

UCDAVIS

Continuing and
Professional Education | Human Services

NATIONAL CORE INDICATORS CALIFORNIA

MOVER LONGITUDINAL STUDY

YEAR FIVE UPDATE

Data collected from January 2016 through March 2020



Acknowledgments

This report is possible thanks to the 619 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.

Message from the California Department of Developmental Services

Mission: The Department of Developmental Services (DDS) works to ensure Californians with developmental disabilities have the opportunity to make choices and lead independent, productive lives as members of their communities in the least restrictive settings.

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, Section 4571. DDS also conducts the Mover Longitudinal Study (MLS), using the NCI surveys with individuals who moved from DCs 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 five years of the MLS. 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. The year six report will be the culminating report of the study and will incorporate data collected over the entire course of the study.





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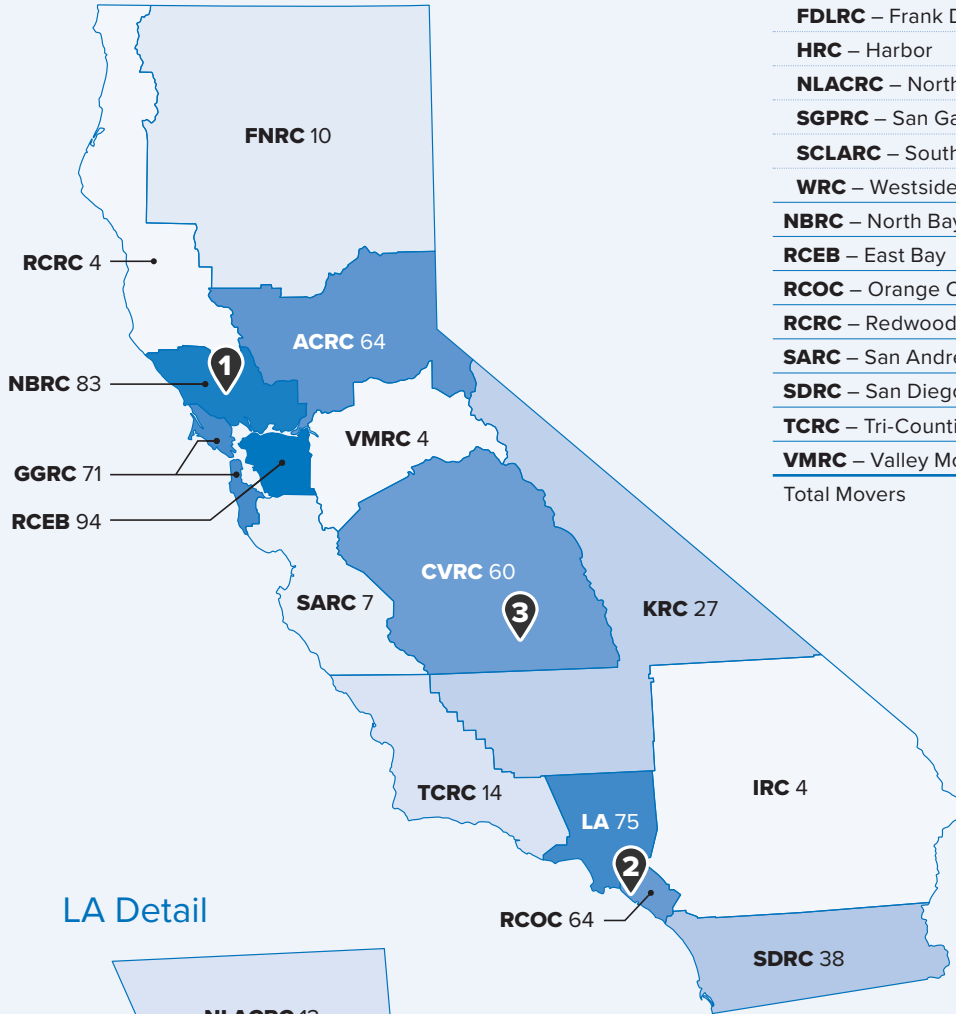
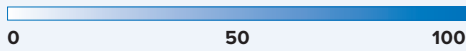
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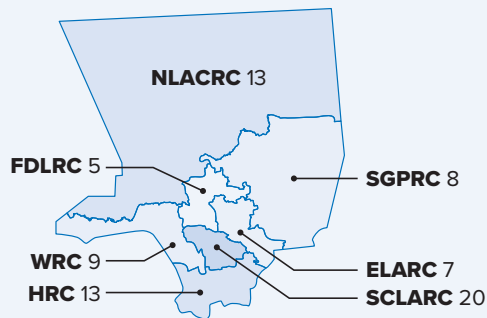




Movers by Regional Centers

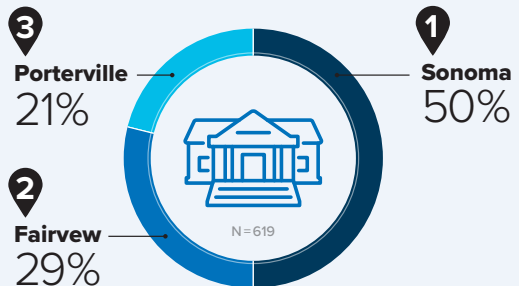


LA Detail



ACRC – Alta California	64
CVRC – Central Valley	60
FNRC – Far Northern	10
GGRC – Golden Gate	71
IRC – Inland	4
KRC – Kern	27
LA County	75
ELARC – Eastern LA	7
FDLRC – Frank D. Lanterman	5
HRC – Harbor	13
NLACRC – North LA County	13
SGPRC – San Gabriel/Pomona	8
SCLARC – South Central LA	20
WRC – Westside	9
NBRC – North Bay	83
RCEB – East Bay	94
RCOC – Orange County	64
RCRC – Redwood Coast	4
SARC – San Andreas	7
SDRC – San Diego	38
TCRC – Tri-Counties	14
VMRC – Valley Mountain	4
Total Movers	619

Movers by Developmental Centers



Mover Longitudinal Study Year Five Update

This study update summarizes the first five years of data collected from individuals with intellectual or developmental disabilities (I/DD) who took part in the Mover Longitudinal Study (MLS). The MLS follows individuals with I/DD who previously lived in a California Developmental Center (DC) and moved into homes within community settings. More information on the study design and methodology is available in the MLS Year 5 Study Update Appendix.

Due to a pause in data collection as a result of the COVID-19 pandemic, this study update is in the form of a data brief and not a full report as in previous years. Shelter in place and social distancing measures precluded the collection of data after March 2020, resulting in relatively few new responses in year five of the study. As such, this update examines trends over the five years of data collection instead of highlighting new data.

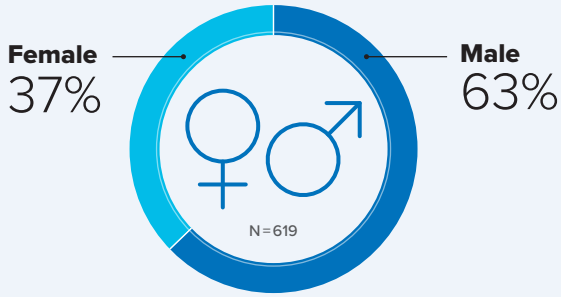
This study is intended to serve as a starting point in evaluating the experience of individuals who moved to the community from a California DC on or after January 1, 2016. Findings related to mover perceptions about service coordination and access, as well as mover life in the community, were selected to be highlighted. Results discussed here can guide further inquiry into continuing or replicating successful care and service coordination.

Pursuant to state law,^[1] the Department of Developmental Services (DDS) was required to close DCs and move residents into homes within the community where they can continue to receive services and supports provided by regional centers (RCs). DDS is required^[2] to evaluate services and supports provided to individuals who have moved from DCs to the community. The MLS and this update are intended to help achieve this statutory mandate and provide DDS and its stakeholders with information about this group of movers, including their experiences following the move to the community.

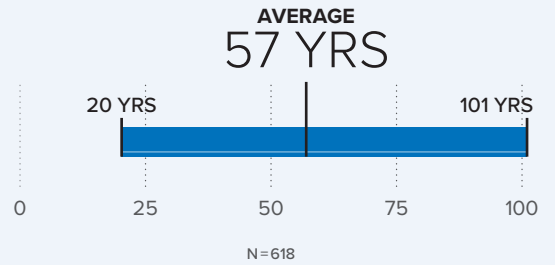


Mover Demographics

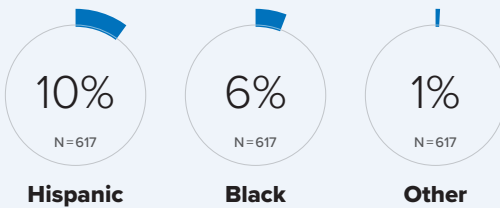
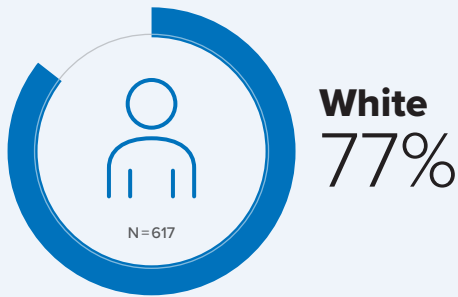
Gender



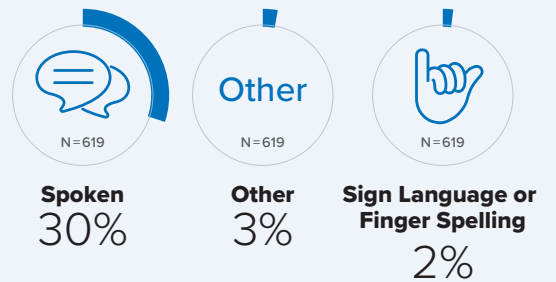
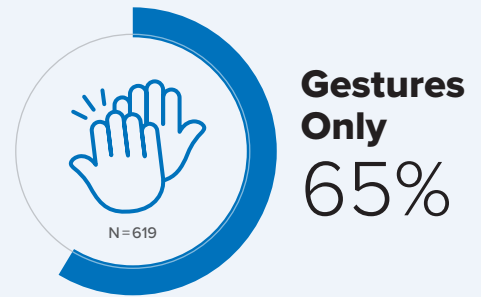
Age Range / Average



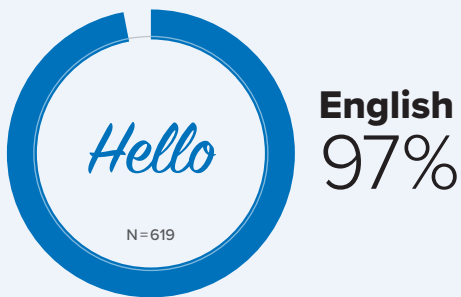
Race & Ethnicity



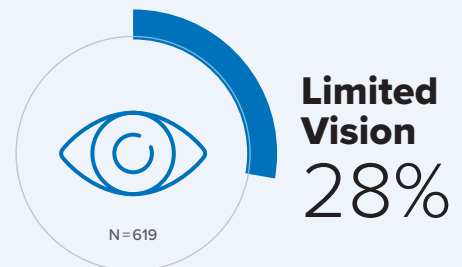
Communication



Language



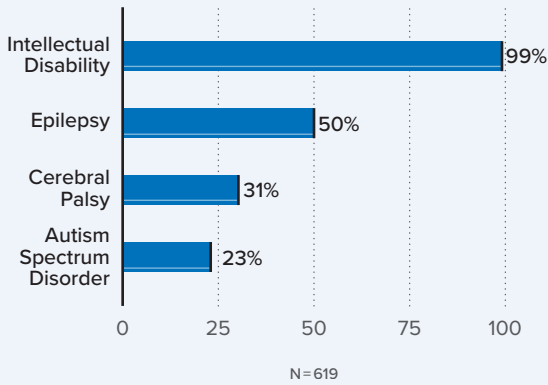
Vision



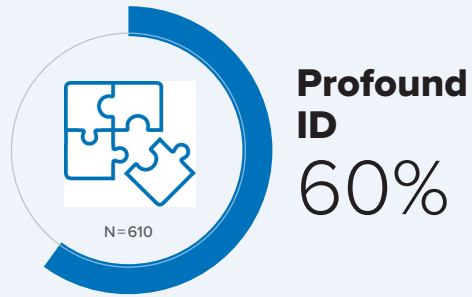
Mover Demographics



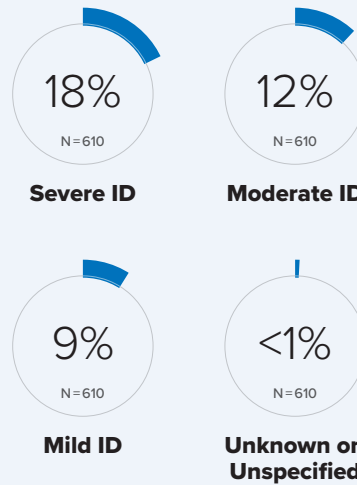
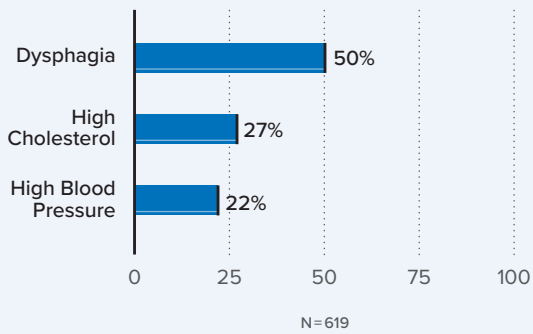
Qualifying Conditions



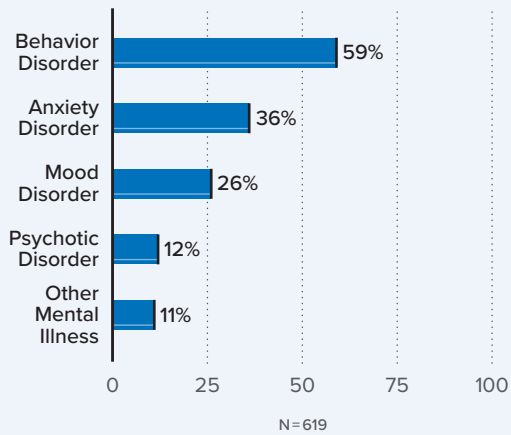
Level of Intellectual Disability



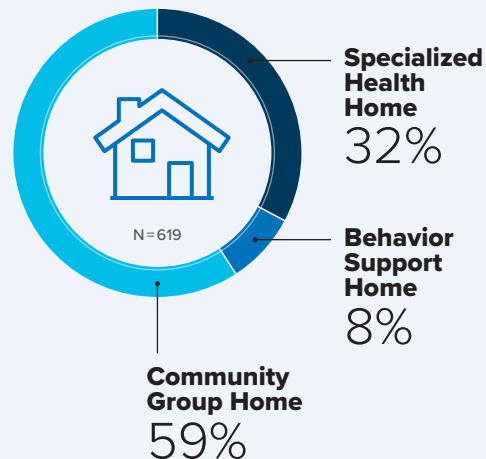
Health Conditions



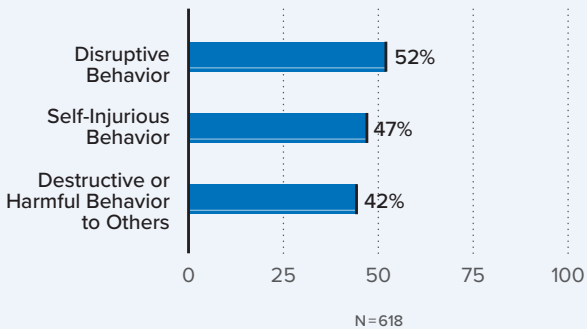
Mental Health Conditions



Residence Type



Needed Support to Manage...





Data Collection for the MLS During the COVID-19 Pandemic

On March 16, 2020, the Department of Developmental Services (DDS) paused data collection for the Mover Longitudinal Study (MLS) in response to the shelter in place and social distancing measures declared by Governor Gavin Newsom to mitigate the spread of COVID-19. At the time, little information existed regarding how to conduct virtual interviews of high-needs individuals with I/DD while maintaining validity and reliability of the data collected. Data collection resumed incrementally starting with the Family/Guardian Survey (FGS) in September 2020 and the Adult Consumer Survey (ACS) in late March 2021.

Due to the pause in data collection, the results contained in this Year Five Study Update do not include information about how the experiences of movers changed during the first year of the pandemic. Now that data collection has resumed virtually, analysis for future reports will take account of data collected pre- and post-pandemic to help shed light on how experiences may have changed in the aftermath of COVID-19.

Adult Consumer Survey (ACS)

105 new ACS surveys representing all time points were added to the MLS in the first part of 2020 before social distancing measures went into effect. Interviews scheduled to occur later in the year could not be completed due to the pandemic, impacting data collection at all time points.

The study methodology normally requires that individuals participate in the 3-month interview in order to be eligible for inclusion in the MLS. Study eligibility requirements, however, have been modified for individuals who missed their 3-month interview because of the COVID-19 pandemic. These individuals will be given the opportunity to join the study at their 1-year post-move time point.

Family Guardian Survey (FGS)

20 new FGS surveys representing all time points were added to the MLS since the previous report. Due to the limited number of new surveys, this study update will not summarize FGS data at this time. However, complete data tables for the FGS are included in the appendix.

Community Inclusion by Mobility

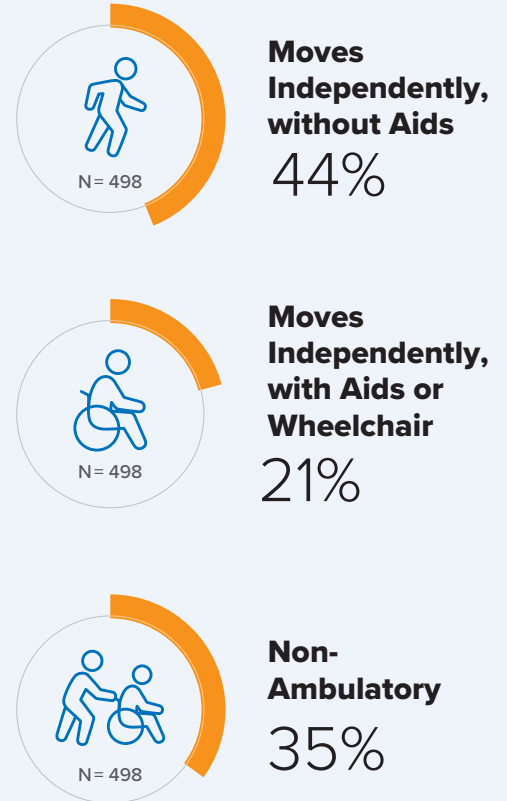
The accessibility of public and private spaces plays a substantial role in the inclusion of disabled people in the community, especially of people with limited mobility. Among movers, more than half (56%) had limited mobility, with one fifth using a mobility aid and over one-third being non-ambulatory.

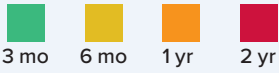
Inaccessible spaces and a lack of accessible transportation can make outings difficult for individuals who use mobility aids or are non-ambulatory. Thus, while looking at the social inclusion of movers as a whole provides insight into overall trends, it is important to determine if these trends are applicable to all movers, and if not, to determine which individuals may need additional supports to participate in social outings. To evaluate potential difference in community engagement for those with mobility challenges, statistical tests were conducted between movers who used aids, those who were non-ambulatory, and those who moved independently. The differences between mobility levels discussed in this section reflect statistically significant difference. The percentages displayed on this page reflect the results of MLS participants after one year in the community.

Although most movers participated in social outings, such as going out for shopping or entertainment, participation varied by mobility status. Individuals who moved independently or used mobility aids had higher rates of social participation than those who were non-ambulatory. Individuals who moved independently were more likely to go out for shopping, entertainment, and errands, and to go out to eat than movers who were non-ambulatory. Additionally, they were more likely to go out to eat than those who used a mobility aid.

Among movers who participated in social outings at least once a month, the frequency of outings also varied by mobility status. Individuals who moved independently participated in social outings more frequently than those who were non-ambulatory. They were more likely to go out for shopping, errands, and entertainment three or more times a month than individuals who were non-ambulatory. Additionally, individuals who moved independently or used mobility aids were more likely to go out to eat three or more times a month than those who were non-ambulatory.

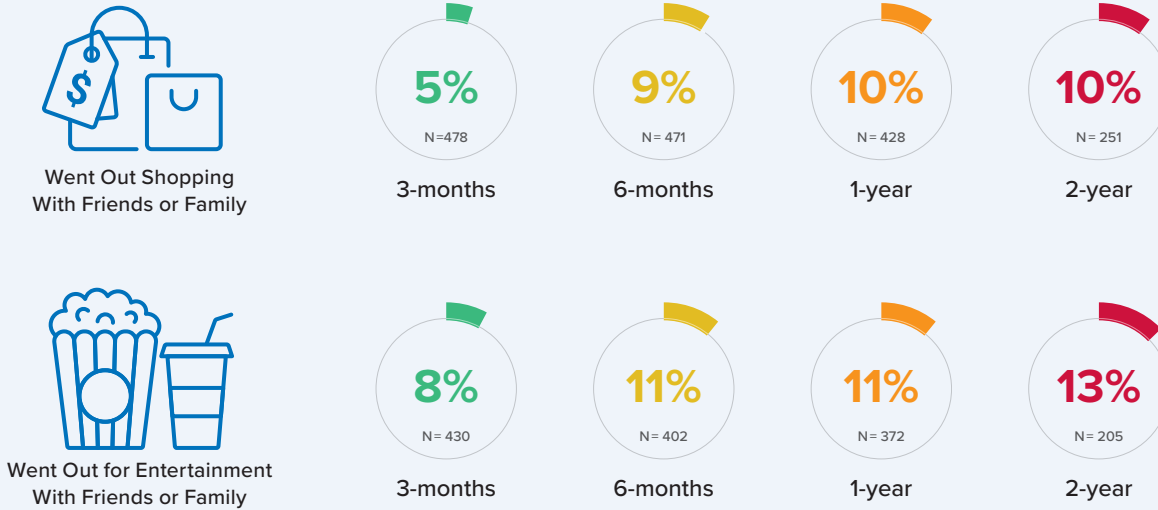
Mobility





Community Inclusion

Larger slices mean more movers went out into the community with friends or family. Percentages shown below represent the portion of movers, at four time points, who said they went out for shopping or entertainment with friends or family.

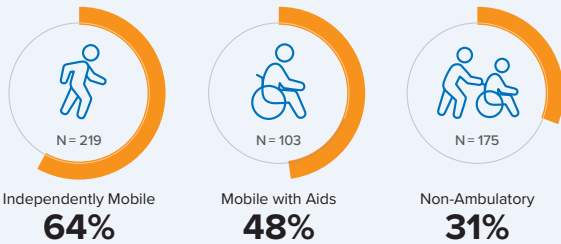


Frequency of Going on Outings by Mobility Status

Larger slices mean more movers went out into the community with friends or family. Percentages shown below reflect the results of MLS participants within each of the mobility categories after one year in the community.

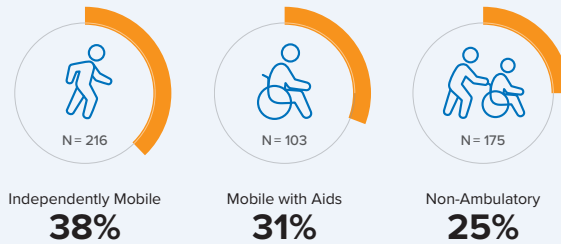
SHOPPING

3 or More Times per Month



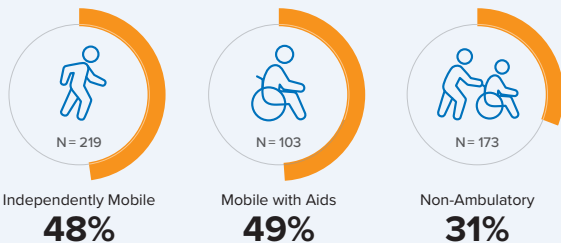
ERRANDS

3 or More Times per Month



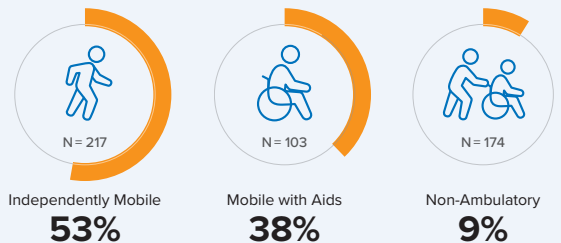
ENTERTAINMENT

3 or More Times per Month



OUT TO EAT

3 or More Times per Month



Mover Outcomes Over Time

The MLS uses a modified version of the 2015-16 National Core Indicator Adult Consumer Survey for data collection at all survey time points. Movers had the opportunity to respond to survey questions at each of four time points (i.e., three-months, six-months, one-year, and two-years after the initial move), allowing for outcomes to be analyzed over time.^[3]

Overall, movers' experiences were positive and stable over time. After an initial adjustment to living in a community home rather than an institution, many movers resumed their normal activities and health patterns. Additionally, movers became increasingly engaged in their communities over time. Healthcare and service needs for the majority of movers were met and stable across the survey time points.

This section summarizes important findings, focusing on what has consistently gone well, what has improved over time, and areas that may benefit from further exploration.



**CONSISTENT
SUCCESSSES**



**IMPROVED
OVER TIME**



**AREAS FOR FURTHER
EXPLORATION**

Community Inclusion



Movers frequently participated in social outings such as going out for shopping, entertainment, and errands. For example, across all four time points, over 70% of movers went out for entertainment at least once a month, most often with staff, housemates, or coworkers.



The longer movers lived in the community, the more they participated in social activities outside of their homes. At each survey point, more and more movers reported going out shopping, running errands, going out for recreation, and going out to eat at least once a month. For example, there was a



substantial increase in the number of movers who went out shopping. Whereas at the three-month time point, three-quarters of movers reported having gone out shopping at least once in the past month, by the two-year time point that number had increased to almost 90% of all movers.

Similarly, the longer movers lived in the community, the more involved their family and friends became in their social outings. From the three-month time point to the two-year time point, more and more family and friends accompanied movers as they went out for entertainment and shopping.



Despite an overall increase in social outings, certain types of outings remained uncommon among movers.

While very few movers participated in community groups or activities, went on vacation, or went out for religious services, some of this low participation may be explained by other contributing factors. Most movers attended a day program or workshop that provided social interaction. In some instances, religious services were offered in the home, so movers had no need to go out for those.

Services and Supports



Movers received a variety of services ranging from case management to transportation to skill

development. Across all survey time points, the most common services included service coordination and case management, residential support services, health care coordination, and dental care coordination.^[4]

Across all survey time points, over 90% of movers did not need additional services or supports, indicating that movers received the services and supports they needed. Furthermore, requests for additional services decreased over time. In particular requests for day services other than employment and for communication technology decreased considerably from the three-month time point to the two-year time point. This indicates that movers'



The longer movers lived in the community, the more involved their family and friends became in their social outings.



Across all survey time points, over 90% of movers did not need additional services or supports, indicating that movers received the services and supports they needed.

service needs are consistently being met and that when additional needs do arise, they are being addressed.

Almost all movers felt that the staff who worked with them had the right training to meet their needs. This is important as the quality of staff and home care services impact movers' well-being.^[5] Properly trained staff provide better basic care, reduce the likelihood of accidents and injuries, and improve the overall quality of life for movers.^[6]

Health



Movers had consistent access to primary and preventative healthcare in their communities. All movers had a primary care doctor at all survey points, and all but a few movers felt that their doctor understood the health needs related to their disability. Across all four time points, movers received basic health care and screenings within the recommended intervals, including annual physical exams, dental exams, and flu vaccines. This suggests that movers maintained the level of care they received in the DCs even after they moved into the community.



Across all four time points, movers received basic health care and screenings within the recommended intervals, including annual physical exams, dental exams, and flu vaccines.

Many movers received cancer screenings within the recommended intervals. By the two-year time point, 62% had a colorectal cancer screening. This is similar to the rate for the general population in the United States. According to the National Cancer Institute, 61% of all adults over age 50 had a colonoscopy in the past five years.^[7]

Consistently across all four time points, over half of female movers received a pap test and/or mammogram within the recommended intervals. According to the Centers for Disease Control and Prevention (CDC), 66% of all women had a pap test in the past three years,^[8] 67% of women over age 40 had a mammogram in the past two years.^[9]

Although screening rates for mammograms and pap tests among movers are lower than screening rates in the general population, they can be considered a

success given the medical needs of movers. Many movers are medically fragile and/or have behavioral challenges that can make invasive health screening difficult. Some physicians may have recommended against invasive health screenings, or conducted less invasive screenings, as the risk of doing some screenings can outweigh potential benefits based on individual circumstances.



The percentage of movers who received a hearing test within recommended intervals decreased over time. At the three-month time point almost three-quarters of movers had received a hearing test within the past five years. By the two-year time point, that number had decreased to half of movers. This suggests that movers may have received hearing tests while in the DCs but may not be getting those tests as consistently in the community. Age-related hearing loss is common among older adults, with one in three adults over the age of 65 experiencing hearing loss.^[10] Hearing loss impacts social functioning, mental health, and overall quality of life and thus it is important that movers, half of whom are over the age of 60, receive regular hearing tests which can facilitate early identification and treatment of hearing loss.

Wellness



Over time, more movers' health was described as excellent or very good. This is consistent with other findings about what is going well for movers. Movers had access to healthcare, received basic health screening at recommended intervals, received the services and supports they needed, and participated socially in their communities, all of which contribute to wellness.



Across all time points, about half of all movers did not exercise or do physical activity. In comparison, 22% of all adults in California did not exercise or do physical activity in the past month according to a 2020 annual report by the United Health Foundation.^[11] Movers' ability to engage in exercise or physical activity may be impacted by limited mobility. Half of movers used mobility aids or were non-ambulatory, which makes certain types of exercise difficult. Additionally, individuals with complex health needs and/or physical disabilities may need medical clearance before exercising. They may also need health care provider guidance on activities that would be suitable for their medical conditions or mobility level. Limited mobility contributes to



Movers had access to healthcare, received basic health screening at recommended intervals, received the services and supports they needed, and participated socially in their communities, all of which contribute to wellness.

increased rates of obesity, which further restricts the ability to exercise.^[12]
At all time points, about half of movers were considered overweight or obese (BMI >25), a rate comparable to that among adults in California.^[13]

Choices



Across all four time points, movers were able to make decisions about their everyday life. Almost all movers decided or had input in deciding their daily schedule, how to spend their free time, and how to spend their own money.



For some movers, the location of their home may impact available day programs or activities. Exploration for the factors contributing to the consistently low levels of choice in day programs or activities is warranted.



Across all four time points, movers were able to make decisions about their everyday life.

Employment and Other Activities



Movers were consistently engaged in some type of daily activity across all four survey time points and engagement in daily activities increased over time. Three months after moving into the community, just over half of movers engaged in unpaid activities at a facility, such as a day habilitation center or senior program. At the end of two years, three-quarters of movers did.



The number of movers participating in unpaid activities was also high and increased over time such that by the two-year time point, over 84% of movers had participated in unpaid activities in the past two weeks. Movers who personally responded to the survey were typically happy with the amount of time they spent at day programs, and satisfaction increased over time. At the two-year time point, almost all movers reported that the amount of time was just right for them or that they would like to spend even more time at the day program or workshop.



At all four survey time points, very few movers engaged in paid work. Movers tended to be older, with half of movers being of retirement age. Additionally, many movers had complex health conditions, which may have



contributed to lower rates of paid employment. In fact, at all four time points, less than 5% of movers had employment as a goal in their Individual Program Plan.

Respect and Rights



Very few movers queried by this survey they were able to assert their rights. Few movers voted or had the opportunity to register to vote but chose not to. This parallels trends in the general population where voter registration and voter turnout is lower among people with disabilities than people without disabilities.^[14]

At all time points, movers had limited privacy with regards to their rooms. Most individuals did not have keys to their homes or the ability to lock their bedroom if they wanted. The 2014 Social Security Act requires that individuals who live in community-based residential settings “must be able to lock the door to their unit or dwelling, that the individual has a key to the door, and that only appropriate staff have keys”.^[15] However, California Fire Marshall regulations prohibit locking devices (i.e., night latch, dead bolt, security chain, or any similar device) on the interior bedroom door for individuals who are unable to independently walk to exit their bedroom.^[16] This health and safety regulation continues to limit privacy.



Summary

Overall, findings based on five years of data collection within the MLS suggest that most movers have experienced a successful transition to the community. The majority of mover experiences were positive and stable over time. Once the initial adjustment was made to living in a community home rather than an institution, many movers resumed their normal activities and health patterns. Healthcare and service needs for the majority of movers were met.



References

1. See Welfare and Institution Code Section 4474.11.
2. See Welfare and Institutions Code Section 4474.12.
3. The majority of surveys were completed by proxy respondents on the movers' behalf (>90%).
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14. Schur, L., & Kruse, D. (2019). Fact sheet: Disability and voter turnout in the 2018 elections. Rutgers School of Management and Labor Relations. https://smlr.rutgers.edu/sites/default/files/Documents/Centers/Program_Disability_Research/Fact%20Sheet%20Disability%20Voter%202018%20Elections.pdf
15. Social Security Act of 1935, 42 C.F.R. § 441.530(a) (1)(vi)(B) (2014). Retrieved from <https://www.govinfo.gov/app/details/FR-2014-01-16/2014-00487/summary>
- 16 California Fire Code. §§ 435.8.3.3 (2019). Retrieved from <https://up.codes/viewer/california/ca-fire-code-2019>



DDS works to ensure Californians with developmental disabilities have the opportunity to make choices and lead independent, productive lives as members of their communities in the least restrictive setting possible.

www.dds.ca.gov

UC DAVIS

Continuing and Professional Education | Human Services

The Human Services evaluation team offers expertise in research and evaluation focused on a variety of human and social services for children, adults and families.

humanservices.ucdavis.edu/research-services

