

THE *JACKSON* LONGITUDINAL STUDY:
FINDINGS OF FIVE YEARS OF RESEARCH

MAY 1998

PREPARED FOR
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Foreword

In 1992, the New Mexico Developmental Disabilities Planning Council (DDPC) commissioned the *Jackson* Longitudinal Study to assess "ongoing consumer satisfaction" among members of the developmentally disabled population who were discharged from state facilities, specifically the Los Lunas Hospital and Training School and the Fort Stanton Hospital, and moving into new living arrangements in the community. The *Jackson* study also sought to continue to discover the changes in the lives of these individuals and their families as they made this major life transition. The DDPC contracted with JRB Associates of Corrales, New Mexico to conduct the research.

This process of "deinstitutionalization" resulted from a Federal District Court ruling in the class action lawsuit, *Jackson vs. Fort Stanton*. The suit was filed in 1987 by the New Mexico Protection and Advocacy System on behalf of a Los Lunas patient and others in a similar situation at Los Lunas and Fort Stanton, New Mexico's two large public intermediate care facilities for the mentally retarded. Judge James A. Parker, in his ruling, found that the state had failed to provide acceptable conditions at both hospitals, and that the state didn't provide the same opportunities for people with severe disabilities to live in the community as it provides for less disabled people.

Judge Parker's 1990 order required the State of New Mexico to (1) develop a plan to correct the constitutional deficiencies found at the hospitals and (2) develop transfer plans to place those individuals who would benefit from care in community settings. It should be noted that in 1997, the state of New Mexico closed its last large public institutional facility housing people with developmental disabilities.

This past year was the final year of research for both the *Jackson* Longitudinal Study and the *Jackson* Family Survey.

The *Jackson* Longitudinal Study

The following is a summary of the overall conclusions of the *Jackson* Longitudinal Study:

More *Jackson* members like living in the community-based residential environments more than liked living in the institutional settings.

- More individuals would prefer to stay at their current residence rather than to move, when posed with the alternatives. Of those who would rather move, most cited wanting to be with their family. Expressing such a preference, however, did not mean that

residents were dissatisfied with their current home, which the researchers regard as an important measurement of consumer satisfaction.

- Field researchers associated with the Study have observed, over time, the absence of barriers to residents' mobility, in addition to improved quality of the physical environment in the community homes.
- Physical access to the community for *Jackson* class members has improved dramatically, which corresponds to the researchers' finding that more individuals either have the adaptive equipment they need or have less need for such equipment in the community environment.
- The majority of staff in both institutions and community homes were found to speak and act respectfully in their relationships with *Jackson* class members, and most staff, regardless of setting, were deemed to be "acceptably knowledgeable" about the health needs of the *Jackson* clients. However, community staffs level of knowledge has decreased over time, likely due to the high rate of turnover among residential staff.
- Choice of day program ("school, training or work") is just as limited in the community setting as was the case in the institutions. There is evidence that a growing minority of residents are dissatisfied that, for the most part, that "someone else" selected their programs.

In the third year report, the researchers hypothesized there was a "quiet revolution of rising expectations" that might explain some contradictions in the *Jackson* data. The hypothesis was posed to explain the finding that while residents were becoming increasingly empowered in the community, some also had expressed increased dissatisfaction with some aspect of their lives. The researchers note in the final report that although this hypothesis was not strongly supported by the final year data, they were reluctant to discard the idea that as residents in the community gained opportunities to make choices in some areas of their lives, they were more likely to express dissatisfaction about areas in which they didn't have these choices.

The *Jackson* Family Survey

In 1993, the DDPC decided to expand the scope of work of the *Jackson* study to include information gathered from parents or from family members who were acting as guardians of *Jackson* clients. This information is compiled in the *Jackson* Family Survey.

The following is a summary of key findings of the *Jackson* Family Survey:

- » Survey respondents report that opportunities for *Jackson* Class members have improved. One exception, however, concerns the matter of recreational activities, which respondents noted that movers are far less likely to participate in physical activities which require planning and more likely to watch television than was the case in the institutional setting.
- Respondents believe that access to special therapies, recreational activities, medical services and transportation has improved since their relatives or wards moved into the community settings.
- The highest mean score given by respondents had to do with the movers' well-being. Overall rankings of welfare and well-being, level of happiness, quality of medical services and the health of relatives have improved in the community environment. The researchers note this global finding is a strong indicator of parental and guardian satisfaction with the outcome of the transition from state institutions to the new homes in the community.
- The researchers conclude the movement of the *Jackson* class members to the community has not had a major impact on the lives of the survey respondents and their families, indicating the adaptability of parents, guardians, and their families to the new living arrangements. They suggest this means that while families are inherently concerned with their *Jackson* class member, they are able to continue in their day-to-day routines just as other families do when a member relocates or changes residences.
- Mean score measures of *Jackson* class family members indicate parents and guardians' concern not only about the general welfare and well-being of their daughter, son, or ward, but also about who is going to care for their relatives when they are no longer capable of doing so.
- The researchers report an overall perception of optimism and approval, despite reports of instances in which survey respondents report dissatisfaction with specific situations. Family members and guardians indicate general satisfaction regarding the improvements in the quality of life and living environment of their son, daughter, or ward.

While both the *Jackson* Longitudinal Study and the *Jackson* Family Survey indicate high levels of satisfaction, the perceptions of satisfaction are not universal. This fact suggests the importance of continuous monitoring of the various quality of life issues related to the transfer from the institutional to the community settings to ensure that the needs of all involved are met.

PREFACE AND ACKNOWLEDGEMENTS

Who we are and what this report is about

This report, the *Jackson Longitudinal Study: Findings of Five Years of Research*, is the result of 459 visits with 98 members of the *Jackson Class* conducted over a period of nearly five years at Los Lunas and Fort Stanton hospitals and in communities throughout New Mexico. JRB Associates' team of professional research associates, Cathleen Cain, David Pieters and Nancy Pieters, used interview and observation instruments developed by John Bretting, Cathleen Cain and John Brown. We were assisted by a "JLS Working Group" consisting of family members, service providers and *Jackson* client advocates, which met three times during the first year.

Comparison with earlier reports in this series.

This report follows the format of earlier reports, providing running notes in the margin that summarize the key points of most paragraphs. We have tried to improve on that format by presenting our findings using a variety of charts that depict the data graphically, using percentages. The original copy of this report uses color in the charts to make interpretation of the data easier. (For those interested, the data tables can be found at **Appendix D.**)

How the report is organized.

Chapter 1 discusses the overall purpose and approach we took in constructing a "longitudinal" study to ascertain changes in the "Quality of Life" of *Jackson Class* members who moved from institutional into community living arrangements. **Chapter 2** describes our methodology and implementation considerations in greater detail. **Chapter 3**, contains two major sections: *Part A* discusses the demographics of the *Jackson* population and our samples. *Part B*, the heart of the report, reports our findings based on the data. **Chapter 4** presents six case studies prepared by our field research associates that illustrate our findings. **Chapter 5** draws conclusions from the findings. It can be read as an **executive summary** of the entire report. Additional special analyses can be found in **Appendix E.**

Why this report should be useful, and to whom.

This report is a tool for policy makers, program managers, and *Jackson Class* members and their relatives. After five years building our time-series data, our field researchers have captured a valid and reliable composite of the *Jackson Class* community residents' Quality of Life and associated levels of "consumer satisfaction." With five points of post-placement data we have been able to construct a picture of *Jackson class* members' lives as they have evolved in the community.

Acknowledgements and thanks.

JRB Associates appreciates the cooperation of residential providers, case managers and especially the staff and members of the New Mexico Developmental Disabilities Planning Council, without whom we could not have conducted this study. We hope we have provided in return a product that will be valuable to all parties concerned with protecting the rights and improving the Quality of Life of persons with developmental disabilities.

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CHAPTER 1

PURPOSE AND APPROACH

BACKGROUND

The JLS is designed to assess the results of community placement for Jackson Class members.

The community placement process stemmed from the Jackson lawsuit.

Initially, 141 individuals were recommended for community placement.

In the first year "pre-move" baseline data were gathered.

This is the fifth and final report on the findings of five years of research for The *Jackson* Longitudinal Study (JLS). The study was commissioned by the New Mexico Developmental Disabilities Planning Council (DDPC) in 1992. It is meant to assess "ongoing consumer satisfaction" among people with developmental disabilities who were being discharged from state-operated congregate housing and care facilities (Fort Stanton Hospital and Training School and Los Lunas Hospital and Training School), and who were moving into new community living arrangements throughout New Mexico.

This "deinstitutionalization" process resulted from a federal district court ruling in a class action lawsuit known as *Jackson vs. Fort Stanton* (or simply "*Jackson*"). In 1987, the New Mexico Protection and Advocacy System filed a class action lawsuit on behalf of a Los Lunas patient and others in a similar situation at Fort Stanton and Los Lunas hospitals. In his ruling, Judge James A. Parker found that the state had failed to provide acceptable conditions at the hospitals, and that the state didn't provide the same opportunities for individuals with severe disabilities to live in the community as it provides for less disabled people.

In December 1990, Judge Parker issued an order which required the State of New Mexico to:

- (1) develop a plan to correct the constitutional deficiencies found at Los Lunas and Fort Stanton Hospitals, and
- (2) develop transfer plans to place in community settings those individuals who were found not to require institutional care.

At the time our study began in January 1993, the two facilities had recommended 141 residents for community placement. This group, which included most of the early movers, constituted the population from which we drew the JLS samples. (Since then another 150 or so individuals were added to the list. Some of them left the institutions before a few who were in the first group.) Initially, it was thought that most *Jackson* class members would be placed within the first year, but the timetable for moving was slowed for a variety of reasons.

During Year 1 (*see The Jackson Longitudinal Study: Year 1 Report*¹) the study established baseline data about *Jackson* class members' levels of satisfaction while they were still residents in the institutions.

This was done through structured interview and observation visits with a representative sample of the population. Then, using the same instruments (which were administered approximately yearly for five years to a larger group of *Jackson* clients at their homes in the community), the process of measuring changes in their quality of life along several dimensions was begun.

In Year 2 the "pre-move" sample was expanded to 60 persons (from 32), and data were collected from additional individuals at two points following their transition to living in the community (four-to-six months and one year). The second year report began to chart trends. By the end of Year 3 there were data on a sufficient number of individuals at four points in time so that patterns of "evolutionary" change were becoming clear.

Table 1.1 below shows the schedule of interview-observation visits the JLS team made each year since inception of the project through the final visits in Year 5. The greater numbers of visits during Years 2 and 3 follow from the fact that T₁ and T₂ visits were often made to the same individual during a single project year. After T₂, visits were scheduled one year apart near the individual's anniversary date in the community.

*We now have data
from five points in time
over four years.*

Table 1.1

Interviews Completed						
Visit	Year 1	Year 2	Year 3	Year 4	Year 5	Total for 5 years
T ₀	32	28				60
T ₁	22	51	16	1		90
T ₂		30	59	7		96
T ₃			35	52	6	93
T ₄				35	49	84
T ₅					36	36
All visits	54	109	110	95	91	459

MEASURING OUTCOMES: WHAT IS "QUALITY OF LIFE"?

Quality of Life must be viewed as much as possible from the perspective of the Jackson Class members.

The JLS was intended to track over time the outcomes of the state's deinstitutionalization strategy in terms of *ongoing consumer satisfaction*. JRB Associates has understood measuring satisfaction to mean that the research should be undertaken principally from the perspectives of the Jackson Class members themselves. The success of the deinstitutionalization policy mandated by the court should, in other words, be viewed in terms of its effects on the quality of their

*Consumer satisfaction
is hard to measure in
many cases.*

lives as *they* (rather than their families or professionals in the field) experience them.

The Request for Proposals that commissioned this study used the terms "consumer satisfaction" and "Quality of Life" (QoL) interchangeably. During the first year of the project, we learned that it is useful to make a distinction between them. These terms express related, but "nested" concepts.

Consumer satisfaction is self-explanatory. It can be ascertained directly from some clients, but is not easy to measure for others. We have not found a way to do so reliably for clients with little or no expressive communication. Earlier longitudinal studies of deinstitutionalization "solved" this problem by talking only to people who have expressive communication abilities.² As described below, one source of information we used was to interview a "proxy" for such a client in the client's presence. People who know a client well may be able through observing subtle changes to discern that person's preferences, attitude, or "mood." However, that cannot be used as the *sole* basis for understanding his or her state of mind or level of well being. Nor can it be very much help in understanding *what* about the client's situation or environment she or he finds to be or not to be "satisfying."

*"Quality of Life" is a
value-laden concept,
which we measure only
indirectly.*

Quality of Life, (QoL) on the other hand, is necessarily a value-laden and subjective concept. It is also difficult to measure directly, for some of the same reasons noted above. But if it is possible to specify a set of *values* denoted by the QoL concept, then it should be possible to observe conditions and situations which indicate the degree to which such values are put into practice and realized. Goode³ describes QoL as "social ecology," concerned with the pattern of interactions between a person and others within that person's environment, in which the reactions of others caused by the subject's own presence and behavior become relevant to his or her QoL. This is a useful perspective, which JRB Associates adopted in developing our "multimethod" approach to assessing Quality of Life *for Jackson* class members.

PROBLEMS IN DETERMINING QUALITY OF LIFE

*The perspective of the
clients is a key, but not
the only, basis for
measurement.*

When people are able to express whether they are satisfied with their living environment and their interactions with and within it, QoL may be substantially the same as "consumer satisfaction." But when they are not able to do so, or when we have reason to suspect that they may not be doing so, the use of other, indirect measures is indicated. Early on in the project, it became evident that our task was to measure changes in the *Jackson* clients' QoL, from their perspectives as much as possible, but that we must not ignore evidence supplied

by others close to the clients or which could be gleaned from observation. Consequently, we determined to use a multimethod approach that included both in-person interviews and structured observations.

JRB Associates was also guided in designing this study by the *The Quality of Life* principles outlined in the Final Report of the DDPC's Quality Assurance Task Force.⁴ That report set forth standards of excellence in supporting people with developmental disabilities, specifically including *Jackson* class members. Its undergirding premise was that quality assurance systems must seek to "include the perspective of people with developmental disabilities in design and process."

Besides raising a number of important issues for design of the JLS, the task force report provided the study team with a list of factors it deemed relevant in measuring QoL. The dimensions of quality suggested by the Quality Assurance Task Force report included:

- safety
- quality of interpersonal relationships
- inclusion within their environment (home)
- having socially-valued roles
- being able to make meaningful choices
- access to adequate information for making choices
- quality of interactions with service providers

JRB Associates used these dimensions of QoL in constructing our instruments. Implicit in our choices was an effort to develop measures capable of tapping into each of these important dimensions.

GENERAL APPROACH TO ASCERTAINING QUALITY OF LIFE

The DDPC clearly intended that the clients' perceptions regarding the quality of their lives to constitute the core of the inquiry. The request for proposals specified that to the extent possible the researchers would seek information along all of these dimensions from the *Jackson* class members themselves.

After initial consultation we formed a JLS Working Group to advise us on the research design.

However, the research team recognized that it would be difficult to ascertain some clients' perceptions *only* through direct interviews with them. Immediately after the project was launched, the JRB Associates team consulted with officials in the Department of Health's Developmental Disabilities Division (DDD) and with a *Jackson* Longitudinal Study Working Group formed to advise the project team. The JLS Working Group consisted of representatives of the DDD and its *Jackson* Office, The Arc of New Mexico, Protection and Advocacy, the Intervenor, the NM case management system, a

DDPC Council member, and the community of persons with developmental disabilities.

Working Group With the JLS Working Group's input, it was decided to supplement the *contributions included:* interview instrument in two ways:

*identifying the client's
"Helper" as a
resource,*

and

*adding an observation
instrument to
supplement the
interviews.*

- (1) Within the institutions, each *Jackson* client had been assigned a "helper," a person who had typically known the individual for a fairly long time, and with whom the individual feels comfortable. In situations where the individual had difficulty in communicating with the interviewer, or in responding to particular items, the helper would be asked to act as a "proxy" for the client in answering interview questions.
- (2) The field data collection effort would include the use of two instruments. The originally planned interview would be conducted with the client (with helper/surrogate participation as noted above). A separate observation instrument, with accompanying "guidelines" was developed to provide additional contextual data about the client's living environment along the QoL dimensions cited above. The observation instrument (which also included specific questions for residence staff) would also help validate the interview data, particularly in cases where the client was unable to communicate with the interviewer.

Our use of both these approaches was supported by the JLS Working Group, and is consistent with recent research findings that suggest that "quality of care" criteria can reasonably be used as "proxy" measures for a person's QoL when information cannot be obtained directly from that person.

LONGITUDINAL MEASUREMENT AND OUR OBJECTIVES FOR YEAR 5

The DDPC asked for a *longitudinal* study of the *Jackson* class members' QoL. What this means is first that the study followed changes in *"Longitudinal" study* defined - a series of clients' lives over a period of time—in this case five years. More specifically, *"snapshots" taken over time.* it means that the researchers asked the same questions and made observations of the same aspects of clients' living environments each year in order to determine possible changes. This can be thought of as being like taking several "snapshots" of the *Jackson* clients in their living environments, and then carefully analyzing the resulting pictures to discover whether and to what extent their lives have changed over time.

During the final year, the JLS research team planned to accomplish four principal objectives. Table 1.2 below summarizes the objectives and the project's performance on each of them.

Table 1.2 Year 5 objectives and performance

OBJECTIVES AND TARGETS	RESULTS ACHIEVED
Survey the remainder of the T ₃ population sample.	A potential for 7 additional visits existed. Field research associates were able to conduct six of the scheduled visits, achieving a total T ₃ cohort of 93.
Survey the full T ₄ sample. We expected our T ₄ database to contain interview/observation visit data on 89 clients by the end of Year 4.	By the end of the JLS Year 5 visit cycle, interview/observation visits were completed with 49 additional movers, bringing the T ₄ total to 84.
Gather T ₅ data on the earliest movers. All of them would have been living in the community for at least four years by September 1997.	The interview/observation visit process continued through October 1997. We were able to gather T ₅ data on 36 individuals. Although this T ₅ sample is smaller than we would prefer, to the extent it confirms or deviates from earlier trends, it can help us validate or cause us to question the reliability of our time-series observations. These are the earliest movers whose quality of life the JLS has tracked since they first moved to the community at least four years ago.
Develop new case studies on representative movers, to enhance the qualitative dimension added to earlier reports. The stories of these individuals provide illustrations of significant findings.	After omitting the case studies in Year 4, in order to focus on more complex data analysis, we developed six new case histories for the final report. These stories enrich our findings by providing a context for understanding the human meaning of the data.

CONSTRAINTS AFFECTING THE STUDY

Constraints affecting the research were built into the Jackson transition process.

It is important to remember that the JLS was subject to the constraints inherent in the *Jackson* placement and transition processes, which affected *when* we could schedule our interview-observation visits and *whom* we were able to visit (the total number as well as specific individuals). Although these issues became less immediately important over time, it is useful to recall them in order to appreciate the circumstances under which the study took place.

*Agency and institution
staff were helpful but
initially suspicious.*

*Transition planning
was a lengthy process.*

*Our samples' size was
limited by problems in
getting guardian
permission*

*Implications for our
study: between 90 and
96 individuals were
visited each year over
the five years.*

- First, the controversy that led to the *Jackson* litigation and the requirements of the court-ordered deinstitutionalization process affected the behavior of officials within the Department of Health and at the institutions with regard to the study. State employees were usually helpful and often critical in providing data and arranging interviews at Los Lunas and Fort Stanton. But the perceived need to avoid legal risks and "work to rule" did account for substantial delays in setting up and accomplishing the baseline ("To") interview/observation visits. That necessitated our shifting some of these visits to the second year, and had cascading effects on the rest of our schedule.
- Second, the "Individual Transition Planning" process mandated by the court order involved twenty-six separate activities (and over 60 "steps"), following a specified time line which at a minimum required 288 days from initiation of the process until the discharge of the client.⁵ Should there be problems in assuring day or residential provider support, finding a home, or a dispute between the client or his/her representatives and the State or case management agency, the process could easily be delayed beyond a year. The JLS research design called for conducting interview-/observation visits with movers only after they had lived in the community for at least four months.
- A third constraint involved the need to obtain parent or legal guardian permission for individuals to participate in the study. During Year 1 and for the first six months of Year 2, JRB Associates made several attempts to contact guardians, where initial letters failed to elicit a response. One of these efforts involved trying to secure the cooperation of case management agencies in providing access to guardians, explaining the study, and assuring the guardians of our objectivity with respect to *Jackson*. In most cases, the case management agencies and individual case managers responded helpfully. A year and a half into our work it became necessary to establish a fixed number of individuals whom we would follow for the remainder of the study, and not to expend additional effort on increasing the size of the sample.

These constraints affected procedural decisions, and raised several implications for the future course of the study. In summary, the following should be noted:

- (1) The "pretest" (pre-moving) sample (T_0) was fixed at $n=60$, the number interviewed in Years 1 and 2.
- (2) The *Jackson* Longitudinal Study included only the 141 "original" members of the *Jackson* class, and not those

subsequently added to the class.

- (3) As we began our field research, 135 individuals within the original group were alive and residing in New Mexico. Of this number, we had guardian permission (or the permission of the individuals themselves in a few cases where it was determined that they were able to give informed consent) to include 96 of them in the JLS sample. (One individual in the original cohort who moved into the community in late 1995 was added to the study in Year 4.) Four of the sample members have subsequently died.
- (4) The number of different individuals we were able to interview and observe in the community *at least once* is 96.

NOTES TO CHAPTER 1

- ¹ Brown, John R. with John G. Bretting (1994, February). *The Jackson Longitudinal Study Year 1 Report*. Corrales, NM: JRB Associates [Santa Fe: New Mexico Developmental Disabilities Planning Council]. This introduction and the next chapter include only a summary of the historical information found in Chapters 1 and 2 of that report. For fuller details *see* the *Year 1 Report*.
- ¹ Conroy, J.W. & Bradley, V.J. (1985). *The Pennhurst Longitudinal Study: A report of five years of research and analysis*. Philadelphia: Temple University Developmental Disabilities Research Center. Boston: Human Services Research Institute.
- ³ Goode, David A. (1990). "Thinking About and Discussing Quality of Life." In Schalock, R.L. and Begab, Michael J., ed. (1990). *Quality of Life: perspectives and issues*. Washington: American Association on Mental Retardation.
- ⁴ New Mexico Developmental Disabilities Planning Council Quality Assurance Task Force (1992, August 31). "Quality Assurance: Framework for Excellence" (unpublished MS). Santa Fe: State of New Mexico. Transition process requirements are documented in Rucker, L. et al. (1991). *The Jackson Management Manual*. Santa Fe: State of New Mexico, Health and Human Services Department.