
National Core Indicators California Mover Longitudinal Study Report

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Year One



UC DAVIS
EXTENSION
CENTER FOR HUMAN SERVICES

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Message from the California Department of Developmental Services

Mission: The Department of Developmental Services (DDS) is committed to providing leadership that results in quality services to the people of California and assures the opportunity for individuals with developmental disabilities to exercise their right to make choices.

DDS is several years into a dedicated quality improvement effort to ensure the appropriate transition of individuals with I/DD who resided in a developmental center (DC) to community living and to improve services and supports to all individuals with I/DD across California. The goal of this quality improvement effort is to ensure we are supporting our mission.

To achieve that goal, DDS participates in the National Core Indicators (NCI), a nationally validated, benchmarked, and reliable quality assurance instrument that assesses individual and family satisfaction and the provision of services to support personal outcomes, in accordance with Welfare and Institutions Code (WIC), Section 4571. DDS also conducts the Mover Longitudinal Study (MLS), using the NCI surveys with individuals who moved from developmental centers to the community after January 1, 2016 to provide information about the quality of life, satisfaction with services, the degree to which individuals achieve their goals pursuant to Welfare and Institutions Code Section 4474.12.

This report contains preliminary findings from the first year of the MLS. Subsequent reports include expanded data and increased participation. Interviews to collect this data were conducted by the State Council on Developmental Disabilities between January 2016 and December 2016 via face to face or proxy interviews with 100 adults. This is an important effort because California can use the MLS reports to monitor changes in the system and to guide strategic planning and quality improvement activities as a result of DC closures.

Acknowledgements

This report is possible because of the 100 individuals who agreed to share about their experiences after moving from a California developmental center to the community. Special acknowledgment goes to their families, friends, and staff members who provided support and participated in the survey process.

List of Selected Abbreviations Used in the Report

ACS—Adult Consumer Survey

ASD—Autism Spectrum Disorder

CA-ODESA—California Online Data Entry Survey Application

CCF—Community Care Facility

CP—Cerebral Palsy

DC—Developmental Center

DD—Developmental Disability

DDS—Department of Developmental Services

FHA—Family Home Agency

HSRI—Human Services Research Institute

ICF—Intermediate Care Facility

ID—Intellectual Disability

IDT—Interdisciplinary Team

ILS/SLS—Independent Living Skills/Supported Living Services

IPP—Individual Program Plan

MLS—Mover Longitudinal Study

N<30—Sample size is below 30

NASDDDS—National Association of State Directors of Developmental Disability Services

NCI—National Core Indicators

SCDD—State Council on Developmental Disabilities

SNF—Skilled Nursing Facility

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Executive Summary

The Mover Longitudinal Study (MLS) is a continuous quality assessment and improvement initiative being carried out by the California Department of Developmental Services (DDS) intended to examine change over time in individuals who moved from a California Developmental Center (DC) to the community across four time points post-move. This MLS Year One Report highlights findings on 100 individuals' experiences during the first three to six months of the transition to the community. These findings focus on the following aspects of living in the community: health, medications, community inclusion, choices, and work.

The results presented in this Year One Report identify early outcomes relevant to understanding the experiences of these 100 individuals. It is important to note that the pattern of findings in this report may have changed as additional data has been collected. Findings from this report were used by the Department of Developmental Services (DDS) and stakeholders to inform service delivery throughout the closure process.

Methodology

The Adult Consumer Survey (ACS) and the Family Guardian Survey (FGS) are tools developed for the National Core Indicator (NCI) project, by the Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disability Services (NASDDDS) and are used in the MLS to evaluate the quality of services provided to adults with developmental disabilities. Data was collected at four time points: three months, six months, one year, and two years from the date an individual moved from a DC to the community. Individuals who chose to participate (hereafter referred to as movers) completed a face-to-face interview (ACS) at each time point. Input from their family members was requested by a mailed survey (FGS) at each time point.

Several additions were made to the standard versions of the ACS and FGS to capture the experience of movers. First, questions were added to both surveys at the three-month time point to assess movers' and family members' experiences during the

transition planning process prior to the move to the community. Second, a set of user-friendly questions were added to the ACS as a pilot to provide movers with greater opportunity to communicate their experiences and potentially increase response rates.

Data Collection

For this report, data was collected and analyzed for 100 movers at three months post-move and 76 participants at six months post-move. Study enrollment continued as individuals moved from developmental centers. Data will continue to be collected at all four time points until all individuals have been living out in the community for two years.

Families responded to the FGS survey about 25 percent of the time.

Data Analysis

Analyses conducted for this report include both single time point and longitudinal (multiple time points) approaches. Single time point data are presented for three-month background information as percentages and averages. These analyses provide a general picture of demographics, health, and work at three months post-move.

Longitudinal data (change between three-month and six-month data) are presented in percentages. These analyses give a glimpse of potential successes or concerns in the transition process for outcomes such as community inclusion, choices, and health.

Highlights of selected outcomes are included in the summary section

Summary of Year One Findings

Overall, MLS responses showed limited changes in responses between three months and six months after moving from a DC. Movers were generally characterized by high levels of ID and support needs. Most indicated they had received health screenings, had a physician, and demonstrated positive change in perceived health status.

Community inclusion was found to be largely stable across this time period, and movers' level of choice was generally high for most outcomes.

Demographics

Movers in the MLS were majority male (62 percent male vs. 38 percent female), primarily White (74 percent), and nearly all indicated English as their primary language (99 percent).

Other Characteristics

All 100 movers had intellectual disability (ID) diagnoses (75 percent had severe or profound ID). Movers also had additional diagnoses, such as behavioral challenges (64 percent) and anxiety (31 percent).

MLS movers needed high levels of support for tasks of daily life. Thirty-nine percent of the movers were either mobile with aids or non-ambulatory. With regard to behavioral support needs, between 47 percent and 59 percent of movers required some or extensive support for self-injurious behavior (47 percent), destructive behavior (49 percent), or disruptive behavior (59 percent).

Health

Health-related questions were examined at three months post-move. Because many of these health screenings are given on an annual basis it is important to revisit health data at the one-year time point to better understand changes in health indicators. Most health-related questions had a high response rate for the “Don’t know, No response, Unclear response” option (greater than 10 percent¹).

Overall, the most common health conditions reported related to cardiovascular issues: high cholesterol (38 percent), high blood pressure (25 percent), and cardiovascular disease (14 percent). Fifty-nine percent of movers also indicated a health diagnosis as “other not listed”. Eleven percent of movers identified as using tobacco. The majority of movers at three months had a primary care physician (98 percent), had received an annual exam within the past year (99 percent), and had a dental exam within the past year (89 percent). More than half of movers (54 percent) received a vision screening within the past year, and two-thirds (66 percent) of movers received a hearing screening within the past five years. Seventy-five percent of movers received a flu shot within the past year.

Only one health question was examined longitudinally regarding a person’s perceived health via self-report or proxy report². The majority of movers (99 percent) indicated

¹ “Don’t know, no response, unclear response” responses were excluded from analyses if below 10%.

² A proxy respondent is a person that knew the mover well (such as a family member, friend, or support worker) that responds in place of the mover to questions regarding observable and objective indicators located in Section II of the ACS.

“fairly good” health or better at three months and all of movers indicated “fairly good” health or better at six months. Nine percent of movers had an increase in their perceived level of health from three to six months.

Medications

At three months, 51 percent of movers took medications for a mood disorder. Of those, the majority (61 percent) took one or two medications, and the remaining 39 percent of movers took three or more medications. Nearly two-fifths (38 percent) of movers took medications for behavioral challenges. Of those, the majority of movers (53 percent) took one or two, and the remaining 47 percent of movers took three or more medications.

Community Inclusion

Most movers (greater than 70 percent) reported participating at least once a month in shopping, errands, entertainment, and going out to eat. These activities were mostly stable in frequency of outing with the exception of going out on errands. Generally, movers went out less frequently on errands or for appointments at six months compared to three months. There was no change in the number of movers who did not go out on errands at all. In other words, although some movers went out on errands less frequently at six months, they still went out at least once per month.

Most movers did not go out to religious activities, and this stayed consistent from three months to six months. Few movers went on vacation within the past year, and this decreased by two people at six months. Based on stakeholder request, these community inclusion indicators will be monitored closely throughout the MLS.

Choices

Movers tended to have high levels of choice for most outcomes. The overall proportion of movers who had a choice about their daily schedule was greater than 79 percent at both time points. Between three months and six months, the percentage movers who choose their daily schedule increased by six percentage points (an increase of four people). Similar findings were seen with choice of how to spend free time. Most movers (90 percent) at six months said they had the choice of how to spend their free time, an increase of six percentage points from three months (84 percent). In contrast to

choosing free time, most movers indicated they did not choose their day activity, and this was stable between three months and six months (68 percent responded they did not have the choice of day activity at both time points). Most movers consistently responded that they did not choose how to spend their money (69 percent of people at both time points).

Work

The proportion of movers who had integrated employment as a goal in their Individual Program Plan (IPP) was 11 percent at three months. Slightly more than half of movers (57 percent) engaged in unpaid facility activities. A smaller group of movers engaged in unpaid community activities (17 percent) or paid facility work (two percent). None of the movers had a paid job in the community at three months. Employment and employment-related services take time to secure, and perception of employment by individuals may differ from what is defined as competitive integrated employment in the community.

Conclusions

Overall, findings based on one year of data collection within the MLS suggest that most movers have experienced a successful transition to the community. Most mover experiences appeared to be positive and stable over the first six months of living in their new community settings. For example, healthcare and service needs were met for most movers. Experiences with life in the community were mainly positive and stable. Nevertheless, findings also demonstrate areas of opportunity to ensure that movers' needs are fully met within the community. While the majority of movers reported good to excellent health and received routine healthcare and related screenings, identifying additional strategies to ensure that such care is provided to all eligible movers and by providers prepared to serve this population could be important. Similarly, while many movers appeared to be engaging in various outings within the community, there is an opportunity to enhance the extent to which movers feel that they are able to participate in outings if they choose.