

Long-Term Services and Supports Quality Review
Adult Face-to-Face
and
Children/Family Mail
Survey Results
2006

Texas Department of Aging and Disability Services
Center for Policy and Innovation
Quality Assurance and Improvement



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1.0 Executive Summary

This report provides summary results from the adult face-to-face experience and children/family mail surveys conducted by the Texas Department of Aging and Disability Services (DADS) in 2006. These survey processes are used by DADS to benchmark the quality of its programs for long-term services and supports. Over time, the data will reveal opportunities for program improvement and the capability to measure the impact of those improvements. These findings will further promote the vision of DADS whereby- *older Texans and persons with disabilities will be supported by a comprehensive and cost-effective service delivery system that promotes and enhances individual well-being, dignity, and choice.*¹

Section 1 provides an executive summary highlighting the major points of the entire report. Section 2 describes in detail the methodology used for conducting the adult face-to-face surveys, while Section 3 details the individual program results. Section 4 provides the methodology used and the results for the children/family mail survey followed by the report conclusion and recommendations in Section 5.

The survey processes are a continued activity of the three-year Real Choice Systems Change Grant awarded by the Centers for Medicare and Medicaid Services (CMS) in 2003 to improve quality for home and community-based programs. A stakeholder task force, comprised of internal and external participants, was an integral part of the process to refine and implement the goals of the grant in partnership with DADS. One of the goals accomplished over the grant period was to research and develop a methodology or tool that accurately reflects experiences of people receiving services, and measure achievement of their goals and aspirations. As a result, DADS joined the National Core Indicators (NCI) project developed by the Human Services Research Institute (HSRI)². This project collaboration is designed to assist member states with developing performance and outcome measurement strategies and provides nationally recognized survey instruments for interviewing people receiving services and supports. DADS will provide results to HSRI for inclusion in their analysis across participating states. This benchmark will provide a broader perspective about the survey data that will be useful for collaboration, planning, and improvement efforts.

Adult face-to-face consumer surveys were conducted using the NCI Consumer survey tool designed for use with adults who have developmental disabilities. The tool includes two sections: Section 1 can only be answered by the person receiving services, and section 2 may be answered by either the person or another respondent that knows the person well enough to answer on their behalf. Categories for the indicators include: Consumer Outcomes; System Performance; Health, Welfare, and Rights; and Self-Determination. Persons interviewed using this tool were people who receive services in the Community Living Assistance and Support Services (CLASS), Consolidated Waiver Program (CWP), Deaf-Blind Multiple Disabilities (DBMD), Home and Community-based Services (HCS), Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR), state mental retardation facilities, and the Texas Home Living (TxHmL) Programs.

The NCI Children/Family Survey was also used as part of the survey process. Surveys were mailed to families of children who receive services in the CLASS, HCS, TxHmL, CWP, and the Medically Dependent Children's Program (MDCP). Section 1 of the tool includes demographic information about the child receiving services and Section 2 contains information about the respondent. Section 3 includes the survey questions with a comment section concluding the tool.

¹ www.dads.state.tx.us

² Human Services Research Institute (www.hsri.org). Member states include: AL, AK, AZ, CT, DE, GA, HI, IN, KY, MA, ME, NC, NM, OK, PA, RI, SC, SD, VT, WA, WV, and WY.

In addition to joining the NCI project, DADS collaborated with the MEDSTAT Group, Inc., who developed the Participant Experience Survey Elderly/Disabled (PES E/D) tool designed for people with physical disabilities and the elderly. The PES E/D tool provides indicators of program participants' experience in areas of Access to Care, Choice and Control, Respect and Dignity, Community Integration/Inclusion, and Self-determination. Interviewers used this tool with people who receive Community-Based Alternatives (CBA) Program services.

For each survey tool, results are derived by calculating indicators using questions from the tools. The indicators are grouped by categories or domains.

The analysis methodology used for the NCI Consumer Survey 2006 results was refined to enhance the ongoing value of the information collected by conforming to the HSRI methodologies. HSRI only includes responses in their analysis if interviewers determined that individuals understood the questions, answered consistently, and answered at least half of the questions in Section 1. The methodology used for this process was consistent with HSRI. Therefore, 1,258 responses from people randomly selected from the HCS, TxHmL, DBMD, CWP, ICF/MR, and state mental retardation facility programs were included in the analysis. For the CLASS Program, results were compared between people who use the Consumer Directed Services (CDS) option and those who do not. CDS is a service delivery option that gives control to the person over their habilitation and respite services. As the employer, the person hires and manages their attendants.

1.1 NCI Key Findings

The NCI Consumer Survey tool contains multiple questions developed to calculate specific indicators. The indicators are grouped by four different domains. Within each domain there are specific areas, or concerns, the tool explores. The results are provided by the domains listed below and give the reader insight into the experiences of people receiving services.

<u>Domain</u>	<u>Concern</u>
Consumer Outcomes	<ul style="list-style-type: none">• People make choices about their lives• People have friends and relationships• People are satisfied with the services and supports they receive• People have support to participate in everyday community activities
System Performance	<ul style="list-style-type: none">• Service coordinators are accessible and responsive• Publicly funded services are readily available
Health, Welfare, Rights	<ul style="list-style-type: none">• People are safe from abuse and neglect• People secure needed health services• Medications are managed effectively and appropriately• People receive the same respect and protections as others in the community• People are supported to maintain healthy habits in areas such as smoking
Self-Determination	<ul style="list-style-type: none">• People are able to have more choice and control over their everyday lives

1.1.1 Consumer Outcomes

People make choices about their lives

Although there are a number of indicators that show a high percentage score, there is room for additional and continuous improvement. One of these areas is control over life decisions. A majority of people report

that they were not provided options about where to live and work. While this is more of an issue for people receiving ICF/MR services, no more than two-thirds of the people receiving any service report being provided options about where to live and work. For a substantial number of people receiving home and community-based, ICF/MR, and state mental retardation facility services, findings show that the majority of these people visited no more than one place before choosing where to live or work.

Choosing the people to live within a residence is another quality indicator related to choice. Only 29% of people in ICFs/MR and 19% of people in state mental retardation facilities report having a choice about the people with whom they live. In contrast, approximately 95% of people in the CLASS and CWP programs, and 87% of the people in the TxHmL Program report having a choice. About 55% of people in the HCS Program report having a choice about the people living with them.

People have friends and relationships

Across the programs, the majority of people report having relationships with friends and family. This concern also includes an indicator for the proportion of people who feel lonely. Overall, program results reflect that about 50% of people in all programs except DBMD (22%) and CLASS-CDS (34%) report feeling lonely “often” or “sometimes.”

People are satisfied with the services and supports they receive

Generally, people are satisfied with where they live, their job or day program and with their personal life.

People have support to participate in everyday community activities

Total integration into the community is an area that warrants further examination. It is noteworthy that most people across services do engage in personal activities of daily life within their communities. However, findings show that very few people in any program attend community meetings, exercise, or play sports in a community setting, which suggests they are not truly integrated into mainstream society.

1.1.2 System Performance

Service coordinators are accessible and responsive

The results reflect that the majority of people interviewed who receive services report that they receive accessible and responsive support from their case manager or service coordinator.

Publicly funded services are readily available

Access to and control over transportation is an issue for many people, primarily those receiving services in state mental retardation facilities. Only 23% of people in State mental retardation facilities have control over their transportation, and only 38% feel that they have adequate transportation. Control over transportation is relatively low for people receiving services in ICF/MR and TxHmL programs, too. Conversely, most people who receive CLASS services and use the CDS option have control over transportation and most of the people in the CLASS, CWP, DBMD, and HCS programs feel that they have adequate transportation.

1.1.3 Health, Welfare, and Rights

People are safe from abuse and neglect

A high number of people in Texas report feeling safe in their homes and neighborhoods; 75% and 77%, respectively.

People secure needed health services

Although most people go to appointments and run errands, people in some programs do not secure needed health services. According to the survey, very few women in the CLASS, CWP, and TxHmL programs have had a gynecological visit in the past year. Most women in the other programs have had a gynecological visit in the past year.

Receiving routine dental exams is another area of concern, especially for people in the CLASS Program. Only about 17% of people in the CLASS Program (whether they use the CDS option or not) have had a routine dental exam in the past 6 months. Most people receiving services in the HCS, ICF/MR, and state mental retardation facility programs have had a dental visit in the past 6 months.

Medications are managed effectively and appropriately

People who receive state mental retardation facility services are 65% more likely to take medications for mood, anxiety, or behavior problems. Conversely, only 9% of people who direct their own services in the CLASS Program are receiving medications for mood, anxiety, or behavior problems.

People receive the same respect and protections as others in the community

The indicators include questions about: whether people knock before entering one's home or bedroom, others reading individuals' mail without permission, being alone with friends, and use of the telephone. Overall, a great majority of people feel respected in these areas. However, at least 50% of people interviewed in each program report that people entered their home without knocking. The exception to this finding is the CLASS Program (those who use the CDS option) where 75% report people knock before entering their home.

In Texas, few people have had the opportunity to participate in self-advocacy activities or in other groups that address rights. A small minority of people in any program are involved in self-advocacy or go to events to learn about self-advocacy. In state mental retardation facilities about half of the people receiving services in state mental retardation facilities have had this opportunity.

People are supported to maintain healthy habits in areas such as smoking

People who reside in state mental retardation facilities are more likely to smoke or use tobacco products.

1.1.4 Self-determination

People are able to have more choice and control over their everyday lives

The grant task force members recommended adding six additional questions to the tool regarding self-determination. The questions relate to opportunities to help other people, have close relationships, earn enough money to buy the things they want, take risks, control their transportation, and decide who comes in and out of their home. Generally, the results are about average in most areas with the exception of transportation as mentioned earlier. A greater majority of people report having the opportunity to have a close relationship, such as a girlfriend or boyfriend, than they did in the other self-determination areas.

1.2 Program Comparisons

For 2006, a goal of this study was to conduct comparisons of quality indicators between people receiving CLASS Program services who use the CDS option and those who do not. In addition, quality indicators were compared between people receiving services in state mental retardation facilities and people receiving services in ICFs/MR.

1.2.1 Consumer Directed Services

In general, people receiving CLASS services who use the CDS option were less likely to have a guardian, more likely to speak English as their primary language, required medical care less often, and needed less support to prevent disruptive behavior.

A significant finding is that people receiving CLASS services who use the CDS option tend to have more control over, and knowledge about, their services, transportation, and decisions. They also feel safer in their homes and more satisfied with their personal lives. In addition, they report feeling lonely less often than people who do not use the CDS option.

1.2.2 Intermediate Care Facilities for Persons with Mental Retardation

In general, people receiving services in ICF/MR facilities tend to be more satisfied with where they live, have more control over and access to transportation and appear to be more integrated into the community.

1.2.3 State Mental Retardation Facility

People receiving services in state mental retardation facilities are more likely to have friends other than family members and support staff, and are more likely to have had the opportunity to participate in self-advocacy activities. More people who reside in state mental retardation facilities appear to need support to help prevent self-injury and require medical care more often.

1.3 Participant Experience Survey Key Findings

The PES E/D survey tool was designed to collect information directly from elderly and non-elderly adults with physical disabilities. The PES E/D survey is a tool used for this survey process for people receiving Community-Based Alternatives (CBA) program services. All 427 responses collected were included in the analysis for this report according to the methodology developed by MEDSTAT Group, Inc.

Overall, people who receive CBA services have their basic needs met; have access to care; are receiving support to prepare meals, eat, and receive needed medications. In addition, they feel they are respected by their day and home staff. Many report they have support to live the life they choose by being free to take risks when they want to, have close relationships, and decide who comes into their home. In general, they feel they are safe from abuse and exploitation.

On the other hand, there is a significant unmet need for community involvement. About 41% of people report they would like to do activities outside of their home but do not. In addition, 33% do not choose their care staff but would like to; 29% who are not currently employed, would like to work; and 40% of people interviewed report they are unable to identify their case manager.

The PES E/D survey tool divides questions into five domains: Access to Care, Choice and Control, Respect/Dignity, Community Integration/Inclusion, and Self-Determination. The PES E/D tool is used to calculate quality indicators with a result listed for each indicator. A few indicators in each domain are listed below including the best results and the areas needing improvement. Some questions are posed as a positive and some as a negative, so care is needed when interpreting the meaning of the percentage scores.

1.3.1 Access to Care

Sometimes unable to eat because there is no one there to help them (1%)

Sometimes go without taking medications because there is no one there to help them (4%)

1.3.2 Choice and Control

Unsure who to report staffing problems to or would report staffing problems to “no one” (4%)

Do not help direct their staff, but would like to (21%)

Do not choose their care staff, but would like to (33%)

Unable to identify their case manager when asked (40%)

1.3.3 Respect and Dignity

Staff do not treat them respectfully in programs outside their homes (0%)

Staff do not listen carefully to their requests for assistance in programs outside their homes (0%)

Home care staff do not listen carefully to their requests for assistance (6%)

Staff do not listen carefully to requests for assistance while using transportation services (9%)

1.3.4 Community Integration/Inclusion

Working, non-elderly people who did not choose their current job (0%)

Working, non-elderly people who do not like their current job (0%)

Non-elderly people who are not currently working but would like to work (29%)

Report an unmet need for community involvement (41%)

1.3.5 Self-Determination

Report not always having transportation when needed (20%)

Free to take risks when they want to (90%)

Decide who comes in and out of their home (82%)

Able to have a close relationship, such as a boyfriend or girlfriend, if they want one (66%)

Earn enough money to buy the things they want (57%)

1.4 Children and Family Mail Survey Key Findings

The NCI Children/Family survey was mailed to all families of children in the Medically Dependent Children Program (MDCP), which includes persons up to 21 years of age. In addition, all families of children under age 18, who live at home with their families, and receive home and community-based services, received a survey. These programs include CLASS, HCS, TxHmL, and the CWP. A total of 2,192 surveys were mailed to families and 801 (36%) responded to the survey. All survey correspondence was mailed to families in both English and Spanish. The survey asks a series of questions in areas such as Information & Planning, Access & Delivery of Supports, Choice & Control, Community Connections, Satisfaction, and Family Outcomes. A section for comments is also available. A five-point Likert scale is used to record responses that determine the level of agreement with an item. A higher agreement represents a positive response; a lower agreement represents a less positive response.

Most families in all programs report that services and supports have helped them to care for their family member more effectively and that staff are respectful of their choices. In addition, the majority of families report that their support plan includes or reflects things that are important to the family, and staff who assist with planning are

knowledgeable and respectful. Families who have children receiving services in CLASS report satisfaction with the level of control they have over their budgets.

1.4.1 Information and Planning

The results indicate that families would like to have more information that is easy to understand in order to plan for their services and supports. Families in CLASS and CWP report higher agreement that their support plan includes or reflects things that are important to the family.

1.4.2 Choice and Control

More families in MDCP, HCS, and TxHmL programs agreed staff are respectful of the choices and decisions made by the family. Families overwhelmingly report lower satisfaction with being able to control their own budgets/supports (i.e., they choose what supports or goods to purchase). Less agreement for choice and control was reported in the CWP, HCS, and TxHmL programs. This indicator is expected to improve as the CDS option is expanded in these programs and used by more people.

1.4.3 Access and Support Delivery

Families whose children receive CWP and CLASS services report highest agreement in areas of access and support delivery. Specifically, families report having access to an adequate array of services and supports. Families who receive CLASS services and use the CDS option report staff or translators are not always available to provide information, services, or supports in the family/family member's primary language or method of communication.

1.4.4 Community Connections

Similar to the results of the face-to-face surveys, families report an unmet need for integrated community services and participation in everyday community activities. Families in all programs, except CWP, report lower agreement in terms of being supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).

1.4.5 Satisfaction

Families are satisfied with the information and supports received, and with the planning, decision-making, and grievance processes. Agreement scores from families in all programs for this indicator fell within a moderate agreement range.

1.4.6 Family Outcomes

Higher agreement for family outcomes occurs when families respond that services and supports have helped them to better care for their family member living at home. Families report this indicator as high in agreement in each program. The majority of comments provided by families in the survey comment section support these positive results.

1.5 Conclusion

The majority of adults in Texas who receive long-term services and supports report satisfaction with their services and their lives. Findings from the surveys also show that people:

-
- Have relationships with friends and family;
 - Receive accessible and responsive support from their case manager or service coordinator;
 - Are able to make choices about many aspects of their lives; and
 - Generally participate in community life.

Findings

Seven key findings from the survey, and related recommendations, are listed below.

Finding: Control over life decisions

Although these are generally positive findings, there is room for additional and continuous improvement in particular areas. One such area is control over life decisions. People should have more options provided when deciding where to live and work. People need to be offered more than one option before a decision is made.

Recommendation: Person-Directed Planning

The state mental retardation facilities staff piloted a new person-directed planning process aimed at developing a Personal Support Plan. The person served or their legally authorized representative, as applicable, directs the plan. The emphasis is placed on supporting the person in making choices about life decisions and in the development of a plan to support choices and identify areas of needs. Based on the success of the pilot, it is recommended that efforts continue to implement or enhance the person-directed planning process in all programs, and additionally provide information on person directed planning to more people who receive services in all programs through literature dissemination, conferences, and other events.

Finding: Health

What is not clear or addressed in this survey is the reason for some of the less positive results in the area of health. For example, women do not obtain health services, such as gynecological exams. Women might choose not to have annual exams. For some women, finding a Medicaid provider might be a barrier. Education and information should be available to inform people who receive services about the benefits of routine health monitoring.

Recommendation: Conduct further research

Conduct additional research to determine recommendations.

Finding: Self-advocacy

With the exception of people receiving services in state mental retardation facilities, a small minority of people in any program are involved in self-advocacy or go to events to learn about self-advocacy. Moreover, only about half of the people receiving services in state mental retardation facilities have had this opportunity.

Recommendation: Consumer Advocacy

Conduct at least one symposium/educational opportunity that targets consumer advocacy. Provide this report and results to a broad audience of advocates, family members, and providers to assist with implementing additional best-practice initiatives on their own.

Finding: Consumer Directed Services

Worth noting is the positive findings for people who receive CLASS services and use the CDS option. These individuals have more choice and control over their everyday lives. They report having more control over their transportation, are less likely to feel lonely, and require medical care less often. They tend to have more control over, and knowledge about, their services and decisions. In addition, they feel safer in their homes and are more satisfied with their personal lives.

Recommendation: Expand the Consumer Directed Services option

Continue efforts to expand the CDS option to all programs.

Finding: ICFs/MR and state mental retardation facilities

The results comparing responses from people who receive services from ICFs/MR and state mental retardation facilities suggest challenges for both. Working to improve community integration, participation in decisions, and encouraging participation in self-advocacy activities for people receiving services in ICFs/MR and state mental retardation facilities are areas for improvement.

Recommendation: Quality Monitoring Program

The Quality Monitoring (QM) Program helps nursing facility providers improve resident care through quality consultants who provide technical assistance and information about evidence-based best practices. Information and best practices are published on the Quality Matters website³. Quality Matters (QMWeb) is a website of evidence-based best practice frameworks compiled from systematic clinical literature reviews. The QM Program can be expanded in partnership with providers to address areas of interest for ICFs/MR and State mental retardation facilities as well as home and community-based programs.

Finding: Children and Families

Overall, people who responded to the Children/Family survey report that the services and supports they received have helped them to better care for their family member living at home. The majority, however, also report they would like to have more information that is easy to understand in order to plan for their family member's services and supports. In addition, families in most programs agreed staff are respectful of the choices and decisions made by the family.

Recommendation: Improve DADS websites

Conduct usability studies for the DADS websites to ensure that information is easily accessed and understood by the general public. Educate the public about the Quality Reporting System (QRS)⁴ on the site to obtain specific information about a particular long-term services and supports provider or to compare providers in a particular area. QRS provides information that can help identify providers that may meet families' needs.

Finding: Continued evaluation

These results reflect the opinions and perceptions of the people and families of individuals who receive services and supports through programs at DADS. This input is an important component when evaluating existing programs and planning for future initiatives to support the mission of DADS.

Recommendation: Consumer Survey Process

Continue the consumer survey process as an annual activity to measure progress and assist with planning program improvements through trend analysis over time. This will be another valuable tool to assist with quality assurance programs.

³ Quality Matters website (QMWeb), <http://mqa.dads.state.tx.us/QMWeb>

⁴ Quality Reporting System (QRS), <http://facilityquality.dads.state.tx.us>

2.0 Introduction

The purpose of this report is to provide summary information regarding the Adult Face-to-Face Experience surveys and the Children/Family surveys conducted by the Texas Department of Aging and Disability Services (DADS) in 2006. Future surveys will provide additional data that will enable DADS staff to analyze and trend over time to identify areas for improvement and to measure if improvement strategies are effective. One of the lessons learned from the 2005 survey project, was that the analysis should be more robust. The decision was made to use the methodology of the Human Services Research Institute (HSRI). Based on this methodology, if an interviewer noted an individual was not able to provide a valid response, did not understand the questions, or was unable to answer questions independently, the individual's response was not included in the analysis. In addition, some indicators were calculated differently this year than in 2005. However, the overall findings are similar to 2005.

On October 3, 2003, the Centers for Medicare and Medicaid Services (CMS) awarded a \$500,000 grant to the Texas Department of Mental Health and Mental Retardation (TDMHMR) to redesign and improve the quality assurance and quality improvement processes in its home and community-based programs. CMS awarded the Real Choice Systems Change grants to assist states in fulfilling their commitment to assuring individuals' health and welfare. Texas was one of 19 states that were awarded the Quality Assurance and Quality Improvement in Home and Community-based Services grant. In September 2004, the grant was transferred to the newly formed DADS agency. The sustained grant activities continued in the Quality Assurance and Improvement (QAI) unit within the Center for Policy and Innovation (CPI) at DADS until the end of the grant period in September 2006.

The three-year grant project was managed in partnership with the Quality Assurance and Quality Improvement (QA/QI) Task Force that included people receiving services and family members, local authority staff, advocacy groups, and provider representatives. One objective of the grant was to identify a personal outcome measurement tool to measure individual experiences and calculate quality indicators in home and community-based programs. The QA/QI Task Force members selected eight survey tools for review. In June 2004, they recommended through consensus that DADS join the National Core Indicators (NCI) Project and use the NCI survey tool.

In 2005, DADS contracted with an existing contractor to conduct the face-to-face interviews statewide. In 2006, DADS advertised a Request for Proposal to contract with an external entity to conduct the adult face-to-face interviews and the children/family mail surveys. The surveys were conducted by NACES Plus Foundation, Inc.⁵ and, based on availability of resources, are conducted annually as a sustained activity of the grant.

The purpose of the project is to obtain information directly from people receiving services about their experiences in DADS programs. The face-to-face surveys were conducted with people who are 18 years of age and older who receive DADS Medicaid waiver or Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) Program services.

The Children/Family surveys were used with all families of children in the Medically Dependent Children Program (MDCP), which may have included persons up to 21 years of age. In addition, families of children under age 18 and who live at home with their family in the Community Living Assistance and Support Services (CLASS), Consolidated Waiver Program (CWP), Home and Community-based Services (HCS), and Texas Home Living (TxHmL) programs were mailed surveys.

⁵ NACES Plus Foundation, Inc. (www.NACESPlus.org)

2.1 Adult Face-to-Face Surveys

2.1.1 Quality Indicators

“The National Core Indicators is a collaboration among participating National Association of State Directors of Developmental Disability Services (NASDDDS) member state agencies and Human Services Research Institute (HSRI), with the goal of developing a systematic approach to performance and outcome measurement. Through the collaboration, participating states pool their resources and knowledge to create performance monitoring systems, identify common performance indicators, work out comparable data collection strategies, and share results. This multi-state collaborative effort to improve performance is unprecedented.

“The core indicators are the foundation for the project. The current set of indicators includes approximately 100 consumer, family, systemic, cost, and health and safety outcomes - outcomes that are important to understanding the overall health of public developmental disabilities agencies. Associated with each indicator is a source from which the data is collected. Sources of information include consumer survey (e.g., empowerment and choice issues) family surveys (e.g., satisfaction with supports), provider survey (e.g., staff turnover), and state systems data (e.g., expenditures, mortality, etc.).”⁶ This project incorporates the indicators calculated from the NCI consumer survey (six of the indicators were added by the QA/QI Task Force).

In addition to the NCI Consumer Survey, the Participant Experience Survey Elderly Disabled Version (PES E/D) was used with people receiving services in the Community-Based Alternatives (CBA) program. “The development of the PES was funded by the Centers for Medicare and Medicaid Services Finance Systems and Budget (FSB) Group in the Center for Medicaid and State Operations (CMSO), in partnership with CMS’ Disabled and Elderly Health Program Group (DEHPG). MEDSTAT Group, Inc. was the contractor who developed and tested the survey. The PES E/D was developed in cooperation with a State-Federal Work Group, who guided the process of identifying the items and priority areas of the instrument.”⁷ The quality indicators (six of the indicators were added by the QA/QI Task Force) were calculated using the results of the PES E/D surveys for programs that provide services to people who are elderly or have physical disabilities.

2.1.2 Methodology

People who participated in the face-to-face surveys were 18 years of age or older receiving services in the HCS, TxHmL, DBMD, CWP, CBA, CLASS, and ICF/MR programs. A proportional sampling strategy was used based on the number of people receiving services in each county who receive services for each program. People receiving services were free to decline to participate in the survey process at any time.

Surveys were conducted in the individual’s home unless s/he chose an alternative interview location. Pre-survey information was obtained by NACES staff from program providers prior to the interview to assist in preparing for the interview. Demographic data including residential setting, ethnicity, legal status, gender, marital status, and language was obtained from DADS automated systems.

In addition, Independent sample t-tests were conducted to compare quality indicators between those who receive CLASS services and use the Consumer Directed Services option to those who do not and between those who receive ICF/MR services to those who receive state mental retardation facility services. Only responses from those individuals or persons who interviewers determined understood the questions and answered consistently were used for these comparisons.

⁶ Human Services Research Institute – www.hsri.org/nci/

⁷ PES Survey Tool E/D User’s Guide - http://www.cms.hhs.gov/HCBS/downloads/4_PESUG_ED.pdf

2.1.3 Instruments

The NCI Consumer Survey (Appendix A) developed by the HSRI in cooperation with the NASDDDS⁸ was used for people receiving services in the HCS, TxHmL, DBMD, CLASS, CWP, and ICF/MR programs.

For the NCI Indicators, there are four domains: Consumer Outcomes; System Performance; Health, Welfare & Rights; and Self-Determination⁹. Under each domain, there is an overview of the domain, as well as identified concerns. Under each concern is one or more quality indicators developed by HSRI and NCI member states or the QA/QI Task Force that address the concern. For each indicator there is a result listed. In addition to the four domains, there are three sub-domains: community inclusion, choice, and decision-making. These indicators are calculated by combining certain items from the survey tool into reliable scale scores.

The NCI survey tool contains two sections. Section 1 may only be answered by face-to-face interviews with the person receiving services. Section 2 contains questions that may be answered by the person, or if needed, by someone who knows the person well such as a guardian or advocate, family member, friend, or staff person.

The NCI survey tool included three questions (25, 26, 27) answered by the interviewer. The questions determine if Section 1 could be completed and if the individual appeared to understand the questions. The responses provided were strictly the opinion of the interviewer.

Indicators with this symbol (▶) are calculated based on questions from Section 1 which is designed to capture the responses only from the individual, not from a proxy. Interviewers determined if individuals responding to Section 1 understood the questions and answered consistently. All responses from both sections of the tool were included in the analysis. Table 1 provides the percentages for each item to assess whether the person understood the questions and answered consistently by program and service type.

⁸ National Association of State Directors of Developmental Disability Services (www.NASDDDS.org)

⁹ The self-determination domain was recommended by the QA/QI Task Force.

Table 1 Understood/Answered Questions

Question	HCS	TxHmL	ICF/MR	STATE MENTAL RETARDATION FACILITIES	CLASS- CDS	CLASS Non- CDS	DBMD	CWP
Question 25: Could Section 1 be completed? Yes, person answered independently or with some assistance.	71%	78%	69%	30%	69%	64%	25%	68%
Question 26: In your opinion, did the individual appear to understand most of the questions or not? Yes, appeared to understand most questions (even if prompted) and could give an opinion.	66%	74%	63%	28%	76%	74%	27%	66%
Question 27: In your opinion, did the individual seem to answer the questions in a consistent manner? (Do you feel his/her responses were valid?) Yes, seemed to give consistent and valid responses.	65%	72%	61%	25%	77%	73%	28%	65%

The PES E/D version developed by MEDSTAT Group, Inc. for CMS (Appendix B) was used with people receiving services in the CBA Program. The PES E/D questions are divided into five domains: Access to Care, Choice and Control, Respect/Dignity, Community Integration/Inclusion, and Self-determination.

The PES E/D tool is used to calculate quality indicators with a result listed for each indicator. The target population for the PES E/D tool is elderly and non-elderly adults with physical disabilities. For 2006, the PES E/D tool was only used for people receiving CBA Program services.

In 2005, members of the QA/QI Task Force identified additional questions relating to self-determination to be added to the surveys that were piloted in Texas. With permission and assistance from the developers of the tools, six additional questions were added to each survey tool. The additional questions on the NCI survey tool are questions 24A through 24F. For the PES E/D survey, the questions are 44A through 44F. Based on the results of the surveys in Texas, HSRI staff will consider adding the self-determination questions to the survey that all states will use each year.

For 2006, the survey tools were modified to include the Day/Vocational/Educational Support module as part of the pre-survey to collect employment services and other day supports information.

2.1.4 Training

Interviewer training was held in April 2006. A two-day training session was conducted by QAI and NACES staff. In addition, Christie Taylor from DADS Consumer Rights and Services provided training on the process for reporting complaints and situations when abuse, neglect, and exploitation were suspected. Interviewers were given the opportunity to participate and observe mock interviews with two volunteers from the task force who were also people receiving DADS services.

Throughout the survey collection period, DADS and NACES staff conducted regular conference calls with the interviewers from across the state to answer questions and identify any areas of concern. The training session was also videotaped and the video was used for additional training needs.

2.1.5 Participants

A total of 2,602 people receiving services were interviewed. One of the lessons learned from the 2005 project was that the results from the NCI survey should be consistent with the methodology used by HSRI. Specifically, responses to Sections 1 and 2 were only included if interviewers determined that individuals understood the questions, answered consistently, and answered at least half of the questions in section 1. This only applies to people who responded to the NCI survey. All responses to the PES E/D survey were reported in all areas. Table 2 provides the number of people who responded to the surveys, and the number with responses that were included in the analysis.

Table 2 Total Respondents

Program	Participated	Valid Responses
CLASS Non-CDS	278	198
CLASS-CDS	200	151
CWP	82	53
DBMD	105	27
HCS	420	267
ICFMR	375	224
STATE MENTAL RETARDATION FACILITIES	357	86
TXHML	358	252
CBA	427	427
Total	2,602	1,685

3.0 Individual Program Results

The following results section is divided by program. A brief description of each program is given and a listing of the services available. In addition, demographics of the people receiving services in 2006 are listed with the total number of people receiving services at the time the sample was drawn. Quality indicators were calculated based on the responses to the survey questions. The indicators were calculated for each program. New demographics added for 2006 include the use of translation services and who responded to Section 2 of the National Core Indicators (NCI) survey.

Results are presented for the NCI in a manner that is consistent with Human Services Research Institute (HSRI) reporting. Specifically, different responses to certain questions are combined in the same way that HSRI combined them in their reports. Many questions have favorable responses and intermediate responses collapsed so that both are equally favorable. As an example, responses of "Yes" and "In-between" are changed into the same favorable response for the question about whether the person likes where they work.

Other questions collapse unfavorable responses and moderate responses as negative. An example of this situation is the question about whether people can see their friends when they want. In this case, answers of "Sometimes" and "No" are changed into the same unfavorable response about the people's ability to see their friends when they want. Most of the answers to questions in Sections 1 and 2 were changed for reporting in this way to make them consistent with HSRI. This is not the way they were reported in the *Measuring Quality Using Experience Survey Adult Face-to-Face 2005* report. In that report, the moderate responses were not included.

Another difference in the way responses are reported in this year's report is that answers of "Does Not Apply" were not included in calculating the percentages or in conducting the comparisons. The differences may have nothing to do with how people actually responded. In future reports, responses from all years will be combined in the same way so that the comparisons show actual differences in people's perceptions, not how the results were scored.

"I would like to have a job mowing lawns. I'm very interested in drafting also. I would like to work."

-W. from Beaumont

"I would like a calling card to call family. I want to rearrange my room."

-J. from Corsicana

"I would like to move to Seminole."

-C. from Lamesa



"Yes, I would like to find a dishwashing job at any restaurant; a bus boy would be great. I would even like a car wash job."

-G. from Houston

"I would like to have recreation time offered more often. I enjoy this part of facility program."

-M. from Bridge City

"I would like to ride horses more often."

-E. from Beaumont

Home and Community-Based Services

The Home and Community-Based Services (HCS) Program for people with cognitive disabilities provides individualized services and supports to people living in their family home, their own homes, or other community settings such as small group homes where no more than four people live. There is no age limit and services include:

- Case Management
- Adaptive Aids
- Residential Assistance (up to 4 people)
- Respite
- Day Habilitation
- Dental Treatment
- Nursing
- Minor Home Modifications
- Counseling and Therapies
- Supported Employment

At the time the sample was drawn, there were 10,020 people receiving HCS services. Of the 10,020 people receiving services, 9,349 were 18 years of age and older. In the final analysis, 267 responses were included.

Table 3 HCS Adult Demographics

Demographic	
Residential Type	%
Own/Family Home	28%
Foster Care	39%
Homes w/ 3 or 4 Persons	33%
Ethnicity	
White	56%
Hispanic	24%
Black	18%
Other	2%
Legal Status	
Private Guardian	29%
Independent	64%
Other	7%
Gender	
Female	42%
Male	58%
Marital Status	
Married	1%
Singe, Never Married	95%
Other	4%
Language	
English	91%
Other	9%
Translation Services Used	
No	99%
Yes	1%
Responded to NCI Section 2	
Consumer	61%
Other	2%
Guardian	7%
Friend/Family	9%
Paid Staff	21%

Day/Vocational/Educational Support - HCS

Table 4 lists six types of vocational/employment services with the average number of hours worked and average total gross wages earned per month.

Table 4 HCS Vocational Support

Support	Average Hours at this Activity Per Month	Average Total Gross Wages Earned at this Activity Per Month
Competitive Employment Have a job of their own in the community	54	\$ 238
Individual Supported Employment Have a job with a community employer and receive periodic publicly-funded assistance	22	\$ 83
Group Supported Employment Two or more individuals employed by a community provider agency	76	\$ 127
Facility-Based Work Programs In settings such as sheltered workshops or work activity centers employed by the provider agency	80	\$ 145
Facility-Based Non-Work Activities A facility that involves the provision of training and other services and supports that are not paid work	99	n/a
Community-Based Non-Work Activities Training and assistance that enables individuals to participate in community activities away from provider-operated facilities	82	n/a

Competitive/Individual Supported Employment	Yes	No
Percent of people who worked 10 out of the last 12 months in a community job	26%	74%
Percent of people who receive benefits at his/her community job (e.g., paid vacation, sick time, health insurance)	4%	96%

Table 5 HCS Consumer Outcomes

DOMAIN Consumer Outcomes		
Consumer outcome indicators concern how well the public system aids adults with developmental disabilities to work, participate in their communities, have friends and sustain relationships, and exercise choice and self-determination. Other indicators in this domain probe how satisfied individuals are with services and supports.		
Concern	<i>People make choices about their lives and are actively engaged in planning their services and supports.</i>	
Quality Indicator(s)	The proportion of people who report having been provided options about where to: 1) live 2) work	1) 46% 2) 31%
Concern	<i>People have friends and relationships.</i>	
Quality Indicator(s)	▶ The proportion of people who have friends and caring relationships with people other than support staff and family members.	75%
	▶ The proportion of people who have a close friend, someone they can talk to about personal things.	84%
	▶ The proportion of people who are able to see their friends and families when they want: 1) friends 2) families	1) 80% 2) 79%
	▶ The proportion of people who feel lonely.	44%
Concern	<i>People are satisfied with the services and supports they receive.</i>	
Quality Indicator(s)	▶ The proportion of people who are satisfied with where they live.	95%
	▶ The proportion of people who are satisfied with their job or day program.	97%
	▶ The proportion of people who are satisfied with [life in general, personal life].	82%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 6 HCS System Performance

DOMAIN System Performance		
The system performance indicators address the following topics: (a) service coordination; (b) family and individual participation in provider-level decisions; (c) the utilization of and outlays for various types of services and supports; (d) cultural competency; and (e) access to services.		
Concern	<i>Service coordinators are accessible, responsive, and support the person's participation in service planning.</i>	
Quality Indicator(s)	▶ The proportion of people reporting that service coordinators help them get what they need.	80%
	▶ The proportion of people who know their service coordinators.	93%
	▶ The proportion of people who report that their service coordinators asked about their preferences.	78%
Concern	<i>Publicly-funded services are readily available to individuals who need and qualify for them.</i>	
Quality Indicator(s)	▶ The proportion of people reporting that they received support to learn or do something new in the past year.	86%
	▶ The proportion of people who did not receive support to learn or do new things in the past year and want help to do so.	49%
	▶ The proportion of people who report having adequate transportation when they want to go somewhere.	71%
	The rate at which people report that "needed" services were not available.	11%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 7 HCS Health, Welfare, and Rights

DOMAIN Health, Welfare and Rights		
These indicators concern the following topics: (a) safety and personal security; (b) health and wellness; and (c) protection of and respect for individual rights.		
Concern	<i>People are safe from abuse, neglect, and injury.</i>	
Quality Indicator(s)	► The proportion of people who report that they feel safe in their: 1) home 2) neighborhood	1) 76% 2) 75%
Concern	<i>People secure needed health services.</i>	
Quality Indicator(s)	The proportion of people who have had a physical exam in the past year.	93%
	The proportion of women who have had a gynecological exam in the past year.	57%
	The proportion of people who have had a routine dental exam in the past six months.	69%
Concern	<i>Medications are managed effectively and appropriately.</i>	
Quality Indicator(s)	The proportion of people taking medications for mood, anxiety, or behavior problems.	45%
Concern	<i>People receive the same respect and protections as others in the community.</i>	
Quality Indicator(s)	► The proportion of people who know their “advocate” or guardian.	87%
	The proportion of people whose basic rights are respected by others: 1) knocking before entering home 2) knocking before entering bedroom 3) reading mail (person reads own mail or gives permission to others) 4) alone with friends 5) use of phone	1) 54% 2) 83% 3) 92% 4) 88% 5) 88%
	► The proportion of people who report satisfaction with the amount of privacy they have.	87%
	► The proportion of people, who have support staff, indicating that most support staff treat them with respect: 1) home staff 2) day program staff	1) 93% 2) 95%
	The proportion of people who had the opportunity to participate in activities of self-advocacy groups or other groups that address rights.	26%
	Concern	<i>People are supported to maintain healthy habits.</i>
Quality Indicator(s)	The proportion of people who maintain healthy habits in such areas as smoking.	85%

	The proportion of people who exercise or play sports: 1) non-integrated setting 2) community setting	1) 47% 2) 31%
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Table 8 HCS Self-Determination

DOMAIN Self-Determination		
The goal of self-determination is “crafting a meaningful life deeply imbedded in one’s own community.” ¹⁰		
Concern	<i>People are able to have more choice and control over their everyday lives.</i>	
Quality Indicator(s) ¹¹	▶ Proportion of people who get to help other people.	76%
	▶ Proportion of people who are able to have a close relationship, such as a boyfriend or girlfriend, if they want one.	75%
	▶ Proportion of people who earn enough money to buy the things they want.	77%
	▶ Proportion of people who are free to take risks when they want to.	70%
	▶ Proportion of people who have control over their transportation.	52%
	▶ Proportion of people who decide who comes in and out of their home.	54%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

¹⁰ Nerney, Thomas. *The System of the Future*. Center for Self-Determination. www.self-determination.com (2004)

¹¹ The Self-Determination indicators were developed by the QA/QI Task Force and have not been validated.

Certain items from the survey tool were combined into reliable scales for the sub-domains: Community Inclusion, Choice, and Decision-Making. There are three scales and the scores are computed by averaging the values of a number of items. In order for a score to be computed, the person (or a proxy respondent) must have answered a minimum number of questions. The scales have been tested for reliability, meaning that the items are all measuring the same concept. In other words, one can be fairly confident that items are measuring the same dimension.

The percentages of people who agree with individual items are presented in the tables immediately following the scale score description. While looking at the individual items is helpful in understanding the impact of each item, the average scale scores cannot be calculated from the percentages in the table.

The sub-domain of Community Inclusion has the following concern statement: *People have support to participate in everyday community activities.* There are seven items from the survey tool that are grouped together to create the scale score for Community Inclusion.

The average scale score for people in the HCS Program on the Community Inclusion sub-domain is .77, indicating that people receiving HCS services feel somewhat included in their community. The percentages of people who agreed with each question used to create the Community Inclusion scale score is provided in Table 9.

Table 9 HCS Community Inclusion

Community Inclusion – Individual participates in	%
shopping	97%
errands/appointments	99%
entertainment	90%
eating out	93%
religious services	72%
community meetings	12%
exercise/play sports in community settings	31%

The sub-domain of Choice and Life Decisions has the following concern statement: *People make choices about their lives and are actively engaged in planning their services and supports.* There are two scales that were used for assessing choice and life decisions. One scale focuses on life decisions and the other focuses on everyday choices.

For Life Decisions, the average scale score is .75, indicating that people in HCS feel that they are somewhat engaged in planning their services and supports. The percentages of people who agreed with each question used to create the Life Decisions scale score is provided in Table 10.

Table 10 HCS Life Decisions

Life Decisions – Individual had some input in choosing	%
home without help	59%
home staff	74%
where to work	60%
staff at work	77%
their case manager	80%

The average scale score for Everyday Choices is .88, which suggests that people feel they have control over making personal choices. The percentages of people who agreed with each question used to create the Everyday Choices scale score is presented in Table 11.

Table 11 HCS Everyday Choices

Everyday Choices – Individual had some input in choosing	%
people s/he lives with	55%
their daily schedule	87%
how to spend free time	94%
what to buy with spending money	97%

*"I'm very happy at home and at center."
-J. from El Paso*

*"I'm waiting for court hearing so I can leave foster home and live with mother."
-C. from El Paso*

*"I want to save money to see my friend Kenny in New Hampshire."
-R. from Lufkin*



*"I'd like an easier process to research for modifications to personal vehicle."
-T. from Houston*

*"I would like my own apartment."
-T. Silsbee*

*"I would like to get a roommate."
-B. from Weatherford*

*"I want more company."
-B. from Carlsbad*

Texas Home Living

The Texas Home Living (TxHmL) Program provides selected essential services and supports to people with cognitive disabilities who live in their family homes or their own homes. There is no age limit and services include:

- Adaptive Aids • Respite • Day Habilitation • Dental Treatment • Nursing • Minor Home Modifications • Specialized Therapies • Supported Employment • Employment Assistance • Behavioral Support • Community Support

At the time the sample was drawn, there were 1,821 people receiving TxHmL Program services. Of those, 1,606 were 18 years of age and over. The number of valid responses for this program was 252.

Table 12 TxHmL Adult Demographics

Demographic	
Residential Type	%
Own/Family Home	98%
Foster Care	0%
Homes w/ 3 or 4 Persons	0%
Other	2%
Ethnicity	
White	39%
Hispanic	32%
Black	26%
Other	3%
Legal Status	
Private Guardian	25%
Independent	69%
Other	6%
Gender	
Female	46%
Male	54%
Marital Status	
Married	1%
Singe, Never Married	94%
Other	5%
Language	
English	90%
Other	10%
Translation Services Used	
No	96%
Yes	4%
Responded to NCI Section 2	
Consumer	59%
Other	0%
Guardian	7%
Friend/Family	29%
Paid Staff	5%

Day/Vocational/Educational Support - TxHmL

Table 13 lists six types of vocational/employment services with the average number of hours worked and average total gross wages earned per month.

Table 13 TxHmL Vocational Support

Support	Average Hours at this Activity Per Month	Average Total Gross Wages Earned at this Activity Per Month
Competitive Employment Have a job of their own in the community	50	\$ 217
Individual Supported Employment Have a job with a community employer and receive periodic publicly-funded assistance	29	\$ 183
Group Supported Employment Two or more individuals employed by a community provider agency	92	\$ 152
Facility-Based Work Programs In settings such as sheltered workshops or work activity centers employed by the provider agency	83	\$ 63
Facility-Based Non-Work Activities A provider facility and involves the provision of training and other services and supports that are not paid work	90	n/a
Community-Based Non-Work Activities Training and assistance that enables individuals to participate in community activities away from provider-operated facilities	47	n/a

Competitive/Individual Supported Employment	Yes	No
Percent of people who worked 10 out of the last 12 months in a community job	19%	81%
Percent of people who receive benefits at his/her community job (e.g., paid vacation, sick time, health insurance)	4%	96%

Table 14 TxHmL Consumer Outcomes

DOMAIN Consumer Outcomes		
<p>Consumer outcome indicators concern how well the public system aids adults with developmental disabilities to work, participate in their communities, have friends and sustain relationships, and exercise choice and self-determination. Other indicators in this domain probe how satisfied individuals are with services and supports.</p>		
Concern	<i>People make choices about their lives and are actively engaged in planning their services and supports.</i>	
Quality Indicator(s)	The proportion of people who report having been provided options about where to: 1) live 2) work	1) 42% 2) 38%
Concern	<i>People have friends and relationships.</i>	
Quality Indicator(s)	► The proportion of people who have friends and caring relationships with people other than support staff and family members.	71%
	► The proportion of people who have a close friend, someone they can talk to about personal things.	78%
	► The proportion of people who are able to see their families and friends when they want : 1) friends 2) families	1) 77% 2) 91%
	► The proportion of people who feel lonely.	48%
Concern	<i>People are satisfied with the services and supports they receive.</i>	
Quality Indicator(s)	► The proportion of people who are satisfied with where they live.	99%
	► The proportion of people who are satisfied with their job or day program.	97%
	► The proportion of people who are satisfied with [life in general, personal life].	84%

Indicators with this symbol (►) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 15 TxHmL System Performance

DOMAIN System Performance		
<p>The system performance indicators address the following topics: (a) service coordination; (b) family and individual participation in provider-level decisions; (c) the utilization of and outlays for various types of services and supports; (d) cultural competency; and (e) access to services.</p>		
Concern	<i>Service coordinators are accessible, responsive, and support the person's participation in service planning.</i>	
Quality Indicator(s)	▶ The proportion of people reporting that service coordinators help them get what they need.	75%
	▶ The proportion of people who know their service coordinators.	92%
	▶ The proportion of people who report that their service coordinators asked about their preferences.	73%
Concern	<i>Publicly-funded services are readily available to individuals who need and qualify for them.</i>	
Quality Indicator(s)	□ The proportion of people reporting that they received support to learn or do something new in the past year.	80%
	▶ The proportion of people who did not receive support to learn or do new things in the past year and want help to do so.	64%
	▶ The proportion of people who report having adequate transportation when they want to go somewhere.	66%
	The rate at which people report that "needed" services were not available.	18%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 16 TxHmL Health, Welfare, and Rights

DOMAIN Health, Welfare, and Rights		
These indicators concern the following topics: (a) safety and personal security; (b) health and wellness; and (c) protection of and respect for individual rights.		
Concern	<i>People are safe from abuse, neglect, and injury.</i>	
Quality Indicator(s)	► The proportion of people who report that they feel safe in their: 1) home 2) neighborhood	1) 74% 2) 81%
Concern	<i>People secure needed health services.</i>	
Quality Indicator(s)	The proportion of people who have had a physical exam in the past year.	58%
	The proportion of women who have had a gynecological exam in the past year.	27%
	The proportion of people who have had a routine dental exam in the past six months.	55%
Concern	<i>Medications are managed effectively and appropriately.</i>	
Quality Indicator(s)	The proportion of people taking medications for mood, anxiety, or behavior problems.	22%
Concern	<i>People receive the same respect and protections as others in the community.</i>	
Quality Indicator(s)	► The proportion of people who know their “advocate” or guardian.	90%
	The proportion of people whose basic rights are respected by others: 1) knocking before entering home 2) knocking before entering bedroom 3) reading mail (reads own mail or give permission to others) 4) alone with friends 5) use of phone	1) 60% 2) 78% 3) 94% 4) 89% 5) 94%
	► The proportion of people who report satisfaction with the amount of privacy they have.	92%
	► The proportion of people, who have support staff, indicating that most support staff treat them with respect: 1) home staff 2) day program staff	1) 89% 2) 98%
	The proportion of people who had the opportunity to participate in activities of self-advocacy groups or other groups that address rights.	21%
	Concern	<i>People are supported to maintain healthy habits.</i>
Quality Indicator(s)	The proportion of people who maintain healthy habits in such areas as smoking.	85%

	The proportion of people who exercise or play sports: 1) non-integrated setting 2) community setting	1) 41% 2) 29%
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Table 17 TxHmL Self-Determination

DOMAIN Self-Determination		
The goal of self-determination is “crafting a meaningful life deeply imbedded in one’s own community”. ¹²		
Concern	<i>People are able to have more choice and control over their everyday lives.</i>	
Quality Indicator(s) ¹³	▶ Proportion of people who get to help other people.	69%
	▶ Proportion of people who are able to have a close relationship, such as a boyfriend or girlfriend, if they want one.	77%
	▶ Proportion of people who earn enough money to buy the things they want.	71%
	▶ Proportion of people who are free to take risks when they want to.	68%
	▶ Proportion of people who have control over their transportation.	42%
	▶ Proportion of people who decide who comes in and out of their home.	60%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

¹² Nerney, Thomas. *The System of the Future*. Center for Self-Determination. www.self-determination.com (2004)

¹³ The Self-Determination indicators were developed by the QA/QI Task Force and have not been validated.

Certain items from the survey tool were combined into reliable scales for the sub-domains: Community Inclusion, Choice, and Decision-Making. There are three scales and the scores are computed by averaging the values of a number of items. In order for a score to be computed, the person (or a proxy respondent) must have answered a minimum number of questions. The scales have been tested for reliability, meaning that the items are all measuring the same concept. In other words, one can be fairly confident that items are measuring the same dimension.

The percentages of people who agree with individual items are presented in the tables immediately following the scale score description. While looking at the individual items is helpful in understanding the impact of each item, the average scale scores cannot be calculated from the percentage in the table.

The sub-domain of Community Inclusion has the following concern statement: *People have support to participate in everyday community activities.* There are seven items from the survey tool that are grouped together to create the scale score for Community Inclusion.

The average score for people in the TxHmL Program is .75, indicating that people in TxHmL feel somewhat included in their community. The percentages of people who agreed with each question used to create the Community Inclusion scale score is provided in Table 18.

Table 18 TxHmL Community Inclusion

Community Inclusion – Individual participates in	%
shopping	98%
errands/appointments	99%
entertainment	88%
eating out	95%
religious services	68%
community meetings	11%
exercise/play sports in a community setting	29%

The sub-domain of Choice and Life Decisions has the following concern statement: *People make choices about their lives and are actively engaged in planning their services and supports.* There are two scales that were used for assessing choice and life decisions. One scale focuses on life decisions and the other focuses on everyday choices.

For life decisions, the average score is .75, indicating that people in TxHmL feel that they are somewhat engaged in planning their services and supports. The percentages of people who agreed with each question used to create the Life Decisions scale score is presented in Table 19.

Table 19 TxHmL Life Decisions

Life Decisions – Individual had some input in choosing	%
home without help	74%
home staff	21%
where to work	62%
staff at work	82%
their case manager	74%

The average score for Everyday Choices is .95, which suggests that people feel they have quite a bit of control over making personal choices. The percentages of people who agreed with each question used to create the Everyday Choices scale score is presented in Table 20.

Table 20 TxHmL Everyday Choices

Everyday Choices – Individual had some input in choosing	%
people s/he lives with	87%
their daily schedule	93%
how to spend free time	97%
what to buy with spending money	96%

"I'm pleased with my program."

-J. from Beaumont

"To get services, they have to take away something that is helping. Suggest combining programs."

-S. from Beaumont



"My sister had cancer. It makes me sad."

-R. from Cleburne

"I like my friend Shannon."

-M. from Keene

"Staff needs more training in assisting clients who are having seizures."

-R. from Andrews

Intermediate Care Facilities for Persons with Mental Retardation Program

The Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) Program provides residential and habilitation services to people with cognitive disabilities and/or a related condition. Private providers, Community Mental Health and Mental Retardation (MHMR) Center providers, as well as state mental retardation facilities, provide ICF/MR services. Services include:

- Residential Services • Habilitation Services • Health Care Services • Skills Training • Comprehensive Behavioral Treatment Services • Vocational Programs • Adjunctive Therapy Services

There were 6,763 people receiving ICF/MR Program services when the sample was drawn. Of those, 6,631 were 18 years of age and over. In the final analysis, 224 responses were included.

Table 21 ICF/MR Adult Demographics

Demographic	
Residential Type	%
Small 1-8	65%
Medium 9-13	9%
Large 14+	26%
Ethnicity	
White	67%
Hispanic	13%
Black	16%
Other	4%
Legal Status	
Private Guardian	33%
Independent	53%
Other	14%
Gender	
Female	46%
Male	54%
Marital Status	
Married	0%
Singe, Never Married	98%
Other	2%
Language	
English	96%
Other	4%
Translation Services Used	
No	96%
Yes	4%
Responded to NCI Section 2	
Consumer	62%
Other	1%
Guardian	0%
Friend/Family	1%
Paid Staff	36%

Day/Vocational/Educational Support - ICF/MR

Table 22 lists six types of vocational/employment services with the average number of hours worked and average total gross wages earned per month.

Table 22 ICF/MR Vocational Support

Support	Average Hours at this Activity per month	Average Total Gross Wages earned at this activity per month
Competitive Employment Have a job of their own in the community	75	\$ 120
Individual Supported Employment Have a job with a community employer and receive periodic publicly-funded assistance	77	\$ 141
Group Supported Employment Two or more individuals employed by a community provider agency	69	\$ 49
Facility-Based Work Programs In settings such as sheltered workshops or work activity centers employed by the provider agency	98	\$ 87
Facility-Based Non-Work Activities A provider facility and involves the provision of training and other services and supports that are not paid work	136	n/a
Community-Based Non-Work Activities Training and assistance that enables individuals to participate in community activities away from provider-operated facilities	87	n/a

Competitive/Individual Supported Employment	Yes	No
Percent of people who worked 10 out of the last 12 months in a community job	27%	73%
Percent of people who receive benefits at his/her community job (e.g., paid vacation, sick time, health insurance)	7%	93%

Table 23 ICF/MR Consumer Outcomes

DOMAIN Consumer Outcomes		
Consumer outcome indicators concern how well the public system aids adults with developmental disabilities to work, participate in their communities, have friends and sustain relationships, and exercise choice and self-determination. Other indicators in this domain probe how satisfied individuals are with services and supports.		
Concern	<i>People have support to participate in everyday community activities.</i>	
Quality Indicator(s)	The proportion of people who report having been provided options about where to: 1) live 2) work	1) 31% 2) 20%
Concern	<i>People have friends and relationships.</i>	
Quality Indicator(s)	▶ The proportion of people who have friends and caring relationships with people other than support staff and family members.	72%
	▶ The proportion of people who have a close friend, someone they can talk to about personal things.	85%
	▶ The proportion of people who are able to see their friends and families when they want: 1) friends 2) families	1) 80% 2) 77%
	▶ The proportion of people who feel lonely.	52%
Concern	<i>People are satisfied with the services and supports they receive.</i>	
Quality Indicator(s)	▶ The proportion of people who are satisfied with where they live.	94%
	▶ The proportion of people who are satisfied with their job or day program.	96%
	▶ The proportion of people who are satisfied with [life in general, personal life].	84%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 24 ICF/MR System Performance

DOMAIN System Performance		
<p>The system performance indicators address the following topics: (a) service coordination; (b) family and individual participation in provider-level decisions; (c) the utilization of and outlays for various types of services and supports; (d) cultural competency; and (e) access to services.</p>		
Concern	<i>Service coordinators are accessible, responsive, and support the person's participation in service planning.</i>	
Quality Indicator(s)	▶ The proportion of people reporting that service coordinators help them get what they need.	85%
	▶ The proportion of people who know their service coordinators.	91%
	▶ The proportion of people who report that their service coordinators asked about their preferences.	78%
Concern	<i>Publicly-funded services are readily available to individuals who need and qualify for them.</i>	
Quality Indicator(s)	▶ The proportion of people reporting that they received support to learn or do something new in the past year.	91%
	▶ The proportion of people who did not receive support to learn or do new things in the past year and want help to do so.	65%
	▶ The proportion of people who report having adequate transportation when they want to go somewhere.	63%
	The rate at which people report that "needed" services were not available.	6%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 25 ICF/MR Health, Welfare, and Rights

DOMAIN Health, Welfare, and Rights		
These indicators concern the following topics: (a) safety and personal security; (b) health and wellness; and (c) protection of and respect for individual rights.		
Concern	<i>People are safe from abuse, neglect, and injury.</i>	
Quality Indicator(s)	► The proportion of people who report that they feel safe in their: 1) home 2) neighborhood	1) 73% 2) 69%
Concern	<i>People secure needed health services.</i>	
Quality Indicator(s)	The proportion of people who have had a physical exam in the past year.	95%
	The proportion of women who have had a gynecological exam in the past year.	84%
	The proportion of people who have had a routine dental exam in the past six months.	84%
Concern	<i>Medications are managed effectively and appropriately.</i>	
Quality Indicator(s)	The proportion of people taking medications for mood, anxiety, or behavior problems.	50%
Concern	<i>People receive the same respect and protections as others in the community.</i>	
Quality Indicator(s)	► The proportion of people who know their “advocate” or guardian.	75%
	The proportion of people whose basic rights are respected by others: 1) knocking before entering home 2) knocking before entering bedroom 3) reading mail (read own mail or give permission to others) 4) alone with friends 5) use of phone	1) 49% 2) 80% 3) 93% 4) 72% 5) 87%
	► The proportion of people who report satisfaction with the amount of privacy they have.	86%
	► The proportion of people, who have support staff, indicating that most support staff treat them with respect: 1) home staff 2) day program staff	1) 93% 2) 95%
	The proportion of people who had the opportunity to participate in activities of self-advocacy groups or other groups that address rights.	20%
	Concern	<i>People are supported to maintain healthy habits.</i>
Quality Indicator(s)	The proportion of people who maintain healthy habits in such areas as smoking.	89%

	The proportion of people who exercise or play sports: 1) non-integrated setting 2) community setting	1) 57% 2) 24%
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Table 26 ICF/MR Self-Determination

DOMAIN Self-Determination		
The goal of self-determination is “crafting a meaningful life deeply imbedded in one’s own community”. ¹⁴		
Concern	<i>People are able to have more choice and control over their everyday lives.</i>	
Quality Indicator(s) ¹⁵	▶ Proportion of people who get to help other people.	82%
	▶ Proportion of people who are able to have a close relationship, such as a boyfriend or girlfriend, if they want one.	84%
	▶ Proportion of people who earn enough money to buy the things they want.	77%
	▶ Proportion of people who are free to take risks when they want to.	70%
	▶ Proportion of people who have control over their transportation.	39%
	▶ Proportion of people who decide who comes in and out of their home.	49%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

¹⁴ Nerney, Thomas. *The System of the Future*. Center for Self-Determination. www.self-determination.com (2004)

¹⁵ The Self-Determination indicators were developed by the QA/QI Task Force and have not been validated.

Certain items from the survey tool were combined into reliable scales for the sub-domains: Community Inclusion, Choice, and Decision-Making. There are three scales and the scores are computed by averaging the values of a number of items. In order for a score to be computed, the person (or a proxy respondent) must have answered a minimum number of questions. The scales have been tested for reliability, meaning that the items are all measuring the same concept. In other words, one can be fairly confident that items are measuring the same dimension.

The percentages of people who agree with individual items are presented in the tables immediately following the scale score description. While looking at the individual items is helpful in understanding the impact of each item, the average scale scores cannot be calculated from the percentage in the table.

The sub-domain of Community Inclusion has the following concern statement: *People have support to participate in everyday community activities.* There are seven items from the survey tool that are grouped together to create the scale score for Community Inclusion.

The average score for people in ICFs/MR on the Community Inclusion sub-domain is .78, indicating that people receiving ICF/MR services feel somewhat included in their community. The percentage of people who agreed with each question used to create the Community Inclusion scale score is provided in Table 27.

Table 27 ICF/MR Community Inclusion

Community Inclusion – Individual participates in	%
shopping	96%
errands/appointments	98%
entertainment	92%
eating out	90%
religious services	75%
community meetings	16%
exercise/play sports in a community setting	24%

The sub-domain of Choice and Life Decisions has the following concern statement: *People make choices about their lives and are actively engaged in planning their services and supports.* Two scales were used for assessing Choice and Life Decisions. One scale focuses on life decisions and the other focuses on everyday choices.

For Life Decisions, the average score is .61, indicating that people in ICFs/MR feel they are engaged in planning their services and supports to some extent. The percentages of people who agreed with each question used to create the Life Decisions scale score is presented in Table 28.

Table 28 ICF/MR Life Decisions

Life Decisions – Individual had some input in choosing	%
home without help	48%
home staff	66%
where to work	45%
staff at work	72%
their case manager	59%

The average score for Everyday Choices is .75, which suggests that people feel they have a moderate degree of control over making personal choices. The percentages of people who agreed with each question used to create the Everyday Choice scale score is presented in Table 29.

Table 29 ICF/MR Everyday Choices

Everyday Choices – Individual had some input in choosing...	%
people s/he lives with	29%
their daily schedule	80%
how to spend free time	88%
what to buy with spending money	95%

*“If a man comes and
knocks on the door, I
don’t let him in.”*

-E. from Corpus Christi

*“I like to work and
make money and
would like to buy a
car.”*

-M. from El Paso

*“I love craft baking
and computers and
shopping.”*

-S. from Houston



*“I need assistance with
getting an accessible
computer. The process
is slow and I’ve been
waiting months.*

-J. from Nederland

*“I like my job very
much. I look forward
to going to work. I
don’t like to stay
home.”*

-R. from Pecos

*“I like to play
basketball.”*

-J. from Lufkin

State Mental Retardation Facilities

There are 13 state mental retardation facilities that provide 24-hour/day residential, treatment, and training services for persons with mental retardation/intellectual disability. Each facility is certified as an Intermediate Care Facility for Persons with Mental Retardation (ICF/MR), a Medicaid-funded federal/state service program. Residential services in a state mental retardation facility are intended to serve individuals with severe or profound mental retardation/intellectual disability and those who are medically fragile or have behavioral problems. Services include:

- 24-hour Residential Care and Support
- Comprehensive Behavioral Treatment Services
- Comprehensive Health Care Services
- Occupational, Physical, Speech Therapies
- Skills Training
- Vocational Programs
- Services to maintain connections between residents and families/natural support systems

At the time the sample was drawn, there were 4,840 people receiving services. Of those, 4,756 were 18 years of age or older. For this program, 86 responses were used in the final analysis.

Table 30 STATE MENTAL RETARDATION FACILITY Adult Demographics

Demographic	
Residential Type	%
Own/Family Home	0%
Other	100%
Ethnicity	
White	64%
Hispanic	22%
Black	13%
Other	1%
Legal Status	
Private Guardian	44%
Independent	52%
Other	4%
Gender	
Female	38%
Male	62%
Marital Status	
Married	0%
Single, Never Married	99%
Other	1%
Language	
English	91%
Other	9%
Translation Services Used	
No	99%
Yes	1%
Responded to NCI Section 2	
Consumer	22%
Other	0%
Guardian	0%
Friend/Family	0%
Paid Staff	78%

Day/Vocational/Educational Support – STATE MENTAL RETARDATION FACILITY

Table 31 lists six types of vocational/employment services with the average number of hours worked and average total gross wages earned per month.

Table 31 STATE MENTAL RETARDATION FACILITY Vocational Support

Support	Average Hours at this Activity Per Month	Average Total Gross Wages Earned at this Activity Per Month
Competitive Employment Have a job of their own in the community	n/a	n/a
Individual Supported Employment Have a job with a community employer and receive periodic publicly-funded assistance	87	\$ 55
Group Supported Employment Two or more individuals employed by a community provider agency	24	\$ 55
Facility-Based Work Programs In settings such as sheltered workshops or work activity centers employed by the provider agency	74	\$ 129
Facility-Based Non-Work Activities A provider facility and involves the provision of training and other services and supports that are not paid work	155	n/a
Community-Based Non-Work Activities Training and assistance that enables individuals to participate in community activities away from provider-operated facilities	6	n/a

Competitive/Individual Supported Employment	Yes	No
Percent of people who worked 10 out of the last 12 months in a community job	16%	84%
Percent of people who receive benefits at his/her community job (e.g., paid vacation, sick time, health insurance)	4%	96%

Table 32 STATE MENTAL RETARDATION FACILITY Consumer Outcomes

DOMAIN Consumer Outcomes		
<p>Consumer outcome indicators concern how well the public system aids adults with developmental disabilities to work, participate in their communities, have friends and sustain relationships, and exercise choice and self-determination. Other indicators in this domain probe how satisfied individuals are with services and supports.</p>		
Concern	<i>People have support to participate in everyday community activities.</i>	
Quality Indicator(s)	The proportion of people who report having been provided options about where to: 1) live 2) work	1) 31% 2) 31%
Concern	<i>People have friends and relationships.</i>	
Quality Indicator(s)	▶ The proportion of people who have friends and caring relationships with people other than support staff and family members.	81%
	▶ The proportion of people who have a close friend, someone they can talk to about personal things.	83%
	▶ The proportion of people who are able to see their friends and families when they want: 1) friends 2) families	1) 84% 2) 73%
	▶ The proportion of people who feel lonely.	52%
Concern	<i>People are satisfied with the services and supports they receive.</i>	
Quality Indicator(s)	▶ The proportion of people who are satisfied with where they live.	76%
	▶ The proportion of people who are satisfied with their job or day program.	92%
	▶ The proportion of people who are satisfied with [life in general, personal life].	83%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 33 STATE MENTAL RETARDATION FACILITY System Performance

DOMAIN System Performance		
<p>The system performance indicators address the following topics: (a) service coordination; (b) family and individual participation in provider-level decisions; (c) the utilization of and outlays for various types of services and supports; (d) cultural competency; and (e) access to services.</p>		
Concern	<i>Service coordinators are accessible, responsive, and support the person's participation in service planning.</i>	
Quality Indicator(s)	▶ The proportion of people reporting that service coordinators help them get what they need.	83%
	▶ The proportion of people who know their service coordinators.	94%
	▶ The proportion of people who report that their service coordinators asked about their preferences.	79%
Concern	<i>Publicly-funded services are readily available to individuals who need and qualify for them.</i>	
Quality Indicator(s)	▶ The proportion of people reporting that they received support to learn or do something new in the past year.	81%
	▶ The proportion of people who did not receive support to learn or do new things in the past year and want help to do so.	45%
	▶ The proportion of people who report having adequate transportation when they want to go somewhere.	38%
	The rate at which people report that "needed" services were not available.	11%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 34 STATE MENTAL RETARDATION FACILITY Health, Welfare, and Rights

DOMAIN Health, Welfare, and Rights		
These indicators concern the following topics: (a) safety and personal security; (b) health and wellness; and (c) protection of and respect for individual rights.		
Concern	<i>People are safe from abuse, neglect, and injury.</i>	
Quality Indicator(s)	► The proportion of people who report that they feel safe in their: 1) home 2) neighborhood	1) 61% 2) 67%
Concern	<i>People secure needed health services.</i>	
Quality Indicator(s)	The proportion of people who have had a physical exam in the past year.	94%
	The proportion of women who have had a gynecological exam in the past year.	77%
	The proportion of people who have had a routine dental exam in the past six months.	83%
Concern	<i>Medications are managed effectively and appropriately.</i>	
Quality Indicator(s)	The proportion of people taking medications for mood, anxiety, or behavior problems.	65%
Concern	<i>People receive the same respect and protections as others in the community.</i>	
Quality Indicator(s)	► The proportion of people who know their “advocate” or guardian.	74%
	The proportion of people whose basic rights are respected by others: 1) knocking before entering home 2) knocking before entering bedroom 3) reading mail (reads own mail or gives permission) 4) alone with friends 5) use of phone	1) 51% 2) 80% 3) 94% 4) 77% 5) 89%
	► The proportion of people who report satisfaction with the amount of privacy they have.	84%
	► The proportion of people, who have support staff, indicating that most support staff treat them with respect: 1) home staff 2) day program staff	1) 91% 2) 89%
	The proportion of people who had the opportunity to participate in activities of self-advocacy groups or other groups that address rights.	51%
	Concern	<i>People are supported to maintain healthy habits.</i>
Quality Indicator(s)	The proportion of people who maintain healthy habits in such areas as smoking.	72%

	The proportion of people who exercise or play sports: 1) non-integrated setting 2) community setting	1) 77% 2) 7%
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Table 35 STATE MENTAL RETARDATION FACILITY Self-Determination

DOMAIN Self-Determination		
The goal of self-determination is “crafting a meaningful life deeply imbedded in one’s own community”. ¹⁶		
Concern	<i>People are able to have more choice and control over their everyday lives.</i>	
Quality Indicator(s) ¹⁷	▶ Proportion of people who get to help other people.	83%
	▶ Proportion of people who are able to have a close relationship, such as a boyfriend or girlfriend, if they want one.	81%
	▶ Proportion of people who earn enough money to buy the things they want.	72%
	▶ Proportion of people who are free to take risks when they want to.	67%
	▶ Proportion of people who have control over their transportation.	23%
	▶ Proportion of people who decide who comes in and out of their home.	51%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

¹⁶ Nerney, Thomas. *The System of the Future*. Center for Self-Determination. www.self-determination.com (2004)

¹⁷ The Self-Determination indicators were developed by the QA/QI Task Force and have not been validated.

Certain items from the survey tool were combined into reliable scales for the sub-domains: Community Inclusion, Choice, and Decision-Making. There are three scales and the scores are computed by averaging the values of a number of items. In order for a score to be computed, the person (or a proxy respondent) must have answered a minimum number of questions. The scales have been tested for reliability, meaning that the items are all measuring the same concept. In other words, one can be fairly confident that items are measuring the same dimension.

The percentages of people who agree with individual items are presented in the tables immediately following the scale score description. While looking at the individual items is helpful in understanding the impact of each item, the average scale scores cannot be calculated from the percentage in the table.

The sub-domain of Community Inclusion has the following concern statement: *People have support to participate in everyday community activities.* There are seven items from the survey tool that are grouped together to create the scale score for Community Inclusion.

The average score for people in state mental retardation facilities on the Community Inclusion sub-domain is .75, indicating that people receiving state mental retardation facility services feel somewhat included in their community. The percentage of people who agreed with each question used to create the Community Inclusion scale score is provided in Table 36.

Table 36 STATE MENTAL RETARDATION FACILITY Community Inclusion

Community Inclusion – Individual participates in	%
shopping	93%
errands/appointments	94%
entertainment	93%
eating out	86%
religious services	81%
community meetings	7%
exercise/play sports in a community setting	7%

The sub-domain of Choice and Life Decisions has the following concern statement: *People make choices about their lives and are actively engaged in planning their services and supports.* There are two scales were used for assessing Choice and Life decisions. One scale focuses on life decisions and the other focuses on everyday choices.

For Life Decisions, the average score is .58, indicating that people in state mental retardation facilities feel they are engaged in planning their services and supports to some extent. The percentages of people who agreed with each question used to create the Life Decisions scale score is presented in Table 37.

Table 37 STATE MENTAL RETARDATION FACILITY Life Decisions

Life Decisions – Individual at least had input in choosing	%
home without help	31%
home staff	64%
where to work	50%
staff at work	74%
their case manager	65%

The average score for Everyday Choices is .70, which suggests that people feel they have a moderate degree of control over making personal choices. The percentages of people who agreed with each question used to create the Everyday Choice scale score is provided in Table 38.

Table 38 STATE MENTAL RETARDATION FACILITY Everyday Choices

Everyday Choices – Individual at least had input in choosing	%
people s/he lives with	19%
their daily schedule	70%
how to spend free time	87%
what to buy with spending money	95%

STATE MENTAL RETARDATION FACILITY and ICF/MR Comparisons

Independent sample t-tests were also conducted to test for significant differences between results of people receiving services in state mental retardation facilities and people receiving services in ICF/MR facilities. Listed in Table 39 are the items that were significantly different ($p < 0.01$). Some of the items are taken from the pre-survey section which includes demographic data and was provided by service providers. The list is sorted in the order in which they appear on the survey tool.

Table 39 STATE MENTAL RETARDATION FACILITY and ICF/MR Comparisons

Question Number	Difference
S1	More people receiving services in ICF/MR facilities tended to be competitively employed.
S4	More people receiving services in state mental retardation facilities tended to be employed in facility-based work programs.
S4.a	Of people employed in facility-based work programs, people receiving services in ICF/MR facilities tended to work more hours.
S6	More people receiving services in ICF/MR facilities tended to be involved in community-based non-work activities.
BI.18	People receiving services in ICF/MR facilities seem to require medical care less often.
BI.23	Fewer people receiving services in ICF/MR facilities appear to smoke or chew tobacco.
BI.37	Fewer people receiving services in ICF/MR facilities appear to need support to help prevent self-injury.
BI.38	Fewer people receiving services in ICF/MR facilities appear to need support to help prevent disruptive behavior.
3	People receiving services in ICF/MR facilities were more likely to like where they live.
11	People receiving services in state mental retardation facilities were more likely to have friends that were not staff or family members.
22	People receiving services in ICF/MR facilities were more likely report that they almost always have a way to get to places they need to go.
24e	More people receiving services in ICF/MR facilities feel that they have control over their transportation at least sometimes.
33	More people receiving services in ICF/MR facilities tend to go to meetings in the community.
34	More people receiving services in ICF/MR facilities tend to exercise or play sports in a community setting.
35	More people receiving services in ICF/MR facilities tended to have at least some input in choosing where they live.
49	More people receiving services in state mental retardation facilities tended to have the opportunity to participate in a self-advocacy group meeting, conference, or event, where available.

"I like this apartment."

-G. from Temple

*"I hope my provider Diane,
will not be changed."*

-J. from El Paso

*"I wash my own clothes
everyday."*

-C. from Pasadena



"I love my friends."

-H. from Corsicana

"I'm very happy with my life."

-B. from Houston

"I like to fish."

-P. from Cleburne

Community Living Assistance and Support Services

The Community Living Assistance and Support Services (CLASS) Program provides home and community-based services to adults and children with related conditions as a cost effective alternative to Intermediate Care Facilities for Mental Retardation (ICF/MR) institutional placement. People with related conditions have a qualifying disability, other than mental retardation, which originated before age 22 that affects their ability to function in daily life. Services include:

Case Management • Adaptive Aids • Consumer Directed Services • Respite • Habilitation • Dental Treatment • Nursing • Minor Home Modifications • Counseling and Therapies

There were 1,814 people receiving CLASS Program services at the time the interviews occurred. Of those, 1,188 were age 18 years of age and over. In the final analysis, 198 responses were analyzed.

Table 40 CLASS Adult Demographics

Demographic	
Residential Type	%
Own/Family Home	98%
Other	2%
Ethnicity	
White	59%
Hispanic	27%
Black	9%
Other	5%
Legal Status	
Private Guardian	34%
Independent	61%
Other	5%
Gender	
Female	47%
Male	53%
Marital Status	
Married	5%
Single, Never Married	93%
Other	2%
Language	
English	93%
Other	7%
Translation Services Used	
No	98%
Yes	2%
Responded to NCI Section 2	
Consumer	62%
Other	1%
Guardian	12%
Friend/Family	22%
Paid Staff	3%

Day/Vocational/Educational Support for CLASS

Table 41 lists six types of vocational/employment services with the average number of hours worked and average total gross wages earned per month.

Table 41 CLASS Vocational Support

Support	Average Hours at this Activity Per Month	Average Total Gross Wages Earned at this Activity Per Month
Competitive Employment Have a job of their own in the community	112	\$ 1105
Individual Supported Employment Have a job with a community employer and receive periodic publicly-funded assistance	32	\$ 150
Group Supported Employment Two or more individuals employed by a community provider agency	n/a	n/a
Facility-Based Work Programs In settings such as sheltered workshops or work activity centers employed by the provider agency	80	n/a
Facility-Based Non-Work Activities A provider facility and involves the provision of training and other services and supports that are not paid work	n/a	n/a
Community-Based Non-Work Activities Training and assistance that enables individuals to participate in community activities away from provider-operated facilities	120	n/a

Competitive/Individual Supported Employment	Yes	No
Percent of people who worked 10 of the last 12 months in a community job	22%	78%
Percent of people who receive benefits at his/her community job (e.g., paid vacation, sick time, health insurance)	10%	90%

Table 42 CLASS Consumer Outcomes

DOMAIN Consumer Outcomes		
Consumer outcome indicators concern how well the public system aids adults with developmental disabilities to work, participate in their communities, have friends and sustain relationships, and exercise choice and self-determination. Other indicators in this domain probe how satisfied individuals are with services and supports.		
Concern	<i>People make choices about their lives and are actively engaged in planning their services and supports.</i>	
Quality Indicator(s)	The proportion of people who report having been provided options about where to: 1) live 2) work	1) 56% 2) 46%
Concern	<i>People have authority and are supported to direct and manage their own services.</i>	
Quality Indicator(s)	The proportion of people who control their own budgets.	73%
Concern	<i>People have friends and relationships.</i>	
Quality Indicator(s)	► The proportion of people who have friends and caring relationships with people other than support staff and family members.	71%
	► The proportion of people who have a close friend, someone they can talk to about personal things.	78%
	► The proportion of people who are able to see their friends and families when they want: 1) friends 2) families	1) 80% 2) 88%
	► The proportion of people who feel lonely.	48%
Concern	<i>People are satisfied with the services and supports they receive.</i>	
Quality Indicator(s)	► The proportion of people who are satisfied with where they live.	99%
	► The proportion of people who are satisfied with their job or day program.	100%
	► The proportion of people who are satisfied with [life in general, personal life].	74%

Indicators with this symbol (►) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 43 CLASS System Performance

DOMAIN System Performance		
<p>The system performance indicators address the following topics: (a) service coordination; (b) family and individual participation in provider-level decisions; (c) the utilization of and outlays for various types of services and supports; (d) cultural competency; and (e) access to services.</p>		
Concern	<i>Service coordinators are accessible, responsive, and support the person's participation in service planning.</i>	
Quality Indicator(s)	▶ The proportion of people reporting that service coordinators help them get what they need.	87%
	▶ The proportion of people who know their service coordinators.	92%
	▶ The proportion of people who report that their service coordinators asked about their preferences.	87%
Concern	<i>Publicly-funded services are readily available to individuals who need and qualify for them.</i>	
Quality Indicator(s)	▶ The proportion of people reporting that they received support to learn or do something new in the past year.	86%
	▶ The proportion of people who did not receive support to learn or do new things in the past year and want help to do so.	59%
	▶ The proportion of people who report having adequate transportation when they want to go somewhere.	75%
	The rate at which people report that "needed" services were not available.	15%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 44 CLASS Health, Welfare, and Rights

DOMAIN Health, Welfare, and Rights

These indicators concern the following topics: (a) safety and personal security; (b) health and wellness; and (c) protection of and respect for individual rights.

Concern	<i>People are safe from abuse, neglect, and injury.</i>	
Quality Indicator(s)	<ul style="list-style-type: none"> ▶ The proportion of people who report that they feel safe in their: 1) home 2) neighborhood 	<ul style="list-style-type: none"> 1) 74% 2) 83%
Concern	<i>People secure needed health services.</i>	
Quality Indicator(s)	The proportion of people who have had a physical exam in the past year.	57%
	The proportion of women who have had a gynecological exam in the past year.	14%
	The proportion of people who have had a routine dental exam in the past six months.	17%
Concern	<i>Medications are managed effectively and appropriately.</i>	
Quality Indicator(s)	The proportion of people taking medications for mood, anxiety, or behavior problems.	16%
Concern	<i>People receive the same respect and protections as others in the community.</i>	
Quality Indicator(s)	▶ The proportion of people who know their “advocate” or guardian.	94%
	The proportion of people whose basic rights are respected by others:	
	1) knocking before entering home	1) 69%
	2) knocking before entering bedroom	2) 81%
	3) read mail (reads own mail or gives permission to others)	3) 95%
	4) alone with friends	4) 94%
5) use of phone	5) 96%	
▶ The proportion of people who report satisfaction with the amount of privacy they have.	96%	
The proportion of people, who have support staff, indicating that most support staff treat them with respect:		
1) home staff	1) 98%	
2) day program staff	2) 96%	
The proportion of people who had the opportunity to participate in activities of self-advocacy groups or other groups that address rights.	34%	
Concern	<i>People are supported to maintain healthy habits.</i>	
Quality Indicator(s)	The proportion of people who maintain healthy habits in such areas as smoking.	81%

	The proportion of people who exercise or play sports: 1) non-integrated setting 2) community setting	1) 42% 2) 22%
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Table 45 CLASS Self-Determination

DOMAIN Self-Determination		
The goal of self-determination is “crafting a meaningful life deeply imbedded in one’s own community”. ¹⁸		
Concern	<i>People are able to have more choice and control over their everyday lives.</i>	
Quality Indicator(s) ¹⁹	▶ Proportion of people who get to help other people.	72%
	▶ Proportion of people who are able to have a close relationship, such as a boyfriend or girlfriend, if they want one.	77%
	▶ Proportion of people who earn enough money to buy the things they want.	62%
	▶ Proportion of people who are free to take risks when they want to.	77%
	▶ Proportion of people who have control over their transportation.	58%
	▶ Proportion of people who decide who comes in and out of their home.	69%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

¹⁸ Nerney, Thomas. *The System of the Future*. Center for Self-Determination. www.self-determination.com (2004)

¹⁹ The Self-Determination indicators were developed by the QA/QI Task Force and have not been validated.

Certain items from the survey tool were combined into reliable scales for the sub-domains: Community Inclusion, Choice, and Decision-Making. There are three scales and the scores are computed by averaging the values of a number of items. In order for a score to be computed, the person (or a proxy respondent) must have answered a minimum number of questions. The scales have been tested for reliability, meaning that the items are all measuring the same concept. In other words, one can be fairly confident that items are measuring the same dimension.

The percentages of people who agree with individual items are presented in the tables immediately following the scale score description. While looking at the individual items is helpful in understanding the impact of each item, the average scale scores cannot be calculated from the percentage in the table.

The sub-domain of Community Inclusion has the following concern statement: *People have support to participate in everyday community activities.* There are seven items from the survey tool that are grouped together to create the scale score for Community Inclusion.

The average score for people in the CLASS program on the Community Inclusion sub-domain is .76, indicating that people receiving CLASS services feel somewhat included in their community. The percentage of people who agreed with each question used to create the Community Inclusion scale score is provided in Table 46.

Table 46 CLASS Community Inclusion

Community Inclusion – Individual participates in...	%
shopping	95%
errands/appointments	99%
entertainment	86%
eating out	90%
religious services	66%
community meetings	33%
exercise/play sports in a community setting	22%

The sub-domain of Choice and Life Decisions has the following concern statement: *People make choices about their lives and are actively engaged in planning their services and supports.* There are two scales that were used for assessing Choice and Life Decisions. One scale focuses on life decisions and the other focuses on everyday choices.

For Life Decisions, the average score is .84, indicating that people in the CLASS program feel they are engaged in planning their services and support. The percentages of people who agreed with each question used to create the Life Decisions scale score is presented in Table 47.

Table 47 CLASS Life Decisions

Life Decisions – Individual had some input in choosing	%
home without help	83%
home staff	74%
where to work	81%
staff at work	80%
their case manager	81%

The average score for Everyday Choices is .95, which suggests that people feel they have quite a bit of control over making personal choices. The percentages of people who agreed with each question used to create the Everyday Choices scale score is presented in Table 48.

Table 48 CLASS Everyday Choices

Everyday Choices – Individual at least had input in choosing	%
people s/he lives with	94%
their daily schedule	94%
how to spend free time	95%
what to buy with spending money	96%

*"I would like to get
more social security."
-W. from Kermit*

*"We need better
transportation. No Metro
available in area."
-T. from Houston*

*"My case manager does a good
job."
-C. from Houston*



*"I have a good support group."
-J. from Del Valle*

*"I want to live independently
and want to learn the bus
system to be more independent."
-L. from Austin*

*"I'm going to be happy
and not afraid."
-J from Glen Rose*

Community Living Assistance and Support Services – Consumer Directed Services

Consumer Directed Services (CDS) is a service delivery option that gives control to the consumer over their habilitation and respite services. As the employer, the consumer hires and manages their attendants and hires a CDS agency to process the payroll and federal and state taxes.

At the time the sample was drawn, there were 1,814 people receiving Community Living Assistance and Support Services (CLASS) Program services. Of those, 1,188 were age 18 years of age and over. There were 386 people were using the CDS option. Of the 386 people using the option, 151 responses were included.

Table 49 CLASS-CDS Adult Demographics

Demographic	
Residential Type	%
Own/Family Home	97%
Other	3%
Ethnicity	
White	72%
Hispanic	14%
Black	11%
Other	3%
Legal Status	
Private Guardian	20%
Independent	77%
Other	3%
Gender	
Female	46%
Male	54%
Marital Status	
Married	7%
Singe, Never Married	86%
Other	7%
Language	
English	96%
Other	4%
Translation Services Used	
No	98%
Yes	2%
Responded to NCI Section 2	
Consumer	66%
Other	0%
Guardian	18%
Friend/Family	14%
Paid Staff	2%

Day/Vocational/Educational Support - CLASS-CDS

Table 50 lists six types of vocational/employment services with the average number of hours worked and average total gross wages earned per month.

Table 50 CLASS-CDS Vocational Support

Support	Average Hours at this Activity Per Month	Average Total Gross Wages Earned at this Activity Per Month
Competitive Employment Have a job of their own in the community	133	n/a
Individual Supported Employment Have a job with a community employer and receive periodic publicly-funded assistance	80	\$ 88
Group Supported Employment Two or more individuals employed by a community provider agency	160	n/a
Facility-Based Work Programs In settings such as sheltered workshops or work activity centers employed by the provider agency	n/a	n/a
Facility-Based Non-Work Activities A provider facility and involves the provision of training and other services and supports that are not paid work	192	n/a
Community-Based Non-Work Activities Training and assistance that enables individuals to participate in community activities away from provider-operated facilities	88	n/a

Competitive/Individual Supported Employment	Yes	No
Percent of people who worked 10 out of the last 12 months in a community job	25%	75%
Percent of people who receive benefits at his/her community job (e.g., paid vacation, sick time, health insurance)	7%	93%

Table 51 CLASS-CDS Consumer Outcomes

DOMAIN Consumer Outcomes		
Consumer outcome indicators concern how well the public system aids adults with developmental disabilities to work, participate in their communities, have friends and sustain relationships, and exercise choice and self-determination. Other indicators in this domain probe how satisfied individuals are with services and supports.		
Concern	<i>People make choice about their lives and are actively engaged in planning their services and supports.</i>	
Quality Indicator(s)	The proportion of people who report having been provided options about where to: 1) live 2) work	1) 62% 2) 52%
Concern	<i>People have authority and are supported to direct and manage their own services.</i>	
Quality Indicator(s)	The proportion of people who control their own budgets.	73%
Concern	<i>People have friends and relationships.</i>	
Quality Indicator(s)	▶ The proportion of people who have friends and caring relationships with people other than support staff and family members.	82%
	▶ The proportion of people who have a close friend, someone they can talk to about personal things.	85%
	▶ The proportion of people who are able to see their friends and families when they want: 1) friends 2) families	1) 81% 2) 92%
	▶ The proportion of people who feel lonely.	34%
Concern	<i>People are satisfied with the services and supports they receive.</i>	
Quality Indicator(s)	▶ The proportion of people who are satisfied with where they live.	96%
	▶ The proportion of people who are satisfied with their job or day program.	96%
	▶ The proportion of people who are satisfied with [life in general, personal life].	86%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 52 CLASS-CDS System Performance

DOMAIN		System Performance	
<p>The system performance indicators address the following topics: (a) service coordination; (b) family and individual participation in provider-level decisions; (c) the utilization of and outlays for various types of services and supports; (d) cultural competency; and (e) access to services.</p>			
Concern	<i>Service coordinators are accessible, responsive, and support the person's participation in service planning.</i>		
Quality Indicator(s)	▶ The proportion of people reporting that service coordinators help them get what they need.		93%
	▶ The proportion of people who know their service coordinators.		99%
	▶ The proportion of people who report that their service coordinators asked about their preferences.		92%
Concern	<i>Publicly-funded services are readily available to individuals who need and qualify for them.</i>		
Quality Indicator(s)	▶ The proportion of people reporting that they received support to learn or do something new in the past year.		83%
	▶ The proportion of people who did not receive support to learn or do new things in the past year and want help to do so.		51%
	▶ The proportion of people who report having adequate transportation when they want to go somewhere.		73%
	The rate at which people report that "needed" services were not available.		22%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 53 CLASS-CDS Health, Welfare, and Rights

DOMAIN Health, Welfare, and Rights

These indicators concern the following topics: (a) safety and personal security; (b) health and wellness; and (c) protection of and respect for individual rights.

Concern	<i>People are safe from abuse, neglect, and injury.</i>	
Quality Indicator(s)	<ul style="list-style-type: none"> ▶ The proportion of people who report that they feel safe in their: <ul style="list-style-type: none"> 1) home 2) neighborhood 	<ul style="list-style-type: none"> 1) 92% 2) 83%
Concern	<i>People secure needed health services.</i>	
Quality Indicator(s)	The proportion of people who have had a physical exam in the past year.	60%
	The proportion of women who have had a gynecological exam in the past year.	21%
	The proportion of people who have had a routine dental exam in the past six months.	17%
Concern	<i>Medications are managed effectively and appropriately.</i>	
Quality Indicator(s)	The proportion of people taking medications for mood, anxiety, or behavior problems.	9%
Concern	<i>People receive the same respect and protections as others in the community.</i>	
Quality Indicator(s)	▶ The proportion of people who know their “advocate” or guardian.	96%
	The proportion of people whose basic rights are respected by others: <ul style="list-style-type: none"> 1) knocking before entering home 2) knocking before entering bedroom 3) read mail (reads own mail or gives others permission) 4) alone with friends 5) use of phone 	<ul style="list-style-type: none"> 1) 75% 2) 86% 3) 94% 4) 98% 5) 98%
	▶ The proportion of people who report satisfaction with the amount of privacy they have.	89%
	▶ The proportion of people, who have support staff, indicating that most support staff treat them with respect: <ul style="list-style-type: none"> 1) home staff 2) day program staff 	<ul style="list-style-type: none"> 1) 98% 2) 100%
	The proportion of people who had the opportunity to participate in activities of self-advocacy groups or other groups that address rights.	41%
Concern	<i>People are supported to maintain healthy habits.</i>	
Quality Indicator(s)	The proportion of people who maintain healthy habits in such areas as smoking.	87%

	The proportion of people who exercise or play sports: 1) non-integrated setting 2) community setting	1) 51% 2) 21%
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Table 54 CLASS-CDS Self-Determination

DOMAIN Self-Determination		
The goal of self-determination is “crafting a meaningful life deeply imbedded in one’s own community”. ²⁰		
Concern	<i>People are able to have more choice and control over their everyday lives.</i>	
Quality Indicator(s) ²¹	▶ Proportion of people who get to help other people.	80%
	▶ Proportion of people who are able to have a close relationship, such as a boyfriend or girlfriend, if they want one.	82%
	▶ Proportion of people who earn enough money to buy the things they want.	56%
	▶ Proportion of people who are free to take risks when they want to.	80%
	▶ Proportion of people who have control over their transportation.	70%
	▶ Proportion of people who decide who comes in and out of their home.	76%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

²⁰ Nerney, Thomas. *The System of the Future*. Center for Self-Determination. www.self-determination.com (2004)

²¹ The Self-Determination indicators were developed by the QA/QI Task Force and have not been validated.

Certain items from the survey tool were combined into reliable scales for the sub-domains: Community Inclusion, Choice, and Decision-Making. There are three scales and the scores are computed by averaging the values of a number of items. In order for a score to be computed, the person (or a proxy respondent) must have answered a minimum number of questions. The scales have been tested for reliability, meaning that the items are all measuring the same concept. In other words, one can be fairly confident that items are measuring the same dimension.

The percentages of people who agree with individual items are presented in the tables immediately following the scale score description. While looking at the individual items is helpful in understanding the impact of each item, the average scale scores cannot be calculated from the percentage in the table.

The sub-domain of Community Inclusion has the following concern statement: *People have support to participate in everyday community activities.* There are seven items from the survey tool that are grouped together to create the scale score for Community Inclusion.

The average score for people in the CLASS on the Community Inclusion sub-domain is .79, indicating that people receiving CLASS services who use the CDS option feel somewhat included in their community. The percentage of people who agreed with each question used to create the Community Inclusion scale score is provided in Table 55.

Table 55 CLASS-CDS Community Inclusion

Community Inclusion – Individual participates in	%
shopping	97%
errands/appointments	99%
entertainment	93%
eating out	95%
religious services	74%
community meetings	28%
exercise/play sports in a community setting	21%

The sub-domain of Choice and Life Decisions has the following concern statement: *People make choices about their lives and are actively engaged in planning their services and supports.* There are two scales that were used for assessing Choice and Life Decisions. One scale focuses on life decisions and the other focuses on everyday choices.

For Life Decisions, the average score is .92, indicating that people in the CLASS Program who use the CDS option feel they are engaged in planning their services and supports to some extent. The percentages of people who agreed with each question used to create the Life Decisions scale score is presented in Table 56.

Table 56 CLASS-CDS Life Decisions

Life Decisions – Individual had some input in choosing	%
home without help	88%
home staff	87%
where to work	89%
staff at work	96%
their case manager	93%

The average score for everyday choices is .98, which suggests that people feel they have a lot of control over making personal choices. The percentages of people who agreed with each question used to create the Everyday Choices scale score is presented in Table 57.

Table 57 CLASS-CDS Everyday Choices

Everyday Choices – Individual at least had input in choosing	%
people s/he lives with	94%
their daily schedule	97%
how to spend free time	97%
what to buy with spending money	99%

CLASS Service Options Comparisons

In addition to calculating indicators for each program, independent sample *t*-tests were conducted to test for significant differences between results of people receiving CLASS using the CDS option and people receiving CLASS that do not. Listed in Table 58 are the items that were significantly different ($p < 0.01$). Some of the items are taken from the pre-survey section, which includes demographic data and was provided by service providers. The list is sorted in the order in which they appear on the survey tool.

Table 58 CLASS Service Options Comparisons

Question Number	Difference
BI.7	People using CDS are less likely to have a guardian appointed or have guardianship to a lesser degree.
BI.12	People using CDS are more likely to have English as their primary language.
BI.18	People using CDS seem to require medical care less often.
BI.38	More people who do not use the CDS option appear to need support to prevent disruptive behavior.
5	More people who do not use the CDS option say that they feel afraid at home at least sometimes.
13	More people who do not use the CDS option say that they feel lonely at least sometimes.
15	More people who use the CDS option are more likely to know their case manager.
21	People who use the CDS option report feeling more satisfied with their personal lives.
23	People who use the CDS option are more likely to know how much money is spent paying for their staff.
24e	People who use the CDS option feel that they have control over their transportation more often.
44	People who use the CDS option tend to have more control over what they buy with their spending money.
45	People who use the CDS option tend to have more input in choosing their case manager/service coordinator.

"I'd like to be in my own apartment."

-A. from Lubbock

"I would like to transfer to a group home."

-C. from Corpus Christi

"I'm ready to move to another home."

-N. from Wichita Falls



"Need a car for our house. All other three group homes have a car be we don't."

-R. from Texarkana

"Pretty much pleased with the way things are going."

-R. from Fort Worth

"I'm Ok so far."

-A. from Amarillo

Deaf-Blind with Multiple Disabilities (DBMD)

This Medicaid waiver program provides home and community-based services (HCS) to people who are 18 years of age or older and who are Deaf-Blind with Multiple Disabilities (DBMD) as a cost-effective alternative to Intermediate Care Facilities for Mental Retardation (ICF/MR) institutional placement. The DBMD program focuses on increasing opportunities for people to communicate and interact with their environment. Program services are provided to people who live in their own or family homes or community-based small group homes with no more than six people. Services include:

Case Management • Assisted Living (up to 6 people) • Adaptive Aids • Consumer Directed Services • Respite • Habilitation • Nursing • Minor Home Modifications • Therapies • Prescription Drugs • Behavior Communication Services • Chore Provider • Environmental Accessibility • Intervener • Orientation and Mobility

At the time the sample was drawn, there were 133 people age 18 or over receiving DBMD Program services. Twenty-seven interviewee responses were included in the final analysis.

Table 59 DBMD Adult Demographics

Demographic	
Residential Type	
Apartment or Shared Housing	90%
Parents	9%
Residential	1%
Ethnicity	
White	70%
Hispanic	11%
Black	17%
Other	2%
Legal Status	
Private Guardian	50%
Independent	33%
Other	17%
Gender	
Female	35%
Male	65%
Marital Status	
Married	0%
Single, Never Married	100%
Language	
English	69%
Other	31%
Translation Services Used	
No	55%
Yes	45%
Responded to NCI Section 2	
Consumer	14%
Other	0%
Guardian	10%
Friend/Family	14%
Paid Staff	62%

Day/Vocational/Educational Support - DBMD

Table 60 lists six types of vocational/employment services with the average number of hours worked and average total gross wages earned per month.

Table 60 DBMD Vocational Support

Support	Average Hours at this Activity Per Month	Average Total Gross Wages earned at this Activity Per Month
Competitive Employment Have a job of their own in the community	25	\$ 40
Individual Supported Employment Have a job with a community employer and receive periodic publicly-funded assistance	31	n/a
Group Supported Employment Two or more individuals employed by a community provider agency	38	\$ 40
Facility-Based Work Programs In settings such as sheltered workshops or work activity centers employed by the provider agency	n/a	n/a
Facility-Based Non-Work Activities A provider facility and involves the provision of training and other services and supports that are not paid work	96	n/a
Community-Based Non-Work Activities Training and assistance that enables individuals to participate in community activities away from provider-operated facilities	37	n/a

Competitive/Individual Supported Employment	Yes	No
Percent of people who worked 10 out of the last 12 months in a community job	12%	88%
Percent of people who receive benefits at his/her community job (e.g., paid vacation, sick time, health insurance)	2%	98%

Table 61 DBMD Consumer Outcomes

DOMAIN Consumer Outcomes		
<p>Consumer outcome indicators concern how well the public system aids adults with developmental disabilities to work, participate in their communities, have friends and sustain relationships, and exercise choice and self-determination. Other indicators in this domain probe how satisfied individuals are with services and supports.</p>		
Concern	<i>People make choices about their lives and are actively engaged in planning their services and supports.</i>	
Quality Indicator(s)	The proportion of people who report having been provided options about where to: 1) live 2) work	1) 47% 2) 37%
Concern	<i>People have authority and are supported to direct and manage their own services.</i>	
Quality Indicator(s)	The proportion of people who control their own budgets.	46%
Concern	<i>People have friends and relationships.</i>	
Quality Indicator(s)	▶ The proportion of people who have friends and caring relationships with people other than support staff and family members.	67%
	▶ The proportion of people who have a close friend, someone they can talk to about personal things.	74%
	▶ The proportion of people who are able to see their friends and families when they want: 1) friends 2) families	1) 71% 2) 70%
	▶ The proportion of people who feel lonely.	22%
Concern	<i>People are satisfied with the services and supports they receive.</i>	
Quality Indicator(s)	▶ The proportion of people who are satisfied with where they live.	96%
	▶ The proportion of people who are satisfied with their job or day program.	100%
	▶ The proportion of people who are satisfied with [life in general, personal life].	89%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 62 DBMD System Performance

DOMAIN		System Performance	
<p>The system performance indicators address the following topics: (a) service coordination; (b) family and individual participation in provider-level decisions; (c) the utilization of and outlays for various types of services and supports; (d) cultural competency; and (e) access to services.</p>			
Concern	<i>Service coordinators are accessible, responsive, and support the person's participation in service planning.</i>		
Quality Indicator(s)	▶ The proportion of people reporting that service coordinators help them get what they need.	85%	
	▶ The proportion of people who know their service coordinators.	93%	
	▶ The proportion of people who report that their service coordinators asked about their preferences.	89%	
Concern	<i>Publicly-funded services are readily available to individuals who need and qualify for them.</i>		
Quality Indicator(s)	▶ The proportion of people reporting that they received support to learn or do something new in the past year.	75%	
	▶ The proportion of people who did not receive support to learn or do new things in the past year and want help to do so.	85%	
	▶ The proportion of people who report having adequate transportation when they want to go somewhere.	70%	
	The rate at which people report that "needed" services were not available.	15%	

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 63 DBMD Health, Welfare, Rights

DOMAIN Health, Welfare, and Rights		
These indicators concern the following topics: (a) safety and personal security; (b) health and wellness; and (c) protection of and respect for individual rights.		
Concern	<i>People are safe from abuse, neglect, and injury.</i>	
Quality Indicator(s)	► The proportion of people who report that they feel safe in their: 1) home 2) neighborhood	1) 78% 2) 70%
Concern	<i>People secure needed health services.</i>	
Quality Indicator(s)	The proportion of people who have had a physical exam in the past year.	89%
	The proportion of women who have had a gynecological exam in the past year.	77%
	The proportion of people who have had a routine dental exam in the past six months.	56%
Concern	<i>Medications are managed effectively and appropriately.</i>	
Quality Indicator(s)	The proportion of people taking medications for mood, anxiety, or behavior problems.	37%
Concern	<i>People receive the same respect and protections as others in the community.</i>	
Quality Indicator(s)	► The proportion of people who know their “advocate” or guardian.	81%
	The proportion of people whose basic rights are respected by others: 1) knocking before entering home 2) knocking before entering bedroom 3) read mail (reads own mail or gives permission to others) 4) alone with friends 5) use of phone	1) 56% 2) 78% 3) 92% 4) 80% 5) 94%
	► The proportion of people who report satisfaction with the amount of privacy they have.	77%
	► The proportion of people, who have support staff, indicating that most support staff treat them with respect: 1) home staff 2) day program staff	1) 96% 2) 100%
	The proportion of people who had the opportunity to participate in activities of self-advocacy groups or other groups that address rights.	40%
	Concern	<i>People are supported to maintain healthy habits.</i>
Quality Indicator(s)	The proportion of people who maintain healthy habits in such areas as smoking.	96%

	The proportion of people who exercise or play sports: 1) non-integrated setting 2) community setting	1) 33% 2) 44%
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Table 64 DBMD Self-Determination

DOMAIN Self-Determination		
The goal of self-determination is “crafting a meaningful life deeply imbedded in one’s own community”. ²²		
Concern	<i>People are able to have more choice and control over their everyday lives.</i>	
Quality Indicator(s) ²³	▶ Proportion of people who get to help other people.	74%
	▶ Proportion of people who are able to have a close relationship, such as a boyfriend or girlfriend, if they want one.	63%
	▶ Proportion of people who earn enough money to buy the things they want.	85%
	▶ Proportion of people who are free to take risks when they want to.	56%
	▶ Proportion of people who have control over their transportation.	48%
	▶ Proportion of people who decide who comes in and out of their home.	56%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

²² Nerney, Thomas. *The System of the Future*. Center for Self-Determination. www.self-determination.com (2004)

²³ The Self-Determination indicators were developed by the QA/QI Task Force and have not been validated.

Certain items from the survey tool were combined into reliable scales for the sub-domains: Community Inclusion, Choice, and Decision-making. There are three scales and the scores are computed by averaging the values of a number of items. In order for a score to be computed, the person (or a proxy respondent) must have answered a minimum number of questions. The scales have been tested for reliability, meaning that the items are all measuring the same concept. In other words, one can be fairly confident that items are measuring the same dimension.

The percentages of people who agree with individual items are presented in the tables immediately following the scale score description. While looking at the individual items is helpful in understanding the impact of each item, the average scale scores cannot be calculated from the percentage in the table.

The sub-domain of Community Inclusion has the following concern statement: *People have support to participate in everyday community activities.* There are seven items from the survey tool that are grouped together to create the scale score for Community Inclusion.

The average score for people in the DBMD Program on the Community Inclusion sub-domain is .84, indicating that people receiving DBMD services feel included in their community. The percentages of people who agreed with each question used to create the Community Inclusion scale score is provided in Table 65.

Table 65 DBMD Community Inclusion

Community Inclusion – Individual participates in	%
shopping	100%
errands/appointments	100%
entertainment	96%
eating out	100%
religious services	70%
community meetings	26%
exercise/play sports in a community setting	44%

The sub-domain of Choice and Life Decisions has the following concern statement: *People make choices about their lives and are actively engaged in planning their services and supports.* There are two scales that were used for assessing Choice and Life Decisions. One scale focuses on life decisions and the other focuses on everyday choices.

For Life Decisions, the average score is .87, indicating that people in the DBMD Program feel they are engaged in planning their services and supports. The percentages of people who agreed with each question used to create the Life Decisions scale score is presented in Table 66.

Table 66 DBMD Life Decisions

Life Decisions – Individual at least had input in choosing	%
home without help	68%
home staff	78%
where to work	53%
staff at work	77%
their case manager	78%

The average score for Everyday Choices is .86, which suggests that people feel they have quite a bit of control over making personal choices. The percentages of people who agreed with each question used to create the Everyday Choices scale score is presented in Table 67.

Table 67 DBMD Everyday Choices

Everyday Choices – Individual at least had input in choosing	%
people s/he lives with	47%
their daily schedule	93%
how to spend free time	89%
what to buy with spending money	100%

*"I would like to go
to camp."
-S. from Sherman*

*"I like my friends."
-J. from San Angelo*

*"Everything is
O.K."
-E. from Slaton*



*"I don't know - I
want to get a job
someday."
- J. from Houston*

*"I am relocating to
Tyler. I hope they
would have found me
a case worker and day
center. I do not want
to sit at home and
watch television."
-L. from Port Lavaca*

*"I like to go to
church."
-G. from San Antonio*

Consolidated Waiver Program

The Consolidated Waiver Program (CWP) is a Medicaid waiver program that began operations in Bexar County in November 2001. The Texas Department of Aging and Disability Services (DADS) staff provides case management. The program provides home and community-based services to people who are eligible for nursing facility care or Intermediate Care Facilities for Persons with Mental Retardation or a Related Condition (ICF-MR/RC) as a cost-effective alternative to institutional placement. Services include:

Adult Foster Care • Assisted Living/Residential Care Services • Adaptive Aids • Consumer Directed Services • Respite • Emergency Response Services • Home Delivered Meals • Nursing • Minor Home Modifications • Therapy Services • Personal Assistance Services • Prescription Drugs • Behavior Communication Specialist • Child Support Services • Dental • Family Surrogate Services • Habilitation • Independent Advocacy • Intervenor Services • Orientation and Mobility Services

At the time the sample was drawn, there were 167 people receiving CWP services. Of those, 106 were age 18 years or older. In 2005, both survey tools (NCI, PES E/D) were used in interviews with CWP participants based on which program the participant was enrolled in prior to enrolling in CWP. In 2006, only the NCI survey tool was used. Fifty-three responses were included in the final results.

Table 68 CWP Adult Demographics

Demographic	
Residential Type	%
Assisted Living	0%
Own/Family	99%
Other	1%
Ethnicity	
White	44%
Hispanic	45%
Black	8%
Other	3%
Legal Status	
Private Guardian	26%
Independent	55%
Other	19%
Gender	
Female	63%
Male	37%
Marital Status	
Married	11%
Singe, Never Married	61%
Other	28%
Language	
English	83%
Other	17%
Translation Services Used	
No	96%
Yes	4%
Responded to NCI Section 2	
Consumer	61%
Other	12%
Guardian	9%
Friend/Family	16%
Paid Staff	2%

Day/Vocational/Educational Support - CWP

Table 69 lists six types of vocational/employment services with the average number of hours worked and average total gross wages earned per month.

Table 69 CWP Vocational Support

Support	Average Hours at this Activity Per Month	Average Total Gross Wages Earned at this Activity Per Month
Competitive Employment Have a job of their own in the community	85	n/a
Individual Supported Employment Have a job with a community employer and receive periodic publicly-funded assistance	n/a	n/a
Group Supported Employment Two or more individuals employed by a community provider agency	n/a	n/a
Facility-Based Work Programs In settings such as sheltered workshops or work activity centers employed by the provider agency	n/a	n/a
Facility-Based Non-Work Activities A provider facility and involves the provision of training and other services and supports that are not paid work	n/a	n/a
Community-Based Non-Work Activities Training and assistance that enables individuals to participate in community activities away from provider-operated facilities	46	n/a

Competitive/Individual Supported Employment	Yes	No
Percent of people who work 10 out of the last 12 months in a community job	3%	97%
Percent of people who receive benefits at his/her community job, (e.g., paid vacation, sick time, health insurance)	1%	99%

Table 70 CWP Consumer Outcomes

DOMAIN Consumer Outcomes		
Consumer outcome indicators concern how well the public system aids adults with developmental disabilities to work, participate in their communities, have friends and sustain relationships, and exercise choice and self-determination. Other indicators in this domain probe how satisfied individuals are with services and supports.		
Concern	<i>People make choice about their lives and are actively engaged in planning their services and supports.</i>	
Quality Indicator(s)	The proportion of people who report having been provided options about where to: 1) live 2) work	1) 59% 2) 50%
Concern	<i>People have friends and relationships.</i>	
Quality Indicator(s)	► The proportion of people who have friends and caring relationships with people other than support staff and family members.	66%
	► The proportion of people who have a close friend, someone they can talk to about personal things.	77%
	► The proportion of people who are able to see their friends and families when they want: 1) friends 2) families	1) 82% 2) 85%
	► The proportion of people who feel lonely.	62%
Concern	<i>People are satisfied with the services and supports they receive.</i>	
Quality Indicator(s)	► The proportion of people who are satisfied with where they live.	98%
	► The proportion of people who are satisfied with their job or day program.	100%
	► The proportion of people who are satisfied with [life in general, personal life].	72%

Indicators with this symbol (►) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 71 CWP System Performance

DOMAIN System Performance		
<p>The system performance indicators address the following topics: (a) service coordination; (b) family and individual participation in provider-level decisions; (c) the utilization of and outlays for various types of services and supports; (d) cultural competency; and (e) access to services.</p>		
Concern	<i>Service coordinators are accessible, responsive, and support the person's participation in service planning.</i>	
Quality Indicator(s)	▶ The proportion of people reporting that service coordinators help them get what they need.	71%
	▶ The proportion of people who know their service coordinators.	89%
	▶ The proportion of people who report that their service coordinators asked about their preferences.	74%
Concern	<i>Publicly-funded services are readily available to individuals who need and qualify for them.</i>	
Quality Indicator(s)	▶ The proportion of people reporting that they received support to learn or do something new in the past year.	66%
	▶ The proportion of people who did not receive support to learn or do new things in the past year and want help to do so.	40%
	▶ The proportion of people who report having adequate transportation when they want to go somewhere.	74%
	The rate at which people report that "needed" services were not available.	26%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

Table 72 CWP Health, Welfare, and Rights

DOMAIN Health, Welfare, and Rights			
These indicators concern the following topics: (a) safety and personal security; (b) health and wellness; and (c) protection of and respect for individual rights.			
Concern	<i>People are safe from abuse, neglect, and injury.</i>		
Quality Indicator(s)	► The proportion of people who report that they feel safe in their: 1) home 2) neighborhood	1) 70% 2) 70%	
Concern	<i>People secure needed health services.</i>		
Quality Indicator(s)	The proportion of people who have had a physical exam in the past year.	85%	
	The proportion of women who have had a gynecological exam in the past year.	11%	
	The proportion of people who have had a routine dental exam in the past six months.	34%	
Concern	<i>Medications are managed effectively and appropriately.</i>		
Quality Indicator(s)	The proportion of people taking medications for mood, anxiety, or behavior problems.	30%	
Concern	<i>People receive the same respect and protections as others in the community.</i>		
Quality	► The proportion of people who know their “advocate” or guardian.	93%	
	The proportion of people whose basic rights are respected by others: 1) knock before entering home 2) knock before entering bedroom 3) read mail (reads own mail or gives permission to others) 4) alone with friends 5) use of phone	1) 64% 2) 81% 3) 98% 4) 93% 5) 94%	
	► The proportion of people who report satisfaction with the amount of privacy they have.	90%	
	► The proportion of people, who have home staff, indicating that most staff treat them with respect: 1) home staff 2) day program staff	1) 100% 2) 100%	
	The proportion of people who had the opportunity to participate in activities of self-advocacy groups or other groups that address rights.	22%	
	Concern	<i>People are supported to maintain healthy habits.</i>	
	Quality Indicator(s)	The proportion of people who maintain healthy habits in such areas as smoking.	91%

Quality Indicator(s)	The proportion of people who exercise or play sports: 1) non-integrated setting 2) community setting	1) 59% 2) 2%
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Table 73 CWP Self-Determination

DOMAIN Self-Determination		
The goal of self-determination is “crafting a meaningful life deeply imbedded in one’s own community”. ²⁴		
Concern	<i>People are able to have more choice and control over their everyday lives.</i>	
Quality Indicator(s) ²⁵	▶ Proportion of people who get to help other people.	59%
	▶ Proportion of people who are able to have a close relationship, such as a boyfriend or girlfriend, if they want one.	72%
	▶ Proportion of people who earn enough money to buy the things that they want.	53%
	▶ Proportion of people who are free to take risks when they want to.	68%
	▶ Proportion of people who have control over their transportation.	55%
	▶ Proportion of people who decide who comes in and out of their home.	64%

Indicators with this symbol (▶) are calculated based on questions from Section 1 of the NCI Survey tool which is designed to capture the responses only from the individual, not from a proxy.

²⁴ Nerney, Thomas. *The System of the Future*. Center for Self-Determination. www.self-determination.com (2004)

²⁵ The Self-Determination indicators were developed by the QA/QI Task Force and have not been validated.

Certain items from the survey tool were combined into reliable scales for the sub-domains: Community Inclusion, Choice, and Decision-Making. There are three scales and the scores are computed by averaging the values of a number of items. In order for a score to be computed, the person (or a proxy respondent) must have answered a minimum number of questions. The scales have been tested for reliability, meaning that the items are all measuring the same concept. In other words, one can be fairly confident that items are measuring the same dimension.

The percentages of people who agree with individual items are presented in the tables immediately following the scale score description. While looking at the individual items is helpful in understanding the impact of each item, the average scale scores cannot be calculated from the percentage in the table.

The sub-domain of Community Inclusion has the following concern statement: *People have support to participate in everyday community activities.* There are seven items from the survey tool that are grouped together to create the scale score for Community Inclusion.

The average score for people in the CWP on the Community Inclusion sub-domain is .65, indicating that people receiving CWP services feel somewhat included in their community. The percentages of people who agreed with each question used to create the Community Inclusion scale score is provided in Table 74.

Table 74 CWP Community Inclusion

Community Inclusion – Individual participates in	%
shopping	89%
errands/appointments	94%
entertainment	67%
eating out	81%
religious services	60%
community meetings	19%
exercise/play sports in a community setting	2%

The sub-domain of Choice and Life Decisions has the following concern statement: *People make choices about their lives and are actively engaged in planning their services and supports.* There are two scales that were used for assessing Choice and Life Decisions. One scale focuses on life decisions and the other focuses on everyday choices.

For Life Decisions, the average score is .88, indicating that people in CWP feel they are engaged in planning their services and supports. The percentages of people who agreed with each question used to create the Choice and Life Decision scale score is presented in Table 75.

Table 75 CWP Life Decisions

Life Decisions – Individual at least had input in choosing	%
home without help	82%
home staff	74%
where to work	63%
staff at work	67%
their case manager	79%

The average score for Everyday Choices is .93, which suggests that people feel they have a lot of control over making personal choices. The percentages of people who agreed with each question used to create the Everyday Choices scale score is presented in Table 76.

Table 76 CWP Everyday Choices

Everyday Choices – Individual at least had input in choosing	%
people s/he lives with	95%
their daily schedule	93%
how to spend free time	93%
what to buy with spending money	94%

"Sometimes I wish there was something I could do to fill in my time."

-B. from Lubbock

"I would like to go to nursing homes and read to residents."

-D. from Gainesville

"A roll-in shower would be very helpful to be more independent. I'm renting since I lost home to Rita."

-D. From Bon Wier



"I visit the sick people at the Plaza home. That makes me feel good to see them. I go on Wednesdays."

-R. from Rockport

"I like to go to Church but transportation is sometimes a problem."

-R. from El Paso

Community-Based Alternatives

The Community-Based Alternatives (CBA) Program provides home and community-based services to people age 21 years or older who disabled or aged and disabled as a cost-effective alternative to institutional care in nursing facilities. Services include:

Adult Foster Care • Assisted Living/Residential Care Services • Adaptive Aids • Consumer Directed Services • Respite • Emergency Response Services • Home Delivered Meals • Nursing • Minor Home Modifications • Therapy Services • Personal Assistance Services • Prescription Drugs

A statistically valid random sample (427) of people receiving services was interviewed during the four-month period using the PES E/D survey tool. At the time the sample was drawn, there were 30,699 people receiving CBA Program services all of whom are 18 years of age or older.

Table 77 CBA Adult Demographics

Demographic	
Residential Type	%
Shared with Other Waiver Participant	5%
Residential Care	11%
Own/Family Home	83%
Adult Foster Care	1%
Ethnicity	
White	46%
Hispanic	33%
Black	18%
Other	3%
Legal Status	
Private Guardian	20%
Independent	67%
Other	13%
Gender	
Female	75%
Male	25%
Marital Status	
Married	21%
Singe, Never Married	63%
Other	16%
Language	
English	76%
Other	24%
Translation Services Used	
No	97%
Yes	3%
Questions Answered by Participant	
All	68%
Most	12%
About Half	4%
Some	3%
A Few	4%
None	9%

Day/Vocational/Educational Support – CBA

Table 78 lists six types of vocational/employment services with the average number of hours worked and average total gross wages earned per month.

Table 78 CBA Vocational Support

Support	Average Hours at this Activity Per Month	Average Total Gross Wages Earned at this Activity Per Month
Competitive Employment Have a job of their own in the community	n/a	n/a
Individual Supported Employment Have a job with a community employer and receive periodic publicly-funded assistance	n/a	n/a
Group Supported Employment Two or more individuals employed by a community provider agency	n/a	n/a
Facility-Based Work Programs In settings such as sheltered workshops or work activity centers employed by the provider agency	n/a	n/a
Facility-Based Non-Work Activities A provider facility and involves the provision of training and other services and supports that are not paid work	120	n/a
Community-Based Non-Work Activities Training and assistance that enables individuals to participate in community activities away from provider-operated facilities	127	n/a

Competitive/Individual Supported Employment	Yes	No
Percent of people who worked 10 out of the last 12 months in a community job	100%	0%
Percent of people who receive benefits at his/her community job (e.g., paid vacation, sick time, health insurance)	100%	0%

The PES E/D can be used to calculate 33 performance indicators for quality monitoring and intervention and the QA/QI Task Force recommended an additional six indicators related to self-determination.

Table 79 CBA Performance Indicators

Indicator Number	Indicator	%
Access to Care		
1	Bathing – The proportion of people receiving services who are sometimes unable to bathe or shower because there is no one there to help them.	8%
2	Dressing – The proportion of people receiving services who are sometimes unable to dress because there is no one there to help them.	5%
3	Transferring – The proportion of people receiving services who are sometimes unable to get out of bed because there is no one there to help them.	7%
4	Eating – The proportion of people receiving services who are sometimes unable to eat because there is no one there to help them.	1%
5	Meal Preparation – The proportion of people receiving services who sometimes go without a meal because there is no one there to help them.	5%
6	Groceries – The proportion of people receiving services who are sometimes unable to get groceries because there is no one there to help them.	6%
7	Housework – The proportion of people receiving services whose housework does not get done sometimes because there is no one there to help them.	8%
8	Laundry – The proportion of people receiving services whose laundry does not get done sometimes because there is no one there to help them.	6%
9	Transportation – The proportion of people receiving services who report not always having transportation when needed.	20%
10	Medication – The proportion of people receiving services who sometimes go without taking medications because there is no one there to help them.	4%
11	Toileting – The proportion of people receiving services who are sometimes unable to get to or use the bathroom because there is no one there to help them.	7%
12	Staff Time – The proportion of people receiving services who report care staff do not spend all the time they are supposed to with the program participant.	4%
13	Adaptive Equipment or Environmental Modifications – The proportion of people receiving services who requested special equipment or environmental modifications who report not receiving them.	12%
Choice and Control		
14	Choice in Staff – The proportion of people receiving services who do not choose their care staff, but would like to.	33%
15	Changing Staff – The proportion of people receiving services who did not know they could change their paid staff.	11%
16	Directing Staff – The proportion of people receiving services who do not help direct their staff, but would like to.	21%
17	Contact for Reporting Staffing Problems – The proportion of people receiving services who would report staffing problems to “no one” or are unsure to whom to report problems.	4%
18	Ability to Identify Case Manager – The proportion of people receiving services who are unable to identify their case manager when asked.	40%
19	Ability to Contact Case Manager – The proportion of people receiving services who report they cannot always talk with their case manager when they need to.	13%
20	Case Manager Helpfulness – The proportion of people receiving services who say their case managers do not always help them when they ask for something.	14%
Respect/Dignity		
21	Respect by Home Care Staff – The proportion of people receiving services who report staff do not treat them respectfully in their homes.	2%

Indicator Number	Indicator	%
22	Careful Listening by Home Care Staff – The proportion of people receiving services who report home care staff do not listen carefully to their requests for assistance.	6%
23	Physical Abuse by Staff – The proportion of people receiving services who report being injured by current staff.	1%
24	Verbal Abuse by Staff – The proportion of people receiving services who report being verbally abused by current staff.	3%
25	Theft by Staff – The proportion of people receiving services who report theft by current staff.	4%
26	Respect by Day Program Staff – The proportion of people receiving services who report staff do not treat them respectfully in programs outside their homes.	0%
27	Careful Listening by Day Program Staff – The proportion of people receiving services who report day program staff do not listen carefully to their requests for assistance in programs outside their homes.	0%
28	Respect by Transportation Staff – The proportion of people receiving services who report transportation staff do not treat them respectfully while using these services.	6%
29	Careful Listening by Transportation Staff – The proportion of people receiving services who report staff do not listen carefully to their requests for assistance while using these services.	9%
Community Integration/Inclusion		
30	Community Involvement – The proportion of people receiving services who report an unmet need for community involvement.	41%
31	Demand for Employment – The proportion of non-elderly people receiving services who are not currently working, but would like to work.	29%
32	Choice in Employment – The proportion of working, non-elderly people receiving services who did not choose their current job.	0%
33	Satisfaction with Employment – The proportion of working, non-elderly people receiving services who do not like their current job.	0%
34 ²⁶	Helping Others – The proportion of people receiving services who get to help other people.	48%
35	Close Relationships – The proportion of people receiving services who are able to have a close relationship, such as a boyfriend or girlfriend, if they want one.	66%
36	Earning Money – The proportion of people receiving services who earn enough money to buy the things that they want.	57%
37	Risks – The proportion of people receiving services who are free to take risks when they want to.	90%
38	Transportation Control – The proportion of people receiving services who have control over their transportation.	64%
39	Home Privacy – The proportion of people receiving services who decide who comes in and out of their home.	82%

²⁶ Indicators 34 - 39 were developed by the QA/QI Task Force and have not been validated.

4.0 Children/Family Surveys

Quality Indicators

The purpose of the Children/Family mail survey project is to obtain information directly from families about their experiences utilizing the Texas Department of Aging and Disability Services (DADS) waiver services for their children. The information gathered from the surveys represents the family member's perspective of their child's services and supports. The survey used the National Core Indicators Children/Family Survey instrument which includes questions about: Information and Planning; Access and Delivery of Supports; Choice and Control; Community Connections; Satisfaction; and Family Outcomes. There is also a page for respondents to provide comments.

Methodology

The survey project employed a three-phased mail-out approach in order to garner the highest response rate possible. All correspondence was sent in English and Spanish versions. The first phase began April 3, 2006, and included a letter mailed to families informing them they would be receiving a survey and encouraged them to assist the department by completing the survey. The next phase began on April 17, 2006, with the mail out of the surveys in English (Appendix C) and Spanish (Appendix D) with a self-addressed, stamped, return envelope. The third and final phase was executed on May 1, 2006, with a follow-up letter reminding them to complete the survey if they had not already done so. The deadline for returning the survey was May 31, 2006.

All families of children in the Medically Dependent Children Program (MDCP), which may have included persons up to 21 years of age, were mailed a survey. In addition, families of children under age 18 and who live at home with their family in the Community Living Assistance and Support Services (CLASS)²⁷, Consolidated Waiver Program (CWP), Home and Community-based Services (HCS), and Texas Home Living (TxHmL) programs were mailed surveys.

A total of 2,192 surveys were mailed to families from the five programs and 801 (36%) of the completed surveys were returned to DADS.

Instruments

The NCI Children/Family survey tool is divided into two parts. Part 1 is information about the family and the services and supports they receive. Part 2 of the survey includes questions about: Information and Planning, Access and Delivery of Supports, Choice and Control, Community Connections, Satisfaction, and Family Outcomes as well as a page for comments. A five-point Likert scale is used to respond as either: 1 - indicating "always or usually", 2 - indicating "sometimes", 3 - indicating "seldom or never", 4 - indicating "don't know", and 5 - indicating "not applicable".

Results

The results section is divided by program and a brief description is given for each program. In addition, demographics about the children receiving services and the person who completed the survey are listed with the total number of surveys mailed and the percent of completed surveys returned. Quality indicators were calculated based on the responses to the survey questions for each program. Family Indicators include the following sub domains: Information and Planning, Choice and Control, Access and Support Delivery, Community Connections, Satisfaction, and Family Outcomes.

²⁷ Participants were those who use the Consumer Directed Services (CDS) option and those who do not.

The quality indicators were obtained by combining individual's responses to relevant questions. Specifically, each person's responses on certain questions were averaged to create a summary score for each indicator. Summary scores were developed for each of the 16 indicators by using the average of the items comprising the indicator (Appendix E). For example, answers to questions 37, 38, and 39 were combined into one score representing the families or family members who participate in integrated activities in their communities. All of the scores range between 1.00 and 3.00. A 1.00 corresponds to "always or usually," 2.00 corresponds to "sometimes," and 3.00 corresponds to "seldom or never." The closer the number is to 1.00, the more people tended to agree with the item; whereas the closer the number is to 3.00, the more people disagreed with the item.

Comments

In addition to closed-ended questions, the survey also allowed respondents to record comments about any topic or issue. Almost 50% of survey respondents provided comments. DADS staff categorized the comments by issue which included --

- Accessing Services – the inability to access a needed service
- Appeals – the appeals process is too long
- Services/Service Providers – the inability to get services or find service providers
- Community Inclusion – the lack of community-based activities for participation
- Disability Awareness – the general public's lack of disability awareness
- Staff Training – the lack of adequate training to carry out or respond to service needs
- Integrated Eligibility System – lack of a comprehensive eligibility system
- Backup Staff – lack of staff to provide backup coverage for staff absences
- Information – lack of information regarding programs and services
- Program Oversight – services and/or supports not being monitored, or lack of accountability
- Program Services – lack of services or supports needed or not able to meet eligibility requirements
- Staff Turnover – continuous change in paid staff and/or case managers
- Survey Tool – survey tool was not clear or the respondent did not understand the program connection to DADS
- Transition Issues – unsure how to plan for services when child reaches adulthood
- Waiting List – complaints about length of time or prioritization process
- Overall Satisfaction – services/supports have met needs to help keep family member at home

Home and Community-Based Services

The Home and Community-Based Services (HCS) Program for people with cognitive disabilities provides individualized services and supports to people living in their family home, their own homes, or other community settings such as small group homes where no more than four people live.

There were 351 families of children under 18 years of age who received HCS Program services and supports and lived at home with family. Each family was mailed a survey. DADS received a total of 117 completed surveys or 33%. Table 80 provides information about the children receiving services.

Table 80 HCS Child Demographics

Demographics		%
Gender	Male	64
	Female	36
Age	0-3	0
	4-10	7
	11-15	42
	16-21	50
Ethnicity	Black	13
	Hispanic	28
	White	48
	Other	11
More than one child with a disability in household	Yes	20
	No	80
Level of help needed for daily activities (such as bathing, dressing, eating)	None	7
	Little	12
	Moderate	33
	Complete	48
Diagnoses	Mental Retardation	84
	Developmental Disabilities	34
	Mental Illness	12
	Autism	35
	Cerebral Palsy	31
	Brain Injury	10
	Seizure Disorder	34
	Chemical Dependency	2
	Vision or Hearing Impairments	29
	Physical Disabilities	29
	Communication Disorder	44
	Down Syndrome	12
	Other Disability	33

Table 81 HCS Child/Family Summary Scores

The questions from the Children/Family Survey used to calculate the indicators are available on the table crosswalk (Appendix E). This table shows the Domain, Sub-Domain, Concern, Indicator, and summary scores of all 16 indicators for the HCS Program.

● = Lowest Agreement (2.34 – 3.00) ◐ = Moderate Agreement (1.67 – 2.33) ○ = Highest Agreement (1.00 – 1.66)

Domain	Overview: The family indicators concern how well the public system assists children with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.			
Sub-Domain	Concern	Indicator	Summary Scores	
Information and Planning	<i>Families/family members with disabilities have the information and support necessary to plan for their services and supports.</i>	Families are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits) in a way that is easy to understand.	1.75	◐
		Families have the information needed to skillfully plan for their services and supports.	1.79	◐
		The support plan includes or reflects things that are important to the family.	1.40	○
		Staff who assist with planning are knowledgeable and respectful.	1.43	○
Choice and Control	<i>Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.</i>	Families control their own budgets/supports (i.e., they choose what supports/goods to purchase).	2.46	●
		Families choose, hire, and manage their service/support providers.	1.58	○
		Staff are respectful of the family choices and decisions.	1.23	○
Access and Support Delivery	<i>Families/family members with disabilities get the services and supports they need.</i>	Having access to an adequate array of services and supports.	1.32	○
		Services/supports are available when needed, even in a crisis.	1.62	○
		Staff or translators are available to provide information, services, and supports in the family/family member's primary language/method of communication.	1.55	○
		Services/supports are flexible to meet the changing needs of the family.	2.01	◐
		Service and support staff/providers are available and capable of meeting family needs.	1.57	○
Community Connections	<i>Families/family members with disabilities use integrated community services and participate in everyday community activities.</i>	Families/family members with disabilities participate in integrated activities in their communities.	1.94	◐
		Families are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	2.12	◐
Satisfaction	<i>Families/family members with disabilities receive adequate and satisfactory supports.</i>	Families are satisfied with the information and supports received and with the planning, decision-making, and grievance processes.	1.71	◐
Family Outcomes	Individual and family supports make a positive difference in the lives of families.	Families feel that services and supports have helped them to better care for their family member living at home.	1.30	○

Demographics of Person Completing Survey for HCS

Table 82 provides information about the respondent.

Table 82 HCS Respondent Demographics

Demographics		
Age		%
	Under 55	86
	55 and Over	14
Relation to Child		
	Parent	96
	Grandparent	3
	Other	1
Primary Caregiver		
	Yes	97
	No	3
Health Status		
	Excellent	17
	Good	52
	Fair	27
	Poor	4
Other Services and Supports Received		
	SSI Financial Support	52
	Other Financial Support	21
	In-Home Support	75
	Out-of-Home Respite Care	52
	Early Intervention	3
	Transportation	24
	Specialized Services and Supports	67

Comments

Of the 117 returned surveys for HCS, 42% included comments. The most frequently mentioned comment from respondents was:

- overall satisfaction with services – services and supports have met needs to help keep family member at home

Other issues reported include:

- information – lack of information regarding programs and/or services
- staff turnover – continuous change in paid staff and/or case managers

Texas Home Living

The Texas Home Living (TxHmL) Program provides selected essential services and supports to people with cognitive disabilities who live in their family homes or their own homes.

There were 224 families of children under 18 years of age who received TxHmL Program services and supports and lived at home with family. Each family was mailed a survey. DADS received a total of 79 completed surveys or 35%. Table 83 provides information about the children receiving services.

Table 83 TxHmL Child Demographics

Demographics		%
Gender	Male	70
	Female	30
Age	0-3	0
	4-10	27
	11-15	41
	16-21	28
Ethnicity	Black	23
	Hispanic	43
	White	33
	Other	1
More than one child with a disability in household	Yes	19
	No	81
Level of help needed for daily activities (such as bathing, dressing, eating)	None	18
	Little	18
	Moderate	36
	Complete	28
Diagnoses	Mental Retardation	63
	Developmental Disabilities	37
	Mental Illness	14
	Autism	33
	Cerebral Palsy	18
	Brain Injury	10
	Seizure Disorder	23
	Chemical Dependency	0
	Vision or Hearing Impairments	22
	Physical Disabilities	23
	Communication Disorder	35
	Down Syndrome	10
Other Disability	22	

Table 84 TxHmL Child/Family Summary Scores

The questions from the Children/Family Survey used to calculate the indicators are available on the table crosswalk (Appendix E). This table shows the Domain, Sub-Domain, Concern, Indicator, and summary scores of all 16 indicators for the TxHmL Program.

● = Lowest Agreement (2.34 – 3.00) ◐ = Moderate Agreement (1.67 – 2.33) ○ = Highest Agreement (1.00 – 1.66)

Domain	Overview: The family indicators concern how well the public system assists children with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.			
Sub-Domain	Concern	Indicator	Summary Scores	
Information and Planning	<i>Families/family members with disabilities have the information and support necessary to plan for their services and supports.</i>	Families are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits) in a way that is easy to understand.	1.75	◐
		Families have the information needed to skillfully plan for their services and supports.	1.97	◐
		The support plan includes or reflects things that are important to the family.	1.66	○
		Staff who assist with planning are knowledgeable and respectful.	1.56	○
Choice and Control	<i>Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.</i>	Families control their own budgets/supports (i.e., they choose what supports/goods to purchase).	2.29	◐
		Families choose, hire, and manage their service/support providers.	1.75	◐
		Staff are respectful of the family choices and decisions.	1.25	○
Access and Support Delivery	<i>Families/family members with disabilities get the services and supports they need.</i>	Having access to an adequate array of services and supports.	1.39	○
		Services/supports are available when needed, even in a crisis.	1.91	◐
		Staff or translators are available to provide information, services, and supports in the family/family member's primary language/method of communication.	1.62	○
		Services/supports are flexible to meet the changing needs of the family.	1.95	◐
		Service and support staff/providers are available and capable of meeting family needs.	1.68	◐
Community Connections	<i>Families/family members with disabilities use integrated community services and participate in everyday community activities.</i>	Families/family members with disabilities participate in integrated activities in their communities.	1.86	◐
		Families are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	2.04	◐
Satisfaction	<i>Families/family members with disabilities receive adequate and satisfactory supports.</i>	Families are satisfied with the information and supports received, and with the planning, decision-making, and grievance processes.	1.87	◐
Family Outcomes	Individual and family supports make a positive difference in the lives of families.	Families feel that services and supports have helped them to better care for their family member living at home.	1.48	○

Demographics of Person Completing Survey for TxHmL

Table 85 provides information about the respondent.

Table 85 TxHmL Respondent Demographics

Demographics		2006
Age		%
	Under 55	83
	55 and Over	17
Relation to Child		
	Parent	82
	Grandparent	15
	Other	3
Primary Caregiver		
	Yes	97
	No	3
Health Status		
	Excellent	8
	Good	52
	Fair	39
	Poor	1
Other Services and Supports Received		
	SSI Financial Support	95
	Other Financial Support	7
	In-Home Support	52
	Out-of-Home Respite Care	48
	Early Intervention	10
	Transportation	21
	Specialized Services and Supports	66

Comments

Of the 79 returned surveys for TxHmL, 34% included comments. The most frequently mentioned comments from respondents were:

- overall satisfaction with services – services and supports have met needs to help keep family member at home
- services/service providers – the inability to get services or find service providers

Other issues reported include:

- survey tool – survey tool was not clear or the respondent did not understand the program connection to DADS

Community Living Assistance and Support Services – Consumer Directed Services

The Community Living Assistance and Support Services-Consumer Directed Services (CLASS-CDS) Program provides home and community-based services to adults and children with related conditions as a cost-effective alternative to ICF/MR institutional placement. People with related conditions have a qualifying disability, which originated before age 22 that affects their ability to function in daily life.

Consumer Directed Services (CDS) is a service delivery option that gives the consumer control over their habilitation and respite services. As the employer, the consumer hires and manages their attendants and hires a CDS agency to process the payroll and federal and state taxes.

Surveys were mailed to 262 families of children under 18 years of age who received CLASS-CDS Program services and supports, who use the CDS option, and lived at home with family. DADS received a total of 94 completed surveys or 36%. Table 86 provides information about the children receiving services.

Table 86 CLASS-CDS Child Demographics

Demographics		%
Gender	Male	56
	Female	42
Age	0-3	0
	4-10	7
	11-15	58
	16-21	35
Ethnicity	Black	3
	Hispanic	22
	White	75
	Other	0
More than one child with a disability in household	Yes	9
	No	91
Level of help needed for daily activities (such as bathing, dressing, eating)	None	0
	Little	4
	Moderate	38
	Complete	58
Diagnoses	Mental Retardation	38
	Developmental Disabilities	34
	Mental Illness	4
	Autism	37
	Cerebral Palsy	44
	Brain Injury	7
	Seizure Disorder	50
	Chemical Dependency	0
	Vision or Hearing Impairments	34
	Physical Disabilities	52
	Communication Disorder	38
	Down Syndrome	4
Other Disability	30	

Table 87 CLASS-CDS Child/Family Summary Scores

The questions from the Children/Family Survey used to calculate the indicators are available on the table crosswalk (Appendix E). This table shows the Domain, Sub-Domain, Concern, Indicator, and summary scores of all 16 indicators for the CLASS-CDS Program.

● = Lowest Agreement (2.34 – 3.00) ◐ = Moderate Agreement (1.67 – 2.33) ○ = Highest Agreement (1.00 – 1.66)

Domain	Overview: The family indicators concern how well the public system assists children with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.			
Sub-Domain	Concern	Indicator	Summary Scores	
Information and Planning	<i>Families/family members with disabilities have the information and support necessary to plan for their services and supports.</i>	Families are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits) in a way that is easy to understand.	1.88	◐
		Families have the information needed to skillfully plan for their services and supports.	1.80	◐
		The support plan includes or reflects things that are important to the family.	1.23	○
		Staff who assist with planning are knowledgeable and respectful.	1.44	○
Choice and Control	<i>Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.</i>	Families control their own budgets/supports (i.e., they choose what supports/goods to purchase).	1.58	○
		Families choose, hire, and manage their service/support providers.	1.17	○
		Staff are respectful of the family choices and decisions.	1.21	○
Access and Support Delivery	<i>Families/family members with disabilities get the services and supports they need.</i>	Having access to an adequate array of services and supports.	1.37	○
		Services/supports are available when needed, even in a crisis.	1.71	◐
		Staff or translators are available to provide information, services, and supports in the family/family member's primary language/method of communication.	2.24	◐
		Services/supports are flexible to meet the changing needs of the family.	1.99	◐
		Service and support staff/providers are available and capable of meeting family needs.	1.47	○
Community Connections	<i>Families/family members with disabilities use integrated community services and participate in everyday community activities.</i>	Families/family members with disabilities participate in integrated activities in their communities.	2.00	◐
		Families are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	2.24	◐
Satisfaction	<i>Families/family members with disabilities receive adequate and satisfactory supports.</i>	Families are satisfied with the information and supports received, and with the planning, decision-making, and grievance processes.	1.47	○
Family Outcomes	Individual and family supports make a positive difference in the lives of families.	Families feel that services and supports have helped them to better care for their family member living at home.	1.18	○

Demographics of Person Completing Survey for CLASS-CDS

Table 88 provides information about the respondent.

Table 88 CLASS-CDS Respondent Demographics

Demographics		
Age		%
	Under 55	95
	55 and Over	5
Relation to Child		
	Parent	99
	Grandparent	0
	Other	1
Primary Caregiver		
	Yes	98
	No	2
Health Status		
	Excellent	34
	Good	45
	Fair	19
	Poor	1
Other Services and Supports Received		
	SSI Financial Support	16
	Other Financial Support	28
	In-Home Support	97
	Out-of-Home Respite Care	40
	Early Intervention	0
	Transportation	6
	Specialized Services and Supports	87

Comments

Of the 94 returned surveys for CLASS-CDS, 49% included comments. The most frequently mentioned comment from respondents was:

- overall satisfaction with services – services and supports have met needs to help keep family member at home

Other issues reported include:

- program services – lack of services or supports needed or not able to meet eligibility requirements
- services/service providers – the inability to get services or find service providers
- accessing services – the inability to access a needed service

Community Living Assistance and Support Services without Consumer Directed Services

The Community Living Assistance and Support Services without Consumer Directed Services (CLASS Non-CDS) Program provides home and community-based services to adults and children with related conditions as a cost-effective alternative to ICF/MR institutional placement. People with related conditions have a qualifying disability, which originated before age 22 that affects their ability to function in daily life.

There were 351 families of children under 18 years of age who received CLASS Non-CDS Program services and supports and lived at home with family. Each family was mailed a survey. DADS received a total of 126 completed surveys or 36%. Table 89 provides information about the children receiving services.

Table 89 CLASS Non-CDS Child Demographics

Demographics		%
Gender	Male	59
	Female	41
Age	0-3	0
	4-10	16
	11-15	52
	16-21	31
Ethnicity	Black	12
	Hispanic	20
	White	65
	Other	3
More than one child with a disability in household	Yes	16
	No	84
Level of help needed for daily activities (such as bathing, dressing, eating)	None	4
	Little	6
	Moderate	37
	Complete	53
Diagnoses	Mental Retardation	44
	Developmental Disabilities	33
	Mental Illness	4
	Autism	18
	Cerebral Palsy	60
	Brain Injury	19
	Seizure Disorder	42
	Chemical Dependency	0
	Vision or Hearing Impairments	37
	Physical Disabilities	59
	Communication Disorder	36
	Down Syndrome	2
	Other Disability	26

Table 90 CLASS Non-CDS Child/Family Summary Scores

The questions from the Children/Family Survey used to calculate the indicators are available on the table crosswalk (Appendix E). This table shows the Domain, Sub-Domain, Concern, Indicator, and summary scores of all 16 indicators for the CLASS Non-CDS Program.

● = Lowest Agreement (2.34 – 3.00) ◐ = Moderate Agreement (1.67 – 2.33) ○ = Highest Agreement (1.00 – 1.66)

Domain	Overview: The family indicators concern how well the public system assists children with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.			
Sub-Domain	Concern	Indicator	Summary Scores	
Information and Planning	<i>Families/family members with disabilities have the information and support necessary to plan for their services and supports.</i>	Families are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits) in a way that is easy to understand.	1.67	◐
		Families have the information needed to skillfully plan for their services and supports.	1.62	○
		The support plan includes or reflects things that are important to the family.	1.21	○
		Staff who assist with planning are knowledgeable and respectful.	1.33	○
Choice and Control	<i>Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.</i>	Families control their own budgets/supports (i.e., they choose what supports/goods to purchase).	1.94	◐
		Families choose, hire, and manage their service/support providers.	1.39	○
		Staff are respectful of the family choices and decisions.	1.16	○
Access and Support Delivery	<i>Families/family members with disabilities get the services and supports they need.</i>	Having access to an adequate array of services and supports.	1.25	○
		Services/supports are available when needed, even in a crisis.	1.65	○
		Staff or translators are available to provide information, services, and supports in the family/family member's primary language/method of communication.	1.84	◐
		Services/supports are flexible to meet the changing needs of the family.	1.96	◐
		Service and support staff/providers are available and capable of meeting family needs.	1.48	○
Community Connections	<i>Families/family members with disabilities use integrated community services and participate in everyday community activities.</i>	Families/family members with disabilities participate in integrated activities in their communities.	1.94	◐
		Families are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	2.03	◐
Satisfaction	<i>Families/family members with disabilities receive adequate and satisfactory supports.</i>	Families are satisfied with the information and supports received, and with the planning, decision-making, and grievance processes.	1.52	○
Family Outcomes	<i>Individual and family supports make a positive difference in the lives of families.</i>	Families feel that services and supports have helped them to better care for their family member living at home.	1.19	○

Demographics of Person Completing Survey for CLASS Non-CDS

Table 91 provides information about the respondent.

Table 91 CLASS Non-CDS Respondent Demographics

Demographics		
Age		%
	Under 55	89
	55 and Over	11
Relation to Child		
	Parent	93
	Grandparent	6
	Other	1
Primary Caregiver		
	Yes	99
	No	1
Health Status		
	Excellent	14
	Good	63
	Fair	21
	Poor	2
Other Services and Supports Received		
	SSI Financial Support	35
	Other Financial Support	25
	In-Home Support	97
	Out-of-Home Respite Care	48
	Early Intervention	11
	Transportation	16
	Specialized Services and Supports	87

Comments

Of the 126 returned surveys for CLASS Non-CDS, 39% included comments. The most frequently mentioned comment from respondents was:

- overall satisfaction with services – services and supports have met needs to help keep family member at home

Other issues reported include:

- program services – lack of services or supports needed or not able to meet eligibility requirements
- services/service providers – the inability to get services or find service providers
- information – lack of information regarding programs and services

Consolidated Waiver Program

The Consolidated Waiver Program (CWP) is a Medicaid waiver program that began operations in Bexar County in November 2001. DADS staff provides case management. The program provides home and community-based services to people who are eligible for nursing facility care or Intermediate Care Facilities for Persons with Mental Retardation or a Related Condition as a cost-effective alternative to institutional placement.

There were 62 families of children under 18 years of age who received CWP services and supports and lived at home with family. Surveys were mailed to all of those families. DADS received a total of 20 completed surveys or 32%. Table 92 provides information about the children receiving services.

Table 92 CWP Child Demographics

Demographics		%
Gender	Male	70
	Female	30
Age	0-3	0
	4-10	35
	11-15	45
	16-21	15
Ethnicity	Black	5
	Hispanic	65
	White	25
	Other	5
More than one child with a disability in household	Yes	10
	No	90
Level of help needed for daily activities (such as bathing, dressing, eating)	None	5
	Little	5
	Moderate	25
	Complete	65
Diagnoses	Mental Retardation	45
	Developmental Disabilities	35
	Mental Illness	10
	Autism	5
	Cerebral Palsy	35
	Brain Injury	15
	Seizure Disorder	45
	Chemical Dependency	10
	Vision or Hearing Impairments	35
	Physical Disabilities	55
	Communication Disorder	40
	Down Syndrome	10
Other Disability	45	

Table 93 CWP Child/Family Summary Scores

The questions from the Children/Family Survey used to calculate the indicators are available on the table crosswalk (Appendix E). This table shows the Domain, Sub-Domain, Concern, Indicator, and summary scores of all 16 indicators for CWP.

● = Lowest Agreement (2.34 – 3.00) ◐ = Moderate Agreement (1.67 – 2.33) ○ = Highest Agreement (1.00 – 1.66)

Domain	Overview: The family indicators concern how well the public system assists children with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.			
Sub-Domain	Concern	Indicator	Summary Scores	
Information and Planning	<i>Families/family members with disabilities have the information and support necessary to plan for their services and supports.</i>	Families are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits) in a way that is easy to understand.	1.74	◐
		Families have the information needed to skillfully plan for their services and supports.	1.53	○
		The support plan includes or reflects things that are important to the family.	1.41	○
		Staff who assist with planning are knowledgeable and respectful.	1.41	○
Choice and Control	<i>Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.</i>	Families control their own budgets/supports (i.e., they choose what supports/goods to purchase).	2.10	◐
		Families choose, hire, and manage their service/support providers.	1.53	○
		Staff are respectful of the family choices and decisions.	1.32	○
Access and Support Delivery	<i>Families/family members with disabilities get the services and supports they need.</i>	Having access to an adequate array of services and supports.	1.23	○
		Services/supports are available when needed, even in a crisis.	1.55	○
		Staff or translators are available to provide information, services, and supports in the family/family member's primary language/method of communication.	1.71	◐
		Services/supports are flexible to meet the changing needs of the family.	1.85	◐
		Service and support staff/providers are available and capable of meeting family needs.	1.53	○
Community Connections	<i>Families/family members with disabilities use integrated community services and participate in everyday community activities.</i>	Families/family members with disabilities participate in integrated activities in their communities.	1.86	◐
		Families are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	1.94	◐
Satisfaction	<i>Families/family members with disabilities receive adequate and satisfactory supports.</i>	Families are satisfied with the information and supports received, and with the planning, decision-making, and grievance processes.	1.67	◐
Family Outcomes	<i>Individual and family supports make a positive difference in the lives of families.</i>	Families feel that services and supports have helped them to better care for their family member living at home.	1.30	○

Demographics of Person Completing Survey for CWP

Table 94 provides information about the respondent.

Table 94 CWP Respondent Demographics

Demographics		
Age		%
	Under 55	100
	55 and Over	0
Relation to Child		
	Parent	95
	Grandparent	0
	Other	5
Primary Caregiver		
	Yes	100
	No	0
Health Status		
	Excellent	20
	Good	45
	Fair	30
	Poor	5
Other Services and Supports Received		
	SSI Financial Support	70
	Other Financial Support	22
	In-Home Support	85
	Out-of-Home Respite Care	47
	Early Intervention	0
	Transportation	21
	Specialized Services and Supports	50

Comments

Of the 20 returned surveys for CWP, 60% included comments. The most frequently mentioned comment from respondents was:

- overall satisfaction with services – services and supports have met needs to help keep family member at home.

Other issues reported include:

- accessing services – the inability to access a needed service
- program services – lack of services or supports needed or not able to meet eligibility requirements
- staff training – the lack of adequate training to carry out or respond to service needs
- survey tool – survey tool was not clear or the respondent did not understand the program connection to DADS

Medically Dependent Children Program

The Medically Dependent Children Program (MDCP) provides a variety of services to support families caring for children under the age of 21 who are medically dependent and to encourage de-institutionalization of children in nursing facilities. Services in this program include adaptive aides, adjunct support services, minor home modifications, and respite.

All 942 families who received MDCP services and supports were mailed a survey. DADS received a total of 361 completed surveys or 38% of the total. Table 95 provides information about the children receiving services.

Table 95 MDCP Child Demographics

Demographics		%
Gender	Male	55
	Female	45
Age	0-3	8
	4-10	33
	11-15	43
	16-21	16
Ethnicity	Black	10
	Hispanic	26
	White	62
	Other	2
More than one child with a disability in household	Yes	10
	No	90
Level of help needed for daily activities (such as bathing, dressing, eating)	None	2
	Little	4
	Moderate	21
	Complete	73
Diagnoses	Mental Retardation	51
	Developmental Disabilities	51
	Mental Illness	4
	Autism	8
	Cerebral Palsy	43
	Brain Injury	22
	Seizure Disorder	56
	Chemical Dependency	1
	Vision or Hearing Impairments	56
	Physical Disabilities	67
	Communication Disorder	49
	Down Syndrome	3
	Other Disability	52

Table 96 MDCP Child/Family Summary Scores

The questions from the Children/Family Survey used to calculate the indicators are available on the table crosswalk (Appendix E). This table shows the Domain, Sub-Domain, Concern, Indicator, and summary scores of all 16 indicators for the MDCP Program.

● = Lowest Agreement (2.34 – 3.00) ◐ = Moderate Agreement (1.67 – 2.33) ○ = Highest Agreement (1.00 – 1.66)

Domain	Overview: The family indicators concern how well the public system assists children with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.			
Sub-Domain	Concern	Indicator	Summary Scores	
Information and Planning	<i>Families/family members with disabilities have the information and support necessary to plan for their services and supports.</i>	Families are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits) in a way that is easy to understand.	1.86	◐
		Families have the information needed to skillfully plan for their services and supports.	1.88	◐
		The support plan includes or reflects things that are important to the family.	1.40	○
		Staff who assist with planning are knowledgeable and respectful.	1.46	○
Choice and Control	<i>Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.</i>	Families control their own budgets/supports (i.e., they choose what supports/goods to purchase).	2.09	◐
		Families choose, hire, and manage their service/support providers.	1.39	○
		Staff are respectful of the family choices and decisions.	1.23	○
Access and Support Delivery	<i>Families/family members with disabilities get the services and supports they need.</i>	Having access to an adequate array of services and supports.	1.36	○
		Services/supports are available when needed, even in a crisis.	1.74	◐
		Staff or translators are available to provide information, services, and supports in the family/family member's primary language/method of communication.	1.80	◐
		Services/supports are flexible to meet the changing needs of the family.	1.99	◐
		Service and support staff/providers are available and capable of meeting family needs.	1.59	○
Community Connections	<i>Families/family members with disabilities use integrated community services and participate in everyday community activities.</i>	Families/family members with disabilities participate in integrated activities in their communities.	1.95	◐
		Families are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	2.11	◐
Satisfaction	<i>Families/family members with disabilities receive adequate and satisfactory supports.</i>	Families are satisfied with the information and supports received, and with the planning, decision-making, and grievance processes.	1.73	◐
Family Outcomes	<i>Individual and family supports make a positive difference in the lives of families.</i>	Families feel that services and supports have helped them to better care for their family member living at home.	1.24	○

Demographics of Person Completing Survey for MDCP

Table 97 provides information about the respondent.

Table 97 MDCP Respondent Demographics

Demographics		
Age		%
	Under 55	93
	55 and Over	6
Relation to Child		
	Parent	94
	Grandparent	5
	Other	1
Primary Caregiver		
	Yes	100
	No	0
Health Status		
	Excellent	20
	Good	58
	Fair	19
	Poor	3
Other Services and Supports Received		
	SSI Financial Support	39
	Other Financial Support	21
	In-Home Support	88
	Out-of-Home Respite Care	20
	Early Intervention	11
	Transportation	14
	Specialized Services and Supports	67

Comments

Of the 361 returned surveys for MDCP, 36% included comments. The most frequently mentioned comment from respondents was:

- overall satisfaction with services – services and supports have met needs to help keep family member at home.

Other issues reported include:

- program services – lack of services or supports needed or not able to meet eligibility requirements
- services/service providers – the inability to get services or find service providers
- information – lack of information regarding programs and services
- accessing services – the inability to access a needed service

5.0 Conclusion

Summary of NCI Findings (CLASS, CWP, DBMD, HCS, ICF/MR, STATE MENTAL RETARDATION FACILITIES, and TxHmL Programs)

The majority of people in Texas who receive services in the home and community-based, state mental retardation facilities, and Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) programs report satisfaction with their services and their lives. They have relationships with friends and family, receive accessible and responsive support from their case manager/service coordinator, are able to make choices about many aspects of their lives, and generally participate in community life.

While the majority of findings were generally positive, there is room for further analysis and opportunities for improvement. One of these areas is control over life decisions. More people need to have the opportunity to choose from more than one place to live and work. Choosing people to live within a residence is another quality indicator related to choice that appears to need improvement. Only 29% of people in ICFs/MR and 19% of people in state mental retardation facilities report having a choice about the people with whom they live. In contrast, approximately 95% of people in the Consolidated Waiver Program (CWP), and Community Living Assistance and Support Services (CLASS) Programs, and 87% of the people in the Texas Home Living (TxHmL) Program report having a choice.

Total integration into the community is another area that should be examined closer. It is noteworthy that most people across services do engage in personal activities of daily life within their communities. However, findings show that very few people in any program attend community meetings, exercise, or play sports in a community setting, which suggests they are not truly integrated into mainstream society.

Although most people go to appointments and run errands, people in some programs do not secure needed health services. According to the survey, very few women in the CLASS, CWP, and TxHmL Programs have had a gynecological visit in the past year. Most women in the other programs have. Routine dental exams is another area of concern that deserves attention, especially for people receiving CLASS services. Only about 17% of people in the CLASS program, whether or not they use the Consumer Directed Services (CDS) option, have had a routine dental exam in the past six months. Most people receiving services in the Home and Community-Based Services (HCS), ICF/MR, and state mental retardation facility programs have had a dental visit in the past six months.

What is unclear, and not addressed in this survey, is the reason for the health services not being obtained. It may be that people choose not to have annual exams and bi-annual dental visits or it may be that finding Medicaid providers is a barrier. Education is needed to inform people who receive services about the benefits of routine health monitoring. Further research will be needed to determine the cause for this area of concern.

For most people, across programs, few participate in self-advocacy activities, or in other groups that address rights. With the exception of people receiving services in state mental retardation facilities, a minority of people are involved in self-advocacy, or go to events to learn about self-advocacy. Moreover, only about half of the people receiving services in state mental retardation facilities have had this opportunity or do participate.

Finally, having access to, and control, over transportation is an issue for some people, primarily those receiving services in state mental retardation facilities. Only 23% of people in state mental retardation facilities have control over their transportation, and only 38% feel that they have adequate transportation. Control over transportation is relatively low for people receiving services in ICF/MR and TxHmL programs, too. Conversely, most people who receive CLASS services and use the CDS option have control over transportation and most of the people in the

CLASS, CWP, Deaf-Blind with Multiple Disabilities (DBMD), and HCS programs feel that they have adequate transportation.

CLASS Service Option Comparisons

Another goal of this study is to identify differences between quality indicators for people receiving CLASS Program services who use the CDS option to those who do not. In general, people receiving CLASS services who use the CDS option were less likely to have a guardian, more likely to speak English as their primary language, required medical care less often, and needed less support to prevent disruptive behavior. With regard to the quality indicators, people receiving CLASS services who use the CDS option tended to have more control over and knowledge about their services, transportation, and decisions. They also felt safer in their homes and more satisfied with their personal lives. Finally, they report feeling lonely less often than people who do not use the CDS option.

State Mental Retardation Facilities and ICF/MR Comparisons

Comparisons were also made between quality indicators for people receiving services in state mental retardation facilities and people receiving services in ICFs/MR. In general, people receiving services in ICF/MR facilities tend to be more satisfied with where they live, have more control over and access to transportation, and are more integrated into the community. On the other hand, people receiving services in state mental retardation facilities are more likely to have friends other than family members and support staff and are more likely to have had the opportunity to participate in self-advocacy activities.

Summary of PES/ED Findings (CBA Program)

Overall, people who receive Community-Based Alternatives (CBA) services have their basic needs met. They have access to care and are receiving support to prepare meals, eat, and receive needed medications. In addition, they feel they are respected by their day and home staff. Many report they have support to live the life they choose by being free to take risks when they want to, have close relationships, and decide who comes into their home. In general, they feel they are safe from abuse and exploitation.

Conversely, there is a significant need for community involvement. Many report case managers are not available and responsive. About a third wish to choose their care staff but do not. Finally, a substantial number of people who are not working currently would like to.

Summary of Children and Family Findings (CLASS, CWP, HCS, TxHmL, and MDCP Programs)

Most families in all programs report that services and supports have helped them to care for their family member more effectively and that staff are respectful of their choices. In addition, the majority report that their support plan includes or reflects things that are important to the family and staff who assist with planning are knowledgeable and respectful. Families who have children receiving services in CLASS report satisfaction with the level of control they have over their budgets.

Lower indicators for choice and control in the HCS, TxHmL, and CWP programs are not surprising because the CDS option was not available in these programs. As this option is used by more people, this indicator is expected to improve. The results indicate that families would like to have more information that is easy to understand in order to plan for their services and supports. Similar to the results of the face-to-face surveys, families report an unmet need for integrated community participation.

Recommendations Based on Last Year's Findings

Many of the areas where it appears people are having less positive experiences this year were reported similarly in 2005 despite the differences in methodologies. Because of the more robust analysis of the data this year, progress cannot be measured through comparative analysis. The 2005 survey results were shared with an internal agency workgroup and the task force members of the 2003 Real Choice Systems Change grant for Quality Assurance and Quality Improvement (QAQI). Both groups were asked to identify and prioritize indicators they felt needed improvement or further exploration. Both groups agreed that the areas of *self-advocacy* and *personal life decisions* were areas that the department, in partnership with stakeholders, should consider addressing first. Task force members believed that if more people receiving services advocated for themselves and were more aware of their rights, then improvements would be seen in other areas.

Both groups were asked to provide recommendations on ways to improve self-advocacy and personal life decisions. The state mental retardation facilities staff piloted a new person-directed planning process aimed at developing a Personal Support Plan that is directed by the person served or their legally authorized representative as applicable. The emphasis is placed on supporting the person in making choices about their lives and the development of a plan to support choices and identified areas of needs. Based on the success of the pilot, efforts are now underway to implement the person-directed planning process and establish self-advocacy groups at all state mental retardation facilities. In addition, information on life decision opportunities for individuals, methods for engaging individuals to participate and make decisions, and materials that providers can use to inform people of self-advocacy opportunities were addressed in training sessions at the 2006 DADS ICF/MR Provider & Surveyor Conference.

Current long-range plans include developing a monitoring tool that will be used when monitoring home and community-based contract performance. Discussions have begun on how to incorporate self-determination, choice, and service outcomes with the more traditional components necessary to minimize risk to people receiving services. The framework used by the Centers for Medicare & Medicaid Services (CMS) may serve as a starting point for the development of this monitoring tool. Although much work remains to be done in this area, it is anticipated that the results of reviews based on the proposed tool can help stakeholders make comparisons regarding providers' performance.

Recommendations

Person-directed Planning

The state mental retardation facilities staff piloted a new person-directed planning process aimed at developing a Personal Support Plan (PSP). The person served or their legally authorized representative, as applicable, directs the plan. The emphasis is placed on supporting the person in making choices about their lives and the development of a plan to support choices and identified areas of needs. Based on the success of the pilot, it is recommended to continue efforts to implement or enhance the person-directed planning process in all programs. In addition, it is recommended that information on person-directed planning be provided to more people who receive services in all programs through literature dissemination, conferences, and other events.

Conduct further research

Conduct additional research to determine recommendations related to the low occurrence of people who receive routine health monitoring.

Consumer Advocacy

Conduct at least one symposium/educational opportunity that targets consumer advocacy. Provide this report and results to a broad audience of advocates, family members, and providers to assist with implementing additional best-practice initiatives on their own.

Expand the Consumer Directed Services Option

Continue efforts to expand the CDS option to all programs.

Quality Monitoring Program

The Quality Monitoring (QM) Program helps nursing facility providers improve resident care through quality consultants who provide technical assistance and information about evidence-based best practices. Information and best practices are published on the QMWeb²⁸, which is a website of evidence-based best practice frameworks compiled from systematic clinical literature reviews. The QM Program can be expanded to home and community-based programs and create partnerships with providers to enhance the program.

Improve DADS websites

Conduct usability studies for the DADS websites to ensure that information is easily accessed and understood by the general public. Educate the public about the Quality Reporting System (QRS) on the DADS site to obtain specific information about a particular long-term services and supports provider, or to compare providers in a particular area. QRS provides information that can help identify providers that may meet families' needs.²⁹

Consumer Survey Process

Continue the consumer survey process as an annual activity to measure progress and assist with planning program improvements, through trend analysis, over time. This will be another valuable tool to assist with quality assurance programs.

One limitation of this study is the inability to compare the 2005 and 2006 results. Being able to trend over time is essential to enable DADS and other stakeholders to evaluate quality improvement strategies. Another limitation is the small sample sizes for some programs. For 2007, over-sampling will be conducted in some programs in order to obtain larger sample sizes.

Finally, these results reflect the opinions and perceptions of the people, and families of people, who receive services and supports through DADS programs. This input is an important component when evaluating existing programs and planning for future initiatives to support the mission of DADS. By gauging program performance through direct feedback, DADS can identify areas where services and supports are resulting in more positive experiences and where they are not. DADS will continue to work with internal agency program areas and external federal, state, and local partners to use the results of this study to implement interventions designed to improve its long-term services and supports.

²⁸ QMWeb: <http://mqa.dads.state.tx.us/QMWeb>

²⁹ QRS: <http://facilityquality.dads.state.tx.us>

Appendix A

National Core Indicators (NCI) Survey

See next page



CONSUMER SURVEY

TEXAS
2006

Pre-Survey Form

BI-1. Survey Code: _____
(ID number)

Note: This code should be provided by the state project coordinator and is for data analysis purposes only. A unique code number should be assigned to each person. Do not use a number that could possibly identify the person (do NOT use social security numbers).

P.1 Interviewer code ___ ___

P.2 Interview Date: ____ / ____ / ____ mm/dd/yyyy

P.3 Reason for Not Participating in Survey:

1. ___ Sick/Hospitalized 2. ___ Participant Declined 3. ___ Guardian declined
4. Reason for Decline (specify) _____

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Guardian information, if applicable:

Guardian Name: First _____ Last _____

Relationship: _____ **Phone:**(_____) _____

PS-1. Contact... Who should the interviewer call to arrange an interview with this person (consumer, parent/guardian, service coordinator, day or residential program staff, etc.)?

Name: First: _____ Last: _____

Relationship: _____ DaytimePhone: _____

Evening Phone: _____ Cell Phone: _____

Note... We would like to talk with persons alone, when appropriate. Some persons may feel uncomfortable with strangers, may have community protection issues, or may have medical or behavioral issues that require them to be under constant supervision by a trained caregiver.

Do you recommend that a caregiver be present while this person is interviewed?

2. ___ Yes 1. ___ No

PS-2. Communication needs... Does this person have any special communication needs? (Examples: primary language other than English, sign language, communication board.) Please explain what arrangements are needed for the interview.

PS-3. Case Manager/Service Coordinator/QMRP... What is the name and phone number of this person's case manager/service coordinator/qualified mental retardation professional?

Name: First: _____ Last: _____

Phone: _____ Cell Phone: _____

PS-4. Advocate... If this person has someone who helps represent him/her at planning meetings and in making important decisions, please provide the advocate's name and relationship. (Note: this may include staff, family, friends, or guardians who are involved in the person's life.)

Name: First _____ Last _____

Relationship: _____

PS-5. Other Interviewees... If this person is unable or unwilling to complete Section II of the survey, please indicate the name(s) and number(s) of others who know the person well and could respond on his/her behalf.

Name: First: _____ Last: _____

Relationship: _____ Phone: _____

PS-7. Support Staff in the Home and During the Day... If there are any people who are paid to provide supports in this person's home, please indicate their first names. If there are several workers, please list the primary staff who spend the most time with this person. Also indicate the first names of any day and/or job support staff.

Home Support Staff: First Name

Day Support Staff/Job Support Staff/Coach: First Name _____

PS-8. Job/Day Activities... If applicable, please indicate what this person calls his/her job, school or day activity program.

Place of work: _____

PS-8a. School: _____

PS-8b. Day program: _____

DAY / VOCATIONAL / EDUCATIONAL SUPPORT

The table below lists six types of vocational/employment services and other day supports. Please see the next two pages for definitions of terms used on this form.

For the most recent month possible, please enter

- a) number of hours worked or spent in each activity; and
- b) total gross wages earned for each category of paid work.

NOTE: Please enter "999" (for hours) and "9999" (for wages) to indicate not applicable. If the person received no salary or worked zero hours enter "0". All other cases enter actual number.

	a) Number of hours at this activity in the last month	b) Total gross wages earned in the last month
S1. Competitive Employment	_ _ _ _	\$ _ _ _ _ . _ _ _
S2. Individual Supported Employment	_ _ _ _	\$ _ _ _ _ . _ _ _
S3. Group Supported Employment	_ _ _ _	\$ _ _ _ _ . _ _ _
S4. Facility-Based Work Programs	_ _ _ _	\$ _ _ _ _ . _ _ _
S5. Facility-Based Non-Work Activities	_ _ _ _	N/A
S6. Community-Based Non-Work Activities	_ _ _ _	N/A

S7. Is this person enrolled in the public school system?

- (1) No
- (2) Yes

S8. What agency or program pays for the day / vocational services this person receives? Please check all that apply.

- (1) HCBS Waiver Program (including Federal + State Match)
- (2) State MR/DD Agency
- (3) Vocational Rehabilitation Agency
- (4) PAS/IRWE Plan (person is buying some of his/her own supports)
- (5) Other
- (6) Not applicable – person does not receive any day / vocational services

Community Employment – If the person has a job in the community (either competitive or supported employment), please answer the following questions:

S9. Did this person work 10 out of the last 12 months in a community job? (Person may have changed jobs or had periods of unemployment/transition.)	(circle one) Yes No N/A
S10. Does this person receive benefits at his/her community job? (e.g. paid vacation, sick time, health insurance)	(circle one) Yes No N/A
S11. How long has this person been working at his/her current job in the community?	__ __ years __ __ months

DEFINITIONS

The term “day supports” means the regular provision of publicly funded training and other assistance to adults with developmental disabilities outside their living arrangement. Day supports include services that are work-oriented, habilitative in nature and/or intended to promote community presence and participation.

For reporting purposes, we have defined six generic subcategories of day supports and other employment.

- **Competitive Employment.** Individuals have a job of their own in the community but are not receiving “supported employment” – that is, they do not routinely receive community job supports or job coaching. They may have access to supports as needed or may receive “follow-along” but is basically working on their own.
- **Individual Supported Employment.** Individuals have a job with a community employer and receive periodic publicly-funded assistance, training and support aimed at securing and/or maintaining employment and/or improving job skills;
- **Group Supported Employment.** Two or more individuals are employed by a community provider agency and perform work as employees of the provider agency at sites in the community (e.g., mobile crews). Group supported employment also includes persons who are employed in an affirmative industry or as part of an enclave;

- **Facility-based Work Programs.** Take place in settings such as sheltered workshops or work activity centers. Individuals are paid a wage in exchange for their production-related activities. They are employed by the provider agency;
- **Facility-Based Non-Work Activities.** Take place at a provider facility and involve the provision of training and other services and supports that are not paid work. These services are commonly labeled “day habilitation,” “day training,” or “day treatment.” Seniors programs and job training programs also fall into this category; and,
- **Community-Based Non-Work Activities.** Includes the provision of training and assistance that enables individuals to participate in community activities, by serving as volunteers, recreating and/or learning skills important for community living. These activities take place away from provider-operated facilities.
- **Total Wages.** Wages earned means the total gross amount (before deductions) actually paid to individuals during the last month. In some cases, there is a difference between the wage rate charged to the business where the person works and the amount actually paid to the individual (e.g., the provider agency functions as an “employment agency” and charges the community business a higher hourly rate than the rate paid to the individual). For data collection purposes, the amount reported should be the total amount paid to individuals by type of day support during the most recent month for which data is available.
- **Number of Hours at this Activity.** For the various work categories, the total number of hours of compensated work during the last month should be reported.

Please note: In the case of individuals who are working in a facility, time in the facility when the person is not earning a wage (e.g., is not engaged in work) should be counted as hours of facility-based non-work activity. For example, if a person is at a facility for 126 hours during the month and is engaged in paid work for 83 hours, the remaining 43 hours would be reported as facility-based non-work activities.

PS-9. Self-Advocacy Organization... What self-advocacy groups are active and well-known in the person's area? (Examples: People First, Self-Advocates Becoming Empowered, Speaking for Ourselves.)

BI-7. Does this person have a legal guardian or conservator appointed?

(check one)

- 1 No, person is independent of guardianship (legally competent or presumed competent)
- 2 Yes, person has private guardian or conservator (including parent/relative or non-relative)
- 3 Yes, person has public guardian or conservator
- 4 Don't know

BI-9. Marital status: (check one)

- 1 Single, never married
- 2 Married
- 3 Single, married in past
- 4 Don't know

BI-12. What is this person's primary language? (What language does s/he understand?)

- 1 English
- 2 Other

BI-13. What is this person's primary means of expression? (check one – most frequently used)

- 1 Spoken
- 2 Gestures/body language
- 3 Sign language or finger spelling
- 4 Communication aid/device
- 5 Other
- 6 Don't know

BI-14. How would you describe this person's mobility? (check one)

- 1 Can move self around environment; walks (with or without aids) or uses wheelchair
- 2 Non-ambulatory, needs assistance to move around environment
- 3 Don't know

BI-16. Does this person currently take medications for...

(check one column for each question):

no yes don't
 know

- 1 2 3 Mood disorders? [Includes any drug prescribed to elevate or stabilize mood (reduce mood swings), e.g., to treat depression, mania, or bipolar disorder.]
- 1 2 3 Anxiety? [Includes any drug prescribed to treat anxiety disorders (including obsessive disorders and panic disorders) or to reduce anxiety symptoms.]
- 1 2 3 Behavior problems? [Includes any drug prescribed for a behavior modification purpose (such as a stimulant, sedative, or beta-blocker), e.g., to treat ADHD, aggression, self-injurious behavior, etc.]
- 1 2 3 Psychotic disorders? [Includes any drug (e.g., anti-psychotic or "neuroleptic") used to treat psychotic disorders such as schizophrenia or psychotic symptoms such as hallucinations.]

BI-17. If this person has seizures, how often do they occur? (check one)

- 0 **NOT APPLICABLE** -- does not have seizures
- 1 Less frequently than once/month
- 2 At least once/month, but not once a week
- 3 At least once/week, or more frequently
- 4 Don't know or not available in records

BI-18. How often does this person require medical care? (check one) (Medical care refers to care that must be performed or delegated by a nurse or physician. Do not include medication administration.)

- 1 Less frequently than once/month
- 2 At least once/month, but not once a week
- 3 At least once/week, or more frequently
- 4 Don't know or not available in records

BI-19. When was his/her last physical exam? (check one)

- 1 In the past year
- 2 Over one year ago
- 3 Don't know or not available in records

BI-20. If female, when was her last OB/GYN exam? (check one)

- 0 **NOT APPLICABLE** -- male
- 1 In the past year
- 2 Over one year ago
- 3 Has never had an OB/GYN exam
- 4 Don't know or not available in records

BI-21. When was his/her last dentist visit? (check one)

- 1 In the last six months
- 2 Over six months ago
- 3 Don't know or not available in records

BI-23. Does this person smoke or chew tobacco?

- 1 No
- 2 Yes
- 3 Don't know

BI-25. How long has this person lived in his/her current home (or with the same caregiver)? Do not count moves with same caregiver.

- 1 Less than 1 year
- 2 1-2 years
- 3 3-5 years
- 4 Over 5 years
- 5 Don't know or not available in records

BI-27. Who owns or leases the place where this person lives? (check one)

- 1 Family, guardian, or friend
- 2 Private agency or home provider/foster family
- 3 State or County agency
- 4 Person rents home (name is on the lease)
- 5 Person owns home (name is on the title)
- 6 Don't know
- 7 Other

BI-37. Does this person need support to prevent self-injury? "Self-injury" refers to attempts to cause harm to one's own body, for example, by hitting or biting self, banging head, scratching or puncturing skin.

- 1 No
- 2 Yes
- 3 Don't Know

BI-37a. If yes, how often does the person need support to manage this behavior? (check one)

- 1 Needs occasional support, less frequently than once/month
- 2 At least once/month, but not once a week
- 3 At least once/week, or more frequently
- 8 Not applicable (no support needed or don't know)

BI-38. Does this person need support to prevent disruptive behavior?

“Disruptive behavior” refers to emotional outbursts that interfere with the activities of others, for example, by starting fights, laughing or crying without apparent reason, yelling or screaming, cursing, throwing objects, or threatening violence.

- 1 No
- 2 Yes
- 3 Don't Know

BI-38a. If yes, how often does the person need support to manage this behavior? (check one)


- 1 Needs occasional support, less frequently than once/month
- 2 At least once/month, but not once a week
- 3 At least once/week, or more frequently
- 8 Not applicable (no support needed or don't know)

Please indicate who provided all of this pre-survey information: (check yes to all that apply and no to all that do not apply)

- | | | | |
|---------|--------------------------------|---------------------------------|--|
| BI.99.1 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Person receiving services |
| BI.99.2 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Advocate, Parent, Guardian, Personal Representative, Relative |
| BI.99.3 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Staff who provides supports where person lives |
| BI.99.4 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Staff who provides supports at a day or other service location |
| BI.99.5 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Case Manager, service coordinator, social worker |
| BI.99.6 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Other Person |
| BI.99.7 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | State data system |

SECTION I: Direct Interview with Person Receiving Services and Supports

General Instructions:

- ✧ This section may only be completed by directly interviewing the person receiving services and supports.
- ✧ Do not use responses from any other person to complete this section.
- ✧ Consumers may skip any question. If the person receiving services does not respond to a question or gives an unclear response, code the question as "9."
- ✧ Do not leave any questions blank.
- ✧ Be sure to read all instructions carefully.
- ✧ If possible, the interview should be conducted in private. Parents or guardians may be present if they insist. Others may be present if the consumer requests it, or if another person is needed for interpretation purposes. If staff believe that a private interview may pose risks to interviewers, then staff should be present. If others are providing assistance, interviewers should emphasize that we are trying to find out the consumer's perspective.
- ✧ Help the person with any words that are not understood. You may repeat or rephrase questions to improve understanding. Some questions have suggested rephrasing in parentheses - you do not need to limit yourself to these suggestions.
- ✧ Prior to the interview, interviewers should use the pre-survey form to fill in the blanks throughout the survey. Using familiar names and terms during the interview will help ensure that the person understands the questions. Questions that refer to pre-survey information are indicated with a bell symbol: 
- ✧ A wide margin is provided for recording notes as necessary. Please be sure to fill out the Interviewer Feedback Sheet after each interview.

Take a few minutes to introduce yourself and make the person feel comfortable. Read or paraphrase the following introduction. Pause after each statement, making sure the respondent understands.

“Hi, my name is _____ and I'm from NACES Plus Foundation. I'm here to conduct a survey for the Texas Department of Aging and Disability Services also known as DADS. I'd like to ask you some questions about where you live, where you work, your friends and family, and the people who help you. By answering these questions, you are helping DADS figure out how people in Texas are doing, and how to make supports and services better.”

“This is not a test, and there are no right or wrong answers to these questions. If you don't understand a question, let me know and I'll try to explain it. It's okay if you don't know how to answer.”

“You don't have to answer any questions that you don't want to. Just tell me if you don't want to answer.”

“I'd like to know your opinions, how you feel about things. Whatever you tell me will be kept private, so you can be honest.”

SECTION I: Direct Interview with Person Receiving Services and Supports

WORK / DAYTIME ACTIVITIES

For Questions 1-2, include all types of work and daytime activities - paid, unpaid, community-based jobs, supported employment, facility-based jobs, day programs, volunteer work, non-vocational programs, training facilities, etc. If respondent has more than one job/day activity, ask how s/he feels in general or "most of the time." If respondent works and attends school, ask about work only.


1. I'd like to start by asking you about what you do during the day – if you have a job or other place that you go to.

PS-8  Do you work at (go to) _____?

Do you like working (going) there?

- __8 **NOT APPLICABLE** – no job or day activity
- __2 Yes
- __1 In-between
- __0 No
- __9 Don't know, no response, unclear response

2. Do you have staff who help you there?

PS-7  Does _____ help you there?

If the person does not have a job or day activity or has no staff, code Question 2 as "NOT APPLICABLE."

Is s/he nice and polite to you?

- __8 **NOT APPLICABLE** - no job or day activity or no staff
- __2 Yes, most staff are nice
- __1 Some staff are nice
- __0 No, most staff are not nice
- __9 Don't know, no response, unclear response

HOME

Now I'm going to ask you about where you live.

3. Do you like your home or where you live? (*Do you like living here?*)

- _2 Yes
- _1 In-between
- _0 No
- _9 Don't know, no response, unclear response

4. Can you be alone if you want to? (*Can you have privacy?*)

Here we are looking at privacy (e.g. going in a room and closing the door), not the person's need for supervision (e.g. staying home alone).

- _8 **NOT APPLICABLE** - lives alone
- _2 Yes, has enough time alone
- _0 No, would like more time alone
- _9 Don't know, no response, unclear response

5. Are you ever afraid or scared when you are at home?

- _2 [Yes] - most of the time
- _1 Sometimes
- _0 [No] - rarely
- _9 Don't know, no response, unclear response

6. Are you ever afraid or scared when you are out in your neighborhood?

- _2 [Yes] - most of the time
- _1 Sometimes
- _0 [No] - rarely
- _9 Don't know, no response, unclear response

7. Do you have staff who help you where you live?

Does _____ help you at home?

Is s/he nice and polite to you?

- _8 **NOT APPLICABLE** - no home support staff
- _2 Yes
- _1 Sometimes
- _0 No
- _9 Don't know, no response, unclear response

PS-7



Do people let you know before they come into your home? (*Do they ring the doorbell or knock first and wait for an answer?*) Do not include people who live in the home.

- _2 Yes
- _1 Sometimes
- _0 No
- _9 Don't know, no response, unclear response

8. Do people let you know before coming into your bedroom?

- _2 Yes
- _1 Sometimes
- _0 No
- _9 Don't know, no response, unclear response

FRIENDS AND FAMILY

Now I'm going to ask you about friends.

9. Do you have a best friend, or someone you are really close to? (*Is there someone you can talk to about personal things?*)

If s/he indicates having a boyfriend or girlfriend, check "Yes."

- _2 Yes
- _0 No
- _9 Don't know, no response, unclear response

10. Do you have friends you like to talk to or do things with?

If s/he answers "yes," ask who the friends are and try to determine if they are family, staff, roommates, co-workers, etc. You can use prompts such as: *Can you tell me their names? Are these friends staff or your family?*

- _2 Yes, has friends who are not staff or family
- _1 Yes, all friends are staff or family, or cannot determine
- _0 No, does not have friends
- _9 Don't know, no response, unclear response



If the person responds "NO" TO BOTH QUESTIONS 10 AND 11, code Questions 12 as "NOT APPLICABLE." Also code Question 47 as "NOT APPLICABLE."

11. Can you see your friends when you want to see them? (*Can you make plans with your friends when you want to?*) We are trying to determine if person gets support to see friends. Try to factor out situations where friends are not available – this is not the issue.

- __8 **NOT APPLICABLE** – does not have any friends
- __2 Yes, can see friends whenever s/he wants to
- __1 Sometimes can't see friends (e.g. not enough staff or transportation)
- __0 No, often unable to see friends
- __9 Don't know, no response, unclear response

12. Do you ever feel lonely? (*Do you ever feel like you don't have anyone to talk to?*)
If s/he responds "yes," probe to determine how often s/he feels lonely.

- __2 [Yes] – often feels lonely
- __1 Sometimes
- __0 [No] – not often
- __9 Don't know, no response, unclear response

13. Do you have family that you see?

If the person lives with family, ask about other family members that do not live in the home.

Can you see your family when you want to? (*Can you pick the times you see them? Does someone help you make plans to see them?*)

If family is not available or does not wish to have contact, code as "NOT APPLICABLE." If the person has family but does not want to see them, code as "2."

- __8 **NOT APPLICABLE** – family not available, person does not have family or family does not wish to have contact
- __2 Yes, sees family whenever s/he wants to, or chooses not to see family
- __1 Sometimes
- __0 No
- __9 Don't know, no response, unclear response

SATISFACTION WITH SERVICES/SUPPORTS

ASK QUESTIONS 15-17 ONLY IF PERSON HAS A CASE MANAGER/SERVICE COORDINATOR. If person does not have a case manager/service coordinator, code these questions as "NOT APPLICABLE". If the person has a case manager/service coordinator but says they do not or do not know him/her, code questions 15-17 as "0."

14. Do you know your case manager/service coordinator?

Do you know _____?

_8 **NOT APPLICABLE** – person does not have case manager/service coordinator

_2 Yes, person knows case manager/service coordinator

_1 Maybe, not sure

_0 No, person does not know case manager/service coordinator

_9 **Don't know, no response, unclear response**

15. Does s/he ask you what you want?

_8 **NOT APPLICABLE** – person does not have case manager/service coordinator, or person does not talk to case manager

_2 Yes

_1 Sometimes

_0 No, does not ask or person does not know case manager/ service coordinator

_9 Don't know, no response, unclear response

17. If you ask for something, does s/he help you get what you need?

_8 **NOT APPLICABLE** – person does not have case manager/service coordinator, or person does not ask for help

_2 Yes, does help

_1 Sometimes helps

_0 No, does not help or person does not know case manager/ service coordinator

_9 Don't know, no response, unclear response

18. Do you know who your advocate or guardian is?

Is _____ your advocate or guardian?

_8 **NOT APPLICABLE** – has no advocate or is own guardian

_2 Yes

_1 Maybe, not sure

_0 No

_9 Don't know, no response, unclear response

PS-3



PS-4



19. Do people help you do or learn new things? *(For example, do you get to try new hobbies or learn new skills?)*

_2 Yes (code Q20 below as "8 – NOT APPLICABLE")

_1 Sometimes

_0 No

_9 Don't know, no response, unclear response

If person responds "No" or "Sometimes," ask Question 20. If "Yes" code Q20 as "8 – NOT APPLICABLE" and go to Q21.

20. Do you want [more] help to do or learn new things?

_8 NOT APPLICABLE (answered "Yes" above to Q19)

_2 Yes

_0 No

_9 Don't know, no response, unclear response

21. Are you happy with your personal life, or do you feel unhappy?

_2 **Happy**

_1 **In-between**

_0 **Unhappy**

_9 **Don't know, no response, unclear response**

22. When you want to go somewhere, do you always have a way to get there?
(Can you get a ride when you need one?)

_2 Yes, almost always

_1 Sometimes

_0 No, almost never

_9 Don't know, no response, unclear response

SELF-DETERMINATION

23. Do you know how much money is spent on paying for your staff? (*Do you know how much money is in your budget?*)
- 8 **NOT APPLICABLE** – does not use self-directed supports
 - 2 Yes
 - 1 Maybe, not sure
 - 0 No
 - 9 Don't know, no response, unclear response
24. When you have your annual meeting, does someone tell you how much money is in your budget? (*Does your case manager tell you how much money the agency has to pay for your staff or services?*)
- 8 **NOT APPLICABLE** – does not use self-directed supports
 - 2 Yes
 - 1 Maybe, not sure
 - 0 No
 - 9 Don't know, no response, unclear response
- 24a. Do you get to help other people? (*Do you get to teach things to other people?*)
- 2 Yes
 - 1 Sometimes
 - 0 No
 - 9 No response, unclear, don't know
- 24b. Can you have a close relationship, such as a boy friend or girlfriend, if you want one?
- 2 Yes
 - 1 Sometimes
 - 0 No
 - 9 No response, unclear, don't know
- 24c. Do you earn enough money to buy the things that you want?
- 2 Yes
 - 1 Sometimes
 - 0 No
 - 9 No response, unclear, don't know
- 24d. Are you free to take risks when you want to? (*Do you feel like it's okay if you make a mistake?*)
- 2 Yes
 - 1 Sometimes
 - 0 No
 - 9 No response, unclear, don't know

24e. Do you have control over your transportation? (*Can you plan a trip or decide when to go out?*)

- 2 Yes
- 1 Sometimes
- 0 No
- 9 No response, unclear, don't know

24f. Do you get to decide who comes in and out of your home?

- 2 Yes
- 1 Sometimes
- 0 No
- 9 No response, unclear, don't know

24g. Is there anything else you would like to talk to me about?

25. Interviewer: Could Section I be completed?

- 1 Yes, person answered independently or with some assistance
- 2 Yes, person answered using alternative/picture response format
- 3 No, person could not communicate sufficiently to complete this section
- 4 No, person was unwilling to participate
- 5 No, other reason

26. Interviewer: In your opinion, did the individual appear to understand most of the questions or not?

- 8 **NOT APPLICABLE** – did not complete
- 2 Yes, appeared to understand most questions (even if prompted) and could give an opinion
- 1 Not sure
- 0 No, appeared to have very little understanding or comprehension

27. Interviewer: In your opinion, did the individual seem to answer the questions in a consistent manner? (Do you feel his/her responses were valid?)

- 8 NOT APPLICABLE – did not complete
- 2 Yes, seemed to give consistent and valid responses
- 1 Not sure
- 0 No, did not seem to give consistent and valid responses

If you answered "yes" to questions 25-27, then determine now if s/he is willing to answer more questions. If the consumer is not willing to continue, or if you believe comprehension or consistency was a problem, then say:

"Thank you for your help. It's been very nice talking to you. You've been very helpful."

If the person receiving services has completed Section I, but has become tired or does not wish to continue with this section, you may interview others that know the person well enough. Use alternative wording when questioning other respondents. Also, check the appropriate box to indicate who is responding.

Otherwise, continue to the next section.

Check here if Section II not completed

If checked - Go to Interviewer Feedback Sheet on last page.

SECTION II: Interview with the Person Receiving Services or with Other Respondents

Interview the person receiving services if possible. If you are unable to interview the person, other respondents may be interviewed (family, advocate, staff) if they are knowledgeable in the areas below.

Ask the person if s/he wishes to continue with the questions, or if s/he would like to take a short break.

COMMUNITY INCLUSION

In this section, we are trying to find out if the person participates in integrated activities. Try to rule out non-integrated activities, for example, Special Olympics. If the person answers "yes," you may ask for an example to verify that the person understood the question.

28. Do you (does this person) go shopping? (*What do you go shopping for? Examples: groceries, clothing, house-wares, tapes/CDs.*)

_2 Yes

_0 No

_9 No response, unclear, don't know

28R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

29. Do you (does this person) go out on errands or appointments? (*Where do you go? Examples: doctor, dentist, bank, post office, hair dressers/barber.*)

_2 Yes

_0 No

_9 No response, unclear, don't know

29R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

30. Do you (does this person) go out for entertainment? (*Where do you go? Examples: movies, library, plays, concerts, museums, art galleries.*)

_2 Yes

_0 No

_9 No response, unclear, don't know

30R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

31. Do you (does this person) always eat at home, or do you sometimes go out to eat? (*What restaurants do you go to?*)

- _2 Sometimes goes out to eat
- _0 Always eats at home
- _9 No response, unclear, don't know

31R. **Indicate respondent:**

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

32. Do you (does this person) go to religious services? (*Where do you go? Examples: church, synagogue, or other place of worship.*)

- _2 Yes
- _0 No
- _9 No response, unclear, don't know

32R. **Indicate respondent:**

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

33. Do you (does this person) go to other meetings in the community? (*Where do you go? Examples: Elks meetings, political groups, hobby groups, Chamber of Commerce, Rotary Club, Civic League, Town Meetings, etc .*)

- _2 Yes
- _0 No
- _9 No response, unclear, don't know

33R. **Indicate respondent:**

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

34. Do you (does this person) exercise or play sports? (*What kind of exercise? Examples: jogging, swimming, riding bike, etc.*)

- _2 Yes, in a community setting
- _1 Yes, gets exercise but in a non-integrated setting
- _0 No
- _9 No response, unclear, don't know

34R. **Indicate respondent:**

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

CHOICES

If the person lives with his/her family, code questions 35-37 as "NOT APPLICABLE".

35. Who chose (or picked) the place where you live? (*Did you choose by yourself or with help?*)

(**Other respondent:** *Who chose the place where s/he lives? Did s/he have any input in making the decision?*)

- _8 NOT APPLICABLE – lives with family
- _2 Person chose without help
- _1 Person had some input
- _0 Someone else chose
- _9 Don't know, no response, unclear response

35R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

36. How many places did you visit before moving here?

(**Other respondent** – *How many places did s/he look at before moving in?*)

- _8 NOT APPLICABLE – lives with family
- _2 Looked at more than one place
- _1 Visited one place only
- _0 Did not visit before moving in
- _9 Don't know, no response, unclear response, can't remember – too long

36R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

37. Did you choose (or pick) the people you live with (or did you choose to live by yourself)? (*Did anyone ask you whom you'd like to live with? Were you given choices, did you get to interview people?*)

Other respondent – *Did this person choose any of the people s/he lives with?*

Or: Did this person choose to live alone?

- _8 NOT APPLICABLE – lives with family
- _2 Yes, chose people s/he lives with, or chose to live alone
- _1 Chose some people or had some input
- _0 No, someone else chose
- _9 Don't know, no response, unclear response

37R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

38. Do you choose (or pick) who helps you at home? (*Do you get to interview them? Did you get to meet different people or was someone assigned to you? If you wanted to change, could you ask for someone different?*)

Did you choose _____ to work with you?

(*Other respondent* – *Does this person choose his/her residential staff?*)

- 8 NOT APPLICABLE - no staff in the home
- 2 Yes, person chooses staff
- 1 Staff are assigned but s/he can request a change if not satisfied
- 0 No, someone else chooses
- 9 Don't know, no response, unclear response

38R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

39. Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)?

(*Other respondent* – *Who decides this person's daily schedule, like when to get up, when to eat, when to go to sleep?*)

- 2 Person decides
- 1 Person has help deciding
- 0 Someone else decides
- 9 Don't know, no response, unclear response

39R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

40. Who decides how you spend your free time (when you are not working, in school or at the day program)?

(*Other respondent* – *Who decides how this person spends his/her free time?*)

- 2 Person decides
- 1 Person has help deciding
- 0 Someone else decides
- 9 Don't know, no response, unclear response

40R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

NOTE: For Questions 41-43, do not include school. If respondent works and attends school, ask about work only.

41. Who chose (or picked) the place where you work (or go during the day)?

(Did you choose by yourself or with help?)

_8 **NOT APPLICABLE** – no work or day activity

_2 Person chose without help

_1 Person had some input

_0 Someone else chose

_9 Don't know, no response, unclear response

PS-8



Did you choose to work at (go to) _____ ?

(Other respondent: Who chose the place where s/he works or goes during the day? Did s/he have any input in making the decision?)

41R. **Indicate respondent:**

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

42. How many places did you visit before working (going) there?

(Other respondent – How many places did s/he look at before working/going there?)

_8 **NOT APPLICABLE** – no work or day activity

_2 Looked at more than one place

_1 Visited one place only

_0 Did not visit beforehand

_9 Don't know, no response, unclear response, can't remember – too long ago

42R. **Indicate respondent:**

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

43. Do you choose (or pick) who helps you at work? *(Do you get to interview them? Was someone assigned to you? Could you request someone different?)*

Did you choose _____ to help you at work?

(Other respondent – Does this person choose his/her work/day activity staff?)

_8 **NOT APPLICABLE** - no job or day activity staff

_2 Yes

_1 Some staff, or staff are assigned but s/he can request someone different

_0 No

_9 Don't know, no response, unclear response

43R. **Indicate respondent:**

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

PS-7



44. Do you choose what you buy with your spending money?

Do not include things like rent or groceries.

(Other respondent – Does this person choose how to spend his/her money?)

_2 Person chooses

_1 Person has help choosing what to buy, or has set limits (such as can buy small items, but not big items)

_0 Someone else chooses

_9 Don't know, no response, unclear response

44R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

45. Did you choose or pick your case manager/service coordinator?

Did you choose _____ to work with you?

(Other respondent – Did this person choose his/her case manager/service coordinator?)

_8 **NOT APPLICABLE** - no case manager/service coordinator

_2 Yes, chose case manager/service coordinator

_1 Case manager/service coordinator was assigned but s/he can request a change if not satisfied

_0 No, someone else chose case manager/service coordinator

_9 Don't know, no response, unclear response

45R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

RIGHTS

46. Do people read your mail without asking you first?

(Other respondent – Does anyone read this person's mail without permission?)

_8 **NOT APPLICABLE** - does not get mail

_2 [Yes] – mail is read without permission

_0 [No] – person reads own mail or others read with permission

_9 Don't know, no response, unclear response

46R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

47. Do your friends ever come over to visit?

If no, code as "NOT APPLICABLE." If yes, ask:

PS-3



47a. Can you be alone with them, or does someone have to be with you?
(Are there rules about having friends over?)

(Other respondent – can this person have privacy to be alone with friends when s/he wants to, or does someone else have to be present?)

- 8 NOT APPLICABLE – no friends or friends do not visit
- 2 Can be alone with friends
- 0 There are rules against being alone with friends
- 9 Don't know, no response, unclear response

47R. Indicate respondent:

- 1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

48. Are you allowed to use the phone when you want to?

If person is unable to use the phone or doesn't have a phone/TTY, code as "NOT APPLICABLE."

(Other respondent – is this person allowed to use the phone when s/he wants to?)

- 8 NOT APPLICABLE - doesn't have phone/TTY or unable to use phone
- 2 Yes, can use anytime, either independently or with assistance, has own phone, or uses email
- 0 There are rules/restrictions on use of phone
- 9 Don't know, no response, unclear response

48R. Indicate respondent:

- 1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

49. Have you ever participated in a self-advocacy group meeting, conference, or event? (A self-advocacy group is where people meet together to talk about things in their lives that are important to them. Some groups include People First, Speaking for Ourselves, and Self-Advocates Becoming Empowered – SABLE.)

(Have you ever gone to a _____ meeting or event?)

(Other respondent – Has this person ever attended a self-advocacy group meeting or event?)

- 8 NOT APPLICABLE – there is no self-advocacy group in the area
- 2 Yes
- 1 Had the opportunity but chose not to participate
- 0 No
- 9 Don't know, no response, unclear response

49R. Indicate respondent:

- 1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

PS-9



ACCESS

50. Do you get the services you need?

(Other respondent – Does this person get the services and supports s/he needs?)

_2 Yes

_1 Sometimes, or doesn't get enough of the services needed

_0 No

_9 Don't know, no response, unclear response

States may decide to collect open-ended responses for their own analysis purposes.
This information is not submitted to NCI for analysis.

[OPTIONAL] Specify service needs:

50R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

50.1. Is there anything else you would like to talk to me about?

50.1.R. Indicate respondent:

1-consumer 2-other 3-guardian 4-friend/family 5-paid staff

51. Interviewer: Please indicate who completed Section II (check yes to all that apply and no to all that do not apply):

51.1. 1. no 2. yes Person receiving services

51.2. 1. no 2. yes Advocate, Parent, Guardian, Personal Representative, Relative

51.3. 1. no 2. yes Staff who provides supports where person lives

51.4. 1. no 2. yes Staff who provides supports at a day or other service location

51.5. 1. no 2. yes Other

INTERVIEWER FEEDBACK SHEET

Instructions to interviewers:

Please take a few minutes to complete a feedback sheet after each interview you complete.

Interviewer's Initials or Code (optional): _____

1. How long did it take to complete the direct interview(s) (Sections I and II only)?

__ __ Hours __ __ Minutes

2. How long did it take to complete the entire form, including phone-calls, arranging and conducting the interviews, travel time, etc.?

__ __ Hours __ __ Minutes

3. Where did the interview take place?

1. __ Person's Home 2. __ Person's Day Program

3. __ Other (specify) _____

4. Was a language translator used?

1. __ No 2. __ Yes

5. Were there any questions that were problematic?

1. __ No 2. __ Yes

If yes, indicate the question number(s) below and describe the problem and any suggestions you have for improvement.

Question: Problem/Suggestions:

Other Comments:

Appendix B

Participant Experience Survey (PES)

See next page

★

PARTICIPANT EXPERIENCE SURVEY

(E/D)

★

Developed by
The MEDSTAT Group, Inc.

for the
Centers for Medicare and Medicaid Services



**TEXAS
2006**

Pre-Survey Form

BI-2. Survey Code: _____
(ID number)

Note: This code should be provided by the state project coordinator and is for data analysis purposes only. A unique code number should be assigned to each person. Do not use a number that could possibly identify the person (do NOT use social security numbers).

P.1 Interviewer code: __ __

P.2 Interview Date: ____/____/____ mm/dd/yyyy

P.3 Reason for Not Participating in Survey:

1. __ Sick/Hospitalized 2. __ Participant Declined 3. __ Guardian declined
4. Reason for declining (specify) _____

(END SURVEY)

Guardian information, if applicable:

Guardian Name: First _____ Last _____

Relationship: _____

Phone:

PS-9. Contact... Who should the interviewer call to arrange an interview with this person (consumer, parent/guardian, service coordinator, day or residential program staff, etc.)?

Name: First _____ Last _____

Relationship: _____ Daytime Phone: _____

Evening Phone : _____ Cell Phone:

Note... We would like to talk with persons alone, when appropriate. Some persons may feel uncomfortable with strangers, may have community protection issues, or may have medical or behavioral issues that require them to be under constant supervision by a trained caregiver.

Do you recommend that a caregiver be present while this person is interviewed?

2. ___ Yes 1. ___ No

PS-9. Communication needs... Does this person have any special communication needs? (Examples: primary language other than English, sign language, communication board.) Please explain what arrangements are needed for the interview.

PS-9. Case Manager/Service Coordinator/QMRP... What is the name and phone number of this person's case manager/service coordinator/qualified mental retardation professional?

Name: First _____ Last _____

Phone: _____ Cell Phone: _____

PS-9. Advocate... If this person has someone who helps represent him/her at planning meetings and in making important decisions, please provide the advocate's name and relationship. (Note: this may include staff, family, friends, or guardians who are involved in the person's life.)

Name: First _____ Last _____

Relationship: _____

PS-9. Other Interviewees... If this person is unable or unwilling to complete Section II of the survey, please indicate the name(s) and number(s) of others who know the person well and could respond on his/her behalf.

Name: First _____ Last _____

Relationship: _____ Phone: _____

PS-7. Support Staff in the Home and During the Day... If there are any people who are paid to provide supports in this person's home, please indicate their first names. If there are several workers, please list the primary staff who spend the most time with this person. Also indicate the first names of any day and/or job support staff.

Home Support Staff: First Name _____

Day Support Staff/Job Support Staff/Coach: First Name _____

PS-8. Job/Day Activities... If applicable, please indicate what this person calls his/her job, school or day activity program.

Place of work: _____

PS-8a School: _____

PS-8b Day program: _____

DAY / VOCATIONAL / EDUCATIONAL SUPPORT

The table below lists six types of vocational/employment services and other day supports. Please see the next two pages for definitions of terms used on this form.

For the most recent month possible, please enter

- c) number of hours worked or spent in each activity; and
- d) total gross wages earned for each category of paid work.

NOTE: Please enter "999" (for hours) and "9999" (for wages) to indicate not applicable. If the person received no salary or worked zero hours enter "0". All other cases enter actual number.

	a) Number of hours at this activity in the last month	b) Total gross wages earned in the last month
S1. Competitive Employment	_ _ _ _	\$ _ _ _ _ . _ _ _
S2. Individual Supported Employment	_ _ _ _	\$ _ _ _ _ . _ _ _
S3. Group Supported Employment	_ _ _ _	\$ _ _ _ _ . _ _ _
S4. Facility-Based Work Programs	_ _ _ _	\$ _ _ _ _ . _ _ _
S5. Facility-Based Non-Work Activities	_ _ _ _	N/A
S6. Community-Based Non-Work Activities	_ _ _ _	N/A

S7. Is this person enrolled in the public school system?

- (1) No
- (2) Yes

S8. What agency or program pays for the day / vocational services this person receives? Please check all that apply.

- (1) HCBS Waiver Program (including Federal + State Match)
- (2) State MR/DD Agency
- (3) Vocational Rehabilitation Agency
- (4) PAS/IRWE Plan (person is buying some of his/her own supports)
- (5) Other
- (6) Not applicable – person does not receive any day / vocational services

Community Employment – If the person has a job in the community (either competitive or supported employment), please answer the following questions:

S9. Did this person work 10 out of the last 12 months in a community job? (Person may have changed jobs or had periods of unemployment/transition.)	(circle one) Yes No N/A
S10. Does this person receive benefits at his/her community job? (e.g. paid vacation, sick time, health insurance)	(circle one) Yes No N/A
S11. How long has this person been working at his/her current job in the community?	__ __ years __ __ months

DEFINITIONS

The term “day supports” means the regular provision of publicly funded training and other assistance to adults with developmental disabilities outside their living arrangement. Day supports include services that are work-oriented, habilitative in nature and/or intended to promote community presence and participation.

For reporting purposes, we have defined six generic subcategories of day supports and other employment.

- **Competitive Employment.** Individuals have a job of their own in the community but are not receiving “supported employment” – that is, they do not routinely receive community job supports or job coaching. They may have access to supports as needed or may receive “follow-along” but is basically working on their own.
- **Individual Supported Employment.** Individuals have a job with a community employer and receive periodic publicly-funded assistance, training and support aimed at securing and/or maintaining employment and/or improving job skills;
- **Group Supported Employment.** Two or more individuals are employed by a community provider agency and perform work as employees of the provider agency at sites in the community (e.g., mobile crews). Group supported employment also includes persons who are employed in an affirmative industry or as part of an enclave;
- **Facility-based Work Programs.** Take place in settings such as sheltered workshops or work activity centers. Individuals are paid a wage in exchange for their production-related activities. They are employed by the provider agency;

- **Facility-Based Non-Work Activities.** Take place at a provider facility and involve the provision of training and other services and supports that are not paid work. These services are commonly labeled “day habilitation,” “day training,” or “day treatment.” Seniors programs and job training programs also fall into this category; and,
- **Community-Based Non-Work Activities.** Includes the provision of training and assistance that enables individuals to participate in community activities, by serving as volunteers, recreating and/or learning skills important for community living. These activities take place away from provider-operated facilities.
- **Total Wages.** Wages earned means the total gross amount (before deductions) actually paid to individuals during the last month. In some cases, there is a difference between the wage rate charged to the business where the person works and the amount actually paid to the individual (e.g., the provider agency functions as an “employment agency” and charges the community business a higher hourly rate than the rate paid to the individual). For data collection purposes, the amount reported should be the total amount paid to individuals by type of day support during the most recent month for which data is available.
- **Number of Hours at this Activity.** For the various work categories, the total number of hours of compensated work during the last month should be reported.

Please note: In the case of individuals who are working in a facility, time in the facility when the person is not earning a wage (e.g., is not engaged in work) should be counted as hours of facility-based non-work activity. For example, if a person is at a facility for 126 hours during the month and is engaged in paid work for 83 hours, the remaining 43 hours would be reported as facility-based non-work activities.

PS-9 Self-Advocacy Organization... What self-advocacy groups are active and well-known in the person's area? (Examples: People First, Self-Advocates Becoming Empowered, Speaking for Ourselves.)

BI-7. Does this person have a legal guardian or conservator appointed? (check one)

- 1 No, person is independent of guardianship (legally competent or presumed competent)
- 2 Yes, person has private guardian or conservator (including parent/relative or non-relative)
- 3 Yes, person has public guardian or conservator
- 4 Don't know

BI-9. Marital status: (check one)

- 1 Single, never married
- 2 Married
- 3 Single, married in past
- 4 Don't know

BI-12. What is this person's primary language? (What language does s/he understand?)

- 1 English
- 2 Other

BI-13. What is this person's primary means of expression? (check one – most frequently used)

- 1 Spoken
- 2 Gestures/body language
- 3 Sign language or finger spelling
- 4 Communication aid/device
- 5 Other
- 6 Don't know

BI-14. How would you describe this person's mobility? (check one)

- 1 Can move self around environment; walks (with or without aids) or uses wheelchair
- 2 Non-ambulatory, needs assistance to move around environment
- 3 Don't know

BI-16. Does this person currently take medications for...

(check one column for each question):

- | | no | yes | don't know | |
|--|----------------------------|----------------------------|----------------------------|--|
| | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | Mood disorders? [Includes any drug prescribed to elevate or stabilize mood (reduce mood swings), e.g., to treat depression, mania, or bipolar disorder.] |
| | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | Anxiety? [Includes any drug prescribed to treat anxiety disorders (including obsessive disorders and panic disorders) or to reduce anxiety symptoms.] |
| | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | Behavior problems? [Includes any drug prescribed for a behavior modification purpose (such as a stimulant, sedative, or beta-blocker), e.g., to treat ADHD, aggression, self-injurious behavior, etc.] |
| | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | Psychotic disorders? [Includes any drug (e.g., anti-psychotic or "neuroleptic") used to treat psychotic disorders such as schizophrenia or psychotic symptoms such as hallucinations.] |

BI-17. If this person has seizures, how often do they occur? (check one)

- 0 **NOT APPLICABLE** -- does not have seizures
- 1 Less frequently than once/month
- 2 At least once/month, but not once a week
- 3 At least once/week, or more frequently
- 4 Don't know or not available in records

BI-18. How often does this person require medical care? (check one) (Medical care refers to care that must be performed or delegated by a nurse or physician. Do not include medication administration.)

- 1 Less frequently than once/month
- 2 At least once/month, but not once a week
- 3 At least once/week, or more frequently
- 4 Don't know or not available in records

BI-19. When was his/her last physical exam? (check one)

- 1 In the past year
- 2 Over one year ago
- 3 Don't know or not available in records

BI-20. If female, when was her last OB/GYN exam? (check one)

- 0 **NOT APPLICABLE** -- male
- 1 In the past year
- 2 Over one year ago
- 3 Has never had an OB/GYN exam
- 4 Don't know or not available in records

BI-21. When was his/her last dentist visit? (check one)

- 1 In the last six months
- 2 Over six months ago
- 3 Don't know or not available in records

BI-23. Does this person smoke or chew tobacco?

- 1 No
- 2 Yes
- 3 Don't know

BI-25. How long has this person lived in his/her current home (or with the same caregiver)? Do not count moves with same caregiver.

- 1 Less than 1 year
- 2 1-2 years
- 3 3-5 years
- 4 Over 5 years
- 5 Don't know or not available in records

BI-27. Who owns or leases the place where this person lives? (check one)

- 1 Family, guardian, or friend
- 2 Private agency or home provider/foster family
- 3 State or County agency
- 4 Person rents home (name is on the lease)
- 5 Person owns home (name is on the title)
- 6 Don't know
- 7 Other

BI-37. Does this person need support to prevent self-injury? "Self-injury" refers to attempts to cause harm to one's own body, for example, by hitting or biting self, banging head, scratching or puncturing skin.

- 1 No
- 2 Yes
- 3 Don't Know

BI-37a. If yes, how often does the person need support to manage this behavior? (check one)

- 1 Needs occasional support, less frequently than once/month
- 2 At least once/month, but not once a week
- 3 At least once/week, or more frequently
- 8 Not applicable (no support needed or don't know)

BI-38. Does this person need support to prevent disruptive behavior?

“Disruptive behavior” refers to emotional outbursts that interfere with the activities of others, for example, by starting fights, laughing or crying without apparent reason, yelling or screaming, cursing, throwing objects, or threatening violence.

- _1 No
- _2 Yes
- _3 Don't Know

BI-38a. If yes, how often does the person need support to manage this behavior? (check one)

- _1 Needs occasional support, less frequently than once/month
- _2 At least once/month, but not once a week
- _3 At least once/week, or more frequently
- _8 Not applicable (no support needed or don't know)

Please indicate who provided all of this pre-survey information: (check yes to all that apply and no to all that do not apply)

- | | | | |
|---------|--------------------------------|---------------------------------|--|
| BI.99.1 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Person receiving services |
| BI.99.2 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Advocate, Parent, Guardian, Personal Representative, Relative |
| BI.99.3 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Staff who provides supports where person lives |
| BI.99.4 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Staff who provides supports at a day or other service location |
| BI.99.5 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Case Manager, service coordinator, social worker |
| BI.99.6 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Other Person |
| BI.99.7 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | State data system |

Survey Instructions

- ✱ Make sure you have the respondent's pre-survey information available when conducting the interview, since you are directed to refer to it at various points during the interview.
- ✱ Text read to the respondent is in mixed case. Text just for you is in all CAPS (with the exception of the Interviewer Comments Section).
- ✱ Please answer every question by checking **one** box, unless instructed to "Check all that apply," in which case multiple boxes may be checked.
- ✱ Do not leave any questions blank. If the respondent does not answer an item, check the box for "No Response."
- ✱ Record **only** responses provided by the respondent.
- ✱ Some questions require you to write in the respondent's answer, like the example below. Please record the respondent's verbatim response as best you can.

Example →

66. What kind of work do you do? (SPECIFY)

- ✱ Some questions are skipped over in this survey. When this is necessary, an arrow directs you to the next question to be asked, like the example below.

- 1 YES
- 2 NO →Skip to Q.15
- 7 UNSURE →Skip to Q.17
- 8 UNCLEAR RESPONSE →Skip to Q.17
- 9 NO RESPONSE →Skip to Q.17

- ✱ If there is **no** arrow next to a response category, like the "YES" response above, please continue with the very next item in the sequence.
- ✱ Some items have instruction boxes, like the example below. These boxes are intended to provide you with additional information or instructions. Do not read these to the respondent.

Refer to the pre-survey information for the case manager's or support coordinator's name.

- 1 NAMES CASE MANAGER/SUPPORT COORDINATOR
- 2 DOES NOT NAME CASE MANAGER/SUPPORT COORDINATOR
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

Take a few minutes to introduce yourself and make the person feel comfortable. Read or paraphrase the following introduction. Pause after each statement, making sure the respondent understands.

“Hi, my name is _____ and I'm from NACES Plus Foundation. I'm here to conduct a survey for the Texas Department of Aging and Disability Services also known as DADS. I'd like to ask you some questions about where you live, where you work, your friends and family, and the people who help you. By answering these questions, you are helping DADS figure out how people in Texas are doing, and how to make supports and services better.”

“This is not a test, and there are no right or wrong answers to these questions. If you don't understand a question, let me know and I'll try to explain it. It's okay if you don't know how to answer.”

“You don't have to answer any questions that you don't want to. Just tell me if you don't want to answer.”

“I'd like to know your opinions, how you feel about things. Whatever you tell me will be kept private, so you can be honest.”

A. ACCESS TO CARE

The first set of questions I am going to ask you have to do with some everyday activities, like getting dressed and taking a bath. Some people have no problem doing these things by themselves. Other people need somebody to help them.

1. Is there any special help that you need to take a bath or shower?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

1.a REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.4
8 UNCLEAR RESPONSE→Skip to Q.4
9 NO RESPONSE →Skip to Q.4

2. Do you ever go without a bath or shower when you need one?

- 1 YES
2 NO →Skip to Q.4
7 UNSURE →Skip to Q.4
8 UNCLEAR RESPONSE →Skip to Q.4
9 NO RESPONSE →Skip to Q.4

3. Is this because there is no one there to help you?

- 1 YES
2 NO
7 UNSURE
8 UNCLEAR RESPONSE
9 NO RESPONSE

4. Is there any special help that you need to get dressed? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

4a. REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.7
8 UNCLEAR RESPONSE→Skip to Q.7
9 NO RESPONSE →Skip to Q.7

5. Do you ever go without getting dressed when you need to?

- 1 YES
2 NO →Skip to Q.7
7 UNSURE →Skip to Q.7
8 UNCLEAR RESPONSE →Skip to Q.7
9 NO RESPONSE →Skip to Q.7

6. Is this because there is no one there to help you?

- 1 YES
2 NO
7 UNSURE
8 UNCLEAR RESPONSE
9 NO RESPONSE

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

7. Is there any special help that you need to get out of bed?

7a. REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.10
- 8 UNCLEAR RESPONSE →Skip to Q.10
- 9 NO RESPONSE →Skip to Q.10

8. Do you ever go without getting out of bed when you need to?

- 1 YES
- 2 NO →Skip to Q.10
- 7 UNSURE →Skip to Q.10
- 8 UNCLEAR RESPONSE →Skip to Q.10
- 9 NO RESPONSE →Skip to Q.10

9. Is this because there is no one there to help you?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

10. Is there any special help that you need to eat?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

10a. REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.13
- 8 UNCLEAR RESPONSE →Skip to Q.13
- 9 NO RESPONSE →Skip to Q.13

11. Do you ever go without eating when you need to?

- 1 YES
- 2 NO →Skip to Q.13
- 7 UNSURE →Skip to Q.13
- 8 UNCLEAR RESPONSE →Skip to Q.13
- 9 NO RESPONSE →Skip to Q.13

12. Is this because there is no one there to help you?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

13. Is there any special help that you need to make your meals?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

13a. REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.16
- 8 UNCLEAR RESPONSE →Skip to Q.16
- 9 NO RESPONSE →Skip to Q.16
- 95 NOT APPLICABLE , TUBE FED →Skip to Q.19

14. Do you ever go without a meal when you need one?

- 1 YES
- 2 NO →Skip to Q.16
- 7 UNSURE →Skip to Q.16
- 8 UNCLEAR RESPONSE →Skip to Q.16
- 9 NO RESPONSE →Skip to Q.16

15. Is this because there is no one there to help you?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

16. Is there any special help that you need to get groceries?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

16a. REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.19
- 8 UNCLEAR RESPONSE →Skip to Q.19
- 9 NO RESPONSE →Skip to Q.19
- 95 NOT APPLICABLE, TUBE FED→Skip to Q.19

17. Are you sometimes unable to get groceries when you need them?

- 1 YES
- 2 NO →Skip to Q.19
- 7 UNSURE →Skip to Q.19
- 8 UNCLEAR RESPONSE →Skip to Q.19
- 9 NO RESPONSE →Skip to Q.19

18. Is this because there is no one there to help you?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

19. Is there any special help that you need to do housework – things like straightening up or doing dishes?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

19.a. REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.22
- 8 UNCLEAR RESPONSE →Skip to Q.22
- 9 NO RESPONSE →Skip to Q.22

20. Does the housework not get done sometimes?

- 1 YES
- 2 NO →Skip to Q.22
- 7 UNSURE →Skip to Q.22
- 8 UNCLEAR RESPONSE →Skip to Q.22
- 9 NO RESPONSE →Skip to Q.22

21. Is this because there is no one there to help you?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

22. Is there any special help that you need to do laundry?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

22a. REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.25
- 8 UNCLEAR RESPONSE →Skip to Q.25
- 9 NO RESPONSE →Skip to Q.25

23. Does the laundry not get done sometimes?

- 1 YES
- 2 NO →Skip to Q.25
- 7 UNSURE →Skip to Q.25
- 8 UNCLEAR RESPONSE →Skip to Q.25
- 9 NO RESPONSE →Skip to Q.25

24. Is this because there is no one there to help you?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

25. Can you always get to the places you need to go, like work, shopping, the doctor's office, or a friend's house?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

26. Is there any special help that you need to take medicine, such as someone to pour it or set up your pills?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

26a. REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.29
- 8 UNCLEAR RESPONSE →Skip to Q.29
- 9 NO RESPONSE →Skip to Q.29

27. Do you ever go without taking your medicine when you need it?

- 1 YES
- 2 NO →Skip to Q.29
- 7 UNSURE →Skip to Q.29
- 8 UNCLEAR RESPONSE →Skip to Q.29
- 9 NO RESPONSE →Skip to Q.29

28. Is this because there is no one there to help you?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

29. Is there any special help that you need to get to or use the bathroom?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

29a. REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.32
- 8 UNCLEAR RESPONSE →Skip to Q.32
- 9 NO RESPONSE →Skip to Q.32

30. Are you ever unable to get to or use the bathroom when you need to?

- 1 YES
- 2 NO →Skip to Q.32
- 7 UNSURE →Skip to Q.32
- 8 UNCLEAR RESPONSE →Skip to Q.32
- 9 NO RESPONSE →Skip to Q.32

31. Is this because there is no one there to help you?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

32. Think about the people who are paid to help you with the everyday activities we have been discussing.

Do they spend all the time with you that they are supposed to?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE
- 95 NO HOME SUPPORT STAFF

33. Have you ever talked with your case manager or support coordinator about any special equipment, or changes to your home, that might make your life easier?

- 1 YES
- 2 NO →Skip to Q.36
- 7 UNSURE →Skip to Q.36
- 8 UNCLEAR RESPONSE →Skip to Q.36
- 9 NO RESPONSE →Skip to Q.36

34. What equipment or changes did you talk about? (SPECIFY)

35. Did you get the equipment or make the changes you needed?

- 1 YES
- 2 NO
- 3 IN PROCESS
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

B.Choice and Control

These next few questions are about how much choice and control you have in the help you get, and the assistance you receive from your case manager or support coordinator.

36. Do you help pick the people who are paid to help you?

- 1 YES →Skip to Q.38
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE →Skip to Q.38
- 9 NO RESPONSE →Skip to Q.38
- 95 NO PERSONAL CARE STAFF →Skip to Q.41

Include anyone paid to provide assistance in any setting.

37. Would you like to help pick the people who are paid to help you?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

38. Did you know you can change the people who are paid to help you if you want to?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

39. Thinking again about the people who are paid to help you, do you tell them what to help you with?

- 1 YES →Skip to Q.41
- 2 NO
- 3 SOMETIMES →Skip to Q.41
- 7 UNSURE
- 8 UNCLEAR RESPONSE →Skip to Q.41
- 9 NO RESPONSE →Skip to Q.41

40. Would you like to tell them the things you want help with?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

41. If there is something wrong with the help you are getting, who do you talk with to get the problem fixed? (CHECK ALL THAT APPLY)

- 1 NO ONE
- 2 FAMILY/FRIEND
- 3 CASE MANAGER/SUPPORT COORDINATOR/OTHER STAFF
- 4 OTHER (SPECIFY) _____
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

*Probe,
if necessary,
to place the
response in the
appropriate
category.*

42. Who is your case manager or support coordinator?

- 1 NAMES CASE MANAGER/SUPPORT COORDINATOR
- 2 DOES NOT NAME CASE MANAGER/SUPPORT COORDINATOR
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

*Refer to the pre-
survey information
for the case
manager's or
support
coordinator's
name.*

43. Can you talk to your case manager or support coordinator when you need to?

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE
- 95 NOT APPLICABLE – HAVE NOT TRIED

44. Does your case manager or support coordinator help you when you ask for something?

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE
- 95 NOT APPLICABLE – HAVE NOT TRIED

44a. Do you get to help other people? (Do you get to teach things to other people?)

- 2 YES
- 1 SOMETIMES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

44b. Can you have a close relationship, such as a boyfriend or girlfriend, if you want one?

- 2 YES
- 1 SOMETIMES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

44c. Do you earn enough money to buy the things that you want?

- 2 YES
- 1 SOMETIMES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

44d. Are you free to take risks when you want to? (Do you feel like it's okay if you make a mistake?)

- 2 YES
- 1 SOMETIMES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

44e. Do you have control over your transportation? (*Can you plan a trip or decide when to go out?*)

- 2 YES
- 1 SOMETIMES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

44f. Do you get to decide who comes in and out of your home?

- 2 YES
- 1 SOMETIMES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

C. Respect/Dignity

Now I would like to ask you about how you are treated by the people who are paid to help you. The next two questions are about people who come to your home.

45. Do the people paid to help you treat you respectfully in your home?

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE
- 95 NO STAFF IN HOME →Skip to Q.47

46. Do the people paid to help you listen carefully to what you ask them to do in your home?

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

47. Have you ever been injured by any of the people paid to help you now?

- 1 YES
- 2 NO →Skip to Q.49
- 7 UNSURE →Skip to Q.49
- 8 UNCLEAR RESPONSE →Skip to Q.49
- 9 NO RESPONSE →Skip to Q.49
- 95 NOT APPLICABLE (DOES NOT INTERACT WITH ANY PAID STAFF)→Skip to Q.59

Reminder:

Refer to your state's policy on reporting for any suspected incidents of abuse or neglect. Record only reports of current abuse.

48. What happened? When? Would you like any help with this problem?

49. Are any of the people paid to help you now mean to you, or do they yell at you?

Reminder:
Refer to your state's policy on reporting for any suspected incidents of abuse or neglect. Record only reports of current abuse.

- 1 YES
- 2 NO →Skip to Q.51
- 3 SOMETIMES
- 7 UNSURE →Skip to Q.51
- 8 UNCLEAR RESPONSE →Skip to Q.51
- 9 NO RESPONSE →Skip to Q.51

50. What happens? Would you like any help with this problem?

51. Have any of the people paid to help you now ever taken your things without asking?

Reminder:
Refer to your state's policy on reporting for any suspected incidents of abuse or neglect. Record only reports of current abuse.

- 1 YES
- 2 NO →Skip to Q.53
- 7 UNSURE →Skip to Q.53
- 8 UNCLEAR RESPONSE →Skip to Q.53
- 9 NO RESPONSE →Skip to Q.53

52. What happened? When? Would you like any help with this problem?

53. Do you go to a day program outside your home?

- 1 YES
- 2 NO →Skip to Q.56
- 7 UNSURE →Skip to Q.56
- 8 UNCLEAR RESPONSE →Skip to Q.56
- 9 NO RESPONSE →Skip to Q.56

54. Do the people paid to help you at a day program outside your home treat you respectfully?

Use specific information from the pre-survey information about services provided outside the home.

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

55. Do the people paid to help you at a day program outside your home listen carefully to what you ask them to do?

Use specific information from the pre-survey information about services provided outside the home.

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

56. Do you ride a van or use other transportation services?

- 1 YES
- 2 NO →Skip to Q.59
- 7 UNSURE →Skip to Q.59
- 8 UNCLEAR RESPONSE →Skip to Q.59
- 9 NO RESPONSE →Skip to Q.59

57. Do the people paid to help you on the van or with other transportation treat you respectfully?

Use specific information from the pre-survey information about services provided outside the home.

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

58. Do the people paid to help you on the van or with other transportation listen carefully to what you ask them to do?

Use specific information from the pre-survey information about services provided outside the home.

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

D.Community Integration/Inclusion

The last few questions I'd like to ask you are about things you do in your community and the help you get to do these things.

59. Is there anything you want to do outside your home that you don't do now?

- 1 YES
- 2 NO →Skip to Q.61
- 7 UNSURE →Skip to Q.61
- 8 UNCLEAR RESPONSE →Skip to Q.61
- 9 NO RESPONSE →Skip to Q.61

60. What would you like to do? What do you need to make this happen? (SPECIFY)

61. Is there anything else you want to talk to me about?

BOX 1
IF RESPONDENT IS UNDER 65 YEARS OF AGE,
ASK Q.62
OTHERWISE END INTERVIEW.

The last few questions I'd like to ask you have to do with your work experiences.

62. Are you working right now?

- 1 YES
- 2 NO →Skip to Q.66
- 7 UNSURE →End of interview
- 8 UNCLEAR RESPONSE → End of interview
- 9 NO RESPONSE → End of interview

63. What kind of work do you do? (SPECIFY)

64. Did you help pick the job you have now?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

65. Do you like your job?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

} → End of interview

66. Do you want to work?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

INFORMAL PARTING "Thank you for your help. It's been very nice talking to you. You've been very helpful."

INTERVIEWER FEEDBACK SHEET

Instructions to interviewers:

Please take a few minutes to complete a feedback sheet after each interview you complete.

99. What amount of the questions did the program participant answer by him/herself?

- 1 ALL
- 2 MOST
- 3 ABOUT HALF
- 7 SOME
- 8 A FEW
- 9 NONE

99a. Who else provided responses? (If applicable)

99b. Where did the interview take place? (check one)

- 1. ___ Participant's home
- 2. ___ Participant's day program
- 3. ___ Other (specify) _____

99c. Was a language translator used?

- 1. ___ Yes
- 2. ___ No

99d. Were there any questions that were problematic? If yes, indicate the question number(s) below and describe the problem and any suggestions you have for improvement.

E. Interviewer Comments and Observations

Appendix C

National Core Indicators (NCI) Children/Family Survey (English)

See next page

Children/Family Survey (English/Inglés)

Opinions of Services and Supports for Children with Disabilities and their Families in Texas

Thank you for helping us by completing the attached questionnaire. Your opinions will make it possible to improve services and supports to children with disabilities and their families in Texas. The results of this survey will also allow us to compare family satisfaction with similar information collected in other states. We expect that it will only take about 20 minutes to complete this survey.

INSTRUCTIONS:

Note: If there is more than one child receiving services in your family, please answer for the oldest child.



For most questions, all you need to do is check the box that applies to you. All responses will remain confidential. Your answers will not affect the services and supports you are receiving. If you come to a question that you feel uncomfortable answering, skip it. However, for us to get complete information, it is very important that you try to answer each question as accurately as you can.



When you have completed the questionnaire, please return it in the enclosed pre-addressed and pre-stamped envelope. Please try to return the survey as soon as possible.

Again, THANK YOU!

Part 1: INFORMATION ABOUT YOUR FAMILY



Please answer the following questions about your family member with a disability.

a.) Does your child with a disability live at home with you?

1. Yes 2. No

Note: If you answered "no" to the question above, please stop here and return the survey.

b.) Is there more than one child with a disability in your household?

1. Yes 2. No

Reminder: If yes, please answer for the oldest child.

c.) How old is this child? _____ years

d.) What is the gender of this child?

1. Male 2. Female

e.) About how much help does this child need with daily activities (such as bathing, dressing, eating)? (check one)

1. None 3. Moderate
 2. Little 4. Complete

f.) Has this child been diagnosed with any of the following? (check all that apply)

1. Mental retardation
 2. Other developmental disability
 3. Mental illness (e.g. depression)
 4. Autism
 5. Cerebral Palsy
 6. Brain injury
 7. Seizure disorder/neurological problem
 8. Chemical dependency
 9. Vision or hearing impairments
 10. Physical disabilities
 11. Communication disorder
 12. Down Syndrome
 13. Other disabilities not listed

g.) What is this child's race? (check all that apply)

1. American Indian or Alaska Native
 2. Asian
 3. Black or African-American
 4. Native Hawaiian or Other Pacific Islander
 5. White
 6. Other/Unknown
 7. Two or More Races
 8. Hispanic or Latino

Please answer the following questions about yourself.

h.) What is your age?

1. Under 35 3. 55 - 74
 2. 35 - 54 4. 75 or Older

i.) How would you describe your health? (check one)

1. Excellent 3. Fair
 2. Good 4. Poor

j.) What is your relationship to this child? (check one)

1. Parent (biological, adoptive, or foster)
 2. Sibling
 3. Grandparent
 4. Other (please describe) _____

k.) Are you a primary caregiver for this child?

1. Yes 2. No

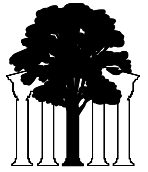
SERVICES AND SUPPORTS RECEIVED




Please check whether your family or your child with a disability is currently receiving any of the services or supports described below.

	YES	NO	DON'T KNOW
i. SSI Financial Support -- your family receives SSI payments.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
ii. Other Financial Support -- family receives money (cash, stipends, vouchers, or reimbursement) to purchase items, equipment, or needed services for your child with a developmental disability.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
iii. In-Home Support -- people are paid to come to your home to provide assistance to your child with a disability.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
iv. Out-of-Home Respite Care -- someone takes care of your child with a disability outside of your home to give your family a break.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
v. Early Intervention -- your child attends a special stimulation program for children under age 5.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
vi. Transportation -- someone arranges for specialized transportation for your child with a disability to go to community activities, medical appointments, etc.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
vii. Specialized Services/Supports -- your child with a disability receives mental health care or other kinds of therapies (such as physical therapy, occupational therapy, speech therapy, or recreational therapy).	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Part 2: QUESTIONS ABOUT SERVICES AND SUPPORTS





Please answer the following questions about services you currently receive from the Department of Aging and Disability Services. Check one response for each question. If a question does not apply to you, please check the last column.


 INFORMATION & PLANNING		Always or Usually	Sometimes	Seldom or Never	Don't Know	NA
3.	Do you receive information about the services and supports that are available to your child and family?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4.	If you receive information, is it easy to understand?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5.	Do you receive information about the status of your child's development?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6.	If yes, is this information easy to understand?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7.	Do you get enough information to help you participate in planning services for your family?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8.	If your family has a service plan, did you help develop the plan?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9.	If your family has a service plan, does the plan include things that are important to you?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10.	Do the staff who assist you with planning help you figure out what you need as a family to support your child?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11.	Do the staff who assist you with planning respect your choices and opinions?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12.	Does someone talk to you about the public benefits that are available to you? (e.g. food stamps, Texas Health Steps, Supplemental Security Income, etc.)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13.	Are the staff who assist you with planning generally respectful and courteous?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14.	Are the staff who assist you with planning generally effective?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
15.	Can you contact the staff who assist you with planning whenever you want to?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5


**ACCESS & DELIVERY OF SUPPORTS**

	Always or Usually	Some- times	Seldo m or Never	Don't Know	NA
16. When you ask your case manager/service coordinator for assistance, does s/he help you get what you need?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
17. Does your family get the services and supports you need?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
18. Do the services and supports offered meet your family's needs?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
19. Are supports available when your family needs them?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
20. Do families in your area request that different types of services and supports be made available in your area?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
21. If yes, does either the state agency or provider agency respond to their requests?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
22. If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
23. If English is <u>not</u> your first language, are there support workers or translators available to speak with you in your preferred language?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
24. If your child does not speak English or uses a different way to communicate (for example, sign language), are there enough support workers available who can communicate with him/her?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
25. Does your child have access to the special equipment or accommodations that s/he needs (e.g., wheelchair, ramp, communication board)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
26. Do you have access to health services for your child?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
27. Do you have access to dental services for your child?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
28. Do you have access to necessary medications for your child?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
29. Are frequent changes in support staff a problem for your family?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
30. Are support staff generally respectful and courteous?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

 CHOICE & CONTROL		Always or Usually	Sometimes	Seldom or Never	Don't Know	NA
31.	Do you choose the agencies or providers who work with your family?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
32.	Do you choose the support workers who work with your family?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
33.	Do you have control and/or input over the hiring and management of your support workers?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
34.	Do you <u>want</u> to have control and/or input over the hiring and management of your support workers?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
35.	Do you know how much money is spent by the Department of Aging and Disability Services on behalf of your child with a developmental disability?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
36.	Do you get to decide how this money is spent?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

 COMMUNITY CONNECTIONS		Always or Usually	Sometimes	Seldom or Never	Don't Know	NA
37.	If you want to use typical supports in your community (for example, through recreation departments or churches), do either the staff who help you plan or who provide support help connect you to these supports?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
38.	If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
39.	Do you feel that your child has access to community activities?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
40.	Does your child participate in community activities?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
41.	Does your child spend time with children who do not have developmental disabilities?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

 SATISFACTION		Always or Usually	Sometimes	Seldom or Never	Don't Know	NA
42.	Overall, are you satisfied with the services and supports your child and family currently receive?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
43.	Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
44.	Are you satisfied with the way complaints or grievances are handled and resolved?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

 OUTCOMES		Always or Usually	Sometimes	Seldom or Never	Don't Know	NA
45.	Do you feel that family supports have made a positive difference in the life of your family?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
46.	Do you feel that family supports have improved your ability to care for your child?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
47.	Do you feel that family supports have helped you to keep your child at home?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
48.	Overall, do you feel that your child is happy?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Part 3: **YOUR COMMENTS**



Thank you for taking the time to complete these questions. Your opinion is very important to us. Please use the space below for any other comments you would like to make.

Appendix D

National Core Indicators (NCI) Children/Family Survey (Spanish)

See next page

Encuesta de niños/familia (Español/Spanish)

Opiniones acerca de servicios y apoyos para niños con discapacidades y sus familias en el Estado de Texas

Gracias por ayudarnos completando el cuestionario adjunto. Su opinión hará posible la mejora de servicios y apoyo para niños con discapacidades y sus familias en el Estado de Texas. Los resultados de esta encuesta también nos permitirán comparar la necesidad de la familia con información similar recolectada en otros estados. Prevemos que completar esta encuesta sólo llevará unos 25 minutos.

INSTRUCCIONES:

Nota: Si hay más de un niño que recibe los servicios en su familia, por favor, responda a las preguntas teniendo en cuenta a la persona que se nombra en la carta que recibió.



Para la mayoría de las preguntas, todo lo que necesita hacer es marcar el casillero que le corresponde a usted. Todas las respuestas serán confidenciales. Sus respuestas no afectarán los servicios y los apoyos que usted está recibiendo. Si le incomoda responder alguna pregunta, déjela pasar. Sin embargo, para que nosotros obtengamos toda la información, es muy importante que usted sea lo más exacto posible al responder cada pregunta.



Cuando haya completado el cuestionario, por favor envíelo en el sobre adjunto que ya tiene la dirección y las estampillas. Por favor, trate de enviar la encuesta lo más rápido posible.

Nuevamente, ¡GRACIAS!

Parte 1: INFORMACIÓN ACERCA DE SU FAMILIA



Por favor responda las siguientes preguntas acerca del miembro de su familia con discapacidad.

a.) ¿Su niño discapacitado vive con usted en la casa?

1. Sí 2. No

Nota: Si responde "no" a la pregunta anterior, por favor deténgase aquí y envíe la encuesta.

b.) ¿Hay más de un niño discapacitado en su casa?

1. Sí 2. No

Recuerde: Si su respuesta es sí, por favor responda para el niño mayor.

c.) ¿Cuántos años tiene este niño?
_____ años

d.) ¿De qué sexo es este niño?

1. Masculino 2. Femenino

e.) ¿Cuánta ayuda necesita este niño con las actividades diarias (bañarse, vestirse, comer)? (marque una)

1. Ninguna 3. Moderada
 2. Poca 4. Toda

f.) ¿Este niño ha sido diagnosticado con alguna de las siguientes discapacidades? (marque todas las que correspondan)

1. Retraso mental
 2. Otra discapacidad de desarrollo
 3. Enfermedad mental (por ejemplo, depresión)
 4. Autismo
 5. Parálisis cerebral
 6. Lesión cerebral
 7. Convulsiones/problema neurológico
 8. Adicción a las drogas
 9. Problemas de la vista o de la audición
 10. Discapacidades físicas
 11. Problemas de comunicación
 12. Síndrome de Down
 13. Otras discapacidades no nombradas

f.2.) Si este niño tiene diagnosticado retraso mental ¿qué grado de retraso tiene? (marque una)

1. No corresponde, no tiene RM
 2. Leve
 3. Moderado
 4. Grave
 5. Profundo
 6. No sabe o el grado no fue especificado

g.) ¿De qué raza es este niño? (marque todas las que correspondan)

1. Indígena americano o Nativo de Alaska
 2. Asiático
 3. Negro o afroamericano
 4. Nativo de Hawai o de otras islas del Pacífico
 5. Blanco
 6. Otra/Desconocida
 7. Dos o más razas
 8. Hispano o Latino

SERVICIOS Y APOYOS RECIBIDOS




Por favor, verifique si su familia o su niño discapacitado reciben actualmente alguno de los servicios o apoyos descritos abajo y si usted está autorizado para recibir la cantidad de servicios que precisa para cubrir sus necesidades.

	Si,	No	No Sé
i. Ayuda económica de SSI: su familia recibe pagos provenientes del Seguro de Ingreso Suplementario (SSI).	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
ii. Otra ayuda económica: su familia recibe dinero (efectivo, sueldos, vales o reembolso) para comprar artículos, equipos o servicios necesarios para su niño con una discapacidad de desarrollo.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
iii. Asistencia en el hogar: se le paga a las personas que van a su casa para brindarle asistencia a su niño discapacitado.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
iv. Cuidado de relevo: alguien cuida a su niño discapacitado, fuera de su casa, para que su familia descanse.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
v. Intervención temprana: su niño tiene menos de 5 años y recibe servicios para mejorar su desarrollo.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
vi. Transporte: alguien se encarga de brindarle transporte especializado para que su niño discapacitado asista a actividades comunitarias, visitas médicas, etc.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
vii. Servicios especializados/apoyos: su niño discapacitado recibe cuidados para la salud mental u otros tipos de terapias (como fisioterapia, terapia ocupacional, logopedia o terapia recreativa).	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Parte 2: PREGUNTAS ACERCA DE SERVICIOS Y APOYOS




Por favor, responda las siguientes preguntas acerca de los servicios que recibe en la actualidad de la Departamento de Servicios para Adultos Mayores y Personas Discapacitadas. Marque una respuesta por cada pregunta. Si una pregunta no le corresponde, por favor, marque la última columna.


 INFORMACIÓN Y PLANIFICACIÓN		Siempre o usualmente	A veces	Pocas veces o nunca	No sabe	NC
49.	¿Recibe información acerca de servicios y apoyos disponibles para su niño y su familia?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
50.	Si recibe información, ¿es fácil de entender?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
51.	¿Recibe información sobre el estado de desarrollo de su niño?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
52.	Si su respuesta es sí, ¿esta información es fácil de entender?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
53.	¿Recibe información suficiente para que usted pueda participar en la planificación de los servicios para su familia?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
54.	Si su familia tiene un plan de servicios, ¿usted colaboró para elaborarlo?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
55.	Si su familia tiene un plan de servicios, ¿éste incluye las cosas que son importantes para usted?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
56.	¿El personal que lo asiste en la planificación, le ayuda a determinar qué necesita como familia para apoyar a su niño?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
57.	¿El personal que lo asiste en la planificación respeta sus elecciones y opiniones?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
58.	¿Alguien le comenta sobre los beneficios públicos disponibles para usted? (por ejemplo, estampillas para alimentos, Pasos Sanos de Tejas, Seguro de Ingreso Suplementario, etc.)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
59.	¿El personal que lo asiste en la planificación es respetuoso y educado?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
60.	¿El personal que lo asiste en la planificación es generalmente eficiente?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
61.	¿Puede contactar al personal que lo asiste en la planificación cuando usted lo desea?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5




ACCESO Y ENTREGA DEL APOYO


		Siempre o usualmente	A veces	Pocas veces o nunca	No sabe	NC
62.	Cuando usted le pide asistencia a su administrador de caso/coordinador de servicios, ¿él/ ella le ayuda en lo que necesita?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
63.	¿Su familia obtiene los servicios y apoyos que necesita?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
64.	¿Los servicios y apoyos ofrecidos cubren las necesidades de su familia?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
65.	¿El apoyo está disponible cuando su familia lo necesita?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
66.	¿Las familias que viven en su área solicitan que se pongan a disposición otros tipos de servicios y apoyos?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
67.	Si su respuesta es sí, ¿la agencia estatal o la agencia de provisión responden a sus pedidos?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
68.	Si alguna vez solicitó servicios y apoyos en una emergencia o crisis, ¿le brindaron ayuda rápidamente?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
69.	Si el inglés <u>no</u> es su idioma principal, ¿hay trabajadores de apoyo o traductores disponibles que hablen con usted en su idioma de preferencia?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
70.	Si su niño no habla inglés o utiliza otra manera de comunicarse (por ejemplo, lenguaje de señas), ¿hay suficientes trabajadores de apoyo disponibles para comunicarse con él/ ella?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
23.	¿Su niño tiene acceso a los equipos o adaptaciones especiales que él/ ella necesita (por ejemplo, silla de ruedas, rampa, pizarra para comunicarse)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
24.	¿Tiene acceso a servicios de salud para su niño?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
25.	¿Tiene acceso a servicios dentales para su niño?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
26.	¿Tiene acceso a los medicamentos que necesita su niño?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
27.	¿Los cambios frecuentes del personal de apoyo, son un problema para su familia?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
28.	¿El personal de apoyo es generalmente respetuoso y educado?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

 ELECCIÓN Y CONTROL		Siempre o usualmente	A veces	Pocas veces o nunca	No sabe	NC
29.	¿Usted elige las agencias o los proveedores que trabajan con su familia?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
30.	¿Usted elige los trabajadores de apoyo que trabajan con su familia?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
31.	¿Usted colabora en la contratación y la administración de sus trabajadores de apoyo o tiene control sobre ello?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
32.	¿Usted <u>desea</u> colaborar en la contratación y la administración de sus trabajadores de apoyo o tener control sobre ello?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
33.	¿Sabe cuánto dinero gasta el Departamento de Servicios para Adultos Mayores y Personas Discapacitadas a favor de su niño con una discapacidad de desarrollo?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
34.	¿Usted decide cómo se gasta este dinero?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

 CONEXIONES CON LA COMUNIDAD		Siempre o usualmente	A veces	Pocas veces o nunca	No sabe	NC
35.	Si usted desea utilizar el apoyo típico de su comunidad (por ejemplo, a través de departamentos de recreación o iglesias), ¿el personal que lo asiste en la planificación o le provee apoyo lo pone en contacto con este apoyo?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
36.	Si usted deseara que su familia, amigos o vecinos le provean algún tipo de apoyo que su familia necesita, ¿el personal que lo asiste en la planificación o le provee apoyo colabora para que eso sea posible?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
37.	¿Cree que su niño tiene acceso a actividades comunitarias?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
38.	¿Su niño participa en actividades comunitarias?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
39.	¿Su niño pasa tiempo con niños que no tienen discapacidades de desarrollo?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

 SATISFACCIÓN		Siempre o usualmente	A veces	Pocas veces o nunca	No sabe	NC
40.	En general, ¿está satisfecho con los servicios y apoyos que su niño y su familia reciben actualmente?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

41.	¿Conoce los procesos para presentar una queja o reclamo con respecto a los servicios que recibe o el personal que los provee?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
42.	¿Está satisfecho con la manera en la que se manejan y resuelven las quejas o reclamos?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

		RESULTADOS				
		Siempre o usualmente	A veces	Pocas veces o nunca	No sabe	NC
43.	¿Considera que el apoyo para la familia marcó una diferencia positiva en la vida de su familia?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
44.	¿Cree que el apoyo para la familia ha mejorado su capacidad para cuidar a su niño?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
45.	¿Cree que el apoyo para la familia le ha ayudado a cuidar a su niño en su hogar?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
46.	En general, ¿considera que su niño es feliz?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Parte 3: **SUS COMENTARIOS**



Gracias por tomarse el tiempo de completar estas preguntas. Por favor utilice el siguiente espacio para cualquier otro comentario que desee hacer.

Appendix E

National Core Indicators (NCI) Children/Family Survey Crosswalk

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DOMAIN	FAMILY INDICATORS		
	<p>Overview: The family indicators concern how well the public system assists children and adults with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.</p>		
SUB-DOMAIN	CONCERN	INDICATOR	CHILD FAMILY SURVEY DATA SOURCE
Information and Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.	The proportion of families who report they are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	Q1, Q2, Q3, Q4, Q10, Q13
		The proportion of families who report they have the information needed to skillfully plan for their services and supports.	Q5
		The proportion of families reporting that their support plan includes or reflects things that are important to them.	Q6, Q7
		The proportion of families who report that staff who assist with planning are knowledgeable and respectful.	Q8, Q9, Q11, Q12
Choice & Control	Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.	The proportion of families reporting that they control their own budgets/supports (i.e. they choose what supports/goods to purchase).	Q33, Q34
		The proportion of families who report they choose, hire and manage their service/support providers.	Q29, Q30, Q31, Q32
		The proportion of families who report that staff are respectful of their choices and decisions.	Q11, Q28
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.	The proportion of eligible families who report having access to an adequate array of services and supports.	Q15, Q16, Q23, Q24, Q25, Q26
		The proportion of families who report that services/supports are available when needed, even in a crisis.	Q17, Q20
		The proportion of families reporting that staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication.	Q21, Q22
		The proportion of families who report that services/supports are flexible to meet their changing needs.	Q14, Q15, Q16, Q17, Q27, Q28
		The proportion of families who report that service and support staff/providers are available and capable of meeting family needs.	Q18, Q19
Community Connections	Families/family members use integrated community services and participate in everyday community activities.	The proportion of families/family members who participate in integrated activities in their communities.	Q37, Q38, Q39
		The proportion of families who report they are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	Q35, Q36
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.	The proportion of families who report satisfaction with the information and supports received, and with the planning, decision-making, and grievance processes.	Q40, Q41, Q42
Family Outcomes	Individual and family supports make a positive difference in the lives of families.	The proportion of families who feel that services and supports have helped them to better care for their family member living at home.	Q43, Q44, Q45, Q46

Appendix F

Acronyms

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Acronyms

CBA	Community Based Alternatives
CDS	Consumer Directed Services
CLASS	Community Living and Support Services
CLASS Non-CDS	Community Living and Support Services Non Consumer Directed Services
CLASS-CDS	Community Living and Support Services Consumer Directed Services
CMS	Centers for Medicare and Medicaid Services
CWP	Consolidated Waiver Program
DADS	Department of Aging and Disability Services
DBMD	Deaf Blind and Multiple Disabilities
HCS	Home and Community-Based Services
HSRI	Health Services and Research Institute
ICF/MR	Intermediate Care Facilities for Persons with Mental Retardation
MDCP	Medically Dependent Childrens Program
NCI	National Core Indicators
PES	Participant Experience Survey
PES E/D	Participant Experience Survey Elderly/Disabled
TxHmL	Texas Home Living
QM	Quality Matters
QMWeb	Quality Matters Website
QRS	Quality Reporting System
TDMHMR	Texas Department of Mental Health and Mental Retardation
QAI	Quality Assurance and Improvement
CPI	Center for Policy and Innovation
QA/QI	Quality Assurance and Quality Improvement (Task Force)
NASDDDS	National Association of State Directors of Developmental Disability Services
FSB	Finance Systems and Budget (Group)
CMSO	Center for Medicaid and State Operations
DEHPG	Disabled and Elderly Health Program Group
PSP	Personal Support Plan