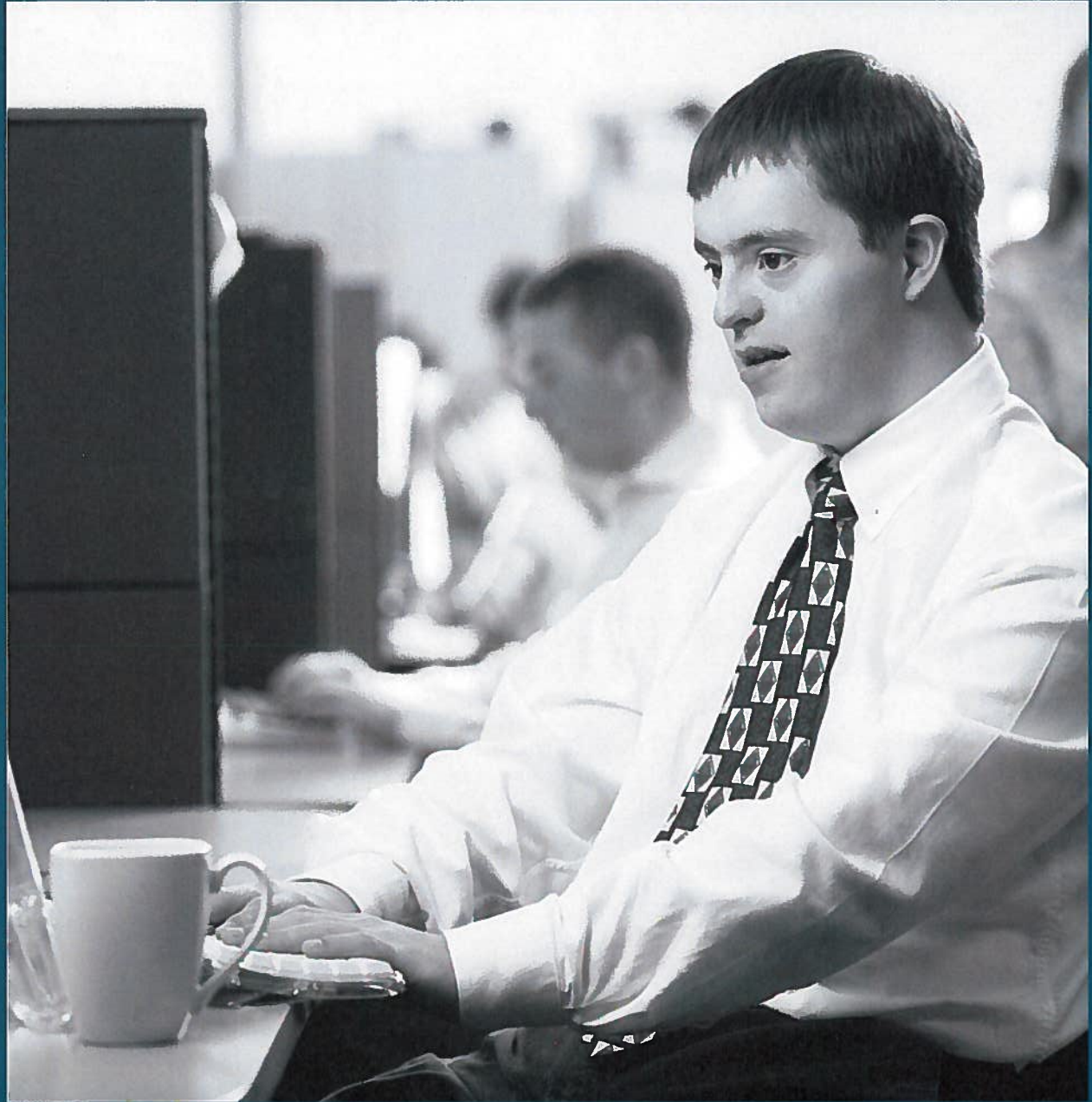


LONG-TERM SERVICES AND SUPPORTS QUALITY REVIEW



LTSS

BIENNIAL SUMMARY REPORT 2015

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EXECUTIVE SUMMARY

PURPOSE: The Texas Department of Aging and Disability Services (DADS) administers multiple long-term services and support programs for the aging, for people with intellectual or developmental disabilities (IDD), and for people with physical disabilities. The Long-term Services and Supports Quality Review (LTSS) is a statewide survey of people receiving services and supports through home and community-based and institutional programs 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 over time.

FINDINGS: Findings from LTSS 2015 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 their 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. More detail is provided below.

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.

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 well-being, dignity, and choice.

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.

METHODS: DADS used three nationally recognized survey instruments for measuring specific consumer indicators – the National Core Indicators Adult Consumer (NCI) and National Core Indicators Child and Family Survey (CF) for the IDD population, and the Participant Experience Survey Elderly/Disabled (PES) version for older individuals with a disability. The LTSS 2015 survey collected data from 4,469 adults and 1,430 families of children with disabilities from April through November 2013. Data were collected on the following broad domains: services satisfaction, systems performance, health and welfare, individual choice and respect, and work and community inclusion.

BACKGROUND AND HISTORY

The Long-Term Services and Supports Quality Review (LTSS) report is mandated by the Texas Legislature, 2014-2015 General Appropriations Act, Article II, and the Department of Aging and Disability Services (DADS), Rider 13, House Bill 1, 83rd Legislature, Regular Session, 2013. 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 with understanding how DADS consumers feel about their quality of life.

The report enables 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.

A task force was created to determine 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 in home and community-based programs. 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 (ICF/IID).

LTSS Vision:

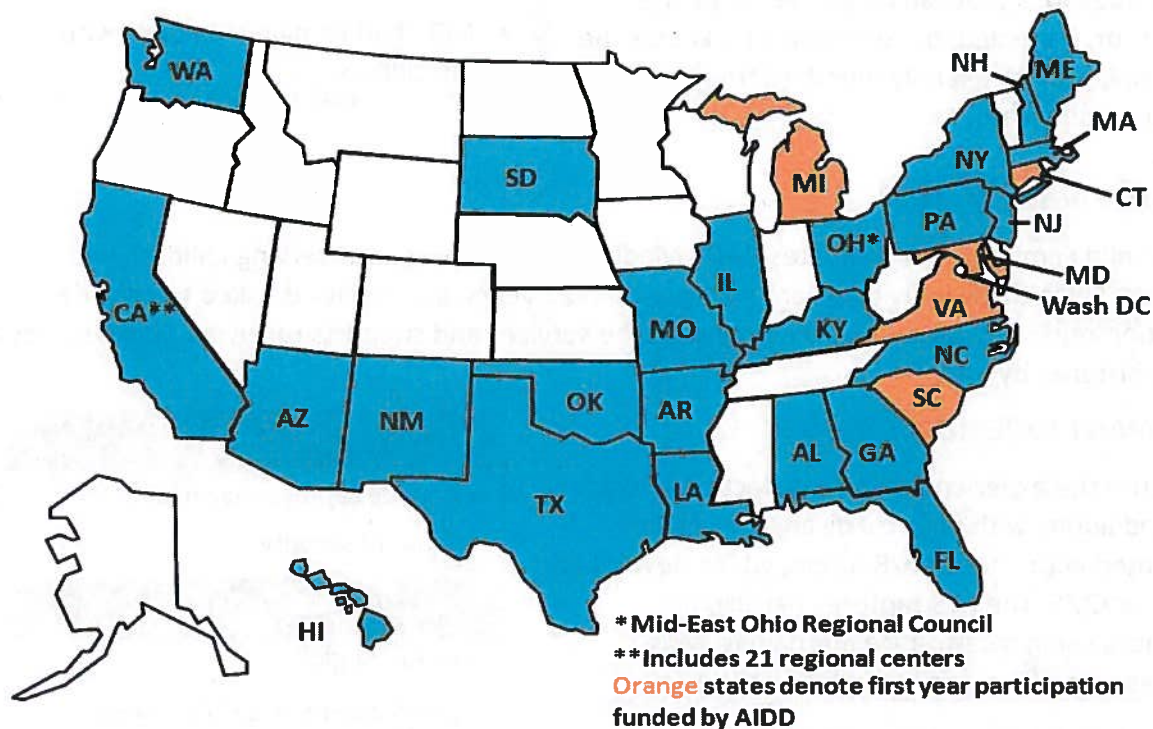
- Improve practice at the state level
- Influence state and national policy
- Add knowledge to the field
- Inform stakeholders for strategic planning and priority setting

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 consumers with disabilities, the Thomson/Reuters' Participant Experience Survey (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 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 (NASDD) 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 29 states. In 2012, NCI surveyed more than 20,000 individuals and families (Figure 1).

Figure 1. STATES PARTICIPATING IN NCI SURVEYS 2011 - 2012



Source: National Core Indicators' Annual Summary Report 2011-2012, NASDD & HSRI, November 2013

DATA COLLECTION INSTRUMENTS

This report is developed from three nationally validated survey instruments that 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.

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.

LTSS Created From 3 Surveys:

- NCI Adult Consumer – Adults with IDD
- PES – Elderly with disabilities
- NCI Child Family – Children with disabilities

NCI CHILD FAMILY SURVEY

The NCI Child Family survey evaluates DADS Medicaid waiver programs serving children with disabilities. Since 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.

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 interviews. Most responses come from the individual, not a proxy.

CORE PERFORMANCE INDICATORS

The three surveys are organized across five general topics: services satisfaction, systems performance, health and welfare, individual choice and respect, and community inclusion – 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/>.

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

Domains and Sub-domains addressed in this report

METHODS

DATA COLLECTION

DADS contracted with an external vendor, the Nurse Aide Competency Evaluation Service Plus Foundation, Inc. (NACES), to administer the surveys. NACES hired and supervised the interviewers, who participated in a standardized training program. The interviewers were licensed nurses and social workers, all disinterested third parties, and experienced in working with individuals who are aging or have disabilities. Interviews took place in the individual's home unless he or she chose an alternative location. To prepare for the interviews, NACES staff obtained pre-survey, background, and day activity information from program providers. The demographic data provided by automated DADS systems 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 elderly, are gathered using the PES in face-to-face interviews. Information about children with disabilities is gathered from their families using the NCI Child Family survey, which is administered by mail. DADS typically interviews a random sample of 4,000 to 6,000 individuals for each report.

PROXY RESPONDENTS

For all survey questions where a proxy was needed and allowed, respondents were most frequently a parent of the family member with a disability (86 percent NCI, 41 percent PES, 94 percent CF). Other respondents included a sibling or other family member. In some cases a staff person completed the survey.

SAMPLE CHARACTERISTICS

TARGET POPULATION

The sampling goal of the 2013 LTSS survey for the 2015 report was to interview a representative sample of individuals from all DADS programs. Table 1 below provides an overview of the target populations. The survey population encompasses 22 programs, including six 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 TARGET POPULATION BY DATA COLLECTION INSTRUMENT 2013

| Survey | Target Population | Method of Administration | Total # Served | Total # Surveyed |
|----------------------------|---|--------------------------|----------------|------------------|
| NCI Survey | Adults 22 and older with IDD receiving at least one service besides case management | In-person interview | 31,949 | 1,699 |
| PES Survey | Adults, primarily older adults, with physical disabilities | In-person interview | 112,989 | 2,770 |
| Child Family Survey | Families of children with disabilities, under 22 living at home | Mail | 10,631 | 1,430 |

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 2013, DADS collected 4,469 adult face-to-face surveys (1,699 adults with IDD and 2,770 older adults with physical disabilities highlighted in Table 1 above), and 1,430 CF surveys.

5,899
 Consumers interviewed for
 the *Long-term Services and
 Supports Quality Review
 2013*

SAMPLING PERIOD

The data for the 2013 LTSS report were collected between April 2013 and November 2013 for the January 2015 legislative report. 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 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 children and adults (HCS, CLASS, and TxHmL). Samples were chosen from each program for the children and for the adults.

In addition to sampling by program, the 2013 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 |
| 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 | | | | | | | ✓ |
| Hospice | 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 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.

OVERVIEW OF REPORTS

For 2015, DADS produced three versions of the LTSS Survey Report: a one-page data brief to provide key information at a glance, 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 all three versions of the LTSS 2015 reports are available at: <http://LTSS.dads.state.tx.us/reports>.

This report is the LTSS Biennial Summary Report 2015, featuring data collected in 2013 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.

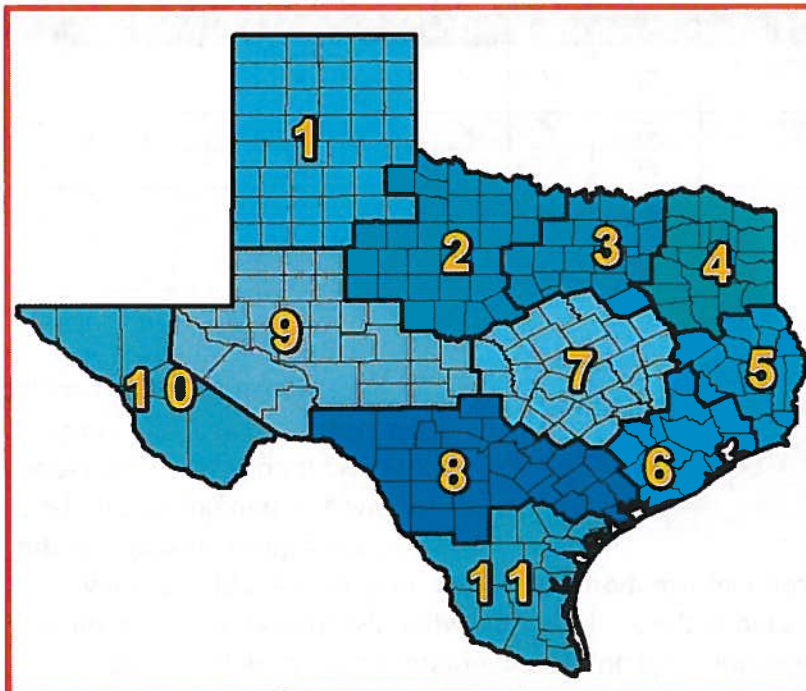
Fact: People living with disabilities don't all have the same experiences or the same perspective.

SELECTED 2013 LTSS SURVEY RESULTS FOR THE 2015 REPORT

PROGRAM ENROLLEMENT 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 make accurate statements based upon the responses. Selecting a sample across 11 geographic public health regions and 22 programs is difficult. Regional and program-specific data are presented in the comprehensive 2015 Long-Term Services and Supports Survey 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 exactly 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.

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 participants in these programs have an intellectual disability and are presumed to need some support and guidance 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 and whose medical needs qualify them for nursing home services. Services in these programs can include community inclusion, respite care, assistance with transportation, and assistance in obtaining medical care.

The PES is used for adults whose physical disabilities place them at risk of entering a nursing facility (NF). Many already qualify medically for NF 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 matters are not included in 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 (60 percent for both), while two thirds (67 percent) of the adults with physical disabilities responding to the PES survey were female. On average, individuals for whom the PES survey was completed were approximately three decades older than those completing the NCI survey (69 years compared to 41). 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. An overview of respondent demographics for both adult populations is presented in Table 3 and Table 4. CF survey demographics are presented in Table 5.

Table 3. 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 60% | Range 22-95 | White 55% | African American 16% | English 92% | Lives with parents/relatives 50% | ICF group home 32% |
| Female 40% | Average 41 | Hispanic 27% | Other 2% | Other 8% | Lives alone 6% | SSLC 12% |

Table 4. 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 33% | Range 18-103 | White 33% | African American 27% | English 74% | Lives with parents/relatives 42% | Lives with others 6% |
| Female 67% | Average 68 | Hispanic 34% | Other 6% | Spanish 25% | Lives alone 52% | |

Table 5. GENDER, AGE, RACE/ETHNICITY, PRIMARY LANGUAGE AND RESIDENCE OF CHILD SURVEY PARTICIPANTS

| Children with Disabilities | | | | | | |
|----------------------------|---------------|-----------------|-------------------------|------------------|----------|-------------------------------------|
| Gender | Age | Race/Ethnicity | | Primary Language | | Residence |
| Male 60% | Range 1-22 | White 47% | African American 14% | English 83% | | Lives with parents/relatives 99% |
| Female 40% | Average 14 | Hispanic 34% | Other 5% | Spanish 11% | Other 5% | Live elsewhere 1% |

RESIDENCE

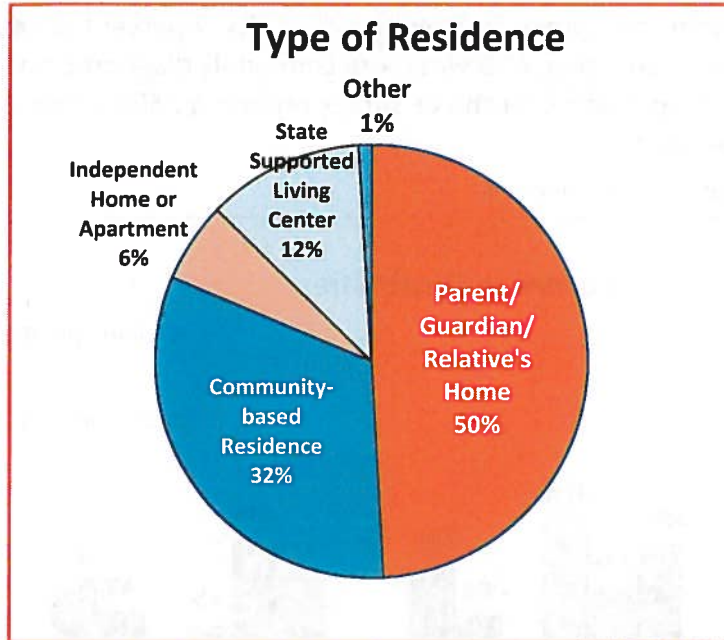
Half of the adult respondents with IDD lived with their parents, relatives or guardians (50 percent), see Figure 3 below. A lower percentage of adults with physical disabilities lived with relatives (42 percent). Adults with IDD who did not live with relatives most frequently lived in community-based residences (32 percent) or group home settings, such as large

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.

intermediate care facilities or state supported living centers (12 percent). Among adults with physical disabilities, 52 percent reported they lived alone. More than 99 percent of the children surveyed lived with their parents or relatives.

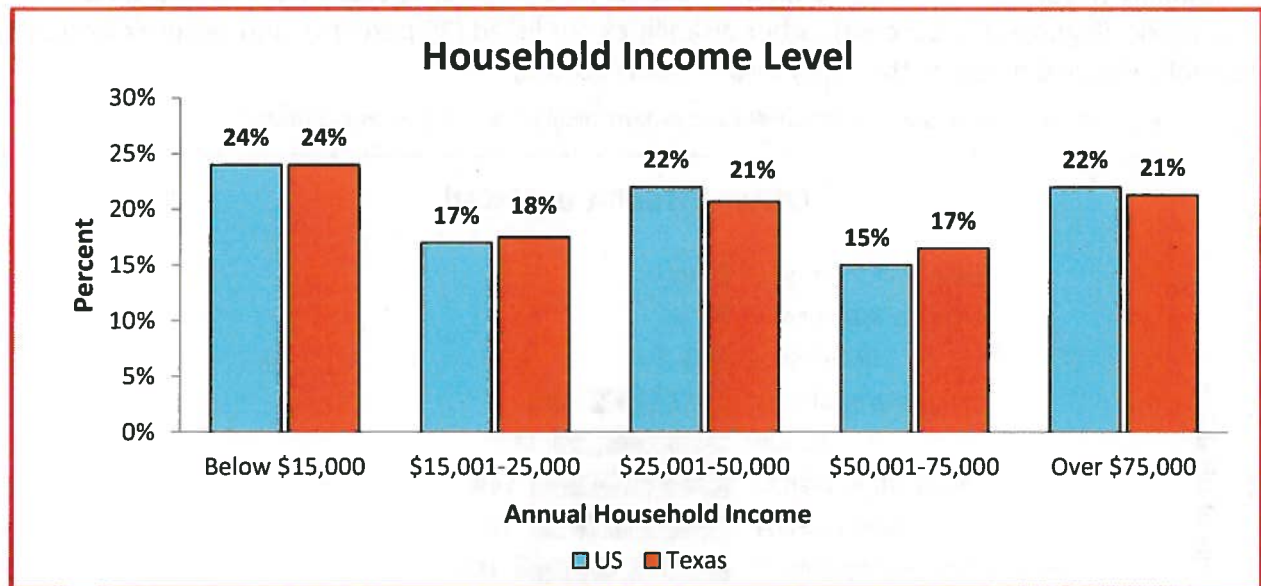
Figure 3. PROPORTION OF ADULTS WITH IDD BY TYPE OF RESIDENCE



INCOME LEVELS

Household income information was collected in the CF survey. A majority of respondents fall within a range at or below \$25,001 to \$50,000 per year (see Figure 4 below). Income levels for respondents to the survey in other states were similar to Texas.

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

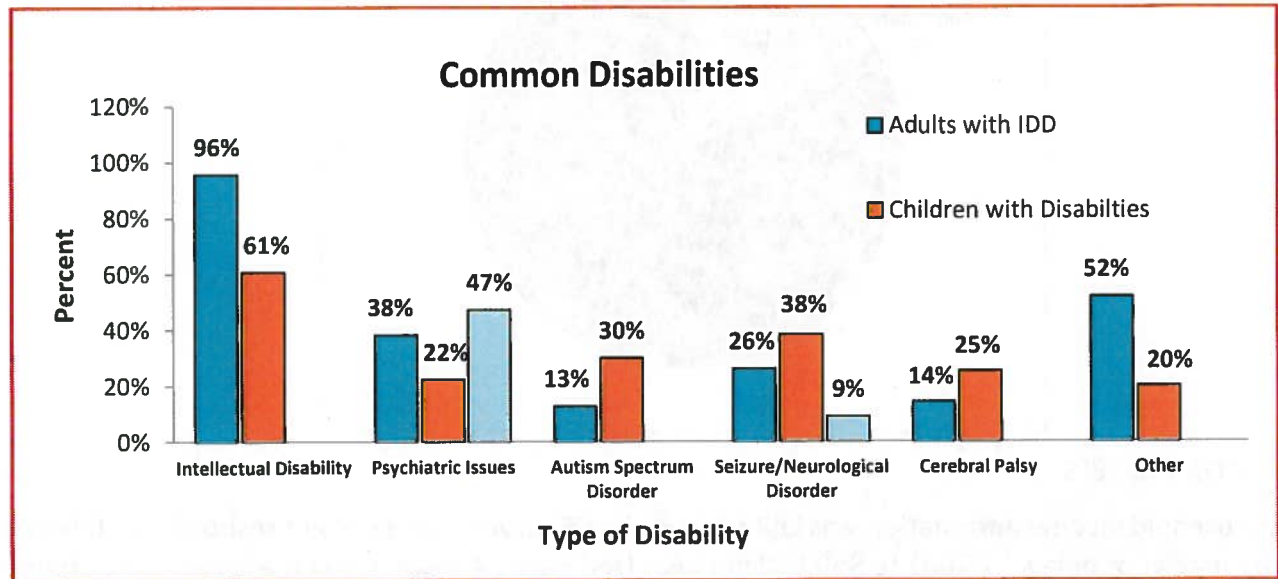


DISABILITIES

As illustrated in Figure 5, the most commonly reported primary disabilities were intellectual disability, mental illness, autism spectrum disorder (ASD), seizure/neurological disorder, and cerebral palsy. A majority of adult consumers taking the NCI survey had an intellectual disability (96 percent) and almost two-thirds of children had this diagnosis (61 percent). The question about

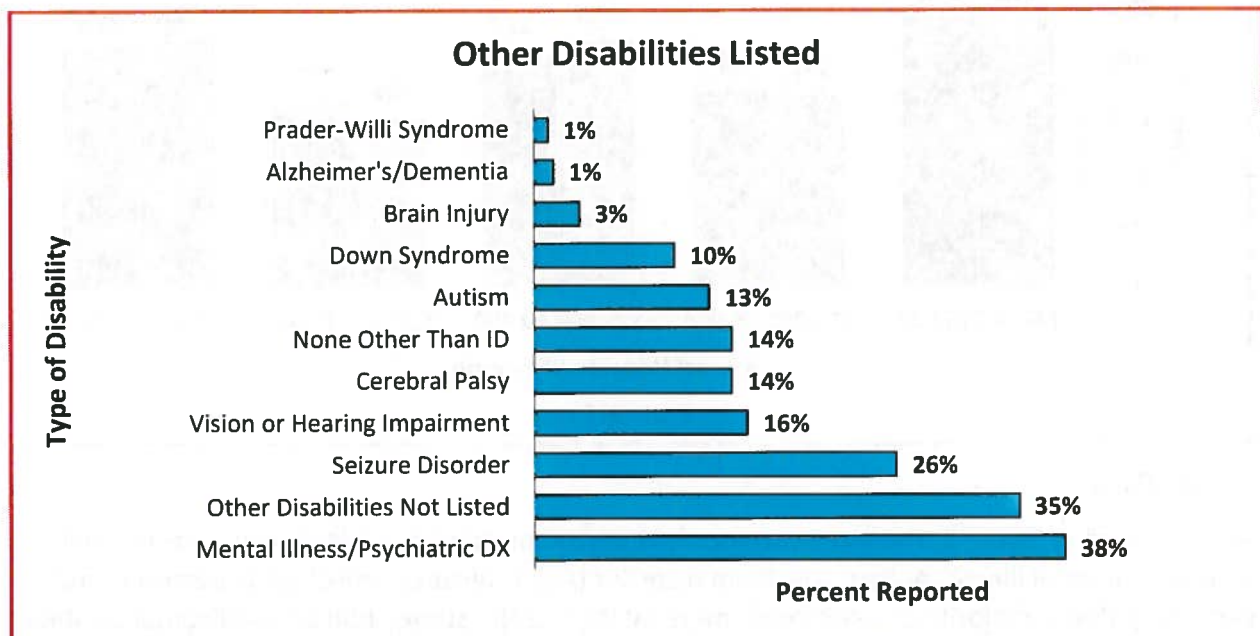
intellectual disabilities was not asked in the PES survey of adults with physical disabilities, but using guardianship/conservatorship as a proxy for cognitive disability, 7 percent of adults with physical disabilities reported having a guardian. ASD was more commonly diagnosed among children, with more than twice as many respondents for the CF survey reporting ASD (30 percent) compared to adults with IDD (NCI 13 percent).

Figure 5. MOST COMMON DISABILITIES BY SURVEY TYPE



The majority of people surveyed among adults with IDD (85 percent) reported more than one type of disability (Figure 6). The most common secondary disabilities reported were mental illness or psychiatric diagnosis (38 percent), other disabilities not listed (35 percent), and seizure disorder (26 percent). Figure 6 presents the other disabilities reported.

Figure 6. PROPORTION OF ADULTS WITH IDD HAVING SECONDARY DISABILITIES BY TYPE OF DISABILITY



HEALTH AND WELFARE

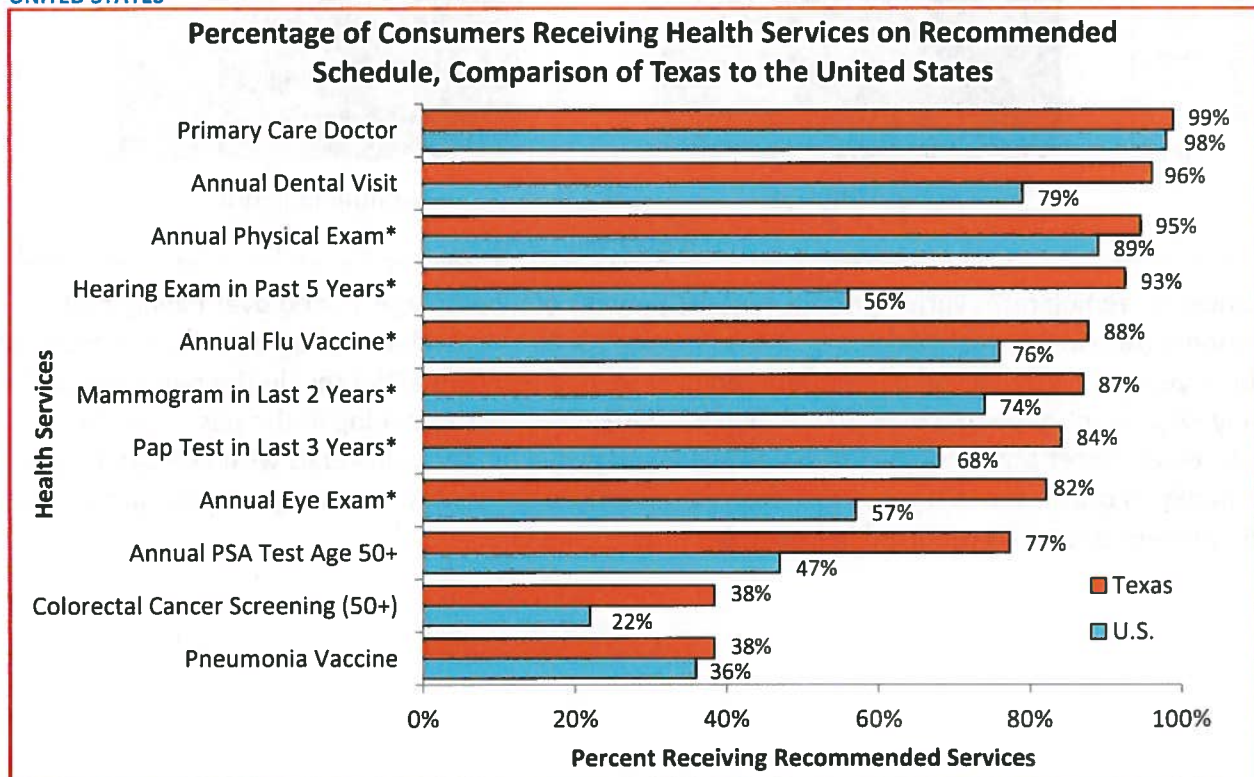
Findings

- Texas adults with IDD received more routine and preventive health care than people with IDD nationally, and also received significantly higher rates of care on six of 11 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 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 (98 percent of NCI and 66 percent of PES respondents, respectively). The surveys collected health indicator information. Five percent of the adults with IDD and 20 percent of adults with physical disabilities used tobacco products, and 31 percent of the NCI and 45 percent of the PES respondents' BMI scores indicated that they were obese. Reported mobility – the ability to move around their environment – was high for both groups (92 percent NCI and 89 percent PES). Most of the adults with IDD surveyed had routine health care, 99 percent had a primary care doctor, and 95 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 was not collected in the PES.

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



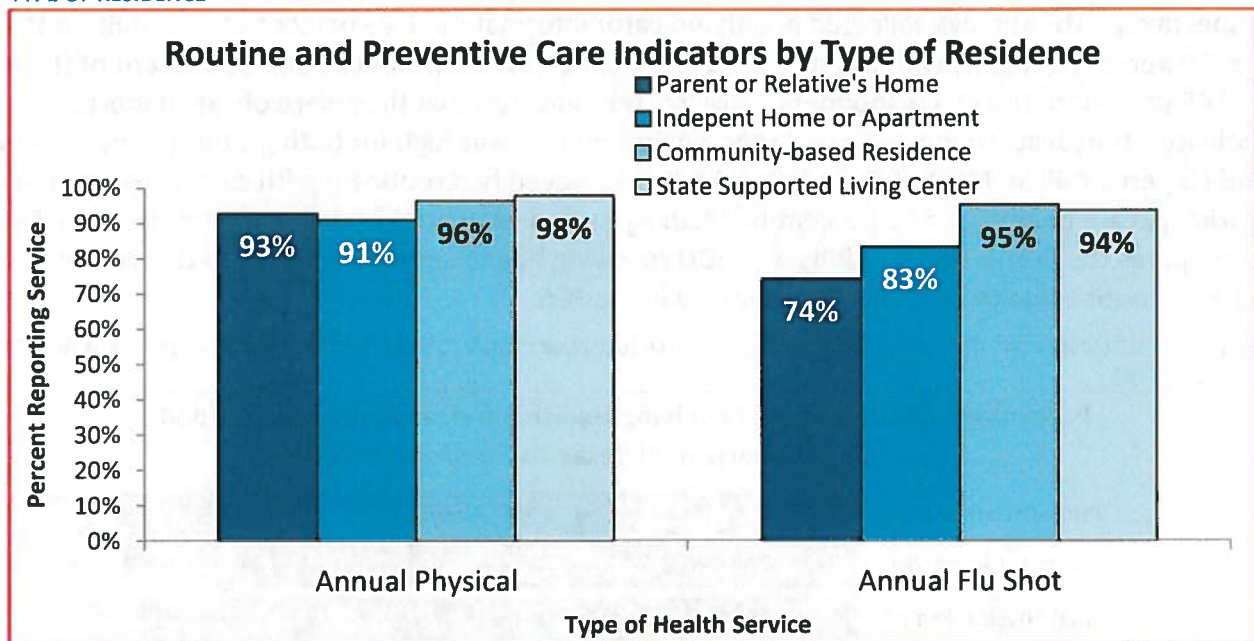
* Statistically significantly higher rates than the national average.

The proportion of people with IDD who received more specialized preventive health care was also high. Of Texas respondents, 96 percent had visited a dentist in the past year, 93 percent had received a hearing exam in the past five years, 82 percent had received an eye exam in the past year, and 88 percent had received a flu vaccination in the past year, exceeding national rates in all categories. Texas rates exceeded U.S. rates on every health indicator reported and were significantly higher for six out of the 11 health indicators.

96% of respondents had an annual dental exam

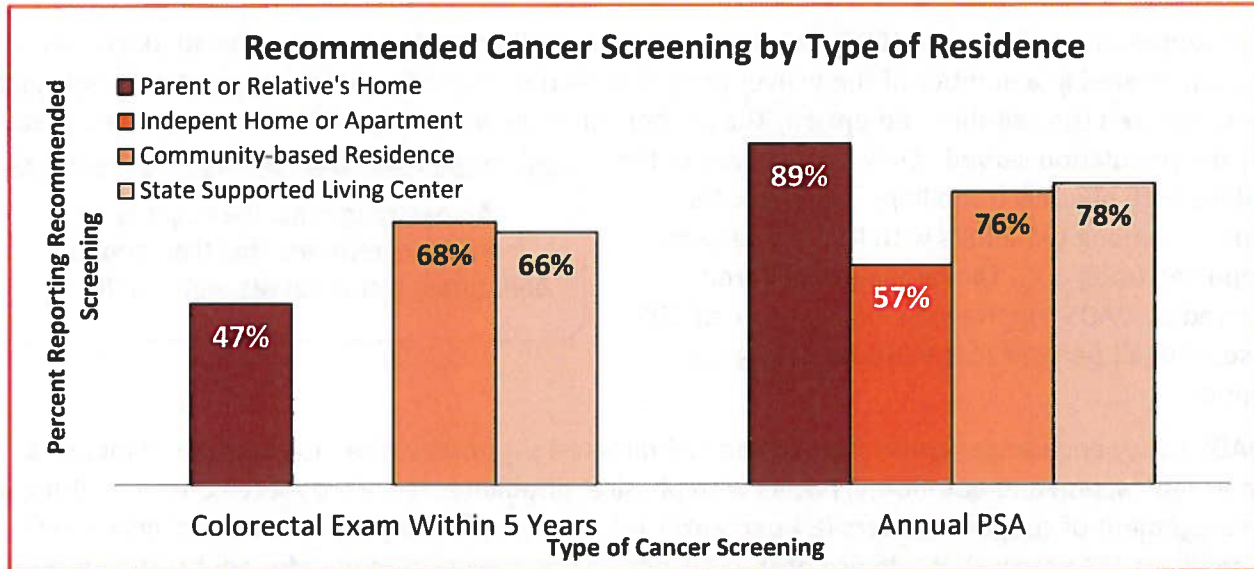
Rates of routine and preventive health care tests and exams varied by where adults with IDD resided (Figures 8 and 9). Figure 8 illustrates the variation in routine (annual physicals) and routine preventive health care (annual flu shot) by type of residence, while Figure 9 presents selected cancer screening data (colorectal cancer and prostate cancer (PSA) screening) 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, with 87 percent of women age 40 and over having had a mammogram in the past two years, and 83 percent of all women having had a Pap test in the past three years. Seventy-seven percent of men over 50 had received a PSA test in the past year, while only 38 percent of people over 50 had had a colorectal cancer screening in the past year. As colorectal cancer screening is recommended every five years for individuals with average risk, not annually as presented in the national figures, the colorectal cancer screening rate within five years (67 percent overall) is reported in Figure 9.

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



*Number of persons who reported colorectal cancer screening and lived independently too small to present

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 well-being 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 (84 percent NCI and 85 percent PES); 86 percent of NCI respondents and 84 percent of PES respondents said they were not afraid in their neighborhoods; and 89 percent 96 percent, respectively, reported that 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 90 percent of NCI and 94 percent of PES respondents said they did. By 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 made decisions about where they live, their daily schedule and where they go during the day.
- Most people reported that the staff that were paid to help them were respectful.

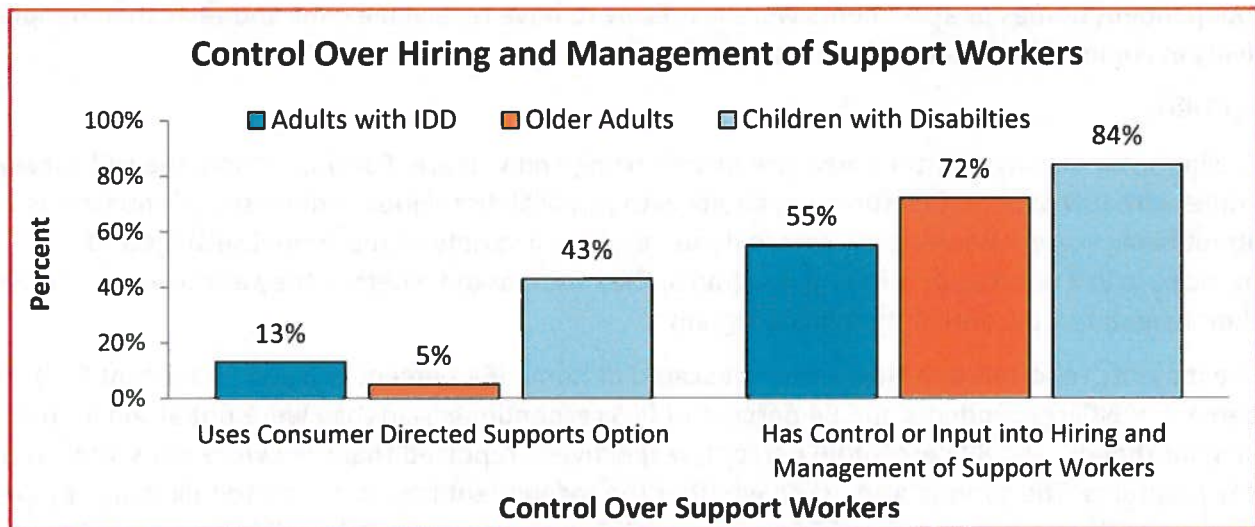
SELF DIRECTION

Consumer-directed services (CDS), where the consumer directs their services and supports, is an option offered in a number of the waiver programs. Across the three survey populations, only eight percent used the self-directed option. The proportion of people using CDS, however, varied greatly by the population served. Only five percent of the adults with physical disabilities used the CDS option. Among the adults with IDD, 13 percent reported using CDS. The families of children served by DADS reported the highest rate of CDS use, with 43 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 where appropriate to increase their satisfaction and autonomy. Adults with physical disabilities reported more control in hiring and management of support workers (84 percent) than adults with IDD (55 percent) or children with disabilities (72 percent). While use of the CDS option was lowest among older adults, they reported the highest levels of control over and input into hiring and managing their staff (Figure 10).

Figure 10. CONTROL OF SUPPORT WORKERS BY POPULATION

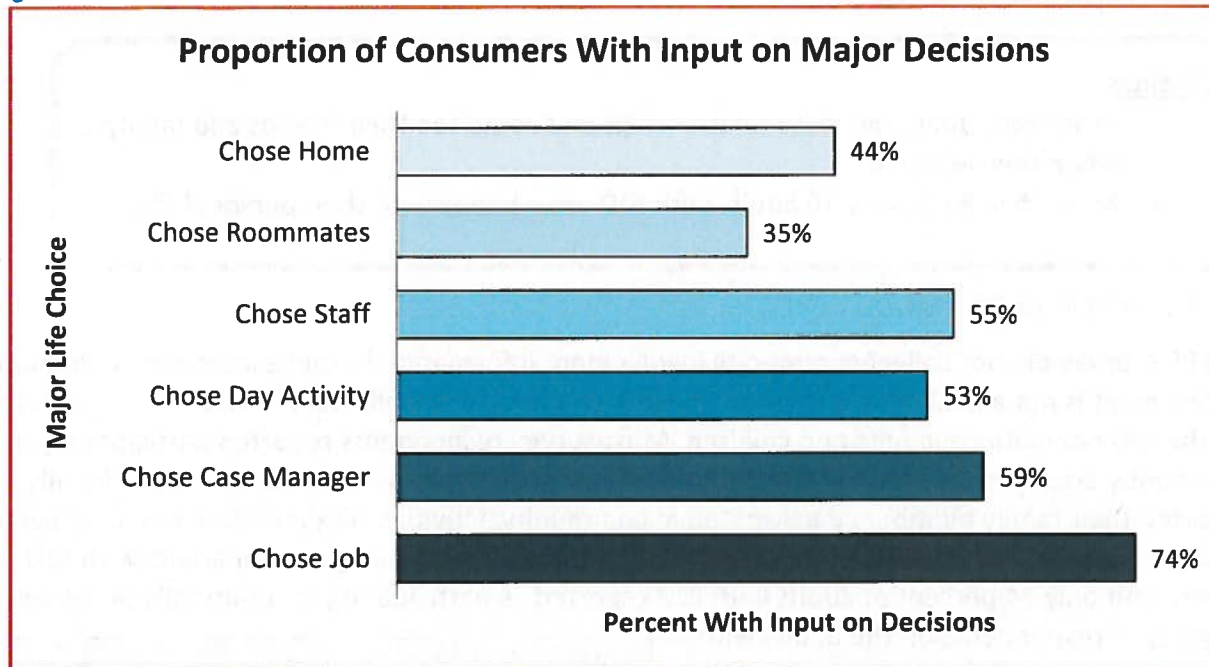


LIFE CHOICES AND DECISION-MAKING

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 (88 percent) reported that they controlled who entered their homes, and 80 percent said that they could have a close personal relationship. A majority, 72 percent, chose their own staff, and 55 percent had control over their transportation.

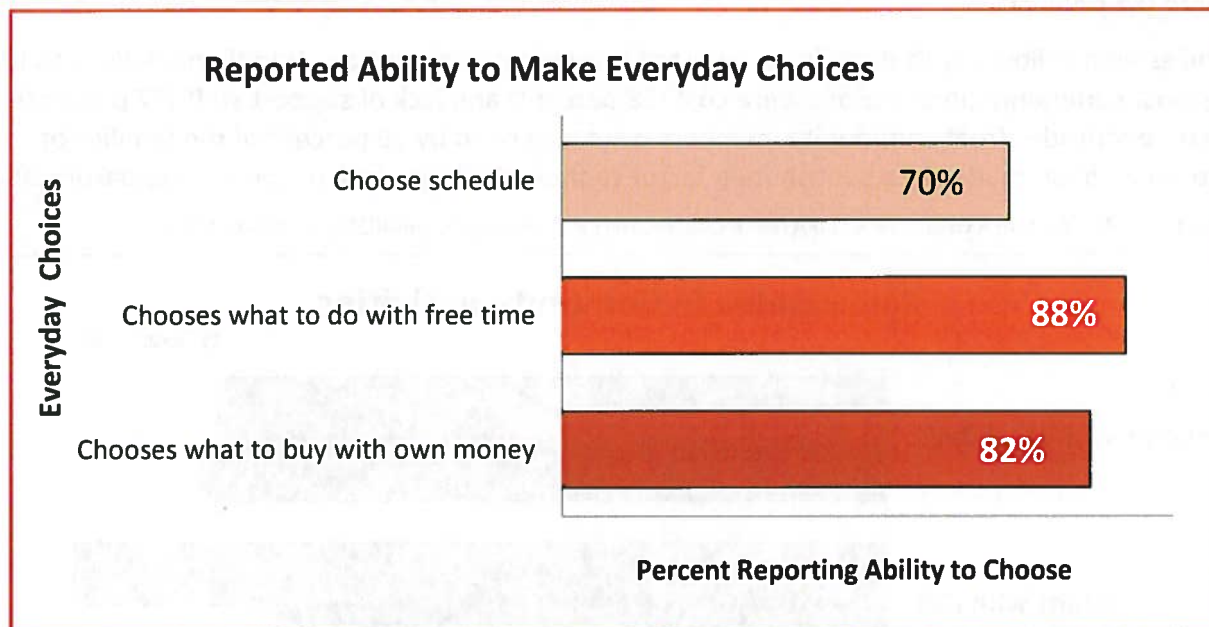
Many adults with IDD reported that they did not have input into major life decisions such as where and with whom they live and where they go during the day. As illustrated in Figure 11, only 44 percent of adults with IDD chose their home, and 35 percent chose their roommates. Though 74 percent had input into where they work, only 53 percent had input into where they go during the day (their non-work day activity). Choosing staff is a very personal decision, but only 55 percent of adults with IDD had input into choosing their staff, and 59 percent chose his/her case manager.

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



A higher proportion of people with IDD reported having input into everyday decisions such as choosing their own schedule (70 percent), how to spend free time (88 percent), and how to spend their money (82 percent) (Figure 12) than reported having input into major decisions.

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.

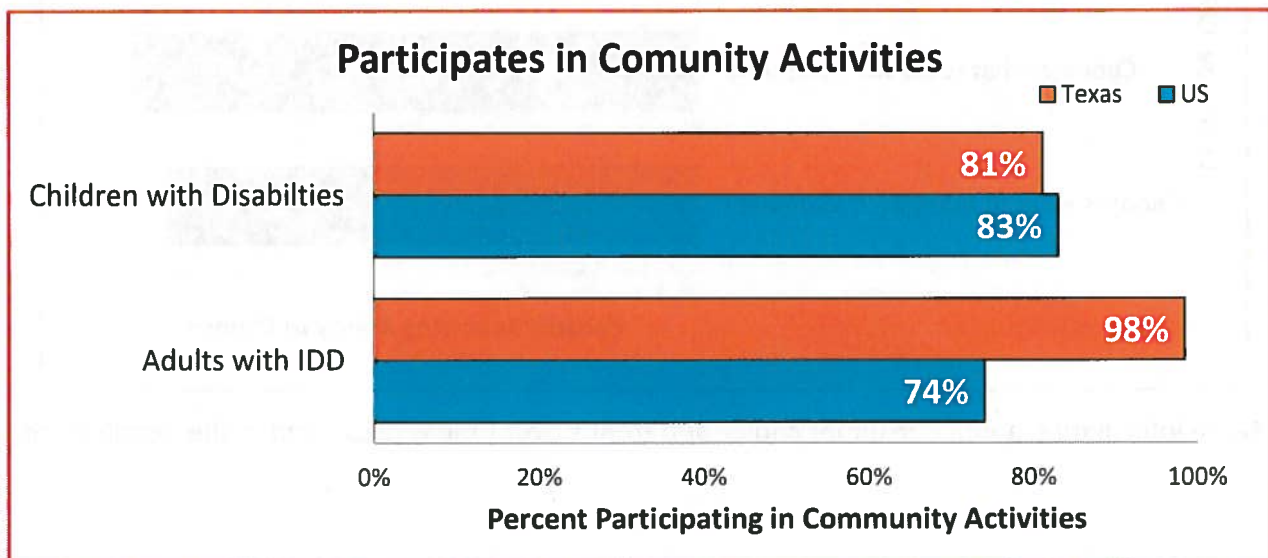
PARTICIPATION IN COMMUNITY EVENTS

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: 98 percent of adults with IDD, 81 percent of children with disabilities). National figures for adults with IDD were lower, with only 74 percent of adults with IDD reported as participating in community activities. The majority of respondents on the adults with IDD survey reported that in the last month they had been shopping (86 percent), gone out for entertainment (79 percent), had visited a restaurant or coffee shop (81 percent), and had attended a religious service (54 percent).

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

Families with children with disabilities reported less community participation than adults with IDD. The most commonly cited reasons were cost (28 percent) and lack of support staff (27 percent). Negative attitudes from community members were also cited by 19 percent of the families of children with disabilities as a contributing factor to their children's lack of community participation.

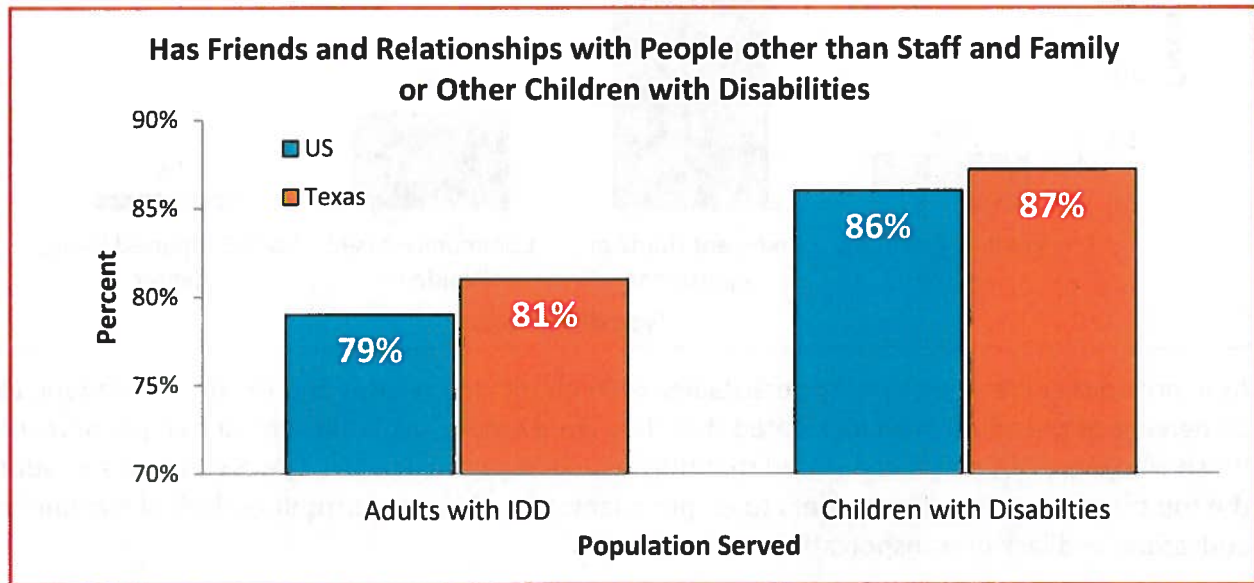
Figure 13. FAMILY MEMBER OF IDD PARTICIPATES IN COMMUNITY ACTIVITIES, COMPARISON OF TEXAS AND US



As illustrated in Figure 14 below, over three-quarters of adult with IDD respondents nationally and

in Texas reported they had meaningful relationships with people other than support workers and family (79 percent U.S. and 81 percent Texas). Eighty-seven percent of Texas CF survey respondents indicated the child spends time with children without disabilities. The PES did not include questions about personal relationships.

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



EMPLOYMENT

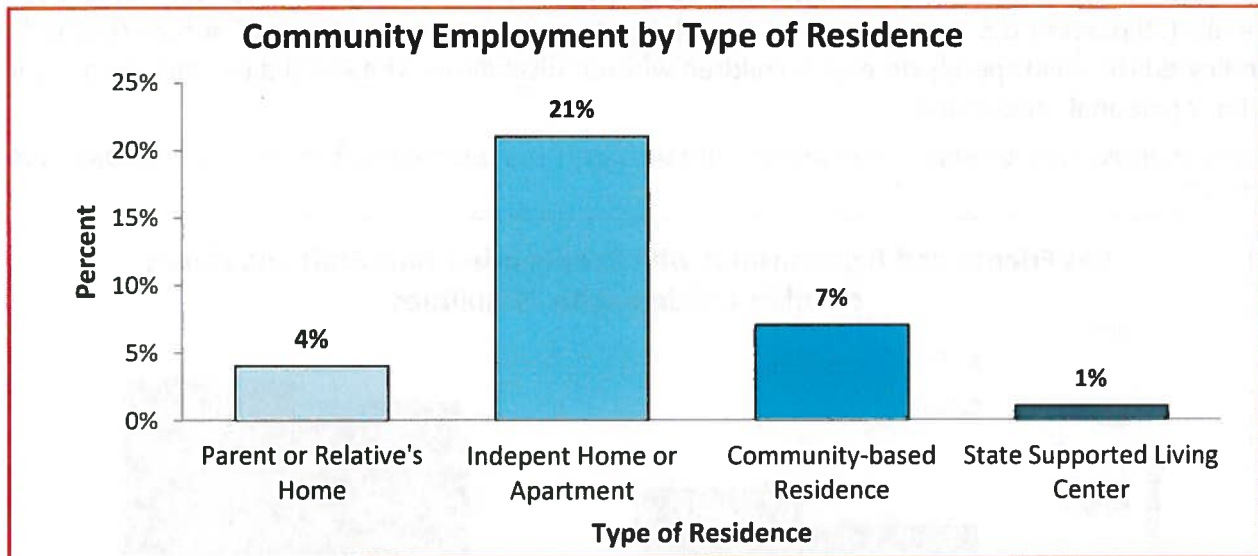
Research suggests employment benefits people with disabilities by reducing the economic and social disparities they face and helping them gain economic security and become more fully integrated and engaged in mainstream society.¹ In 2011-2012, nationally, 15 percent of people with IDD had a paid job in the community, while in 2013, only eight percent of adults with IDD in Texas had community-based jobs.

Of the people with IDD who worked in the community, 21 percent lived in their own home or apartment, seven percent lived in community-based residences, and four percent lived with a parent or relative (Figure 15). Ten percent of adults with IDD in Texas had paid, facility-based jobs, and 31 percent participated in unpaid facility activities. Only nine percent of people with IDD who worked received benefits (vacation and/or sick leave), compared to 26 percent nationally. Of people surveyed, the four most common types of paid community jobs were: food preparation (39 percent), cleaning and maintenance (29 percent), retail (10 percent), and assembly and manufacturing (7 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 23 percent of the adults with IDD stated that they were employed, while almost half (46 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

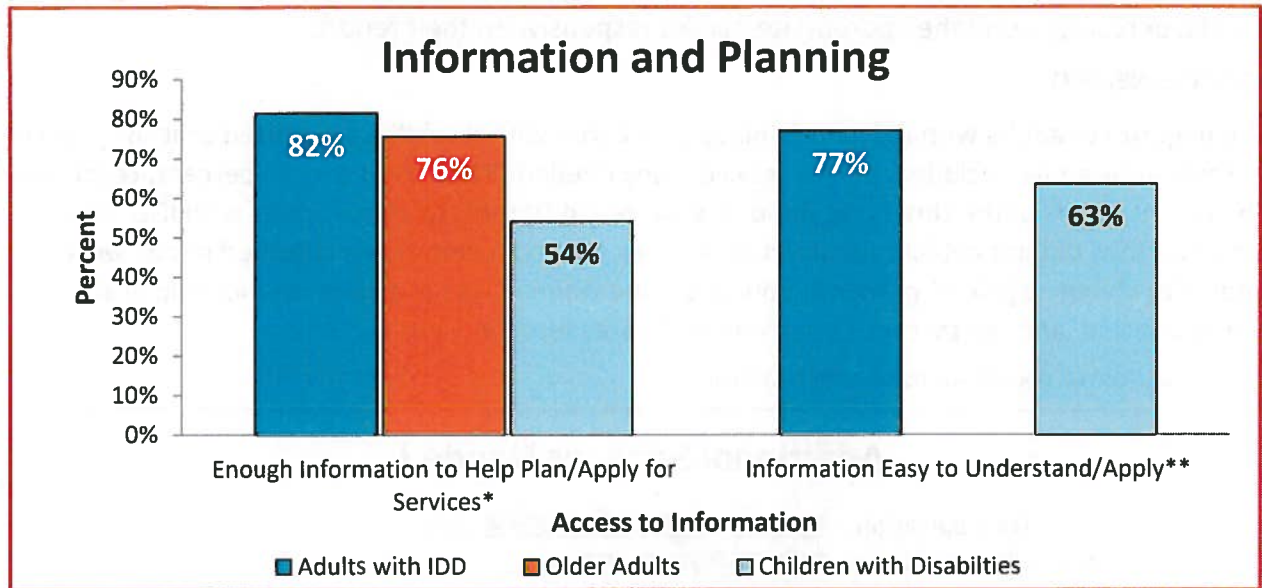
The primary purpose of the LTSS survey is to measure consumer satisfaction with DADS services and supports. A key component of satisfaction is system performance, and two key measures of system performance are access to and delivery of services. If consumers do not have access to the services and equipment 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 half of the respondents for the three surveys said they receive enough information to help plan their family member's services or apply for services – 82 percent in the NCI, 76 percent in the PES and 54 percent in the CF (see Figure 16). Most reported that the information about services and supports was easy to understand and use (77 percent NCI and 63 percent CF).

Figure 16. INFORMATION ABOUT SERVICES AND SUPPORTS

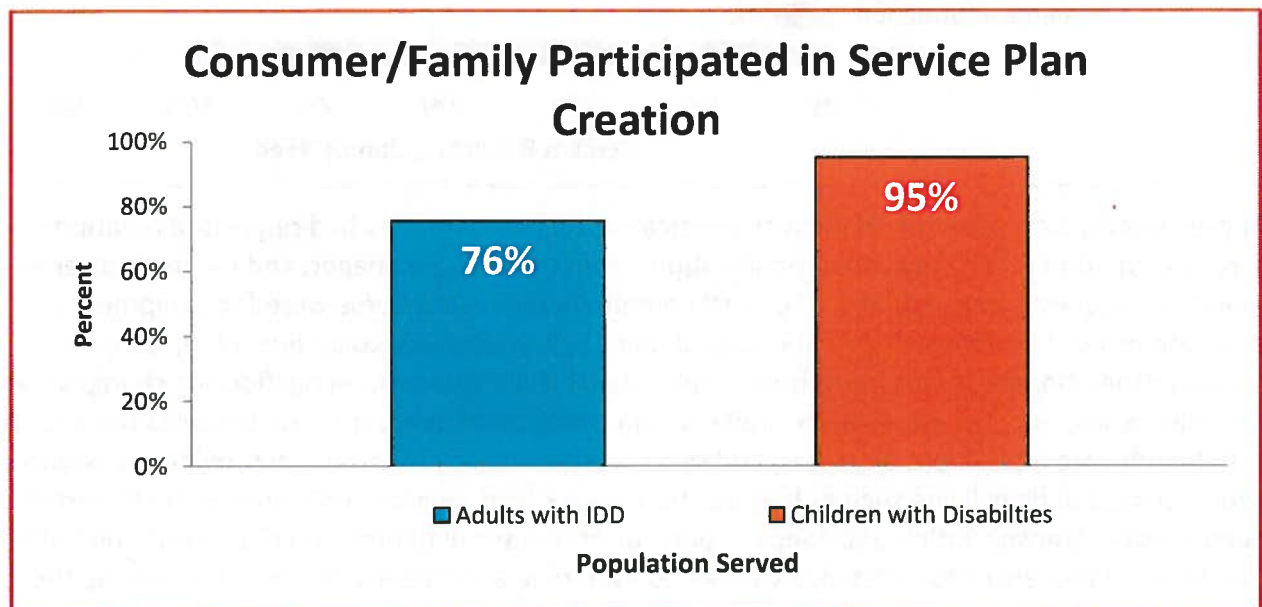


*The questions are worded slightly differently in each questionnaire.

**This question was not asked of adults with physical disabilities

As illustrated in Figure 17 below, 76 percent of respondents to the adults with IDD survey and 95 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



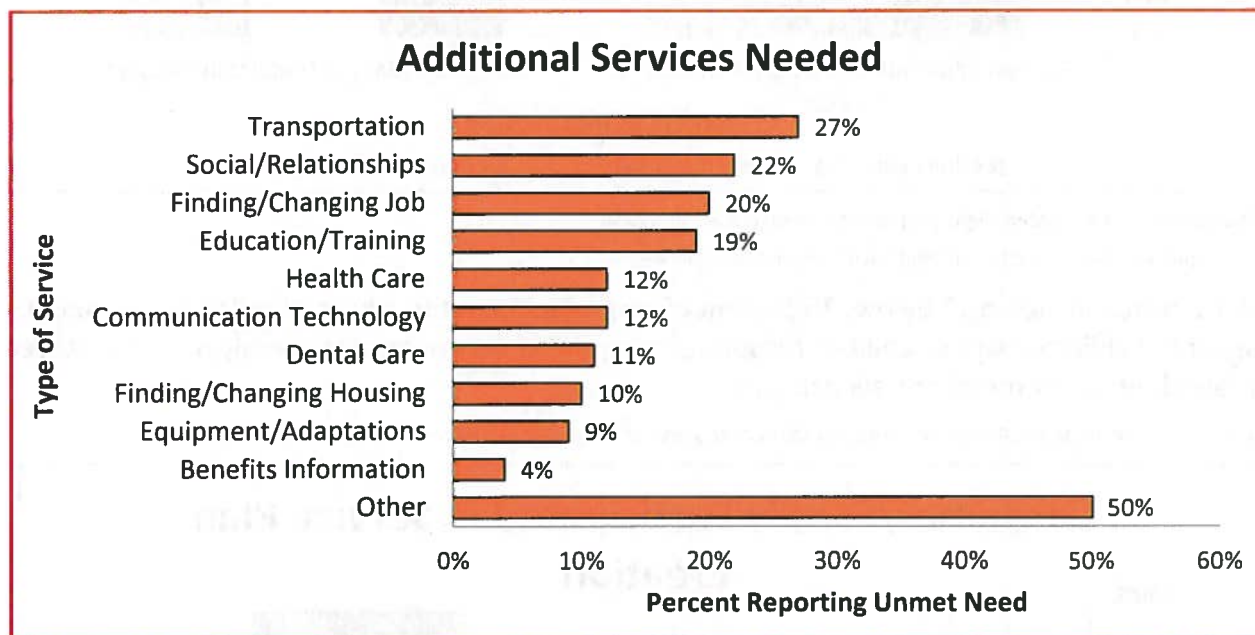
The majority of CF survey respondents knew how to file complaints or grievances about provider agencies or staff (75 percent, compared to 55 percent nationally). Families also reported they were satisfied with the way complaints and grievances were handled (85 percent). Respondents also knew how to report abuse or neglect (89 percent, compared to 75 percent nationally). However, of those who said abuse or neglect had occurred within the past year, only 48 percent reported the problem. Nationally only 38 percent reported the abuse, which was a statistically significant

difference. Of those who filed a report of abuse or neglect in the past year, more than eight out of ten (82 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, all the services they needed (82 percent and 78 percent, respectively). The unmet needs of the three populations were very different. Of those adults with IDD who reported they did not get all their needed services, the most commonly specified needs were: finding or changing jobs (4 percent), education and training, social and/or relationship areas, transportation, and dental care (3 percent each) presented in Figure 18 below.

Figure 18. REPORTED SERVICE NEEDS OF ADULTS WITH IDD



Approximately 32 percent of adults with physical disabilities said they had requested additional services, equipment, or household modifications from their case manager, and 67 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. Nine percent of the requests were for help with health-care equipment or access, and seven percent were for additional provider assistance with activities of daily living such as bathing, housework, and physical assistance going to and from doctor visits. Transportation assistance (3 percent of requests), dental care (2 percent), nutritional assistance (2 percent) and assistance with air conditioning and heating (2 percent) made up the remainder of the requests for extra assistance.

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 promised services, the manner in which the services were delivered, and the timeliness of those services. All measures are as reported by the survey respondent. Texas CF survey respondents reported that their family member received all services listed in their service

plan at higher rates than those reported nationally (86 percent compared to 83 percent in national CF). Failure of children with disabilities to receive needed equipment has decreased since 2005 (Figure 19).

Figure 19. CHILDREN WHO FAILED TO RECEIVE NEEDED EQUIPMENT, TRENDS 2005 – 2013

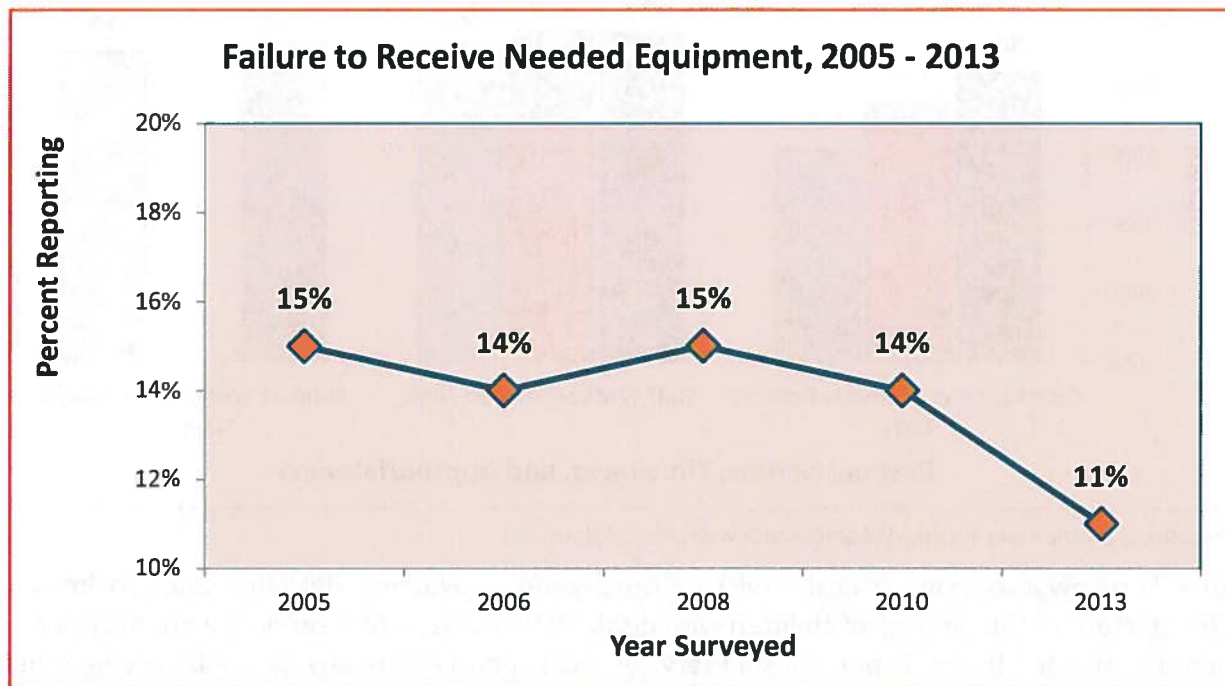
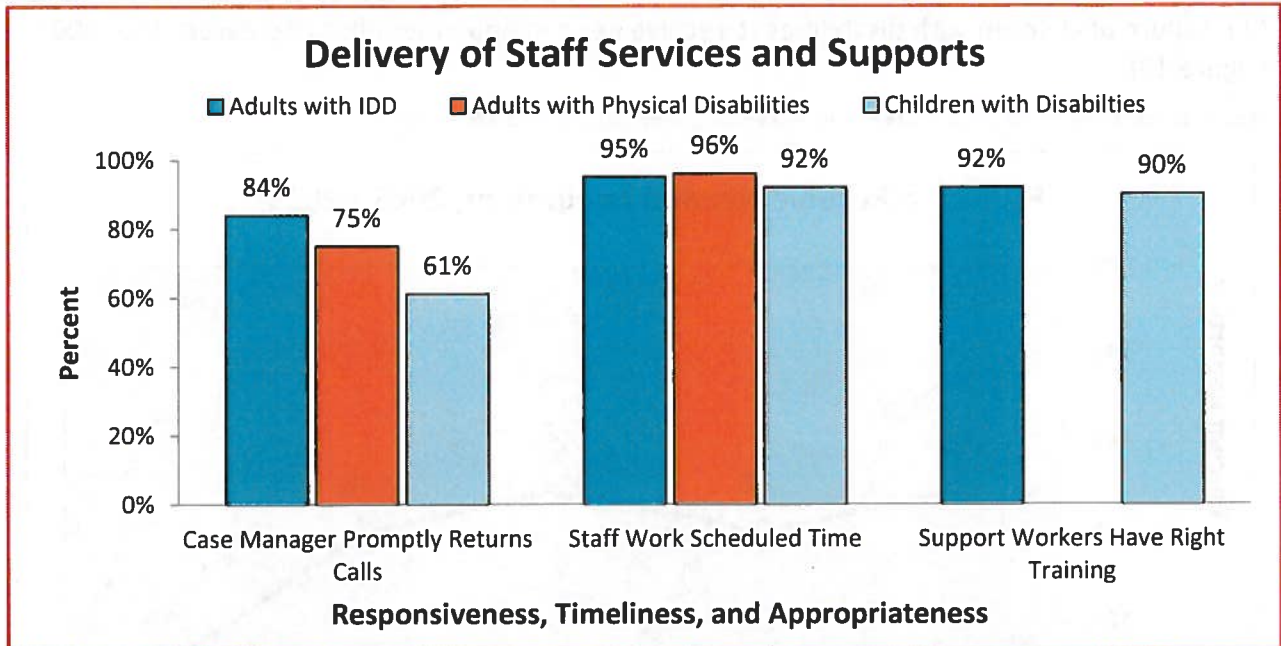


Figure 20 below shows three critical service delivery issues: responsiveness, timeliness and appropriateness. The responses from all three populations are positive for all three measures. Case managers responded promptly when called. The question in the NCI and PES surveys allowed three response choices; “calls back right away” is the response reported here. NCI and PES respondents reported that their case managers called them back right away 84 percent and 75 percent of the time, respectively. The CF survey used a five-point scale, and “always” is reported here. If the response category “usually” is included with “always,” the percentage of positive responses rises from 61 percent to 89 percent.

Timeliness, as measured by support staff arriving on time and when scheduled, was excellent for all three surveyed populations, with 95 percent of adults with IDD, 96 percent of adults with physical disabilities, and 93 percent of families of children with disabilities reporting that their support staff were prompt and came when scheduled. The appropriateness measure was also quite positive, with 92 percent of adults with IDD and 90 percent of children with disabilities reporting that their support staff have the right training. This question was not asked in the PES survey.

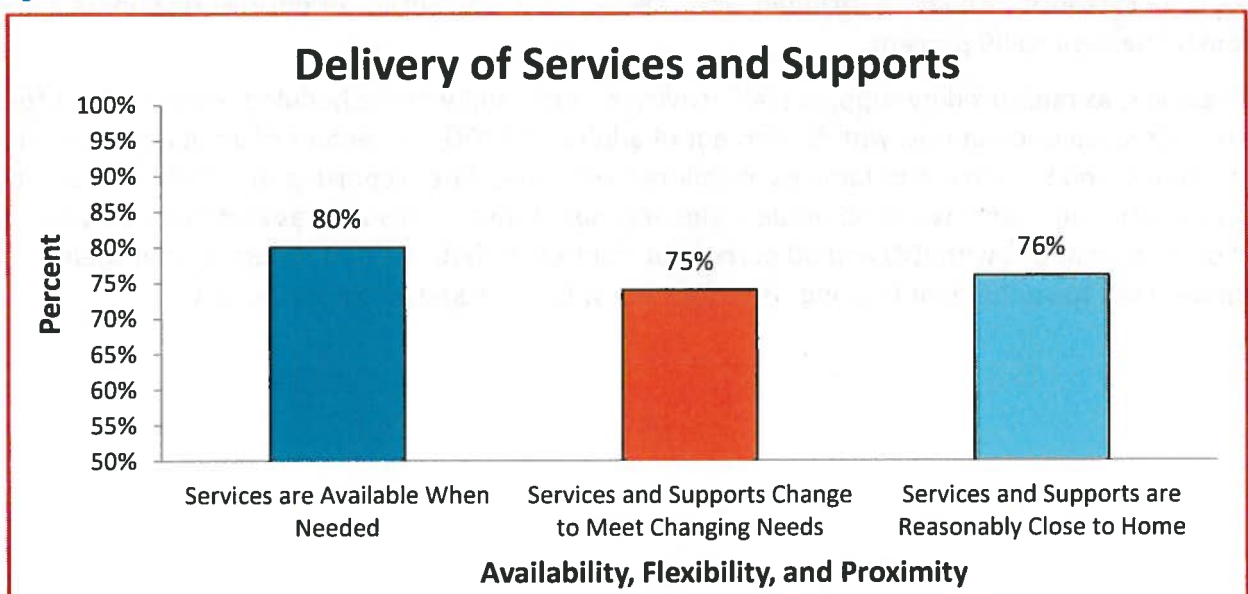
Figure 20. RESPONSIVENESS, TIMELINESS, AND APPROPRIATENESS OF STAFF SERVICES AND SUPPORTS BY SURVEY POPULATION



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

Figure 21 below also shows critical service delivery issues: availability, flexibility, and proximity. Eighty percent of the families of children with disabilities reported that services were available when they needed them; 47 percent said services and supports were always available when they needed them. Three-quarters of the CF survey respondents reported flexible services and supports, which usually changed to meet their family member’s changing needs (75 percent). And 76 percent of the families of children with disabilities reported that their services and supports were always or usually reasonably close to home. Forty six percent said the services were always close to home, compared to 40 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 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 that were respectful of them and their culture. The responses ranged from a low of 77 percent, reported by families of children with disabilities, to a high of 91 percent reported by adults with IDD. Many respondents wrote positive comments about their support staff's dedication and caring attitudes.

SERVICES SATISFACTION

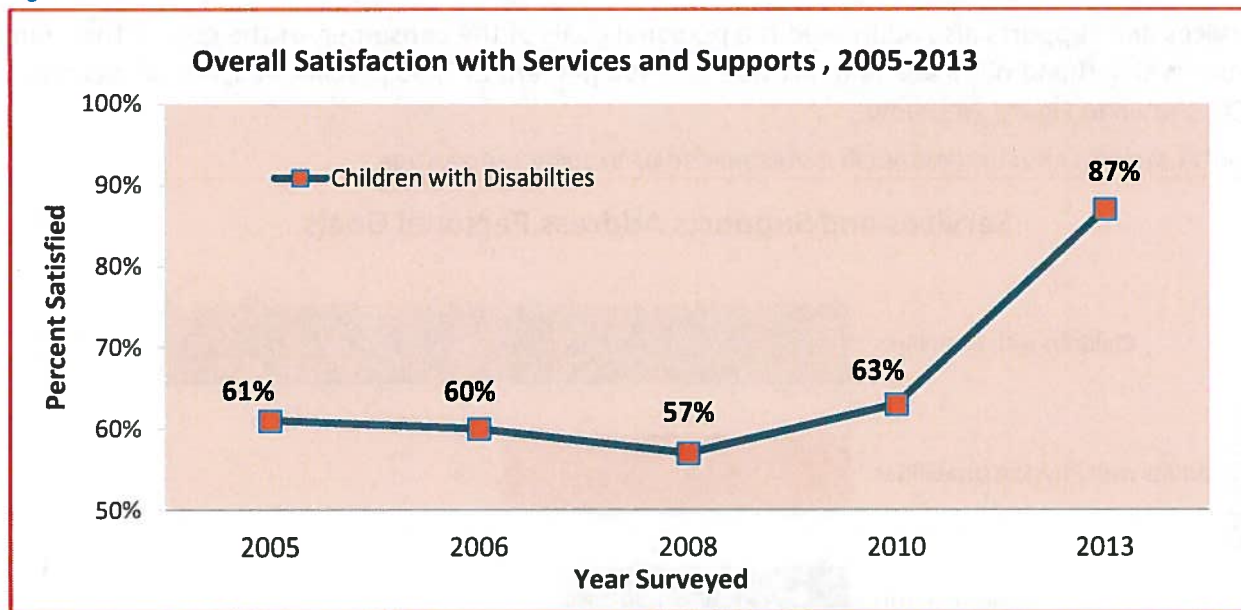
The information above creates a picture of the level of need and satisfaction of people served by DADS. The three surveys also included several specific questions about overall satisfaction and how well individual goals and health and well-being needs were met.

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

OUTCOMES

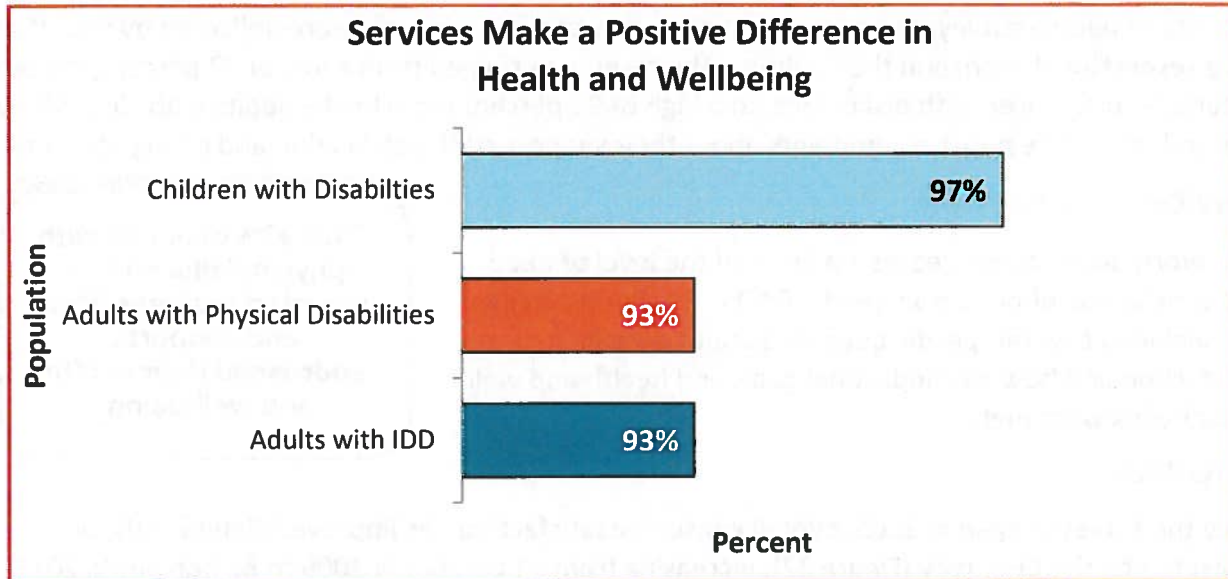
Since the surveys began in 2005, overall consumer satisfaction has improved significantly, as measured by the CF survey (Figure 22), increasing from 61 percent in 2005 to 87 percent in 2013.

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 97 percent, followed closely by adults with IDD and physical disabilities, with 93 percent of both groups reporting that services and supports addressed their health and well-being (Figure 23).

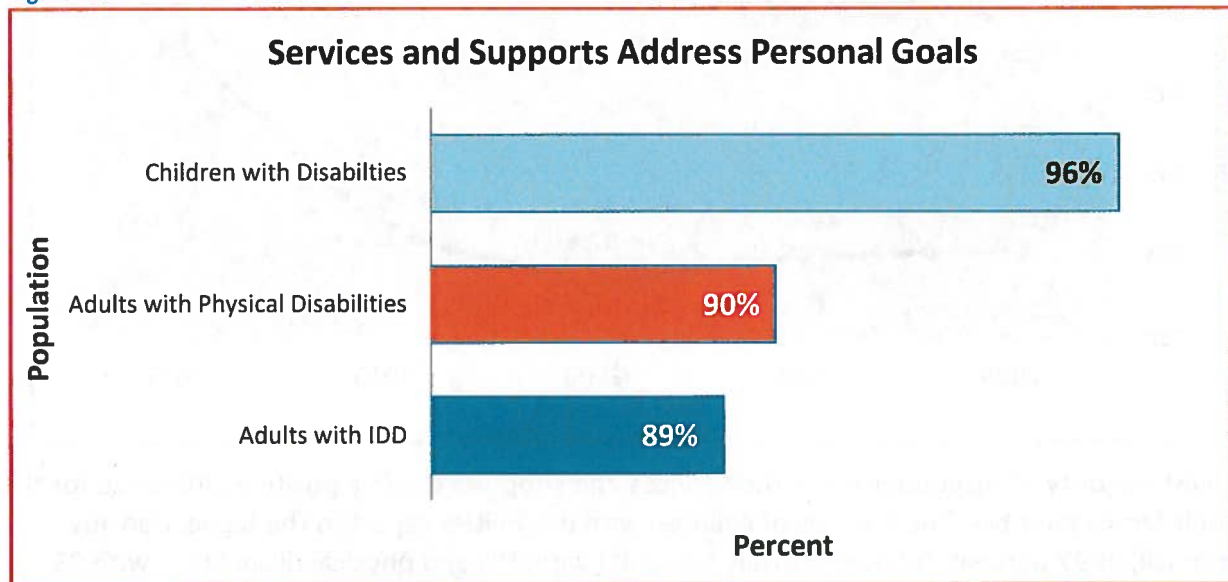
Figure 23. SERVICES AND SUPPORTS MAKE A POSITIVE DIFFERENCE IN FAMILY/INDIVIDUAL'S HEALTH AND WELLBEING



*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 (96 percent CFS, 90 percent PES, and 89 percent NCI), shown in Figure 24 below.

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



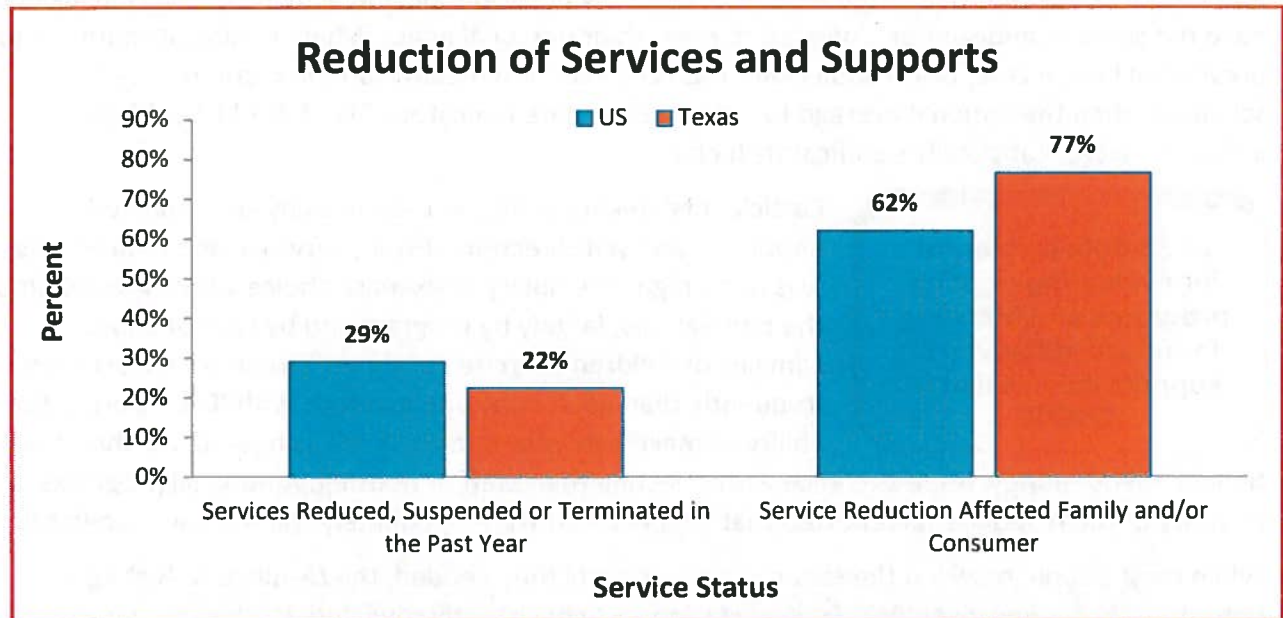
*The question in CF questionnaire is worded slightly differently.

REDUCTION OF SERVICES AND SUPPORTS

These positive responses 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-third of respondents nationally and one-fourth of respondents in Texas reported that their services for children with disabilities had been reduced, suspended, or terminated in the past year (35 percent nationally; 22 percent Texas). Of the

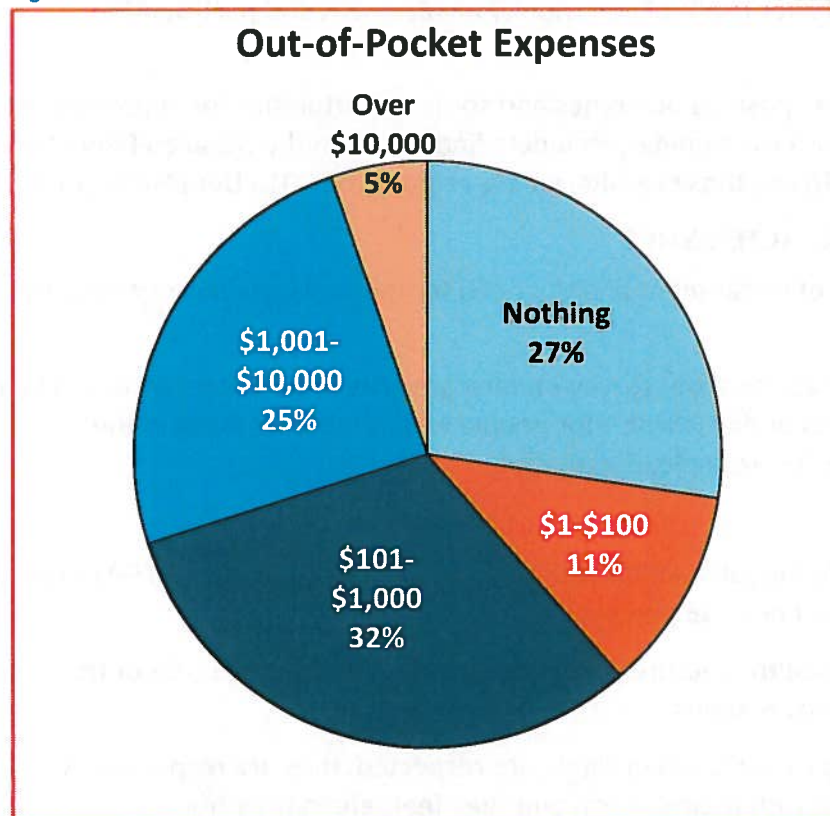
respondents whose family member had services reduced in the past year, 75 percent nationally and 77 percent in Texas said the reduction had negatively affected their family member.

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



One primary negative result of these service reductions was 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



Forty-two percent (42 percent) of the families of children with disabilities in Texas reported annual incomes of \$25,000 or less. Annual out-of-pocket expenses for almost one-third (30 percent) of the CF survey households exceeded \$1,000. Five 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 received more health care on recommended schedules than the national average for all 11 health care indicators. Six of the 11 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 many activities within the community, 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 2015 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, for example, is essential.

POSITIVE OUTCOMES:

- Individuals reported overwhelming satisfaction with their residence (84 percent to 99 percent), jobs, and day programs (89 percent to 96 percent).
- All 11 routine and preventive health measures exceeded the national averages; six of them 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.

- More than 75 percent of the participants in all programs reported that they know their case managers, and they are satisfied with service availability (76 percent to 95 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 21 percent and 62 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.
- About half of the individuals reported that they earn 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 recommendations.
- Individuals in community-based housing and ICF/IID facilities (14 percent) and individuals in state supported living centers (1%) reported they have options regarding choice of residence. Most adults with IDD did not have options about where they lived.
- About a third of adults with physical disabilities are lacking important immunizations – 32 percent lack influenza vaccinations, and 37 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 (71 percent), vision (49 percent), or hearing (65 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 with IDD, the use of psychiatric drugs without a corresponding psychiatric diagnosis is troublingly common. This might reflect a lack of information about diagnoses, or it might 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 well-being. 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. 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 and Data Brief are available on the DADS website.





DADS Routing Coordination

November 2014

Due Date
12.12.14

Assignment Number: _____

Date: 12.1.14 Subject Matter Expert: Rebecca Martin Extension: 4424

The attached document/correspondence is for review and/or signature. Please review and forward it to the next appropriate staff as indicated below.

Allow **five business days** for action regarding the commissioner's signature.

Subject: 2015 Long Term Services and Supports Quality Review Summary Report

| Sequence | Date Received | | Signature | Date Approved |
|----------|---------------|--|-------------------------|---------------|
| | | Internal Audit | | |
| | | Comments: | | |
| | | Information Technology | | |
| | | Comments: | | |
| | | Legal Services | | |
| | | Comments: | | |
| 2 | 12/4 | Center for Consumer and External Affairs | <i>All Lowrey</i> | 12/4/14 |
| | | Comments: Allison Lowrey | | |
| 5 | | Center for Policy and Innovation | | |
| | | Comments: Donna Jessee | | |
| 6 | | Asst. Commissioner for Regulatory Services | | |
| | | Comments: Mary Henderson | | |
| 4 | | Asst. Commissioner for Access and Intake <i>AS</i> | <i>Eliza Garza</i> | 12/10/14 |
| | | Comments: Eliza Garza <i>E comments</i> | | |
| 3 | | Asst. Commissioner for State Supported Living Centers | <i>Scott Schalchin</i> | 12/5/14 |
| | | Comments: Scott Schalchin | | |
| | | Chief Financial Officer | | |
| | | Comments: | | |
| | | Chief Operating Officer | | |
| | | Comments: | | |
| 7 | | Deputy Commissioner | <i>Chris Adams</i> | 12-21-2014 |
| | | Comments: Chris Adams | <i>one edit on memo</i> | |
| 8 | 12/22 | Associate Commissioner | <i>Kristi Jordan</i> | 12/22/14 |
| | | Comments: Kristi Jordan | | |

Additional Approvals:

| | | | | |
|---|--|-----------------|------------------|---------|
| 1 | | Michelle Martin | <i>M. Martin</i> | 12-4-14 |
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Make sure the form has the appropriate signature based on the program or support area before sending it to the commissioner's office.

Routing Contact: Angel Rivera Division: CPI Extension: 2116 or 3512