

# Minnesota's Olmstead Plan Quality of Life Survey Pilot Study Report

February 20, 2015

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# Quality of Life Survey Pilot Study Executive Summary

## Purpose of the Study

Since June 2014, the Improve Group has supported the Olmstead Implementation Office in piloting the Center for Outcome Analysis Quality of Life Survey tool. The purpose of the pilot study is twofold. First, we tested the survey tool to ensure that it was effective a number of different settings, and across diverse groups of people with disabilities. Second, we identified and addressed challenges in the survey administration process so that the survey process goes as smoothly as possible in future iterations.

## Survey tool

The Center for Outcome Analysis Quality of Life survey tool was selected because it is reliable, valid, low-cost, and repeatable, and it applies to all people with disabilities. In early 2014, Olmstead Implementation Office staff reviewed seven tools used locally and nationally to examine how well they would measure participant quality of life over time for the Olmstead Plan. The criteria used to judge the tools include applicability across multiple disability groups and ages, validity and reliability, ability to measure changes over time, and whether integration is included as an indicator in the survey. The Center for Outcome Analysis Quality of Life survey tool was the only tool to fully meet all the requirements listed. Studies about the reliability and validity of the tool are found in [Appendix D](#). Olmstead Implementation Office staff presented the survey options to the Olmstead Sub-Cabinet at the April 22, 2014 meeting. At that time, the Sub-Cabinet voted to approve the Center for Outcome Analysis Quality of Life survey tool.

## Methodology

### Samples and Settings

The Improve Group worked with the Minnesota Department of Employment and Economic Development, the Department of Human Services and the Department of Education to obtain survey samples. We sampled over 400 people and conducted 105 surveys in nine settings. This includes Adult Foster Care, Boarding Care, Board and Lodging, Center-Based Employment, Day Training and Habilitation, Intermediate Care Facilities for Persons with Developmental Disabilities, School Settings, Nursing Home, Assisted Living and Supervised Living Facilities.

### Disability populations

Through the pilot process, the survey was tested with people with physical disabilities, people with intellectual disabilities, people with mental illness, people with brain injuries, people who are Blind, and people who are Deaf. The majority of the surveys were administered by interviewers with disabilities recruited by the Improve Group for this project.

## Pilot Results

A rigorous analysis of quantitative and qualitative data shows that the Center for Outcome Analysis Quality of Life Survey tool worked well across disability groups and across settings. We recommend a few adjustments to the tool, and all recommended adjustments to the tool have been approved by the developer.

## Key Recommendations

A complete list of recommendations for survey administration is available in the body of the report, starting on page 47.

1. Use the Center for Outcome Analysis Quality of Life Survey tool, with the modifications listed in the body of the report, to conduct the Olmstead Quality of Life baseline survey. By surveying approximately 3,000 individuals in the settings selected each year, the State will be able to extrapolate the results to the general population with a 95% confidence level and a 5% confidence interval. The survey developer has proposed a follow-up strategy in which 500 participants are surveyed each subsequent year to measure changes over time.
2. Plan for a three- to six-month design phase for the study followed by a survey period of at least four to five months.
3. The Olmstead Implementation Office should work to secure access to participant data through the support of the Sub-Cabinet, by using legislation, a court order, or other means. Establish a plan or structure for each agency to share data (survey samples) with the Olmstead Implementation Office and the Survey Administrator.
4. The Survey Administrator should work with liaisons in each agency to draw the survey sample. It is recommended that the sample be a stratified random sample, with stratification by setting. The data request should include disability and demographic information for each person included in the sample.
5. The Survey Administrator should have the state agencies select a sample four times larger than the number of individuals the State hopes to interview. For example, to achieve 3,000 participants, the sample should include 12,000 people.
6. The survey should be arranged so that the sections of greatest interest for the Olmstead Plan are at the beginning of the survey. This will ensure that the most important sections have the highest response rate.
7. Future trainings with survey interviewers should include more depth about survey content, methods for recording responses, and how the results will be used. State agencies should also provide tools for training interviewers about programs and services. This will prepare interviewers to respond to questions from survey participants and their loved ones.
8. The Olmstead Implementation Office should develop a marketing strategy for the survey so that participants and providers are familiar with the survey efforts before they are asked to participate. Take advantage of existing communication channels to market the survey to providers and potential survey respondents.

## Background

### About Olmstead

#### The Olmstead Decision

In the 1999 civil rights case, *Olmstead v. L.C.*, the U.S. Supreme Court held that it is unlawful for governments to keep people with disabilities in segregated settings when they can be supported in the community. This means that states must offer services in the most integrated setting, including providing community based services when possible. The Court also emphasized it is important for governments to develop and implement a plan to increase integration. This plan is referred to as an Olmstead Plan.

#### The Jensen Settlement

In 2009, a federal class action lawsuit was filed on behalf of individuals who had been secluded or restrained at the Minnesota Extended Treatment Options (METO) program. The resulting settlement agreement requires policy changes to significantly improve the care and treatment of individuals with developmental and other disabilities. One provision of the Jensen settlement agreement is that Minnesota will develop and implement an Olmstead Plan.

#### Minnesota's Olmstead Plan

Minnesota is required to develop and implement an Olmstead Plan as a part of the Jensen Settlement agreement. An Olmstead Plan is a way for government entities to document its plans to provide services to individuals with disabilities in the most integrated setting appropriate to the individual. In January 2013, Governor Mark Dayton signed an executive order establishing an Olmstead Sub-Cabinet to develop the Olmstead plan. The 2013 plan has been provisionally accepted, and the US District Judge overseeing the Jensen settlement agreement must approve all plan modifications.

The goal of Minnesota's Olmstead Plan is to make Minnesota a place where "people with disabilities are living, learning, working, and enjoying life in the most integrated setting."

### About the Olmstead Quality of Life Project

The Quality of Life survey is one component of the Quality Assurance and Accountability section of the Olmstead Plan. The Plan requires Minnesota to conduct annual surveys of people with disabilities on quality including level of integration and autonomy over decision-making. The survey will be used to measure changes in the lives of people with disabilities over time.

The project is a longitudinal study. In the first year, people with disabilities from across the state will be surveyed to collect a baseline. Throughout the report, this is referred to as the baseline survey. In the following years, it has been recommended by the survey developer that a smaller sample will be selected from the baseline participants to complete the survey again. The results will be used to track Minnesota's progress on the Olmstead Plan.



## About Quality of Life Survey Tool

The Quality of Life survey was created by the Center for Outcome Analysis to measure changes in quality of life as people with disabilities move to more integrated settings. The tool was selected because it is reliable, valid, low-cost, and repeatable, and it applies to all people with disabilities. In early 2014, Olmstead Implementation Office staff reviewed seven tools used locally and nationally to examine how well they would measure participant quality of life over time for the Olmstead Plan. The criteria used to judge the tools include applicability across multiple disability groups and ages, validity and reliability, ability to measure changes over time, and whether integration is included as an indicator in the survey. The Center for Outcome Analysis Quality of Life survey tool was the only tool to fully meet all the requirements listed. Studies about the reliability and validity of the tool are found in [Appendix D](#). Olmstead Implementation Office staff presented the survey options to the Olmstead Sub-Cabinet at the April 22, 2014 meeting. At that time, the Sub-Cabinet voted to approve the Center for Outcome Analysis Quality of Life survey tool.

The Quality of Life survey will measure:

- How well people with disabilities are integrated into and engaged with their community;
- How much autonomy people with disabilities have in day to day decision making; and
- Whether people with disabilities are working and living in the most integrated setting that they choose.

Several areas of the survey are required as a part of the Olmstead Plan and cannot be changed. This includes the target population, the primary sampling method, and the timeline. These aspects of the project are strictly defined, and the Quality of Life survey must be implemented according to these requirements.

The Quality of Life survey is only one way in which the experiences of people with disabilities will be gathered. The survey is intended to a tool for providing oversight and accountability for the plan. Minnesota will use additional methods including collecting individual stories to enhance the survey data.

## About the Pilot

The purpose of the pilot survey is to learn how best to administer the baseline and follow-up surveys, including identifying challenges that may arise from conducting the survey in a variety of settings. The data collected during the pilot study will be used to evaluate the project and will not be publicly available.

The primary goal of the pilot is to test the tool in a variety of settings and with people with a range of disability types. In addition, the pilot is an opportunity to test and reflect on elements of the project in order to plan for the baseline study including:

- Recruitment plan
- Sampling strategy
- Sample size
- Survey locations

- Interviewer recruitment and training

## **Key Players in the Olmstead Quality of Life Survey Pilot Study**

In June 2014, the Improve Group was selected to conduct the pilot study through a contract with Minnesota Management Analysis & Development (MAD). The work has been guided by the Olmstead Implementation Office, with support by individuals listed below. Collectively, this group is referred to as the “Olmstead Team” throughout the report.

### **Olmstead Implementation Office**

The Olmstead Implementation Office (OIO) was created by the Olmstead Sub-Cabinet to assure the “Promise of Olmstead” becomes a reality. The OIO is responsible for making sure the vision, goals, and time-sensitive tasks of the plan are achieved. Overseeing the Quality of Life Survey is one of the OIO’s responsibilities. The OIO will report the survey progress and results to the Olmstead Sub-Cabinet.

### **The Improve Group**

The Improve Group, an independent research and evaluation consulting firm located in St. Paul, is responsible for administering the pilot survey, as well as drafting recommendations for administering the baseline survey. The Improve Group has expertise in evaluating health and human services programs, with significant experience in the area of home and community-based programs and mental health service delivery systems in Minnesota.

### **The Olmstead Team**

Improve Group staff worked closely with the Olmstead Implementation Office throughout the study. In addition, individuals from multiple agencies contributed to the study by providing information about Minnesota’s systems that serve people with disabilities. Collectively, this group is referred to the “Olmstead Team” throughout the report.

### **Funder**

The study was funded by the Minnesota Housing Finance Agency.

## About the Report

The purpose of this report is to evaluate the process of administering the Olmstead Quality of Life Survey. The report is divided into sections depending on the phase of the project. Each section of the report includes the steps taken in the phase. Each step has the original plan (either based on the contract or scope of work or early decisions made by the Olmstead Team), what actually happened, and the recommendations for future surveys based on the pilot.

**Planning Phase** includes selecting the survey instrument, the settings, identifying the population of interest, the timeline, and selecting the contractor.

**Design Phase** includes the steps taken before individuals are invited to participate in the survey such as working with agencies, selecting the sample, provider outreach, and interviewer training.

**Administration Phase** includes working with providers, scheduling interviews, and data collection.

**Analysis Phase** includes reviewing the data, analyzing response patterns, identifying problematic questions and terms, and recommendations for the baseline.

## Planning Phase

### Selecting the Survey Tool

The Olmstead Implementation Office contracted with the Center for Outcome Analysis to use a Quality Of Life (QOL) assessment tool that is specific to the Minnesota Olmstead Plan's requirements. The Center for Outcome Analysis has previously developed QOL scales that can be used across multiple disabilities, ages, and setting types. The tool was delivered to Minnesota on March 31, 2014.

The Quality of Life tool was selected from a small number of survey instruments that met the rigorous requirements of the Olmstead Plan, including being a valid and reliable tool that has been tested with people with a wide range of disabilities. The contract includes survey development, administration instructions, documentation of validity and reliability studies, and the authorization to use the tool through December 2018. This agreement providing authorization to use the tool could be renewed beyond December 2018. The author of the tool, Jim Conroy, was the content expert for Minnesota's Olmstead Plan.

### Population

The population of interest for the Quality of Life survey is people with disabilities who are living, working, or going to school in segregated settings. While the level of segregation varies person to person, the intent is to survey people who will be most impacted by the state's efforts to provide services in the most integrated setting appropriate to the individual.

The sample should also reflect the diversity of Minnesota's population including: disability type, culture, race and ethnicity, location within the state, and other demographics. The primary disability types included in the sample are:

- People with physical disabilities
- People with intellectual / developmental disabilities
- People with mental health needs / dual diagnosis
- People who are deaf or hard of hearing
- People who are blind or visually impaired
- People with traumatic brain injury

### Settings

Participants were selected from nine different settings where people with disabilities receive services. The setting list represents the most segregated settings where people receive services.

The settings included in the pilot were:

- Center Based Employment, a Minnesota Department of Employment and Economic Development (DEED) setting
- Children in segregated school settings, a Minnesota Department of Education (MDE) setting
- Day Training & Habilitation, a Minnesota Department of Human Services (DHS) setting
- Board and Lodging, a DHS setting

- Supervised Living Facilities, a DHS setting
- Boarding Care, a DHS setting
- Nursing Homes and Assisted Living, a DHS setting
- Adult Foster Care, a DHS setting
- Intermediate Care Facilities for Persons with Developmental Disabilities (ICF-DD), a DHS setting

## Timeline

### Original Plan

Table 1 below shows the original timeline for the study at the initial proposal from the Improve Group, the modified proposal at contract execution, and the actual timeline for the four phases of the study.

**TABLE 1: PILOT STUDY TIMELINE**

Phase	Original Timeline at Initial Proposal	Modified Timeline at Contract Execution	Actual Timeline
Kick-off	April 2014	June 2014	June 2014
Design Phase	May – July	June – July	June – September
Data Collection	July – October	Late July – October	October – November
Analysis Phase	November – December	November – December	November - December

### What Really Happened

Getting access to participant data in order to contact people to take the survey took significantly longer than expected, resulting in a longer design phase and a truncated data collection period. In order to have access to the names of people receiving services in Center Based Employment and Segregated School Settings, each agency had to obtain consent to release information from participants and, if applicable, their guardians. For participants in other settings, the Improve Group was able to secure a data sharing agreement with DHS that allowed for access to participant data without an additional consent to release information.

The invitation process also impacted the time available for conducting surveys. For everyone except participants living in Adult Foster Care and Supervised Living Facilities, the process was to send a packet to the provider about the survey, and request the provider’s help with inviting people to participate and scheduling interviews. This process, including initial and follow up phone calls, provider follow up with clients, and scheduling an interview time, took no less than 2 weeks. If we needed to obtain a consent to release information or guardian consent, it could take more than a month to schedule an interview.

Turnaround time was calculated from the date the initial invitation was mailed to the date interviews were scheduled and to the date the interviews were completed. If all of the participants at location declined to participate, the date the provider informed us of this was record as the interview scheduled date. Providers that did not respond to outreach efforts or refused to participate are not included in the calculations.

**TABLE 2: TIME TO SCHEDULE AND COMPLETE INTERVIEWS BY SETTING**

<b>Setting</b>	<b>Average days to schedule interviews after first invitation</b>	<b>Average days to complete interviews after first invitation</b>	<b>Minimum number of days to schedule interviews after first invitation</b>	<b>Maximum number of days to schedule interviews after first invitation</b>
Adult Foster Care	33	39	30	44
Boarding Care	13	25	20	33
Board And Lodge With Special Services	8	18	7	29
Center-Based Employment	26	36	24	56
Day Training and Habilitation	18	29	23	36
Intermediate Care Facility for Persons with Developmental Disabilities	43	49	43	60
Segregated School Settings	16	16	12	19
Nursing Homes and Assisted Living	12	26	14	34
Supervised Living Facilities	2	6	2	6

Because it took so long to get access to participant data, the data collection phase was 8 weeks long instead of 13-16 weeks. In order to conduct as many interviews as possible during the shortened timeframe, most of the providers we selected were in the Minneapolis-St. Paul metro area. In addition, interviews were conducted in St. Louis County, Stearns County, Goodhue County, and Renville County. Because not all of the settings or populations of interest were reached during the data collection phase, additional interviews were scheduled in December with deaf individuals and individuals receiving services in greater Minnesota.

See recommendations for the planning phase in future survey administration [on page 46 of this report](#).

## Design Phase

### Research Approvals and Human Subjects Protection

#### Original Plan

The Improve Group's original proposed approach was to determine whether the study required approval from an Institutional Review Board (IRB). If IRB approval was deemed necessary, the plan was to work with an independent IRB to get research approval. At contract execution with the Improve Group, the plan for obtaining consent from individuals had not been finalized.

#### What Really Happened

It was determined that the Olmstead Quality of Life Survey is exempt from IRB approval under [Federal regulation §46.101](#), available at <http://www2.ed.gov/policy/fund/guid/humansub/overview.html>.

Before it was determined that this study was exempt from IRB approval, the Improve Group completed an application for the Heartland Institutional Review Board. This application was ultimately not submitted. However, the application outlined steps for protection of human subjects and data security that were incorporated the study's data security plan.

Additionally, the Improve Group used an internal review process for project materials. The team also required active consent from all survey participants and obtained guardian consent for participants who are unable to give informed consent.

#### *Internal Review*

All project materials, including surveys, consent forms, communication materials, and questionnaires, were reviewed by the Olmstead Team. Additional review was provided by the Advisory Group and Improve Group Directors that were involved in the study.

#### *Informed Consent*

Participants were asked to give informed consent at the time of the interview. If the individual did not give consent, or if they did not understand the consent form, they were not interviewed. Alternate documentation of consent, such as a witness observing a participant's verbal or visual consent, was used with individuals with disabilities that limited their ability to sign a consent form. Participants who were not able to give informed consent, such as people under 18 and individuals under guardianship, were asked to provide assent at the time of the interview, and were only contacted after the guardian gave consent.

#### *Data Security*

The Improve Group developed a project-specific data security plan, and the Olmstead Team reviewed the plan. Protections include:

- storing project materials in locked cabinets

- encrypting files and folders with personal or protected data
- limiting access to encrypted files to project staff
- training staff and contractors in data security, confidentiality, and human subjects protections

See recommendations for Human Subjects Protections in future survey administration [on page 46 of this report](#).

## Preparing the tool

### Original Plan

Consult with Jim Conroy to finalize the survey instrument with the Minnesota context in mind (with particular attention to demographic questions) and make sure we collect the data in a way that can be compared to national results.

Prepare the survey for administration using a laptop or tablet as well as a web-based version of the survey for people who would prefer to take the survey on their own or without an interviewer present.

### What Really Happened

Finalizing the survey was an ongoing process that extended into the administration phase. There were no major changes to the structure or content of the survey after the interviews started. However, there were minor changes to language and question routing in reaction to notes from survey administrators. Question routing allows interviewers to skip questions that are not relevant to the participant. These changes were made to improve the interview flow and to clarify the meaning of questions or response options.

### *Changes to the survey*

The biggest change to the survey was adding response options to make the survey more inclusive or better suited to the current context. For example, “something else” was added as a response option for questions about gender or race and ethnicity. A “Don’t Know” option was added to the questions that did not already have that option. In addition, scripts were added to smooth the transition between sections and to help interviewers explain the survey. Finally, question routing and question piping was added. Question piping customizes each survey for participants by taking a response from one question and automatically inserting it into a future question.

A complete list of changes to the survey, including the rationale for each change, can be found in [Appendix A](#).

### *Preparing the tool for administration*

The survey was prepared for administration using laptops or tablets using SNAP Survey software, which has the capability of creating surveys for the web or for paper and pencil administration. Question routing, piping and scripts for interviewers were added to the survey to streamline administration and make the survey more consistent across interviewers.



In addition to routing and piping, a question was added to end of each page or section about any items or terminology the primary respondent had difficulty with. The responses to these questions were used to identify questions that were difficult for participants and to make technical changes to the survey. Interviewers also used these questions to make notes about technical problems with the survey.

A modified web-based version of the survey was created for people who would prefer to take the survey on their own. The modified survey was the same as the interview version except that some of the scripts and interviewer instructions were removed. The feedback questions at the end of each section were reworded to address the participant. The web version of the survey was made it available to people who requested it.

### ***Accessibility***

The survey tools and communication materials were used by Improve Group staff and interviewers. The materials were read to participants. Neither the survey nor the communication materials were tested for accessibility. A plain text version of the survey was created; however that version was not used or tested. None of the pilot participants requested a version of the survey for screen readers or large print versions of the survey; however only a small number of individuals who are blind or visually impaired were surveyed.

**See recommendations for Preparing the Tool for future survey administration [on pages 47 of this report](#).**

## **Translation and Interpretation**

### **Original Plan**

Translation and interpretation were not included in the original pilot plan or scope of work. As a result, no funds were available for providing alternate versions of the survey for the deaf or hard of hearing, blind or visually impaired, or non-English speakers.

### **What Really Happened?**

The Improve Group entered into an agreement with an American Sign Language (ASL) interpretation provider for individuals who requested an interpreter. For other non-English speakers, the Improve Group provided an interpreter if one was needed and requested. All materials, including consent forms and recruitment materials, were only available in English and were interpreted onsite. Two interviews were conducted in ASL and one was conducted in Amharic.

We asked providers when we scheduled interviews if any of the participants needed any accommodations, including if any of the participants would need an interpreter. However, the providers did not always have this information. Some participants completed the survey even though their primary language was something other than English. One interview had to be stopped early because the participant requested a Mandarin interpreter during the survey. We were not able to reschedule that interview.

One set of ASL interviews and the Mandarin interview had to be cancelled because we were unable to schedule interpreters. We attempted to reschedule the Mandarin interview twice and interpreters were not available either time.

**See recommendations for Translation and Interpretation [on page 47 of this report](#).**

## **Sampling Strategy**

### **Original Plan**

Randomly select 200-250 people to participate in the survey using setting as the primary selection criteria, disability type as a secondary selection criteria, and demographic and other characteristics as tertiary selection criteria.

The nine settings to be included in the sample were:

- Center-based employment
- Children in segregated school settings
- Day Training & Habilitation (DT&H)
- Board & Lodging
- Supervised Living Facilities
- Nursing Home / Assisted Living
- Adult Foster Care
- Intermediate Care Facilities for Persons with Developmental Disabilities (ICF / DD)

The proposed secondary selection criteria were:

- Physical Disabilities
- Developmental Disabilities
- Mental Health Needs
- Brain Injury
- Deaf or Hearing Impaired
- Blind or Visually Impaired

Demographic and other characteristics tertiary selection criteria included:

- Geographic location
- Race / ethnicity
- Age
- Make extra efforts to include culturally diverse populations

### **What Really Happened**

An initial sample of 455 individuals in eight of the settings was selected to take the survey. In addition, volunteers were recruited in order to ensure the survey was tested in all of the settings and with all of the populations of interest.

With input from the Olmstead Team, the Improve Group selected five to ten providers per setting to participate in the pilot. Providers were selected that represent diverse disability groups and some providers were selected for the diverse demographic populations they serve. Once the providers were selected, the secondary selection criteria were only used to identify individuals with hearing or vision needs in DHS settings. Because the data structure and information maintained about individuals receiving services varies by agency and provider, demographic information was not used as a selection criterion for individual participants after the providers were selected.

### ***Setting***

The Olmstead Team used licensing information and agency guidance to identify organizations that provide services in each of the setting types. The agencies then helped to select a sample of individuals from each provider to invite to the survey. Forty-nine providers were selected as pilot sites. In all, we conducted interviews with participants from 29 providers. Of the 20 providers for which we did not conduct interviews:

- Six providers declined to participate.
- We were unable to schedule interviews with the other nine providers for which we had a sample.
- Additionally, we were not able to get a sample for nine providers, but four of those providers allowed us to interview volunteers.

Identifying providers to select a sample from was more complicated than expected, especially for DHS providers. The biggest challenge is that the different settings are not clearly defined, and providers may offer services for multiple setting types at the same location. It is also possible that providers may also provide services for participants through multiple funding streams. This complexity poses a challenge for ensuring the setting types are well represented without looking at the participant's funding source.

### ***Disability Type***

During the early planning stages, the Improve Group created a grid of settings and disability types with the impression that the Olmstead Team would be able to identify which settings would have a greater number of individuals with certain disability types.

Each of the state agencies collects and report disability type differently, which made it difficult to consistently use disability type as a selection criteria. Disability type was not included in the sampling criteria for DEED or MDE participants because the Improve Group did not have access to participant data. For participants in DHS-funded settings, we attempted to capture variety in disability type by selecting providers that specialize in working with certain disabilities. In addition, the houses in the adult foster care and supported living services sample were selected because one or more individuals in the home had hearing or vision needs.

The number of people with vision or hearing disabilities in the initial sample was not large enough to provide reliable feedback about the survey. In order to reach enough people to test the survey, organizations that provide services that do not fall into the 9 survey settings were approached to serve

as pilot locations. Individuals who were surveyed in these locations were asked to provide additional feedback about accessibility and interpretation.

### ***Demographic and Other Characteristics***

Selecting the sample required working with state agencies to define setting types and to select appropriate providers. A different approach was used to select the sample from each state agency. The approaches reflect the different data structures and level of data access for each agency.

**[See recommendations for Sampling Strategy on page 47 of this report.](#)**

## **Working with State Agencies**

The settings included in the sample are funded by three different agencies: Minnesota Department of Human Services (DHS), Minnesota Department of Education (MDE), and Minnesota Department of Employment and Economic Development (DEED). The Olmstead Team worked with the agencies to find liaisons to help access data and generate the survey sample. Each agency has different data structures and different data sharing requirements. The process for working with each agency follows.

### **Department of Employment and Economic Development**

DEED holds the data for people who receive services through Center Based Employment. In order to share participant data with the Improve Group, DEED required Consent to Release Information Form from each program participant or their guardian. DEED maintains data on participant's legal representatives, but the Improve Group could not access that information to contact guardians directly.

The process for selecting and inviting DEED participants to the survey was as follows:

- The Olmstead Team, with guidance from DEED about appropriate providers, identified 5 metro area center-based employment providers from which to select the sample;
- DEED selected the sample using guidance from the Improve Group;
- The Improve Group prepared a provider packet that included project information, consent to release information forms, and guardian consent forms for participants with legal guardians. The packet included instructions on completing and returning the forms as well as contact information for the Improve Group. DEED sent the packets along with a cover letter from DEED employee John Sherman encouraging providers to participate to the sites;
- Providers were asked to manage collecting first consent, including obtaining consent from participants' guardians; and
- Interviews were scheduled at the providers' offices to make it easier for participants to take the survey during the workday.

### ***Challenges***

- Staff turnover at DEED caused a delay in selecting the sample and sending information to providers.

- The arrangement with DEED required obtaining consent to release information from participants and guardians before the Improve Group could contact them about the survey. This meant that significant “leg work” for the survey had to be completed by DEED staff.

### **Department of Human Services**

DHS holds the data for individuals in seven of the nine settings. The Improve Group was able to secure a data sharing agreement with DHS, which gave the Improve Group permission to contact individuals directly. The Olmstead Team selected providers to sample from, and DHS provided the sample of individuals within each setting if that information was available. However, the data for several settings was limited, and the lack of participant information in Supervised Living Facilities, Boarding Care, and Board and Lodge with Special Services presented an additional challenge. DHS maintains information guardianship status for some participants. However, guardian contact information for people receiving DHS services is held at the county level.

The process for selecting the DHS sample is as follows:

- The Olmstead Team, with guidance from DHS, selected 5-10 providers from which to select the sample. The number of providers depended on the type of service, with smaller settings having more providers.
- DHS data liaisons selected a sample from each provider. If the provider had fewer than 15 participants, all of the people receiving services at that setting were included in the sample.
- DHS transmitted the sample directly to the Improve Group, and the Improve Group obtained first consent.
- The Improve Group requested support from providers with obtaining guardian consent to contact individuals to participate. Providers also helped to facilitate the survey by encouraging individuals to participate and arranging interview times.

### ***Challenges***

- DHS uses multiple systems to manage data for individuals in different settings, which caused a delay in getting data for multiple settings. Determining which system to use to pull data for each setting, creating the code, and searching for providers within the system was also time consuming.
- There is no plain language definition of settings, and many of the providers hold multiple licenses. This made selecting providers and the sample difficult. In addition, not all of the providers we selected were in the databases, particularly Board and Lodging and Boarding Care providers.

## Minnesota Department of Education

MDE oversees programs for students with disabilities up to age 22. However, each district maintains information on students and their guardians, and neither MDE nor the Improve Group had access to the data.

The Improve Group worked with MDE to identify metro-area schools to include in the pilot. The schools were selected based on the number of students in segregated school settings over age 7 and geographic location. Two schools, one in the south metro and one in the west metro, were selected to participate in the pilot. MDE contacted district superintendents about the project, and the Special Services office of each school worked with the Improve Group to recruit participants.

The process for selecting the MDE sample was as follows:

- Two school districts were selected to participate based on student population and geographic location. The schools were selected because MDE data showed they had 30-50 students in segregated school settings;
- MDE contacted the School Superintendent in each district, requesting their participation in the project;
- The Improve Group worked with the Special Services Offices to send invitations to all families with students receiving services in Federal Special Education Settings 3 and 4. The invitations included background information about the project and guardian consent forms;
- Parents and guardians returned consent forms to the Improve Group; and
- Interviews were scheduled with the families in their homes or at a neutral location.

### *Challenges*

- Both school districts had nearly 90 students in segregated settings, not the 30-50 we expected based on the information from MDE.
- Not having access to student data limited the options for follow up. Both school districts provided additional support with encouraging families to participate, but only 11% of families returned a consent form.
- Both schools used their resources to encourage families to participate in the project, but the relationship between the schools and the families was not as conducive to getting people to participate as the other providers. There are some fundamental differences in education programs and residential or vocational programs.

See recommendations for Working with State Agencies [on page 47 of this report](#).

## Advisory Group

### Original Plan

The Improve Group recommended engaging an advisory group to provide insights about recruiting, administration, and interpretation of data. The advisory group would have 6-10 members and would meet up to four times during the project. The advisory group would help the Olmstead team to make sure that the concerns and needs of the community were heard throughout the process. The advisory group would provide feedback on surveys and communication tools to make sure the Olmstead Team was “speaking the language” of the community.

The ideal advisory group member would:

- Have a disability or be an advocate for people with disabilities
- Be close to the survey experience
- Be from the community rather than a government agency
- Be an advocate for the Olmstead Quality of Life Survey

### What Really Happened

The Olmstead Team identified members of the community and advocates for people with disabilities to invite to the advisory group. Five people from a range of backgrounds and experience agreed to join the group. Extra effort was made to help ensure the advisory group was inclusive of people from multiple disability groups.

The advisory group met once, in early November. Several attempts were made to schedule an in-person meeting in August or September, but it was difficult to find a time when everyone could meet. In order to get advisory group feedback before starting surveys, the Olmstead Team asked group members to review documents and provide feedback individually. Advisory group members provided feedback on the pilot review questionnaire, interview topics, and lessons learned from other initiatives.

At the November meeting, the Olmstead Team shared how the project was working so far, and asked for feedback about the project. It was a time for members to meet, here progress about the survey and share feedback about the process. The Advisory Group members shared that it is important that individuals with disabilities and individuals that represent the diverse communities of Minnesota conduct the survey as much as possible. Racial, ethnic, and cultural diversity were shared as being particularly important.

The plan was to meet with the Advisory Group in December to share initial findings. The condensed time of the study did not allow for this meeting. The Olmstead Team will share a summary of findings with Advisory Group members and invite their participation in future discussion about the study in the baseline year.

See recommendations on the Advisory Group [on page 48 of this report](#).

### **Reporting Abuse and Neglect**

The Olmstead Team identified the need to develop a protocol for documenting interviews in which people threaten to hurt themselves or others or incidents of reported or suggested abuse or neglect. The Improve Group developed a protocol for reporting suspected abuse or neglect using DHS resources for mandated reporters. This protocol required that all incidents or self-reported, observed, or suspected abuse or neglect be reported to the common entry point within 24 hours of the interview. If the participant was in immediate danger, the interviewer was to call 911 immediately. The Improve Group created a form for internally documenting reports of abuse or neglect.

In all, there were three incidents of suspected abuse or neglect. Of these cases, one resulted in a report to the common entry point, and the other two were cases that were previously reported and resolved.

See recommendations on Reporting Abuse and Neglect [on page 48 of this report](#).



## Administration Phase

### Working with Providers and School Districts

#### Original Plan

Send at least two letters to providers to let them know about the survey and their role as well as to help get information to participants about the survey and encourage them to participate.

#### What Really Happened

Providers had an active role in supporting the survey, including helping to obtain first consent from participants and their guardians, scheduling appointments, and arranging space for interviews. Providers also played a huge role in getting people to participate in the survey. For all of the settings except schools, most of the interviews were conducted on-site. The school districts helped with outreach and provided space to conduct surveys; however, families of school-aged children generally preferred to be interviewed at home or in a neutral location.

In residential and vocational settings, the close relationship between the providers and participants also helped to prepare interviewers for the appointment. Staff members shared tips for communicating with individuals, provided context about participant's situation, and supported participants during the survey when requested. Many of the providers played the dual role of advocating for the project and their clients.

While most of the providers were supportive of the project, some were hesitant to get involved and a few refused to participate. Providers that were hesitant cited multiple surveys from different agencies, demands on staff, or the likelihood that their participants would not be interested in the project. Providers were surprised they had not heard about the Olmstead Quality of Life survey prior to receiving the provider packet, and some were concerned that DHS might not sanction the project. Reasons some providers gave for opting out of the survey included: clients would not be interested, lack of time, or lack of information. Other providers did not return phone calls.

The letter providers received from the state agency inviting them to participate was often the first they had heard of the project. If the provider did not receive the letter or if the packet got shuffled around and lost, the phone call was the first they heard of it. Because the project was a surprise, it was hard to find the appropriate contact, which sometimes ended up leading to calling in circles. Also, because the packets were sent to the individual homes for ICF / DD and foster care settings, sometimes we had guardian consent forms before the provider had figured out what the next steps were.

Because the providers were the primary method of reaching potential participants, gaining their support was essential to the project. To gain this support, someone from the Improve Group contacted each provider at least twice before attempting to schedule interviews. While the letters sent by agency liaisons helped to establish credibility and authority with the providers, many of the providers required additional evidence that their participants' rights and privacy would be protected.

On the whole, the providers we talked to were aware of the Olmstead Plan and supported efforts to improve services for their participants. Many of them said they thought the project was important, and

that they were encouraging people to participate. Several providers rescheduled interviews to make sure that everyone who had agreed to take part in the survey was available.

See recommendations on Working with Providers and School Districts [on page 48 of this report](#).

## Recruitment and Communication Strategies

### Original Plan

Develop recruitment and communication tools for providers and survey respondents. Two letters to providers and facilities about the survey letting them know that we would be contacting them and participants.

### What Really Happened

The Improve Group worked with state agencies to reach out to providers about the survey. The Improve Group prepared packet of materials to the providers or school districts that included information about the survey, provider roles, guardian consent forms, and, if available, a list of participants. For every setting except Adult Foster Care and ICF / DD, materials were sent from the state agency. The Improve Group contacted ICF / DD providers and adult foster care participants directly.

After the packet was sent, the Improve Group called providers to give them more information and answer questions. As soon as the providers were onboard, we began coordinating guardian consent and scheduling interviews. Scheduling and coordination was also done via email. Depending on the setting and provider, the turnaround time ranged from a couple of days to over a month. Recruitment efforts took much longer in Adult Foster Care and ICF / DD because the packets were sent directly to homes instead of to the provider's main office. This approach made tracking down the right person to talk to much more difficult.

Some providers contacted the Improve Group as soon as they got the packet to ask questions and coordinate scheduling, while others never received the packet. The contact information and mailing addresses for some providers were out of date or incorrect.

See recommendations on Recruitment and Communication Tools [on page 49 of this report](#).

## Consent Process

### Original Plan

Obtain informed consent from all participants before starting the survey. For participants with guardians, obtain guardian consent and participant assent. Allow for alternate documentation of consent for participants with disabilities that keep them from signing their name.

### What Really Happened

All participants were given the option to opt out of the survey before an interview was scheduled and at the time of the appointment. Even if the person agreed to participate, the survey was not conducted if the interviewer did not think the person understood the consent form. Some individuals who agreed to participate declined at the time of the interview, either by not showing up for the appointment or by

declining to answer questions. People were most likely to decline at the time of the interview in residential settings, especially Boarding Care and Nursing Homes / Assisted Living. In several cases the contact person could not find the person at the time of the interview, and the contact person felt those individuals were passively opting out of the survey. In other cases the guardian had given permission to contact the individual but the person was not interested in participating.

The Improve Group obtained guardian consent before contacting individuals to participate in the survey. However, the Improve Group did not have access to guardian information, so providers were asked to help obtain guardian consent either by contacting guardians directly or by providing contact information.

If a person who could not consent had a guardian present, the guardian was given the option to complete the survey. Seventeen guardians were present for the survey, and in seven cases the guardian was the primary respondent. In all of the cases where guardian was the primary respondent, the focus person was a student in segregated school settings.

**See recommendations on the Consent Process [on page 49 of this report](#).**

## **Survey Administration**

### **Original Plan**

The Improve Group will administer 85 surveys. We hope to administer 40-45 surveys among our staff and then reflect on and document lessons learned. At that point will recruit and train people with disabilities to administer the surveys, and then co-administer the remaining 40-45 surveys as training and coaching opportunities. Each survey administrator would then administer up to 30-40 additional surveys. In total, we anticipate that 205-245 surveys will be administered.

### **What Really Happened**

The shortened survey timeline and longer design phase meant that Improve Group staff did not administer the first group of surveys. Instead, the first round of interviews were used for training and coaching purposes, and Improve Group staff administered surveys when other interviewers were not available. Having interviewers conduct the surveys instead of Improve Group staff allowed for conducting more surveys because of budget constraints that resulted in more time spent during the design phase gathering samples than was originally anticipated.

At the end of the administration phase 105 surveys were attempted or completed. Because some of the target populations were not reached during the administration period, an additional four surveys were completed in December. In addition, six partial surveys were conducted at Vision Loss Resources to get feedback from people with vision loss about the survey.

The original plan estimated 3 hours per survey including scheduling, travel, meeting and greeting participants, and survey administration. In practice, it took an average of 4 hours to schedule and complete each survey. This estimate includes 2 hours for coordinating with providers and scheduling interviews, an hour to conduct the interview, and one hour for travel, setup and breakdown. The coordination time includes time spent explaining the survey to providers and family.

Most of the surveys were conducted using laptops and an internet-based survey program. Each interviewer had a password-protected hotspot to bring with them to survey participants rather than relying on the survey location for internet access. We chose this administration method because we were able to record participant responses and transmit data securely to the Improve Group servers. In most cases this administration mode worked well; however, there are some limitations to using computers to administer the survey.

First, there were many settings where the hotspot did not work or it worked intermittently. This meant interviewers had to move rooms to complete the survey or switch to paper part of the way through the interview. In addition, sometimes the hotspot worked, but the signal was not strong enough to move fluidly through the survey. The problems with internet access were disruptive enough that we do not recommend using an internet-based survey.

Second, many of the interviews were conducted in small spaces such as the participant's bedroom or a small office. The interviewers had a hard time navigating the small spaces with the laptop while trying to be respectful of the participant's space. If the interviewer had several interviews in one day they would have to find a place to plug in the computer during the survey, limiting the where the survey could be administered.

When we were not able to use a computer because of internet access or other barriers, the survey was conducted on paper. This allowed for the interviewer to take notes about the responses and made it easier to go back to sections if the participant provided more information during the interview. However, paper surveys did require extra time for data entry after the interview.

**See recommendations on Survey Administration [on page 49 of this report](#).**

## Special Populations

### Survey Administration in Greater Minnesota

#### Original Plan

We will choose three additional locations in greater Minnesota to provide some geographic representation, including one rural area with few services or resources and an "outstate hub" with more services and resources.

#### What Really Happened

A total of 15 interviews were conducted in greater Minnesota. Eleven during the survey administration period and four after the administration phase ended. The interviews were conducted in St. Louis County, Stearns County, Goodhue County, and Renville County. The St. Cloud provider was selected because it is a service provider for several rural counties. In addition, we contacted providers in Pope and Faribault Counties, but were unable to schedule interviews.

A Center-Based Employment provider in Goodhue County and two providers in Duluth, an ICF / DD and a Board and Lodge with Special Services, were included in the original sample. Six people at the Center-

Based Employment provider and one person at the ICF / DD agreed to participate and were interviewed. The Board and Lodge declined to participate.

We sent information to six foster care houses and a DT&H in Pope County. The notification inadvertently was delayed for Pope County and providers were asked to participate at the end of the survey administration period. The DT&H declined because of the tight timeline for getting guardian consent and scheduling interviews. No one from the foster care houses agreed to participate.

In order to include more individuals receiving services in rural areas in the survey, the Improve Group reached out to providers in greater Minnesota. In order to schedule interviews quickly, we selected settings where participants were less likely to have guardians based on our experiences in the metro area.

When confirming the appointment time with one provider, we found out that all of the participants would require guardian consent. The contact person said it was a common practice in rural areas to obtain guardian consent over the phone. However, we felt the guardian consent form was too complicated to administer over the phone and rescheduled the interviews in order to allow more time to obtain guardian consent.

In general, the challenges with scheduling and conducting interviews in greater Minnesota were similar to the challenges in the metro area. However, the process was complicated by travel time and interviewer travel limitations. For example, it was difficult to find interviewers who were available to travel outside of the metro area at the times that worked for the participants. This challenge was even greater for interviews that required overnight travel.

**See recommendations on Survey Administration in Greater Minnesota [on page 50 of this report](#).**

### **Blind or Visually Impaired or Deaf and Hard of Hearing**

We attempted to include people who are blind or deaf in the sample by using vision and hearing needs as a sampling criteria. The Adult Foster Care and Supported Living Services houses that were selected as survey locations were selected because at least one resident had vision or hearing needs. However, approach was not successful in recruiting blind participants. Some providers declined to participate because of the resident's vision or hearing needs, particularly in homes where participants were receiving Supported Living Services

DEED was not able to use hearing or vision needs as a sampling criteria because there are very few individuals with these needs in Center-Based Employment, particularly in the metro area. We also attempted to survey students at the Minnesota Academies, but were not able to schedule interviews.

One boarding care provider was selected as a survey location because they have a program that specializes in deaf services. However, only two interviews were conducted at that provider. In order to test the survey with more individuals who required ASL interpretation, we scheduled interviews with

participants receiving services from the Minnesota Employment Center (MEC) for People Who are Deaf or Hard of Hearing, but were not able to conduct the interviews.

In order to reach more people with vision loss, we tested the survey at a peer counseling meeting at Vision Loss Resources. Due to time limitations, we divided the survey into two sections and had volunteers provide feedback on those sections.

**See recommendations on Blind or Visually Impaired and Deaf or Hard of Hearing Participants [on page 50 of this report.](#)**

## Analysis and Reporting

### Pilot Results

A rigorous analysis of quantitative and qualitative data shows that the Center for Outcome Analysis Quality of Life Survey tool worked well across disability groups and across settings. We recommend a few adjustments to the tool, and have consulted with the tool's developer about making those adjustments.

### Qualitative Analysis

There were three main sources of data for the qualitative analysis of the pilot: the Pilot Review Questionnaire, interviewer notes recorded during the survey, and interviewer reflections. These sources were analyzed to evaluate the survey instrument and the administration process.

### Survey Tool Questions

A question was added to the end of each section of the survey for interviewers to note any problems the participant had with the survey. This question was also used to report technical problems with the survey and to make notes about the participant's behavior. These responses were analyzed for trends related to questions and terminology that caused problems for the participant.

### Pilot Review Questionnaire

For each survey the interviewers completed a Pilot Review Questionnaire that included information about the participant, the setting, and the survey process. These responses were compared to the survey results to identify patterns survey non-completion and problem areas.

The questionnaire also allowed the interviewer to share successful interview techniques or unusual situations. These responses were used to provide ongoing coaching to interviewers and to make adjustments to the administration process. The responses were also used to make recommendations for the baseline survey.

### Interviewer Reflections

As the people working in the field, the interviewers had the most extensive knowledge of what worked well during the pilot and what needed to be changed. In order to share this experience, the interviewers regularly debriefed staff about their experiences in the field. These conversations were used to improve processes throughout the administration phase. Because the interviewers had time to reflect more on their experiences before debriefing, these reflections were often more in depth than the pilot review questionnaire allowed. Interviewers also provided feedback about the pilot project at the end of the survey administration period. Their feedback was used reinforce findings and recommendations.

### Quantitative Analysis

The survey responses were analyzed for response rate, survey completion rates, and survey length. Participant's responses to race and ethnic identity and disability type and perceived significance questions were also compiled.

## Response Rate

Approximately 450 individuals from 9 settings were invited to take the survey, and 105 individuals agreed to participate for an overall response rate of approximately 22%. A handful of providers volunteered to ask everyone they serve to participate in the study. Because the number of people these providers serve is unknown, it is not possible to calculate survey response rate. This includes an estimate of the number of people who were invited to participate during community meetings at the Anoka Metro Regional Treatment Center. Volunteers were recruited in Board and Lodging but were not used to calculate the response rate.

Two settings, Adult Foster Care and School Settings, had response rates around 10%. However, these settings had unique recruitment issues that may have depressed the response rate. The Adult Foster Care response rate includes participants receiving Supported Living Services, and no interviews were conducted in those homes. Of the participants receiving funding through the CAD1, CAC, and BI waivers the response rate was 18%. For school settings, the response rate was likely affected by the fact that there was no way for the Improve Group to follow up with families after the initial letter.

At each setting there were individuals who agreed to take the survey but who declined at the time of the interview. In some settings, most notably Boarding Care and Nursing Homes, there were people who agreed to take the survey but did not show up for their appointment. Other people agreed to the survey but were unable to participate because of scheduling conflicts. A longer survey administration period would give these individuals more opportunities to participate.

**TABLE 3: RESPONSE RATE BY SETTING**

Setting	Number of Invitations	Number of Surveys	Response Rate
Adult Foster Care	57	5	9%
Boarding Care	28	12	42%
Board and Lodge with Special Services (participants were recruited at the time of the interview)	0	10	-
Center-Based Employment	60	22	35%
Day Training and Habilitation	47	9	19%
Intermediate Care Facilities for Persons with Developmental Disabilities	25	8	32%
School Settings	166	18	11%
Nursing Homes and Assisted Living	50	15	30%
Supervised Living Facilities	30	6	20%
Total	455	105	22%

## Survey Completion

Overall, 88% of participants completed the required sections of the survey, and 60% completed all but the last section. Only 34% of participants completed all the survey sections. This is in part due to



participant fatigue and in part because interviewers were told to give the participant the option to stop the survey after 60 minutes. At least 80% of participants completed the required sections in every setting except DT&H and Boarding Care. The low completion rate (56%) in DT&H is because many of the participants had barriers to completing the survey that are related to their disabilities. The completion rate was also lower (67%) in Boarding Care. This is due to people who agreed to take the survey but who decided to stop during the first section. Survey completion rates by setting are shown in Table 4. The four surveys conducted after the survey administration period are not included in the results.

Most of the participants who stopped at the end of the required sections or after the Person-Centered Planning section stopped because of fatigue or because of other appointments. However, some participants declined to complete the Close Relationships Inventory because they were concerned the section would be too personal. In Segregated School Settings, only one participant completed the Close Relationship Inventory. Several parents declined to complete the section because their child “didn’t have any friends.” We recommend adding more training around framing this section to increase completion rates.

**TABLE 4: SURVEY COMPLETION BY SETTING (PERCENT COMPLETED)**

Setting	Attempted Surveys	Did Not Complete Required Sections	Completed Required Sections	Person-Centered Planning	All Sections
Adult Foster Care	5	0%	100%	40%	40%
Boarding Care	12	33%	67%	50%	17%
Board and Lodging	6	0%	100%	67%	67%
Center-Based Employment	22	5%	95%	68%	64%
Day Training and Habilitation	9	44%	56%	56%	33%
Intermediate Care Facilities for Persons with Developmental Disabilities	8	0%	100%	13%	13%
Segregated School Settings	18	0%	100%	94%	6%
Nursing Home / Assisted Living	19	16%	84%	42%	26%
Supervised Living Facility	6	0%	100%	67%	17%
<b>All Settings</b>	<b>105</b>	<b>11%</b>	<b>90%</b>	<b>59%</b>	<b>32%</b>

### Survey Completion Time

The total time needed to complete the survey varied by setting. Across all settings, the average survey length was 42 minutes with a maximum length of 91 minutes. Average, minimum, and maximum survey length by setting is shown in Table 5. The minimum survey length includes surveys that were started but not completed. Unless noted, this calculation does not include interviews that were recorded using paper and pencil.

An important consideration in survey length time is the relationship between survey length and survey completion. Overall, the higher the survey completion rate the longer the survey took to finish. This is of particular importance in settings where participants have higher barriers to participation or communication needs that will lead to longer surveys such as DT&H. Also, interviews that took place at a provider were scheduled for 60 minutes and most surveys were stopped if they lasted over an hour. Participants were also reminded of their option to end the survey after the required sections or when they showed signs of fatigue.

**TABLE 5: SURVEY LENGTH BY SETTING (MINUTES)**

Setting	Average Survey Length	Minimum Survey Length	Maximum Survey Length
Adult Foster Care	46.7	34.6	60.7
Boarding Care	27.8	4.1	54.8
Board and Lodging	36.7	29	48.2
Center-Based Employment	46.5	30.8	70.4
Day Training and Habilitation	20.3	2.4	45
Intermediate Care Facilities for Developmental Disabilities	34.5	26.4	40.8
School Settings	54.3	29.9	90.7
Nursing Homes and Assisted Living	45.2	7.9	89.8
Supervised Living Facility (includes paper surveys)	32.2	22.5	46.7
<b>All Settings</b>	<b>41.8</b>	<b>2.4</b>	<b>90.7</b>

### Respondent Characteristics

Participants were asked to provide their race and ethnic identity followed by primary ethnic identity. Participants could select more than one response for race and ethnic identity, but only one primary ethnic identity. If the participant only selected one race or ethnic identity, the interviewer chose the same response for primary ethnic identity.

When asked to choose their primary ethnic identity, 63% of participants identified as Caucasian or White, and 12% identified as African American or Black. Ten percent responded “Something Else” and 8% of participants refused or did not understand the questions. Respondent’s primary ethnicity identity is shown in Table 6.

**TABLE 6: PRIMARY RACE AND ETHNICITY**

Race and Ethnicity	Number	Percent
African American / Black	13	12%
American Indian or Alaskan Native	4	4%
Asian	1	1%

Race and Ethnicity	Number	Percent
Native Hawaiian or Other Pacific Islander	0	0.0
Hispanic or Latino	2	2%
Caucasian or White	67	63%
Something Else	11	10%
Refused, left blank	8	8%

The Quality of Life tool includes a list of disabilities. For each item on the list, participants were asked if that disability applied to them and, if yes, if they perceived the disability to be of “Major” or “Some” significance. At least one participant reported a “Major” disability for all of the items except Dementia. Some participants responded “None” for all of the items on the list.

People from all five of the disability types included in the sampling guidelines were interviewed during the pilot. The most frequently mentioned disabilities were Mental Illness (49%), Intellectual Disability (43%), Major Health Problems (38%), and Communication (36%). Walking (38%) was not included as an option on all of the surveys, as it was inadvertently left out of the first surveys administered. Four participants reported a “major” hearing disability and seven reported a “major” vision disability. These numbers reflect the difficulty we had with recruiting deaf and blind participants.

**TABLE 7: DISABILITIES AND PERCEIVED SIGNIFICANCE**

Disability	Major	Some	None	Percent Major / Some
Autism	10	7	83	17%
Behavior: Aggressive or Destructive	5	15	80	20%
Behavior: Self-Abusive	2	14	85	16%
Brain Injury	8	13	75	21%
Cerebral Palsy	4	4	90	8%
Communication	20	17	50	37%
Dementia (Including Alzheimer's Disease)	0	4	91	4%
Health Problems (Major)	20	18	50	38%
Hearing	4	20	74	25%
Intellectual Disability	21	21	55	42%
Mental Illness	26	22	50	57%
Physical Disability Other Than Ambulation (walking)	12	15	72	27%
Seizures	4	14	81	18%
Substance Abuse	8	8	82	16%
Swallowing: Inability to swallow independently	2	9	87	11%
Vision	7	19	74	26%
Walking (this item was not asked of everyone)	17	14	52	37%
Other	15	12	60	30%

## Lessons learned by setting

### Working in Different Settings

Initially, 46 providers were selected as pilot sites, and additional providers were added throughout the administration phase in order to reach all of the target populations. In total, we contacted 51 providers about the project, and interviewed participants from 29 providers. Reasons interviews were not conducted at the other providers include scheduling problems, lack of participant interest, and because the providers refused to participate. In addition, some of the providers were not appropriate settings for the Quality of Life Survey because they do not provide services to people with disabilities.

The process for working with providers in each setting follows.

#### Adult Foster Care

Invitations to participate in the pilot were sent from the Improve Group to participants that live in Adult Foster Care and receive services from the Community Alternatives for Disabled Individuals (CADI), Brain Injury (BI) or Community Alternative Care (CAC) waiver programs. A separate letter was sent to the provider explaining the survey and asking for help in obtaining guardian consent when needed. Interviews were either scheduled with the focus person or through a house manager depending on the number of people in the home who agreed to participate. All the residents of the home, including people who were not a part of the sample, were given the opportunity to participate in the pilot. Three of the four providers participated in the survey. The interviews were conducted in common rooms and resident's bedrooms.

Invitations for participants in living in Supported Living Services homes and receiving services from the Developmental Disabilities (DD) waiver were sent to the provider and to individual homes. The Improve Group then reached out to the providers and individual houses to recruit participants, but no interviews were scheduled. Two providers contacted us to discuss the project and to address concerns about the pilot and the baseline survey.

Scheduling interviews with foster care residents was complicated by the different schedules of the people living in the home. We tried to schedule multiple interviews for a single visit, but it was difficult to find times that worked for multiple residents. Many of the interviews had to be rescheduled or cancelled on short notice because the participant was not available. This happened both when the interview was scheduled through house staff or with the individual. For many of the participants work opportunities, leisure activities, and sleep took priority over participating in the survey.

#### Boarding Care

A packet of information, including a list of participants if available, was sent from DHS to Boarding Care providers. DHS was only able to pull a sample for two of the five providers that were selected as pilot sites. The other providers were not found in MAXIS. Although we were not able to get a sample for the provider, we reached out to a third Boarding Care provider that has a deaf services program. All the participants in that program were invited to participate.

We worked with providers to schedule a time when most of the participants would be available for interviews. Most of the interviews were conducted in a semi-public space such as a dining hall or multi-purpose room. Staff helped to coordinate interviews by finding participants and escorting them to the interview.

Getting individuals to start and to complete the survey was more difficult than at other settings. Although most of the people selected initially agreed to the survey, many participants could not be located when it was time for their interview. Based on feedback from providers we believe that at least some of those people did not feel comfortable declining to participate. Several participants consented to the survey, but stopped during the first section because they were uncomfortable with the questions and how their responses would be used. At one provider we recruited volunteers to complete the survey.

### **Board & Lodge with Special Services**

A packet of information was sent from DHS to Board & Lodge providers. However, DHS was not able to select a sample for any of the providers. Instead of selecting a sample, we contacted the providers and asked for volunteer participants. One provider agreed, two declined, and we were unable to reach the contact person at the other two. The Improve Group reached out to an additional Board and Lodge provider greater Minnesota, and we were able to conduct interviews at that provider. The interviews were conducted in offices or semi-private spaces at the providers.

The biggest problem with selecting Board and Lodge participants was identifying appropriate providers. The lack of plain language definitions compounded this problem. All of the providers we selected were listed as receiving Group Residential Housing funding, but four of the providers could not be found in the eligibility databases. One provider we selected did not provide services based on participant's disabilities. The residents at one provider opted out of the survey because of concerns related to their disabilities, specifically mental health concerns. We were not able to make contact with the appropriate person at the other providers.

### **Center-Based Employment**

A packet of information, including a list of participants, was sent from DEED to Center-Based Employment providers. The providers helped with obtaining consent to release information to the Improve Group from participants and their guardians. When applicable, the providers also obtained guardian consent to survey participants. The providers also scheduled interview times and reserved space in their offices to conduct the interviews during the participant's work day. Everyone who was available during the interview time was given the chance to participate. Some of the providers paid the survey participants for missed work time.

We were able to schedule interviews at four providers. The fifth provider agreed to participate, but no interviews were scheduled. Two of the providers rescheduled interviews to make sure most of the people who agreed to take the survey were available. One provider requested the web version of the survey, and two of their participants completed the survey online.

Some of the people in the Center-Based Employment sample work offsite in an enclave or job crew. It was difficult to schedule interviews with those individuals without either extending their work day or disrupting programming. Because of transportation limitations, it was not possible to move people from their worksite back to the interview location. The providers suggested trying to interview people at the end of the work day, but warned that most of the individuals would be ready to go home and likely not have enough energy to complete the survey. In addition, people who were interviewed at the end of the day were concerned about missing their ride home.

One solution to these problems is to schedule interviews with people in Center-Based Employment outside of work hours. These interviews could be scheduled at the person's home or at a location of the person's choice. However, the providers played a significant role in encouraging people to participate, including reminding them that they had made a commitment and needed to follow through. If interviews are scheduled outside of the work day, this support will be lost. Based on our experiences in other settings, it may be more difficult to schedule interviews without the provider support. Interviews could also be scheduled at the participant's work site.

Finally, the Decision Control Inventory scale was not relevant to people who live independently or with family. When interviewing people who do not have paid staff, we recommend using the alternate scale for people without staff to capture whether the participant feels like they have control over the choices that are being made. The alternate scale is explained [on page 42 of this report in the "Decision Control Inventory" section](#).

### **Day Training and Habilitation**

A packet of information, including a list of participants, was sent from DHS to Day Training and Habilitation (DT&H) providers. The providers managed obtaining guardian consent to survey participants. The providers also scheduled interviews, reserved space in their offices to conduct the interviews while the participant was on site, and served as a support person during interviews.

We were able to schedule interviews at four of the six providers we contacted. One provider declined to participate because of the short timeline for obtaining guardian consent. The other provider obtained guardian consent for several participants, but we were unable to connect with the contact person to schedule interviews.

All of the DT&H participants had barriers to completing the survey that were related to their disability. This included non-verbal participants, individuals who were deaf and had no way of communicating beyond communicating their basic needs, and deaf-blind participants. In addition, staff shared that the participants with Autism had difficulty participating in the survey because of the disruption to their normal routine. All of the DT&H participants required a support person to help complete the survey.

As with Center-Based Employment participants, some DT&H participants work offsite which makes it difficult to conduct those interviews at the provider. During the pilot at least one person who wanted to participate in the survey was not interviewed because he was not able to make the appointment. Because people who work offsite rely on the provider for transportation, there is a short window to

interview them at the provider. Interviews with those individuals should be scheduled at a time and place that is convenient for the person.

### **Intermediate Care Facilities for Persons with Developmental Disabilities**

A packet of information, including a list of participants, was sent from the Improve Group to Intermediate Care Facilities for Persons with Developmental Disabilities (ICF / DD) providers. The providers managed obtaining guardian consent to survey participants. Provider staff also scheduled interviews and served as support people during interviews.

We were able to schedule interviews at four of the five ICF / DD homes, although all of the providers agreed to participate. Interviews were not scheduled at the fifth home because the participants' behavior issues were a safety concern. However, there were challenges to scheduling and conducting interviews at all of the ICF / DDs. In some cases difficult relationships with guardians were a barrier to obtaining consent.

We encountered challenges when administering the survey at ICF / DD providers. Many of the participants were non-verbal or had other barriers to participation related to their disability. For those individuals it was important to have a support person present, and a staff person was often the most appropriate person to help with the interview. For many participants, their support staff has the most experience communicating with them and knows most about their activities. This does cause a problem if the person wants to but does not feel comfortable providing negative feedback. We also had problems obtaining guardian consent and making contact with providers.

### **Nursing Homes and Assisted Living**

A packet of information, including a list of participants, was sent from DHS to Nursing Home and Assisted Living providers. The providers managed obtaining guardian consent, scheduled interviews, and coordinated appointments.

Ten Nursing Home or Assisted Living providers were originally selected for the pilot. We conducted interviews at only four of the 10 providers due to time constraints and because there was a large enough sample at the four facilities for the needs of the pilot. We were not able to conduct surveys with any participants who had guardians. One provider did not reach out to guardians, and a second provider's sample included several individuals in a persistent vegetative state. The guardians of those individuals were not contacted for the pilot.

One provider scheduled appointments for each of the participants, and we were able to interview everyone who agreed to take the survey. The other providers scheduled a block of time during which to conduct interviews. At those providers, many of the participants chose to attend other activities or appointments during the interview time.

Most of the interviews were conducted in an office or a semi-public space in the facility. In some cases the interviews were conducted in the person's bedroom. In those situations, the small bedrooms made it hard to use the laptop and for interviewers with mobility limitations to get around.

## Segregated School Settings

The individual school districts managed invitations and initial consent. The school districts sent letters to the families and guardians of students receiving services in Federal Special Education Settings 3 and 4 inviting them to participate in the survey. All students were invited to participate in the pilot. The mailings included background information about the project and a guardian consent form. The student's guardian was asked to complete and return the consent form to the Improve Group. An interviewer then contacted the parent or guardian to schedule an interview.

Because the initial mailing had a low response rate, the school districts provided additional support by attempting to recruit families during parent / teacher conferences and calling parents to encourage them to participate. Eighteen students and their guardians participated in the pilot. Most of the interviews were conducted at the student's home; one student was interviewed at school.

The biggest challenges with administering the survey to students in segregated school settings were scheduling appointments and interviewing students. Another concern is that the Decision Control Inventory is not appropriate for students who live with their family.

Almost all of the parents or guardians wanted to be present for the interviews, and some said they would prefer for their child to not be present. In addition, many of the parents wanted to complete the survey for their child, either because they felt the student was not capable of responding to a survey or because the student did not have the attention span for participating in the survey. Our policy was to allow parents or guardians to participate in the survey, but to ask to have the child present. In many cases, the student only answered a few questions or did not participate at all. Only one student completed the survey without a parent or guardian present. Because of the way the interviews were conducted, it is uncertain if the students would have been able to participate if their parents were not present.

A second consideration when scheduling interviews with students in segregated school settings is that interviews had to be scheduled in the evening or on weekends. This meant that many of the surveys were scheduled close to dinner time or at another time that was disruptive to the student's schedule. One parent did ask for the survey to be scheduled during the school day, and the interview was conducted in a school office. However, scheduling surveys during the school day requires coordination with the school and requires the student's service providers to be present.

Finally, the Decision Control Inventory scale was not relevant to children living in their parent's home because most of the decisions are made by parents. For this, we recommend using the alternate scale for people without staff to capture whether the participant feels like they have control over the choices that are being made. The alternate scale is explained [on page 42 of this report in the "Decision Control Inventory" section](#).



## Supervised Living Facilities

Supervised Living Facilities are various treatment and rehabilitation programs licensed by the Minnesota Department of Health. They include:

- Detoxification Programs
- Chemical Dependency Treatment Program
- Residential Facilities for Adults with Mental Illness
- Residential Services for People with Developmental Disabilities, not certified as ICF / DD
- Residential Services for People with Developmental Disabilities, certified as ICF / DD

It was very challenging to select a sample of Supervised Living Facilities for this study. As described above, ICF / DD facilities are licensed as a Supervised Living Facility, but they are already included in the sample. The Olmstead Team did not believe that it was the intent to include Detoxification Programs, Chemical Dependency Treatment Programs, or Intensive Residential Treatment Services (IRTS) as they are all limited-term treatment programs and not residential settings. The only program included in this sample is the Anoka Metro Regional Treatment Center. DHS did not have access to the names of people in the Supervised Living Facility, so the DHS liaison reached out to the provider for a list of people receiving services in the Anoka Metro Regional Treatment Center. The Anoka leadership team was not comfortable with DHS selecting a random sample, primarily due to treatment and safety concerns. They proposed inviting the residents to participate in the survey during a community meeting. The Olmstead Team agreed to this approach. The residents of two units were invited to participate in the survey. A representative from the leadership team presented the project to residents and collected interest forms. The interviews were scheduled through the nurses' station in each unit.

The team had three main concerns about selecting a sample of residents. The concerns were:

- Involuntary clients: people who are in Anoka are there by court order. Leadership felt that asking a sample to participate in the study would feel coercive, but making it a volunteer opportunity would be better.
- Safety: Leadership suggested it was not always safe to interview clients.
- Length of stay: The average length of stay is 90 days, so creating a sample using our guidance was not feasible. They suggested it would be easier to contact discharged patients.

We were not able to get a list of providers to contact. Based on the pilot experiences, the Olmstead Team should gather more information about Supervised Living Facilities to determine whether they should be included in the baseline sample.

## Recommendations to Tweak the Survey Tool

After the completion of the pilot surveys, Improve Group researchers analyzed the completed surveys and the completed pilot review questionnaire to identify trends in problem questions or sections in the Olmstead Quality of Life survey tool. We analyzed trends in problem areas for all participants as well as by setting type. Overall, the tool performed well and consistently across settings. Therefore, it is the Improve Group's recommendation to that the Olmstead Implementation Office use the Center for Outcome Analysis Quality of Life Survey for the baseline and follow-up surveys, with the modifications listed below. These recommendations have been discussed with and approved by the survey author.

Survey respondents had the biggest challenges were with the demographic and housing questions at the beginning of the survey. For that reason, we are recommending creating a "prescreening" process to gather information that is particularly difficult for participants to share. There are also a few areas where survey questions need to be reviewed for content in order to reflect the experiences of the participants. Finally, there were instances where interviewers require more training and content knowledge, and / or the survey prompts are needed to ensure the questions are asked consistently across interviewers.

The complete list of questions that need to be tweaked, including the problem that needs to be addressed and our recommended approach can be found in [Appendix A](#).

### Prescreening

A prescreening process should be developed to collect demographic, disability, and housing information about the participant. These questions were consistently the most difficult for participants to answer, and it is more important to have accurate information than to get the response from the participant. The answers to these questions can be obtained from other sources, including agency records, providers, and the county from which the participant receives services. The only exception is housing information for people who live independently or with family. For those individuals, the information may be obtained from the focus person or someone providing support.

Collecting disability information during a prescreening process would change how the perceived significance scale works. If the person is eligible for services because of a disability, then that disability would be recorded as "major." If a person has other disabilities, but is not eligible for services because of that disability, the disability would be recorded as "some." This method does not allow for capturing the person's perception.

According to Jim Conroy, the perceived significance of the person's disability is not an outcome measure, meaning significance is not expected to change greatly over time. However, it is possible that as people move into the community they will perceive their disabilities to be less significant. We recommend omitting these questions from the survey as they were such difficult questions for participants to answer. However, if it is decided to gather this information, disability information could

be collected before the interview so that the focus person was only asked about the significance of disabilities that pertain to them.

## **Content**

Because the survey is designed to be modular, the order of the sections is not important. Therefore, the Olmstead Implementation Office should arrange the survey so that the sections greatest interest for the Olmstead Plan are at the beginning of the survey. This will ensure that the most important sections have the highest response rate.

### **Community Integration and Engagement: Time, Money & Integration – During the Day**

State agencies should provide plain language definition of work settings and programs that reflect the participant’s understanding of the services they are receiving. The Olmstead Implementation Office should work with an advisory group to ensure the plain language definitions provided by the agencies matches the participants’ understanding of how they spend their time. Interviewers should also be given guidance on how to rephrase questions and explain terms to help participants answer questions, while still maintaining the integrity of the survey.

### **Community Integration and Engagement: Integrative Activities Scale**

Some of the activities listed may not match the participant’s experiences, either because common activities are not included or because some activities have become less common over time. After the baseline survey the list may need to be updated to include activities reflect the activities people are engaging in. This means adding “other” responses with a high frequency and removing activities that may be becoming less common such as going to the bank or the post office.

The scale for this question was difficult for interviewers and participants. Participants were asked “Do you normally have interactions with community members during this kind of trip or outing?” If they said yes, they were then asked if they had a little, some, much, or very much interaction with community members. Participants and interviewers had a hard time with the difference between much and very much. We could not find a way to phrase the question that was not awkward, and it took so long to explain the scale that the question had to be asked several times.

We propose changing the scale to a four-point scale: none, little, some, a lot. Simplifying the scale would reduce the burden on participants. Although changing the scale would mean the results from this section would not be comparable to those in other states, we believe the change would lead to higher quality data. If this change is made, Jim Conroy would work with the Olmstead Implementation Office and the survey administrator to validate the approach.

### **Decision Control Inventory**

Overall, the Decision Control Inventory scale works well across settings with the exception of people who live independently or with family. For those participants, there was no way to differentiate between decisions that were being made for them by unpaid caretakers and decisions the person was making for themselves. The Center for Outcome Analysis created an alternate scale for people without paid staff that asks if decisions are made by the person or by relatives, friends, or advocates. The scores

for both scales measure how much power the focus person is able to exert in making choices, and the two scales can be analyzed together.

### **Elements of Person-Centered Planning**

Each question in this section has an element of the person-centered planning process, a plain language statement about that element, and a definition of the term that uses technical language and jargon. The jargon was included in case the participant needed more explanation about the statement. Although some participants asked for more information about some of the terms, especially person-centered planning, the interviewers did not use the jargon. In addition, some of the interviewers found the jargon distracting. Therefore, we recommend removing the jargon from the survey.

### **Interviewer Training**

The abbreviated training period did not allow enough time for thoroughly training interviewers on the survey content and context. While the interviewers had enough information to conduct the survey, they would have benefited from additional training in survey content and context to answer questions from participants. Future trainings with survey interviewers should include more depth about survey content, methods for recording responses, and how the results will be used. State agencies should also provide tools for training interviewers about programs and services.

In practice, the tool more closely resembles a supported interview than a survey, and learning how to best conduct the interview in the field was difficult for survey administrators. More time should be dedicated to breaking down and administering the scales and for recording “out of range” responses. Interviewers should be trained both in administering the survey as written and supporting participants through the survey. Trainings should also include an overview of how section scores will be calculated and compared over time. This training will help interviewers become more comfortable with using the scales and increase consistency across interviewers.

In order to feel comfortable explaining settings and terminology to participants, interviewers should have training on the services offered to people with disabilities. This training should include information about the different settings they will be visiting and programs in the Community Integration section. Interviewers should also have some training around person-centered planning and the types of planning groups participants may have. This training will provide content knowledge for supporting participants during the interview and increase the accuracy of recorded responses.

The list of questions that will need particular attention for interviewer trainings and recommendations for training is provided in [Appendix A](#).

## First Steps for the Baseline Survey Planning Phase

### Access to Data

One of the largest delays during the pilot project was securing access to data. These delays led to a shorter survey administration period because of the time it took to secure multiple releases or data sharing agreements. In addition, because we did not have access to guardian information, we had to rely on providers to communicate with guardians about the survey.

The Olmstead Implementation Office should work to secure access to participant data through legislation or court order. The legislation or court order should include access to data for contractors. If needed, state agency liaisons should make sure data sharing agreements are in place early in the process.

### Finalize Sampling Strategy

The project budget and timeline are dependent on the number of interviews to be conducted during the baseline. The Olmstead Sub-Cabinet and Olmstead Implementation Office will need to determine a final sample size and sampling guidelines.

As demonstrated in [Appendix B](#), by surveying just under 3,000 individuals in the settings selected, you will be able to extrapolate your results to the general population with a 95% confidence level plus or minus 5%. The survey developer has proposed a follow-up strategy in which 500 participants are surveyed each subsequent year to measure changes over time. The agencies should select a sample four times larger than the number of individuals you hope to interview. For example, to achieve 3,000 participants, the sample should include 12,000 people.

### Plain Language Definitions of Settings

State agencies should provide plain language definition of work settings and programs that reflect the participant's understanding of the services they are receiving. The Olmstead Implementation Office should work with an advisory group to ensure the plain language definitions provided by the agencies matches the participants' understanding of how they spend their time.

### Translation of Survey Materials

Survey materials, including the Quality of Life tool, consent forms, and communication materials should be translated for non-English speaking participants. The materials should be translated into the languages spoken by a substantial number of people eligible for the survey, including American Sign Language.

### Lead Agency Roles

In past projects, DHS has reached out to county and tribal case managers for help with obtaining guardian consent for survey participants. In most cases, DHS is able to identify if a particular participant has a guardian or conservator, but DHS does not hold information on the guardian name or contact information. The information is maintained at the county or tribal government level. Through the pilot study, this information was gathered through providers. In the baseline survey, the Olmstead

Implementation Office and Survey Administrator should consider working with DHS to contact county case managers for this information.

## Recommendations for Baseline and Follow-Up Survey Administration

The recommendations below represent lessons learned from the pilot study. Many of the following recommendations are practical, technical recommendations for the Survey Administrator of the baseline and follow-up Olmstead Quality of Life surveys. Some recommendations are for the Olmstead Sub-Cabinet, the Olmstead Implementation Office, or others, and are labeled accordingly.

### Recommendations for the Planning Phase

- The Olmstead Team should use the Center for Outcome Analysis Quality of Life Survey tool to conduct the Olmstead Quality of Life baseline survey. The Olmstead Sub-Cabinet and Olmstead Implementation Office will need to determine a final sample size. As demonstrated in [Appendix B](#), by surveying approximate 3,000 individuals in the settings selected, you will be able to extrapolate your results to the general population with a 95% confidence level and a 5% confidence interval. The survey developer has proposed a follow-up strategy in which 500 participants are surveyed each subsequent year to measure changes over time.
- The Olmstead Sub-Cabinet and Olmstead Implementation Office should create a survey timeline for the baseline study, including a three to six month design phase for the study, followed by a survey period of at least four to five months, and a reporting period of two to three months. The design phase should include up to four weeks to obtain participant data from state agencies after the request is submitted.
- The Olmstead Implementation Office should work to secure access to participant data through the support of the Sub-Cabinet, by using legislation, a court order, or other means. If using legislation or court order, it should include access to data for contractors. If needed, state agency liaisons should make sure data sharing agreements are in place early in the process.
- The Olmstead Implementation Office should ensure sufficient budget is included for translating project materials, providing interpreters, and interviewer training.

### Recommendations on Human Subjects Protections

- The Olmstead Team should use multiple levels of review for documents, forms, and communication material, including obtaining feedback from advocates and self-advocates.
- The Survey Administrator should develop and institute a robust data protection plan and include several layers of human subjects protections for future surveys. The Olmstead Implementation Office and agency liaisons should review and approve the data protection plan.
- The Survey Administrator should empower individuals with disabilities to make their own decisions about whether or not to participate through a transparent consent / assent process that centers on protecting the rights and safety of the participants.

- The Olmstead Implementation Office and stage agencies should include language about the Institutional Review Board exempt status of the project in communication materials with providers.

### **Recommendations on Preparing the Tool**

- Questions and response options should reflect Minnesota programs and offerings, especially in employment settings and housing questions. DEED, DHS, and MDE should provide the Olmstead Implementation Office with plain language definitions of these settings and programs for the survey.
- The Survey Administrator should prepare accessible and large print versions of the survey.
- A self-administered web-based version of the survey has limited appeal to participants. The Survey Administrator should provide other alternatives for interviewing people who might find an in-person interview disruptive should be explored, such as offering a Skype or video chat option.

### **Recommendations on Translation and Interpretation**

- The Survey Administrator should include translation and interpretation costs in the project budget. This includes project materials, recruitment tools, communication tools, marketing and outreach materials, as well as the survey itself.
- The Survey Administrator should recruit interviewers who speak target languages, including American Sign Language, to help address potential issues with scheduling interpreters.
- The Survey Administrator should plan on additional time to schedule interviews with interpreters. The Survey Administrator should also consider working with multiple interpretation providers.

### **Recommendations on Sampling Strategy**

- The Survey Administrator should work with liaisons in each agency to draw the survey sample. It is recommended that the sample be a stratified random sample, with stratification by setting. The data request should include disability and demographic information.
- The Survey Administrator should have the state agencies select a sample four times larger than the number of individuals you hope to interview. For example, to achieve 3,000 participants, the sample should include 12,000 people.

### **Recommendations on Working with State Agencies**

- As stated above, securing access to data through legislation or court order will eliminate the need for obtaining consent to release information to the Olmstead Implementation Office or the contractor responsible for the survey.



- The Survey Administrator should engage agency liaisons early in the planning process to streamline access to data and selecting the sample.
- The Survey Administrator should be aware of and plan for needing time to engage agency liaisons and bringing them up to speed on the project and survey. Be aware that this is another item on the liaisons' and the data person's to do list.

### **Recommendations on the Advisory Group**

- The Olmstead Implementation Office and Survey Administrator should collaborate on recruiting members for an advisory group. The advisory group should be engaged early in the planning process. The sooner the advisory group can provide ongoing feedback about outreach, communication, and recruitment, the more effective the group will be. Consider using Advisory Group members from the Pilot Study period.
- To gain legitimacy and to ensure that all voices are heard, the advisory group should include members from multiple disability. Members should be dedicated to gaining community support for the project and promoting transparency.
- Be creative about getting input from the advisory group. In person meetings are ideal, but not always feasible. Use technological solutions such as surveys, online discussion boards, and skype to convene virtual meetings and allow the group members to collaborate on their own schedule.
- Be honest and transparent about what can and cannot change as a result of the advisory group feedback. The details that are set in stone and the reasons for those decisions should be addressed from the beginning.

### **Recommendations on Reporting Abuse or Neglect**

- The Survey Administrator should develop a protocol for documenting and reporting suspected abuse and / or neglect to the common entry point and to the Olmstead Implementation Office.
- The Survey Administrator should include a module on mandated reporting during interviewer training.
- Communications to providers should include notification that the interviewers are required to report suspected abuse and or neglect to the appropriate agency.

### **Recommendations on Working with Providers and School Districts**

- The Survey Administrator should work with Agency Liaisons to identify the appropriate person at each provider to contact about the survey. This should be someone at the director level who is empowered to make decisions about the project.

- Many providers, especially providers receiving funding from DHS, are asked to support the administration of multiple surveys throughout the year. The Survey Administrator should be mindful of the various requests the providers are balancing.
- Communications to providers should include information about how the Survey Administrator and Olmstead Implementation Office will protect participants' privacy and rights during and after the survey.

## **Recommendations on Recruitment and Communication Strategies**

- The Olmstead Implementation Office should develop a marketing strategy for the survey so that participants and providers are familiar with the survey efforts before they are asked to participate. Take advantage of existing communication channels to market the survey to providers and potential survey respondents.
- Establish credibility and authority with providers by having agency liaisons make first contact with directors about the Olmstead Quality of Life Survey. This shows that the state agency supports the project and the administration team. This outreach should start early in the planning phase of the baseline study, and can build on outreach efforts during the pilot study.
- The Olmstead Implementation Office should work with agency liaisons develop a strategy for gaining provider support for the baseline survey. Regardless of how the participants are invited to take the survey, having the providers support will increase response rates.
- The Survey Administrator should engage the advisory group in developing an outreach and marketing strategy for participants. The strategy should include reaching participants and their families through community programs and online communities such as Facebook groups.

## **Recommendations on the Consent Process**

- The Survey Administrator should work with county case managers to collect guardian information for participants selected through DHS. Case managers could also be asked to help obtain guardian consent. Guardian information should be included in the data request to DEED and to districts through MDE.
- When it is not possible to work with case managers, the Survey Administrator should reach out to providers for help with obtaining guardian consent. The relationships providers have with participants and guardians added credibility to the pilot project, and that relationship could also be helpful for the baseline survey.
- The recruitment strategy should give participants time to formulate their response about whether they would like to take the survey. People may not feel comfortable saying no to a person in an authority position when they are first approached.

## **Recommendations on Survey Administration**

- The Survey Administrator should plan for 4 hours per survey for coordination, travel, and survey administration in the Metro area. Travel in Greater Minnesota will be higher.
- The Survey Administrator should be prepared for no-shows and cancelled interviewers. A protocol for following up with participants who miss, cancel, or reschedule interviewers should be developed that ensures everyone has the opportunity to take the survey while respecting the right to decline in their own way.
- The Survey Administrator should select a survey administration mode that balances the need for data security and efficient data collection. The administrator should take into account the limitations of paper and computer administered surveys discussed in the report. We do not recommend administering the survey using an Internet-based platform because of unreliable wireless access in rural areas and buildings.

## **Recommendations on Survey Administration in Greater Minnesota**

- Hire interviewers from greater Minnesota to reduce the travel time needed for surveys conducted outside of the metro area. In addition, interviewers from outside of the metro area may offer regional expertise that will add to the value of the survey.

## **Recommendations on Blind or Visually Impaired or Deaf and Hard of Hearing Participants**

- The Advisory Group should help develop strategies for outreach and recruiting participants who are deaf or blind.
- The Survey Administrator should prepare the Quality of Life tool for administration with screen readers.
- The Survey Administrator should work with an American Sign Language interpreter to translate consent forms and the Quality of Life tool. The translation help to standardize interpreted interviews.
- The Survey Administrator should include modules on working with individuals who are blind, deaf, and deafblind in the interviewer training.

## Appendix A: Recommended changes to the survey

### Prescreening Questions

A prescreening process should be developed to collect demographic, disability, and housing information about the participant. These questions were consistently the most difficult for participants to answer, it is important to have accurate information about these items, and there are other sources from which this information can be gathered. The answers to these questions can be obtained from other sources, including agency records, providers, and the county from which the participant receives services. Table 8 includes the question we recommend collecting during prescreening and a potential data source.

**TABLE 8: PRESCREENING QUESTIONS AND RECOMMENDED SOURCES**

Question	Source
What is your race and / or ethnicity?	State Agency
What is your marital status?	State Agency
What is your legal status?	State Agency
Disabilities and Perceived Significance	State Agency
What type of home are you living in now?	Department of Human Services (unless the person lives with friends for family)
How many people live in this home right now?	Providers
How many direct care staff work at this home?	State Licensing Information
Have you ever lived in a regional treatment center, state hospital or state institution?	Department of Human Services

### Content

Several survey questions need to be reviewed for content in order to reflect the experiences of the participants. The following tables include the question that needs to be addressed, the problem, and our recommendation for solving the problem.

In addition, the Olmstead Implementation Office should arrange the survey so that the sections of greatest interest for the Olmstead Plan are at the beginning of the survey. This will ensure that the most important sections have the highest response rate.

**TABLE 9: COMMUNITY INTEGRATION AND ENGAGEMENT: TIME, MONEY & INTEGRATION – DURING THE DAY**

Question	Problem	Recommendation
Do you work in any of the following settings? (work, school, and day activities)	Settings do not match participant’s understanding of services.	Plain language definitions from state agencies.

**TABLE 10: COMMUNITY INTEGRATION AND ENGAGEMENT: INTEGRATIVE ACTIVITIES SCALE**

Question	Problem	Recommendation
About how many times did you do each of the following in the past four weeks?	Activities may not reflect the activities people engage in	Monitor responses and revise list after the baseline survey.
Do you normally have any interactions with community members during this kind of trip or outing?	Scale is difficult.	Change the scale to a 4-point scale (none, little, some, a lot). Work with the survey developer to validate the scale.

**TABLE 11: DECISION CONTROL INVENTORY**

Question	Problem	Recommendation
All questions	The scale is not relevant to people who live independently or with family.	Use the alternate scale for people without paid staff.
Interviewer: Check here if you wish to report perception of possibly unfair or excessive domination of this person’s life by anyone.	This was not checked, even in situations with suspected abuse or neglect.	Move to the end of the survey and add language about reporting abuse and neglect.

**TABLE 12: PERCEIVED QUALITIES OF LIFE**

Question	Problem	Recommendation
How would you rate your quality of life related to getting out and getting around?	“Getting out and getting around” is vague.	Work with the survey developer to add language to clarify the question.

**TABLE 13: ELEMENTS OF PERSON-CENTERED PLANNING**

Question	Problem	Recommendation
My planning process is person-centered	Participants do not know what “person-centered” means	State agencies should provide a plain language definition of person-centered planning

## Interviewer Training

The abbreviated training period did not allow enough time for thoroughly training interviewers on the survey content and context. While the interviewers had enough information to conduct the survey, future trainings should go into more depth about survey content, methods for recording responses, and how the results will be used. Many of the questions require additional training to ensure interviewers are able to support the participant in answering the questions. The following tables include the

question, the problem that arose during interviews, and our recommended strategy for addressing the problem.

**TABLE 14: COMMUNITY INTEGRATION AND ENGAGEMENT: TIME, MONEY & INTEGRATION – DURING THE DAY**

<b>Question</b>	<b>Problem</b>	<b>Recommended Strategy</b>
How many hours per week did you work, on average, in each kind of work setting?	Participants do not know how many hours a week they work.	Ask the participant to describe their work schedule. For example, ask when they start work and when they are done. Then ask if they work every day.
Estimate how much money per week you earn from each activity on average.	Participants do not know their earnings or know how much they are paid but are not paid weekly.	Ask about hourly wage or what they earned on their last paycheck. Calculate average weekly earnings based on wages. There should also be a strategy for recording wages for people who are paid in piecework.
For each of the places you worked, how integrated were you in that facility?	Scale is difficult.	Once the scale is explained, ask participants if they are only with people with disabilities or if they are with people without disabilities.
Estimate how many hours per week you spend, on average, in each educational setting.	Participants do not know how many hours a week they attend school.	Ask the participant to describe their schedule. For example, ask when they start school and when they are done. Then ask if they go to school every day.
For each of the school settings you mentioned, how integrated were you in that setting?	Scale is difficult.	Once the scale is explained, ask participants if they are only with people with disabilities or if they are with people without disabilities.
Estimate how many hours per week you spend, on average, at each setting.	Participants do not know how many hours a week they spend at each setting.	Ask the participant to describe their schedule. For example, ask when they start the program and when they are done. Then ask if they go every day.
For each of the programs or activities you mentioned, how integrated were you in that setting?	Scale is difficult.	Once the scale is explained, ask participants if they are only with people with disabilities or if they are with people without disabilities.

**TABLE 15: COMMUNITY INTEGRATION AND ENGAGEMENT: INTEGRATIVE ACTIVITIES SCALE**

<b>Question</b>	<b>Problem</b>	<b>Recommended Strategy</b>
About how many times did you do each of the following in the past four weeks?	Recall.	You may also ask the person how many times a week they do each activity and multiply by four.
What is the average group size in which you had each kind of experience?	Participants respond with a range.	Record the average.
Do you normally have any interactions with community members during this kind of trip or outing?	Scale is difficult.	Once the question is established, tailor the question for each activity. For example, "Do you talk to other shoppers or people who work at the store?" or "Do you talk to other people on the bus?"

**TABLE 16: DECISION CONTROL INVENTORY**

<b>Question</b>	<b>Problem</b>	<b>Recommended Strategy</b>
All questions	Participant does not have paid staff.	Use the alternate scale for people who live independently.
Support Agencies and Staff	Participant does not know which service agencies work with them.	Interviewers should have training about service agencies and providers.

**TABLE 17: ELEMENTS OF PERSON-CENTERED PLANNING**

<b>Question</b>	<b>Problem</b>	<b>Recommended Strategy</b>
All questions	The participant has multiple planning groups.	Ask them to respond about the planning group for the service agency they were selected through.
All questions	The participant is unsure about the role of planning groups.	Interviewers should have training about planning meetings in each agency.

**TABLE 18: CLOSE RELATIONSHIPS INVENTORY**

Question	Problem	Recommended Strategy
Can you tell me the names of the 5 people who know you best?	The focus person or their ally says the person has no friends.	Clarify this is not just friends, but close relationships. The person may talk about relatives, service providers, neighbors, or anyone they feel they have a relationship with.
Can you tell me the names of the 5 people who know you best?	The focus person thinks the questions will be too personal.	<p>Explain the questions that will be asked. For example, I'm just going to ask you a little bit about how you know the person and often you see them.</p> <p>Tell the person they do not have to give you names if they do not want to.</p>
What kind of a relationship do you have with that person? Are they a...	The focus person says the individual is a friend.	Ask, "how do you know this person?" and select the most appropriate category.
What is the person's gender?	The focus person indicates the individual's gender in the response.	Do not ask if gender was implied.
Is this relationship romantic?	The focus person indicates a non-romantic relationship with the response.	Do not ask if non-romantic was implied, such as a relative.
Is this person involved in planning meetings or Person Centered Planning?	The focus person does not know or is not sure.	Asked if the person helped plan their services.
About how long have you know this person?	The focus person says "all my life."	Record the focus person's age even if the relationship is with an older relative.
About how many times did you have any contact with this person in the past four weeks?	The focus person is unsure.	Ask clarifying questions such as "how many times a week do you see this person?" or "do you see them every day?"



## Appendix B: Selecting a sample for the Olmstead Quality of Life baseline survey

The Olmstead Sub-Cabinet and Olmstead Implementation Office will have to consider a few factors in selecting a baseline sample size. The confidence level will tell you how sure you are that the number you found in your study applies to the broader population. The confidence interval (margin of error) is the range that the result falls within. The Survey System provides additional [plain language definitions](#) of confidence level and confidence intervals at <http://www.surveysystem.com/sscalc.htm#one>.

If you selected the 95% confidence level plus or minus 5% confidence interval, you could say:

On average, Minnesotans with disabilities rated their health as 4.2 on a 1 to 5 scale, where 1= very bad and 5= very good. I am 95% certain that the “true” rating for Minnesotans with disabilities is between 4.02 and 4.22.

Table 19 below shows the sample needed for a 5% confidence interval at various confidence levels. This stratified sampling strategy will allow you to demonstrate differences by setting. Most researchers use a 95% confidence level and try to get the confidence interval as small as possible. The [sample size calculator](#) used for Table 19 from Calculator.net is available at <http://www.calculator.net/sample-size-calculator.html>.

**TABLE 19: CONFIDENCE LEVEL AND WITH A 5% MARGIN OF ERROR FOR A STRATIFIED SAMPLE**

Setting	Total population	98% confidence level + / - 5% confidence interval	95% confidence level + / - 5% confidence interval	90% confidence level + / - 5% confidence interval
Center Based Employment	2,497	447	334	246
Children in segregated school settings 50% or more of the time	4,472	485	354	257
DT&H	10,135	516	371	266
Board and Lodging	3,070	462	342	251
Supervised Living Facilities	1,046	358	282	217
Boarding care	521	267	222	180
Nursing Homes and Assisted Living Facilities	24,407	543	385	273
Adult Foster Care	5,318	493	359	260

Setting	Total population	98% confidence level + / - 5% confidence interval	95% confidence level + / - 5% confidence interval	90% confidence level + / - 5% confidence interval
ICF / DD	1,697	412	314	235
<b>Total</b>	<b>53,163</b>	<b>3,983</b>	<b>2,963</b>	<b>2,185</b>

## Appendix C: Pilot tools and materials that could be modified for the baseline survey

### **Participant consent form language**

We're going to ask you about your services and your life. We'll use what we learn to try to make services better for you and for others.

#### **The purpose of the work**

To find out if the services and supports you're getting are good or bad or in between. We want to find out if there are ways we can make things better for you.

#### **What we're going to ask you to do**

To talk with us for about an hour. We will write down or record on the computer what we find out about your life and your services. This could happen again next year.

#### **The risks to you**

The only risks we can think of from this would be if it bothers you to talk about your services and your life. Almost no one has been bothered by this kind of talking in many years, and your privacy will be kept – that's the law.

#### **The benefits to you**

Thinking about quality in new ways may help you get better at asking for and shopping for the supports you really need for a good life.

#### **The benefits to other people**

What we learn from talking to you may help us learn how to give better services to everyone. We will write reports about what we learn. We might even write an article about the quality of services in Minnesota. (But no one's name will ever be used, and everything you tell us will stay private.) We will also use your answers to make the survey better for people who take it next year.

#### **You can refuse, and that's no problem**

There will be absolutely no problem to you or anyone else if you decide not to take part in this. Even if you agree to take the survey, you can stop at any time with no problem. You can even decide not to answer part of the survey. If there is a question you do not want to answer, you do not have to answer it.

## **We will protect your privacy**

We will keep everything private and protect your privacy – unless you're in danger. We will not tell anyone in the agency, your providers, or family anything you tell us in private.

## **Contacts and Questions**

If you have any questions, please contact Elizabeth Radel Freeman, Research and Evaluation Director, at:

The Improve Group:

700 Raymond Ave., Suite 140

St. Paul, MN 55114

Phone: (651) 315-8922.

Email: [lizf@theimprovegroup.com](mailto:lizf@theimprovegroup.com)

## **Tennessee Warning:**

State and federal privacy laws protect my information. I know:

- Why I am being asked these questions;
- How my answers will be used;
- That I do not have to answer these questions. I can decide to stop at any time, no problem;
- I can take back this consent at any time. I can ask to have my responses erased by contacting Elizabeth Radel Freeman before December 1, 2014.
- My information will be combined with all the other answers to this survey, and this information may be shared with Minnesota state agencies to improve services for people with disabilities. The combined information will also be publicly available. My individual responses will be kept private.

## **Sign or check the space below if you agree to be a part of this study**

The participant has chosen these individuals to help them with the survey:

## **Guardian consent form language**

### **Background**

Researchers from the Improve Group are conducting a survey of individuals with disabilities for the Olmstead Implementation Office. Your child or an individual you serve as a guardian for has been selected to participate in this study. The Olmstead Quality of Life Survey is designed to collect information from people with disabilities about their daily lives. The survey includes questions about where your child or ward lives, their activities, closest relationships, and who makes decisions in different areas of their life.

This study is designed to get a better idea of the quality of life of people with disabilities living in Minnesota. The results of this survey will be used to show how well Minnesota is doing in achieving its goal of making Minnesota a place where people with disabilities are living, learning, working, and enjoying life in the most integrated setting. This pilot study will also be used to make changes to future surveys.

### **Procedures**

The interviewer will ask your child or ward for permission to participate in the study. If they agree to participate, the interviewer will ask your child or ward some questions about their regular activities and their quality of life. Your child or ward will be asked to answer the questions to the best of their ability. If your child or ward is able to participate in the survey but needs assistance, they may elect to have you or another person who knows them best help with some of the questions. The survey will take about 60 minutes.

### **Risk**

There is minimal risk for participating in this study. Talking about their lives or services may upset some participants.

### **Benefits**

Thinking about quality of life in new ways may help participants get better at asking for and shopping for the supports they need for a good life. The results of the study may be used to improve the quality of life for people with disabilities in Minnesota.

### **Confidentiality**

Although your child or ward's name and contact information are on the survey, they will not be included in the database with their survey responses. Their responses will be combined with all of the other responses to the survey. All publicly available data will be reported at the state level. Individual

responses will not be made public. You may ask to have your child or ward's information removed from research records or returned.

### **Costs and Payment**

There is no cost to you for participating in this study. You will not be paid for your participation in this study.

### **Voluntary Participation & Disclosure of Health and Private Information**

You do not have to take part in this study or agree to release private information. Your decision to participate in the study and release private information is completely voluntary. Your decision not to participate, to withdraw, or to not release records will not affect your child or ward's treatment or benefits in any way.

By agreeing to participate and by signing this form, you are not giving up or waiving any of your legal rights or your child or ward's legal rights. However, you are agreeing to allow researchers to obtain private information about you for the reasons described above.

### **Abuse and Neglect**

Interviewers are required to report suspected abuse or neglect to the appropriate agency.

### **Contacts and Questions**

If you have any questions, please contact Elizabeth Radel Freeman, Research and Evaluation Director, at:

The Improve Group:

700 Raymond Ave., Suite 140

St. Paul, MN 55114

Phone: (651) 315-8922.

Email: [lizf@theimprovetgroup.com](mailto:lizf@theimprovetgroup.com)

### **Tennessee Warning:**

State and federal privacy laws protect my information. I know:

- Why my child or ward is being asked to participate in this survey;
- How the responses will be used;

- That my child or ward is not required to take part in this survey. My child or ward may stop the survey at any time. If they stop the survey, the survey will be destroyed and the answers will not be used in the study.
- Participation is voluntary, and will not change the services received;
- My child or ward's information will be combined with all the other answers to this survey, and this information may be shared with Minnesota state agencies to improve services for people with disabilities. The combined information will also be publicly available. Individual responses will be kept private; and

I have reviewed the study information and agree to allow my child or ward to participate in the study if they choose.

Participant Name (please print)

Parent / Guardian Name (please print)

Parent / Guardian Signature

Date

**Please return signed consent forms to:**

The Improve Group

700 Raymond Ave., Suite 700

St. Paul, MN 55114

**Accommodations**

The survey will be conducted in English by interviewers. Participants will be given a copy of the survey at the time of the interview and will be encouraged to read along. If your child or ward requires accommodations to participate in the survey, please complete this section.

My child or ward requires the following accommodations:

## **Introductory script about the survey for participants**

Hi, my name is [name] and I am here to ask you some questions for the Olmstead Quality of Life Survey. I work for the Improve Group, a research company in Saint Paul, and we are helping conduct the survey. This survey will let Minnesota know if the state is doing a good or bad job at making life better for people with disabilities.

We are going to ask you about your services and your life. We will use what we learn to try to make services better for you and for others. The survey will take about an hour, but we can take longer if you need to so that you can do it your favorite way.

We spoke earlier about doing the interview now, is this still a good time?



## Introductory script about the survey for providers and families

I am visiting [name] and collecting information about his / her situation as part of the Olmstead Plan Quality of Life Survey. I have the permission of the [agency] to visit [name] and collect information by interviewing him / her if possible and the staff or others who know him / her best.

In *Olmstead v. L.C.*, (1999), the U.S. Supreme Court held that it is unlawful for governments to keep people with disabilities in segregated settings when they can be supported in the community. Many states, including Minnesota, have implemented an Olmstead Plan to document plans to provide services to individuals with disabilities in the most integrated setting appropriate for the individual. Minnesota is also required to develop and implement an Olmstead Plan as a part of a settlement agreement in a federal court case. This survey is required as a part of the plan.

Under State and Federal regulations for the protection of human subjects in research, this activity is not research, but rather ongoing quality assurance conducted by the funding agency. Nevertheless, any individual's wish to decline to participate will be respected by our staff.

The survey will let Minnesota know if the state is doing a good or bad job at making life better for people with disabilities. Areas of quality include: community integration and engagement, autonomy, quality of life, person-centered planning, and close relationships.

Any questions about the study can be directed to:

Elizabeth Radel Freeman  
Research and Evaluation Director  
The Improve Group  
(651) 315-8922  
lizf@theimprovementgroup.com

And / or

Darlene Zangara  
Executive Director  
Olmstead Implementation Office  
(651) 259-0505  
Darlene.zangara@state.mn.us

## Letter about the survey to participants that do not have a guardian

Hello,

I'm Elizabeth, and I work for the Improve Group. The Improve Group is working to survey people with disabilities for the Olmstead Plan. The survey is a part of Minnesota's plan to support all people to be living, learning, working, and enjoying life in the community. If you would like to learn more about the Olmstead Plan, please read the handout I put in this letter.

I'm asking you to take the Olmstead Quality of Life survey in November. We are asking to survey you because of the services you receive. We will be interviewing people all over the state to ask them about their services and their lives. We will use what we learn to try to make services better for you and for others. For each person, we want to be able to answer the question "Are you better off now than you were before?"

If you'd like to be interviewed for this project, we will schedule a time to come talk with you for about an hour. Everything you say during the interview will be kept private. If you do not want to be interviewed, that is just fine.

If you do want to participate, please fill out the form on the next page and send it to us.

Thank you for your time. If you have any questions, please contact me by email ([lizf@theimprovetgroup.com](mailto:lizf@theimprovetgroup.com)) or phone at (651) 315-8922.

Sincerely,

Elizabeth Radel Freeman  
Research and Evaluation Director  
The Improve Group

Please fill out this form and send it in the envelope we provided.

Choose one:

- Yes, I would like to be interviewed for the Olmstead Quality of Life Survey
- No, I would not like to be interviewed for the Olmstead Quality of Life Survey
- I'm not sure

First Name:

Last Name:

Street Address:

City:

Zip code:

Phone number:

Email:

If you would like to participate, do you need any accommodations, like an interpreter or a copy of the survey in Braille?

- Yes, I need:
- No, I do not need accommodations
- I'm not sure

## Letter about the survey to guardians

Dear [Guardian name],

Someone you serve as a guardian for has been selected to participate in the Olmstead Quality of Life Survey. The survey is a part of Minnesota's plan to support all people to be living, learning, working, and enjoying life in the community (the Olmstead Plan). More information about the Olmstead Plan and Quality of Life survey is enclosed.

The Improve Group is an independent firm conducting the survey on behalf of the Department of Human Services and the Olmstead Implementation Office. [Editor's note: while this reflects the language used, it should have stated the survey was conducted on behalf of the Olmstead Sub-Cabinet]. We will be interviewing people all over the state to ask them about their services and their lives. We will use what they learn to prepare to survey thousands of people with disabilities in 2015 and beyond. Ultimately, they will use what they learn to try to make services better people with disabilities across the state.

The survey will be conducted in person and will be scheduled at a time and place for participants. The interview will take **about an hour**, and you may participate with your student if you'd like. Everything said during the interview will be kept private. If you do not want your child or ward to be included in the survey, that is just fine.

If you consent to have your child or ward to be interviewed for this project, send the completed guardian consent form to the Improve Group using the enclosed return envelope. Someone from the Improve Group will follow up with you to confirm your participation and schedule an interview.

Thank you for your time. If you have any questions about the project, please contact me by email ([lizf@theimprovetgroup.com](mailto:lizf@theimprovetgroup.com)) or phone at (651) 315-8922.

Sincerely,

Elizabeth Radel Freeman  
Research and Evaluation Director  
The Improve Group

## Letter about the survey to providers

Dear [Provider name or contact]

The Minnesota Olmstead Plan is a Federal Court mandated plan to move Minnesota forward towards greater integration and inclusion for people with disabilities. The plan requires an annual Quality of Life survey of people with disabilities starting in 2015. The results of the survey will be used to measure changes in the lives of people with disabilities over time. More information about the Minnesota Olmstead Plan and Quality of Life survey is attached.

The Olmstead Implementation Office has hired the Improve Group, an independent research and evaluation firm, to conduct a pilot of the survey before it is administered statewide. Your organization has been selected as an interview site for the pilot.

The survey will take about 60 minutes of your participants' time and will be conducted at a time that minimizes the disruption of programs or service delivery. The results of the pilot survey will be used when planning the statewide Quality of Life Survey in 2015. The results will not be used to determine program eligibility or to evaluate the services your agency provides. Any public reports use data aggregated to the state level. Individuals and providers will not be identified.

A list of people who have been selected to participate in the survey is included in this packet. We are asking that you take a few minutes with each of these individuals to explain the survey and let them know that someone from the Improve Group will be contacting them to schedule an interview. If they are not interested, let them know that is just fine. If the participant has a legal guardian, we are also requesting your assistance with obtaining the guardian's consent to include the participant in the survey. Interviews will begin in early October.

Thank you in advance for your help with this important project. More information about the Olmstead Plan, the Quality of Life Survey, and provider roles are enclosed. A representative from the Improve Group will follow up with you in 3-5 days to answer any questions and to schedule interviews. If you have any concerns, please feel free to contact me at (651) 315-8922 or LizF@theimprovegroup.com.

Sincerely,

Elizabeth Radel Freeman  
Research and Evaluation Director  
The Improve Group

# Olmstead Quality of Life Pilot Survey Interviewer Training Agenda

## Interviewer Training

Day 1

Friday September 19, 2014

9 am – 1 pm

1. Welcome and Introductions (10 minutes)
2. Training Overview and Olmstead Pilot Survey Overview (10 minutes)
  - a. Go over training plan
  - b. Goals of Pilot Survey
    - i. Test a survey tool with multiple groups of people
    - ii. Work out the kinks of the project so some of these are figured out prior to 2015 administration
3. Improve Group Policies (30 minutes)
  - a. **Materials: Employee Handbook, October Calendar, New Hire Paperwork**
  - b. Confidentiality
  - c. Communication
  - d. Equipment
  - e. Travel
  - f. Paperwork
4. FAQs and responses (30 minutes)
  - a. **Materials: Olmstead Quick Guide**
  - b. **What is Olmstead?**  
[http://www.mn.gov/mnddc/meto\\_settlement/shamusOmeara/olmstead.html](http://www.mn.gov/mnddc/meto_settlement/shamusOmeara/olmstead.html)
  - c. Talking points
    - i. Olmstead v. L.C.
    - ii. Jensen and METO settlements
    - iii. Olmstead Plan
    - iv. Quality of Life Survey – pilot & baseline
  - d. **Materials: Olmstead FAQs, Interviewer FAQs**
  - e. Little steps, big dreams (2:42)  
[http://www.mn.gov/mnddc/meto\\_settlement/selfAdvocates/big-dreams.html](http://www.mn.gov/mnddc/meto_settlement/selfAdvocates/big-dreams.html)
  - f. Person-centered planning (3:18):  
[http://www.mn.gov/mnddc/meto\\_settlement/selfAdvocates/person-centered.html](http://www.mn.gov/mnddc/meto_settlement/selfAdvocates/person-centered.html)
  - g. About the project
    - i. Olmstead Sub-cabinet, Olmstead Implementation Office
    - ii. Integration and opportunity
  - h. About the consent process
    - i. Empower people to participate
    - ii. Protect participants
  - i. About the survey
    1. Jim Conroy and Center for Outcome Analysis
    2. Studying the impact of moving from institutions to the community (1:50)  
[http://www.mn.gov/mnddc/jim\\_conroy/jimConroy06.html](http://www.mn.gov/mnddc/jim_conroy/jimConroy06.html)
  - j. What other questions do interviewers anticipate?

5. Working with providers, family, caretakers (20 minutes)
  - a. **Materials: Provider introduction script**
  - b. Before the interview
  - c. On site
  - d. Requesting accommodations
6. Common accommodations or communication tools (15 minutes)
  - a. Interpreters
  - b. Large print
  - c. Augmentative and alternative communication
  - d. Accessibility for mobility
7. Break
8. Reporting Abuse / Neglect (30 minutes)
  - a. **Materials: Mandated Reporting Resource Guide, Abuse / Neglect Reporting Form, Vulnerable Adult Guide**
  - b. Definitions
    - i. Vulnerable adult:
      1. Lives in a facility that is licensed for adult care
      2. An adult who has a physical, mental, or emotional disability that keeps them from being able to meet their own needs for food, shelter, clothing, health care, supervision, or safety; and this disability prevents this person from self-protection from maltreatment.
      3. Or a person who has home care, a PCA, caregivers in the home, is staying somewhere they get care services or help
    - ii. Abuse
      1. Physical, emotional
    - iii. Neglect
      1. Not providing the resources the person needs to survive / thrive
    - iv. Financial exploitation
  - c. Legal requirements
    - i. Mandated reporters legally have to make a report; we've decided to hold ourselves to that standard.
    - ii. Report to common entry point (adult protection or child protection) within 24 hours
    - iii. Written report within 72 hours
  - d. Protecting yourself and the respondent
    - i. If you or the person you are interviewing are not safe, call 911
  - e. Procedures for documenting and reporting abuse
    - i. Make sure the person is safe (not in immediate danger)
    - ii. Fill out the abuse/neglect form
    - iii. Call Liz or Becky after the interview
    - iv. Call in the report, send in the written report
9. Pilot Review Questionnaire (45 minutes)
  - a. **Materials: Pilot Review Questionnaire**
  - b. Introduction and purpose
  - c. Q by Q
  - d. Recording responses

## Interviewer Training

Day 2

Monday September 22, 2014

8 am – 12 pm

1. Check in about Day 1
  - a. Any questions about Friday's training
  - b. Scenarios for role play
  - c. Calendars and logistics
2. Human Subjects Protections (30 minutes)
  - a. **Materials: Participant Consent Form, Guardian Consent Form**
  - b. Review of Human Subjects Training
    - i. Questions interviews have after taking it
  - c. Olmstead Specific steps (30 minutes)
    - i. Consent process (obtaining and documenting)
      1. Consent / assent
      2. Adapting consent to meet participant's needs
    - ii. Protecting personal information
    - iii. Data security
3. Orientation to the survey tool (60 minutes)
  - a. **Materials: Quality of Life Survey**
  - b. Introduction to each section and purpose
  - c. Q by Q
  - d. Using scales
  - e. Probing
  - f. Recording responses
    - i. Using computer
    - ii. Using paper and pencil
4. Role Play (2 hours)
  - a. **Materials: Role Play Scenarios & Computers**
5. Technology overview and troubleshooting (45 minutes)
  - a. **Materials: Laptops**
  - b. Survey software
  - c. IG software
6. Questions?



# Olmstead Quality of Life Pilot Survey Background Information

## What is the Olmstead Plan?

### The Olmstead Decision

In the 1999 civil rights case, *Olmstead v. L.C.*, the U.S. Supreme Court held that it is unlawful for governments to keep people with disabilities in segregated settings when they can be supported in the community. This means that states must offer services in the most integrated setting, including providing community based services when possible. The Court also emphasized it is important for governments to develop and implement a plan to increase integration. This plan is referred to as an Olmstead Plan.

### The Jensen Settlement

In 2009, a federal class action lawsuit was filed on behalf of individuals who had been secluded or restrained at the Minnesota Extended Treatment Options (METO) program. The resulting settlement agreement requires policy changes to significantly improve the care and treatment of individuals with developmental and other disabilities. One provision of the Jensen settlement agreement is that Minnesota will develop and implement an Olmstead Plan.

### Minnesota's Olmstead Plan

Minnesota is required to develop and implement an Olmstead Plan as a part of the Jensen Settlement agreement. An Olmstead Plan is a way for government entities to document its plans to provide services to individuals with disabilities in the most integrated setting appropriate to the individual. In January 2013, Governor Mark Dayton signed an executive order establishing an Olmstead Sub-Cabinet to develop the Olmstead plan. The 2013 plan has been provisionally accepted, and the US District Judge overseeing the Jensen settlement agreement must approve all plan modifications.

The goal of Minnesota's Olmstead Plan is to make Minnesota a place where "people with disabilities are living, learning, working, and enjoying life in the most integrated setting."

## What is the Quality of Life Survey?

### Quality of Life Survey

The Quality of Life survey is one component of the Quality Assurance and Accountability section of the Olmstead Plan. The Plan requires Minnesota to conduct annual surveys of people with disabilities on quality including level of integration and autonomy over decision making. The survey will be used to measure changes in the lives of people with disabilities over time.

The Quality of Life survey will measure:

- How well people with disabilities are integrated into and engaged with their community;
- How much autonomy people with disabilities have in day to day decision making; and
- Whether people with disabilities are working and living in the most integrated setting that they choose.

Several areas of the survey are required as a part of the Olmstead Plan and cannot be changed. This includes the target population, the primary sampling method, and the timeline. These aspects of the project are strictly defined, and the Quality of Life survey must be implemented according to these constraints.

The Quality of Life survey is only one way in which the experiences of people with disabilities will be gathered. The survey is not intended to be comprehensive, but rather a tool for providing oversight and accountability for the plan. Minnesota will use additional methods including collecting individual stories to enhance the survey data.

### **Quality Of Life Assessment Tool**

The Olmstead Implementation Office contracted with the Center for Outcome Analysis to use a Quality Of Life (QOL) assessment tool that is specific to the Minnesota Olmstead Plan's requirements. The Center for Outcome Analysis has previously developed QOL scales that can be used across multiple disabilities, ages, and setting types. The contract includes survey development, administration instructions, documentation of validity and reliability studies, and the authorization to use the tool through December 2018.

### **Who will be surveyed?**

A sample of people with disabilities will be invited to participate in the survey starting in August 2014. Individuals will be invited to participate in the survey by phone or mail, and will be asked to schedule an interview at a time and location that is convenient for them. Individuals who wish to participate but would prefer not to be interviewed may opt to take an online version of the survey. Potential participants will be selected to reflect diversity in disability type, culture, location within the state, and demographics. The primary disability types included in the sample are:

- People with physical disabilities
- People with developmental disabilities
- People with mental health needs / dual diagnosis
- People who are deaf or hard of hearing
- People who are blind or visually impaired
- People with traumatic brain injury

### **How many surveys will be conducted?**

Approximately 200-250 surveys will be conducted during the pilot.

### **What settings are included?**

The purpose of the pilot survey is to learn how best to administer the baseline survey, including identifying challenges that may arise from conducting the survey in a variety of settings. For that reason, setting type will be the primary consideration for selecting a sample. The following settings will be included in the pilot survey:

- Center Based Employment

- Children in segregated school settings
- Day Training & Habilitation
- Board and Lodging
- Supervised Living Facilities
- Boarding Care
- Nursing Home, Assisted Living
- Adult Foster Care
- Intermediate Care Facilities / Developmental Disabilities

While this list does not include all of the settings where people with disabilities can be found, the selected settings were selected to attempt to balance including as many people as possible while being mindful of budgetary and logistical constraints.

### **Where will surveys be conducted?**

Face-to-face interviews will be conducted at a location that is convenient and comfortable for the participant. This may mean at the person's home, worksite, or a public setting. When possible, the person being interviewed will choose the interview location. Some participants may opt to complete an online version of the survey.

### **How long will the survey take?**

The survey takes about 60 minutes to complete. This includes time for the person to get comfortable with the interviewer before starting the survey.

### **When will people be surveyed?**

The Improve Group will start conducting interviews in early September. The interviews will continue through October 2014.

### **Who is conducting the survey?**

#### **Olmstead Sub-Cabinet**

The Olmstead Sub-Cabinet was created by executive order to develop and implement Minnesota's Olmstead Plan. The Sub-Cabinet is chaired by Lieutenant Governor Yvonne Prettner Solon, and includes the commissioner or commissioner's designee from eight state agencies as well as two ex-officio members. The Sub-Cabinet is responsible for drafting the Olmstead Plan, inviting comments from the public, reviewing feedback and modifying the plan. The Sub-Cabinet will review and modify the plan every six months. The Sub-Cabinet has other responsibilities for certain tasks.

#### **Olmstead Implementation Office**

The Olmstead Implementation Office (OIO) was created by the Olmstead Sub-Cabinet to assure the "Promise of Olmstead" becomes a reality. The OIO is responsible for making sure the vision, goals, and time-sensitive tasks of the plan are achieved. Overseeing the Quality of Life Survey is one of the OIO's responsibilities. The OIO will report the survey progress and results to the Olmstead Sub-Cabinet.

### **The Improve Group**

The Improve Group, an independent research and evaluation consulting firm located in St. Paul, is responsible for administering the pilot survey, as well as drafting recommendations for administering the baseline survey. The Improve Group has extensive experience conducting research to help improve services for people with disabilities, including Region 4 Mental Health Needs Assessment, to improve services for people with mental health needs in west central Minnesota.

## Appendix D: Center for Outcome Analysis Survey Studies

### Reliability Studies Related to the Personal Life Quality Protocol and Component Scales

Fullerton, A. Douglass, M. & Dodder, R. (1999). A reliability study of measures assessing the impact of deinstitutionalization. *Research in Developmental Disabilities, Vol. 20, No. 6*, pp. 387-400.

Fullerton, A. Douglass, M. & Dodder, R. (1996). *A systematic study examining the reliability of quality assurance measures*. Report of the Oklahoma State University Quality Assurance Project. Stillwater, OK.

Conroy, J. (1995, January, Revised December). *Reliability of the Personal Life Quality Protocol. Report Number 7 of the 5 Year Coffelt Quality Tracking Project*. Submitted to the California Department of Developmental Services and California Protection & Advocacy, Inc. Ardmore, PA: The Center for Outcome Analysis.

Devlin, S. (1989). *Reliability assessment of the instruments used to monitor the Pennhurst class members*. Philadelphia: Temple University Developmental Disabilities Center.

Conroy, J., Efthimiou, J., & Lemanowicz, J. (1981). *Reliability of the Behavior Development Survey: Maladaptive behavior section* (Pennhurst Study Brief Report No. 11). Philadelphia: Temple University Developmental Disabilities Center.

Conroy, J. (1980). *Reliability of the Behavior Development Survey* (Technical Report 80-1-1). Philadelphia: Temple University Developmental Disabilities Center.

Lemanowicz, J., Feinstein, C., & Conroy, J. (1980). *Reliability of the Behavior Development Survey: Services received by clients*. Pennhurst Study Brief Report 2. Philadelphia: Temple University Developmental Disabilities Center/UAP.

Isett, R., & Spreat, S. (1979). Test-retest and interrater reliability of the AAMD Adaptive Behavior

Dodder, R., Foster, L., & Bolin, B. (1999). Measures to monitor developmental disabilities quality assurance: A study of reliability. *Education and Training in Mental Retardation and Developmental Disabilities, 34, 1*, 66-76.

## A sample of studies using the Center for Outcome Analysis Survey Tool to measure change over time

The Center for Outcome Analysis Quality of Life Survey tool has been used since the 1980s to track improvements in integration when people move out of institutions. The study is sensitive to changes over time, and can be used to track progress on integration. A sample of the studies, with brief descriptions, is included below.

Conroy, J.W., Seiders, J.X., & Brown, M. (2000, June). *How Are They Doing? Year 2000 Report of the Quality of Life Evaluation Of People with Developmental Disabilities Moving from Developmental Centers into the Community (The "Quality Tracking Project")*. Final Report (Year 1). Submitted to California Department of Developmental Services. Rosemont, PA: Center for Outcome Analysis.

Study description: This study used the survey tool to measure outcomes over time for 2,400 people in California that were deinstitutionalized.

Conroy, J., Feinstein, C., Lemanowicz, J., Devlin, S., & Metzler, C. (1990). *The report on the 1990 National Consumer Survey*. Washington DC: National Association of Developmental Disabilities Councils.

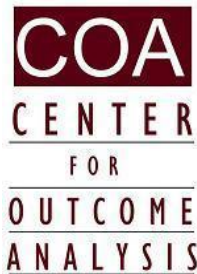
Study description: The study used the survey tool to measure outcomes over time for individuals participating in the 1990 National Consumer Survey mandated by the U.S. Congress.

Conroy, J., Fullerton, A., Brown, M., & Garrow, J. (2002, December). Outcomes of the Robert Wood Johnson Foundation's National Initiative on Self-Determination for Persons with Developmental Disabilities: Final Report on Three Years of Research and Analysis. Submitted to the Robert Wood Johnson Foundation as the Impact Assessment of the Foundation's National Initiative entitled Self-Determination for Persons with Developmental Disabilities. Narberth, PA: Center for Outcome Analysis.

Study description: Over this five year study of the Robert Wood Johnson Foundation's National Self-Determination Initiative for Persons with Developmental Disabilities, participants were shown to experience significant increases in integration.

## Personal Life Quality Protocol

# Outcome Measurement Tools for Tracking Implementation of the Olmstead Integration Mandate



*Center for Outcome Analysis*

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# INFORMATION ABOUT THE PERSON

## Part 1: Individual Information

1. \_\_\_\_\_ 2. \_\_\_\_\_ 3. \_\_\_\_\_  
First Name M.I. Last Name

4. Identification number \_\_\_\_\_

5. \_\_\_\_\_  
Complete Mailing Address, Including Apartment #

6. \_\_\_\_\_ 7. \_\_\_\_\_ 8. \_\_\_\_\_  
City or Town State Zip Code

9. \_\_\_\_\_  
Home Area Code and Telephone Number

10. \_\_\_\_\_ 11. \_\_\_\_\_  
Primary Respondent's Name Title or Relationship

12. \_\_\_\_\_  
Today's Date

## Part 2: Demographics, Legal Status, and Disability

1. PERSON'S DATE OF BIRTH

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 Month      Day      Year

2. PERSON'S AGE

\_\_\_\_\_

3. SEX

\_\_\_\_\_ 1 Male  
 \_\_\_\_\_ 2 Female

4. ETHNIC IDENTIFICATION

<b>Check All That Apply</b>	
	1 White or Caucasian
	2 Black or African-American
	3 American Indian or Alaska Native
	4 Asian
	5 Native Hawaiian or Other Pacific Islander
	6 Hispanic or Latino
	7 Other
	99 Refused, left blank

5. **PRIMARY** ETHNIC IDENTIFICATION

<b>Check ONE Primary</b>	
	1 White or Caucasian
	2 Black or African-American
	3 American Indian or Alaska Native
	4 Asian
	5 Native Hawaiian or Other Pacific Islander
	6 Hispanic or Latino
	7 Other
	99 Refused, left blank

6. MARITAL STATUS

\_\_\_\_\_ 1 Never married  
 \_\_\_\_\_ 2 Married now  
 \_\_\_\_\_ 3 Married in past, single now  
 \_\_\_\_\_ 99 Refused, Don't know

7. PARENTAL STATUS

\_\_\_\_\_ 7a. Number of children  
 \_\_\_\_\_ 7b. Number of dependent children

8. LEGAL STATUS

- 1 No guardian or conservator
- 2 Guardian
- \_\_\_\_\_ 3 Conservator
- \_\_\_\_\_ 4 Don't Know

9. DISABILITIES AND PERCEIVED SIGNIFICANCE

**1 = Major disability 2 = Some disability 3 = No disability**

**Note: Please allow the person and the person's assistants to define what "some" and "major" mean**

	Description	Major Disability 1	"Some" Disability 2	No Disability 3	D/K 99
9A.	Ambulation (Walking)	1	2	3	99
9B.	Autism	1	2	3	99
9C.	Behavior: Aggressive or Destructive	1	2	3	99
9D.	Behavior: Self-Abusive	1	2	3	99
9E.	Brain Injury	1	2	3	99
9F.	Cerebral Palsy	1	2	3	99
9G.	Communication	1	2	3	99
9H.	Dementia (Including Alzheimer's Disease)	1	2	3	99
9I.	Health Problems (Major)	1	2	3	99
9J.	Hearing	1	2	3	99
9K.	Intellectual Disability (Intentionally redundant with Item8)	1	2	3	99
9L.	Mental Illness	1	2	3	99
9M.	Physical Disability Other Than Ambulation	1	2	3	99
9N.	Seizures	1	2	3	99
9O.	Substance Abuse	1	2	3	99
9P.	Swallowing: Inability to swallow independently	1	2	3	99
9Q.	Vision	1	2	3	99
9R.	Other (s) _____	1	2	3	99

## Part 3: Housing

1. TYPE OF HOME: What type of home is the person living in now?

Check ONE	
	1A. Living with family or friends
	1B. Board and Lodging
	1C. Housing with Services
	1D. Supervised Living Facilities
	1E. Boarding Care
	1F. Shelter
	1G. Transitional Housing
	1H Nursing Homes, Assisted Living
	1I. Adult Foster Care
	1j. ICF/DD

2. HOW MANY PEOPLE LIVE IN THIS HOME RIGHT NOW?

("HOME" can usually be interpreted as a unique MAILING ADDRESS - - a group dwelling or individual home or apartment. If this is a congregate care facility, use cottage or living unit or building or wing or other meaningful sub-unit. If there are vacancies, only count how many people live here RIGHT NOW.)

	2A. People in this home (or cottage or living unit etc.)
	2B. People with disabilities (unpaid cohabitants)
	2C. People without disabilities (unpaid cohabitants)
	2D. Paid staff who <u>live</u> here (paid cohabitants)

3. WITH HOW MANY PEOPLE DOES THIS PERSON SHARE A BEDROOM? \_\_\_\_\_ People

4. HOW MANY DIRECT CARE STAFF WORK AT THIS HOME? (Counting all shifts.)

4A. \_\_\_\_\_ Full Time Staff (Enter 0 if none)

4B. \_\_\_\_\_ Part Time Staff (Enter 0 if none)

5. WHAT WAS THE LAST MONTH AND YEAR IN WHICH THIS PERSON LIVED IN A STATE DEVELOPMENTAL CENTER or STATE PSYCHIATRIC INSTITUTION?

5A. \_\_\_\_\_ / 5B. \_\_\_\_\_ OR 5C. \_\_\_\_\_ Check here if never lived in state institution  
 Month                      Year

***NOTE: Information about employment/day activity or education setting are collected in next section***

# COMMUNITY INTEGRATION AND ENGAGEMENT

## Part 1: Time, Money, & Integration – During the Day

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**Please describe your (the person’s) past week – if last week wasn’t usual, please describe a usual week.**

**HOURS:** Estimate how many hours per week are or were worked, on average, in each kind of work setting

**EARNINGS:** Estimate how much money per week the person earned or earns from each kind of activity on average

**INTEGRATION:** Write the number for HOW INTEGRATED the person was:

1	Completely segregated	Never in the presence of people without disabilities
2	Mostly segregated	Some or a little of the time in the presence of people without disabilities
3	In between	In Between
4	Mostly integrated	Often in situation where people without disabilities are, or might be, present
5	Completely integrated	Nearly always in a situation where people without disabilities might be, present

Type of Day Activity	# Hours Work Per Week	\$ Earned Per Week	Integration Level
1. Self-Employed: Has His/Her Own Business			
2. Regular Job (Competitive Employment)			
3. Supported Employment – in Regular Community Job			
4. Supported Employment – Enclave or Job Crew model			
5. Sheltered Employment or Workshop Employment			
6. Pre-Vocational Program or Vocational Rehabilitation Program			
7. Day Habilitation Program (Adult Day Program, Non-Vocational Day Program)			
8. Senior Citizen Program			
9. Partial Hospitalization Program - Mental Health Oriented			
10. Volunteer Work			
11. Public School			
12. Private School			
13. Adult Education - GED, Adult Ed, Trade School, etc.			
14. Community Experience			
15. Other _____			
<b>TOTAL HOURS</b>			xxx

# COMMUNITY INTEGRATION AND ENGAGEMENT

## Part 2: Integrative Activities Scale – In the Past Four Weeks

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ABOUT HOW MANY TIMES did this person do each of the following in the past four weeks?  
**(Rough estimates are fine.** If the past month was not typical, ask about the average month during the past year. Write DK if "Don't Know.")

Next, what is the **AVERAGE** group size in which the person had each kind of experience?

Finally, does this person normally have **ANY** interaction with community members when out?

	How Many Times?	Average Group Size Including Staff?	Does This Person Normally Have Any Interaction with Community Members during this kind of trip or outing? (Neighbors, Shoppers, Travelers, any citizens who are not in the "disability system")				
			None 1	Little 2	Some 3	Much 4	Very Much 5
1. Visit with close friends, relatives or neighbors			1	2	3	4	5
2. Go to a grocery store			1	2	3	4	5
3. Go to a restaurant			1	2	3	4	5
4. Go to a place of worship			1	2	3	4	5
5. Go to a shopping center, mall or other retail store to shop			1	2	3	4	5
6. Go to bars, taverns, night clubs, etc.			1	2	3	4	5
7. Go to a bank			1	2	3	4	5
8. Go to a movie			1	2	3	4	5
9. Go to a park or playground			1	2	3	4	5
10. Go to a theater or cultural event (including local school & club events)			1	2	3	4	5
11. Go to a post office			1	2	3	4	5
12. Go to a library			1	2	3	4	5
13. Go to a sports event			1	2	3	4	5
14. Go to a health or exercise club, spa, or center			1	2	3	4	5
15. Use public transportation (May be marked "N/A")			1	2	3	4	5
16. Other kinds of "getting out" not listed above			1	2	3	4	5

# AUTONOMY OVER DAILY LIFE: Decision Control Inventory

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Ask the person and/or the person's chosen ally to say who actually makes decisions in each area. Use the "Two Either-Or Questions" approach. (e.g., "How do foods for the home get chosen, by paid staff, or by you and your friends/housemates/family?" Then follow up with "OK, would you say Mostly or All that way?") Once the pattern is clear, this scale can be done quickly with just the numbers.

## WHO MAKES DECISIONS?

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>99</b>
<b>All or Nearly All Decisions Made by Paid Folks</b>	<b>Mostly Made by Paid Folks</b>	<b>Equally Shared Decisions</b>	<b>Mostly Made by Person and/or Freely Chosen Allies</b>	<b>All or Nearly All Made by Person and/or Freely Chosen Allies – relatives, friends, advocates</b>	<b>D/K, N/A</b>

	All Paid 1	Most Paid 2	Equal 3	Most Unpaid 4	All Unpaid 5	D/K
<b>FOOD</b>						
1 What foods to buy for the home when shopping	1	2	3	4	5	99
2 What to have for breakfast	1	2	3	4	5	99
3 What to have for dinner	1	2	3	4	5	99
4 Choosing restaurants when eating out	1	2	3	4	5	99
<b>CLOTHES AND GROOMING</b>						
5 What clothes to buy in store	1	2	3	4	5	99
6 What clothes to wear on weekdays	1	2	3	4	5	99
7 What clothes to wear on weekends	1	2	3	4	5	99
8 Time and frequency of bathing or showering	1	2	3	4	5	99
<b>SLEEP AND WAKING</b>						
9 When to go to bed on weekdays	1	2	3	4	5	99
10 When to go to bed on weekends	1	2	3	4	5	99
11 When to get up on weekends	1	2	3	4	5	99
12 Taking naps in evenings and on weekends	1	2	3	4	5	99
<b>RECREATION</b>						
13 Choice of places to go	1	2	3	4	5	99
14 What to do with relaxation time, such as choosing TV, music, hobbies, outings, etc.	1	2	3	4	5	99
15 Visiting with friends outside the person's residence	1	2	3	4	5	99
16 Choosing to <u>decline</u> to take part in group activities	1	2	3	4	5	99
17 Who goes with you on trips, errands, outings	1	2	3	4	5	99
18 Who you hang out with in and out of the home	1	2	3	4	5	99
<b>SUPPORT AGENCIES AND STAFF</b>						
19 Choice of which service agency works with person	1	2	3	4	5	99
20 Choice of Case Manager (or other term such as SSA, SC, etc.)	1	2	3	4	5	99
21 Choice of agency's support persons/staff (N/A if family)	1	2	3	4	5	99
22 Choice of support personnel: option to hire and fire support personnel	1	2	3	4	5	99
<b>ECONOMIC RESOURCES</b>						
23 What to do with personal funds	1	2	3	4	5	99
24 How to spend residential funds	1	2	3	4	5	99
25 How to spend day activity funds	1	2	3	4	5	99
<b>HOME</b>						
26 Choice of house or apartment	1	2	3	4	5	99
27 Choice of people to live with	1	2	3	4	5	99
28 Choice of furnishings and decorations in the home	1	2	3	4	5	99
<b>WORK OR OTHER DAY ACTIVITIES</b>						
29 Type of work or day program	1	2	3	4	5	99
30 Amount of time spent working or at day program	1	2	3	4	5	99

31 Type of transportation to and from day program or job	1	2	3	4	5	99
<b>OTHER</b>						
32 Express affection, including sexual	1	2	3	4	5	99
33 "Minor vices" - use of tobacco, alcohol, caffeine, explicit magazines, etc.	1	2	3	4	5	99
34 Whether to have pet(s) in the home	1	2	3	4	5	99
35 When, where, and how to worship	1	2	3	4	5	99

\_\_\_ 36. Check here if you wish to report perception of possibly unfair or excessive domination of this person's life by ANYONE.



## PERCEIVED QUALITIES OF LIFE

(To Be Answered by the Person or Whoever Knows the Person Best)

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### RESPONDENT:

Ask the person to rate the qualities of his/her own life. **If the person can't answer, accept answers from whoever knows the person best.** You must find someone who the person will allow to answer, or who knows the person on a **day to day basis** better than anyone else.

### METHOD:

Each quality item is approached as two “Either-Or” questions. For example, the first Either-Or question on the first item is “Would you say your health is good or bad?” (“In between” is implied, if the person says “neither” or “OK” or “neither” or any similar response. But answers like that have to be checked by probing with “Oh, so it’s in between, not really good or bad?”) Once the person answers, for example, “good,” the follow-up is a second Either-Or question: “Would you say good or very good?”

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>99</b>
<b>Very Bad</b>	<b>Bad</b>	<b>In Between</b>	<b>Good</b>	<b>Very Good</b>	<b>Don't know, N/A</b>

Life Quality Area	Very Bad	Bad	In Between	Good	Very Good	Don't know, N/A
1 Health	1	2	3	4	5	99
2 Running my own life, making choices	1	2	3	4	5	99
3 Family relationships	1	2	3	4	5	99
4 Relationships with friends	1	2	3	4	5	99
5 Getting out and getting around	1	2	3	4	5	99
6 What I do all day	1	2	3	4	5	99
7 Food	1	2	3	4	5	99
8 Happiness	1	2	3	4	5	99
9 Comfort	1	2	3	4	5	99
10 Safety	1	2	3	4	5	99
11 Treatment by staff/attendants	1	2	3	4	5	99
12 Health care	1	2	3	4	5	99
13 Privacy	1	2	3	4	5	99
14 Overall quality of life	1	2	3	4	5	99

15. How many of these 14 questions were answered by the Focus Person, even if assistance or interpretation was involved? \_\_\_\_\_ (from 0 to 14)