National Core Indicators

California Mover Longitudinal Study

Year Two Report

Data collected from January 1, 2016 through December 31, 2017

UCDAVIS
Continuing and
Professional Education

PREPARED BY THE
CENTER FOR HUMAN SERVICES
AT THE UNIVERSITY OF CALIFORNIA, DAVIS
FOR THE
CALIFORNIA DEPARTMENT OF DEVELOPMENTAL SERVICES

1600 9TH STREET

PO BOX 944202

SACRAMENTO, CA 94244-2020

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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 two-years of the MLS. Subsequent reports will include expanded data and increased participation. Interviews to collect this data were conducted by the State Council on Developmental Disabilities between January 2016 and December 2017 via face to face or proxy interviews with 224 adults. This is an important effort because California can use the MLS reports to monitor changes in the system and to guide strategic planning and quality improvement activities as a result of DC closures.

Acknowledgements

This report is possible thanks to the 224 individuals who agreed to share about their experiences after moving from a California developmental center to the community. Special acknowledgment goes to their families, friends, and staff members who provided support and participated in the survey process.

List of Selected Abbreviations Used in the Report

ACS—Adult Consumer Survey

ASD—Autism Spectrum Disorder

CA-ODESA—California Online Data Entry Survey Application

CCF—Community Care Facility

CP—Cerebral Palsy

DC—Developmental Center

DD—Developmental Disability

DDS—Department of Developmental Services

FHA—Family Home Agency

HSRI—Human Services Research Institute

ICF—Intermediate Care Facility

ID—Intellectual Disability

IDT—Interdisciplinary Team

ILS/SLS—Independent Living Skills/Supported Living Services

IPP—Individual Program Plan

MLS—Mover Longitudinal Study

N<30—Sample size is below 30

NASDDDS—National Association of State Directors of Developmental Disability Services

NCI—National Core Indicators

SCDD—State Council on Developmental Disabilities

SNF—Skilled Nursing Facility

Table of Contents

Executive Summary

The Mover Longitudinal Study (MLS) is a continuous quality assessment and improvement initiative being carried out by the California Department of Developmental Services (DDS). This is an important effort to collect accurate, reliable, and valid satisfaction and outcome data among individuals with intellectual or developmental disabilities (I/DD) across the state who moved from a California developmental center (DC) to community living since January 2016. This report 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 years[1].. This report summarizes data collected between January 2016 and December 2017, 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).

Background

State law provides DDS with the responsibility for overseeing the coordination of services and supports to people with I/DD. DDS does this in two primary 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 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

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[1] The Sonoma DC closed in December 2018, and the Fairview and Porterville General Treatment 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.

and its stakeholders with information about this group of individuals who moved from a DC to the community, including their experiences following the move into the community.

Study Participants

This report highlights findings of the experiences of 224 individuals with I/DD who moved from a DC (i.e., movers)[2], as well as 78 conservators/family members (i.e., family respondents)[3], during the first three to 12 months of the transition to the community. The movers were mostly male (63% male vs. 37% female), primarily White (75%), and nearly all indicated English as their primary language (97%). Nearly all movers had a diagnoses of intellectual disability (ID), and most need high levels of support for daily life. Nearly half of the movers (47%) had mobility challenges or are non-ambulatory. Family respondents were mostly 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)[4]. These surveys collect demographic information and consumer/family perceptions about service coordination/access and life in the community. These measures were based on those developed as a part of the National Core Indicator (NCI) project by the Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disability Services (NASDDDS).

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[2] Referred to throughout this report as “movers”.

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

[4] Data from the first three survey time points are presented in this report since none of the movers had yet reached two years post-move by December 31, 2017 (the point at which data was downloaded for this report).

Study Findings

The results presented in this report are intended to highlight *successes* and things that went well with the movers' transitions to the community and *potential areas in need of explanation or improvement*.

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 should be used to guide further exploration regarding successes that could be continued or replicated, and opportunities for improvement within the care and coordination experienced by the movers and their families.

Successes

Most healthcare and service needs were met and were stable over time[5].

- Over 60 percent of people 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 prior year.
- The majority of people, about 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 were generally stable across survey time points[6].

- Most mover self-reports regarding connections with friends and family were positive.
- All movers reported having a way to get places when they needed to, and nearly all reported having a way to get places when they wanted to.

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[5] For more detailed information, refer to pages 151-153 and 178 of the MLS Year 2 Report Appendix.
[6] For more detailed information, refer to pages 165-167, 171, 174-176 of the MLS Year 2 Report Appendix.

- 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 helped them to live a good life.

> *"Her main caretaker came to take her on an outing last Saturday even though it was her day off. That was amazing!"*
>
> *–Family Respondent*

A majority of family respondents were satisfied with most aspects of the services their family members received in the community[7].

- After the transition to the community, most family respondents indicated that they really liked the new homes into which movers transitioned.
- The majority of family respondents felt positively about the information and planning support that they received to help plan for services and remain engaged in that process.
- Eighty percent or more of 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 as they wanted. The majority also reported that they were able to contact support workers when wanted.

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[7] For more detailed information, refer to pages 250-254 and 256 of the MLS Year 2 Report Appendix.

- The majority of family respondents reported that services were delivered to movers in ways that were respectful of their culture.

> *"Our family member gets to live in a house and be part of a real family! She gets to watch staff cook and smell the food! Our family member is enjoying a rich and satisfying life in a real home atmosphere…We got our family member out of a developmental center and…she is thriving and blooming in her new world!"*
>
> *–Family Respondent*

Areas in Need of Further Exploration

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. Examples of these situations are provided in the bulleted list below. In addition, some movers were not aware of changes that they could make if they were not happy with their services. There may be an opportunity to strengthen individual and family or conservator engagement in the service-planning process and enhance their knowledge of the services and supports that movers receive.

It may be beneficial to identify strategies designed to improve mover and family respondent knowledge and engagement in service-planning[8].

- Family respondents did not always know that they, or the movers who received services, could make certain types of choices (e.g., that they can change service coordinators, or the agency that provides regional center funded services, and other staff who provide services).

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[8] For more detailed information, refer to pages 253-259 and 261 of the MLS Year 2 Report Appendix.

- One in five family respondents did not know if the movers received all services listed in the IPP.
- Nearly half of family respondents indicated that they did not know whether or not services or supports for their family member who moved from a DC had changed in the past year.
- One-quarter of movers reported they were not aware that they could change their service coordinator if they wanted to.

"I was not provided an array of options, just informed of what he will get. I feel every time we meet I learn of a possible service which would have benefitted him from the beginning."

–Family Respondent

There may be room to improve services and supports to promote health and wellness and prevent illness with movers[9].

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 from providers who are prepared to serve this population. Exercise, physical activity, and healthy weight management is another opportunity area to help movers remain healthy within the community setting.

- About 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 approximately one-third of movers.
- Slightly less than half of female movers had not received a pap test within the past three years, and one-third of women over age 40 had not received a mammogram in the past two years.
- About two out of three movers were considered overweight or obese (BMI>25).
- Half of movers reported they did not exercise or do physical activity.

> *"Medical/dental visits usually take quite a lot of time to access-only solution for emergency or weekend medical needs is the emergency room. Family member has had 2-3 different changes of doctor in the past year."*
>
> *–Family Respondent*

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[9] For more detailed information, refer to pages 151-153 and 178 of the MLS Year 2 Report Appendix.

Most movers generally went on outings within the community, but many could increase the frequency and types of community outings and activities that they participate in[10].

It may be worthwhile to explore reasons and potential barriers for why many movers were staying home and not increasingly participating in community outings and activities.

> *"My family member rips his clothing, breaks furniture and requires 1 to 1 constant support. Due to lack of clothing and 1 to 1 support, he cannot or will not leave home."*
>
> *–Family Respondent*

- Around 20 percent of movers did not go on outings such as shopping, running errands, entertainment, and going out to eat. Fewer than one in five went out with friends or family.
- Over 90 percent of movers did not participate in community groups or activities.
- Only one in five movers engaged in unpaid activities (e.g., skills training or volunteering, day habilitation or seniors' programs).

Although mover services and supports should be funded by regional centers, some family respondents reported spending their own money on services for the movers[11].

- After the move to the community, some family respondents indicated that they spent their own money for movers' services. It may be beneficial to explore reasons why and when family respondents spent their own funds on services, and what services they spent money on.

Conclusions

Overall, findings based on two years of data collection within the Mover Longitudinal Study suggest that most movers have experienced a successful transition to the community. Most mover experiences appeared to be positive and stable over time as

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[10] For more detailed information, refer to pages 164, 171-174 of the MLS Year 2 Report Appendix.
[11] For more detailed information, refer to page 187 of the MLS Year 2 Report Appendix.

movers live within community settings. For example, healthcare and service needs were generally met continuously over time. Experiences with life in the community were mainly positive and stable. In addition, family members seemed to be satisfied with services the movers received in the community. Stability in mover experiences demonstrates continued support and care within community settings that is comparable to what movers received at the developmental centers. Nevertheless, findings also demonstrate areas of opportunity to ensure that movers' needs are fully met within the community. For example, movers' families or guardians may benefit from more engagement in and knowledge of service-planning. While the majority of movers reported good to excellent health and received routine healthcare and related screenings, 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 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 for areas where things are going well and areas where there is room for improvement. This report is intended to be a starting point in evaluating the experience of individuals who have moved to the community from a California developmental center (DC) on or after January 1, 2016. Although longitudinal analyses were not run for this report cycle (due to limited sample sizes), most ACS responses appeared to be generally stable across survey time points.

The ACS includes three major sections: *Background Information*, *Section I*, and *Section II*. The *Background Information* section contains questions about the mover's health status and medical exam history, qualifying condition and other diagnoses, residence type, employment/day activity or program, and regional center 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 individual who moved from a DC. *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.

Background Information

Background information was compiled for each individual who moved from a DC prior to the in-person interview. Information about demographics and type of residence provided in this section is captured for all movers at the three-month survey time point. Information summarized on health conditions, health care, screenings and medications, services and supports, behavioral support needs, and employment and other daily activities, includes responses given at three survey time points.

Demographic Information

The sample was made up of movers who were predominantly white males (i.e., 63% male; 75% White) with an average age of 55 years; less than 20 percent identified as Hispanic or Black/African American. Nearly all movers had English as their preferred language. More than half used gestures or body language as their primary means of communication, while around one-third used spoken language. Over half of movers were able to move independently without aids and over a quarter were non-ambulatory.

Nearly all movers had a diagnosis of Intellectual Disability (ID) with over half of all movers having 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 (40%).

Rates of co-occurring mental health conditions were relatively high. In particular, many movers reported having 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). One in five movers had a disability not listed on the survey.

Type of Residence

New homes were specifically developed for many individuals who moved from DCs and included homes that specialized in caring for those with special health needs or who required behavioral supports. Over half of movers moved into a Specialized Residential Facility (SRF). Slightly under one-quarter of movers were moved into a home 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 were generally reflective of an aging population. Most movers had at least one health condition; the rates of all health conditions remained stable over time. At all three survey time points, the most common health conditions were dysphagia, high cholesterol, high blood pressure, and cardiovascular disease. In addition, the majority of movers were diagnosed with another health condition not listed on the survey at all three survey time points. Health conditions that were not listed on the survey but were frequently reported include osteoporosis, dementia, thyroid dysfunction, anemia, periodontal disease, and gastro-esophageal reflux. About two out of three movers were considered overweight or obese (BMI>25).

Health Care, Screenings, and Medications

All movers had a primary care doctor, and nearly all had an annual exam in the last year. In general, the majority of movers were getting their health care and screenings within the recommended intervals. This included annual dental exams, vision screenings, hearing tests, and flu vaccines. Slightly less than half of female movers had not had a pap test within the past three years, and one-third of women over age 40 had not received a mammogram in the past two years. About 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 approximately one-third of movers. In contrast, Centers for Disease Control and Prevention (CDC) and National Cancer Institute (NCI) have reported higher rates for the general population in the United States. The CDC reported that 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 years[12], and the NCI reported 61 percent of adults over age 50 had a colonoscopy in the past five years[13]. The people who have moved from DCs were generally medically fragile or had behavioral challenges, 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. About half of movers took medications to treat mood, anxiety, or psychotic disorders. Slightly more than one-third of movers took medications for behavioral challenges. Among movers who had epilepsy, most had seizures under control.

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[12] https://www.cdc.gov/nchs/fastats/mammography.htm

[13] https://progressreport.cancer.gov/detection/colorectal_cancer

Services and Supports

Most movers received service coordination, health and dental care coordination, and residential support services[14]. Most also received transportation and information on benefits/insurance. About half received education, training, or skills development. Less than half received environmental adaptations or home modifications or help with social/relationship issues and meeting people. Less than a quarter of movers received assistance finding, maintaining or changing jobs, communication technology, or another service or support that was 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, disruptive behavior, or behavior that is destructive or harmful to others. A smaller percentage needed extensive support to manage these types of behavior.

Employment and Other Daily Activities

The majority of movers were engaged in some type of unpaid daily activity at all survey time points. Nearly two-thirds of movers engaged in unpaid activities in a facility-based[15] setting, averaging over 50 hours in a two-week period. Such activities in a facility-based setting included day habilitation or senior programs. Participation in unpaid activities in a community-based[16] setting was lower, with around one in five movers engaged in an unpaid activity, and averaging over 40 hours in a two-week period. This included activities such as skills training or volunteering. Most movers received regional center services or supports to participate in these activities.

Few movers had community employment as a goal in their IPP and few were engaged in paid work, either in the community or in a facility-based setting.

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[14] 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.

[15] Facility-based setting is a place where most people do have disabilities.

[16] Community-based setting is a place where most people do not have disabilities.

Section I

Survey questions within *Section I* can only be answered by the mover to assess their personal experiences across multiple topics, 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 of individuals. 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 either in a home with independent living services or supported living services (ILS/SLS) or a specialized residential facility (SRF). Information from *Background Information* and *Section II* was typically reported via proxies.

Due to their disabilities, the majority of movers were unable to communicate their experiences; as such, sample sizes for *Section I* are low (i.e., less than 34 mover responses at each survey time point), therefore findings are not generalizable to the entire population of individuals moving from a California DC to the community. Nevertheless, responses to questions in *Section I* provide a unique opportunity to understand mover perspective and experiences and are provided as a supplement to more generalizable findings provided in *Background Information* and *Section II*.

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 needs of the movers. Over half indicated they had day programs or day activities to choose from when planning the move. Most movers indicated they had the equipment they needed in their homes; this increased over time (i.e., from 3-Month: 58%** to 6-Month: 90%**)[17].

Home

The movers' perception of the homes that they were living in were generally positive and stable over time. Almost all movers reported liking their homes at all three survey time points. Despite liking their homes, some movers (i.e., 3-Month: 45%**, 6-Month: 52%**, 1-Year: 35%**) also indicated they wanted to live somewhere else.

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

Employment and Other Daily Activities

Most movers participated in some sort of daily activity at all survey time points and indicated they had employment in the community. The majority of movers reported attending a day program or workshop at all three survey time points. At three-months the majority wanted to spend more, rather than less, time at their day programs, and at six-months they were satisfied with the amount of time spent at their day programs. Most movers indicated that staff spoke their preferred language at their day programs.

Relative to attending a day program, few movers indicated they volunteered or took classes or trainings to help them get a job. While few movers were employed, perception of having employment was higher than was reported in the *Background Information* section of the survey, which is largely based on administrative data. Most of those who reported not having a job indicated that they wanted one.

Feeling Safe

Most movers reported they felt safe and did not feel afraid anywhere, which remained true at all survey time points. Among those who did feel afraid somewhere, the most common locations were walking in the community (three-months) or at home (reported

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[17] ** Indicates 11-29 responses were recorded for this item. Results should be interpreted with caution due to the small number of individuals represented in these percentages.

at six-months and one-year). Most 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, while fewer indicated they had friends that only included staff or family or did not have friends at all. These findings were consistent across all three survey time points. Nearly two-thirds reported being able to see their friends when they wanted while roughly one-third indicated they wanted additional help to make or keep in contact with friends. The majority of movers reported having other ways to communicate with friends if they could not see them. Most also indicated they were able to date and see their family when they wanted. When asked if they were lonely, the most common answer was “no, not often”. Less than one-quarter of movers answered that they were often lonely at any of the three survey time points.

Community Participation and Leisure

Over 60 percent of movers at all time points indicated they were able to go out and do things they liked to do which. Most also indicated that they were able to go out and do the things they liked to do as much as they wanted. Less than one-third said there were some things they liked to do but could not do. About three-quarters of movers indicated they had enough things they liked to do at home so they were not bored. Generally, community participation and leisure activities were stable over time.

Rights and Privacy

In general, self-reported responses indicated that rights and privacy were respected at all survey time points. Most movers indicated they read their own mail or email, or that others read it with their permission, while a minority indicated that their mail or email was read without their permission. Most also indicated there were not rules about having visitors at their home and that they could be alone with visitors at home. The majority of movers also indicated that they were allowed to use the phone and internet any time, either independently or with assistance, while a minority reported that there were rules or restrictions on phone or internet use.

Satisfaction with Services and Supports

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. All mover responses indicated that staff generally treated them with respect. Likewise, almost all movers reported they were mostly supported in a way that was respectful to their culture by all or some staff. They also indicated that staff come and leave when scheduled. All movers reported having a way to get places when they needed to, and nearly all reported having a way to get places when they wanted to.

The majority of movers had met their service coordinators and reported their service coordinators asked what they wanted. Most also reported they participated in the last Individual Program Plan (IPP) meeting, understood what was being discussed, and received the IPP in their preferred language. Most were able to choose the services that were included in their IPP and could include the people they wanted in the meeting. Similarly, high percentages of individuals reported they had staff who helped with daily activities and that they were able to contact the service coordinators when they wanted to.

Section II

Section II can be answered by the mover or by a proxy respondent, as it assesses observable behaviors across multiple topics, 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 once or twice a month for shopping, errands, entertainment, and/or dining out. Movers were most likely to have gone on each of these types of outings one to two times in a month, and to have gone out with staff, housemates, or coworkers. Fewer than one in five went out with friends or family.

Most movers did not go to a religious service or spiritual practice. Those who did most often went one to two times in a month, and did so with staff, housemates, or coworkers. Most movers also did not participate in community groups or activities. The few who did mostly went with staff, housemates, or coworkers.

Choices

Movers predominately affirmed their ability to make choices about their own life decisions, an opinion which was 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. Lower rates for choice were found for choosing their homes, roommates, staff, or day programs/activities. Three-quarters of movers reported they were aware they could change their service coordinators if they wanted to.

Rights

The percentage of movers able to assert their rights (e.g., lock their bedroom door or vote) was stable over time but low (i.e., always under 10%). The vast majority of movers did not have a key to their homes, nor were they able to lock their bedrooms if they wanted to. Few participated or had the opportunity to participate in a self-advocacy group event. Similarly, few movers voted or had the opportunity but chose not to.

Access to Needed Services and Supports

The percentage of movers who requested additional services or supports that were not being provided to them was low (i.e., always under 6%) and stable over time. This included assistance finding, maintaining, or changing jobs; assistance with social/relationship issues and meeting people; obtaining benefits or insurance information; dental care coordination; education, training, or skills development; securing environmental adaptations/home modifications; healthcare coordination; receiving residential support services; and transportation.

Three categories of services/supports showed somewhat higher percentages than others at three-months, which decreased over time. These were communication technology, additional access to day services other than employment, and other services and supports not listed on the survey.

Health and Wellness

Mover perceptions of their health were very 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. Half of movers reported they did not exercise or do physical activity. In comparison, the 2019 annual report by the United Health Foundation found that 21 percent of all adults in California did not exercise or do physical activity in the past month[18].

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[18] America's Health Rankings Annual Report, United Health Foundation. (2020). Physical Inactivity. Retrieved from https://www.americashealthrankings.org/explore/annual/measure/Sedentary/state/CA

Family Guardian Survey—Summary of Findings

Data for all family respondents[19] who completed the FGS are included in this report for all survey time points (i.e., three-months, six-months, and one-year post move), regardless of whether or not they completed a survey at three-months or other survey time points. Findings are summarized below for each section in the Family Guardian Survey (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/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. Therefore, the majority of data summarized below is not discussed in terms of change across time. Depending on the survey question, stability in percentages across survey time points will 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.

Notably, the answer choice "don't know" was selected at a rate of 20 percent 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.

Family respondents also had the opportunity to provide qualitative feedback on the FGS. The qualitative analysis was completed for the three-month, six-month, and one-year survey time points. Generally, family respondents noted that they were satisfied with most aspects related to the services their family member received in the

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[19] In this report, individuals who filled out and submitted a completed FGS (i.e., family members of the individuals who are receiving services) are referred to as "family respondents", and individuals who receive services and moved from Developmental Centers to the community are referred to as "movers".

community. Family respondents noted less satisfaction with the timelines of dental and medical services.

Background

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

The majority of family respondents were family members of movers, specifically parents and siblings. One-third of family respondents saw movers more than 12 times per year, while between 18 percent and 34 percent saw movers less than three times per year.

Out-of-Pocket Spending by Family Respondents for Mover Services and Supports

Three months after movers moved to the community, 25 percent of family respondents indicated that they spent some of their own money for the movers' services. At the one-year survey time point, 38 percent respondents indicated spending something out-of-pocket.

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, over 85 percent of family respondents, at all survey time points, 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 to remain engaged in that process. Specifically, most family respondents indicated they always or usually got enough information to take part in planning services for movers and felt the information they received was easy to understand. The majority of family respondents also indicated that staff at the residential agencies where movers live always or usually kept them informed about how movers were doing. Most family respondents felt that service coordinators respected family choices and opinions.

More than 80 percent of family respondents indicated that movers had an Individual Program Plan (IPP) and approximately 90 percent or higher indicated that the IPP included all of the services and supports movers needed. Approximately 20 percent of family respondents did not know if the movers received 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; however, between 33 percent to 53 percent of family respondents felt prepared to handle the needs of movers in an emergency.

Access and Delivery of Supports

Overall, family respondents were always or usually satisfied with the services and supports the movers received. Nearly 90 percent of family respondents indicated that they were always or usually able to contact movers' service coordinators, and 80 percent to 100 percent were able to always or usually contact movers' support workers. The vast majority of family respondents indicated that support workers always or usually spoke to them in a way they understood and in a language they preferred. Services were delivered to movers in a way that was respectful to family respondent culture at a frequency of 90 percent.

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

Choice, Decision Making, and Control

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

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

Knowledge of Reporting Procedures

Family member awareness about how to report suspected abuse and neglect or a grievance increased over time. Half of family respondents indicated that they knew how to file a grievance about provider agencies or staff three months after movers moved to the community. That increased to over 60 percent at the six-month and one-year survey time points. At the three-month survey time point, 55 percent of family respondents indicated that they knew how to report abuse and neglect, whereas, at the six-month and one-year time points, over 75 percent reported knowing how to file a report of abuse or neglect.

Outcomes of Services and Supports

Family respondents believed that services and supports have made a difference in mover life, increasing from 80 percent at three-months to 96 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 82 percent at three-months to 91 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. About half, however, indicated they did not know whether or not services or supports had been increased over that year.