

LONG-TERM SERVICES AND SUPPORTS QUALITY REVIEW



LTSS

BIENNIAL SUMMARY REPORT 2017

TABLE OF CONTENTS

EXECUTIVE SUMMARY	v
BACKGROUND AND HISTORY	1
HISTORY.....	1
NATIONAL CORE INDICATORS.....	2
DATA COLLECTION INSTRUMENTS.....	2
NCI ADULT CONSUMER SURVEY	3
NCI CHILD FAMILY SURVEY.....	3
PARTICIPANT EXPERIENCE SURVEY.....	3
CORE PERFORMANCE INDICATORS	3
METHODS.....	4
DATA COLLECTION	4
DATA SOURCES.....	4
PROXY RESPONDENTS.....	4
SAMPLE CHARACTERISTICS	4
TARGET POPULATION.....	4
SAMPLE SIZE.....	5
SAMPLING PERIOD	5
SAMPLE SELECTION METHOD	5
ANALYSIS	6
OVERVIEW OF REPORTS.....	7
SELECTED 2015 LTSS SURVEY RESULTS FOR THE 2017 REPORT	7
PROGRAM ENROLLEMENT AND SURVEY RESPONSE DISTRIBUTION	7
PROGRAM CHARACTERISTICS	8
SELECTED DEMOGRAPHICS.....	8
GENDER, AGE, RACE/ETHNICITY, AND LANGUAGE	8
RESIDENCE.....	9
INCOME LEVELS.....	10
DISABILITIES.....	10
HEALTH AND WELFARE	12
ROUTINE AND PREVENTIVE HEALTHCARE	12
SECURITY	14
CHOICE AND RESPECT	14
SELF DIRECTION.....	15
LIFE CHOICES AND DECISION-MAKING.....	15

COMMUNITY INCLUSION	17
PARTICIPATION IN COMMUNITY EVENTS	17
EMPLOYMENT	18
SYSTEM PERFORMANCE.....	19
ACCESS TO SERVICES AND SUPPORTS.....	19
DELIVERY OF SERVICES AND SUPPORTS.....	22
SERVICES SATISFACTION	24
OUTCOMES.....	24
REDUCTION OF SERVICES AND SUPPORTS.....	25
ACCOMPLISHMENTS, ACTIVITIES, AND ON-GOING EFFORTS.....	27
IMPORTANT POPULATION CHARACTERISTICS	27
POSITIVE OUTCOMES	27
OPPORTUNITIES FOR IMPROVEMENT.....	28

TABLE OF FIGURES

Figure 1. STATES PARTICIPATING IN NCI SURVEYS 2014 - 2015.....	2
Figure 2. TEXAS HEALTH AND HUMAN SERVICES PUBLIC HEALTH REGIONS.....	7
Figure 3. PROPORTION OF ADULTS WITH IDD BY TYPE OF RESIDENCE	10
Figure 4. COMPARISON OF TEXAS AND US ANNUAL HOUSEHOLD INCOME BY CHILD AND FAMILY SURVEY	10
Figure 5. MOST COMMON DISABILITIES BY SURVEY TYPE	11
Figure 6. PROPORTION OF ADULTS WITH IDD HAVING SECONDARY CONDITIONS BY TYPE OF CONDITION	11
Figure 7. COMPARISON OF THE PROPORTION OF ADULTS WITH IDD WHO RECEIVED HEALTH SERVICES BETWEEN TEXAS AND THE UNITED STATES	12
Figure 8. PROPORTION OF ADULTS WITH IDD WHO RECEIVED SELECTED ROUTINE AND PREVENTIVE HEALTH CARE BY TYPE OF RESIDENCE.....	13
Figure 9. PROPORTION OF ADULTS WITH IDD WHO RECEIVED SELECTED CANCER SCREENING BY TYPE OF RESIDENCE	14
Figure 10. CONTROL OF SUPPORT WORKERS BY POPULATION	15
Figure 11. PROPORTION OF ADULTS WITH IDD WHO HAVE INPUT INTO MAJOR LIFE CHOICES.....	16
Figure 12. PROPORTION OF ADULTS WITH IDD WHO HAVE INPUT INTO EVERDAY DECISIONS	16
Figure 13. FAMILY MEMBER OF IDD PARTICIPATES IN COMMUNITY ACTIVITIES, COMPARISON OF TEXAS AND US.....	17
Figure 14. PEOPLE WITH DISABILITIES HAVE FRIENDS AND RELATIONSHIPS WITH PEOPLE WITHOUT DISABILITIES, COMPARISON OF TEXAS AND US	18
Figure 15. ADULTS WITH IDD EMPLOYMENT STATUS BY TYPE OF RESIDENCE.....	19
Figure 16. INFORMATION ABOUT SERVICES AND SUPPORTS	20
Figure 17. PROPORTION OF FAMILIES PARTICIPATING IN SERVICE PLAN CREATION BY SURVEY POPULATION.....	20
Figure 18. REPORTED SERVICE NEEDS OF ADULTS WITH IDD	21
Figure 19. CHILDREN WHO FAILED TO RECEIVE NEEDED EQUIPMENT, TRENDS 2005 – 2015	22
Figure 20. RESPONSIVENESS, TIMELINESS, AND APPROPRIATENESS OF STAFF SERVICES AND SUPPORTS BY SURVEY POPULATION	23
Figure 21. AVAILABILITY, FLEXIBILITY, AND PROXIMITY OF SERVICES AND SUPPORTS FOR CHILDREN WITH DISABILITIES	23
Figure 22. CHILD AND FAMILY CONSUMER SATISFACTION WITH SERVICES AND SUPPORTS AVAILABILITY OVER TIME	24

Figure 23. SERVICES AND SUPPORTS MAKE A POSITIVE DIFFERENCE IN FAMILY/INDIVIDUAL'S HEALTH AND WELLBEING25

Figure 24. SERVICES AND SUPPORTS ADDRESS PERSONAL GOALS BY SURVEY POPULATION.....25

Figure 25. COMPARISON OF SERVICES AND SUPPORTS REDUCTIONS AND THEIR IMPACT ON FAMILIES BETWEEN TEXAS AND US CHILD AND FAMILY SURVEY HOUSEHOLDS26

Figure 26. ANNUAL OUT-OF-POCKET EXPENSES NOT COVERED FROM CHILD AND FAMILY SURVEY HOUSEHOLDS.....26

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: Findings from the 2017 LTSS suggest that consumers are satisfied with the information they receive about how to access long-term services and supports, and receive the services they need. Individuals who use DADS services participate in their communities, and most make their own everyday choices. The majority of consumers reported feeling safe in their homes, neighborhoods, and day activity sites.

Specific areas identified for improving long-term services and supports were primarily in the domains of choice, control, and autonomy over services and supports, as well as community integration. Consumers expressed interest in increasing their ability to choose the staff that helps them, including their case managers; having control over their transportation; increasing their opportunities to work; and improving access to timely preventive health care.

The quality review process has been in effect since 2005 as a continued activity of a Real Choice Systems Change Grant awarded by the Centers for Medicare and Medicaid Services (CMS). The review is not regulatory in nature, but rather a method to identify areas of need and for improvement. People receiving services and supports, or their family members and guardians, provide valuable feedback through face-to-face and mailed interviews. These surveys obtain the individual's perspective about their lives, services, and supports.

The LTSS survey provides baseline information for continuous quality improvement, monitoring, and intervention, helping the agency build a quality management strategy, identify trends, develop innovations, and provide information to stakeholders and CMS. Intervention strategies based on these findings will further promote the vision of DADS:

Older Texans and persons with disabilities will be supported by a comprehensive and cost-effective service delivery system that promotes and enhances individual wellbeing, dignity, and choice.

METHODS: DADS used three nationally recognized survey instruments for measuring specific consumer indicators – the National Core Indicators Adult Consumer and National Core Indicators Child and Family Survey for the IDD population, and the Participant Experience Survey Elderly/Disabled version for older individuals and individuals with a physical disability. The LTSS 2017 survey collected data from 4,971 adults and 1,913 families of children with disabilities from January through August 2015. Data were collected on the following broad domains: health and welfare, individual choice and respect, community inclusion and work, systems performance, and services satisfaction.

BACKGROUND AND HISTORY

Prior to the 2017 Long-Term Services and Supports Quality Review (LTSS) editions, the reports were mandated by the Texas Legislature in the General Appropriations Act. The reports provide information on consumers' experiences receiving services in DADS programs to the Texas Health and Human Services Commission, DADS, researchers, and stakeholders. The reports also include 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 with understanding how DADS consumers feel about their quality of life.

The reports enable DADS staff to assess success and deficiencies over time, identify areas for improvement, and measure the effectiveness of implemented improvement strategies. The review 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 (TDMHMR) a Real Choice Systems Change grant to redesign and improve quality in its home and community-based programs.

One of the grant's objectives was to identify or develop a tool to measure individual experiences and calculate quality indicators in home and community-based programs. A task force charged with implementing the grant 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 Vision:

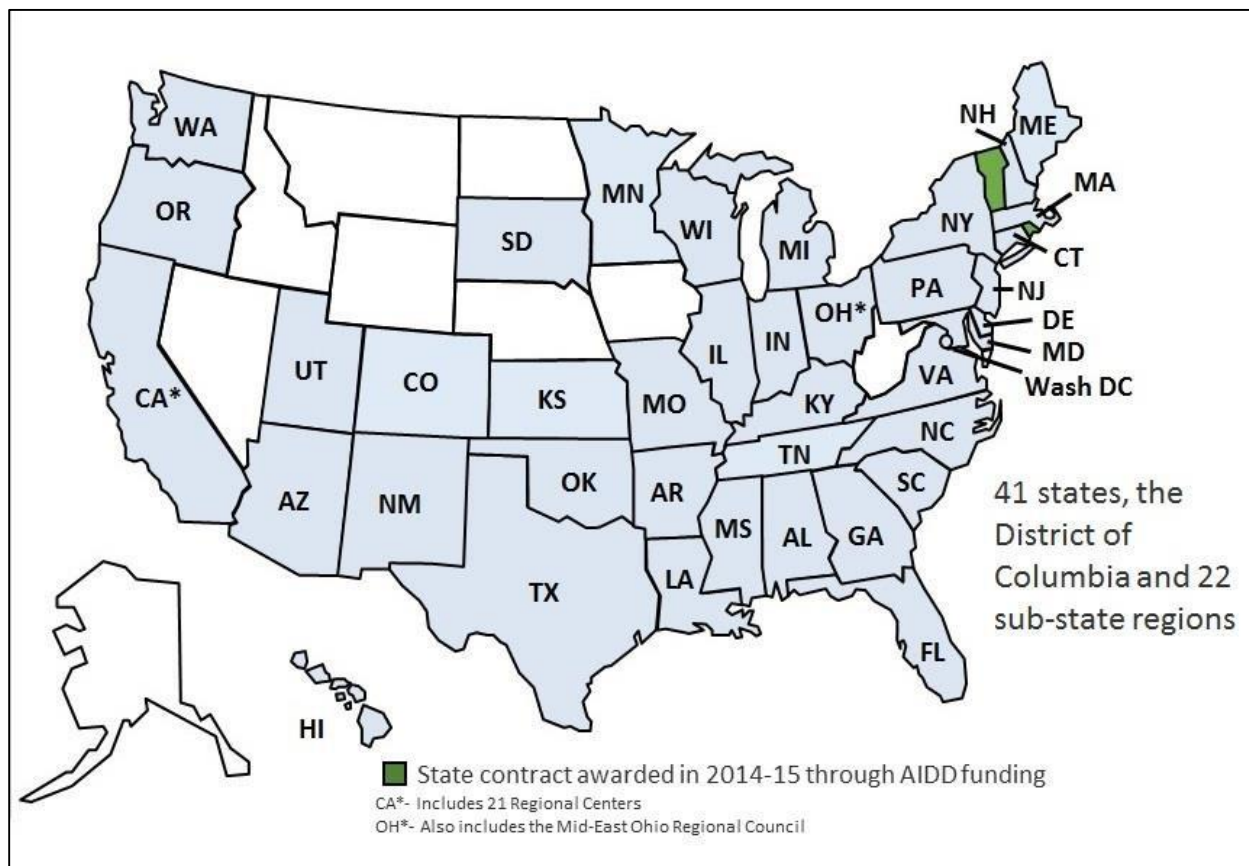
- Improve practice at the state level
- Influence state and national policy
- Add knowledge to the field
- Inform stakeholders for strategic planning and priority setting

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, and became DADS. With the addition of older individuals and adults with physical disabilities, the Thomson/Reuters' Participant Experience Survey – Elderly/Disabled (PES) was selected to collect their experiences. The three survey instruments are designed to solicit feedback from the individual's perspective about the quality of the services and supports provided by DADS and their quality of life. The LTSS report has been published since 2005. When national numbers are cited, they refer to the NCI national survey results. National numbers for the PES are not available.

NATIONAL CORE INDICATORS

The NCI survey 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. Currently, the NCI collaboration includes 41 states (Figure 1), but some states participate biennially, not annually. In 2015, NCI surveyed more than 29,100 individuals and families from 34 states and the District of Columbia.

Figure 1. STATES PARTICIPATING IN NCI SURVEYS 2014 – 2015



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

DATA COLLECTION INSTRUMENTS

This report is developed 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.

NCI CHILD FAMILY SURVEY

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

NCI ADULT CONSUMER SURVEY

The NCI Adult Consumer survey (referred to as NCI in this report) is administered to people receiving DADS adult IDD services and supports. Section I of the survey 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.

PARTICIPANT EXPERIENCE SURVEY

To measure the experiences and satisfaction of older adults and adults with physical disabilities, DADS collaborated with Thomson/Reuters, which developed the PES for CMS. The PES captures participant experiences using face-to-face and telephone interviews. Most responses come from the individual, not a proxy. Throughout this report older adults and adults with physical disabilities will be referred to as "adults with physical disabilities" for the sake of brevity.

CORE PERFORMANCE INDICATORS

The three surveys are organized across five general topics or domains – health and welfare, 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 full list of NCI core indicators can be viewed on the NCI website at: <http://nationalcoreindicators.org/indicators/>.

LTSS Created From 3 Surveys:

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

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

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 a mix of phone, mail, and web interviews. To prepare for the interviews, PPRI staff obtained pre-survey, background, and day activity information from program providers. The demographic data was provided by automated DADS systems and included age, gender, and ethnicity.

DATA SOURCES

Three primary data sources were used to create this report. The NCI Adult Consumer survey gathers information from face-to-face interviews with adults with IDD receiving DADS services and supports. Data on the adult population with physical disabilities, primarily older adults, are gathered using the PES in face-to-face, telephone, and web interviews. Information about children with disabilities is gathered from their families using the NCI Child Family (CF) survey, which is administered by mail, telephone, and web. DADS typically interviews a random sample of 4,000 to 7,000 individuals for each report.

PROXY RESPONDENTS

The majority of the questions were answered by the selected individual, with the exception of the Child Family survey. For all survey questions where a proxy was needed and allowed, respondents were frequently family members of the person with a disability (44 percent NCI, 89 percent PES, 90 percent CF). In about half of the NCI interviews, a staff person assisted the respondent with the second section of the survey. Section I of the NCI had to be completed by the selected participant.

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 DADS population was sampled and data collected in 2015 for the 2017 report. Table 1 below provides an overview of the target populations. The survey population encompasses 17 programs, including 5 waiver programs (see Table 2 below).

Table 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 program, the survey type, and the total number of surveys collected overall.

Table 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

SAMPLE SIZE

The sample size for each program was calculated to obtain a confidence level of 95 percent and a confidence interval of 5. 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 face-to-face 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

The data for the 2017 LTSS report were collected between January 2015 and August 2015. DADS uses the LTSS survey to track trends. While not every program has been surveyed every year, data have been collected from individuals enrolled in DADS programs since 2005. Table 2 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 sampling was used to select the study sample. Representative samples were randomly 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 and programmatic 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. Three programs serve both children and adults (HCS, CLASS, and TxHmL, see definitions in Table 2 below). Samples were chosen from each program for the children and for the adults. Some programs are no longer operated by DADS (e.g., CBA, CWP) or were too small to sample (e.g., AFC, Hospice), and were not included in the 2017 report sample.

In addition to sampling by program, the 2017 LTSS survey focused on the Consumer Directed Services (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 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	✓	✓			✓			
ICF/IDD – Intermediate Care Facility	NCI	✓	✓	✓	✓	✓		✓	✓
SSLC – State Supported Living Centers	NCI	✓	✓	✓	✓	✓	✓	✓	✓
CBA – Community Based Alternatives Waiver	PES	✓	✓	✓	✓	✓		✓	
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				✓		✓		
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	✓	✓		✓				

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 tables and figures throughout the report. In

addition to percentages, trend information is provided on select variables. NCI Section I survey responses were included in the analyses only when the interviewer determined that the individual understood the questions and answered independently or with limited assistance.

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 LTSS 2017 reports are available at: <http://hhs.texas.gov/sites/hhs/files//ltssqr2017.pdf>.

This report is the LTSS Biennial Summary Report 2017, featuring data collected in 2015 from a representative sample of Texans receiving DADS services and supports. Sub-domains 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.

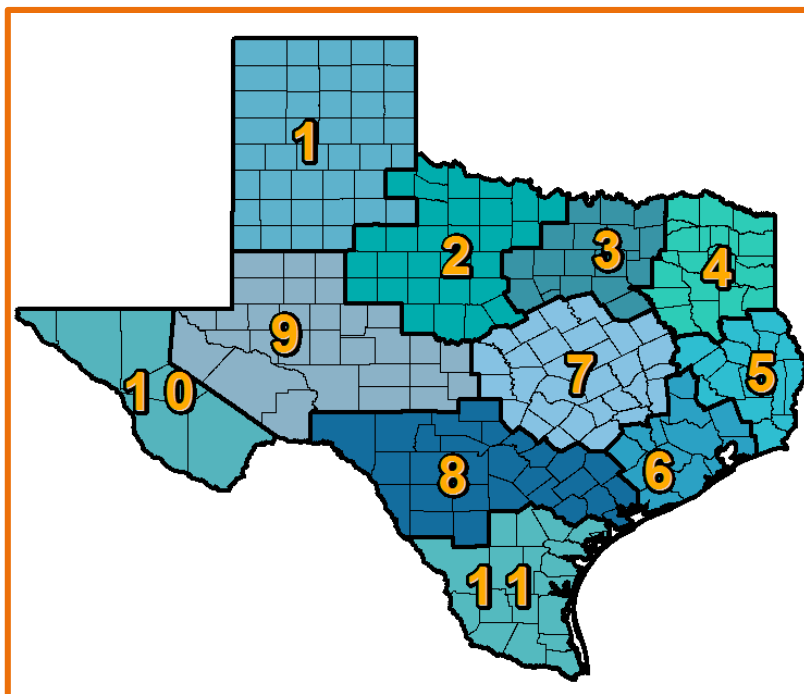
Fact: People living with disabilities don't all have the same experiences or the same perspective.

SELECTED 2015 LTSS SURVEY RESULTS FOR THE 2017 REPORT

PROGRAM ENROLLEMENT AND SURVEY RESPONSE DISTRIBUTION

One goal of survey design is to select a sample that is representative of the population and large enough to make accurate statements based upon the responses. Selecting a sample across 11 geographic public health regions, each containing more land mass than some states, and across 17 programs is difficult. Regional and program-specific data are presented in the detailed 2017 LTSS report. The public health regions are presented below in Figure 2, the programs in Table 2 above.

Figure 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 as a group as well as by program.

PROGRAM CHARACTERISTICS

The three surveys are used for three distinct populations with different programs serving individuals with different needs. The goals of the programs vary by the population they serve. The NCI survey is used with adults with IDD. Services in these programs can include community inclusion, daytime habilitation or work programs, and assistance in obtaining medical care. When the participant is not served in his or her own home, the residential service provider is responsible for community inclusion, day programs, and similar services. Most people in these programs have an intellectual disability and most are presumed to need some support in life choices.

The CF survey was used for children who have intellectual or developmental disabilities or severe medical needs. They may be served by the same programs that serve adults with IDD/related conditions (HCS, TxHmL, and CLASS) or by a program (MDCP) aimed at children who have developmental disabilities or whose medical needs qualify them for nursing facility services. Services in these programs can include community inclusion, respite care, assistance with transportation, and assistance in obtaining medical, dental, and mental health care.

The PES is used for adults whose physical disabilities place them at risk of entering a nursing facility. Many already qualify medically for nursing facility care. Services may address medical needs, activities of daily living (bathing, dressing, mobility) and instrumental activities of daily living (cooking, cleaning, shopping, laundry). Community inclusion, day activities, and similar services are not included as part of most DADS programs for people with physical disabilities. Individuals are presumed to be independent in making their own life choices and arranging their own health care.

SELECTED DEMOGRAPHICS

GENDER, AGE, RACE/ETHNICITY, AND LANGUAGE

For the NCI and CF survey respondents, a higher percentage were male (61 percent for CF and 57 percent for NCI), while two-thirds (70 percent) of the adults with physical disabilities responding to the PES survey were female. On average, individuals completing the PES survey were approximately two decades older than those completing the NCI survey (63 years compared to 42). The average age of children for whom the CF survey was completed was 14.

The racial/ethnic composition and primary language varied by survey population. Among adults with physical disabilities, 31 percent used Spanish as their primary language. Texas had the second highest percentage of respondents whose primary language was not English, after California. Highlights of respondent demographics are presented below in Tables 3, 4, and 5.

Table 3. GENDER, AGE, RACE/ETHNICITY, PRIMARY LANGUAGE AND RESIDENCE OF CHILD SURVEY PARTICIPANTS

Demographics of 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%	Live elsewhere 2%

Table 4. GENDER, AGE, RACE/ETHNICITY, PRIMARY LANGUAGE, AND RESIDENCE OF ADULT RESPONDENTS 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/ Group home 35%
Female 43%	Average 42	Hispanic 27%	Other 6%	Spanish 10%	Lives alone 6%	SSLC 11%

Table 5. GENDER, AGE, RACE/ETHNICITY, PRIMARY 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%	

RESIDENCE

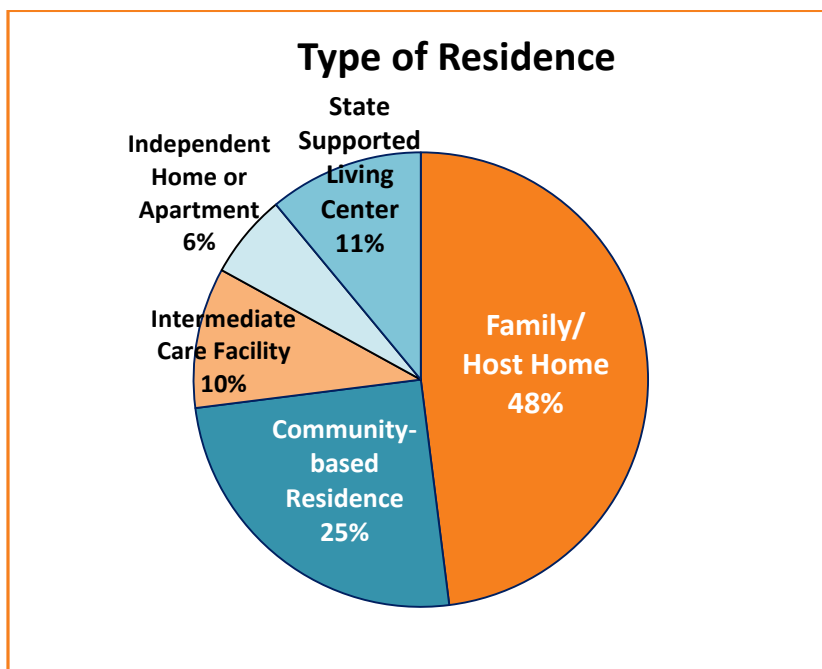
Almost half of the adult respondents with IDD lived with their parents, relatives, or guardians (48 percent), see Figure 3 below. A lower percentage of adults with physical disabilities (43 percent) lived with relatives, including spouses, as 18 percent of adults with physical disabilities were married. Adults with IDD who did not live with relatives most frequently

Myth: People with disabilities always need help.

Fact: Many people with disabilities are independent and are capable of giving help. If you would like to help someone with a disability, ask if he or she needs it before you act.

lived in community-based group home settings (25 percent), intermediate care facilities (10 percent), or state supported living centers (11 percent). Six percent of adults with IDD lived alone. Among adults with physical disabilities, 53 percent reported they lived alone. More than 98 percent of the children surveyed lived with their parents or relatives.

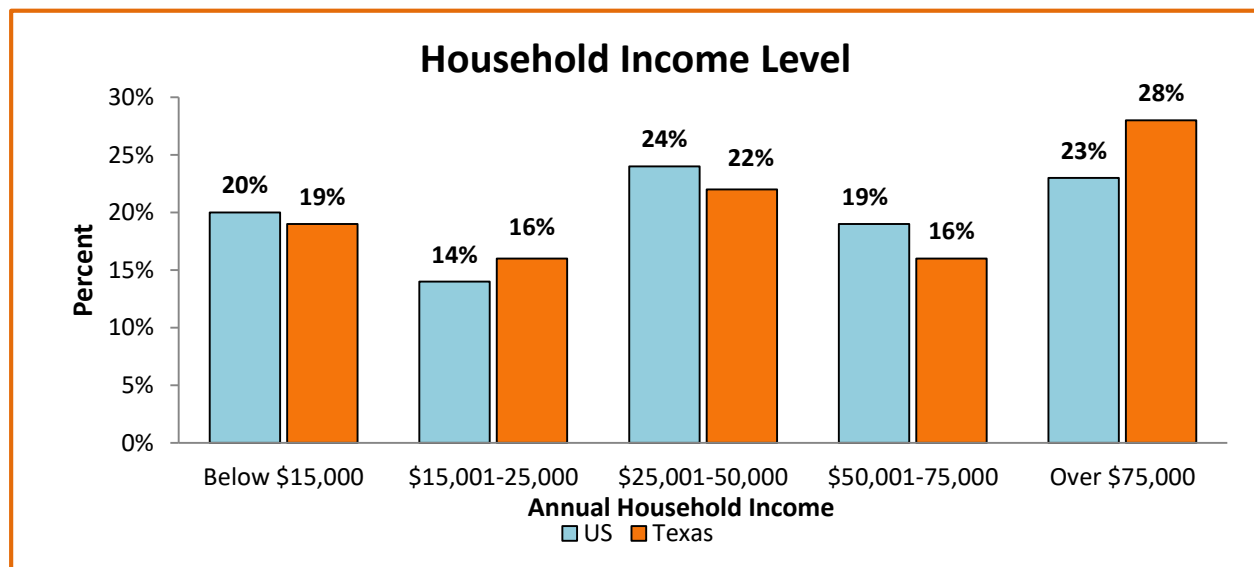
Figure 3. PROPORTION OF ADULTS WITH IDD BY TYPE OF RESIDENCE



INCOME LEVELS

Household income information was collected in the CF survey. A majority of Texas respondents (57 percent) fall at or below \$50,000 per year (see Figure 4 below). Income levels for survey respondents nationally were similar to Texas.

Figure 4. COMPARISON OF TEXAS AND US ANNUAL HOUSEHOLD INCOME BY CHILD AND FAMILY SURVEY

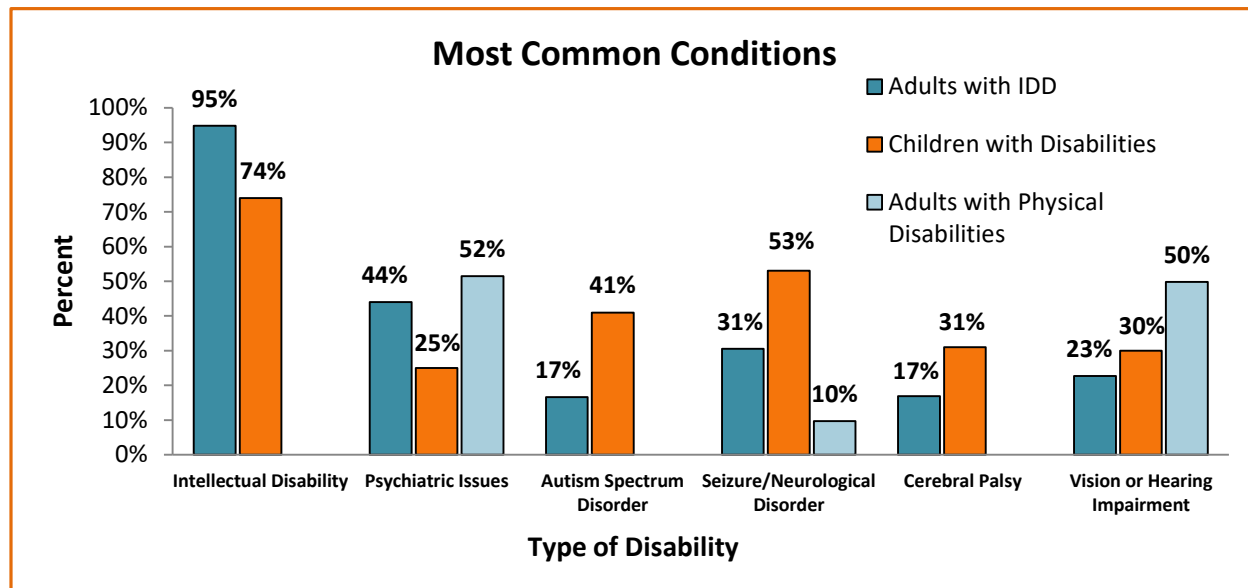


DISABILITIES

As illustrated in Figure 5, the most commonly reported primary disabilities were intellectual disability, mental illness, autism spectrum disorder (ASD), seizure/neurological disorder, cerebral palsy, and significant vision or hearing impairment. A majority of adult consumers taking the NCI survey had an intellectual disability (95 percent) and almost three-quarters of children had this

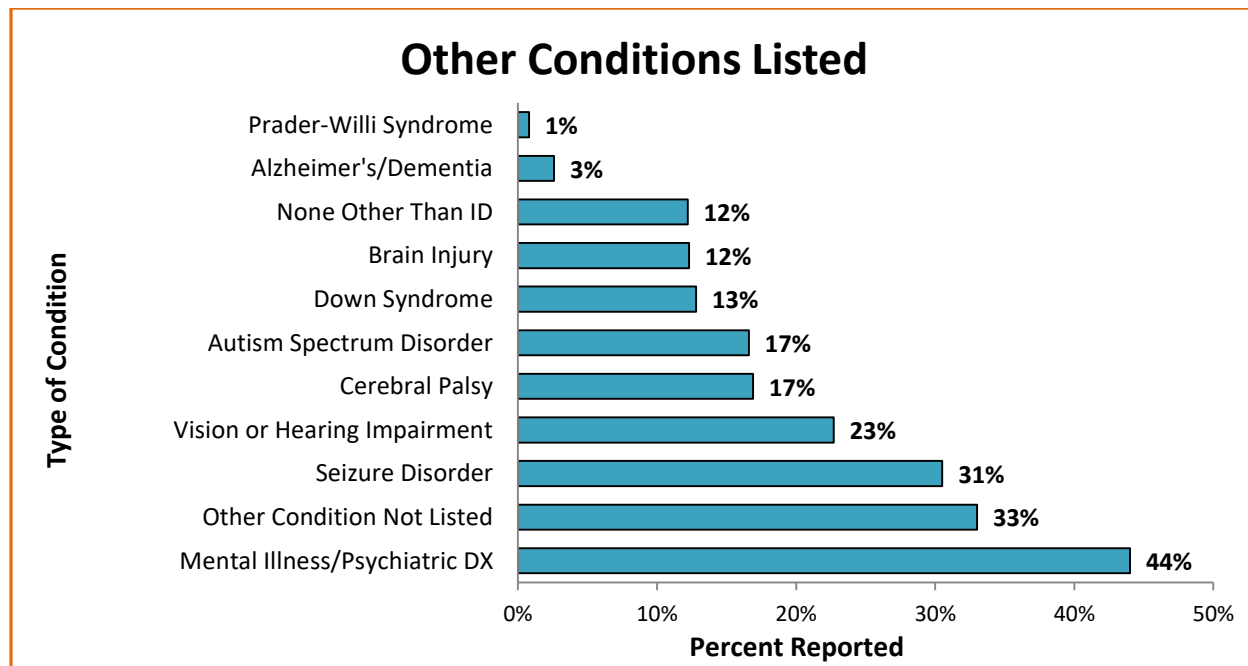
diagnosis (74 percent). The question about intellectual disabilities was not asked in the PES survey of adults with physical disabilities, but using guardianship/conservatorship as a proxy for cognitive issues, 26 percent of adults with physical disabilities reported having a guardian. ASD was more commonly diagnosed among children, with more than twice as many respondents for the CF survey reporting ASD (41 percent) compared to adults with IDD (NCI 17 percent).

Figure 5. MOST COMMON CONDITIONS BY SURVEY TYPE



The majority of people surveyed among adults with IDD (88 percent) reported more than one type of disability (Figure 6). The most common secondary conditions reported were mental illness or psychiatric diagnosis (44 percent), seizure disorder (31 percent), and other condition not listed (33 percent). Figure 6 presents the other conditions reported.

Figure 6. PROPORTION OF ADULTS WITH IDD HAVING SECONDARY CONDITIONS BY TYPE OF CONDITION



HEALTH AND WELFARE

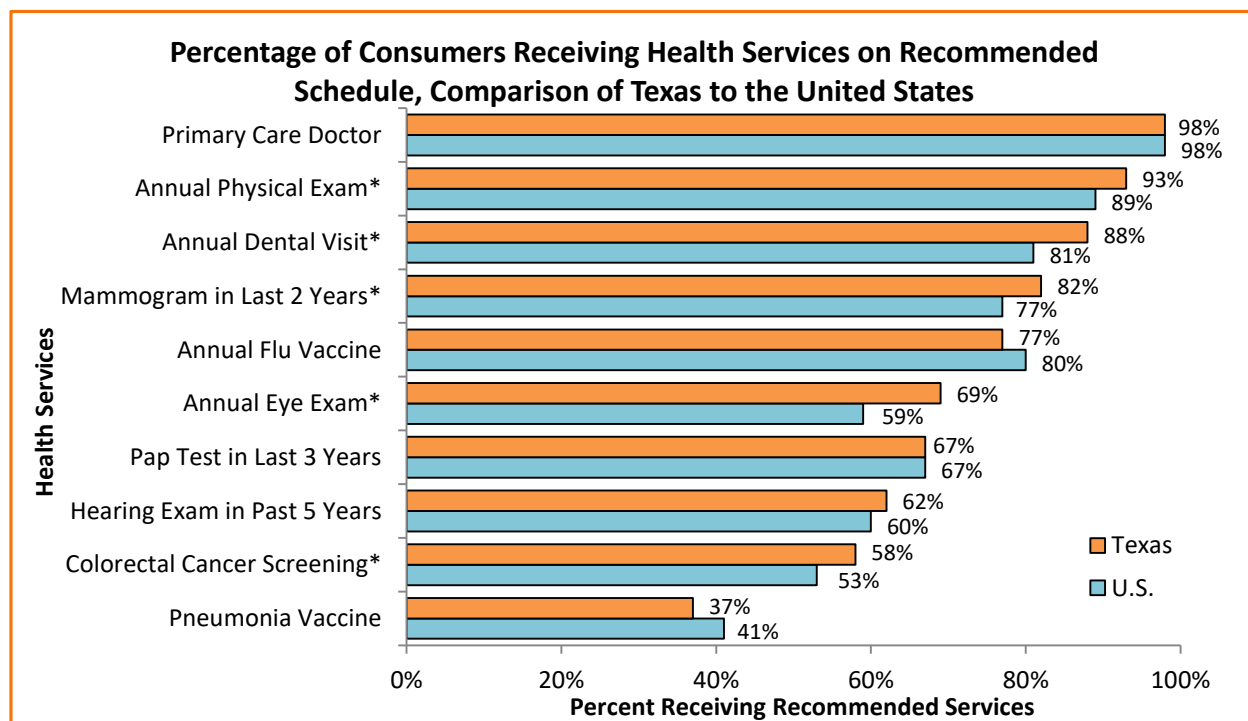
Findings

- Texas adults with IDD received more routine and preventive health care than people with IDD nationally and significantly higher rates of care on 5 of 10 health indicators
- Adults with IDD living in state supported living centers or community-based housing received higher rates of routine and preventive care than those living alone or with family

ROUTINE AND PREVENTIVE HEALTHCARE

Health and welfare questions were asked in the NCI and PES surveys of adults. The majority of those surveyed were in fairly good health or better (96 percent of NCI and 63 percent of PES respondents). The surveys collected health indicator information. Six percent of the adults with IDD and 19 percent of adults with physical disabilities used tobacco products, and 33 percent of the NCI and 48 percent of the PES respondents' body mass index (BMI) scores indicated that they were obese. Reported mobility – the ability to move around their environment – was high for both groups (88 percent NCI and 90 percent PES). Most of the adults with IDD surveyed had routine health care, 98 percent had a primary care doctor, and 93 percent had had a physical exam in the past year (see Figure 7). Figure 7 compares the proportion of adults with IDD receiving health services in Texas to the United States. Data on routine health care for adults with physical disabilities are presented in the detailed report.

Figure 7. COMPARISON OF THE PROPORTION OF ADULTS WITH IDD WHO RECEIVED HEALTH SERVICES BETWEEN TEXAS AND THE UNITED STATES



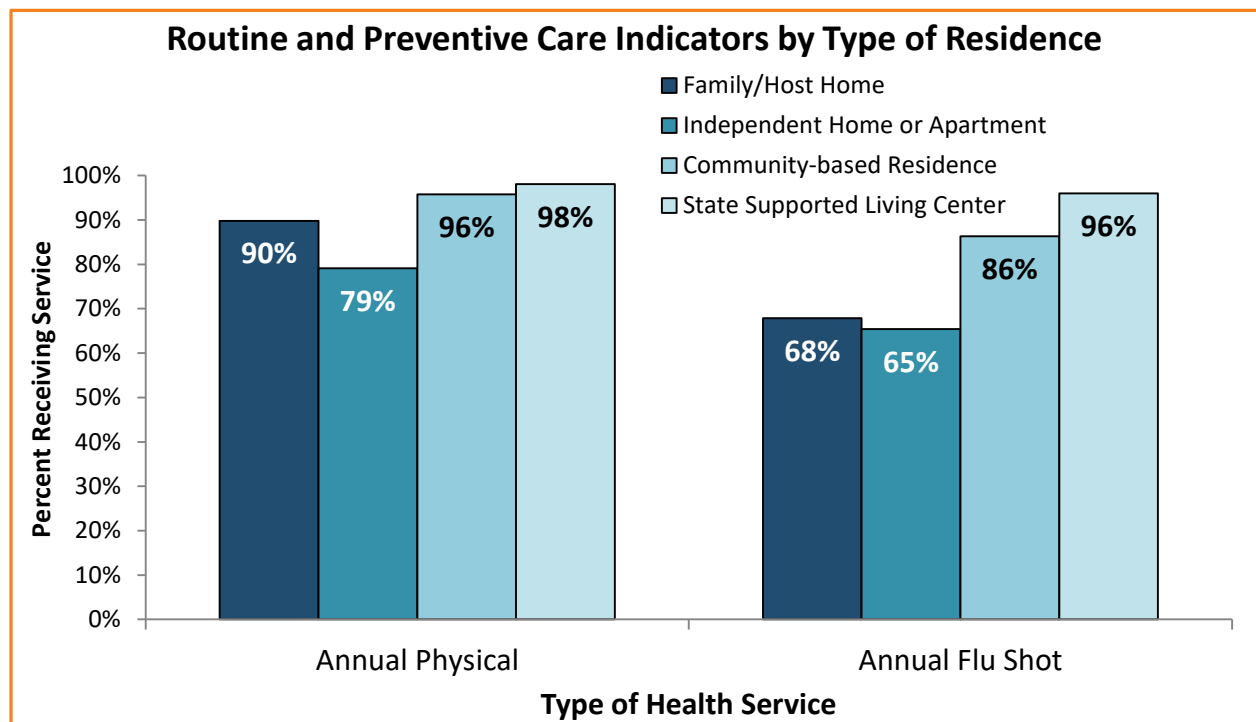
*Statistically significantly higher rates than the national average.

The proportion of people with IDD who received more specialized preventive health care was also high. 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 rates met or exceeded US rates on every health indicator reported, with the exception of pneumonia and flu vaccination, and were significantly higher for 5 out of the 10 health indicators.

88% of respondents had an annual dental exam

Rates of routine and preventive health care tests and exams varied by where adults with IDD resided (Figures 8 and 9). Figure 8 illustrates the variation in routine (annual physicals) and routine preventive health care (annual flu shot) by type of residence, while Figure 9 presents selected cancer screening data (colorectal and breast cancer) by type of residence.

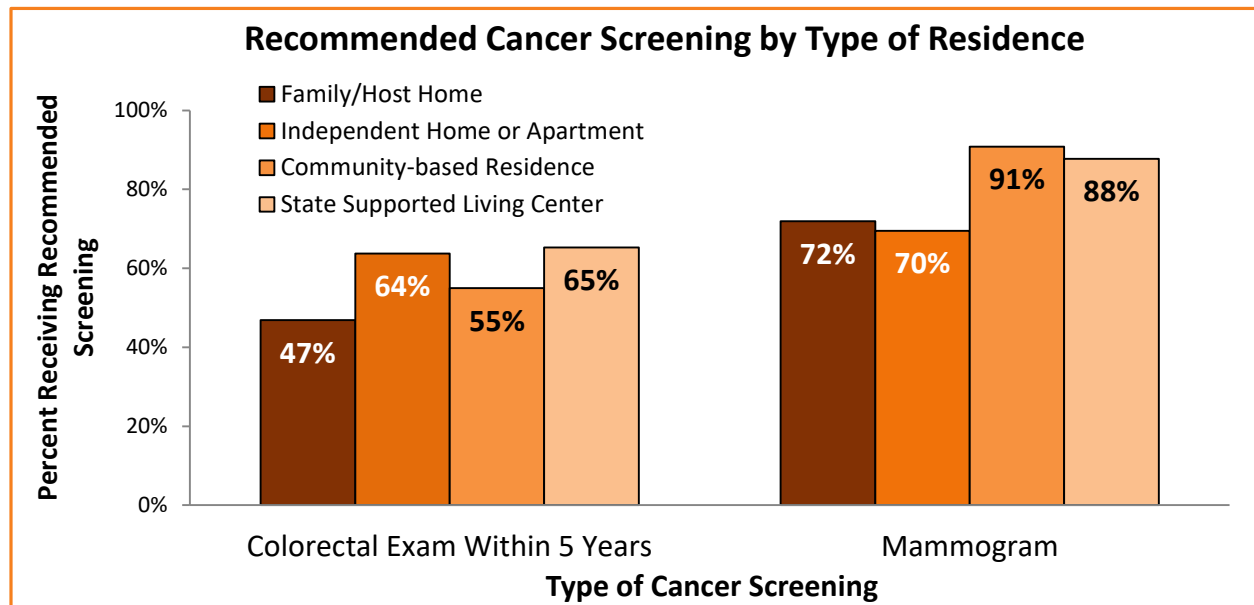
Figure 8. PROPORTION OF ADULTS WITH IDD WHO REPORTED RECEIVING SELECTED ROUTINE AND PREVENTIVE HEALTH CARE BY TYPE OF RESIDENCE



Cancer screening rates varied greatly among adults with IDD. Eighty-two percent (82 percent) of women age 40 and over had a mammogram in the past two years, and 67 percent of all women had a Pap test in the past three years, while only 27 percent of people over 50 had had a colorectal cancer screening in the past year. As colorectal cancer screening is recommended every 5 to 10 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 9.

Cancer screening rates among adults with physical disabilities did not meet recommended levels. Seven percent (7 percent) of women with physical disabilities had never received cervical cancer screening. Breast cancer screening rates were worse, with 10 percent of adult women age 40 and older with physical disabilities never having received a mammogram. About 3 out of every 10 adults over age 49 with physical disabilities, 32 percent, had never had a colorectal cancer screening test.

Figure 9. PROPORTION OF ADULTS WITH IDD WHO REPORTED RECEIVING SELECTED CANCER SCREENING BY TYPE OF RESIDENCE



For almost all 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 institutions.

SECURITY

Feeling secure is an important measure of wellbeing and welfare. For this reason, the NCI survey of adults with IDD and the PES survey of adults with physical disabilities contain 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 NCI and 81 percent PES); 81 percent of NCI respondents and 86 percent of PES respondents said they were not afraid in their neighborhoods; and 86 percent and 95 percent, respectively, reported they were not scared in their day programs. The surveys also asked whether the respondent had someone to talk to if they are afraid, and 89 percent of NCI and 90 percent of PES respondents said they did. By self-report, the majority had a sense of security.

CHOICE AND RESPECT

Findings:

- Control over transportation remains an issue; less than half of respondents in some 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 adults with IDD made decisions about where they live, their housemates, and selecting their staff
- Most people reported the staff paid to help them were respectful

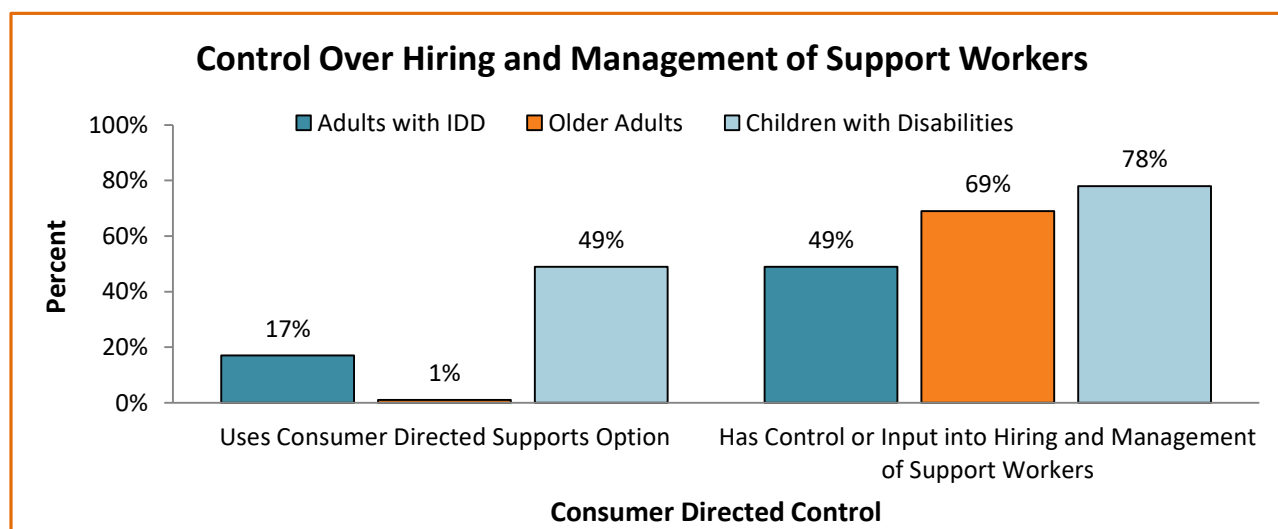
SELF DIRECTION

Consumer-directed services (CDS), where the consumer manages their own services and supports, is an option offered in a number of the waiver programs. Across the three survey populations, the proportion of people using CDS varied greatly by the population served. Less than one percent (1 percent) of the adults with physical disabilities used the CDS option. Among adults with IDD, 17 percent reported using CDS, compared to 9 percent nationally. The families of children served by DADS reported the highest rate of CDS use, with 49 percent of the families using the option.

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

DADS policy encourages consumers to use self-directed supports to increase their satisfaction and autonomy. Families of children with disabilities reported more control or input in hiring and management of support workers (78 percent) than adults with IDD (48 percent) or adults with physical disabilities (69 percent). While use of the CDS option was lowest among older adults, they reported high levels of control over and input into hiring and managing their staff (Figure 10).

Figure 10. CONTROL OF SUPPORT WORKERS BY POPULATION

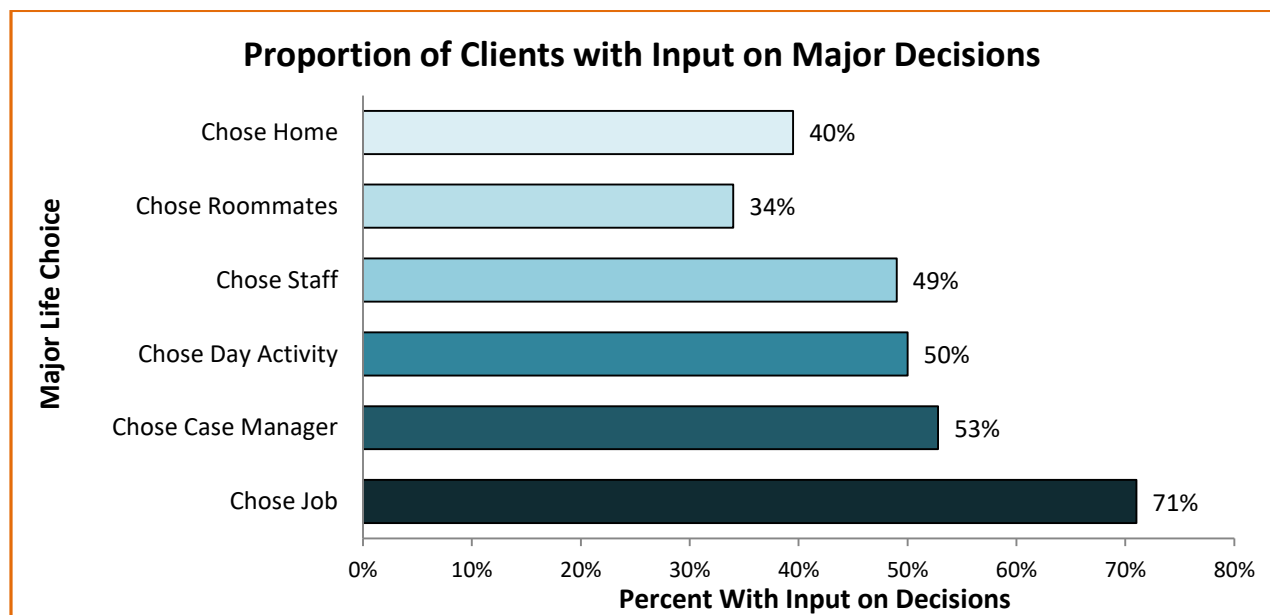


LIFE CHOICES AND DECISION-MAKING

Choice over major life and everyday decisions is critical to quality of life and satisfaction with services and supports. More than three-quarters of the adults with physical disabilities (87 percent) reported that they controlled who entered their homes, and 70 percent said that they could have a close personal relationship. A majority, 58 percent, had control over their transportation.

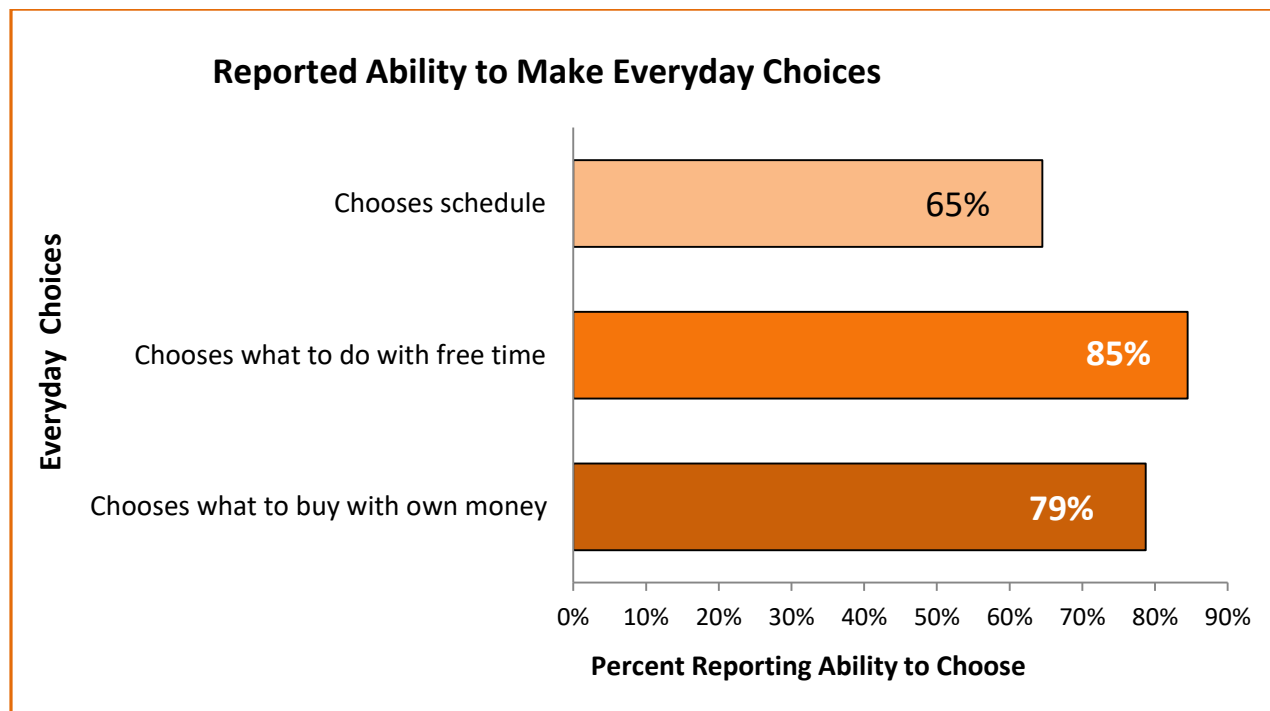
Many adults with IDD reported that they did not have input into major life decisions such as where and with whom they live and where they go during the day. Texas scored only 47 percent compared to the national average of 60 percent on the composite NCI "Life Decisions Scale" - finishing ahead of only 3 other states out of 32 states reporting. As illustrated in Figure 11, 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 chose his/her case manager.

Figure 11. PROPORTION OF ADULTS WITH IDD WHO HAVE INPUT INTO MAJOR LIFE CHOICES



Compared to major life decisions, a higher 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 12). While Texas everyday decision percentages were higher compared to major life decisions, on the NCI composite “Everyday Choices Scale,” Texas scored 78 percent compared to the national average of 86 percent, finishing only above New Jersey.

Figure 12. PROPORTION OF ADULTS WITH IDD WHO HAVE INPUT INTO EVERYDAY DECISIONS



More information about consumer choice and trends over time is presented in the detailed report.

COMMUNITY INCLUSION

Findings

- Most individuals had close relationships and could see their friends and family when they wanted
- More than 8 of every 10 adults with IDD were happy with their personal life

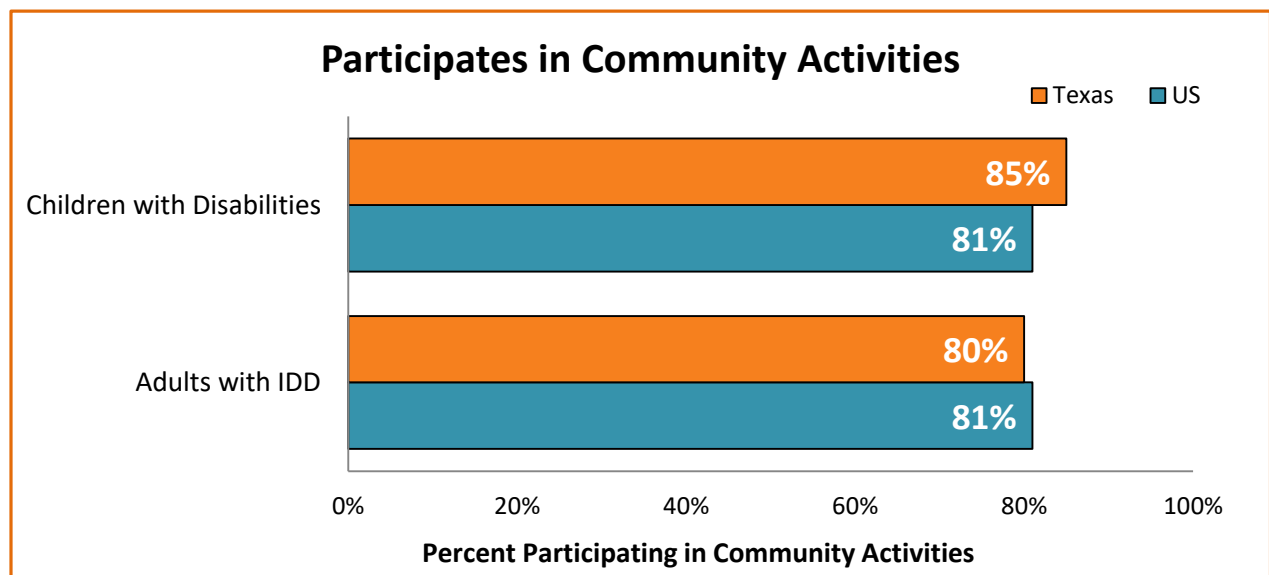
PARTICIPATION IN COMMUNITY EVENTS

The PES survey did not collect community involvement information because increasing community involvement is not a goal of programs for those with physical disabilities. The data reported here are for the IDD populations, adults and children. Most survey respondents reported participating in community activities. As seen in Figure 13, the majority of respondents in Texas and nationally reported their family members participated in community activities (Texas respondents: 80 percent of adults with IDD, 85 percent of children with disabilities). National figures for adults with IDD were similar, with 81 percent of adults with IDD participating in community activities. The majority of respondents on the adults with IDD 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 attended a religious service (53 percent).

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

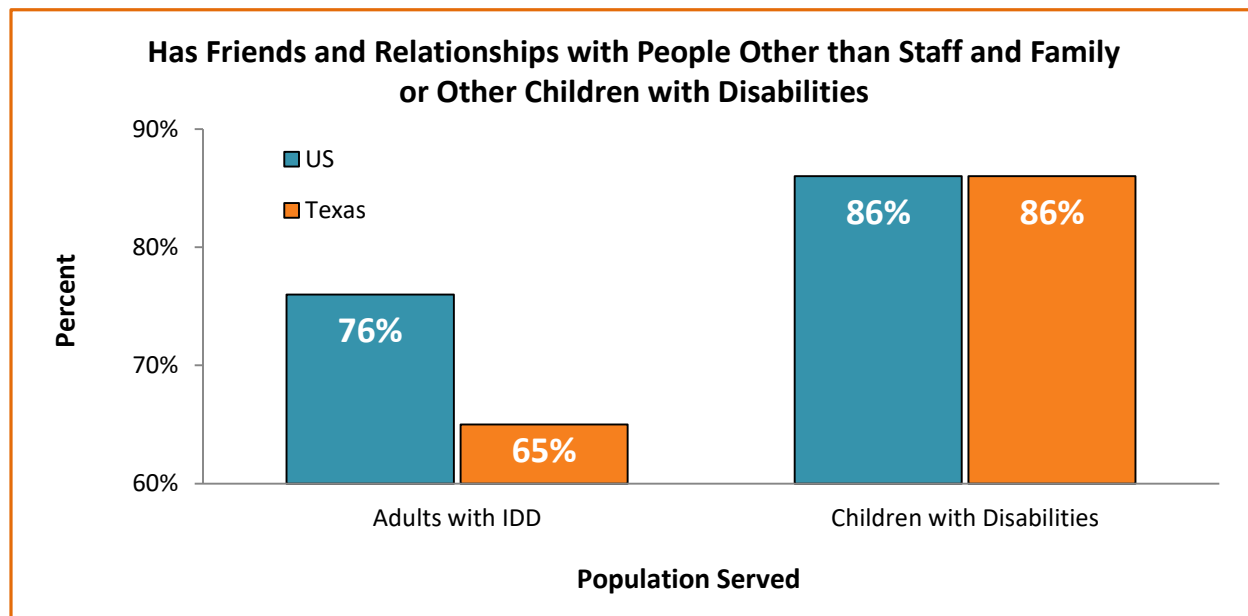
Families of children with disabilities reported more community participation than adults with IDD. The reasons most commonly cited for their children’s lack of community participation were lack of support staff (20 percent) and transportation (17 percent). Cost and negative attitudes from community members, 12 percent and 11 percent respectively, were also cited by families as contributory reasons.

Figure 13. FAMILY MEMBER OF IDD PARTICIPATES IN COMMUNITY ACTIVITIES, COMPARISON OF TEXAS AND US



As illustrated in Figure 14 below, nationally over three-quarters of adults with IDD reported they had meaningful relationships with people other than support workers and family (76 percent), while in Texas only 65 percent reported having friends other than family or staff. Eighty-six percent (86 percent) of CF survey respondents in Texas and the US indicated their child spends time with children without disabilities. The PES did not include questions about personal relationships.

Figure 14. PEOPLE WITH DISABILITIES HAVE FRIENDS AND RELATIONSHIPS WITH PEOPLE WITHOUT DISABILITIES, COMPARISON OF TEXAS AND US



EMPLOYMENT

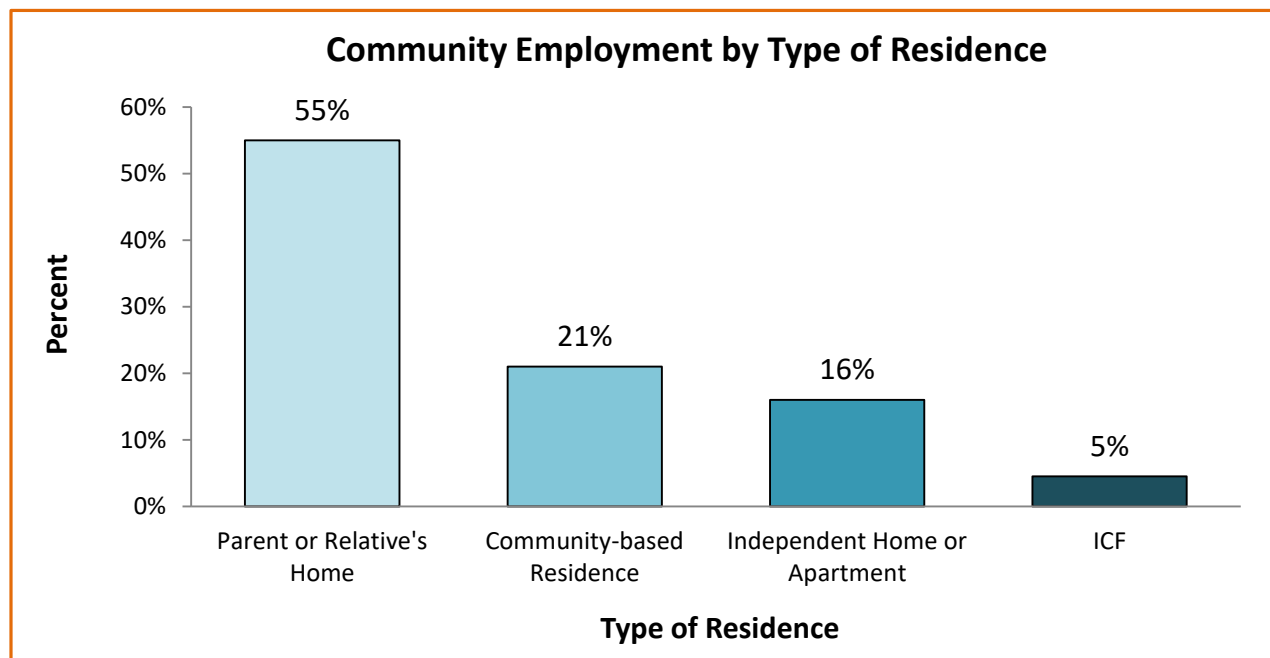
Research suggests employment reduces the economic and social disparities people with disabilities face and helps them gain economic security and become more fully integrated and engaged in mainstream society.¹ In 2014-2015, nationally, 17 percent of people with IDD had a paid job in the community, while only 10 percent of adults with IDD in Texas 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 15). Twelve percent (12 percent) of adults with IDD in Texas had paid, facility-based jobs, and 42 percent participated in unpaid facility activities. Twenty four percent of people with IDD who worked received benefits (vacation and/or sick leave), compared to 23 percent nationally. Of people surveyed, the four most common types of paid community jobs were: food preparation (22 percent), cleaning and maintenance (23 percent), retail (21 percent), and assembly and manufacturing (12 percent).

Across programs, most individuals were not employed

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.

Figure 15. ADULTS WITH IDD REPORTING EMPLOYMENT STATUS BY TYPE OF RESIDENCE



As in previous surveys, a disparity persists between employment rates and the desire to work. Only 19 percent of the adults with IDD stated that they were employed (22 percent had confirmed paid employment, the 19 percent reported here is based upon self-report), while 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.

SYSTEM PERFORMANCE

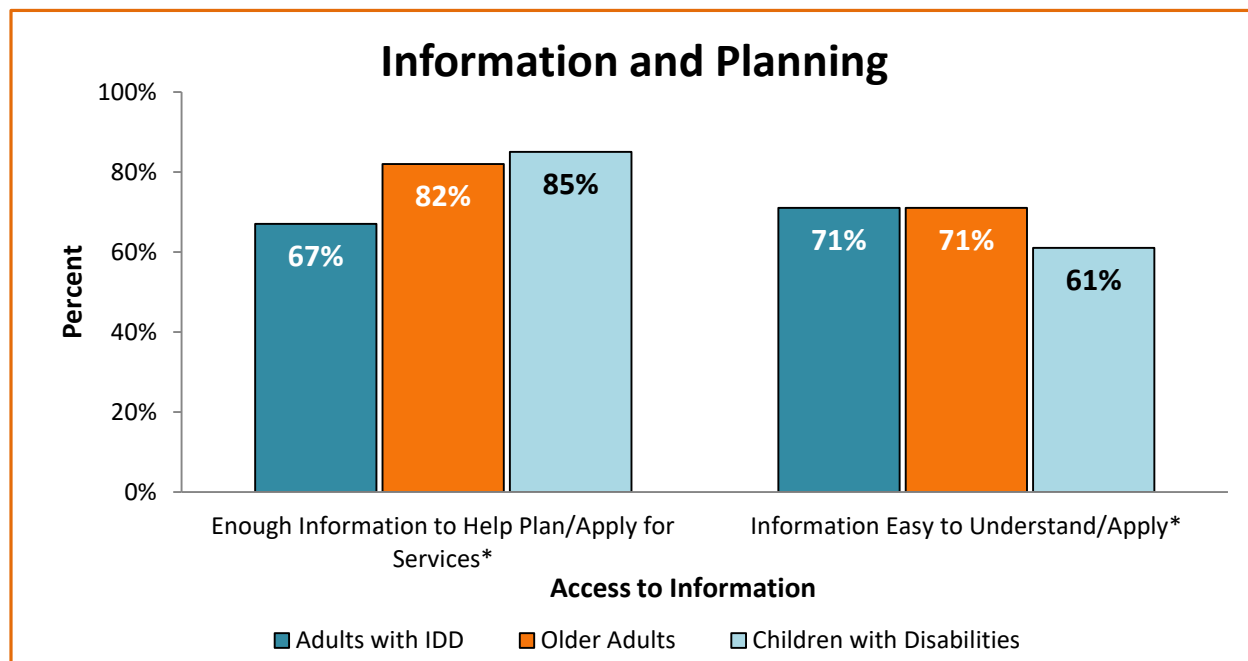
The primary purpose of the LTSS survey is to measure consumer satisfaction with DADS services and supports, a key component of which is system performance. Two key measures of system performance are access to and delivery of services. If consumers do not have access to the services and equipment they need, or do not receive the services or supports 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.

ACCESS TO SERVICES AND SUPPORTS

INFORMATION AND PLANNING

Information about services and consumer participation in service planning are important access issues. More than two-thirds of the respondents for the three surveys said they receive enough information to help plan their family member's services or apply for services – 67 percent in the NCI, 82 percent in the PES, and 85 percent in the CF (see Figure 16). Most reported that the information about services and supports was easy to understand and use (71 percent NCI and 61 percent CF). Most of the adults with physical disabilities (71 percent) said that it was easy to apply for services.

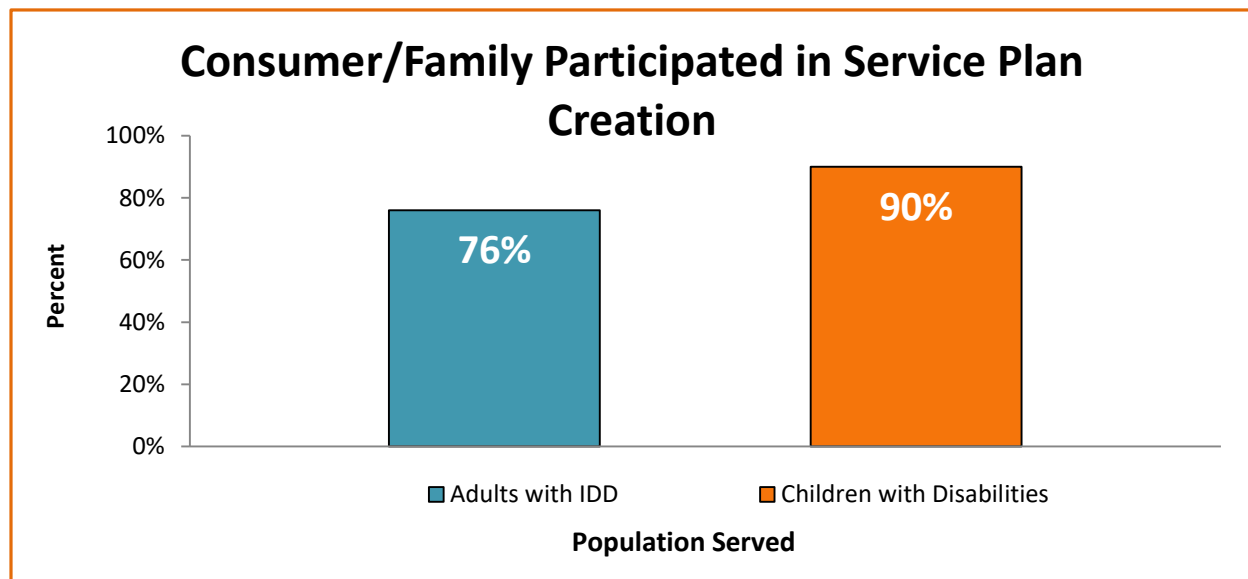
Figure 16. INFORMATION ABOUT SERVICES AND SUPPORTS



*The questions are worded slightly differently in each questionnaire.

As illustrated in Figure 17 below, 76 percent of respondents to the adults with IDD survey and 90 percent of children with disabilities respondents reported they or another family member helped create their family member’s service plan.

Figure 17. PROPORTION OF FAMILIES PARTICIPATING IN SERVICE PLAN CREATION BY SURVEY POPULATION



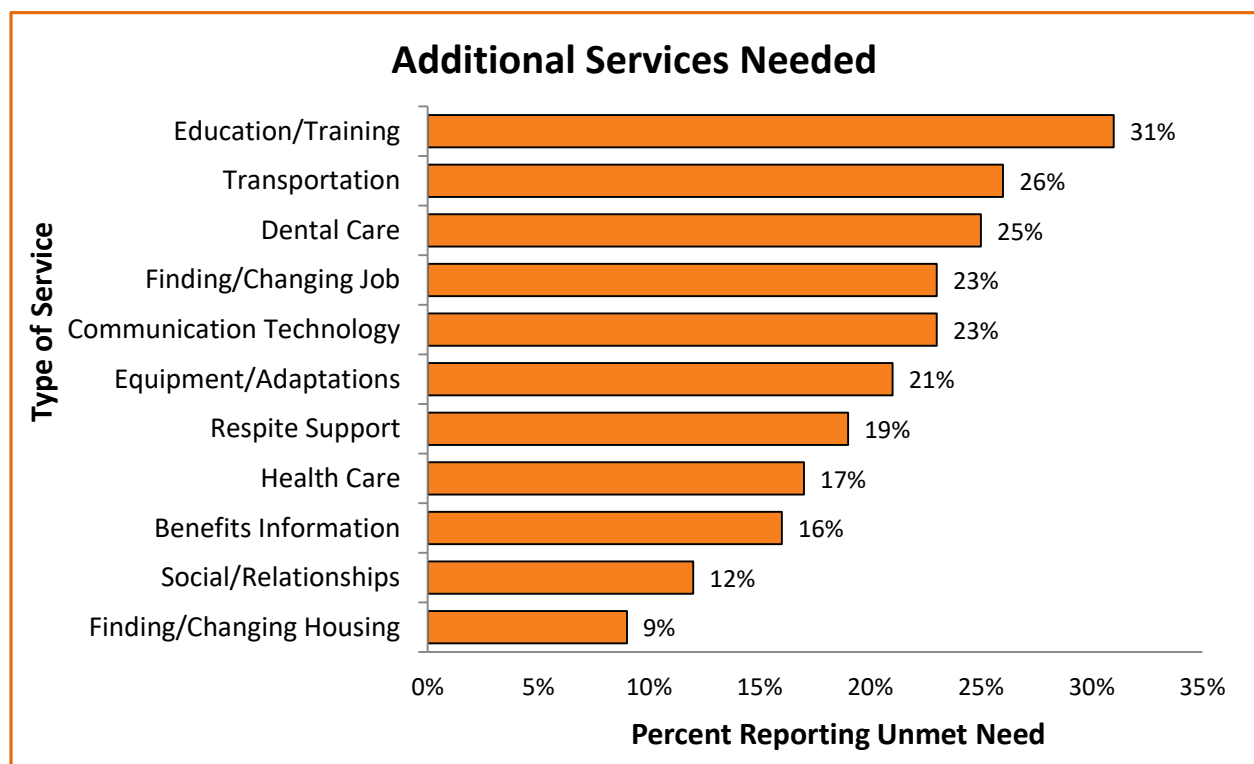
The majority of CF survey respondents knew how to file complaints or grievances about provider agencies or staff (72 percent, compared to 52 percent nationally) and were satisfied with the way complaints and grievances were handled (83 percent). Respondents also knew how to report abuse or neglect (85 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. While the low

rates of reporting abuse are discouraging, the percentage who reported abuse nationally was identical to Texas. Of those who filed a report of abuse or neglect in Texas in the past year, more than eight out of ten (81 percent), found the appropriate parties responsive to their report.

SERVICES NEEDED

The majority of adults with IDD and families of children with disabilities reported that they received, or their service plan included, the services they needed (89 percent NCI and 72 percent CF). The unmet needs of the three populations, however, were very different. Among adults with IDD who needed additional services, the most commonly specified needs were: education/training (31 percent), transportation, (26 percent), dental care (25 percent), communication technology, and environmental adaptations/home modifications (23 percent each) presented in Figure 18 below.

Figure 18. REPORTED SERVICE NEEDS OF ADULTS WITH IDD



Approximately 34 percent of adults with physical disabilities requested additional services, equipment, or household modifications from their case manager, and 64 percent reported that those requests were fulfilled. The most commonly requested items 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 respondents requested help with health-care equipment, therapies, or access, and 6 percent requested additional provider assistance with activities of daily living such as bathing, housework, and physical assistance going to and from doctor visits. A new request this survey period was for personal emergency assistance buttons, with two percent (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 one percent (1 percent) of respondents.

DELIVERY OF SERVICES AND SUPPORTS

Quality of delivery of services and supports, for the purpose of this report, is measured by the receipt and completeness of promised services, the manner in which the services were delivered, and the timeliness of those services. 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). Failure of children with disabilities to receive needed equipment has increased since 2013 (Figure 19), when the rate of children receiving all of the services listed in the service plan was higher.

Figure 19. CHILDREN WHO FAILED TO RECEIVE NEEDED EQUIPMENT, TRENDS 2005 – 2015

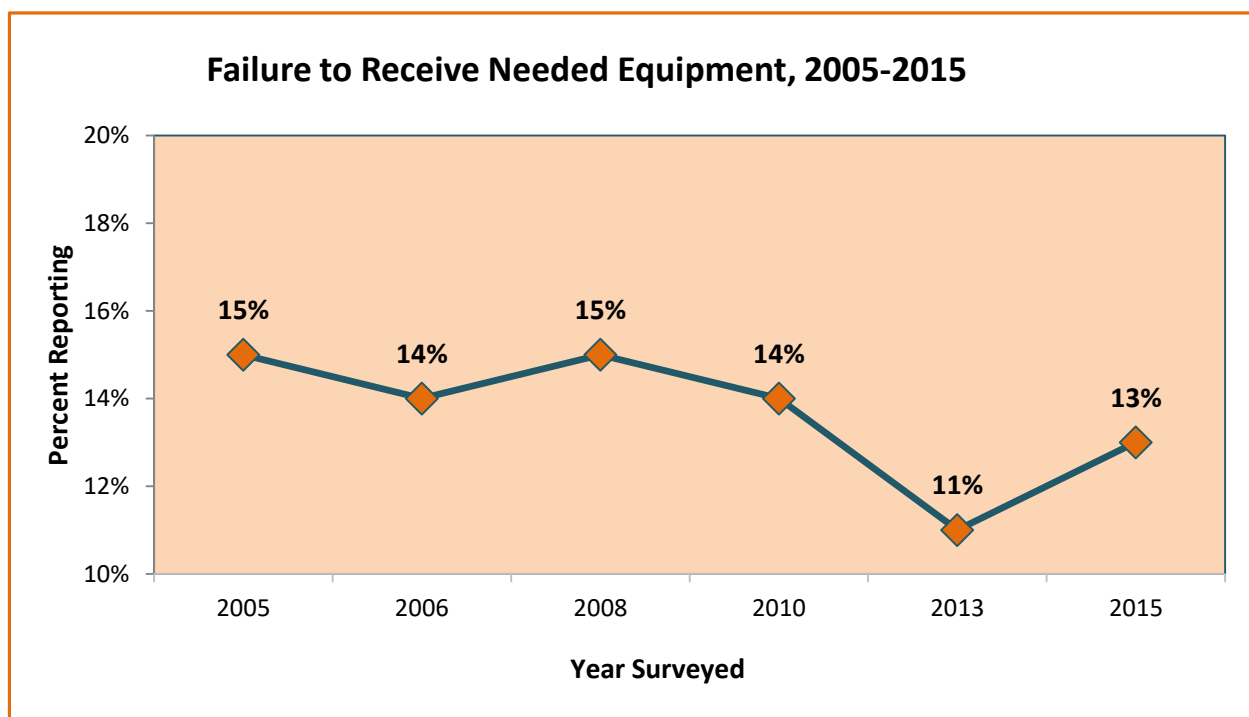
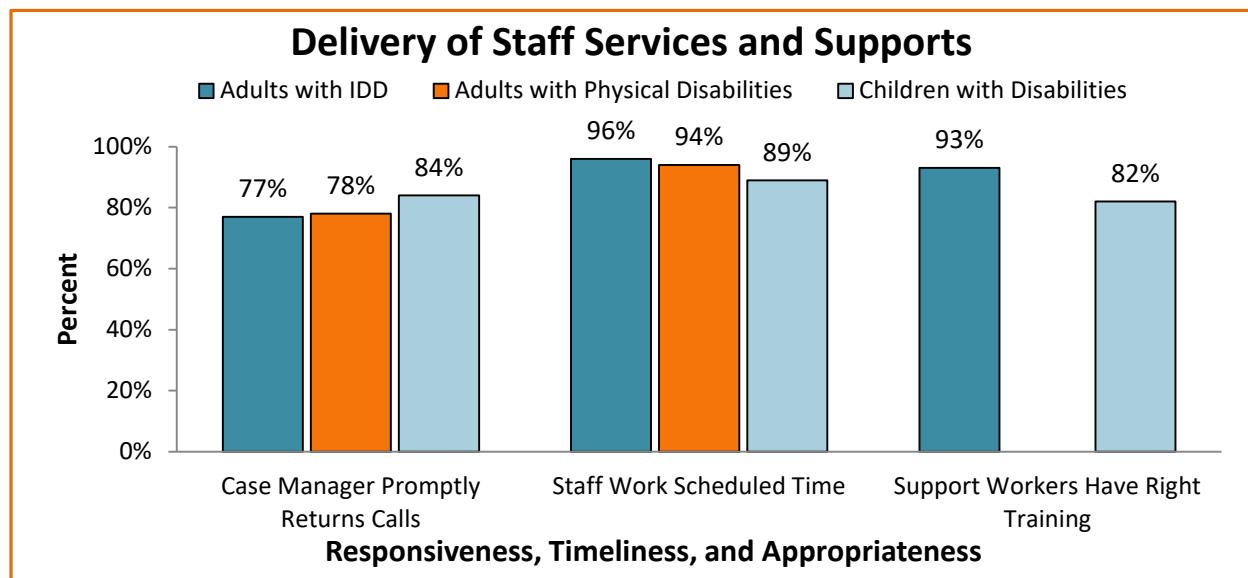


Figure 20 below shows three critical service delivery issues: responsiveness, timeliness, and appropriateness. The responses from all populations are positive for the three measures. Regarding responsiveness, case managers responded promptly when called. The question in the NCI and PES surveys allowed three response choices; “calls back right away” is the response reported here. NCI and PES respondents reported that their case managers called them back right away 77 percent and 78 percent of the time, respectively. The CF survey used a five-point scale; “usually” and “always” are reported here. When the response category “usually” is included with “always,” the percentage of positive responses rises from 58 percent to 84 percent.

Timeliness, as measured by support staff arriving on time and when scheduled, was good for all three surveyed populations, with 96 percent of adults with IDD, 94 percent of adults with physical disabilities, and 89 percent of families of children with disabilities reporting that their support staff were prompt and came when scheduled. The appropriateness measure was also positive, with 93 percent of adults with IDD and 82 percent of children with disabilities reporting that their support staff have the right training. This question was not asked in the PES survey.

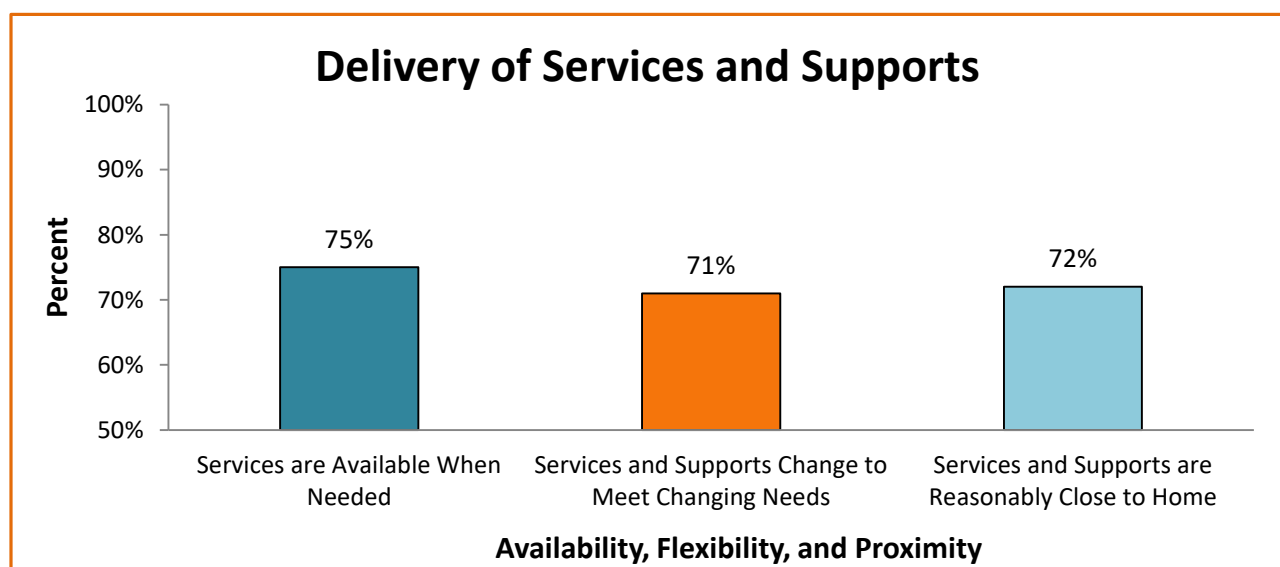
Figure 20. RESPONSIVENESS, TIMELINESS, AND APPROPRIATENESS OF STAFF SERVICES AND SUPPORTS BY SURVEY POPULATION



*The training question was not asked of older adults with physical disabilities.

Figure 21 below also shows critical service delivery issues among families of children with disabilities: availability, flexibility, and proximity. Seventy-five percent (75 percent) of the families reported that services were usually or always available when they needed them; 42 percent said services and supports were *always* available when they needed them, compared to 34 percent nationally. More than two-thirds of the CF survey respondents reported flexible services and supports, which usually changed to meet their family member’s changing needs (71 percent), and 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. All three of these measures exceeded national benchmarks.

Figure 21. AVAILABILITY, FLEXIBILITY, AND PROXIMITY OF SERVICES AND SUPPORTS FOR CHILDREN WITH DISABILITIES



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. The responses ranged from a low of 76 percent, reported by families of children with disabilities, to a high of 97 percent reported by adults with physical disabilities. Many respondents wrote positive comments about their support staff's dedication and caring attitudes.

SERVICES SATISFACTION

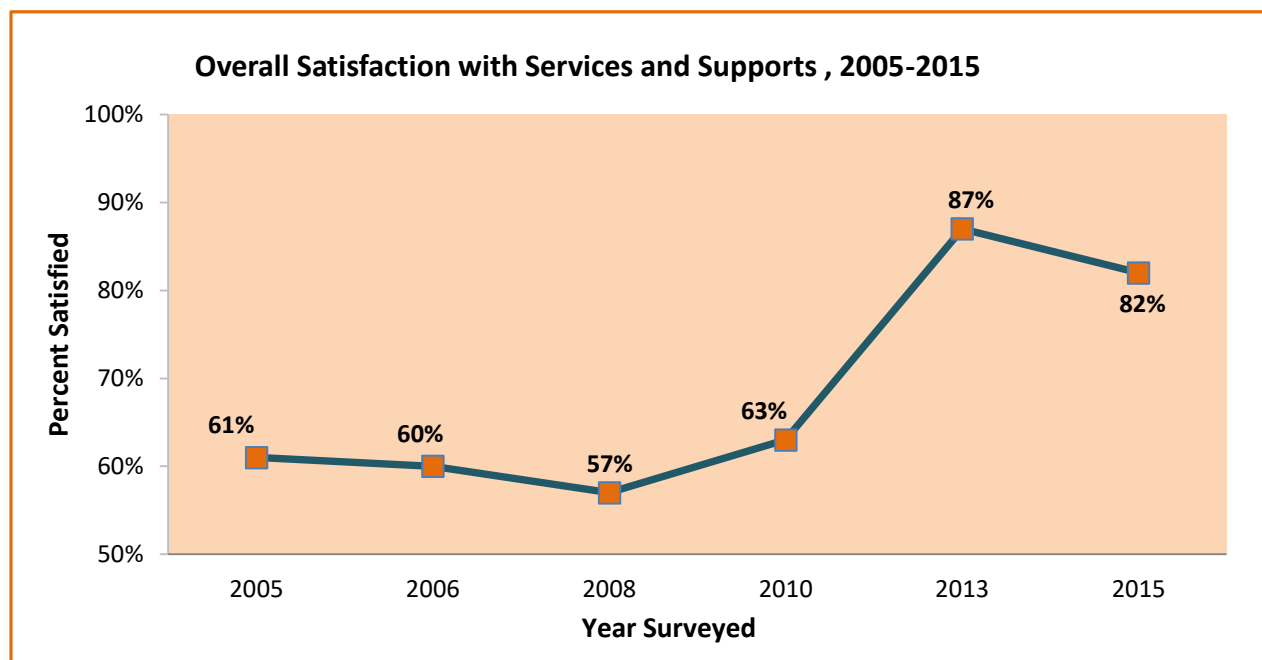
The information above creates a picture of the level of need and satisfaction of people served by DADS. The three surveys also included several specific questions about overall satisfaction as well as how well individual goals and health and wellbeing needs were met.

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

OUTCOMES

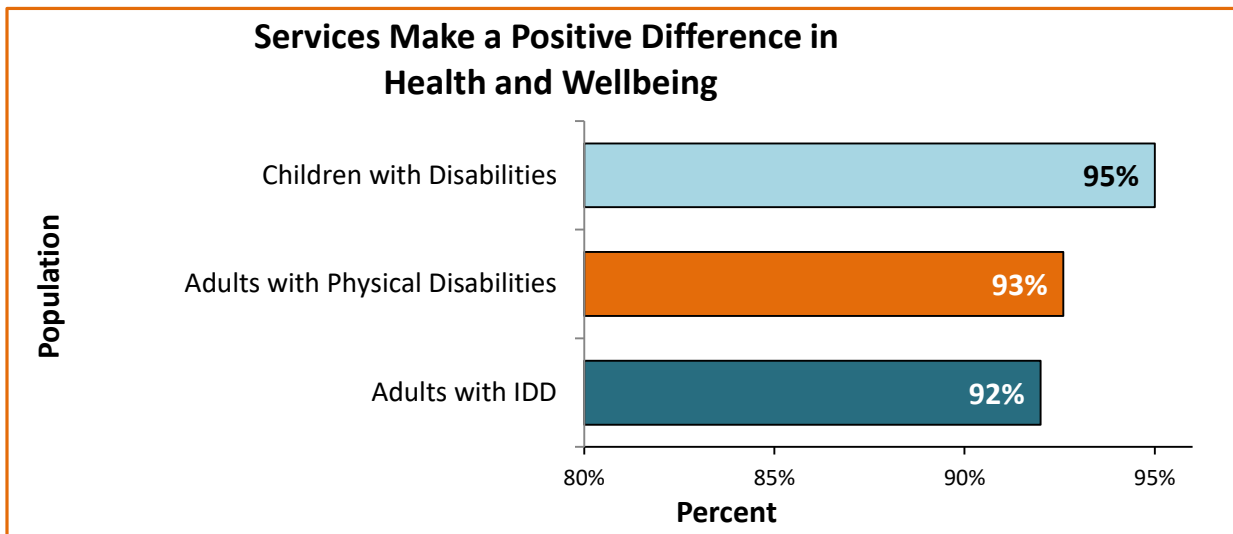
Since the surveys began in 2005, overall consumer satisfaction has improved significantly, as measured by the CF survey (Figure 22), increasing from 61 percent in 2005 to 82 percent in 2015, but falling off from the 2013 high of 87 percent. Among adults with physical disabilities, 91 percent reported they were satisfied.

Figure 22. CHILD AND FAMILY CONSUMER SATISFACTION WITH SERVICES AND SUPPORTS AVAILABILITY OVER TIME



The vast majority of respondents felt the services and supports made a positive difference for them or their family member. The families of children with disabilities reported the highest positive difference, at 95 percent, followed closely by adults with physical disabilities, at 93 percent, and adults with IDD, with 92 percent reporting that services and supports addressed their health and wellbeing (Figure 23).

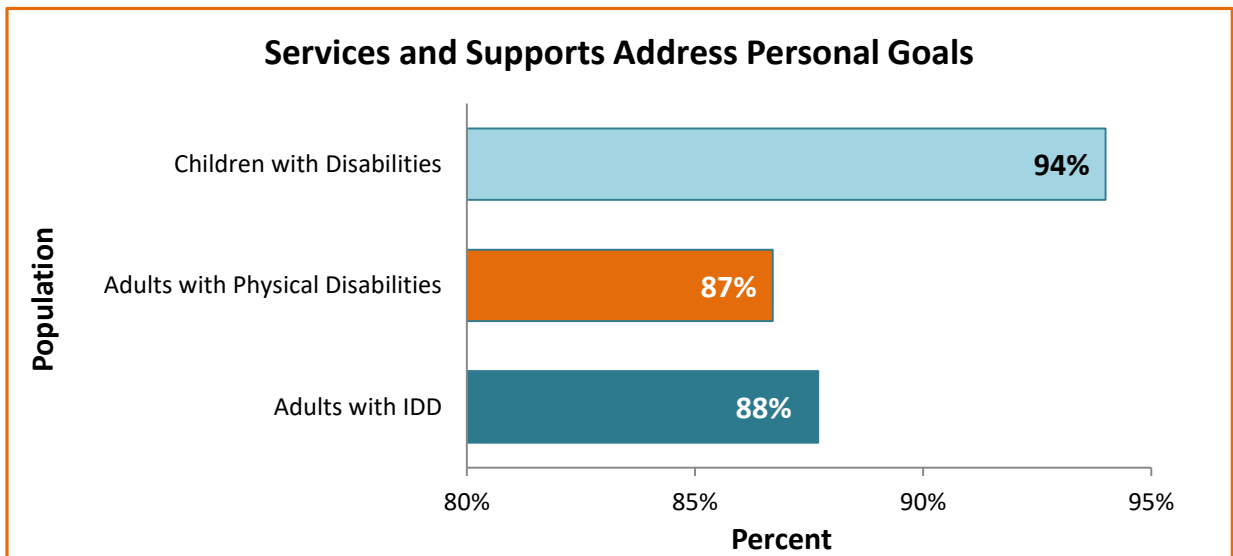
Figure 23. SERVICES AND SUPPORTS MAKE A POSITIVE DIFFERENCE IN FAMILY/INDIVIDUAL'S HEALTH AND WELLBEING



*The question in CF questionnaire is worded slightly differently.

Services and supports also addressed the personal goals of the consumer, or the goal of their family of increasing the family's ability to provide care (94 percent CF, 87 percent PES, and 88 percent NCI), shown in Figure 24 below.

Figure 24. SERVICES AND SUPPORTS ADDRESS PERSONAL GOALS BY SURVEY POPULATION

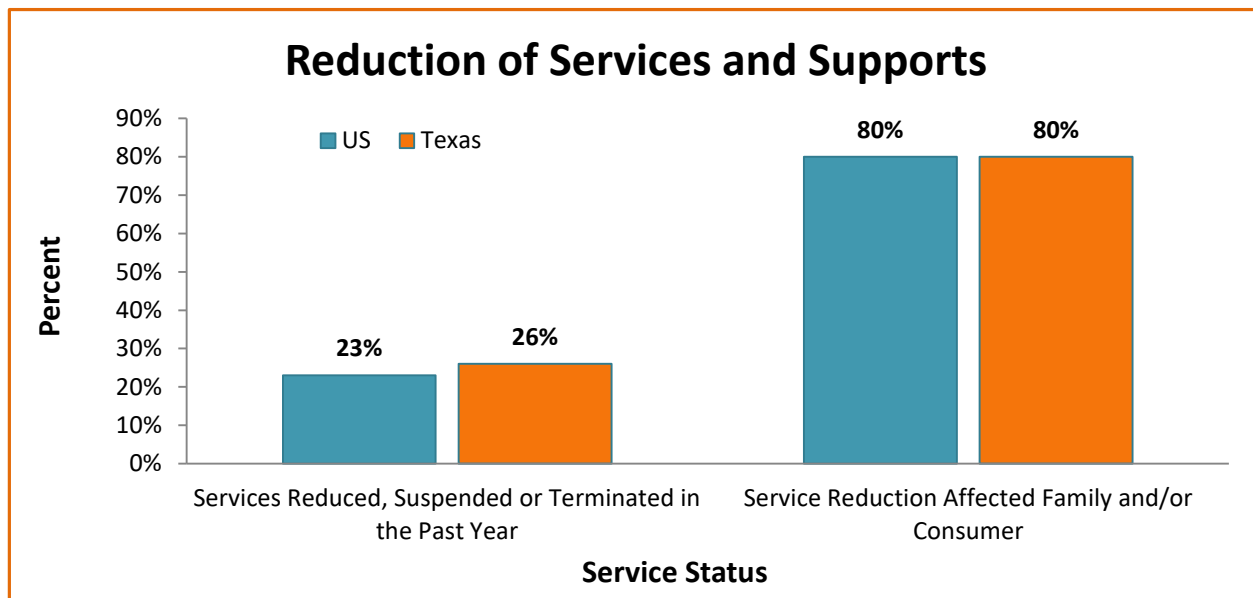


*The question in CF questionnaire is worded slightly differently.

REDUCTION OF SERVICES AND SUPPORTS

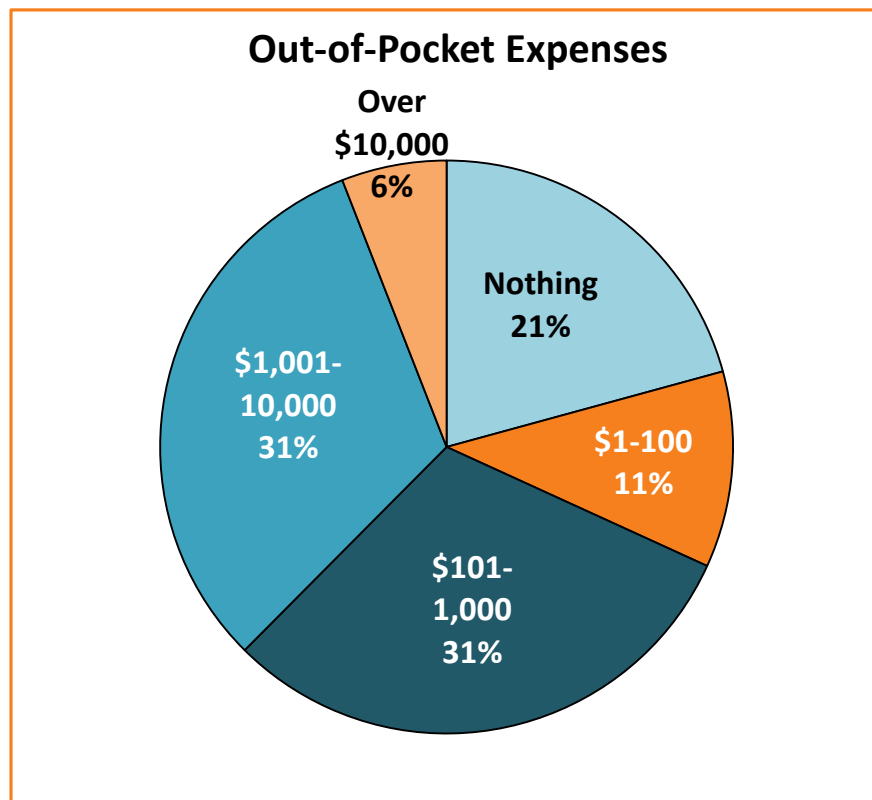
The positive responses presented above occurred as services and supports were being reduced for many families. Only the CF survey asked questions about service reductions and the impact upon their families. As illustrated in Figure 25 below, approximately one-fourth of respondents in Texas and nationally reported that the services for their children with disabilities had been reduced, suspended, or terminated in the past year (23 percent nationally; 26 percent Texas). Of the respondents whose family member had services reduced in the past year, 80 percent in both Texas and the US said the reduction had negatively affected their family member.

Figure 25. COMPARISON OF SERVICES AND SUPPORTS REDUCTIONS AND THEIR IMPACT ON FAMILIES BETWEEN TEXAS AND US CHILD AND FAMILY SURVEY HOUSEHOLDS



These service reductions resulted in an increase in out-of-pocket expenses for families to secure needed services (see Figure 26 below).

Figure 26. ANNUAL OUT-OF-POCKET EXPENSES NOT COVERED FROM 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. Meanwhile, annual out-of-pocket expenses for more than one-third (38 percent) of the CF survey households exceeded \$1,000, and 6 percent reported out-of-pocket expenses of more than \$10,000. Figure 26 shows the annual out-of-pocket expenses for families of Texas children with disabilities.

ACCOMPLISHMENTS, ACTIVITIES, AND ON-GOING EFFORTS

The results of the surveys were encouraging. Texas exceeded national benchmarks for more than half of the measures for adults with IDD and children with disabilities. In adult programs, the vast majority of people felt supported in their community participation and activities of daily living and have the services and supports needed to meet their personal goals. When looking at routine and preventive health care, DADS adults with IDD met or received more health care on recommended schedules than the national average for 9 out of 10 health care indicators. Five of the 10 health care indicators were statistically significantly higher.

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

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 consumer-directed services more frequently than adult consumers. Adults with IDD reported the ability to make everyday choices, such as how to use their free time or spend money, but less choice with selecting their staff or housing. Among all programs, a majority of the respondents reported that support staff were adequately trained and respectful.

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 a lack of control and access to transportation when they needed it. Limited transportation reduces opportunities for people to engage in community activities, to work, or to readily access preventive healthcare. Not surprisingly, transportation difficulties correlated highly with lower levels of community involvement and participation in integrated activity settings.

Overall, the surveys identified many positive outcomes and some opportunities for improvement. The following presents a sample of these findings, including findings from the Detailed Report not included in this summary report. To see those results, please refer to the 2017 Detailed Report.

IMPORTANT POPULATION CHARACTERISTICS

- Among adults with IDD, levels of impairment and the need for medical care varied widely by program.
- Among adults with physical disabilities, the survey underscored the importance of non-technical help with instrumental activities of daily living—for people with disabilities living in the community, help with laundry or grocery shopping, for example, is essential.

POSITIVE OUTCOMES

- Individuals reported satisfaction with their residence (varying by program from 79 percent to 93 percent), jobs, and day programs (86 percent to 94 percent).
- All 10 routine and preventive health measures met or exceeded the national averages; 5 of the Texas health measures were higher by statistically significant margins.
- The majority of individuals reported that their rights are respected, they are respected by support staff, they are satisfied with their privacy, and they feel safe in their homes.

- The majority of the participants in IDD programs (87 percent to 95 percent) reported that they know their case managers, with the exception of participants in the SSLCs, where only 27 percent reported that they knew their case manager. The lower percentage for SSLCs may result from the use of the term “case manager.” Residents of SSLCs are familiar with the term “Qualified Intellectual Disability Professional,” or QIDP, for staff that coordinates their services.
- Among all programs, participant satisfaction with service availability ranged from 71 percent to 87 percent. The vast majority of individuals across programs said their case managers help them get what they want and need.
- Services and supports made a positive difference in respondents’ lives.

OPPORTUNITIES FOR IMPROVEMENT

- Between 22 percent and 65 percent of adults in all programs reported control over their transportation. The rest depend upon the decisions and willingness of others to get to their destinations.
- Most adults with IDD did not have options about where they lived. Individuals in community-based housing and ICF facilities (approximately 38 percent each) and individuals in state supported living centers (18 percent) reported they have options regarding choice of residence.
- About one-third of the adults with physical disabilities reported that they have enough money to buy the things they want.
- Cancer screening protocols need to be reviewed for all adults receiving DADS services and brought into compliance with current American Medical Association and American Congress of Obstetricians and Gynecologists, and United States Preventive Services Task Force recommendations for cancer screening.
- About one-third of adults with physical disabilities are lacking important immunizations – 32 percent lack influenza vaccinations, and 29 percent lack pneumococcal vaccinations. Since individuals in this group have significant health risks, lack of immunization is a concern.
- Again in adults with physical disabilities, large percentages had not had recent dental (62 percent), vision (42 percent), or hearing (62 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.
- Among adults, the use of psychiatric drugs without a corresponding psychiatric diagnosis is troublingly common. While the gap has narrowed since the 2015 report, the discrepancy may reflect the inappropriate use of psychoactive drugs.

Overall, the survey results indicate that people are receiving the services and supports they need to maintain their health and wellbeing. Respondents’ 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 among adults with IDD and children. The results of the LTSS survey positively reinforce internal and external strategic initiatives.

Finally, these survey results are a valuable part of a much broader quality management 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.

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LINKS TO REPORTS

Detailed report is available on the HHS website.

