

LIFE AFTER JOHNSTONE: IMPACTS ON CONSUMER COMPETENCIES, BEHAVIORS, AND QUALITY OF LIFE

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I. EXECUTIVE SUMMARY

Introduction

During 1996/1997, the Developmental Disabilities (DD) Planning Institute obtained information on 155 former Johnstone DD Center residents, over four years after they had left the facility in 1992. Information was collected on a variety of quality of life issues by interviewing consumers, staff, and family members/guardians, and by performing on-site observation of the current living arrangements and social contexts of the residences where consumers lived. The DD Planning Institute's evaluation is a follow-up of earlier evaluations conducted by Conroy and Feinstein in 1991 and 1993.

Sample Comparisons

The total 1996/1997 sample was representative of the 1991 and 1993 Conroy and Feinstein samples with respect to the following characteristics: initial age, gender, mental retardation level, cognitive and communication competencies, physical mobility, social-emotional functioning, self-care capabilities, and challenging behaviors. However, there was clear evidence that those who were placed in the community directly from Johnstone were quite different from those who were moved to other state institutions, and lived there exclusively since 1992. Consistent community residents, as well as those who moved back and forth between institutional and community settings between 1992 and 1996/1997, were significantly different from consistent institutional dwellers. More of those who lived in the community were classified, in 1991, as having higher scores on cognitive competencies, social-emotional functioning, and self-care skills, and had lower scores on challenging behaviors.

Sources of Information

Face-to-face interviews were conducted with 109 different staff/caregivers in 92 distinct sites about the following quality of life domains: (1) material well-being (e.g., food, clothing, shelter); (2) health (e.g., not sick, well); (3) productivity (e.g., work, job, activity); (4) intimacy (e.g., friends, staff, family); (5) safety (e.g., freedom from harm, possession privacy and safety); (6) community integration (e.g., participation, place in community); (7) emotional well-being (e.g., not anxious, sad, distressed); and (8) autonomy (e.g., choice, freedom to come and go). Interviews were also conducted with 115 family members/guardians about similar quality of life issues.

Out of 155 consumers, 94 were able to respond to questions about what made them happy and unhappy using response formats of spoken "words" and "smiling/sad faces." Numerous questions were asked twice in order to determine whether responses were consistent. A total of 57 consumers were deemed reliable, and were capable of responding to the same questions as staff/caregivers and family members/guardians within the eight quality of life domains.

Consumers and family members/guardians were also asked about their evaluations of life at Johnstone, including items about their desire to live there or "somewhere else." **Remembering Johnstone**

Family members/guardians and consumers had different recollections about Johnstone and its closure. While both groups tended to provide satisfactory ratings of rules, food, safety, staff, and friends at Johnstone, the ratings of satisfaction by family members/guardians were consistently higher than consumer recollections.

Consumers were also more likely to recall that they wanted to leave Johnstone at the time of closure - by a margin of 65 to 34 percent. When asked about returning to Johnstone in 1996/1997, consumers were clearly in favor of living "somewhere else" - 71 percent of the institutional residents and 100 percent of the community residents chose "somewhere else." By 1996/1997, a majority of parents also chose "somewhere else" over Johnstone - 58 percent of institutional residents' family members and 81 percent of community residents' family members.

Changes in Consumer Competencies and Challenging Behaviors

Analyses of residential patterns since 1991 revealed that the sample of 155 consumers could be divided into three distinct groups: (1) those who consistently lived in the community since leaving Johnstone (N = 44); (2) those who consistently resided in institutional placements since leaving Johnstone (N = 80); and (3) persons who had moved between community residences and institutions since that time (N =31). Both consistent community and consistent institutional residents showed significant overall improvement in their multi-cognition, including their social-emotional functioning and • domestic self-care skills. There were no significant changes in the challenging behavior scores of consistent community and institutional dwellers. In contrast, consumers with mixed residential patterns had overall increased challenging behavior scores, while displaying no overall improvements in their multi-cognition. Use of **Psychotropic**

Medication

Two types of psychotropic medication utilization patterns were analyzed: changes in behavior control drugs and anti-depressant medications. Behavior control medications

were more likely to be used - regardless of current residential setting type or placement patterns for persons with high physical mobility and diagnosed mental illness.

Different factors, or variables, helped to explain the current prevalence of anti-depressant usage among former Johnstone residents: anti-depressant use was much higher if consumers were women, lived in the community consistently or in a mixed pattern, and, to a lesser degree, if there was a diagnosis of mental illness. **Productivity Changes**

All former Johnstone residents were clearly earning more in 1996/97, while working the same or fewer hours, than they had prior to the closure. Former residents who had exclusively lived in the community since relocating, however, earned \$31.88 more per week for the same amount of work, while persons who lived exclusively in institutions since the closure earned \$10.07 more per week while working 6.55 fewer hours weekly than they had at Johnstone. The overall gains in earnings by consistent community residents were significantly higher than those made by consistent institutional residents. Given that persons with exclusive community living experiences had higher multi-cognitive competencies from the outset than those who had been exclusively insitutionalized since the closure, these findings were not surprising. **Assessing Quality of Life**

Statistical analyses of the staff/caregivers responses to quality of life questions provided evidence that the following areas of living - or domains - could be measured reliably with specific items referring to: (1) material well-being; (2) health; (3) productivity; (4) intimacy; (5) community integration; (6) emotional well-being; and (7) autonomy. The safety domain failed to yield a reliable single measure. Therefore,

discrete items were used to assess satisfaction with consumers' personal and possession safety.

The same quality of life questions also proved to be reliable measures of life quality as assessed by consumers. A comparison of quality of life scores between consumers and their staff/caregivers for each domain found no significant differences, except for the rating of personal safety. Staff/caregivers rated the personal safety of consumers to be higher than the ratings given by consumers themselves. Because of the similarities in ratings between reliable consumers and their staff/caregiver respondents for all domains - except personal safety - the staff/caregiver assessments for the 98 consumers unable to provide reliable ratings were used to assess the life quality of these former Johnstone residents.

With the exception of family intimacy and autonomy measures (not asked of family members), the quality of life items were also found to form reliable measures for use with family members/guardians. Comparisons of scores between staff/caregivers and family members/guardians disclosed significant differences only on the current safety and health of consumers. Family members/guardians were more pessimistic in these areas than were staff/caregivers. Comparisons of family member/guardian and consumer scores revealed a difference only with regard to the safety of consumers' possessions, with consumers feeling a greater sense of satisfaction in this area than their family members/guardians did. On all other measures of life quality, consumers and family member/guardian scores were comparable.

Perspectives on Quality Of Life And Current Dwellings Examined by Residential Setting Type

Besides their views about living at Johnstone or somewhere else, consumers and family members/guardians were systematically compared on a variety of quality of life indicators, while controlling for their current residential setting type. The responses of both groups were also compared to the judgments of staff/caregivers. Comparisons of the responses of the three groups revealed agreement on four indicators of current quality of life:

- (1) Community residents were happier than institutional residents about where they now lived.
- (2) Community residents were more likely than institutional residents to want to stay in their current residences as opposed to moving elsewhere.
- (3) Community residents reported higher material well-being than institutional residents.
- (4) Community residents were more likely than institutional residents to participate in community activities.

Besides agreeing on those four indicators, consumers and staff/caregivers also agreed quite strongly about two more quality of life indicators:

- (5) Community residents were more likely than institutional residents to have a higher degree of autonomy in daily living activities.
- (6) Community residents were more likely than institutional residents to have a higher degree of global autonomy.

These findings indicated with great confidence that community living was associated with a higher quality of life on 6 of the 12 indicators measured. Findings in the other domains were either non-significant or inconclusive due to lack of consensus across the sample groups.

Influences on Quality of Life

To assess whether living in the community was indeed associated with higher quality of life, expanded statistical analyses were undertaken. These analyses included testing whether the following variables were more powerful than current community living in explaining quality of life: age, gender, physical mobility, multi-cognitive competencies, challenging behaviors, lack of social control in consumers' residential environments, and training in daily living skills. Living in residences with few institutional features was clearly the most powerful factor explaining quality of life in the areas of community integration, daily autonomy and material well-being. Living in environments with few institutional features also influenced quality of life - to a more limited extent - in the areas of possession safety and personal safety.

Other variables such as gender, multi-cognition, the extent of challenging behaviors, and/or skills training were more strongly associated with quality of life in the domains of emotional well-being, health, global autonomy, and social intimacy. These variables also had some impact on daily autonomy and material well-being, though they were less influential than the lack of institutionalization in consumers' current residences.

Summary and Conclusions

Living in community residences at the time of the survey had a substantial impact on the quality of life of former Johnstone residents. Quality of life, as characterized by community integration and daily autonomy, was strongly impacted by current residence in less institutionalized environments, while material well-being was moderately affected by this variable. Perceived personal and possession safety were also slightly, but significantly, impacted by current residence in less institutionalized environments.

While the closure of Johnstone may not have impacted on the quality of life of its former residents in all relevant domains, and may have had little or no impact on increasing the adaptive living skills of consumers, it was clearly associated with three distinctive quality of life gains for those currently living in the community - increased community integration, daily autonomy, and material well-being. The only major risk associated with community living appeared to be the increased use of anti-depressant medication over and above the existence of psychiatric diagnoses.

In addition to improvements in quality of life, former Johnstone residents currently residing in the community were more satisfied about living "somewhere else" (rather than at Johnstone) than those placed in institutions. Community residents were also far happier about life within their current homes than those remaining in developmental centers. Community residents were more likely than institutional residents to want to remain in their current homes as opposed to moving elsewhere. Finally, the family members/guardians of current community residents were also more satisfied about consumers living "somewhere else" (rather than at Johnstone), happier about their current homes, and wanted consumers to remain in their current residential settings as opposed to moving elsewhere.

This study's findings have implications for all persons with developmental disabilities in the areas of policy development and service delivery. Recommendations based on these findings include the:

- (1) reduction of institutional features within consumer living environments;
- (2) establishment of policy goals which accommodate consumer choices;
- (3) monitoring of antidepressant medication usage within community settings; and

- (4) implementation of outcome-based quality assurance systems to measure and monitor consumer functioning and well-being.