

LONG-TERM SERVICES AND SUPPORTS QUALITY REVIEW



LTSS

BIENNIAL DETAILED REPORT 2017

Table of Contents

| | |
|--|----|
| TABLE OF TABLES AND FIGURES | v |
| EXECUTIVE SUMMARY | ix |
| CHAPTER 1: BACKGROUND..... | 1 |
| HISTORY | 1 |
| NATIONAL CORE INDICATORS..... | 1 |
| OVERVIEW OF REPORTS..... | 2 |
| LTSS DATA COLLECTION INSTRUMENTS | 3 |
| NCI CHILD & FAMILY SURVEY..... | 3 |
| NCI ADULT CONSUMER SURVEY | 3 |
| PARTICIPANT EXPERIENCE SURVEY..... | 3 |
| CORE PERFORMANCE INDICATORS..... | 3 |
| SAMPLE CHARACTERISTICS..... | 4 |
| TARGET POPULATION | 4 |
| DATA COLLECTION | 4 |
| PROGRAM ENROLLMENT AND SURVEY RESPONSE DISTRIBUTION..... | 5 |
| DADS VISION | 6 |
| DADS MISSION | 6 |
| CHAPTER 2: CHILDREN WITH DISABILITIES | 7 |
| OVERVIEW OF PROGRAMS AND SERVICES | 7 |
| INDIVIDUAL DEMOGRAPHICS | 9 |
| GENDER, AGE, RACE/ETHNICITY, AND LANGUAGE..... | 9 |
| RESIDENCE | 10 |
| INCOME LEVELS..... | 10 |
| INFORMATION ON FUNCTIONAL LEVEL..... | 10 |
| CAREGIVER DEMOGRAPHICS | 11 |
| HEALTH AND WELFARE | 11 |
| DISABILITIES AND CONDITIONS | 11 |
| HEALTH CARE | 12 |
| MENTAL AND BEHAVIORAL HEALTH ISSUES..... | 13 |
| SAFETY AND SECURITY | 13 |
| CHOICE AND PRIVACY | 14 |
| SERVICE CHOICES | 14 |
| COMMUNITY INCLUSION | 15 |
| COMMUNITY PARTICIPATION AND FRIENDS AND FAMILY..... | 15 |
| SYSTEM PERFORMANCE | 16 |

| | |
|---|----|
| INFORMATION AND PLANNING | 17 |
| ACCESS TO SERVICES AND SUPPORTS..... | 17 |
| ACCESS TO STAFF | 18 |
| ACCESS TO HEALTH SERVICES | 19 |
| DELIVERY OF SERVICES AND SUPPORTS..... | 19 |
| SERVICES SATISFACTION | 21 |
| OVERALL SATISFACTION..... | 21 |
| SATISFACTION WITH HEALTH CARE SERVICES | 24 |
| REDUCTION OF SERVICES AND SUPPORTS | 24 |
| CHAPTER 3: ADULTS WITH INTELLECTUAL DISABILITIES..... | 27 |
| OVERVIEW OF PROGRAMS AND SERVICES | 27 |
| INDIVIDUAL DEMOGRAPHICS | 30 |
| GENDER, AGE, RACE/ETHNICITY, AND LANGUAGE..... | 30 |
| RESIDENCE | 30 |
| INFORMATION ON FUNCTIONAL LEVEL..... | 31 |
| HEALTH AND WELFARE | 33 |
| HEALTH STATUS AND HEALTH HABITS..... | 33 |
| DISABILITIES AND CONDITIONS | 35 |
| HEALTH CARE | 36 |
| MENTAL AND BEHAVIORAL HEALTH ISSUES..... | 39 |
| SAFETY AND SECURITY | 40 |
| CHOICE AND PRIVACY | 41 |
| LIFE CHOICES..... | 41 |
| SERVICE CHOICES | 42 |
| PRIVACY..... | 44 |
| COMMUNITY INCLUSION | 44 |
| EMPLOYMENT | 44 |
| COMMUNITY PARTICIPATION | 46 |
| FRIENDS AND FAMILY | 47 |
| SYSTEM PERFORMANCE | 47 |
| CURRENT SERVICES | 47 |
| INFORMATION AND PLANNING | 48 |
| ACCESS TO SERVICES AND SUPPORTS..... | 49 |
| DELIVERY OF SERVICES AND SUPPORTS..... | 51 |
| SERVICES SATISFACTION | 52 |
| QUALITY OF LIFE..... | 52 |

| | |
|--|----|
| OVERALL SATISFACTION..... | 54 |
| CHAPTER 4: OLDER ADULTS AND ADULTS WITH PHYSICAL DISABILITIES..... | 55 |
| OVERVIEW OF PROGRAMS AND SERVICES..... | 56 |
| INDIVIDUAL DEMOGRAPHICS..... | 59 |
| GENDER, AGE, RACE/ETHNICITY, AND LANGUAGE..... | 59 |
| RESIDENCE..... | 60 |
| INFORMATION ON FUNCTIONAL LEVEL..... | 61 |
| HEALTH AND WELFARE..... | 64 |
| HEALTH STATUS AND HEALTH HABITS..... | 64 |
| DISABILITIES AND CONDITIONS..... | 65 |
| HEALTH CARE..... | 65 |
| MENTAL AND BEHAVIORAL HEALTH ISSUES..... | 67 |
| SAFETY AND SECURITY..... | 68 |
| CHOICE AND PRIVACY..... | 69 |
| LIFE CHOICES..... | 69 |
| SERVICE CHOICES..... | 70 |
| PRIVACY..... | 71 |
| COMMUNITY INCLUSION..... | 72 |
| EMPLOYMENT..... | 72 |
| COMMUNITY PARTICIPATION..... | 72 |
| SYSTEM PERFORMANCE..... | 73 |
| CURRENT SERVICES..... | 73 |
| INFORMATION AND PLANNING..... | 73 |
| ACCESS TO SERVICES AND SUPPORTS..... | 75 |
| ACCESS TO TRANSPORTATION..... | 75 |
| DELIVERY OF SERVICES AND SUPPORTS..... | 75 |
| RESPONSIVENESS..... | 76 |
| SERVICES SATISFACTION..... | 77 |
| OUTCOMES..... | 77 |
| REDUCTION OF SERVICES AND SUPPORTS..... | 78 |
| CHAPTER 6: METHODS..... | 79 |
| DATA COLLECTION..... | 79 |
| DATA SOURCES..... | 79 |
| DATA COLLECTION INSTRUMENTS..... | 79 |
| CORE PERFORMANCE INDICATORS..... | 80 |
| SAMPLE CHARACTERISTICS..... | 80 |

| | |
|---|----|
| TARGET POPULATION | 80 |
| SAMPLE SIZE..... | 81 |
| SAMPLING PERIOD | 81 |
| SAMPLE SELECTION METHOD..... | 81 |
| ANALYSIS..... | 82 |
| OVERVIEW OF REPORTS..... | 83 |
| CHAPTER 7: ACCOMPLISHMENTS, ACTIVITIES, AND ON-GOING EFFORTS..... | 85 |
| IMPORTANT POPULATION CHARACTERISTICS..... | 85 |
| CHILDREN | 85 |
| ADULTS WITH IDD | 86 |
| ADULTS WITH PHYSICAL DISABILITIES | 86 |
| POSITIVE OUTCOMES:..... | 86 |
| CHILDREN - | 86 |
| ADULTS WITH IDD - | 87 |
| ADULTS WITH PHYSICAL DISABILITIES | 87 |
| OF SPECIAL NOTE | 88 |
| OPPORTUNITIES FOR IMPROVEMENT: | 88 |
| CHILDREN - | 88 |
| ADULTS WITH IDD | 88 |
| ADULTS WITH PHYSICAL DISABILITIES - | 89 |
| SUMMARY..... | 90 |
| DADS VISION | 90 |
| DADS MISSION | 90 |
| HHS CONTACTS: | 91 |
| LINKS TO REPORTS | 91 |
| APPENDICES | 91 |

TABLE OF TABLES AND FIGURES

| | |
|--|----|
| FIGURE 1-1. STATES PARTICIPATING IN 2011 – 2012 NCI SURVEYS..... | 2 |
| TABLE 1-1. OVERVIEW OF TARGET POPULATION BY DATA COLLECTION INSTRUMENT 2013..... | 4 |
| TABLE 1-2. PROGRAMS SURVEYED BY DATA COLLECTION INSTRUMENT AND YEAR DATA WAS COLLECTED..... | 4 |
| FIGURE 1-2. TEXAS HEALTH AND HUMAN SERVICES PUBLIC HEALTH REGIONS..... | 6 |
| TABLE 2-1. GENDER, AGE, RACE/ETHNICITY, PRIMARY LANGUAGE AND RESIDENCE OF CHILD SURVEY PARTICIPANTS..... | 9 |
| FIGURE 2-1. TEXAS AND US ANNUAL HOUSEHOLD INCOME OF CHILD AND FAMILY SURVEY HOUSEHOLDS..... | 10 |
| TABLE 2-2. PRIMARY MEANS OF EXPRESSION BY PROGRAM..... | 10 |
| FIGURE 2-2. MOST COMMON CONDITIONS, COMPARISON OF TEXAS TO US..... | 11 |
| FIGURE 2-3. PROPORTION OF CHILDREN WITH IDD HAVING SECONDARY CONDITIONS, COMPARISON OF TEXAS TO US..... | 12 |
| FIGURE 2-4. FREQUENCY OF MEDICAL TREATMENT, COMPARISON OF TEXAS TO US..... | 12 |
| FIGURE 2-5. MENTAL HEALTH DIAGNOSES, COMPARISON OF TEXAS TO US..... | 13 |
| FIGURE 2-6. FAMILY REPORTED ABUSE OR NEGLECT IF ABUSE OCCURRED, COMPARISON OF TEXAS TO US..... | 13 |
| FIGURE 2-7. FAMILY PARTICIPATE IN SERVICE PLAN CREATION OVER TIME, 2005 – 2013..... | 14 |
| FIGURE 2-8. SELECTION OF PROVIDER AGENCY AND CONTROL OVER STAFF HIRING, COMPARISON OF TEXAS TO US..... | 15 |
| FIGURE 2-9. COMMUNITY INCLUSION AND RELATIONSHIPS WITH PEOPLE WITHOUT DISABILITIES, TEXAS TO US..... | 16 |
| FIGURE 2-10. FAMILY ALWAYS HAS ENOUGH EASY TO USE INFORMATION ABOUT AVAILABLE SERVICES, TEXAS TO US..... | 17 |
| FIGURE 2-11. CONSUMER UNABLE TO ACCESS NEEDED EQUIPMENT, TRENDS 2005 – 2013..... | 18 |
| FIGURE 2-12. ACCESS TO NEEDED STAFF, COMPARISON OF TEXAS TO US..... | 18 |
| FIGURE 2-13. ACCESS TO DENTAL HEALTH SERVICES, 2005 – 2013..... | 19 |
| FIGURE 2-14. RESPONSIVENESS, TIMELINESS, AND APPROPRIATENESS OF STATE SERVICES BY SURVEY POPULATION..... | 20 |
| FIGURE 2-15. AVAILABILITY, FLEXIBILITY, AND PROXIMITY OF CHILDREN WITH DISABILITIES SERVICES AND SUPPORTS..... | 20 |
| FIGURE 2-16. CHILD AND FAMILY CONSUMER SATISFACTION WITH SERVICES AND SUPPORTS, TEXAS TO US..... | 21 |
| FIGURE 2-17. CHILD AND FAMILY CONSUMER SATISFACTION WITH SERVICES AND SUPPORTS OVER TIME, 2005 – 2013..... | 22 |
| FIGURE 2-18. SERVICES AND SUPPORTS MAKE A POSITIVE DIFFERENCE IN FAMILY'S LIFE..... | 22 |
| FIGURE 2-19. SERVICES AND SUPPORTS MAKE A POSITIVE DIFFERENCE IN FAMILY'S LIFE, 2005 – 2013..... | 23 |
| FIGURE 2-20. SERVICES AND SUPPORTS IMPROVE ABILITY TO CARE FOR CHILD, 2005 – 2013..... | 23 |
| FIGURE 2-21. CHILD AND FAMILY CONSUMER SATISFACTION WITH HANDLING GRIEVANCES OVER TIME, 2005 - 2013..... | 24 |
| FIGURE 2-22. COMPARISON OF SERVICE REDUCTIONS AND THEIR IMPACT ON FAMILIES BETWEEN TEXAS AND US..... | 25 |
| FIGURE 2-23. OUT-OF-POCKET EXPENSES NOT COVERED FOR CHILD AND FAMILY SURVEY HOUSEHOLDS..... | 25 |
| TABLE 3-1. GENDER, AGE, RACE/ETHNICITY, PRIMARY LANGUAGE AND RESIDENCE OF ADULTS WITH IDD..... | 30 |

| | |
|--|----|
| FIGURE 3-1. PROPORTION OF ADULTS WITH IDD BY TYPE OF RESIDENCE..... | 31 |
| FIGURE 3-2. LEVEL OF INTELLECTUAL DISABILITY OF ADULTS WITH IDD BY TYPE OF RESIDENCE..... | 31 |
| FIGURE 3-3. COMPARISON OF ADULTS WITH IDD IN TEXAS AND US BY LEVEL OF INTELLECTUAL DISABILITY..... | 32 |
| FIGURE 3-4. COMPARISON OF ADULTS WITH IDD BY LEVEL OF INTELLECTUAL DISABILITY BY PROGRAM | 32 |
| FIGURE 3-5. COMPARISON OF OVERALL HEALTH STATUS, TEXAS TO US..... | 33 |
| FIGURE 3-6. COMPARISON OF THE FREQUENCY OF REQUIRED MEDICAL CARE BY PROGRAM | 34 |
| FIGURE 3-7. COMPARISON OF MOBILITY STATUS BY PROGRAM | 34 |
| FIGURE 3-8. MOST COMMON CONDITIONS AMONG ADULTS WITH IDD, TEXAS AND US COMPARISON..... | 35 |
| FIGURE 3-9. ADULTS WITH IDD WITH SECONDARY CONDITIONS BY TYPE OF CONDITION, TEXAS AND US..... | 36 |
| FIGURE 3-10. ADULTS WITH IDD WHO RECEIVED HEALTH CARE SERVICES , TEXAS AND THE US | 37 |
| FIGURE 3-11. ADULTS WITH IDD WHO RECEIVED SELECTED ROUTINE AND PREVENTIVE HEALTH CARE BY TYPE OF RESIDENCE | 38 |
| FIGURE 3-12. ADULTS WITH IDD WHO RECEIVED ROUTINE DENTAL AND EYE EXAMINATIONS BY TYPE OF RESIDENCE..... | 38 |
| FIGURE 3-13. ADULTS WITH IDD WHO RECEIVED SELECTED CANCER SCREENING BY TYPE OF RESIDENCE..... | 39 |
| FIGURE 3-14. ADULTS WITH IDD DIAGNOSED WITH MENTAL ILLNESS BY TYPE OF DIAGNOSIS | 39 |
| FIGURE 3-15. ADULTS WITH IDD DIAGNOSED WITH MENTAL ILLNESS COMPARED TO THE PROPORTION RECEIVING PSYCHIATRIC MEDICATIONS | 40 |
| TABLE 3-2. COMPARISON OF ADULTS WITH IDD DIAGNOSED WITH PSYCHIATRIC OR BEHAVIORAL HEALTH DIAGNOSES TO THE PROPORTION RECEIVING PSYCHIATRIC MEDICATIONS BY PROGRAM..... | 40 |
| FIGURE 3-16. THE PROPORTION OF ADULTS WITH IDD IN TEXAS AND US WHO HAVE INPUT INTO EVERYDAY DECISIONS ... | 41 |
| FIGURE 3-17. THE PROPORTION OF ADULTS WITH IDD IN TEXAS AND US WHO HAVE INPUT INTO MAJOR LIFE CHOICES | 42 |
| FIGURE 3-18. CONSUMER HELPS MAKE SERVICE PLAN BY PROGRAM | 43 |
| FIGURE 3-19. CONSUMER INPUT INTO SERVICES AND SUPPORTS, COMPARISON OF TEXAS TO US | 43 |
| FIGURE 3-20. EMPLOYMENT STATUS OF ADULTS WITH IDD BY TYPE OF RESIDENCE | 44 |
| FIGURE 3-21. TYPE OF EMPLOYMENT ADULTS WITH IDD HAVE IN THE COMMUNITY | 45 |
| FIGURE 3-22. COMMUNITY EMPLOYMENT AS A GOAL IN SERVICE PLAN FOR ADULTS WITH IDD FOR US, TEXAS, AND PROGRAMS | 45 |
| FIGURE 3-23. COMPARISON OF PARTICIPATION OF ADULTS WITH IDD IN COMMUNITY ACTIVITIES, TEXAS TO US | 46 |
| FIGURE 3-24. PROPORTION OF ADULTS WITH IDD RECEIVING SPECIAL SERVICES BY PROGRAM | 48 |
| FIGURE 3-25. ACCESS TO INFORMATION ABOUT SERVICES AND SUPPORTS | 48 |
| FIGURE 3-26. REPORTED ADDITIONAL SERVICES NEEDED BY ADULTS WITH IDD | 49 |
| FIGURE 3-27. REPORTED UNMET NEEDS OF ADULTS WITH IDD BY PROGRAM | 50 |
| FIGURE 3-28. RESPONSIVENESS, TIMELINESS, AND APPROPRIATENESS OF STAFF SERVICES AND SUPPORTS..... | 51 |

| | |
|---|----|
| FIGURE 3-29. REPORTED LONELINESS BY TYPE OF RESIDENCE..... | 53 |
| FIGURE 3-30. IMPACT OF LONELINESS ON SATISFACTION WITH PERSONAL LIFE..... | 53 |
| FIGURE 3-31. SERVICES AND SUPPORTS MAKE A POSITIVE DIFFERENCE IN FAMILY/INDIVIDUAL'S LIFE..... | 54 |
| TABLE 4-1. GENDER, AGE, RACE/ETHNICITY, LANGUAGE AND RESIDENCE OF ADULTS WITH PHYSICAL DISABILITIES..... | 60 |
| FIGURE 4-1. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES BY TYPE OF RESIDENCE | 60 |
| FIGURE 4-2. PROPORTION OF NON-AMBULATORY ADULTS WITH PHYSICAL DISABILITIES BY PROGRAM | 61 |
| FIGURE 4-3. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES REQUIRING ASSISTANCE WITH ADLs..... | 62 |
| FIGURE 4-4. ADULTS WITH PHYSICAL DISABILITIES UNABLE TO ACCOMPLISH ADLs BECAUSE HELP WAS UNAVAILABLE | 62 |
| FIGURE 4-5. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES REQUIRING ASSISTANCE WITH IADLs..... | 63 |
| FIGURE 4-6. ADULTS WITH PHYSICAL DISABILITIES UNABLE TO ACCOMPLISH IADLs BECAUSE HELP WAS UNAVAILABLE | 63 |
| FIGURE 4-7. OVERALL HEALTH, ADULTS WITH PHYSICAL DISABILITIES AND ALL TEXANS AGE 60 AND OVER..... | 64 |
| FIGURE 4-8. COMPARISON OF THE FREQUENCY OF REQUIRED MEDICAL CARE BY PROGRAM | 66 |
| FIGURE 4-9. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO RECEIVED HEALTH CARE SERVICES | 67 |
| FIGURE 4-10. ADULTS WITH PHYSICAL DISABILITIES TREATED FOR MENTAL ILLNESS BY TYPE OF MENTAL ILLNESS | 67 |
| FIGURE 4-11. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO REPORTED THEY WERE AFRAID | 68 |
| FIGURE 4-12. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO REPORTED INURY OR THEFT BY STAFF..... | 68 |
| FIGURE 4-13. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO REPORTED STAFF YELLING OR MEANNESS..... | 69 |
| FIGURE 4-14. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO HAVE INPUT INTO EVERYDAY DECISIONS | 70 |
| FIGURE 4-15. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO HAVE INPUT INTO STAFFING CHOICES | 71 |
| FIGURE 4-16. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO HAVE INPUT INTO SERVICES AND SUPPORTS .. | 71 |
| FIGURE 4-17. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES PARTICIPATING IN COMMUNITY ACTIVITIES | 72 |
| FIGURE 4-18. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES RECEIVING SPECIFIED SERVICES..... | 73 |
| FIGURE 4-19. ACCESS TO INFORMATION ABOUT SERVICES AND SUPPORTS | 74 |
| FIGURE 4-20. SOURCE OF INFORMATION ABOUT SERVICES AND SUPPORTS | 74 |
| FIGURE 4-21. REPORTED SERVICE NEEDS OF ADULTS WITH PHYSICAL DISABILITIES..... | 75 |
| FIGURE 4-22. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES SHOWN RESPECT BY TYPE OF STAFF | 76 |
| FIGURE 4-23. RESPONSIVENESS, TIMELINESS, AND APPROPRIATENESS OF STAFF SERVICES AND SUPPORTS..... | 77 |
| FIGURE 4-24. SERVICES AND SUPPORTS MAKE A POSITIVE DIFFERENCE FOR ADULTS WITH PHYSICAL DISABILITIES | 78 |
| TABLE 5-1. OVERVIEW OF TARGET POPULATION BY DATA COLLECTION INSTRUMENT 2013..... | 81 |
| TABLE 5-2. PROGRAMS SURVEYED BY TOOL AND YEAR DATA WAS COLLECTED | 82 |

EXECUTIVE SUMMARY

PURPOSE: The Texas Department of Aging and Disability Services (DADS) administered multiple long-term services and support programs for older individuals, for people with intellectual or developmental disabilities (IDD), and for people with physical disabilities until September 1, 2016. At that time, many of DADS services and supports were transferred to Texas Health and Human Services. As the data in this report were collected in 2015, this report refers to DADS. The Long-term Services and Supports Quality Review (LTSS) is a statewide survey of people receiving in-home, community-based, or institutional services and supports offered by DADS. The purpose of the LTSS survey is to describe the perceived quality and adequacy of long-term services and supports administered by DADS, consumer quality of life, and trends in long-term services and supports.

FINDINGS: The results of the surveys were encouraging. Texas exceeded national averages for more than half of the benchmark measures for adults with IDD and children with disabilities. Adults with IDD met or received more routine and preventive health care on recommended schedules than the national average for all but two of the ten health care indicators. Five out of the ten health care indicators were statistically significantly higher than the national averages.

Participants' quality of life, as measured by self-reported happiness and self-direction of staff, services, and relationships, was quite high. A majority of the individuals and families reported that support staff were adequately trained and respectful. Respondents overwhelmingly reported that their rights are respected, they are satisfied with their privacy, they feel safe in their homes and neighborhoods, and they know how to report abuse or problems. In adult programs, people have the services and supports needed to meet most of their personal goals.

The results also highlight opportunities for improvement. Respondents consistently reported transportation as a barrier. Individuals from all programs reported lack of control over and access to transportation when they needed it. Not surprisingly, transportation difficulties correlated highly with lower levels of community involvement and participation in integrated activity settings.

Families of children with disabilities requested increased access to therapy services (e.g., speech, occupational, aqua, and equine). More than one out of every ten families of children with disabilities reported problems with access to dental care. Among adults with physical disabilities, responses underscored the importance of non-technical help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs)—for people with disabilities living in the community, help with bathing or laundry, for example, is essential.

About a third of adults with physical disabilities are lacking important immunizations such as influenza and pneumococcal vaccinations. Since individuals in this group have significant health risks, lack of immunization is a critical issue. Among adults with IDD and with physical disabilities, the use of psychoactive drugs without a psychiatric diagnosis is troublingly common.

METHODS: DADS used three nationally recognized survey instruments for measuring specific consumer indicators. The LTSS 2017 survey collected representative data from 4,971 adults and 1,913 families of children with disabilities from January through August 2015. The LTSS survey provides baseline information for continuous quality improvement, helping the agency build a quality management strategy, develop innovations, and provide information to stakeholders.

CHAPTER 1: BACKGROUND

Prior to the 2017 Long-Term Services and Supports Quality Review (LTSS) reports, the reports were mandated by the Texas Legislature in the General Appropriations Act, Article II, and the Department of Aging and Disability Services (DADS), Rider 13 in House Bill 1. The rider was removed by the 84th Texas Legislature in 2015. The report provides information on consumers' experiences receiving services in DADS programs to the Texas Legislature, the Texas Health and Human Services Commission, DADS, and stakeholders. The report also includes data about quality of life, which encompasses aspects of a person's life that are not necessarily related to the direct delivery of services or supports (e.g., whether a person has relationships or friends), but help demonstrate how satisfied DADS consumers feel about the quality of their lives.

The surveys enable DADS staff to assess success and deficiencies over time, identify areas for improvement, and measure the effectiveness of implemented improvement strategies. The report is not regulatory in nature, but rather a method to identify areas for improvement.

HISTORY

In 2003, the Centers for Medicare and Medicaid Services (CMS) awarded the Texas Department of Mental Health and Mental Retardation a Real Choice Systems Change grant to improve quality in its home and community-based programs. A task force determined how to implement the grant.

One of the grant's objectives was to identify or develop a tool to measure individual experiences and calculate quality indicators. The task force recommended the National Core Indicators (NCI) tools (Adult Consumer and Child Family surveys) to measure experiences of people receiving services in Medicaid waiver programs and in intermediate care facilities for individuals with an intellectual disability or related conditions (ICF/IID).

LTSS Quality Review Vision:

- Improve practice at the state level
- Influence state and national policy
- Add knowledge to the field
- Inform strategic planning and priority setting

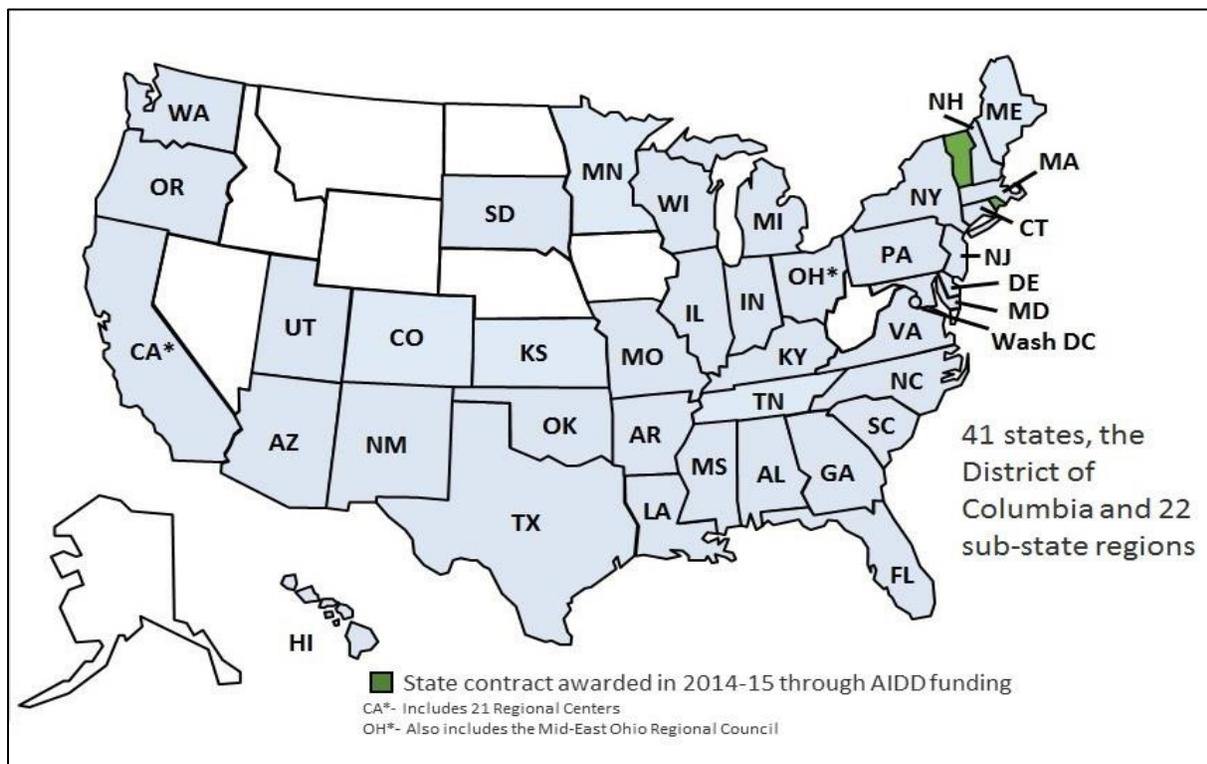
On September 1, 2004, these programs merged with the long-term care programs of the Texas Department of Human Services and the Texas Department on Aging under the newly established DADS. With the addition of older clients with disabilities, the Thomson/Reuters' Participant Experience Survey (PES) was selected to collect their experiences. The three survey instruments solicit the individual's perspective about the quality of the services and supports provided by DADS and quality of life. The LTSS report has been published since 2005. When the report cites national numbers, it refers to the NCI results. National numbers for the PES are not available.

NATIONAL CORE INDICATORS

The NCI began as a collaboration between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) in 1997 to encourage agencies to develop a standard set of performance measures to manage quality and facilitate comparisons across states. Fifteen states initially agreed to participate. Texas joined the cooperative in 2005. In 2015, the NCI collaboration includes 41 states. The goal is to increase

NCI participation to all 50 states, Washington D.C., and all U.S. territories by 2016. In 2015, NCI surveyed more than 29,100 individuals and families from 34 states and D.C. (Figure 1).

Figure 1-1. STATES PARTICIPATING IN 2014 – 2015 NCI SURVEYS



Source: National Core Indicators' Annual Summary Report 2014-2015, NASDDDS & HSRI, January 2016

OVERVIEW OF REPORTS

For 2017, DADS produced two versions of the LTSS survey report, a summary report to highlight specific findings and a detailed report for individuals interested in capturing the wealth of information in the LTSS surveys. Both versions of the 2017 reports are available on the DADS website at: <http://hhs.texas.gov/sites/hhs/files//ltssqr2017.pdf>.

This report is the *LTSS Biennial Detailed Report 2017*, featuring data collected in 2015 from a representative sample of Texans receiving DADS services and supports. The report is organized into chapters by the population served (children with disabilities, adults with intellectual disabilities, and adults with physical disabilities), and each population is described using the five domains (Health and Welfare, Choice and Respect, Community Inclusion, Systems Performance, and Services Satisfaction). The domains are described throughout the report in plain language and illustrated with graphs and/or tables.

All results are presented as percentages, with the exception of age and dollars. Percentages at or over .5 are rounded up to the next highest number. For example, 1.5 is reported as 2, while 1.49 is reported as 1. Ages are not rounded up; only completed years are used. For example, if the average age is 69.9, the average age is reported as 69 years. In the appendices, where all of the survey findings are presented, the percentages may not add up to 100 due to rounding issues. The findings given in the text of this report represent a selection of the entire list of quality indicators. Results of all of the variables are available upon request.

LTSS DATA COLLECTION INSTRUMENTS

This report includes results from three nationally validated survey instruments used for data collection across DADS programs and consumer types. Using nationally recognized surveys allows DADS to share data nationally and to conduct additional analyses by benchmarking Texas' performance in the national arena.

LTSS Created from Three Surveys:

- NCI Child & Family – Children with disabilities
- NCI Adult Consumer – Adults with IDD
- PES – Older adults with disabilities

NCI CHILD & FAMILY SURVEY

The NCI Child Family (CF) survey evaluates DADS Medicaid waiver programs serving children with disabilities. Since these individuals are younger than 21 years, a caregiver provides information regarding overall experiences with the services and supports received. The surveys are administered by telephone, mail and web.

NCI ADULT CONSUMER SURVEY

The NCI Adult Consumer survey (referred to as NCI in this report), is administered to DADS adult intellectual and development disability (IDD) services and supports recipients. Section I can only be answered by the consumer in a face-to-face interview. The interviewer records the respondent's comprehension and response consistency. Section II contains questions that may be answered by the consumer or, if needed, someone who knows the person well, such as a family member, friend, guardian, or advocate.

PARTICIPANT EXPERIENCE SURVEY

To measure the experiences and satisfaction of older adults and adults with physical disabilities, DADS collaborated with Thomson/Reuters (formerly MEDSTAT Group), which developed the PES tool for CMS. The PES captures participant experiences using telephone and face-to-face interviews. Most responses come from the individual, not a proxy.

CORE PERFORMANCE INDICATORS

The three surveys are organized across five general topics or domains: health and welfare, individual choice and respect, community inclusion, systems performance, and services satisfaction – each of which is divided into sub-domains (e.g., “employment” is a sub-domain of community inclusion).

The sub-domains are measured by one or more performance indicators, which were developed based upon criteria such as the performance measure's usefulness as a benchmark and feasibility of collecting the data. The full list of NCI core indicators can be viewed on the NCI website at: <http://nationalcoreindicators.org/indicators/>.

Domains and sub-domains addressed in this report

Health and Welfare

- Routine & preventive healthcare
- Sense of security

Choice and Respect

- Self-direction
- Life choices & decision-making

Community Inclusion

- Participation in community events
- Employment

Systems Performance

- Access to services
- Support delivery

Services Satisfaction

- Information and access
- Overall satisfaction

SAMPLE CHARACTERISTICS

TARGET POPULATION

The sampling goal of the 2017 LTSS report was to interview a representative sample of individuals from all DADS programs, excluding nursing facilities. The target population for the 2017 LTSS encompasses three distinct populations: adults, age 19 years and older with intellectual and/or developmental disabilities; adults, primarily older adults, with physical disabilities; and children under age 22 with disabilities (Table 1-1).

The survey population encompasses 17 programs, including six waiver programs (see Table 1-2 below). Table 1-1 provides a brief description of the target population for each survey, the method of survey administration, the total number of consumers served by each programs, survey type, and the total number of surveys collected overall.

Table 1-1. OVERVIEW OF 2015 TARGET POPULATION BY DATA COLLECTION INSTRUMENT

| Survey | Target Population | Method of Administration | Total # Served | Total # Surveyed |
|----------------------------|---|--------------------------|----------------|------------------|
| NCI Survey | Adults age 19 and older with IDD receiving at least one service besides case management | In-person interview | 32,901 | 2,302 |
| PES Survey | Adults, primarily older adults, with physical disabilities | In-person, phone & web | 56,595 | 2,669 |
| Child Family Survey | Families of children with disabilities, under age 22 living at home | Mail, phone, web | 10,356 | 1,913 |

DATA COLLECTION

The DADS population was sampled and data collected between January 2015 and August 2015 for the January 2017 LTSS report. Table 1-2 below provides an overview of the programs surveyed, the data collection instrument or survey tool used, and the years each program was surveyed. The first surveys were conducted in 2005. After 2009, the surveys were conducted every other year, not annually. There is discussion about returning to an annual survey schedule.

All of the survey data is collected by an outside contractor. In 2015, DADS contracted with the Public Policy Research Institute at Texas A&M University (PPRI), to administer the surveys. PPRI hired and supervised the interviewers, who participated in a standardized training program. The face-to-face interviewers were special education teachers and social workers, all disinterested third parties, experienced in working with individuals who are older or have disabilities.

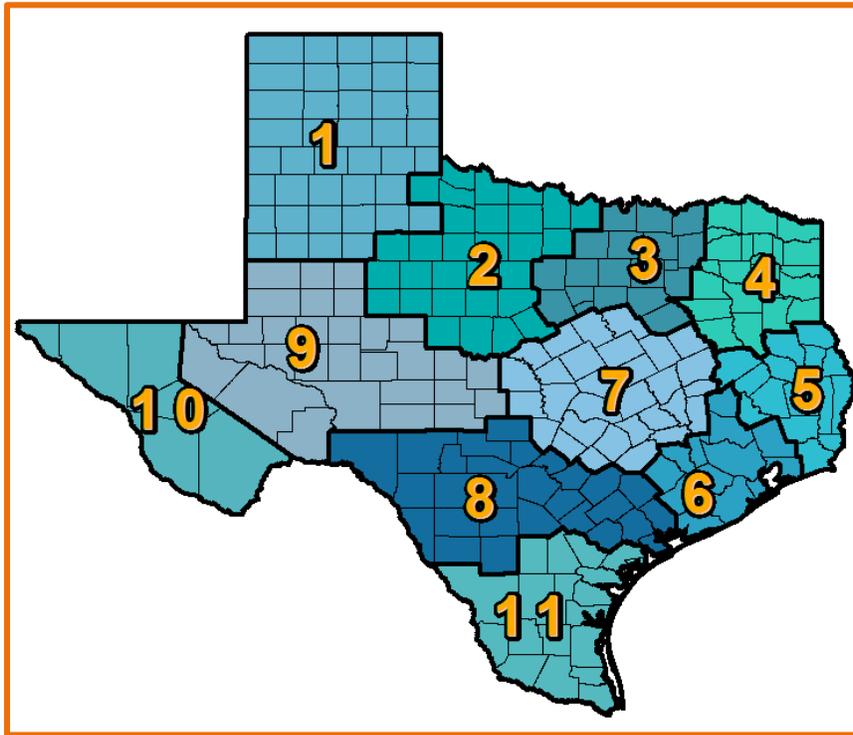
Table 1-2. PROGRAMS SURVEYED BY DATA COLLECTION INSTRUMENT AND YEAR DATA WAS COLLECTED

| Program | Survey Tool | Year Surveyed | | | | | | | |
|--|-------------|---------------|------|------|------|------|------|------|------|
| | | 2005 | 2006 | 2007 | 2008 | 2009 | 2011 | 2013 | 2015 |
| CLASS - Community Living Assistance and Support Services Waiver | NCI | ✓ | ✓ | | ✓ | ✓ | | ✓ | ✓ |
| HCS – Home and Community-based Services Waiver | NCI | ✓ | ✓ | ✓ | | ✓ | | ✓ | ✓ |
| TxHmL - Texas Home Living Waiver | NCI | ✓ | ✓ | | | ✓ | | ✓ | ✓ |
| DBMD – Deaf Blind with Multiple Disabilities Waiver | NCI | ✓ | ✓ | | | ✓ | | ✓ | ✓ |
| CWP – Consolidated Waiver Program | NCI | ✓ | ✓ | | | ✓ | | NA | NA |
| ICF/IDD – Intermediate Care Facility | NCI | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ | ✓ |
| SSLC – State Supported Living Centers | NCI | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| CBA – Community Based Alternatives Waiver | PES | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ | NA |
| CAS – Community Attendant Services | PES | | | ✓ | | | ✓ | ✓ | ✓ |
| CMPAS – Consumer Managed Personal Attendant Services | PES | | | | | | ✓ | ✓ | ✓ |
| PHC – Primary Home Care | PES | | | | | | ✓ | ✓ | ✓ |
| AFC – Adult Foster Care | PES | | | ✓ | | | ✓ | | |
| Family Care | PES | | | ✓ | | | ✓ | ✓ | ✓ |
| PACE – Programs of All-Inclusive Care for the Elderly | PES | | | | | | ✓ | ✓ | ✓ |
| Residential Care | PES | | | | | | ✓ | ✓ | ✓ |
| SSPD – Special Services to Persons with Disabilities | PES | | | | | | ✓ | ✓ | ✓ |
| SSPD SAC -SSPD with 24-hour Shared Attendant Care | PES | | | | | | ✓ | ✓ | ✓ |
| DAHS – Day Activity and Health Services | PES | | | | | | | ✓ | ✓ |
| General Revenue | PES | | | | ✓ | | ✓ | NA | NA |
| IHFS – In-Home Family Support | PES | | | | | | | ✓ | ✓ |
| Children’s Programs | | | | | | | | | |
| CLASS – Community Living Assistance and Support Services Waiver | CF | ✓ | ✓ | | ✓ | | ✓ | ✓ | ✓ |
| HCS – Home and Community-based Services Waiver | CF | ✓ | ✓ | | ✓ | | ✓ | ✓ | ✓ |
| TxHmL – Texas Home Living Waiver | CF | ✓ | ✓ | | ✓ | | ✓ | ✓ | ✓ |
| MDCP – Medically Dependent Children Program Waiver | CF | ✓ | ✓ | | ✓ | | ✓ | ✓ | ✓ |
| CWP – Consolidated Waiver Program | CF | ✓ | ✓ | | ✓ | | | | NA |

PROGRAM ENROLLMENT AND SURVEY RESPONSE DISTRIBUTION

A goal of survey design is to select a sample that is representative of the population and is large enough to be able to make accurate statements based upon the responses. Selecting a sample across 11 geographic public health regions and 17 programs is difficult. Regional and program-specific data are presented in this detailed 2017 Long-Term Services and Supports Survey report. The public health regions are presented below in Figure 1-2, the programs in Table 1-2 above.

Figure 1-2. TEXAS HEALTH AND HUMAN SERVICES PUBLIC HEALTH REGIONS



The data in this report have been weighted or adjusted to mirror the actual proportion of people receiving services in the various programs. The proportion or distribution of people who responded to the surveys is the same as the distribution of people actually served in each of the programs. This allows DADS to make statements about individuals with IDD as a group as well as by program.

DADS VISION

Aging Texans and individuals with disabilities will be supported by a comprehensive and cost-effective service delivery system that promotes and enhances individual well-being, dignity, and choice.

DADS MISSION

The DADS mission is to provide a comprehensive array of aging and disability services, supports, and opportunities that are easily accessed in local communities.

Our key responsibilities to the citizens of Texas include:

- Working in partnership with consumers, caregivers, service providers, and other stakeholders
- Developing and improving service options that are responsive to individual needs and preferences
- Ensuring and protecting self-determination, consumer rights, and safety

CHAPTER 2: CHILDREN WITH DISABILITIES

The 2017 LTSS Detailed Report provides results from the NCI Child Family (CF) surveys completed in 2015. Surveys were sent to families of children receiving services from DADS to obtain information from family members about their experiences. LTSS used the NCI CF survey to gather feedback from families from four programs administered by DADS to children with disabilities in Texas: Home and Community-based Services (HCS), Community Living Assistance and Support Services (CLASS), Texas Home Living (TxHmL), and the Medically Dependent Children Program (MDCP). The data were analyzed and reviewed as a group (for all children with disabilities served by DADS) and separately for each of the four programs. Comparison of differences between Texas children with disabilities and national NCI results was also conducted.

PPRI mailed 5,790 CF letters inviting families in four programs to participate; 196 were undeliverable reducing our sample to 5,594. Thirty-four percent of the surveys were completed, 51 percent by phone, 30 percent on paper, and 19 percent on the web. DADS received 1,913 completed surveys.

The next section provides information on the services offered by each program. Generally, statistics are presented for the whole survey population. Statistics for each program are included for survey questions where the responses for a specific program were different from the population. For a complete list of individual program findings of the CF survey, see Appendix C.

OVERVIEW OF PROGRAMS AND SERVICES

| Home and Community-based Services (HCS) | |
|---|---|
| <p>There were 1,552 children receiving HCS services when the sample was taken. The sample size was 472.</p> | |
| <p>The HCS program is the largest Texas waiver program serving adults and children with intellectual or developmental disabilities. Local intellectual and developmental disability authorities deliver case management and provider agencies deliver direct services. With this service, individuals may live in their own or a family home, a host home/companion care setting; or a small group home where no more than four individuals live. Services are an alternative to residing in an ICF/IID. The HCS program receives funding from Medicaid and state funds. The HCS program is authorized by a 1915(c) waiver.</p> | |
| <p>Services Include:</p> <ul style="list-style-type: none"> • Adaptive Aids • Case Management • Counseling and Specialized Therapies • Day Habilitation • Dental Treatment | <ul style="list-style-type: none"> • Minor Home Modifications • Nursing • Residential Assistance • Respite Care • Supported Employment |

Community Living Assistance and Support Services (CLASS)

There were **1,798** children receiving CLASS services when the sample was taken.
The sample size was **431**.

The CLASS program provides home and community-based services to adults and children with “related conditions” (e.g., cerebral palsy, autism, etc.) as a cost-effective alternative to living in an ICF/IID. Separate agencies provide case management and direct services. Qualifying conditions originate before age 22 and affect one’s ability to function in daily life. Intellectual disability alone does not qualify. Individuals served typically have substantial limitations in at least three of the following areas: self-care, language, learning, mobility, self-direction, and capacity for independent living. The CLASS program receives funding from Medicaid and state funds. The CLASS program is authorized by a 1915(c) waiver.

Services include:

- | | |
|---|--|
| <ul style="list-style-type: none"> • Specialized Therapies • Adaptive Aids and Medical Supplies • Habilitation and Respite Care • Transition Assistance Services • Case Management | <ul style="list-style-type: none"> • Minor Home Modifications • Nursing Services • Prescription Drugs • Psychological Services |
|---|--|

Texas Home Living (TxHmL)

There were **1,780** children receiving TxHmL services when the sample was taken.
The sample size was **487**.

The TxHmL program provides selected essential services and supports to adults and children with an intellectual disability who live in their family homes or their own homes. It is a cost-effective alternative to living in an ICF/IID. Separate agencies provide case management and direct services. Eligibility includes diagnosis, financial requirements, own home or family residence, and service needs that do not exceed the program’s cost cap. The TxHmL program receives funding from Medicaid and state funds. The TxHmL program is authorized by a 1915(c) waiver.

Services include:

- | | |
|---|---|
| <ul style="list-style-type: none"> • Adaptive Aids and Minor Home Modifications • Behavioral Support • Community Support • Day Habilitation • Dental Treatment | <ul style="list-style-type: none"> • Employment Assistance and Supported Employment • Nursing • Respite • Specialized therapies |
|---|---|

Medically Dependent Children Program (MDCP)

There were **5,226** children receiving MDCP services when the sample was taken. The sample size was **356**.

The MDCP program provides a variety of services to support families caring for children (under the age of 22) who are medically dependent. The program enables families to avoid nursing facility placement or remove children from nursing facilities. Participants must meet disability criteria, be Medicaid eligible, and have medical necessity for nursing home services. MDCP receives funding from Medicaid and state funds. The MDCP program is authorized by a 1915(c) waiver.

Services Include:

- | | |
|---|--|
| <ul style="list-style-type: none"> • Adaptive Aides • Adjunct Support Services • Financial Management Services | <ul style="list-style-type: none"> • Respite Care • Minor Home Modifications • Transition Assistance Services |
|---|--|

INDIVIDUAL DEMOGRAPHICS

GENDER, AGE, RACE/ETHNICITY, AND LANGUAGE

The demographics presented here are for all of the children with disabilities. Overall, there were only minor demographic variations between programs. Program-specific demographic numbers can be found in Appendix C.

A higher percentage of the children receiving services were male (61 percent). The average age of children for whom the CF survey was completed was 14 years; the range was less than one year to age 21. The children served by HCS and CLASS were slightly older, their ages ranging from 9 years to 21 in HCS and 10 to 21 years in CLASS.

The racial/ethnic composition and primary language varied by program population. Overall, 40 percent of the children surveyed were white non-Hispanic, 14 percent were Black non-Hispanic, 38 percent were Hispanic and 9 percent were other racial or ethnic groups. The largest percentage of children served by TxHmL and HCS was Hispanic (49 percent and 39 percent, respectively), while the majority of the children served by CLASS (52 percent) and MDCP (48 percent) were white non-Hispanic. An overview of children with disability demographics is presented in Table 2-1. English was the primary language of 89 percent of the children. Eleven percent reported Spanish as their primary language and less than one percent spoke other languages.

Table 2-1. GENDER, AGE, RACE/ETHNICITY, PRIMARY LANGUAGE AND RESIDENCE OF CHILD SURVEY PARTICIPANTS

| Children with Disabilities | | | | | | |
|----------------------------|----------------|-----------------|----------------------------|------------------|--------------|--|
| Gender | Age | Race/Ethnicity | | Primary Language | | Residence |
| Male 61% | Range <1-21 | White 40% | African American 14% | English 89% | | Lives with parents/relatives 98% |
| Female 39% | Average 14 | Hispanic 38% | Other 9% | Spanish 11% | Other <1% | Lives elsewhere 2% |

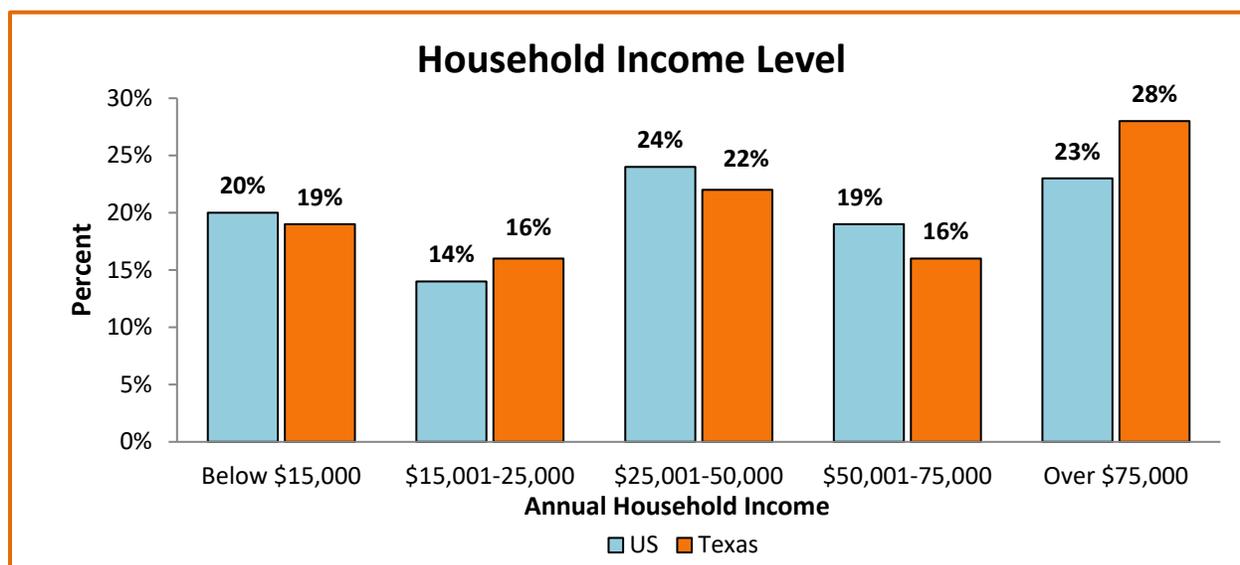
RESIDENCE

More than 98 percent of the children surveyed lived with their parents or relatives.

INCOME LEVELS

Household income information was collected in the CF survey. Comparing Texas and national results, a majority of respondents (57 percent) fall within a range between \$0 to \$50,000 per year (see Figure 2-1 below); however, household income among programs may vary. For example, fifty percent (36 percent) of the households served by TxHmL made \$15,000 a year or less, and 64 percent made \$25,000 a year or less.

Figure 2-1. TEXAS AND US ANNUAL HOUSEHOLD INCOME OF CHILD AND FAMILY SURVEY HOUSEHOLDS



INFORMATION ON FUNCTIONAL LEVEL

DADS serves children with multiple disabilities, including intellectual and developmental disabilities. The majority of the children surveyed have been diagnosed with an intellectual disability (74 percent). More than half, 52 percent, did not use the spoken word as their primary means of communication, as illustrated in Table 2-2. The children served by TxHmL were reported to use spoken language the most frequently (61 percent). The overall percentage of children using sign language or communication devices was relatively consistent across programs, at 4 percent each.

Table 2-2. PRIMARY MEANS OF EXPRESSION BY PROGRAM

| Primary Means of Expression | Program | | | | |
|-----------------------------------|--------------|-----|-------|-------|------|
| | All Children | HCS | CLASS | TxHmL | MDCP |
| Spoken Language | 48% | 54% | 55% | 61% | 38% |
| Gestures/Body Language | 34% | 32% | 31% | 22% | 41% |
| Sign Language/ Finger Spelling | 5% | 4% | 4% | 9% | 4% |
| Communication Device | 4% | 4% | 4% | 4% | 5% |
| Other | 9% | 6% | 6% | 4% | 13% |

CAREGIVER DEMOGRAPHICS

As children with disabilities primarily live with parents and relatives (more than 98 percent), caregiver demographics were collected for this survey population. Parents were the primary caregivers for the children surveyed in most cases (90 percent), followed by grandparents (5 percent). Most of the caregivers were 35 to 54 years old (70 percent), were in good health (75 percent), and lived in households with two adults in residence (62 percent). Forty-three percent had college degrees.

HEALTH AND WELFARE

Findings

- 27 percent of Texas children with disabilities required medical care by a trained medical provider at least once a week, compared to 11 percent nationally
- Most Texas children with intellectual disabilities reported multiple conditions in addition to intellectual disabilities
- 25 percent of the children had a mental health or behavioral disorder diagnosis
- 85 percent of Texas families knew how to report abuse and neglect compared to 73 percent of families nationally – a statistically significant difference

DISABILITIES AND CONDITIONS

As illustrated in Figure 2-2, the most commonly reported conditions were intellectual disability (74 percent), psychiatric issues (25 percent), seizure/neurological disorder (53 percent), autism spectrum disorder (41 percent), cerebral palsy (31 percent), and limited or no vision (30 percent). Most children had more than one condition.

Figure 2-2. MOST COMMON CONDITIONS, COMPARISON OF TEXAS TO US

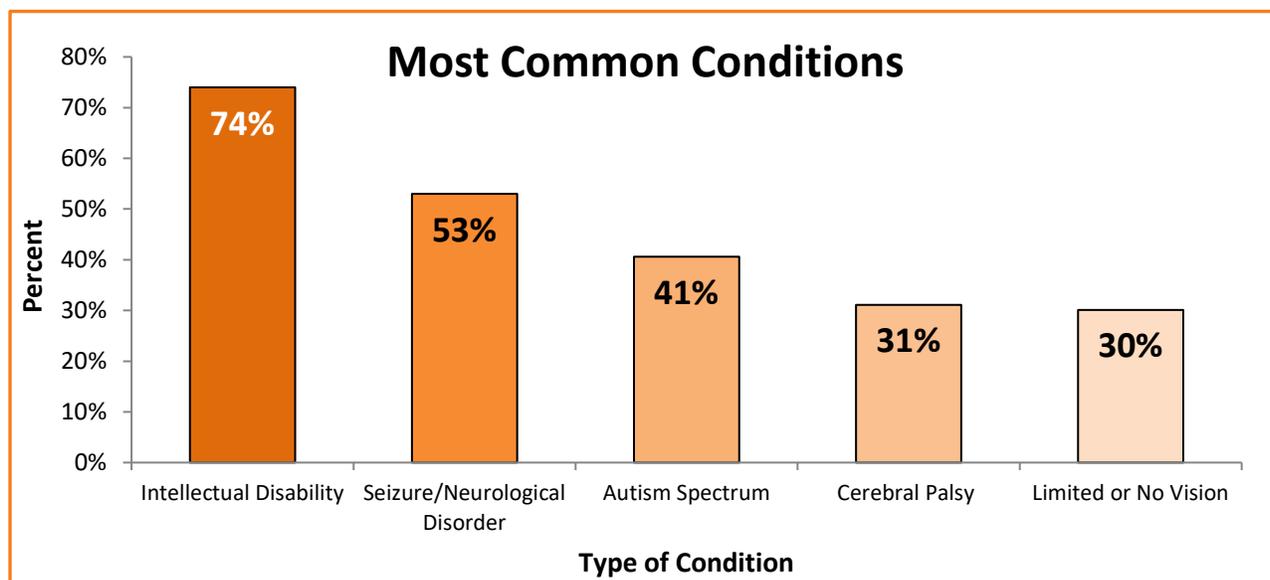
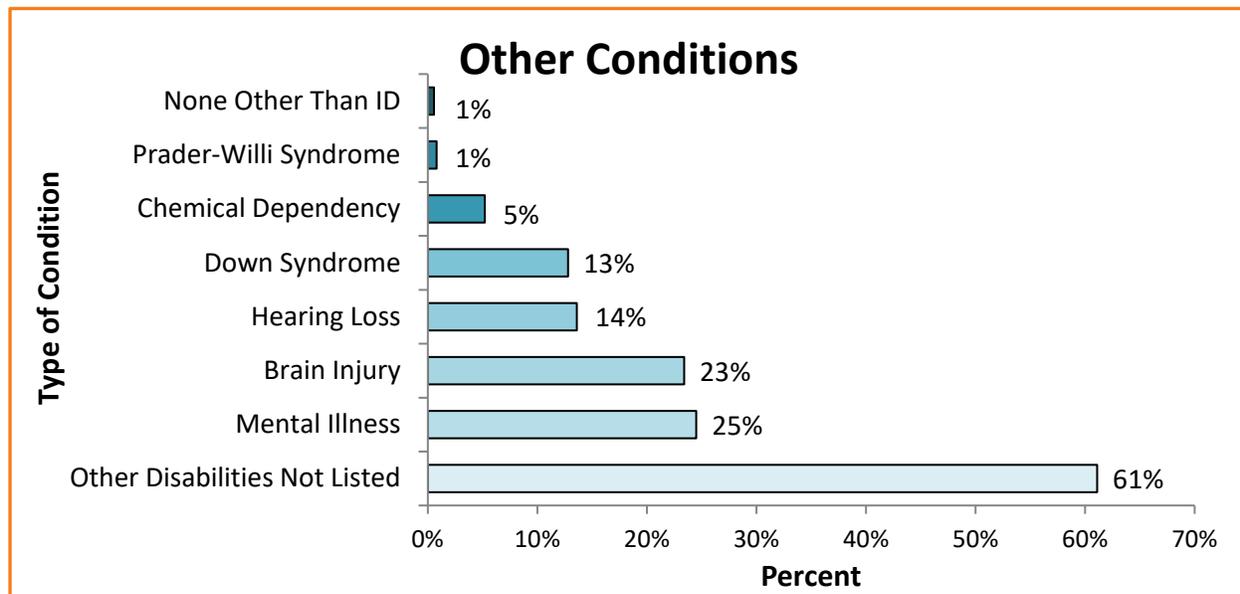


Figure 2-3 lists other conditions reported among Texas children with disabilities. The Texas average for children with no disability other than ID (1 percent) is slightly lower than the rate in the US (2

percent), or 99 percent of Texas children with an intellectual disability had at least one more disability, compared to 98 percent of children with intellectual disabilities in the US.

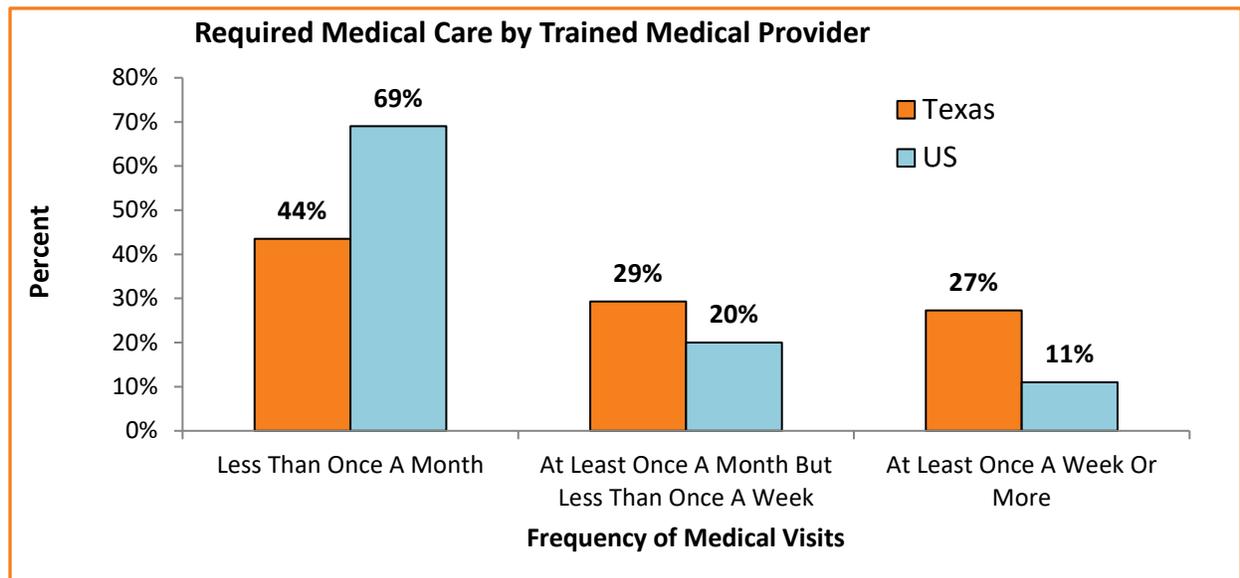
Figure 2-3 . PROPORTION OF CHILDREN WITH IDD HAVING SECONDARY CONDITIONS, COMPARISON OF TEXAS TO US



HEALTH CARE

The CF survey respondents reported that 98 percent of their children with disabilities had access to medical care. Texas had higher satisfaction with the quality of their children’s health care providers (95 percent) than reported in the Human Services Research Institute’s *2014-15 National Core Indicators Child Family Survey* (94 percent). Comparing states, Texas children with disabilities reported the highest percentage of children requiring medical care by a trained medical provider at least once a week or more (Figure 2-4). This is consistent with the high frequency of disabilities and conditions reported above.

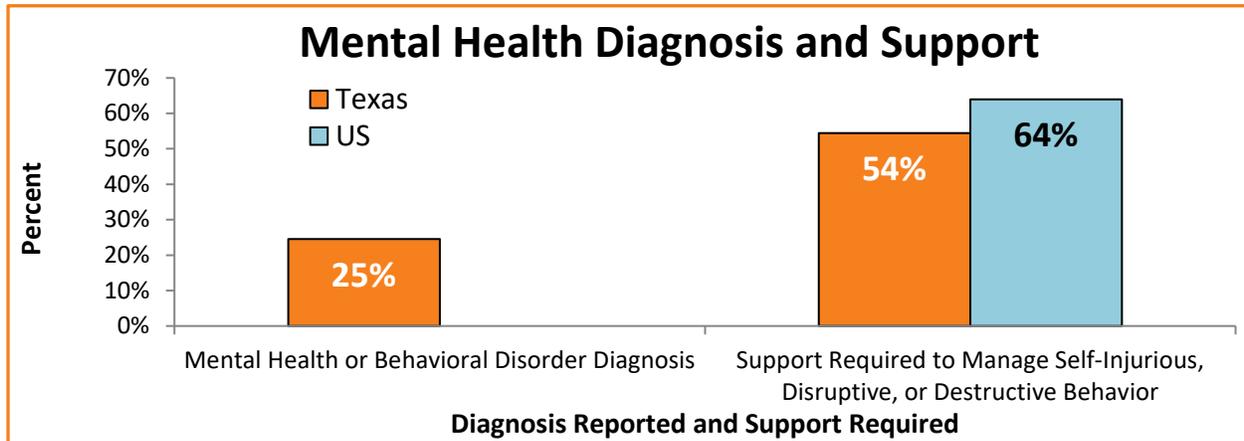
Figure 2-4. FREQUENCY OF MEDICAL TREATMENT, COMPARISON OF TEXAS TO US



MENTAL AND BEHAVIORAL HEALTH ISSUES

One in four children with disabilities served by DADS in Texas (25 percent) was diagnosed with a mental or behavioral health issue (Figure 2-5). While only a quarter of the children surveyed were diagnosed with a mental health disorder, the percentage requiring support to manage self-injurious, disruptive, or destructive behavior was more than twice the mental health diagnosis rate (54 percent). The national percentage requiring support to manage behavioral issues was 64 percent.

Figure 2-5. MENTAL HEALTH DIAGNOSES, COMPARISON OF TEXAS TO US

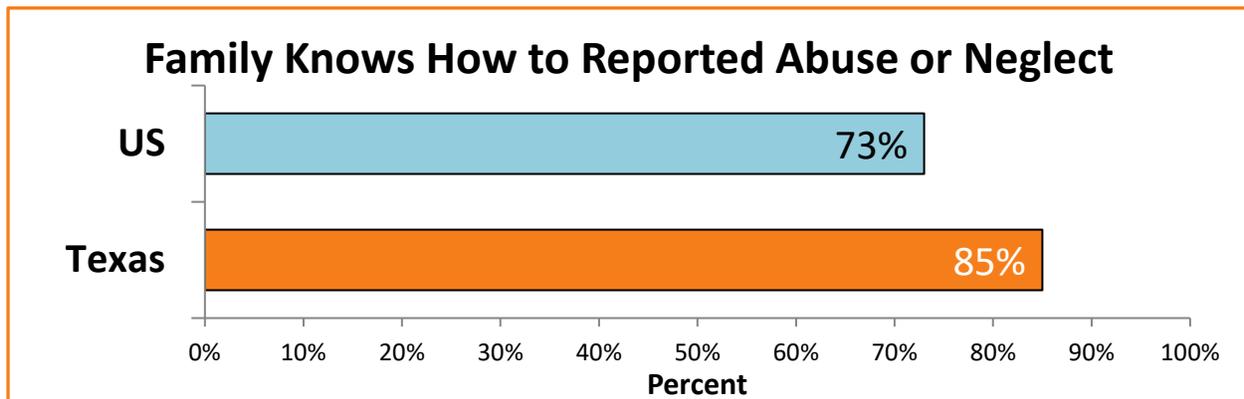


The majority of Texas families surveyed reported that they had access to mental health services (86 percent), which was slightly lower than the national rate of access to mental health services (89 percent). Families with access to mental health care also were asked if they were satisfied with the quality of the mental health providers. Almost all, 96 percent, were satisfied with their mental health care providers. Texas reported satisfaction levels slightly higher than the national average of 93 percent.

SAFETY AND SECURITY

Families were asked a series of questions about reporting abuse and neglect. Significantly more Texas families knew how to report abuse or neglect (85 percent) than reported nationally (73 percent). See Figure 2-6. Of equal importance, families in Texas reported abuse that occurred in the past year (43 percent). Texas reported abuse at the same rate as the national average of 43 percent. Ideally all abuse and neglect should be reported. It is unclear why abuse reporting rates are so low.

Figure 2-6. FAMILY KNOWS HOW TO REPORT ABUSE OR NEGLECT, COMPARISON OF TEXAS TO US



Of note, families reporting abuse felt that agencies were responsive to the abuse report only 81 percent of the time, less than the 85 percent recorded nationally.

CHOICE AND PRIVACY

Findings:

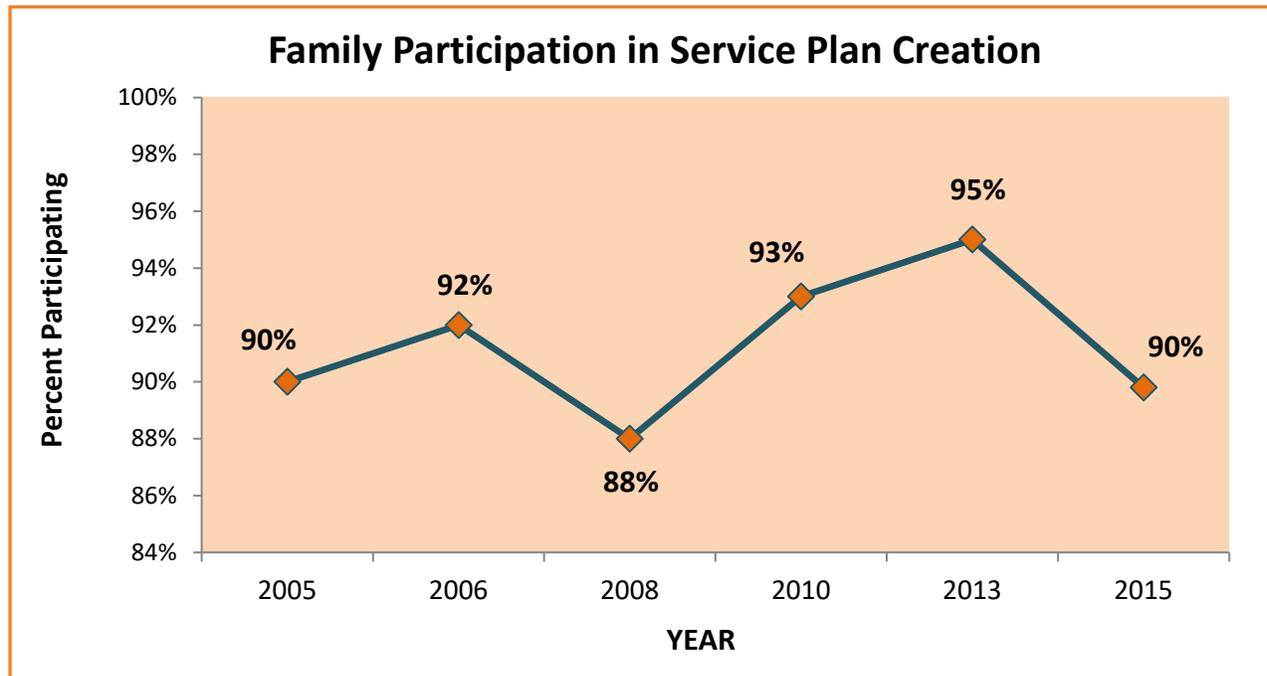
- 90 percent of families participated in the creation of their service plan
- More than three-quarters of families reported being able to choose their provider agency
- 78 percent of families reported having control over hiring and management of support workers

SERVICE CHOICES

SERVICE CHOICES: SELF-DIRECTION

Increasing consumer independence and autonomy through consumer choice and self-direction are strategic goals of DADS. Family participation in service plan creation has remained relatively static since 2005 when the LTSS survey was first employed (Figure 2-7). Family participation in the creation of the service plan for their child continues to fluctuate around 90 percent.

Figure 2-7. FAMILY PARTICIPATE IN SERVICE PLAN CREATION OVER TIME, 2005 – 2015

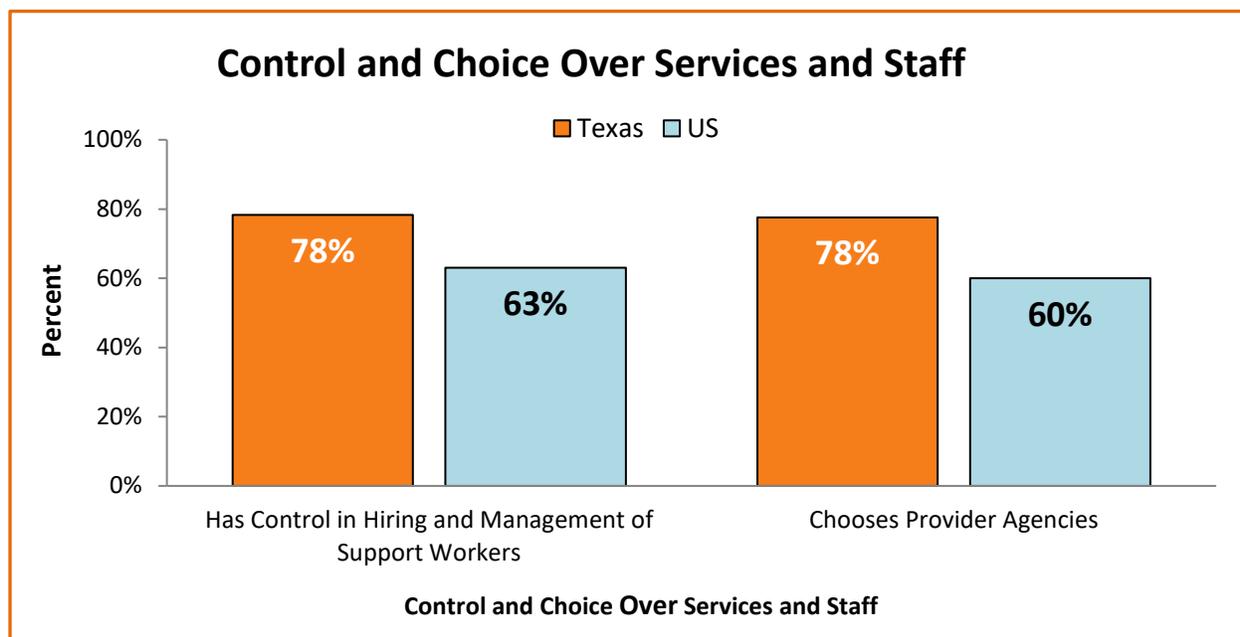


SERVICE CHOICES: PROVIDERS AND STAFF

Consumer-directed services (CDS), where consumers manage the provision of their services and supports (e.g., hiring and supervising the service provider), is an option offered in a number of the waiver programs. The families of children served by DADS reported high rates of CDS use, with 49 percent of the families using the CDS option. Choosing staff is a very personal decision, and 78 percent of families of children with disabilities had control in hiring and managing their staff,

compared to 63 percent nationally (Figure 2-8). Seventy-eight percent (78 percent) chose their provider agency, compared to 60 percent nationally. Both of these Texas percentages are significantly higher than the corresponding national average. DADS policy encourages consumers to use self-directed supports where appropriate to increase their satisfaction and autonomy.

Figure 2-8. SELECTION OF PROVIDER AGENCY AND CONTROL OVER STAFF HIRING, COMPARISON OF TEXAS TO US



COMMUNITY INCLUSION

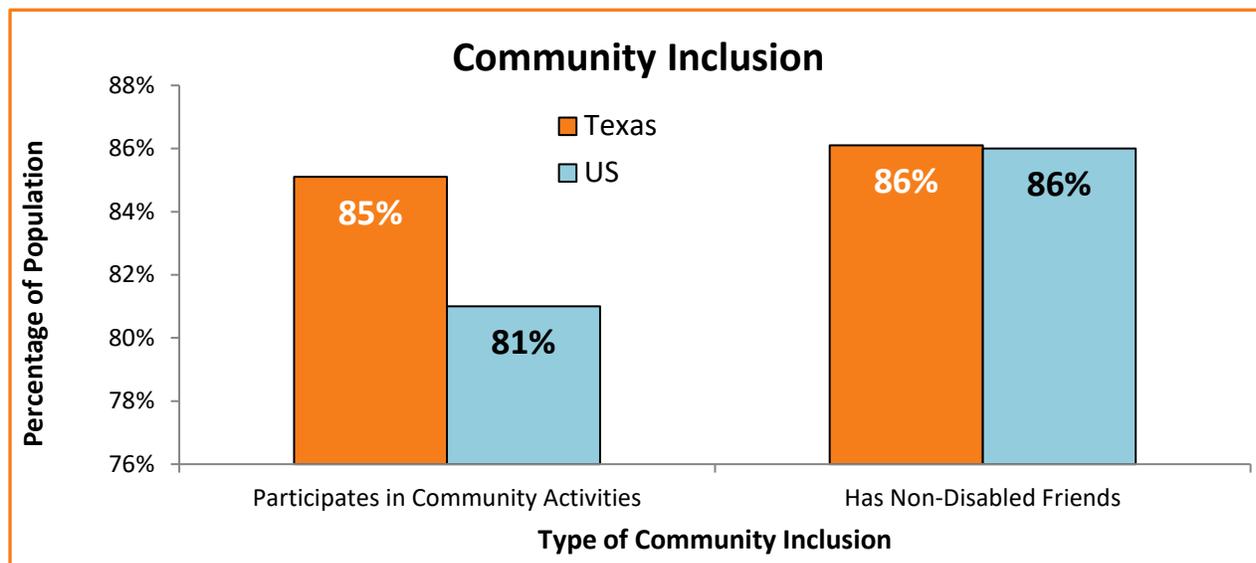
Findings

- 86 percent of children with disabilities had friends who did not have a disability
- 85 percent of children with disabilities participated in community activities

COMMUNITY PARTICIPATION AND FRIENDS AND FAMILY

Most of the survey respondents reported having friendships with people without disabilities and participating in community activities. Eighty-six percent (86 percent) of Texas and national CF survey respondents indicated their child spends time with children without disabilities. As seen in Figure 2-9, the majority of respondents, in Texas and nationally, reported their family member participated in community activities, however, Texas respondents reported higher rates of community participation (85 percent) compared to national respondents (81 percent).

Figure 2-9. COMMUNITY INCLUSION AND RELATIONSHIPS WITH PEOPLE WITHOUT DISABILITIES, TEXAS TO US



The most commonly cited reasons for lack of community participation for children with disabilities were lack of transportation (17 percent) and lack of support staff (20 percent). Cost was also cited by 12 percent of the families of children with disabilities as a contributing factor to their children’s lack of community participation.

SYSTEM PERFORMANCE

Findings:

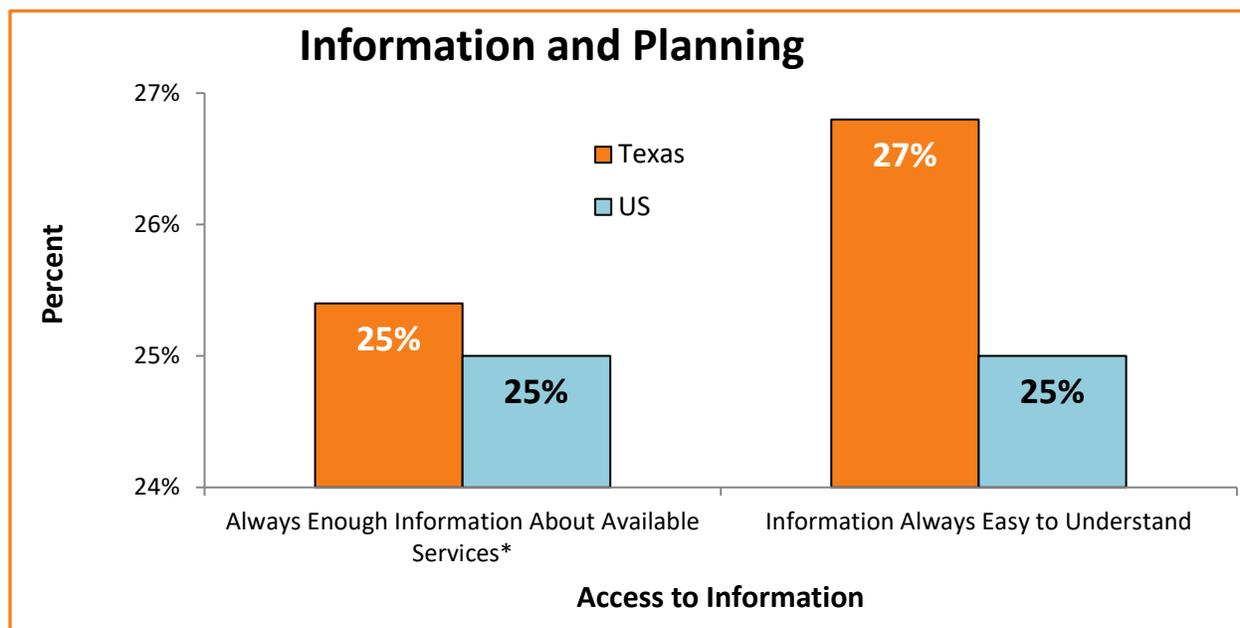
- 72 percent of families reported they knew how to report grievances against staff, significantly higher than the 52 percent reported nationally
- One out of every eight children failed to access needed equipment such as wheelchairs, ramps, or communication devices
- 96 percent of children had access to dental care, slightly higher than the national benchmark of 95 percent

The primary purpose of the LTSS survey is to measure consumer satisfaction with DADS services and supports. A key component of satisfaction is system performance, and two key measures of system performance are delivery of and access to services. If individuals do not have access to the services and equipment they need, or do not receive the services or supports identified in their service plans, they will not be satisfied. Service access is measured here by the availability of information about services and participation in service planning, the amount of reported unmet need, and the receipt of requested services and supports.

INFORMATION AND PLANNING

Information about services and consumer participation in service planning are important access issues. Fifty-one percent of survey respondents reported they receive information about available services and supports (see Figure 2-10). Most reported that the information about services and supports was always or usually easy to understand and use (61 percent).

Figure 2-10. FAMILY ALWAYS HAS ENOUGH EASY TO USE INFORMATION ABOUT AVAILABLE SERVICES, TEXAS TO US



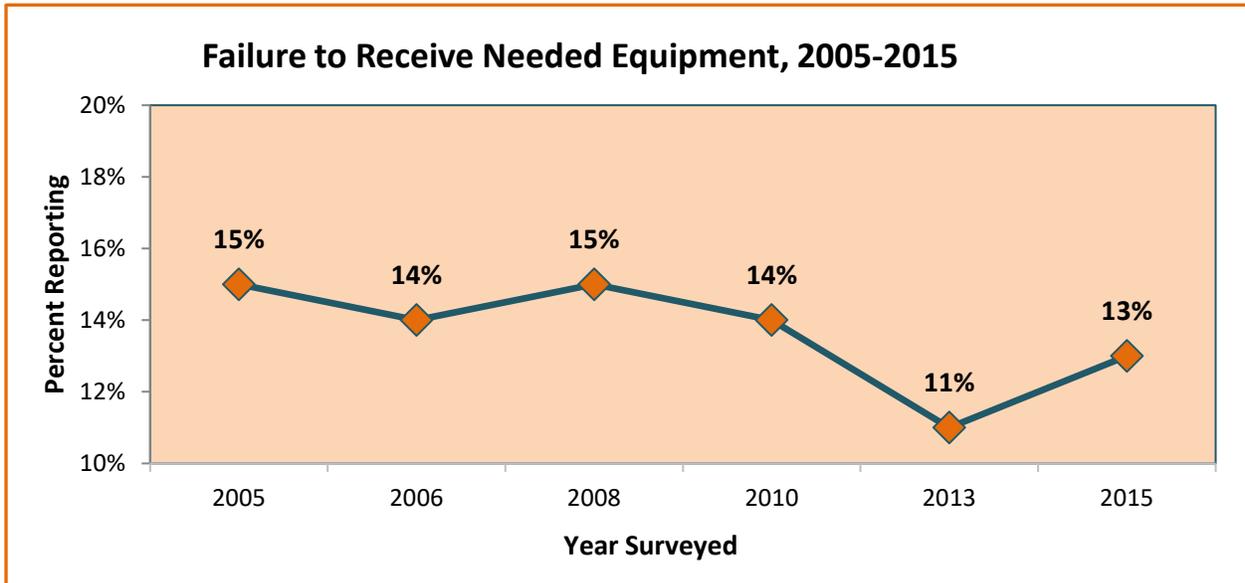
Most families (85 percent) reported they had all the information needed to make decisions on spending agency-provided funds for their child. Case managers were reported to be the primary source of information about services and supports available to children with disabilities and their families (65 percent).

The majority of CF survey respondents knew how to file complaints or grievances about provider agencies or staff (72 percent compared to 52 percent nationally, which is significantly higher). Families also reported they were satisfied with the way complaints and grievances were handled (83 percent). Respondents also knew how to report abuse or neglect (85 percent compared to 73 percent nationally). However, of those who said abuse or neglect had occurred within the past year, only 43 percent reported the problem. This was identical to the rate reported nationally (43 percent). Of those who filed a report of abuse or neglect in the past year, more than eight out of ten (81 percent in Texas and 85 percent nationally), found the appropriate parties responsive to their report.

ACCESS TO SERVICES AND SUPPORTS

The majority of families of children with disabilities reported that their service plan included all the services they needed (72 percent). At the same time, 42 percent reported that their child needs other services that are not currently offered or available. Only 50 percent reported that their child always had access to the special equipment or accommodations that he/she needed (e.g., wheelchair, ramp, communication board, etc.). Thirteen percent reported that they seldom or never had access to the special equipment or accommodations their child needs (Figure 2-11).

Figure 2-11. CONSUMER UNABLE TO ACCESS NEEDED EQUIPMENT, TRENDS 2005 - 2015

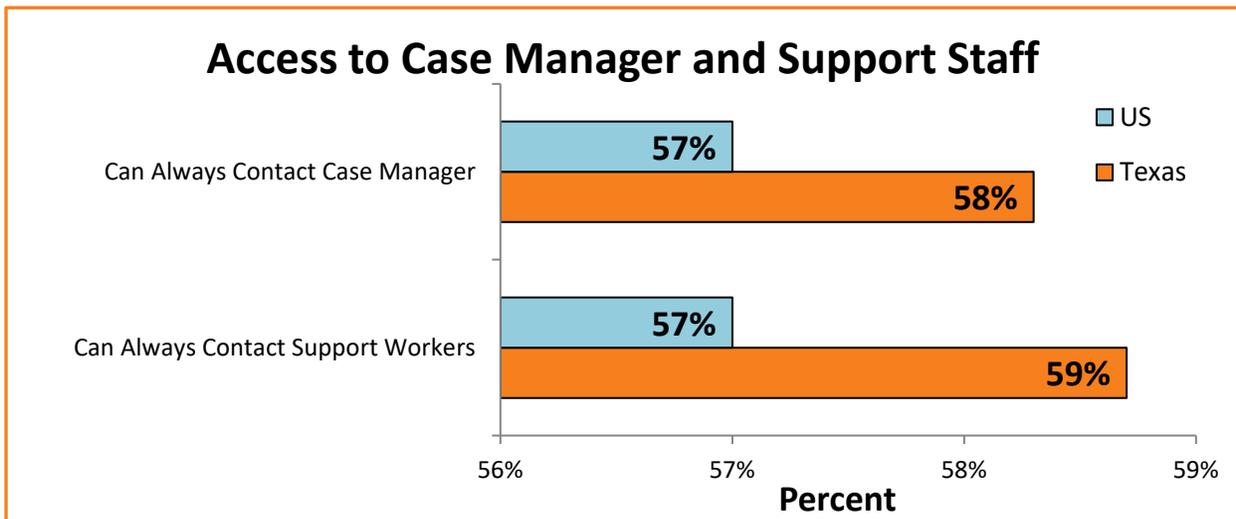


The percentage of children with disabilities who did not have access to needed equipment has decreased since the survey started in 2005, from a high of 15 percent in 2005 and 2008 to a low of 11 percent in 2013, but has increased to 13 percent since 2013. While 13 percent is lower than the national benchmark of 15 percent, this is a negative finding. About one out of every eight children does not have needed equipment.

ACCESS TO STAFF

To need services or supports and be unable to access the system (e.g., your case manager) to obtain benefits can be a frustrating experience. While Texas has a lot of room for improvement in the accessibility of case managers and support staff, the positive response rates in Texas exceeded the national benchmarks (Figure 2-12).

Figure 2-12. ACCESS TO NEEDED STAFF, COMPARISON OF TEXAS TO US



Fifty-eight percent of children’s services consumers reported that they could always contact their case manager and 59 percent could always contact their support staff, compared to 57 percent for

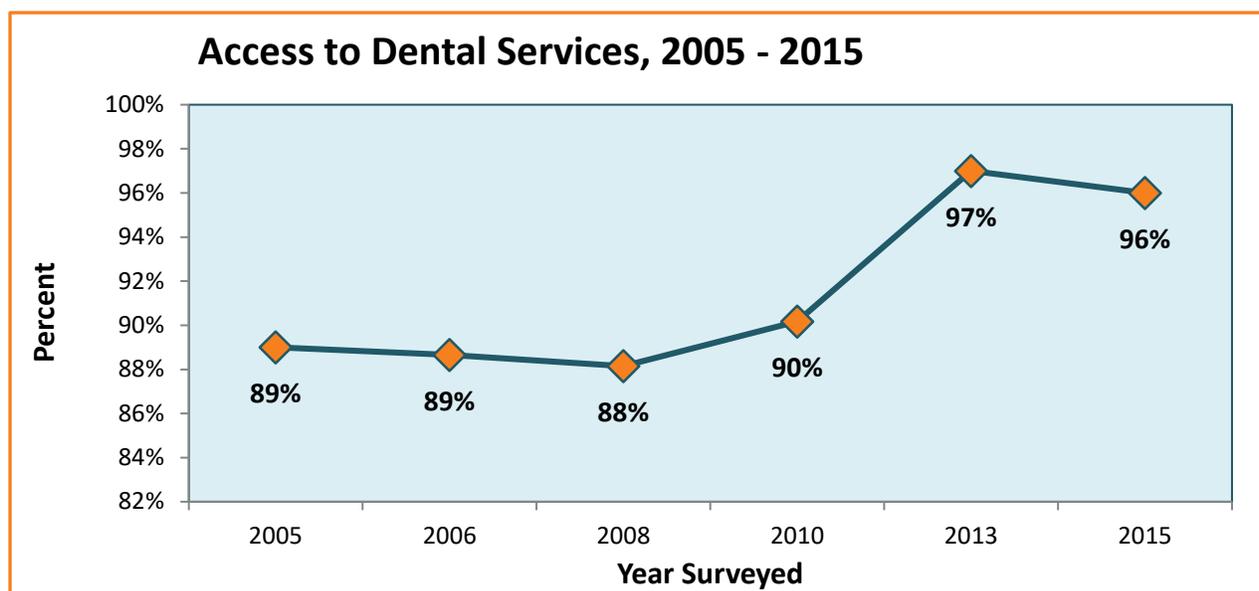
both case managers and support staff nationally. These rates surge to 84 and 85 percent when looking at respondents who could always *or usually* contact their case manager and support staff, respectively, demonstrating that Texas consumers have good access to staff in children’s programs.

ACCESS TO HEALTH SERVICES

Access to health services was high in Texas and nationally (98 percent each). Access to dental care for this special population was statistically significantly higher than the national average, 96 percent compared to 95 percent nationally. Almost all, 98 percent, of the families in Texas and nationally reported that they had access to the medications their child needed. Mental health care access was higher in the US than in Texas, with 89 percent and 86 percent reporting access respectively.

Access to dental health services has improved significantly since 2005 (Figure 2-13). In 2005, only 89 percent of families reported access to dental care for their child. By 2015, the majority of respondents (96 percent) reported having access to dental care.

Figure 2-13. ACCESS TO DENTAL HEALTH SERVICES, 2005 – 2015



DELIVERY OF SERVICES AND SUPPORTS

The quality of delivery of services and supports, for the purpose of this report, is measured by the receipt and completeness of authorized services, the manner in which the services were delivered, and the timeliness of those services and supports. Texas CF survey respondents reported that their family member received all services listed in their service plan at lower rates than those reported nationally (80 percent compared to 85 percent in national CF survey). Figure 2-14 below shows three critical service delivery issues: responsiveness, timeliness, and appropriateness. The responses are positive for all three measures.

Responsiveness is measured by a number of factors, such as accessibility of case managers and support staff, as discussed above, or staff responsiveness to abuse reporting. Staff responsiveness to abuse reporting is used as the proxy for responsiveness in Figure 2-14 below. Eighty-one percent (81 percent) of appropriate staff were responsive to consumer abuse or neglect complaints. The rate of “responsiveness” was lower than the national average of 85 percent.

Timeliness, as measured by support staff arriving on time and when scheduled, was very good, with 89 percent of the families of children with disabilities reporting that their support staff were prompt and came when scheduled. Appropriateness of services (as measured by support staff having the right training) was also positive, with 82 percent of the families of children with disabilities reporting that their support staff have the right training.

Figure 2-14. RESPONSIVENESS, TIMELINESS, AND APPROPRIATENESS OF STATE SERVICES BY SURVEY POPULATION

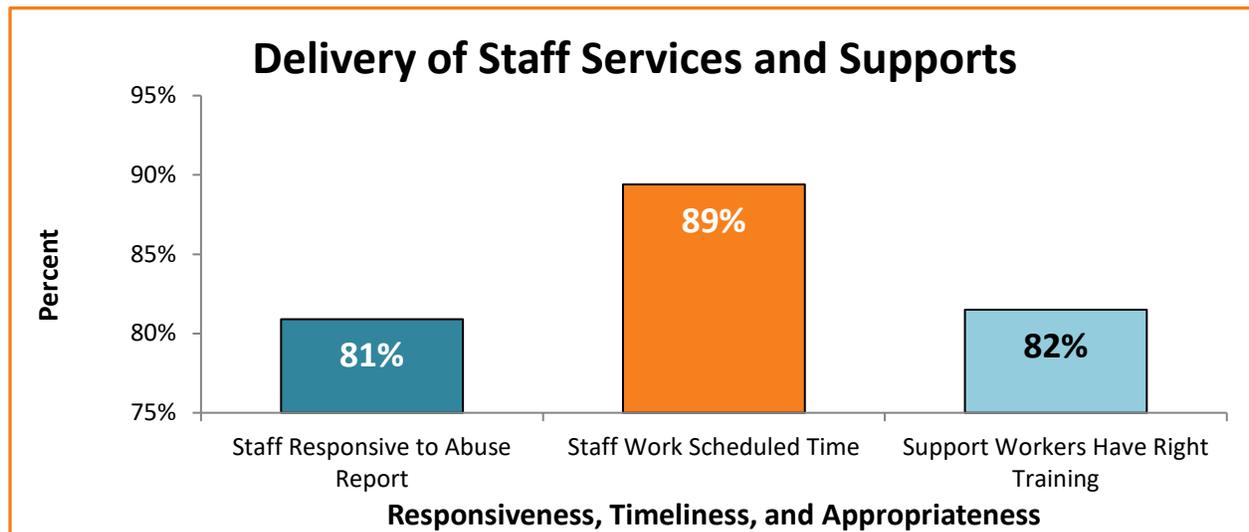
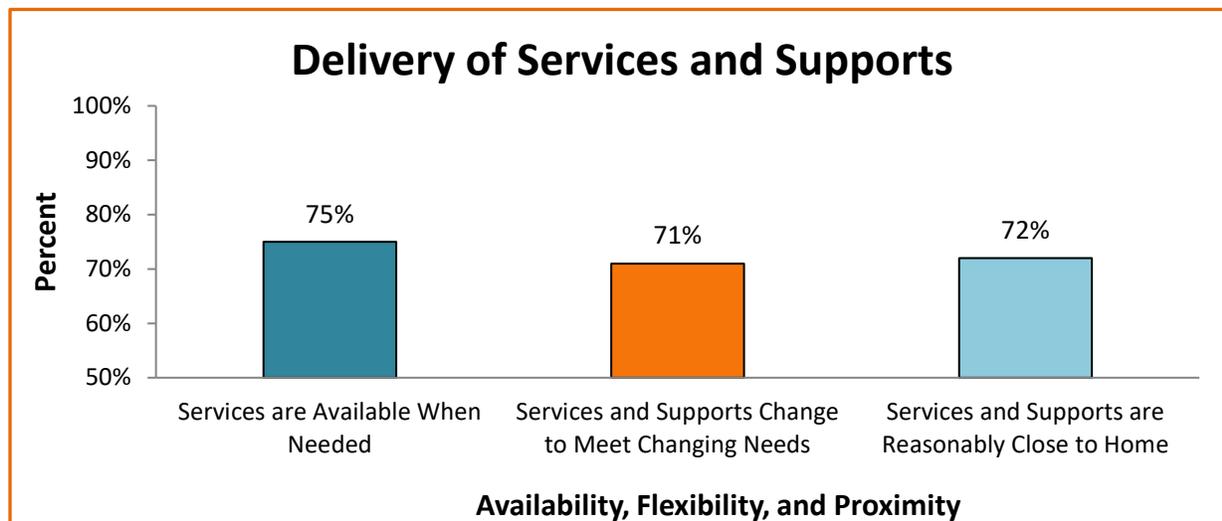


Figure 2-15 also shows critical service delivery issues: availability, flexibility, and proximity. Seventy-five percent of the families of children with disabilities reported that services were available when they needed them; 42 percent said services and supports were always available when they needed them. Almost three-quarters (71 percent) of the CF survey respondents reported flexible services and supports, which usually changed to meet their family member’s changing needs. Moreover, 72 percent of the families of children with disabilities reported that their services and supports were always or usually reasonably close to home. Thirty-nine percent said the services were always close to home, compared to 37 percent nationally. Considering the geographic distances in Texas, this is an accomplishment. Two out of three of these measures were lower than national benchmarks.

Figure 2-15. AVAILABILITY, FLEXIBILITY, AND PROXIMITY OF CHILDREN WITH DISABILITIES SERVICES AND SUPPORTS



The manner in which services are delivered is a very important factor in customer satisfaction. The majority of people surveyed reported that their services and supports were delivered by staff who were respectful of them and their culture. The responses ranged from a low of 72 percent who said that emergency services were provided when needed, to highs of 93 percent reporting their case manager respects family’s choices and opinions, and 94 percent who reported that services were delivered in a culturally respectful manner. Many respondents wrote positive comments about the dedication and caring attitudes of their support staff in the comments section of the survey.

SERVICES SATISFACTION

Findings

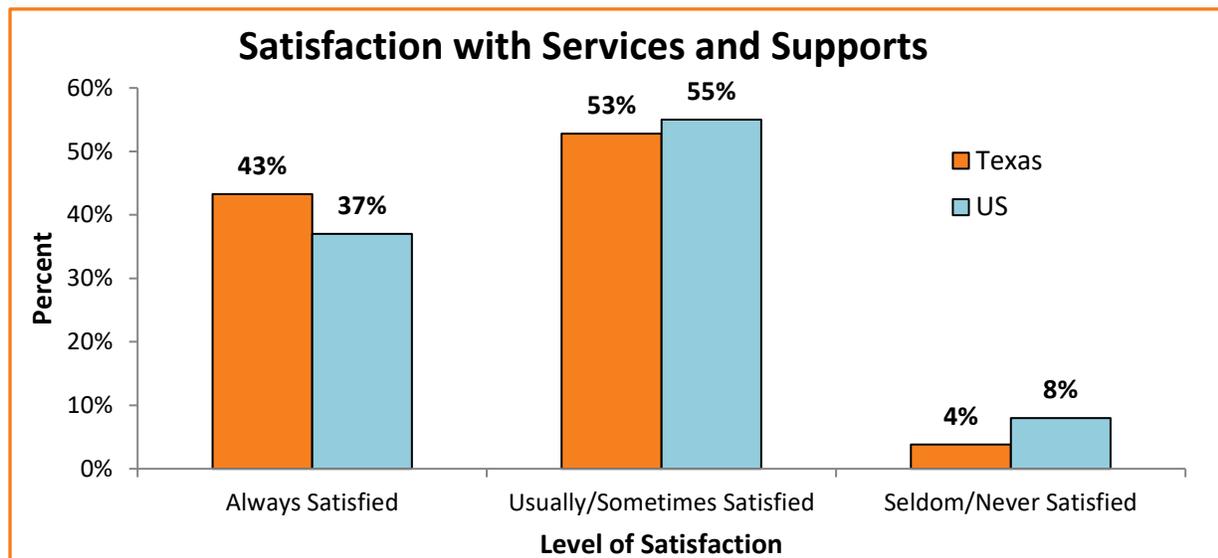
- 82 percent of families served reported that they were always or usually satisfied overall with their services and supports, up from 61 percent in 2005 and higher than the national average of 77 percent
- 2 out of 4 health care satisfaction measures were better than the national average; all four reported above 94 percent satisfied
- 80 percent said service reductions had negatively affected their child or family

The survey information provided above creates a picture of the level of needs and satisfaction of people served by DADS. The survey includes several specific questions about overall satisfaction and how well individual goals and health and wellbeing needs were met.

OVERALL SATISFACTION

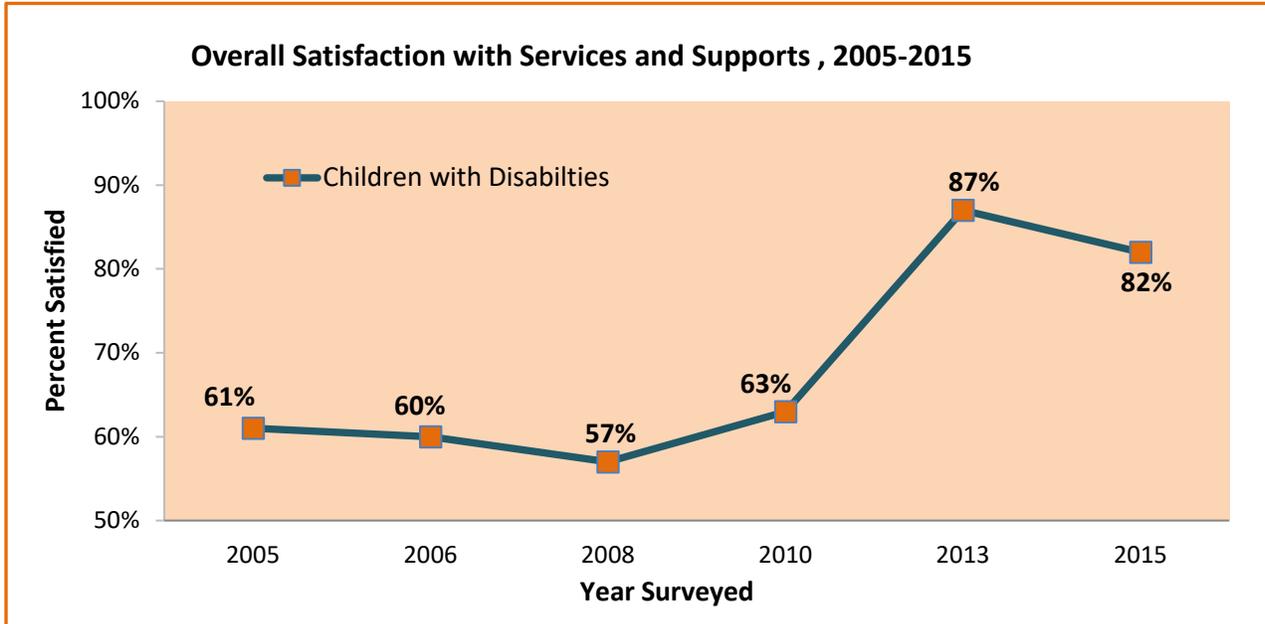
The survey asks respondents to rate their overall satisfaction with the services and supports their family currently receives. The overall satisfaction with services and supports (82 percent always or usually satisfied) reported by Texas consumers was higher than the national average (77 percent). Forty-three percent (43 percent) of Texas families reported that they were always satisfied with their services, which was higher than the national average of 37 percent (Figure 2-16).

Figure 2-16. CHILD AND FAMILY CONSUMER SATISFACTION WITH SERVICES AND SUPPORTS, TEXAS TO US



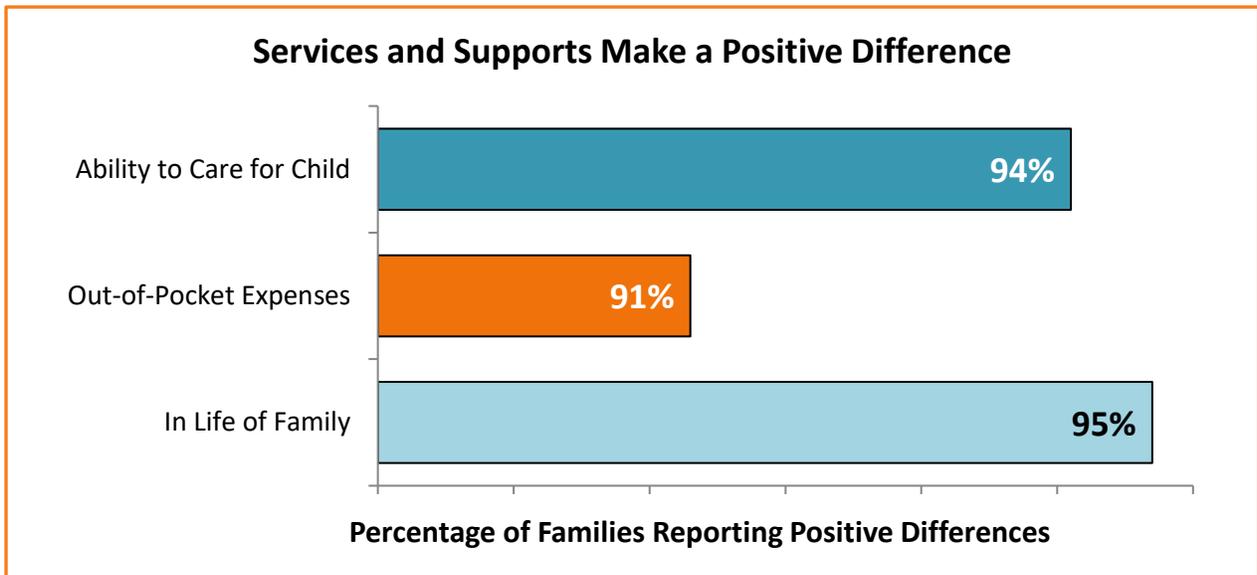
Since the surveys began in 2005, overall consumer satisfaction has improved significantly, as measured by the CF survey (Figure 2-17), increasing from 61 percent in 2005 to a high of 87 percent in 2013. The overall satisfaction rate in 2015 was down slightly at 82 percent.

Figure 2-17. CHILD AND FAMILY CONSUMER SATISFACTION WITH SERVICES AND SUPPORTS OVER TIME, 2005 – 2015



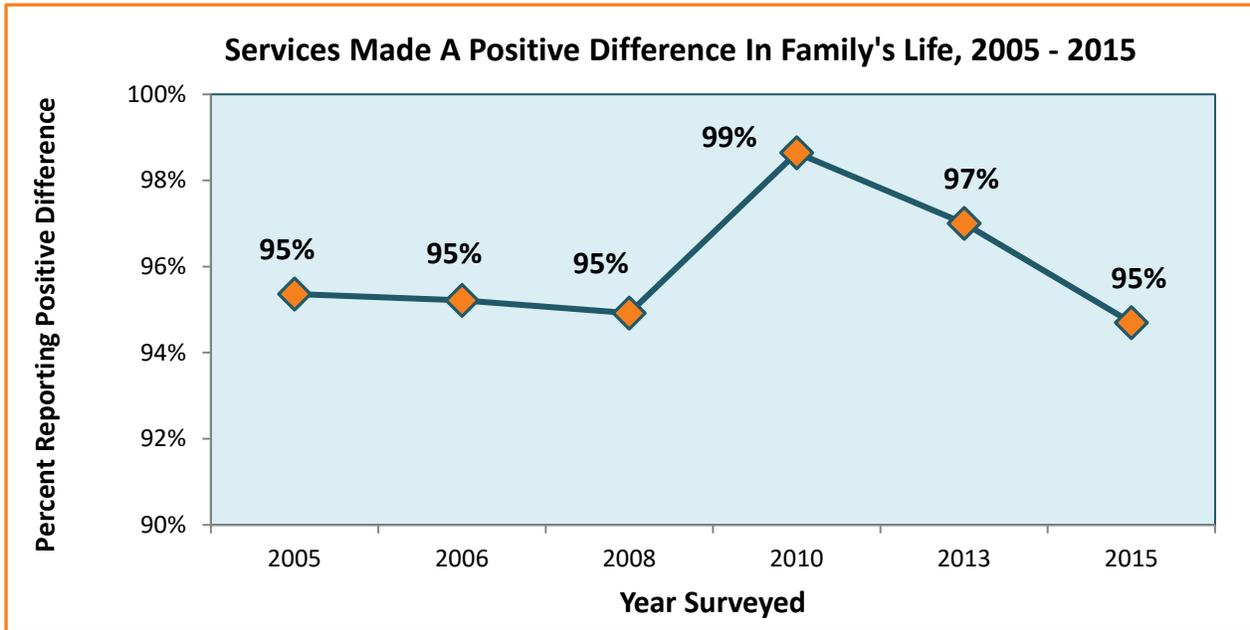
The vast majority of respondents felt the services and supports made a positive difference for them or their family member (Figure 2-18). Positive differences were reported in three areas: their ability to care for their child with disabilities (94 percent); reduction in out-of-pocket expenses (91 percent); and in the life of their family (95 percent).

Figure 2-18. SERVICES AND SUPPORTS MAKE A POSITIVE DIFFERENCE IN FAMILY'S LIFE



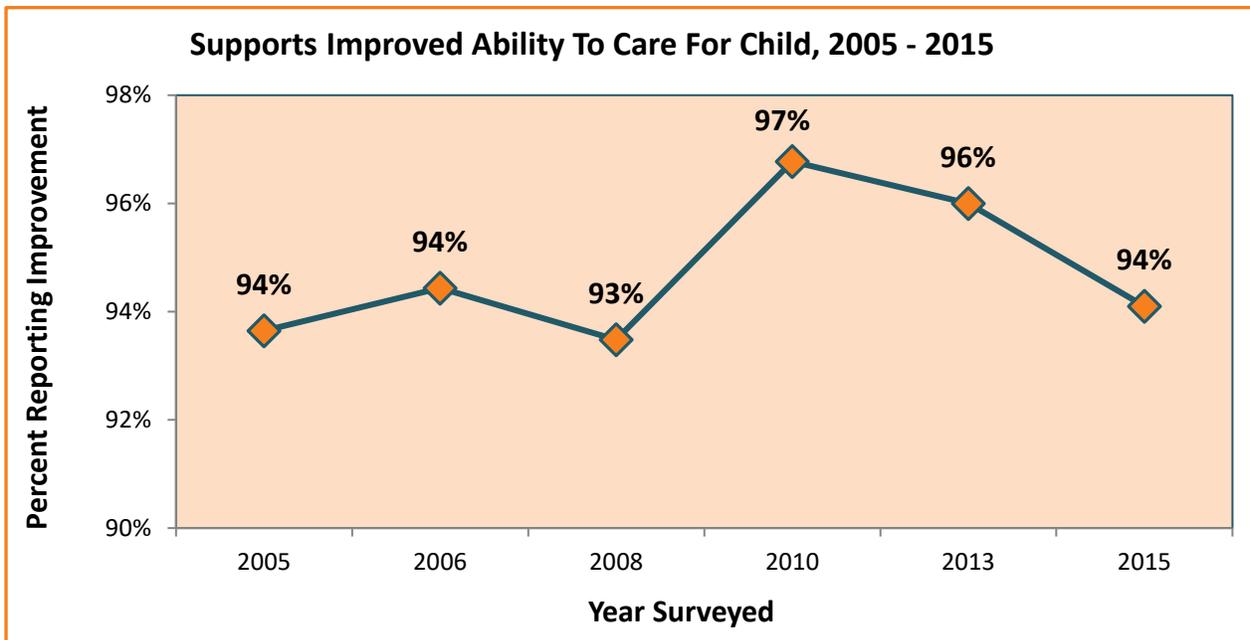
This positive impact on consumers' family life has been high since the survey first was administered in 2005, when a positive difference was reported by 95 percent of consumers, which is where the rate remains 11 years later in 2015. This is down from the high of 99 percent in 2010 (Figure 2-19).

Figure 2-19. SERVICES AND SUPPORTS MAKE A POSITIVE DIFFERENCE IN FAMILY'S LIFE, 2005 – 2015



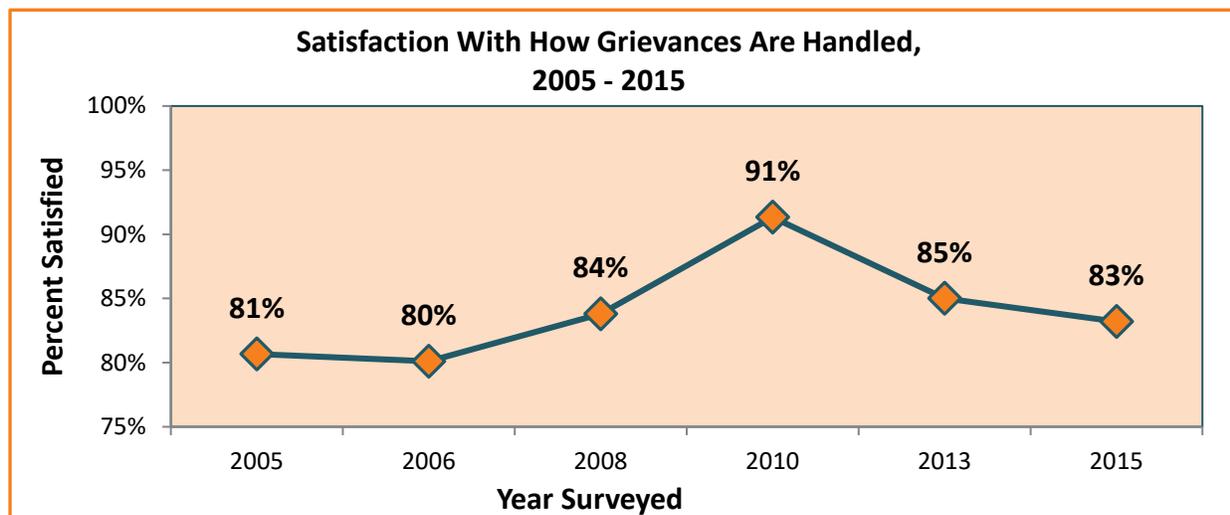
Services and supports also addressed the family’s goal to provide care for their child with disabilities (94 percent), shown in Figure 2-20 below. Improvement in the ability to care for their child increased slightly in 2010 and 2013. The rate has reverted to the 2005 levels in 2015.

Figure 2-20. SERVICES AND SUPPORTS IMPROVE ABILITY TO CARE FOR CHILD, 2005 – 2015



Satisfaction with how complaints or grievances about provider agencies or staff were handled is also an important measure of overall consumer satisfaction. Eighty-three percent (83 percent) of CF survey respondents stated that they were satisfied with how grievances were handled (Figure 2-21). Satisfaction has increased slightly since 2005 from 81 percent to 83 percent in 2015.

Figure 2-21. CHILD AND FAMILY CONSUMER SATISFACTION WITH HANDLING GRIEVANCES OVER TIME, 2005 – 2015



Of note on the last three figures (Figure 2-19, 2-20, and 2-21), reported satisfaction was highest during the 2010 survey period. During the current survey period, 23 percent reported that their service plan did not include all the services and supports the family wanted; 42 percent reported that there were other services and supports not currently offered that the family needed; and 80 percent said service reductions had negatively affected their child or family. The reason for the decrease in satisfaction is unknown.

SATISFACTION WITH HEALTH CARE SERVICES

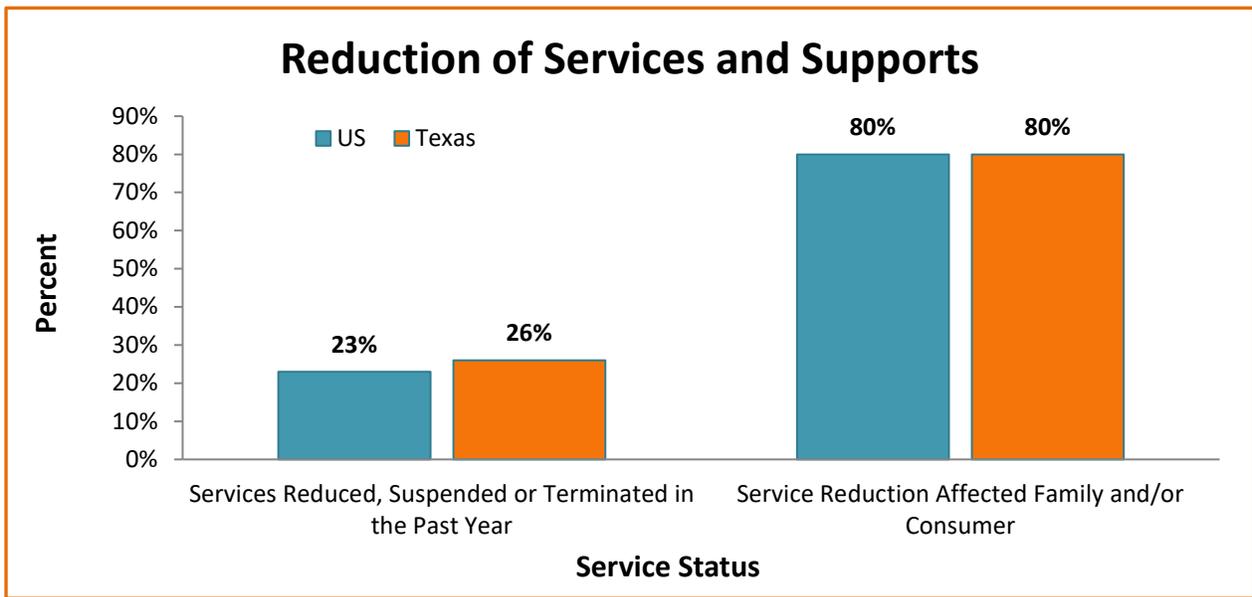
Health-related services are a core function of DADS services and supports for children. The CF survey asks a series of health care services satisfaction questions to determine not only if families have access to and are receiving health care services, but how satisfied they are with the services they receive and the providers. Satisfaction questions are asked about medical, dental, and mental health providers, and how carefully their child’s medications are monitored.

Consumer satisfaction with health care providers and medication monitoring was overwhelmingly positive. Satisfaction ranged from a high of 96 percent for the quality of mental health care providers to a “low” of 94 percent for satisfaction with dental providers. Ninety-five percent (95 percent) of consumers were satisfied with their medical providers, and 95 percent were satisfied with how medications were monitored. The corresponding satisfaction with health providers nationally was 94 percent for medical providers, 96 percent for dental providers, 96 percent for medication monitoring, and 93 percent for mental health providers. Two out of four Texas health care satisfaction responses were slightly higher than the national average. Satisfaction with dental care providers was lower again this survey period than the national average.

REDUCTION OF SERVICES AND SUPPORTS

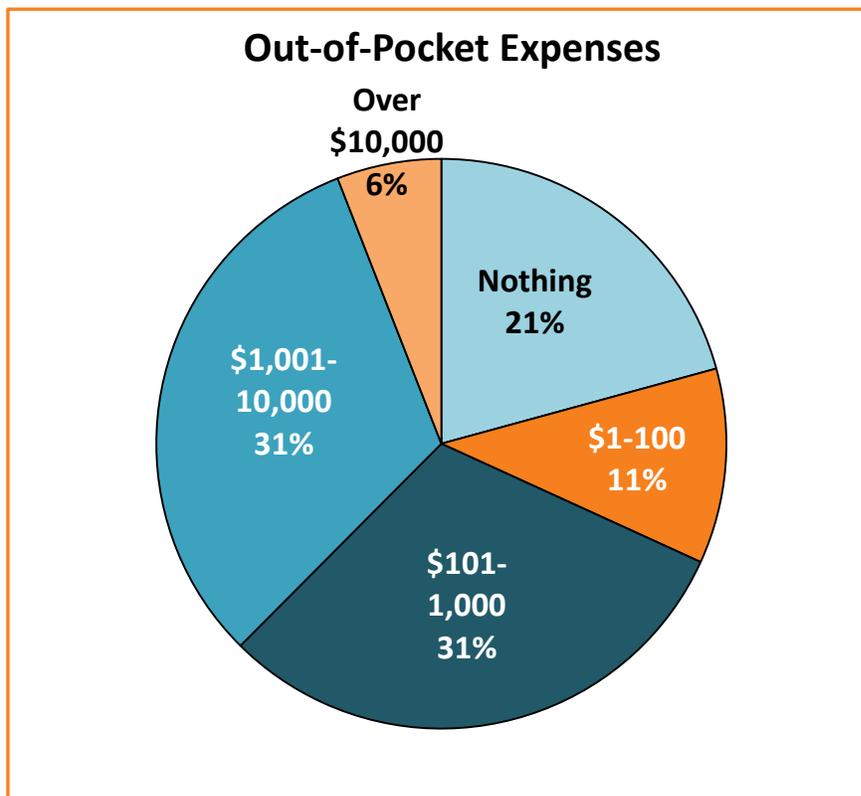
The positive response to services and supports occurred as services and supports were being reduced for many families. As illustrated in Figure 2-22 below, approximately one-quarter of respondents nationally and in Texas reported that their children’s services had been reduced, suspended, or terminated in the past year (23 percent nationally, and 26 percent in Texas). Of the respondents whose family member had services reduced in the past year, 80 percent nationally and in Texas said the reduction negatively affected their family member.

Figure 2-22. COMPARISON OF SERVICE REDUCTIONS AND THEIR IMPACT ON CHILDREN'S FAMILIES, TEXAS AND US



One of the primary negative results of these service reductions was an increase in out-of-pocket expenses for families to secure needed services. Figure 2-23 shows information on out of pocket expenses.

Figure 2-23. OUT-OF-POCKET EXPENSES NOT COVERED FOR CHILD AND FAMILY SURVEY HOUSEHOLDS



Thirty-five percent (35 percent) of the families of children with disabilities in Texas reported annual incomes of \$25,000 or less. Annual out-of-pocket expenses for more than one-third (38 percent) of the Texas CF survey households exceeded \$1,000 (this includes those whose out-of-pocket expenses exceeded \$10,000). Figure 2-23 shows the annual out-of-pocket expenses for families of Texas children with disabilities.

All of the responses for the CF survey, by program, can be seen in Appendix C.

CHAPTER 3: ADULTS WITH INTELLECTUAL DISABILITIES

The Detailed LTSS report provides summary results from the NCI Adult Consumer Survey completed in 2015. The Public Policy Research Institute at Texas A&M University (PPRI) conducted face-to-face interviews with adults with IDD and their families or caregivers receiving services from DADS and obtained information about their experiences. LTSS used the NCI Adult Consumer Survey to gather feedback from individuals in six programs administered by DADS to adults with IDD in Texas. Surveyed programs include: Home and Community-based Services (HCS), Community Living Assistance and Support Services (CLASS), the Texas Home Living (TxHmL), Deaf Blind with Multiple Disabilities (DBMD), Intermediate Care Facilities for Individuals with Intellectual Disabilities or Related Conditions (ICF), and State Supported Living Centers (SSLCs). The data were analyzed and reviewed as a group (adults with IDD), and separately for each of the six programs. Comparisons of differences between Texas adults with IDD and national NCI benchmark results were also conducted.

At the time the sample was selected there were 32,901 adults age 19 and older with IDD receiving at least one service. DADS received 2,302 completed surveys. Fifty-eight percent of the 3,944 attempted interviews were completed.

Information is provided regarding the services offered by each program in the next section. Generally, statistics are presented for the whole survey population. Statistics for each program are included for survey questions where the responses for a specific program were different from the overall population. For a complete list of individual program findings of the NCI Adult Consumer Survey, see Appendix D.

OVERVIEW OF PROGRAMS AND SERVICES

| Home and Community-based Services (HCS) | |
|---|---|
| <p>There were 18,625 adults receiving HCS services when the sample was taken. The sample size was 805.</p> | |
| <p>The HCS program is the largest Texas waiver program serving adults and children with intellectual or developmental disabilities. Local intellectual and developmental disability authorities deliver case management and provider agencies deliver direct services. With this service, individuals may live in their own or a family home, a host home/companion care setting; or a small group home where no more than four individuals live. Services are an alternative to residing in an ICF/IID. The HCS program receives funding from Medicaid and state funds. The HCS program is authorized by a 1915(c) waiver.</p> | |
| <p>Services Include:</p> <ul style="list-style-type: none"> • Adaptive Aids • Case Management • Counseling and Specialized Therapies • Day Habilitation • Dental Treatment | <ul style="list-style-type: none"> • Minor Home Modifications • Nursing • Residential Assistance • Respite Care • Supported Employment |

Community Living Assistance and Support Services (CLASS)

There were **2,402** adults receiving CLASS services when the sample was taken.
The sample size was **352**.

The CLASS program provides home and community-based services to adults and children with “related conditions” (e.g., cerebral palsy, autism, etc.) as a cost-effective alternative to living in an ICF/IID. Separate agencies provide case management and direct services. Qualifying conditions originate before age 22 and affect one’s ability to function in daily life. Intellectual disability alone does not qualify. Individuals served typically have substantial limitations in at least three of the following areas: self-care, language, learning, mobility, self-direction, and capacity for independent living. The CLASS program receives funding from Medicaid and state funds. The CLASS program is authorized by a 1915(c) waiver.

Services include:

- | | |
|---|--|
| <ul style="list-style-type: none"> • Specialized Therapies • Adaptive Aids and Medical Supplies • Habilitation and Respite Care • Transition Assistance Services • Case Management | <ul style="list-style-type: none"> • Minor Home Modifications • Nursing Services • Prescription Drugs • Psychological Services |
|---|--|

Texas Home Living (TxHmL)

There were **4,503** adults receiving TxHmL services when the sample was taken.
The sample size was **332**.

The TxHmL program provides selected essential services and supports to adults and children with an intellectual disability who live in their family homes or their own homes. It is a cost-effective alternative to living in an ICF/IID. Separate agencies provide case management and direct services. Eligibility includes diagnosis, financial requirements, own home or family residence, and service needs that do not exceed the program’s cost cap. The TxHmL program receives funding from Medicaid and state funds. The TxHmL program is authorized by a 1915(c) waiver.

Services include:

- | | |
|---|---|
| <ul style="list-style-type: none"> • Adaptive Aids and Minor Home Modifications • Behavioral Support • Community Support • Day Habilitation • Dental Treatment | <ul style="list-style-type: none"> • Employment Assistance and Supported Employment • Nursing • Respite • Specialized therapies |
|---|---|

Deaf Blind with Multiple Disabilities (DBMD)

There were **185** adults receiving DBMD services when the sample was taken.

The sample size was **42**.

The DBMD program provides home and community-based services to people who are deaf blind and have another disability. This is a cost-effective alternative to ICF/IID. The DBMD program focuses on increasing opportunities for consumers to communicate and interact with their environment. The DBMD program receives funding from Medicaid and state funds. The DBMD program is authorized by a 1915(c) waiver.

Services Include:

- | | |
|---|--|
| <ul style="list-style-type: none"> • Audiology • Assisted Living • Residential and Day Habilitation • Dietary | <ul style="list-style-type: none"> • Employment Assistance and Supported Employment • Behavioral Support • Transition Assistance Services |
|---|--|

Intermediate Care Facilities for Individuals with an Intellectual Disability or Related Conditions (ICF/IID)

There were **4,635** people receiving ICF/IID services in ICFs when the sample was taken. The sample size was **429**.

The ICF/IID program provides 24-hour residential and habilitation services to people with an intellectual disability or conditions related to ID. Facilities classified as small house one to eight individuals; those classified as medium enroll nine to thirteen individuals. ICF/IID facilities classified as large serve 14 or more individuals. Private providers and Local IDD Authorities (LIDDAs) offer these services. ICF/IID services are funded by Title XIX Medicaid funds and state funds.

Services include:

- | | |
|---|---|
| <ul style="list-style-type: none"> • Adjunctive Therapy (Occupational Therapy, Physical Therapy, and Speech therapy) • Comprehensive Behavioral Treatment • Habilitation | <ul style="list-style-type: none"> • Health Care Services (Medical, Nursing, and Dental) • Residential Services • Skills Training • Vocational Programs |
|---|---|

State Supported Living Centers (SSLC)

There were **3,310** people receiving services in SSLC facilities when the sample was taken. The sample size was **342**.

There are 13 SSLCs (12 state ID facilities and one state center) that provide 24-hour residential, treatment, and training services for individuals with an intellectual disability. Each facility is certified as an ICF/IID. Residential services in an SSLC are intended to serve individuals with severe or profound intellectual disabilities and those who are medically fragile or need behavioral support. SSLC services are funded by Title XIX Medicaid funds and state funds.

Services Include:

- | | |
|---|---|
| <ul style="list-style-type: none"> • 24-hour Residential Care and Support • Comprehensive Behavioral Treatment • Comprehensive Health Care • Occupational, Physical, Speech Therapies | <ul style="list-style-type: none"> • Services to maintain connections between residents and families/natural support systems • Skills Training • Vocational Programs |
|---|---|

INDIVIDUAL DEMOGRAPHICS

GENDER, AGE, RACE/ETHNICITY, AND LANGUAGE

For the NCI Adult Consumer survey respondents, a higher percentage was male (57 percent) than female. Consumers ranged in age from 19 to 95 years old. The average age was 42 years. An overview of adult respondent demographics is presented in Table 3-1.

Table 3-1. GENDER, AGE, RACE/ETHNICITY, PRIMARY LANGUAGE AND RESIDENCE OF ADULTS WITH IDD

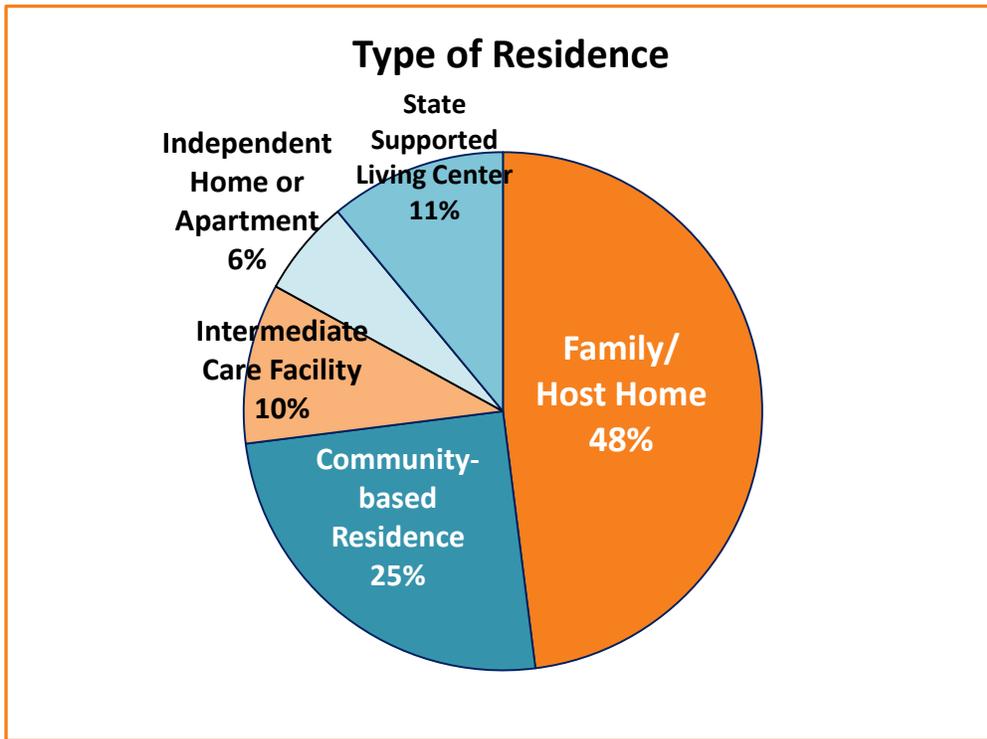
| Demographics of Adults with IDD | | | | | | |
|---------------------------------|----------------|-----------------|-------------------------|------------------|--------------------------------|--------------------------------|
| Gender | Age | Race/Ethnicity | | Primary Language | Residence | |
| Male 57% | Range 19-95 | White 48% | African American 19% | English 90% | Lives with parents/host 48% | Small ICF or Group home 35% |
| Female 43% | Average 42 | Hispanic 27% | Other 6% | Other 10% | Lives alone 6% | SSLC 11% |

Forty-eight percent (48 percent) of those surveyed were white non-Hispanic, 27 percent Hispanic, 19 percent Black and 6 percent of other races, primarily Asian. English was the primary language spoken, with 90 percent reporting English as their primary language.

RESIDENCE

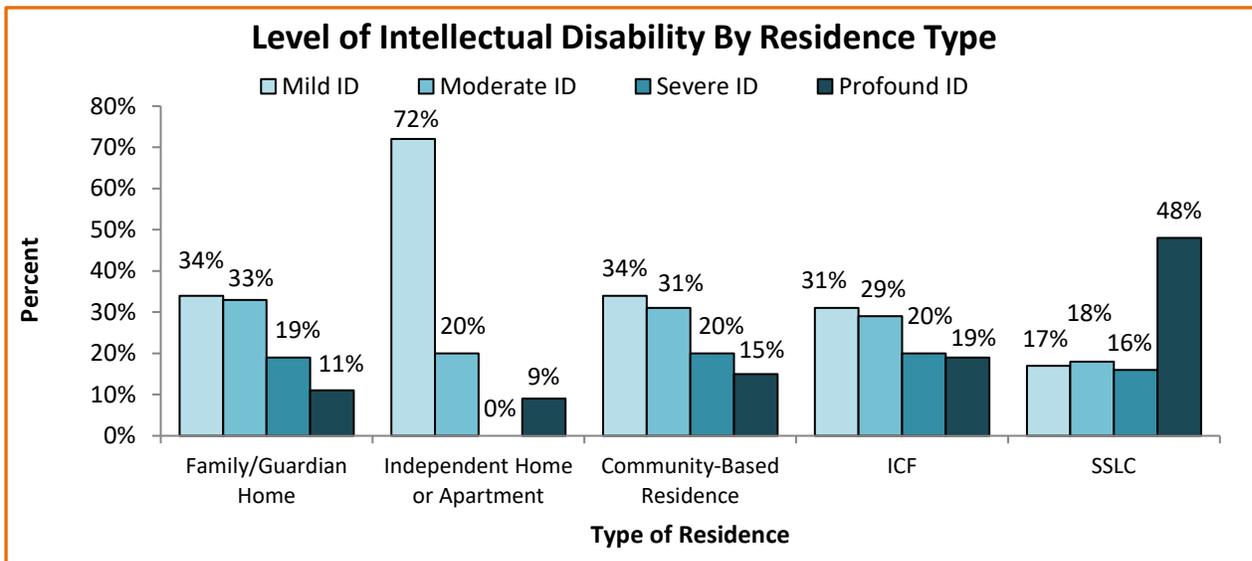
Almost half (48 percent) of the adult respondents with IDD lived with their parents, relatives, or guardians (see Figure 3-1 below). Adults with IDD who did not live with relatives lived in community residences such as 3-4 person homes under the HCS program (25 percent). Eleven percent (11 percent) lived in SSLCs, 10 percent lived in ICFs, and 6 percent reported that they lived alone.

Figure 3-1. PROPORTION OF ADULTS WITH IDD BY TYPE OF RESIDENCE



The level of intellectual disability correlated significantly to where the person lived, Figure 3-2.

Figure 3-2. LEVEL OF INTELLECTUAL DISABILITY OF ADULTS WITH IDD BY TYPE OF RESIDENCE

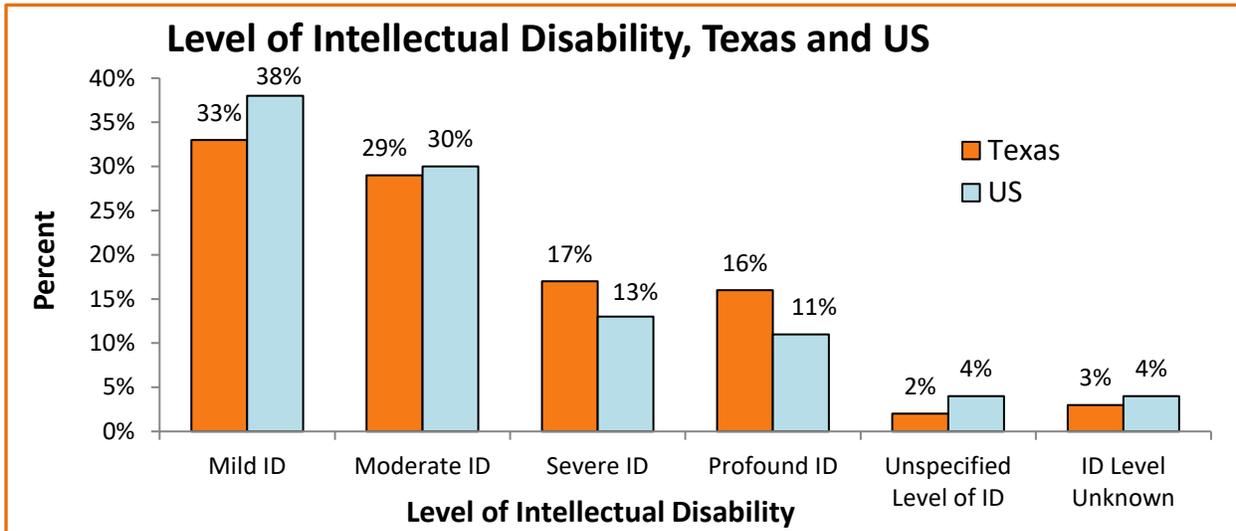


Individuals who lived independently overwhelmingly had mild intellectual disabilities (72 percent), while almost half of persons living in SSLCs reported having profound ID (48 percent).

INFORMATION ON FUNCTIONAL LEVEL

The distribution of people with ID by level of disability, served in Texas and the US, is different (Figure 3-3). DADS serves more individuals with severe or profound ID (33 percent) than is reported nationally (24 percent).

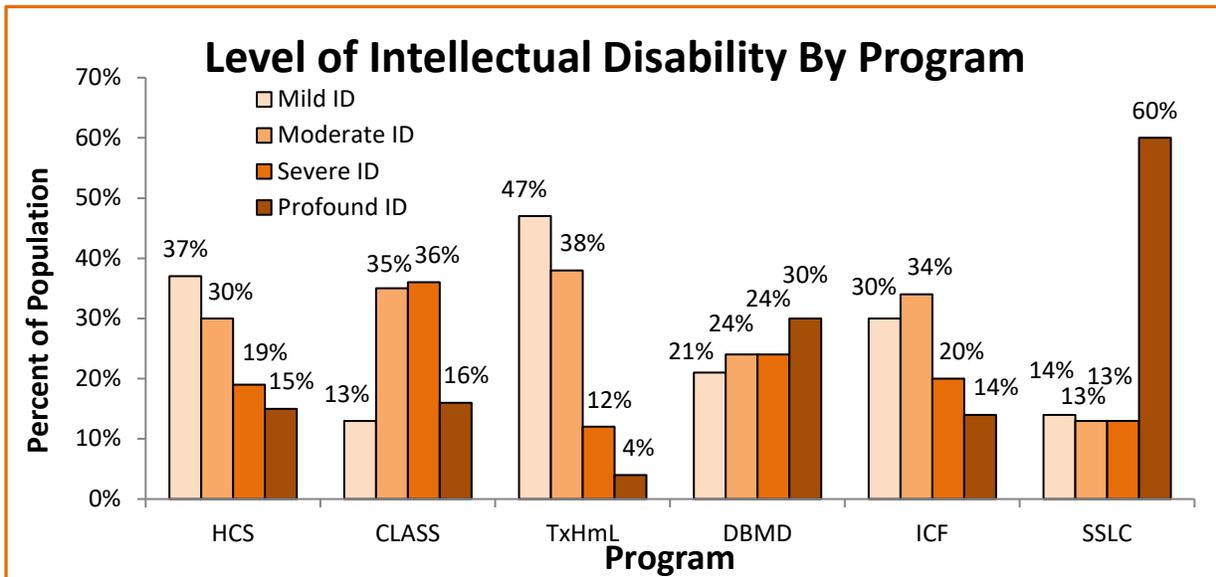
Figure 3-3. COMPARISON OF ADULTS WITH IDD IN TEXAS AND US BY LEVEL OF INTELLECTUAL DISABILITY



The distribution of level of disability is also very different when examined by the program that serves them (Figure 3-4). Only 4 percent of the people served by TxHmL have been diagnosed with profound ID. The proportion of profound ID is also low in HCS, CLASS, and the ICF programs (14 to 16 percent). In contrast, 30 percent of the individuals served by the DBMD program are classified as having profound ID, and 60 percent of the people served by the SSLCs have been diagnosed as having profound ID. The level of ID distribution in Figure 3-4 is slightly different than what is presented in the residence Figure 3-2 above, as this information was acquired from DADS program records at the time the sample was selected and not based upon where an individual was actually living when the data was collected. Individuals move between residence types.

Myth: All people with disabilities are the same, and you can talk about them as one single group.

Figure 3-4. COMPARISON OF ADULTS WITH IDD BY LEVEL OF INTELLECTUAL DISABILITY BY PROGRAM



Information about level of disability is critical when comparing programs and outcomes, as the program’s populations are not comparable and different outcomes should be expected.

HEALTH AND WELFARE

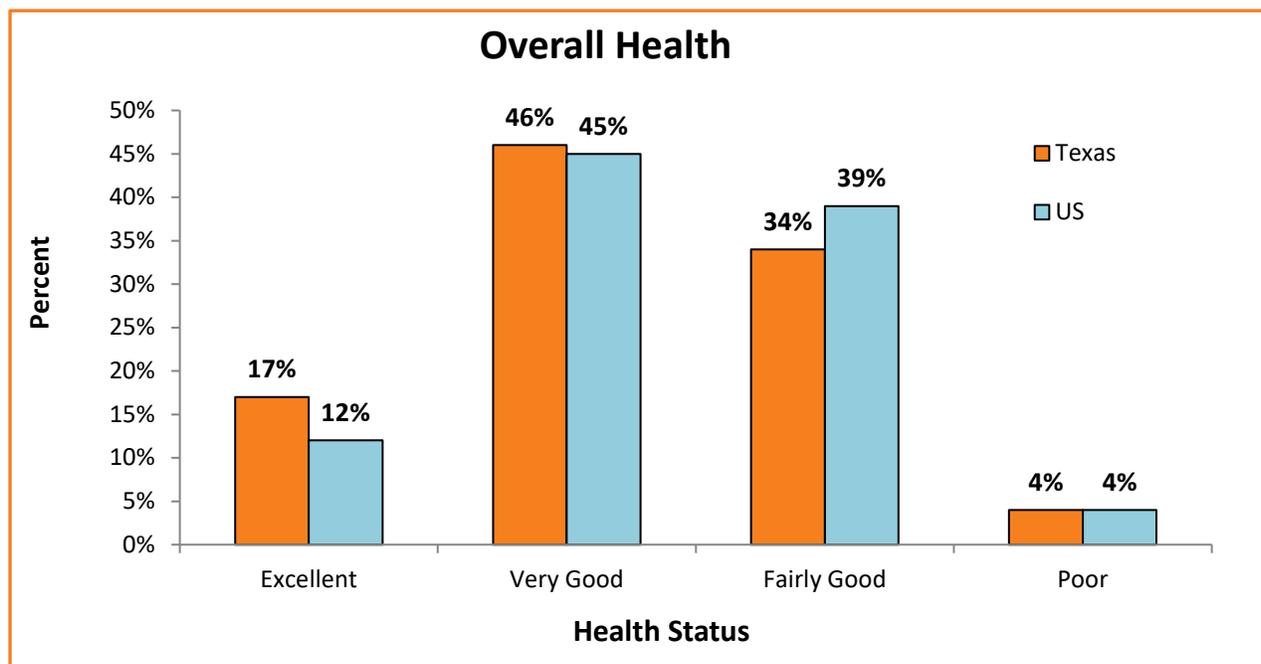
Findings

- Texas adults with IDD received significantly more routine and preventive health care than reported nationally on 5 out of 10 health care indicators
- 98 percent of adults with IDD had primary health care providers
- Adults with IDD living in an SSLC, or community-based group home, received higher rates of routine and preventive care than those living with family

HEALTH STATUS AND HEALTH HABITS

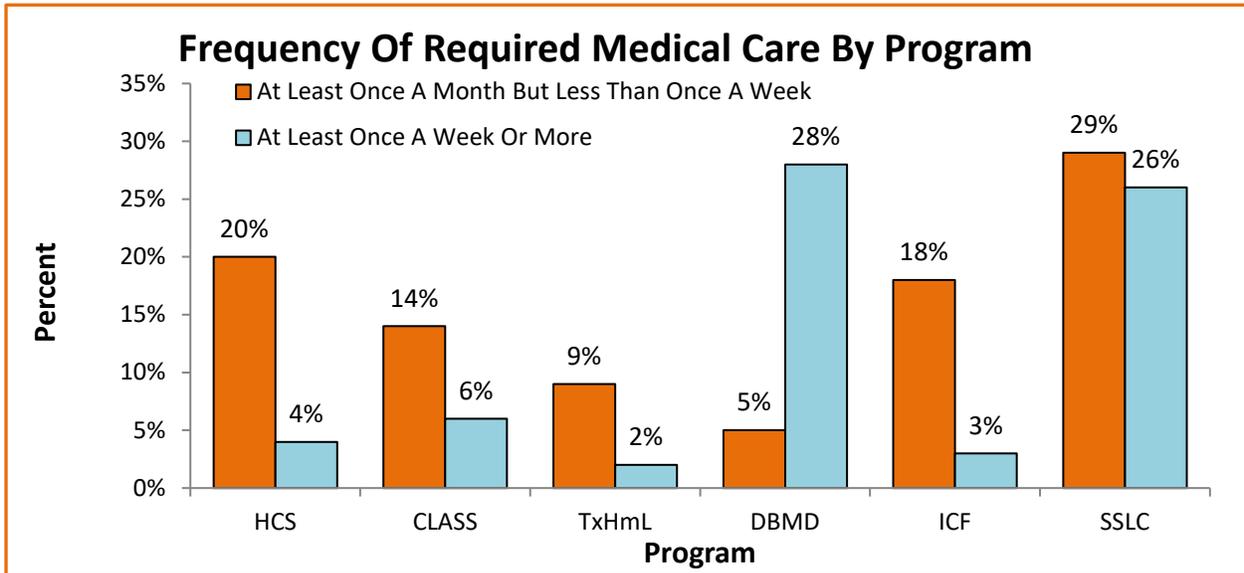
The health status of adults with IDD served by DADS is very good. More than two-thirds of those surveyed (63 percent) reported that their health was excellent or very good (Figure 3-5). Only 4 percent reported that they suffered from poor health.

Figure 3-5. COMPARISON OF OVERALL HEALTH STATUS, TEXAS TO US



While overall health was good, adults with IDD required frequent medical care, with 23 percent of those surveyed reporting requiring medical care by a trained medical provider once a month or more frequently. Again, as with level of intellectual disability, the frequency of required medical treatments varied considerably by program, see Figure 3-6.

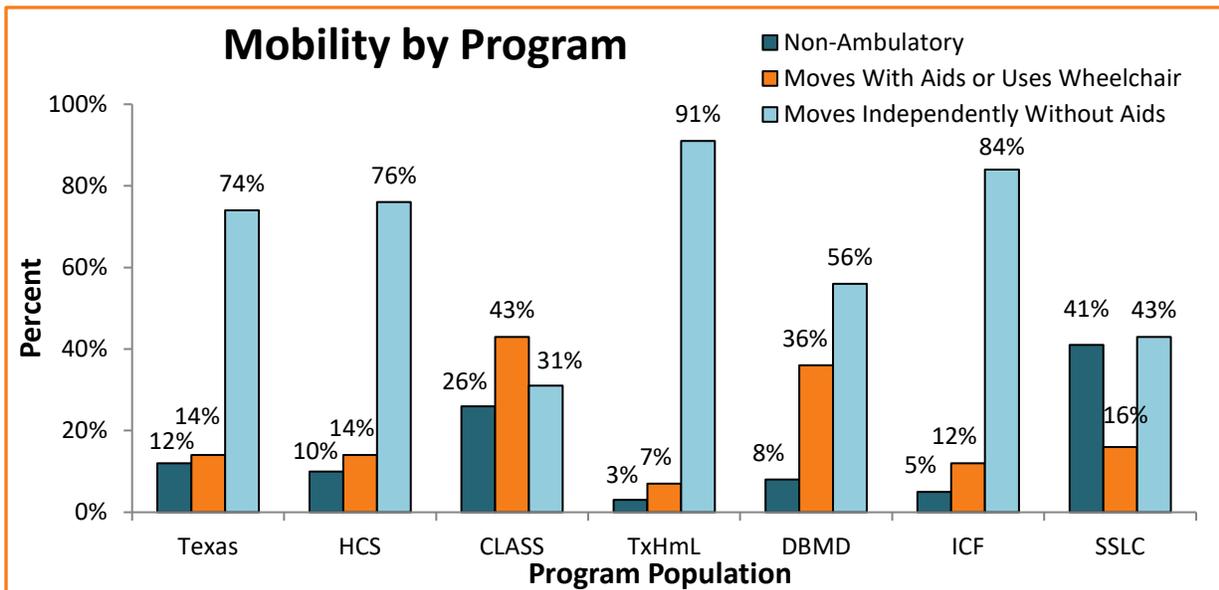
Figure 3-6. COMPARISON OF THE FREQUENCY OF REQUIRED MEDICAL CARE BY PROGRAM



More than half of the persons in SSLCs required frequent medical care (55 percent), compared to 24 percent of those in the community-based HCS program, and only 11 percent of people receiving TxHmL services. The numbers for the DBMD program are very small and, therefore, unstable.

Mobility, the ability to move about, was another variable that was program specific (Figure 3-7). Respondents were classified as moving independently without aids or a wheelchair, moving with aids or a wheelchair, or non-ambulatory.

Figure 3-7. COMPARISON OF MOBILITY STATUS BY PROGRAM



Independent mobility overall was high in Texas (74 percent) and specifically in HCS, TxHmL, and ICF, where the independent mobility rates exceeded 75 percent. TxHmL had the lowest proportion of non-ambulatory people, with only three percent (3 percent). Significantly, 26 percent of people served by the CLASS program and 41 percent of SSLC participants were non-ambulatory, a critical consideration when making policy decisions or strategic plans.

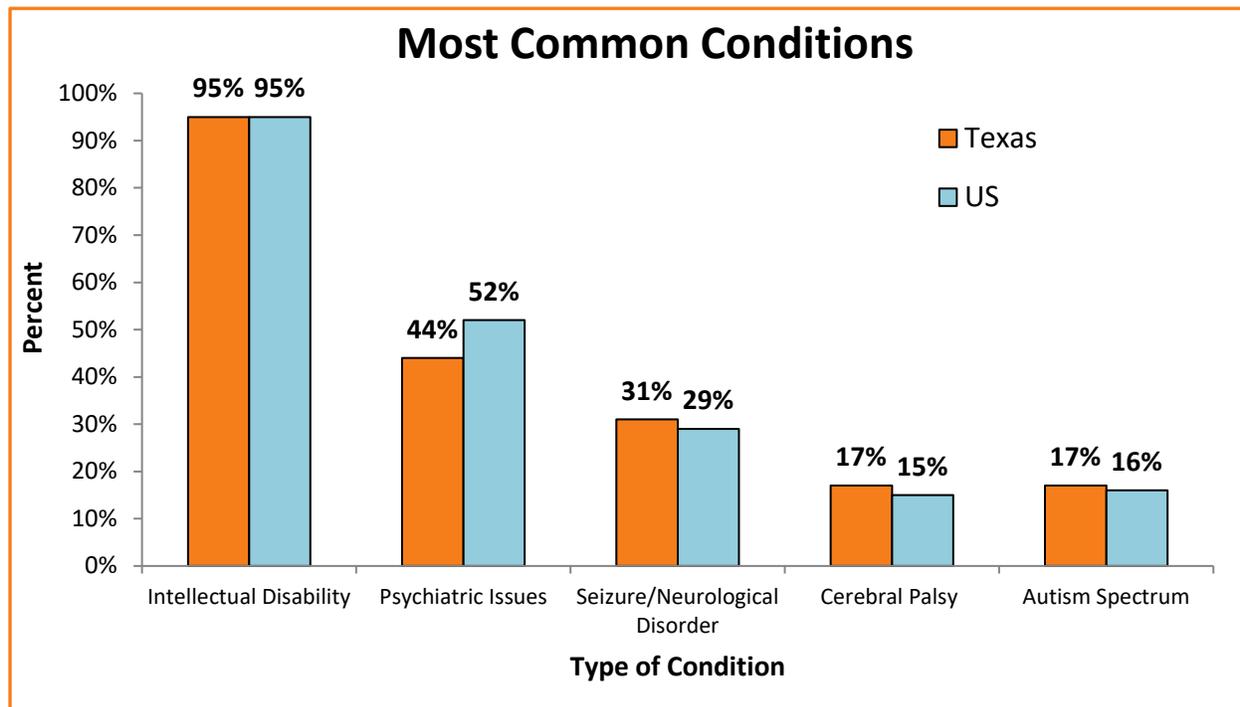
Health habit indicators were mixed. Only six percent (6 percent) of the adults with IDD used tobacco products. Thirty-three percent (33 percent) of the NCI respondents' body mass indicator (BMI) scores indicated that they were obese.

DISABILITIES AND CONDITIONS

As illustrated in Figure 3-8, the most commonly reported conditions were intellectual disability (95 percent), mental illness (44 percent), seizure/neurological disorder (31 percent), autism spectrum disorder (17 percent), and cerebral palsy (17 percent). The rate of intellectual disability among Texas and national respondents was identical, at 95 percent. Rates for the most commonly reported conditions were very similar between the US and Texas, as can be seen in Figure 3-8.

Fact: There is no one thing that can be said about people living with disabilities, they don't all have the same experiences or the same perspective.

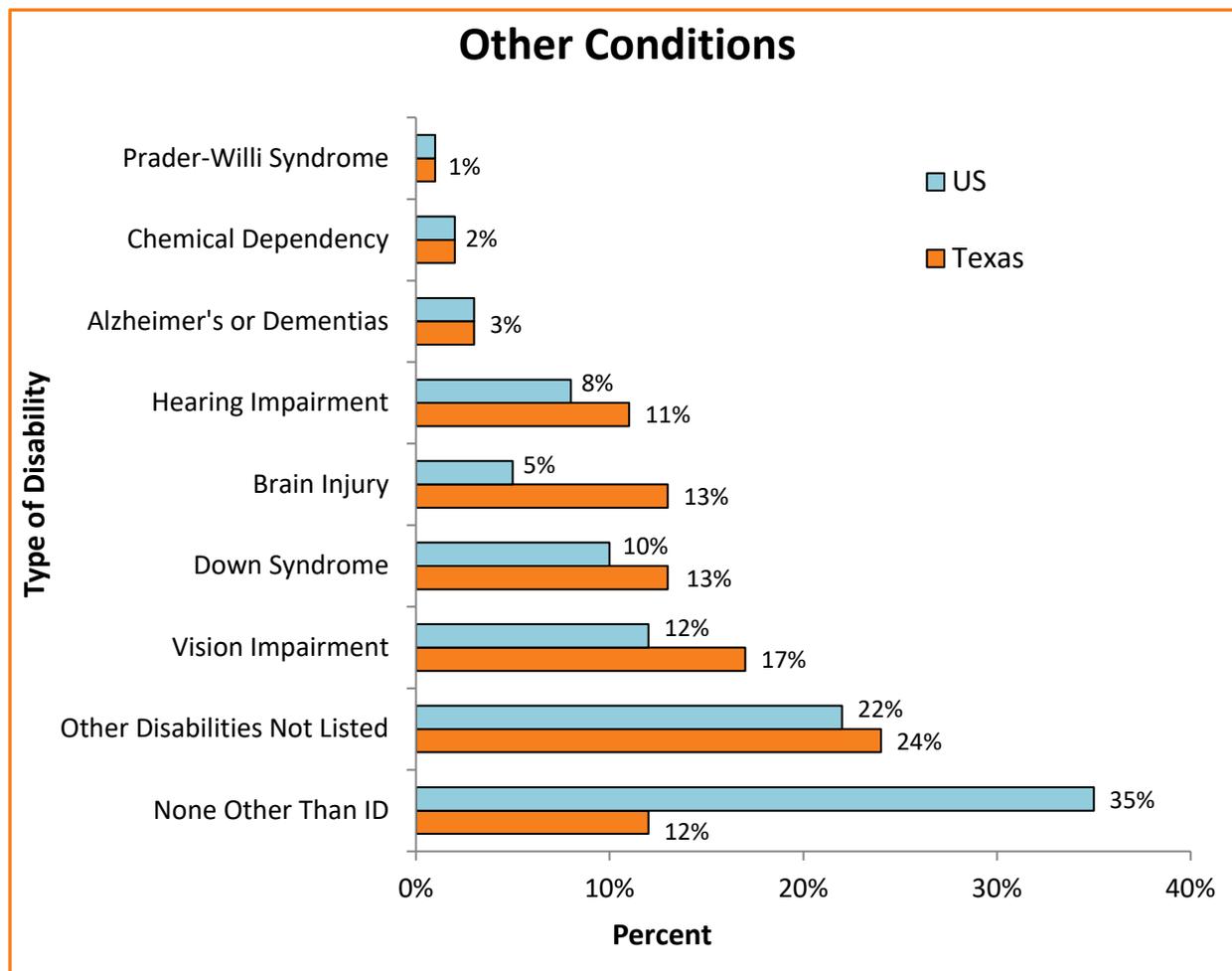
Figure 3-8. MOST COMMON CONDITIONS AMONG ADULTS WITH IDD, TEXAS AND US COMPARISON



The majority of adults with IDD surveyed (88 percent) reported more than one type of condition (Figure 3-9), significantly higher than the US average of 65 percent. The most common secondary conditions reported were vision impairment (17 percent), Down syndrome (13 percent), and other disabilities not listed (24 percent). Others conditions not listed, which includes disabilities, were reported by 33 percent of respondents. Figure 3-9 presents the secondary conditions listed.

Myth: People with physical disabilities also have mental or intellectual disabilities.

Figure 3-9. ADULTS WITH IDD WITH SECONDARY CONDITIONS BY TYPE OF CONDITION, TEXAS AND US



Texas reported higher rates of secondary conditions and disabilities than the US for most conditions.

HEALTH CARE

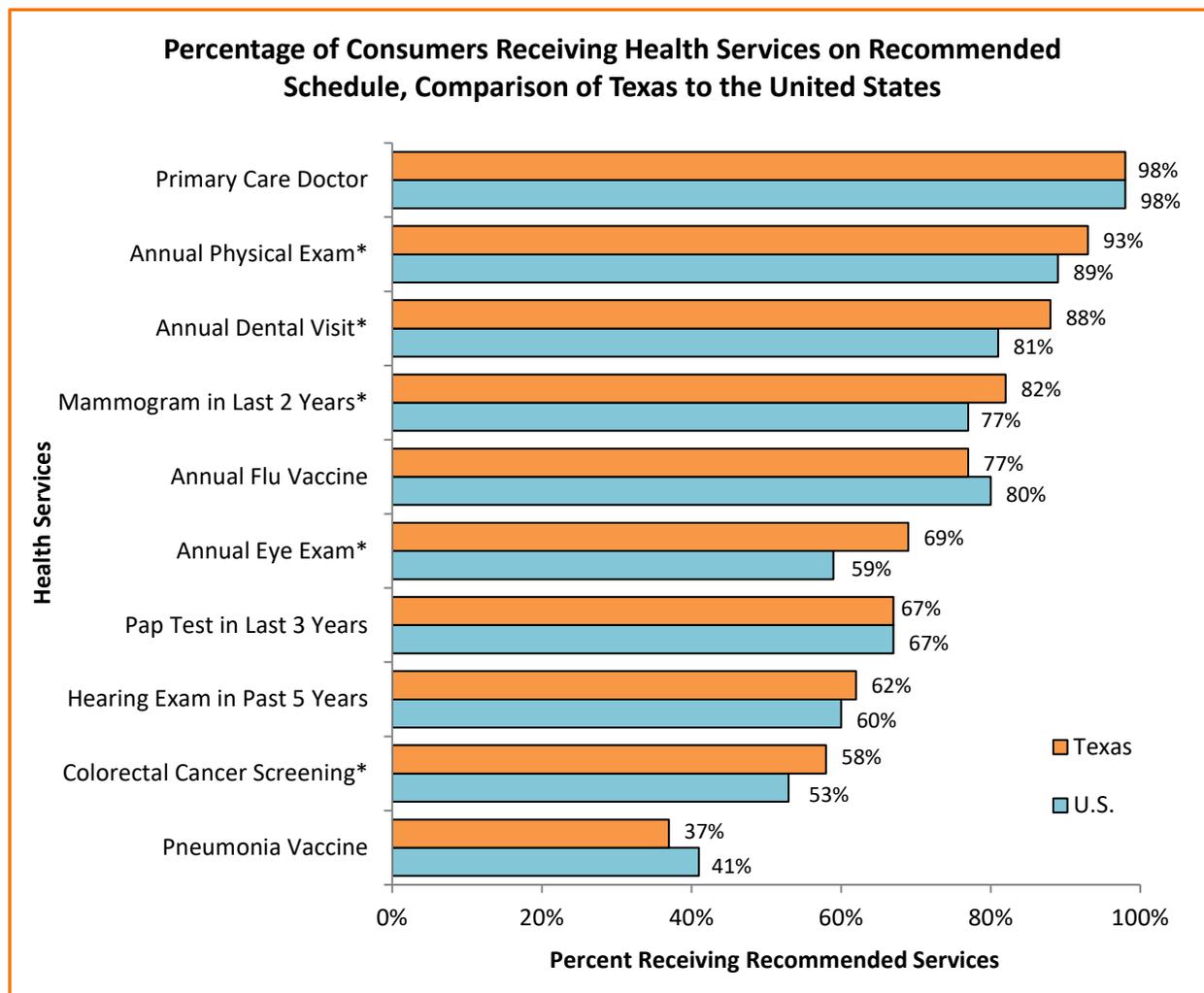
ROUTINE HEALTH CARE

Health and welfare questions were asked in the NCI survey of adults with IDD. Most people surveyed had routine care – 98 percent had a primary care doctor and 93 percent had received a physical exam in the past year (see Figure 3-10). Figure 3-10 compares the proportion of consumers receiving health services in Texas to the United States. Texas rates exceeded US rates for all but 1 of the 10 health care indicators, and 5 out of the 10 were statistically significantly higher.

PREVENTIVE HEALTH CARE

The proportion of people who received more specialized preventive health care was lower than routine health care, but still higher than national averages. Of Texas respondents, 88 percent had visited a dentist in the past year, 62 percent had received a hearing exam in the past five years, 69 percent had received an eye exam in the past year, and 77 percent had received a flu vaccination in the past year. Texas met or exceeded national rates of preventive health care in all but two out of ten categories (Figure 3-10).

Figure 3-10. ADULTS WITH IDD WHO RECEIVED HEALTH CARE SERVICES, TEXAS AND THE US



*Statistically significantly different

Rates of routine and preventive health care tests and exams varied by where adults with IDD resided (Figures 3-11 and 3-12). Figure 3-11 illustrates the variation in routine (e.g., annual physicals) and preventive health care (e.g., annual flu shot) by type of reported residence (not the program in which the respondent was enrolled), while Figure 3-12 presents annual dental and eye examination data by type of residence.

88% of respondents had an annual dental exam

For all of the health services, adults with IDD living with parents or relatives and those living in independent homes or apartments were less likely to have received exams and tests than people living in community-based residences and in institutions. Whether the dental and eye exam data are examined by where the participant lives (Figure 3-12), or the program in which respondents are enrolled (Appendix D), the exam rates are quite high. For example, the annual dental examination rate among participants in the SSLC program was 99 percent and the annual eye examination rate was 74 percent, compared to 78 percent receiving annual dental exams and 59 percent receiving annual eye exams for those living independently.

Figure 3-11. ADULTS WITH IDD WHO RECEIVED SELECTED ROUTINE AND PREVENTIVE HEALTH CARE BY TYPE OF RESIDENCE

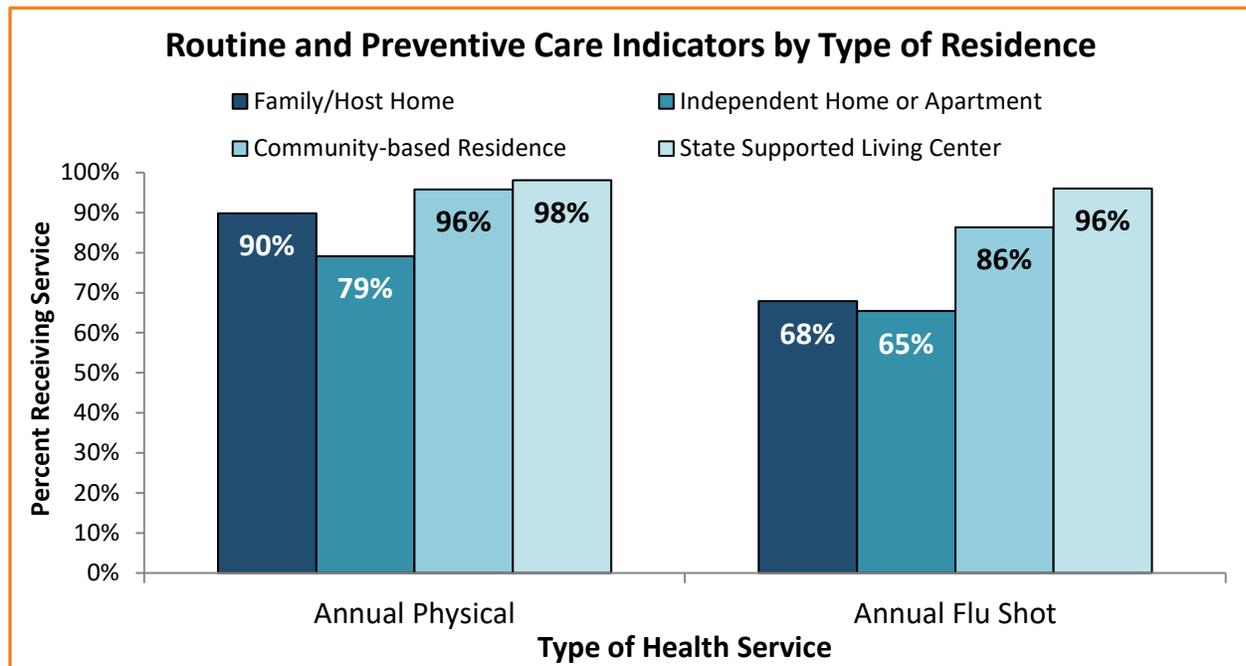
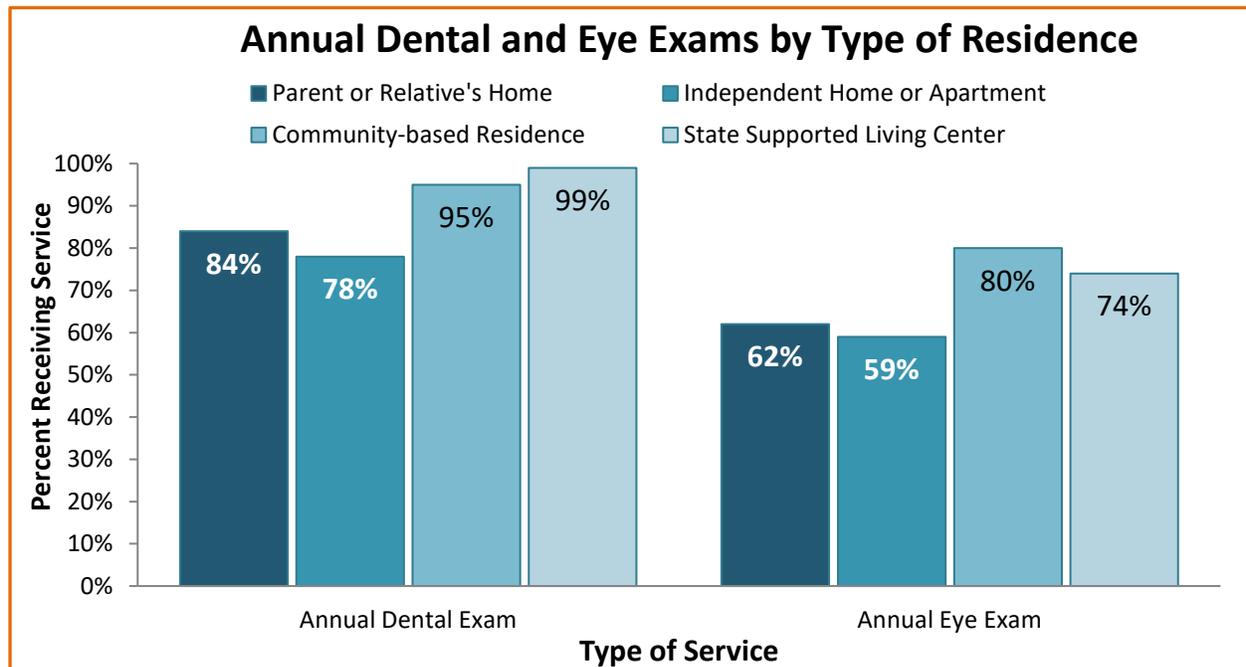
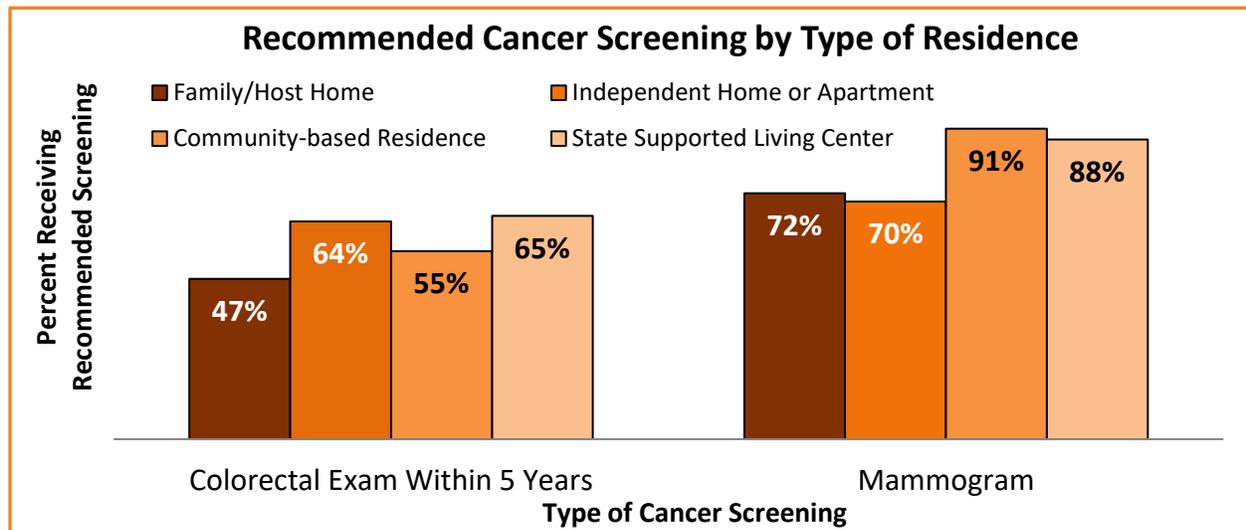


Figure 3-12. ADULTS WITH IDD WHO RECEIVED ROUTINE DENTAL AND EYE EXAMINATIONS BY TYPE OF RESIDENCE



Cancer screening rates varied greatly, with 82 percent of women age 40 and over having had a mammogram in the past two years, and 66 percent of all women having had a Pap test in the past three years. Fifty-eight percent (58 percent) of people over 50 had received a colorectal cancer screening in the past 5 years. Figure 3-13 presents selected cancer screening data (colorectal cancer and breast cancer screening) by type of residence. The national data for colorectal cancer screening is based upon annual examinations.

Figure 3-13. ADULTS WITH IDD WHO RECEIVED SELECTED CANCER SCREENING BY TYPE OF RESIDENCE

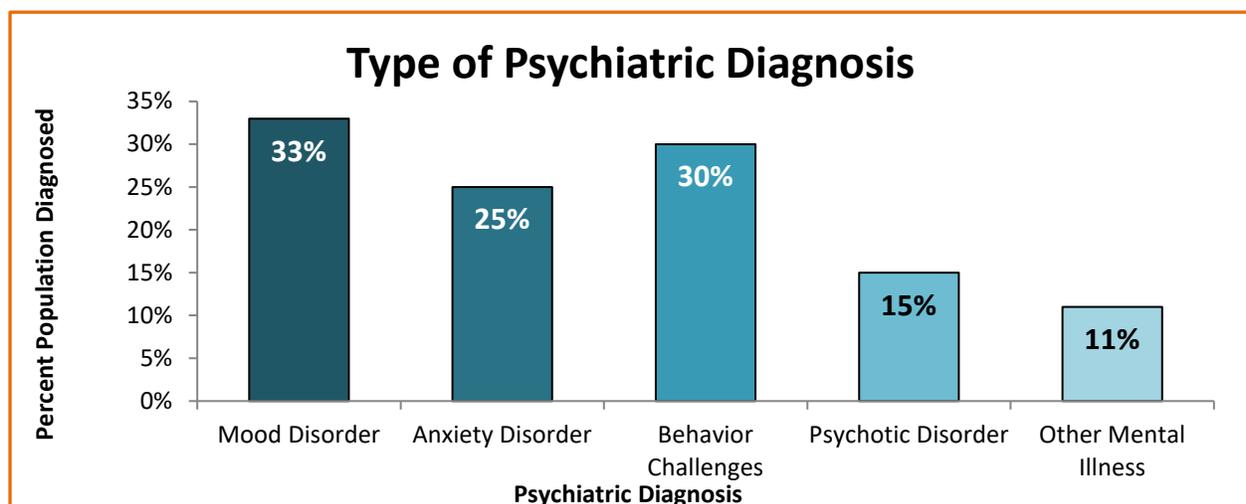


As colorectal cancer screening is recommended every 5 years for individuals with average risk, not annually as presented in the national figures, the colorectal cancer screening rate within 5 years (58 percent overall) is reported in Figure 3-13.

MENTAL AND BEHAVIORAL HEALTH ISSUES

More than one-third of adults with IDD served by DADS (44 percent) were diagnosed with a mental health issue. The most commonly diagnosed psychiatric disorders were mood disorders, with 33 percent of adults with IDD having a diagnosed mood disorder (Figure 14). Behavioral challenges (30 percent), anxiety disorders (25 percent), psychotic disorders (15 percent), and other mental illness (11 percent) were also diagnosed.

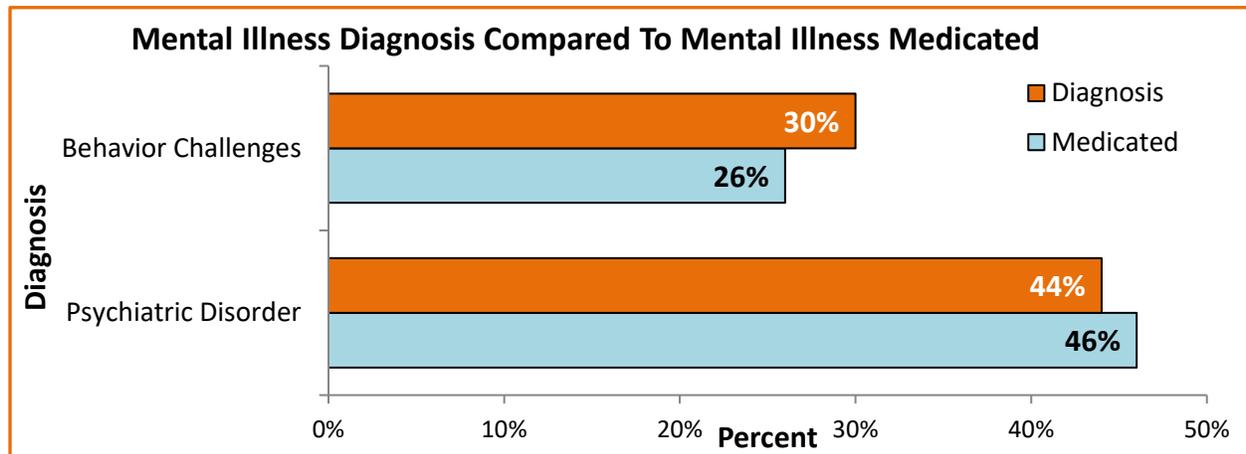
Figure 3-14. ADULTS WITH IDD DIAGNOSED WITH MENTAL ILLNESS BY TYPE OF DIAGNOSIS



Of growing concern in Texas and nationally is the proportion of persons with disabilities who are medicated with psychiatric medications without having documentation of having psychiatric disorders. Figure 3-15 shows the distribution of psychiatric diagnoses among respondents and the proportion being treated with psychiatric medications. The proportion of adults with IDD receiving psychiatric medications exceeds the percentage with a psychiatric diagnoses, but by significantly

less than in 2013 and statistically significantly below the national average of 49 percent. Behavioral diagnoses exceeded the percentage medicated, but again is an improvement over 2013 when the percentage medicated was much higher.

Figure 3-15. ADULTS WITH IDD DIAGNOSED WITH MENTAL ILLNESS COMPARED TO THE PROPORTION RECEIVING PSYCHIATRIC MEDICATIONS



The distribution of psychiatric and behavioral diagnoses varies across programs. The incidence of all types of psychiatric diagnoses was higher among consumers served by the HCS, ICF and SSLC programs (Table 3-2). CLASS, TxHmL, and DBMD programs had much lower levels of psychiatric diagnoses than the state averages.

Table 3-2. COMPARISON OF ADULTS WITH IDD DIAGNOSED WITH PSYCHIATRIC OR BEHAVIORAL HEALTH DIAGNOSES TO THE PROPORTION RECEIVING PSYCHIATRIC MEDICATIONS BY PROGRAM

| | HCS | CLASS | TxHmL | DBMD | ICF | SSLC |
|------------------------------------|-----|-------|-------|------|-----|------|
| Behavior Challenges Diagnosis | 35% | 20% | 16% | 39% | 34% | 36% |
| Medicated For Behavior Challenges | 32% | 12% | 19% | 36% | 35% | 26% |
| 1-2 Medications | 62% | 63% | 82% | 57% | 61% | 72% |
| 3+ Medications | 38% | 37% | 18% | 43% | 39% | 28% |
| Psychiatric Disorder Diagnosis | 50% | 24% | 29% | 26% | 53% | 39% |
| Medicated For Psychiatric Disorder | 54% | 29% | 31% | 23% | 55% | 39% |
| 1-2 Medications | 52% | 73% | 69% | 33% | 59% | 70% |
| 3+ Medications | 48% | 27% | 31% | 67% | 41% | 30% |

SAFETY AND SECURITY

Feeling secure is an important measure of wellbeing and welfare. For this reason, the NCI survey of adults with IDD contains several questions about being scared. Because the respondents reside in a variety of residential settings and participate in a number of different programs, they were asked whether they are scared at home, in their neighborhood, and in their day programs.

The majority reported that they were not scared at home (77 percent); 81 percent of respondents said they were not afraid in their neighborhoods; and 86 percent reported that they were not

scared in their day programs. The survey also asked whether the respondent had someone to talk to if they are afraid, and 89 percent of respondents said they did. By self-report, the majority had a sense of security.

CHOICE AND PRIVACY

Findings:

- Most adults felt like they could make decisions about taking risks and helping other people
- While individuals in CLASS and DBMD programs had control over their transportation, less than half in the other programs reported having control over their transportation
- Most adults with IDD made decisions about how they spend their free time and spending money
- Less than half of the respondents made decisions about where they live, who they lived with, and the staff who supported them

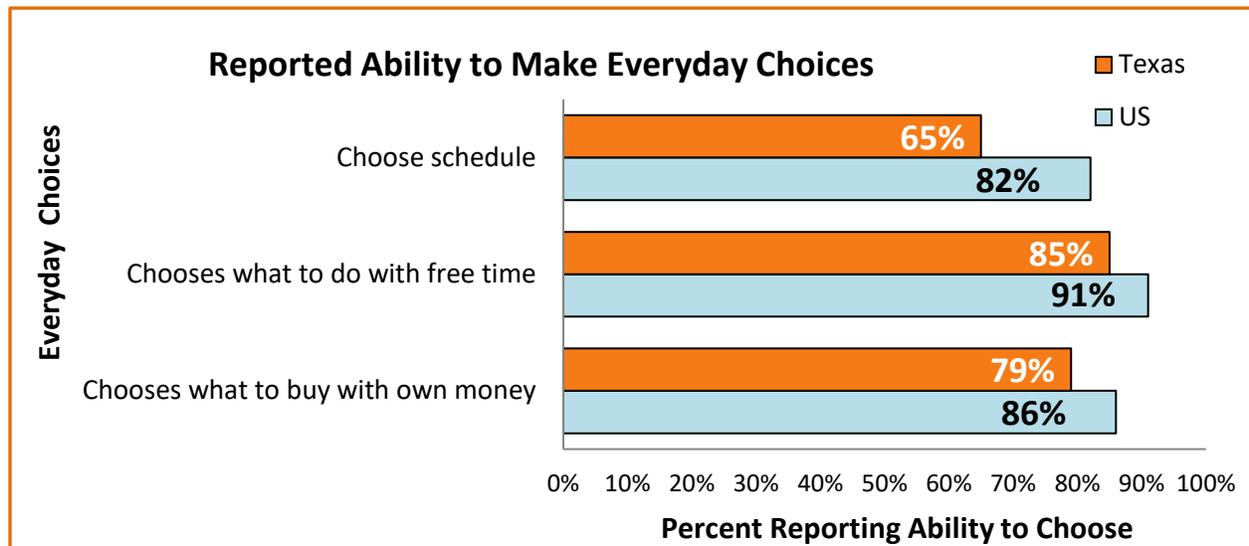
LIFE CHOICES

Choice over major life and everyday decisions is critical to quality of life and satisfaction with services and supports. One of DADS fundamental goals is to increase consumer choice and autonomy.

LIFE CHOICES: LIFESTYLE

A high proportion of people with IDD reported having input into everyday decisions, such as: choosing their own schedule (65 percent); how to spend free time (85 percent); and how to spend their money (79 percent) (Figure 3-16). All three of these measures, however, fell short of the corresponding national benchmarks. While Texas everyday decision percentages were higher than major life decisions, on the NCI composite “Everyday Choices Scale”, Texas scored a 78 percent compared to the national average of 86 percent, finishing only above New Jersey.

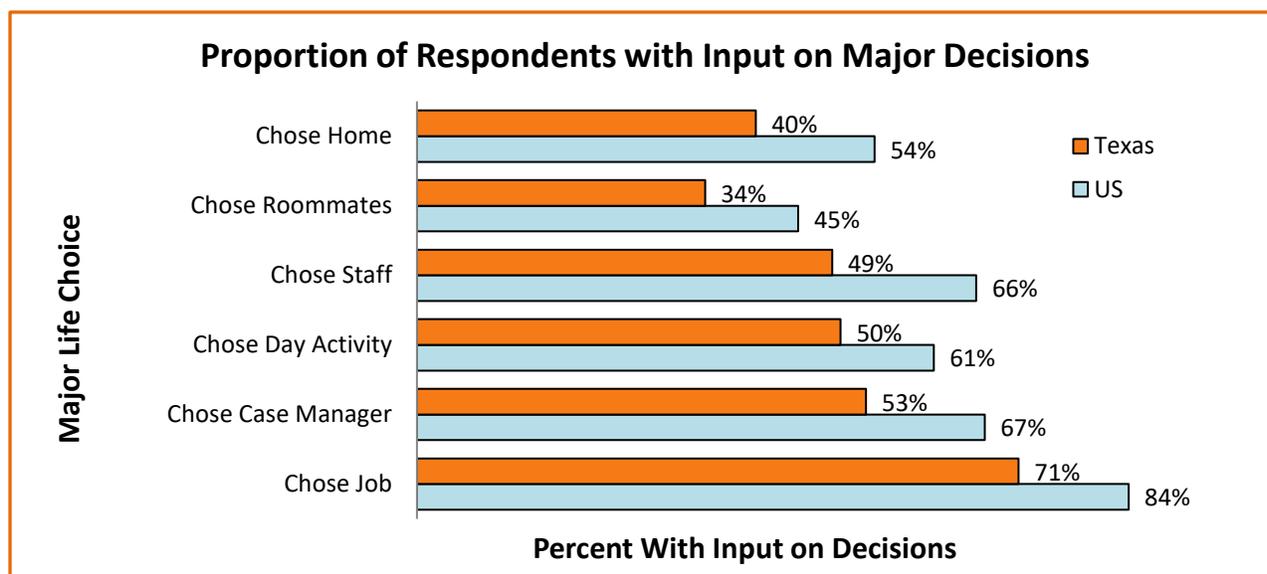
Figure 3-16. THE PROPORTION OF ADULTS WITH IDD IN TEXAS AND US WHO HAVE INPUT INTO EVERYDAY DECISIONS



LIFE CHOICES: HOUSING AND LIVING

Many adults with IDD reported that they did not have input in major life decisions, such as where and with whom they live and where they go during the day. As illustrated in Figure 3-17, only 40 percent of adults with IDD chose their home, and 34 percent chose their roommates. Though 71 percent had input into where they work, only 50 percent had input into where they go during the day (their non-work day activity). Choosing staff is a very personal decision, but only 49 percent of adults with IDD had input into choosing their staff, and 53 percent of persons surveyed chose their case managers, again below the national averages for these measures. Texas scored only 47 percent compared to the national average of 60 percent on the composite NCI “Life Decisions Scale” - finishing ahead of only 3 other states out of 32 states reporting.

Figure 3-17. THE PROPORTION OF ADULTS WITH IDD IN TEXAS AND US WHO HAVE INPUT INTO MAJOR LIFE CHOICES



LIFE CHOICES: TRANSPORTATION

Only 58 percent of adults with IDD had control over their transportation.

LIFE CHOICES: FRIENDS AND FAMILY

Three-quarters of the adults with IDD (70 percent) said that they could have a close personal relationship or date if they wanted.

SERVICE CHOICES

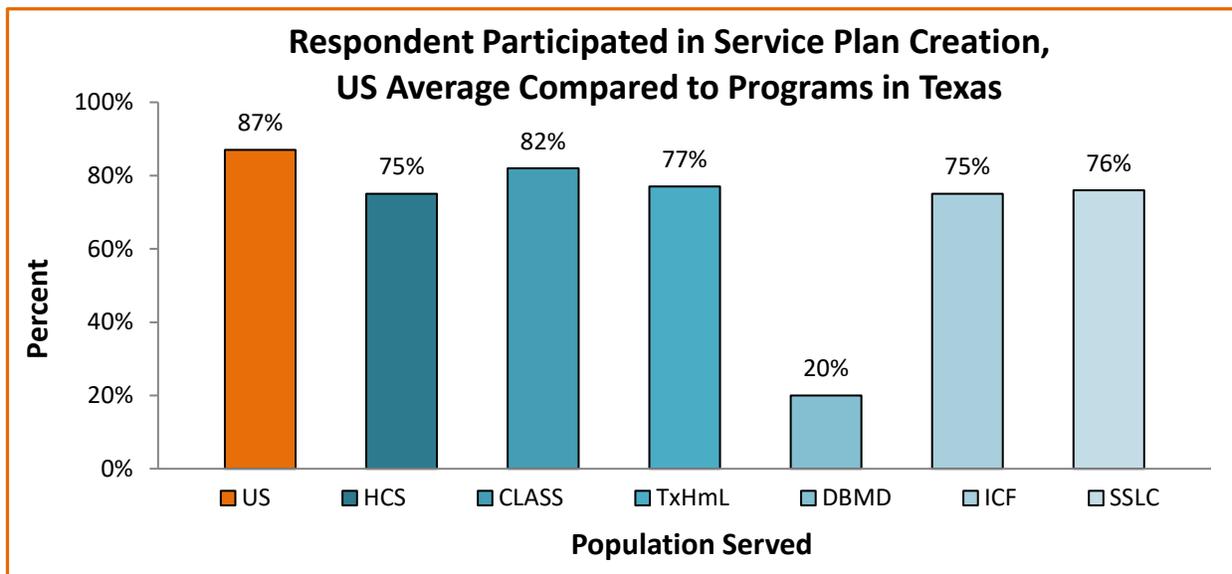
Consumer-directed services (CDS), where consumers direct their services and supports, as discussed in Chapter 2, is an option offered in a number of the waiver programs, but not ICF or SSLC programs.

SERVICE CHOICES: SELF DIRECTION

Only 17 percent of the adults with IDD used the CDS option, which was significantly higher than the national average of 9 percent. DADS policy encourages consumers to use self-directed supports where appropriate to increase their satisfaction and autonomy. Though most adults with IDD did not use the CDS option, they or their families participated in creating their individualized service plan (76 percent). Service plan participation in Texas was below the national average of 87 percent participation (Figure 3-18).

The wide variation in consumers' level of intellectual disability by program may have impacted consumer participation in creating service plans, which also varied widely by program. Consumers in the DBMD program, which had the highest percentage of consumers with profound ID (30 percent) behind SSLCs (60 percent), reported the lowest level of participation (20 percent) in service plan creation. Consumers in CLASS, the only Texas program to approach the national average, reported the highest participation rate, at 82 percent.

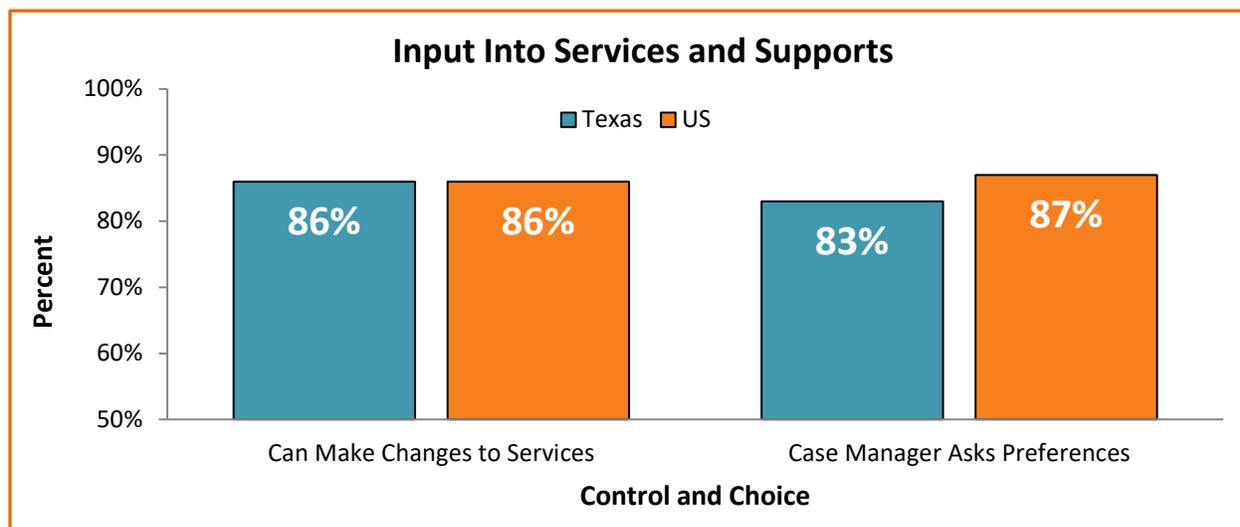
Figure 3-18. CONSUMER HELPS MAKE SERVICE PLAN BY PROGRAM



SERVICE CHOICES: PROVIDERS AND STAFF

Adults with IDD had input into choosing their case manager (53 percent) and support staff (49 percent). Eighty-six percent (86 percent) reported that they are able to make changes to their services or budget, the same as the national benchmark (Figure 3-19).

Figure 3-19. CONSUMER INPUT INTO SERVICES AND SUPPORTS, COMPARISON OF TEXAS TO US



Fewer Texas consumers reported that their case managers asked them about their preference (83 percent) than the national average (87 percent), but this is not a statistically significant difference.

PRIVACY

Five privacy measures were included in the NCI Adult Consumer Survey, including the question, “Do you have enough privacy at home?” Ninety-one percent (91 percent) of respondents reported that they had enough privacy at home. Most reported that people let them know before entering their home or bedroom, 87 percent and 79 percent respectively. Eighty-two percent (82 percent) reported that their mail and email were private; people did not read them without asking first.

COMMUNITY INCLUSION

Findings

- Only 10 percent of adults with IDD had community-based jobs
- Many individuals had close relationships and friends other than family and staff
- Texas rates of community participation were lower than the national average

EMPLOYMENT

Research suggests employment benefits people with disabilities by reducing the economic and social disparities they face, helping them gain economic security, and increasing their integration and engagement in mainstream society.¹

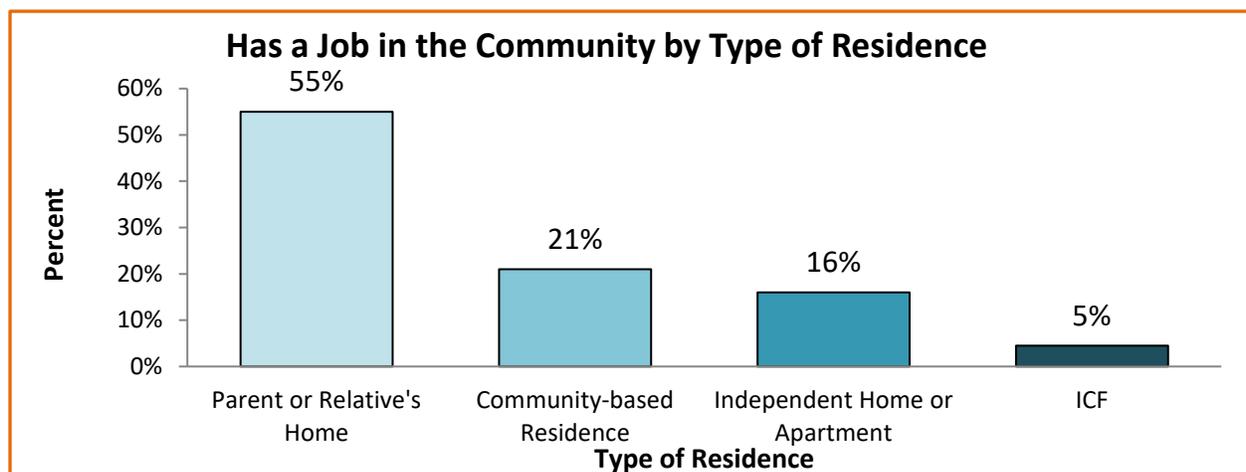
COMMUNITY-BASED EMPLOYMENT

In 2015, nationally, 17 percent of people with IDD had a paid job in the community, while in Texas only 10 percent had community-based jobs. Of the people with IDD who worked in the community, 16 percent lived in their own home or apartment, 21 percent lived in community-based residences, and 55 percent lived with a parent or relative (Figure 3-20).

Twenty-four percent (24 percent) of people with IDD who worked received benefits (e.g., vacation and/or sick leave), compared to 23 percent nationally.

Across programs, most individuals were not employed

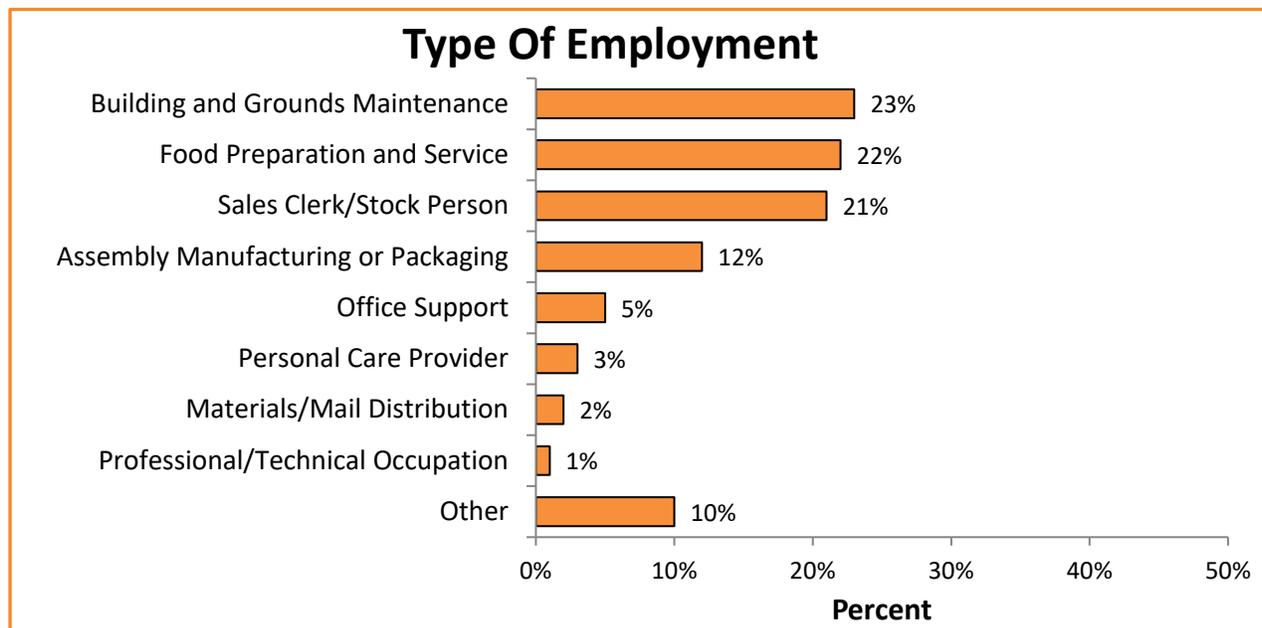
Figure 3-20. EMPLOYMENT STATUS OF ADULTS WITH IDD BY TYPE OF RESIDENCE



¹ Shur, L. (2002). The difference a job makes: the effects of employment among people with disabilities. *Journal of Economic Issues*, 36(2), 339-347.

Of people surveyed, the four most common types of paid community jobs were building and grounds maintenance (23 percent), food preparation (22 percent), retail (21 percent), and assembly and packaging (12 percent). See Figure 3-21.

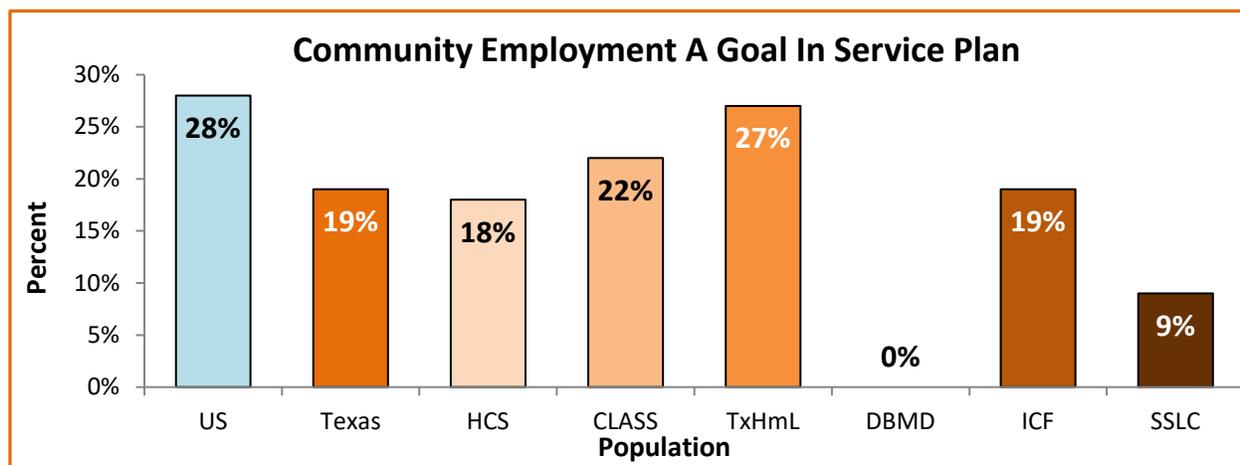
Figure 3-21. TYPE OF EMPLOYMENT ADULTS WITH IDD HAVE IN THE COMMUNITY



A disparity persists between employment rates and the desire to work. Nineteen percent (19 percent) of adults with IDD stated that they were employed, but only 10 percent were employed in the community, with the remainder having facility-based employment. Almost half (44 percent) of those who were not employed stated that they would like to have a job. DADS continues to address the top three items listed as barriers to employment: lack of job opportunities, lack of training or education, and lack of transportation.

Community employment remains a goal of DADS, and having community employment is included as a goal, where appropriate, in individuals' service plans. The percentage of adults with IDD who have community employment as a goal in their service plan in Texas (19 percent), falls short of the national benchmark of 28 percent by a statistically significant margin (Figure 3-22).

Figure 3-22. COMMUNITY EMPLOYMENT AS A GOAL IN SERVICE PLAN FOR ADULTS WITH IDD FOR US, TEXAS, AND PROGRAMS



It should be noted, however, that the national percentage of persons with severe or profound ID is 9 percentage points lower than the Texas average, 24 percent compared to 33 percent. This is the same margin (9 percentage points) as the difference between the national and Texas rates of including an employment goal in service plans. It may not be feasible for Texas to meet or exceed the national benchmark.

The rates of having community employment as a goal in client service plans vary greatly between programs. It is a goal in 27 percent of ICF clients' service plans, but appears in only 9 percent of SSLC service plans. Community employment was not a goal for any of the DBMD recipients interviewed.

FACILITIES-BASED EMPLOYMENT

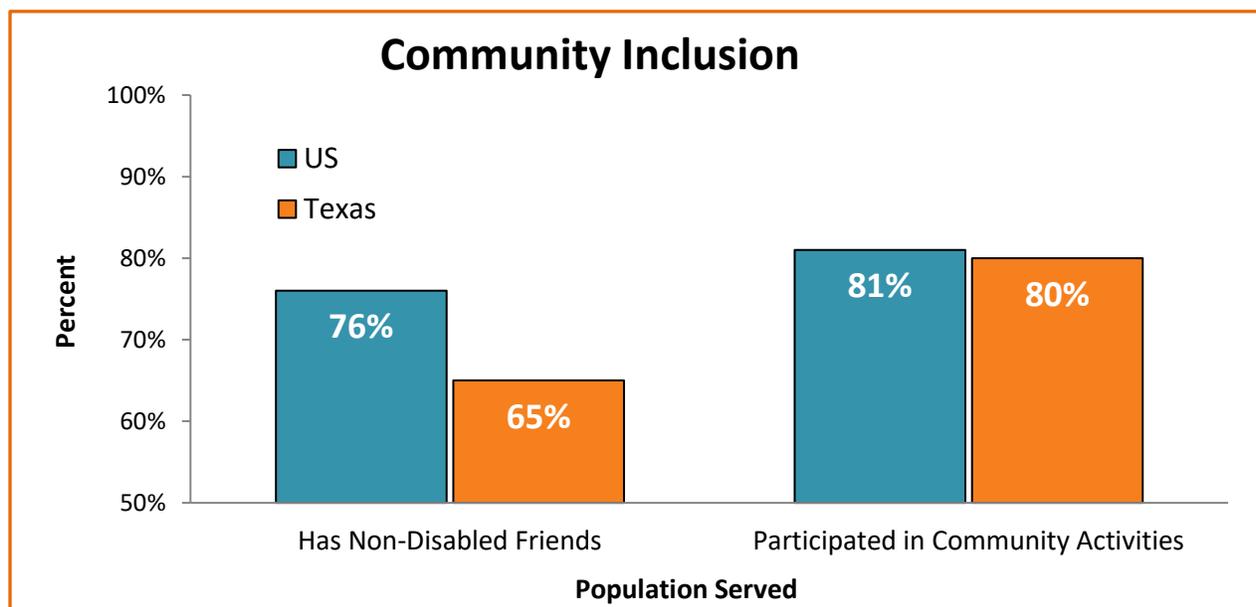
Twelve percent (12 percent) of adults with IDD in Texas had paid facility-based jobs and 42 percent participated in unpaid facility activities. While 19 percent of program participants reported that they were employed, 22 percent of the adult IDD population were employed in some capacity according to their case managers or family (10 percent in community-based jobs and 12 percent in facility-based jobs).

COMMUNITY PARTICIPATION

Most of the survey respondents reported participating in community activities (80 percent). In national results, 81 percent of adults with IDD reported participating in community activities (Figure 3-23). The majority of Texas respondents on the NCI Adult Consumer Survey reported that in the last month they had been shopping (82 percent), gone out for entertainment (73 percent), visited a restaurant or coffee shop (79 percent), and/or attended a religious service (53 percent). Texas lags slightly behind national rates of community participation.

Myth: The lives of people with disabilities are very different from the lives of people without disabilities.

Figure 3-23. COMPARISON OF PARTICIPATION OF ADULTS WITH IDD IN COMMUNITY ACTIVITIES, TEXAS TO US



FRIENDS AND FAMILY

As illustrated in Figure 3-23 above, approximately two-thirds of respondents in Texas and three-quarters nationally reported they have meaningful relationships with people other than support workers and family (76 percent nationally and 65 percent Texas). Seventy-two percent (72 percent) reported that they had a best friend, 81 percent said that they had family that they saw when they wanted, and 31 percent often talked to their neighbors.

SYSTEM PERFORMANCE

Findings

- 71 percent of adults with IDD or their families found the information they were provided easy to understand, compared to 77 percent nationally
- Most individuals (89 percent) reported they received all the services they needed
- 97 percent of those surveyed responded that they did go to the doctor when necessary
- Adults with IDD reported that they were treated respectfully by their support staff (92 percent)

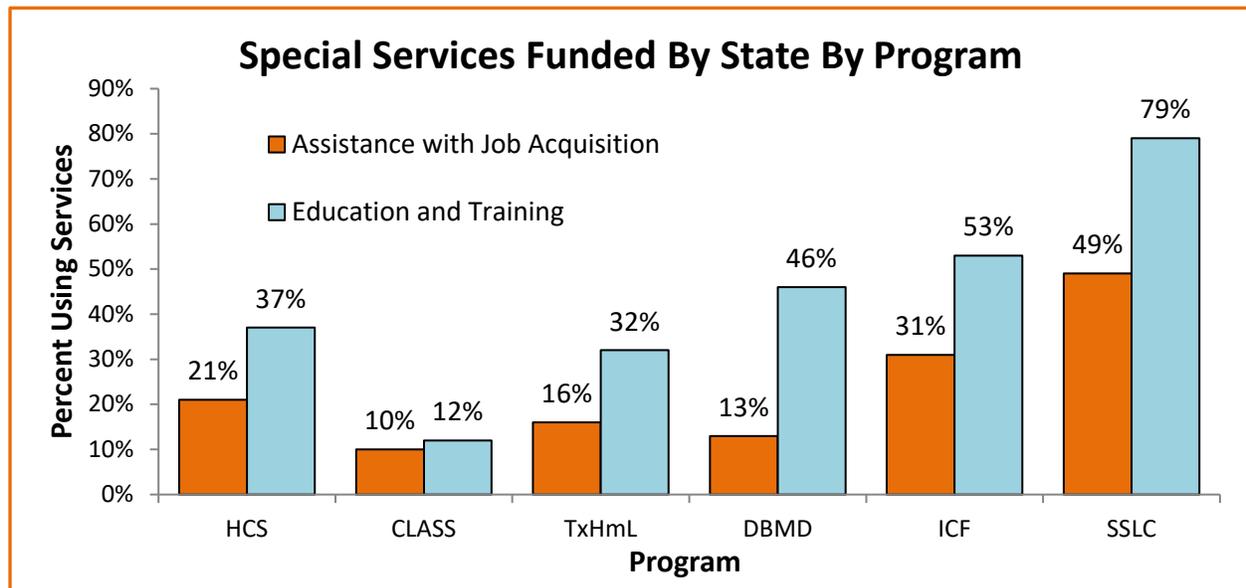
The primary purpose of the LTSS survey is to measure consumer satisfaction with DADS services and supports. A key component of satisfaction is system performance, and two key measures of system performance are delivery of and access to services. If clients do not have access to the services and equipment they need, or they do not receive the services or supports promised in their service plans, they will not be satisfied. Service access is measured here by the availability of information about services and participation in service planning, the amount of reported unmet need, and the receipt of requested services and supports.

CURRENT SERVICES

Information about the type of services consumers receive was also collected in the survey. Sixty percent (60 percent) of the adults with IDD receive Medicare. The majority (84 percent) of people have staff to help them. Sixty-three percent (63 percent) receive transportation services, where someone arranges or provides transportation for the client. Less than one-third (30 percent), receive environmental adaptations or home modifications, and 23 percent have assistance with finding, maintaining, or changing jobs.

Figure 3-24 shows the proportion of DADS consumers receiving state-funded special services (e.g., assistance with job acquisition or education and training) by program. SSLC clients received more state-funded special services than other programs, with 79 percent of SSLC consumers receiving education and training services and 49 percent receiving assistance with job acquisition. CLASS recipients reported the lowest levels of educational training (12 percent) and assistance with job acquisition (10 percent), yet community employment was listed as a goal in 22 percent of CLASS service plans, and 11 percent of CLASS recipients worked in community-based jobs. These percentages were the second highest behind TxHmL, where 27 percent of the service plans included community employment as a goal and 16 percent of respondents were employed in the community.

Figure 3-24. PROPORTION OF ADULTS WITH IDD RECEIVING SPECIAL SERVICES BY PROGRAM

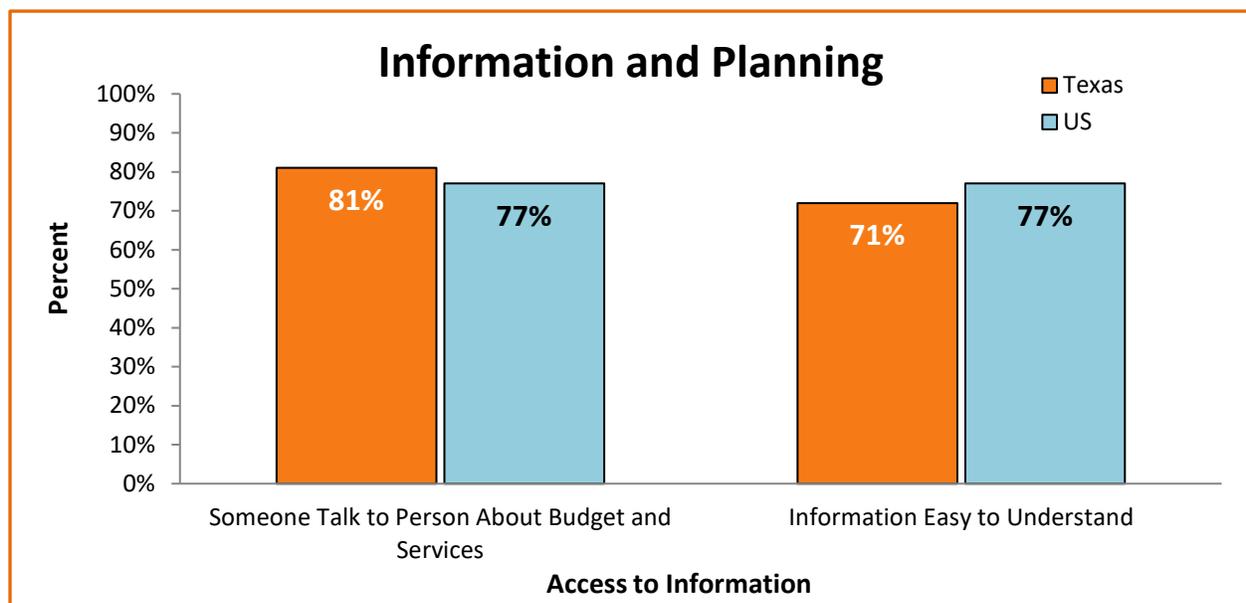


Only 33 percent of the families receive respite care (someone to care for their family member with IDD to give the family a break).

INFORMATION AND PLANNING

Information about services and consumer participation in service planning are important access issues. More than three-quarters of the respondents (81 percent) reported that someone talked to them about their services and budget (Figure 3-25). Most reported that the information about services and supports was easy to understand and use (71 percent).

Figure 3-25. ACCESS TO INFORMATION ABOUT SERVICES AND SUPPORTS

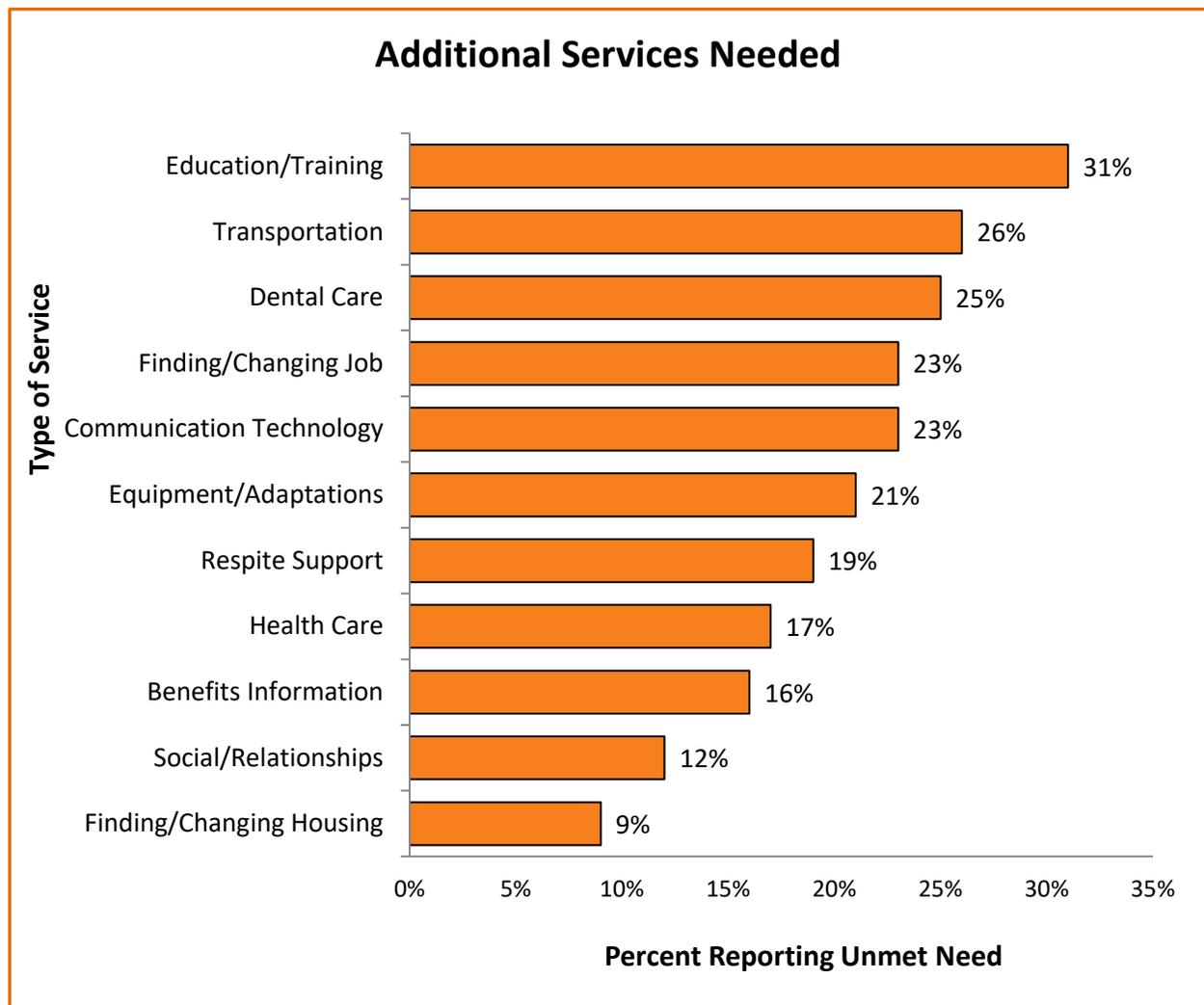


Eighty-five percent (85 percent) had someone to help them make budget and service decisions, and 67 percent said they did not want any more help deciding how to use their budget or services; only 26 percent said they wanted more help.

ACCESS TO SERVICES AND SUPPORTS

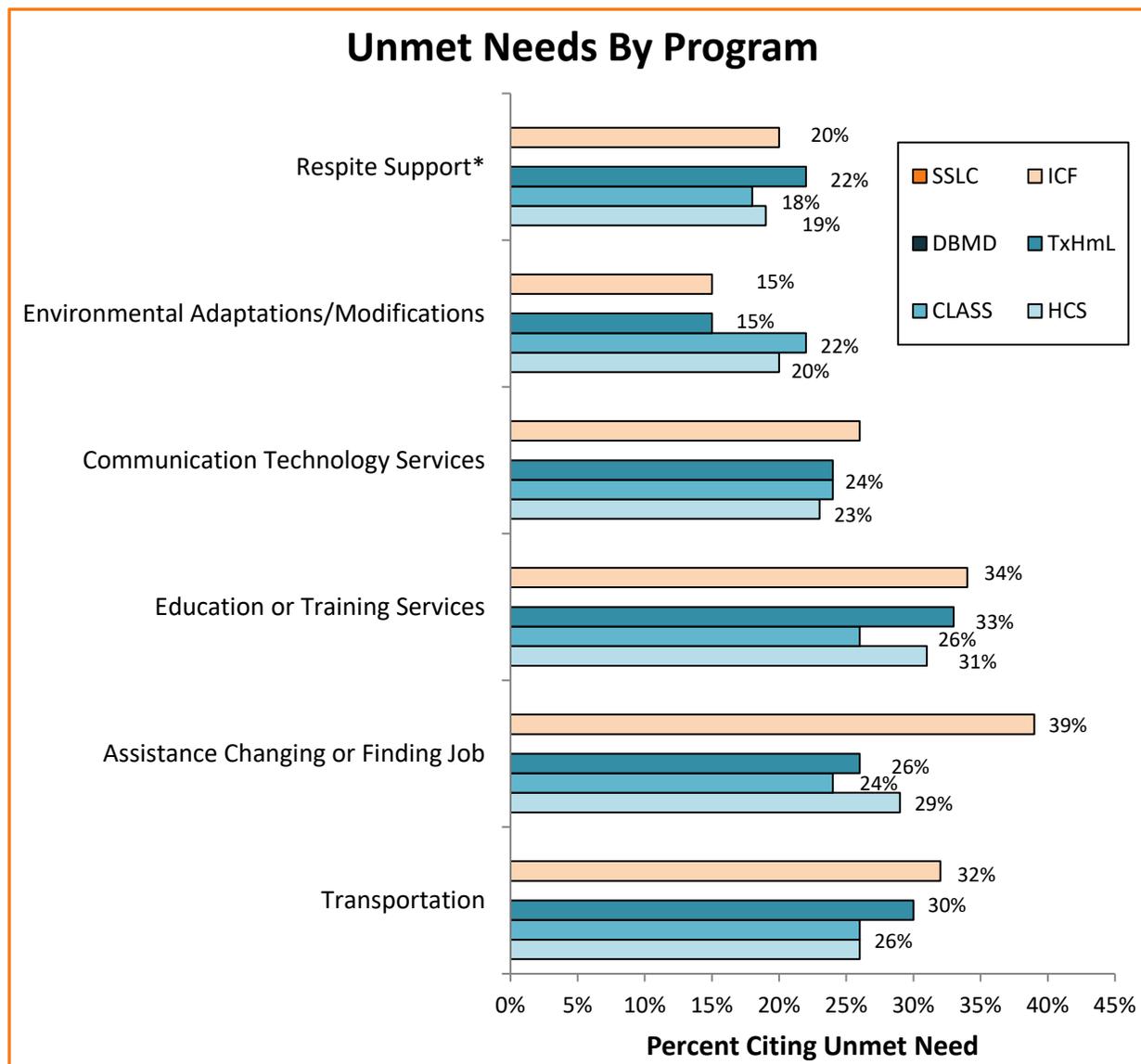
The majority of adults with IDD reported that they received or their service plan included all the services they needed (89 percent). Eleven percent (11 percent), however, said that they did not receive all of the services they needed or they needed more of the services they were already receiving. Among the 11 percent of adults with IDD who reported needing additional services, the most commonly identified needs were: education and training (31 percent), transportation (26 percent), dental care (25 percent), assistance with communication technology (23 percent), and assistance with finding a job (23 percent) presented in Figure 3-26 below.

Figure 3-26. REPORTED ADDITIONAL SERVICES NEEDED BY ADULTS WITH IDD



Of the 11 percent of adults with IDD who said that they needed additional services, the type and amount of need was different for each program. Figure 3-27 is complex, but it shows graphically the differences between program population needs. Assistance with finding a job, education, and control over transportation were the most important issues for ICF clients, while DBMD consumers also placed those 3 needs at the top of their list, education was most important. HCS, CLASS, and TxHmL recipients reported requiring assistance with all six areas of need, but the percentage of people requiring additional assistance varied by need and program.

Figure 3-27. REPORTED UNMET NEEDS OF ADULTS WITH IDD BY PROGRAM



* The numbers responding for SSLCs and DBMD were too small to report.

ACCESS TO TRANSPORTATION

Transportation for adults with IDD is an issue nationally and in Texas. The state’s size and large rural areas with low population density and few services make transportation a critical issue for Texas. Even with these potential barriers to services, 45 percent of adults with IDD served by DADS reported that they had control over their transportation, and 77 percent said that they almost always got where they needed to go. The most common mode of transportation was family or friends (41 percent), followed closely by agency vans or vehicles (34 percent).

ACCESS TO HEALTH SERVICES

From the excellent health data in the Health Care section above, it is easy to assume that the adult with IDD has easy access to medical care. The NCI Adult Consumer Survey includes a specific question about health care access to remove ambiguity, “Does this person go to the doctor when

necessary?” Ninety-seven percent (97 percent) of those surveyed responded that they did go to the doctor when necessary, confirming the positive findings detailed in the previous section.

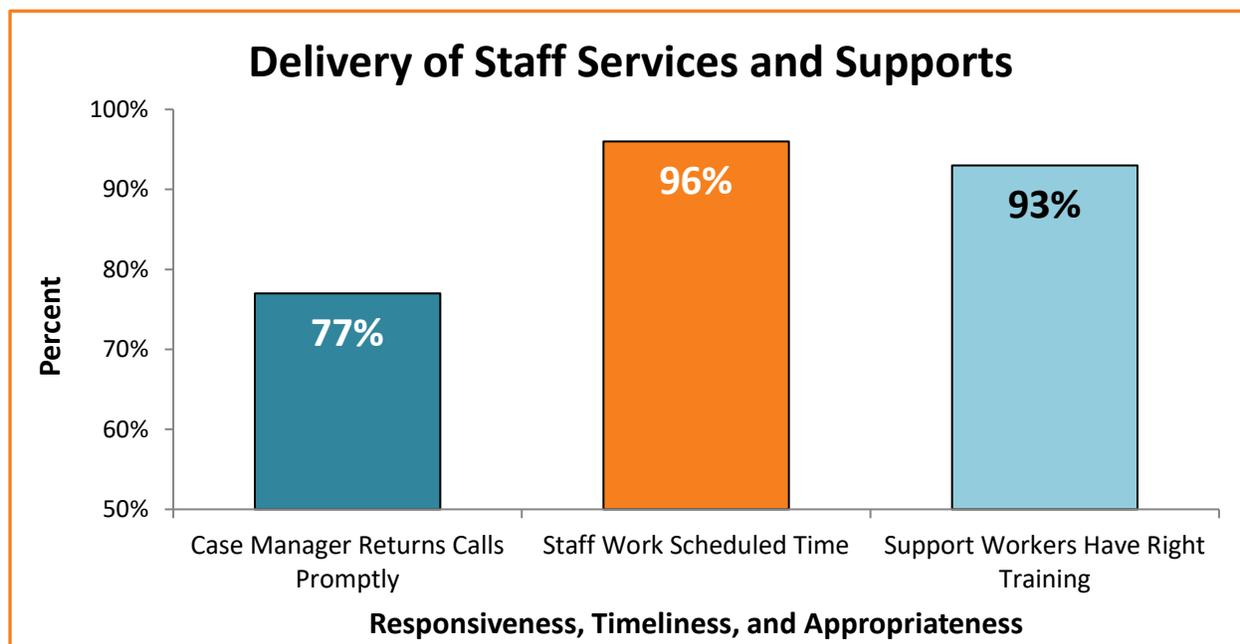
DELIVERY OF SERVICES AND SUPPORTS

The quality of delivery of services and supports, for the purpose of this report, is measured by receipt and completeness of promised services, the manner in which the services are delivered, and the timeliness of those services and supports.

ACCESS TO AND RESPONSIVENESS OF STAFF

Figure 3-28 below shows three critical service delivery issues: responsiveness, timeliness and appropriateness. The responses are positive for all three measures. Responsiveness was measured by case managers responding promptly when called. NCI respondents reported that their case managers called them back right away 77 percent of the time. Timeliness, as measured by support staff arriving on time and when scheduled, was excellent, with 96 percent of adults with IDD reporting that their support staff were prompt and came when scheduled. The appropriateness measure, as assessed by appropriate staff training, was also quite positive, with 93 percent of adults with IDD reporting that their support staff have the right training.

Figure 3-28. RESPONSIVENESS, TIMELINESS, AND APPROPRIATENESS OF STAFF SERVICES AND SUPPORTS



RESPECT

The manner in which services are delivered is a very important factor in customer satisfaction. The majority of people surveyed reported that their services and supports were delivered by staff that were respectful of them and their culture. Adults with IDD (92 percent) also reported that their support staff treated them respectfully. Many respondents said nice things

Across programs, the majority of individuals reported that their support staff treat them with respect and dignity.

about the dedication and caring attitudes of their support staff in the comments section of the survey.

SERVICES SATISFACTION

Findings

- 85 percent of the adults with IDD reported that they were happy
- Consumers who live in institutional facilities (ICFs and SSLCs) were much more likely to report that they were lonely
- 92 percent adults with IDD reported that services and supports made a positive difference in their health and wellbeing

The information presented above creates a picture of the level of needs and satisfaction of people served by DADS. The survey does not force the reader to create their own overall services satisfaction summary, but asks several specific questions about quality of life, overall satisfaction, and how well individual goals and health and wellbeing needs were met.

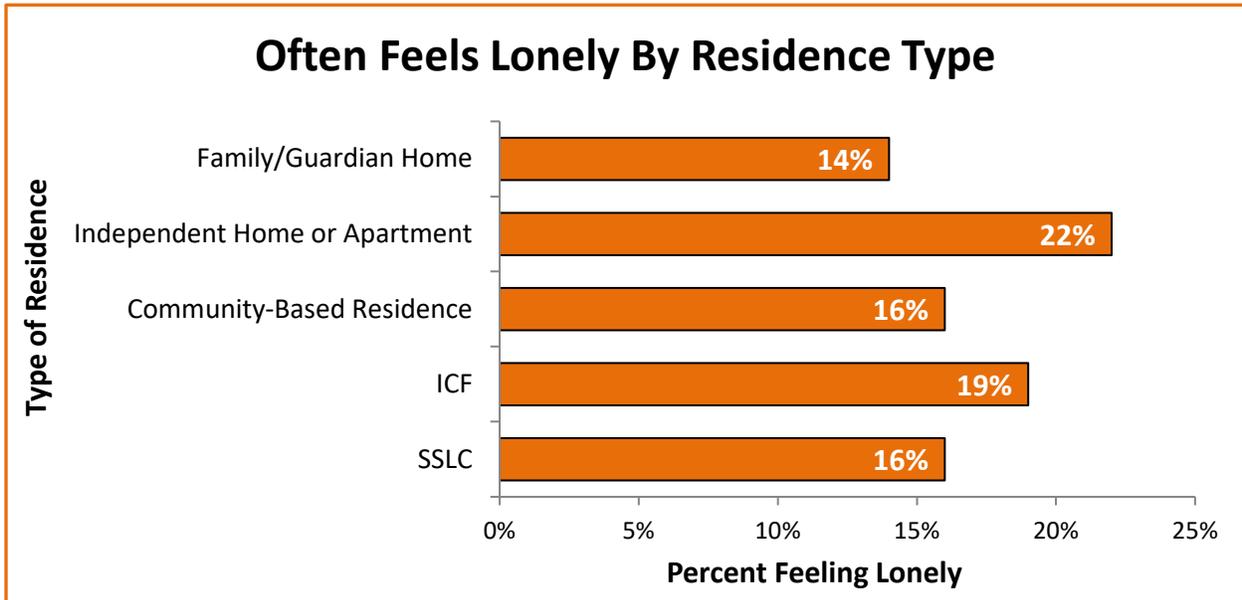
QUALITY OF LIFE

Quality of life is difficult to assess and measure, yet it is an important part of services and support satisfaction. If quality of life is poor, the best services in the world will not be enough. The NCI Adult Consumer survey asks several specific questions about quality of life and satisfaction with life.

Survey respondents were asked if they like their home or where they live, and would they like to live somewhere else. Both responses were positive. Ninety-one percent (91 percent) of respondents said that they liked where they lived; though a significant percentage of clients receiving SSLC and ICF services said they would like to live somewhere else (43 percent of SSLC and 35 percent of ICF consumers). See Appendix D for more details.

Two specific quality of life questions were asked, “Are you happy with your personal life, or do you feel unhappy?” and “Do you ever feel lonely?” While 85 percent of the adults with IDD reported that they were happy, only 64 percent responded that they were never or seldom lonely. Examining the loneliness question by where the respondent lived sheds light on the seeming disparity between the two responses (Figures 3-29).

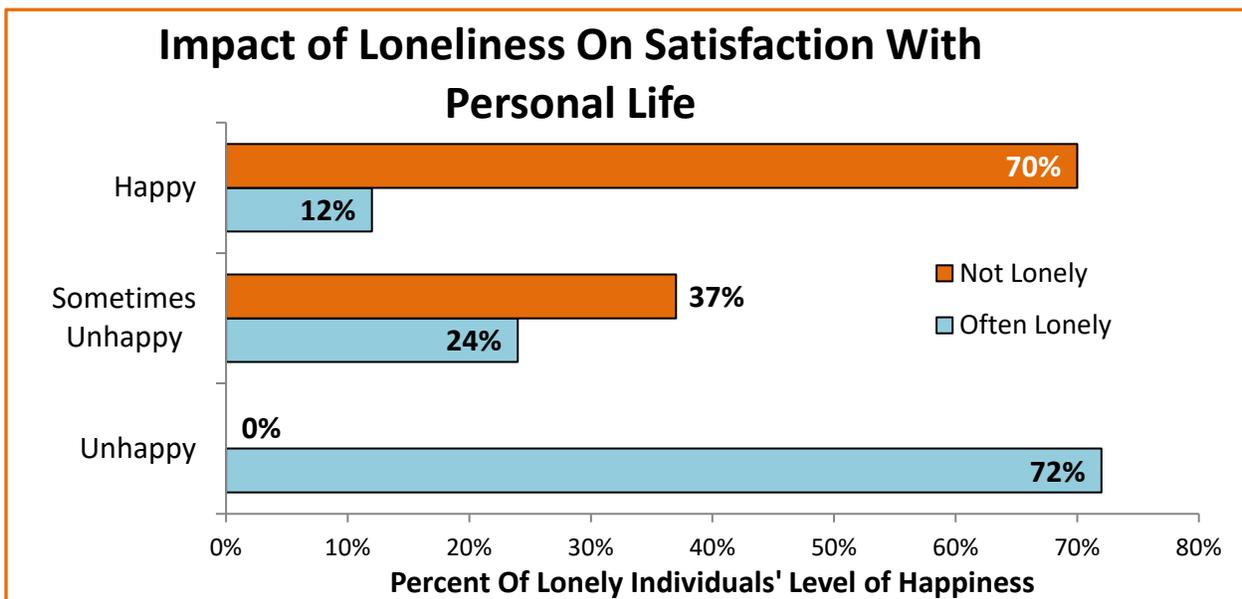
Figure 3-29. REPORTED LONELINESS BY TYPE OF RESIDENCE



Individuals who live in family-type environments (14 percent) were less likely to report that they often felt lonely compared to those who lived alone (22 percent), in ICFs (19 percent) or community-based residences or SSLCs (16 percent each).

Loneliness had a negative impact on the happiness of adults with IDD. While overall, 85 percent of those surveyed reported that they were happy, when examined by whether they were lonely or not, the statistics change (Figure 3-30). Seventy percent (70 percent) of those who stated that they were happy also said they were not lonely. Only 12 percent of those who reported that they were happy also said that they were lonely. Among those who reported being unhappy, 72 percent were also often lonely. Fostering relationships to decrease loneliness is something that DADS can work on to improve happiness and quality of life.

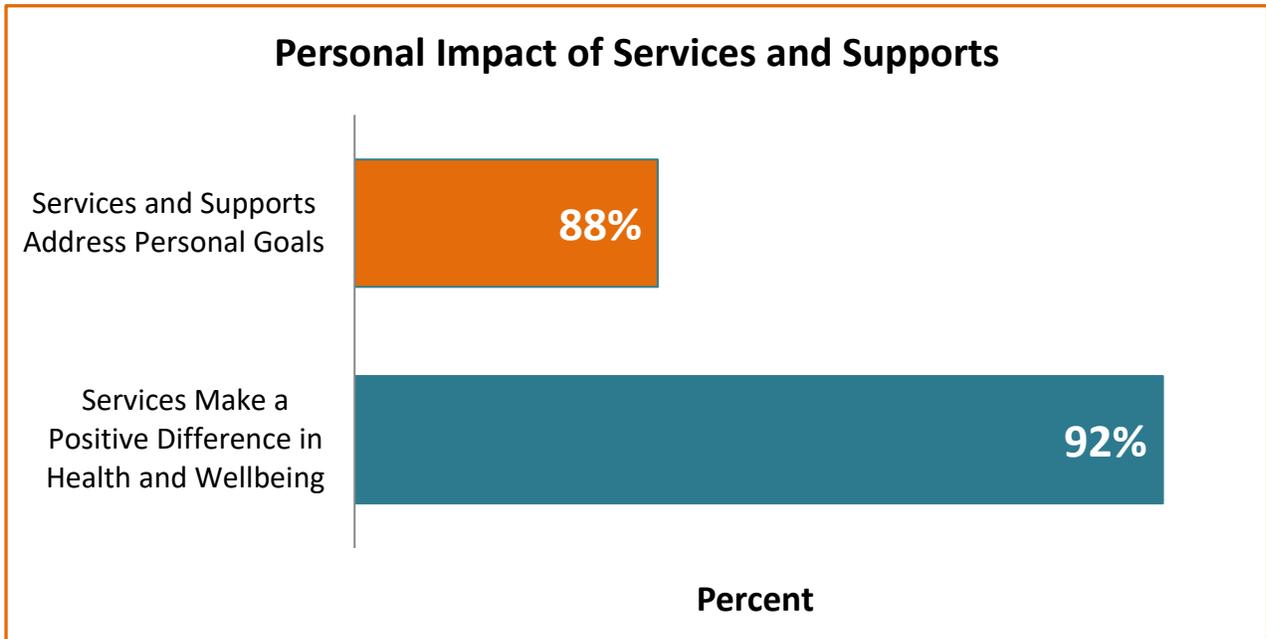
Figure 3-30. IMPACT OF LONELINESS ON SATISFACTION WITH PERSONAL LIFE



OVERALL SATISFACTION

The vast majority of respondents felt the services and supports made a positive difference for them or their family member. Ninety-two percent (92 percent) of adults with IDD reported that services and supports made a positive difference in their health and wellbeing (Figure 3-31). Services and supports also addressed the personal goals of the consumer. Eighty-eight percent (88 percent) said that DADS services and supports addressed their personal goals.

Figure 3-31. SERVICES AND SUPPORTS MAKE A POSITIVE DIFFERENCE IN THE LIFE OF ADULT'S WITH IDD



All of the responses for the NCI Adult Consumer Survey, for the entire population and by program, can be seen in Appendix D.

CHAPTER 4: OLDER ADULTS AND ADULTS WITH PHYSICAL DISABILITIES

The 2017 Detailed LTSS report provides results collected in 2015 from the Participant Experience Survey – Elderly/Disabled (PES) developed by the MEDSTAT Group for the Centers for Medicare and Medicaid Services (CMS). The PES was used with older adults or adults with physical disabilities whose physical disabilities place them at risk of entering a nursing facility (NF). Many already qualify medically for NF care. Throughout this report older adults and adults with physical disabilities will be referred to as “adults with physical disabilities” for the sake of brevity. Please keep in mind that the adults with physical disabilities population is primarily composed of older adults.

The LTSS used the PES survey to gather feedback from individuals from ten programs, results from eight programs are reported here. Programs administered by DADS to adults with physical disabilities in Texas include the following: Adult Foster Care (AFC), Community Attendant Services (CAS), Day Activity and Health Services (DAHS), Family Care, In-Home and Family Support (IHFS), Primary Home Care (PHC), Residential Care, Consumer Managed Personal Attendant Service (CMPAS), Programs of All-Inclusive Care for the Elderly (PACE), and Special Services to Persons with Disabilities (SSPD). The data were analyzed and reviewed as a group (adults with physical disabilities) and separately for each of the ten programs. Programs with less than 30 people are not included in the sample or program-specific analyses due to confidentiality and privacy concerns. Program-specific data concerning AFC and SSPD were not included in this report.

DADS received 2,669 completed surveys:
93 percent by telephone
4 percent face-to-face interviews
3 percent completed on the web

PPRI conducted telephone, web-based, and face-to-face interviews with adults with physical disabilities, primarily older adults, receiving services from DADS and obtained information about their experiences. PPRI sent 8,473 letters requesting interviews to individuals in ten programs. Thirty-two percent (32 percent) of the letters resulted in completed interviews. People were allowed to choose their survey method. DADS received 2,669 completed surveys, 93 percent completed by phone, 4 percent completed in person and 3 percent completed on the web.

The following section summarizes the services provided by the ten programs surveyed, the eligibility requirements and the funding sources. The domains in the PES are somewhat different than for the

**PES includes additional domains:
Activities of Daily Living (ADLs)
Instrumental Activities of Daily Living (AIDLs)**

IDD populations. Services may address medical needs, activities of daily living (bathing, dressing, mobility) and instrumental activities of daily living (cooking, cleaning, shopping, laundry). Services related to community

inclusion, day activities, and similar matters are not included. Individuals are presumed to be independent in making their own life choices and arranging their own health care. Most became disabled as adults, usually late in life.

Generally, statistics are presented for the entire survey population. Statistics for each program are included for survey questions where the responses for a specific program were different from the population. For a complete list of individual program findings of the PES survey, see Appendix E.

OVERVIEW OF PROGRAMS AND SERVICES

| Community Attendant Services (CAS) | |
|---|---|
| <p>There were 43,863 adults receiving CAS services when the sample was taken. The sample size was 552.</p> | |
| <p>CAS is one of three programs that provide non-technical attendant services for persons with a medical need for assistance with activities of daily living. Eligibility is limited to persons of any age with incomes up to three times the supplemental security income (SSI) limit, or 225 percent of the federal poverty level. Countable resources are limited to \$2000 for an individual or \$3000 for a couple. Services may be provided through an agency or through consumer directed services. CAS is funded with Federal Medicaid funds and state funds.</p> | |
| <p>Services Include:</p> <ul style="list-style-type: none"> • Bathing • Dressing • Grooming • Preparing Meals | <ul style="list-style-type: none"> • Housekeeping • Shopping • Arranging or accompanying individuals on trips to receive medical treatment |

| Day Activity and Health Services (DAHS) | |
|--|---|
| <p>There were 2,627 adults receiving DAHS services when the sample was taken. The sample size was 610.</p> | |
| <p>The DAHS program provides weekday daytime services at licensed day activity and health services centers for adults (18 or over). Services are provided as an alternative to nursing facility or other institutional care. Individuals may receive up to six hours of service per day. Participants must have one or more personal care or restorative needs that can be stabilized, maintained, or improved by participation in DAHS and a need for nursing care. Individuals must be eligible for Medicaid or meet Title XX income guidelines—up to 225 percent of the federal poverty level. DAHS services are funded by Medicaid, State Funds, and Title XX Social Services funds.</p> | |
| <p>Services include:</p> <ul style="list-style-type: none"> • Nursing care • Personal care • A noontime meal and snacks | <ul style="list-style-type: none"> • Transportation • Social, educational and recreational activities |

Family Care (FC)

There were **4,515** adults receiving Family Care services when the sample was taken. The sample size was **542**.

FC is one of three programs that provide non-technical attendant services for persons with a medical need for assistance with activities of daily living. Eligibility is limited to persons with incomes up to three times the SSI limit, or 225 percent of the federal poverty level. Countable resources are limited to \$5,000. Services may be provided through an agency or through CDS. FC is funded with Federal Title XX Social Services funds and state funds.

Services Include:

- Bathing
- Dressing
- Grooming
- Preparing Meals

- Laundry
- Housekeeping
- Shopping
- Arranging or accompanying individuals on trips to receive medical treatment

In-Home and Family Support Program (IHFS)

There were **2,652** people receiving IHFS services when the sample was taken. The sample size was **366**.

The In-Home and Family Support Program provides direct grants to individuals with disabilities to enable them to purchase services or equipment that help them to live in the community. The IHFS provides up to \$1,200 per certification year in funds for eligible people. Persons with incomes above the state median must make co-payments. IHFS is funded with state funds.

Services can include:

- Attendant Care
- Home Health Services
- Health Services
- Transportation
- Help with ADLs and IADLs

- Equipment or home modifications
- Respite Care
- Counseling or training for caregivers
- Medications
- Specialized Therapies

Primary Home Care (PHC)

There were **1,133** people receiving PHC services when the sample was taken.
The sample size was **291**.

Primary Home Care is one of three programs that provide non-technical attendant services for persons with a medical need for assistance with activities of daily living. Eligibility is limited to persons over 21 with incomes at the SSI level, equivalent to 75 percent of the federal poverty level. Countable resources are limited to \$2000 for an individual or \$3000 for a couple. Services may be provided through an agency or through CDS. PHC is funded with Federal Medicaid funds and state funds.

Services Include:

- Bathing
- Dressing
- Grooming
- Preparing Meals
- Housekeeping
- Shopping
- Arranging or accompanying individuals on trips to receive medical treatment

Residential Care (RC)

There were **310** people receiving Residential Care services when the sample was taken.
The sample size was **30**.

Residential Care provides services for adults who require 24-hour access to care, but who do not require daily nursing intervention. Care is provided in DADS-licensed assisted living facilities. The recipient pays the provider for room and board and may have co-payment liability. Services are provided through residential care or emergency care. Emergency care is a temporary arrangement. RC is funded through Title XX Social Services funds and state funds.

Services can include:

- 24 hour living arrangement
- Emergency Care

Consumer Managed Personal Attendant Services (CMPAS)

There were **342** people receiving CMPAS services when the sample was taken.
The sample size was **74**.

Consumer Managed Personal Attendant Services provides personal attendant services to people with physical disabilities who manage their attendants, including selection, training, supervision, and firing. The program operates in a limited number of counties. CMPAS is funded through Title XX Social Services funds and state funds.

Services can include:

- | | |
|--|--|
| <ul style="list-style-type: none"> • Personal Attendants • Bathing • Dressing • Grooming • Health care tasks prescribed by MD | <ul style="list-style-type: none"> • Housekeeping • Shopping • Laundry • Preparing Meals |
|--|--|

Programs of All-inclusive Care for the Elderly (PACE)

There were **1,081** people receiving PACE services when the sample was taken.
The sample size was **172**.

PACE provides community-based services in El Paso, Amarillo/Canyon, and Lubbock for people 55 or older who qualify for nursing facility admission, both medically and financially. PACE uses a comprehensive care approach, providing an array of services for a capitated monthly fee. PACE receives funding from Medicare, Medicaid, and state funds.

PACE provides all health-related services:

- | | |
|--|---|
| <ul style="list-style-type: none"> • Licensed Day Activity and Health Services • In- and Out-patient Medical Care • Dentistry and Podiatry • Social Services | <ul style="list-style-type: none"> • In-Home Care • Meals • Transportation • Physical, Occupational and Recreational Therapy • Social Work/Social Services |
|--|---|

INDIVIDUAL DEMOGRAPHICS

GENDER, AGE, RACE/ETHNICITY, AND LANGUAGE

In contrast to the IDD respondents, for the PES respondents, a higher percentage was female (70 percent). Consumers ranged in age from 19 to 101 years old. The average age was 63 years. An overview of adult respondent demographics is presented in Table 4-1.

Table 4-1. GENDER, AGE, RACE/ETHNICITY, LANGUAGE AND RESIDENCE OF ADULTS WITH PHYSICAL DISABILITIES

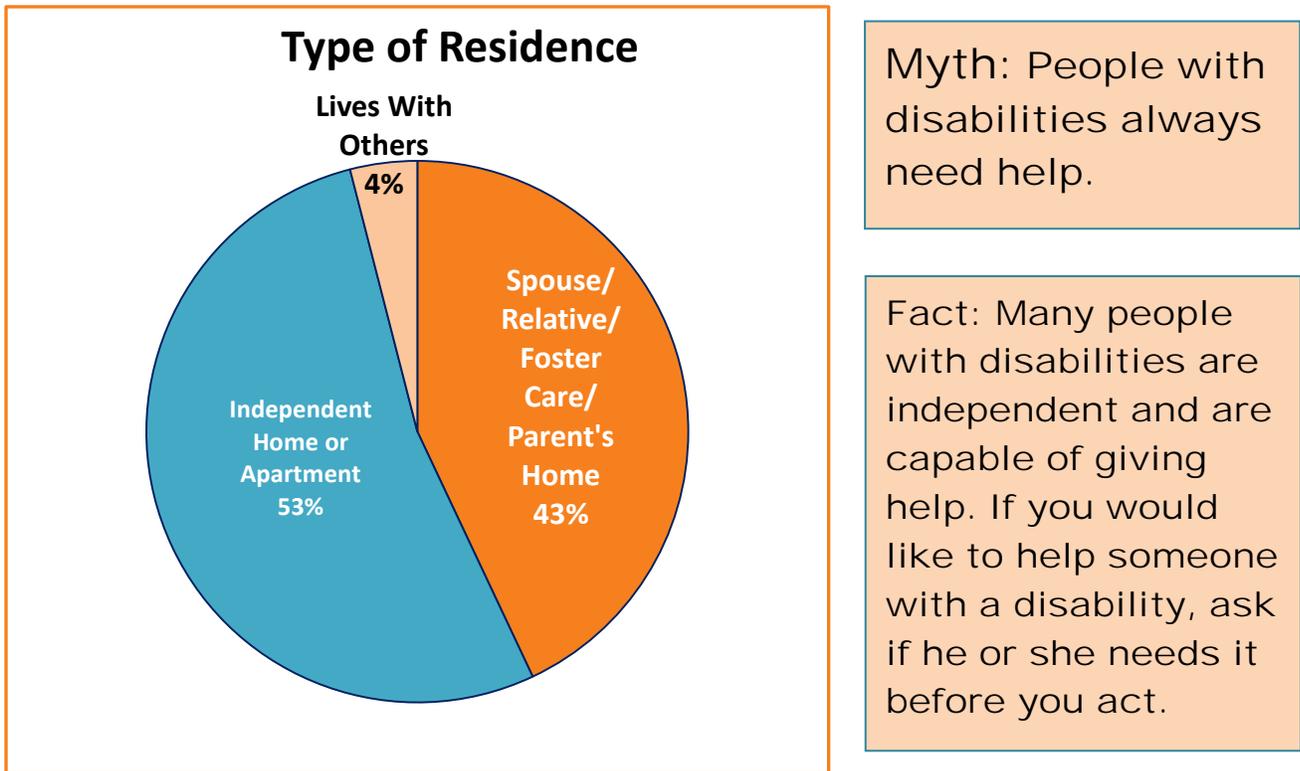
| Demographics of Adults with Physical Disabilities | | | | | | |
|---|-----------------|-----------------|-------------------------|------------------|-------------------------------------|-------------------------|
| Gender | Age | Race/Ethnicity | | Primary Language | Residence | |
| Male 30% | Range 19-101 | White 34% | African American 20% | English 64% | Lives with parents/relatives 43% | Lives with others 4% |
| Female 70% | Average 63 | Hispanic 46% | Other 1% | Spanish 31% | Lives alone 53% | |

Thirty-four percent (34 percent) of those surveyed were white non-Hispanic, 46 percent Hispanic, 20 percent Black, and 1 percent of other races, primarily Asian. English was the primary language spoken, with 64 percent reporting English as their primary language. Spanish was the primary language of 31 percent of adults with physical disabilities surveyed.

RESIDENCE

More than half of the respondents lived in an independent home or apartment (53 percent), see Figure 4-1 below. Sixty-three percent (63 percent) have their name on the lease or title. More than half (57 percent) had lived in the same home for more than 5 years. Adults with physical disabilities who did not live alone were likely to live with spouses or other relatives, in host-home care, or with a guardian (43 percent). Four percent (4 percent) reported they lived with persons other than relatives, guardians, or host home companions.

Figure 4-1. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES BY TYPE OF RESIDENCE



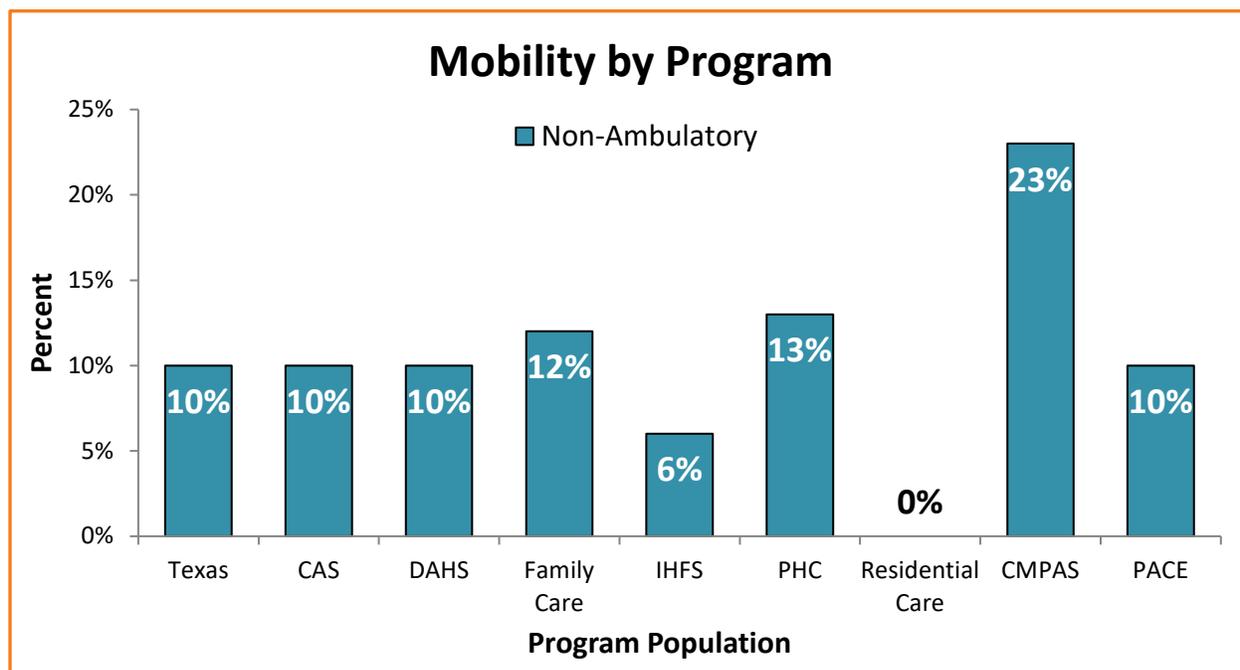
INFORMATION ON FUNCTIONAL LEVEL

Findings

- 10 percent of adults with physical disabilities are non-ambulatory
- Bathing, dressing, and getting in and out of bed were the most commonly reported ADL problems requiring assistance from an attendant
- Most adults with physical disabilities reported that they needed help with housework, laundry, cooking, taking medications, and grocery shopping

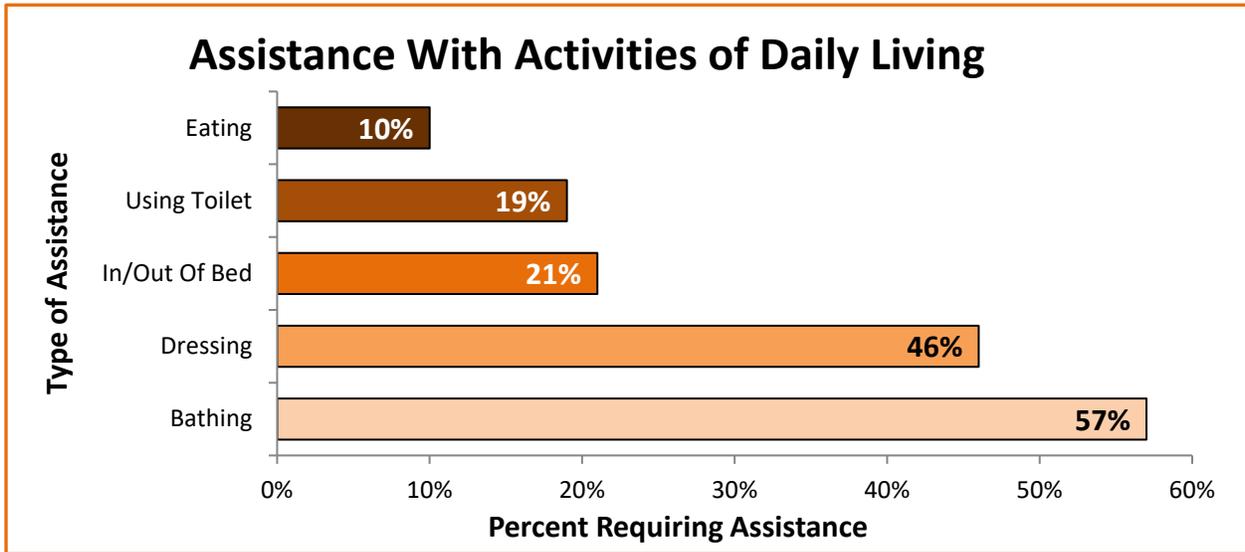
Information about functional level is critical when talking about individuals with physical disabilities and comparing programs and outcomes, as the program's populations are not comparable. As shown in Figure 4-2, the percentage on non-ambulatory clients ranges from zero in the Residential Care program to 23 percent in the CMPAS program.

Figure 4-2. PROPORTION OF NON-AMBULATORY ADULTS WITH PHYSICAL DISABILITIES BY PROGRAM



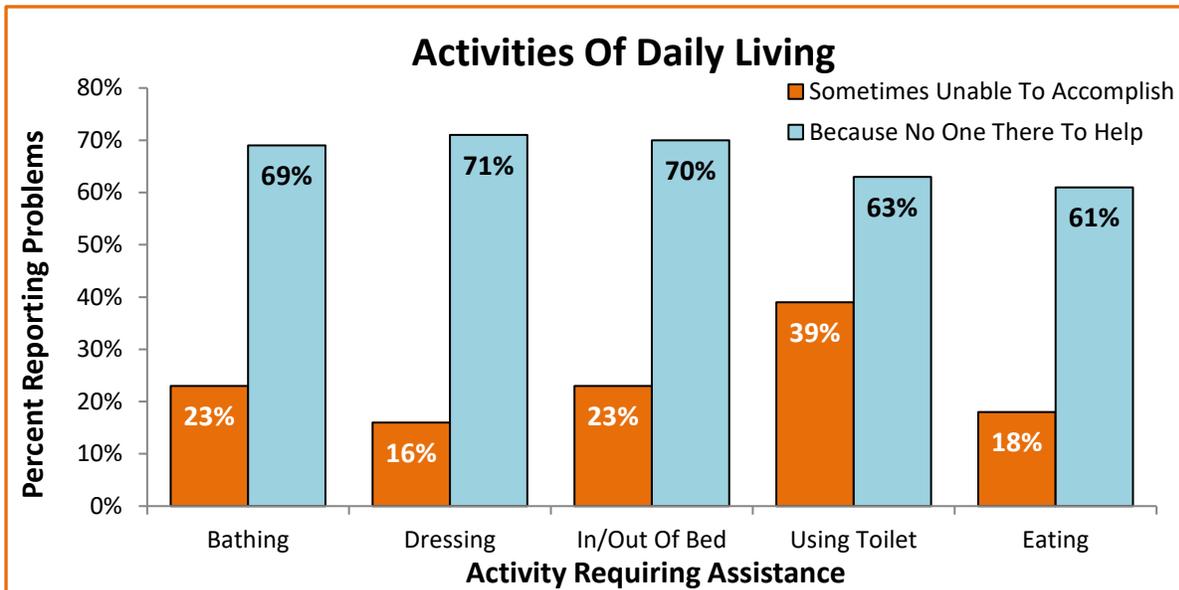
A primary focus of programs for individuals with physical disabilities is assisting with activities of daily living (ADLs) or instrumental activities of daily living (IADLs). ADLs are defined as routine functional tasks that a person does daily without needing assistance. Basic ADLs include bathing, dressing, using the toilet, eating, and getting in and out of bed. Individuals surveyed reported needing some assistance with each of these to varying degrees (Figure 4-3). Only 10 percent reported needing assistance with eating, while almost half and more needed help with dressing (46 percent) or bathing (57 percent).

Figure 4-3. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES REQUIRING ASSISTANCE WITH ADLs



The PES survey asks a series of three questions about each ADL: “Is there any special help that you need to...”; “Do you ever go without...”; and “Is this because there is no one there to help you?” This is done to determine the prevalence of the person’s doing without, and whether it is voluntary (they choose to skip a meal) or due to lack of assistance. For each ADL, Figure 4-4 shows the percentage of consumers doing without (the specified ADL) and the percentage who do without because they do not have assistance.

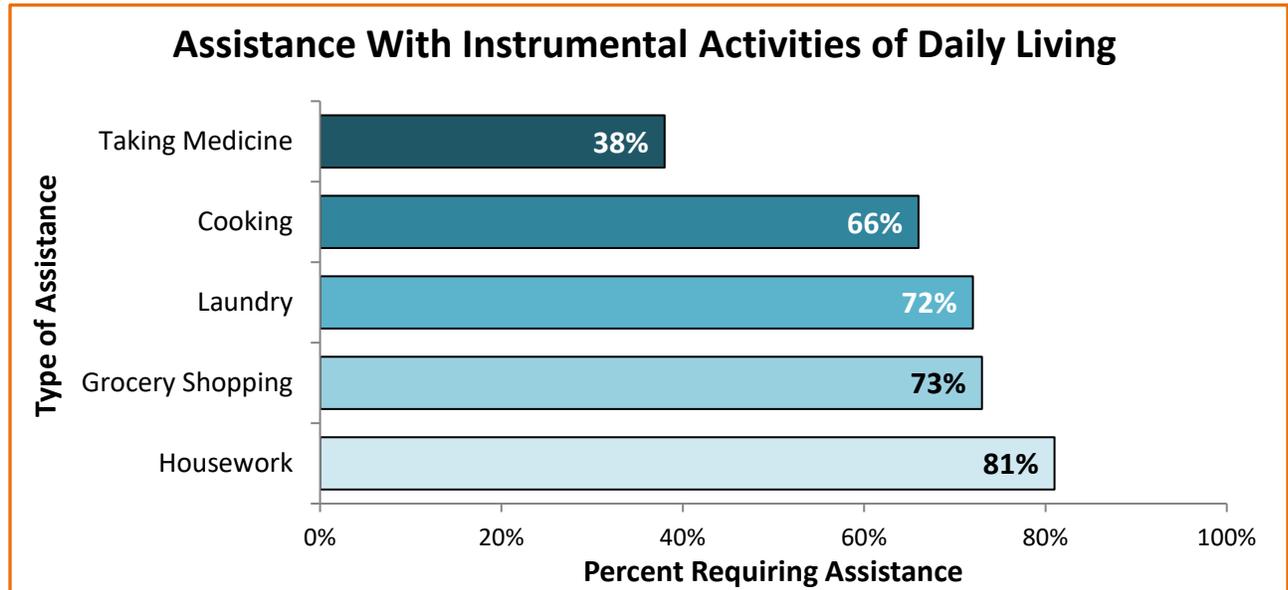
Figure 4-4. ADULTS WITH PHYSICAL DISABILITIES UNABLE TO ACCOMPLISH ADLs BECAUSE HELP WAS UNAVAILABLE



Although bathing and dressing were the ADLs where individuals most often needed help (Figure 4-3), it was using the toilet and getting out of bed that they were most often unable to accomplish (Figure 4-4). Usually, if the individual was unable to accomplish an ADL, it was because no one was there to help. Help was especially critical for dressing and getting in and out of bed. Twenty-three percent (23 percent) of respondents reported that they sometimes did not get in or out of bed, and 70 percent stated that it was because there was no one there to help them.

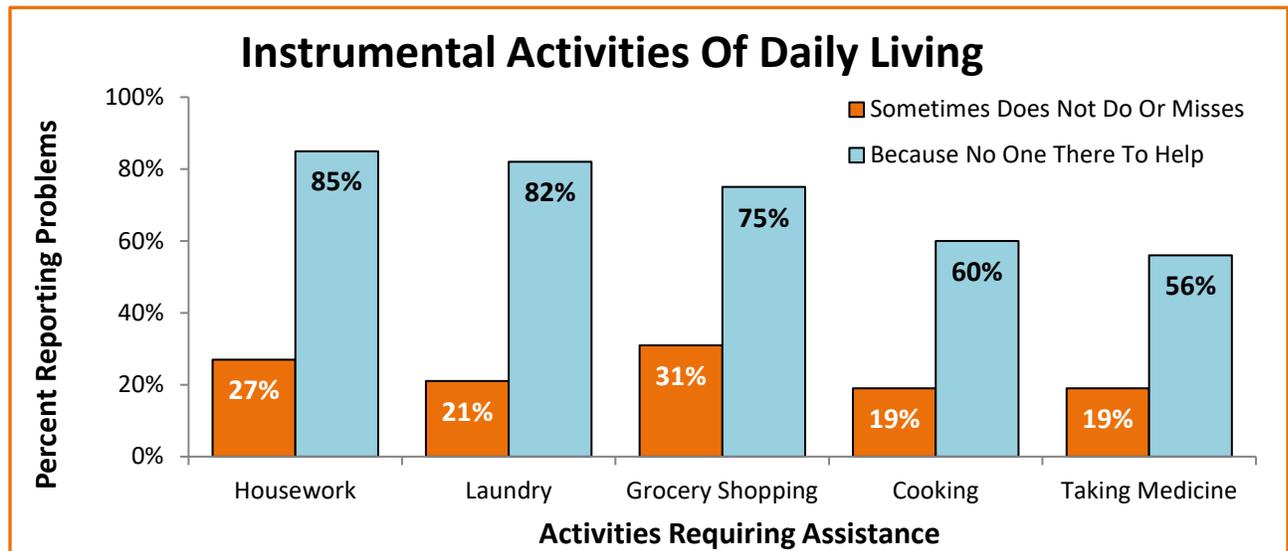
IADLs are functional self-management tasks – tasks that are not necessary for fundamental functioning, like eating, but are core functions that let an individual live independently in the community. Examples of IADLs are housekeeping, meal preparation, laundry, grocery shopping, or taking medicine. Figure 5 shows the proportion of consumers who reported needing assistance with specific IADLs.

Figure 4-5. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES REQUIRING ASSISTANCE WITH IADLS



Housework was the most commonly reported IADL identified as requiring assistance (81 percent), followed closely by grocery shopping and laundry (73 percent and 72 percent respectively). For four out of five IADLs, more than 50 percent of the respondents reported requiring assistance (Figure 4-5). Help taking medicines was the exception, with only 38 percent requiring assistance. Figure 4-6 shows the proportion of adults with physical disabilities who sometimes miss doing an IADL because there is no one there to help.

Figure 4-6. ADULTS WITH PHYSICAL DISABILITIES UNABLE TO ACCOMPLISH IADLS BECAUSE HELP WAS UNAVAILABLE



The most commonly missed IADLs were grocery shopping (31 percent) or housework (27 percent), but those that were missed most frequently because the respondent did not have help in Figure 4-6 were laundry (82 percent) and housework (85 percent).

HEALTH AND WELFARE

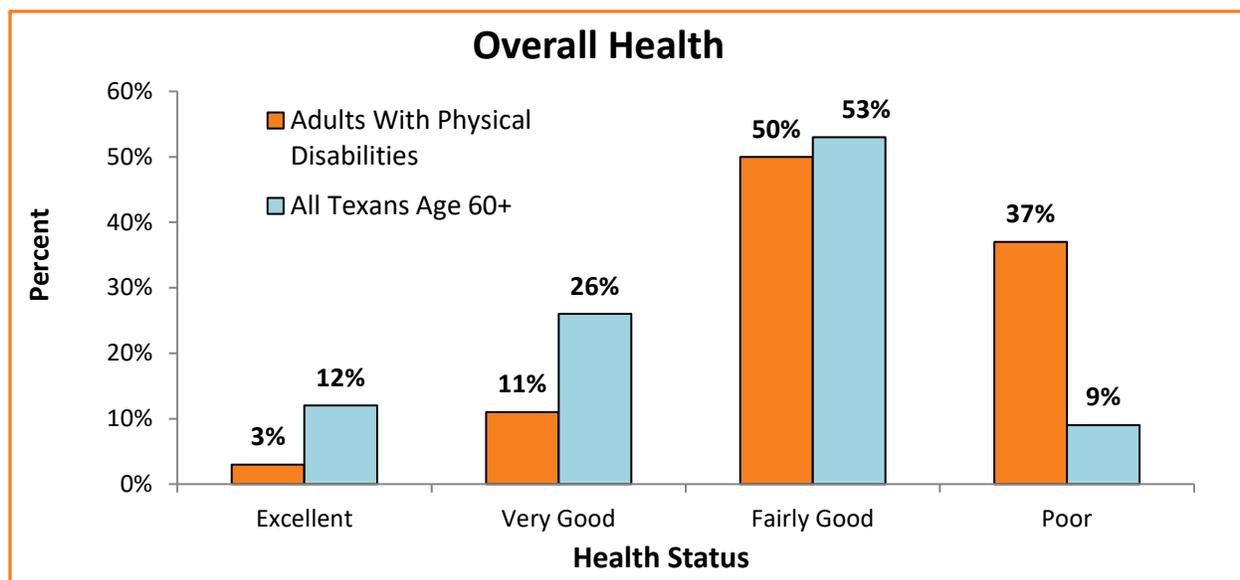
Findings

- 37 percent of adults with physical disabilities reported their health was poor
- 14 percent required weekly or more frequent treatment by a medical provider
- Health habits were problematic: 19 percent of adults with physical disabilities use tobacco products, 48 percent were obese, and only 35 percent participated routinely in moderate exercise
- 81 percent had an annual physical examination
- Approximately half had received cancer screening for breast, prostate, and colorectal cancer

HEALTH STATUS AND HEALTH HABITS

The information on health status of adults with physical disabilities receiving services from DADS can be made more useful by comparing it to information about Texas as a whole. As the average age of persons surveyed was 63, Texans age 60 and over from the 2014 Texas Behavioral Risk Factor Surveillance Survey were chosen as a reference population. Figure 4-7 compares the two populations of Texans' overall health status.

Figure 4-7. OVERALL HEALTH, ADULTS WITH PHYSICAL DISABILITIES AND ALL TEXANS AGE 60 AND OVER



Only 9 percent of Texans age 60 or older reported that they had poor health, while 37 percent of adults with physical disabilities said their health was poor. At the other end of the spectrum, only 14 percent of PES respondents said that their health was excellent or very good, compared to 38 percent of older Texans. These findings are not unexpected, as it explains why the PES respondents require DADS services.

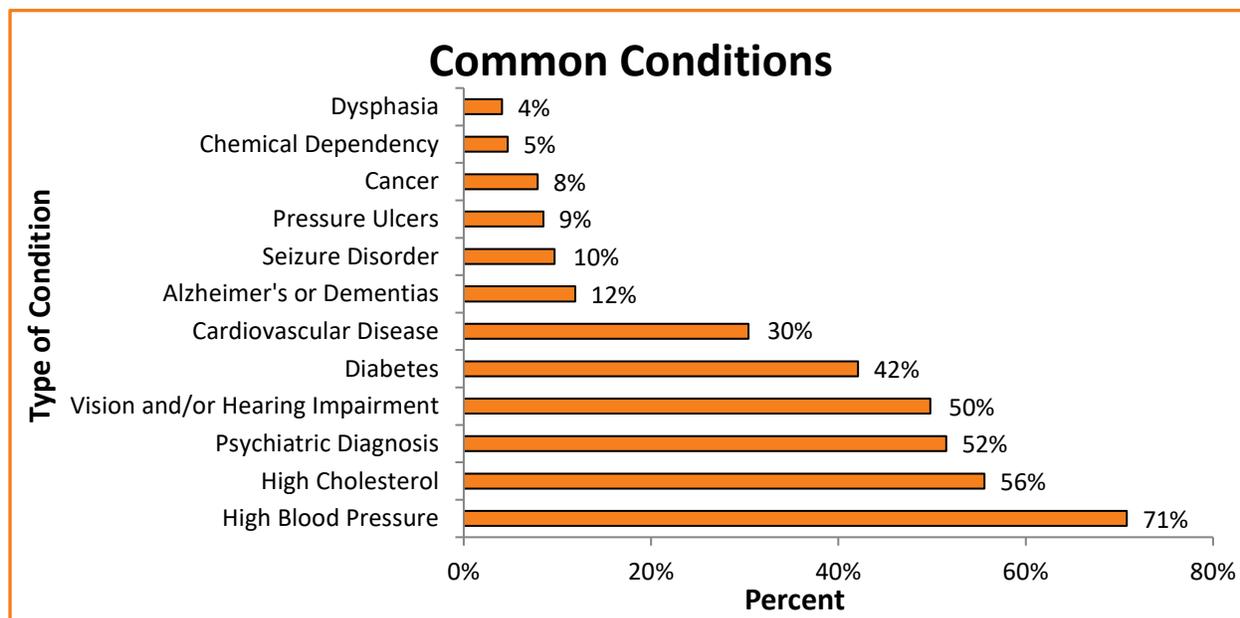
Health habit indicators were poor. Nineteen percent (19 percent) of the adults with physical disabilities used tobacco products. Forty-eight percent (48 percent) of the PES respondents' body mass index (BMI) scores indicated that they were obese. Only 35 percent reported that they routinely engaged in any moderate physical activity. In some cases, disability may have made exercise difficult or impossible.

DISABILITIES AND CONDITIONS

The focus of the PES survey is quite different compared to the NCI Adult Consumer and Child and Family surveys, with significantly less emphasis on the types of conditions and more emphasis on functional issues, like activities of daily living, which were discussed above, and mental health issues, which are discussed below. Health condition information was collected, however, as it is pertinent to the need for services and supports.

As illustrated in Figure 4-8, the most commonly reported conditions were high blood pressure (71 percent), high cholesterol (56 percent), mental illness (52 percent), severe or profound vision or hearing impairment (50 percent), diabetes (42 percent), and cardiovascular disease (30 percent). Less common but important conditions included dementias (12 percent), seizure disorders (10 percent), pressure ulcers (9 percent), cancer (8 percent), chemical dependency (5 percent), and dysphasia (4 percent). The question about intellectual disabilities or cognitive function was not asked in the PES survey of adults with physical disabilities, but using guardianship/conservatorship as a proxy for cognitive disability, 26 percent of adults with physical disabilities reported having a guardian.

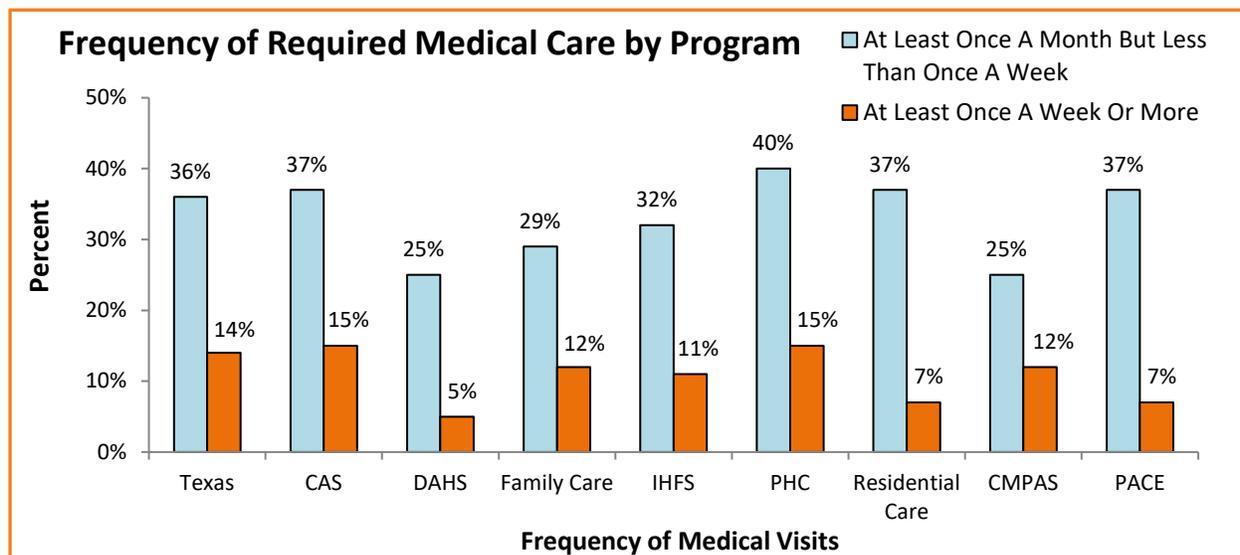
Figure 4-8. THE FREQUENCY OF HEALTH CONDITIONS AMONG ADULTS WITH PHYSICAL DISABILITIES



HEALTH CARE

While overall health was fairly good or better for almost two-thirds of those surveyed (64 percent), adults with physical disabilities required frequent medical care, with 50 percent of those surveyed reporting requiring medical care by a trained medical provider once a month or more frequently. The frequency of required medical treatments varied considerably by program. See Figure 4-9.

Figure 4-9. COMPARISON OF THE FREQUENCY OF REQUIRED MEDICAL CARE BY PROGRAM



Individuals in the DAHS program required the least frequent medical care, with only 30 percent requiring care once a month or more. People in the CAS and PHC programs required the most frequent medical care, with 42 percent (CAS) and 55 percent (PHC) of respondents seeing health care providers once a month or more.

ROUTINE AND PREVENTIVE HEALTH CARE

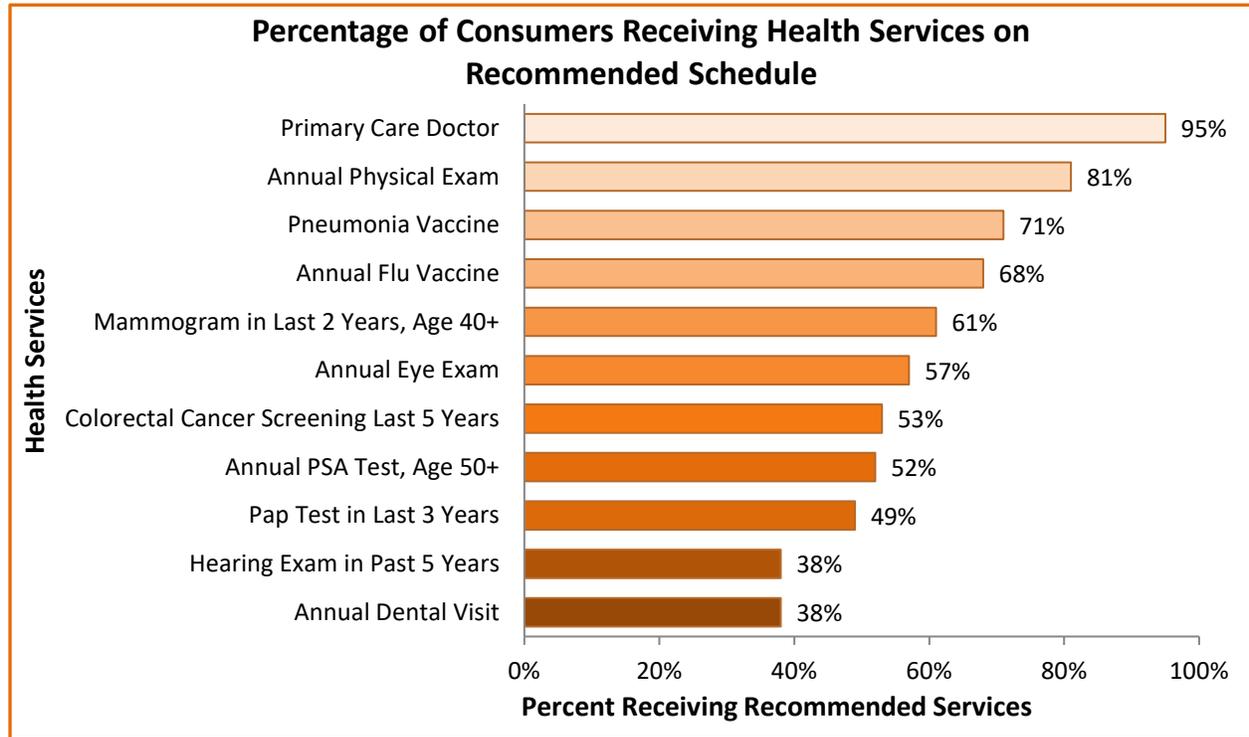
Health and welfare questions were asked in the PES survey of adults with physical disabilities. Most people surveyed had routine care – 95 percent had a primary care doctor and 81 percent had received a physical exam in the past year (see Figure 4-10). At the same time, a high share of respondents were not being monitored for the types of oral, vision, and hearing problems that become more frequent with age. Only 38 percent of respondents had a dental visit in the past year or a hearing exam in the past five years, and 57 percent received an eye exam in the past year.

68% of respondents had an annual flu shot

The proportion of people who received more specialized preventive health care was lower than the rate receiving routine annual physicals. Only 68 percent received a flu vaccination in the past year, and 71% had received a pneumococcal vaccine. Approximately one-third of people surveyed were vulnerable to flu and pneumonia infections that can be life-threatening for people who are aging or have disabilities. Cancer is a major cause of morbidity and death in adults who are older, yet almost half had failed to receive the recommended screening for breast (39 percent), prostate (48 percent), and colorectal cancers (47 percent), all among the top causes of cancer deaths. About 3 out of every 10 adults over age 49 with physical disabilities, 32 percent, had never had a colorectal cancer screening test; 10 percent had never received a mammogram; and 7 percent had never had a PAP examination for cervical cancer.

It should be noted that most of the programs included in the PES do not include routine or preventive health care. While most respondents likely had Medicare and/or Medicaid, responsibility for arranging and obtaining routine health care rests with the individual, not the service provider.

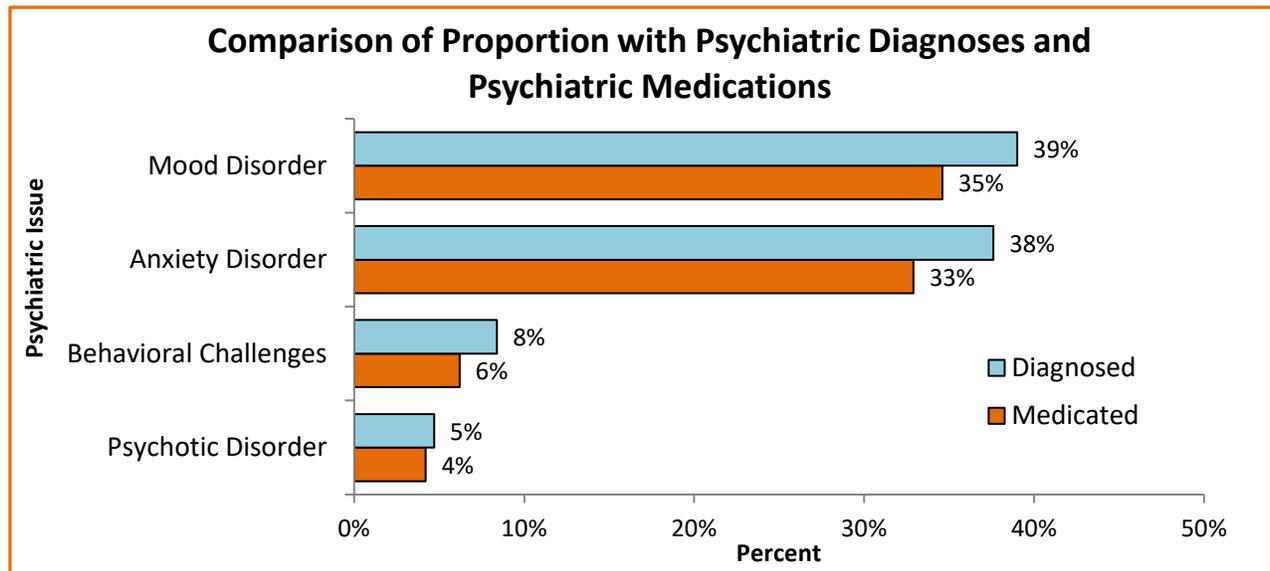
Figure 4-10. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO RECEIVED HEALTH CARE SERVICES



MENTAL AND BEHAVIORAL HEALTH ISSUES

Fifty-two percent (52 percent) of adults with physical disabilities served by DADS in Texas were diagnosed with a mental or behavioral health issue. The most commonly diagnosed psychiatric issues were mood (39 percent) and anxiety disorders (38 percent). The proportion treated for psychiatric issues paralleled the diagnoses (Figure 4-11), with 35 percent taking medication for treatment of a mood disorder, and 33 percent for anxiety disorders. Behavioral challenges (6 percent), and psychotic disorders (4 percent) were also treated.

Figure 4-11. ADULTS WITH PHYSICAL DISABILITIES TREATED FOR MENTAL ILLNESS BY TYPE OF MENTAL ILLNESS

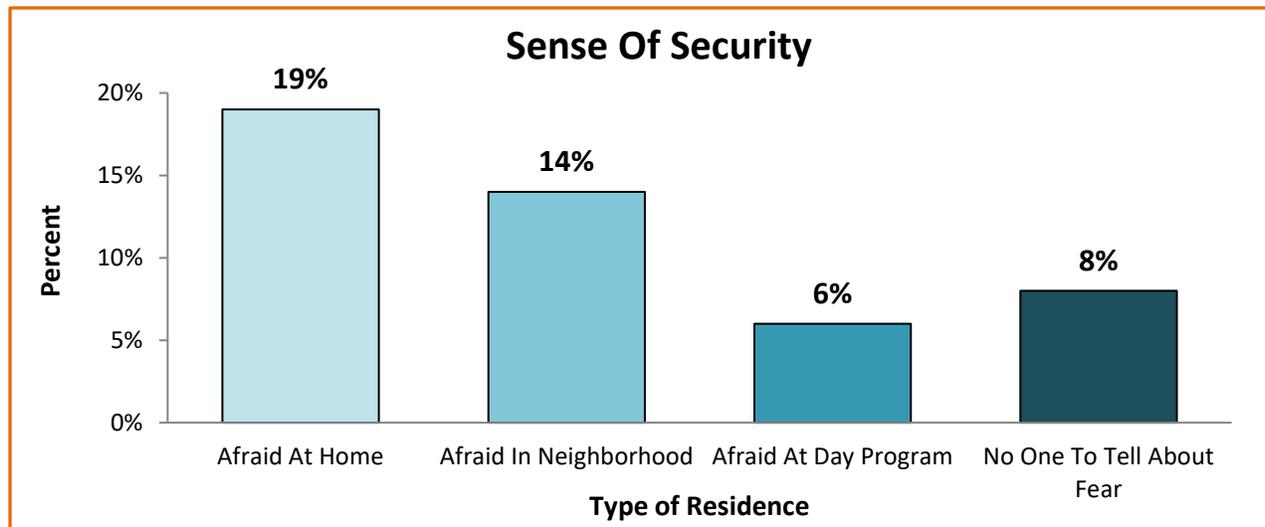


SAFETY AND SECURITY

Feeling secure is an important measure of wellbeing and welfare and is of special importance to this vulnerable older population. For this reason, the survey of adults with physical disabilities contains several questions about being scared. Because the respondents reside in a variety of residential settings and participate in a number of different programs, they were asked whether they are scared at home, in their neighborhood, and in their day programs.

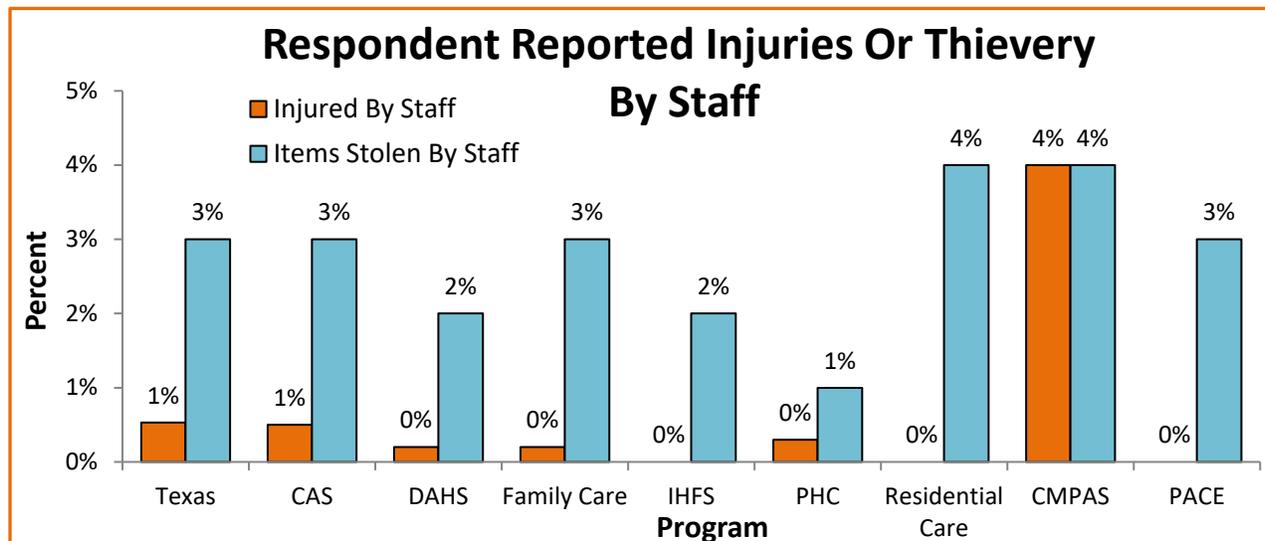
The majority reported that they were not scared at home (81 percent); 86 percent of PES respondents said they were not afraid in their neighborhoods; and, of those who participated in a day program, 94 percent reported that they were not scared there (Figure 4-12). The survey also asked whether the respondent had someone to talk to if they are afraid, and 92 percent of PES respondents said that they did. By report, the majority had a sense of security.

Figure 4-12. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO REPORTED THEY WERE AFRAID



The PES survey probes further into safety by asking questions about staff abuse. Figure 4-13 shows the statistics for staff-inflicted injuries and theft during the twelve months prior to the survey.

Figure 4-13. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO REPORTED INJURY OR THEFT BY STAFF

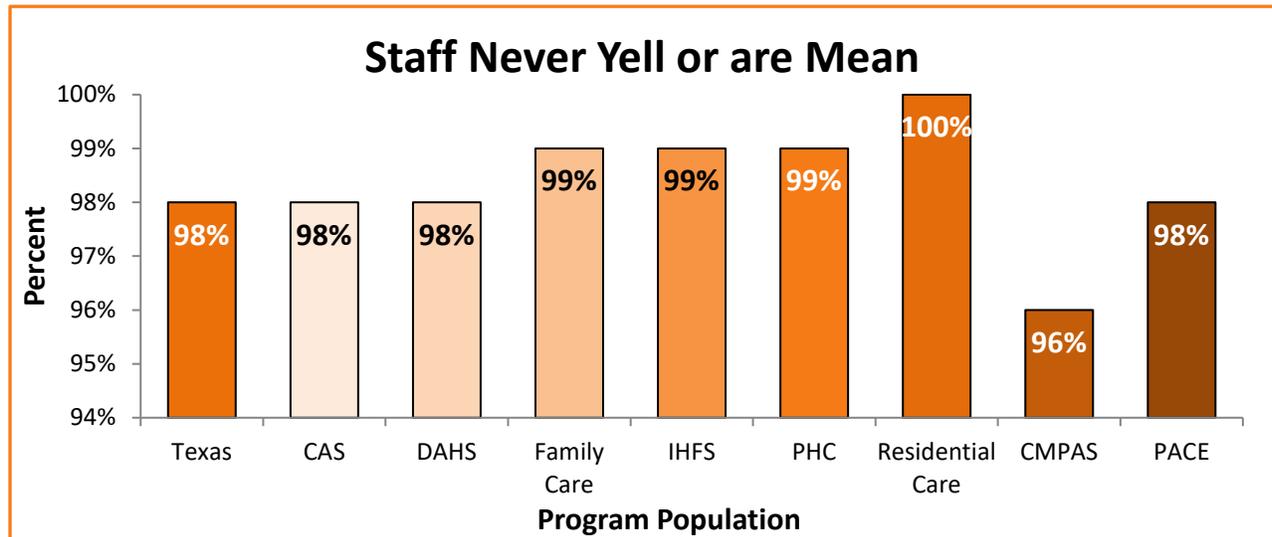


Fortunately, injury or thievery by staff occurred rarely. Thirteen people out of 2,669 reported injuries. Three of the programs reported no injuries (IHFS, Residential Care, and PACE), and of those that did report injuries, the highest reported rate was four percent (4 percent) in CMPAS. Most of the reported injuries were accidental, minor bruises from being gripped or held to prevent a fall, for example.

Thievery did occur in all eight of the programs, again rarely, with four percent (4 percent) or less of the respondents in all programs reporting thievery. Reading the written explanations corresponding to the reports, the thefts were for small items, like watches, or for small amounts of money.

Those surveyed were also asked if the staff ever yelled at them or were mean to them. Figure 4-14 shows the results of this question. With the exception of the CMPAS program, 98 percent or more of the respondents reported that the staff never yell at them or are mean. Reading respondents reports on yelling, it quickly became clear that the issue was primarily family members hired as staff. Occasionally other staff displayed some temper or attitude, but the offenders were primarily family

Figure 4-14. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO REPORTED STAFF YELLING OR MEANNESS



CHOICE AND PRIVACY

Findings:

- Many adults felt like they could make decisions about taking risks (65 percent) and helping other people (40 percent)
- 35 percent did not have control over their transportation
- Most adults with physical disabilities did not use consumer directed services (1 percent)

LIFE CHOICES

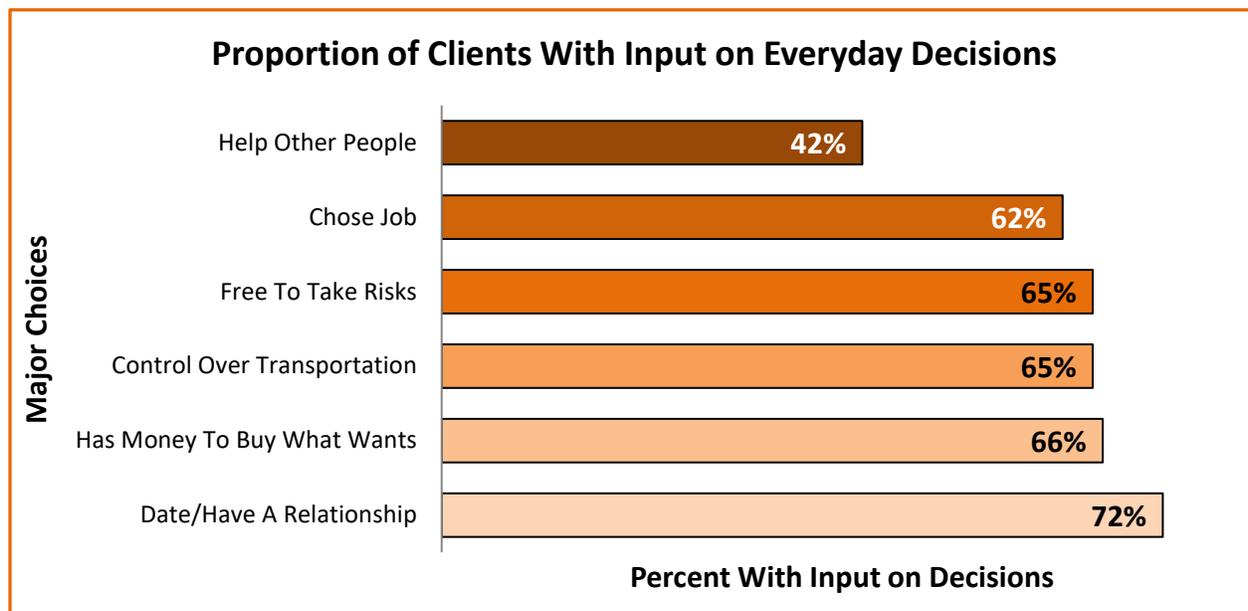
Choice over major life and everyday decisions is a critical component of quality of life and satisfaction with services and supports. Choice has less emphasis in the PES survey compared to the NCI Adult Consumer survey, as the majority of the adults with physical disabilities, 74 percent, do

not have guardians and make their own decisions and choices.

LIFE CHOICES: LIFESTYLE

A high proportion of people with physical disabilities reported having input into everyday decisions, such as whether to date or have a relationship (72 percent), and whether to take a risk (65 percent) (Figure 4-15).

Figure 4-15. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO HAVE INPUT INTO EVERYDAY DECISIONS



Of note is the percentage who reported control over transportation (65 percent). Control over transportation is very important, as a significant number of adults with physical disabilities require frequent medical care; 36 percent require monthly or more frequent care, and an additional 14 percent require weekly medical care. The ability to get where they need to go when they need to go is a major factor in satisfaction with services.

SERVICE CHOICES

Consumer-directed supports (CDS), where the consumer directs their services and supports, as previously discussed, is an option offered in a number of the waiver programs, but rarely in programs for the physically disabled.

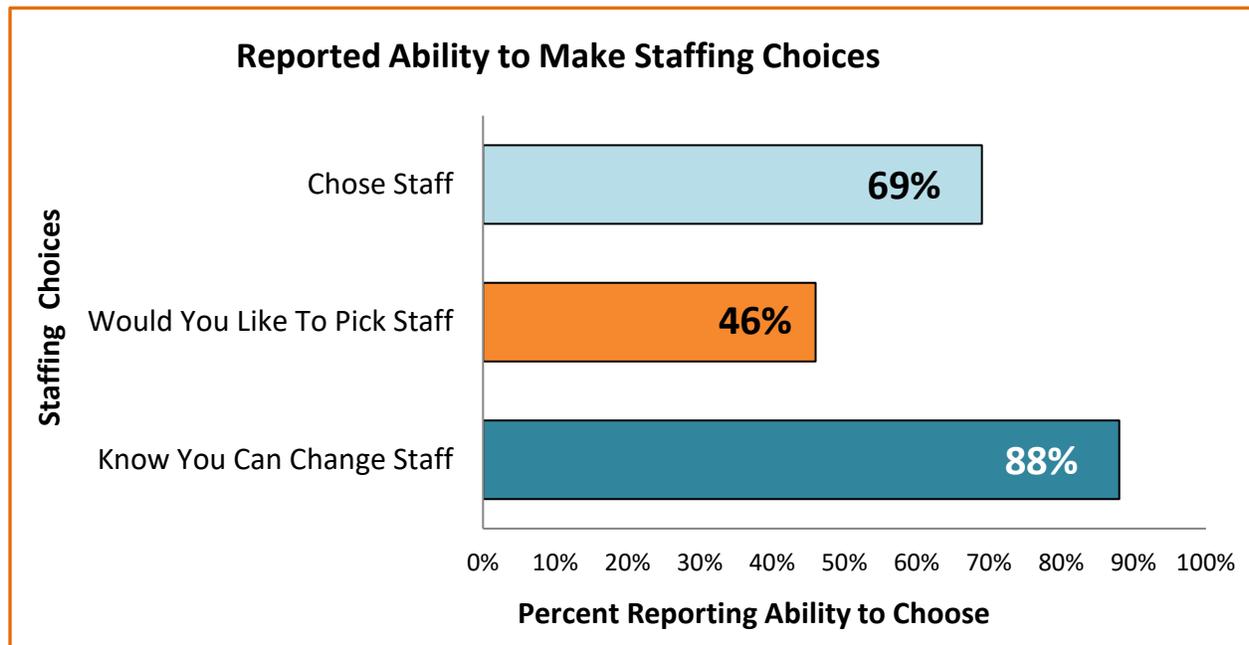
SERVICE CHOICES: SELF DIRECTION

With the Community-Based Alternatives program moving to Health and Human Services, only 1 percent of the adults with physical disabilities used the CDS option. While not using the CDS option, the majority of PES respondents reported that they made most of their own decisions. DADS policy encourages consumers to exercise choice where appropriate to increase their satisfaction and autonomy.

SERVICE CHOICES: PROVIDERS AND STAFF

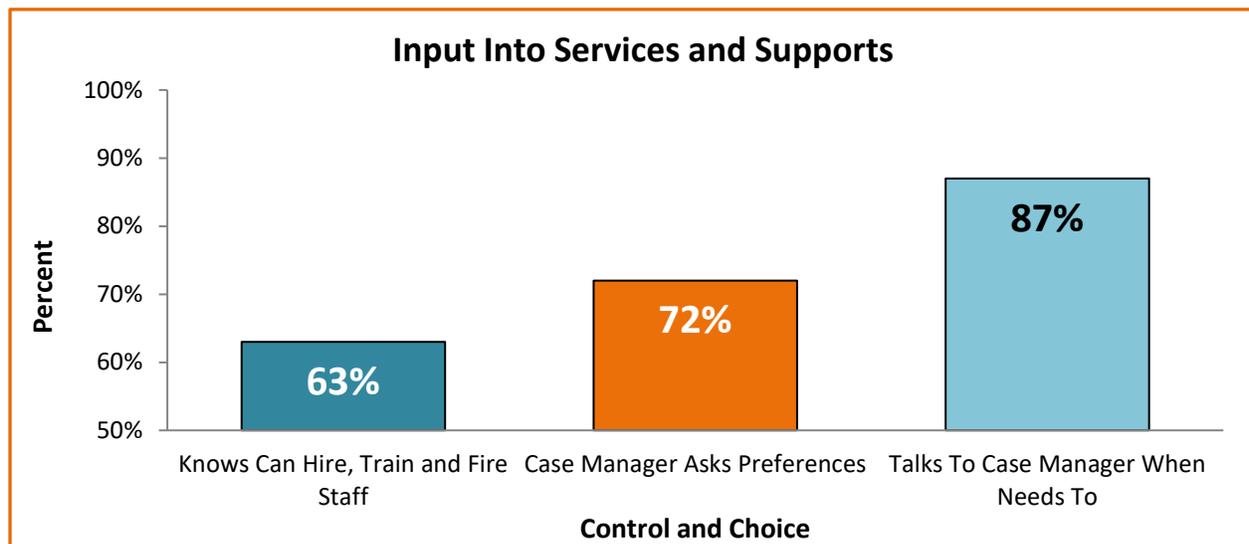
Adults with physical disabilities had input into choosing their support staff (69 percent). Eighty-eight percent (88 percent) reported that they knew they could make changes to their staff and services (Figure 4-16). Less than half (46 percent) reported that they would like to pick their staff.

Figure 4-16. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO HAVE INPUT INTO STAFFING CHOICES



Most of these older consumers also had input into their services and supports (Figure 4-17). In addition to knowing that they could make changes to their staff, they reported that their case managers asked them about their preferences (72 percent), and that they talked to their case managers when they needed something or wanted to express an opinion (87 percent).

Figure 4-17. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES WHO HAVE INPUT INTO SERVICES AND SUPPORTS



PRIVACY

Privacy, as with choice, is not as significant an issue with adults with physical disabilities compared to those with ID. More than half of the respondents lived in their own homes or apartments. The PES survey does include one privacy question about controlling who came into their homes. More than three-quarters of the adults with physical disabilities (87 percent) reported that they controlled who entered their homes.

COMMUNITY INCLUSION

Findings

- 31 percent expressed the desire to do things outside their home
- While only 1 percent worked, 31 percent said they wanted to work

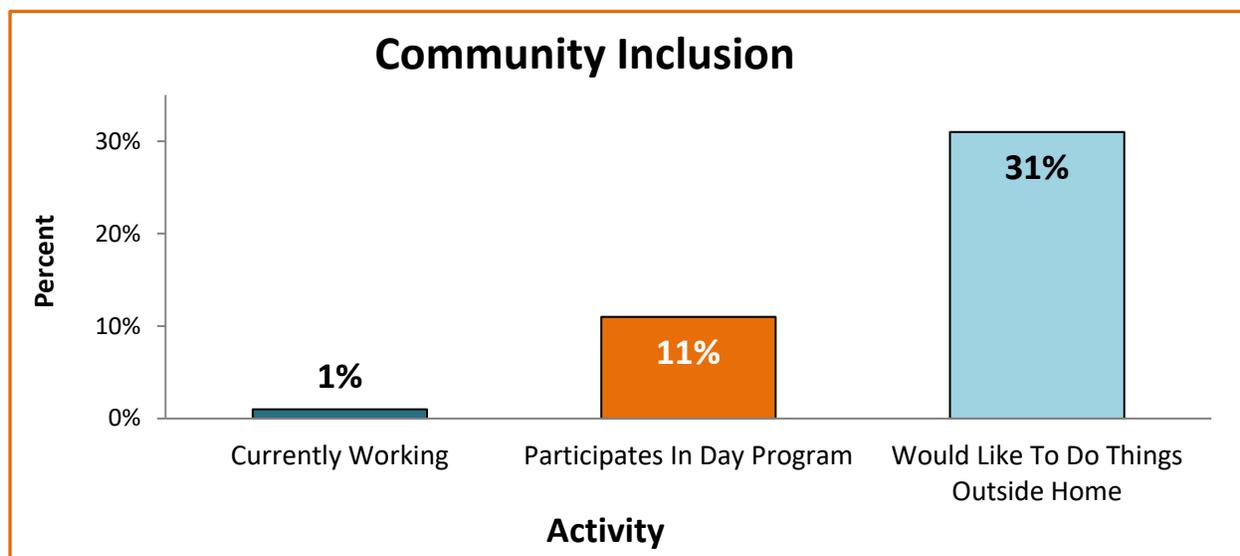
EMPLOYMENT

As the majority of those surveyed were over retirement age, the percentage of those still working was quite low. Only one percent (1 percent) reported that they had a job in the community. Almost one-third of the respondents (31 percent) indicated that they would like to have a job. Employment-related services are not usually part of the programs covered by the PES.

COMMUNITY PARTICIPATION

The NCI Adult Consumer survey places significant emphasis on community participation. The PES survey contains many less questions about community inclusion, as while a worthy topic, this is not a goal in DADS strategic plan for adults with physical disabilities. Community inclusion can be a significant problem for adults with physical disabilities as they have transportation, mobility, and health issues (discussed above) that can isolate them. As shown in Figure 4-18, 31 percent of those surveyed reported that they would like to do things outside of their home. Only 11 percent participated in a day program, and only 1 percent worked in the community.

Figure 4-18. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES PARTICIPATING IN COMMUNITY ACTIVITIES



Less than half of the adults with physical disabilities reported that they help other people or do volunteer work (42 percent). Fourteen percent (14 percent) said that they had participated in self-advocacy group events, but 83 percent reported that they did not want to participate in self-advocacy events.

SYSTEM PERFORMANCE

Findings

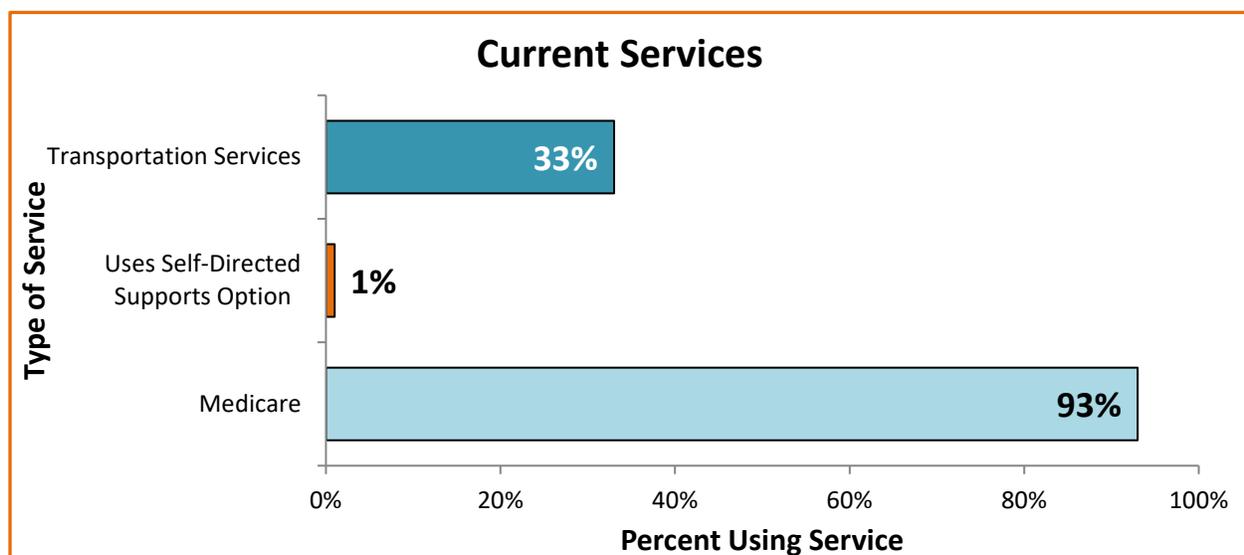
- 82 percent reported that they had enough information about available services
- The DADS website (9 percent) and advocacy organizations (3 percent) did not contribute significantly to consumers' information about services received
- 34 percent of adults with physical disabilities said that they had requested additional services, equipment, or household modifications
- Adults with physical disabilities reported that they were treated respectfully by their support staff

The primary purpose of the LTSS survey is to measure consumer satisfaction with DADS services and supports. A key component of satisfaction is system performance, and two key measures of system performance are delivery of and access to services. If clients do not have access to services and equipment that they need, or they do not receive the services or supports promised, they are not going to be satisfied. The quality of services access is measured here by availability of information about services and participation in service planning, amount of reported unmet need, and receipt of requested services and supports.

CURRENT SERVICES

Information about the type of services consumers were receiving was collected in the survey (Figure 4-19). Most of the adults with physical disabilities receive Medicare (93 percent). Thirty-three percent (33 percent) receive transportation services, where someone arranges or provides transportation for the client. Only one percent (1 percent) used the self-directed supports option.

Figure 4-19. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES RECEIVING SPECIFIED SERVICES

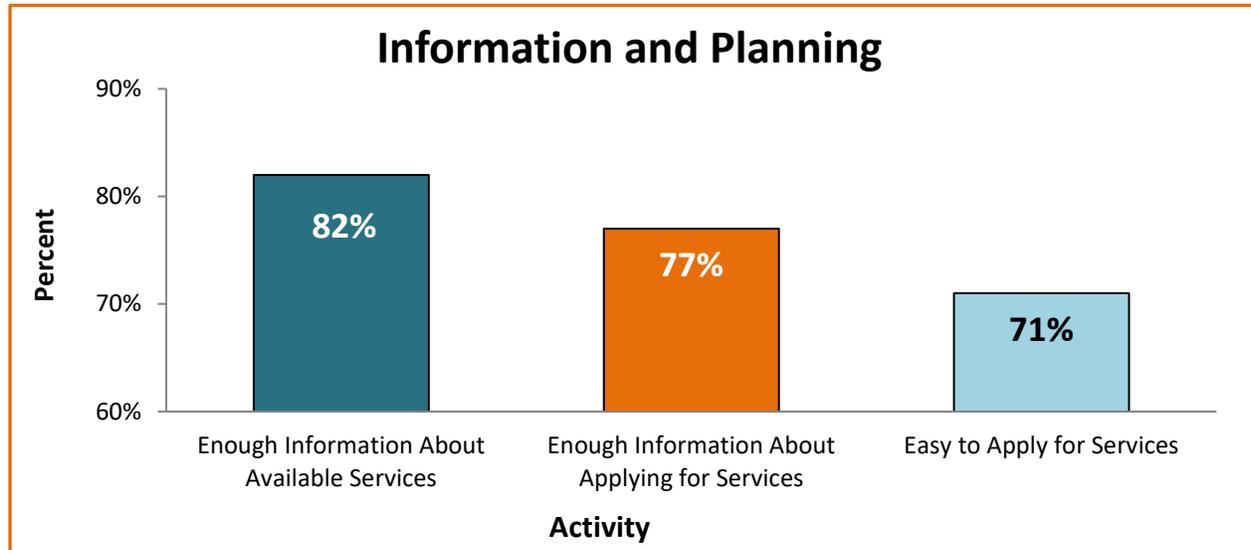


INFORMATION AND PLANNING

Information about services and consumer participation in service and supports planning are important access issues (Figure 4-20). More than three-quarters of the respondents (82 percent)

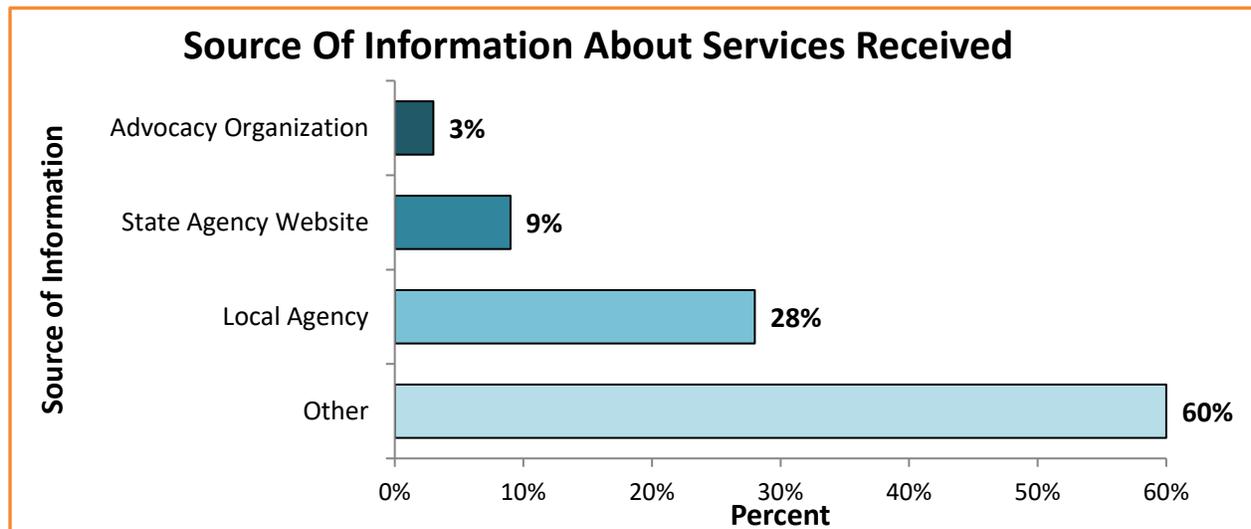
reported that they had enough information about available services. Most reported that they had enough information about applying for services (77 percent). Slightly less (71 percent), however, reported that it was easy to apply for services.

Figure 4-20. ACCESS TO INFORMATION ABOUT SERVICES AND SUPPORTS



The PES survey included a question about how clients found out about the services they received (Figure 4-21). The question provided several response options including “Other.” Just over one-quarter (28 percent) said that they had found out about their services through a local agency. Sixty percent (60 percent) selected “Other, please specify.” The text responses revealed that several other choices should be added to the response options, as a significant number of the respondents reported that they found out about their services from churches; family, friends, and neighbors; and medical providers, including hospitals and social workers.

Figure 4-21. SOURCE OF INFORMATION ABOUT SERVICES AND SUPPORTS

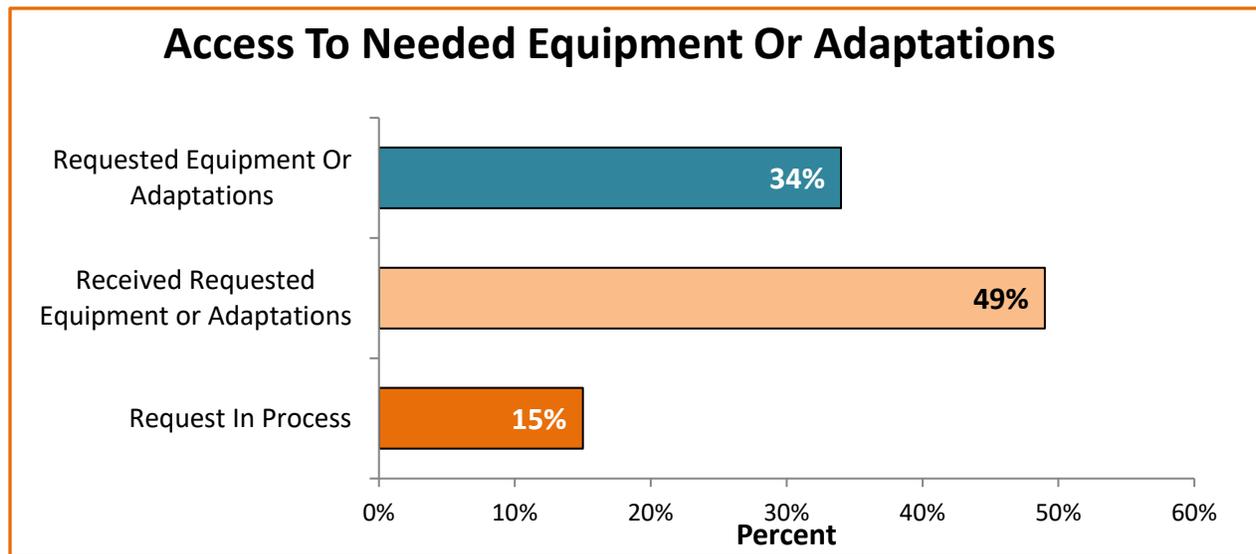


The DADS website and advocacy organizations did not contribute significantly to consumers’ information about services received.

ACCESS TO SERVICES AND SUPPORTS

The geographic distances encompassed by Texas are access and delivery challenges. Yet, 84 percent of adults with physical disabilities reported that their services and supports are within a reasonable distance of home. Also 84 percent reported that their services and supports were available when they needed them. While services and supports were available when needed and within a reasonable distance from home, more than one-third (34 percent) of adults with physical disabilities said that they had requested additional services, equipment, or household modifications from their case manager. Almost two out of every three of those requesting additional services (64 percent) reported that they had received their requests or the request was in process (Figure 4-22).

Figure 4-22. REPORTED SERVICE NEEDS OF ADULTS WITH PHYSICAL DISABILITIES



The most commonly tendered requests were for equipment or adaptations like bathroom modifications (grab bars, roll-in showers, toilet lifts, etc.), ramps for access to their homes, minor household modifications (rails, door widening, flooring changes), and ambulatory aids such as wheelchairs, walkers, and canes. Sixteen percent (16 percent) of the requests were for help with health care equipment, therapies, supplies, or access, and 6 percent of the requests were for additional provider assistance with activities of daily living such as bathing, housework, and physical assistance going to and from the doctors. A new request this survey period was for personal emergency assistance buttons, with 2 percent of respondents asking for emergency assistance buttons. Transportation assistance, assistance with medications, dental care, nutritional assistance, and assistance with air conditioning and heating were each requested by 1 percent of respondents.

ACCESS TO TRANSPORTATION

Thirty-four percent (34 percent) of adults with physical disabilities reported that they did not have control over their transportation.

DELIVERY OF SERVICES AND SUPPORTS

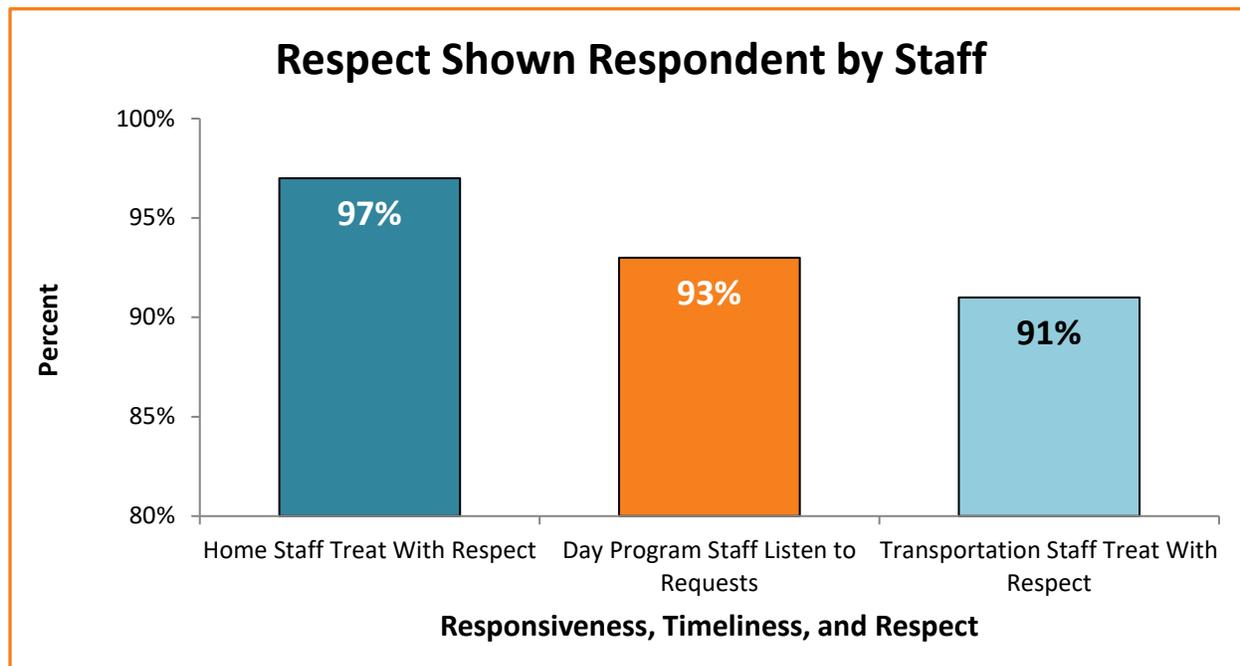
RESPECT

The manner in which services are delivered is a very important factor in customer satisfaction.

Across programs, the majority of individuals reported that their support staff treats them with respect and dignity.

The majority of people surveyed reported that their services and supports were delivered by staff that were respectful of them (Figure 4-23). The PES survey contained several respect questions specifically targeted at the type of staff delivering the services. Adults with physical disabilities reported that they were treated respectfully by their home staff (97 percent); the staff in their day programs (93 percent); and the transportation staff that assisted their getting to and from their destinations (91 percent).

Figure 4-23. PROPORTION OF ADULTS WITH PHYSICAL DISABILITIES SHOWN RESPECT BY TYPE OF STAFF



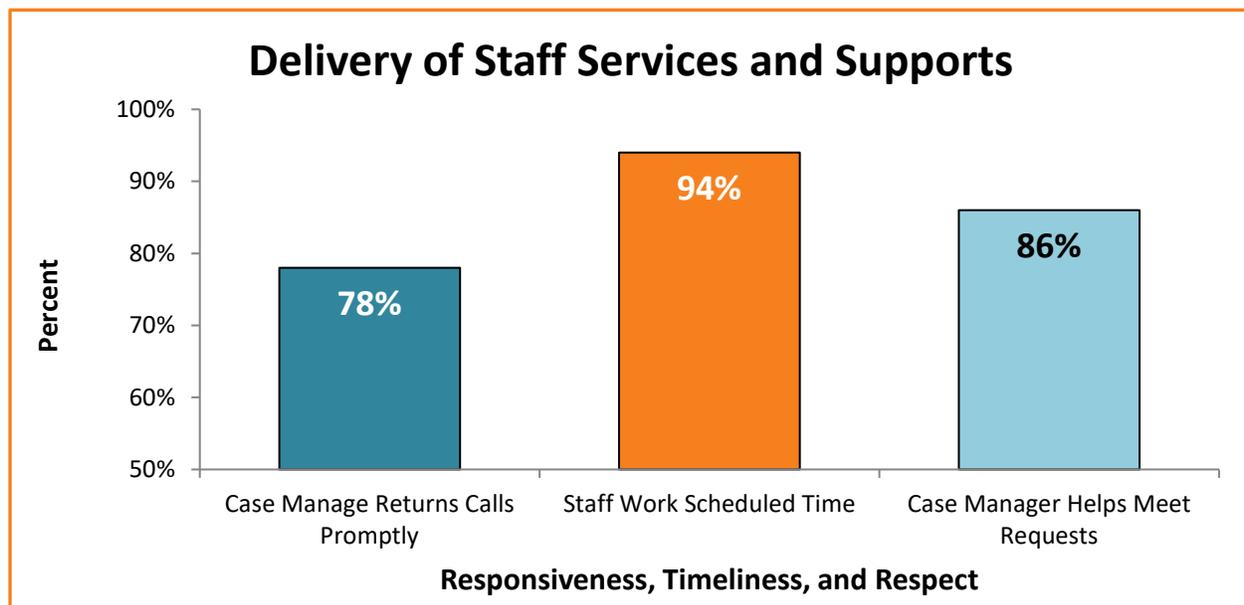
Many respondents said nice things about the dedication and caring attitudes of their support staff in the comments section of the survey.

RESPONSIVENESS

Figure 4-24 below shows three critical service delivery issues: responsiveness, timeliness, and appropriateness. The responses are positive for all three measures.

Responsiveness was measured by case managers responding promptly when called. PES respondents reported that their case managers called them back right away 78 percent of the time. Timeliness, as measured by support staff arriving on time and when scheduled, was excellent, with 94 percent of adults with physical disabilities reporting that their support staff put in the time they were supposed to work. The appropriateness measure, as assessed by assistance from their case manager in meeting needs, was also positive, with 86 percent of adults with physical disabilities reporting that their case managers try to meet requests.

Figure 4-24. RESPONSIVENESS, TIMELINESS, AND APPROPRIATENESS OF STAFF SERVICES AND SUPPORTS



SERVICES SATISFACTION

Findings

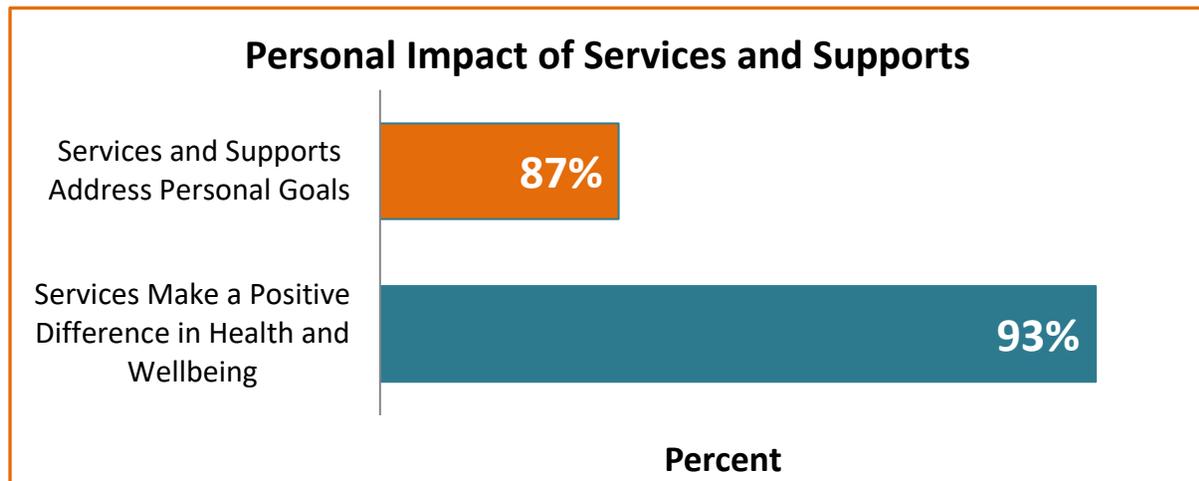
- 93 percent of adults with physical disabilities reported that services and supports made a positive difference in their health and wellbeing
- Overall, 91 percent of adults with physical disabilities reported that they were satisfied with the services and supports they receive

The information presented above can be used to create a picture of the level of needs and satisfaction of adults with physical disabilities served by DADS. The survey does not force the reader to create their own overall services satisfaction summary, however, it asks several specific questions about how well individual goals and health and wellbeing needs were met.

OUTCOMES

The vast majority of respondents felt services and supports made a positive difference for them or their family member (Figure 4-25). Adults with physical disabilities reported that the services and supports provided by DADS made a positive difference in their health and wellbeing (93 percent). DADS services and supports also addressed the personal goals of the consumers in most cases (87 percent). Overall, 91 percent of respondents reported that they were always or usually satisfied with the services and supports they received.

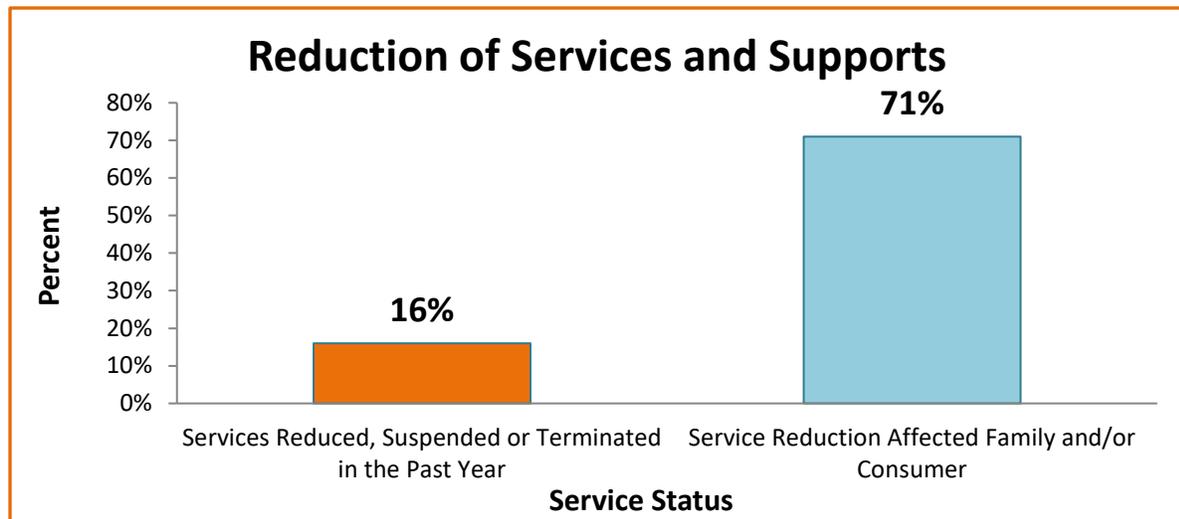
Figure 4-25. SERVICES AND SUPPORTS MAKE A POSITIVE DIFFERENCE FOR ADULTS WITH PHYSICAL DISABILITIES



REDUCTION OF SERVICES AND SUPPORTS

The positive response to services and supports occurred even as services and supports were reduced for some people. As illustrated in Figure 4-26 below, approximately 16 percent of respondents reported that their services had been reduced, suspended, or terminated in the past year. Of the respondents whose services were reduced in the past year, 71 percent said the reduction negatively affected their life.

Figure 4-2. COMPARISON OF SERVICE REDUCTIONS AND THEIR IMPACT ON CHILDREN'S FAMILIES, TEXAS AND US



All of the responses for the PES survey, by program, can be seen in Appendix E.

CHAPTER 6: METHODS

DATA COLLECTION

DADS contracted with an external vendor, the Public Policy Research Institute at Texas A&M University (PPRI), to administer the surveys. PPRI hired and supervised the interviewers, who participated in a standardized training program. The face-to-face interviewers were special education teachers and social workers, all disinterested third parties, experienced in working with older individuals or people who have disabilities. Interviews with adults with IDD and some adults with physical disabilities took place in the individual's home unless he or she chose an alternative location.

The majority of interviews with adults with physical disabilities took place over the telephone. Child Family surveys were administered by phone, mail, and web. To prepare for the interviews, PPRI staff obtained pre-survey, background, and day activity information from program providers. The demographic data provided by automated DADS systems included age, gender, ethnicity. DADS interviews a randomly selected, proportional probability for size (PPS) sample of 4,000 to 7,000 individuals biennially.

DATA SOURCES

Three primary data sources were used to create this report. Information about children with disabilities was gathered from their families using the NCI Child/Family Survey (CF). The NCI-Adult Consumer Survey (NCI) gathers information from face-to-face interviews with adults with IDD receiving DADS service and supports. Data on the adult population with physical disabilities, primarily older adults, are gathered using the Participant Experience Survey – Elderly/Disabled (PES).

PROXY RESPONDENTS

While most surveys did not require a proxy, for all survey questions where a proxy was used, proxy respondents were most frequently a parent of the person with a disability. Other respondents included a sibling or other family member. In some cases, a staff person or caretaker completed the proxy-allowed questions in the survey. Some questions could not be answered by proxies.

DATA COLLECTION INSTRUMENTS

This report is developed from three nationally validated survey instruments, which are used for data collection across DADS programs and consumer types. Using nationally recognized surveys allows DADS to share data nationally and to conduct additional analyses by benchmarking Texas' performance in the

national arena.

LTSS Created From 3 Surveys:

- NCI Adult Consumer – IDD adults
- PES – Elderly /Disabled
- NCI Child Family – Children with disabilities

NCI ADULT CONSUMER SURVEY

The NCI Adult Consumer survey (referred to as NCI in this report) is administered to DADS adult IDD services and supports recipients. Section I can only be answered by the consumer in a face-to-face interview. The interviewer records the respondent's comprehension and response consistency.

Section II contains questions that can be answered by the consumer or, if needed, by someone who knows the person well, such as a family member, friend, guardian, or advocate.

NCI CHILD FAMILY SURVEY

The NCI Child Family (CF) survey evaluates DADS Medicaid waiver programs serving children with disabilities. Since the majority of these individuals are younger than 21 years, a caregiver is asked to provide information regarding overall experiences with the services and supports received. The surveys are administered by phone, mail, and web.

PARTICIPANT EXPERIENCE SURVEY

To measure the experiences and satisfaction of older adults and adults with physical disabilities, DADS collaborated with Thomson/Reuters (formerly MEDSTAT Group), which developed the PES tool for CMS. The PES captures participant experiences using telephone, face-to-face, and web interviews. Most responses come from the individual, not a proxy.

CORE PERFORMANCE INDICATORS

The three surveys are organized across five general topics or domains: health and welfare, individual choice and respect, community inclusion, systems performance, and services satisfaction – each of which is divided into sub-domains. For example, “employment” is a sub-domain of community inclusion.

The sub-domains are measured by one or more performance indicators, which were developed based upon criteria such as their usefulness as a benchmark and feasibility to collect. The three surveys may be seen in Appendix A.

SAMPLE CHARACTERISTICS

TARGET POPULATION

The sampling goal for the 2017 LTSS report was to interview individuals from all DADS programs, except nursing facility services, which are covered in a separate report. The DADS population was sampled and data collected in 2015 for the 2017 report. The target population for the 2017 LTSS report encompasses three distinct populations: children under age 18 (or under age 22 if still in the school system) with disabilities, adults, age 18 years and older with intellectual and/or developmental disabilities; and adults, primarily older adults, with physical disabilities (Table 5-1). The survey population encompasses 17 programs, including 5 waiver programs (see Table 5-2 below).

Domains and Sub-domains addressed in this report

Health and Welfare

- Routine & preventive healthcare
- Sense of security

Choice and Respect

- Self-direction
- Life choices & decision-making

Community Inclusion

- Participation in community events
- Employment

Systems Performance

- Access to services
- Support delivery

Services Satisfaction

- Information and access
- Overall satisfaction

Table 5-1 provides a brief description of the target population for each survey, the method of survey administration, the total number of clients served by included programs, survey type, and the total number of surveys collected overall.

Table 5-1. OVERVIEW OF TARGET POPULATION BY DATA COLLECTION INSTRUMENT 2013

| Survey | Target Population | Method of Administration | Total # Served | Total # Surveyed |
|----------------------------|---|--------------------------|----------------|------------------|
| NCI Survey | Adults 18 and older with IDD receiving at least one service besides case management | In-person interview | 32,901 | 2,302 |
| PES Survey | Adults, primarily older adults, with physical disabilities | In-person, phone, web | 56,595 | 2,669 |
| Child Family Survey | Families of children with disabilities, under 18 (or under 22 if still in the school system) living at home | Mail, phone, web | 10,356 | 1,913 |

SAMPLE SIZE

The sample size for each program was calculated to obtain a confidence level of 95 percent and a confidence interval of five. The number of people chosen was proportional to the number of people in the selected program served in each county. In 2015, DADS collected 4,971 adult surveys (2,302 adults with IDD and 2,669 older adults with physical disabilities highlighted in Table 1 above) and 1,913 CF surveys.

6,884
Consumers interviewed for the **Long Term Services and Supports Quality Review 2017**

SAMPLING PERIOD

Questionnaires for the 2017 LTSS reports were completed between January 2015 and August 2015. Data has been collected from individuals enrolled in DADS programs since 2005. While not every program has been surveyed every year, programs have been surveyed multiple years to allow for trend analyses. Table 5-2, below, shows specific DADS programs’ survey status by year and type of data collection instrument used for each program since 2005.

SAMPLE SELECTION METHOD

Proportional probability for size (PPS) sampling was used to select the study sample. Representative samples were drawn from each program so that findings could be generalized to all individuals in a specific program. The target population was stratified by county and program to ensure geographic diversity. The number of people chosen was proportional to the number of people in the selected program served in each county. Participants were then randomly chosen from people in each stratum who had service authorizations for the programs included in the survey.

In addition to sampling by program, the 2015 LTSS survey focused on the CDS option. Because sampling stratified by county and program and by CDS was cost-prohibitive (the required sample size would have been very large), DADS ensured an adequate sample to compare people who used the CDS option to those who did not across all programs.

Table 5-2. PROGRAMS SURVEYED BY TOOL AND YEAR DATA WAS COLLECTED

| Program | Survey Tool | Year Surveyed | | | | | | | |
|---|-------------|---------------|------|------|------|------|------|------|------|
| | | 2005 | 2006 | 2007 | 2008 | 2009 | 2011 | 2013 | 2015 |
| CLASS - Community Living Assistance and Support Services Waiver | NCI | ✓ | ✓ | | ✓ | ✓ | | ✓ | ✓ |
| HCS – Home and Community-based Services Waiver | NCI | ✓ | ✓ | ✓ | | ✓ | | ✓ | ✓ |
| TxHmL - Texas Home Living Waiver | NCI | ✓ | ✓ | | | ✓ | | ✓ | ✓ |
| DBMD – Deaf Blind with Multiple Disabilities Waiver | NCI | ✓ | ✓ | | | ✓ | | ✓ | ✓ |
| CWP – Consolidated Waiver Program | NCI | ✓ | ✓ | | | ✓ | | NA | NA |
| ICF/IDD – Intermediate Care Facility | NCI | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ | ✓ |
| SSLC – State Supported Living Centers | NCI | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| CBA – Community Based Alternatives Waiver | PES | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ | NA |
| CAS – Community Attendant Services | PES | | | ✓ | | | ✓ | ✓ | ✓ |
| CMPAS – Consumer Managed Personal Attendant Services | PES | | | | | | ✓ | ✓ | ✓ |
| PHC – Primary Home Care | PES | | | | | | ✓ | ✓ | ✓ |
| AFC – Adult Foster Care | PES | | | ✓ | | | ✓ | | |
| Family Care | PES | | | ✓ | | | ✓ | ✓ | ✓ |
| PACE – Programs of All-Inclusive Care for the Elderly | PES | | | | | | ✓ | ✓ | ✓ |
| Residential Care | PES | | | | | | ✓ | ✓ | ✓ |
| SSPD – Special Services to Persons with Disabilities | PES | | | | | | ✓ | ✓ | ✓ |
| SSPD SAC-SSPD with 24-hour Shared Attendant Care | PES | | | | | | ✓ | ✓ | ✓ |
| DAHS – Day Activity and Health Services | PES | | | | | | | ✓ | ✓ |
| General Revenue | PES | | | | ✓ | | ✓ | NA | NA |
| IHFS – In-Home Family Support | PES | | | | | | | ✓ | ✓ |
| Children’s Programs | | | | | | | | | |
| CLASS – Community Living Assistance and Support Services Waiver | CF | ✓ | ✓ | | ✓ | | ✓ | ✓ | ✓ |
| HCS – Home and Community-based Services Waiver | CF | ✓ | ✓ | | ✓ | | ✓ | ✓ | ✓ |
| TxHmL – Texas Home Living Waiver | CF | ✓ | ✓ | | ✓ | | ✓ | ✓ | ✓ |
| MDCP – Medically Dependent Children Program Waiver | CF | ✓ | ✓ | | ✓ | | ✓ | ✓ | ✓ |
| CWP – Consolidated Waiver Program | CF | ✓ | ✓ | | ✓ | | | NA | NA |

ANALYSIS

Myth: All people with disabilities are the same, and you can talk about them as one single group.

LTSS data management and analysis are coordinated by DADS’ Center for Policy and Innovation (CPI). Data are presented as percentages in data tables and figures throughout the

report. In addition to percentages, trend information is provided on select variables. Survey responses for NCI Section I were included in the analyses only when the interviewer determined that the individual understood the questions and answered independently or with limited assistance. National benchmarks from HSRI’s NCI reports are presented for comparison when available and relevant.

OVERVIEW OF REPORTS

For 2017, DADS produced two versions of the LTSS Survey Report: a summary report to highlight specific findings, and a detailed report for individuals interested in capturing the wealth of information in the LTSS surveys. A copy of both versions of the 2017 LTSS reports are available at: <http://hhs.texas.gov/sites/hhs/files/ltssqr2017.pdf>.

This report is the LTSS Biennial Detailed Report 2017, featuring data collected in 2015 from a representative sample of Texans receiving DADS services and supports. Sub-domains or quality indicators are described in plain language and accompanying graphs and/or tables. The findings in this report represent a small selection of the entire list of quality indicators. The three surveys may be seen in their entirety in Appendix A. The next chapter summarizes DADS accomplishments and on-going quality improvement activities.

Fact: There is no one thing that can be said about people living with disabilities, they don't all have the same experiences or the same perspective.

CHAPTER 7: ACCOMPLISHMENTS, ACTIVITIES, AND ON-GOING EFFORTS

The results of the surveys were encouraging. Texas met or exceeded national benchmarks for almost all of the benchmark measures for adults with IDD and children with disabilities. When looking at routine and preventive health care, DADS adults with IDD received more health care on recommended schedules than the national average for nine of the ten health care indicators. Five out of the ten health care indicators were statistically significantly higher. Families of children participating in DADS services reported access to health care was very positive.

Over 93% of adults with physical disabilities reported their services and supports addressed their health and well-being.

Participants' quality of life, as measured by self-reported happiness and self-direction of staff, services, and relationships, was quite high. The ability to exercise choice varied greatly among the populations, largely by program, and by type of choices. Families of children exercise the consumer directed services more frequently than adult consumers. Adults with IDD reported the ability to make every day choices, such as how to use their free time or spend money, but less choice with selecting their staff or housing. Among adult and children's programs, a majority of the individuals and families reported that support staff were adequately trained and respectful. In adult programs, the vast majority of people were supported in their activities of daily living and have the services and supports needed to meet most of their personal goals.

LTSS data is integral for evaluating existing programs and planning for future initiatives to support the mission of DADS.

While most people received the services and supports they needed, the results also highlight opportunities for improvement. Transportation was consistently reported as a barrier. Individuals from all programs reported lack of control over and access to transportation when they needed it. Limited transportation reduces opportunities for people to engage in many activities within the community, to work or readily access preventive health care. Not surprisingly, transportation difficulties correlated

highly with lower levels of community involvement and participation in integrated activity settings.

Overall, the CF, NCI, and PES Surveys present important information, identified many positive outcomes, and some opportunities for improvement. The following presents a sample of these findings.

IMPORTANT POPULATION CHARACTERISTICS

CHILDREN

Most Texas children with intellectual disabilities reported multiple conditions in addition to intellectual disabilities. One out of four of the children (25 percent) had a mental health or behavioral disorder diagnosis. Texas children with disabilities required significantly more medical care by a trained medical provider at least once a week (27 percent), compared to 11 percent nationally. Families of children with disabilities requested trained respite care providers, increased access to therapy services (speech, occupational, aqua, equine, etc.), shorter waiting lists for waiver programs like CLASS, and more help with creating transition plans as their children age out of certain services.

ADULTS WITH IDD

Adults with IDD reported very good or excellent health (62 percent). The percentage of adults with severe or profound intellectual disability was significantly higher in Texas (33 percent) compared to the national average (24 percent). While lower than the national average (52 percent), 44 percent of Texas adults with IDD had psychiatric diagnoses. One out of every eight adults with IDD were non-ambulatory. Among adults with IDD, levels of impairment, and the need for medical care varied widely by program - highlighting the need to look at program-specific data when creating policy.

ADULTS WITH PHYSICAL DISABILITIES

More than one third (37 percent) of adults with physical disabilities reported their health was poor; 14 percent required weekly or more frequent treatment by a medical provider. Health habits were problematic: 19 percent of adults with physical disabilities use tobacco products, 48 percent were obese, and only 35 percent participated routinely in moderate exercise. One out of every ten adults with physical disabilities was non-ambulatory. Among adults with physical disabilities, the survey underscored the importance of non-technical help with ADLs and IADLs—for people with disabilities living in the community, help with bathing or laundry, for example, is essential.

POSITIVE OUTCOMES:

CHILDREN -

- Respondents give system performance good marks.
 - Seventy-five percent of the families of children with disabilities reported that services were available when they needed them.
 - Almost three-quarters (71 percent) of the CF survey respondents reported flexible services and supports, which usually changed to meet their family member's changing needs.
 - Moreover, 72 percent of the families of children with disabilities reported that their services and supports were always or usually reasonably close to home. Thirty-nine percent (39 percent) said the services were always close to home, compared to 37 percent nationally. Considering the geographic distances in Texas, this is an accomplishment.
- Two out of 4 health care satisfaction measures were better than the national average; all 4 reported above 94 percent satisfied. Access to dental providers trained and willing to treat children with disabilities has improved steadily since 2005, rising from 89 percent in 2005 to 96 percent in 2015.
- Integration into the community was good, with 85 percent of children with disabilities participating in community activities and 86 percent having friends who did not have a disability.
- Significantly more Texas families knew how to report abuse and neglect (85 percent), compared to 73 percent of families nationally. Knowledge of how to report grievances against staff was also significantly higher in Texas (72 percent), than the 52 percent reported nationally.

- Choice in staffing was high. More than three-quarters of families reported being able to choose their provider agency and 78 percent of families reported having control over hiring and management of support workers.
- Overall, 82 percent of families served reported that they were always or usually satisfied with their services and supports, up from 61 percent in 2005 and higher than the national average of 77 percent.

ADULTS WITH IDD -

- Texas adults with IDD met or exceeded 8 out of 10 routine and preventive health care measures, receiving significantly more routine and preventive health care than reported nationally on 5 out of 10 health care indicators. Adults with IDD living in an SSLC, or community-based group home, received higher rates of routine and preventive care than those living with family. Almost all (98 percent) of adults with IDD had primary health care providers.
- Most adults with IDD made everyday choices, such as how they spend their free time (85 percent) and what to buy with their spending money (79 percent).
- The majority of adults with IDD participated in the community. Many adults with IDD had close relationships and friends other than family and staff. Eighty-five percent (85 percent) of the adults with IDD reported that they were happy.
- Individuals reported overwhelming satisfaction with their residence (91 percent), jobs, and day programs (92 percent and 88 percent, respectively). Adults with IDD reported that they were treated respectfully by their support staff (92 percent).
- Ninety-three percent (92 percent) adults with IDD reported that services and supports made a positive difference in their health and wellbeing.

ADULTS WITH PHYSICAL DISABILITIES

- The top three most common health conditions; high blood pressure; high cholesterol; and psychiatric issues (primarily anxiety and mood disorders); are very treatable.
- The majority of individuals reported that their rights are respected, they are treated respectfully by their support staff, they are satisfied with their privacy, they feel safe in their homes and neighborhoods, and they know how to report abuse or problems.
- Adults with physical disabilities had input into choosing their support staff. Most knew that they could change their staff (88 percent) and 87 percent said that they could talk to their case manager when they needed assistance or had needs. The vast majority of individuals across programs said their service coordinators help them get what they want and need.
- Services and supports made a positive difference in adults with physical disabilities' health and wellbeing (93 percent).
- Overall, 91 percent of adults with physical disabilities reported that they were satisfied with the services and supports they receive.

OF SPECIAL NOTE

- Among adults with IDD and adults with physical disabilities, the use of psychoactive drugs without a corresponding psychiatric diagnosis decreased significantly between 2013 and 2015.
- Services and supports made a positive difference in respondents' lives.

OPPORTUNITIES FOR IMPROVEMENT:

CHILDREN -

- One out of every ten families did not participate in the creation of their service plan (10 percent). The level of family participation in service plan creation was the same as reported in 2005.
- Approximately 1 out of every 8 children with disabilities failed to access needed equipment such as wheelchairs, ramps, or communication devices, and to receive needed services (13 percent). Most frequently requested services were for various therapies (speech, physical, occupational, aqua, equine) and for trained respite care providers. Failure to receive needed equipment, services and supports had been steadily declining since 2005, but increased slightly from 2013.
- In the comments section of the CF survey, the years-long wait for enrollment in programs like CLASS and HCS was a matter of anxiety and hardship for many families.
- Almost one quarter (23 percent) had services reduced, suspended or terminated during this survey cycle, and 80 percent said service reductions had negatively affected their child.

ADULTS WITH IDD

- Individuals living independently or with their families received less routine and preventive health care than those living in community-based homes or institutional settings on every health measure. Routine and preventive health care examinations are critical to avoiding or ameliorating conditions affecting quality of life, morbidity, or mortality, and their associated costs.
- Less than half of the respondents made major life decisions about where they live, who they lived with, and the staff who supported them. Most adults with IDD did not have options about where they lived. Individuals in community-based housing, ICF/IID facilities, and individuals in SSLCs had significantly less options regarding choice of residence compared to other programs.
- Less than half (45 percent) of adults with IDD reported control over their transportation. The rest were dependent upon the decisions and willingness of others to get to their destinations. Texas performed worse on "choice" benchmark measures than the US in all categories, however, keep in mind that the percentage of people with severe and profound ID was significantly higher in Texas, which may have impacted the results.
- Respondents who live in institutional facilities (ICFs and SSLCs) were much more likely to report that they were lonely.

- Texas rates of community participation were lower than the national average. Only 1 out of ten adults with IDD had community-based jobs.
- One out of 10 people reported they did not receive all the services they needed. Education and training, assistance with transportation, and assistance with finding a job are highly correlated services and were among the top four services requested.

ADULTS WITH PHYSICAL DISABILITIES -

- Adults with physical disabilities said that they were unable to accomplish activities of daily living and instrumental activities of daily living because no one was there to help them, at discouragingly high rates.
 - People reported they missed meals because there was no one there to help them eat (11 percent) or cook their meals (11 percent); 23 percent did not get groceries.
 - One out of every six people (16 percent) reported there were times they did not get out of or into bed or take a bath because they had no help; one out of every four (25 percent) reported failing to get to the bathroom.
 - Eleven percent skipped taking medications because they did not have the help they needed. One of the primary service requests was for additional provider assistance, especially on weekends.
- Almost one out of every five adults with physical disabilities (19 percent) had not had an annual physical examination.
- About a third of adults with physical disabilities are lacking important influenza immunizations (32 percent). Since individuals in this group have significant health risks, lack of immunization could place the unimmunized at significant risk.
- In adults with physical disabilities, large percentages had not had recent dental (62 percent), hearing (62 percent), or vision (43 percent) examinations. Poor dental care can compromise overall health, and vision and hearing impairment become increasingly common with age. These individuals are at risk of further debility and disability as a result not receiving routine health care screening.
- Cancer screening rates on recommended schedules was poor. Approximately half had received cancer screening for breast, cervical, prostate, and colorectal cancer. People age 50 and older are at increased risk of cancer.
- While rates of physical injuries or thievery by staff were very low (less than 1 percent and 3 percent, respectively), any injuries or thievery are unacceptable.
- More than one-third (35 percent) did not have control over their transportation, a critical issue for accessing medical care and for community inclusion.
- The DADS website (9 percent) and advocacy organizations (3 percent) did not contribute significantly to consumers' information about services received.
- About one out of every nine (12 percent) adults with physical disabilities had unmet needs. Thirty-four percent (34 percent) of adults with physical disabilities requested additional services, equipment, or household modifications, and 64 percent received or were in the process of receiving their requests. The most commonly tendered requests were for

equipment or adaptations like grab bars, roll-in showers, door widening, etc., ramps, and ambulatory aids such as walkers, and wheelchairs. But 16 percent of the requests were for help with healthcare equipment, therapies, or supplies, and 6 percent of the requests were for additional provider assistance with ADLs, IADLs, and going to and from the doctors.

- Almost one out of every six adults with physical disabilities (16 percent) had services reduced, suspended or terminated during this survey cycle, and 71 percent said service reductions had negatively affected their lives.

SUMMARY

Overall, the survey results indicate that people are receiving the services and supports they need to maintain their health and wellbeing. Participants' health and welfare appear to be protected as reports of staff disrespect, neglect, or abuse are very low, and people are generally satisfied with their services. To support choice and control for people receiving services, the agency has continued to expand the CDS option in waiver programs. The results of the LTSS survey positively reinforce internal and external strategic initiatives.

The LTSS report is an integral part of evaluating existing programs and planning for future initiatives to support the mission and vision of DADS. By measuring program performance through direct feedback from program participants and their families, DADS can identify areas where services and supports are creating positive results and where there are unmet needs. DADS will continue to work within the agency and with federal, state, and local partners to use the results of this quality review to implement changes to improve upon the long-term services and supports for the people of Texas with disabilities.

Finally, these survey results are a valuable part of a much broader quality improvement effort within DADS. The results, based upon the perspective of people who received DADS services, help to inform internal and external stakeholders. This review also allows DADS to assess the quality of its services over time to ensure they are of the highest possible quality.

DADS VISION

Aging Texans and individuals with disabilities will be supported by a comprehensive and cost-effective service delivery system that promotes and enhances individual well-being, dignity, and choice.

DADS MISSION

The DADS mission is to provide a comprehensive array of aging and disability services, supports, and opportunities that are easily accessed in local communities.

Our key responsibilities to the citizens of Texas include:

- Working in partnership with consumers, caregivers, service providers, and other stakeholders
- Developing and improving service options that are responsive to individual needs and preferences
- Ensuring and protecting self-determination, consumer rights, and safety

HHS CONTACTS:

Rebecca Martin, Ph.D.

Janie Eubanks, Ph.D.

LINKS TO REPORTS

Summary report is available on the HHSC website.

APPENDICES

Survey questionnaires, as well complete records of the responses to all of the questions contained on those questionnaires, by population (Child and Family, Adults with IDD, and Adults with Physical Disabilities) and by program (HCS, TxHmL, PACE, MDCP, etc.), are included in the appendices. The appendices are available upon request.