
National Core Indicators California Annual Mover Survey

Fiscal Years 2015-2016, 2016-2017, and 2017-2018



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Message from the California Department of Developmental Services

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

For nearly a decade, since the closure of Lanterman Developmental Center, DDS has coordinated a dedicated quality improvement effort to ensure the appropriate and successful transition of individuals with I/DD who resided in a developmental center (DC) to community living and to improve services and supports available to former DC residents. This is an important effort to collect accurate, reliable, and valid data focused on the experience of individuals with developmental disabilities in California who have transitioned from DCs to homes in the community. Over time, results have been used to identify areas of strength and areas in need of additional evaluation, planning and monitoring.

This report contains the results of California's sixth (2015-2016), seventh (2016-2017), and eighth (2017-2018) yearly data collection cycles. Former DC residents were invited to participate in structured interviews to assess access to services and supports provided to them since their move into the community. During that time, 1,626 surveys were conducted by the State Council on Developmental Disabilities (SCDD) with adults (age 18 and over) with developmental disabilities who moved from a developmental center to the community (i.e., movers) or their proxy.

The findings provide insight regarding key areas of interest, including health and safety, employment, rights, service planning and delivery, community inclusion, and individual choice. The material presented in this report is used as a tool by policy makers and other stakeholders to guide strategic planning and to monitor quality improvement activities. Over time, results identify areas of strength and those in need of additional evaluation or systemic improvement.

Acknowledgements

This report would not be possible without the many individuals with developmental disabilities who agreed to participate in the Annual Mover Survey during data collection cycles in fiscal years 2015-2016, 2016-2017, and 2017-2018, offered their time, and discussed their lives in order to help improve services for people with developmental disabilities in California. Special acknowledgment also goes to the families, friends, and staff members who provided support and participated in the survey process.

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A. Executive Summary

This report describes findings from the Annual Mover Survey—a continuous quality assessment and improvement initiative by the California Department of Developmental Services (DDS). The Annual Mover Survey is intended to assess the performance of services and supports provided to people with developmental disabilities across the state who moved from a California developmental center (DC) starting in 2010 to a home in the community (i.e., movers). Study participants include all individuals who moved from Lanterman Developmental Center between July 1, 2009 and December 23, 2014 (when Lanterman closed) and a sample of individuals who moved from all other developmental centers (Fairview, Porterville and Sonoma Developmental Centers) and have lived in the community up to five years.

Findings in this report provide an opportunity to inform DDS and its stakeholders about the performance of the California service delivery system, including services and supports provided to movers following their transitions to homes in the community. Themes highlighted herein include areas where the move to the community went well and could be considered successful. This report also highlights areas where there may be room for further inquiry to help strengthen and improve service delivery and ultimately improve the quality of life for those who receive services and supports funded by DDS.

Report Structure

This report contains individual chapters focused on data collected during each of three fiscal years: 2015-2016 (survey year six), 2016-2017 (survey year seven), and 2017-2018 (survey year eight). Each of these chapters includes a Summary of Findings with selected results of quantitative analyses and a Data Table of Findings with results for all quantitative analyses.¹ The Data Tables are intended to be used as a reference to

¹ In order to protect the identity of survey participants, findings are not provided in either summaries or data tables in instances when sample sizes were less than or equal to ten. Findings based on sample sizes of 11-29 are reported within data tables. Due to the small number of individuals represented within sample sizes of 11-29, such results are not generalizable and are thus generally omitted from text-based descriptions and only highlighted in rare instances (i.e., when reporting on items from *Section I* of the Adult Consumer Survey).

review results from individual survey items for specific survey cycles. The Summary of Findings sections provide an overview of those results. The Executive Summary provides a high-level overview of findings from all three survey years. Details regarding the methods used to collect data and generate findings are located in the Appendices¹ document created to supplement the information provided in this report.

Background

State law provides DDS with the responsibility for overseeing the coordination and delivery of services and supports to people with I/DD. It does this in primarily two ways: operating DCs and community facilities for the provision of residential care to individuals with I/DD, and funding private nonprofit regional centers (RCs) to develop, purchase and manage services and supports for individuals with I/DD and their families.

To provide oversight of this responsibility, California participates in the National Core Indicators (NCI) project. The NCI project is an ongoing opportunity for public departments of developmental disabilities across the country to track and monitor the performance of their public service delivery systems. Pursuant to Welfare and Institutions Code Section 4571, California has participated in the NCI project since 2010 and has thus implemented an annual statewide quality assessment survey since that time.² The NCI focuses on a series of core indicators, including individual outcomes; health, welfare, and rights; and system performance. Through collection of data focused on these core indicators, the NCI project is intended to provide DDS and its stakeholders with opportunities for continuous improvement in the quality of California's service delivery system.

Using the NCI core indicators, the Annual Mover Survey allows DDS to monitor the transition of individuals with developmental disabilities who have moved from a DC into homes in the community. The survey is fulfillment of a commitment by DDS to survey the Lanterman DC movers for ten years after its closure and compare them to the experiences of the movers from the remaining California DCs which were open at the time of the Lanterman DC closure; Sonoma DC, Porterville DC, and Fairview DC. This

¹ Appendices to the California Annual Mover Survey Report: Fiscal Years 2015-2016, 2016-2017, and 2017-2018

² <https://www.dds.ca.gov/rc/nci/>

report summarizes data collected annually over three years of the Annual Mover Survey.

Study Participants

The Annual Mover Study evaluates the experiences of individuals with developmental disabilities (i.e., movers) who moved from California DCs to homes in the community at some point after 2009 and before January 2016. The Annual Mover Survey is different than the Mover Longitudinal Study (MLS) which evaluates the experiences of movers who moved from a California DC to the community since January 2016 at standard points in time (i.e. at three months, six months, one year, and two years following discharge). The MLS allows for analysis over time while the Annual Mover Survey only allows for analysis for one data collection period at a time. Findings in this report are based on data collected during fiscal survey years 2015-2016, 2016-2017, and 2017-2018 from the following two groups of movers:

- Movers from the Lanterman DC who moved to the community on or after July 1, 2009 (Lanterman movers or LM) and were still living in the community during the three data collection cycles.
- Movers from other DCs (Sonoma DC, Porterville DC, and Fairview DC) who moved to the community during the five years prior to the three data collection cycles (known in this report as Other movers or OM).

Sample Sizes for Mover Groups by Fiscal Year

Mover Group	FY 2015-2016	FY 2016-2017	FY 2017-2018
Lanterman Movers (LM)	314	301	294
Other Movers (OM)	260	397	60

Table 1: Sample Sizes for Mover Groups by Fiscal Year

In all three years, both mover groups were made up predominantly of middle-aged White males with English as their primary language. Nearly all movers had a diagnosis of Intellectual Disability (ID), with most having profound or severe ID. Individuals with

severe or profound ID typically have more limited ability to communicate and are more likely to have physical limitations that require more extensive daily supports relative to those with mild or moderate ID. Most individuals in both groups had at least one additional developmental disorder diagnosis in addition to ID (e.g., epilepsy, autism spectrum disorder, cerebral palsy). Rates of co-occurring mental health conditions were relatively high among both groups. The majority of movers in both groups used gestures or body language as their primary means of communication. Nearly all individuals in both groups required 24-hour on-site support or supervision in their home. The majority of movers in both groups needed some support to manage either self-injurious or disruptive behavior. Additional details describing similarities and differences between the participants in the Lanterman and Other mover groups within each survey year can be found in the Chapters for each survey year.

Study Methods

Data was collected annually using the Adult Consumer Survey (ACS) via in-person interviews with movers when possible, as well as proxies and other staff or administrators as needed. The ACS provides information on mover demographics; individual outcomes in the areas of choice and decision-making, community inclusion, relationships, and work; health, welfare, and rights; and system performance (e.g., access, service coordination). The ACS was developed as a part of the NCI project by the Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disability Services (NASDDDS).

The ACS includes three major sections: *Background Information*, *Section I*, and *Section II*. Some questions can only be answered by the individual receiving services, while for other questions, a proxy respondent is allowed. Additional details regarding study methods can be found in the separate Appendices¹ document to this report.

Study Findings

This summary highlights both successes and potential areas for further investigation that were identified via data collected over three survey years (i.e., FY 2015-2016,

¹ Appendices to the California Annual Mover Survey Report: Fiscal Years 2015-2016, 2016-2017, and 2017-2018

2016-2017, 2017-2018). Findings for each survey year are organized into two subsections: *Background Information* and *Section II* followed by *Section I*. *Section I* data is valuable because it was self-reported by the movers rather than proxies. Results based on data from *Background Information* and *Section II* are presented separately from those based on *Section I* data.

Findings are intended to inform DDS and its stakeholders on service delivery to ensure that clients' needs continue to be met after moving to homes in the community. Results highlighted herein should be used to guide further investigation regarding successes that could be continued or replicated, and opportunities for improvement in the care and service coordination experienced by movers.

Successes with the Transition from a DC to the Community

Overall, the mover groups that were evaluated during the three survey years appear to be healthy and have had positive experiences as they transitioned from DCs to homes in the community. They appear to have received adequate services and supports during the transition and beyond.

Mover experiences with life in the community were generally positive.

- Movers were involved in making some life decisions (e.g., choices related to their daily schedules, how they spend their free time).
- Most movers went on outings within the community (e.g., shopping, errands, entertainment, and eating out).
- Most movers had transportation when they needed it.
- Most movers were engaged in unpaid community and facilities activities, such as volunteer activities, skills training, school, day habilitation, and prevocational and seniors' programs).

Mover experiences in their homes were also positive.

- Almost all movers liked their homes.
- Most movers felt that staff in the homes treated them with respect.
- Most movers felt that their privacy was respected at home.

Most movers received adequate services and supports that contributed positively to their lives.

- Almost all movers received regional center services or supports to participate in community- and facility-based activities.
- Most movers felt that the services and supports they received were helping them to live a good life.
- Nearly all movers received health and dental care coordination.

Movers felt healthy and were getting appropriate health care and preventative screenings.

- Movers had largely positive perceptions of their health.
- Most movers received health care and preventative screenings within recommended intervals, including dental exams, vision screenings, flu vaccines, and hearing tests.

Areas in Need of Possible Exploration to Strengthen Service Delivery

Movers evaluated during the three survey years generally received suitable services/supports and reported positive experiences in the community and with their homes. There may be areas worth further exploration that could help to improve the service delivery system that provides care and support for individuals with developmental disabilities living in the community.

Some movers may benefit from additional services and supports within the community.

- Many movers reported needing additional services and supports (e.g., assistance with housing, jobs, and getting education, training, or skills development).
- Some movers may not be getting routine dental exams, vision screenings, and hearing tests at recommended intervals.

It is recommended to explore barriers to receipt of services and identify if any particular groups of movers are less likely to receive the services that they want or need. This could facilitate initiatives that help to overcome barriers to receiving services with the populations that are most in need of this support.

A. Executive Summary

Some movers may benefit from supports focused on healthy weight management and those intended to encourage physical activity/exercise so that movers maintain their health within the community.

- For each of the three survey years focused on in this report, more than half of movers were considered overweight or obese (i.e., BMI greater than 25), although this is consistent with rates in the general population in the state of California.
- Many movers reported that they did not exercise or do physical activity.

Further investigation could help identify reasons why movers may not be exercising, as well as whether weight status is changing over time and factors that may be contributing to this.

Although most movers went on various outings in the community, it is unclear whether they are going out at rates that they are satisfied with and going to places that they want to go to.

- Most movers went on community outings (e.g., shopping, errands, entertainment) only once or twice a month.

Further inquiry could include exploring mover preferences regarding type and frequency of outings and their ability to go where they would like.

Movers may need assistance with social activities and relationships.

- Some movers expressed feelings of loneliness and wanted help with making friends or keeping in contact with friends.

Feelings of loneliness could be evaluated over time to assess whether they subside as movers live in their community settings for longer lengths of time and have more opportunities to make friends and engage with others.

Movers may benefit from being given the opportunity to make independent life choices, if they want.

- Some movers reported that they did not have input on making some life choices (e.g., choice of home, roommates).

It may be worthwhile exploring the extent to which movers want to make independent decisions about things such as who they live with and the reasons why others may be making such decisions on their behalf.

Conclusion

The findings and suggestions described in this report are provided to the California DDS with the intention of helping them assess the performance of services and supports that are provided to people with developmental disabilities who moved from a California DC, including the Lanterman DC, to a home within the community. Findings herein demonstrate how movers have had positive experiences as they transitioned from DCs to community settings and appear to have received adequate services and supports during the transition and beyond. Nonetheless, there is variation in select items, which suggests room for improvement in the services and supports that are being offered.

It may be useful to identify the specific populations and/or contexts in which movers are thriving within the community so that these experiences can be replicated. In addition, there may be areas worth further exploration that could help to improve the service delivery system and promote more widespread success. Continued quality assurance and improvement efforts, such as this one, are essential to ensuring that individuals with developmental disabilities receive services and supports that help them lead healthy, meaningful, high quality lives.

B. Annual Mover Survey- Year Six

Summary of Findings

Findings in this chapter are based on data collected from two groups during survey year 2015-2016:

- Movers from the Lanterman DC who moved to the community on or after July 1, 2009 (Lanterman movers or L6). Data from a total of 314 individuals were available for the L6 group.
- Movers from other DCs (Sonoma DC, Porterville DC and Fairview DC) who moved from a DC to the community within five years prior to the 2015-2016 data collection cycle (Other movers or OM6). Data from a total of 260 individuals were available for the OM6 group.

Findings are organized into two sub-sections: *Background Information and Section II* followed by *Section I*. Information based on data from *Background Information and Section II* are presented separately from those based on *Section I* data. *Section I* data is valuable since it was self-reported by the movers rather than proxies, but is more limited due to low response rates. Findings are organized by the survey sections: Demographic Information, Choices and Decision Making, Employment and Other Daily Activities, Community Inclusion, Friends and Family, Service Coordination, Other Services and Supports, Health, Wellness, Respect and Rights, Safety, and Access.

Findings that indicated an opportunity to inform areas where things were going well and areas where further exploration may be warranted are highlighted within each theme/area and are also listed at the end of this Summary of Findings. Data tables containing percentages and counts for all of the questions asked during this survey year are located in the separate Appendices document, which was created to supplement this report¹.

¹ Appendices to the California Annual Mover Survey Report: Fiscal Years 2015-2016, 2016-2017, and 2017-2018

Group Comparisons

The L6 group is a sample of individuals who transitioned from the Lanterman DC into a community residence between July 1, 2009 and December 23, 2014¹; they had thus been living in a community setting between one and seven years at the time of data collection. The OM6 group is a sample of individuals who transitioned from a DC other than Lanterman DC into a community residence, and had been living in a community setting for five years or less since the date of data collection. Besides the difference in the range of years/time each group had been living in the community, there were differences in demographic characteristics between the two groups (L6 and OM6) that should be considered when interpreting comparisons made in this summary (see Demographic Information section below).

In this chapter, L6 were compared to OM6 as a reference point to better understand the transition of both groups to a community residence as well as integration into the larger community. Descriptive results are also provided for each group individually, given the limitations of these comparisons due to significant differences between the two groups (described below).

Background Information and Section II Demographic Information

Sociodemographic Characteristics

Summary of Differences Between L6 and OM6 in Demographic Information

The L6 group included fewer males and were older compared to the OM6 group. L6 had significantly higher rates of ID and higher rates of having profound ID compared to OM6. More L6 used gestures or body language compared to OM6, and only a few L6 used spoken language as their primary means of communication. The L6 have also been living out in the community for longer periods than the OM6. Overall, these group differences have implications regarding the utility of making comparisons across these

¹ <https://www.dds.ca.gov/Lanterman/>

two groups and should be considered when reviewing the group comparisons reported below.

Age, Race and Gender

Both L6 and OM6 were made up predominantly of White males with English as their primary language. For both groups, the second largest race or ethnicity selected was Hispanic/Latino; Spanish was the second largest language selected, although only five percent primarily spoke Spanish in both groups. The average age was 56 years old for L6 and 50 years old for OM6. Despite both groups being predominately male and having a similar average age, there were significantly fewer males and significantly older individuals in the L6 group (59 percent male) compared to OM6 group (74 percent male).

Additionally, more than three fourths of L6 had a legally appointed guardian or conservator compared to nearly one third of OM6. This was a significant difference between the two groups. It is unclear whether a higher proportion of legally appointed guardians or conservators in the L6 group may have impacted the quality and quantity of services and supports received; this is a potential area for further investigation.

Developmental Disorders

All L6 had a diagnosis of Intellectual Disability (ID) with nearly all having a diagnosis of profound or severe ID. Individuals with severe or profound ID typically have more limited ability to communicate and were more likely to have physical limitations that require more extensive daily supports relative to those with mild or moderate ID. Nearly all OM6 had a diagnosis of ID with about three of every five having a diagnosis of profound or severe ID. Despite the large majority of both groups having a diagnosis of profound or severe ID, L6 had significantly higher rates of ID as well as higher rates of having profound ID compared to OM6. In general, the high rates of severe and profound ID among L6 may provide context for the low number of responses from L6 in *Section I* of the survey.

Most individuals in both groups had at least one additional developmental disorder diagnosis (e.g., epilepsy, autism spectrum disorder, cerebral palsy) in addition to ID.

Although individuals from both groups have multiple developmental diagnoses, a significantly higher number of L6 had cerebral palsy (CP) or epilepsy compared to OM6.

Rates of co-occurring mental health conditions were relatively high among both groups. Many L6 and OM6 reported behavior challenges (e.g., aggression, self-injurious behavior, pica), having an anxiety disorder (e.g., obsessive disorders, panic disorders), or having a mood disorder (e.g., depression, mania, bipolar disorder).

Communication and Mobility

Other areas of significant differences between L6 and OM6 were present. A significantly higher number of L6 used gestures or body language compared to OM6, and a significantly lower number of L6 used spoken language as their primary means of communication. This difference in primary means of communication may have implications for ability to respond to *Section I* questions, which can only be answered by the individual. For example, fewer L6 may be responding to *Section I* questions since this group had fewer individuals who use spoken language compared to OM6.

In both groups, the most common mobility type was the ability to move independently without aids. However, a significantly lower number of L6 reported moving independently without aid compared to OM6. The second most common mobility type in both groups was being able to move independently with aids or a wheelchair, and L6 indicated this at significantly higher rates compared to OM6. The third mobility type of being non-ambulatory was reported by L6 at significantly higher rates relative to OM6.

Residence

Nearly all individuals in both groups required 24-hour on-site support or supervision in their home. While the majority of both groups lived in Community Care Facilities (CCF), there were significantly more L6 living in CCF with four to six residents compared to OM6. There was also a significant difference in the length of time living in their current homes. L6 had significantly higher rates of living in their current homes for one to three years compared to OM6. Durations of less than one year, between three to five years, or more than five years were comparable across the groups. While there is a difference between L6 and OM6 for living one to three years in their current residences, it is unclear whether this difference is expected, more investigation on this issue may be

warranted (e.g., did residential moves occur as expected or did moves occur due to external circumstances).

Health Conditions

Findings regarding health conditions were generally reflective of an aging sample. The most common health conditions among both L6 and OM6 were dysphagia, high cholesterol, high blood pressure, and limited or no vision. More than one in four L6 had dysphagia compared to one in five OM6, which was a significant difference. In addition, two in five L6 and OM6 were diagnosed with another health condition not listed on the survey; further investigation on the types of other health conditions experienced by movers may be warranted.

Behavioral Support Needs

A majority of L6 and OM6 needed some support to manage either self-injurious or disruptive behavior. About one half of both mover groups needed some support to manage behavior that was destructive or harmful to others. A significantly larger number of L6 needed some support to manage self-injurious behaviors compared to OM6, and only a small percentage in both mover groups needed extensive support. About one third of L6 and OM6 needed extensive support to manage disruptive behaviors.

Medications for Behavioral Challenges

Rates of medication use in the two mover samples were similar. More than half of L6 and OM6 took medications to treat mood, anxiety, or psychotic disorders. About one third of L6 and OM6 took medications for other behavioral challenges.

Choices and Decision Making

A majority of L6 and OM6 reported being involved in making choices related to their daily schedules, how they spend their free time, and being able to change their service coordinator if desired. While a majority of both mover groups indicated high involvement in making these choices, L6 had significantly lower rates compared to OM6. For example, 66 percent of L6 reported they were aware they could change their service coordinators if they wanted to, which was significantly lower compared to 85 percent of OM6. In making other choices, such as those pertaining to day programs, where they

live, selection of roommates, how they spend their money, L6 reported significantly less ability compared to OM6.

Overall, L6 reported significantly lower rates of being involved in making choices compared to OM6. The higher number of L6 with profound or severe ID and lower rates of spoken language could explain the lower rates of being able to make independent choices or life decisions. Generally, L6 may benefit from increased opportunities to make choices and practice independence.

Employment and Other Daily Activities

Unpaid Activities

Movers had opportunities to participate and engage in unpaid community- and facility-based activities, which are activities that may offer chances for building social relationships and skills engagement. Most movers in both groups were engaged in unpaid community activities (e.g., volunteer activities, skills training, school) and unpaid facilities activities (e.g., day habilitation, prevocational, seniors' programs).

Half of L6 and slightly more than half of (six out of ten) OM6 engaged in a facility-based activity, which was a significant difference. Both groups spent a similar amount of time at facility-based activities, averaging slightly more than 50 hours per two-week period. For community-based activities, a significantly different and slightly higher number of L6, three out of ten, participated compared to two out of ten OM6. The amount of time spent at community activities in a two-week period was significantly higher for the L6 group, which spent an average of 45 hours compared to OM6 who spent an average of 34 hours.

Almost all L6 and OM6 received regional center services or supports to participate in these community- and facility-based activities. Nearly all L6 and OM6 reported that activities were primarily done by people with disabilities, although the L6 group (nine out of ten) was slightly lower compared to OM6 (ten out of ten).

Employment as IPP Goal

Having paid community employment as a goal in their Individual Program Plan (IPP) was related to higher chances of having a paid job. For example, eight out of ten OM6 with a paid job had employment as a goal in their IPP. Regardless of whether someone

had a paid job, very few L6 (three percent) had community employment as a goal in their IPP, which was significantly lower compared to the 21 percent of OM6. This may be related to more advanced age of L6. The retirement age for adults with developmental disabilities is 50 years old, and with more people in the L6 group above the retirement age, fewer individuals may have wanted community employment as a goal in their IPP. This may be an area for further investigation, such as whether individuals who were able to work and were interested in having a paid job want to include community employment as a goal in their IPP

Community Inclusion

Both L6 and OM6 went on outings in the community, but there is room for improvement in the frequency of going on outings. L6 and OM6 most frequently went out at least once a month for shopping, errands, entertainment, and eating out. Generally, those who went out for one of these types of outings were most likely to have gone once or twice in a month, and to have gone out with staff, housemates, or coworkers – the most common companion types. However, L6 reported going out with housemates significantly more than OM6. Most movers did not go to a religious service or spiritual practice; for those who did attend, both L6 and OM6 typically went once or twice in a month, and did so with staff, housemates, or coworkers.

One in four L6 participated in community groups or activities (e.g., church groups, formal or informal community groups), which was significantly lower compared to two in five OM6. Movers in both groups who participated in community groups or activities often went with staff, housemates, or coworkers. One in ten L6 went on vacation in the prior year, which was significantly lower compared to about three in ten OM6.

Service Coordination and Other Services and Supports

Nearly all L6 and OM6 reported that they received service coordination/case management, health and dental care coordination, and residential support services¹. A majority of L6 and OM6 also received transportation, day services other than employment, and indicated that they had a behavior plan. Although, percentagewise, L6

¹ In reality, all participants received service coordination/case management, health and dental care coordination, and residential support services, even though a small percent of participants did not report this within the surveys.

received only slightly more dental care coordination and information on benefits/insurance than OM6, the difference was still statistically significant. Although about three quarters or more of movers in both groups received Medicare, the number of L6 receiving Medicare was significantly higher than OM6.

Most L6 and OM6 received assistance finding, maintaining, or changing housing or help with social/relationship issues and meeting people. About one third of L6 and OM6 received environmental adaptations or home modifications. About 10 percent of L6 and OM6 received communication technology, respite/family support, or another service or support that was not listed in the survey.

One third of L6 and nearly half of OM6 reported that they received education, training, or skills development. Significantly fewer L6 received education, training, or skills development compared to OM6. This difference in receipt of education, training, or skills development may be related to the age of L6, who were on average older than OM6. With more people in the L6 group above the retirement age, which is 50 years old for adults with developmental disabilities, fewer individuals may have wanted education, training, or skills development. One in ten L6 reported getting assistance finding, maintaining, or changing jobs, which was significantly lower compared to one in four OM6.

Health

Perceived Health Status

L6 and OM6 perceptions of their health were positive. When movers were asked how they would describe their health, the majority of L6 and OM6 responded either excellent or very good, with the next most prevalent response being fairly good. Very few movers in both groups indicated they were in poor health.

Health Care and Preventative Screenings

Overall, health care needs were being met. Nearly all L6 and OM6 had a primary care doctor, and nearly all movers had an annual exam in the last year. However, a significantly higher rate of L6 had an annual exam compared to OM6.

B. 2015-2016 Findings

In general, the majority of movers were getting their health care and screenings within the recommended intervals. This included annual dental exams, annual vision screenings, annual flu vaccines, and hearing tests within the past five years.

There were some differences between mover groups. While most OM6 had regular dental exams, vision screenings, and hearing tests, screening rates for these tests were significantly higher among L6. About one in seven L6 and one in six OM6 did not know if they had a hearing test in the past five years.

A majority of female L6 and OM6 had a pap test in the past three years with about another 20 percent uncertain about whether they had a pap test in the past three years. While a majority of women over age 40 received a mammogram within the past two years, significantly more L6 received this screening compared to OM6. Similar to the pap test, over 10 percent of female movers in both groups did not know if they had received this screening. There is room to improve the frequency of getting preventative screenings completed within recommended intervals and increase mover awareness of when screenings are done.

Roughly 60 percent of L6 and OM6 over age 50 never had a colorectal cancer screening, and whether a screening had ever been done was unknown for almost one quarter of movers in both groups. These findings demonstrate room for improvement in ensuring movers receive and understand the purpose of these specialty health screenings and further investigation to understand gaps in cancer screening.

Wellness

Overall, body weights and levels of physical activity may be an area worth further exploration for both L6 and OM6. Two in five L6 were overweight (i.e., BMI great than 25), which was significantly lower compared to three in five OM6. One third of L6 and one fourth of OM6 reported that they do not exercise or do physical activity, such as brisk walking, swimming, and bicycling. A significantly higher number of OM6 (19 percent) were tobacco users compared to L6 (two percent).

Respect and Rights

Based on select rights asked about in the survey, the percentage of L6 and OM6 who were able to assert their rights was low. About one in seven L6 could lock their bedroom

doors compared to one in five OM6. Separately, very few L6 (three percent) had a key to their homes, which was significantly lower compared to OM6 (17 percent). The low percentages can be attributed to contradictory Federal, State, and local regulations¹. Very few movers in both groups reported having ever voted or having had the opportunity to register but chose not to. About one in ten movers in both groups indicated that they participated in a self-advocacy group or meeting. More information may be gathered to understand why movers may not be voting or attending self-advocacy groups at higher rates.

Access

Nearly all OM6 indicated they felt that staff who work with them had the right training to meet their needs. For OM6 who needed additional services and supports, about 40 percent reported that they needed assistance finding, maintaining, or changing housing or jobs, and education, training, or skills development. L6 responses are not provided because the sample size was too low (i.e. 0-10 responses per question).

Section I

Findings based on data from *Section I* are presented separately from findings based on data from *Background Information* or *Section II* because *Section I* questions, which can only be answered by the individual, had lower response rates. Yet, these data are valuable as it was self-reported by the movers themselves rather than proxies. Proxies can respond to questions within *Background Information* and *Section II*. These responses provided valuable insight regarding movers' true perceptions, although the findings are not generalizable and should be interpreted with caution due to the small number of movers who were able to independently respond. In general, more Other movers responded to *Section I* questions, which is consistent with the significantly greater number of OM6 who were able to use spoken language in comparison to L6. Due to small sample sizes for L6 on *Section I* items, testing for group differences on

¹ 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>; California Fire Code. §§ 435.8.3.3 (2019). Retrieved from <https://up.codes/viewer/california/ca-fire-code-2019>

Section I items was not performed, and most findings reported below focused on the OM6 group.

Employment and Other Daily Activities

A majority of movers from both groups³ indicated that they attended a day program or workshop. Roughly one quarter of movers in both groups³ reported that they volunteered. Very few L6¹ and OM6 were engaged in paid work, either in a community² or facility-based³ employment setting.

Perceptions of paid work and day programs among OM6 were mostly positive. The majority of OM6 (87%) perceived that they liked their jobs, while one third of OM6 indicated that they wanted to work elsewhere. One quarter of OM6 reported wanting to go to their day programs more often; it may be worthwhile to explore ways to give movers more opportunities to participate in day programs more often. This positive sentiment from OM6 may reflect their general satisfaction with work options and day programs.

Community Inclusion

Nearly all OM6 reported being able to go out and do things they liked. Separately, nearly all OM6 said they had enough things that they like to do at home.

Friends and Family

Findings regarding friends and family were largely positive. Roughly two thirds of OM6 indicated that they had friends who were not staff or family. One half of OM6 reported being able to see their friends. A majority of OM6 reported having other ways to communicate with friends if they could not see them. Many OM6 also reported being able to see their family or date when they wanted. Approximately four out of ten OM6 indicated that they felt or sometimes felt lonely. Roughly one third of OM6 said they wanted help keeping in contact with or making friends. It may be beneficial to explore ways to further support movers in establishing and maintaining friendships.

¹ Results should be interpreted with caution due to the small number of individuals (i.e., 11-29 responses) who provided information.

² Community-based setting is a place where most people do not have disabilities.

³ Facility-based setting is a place where most people do have disabilities.

Service Coordination

Overall, OM6 reported positive experiences with service coordination. Nearly all L6¹ and OM6 had met their service coordinators, had staff who helped them, and had staff who came and left when scheduled. These findings reflect successful service coordination within the community homes.

Nine out of ten OM6 had an IPP, and nearly all reported that they participated in their last IPP meeting, understood what was talked about in the meeting, felt that the meeting included people they wanted to be there, received the IPP in their preferred language, and were able to choose or had input regarding the services that were included. Among OM6, a majority reported that their service coordinators asked them what they wanted and that they were able to contact their service coordinators when desired.

Other Services and Supports

Overall, nearly all L6¹ and OM6 movers felt that services and supports they received were helping them live a good life. Among L6 and OM6, perceptions of their current homes were generally positive. Nearly all L6¹ and OM6 movers reported liking their homes. Interestingly, one in ten L6¹ and five in ten OM6 wanted to live somewhere else. Given that community homes were specially constructed to meet the special care needs for many L6 and OM6, there may be limited options for moving. There may be opportunities to improve the experiences in current homes if movers can identify specific elements that cause dissatisfaction.

Respect and Rights

All L6¹ and OM6 reported that staff always treated them with respect. Most movers felt that their privacy was respected. Over 90 percent of L6¹ and OM6 felt they had enough privacy at home. A majority of L6² and OM6 reported that visitors announced themselves before entering their homes or their bedrooms.

¹ Results should be interpreted with caution due to the small number of individuals (i.e., 11-29 responses) who provided information.

² Results should be interpreted with caution due to the small number of individuals (i.e., 11-29 responses) who provided information.

Three quarters of OM6 reported that they could be alone with visitors at home, although most OM6 reported there were rules about being alone with friends or visitors. Nearly all OM6 indicated that they were allowed to use the phone and internet any time, independently or with assistance. A small number of OM6 indicated that they read their own mail or email, or that others read it with their permission, while a majority indicated that their mail or email was read without their permission. Further exploration in this area could help discern whether movers have preferences regarding whether others read their mail/email without their permission. Understanding of such preferences would help determine if this issue is problematic and needs to be addressed.

Safety

Overall, L6 and OM6 felt safe in their environments. Roughly three quarters of L6¹ and OM6 reported that they do not feel afraid anywhere. Nearly all OM6 indicated that they had someone to talk to if afraid.

Access

All L6¹ and nearly all OM6 reported that they always had a way to get places when needed. Three in five OM6 reported being able to get to places when wanted.

Overall Summary of Findings Successes

When L6 and OM6 moved from a DC into community homes, their experiences with life in the community were generally successful.

- Movers from both groups were involved in making some life decisions.
- A majority of L6 and OM6 were engaged in routine activities outside of their home, such as community- and facility-based activities.
- Most L6 and OM6 went on outings in the community.
- All L6 and nearly all OM6 reported that they had transportation when they needed it.

Movers were positive about services and supports they received.

- Nearly all L6 and OM6 reported liking their homes.

- Nearly all L6 and OM6 felt that services and supports they received were helping them live a good life.
- Nearly all L6 and OM6 indicated that they received service coordination or case management, health and dental care coordination, or residential support services.
- Almost all OM6 indicated that they felt that staff had the right training to meet their needs.
- All L6 and OM6 from both groups felt that staff always treated them with respect.
- Nearly all OM6 indicated that they had someone to talk to if they felt afraid. Movers from both groups said that they felt safe in their environments.
- Nearly all L6 and OM6 felt that their privacy was respected, especially at home.

Health care and services needs were being met.

- L6 and OM6 had largely positive perceptions of their health.
- The majority of L6 and OM6 were getting their health care and preventative screenings within the recommended intervals.

Areas in Need of Possible Exploration

There may be room to improve both general services and supports movers receive, and specific services related to health and wellness promotion and illness prevention in movers. This includes quicker access to dental/medical services and receiving health screenings at recommended intervals. Movers may also benefit from supports to encourage exercise/physical activity and healthy weight management.

- Most OM6 reported needing additional services and supports, specifically assistance with housing, with jobs, and getting education, training, or skills development.
- Screening rates for regular dental exams, vision screenings, and hearing tests, were significantly higher among L6 compared to OM6.
- Half of movers in both groups were considered overweight or obese (i.e., BMI greater than 25).
- One third of L6 and one quarter of OM6 reported they did not exercise or do physical activity.

Although most movers generally went on outings within the community, there is room to improve their integration within the community if desired by the mover and help increase their ability to go out into the community when and where they want to. Movers may also appreciate more help making and maintaining friendships.

- Most L6 and OM6 went out only once or twice a month for things like shopping, running errands, entertainment, and going out to eat.
- Almost half of OM6 felt lonely and wanted help making friends or keeping in contact with friends.

It may be beneficial to help movers understand their choices and privacy options.

- Some movers in both groups were not aware that they could change their service coordinators if they wanted to; L6 had lower awareness of this compared to OM6.
- Most movers reported being involved in making choices related to things like their daily schedules, how they spend their free time, and how to spend their money, although L6 had significantly lower rates compared to OM6.
- In terms of privacy, a majority of OM6 reported that their mail or email was often read without their permission.

C. Annual Mover Survey- Year Seven

Summary of Findings

Findings in this chapter are based on data collected from two groups during survey year 2016-2017:

- Movers from the Lanterman DC who moved to the community on or after July 1, 2009 (Lanterman movers or L7). Data from a total of 301 individuals were available for the L7 group.
- Movers from other DCs (Sonoma DC, Porterville DC, and Fairview DC) who moved from a DC to the community within five years prior to the 2016-2017 data collection cycle (Other movers or OM7). Data from a total of 397 individuals were available for the OM7 group.

As with Year Six, findings are organized into two sections: *Background Information and Section II* followed by *Section I*. Conclusions based on data from *Background Information and Section II* are presented separately from those based on *Section I* data. *Section I* data valuable as it was self-reported by the movers rather than proxies but is more limited due to low response rates. Results are organized by survey sections. Data tables containing percentages and counts for all of the questions asked during this survey year are located in a separate appendix document created to supplement this report¹.

Group Comparisons

This survey year, L7 had been living in a community setting between two and eight years at the time of data collection. The OM7 transitioned into a community residence between June 2011 and June 2016, and had thus been living in a community setting for five years or less at the time of data collection. Besides the difference in the range of years/time each group has been living in the community, there were differences in demographic characteristics between the two groups that should be considered when

¹ Appendices to the California Annual Mover Survey Report: Fiscal Years 2015-2016, 2016-2017, and 2017-2018

interpreting comparisons made in this summary (see Demographic Information section below).

As previously described, L7 were compared to OM7 as a reference point to better understand the transition of both groups to a community residence as well as integration into the larger community. Descriptive results are also provided for each group individually, given the limitations of these comparisons due to significant differences between the two groups.

Background Information and Section II Demographic Information

Sociodemographic Characteristics

Summary of Differences Between L7 and OM7 in Demographic Information.

In summary, the L7 group included fewer males and were older compared to the OM7 group. L7 had significantly higher rates of ID and higher rates of having profound ID compared to OM7. More L7 used gestures or body language compared to OM7, and only a few L7 used spoken language as their primary means of communication. L7 have also been living out in the community for longer periods than OM7. Overall, these group differences have implications regarding the utility of making comparisons across these two groups and should be considered when reviewing the group comparisons reported below.

Age, Race and Gender

Both L7 and OM7 groups were made up predominantly of White males with English as their primary language. For both groups, the second largest race or ethnicity selected was Hispanic/Latino, and Spanish was the second largest language selected, although only four percent for both groups.

The average age was 57 years old for L7 and OM7 was 50 years old. Despite both groups being predominately male and having a similar average age, there were significantly fewer males and significantly older individuals in the L7 group (59 percent male) compared to OM7 group (69 percent male).

Additionally, about two thirds of L7 had a legally appointed guardian or conservator compared to nearly one quarter of OM7 with a legally appointed guardian. This was a significant difference between the two groups. It is possible that a higher proportion of legally appointed guardians or conservators in the L7 group may have impacted the quality and quantity of services and supports received; this is a potential area for further exploration.

Developmental Disorders

Nearly all L7 had a diagnosis of Intellectual Disability (ID) with nearly all having a diagnosis of profound or severe ID. Despite the large majority of both groups having a diagnosis of profound or severe ID, L7 had significantly higher rates of having profound ID compared to OM7.

Most individuals in both groups had at least one additional developmental disorder diagnosis (e.g., epilepsy, autism spectrum disorder, cerebral palsy) in addition to ID. Although individuals from both groups have multiple developmental diagnoses, a significantly higher number of L7 had cerebral palsy (CP) or epilepsy compared to OM7. Among movers who had epilepsy, half of L7 had seizures under control, which was significantly less compared to two thirds of OM7. Additionally, four in ten L7 reported having seizures less than once a month, and this was significantly more compared to three in ten OM7.

Rates of co-occurring mental health conditions were relatively high among both groups. Many L7 and OM7 reported behavior challenges (e.g., aggression, self-injurious behavior, pica), having an anxiety disorder (e.g., obsessive disorders, panic disorders), or having a mood disorder (e.g., depression, mania, bipolar disorder). L7 had significantly higher rates of having a mood disorder compared to OM7.

Communication & Mobility

Other areas of significant differences between L7 and OM7. A significantly higher number of L7 used gestures or body language compared to OM7, and a significantly lower number of L7 used spoken language as their primary means of communication. This difference in primary means of communication may have implications for ability to respond to *Section I* questions, which can only be answered by the individual. In both

groups, the most common mobility type was the ability to move independently without aids. However, a significantly lower number of L7 reported moving independently without aid compared to OM7, followed by moving independently with aids or a wheelchair. L7 indicated this mobility type at significantly higher rates compared to OM7. The third mobility type of being non-ambulatory was reported by L7 and OM7 at similar rates.

Residence

Nearly all individuals in both groups required 24-hour on-site support or supervision in their home with the majority of both groups living in Community Care Facilities (CCF). There were significantly more L7 living in CCF with four to six residents compared to OM7. L7 had significantly higher rates of living in their current homes for more than five years compared to OM7, whereas shorter durations of continuous residence were comparable across the groups (e.g. less than one year, between one to three years, or between three to five years). The majority of L7 and OM7 were living in their current homes between one to three years or between three to five years. While there is a difference between L7 and OM7 for living more than five years in their current residences, it is unclear whether this difference is expected, and more investigation on this issue may be warranted.

Health Conditions

Findings regarding health conditions were generally reflective of an aging sample. The most common health conditions among both L7 and OM7 were dysphagia, high blood pressure, and limited or no vision. One in three L7 had dysphagia compared to one in four OM7, which was a significant difference and reflects increases in both mover groups. In addition, roughly half of L7 and OM7 were diagnosed with another health condition not listed on the survey.

Behavioral Support Needs

A majority of L7 and OM7 needed some support to manage either self-injurious or disruptive behavior. About one half of both mover groups needed some support to manage behavior that was destructive or harmful to others.

Medications for Behavioral Challenges

Rates of medication use in the two mover samples were similar. Half of L7 and OM7 took medications to treat mood, anxiety, or psychotic disorders. About one third of L7 and OM7 took medications for other behavioral challenges.

Choices and Decision Making

A majority of L7 and OM7 reported being involved in making choices related to their daily schedules, how they spend their free time, how to spend their money, and being able to change their service coordinator if desired. While a majority of both mover groups indicated high involvement in making these choices, L7 had significantly lower rates compared to OM7 for choosing how they spent money. Responses to making other life choices (i.e., pertaining to day program, home, roommates) were generally low among movers in both groups. However, L7 reported significantly less ability in making choices about their homes compared to OM7.

Overall, L7 reported significantly lower rates of being involved in making choices compared to OM7. The higher number of L7 with profound or severe ID and lower rates of spoken language could explain the lower rates of being able to make independent choices or life decisions. Generally, L7 may benefit from increased opportunities to make choices and practice independence.

Employment and Other Daily Activities

Unpaid Activities

Movers had opportunities to participate and engage in unpaid community- and facility-based activities. These activities offer chances for building social relationships and skills engagement. Most movers in both groups were engaged in unpaid community-based activities (e.g., volunteer activities, skills training, school) and unpaid facility-based activities (e.g., day habilitation, prevocational, seniors' programs).

Almost half of L7 (46 percent) and slightly more than half (55 percent) of OM7 engaged in a facility-based activity, which was a significant difference. Both groups spent a similar amount of time on facility-based activities, averaging roughly 50 hours per two-week period. For community-based activities, a significantly higher number of L7, four out of ten, participated compared to two out of ten OM7. The amount of time spent on

community-based activities in a two-week period was significantly higher for the L7 group (an average of 53 hours) compared to OM7 (an average of 46 hours).

Almost all L7 and OM7 received regional center services or supports to participate in these community- and facility-based activities, although significantly more Lanterman movers received these supports. Nearly all L7 and OM7 reported that activities were primarily done by people with disabilities, although the L7 group (nine out of ten) was significantly and slightly higher compared to OM7 (eight out of ten).

Employment as IPP Goal

Having paid community employment as a goal in their Individual Program Plan (IPP) was related to higher chances of having a paid job. For example, seven out of ten OM7 with a paid job had employment as a goal in their IPP. Very few L7 (one percent) had community employment as a goal in their IPP regardless of whether someone had a paid job, which was significantly lower compared to the 19 percent of OM7. This may be an area worth investigating further; additional supports may be needed so that individuals who are able to work and interested in having a paid job can include community employment as a goal in their IPP.

Community Inclusion

Both L7 and OM7 went on outings in the community, generally going on outings only once or twice a month. L7 and OM7 most frequently went out at least once a month for shopping, errands, entertainment, and eating out. Going out with staff or with housemates or coworkers were the most common companion types, with L7 reporting going out with housemates significantly more than OM7. Most movers did not go to a religious service or spiritual practice. For L7 and OM7 who did attend, individuals typically went three or four times a month, and did so with staff, housemates, or coworkers.

One in five L7 participated in community groups or activities (e.g., church groups, formal or informal community groups), which was significantly higher compared to one in ten OM7. Movers in both groups who participated in community groups or activities often went with staff, housemates, or coworkers. One in ten L7 went on vacation in the previous year, which was significantly lower compared to about two in ten OM7.

Service Coordination

A majority of L7 and OM7 indicated that they had a behavior plan.

Other Services and Supports

Similarly, nearly all L7 and OM7 reported that they received service coordination/case management, health and dental care coordination, or day services other than employment¹. A majority of L7 and OM7 also received residential support services, transportation, assistance finding, maintaining, or changing housing, or information on benefits/insurance. Although, percentage-wise, L7 received only slightly more health care coordination, dental care coordination, or day services other than employment than OM7, the difference was still statistically significant. L7 received significantly less assistance finding, maintaining, or changing housing than OM7. This may be related to significantly more L7 living in their current homes for more than five years.

Over three quarters of movers in both groups received Medicare. The number of L7 receiving Medicare was significantly higher than OM7.

There were significantly more L7 who received help with social/relationship issues and meeting people than OM7, while there were many movers getting this support in both groups. About one third of L7 and OM7 received environmental adaptations or home modifications. About 15 percent of L7 and OM7 received communication technology or education, training, or skills development. One in ten L7 reported getting assistance finding, maintaining, or changing jobs, which was significantly lower compared to one in five OM7.

Health

Perceived Health Status

L7 and OM7 perceptions of their health were positive. The majority of L7 and OM7 described their health as either excellent or very good when asked. Very few movers in both groups indicated they were in poor health.

¹ In reality all participants received service coordination/case management as well as health and dental care coordination even though a small percent of participants did not report this within the surveys.

Health Care and Preventative Screenings

Overall, health care needs were being met. Nearly all L7 and OM7 had a primary care doctor, and nearly all movers had an annual exam in the last year.

The majority of movers were getting their health care and screenings within the recommended intervals, including annual dental exams, annual vision screenings, annual flu vaccines, annual pneumonia vaccine, and hearing tests within the past five years. While most of OM7 had regular dental exams, vision screenings, hearing tests, and annual pneumonia vaccines, screening rates for these tests were significantly higher among L7. About one in five L7 and OM7 did not know if they had a hearing test in the past five years.

A majority of female L7 and female OM7 had a pap test in the past three years. A majority of women over age 40 in both mover groups received a mammogram within the past two years. However, about 20 percent of female movers in both groups did not know whether they had a pap test in the past three years or whether they had a mammogram within the past two years.

Roughly 70 percent of L7 and 50 percent of OM7 over age 50 never had a colorectal cancer screening, and whether a screening had ever been done was unknown for 31 percent of L7 and 22 percent of OM7.

It may be worthwhile to explore ways to ensure that all movers receive preventative screenings within recommended intervals, or better understand barriers to such screenings.

Wellness

Overall, body weights and levels of physical activity may be an area worth further exploration for both L7 and OM7. Two in five L7 were overweight (i.e., BMI great than 25), which was significantly lower compared to three in five OM7. Two in five L7 and OM7 reported that they do not exercise or do physical activity. Examples of physical activity included brisk walking, swimming, and bicycling. A significantly higher number of OM7 (16 percent) were tobacco users compared to L7 (less than 1 percent).

Respect and Rights

Based on select rights asked about in the survey, the percentage of L7 and OM7 who were able to assert their rights was low. Significantly fewer L7 (18 percent) could lock their bedroom doors compared to OM7 (25 percent). Separately, few L7 (9 percent) had a key to their home, which was significantly lower compared to OM7 (14 percent). The low percentages can be attributed to contradictory Federal, State, and local regulations¹. Very few movers in both groups reported having ever voted or having had the opportunity to register but chose not to. One in ten movers in both groups indicated that they participated in a self-advocacy group or meeting. More information may be needed to understand why movers may not be asserting their rights, or if they prefer to have more opportunities to do so.

Access

Nearly all OM7 indicated they felt that staff who work with them had the right training to meet their needs. For OM7 who needed additional services and supports, about 30 to 40 percent reported that they needed assistance finding, maintaining, or changing housing or jobs, and education, training, or skills development.

Section I

Findings from *Section I* are presented separately from findings based on data from *Background Information* or *Section II*, because *Section I* questions, which can only be answered by the individual, had lower response rates. These responses provided valuable insight regarding movers' true perceptions, although they should be interpreted with caution and are not generalizable due to the small number of mover respondents. More OM7 responded to *Section I* questions in comparison to L7, likely due to differences in verbal ability. Due to small sample sizes for L7 in this section, testing for group differences was not performed, and most findings reported below focused on OM7.

¹ 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>; California Fire Code. §§ 435.8.3.3 (2019). Retrieved from <https://up.codes/viewer/california/ca-fire-code-2019>

Employment and Other Daily Activities

A majority of movers from both groups³ indicated that they attended a day program or workshop. One in three OM7 were engaged in paid work, either in a community¹ or facility-based² employment setting; Of the few L7³ who responded, none had paid work.

Perceptions of paid work and day programs among OM7 were mostly positive. The majority of OM7 perceived that they liked their job, while half of OM7 indicated that they wanted to work elsewhere. Two in five OM7 reported that they volunteered. Most OM7 reported being happy with the amount of time they spend at their day programs. This positive sentiment from OM7 may reflect their general satisfaction with work options and day programs.

Community Inclusion

Nearly all OM7 reported being able to go out and do things they liked and also had enough things that they like to do at home.

Friends and Family

Findings regarding friends and family were largely positive. Roughly three quarters of OM7 indicated that they had friends who were not staff or family and two thirds of OM7 reported being able to see their friends. Nearly all OM7 reported having other ways to communicate with friends if they could not see them. A majority of OM7 also reported being able to see their family or go on dates when they wanted. Half of OM7 indicated that they felt or sometimes felt lonely. Almost one third of OM7 said they wanted help making friends or keeping in contact with friends; it may be beneficial to consider providing further supports in this area.

Service Coordination

OM7, overall, reported positive experiences with service coordination. Nearly all felt that the services and supports they received were helping them live a good life and had met their service coordinator. Nine out of ten OM7 had an IPP, and nearly all reported that

¹ Community-based setting is a place where most people do not have disabilities.

² Facility-based setting is a place where most people do have disabilities.

³ Results should be interpreted with caution due to the small number of individuals (i.e., 11-29 responses) who provided information.

they participated in their last IPP meeting, understood what was talked about in the meeting, felt that the meeting included people they wanted to be there, received the IPP in their preferred language, and were able to choose or had input regarding the services that were included. Among OM7, a majority reported that their service coordinators asked them what they wanted and that they were able to contact their service coordinators when desired.

All L7¹ and nearly all OM7 had staff who helped them. Nearly all OM7 had staff who came and left when scheduled.

Other Services and Supports

Among L7 and OM7, perceptions of their current homes were generally positive. Nearly all L7 and OM7 reported liking their homes, yet one in ten L7¹ and four in ten OM7 wanted to live somewhere else. Given that community homes were specially constructed for L7 and OM7, there may be limited options for moving between different homes. There may be opportunities to improve the experiences in current homes if movers can identify specific elements that cause dissatisfaction.

Respect and Rights

Most movers felt that their privacy was respected. All L7¹ and nearly all OM7 felt they had enough privacy at home. Nearly all L7¹ and OM7 reported that visitors announced themselves before entering their homes or their bedrooms.

Nearly all OM7 reported that staff always treated them with respect. Three quarters of OM7 reported that they could be alone with friends or visitors at home. Most OM7 reported there were rules about being alone with visitors. Nearly all OM7 indicated that they were allowed to use the phone and internet any time. Very few OM7 indicated that they read their own mail or email, or that others read it with their permission, while a majority indicated that their mail or email is read without their permission. This may warrant further exploration.

¹ Results should be interpreted with caution due to the small number of individuals (i.e., 11-29 responses) who provided information.

Safety

A majority of L7¹ and OM7 reported that they do not feel afraid anywhere. OM7 felt safe in their environments, and nearly all Other movers indicated that they had someone to talk to if afraid.

Access

Nearly all OM7 reported that they always had a way to get places when needed. Two thirds of OM7 reported being able to get to places when wanted.

Overall Summary of Findings

Successes

When L7 and OM7 moved from a DC into a community home, their experiences with life in the community were generally successful.

- Movers from both groups were involved in making some life decisions.
- A majority of L7 and OM7 were engaged in routine activities outside of their home, such as community- and facility-based activities.
- Most L7 and OM7 went on outings in the community.
- Nearly all OM7 reported that they had transportation when they needed it.

Movers were positive about services and supports they received.

- Nearly all L7 and OM7 reported liking their homes.
- Nearly all OM7 felt that services and supports they received were helping them live a good life.
- Nearly all L7 and OM7 indicated that they received service coordination or case management, health and dental care coordination, and day services other than employment.
- Nearly all OM7 indicated that they felt that staff had the right training to meet their needs.
- Nearly all OM7 felt that staff always treated them with respect.
- Nearly all OM7 indicated that they had someone to talk to.

¹ Results should be interpreted with caution due to the small number of individuals (i.e., 11-29 responses) who provided information.

- Nearly all L7 and OM7 felt that their privacy was respected, especially at home.

Health care and services needs were being met.

- L7 and OM7 had largely positive perceptions of their health.
- The majority of L7 and OM7 were getting their health care and screenings within the recommended intervals.

Areas in Need of Possible Exploration

There may be room to improve both general services and supports movers receive, and specific services related to health and wellness promotion and illness prevention in movers. Movers may also benefit from supports to encourage exercise/physical activity and healthy weight management.

- Regular dental exams, vision screenings, hearing tests, and annual pneumonia vaccines were significantly higher among L7 compared to OM7.
- Half of movers in both groups were considered overweight or obese (i.e., BMI greater than 25).
- Nearly half of L7 and one quarter of OM7 reported they did not exercise or do physical activity.
- Most OM7 reported needing additional services and supports, specifically assistance with housing, with jobs, and getting education, training, or skills development.

Although most movers generally went on outings within the community, there may be room to improve their level of community integration if desired by the mover.

Additionally, movers may appreciate more help making and maintaining friendships.

- Most L7 and OM7 went out only once or twice a month for things like shopping, running errands, entertainment, and going out to eat.
- Half of OM7 felt lonely and wanted help making friends or keeping in contact with friends.

It may be beneficial to help movers better understand their choices and privacy options.

L7 may benefit from help making life choices independently (e.g., spending money).

These areas may warrant further exploration.

- Most movers reported being involved in making choices related to things like their daily schedules, how they spend their free time, and how to spend their money, although L7 had significantly lower rates compared to OM7.
- In terms of privacy, a majority of OM7 reported that their mail or email was often read without their permission.

D. Annual Mover Survey- Year Eight

Summary of Findings

Findings in this chapter are based on data collected from two groups during survey year 2017-2018:

- Movers from the Lanterman DC who moved to the community on or after July 1, 2009 (Lanterman movers or L8). Data from a total of 294 individuals were available for the L8 group.
- Movers from other DCs (Sonoma DC, Porterville DC, and Fairview DC) who moved from a DC to the community within five years prior to the 2017-2018 data collection cycle (Other movers or OM8). Data from a total of 60 individuals were available for the OM8 group.

Findings are organized into two sections: *Background Information* and *Section II* followed by *Section I*, as *Section 1* data was self-reported by the movers rather than proxies and is more limited due to low response rates. Findings are organized by survey sections. Data tables containing percentages and counts for all of the questions asked during this survey year are located in the separate Appendices document, which was created to supplement this report¹.

Group Comparisons

This survey year, the L8 group had been living in a community setting between three and nine years at the time of data collection. The OM8 group transitioned into a community residence between June 2012 and June 2017, and had thus been living in a community setting for five years or less at the time of data collection. Due to the limited sample size of OM8 included in this data collection cycle, no comparisons are made between OM8 and L8 movers.

In this chapter, descriptive results are provided for each group individually.

¹ Appendices to the California Annual Mover Survey Report: Fiscal Years 2015-2016, 2016-2017, and 2017-2018

Background Information and Section II Demographic Information

Sociodemographic Characteristics

Summary of Differences Between L8 and OM8 in Demographic Information

The L8 group included fewer males and were older compared to the OM8 group. L8 movers had higher rates of ID and higher rates of having profound ID compared to OM8. More L8 used gestures or body language as their preferred means of expression compared to OM8. L8 have also been living out in the community for longer periods than OM8. Overall, these group differences have implications regarding the utility of making comparisons across these two groups and should be considered when reviewing the group comparisons reported below.

Age, Race and Gender

Both the L8 and OM8 groups were made up predominantly of White males with English as their primary language. For both groups, the second largest race or ethnicity selected was Hispanic/Latino, and Spanish was the second largest language selected, although only six percent for L8 and two percent for OM8. The average age was 58 years old for L8 and 50 years old for OM8.

Two in three L8 had a legally appointed guardian or conservator compared to one in three OM8. A potential area for further investigation is whether the proportion of legally appointed guardians or conservators impacted the quality and quantity of services and supports received.

Developmental Disorders

The comparison of disabilities between the two Mover groups was essentially unchanged from the previous two survey years. All L8 had a diagnosis of Intellectual Disability (ID) with nearly all having a diagnosis of profound or severe ID. Nearly all OM8 had a diagnosis of ID with about three of every five having a diagnosis of profound or severe ID.

Most individuals in both groups had at least one additional developmental disorder diagnosis (e.g., epilepsy, autism spectrum disorder, cerebral palsy) in addition to ID. Among L8 who had epilepsy, about three quarters had seizures under control.

Rates of co-occurring mental health conditions were relatively high among both groups. Many L8 and OM8 reported behavior challenges (e.g., aggression, self-injurious behavior, pica), having an anxiety disorder (e.g., obsessive disorders, panic disorders), or having a mood disorder (e.g., depression, mania, bipolar disorder).

Communication & Mobility

The majority of movers in both groups used gestures or body language as their primary means of communication. The second largest communication method used by L8 (20 percent) and OM8 (38 percent) was spoken language. Most Movers in both groups reported moving independently without aids. The other mobility types – being able to move independently with aids or a wheelchair or being non-ambulatory – were reported by movers in both groups at similar rates.

Residence

Nearly all individuals in both groups required 24-hour on-site support or supervision in their home. The majority of L8 and OM8 lived in Community Care Facilities (CCF), specifically in CCF with four to six residents. The majority of L8 were living in their current homes between three to five years or more than five years. The majority of OM8 were living in their current homes between one to three years.

Health Conditions

Findings regarding health conditions were generally reflective of an aging sample. the most common health conditions among both L8 and OM8 were dysphagia, high cholesterol, and limited or no vision. In addition, roughly half of L8 and OM8 were diagnosed with another health condition not listed on the survey.

Behavioral Support Needs

A majority of L8 and OM8 needed some support to manage either self-injurious or disruptive behavior. About one half of both mover groups needed some support to manage behavior that was destructive or harmful to others.

Medications for Behavioral Challenges

Rates of medication use in the two mover samples were similar. Half of L8 and OM8 took medications to treat mood, anxiety, or psychotic disorders. About one third of L8 and OM8 took medications for other behavioral challenges.

Choices and Decision Making

A majority of L8 and OM8 reported being involved in making choices related to their daily schedules, how they spend their free time, how to spend their money, and being able to change their service coordinator if desired. Responses to making other life choices (i.e., pertaining to day program, home, roommates) were generally low among movers in both groups.

Employment and Other Daily Activities

Unpaid Activities

Movers had opportunities to participate and engage in unpaid community- and facility-based activities, which offer chances for building social relationships and skills engagement. Most Movers in both groups were engaged in unpaid facility-based activities (e.g., day habilitation, prevocational, seniors' programs). Few movers in either group were engaged in unpaid community-based activities (e.g., volunteer activities, skills training, school).

Over half of L8 (61 percent) and slightly more than half (52 percent) of OM8 engaged in a facility-based activity. L8 spent an average of 49 hours per two-week period on facility-based activities, while OM8 spent an average of 53 hours per two-week period. About one in five L8 participated in community-based activities. L8 spent an average of 54 hours per two-week period in community-based activities.

Almost all L8 received regional center services or supports to participate in these community- and facility-based activities. Nearly all L8 reported that activities were primarily done by people with disabilities.

Employment as IPP Goal

Very few L8 (three percent) had community employment as a goal in their IPP compared to 21 percent of OM8.

Community Inclusion

Both L8 and OM8 went on outings in the community. L8 and OM8 most frequently went out with staff, housemates, or coworkers-the most common companion types. Most movers did not go to a religious service or spiritual practice. Of the few L8 movers that did, they chose the type of religious or spiritual service that they attended, typically went once or twice a month, and generally with staff, housemates, or coworkers.

Few L8 and OM8 participated in community groups or activities (e.g., church groups, formal or informal community groups). About one in ten L8 and OM8 went on vacation in the prior year.

Service Coordination

The majority of L8 and OM8 indicated that they had a behavior plan.

Other Services and Supports

Similarly, nearly all L8 and OM8 reported that they received service coordination/case management, health and dental care coordination, transportation, or day services other than employment¹. A majority of L8 and OM8 also received residential support services, assistance finding, maintaining, or changing housing, or information on benefits/insurance. Over three quarters of movers in both groups received Medicare.

About one third of L8 and OM8 received environmental adaptations or home modifications. About one quarter of movers in both groups received help with social/relationship issues and meeting people.

Health

Perceived Health Status

L8 and OM8 perceptions of their health were positive. When movers were asked how they would describe their health, the majority responded either excellent or very good, followed by fairly good. Very few movers in either group indicated they were in poor health.

¹ In reality, all participants received service coordination/case management as well as health and dental care coordination even though a small percent of participants did not report this within the surveys.

Health Care and Preventative Screenings

Overall, health care needs were being met. Nearly all L8 and OM8 had a primary care doctor, and nearly all movers had an annual physical exam in the last year.

The majority of movers were getting their health care and screenings within the recommended intervals, including annual dental exams, annual vision screenings, annual flu vaccines, and hearing tests within the past five years. About one in five L8 and OM8 did not know if they had a hearing test in the past five years. Half of L8 received an annual pneumonia vaccine compared to one quarter of OM8. About one in ten movers in both groups did not know if they had received an annual pneumonia vaccine.

Most female L8 had a pap test in the past three years and a majority of L8 women who were over age 40 received a mammogram within the past two years. However, about one in ten female movers in both groups did not know whether they had a pap test in the past three years or whether they had a mammogram within the past two years.

Three quarters of L8 over age 50 never had a colorectal cancer screening, and whether a screening had ever been done was unknown for 16 percent of OM8.

Wellness

Overall, body weights and levels of physical activity may be an area for further exploration for both L8 and OM8. Half of L8 and two thirds of OM8 were overweight (i.e., BMI great than 25). Half of L8 and one third of OM8 reported that they do not exercise or do physical activity (e.g., brisk walking, swimming, and bicycling). One in ten OM8 (16 percent) were tobacco users compared to less than 1 percent of L8.

Respect and Rights

Based on select rights asked about in the survey, the percentage of L8 and OM8 who were able to assert their rights was low (e.g., lock their bedroom door or vote) was low. A small number of L8 (13 percent) and OM8 (21 percent) could lock their bedroom doors. Separately, few L8 and OM8 had keys to their homes. The low percentages can

be attributed to contradictory Federal, State, and local regulations¹. Very few movers in either group reported having ever voted or having had the opportunity to register but chose not to. Few movers in both groups indicated that they participated in a self-advocacy group or meeting. More information may be needed to understand why movers may not be asserting their rights, or if they prefer to have more opportunities to do so.

Access

The majority of OM8² indicated they felt that staff who work with them had the right training to meet their needs. For L8¹ who needed additional services and supports, about 40 percent reported that they needed assistance with social or relationships issues and meeting people, and other services or supports not listed on the survey.

Section I

The findings below should be interpreted with caution and are not generalizable due to the small number of movers who were able to independently respond to *Section I* survey questions. Regardless, these responses provided valuable insight regarding movers' true perceptions.

Employment and Other Daily Activities

Few L8³ and some OM8¹ were engaged in paid work. Nearly all L8¹ and OM8¹ indicated that they attended a day program or workshop. Most L8¹ and OM8¹ reported being happy with the amount of time they spend at their day programs. One in five L8¹ and OM8¹ reported that they volunteered.

Community Inclusion

All L8¹ and nearly all OM8¹ reported being able to go out and do things they liked. Nearly all L8¹ and OM8¹ said they had enough things that they like to do at home.

¹ 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>; California Fire Code. §§ 435.8.3.3 (2019). Retrieved from <https://up.codes/viewer/california/ca-fire-code-2019>

² Results should be interpreted with caution due to the small number of individuals (i.e., 11-29 responses) who provided information.

Friends and Family

Findings regarding friends and family were largely positive for L8 and OM8. Three quarters of L8¹ and OM8¹ indicated that they had friends who were not staff or family. A majority of L8¹ and half of OM8¹ reported being able see their families when they wanted. One third of L8¹ and two thirds of OM8¹ indicated that they felt or sometimes felt lonely. Almost two thirds of L8¹ and one third of OM8¹ said they wanted help making friends or keeping in contact with friends; given the percentage difference between the two mover groups and the low number of responses, further exploration about this issue may be warranted.

Service Coordination

Overall, L8 and OM8 reported positive experiences with service coordination all L8¹ and nearly all OM8¹ had staff who helped them. Nearly all L8¹ and OM8¹ had met their service coordinators and had staff who came and left when scheduled. All L8¹ and two thirds of OM8¹ reported that their service coordinators asked them what they wanted.

Other Services and Supports

All L8¹ and most OM8¹ reported liking their homes. All L8¹ and three quarters of OM8¹ felt that services and supports they received were helping them live a good life.

Respect and Rights

Most movers felt that their privacy was respected. Nearly all L8¹ and OM8¹ felt they had enough privacy at home. Nearly all L8¹ and OM8¹ reported that visitors announced themselves before entering their homes or their bedrooms.

All L8¹ and nearly all OM8¹ reported that staff always treated them with respect. Three in five L8¹ and OM8¹ reported that they could be alone with friends or visitors at home. All L8¹ and nearly all OM8¹ indicated that they were allowed to use the phone and internet any time. All OM8¹ reported that they read their own mail or email, or that others read it with their permission. Very few L8¹ indicated that they read their own mail or email, or that others read it with their permission, while a majority indicated that their

¹ Results should be interpreted with caution due to the small number of individuals (i.e., 11-29 responses) who provided information.

mail or email is read without their permission. Further exploration in this area is warranted before any conclusions are drawn.

Safety

Generally, L8 and OM8 felt safe in their environments. Three in five L8¹ and nearly all OM8¹ reported that they do not feel afraid anywhere. A majority of L8¹ and OM8¹ indicated that they had someone to talk to if afraid.

Access

Nearly all L8¹ and OM8¹ reported that they always had a way to get places when needed, and nearly all indicated being able to get to places when wanted.

Overall Summary of Findings Successes

When L8 and OM8 moved from a DC into a community home, their experiences with life in the community were generally successful.

- Movers from both groups were involved in making some life decisions.
- A majority of L8 and OM8 were engaged in routine activities, such as community- and facility-based activities.
- Most L8 and OM8 went on outings in the community.
- Nearly all L8 and OM8 reported that they had transportation when they needed it.

Movers were generally positive about services and supports they received.

- All L8 and most OM8 reported liking their homes.
- All L8 and many OM8 felt that services and supports they received were helping them live a good life.
- Nearly all L8 and OM8 indicated that they received service coordination or case management, health and dental care coordination, transportation, and day services other than employment.
- All L8 and nearly all OM8 felt that staff always treated them with respect.
- A majority of L8 and OM8 indicated that they had someone to talk to.
- Nearly all L8 and OM8 felt that their privacy was respected, especially at home.

Health care and services needs were generally being met.

- L8 and OM8 had largely positive perceptions of their health.
- The majority of L8 and OM8 were getting their health care and screenings within the recommended intervals.

Areas in Need of Possible Exploration

There may be room to improve services and supports so that they better help to promote health and wellness, prevent illness in movers, and encourage exercise/physical activity and healthy weight management.

- Half of L8 and two thirds of OM8 were considered overweight or obese (i.e., BMI greater than 25).
- Half of L8 and one third of OM8 reported they did not exercise or do physical activity.

Given the low number of responses, findings still suggest further inquiry into mover integration within the community, including the frequency and types of community outings and activities that movers participate in and whether movers may appreciate more help making and maintaining friendships may be warranted.

- Most L8 and OM8 went out only once or twice a month for outings like shopping, running errands, entertainment, and going out to eat.
- Many L8 and some OM8 felt lonely and wanted help making friends or keeping in contact with friends.

Although there were too few responses to make conclusive findings, it may be beneficial to explore movers' understanding of their choices and privacy options and if they would benefit from help making life choices independently, such as spending money.

- Although most movers reported being involved in making choices related to some things (e.g., daily schedules, how they spend their free time, how to spend their money), involvement in decisions regarding other choices (e.g., day program, home, roommates) was generally low among movers in both groups.
- In terms of privacy, a majority of L8 reported that their mail or email was often read without their permission.