

Mover Longitudinal Study Design

January 2016-December 2019

Overarching Purpose of Study

The Mover Longitudinal Study (MLS) will follow individuals who move from a Developmental Center (DC) into the community. The goal of the study is to describe changes in safety, health, and well-being among individuals with developmental disabilities after a move into the community at four different time points (three-months, six months, one year, and two-years). Additionally, family member perceptions of the quality of services received, system responsiveness, and overall satisfaction will be assessed over the same two year timeframe. The proposed MLS will also examine an individual mover's and family member's experience of the transition planning meeting.

Participant Outreach and Recruitment Plan

The Department of Developmental Services (DDS) and the State Council on Developmental Disabilities (SCDD) will undertake an outreach campaign to inform and encourage individuals moving from a DC and their family member to participate in the MLS. DDS and SCDD will produce outreach materials that will include explanatory letters, informational postcards and presentations given to key stakeholder groups. The regional center representative who participates in the Interdisciplinary Team (IDT) meeting held prior to an individual's move will explain the MLS and provide additional written materials to the meeting participants.

Study participants will be drawn from the current population of DC residents planning to move into the community within the next two years. A minimum of 100 individuals will be sought to participate in the study. In order to account for incomplete responses and other potential issues in conducting the analyses, UC Davis recommends the total number of individuals surveyed be expanded by approximately 25%, or a target of 125. Family members of enrolled movers will also be contacted and asked to participate in the study. The individual and family participant is considered "enrolled" in the MLS study at the time of consent. The number of enrolled family participants is anticipated to be lower than the number of enrolled individuals because not all participants have an

involved family member. Participant recruitment will be ongoing as individual's transition from the DCs, beginning January 2016. Recruitment of individuals and their family members will continue for a minimum of 12 months but no longer than 18 months.

Individuals who move from a DC to their family home will not be asked to participate in the MLS due to the infrequency of such moves and therefore a lack of a representative sample.

Data Collection Timeline

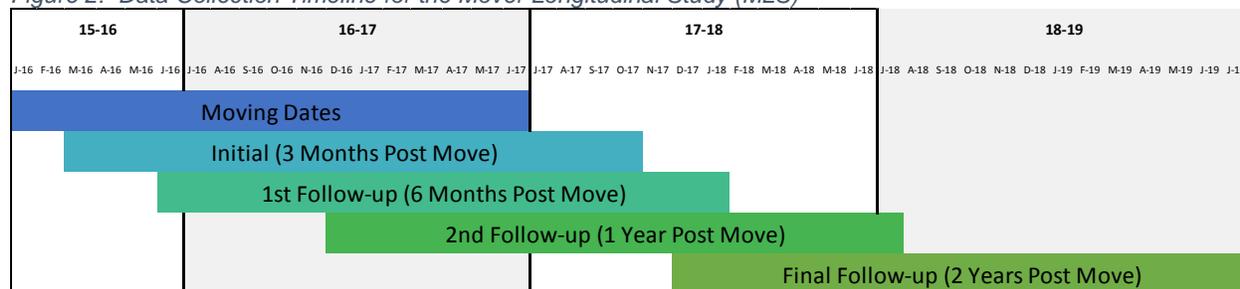
Each study participant will be tracked over two years following their official move date. Data will be collected at four specific target dates: three-months, six-months, one-year, and two-years. Interviews will be conducted as close to the target date as possible with a two week window in which surveys can be conducted on either side of the target date. See Figure 1 as an example of an individual's data collection schedule.

Figure 1: Example of Data Collection Schedule for a Potential Participant

Move Date: January 2 nd , 2016			
Data Collection Point	Window Begins	Target Date	Window Ends
Initial (3 months after the move)	March 19 th , 2016	April 2nd, 2016	April 16 th , 2016
1st Follow-up (6 months after the move)	June 19 th , 2016	July 2nd, 2016	July 16 th , 2016
2nd Follow-up (1 year after the move)	December 19 th , 2016	January 2nd, 2017	January 16 th , 2017
3rd Follow-up (2 years after the move)	December 19 th , 2017	January 2nd, 2018	January 16 th , 2018

The window for data collection will open March 2016 and close in July 2019. Figure 2 illustrates the timeline for data collection.

Figure 2: Data Collection Timeline for the Mover Longitudinal Study (MLS)



Survey Tools

The following National Core Indicator (NCI) surveys will be utilized for the MLS:

- *Adult Consumer Survey (ACS)* version year 15-16
- *Family Guardian Survey (FGS)* version year 15-16

The ACS is a face-to-face interview with adults who have Intellectual Disabilities and/or Developmental Disabilities and, when appropriate, proxy respondents, i.e. people who know the individual well. The FGS is a paper-based survey that is mailed to a family member of the individual participating in the ACS. Additional questions unique to the MLS will be added to both surveys. The three month survey will have additional questions that focus on the IDT meeting and transitional planning process. The six months, one year, and two years surveys will have additional questions about agreed services received. Using these questions, we intend to capture information required by the Centers for Medicaid and Medicare (CMS) agreement as part of the approved DC closure plan.

The *User Friendly Section I of the ACS* will be piloted throughout the MLS data collection period. Section I survey questions of the ACS can only be answered by the individual receiving services, unlike other sections of the survey which can be answered with administrative data or by proxy respondents. This is because Section I includes questions that require subjective judgments and personal experiences (e.g., “Do you like where you live?”). The *User Friendly Section I* survey questions were developed as an alternate way for an individual to answer these questions. Historically, individuals who have been unable to complete Section I of the ACS have higher levels of intellectual disability (or multiple disabilities) that inhibit, complicate or totally prevent

receptive and/or expressive communication necessary for a traditional interview format. The *User Friendly Section I* survey is comprised of questions similar to Section I of the ACS but with simplified wording and pictures. Offering this alternate way to answer questions in Section I of the ACS is intended to increase responses to more subjective questions such as satisfaction with services.

The same survey version, (the ACS and FGS published during the 15-16 data collection cycle), will be used for the entire MLS which is planned to last until 2019. Using the same version of the ACS and FGS throughout the MLS will provide more valid longitudinal comparisons between relevant study outcomes. Caution should be used when making modifications to the survey as it can impact comparison of questions when slight changes are made year-to-year.

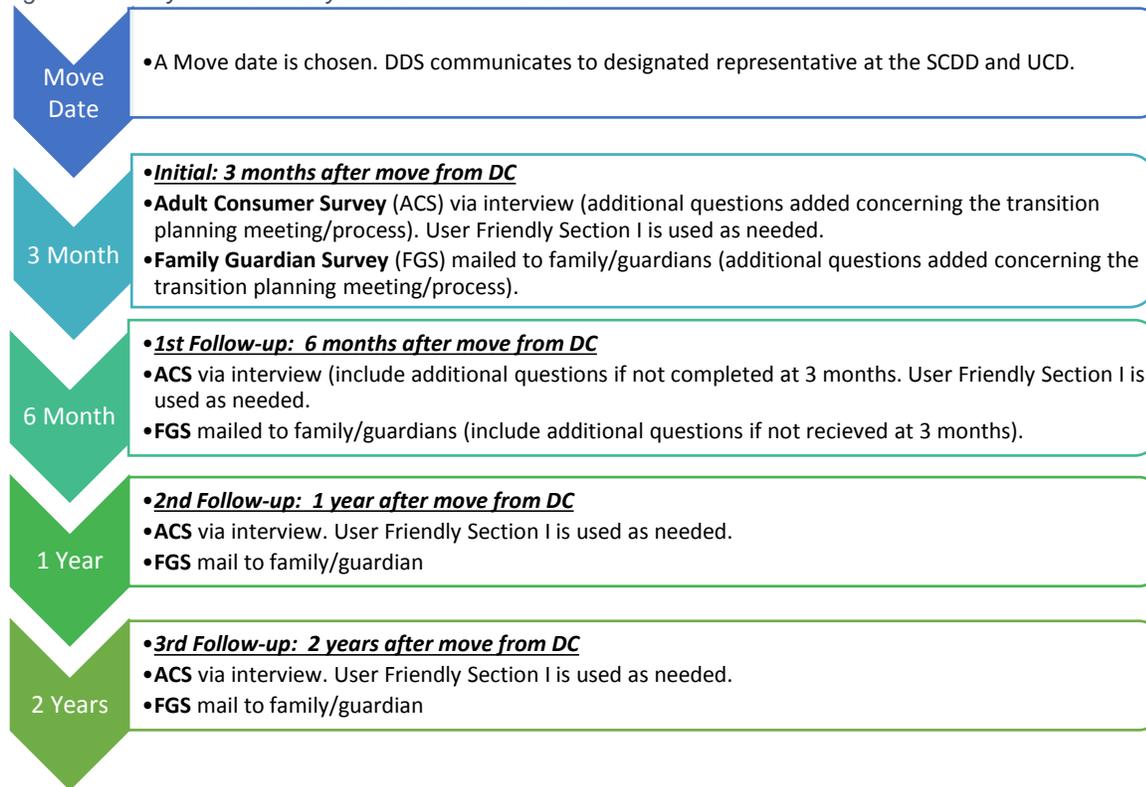
Data Collection Methods

Data collection for the MLS will be conducted by the SCDD. For detailed information on the processes and procedures used during data collection please contact the Department of Developmental Services (DDS).

The ACS will be collected through in-person interviews conducted by experienced NCI interviewers. Interviews will often be conducted by SCDD Quality Assurance Coordinators (QAC). All interviewers used during the MLS will receive additional training to prepare them to conduct the MLS interview including how to correctly administer the *User Friendly Section I* questions. Every effort will be made for individuals to have the same interviewer for the entire study.

The FGS survey will be mailed to family members identified in the regional center records of the mover enrolled in the MLS. The survey will be mailed out on the same schedule as the ACS outlined in Figure 3. It is recommended that the QAC (or other SCDD representative) personally contact designated family members to encourage participation in the MLS and reinforce its importance.

Figure 3: Survey Tools Used by Data Collection Point



The accuracy of contact information is vital to the success of the FGS process. Obtaining and maintaining correct address and phone records for family members will significantly improve survey response rates. The DDS is working with the RCs to improve the integrity of address and phone records.

The California Online Data Entry Survey Application (CA-ODESA), developed and managed by the Human Services Research Institute (HSRI), will be utilized as the data management system for entering survey data. Scheduling functionality is being built into the CA-ODESA which will allow DDS, SCDD, HSRI and UC Davis the ability to monitor data collection process and review data. Data will be pulled from CA-ODESA and reviewed at regular intervals to allow UC Davis to perform quality checks and determine adherence to interview protocols. Any irregularities or administrative issues will be brought forward to DDS and SCDD for immediate action. Additionally, representatives from DDS and UC Davis will shadow approximately 25% or approximately 32 of the initial ACS interviews conducted during the 3 month time point for data collection (March 2016-September 2017).

Functionality will also be built into CA-ODESA enabling interviewers to activate the User Friendly Section I questions. Interviewers will be able to activate the User Friendly Section I questions by checking a box in the CA-ODESA system indicating that they completed screening procedures for the use of the alternate set of questions.

DDS is responsible for sending a letter to individual’s family members informing them of the study within four weeks of the move date. DDS will manually enter contact information for individuals and family members into CA-ODESA within four weeks of an individual’s move date. When the participant’s information is entered into the CA-ODESA the data-collection start date will be activated in the system (see Figure 4).

Figure 4: An Example of a Schedule for a Participant with the Reminders

Move Date: January 2 nd , 2016					
4 Week Reminder	2 Week Reminder	Window Begins (2 weeks before target)	Target Date for ACS interview and mailing the FGS	Warning Message (1 week until window closes)	Window Ends (2 weeks after target)
February 19 th , 2016	March 5 th , 2016	March 19 th , 2016	April 2 nd , 2016	April 9 th , 2016	April 16 th , 2016
May 19 th , 2016	June 5 th , 2016	June 19 th , 2016	July 2 nd , 2016	July 9 th , 2016	July 16 th , 2016
November 19 th , 2016	December 5 th , 2016	December 19 th , 2016	January 2 nd , 2016	January 9 th , 2017	January 16 th , 2017
November 19 th , 2017	December 5 th , 2017	December 19 th , 2017	January 2 nd , 2018	January 9 th , 2018	January 16 th , 2018

Reminder messages will be sent to the designated interviewer and QAC at four weeks prior to the data collection window and again two weeks prior to data collection prompting them to complete specific tasks.

- Four Week Reminder:**
- 1) QAC will be prompted to assign an interviewer to the participant. (This is required for the initial data collection period or if a change in interviewer is needed)
 - 2) QAC will be prompted to send out letters to individuals and their families
 - 3) Interviewer will be prompted to schedule an interview

- Two Week Reminder:**
- 1) QAC will be prompted to send out the FGS to the identified family member.
 - 2) Interviewer will be prompted to schedule or confirm interview.

Warning Message: The warning message should be sent out to the NCI project lead at SCDD, the QAC, and the interviewer one week before the data collection window closes.

To ensure data integrity, CA-ODESA will not allow ACS data to be entered for movers whose window has expired at any of the time points. Further constraints are not necessary as UC Davis will monitor missing time point data at the time of analysis.

FGS data must be entered into the CA-ODESA within four weeks of receipt by SCDD. The survey return date will determine which data collection period FGS surveys are captured.

Additional administrative data regarding the specific placement type of individuals participating in the study will be sent from DDS to UC Davis directly. The question about residence type in the ACS and FGS has broader categories in which similar facility types are grouped together. For the purpose of the MLS more precise information about the type of facility individuals are living in is desired. The data will be identified by the individuals unique consumer identification code (UCI) allowing it to be integrated into the survey data.

Linking ACS and FGS Data

It is important to link an enrolled individual's ACS data to their family's FGS data. DDS will include the individual's UCI in the participant records uploaded to the CA-ODESA. All ACS data collected will be linked to the participants UCI.

SCDD will include a survey identification code (SIC) on each FGS mailed to family members participating in the study. The SCDD NCI project manager will maintain a database linking the UCI of individuals and the SIC of family members. The SDCC project manager or alternate will have access to the database. A spreadsheet containing the UCIs and corresponding SICs will be given to UC Davis in order to match

data collected from both groups without having access to the identity of the study participants.

Data across Comparison Groups

The MLS adds an additional layer of data collection to the existing data collection cycles of the NCI project. MLS data will also be utilized in the annual analyses of Mover, Lanterman Mover, and Sonoma Mover (forthcoming) groups. Because additional ACS questions are being given to enrolled MLS participants and because the ACS survey will stay the same through 2019; individuals enrolled in the MLS will not be eligible for sampling during the annual data collection of the ACS of movers. Instead, relevant questions in the MLS data will be manually added into applicable data sets by UC Davis at the time of data analysis for the mover report. This will ensure continuity and minimize data loss due to variability in survey questions between the 15-16 ACS version and any subsequent versions.

Family participants of the MLS will also be excluded from the regularly occurring sampling for the FGS during the course of the MLS. Similarly, the FGS data will be manually added into applicable data sets by UC Davis at the time of data analysis. Again, this will ensure continuity and minimize data loss due to variability in survey questions between the 15-16 FGS version and any subsequent versions.

Reporting Findings

Data briefs will be provided at the mid- and endpoint of each phase of data collection. The briefs will summarize the findings to date and describe any recommended modifications to the study design. UC Davis will request data from HSRI at the mid- and endpoint for each phase of data collection. HSRI typically requires a three-week turnaround time to send data. It is estimated that UC Davis will produce a data brief to DDS two months after receiving the data from HSRI.

At the conclusion of data collection, a final comprehensive report will be compiled by UC Davis. The projected completion date of the final report is December 2019.