Measuring Quality Using Experience Surveys: Children/Family Mail Out Survey Results 2005

Texas Department of Aging and Disability Services

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Center for Policy and Innovation
Quality Assurance and Improvement

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Executive Summary

The purpose of this report is to provide summary information regarding the Children/Family Surveys mailed to families of children under 18 years of age who received services in programs operated by the Texas Department of Aging and Disability Services (DADS) in 2005. The information gathered from the surveys represents the family member's perspective of their child's services and supports. The survey includes questions about: Information and Planning; Access and Delivery of Supports; Choice and Control; Community Connections; Satisfaction; and Family Outcomes. There is also a page for respondents to provide comments.

On October 3, 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 community-based programs. The grant activities continue in DADS within the Quality Assurance and Improvement unit of the Center for Policy and Innovation. Based on the recommendations from the Quality Assurance and Quality Improvement Task Force, DADS joined the National Core Indicators (NCI) Project in 2005. The National Core Indicators Children/Family Survey instrument was used for the mail out project.

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

The survey project employed a three-phased mail-out approach in order to garner the highest response rate possible. All correspondence was sent in English and Spanish versions. The first phase was initiated on October 3, and included a letter mailed to families informing them they would be receiving a survey and encouraged them to assist the department by completing the survey. The next phase began on October 17, with the mail out of the surveys in English (See Appendix A) and Spanish (See Appendix B) and a self-addressed stamped return envelope. The third phase was executed on November 7, with a follow-up letter to all families reminding them to complete the survey if they had not already done so. The deadline for returning the surveys to DADS was December 15, 2005.

All families of children in the Medically Dependent Children Program (MDCP), which may have included participants up to 21 years of age, were mailed a survey. In addition, families of children under age 18 and who live at home with their family in the Community Living Assistance and Support Services (CLASS), Consolidated Waiver Program (CWP), Home and Community-Based Services (HCS), and Texas Home Living (TxHmL) Programs were mailed surveys. A total of 2060 surveys were mailed to families and 800 (39%) of the completed surveys were returned to DADS.

The purpose of the project was to obtain information directly from families about their experiences utilizing DADS waiver services for their children. Data collected during this inaugural survey will provide 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 being effective. In addition, lessons learned during the implementation of this initial project will enable DADS to identify areas for process improvement.

Results

Family Indicators include the following sub-domains: **Information and Planning, Choice and Control, Access and Support Delivery, Community Connections, Satisfaction, and Family Outcomes**. For each program a total of 16 quality indicators were calculated based on the responses to the survey questions. Only responses 1, 2, and 3 were used (1= "always or usually", 2 = "sometimes", 3 = "seldom or never", 4 = "don't know", 5 = "not applicable"). Responses with 4 or 5 were not used to calculate the indicators.

Summary scores were developed for each of the 16 indicators by using the average of the items comprising the indicator (See Appendix C). For example, answers to questions #37, #38, and #39 were combined into one score representing the families/family members who participate in integrated activities in their communities. All of the scores range between 1.00 and 3.00. A 1.00 corresponds to "always or usually", 2.00 corresponds to "sometimes", and 3.00 corresponds to "seldom or never".[1] The closer the number is to 1.00 the more people tended to agree with the item whereas the closer the number is to 3.00 the more people disagreed with the item.

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[1] Question 27 was recoded to reverse responses to correspond with other questions.

Major Findings are listed below by program

Home and Community-Based Services

Indicators where summary scores reflect more *agreement* with the item--

- Families reporting that their support plan includes or reflects things that are important to them.
- Families who report that staff are respectful of their choices and decisions.
- Families who feel that services and support have helped them to better care for their family member living at home.

Indicators where summary scores reflect more *disagreement* with the item--

- Families reporting that they control their own budgets/supports (i.e. they choose what supports/goods to purchase).
- Families/family members who participate in integrated activities in their communities.
- Families who report they are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).

Texas Home Living

Indicators where summary scores reflect more *agreement* with the item--

- Families who report that staff are respectful of their choices and decisions.

Indicators where summary scores reflect more *disagreement* with the item--

- Families reporting that they control their own budgets/supports (i.e. they choose what support/goods to purchase).

Community Living Assistance and Support Services

Indicators where summary scores reflect more *agreement* with the item--

- Families who report that staff are respectful of their choices and decisions.
- Eligible families who report having access to an adequate array of services and supports.

Indicators where summary scores reflect more *disagreement* with the item--

- Families reporting that staff or translators are available to provide information, services and support in the family/family member’s primary language/method of communication.
- Families who report they are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).

Consolidated Waiver Program

Indicators where summary scores reflect more *agreement* with the item--

- Families reporting that their support plan includes or reflects things that are important to them.
- Eligible families who report having access to an adequate array of services and supports.
- Families reporting that staff or translators are available to provide information, services and supports in the family/family members' primary language/method of communication.
- Families who feel that services and support have helped them to better care for their family member living at home.

Indicators where summary scores reflect more *disagreement* with the item--

- Families/family members who participate in integrated activities in their communities.

Medically Dependent Children Program

Indicators where summary scores reflect more *agreement* with the item--

- Families who report that staff are respectful of their choices and decisions.
- Families who feel that services and support have helped them to better care for their family member living at home.

Indicators where summary scores reflect more *disagreement* with the item--

- Families reporting that they control their own budgets/supports (i.e. they choose what support/goods to purchase).
- Families/family members who participate in integrated activities in their communities.
- Families who report they are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).

Introduction

The purpose of this report is to provide summary information regarding Children/Family Surveys mailed to families of children under 18 years of age who receive services in programs operated by the Texas Department of Aging and Disability Services (DADS) in 2005. The information gathered from the surveys is related to the family member's perspective of their child's services and supports. The survey includes questions about: Information and Planning; Access and Delivery of Supports; Choice and Control; Community Connections; Satisfaction; and Family Outcomes. There is also a page for respondents to provide comments.

On October 3, 2003, the Centers for Medicare and Medicaid Services (CMS) awarded the Texas Department of Mental Health and Mental Retardation (TDMHMR) $500,000 to redesign and improve the quality assurance and quality improvement processes in its Medicaid waiver programs for people with cognitive disabilities. CMS awarded the Real Choice Systems Change grants to assist states in fulfilling their commitment to assuring individuals' health and welfare. TDMHMR was one of 19 states that were awarded the Quality Assurance and Quality Improvement in Home and Community-Based Services grant.

On September 1, 2004, the mental retardation programs of the Texas Department of Mental Health and Mental Retardation merged with the long-term care programs of the Texas Department of Human Services and the Texas Department on Aging and became the Texas Department of Aging and Disability Services (DADS). The grant activities continue in DADS within the Quality Assurance and Improvement unit of the Center for Policy and Innovation.

The project is being conducted in partnership with a Quality Assurance and Quality Improvement (QA/QI) Task Force that includes people receiving services and family members, local authority staff, advocacy groups, and provider representatives. One objective of the grant was to identify a personal outcome measurement tool to measure individual experiences and calculate quality indicators in home and community-based programs. The QA/QI Task Force members reviewed eight survey tools that were identified by the members. In June 2004, they recommended that the department join the National Core Indicators (NCI) Project and use the National Core Indicators tools to measure experiences people have in receiving services in DADS programs. The Children/Family survey tool was used for this project.

Quality Indicators

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

"The core indicators are the foundation for the project. The current set of indicators includes approximately 100 consumer, family, systemic, cost, and health and safety outcomes - outcomes that are important to understanding the overall health of public developmental disabilities agencies. Associated with each indicator is a source from which the data is collected. Sources of information include consumer survey (e.g., empowerment and choice issues) family surveys (e.g., satisfaction with supports), provider survey (e.g., staff turnover), and state systems data (e.g., expenditures, mortality, etc.)."[2] This project incorporates only the 16 indicators calculated from the Children/Family Survey.

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[2] Human Services Research Institute – www.hsri.org/nci/

Methodology

The survey project employed a three-phased mail-out approach in order to garner the highest response rate possible. All correspondence was sent in English and Spanish versions. The first phase began October 3, and included a letter mailed to families informing them they would be receiving a survey and encouraged them to assist the department by completing the survey. The next phase began on October 17, with the mail out of the surveys in English (See Appendix A) and Spanish (See Appendix B) with a self-addressed stamped return envelope. The third phase was executed on November 7, with a follow-up letter reminding them to complete the survey if they had not already done so. The deadline for returning the survey was December 15, 2005.

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

A total of 2060 surveys were mailed to families from the five programs and 800 (39%) of the completed surveys were returned to DADS.

Instruments

The National Core Indicators Children/Family survey was used. Both English and Spanish versions of the instrument were mailed to all of the families. The tool is divided into two parts. Part 1 is information about the family and the services and supports they receive. Part 2 of the survey includes questions about: Information and Planning; Access and Delivery of Supports; Choice and Control; Community Connections; Satisfaction; and Family Outcomes as well as a page for comments. A five-point Likert scale is used to respond as either: 1 indicating “always or usually”, 2 indicating “sometimes”, 3 indicating “seldom or never”, 4 indicating “don’t know”, and 5 indicating “not applicable”.

Results

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

The quality indicators were obtained by combining individual’s responses to relevant questions. Specifically, each person’s responses on certain questions were averaged to create a summary score for each indicator. Summary scores were developed for each of the 16 indicators by using the average of the items comprising the indicator (See Appendix C). For example, answers to questions #37, #38, and #39 were combined into one score representing the families/family members who participate in integrated activities in their communities. All of the scores range between 1.00 and 3.00. A 1.00 corresponds to “always or usually”, 2.00 corresponds to “sometimes”, and 3.00 corresponds to “seldom or never”.[3] The closer the number is to 1.00 the more people tended to agree with the item whereas the closer the number is to 3.00 the more people disagreed with the item.

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[3] Question 27. was recoded to reverse responses to correspond with other questions.

Comments

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

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

Home and Community-Based Services (HCS)

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

In March 2005, there were 254 families of children under 18 years of age who receive HCS Program services and supports. Surveys were mailed to all of those families. DADS received a total of 95 completed surveys or 37%. Based on the sample size, one can be 95% confident that each summary score falls within ± 8% of the number listed. The tables below provide information about the children in this program.

Demographics of Child Receiving HCS Program Services

Gender	%	Age	%	Ethnicity	%
Male	**68**	0-3	**0**	Black	**17**
Female	**32**	4-10	**1**	Hispanic	**29**
		11-15	**56**	White	**45**
		16-21	**43**	Other	**9**

		%
More than one child with a disability in household	Yes	**19**
	No	**81**

		%
Level of help needed for daily activities (such as bathing, dressing, eating)	None	**10**
	Little	**10**
	Moderate	**26**
	Complete	**53**

Diagnoses	%
Mental Retardation	**79**
Developmental Disabilities	**33**
Mental Illness	**10**
Autism	**30**
Cerebral Palsy	**33**
Brain Injury	**12**
Seizure Disorder	**43**
Chemical Dependency	**2**
Vision or Hearing Impairments	**37**
Physical Disabilities	**35**
Communication Disorder	**45**
Down Syndrome	**14**
Other Disability	**31**

Family Indicators

The table below details the Family Sub-Domains, Concerns, and Indicators. The questions from the Children/Family Survey used to calculate the indicators are available on the table crosswalk (See Appendix C). This table shows the summary scores of all 16 indicators for the **HCS Program**.

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

DOMAIN	Overview: The family indicators concern how well the public system assists children with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.			
SUB-DOMAIN	CONCERN	INDICATOR	SUMMARY SCORES	
Information and Planning	*Families/family members with disabilities have the information and support necessary to plan for their services and supports.*	Families are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	1.78	◐
		Families have the information needed to skillfully plan for their services and supports.	1.78	◐
		The support plan includes or reflects things that are important to the family.	1.30	●
		Staff who assist with planning are knowledgeable and respectful.	1.47	●
Choice & Control	*Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.*	Families control their own budgets/supports (i.e. they choose what supports/goods to purchase).	2.55	○
		Families choose, hire and manage their service/support providers.	1.55	●
		Staff are respectful of the family choices and decisions.	1.24	●
Access & Support Delivery	*Families/family members with disabilities get the services and supports they need.*	Having access to an adequate array of services and supports.	1.32	●
		Services/supports are available when needed, even in a crisis.	1.74	◐
		Staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication.	1.79	◐
		Services/supports are flexible to meet the changing needs of the family.	1.99	◐
		Service and support staff/providers are available and capable of meeting family needs.	1.59	●
Community Connections	*Families/family members use integrated community services and participate in everyday community activities.*	Families/family members participate in integrated activities in their communities.	2.00	◐
		Families are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	2.11	◐
Satisfaction	*Families/family members with disabilities receive adequate and satisfactory supports.*	Families are satisfied with the information and supports received, and with the planning, decision-making, and grievance processes.	1.73	◐
Family Outcomes	*Individual and family supports make a positive difference in the lives of families.*	Families feel that services and supports have helped them to better care for their family member living at home.	1.27	●

Demographics of Person Completing Survey for HCS

The table below provides information about the respondent.

Demographics	%
Age	
Under 55	93
55 and Over	7
Relation to Child	
Parent	95
Grandparent	2
Other	2
Primary Caregiver	
Yes	98
No	2
Health Status	
Excellent	20
Good	49
Fair	24
Poor	7
Other Services and Supports Received	
SSI Financial Support	52
Other Financial Support	19
In-Home Support	78
Out-of-Home Respite Care	54
Early Intervention	5
Transportation	26
Specialized Services and Supports	72

Comments

Of the 95 returned surveys, 13% provided comments. The most frequently mentioned comment from respondents was:

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

Other issues reported include:

- survey tool – survey tool was not clear or the respondent did not understand the program connection to DADS;
- information – lack of information regarding programs and services;
- program oversight – services and/or supports not being monitored or lack of accountability; and
- services/service providers – the inability to get services or find service providers.

Texas Home Living (TxHmL)

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

In March 2005, there were 97 families of children under 18 years of age who receive TxHmL Program services and supports. Surveys were mailed to all 97 families. DADS received a total of 36 completed surveys or 37%. Based on the sample size, one can be 95% confident that each summary score falls within ± 13% of the number listed. The tables below provide information about the children in this program.

Demographics of Child Receiving TxHmL Program Services

Gender	%	Age	%	Ethnicity	%
Male	**64**	0-3	**3**	Black	**22**
Female	**36**	4-10	**18**	Hispanic	**41**
		11-15	**58**	White	**41**
		16-21	**21**	Other	**0**

		%
More than one child with a disability in household	Yes	**18**
	No	**82**

		%
Level of help needed for daily activities (such as bathing, dressing, eating)	None	**12**
	Little	**6**
	Moderate	**42**
	Complete	**39**

Diagnoses	%
Mental Retardation	**75**
Developmental Disabilities	**41**
Mental Illness	**16**
Autism	**47**
Cerebral Palsy	**19**
Brain Injury	**6**
Seizure Disorder	**19**
Chemical Dependency	**0**
Vision or Hearing Impairments	**22**
Physical Disabilities	**9**
Communication Disorder	**44**
Down Syndrome	**9**
Other Disability	**25**

Family Indicators

The table below details the Family Sub-Domains, Concerns, and Indicators. The questions from the Children/Family Survey used to calculate the indicators are available on the table crosswalk (See Appendix C). This table shows the summary scores of all 16 indicators for the **TxHmL Program**.

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

DOMAIN	Overview: The family indicators concern how well the public system assists children with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.			
SUB-DOMAIN	CONCERN	INDICATOR	SUMMARY SCORES	
Information and Planning	*Families/family members with disabilities have the information and support necessary to plan for their services and supports.*	Families are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	1.81	◐
		Families have the information needed to skillfully plan for their services and supports.	1.91	◐
		The support plan includes or reflects things that are important to the family.	1.55	●
		Staff who assist with planning are knowledgeable and respectful.	1.41	●
Choice & Control	*Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.*	Families control their own budgets/supports (i.e. they choose what supports/goods to purchase).	2.12	◐
		Families choose, hire and manage their service/support providers.	1.86	◐
		Staff are respectful of family choices and decisions.	1.17	●
Access & Support Delivery	*Families/family members with disabilities get the services and supports they need.*	Having access to an adequate array of services and supports.	1.34	●
		Services/supports are available when needed, even in a crisis.	1.63	●
		Staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication.	1.74	◐
		Services/supports are flexible to meet the changing needs of the family.	1.72	◐
		Service and support staff/providers are available and capable of meeting family needs.	1.57	●
Community Connections	*Families/family members use integrated community services and participate in everyday community activities.*	Families/family members participate in integrated activities in their communities.	1.88	◐
		Families are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	1.98	◐
Satisfaction	*Families/family members with disabilities receive adequate and satisfactory supports.*	Families are satisfied with the information and supports received, and with the planning, decision-making, and grievance processes.	1.69	◐
Family Outcomes	*Individual and family supports make a positive difference in the lives of families.*	Families feel that services and supports have helped them to better care for their family member living at home.	1.44	●

Demographics of Person Completing Survey for TxHmL

The table below provides information about the respondent.

Demographics	%
Age	
Under 55	**85**
55 and Over	**15**
Relation to Child	
Parent	**85**
Grandparent	**6**
Other	**9**
Primary Caregiver	
Yes	**100**
No	**0**
Health Status	
Excellent	**6**
Good	**53**
Fair	**41**
Poor	**0**
Other Services and Supports Received	
SSI Financial Support	**91**
Other Financial Support	**21**
In-Home Support	**66**
Out-of-Home Respite Care	**66**
Early Intervention	**3**
Transportation	**41**
Specialized Services and Supports	**65**

Comments

Of the 36 returned surveys, 4% provided comments. The most frequently mentioned comment from respondents was:

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

Other issues reported include:

- survey tool – survey tool was not clear or the respondent did not understand the program connection to DADS;
- services/service providers – the inability to get services or find service providers;
- information – the lack of information regarding programs and services; and
- staff training – the lack of adequate training to carry out or respond to service needs.

Community Living Assistance and Support Services (CLASS)

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, which originated before age 22, that affects their ability to function in daily life. Services include:

- Case Management
- Adaptive Aids
- Respite
- Habilitation
- Nursing
- Minor Home Modifications
- Specialized Therapies
- Psychological Services
- Transition Assistance
- Support Family Services
- Occupational, Speech, Physical Therapies

In March 2005, there were 634 families of children under 18 years of age who receive CLASS Program services and supports. Surveys were mailed to all of those families. DADS received a total of 260 completed surveys or 41%. Based on the sample size, one can be 95% confident that each summary score falls within ± 5% of the number listed. The tables below provide information about the children in this program.

Demographics of Child Receiving CLASS Program Services

Gender	%	Age	%	Ethnicity	%
Male	**59**	0-3	**0**	Black	**8**
Female	**41**	4-10	**11**	Hispanic	**21**
		11-15	**48**	White	**70**
		16-21	**41**	Other	**1**

		%
More than one child with a disability in household	Yes	**14**
	No	**86**

		%
Level of help needed for daily activities (such as bathing, dressing, eating)	None	**1**
	Little	**3**
	Moderate	**40**
	Complete	**56**

Diagnoses	%
Mental Retardation	**47**
Developmental Disabilities	**34**
Mental Illness	**5**
Autism	**27**
Cerebral Palsy	**53**
Brain Injury	**15**
Seizure Disorder	**47**
Chemical Dependency	**1**
Vision or Hearing Impairments	**37**
Physical Disabilities	**55**
Communication Disorder	**39**
Down Syndrome	**3**
Other Disability	**28**

Family Indicators

The table below details the Family Sub-Domains, Concerns, and Indicators. The questions from the Children/Family Survey used to calculate the indicators are available on the table crosswalk (See Appendix C). This table shows the summary scores of all 16 indicators for the **CLASS Program**.

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

DOMAIN	Overview: The family indicators concern how well the public system assists children with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.			
SUB-DOMAIN	CONCERN	INDICATOR	SUMMARY SCORES	
Information and Planning	*Families/family members with disabilities have the information and support necessary to plan for their services and supports.*	Families are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	1.77	◐
		Families have the information needed to skillfully plan for their services and supports.	1.76	◐
		The support plan includes or reflects things that are important to the family.	1.32	●
		Staff who assist with planning are knowledgeable and respectful.	1.45	●
Choice & Control	*Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.*	Families control their own budgets/supports (i.e. they choose what supports/goods to purchase).	1.85	◐
		Families choose, hire and manage their service/support providers.	1.34	●
		Staff are respectful of the family choices and decisions.	1.25	●
Access & Support Delivery	*Families/family members with disabilities get the services and supports they need.*	Having access to an adequate array of services and supports.	1.29	●
		Services/supports are available when needed, even in a crisis.	1.69	◐
		Staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication.	2.03	◐
		Services/supports are flexible to meet the changing needs of the family.	1.93	◐
		Service and support staff/providers are available and capable of meeting family needs.	1.50	●
Community Connections	*Families/family members use integrated community services and participate in everyday community activities.*	Families/family members participate in integrated activities in their communities.	1.97	◐
		Families are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	2.18	◐
Satisfaction	*Families/family members with disabilities receive adequate and satisfactory supports.*	Families are satisfied with the information and supports received, and with the planning, decision-making, and grievance processes.	1.61	●
Family Outcomes	*Individual and family supports make a positive difference in the lives of families.*	Families feel that services and supports have helped them to better care for their family member living at home.	1.24	●

Demographics of Person Completing Survey for CLASS

The table below provides information about the respondent.

Demographics	%
Age	
Under 55	91
55 and Over	9
Relation to Child	
Parent	96
Grandparent	4
Other	0
Primary Caregiver	
Yes	98
No	2
Health Status	
Excellent	27
Good	54
Fair	17
Poor	2
Other Services and Supports Received	
SSI Financial Support	29
Other Financial Support	26
In-Home Support	97
Out-of-Home Respite Care	48
Early Intervention	5
Transportation	10
Specialized Services and Supports	86

Comments

Of the 260 returned surveys, 30% provided comments. The most frequently mentioned comment from respondents was:

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

Other issues reported include:

- services/service providers – the inability to get services or find service providers;
- information – lack of information regarding programs and services;
- program oversight – services and/or supports not being monitored or lack of accountability; and
- staff turnover – continuous change in paid staff and/or case managers.

Consolidated Waiver Program (CWP)

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*
- Home Delivered Meals*
- Emergency Response Services*
- 24 hour Residential Habilitation*
- Adaptive Aids/Medical Supplies
- Nursing
- Minor Home Modifications
- Therapy Services
- Personal Assistance Services
- Psychological Services
- Dietary
- Respite
- Audiology
- Social Work
- Transportation
- Prescription Drugs
- Child Support Services
- Dental
- Family Surrogate Services
- Habilitation
- Independent Advocacy
- Intervenor Services
- Orientation and Mobility Services
- Behavior Communication Specialist

In March 2005, there were 65 families of children under 18 years of age who receive CWP services and supports. Surveys were mailed to all of those families. DADS received a total of 25 completed surveys or 39%. Based on the sample size, one can be 95% confident that each summary score falls within ± 16% of the number listed. The tables below provide information about the children in this program.

Demographics of Child Receiving CWP Services

Gender	%	Age	%	Ethnicity	%
Male	57	0-3	0	Black	10
Female	43	4-10	35	Hispanic	62
		11-15	39	White	30
		16-21	26	Other	0

		%
More than one child with a disability in household	Yes	9
	No	91

		%
Level of help needed for daily activities (such as bathin*g, dressing, eating)	None	0
	Little	13
	Moderate	30
	Complete	57

Diagnoses	%
Mental Retardation	71
Developmental Disabilities	43
Mental Illness	0
Autism	14
Cerebral Palsy	43
Brain Injury	14
Seizure Disorder	38
Chemical Dependency	5
Vision or Hearing Impairments	38
Physical Disabilities	52
Communication Disorder	38
Down Syndrome	10
Other Disability	29

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* CWP services available to waiver participants age 18 or older.

Family Indicators

The table below details the Family Sub-Domains, Concerns, and Indicators. The questions from the Children/Family Survey used to calculate the indicators are available on the table crosswalk (See Appendix C). This table shows the summary scores of all 16 indicators for **CWP**.

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

DOMAIN	Overview: The family indicators concern how well the public system assists children with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.			
SUB-DOMAIN	CONCERN	INDICATOR	SUMMARY SCORES	
Information and Planning	*Families/family members with disabilities have the information and support necessary to plan for their services and supports.*	Families are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	1.61	●
		Families have the information needed to skillfully plan for their services and supports.	1.57	●
		The support plan includes or reflects things that are important to the family.	1.27	●
		Staff who assist with planning are knowledgeable and respectful.	1.32	●
Choice & Control	*Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.*	Families control their own budgets/supports (i.e. they choose what supports/goods to purchase).	1.77	◐
		Families choose, hire and manage their service/support providers.	1.42	●
		Staff are respectful of the family choices and decisions.	1.33	●
Access & Support Delivery	*Families/family members with disabilities get the services and supports they need.*	Having access to an adequate array of services and supports.	1.25	●
		Services/supports are available when needed, even in a crisis.	1.58	●
		Staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication.	1.30	●
		Services/supports are flexible to meet the changing needs of the family.	1.67	◐
		Service and support staff/providers are available and capable of meeting family needs.	1.48	●
Community Connections	*Families/family members use integrated community services and participate in everyday community activities.*	Families/family members participate in integrated activities in their communities.	1.99	◐
		Families are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	1.86	◐
Satisfaction	*Families/family members with disabilities receive adequate and satisfactory supports.*	Families are satisfied with the information and supports received, and with the planning, decision-making, and grievance processes.	1.56	●
Family Outcomes	*Individual and family supports make a positive difference in the lives of families.*	Families feel that services and supports have helped them to better care for their family member living at home.	1.09	●

Demographics of Person Completing Survey for CWP

The table below provides information about the respondent.

Demographics	%
Age	
Under 55	**96**
55 and Over	**4**
Relation to Child	
Parent	**96**
Grandparent	**4**
Other	**0**
Primary Caregiver	
Yes	**100**
No	**0**
Health Status	
Excellent	**22**
Good	**48**
Fair	**26**
Poor	**4**
Other Services and Supports Received	
SSI Financial Support	**74**
Other Financial Support	**6**
In-Home Support	**87**
Out-of-Home Respite Care	**48**
Early Intervention	**5**
Transportation	**18**
Specialized Services and Supports	**71**

Comments

Of the 25 returned surveys, 13% provided comments. The most frequently mentioned comment from respondents was:

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

Other issues reported include:

- services/service providers – the inability to get services or find service providers;
- accessing services – the inability to access a needed service;
- information – lack of information regarding programs and services; and
- program oversight – services and/or supports not being monitored or lack of accountability.

Medically Dependent Children Program (MDCP)

The MDCP provides a variety of services to support families caring for children under the age of 21 who are medically dependent and to encourage de-institutionalization of children in nursing facilities. Services include:

- Adaptive Aids
- Adjunct Support Services
- Minor Home Modifications
- Respite

In March 2005, all 1,024 families who receive MDCP services and supports were mailed a survey. DADS received a total of 383 completed surveys or 37% of the total. The tables below provide information about the children in this program.

Demographics of Child Receiving MDCP Services

Gender	%	Age	%	Ethnicity	%
Male	**55**	0-3	**2**	Black	**10**
Female	**45**	4-10	**30**	Hispanic	**26**
		11-15	**43**	White	**59**
		16-21	**25**	Other	**5**

		%
More than one child with a disability in household	Yes	**10**
	No	**90**

		%
Level of help needed for daily activities (such as bathing, dressing, eating)	None	**1**
	Little	**6**
	Moderate	**15**
	Complete	**78**

Diagnoses	%
Mental Retardation	**53**
Developmental Disabilities	**51**
Mental Illness	**5**
Autism	**6**
Cerebral Palsy	**51**
Brain Injury	**24**
Seizure Disorder	**61**
Chemical Dependency	**2**
Vision or Hearing Impairments	**56**
Physical Disabilities	**71**
Communication Disorder	**50**
Down Syndrome	**4**
Other Disability	**52**

Family Indicators

The table below details the Family Sub-Domains, Concerns, and Indicators. The questions from the Children/Family Survey used to calculate the indicators are available on the table crosswalk (See Appendix C). This table shows the summary scores of all 16 indicators for the **MDCP Program**.

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

DOMAIN	Overview: The family indicators concern how well the public system assists children with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.			
SUB-DOMAIN	CONCERN	INDICATOR	SUMMARY SCORES	
Information and Planning	*Families/family members with disabilities have the information and support necessary to plan for their services and supports.*	Families are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	1.84	◐
		Families have the information needed to skillfully plan for their services and supports.	1.93	◐
		The support plan includes or reflects things that are important to the family.	1.45	●
		Staff who assist with planning are knowledgeable and respectful.	1.46	●
Choice & Control	*Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.*	Families control their own budgets/supports (i.e. they choose what supports/goods to purchase).	2.16	◐
		Families choose, hire and manage their service/support providers.	1.39	●
		Staff are respectful of the family choices and decisions.	1.19	●
Access & Support Delivery	*Families/family members with disabilities get the services and supports they need.*	Having access to an adequate array of services and supports.	1.33	●
		Services/supports are available when needed, even in a crisis.	1.74	◐
		Staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication.	1.77	◐
		Services/supports are flexible to meet the changing needs of the family.	1.98	◐
		Service and support staff/providers are available and capable of meeting family needs.	1.57	●
Community Connections	*Families/family members use integrated community services and participate in everyday community activities.*	Families/family members participate in integrated activities in their communities.	2.03	◐
		Families are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	2.19	◐
Satisfaction	*Families/family members with disabilities receive adequate and satisfactory supports.*	Families are satisfied with the information and supports received, and with the planning, decision-making, and grievance processes.	1.71	◐
Family Outcomes	*Individual and family supports make a positive difference in the lives of families.*	Families feel that services and supports have helped them to better care for their family member living at home.	1.25	●

Demographics of Person Completing Survey for MDCP

The table below provides information about the respondent.

Demographics	%
Age	
Under 55	**90**
55 and Over	**10**
Relation to Child	
Parent	**93**
Grandparent	**5**
Other	**2**
Primary Caregiver	
Yes	**98**
No	**2**
Health Status	
Excellent	**21**
Good	**52**
Fair	**23**
Poor	**5**
Other Services and Supports Received	
SSI Financial Support	**45**
Other Financial Support	**22**
In-Home Support	**89**
Out-of-Home Respite Care	**23**
Early Intervention	**5**
Transportation	**17**
Specialized Services and Supports	**66**

Comments

Of the 383 returned surveys, 13% provided comments. The most frequently mentioned comment from respondents was:

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

Other issues reported include:

- information – lack of information regarding programs and services;
- services/service providers – the inability to get services or find service providers; and
- survey tool – survey tool was not clear or the respondent did not understand the program connection to DADS.

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 families whose children receive 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 family indicator that is shown to be the highest in agreement across all five programs is - *families who feel that services and supports have helped them to better care for their family member living at home*. The program with the highest rating for this indicator is from people in the CWP Program.

Other family indicators that were reported highest in agreement in descending order include –

- *Families who report that staff are respectful of their choices and decisions*
- *Families reporting that their support plan includes or reflects things that are important to them*
- *Eligible families who report having access to an adequate array of services and supports*
- *Families reporting that staff or translators are available to provide information, services and supports in the family/family members' primary language/method of communication* (Only for the CWP Program)

On the opposite end of the spectrum are family indicators that were reported the lowest in agreement. The indicator shown to be the lowest is – *families who report they are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services)*.

Other family indicators that were reported lowest in agreement in descending order include –

- *Families/family members who participate in integrated activities in their communities*
- *Families reporting that they control their own budgets/supports (i.e., they choose what supports/goods to purchase)*
- *Families reporting that staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication* (Only for the CLASS Program)

Currently, initiatives are underway to expand the options for families to direct their children's services such as Consumer Directed Services (CDS). CDS is a long-term care service delivery option in which individuals, guardians, or designated representatives have increased choice and control over the services they receive. The CDS option allows these people (instead of a provider agency) to directly hire, train, supervise and if necessary, fire service workers. CDS is one option for service delivery and does not preclude the use of the traditional agency-based service delivery option. CBA, CLASS, and DB-MD Programs offer the CDS option to individuals receiving services. The MDCP Program implemented the CDS option in January 2006 and it is anticipated that the HCS and TxHmL Programs will offer this option in 2007.

Overall, the results indicate that families feel services and supports have helped their family members to remain living at home. But at the same time, the area of highest concern for families is being able to *use integrated community services and participate in everyday community activities*.

Limitations identified as a result of this project include small sample sizes in some programs and the lack of accurate and up-to-date consumer mailing information. Approximately 7 percent of the surveys were returned as undeliverable.

Appendix A –Children/Family Survey (English)

See next page

Children/Family Survey (English/Inglés)

Opinions of Services and Supports for Children with Disabilities and their Families in Texas

Thank you for helping us by completing the attached questionnaire. Your opinions will make it possible to improve services and supports to children with disabilities and their families in Texas. The results of this survey will also allow us to compare family satisfaction with similar information collected in other states. We expect that it will only take about 20 minutes to complete this survey.

INSTRUCTIONS:

Note: If there is more than one child receiving services in your family, please answer for the oldest child.

For most questions, all you need to do is check the box that applies to you. All responses will remain confidential. Your answers will not affect the services and supports you are receiving. If you come to a question that you feel uncomfortable answering, skip it. However, for us to get complete information, it is very important that you try to answer each question as accurately as you can.

When you have completed the questionnaire, please return it to us in the enclosed pre-addressed and pre-stamped envelope. Please try to return the survey as soon as possible.

Again, THANK YOU!

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Part 1: **INFORMATION ABOUT YOUR FAMILY**

Please answer the following questions about your family member with a disability.

a.) Does your child with a disability live at home with you?

☐ 1. Yes ☐ 2. No

Note: If you answered "no" to the question above, please stop here and return the survey.

b.) Is there more than one child with a disability in your household?

☐ 1. Yes ☐ 2. No

Reminder: If yes, please answer for the oldest child.

c.) How old is this child? ______ years

d.) What is the gender of this child?

☐ 1. Male ☐ 2. Female

e.) About how much help does this child need with daily activities (such as bathing, dressing, eating)? (check one)

☐ 1. None ☐ 3. Moderate
☐ 2. Little ☐ 4. Complete

f.) Has this child been diagnosed with any of the following? (check all that apply)

☐ 1. Mental retardation
☐ 2. Other developmental disability
☐ 3. Mental illness (e.g. depression)
☐ 4. Autism
☐ 5. Cerebral Palsy
☐ 6. Brain injury
☐ 7. Seizure disorder/neurological problem
☐ 8. Chemical dependency
☐ 9. Vision or hearing impairments
☐ 10. Physical disabilities
☐ 11. Communication disorder
☐ 12. Down Syndrome
☐ 13. Other disabilities not listed

g.) What is this child's race?
(check all that apply)

☐ 1. American Indian or Alaska Native
☐ 2. Asian
☐ 3. Black or African-American
☐ 4. Native Hawaiian or Other Pacific Islander
☐ 5. White

- ☐ 6. Other/Unknown
- ☐ 7. Two or More Races
- ☐ 8. Hispanic or Latino

Please answer the following questions about yourself.

h.) What is your age?

- ☐ 1. Under 35
- ☐ 2. 35 - 54
- ☐ 3. 55 - 74
- ☐ 4. 75 or Older

i.) How would you describe your health? (check one)

- ☐ 1. Excellent
- ☐ 2. Good
- ☐ 3. Fair
- ☐ 4. Poor

j.) What is your relationship to this child? (check one)

- ☐ 1. Parent (biological, adoptive, or foster)
- ☐ 2. Sibling
- ☐ 3. Grandparent
- ☐ 4. Other (please describe)______________

k.) Are you a primary caregiver for this child?

☐ 1. Yes ☐ 2. No

SERVICES AND SUPPORTS RECEIVED

Please check whether your family or your child with a disability is currently receiving any of the services or supports described below.

		YES	NO	DON'T KNOW
i.	SSI Financial Support -- your family receives SSI payments.	☐ 1	☐ 2	☐ 3
ii.	Other Financial Support -- family receives money (cash, stipends, vouchers, or reimbursement) to purchase items, equipment, or needed services for your child with a developmental disability.	☐ 1	☐ 2	☐ 3
iii.	In-Home Support -- people are paid to come to your home to provide assistance to your child with a disability.	☐ 1	☐ 2	☐ 3
iv.	Out-of-Home Respite Care -- someone takes care of your child with a disability outside of your home to give your family a break.	☐ 1	☐ 2	☐ 3
v.	Early Intervention -- your child attends a special stimulation program for children under age 5.	☐ 1	☐ 2	☐ 3
vi.	Transportation -- someone arranges for specialized transportation for your child with a disability to go to community activities, medical appointments, etc.	☐ 1	☐ 2	☐ 3
vii.	Specialized Services/Supports -- your child with a disability receives mental health care or other kinds of therapies (such as physical therapy, occupational therapy, speech therapy, or recreational therapy).	☐ 1	☐ 2	☐ 3

Part 2: **QUESTIONS ABOUT SERVICES AND SUPPORTS**

Please answer the following questions about services you currently receive from the Department of Aging and Disability Services. Check one response for each question. If a question does not apply to you, please check the last column.

INFORMATION & PLANNING		Always or Usually	Some-times	Seldom or Never	Don't Know	NA
1.	Do you receive information about the services and supports that are available to your child and family?	☐1	☐2	☐3	☐4	☐5
2.	If you receive information, is it easy to understand?	☐1	☐2	☐3	☐4	☐5
3.	Do you receive information about the status of your child's development?	☐1	☐2	☐3	☐4	☐5
4.	If yes, is this information easy to understand?	☐1	☐2	☐3	☐4	☐5
5.	Do you get enough information to help you participate in planning services for your family?	☐1	☐2	☐3	☐4	☐5
6.	If your family has a service plan, did you help develop the plan?	☐1	☐2	☐3	☐4	☐5
7.	If your family has a service plan, does the plan include things that are important to you?	☐1	☐2	☐3	☐4	☐5
8.	Do the staff who assist you with planning help you figure out what you need as a family to support your child?	☐1	☐2	☐3	☐4	☐5
9.	Do the staff who assist you with planning respect your choices and opinions?	☐1	☐2	☐3	☐4	☐5
10.	Does someone talk to you about the public benefits that are available to you? (e.g. food stamps, Texas Health Steps, Supplemental Security Income, etc.)	☐1	☐2	☐3	☐4	☐5
11.	Are the staff who assist you with planning generally respectful and courteous?	☐1	☐2	☐3	☐4	☐5
12.	Are the staff who assist you with planning generally effective?	☐1	☐2	☐3	☐4	☐5
13.	Can you contact the staff who assist you with planning whenever you want to?	☐1	☐2	☐3	☐4	☐5

ACCESS & DELIVERY OF SUPPORTS		Always or Usually	Some-times	Seldom or Never	Don't Know	NA
14.	When you ask your case manager/service coordinator for assistance, does s/he help you get what you need?	☐1	☐2	☐3	☐4	☐5
15.	Does your family get the services and supports you need?	☐1	☐2	☐3	☐4	☐5
16.	Do the services and supports offered meet your family's needs?	☐1	☐2	☐3	☐4	☐5
17.	Are supports available when your family needs them?	☐1	☐2	☐3	☐4	☐5
18.	Do families in your area request that different types of services and supports be made available in your area?	☐1	☐2	☐3	☐4	☐5
19.	If yes, does either the state agency or provider agency respond to their requests?	☐1	☐2	☐3	☐4	☐5
20.	If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?	☐1	☐2	☐3	☐4	☐5
21.	If English is <u>not</u> your first language, are there support workers or translators available to speak with you in your preferred language?	☐1	☐2	☐3	☐4	☐5
22.	If your child does not speak English or uses a different way to communicate (for example, sign language), are there enough support workers available who can communicate with him/her?	☐1	☐2	☐3	☐4	☐5
23.	Does your child have access to the special equipment or accommodations that s/he needs (e.g., wheelchair, ramp, communication board)?	☐1	☐2	☐3	☐4	☐5
24.	Do you have access to health services for your child?	☐1	☐2	☐3	☐4	☐5
25.	Do you have access to dental services for your child?	☐1	☐2	☐3	☐4	☐5
26.	Do you have access to necessary medications for your child?	☐1	☐2	☐3	☐4	☐5
27.	Are frequent changes in support staff a problem for your family?	☐1	☐2	☐3	☐4	☐5
28.	Are support staff generally respectful and courteous?	☐1	☐2	☐3	☐4	☐5

	CHOICE & CONTROL	Always or Usually	Sometimes	Seldom or Never	Don’t Know	NA
29.	Do you choose the agencies or providers who work with your family?	☐1	☐2	☐3	☐4	☐5
30.	Do you choose the support workers who work with your family?	☐1	☐2	☐3	☐4	☐5
31.	Do you have control and/or input over the hiring and management of your support workers?	☐1	☐2	☐3	☐4	☐5
32.	Do you want to have control and/or input over the hiring and management of your support workers?	☐1	☐2	☐3	☐4	☐5
33.	Do you know how much money is spent by the Department of Aging and Disability Services on behalf of your child with a developmental disability?	☐1	☐2	☐3	☐4	☐5
34.	Do you get to decide how this money is spent?	☐1	☐2	☐3	☐4	☐5

	COMMUNITY CONNECTIONS	Always or Usually	Sometimes	Seldom or Never	Don’t Know	NA
35.	If you want to use typical supports in your community (for example, through recreation departments or churches), do either the staff who help you plan or who provide support help connect you to these supports?	☐1	☐2	☐3	☐4	☐5
36.	If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this?	☐1	☐2	☐3	☐4	☐5
37.	Do you feel that your child has access to community activities?	☐1	☐2	☐3	☐4	☐5
38.	Does your child participate in community activities?	☐1	☐2	☐3	☐4	☐5
39.	Does your child spend time with children who do not have developmental disabilities?	☐1	☐2	☐3	☐4	☐5

SATISFACTION		Always or Usually	Some-times	Seldom or Never	Don't Know	NA
40.	Overall, are you satisfied with the services and supports your child and family currently receive?	☐**1**	☐**2**	☐**3**	☐**4**	☐**5**
41.	Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?	☐**1**	☐**2**	☐**3**	☐**4**	☐**5**
42.	Are you satisfied with the way complaints or grievances are handled and resolved?	☐**1**	☐**2**	☐**3**	☐**4**	☐**5**

OUTCOMES		Always or Usually	Some-times	Seldom or Never	Don't Know	*NA*
43.	Do you feel that family supports have made a positive difference in the life of your family?	☐**1**	☐**2**	☐**3**	☐**4**	☐**5**
44.	Do you feel that family supports have improved your ability to care for your child?	☐**1**	☐**2**	☐**3**	☐**4**	☐**5**
45.	Do you feel that family supports have helped you to keep your child at home?	☐**1**	☐**2**	☐**3**	☐**4**	☐**5**
46.	Overall, do you feel that your child is happy?	☐**1**	☐**2**	☐**3**	☐**4**	☐**5**

Part 3: YOUR COMMENTS

Thank you for taking the time to complete these questions. Your opinion is very important to us. Please use the space below for any other comments you would like to make.

Appendix B –Children/Family Survey (Spanish)

See next page

Encuesta de niños/familia (Español/Spanish)

Opiniones acerca de servicios y apoyos para niños con discapacidades y sus familias en el Estado de Texas

Gracias por ayudarnos completando el cuestionario adjunto. Su opinión hará posible la mejora de servicios y apoyo para niños con discapacidades y sus familias en el Estado de Texas. Los resultados de esta encuesta también nos permitirán comparar la necesidad de la familia con información similar recolectada en otros estados. Prevemos que completar esta encuesta sólo llevará unos 25 minutos.

INSTRUCCIONES:

Nota: Si hay más de un niño que recibe los servicios en su familia, por favor, responda a las preguntas teniendo en cuenta a la persona que se nombra en la carta que recibió.

Para la mayoría de las preguntas, todo lo que necesita hacer es marcar el casillero que le corresponde a usted. Todas las respuestas serán confidenciales. Sus respuestas no afectarán los servicios y los apoyos que usted está recibiendo. Si le incomoda responder alguna pregunta, déjela pasar. Sin embargo, para que nosotros obtengamos toda la información, es muy importante que usted sea lo más exacto posible al responder cada pregunta.

Cuando haya completado el cuestionario, por favor envíelo en el sobre adjunto que ya tiene la dirección y las estampillas. Por favor, trate de enviar la encuesta lo más rápido posible.

Nuevamente, ¡GRACIAS!

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Parte 1: INFORMACIÓN ACERCA DE SU FAMILIA

Por favor responda las siguientes preguntas acerca del miembro de su familia con discapacidad.

a.) ¿Su niño discapacitado vive con usted en la casa?

☐ 1. Sí ☐ 2. No

Nota: Si responde "no" a la pregunta anterior, por favor deténgase aquí y envíe la encuesta.

b.) ¿Hay más de un niño discapacitado en su casa?

☐ 1. Sí ☐ 2. No

Recuerde: Si su respuesta es sí, por favor responda para el niño mayor.

c.) ¿Cuántos años tiene este niño?
______ años

d.) ¿De qué sexo es este niño?

☐ 1. Masculino ☐ 2. Femenino

e.) ¿Cuánta ayuda necesita este niño con las actividades diarias (bañarse, vestirse, comer)? (marque una)

☐ 1. Ninguna ☐ 3. Moderada
☐ 2. Poca ☐ 4. Toda

f.) ¿Este niño ha sido diagnosticado con alguna de las siguientes discapacidades? (marque todas las que correspondan)

☐ 1. Retraso mental
☐ 2. Otra discapacidad de desarrollo
☐ 3. Enfermedad mental (por ejemplo, depresión)
☐ 4. Autismo
☐ 5. Parálisis cerebral
☐ 6. Lesión cerebral
☐ 7. Convulsiones/problema neurológico
☐ 8. Adicción a las drogas
☐ 9. Problemas de la vista o de la audición
☐ 10. Discapacidades físicas
☐ 11. Problemas de comunicación
☐ 12. Síndrome de Down
☐ 13. Otras discapacidades no nombradas

f.2.) Si este niño tiene diagnosticado retraso mental ¿qué grado de retraso tiene? (marque una)

☐ 1. No corresponde, no tiene RM
☐ 2. Leve
☐ 3. Moderado
☐ 4. Grave
☐ 5. Profundo

☐ 6. No sabe o el grado no fue especificado

g.) ¿De qué raza es este niño?
(marque todas las que correspondan)

☐ 1. Indígena americano o Nativo de Alaska
☐ 2. Asiático
☐ 3. Negro o afroamericano
☐ 4. Nativo de Hawai o de otras islas del Pacífico
☐ 5. Blanco
☐ 6. Otra/Desconocida
☐ 7. Dos o más razas
☐ 8. Hispano o Latino

Por favor responda las siguientes preguntas acerca de usted mismo.

h.) ¿Cuántos años tiene <u>usted</u>?

☐ 1. Menos de 35
☐ 2. 35 - 54
☐ 3. 55 - 74
☐ 4. 75 ó más

i.) ¿Cómo describiría su estado de salud? (marque una)

☐ 1. Excelente
☐ 2. Bueno
☐ 3. Bastante bueno
☐ 4. Malo

j.) ¿Qué relación tiene con este niño?
(marque una)

☐ 1. Padre/madre (biológico/a, adoptivo/a, o tutor/a)
☐ 2. Hermano/a
☐ 3. Abuelo/a
☐ 4. Otra (por favor descríbala)______________

k.) ¿Usted es el que le brinda los cuidados principales a este niño?

☐ 1. Sí ☐ 2. No

SERVICIOS Y APOYOS RECIBIDOS

Por favor, verifique si su familia o su niño discapacitado reciben actualmente alguno de los servicios o apoyos descritos abajo y si usted está autorizado para recibir la cantidad de servicios que precisa para cubrir sus necesidades.

	Sì,	No	No Sé
i. Ayuda económica de SSI: su familia recibe pagos provenientes del Seguro de Ingreso Suplementario (SSI).	☐ 1	☐ 2	☐ 3
ii. Otra ayuda económica: su familia recibe dinero (efectivo, sueldos, vales o reembolso) para comprar artículos, equipos o servicios necesarios para su niño con una discapacidad de desarrollo.	☐ 1	☐ 2	☐ 3
iii. Asistencia en el hogar: se le paga a las personas que van a su casa para brindarle asistencia a su niño discapacitado.	☐ 1	☐ 2	☐ 3
iv. Cuidado de relevo: alguien cuida a su niño discapacitado, fuera de su casa, para que su familia descanse.	☐ 1	☐ 2	☐ 3
v. Intervención temprana: su niño tiene menos de 5 años y recibe servicios para mejorar su desarrollo.	☐ 1	☐ 2	☐ 3
vi. Transporte: alguien se encarga de brindarle transporte especializado para que su niño discapacitado asista a actividades comunitarias, visitas médicas, etc.	☐ 1	☐ 2	☐ 3
vii. Servicios especializados/apoyos: su niño discapacitado recibe cuidados para la salud mental u otros tipos de terapias (como fisioterapia, terapia ocupacional, logopedia o terapia recreativa).	☐ 1	☐ 2	☐ 3

Parte 2: **PREGUNTAS ACERCA DE SERVICIOS Y APOYOS**

Por favor, responda las siguientes preguntas acerca de los servicios que recibe en la actualidad de la Departamento de Servicios para Adultos Mayores y Personas Discapacitadas. Marque una respuesta por cada pregunta. Si una pregunta no le corresponde, por favor, marque la última columna.

INFORMACIÓN Y PLANIFICACIÓN		Siempre o usualmente	A veces	Pocas veces o nunca	No sabe	NC
1.	¿Recibe información acerca de servicios y apoyos disponibles para su niño y su familia?	☐1	☐2	☐3	☐4	☐5
2.	Si recibe información, ¿es fácil de entender?	☐1	☐2	☐3	☐4	☐5
3.	¿Recibe información sobre el estado de desarrollo de su niño?	☐1	☐2	☐3	☐4	☐5
4.	Si su respuesta es sí, ¿esta información es fácil de entender?	☐1	☐2	☐3	☐4	☐5
5.	¿Recibe información suficiente para que usted pueda participar en la planificación de los servicios para su familia?	☐1	☐2	☐3	☐4	☐5
6.	Si su familia tiene un plan de servicios, ¿usted colaboró para elaborarlo?	☐1	☐2	☐3	☐4	☐5
7.	Si su familia tiene un plan de servicios, ¿éste incluye las cosas que son importantes para usted?	☐1	☐2	☐3	☐4	☐5
8.	¿El personal que lo asiste en la planificación, le ayuda a determinar qué necesita como familia para apoyar a su niño?	☐1	☐2	☐3	☐4	☐5
9.	¿El personal que lo asiste en la planificación respeta sus elecciones y opiniones?	☐1	☐2	☐3	☐4	☐5
10.	¿Alguien le comenta sobre los beneficios públicos disponibles para usted? (por ejemplo, estampillas para alimentos, Pasos Sanos de Tejas, Seguro de Ingreso Suplementario, etc.)	☐1	☐2	☐3	☐4	☐5
11.	¿El personal que lo asiste en la planificación es respetuoso y educado?	☐1	☐2	☐3	☐4	☐5
12.	¿El personal que lo asiste en la planificación es generalmente eficiente?	☐1	☐2	☐3	☐4	☐5
13.	¿Puede contactar al personal que lo asiste en la planificación cuando usted lo desea?	☐1	☐2	☐3	☐4	☐5

ACCESO Y ENTREGA DEL APOYO		Siempre o usualmente	A veces	Pocas veces o nunca	No sabe	NC
14.	Cuando usted le pide asistencia a su administrador de caso/coordinador de servicios, ¿él/ ella le ayuda en lo que necesita?	☐1	☐2	☐3	☐4	☐5
15.	¿Su familia obtiene los servicios y apoyos que necesita?	☐1	☐2	☐3	☐4	☐5
16.	¿Los servicios y apoyos ofrecidos cubren las necesidades de su familia?	☐1	☐2	☐3	☐4	☐5
17.	¿El apoyo está disponible cuando su familia lo necesita?	☐1	☐2	☐3	☐4	☐5
18.	¿Las familias que viven en su área solicitan que se pongan a disposición otros tipos de servicios y apoyos?	☐1	☐2	☐3	☐4	☐5
19.	Si su respuesta es sí, ¿la agencia estatal o la agencia de provisión responden a sus pedidos?	☐1	☐2	☐3	☐4	☐5
20.	Si alguna vez solicitó servicios y apoyos en una emergencia o crisis, ¿le brindaron ayuda rápidamente?	☐1	☐2	☐3	☐4	☐5
21.	Si el inglés no es su idioma principal, ¿hay trabajadores de apoyo o traductores disponibles que hablen con usted en su idioma de preferencia?	☐1	☐2	☐3	☐4	☐5
22.	Si su niño no habla inglés o utiliza otra manera de comunicarse (por ejemplo, lenguaje de señas), ¿hay suficientes trabajadores de apoyo disponibles para comunicarse con él/ ella?	☐1	☐2	☐3	☐4	☐5
23.	¿Su niño tiene acceso a los equipos o adaptaciones especiales que él/ ella necesita (por ejemplo, silla de ruedas, rampa, pizarra para comunicarse)?	☐1	☐2	☐3	☐4	☐5
24.	¿Tiene acceso a servicios de salud para su niño?	☐1	☐2	☐3	☐4	☐5
25.	¿Tiene acceso a servicios dentales para su niño?	☐1	☐2	☐3	☐4	☐5
26.	¿Tiene acceso a los medicamentos que necesita su niño?	☐1	☐2	☐3	☐4	☐5
27.	¿Los cambios frecuentes del personal de apoyo, son un problema para su familia?	☐1	☐2	☐3	☐4	☐5
28.	¿El personal de apoyo es generalmente respetuoso y educado?	☐1	☐2	☐3	☐4	☐5

ELECCIÓN Y CONTROL		Siempre o usualmente	A veces	Pocas veces o nunca	No sabe	NC
29.	¿Usted elige las agencias o los proveedores que trabajan con su familia?	☐1	☐2	☐3	☐4	☐5
30.	¿Usted elige los trabajadores de apoyo que trabajan con su familia?	☐1	☐2	☐3	☐4	☐5
31.	¿Usted colabora en la contratación y la administración de sus trabajadores de apoyo o tiene control sobre ello?	☐1	☐2	☐3	☐4	☐5
32.	¿Usted desea colaborar en la contratación y la administración de sus trabajadores de apoyo o tener control sobre ello?	☐1	☐2	☐3	☐4	☐5
33.	¿Sabe cuánto dinero gasta el Departamento de Servicios para Adultos Mayores y Personas Discapacitadas a favor de su niño con una discapacidad de desarrollo?	☐1	☐2	☐3	☐4	☐5
34.	¿Usted decide cómo se gasta este dinero?	☐1	☐2	☐3	☐4	☐5

CONEXIONES CON LA COMUNIDAD		Siempre o usualmente	A veces	Pocas veces o nunca	No sabe	NC
35.	Si usted desea utilizar el apoyo típico de su comunidad (por ejemplo, a través de departamentos de recreación o iglesias), ¿el personal que lo asiste en la planificación o le provee apoyo lo pone en contacto con este apoyo?	☐1	☐2	☐3	☐4	☐5
36.	Si usted deseara que su familia, amigos o vecinos le provean algún tipo de apoyo que su familia necesita, ¿el personal que lo asiste en la planificación o le provee apoyo colabora para que eso sea posible?	☐1	☐2	☐3	☐4	☐5
37.	¿Cree que su niño tiene acceso a actividades comunitarias?	☐1	☐2	☐3	☐4	☐5
38.	¿Su niño participa en actividades comunitarias?	☐1	☐2	☐3	☐4	☐5
39.	¿Su niño pasa tiempo con niños que no tienen discapacidades de desarrollo?	☐1	☐2	☐3	☐4	☐5

SATISFACCIÓN		Siempre o usualmente	A veces	Pocas veces o nunca	No sabe	NC
40.	En general, ¿está satisfecho con los servicios y apoyos que su niño y su familia reciben actualmente?	☐1	☐2	☐3	☐4	☐5
41.	¿Conoce los procesos para presentar una queja o reclamo con respecto a los servicios que recibe o el personal que los provee?	☐1	☐2	☐3	☐4	☐5
42.	¿Está satisfecho con la manera en la que se manejan y resuelven las quejas o reclamos?	☐1	☐2	☐3	☐4	☐5

RESULTADOS		Siempre o usualmente	A veces	Pocas veces o nunca	No sabe	*NC*
43.	¿Considera que el apoyo para la familia marcó una diferencia positiva en la vida de su familia?	☐1	☐2	☐3	☐4	☐5
44.	¿Cree que el apoyo para la familia ha mejorado su capacidad para cuidar a su niño?	☐1	☐2	☐3	☐4	☐5
45.	¿Cree que el apoyo para la familia le ha ayudado a cuidar a su niño en su hogar?	☐1	☐2	☐3	☐4	☐5
46.	En general, ¿considera que su niño es feliz?	☐1	☐2	☐3	☐4	☐5

Parte 3: SUS COMENTARIOS

Gracias por tomarse el tiempo de completar estas preguntas. Por favor utilice el siguiente espacio para cualquier otro comentario que desee hacer.

Gracias por su tiempo. ¡Su opinión es muy importante para nosotros!

Appendix C – Family Indicators Crosswalk

DOMAIN	FAMILY INDICATORS Overview: The family indicators concern how well the public system assists children and adults with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.		
SUB-DOMAIN	CONCERN	INDICATOR	CHILD FAMILY SURVEY DATA SOURCE
Information and Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.	The proportion of families who report they are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	Q1, Q2, Q3, Q4, Q10, Q13
		The proportion of families who report they have the information needed to skillfully plan for their services and supports.	Q5
		The proportion of families reporting that their support plan includes or reflects things that are important to them.	Q6, Q7
		The proportion of families who report that staff who assist with planning are knowledgeable and respectful.	Q8, Q9, Q11, Q12
Choice & Control	Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.	The proportion of families reporting that they control their own budgets/supports (i.e. they choose what supports/goods to purchase).	Q33, Q34
		The proportion of families who report they choose, hire and manage their service/support providers.	Q29, Q30, Q31, Q32
		The proportion of families who report that staff are respectful of their choices and decisions.	Q11, Q28
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.	The proportion of eligible families who report having access to an adequate array of services and supports.	Q15, Q16, Q23, Q24, Q25, Q26
		The proportion of families who report that services/supports are available when needed, even in a crisis.	Q17, Q20
		The proportion of families reporting that staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication.	Q21, Q22
		The proportion of families who report that services/supports are flexible to meet their changing needs.	Q14, Q15, Q16, Q17, Q27, Q28
		The proportion of families who report that service and support staff/providers are available and capable of meeting family needs.	Q18, Q19
Community Connections	Families/family members use integrated community services and participate in everyday community activities.	The proportion of families/family members who participate in integrated activities in their communities.	Q37, Q38, Q39
		The proportion of families who report they are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	Q35, Q36
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.	The proportion of families who report satisfaction with the information and supports received, and with the planning, decision-making, and grievance processes.	Q40, Q41, Q42
Family Outcomes	Individual and family supports make a positive difference in the lives of families.	The proportion of families who feel that services and supports have helped them to better care for their family member living at home.	Q43, Q44, Q45, Q46

TEXAS
Department of Aging
and Disability Services

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