
National Core Indicators California Mover Longitudinal Study

Year Three Report

Data collected from January 1, 2016 through
December 31, 2018



UC DAVIS
Continuing and
Professional Education

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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.

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

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

This report contains preliminary findings from the first three years of the MLS. Subsequent reports will include expanded data and increased participation. This is an important effort because California can use the MLS reports to monitor changes in the system and to guide strategic planning and quality improvement activities as a result of Developmental Centers (DC) closures.

Acknowledgements

This report is possible thanks to the 477 individuals who agreed to share about their experiences after moving from a California developmental center to the community. Special acknowledgment goes to their families, friends, and staff members who provided support and participated in the survey process.

List of Abbreviations and Notations Used in the Report

ACS—Adult Consumer Survey

ASD—Autism Spectrum Disorder

CA-ODESA—California Online Data Entry Survey Application

CCF—Community Care Facility

CP—Cerebral Palsy

DC—Developmental Center

I/DD—Intellectual or Developmental Disability

DDS—Department of Developmental Services

FHA—Family Home Agency

HSRI—Human Services Research Institute

ICF—Intermediate Care Facility

ID—Intellectual Disability

IDT—Interdisciplinary Team

ILS/SLS—Independent Living Skills/Supported Living Services

IPP—Individual Program Plan

MLS—Mover Longitudinal Study

N<30—Sample size is below 30

NASDDDS—National Association of State Directors of Developmental Disability Services

NCI—National Core Indicators

SCDD—State Council on Developmental Disabilities

SNF—Skilled Nursing Facility

*—Used to indicate 0-10 responses were recorded for this item.

**—Used to indicate 11-29 responses were recorded for this item.

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Executive Summary

The MLS is a continuous quality assessment and improvement initiative being carried out by DDS. This is an important effort to collect accurate, reliable, and valid satisfaction and outcome data among individuals with I/DD across the state who moved from a California DC to a community setting since January 2016. The MLS is part of the Department's continuous effort to improve services and supports to all individuals with I/DD across California. Over time, results can be used to identify areas of strength and areas in need of additional evaluation, planning and monitoring.

Study enrollment continued until all individuals moved from developmental centers. Data will continue to be collected at all four time points until all individuals have been living out in the community for two years¹. This report summarizes data collected between January 2016 and December 2018, with data being requested four times after each individual moved into the community (i.e., three-months, six-months, one-year, and two-years after the initial move).

Overall, movers' experiences were positive and remained relatively stable as they were living out in the community. Areas in which changes occurred over time are highlighted in this report. This Executive Summary provides an overview of the study background and main findings.

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.

Assembly Bill (AB) 1405 (2015) required DDS to close DCs and move DC residents into homes within the community where they continue to receive services and supports

¹ The Sonoma DC closed in December 2018, and the Fairview and Porterville DCs are scheduled to be closed in December 2019 and October 2021, respectively. As such, data collection for all movers should be completed by October 2023.

provided by RCs. Senate Bill (SB) 982 (2016) required DDS to evaluate services and supports provided to individuals who have moved from DCs to the community. The MLS and this report are intended to help achieve this legislative mandate and provide DDS and its stakeholders with information on this group of individuals who moved from a DC to the community, including their experiences following the move to the community.

Study Participants

This report highlights findings of the experiences of 477 individuals with I/DD who moved from a DC (i.e., movers)², as well as 109 conservators or family members (i.e., family respondents)³, during the first three months to two years of the transition to the community. The movers were mostly male (60% male vs. 40% female), primarily white (80%), and nearly all indicated English as their primary language (98%). Nearly all movers had a diagnoses of intellectual disability (ID), and most needed high levels of support for daily life. More than half of the movers (57%) had mobility challenges or were non-ambulatory. Family respondents were usually related to the movers (e.g., parents and siblings), although a small number were non-familial conservators. The level of engagement between the family respondents and movers varied, with one third of family respondents seeing movers more than 12 times per year, and another third seeing movers less than three times per year.

Study Methods

The MLS uses the Adult Consumer Survey (ACS 2015-16 version) and the Family Guardian Survey (FGS 2015-16 version) for data collection at four survey time points (i.e., three-months, six-months, one-year, and two-years after the date each mover transitions from a DC to living in the community). These surveys collect demographic information and mover and family perceptions about service coordination, access and life in the community. Interviewers who collect data from movers also have the opportunity to provide comments on the surveys. These surveys were developed as a part of the National Core Indicator (NCI) project by the Human Services Research

² Referred to throughout this report as “movers”.

³ Referred to throughout this report as “family respondents”.

Institute (HSRI) and the National Association of State Directors of Developmental Disability Services (NASDDDS). Data collected from the ACS were analyzed at each individual survey time point and over time (i.e., longitudinally over time) so that the level of stability and change in mover experiences can be identified.

Study Findings

The results presented are intended to highlight *successes* and things that were going well with the movers' transitions to the community and *potential areas in need of further exploration* or improvement. In general, mover experiences were stable over time and were generally positive. Sample comments by family respondents are included, when possible, to complement themes from quantitative findings.

Findings are intended to be used to inform DDS and its stakeholders about the capability and evolution of service delivery throughout the closure process to ensure that clients' needs continue to be met within the community and their quality of life improves as they settle into their new settings. Results highlighted herein can be used to guide further exploration regarding successes to be continued or replicated, and opportunities for improvement within the care and coordination experienced by the individuals who moved from DCs and their families.

Successes

Healthcare and service needs were generally met and stable across survey time points.

- Over 60 percent of individuals who moved from DCs indicated that they were in excellent or good health
- Overall, health care needs were met. For example, all movers had a primary care doctor, and nearly all had an annual physical exam in the past year.
- The majority of people, 90 percent or more at all time points, who moved from DCs, received service coordination, health and dental care coordination, and residential support services.

Experiences with life in the community were largely positive and stable across survey time points.

- Mover self-reports regarding connections with friends and family were largely positive and stable.
- About 75 percent of movers indicated they were able to go out and do things they liked to do at the first three time points⁴.
- Nearly all movers reported having a way to get places when they *needed* to, and most reported having a way to get places when they *wanted* to.
- A majority of movers indicated that they chose or had some input in choosing their daily schedule, how to spend their free time, and how to use their spending money.
- All movers indicated that services and supports generally helped them to live a good life.

“Family member participates in Meals on Wheels and many senior/community activities that involved himself and others, teaching him to care for human life/animals.”

–Family Respondent

Family respondents were generally satisfied with most aspects of the services their family members received in the community, which remained stable over time.

- After the transition to the community, most family respondents indicated that they liked the new homes into which movers transitioned.

“The group home which our family member resides in gets him involved with a lot of community activities.”

–Family Respondent

- The majority of family respondents felt they got enough information to take part in planning support for movers, and that the information they received was easy to understand.

⁴ There were not enough responses collected at the 2-year time point to analyze this question.

- Most family respondents were aware that movers had an Individual Program Plan (IPP) and reported that the IPP included all of the services and supports movers needed.
- Most family respondents reported that they were able to contact service coordinators and support workers, as needed.
- Family respondents reported that services were delivered to movers in ways that were respectful of their culture.

Areas in Need of Further Exploration

It may be beneficial to identify strategies designed to improve family respondent knowledge and engagement in service-planning.

There was a group of family respondents who consistently reported that they “don’t know” about various aspects of mover services and their transitions to the community. This presents an opportunity to strengthen family and conservator engagement in the service-planning process and enhance their knowledge of the services and supports that movers receive.

- Family respondents did not always know that they, or the movers who received services, could make certain types of choices (e.g., that they could change service coordinators, the agency that provides regional center funded services, and staff that provided services).
- At all survey time points, one in five family respondents did not know if the movers received all services listed in the IPP.

“She is doing things she has never done before because of her past institutional setting. She goes to a day program during the week. On the weekend, staff takes her to the zoo, on a ferry to the farmers market, to factory outlet stores...”

–Family Respondent

- At the three-month survey time point, two-thirds of family respondents indicated they did not know whether or not services or supports for the movers had changed, although this decreased to only one-third at the one-year survey time point, which suggests that family respondent knowledge of mover services and supports may be improving over time⁵.

“Turnover in staff (both home and Regional Center) has been noticeable and sometimes interfered with communication.”

–Family Respondent

- Over half of family respondents indicated that handling movers’ emergencies was discussed at the last IPP meeting; however, more than half of family respondents did not feel prepared to handle needs of movers in an emergency.

There may be room to improve services and supports so that they better help to promote health and wellness and prevent illness in movers.

Many of the individuals who moved from DCs were medically fragile or had behavior challenges that may have required different strategies for completion of routine health screenings. Responses indicated that movers may benefit from quicker access to dental or medical services or additional health screenings from providers that are prepared to serve this population. Exercise, physical activity, and healthy weight management are other areas of opportunity to help movers remain healthy within the community setting.

- Respondents were not always satisfied with the timelines of dental and medical services.
- About one quarter of movers over age 50 never had a colorectal cancer screening. Whether a screening had ever been done was unknown for approximately one third of movers.
- Over half of movers were considered overweight or obese (BMI>25).
- Half of movers reported they did not exercise or do physical activity.

⁵ Refer to page 260 in the MLS Year 3 Appendix for specific percentages.

Most movers went on outings within the community but many could increase the frequency and types of community outings and activities in which they participate.

It may be worthwhile to explore the reasons and potential barriers for why many movers stayed home and did not increasingly participate in community outings and activities.

- Most movers went out once or twice a month for things like shopping, running errands, and entertainment. Fewer than one in five went out with friends or family.
 - Ninety percent or more of movers did not participate in community groups or activities.
 - Nearly four out of five movers engaged in unpaid activities in a facility-based setting at two-years (e.g., skills training or volunteering, day habilitation or seniors programs). One in five movers engaged in unpaid activities in the community.
- “Staff drivers at family member’s home provide transportation for [outings]. The problem is that not all staff members are cleared to drive. Therefore, there are days when my family member does not get out at all.”*
- Family Respondent*

Although services and supports for movers are funded by regional centers, some family respondents reported spending their own money on services for the movers.

It may be beneficial to further explore reasons why family respondents spent their own funds on services.

- After the move into the community, approximate one quarter of family respondents indicated that they spent their own money for movers’ services.

Conclusions

Overall, most movers experienced a successful transition to the community, based on three years of data collection. Most mover experiences with life in the community were generally positive and stable over time. Stability in mover experiences demonstrates continued services and supports within community settings that are comparable to what

movers received at the developmental centers. Family members were also satisfied with services the movers received in the community. Nevertheless, findings also demonstrate areas of opportunity to ensure that movers' needs are fully met within the community. For example, movers' families and guardians may benefit from more engagement in and knowledge of service-planning. While the majority of movers received routine healthcare and related screenings and reported good or excellent health, it may be beneficial to identify strategies to ensure that such care is provided to all eligible movers and by providers prepared to serve this population. Similarly, while many movers appeared to be engaging in various outings within the community, there is an opportunity to enhance the extent to which movers feel that they are always able to participate in outings of their choice.

Adult Consumer Survey—Summary of Findings

Findings from the Adult Consumer Survey (ACS) were selected to be included in this summary where things were going well and areas where there may be room for improvement. This report is intended to be a starting point in evaluating the experience of individuals who moved to the community from a California developmental center (DC) on or after January 1, 2016 (known as movers⁶). Overall, there was very little change in the findings from the ACS between the year-two and year-three reporting periods⁷. Although longitudinal analyses were not completed for this report cycle due to limited sample sizes, most ACS responses appeared to be stable across survey time points.

The ACS includes three major sections: *Background Information*, *Section I*, and *Section II*. The *Background Information* section contains questions on the mover's health status and medical examination history, qualifying condition and other diagnoses, residence type, employment or day activity or program, and funded services and supports. *Section I* contains questions about the mover's subjective judgments and personal experiences, such as satisfaction with services. For this reason, *Section I* may only be answered by the mover. *Section II* contains questions about involvement in the community, choices, and access to services. *Section II* questions may be answered by the mover or by a proxy respondent, such as a family member, friend, or support worker. The ACS also includes space for interviewers to provide comments and feedback.

Background Information

Background information was compiled for each mover prior to the in-person interview. Information about demographics and type of residence provided in this section is summarized for all movers at the three-month survey time point. Information summarized below on health conditions, health care, screenings and medications, services and supports, behavioral support needs, and employment and other daily

⁶ In this report, individuals who receive services and moved from a DC to the community are referred to as "movers", while individuals who filled out and submitted a completed FGS (i.e., family members of movers) are referred to as "family respondents".

⁷ The current Year 3 Report includes findings from data collected from movers who moved into the community between 1/1/16 and 12/31/18, whereas the Year 2 Report includes findings from data collected from movers who moved between 1/1/16 and 12/31/17.

activities includes responses given at all four survey time points, as they may change over time.

Demographic Information

The movers were predominantly white males (i.e., 60% male; 80% White) with an average age of 58 years; less than 15 percent identified as Hispanic or Black/African American. English was the preferred language for nearly all movers. More than two thirds used gestures or body language as their primary means of communication, while slightly less than one third used spoken language. More than one third of movers were able to move independently without aids, while slightly over one third were non-ambulatory, and one in five moved with assistive devices or a wheelchair.

Nearly all movers had a diagnosis of Intellectual Disability (ID) and over three quarters of all movers had a diagnosis of profound or severe ID. Many movers also had other developmental disabilities (e.g., epilepsy, autism spectrum disorder, cerebral palsy) in addition to ID. Epilepsy was the second most common diagnosis (51%).

Rates of co-occurring mental health conditions were relatively high. In particular, many movers reported that they had both a behavioral challenge (e.g., aggression, self-injurious behavior, pica), and an anxiety disorder (e.g., obsessive disorders, panic disorders), or a mood disorder (e.g., depression, mania, bipolar disorder). More than a quarter of movers had limited or no vision, and about one in ten movers had a disability not listed on the survey.

Type of Residence

New homes were specifically developed for many movers, and included homes that specialized in caring for those with special health needs or those who required behavioral supports. Over one third of movers moved into a Specialized Residential Facility (SRF). More than one quarter of movers were moved into homes that specialized in care for those with extensive health needs, either an Adult Residential

Facility for Persons with Special Health Needs (ARFPSHN) or an Intermediate Care Facility/Developmentally Disabled (ICF/DD) home.

Health Conditions

Findings regarding health conditions generally reflected an aging population. Most movers had at least one health condition; the rates of all health conditions remained relatively stable over time. At all four survey time points, the most common health conditions were dysphagia, high cholesterol, high blood pressure, and cardiovascular disease. In addition, at all four survey time points, the majority of movers were diagnosed with another health condition not listed on the survey. Health conditions not listed on the survey but frequently reported included osteoporosis, dementia, thyroid dysfunction, anemia, post-traumatic stress disorder, periodontal disease, and gastro-esophageal reflux. At each survey time point, over half of movers were considered overweight or obese (BMI>25); this is consistent with rates in the general population in the state of California⁸.

Health Care, Screenings, and Medications

All movers had a primary care doctor, and nearly all had an annual physical exam in the last year. This remained true at the one- and two-year survey time points, reflecting care that occurred after moving into the community. In general, the majority of movers got their health care and health screenings within the recommended intervals. There was no appreciable decrease in health care and health screenings at the one- or two-year survey time points, indicating that care was maintained once movers were living in the community. This included annual dental exams, vision screenings, and flu vaccines, as well as hearing tests.

Half of female movers had not had a Pap test within the last three years, and almost half of women over age 40 had not received a mammogram in the past two years. Nearly one quarter of movers over age 50 had never had a colorectal cancer screening, and whether a screening had ever been done was unknown for over one quarter of movers. In comparison, Centers for Disease Control and Prevention (CDC) and

⁸ Wolstein J, Babey SH, Diamant AL. *Obesity in California*. Los Angeles, CA: UCLA Center for Health Policy Research, 2015.

National Cancer Institute (NCI) have reported higher rates for these health screenings in the general population in the United States. According to the CDC, 69 percent of women had a pap test in the past three years, 65 percent of women over age 40 had a mammogram in the past two years⁹, and the NCI reported 61 percent of adults over age 50 had a colonoscopy in the past five years¹⁰. The people who moved from DCs were generally medically fragile or had a behavioral challenge, which may have limited their ability to participate in these invasive health screenings or procedures.

Rates of medication use in the sample were largely stable. Nearly half of movers took medications to treat mood, anxiety, or psychotic disorders. Around one third of movers took medications for behavioral challenges. Among movers with epilepsy, most had seizures under control.

Services and Supports

Most movers received service coordination, health and dental care coordination, and residential support services¹¹. Most also received transportation, day services other than employment, information on benefits/insurance, and assistance finding, maintaining, or changing housing. Less than half received education, training, or skills development, environmental adaptations or home modifications, or help with social or relationship issues and meeting people. Less than a quarter of movers received assistance finding, maintaining, or changing jobs, respite or family support, communication technology, or another service or support not listed in the survey.

Behavioral Support Needs

At all survey time points, roughly one third of movers needed some support to manage either self-injurious behavior or disruptive behavior, and about one quarter needed some support to manage behavior that was destructive or harmful to others. Less than a quarter needed extensive support to manage these types of behaviors.

⁹ <https://www.cdc.gov/nchs/fastats/mammography.htm>

¹⁰ https://progressreport.cancer.gov/detection/colorectal_cancer

¹¹ In reality, all participants receive 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.

Employment and Other Daily Activities

The majority of movers were engaged in some type of daily activity at all survey time points and most movers received regional center services or supports to participate in these activities. Around two thirds of movers engaged in unpaid activities in a facility-based setting such as day habilitation or seniors programs, and averaged over 50 hours in a two-week period. Few movers had community employment as a goal in their IPP and few movers were engaged in paid work, either in a community-¹² or facility-based¹³ employment setting, and few movers had community employment as a goal in their IPP. Participation in unpaid community activities was higher, with around one in ten movers engaged in activities such as skills training or volunteering. Those who participated in a community activity averaged over 40 hours in a two-week period.

Section I

Survey questions within *Section I* can only be answered by the mover to assess their personal experiences across multiple domains, including: Transition to the Community, Home, Employment and Other Daily Activities, Feeling Safe, Friends and Family, Community Participation and Leisure, Rights and Privacy, and Satisfaction with Services and Supports. Information from *Section I* summarized below was “self-reported” by a small group individuals as the majority of movers were unable to communicate their experiences in this section of the survey. Movers able to respond to the questions in *Section I* tended to have mild or moderate ID. They were also more likely to use spoken language as their primary means of communication. The majority lived in a SRF, with fewer living in another type of setting.

At the two-year time point, sample sizes were too few to report on any questions in this section. Therefore, the *Section I* summary only discusses the first three survey time points (three-months, six-months, and one-year). Because of low sample sizes, findings are not generalizable to the entire population of individuals moving from a California DC to the community. Nevertheless, their responses provide a unique opportunity to understand their perspectives and experiences and are thus provided as a supplement

¹² Community-based setting is a place where most people do not have disabilities.

¹³ Facility-based setting is a place where most people do have disabilities.

to more generalizable findings provided in *Background Information* and *Section II* which can be completed via proxies.

Transition to the Community

Transition planning questions were only asked at the first survey time point. Responses suggested that planning incorporated mover needs and choices. Most movers indicated that they were asked what they wanted at transition planning meetings, and that they felt comfortable and relaxed at these meetings. Half of movers indicated they had homes to choose from when planning the move. This may be a reflection that often homes were specifically designed to meet individual mover needs. More than half indicated they had day programs or day activities to choose from when planning the move.

The question pertaining to having needed equipment in the home was asked at all survey time points. Most movers indicated they had the equipment they needed in their homes; this increased considerably (i.e., from 59% to 92%) from three- to six-months and remained high over time.

Home

The movers' perceptions of the homes that they were living in were generally positive and stable over time. Almost all movers reported liking their homes. Despite liking their homes, at each survey time point, around one third of movers also indicated that they wanted to live somewhere else.

Most movers indicated that staff spoke their preferred language at home. They also typically reported that they had a place to be alone at home and that people announced themselves before entering the home and their bedroom.

Employment and Other Daily Activities

Most movers participated in some daily activity at all survey time points. The majority reported attending a day program or work activity program¹⁴. When asked if they

¹⁴ Day programs are community-based programs for individuals served by a regional center. Types of services available through day programs include, for example, developing self-care skills, developing employment skills, behavior management, developing social skills.

wanted to spend more or less time at their day programs, most movers responded either “more” or “about the same” at three and six months, but at the one-year survey time point, there was an increase in the percentage of movers who responded “less”. Relative to attending a day program, few movers indicated they took classes or trainings to help them get a job. This finding may be related to the average age of movers being at or near retirement age (average age was 58 years old). At three-months, few movers reported they participated in volunteer work, but at the six-month and one-year survey time points, the percentages increased.

While few movers reported paid employment, perception of having employment was higher than what was reported in the *Background Information* section of the survey. This may be because some movers perceived their day program or other activities they participated in as work. Most movers who reported not having a job indicated that they wanted one.

Feeling Safe

Most movers reported they did not feel afraid anywhere. Among the smaller percentage of who did feel afraid somewhere, the most common locations were walking in the community, at home, and other places that were not listed in the survey and varied by survey time point. Nearly all movers indicated that they had someone to talk to if they felt afraid.

Friends and Family

Mover self-reports regarding friends and family were largely positive. Most movers indicated they had friends who were not staff or family. Fewer indicated they had friends that only included staff or family or did not have friends at all; these findings were consistent over time. At three-months, over half of movers indicated they wanted additional help making or keeping in contact with friends. This decreased to about a quarter of movers who wanted additional help at later survey time points. The majority of movers reported having other ways to communicate with friends if they could not see them. Most movers also reported being able to date and being able to see their family when they wanted. When asked if they were lonely, more than half answered “no, not

often” and less than half answered “sometimes”. Fewer than one in five movers answered that they were often lonely.

Community Participation and Leisure

Generally, participation in community and leisure activities was stable over time. Most movers (75% or higher) indicated they were able to go out and do things they liked to do and were able to do these activities as much as they liked. The majority also indicated they had enough things they liked to do at home so they were not bored. Less than one quarter said there were some things they liked to do but could not do.

Rights and Privacy

In general, self-report responses indicated that rights and privacy were respected. Most movers indicated they read their own mail or email, or that others read it only with their permission. A majority also indicated they could be alone with visitors at home. At three- and six-months, most movers reported there were no rules about being alone with visitors. At one-year, responses were evenly split between not having rules and having rules about being alone with visitors. Most movers also indicated that they were allowed to use the phone and internet any time, either independently or with assistance. A minority reported that there were rules or restrictions on phone or internet use at three- and six-months but not one year.

Satisfaction with Services and Supports

Almost all movers indicated that services and supports helped them to live a good life. On the whole, mover responses at all survey time points indicated high levels of access to supports and services that were responsive to their needs. Most indicated they have a way to get places when needed, and when they wanted. Nearly all mover responses indicated that all staff always treated them with respect. Likewise, almost all movers reported that they were supported in a way that was respectful of their culture by all staff. Most also indicated that staff came and left when scheduled.

The majority of movers reported they met their service coordinators and their service coordinators asked what they want during IPP meetings. Most also reported they participated in the last IPP meeting, understood what was discussed, were able to

choose or have input regarding the services that were included in their IPP, and that the meeting included the people they wanted there. Similarly, high percentages of movers reported that they were able to contact service coordinators when they wanted and had staff that helped with daily activities.

Section II

Section II can be answered by the mover or by a proxy respondent, as it assesses observable behaviors across multiple domains, including Community Inclusion, Choices, Rights, Access to Needed Services and Supports, and Health and Wellness.

Community Inclusion

Movers generally went on outings in the community at all survey time points. Movers most frequently went out for either shopping, errands, entertainment, and/or eating out at least once a month. Those who went out for one of these types of outings were most likely to have gone one to two times in a month, and generally went with staff, housemates, and/or coworkers. Fewer than one in five went out with friends or family.

Over 80 percent of movers did not attend religious services or spiritual practices. Those who did attend these services most often went one to two times in a month, and did so with staff, housemates, and/or coworkers. More than 90 percent did not participate in community groups or activities, and those who did mostly went with staff, housemates, or coworkers.

Choices

Most movers affirmed they made some of their own life decisions; a perspective that remained stable over time. A majority of movers indicated they chose or had some input in choosing their daily schedules, how to spend their free time, and how to spend their money. Choosing their homes, roommates, staff, or day programs/activities reflected lower rates of personal choice. Given that homes were often specifically designed with individual movers in mind, choice of homes, roommates, and staff may have been limited. Around two thirds of movers also reported that they were aware they could change their service coordinators if they wanted.

Rights

Based on select rights asked about in the survey, the percentages of movers able to assert their rights (e.g., lock their bedroom door or vote) was stable over time but low. The large majority of movers did not have a key to their homes and/or were unable to lock their bedrooms if they wanted. Few movers participated or had the opportunity to participate in self-advocacy group events. Similarly, few movers voted or had the opportunity to register but chose not to.

Access to Needed Services and Supports

Most movers indicated they felt that staff that worked with them had the right training to meet their needs.

A small percent of movers requested additional services or supports that were not being provided to them, including assistance finding, maintaining, or changing housing or jobs; assistance with social/relationship issues or meeting people; benefits or insurance information; dental care coordination; education, training, or skills development; environmental adaptations/home modifications; healthcare coordination; residential support services; and transportation.

A slightly higher percent of movers reported additional service needs related to communication technology, additional access to day services other than employment, and needing services or supports of a type that was not listed on the survey; responses indicated these needs decreased over time.

Health and Wellness

Mover perceptions of their health were positive and stable over time. When movers were asked how they would describe their health, most responded either excellent or very good, followed by fairly good. Very few movers indicated they were in poor health. Around half of movers reported they did not exercise or do physical activity.

Family Guardian Survey—Summary of Findings

Data for all family respondents¹⁵ who completed the Family Guardian Survey (FGS) are included in this report for all survey time points (i.e., three-months, six-months, one-year, and two-years post-move), regardless of whether or not they completed a survey at three-months or other time points. Findings are summarized below for each section in the FGS. Findings highlighted in this section are intended to be a starting point in evaluating the family members' perceived satisfaction with services and support made available to those who moved from developmental centers (DC) into the community.

Overall, there was very little change in the findings from one survey time point to another. In general, when responses or percentages were high at one survey time point, they tended to be high at all time points. Likewise, when percentages were low, they tended to be low at all survey time points. Depending on the survey question, stability in percentages across survey time points could have different meanings. In some instances, response stability is considered a positive finding. In other instances, a change in percentage over time would be expected, and the lack of change might suggest an area where modifications to the service delivery system could be considered to foster improvements. In addition to the fact that there was very little change in the findings between survey time points within the current reporting period, there was also very little change in the findings between the year-two and year-three reporting periods¹⁶. Because responses were mostly stable over time, the majority of data summarized below is not discussed in terms of change across time.

Notably, the answer choice “don't know” was selected 20 percent of the time or higher for many survey questions. The summaries below discuss the “don't know” responses when a high rate of “don't know” may be meaningful (e.g., when a high number of family

¹⁵ In this report, individuals who filled out and submitted a completed FGS (i.e., conservators and family members of the individuals who are receiving services) are referred to as “family respondents”, and individuals who receive services and moved from DCs to the community are referred to as “movers”.

¹⁶ The current Year 3 Report includes findings from data collected from movers who moved into the community between 1/1/16 and 12/31/18, whereas the Year 2 Report includes findings from data collected from movers who moved between 1/1/16 and 12/31/17.

respondents may not know information about the type and quality of services being provided to the movers).

Family respondents also had the opportunity to provide qualitative feedback on the FGS. The qualitative analysis was completed for the three-month, six-month, one-year, and two-year survey time points. Generally, family respondents noted that they were satisfied with most aspects related to the services their movers received in the community. Some family respondents of movers with more intensive medical or behavioral needs indicated these movers had more difficulty adjusting to their new settings. When analyzed over time, two-thirds of family respondents reported that they were satisfied from one survey time point to the next, and one third of family respondents consistently reported problems, or reported problems that grew over time.

Background

Relationship to the Participant (i.e., Mover)

The majority of family respondents were family members of movers, specifically parents and siblings. Approximately one-third of family respondents saw movers more than 12 times per year, while a little more than one-third saw movers three times or less each year.

Mover Services and Supports

Three-months after the move to the community, nearly 80 percent of family respondents indicated that movers received Social Security payments. By the one-year survey time point, nearly all family respondents indicated that the movers received Social Security payments. The number of family respondents who did not know whether the mover received Social Security payments decreased from 13 percent at three-months to zero percent at the one-year survey time point.

Approximately one quarter of family respondents indicated that, in the past year, they spent some of their own money for movers' services. The amount spent each year decreased over time. At three-months, 15 percent of family respondents reported spending between \$101 and \$1000 on mover services, and 5 percent reported spending between that amount at one year.

Community Transition Planning and Services

There was a sizeable increase in positive feelings regarding movers' transitions to the community. When asked to think back to the time they first heard that movers would be moving to the community, less than 20 percent of family respondents reported that they supported the move to the community. In contrast, after the transition to the community, the majority of family respondents indicated they really liked the new homes.

Services and Supports

Information and Planning

The majority of family respondents felt positively about the information and support that they received to help plan for services and remained engaged in that process.

Specifically, most family respondents indicated they always or usually got enough information to take part in planning services for movers. Additionally the feeling that the information they received was always easy to understand increased over time. At the three-month survey time point, about half of family respondents felt the information received was always easy to understand; by one-year, 62 percent felt it was always easy to understand. The majority of family respondents also indicated that staff at the residential agencies where movers lived always or usually kept them informed about how movers were doing. The percent of family respondents who indicated they were always kept informed increased over time, while the percentages of family respondents who indicated they were usually or sometimes kept informed decreased at the one-year time point. Similarly, family respondents who reported they always felt respected by service coordinators increased at the one-year survey time point and those who indicated usually or sometimes feeling respected decreased at the one-year time point.

About 80 percent of family respondents indicated that movers had an Individual Program Plan (IPP) and approximately 90 percent indicated that the IPP included all of the services and supports movers needed. Approximately 20 percent did not know if the movers receive all the services listed in the IPP.

Of the family respondents who attended the last IPP meeting, more than half discussed how to handle emergencies, and fewer felt prepared to handle the needs of movers in an emergency.

Access and Delivery of Supports

Three months after the move to the community, 83 percent of family respondents indicated that they were always or usually able to contact movers' support workers when they wanted. The ability to contact movers' support workers when wanted increased to 95 percent by the one-year survey time point. Most family respondents indicated they were always or usually able to contact movers' service coordinators when they wanted. The vast majority of family respondents indicated that support workers always or usually spoke to them in their preferred language or in a way they understood. Almost all family respondents indicated that services were delivered to movers in a way that was respectful to family respondent culture.

For the movers who took medication, approximately 80 percent of family respondents knew what the medication was for. Nearly half did not know what was needed to safely take the medication.

Choice, Decision Making, and Control

Over two-thirds of family respondents indicated they did not know that they could change the service coordinator. Similarly, nearly two thirds of family respondents did not know that they could choose or change the agency and/or staff that provided services to the mover.

About half of family respondents indicated the agency that provided residential services to the mover always or usually involved the mover in important decisions. Approximately one third of family respondents did not know if the mover was involved in making important decisions.

Satisfaction

Overall, family respondents were always or usually satisfied with the services and supports the movers received. Three-months after movers moved to the community, half of family respondents indicated that they knew how to file a grievance about provider agencies or staff. Family respondents who indicated they knew how to file a grievance increased at the one-year survey time point to over 60 percent. The rate at which family respondents indicated knowing how to report abuse or neglect also

increased across survey time points. At the three-month survey time point, two thirds of family respondents indicated that they knew how to report abuse and neglect, whereas, by the one-year time point, nearly three fourths reported knowing how to file a report of abuse or neglect.

Outcomes of Services and Supports

The vast majority of family respondents believed that services and supports have made a difference in mover life; rates increased from 79 percent at three-months to 87 percent at one-year. Similarly, the percentages at which family respondents indicated that services and supports have helped movers live a good life increased from 81 percent at three-months to 87 percent at one-year. The majority of family respondents indicated that services and supports had not been reduced, suspended, or terminated in the past year. And, more than half indicated they did not know whether or not services or supports had been increased in the past year.