

Summary

The purpose of this report is to provide summary information regarding face-to-face experience surveys conducted by the Department of Aging and Disability Services (DADS) in 2005. The face-to-face surveys were conducted with people who are 18 years of age and older who receive DADS Medicaid waiver or Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) Program services.

On September 1, 2003, the Texas Department of Mental Health and Mental Retardation (TDMHMR) was awarded a Real Choice Systems Change Grant to redesign and improve quality in its home and communitybased programs. The grant activities continue in DADS within the Quality Assurance and Improvement unit. Based on the recommendations from the Quality Assurance and Quality Improvement Task Force, DADS joined the National Core Indicators Project and contracted with an external entity to conduct the face-to-face interviews. The surveys were conducted by NACES Plus Foundation, Inc. and occurred during the months of May through August 2005.

Measuring Quality Using Experience Surveys is the first project of its size and scope conducted by DADS. Texas is one of the few states in the country that undertakes a survey of this size. The purpose of the project is to obtain information from the person's perspective about their experiences receiving services in DADS programs. This first phase provides an initial baseline of data that DADS will build upon. Future surveys will provide additional data that will enable DADS staff to trend and analyze over time to identify areas for improvement and to measure if improvement strategies are effective. Lessons learned will enable DADS to identify areas for process improvement.

The National Core Indicators (NCI) Consumer Survey was used for people receiving services in the TxHmL, HCS, CLASS, DB-MD, and ICF/MR Programs. The tool contains two sections. Section I may only be answered by face-to-face interviews with the person receiving services. Section II contains questions that may be answered by someone who knows the person well, such as a family member, friend, staff person, guardian or advocate. All responses from both sections of the tool were included in the analysis.

The Participant Experience Survey (PES), Elderly/Disabled version developed by MEDSTAT Group, Inc. (Medstat) for the Centers for Medicare and Medicaid Services, was used with people receiving services in the Community-Based Alternatives Program (CBA). Both the NCI and PES were used with people receiving services in the Consolidated Waiver Program (CWP). The NCI was used with people whose name was on the HCS, CLASS, or DB-MD Program interest list prior to enrollment in CWP. For people whose name was on the CBA interest list prior to enrollment the PES was used. Both tools have been tested for reliability and validity. A total of 30 quality indicators (6 of the indicators were added by the QA/QI Task Force) were calculated from responses to the NCI Consumer Survey and 39 (6 of the indicators were added by the QA/QI Task Force) were calculated from responses to the PES tool.

A total of 1980 face-to-face surveys were conducted. Valid random samples were drawn from the TxHmL, HCS, DB-MD, CWP, CBA, CLASS, and ICF/MR (including State Mental Retardation Facilities) Programs. A proportional sampling strategy was used for each program based on the number of people receiving services in each county. People receiving services were free to decline to participate in the survey process at any time. Demographic data was obtained from DADS automated systems in March 2005 and pre-survey data was obtained from providers prior to the interview and is included in the analysis. Unless otherwise specified, all sample sizes are valid at the 95% confidence level with a confidence interval of 5.

Major Findings are listed below by program.

Home and Community-Based Services

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

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

A statistically valid random sample of people receiving services was interviewed during the four-month period using the NCI Consumer Survey. At the time the sample was drawn, there were 8,990 people receiving HCS services. Of the 8,990 people receiving services, 8,499 were age 18 years of age and over. 551 people receiving services were contacted and a total of 367 people receiving services were interviewed (33% decline rate).

Indicators over 69% and less than 31% for people receiving HCS Program services--

- 93% "needed" services were available
- 74% are satisfied with where they live
- 71% are satisfied with the amount of privacy they have
- 92% have had a physical exam in the past year
- 88% do not feel lonely
- 77% participate in integrated activities in their community
- o 23% women have had an OB/GYN exam in the past year
- 16% people have participated in activities of self-advocacy groups or other groups that address rights
- o 1) 24%, 2) 25% people report having been provided options about where to 1) live and 2) work
- 17% people make choices about important life decisions including: housing, roommates, support staff or providers, daily routines, social activities, job, and services coordination

Texas Home Living

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

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

A statistically valid random sample of people receiving services was interviewed during the four-month period using the NCI Consumer Survey. At the time the sample was drawn, there were 1,430 people receiving TxHmL Program services. Of those, 1,332 were age 18 years of age and over. 482 people receiving services were contacted and a total of 318 people were interviewed (34% decline rate).

Indicators over 69% and less than 31% for people receiving TxHmL Program services--

- 93% "needed" services were available
- 84% are satisfied with where they live
- 76% are satisfied with life in general, personal life
- 74% are satisfied with the amount of privacy they have
- 76% know their service coordinator
- 73% were asked about their preferences from their service coordinator
- 77% are able to see their families when they want
- 72% have had a physical exam in the past year
- 93% do not feel lonely
- 76% participate in integrated activities in their community
- o 14% women have had an OB/GYN exam in the past year
- 9% people have participated in activities of self-advocacy groups or other groups that address rights
- o 1) 7%, 2) 22% people report having been provided options about where to 1) live and 2) work
- o 16% people indicate that most staff who come to their home treat them with respect
- 15% people make choices about important life decisions including: housing, roommates, support staff or providers, daily routines, social activities, job, and services coordination

Intermediate Care Facilities for Persons with Mental Retardation

The ICF/MR Program provides residential and habilitation services to people with cognitive disabilities and/or a related condition. Private providers, Community MHMR Center providers as well as State Mental Retardation Facilities provide ICF/MR services. Services include:

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

A statistically valid random sample of people receiving services was interviewed during the four-month period using the NCI Consumer Survey. At the time the sample was drawn, there were 11,916 people receiving ICF/MR Program services. Of those, 11,681 were age 18 years of age and over. 607 people were contacted and a total of 372 people were interviewed (39% decline rate) in Private, Community MHMR Center and State Mental Retardation Facilities.

Indicators over 69% and less than 31% for people receiving ICF/MR Program services--

- 98% "needed" services were available
- 96% have had a physical exam in the past year
- 88% do not feel lonely
- 70% participate in integrated activities in their community
- o 12% have participated in activities of self-advocacy groups or other groups that address rights
- o 28% have control over their transportation
- o 29% decide who comes in and out of their home
- o 1) 16%, 2) 15% report having been provided options about where to 1) live and 2) work
- 9% people make choices about important life decisions including: housing, roommates, support staff or providers, daily routines, social activities, job, and services coordination

Community Living Assistance and Support Services

The CLASS program provides home and community-based services to adults and children with related conditions as a cost effective alternative to ICF/MR institutional placement. People with related conditions have a qualifying disability, other than mental retardation, which originated before age 22 that affects their ability to function in daily life. Services include:

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

A statistically valid random sample of people receiving services was interviewed during the four-month period using the NCI Consumer Survey. At the time the sample was drawn, there were 1,740 people receiving CLASS Program services. Of those, 1,166 were age 18 years of age and over. 431 people receiving services were contacted and a total of 295 people were interviewed (32% decline rate).

Indicators over 69% and less than 31% for people receiving CLASS Program services--

- 93% "needed" services were available
- 71% are satisfied with where they live
- 88% do not feel lonely
- 74% participate in integrated activities in their community
- o 25% people are satisfied with their job or day program
- o 10% women have had an OB/GYN exam in the past year
- o 23% people have had a routine dental exam in the past six months
- 21% people have participated in activities of self-advocacy groups or other groups that address rights
- o 1) 14%, 2) 9% people report having been provided options about where to 1) live and 2) work
- o 23% people indicate that most day program staff treat them with respect

Deaf-Blind with Multiple Disabilities

This Medicaid waiver program provides home and community-based services to people who are 18 years of age or older and who are Deaf-Blind with Multiple Disabilities as a cost-effective alternative to ICF/MR institutional placement. The DB-MD program focuses on increasing opportunities for people to communicate and interact with their environment. Services include:

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

A random sample of people receiving services was interviewed during the four-month period using the NCI Consumer Survey. At the time the sample was drawn, there were 132 people age 18 or over receiving DB-MD Program services. 83 people were contacted and a total of 61 people were interviewed using the NCI Consumer Survey (27% decline rate). Because the sample for this program was small, results can be generalized at the 95% confidence level but the confidence interval is 9.4.

(Results are valid plus or minus 9.4 percent because of the small sample size)

Indicators over 69% and less than 31% for people receiving DB-MD Program services--

- 98% "needed" services were available
- 90% have had a physical exam in the past year
- 92% do not feel lonely
- o 28% women have had an OB/GYN exam in the past year
- 15% people have participated in activities of self-advocacy groups or other groups that address rights
- o 1) 10%, 2) 10% people report having been provided options about where to 1) live and 2) work
- 26% people report having friends and caring relationships with people other than support staff and family members
- o 26% people report having a close friend, someone they can talk to about personal things
- o 30% people are able to see their friends when they want
- o 18% people report that service coordinators help them get what they need
- o 21% people know their service coordinators
- o 21% people report that their service coordinators asked about their preferences
- o 1) 20% 2) 20% people who report that they feel safe in their 1) home and 2) neighborhood
- o 15% people have an "advocate" or someone who speaks on their behalf
- o 20% people report basic rights are respected by others: use of phone
- o 28% people get to help other people
- o 26% people are able to have a close relationship, such as a boyfriend or girlfriend, if they want one
- o 28% people earn enough money to buy the things that they want
- o 21% people are free to take risks when they want

Consolidated Waiver Program - NCI

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

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

A statistically valid random sample of people receiving services was interviewed during the four-month period using the PES survey tool. At the time the sample was drawn, there were 186 people receiving CWP services. Of those, 121 were age 18 years or older. A total of 121 people were contacted and 88 people were interviewed. 78 people were contacted and 51 people were interviewed using the NCI tool (35% decline rate). Results are valid plus or minus 9.6 percent because of the small sample size. 45 people were contacted and 37 were interviewed using the PES tool (18% decline rate). Results are valid plus or minus 4.6 percent because of the small sample size. The choice of tool was based on the program waiting list that the person's name had been on prior to enrollment in CWP. The PES was used for those whose name was on the CBA interest list. The NCI was used for those whose name was on the HCS, DB-MD, or CLASS interest list.

(Results are valid no more than plus or minus 9.6 percent because of the small sample size)

Indicators over 69% and less than 31% for people receiving CWP services--

- 88% "needed" services were available
- 78% have had a physical exam in the past year
- 84% do not feel lonely
- o 4% women have had an OB/GYN exam in the past year
- 20% people have participated in activities of self-advocacy groups or other groups that address rights
- o 1) 6%, 2) 22% people report having been provided options about where to1) live and 2) work
- 18% people make choices about important life decisions including: housing, roommates, support staff or providers, daily routines, social activities, job, and services coordination

Consolidated Waiver Program - PES

(Results are valid plus or minus 4.6 percent because of the small sample size)

The Participant Experience Survey (PES) was used with people receiving services in the CBA Program and those in the CWP whose name was on the CBA interest list prior to enrollment in the CWP Program. The results below reflect the major findings from the PES indicators calculated from the PES surveys for CWP and CBA.

3% or less of people receiving services in the Consolidated Waiver Program report they:

- 0% are sometimes unable to eat because there is no one there to help them
- 0% do not help direct their staff, but would like to
- 3% are not treated respectfully by staff in their homes
- 0% have been injured by current staff
- 0% have staff who do not listen carefully to their requests for assistance in programs outside their homes
- 3% are verbally abused by current staff
- 0% are not treated respectfully by staff while using transportation services
- 0% did not choose their current job
- 0% do not like their current job

(Results are valid plus or minus 12.5 percent because of the small sample size)

Other findings:

- o 30% do not get their housework done sometimes because there is no one there to help them
- o 69% do not choose their care staff, but would like to
- o 50% report an unmet need for community involvement
- o 38% of non-elderly are not currently working, but would like to work

Community Based Alternatives

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

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

A statistically valid random sample of people receiving services was interviewed during the four-month period using the PES survey tool. At the time the sample was drawn, there were 29,353 people receiving CBA Program services all of whom are 18 years of age or older. 611 people were contacted and a total of 379 people were interviewed (37% decline rate)

3% or less of people receiving services in the CBA Program report they:

- 2% are sometimes unable to eat because there is no one there to help them
- 3% sometimes go without a meal because there is no one there to help them prepare it
- 3% are unsure who to report staffing problems to or would report staffing problems to "no one"
- 1% have been injured by current staff
- 0% did not choose their current job
- 0% do not like their current job

Other findings

- o 39% do not choose their care staff, but would like to
- o 31% do not help direct their staff, but would like to
- o 37% earn enough money to buy the things they want
- o 64% report an unmet need for community involvement

Consumer Directed Services

CDS is a long-term care service delivery model in which individuals, guardians or designated representatives have increased choice and control over the services they receive. The CDS model allows these people (instead of a provider agency) to directly hire, fire, and train service workers. The CDS model is one option for service delivery and does not preclude the use of the traditional agency-based service delivery system. The CBA, CLASS, and DB-MD Programs offer the CDS option to people receiving services.

Individuals who participate in the CDS option were identified in the data set with a CDS flag. The survey was not designed to detect differences between responses from people who receive services and participate in the CDS option and those who do not participate in the CDS option. However, an analysis of NCI indicators was conducted using responses from people receiving DB-MD and CLASS services who participate in the CDS option and comparing them to responses from people who do not. At the time the sample was drawn the total number of people, 18 years of age and over, and receiving CLASS and DB-MD Program services was 1298. The total sample size for the CLASS and DB-MD Programs was 356. Of those 356 people, 47 do participate in CDS and 309 do not participate in CDS. The preliminary results suggest that:

- people who participate in the CDS option report that people let them know before they come into their bedroom more often than people who do not participate in the CDS option;
- people who participate in the CDS option report that people let them know before they come into their home more often than people who do not participate in the CDS option;
- people who participate in the CDS option report they can be alone with their friends more than people who do not participate in the CDS option;
- people who participate in the CDS option report knowing whom their guardian is more often than people who do not participate in the CDS option;
- people who participate in the CDS option report choosing the people with whom to live more often than people who do not participate in the CDS option;
- more people who participate in the CDS option report participating in a self-advocacy group than people who do not participate in the CDS option; and
- more people who participate in the CDS option report making life decisions than people who do not participate in the CDS option.

Conclusion

The results of the surveys have provided DADS staff and stakeholders a baseline of information that will be used to build upon as surveys are conducted each year and trends can be identified over time. The data will be used as part of an overall quality management strategy for DADS that includes identifying where people receiving services are having more positive experiences, as well as identifying areas that warrant further exploration to identify issues that may need to be addressed.

In addition to the results for each program, some patterns emerged across programs. The majority of people receiving services in the HCS, TxHmL, ICF/MR, CLASS, DB-MD, and CWP report they receive the services they need, have had a physical exam in the past year, and do not feel lonely. The majority of people receiving services in the HCS, TxHmL, and CLASS Programs are satisfied with where they live.

Patterns across HCS, TxHmL, ICF/MR, CLASS, DB-MD, and CWP using the NCI tool that need to be investigated further are the low proportion of:

- ✤ Women who have had an OB/GYN visit in the last year
- People receiving services who reported that they had participated in activities of selfadvocacy groups or other groups that address rights
- People who were provided options about where to live and work
- People who make choices about important life decisions

The DB-MD Program merits further review, as many of the indicators appear to be somewhat lower overall than the other programs. Communication challenges may have an effect on the results more so in this program than in other programs and should be considered in the review as well as the small sample size for that program.

There are five indicators that can be calculated for both the NCI and PES tools, because the language of the relevant survey items was deemed to be sufficiently comparable across the two tools. The table below reflects the results across programs for the indicators.

| Indicator | HCS | TxHmL | ICF/MR | CLASS | DB- MD | CBA | CWP |
|--------------------------------------------------------------------------------|----------------------|----------------|----------------|----------------|----------------|-----|-----|
| % of people who have adequate transportation when they want to go somewhere. | 55 | 64 | 46 | 57 | 34 | 76 | 73 |
| % of people indicating that most 1) home 2) day staff treat them with respect. | 1) 53 2) 67 | 1) 16 2) 66 | 1) 63 2) 52 | 1) 64 2) 23 | 1) 38 2) 36 | 95 | 97 |
| % of people who know their service coordinator. | 64 | 76 | 47 | 64 | 21 | 91 | 89 |
| % of people who report that service coordinators help them get what they need. | 56 | 69 | 50 | 61 | 18 | 85 | 92 |
| % of people who participate in integrated activities in their communities. | 77 | 76 | 70 | 74 | 69 | 36 | 50 |

PES indicators that were consistent across the CBA and Consolidated Waiver Programs include the majority of people:

Are able to eat when they need to because there is someone there to help them Have not been injured by their current staff Have chosen their current job if they are working Like their current job

In addition, 69% of people receiving services in the CWP and 39% of people receiving services in the CBA Program report they do not choose their care staff, but would like to. Investigation is needed to determine why individuals in the CBA Program do not participate in the CDS option but report they would like to choose their care staff. Also, individuals receiving services in both programs report an unmet need for community involvement (CWP-50%, CBA 64%). Last, over one third of individuals receiving CWP services who are not elderly report they would like to work.

The analyses of the results of the differences between people receiving services in the CLASS and DB-MD Program who participate in the CDS option and those who do not merits further research. Although the sample size was adequate to make some inferences, a more robust analysis would include focusing on a specific program and obtaining a stratified sample of those who participate in CDS and those who do not. Results from this type of analysis might prove more beneficial because more in depth analysis can be conducted using demographics of those who participate and comparing to those who do not participate.

One limitation of this study is the proportional sampling methodology. Using this methodology excludes counties with very low numbers of individuals receiving services in the various programs. Individuals in these rural areas may have responses different than those in the more populated areas of the state.