding community living at 3, 15 and 27 months. This does not mean that the remaining 7 variables are unrelated to institutionalization, but rather that they do not make unique contributions to explaining it.

Table V-3 provides 2 distinct pieces of information for each time period:

1. The level of statistical significance between the variables and community living;
- and

2. The odds that the specific variables predict community residence.

The first variable, staff beliefs that quality-of-life goals are more likely to occur in community residence, had an odds ratio that varied between a low of 35.2 (at 15 months) to 63.1:1 (at 3 months). Compared to the other variables, it is clear that this variable is the strongest predictor for explaining the difference between environments. Thus, staff who think that ideal goals are more likely to occur in community settings are strongly associated with less institutional environments.

The second variable that makes a unique contribution in predicting the likelihood of community living is low social control. While the significance level appears similar to quality-of-life goals, the odds ratios are much more modest – between 4.8:1 (at 3 months) and 7.6:1 (at 27 months).

Of the 3 psychiatric variables that were significant at an individual level of analysis, only the use of antipsychotic medication makes a unique contribution in understanding community living. The association at 15 months was only $p < .02$ with an odds ratio of 2.3:1, but was more strongly associated at 3 and 27 months – with odds ratios between 2.6 and 3.3:1. While antipsychotic medication is indeed correlated with psychiatric diagnoses, it is the higher use of psychoactive medication that makes a unique contribution in understanding community residence for this particular sample.

The fourth variable, the teaching of domestic skills, had a strong significant association at all time periods – with odds ratios ranging from 3.3 to 4.7:1.

Social Controls

While the presence of low social controls is capable of making a unique contribution in differentiating the degree of institutionalization within environments, a separate analysis is required to understand the special correlates of social control. For example, low social

control is correlated with older age ($p < .0001$), lower physical mobility ($p < .0001$), and community residence ($p < .0001$). In order to locate the variables that made a unique statistical contribution in understanding the presence of low social controls, a multivariate regression analysis was performed. The final results of this multivariate analysis are depicted in Table V-4 for 3, 15, and 27 months.

The percent of the variability – or the variance – explained by each variable is referred to as R^2 . R^2 can vary between 0 and 100%. The closer that the R^2 is to 100%, the greater the explanatory power of the variable.

The 3 variables that made a unique contribution that were consistent at each time period were: (1) community residence; (2) low mobility; and (3) low inappropriate/aggressive behaviors. The first variable – community residence – refers to the social context of the residence where low social control is more likely to occur. Community residence explained between 9.8% (at 3 months) to 12.5% (at 27 months) of the variance. The use of social controls in institutional settings was a complaint of one family member who stated when asked what he/she would like to change about her relative's living environment,

(I would want him in) “an unlocked cottage at the same developmental center. Now he is in a locked cottage.”

The other variables refer to individual characteristics that consumers bring to an environmental context. For the purpose of explaining the degree of variance, it is the lower mobility and inappropriate/aggressive behaviors that have unique amounts of explanatory power. It is important to note that these personal characteristics can be found in both community and institutional residences. Therefore, low social controls can occur because the inappropriate or aggressive behaviors displayed by consumers are less challenging and/or

consumers are less able to move around independently. Each of these variables can contribute independently to explaining the extent to which social controls are used.

However, the contributions of these personal characteristics are not equal in importance. Low physical mobility explains a much greater degree of the variance than behaviors. The amount of variance explained by mobility varies from 10.4% (at 15 months) to 12.1% (at 27 months). The explanatory ability of low inappropriate/aggressive behavior, in turn, fluctuates in a more narrow range – 2.2 to 2.9%.

Viewing the explanatory models for each time period, it is evident that the 2 most important variables in explaining the use of low social controls are low mobility and residence in the community. When both are present the likelihood of low social controls is stronger.

Table V-4: Consistent Findings of Multivariate Analysis of Variables that Best Explain Low Social Controls
(Based on the Maximum Number for Each Analysis)

Variables	<u>3 Months</u>		<u>15 Months</u>		<u>27 Months</u>	
	Significance	Partial R ²	Significance	Partial R ²	Significance	Partial R ²
Community Residence	p<.0001	9.8%	p<.0001	12.1%	p<.0001	12.5%
Low Mobility	p<.0001	11.6%	p<.0001	10.4%	p<.0001	12.1%
Low Inappropriate/ Aggressive Behaviors	p<.004	2.2%	p<.001	2.9%	p<.003	2.5%
	Total R ² =	23.6%	Total R ² =	25.4%	Total R ² =	27.2%

Summary of Findings

Two measures of the residential environment associated with consumers' places of residence proved to be reliable at all time periods. The environmental index referred to the degree to which residences were "less institutional" and the social control index referred to the extent to which social controls were less likely to be employed in dealing with consumers. Community residences – low institutional environments – are described as

having the following features: (1) the outside of residences look like others in the neighborhood; (2) the inside of residences look like others in the neighborhood; (3) residences have a smaller number of persons residing in them; (4) consumers have more personal possessions evident; and (5) staff are more likely to have more informal interactions.

Lower social controls means that there are fewer uses of time outs, point systems, loss of privileges, and manual restraints. Analyses indicates that community residences are much more likely to be associated with staff who believe that 10 quality-of-life goals – like independence, choices, emotional and physical well-being, and personal safety – can best be realized in a community residence. Besides staff attitudes and beliefs, community settings are also more likely to be associated with low formal social controls and the teaching of domestic skills to consumers.

In addition, community residences are much more likely to have consumers who use antipsychotic medications. Consumers in these residences who came from NPDC had an increased likelihood of having psychiatric diagnoses. Prior analyses done in 1994 – before the announcement was even made to close NPDC – indicated that this DD Center had more persons with psychiatric problems and medication usage than other DD Centers. Therefore, it is not surprising that those now found in community settings are more likely to be using antipsychotic medications.

Further analyses on the use of low social controls reveal that their usage is associated with community residence and specific individual characteristics. Persons with low mobility are much less likely to experience social controls. Additionally, lower social control is also associated with fewer inappropriate/aggressive behaviors. These personal characteristics can be found in institutions and community residences. In brief, social controls can be found in

institutions, as well as community residences (due to individual characteristics), but they are less likely to occur in the community.

Chapter VI: Implementation of Consumer Choices

Introduction

In the 3-month progress report, Closing Old Doors – Opening New Ones (Apgar et al., 1999), it was noted that a unique aspect of the NPDC closure was the use of “person-centered” planning to guide providers in developing postclosure supports and services for consumers. Since its inception in the early 1980s, varying approaches to person-centered planning have emerged (Everson, 1996). These approaches have been implemented with mixed successes due to such barriers as time, resources, existing service system policies, and adherence to older program designs (Everson, 1996; O’Brien et al., 1997). These barriers have often discouraged attempts at large-scale implementation of this approach to planning.

In a serious attempt to actually carry out person-centered planning for all of the 488 persons who were targeted to move into the community as part of the NPDC closure process, the Division of Developmental Disabilities launched a series of activities that included the following:

1. Training consumers, family members, and transitional care managers in the underlying ideals of person-centered planning;
2. Developing Individual Support Plans (ISPs) for all persons at NPDC based on input from consumers, family members, and concerned others by transitional care managers (for a detailed description and qualitative analyses of the ISP planning process, as practiced, see Lerman et al., 1996);
3. Distributing ISPs with the Request for Planning Proposals (RFPs) to community providers;
4. Reviewing proposals by providers which were to be based on the preferences, choices, and recommended support needs;
5. Rating of proposals by regional DDD personnel using abbreviated ISP preferences/support “Indicator Sheets”;
6. Accepting proposals by the family members and consumers; and

7. Awarding of contracts by DDD to community providers based on the ratings and approvals.

In the 3-month progress report, Closing Old Doors – Opening New Ones (Apgar et al., 1999), empirical evidence was provided on how successfully the person-centered process had actually been realized – by assessing the extent to which services and support and choices and preferences occurred by the end of 3 months. Using information obtained from interviewer observations and staff interviews, the extent to which supports and preferences were completely or definitely met, partially met, or not met was assessed.

Rating Supports and Consumer-Oriented Choices

In the 3-month progress report, Closing Old Doors – Opening New Ones (Apgar et al., 1999), it was concluded that the following recommended supports and services were “completely met” to the extent indicated:

1. Supervision – 100%
2. Medical Monitoring – 98%
3. Safety – 97%
4. Accessibility – 93%
5. Psychiatric Medication – 88%
6. Psychiatric Follow-up – 63%

It was evident that except for psychiatric follow-up, there was high implementation for 5 of the 6 recommended supports and services.

Consumer choices and/or preferences (as interpreted by families or staff in the cases where consumers were unable to communicate) were actually implemented at a much lower rate than the support and services. In Table VI-1, the extent to which consumer choices were completely met is presented for the total sample of “movers,” by type of living arrangement (i.e., community versus institution).

**Table VI-1: Implementation of Individual Consumer-Oriented Choices for Total “Mover” Sample and According to Living Environment
(Based on the Maximum Number for Each Analysis)**

Variable (Max. N)	A. All “Movers” % Completely Met	B. Percent completely met		Significance
		Community	Institution	
Leisure (141)	78%	81%	69%	NS
Smoking (139)	73%	78%	59%	p<.03
Geographic Locale (117)	58%	61%	50%	NS
Number Live With (110)	58%	71%	16%	p<.0001
Roommate Choice (127)	58%	58%	59%	NS
Atmosphere (135)	53%	55%	44%	NS
Live Near (121)	46%	47%	45%	NS
Work Type (136)	41%	48%	22%	p<.009
Live With (100)	35%	36%	31%	NS

NS = Not Significant

As Part A makes clear, only 2 of the 9 consumer-oriented choices were “completely met” to the extent that about $\frac{3}{4}$ of the choices in these areas were completely realized (i.e., 78% for leisure activities and 73% for smoking preferences). Only slightly more than half (53-58%) of another group of choices were totally met (i.e., those related to geographic locales, number of persons to live with, choice of roommates, and type of residence atmosphere). Whom people live near and the type of work were implemented below a majority – 41 to 46%. The lowest implementation of choice pertained to whom consumers actually lived with (35%) – such as specific friends they had known in the institution.

In Part B, information is presented by whether consumers were living in community versus institutional settings at 3 months – since not all “movers” were placed in community settings, like group homes (see Chapter IV). It is clear that only 3 types of choices – the number of persons to live with, smoking, and work type – are significantly associated with living arrangement. The implementation of the other choices is just as likely to occur in community versus institutional residences.

Controlling for Multiple Choices

The evidence presented in Table VI-1 is based on the analyses of each type of choice considered independently of the other choices. But when persons make multiple choices, then it is important to assess the choices simultaneously in order to determine which ones are uniquely associated with environmental types. Based on the results portrayed in Table VI-1, there are five types of choices that are worth considering together in a logistic regression. They are: (1) number of people to live with; (2) leisure; (3) atmosphere; (4) type of work; and (5) smoking. Table VI-2 presents the results of a statistical analysis when the choices associated with type of environment are considered simultaneously.

Table VI-2: Odds Ratios and Significance of the Association of Consumer Choices and Community Residence

Variables	Significance	Odds Ratios
1. Number Live With	$p < .0003$	12.6:1
2. Leisure	NS	1.2:1
3. Atmosphere	NS	0.95:1
4. Type of Work	NS	2.3:1
5. Smoking	NS	1.1:1

NS = Not Significant

Of the five variables considered simultaneously only the number of people to live with, is uniquely associated with community residence. The odds ratio of living in a residence with the desired number of people is about 12.6:1 if a consumer lives in a community setting.

In order to be certain that consumer functioning did not influence the unique association between the choice of number to live with and living in a community setting, a second logistic regression using self-care as a control variable was conducted (table not shown). When self-care is entered together with number to live with, the significance of having this choice realized in a community setting remains quite strong ($p < .0001$) and the

odds ratio is virtually the same (12.4:1). This finding indicates that the environment is more important than the self-care capabilities of consumers in having this choice met.

Summary of Findings

As part of the NPDC closure, the Division of Developmental Disabilities (DDD) initiated a major effort to conduct person-centered planning for all persons leaving NPDC. Copies of the Individual Support Plan Indicator Sheet used by DD regional personnel in evaluating service proposals by nonprofit providers were used as a basis of rating whether suggested consumer-oriented choices and supports and services were, in fact, provided to consumers by 3 months. Five of 6 support service recommendations were completely delivered at the rate of 88 to 100% by 3 months. These services included supervision, medical monitoring, safety precautions, accessible housing, and the receipt of psychiatric medication. Only psychiatric follow-ups had a lower rate of implementation (63%) at 3 months.

Consumer-oriented choices were implemented with greater variability – ranging from a high of 78% for leisure choices to 35% for choices related to whom to live with. When consumer-oriented choices were examined by whether they were most likely to be completely met in community versus institutional living environments, only 3 type of choices were significantly related to environment type: smoking ($p<.03$), work type ($p<.009$), and number of persons to live with ($p<.0001$). When these 3 choices were examined simultaneously, only one type of implementation choice was uniquely associated with community residence – the number of persons to live with.

Person-centered planning that attempted to deliver consumer-oriented choices can be implemented in both community residences and institutions, with the exception of the choice regarding the size of the residence. To date, only community-based residences do, in

fact, offer living arrangements with fewer people -- the ideal choice of consumers or persons making decisions on their behalf.

Chapter VII: Consumer Competencies

Introduction

The primary data source for assessing any changes in consumer competencies were items based on the New Jersey Client Assessment Form (CAF) – a questionnaire developed by staff of the Developmental Disabilities (DD) Planning Institute in 1994 after reviewing and modifying existing forms used by the states of California, Connecticut and New York and then conducting pilot studies. The items constructed for the CAF were initially designed to assess specific domains or areas of functioning by relying on the responses of knowledgeable caregivers for a random sample of 1,190 persons residing in 8 New Jersey DD Centers. The forms were completed in 20-30 minutes and completion was supervised by DD Planning Institute staff. All initial data analyses were conducted using SAS software. First-order factor analyses revealed that five distinct domains were assessed: (1) Cognition – 16 items referring to knowledge of space, time, color, size, reading, etc.; (2) Communication – 11 items referring to understanding and using speech; (3) Mobility/Motor Skills – 10 items referring to ambulation and motor skills; (4) Self-Care – 21 items referring to basic skills of eating, drinking, and toileting as well as independence and household skills; (5) Socio-Emotional Functioning – 13 items referring to sociability, friendliness, and caring for others. Two other domains referring to special behaviors (24 items referring to disruptive and aggressive behavior towards others and self) also emerged and will be discussed in the next chapter.

After the initial competency domains were statistically verified, additional second-order factor analyses were conducted in order to examine any possible overlap between factors associated with each domain of functioning. Second-order factor analyses of the 40 items that constituted the initial domains of cognition, communication, and socio-emotional

functioning revealed that there was indeed overlap among these 3 areas. All of the 40 items actually referred to a single broader domain of “multicognitive” functioning.

The 10 items referring to ambulation, motor skills, and physical skills continued to function as a distinctive single domain and did not load with the multicognitive items in the second-order factor analyses. In contrast, the 21 self-care items loaded at a high level on both the multicognitive and mobility domains. The self-care domain was, therefore, conceived as an overlapping domain, dependent on both multicognitive and mobility competencies.

In order to test the reliability of these findings over time, a special test-retest study was conducted on a random sample of 350 of the original 1,190 consumers – including an oversampling of NPDC residents. The same staff caregivers were asked to complete assessments on the same consumers 15-18 months later. The test-retest correlation coefficients between the 2 time periods were .94 for multi-cognition, .98 for self-care, and .94 for mobility/motor skills. Since a perfect correlation would have been 1.0, these were deemed strong confirmations of the reliability of the measures.

Besides these pre-closure reliability studies of the competency measures, the items were once again tested with the initial “mover” and “stayer” samples at the first evaluation assessment in 1997/98 at T_3 . A factor analysis of each competency measure for the combined samples of “movers” and “stayers” confirmed that all of the 40 multicognitive items, all of the 21 self-care items, and all of the 10 mobility/motor skills items were statistically an integral part of each factor (see Appendix E for examples of the types of items). In addition, the correlation of the combined sample in 1994 (T_1) and 1997/98 (T_3) were compared to assess the likelihood that the measures would still be strongly correlated after a period of 3 to 4 years, depending on when movement out of NPDC occurred.

The correlations for each competency measure for the combined samples between T_1 and T_3 were .83 for multicognition, .85 for total self-care, and .88 for mobility/motor skills. Given these high inter-correlations over time, it is readily apparent that the measures have maintained a high degree of reliability. While all measures, particularly those dealing with human behavior, have some degree of error as part of the assessment process, correlations over a time period of 3-4 years that are above .80 are considered to be very strong. These high correlations are customarily accepted as significant indicators that the measures are still functioning reliably over time.

Initial Matching on Competencies and Assessment Design

As part of the evaluation design, all “movers” and “stayers” were initially matched on their 1994 (T_1) competency and behavioral scores, as well as age and gender. Successful implementation of the research design meant that the 2 comparison groups were statistically similar with regard to these competency characteristics prior to the closure of NPDC. All “movers” and “stayers” were assessed again at 3, 15 and 27 months (or at T_3 , T_5 and T_6 , respectively) after “movers” had left NPDC.

In the 3- and 15-month reports, evidence was provided that the “movers” and “stayers” had similar levels of functioning based on interviews completed with knowledgeable caregivers at group homes and DD Centers. These findings provided empirical support for the inference that moving *per se* did not have an adverse impact on the daily functioning of the former NPDC residents. While this is an important finding, this type of comparison does not permit a rigorous assessment of whether moving into a non-institutional environment had a positive or negative impact on consumer competencies. The reason for this reservation is because 40 of the “movers” left NPDC and went into other

institutions, such as other DD Centers, nursing homes, or private institutions by the time of the first follow-ups at 3 months (see Chapter IV, Table IV-I).

In order to properly compare the post-institutional competencies of “movers” who actually moved into the community with matched “stayers” who remained in institutions, it is necessary to first exclude the 40 “movers” who went to other institutions. The remaining 110 community “movers” can then be compared to their 110 matched “stayers,” in order to assess any changes in competencies from the time of the first baseline measurements in 1994 (T_1) to subsequent assessments in 1997/98 (T_3), in 1998/99 (T_5) and in 2000/01 (T_6). This type of analysis of matched community and institutional consumers can also yield insights on the impacts of remaining in institutions compared to moving into community residences for 27 months.

Comparisons of Average Competency Scores Within Matched Samples Over Time

Table VII-1 provides the average scores for matched pairs of community “movers” and institutional “stayers” at 4 time periods for the 3 major competency measures: (1) multicognition; (2) self-care; and (3) mobility. At the 1994 baseline year (T_1), there were no significant differences between the matched samples for each competency measure (tables not shown). At this time period, there were also no significant differences between community and institution matched pairs on the other matching variables of age, behavior towards others, and behavior towards self (tables not shown). However, assessment of the scores over time within each competency measure for each residential type reveals that diverse patterns of change have occurred. In reviewing these findings, it is important to note that the number of matched pairs for each time period progressively decreases due to deaths and missing data. Table VII-1 provides an overview of trends using the maximum number of matched pairs for each time period.

In Part A, examination of the institutional “stayers” multicognition scores reveals a continued reduction in the mean score from 22.8 (T_1) to 19.7 (T_3) to 19.2 (T_5) and then down to 18.3 (T_6). The community “movers” do not exhibit this type of pattern. There is a fluctuation upward at T_3 , but a slight move downward at T_5 (24.1), yielding no significant change. The final score at T_6 is slightly lower than at T_1 (23.2). A statistical analysis of their overall changes in the multicognition scores within each residential type controlling for comparable persons across time, indicates that the decrease in scores for “stayers” is statistically significant ($p < .0001$). In contrast, the fluctuation of the community “movers” since T_1 is not statistically significant.

Part B reveals a different pattern for the changes in self-care scores. The institutional “stayers” appear to have decreased scores over time. However, further analyses reveal that when the same persons are repeatedly compared over time, any fluctuation of the mean self-care scores of institutional “stayers” is not statistically significant. The community “movers,” in contrast, exhibit a shift upward in their scores over time. Statistical analysis confirms that this change within the community sample is significant ($p < .0001$). Therefore, the self-care pattern of change appears significantly different for “movers” and “stayers.”

Part C reveals that both residential types have had a decrease in mobility since 1994 ($p < .0001$, respectively).

**Table VII-1: Overview of Mean Competency Scores Across Time Periods,
By Residence Type**
(Based on the Maximum Number of Matched Pairs for Each Time Period)

<u>A. Multicognition</u>					
Residential Types	1994 Baseline	1997-98 Post-3 Months	1998-99 Post-15 Months	2000-01 Post-27 Months	Probability of Significant Change since Time 1 ¹
	Time 1 (T ₁)	Time 3 (T ₃)	Time 5 (T ₅)	Time 6 (T ₆)	
Stay in Institution	22.8	19.7	19.2	18.3	p<.0001
Move to Community	24.1	24.7	24.1	23.2	NS
Maximum N	110 Pairs	96 Pairs	96 Pairs	88 Pairs	
<u>B. Self-Care</u>					
Residential Types	1994 Baseline	1997-98 Post-3 Months	1998-99 Post-15 Months	2000-01 Post-27 Months	Probability of Significant Change since Time 1 ²
	Time 1 (T ₁)	Time 3 (T ₃)	Time 5 (T ₅)	Time 6 (T ₆)	
Stay in Institution	26.9	23.8	25.3	23.9	NS
Move to Community	26.9	29.1	31.4	29.7	p<.0001
Maximum N	110 Pairs	101 Pairs	96 Pairs	92 Pairs	
<u>C. Mobility</u>					
Residential Types	1994 Baseline	1997-98 Post-3 Months	1998-99 Post-15 Months	2000-01 Post-27 Months	Probability of Significant Change since Time 1 ³
	Time 1 (T ₁)	Time 3 (T ₃)	Time 5 (T ₅)	Time 6 (T ₆)	
Stay in Institution	20.1	18.9	15.8	18.2	p<.0001
Move to Community	20.2	19.8	16.4	19.5	p<.0001
Maximum N	110 Pairs	102 Pairs	98 Pairs	90 Pairs	

NS = Not Significant

¹The number of persons used for the analyses within each residential type that have usable scores for all time periods is 72 for each residential type. These 72 persons are also matched between residential types; so the trends are based on matched pairs within and between samples. A repeated ANOVA statistical analysis of within effects was used for the analysis for each type.

²The self-care analysis relies on 79 matched pairs and is similar to the analysis of multicognition.

³The mobility analysis relies on 80 matched pairs and is similar to the analysis of multicognition.

Assessment of Multicognitive Scores Between Residential Types

Table VII-1 provided evidence that multicognitive scores became lower over time for consumers living in institutions, but remained fairly comparable over time in community residences. In order to assess whether these trends over time resulted in significant differences between residential types, it is necessary to simultaneously control for changes over all of the time periods since T_1 , while assessing changes between the residential types. Table VII-2 reports the results of this type of analysis using a repeated multiple analysis of variance test (or MANOVA) to assess any differences.

Part A of Table VII-2 assesses changes from 3 time perspectives, in order to determine whether the patterns of change are similar under 3 conditions: (1) T_1 and T_3 only; (2) T_1 , T_3 , and T_5 only; and (3) T_1 , T_3 , T_5 , and T_6 simultaneously. For each time period comparison, the analysis determines whether there are significant differences if only time changes are considered, if only residential differences are considered, and if the combination of time and residential changes are considered. The combination of time and residential type is the crucial test of whether there was a significant difference in the scores of the residential types over time.

Significant change in time only occurred in the comparisons that included T_5 and T_6 , but not when only T_3 was considered alone. A similar pattern occurred for residence type only. However, the interaction of time and residence type was significant at all time comparisons. This finding indicates that significant differences in scores emerged over time between the residential types when modified by time.

Part B expands the analysis by examining differences between residential types at specific time periods – after demonstrating that significant overall differences emerged in Part A. As expected, there were no differences at T_1 , when all consumers lived in DD

Centers and were matched on multicognitive scores. Differences emerged at T_3 , and then continued at T_5 and T_6 . While all of their differences are highly significant ($p < .0001$), an appraisal of the test statistics (F values) indicates that the largest difference occurred between T_1 and T_5 .

These analyses provide convincing evidence that the significant lowering of multicognitive scores of consumers remaining in institutions set them apart from those who moved into community residences. Remaining in an institution from 1994 to 2000/01 had negative consequences for the “stayers.” Community “movers” did not gain in scores; rather, they were more likely to maintain their levels of multicognition over time. These divergent trends produced the differences displayed in both parts of Table VII-2.

Table VII-2: Changes in Multicognitive Scores Since 1994
(Based on Repeated MANOVA Tests)

<u>A. Between Time Period Comparisons of Mean Scores</u>				
Types of Analyses	T ₁ and T ₃	T ₁ , T ₃ , and T ₅	T ₁ , T ₃ , T ₅ , and T ₆	
Time Only	NS	p<.02	p<.004	
Residence Only	NS	p<.05	p<.02	
Interaction of Time and Residence	p<.0004	p<.0001	p<.0002	
<u>B. Comparisons Between Community and Institution Scores¹</u>				
	1994	At 3 Months	At 15 Months	At 27 Months
Probability of Differences in Mean Scores	NS	p<.01	p<.003	p<.007

NS = Not Significant

¹Comparison between scores based on adjustment of multiple comparisons using Dunnett's Adjustment of Least Squares Means after MANOVA analyses of time period comparisons in Part A.

Assessment of Self-Care Scores Between Residential Types

Table VII-1 disclosed that consumer self-care scores increased over time for community “movers,” but did not change for their institutional matches. In order to determine whether these changes within residential types yielded significant differences between the 2 types of consumers, a repeated MANOVA analysis was conducted. The results are depicted in Table VII-3.

Table VII-3 is organized in a manner similar to Table VII-2. Analyses are repeated for 3 time comparisons in Part A in order to confirm the consistency of the findings for different comparisons. Differences for time only occurred for 2 of the 3 time comparisons. There are no distinct resident type only differences for any time comparisons. However, there are strong interactions of time and resident type for all of the time comparisons.

The interaction of time and residence type is confirmed in Part B, where comparisons of resident type are analyzed. There is a significant difference at T_3 , but there is an even stronger difference between the types at T_5 and T_6 .

These multiple analyses provide convincing evidence that the significant increase of self-care scores of consumers moving into community residences set them apart from those who remained in DD Centers. Remaining in institutions from 1994 to 2000/01 had no significant impact on self-care scores of “stayers.” Community “movers,” however, increased their competence over time. These divergent trends produced the differences displayed in Table VII-3.

**Table VII-3: Changes in Self-Care Scores Since 1994
(Based on Repeated MANOVA Tests)**

<u>A. Between Time Period Comparisons of Mean Scores</u>				
Types of Analyses	T ₁ and T ₃	T ₁ , T ₃ , and T ₅	T ₁ , T ₃ , T ₅ , and T ₆	
Time Only	NS	p<.04	p<.01	
Residence Only	NS	NS	NS	
Interaction of Time and Residence	p<.0001	p<.0001	p<.0001	
<u>B. Comparisons Between Community and Institution Scores¹</u>				
	1994	At 3 Months	At 15 Months	At 27 Months
Probability of Differences in Mean Scores	NS	p<.05	p<.007	p<.008
NS = Not Significant				

¹Comparison between scores based on adjustment of multiple comparisons using Dunnett's Adjustment of Least Squares Means after MANOVA analyses of time period comparisons in Part A.

Assessment of Mobility Scores Between Residential Types

Table VII-4 assesses the changes in mobility between residential types over time. In Part A, analysis of time only differences in the 3 time comparisons reveals significant differences in all comparisons. However, assessments of residency type only and interaction of time and residence type reveal no significant difference for any time comparison. Part B confirms the nonsignificant findings of any residential differences over time by revealing that there are no differences at any time period.

The multiple analyses provide convincing evidence that the significant decrease in mobility within both residential types over time yields time only differences. There are no significant differences between consumers in the residential types regarding the degree of loss. Both residential types have experienced mobility loss that is comparable between 1994 and 2000/01.

Table VII-4: Changes in Mobility Scores Since 1994
(Based on Repeated MANOVA Tests)

<u>A. Between Time Period Comparisons of Mean Scores</u>				
Types of Analyses	T ₁ and T ₃	T ₁ , T ₃ , and T ₅	T ₁ , T ₃ , T ₅ , and T ₆	
Time Only	p<.02	p<.0001	p<.0001	
Residence Only	NS	NS	NS	
Interaction of Time and Residence	NS	NS	NS	
<u>B. Comparisons Between Community and Institution Scores¹</u>				
	1994	At 3 Months	At 15 Months	At 27 Months
Probability of Differences in Mean Scores	NS	NS	NS	NS
NS = Not Significant				

¹Comparison between scores based on adjustment of multiple comparisons using Dunnett's Adjustment of Least Squares Means after MANOVA analyses of time period comparisons in Part A.

Locating the Time Period When Self-Care Changed

The previous analyses confirm that significant gains in self-care have occurred within the community “movers” sample over time, but the evidence does not actually specify whether some of the gains might have occurred within the institution, before placement in the community actually occurred. Over 3 years elapsed between the 1994 baseline (T₁) measures and the first post-placement assessment at T₃ (in 1997/98). The public announcement that NPDC was scheduled for closure and residents were to be moved took place in April, 1995 – about 6 months after completing T₁ measures in the Fall of 1994. It is conceivable that more competent residents may have realized that they had something to look forward to, and dedicated staff may have begun to prepare them for noninstitutional living.

In order to assess when changes in self-care actually occurred, all of the available surveys conducted by DD Planning Institute for the entire population of NPDC are used. Surveys were conducted at NPDC in 1996, with comparable competency instruments, in

order to provide information to service providers about persons who might be candidates for receiving services in the community. Focusing solely on those former NPDC residents in our sample who were destined to become “movers” in community residences, it is possible to conduct a comparison between 1994 (T_1) and 1996 (T_2) – prior to moving into the community. Unfortunately, comparable information for the matched institutional “stayers” is not available. However, it is not necessary since the interest is in locating when the community “movers” gained self-care skills.

In addition to the T_2 data, data is also available on community “movers” 9 months after leaving NPDC. These measurements constitute T_4 assessments. Using all of the available DDPI data for community “movers,” a more complete time series can be constructed from 1994 to 1996 (T_1 - T_2), 1996 to 1997/98 (T_2 - T_3), 1997/98 to 1998 (T_3 - T_4), and 1998/99 to 2000/01 (T_5 - T_6). Table VII-5 provides the information for assessing differences within the community “movers” sample over time. Besides the data on total self-care scores, tests of differences are also provided on the 3 sub-indexes – basic self-care, independence, and household skills – contained within the overall index of self-care.

The 3 self-care sub-indexes that are used in Table VII-5 contain the following items:

<u>Basic Sub-index</u> (7 items)	<u>Independent Sub-index</u> (9 items)	<u>Household Sub-index</u> (5 items)
Feed self	Make bed	Shop simple needs
Drink from cup	Clean room	Prepare food
Toileting/bladder	Do laundry	Uses stove/microwave
Toileting/bowel	Care for own clothes	Wash dishes
Dress self	Use money/not count change	Use public transportation
Move in familiar setting	Use money/count change	
Chewing/swallowing food	Identify items to buy	
	Orders food in public	
	Chooses/buys items	

In Part A of Table VII-5, the results for testing total self-care scores for all time comparisons – including the time period within the institution (T_1 vs. T_2) – are statistically significant. However, in Part B, none of the time comparisons for the basic sub-index are

statistically significant, including T_1 vs. T_2 . In contrast, all of the time comparisons – except T_1 vs. T_2 – are statistically significant for the sub-indexes of independence and household skills. The findings indicate that change is occurring within the community for the more complex self-care skills of independence and household skills, but not for basic self-care skills.

The findings in Table VII-5 also reveal that the T_1 vs. T_2 comparison does not yield a significant difference for any of the 3 sub-indexes. The only change that may have occurred in the institution (between T_1 and T_2) is for the total score, but not when all of the item scores are disaggregated. However, since there are no changes over time within the institution for the sub-indexes, it is possible that the total self-care scores change between T_1 and T_2 could have occurred by chance. Some change in self-care may have begun within the institution, but there is no statistical evidence that it occurred for any specific types of competencies.

Table VII-5: Changes in Self-Care Scores Within the Community Only, By Time Period
(Based on Repeated MANOVA Tests)

Specific Time Periods	<u>Types of Self-Care Competencies¹</u> (n=83)			
	A. Total Self-Care Scores	B. Basic Self-Care Only	C. Independent Self-Care Only	D. Household Skills Only
T ₁ vs T ₂	p<.02	NS	NS	NS
T ₁ vs T ₃	p<.0001	NS	p<.0001	p<.0004
T ₁ vs T ₄	p<.0001	NS	p<.0001	p<.0001
T ₁ vs T ₅	p<.0001	NS	p<.0001	p<.0001
T ₁ vs T ₆	p<.0001	NS	p<.0001	p<.0007
Overall Time Periods	p<.0001	NS	p<.0001	p<.0001

NS = Not Significant

¹See text for types and number of items for the sub-indexes of self-care.

Sources of Gains in Self-Care

The previous analyses have confirmed that gains in self-care by community “movers” occurred over time. The analyses that follow attempt to identify some of the variables that may have contributed to the gains over time. In order to conduct this type of explanatory analysis, it is useful to conceptualize the potential variables of influence for both institutional or community residents. The variables to be assessed are as follows:

- (1) **1994 (T₁) Matching Variables** – The 7 matching variables must be controlled in order to identify additional influences for both samples.
- (2) **Other 1994 (T₁) Variables** – Other variables which were not controlled were found to differentiate the samples and might also be influences, such as having psychiatric diagnoses or attending day programs.
- (3) **3-, 15-, and 27-Month Program Variables** – As Chapter V disclosed, community residences and institutions differed on a variety of characteristics, like size, teaching domestic skills, staff attitudes, attending day programs, and degree of social control. These variables can be used to identify potential influences on self-care after moving into the community.

Using this conceptual approach, T₁ matching and other variables were used in a series of multiple regression analyses in order to first identify the potential variables that existed before any persons moved into the community. After identifying the best T₁ variables to explain or account for the self-care scores at T₃, T₃ program variables were used to identify those that might add to our understanding of the influences on self-care scores at T₃. The final results of the regression analyses for T₃ are depicted in Part A of Table VII-6. Part B uses the variables identified in the best model at T₃ in order to assess whether the influences are consistent across time periods at T₅ and T₆.

The best T_1 variables that emerged from the analyses were 3 of the initial matching variables. Higher self-care scores at T_1 are, not surprisingly, the best predictors for explaining which consumers were likely to have higher self-care scores at T_3 . Together with higher mobility and younger age, these 3 variables are capable of explaining 67.6 percent of the variability in T_3 self-care scores. This is an unusually high amount of explained variance (or R^2) for any model and is primarily due to the strong correlation between self-care scores at T_1 and T_3 .

The standardized “beta values” are indicators of how strongly each independent variable is correlated with self-care at T_3 , compared to all of the others in a model. These values can vary between 0 and 1. Clearly the beta value of .74 from T_1 self-care is much stronger than the values of .11 or -.09. The negative beta value for age means that the older the consumer was at T_1 , the more likely he/she will have a lower self-care score at T_3 .

Self-care at T_3 is also strongly correlated to multicognition at T_1 , but the inclusion of multicognition biased the model because it was too strongly correlated to self-care at T_1 . Although multicognition was excluded as an explanatory variable, it is important to note that higher T_1 self-care scores are also indicators of high multicognition scores.

It is useful to conceive of the best variables of T_1 as the control variables, since even without any introduction of program variables, the amount of variances explained is inordinately high. In the next analyses, the best program variables that emerged are those that are clearly associated with community residence – teaching domestic skills and small size of the residence. Both variables contribute an additional 10 percent of the variance to the total explanatory model. Of the 2 program variables, teaching domestic skills is clearly the most important (beta value of .31 compared to .08). As Chapter V indicated, the odds are

about 3.3 to 4.7:1 that domestic skills are more likely to be taught in a community residence than in a DD Center.

The final model depicted in Part A of Table VII-6 represents the usefulness of testing all of the variables that were found to be associated with community residence in Chapter V. The 2 program variables found to best explain self-care at T_3 were statistically significant and made independent contributions to the total model. It is important to note, however, that the control variables of age just missed being statistically significant in the T_3 model when the program variables were entered. While the probability of age was only $p < .07$, it was retained because it is theoretically plausible that age can be a control variable at other time periods.

Part B provides evidence that all of the variables are statistically significant at T_5 – including age. In addition, the relative contributions of these variables are quite similar to the results obtained at T_3 . Clearly self-care scores at T_1 remain as the most important, followed by teaching domestic skills. However, the third most important variable is age, since the beta value is now higher than that for mobility at T_1 and small size of the residence at T_3 .

A review of T_6 reveals that the overall amount of variance explained is again similar to that explained at T_3 and T_5 . However, age is the least important variable in the model at T_6 (beta of $-.06$ and $p < .09$).

Table VII-6: Creating and Assessing the Best Model for Explaining Self-Care Scores at 3 Time Periods
(Based on Multiple Regression Analyses with Maximum Number of Matched Pairs)

<u>A. Creating the Best Model at T₃</u> (n=200)				
Specific Time Periods	<u>Testing Control Variables</u>		<u>Adding Program Variables</u>	
	R ² Contribution	Standardized Beta Values	R ² Contribution	Standardized Beta Values
<u>Control Variables</u>	67.6%		67.5%	
Self-Care (T ₁)		.74***		.60***
Mobility (T ₁)		.11*		.12**
Age (T ₁)		-.09*		-.06
<u>Program Variables</u>			10.0%	
Teach Domestic Skills (T ₃)				.31***
Small Residence Size (T ₃)				.08*
Adjusted R ²	67.6%		76.9%	
<u>B. Creating the Best Model at T₅ and T₆</u>				
Specific Time Periods	<u>15 Months (T₅)</u> (n=190)		<u>27 Months (T₆)</u> (n=180)	
	R ² Contribution	Standardized Beta Values	R ² Contribution	Standardized Beta Values
<u>Control Variables</u>	64.6%		65.5%	
Self-Care (T ₁)		.60***		.59***
Mobility (T ₁)		.12**		.15**
Age (T ₁)		-.14**		-.06
<u>Program Variables</u>	12.7%		11.1%	
Teach Domestic Skills (T ₃)		.33***		.33***
Small Residence Size (T ₃)		.09*		.09*
Adjusted R ²	76.7%		75.9%	
	* p< .05	** p<.01	***p<.001	

Interpreting the Findings

The introduction to this chapter described the efforts to ensure the reliability of these critical measures of competencies. While T_1 to T_3 correlations were quite high (.83 or higher), it is arguable that the competency findings could have been produced by the error remaining between the results and a “perfect” correlation. However, proponents of this line of reasoning would have to deal with the paradoxical facts that institutional measures of multicognition were significantly lower over time, while community “movers” had no significant changes in scores from 1994 to 2000/01. Differences due to random error would customarily affect both samples in a similar fashion, but this did not occur. It is also useful to note that the competency measures were initially developed to assess an institutional only sample in 1994. Therefore, it is difficult to accept an assumption that the wording of the competency items were skewed in favor of the community “movers” when the same wording was used at all time periods with both samples of consumers. If we accept the inference that the findings are indeed based on substantive and reasonably accurate measurements over time and across samples, then the results can have implications for the research literature and public policy, especially for the State of New Jersey.

In the past several years, there have been reviews of research on deinstitutionalization in America (Kim et al., 2001), the United Kingdom (Emerson and Hatton, 1996; Felce and Emerson, 2001), and Australia (Young et al., 1998). These reviews report that there are likely to be improvements in “adaptive behaviors” by people who leave institutions and move to smaller residences in the community. These studies, however, tend to vary in methodological rigor. In the most recent American review of research in deinstitutionalization, Kim et al. (2001) screened “over 250 studies” and found only 38 that met minimal standards of research adequacy. However, only 14 of 38 acceptable American

studies included a “contrast” group of comparable institutional “stayers.” Out of the 14 more rigorous studies, 11 reported statistically significant findings that “adaptive behaviors” improved more for community residents than their institutional matches. While the other 3 studies reported positive gains for community residents, these gains were not significantly different than the contrast group. The current NPDC study uses a controlled research design of matched samples that is as good as or better than the reported studies, and thus, the findings make an important contribution to the research literature.

This study’s findings that self-care – an important aspect of adaptive behaviors – is more likely to improve in community “movers” is in harmony with most of the best studies reported in the research literature. The fact that the gains by community “movers” tend to level off within the first year of leaving the institution is also congruent with the other well-designed studies. In the United Kingdom, this leveling effect of adaptive behavior gains is termed a “plateau effect.” However, there are no published American studies that have systematically collected data using a matched research design with repeated measures for over five years. This study may also be unique in statistically documenting the significant loss in multicognitive competencies by persons remaining in institutions over a 6-7 year period.

This study’s dual set of significant findings – loss in multicognitive competencies by institutional residents over a 6-7 year period and significant gains in self-care competencies by community “movers” over the same time period – has important implications for public policy, as well as for deinstitutionalization research. An evaluative study of limited duration may not be sufficiently long enough to carefully document the long-term consequences of remaining in institutions. This research study began with the general aim of finding out whether the level of living of community “movers” was “equal to or better than” it would

have been if they had remained in institutional settings. However, this study's finding of significant losses in multicognitive competencies by institutional residents was unexpected and too striking to ignore.

Remaining in institutions for 6-7 years by persons who were similar to community "movers" in 1994 (when they were both about 48 years of age) is quite costly in human terms. This study has provided the State of New Jersey with empirical evidence that failure to increase the rate of deinstitutionalization may have a negative impact on those remaining in DD Centers for another 6-7 years. Negative impact may be most likely to occur for persons who had lower multicognitive scores.

While the NPDC community "movers" and their institutional matches do not represent New Jersey's institutional population, this study's findings offer the closest approximation to what is likely to occur over time. This approximate outcome is likely because the institutional matches were selected from all of the DD Centers. Though they resided in different DD Centers, institutional residents who had characteristics similar to the community "movers" exhibited significant losses in multicognition from 1994 to 2000/01, and did not have the opportunity to gain in self-care competencies, which probably would have occurred if they had moved into smaller residences in the community due to the teaching of domestic skills.

Summary of Findings

Earlier reports at 3, 9 and 15 months have focused on competency changes between the total “mover” and “stayer” samples. These analyses provided evidence that there were no differences between the samples and indicated that moving *per se* did not have an impact on the competencies of those who left NPDC in 1997/98. However, this line of analysis was not an accurate portrait of the differences between those who moved to community residences and those who stayed in the institutions, since 40 “movers” actually were placed in other institutional residences (i.e., other DD Centers, nursing homes, or private institutions). Therefore, this chapter focused solely on the initial 110 “movers” who went into community residences and their 110 matched “stayers” who remained in the 7 DD Centers in New Jersey.

Using reliable measures of multicognition, self-care, and mobility tested before and after the evaluation began, the analyses focused on changes within and between samples. Changes within samples from 1994 (T_1) to 2000/01 (T_6) disclosed that institutional “stayers” had significantly lower multicognition during and at the end of the evaluation period than at the outset. In contrast, community “movers” were able to maintain their multicognition levels over the same 6-7 year period. In addition, community “movers” were able to increase self-care competencies between T_1 and T_6 . Both samples decreased their mobility over time.

Some of the gains in self-care competencies may have possibly occurred while “movers” were still in the institution after the closure of NPDC had been announced, but before any movement occurred out of the institution. But the major gains in independence and household skills occurred after “movers” left NPDC and entered community residences. These gains in increased independence and household skills were linked to small residences

where informal teaching of domestic skills was more likely to occur. Both of these program variables are strongly associated with community living. Gains tended to level off between 9 and 15 months, but were maintained as of 27 months.

Differences between the samples on multicognition were statistically significant because of the decreased scores of institutional “stayers” over a 6-7 year period, and not because of community “movers.” Differences between the samples on self-care were primarily due to the significant gains made by community “movers.”

The findings on self-care for the community “movers” are in harmony with the best research studies on deinstitutionalization reported in the literature. Few studies have periodically evaluated matched samples over an extended period, and this study’s findings on the loss by institutional “stayers” for multicognition over a 6-7 year period may be unique.

This study’s findings have important implications for research and public policy in New Jersey. Remaining in institutions for 6-7 years (beginning at about the age of 48 years) with the same characteristics as the NPDC “movers” who moved into community residences is deleterious to multicognitive well-being. Multicognitive competencies of institutional “stayers” – particularly those who had lowest competencies in 1994 – were significantly lower in 2000/01 as compared with 1994. If they had been able to prepare for and actually move like the NPDC matches, their multicognitive competencies probably would have been maintained. Clearly, the “stayers” are “worse off” after 6-7 years and the community “movers” are “better off” than if they had remained institutionalized, based on assessments of their competencies.

Chapter VIII: Aggressive and Inappropriate Behaviors

Introduction

Past evaluation studies of persons with developmental disabilities who were moved from institutions into community placements have found inconsistent empirical findings pertaining to special or challenging behaviors. While some studies have found no significant or clinically meaningful changes in the behavioral difficulties of individuals after moving (Wing, 1989; Brook and Bowler, 1992), other researchers have found an increase in maladaptive behaviors (Bowen and Gerry, 1995) by persons moving out of institutions. A recent review of 12 contrast group studies found only one study that had a significant difference between “movers” and “stayers” (Kim et al., 2001). Given the mixed findings, and general awareness that undesirable behaviors could be a major factor in disrupting placements, “movers” and “stayers” were matched on their known behavioral scores in 1994 (as well as on other matching criteria discussed in earlier chapters).

The 2 behavioral indices used in 1994 for the matching were based on asking knowledgeable staff to report on behavior towards others and towards self that occurred during the past year. These measures had proven moderately reliable over time, when a special reliability study was conducted for these and the other matching measures (Jagannathan et al., 1997). However, the NPDC evaluation asked knowledgeable staff to rate consumers’ behaviors during the past 3 months. It was assumed that caregivers could accurately report on behaviors within a 3-month time period. After conducting factor analyses on the behaviors of “movers” and “stayers” – based on 3-months data – it was concluded that the behavioral indexes needed to be revised. The procedures for establishing the reliability of the new behavioral indexes and checking on their validity with the 1994 measures were as follows:

- 1) The frequencies of all behavioral items collected at 3 months were screened in order to remove those with low variability (i.e., fewer than 10% of consumers were reported to have these behaviors). A total of 7 out of 24 items were removed as potentially unreliable indications of behavior towards others or self.
- 2) The remaining 17 items were entered into a series of confirmatory factor analyses – with 11 items representing inappropriate and/or aggressive behavior towards others and 6 items representing behavior towards self. After examining the results of the first- and second-order factor analyses, the 2 types of behavioral measures were provisionally confirmed.
- 3) The items for each behavior measure were subjected to item analyses, and only those items that correlated .40 or higher with the total measures were retained.
- 4) The revised indexes and items that proved to be reliable at 3 months and were confirmed with 15-month data are as follows:
 - a) Aggressive and Inappropriate Behavior Towards Others – measured by 9 items that refer to tantrums/outbursts, noises/curses, disruptive activities, disobedience to known directions, bothering/harassing, verbal threats, physical threats, hitting, grabbing or scratching (Cronbach alpha = .84 at 3 months).
 - b) Behavior Towards Self – measured by 3 items that refer to hitting own body, hitting own face or head, and banging head (Cronbach alpha = .79 at 3 months).
- 5) In order to make certain that the “movers” and “stayers” were still comparable on the revised behavioral items, the data collected in 1994 were reanalyzed. Confirmatory factor analyses of the 1994 data set, using only the revised behavioral items, revealed that they formed reliable indexes. “Movers” and “stayers” were compared using the 2 new

behavioral indexes. There were no significant differences found, indicating that the 2 samples were still initially comparable with regard to their maladaptive behaviors.

The behavioral findings at 3, 15, and 27 months will be discussed separately in the sections that follow. Unfortunately, comparisons with 1994 cannot be performed because the scoring was influenced by whether the items refer to the past year or the past 3 months.

Analytic Strategy and Past Findings

Earlier reports at 3 and 15 months relied on comparisons of all “movers” and “stayers.” As noted earlier, there were forty “movers” who were transferred to other DD Centers and were included in the analyses. In order to further understand what happened to community “movers,” it is useful to set aside these forty “movers” and their forty matches and focus exclusively on “movers” who were placed in community residences and their matches.

Before presenting these more focused analyses, it is useful to summarize earlier findings for “movers” and their “stayers.” Regarding behaviors toward others, prior analyses revealed that there were no differences between the 2 groups at each time period or between time periods at 3 and 15 months.

Regarding behavior towards self, earlier analyses revealed that there were no differences between the “movers” and “stayers” at each time period or between time periods at 3 and 15 months.

Subsequent analyses using only community “movers” and institutional “stayers” are designed to determine whether these findings are replicated using 27-month data and community “movers” and their institutional matches.

Comparisons of Scores Within Matched Samples at Each Time Period

Table VIII-1 provides an overview of the mean behavioral scores across time periods. Part A presents the data for the behavior towards others and Part B displays the findings for behavior towards self. Reviewing Part A, behavior towards others, it is clear that the scores of the institutional “stayers” did not change appreciably and a statistical test of the change since 3 months indicates that the small change was not significant. However, the matched community “movers” change over time was statistically significant ($p < .04$).

Part B discloses that the matched “movers” had higher scores at 27 months (T_0), but this change was not statistically significant. The institutional “stayers” appeared to have lower scores, but this shift was also not statistically significant.

Further analyses attempt to assess whether any of the shifts have resulted in differences between the 2 matched groups over time.

**Table VIII-1: Overview of Mean Behavioral Scores Across Time Periods,
By Residence Type**

(Based on the Maximum Number of Matched Pairs for Each Time Period)

A. Behavior Towards Others				
Residential Types	1997-98 Post-3 Months	1998-99 Post-15 Months	2000-01 Post-27 Months	Probability of Significant Change since 3 Months
	Time 3 (T_3)	Time 5 (T_5)	Time 6 (T_6)	
Stay in Institution	2.95	3.12	3.12	NS
Move to Community	2.35	2.98	2.91	.04
Maximum N	104 Pairs	99 Pairs	92 Pairs	
B. Behavior Towards Self				
Residential Types	1997-98 Post-3 Months	1998-99 Post-15 Months	2000-01 Post-27 Months	Probability of Significant Change since 3 Months
	Time 3 (T_3)	Time 5 (T_5)	Time 6 (T_6)	
Stay in Institution	0.41	0.44	0.29	NS
Move to Community	0.35	0.40	0.53	NS
Maximum N	104 Pairs	99 Pairs	92 Pairs	

NS = Not Significant

Assessment of Behavior Towards Others' Scores Between Residential Types

Table VIII-2 is divided into 2 sections. Part A assesses whether there are any changes between the 2 samples between 2 time comparisons – 3 and 15 months, and 3, 15, and 27 months. Using a repeated measure analysis of variance approach, the results are broken down by 3 types of analyses: 1) whether there is any change over time between specific time periods, regardless of the type of sample; 2) whether there is any change over time by residence; and 3) whether there is any interaction of time and residence for each time comparison. It is this latter statistical comparison that is critical in determining whether there are differences between the matched groups for specific time periods.

The data in Part A reveal that there is a “time only” change when comparing 3 and 15 months, but this impact was not statistically significant when all time periods were considered simultaneously. There were no statistically significant results for the “residence only” analysis. There was also no significant impact for the interaction of time and residence. Part B confirms that there were also no significant differences between the 2 matched groups at each specific time period.

On the basis of the results of Part A of Table VIII-2, we can conclude that there are no significant differences between the 2 groups, despite the fact that there has been some change over time in the scores of each group.

**Table VIII-2: Changes in Behavior Towards Others' Scores Since 3-Month Follow-up
(Based on Repeated MANOVA Tests)**

A. Between Time Period Comparisons of Mean Scores

Types of Analyses	T ₃ and T ₅	T ₃ , T ₅ , and T ₆
Time Only	.02	NS
Residence Only	NS	NS
Interaction of Time and Residence	NS	NS

B. Comparisons Between Community and Institution Scores¹

	At 3 Months	At 15 Months	At 27 Months
Probability of Differences in Mean Scores	NS	NS	NS

NS = Not Significant

¹Comparison between scores based on adjustment of multiple comparisons using Dunnett's Adjustment of Least Squares Means after MANOVA analyses of time period comparisons in Part A, using maximum number of pairs for each comparison.

Assessment of Behavior Towards Self Scores Between Resident Types

Table VIII-3 provides the results of the repeated measures analysis of variance for behavior towards self. Part A reveals that there were no “time only” or “residence only” differences that were statistically significant. The interaction of time and residence was also not significant when only 3 and 15 months are considered. However, it is evident that there was a significant difference between the matched groups when a longer time span was included.

While Part B discloses that there were no statistically significant differences between the 2 matched samples at a specific time period, the finding of an interaction between time and residences when 27-month data is included indicates that further analyses are warranted. Specifically, these analyses focused on determining whether moving into a community residence increased the likelihood of engaging in behavior towards self by 27 months.

**Table VIII-3: Changes in Behavior Towards Self Scores Since 3-Month Follow-up
(Based on Repeated MANOVA Tests)**

A. Between Time Period Comparisons of Mean Scores

Types of Analyses	T ₃ and T ₅	T ₃ , T ₅ , and T ₆
Time Only	NS	NS
Residence Only	NS	NS
Interaction of Time and Residence	NS	.02

B. Comparisons Between Community and Institution Scores¹

	At 3 Months	At 15 Months	At 27 Months
Probability of Differences in Mean Scores	NS	NS	NS

NS = Not Significant

¹Comparison between scores based on adjustment of multiple comparisons using Dunnett's Adjustment of Least Squares Means after MANOVA analyses of time period comparisons in Part A, using maximum number of pairs for each comparison.

Explaining Behavior Towards Self at 27 Months

Besides finding that there may be a change in behavior towards self scores for matched pairs over 27 months, earlier analyses also disclosed a similar finding when all “movers” and “stayers” were assessed. Since the “movers” and “stayers” samples are larger than the community matched samples, we proposed to expand the analyses as follows:

- 1) Use the total available sample of “movers” and “stayers” at 27 months, but use residence type as a control variable;
- 2) Examine other variables that were significantly associated with behavior towards self, and then use them in multivariate analyses with community residence as a control variable; and
- 3) Expand the understanding of behavior towards self by including all persons who had engaged in at least one such behavior in the past 3 months as the dependent variable to be explained.

Part A of Table VIII-4 reports the findings for 5 variables that were found to be significant at 27 months, as well as at all time periods. For example, persons with one or more “self” behaviors were more likely to have psychiatric diagnoses ($p < .05$). The associations between behavior towards self and seeing a psychiatrist and using psychotropic medication were even stronger (i.e., 59% to 29%, $p < .0001$ and 71% to 42%, $p < .0002$, respectively). While having low emotional well-being and living in the community were also statistically significant, the relationships were weaker than the psychiatric indicators. Combining all of the variables into a single logistic analysis revealed that there were 2 variables that constituted the “best model” – psychiatric visits and medication.

Part B of Table VIII-4 presents the 2 best variables that were found to explain those who had one or more behavior towards self at 27 months – seeing a psychiatrist and

receiving psychotropic medications. When community residence was entered as a third variable, it did **not** make a unique contribution to understanding behavior towards self – since the significance was reduced from $p < .04$ when viewed alone to $p < .63$ when combined with other significant variables. The odds of having one or more behaviors is only 1.2:1 for community residence – almost even – compared to 2.3:1 for each of the psychiatric indicators.

Thus, it can be concluded that it is not residing in the community that contributed to increases in behavior towards self, but rather having psychiatric problems requiring psychiatrist visits or psychotropic medications. As Chapter V noted, “movers” had a higher rate of psychiatric problems and received more psychotropic medication before moving and at 3 months. While the matching of behaviors at 3 months did not reveal any differences between “movers” and “stayers,” psychiatric problems over time became linked to more behavior towards self at 27 months by “movers” living in community residences.

**Table VIII-4: Significant Correlates of Behavior Directed at Self at 27 Months
(Based on the Maximum Number for Each Analysis)**

A. Using Individual Variables

Variables	Percent Associated with		Significance
	1 or More Behaviors	No Behaviors	
Psychiatric Diagnosis	67%	53%	$p < .05$
Seeing Psychiatrist	59%	29%	$p < .0001$
Psychotropic Medication	71%	42%	$p < .0002$
Low Emotional Well-Being	57%	41%	$p < .04$
Community Residence	50%	35%	$p < .04$

B. Best Model, Using Multiple Variables Simultaneously

Variables	Significance	Odds Ratios
Seeing Psychiatrist	$p < .02$	2.3:1
Psychotropic Medication	$p < .02$	2.3:1
Community Residence	$p < .63$	1.2:1

Summary of Findings

Earlier studies of deinstitutionalization have been associated with mixed findings with regard to its impacts on special or challenging behaviors. Some studies have found a positive impact on behaviors, while others have not. Part of the reason for the mixed findings may be due to the aggregation of behaviors into one overall composite measure for all types of “maladaptive behaviors.” In contrast, this study has relied on using 2 indexes for difference types of special (or maladaptive) behaviors – those towards others and those towards self. By using distinctive measures for matching and continued measurement at 3, 15, and 27 months, more specific assessments and comparisons were made.

Analyses of behavior towards others – measured by items referring to aggressive or inappropriate behaviors – revealed that there were no significant differences between community “movers” and matched “stayers” at 3, 15, or 27 months. While community “movers” behaviors increased over time, they were not sufficient to change the comparability between “movers” and “stayers.”

In contrast, analyses of behavior towards self revealed that a statistically significant difference was found at 27 months. The mean scores of “movers” had increased sufficiently, so that the mean changes between community “movers” and “stayers” were also significant when modified by time. However, further multivariate statistical analyses disclosed that other variables – particularly ones associated with psychiatric problems, psychiatrist visits, and psychotropic medication – were also linked to having one or more behaviors directed at self at 27 months. Further multivariate analyses disclosed that it was these types of psychiatric indicators – rather than community residence – that were uniquely associated with higher behavior towards self. These findings were congruent with earlier findings that NPDC “movers” had higher rates of psychiatric problems and medication

usage than those in the other DD Centers. Increased behavior towards self was, therefore, best explained by the prior existence and continuation of psychiatric problems and treatments, rather than by moving into a community residence per se.

Chapter IX: Relationships with Family and Peers

Introduction

In recent years, there has been a growing interest in the role of families in the lives of persons with developmental disabilities. However, much of this literature has focused on families caring for persons with disabilities in their own homes (Englehardt et. al., 1988; Seltzer and Krauss, 1989; Heller and Factor, 1994). Recently, the State of New Jersey Division of Developmental Disabilities funded the first statewide study of the stresses on families caring for relatives with developmental disabilities living in their own homes (Apgar et al., 2000). More recently there has been an interest in family involvement with adults with mental retardation, after they have left their own homes and moved into a “non-parental living situation” (Seltzer et al., 2001). However, there is a minimal amount of knowledge about the impact of deinstitutionalization over time on the family contacts of consumers (Conroy and Feinstein, 1987; Conroy and Wang, 1987; Larson and Lakin, 1991). This study, in contrast to previous assessments, has attempted to measure family contact at more than one point of time – before the NPDC closure – and at 3, 15 and 27 months after consumers left the institution.

Family Contacts Before “Movers” Left NPDC

In 1994, when the evaluation sample of “movers” and “stayers” was constructed, information was also collected about family contacts while all consumers were still in institutions. In 1994, knowledgeable caregivers were asked to report on whether there had been any phone contacts or visits by any family members in the past 6 months. Table IX-1 provides preclosure, baseline information on the proportion of matched pairs of “movers” and “stayers” who had received one or more phone contacts or actual visits in the past 6 months.

**Table IX-1: Family Contact in 1994 of Matched “Movers” and “Stayers”
While Living in DD Centers
(Max. n = 137 Matched Pairs for Each Comparison)**

Contact Type	<u>Percent with Contact</u>		Significance
	“Movers”	“Stayers”	
Phone Call	45%	50%	NS
Visits	48%	48%	NS

NS = Not Significant

As Table IX-1 makes clear, there were no statistically significant differences between “movers” and “stayers” receiving phone calls from members of their families. The proportion of “movers” and “stayers” receiving visits over the past 6 months was exactly the same – 48% of each group had received one or more visits. Thus, it can be concluded that while “movers” lived in North Princeton they received the same proportion of phone contacts and visits as matched “stayers” living in the other 7 DD Centers.

Family Phone Contacts at 3, 15, and 27 Months

In previous reports, evidence was presented that significantly more “movers” were likely to receive phone contacts at 3 and 15 months than the matched group of “stayers.” In Table IX-2 data is presented for all postclosure time periods in order to assess family phone contacts over a 2-year period.

**Table IX-2: Phone Contacts Reported by Staff and Family Members/Guardians
For “Movers” and “Stayers” at 3, 15 and 27 Months
(Based on the Maximum Number of Matched Pairs for Each Comparison)**

<u>A. Phone Contacts - Staff Reports</u>				
	3 Months	Time Periods 15 Months	27 Months	Change 3-27 Months Significance
“Movers”	55%	54%	51%	NS
“Stayers”	37%	36%	30%	NS
Significance	p<.004	p<.005	p<.002	
<u>B. Phone Contacts - Family Member/Guardian Reports</u>				
	3 Months	Time Periods 15 Months	27 Months	Change 3-27 Months Significance
“Movers”	83%	76%	80%	NS
“Stayers”	54%	52%	67%	NS
Significance	p<.0001	p<.0002	p<.07	

NS = Not Significant

Table IX-2 reports phone contacts as reported by staff (Part A) or reported by family members/guardians (Part B). It is important to note that the postclosure for both respondent groups is based on asking each respondent group to refer to the previous 3-month period in contrast to the 6-month period used in 1994. Therefore, the proportions reported for 1994 and postclosure time periods cannot be used for comparisons. The primary issue is whether there are differences between the proportions of “movers” and “stayers” who received phone contact at one or more of the time periods after closure.

In Part A, relying on staff input about the previous 3 months, there are statistically significant differences between “movers” and “stayers” at each time period. The fluctuations in the reports between 3 and 27 months for each group are minimal and are not statistically significant.

In Part B, relying on family member/guardian reports, the proportion of consumers receiving phone contacts in the previous 3 months is higher for “movers” and “stayers” at

each time period when compared to the reports of staff. However, family members/guardians of “movers” report a higher rate of contact than their “stayer” counterparts for all time periods, but only the differences at 3 and 15 months are statistically significant ($p < .0001$ and $p < .0002$, respectively). The difference at 27 months only approaches statistical significance ($p < .07$). The change over time between 3 and 27 months is not statistically significant for either group.

Based on the findings, it is reasonable to infer that more “movers” were likely to receive phone contacts at 3 and 15 months according to both staff and family members/guardians. More “movers” may have also received phone contact at 27 months as evidenced by data collected by staff, though this finding is not as firmly supported by family member/guardian reports.

Family Visits at 3, 15, and 27 Months

Table IX-3 provides data on actual visits for each time period, based on staff reports (Part A) and family member/guardian reports (Part B). The differences in visits of “movers” and “stayers” were statistically significant at 3 and 15 months. However, no difference was found at 27 months due to the significant drop in the number of “movers” who had visits at 27, compared to 3, months ($p < .0001$). The proportion of “stayers” who had visits was fairly stable between 3 and 27 months and is not statistically significant.

In Part B (based on family member/guardian reports), only the difference at 3 months is statistically significant. Family members/guardians of both “movers” and “stayers” reported higher rates of visits than their staff counterparts. Though higher, family member/guardian reports were similar to those of staff over time. There was a significant drop in the proportion of “movers” who received visits, while the “stayers” who received visits was fairly stable over time.

**Table IX-3: Family Visits According to Staff and Family Members
For “Movers” and “Stayers” at 3, 15, and 27 Months
(In percent for each time period)**

<u>A. Visits - Staff Reports</u>				
	Time Periods			Change 3-27 Months
	3 Months	15 Months	27 Months	Significance
“Movers”	56%	50%	36%	p<.0001
“Stayers”	38%	35%	34%	NS
Significance	p<.004	p<.01	NS	
<u>B. Visits - Family Member/Guardian Reports</u>				
	Time Periods			Change 3-27 Months
	3 Months	15 Months	27 Months	Significance
“Movers”	85%	74%	68%	p<.0007
“Stayers”	56%	63%	59%	NS
Significance	p<.0001	NS	NS	

NS = Not Significant

Based on the findings, it is reasonable to infer that “movers” are more likely to receive visits at 3 months and perhaps at 15 months. There are clearly no significant differences at 27 months. In contrast to phone contacts, there were dramatic decreases in the proportion of “movers” who received visits at 27 months compared to 3 months, according to both staff and family/guardian reports.

Does Community Placement Help Explain Phone Contacts and Visits?

While the trends for phone contacts and visits between “movers” and “stayers” over time are clear, more analyses are necessary in order to determine whether moving into a community residence makes a unique contribution in explaining any increase in contacts and visits. In order to address the issue of whether community placement makes a unique, independent contribution in explaining higher rates of phone contacts and visits, it is necessary to engage in multivariate analyses for each time period while controlling for critical matching variables. The analyses in the previous section did not consider whether age, multicognition, or mobility also has an impact on phone contact and/or visits.

When community residence is simultaneously assessed with consumer characteristics in a series of logistic regression analyses, then the results can be summarized as in Table IX-4. In Part A, the findings of staff reports and family member/guardian reports of phone contacts are independently summarized for each time period.

Table IX-4: Summary of Multivariate Analyses of Phone Contacts and Visits Using Staff and Family/Guardian Data
(Based on the Maximum Number of Consumers in the Total Sample for Each Analysis)

<u>A. Related to Phone Contacts</u>						
<u>Characteristics</u>		<u>Staff Reports</u>		<u>Family Member/Guardian Reports</u>		
	3 Months	15 Months	27 Months	3 Months	15 Months	27 Months
Consumer Characteristics?	Yes ¹	No	Yes ²	No	No	Yes ³
Community Residence?	Yes	Yes	Yes	Yes	Yes	Yes
<u>B. Related to Visits</u>						
<u>Characteristics</u>		<u>Staff Reports</u>		<u>Family Member/Guardian Reports</u>		
	3 Months	15 Months	27 Months	3 Months	15 Months	27 Months
Consumer Characteristics?	No	No	Yes ⁴	No	No	No
Community Residence?	Yes	Yes	No	Yes	No	Yes

¹Higher mobility was statistically significant at 3 months

²Higher multicognition was statistically significant at 27 months

³High self-care and high mobility were statistically significant at 27 months

⁴Younger age was statistically significant at 27 months

Consumer characteristics are likely to influence the increased likelihood of phone contacts at 3 and 27 months, according to staff and family members/guardians. But community residence makes a unique, independent, contribution to explaining the receipt of phone contact at all time periods, even after controlling for significant consumer characteristics. Living in a community residence increases the likelihood of receiving one or more phone contacts from family members within a 3-month period, according to both staff and family members/guardians themselves.

As depicted in Part B, the influence of community residence is not as consistent for actual visits for all time periods. Living in the community is significantly related to visits at 3 months, according to both staff and family members/guardians. For staff, community residence is also influential at 15 months and for family members/guardians, it is influential at 27 months. However, these 2 groups do not provide consistent evidence that community living is related to family visits at these 2 time periods.

Reviewing the findings of both Parts A and B, it is evident that consumer characteristics (such as having higher mobility, multicognition, and self-care and being younger) are also somewhat related to receiving phone contacts and/or visits.

Friendships at 3, 15, and 27 Months

Recent paradigms of services for persons with developmental disabilities have emphasized the importance of natural supports – including friends as a component of well-being. In order to determine whether leaving institutional care had any impact on the development of close friends or the number of friends, “mover” and “stayer” data from staff interviews were analyzed at 3, 15, and 27 months. Multivariate analyses were also conducted for community versus institutional residents.

**Table IX-5: Assessments of Friendships of Matched “Movers” and “Stayers”
According to their Staff at 3, 15, and 27 Months
(Based on the Maximum Number for Each Analysis)**

<u>Friendship Measures</u>	<u>3 Months</u>	<u>15 Months</u>	<u>27 Months</u>
% Have Close Friends	“Movers” Higher	Same	Same
Average Number of Friends	“Stayers” Higher	Same	Same
Average Number of Staff Friends	“Stayers” Higher	Same	Same
Average Number of Peer Friends	Same	Same	Same

In Table IX-5, four types of friendship measures were used to compare “movers” and “stayers” at each time period. At 3 months, more “movers” were reported to have close friends than “stayers,” but this finding was not replicated at 15 and 27 months. When the average number of friends and the average number of staff friends were computed at 3 months, “stayers” were reported to have the statistically higher average. However, this finding was also not sustained at 15 and 27 months. As for the average number of peer friends – perhaps the most important indicator of “natural support” – there were no differences between “movers” and “stayers” at any time period.

Besides examining types of friendships between “movers” and “stayers,” analyses were also conducted to determine whether type of residence (i.e., community or institutional) was a potential influence on friendships. In Table IX-6, the results of multivariate analyses of characteristics that influenced the average number of peer friends are presented.

**Table IX-6: Assessing Impacts on the Number of Peer Friends
at 3, 15, and 27 Months
(Based on the Maximum Number of Consumers in the Total Sample for Each Analysis)**

<u>Characteristics</u>	<u>3 Months</u>	<u>15 Months</u>	<u>27 Months</u>
High Self-Care	p<.0001	p<.0001	NS
High Multicognition	NS	NS	p<.0001
Low Aggressive Behavior	NS	NS	p<.04
Community Residence	NS	NS	NS

NS = Not Significant

The evidence is clear that living in the community did not increase or decrease the average number of peer friends over time. However, higher self-care competencies were associated with having more peer friends at 3 and 15 months. At 27 months, both higher multicognition and lower aggressive behaviors were also found to increase the likelihood of having more peer friends. It is concluded, therefore, that personal characteristics, rather than type of residence, influence whether consumers will have peer friends.

Summary of Findings

Phone contacts by family members/guardians were definitely more likely to occur if individuals were residing in community residences, regardless of their own characteristics. Family visits were also more likely to occur in community residences at 3 months. However, there were sharp decreases in visits thereafter, so there was no significant difference between “movers” and “stayers” by 27 months, according to both staff and family member/guardian reports. Despite this finding, there is some support by both staff and family members/guardians that living in a community residence may have some significant relationship with visits, though these findings are not consistent.

The acquisition of more peer friends is not influenced by community living at any time period. Instead, having peer friends is determined by higher levels of competencies and displaying lower rates of aggressive behaviors at different time periods.

Chapter X: Health Services Utilization

Introduction

Two major areas of concern to families, guardians, and other interested persons pertain to the health and safety of consumers in all types of residential settings. This chapter focuses on the indicators of health service utilization that were collected from staff at 3, 15, and 27 months. The next chapter will include safety as one of the quality-of-life domains systematically measured with comparable indicators from consumers, family members/guardians, and staff.

In order to assess the health domain, similar questions concerning the utilization of medical and health-related services were addressed to staff in community and institutional residences. Specifically, knowledgeable staff were asked whether consumers went to (1) physicians, (2) dentists, (3) gynecologists (if women), (4) psychiatrists (if had a psychiatric diagnosis), (5) counselors, (6) physical therapists, and (7) speech therapists. Besides being asked these factual questions about health care utilization within the 3 months prior to being interviewed, staff were also asked to judge whether the “health needs” of consumers were being met by their current health care providers.

Utilization of Services at 3, 15, and 27 Months

Previous analyses done with 3-month data had found that “movers” or community residents were significantly more likely to see doctors, gynecologists (if women) and psychiatrists. However, “stayers,” or institutional residents, were more likely than “movers” to receive dental care and speech therapy at 3 months. These 3-month findings are reproduced in Table X-1 (Part A).

Similar analyses were conducted at 15 and 27 months on “movers” and their matched “stayers” and also on community residents versus institutional residents. As seen in

Part B and C of Table X-1, there were no difference in the proportion of “movers” and “stayers” who had been to (1) doctors, (2) dentists, (3) gynecologists (if women), or (4) counselors. Additionally, staff of both groups reported comparable ratings of consumers having their health needs met.

The 3 areas where differences emerged (or continued) were for seeing a psychiatrist and receiving physical and speech therapies (services #4, #7, and #8, respectively).

Table X-1: Utilization of Health Services by Matched “Movers” and “Stayers” in the Random Sample and Community and Institutional Residents Using Staff Data

<u>Indicator Number</u>	<u>Health Services</u>	<u>A. 3 Months</u>	<u>B. 15 Months</u>	<u>C. 27 Months</u>
		Highest Utilization	Highest Utilization	Highest Utilization
1	Been to Doctors?	“Movers” (p<.0006) Community Residents (p<.0001)	No Difference No Difference	No Difference No Difference
2	Been to Dentists?	“Stayers” (p<.04) Institutional Residents (p<.008)	No Difference No Difference	No Difference No Difference
3	Been to Gynecologists?	“Movers” (p<.0002) Community Residents (p<.03)	No Difference No Difference	No Difference No Difference
4	Been to Psychiatrists?*	“Movers” (p<.0005) Community Residents (p<.0006)	“Movers” (p<.0005) Community Residents (p<.0001)	“Movers” (p<.0001) Community Residents (p<.0001)
5	Been to Counselors?	No Difference	No Difference	No Difference
6	Health Needs Met?	No Difference Institutional Residents (p<.03)	No Difference No Difference	No Difference No Difference
7	Physical Therapy?	No Difference No Difference	“Stayers” (p<.03) Institutional Residents (p<.04)	“Stayers” (p<.01) Institutional Residents (p<.0004)
8	Speech Therapy?	No Difference Institutional Residents (p<.0005)	No Difference No Difference	“Stayers” (p<.004) Institutional Residents (p<.04)

*Only consumers with a psychiatric diagnosis are used in these comparisons

Explaining Visits to Psychiatrists

In order to assess whether community residence had a unique, independent, contribution in explaining psychiatric utilization, multivariate analyses were undertaken only with consumers with psychiatric diagnoses. All of the primary consumer characteristics used for matching – multicognition, self-care, mobility, behavior towards self and others, age, and gender – were examined simultaneously to assess their statistical association with visits to a psychiatrist at 3 distinct time periods. Only 2 of the characteristics – related to the behaviors of consumers – displayed any associations at one time period that were statistically significant. When these 2 variables were entered simultaneously with place of residence into a logistic regression, community residence continued to be quite important for all time periods.

Table X-2 provides strong evidence that the odds of visiting a psychiatrist for consumers living in a community residence are 3.5:1, 3.9:1 and 4.5:1 (at 3, 15, and 27 months, respectively). Only at 27 months are the behavior variables important – and only aggressive behavior is actually statistically significant ($p < .04$). Therefore, residence in the community significantly increases the chances that consumers with psychiatric diagnoses will see psychiatrists (in the 3-month period prior to being interviewed) for all time periods.

**Table X- 2: Comparing Best Models for Explaining Visits to Psychiatrists by Consumers with a Psychiatric Diagnosis at 3, 15, and 27 Months
(Based on the Maximum Number for Each Analysis)**

<u>Significant Variables</u>	<u>A. 3 Months</u>		<u>B. 15 Months</u>		<u>C. 27 Months</u>	
	Significance	Odds Ratios	Significance	Odds Ratios	Significance	Odds Ratios
Aggressive Behavior (High)	NS	1.2:1	NS	1.6:1	$p < .04$	2.1:1
Self Behavior (High)	NS	1.9:1	NS	1.1:1	NS	2.3:1
Community Residence	$p < .0004$	3.5:1	$p < .0001$	3.9:1	$p < .0001$	4.5:1

NS = Not Significant

Explaining Receipt of Physical Therapy

In order to determine whether residence in an institution had a unique, independent, impact in explaining the receipt of physical therapy, multivariate analyses were undertaken. Besides entering consumer characteristics simultaneously with place of residence, analyses also included whether consumers had a muscular-skeletal condition “such as muscular difficulties with arms and/or legs or osteoporosis” or needed frequent “turning or positioning to protect skin integrity.” The “best variables” that emerged from these analyses are listed in Table X-3, and their statistical probabilities and odds ratios for “explaining” physical therapy utilization at 3, 15 and 27 months are noted in Parts A, B and C.

Table X-3: Comparison of Best Variables Explaining Deliveries of Physical Therapy at 3, 15 and 27 Months
(Based on the Maximum Number for Each Analysis)

<u>Significant Variables</u>	<u>A. 3 Months</u>		<u>B. 15 Months</u>		<u>C. 27 Months</u>	
	Significance	Odds Ratios	Significance	Odds Ratios	Significance	Odds Ratios
Low Mobility	p<.0001	11.4:1	p<.003	4.3:1	p<.006	3.3:1
Muscular/Skeletal Condition	p<.02	2.3:1	p<.0009	4.0:1	p<.0005	4.5:1
Age is 60 or Below	NS	1.9:1	p<.01	2.9:1	p<.03	2.5:1
Lives in Institution	NS	0.7:1	NS	2.0:1	NS	1.9:1

NS = Not Significant

At 3 months (Part A), only 2 variables are statistically significant – having low mobility (p<.0001) and a muscular-skeletal condition (p<.02). At 15 months (Part B), and 27 months (Part C), younger age is clearly important with probabilities of p<.01 and p<.03 and odd ratios of 2.9:1 and 2.5:1. At both time periods, low mobility and having muscular-skeletal conditions continue to be statistically important. Each of these 3 variables clearly makes a unique, independent, contribution to explaining the receipt of physical therapy.

The role of institutional residence is less clear using statistical criteria. When residence in an institution was considered as a single variable at 27 months, then the

significance was $p < .004$, the strongest association for any time period. However, when residence in an institution is included in analyses with other variables simultaneously, then the significance has diminished to $p < .13$. In addition, using a statistical test recommended by Hosmer and Lemeshow (1989, pg. 30-34), residence does not increase the overall significance of the best model when the other variables are considered. This means that physical therapy is more likely in any type of residence if consumers are younger, have a muscular-skeletal condition, and possess lower mobility. However, as noted in Chapter IV, “movers” who moved to an institution were much more likely to have lower mobility and related muscular-skeletal problems (see Table IV-2).

Explaining Receipt of Speech Therapy

In order to determine whether residence in an institution had a unique, independent, impact in explaining the receipt of speech therapy, multivariate analyses were undertaken. Consumer characteristics were analyzed simultaneously with place of residence on data collected on all consumers in the evaluation sample. Since multivariate analyses control for consumer characteristics, use of data on all consumers, not just those who were matched in the random sample, was possible. Results of these analyses revealed that there were no reliable predictors of the receipt of speech therapy. Consumer characteristics – including multicognition which includes assessments of consumers’ communication skills – did not explain the receipt of speech therapy. In addition, institutional living was also not an independent predictor of speech therapy when consumer characteristics and data from all consumers in the sample were considered.

Summary of Findings

Almost all of the initial health differences found at 3 months, between the utilization of health care services by “movers/stayers” or community/ institutional residents had dissipated at 15 and 27 months. Differences continued to be found for seeing a psychiatrist (if a psychiatric diagnosis existed) at all time periods. Residence in the community made a unique, independent, contribution in explaining psychiatric utilization even after controlling for consumer characteristics.

There were no differences in the receipt of physical therapy by sample types at 3 months, but they appeared at 15 and 27 months. When type of residence was assessed with other significant variables, the statistical importance of institutional residence diminished sharply. Low mobility, having muscular/skeletal conditions, and being under 60 are clearly the most important variables in receiving physical therapy. Separately and together, they are clearly more important than place of residence. Place of residence was not independently related to the receipt of speech therapy when consumer characteristics were considered.

Chapter XI: Quality-of-Life

Introduction

The 15-month report, A Year Later (Apgar et al., 2001), provided 2 distinct comparisons between those living in the community versus DD Centers with regard to quality-of-life. They included comparing: (1) the attitudes of staff and family members/guardians towards 10 specific quality-of-life goals; and (2) assessments of whether evidence existed that residence type actually was related to a higher quality-of-life in specific domains, as measured by the responses of staff, family members/guardians, and consumers. This chapter will summarize all the data on staff and family members' attitudes and assessments of 4 quality-of-life domains – community participation, autonomy, emotional well-being, and safety. In addition, assessments of productivity and material well-being will also be presented based on staff data only. A subsequent chapter will synthesize the information from earlier chapters dealing with health, family contacts and friendships, behaviors, and competencies with the findings of this chapter in order to provide an overall synthesis of quality-of-life assessments during the evaluation period.

Attitudes Towards Promoting Quality-of-Life Goals

In order to assess the attitudes of family members/guardians and staff, questions about specific goals were asked with the following preamble, regardless of where the consumer actually lived:

“Now I am going to read you some goals that persons concerned with the care and support of individuals with developmental disabilities could have. Please tell me whether you feel that these goals can best be achieved in a developmental center, community residence, or equally in both of these settings.”

Respondents were then asked separately about each of 10 quality-of-life goals. The 10 goals that were asked of staff and family members/guardians were worded exactly the same way and referred to promoting:

1. Self-care and independence;
2. Choices and freedom to come and go;
3. Emotional well-being;
4. Community involvement and leisure;
5. Friendship and family ties;
6. Material well-being;
7. Personal safety;
8. Productivity;
9. Physical well-being (health); and
10. Appropriate behaviors.

Each response was coded according to the type of residence which was felt to best promote the goal in that area with a 1 given to responses of DD Centers, 2 for equally in both settings, and 3 assigned for responses of community residence. The first level of analysis involved comparing the responses of family members only with relatives living in community residences with the responses provided by those who have relatives in DD Centers. At 3 and 15 months, **community family members** scored significantly higher on each of the 10 goals at probability levels that were quite striking ($p < .0001$ for each of 10 comparisons). Similar results were also obtained when the responses of **community staff** were compared to those of institutional staff at 3 and 15 months ($p < .0001$ for each goal at each time period). These findings meant that staff working in the community and family members with relatives living in these settings were much more likely to indicate that the life

quality of consumers in each of the 10 areas was better in community residences when compared to the responses of their institutional counterparts.

Given the consistent findings for both families and staff for each of the 10 goals, factor analyses were then conducted to determine if these measures could be used together as an overall reliable index to assess respondent attitudes. The results clearly indicated that the 10 items assessed the underlying construct, namely respondent attitudes towards community versus institutional living to promote consumer life quality (see Appendix F for the results on staff and family factor analyses). Scores for either staff or families could have ranged from 10 (indicating beliefs that institutional living was beneficial to all life-quality areas) to 30 (indicating beliefs that community living was beneficial to all life-quality areas).

Table XI-1 provides the actual scores of staff and family members separated by the type of residence where consumers actually lived at the 3 follow-up periods – 3, 15, and 27 months.

As depicted in Part A, the average index score of community staff at 3 months is 27.5 compared to a score of 19.4 for institutional staff. This statistically significant result ($p < .0001$) is repeated in a comparison of community family members and institutional family members (25.0 versus 15.2, $p < .0001$). Similar patterns of differences between community and institutional staff and family members can be found at 15 and 27 months (Parts B and C, respectively). It is quite clear that staff and family members of consumers living in the community respond quite differently than those who are associated with consumers living in DD Centers at all time periods. The differences between respondent types emerge by 3 months and hardly change over the next 2 years.

Table XI-1 also permits us to compare the responses between staff and family members for each residence type. For example, in Part A (at 3 months) community staff

attitudes are significantly higher than community family members ($p < .005$), but at 15 months the differences between the 2 types of respondents is not statistically significant. However, the significant differences in attitudes of community family members and staff reemerge at 27 months. Examining the pattern for institutional comparisons indicates that family members have significantly lower scores than their staff counterparts at 3, 15, and 27 months.

Table XI-1: Comparisons of Life-Quality Goal Index Scores of Staff versus Family Members at 3, 15, and 27 Months
(Based on the Maximum Number for Each Analysis)

A. 3 Months

<u>Respondent Type</u>	<u>Consumers Live in Community</u>	<u>Consumers Live in Institutions</u>	<u>Significance</u>
Staff	27.5	19.4	$p < .0001$
Family Members	<u>25.0</u>	<u>15.2</u>	$p < .0001$
Significance	$p < .005$	$p < .0001$	

B. 15 Months

<u>Respondent Type</u>	<u>Consumers Live in Community</u>	<u>Consumers Live in Institutions</u>	<u>Significance</u>
Staff	26.7	18.8	$p < .0001$
Family Members	<u>25.2</u>	<u>15.8</u>	$p < .0001$
Significance	NS	$p < .0001$	

C. 27 Months

<u>Respondent Type</u>	<u>Consumers Live in Community</u>	<u>Consumers Live in Institutions</u>	<u>Significance</u>
Staff	27.0	18.8	$p < .0001$
Family Members	<u>24.9</u>	<u>16.1</u>	$p < .0001$
Significance	$p < .03$	$p < .003$	

NS = Not Significant

Multivariate Analyses of Life-Quality Goals for Family Members

Due to the intense interest in how families responded to the deinstitutionalization of their relatives, it was deemed important to examine their attitudes in additional analyses. The previous analyses in Table XI-1 were based on comparing family responses that did not take into account any consumer characteristics – such as age, self-care, mobility, or other variables. To make certain that the differences in attitudes between community and institutional family members were really attributable to residence type, and not these consumer characteristics, all variables were simultaneously entered into multivariate statistical analyses. When this was done for all time periods for all family members only, the most important variable that accounted for high index scores was the place of residence of the consumers. Table XI-2 depicts the final best explanatory models accounting for family index scores at 3, 15, and 27 months.

At 3 months, only 2 variables were associated with quality-of-life index scores – low teaching of basic skills and community residence of consumers. While both variables are statistically significant, the place where consumers live accounts for a far higher percent of the variability in scores (i.e., the R^2 as noted in the footnote of Table XI-2). Community residence “explains” 43.8% of the variability in the index scores, compared to only 2.7% for the basic skills variable. At 15 and 27 months, community residence again emerges as the strongest “explanation” for the index scores – explaining 43.8% to 39.1% of the variance, respectively.

The positive views of community family members toward these settings were voluntarily articulated when they were interviewed. For example, one family member stated:

“The last time I visited (the consumer), I was amazed. The location is great. The home is great, including the staff and other residents. They are teaching her to speak. In the institution, she lost whatever little speech she had. A lot of love is shown.”

Another family member had this to say about the move to the community:

“I am very happy where (the consumer) is. We feel he has a family at his community residence. I can’t say enough about the good care he is getting. The staff is excellent.”

Table XI-2: Best Models for Explaining Family Goals at 3, 15, and 27 Months

<u>A. 3 Months</u> (Max. n=93)		
<u>Variables</u>	<u>R²</u>	<u>Significance</u>
Low Teaching of Basic Skills	2.7%	p<.04
Community Residence	43.8%	p<.0001
Total R ²	46.5%	
<u>B. 15 Months</u> (Max. n=97)		
<u>Variables</u>	<u>R²</u>	<u>Significance</u>
Higher Multicognition	3.5%	p<.01
Community Residence	43.8%	p<.0001
Total R ²	47.3%	
<u>C. 27 Months</u> (Max. n=97)		
<u>Variables</u>	<u>R²</u>	<u>Significance</u>
More Phone Contacts with Staff	3.5%	p<.02
Community Residence	39.1%	p<.0001
Total R ²	42.6%	

R² refers to the proportion of variability in responses that can be attributed to specific explanatory variables. Theoretically, R² can vary between 0 and 100% representing no explanation to a complete explanation of the variability, respectively.

Assessing Quality-of-Life Domains – Introduction

As noted earlier, consistent assessments of consumer quality-of-life at all time periods were made in 4 distinct domains: autonomy, community participation, emotional well-being, and safety. In addition, objective information obtained only from staff concerning out-of-home day programs, hours worked, and wages were used to assess the domain of productivity. Each of the five domains was assessed using indexes containing multiple items. The items used in the indexes are displayed in Table XI-3. These items were found to be the most reliable for each group at all time periods (see Moving On, Progress Report #2, for formation of the indexes).

The first domain, autonomy, refers to the extent to which consumers were able to make decisions about their own lives on a daily basis – like waking up, going to bed, choosing clothes, or spending their own money (see item examples in Table XI-3). The second domain, community participation, refers to the extent to which consumers actually went to diverse places away from their residences – like going to stores, restaurants, movies, or parks. The third domain, safety, refers to whether consumers felt they would not be hurt, scared, or afraid in their living environments. The fourth domain, emotional well-being, refers to whether consumers recently cried or appeared upset, angry, or sad. The fifth domain, productivity, refers to type of job, time on the job, and any earned money.

Consumers who were interviewed in depth about their well-being were asked about all of the domains, except productivity. As the table makes clear, only safety and emotional well-being used the same number of items for each domain for each respondent group. These differences were primarily due to 3 reasons: first, item analyses indicated that fewer items formed reliable indexes with consumer and family member/guardian responses; second, many “don’t know” responses were also obtained from family members/guardians;

and third, family members/guardians were asked fewer autonomy and community participation items in order to complete interviews within a shorter time period.

Table XI-3: Items Used to Reliably Measure Consumer Quality-of-Life at 3, 15, and 27 Months, Using the Maximum Number of Respondents

Questions Used to Reliably Assess Domain by:¹

<u>Domains and Item Examples</u>	<u>Staff</u>	<u>Consumers</u>	<u>Family Members/Guardians</u>
Autonomy	(3- to 27-month Cronbach alphas=.87-.89)	(3- to 27-month Cronbach alphas=.79-.81)	(3- to 27-month Cronbach alphas=.83-.85)
Bedroom Alone	YES	YES	YES
Bath/Shower Time	YES	YES	YES
Clothes	YES	YES	YES
Money	YES	NO	YES
Food Type	YES	YES	YES
Mealtime	YES	YES	NO
Wake Up	YES	YES	NO
Bedtime	YES	YES	NO
Bedroom Visitors	YES	YES	NO
Free Time	YES	YES	NO
Community Participation	(3- to 27-month Cronbach alphas=.84-.87)	(3- to 27-month Cronbach alphas=.53-.68) ²	(3- to 27-month Cronbach alphas=.82-.85)
Store	YES	YES	YES
Restaurant	YES	YES	YES
Movie	YES	YES	YES
Supermarket	YES	NO	NO
Bank	YES	YES	NO
Post Office	YES	YES	NO
Park	YES	NO	NO
Safety	(3- to 27-month Cronbach alphas=.72-.82)	(3- to 27-month Cronbach alphas=.71-.89)	(3- to 27-month Cronbach alphas=.73-.85)
Hurt	YES	YES	YES
Scared	YES	YES	YES
Afraid	YES	YES	YES
Emotional Well-Being	(3- to 27-month Cronbach alphas=.73-.75)	(3- to 27-month Cronbach alphas=.75-.82)	(3- to 27-month Cronbach alphas=.78-.90)
Angry	YES	YES	YES
Cry	YES	YES	YES
Upset	YES	YES	YES
Sad	YES	YES	YES
Productivity	(3- to 27-month Cronbach alphas=.80-.87)		
Job Time	YES	NO	NO
Job Type	YES	NO	NO
Money	YES	NO	NO

¹See Moving On, Progress Report #2, for information on original formation of indexes using staff and family member/guardian data.

Agreement of Family Member/Guardian and Consumer Responses with Staff

Before comparing the quality-of-life ratings by community/institutional comparisons, it is important to assess the extent to which family members/guardians and consumers agree with staff on the quality-of-life ratings for consumers in the sample at each time period. By assessing the strength of the correlations between staff and other respondent groups, independent assessments are provided of the validity of staff ratings. In Table XI-4 the correlations between staff and family member/guardian ratings and staff and consumer ratings are provided at the 3 time periods.

As depicted in Part A, the correlations between staff and family members/guardians indicate fairly strong agreement in the ratings for community participation at all time periods – despite the fact that staff are using 10 items and family members/guardians are using only five items. The correlations for autonomy have a probability of $p < .0001$, but the correlations are clearly not as high as for community participation (.51-.57 versus .72-.77, respectively). It is important to note that there are no statistically significant correlations for the domains of emotional well-being and safety. The findings in Part A are also reproduced when only family member correlations are used.

As seen in Part B, the correlations between staff and consumers who can communicate at each time period reveals modestly strong agreement for autonomy and community participation. In addition, the consumers and staff also have a significant degree of agreement for emotional well-being at 3 and 15 months and for safety at 27 months.

These findings indicate that staff ratings are closer to those of consumers than they are to family responses for 2 areas – emotional well-being and safety. Evidently staff are more knowledgeable than family members about consumer emotional well-being at 2 out of 3 time periods and consumer safety at 27 months – using consumers as the validation group.

If all the findings are reviewed, it is possible to conclude that staff, family members/guardians, and consumers have moderate to strong agreement for the ratings of autonomy and community participation. Staff reports appear to be closer to consumer responses than to family member/guardian reports, as evidenced by significant relationships for emotional well-being at 3 and 15 months and safety at 27 months.

**Table XI-4: Degree of Agreement on Quality-of-Life Ratings of Staff and Other Respondent Groups for Three Time Periods
(Based on the Maximum Number for Each Analysis)**

A. Staff versus Family Member/Guardian Correlations

	<u>Autonomy¹</u>	<u>Community¹</u>	<u>Emotional</u>	<u>Safety</u>
3 Months	.57	.77	NS	NS
15 Months	.51	.72	NS	NS
27 Months	.56	.72	NS	NS

B. Staff versus Consumer Correlations

	<u>Autonomy²</u>	<u>Community¹</u>	<u>Emotional³</u>	<u>Safety⁴</u>
3 Months	.56	.69	.46	NS
15 Months	.65	.61	.58	NS
27 Months	.56	.69	NS	.36

NS = Not Significant

¹ Probabilities are $p < .0001$.

² Probabilities vary from $p < .001$ (at 27 months) to $p < .0001$ (at 15 months).

³ Probabilities vary from $p < .004$ (at 3 months) to $p < .0001$ (at 15 months).

⁴ Probabilities are $p < .03$ at 27 months.

Comparisons Between Respondent Groups

Besides assessing the extent to which the reports of staff agree with other respondent groups, analyses were also conducted to assess whether reports on the quality-of-life domains were associated with type of placement (community versus institutional) at all time periods. In order to fully assess whether any significant relationships existed between quality-of-life scores and residence type for each domain, for each respondent group, for each time period, a series of multivariate analyses were undertaken. The multivariate analyses controlled for each of the critical matching variables in order to make certain that any differences were solely attributable to residence type, and not the characteristics of those persons living in these environments.

In Table XI-5, the 4 domains that were assessed by all 3 respondent groups are depicted separately. A separate analysis was also conducted for “family only” in order to distinguish these respondents from the combined family member/guardian grouping. A positive association with living in a community residence is noted in Table XI-5 only if the association is significant after simultaneously controlling for significant matching variables – like age, self-care, multicognition, or mobility. A “yes” in Table XI-5 indicates that community residence is positively associated with an enhanced life quality in that area according to a specific respondent group.

In Part A, it is evident that at all time periods community residence is positively associated with community participation according to all respondent groups. Thus, it is reasonable to infer that a positive association exists between community living and participation as evidenced by significant relationships in 12 out of 12 possible comparisons (i.e., 3 time periods by 4 respondent groups). Persons living in community residences clearly

have more experiences in participating in community activities than those living in DD Centers.

The lack of community activities was a concern for many of the family members with relatives living in DD Centers. When these family members were asked what things they would like their relatives to do that they are not doing now, they stated that they wanted:

“Some recreation activity – go shopping, go out to dinner, go to a movie, go to church.”

“Get out more to organized sports events (as a spectator), such as baseball games, football, hockey, etc. Take him out to dinner.”

“More trips into the community.”

“More day trips – community outings.”

These concerns were also articulated by consumers who were able to reliably answer interview questions. Many of these consumers indicated a strong desire to:

“Go on more trips.”

“Go and have some fun – trips and visits with relatives.”

(Go) “to movies and dinner.”

“Go out.”

In Part B, the evidence that autonomy is related to community living is equally strong for 3 of the 4 respondent groups – staff, consumers, and family members/guardians – at all time periods. Families only indicate a significant relationship at 15 months, but not at the other time periods when multivariate analyses were conducted. Given these outcomes, it is reasonable to infer that there is moderately strong evidence for a relationship between autonomy and community residence as evidenced by 10 out of 12 possible comparisons.

Persons living in community residences are more likely to have more choices in their daily lives than those living in DD Centers.

In Part C, the evidence is fairly weak that there is any association between emotional well-being and community living. Only one out of 12 comparisons provides evidence of a positive association – consumers at 15 months. There is little evidence that persons living in community residences have higher emotional well-being than those living in DD Centers.

In Part D, the evidence provided by consumers matched the results offered by staff – a positive association between perceived safety and community residence for all time periods. The evidence is weaker when reviewing the multivariate analyses conducted for family members/guardians and family members only – since only the 27-month results are positive for both groups. Based on all of the evidence, it is reasonable to infer that the evidence is moderately strong that community residents feel safer than DD Center residents – since there is a positive association in 8 out of 12 comparisons. Persons living in community residences are more likely to perceive that they are living in a safe environment – especially at 27 months – than consumers living in DD Centers.

This feeling of enhanced safety in the community was voluntarily communicated by a family member who stated the following,

“He’s much happier in the community home than he was in the institution. He’s more loving, more in tune with things, much happier, and more alert. It’s more similar to a home environment. He feels safer. I feel this has promoted his emotional well-being.

Table XI-5: Surveys of Significant Relationships of Quality-of-Life Domains and Community Residence, by Respondent Group for all Time Periods¹
(Based on the Maximum Number for Each Analysis)

<u>A. Community Participation</u>	<u>Staff</u>	<u>Consumers</u>	<u>Family Members/Guardians</u>	<u>Family Only</u>
3 Months	Yes	Yes	Yes	Yes
15 Months	Yes	Yes	Yes	Yes
27 Months	Yes	Yes	Yes	Yes
<u>B. Autonomy</u>	<u>Staff</u>	<u>Consumers</u>	<u>Family Members/Guardians</u>	<u>Family Only</u>
3 Months	Yes	Yes	Yes	No
15 Months	Yes	Yes	Yes	Yes
27 Months	Yes	Yes	Yes	No
<u>C. Emotional Well-Being</u>	<u>Staff</u>	<u>Consumers</u>	<u>Family Members/Guardians</u>	<u>Family Only</u>
3 Months	No	No	No	No
15 Months	No	Yes	No	No
27 Months	No	No	No	No
<u>D. Safety</u>	<u>Staff</u>	<u>Consumers</u>	<u>Family Members/Guardians</u>	<u>Family Only</u>
3 Months	Yes	Yes	No	No
15 Months	Yes	Yes	No	No
27 Months	Yes	Yes	Yes	Yes

¹A "Yes" indicates that there is a statistically significant positive association with community residence, while simultaneously controlling for key consumer characteristics (i.e., gender, age, multicognition, self-care, mobility, and behavior towards self and others).

Productivity

As noted earlier, the evidence for whether the ideal goal of productivity was achieved was available only for staff. A 3-item index was constructed using work type, time, and earnings. Work type referred to whether persons were engaged in employment-focused activities outside their residences (2 points); socialization activities outside their residences (1 point); or were not engaged in any daily activities outside their residences (0 points). Time at work was split into 4 categories – persons engaged in day activities 30 or more hours (3 points); 20-29 hours (2 points); 1-19 hours (1 point); and no hours (0 points). Earnings were a dichotomous variable with any persons earning money for their activities scoring a 1 and those with no earnings earning a 0. Total scores ranged from 0 to 6 and formed a 3-item index that had a Cronbach alpha that ranged from .80 to .87 for all time periods.

Community residence was positively associated with these objective indicators of productivity for each time period and the correlation increased over time from .30 (3 months) to .37 (15 months) to .44 (27 months). However, as might be expected, higher productivity scores were also positively associated with the following individual characteristics: (1) multicognition; (2) self-care; (3) mobility; and (4) low aggressive behaviors. In order to ascertain whether community residence made a unique, independent contribution to explaining productivity, it was necessary to run these variables together in multivariate statistical analyses for each time period. Table XI-6 presents the findings for the best models for each time period.

Table XI-6: Variables that Best Explained Productivity at 3, 15, and 27 Months
(Based on the Maximum Number for Each Analysis)

<u>Best Variables</u>	<u>Time Periods</u>		
	<u>Significance</u> <u>3 Months</u>	<u>Significance</u> <u>15 Months</u>	<u>Significance</u> <u>27 Months</u>
Community Residence	p<.0007	p<.0001	p<.0001
High Self-Care	p<.01	p<.003	p<.01
High Mobility	p<.11	p<.008	p<.02
Total R ²	17.1%	28.5%	30.9%

It is evident from Table XI-6 that community residence is strongly associated with productivity at all times, even when controlling for high self-care and high mobility scores. In addition, the models get stronger at each time period, since the amount of variability (as measured by the R²) increases over time from 17.1% to 30.9% at 27 months. Based on the evidence of these objective indicators of productivity – work type, work time, and earnings – consumers living in the community have a much greater likelihood of spending time outside the home in a productive manner.

Material Possessions and Their Safety

Each of the surveys asked questions about the consumers' material well-being by asking staff how consumers felt about the following: the food served in their residences; living at the residence; and their clothing. These items had proven to provide a single reliable index of material well-being in the evaluation of the E.R. Johnstone Training and Research Center as assessed by staff, former Johnstone residents, and their family members/guardians (Apgar et al., 1998). However, attempts in this study to confirm the reliability of these items to form an index at 3 months were not successful. In order to obtain some indicators of material well-being, more objective indicators of well-being, such

as assessing actual possessions as reported by staff and observations by interviewers were obtained at 27 months. In addition, staff were asked specific questions about whether possessions had been broken or stolen.

At 27 months, staff in all types of residences were asked if consumers owned one of the following five items: (1) a television; (2) a radio; (3) a tape cassette or CD player; (4) a VCR; and (5) a watch or clock. The five items constituted a single factor and proved to have a Cronbach alpha of .73 (see Appendix G for specific details). An index was formed and scores ranged from 0 to 5. An initial analysis with matched pairs of “movers” and “stayers” at 27 months disclosed that “movers” had an average of 2.48 possessions compared to “stayers” with an average of 1.96. This difference was statistically significant ($p < .03$).

However, material possession scores were also related to multicognition, self-care, and low social control. Therefore, it was necessary to use these variables in a multivariate statistical analysis with community residence. When this was done, community residence proved to be a nonsignificant influence in explaining who was likely to have more possessions ($p < .53$). The 2 most important variables that accounted for over 23% of the variability in scores were: high multicognition and a residence with low social control (table not shown). These findings indicate that consumers must have sufficient cognitive competencies in order to own and use material objects. In addition, consumers living in a residence with low social controls are also more likely to own these types of technological objects.

The results of the possession analysis stimulated a hypothesis that places with low social controls might be safer places for consumer possessions. In order to test this hypothesis, a special index was constructed that referred to safety of material possessions. At 27 months, the following additional questions were asked of staff:

- 1) Have any of the consumers things been broken by someone?
- 2) Have any of the consumers things been stolen by someone?
- 3) How does the consumer feel about his/her ability to keep his/her things from being broken?
- 4) How does the consumer feel about his/her ability to keep his/her things from being stolen?

The first 2 items were answered with yes or no. The third and fourth items were scored as happy, unhappy, and in-between. These 4 items were entered into a factor analysis and proved capable of assessing a single dimension that was labeled “possession safety.” The 4 items formed a reliable index (Cronbach alpha = .72). While it is related to the safety from harm index (discussed earlier), the correlation was weak (.16) – indicating that safety of possessions can be distinguished from safety of persons.

The possession safety index was found to be positively related to living in a community residence – but not to low social control. When place of residence was simultaneously entered into a multivariate analysis with the other variables, in order to control for personal characteristics, the positive association with a community residence remained ($p < .01$, table not shown).

The concern of family members with relatives living in institutions about the safety of possessions was clearly expressed by 2 different family members – one of whom attributed the problem to a lack of private space. These family members stated:

“I’d like (the consumer) to have more privacy – a room with just 2 people as opposed to a dorm. This way, (the consumer) can have more freedom and can have some of her own possessions.”

“(In the DD Center), her clothes and other possessions have been stolen.”

In assessing the overall findings about material possessions, it is reasonable to infer that community living may be indirectly linked to material well-being via being a place of low

social controls. In addition, community residences are more likely to be places with higher possession safety – even after controlling for individual competencies.

Summary of Findings

Within 3 months of consumers moving to the community, family members of these consumers were far more likely than institutional families to believe that ideal quality-of-life goals could best be achieved outside of DD Centers. These beliefs about the best place to achieve ideals continued at 15 and 27 months. Family members of consumers living in community residences consistently believe that each of the following ideal goals could best be achieved in the community:

1. Self-care and independence;
2. Choices and freedom to come and go;
3. Emotional well-being;
4. Community involvement and leisure;
5. Friendship and family ties;
6. Material well-being;
7. Personal safety;
8. Productivity;
9. Physical well-being; and
10. Appropriate behaviors.

In contrast, family members of institutional residents consistently believe that the ideal goals could best be achieved in DD Centers at all time periods. When the 10 ideal goals were combined to form a single index of ideal goals, family members of institutional residents were more “pro-institutional” in their beliefs than staff members who were asked similar questions about ideal goals.

In an effort to assess whether ideal goals were actually realized in practice, family members/guardians, family members only, consumers, and staff were asked specific questions about community participation, autonomy, emotional well-being, and safety. In addition, staff data were used to assess items about productivity and material well-being. The response patterns for each quality-of-life domain were as follows:

1. Community Participation – Staff, family members/guardians, family only, and consumers all agreed that community participation was higher among community residents at all time periods.
2. Autonomy – Staff, family members/guardians, and consumers all agreed that community residents had higher autonomy at all time periods. Family members only judged that persons living in the community had more autonomy only at 15 months.
3. Emotional Well-Being – There is little evidence that emotional well-being is related to the type of residence of consumers. Only consumers at 15 months indicated that community living was tied to their emotional well-being.
4. Personal Safety – Staff and consumers agreed that living in the community felt safer than living in the DD Centers. However, no differences were reported for family members/guardians or family only – with the exception of 27 months when they agreed with staff and consumers.
5. Productivity – According to staff, consumers living in the community have higher productivity than DD Center residents based on objective indicators, such as out-of-home work, work time, and earnings, at all time periods.
6. Material Well-Being – Community residents did not have higher material well-being at 27 months than their DD Center counterparts according to staff. However, persons living in environments with low social controls (which are significantly related to community

living) had more possessions. In addition, safety of possessions was found to be higher in community residences.

The evidence about the actual quality-of-life of consumers indicates that the ideal goals of community family members are realized in varying degrees. There is direct strong evidence in support of productivity and community participation being linked to community placement, moderately direct strong evidence in support of autonomy and perceived safety and quite weak support of emotional well-being. There is also indirect support that improvement in material well-being is associated with community living as it has lower social controls.

Chapter XII: Quality-of-Life: A Synthesis of Findings

Introduction

The last chapter discussed the attitudes of family members and staff toward the best place to achieve 10 quality-of-life goals – either in a community residence or a DD Center or in both settings. Empirical evidence that assesses whether some of these goals were actually best achieved in DD Centers or community residences were presented and discussed in the last chapter. In addition, earlier chapters on competencies, behaviors, family contacts, peer relationships, and mental and physical health utilization also presented empirical evidence about the relationships between outcomes and place of residence. In this chapter, all of the findings from the last and earlier chapters are presented together in order to obtain a synthesized overview of the extent to which ideal outcomes were positively associated with place of residence (i.e., community living) – even after controlling for individual characteristics in multivariate analyses.

Table XII-1 is divided into 4 sections. Part A lists the ideal family and staff goals with the strongest empirical evidence that they were significantly associated with community residence for all 3 time periods. Part B presents ideal family and staff goals with moderately strong relationships with community residence and Part C presents ideal family and staff goals with the weakest empirical evidence. Part D presents ideal family and staff goals with no empirical evidence that link them to better outcomes in community residences.

Quality-of-Life Findings with the Strongest Empirical Evidence

In Part A, 6 ideal quality-of-life goals are identified. These goals were believed to be best achieved in community settings by family members and staff of consumers living in these residences. Contrarily, they were believed to be best achieved in DD Centers by family members and staff of consumers living in these residences. In the second column, indicators

are listed that were used to provide evidence whether a relationship existed between these goals and residential setting at each time period. The last column refers to the actual number of statistically significant findings that were found for each respondent source for each time period, while controlling for key consumer characteristics. For example, the ideal goal of promoting community participation was measured by the participation index (discussed in Chapter XI). Staff, family members/guardians, family only, and consumers were used as respondent groups at each time period to assess this domain. All assessments were made at 3 time periods (3, 15, and 27 months) for each of the 4 respondent groups. Thus, there were a total of 12 analyses conducted (i.e., 4×3 equals 12 possible analyses). All 12 analyses indicated significant positive associations between community living and participation – even after controlling for individual characteristics in a multivariate analysis. The actual data for these findings can be found in Chapter XI.

Promoting family ties via phone contacts involved assessing evidence from staff, family only, and family members/guardians – or 3 groups. All 3 groups indicated significant relationships between family phone contact and community residence at the 3 time periods (i.e., a total of 9 out of 9 assessments), even after controlling for key consumer characteristics.

The third, fourth, fifth, and sixth ideal goals in Part A (promoting self-care, freedom, mental health, and productivity, respectively) were assessed with indicators that involved only staff respondents. Therefore, only 3 possible analyses were possible for each ideal goal. In each case, these analyses indicated that there were significant relationships between these domains and community residence. The evidence for these analyses can be found in Chapter VII (for promoting self-care), Chapter V (for promoting freedom via lower social

controls), Chapter IX (for family ties), Chapter X (for mental health utilization), and Chapter XI (for productivity).

Reviewing the evidence in Part A, it is reasonable to infer that there exists very strong evidence that the following ideal quality-of-life goals were, in fact, actually achieved to a greater extent in community residences, rather than in DD Centers: (1) community participation; (2) family phone contacts; (3) self-care; (4) freedom; (5) mental health utilization; and (6) productivity.

Quality-of-Life Findings with Moderately Strong Empirical Evidence

In Part B, there are 3 ideal goals listed in which the preponderance, but not all, of the evidence indicates that they are significantly related to community residence. An autonomy index was used with all 4 respondent groups. A total of 10 out of 12 analyses yielded significantly positive associations with community residence. Family visits yielded 6 out of 9 positive associations.

Safety was assessed with 2 types of indicators. Perceived safety from personal harm items were used at all time periods with all respondent groups, and 8 out of 12 analyses indicated that these items were significantly associated with community living – using multivariate analyses to control for other significant variables. At 27 months only, staff survey items were also included that dealt with the safety of personal possessions. For this single time period, there was a significant positive association with community residence. The data for promoting choices can be found in Chapter XI, for family visits in Chapter IX, and for the 2 safety indicators in Chapter XI.

Reviewing the evidence indicated in Part B, it is reasonable to infer that there is moderately strong evidence that the following ideal goals are, in fact, more likely to be achieved in community residences, rather than in DD Centers: (1) individual choices or

autonomy; (2) family visits; and (3) safety from personal harm and of one's personal possessions.

Quality-of-Life Findings with the Weakest Empirical Evidence

In Part C, two goals are listed in which there is weak evidence to indicate any association with community living. Physical health utilization (discussed in Chapter X) was significant in only one out of 3 analyses – using staff reports. Additionally, only consumers at one time period reported that their emotional well-being was higher in these community settings.

Quality-of-Life Findings with No Empirical Evidence

In Part D, there are 3 goals listed in which there exists no direct evidence that place of residence has any impact on their achievement. Therefore, it is reasonable to infer that community living is probably not associated with any of the following: (1) friendships with peers; (2) reducing inappropriate behaviors; and (3) material well-being.

Table XII- 1: Synthesis of All Quality-of-Life (QOL) Findings Associated with Community Residence in Multivariate Analysis
 (Based on Maximum Numbers for the Analyses Presented in Earlier Chapters)

Family Member/Staff Ideal Goals	Indicators	# of Respondent Sources	Number of Significant Findings out of Possible Analyses
<u>A. QOL Findings with Very Strong Evidence for Community Association</u>			
1. Community Involvement	Participation Index	4 Groups	12 out of 12
2. Promote Family Ties	Phone Contacts	3 Groups	9 out of 9
3. Promote Freedom	Low Social Control	Staff	3 out of 3
4. Promote Self-Care; Independence	Self-Care Index	Staff	3 out of 3
5. Promote Mental Health	Visit Psychiatrist	Staff	3 out of 3
6. Promote Productivity	Outside Activity Index	Staff	3 out of 3
<u>B. QOL Findings with Moderately Strong Evidence of Community Association</u>			
1. Promote Choices	Autonomy Index	4 Groups	10 out of 12
2. Promote Family Ties	Visits	3 Groups	6 out of 9
3. Promote Safety	Personal Harm Index	4 Groups	8 out of 12
	Possession Index	Staff	1 out of 1
<u>C. QOL Findings with Weakest Evidence of Community Association</u>			
1. Promote Physical Health	Utilization Items	Staff	1 out of 3
2. Emotional Well-Being	Well-Being Index	4 Groups	1 out of 12
<u>D. QOL Findings with No Evidence of Any Community Association</u>			
1. Promote Friendship	Close Peer Items	Staff	0 out of 3
2. Reduce Inappropriate Behavior	Towards Others Index	Staff	0 out of 3
	Towards Self Index	Staff	0 out of 3
3. Material Well-Being	Possessions Index	Staff	0 out of 1

Summary of Findings

A synthesis of all the major findings of this 27-month evaluation leads to the following conclusions:

- ❖ There is **strong** evidence that community residence is positively associated with a better quality-of-life in the following areas:
 1. Community participation;
 2. Promoting family phone contacts;
 3. Promoting self-care, particularly independent and household skills;
 4. Promoting freedom via lower social controls;
 5. Promoting mental health utilization; and
 6. Promoting productivity.
- ❖ There is **moderately strong** evidence that community residence is positively associated with a better quality-of-life in the following areas:
 1. Promoting personal choices and autonomy;
 2. Promoting family visits; and
 3. Promoting safety from personal harm and of one's personal possessions.
- ❖ There is **weak** evidence that community residence is positively associated with a better quality-of-life in the following areas:
 1. Promoting physical health care utilization; and
 2. Promoting emotional well-being.

- ❖ There is **no evidence** that any of the following specific quality-of-life areas are better achieved in either community settings or DD Centers:

1. Peer friendships;
2. Reducing inappropriate behaviors; and
3. Promoting material well-being.

In short, after reviewing all of the evidence, there is very strong or moderately strong evidence that consumers residing in community settings had higher quality-of-life, due to their residential placements, in the following 7 ideal goal areas:

1. Community participation;
2. Family ties;
3. Self-care;
4. Choices and freedom;
5. Productivity;
6. Mental health utilization (but not physical health utilization); and
7. Safety (from personal harm and of material possessions).

Chapter XIII: Consumers and Families Look Back at Life at NPDC

Introduction

At the time of consumers' 3-month follow-ups, family members and guardians were asked whether they wanted consumers to leave NPDC at the time of closure and whether they were satisfied with consumers' residences at 3 months (Apgar et al., 1999). These questions were repeated at the times of the 27-month interviews, together with other questions about their overall satisfaction with consumers' lives. This chapter assesses the responses of family members/guardians to these types of questions at different time periods. The views of consumers about their overall satisfaction at different time periods are also included.

Family Member/Guardian Views About Consumers Leaving NPDC

Table XIII-1 provides information on the proportion of family members/guardians who remembered wanting consumers to leave NPDC at 3 months in Part A. At the time of the closure, family members/guardians of institutional residents were less likely to want their relatives to leave NPDC, in comparison to those of community residents (i.e., 45 to 60%, respectively). However, this difference was not statistically significant. When asked if at 3 months they wanted relatives to live at NPDC or elsewhere, more family members/guardians of community residents were likely to say "elsewhere" than institutional family members/guardians (i.e., 89 to 60%, $p < .05$). Analysis of the data in Part A also reveals that the proportion of family members/guardians of community residents who favored living outside of NPDC increased (i.e., from 60 to 89%, $p < .0001$).

In Part B, the responses to similar questions asked at 27 months are presented. Remembering back, the difference of family members/guardians who now reported that they wanted consumers to leave NPDC at the time of the closure was statistically significant

(i.e., 36 to 70%, $p < .04$). When asked at 27 months whether they would like consumers to live at NPDC or “elsewhere,” family members/guardians of community residents were much more likely to reject NPDC and say elsewhere (i.e., 91 to 45%, $p < .02$). The increase in the proportion of community family members who wanted their loved ones to leave NPDC before closure and after (at 27 months) is statistically significant (i.e., 70 to 91%, $p < .0003$).

Based on the evidence in Table XIII-1, it is reasonable to infer that by 27 months community families are nearly unanimous (i.e., 91%) that it is better to live elsewhere than at NPDC. Institutional families do not feel the same way.

**Table XIII-1: Family Member/Guardian Views About Leaving NPDC
at 3 and 27 Months
(Based On the Maximum Number Remembering NPDC)**

<u>A. At 3 Months</u>			
	<u>Before: Want to Leave NPDC or Stay</u>	<u>After: Live at NPDC or Elsewhere</u>	<u>Significance</u>
Institutional Family Members/Guardians	45% say leave	60% elsewhere	NS
Community Family Members/Guardians	60% say leave	89% elsewhere	$p < .0001$
Significance	NS	$p < .05$	
<u>B. At 27 Months</u>			
	<u>Before: Want to Leave NPDC or Stay</u>	<u>After: Live at NPDC or Elsewhere</u>	<u>Significance</u>
Institutional Family Members/Guardians	36% say leave	45% elsewhere	NS
Community Family Members/Guardians	70% say leave	91% elsewhere	$p < .0003$
Significance	$p < .04$	$p < .02$	

NS = Not Significant

Family Member/Guardian Views about Consumers' Lives Overall at NPDC and at 3 and 27 Months

Further analyses were conducted at 3 and 27 months to compare the opinions of family members/guardians about the “overall” well-being of consumers at NPDC and at present. Family members/guardians were asked to rate, on a 3-point Likert-type scale, consumers' overall life quality at NPDC and at present with the following scoring: 1=Unhappy; 2=In Between; and 3=Happy. The responses of family members/guardians at 3 months are depicted in Part A of Table XIII-2.

Analyses at 3 months revealed that the overall life at NPDC was rated as happier by institutional family members/guardians, compared to community family members/guardians – but this difference was not statistically significant (i.e., 2.45 to 2.15). When asked to assess the lives of consumers at 3 months, the assessments of community family members/guardians increased from 2.15 to 2.53 ($p<.01$) – but the ratings of institutional family members/guardians did not significantly change. When directly comparing the assessments of consumers' lives overall now, there is no significant difference between the 2 types of family members/guardians.

Part B discloses that the recollections of family members/guardians at 27 months reveal significant differences between the types of family members/guardians. Life overall at NPDC was rated 1.95 by community family members/guardians, in comparison to a much higher score of 2.58 by institutional family members/guardians ($p<.01$). When asked about “overall life now” at 27 months, there is again a clear difference between the 2 types of family members/guardians (i.e., 2.00 and 2.57 for community and institutional – respectively, $p<.01$). The difference between the pre-move ratings and the 27-month ratings are statistically significant for the community.

Based on the evidence of Table XIII-2, it is reasonable to infer that at both 3 and 27 months, community family members/guardians believe that life overall is significantly better for consumers in the present than it was at NPDC. Institutional family members/guardians did not significantly change their views about consumers' lives overall at NPDC and at present at either 3 or 27 months. All of the relationships were reproduced when only family members were analyzed.

Table XIII-2: Family Member/Guardian Views About Consumers' Lives Overall at NPDC and Now at 3 and 27 Months
(Based on the Maximum Number Remembering Life Overall At NPDC)

<u>A. At 3 Months</u>			
	Pre-Move: Life Overall at <u>NPDC</u>	<u>Life Overall Now</u>	<u>Significance</u>
Consumers in Institutions	2.45	2.30	NS
Consumers in Community	2.15	2.53	p<.01
Significance	NS	NS	
<u>B. At 27 Months</u>			
	Pre-Move: Life Overall at <u>NPDC</u>	<u>Life Overall Now</u>	<u>Significance</u>
Consumers in Institutions	2.58	2.00	NS
Consumers in Community	1.95	2.57	p<.0002
Significance	p<.01	p<.01	

NS = Not Significant

See text for scoring of responses to questions about life overall at NPDC and now.

Opinions of “Movers” About Leaving NPDC

Consumers in this evaluation were asked comparable questions about the care at NPDC to those asked of their family members/guardians. First, consumers were asked whether they wanted to leave NPDC at the time of the closure and whether they wanted to live somewhere other than NPDC now. The responses of reliable consumers used in these analyses are depicted in Table XIII-3.

Data collected at 3 months is displayed in Part A. At the time of the closure, almost all of the consumers wanted to leave NPDC, with no marked differences between those who moved to institutions versus community settings. At 3 months, there were still no significant differences between these groups with the majority still wanting to live elsewhere. Comparable findings were seen at 27 months (Part B).

These findings differed from the responses of family members/guardians which showed that family members/guardians of community residents were much more likely than their institutional counterparts to indicate a desire for consumers to live in settings other than NPDC. This difference in family member/guardian attitudes is primarily due to a significant increase in their views toward community placements from the time of the closure to the 3- and 27-month follow-ups.

Table XIII-3: Reliable Consumer Views About Leaving NPDC at 3 and 27 Months
(Based on the Maximum Number Remembering NPDC)

<u>A. At 3 Months</u>			
	Before: Want to Leave <u>NPDC or Stay</u>	After: Live at NPDC or <u>Elsewhere</u>	<u>Significance</u>
Consumers in Institutions (N=4)	100% say leave	75% elsewhere	NS
Consumers in Community (N=15)	93% say leave	93% elsewhere	NS
Significance	NS	NS	
<u>B. At 27 Months</u>			
	Before: Want to Leave <u>NPDC or Stay</u>	After: Live at NPDC or <u>Elsewhere</u>	<u>Significance</u>
Consumers in Institutions (N=5)	60% say leave	60% elsewhere	NS
Consumers in Community (N=19)	89% say leave	89% elsewhere	NS
Significance	NS	NS	

NS = Not Significant

“Mover” Assessments of Their Lives Overall

“Movers” were also asked to rate the overall quality of their lives on a 3-point scale as they recalled it to be at NPDC and now. The 3-month and 27-month responses of “movers” are seen in Table XIII-4. As depicted, community “movers” rated their quality-of-life now (at 3 months – Part A and at 27 months – Part B) as significantly happier than they recalled it to be at NPDC. No significant gain in life satisfaction was found among “movers” who were still institutionalized at the times of their follow-ups. Community dwellers also were more satisfied with their lives than institutional dwellers 3 months after leaving NPDC. However, these findings were not reproduced at 27 months. Conclusions based upon consumer assessments should be approached with some caution given the small number of consumers used in the overall analyses and the extremely small number of reliable

consumers who were living in institutions after leaving NPDC. However, the overall findings that reliable consumers rated their lives 3 and 27 months after moving as significantly happier than they recalled them to be at NPDC are positive ones.

Table XIII-4: Reliable Consumer Views About Consumers' Lives Overall at NPDC and Now at 3 and 27 Months
(Based on the Maximum Number Remembering Life Overall At NPDC)

<u>A. At 3 Months</u>			
	<u>Pre-Move: Life Overall at NPDC</u>	<u>Life Overall Now</u>	<u>Significance</u>
Consumers in Institutions (N=4)	1.75	2.25	NS
Consumers in Community (N=15)	1.47	2.93	p<.0001
Significance	NS	p<.001	
<u>B. At 27 Months</u>			
	<u>Pre-Move: Life Overall at NPDC</u>	<u>Life Overall Now</u>	<u>Significance</u>
Consumers in Institutions (N=5)	2.00	2.20	NS
Consumers in Community (N=18)	1.50	2.78	p<.0001
Significance	NS	NS	

NS = Not Significant

See text for scoring of responses to questions about life overall at NPDC and now.

Summary of Findings

Family members and guardians were asked whether they wanted consumers to leave NPDC at the time of closure, and whether they were satisfied with consumers' residences at 3 and 27 months. Responses indicated that family members/guardians of consumers living in community residences, as opposed to institutional settings, were much more likely at 3 and 27 months to indicate a desire for consumers to live in settings other than NPDC. This difference was primarily attributable to positive shifts in the attitudes of community family

members/guardians toward alternative placements from their recollections of the time of the closure to 3 and 27 months.

In order to assess their satisfaction, “movers” were asked whether they wanted to leave NPDC at the time of the closure and whether they wanted to live somewhere else other than NPDC now. The majority of reliable “mover” respondents indicated that they wanted to leave at the time of the closure and reported at 3 and 27 months that they wanted to live elsewhere. There were no significant differences between those residing in institutional versus community settings after the closure. However, when asked to assess their lives overall at NPDC and now, consumers living in the community reported marked increases between the life satisfaction recalled at NPDC and reported at both 3 and 27 months. No significant gains were found in the life satisfaction of consumers still living in institutions.

Chapter XIV: Summary and Conclusions

Introduction

The aims of this evaluation were to assess the impacts of deinstitutionalization on the former residents of the North Princeton Developmental Center (NPDC). In order to achieve the aims of this study, the research design relied on surveys, on-site observations, and reviews of records. Data on the “movers” and “stayers” used in the analyses for this report were based upon face-to-face interviews with staff and consumers, as well as telephone interviews with family members/guardians.

Analyses revealed that the matched 150 “movers” (including 136 persons chosen randomly and 14 chosen to represent the medically frail) and 150 “stayers” were statistically equivalent on age, gender, multicognition, self-care, mobility, and behavior towards self and others. In addition, the 136 person random “mover” sample can be generalized with great confidence to the experiences of all former residents of NPDC who resided there immediately prior to its closure. Thus, the experiences of the random sample “movers” can represent the 27-month outcomes of the nearly 500 persons who lived at NPDC in 1996 prior to its closure. Additionally, assessments of the competencies, behaviors, and quality-of-life of “movers” can be compared with those made for “stayers,” as these 2 groups are statistically the same on age, gender, multicognition, self-care, mobility, and behavior towards self and others.

Sample Status and Survey Respondents

Since the onset of the evaluation, there was some attrition in the evaluation sample due to consumer deaths. A total of 35 “movers” and “stayers” had died by the times of their 27-month follow-ups. Prior analyses have shown that community living had no impact on the death rates of consumers. While staff of the DD Planning Institute met with all the consumers in the evaluation

sample (i.e., those who left NPDC and their comparisons), only a very small proportion could be interviewed about their current well-being. Using a prescreening tool, consumers were assessed for their reliability. Analyses revealed that the proportion of consumers who were found reliable was quite stable over time. Data collected from current staff and family members/guardians was seen as critical for the evaluation. High response rates of family members/guardians were obtained for both “movers” and “stayers.”

Where Do They Live and Work Now?

The living arrangements of “movers” and “stayers” have not changed dramatically since the 3-month follow-ups. Approximately, three-fourths of “movers” resided in community settings, with the preponderance of these individuals residing in group homes. Almost all of the “stayers,” remained in institutional residences.

Additional analyses were done on the “movers” to determine which consumer characteristics were associated with those remaining in institutional settings after leaving NPDC. Having a swallowing problem and low mobility were significant independent predictors in explaining who was placed in institutional settings after the closure.

Higher mobility by consumers, community residence, and living in the Southern Region were significant in distinguishing between those who received out-of-home versus in-home day services.

When examining the differences between those who leave their homes and those who do not for structured day activities, marked differences were seen in the focus, time spent in activities, and compensation of these 2 groups. Most consumers in in-home programs were engaged in socialization activities, while about half of those who leave their homes were participating in these social tasks. In addition, those leaving their homes during the day were spending significantly more time engaged in structured activities than their in-

home counterparts. Only a small percentage of individuals staying home were paid for their efforts and all of these were compensated directly by their residential providers.

Characteristics and Correlates of Living Environments

Two measures of the residential environment associated with consumers' places of residence proved to be reliable at all time periods. The environmental index referred to the degree to which residences were "less institutional" and the social control index referred to the extent to which social controls were less likely to be employed in dealing with consumers. Community living arrangements are described as having the following features: (1) the outside of residences look like others in the neighborhood; (2) the inside of residences look like others in the neighborhood; (3) residences have a smaller number of persons residing in them; (4) consumers have more personal possessions evident; and (5) staff are more likely to have more informal interactions. Lower social controls means that there are fewer uses of time outs, point systems, loss of privileges, and manual restraints.

Analyses indicates that community residences are much more likely to be associated with staff who believe that 10 quality-of-life goals – like independence, choices, emotional and physical well-being, and personal safety – can best be realized in a community residence. Besides staff attitudes and beliefs, community settings are also more likely to be associated with low formal social controls and the teaching of domestic skills to consumers.

In addition, community residences are much more likely to have consumers who use antipsychotic medications. Consumers in these residences who came from NPDC had an increased likelihood of having psychiatric diagnoses. Prior analyses done in 1994 – before the announcement was even made to close NPDC – indicated that this DD Center had more persons with psychiatric problems and medication usage than other DD Centers. Therefore, it is not surprising that those now found in community settings are more likely to be using antipsychotic medications.

Further analyses on the use of low social controls reveal that their usage is associated with community living and specific individual characteristics. Persons with low mobility are much less likely to experience social controls. Additionally, lower social control is also associated with fewer inappropriate/aggressive behaviors. These personal characteristics can be found in institutions and community residences. In brief, social controls can be found in institutions as well as community residences (due to individual characteristics), but they are less likely to occur in the community.

Implementation of Consumer Choices

As part of the NPDC closure, the Division of Developmental Disabilities (DDD) initiated a major effort to conduct person-centered planning for all persons leaving NPDC. Copies of the Individual Support Plan Indicator Sheet used by DD regional personnel in evaluating service proposals by nonprofit providers were used as a basis of rating whether suggested consumer-oriented choices and supports and services were, in fact, provided to consumers by 3 months. Five of 6 support service recommendations were completely delivered at the rate of 88 to 100% by 3 months. These services included supervision, medical monitoring, safety precautions, accessible housing, and the receipt of psychiatric medication. Only psychiatric follow-ups had a lower rate of implementation (63%) at 3 months.

Consumer-oriented choices were implemented with greater variability – ranging from a high of 78% for leisure choices to 35% for choices related to whom to live with. When consumer-oriented choices were examined by whether they were most likely to be completely met in community versus institutional settings, only 3 types of choices were significantly related to environment type – smoking, work type, and number of persons to live with. When these 3 choices were examined simultaneously, only one type of

implementation choice was uniquely associated with community residence – the number of persons to live with.

Person-centered planning that attempted to deliver consumer-oriented choices can be implemented in both community residences and institutions, with the exception of the choice regarding the size of the residence. To date, only community-based residences do, in fact, offer living arrangements with fewer people – the ideal choice of consumers or persons making decisions on their behalf.

Consumer Competencies

Detailed statistical analyses of matched pairs reveal that institutional “stayers” had much lower multicognition over time, while community “movers” did not exhibit any significant changes in this area over time. Community “movers” made significant gains in self-care – especially with regard to independent and household skills. Both groups showed marked decreases in their mobility over time.

Aggressive and Inappropriate Consumer Behaviors

Analyses of behavior towards others – measured by items referring to aggressive or inappropriate behaviors – revealed that there were no significant differences between “movers” and “stayers” at 3, 15, or 27 months. While “movers” behavior towards others increased over time, they were not sufficient to change the comparability between “movers” and “stayers.”

In contrast, analyses of behavior towards self revealed that a significant difference was found at 27 months. The mean scores of “movers” had increased sufficiently, so that the mean changes between “movers” and “stayers” were also significant over time. However, further statistical analyses disclosed that other variables – particularly ones associated with psychiatric problems, psychiatrists’ visits, and antipsychotic medication – were also linked to one or more behaviors directed at self at 27 months. Further

multivariate analyses disclosed that it was these types of psychiatric indicators – rather than community residence – that were uniquely associated with higher behavior towards self. These findings were congruent with earlier findings that NPDC “movers” had higher rates of psychiatric problems and medications. Increased activities toward self are, therefore, best explained by the prior existence and continuation of psychiatric problems and treatments, rather than by community residence per se.

Relationships with Family and Peers

Phone contacts by family members/guardians were definitely more likely to occur if individuals were residing in community residences, regardless of their own characteristics. Family visits were also more likely to occur in community residences at 3 months. However, there were sharp decreases in visits thereafter, so there are no significant differences between “movers” and “stayers” by 27 months, according to both staff and family member/guardian reports. Despite this finding, there is some support by both staff and family members/guardians that living in a community residence may have some significant relationship with visits, though these findings are not consistent.

The acquisition of more peer friends is not influenced by community living at any time period. Instead, having peer friends is determined by higher levels of competencies and displaying lower rates of aggressive behavior at different time periods.

Health Services Utilization

Almost all of the initial health differences found at 3 months, between the utilization of health care services by “movers/stayers” or community/institutional residents, had dissipated at 15 and 27 months. Differences continued to be found for seeing a psychiatrist (if a psychiatric diagnosis existed) at all time periods. Residence in the community made a unique, independent, contribution in explaining psychiatric utilization even after controlling for consumer characteristics.

There were no differences in the receipt of physical therapy by sample types at 3 months, but they appeared at 15 and 27 months. When type of residence was assessed with other significant variables, the statistical importance of institutional residence diminished sharply. Low mobility, having muscular/skeletal conditions, and being under 60 are clearly the most important variables in receiving physical therapy. Separately and together, they are clearly more important than place of residence. Place of residence was not independently related to the receipt of speech therapy when consumer characteristics were considered.

Quality-of-Life

Within 3 months of consumers moving to the community, family members of these consumers were far more likely than institutional families to believe that ideal quality-of-life goals could best be achieved outside of DD Centers. These beliefs about the best place to achieve ideals continued at 15 and 27 months. Family members of consumers living in community residences consistently believe that each of the following ideal goals could best be achieved in the community:

1. Self-care and independence;
2. Choices and freedom to come and go;
3. Emotional well-being;
4. Community involvement and leisure;
5. Friendship and family ties;
6. Material well-being;
7. Personal safety;
8. Productivity;
9. Physical well-being; and
10. Appropriate behaviors.

In contrast, family members of institutional residents consistently believe that the ideal goals could best be achieved in DD Centers at all time periods. When the 10 ideal goals were combined to form a single index of ideal goals, family members of institutional residents were more “pro-institutional” in their beliefs than staff members who were asked similar questions about ideal goals.

In an effort to assess whether ideal goals were actually realized in practice, family members/guardians, family members only, consumers, and staff were asked specific questions about community participation, autonomy, emotional well-being, and safety. In addition, staff data were used to assess items about productivity and material well-being. The response patterns for each quality-of-life domain were as follows:

1. Community Participation – Staff, family members/guardians, family only, and consumers all agreed that community participation was higher among community residents at all time periods.
2. Autonomy – Staff, family members/guardians, and consumers all agreed that community residents had higher autonomy at all time periods. Family members only judged that persons living in the community had more autonomy only at 15 months.
3. Emotional Well-Being – There is little evidence that emotional well-being is related to the type of residence of consumers. Only consumers at 15 months indicated that community living was tied to their emotional well-being.
4. Safety – Staff and consumers agreed that living in the community felt safer than living in the DD Centers. However, no differences were reported for family members/guardians or family only – with the exception of 27 months when they agreed with staff and consumers.

5. Productivity – According to staff, consumers living in the community have higher productivity than DD Center residents based on objective indicators, such as out-of-home work, work time, and earnings, at all time periods.
6. Material Well-Being – Community residents did not have higher material well-being at 27 months than their DD Center counterparts according to staff. However, persons living in environments with low social controls (which are significantly related to community living) had more possessions. In addition, safety of possessions was found to be higher in community residences.

The evidence about the actual quality-of-life of consumers indicates that the ideal goals of community family members are realized in varying degrees. There is direct strong evidence in support of productivity and community participation being linked to community placement, moderately direct strong evidence in support of autonomy and perceived safety and quite weak support of emotional well-being. There is also indirect support that improvement in material well-being is associated with community living as it has lower social controls.

Quality-of-Life: A Synthesis of Findings

A synthesis of all the major findings of this 27-month evaluation leads to the following conclusions:

- ❖ There is **strong** evidence that community residence is positively associated with a better quality-of-life in the following areas:
 1. Community participation;
 2. Promoting family phone contacts;
 3. Promoting self-care;
 4. Promoting freedom via lower social controls;
 5. Promoting mental health utilization; and
 6. Promoting productivity.
- ❖ There is **moderately strong** evidence that community residence is positively associated with a better quality-of-life in the following areas:
 1. Promoting personal choices and autonomy;
 2. Promoting family visits; and
 3. Promoting safety from personal harm and of one's personal possessions.
- ❖ There is **weak** evidence that community residence is positively associated with a better quality-of-life in the following areas:
 1. Promoting physical health care utilization; and
 2. Promoting emotional well-being.
- ❖ There is **no evidence** that any of the following specific quality-of-life areas are better achieved in either community settings or DD Centers:
 1. Peer friendships;
 2. Reducing inappropriate behaviors; and
 3. Promoting material well-being.

In short, after reviewing all of the evidence, there is very strong or moderately strong evidence that consumers residing in community settings had higher quality-of-life, due to their residential placements, in the following 6 ideal goal areas:

1. Community participation;
2. Family ties;
3. Self-care;
4. Choices and freedom;
5. Productivity;
6. Mental health utilization (but not physical health utilization); and
7. Safety.

Consumers and Families Look Back at Life at NPDC

Family members and guardians were asked whether they wanted consumers to leave NPDC at the time of closure and whether they were satisfied with consumers' residences at 3 and 27 months. Responses indicated that family members/guardians of consumers living in community residences, as opposed to institutional settings, were much more likely at 3 and 27 months to indicate a desire to live in settings other than NPDC. This difference was primarily attributable to positive shifts in the attitudes of community family members/guardians toward alternative placements from their recollections of the time of the closure to 3 and 27 months.

In order to assess their satisfaction, "movers" were asked whether they wanted to leave NPDC at the time of the closure and whether they wanted to live somewhere else other than NPDC now. The majority of reliable "mover" respondents indicated that they wanted to leave at the time of the closure and reported at 3 and 27 months that they wanted to live elsewhere. There were no significant differences between those residing in institutional versus community settings after the closure. However, when asked to assess

their lives overall at NPDC and now, consumers living in the community reported marked increases between the life satisfaction recalled at NPDC and reported at both 3 and 27 months. No significant gains were found in the life satisfaction of consumers still living in institutions.

Conclusions and Implications

The aims of an evaluation are to assess actual outcomes against ideal policy or programmatic intents. The data presented in this report provide empirical evidence as to the whereabouts and well-being of persons who left NPDC as a result of the closure. In addition, it assesses the degree to which person-centered planning was realized once persons left the facility. Careful examination of this information within the context of desired policy outcomes illustrates several important conclusions.

First, it is useful to examine the actual outcomes of the person-centered planning process in light of desired policy objectives. Empirical data collected 3 months after consumers left indicate that most of their preferences were not met with regard to whom consumers lived with, the type of work that they did, and the proximity of their residences to desired resources. In addition, only about half of consumers had their desires realized with regard to the geographic locales of their residences, the number of persons that they lived with, their roommates, and the type of atmosphere in their homes. Thus, while the use of person-centered planning had strong ideological appeal, consumer wishes were not always respected when confronted with the realities of planning for postclosure placements. Future efforts for person-centered planning should include similar evaluations to determine the extent to which consumer choices are actually fulfilled. In addition, barriers in the current planning and provider systems which prevented the realization of more consumer choice should be examined if this movement towards consumer choice is to continue. Though not tested as part of this evaluation, there may have been an unanticipated positive outcome of

the use of person-centered planning. The families of “movers” were much more likely to contact their relatives by phone and visit initially after their moves. This heightened involvement may have resulted from their involvement in meetings to formulate Individual Support Plans (ISPs). While the exact reason for this increased contact is not known, consumers were receiving more phone contacts and initial visits after the closure.

Second, at the time of the closure, there was a commitment made by the former Director of DDD that all those residing at NPDC – even those with extremely intensive needs – would be served within community settings. Information on the whereabouts of former NPDC residents since the closure reveals that about a fourth of former NPDC remain in institutional placements, such as DD Centers and nursing homes. Further analyses of the types of consumers who initially went to other institutions after leaving NPDC revealed that they were more likely to have low mobility and swallowing problems. Thus, while the ideal policy directive was to serve all consumers in the community, this goal was only partially realized. If community placement for all consumers remains an ideal goal of DDD, careful examination of the ability of the current provider network to serve those with all types of needs – including the needs of those with ambulatory and/or swallowing problems – must be made.

Lastly, at the time of the closure, there was a commitment by the Department of Human Services that all persons leaving NPDC would have placements “equal to or better” than the institution (DHS, 1995). The former NPDC residents who were transferred to other institutional settings and their family members rated life quality in these new settings as comparable to what it was remembered to be at NPDC. They also showed no preference for wanting to stay in their current placements as opposed to living at NPDC. These assessments are indicators that these consumers and their families perceive their current institutional placements to be generally equal to NPDC.

However, analyses of all the data collected for more than 2 years on the former NPDC residents and those in the comparison group clearly indicate that life in the community is “equal to or better” than that in institutions. There is very or moderately strong support that community living enhances quality-of-life in the areas of community participation, family ties, self-care, choices and freedom, productivity, mental health utilization, and safety. In the other quality-of-life areas, community and institutional living appeared comparable. In addition, community residents were more likely to live in settings in which: (1) the outside looked like others in the neighborhood; (2) the inside looked like others in the neighborhood; (3) there were a smaller number of persons residing in them; (4) consumers had more personal possessions evident; (5) staff engaged in more informal interactions; (6) fewer social controls were used; and (7) more domestic skills were taught.

There is no evidence that deinstitutionalization in New Jersey is associated with increased mortality and no other negative consequences of deinstitutionalization were found. However, there was strong evidence that continued residence in institutions for persons comparable to community “movers” resulted in decreases in their multicognitive abilities. These losses were most likely to occur amongst institutional “stayers” who had the lowest initial multicognitive abilities in 1994. Significant losses in multicognition were not found for those living in community settings.

Despite opposition to the closure of NPDC by some family members, there is now strong support of community living by a clear majority of NPDC family members. These positive subjective assessments by the relatives of former residents – coupled with empirical data supporting “equal to or better” quality-of-life for consumers living in the community – provide strong support for expanding and accelerating community living alternatives for many persons currently living in New Jersey’s DD Centers.

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Appendix A: The Evaluation Sample

(Adapted from Closing Old Doors – Opening New Ones (Apgar et al., 1999))

Central to the usefulness and generalizability of any rigorous evaluation is the adequacy of the study sample. This section will explain the sample selection and the degree to which this sample group represents all those who composed the total population of persons who lived at NPDC immediately prior to its closure. First, procedures used to choose the 150 persons in the “mover” evaluation sample will be described. Then, the comparability of these individuals with those who resided in NPDC immediately prior to its closure will be examined on an array of characteristics.

Sample Selection and Description

The “mover” sample has its genesis in prior assessment activities conducted by the DD Planning Institute. In 1994, the DD Planning Institute was asked by DDD to systematically and comprehensively describe persons who were residing in all 8 of New Jersey’s DD Centers. In order to achieve these aims, a random sample of 1,190 persons who were living in the 8 DD Centers at that time was selected. This sample included approximately 28% of the total population of 4,336 DD Center residents at that time. In order to insure that these individuals represented the proportion of all persons being served in different institutional and cottage types, a random stratified sampling strategy was used with individuals chosen by institutional type (high versus low functioning) and cottage profile (behavioral, medical, other special). Due to the relatively low numbers of persons who were residing in medical cottages at DD Centers serving higher functioning individuals (including NPDC), an oversampling of all these persons (n=100) was included in this study. A total of 171 individuals who were residing at NPDC in 1994 were included in the overall 1,190 person sample. (For a detailed explanation of the sampling procedures used in the

DD Centers study, see Lerman et al., 1995).

In preparing for an evaluation of the closure of NPDC 2 years later in Spring 1996, the knowledge about the 171 persons was used as a strategic starting point for the research design. The use of these 171 individuals was believed to be ideal, since comprehensive assessments of their competencies and behaviors, as well as medical conditions and adaptive equipment and service needs, had already been made in 1994. These assessments provided valuable baseline information from knowledgeable staff about how these individuals were functioning in this facility prior to the closure announcement. These baseline measures were very important, since the closure announcement could impact on staff ratings of consumers' abilities and behaviors. While following all of the 171 persons would have been desirable, only 150 NPDC residents were included in the final evaluation sample – since 21 persons had died, relocated to other DD Centers prior to the actual closure process, or were in the Moderate Security Unit (MSU) and, therefore, not eligible to be placed in the community due to their legal status.

The 150-person “mover” sample was established in Spring 1996, using the methods outlined above. It was then anticipated that the onset of data collection, as outlined in the proposed research design, would begin with the first departure by one of the sample members moving into a new living arrangement as part of the NPDC closure. Notification was made of the departure of the first “mover” from NPDC in January 1997, which marked the official start of the evaluation. However, due to the passage of time between the finalization of the study sample and the first official move by a sample member, there was some attrition in the sample which required replacement. In replacing “movers,” a randomly selected pool of NPDC residents not in the original 1,190 sample was used.

Ten original “movers” had to be replaced for a variety of reasons. Two had died prior to January 1997, 6 individuals had moved without notification before the evaluation start date, and one was excluded due to participation in a previous DD Planning Institute evaluation of the E.R. Johnstone Research and Training Center closure. As part of such prior participation, this former Johnstone resident was exposed to similar survey questions which could have impacted on item responses in this evaluation, thereby warranting replacement in the “mover” sample. In a final replacement case, a move that occurred after the evaluation start date was not communicated to DD Planning Institute personnel in time for a 3-month follow-up interview to occur. Thus, the final “mover” evaluation sample refers to former NPDC residents who left the facility on or after January 7, 1997. Similar adjustments had to be made for the matched “stayer” sample.²

In all subsequent text and analyses contained in this report, the “movers” or “mover” sample will refer to the 150 persons who left NPDC after the official evaluation start date (January 7, 1997), including the sample replacements as described above. It is useful to understand the key characteristics of this important study group. Since the evaluation sample was predominately drawn from the original 171-person group who were living at NPDC at the time of the DD Center study, it contained an oversampling of persons who were residing in medical cottages (n=14 persons in oversampling with 25 individuals residing in medical cottages at NPDC overall). Inclusion of this oversampling in the NPDC evaluation was believed to be important as these individuals were the most medically frail and, thus, extremely vulnerable to environmental and personnel changes. In order to assess

² Sample replacements were also made to the “stayer” sample. Nineteen original “stayers” also had to be replaced as 7 had died, 7 had moved prior to January 7, 1997, and 5 were interviewed as part of a previous evaluation. The original 1,190 sample was used to replace these individuals. Additionally, the original 1,190 sample was used to identify appropriate new matches (“stayers”) for the replaced “movers.” New “stayers” were selected using the original matching strategy as outlined in the next section. In all, a total of 39 original sample members, including 10 “mover/stayer” pairs and 19 additional “stayers,” were replaced.

the impacts of the NPDC closure on this potentially at-risk group, it was necessary to include enough of them in the sample to permit sound statistical analyses.

Do the “Movers” Represent All Those Who Lived at NPDC?

To assess the comparability of these sample groups with all of the consumers who resided at NPDC at the time of its closure, statistical analyses were used to compare these groups on age, gender, multicognition, self-care functioning, mobility, special behaviors, and official mental retardation classification. These analyses used data collected by the DD Planning Institute on all persons living at NPDC in 1996 **prior** to the closure, as well as information retained in the institutional database.

While there were 523 individuals initially included in the NPDC initiative, not all of these individuals were included in the analyses that follow. By January 1997, it was decided by DDD administrators that the 28 individuals who were residing in a Moderate Security Unit (MSU) at NPDC would be excluded from community placement initiatives because they were court-ordered to remain in institutional care. Therefore, no MSU residents were represented in the “mover” sample. Additionally, 6 individuals who were included in the NPDC initiative were designated as “purchase of care” and living in other private institutions. Since these 6 persons were never actual residents of NPDC, they were not represented in the “mover” sample. In summary, a total of 34 consumers were not eligible to be in the total “mover” sample and were excluded from the evaluation study. For the purpose of this evaluation, the total eligible sampling frame comprised 489 NPDC residents, as of January 1997.

A comparison between the study sample of “movers” and those living at NPDC immediately prior to its closure, using 1996 data, is displayed in Table A-1. There are no statistical differences between the “mover” sample excluding the oversampling of those who

are medically frail and the total persons residing at NPDC immediately prior to its closure, thereby allowing findings based on this group to be generalized to the experiences of all those who were residing at NPDC immediately prior to its closure. As expected, significant differences were found between the total “mover” sample, including those in the original medical oversampling and all of the former NPDC residents. Specifically, the 150 total “movers” were significantly older and less mobile than the total NPDC population immediately prior to its closure. Since this group contained a larger proportion of those who were living in medical cottages (i.e., medically frail), the increased age and decreased ambulation of this group is not surprising. Thus, it can be confidently concluded that the “mover” sample without the oversampling is representative of the total NPDC population on the critical matching characteristics established in the research design, while the total “movers” sample is similar to all former NPDC residents on many key characteristics.

Table A-1: Comparisons of Evaluation Samples with Overall North Princeton Developmental Center Population¹
(Based on 1996 Data)*

	(I)	(II)	(III)		
<u>Individual Characteristics</u>	<u>All Former NPDC Residents</u> (Max. n=489)	<u>NPDC Evaluation Sample, excluding Medically-Frail Oversample</u> (Max. n=136)	<u>NPDC Evaluation Total “Mover” Sample</u> (Max. n=150)	<u>Significant Differences Between Groups I and II</u>	<u>Significant Differences Between Groups I and III</u>
<u>Demographics</u>					
Mean Age in Years (as of Jan. 97)	50.2 (n=489)	51.4 (n=136)	52.4 (n=150)	None	Yes (p<.05)
Gender - % Male	57.1 (n=489)	60.3 (n=136)	58.7 (n=150)	None	None
<u>Official Mental Retardation Level</u>					
Profound	40.6%	44.1%	45.3%	None	None
Severe	24.0	19.9	21.3		
Moderate	15.8	18.4	16.7		
Mild or Borderline	18.0	15.4	14.7		
Normal or Above	1.0	0.7	0.7		
Not Determined	0.6 (n=488)	1.5 (n=136)	1.3 (n=150)		
<u>Mean Competency and Behavioral Scores</u>					
Multicognition	24.4	23.8	23.7	None	None
Self-Care	27.4	27.3	25.6	None	None
Mobility	19.2	19.1	17.9	None	Yes (p<.01)
Behavior Towards Others	10.6	11.2	10.9	None	None
Behavior Towards Self	4.4 (Max. n=462)	4.6 (Max. n=136)	4.3 (Max. n=150)	None	None

* Data collected in 1994 instead of 1996 were used for 10 "movers" who were replaced between the time that the sample was initially selected in Spring 1996 and finalized in January 1997. These replacements were not in the original 1,190 person study and, therefore, data was not collected on them in 1994.

¹While data for all persons in the 3 groups are depicted in the table, analyses to determine significant differences between the "random movers" and total "movers" as compared with the NPDC population overall were completed with the 136 and 150 individuals removed from the 489 person total, respectively.

Comparability of “Movers” versus “Stayers”

In order to assess competency and behavioral changes made by former NPDC residents in their new residences, as opposed to predicted fluctuations which would have occurred had they remained in DD Centers, a statistically matched comparison group was required. Since all NPDC residents were expected to move into the community, there was not a random selection of persons staying at the facility which could act as a control group for the evaluation. Instead, a logical source for creating a comparison group was used and a comparison group was selected from a pool of similar residents remaining in the 7 other DD Centers.

The first step in creating a “stayer” comparison group for this study relied on using an available prior sample of New Jersey DD Center residents. This prior sample was drawn in 1994 to assess the competencies, behaviors, and special problems of DD Center residents (Lerman et al., 1995). A total of 1,190 residents from all 8 DD Centers, or 28% of all institutionalized residents at that time, were selected for this statewide assessment study. The statewide sample was selected using probability sampling methods for residents living in specific types of residential units.³ As mentioned, 28% of persons (n=1,133) were randomly selected from each of the following categories: (1) persons living in behavioral cottages in facilities serving higher functioning individuals; (2) persons living in special other cottages in facilities serving higher functioning individuals; (3) persons living in behavioral cottages in facilities serving lower functioning individuals; (4) persons living in special other cottages in facilities serving lower functioning individuals; and (5) persons living in medical cottages in facilities serving lower functioning individuals. Additionally, an oversampling of all persons

³ For a detailed explanation of this sample, refer to the DD Planning Institute Report: Implementing a Policy of “Equal to or Better” Community Placements: The Use of Empirical Indicators to Set Specific Targets (June, 1995).

(n=57) living in medical cottages in DD Centers serving higher functioning persons (NPDC, New Lisbon, and Greenbrook) was included in this 1994 study. This overall, large, and diverse sample (n=1,190) contained residents with varying levels of competencies, and special behavioral and medical problems. This 1994 sample provided this evaluation study with a large pool of DD Center “stayers” (i.e., all those not living at NPDC) whose characteristics were known and who could be matched to those “movers” leaving NPDC.

Identifying the Measures Used for Matching

As previously mentioned, a total of 171 residents of the 1,190 persons in the 1994 study were living in NPDC. From this sample of 171 residents, the 150 “movers” were selected according to the procedures described previously.

A comparison group of 150 “stayers” that matched the characteristics of the 150 “movers” was selected from the remainder of the initial 1,190 sampling pool (n=1,019). To secure the best comparison group, statistical matching was conducted using 7 measures: age, gender, and five key competency and behavioral assessments. Three competency measures assessed consumers’ abilities to engage in multicognitive tasks, self-care routines of daily living, and mobility (see previous discussion of research design and evaluation measures). Two behavioral measures assessed reported acts of abuse toward others and self.

Prior analyses provided evidence that these five measures had strong inter-rater reliability with independent raters and were reliable and valid over a 15-18 month time period using the same rater (Lerman et al., 1995; Jagannathan et al., 1997). Therefore, the measures used to match “movers” and “stayers” had a proven record of being reliable and valid with New Jersey DD Center residents within and over time.⁴

⁴ For a detailed analysis of the stability of the 5 key measures over time, see the DID Planning Institute Report: The New Jersey Client Assessment Form: An Analysis of Its Stability Over Time (July 1997).

Age and Gender Matching

Initial actions at creating a final evaluation sample of “stayers” consisted of matching persons living in the DD Centers with the NPDC “movers” who were the same gender. Then, attempts were made to match DD Center residents with “movers” who had similar competencies and behaviors and were within five-year age spans of themselves. This was not possible for over one-third of the projected comparison sample. Therefore, matching according to broader aggregate age groups was required. However, no natural age groupings for persons with comparable functioning levels were known for this population nor were they readily evident when comparing age distributions of NPDC and all other DD Center residents. Various age groups were provisionally created and statistical tests were conducted to determine whether there were significant differences in the actual mean ages between “movers” and “stayers” in these age groups. This empirical approach resulted in the construction of 3 age groups within which there were no significant mean age differences between the final “mover” and “stayer” samples. Final matching proceeded using the following age stratification groups: young (18-34 years), middle (35-49 years), and mature (50 years and over). These age groups were additionally chosen as it was believed that differences could exist in the self-care, mobility, and other competency and behavioral characteristics of persons who were younger, middle aged, and older.

Table A-2 provides comparisons of “movers” and “stayers” for the final evaluation samples, using known characteristics available in the State of New Jersey’s data files. Note that the mean ages for the evaluation samples of “movers” and “stayers” is nearly identical – 52.4 and 52.2. The distribution within age groups is also comparable. It should be noted, however, that earlier analyses revealed that the former NPDC residents were an older population than residents from other DD Centers; therefore, the overall mean age of the

“stayers” is significantly different from that of the original “stayer” sampling frame. This means that while the evaluation sample of “movers” and “stayers” is comparable with regard to age, the age of the “stayers” selected for the evaluation does **not** represent that of all persons remaining in the other DD Centers. The final “stayer” sample was deliberately chosen to mirror those leaving NPDC with regard to age and other characteristics, thereby allowing them to serve as a comparison group for analyses in the evaluation. Since those leaving NPDC generally were not identical to all DD Center residents on all demographic, functional, and behavioral characteristics and the “mover” sample contained more persons who were medically needy, the characteristics of the “mover” and “stayer” samples were not representative of those of all DD Center residents generally.

Fundamental to the final evaluation design was that each of the “mover” and “stayer” pairs also be matched by gender. As evidenced in Table A-2, “movers” and “stayers” were successfully matched according to gender. Unlike age, there were no differences in gender distribution between NPDC and other DD Center residents in the original sampling frame.

While official intellectual assessment was not used for matching, analyses were done to check whether the final evaluation samples differed according to official ratings conducted by DD Center staff prior to the 1994 surveys. Due to the strong correlation between the multicognitive scores – a characteristic used to match the “movers” and “stayers” – and official intellectual assessment, it was not surprising that these 2 final samples were not significantly different on their official mental retardation levels. Minor differences observed within intellectual categories, as depicted in Table A-2, are not statistically significant. As with age, the NPDC residents differed from those in other DD Centers regarding their official intellectual assessments with fewer persons classified as

profoundly retarded. Thus, while the “movers” and “stayers” were officially assessed at the same intellectual levels, these groups were not reflective of all those in DD Centers, who were more profoundly impaired.

Competency and Behavioral Matching

Previous analyses of consumers’ competencies and special behaviors, as obtained from the 1994 study using the Client Assessment Form (CAF), resulted in the development of five key measures to assess competencies and behaviors. Besides age and gender, “movers” and “stayers” were further matched on these five individual scores. These scores assessed individuals’ competencies and behaviors within five key domains: multicognition, self-care abilities, mobility, behavior towards others, and behavior towards self.

Multicognition refers to a combination of cognitive, verbal communication, and social-emotional competencies. Self-care refers to a combination of basic, independent, and household self-care skills. Mobility refers to physical mobility and motor skills. Lastly, behavior towards others refers to a combination of aggressive (i.e., physical/verbal abuse), annoying, (i.e., grabs others) and disruptive behaviors (i.e., tantrums) while behavior towards self refers to self-abuse (i.e., head banging), danger to self (i.e., runs/wanders away) and sexually inappropriate behaviors.

As noted earlier, the “mover” and “stayer” sampling frames were initially sorted into 3 predefined age groupings, and then by gender. Each group was then individually sorted by the five key measures in the following hierarchical sequence: multicognition, self-care, mobility, other behavior, and self-behavior scores, respectively.

Matching by the five key measures consisted of selecting 150 individual “stayers” who scored on the same decile rank or within one decile rank score of the NPDC residents in the evaluation sample on each measure. For each “mover,” initial priority was given to

matching on the 3 competency measures. After this was successfully accomplished, matching was then achieved with the 2 behavioral measures. If more than one appropriate “stayer” was identified for a “mover,” the “stayer” with the closest raw scores on the competency and behavioral measures to the “mover” was selected. Table A-2 shows how comparable the “movers” and “stayers” are based on their raw scores for each of the five key measures. As depicted, it is evident that the raw scores for the “mover” and “stayer” evaluation samples are quite close and any observed differences are not statistically significant.

Table A-2: Known Demographic Characteristics of the Final North Princeton Evaluation Samples: Comparisons of “Movers” and “Stayers”
(Using 1994 Data)

<u>Characteristics</u>	<u>Final Evaluation Samples</u>	
	<u>“Movers”</u> (n=150)	<u>“Stayers”</u> (n=150)
I. <u>Mean Age</u>		
(A) Total Sample	52.4	52.2
(B) By Age Group		
18 – 34 (n=14 matched pairs)	31.6	29.8
35 – 49 (n=56 matched pairs)	42.4	43.0
50 and over (n=80 matched pairs)	63.1	63.2
II. <u>Gender</u>		
Female	41.3%	41.3%
III. <u>Official Intellectual Assessment</u>¹ (percent in each category)		
Normal or above	0.0%	0.7%
Mild/Borderline	13.5	14.1
Moderate Retardation	13.5	14.1
Severe Retardation	23.7	14.8
Profound Retardation	49.3	55.7
Not determined	0.0	0.7
(Missing Data)	(n=2)	(n=1)
IV. <u>Key Matching Measures</u>		
Multicognition	23.3	22.1
Self-Care	24.2	24.7
Mobility	18.5	18.5
Other Behavior	11.8	11.5
Self Behavior	4.5	5.2

¹These assessments are entered into the State of New Jersey's database for each consumer. However, dates of determination are not computerized as part of these records.

Appendix B: Deaths in the Total Sample by 27 Months

(Adapted from A Year Later: Life After North Princeton Developmental Center (Apgar et al., 2001))

Introduction

In the past few years, leaders in the field of developmental disabilities have paid a great deal of attention to the findings of a California study of deinstitutionalization which focused on the difference in mortality rates of persons who have moved into the community compared with those who remain institutionalized. This California study found that the persons placed in the community were associated with a higher rate of mortality than those who remained in institutions (Strauss, Kastner, and Shavelle, 1998; Shavelle and Strauss, 1999). There has been some debate in the literature concerning the data gathering procedures employed in this study (Taylor, 1998) and the use of a research design that reconstructed a comparison group after deinstitutionalization occurred in only one state. However, despite this ongoing methodological debate, the findings have led some persons and groups to question current policies that favor closing institutions for persons with developmental disabilities.

In constructing the research design for this evaluation, the Co-Principal Investigators were keenly aware of the findings and the methodological issues of the California study. In order to strengthen our research design, a “stayer” comparison group was deliberately constructed – by matching consumers in DD Centers as closely as possible with “movers” on critical variables collected in a uniform fashion – before the “movers” had left NPDC (see Appendix A for sample selection and matching procedures). While some degree of sample attrition of “movers” and “stayers” was expected due to deaths, it was hypothesized that the rates of mortality might be comparable for the 2 groups, and statistical comparisons could indicate whether any differences were within the boundaries of chance. This section

discusses sample attrition of both “movers” and “stayers” due to deaths by the times of their 27-month follow-ups. While the preponderance of this report utilizes data from the times of the 15-month follow-ups, this section is the only one to utilize data from the 27-month follow-ups. As this 27-month data were available at the time that this progress report was being prepared, it was utilized, since it represented the most current information on this important subject.

Methods of Assessing Deaths

The first awareness that any deaths had occurred became apparent at the 3-month follow-ups of “movers” and “stayers.” While “movers” left NPDC at staggered times after January 7, 1997, “movers” and their “stayer” matches were provided with individualized follow-up dates at 3, 9, 15, and 27 months. Therefore, the number of deaths at each follow-up occurred during a similar elapse of time for “movers” and their respective matches.

At each time period, the actual whereabouts of each “mover” and “stayer” were established, in order to interview staff and the consumers (whenever possible). When told by the contact person that the “mover” or “stayer” had died during the time periods of relocation to 3 months, 3-9 months, 9-15 months, and 15-27 months, attempts were made to find out the date of the death and the cause. Unfortunately, staff were often unable to report the precise cause of death, and death certificates were not always available to provide vital information about primary and secondary causes. However, staff were always able to provide the exact dates of deaths. For the purposes of the analyses to follow, **deaths** refers to a confirmation by DDPI staff that a “mover” or “stayer” had died on a known date between a specified time period since the onset of relocation of the “movers.”

Number of Deaths by 3, 15, and 27 Months

Since “stayers” were not contacted at 9 months, the fairest comparisons of deaths between “movers” and “stayers” were for the follow-up dates of 3, 15, and 27 months. By the time of the first follow-up at 3 months, a total of 9 persons had died – 4 “movers” and 5 “stayers.” At 15 months, a total of 23 persons had died – 13 “movers” and 10 “stayers.” By the time of the last follow-up at 27 months, a total of 35 deaths were recorded – 22 “movers” and 13 “stayers.”

The crude rate of deaths for the 150 “movers” at 27 months – without controlling for any variables – was 14.7%, compared to a rate of 8.7% for the 150 “stayers.” This difference could have occurred by chance 11 times out of a hundred (or $p < .11$). Using a statistical standard of less than five times in a hundred (or $p < .05$), this difference is not statistically significant. A closer examination of the 35 deaths can reveal whether there are any differences between “movers” and “stayers,” when other variables are taken into account.

Searching for the Risks Associated with Deaths by 27 Months

While the evaluation began with a focus on comparing just the rates of deaths of the “movers” and “stayers,” it became apparent that a fuller understanding of mortality risks required detailed analyses of the actual assigned living arrangements and demographic characteristics of the total sample. For example, it is important to note that the “mover” sample consisted of 136 NPDC “movers” chosen randomly from the 488 persons who began leaving NPDC in January, 1997 – plus an oversampling of 14 persons residing in medical living units prior to leaving NPDC (Apgar et al., 1999). These 14 individuals were slightly older than the random sample and deemed to be potentially high-risk medical candidates, but were included in the crude rate comparison reported in the previous section.

By 27 months, the oversampled medical cottage “mover” group had a death rate of 43% compared to a rate of 12% for the random “movers.” Therefore, the type of preclosure institutional cottage, as well as age, has to be conceived as indicators of potential risk.

It is also important to note that 103 “movers” initially relocated to group homes and 7 moved to supervised apartments. The other 40 relocated to nursing homes (n=17) or to other DD Centers/congregate facilities (n=23). The decision to relocate these 40 persons to alternative institutional-type residences were made by DD staff on the basis of their individual assessments of medical, daily care, and social needs. A full analysis of the mortality impact of moving into the community must take into account those who did and did not relocate to community-based residences – like group homes or supervised apartments or to alternative institutional types of facilities. These results are listed in Part C of Table B-2.

A third consideration involves taking into account the stability of placements that occurred after the initial placements. Of the 150 “movers,” a total of 39 had 2 or more placements after their initial placements. Only five of the 150 “stayers” had 2 or more placements during the 27-month follow-up period. The potential risk of multiple placements on “mover” mortality was, therefore, examined. However, it was found not to be important. Of the 22 “mover” deaths, only one person had 2 or more placements. This means that 21 of the 22 “mover” deaths occurred in the initial placement after leaving NPDC. Therefore, the analyses must pay primary attention to initial placements.

A final consideration in comparing death rates involves taking into account specific risk factors that apply to the total sample – to both “movers” and “stayers.” While attempts were made to control for 7 distinct risk factors when matching “stayers” with “movers,” there are others – like prior residence in a medical cottage and presence of autism, cerebral

palsy, or epilepsy/seizure disorders – that were not taken into account. Full analyses of the mortality rates of the “movers” and “stayers” must attempt to identify the maximum number of significant preclosure risk factors associated with those who died during the 27 months of the evaluation. Using these risk factors as control variables, it was possible to assess whether the relative influence of moving away from NPDC into new living arrangements had any unique impact on the rates of deaths by 27 months.

Locating the Critical Risk Variables Associated with Deaths by 27 Months

In order for characteristics to be deemed to be preclosure risk factors significantly associated with the 35 deaths, it is necessary that any risks exist prior to the January, 1997 onset of the relocation from NPDC and exist for both “movers” and “stayers.” In order to identify risk-variable candidates, data were examined that had been uniformly collected for both “movers” and “stayers” in 1994 (Lerman et al., 1995). After examining the 1994 data, distinct 1994 characteristics that were candidates as risk factors for the total sample were identified – based on significant associations with the 35 deaths for the entire 27-month period of time.

Table B-1 lists the 2 major types of risk variables that were deemed to be candidates for multivariate analyses: (1) preclosure 1994 variables that were assessed long before consumers left NPDC and before anyone was aware of who might die between January 1997 and August 2000; and (2) the postclosure initial placement variables of “mover/stayer” status and placement type. Part A lists 12 preclosure 1994 variables. All 12 variables were subjected to a single logistic analysis as possible unique “explanations” for the 35 deaths for the total sample. Ten of the 12 risk variables yielded significant probabilities beyond a chance criteria of five times out of hundred (or $p < .05$). In addition the relative odds of the presence of each of the 10 risk variables indicate that the chances of being dead by 27

months ranged from very high (8.06:1 for those 60 years and above prior to the closure in 1994) to fair (2.42:1 for those living in medical cottages prior to the closure). These initial results indicated that variables with the highest odds ratios were those most likely to be linked to deaths for both “movers” and “stayers.” However, these variables must be analyzed simultaneously in a multivariate logistic analysis, in order to assess whether each variable had independent impacts.

Part B of Table B-1 indicates that of the 3 postclosure initial placement variables, the strongest statistical probabilities and the highest odds ratios were associated with a nursing home placement (6.99:1) and the lowest probability and odds to “mover” status (1.81:1). These risk variables must also be examined simultaneously with the 1994 risk variables.

Table B-1: Risk Variables Associated with Mortality by 27 Months
(for each variable df=1)

<u>A. Preclosure 1994 Variables</u>	<u>Association with Probability of Being Deceased</u>	<u>Odds Ratios for 27-Month Deaths</u>
Age (<60/60+)	.0001	8.06 : 1
Medical Conditions (0/1+)	.0002	7.52 : 1
Mobility (High/Low)	.0001	5.82 : 1
Medical Treatments (0/1+)	.0001	4.22 : 1
Turning/Positioning (No/Yes)	.0005	3.62 : 1
Self-Care (High/Low)	.0018	3.54 : 1
Behavior Towards Self (High/Low)	.003	3.21 : 1
Epilepsy/Seizure Disorder (No/Yes)	.002	3.12 : 1
Lived in Medical Cottage (No/Yes)	.024	2.42 : 1
Behavior Towards Others (High/Low)	.043	2.15 : 1
Multicognition (High/Low)	.649	1.18 : 1
Gender (Female/Male)	.606	0.83 : 1
<u>B. Postclosure Initial Placement Variables</u>		
Community/Institution (Community/Institution)	.02	2.98 : 1
“Mover” Status (“Stayer/Mover”)	.07	1.81 : 1
Nursing Home (No/Yes)	.0001	6.99 : 1

All of the risk variables were assessed simultaneously in several analytic stages in order to retain a maximum number of deaths in the analyses. The first stage used the following preclosure 1994 variables in a logistic regression analysis for the total sample: age;

mobility; self-care skills; presence of epilepsy/seizure disorders; medical conditions; and the report that the person required turning and positioning. This initial multivariate analysis disclosed that the 1994 measures of age, epilepsy/seizure disorders, self-care, and medical conditions were significantly associated with the 35 deaths by 27 months. Using $p < .25$ as a beginning multivariate statistical decision standard as recommended by Hosmer and Lemeshow (1989), the model ruled out the importance of mobility and turning/positioning.

In the second stage of the multivariate analysis, the other 1994 variables were also assessed simultaneously for the total sample. After examining the simultaneous contribution of all of the preclosure variables, the only variables that were deemed statistically significant were the 1994 measures that emerged earlier – namely, age, epilepsy/seizure disorders, self-care, and medical conditions. The third and final stage of the multivariate analysis focused exclusively on these 4 preclosure risk variables, and then examined the inclusion of the postclosure initial placement variables.

Findings from the Best Statistical Model Predicting 35 Deaths

Table B-2 provides the findings of the multivariate statistical analysis that relied on the 4 best preclosure 1994 risk variables to predict the persons who died by the time of the 27-month follow-ups (which began in January, 1997 and ended in August, 2000). The analysis used logistic regression for the total sample in order to assess the relative importance of each risk variable when statistically controlling for the other 3 variables.

Using logistic regression, the model began with the specific data to be explained for the entire sample – that is, both the 35 deaths and the 265 persons still living by 27 months (see Part A of Table B-2). The variables of age, medical conditions, self-care, and the presence of epilepsy/seizure disorders were then entered simultaneously as the best predictor variables. Age in 1994 was categorized as below age 60 (coded 0) or 60 years and

above (coded 1); chronic medical conditions in 1994 as 0 or 1 or more; epilepsy/seizure disorders in 1994 as absent (coded 0) or present (coded 1); and self-care scores in 1994 was coded as below the total sample median (coded 1) or above the median (coded 0).

In Part B, it is clear that each variable was statistically significant -- beyond chance ($p < .05$) or our initial statistical decision standard ($p < .25$) as predictors of the 35 deaths. In addition, the logistic procedure provided information that being 60 years or above in 1994 gave persons a 10.95:1 chance of dying by the times of their 27-month follow-ups compared to those below 60 years of age. The odds ratio for dying when having low self-care in 1994 was not as high -- (2.88:1), the odds ratio for dying when having epilepsy/a seizure disorder in 1994 was 2.86:1, and the odds ratio for 1994 medical conditions was 4.71:1. The odds ratio for each variable (when the other variables are present) refers to the entire combined sample of "movers" and "stayers." Persons assessed in 1994 as having one or more of these designated characteristics would be more likely to be dead at 27 months than those who did not have any of these characteristics. The entire model indicates that there is a strong likelihood that these results could not have occurred by chance, since the probability is one in ten thousand (or $p < .0001$).

While this model to explain the probability of dying appears to be a "good fit," additional analyses are necessary to examine its strength. An important measure of strength is obtained by comparing the characteristics of those living versus those who died. Multiplying the 264 living persons by the 35 who died produces 9,240 comparisons that can be made to see if the 1994 preclosure variables can correctly distinguish between these 2 groups. Using this approach, the model has a concordance rate of 81.7% out of a possible 100%. This finding provides evidence that the model is quite strong.

Part C reports on the results of adding each postclosure variable to the “best 1994 model.” When “mover” status was entered the probability was above the initial decision criterion for being part of the predictive model ($p < .289$) and, thus, was deemed to be statistically unimportant in improving the “best” model. Adding placement type of community/institution was also considered statistically unimportant ($p < .447$). Only nursing home as a placement type added statistically important information to the model and was retained ($p < .001$). Part D provides the information that assesses the five key risk variables simultaneously – the 4 1994 preclosure variables and the postclosure information of nursing home placement.

Part D provides evidence that adding the postclosure variable, initial placement in a nursing home, to the 1994 risk variables improves the explanation of deaths. Nursing home placement remains an important variable, even when simultaneously controlling for the 1994 variables of age, medical conditions, self-care, and epilepsy/seizure disorders. When added to the model, nursing home placement as a predictor of deaths had a probability of .001 and an odds ratio of 7.91:1. In addition, the preclosure model is strengthened since it is able to account for a greater number of observations associated with predicting either the 35 persons who died or the 264 individuals who had not died. The total model had a concordance of 85.0%.

Table B-2: Statistical Model Using 1994 Risk Variables to Predict Deaths at 27 Months, Using the Total Sample

A. Data on Deaths from January, 1997 to 27 Months

1. Number of Deaths within Total Sample = 35
2. Number of Persons Living Remaining in the Total Sample = 265

B. Best 1994 Predictive Risk Variables¹

<u>Preclosure Risk Variables</u>	<u>Significance Levels</u>	<u>Odds Ratios</u>
1. Age is 60 Years or Above	p<.0001	10.95 : 1
2. Medical Conditions (0/1+)	p<.008	4.71 : 1
3. Self-Care (High/Low)	p<.028	2.88 : 1
4. Presence of Epilepsy/Seizure Disorder	p<.018	2.86 : 1

C. Adding Postclosure Variables¹

<u>Placement Types</u>	<u>Significance Levels</u>	<u>Odds Ratios</u>
1. "Mover" Statues ("Stayer/Mover")	p<.289	1.60 : 1
2. Community/Institution (Comm./Inst.)	p<.447	0.72 : 1
3. Nursing Home (No/Yes)	p<.001	7.91 : 1

D. Best 1994 and Postclosure Variables¹

<u>Risk Variables</u>	<u>Significance Levels</u>	<u>Odds Ratios</u>
1. Age	p<.0001	7.88 : 1
2. Medical Conditions	p<.023	3.92 : 1
3. Self-Care	p<.021	3.32 : 1
4. Epilepsy/Seizure Disorder	p<.122	2.08 : 1
5. Nursing Home	p<.001	7.91 : 1

¹ Because of missing data on the medical conditions of one person, the number of persons living was reduced to 264 for the analyses.

Understanding Nursing Home Placements

The evidence from the previous section indicated that placement in a nursing home increased our understanding of which persons were most likely to die by 27 months. Since 17 of the 18 placements in nursing homes consisted of “movers,” it is important to understand what kinds of persons were placed there and their length of postclosure survival compared to other placement types. A close examination of the 17 “movers” placed in nursing homes indicated that 16 had not moved from their initial placement prior to their deaths. Therefore, extra placements were not linked to their deaths. The persons who died in nursing homes had been moved to these initial placements that proved to be quite stable. The frequency of moving were, therefore, not an issue.

Besides placement stability, the length of time that nursing home placements survived **after** their initial placements, compared to all of those who died in another placement type, was examined. The persons placed in a nursing home who died had survived for an average time of 640.4 days, while those who died in all other placements survived an average of 562.4 days. Because this difference could have occurred by chance ($p < .49$), it is clear that placement in a nursing home did **not** hasten the deaths of those placed in this type of residence. The time since placement, therefore, did not appear to be an important consideration in assessing the importance of nursing home placements.

Besides examining placement stability and the time of survival, the types of risks associated with nursing home placement were examined. Logistic analyses were done to predict nursing home placements. These analyses indicated that the following preclosure 1994 risk variables were also significantly associated with a placement in a nursing home: being age 60 years or plus; having low self-care scores; having epilepsy/seizure disorders; and/or having one or more medical conditions. When these preclosure 1994 risk variables

were simultaneously examined with more recent medical information from 3 months postclosure, the following statistically significant variables emerged as the “best model” for explaining nursing home placements:⁵

- 1994 Age (60 years plus) – odds ratio of 15.2:1 ($p < .0001$)
- 1994 Epilepsy/Seizure Disorder – odds ratio of 6.2:1 ($p < .008$)
- 1994 Medical Condition (1+) – odds ratio of 4.2:1 ($p < .10$)
- Post-3 Month Medical Treatment (1+) – odds ratio of 6.6:1 ($p < .004$)

It is evident that persons with a concentration of prior risk conditions, as well as receiving more recent medical treatments at 3 months – like turning/positioning, special feeding, and frequent medical injections – were selected to be placed in nursing homes. If the consumers who were “movers” had remained in DD Centers, they would have had the same types of concentrated risk conditions – age, epilepsy/seizure disorders, one or more 1994 medical conditions, and recent medical treatments. While there is no evidence that placement in nursing homes hastened their deaths, there is strong evidence that multiple preclosure risk variables and more recent medical problems were related to case managers’ recommendations for postclosure placements in nursing homes. “Stayers” with similar risk variables were much less likely to be initially moved to nursing homes. Over the entire 27-month period, a total of 30 “movers” were placed in nursing homes (i.e., 17 initial and 13 as a second, third, fourth, or fifth placements) versus one “stayer.”

The use of nursing homes, rather than institutional medical cottages or hospitals, was much higher for “movers” due to the NPDC closure process. Evidently nursing homes as alternatives are not as widely used by staff of “stayers” even when they are high-risk persons.

⁵ Self-care was not significant in this model.

The Importance of the Epilepsy/Seizure Disorder Variable

As noted in the 3-month report, Closing Old Doors – Opening New Ones (Apgar et al., 1999), “stayers” were matched with “movers” on 7 key variables – age, gender, multicognition, mobility, self-care, and behavior towards others and self. A statistical comparison of “movers” and “stayers” in the 3-month progress report, Closing Old Doors – New Ones, revealed that the matching procedures were successful for the random sample (Apgar et al., 1999). However, it was unknown that the “movers” and “stayers” might differ with respect to epilepsy/seizure disorders. After finding out that epilepsy/seizure disorders constituted a high-risk variable for death and nursing home placement, the “movers/stayers” samples were reexamined on this key variable. Forty-four percent of the “movers” (66 persons) had a seizure disorder, compared to only 27% of “stayers” (41 persons). This difference was statistically significant ($p < .003$). A similar analysis of 1994 medical conditions and postclosure medical treatments (2 other high-risk variables) did not reveal any statistically significant difference between “movers” and “stayers.” This finding was not surprising given that NPDC was the New Jersey Village for Epileptics until 1953.

In order to double check the finding that the “movers” had a significantly higher proportion of persons with epilepsy/seizure disorders than the “stayers” based on 1994 data, we undertook a fuller multivariate reanalysis of the comparison of the initial samples. We reanalyzed the “mover/stayer” comparisons by recoding age, mobility, self-care, and multicognition as dichotomous (high/low) – rather than as continuous. Using being a “mover” as the variable to be explained, we then entered all of the recoded matching variables plus epilepsy/seizure disorders into a multivariate logit analysis. The only variable that was statistically significant was epilepsy/seizure disorder ($p < .0019$). None of the other matching variables was statistically significant. This finding meant that even when all of the

matching variables were statistically controlled, there was a 2.31:1 chance that “movers” were more likely to have persons with an epilepsy/seizure disorder than the “stayers” when the evaluation sample was constructed using 1994 information.

The finding that the “movers” began the evaluation period with a **higher** risk of dying because of more epilepsy/seizure disorders was, of course, not known at the outset of the study. Nor did we know that epilepsy/seizure disorders would be strongly linked to nursing home placements. Rather, these facts emerged as an attempt was made to identify the best risk variables that were associated with deaths for both “movers” and “stayers.”

This study is not alone in finding that epilepsy/seizure disorders constitute a high-risk variable for persons with developmental disabilities. A Danish study found that persons with pervasive developmental disorders who had epilepsy were known to have excess mortality rates (Isager et al., 1999). Additionally, a recent study by McKee and Bodfish (2000) which examined a North Carolina institution for mental retardation found that persons with epilepsy/seizure disorders also died at a higher rate than those without this disability. In their review of the literature, they stated that “the overall mortality in those with epilepsy is reported to be 2 to 3 times greater than that of the general population for age-matched controls” (McKee and Bodfish, 2000, p.229). In addition, McKee and Bodfish found that those with seizure disorders were more likely to have “unexpected deaths,” regardless of age or gender.

Limitations of the Model

While the model that emerged as a result of the detailed analyses of the 27-month data is quite capable of accounting for the 35 deaths far beyond chance, it is important to note the limitations of the model. Additional analyses disclose that the model has a high degree of sensitivity in correctly identifying deaths – since all of those who died had one or

more of the risk variables, but it has a lower degree of selectivity – since many persons who were 60 years of age and above and/or had one or more risk variables did not die during the evaluation period. This finding suggests that those persons who died may have had other special medical conditions that were not measured and linked to a risk variable – whereas, those who did not die and had the risk variables might not have had these other medical conditions. Unfortunately, more precise medical data – that might be capable of distinguishing more precisely those who died – was lacking. Future studies should try and specify other medical conditions that may be linked to increased age, epilepsy/seizure disorders, low self-care, medical conditions, and treatments.

The final model provides evidence that placement in a nursing home had a unique impact on the likelihood of dying, even after controlling for the 4 preclosure 1994 variables. There is also strong evidence that nursing homes are much more likely to receive older persons with more medical conditions and epilepsy/seizure disorders (assessed in 1994), as well as persons receiving more medical treatments after January, 1997. Supplementary data is necessary to determine whether nursing home residents have additional medical conditions which were not measured or whether it is attributes of these settings that contribute to the higher mortality rates found. Additionally, it is also important to note that the model is limited by the amount of time that has elapsed since the NPDC closure. It is quite likely that if the time were extended beyond 27 months, more persons who had the identified risk characteristics would have died. However, it is impossible to determine without additional data. Only a longer follow-up period could assess the continued power of the model to predict deaths.

Summary of Findings

The death rates of “movers” and “stayers” were quite comparable at 27 months, particularly after controlling for critical high-risk variables. A detailed statistical analysis revealed that identifying those persons who were 60 years and above in 1994, and those who had one or more preclosure 1994 medical conditions, low 1994 self-care scores, and epilepsy/seizure disorders in 1994, yielded a strong prediction model for the 35 deaths that occurred by the end of the 27-month follow-ups ($p < .0001$). The model improved when nursing home placements were added.

Statistical analysis revealed that those 60 years and above in 1994 had an odds ratio of over 7.9:1 and those with the other risk variables had significant odd ratios between 2.1:1 and 3.9:1 in predicting their deaths by 27 months. The statistical model that used these key risk variables predicted that other samples with similar risk characteristics could identify those likely to die. Adding “mover/stayer” status or institutional/community residence as variables did not change the explanatory power of the model in predicting those who died by the 27-month follow-up dates.

Detailed analyses also disclosed that “movers” designated to live in nursing homes were much more likely to be older, have epilepsy/seizure disorders, and have other medical conditions in 1994 than any others in the sample. In addition, person chosen for nursing home placements also received more medical treatments postclosure at 3 months. Given these characteristics, the nursing-home “movers” died at a much higher rate than “movers” who went to DD Centers or community homes, or “stayers” who remained in DD Centers.

The evidence from this study clearly indicates that being a “mover” and/or having stability in placement (i.e., number of moves or having different lengths of stay) since postclosure do not account for deaths. Rather, it is the individual and combined risk

variables that best explain who was likely to die in the 27 months since the NPDC closure. The diagram in Table B-3 captures the relationships between the critical variables.

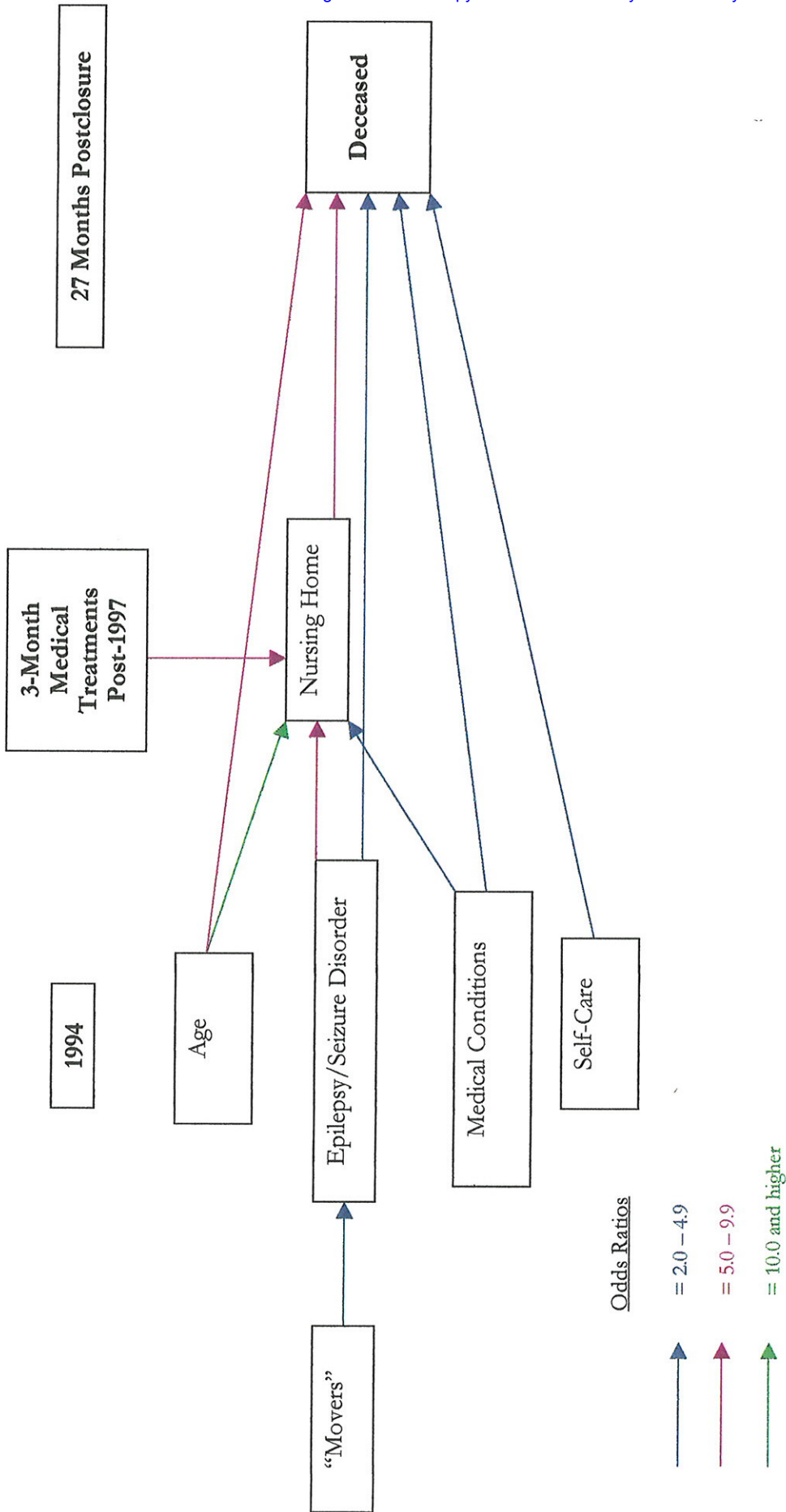
As Table B-3 makes clear, there are 4 preclosure 1994 risk variables plus nursing home placements that best account for who died. In addition, 3 of the 4 1994-risk variables and recent medical treatments (at 3 months) account for initial placements in nursing homes. These risk variables — and not moving to the community per se — are associated with the rate of mortality in this study. The only risk variable depicted in Table B-3 that distinguished “movers” and “stayers” was the presence of epilepsy/seizure disorders. The “mover” sample was much more likely to contain persons with this risk condition that was linked to mortality directly and indirectly (via nursing home placements). This finding was not surprising given that NPDC was the New Jersey Village for Epileptics until 1953.

These findings are important to disseminate within New Jersey and across the country. The mortality issue has become quite important since the first report about mortality rates in California in 1996 (Strauss and Kastner, 1996). Our findings differ sharply from the updated report about California authored by Strauss, Kastner, and Shavelle (1998). New Jersey “movers” were not at a higher risk of dying compared to “stayers” when critical risk variables were considered. These differences between the California and NPDC mortality analyses could be due to the differences in the policies and practices of the state agencies, characteristics of the state populations, or different time periods. However, it is also important to note that this study differs from the California studies in certain important methodological respects: (1) our design is prospective, rather than retrospective; (2) our design is based on the first hand knowledge of DDPI staff about all deaths and not on the consistency of reports of archival records; (3) our measurements of preclosure 1994 risk variables were performed by DDPI staff without knowing of any death outcomes in 1999

and 2000, whereas a coding of retrospective data presented problems in California; (4) our study has a single community exposure time of 27 months for “movers,” rather than the varying starting points and cutoff dates of the California study; and (5) we were able to visually identify the actual living arrangements of both “movers” and “stayers” at each follow-up prior to any deaths, without having to rely on incomplete official records.

While the critical risk variables identified in this study are not capable of being directly prevented by the Division of Developmental Disabilities, awareness of the significance of persons becoming 60 years of age and/or having epilepsy/seizure disorders (at any age), for example, can be used to develop special monitoring procedures to deal with these high-risk groups. Special monitoring and care procedures can be developed in all living arrangements – whether in the community, DD Centers, or nursing homes.

Table B-3: Graphic Model of Odds Ratios of Mortality Risk Variables¹



¹Odds Ratios are based on Part D of Table B-2 and text discussion of nursing homes and epilepsy/seizure disorder variable.

Appendix C

**Table C-1: Internal Reliability of Index to Measure the Lack of Institutionalization
Within the Living Environments of Consumers**

<u>Description of Items</u>	Unduplicated Sites at 3-Month Follow-ups (N=162)		Unduplicated Sites at 15-Month Follow-ups (N=164)		Unduplicated Sites at 27-Month Follow-ups (N=162)	
	(Cronbach alpha = .96)		(Cronbach alpha = .96)		(Cronbach alpha = .96)	
	<u>Factor loadings</u>	<u>Correlation with Total</u>	<u>Factor loadings</u>	<u>Correlation with Total</u>	<u>Factor loadings</u>	<u>Correlation with Total</u>
Handicapped Parking	.96	.95	.83	.79	.86	.83
Dumpster(s)	.91	.87	.88	.85	.84	.80
ID Plaque	.95	.93	.95	.92	.94	.92
Visitor Parking	.86	.83	.76	.71	.78	.73
Homelikeness of Living Room	.91	.89	.91	.89	.93	.91
Homelikeness of Bathroom	.89	.87	.90	.86	.89	.86
Staff Eat with Residents	.78	.72	.87	.83	.84	.79
Personalization of Bedrooms	.60	.54	.60	.54	.72	.67
Lighted Exit Signs	.94	.92	.91	.87	.92	.90
Exposed Fire Sprinklers	.74	.69	.84	.79	.82	.78

Appendix D

Table D-1: Internal Reliability of Index to Measure Freedom from Social Controls Within the Living Environments of Consumers

<u>Description of Items</u>	Unduplicated Sites at 3-Month Follow-ups (N=162)		Unduplicated Sites at 15-Month Follow-ups (N=164)		Unduplicated Sites at 27-Month Follow-ups (N=162)	
	(Cronbach alpha = .68)		(Cronbach alpha = .63)		(Cronbach alpha = .71)	
	<u>Factor loadings</u>	<u>Correlation with Total</u>	<u>Factor loadings</u>	<u>Correlation with Total</u>	<u>Factor loadings</u>	<u>Correlation with Total</u>
Do Not Utilize:						
Room Restriction or Time Out	76	.51	55	.30	64	.40
Point Systems/Demerits	65	.40	69	.39	70	.45
Loss of Privileges	75	.50	79	.51	80	.58
Emergency Manual/ Nonphysical Restraints	72	.46	70	.42	78	.55

Appendix E

Table E-1: Indexes to Measure Consumer Functioning and Behaviors Based on Staff Responses in the North Princeton Information Form

<u>Domain</u>	<u>Number of Items</u>	<u>Range of Actual Scores at 27 Months</u>	<u>Item Examples</u>
(1) Multicognition	40	0-50	Sorts by color, size and shape; reads and writes sentences Uses simple words; speech not understood by stranger Responds to others; considerate; helps others
(2) Self-Care	21	0-60	Uses money; cleans room; makes bed; laundry Feeds self; self-toilet; drinks with cup Uses stove; sets up simple meal; prepares food
(3) Mobility	10	0-24	Ascends/descends stairs; walks independently; sits up by self
(4) Behavior Towards Others	9	0-9	Tantrums/outbursts; makes noises/curses; disrupts; disobeys known directions; bothers/harasses; verbal threats; physical threats; hits; grabs/scratches
(5) Behavior Towards Self	3	0-3	Hits own body; hits own face/head; bangs head

Appendix F

**Table F-1: Staff Attitudes About Community versus Institutional Placements
for Consumer Well-Being**

<u>Description of Items</u>	Unduplicated Staff at 3-Month Follow-ups (N=282) (Cronbach alpha = .91)		Unduplicated Staff at 15-Month Follow-ups (N=210) (Cronbach alpha = .93)		Unduplicated Staff at 27-Month Follow-ups (N=208) (Cronbach alpha = .93)	
	<u>Correlation with Total</u>	<u>Alpha if Deleted</u>	<u>Correlation with Total</u>	<u>Alpha if Deleted</u>	<u>Correlation with Total</u>	<u>Alpha if Deleted</u>
Promoting:						
Community Involvement	.58	.91	.63	.92	.72	.93
Self-Care and Independence	.71	.90	.72	.92	.79	.92
Choices and Freedom to Come and Go	.58	.91	.60	.93	.66	.93
Emotional Well-Being	.79	.90	.81	.91	.85	.92
Friendships and Family Ties	.62	.91	.74	.92	.75	.93
Productivity	.69	.90	.73	.92	.66	.93
Material Well-Being	.73	.90	.75	.92	.82	.92
Personal Safety	.76	.90	.80	.91	.76	.93
Physical Health	.72	.90	.72	.92	.73	.93
Appropriate Behavior	.65	.91	.66	.92	.66	.93

**Table F-2: Family Attitudes About Community versus Institutional Placements
for Consumer Well-Being**

<u>Description of Items</u>	Unduplicated Family Members at 3-Month Follow-ups (N=120) (Cronbach alpha = .96)		Unduplicated Family Members at 15-Month Follow-ups (N=128) (Cronbach alpha = .96)		Unduplicated Family Members at 27-Month Follow-ups (N=125) (Cronbach alpha = .96)	
	<u>Correlation with Total</u>	<u>Alpha if Deleted</u>	<u>Correlation with Total</u>	<u>Alpha if Deleted</u>	<u>Correlation with Total</u>	<u>Alpha if Deleted</u>
Promoting:						
Community Involvement	.81	.95	.83	.95	.85	.96
Self-Care and Independence	.88	.95	.82	.95	.86	.96
Choices and Freedom to Come and Go	.76	.95	.79	.95	.84	.96
Emotional Well-Being	.85	.95	.88	.95	.87	.96
Friendships and Family Ties	.80	.95	.86	.95	.78	.96
Productivity	.80	.95	.76	.95	.80	.96
Material Well-Being	.81	.95	.81	.95	.89	.96
Personal Safety	.76	.95	.81	.95	.82	.96
Physical Health	.83	.95	.84	.95	.87	.96
Appropriate Behavior	.76	.95	.69	.96	.76	.96

Appendix G

Table G-1: Index to Measure Material Well-Being of Consumers at 27 Months

(Cronbach alpha = .73)

<u>Description of Items</u>	<u>Factor loadings</u>	<u>Correlation with Total</u>	<u>Alpha if Deleted</u>
OWNS:			
Television	.66	.47	.69
Radio	.80	.59	.64
Tape Cassette/CD Player	.74	.51	.68
VCR	.65	.44	.70
Watch/Clock	.65	.45	.70

