June 2015

National Core Indicators

California Child Family Survey

Supplemental Report:

Fiscal Year 2012–2013

PREPARED BY

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FOR THE

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Message from the California Department of Developmental Services

Mission: The Department of Developmental Services (DDS) is committed to providing leadership that results in quality services to the people of California and assures the opportunity for individuals with developmental disabilities to exercise their right to make choices.

This is a supplemental report to findings in the California National Core Indicators (NCI) Child Family Survey. The NCI Child Family report was compiled by the Human Services Research Institute (HSRI) and is in accordance with Welfare and Institutions Code (WIC), Section 4571. It is an important effort to collect accurate, reliable, and valid consumer and family satisfaction measures as well as consumer outcome data. More information about the California NCI can be found at http://www.dds.ca.gov/QA/. This supplemental report was prepared by the Center for Human Services, University of California Davis (UC Davis).

The Child Family Survey collected data from July 2012 through June 2013. During that time, 8,109 families of a child with developmental disabilities provided their input through mail surveys sent by the State Council on Developmental Disabilities (SCDD). These findings contribute to our understanding of how California's system is performing. California can use future reports to make meaningful comparisons to monitor changes in the system and to guide strategic planning and quality improvement activities. Regional centers can use the data in a similar fashion at the local level.

This data should be interpreted in the context of legislative changes in California that have impacted services received by families of children with developmental disabilities. Regional centers enacted over 25 savings proposals since the fiscal year 2009-10 budget, including the restructure, reduction, or suspension of some services. In addition, SB 946, the California Autism Insurance Law which took effect in 2012, transferred responsibility of behavioral health treatment for individuals with a diagnosis of autism to health plan providers. These changes in service delivery should be kept in mind when reading this report.

The second Child Family Survey will take place in fiscal year 2015-16. DDS will then have the opportunity to compare data from the first cycle of data collected to the second cycle of data and strategically plan system improvements for the future.

Acknowledgements

This report would not be possible without the 8,109 families who agreed to offer their time to discuss their lives, to assist in improving the services for all people with developmental disabilities in California.

List of Abbreviations Used in the Report

ASD—Autism Spectrum Disorder

CA-ODESA—California Online Data Entry Survey Application

CCF—Community Care Facility

CP—Cerebral Palsy

CFS1—Child Family Survey FY 12/13

DD—Developmental Disabilities

DDS—Department of Developmental Services

HSRI—Human Services Research Institute

ID—Intellectual Disability

IPP—Individual Program Plan

NASDDDS—National Association of State Directors of Developmental Disabilities Services

NCI—National Core Indicator

SCDD—State Council on Developmental Disabilities

WIC—Welfare and Institutions Code

List of Regional Center Abbreviations

ACRC—Alta California Regional Center

CVRC—Central Valley Regional Center

ELARC—Eastern Los Angeles Regional Center

FNRC—Far Northern Regional Center

FDLRC—Frank D. Lanterman Regional Center

GGRC—Golden Gate Regional Center

HRC—Harbor Regional Center

IRC—Inland Regional Center

KRC—Kern Regional Center

NBRC—North Bay Regional Center

NLARC—North Los Angeles County Regional Center

RCEB—Regional Center of the East Bay

RCOC—Regional Center of Orange County

RCRC—Redwood Coast Regional Center

SARC—San Andreas Regional Center

SDRC—San Diego Regional Center

SG/PRC—San Gabriel/Pomona Regional Center

SCLARC—South Central Los Angeles Regional Center

TCRC—Tri-Counties Regional Center

VMRC—Valley Mountain Regional Center

WRC—Westside Regional Center

Organization of Report

This report, prepared by the Center for Human Services, University of California, Davis (UC Davis), presents supplemental findings from specific subgroups that are of interest to the Department of Developmental Services (DDS) and stakeholders.

The report is organized under the following chapters:

I. Introduction: Provides a brief overview of the purpose of the report

II. Methodology: Explains the sampling design, data collection process used in administering the survey, and the statistical methods used to complete the analysis

III. Intellectual Disability (ID): results are presented for children with ID compared to children without ID

IV. Autism Spectrum Disorder (ASD) : results are presented for children with ASD compared to children without ASD

V. Cerebral Palsy (CP) : results are presented for children with CP compared to children without CP

VI. Epilepsy: results are presented for children with epilepsy compared to children without epilepsy

VII. Appendices: Includes additional analysis information and item-by-item results in table format

Table of Contents

I. Introduction

The purpose of this report is to serve as a supplemental report to the California Child Family Survey Report prepared by the Human Services Research Institute (HSRI). This report prepared by the Center for Human Services, UC Davis provides findings from specific subgroups served by the California Developmental Service system that are of special interest to DDS and stakeholders. The subgroups include families of children with a diagnosis of intellectual disability (ID), autism spectrum disorder (ASD), cerebral palsy (CP), or epilepsy.

II. Methodology

This chapter summarizes information on sample design, survey administration, and methods for analyzing the data for specific subgroups.

Administration

Proposed Sampling Strategy

A statewide sample size of 7,000 surveys was recommended by the Human Services Research Institute (HSRI) for the Child Family Survey FY 12/13 (CFS1) with the expectation of a 40% return rate or greater (yielding 300 or more usable surveys per regional center). To ensure that at least 300 usable surveys per regional center (RC) were received, it was recommended that a random sample of at least 1,000 families was selected for each RC. To be eligible for the random sample families:

1. Had a child (18 years old or younger, or age unknown) with a developmental disability living at home; and
2. Received at least one direct service or support other than service coordination.

The State Council on Developmental Disabilities (SCDD) mailed out the paper survey to all families selected in the statewide sample. A final sample size of 7,000 would guarantee a +/- 5% margin of error (p<.05 level[1]) and a 95% confidence level when interpreting the results.

Response Rates

Actual response rates fell short of expectation and additional surveys were sent to increase the number of usable surveys received. Table II-1 shows the total child population, surveys mailed out by SCDD, usable surveys received, response rates, and each RCs margin of error. Please note that the numbers in the table do not reflect surveys that were excluded during the analyses. Reasons for these exclusions are provided later in this report.

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[1] P<.05 refers to the how likely a finding in the data is due to chance and when p<.05 we have confidence that the finding is not due to chance. This finding of statistical significance does not necessarily mean that the finding is an important finding.

Table II-1: Child Family Survey–Response Rates by Regional Center

RC	Total Child Population	Surveys Mailed	Usable Surveys Returned[1]	Response Rate	Margin of Error
ACRC	6,472	2265	420	19%	4.62%
CVRC	5,208	2481	437	18%	4.49%
ELARC	3,973	2196	407	19%	4.60%
FDLRC	3,523	2240	401	18%	4.61%
FNRC	1,901	1331	280	21%	5.41%
GGRC	2,277	1796	392	22%	4.50%
HRC	4,165	2422	409	17%	4.60%
IRC	9,142	2249	412	18%	4.72%
KRC	2,490	1877	340	18%	4.94%
NBRC	2,403	1870	366	20%	4.72%
NLARC	7,844	2234	406	18%	4.74%
RCEB	5,615	2367	401	17%	4.72%
RCOC	6,069	2273	407	18%	4.69%
RCRC	861	728	145	20%	7.43%
SARC	5,168	2178	396	18%	4.73%
SDRC	4,342	2250	451	20%	4.37%
SG/PRC	7,349	2244	394	18%	4.80%
SCLARC	3,623	2390	410	17%	4.56%
TCRC	3,910	2224	400	18%	4.64%
VMRC	3,889	2302	402	17%	4.63%
WRC	2,952	2169	403	19%	4.54%

Data Entry and Preparation

The SCDD entered the surveys received into the California Online Data Entry Survey Application (CA-ODESA). HSRI extracted the data files for cleaning. All raw data files were reviewed for completeness, invalid responses were eliminated, and quality checks were performed. The data files were then cleaned and merged to create the statewide dataset.

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[1] An additional 30 usable surveys were received in which the RC could not be determined.

Data were considered invalid, and therefore excluded, based on the following three criteria:

1. The family/survey respondent indicated that the child lived outside the family home.
2. Demographic information was entered into the file, but no survey questions were answered.
3. Information on child's developmental disability (or disabilities) was missing.

Data Analysis by Subgroups

Results of individual outcomes are presented in chapters 3 through 6 of this report summarizing results by subgroup, defined by the four qualifying conditions for service eligibility within California: intellectual disability (ID), autism spectrum disorder (ASD), cerebral palsy (CP), and epilepsy. Each analysis used the overall State sample, split into subgroups of children with and without each particular qualifying condition. The total sample is reflected in the introduction to each subgroup chapter. It should be noted these analyses might overlap, as children may have more than one qualifying condition.

Each chapter is organized into sections that follow the question groupings of the Child Family Survey (CFS1). Responses from several of the questions in the CFS1 were recoded to represent the National Core Indicators. See Appendix A for specific rules used to recode and collapse response codes for each outcome variable. All of the “Don’t Know” responses were treated as missing responses except for three questions: 1. *Do you know how much money is spent by the regional center on behalf of your child?* 2. *Do you know the process for filing a complaint or grievance against provider agencies or staff?* 3. *Do you know how to report abuse or neglect?* For these three questions, “Don’t Know” responses were recoded as a “No Response.”

Statistical Methods

Comparisons by subgroups were conducted using statistical tests (e.g., independent sample t-tests, chi-square tests, Mann-Whitney U-tests) to determine whether observed differences were due to chance. Differences that were statistically significant at the $p<.05$ level are noted in the text. Statistical significance does not necessarily imply meaningful differences; but, because the testing suggests that the difference between subgroups is not random, it can be used to point out areas that may be worth further examination.

The specific test used to determine significant subgroup differences depended on the type of survey question (e.g., dichotomous, categorical, ordinal, continuous). For survey questions with dichotomous or categorical response options, a chi-square test was conducted to determine whether there were subgroup differences in the way families answered the question. To further understand the source of the subgroup differences, we examined the specific levels of the response options (e.g., “Yes” vs. “No,” language types) to see where one subgroup’s responses were different from the other subgroup’s responses. For survey questions with ordinal responses options, a Mann-Whitney U-test was conducted to determine whether there were subgroup differences in the overall pattern of responses given by the families. Mann-Whitney U test is a test for assessing group differences in ordinal data (e.g., in which normality assumptions are questionable). To further understand the source of the subgroup differences, we examined the overall pattern of response options (e.g., “Always,” “Usually,” “Sometimes,” “Never”) to see where one subgroup’s pattern of responses might be different from the other subgroup. For survey questions with continuous responses options, an independent samples t-test (e.g., t-test of independent means) was conducted to determine whether there were mean subgroup differences in the way families answered the question. We examined whether there were subgroup differences such that one subgroup’s mean responses (e.g., average age) were different from the other subgroup’s mean responses. For information on the specific test of significant subgroup differences that was conducted for each survey question, refer to Appendix B.

Final Sample Size of Subgroups

Out of the 8,109 surveys collected in the CFS1 114 surveys were excluded from the analysis because the child’s age was greater than 18 years old. Another 287 surveys were excluded from analysis because there was no information about presence or absence of ID, ASD, CP, or epilepsy. Thus, 7,708 people who provided information about children with ID, ASD, CP or epilepsy and who were age-eligible (i.e., age 18 or under, age unknown) were included in the four comparisons. It should be noted that the total sample varies in each comparison analysis.

Children with ID Compared to Children without ID

Of the 7,668 surveys included in this comparison, 2,733 children had an ID diagnosis and 4,935 children did not have an ID diagnosis.

Children with ASD Compared to Children without ASD

Of the 7,648 surveys included in this comparison, 4,665 children had an ASD diagnosis and 2,983 children did not have an ASD diagnosis.

Children with CP Compared to Children without CP

Of the 7,622 surveys included in this comparison, 887 children had a CP diagnosis and 6,735 children did not have a CP diagnosis.

Children with Epilepsy Compared to Children without Epilepsy

Of the 7,630 surveys included in this comparison, 1,101 children had an epilepsy diagnosis and 6,529 children did not have an epilepsy diagnosis.

Analysis by Qualifying Condition

The following chapters summarize demographic information and statistically significant findings by subgroup, defined by the four qualifying conditions for service eligibility within California: intellectual disability (ID), autism spectrum disorder (ASD), cerebral palsy (CP), and epilepsy.

III. Intellectual Disability

This chapter summarizes demographics and statistically significant outcomes for children with a diagnosis of intellectual disability (ID) compared to children without a diagnosis of ID. Results reflect responses from 2,733 families of children with ID and 4,935 families of children without ID.

Summary of Observations by ID

Results for demographics and statistically significant outcome measures comparing children with ID and children without ID are summarized below. Where noted, differences between the two subgroups were statistically significant at $p<.05$[1]. The statistical tests used to determine significant subgroup differences for each survey question are found in Appendix B. Complete tables describing all outcomes with respective sample sizes are found in Appendix C.

Selected Key Findings

In the Child's Demographic Information section, children with ID compared to children without ID were older, less likely to be male, more likely to be female, and more likely to have additional qualifying conditions and disability diagnoses. Children with ID were less likely to use spoken language as their primary means of expression compared to children without ID. There were also fewer children with ID who spoke English as their preferred language compared to children without ID. Families of children with ID have a significant difference in the amount of help needed to care for their child compared to families of children without ID.

In the Family/Survey Respondent's Demographic Information section, families of children with ID were less likely to have parents complete the CFS1 survey compared to families of children without ID. Families of children with ID were less likely to have a college degree compared to families of children without ID. Families of children with ID have significant differences in quality of health, total household income, and out-of-pocket expenses compared to families of children without ID.

In the Services and Supports Received section, families of children with ID were more likely to receive financial support, in-home support, out-of-home respite care, transportation assistance, and Social Security benefits compared to families of children

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[1] P<.05 refers to the how likely a finding in the data is due to chance and when p<.05 we have confidence that the finding is not due to chance. This finding of statistical significance does not necessarily mean that the finding is a really important finding.

without ID. Children with ID were less likely to receive early intervention and other services and supports compared to children without ID.

In the Information and Planning section, there was no significant difference in receiving information about available services and supports between families of children with ID and families of children without ID. There were no significant differences between children with ID and children without ID in having an individual program plan (IPP) and families helping develop the IPP. There was no significant difference between families of children with ID and families of children without ID in receiving information about their rights.

In the Access and Delivery section, there was no significant difference in ability to contact support workers and service coordinators when needed between families of children with ID and families of children without ID. There was no significant difference between families of children with ID and families of children without ID in support workers having the right training to meet their child’s needs.

In the Choice and Control section, there was no significant difference in choosing provider agencies between families of children with ID and families of children without ID. There was a significant difference in choosing individual support workers between families of children with ID and families of children without ID. Families of children with ID were less likely to know how much money was spent by the regional center on behalf of their child compared to families of children without ID. Families of children with ID were more likely to have a say in how regional center money was spent on behalf of their child compared to families of children without ID.

In the Community Connections section, children with ID compared to children without ID were less likely to participate in community activities and less likely to spend time with children without a developmental disability.

In the Satisfaction with Services and Supports section, there was no significant difference in satisfaction with services and supports received by families of children with ID and families of children without ID. Families of children with ID were more likely to be satisfied with how complaints were handled by provider agencies and more likely to know how to report abuse or neglect compared to families of children without ID.

In the Family Outcomes section, there was no significant difference between families of children with ID and families of children without ID in services and supports making a positive impact in their family’s life. Families of children with ID were less likely to report that family supports improved their ability to care for their child compared to families of children without ID. There was no significant difference in services and supports being reduced or terminated in the past year between families of children with ID and families of children without ID.

Demographics by ID

Child's Demographic Information

The section on Child's Demographic Information in the Child Family Survey includes indicators about: *Basic Information, Primary Expression and Language,* and *Amount of Help Needed for Child.* All results are presented here.

Selected Findings on Child's Demographic Information

Families of children with ID were more likely to have more than one child with disability living in the household compared to families of children without ID (ID: 19%, No ID: 17%). Children with ID on average were older than children without ID (ID: 11.66 years old, No ID: 9.52 years old). Children with ID were less likely to be male compared to children without ID (ID: 59%, No ID: 75%). Children with ID were more likely to be female compared to children without ID (ID: 39%, No ID: 22%). Children with ID were more likely to be Hispanic/Latino compared to children without ID (ID: 45%, No ID: 40%). Children with ID were more likely to be Black/African American compared to children without ID (ID: 8%, No ID: 6%). Children with ID were less likely to be Asian compared to children without ID (ID: 9%, No ID: 15%). Children with ID were more likely to have a Mixed racial background (two or more races) compared to children without ID (ID: 13%, No ID: 11%). Children with ID were less likely to have an autism spectrum disorder as an additional qualifying condition compared to children without ID (ID: 34%, No ID: 75%). Children with ID were more likely to have cerebral palsy as an additional qualifying condition compared to children without ID (ID: 18%, No ID: 8%). Children with ID were more likely to have epilepsy as an additional qualifying condition compared to children without ID (ID: 26%, No ID: 8%). Children with ID were more likely to have a mental illness/psychiatric diagnosis/behavioral disorder compared to children without ID (ID: 19%, No ID: 9%). Children with ID were more likely to have a brain injury compared to children without ID (ID: 8%, No ID: 3%). Children with ID were more likely to have a chemical dependency compared to children without ID (ID: 1%, No ID: 0%). Children with ID were more likely to have limited/no vision or be legally blind compared to children without ID (ID: 12%, No ID: 3%). Children with ID were more likely to have hearing loss compared to children without ID (ID: 5%, No ID: 2%). Children with ID were more likely to have Down syndrome compared to children without ID (ID: 10%, No ID: 9%). Children with ID were more likely to have another unlisted disability compared to children without ID (ID: 25%, No ID: 11%). Children with ID compared to children without ID were more likely to have no other disabilities (ID: 3%, No ID: 2%) and have families who did not know (ID: 2%, No ID: 0%) if their child had any other disabilities.

Children with ID were less likely to use spoken language as their primary means of expression compared to children without ID (ID: 54%, No ID: 69%). Children with ID were more likely to use gestures/body language as their primary means of expression compared to children without ID (ID: 30%, No ID: 19%). Children with ID were more likely to use other methods as their primary means of expression compared to children without ID (ID: 7%, No ID: 4%). Children with ID were less likely to speak English as their preferred language compared to children without ID (ID: 68%, No ID: 75%). Children with ID were more likely speak Spanish as their preferred language compared to children without ID (ID: 26%, No ID: 20%).

Children with ID had significant differences in the frequency of medical care needed compared to children without ID[1] (e.g., medical care needed at least once per week; ID: 11%, No ID: 7%). Children with ID had significant differences in the amount of behavioral support needed compared to children without ID[1] (e.g., extensive behavioral support needed; ID: 20%, No ID: 14%). Children with ID had significant differences in the amount of help needed for daily activities compared to children without ID[1] (e.g., complete help needed; ID: 44%, No ID: 27%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with ID compared to Family/Survey Respondents of children without ID.

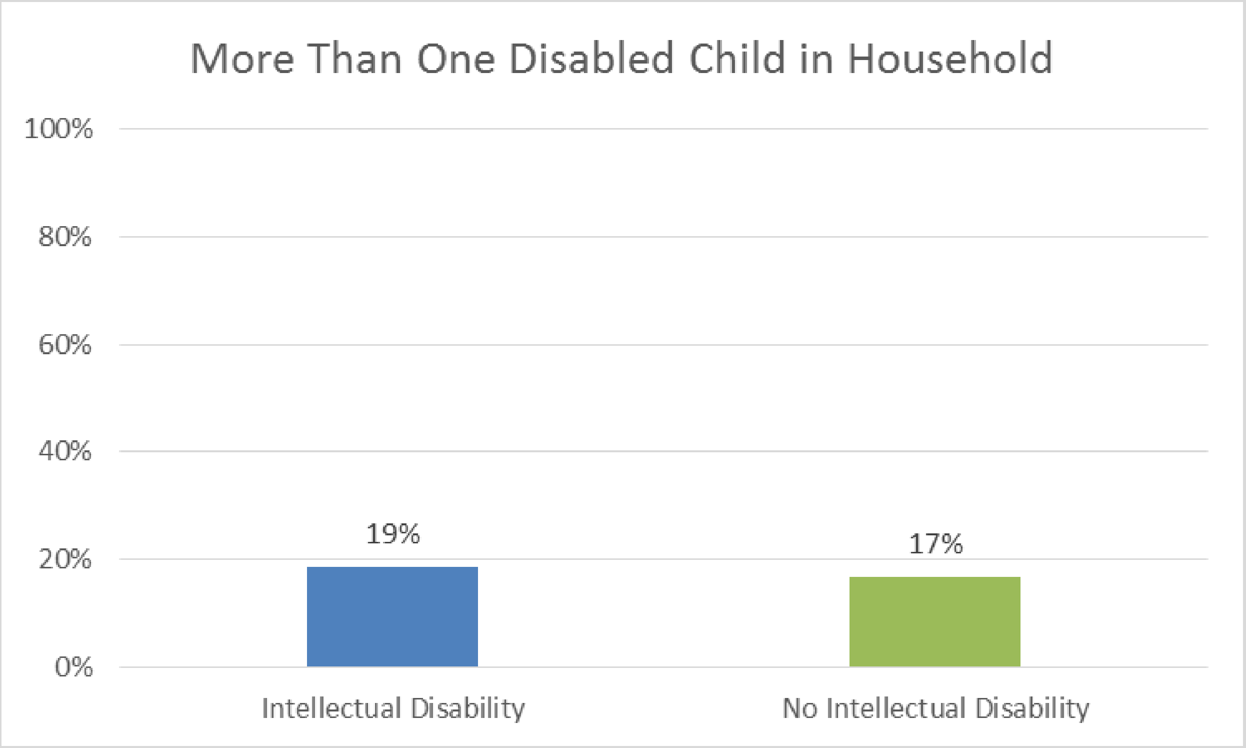

Table III-1: More Than One Disabled Child in Household by ID

	Yes	N
ID	19%	2420
No ID	17%	4394

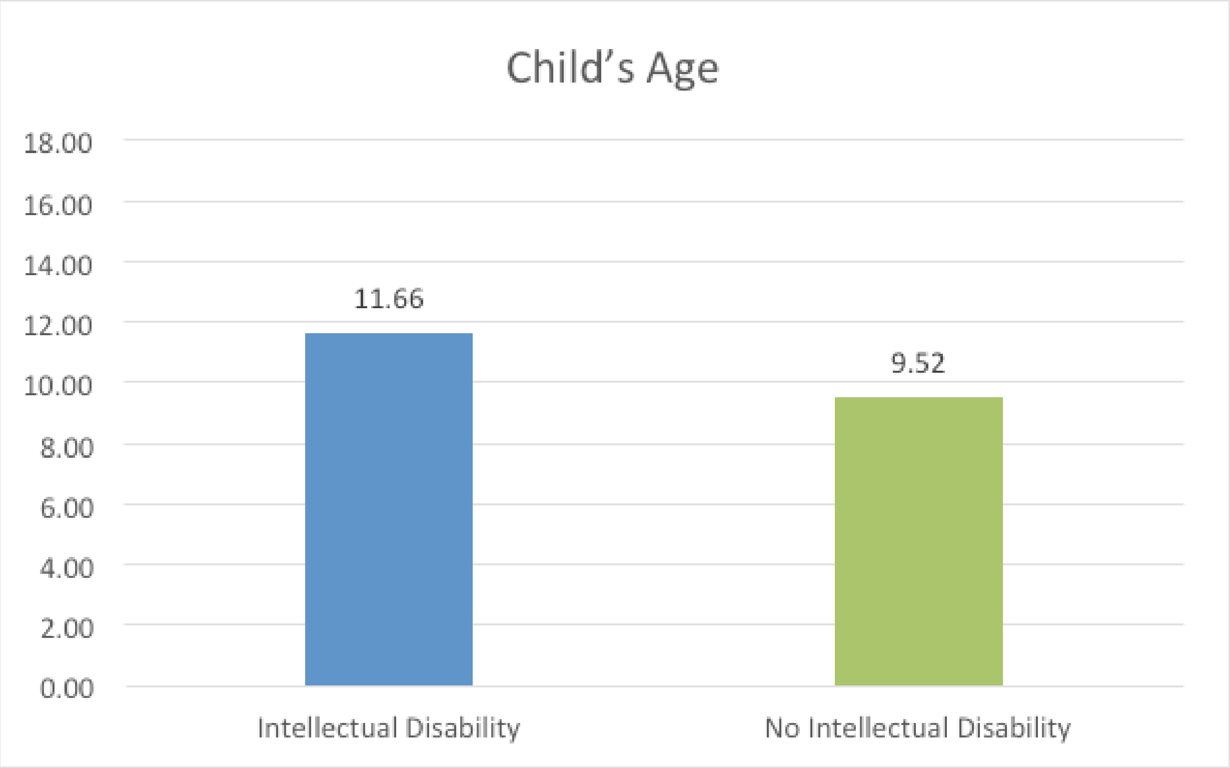

Table III-2: Child’s Age by ID

	Average Age	N
ID	11.66	2668
No ID	9.52	4795

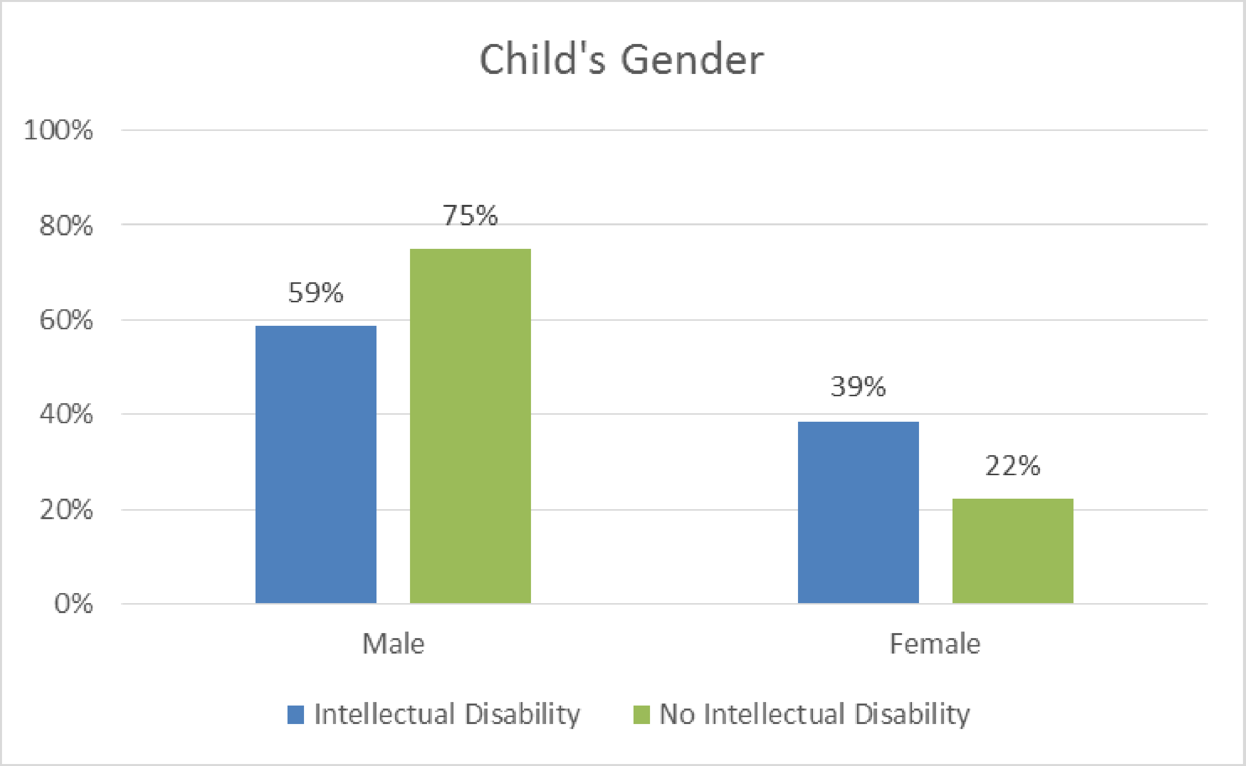

Table III-3: Child's Gender by ID

	Male	Female	N
ID	59%	39%	2660
No ID	75%	22%	4786

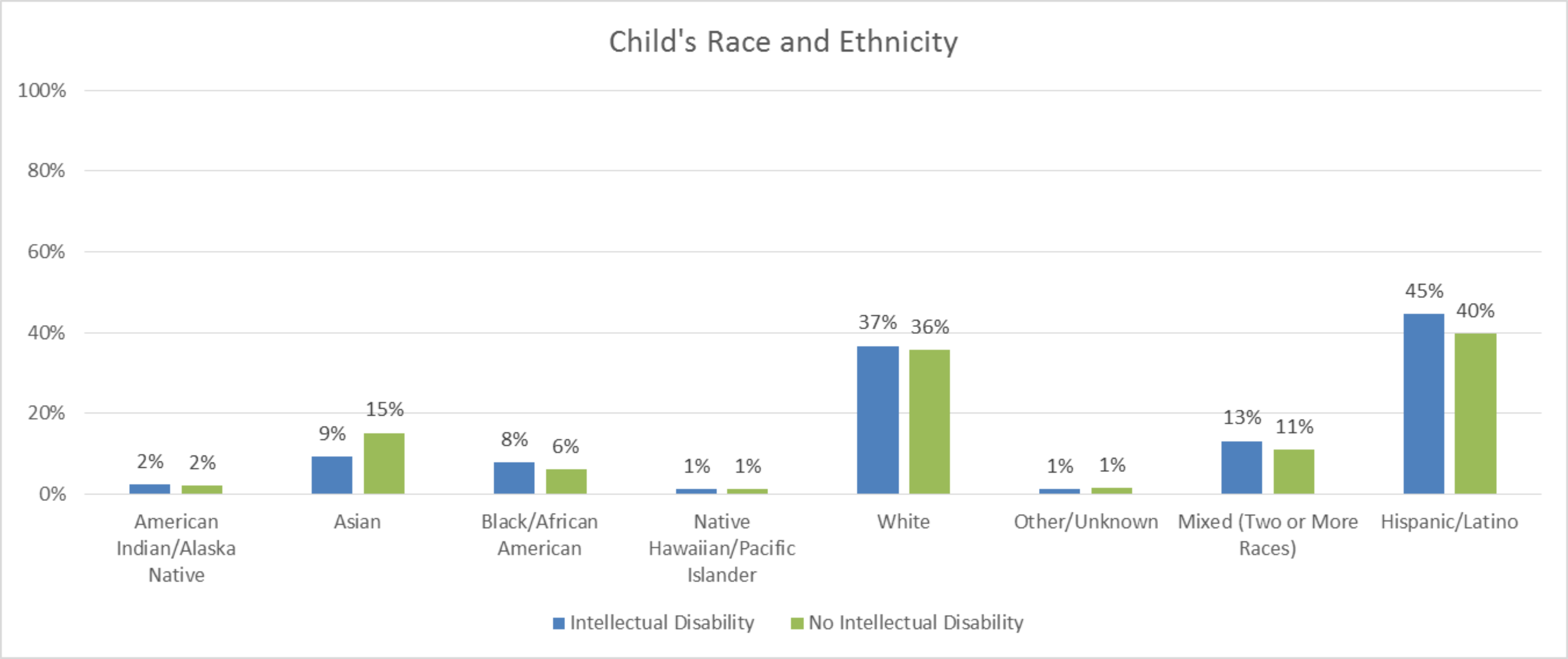

Table III-4: Child's Race and Ethnicity by ID[1],[2]

	American Indian/ Alaska Native	Asian	Black/ African American	Native Hawaiian/ Pacific Islander	White	Other/ Unknown	Mixed (Two or More Races)	Hispanic/ Latino
ID	2%	9%	8%	1%	37%	1%	13%	45%
No ID	2%	15%	6%	1%	36%	1%	11%	40%

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[1] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

[2] Results for “American Indian/Alaska Native,” “Native Hawaiian/Pacific Islander,” “White,” and “Other/Unknown” were not statistically significant.

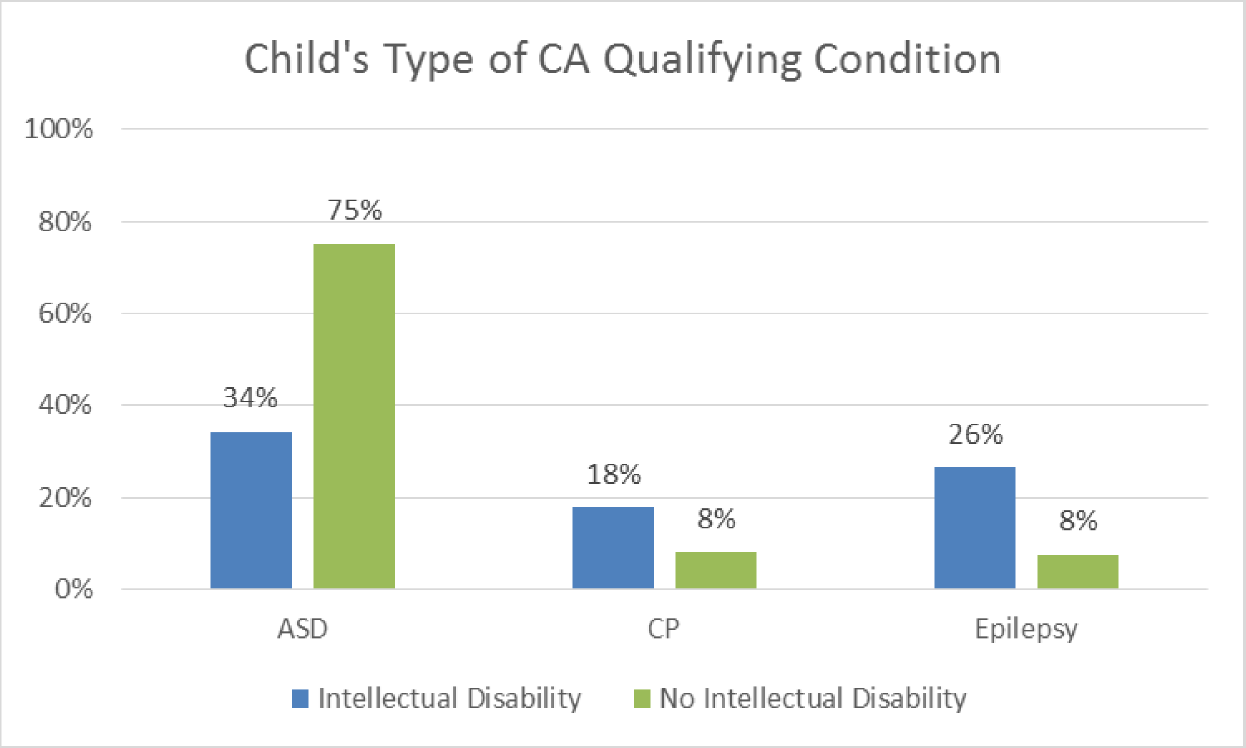

Table III-5: Child's Type of CA Qualifying Condition by ID[1]

	ASD	CP	Epilepsy
ID	34%	18%	26%
No ID	75%	8%	8%

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[1] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

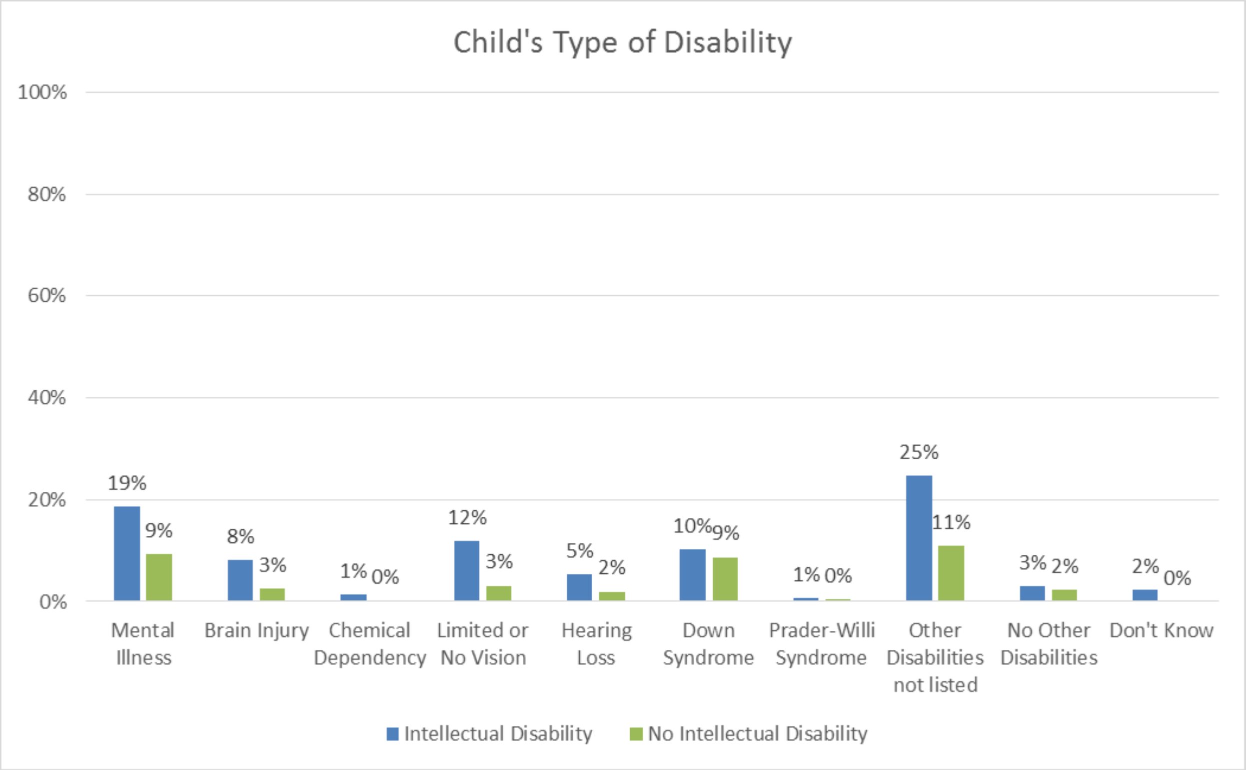

Table III-6: Child's Type of Disability by ID[1],[2]

	Mental Illness/ Psychiatric Diagnosis/ Behavioral Disorder	Brain Injury	Chemical Dependency	Limited or No Vision/ Legally Blind	Hearing Loss (Severe or Profound)	Down Syndrome	Prader-Willi Syndrome	Other Disabilities not listed	No Other Disabilities	Don't Know
ID	19%	8%	1%	12%	5%	10%	1%	25%	3%	2%
No ID	9%	3%	0%	3%	2%	9%	0%	11%	2%	0%

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[1] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.
[2] Results for “Prader-Willi Syndrome” were not statistically significant.

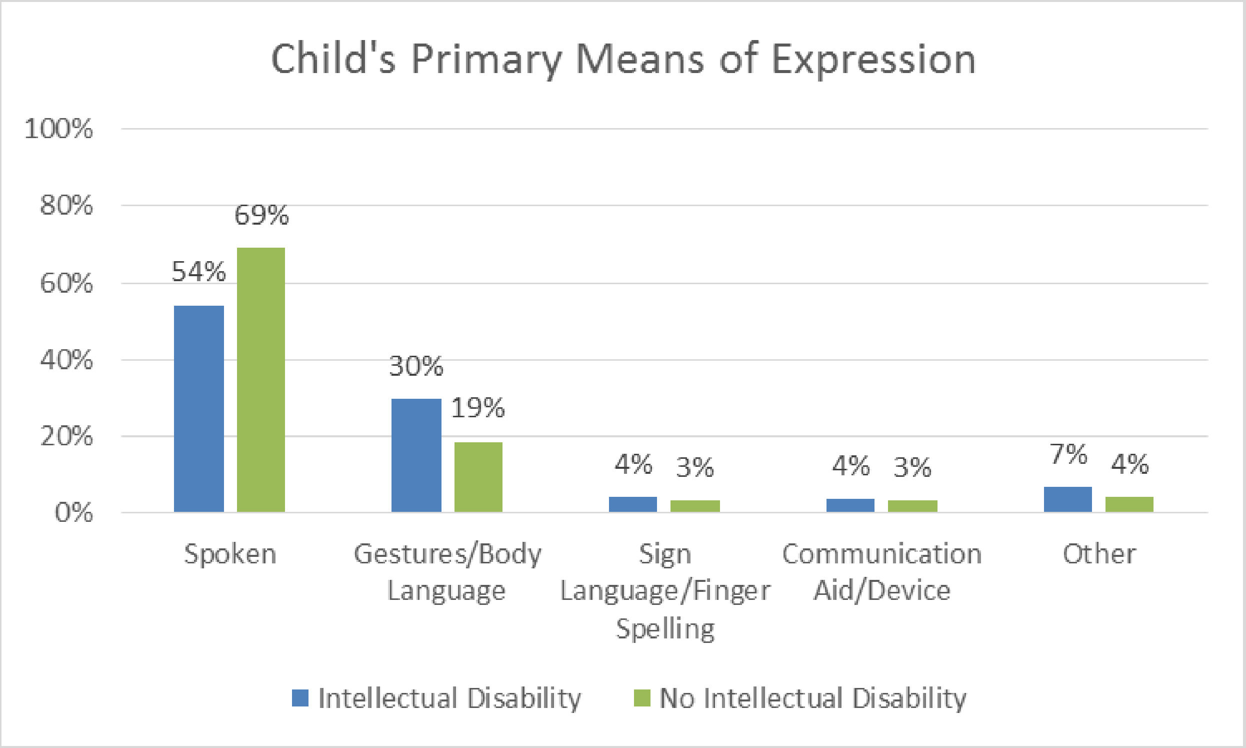

Table III-7: Child's Primary Means of Expression by ID[1], [2]

	Spoken	Gestures/ Body	Sign Language/ Finger Spelling	Communication Aid/ Device	Other	N
ID	54%	30%	4%	4%	7%	2674
No ID	69%	19%	3%	3%	4%	4853

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[1] Results for “Sign Language/Finger Spelling,” and “Communication Aid/Device” were not statistically significant.
[2] Percentages add up to less than 100% due to missing responses.

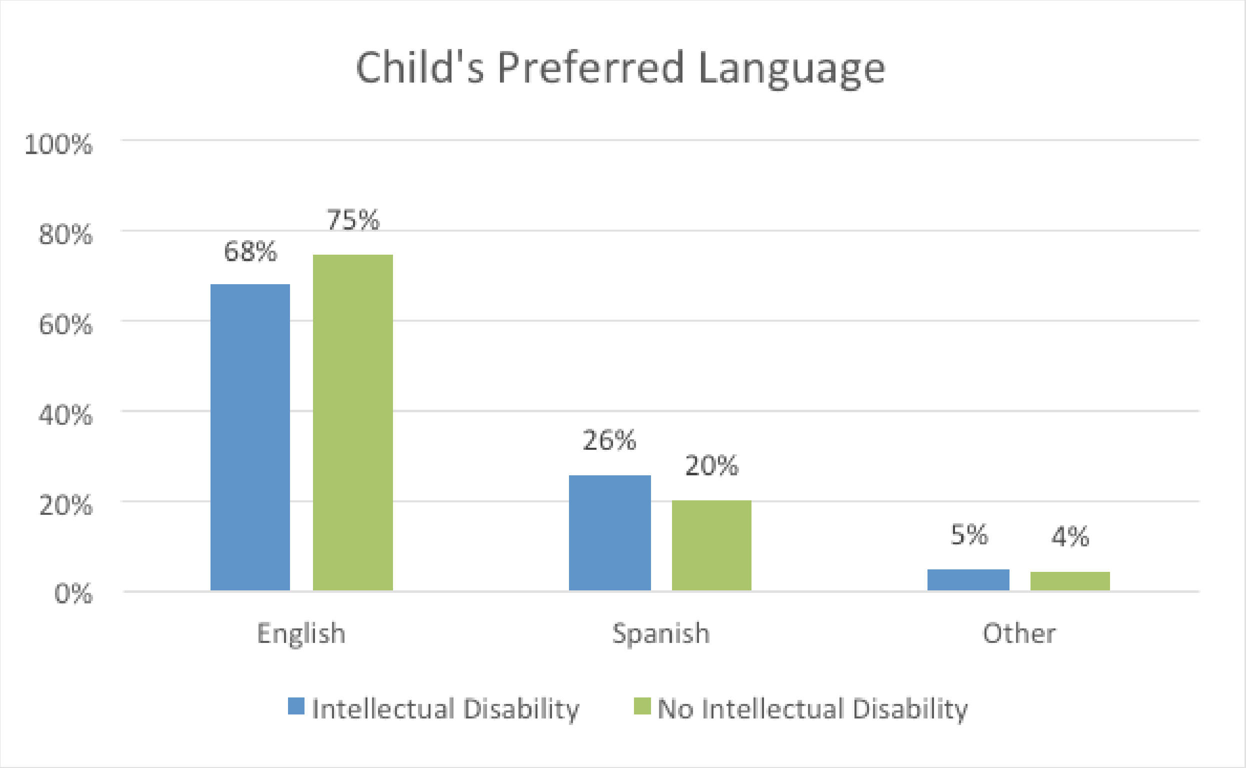

Table III-8: Child's Preferred Language by ID[1],[2]

	English	Spanish	Other	N
ID	68%	26%	5%	2697
No ID	75%	20%	4%	4886

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[1] Results for “Other” were not statistically significant.

[2] Percentages add up to less than 100% due to missing responses.

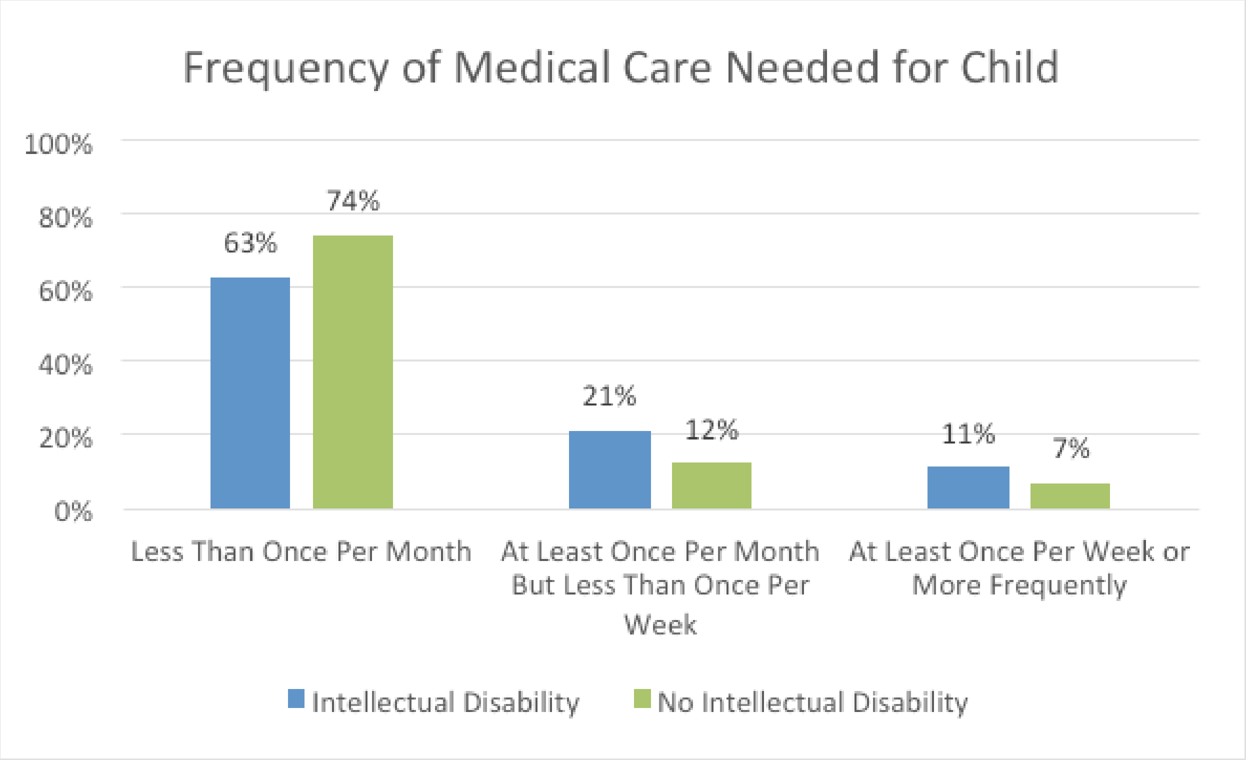

Table III-9: Frequency of Medical Care Needed for Child by ID[1]

	Less Than Once Per Month	At Least Once Per Month But Less Than Once Per Week	At Least Once Per Week or More Frequently	N
ID	63%	21%	11%	2596
No ID	74%	12%	7%	4611

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[1] Percentages add up to less than 100% due to missing responses.

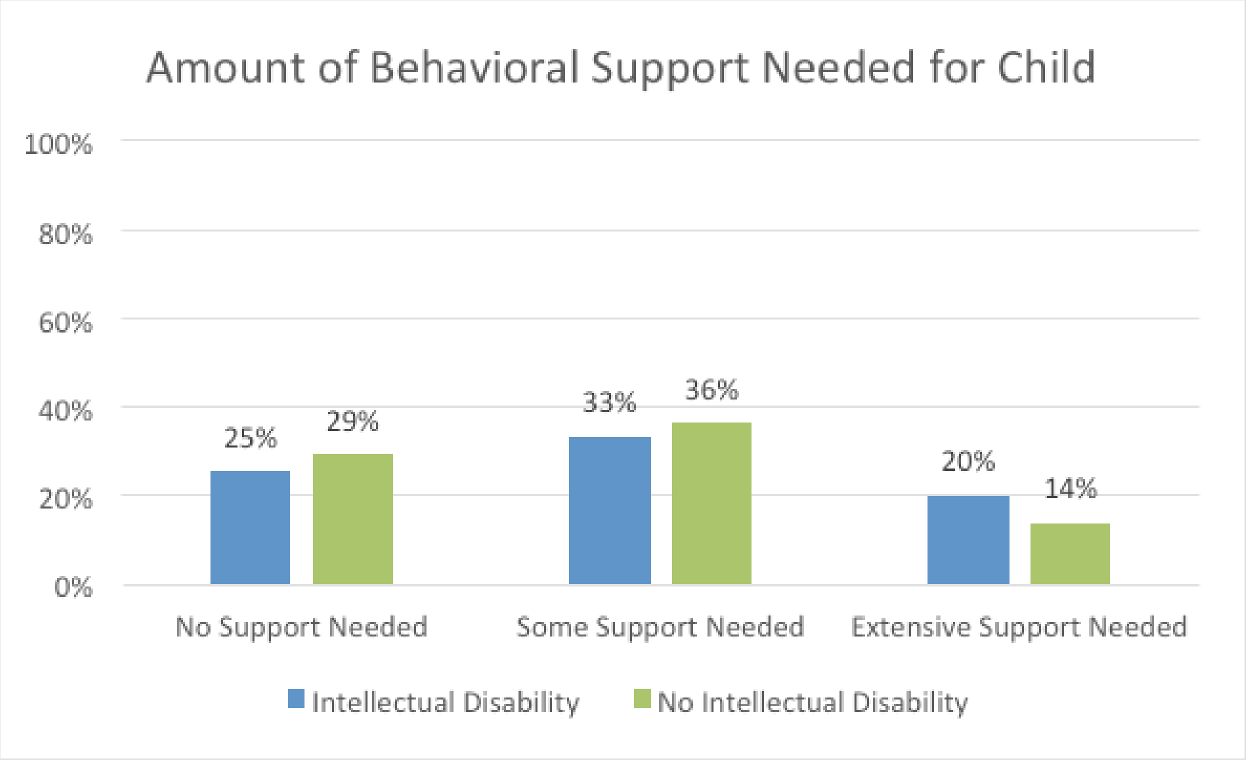

Table III-10: Amount of Behavioral Support Needed for Child by ID[1]

	No Support Needed	Some Support Needed	Extensive Support Needed	N
ID	25%	33%	20%	2138
No ID	29%	36%	14%	3900

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[1] Percentages add up to less than 100% due to missing responses.

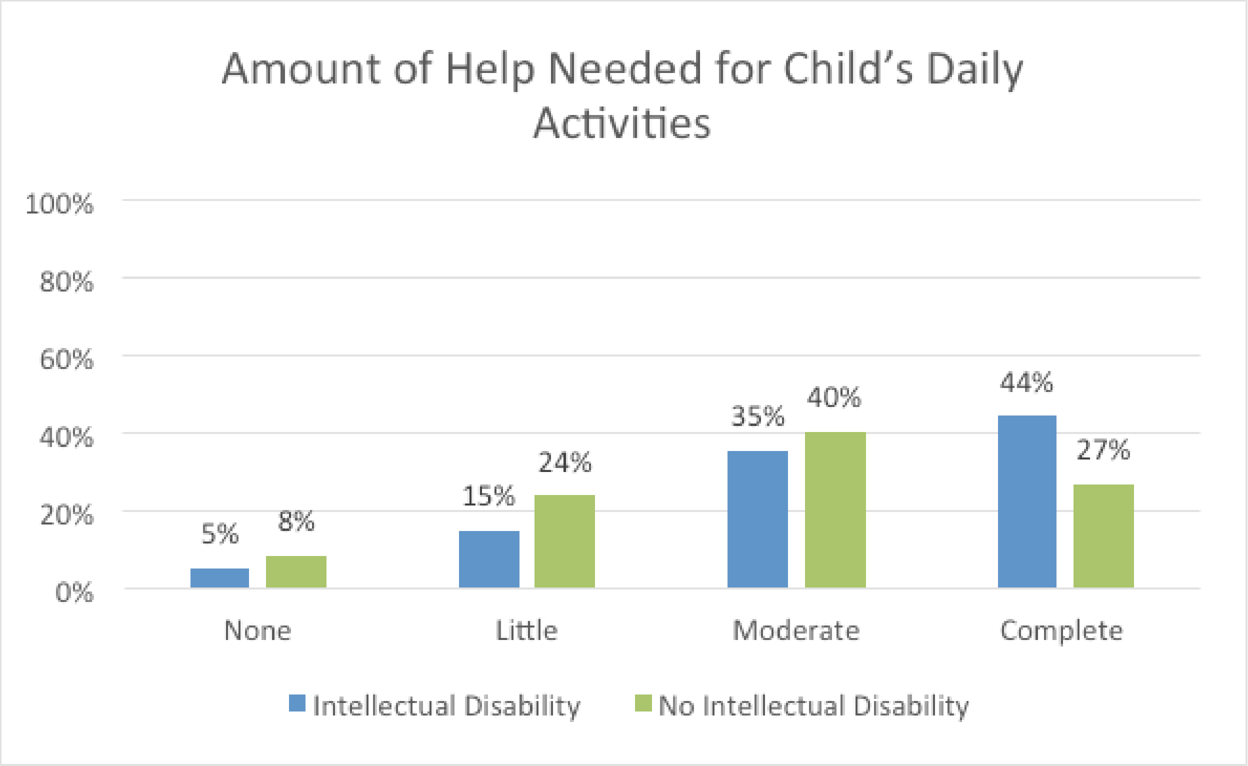

Table III-11: Amount of Help Needed for Child's Daily Activities by ID[1]

	None	Little	Moderate	Complete	N
ID	5%	15%	35%	44%	2724
No ID	8%	24%	40%	27%	4905

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[1] Percentages add up to less than 100% due to missing responses.

Family/Survey Respondent's Demographic Information

The section on Family/Survey Respondent's Demographic Information in the Child Family Survey includes indicators about: *Basic Information about Family/Survey Respondent* and *Household Composition and Income.* All results are presented here.

Selected Findings on Family/Survey Respondent's Demographic Information

Survey respondents of children with ID compared to respondents of children without ID had significant differences in age[1] (e.g., age of survey respondent between 35-54 years old, ID: 63%, No ID: 68%). Survey respondents of children with ID compared to respondents of children without ID had differences in quality of health[1] (e.g., excellent health, ID: 19%, No ID: 23%). Children with ID were less likely to have parents complete the CFS1 survey compared to children without ID (ID: 94%, No ID: 97%). Children with ID were more likely to have a sibling complete the CFS1 survey compared to children without ID (ID: 1%, No ID: 0%). Children with ID were also more likely to have a grandparent complete the CFS1 survey compared to children without ID (ID: 3%, No ID: 2%). Survey respondents of children with ID compared to survey respondents of children without ID were more likely to have no High School diploma or GED (ID: 21%, No ID: 17%). Survey respondents of children with ID compared to respondents of children without ID were more likely to only have some college education (ID: 21%, No ID: 19%). Survey respondents for families of children with ID compared to survey respondents for families of children without ID were less likely to have a college degree (ID: 33%, No ID: 40%).

Families of children with ID had significant differences in total household income compared to families of children without ID[1] (e.g., income over $75,000, ID: 19%, No ID: 24%). Families of children with ID had significant differences in out-of-pocket expenses for their child in the past year compared to families of children without ID[1] (e.g., expenses over $10,000, ID: 5%, No ID: 7%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with ID compared to Family/Survey Respondents of children without ID.

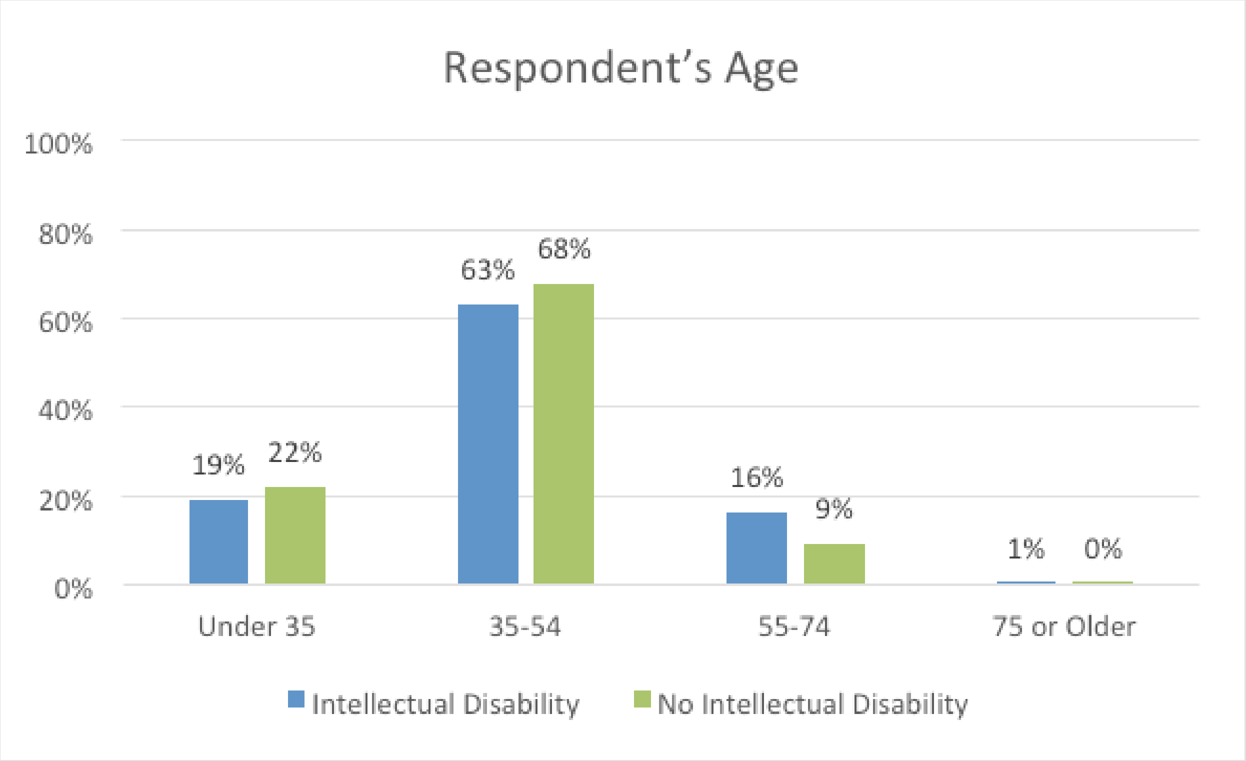

Table III-12: Respondent's Age by ID

	Under 35	35–54	55–74	75 or Older	N
ID	19%	63%	16%	1%	2714
No ID	22%	68%	9%	0%	4908

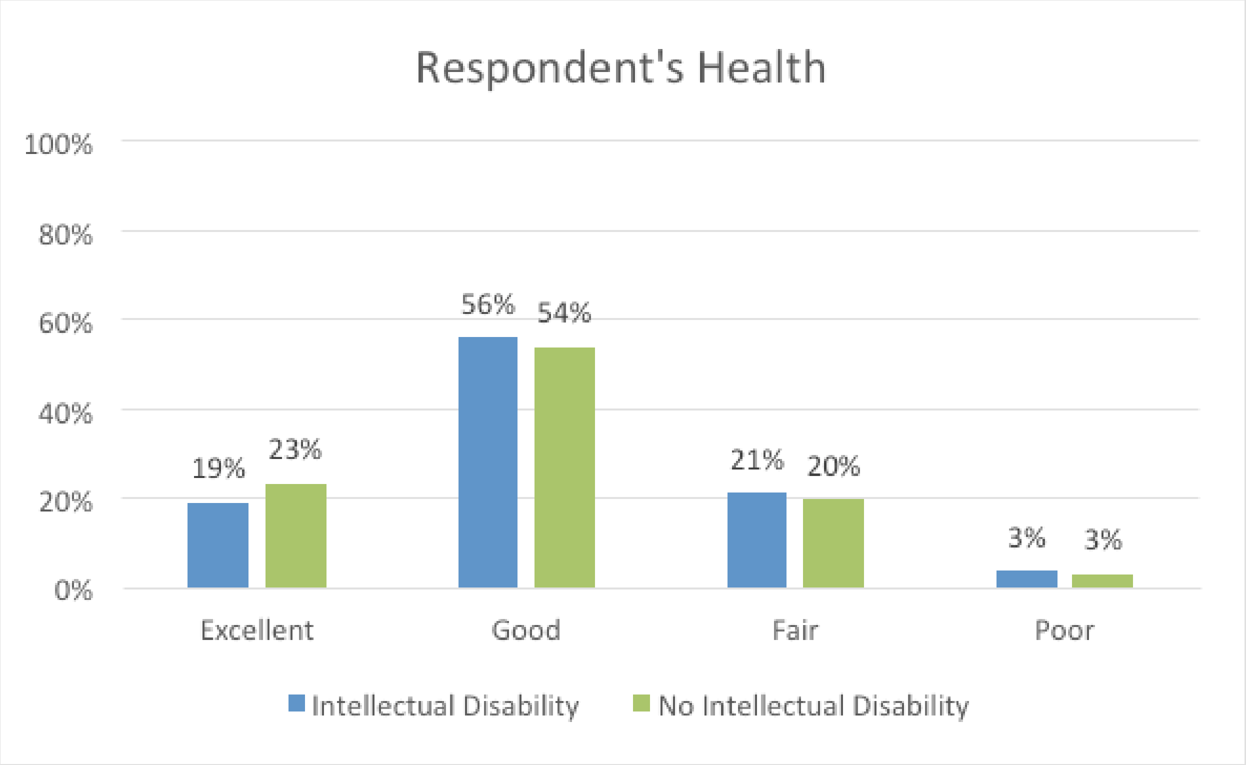

Table III-13: Respondent's Health by ID[1]

	Excellent	Good	Fair	Poor	N
ID	19%	56%	21%	3%	2715
No ID	23%	54%	20%	3%	4900

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[1] Percentages add up to less than 100% due to missing responses.

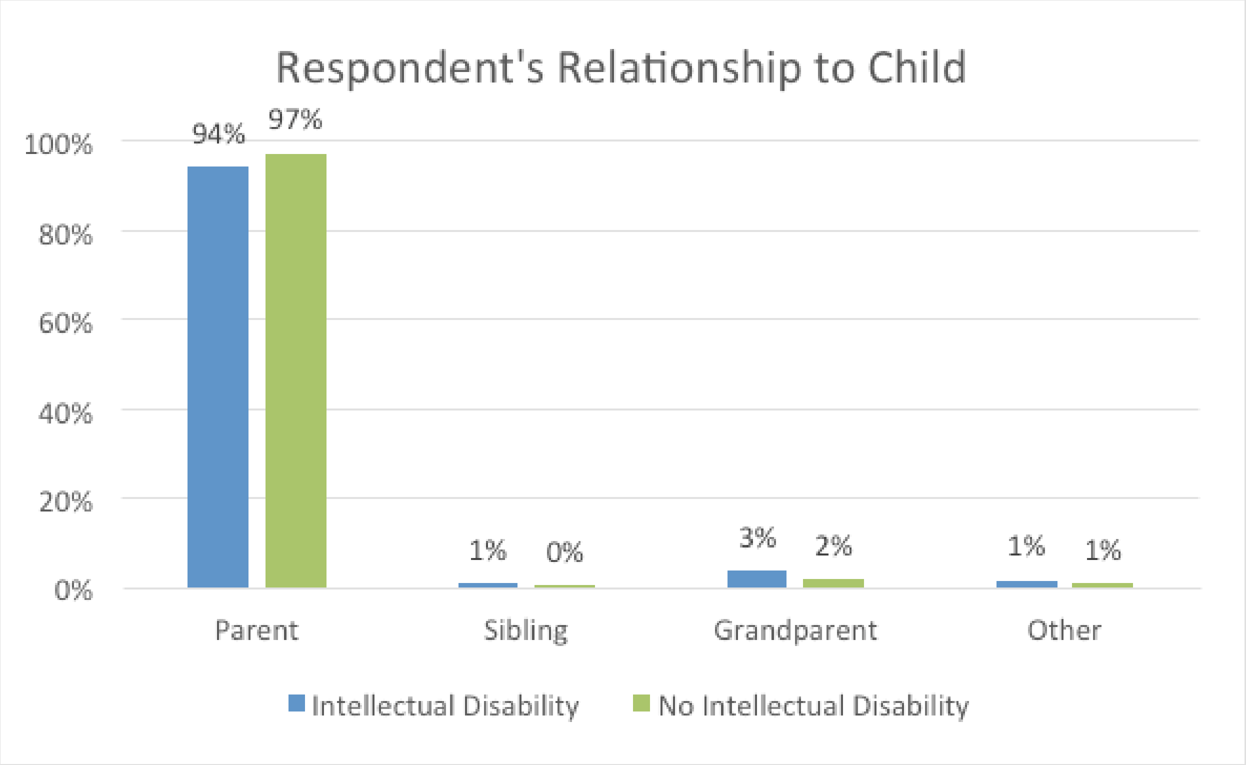

Table III-14: Respondent's Relationship to Child by ID[1]

	Parent	Sibling	Grandparent	Other	N
ID	94%	1%	3%	1%	2725
No ID	97%	0%	2%	1%	4922

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[1] Percentages add up to less than 100% due to missing responses.

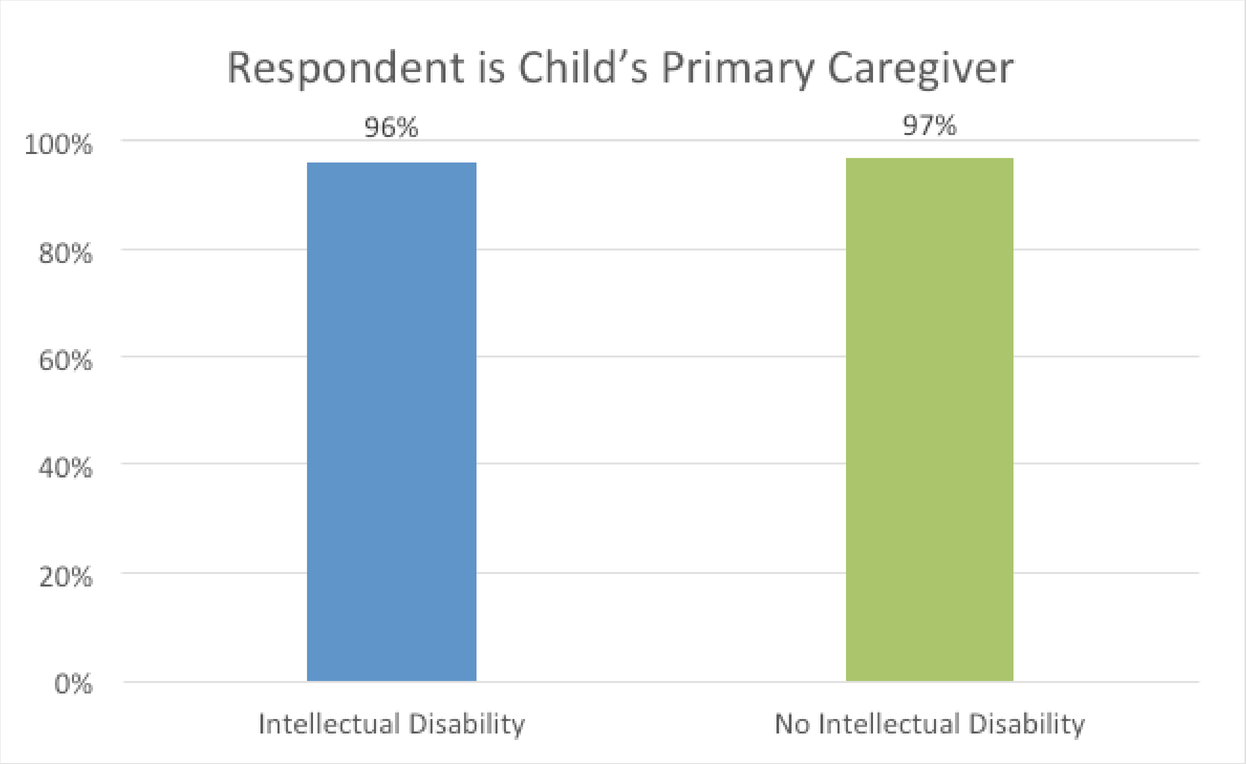

Table III-15: Respondent is Child's Primary Caregiver by ID[1]

	Yes	N
ID	96%	2691
No ID	97%	4878

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[1] Results were not statistically significant.

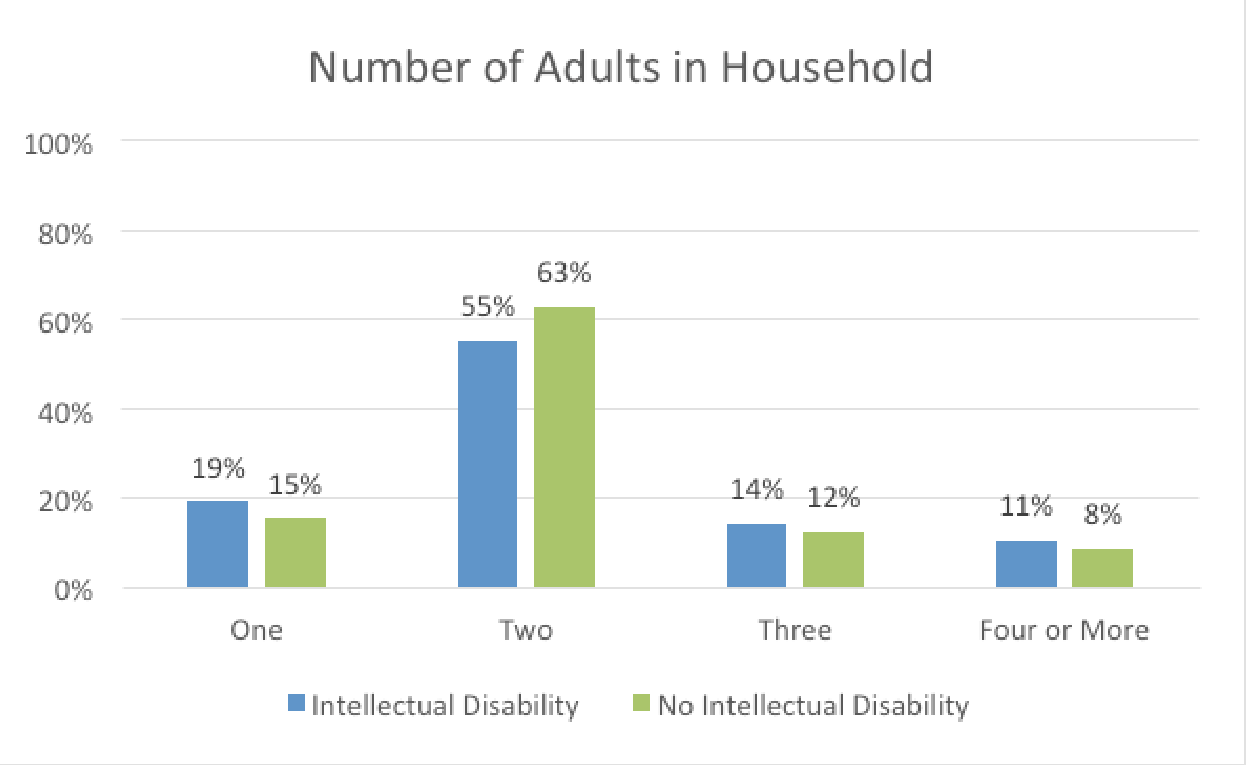

Table III-16: Number of Adults in Household by ID[1], [2]

	One	Two	Three	Four or More	N
ID	19%	55%	14%	11%	2703
No ID	15%	63%	12%	8%	4877

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[1] Results were not statistically significant.

[2] Percentages add up to less than 100% due to missing responses.

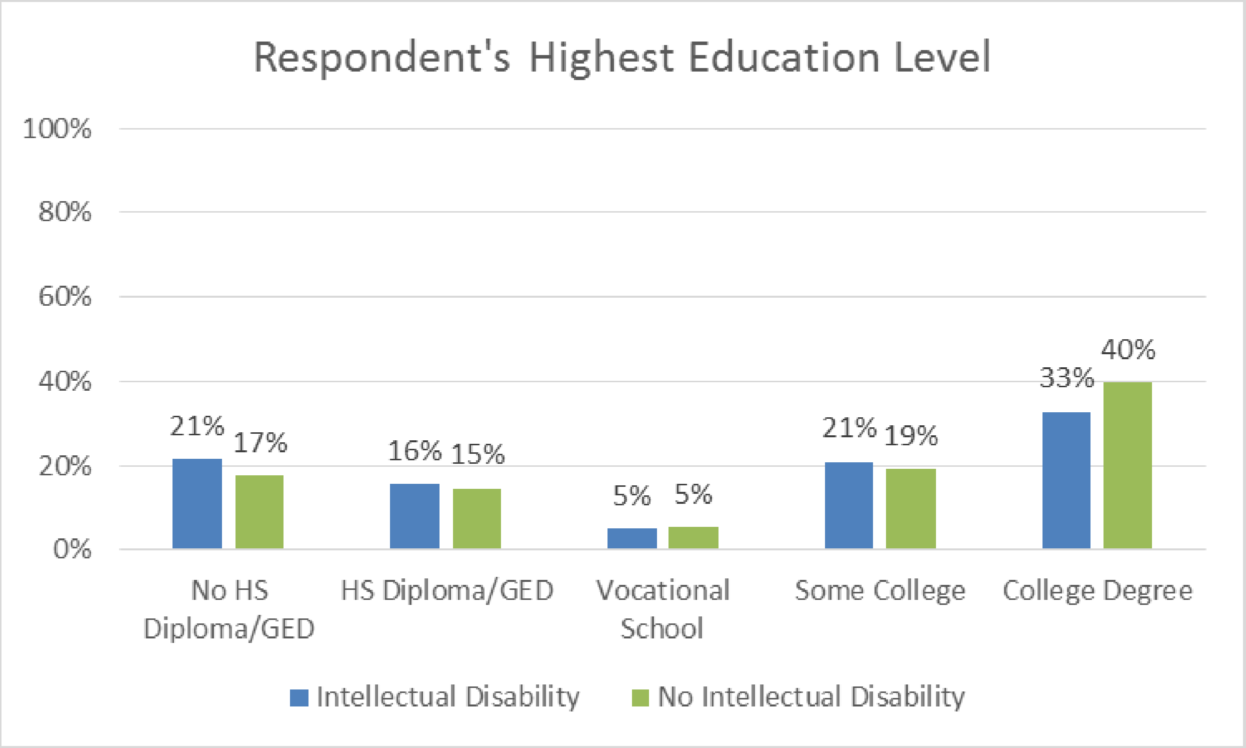

Table III-17: Respondent's Highest Education Level by ID[1], [2]

	No HS Diploma/ GED	HS Diploma/ GED	Vocational School	Some College	College Degree	N
ID	21%	16%	5%	21%	33%	2624
No ID	17%	15%	5%	19%	40%	4751

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[1] Results for “HS Diploma/GED” and “Vocational School” were not statistically significant.

[2] Percentages add up to less than 100% due to missing responses.

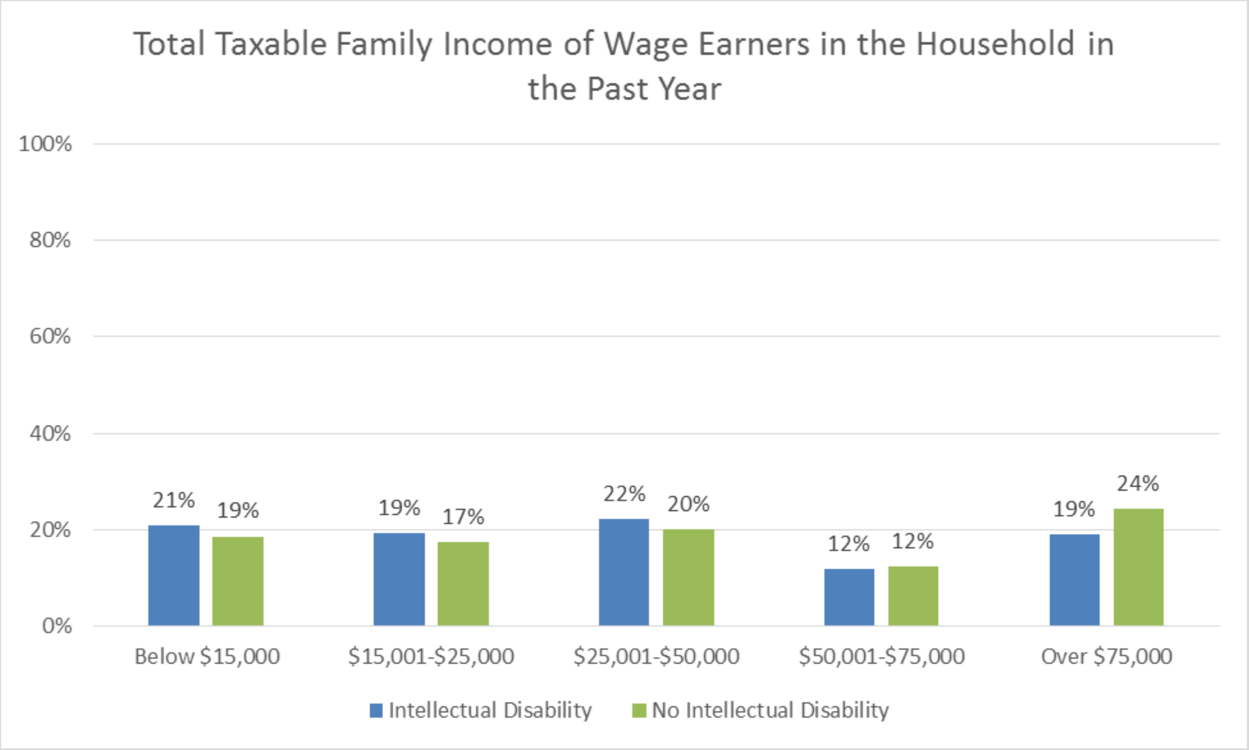

Table III-18: Total Taxable Family Income of Wage Earners in the Household in the Past Year by ID[1]

	Below $15,000	$15,001–$25,000	$25,001–$50,000	$50,001–$75,000	Over $75,000	N
ID	21%	19%	22%	12%	19%	2542
No ID	19%	17%	20%	12%	24%	4576

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[1] Percentages add up to less than 100% due to missing responses.

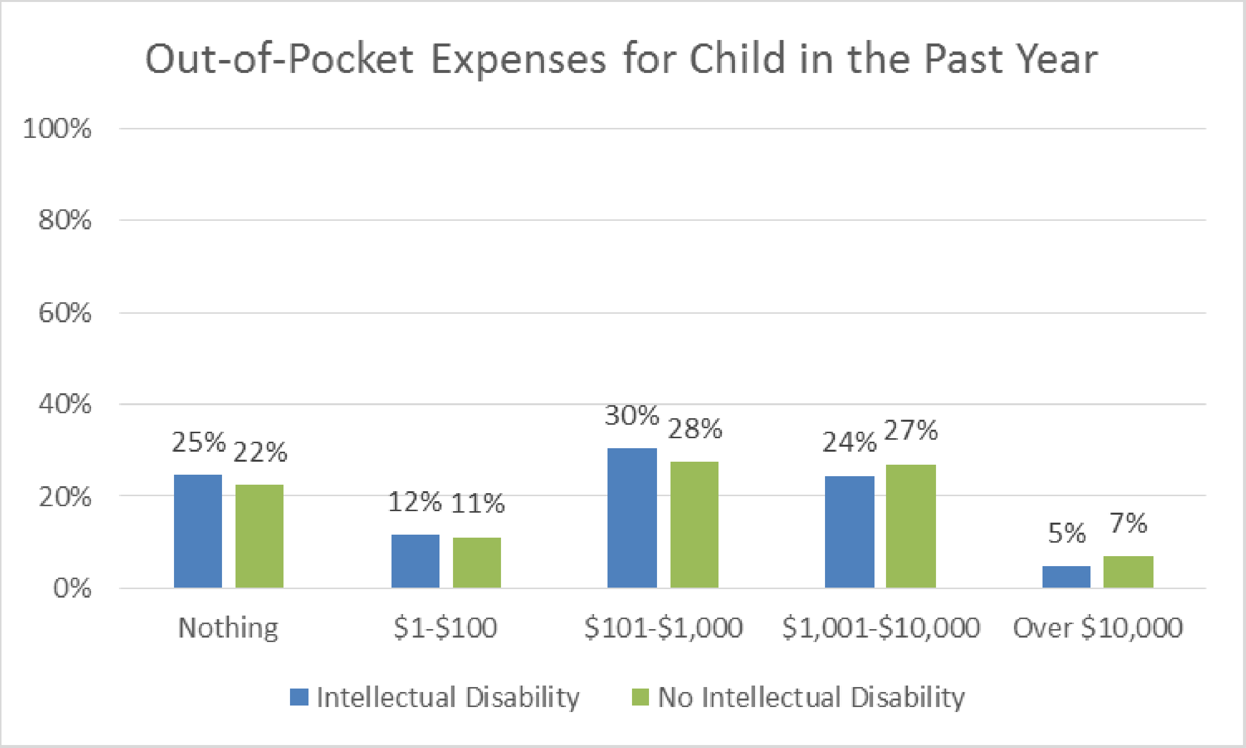

Table III-19: Out-of-Pocket Expenses for Child in the Past Year by ID[1]

	Nothing	$1–$100	$101–$1,000	$1,001–$10,000	Over $10,000	N
ID	25%	12%	30%	24%	5%	2614
No ID	22%	11%	28%	27%	7%	4688

---

[1] Percentages add up to less than 100% due to missing responses.

Services and Supports Received by ID

The section on Services and Supports Received in the Child Family Survey includes one indicator that has seven types of services or supports received. All results are presented here.

Selected Findings on Services and Supports Received

Families of children with ID were more likely to receive financial support compared to families of children without ID (ID: 11%, No ID: 9%). Families of children with ID were more likely to receive in-home support compared to families of children without ID (ID: 53%, No ID: 48%). Families of children with ID were more likely to receive out-of-home respite care compared to families of children without ID (ID: 30%, No ID: 25%). Children with ID were less likely to receive early intervention compared to children without ID (ID: 11%, No ID: 18%). Families of children with ID were more likely to receive transportation assistance compared to families of children without ID (ID: 25%, No ID: 20%). Families of children with ID were less likely to receive other types of services or supports compared to families of children without ID (ID: 44%, No ID: 48%). Families of children with ID were more likely to receive Social Security benefits compared to families of children without ID (ID: 46%, No ID: 38%).

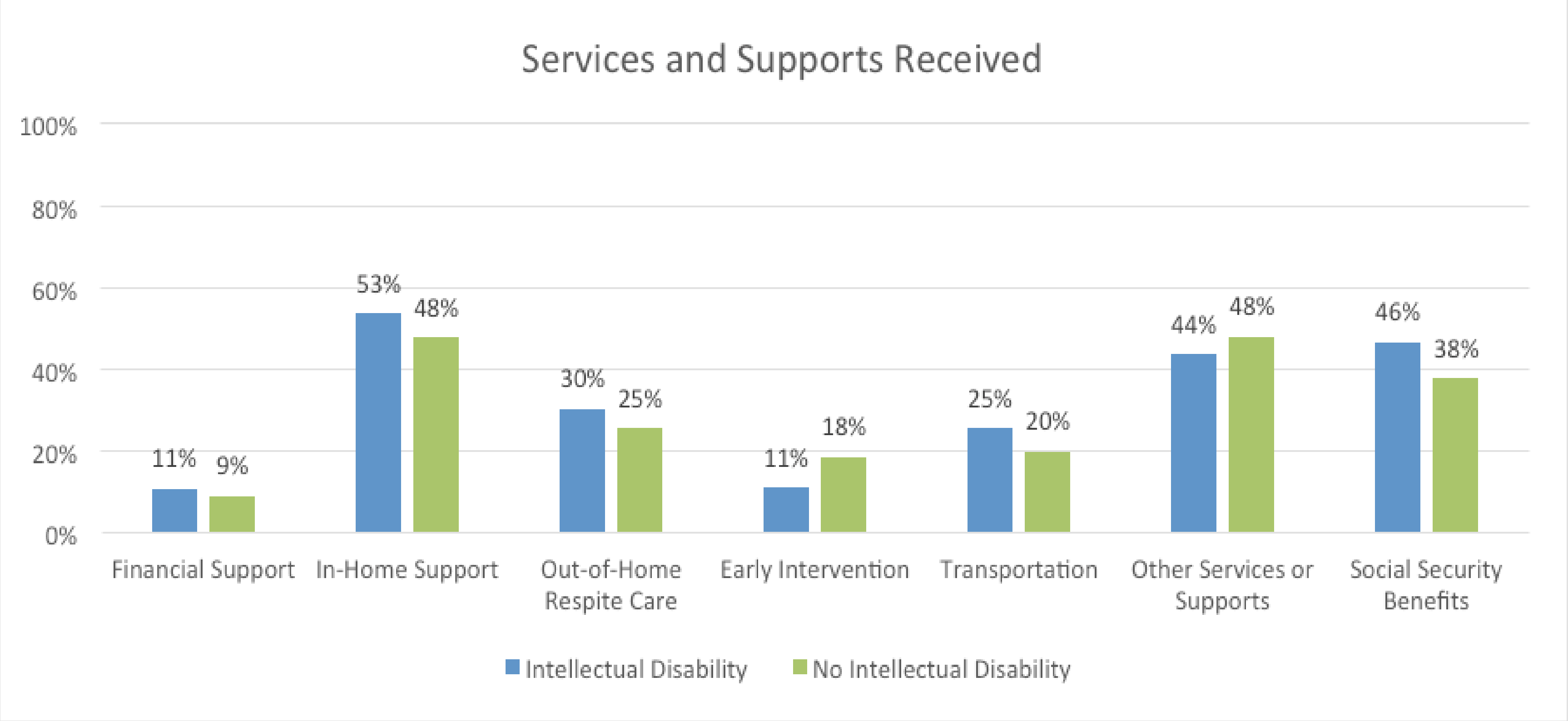

Table III-20: Services and Supports Received by ID[1]

	Financial Support	In-Home Support	Out-of-Home Respite Care	Early Intervention	Transport-ation	Other Services or Supports	Social Security Benefits
ID	11%	53%	30%	11%	25%	44%	46%
No ID	9%	48%	25%	18%	20%	48%	38%

---

[1] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

Information and Planning by ID

The section on Information and Planning in the Child Family Survey includes indicators about: *Available Services and Supports, Planning with Service Coordinator,* and *Child's Individual Program Plan (IPP)*. Results that were statistically significant are presented here. The complete list of results for children with ID is located in Appendix C.

Selected Findings on Information and Planning

Families of children with ID were less likely to have discussed how to handle emergencies related to their child at the last IPP meeting compared to families of children without ID (ID: 36%, No ID: 41%).

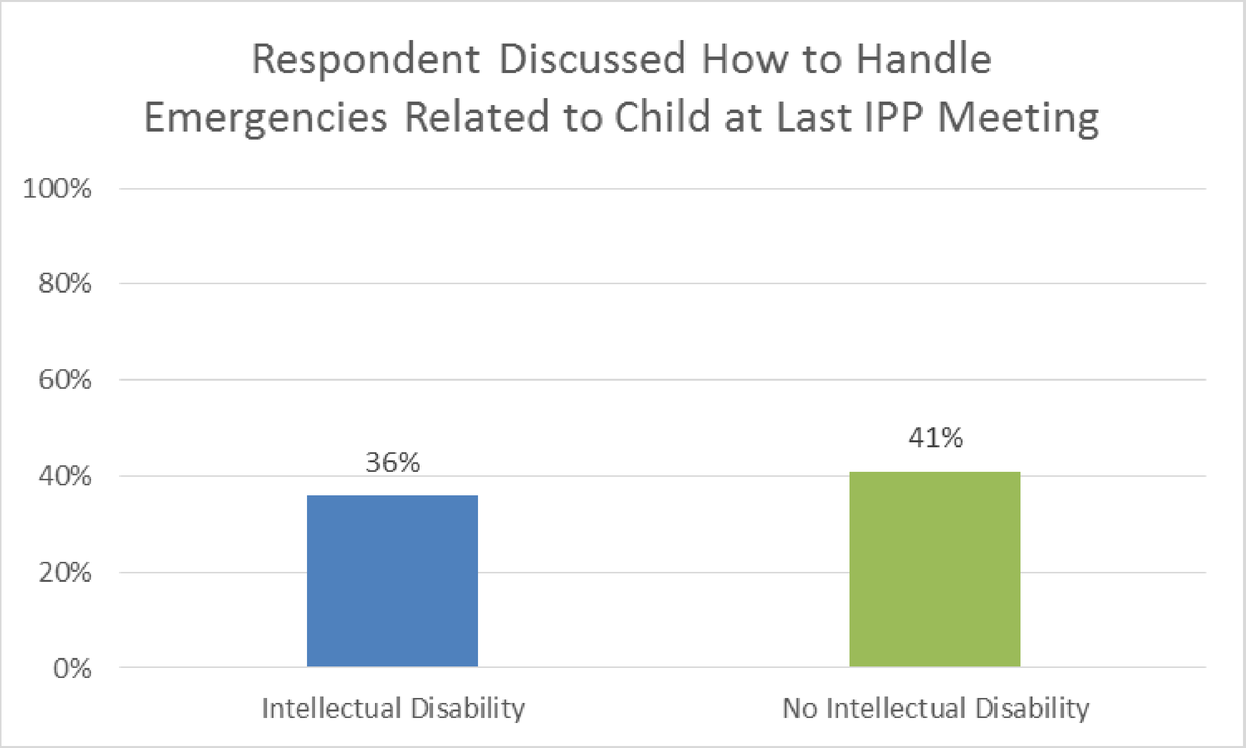

Table III-21: Did you discuss how to handle emergencies related to your child at the last IPP meeting?

	Yes	N
ID	36%	1523
No ID	41%	2672

Access and Delivery of Services and Supports by ID

The section on Access and Delivery in the Child Family Survey includes indicators about: *Accessibility of Support Workers and Service Coordinators, Accessibility of Supports and Services, Communication with Workers,* and *Delivery of Specific Services*. Results that were statistically significant are presented here. The complete list of results for children with ID is located in Appendix C.

Selected Findings on Access and Delivery

There were no significant differences in the indicators in the Access and Delivery section between children with ID and children without ID.[1]

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[1] See Appendix C for tables describing all indicators with respective sample sizes in this section.

Choice and Control by ID

The section on Choice and Control in the Child Family Survey includes indicators about: *Choosing Provider Agencies, Choosing Support Workers,* and *Control over Management of Money Spent on Child*. Results that were statistically significant are presented here. The complete list of results for children with ID is located in Appendix C.

Selected Findings on Choice and Control

Families of children with ID had significant differences in the ability to choose individual support workers who work with the family compared to children without ID[1] (e.g., always able to choose individual support workers, ID: 25%, No ID: 21%). Families of children with ID were more likely to choose different support workers if desired compared to children without ID[1] (always able to choose different support workers if desider, ID: 25%, No ID: 23%). Families of children with ID were more likely to have control or input over the hiring and management of family's support workers compared to families of children without ID (ID: 26%, No ID: 23%). Families of children with ID were less likely to know how much money was spent by the regional center on behalf of their child compared to families of children without ID (ID: 28%, No ID: 31%). Families of children with ID were more likely to have a say in how regional center money was spent on behalf of their child compared to families of children without ID (ID: 12%, No ID: 10%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with ID compared to Family/Survey Respondents of children without ID.

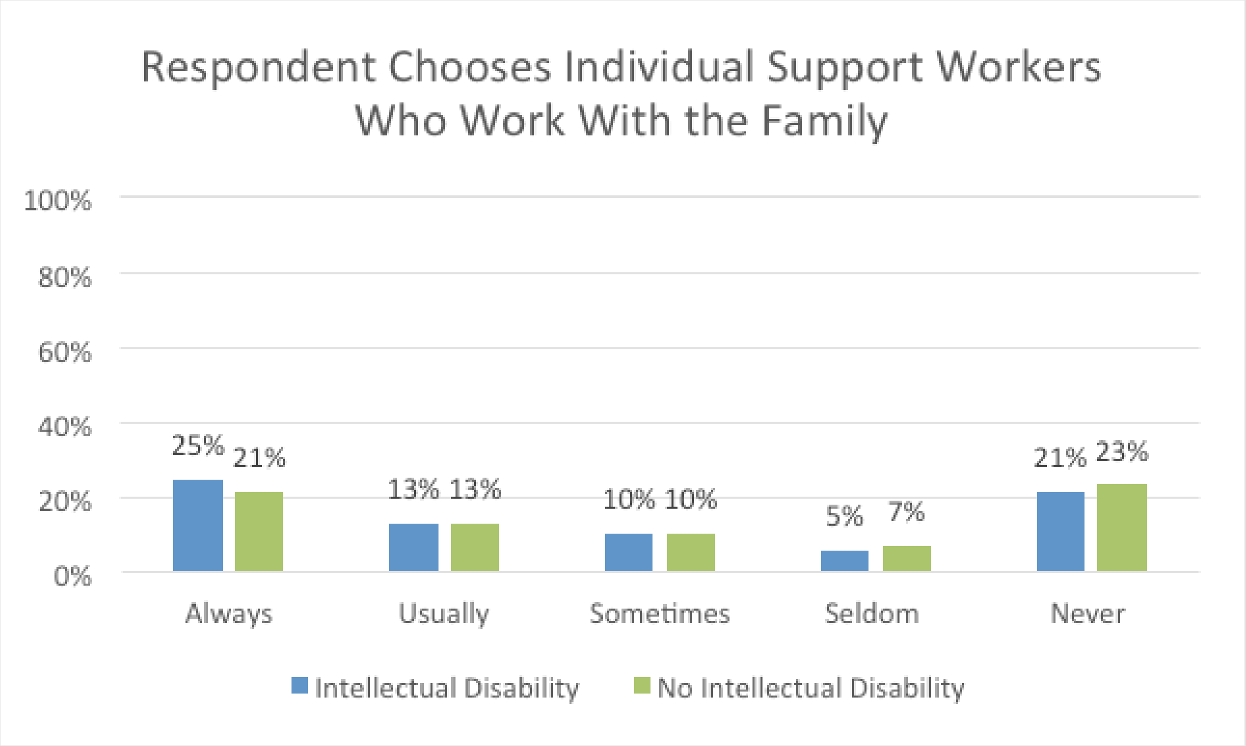

Table III-22: Do you choose the individual support workers who work directly with your family?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ID	25%	13%	10%	5%	21%	2037
No ID	21%	13%	10%	7%	23%	3664

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

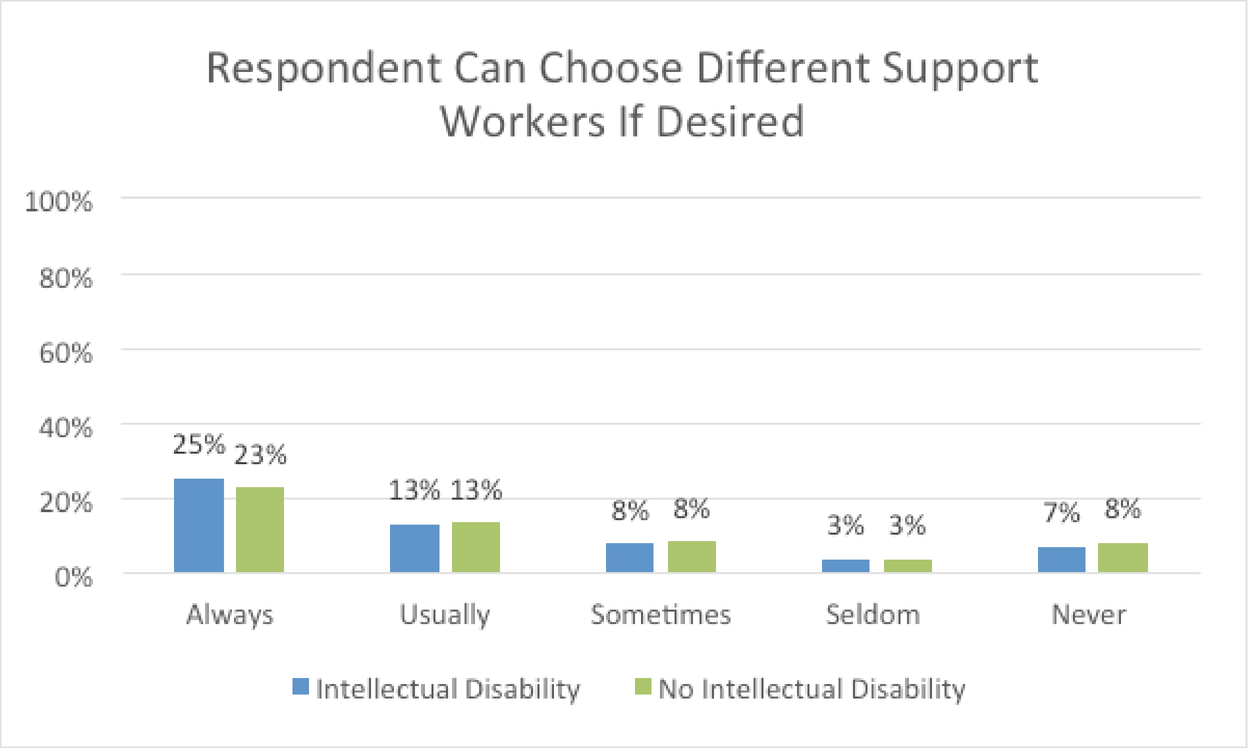

Table III-23: Can you choose different support workers if you want to?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ID	25%	13%	8%	3%	7%	1535
No ID	23%	13%	8%	3%	8%	2734

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

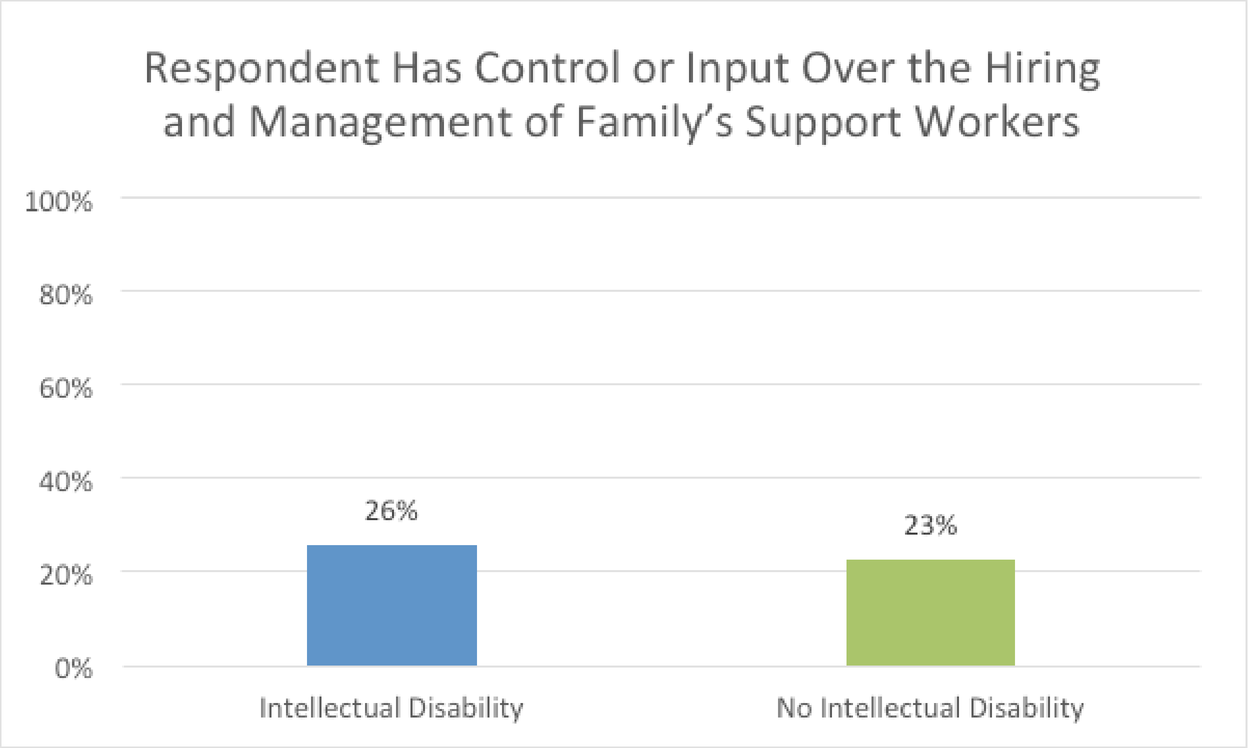

Table III-24: Do you have control or input over the hiring and management of your family's support workers?

	Yes	N
ID	26%	1867
No ID	23%	3271

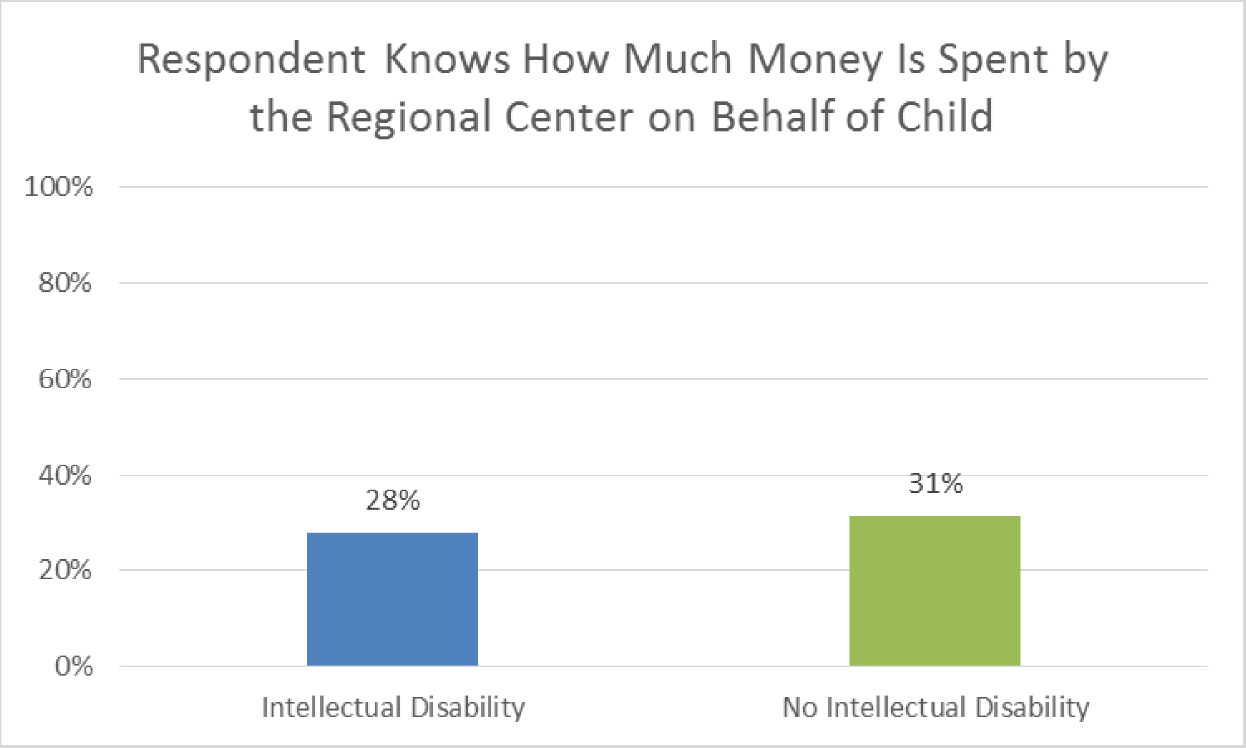

Table III-25: Do you know how much money is spent by the regional center on behalf of your child?

	Yes	N
ID	28%	2648
No ID	31%	4743

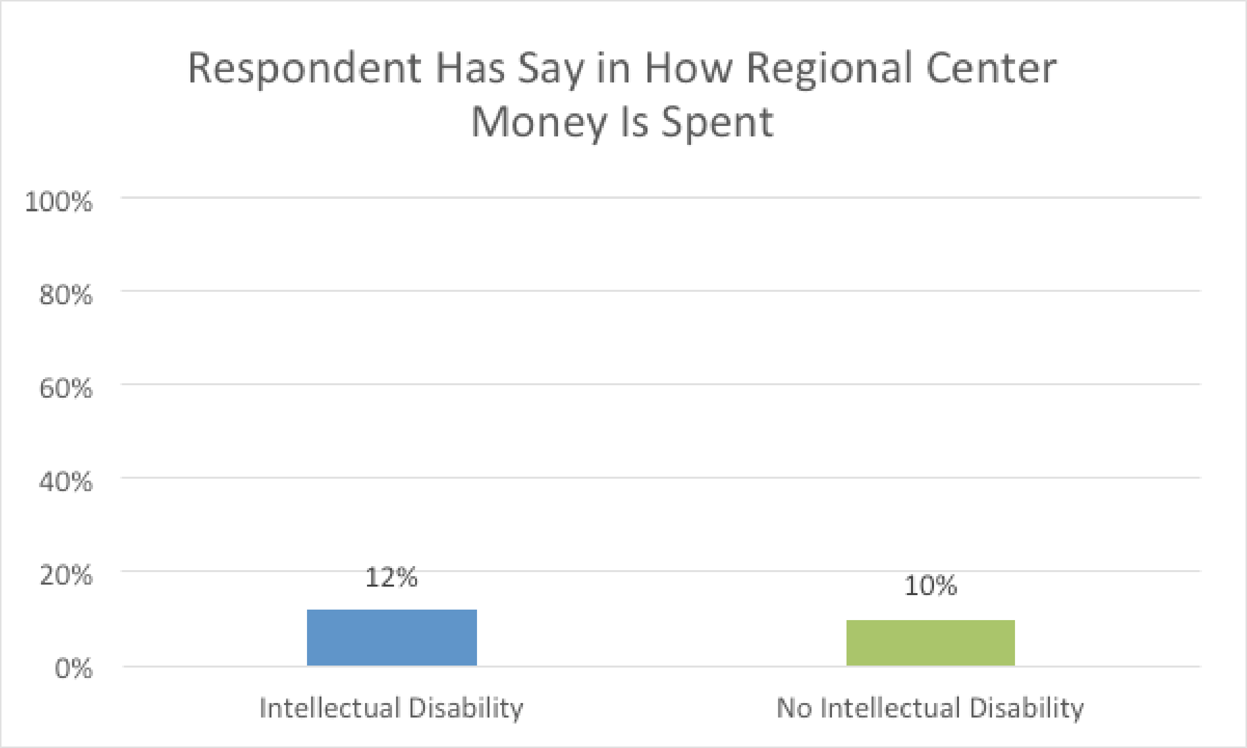

Table III-26: Do you have a say in how regional center money is spent?

	Yes	N
ID	12%	1669
No ID	10%	3084

Community Connections by ID

The section on Community Connections in the Child Family Survey includes indicators about: *Participation in Community.* Results that were statistically significant are presented here. The complete list of results for children with ID is located in Appendix C.

Selected Findings on Community Connections

Children with ID were less likely to participate in community activities compared to children without ID (ID: 67%, No ID: 73%). Children with ID compared to children without ID were less likely to spend time with children who do not have a developmental disability (ID: 76%, No ID: 78%).

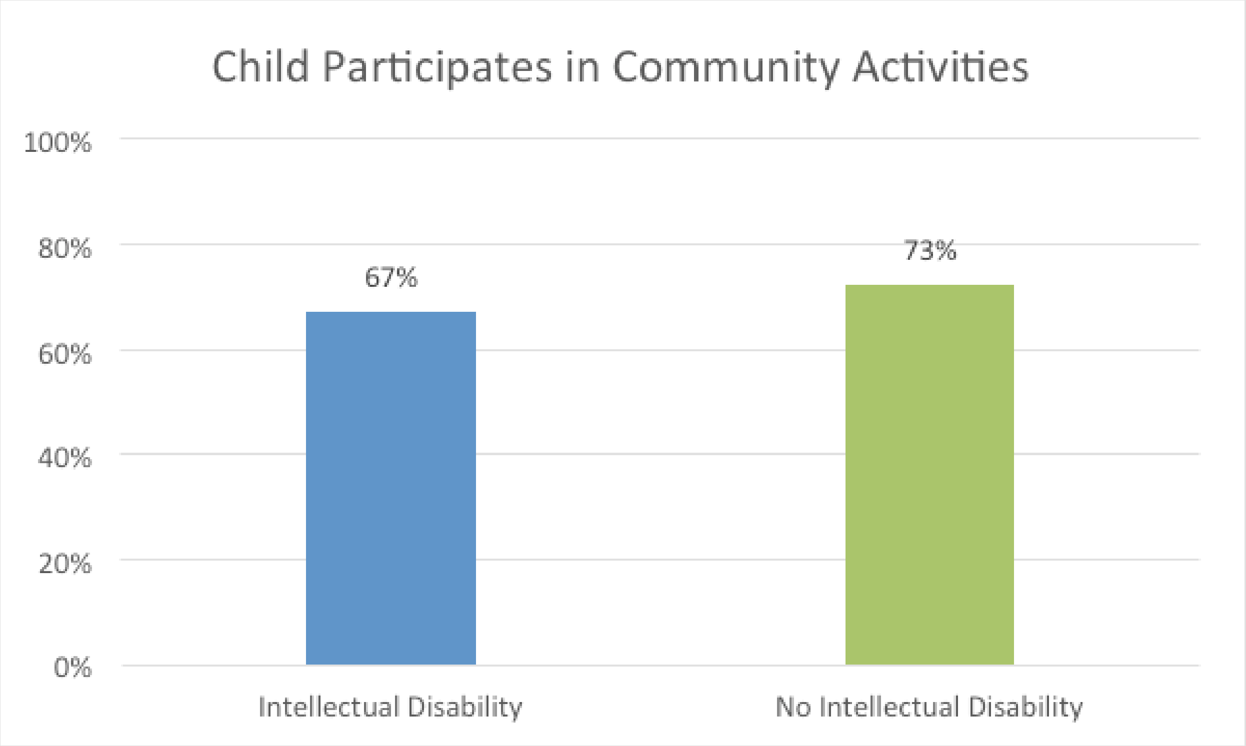

Table III-27: Does your child participate in community activities (such as going out to a restaurant, movie, or sporting event)?

	Yes	N
ID	67%	2589
No ID	73%	4678

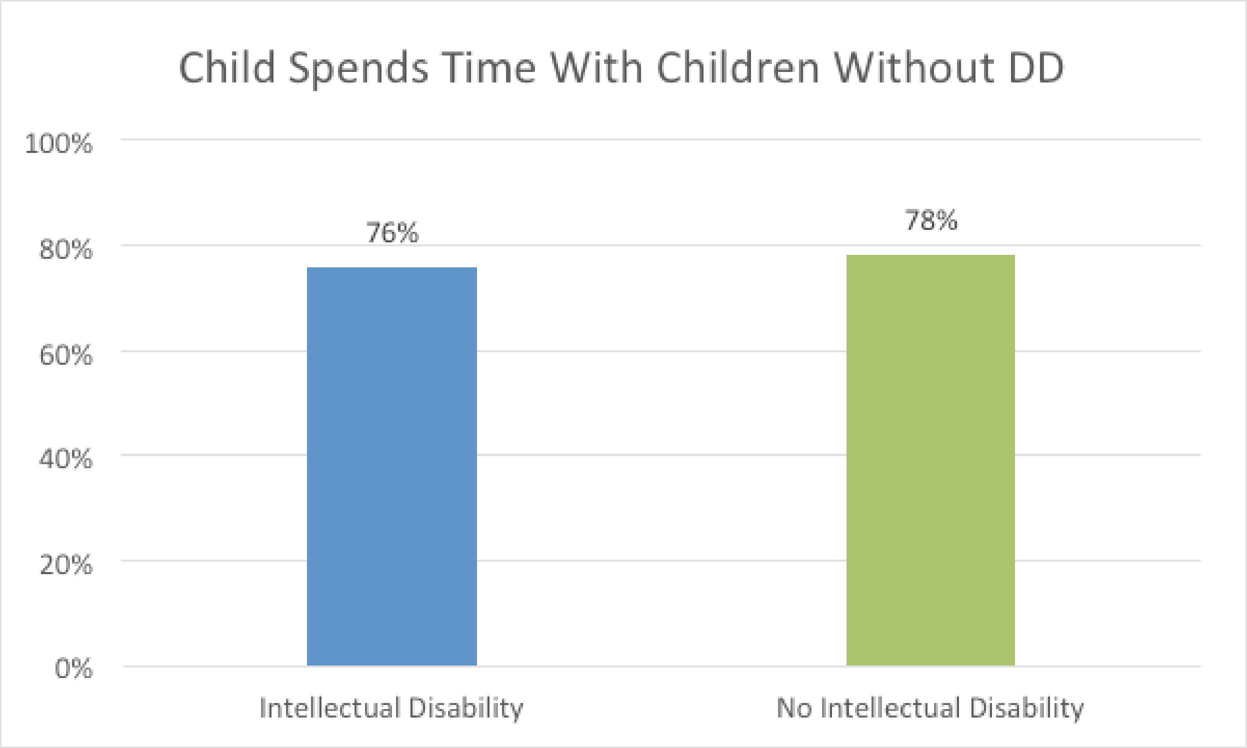

Table III-28: Does your child spend time with children who do not have developmental disabilities?

	Yes	N
ID	76%	2535
No ID	78%	4567

Satisfaction with Services and Supports by ID

The section on Satisfaction with Services and Supports in the Child Family Survey includes indicators about: *Satisfaction with Services and Supports* and *Knowing How to Report Complaints.* Results that were statistically significant are presented here. The complete list of results for children with ID is located in Appendix C.

Selected Findings on Satisfaction with Services and Supports

Families of children with ID were more likely to be satisfied with how complaints or grievances were handled by provider agencies compared to families of children without ID (ID: 23%, No ID: 20%). Families of children with ID were more likely to know how to report abuse or neglect compared to families of children without ID (ID: 58%, No ID: 55%).

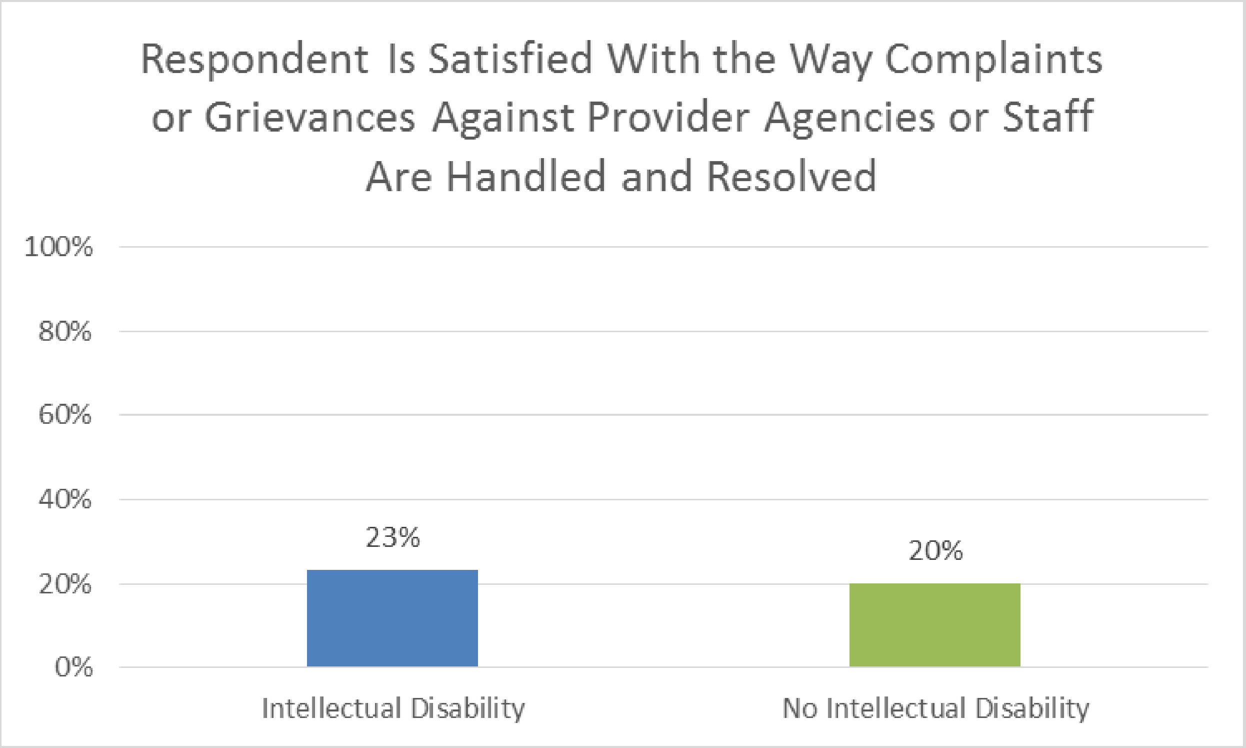

Table III-29: Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

	Yes	N
ID	23%	2546
No ID	20%	4612

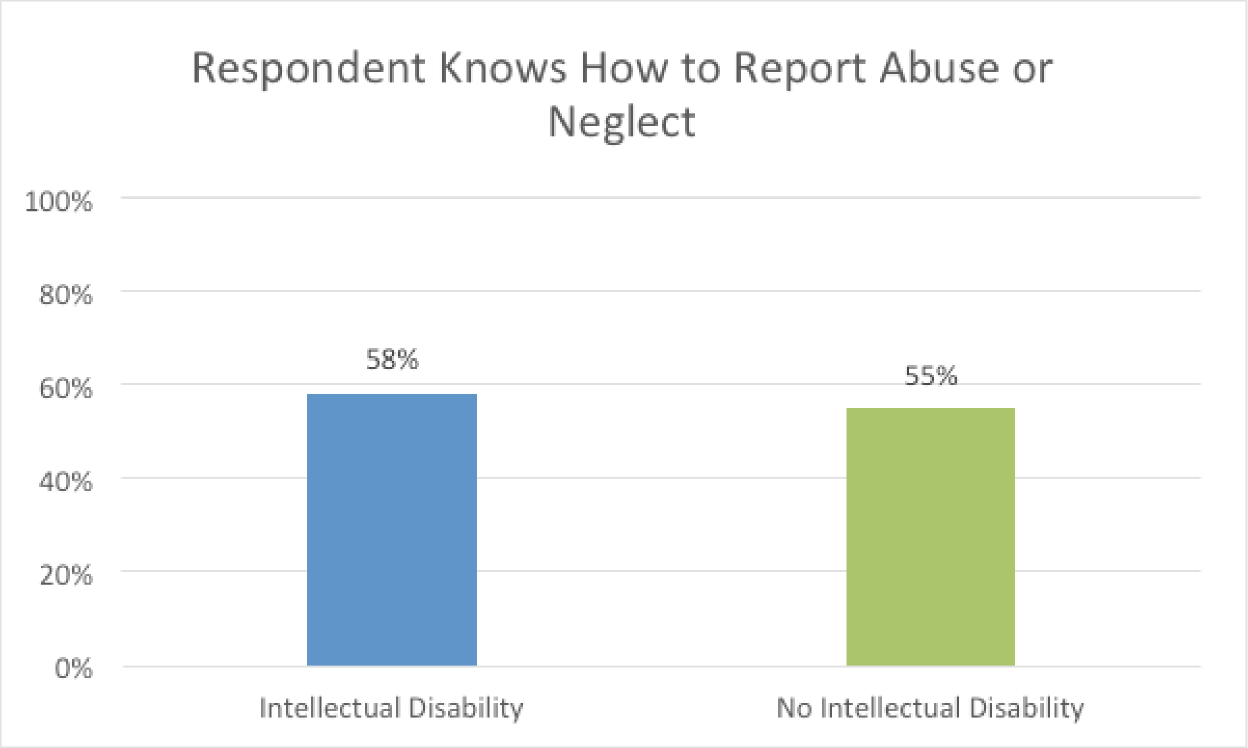

Table III-30: Do you know how to report abuse or neglect?

	Yes	N
ID	58%	2633
No ID	55%	4733

Family Outcomes by ID

The section on Family Outcomes in the Child Family Survey includes indicators about: *Positive Impact of Services and Supports* and *Reduction of Services and Supports.* Results that were statistically significant are presented here. The complete list of results for children with ID is located in Appendix C.

Selected Findings on Outcomes

Families of children with ID were less likely to report that services and supports improved family's ability to care for their child compared to families of children without ID (ID: 68%, No ID: 72%).

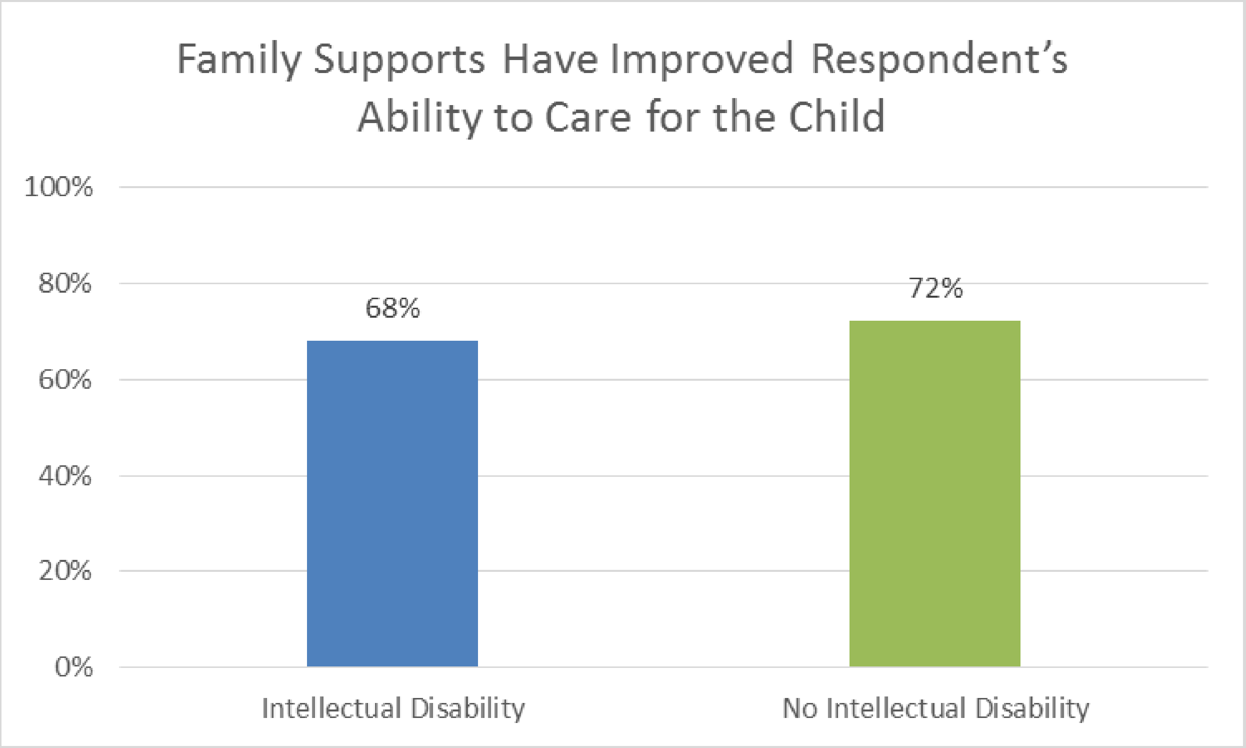

Table III-31: Do you feel that family supports have improved your ability to care for your child?

	Yes	N
ID	68%	2238
No ID	72%	4067

IV. Autism Spectrum Disorder

This section summarizes demographics and statistically significant outcomes for children with a diagnosis of autism spectrum disorder (ASD) compared to children without a diagnosis of ASD. Results reflect responses from 4,665 families of children with ASD and 2,983 families of children without ASD.

Summary of Observations by ASD

Results for demographics and statistically significant outcome measures comparing children with ASD and children without ASD are summarized below. Where noted, differences between the two subgroups were statistically significant at *p*<.05[1]. The statistical tests used to determine significant subgroup differences for each survey question are found in Appendix B. Complete tables describing all outcomes with respective sample sizes are found in Appendix D.

Selected Key Findings

In the Child's Demographic Information section, children with ASD compared to children without ASD were younger, more likely to be male, less likely to be female, and less likely to have additional qualifying conditions and disability diagnoses. Children with ASD were more likely to use spoken language as their primary means of expression compared to children without ASD. Children with ASD were also more likely to speak English as their preferred language compared to children without ASD. Families of children with ASD have a significant difference in the amount of help needed to care for their child compared to families of children without ASD.

In the Family/Survey Respondent's Demographic Information section, families of children with ASD were more likely to have parents complete the CFS1 survey and more likely to have a college degree compared to families of children without ASD. Families of children with ASD have significant differences in the quality of health, total household income, and out-of-pocket expenses compared to families of children without ASD.

In the Services and Supports Received section, children with ASD were more likely to receive early intervention compared to children without ASD. Families of children with ASD were less likely to receive financial support, out-of-home respite care, transportation assistance, and Social Security benefits compared to families of children

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[1] P<.05 refers to the how likely a finding in the data is due to chance and when p<.05 we have confidence that the finding is not due to chance. This finding of statistical significance does not necessarily mean that the finding is a really important finding.

without ASD. There were no differences in receiving in-home support and other services and supports between families of children with ASD and families of children without ASD.

In the Information and Planning section, there was a significant difference in receiving information about available services and supports between families of children with ASD and families of children without ASD. Children with ASD were more likely to have an individual program plan (IPP) compared to children without ASD. There were no significant differences between families of children with ASD and families of children without ASD in helping develop an IPP and families receiving information about their rights.

In the Access and Delivery section, there were significant differences between families of children with ASD and families of children without ASD in their ability to contact support workers and service coordinators when needed. There was a significant difference between families of children with ASD and families of children without ASD in support workers having the right training to meet their child's needs.

In the Choice and Control section, there was no significant difference in choosing provider agencies between families of children with ASD and families of children without ASD. There was a significant difference in choosing individual support workers between families of children with ASD and families of children without ASD. Families of children with ASD were more likely to know how much money was spent by the regional center on behalf of their child compared to families of children without ASD. There was no significant difference in having a say in how regional center money was spent on behalf of their child between families of children with ASD and families of children without ASD.

In the Community Connections section, children with ASD were more likely to participate in community activities and less likely to spend time with children who do not have a developmental disability compared to children without ASD.

In the Satisfaction with Services and Supports section, there was a significant difference in satisfaction with services and supports received by families of children with ASD and families of children without ASD. Families of children with ASD were less likely to be satisfied with how complaints were handled by provider agencies compared to families of children without ASD. There was no significant difference in knowing how to report abuse or neglect between families of children with ASD and families of children without ASD.

In the Family Outcomes section, there was no significant difference between families of children with ASD and families of children without ASD in services and supports making a positive impact in their family’s life. There was no significant difference between families of children with ASD and families of children without ASD in reporting that family supports improved their ability to care for their child. Families of children with ASD were more likely to have services and supports reduced or terminated in the past year compared to families of children without ASD.

Demographics by ASD

Child’s Demographic Information

The section on Child’s Demographic Information in the Child Family Survey includes indicators about: *Basic Information, Primary Means Expression and Language,* and *Amount of Help Needed for Child.* All results are presented here.

Selected Findings on Child’s Demographic Information

Families of children with ASD were more likely to have more than one child with a disability living in the household compared to families of children without ASD (ASD: 19%, No ASD: 15%). Children with ASD on average were younger than children without ASD (ASD: 9.81 years old, No ASD: 11.03 years old). Children with ASD were more likely to be male compared to children without ASD (ASD: 79%, No ASD: 53%). Children with ASD were less likely to be female compared to children without ASD (ASD: 18%, No ASD: 44%). Children with ASD were more likely to be White compared to children without ASD (ASD: 38%, No ASD: 32%). Children with ASD were less likely to be Hispanic/Latino compared to children without ASD (ASD: 37%, No ASD: 48%). Children with ASD were more likely to be Asian compared to children without ASD (ASD: 15%, No ASD: 9%). Children with ASD were more likely to have a Mixed racial background (two or more races) compared to children without ASD (ASD: 12%, No ASD: 10%). Children with ASD were less likely to have cerebral palsy as an additional qualifying condition compared to children without ASD (ASD: 3%, No ASD: 25%). Children with ASD were less likely to have ID as an additional qualifying condition compared to children without ASD (ASD: 20%, No ASD: 59%). Children with ASD were less likely to have epilepsy as an additional qualifying condition compared to children without ASD (ASD: 8%, No ASD: 25%). Children with ASD were less likely to have a brain injury compared to children without ASD (ASD: 1%, No ASD: 9%). Children with ASD were less likely to have a chemical dependency compared to children without ASD (ASD: 0%, No ASD: 1%). Children with ASD were less likely to have limited/no vision or be legally blind compared to children without ASD (ASD: 2%, No ASD: 12%). Children with ASD were less likely to have hearing loss compared to children without ASD (ASD:

1%, No ASD: 6%). Children with ASD were less likely to have Down syndrome compared to children without ASD (ASD: 1%, No ASD: 21%). Children with ASD were less likely to have Prader-Willi syndrome compared to children without ASD (ASD: 0%, No ASD: 1%). Children with ASD were less likely to have another unlisted disability compared to children without ASD (ASD: 9%, No ASD: 27%). Children with ASD were more likely than children without ASD to have families who did not know (ID: 1%, No ID: 0%) if their child had any other disabilities.

Children with ASD were more likely to use spoken language as their primary means of expression compared to children without ASD (ASD: 69%, No ASD: 55%). Children with ASD were less likely to use gestures/body language as their primary means of expression compared to children without ASD (ASD: 19%, No ASD: 28%). Children with ASD less likely to use sign language/finger spelling as their primary means of expression compared to children without ASD (ASD: 3%, No ASD: 5%). Children with ASD were less likely to use other methods as their primary means of expression compared to children without ASD (ASD: 4%, No ASD: 7%). Children with ASD were more likely to speak English as their preferred language compared to children without ASD (ASD: 79%, No ASD: 62%). Children with ASD were less likely to speak Spanish as their preferred language compared to children without ASD (ASD: 16%, No ASD: 31%). Children with ASD were less likely to speak a different language (other) not listed as their preferred language compared to children without ASD (ASD: 4%, No ASD: 5%).

Children with ASD had significant differences in the frequency of medical care needed compared to children without ASD[1] (e.g., medical care needed at least once per week, ASD: 6%, No ASD: 13%). Children with ASD had significant differences in the amount of behavioral support needed compared to children without ASD[1] (e.g., extensive behavioral support needed, ASD: 17%, No ASD: 14%). Children with ASD had significant differences in the amount of help needed for daily activities compared to children without ASD[1] (e.g., complete help needed, ASD: 25%, No ASD: 45%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with ASD compared to Family/Survey Respondents of children without ASD.

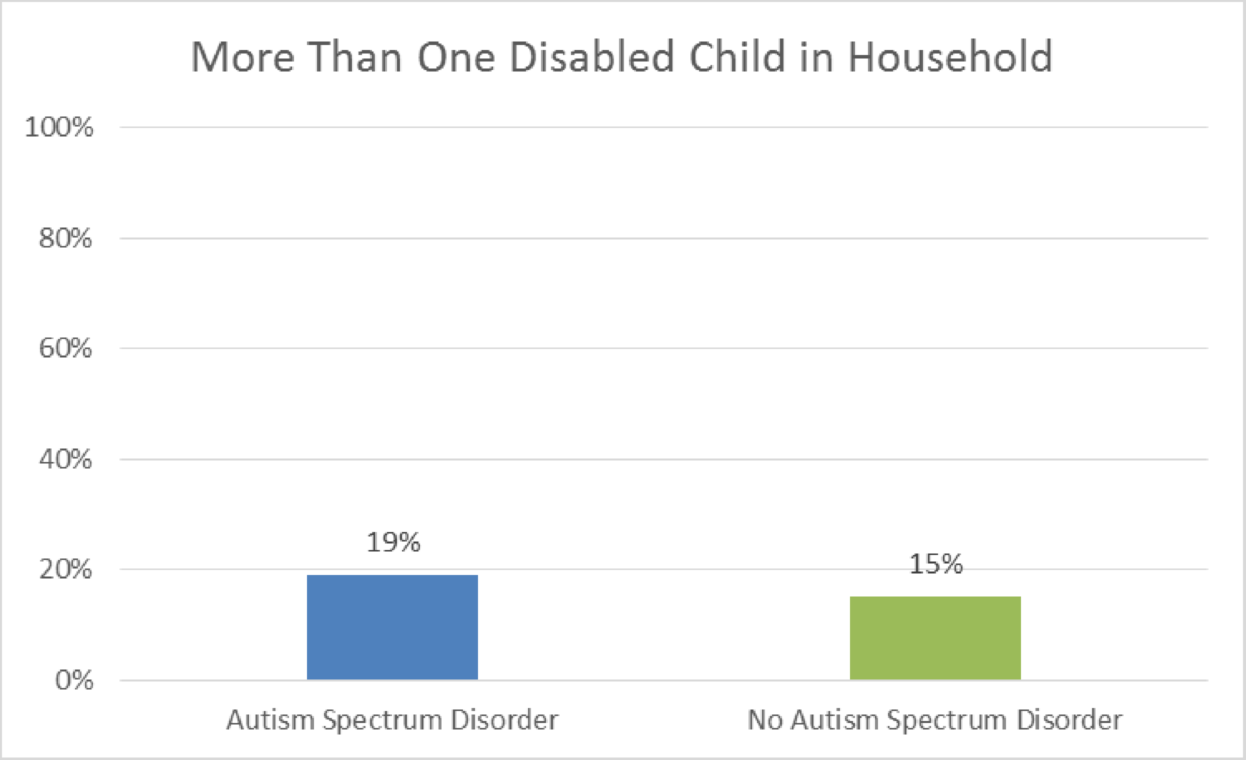

Table IV-1 More Than One Disabled Child in Household by ASD

	Yes	N
ASD	19%	4215
No ASD	15%	2579

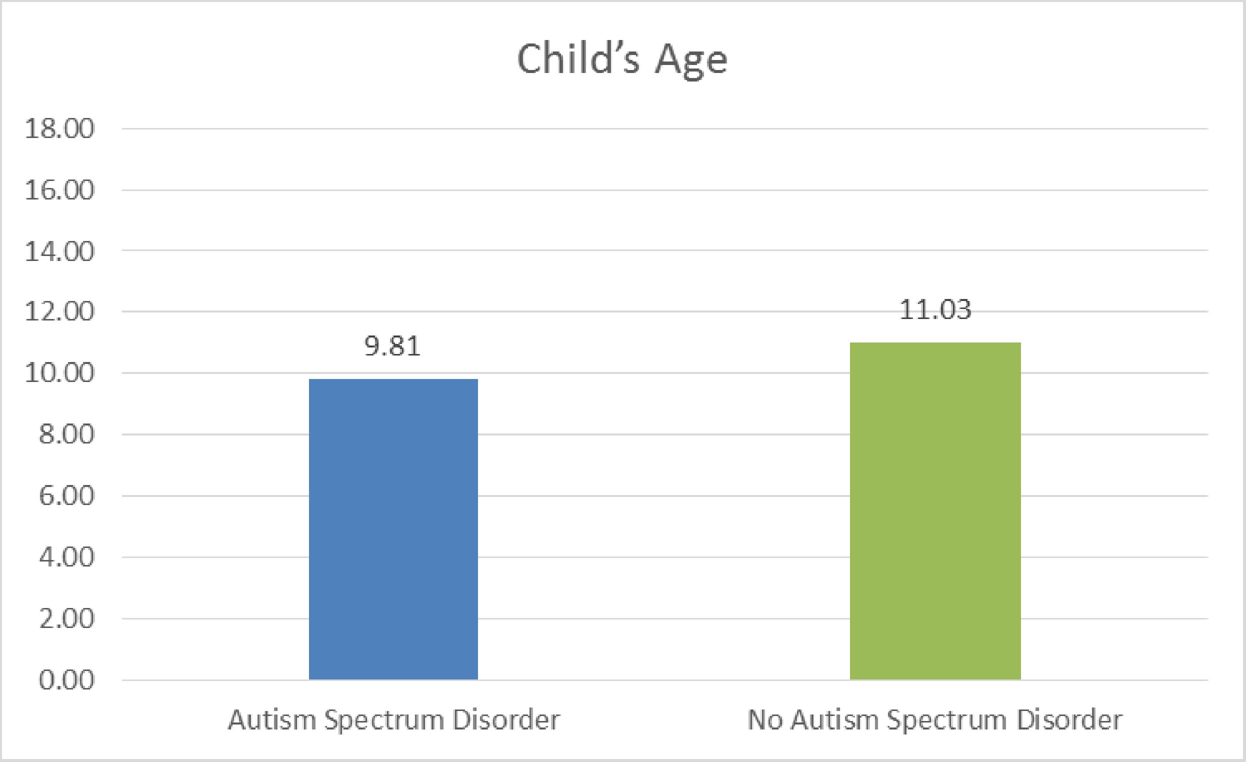

Table IV-2: Child's Age by ASD

	Average Age	N
ASD	9.81	4567
No ASD	11.03	2875

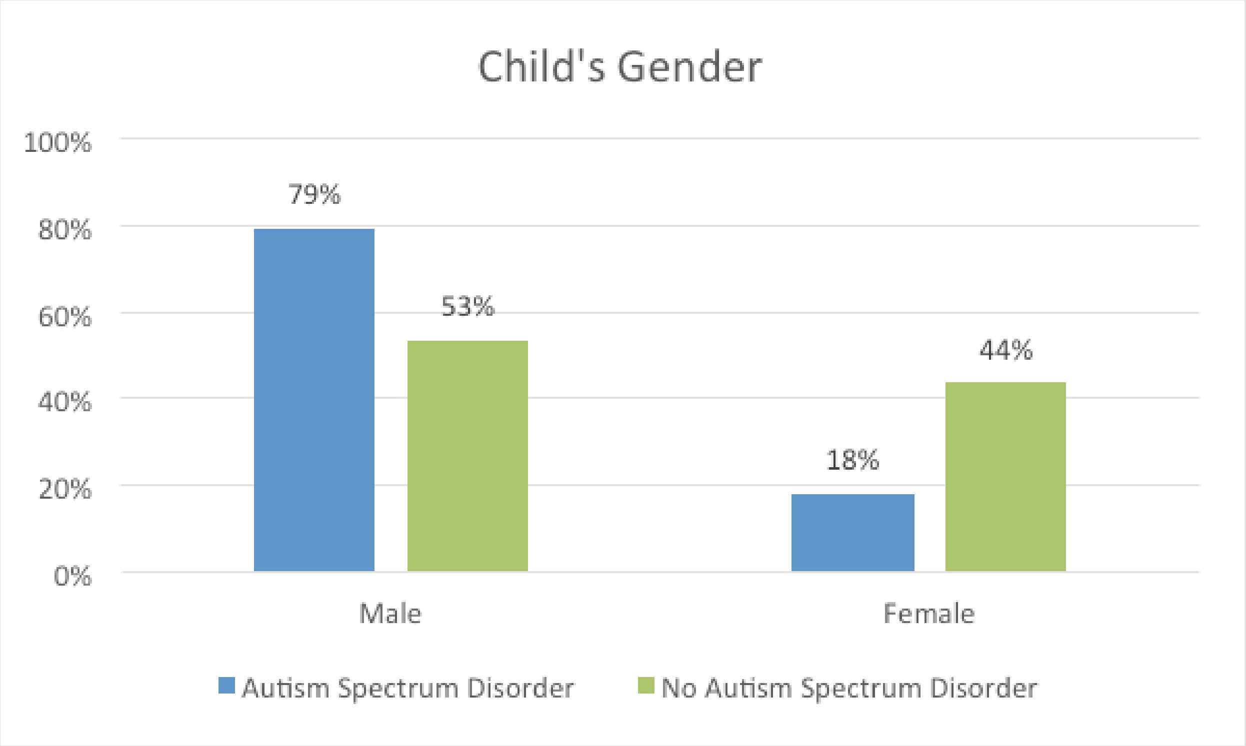

Table IV-3: Child's Gender by ASD

	Male	Female	N
ASD	79%	18%	4531
No ASD	53%	44%	2894

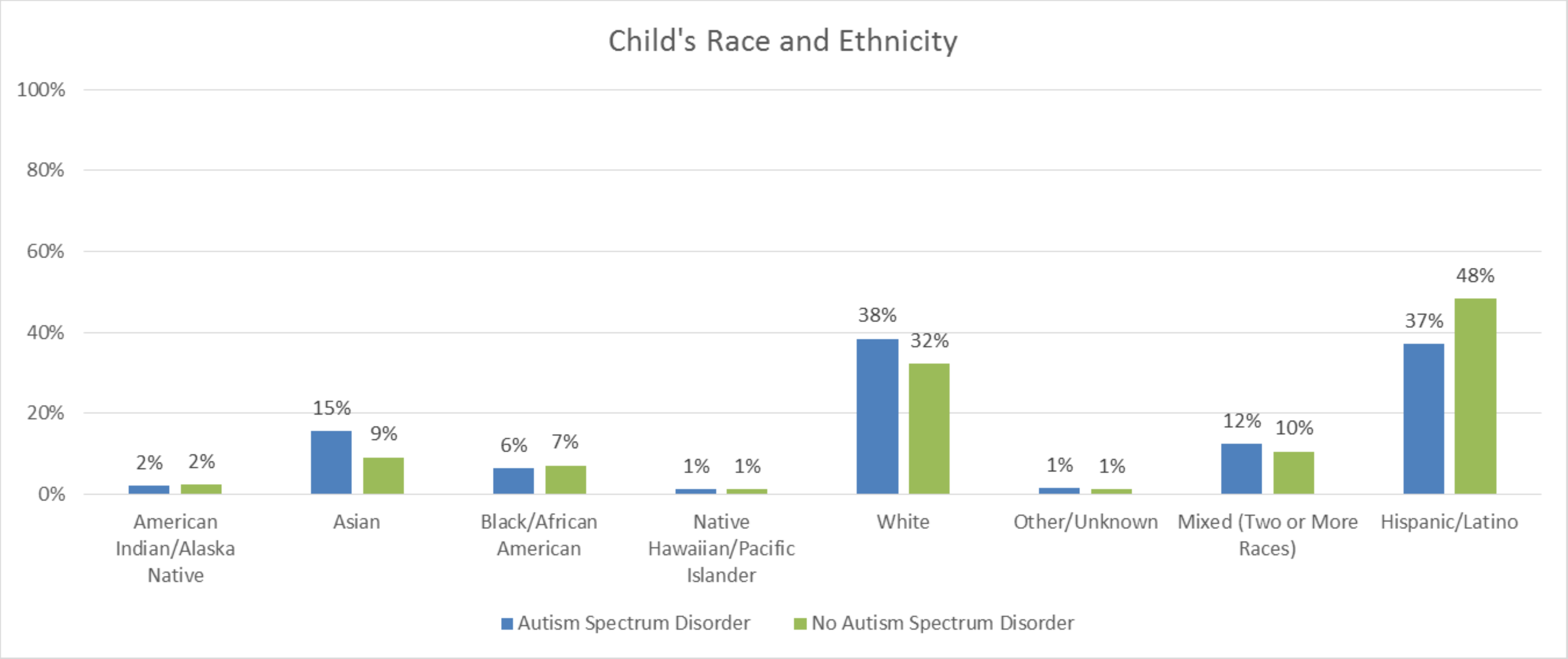

Table IV-4: Child's Race and Ethnicity by ASD[1],[2]

	American Indian/ Alaska Native	Asian	Black/ African American	Native Hawaiian/ Pacific Islander	White	Other/ Unknown	Mixed (Two or More Races)	Hispanic/ Latino
ASD	2%	15%	6%	1%	38%	1%	12%	37%
No ASD	2%	9%	7%	1%	32%	1%	10%	48%

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[1] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

[2] Results for “American Indian/Alaska Native,” “Black/African American,” “Native Hawaiian/Pacific Islander,” or “Other/Unknown” were not statistically significant.

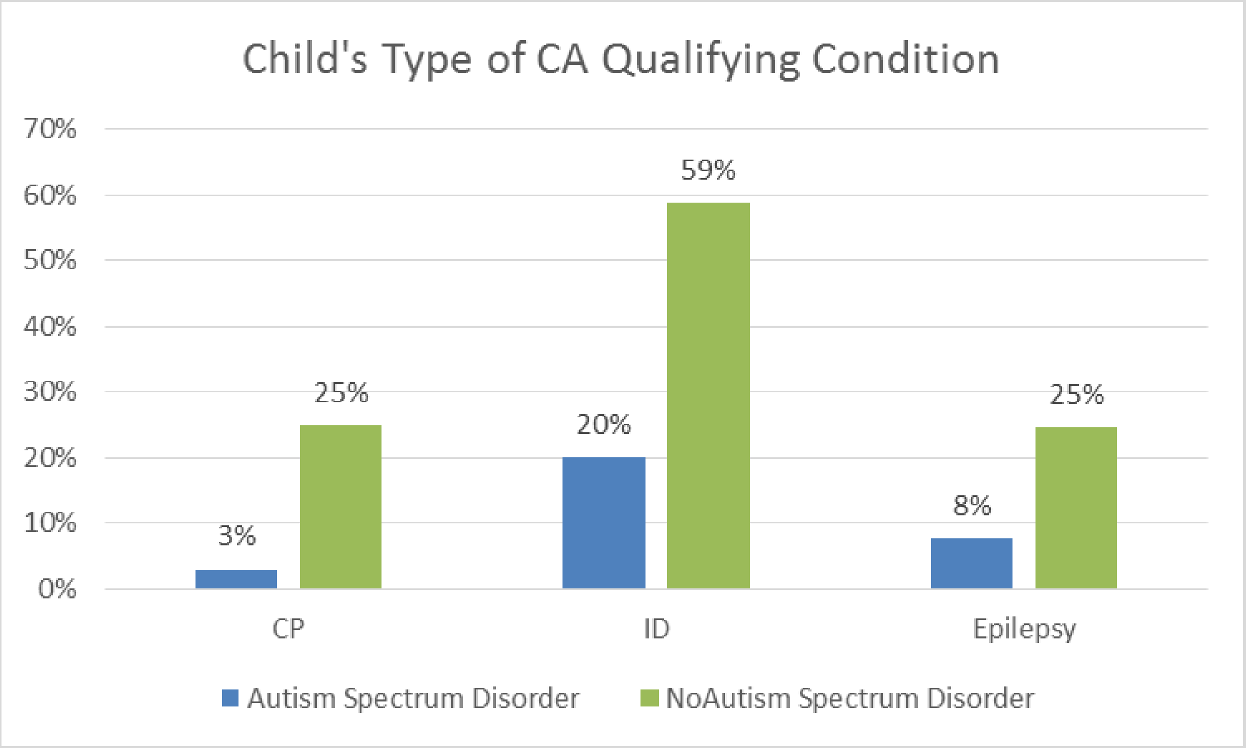

Table IV-5: Child's Type of CA Qualifying Condition by ASD[1]

	CP	ID	Epilepsy
ASD	3%	20%	8%
No ASD	25%	59%	25%

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[1] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

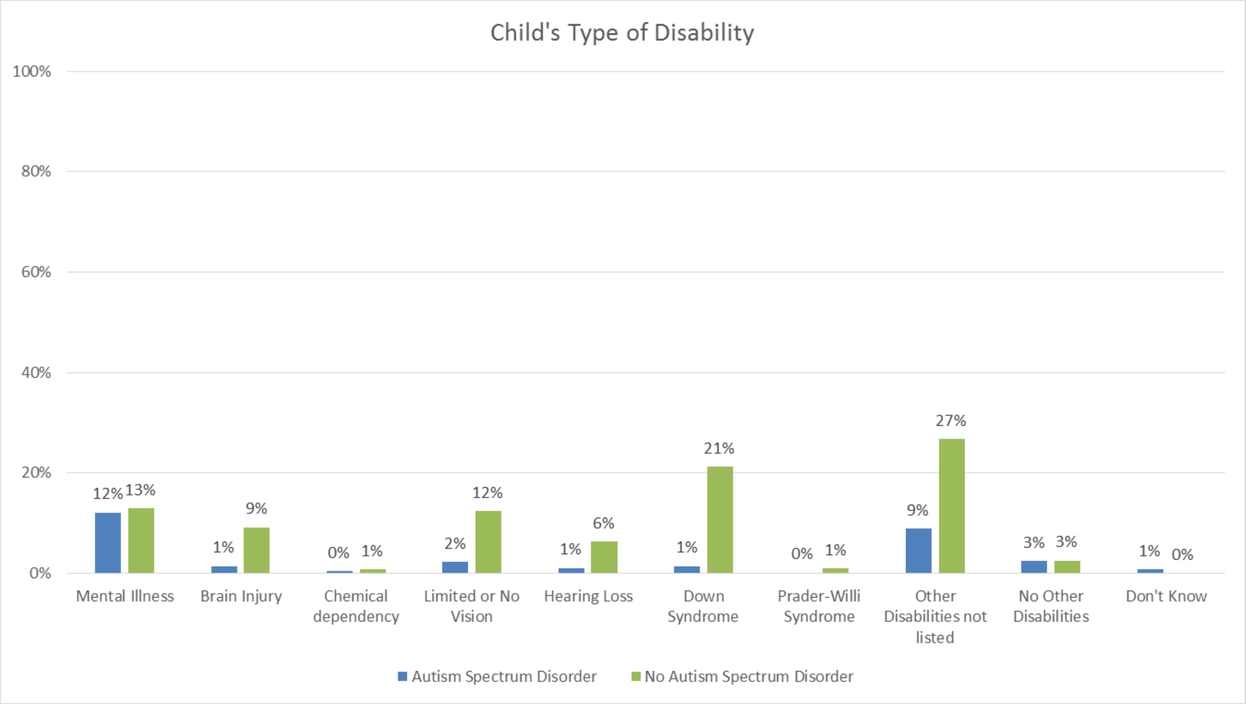

Table IV-6: Child's Type of Disability by ASD[1],[2]

	Mental Illness/ Psychiatric Diagnosis/ Behavioral Disorder	Brain Injury	Chemical Dependency	Limited or No Vision/ Legally Blind	Hearing Loss (Severe or Profound)	Down Syndrome	Prader-Willi Syndrome	Other Disabi-lities not listed	No Other Disabi-lities	Don't Know
ASD	12%	1%	0%	2%	1%	1%	0%	9%	3%	1%
No ASD	13%	9%	1%	12%	6%	21%	1%	27%	3%	0%

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[1] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

[2] Results for “Mental Illness/Psychiatric Diagnosis/Behavioral Disorder” and “No Other Disabilities” were not statistically significant

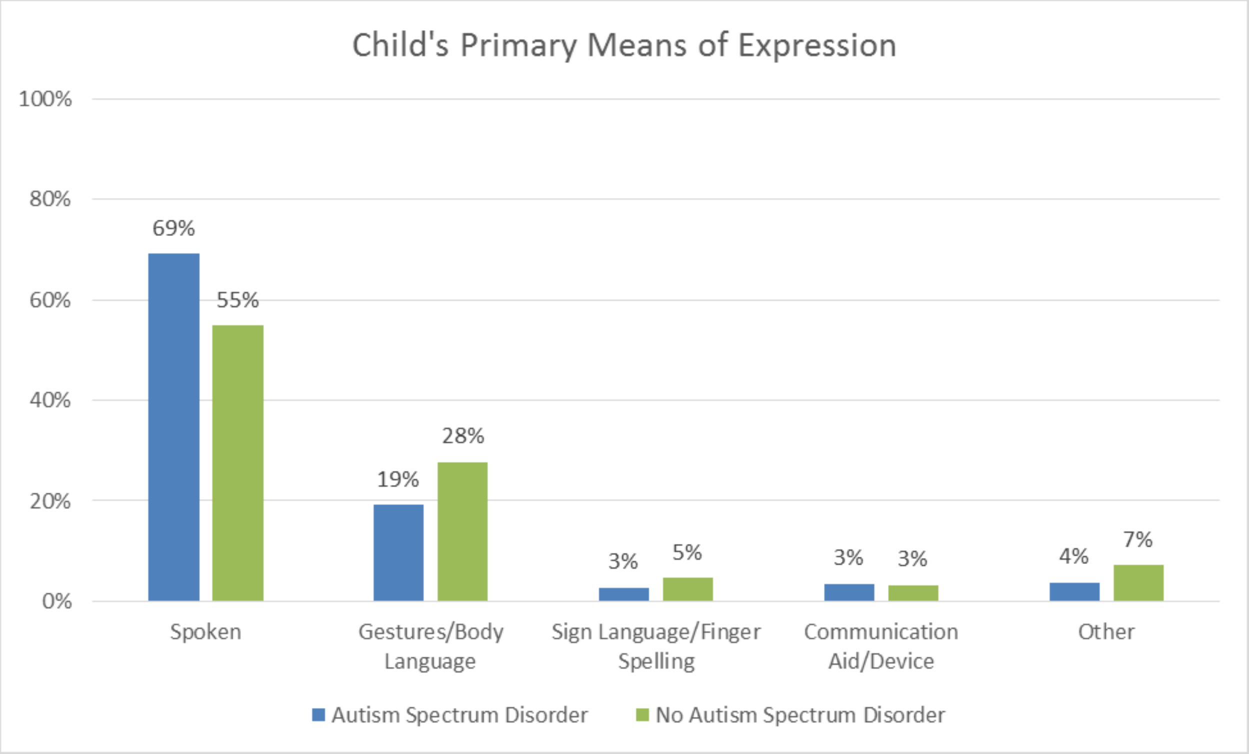

Table IV-7: Child's Primary Means of Expression by ASD[1], [2]

	Spoken	Gestures/ Body Language	Sign Language/ Finger Spelling	Communication Aid/Device	Other	N
ASD	69%	19%	3%	3%	4%	4593
No ASD	55%	28%	5%	3%	7%	2915

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[1] Results for “Communication Aid/Device” were not statistically significant.
[2] Percentages add up to less than 100% due to missing responses.

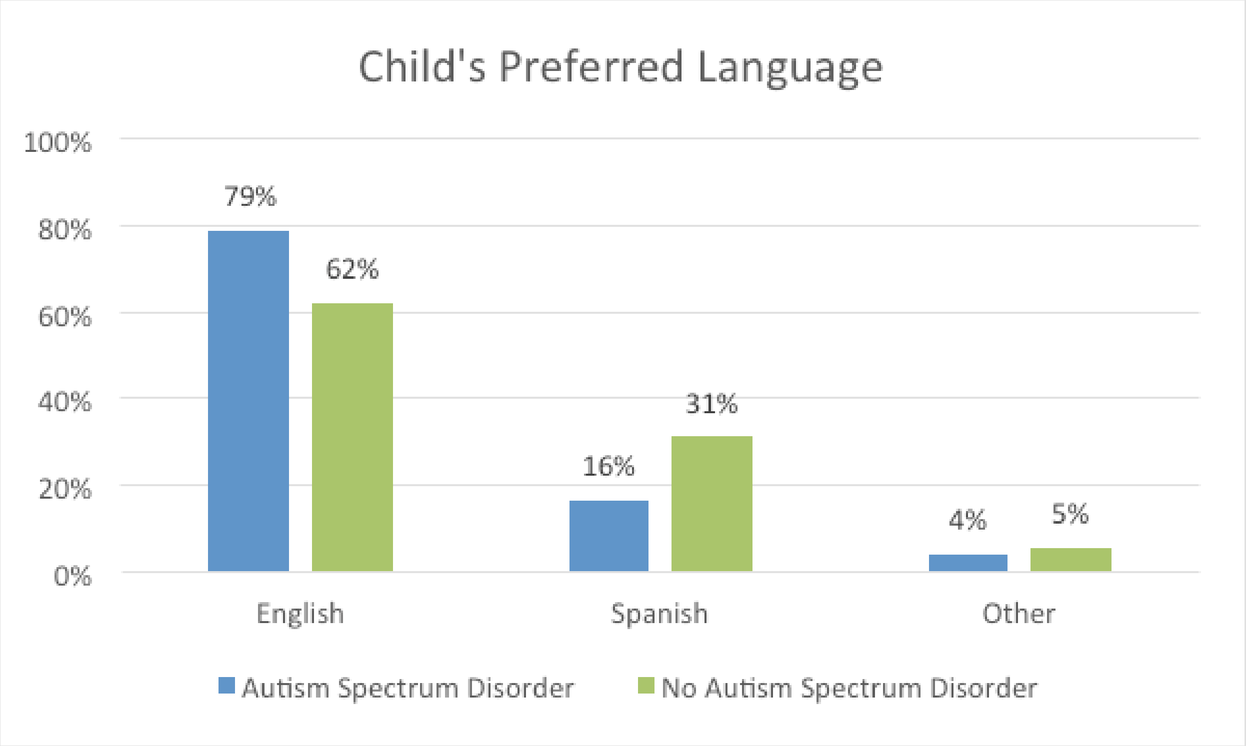

Table IV-8: Child's Preferred Language by ASD[1]

	English	Spanish	Other	N
ASD	79%	16%	4%	4626
No ASD	62%	31%	5%	2938

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[1] Percentages add up to less than 100% due to missing responses.

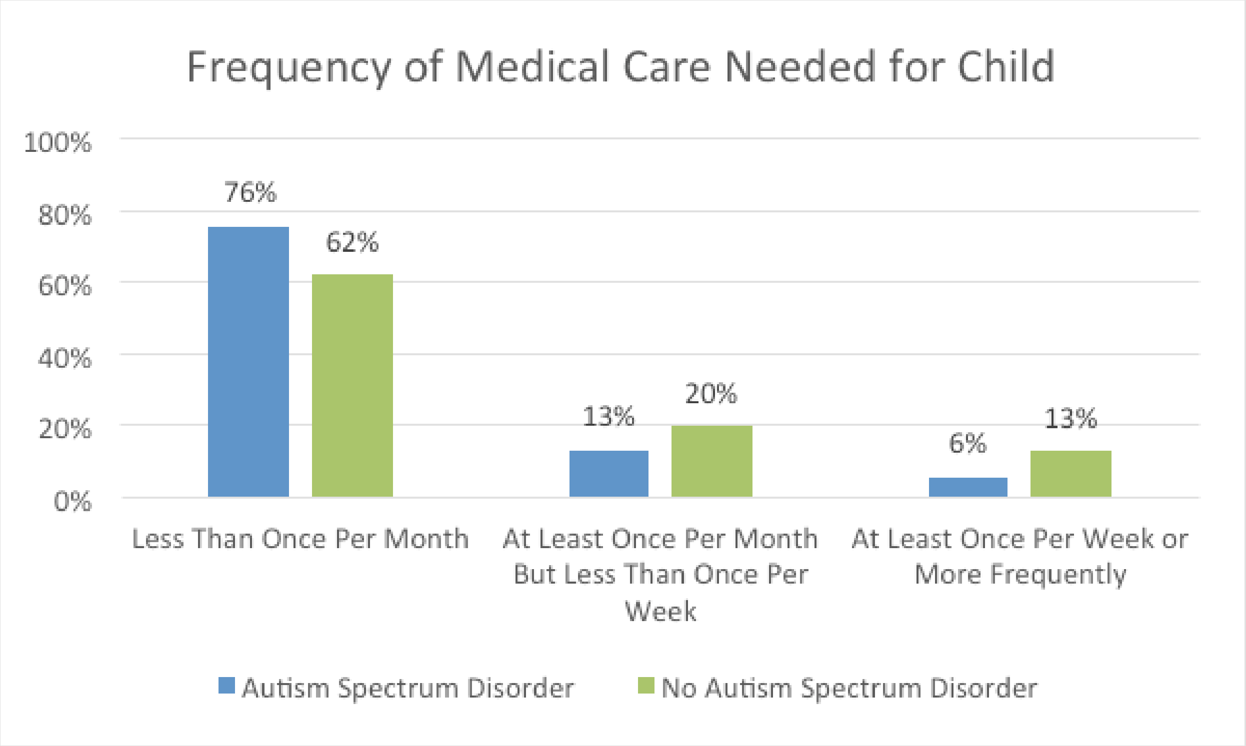

Table IV-9: Frequency of Medical Care Needed for Child by ASD[1]

	Less Than Once Per Month	At Least Once Per Month But Less Than Once Per Week	At Least Once Per Week or More Frequently	N
ASD	76%	13%	6%	4378
No ASD	62%	20%	13%	2811

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[1] Percentages add up to less than 100% due to missing responses.

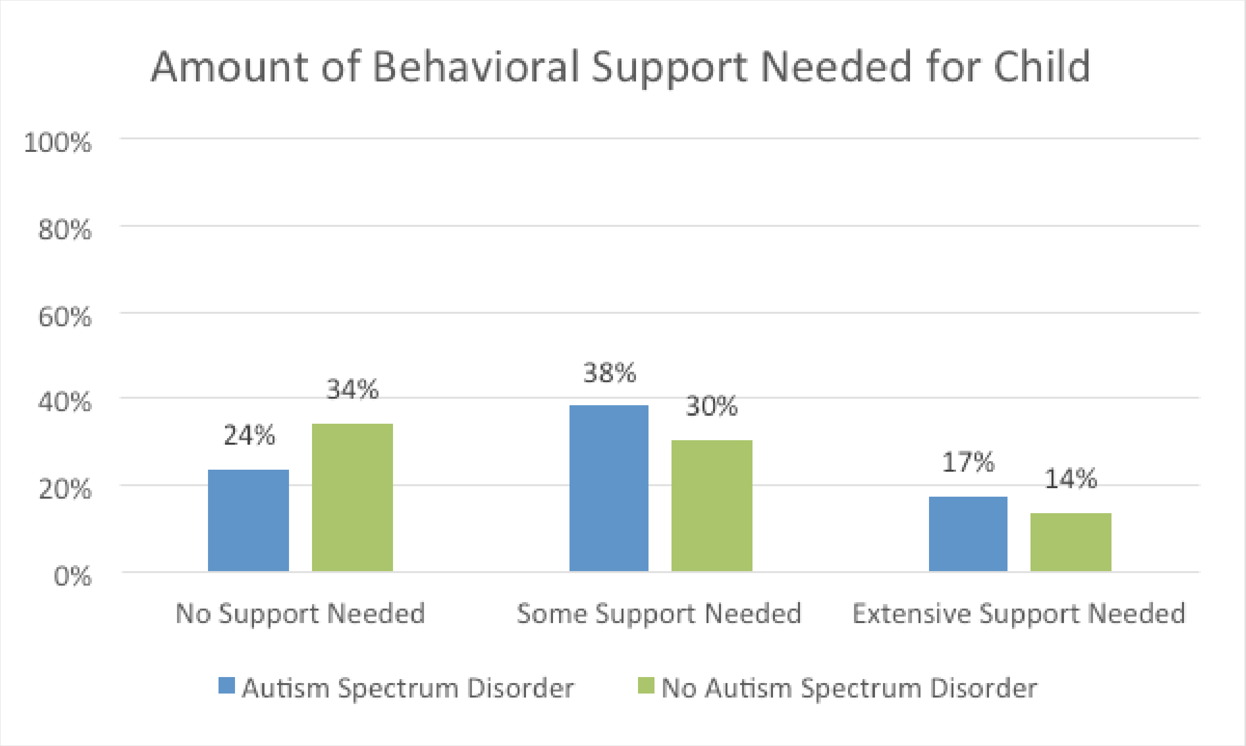

Table IV-10: Amount of Behavioral Support Needed for Child by ASD[1]

	No Support Needed	Some Support Needed	Extensive Support Needed	N
ASD	24%	38%	17%	3695
No ASD	34%	30%	14%	2331

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[1] Percentages add up to less than 100% due to missing responses.

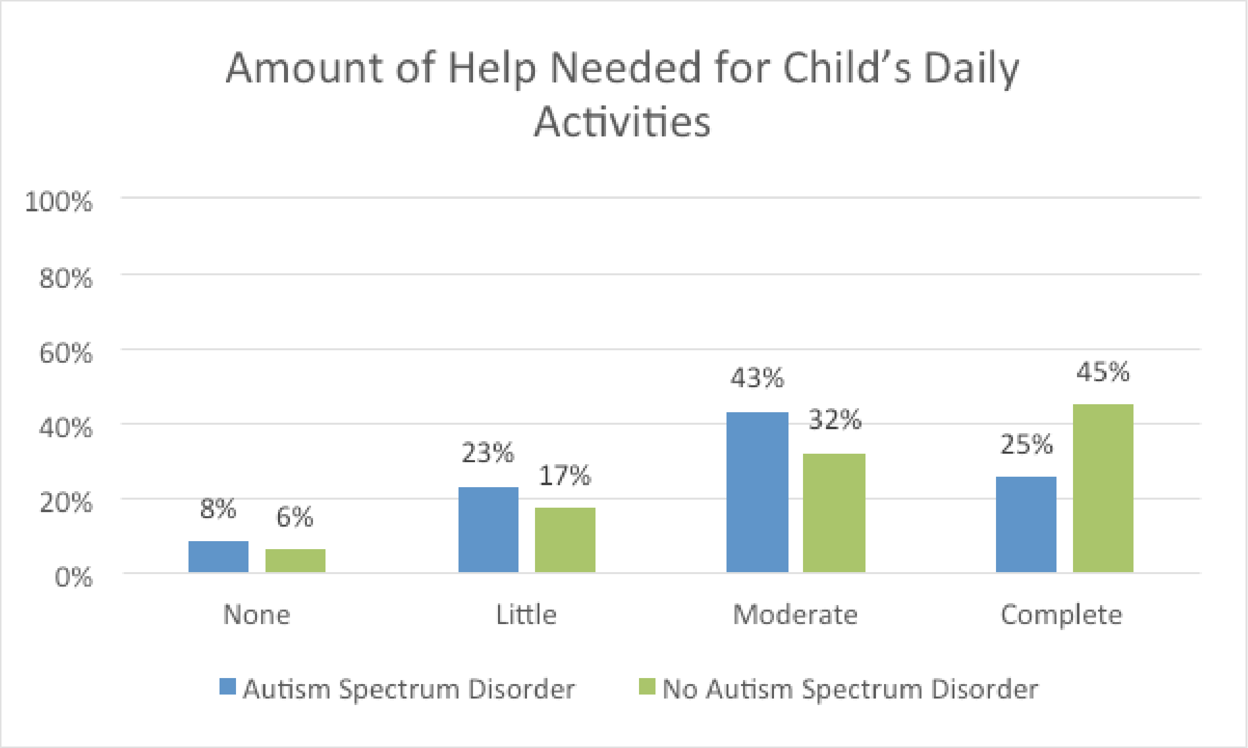

Table IV-11: Amount of Help Needed for Child's Daily Activities by ASD[1]

	None	Little	Moderate	Complete	N
ASD	8%	23%	43%	25%	4635
No ASD	6%	17%	32%	45%	2973

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[1] Percentages add up to less than 100% due to missing responses.

Family/Respondent's Demographic Information

The section on Family/Survey Respondent's Demographic Information in the Child Family Survey includes indicators about: *Basic Information about Family/Survey Respondent* and *Household Composition and Income.* All results are presented here.

Selected Findings on Family/Respondent's Demographic Information

Survey respondents of children with ASD compared to respondents of children without ASD had significant differences in age[1] (e.g., age of survey respondent between 35-54 years old, ASD: 68%, No ASD: 63%). Survey respondents of children with ASD compared to respondents of children without ASD had differences in quality of health[1] (e.g., excellent health, ASD: 22%, No ASD: 21%). Children with ASD were more likely to have parents complete the CFS1 survey compared to children without ASD (ASD: 97%, No ASD: 95%). Children with ASD were less likely to have a sibling complete the CFS1 survey compared to children without ASD (ASD: 0.2%, No ASD: 1%). Children with ASD were less likely to have a grandparent complete the CFS1 survey compared to children without ASD (ASD: 2%, No ASD: 3%). Survey respondents of children with ASD compared to respondents of children without ASD were less likely to have no High School diploma or GED (ASD: 15%, No ASD: 25%). Survey respondents of children with ASD compared to respondents of children without ASD were less likely to have a High School diploma or GED (ASD: 14%, No ASD: 17%). Survey respondents of children with ASD compared to respondents of children without ASD were more likely to have a college degree (ASD: 42%, No ASD: 29%).

Families of children with ASD had significant differences in total household income compared to families of children without ASD[1] (e.g., income over $75,000, ASD: 26%, No ASD: 18%). Families of children with ASD had significant differences in out-of-pocket expenses for their child in the past year compared to families of children without ASD[1] (e.g., expenses over $10,000, ASD: 7%, No ASD: 4%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with ASD compared to Family/Survey Respondents of children without ASD.

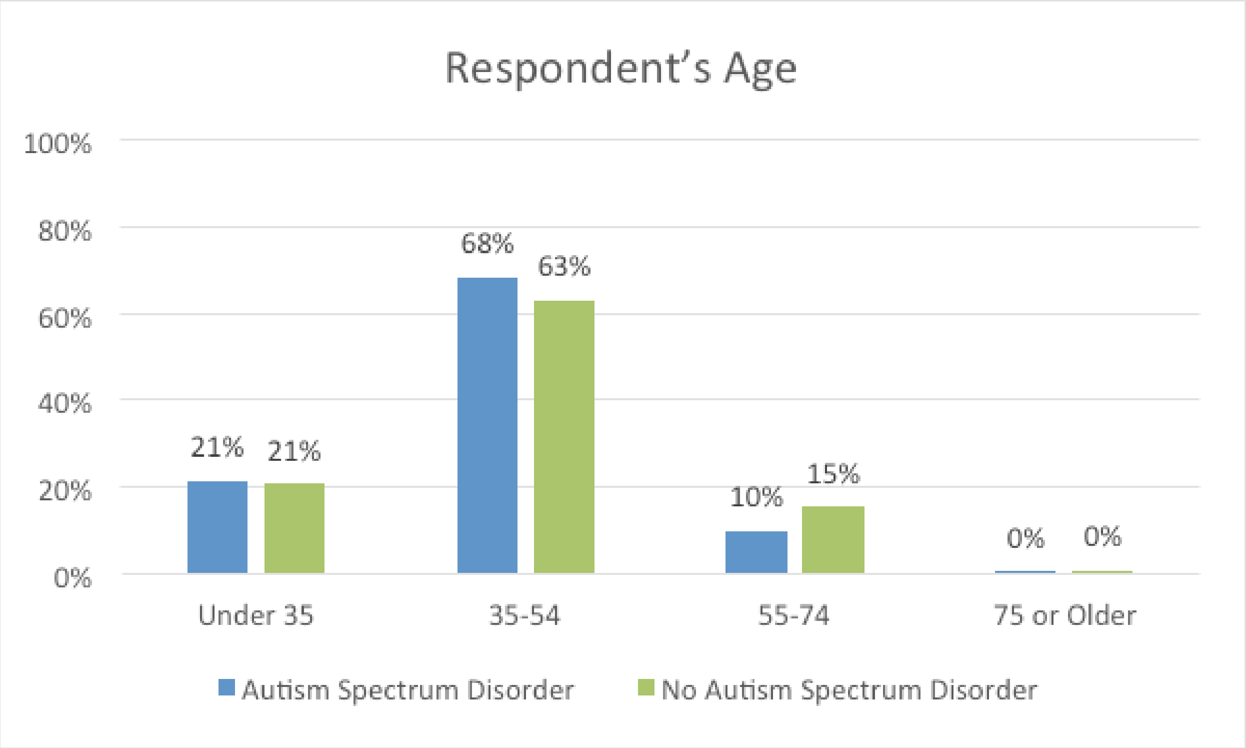

Table IV-12: Respondent's Age by ASD[1]

	Under 35	35–54	55–74	75 or Older	N
ASD	21%	68%	10%	0%	4635
No ASD	21%	63%	15%	0%	2966

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[1] Percentages add up to less than 100% due to missing responses.

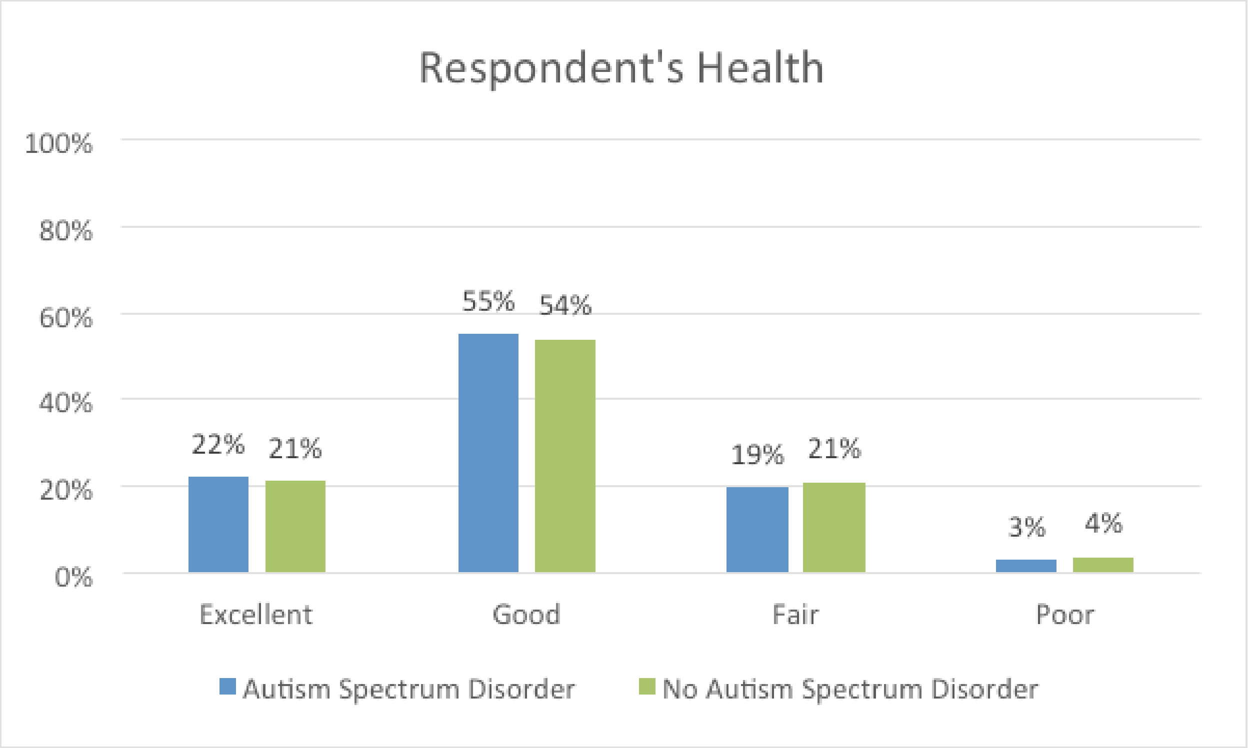

Table IV-13: Respondent's Health by ASD[1]

	Excellent	Good	Fair	Poor	N
ASD	22%	55%	19%	3%	4632
No ASD	21%	54%	21%	4%	2963

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[1] Percentages add up to less than 100% due to missing responses.

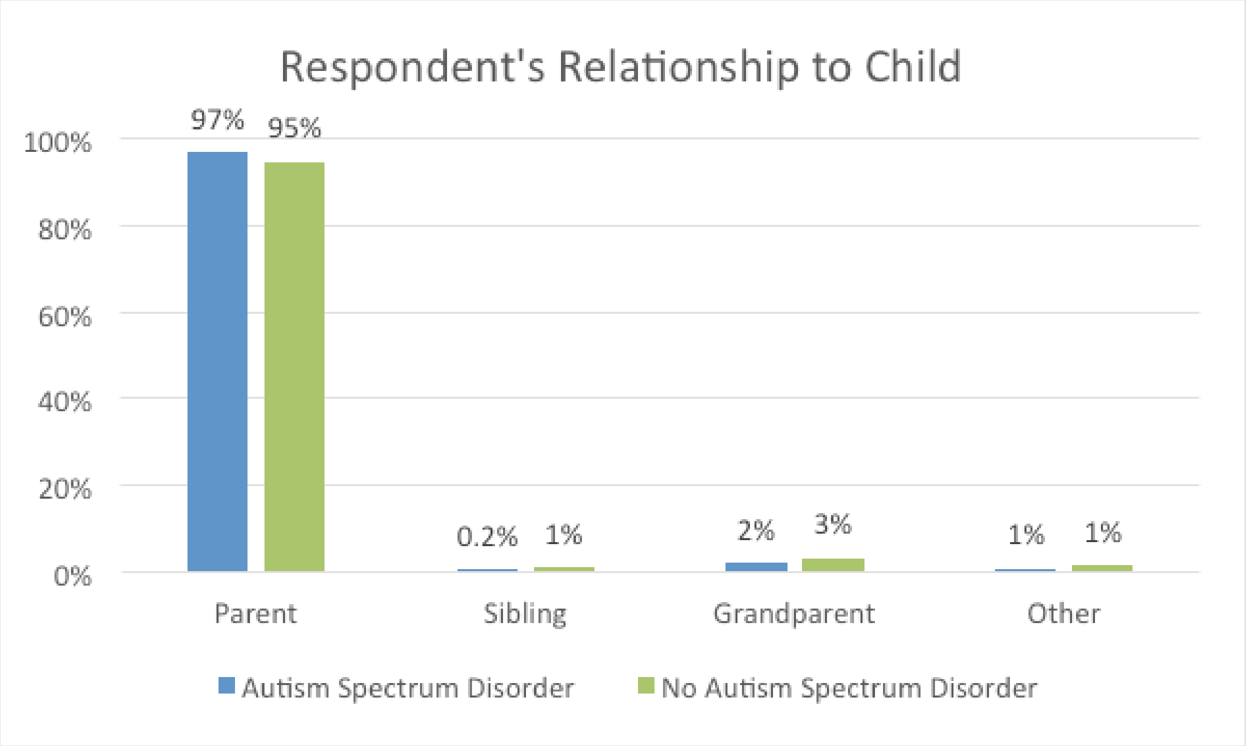

Table IV-14: Respondent's Relationship to Child by ASD

	Parent	Sibling	Grandparent	Other	N
ASD	97%	0.2%	2%	1%	4651
No ASD	95%	1%	3%	1%	2976

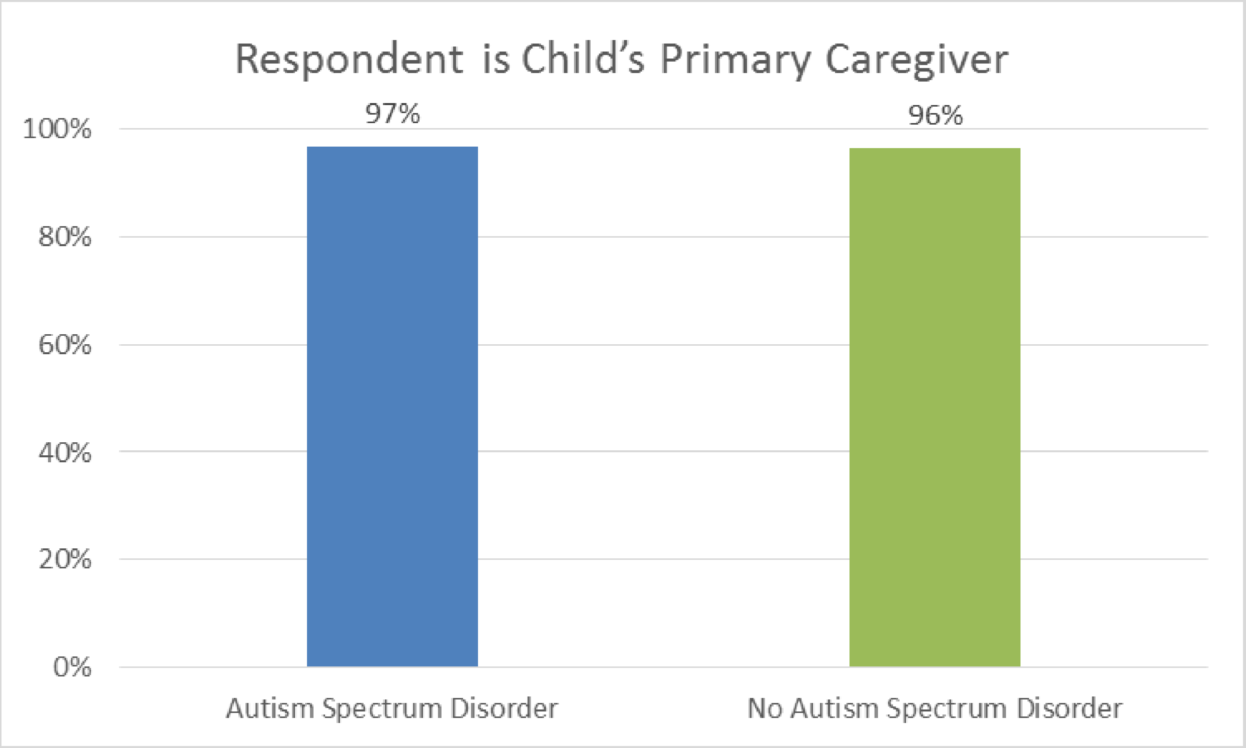

Table IV-15: Respondent is Child's Primary Caregiver by ASD[1]

	Yes	N
ASD	97%	4605
No ASD	96%	2945

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[1] Results were not statistically significant.

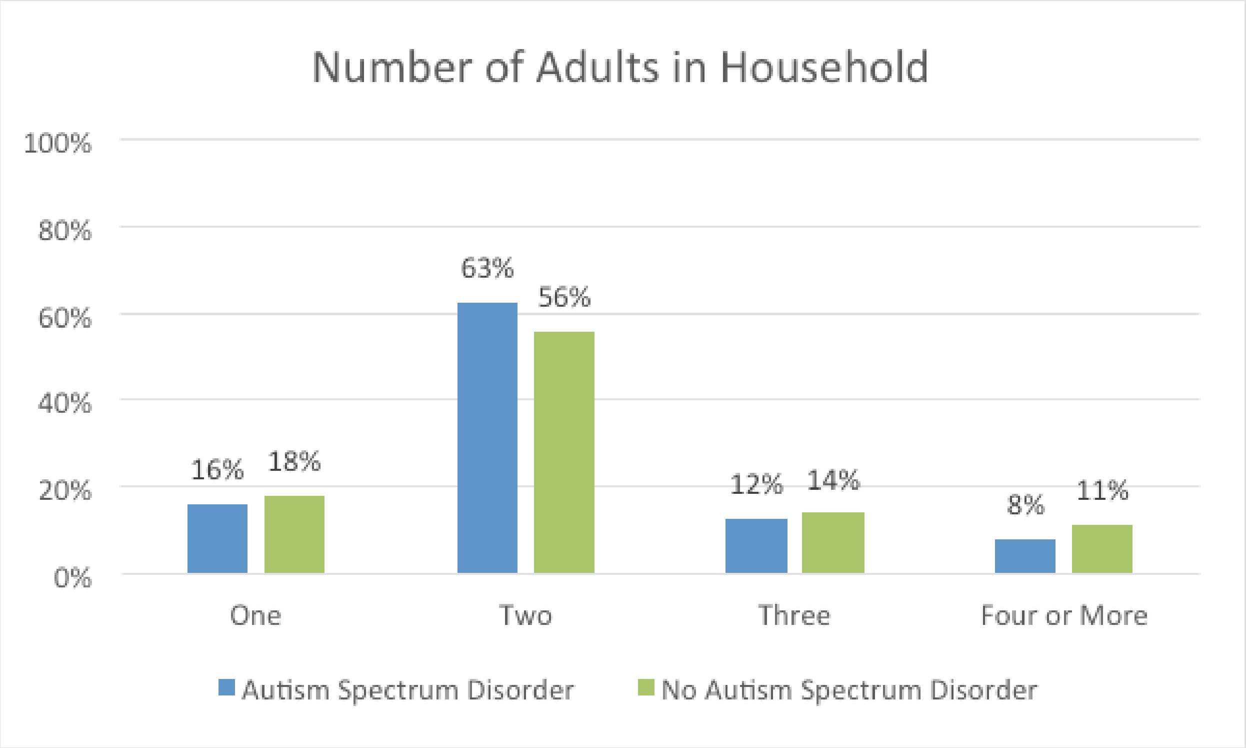

Table IV-16: Number of Adults in Household by ASD[1], [2]

	One	Two	Three	Four or More	N
ASD	16%	63%	12%	8%	4612
No ASD	18%	56%	14%	11%	2949

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[1] Results were not statistically significant.

[2] Percentages add up to less than 100% due to missing responses.

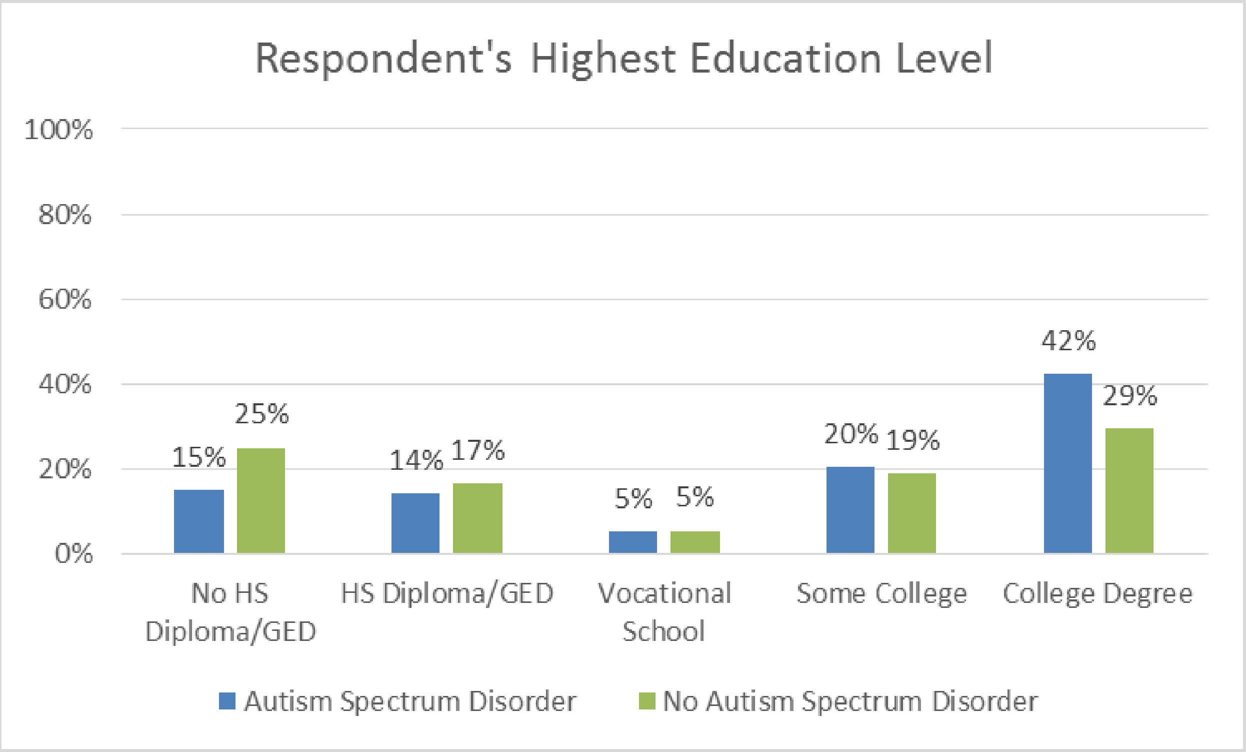

Table IV-17: Respondent's Highest Education Level by ASD[1], [2]

	No HS Diploma/ GED	HS Diploma/ GED	Vocational School	Some College	College Degree	N
ASD	15%	14%	5%	20%	42%	4519
No ASD	25%	17%	5%	19%	29%	2837

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[1] Results for “Vocational School” and “Some College” were not statistically significant.

[2] Percentages add up to less than 100% due to missing responses.

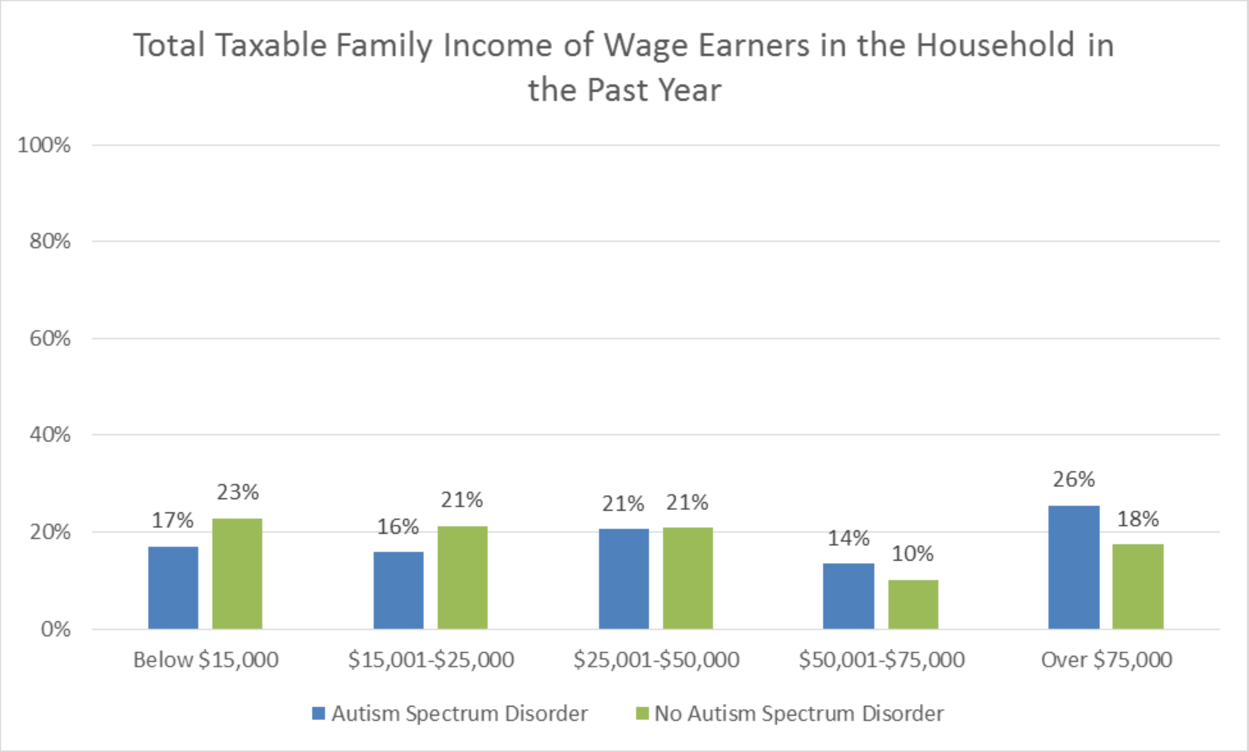

Table IV-18: Total Taxable Family Income of Wage Earners in the Household in the Past Year by ASD[1]

	Below $15,000	$15,001–$25,000	$25,001–$50,000	$50,001–$75,000	Over $75,000	N
ASD	17%	16%	21%	14%	26%	4327
No ASD	23%	21%	21%	10%	18%	2771

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[1] Percentages add up to less than 100% due to missing responses.

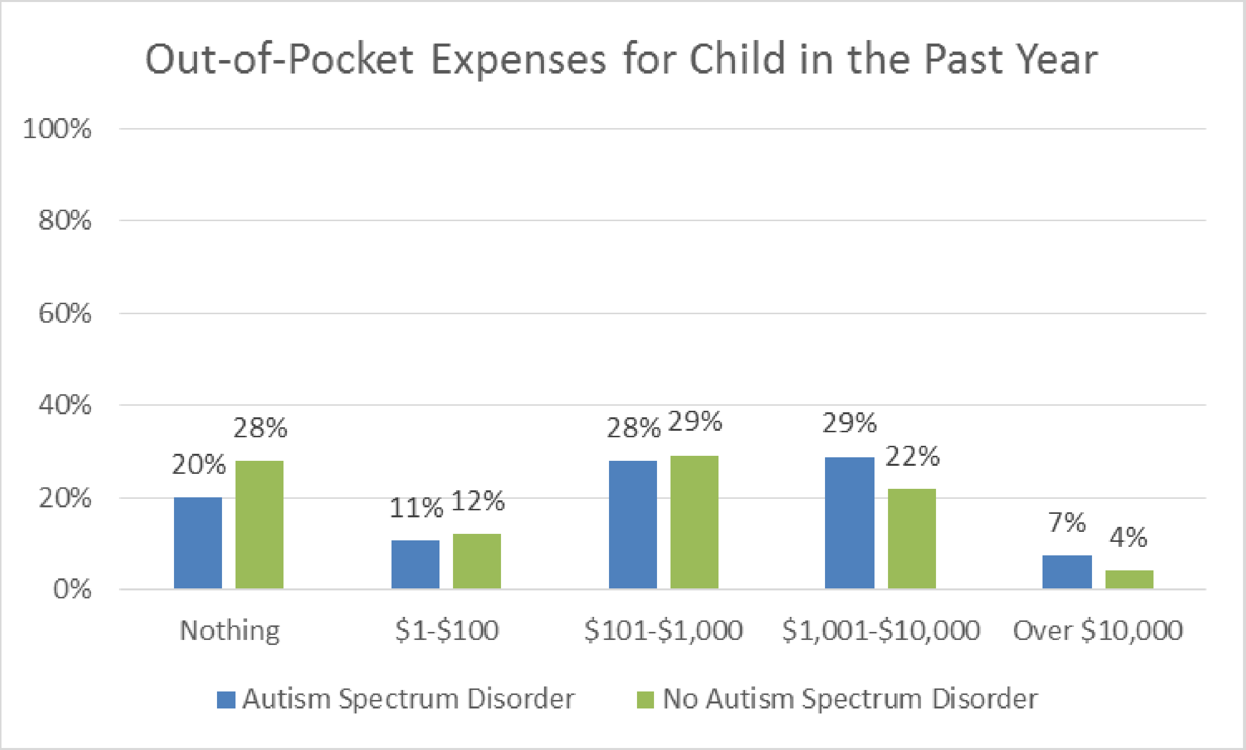

Table IV-19: Out-of-Pocket Expenses for Child in the Past Year by ASD[1]

	Nothing	$1–$100	$101–$1,000	$1,001–$10,000	Over $10,000	N
ASD	20%	11%	28%	29%	7%	4436
No ASD	28%	12%	29%	22%	4%	2853

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[1] Percentages add up to less than 100% due to missing responses.

Services and Supports Received by ASD

The section on Services and Supports Received in the Child Family Survey includes one indicator with seven types of services or supports received. All results are presented here.

Selected Findings on Services and Supports Received

Families of children with ASD were less likely to receive financial support compared to families of children without ASD (ASD: 8%, No ASD: 11%). Families of children with ASD were less likely to receive out-of-home respite care compared to families of children without ASD (ASD: 25%, No ASD: 30%). Children with ASD were more likely to receive early intervention compared to children without ASD (ASD: 17%, No ASD: 14%). Families of children with ASD were less likely to receive transportation assistance compared to families of children without ASD (ASD: 19%, No ASD: 26%). Families of children with ASD were less likely to receive Social Security benefits compared to families of children without ASD (ASD: 37%, No ASD: 47%).

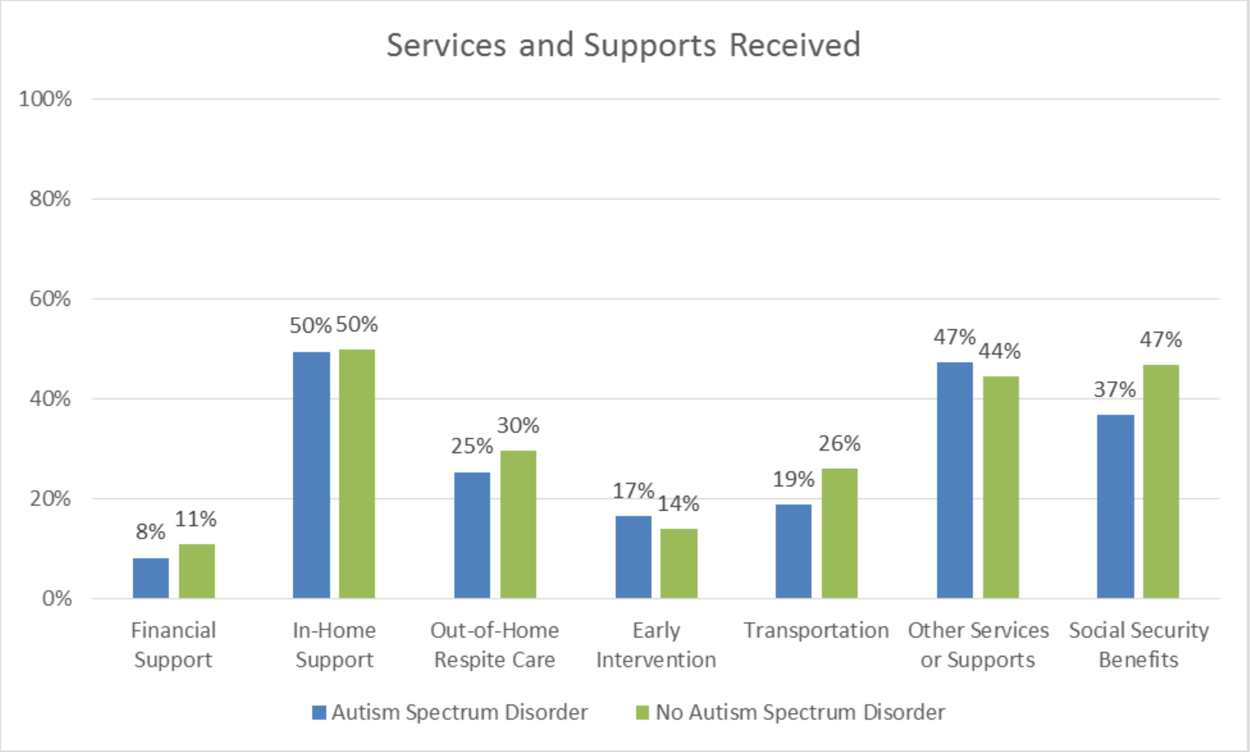

Table IV-20: Services and Supports Received From Regional Center by ASD[1],[2]

	Financial Support	In-Home Support	Out-of-Home Respite Care	Early Intervention	Transport-ation	Other Services or Supports	Social Security Benefits
ASD	8%	50%	25%	17%	19%	47%	37%
No ASD	11%	50%	30%	14%	26%	44%	47%

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[1] Results for “In-Home Support” and “Other Services or Supports” were not statistically significant.

[2] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

Information and Planning by ASD

The section on Information and Planning in the Child Family Survey includes indicators about: *Available Services and Supports, Planning with Service Coordinator,* and *Child's Individual Program Plan (IPP)*. Results that were statistically significant are presented here. The complete list of results for children with ASD is located in Appendix D.

Selected Findings on Information and Planning

Families of children with ASD had significant differences in receiving information about available services and supports compared to families of children without ASD[1] (e.g., always receives information about available services and supports, ASD: 18%, No ASD: 20%). Families of children with ASD had significant differences in receiving information about services and supports from the service coordinator compared to families of children without ASD[1] (e.g., always receives information about services and supports from the service coordinator, ASD: 29%, No ASD: 31%). Families of children with ASD had significant differences in service coordinator respecting the family's choices and opinions compared to families of children without ASD[1] (e.g., service coordinator always respects the family's choices and opinions, ASD: 55%, No ASD: 57%). Families of children with ASD had significant differences in service coordinator telling family about other eligible public services compared to families of children without ASD[1] (e.g., service coordinator always telling family about other eligible public services, ASD: 24%, No ASD: 29%). Children with ASD were more likely to have an IPP compared to children without ASD (ASD: 70%, No ASD: 61%). Children with ASD were less likely to have an IPP that includes all services and supports that the family wants compared to children without ASD (ASD: 56%, No ASD: 62%). Families of children with ASD were less likely to receive all services the family needs compared to families of children without ASD (ASD: 49%, No ASD: 55%). Families of children with ASD were less likely to discuss

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with ASD compared to Family/Survey Respondents of children without ASD.

how to handle emergencies related to their child at the last IPP meeting compared to families of children without ASD (ASD: 41%, No ASD: 48%).

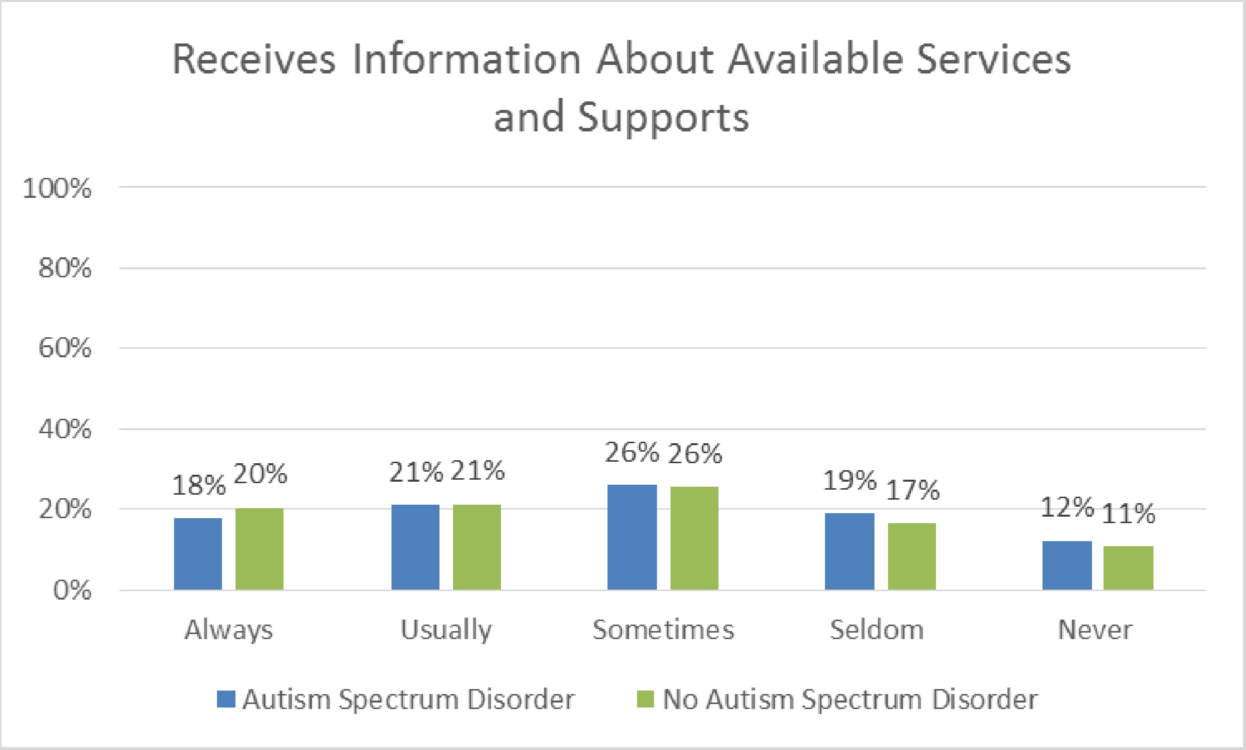

Table IV-21: Do you receive information about the services and supports that are available to your child and family?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	18%	21%	26%	19%	12%	4495
No ASD	20%	21%	26%	17%	11%	2835

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

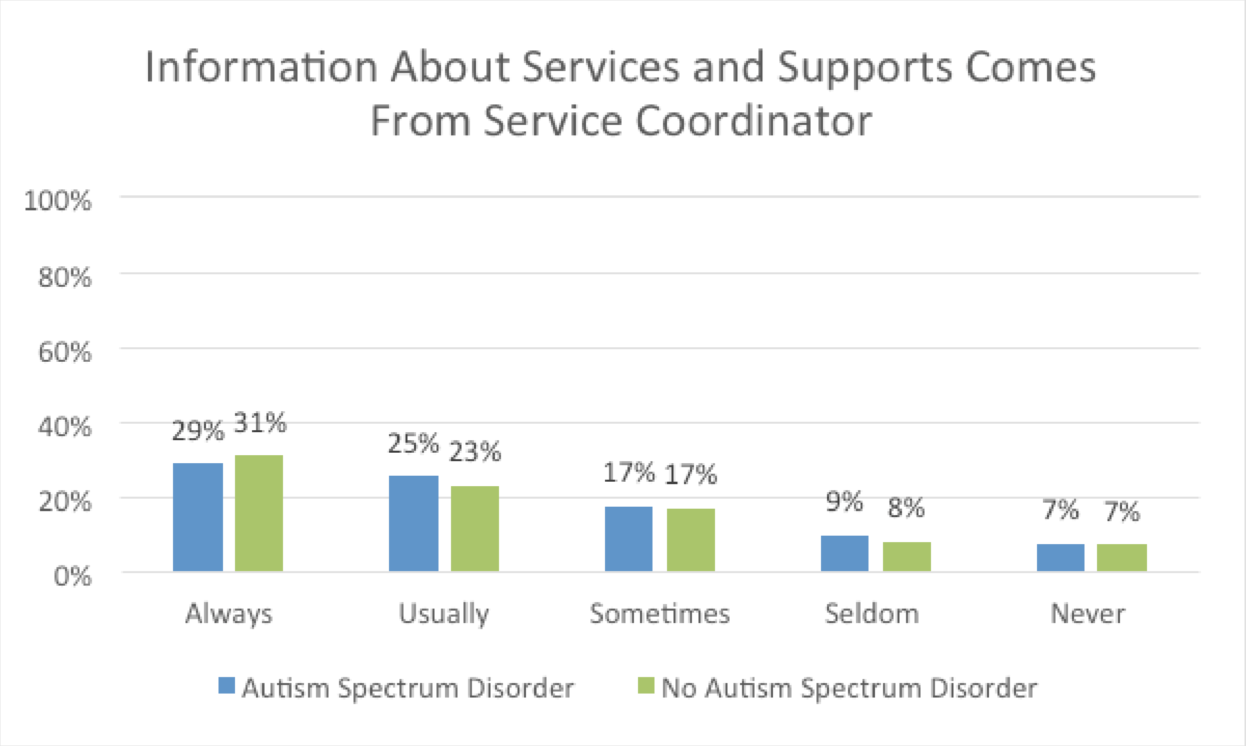

Table IV-22: Does the information you receive primarily come from your service coordinator (as opposed to family, friends, and others outside of state services)?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	29%	25%	17%	9%	7%	3871
No ASD	31%	23%	17%	8%	7%	2476

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

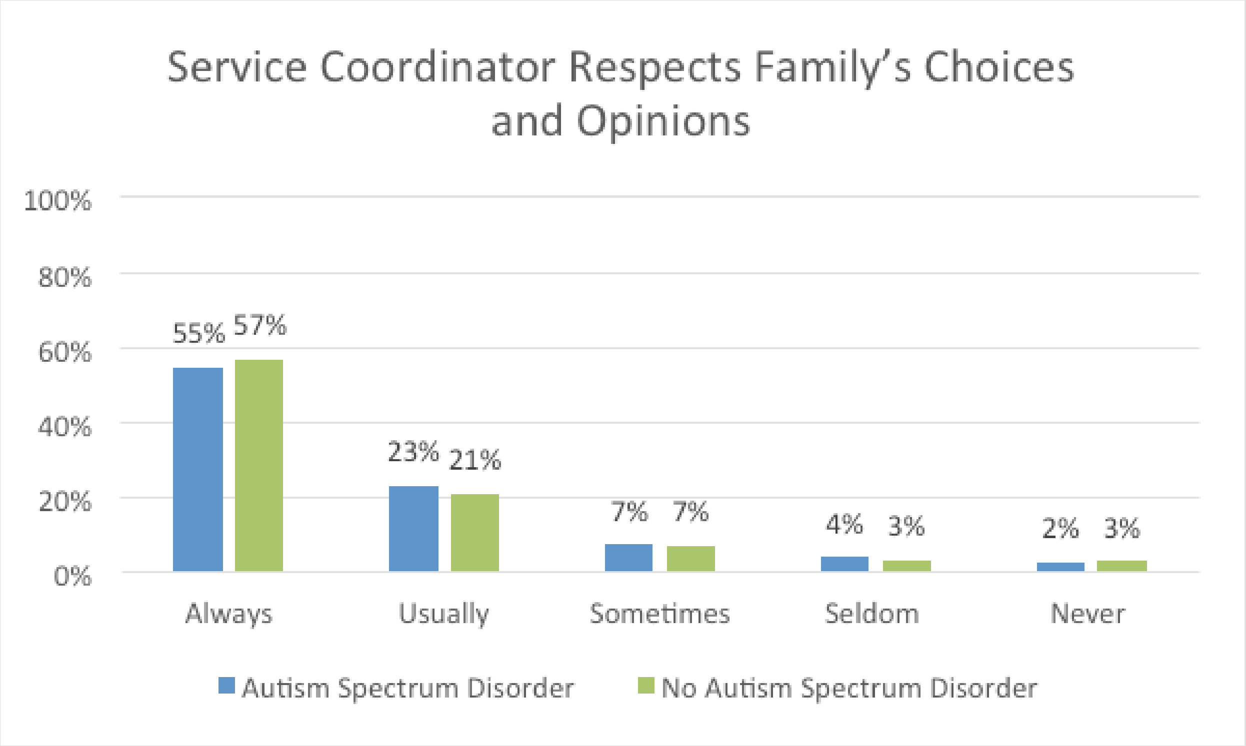

Table IV-23: Does the service coordinator respect your family's choices and opinions?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	55%	23%	7%	4%	2%	4237
No ASD	57%	21%	7%	3%	3%	2670

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[1] Percentages add up to less than 100% due to missing responses, responses of "Don't Know" or "Do Not Apply."

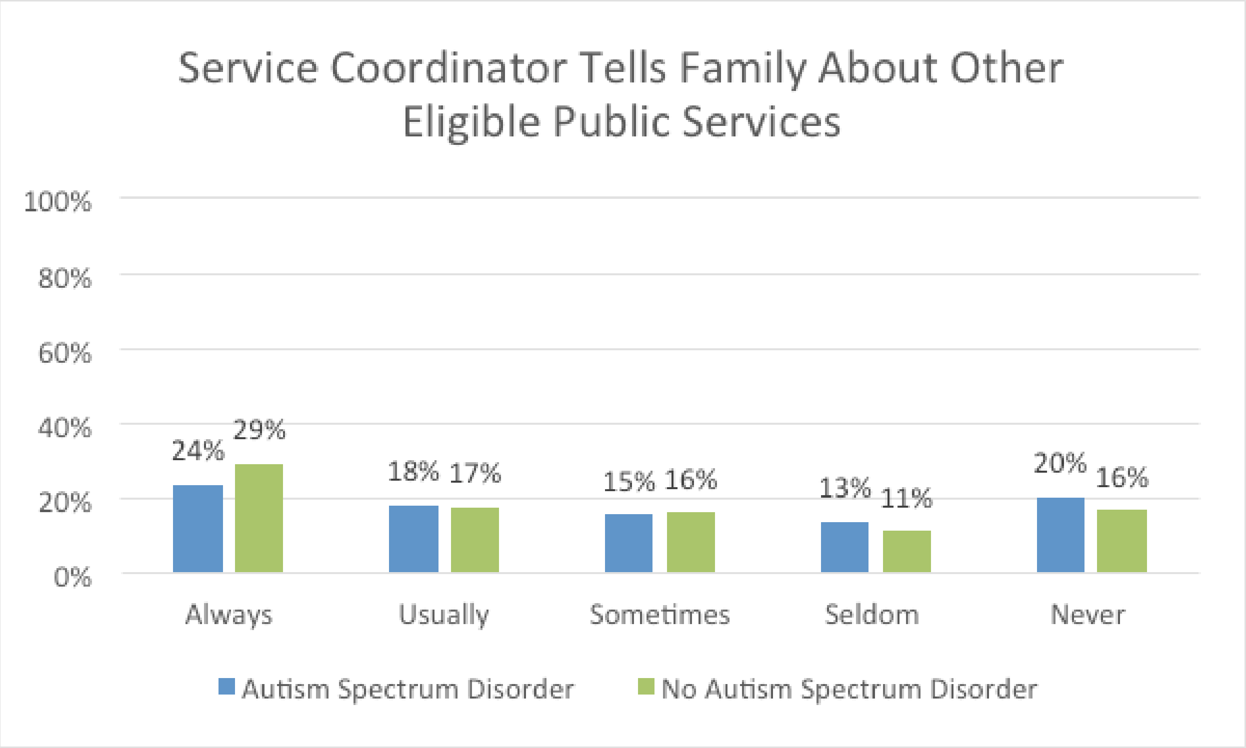

Table IV-24: Does your service coordinator tell you about other public services that you are eligible for (e.g. food stamps, Early Period Screening Diagnosis and Treatment [EPSDT], Supplemental Security Income [SSI], housing subsides, etc.)?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	24%	18%	15%	13%	20%	4204
No ASD	29%	17%	16%	11%	16%	2680

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

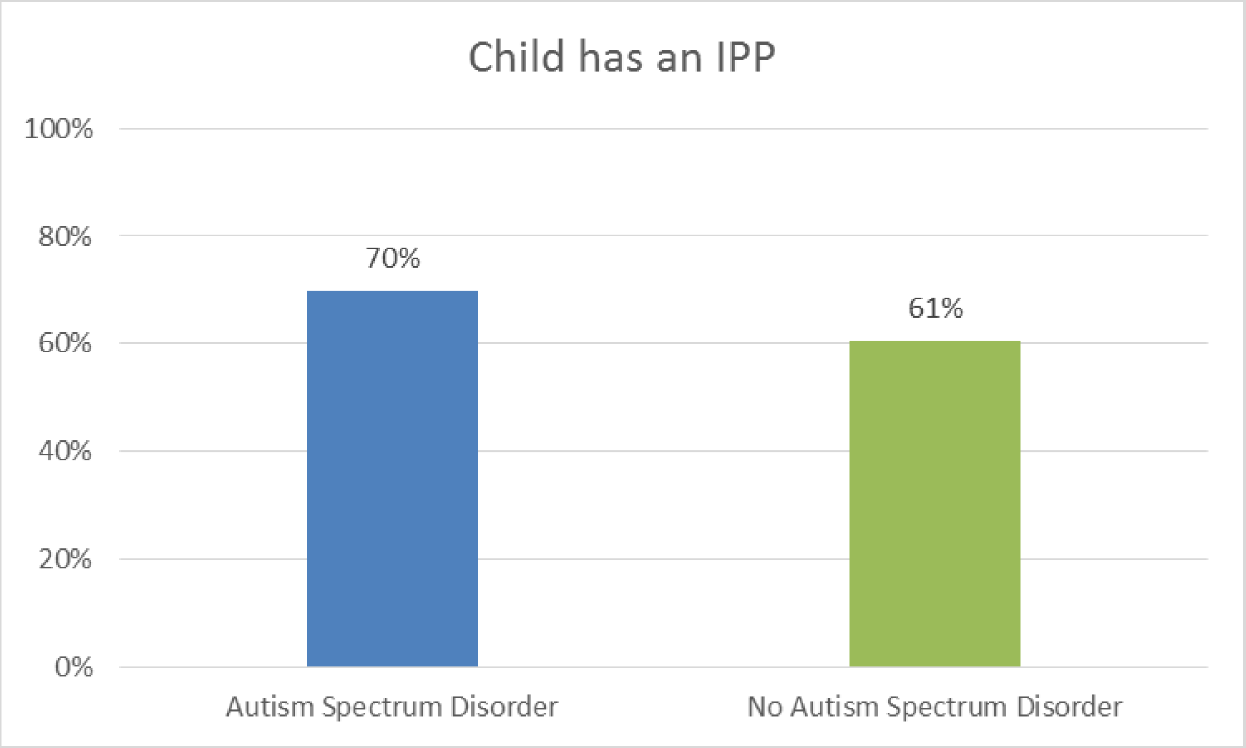

Table IV-25: Does your child have an IPP?

	Yes	N
ASD	70%	3963
No ASD	61%	2369

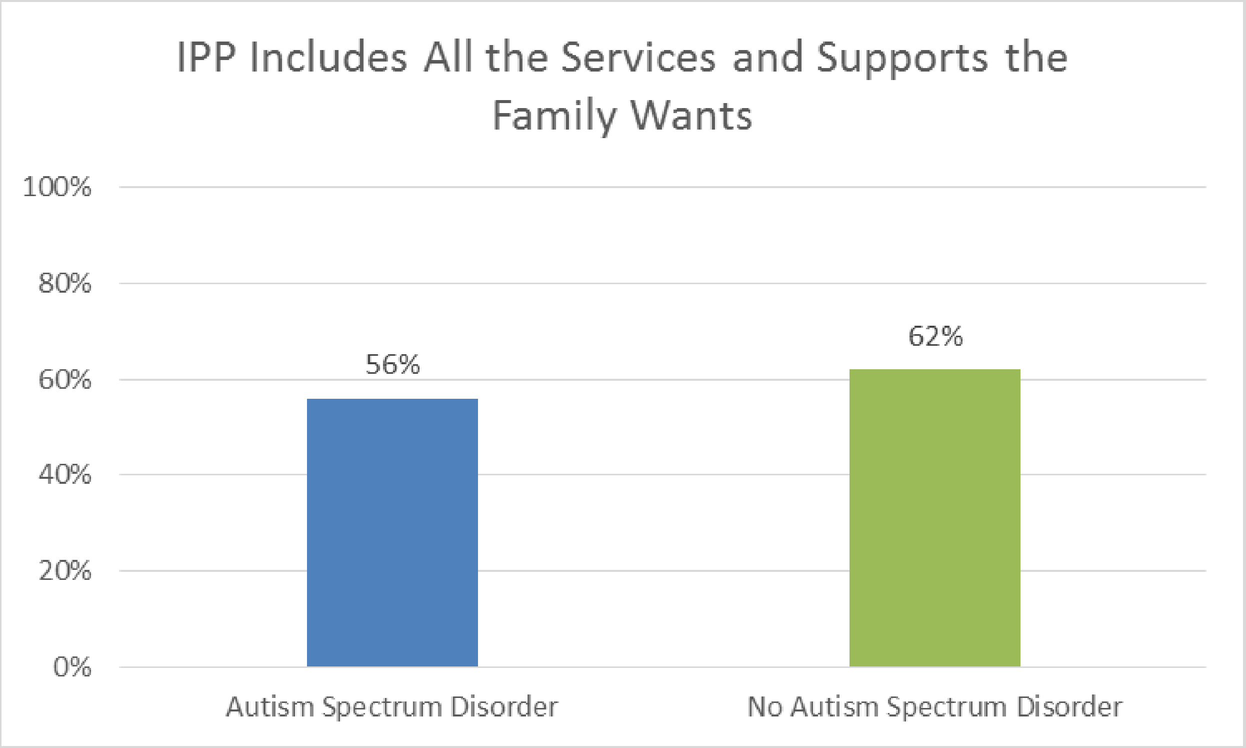

Table IV-26: Does the IPP include all the services and supports your family wants?

	Yes	N
ASD	56%	2766
No ASD	62%	1516

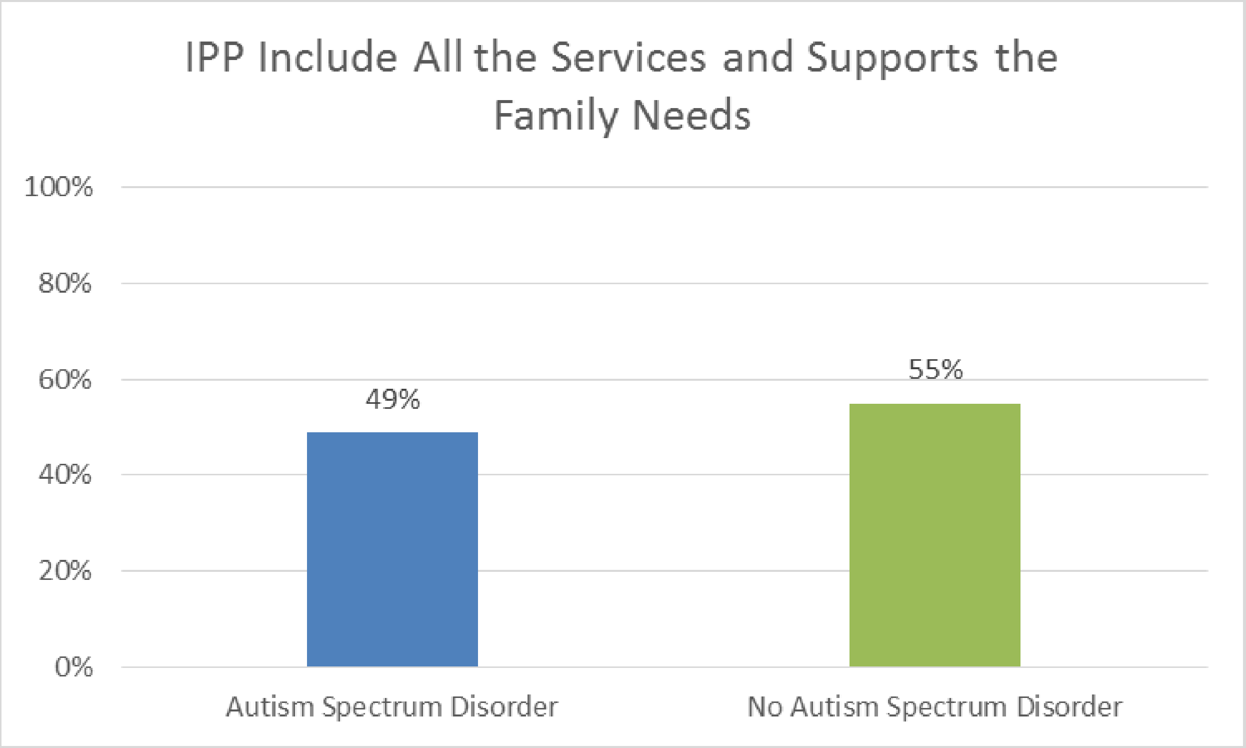

Table IV-27 Does the IPP include all the services and supports your family needs?

	Yes	N
ASD	49%	2704
No ASD	55%	1455

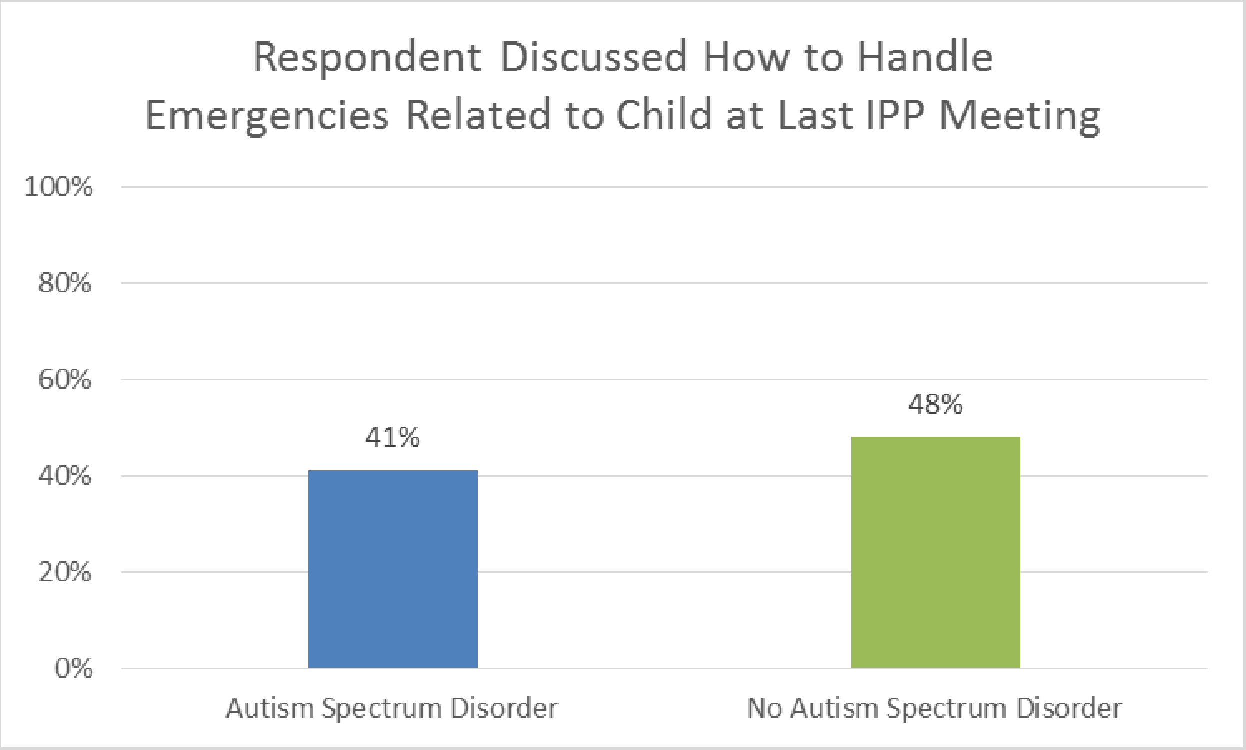

Table IV-28: Did you discuss how to handle emergencies related to your child at the last IPP meeting?[1]

	Yes	N
ASD	41%	2673
No ASD	48%	1515

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know.”

Access and Delivery of Services and Supports by ASD

The section on Access and Delivery in the Child Family Survey includes indicators about: *Accessibility of Support Workers and Service Coordinators, Accessibility of Supports and Services, Communication with Workers,* and *Delivery of Specific Services*. Results that were statistically significant are presented here. The complete list of results for children with ASD is located in Appendix D.

Selected Findings on Access and Delivery

Families of children with ASD had significant differences in ability to contact support workers when needed compared to families of children without ASD[1] (e.g., always able to contact support workers when needed, ASD: 39%, No ASD: 43%). Families of children with ASD had significant differences in ability to contact service coordinator when needed compared to families of children without ASD[1] (e.g., always able to contact service coordinator when needed, ASD: 41%, No ASD: 44%). Families of children with ASD had significant differences in services and supports being available at times they are needed compared to families of children without ASD[1] (e.g., services and supports are always available at times they are needed, ASD: 25%, No ASD: 30%). Families of children with ASD had significant differences in services and supports being available reasonably close to home compared to families of children without ASD[1] (e.g., services and supports are always available reasonably close to home, ASD: 27%, No ASD: 30%). Families of children with ASD had significant differences in services and supports changing when child’s needs change compared to families of children without ASD[1] (e.g., services and supports always change when child’s needs change, ASD: 24%, No ASD: 27%). Families of children with ASD had significant differences in their child having access to special equipment or accommodations needed compared to families of children without ASD[1] (e.g., always have access to special equipment or accommodations needed, ASD: 10%, No ASD: 22%). Families of children with ASD had significant differences in support workers having the right training to meet their child’s

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with ASD compared to Family/Survey Respondents of children without ASD.

needs compared to families of children without ASD[1] (e.g., support workers always have the right training to meet their child’s needs, ASD: 32%, No ASD: 37%). Families of children with ASD had significant differences in support workers arriving at the home on time and when scheduled compared to families of children without ASD[1] (e.g., support workers always arrive at the home on time and when scheduled, ASD: 42%, No ASD: 48%). Families of children with ASD were less likely to be satisfied with quality of child’s health care providers compared to families of children without ASD (ASD: 81%, No ASD: 88%). Families of children with ASD were less likely to have access to necessary medications for their child compared to families of children without ASD (ASD: 73%, No ASD: 83%). Families of children with ASD were less likely to be satisfied with quality of child’s mental health providers compared to families of children without ASD (ASD: 73%, No ASD: 79%). Families of children with ASD were less likely to be satisfied with quality of child’s respite care providers compared to families of children without ASD (ASD: 49%, No ASD: 83%). Families of children with ASD were more likely to need other services that are not currently offered or available compared to families of children without ASD (ASD: 39%, No ASD: 33%).

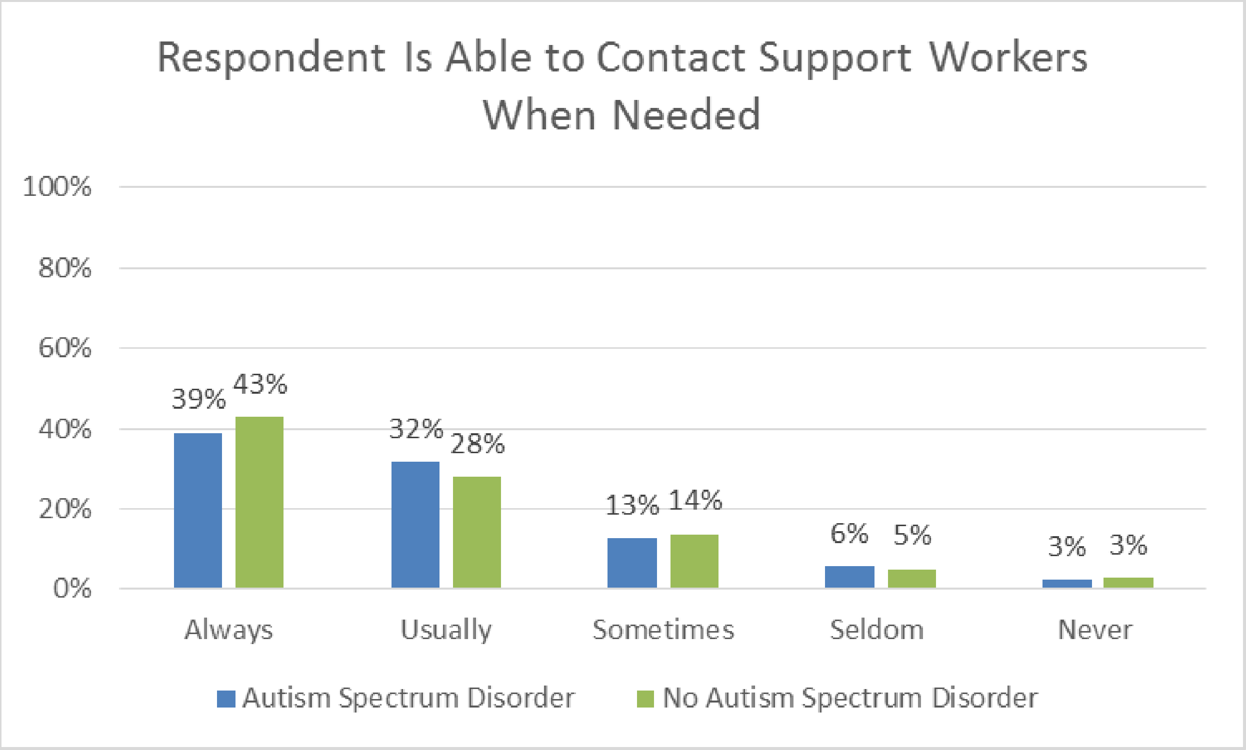

Table IV-29: Are you able to contact your support workers when you need to?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	39%	32%	13%	6%	3%	4280
No ASD	43%	28%	14%	5%	3%	2759

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

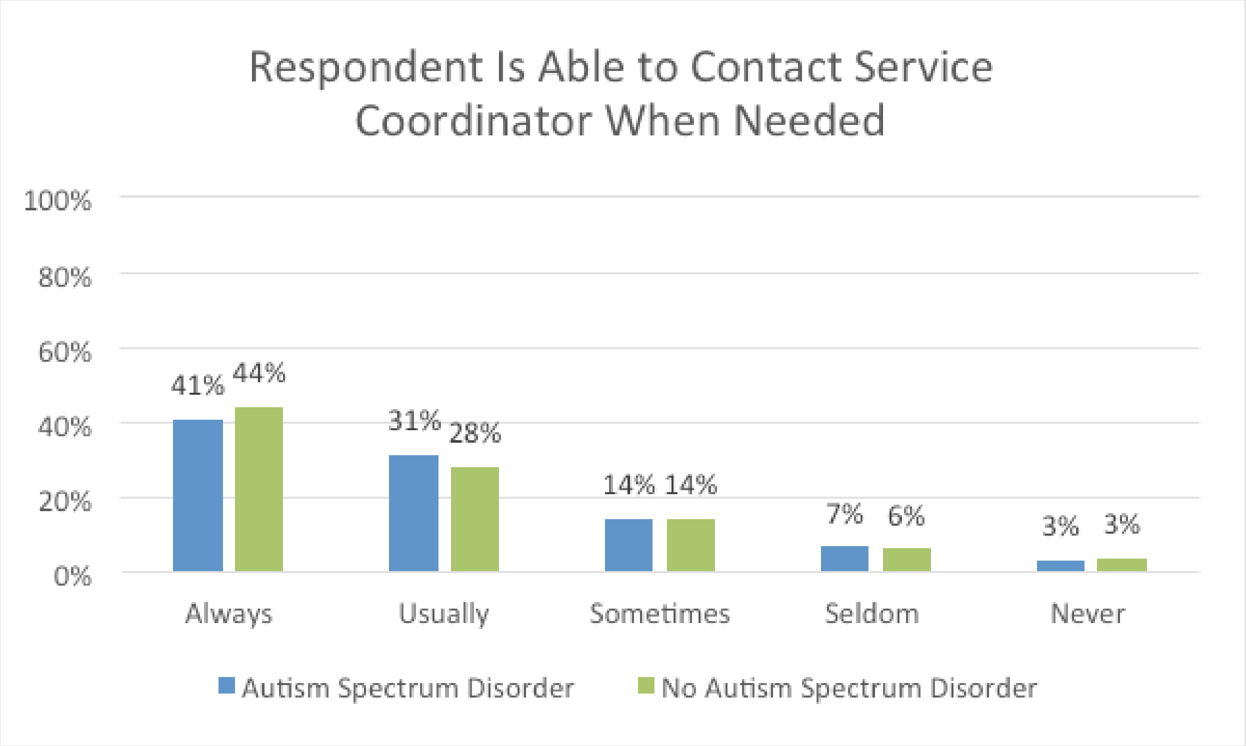

Table IV-30: Are you able to contact service coordinator when you need to?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	41%	31%	14%	7%	3%	4447
No ASD	44%	28%	14%	6%	3%	2841

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

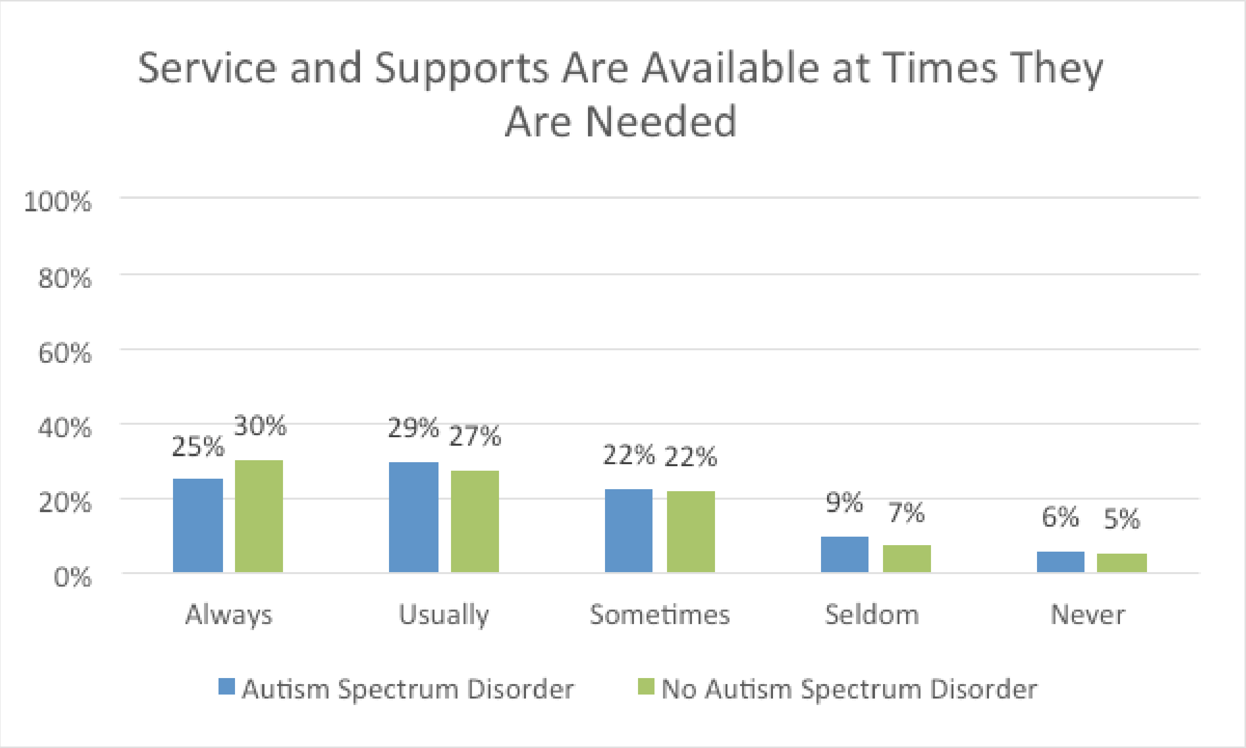

Table IV-31: Are services and supports available when you need them?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	25%	29%	22%	9%	6%	4258
No ASD	30%	27%	22%	7%	5%	2720

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

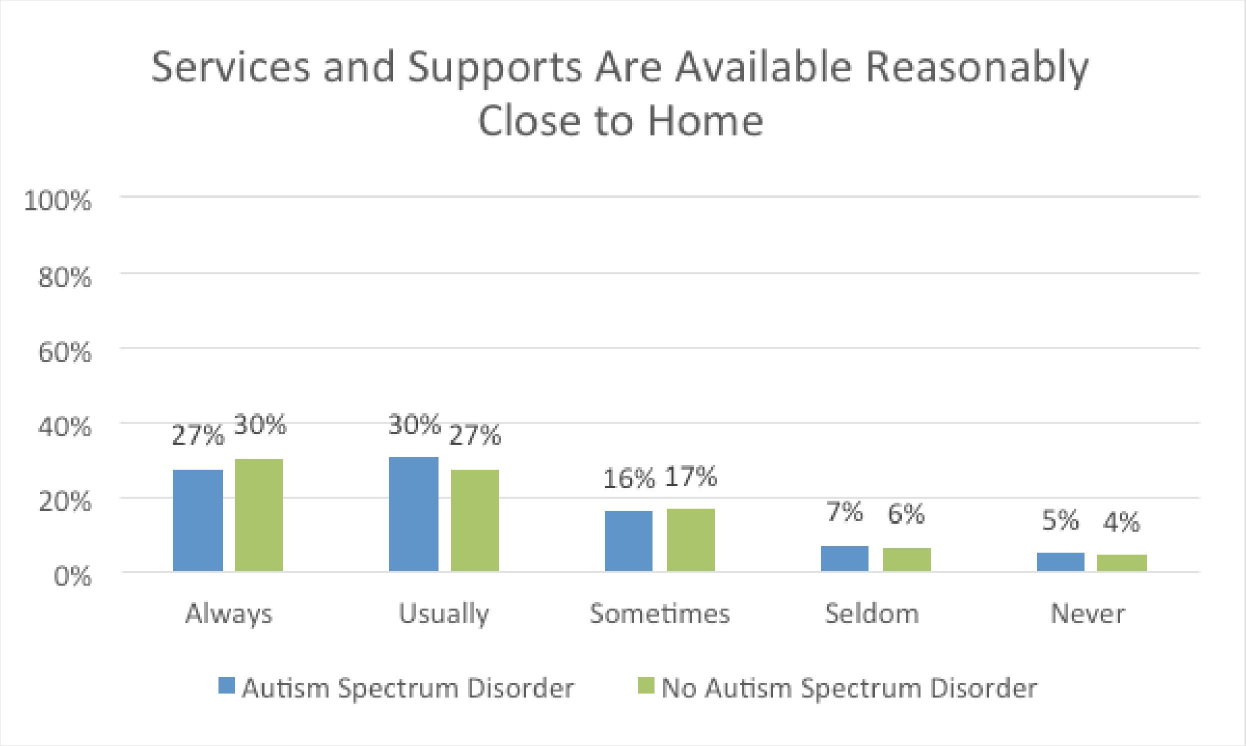

Table IV-32: Are services and supports available within a reasonable distance from your home?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	27%	30%	16%	7%	5%	3970
No ASD	30%	27%	17%	6%	4%	2520

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

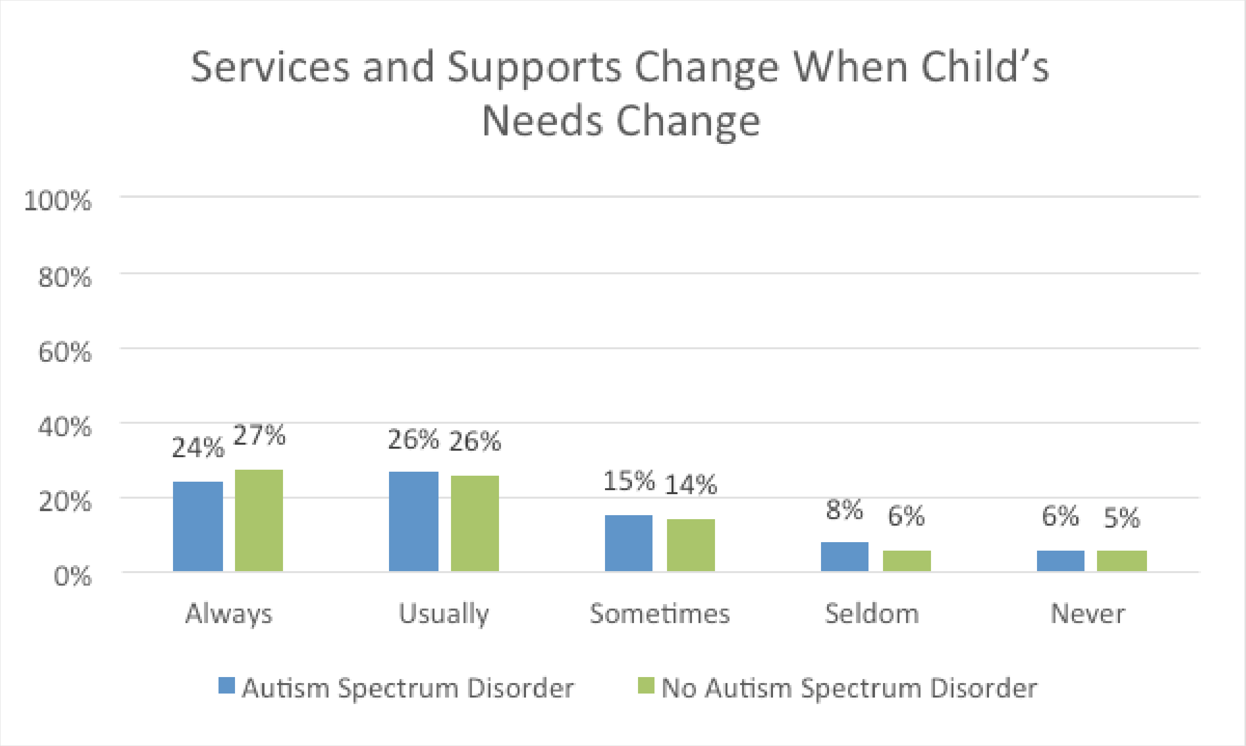

Table IV-33: Do the services and supports change when your child's needs change?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	24%	26%	15%	8%	6%	3670
No ASD	27%	26%	14%	6%	5%	2320

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[1] Percentages add up to less than 100% due to missing responses, responses of "Don't Know" or "Do Not Apply."

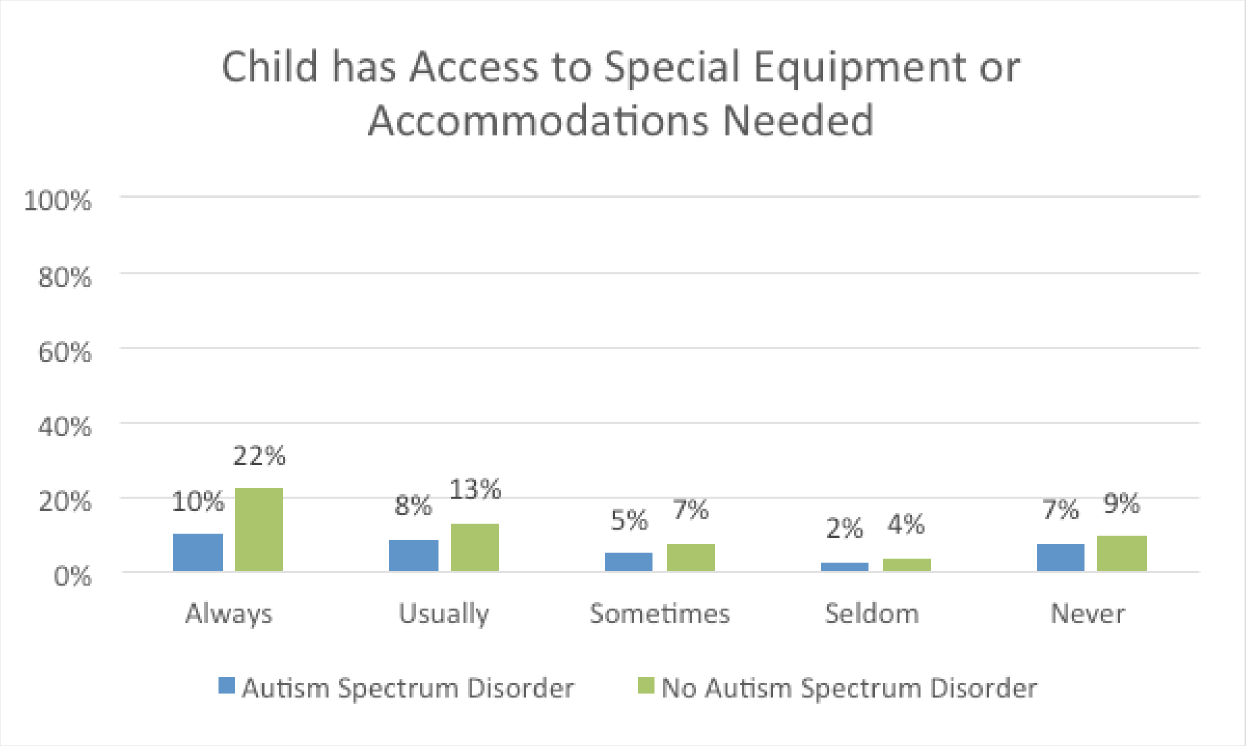

Table IV-34: Does your child have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	10%	8%	5%	2%	7%	1516
No ASD	22%	13%	7%	4%	9%	1646

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

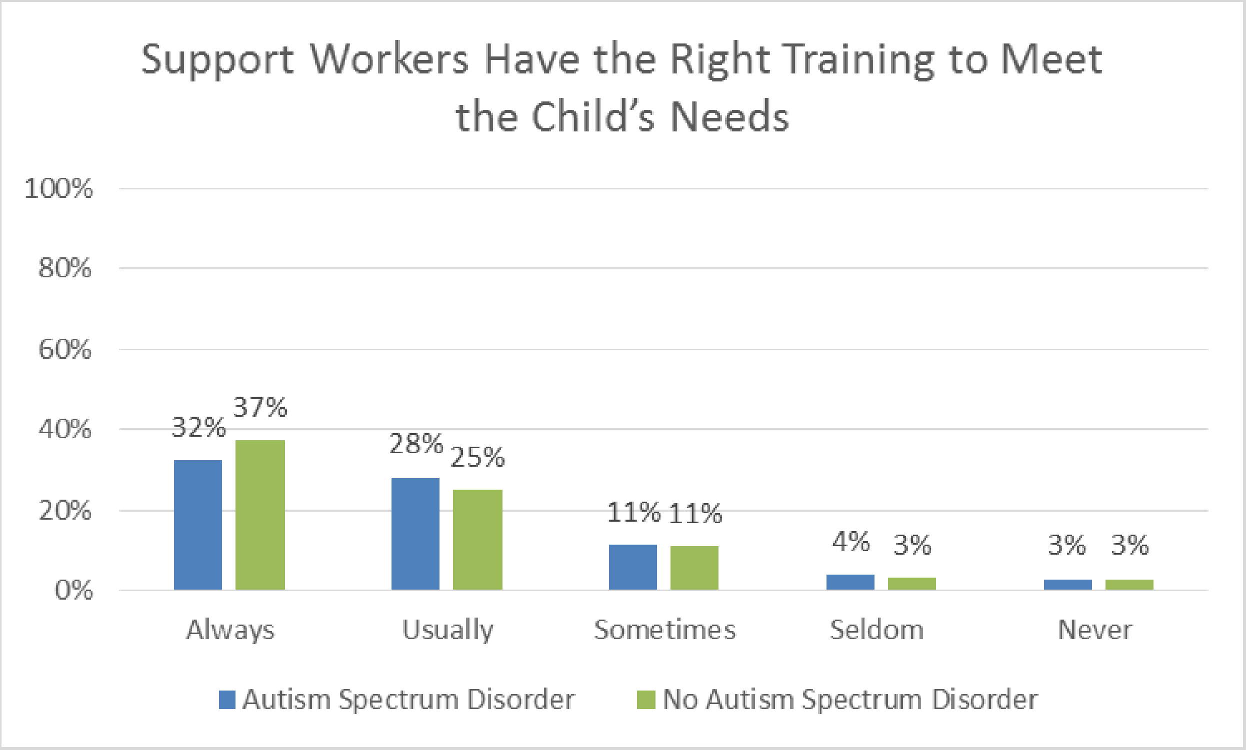

Table IV-35: Do the support workers have the right training to meet your child's needs?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	32%	28%	11%	4%	3%	3650
No ASD	37%	25%	11%	3%	3%	2355

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[1] Percentages add up to less than 100% due to missing responses, responses of "Don't Know" or "Do Not Apply."

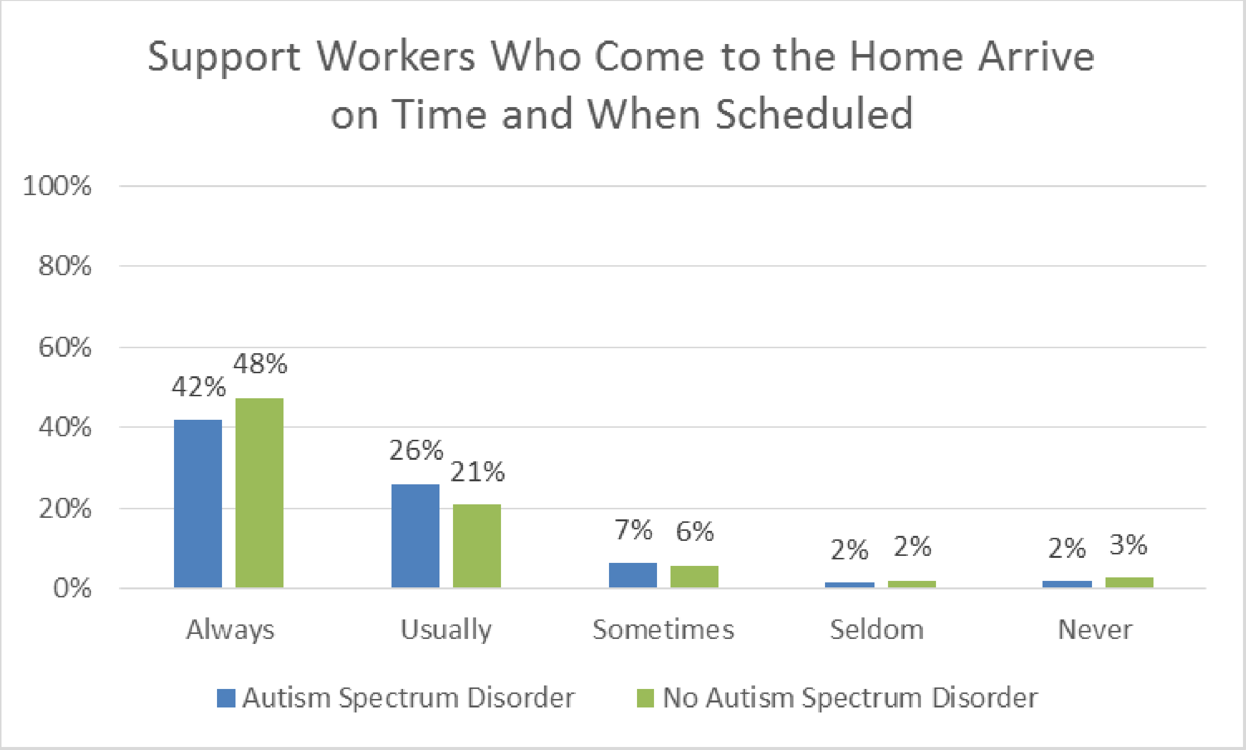

Table IV-36: Do the support workers who come to your home arrive on time and when scheduled?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	42%	26%	7%	2%	2%	3643
No ASD	48%	21%	6%	2%	3%	2352

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

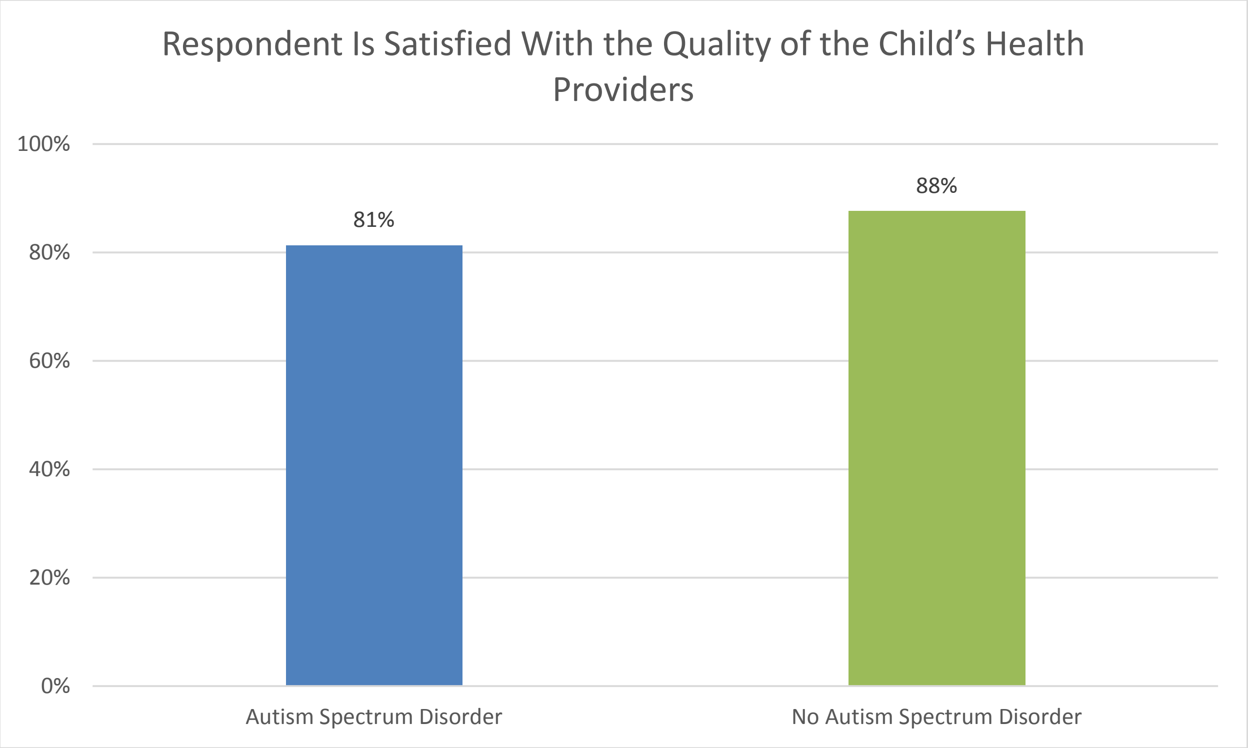

Table IV-37: If you have access to health services for your child, are you satisfied with the quality of these providers?

	Yes	N
ASD	81%	3512
No ASD	88%	2381

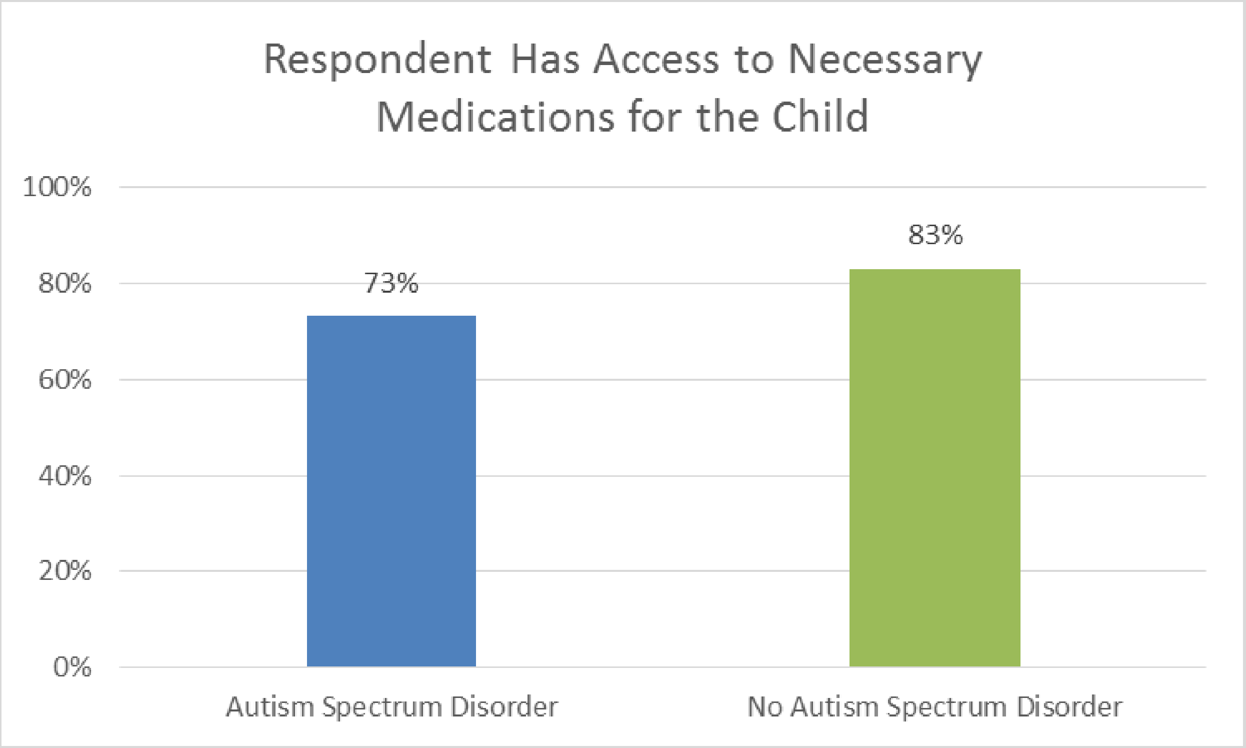

Table IV-38: Are you able to get medications needed for your child?

	Yes	N
ASD	73%	3616
No ASD	83%	2585

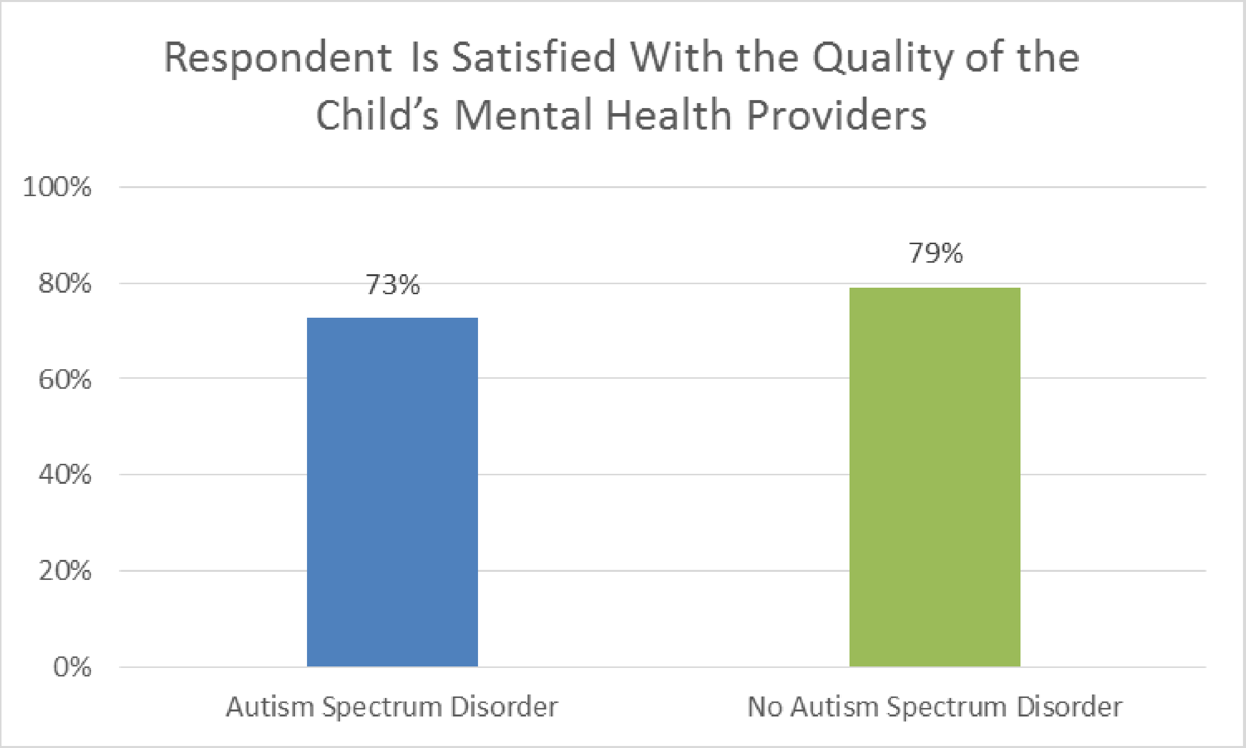

Table IV-39: If you have access to mental health services for your child, are you satisfied with the quality of these providers?

	Yes	N
ASD	73%	2787
No ASD	79%	1594

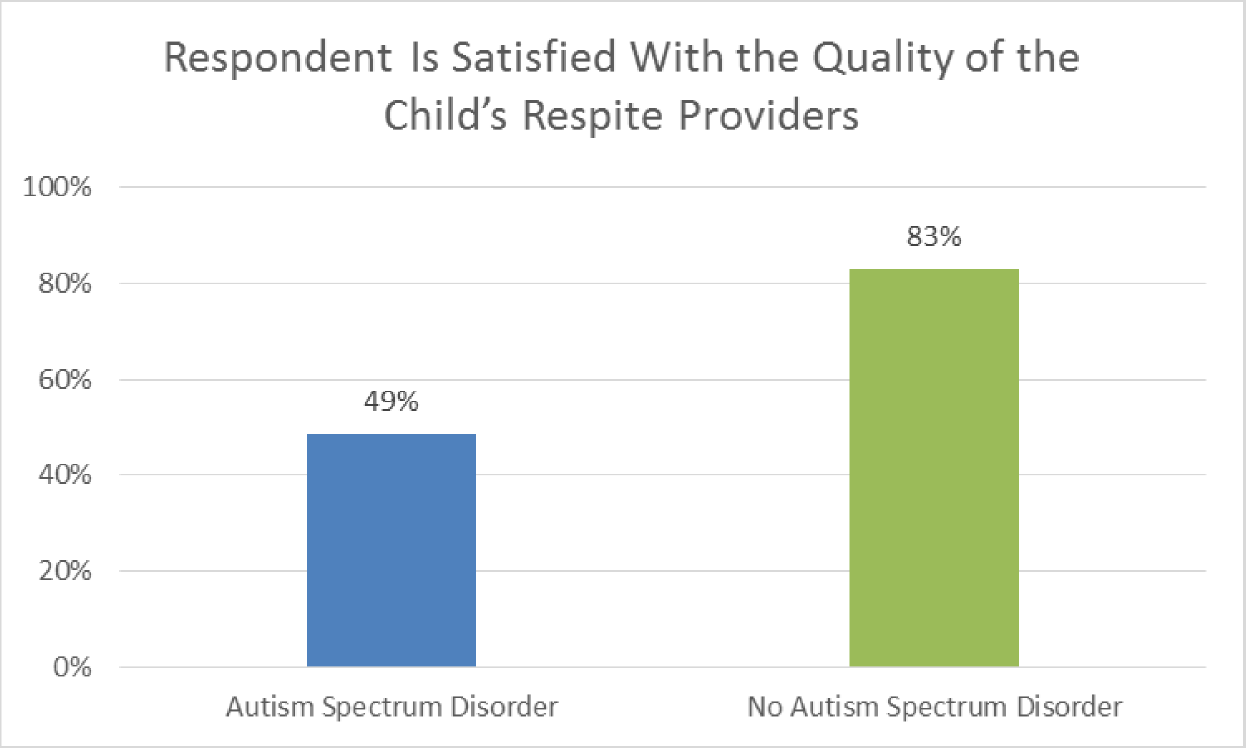

Table IV-40: If you have access to needed respite services, are you satisfied with the quality of these providers?

	Yes	N
ASD	49%	3468
No ASD	83%	2327

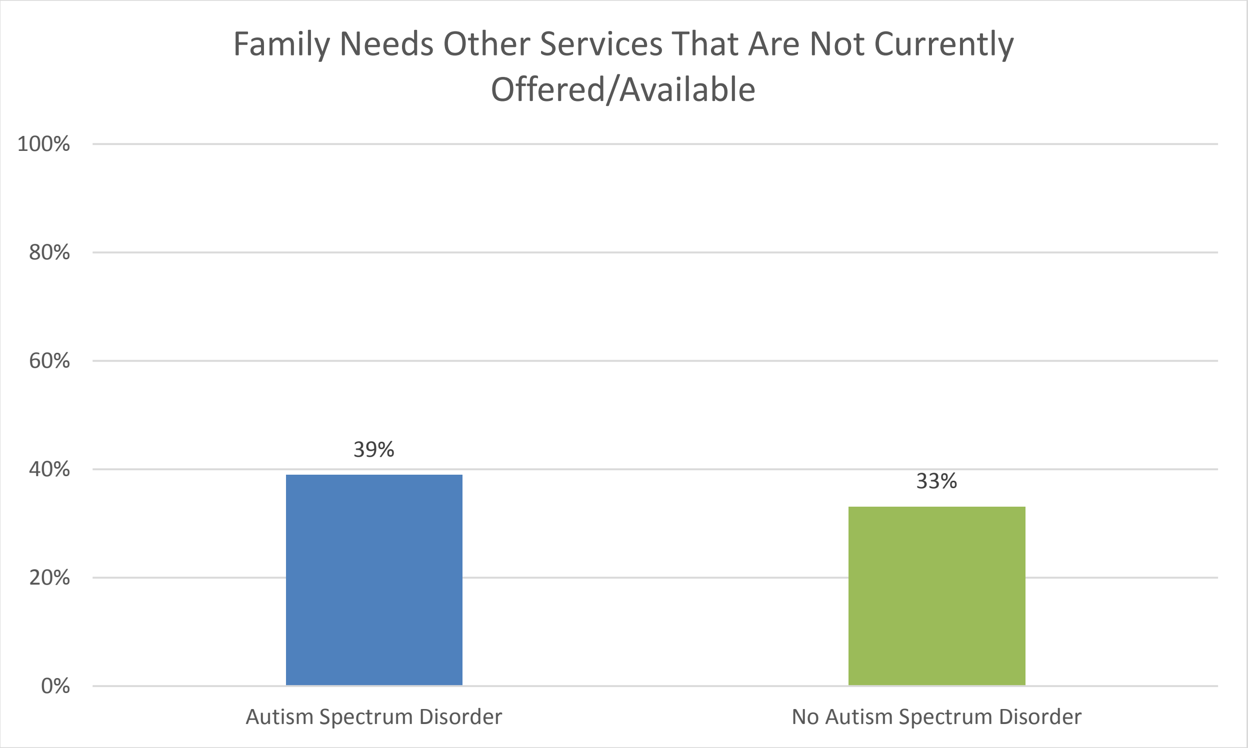

Table IV-41: Are there other services that your family needs that are not currently offered or available?

	Yes	N
ASD	39%	2763
No ASD	33%	1683

Choice and Control by ASD

The section on Choice and Control in the Child Family Survey includes indicators about: *Choosing Provider Agencies, Choosing Support Workers,* and *Control over Management of Money Spent on Child*. Results that were statistically significant are presented here. The complete list of results for children with ASD is located in Appendix D.

Selected Findings on Choice and Control

Families of children with ASD had significant differences in ability to choose a different provider agency if desired compared to families of children without ASD[1] (e.g., always able to choose a different provider agency if desired, ASD: 21%, No ASD: 23%). Families of children with ASD had significant differences in ability to choose individual support workers who work with the family compared to families of children without ASD[1] (e.g., always able to choose individual support workers who work with the family, ASD: 21%, No ASD: 25%). Families of children with ASD had significant differences in ability to choose different support workers if desired compared to families of children without ASD[1] (e.g., always able to choose different support workers if desired, ASD: 22%, No ASD: 25%). Families of children with ASD were less likely to choose the service coordinator compared to families of children without ASD (ASD: 7%, No ASD: 8%). Families of children with ASD were less likely to have control over the hiring and management of the family's support workers compared to families of children without ASD (ASD: 23%, No ASD: 25%). Families of children with ASD were more likely to know how much money was spent by the regional center on behalf of their child compared to families of children without ASD (ASD: 33%, No ASD: 25%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with ASD compared to Family/Survey Respondents of children without ASD.

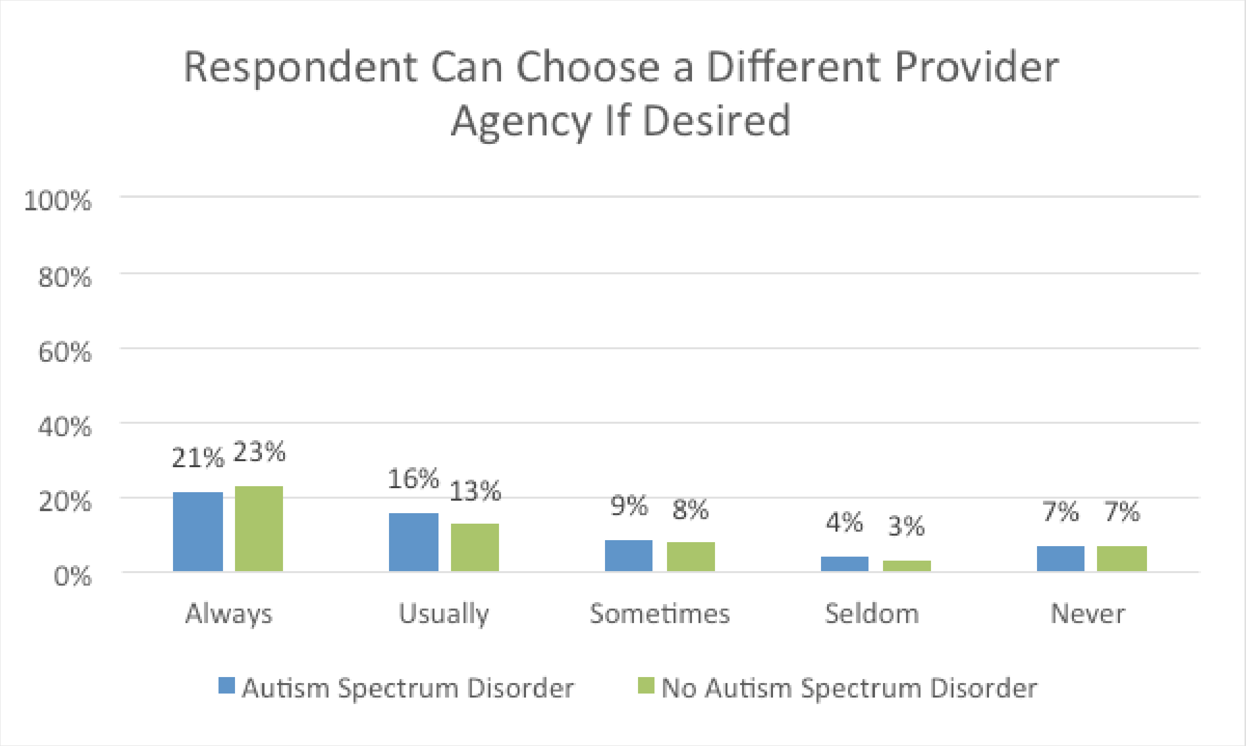

Table IV-42: Can you choose a different provider agency if you want to?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	21%	16%	9%	4%	7%	2636
No ASD	23%	13%	8%	3%	7%	1578

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

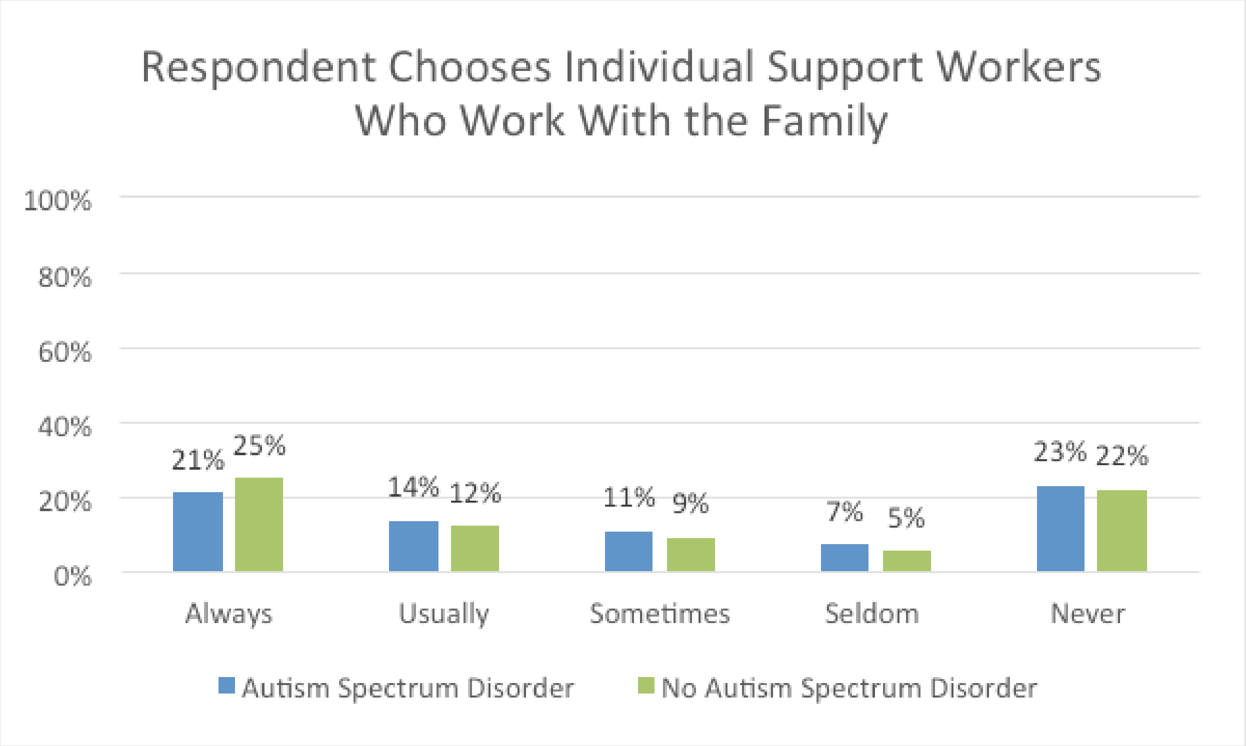

Table IV-43: Do you choose the individual support workers who work directly with your family?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	21%	14%	11%	7%	23%	3503
No ASD	25%	12%	9%	5%	22%	2182

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

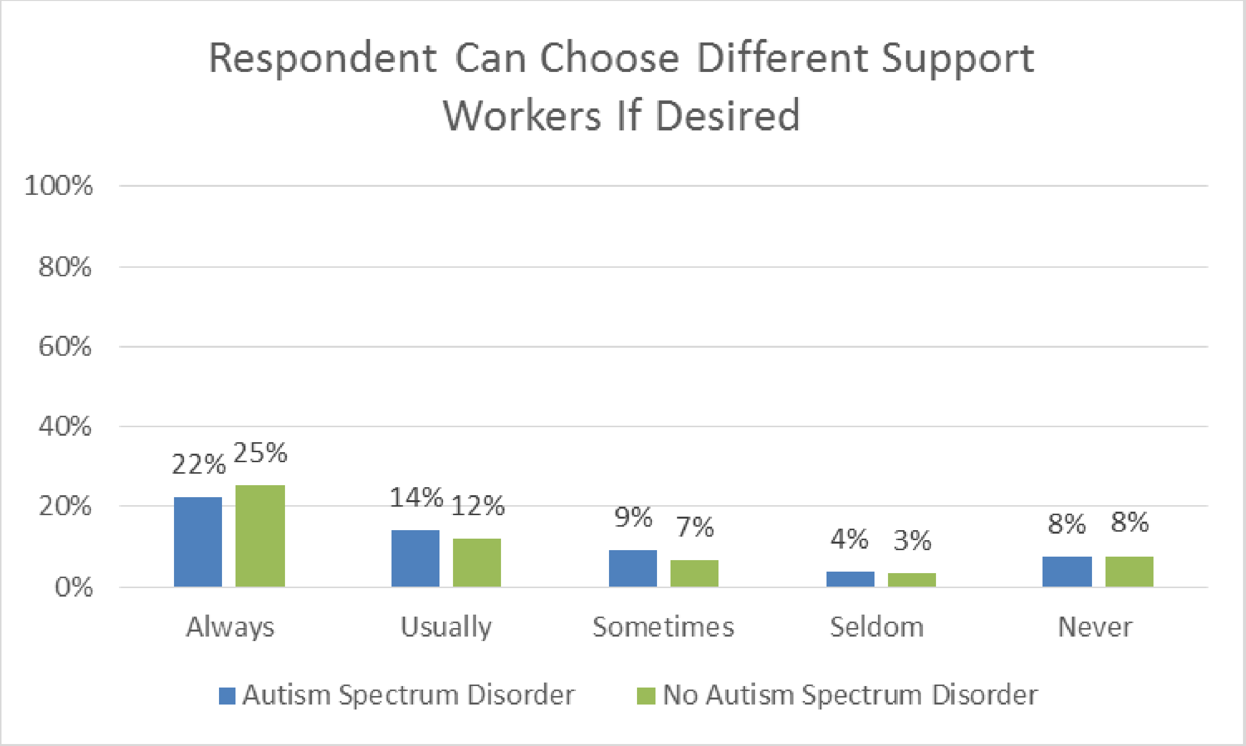

Table IV-44: Can you choose different support workers if you want to?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	22%	14%	9%	4%	8%	2628
No ASD	25%	12%	7%	3%	8%	1632

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

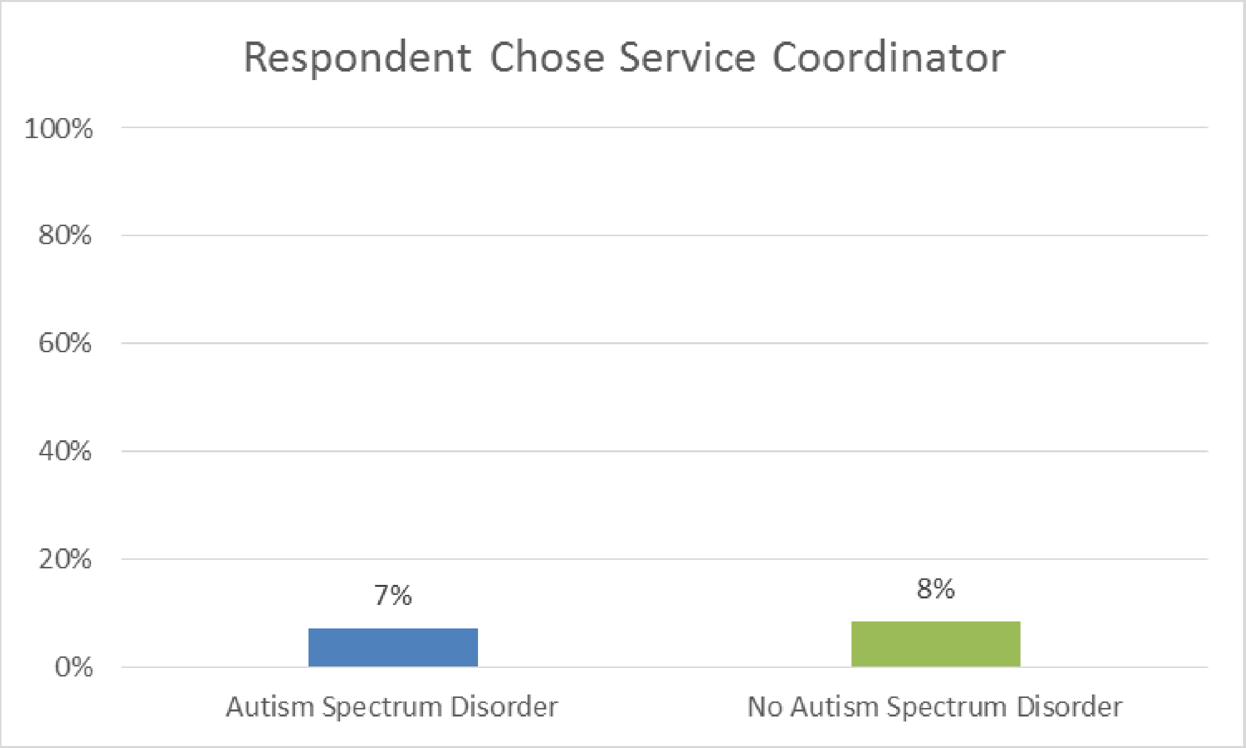

Table IV-45: Did you choose your service coordinator?

	Yes	N
ASD	7%	4193
No ASD	8%	2649

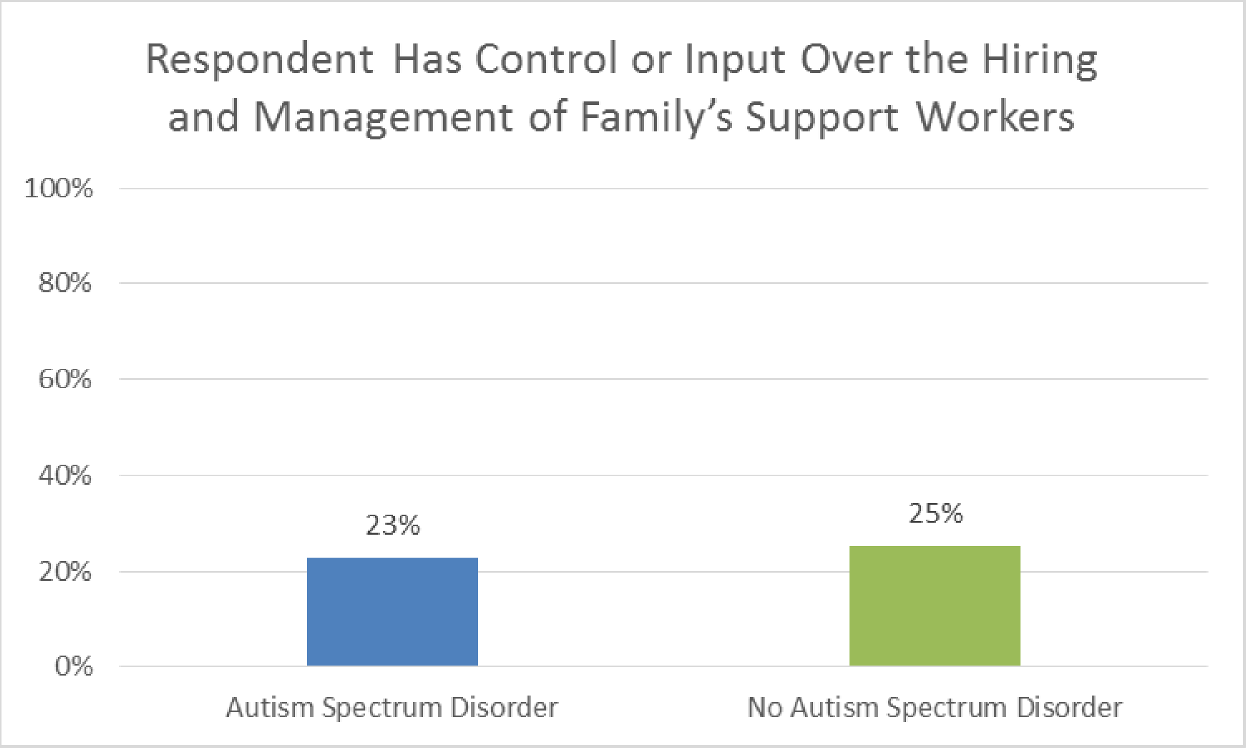

Table IV-46: Do you have control/input over the hiring and management of your family's support workers?

	Yes	N
ASD	23%	3118
No ASD	25%	2009

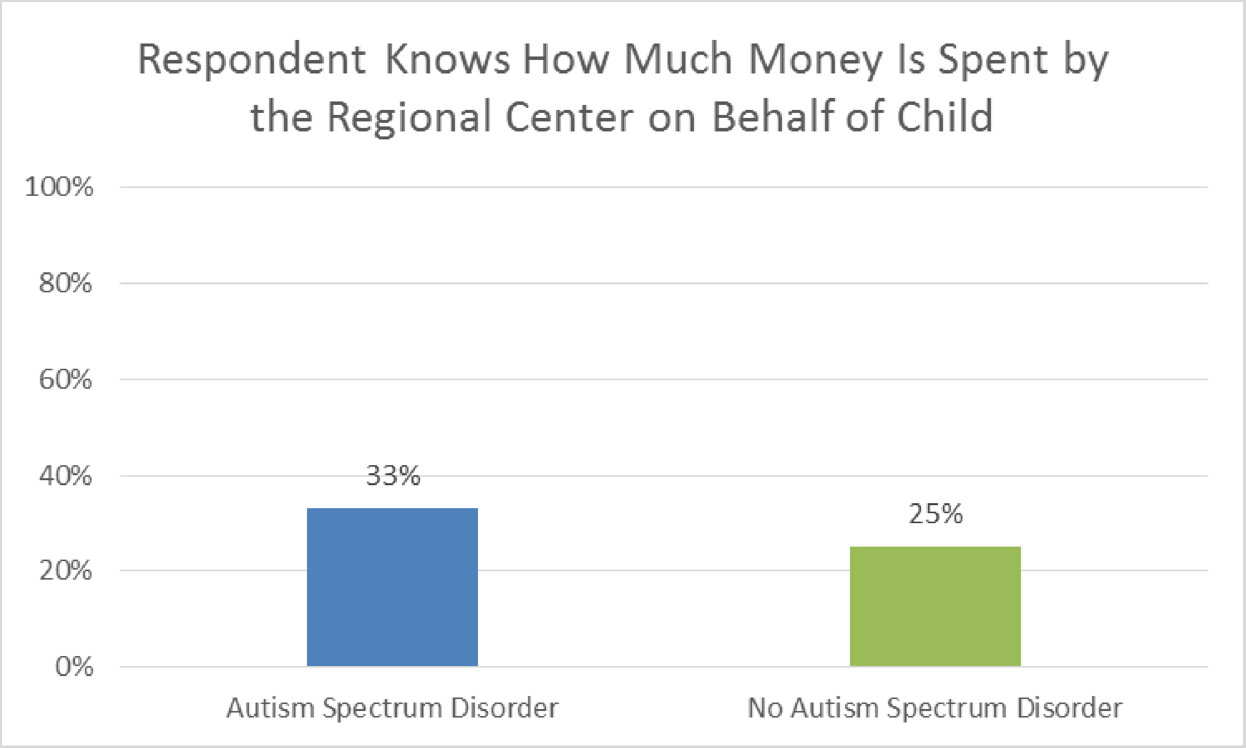

Table IV-47: Do you know how much money is spent by the regional center on behalf of your child?

	Yes	N
ASD	33%	4502
No ASD	25%	2869

Community Connections by ASD

The section on Community Connections in the Child Family Survey includes indicators about: *Participation in Community.* Results that were statistically significant are presented here. The complete list of results for children with ASD is located in Appendix D.

Selected Findings on Community Connections

Children with ASD were more likely to participate in community activities compared to children without ASD (ASD: 72%, No ASD: 68%). Among children who did not participate in community activities, survey respondents provided reasons for why their child did not participate in community activities. Families of children with ASD were more likely to choose “lack of support staff” as one reason for non-participation compared to families of children without ASD (ASD: 27%, No ASD: 20%). Families of children with ASD were more likely to choose “negative attitudes from community members” as another reason for non-participation compared to families of children without ASD (ASD: 22%, No ASD: 11%). Children with ASD compared to children without ASD were less likely to spend time with children who do not have a developmental disabilities (ASD: 76%, No ASD: 80%).

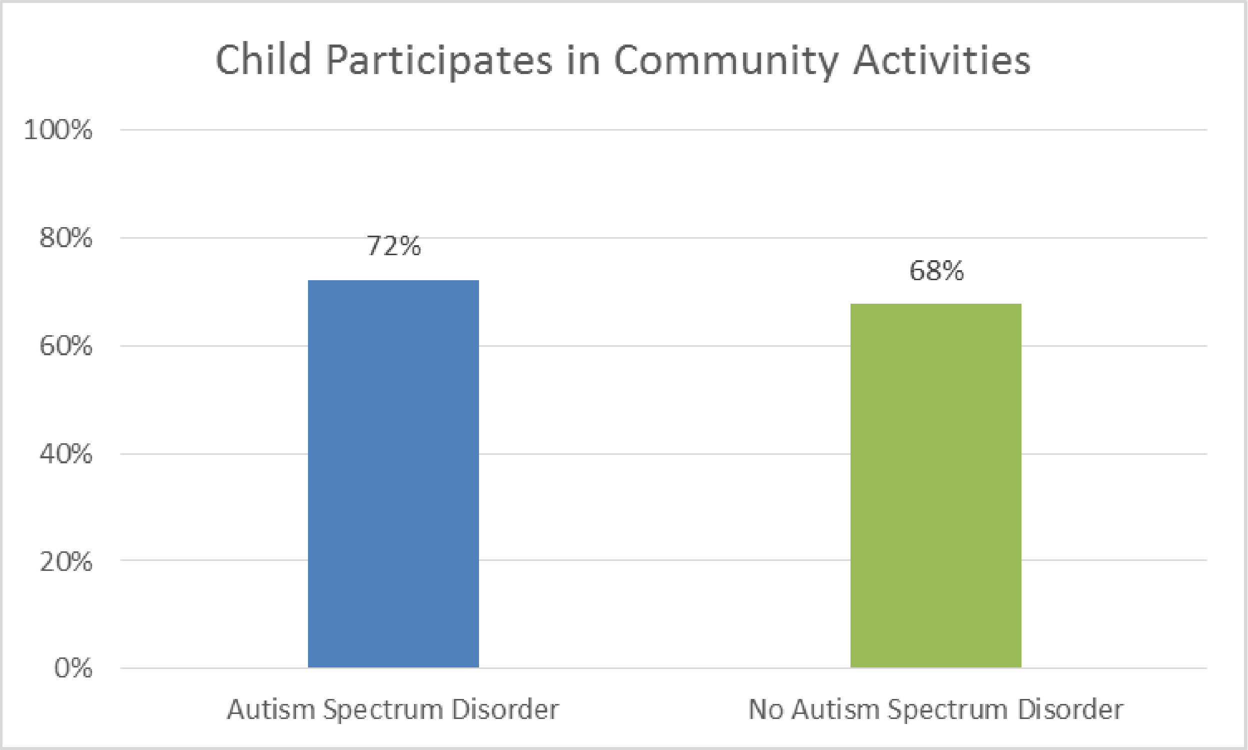

Table IV-48: Does your child participate in community activities (such as going out to a restaurant, movie, or sporting event)?

	Yes	N
ASD	72%	4440
No ASD	68%	2809

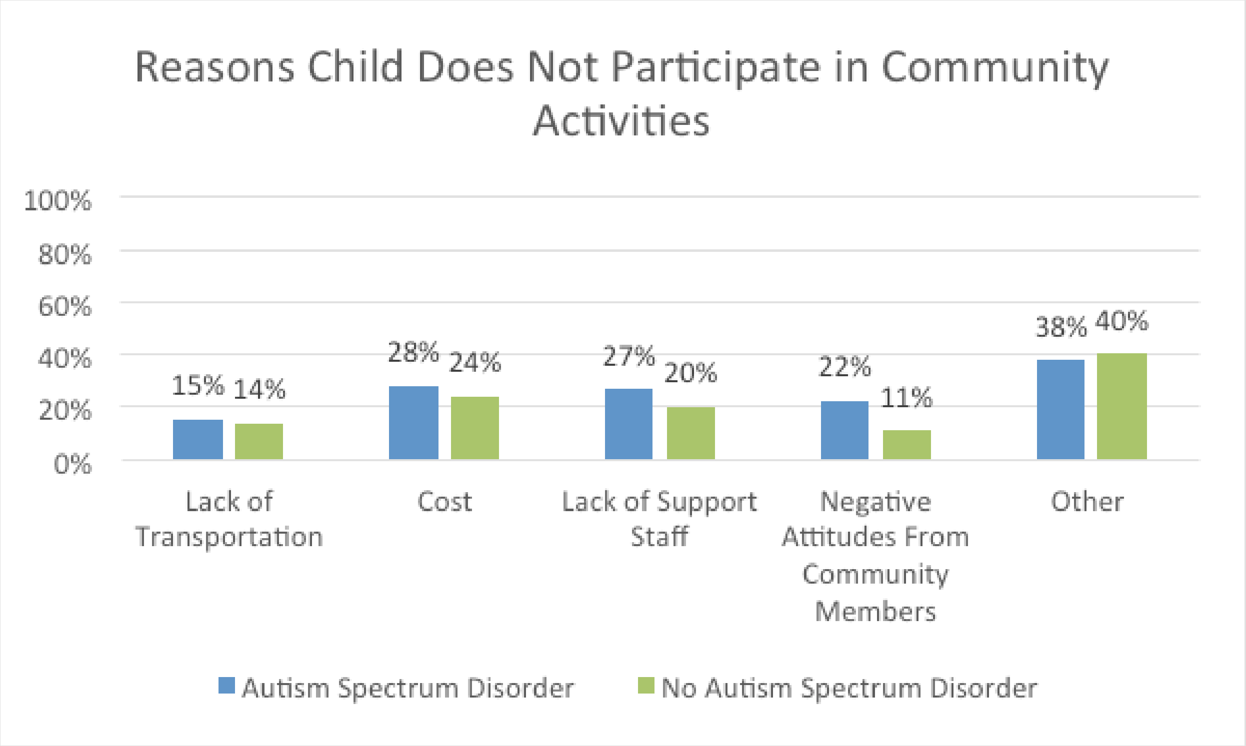

Table IV-49: If you child doesn't participate in community activities, why not?[1], [2]

	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes From Community Members	Other
ASD	15%	28%	27%	22%	38%
No ASD	14%	24%	20%	11%	40%

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[1] Results for "Lack of Transportation," "Cost" and "Other" were not statistically significant.
[2] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

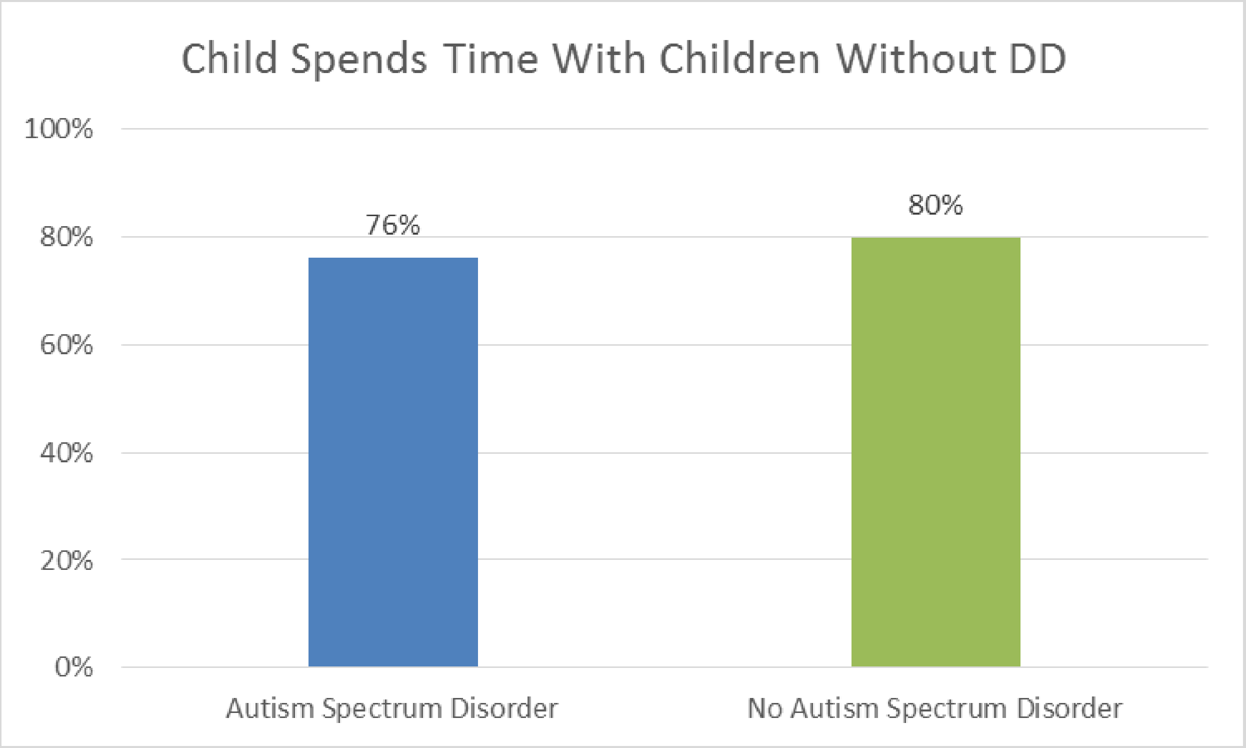

Table IV-50: Does your child spend time with children who do not have developmental disabilities?

	Yes	N
ASD	76%	4332
No ASD	80%	2752

Satisfaction with Services and Supports by ASD

The section on Satisfaction with Services and Supports in the Child Family Survey includes indicators about: *Satisfaction with Services and Supports,* and *Knowing How to Report Complaints.* Results that were statistically significant are presented here. The complete list of results for children with ASD is located in Appendix D.

Selected Findings on Satisfaction with Services and Supports

Families of children with ASD had significant differences in satisfaction with services and supports received compared to families of children without ASD[1] (e.g., always satisfied with services and supports received, ASD: 26%, No ASD: 32%). Families of children with ASD were less likely to be satisfied with how complaints and grievances were handled by provider agencies compared to families of children without ASD (ASD: 20%, No ASD: 23%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with ASD compared to Family/Survey Respondents of children without ASD.

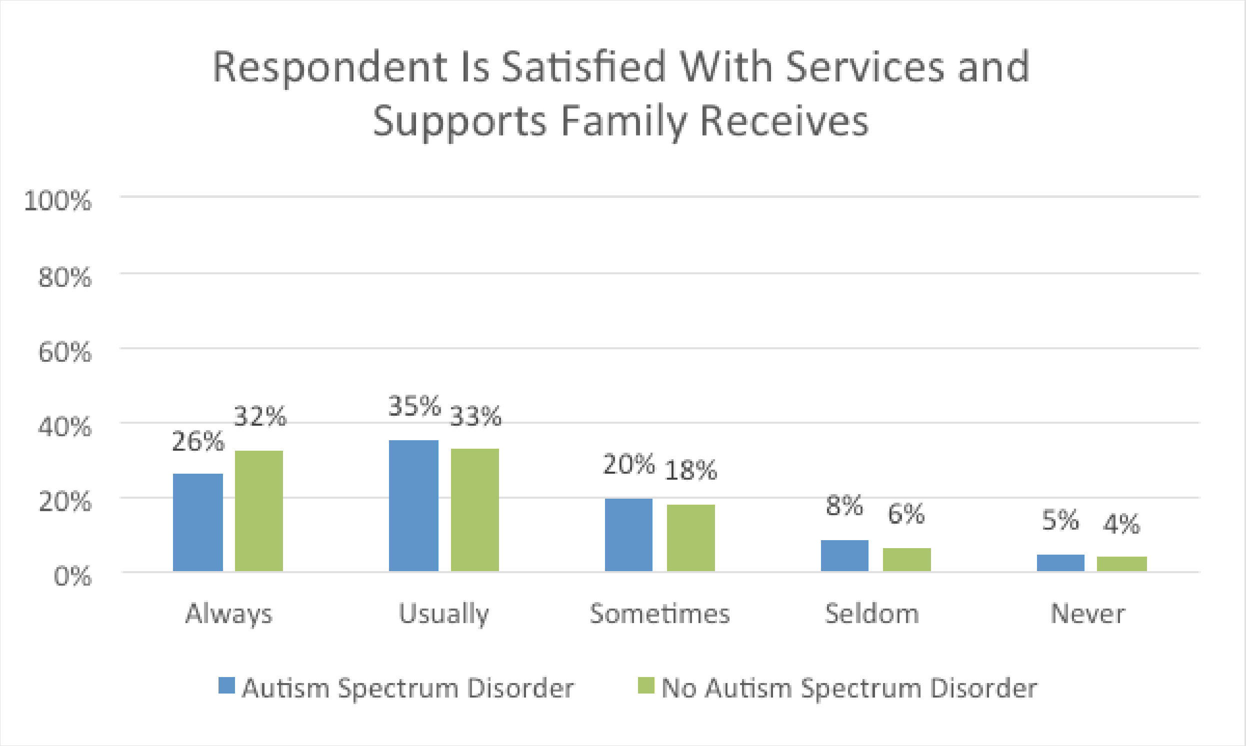

Table IV-51: Overall, are you satisfied with the services and supports your family currently receives?[1]

	Always	Usually	Sometimes	Seldom	Never	N
ASD	26%	35%	20%	8%	5%	4366
No ASD	32%	33%	18%	6%	4%	2773

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

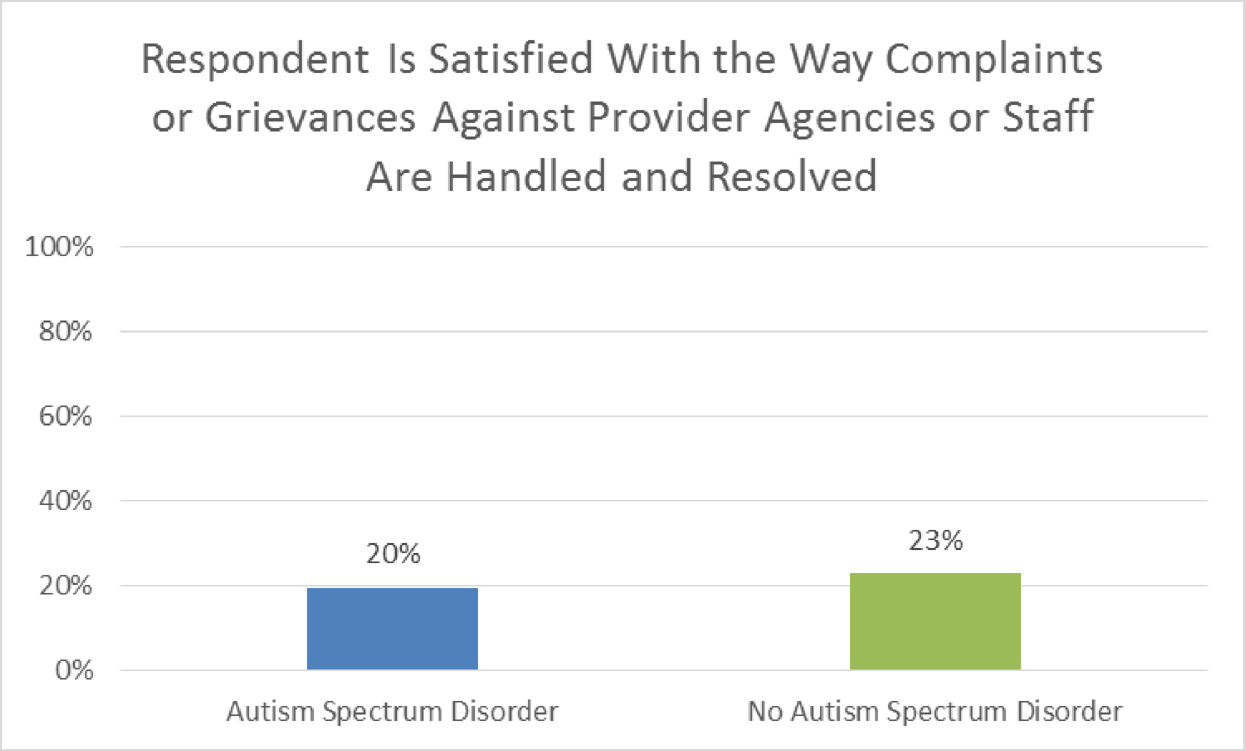

Table IV-52: Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

	Yes	N
ASD	20%	4534
No ASD	23%	2871

Family Outcomes by ASD

The section on Family Outcomes includes in the Child Family Survey indicators about: *Positive Impact of Services and Supports* and *Reduction of Services and Supports.* Results that were statistically significant are presented here. The complete list of results for children with ASD is located in Appendix D.

Selected Findings on Outcomes

Families of children with ASD were more likely to report that services and supports were reduced, suspended or terminated in the past year compared to families of children without ASD (ASD: 38%, No ASD: 29%).

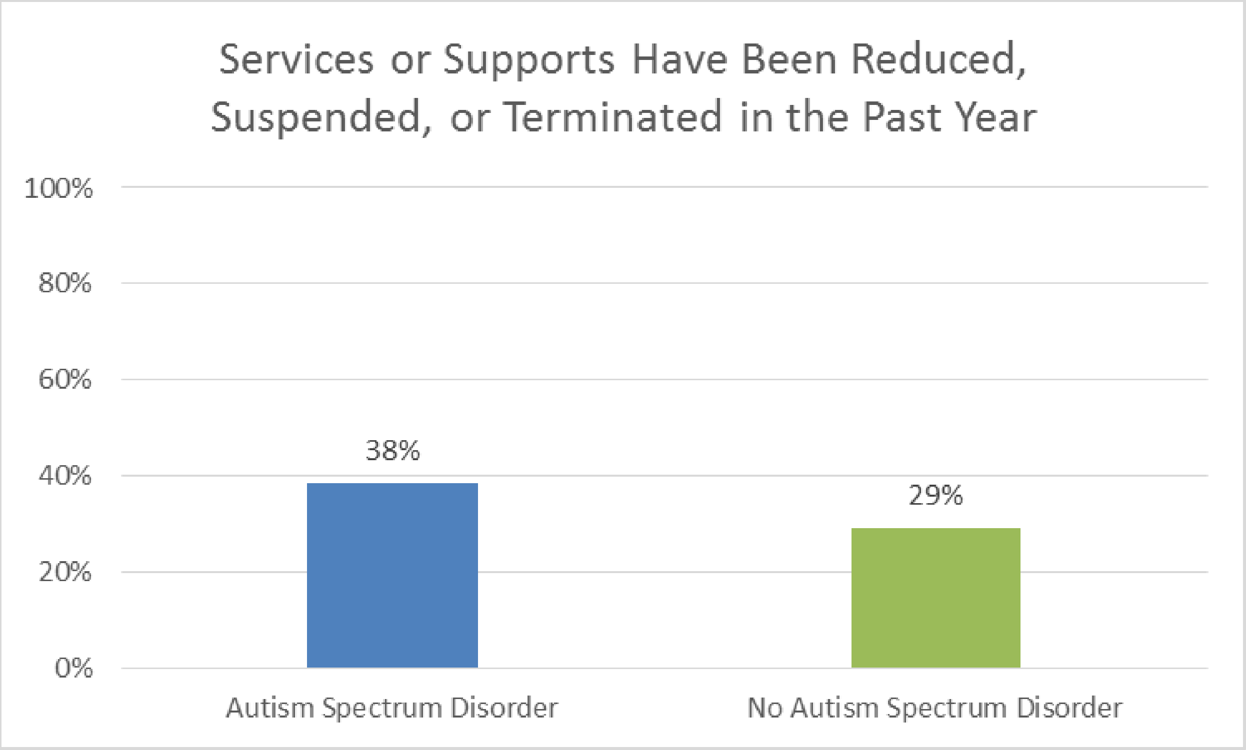

Table IV-53: Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?

	Yes	N
ASD	38%	3899
No ASD	29%	2394

V. Cerebral Palsy

This chapter summarizes demographics and statistically significant outcomes for children with a diagnosis of cerebral palsy (CP) compared to children without a diagnosis of CP. Results reflect responses from 887 families of children with CP and 6,735 families of children without CP.

Summary of Observations by CP

Results for demographics and statistically significant outcome measures comparing children with CP and children without CP are summarized below. Where noted, differences between the two subgroups were statistically significant at $p<.05$[1]. The statistical tests used to determine significant subgroup differences for each survey question are found in Appendix B. Complete tables describing all outcomes with respective sample sizes are found in Appendix E.

Selected Key Findings

In the Child's Demographic Information section, children with CP compared to children without CP were older, less likely to be male, more likely to be female, and more likely to have additional qualifying conditions and disability diagnoses. Children with CP were less likely to use spoken language as their primary means of expression compared to children without CP. There were also fewer children with CP who spoke English as their preferred language compared to children without CP. Families of children with CP have a significant difference in the amount of help needed to care for their child compared to families of children without CP.

In the Family/Survey Respondent's Demographic Information section, there were no significant differences in parents completing the survey or having a college degree between families of children with CP and families of children without CP. There was no significant difference in quality of health between families of children with CP and families of children without CP. Families of children with CP have significant differences in total household income and out-of-pocket expenses compared to families of children without CP.

In the Services and Supports Received section, families of children with CP were more likely to receive financial support, in-home support, transportation assistance, and other services and supports compared to families of children without CP. Children with CP

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[1] P<.05 refers to the how likely a finding in the data is due to chance and when p<.05 we have confidence that the finding is not due to chance. This finding of statistical significance does not necessarily mean that the finding is a really important finding.

were less likely to receive early intervention compared to children without CP. There were no significant differences in receiving out-of-home respite care or Social Security benefits between families of children with CP and families of children without CP.

In the Information and Planning section, there was no significant difference in receiving information about available services and supports between families of children with CP and families of children without CP. There was no significant difference between children with CP and children without CP in having an individual program plan (IPP) and families helping develop the IPP. Families of children with CP were more likely to receive information about their rights compared to families of children without CP.

In the Access and Delivery section, there was no significant difference in ability to contact support workers and service coordinators when needed between families of children with CP and families of children without CP. There was a significant difference between families of children with CP and families of children without CP in support workers having the right training to meet their child’s needs.

In the Choice and Control section, there was no significant difference in choosing provider agencies between families of children with CP and families of children without CP. There was a significant difference in choosing individual support workers between families of children with CP and families of children without CP. There was no significant difference knowing how much money was spent by the regional center on behalf of their child between families of children with CP and families of children without CP. There was a significant difference in having a say in how regional center money was spent on behalf of their child between families of children with CP and families of children without CP.

In the Community Connections section, there were no significant differences in participating in community activities and spending time with children who do not have a developmental disability between children with CP and children without CP.

In the Satisfaction with Services and Supports section, there was a significant difference in satisfaction with services and supports received by families of children with CP and families of children without CP. There was no significant difference in satisfaction with how complaints were handled by provider agencies between families of children with CP and families of children without CP. Families of children with CP were more likely to know how to report abuse or neglect compared to families of children without CP.

In the Family Outcomes section, there were no significant differences between families of children with CP and families of children without CP in services and supports making a positive impact in their family's life and family supports improving their ability to care for their child. There was no significant difference in services and supports being reduced or terminated in the past year between families of children with CP and families of children without CP.

Demographics by CP

Child’s Demographic Information

The section on Child’s Demographic Information in the Child Family Survey includes indicators about: *Basic Information, Primary Expression and Language,* and *Amount of Help Needed for Child.* All results are presented here.

Selected Findings on Child’s Demographic Information

Children with CP on average were older than children without CP (CP: 11.58 years old, No CP: 10.11 years old). Children with CP were less likely to be male compared to children without CP (CP: 55%, No CP: 71%). Children with CP were more likely to be female compared to children without CP (CP: 42%, No CP: 26%). Children with CP were more likely to be White compared to children without CP (CP: 39%, No CP: 36%). Children with CP were less likely to be Asian compared to children without CP (CP: 9%, No CP: 13%). Children with CP were less likely to have autism spectrum disorder as an additional qualifying condition compared to children without CP (CP: 15%, No CP: 67%). Children with CP were more likely to have an intellectual disability as an additional qualifying condition compared to children without CP (CP: 55%, No CP: 33%). Children with CP were more likely to have epilepsy as an additional qualifying condition compared to children without CP (CP: 47%, No CP: 10%). Children with CP were more likely to have a brain injury compared to children without CP (CP: 21%, No CP: 2%). Children with CP were more likely to have a chemical dependency compared to children without CP (CP: 2%, No CP: 0.4%). Children with CP were more likely to have limited/no vision or be legally blind compared to children without CP (CP: 25%, No CP: 4%). Children with CP were more likely to have hearing loss compared to children without CP (CP: 7%, No CP: 3%). Children with CP were less likely to have Down syndrome compared to children without CP (CP: 1%, No CP: 10%). Children with CP were more likely to have Prader-Willi syndrome compared to children without CP (CP: 2%, No CP: 1%). Children with CP were more likely to have another unlisted disability compared to children without CP (CP: 29%, No CP: 14%).

Children with CP were less likely to use spoken language as their primary means of expression compared to children without CP (CP: 39%, No CP: 67%). Children with CP were more likely to use gestures/body language as their primary means of expression compared to children without CP (CP: 38%, No CP: 20%). Children with CP were more likely to use a communication aid/device as their primary means of expression compared to children without CP (CP: 5%, No CP: 3%). Children with CP were more likely to use other methods as their primary means of expression compared to children without CP (CP: 12%, No CP: 4%). Children with CP were less likely to speak English as their preferred language compared to children without CP (CP: 68%, No CP: 73%). Children with CP were more likely to speak a language (other) not listed as their preferred language compared to children without CP (CP: 7%, No CP: 4%).

Children with CP had significant differences in the frequency of medical care needed compared to children without CP[1] (e.g., medical care needed at least once per week, CP: 20%, No CP: 7%). Children with CP had significant differences in the amount of behavioral support needed compared to children without CP[1] (e.g., some behavioral support needed, CP: 21%, No CP: 37%). Children with CP had significant differences in the amount of help needed for daily activities compared to children without CP[1] (e.g., complete help needed, CP: 70%, No CP: 28%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with CP compared to Family/Survey Respondents of children without CP.

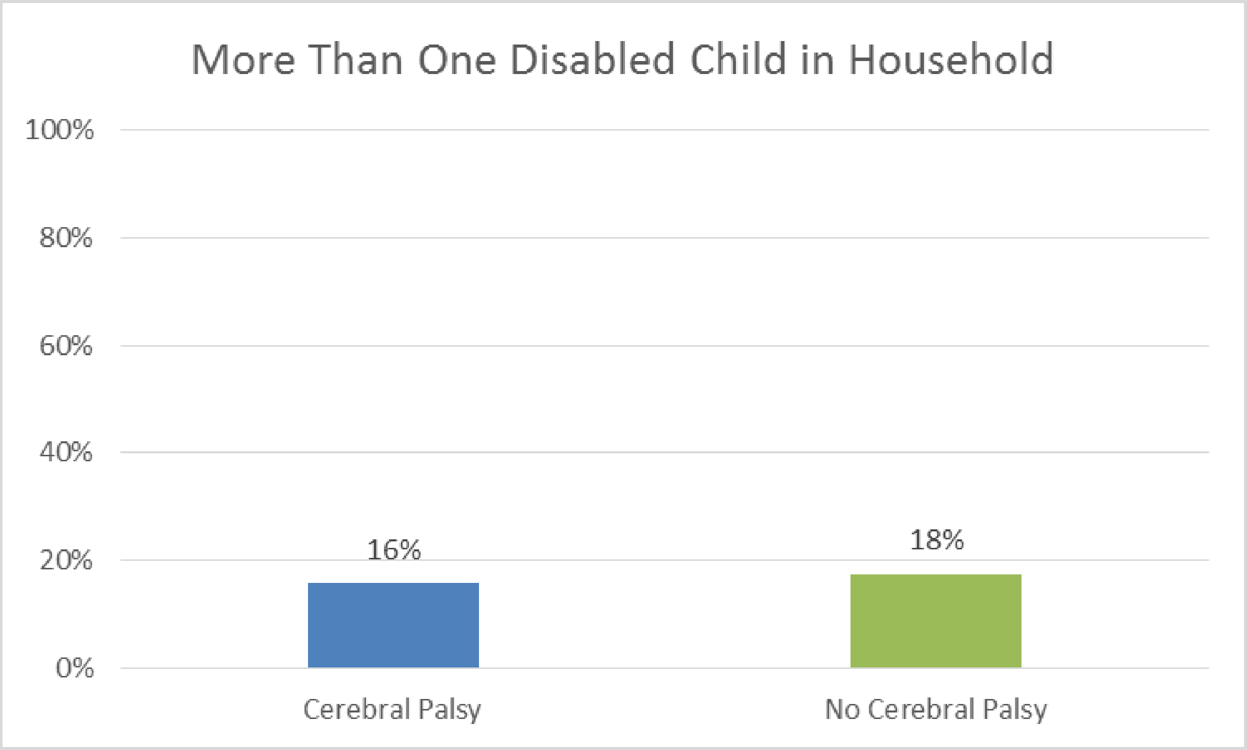

Table V-1: More Than One Disabled Child in Household by CP[1]

	Yes	N
CP	16%	808
No CP	18%	5967

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[1] Results were not statistically significant.

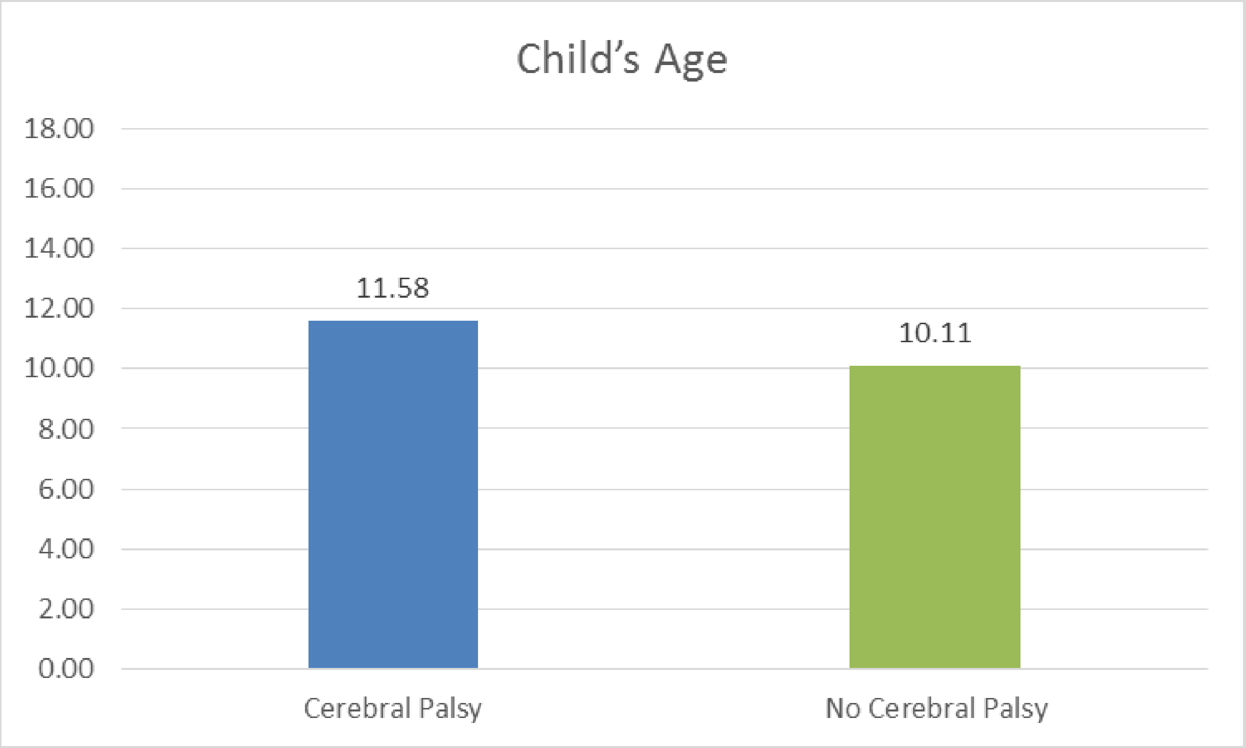

Table V-2: Child's Age by CP

	Average Age	N
CP	11.58	869
No CP	10.11	6551

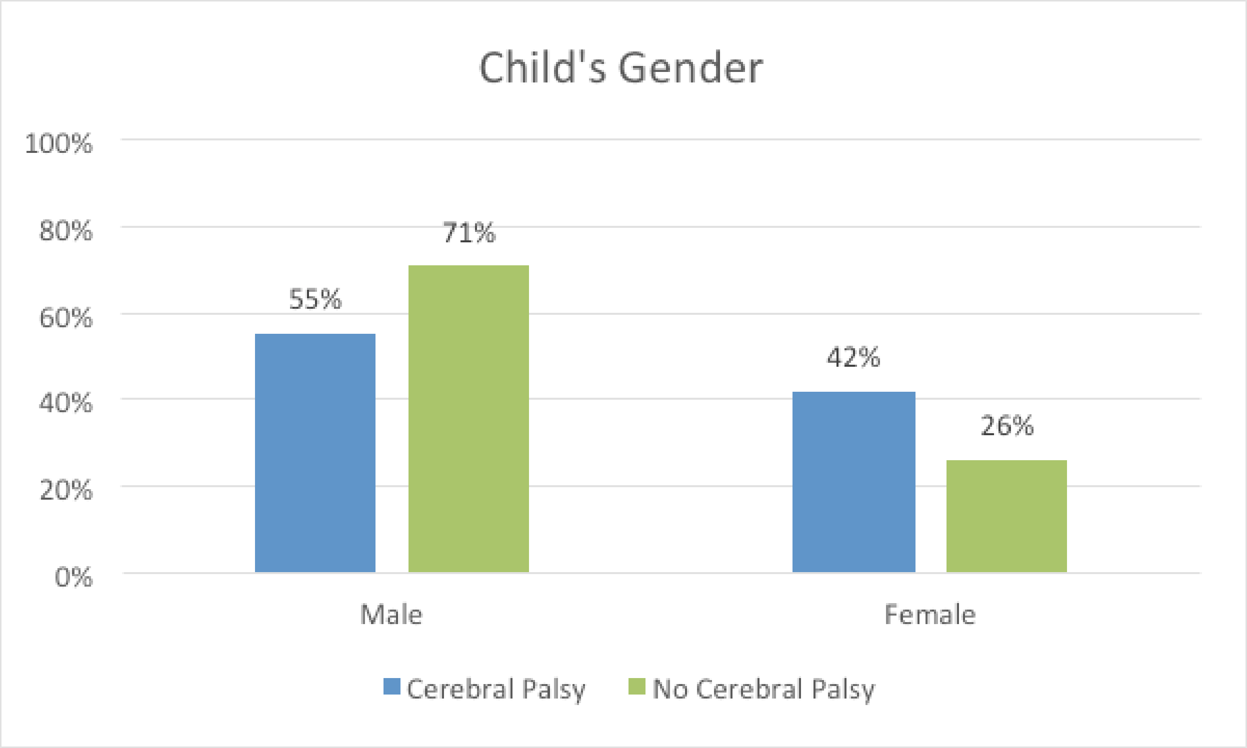

Table V-3: Child's Gender by CP

	Male	Female	N
CP	55%	42%	863
No CP	71%	26%	6540

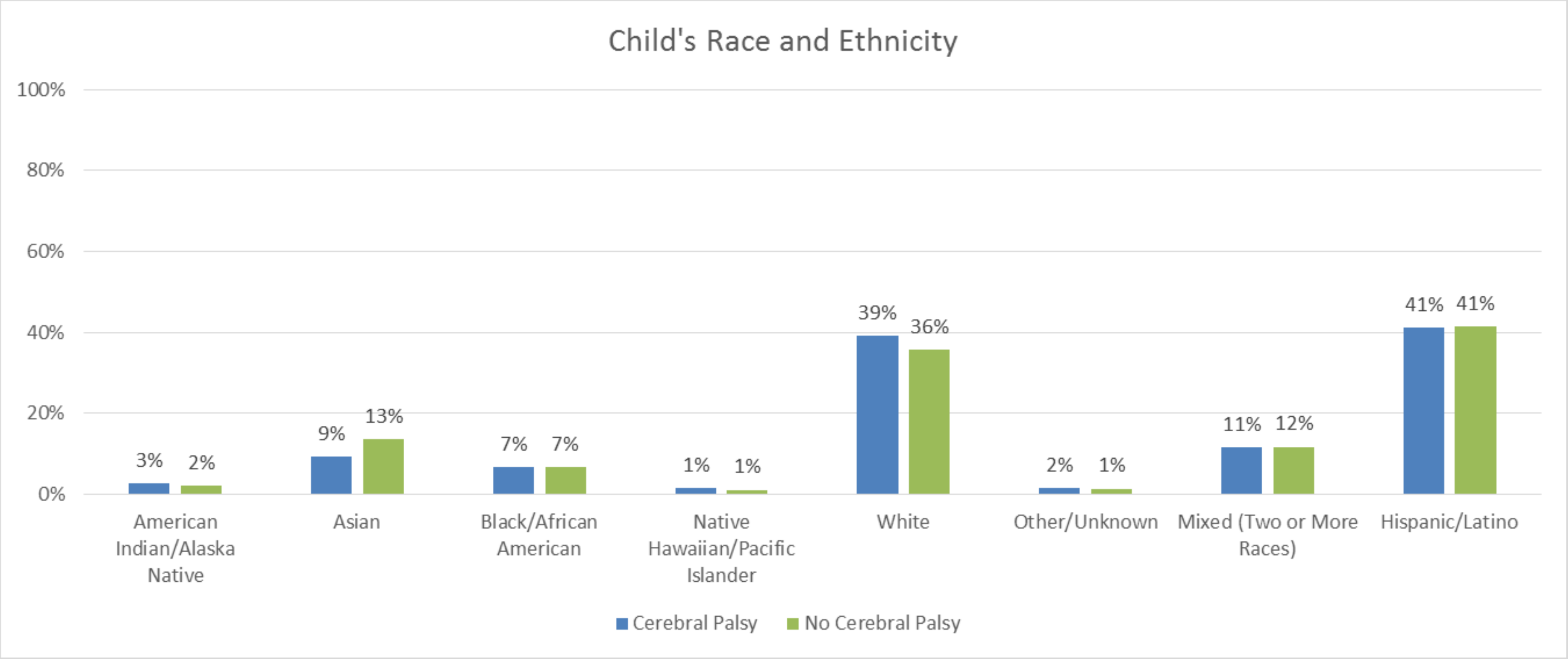

Table V-4: Child's Race and Ethnicity by CP[1][2]

	American Indian/ Alaska Native	Asian	Black/ African American	Native Hawaiian/ Pacific Islander	White	Other/ Unknown	Mixed (Two or More Races)	Hispanic/ Latino
CP	3%	9%	7%	1%	39%	2%	11%	41%
No CP	2%	13%	7%	1%	36%	1%	12%	41%

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[1] Results for “American Indian/Alaska Native”, “Black/African American”, “Native Hawaiian/Pacific Islander”, “Other/Unknown”, “Mixed (Two or More Races)”, and “Hispanic/Latino” were not statistically significant.
[2] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

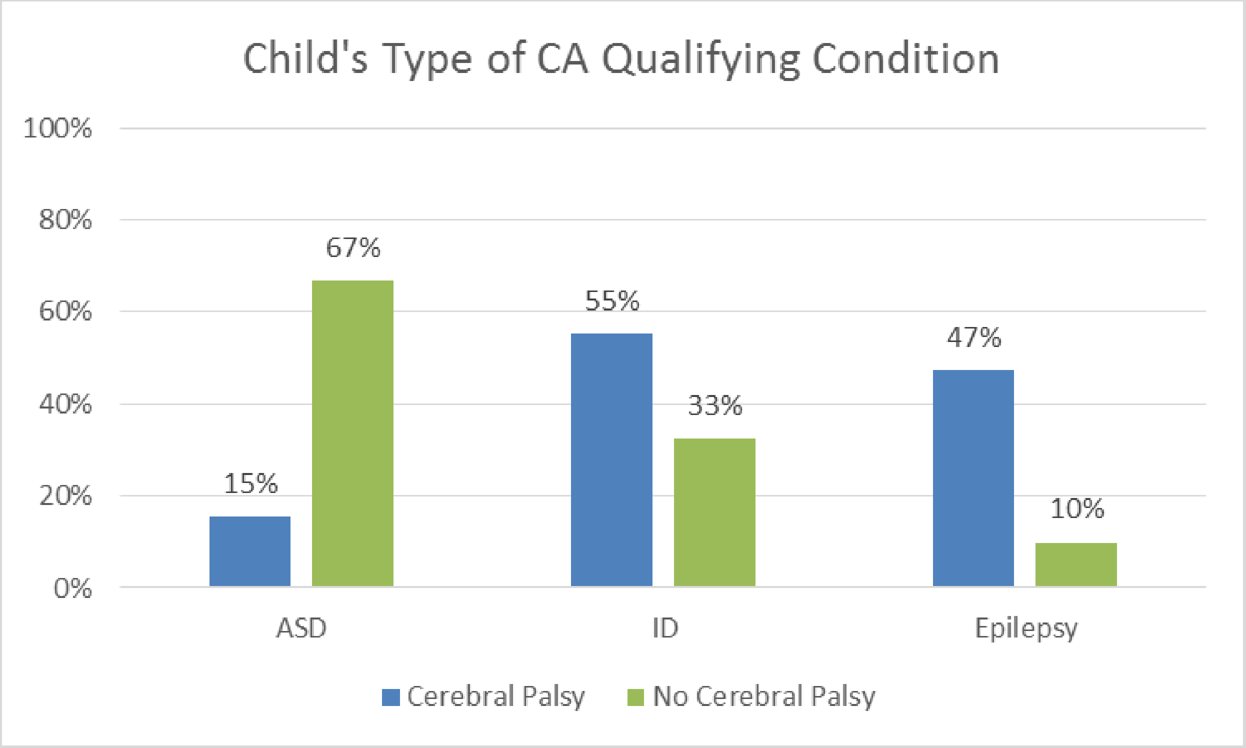

Table V-5: Child's Type of CA Qualifying Condition by CP[1]

	ASD	ID	Epilepsy
CP	15%	55%	47%
No CP	67%	33%	10%

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[1] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

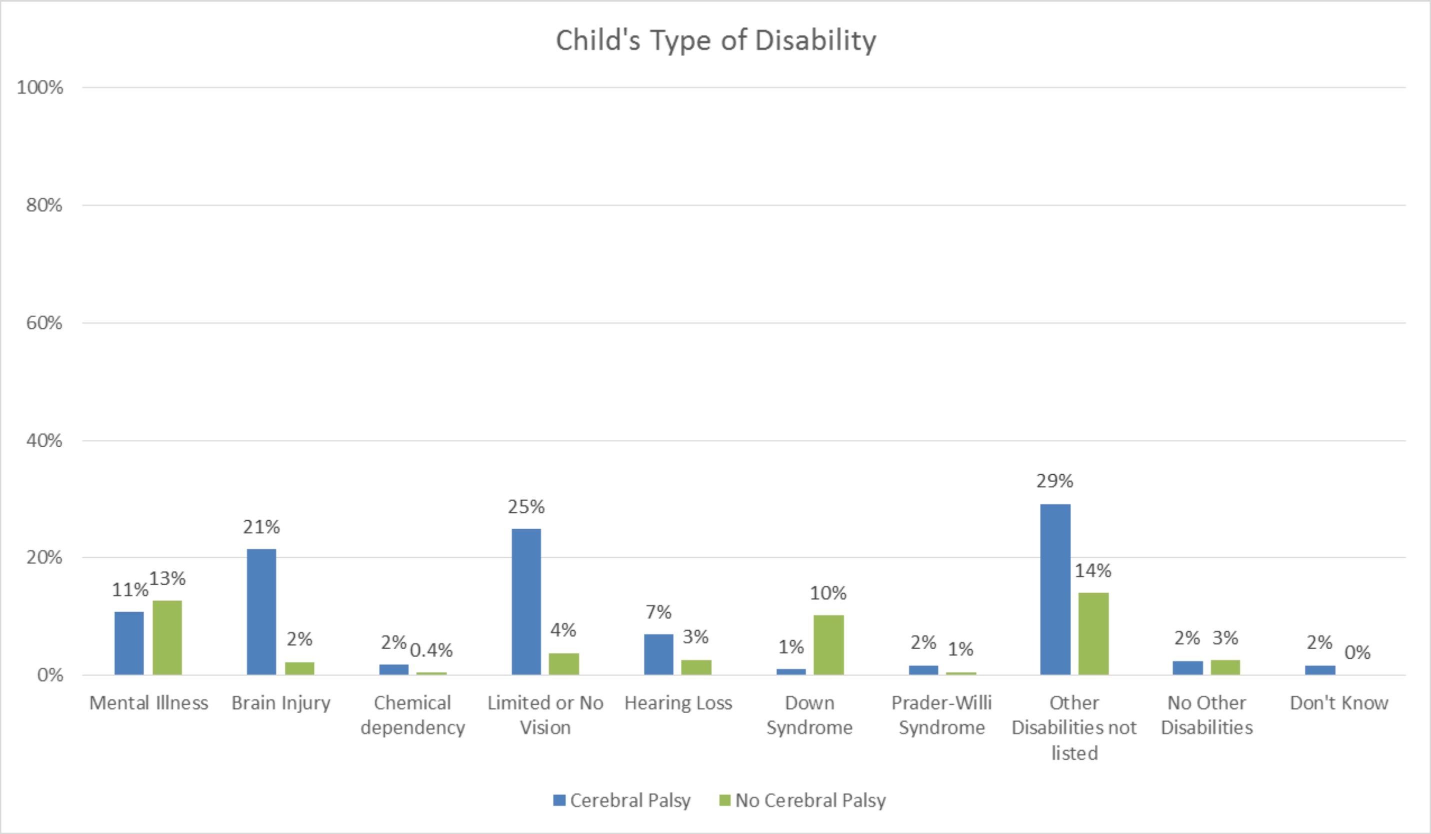

Table V-6: Child's Type of Disability by CP[1],[2]

	Mental Illness/ Psychiatric Diagnosis/ Behavioral Disorder	Brain Injury	Chemical Dependency	Limited or No Vision/ Legally Blind	Hearing Loss (Severe or Profound)	Down Syndrome	Prader-Willi Syndrome	Other Disabi-lities not listed	No Other Disabi-lities	Don't Know
CP	11%	21%	2%	25%	7%	1%	2%	29%	2%	2%
No CP	13%	2%	0.4%	4%	3%	10%	1%	14%	3%	0%

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[1] Results for “Mental Illness/Psychiatric Diagnosis/Behavioral Disorder” and “No Other Disabilities” were not statistically significant.
[2] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

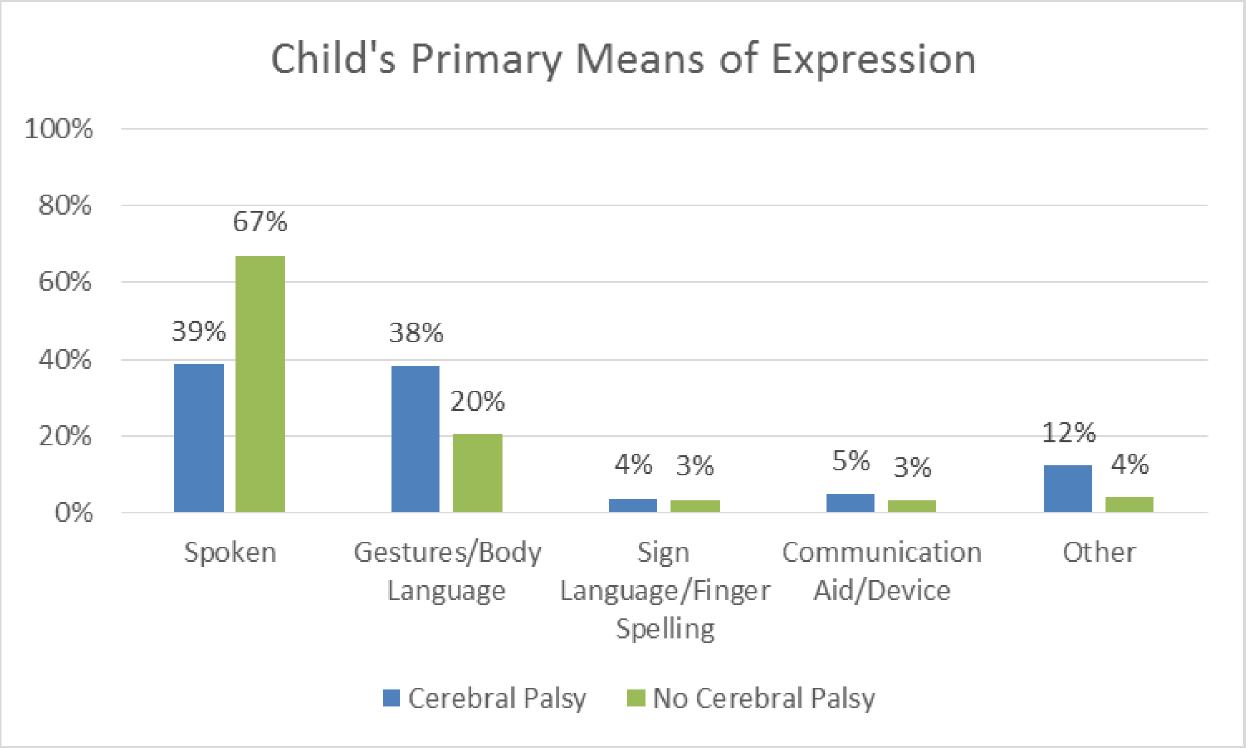

Table V-7: Child's Primary Means of Expression by CP[1], [2]

	Spoken	Gestures/ Body Language	Sign Language/ Finger Spelling	Communication Aid/Device	Other	N
CP	39%	38%	4%	5%	12%	868
No CP	67%	20%	3%	3%	4%	6614

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[1] Results for “Sign Language/Finger Spelling” were not statistically significant.
[2] Percentages add up to less than 100% due to missing responses.

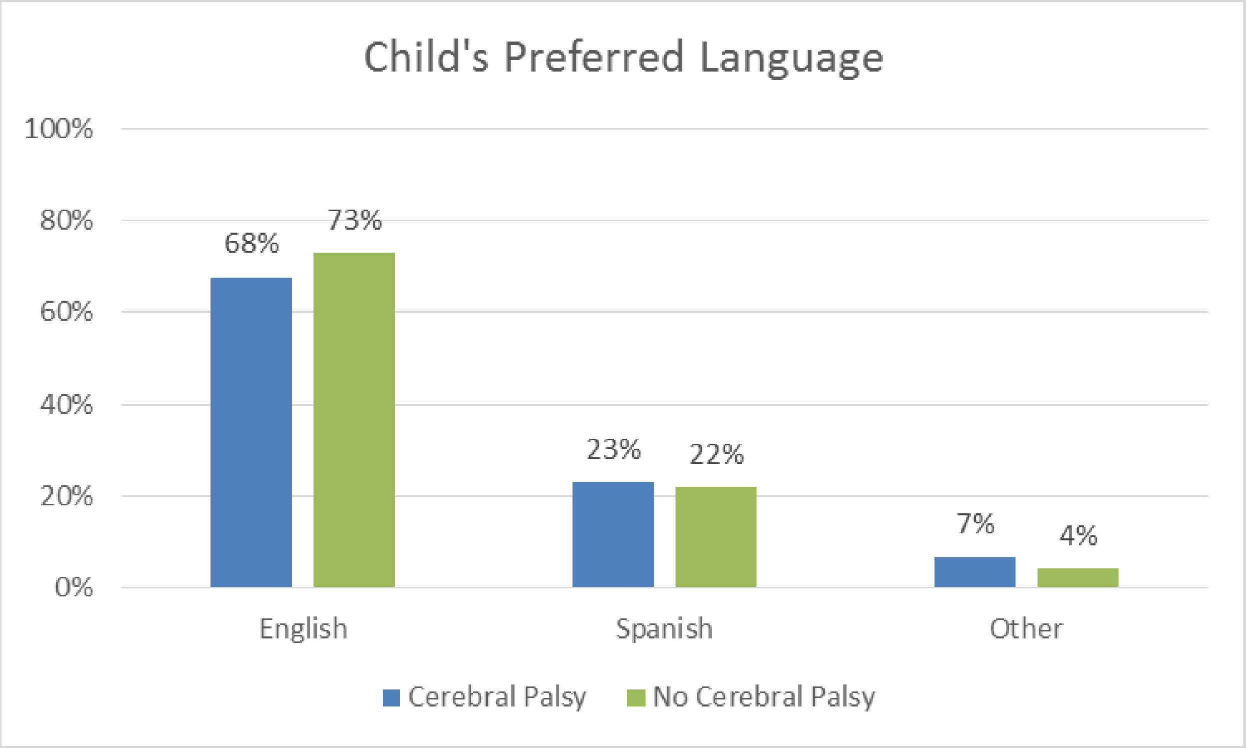

Table V-8: Child's Preferred Language by CP[1], [2]

	English	Spanish	Other	N
CP	68%	23%	7%	864
No CP	73%	22%	4%	6673

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[1] Results for "Spanish" were not statistically significant.

[2] Percentages add up to less than 100% due to missing responses.

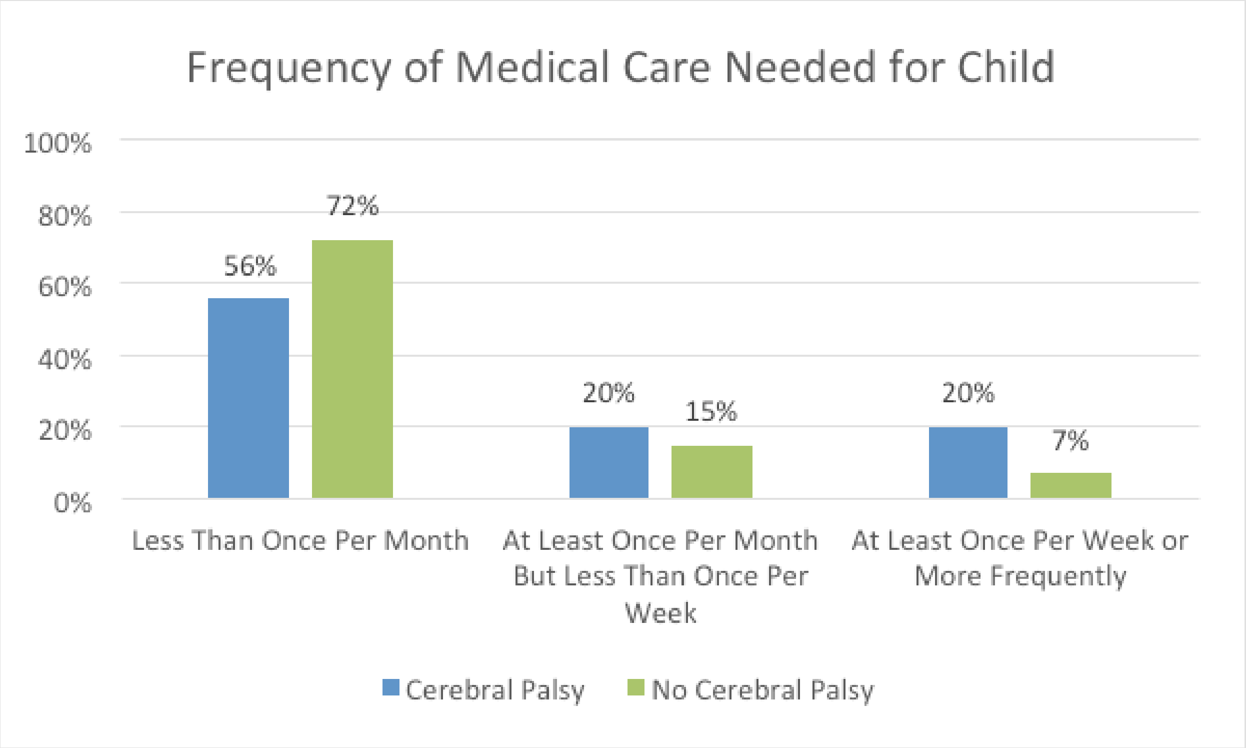

Table V-9: Frequency of Medical Care Needed for Child by CP[1]

	Less Than Once Per Month	At Least Once Per Month But Less Than Once Per Week	At Least Once Per Week or More Frequently	N
CP	56%	20%	20%	846
No CP	72%	15%	7%	6321

---

[1] Percentages add up to less than 100% due to missing responses.

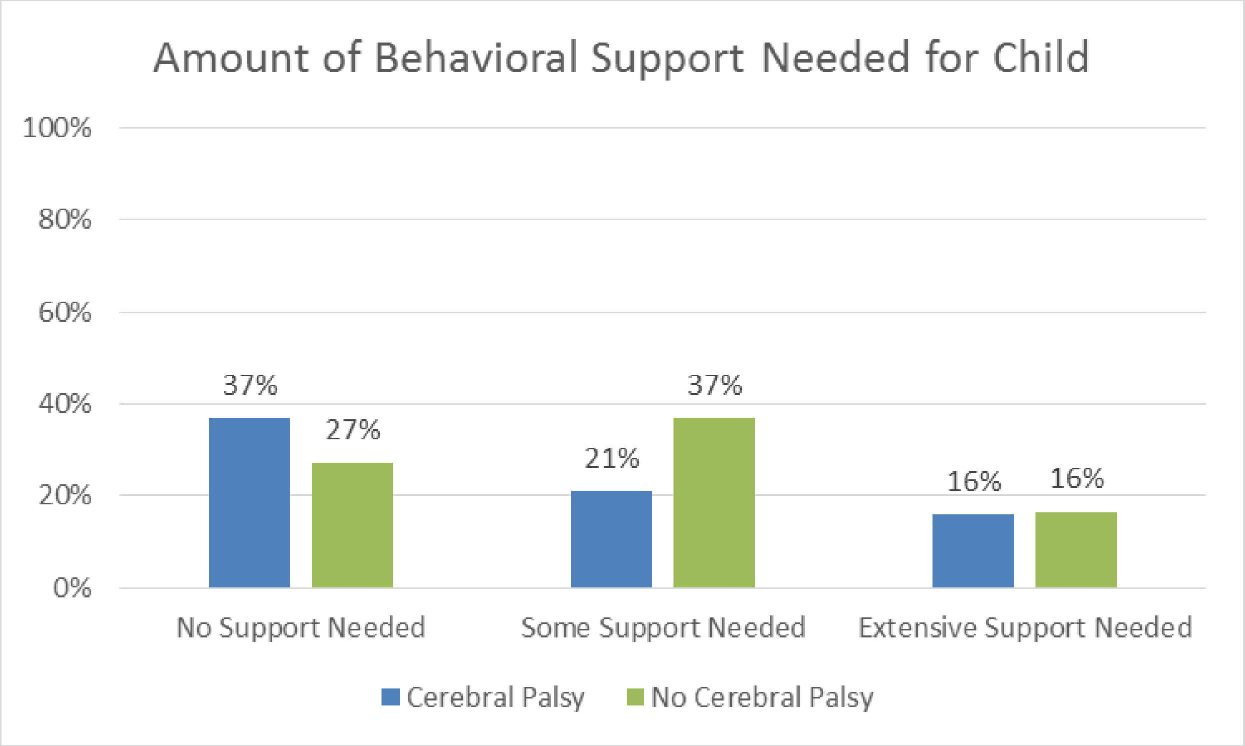

Table V-10: Amount of Behavioral Support Needed for Child by CP[1]

	No Support Needed	Some Support Needed	Extensive Support Needed	N
CP	37%	21%	16%	658
No CP	27%	37%	16%	5349

---

[1] Percentages add up to less than 100% due to missing responses.

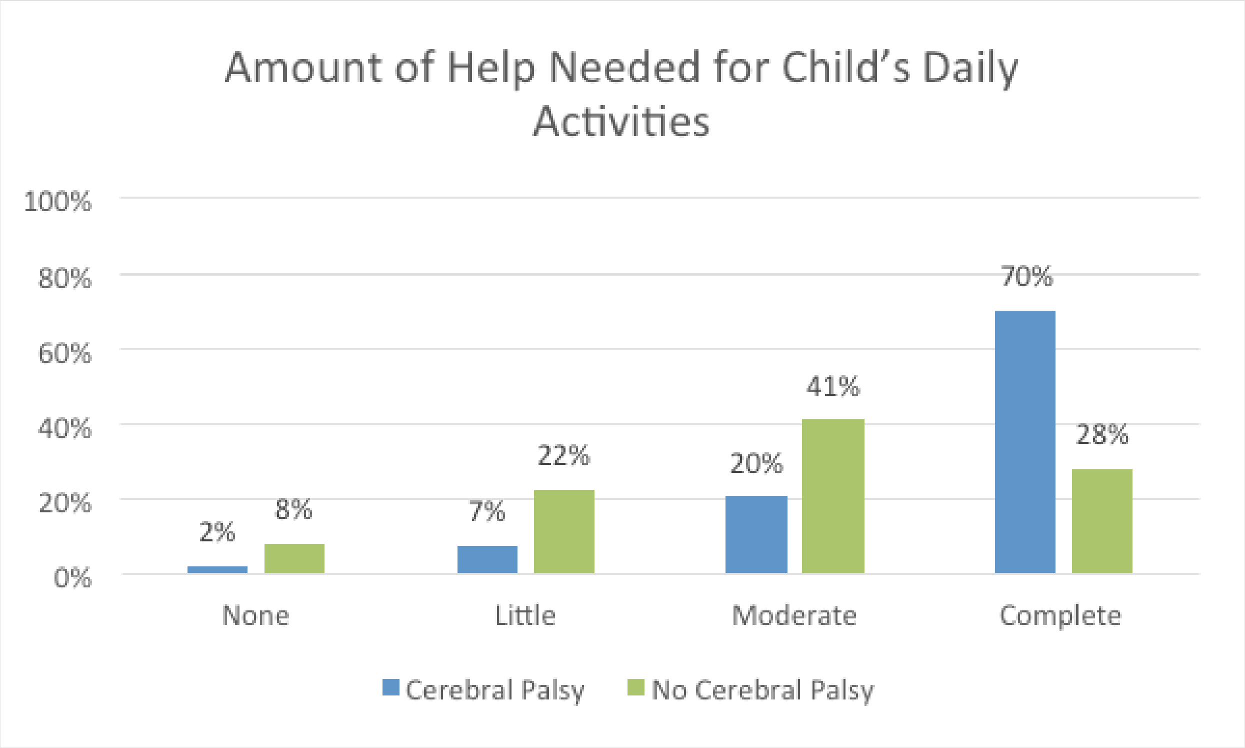

Table V-11: Amount of Help Needed for Child's Daily Activities by CP[1]

	None	Little	Moderate	Complete	N
CP	2%	7%	20%	70%	884
No CP	8%	22%	41%	28%	6699

---

[1] Percentages add up to less than 100% due to missing responses.

Family/Survey Respondent's Demographic Information

The section on Family/Survey Respondent's Demographic Information in the Child Family Survey includes indicators about: *Basic Information about Family/Survey Respondent* and *Household Composition and Income.* All results are presented here.

Selected Findings on Family/Survey Respondent's Demographic Information

Survey respondents of children with CP compared to respondents of children without CP had significant differences in age[1] (e.g., age of survey respondent between 35-54 years old, CP: 63%, No CP: 67%). Children with CP were more likely to have someone other than their parent, sibling, or grandparent complete the CFS1 survey compared to children without CP (CP: 2%, No CP: 1%).

Families of children with CP had significant differences in total household income compared to families of children without CP[1] (e.g., income over $75,000, CP: 24%, No CP: 22%). Families of children with CP had significant differences in out-of-pocket expenses for their child in the past year compared to families of children without CP[1] (e.g., expenses over $10,000, CP: 7%, No CP: 6%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with ASD compared to Family/Survey Respondents of children without ASD.

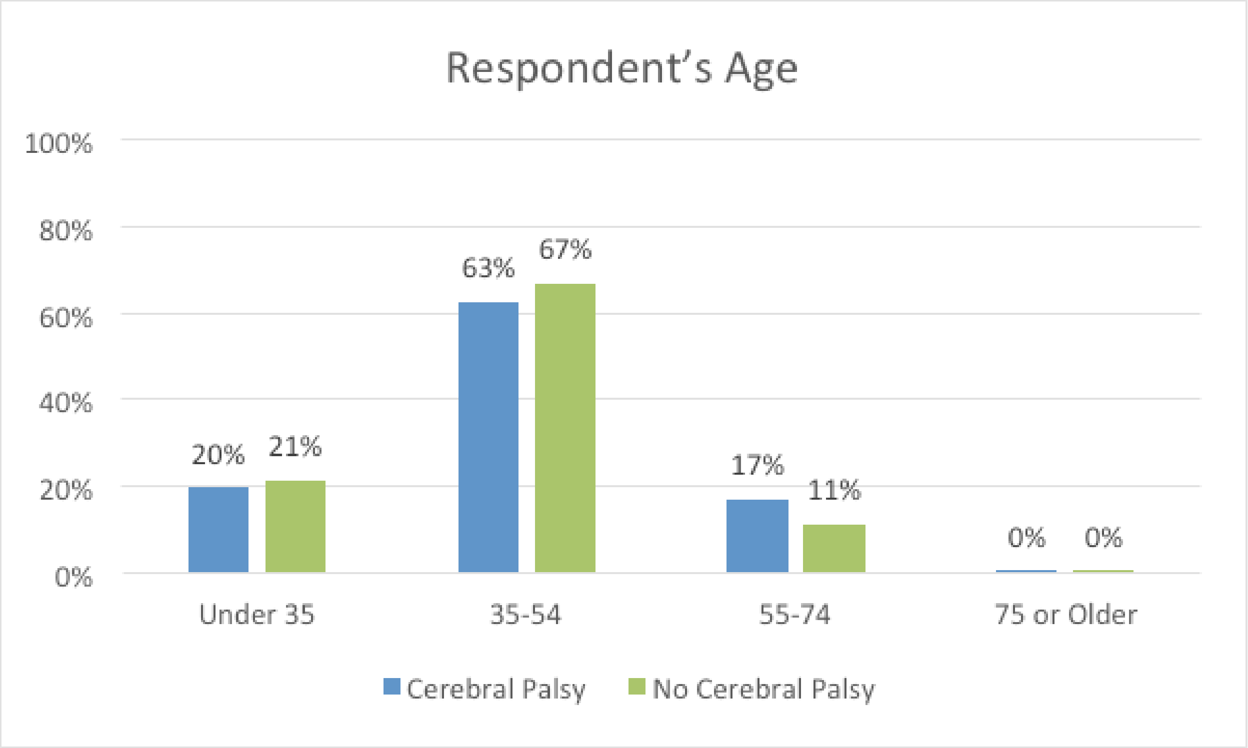

Table V-12: Respondent's Age by CP[1]

	Under 35	35–54	55–74	75 or Older	N
CP	20%	63%	17%	0%	882
No CP	21%	67%	11%	0%	6694

---

[1] Percentages add up to less than 100% due to missing responses.

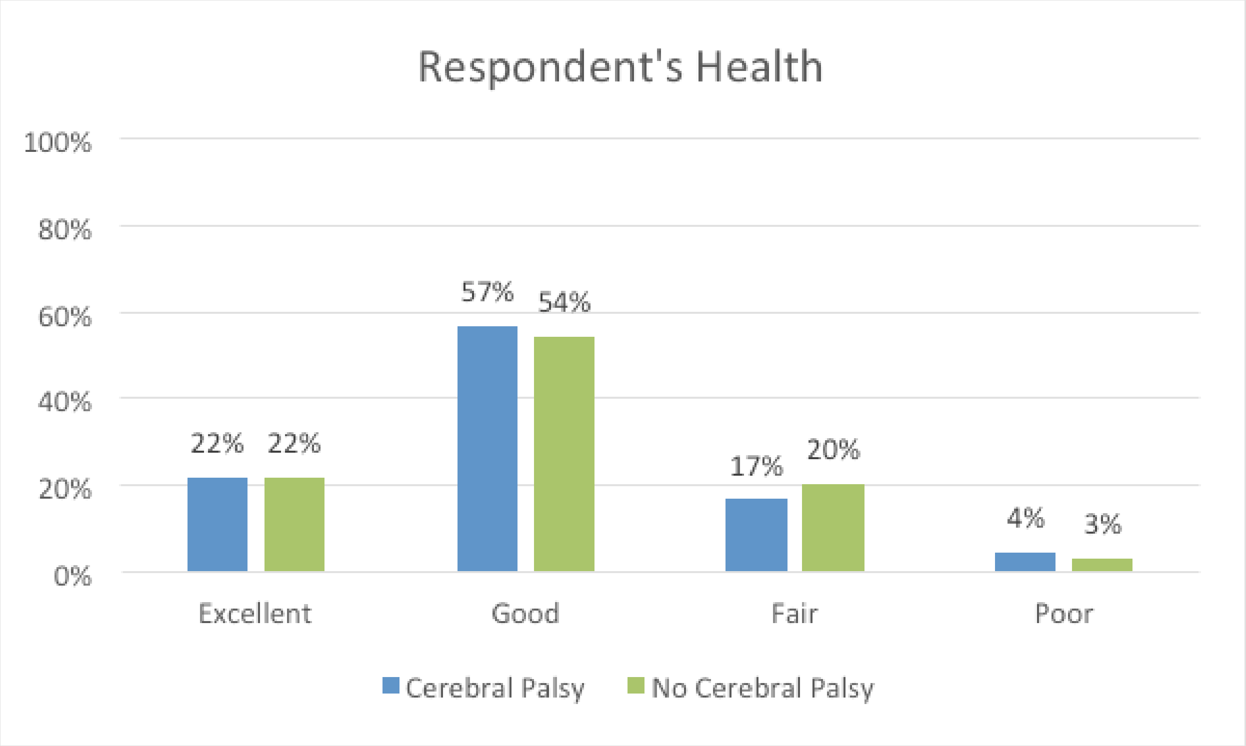

Table V-13: Respondent's Health by CP[1], [2]

	Excellent	Good	Fair	Poor	N
CP	22%	57%	17%	4%	884
No CP	22%	54%	20%	3%	6686

---

[1] Results were not statistically significant.

[2] Percentages add up to less than 100% due to missing responses.

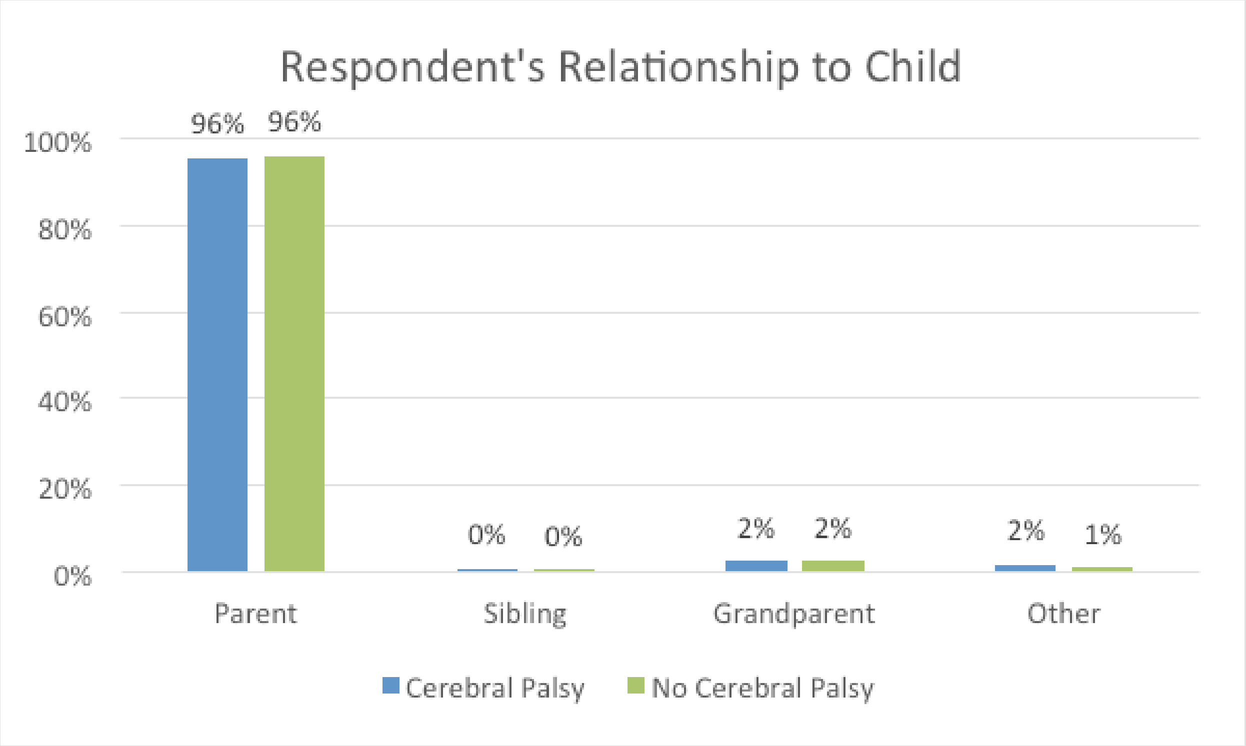

Table V-14: Respondent's Relationship to Child by CP[1], [2]

	Parent	Sibling	Grandparent	Other	N
CP	96%	0%	2%	2%	886
No CP	96%	0%	2%	1%	6715

---

[1] Results for “Parent”, “Sibling” and “Grandparent” were not statistically significant.

[2] Percentages add up to less than 100% due to missing responses.

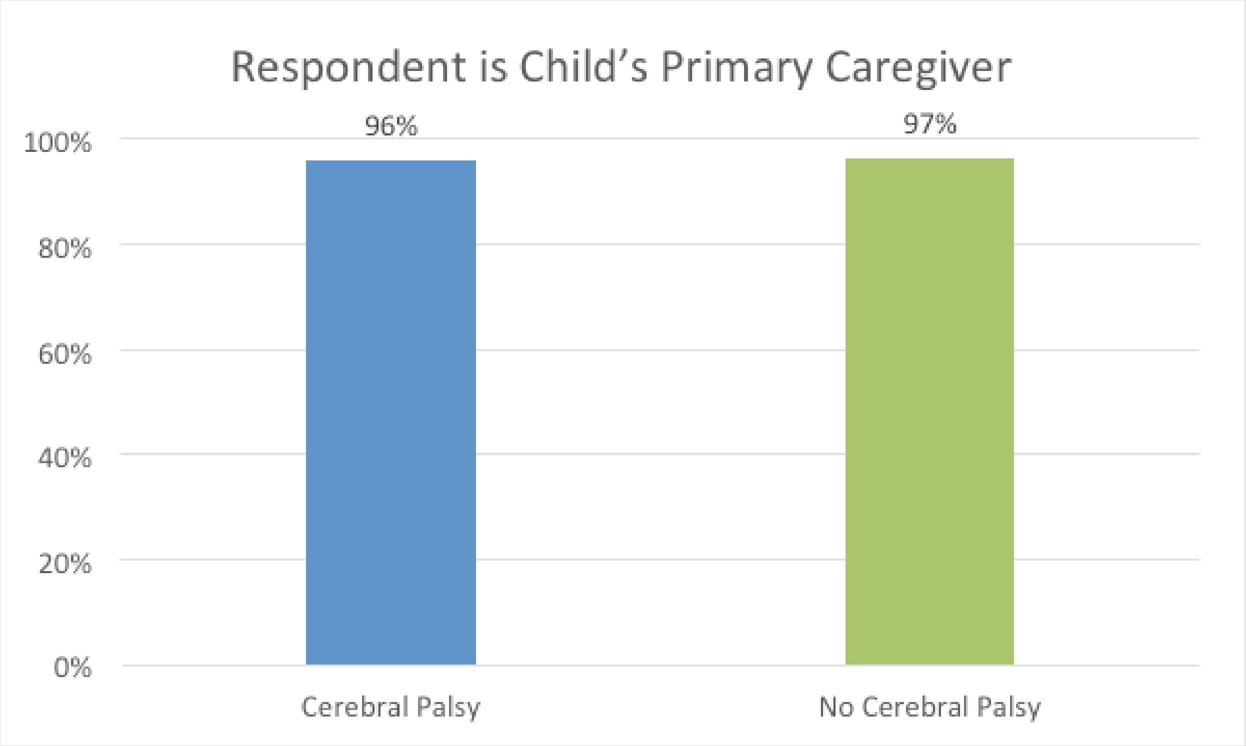

Table V-15: Respondent is Child’s Primary Caregiver by CP[1]

	Yes	N
CP	96%	872
No CP	97%	6652

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[1] Results were not statistically significant.

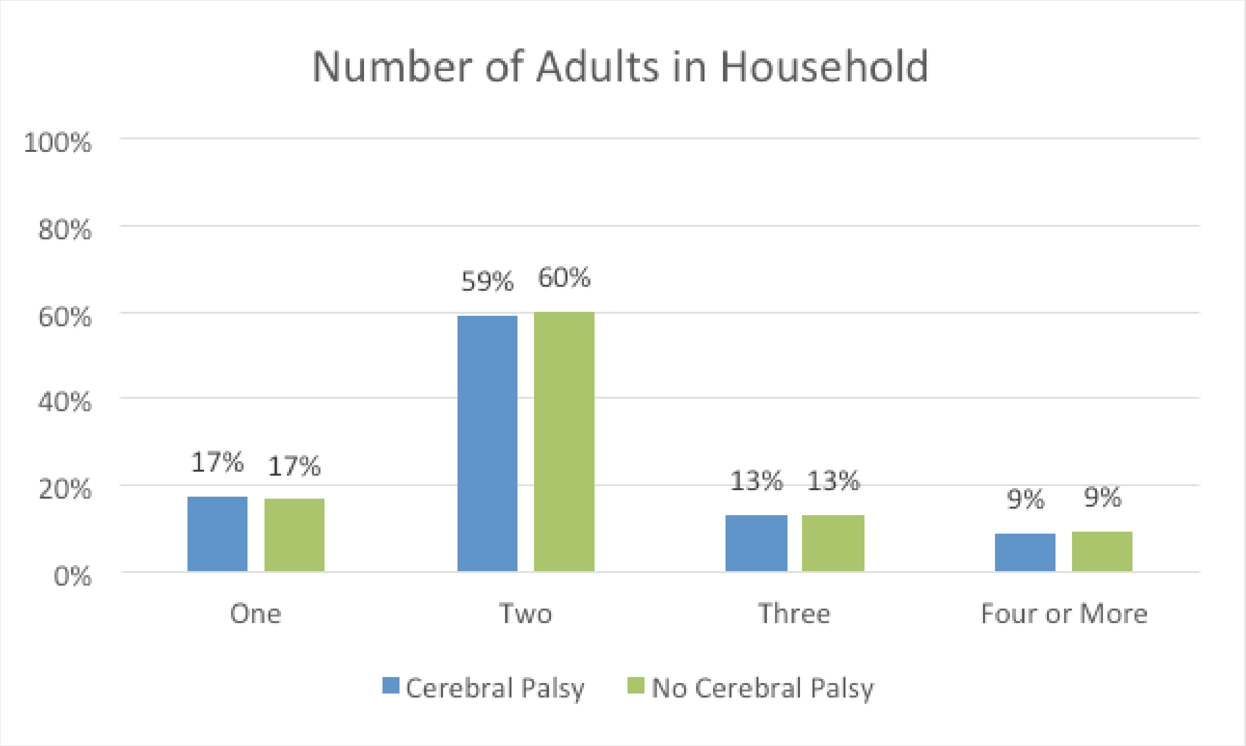

Table V-16: Number of Adults in Household by CP[1], [2]

	One	Two	Three	Four or More	N
CP	17%	59%	13%	9%	874
No CP	17%	60%	13%	9%	6661

---

[1] Results were not statistically significant.

[2] Percentages add up to less than 100% due to missing responses.

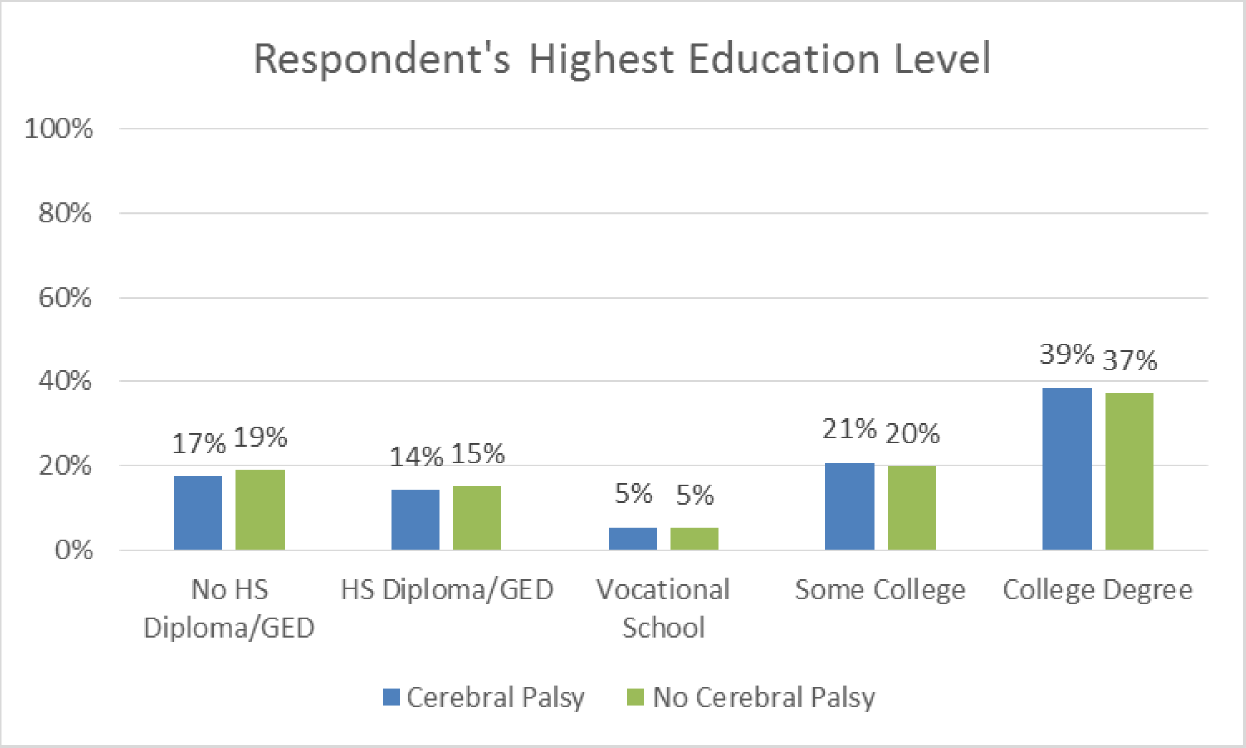

Table V-17: Respondent's Highest Education Level by CP[1], [2]

	No HS Diploma/ GED	HS Diploma/ GED	Vocational School	Some College	College Degree	N
CP	17%	14%	5%	21%	39%	855
No CP	19%	15%	5%	20%	37%	6478

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[1] Results were not statistically significant.

[2] Percentages add up to less than 100% due to missing responses.

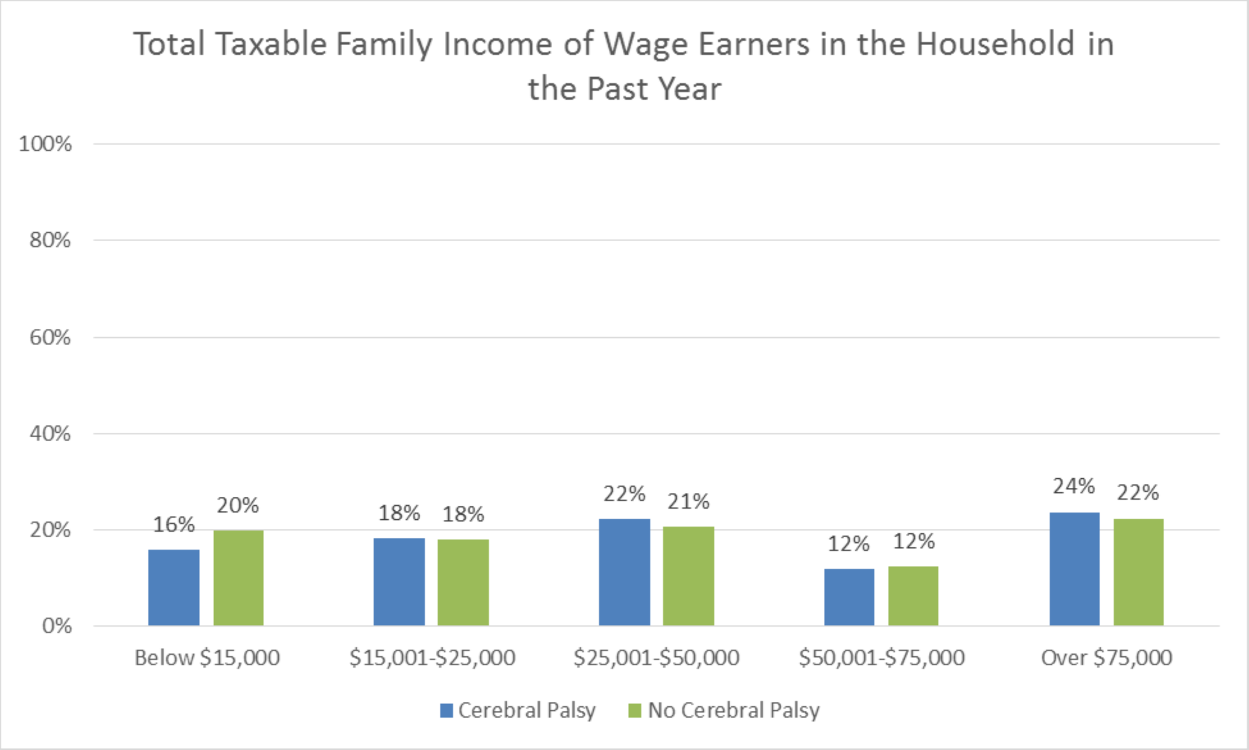

Table V-18: Total Taxable Family Income of Wage Earners in the Household in the Past Year by CP[1]

	Below $15,000	$15,001–$25,000	$25,001–$50,000	$50,001–$75,000	Over $75,000	N
CP	16%	18%	22%	12%	24%	814
No CP	20%	18%	21%	12%	22%	6263

---

[1] Percentages add up to less than 100% due to missing responses.

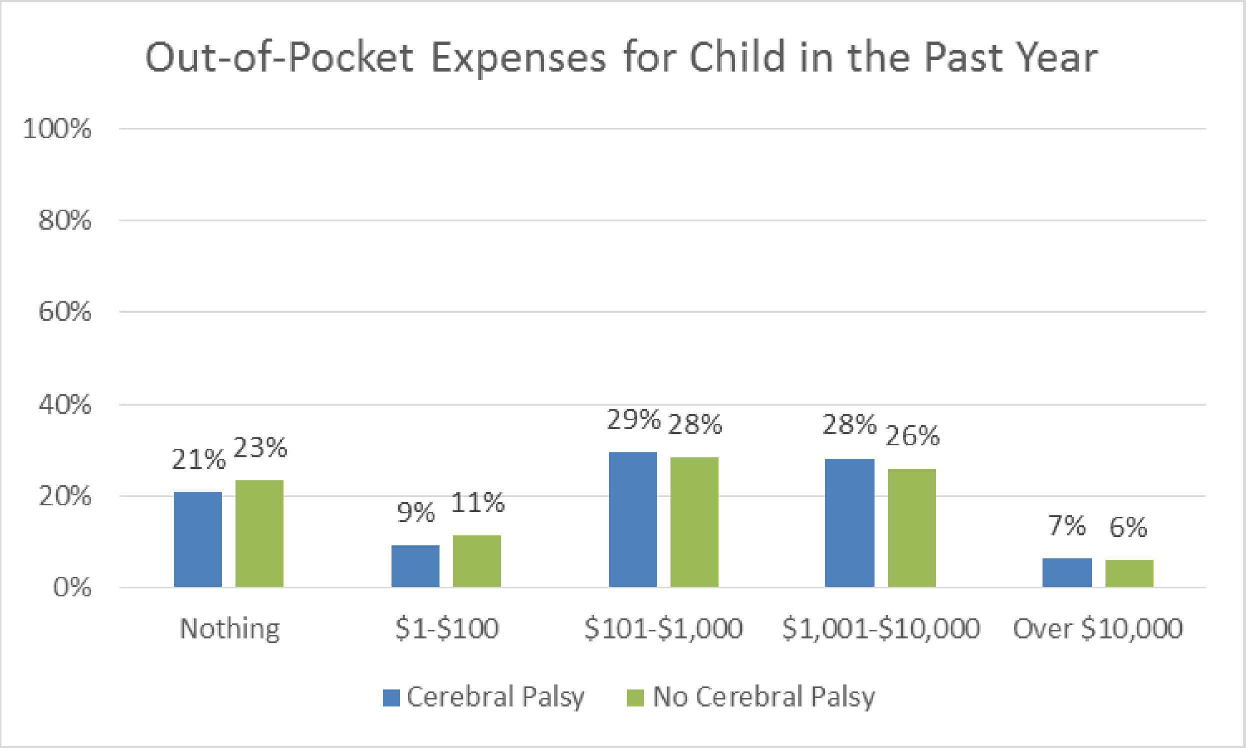

Table V-19: Out-of-Pocket Expenses for Child in the Past Year by CP[1]

	Nothing	$1–$100	$101–$1,000	$1,001–$10,000	Over $10,000	N
CP	21%	9%	29%	28%	7%	839
No CP	23%	11%	28%	26%	6%	6423

---

[1] Percentages add up to less than 100% due to missing responses.

Services and Supports Received by CP

The section on Services and Supports Received in the Child Family Survey includes indicators about: *Types of Services and Supports*. All results are presented here.

Selected Findings on Services and Supports Received

Families of children with CP were more likely to receive financial support compared to families of children without CP (CP: 13%, No CP: 9%). Families of children with CP were more likely to receive in-home support compared to families of children without CP (CP: 67%, No CP: 47%). Children with CP were less likely to receive early intervention compared to children without CP (CP: 11%, No CP: 16%). Families of children with CP were more likely to receive transportation assistance compared to families of children without CP (CP: 25%, No CP: 21%). Families of children with CP were more likely to receive other types of services or supports compared to families of children without CP (CP: 53%, No CP: 45%).

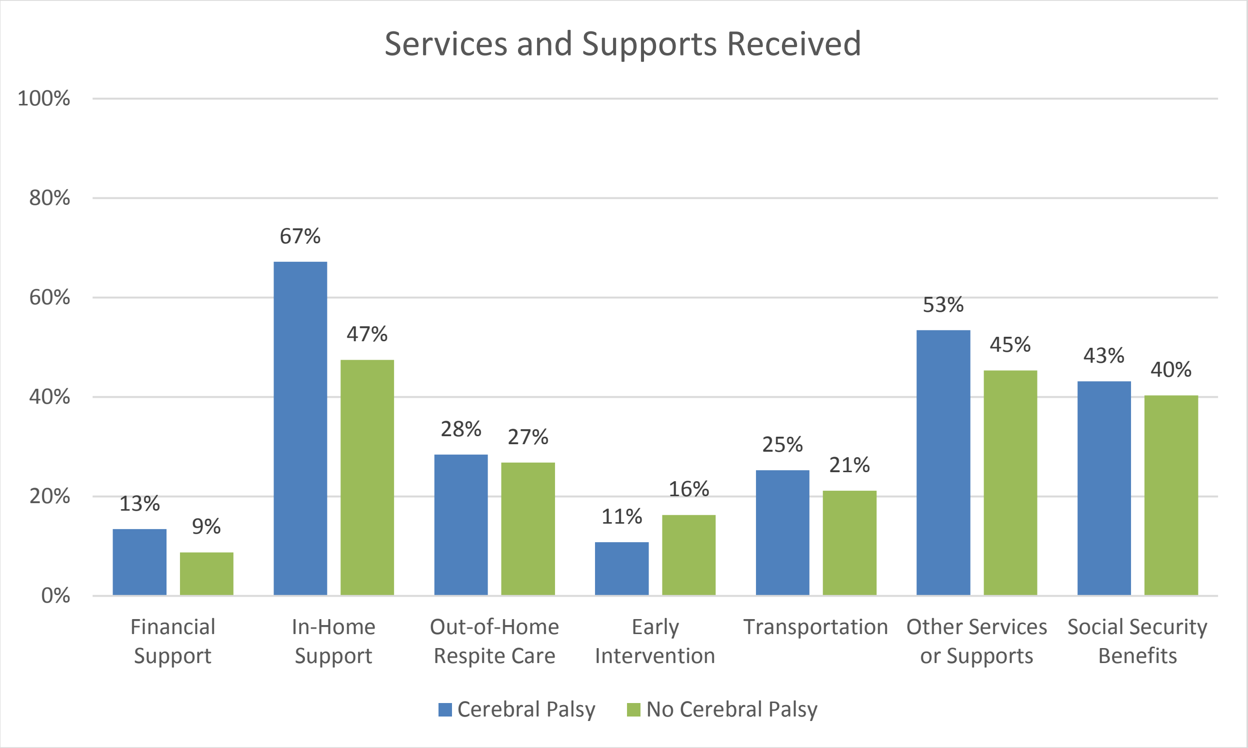

Table V-20: Services and Supports Received by CP[1],[2]

	Financial Support	In-Home Support	Out-of-Home Respite Care	Early Interventi on	Transport -ation	Other Services or Supports	Social Security Benefits
CP	13%	67%	28%	11%	25%	53%	43%
No CP	9%	47%	27%	16%	21%	45%	40%

---

[1] Results for “Out-Of-Home Respite Care” and “Social Security Benefits” were not statistically significant.

[2] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

Information and Planning by CP

The section on Information and Planning in the Child Family Survey includes indicators about: *Available Services and Supports, Planning with Service Coordinator,* and *Child's Individual Program Plan (IPP)*. Results that were statistically significant are presented here. The complete list of results for children with CP is located in Appendix E.

Selected Findings on Information and Planning

Families of children with CP were more likely to receive information about family's rights compared to families of children without CP (CP: 68%, No CP: 65%).

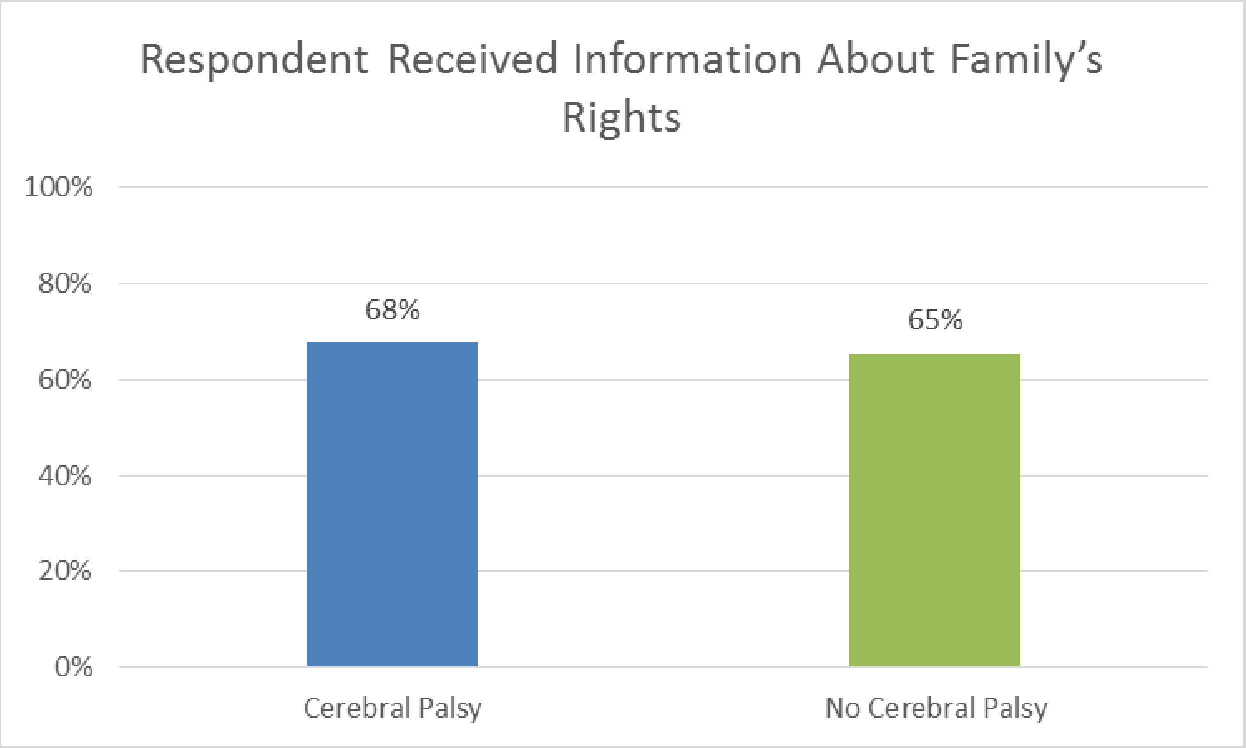

Table V-21: Did you receive information about your family's rights?

	Yes	N
CP	68%	697
No CP	65%	5331

Access and Delivery of Services and Supports by CP

The section on Access and Delivery in the Child Family Survey includes indicators about: *Accessibility of Support Workers and Service Coordinators, Accessibility of Supports and Services, Communication with Workers,* and *Delivery of Specific Services*. Results that were statistically significant are presented here. The complete list of results for children with CP is located in Appendix E.

Selected Findings on Access and Delivery

Families of children with CP had significant differences in support workers' ability to communicate with their child if non-verbal compared to families of children without CP[1] (e.g., always able to communicate with child if non-verbal, CP: 9%, No CP: 6%). Families of children with CP had significant differences in their child having access to special equipment or accommodations needed compared to families of children without CP[1] (e.g., always have access to special equipment or accommodations needed, CP: 38%, No CP: 12%). Families of children with CP had significant differences in support workers having the right training to meet their child's needs compared to families of children without CP[1] (e.g., support workers always have the right training to meet their child's needs, CP: 38%, No CP: 34%). Families of children with CP were more likely to have access to health services compared to families of children without CP (CP: 91%, No CP: 83%). Families of children with CP were more likely to be satisfied with quality of child's health care providers compared to families of children without CP (CP: 88%, No CP: 83%). Families of children with CP were more likely to have access to necessary medications for their child compared to families of children without CP (CP: 87%, No CP: 76%). Families of children with CP were more likely to have access to respite services compared to families of children without CP (CP: 74%, No CP: 63%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with CP compared to Family/Survey Respondents of children without CP.

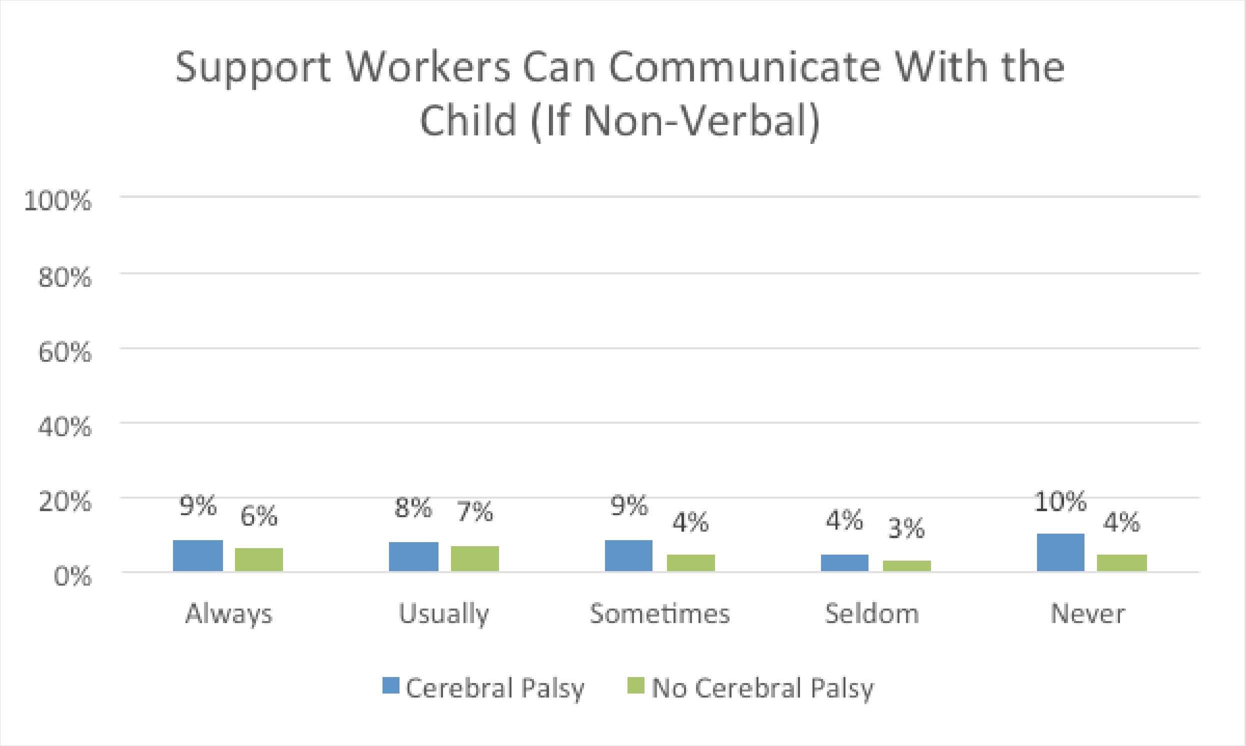

Table V-22: If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?[1]

	Always	Usually	Sometimes	Seldom	Never	N
CP	9%	8%	9%	4%	10%	348
No CP	6%	7%	4%	3%	4%	1593

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

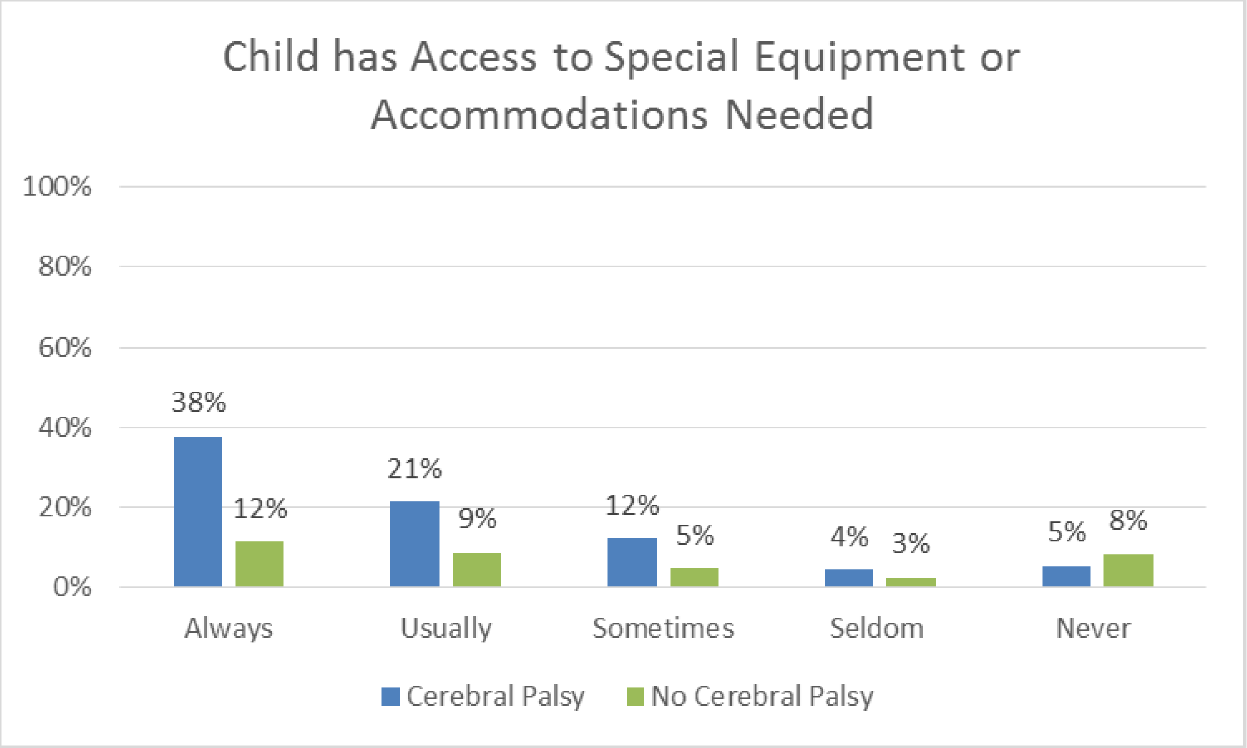

Table V-23: Does your child have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?[1]

	Always	Usually	Sometimes	Seldom	Never	N
CP	38%	21%	12%	4%	5%	720
No CP	12%	9%	5%	3%	8%	2434

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

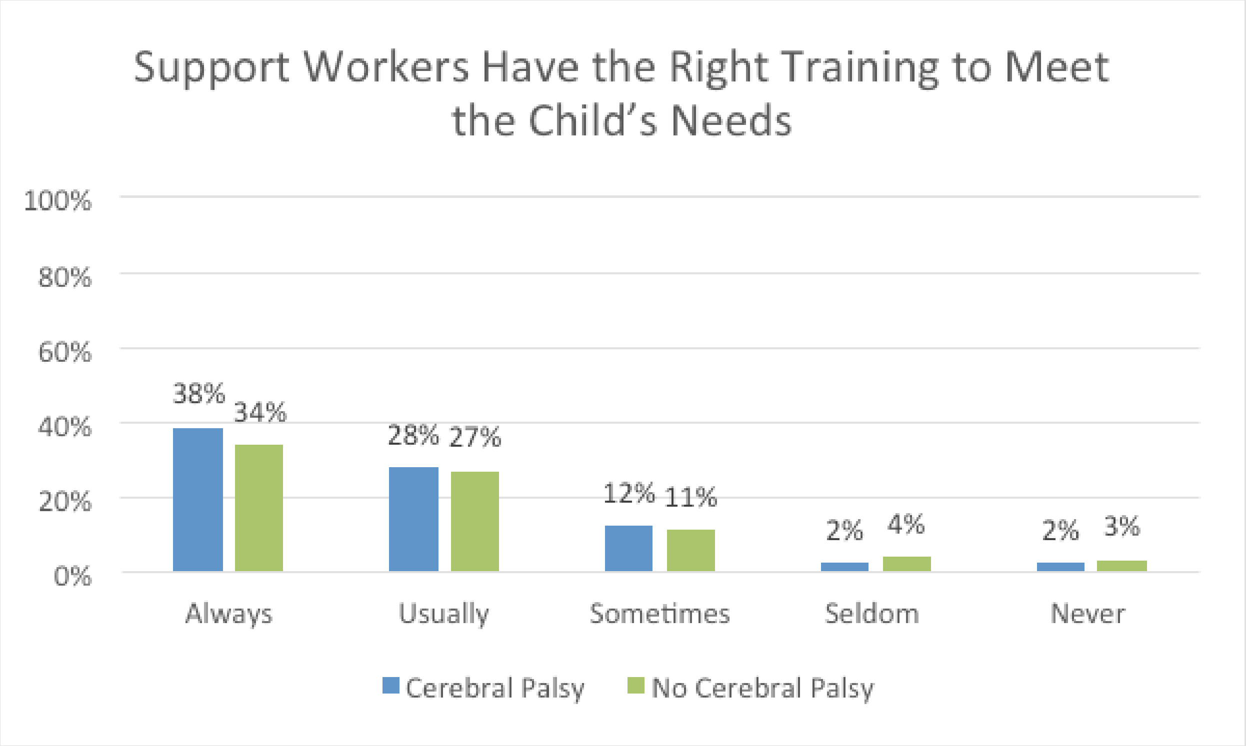

Table V-24: Do the support workers have the right training to meet your child's needs?[1]

	Always	Usually	Sometimes	Seldom	Never	N
CP	38%	28%	12%	2%	2%	731
No CP	34%	27%	11%	4%	3%	5255

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[1] Percentages add up to less than 100% due to missing responses, responses of "Don't Know" or "Do Not Apply."

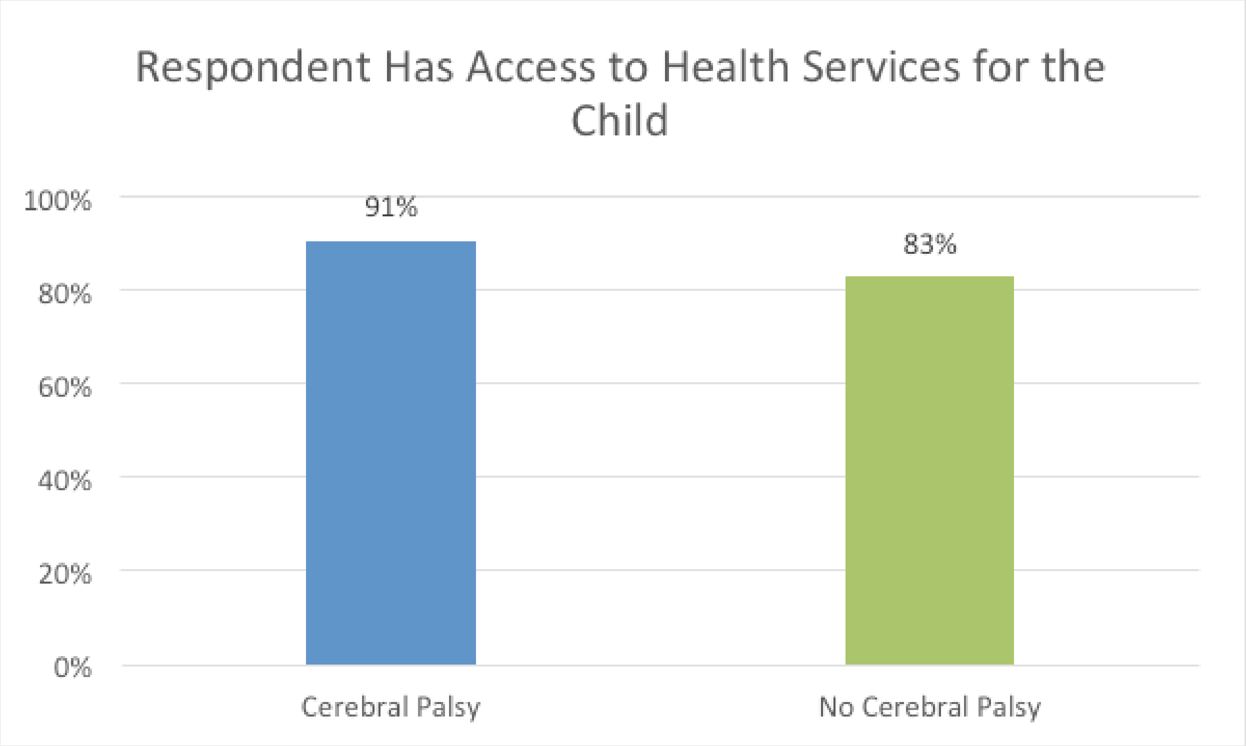

Table V-25: Do you have access to health services for your child?

	Yes	N
CP	91%	828
No CP	83%	5955

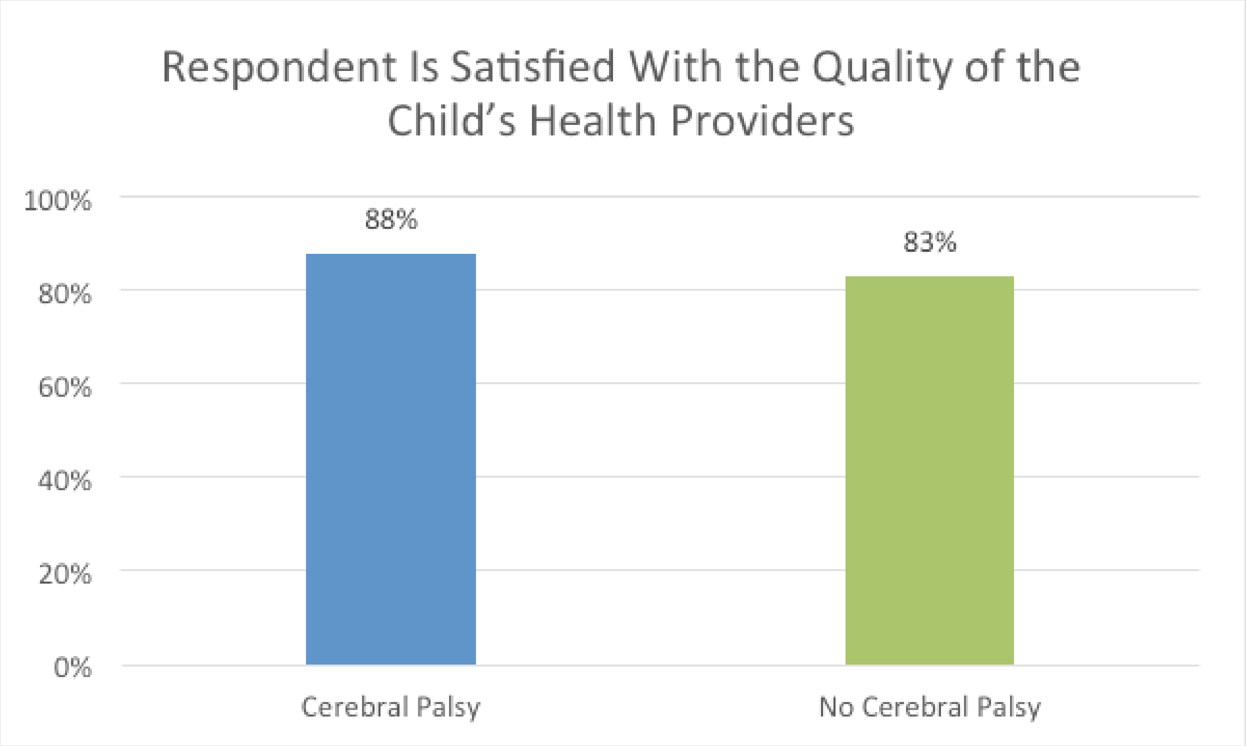

Table V-26: If you have access to health services for your child, are you satisfied with the quality of these providers?

	Yes	N
CP	88%	759
No CP	83%	5123

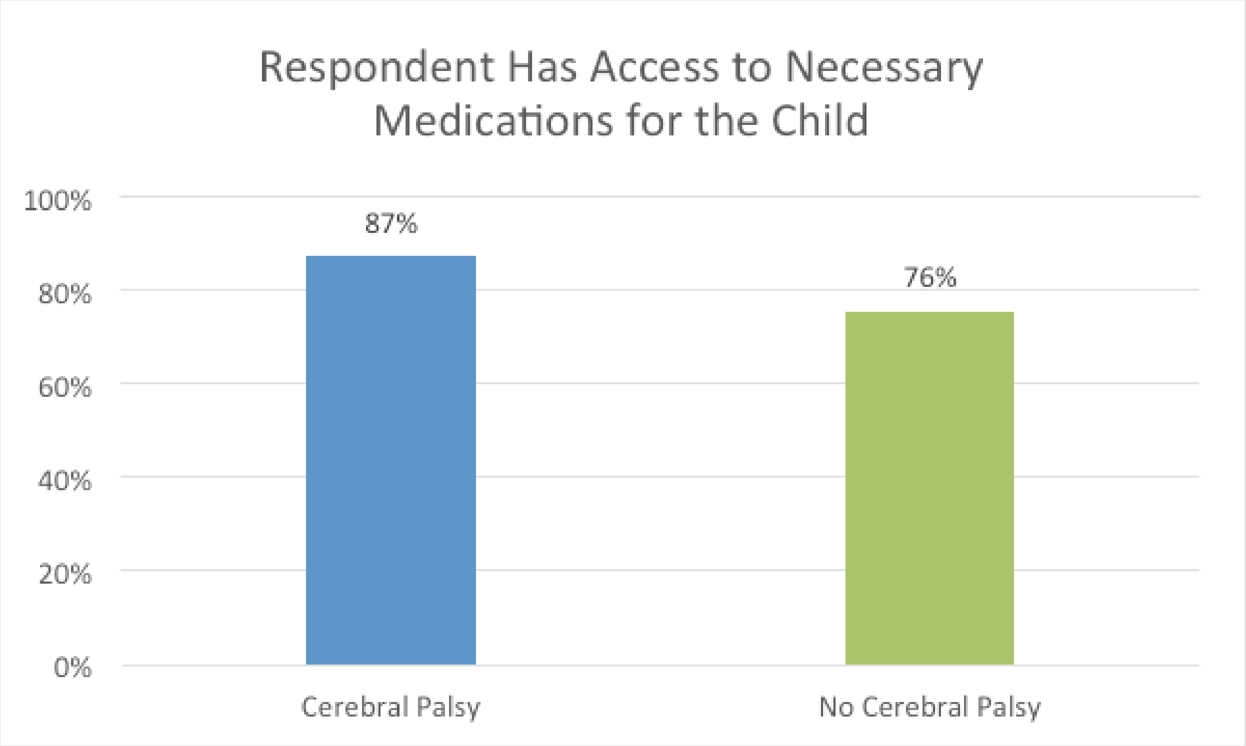

Table V-27: Are you able to get medications needed for your child?

	Yes	N
CP	87%	795
No CP	76%	5384

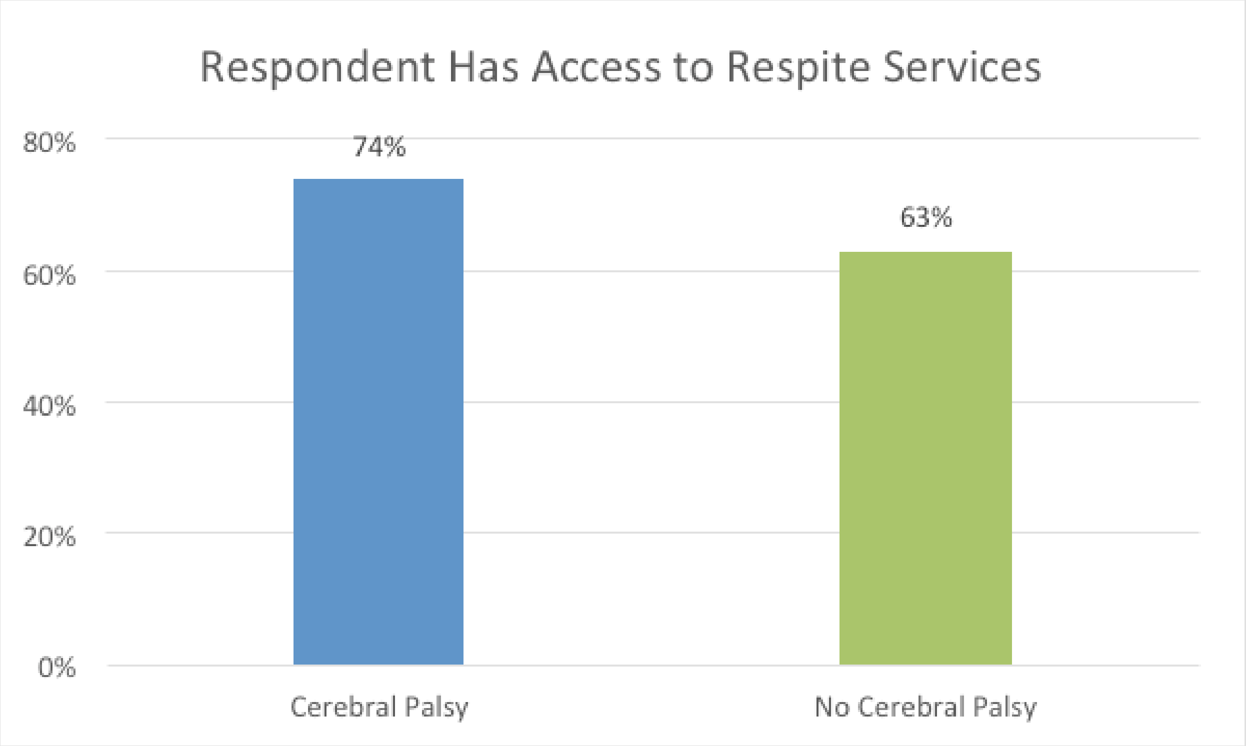

Table V-28: If you need respite services, do you have access to them?

	Yes	N
CP	74%	746
No CP	63%	5034

Choice and Control by CP

The section on Choice and Control in the Child Family Survey includes indicators about: *Choosing Provider Agencies, Choosing Support Workers,* and *Control over Management of Money Spent on Child*. Results that were statistically significant are presented here. The complete list of results for children with CP is located in Appendix E.

Selected Findings on Choice and Control

Families of children with CP had significant differences in ability to choose individual support workers who work with the family compared to families of children without CP[1] (e.g., always able to choose individual support workers who work with the family, CP: 28%, No CP: 22%). Families of children with CP were more likely to have a say in how regional center money was spent on behalf of their child compared to families of children without CP (CP: 12%, No CP: 10%). Families of children with CP were less likely to have all the information they need to decide how to spend regional center money compared to families of children without CP (CP: 43%, No CP: 60%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with CP compared to Family/Survey Respondents of children without CP.

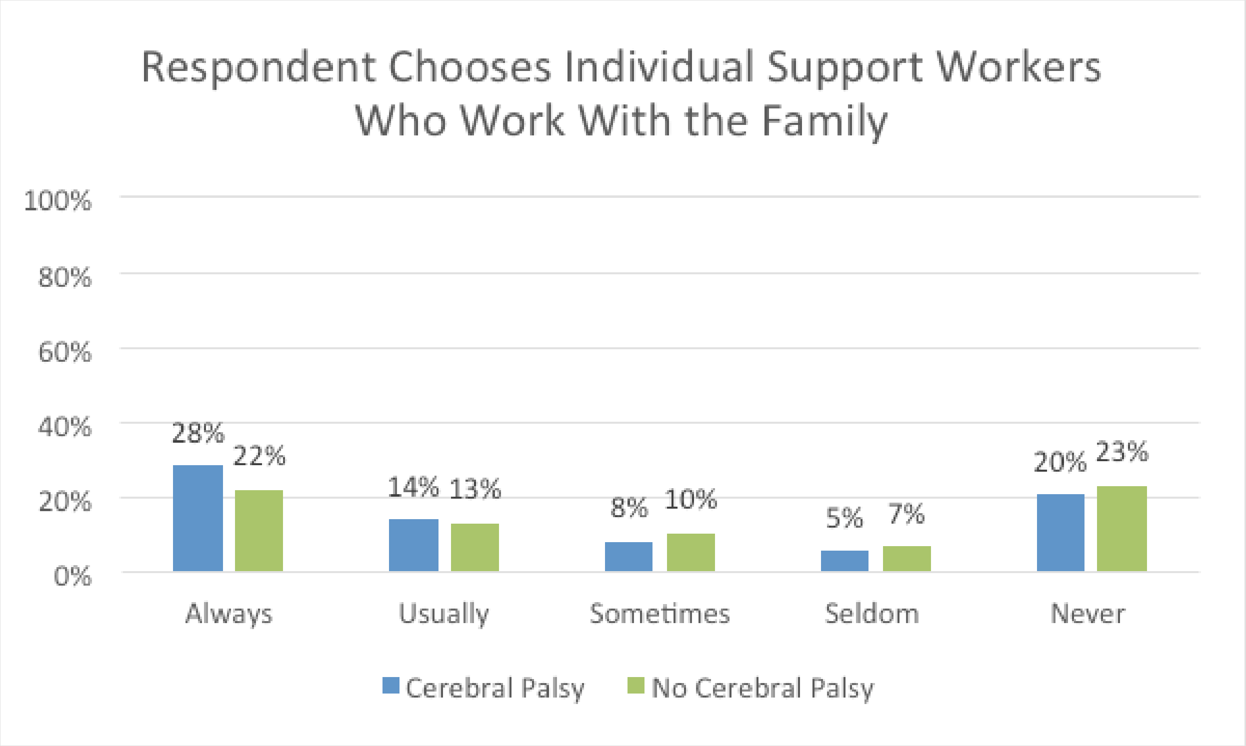

Table V-29: Do you choose the individual support workers who work directly with your family?[1]

	Always	Usually	Sometimes	Seldom	Never	N
CP	28%	14%	8%	5%	20%	671
No CP	22%	13%	10%	7%	23%	4999

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

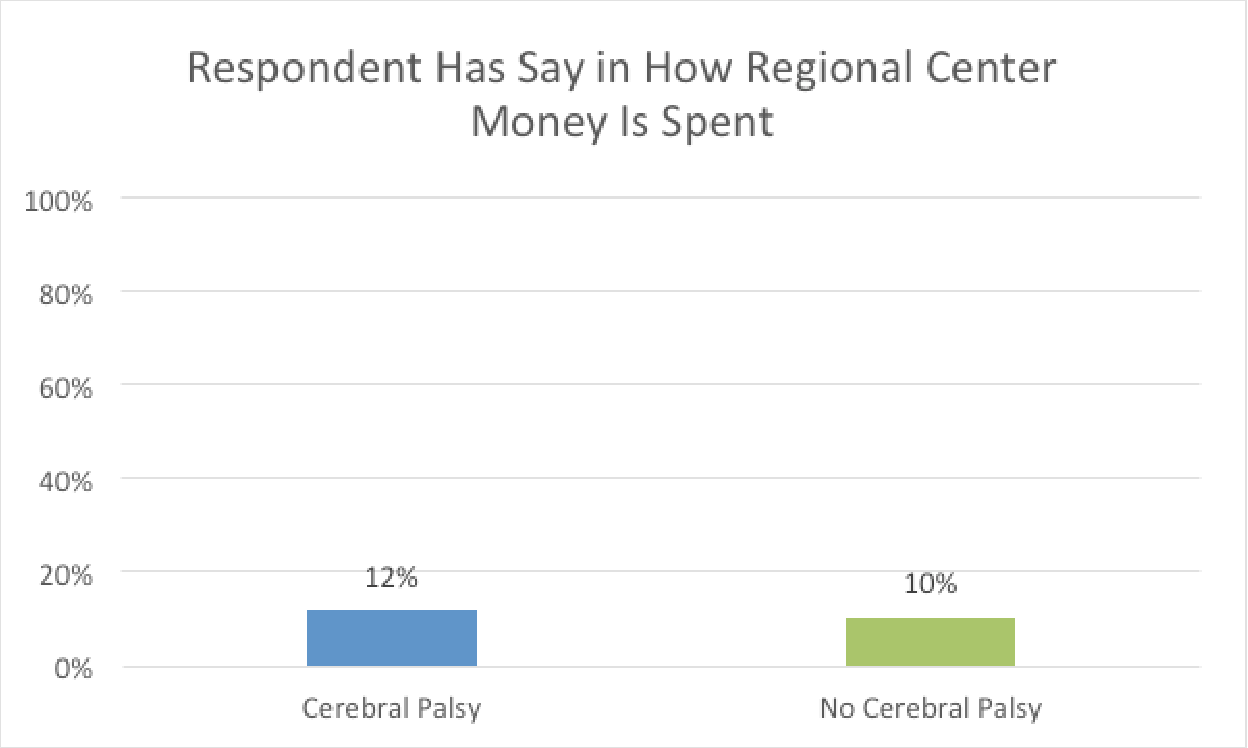

Table V-30: Do you have a say in how regional center money is spent?

	Yes	N
CP	12%	516
No CP	10%	4214

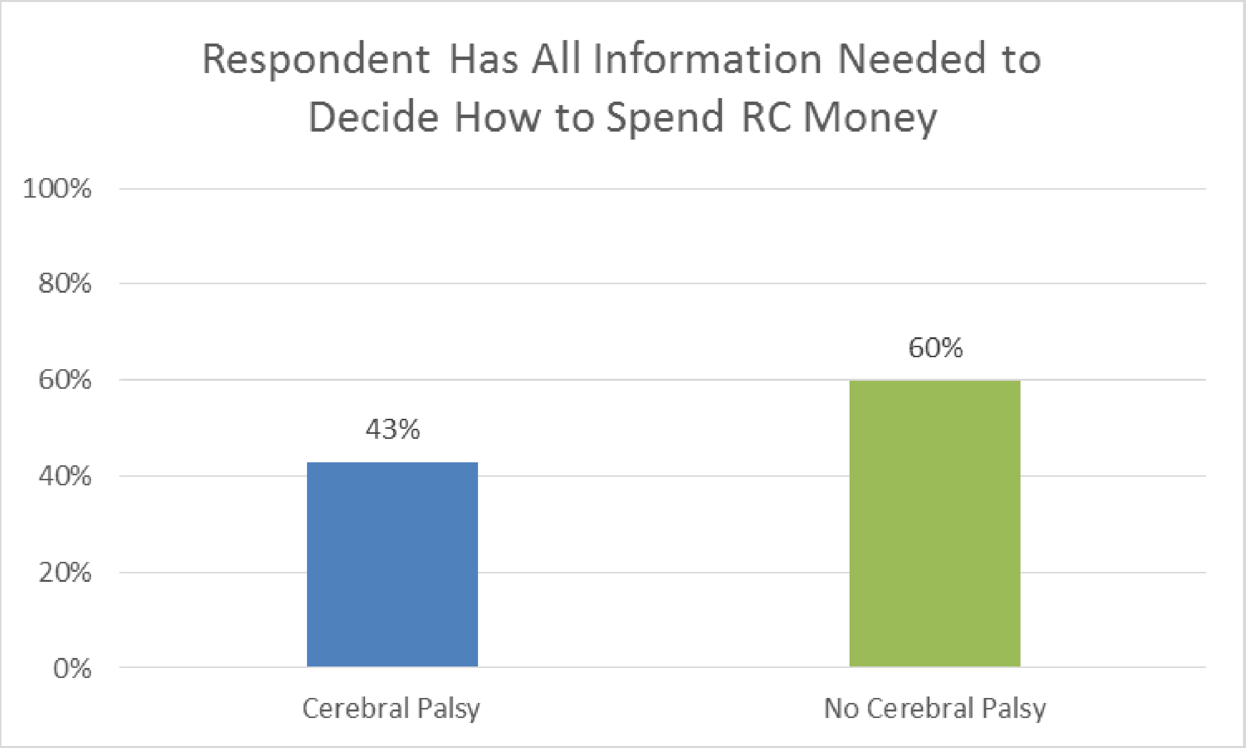

Table V-31: If you have a say in how regional center money is spent, do you have the information you need to make decisions about how to spend this money?

	Yes	N
CP	43%	70
No CP	60%	542

Community Connections by CP

The section on Community Connections in the Child Family Survey includes indicators about: *Participation in Community.* Results that were statistically significant are presented here. The complete list of results for children with CP is located in Appendix E.

Selected Findings on Community Connections

Among children who did not participate in community activities, survey respondents provided reasons for why their child did not participate in community activities. Families of children with CP were more likely to choose “other” (CP: 51%, No CP: 37%) as a response category for the reason for non-participation compared to families of children without CP (e.g., reasons other than lack of transportation, cost, lack of support, negative attitudes from community members).

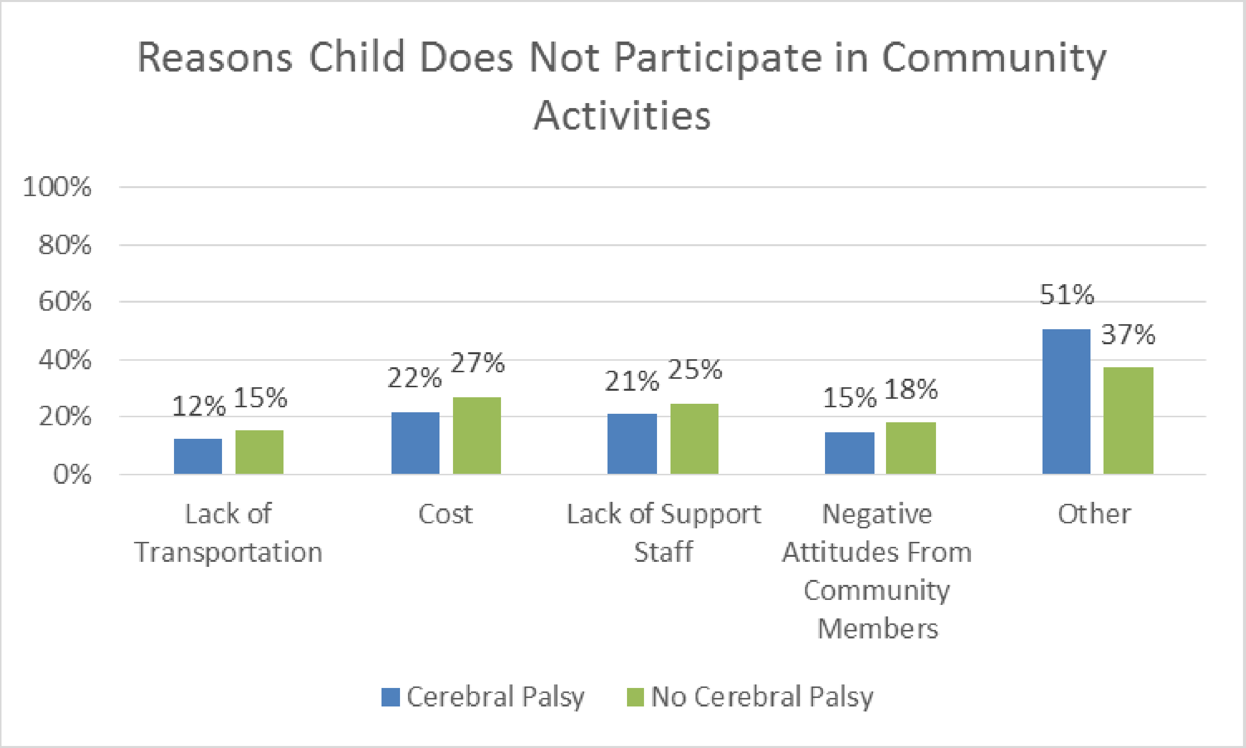

Table V-32: If you child doesn't participate in community activities, why not?[1],[2]

	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes From Community Members	Other
CP	12%	22%	21%	15%	51%
No CP	15%	27%	25%	18%	37%

---

[1] Results for "Lack of Transportation," "Cost," "Lack of Support Staff," and "Negative Attitudes from Community Members" are not statistically significant.

[2] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

Satisfaction with Services and Supports by CP

The section on Satisfaction with Services and Supports in the Child Family Survey includes indicators about: *Satisfaction with Services and Supports,* and *Knowing How to Report Complaints.* Results that were statistically significant are presented here. The complete list of results for children with CP is located in Appendix E.

Selected Findings on Satisfaction with Services and Supports

Families of children with CP had significant differences in satisfaction with services and supports received compared to families of children without CP[1] (e.g., always satisfied with services and supports received, CP: 30%, No CP: 28%). Families of children with CP were more likely to know how to report abuse or neglect compared to families of children without CP (CP: 61%, No CP: 56%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with CP compared to Family/Survey Respondents of children without CP.

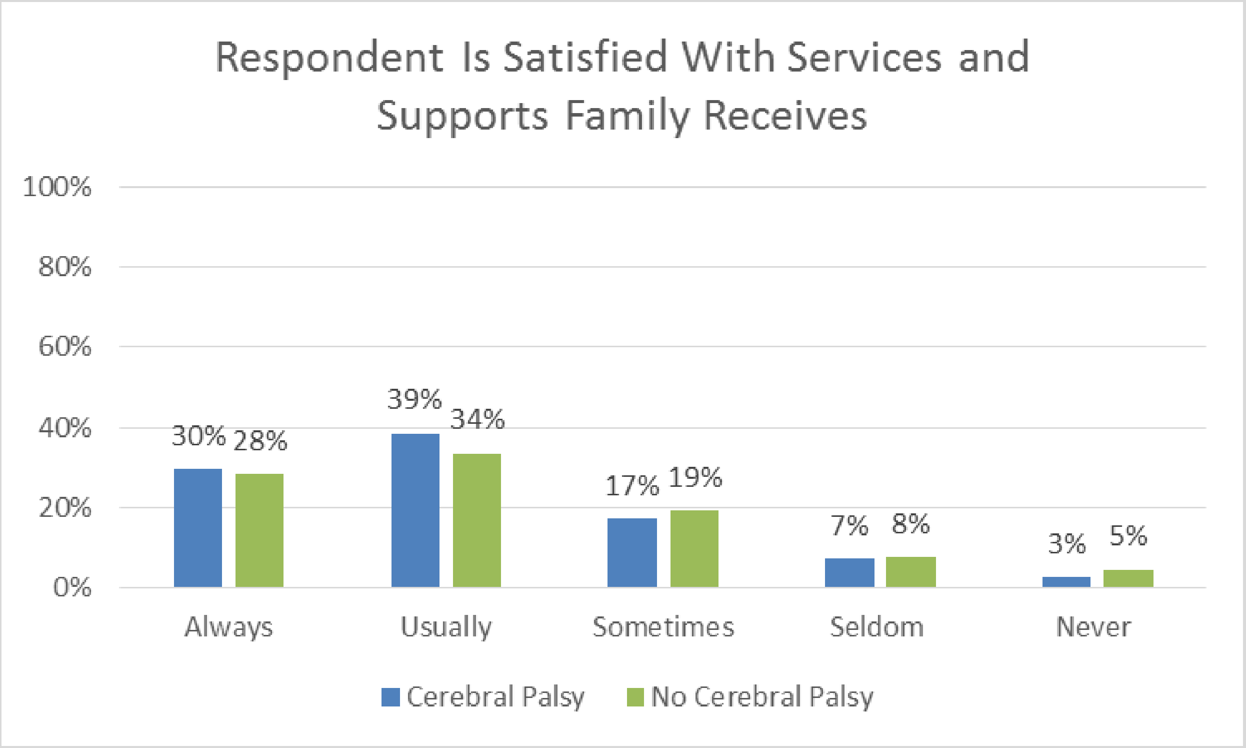

Table V-33: Overall, are you satisfied with the services and supports your family currently receives?[1]

	Always	Usually	Sometimes	Seldom	Never	N
CP	30%	39%	17%	7%	3%	842
No CP	28%	34%	19%	8%	5%	6278

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

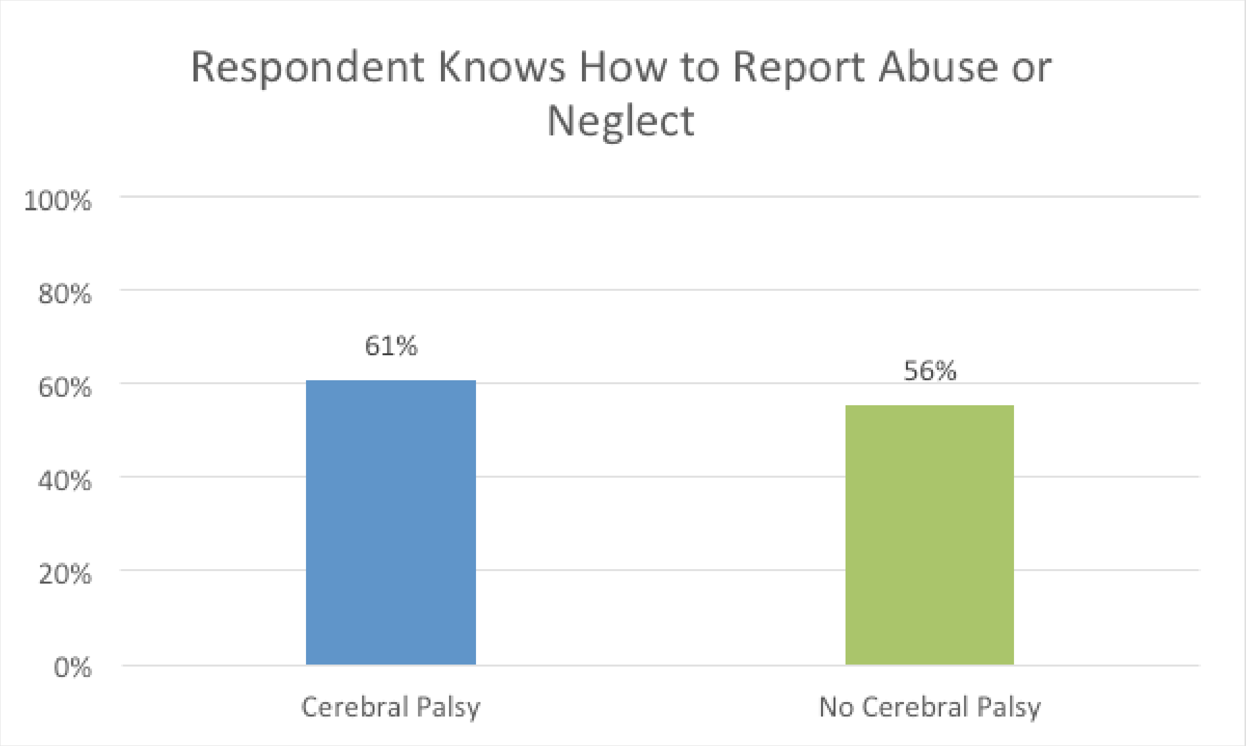

Table V-34: Do you know how to report abuse or neglect?

	Yes	N
CP	61%	857
No CP	56%	6465

Family Outcomes by CP

The section on Family Outcomes in the Child Family Survey includes indicators about: *Positive Impact of Services and Supports* and *Reduction of Services and Supports.* The complete list of results for children with CP is located in Appendix E.

Selected Findings on Outcomes

There were no significant differences in the indicators in the Family Outcomes section between children with CP and children without CP[1].

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[1] See Appendix E for tables describing all indicators with respective sample sizes in this section.

VI. Epilepsy

This chapter summarizes demographics and statistically significant outcomes for children with a diagnosis of epilepsy compared to children without a diagnosis of epilepsy. Results reflect responses from 1,101 families of children with epilepsy and 6,529 families of children without epilepsy.

Summary of Observations by Epilepsy

Results for demographics and statistically significant outcome measures comparing children with epilepsy and children without epilepsy are summarized below. Where noted, differences between the two subgroups were statistically significant at $p<.05$[1]. The statistical tests used to determine significant subgroup differences for each survey question are found in Appendix B. Complete tables describing all outcomes with respective sample sizes are found in Appendix F.

Selected Key Findings

In the Child's Demographic Information section, children with epilepsy compared to children without epilepsy were older, less likely to be male, more likely to be female, and more likely to have additional qualifying conditions and disability diagnoses. Children with epilepsy were less likely to use spoken language as their primary means of expression compared to children without epilepsy. There was no difference in number of children with epilepsy who spoke English as their preferred language compared to children without epilepsy. Families of children with epilepsy have a significant difference in the amount of help needed to care for their child compared with families of children without epilepsy.

In the Family/Survey Respondent's Demographic Information section, there were no significant differences in parents completing the CFS1 survey between families of children with epilepsy and families of children without epilepsy. Families of children with epilepsy were more likely to have a college degree compared to families of children without epilepsy. There was no significant difference in the quality of health of families of children with epilepsy and families of children without epilepsy. Families of children with epilepsy have significant differences in total household income and out-of-pocket expenses compared to families of children without epilepsy.

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[1] P<.05 refers to the how likely a finding in the data is due to chance and when p<.05 we have confidence that the finding is not due to chance. This finding of statistical significance does not necessarily mean that the finding is a really important finding.

In the Services and Supports Received section, families of children with epilepsy were more likely to receive financial support and in-home support compared to families of children without epilepsy. Children with epilepsy were less likely to receive early intervention compared to children without epilepsy. There were no significant differences in receiving out-of-home respite care, transportation assistance, Social Security benefits, and other supports or services between families of children with epilepsy and families of children without epilepsy.

In the Information and Planning section, there was no significant difference in receiving information about available services and supports between families of children with epilepsy and families of children without epilepsy. There was no significant difference in having an individual program plan (IPP) between children with epilepsy and children without epilepsy. Families of children with epilepsy were more likely to help develop an IPP compared to families of children without epilepsy. There was no significant difference between families of children with epilepsy and families of children without epilepsy in receiving information about their family’s rights.

In the Access and Delivery section, there was no significant difference in ability to contact support workers and service coordinators when needed between families of children with epilepsy and families of children without epilepsy. There was no significant difference between families of children with epilepsy and families of children without epilepsy in support workers having the right training to meet their child’s needs.

In the Choice and Control section, there was no significant difference in choosing provider agencies between families of children with epilepsy and families of children without epilepsy. There was a significant difference in choosing individual support workers between families of children with epilepsy and families of children without epilepsy. There was no significant difference knowing how much money was spent by the regional center on behalf of their child between families of children with epilepsy and families of children without epilepsy. There was a significant difference in having a say in how regional center money was spent on behalf of their child between families of children with epilepsy and families of children without epilepsy.

In the Community Connections section, children with epilepsy were less likely to participate in community activities compared to children without epilepsy. There was no significant difference in spending time with children who do not have a developmental disability between children with epilepsy and children without epilepsy.

In the Satisfaction with Services and Supports section, there was no significant difference in satisfaction with services and supports received by families of children with epilepsy and families of children without epilepsy. There was no significant difference in satisfaction with how complaints were handled by provider agencies between families of children with epilepsy and families of children without epilepsy. Families of children with epilepsy were more likely to know how to report abuse or neglect compared to families of children without epilepsy.

In the Family Outcomes section, there were no significant differences between families of children with epilepsy and families of children without epilepsy in services and supports making a positive impact in their family’s life and family supports improving their ability to care for their child. There was no significant difference in services and supports being reduced or terminated in the past year between families of children with epilepsy and families of children without epilepsy.

Demographics by Epilepsy

Child’s Demographic Information

The section on Child’s Demographic Information in the Child Family Survey includes indicators about: *Basic Information, Primary Expression and Language,* and *Amount of Help Needed for Child.* All results are presented here.

Selected Findings on Child’s Demographic Information

Children with epilepsy on average were older than children without epilepsy (Epilepsy: 11.43 years old, No Epilepsy: 10.09 years old). Children with epilepsy were less likely to be male compared to children without epilepsy (Epilepsy: 56%, No Epilepsy: 71%). Children with epilepsy were more likely to be female compared to children without epilepsy (Epilepsy: 42%, No Epilepsy: 26%). Children with epilepsy were more likely to be White compared to children without epilepsy (Epilepsy: 45%, No Epilepsy: 35%). Children with epilepsy were less likely to be Hispanic/Latino compared to children without epilepsy (Epilepsy: 36%, No Epilepsy: 42%). Children with epilepsy were less likely to be Asian compared to children without epilepsy (Epilepsy: 10%, No Epilepsy: 13%). Children with epilepsy were more likely to have a Mixed racial background (two or more races) compared to children without epilepsy (Epilepsy: 15%, No Epilepsy: 11%). Children with epilepsy were less likely to have autism spectrum disorder as an additional qualifying condition compared to children without epilepsy (Epilepsy: 32%, No Epilepsy: 66%). Children with epilepsy were more likely to have cerebral palsy as an additional qualifying condition compared to children without epilepsy (Epilepsy: 38%, No Epilepsy: 7%). Children with epilepsy were more likely to have intellectual disability as an additional qualifying condition compared to children without epilepsy (Epilepsy: 66%, No Epilepsy: 30%). Children with epilepsy were more likely to have a mental illness/psychiatric diagnosis/behavioral disorder compared to children without epilepsy (Epilepsy: 17%, No Epilepsy: 12%). Children with epilepsy were more likely to have a brain injury compared to children without epilepsy (Epilepsy: 20%, No Epilepsy: 2%). Children with epilepsy were more likely to have a chemical dependency compared to children without epilepsy (Epilepsy: 3%, No Epilepsy: 0.4%). Children with epilepsy were more likely to have limited/no vision or be legally blind compared to children without epilepsy (Epilepsy: 23%, No Epilepsy: 3%). Children with epilepsy were more likely to have hearing loss compared to children without epilepsy (Epilepsy: 7%, No Epilepsy: 2%). Children with epilepsy were less likely to have Down syndrome compared to children without epilepsy (Epilepsy: 2%, No Epilepsy: 10%). Children with epilepsy were more likely to have another type of disability compared to children without epilepsy (Epilepsy: 35%, No Epilepsy: 13%).

Children with epilepsy were less likely to use spoken language as their primary means of expression compared to children without epilepsy (Epilepsy: 41%, No Epilepsy: 68%). Children with epilepsy more likely to use gestures/body language as their primary means of expression compared to children without epilepsy (Epilepsy: 38%, No Epilepsy: 20%). Children with epilepsy were more likely to use other methods as their primary means of expression compared to children without epilepsy (Epilepsy: 12%, No Epilepsy: 4%). Children with epilepsy were less likely to speak Spanish as their preferred language compared to children without epilepsy (Epilepsy: 18%, No Epilepsy: 23%). Children with epilepsy were more likely to speak a different language (other) not listed as their preferred language compared to children without epilepsy (Epilepsy: 7%, No Epilepsy: 4%).

Children with epilepsy had significant differences in the frequency of medical care needed compared to children without epilepsy[1] (e.g., medical care needed at least once per week, Epilepsy: 19%, No Epilepsy: 6%). Children with epilepsy had significant differences in the amount of behavioral support needed compared to children without epilepsy[1] (e.g., extensive behavioral support needed, Epilepsy: 22%, No Epilepsy: 15%). Children with epilepsy had significant differences in the amount of help needed for daily activities compared to children without epilepsy[1] (e.g., complete help needed, Epilepsy: 62%, No Epilepsy: 28%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with epilepsy compared to Family/Survey Respondents of children without epilepsy.

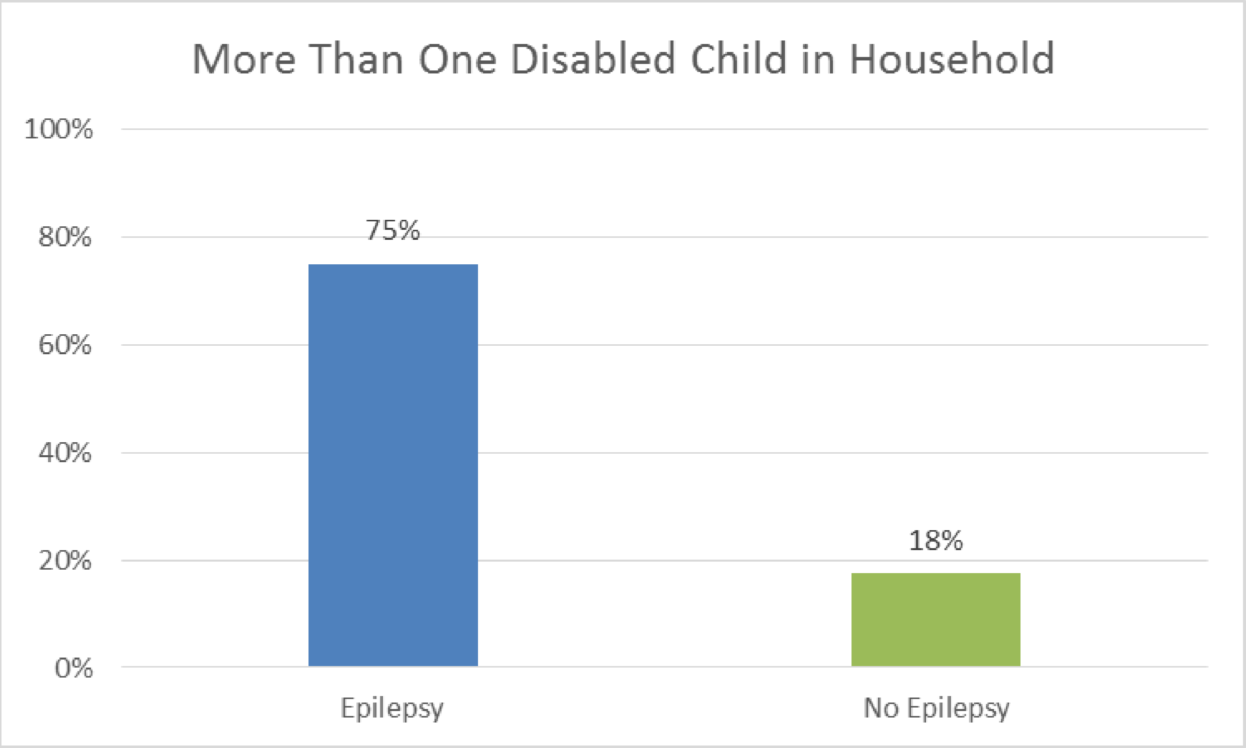

Table VI-1: More Than One Disabled Child in Household by Epilepsy[1]

	Yes	N
Epilepsy	75%	1015
No Epilepsy	18%	5766

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[1] Results were not statistically significant.

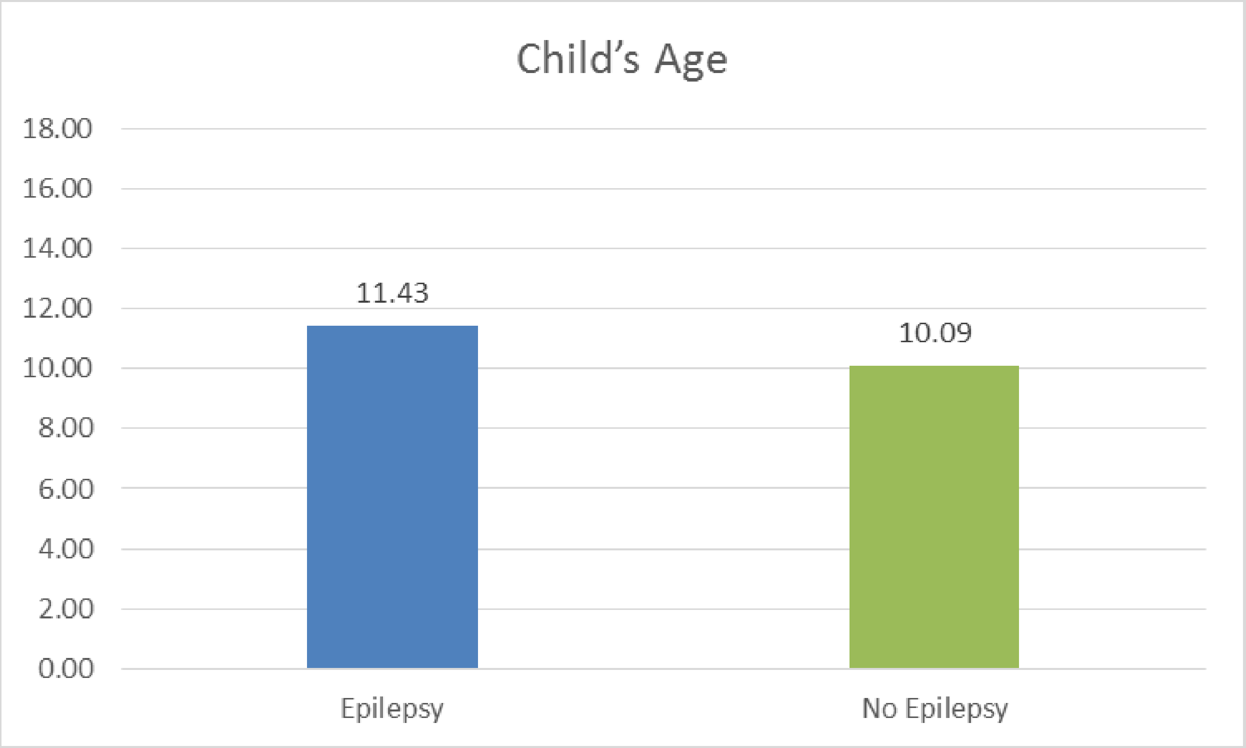

Table VI-2: Child's Age by Epilepsy

	Average Age	N
Epilepsy	11.43	1080
No Epilepsy	10.09	6347

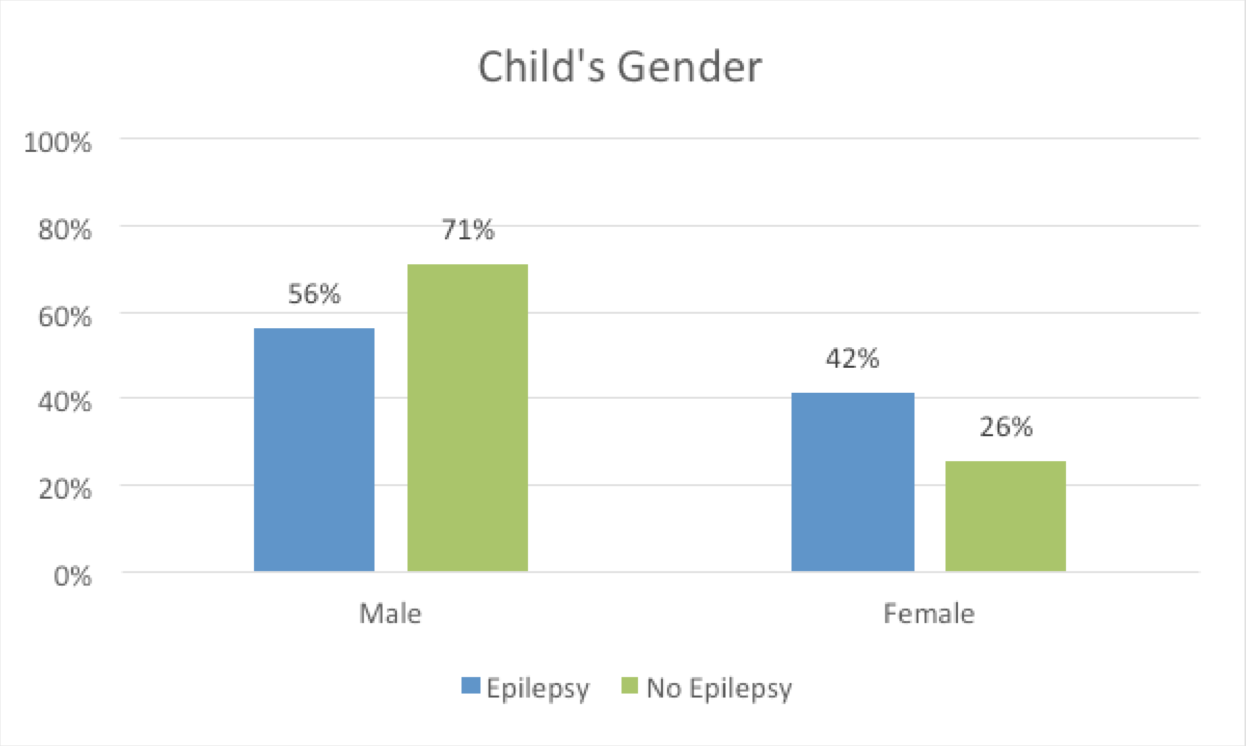

Table VI-3: Child's Gender by Epilepsy[1]

	Male	Female	N
Epilepsy	56%	42%	1078
No Epilepsy	71%	26%	6332

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[1] Percentages add up to less than 100% due to missing responses.

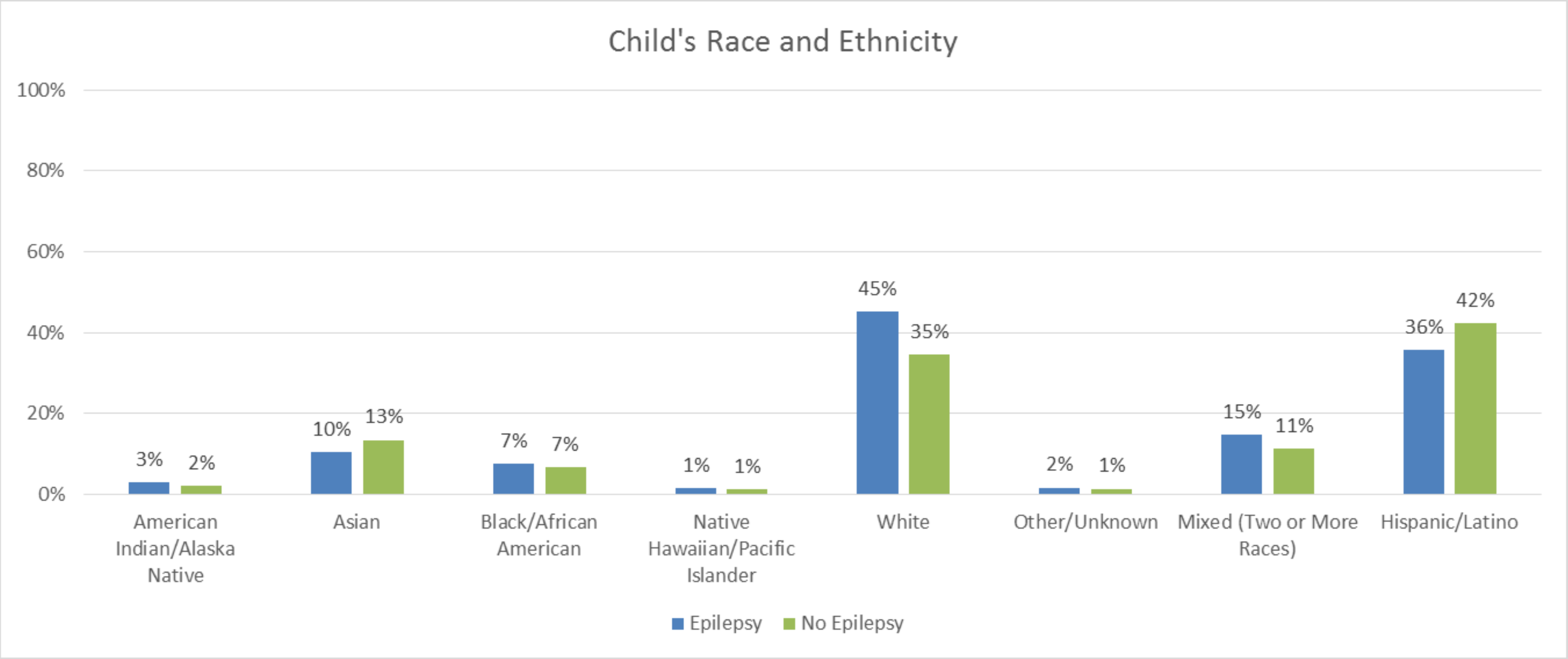

Table VI-4: Child's Race and Ethnicity by Epilepsy[1],[2]

	American Indian/Alaska Native	Asian	Black/African American	Native Hawaiian/ Pacific Islander	White	Other/ Unknown	Mixed (Two or More Races)	Hispanic/ Latino
Epilepsy	3%	10%	7%	1%	45%	2%	15%	36%
No Epilepsy	2%	13%	7%	1%	35%	1%	11%	42%

---

[1] Results for “American Indian/Alaska Native,” “Black/African American,” “Native Hawaiian/Pacific Islander,” and “Other/Unknown” were not statistically significant.
[2] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

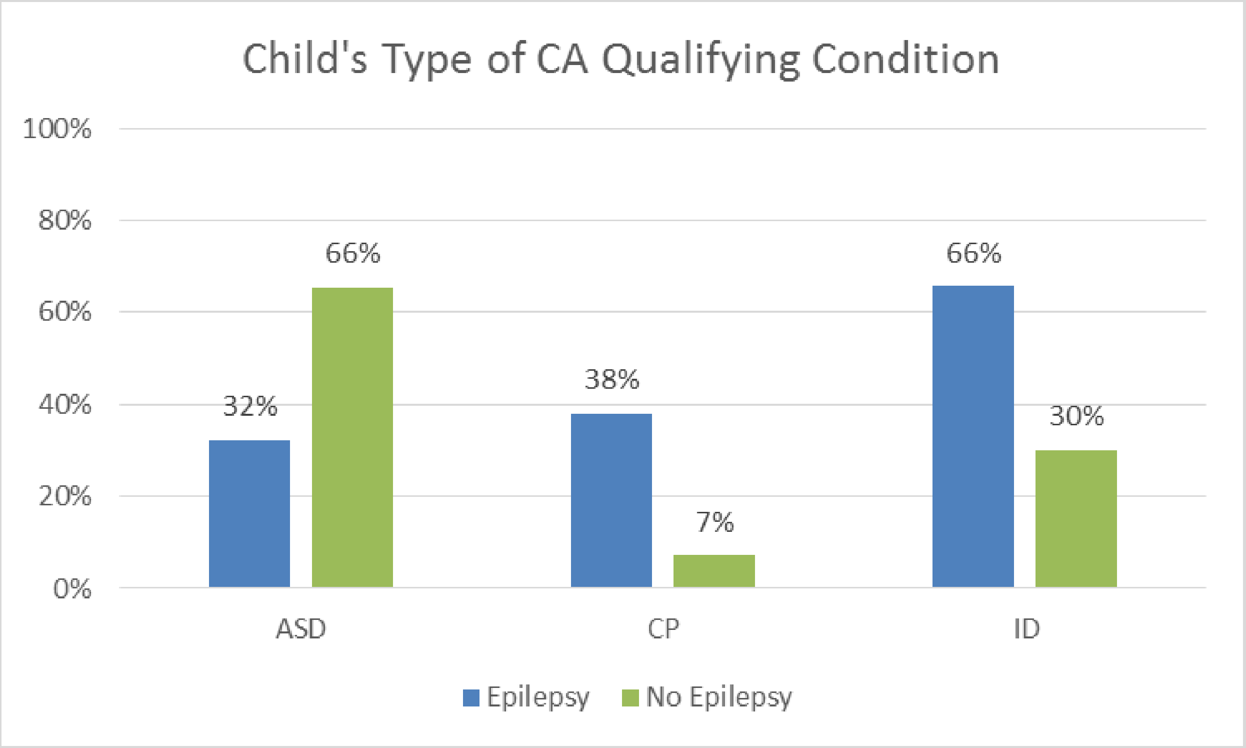

Table VI-5: Child's Type of CA Qualifying Condition by Epilepsy[1]

	ASD	CP	ID
Epilepsy	32%	38%	66%
No Epilepsy	66%	7%	30%

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[1] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

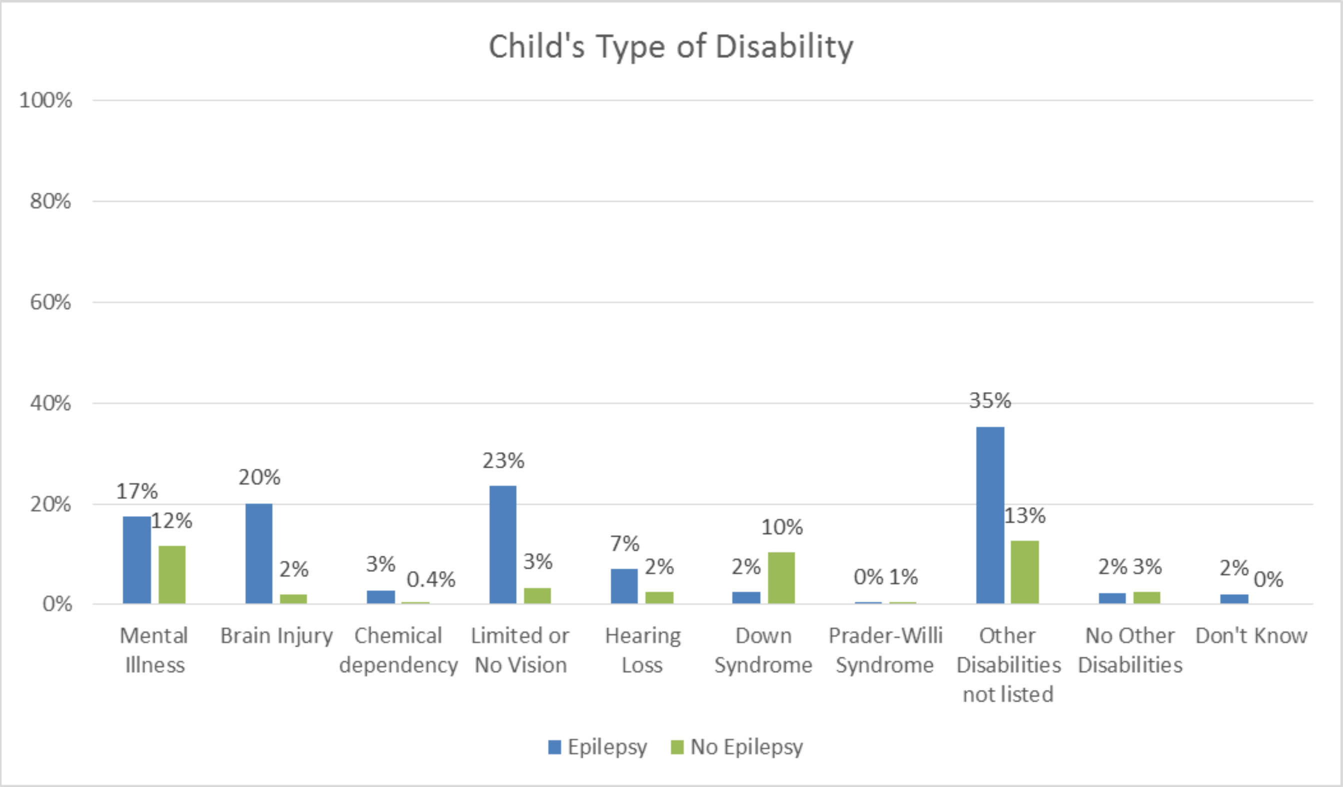

Table VI-6: Child's Type of Disability by Epilepsy[1],[2]

	Mental Illness	Brain Injury	Chemical Dependency	Limited or No Vision	Hearing Loss	Down Syndrome	Prader-Willi Syndrome	Other Disabilities not listed	No Other Disabi-lities	Don't Know
Epilepsy	17%	20%	3%	23%	7%	2%	0%	35%	2%	2%
No Epilepsy	12%	2%	0.4%	3%	2%	10%	1%	13%	3%	0%

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[1] Results for “Prader-Willi Syndrome,” and “No Other Disabilities” were not statistically significant.

[2] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

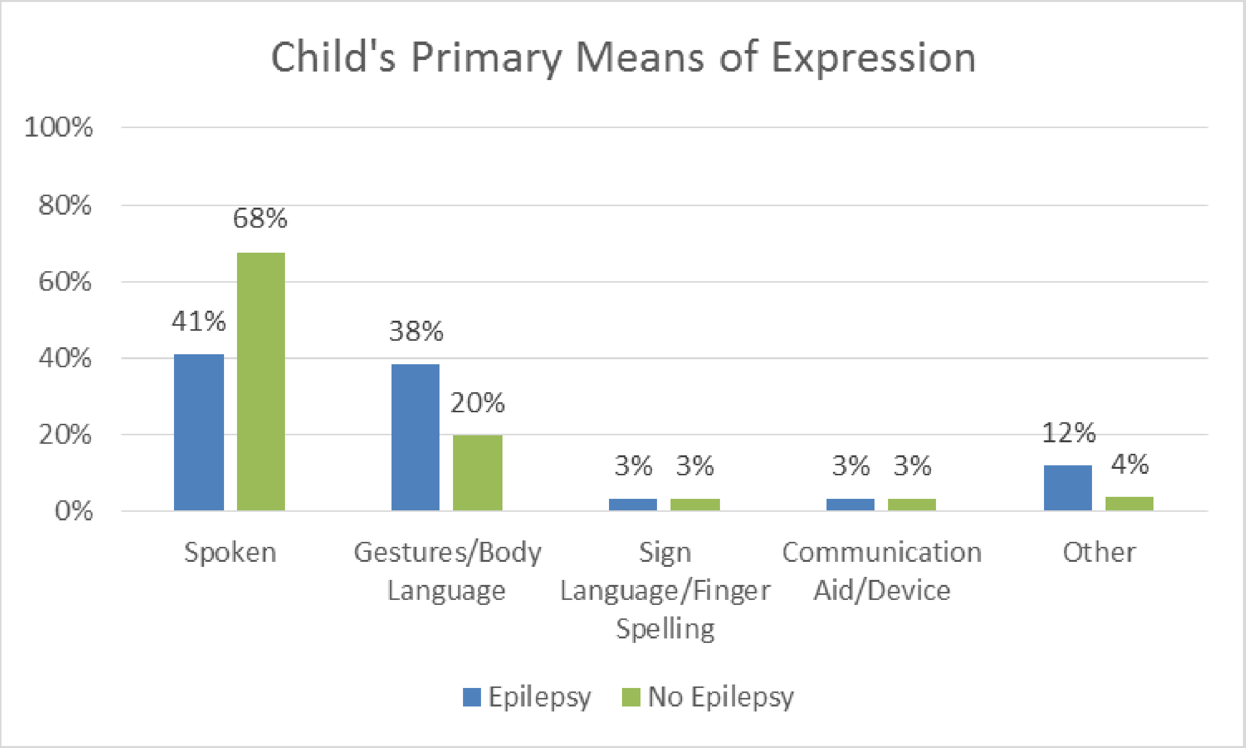

Table VI-7: Child's Primary Means of Expression by Epilepsy[1], [2]

	Spoken	Gestures/ Body Language	Sign Language/ Finger Spelling	Communi cation Aid/Device	Other	N
Epilepsy	41%	38%	3%	3%	12%	1081
No Epilepsy	68%	20%	3%	3%	4%	6408

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[1] Results for “Sign Language/Finger Spelling”, and “Communication Aid/Device” were not statistically significant.
[2] Percentages add up to less than 100% due to missing responses.

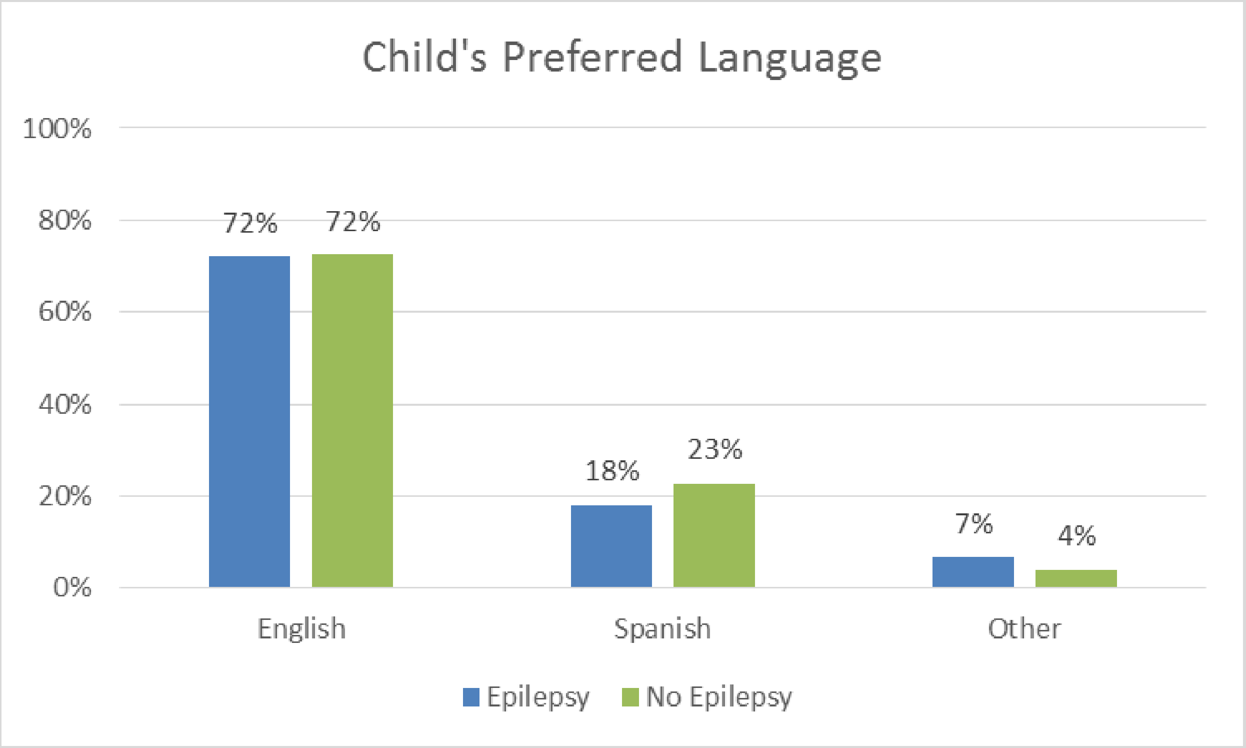

Table VI-8: Child's Preferred Language by Epilepsy[1], [2]

	English	Spanish	Other	N
Epilepsy	72%	18%	7%	1067
No Epilepsy	72%	23%	4%	6478

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[1] Results for “English” were not statistically significant.

[2] Percentages add up to less than 100% due to missing responses.

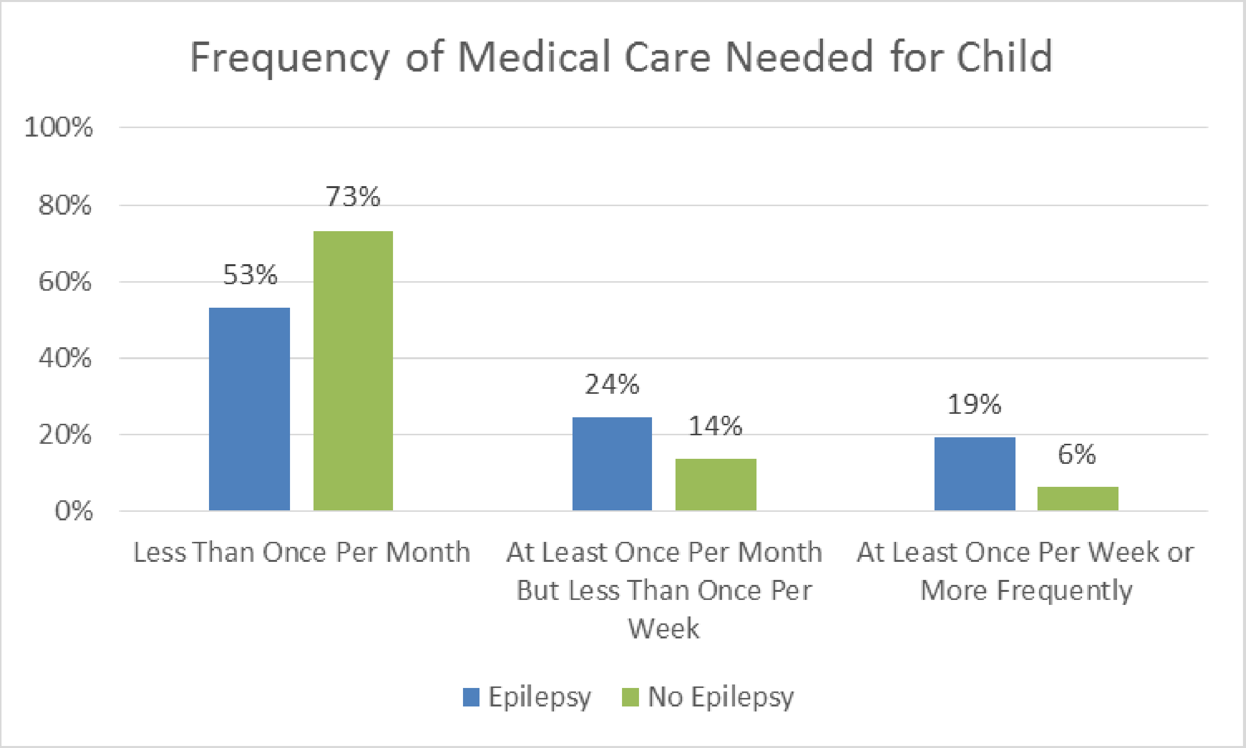

Table VI-9: Frequency of Medical Care Needed for Child by Epilepsy[1]

	Less Than Once Per Month	At Least Once Per Month But Less Than Once Per Week	At Least Once Per Week or More Frequently	N
Epilepsy	53%	24%	19%	1065
No Epilepsy	73%	14%	6%	6109

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[1] Percentages add up to less than 100% due to missing responses.

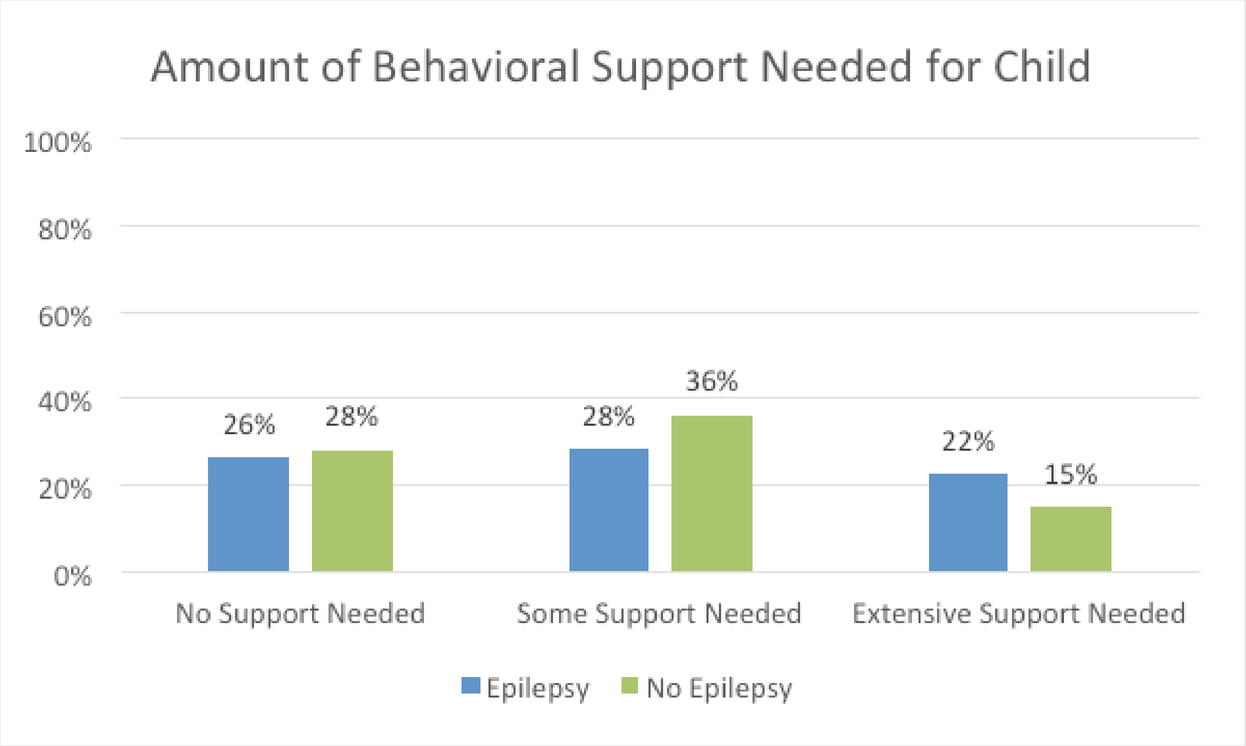

Table VI-10: Amount of Behavioral Support Needed for Child by Epilepsy[1]

	No Support Needed	Some Support Needed	Extensive Support Needed	N
Epilepsy	26%	28%	22%	847
No Epilepsy	28%	36%	15%	5163

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[1] Percentages add up to less than 100% due to missing responses.

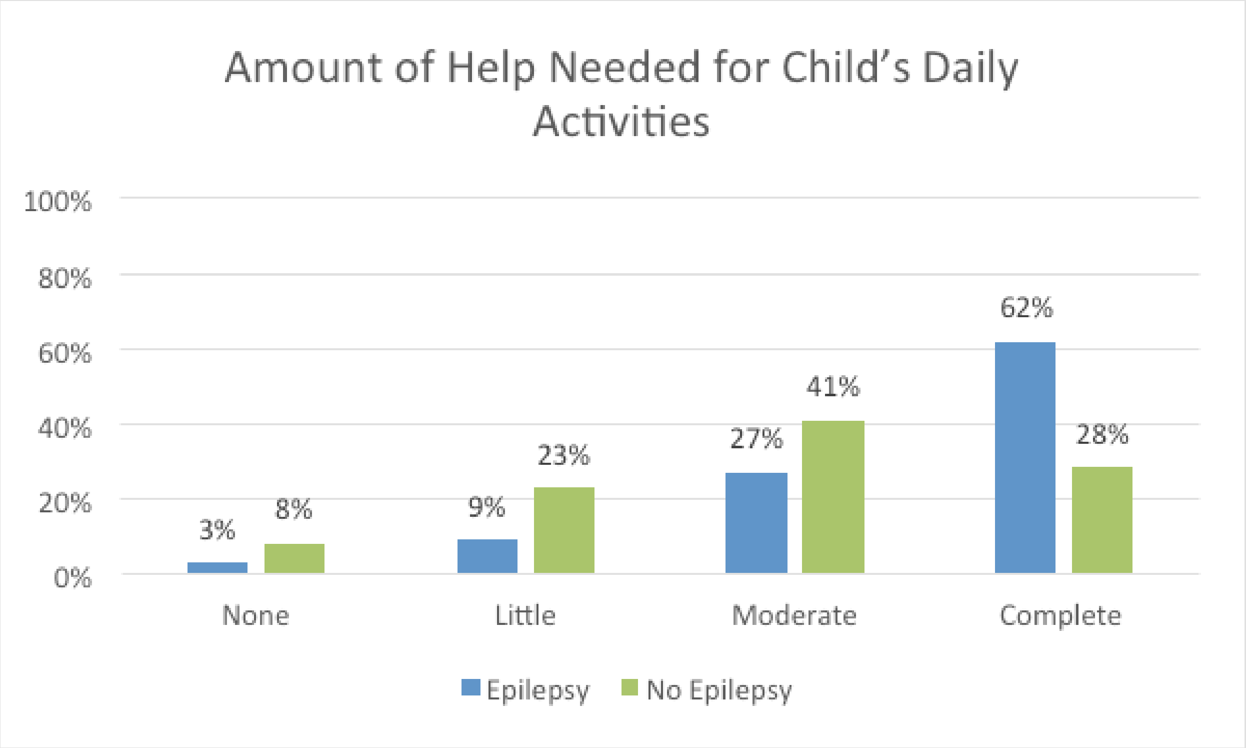

Table VI-11: Amount of Help Needed for Child's Daily Activities by Epilepsy

	None	Little	Moderate	Complete	N
Epilepsy	3%	9%	27%	62%	6492
No Epilepsy	8%	23%	41%	28%	1099

Family/Survey Respondent's Demographic Information

The section on Family/Survey Respondent's Demographic Information in the Child Family Survey includes indicators about: *Basic Information about Family/Survey Respondent* and *Household Composition and Income.* All results are presented here.

Selected Findings on Family/Survey Respondent's Demographic Information

Survey respondents of children with Epilepsy compared to respondents of children without Epilepsy had significant differences in age[1] (e.g., age of survey respondent between 35-54 years old, Epilepsy: 65%, No Epilepsy: 66%). Survey respondents for families of children with epilepsy were less likely to have no High School diploma or GED compared to survey respondents for families of children without epilepsy (Epilepsy: 16%, No Epilepsy: 19%). Survey respondents for families of children with epilepsy were less likely to have a high school diploma/GED education compared to survey respondents for families of children without epilepsy (Epilepsy: 13%, No Epilepsy: 15%). Survey respondents for families of children with epilepsy were more likely to have a college degree compared to survey respondents for families of children without epilepsy (Epilepsy: 41%, No Epilepsy: 37%).

Families of children with epilepsy had significant differences in total household income compared to families of children without epilepsy[1] (e.g., income over $75,000, Epilepsy: 25%, No Epilepsy: 22%). Families of children with epilepsy had significant differences in out-of-pocket expenses for their child in the past year compared to families of children without epilepsy[1] (e.g., expenses over $10,000, Epilepsy: 8%, No Epilepsy: 6%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with ASD compared to Family/Survey Respondents of children without ASD.

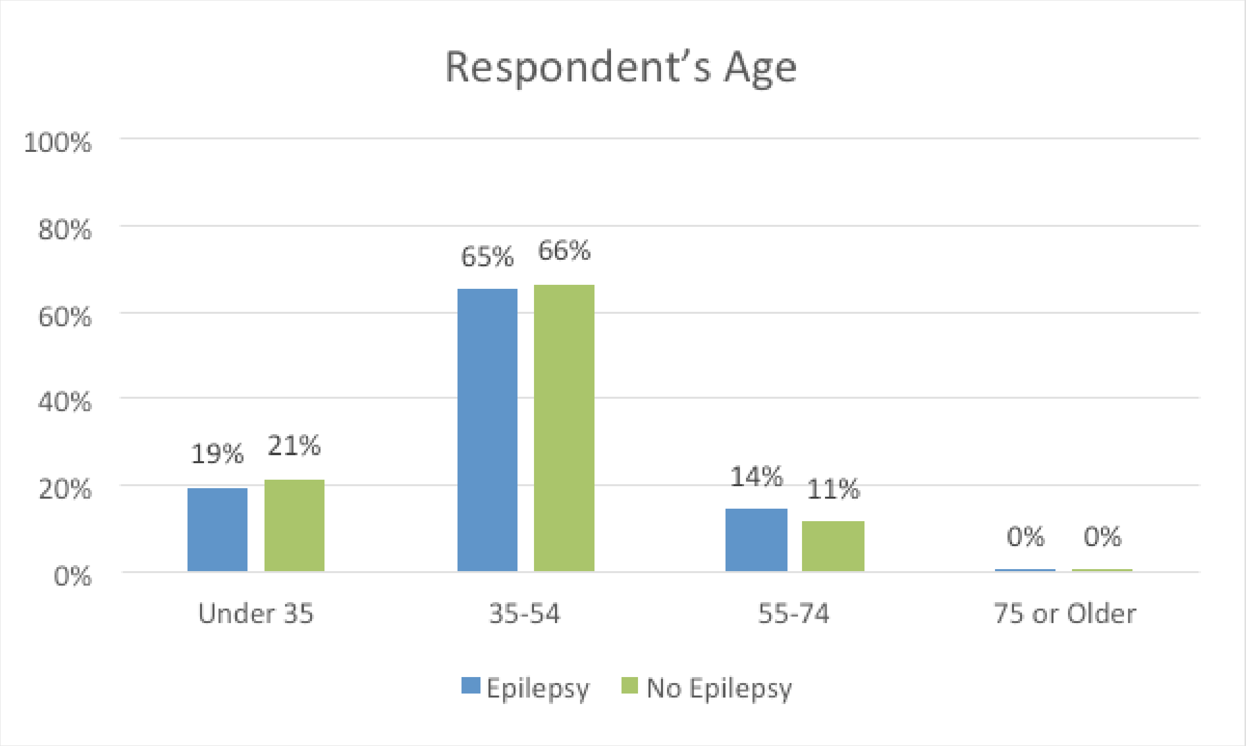

Table VI-12: Respondent's Age by Epilepsy[1]

	Under 35	35–54	55–74	75 or Older	N
Epilepsy	19%	65%	14%	0%	1094
No Epilepsy	21%	66%	11%	0%	6490

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[1] Percentages add up to less than 100% due to missing responses.

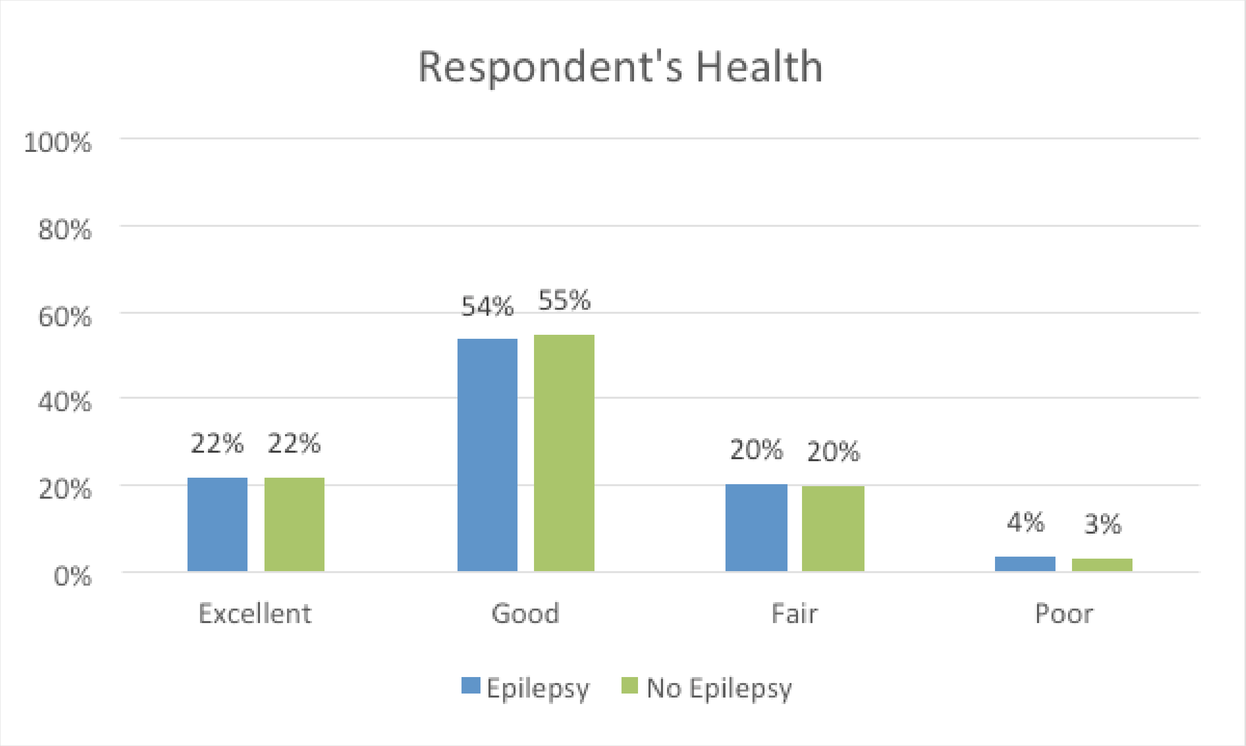

Table VI-13: Respondent's Health by Epilepsy[1]

	Excellent	Good	Fair	Poor	N
Epilepsy	22%	54%	20%	4%	1093
No Epilepsy	22%	55%	20%	3%	6484

---

[1] Results were not statistically significant.

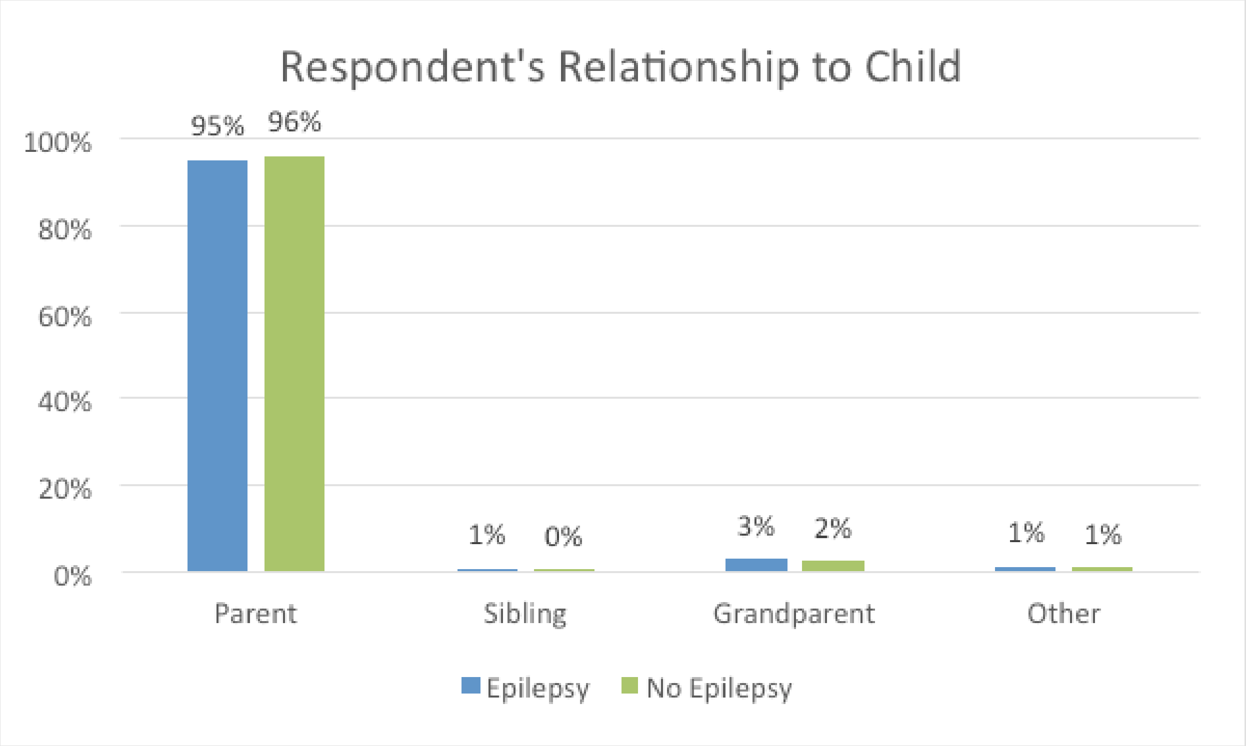

Table VI-14: Respondent's Relationship to Child by Epilepsy[1], [2]

	Parent	Sibling	Grandparent	Other	N
Epilepsy	95%	1%	3%	1%	1098
No Epilepsy	96%	0%	2%	1%	6511

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[1] Results were not statistically significant.
[2] Percentages add up to less than 100% due to missing responses.

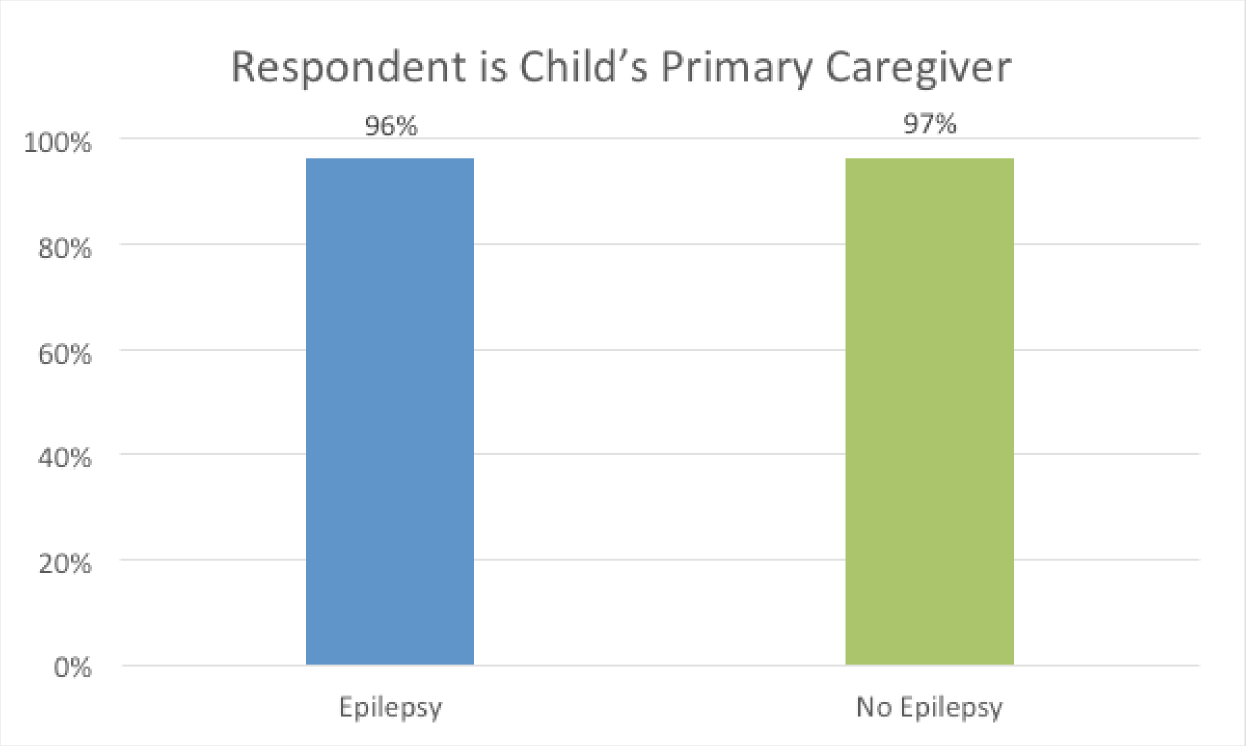

Table VI-15: Respondent is Child’s Primary Caregiver by Epilepsy[1]

	Yes	N
Epilepsy	96%	1083
No Epilepsy	97%	6449

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[1] Results were not statistically significant.

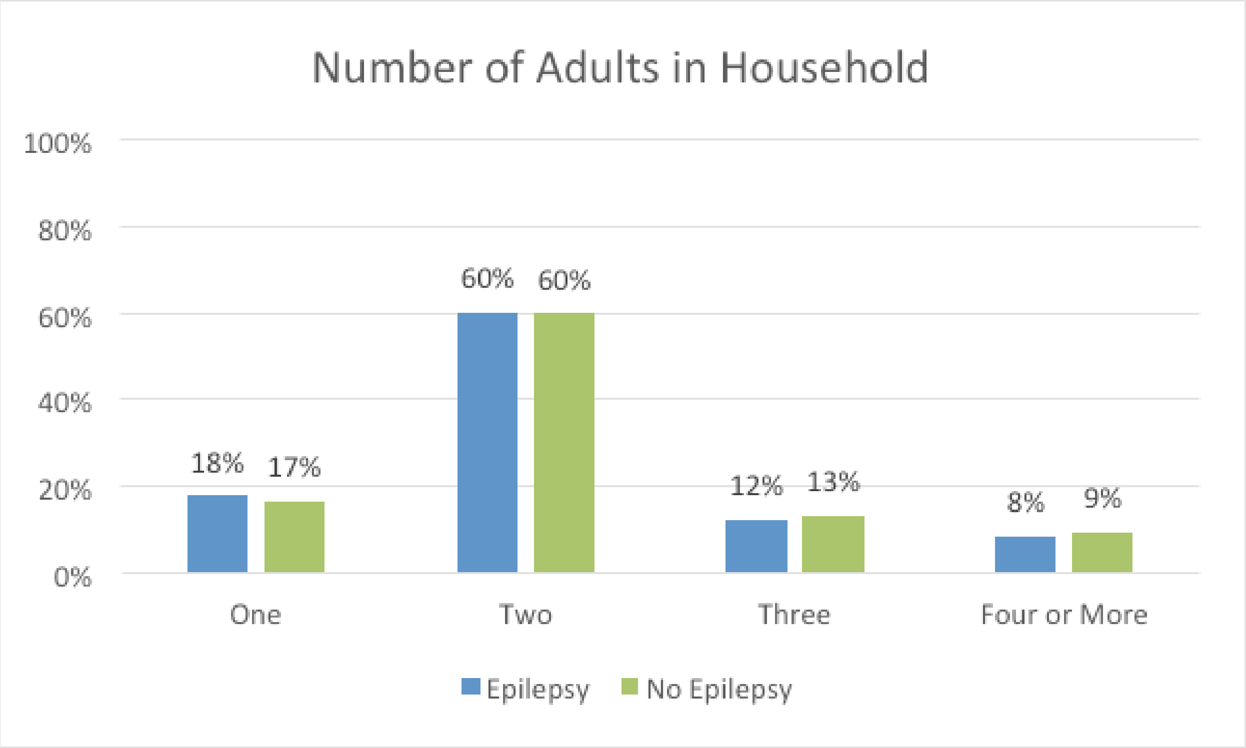

Table VI-16: Number of Adults in Household by Epilepsy[1], [2]

	One	Two	Three	Four or More	N
Epilepsy	18%	60%	12%	8%	1085
No Epilepsy	17%	60%	13%	9%	6458

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[1] Results were not statistically significant.

[2] Percentages add up to less than 100% due to missing responses.

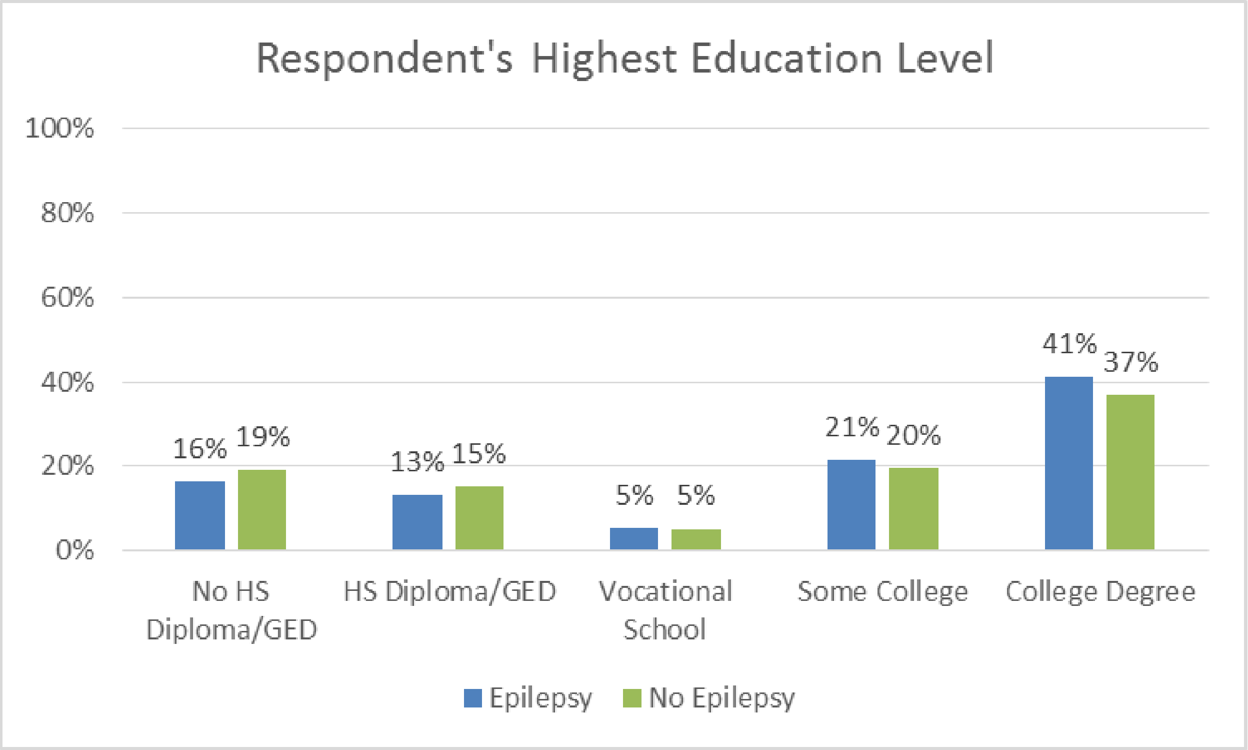

Table VI-17: Respondent's Highest Education Level by Epilepsy[1], [2]

	No HS Diploma/ GED	HS Diploma/ GED	Vocational School	Some College	College Degree	N
Epilepsy	16%	13%	5%	21%	41%	1075
No Epilepsy	19%	15%	5%	20%	37%	6268

---

[1] Results for “Vocational School” and “Some College” were not statistically significant.
[2] Percentages add up to less than 100% due to missing responses.

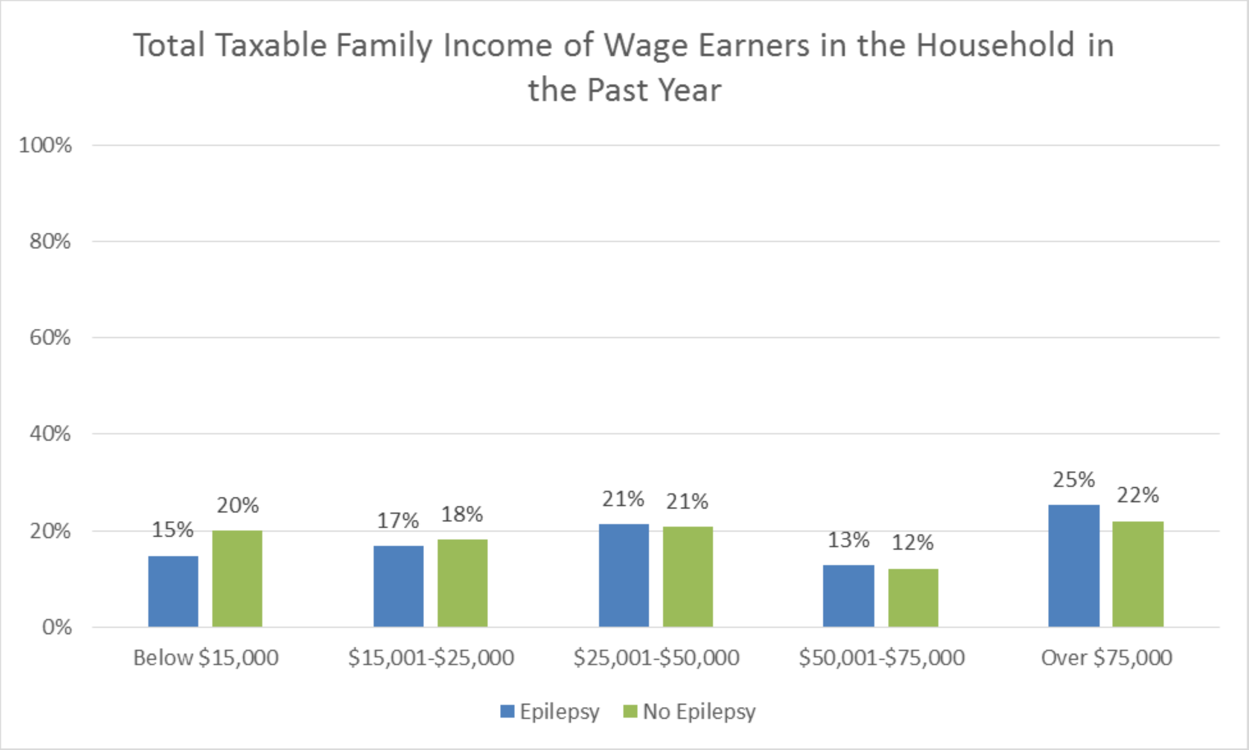

Table VI-18: Total Taxable Family Income of Wage Earners in the Household in the Past Year by Epilepsy[1]

	Below $15,000	$15,001–$25,000	$25,001–$50,000	$50,001–$75,000	Over $75,000	N
Epilepsy	15%	17%	21%	13%	25%	1003
No Epilepsy	20%	18%	21%	12%	22%	6082

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[1] Percentages add up to less than 100% due to missing responses.

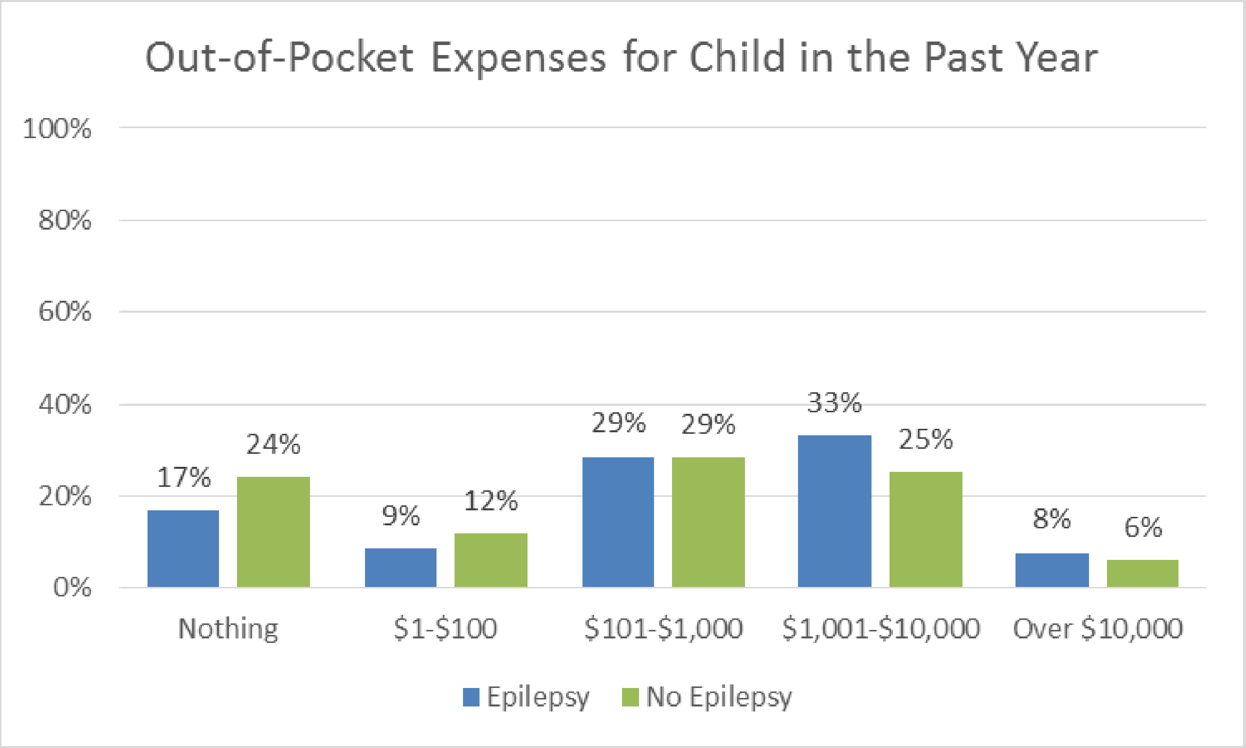

Table VI-19: Out-of-Pocket Expenses for Child in the Past Year by Epilepsy[1]

	Nothing	$1–$100	$101–$1,000	$1,001–$10,000	Over $10,000	N
Epilepsy	17%	9%	29%	33%	8%	1042
No Epilepsy	24%	12%	29%	25%	6%	6227

---

[1] Percentages add up to less than 100% due to missing responses.

Services and Supports Received by Epilepsy

The section on Services and Supports Received in the Child Family Survey includes indicators about: *Types of Services and Supports*. All results are presented here.

Selected Findings on Services and Supports Received

Families of children with epilepsy were more likely to receive financial support compared to families of children without epilepsy (Epilepsy: 12%, No Epilepsy: 9%). Families of children with epilepsy were more likely to receive in-home support compared to families of children without epilepsy (Epilepsy: 64%, No Epilepsy: 47%). Children with epilepsy were less likely to receive early intervention compared to children without epilepsy (Epilepsy: 10%, No Epilepsy: 17%).

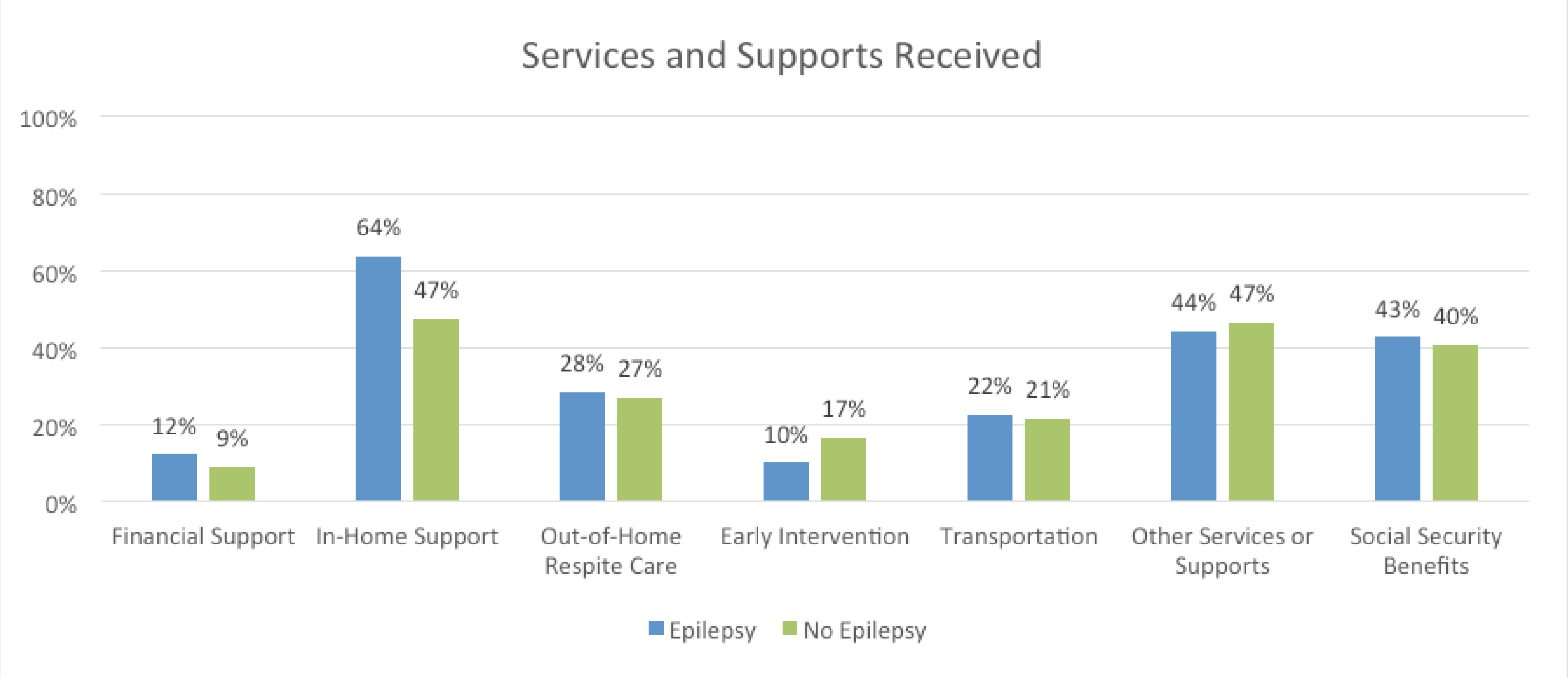

Table VI-20: Services and Supports Received by Epilepsy[1],[2]

	Financial Support	In-Home Support	Out-of-Home Respite Care	Early Intervention	Transportation	Other Services or Supports	Social Security Benefits
Epilepsy	12%	64%	28%	10%	22%	44%	43%
No Epilepsy	9%	47%	27%	17%	21%	47%	40%

---

[1] Results for “Out-Of-Home Respite Care,” “Transportation,” “Other Services or Supports” and “Social Security Benefits” were not statistically significant.
[2] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

Information and Planning by Epilepsy

The section on Information and Planning in the Child Family Survey includes indicators about: *Available Services and Supports, Planning with Service Coordinator,* and *Child's Individual Program Plan (IPP)*. Results that were statistically significant are presented here. The complete list of results for children with epilepsy are located in Appendix F.

Selected Findings on Information and Planning

Families of children with epilepsy were more likely to help develop their child's IPP compared to families of children without epilepsy (Epilepsy: 89%, No Epilepsy: 86%). Children with epilepsy were more likely to have an IPP that includes all services and supports that the family wants compared to children without epilepsy (Epilepsy: 61%, No Epilepsy: 58%). Families of children with epilepsy were more likely to have discussed how to handle emergencies related to their child at the last IPP meeting compared to families of children without epilepsy (Epilepsy: 52%, No Epilepsy: 42%).

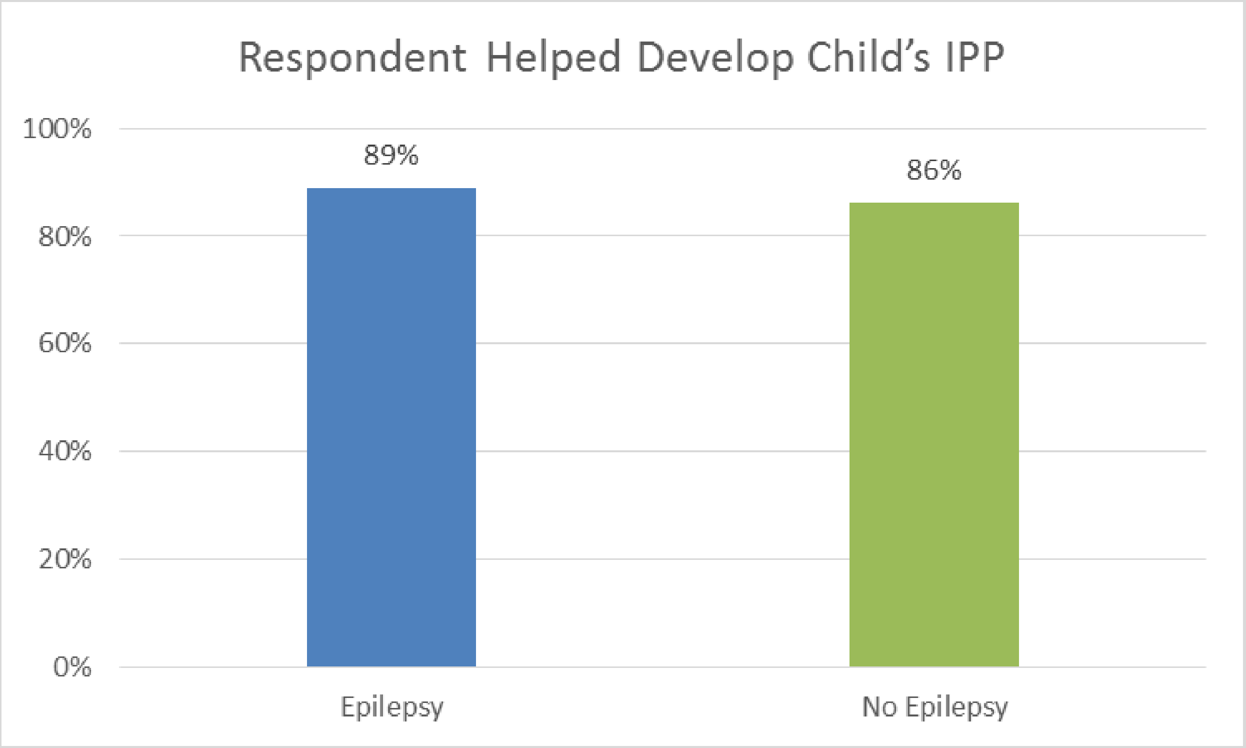

Table VI-21: Did you help develop your child's IPP?

	Yes	N
Epilepsy	89%	696
No Epilepsy	86%	4022

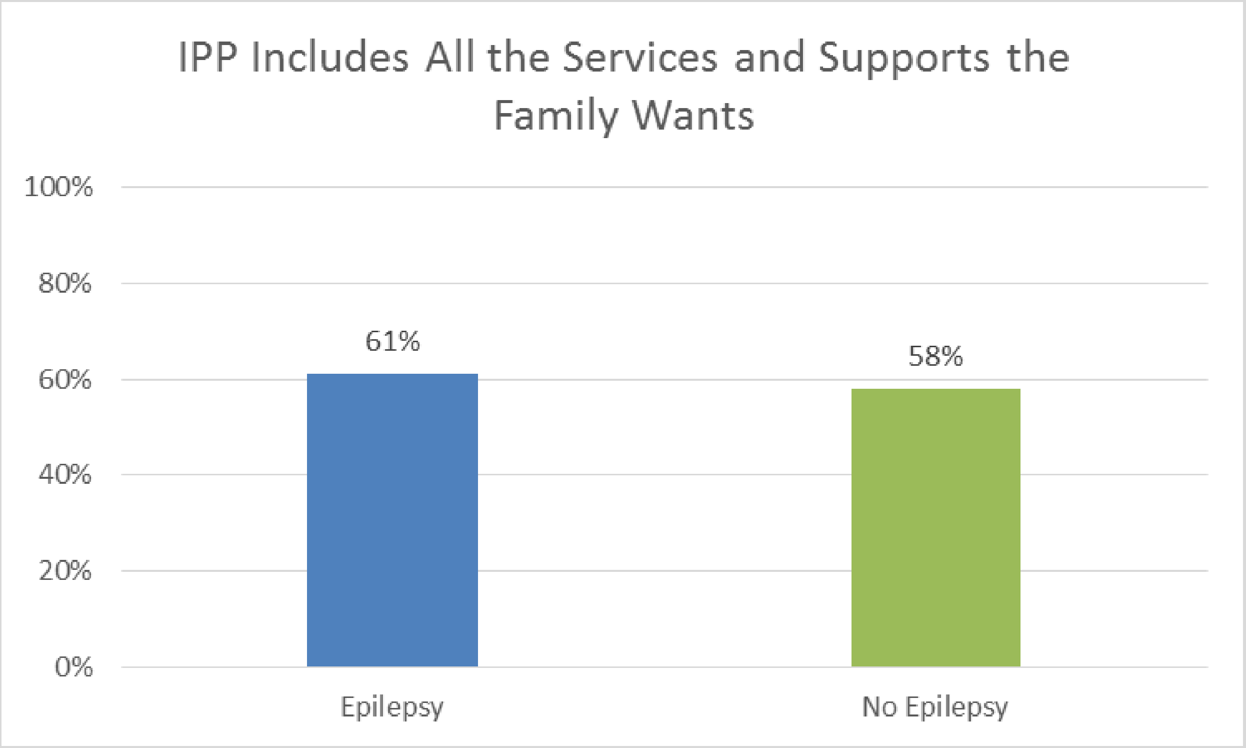

Table VI-22: Does the IPP include all the services and supports your family wants?

	Yes	N
Epilepsy	61%	618
No Epilepsy	58%	3660

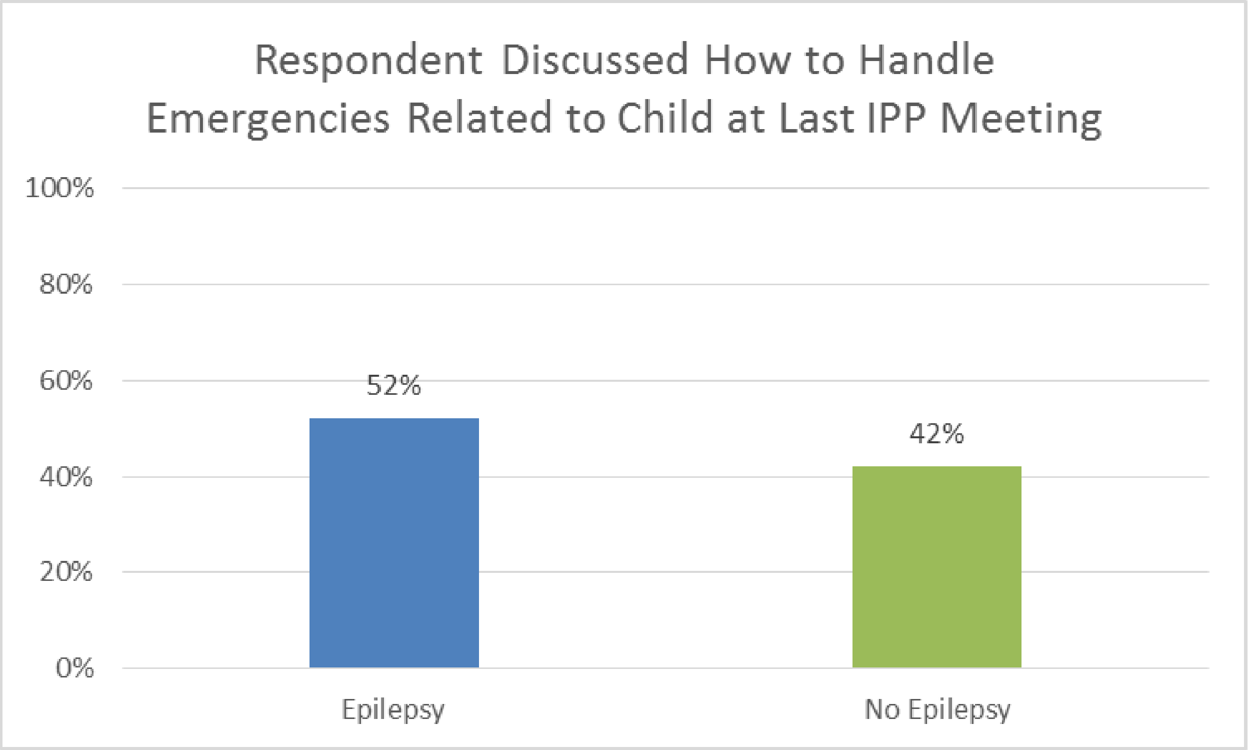

Table VI-23: Did you discuss how to handle emergencies related to your child at the last IPP meeting?

	Yes	N
Epilepsy	52%	628
No Epilepsy	42%	3555

Access and Delivery of Services and Supports by Epilepsy

The section on Access and Delivery in the Child Family Survey includes indicators about: *Accessibility of Support Workers and Service Coordinators, Accessibility of Supports and Services, Communication with Workers,* and *Delivery of Specific Services*. Results that were statistically significant are presented here. The complete list of results for children with epilepsy are located in Appendix F.

Selected Findings on Access and Delivery

Families of children with epilepsy had significant differences in support workers' ability to communicate with their child if non-verbal compared to families of children without epilepsy[1] (e.g., always able to communicate with child if non-verbal, Epilepsy: 8%, No Epilepsy: 6%). Families of children with epilepsy had significant differences in their child having access to special equipment or accommodations needed compared to families of children without epilepsy[1] (e.g., always have access to special equipment or accommodations needed, Epilepsy: 27%, No Epilepsy: 13%). Families of children with epilepsy were more likely to get crisis or emergency services when needed if requested compared to families of children without epilepsy (Epilepsy: 19%, No Epilepsy: 14%). Families of children with epilepsy were more likely to have access to health services for their child compared to families of children without epilepsy (Epilepsy: 87%, No Epilepsy: 83%). Families of children with epilepsy were more likely to be satisfied with quality of child's health care providers compared to families of children without epilepsy (Epilepsy: 88%, No Epilepsy: 83%). Families of children with epilepsy were more likely to have access to necessary medications for their child compared to families of children without epilepsy (Epilepsy: 90%, No Epilepsy: 75%). Families of children with epilepsy were more likely to be satisfied with how their child's medication needs were monitored compared to families of children without epilepsy (Epilepsy: 87%, No Epilepsy: 85%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with epilepsy compared to Family/Survey Respondents of children without epilepsy.

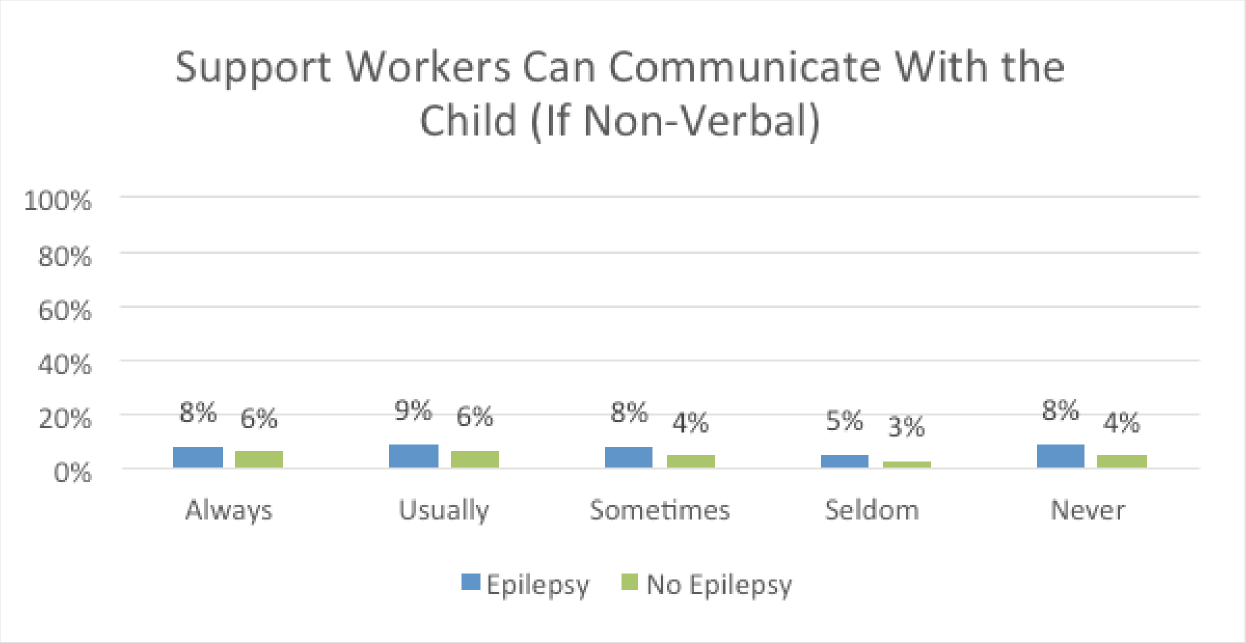

Table VI-24: If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?[1]

	Always	Usually	Sometimes	Seldom	Never	N
Epilepsy	8%	9%	8%	5%	8%	711
No Epilepsy	6%	6%	4%	3%	4%	4003

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

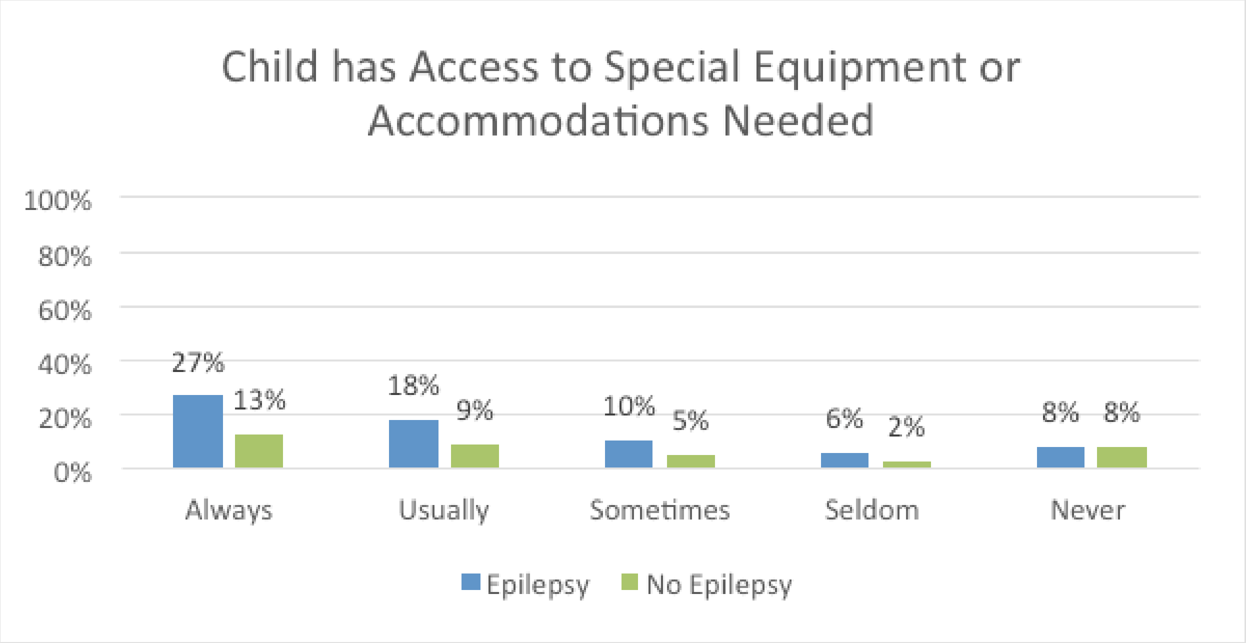

Table VI-25: Does your child have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?[1]

	Always	Usually	Sometimes	Seldom	Never	N
Epilepsy	27%	18%	10%	6%	8%	412
No Epilepsy	13%	9%	5%	2%	8%	1528

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

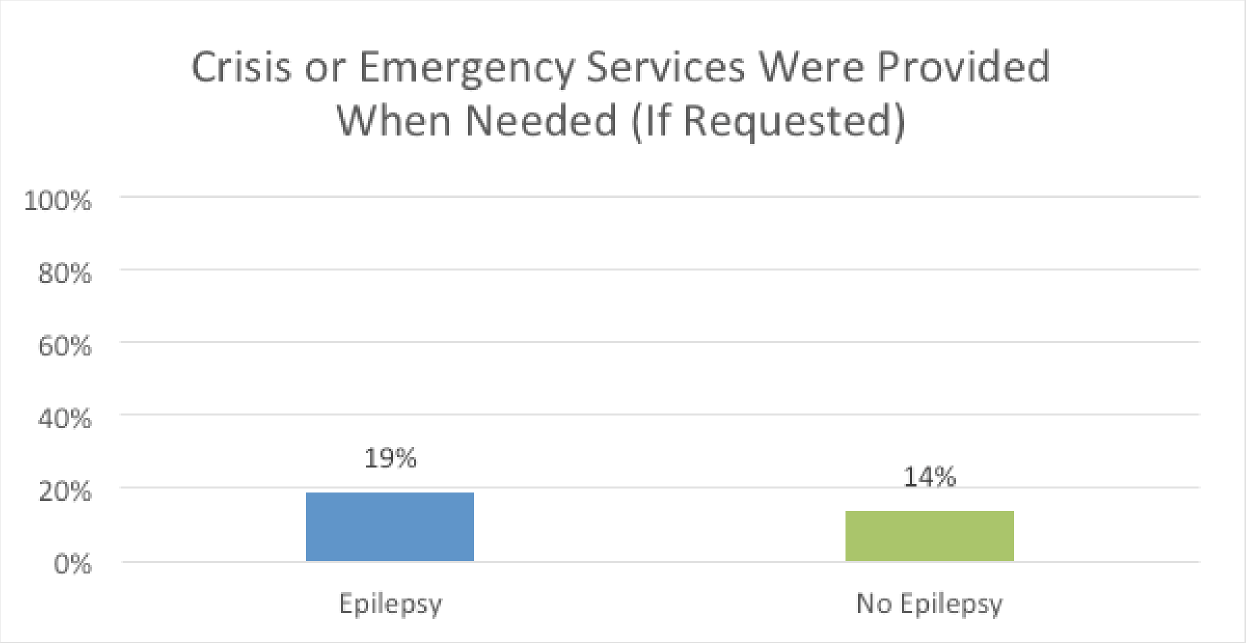

Table VI-26: If you asked for crisis/emergency services during the past year, were services provided when needed?

	Yes	N
Epilepsy	19%	301
No Epilepsy	14%	1669

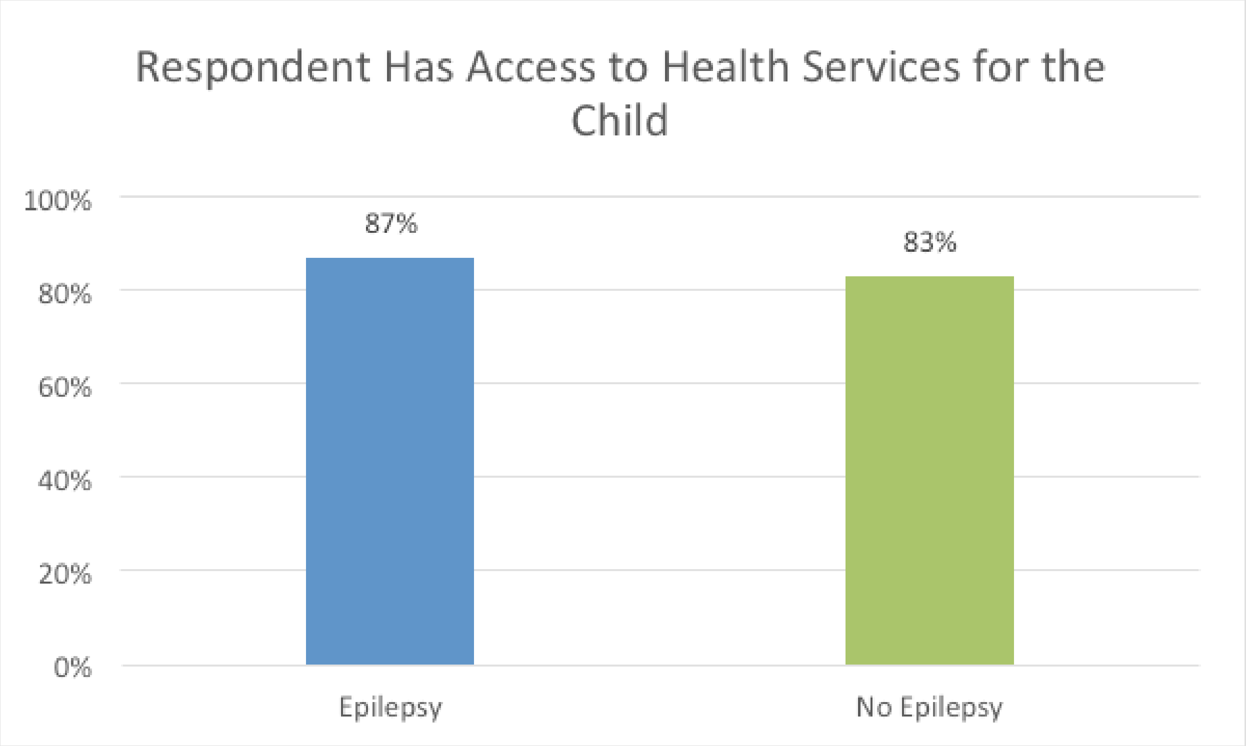

Table VI-27: Do you have access to health services for your child?

	Yes	N
Epilepsy	87%	1000
No Epilepsy	83%	5788

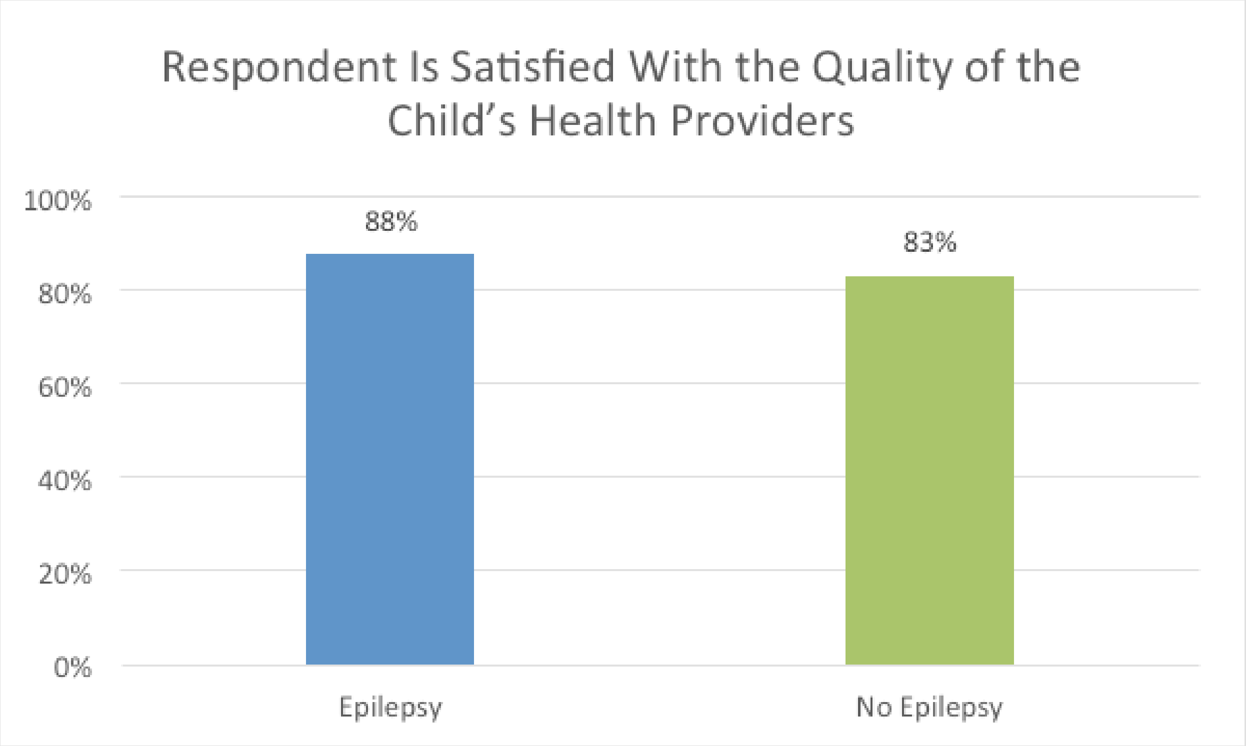

Table VI-28: If you have access to health services for your child, are you satisfied with the quality of these providers?

	Yes	N
Epilepsy	88%	903
No Epilepsy	83%	4985

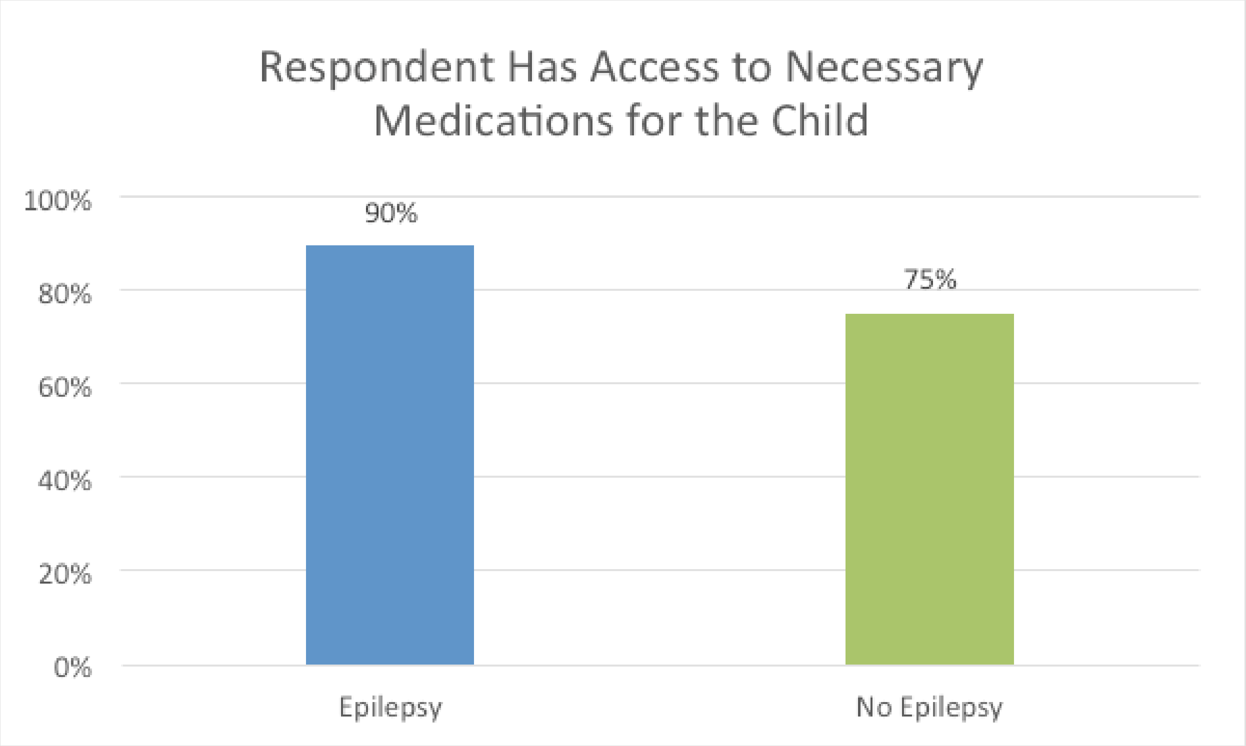

Table VI-29: Are you able to get medications needed for your child?

	Yes	N
Epilepsy	90%	1018
No Epilepsy	75%	5171

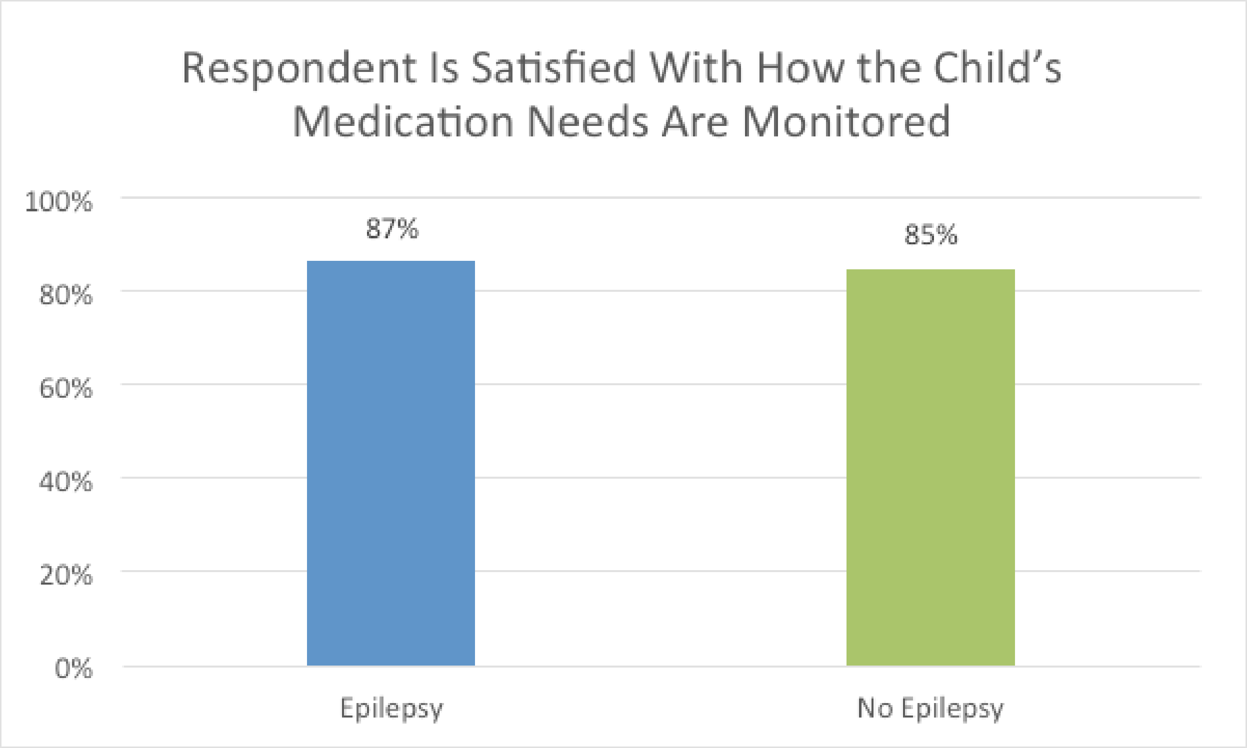

Table VI-30: If you have access to needed medications for your child, are you satisfied with how your child's medication needs are monitored?

	Yes	N
Epilepsy	87%	921
No Epilepsy	85%	4370

Choice and Control by Epilepsy

The section on Choice and Control in the Child Family Survey includes indicators about: *Choosing Provider Agencies, Choosing Support Workers,* and *Control over Management of Money Spent on Child*. Results that were statistically significant are presented here. The complete list of results for children with epilepsy are located in Appendix F.

Selected Findings on Choice and Control

Families of children with epilepsy had significant differences in ability to choose individual support workers who work with the family compared to families of children without epilepsy[1] (e.g., always able to choose individual support workers who work with the family, Epilepsy: 25%, No Epilepsy: 22%). Families of children with epilepsy were more likely to have control over the hiring and management of the family's support workers compared to families of children without epilepsy (Epilepsy: 27%, No Epilepsy: 23%). Families of children with epilepsy were more likely to have a say in how regional center money was spent on behalf of their child compared to families of children without epilepsy (Epilepsy: 13%, No Epilepsy: 10%).

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[1] The Mann-Whitney U-test was conducted to determine whether there was a difference in the pattern of responses given by Family/Survey Respondents of children with epilepsy compared to Family/Survey Respondents of children without epilepsy.

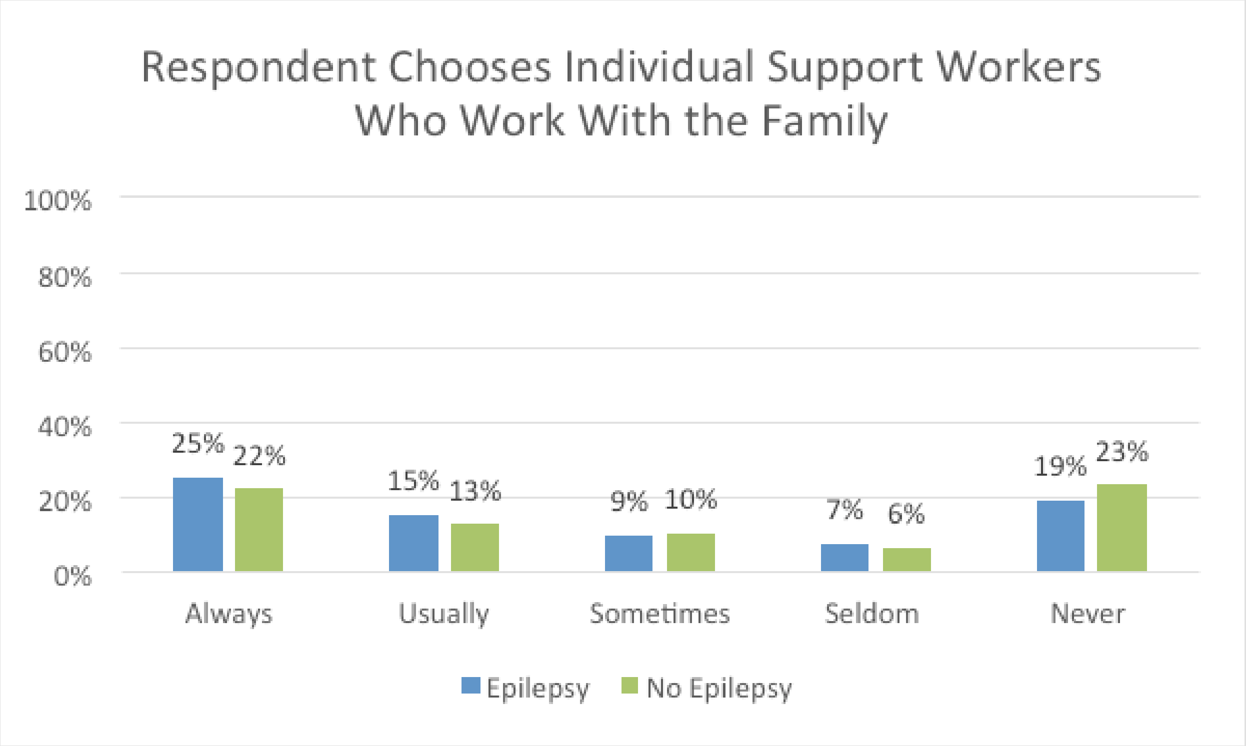

Table VI-31: Do you choose the individual support workers who work directly with your family?[1]

	Always	Usually	Sometimes	Seldom	Never	N
Epilepsy	25%	15%	9%	7%	19%	840
No Epilepsy	22%	13%	10%	6%	23%	4837

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[1] Percentages add up to less than 100% due to missing responses, responses of “Don’t Know” or “Do Not Apply.”

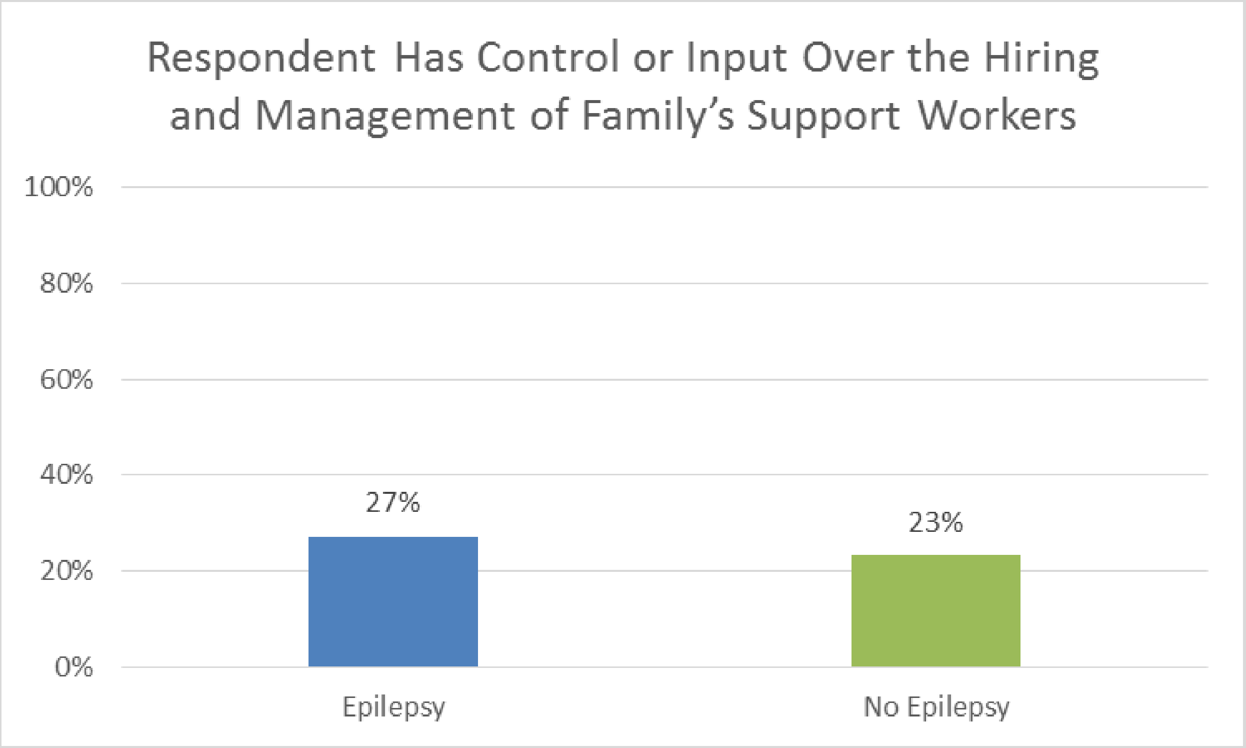

Table VI-32: Do you have control/input over the hiring and management of your family's support workers?

	Yes	N
Epilepsy	27%	737
No Epilepsy	23%	4377

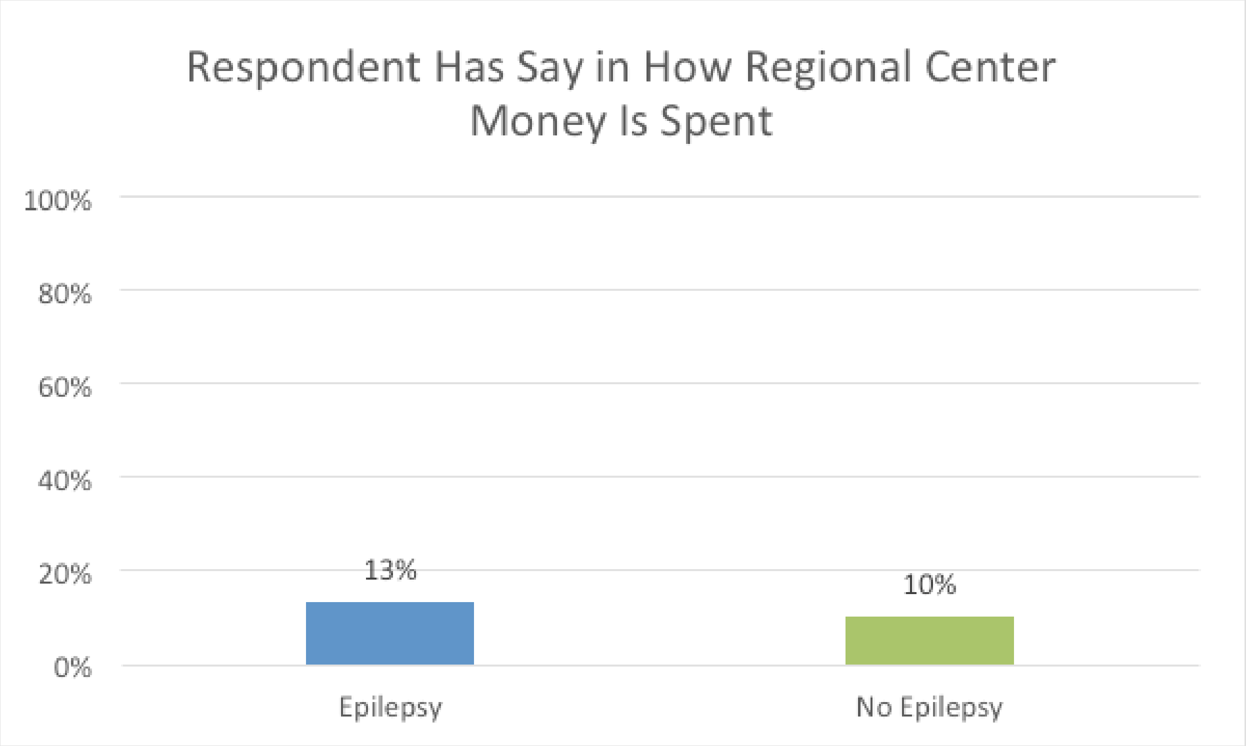

Table VI-33: Do you have a say in how regional center money is spent?

	Yes	N
Epilepsy	13%	669
No Epilepsy	10%	4067

Community Connections by Epilepsy

The section on Community Connections in the Child Family Survey includes indicators about: *Participation in Community.* Results that were statistically significant are presented here. The complete list of results for children with epilepsy are located in Appendix F.

Selected Findings on Community Connections

Children with epilepsy were less likely to participate in community activities compared to children without epilepsy (Epilepsy: 65%, No Epilepsy: 71%). Among children who did not participate in community activities, survey respondents provided reasons why their child did not participate in community activities. Families of children with epilepsy were less likely to choose “cost” as one reason for non-participation compared to families of children without epilepsy (Epilepsy: 19%, No Epilepsy: 28%). Families of children with epilepsy were more likely to choose “other” as a response category for the reason for non-participation (e.g., reasons other than lack of transportation, cost, lack of support, negative attitudes from community members) compared to families of children without epilepsy (Epilepsy: 47%, No Epilepsy: 37%).

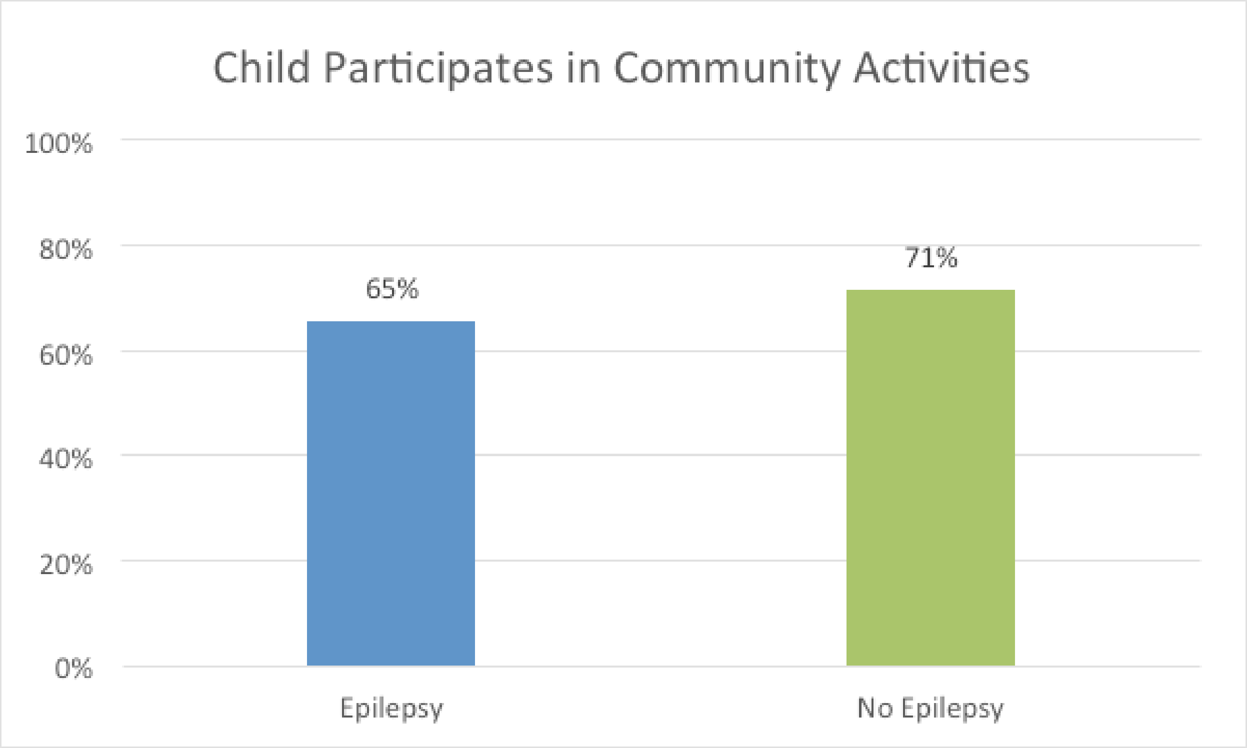

Table VI-34: Does your child participate in community activities (such as going out to a restaurant, movie, or sporting event)?

	Yes	N
Epilepsy	65%	1045
No Epilepsy	71%	6183

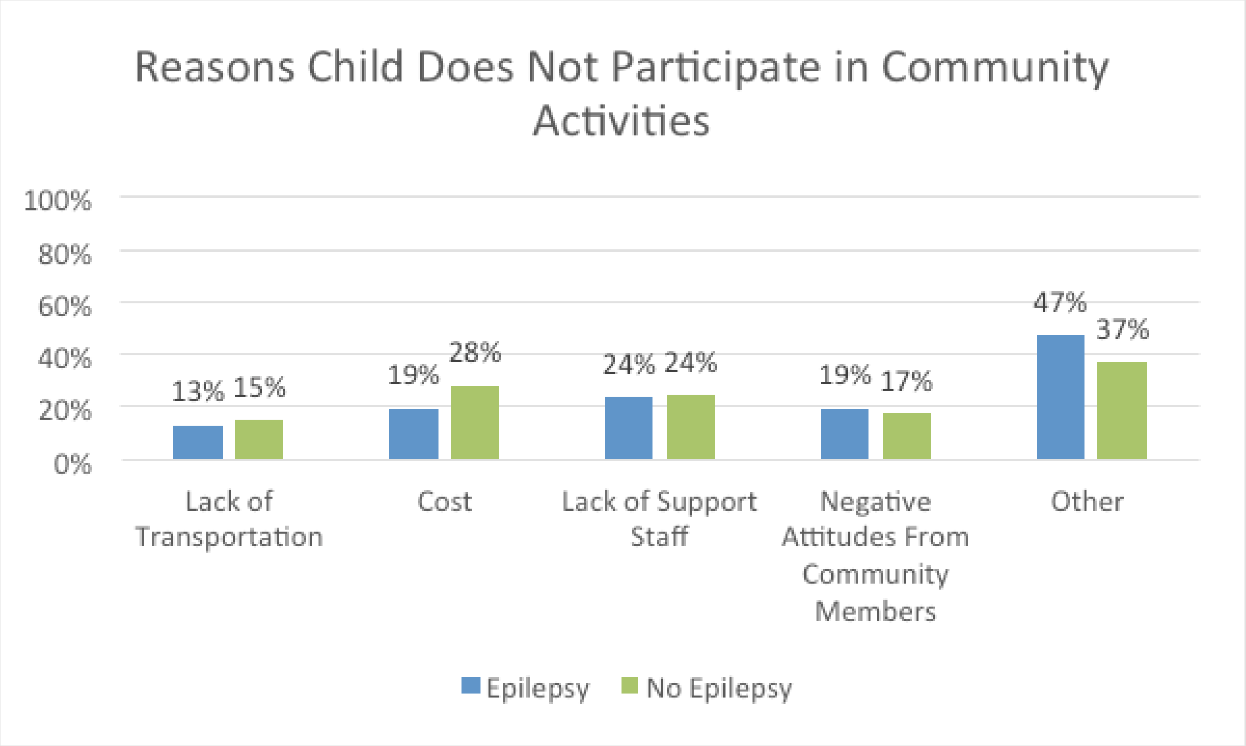

Table VI-35: If you child doesn't participate in community activities, why not?[1], [2]

	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes From Community Members	Other
Epilepsy	13%	19%	24%	19%	47%
No Epilepsy	15%	28%	24%	17%	37%

---

[1] Results for "Lack of Transportation," "Lack of Support Staff" and "Negative Attitudes from Community Members" were not statistically significant.

[2] Categories are not mutually exclusive, and therefore some results may add up to more than 100%.

Satisfaction with Services and Supports by Epilepsy

The section on Satisfaction with Services and Supports in the Child Family Survey includes indicators about: *Satisfaction with Services and Supports,* and *Knowing How to Report Complaints.* Results that were statistically significant are presented here. The complete list of results for children with epilepsy are located in Appendix F.

Selected Findings on Satisfaction with Services and Supports

Families of children with epilepsy were more likely to know how to report abuse or neglect compared to families of children without epilepsy (Epilepsy: 61%, No Epilepsy: 55%). Families of children with epilepsy were more likely to have reported abuse or neglect in the past year compared to families of children without epilepsy (Epilepsy: 6%, No Epilepsy: 5%).

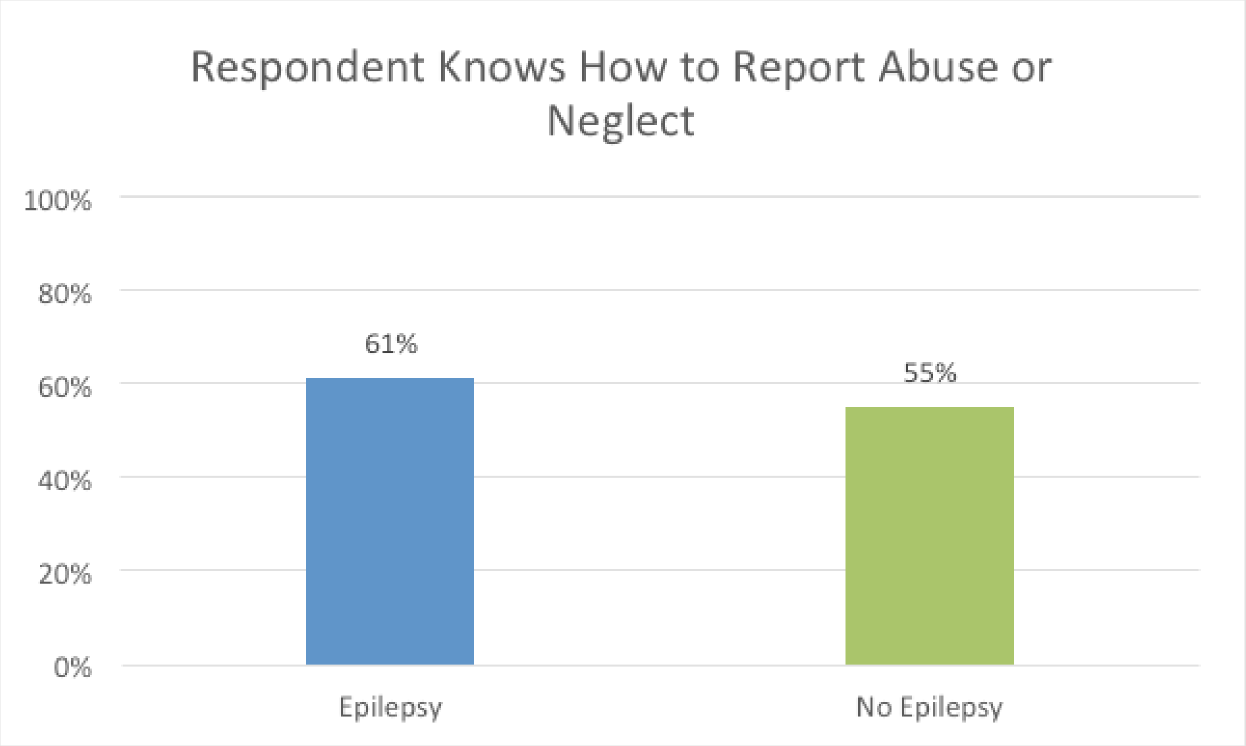

Table VI-36: Do you know how to report abuse or neglect?

	Yes	N
Epilepsy	61%	1064
No Epilepsy	55%	6265

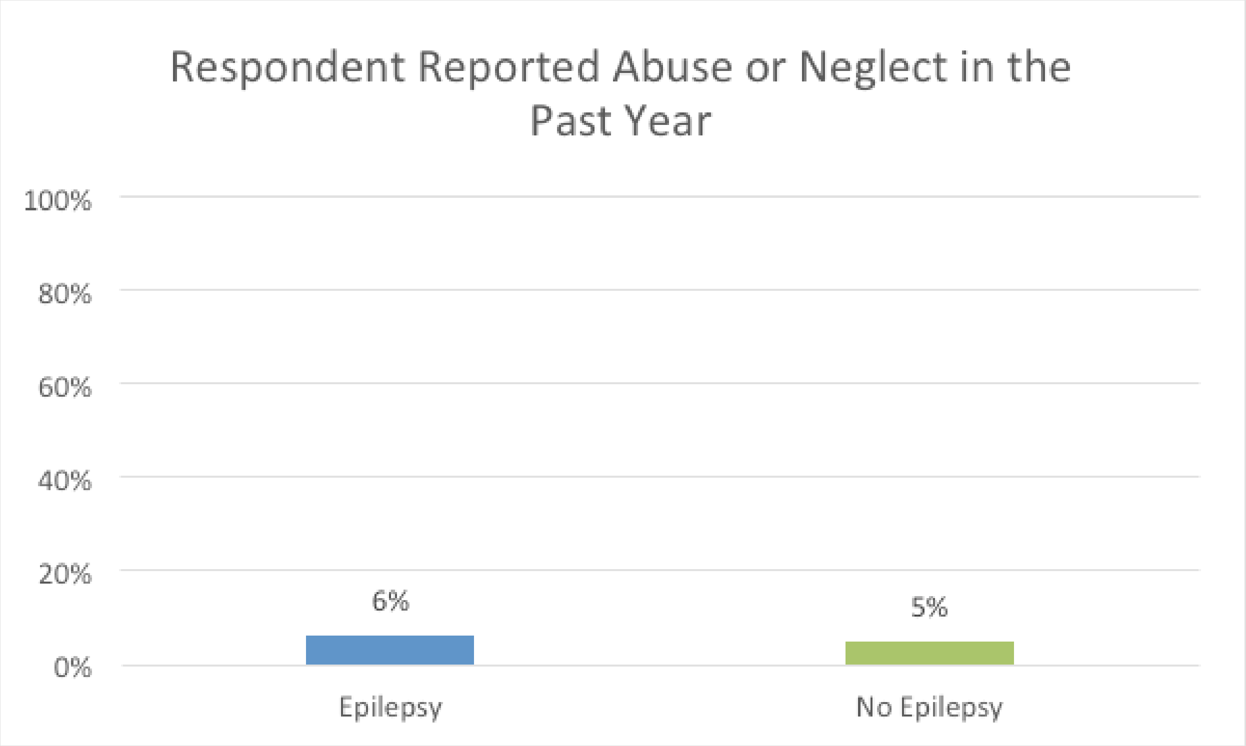

Table VI-37: Within the past year, if abuse or neglect occurred, did you report it?

	Yes	N
Epilepsy	6%	257
No Epilepsy	5%	1537

Family Outcomes by Epilepsy

The section on Family Outcomes in the Child Family Survey includes indicators about: *Positive Impact of Services and Supports* and *Reduction of Services and Supports.* Results that were statistically significant are presented here. The complete list of results for children with epilepsy are located in Appendix F.

Selected Findings on Family Outcomes

There were no significant differences in the indicators in the Family Outcomes section between children with epilepsy and children without epilepsy[1].

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[1] See Appendix F for tables describing all indicators with respective sample sizes in this section.

VII. Appendices

Appendix A: How Responses are Presented (Recode or Collapse)

Survey Item #	Variable Name	Recode or Collapse?
A	**A_ATHOME**	Recode *No* (2) as *No* (0)
B	**B_MORE1**	Recode *No* (2) as *No* (0)
C	**C_AGEFM**	As is
D	**D_GENDER**	Recode *Male* (1) as *Male* (0) and *Female (2) as Female (1)*
E	**E_ID, E_MI, E_AUTISM, E_CP, E_TBI, E_SEIZUR, E_CHEM, E_VISION, E_HEAR, E_DOWNS, E_PWSYND, E_OTHER, E_NOOTH, E_DONTKW**	Recode *No* (2) as *No* (0) (except for when E_DONTKW is *Yes* (1), treat all other *No* (2) responses as missing
F	**F_AMERIN, F_ASIAN, F_BLACK, F_HAWAII, F_WHITE, F_OTHER, F_MIXED, F_LATINO**	Recode *No* (2) as *No* (0)
G	**G_EXPRES**	As is
H	**H_LANG**	As is
I	**I_MEDCARE**	As is
J	**J_SUPBEH**	As is
K	**K_ADL**	As is
L	**L_AGERSP**	As is
M	**M_HLTHRS**	As is
N	**N_RELATN**	As is
O	**O_CAREGV**	Recode *No* (2) as *No* (0)
P	**P_ADULTS**	As is
Q	**Q_RHEL**	As is
R	**R_INCOME**	As is
S	**S_EXPENSE**	As is
T	**T_CNTY**	As is
QI-QVII	**QI_FINAN, QII_INHM, QIII_OUT, QIV_EARLY, QV_TRANS, QVI_SPC, QVII_SSB**	Recode *No* (2) as *No* (0), treat *Don't Know* (3) as missing
Q1	**CFS_ENUF**	Treat *Don't Know* (6) and *N/*A (7) as missing
Q2	**CFS_EASY**	Treat *Don't Know* (6) and *N/*A (7) as missing
Q3	**CFS_INFCM**	Treat *Don't Know* (6) and *N/*A (7) as missing
Q4	**CFS_RSPCT**	Treat *Don't Know* (6) and *N/*A (7) as missing
Q5	**CFS_PSERV**	Treat *Don't Know* (6) and *N/*A (7) as missing
Q6	**CFS_HASSP**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q7	**CFS_DEVP**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing

Survey Item #	Variable Name	Recode or Collapse?
Q8	**CFS_IMPT12**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q9	**CFS_ALLSERV**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q10	**CFS_RSSP12**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q11	**CFS_EMERG**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q12	**CFS_RIGHT**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q13	**CFS_CNTC**	Treat *Don't Know* (6) and *N/A* (7) as missing
Q14	**CFS_CNTCCM**	Treat *Don't Know* (6) and *N/A* (7) as missing
Q15	**CFS_AVAL**	Treat *Don't Know* (6) and *N/A* (7) as missing
Q16	**CFS_DIST**	Treat *Don't Know* (6) and *N/A* (7) as missing
Q17	**CFS_SCHNG**	Treat *Don't Know* (6) and *N/A* (7) as missing
Q18	**CFS_LANG**	Treat *Don't Know* (6) and *N/A* (7) as missing
Q19	**CFS_COMME**	Treat *Don't Know* (6) and *N/A* (7) as missing
Q20	**CFS_COMMNE11**	Treat *Don't Know* (6) and *N/A* (7) as missing
Q21	**CFS_CULT**	Treat *Don't Know* (6) and *N/A* (7) as missing
Q22	**CFS_EQUIP**	Treat *Don't Know* (6) and *N/A* (7) as missing
Q23	**CFS_STFTRN**	Treat *Don't Know* (6) and *N/A* (7) as missing
Q24	**CFS_ONTIME**	Treat *Don't Know* (6) and *N/A* (7) as missing
Q25	**CFS_CRIS**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q26	**CFS_HLTH**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q26A	**CFS_HLTHS**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q27	**CFS_DNTL**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q27A	**CFS_DNTLS**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q28	**CFS_MEDS**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q28A	**Q28_MEDSS**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q29	**CFS_MHS**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q29A	**CFS_MHSS**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q30	**CFS_RSPT**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q30A	**CFS_RSPTS**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing
Q31	**CFS_OTHER12**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/A* (7) as missing

Survey Item #	Variable Name	Recode or Collapse?
Q31A	**CFS_OTHER**	As is
Q32	**CFS_AGY**	Treat *Don't Know* (6) and *N/*A (7) as missing
Q33	**CFS_NUMAGY12**	Treat *Don't Know* (6) and *N/*A (7) as missing
Q34	**CFS_WRKR**	Treat *Don't Know* (6) and *N/*A (7) as missing
Q35	**CFS_DIFFCHO**	Treat *Don't Know* (6) and *N/*A (7) as missing
Q36	**CFS_CMSC**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q37	**CFS_CNTL**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q38	**CFS_MONY**	Recode *Don't Know* (6) and *N/*A (7) as *No* (0)
Q39	**CFS_DECD**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q39A	**CFS_SPEND**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q40	**CFS_PRTC**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q40A	**CFS_PRTCNO1,** **CFS_PRTCNO2,** **CFS_PRTCNO3,** **CFS_PRTCNO4,** **CFS_PRTCNO5,** **CFS_PRTCNO_OTHER**	Recode *No* (2) as *No* (0), except CFS_PRTCNO_OTHER treated as is
Q41	**CFS_TIME**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q42	**CFS_SAT**	Treat *Don't Know* (6) and *N/*A (7) as missing
Q43	**CFS_FGRV09**	Recode *No* (5), *Don't Know* (6), and *N/*A (7) as *No* (0)
Q44	**CFS_HGRV09**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q45	**CFS_ABUSE**	Recode *No* (5), *Don't Know* (6), and *N/*A (7) as *No* (0)
Q46	**CFS_REPT**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q46A	**CFS_RESREPT**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q47	**CFS_POS**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q48	**CFS_REDUCE**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q49	**CFS_CARE**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q50	**CFS_RDUCE**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing
Q50A	**CFS_AFFECT**	Recode *No* (5) as *No* (0), treat *Don't Know* (6) and *N/*A (7) as missing

Appendix B: Type of Significance Testing Conducted by Question

Section/Question	Test of Significant Difference
Child's Demographic Information	
More Than One Disabled Child in Household	Chi-Square Test
Child's Age	T-Test of Independent Means
Child's Gender	Chi-Square Test
Child's Race and Ethnicity	Chi-Square Test
Child's Type of CA Qualifying Condition	Chi-Square Test
Child's Type of Disability	Chi-Square Test
Child's Primary Means of Expression	Chi-Square Test
Child's Preferred Language	Chi-Square Test
Frequency of Medical Care Needed for Child	Mann-Whitney Test
Amount of Behavioral Support Needed for Child	Mann-Whitney Test
Amount of Help Needed for Child's Daily Activities	Mann-Whitney Test
Family/Survey Respondent's Demographic Information	
Respondent's Age	Mann-Whitney Test
Respondent's Health	Mann-Whitney Test
Respondent's Relationship to Child	Chi-Square Test
Respondent is Child's Primary Caregiver	Chi-Square Test
Number of Adults in Household	Mann-Whitney Test
Respondent's Highest Education Level	Chi-Square Test
Total Taxable Family Income of Wage Earners in the Household in the Past Year	Mann-Whitney Test
Out-of-Pocket Expenses for Child in the Past Year	Mann-Whitney Test
Services and Supports Received	
Financial Support	Chi-Square Test
In-Home Support	Chi-Square Test
Out-of-Home Respite Care	Chi-Square Test
Early Intervention	Chi-Square Test
Transportation	Chi-Square Test
Other Services or Supports	Chi-Square Test
Social Security Benefits	Chi-Square Test

Section/Question	Test of Significant Difference
Information and Planning	
Receives Information About Available Services and Supports	Mann-Whitney Test
Information About Services and Supports Is Easy to Understand	Mann-Whitney Test
Information About Services and Supports Comes from Service Coordinator	Mann-Whitney Test
Service Coordinator Respects Family’s Choices and Opinions	Mann-Whitney Test
Service Coordinator Tells Family About Other Eligible Public Services	Mann-Whitney Test
Child Has an IPP	Chi-Square Test
Respondent Helped Develop Child’s IPP	Chi-Square Test
IPP Includes All the Services and Supports the Family Wants	Chi-Square Test
IPP Includes All the Services and Supports the Family Needs	Chi-Square Test
Family/Child Receives All Services Listed in Plan	Chi-Square Test
Respondent Discussed How to Handle Emergencies Related to Child at Last IPP Meeting	Chi-Square Test
Respondents Received Information About Family’s Rights	Chi-Square Test
Access and Delivery of Services and Supports	
Respondent Is Able to Contact Support Workers When Needed	Mann-Whitney Test
Respondent Is Able to Contact Service Coordinator When Needed	Mann-Whitney Test
Service and Supports Are Available at Times They Are Needed	Mann-Whitney Test
Services and Supports Are Available Reasonably Close to Home	Mann-Whitney Test
Services and Supports Change When Child’s Needs Change	Mann-Whitney Test
Support Workers or Translators Are Available Who Can Speak to Respondent in Their Preferred Language (If Not English)	Mann-Whitney Test
Support Workers Communicate Effectively in Respondent’s Primary Language (If English)	Mann-Whitney Test
Support Workers Can Communicate With the Child (If Non-Verbal)	Mann-Whitney Test
Services Are Delivered in a Manner That Is Respectful to Family’s Culture	Mann-Whitney Test
Child Has Access to Special Equipment or Accommodations Needed	Mann-Whitney Test

Section/Question	Test of Significant Difference
Support Workers Have the Right Training to Meet the Child's Needs	Mann-Whitney Test
Support Workers Who Come to the Home Arrive on Time and When Scheduled	Mann-Whitney Test
Crisis or Emergency Services Were Provided When Needed (If Requested)	Chi-Square Test
Respondent Has Access to Health Services for the Child	Chi-Square Test
Respondent Is Satisfied With the Quality of the Child's Health Providers	Chi-Square Test
Respondent Has Access to Dental Services for the Child	Chi-Square Test
Respondent Is Satisfied With the Quality of the Child's Dental providers	Chi-Square Test
Respondent Has Access to Necessary Medications for the Child	Chi-Square Test
Respondent Is Satisfied With How the Child's Medication Needs Are Monitored	Chi-Square Test
Respondent Has Access to Mental Health Services for the Child	Chi-Square Test
Respondent Is Satisfied With the Quality of the Child's Mental Health Providers	Chi-Square Test
Respondent Has Access to Respite Services	Chi-Square Test
Respondent Is Satisfied With the Quality of the Child's Respite Providers	Chi-Square Test
Family Needs Other Services That Are Not Currently Offered/Available	Chi-Square Test
Choice and Control	
Respondent Chooses the Provider Agencies Who Work With the Family	Mann-Whitney Test
Respondent Can Choose a Different Provider Agency If Desired	Mann-Whitney Test
Respondent Chooses Individual Support Workers Who Work With the Family	Mann-Whitney Test
Respondent Can Choose Different Support Workers If Desired	Mann-Whitney Test
Respondent Chose Service Coordinator	Chi-Square Test
Respondent Has Control or Input Over the Hiring and Management of Family's Support Workers	Chi-Square Test
Respondent Knows How Much Money Is Spent by the Regional Center or Behalf of Child	Chi-Square Test
Respondent Has Say in How Regional Center Money Is Spent	Chi-Square Test
Respondent Has All Information Needed to Decide How to Spend Regional Center Money	Chi-Square Test

Section/Question	Test of Significant Difference
Community Connections	
Child Participates in Community Activities	Chi-Square Test
Reasons Child Does Not Participate in Community Activities	Chi-Square Test
Child Spends Time With Children Without DD	Chi-Square Test
Satisfaction With Services and Supports	
Respondent Is Satisfied With Services and Supports Family Receives	Mann-Whitney Test
Respondent Knows How to File a Complaint or Grievance Against Provider Agencies or Staff	Chi-Square Test
Respondent Is Satisfied With the Way Complaints or Grievances Against Provider Agencies or Staff Are Handled and Resolved	Chi-Square Test
Respondent Knows How to Report Abuse or Neglect	Chi-Square Test
Respondent Reported Abuse or Neglect in the Past Year	Chi-Square Test
Appropriate People Were Responsive to Report Abuse or Neglect (Past Year)	Chi-Square Test
Family Outcomes	
Family Supports have Made a Positive Difference in Family’s Life	Chi-Square Test
Services and Supports Have Reduced Out-of-Pocket Expenses	Chi-Square Test
Family Supports Have Improved Respondent’s Ability to Care for the Child	Chi-Square Test
Services or Supports Have Been Reduced, Suspended, or Terminated in the Past Year	Chi-Square Test
Reduction, Suspension, or Termination of Services in the Past Year Affected the Family Negatively	Chi-Square Test

Appendix C: Summary of Results by ID

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Child's Demographic Information					
Subgroup Sample Size			2733		4935
More Than One Child with a Disability in Household	**Yes**				
Yes		19%	508	17%	830
No		70%	1912	72%	3564
Child's Age	**Yes**	11.66 years old	2668	9.52 years old	4795
Child's Gender	**Yes**				
Male		59%	1604	75%	3698
Female		39%	1056	22%	1088
Child's Race and Ethnicity					
American Indian/Alaska Native	No	2%	62	2%	101
Asian	**Yes**	9%	252	15%	745
Black/African American	**Yes**	8%	214	6%	300
Native Hawaiian/Pacific Islander	No	1%	33	1%	53
White	No	37%	1002	36%	1760
Other/Unknown	No	1%	33	1%	71
Mixed (Two or More Races)	**Yes**	13%	358	11%	540
Hispanic/Latino	**Yes**	45%	1220	40%	1958
Child's Type of CA Qualifying Condition					
Autism Spectrum Disorder	**Yes**	34%	938	75%	3706
Cerebral Palsy	**Yes**	18%	489	8%	394
Intellectual Disability	n/a	n/a	n/a	n/a	n/a
Epilepsy	**Yes**	26%	722	8%	372

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[1] The Sig. column indicates whether there was a significant difference between children with the qualifying condition and those without. The specific test of significant group difference varied based on the type of question and response choices in the survey. See Appendix B for specific test used for each survey question.

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Child's Type of Disability					
Mental Illness/Psychiatric Diagnosis/Behavioral Disorder	**Yes**	19%	507	9%	456
Brain Injury	**Yes**	8%	223	3%	125
Chemical Dependency	**Yes**	1%	38	0%	6
Limited or No Vision/Legally Blind	**Yes**	12%	326	3%	154
Hearing Loss (Severe or Profound)	**Yes**	5%	147	2%	97
Down Syndrome	**Yes**	10%	278	9%	431
Prader-Willi Syndrome	No	1%	17	0%	22
Other Disabilities Not Listed	**Yes**	25%	674	11%	539
No Other Disabilities	**Yes**	3%	83	2%	110
Don't Know	**Yes**	2%	61	0%	0
Child's Primary Means of Expression					
Spoken	**Yes**	54%	1479	69%	3406
Gestures/Body Language	**Yes**	30%	807	19%	920
Sign Language/Finger Spelling	No	4%	109	3%	158
Communication Aid/Device	No	4%	100	3%	160
Other	**Yes**	7%	179	4%	209
Child's Preferred Language					
English	**Yes**	68%	1860	75%	3691
Spanish	**Yes**	26%	706	20%	989
Other	No	5%	131	4%	206
Frequency of Medical Care Needed for Child	**Yes**				
Less Than Once Per Month		63%	1715	74%	3675
At Least Once Per Month But Less Than Once Per Week		21%	579	12%	603
At Least Once Per Week or More Frequently		11%	302	7%	333
Amount of Behavioral Support Needed for Child	**Yes**				
No Support Needed		25%	692	29%	1436
Some Support Needed		33%	908	36%	1784
Extensive Support Needed		20%	538	14%	680

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Amount of Help Needed for Child's Daily Activities	**Yes**				
None		5%	137	8%	419
Little		15%	408	24%	1177
Moderate		35%	966	40%	1986
Complete		44%	1213	27%	1323
Family/Survey Respondent's Demographic Information					
Respondent's Age	**Yes**				
Under 35		19%	523	22%	1084
35–54		63%	1727	68%	3351
55–74		16%	449	9%	460
75 or Older		1%	15	0%	13
Respondent's Health	**Yes**				
Excellent		19%	518	23%	1135
Good		56%	1530	54%	2661
Fair		21%	572	20%	965
Poor		3%	95	3%	139
Respondent's Relationship to Child					
Parent	**Yes**	94%	2574	97%	4792
Sibling	**Yes**	1%	18	0%	14
Grandparent	**Yes**	3%	95	2%	82
Other	**Yes**	1%	38	1%	34
Respondent is Child's Primary Caregiver	No				
Yes		96%	2630	97%	4774
No		2%	61	2%	104
Number of Adults in Household	No				
One		19%	522	15%	759
Two		55%	1511	63%	3093
Three		14%	383	12%	611
Four or More		11%	287	8%	414

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Respondent's Highest Education Level					
No HS Diploma/GED	**Yes**	21%	586	17%	863
HS Diploma/GED	No	16%	430	15%	724
Vocational School	No	5%	137	5%	262
Some College	**Yes**	21%	574	19%	944
College Degree	**Yes**	33%	897	40%	1958
Total Taxable Family Income of Wage Earners in the Household in the Past Year	**Yes**				
Below $15,000		21%	568	19%	917
$15,001–$25,000		19%	527	17%	857
$25,001–$50,000		22%	605	20%	987
$50,001–$75,000		12%	323	12%	614
Over $75,000		19%	519	24%	1201
Out-of-Pocket Expenses for Child in the Past Year	**Yes**				
Nothing		25%	670	22%	1105
$1–$100		12%	316	11%	548
$101–$1,000		30%	828	28%	1361
$1,001–$10,000		24%	669	27%	1331
Over $10,000		5%	131	7%	343
Services and Supports Received					
Services and Supports Received					
Financial Support	**Yes**	11%	287	9%	430
In-Home Support	**Yes**	53%	1460	48%	2351
Out-of-Home Respite Care	**Yes**	30%	821	25%	1249
Early Intervention	**Yes**	11%	293	18%	907
Transportation	**Yes**	25%	693	20%	966
Other Services or Supports	**Yes**	44%	1190	48%	2357
Social Security Benefits	**Yes**	46%	1269	38%	1856

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Information and Planning					
Receives Information About Available Services and Supports	No				
Always		19%	528	19%	920
Usually		21%	572	21%	1054
Sometimes		26%	713	26%	1280
Seldom		18%	480	18%	909
Never		12%	325	11%	565
Information About Services and Supports Is Easy to Understand	No				
Always		26%	704	25%	1246
Usually		30%	825	32%	1560
Sometimes		20%	542	20%	986
Seldom		6%	153	5%	269
Never		1%	29	1%	53
Information About Services and Supports Comes from Service Coordinator	No				
Always		30%	826	29%	1442
Usually		23%	637	25%	1235
Sometimes		17%	471	17%	839
Seldom		9%	239	9%	431
Never		7%	202	7%	359
Service Coordinator Respects Family's Choices and Opinions	No				
Always		56%	1535	55%	2726
Usually		20%	560	23%	1129
Sometimes		7%	188	7%	342
Seldom		4%	99	3%	159
Never		3%	84	2%	103

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Service Coordinator Tells Family About Other Eligible Public Services	No				
Always		27%	745	25%	1229
Usually		17%	476	18%	889
Sometimes		16%	424	16%	769
Seldom		12%	325	13%	624
Never		18%	505	19%	917
Child Has an IPP	No				
Yes		65%	1789	67%	3284
No		17%	454	16%	814
Respondent Helped Develop Child's IPP	No				
Yes		87%	1558	86%	2812
No		7%	119	7%	244
IPP Includes All the Services and Supports the Family Wants	No				
Yes		59%	1061	58%	1896
No		25%	444	27%	891
IPP Includes All the Services and Supports the Family Needs	No				
Yes		53%	945	51%	1663
No		30%	535	31%	1030
Family/Child Receives All Services Listed in Plan	No				
Yes		72%	1289	70%	2296
No		13%	231	13%	426
Respondent Discussed How to Handle Emergencies Related to Child at Last IPP Meeting	**Yes**				
Yes		36%	639	41%	1339
No		49%	884	41%	1333
Respondents Received Information About Family's Rights	No				
Yes		66%	1792	66%	3245
No		14%	382	13%	644

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Access and Delivery of Services and Supports					
Respondent Is Able to Contact Support Workers When Needed	No				
Always		42%	1135	40%	1975
Usually		29%	788	31%	1533
Sometimes		14%	385	13%	632
Seldom		5%	148	5%	264
Never		3%	72	3%	128
Respondent Is Able to Contact Service Coordinator When Needed	No				
Always		43%	1170	42%	2061
Usually		29%	797	31%	1506
Sometimes		14%	391	14%	668
Seldom		6%	172	6%	313
Never		3%	86	3%	143
Service and Supports Are Available at Times They Are Needed	No				
Always		28%	756	26%	1305
Usually		28%	752	29%	1443
Sometimes		23%	620	22%	1062
Seldom		8%	226	9%	420
Never		6%	156	5%	255
Services and Supports Are Available Reasonably Close to Home	No				
Always		28%	770	29%	1407
Usually		29%	780	29%	1452
Sometimes		16%	447	16%	799
Seldom		7%	187	6%	309
Never		6%	152	4%	202

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Services and Supports Change When Child's Needs Change	No				
Always		26%	705	25%	1235
Usually		26%	701	26%	1296
Sometimes		15%	411	14%	713
Seldom		7%	188	7%	331
Never		6%	171	5%	251
Support Workers or Translators Are Available Who Can Speak to Respondent in Their Preferred Language (If Not English)	No				
Always		16%	428	13%	631
Usually		6%	175	5%	255
Sometimes		3%	79	2%	120
Seldom		1%	31	1%	45
Never		1%	23	1%	30
Support Workers Communicate Effectively in Respondent's Primary Language (If English)	No				
Always		42%	1154	44%	2159
Usually		13%	353	14%	708
Sometimes		3%	76	3%	147
Seldom		1%	18	1%	48
Never		1%	31	1%	40
Support Workers Can Communicate With the Child (If Non-Verbal)	No				
Always		7%	204	5%	271
Usually		8%	227	6%	289
Sometimes		7%	185	4%	188
Seldom		3%	89	3%	127
Never		6%	171	4%	201

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Services Are Delivered in a Manner That Is Respectful to Family's Culture	No				
Always		54%	1486	53%	2626
Usually		21%	562	22%	1092
Sometimes		5%	146	5%	245
Seldom		2%	45	2%	77
Never		2%	66	2%	86
Child Has Access to Special Equipment or Accommodations Needed	No				
Always		19%	506	12%	611
Usually		13%	353	9%	424
Sometimes		8%	209	5%	234
Seldom		4%	109	2%	103
Never		10%	266	7%	353
Support Workers Have the Right Training to Meet the Child's Needs	No				
Always		34%	937	34%	1688
Usually		26%	699	27%	1354
Sometimes		11%	310	11%	540
Seldom		4%	110	3%	167
Never		3%	89	3%	124
Support Workers Who Come to the Home Arrive on Time and When Scheduled	No				
Always		46%	1245	43%	2142
Usually		24%	649	24%	1198
Sometimes		6%	157	7%	321
Seldom		2%	49	2%	82
Never		3%	72	2%	95
Crisis or Emergency Services Were Provided When Needed (If Requested)	No				
Yes		16%	449	13%	661
No		13%	357	10%	513

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Respondent Has Access to Health Services for the Child	No				
Yes		86%	2340	83%	4079
No		5%	140	5%	260
Respondent Is Satisfied With the Quality of the Child's Health Providers	No				
Yes		86%	2001	83%	3386
No		8%	186	8%	341
Respondent Has Access to Dental Services for the Child	No				
Yes		83%	2280	80%	3944
No		9%	253	10%	479
Respondent Is Satisfied With the Quality of the Child's Dental Providers	No				
Yes		84%	1921	83%	3260
No		8%	190	7%	281
Respondent Has Access to Necessary Medications for the Child	No				
Yes		83%	2257	74%	3653
No		4%	103	4%	202
Respondent Is Satisfied With How the Child's Medication Needs Are Monitored	No				
Yes		88%	1986	84%	3061
No		5%	104	4%	164
Respondent Has Access to Mental Health Services for the Child	No				
Yes		47%	1292	43%	2124
No		13%	363	12%	614
Respondent Is Satisfied With the Quality of the Child's Mental Health Providers	No				
Yes		79%	1015	73%	1551
No		6%	78	6%	132

	Sig.[1]	**ID (%)**	**ID (N)**	**No ID (%)**	**No ID (N)**
Respondent Has Access to Respite Services	No				
Yes		68%	1848	62%	3070
No		13%	344	11%	547
Respondent Is Satisfied With the Quality of the Child's Respite Providers	No				
Yes		81%	1506	79%	2414
No		8%	143	7%	230
Family Needs Other Services That Are Not Currently Offered/Available	No				
Yes		39%	1055	36%	1754
No		22%	601	21%	1045
Choice and Control					
Respondent Chooses the Provider Agencies Who Work With the Family	No				
Always		25%	681	25%	1229
Usually		18%	503	20%	979
Sometimes		14%	384	12%	580
Seldom		6%	154	6%	291
Never		17%	467	17%	863
Respondent Can Choose a Different Provider Agency If Desired	No				
Always		22%	592	22%	1093
Usually		14%	395	15%	720
Sometimes		9%	235	8%	397
Seldom		3%	92	4%	173
Never		7%	178	7%	348
Respondent Chooses Individual Support Workers Who Work With the Family	**Yes**				
Always		25%	676	21%	1047
Usually		13%	356	13%	636
Sometimes		10%	276	10%	492
Seldom		5%	150	7%	342
Never		21%	579	23%	1147

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Respondent Can Choose Different Support Workers If Desired	**Yes**				
Always		25%	684	23%	1114
Usually		13%	357	13%	654
Sometimes		8%	209	8%	406
Seldom		3%	95	3%	172
Never		7%	190	8%	388
Respondent Chose Service Coordinator	No				
Yes		8%	225	7%	360
No		82%	2239	82%	4036
Respondent Has Control or Input Over the Hiring and Management of Family's Support Workers	**Yes**				
Yes		26%	706	23%	1113
No		42%	1161	44%	2158
Respondent Knows How Much Money Is Spent by the Regional Center or Behalf of Child	**Yes**				
Yes		28%	760	31%	1542
No/Don't Know/ Does Not Apply		69%	1888	65%	3201
Respondent Has Say in How Regional Center Money Is Spent	**Yes**				
Yes		12%	320	10%	482
No		49%	1349	53%	2602
Respondent Has All Information Needed to Decide How to Spend Regional Center Money	No				
Yes		13%	178	11%	283
No		5%	64	3%	89
Community Connections					
Child Participates in Community Activities	**Yes**				
Yes		67%	1835	73%	3578
No		28%	754	22%	1100

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Reasons Child Does Not Participate in Community Activities					
Lack of Transportation	No	15%	111	14%	159
Cost	No	26%	197	26%	289
Lack of Support Staff	No	25%	189	23%	257
Negative Attitudes From Community Members	No	16%	120	18%	201
Other	No	40%	304	38%	416
Child Spends Time With Children Without DD	**Yes**				
Yes		76%	2078	78%	3871
No		17%	457	14%	696
Satisfaction With Services and Supports					
Respondent Is Satisfied With Services and Supports Family Receives	No				
Always		30%	814	28%	1373
Usually		32%	888	35%	1728
Sometimes		19%	522	19%	926
Seldom		7%	195	8%	384
Never		5%	127	4%	201
Respondent Knows How to File a Complaint or Grievance Against Provider Agencies or Staff	No				
Yes		38%	1033	36%	1765
No/Don't Know/ Does Not Apply		60%	1631	61%	2996
Respondent Is Satisfied With the Way Complaints or Grievances Against Provider Agencies or Staff Are Handled and Resolved	**Yes**				
Yes		23%	633	20%	980
No		12%	329	13%	644
Respondent Knows How to Report Abuse or Neglect	**Yes**				
Yes		58%	1592	55%	2710
No/Don't Know/ Does Not Apply		38%	1041	41%	2023

	Sig.[1]	ID (%)	ID (N)	No ID (%)	No ID (N)
Respondent Reported Abuse or Neglect in the Past Year	No				
Yes		6%	173	5%	226
No		21%	563	17%	844
Appropriate People Were Responsive to Report Abuse or Neglect (Past Year)	No				
Yes		16%	90	13%	112
No		4%	22	5%	39
Family Outcomes					
Family Supports have Made a Positive Difference in Family's Life	No				
Yes		73%	1994	76%	3731
No		8%	230	8%	380
Services and Supports Have Reduced Out-of-Pocket Expenses	No				
Yes		61%	1664	62%	3078
No		19%	522	18%	887
Family Supports Have Improved Respondent's Ability to Care for the Child	**Yes**				
Yes		68%	1862	72%	3564
No		14%	376	11%	533
Services or Supports Have Been Reduced, Suspended, or Terminated in the Past Year	No				
Yes		34%	933	35%	1722
No		48%	1302	48%	2352
Reduction, Suspension, or Termination of Services in the Past Year Affected the Family Negatively	No				
Yes		48%	620	47%	1105
No		12%	157	14%	337

Appendix D: Summary of Results by ASD

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Child's Demographic Information					
Subgroup Sample Size			4665		2983
More Than One Disabled Child in Household	**Yes**				
Yes		19%	880	15%	450
No		71%	3335	71%	2129
Child's Age	**Yes**	9.81 years old	4567	11.03 years old	2875
Child's Gender	**Yes**				
Male		79%	3697	53%	1595
Female		18%	834	44%	1299
Child's Race and Ethnicity					
American Indian/Alaska Native	No	2%	96	2%	67
Asian	**Yes**	15%	723	9%	270
Black/African American	No	6%	300	7%	210
Native Hawaiian/Pacific Islander	No	1%	54	1%	32
White	**Yes**	38%	1792	32%	959
Other/Unknown	No	1%	68	1%	37
Mixed (Two or More Races)	**Yes**	12%	582	10%	313
Hispanic/Latino	**Yes**	37%	1731	48%	1439
Child's Type of CA Qualifying Condition					
Autism Spectrum Disorder	n/a	n/a	n/a	n/a	n/a
Cerebral Palsy	**Yes**	3%	137	25%	740
Intellectual Disability	**Yes**	20%	938	59%	1754
Epilepsy	**Yes**	8%	355	25%	731

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[1] The Sig. column indicates whether there was a significant difference between children with the focus diagnosis and those without. The specific test of significant group difference varied based on the type of question and response choices in the survey. See Appendix B for specific test used for each survey question.

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Child's Type of Disability					
Mental Illness/Psychiatric Diagnosis/Behavioral Disorder	No	12%	567	13%	386
Brain Injury	**Yes**	1%	69	9%	274
Chemical Dependency	**Yes**	0%	19	1%	25
Limited or No Vision/Legally Blind	**Yes**	2%	107	12%	369
Hearing Loss (Severe or Profound)	**Yes**	1%	52	6%	190
Down Syndrome	**Yes**	1%	69	21%	636
Prader-Willi Syndrome	**Yes**	0%	8	1%	31
Other Disabilities Not Listed	**Yes**	9%	415	27%	797
No Other Disabilities	No	3%	117	3%	77
Don't Know	**Yes**	1%	41	0%	0
Child's Primary Means of Expression					
Spoken	**Yes**	69%	3230	55%	1638
Gestures/Body Language	**Yes**	19%	898	28%	827
Sign Language/Finger Spelling	**Yes**	3%	127	5%	137
Communication Aid/Device	No	3%	163	3%	97
Other	**Yes**	4%	175	7%	216
Child's Preferred Language					
English	**Yes**	79%	3676	62%	1856
Spanish	**Yes**	16%	768	31%	926
Other	**Yes**	4%	182	5%	156
Frequency of Medical Care Needed for Child	**Yes**				
Less Than Once Per Month		76%	3523	62%	1851
At Least Once Per Month But Less Than Once Per Week		13%	597	20%	583
At Least Once Per Week or More Frequently		6%	258	13%	377
Amount of Behavioral Support Needed for Child	**Yes**				
No Support Needed		24%	1100	34%	1020
Some Support Needed		38%	1787	30%	905
Extensive Support Needed		17%	808	14%	406

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Amount of Help Needed for Child's Daily Activities	**Yes**				
None		8%	380	6%	179
Little		23%	1073	17%	506
Moderate		43%	1996	32%	950
Complete		25%	1186	45%	1338
Family/Survey Respondent's Demographic Information					
Respondent's Age	**Yes**				
Under 35		21%	986	21%	614
35–54		68%	3190	63%	1883
55–74		10%	446	15%	455
75 or Older		0%	13	0%	14
Respondent's Health	**Yes**				
Excellent		22%	1023	21%	627
Good		55%	2573	54%	1612
Fair		19%	909	21%	618
Poor		3%	127	4%	106
Respondent's Relationship to Child					
Parent	**Yes**	97%	4525	95%	2830
Sibling	**Yes**	0.2%	10	1%	22
Grandparent	**Yes**	2%	83	3%	87
Other	**Yes**	1%	33	1%	37
Respondent is Child's Primary Caregiver	No				
Yes		97%	4510	96%	2876
No		2%	95	2%	69
Number of Adults in Household	No				
One		16%	740	18%	533
Two		63%	2927	56%	1669
Three		12%	581	14%	411
Four or More		8%	364	11%	336

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Respondent's Highest Education Level					
No HS Diploma/GED	**Yes**	15%	700	25%	744
HS Diploma/GED	**Yes**	14%	657	17%	495
Vocational School	No	5%	239	5%	161
Some College	No	20%	950	19%	560
College Degree	**Yes**	42%	1973	29%	877
Total Taxable Family Income of Wage Earners in the Household in the Past Year	**Yes**				
Below $15,000		17%	798	23%	683
$15,001–$25,000		16%	741	21%	635
$25,001–$50,000		21%	964	21%	624
$50,001–$75,000		14%	632	10%	305
Over $75,000		26%	1192	18%	524
Out-of-Pocket Expenses for Child in the Past Year	**Yes**				
Nothing		20%	934	28%	836
$1–$100		11%	501	12%	362
$101–$1,000		28%	1308	29%	872
$1,001–$10,000		29%	1347	22%	654
Over $10,000		7%	346	4%	126
Services and Supports Received					
Services and Supports Received					
Financial Support	**Yes**	8%	384	11%	327
In-Home Support	No	50%	2311	50%	1491
Out-of-Home Respite Care	**Yes**	25%	1186	30%	882
Early Intervention	**Yes**	17%	777	14%	418
Transportation	**Yes**	19%	877	26%	780
Other Services or Supports	No	47%	2210	44%	1325
Social Security Benefits	**Yes**	37%	1714	47%	1397

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Information and Planning					
Receives Information About Available Services and Supports	**Yes**				
Always		18%	834	20%	611
Usually		21%	983	21%	635
Sometimes		26%	1218	26%	767
Seldom		19%	892	17%	497
Never		12%	568	11%	325
Information About Services and Supports Is Easy to Understand	No				
Always		24%	1137	27%	807
Usually		33%	1529	28%	844
Sometimes		19%	904	21%	623
Seldom		5%	252	6%	170
Never		1%	49	1%	32
Information About Services and Supports Comes from Service Coordinator	**Yes**				
Always		29%	1337	31%	924
Usually		25%	1180	23%	688
Sometimes		17%	803	17%	502
Seldom		9%	440	8%	230
Never		7%	349	7%	210
Service Coordinator Respects Family's Choices and Opinions	**Yes**				
Always		55%	2552	57%	1695
Usually		23%	1075	21%	614
Sometimes		7%	328	7%	198
Seldom		4%	172	3%	86
Never		2%	110	3%	77

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Service Coordinator Tells Family About Other Eligible Public Services	**Yes**				
Always		24%	1101	29%	866
Usually		18%	838	17%	521
Sometimes		15%	714	16%	474
Seldom		13%	621	11%	327
Never		20%	930	16%	492
Child Has an IPP	**Yes**				
Yes		70%	3254	61%	1809
No		15%	709	19%	560
Respondent Helped Develop Child's IPP	No				
Yes		86%	2813	86%	1550
No		7%	236	7%	125
IPP Includes All the Services and Supports the Family Wants	**Yes**				
Yes		56%	1835	62%	1114
No		29%	931	22%	402
IPP Includes All the Services and Supports the Family Needs	**Yes**				
Yes		49%	1610	55%	994
No		34%	1099	25%	461
Family/Child Receives All Services Listed in Plan	No				
Yes		71%	2302	70%	1274
No		13%	436	12%	223
Respondent Discussed How to Handle Emergencies Related to Child at Last IPP Meeting	**Yes**				
Yes		41%	1350	48%	868
No		41%	1323	36%	647
Respondents Received Information About Family's Rights	No				
Yes		67%	3120	64%	1899
No		13%	606	14%	420

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Access and Delivery of Services and Supports					
Respondent Is Able to Contact Support Workers When Needed	**Yes**				
Always		39%	1817	43%	1281
Usually		32%	1484	28%	833
Sometimes		13%	600	14%	411
Seldom		6%	262	5%	150
Never		3%	117	3%	84
Respondent Is Able to Contact Service Coordinator When Needed	**Yes**				
Always		41%	1901	44%	1314
Usually		31%	1461	28%	837
Sometimes		14%	646	14%	413
Seldom		7%	307	6%	179
Never		3%	132	3%	98
Service and Supports Are Available at Times They Are Needed	**Yes**				
Always		25%	1155	30%	898
Usually		29%	1373	27%	815
Sometimes		22%	1033	22%	646
Seldom		9%	438	7%	209
Never		6%	259	5%	152
Services and Supports Are Available Reasonably Close to Home	**Yes**				
Always		27%	1268	30%	901
Usually		30%	1414	27%	815
Sometimes		16%	746	17%	493
Seldom		7%	314	6%	184
Never		5%	228	4%	127

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Services and Supports Change When Child's Needs Change	**Yes**				
Always		24%	1111	27%	819
Usually		26%	1233	26%	762
Sometimes		15%	707	14%	413
Seldom		8%	354	6%	165
Never		6%	265	5%	161
Support Workers or Translators Are Available Who Can Speak to Respondent in Their Preferred Language (If Not English)	No				
Always		10%	479	19%	581
Usually		5%	222	7%	208
Sometimes		2%	84	4%	113
Seldom		1%	40	1%	37
Never		1%	24	1%	29
Support Workers Communicate Effectively in Respondent's Primary Language (If English)	No				
Always		46%	2143	39%	1157
Usually		15%	708	12%	346
Sometimes		3%	148	2%	74
Seldom		1%	51	1%	16
Never		1%	41	1%	31
Support Workers Can Communicate With the Child (If Non-Verbal)	No				
Always		5%	252	8%	225
Usually		6%	293	8%	224
Sometimes		4%	191	6%	183
Seldom		3%	117	3%	97
Never		4%	200	6%	172

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Services Are Delivered in a Manner That Is Respectful to Family's Culture	No				
Always		53%	2453	55%	1641
Usually		22%	1042	20%	610
Sometimes		5%	221	6%	170
Seldom		2%	81	1%	41
Never		2%	87	2%	65
Child Has Access to Special Equipment or Accommodations Needed	**Yes**				
Always		10%	456	22%	658
Usually		8%	390	13%	384
Sometimes		5%	222	7%	219
Seldom		2%	103	4%	108
Never		7%	345	9%	277
Support Workers Have the Right Training to Meet the Child's Needs	**Yes**				
Always		32%	1508	37%	1111
Usually		28%	1308	25%	740
Sometimes		11%	520	11%	326
Seldom		4%	182	3%	95
Never		3%	132	3%	83
Support Workers Who Come to the Home Arrive on Time and When Scheduled	**Yes**				
Always		42%	1959	48%	1418
Usually		26%	1217	21%	623
Sometimes		7%	306	6%	172
Seldom		2%	71	2%	61
Never		2%	90	3%	78
Crisis or Emergency Services Were Provided When Needed (If Requested)	No				
Yes		14%	637	16%	474
No		11%	504	12%	368

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Respondent Has Access to Health Services for the Child	No				
Yes		83%	3862	85%	2540
No		5%	253	5%	149
Respondent Is Satisfied With the Quality of the Child's Health Providers	**Yes**				
Yes		81%	3141	88%	2225
No		10%	371	6%	156
Respondent Has Access to Dental Services for the Child	No				
Yes		80%	3739	83%	2468
No		10%	461	9%	270
Respondent Is Satisfied With the Quality of the Child's Dental Providers	No				
Yes		82%	3080	85%	2091
No		8%	292	7%	176
Respondent Has Access to Necessary Medications for the Child	**Yes**				
Yes		73%	3418	83%	2478
No		4%	198	4%	107
Respondent Is Satisfied With How the Child's Medication Needs Are Monitored	No				
Yes		84%	2858	88%	2173
No		5%	163	4%	105
Respondent Has Access to Mental Health Services for the Child	No				
Yes		46%	2158	42%	1249
No		13%	629	12%	345
Respondent Is Satisfied With the Quality of the Child's Mental Health Providers	**Yes**				
Yes		73%	1570	79%	989
No		0%	147	5%	64

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Respondent Has Access to Respite Services	No				
Yes		100%	2922	66%	1982
No		19%	546	12%	345
Respondent Is Satisfied With the Quality of the Child's Respite Providers	**Yes**				
Yes		49%	2266	83%	1640
No		5%	248	6%	126
Family Needs Other Services That Are Not Currently Offered/Available	**Yes**				
Yes		39%	1817	33%	987
No		20%	946	23%	696
Choice and Control					
Respondent Chooses the Provider Agencies Who Work With the Family	No				
Always		24%	1136	26%	771
Usually		20%	950	17%	522
Sometimes		13%	600	12%	360
Seldom		6%	283	5%	162
Never		18%	820	17%	510
Respondent Can Choose a Different Provider Agency If Desired	**Yes**				
Always		21%	997	23%	683
Usually		16%	734	13%	378
Sometimes		9%	402	8%	226
Seldom		4%	180	3%	86
Never		7%	323	7%	205
Respondent Chooses Individual Support Workers Who Work With the Family	**Yes**				
Always		21%	973	25%	742
Usually		14%	631	12%	359
Sometimes		11%	494	9%	269
Seldom		7%	333	5%	159
Never		23%	1072	22%	653

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Respondent Can Choose Different Support Workers If Desired	**Yes**				
Always		22%	1037	25%	753
Usually		14%	654	12%	353
Sometimes		9%	418	7%	197
Seldom		4%	167	3%	100
Never		8%	352	8%	229
Respondent Chose Service Coordinator	**Yes**				
Yes		7%	334	8%	250
No		83%	3859	80%	2399
Respondent Has Control or Input Over the Hiring and Management of Family's Support Workers	**Yes**				
Yes		23%	1065	25%	751
No		44%	2053	42%	1258
Respondent Knows How Much Money Is Spent by the Regional Center or Behalf of Child	**Yes**				
Yes		33%	1545	25%	746
No/Don't Know/ Does Not Apply		63%	2957	71%	2123
Respondent Has Say in How Regional Center Money Is Spent	No				
Yes		10%	473	11%	328
No		53%	2478	49%	1472
Respondent Has All Information Needed to Decide How to Spend Regional Center Money	No				
Yes		59%	278	55%	182
No		21%	98	17%	55
Community Connections					
Child Participates in Community Activities	**Yes**				
Yes		72%	3367	68%	2022
No		23%	1073	26%	787

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Reasons Child Does Not Participate in Community Activities					
Lack of Transportation	No	15%	164	14%	107
Cost	No	28%	301	24%	190
Lack of Support Staff	**Yes**	27%	288	20%	159
Negative Attitudes From Community Members	**Yes**	22%	238	11%	85
Other	No	38%	406	40%	316
Child Spends Time With Children Without DD	**Yes**				
Yes		76%	3551	80%	2378
No		17%	781	13%	374
Satisfaction With Services and Supports					
Respondent Is Satisfied With Services and Supports Family Receives	**Yes**				
Always		26%	1213	32%	964
Usually		35%	1635	33%	972
Sometimes		20%	914	18%	536
Seldom		8%	388	6%	190
Never		5%	216	4%	111
Respondent Knows How to File a Complaint or Grievance Against Provider Agencies or Staff	No				
Yes			1733		1062
No/Don't Know/ Does Not Apply		60%	2801	61%	1809
Respondent Is Satisfied With the Way Complaints or Grievances Against Provider Agencies or Staff Are Handled and Resolved	**Yes**				
Yes		20%	919	23%	690
No		13%	619	12%	352
Respondent Knows How to Report Abuse or Neglect	No				
Yes		56%	2619	56%	1666
No/Don't Know/ Does Not Apply		40%	1873	40%	1188

	Sig. [1]	ASD (%)	ASD (N)	No ASD (%)	No ASD (N)
Respondent Reported Abuse or Neglect in the Past Year	No				
Yes		5%	230	6%	166
No		16%	766	22%	642
Appropriate People Were Responsive to Report Abuse or Neglect (Past Year)	No				
Yes		47%	109	55%	91
No		16%	37	14%	23
Family Outcomes					
Family Supports have Made a Positive Difference in Family's Life	No				
Yes		75%	3482	75%	2224
No		8%	377	8%	232
Services and Supports Have Reduced Out-of-Pocket Expenses	No				
Yes		63%	2921	61%	1806
No		18%	845	19%	565
Family Supports Have Improved Respondent's Ability to Care for the Child	No				
Yes		72%	3348	69%	2062
No		12%	549	12%	358
Services or Supports Have Been Reduced, Suspended, or Terminated in the Past Year	**Yes**				
Yes		38%	1787	29%	865
No		45%	2112	51%	1529
Reduction, Suspension, or Termination of Services in the Past Year Affected the Family Negatively	No				
Yes		65%	1169	64%	553
No		19%	335	18%	158

Appendix E: Summary of Results by CP

	Sig.[1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Child's Demographic Information					
Subgroup Sample Size			887		6735
More Than One Disabled Child in Household	No				
Yes		16%	142	18%	1185
No		75%	666	71%	4782
Child's Age	**Yes**	11.58 years old	869	10.11 years old	6551
Child's Gender	**Yes**				
Male		55%	492	71%	4780
Female		42%	371	26%	1760
Child's Race and Ethnicity					
American Indian/Alaska Native	No	3%	24	2%	138
Asian	**Yes**	9%	81	13%	908
Black/African American	No	7%	59	7%	449
Native Hawaiian/Pacific Islander	No	1%	13	1%	72
White	**Yes**	39%	347	36%	2401
Other/Unknown	No	2%	14	1%	90
Mixed (Two or More Races)	No	11%	102	12%	788
Hispanic/Latino	No	41%	365	41%	2790
Child's Type of CA Qualifying Condition					
Autism Spectrum Disorder	**Yes**	15%	137	67%	4492
Cerebral Palsy	N/A	N/A	N/A	N/A	N/A
Intellectual Disability	**Yes**	55%	489	33%	2194
Epilepsy	**Yes**	47%	419	10%	667

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[1] The Sig. column indicates whether there was a significant difference between children with the focus diagnosis and those without. The specific test of significant group difference varied based on the type of question and response choices in the survey. See Appendix B for specific test used for each survey question.

	Sig. [1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Child's Type of Disability					
Mental Illness/Psychiatric Diagnosis/Behavioral Disorder	No	11%	95	13%	850
Brain Injury	**Yes**	21%	190	2%	155
Chemical Dependency	**Yes**	2%	16	0.4%	27
Limited or No Vision/Legally Blind	**Yes**	25%	221	4%	256
Hearing Loss (Severe or Profound)	**Yes**	7%	62	3%	180
Down Syndrome	**Yes**	1%	9	10%	692
Prader-Willi Syndrome	**Yes**	2%	15	1%	39
Other Disabilities not listed	**Yes**	29%	259	14%	947
No Other Disabilities	No	2%	22	3%	170
Don't Know	**Yes**	2%	15	0%	0
Child's Primary Means of Expression					
Spoken	**Yes**	39%	344	67%	4515
Gestures/Body Language	**Yes**	38%	340	20%	1376
Sign Language/Finger Spelling	No	4%	34	3%	228
Communication Aid/Device	**Yes**	5%	42	3%	218
Other	**Yes**	12%	108	4%	277
Child's Preferred Language					
English	**Yes**	68%	600	73%	4918
Spanish	No	23%	205	22%	1479
Other	**Yes**	7%	59	4%	276
Frequency of Medical Care Needed for Child	**Yes**				
Less Than Once Per Month		56%	494	72%	4871
At Least Once Per Month But Less Than Once Per Week		20%	175	15%	996
At Least Once Per Week or More Frequently		20%	177	7%	454
Amount of Behavioral Support Needed for Child	**Yes**				
No Support Needed		37%	326	27%	1794
Some Support Needed		21%	186	37%	2491
Extensive Support Needed		16%	146	16%	1064

	Sig. [1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Amount of Help Needed for Child's Daily Activities	**Yes**				
None		2%	16	8%	538
Little		7%	65	22%	1509
Moderate		20%	180	41%	2762
Complete		70%	623	28%	1890
Family/Survey Respondent's Demographic Information					
Respondent's Age	**Yes**				
Under 35		20%	174	21%	1423
35–54		63%	555	67%	4499
55–74		17%	150	11%	749
75 or Older		0%	3	0%	23
Respondent's Health	No				
Excellent		22%	192	22%	1456
Good		57%	505	54%	3669
Fair		17%	148	20%	1368
Poor		4%	39	3%	193
Respondent's Relationship to Child					
Parent	No	96%	848	96%	6479
Sibling	No	0%	4	0%	28
Grandparent	No	2%	20	2%	151
Other	**Yes**	2%	14	1%	57
Respondent is Child's Primary Caregiver	No				
Yes		96%	853	97%	6508
No		2%	19	2%	144
Number of Adults in Household	No				
One		17%	154	17%	1118
Two		59%	525	60%	4052
Three		13%	116	13%	870
Four or More		9%	79	9%	621

	Sig. [1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Respondent's Highest Education Level					
No HS Diploma/GED	No	17%	155	19%	1275
HS Diploma/GED	No	14%	126	15%	1016
Vocational School	No	5%	48	5%	351
Some College	No	21%	184	20%	1327
College Degree	No	39%	342	37%	2509
Total Taxable Family Income of Wage Earners in the Household in the Past Year	**Yes**				
Below $15,000		16%	140	20%	1334
$15,001–$25,000		18%	162	18%	1208
$25,001–$50,000		22%	197	21%	1385
$50,001–$75,000		12%	105	12%	831
Over $75,000		24%	210	22%	1505
Out-of-Pocket Expenses for Child in the Past Year	**Yes**				
Nothing		21%	186	23%	1578
$1–$100		9%	83	11%	773
$101–$1,000		29%	261	28%	1915
$1,001–$10,000		28%	251	26%	1744
Over $10,000		7%	58	6%	413
Services and Supports Received					
Services and Supports Received					
Financial Support	**Yes**	13%	119	9%	589
In-Home Support	**Yes**	67%	596	47%	3196
Out-of-Home Respite Care	No	28%	252	27%	1806
Early Intervention	**Yes**	11%	96	16%	1097
Transportation	**Yes**	25%	224	21%	1425
Other Services or Supports	**Yes**	53%	474	45%	3054
Social Security Benefits	No	43%	383	40%	2715

	Sig. [1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Information and Planning					
Receives Information About Available Services and Supports	No				
Always		19%	166	19%	1278
Usually		23%	203	21%	1414
Sometimes		26%	227	26%	1749
Seldom		19%	169	18%	1216
Never		11%	94	12%	790
Information About Services and Supports Is Easy to Understand	No				
Always		27%	241	25%	1702
Usually		30%	264	31%	2107
Sometimes		21%	184	20%	1336
Seldom		6%	51	5%	366
Never		1%	9	1%	72
Information About Services and Supports Comes from Service Coordinator	No				
Always		28%	249	30%	2006
Usually		24%	214	25%	1651
Sometimes		18%	160	17%	1141
Seldom		9%	80	9%	588
Never		7%	65	7%	491
Service Coordinator Respects Family’s Choices and Opinions	No				
Always		59%	526	55%	3714
Usually		20%	180	22%	1505
Sometimes		8%	68	7%	456
Seldom		3%	23	3%	233
Never		2%	16	3%	170

	Sig. [1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Service Coordinator Tells Family About Other Eligible Public Services	No				
Always		27%	236	26%	1728
Usually		17%	148	18%	1209
Sometimes		17%	149	15%	1036
Seldom		14%	120	12%	825
Never		18%	156	19%	1257
Child Has an IPP	No				
Yes		66%	586	66%	4467
No		15%	129	17%	1132
Respondent Helped Develop Child's IPP	No				
Yes		59%	524	57%	3830
No		4%	34	5%	325
IPP Includes All the Services and Supports the Family Wants	No				
Yes		40%	353	38%	2592
No		16%	138	18%	1191
IPP Includes All the Services and Supports the Family Needs	No				
Yes		34%	298	34%	2303
No		20%	177	20%	1378
Family/Child Receives All Services Listed in Plan	No				
Yes		49%	432	47%	3138
No		8%	68	9%	587
Respondent Discussed How to Handle Emergencies Related to Child at Last IPP Meeting	No				
Yes		32%	287	29%	1926
No		25%	222	26%	1745
Respondents Received Information About Family's Rights	**Yes**				
Yes		68%	601	65%	4410
No		11%	96	14%	921

	Sig. [1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Access and Delivery of Services and Supports					
Respondent Is Able to Contact Support Workers When Needed	No				
Always		41%	363	40%	2725
Usually		32%	280	30%	2032
Sometimes		14%	125	13%	887
Seldom		5%	43	5%	364
Never		2%	18	3%	182
Respondent Is Able to Contact Service Coordinator When Needed	No				
Always		42%	370	42%	2836
Usually		34%	298	30%	1995
Sometimes		14%	122	14%	933
Seldom		5%	46	6%	437
Never		2%	21	3%	207
Service and Supports Are Available at Times They Are Needed	No				
Always		28%	248	27%	1796
Usually		30%	263	29%	1925
Sometimes		24%	211	22%	1460
Seldom		7%	65	9%	579
Never		4%	33	6%	376
Services and Supports Are Available Reasonably Close to Home	No				
Always		27%	241	28%	1918
Usually		32%	281	29%	1942
Sometimes		16%	146	16%	1092
Seldom		6%	53	7%	442
Never		5%	41	5%	312

	Sig. [1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Services and Supports Change When Child's Needs Change	No				
Always		26%	233	25%	1693
Usually		27%	240	26%	1747
Sometimes		14%	126	15%	996
Seldom		7%	61	7%	455
Never		4%	36	6%	385
Support Workers or Translators Are Available Who Can Speak to Respondent in Their Preferred Language (If Not English)	No				
Always		14%	126	14%	927
Usually		7%	58	5%	367
Sometimes		3%	30	2%	168
Seldom		1%	7	1%	69
Never		1%	5	1%	48
Support Workers Communicate Effectively in Respondent's Primary Language (If English)	No				
Always		43%	384	43%	2914
Usually		14%	127	14%	927
Sometimes		2%	16	3%	204
Seldom		0%	3	1%	63
Never		1%	6	1%	64
Support Workers Can Communicate With the Child (If Non-Verbal)	**Yes**				
Always		9%	76	6%	395
Usually		8%	69	7%	444
Sometimes		9%	76	4%	294
Seldom		4%	39	3%	176
Never		10%	88	4%	284

	Sig. [1]	**CP (%)**	**CP (N)**	**No CP (%)**	**No CP (N)**
Services Are Delivered in a Manner That Is Respectful to Family's Culture	No				
Always		56%	496	53%	3589
Usually		21%	188	22%	1455
Sometimes		5%	45	5%	345
Seldom		1%	7	2%	115
Never		1%	12	2%	138
Child Has Access to Special Equipment or Accommodations Needed	**Yes**				
Always		38%	335	12%	779
Usually		21%	189	9%	587
Sometimes		12%	110	5%	330
Seldom		4%	38	3%	174
Never		5%	48	8%	564
Support Workers Have the Right Training to Meet the Child's Needs	**Yes**				
Always		38%	341	34%	2271
Usually		28%	245	27%	1796
Sometimes		12%	107	11%	739
Seldom		2%	19	4%	255
Never		2%	19	3%	194
Support Workers Who Come to the Home Arrive on Time and When Scheduled	No				
Always		49%	434	44%	2933
Usually		25%	219	24%	1618
Sometimes		6%	52	6%	421
Seldom		2%	16	2%	115
Never		2%	16	2%	151
Crisis or Emergency Services Were Provided When Needed (If Requested)	No				
Yes		16%	142	14%	960
No		10%	93	11%	773

	Sig. [1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Respondent Has Access to Health Services for the Child	**Yes**				
Yes		91%	804	83%	5582
No		3%	24	6%	373
Respondent Is Satisfied With the Quality of the Child's Health Providers	**Yes**				
Yes		88%	707	83%	4650
No		6%	52	8%	473
Respondent Has Access to Dental Services for the Child	No				
Yes		85%	754	81%	5434
No		9%	78	10%	651
Respondent Is Satisfied With the Quality of the Child's Dental providers	No				
Yes		85%	639	83%	4517
No		8%	60	7%	406
Respondent Has Access to Necessary Medications for the Child	**Yes**				
Yes		87%	775	76%	5101
No		2%	20	4%	283
Respondent Is Satisfied With How the Child's Medication Needs Are Monitored	No				
Yes		89%	689	85%	4327
No		5%	40	4%	227
Respondent Has Access to Mental Health Services for the Child	No				
Yes		40%	352	45%	3044
No		11%	95	13%	876
Respondent Is Satisfied With the Quality of the Child's Mental Health Providers	No				
Yes		78%	274	75%	2280
No		4%	15	6%	194

	Sig. [1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Respondent Has Access to Respite Services	**Yes**				
Yes		74%	655	63%	4235
No		10%	91	12%	799
Respondent Is Satisfied With the Quality of the Child's Respite Providers	No				
Yes		83%	543	79%	3352
No		7%	44	8%	329
Family Needs Other Services That Are Not Currently Offered/Available	No				
Yes		37%	325	37%	2471
No		22%	191	21%	1448
Choice and Control					
Respondent Chooses the Provider Agencies Who Work With the Family	No				
Always		26%	230	25%	1672
Usually		20%	173	19%	1300
Sometimes		12%	109	13%	846
Seldom		7%	62	6%	383
Never		17%	147	17%	1177
Respondent Can Choose a Different Provider Agency If Desired	No				
Always		22%	197	22%	1483
Usually		14%	124	15%	985
Sometimes		8%	70	8%	556
Seldom		4%	32	3%	234
Never		7%	63	7%	461
Respondent Chooses Individual Support Workers Who Work With the Family	**Yes**				
Always		28%	250	22%	1465
Usually		14%	121	13%	868
Sometimes		8%	71	10%	687
Seldom		5%	48	7%	443
Never		20%	181	23%	1536

	Sig. [1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Respondent Can Choose Different Support Workers If Desired	No				
Always		26%	232	23%	1558
Usually		14%	122	13%	884
Sometimes		6%	49	8%	564
Seldom		4%	37	3%	229
Never		7%	64	8%	511
Respondent Chose Service Coordinator	No				
Yes		8%	73	8%	507
No		82%	730	82%	5512
Respondent Has Control or Input Over the Hiring and Management of Family's Support Workers	No				
Yes		26%	232	23%	1580
No		42%	370	43%	2928
Respondent Knows How Much Money Is Spent by the Regional Center or Behalf of Child	No				
Yes		30%	264	30%	2027
No/Don't Know/ Does Not Apply		67%	596	66%	4459
Respondent Has Say in How Regional Center Money Is Spent	**Yes**				
Yes		12%	105	10%	694
No		46%	411	52%	3520
Respondent Has All Information Needed to Decide How to Spend Regional Center Money	**Yes**				
Yes		43%	45	60%	415
No		24%	25	18%	127

	Sig. [1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Community Connections					
Child Participates in Community Activities	No				
Yes		69%	613	71%	4770
No		26%	231	24%	1610
Reasons Child Does Not Participate in Community Activities					
Lack of Transportation	No	12%	28	15%	240
Cost	No	22%	50	27%	434
Lack of Support Staff	No	21%	48	25%	395
Negative Attitudes From Community Members	No	15%	34	18%	287
Other	**Yes**	51%	117	37%	597
Child Spends Time With Children Without DD	No				
Yes		78%	691	78%	5225
No		15%	132	15%	1014
Satisfaction With Services and Supports					
Respondent Is Satisfied With Services and Supports Family Receives	**Yes**				
Always		30%	262	28%	1909
Usually		39%	342	34%	2263
Sometimes		17%	152	19%	1288
Seldom		7%	63	8%	514
Never		3%	23	5%	304
Respondent Knows How to File a Complaint or Grievance Against Provider Agencies or Staff	No				
Yes		38%	340	36%	2452
No/Don't Know/ Does Not Apply		58%	518	60%	4071
Respondent Is Satisfied With the Way Complaints or Grievances Against Provider Agencies or Staff Are Handled and Resolved	No				
Yes		22%	193	21%	1413
No		12%	104	13%	867

	Sig. [1]	CP (%)	CP (N)	No CP (%)	No CP (N)
Respondent Knows How to Report Abuse or Neglect	**Yes**				
Yes		61%	541	56%	3741
No/Don't Know/ Does Not Apply		36%	316	40%	2724
Respondent Reported Abuse or Neglect in the Past Year	No				
Yes		5%	42	5%	351
No		18%	160	18%	1239
Appropriate People Were Responsive to Report Abuse or Neglect (Past Year)	No				
Yes		50%	21	51%	178
No		10%	4	16%	55
Family Outcomes					
Family Supports have Made a Positive Difference in Family's Life	No				
Yes		77%	683	74%	5009
No		7%	60	8%	547
Services and Supports Have Reduced Out-of-Pocket Expenses	No				
Yes		66%	584	61%	4132
No		20%	173	18%	1232
Family Supports Have Improved Respondent's Ability to Care for the Child	No				
Yes		73%	647	71%	4750
No		11%	100	12%	804
Services or Supports Have Been Reduced, Suspended, or Terminated in the Past Year	No				
Yes		34%	303	35%	2339
No		49%	439	47%	3194
Reduction, Suspension, or Termination of Services in the Past Year Affected the Family Negatively	No				
Yes		68%	205	65%	1512
No		16%	48	19%	445

Appendix F: Summary of Results by Epilepsy

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Child's Demographic Information					
Subgroup Sample Size			1101		6529
More Than One Disabled Child in Household	No				
Yes		75%	826	18%	1143
No		17%	189	71%	4623
Child's Age	**Yes**	11.43 years old	1080	10.09 years old	6347
Child's Gender	**Yes**				
Male		56%	621	71%	4657
Female		42%	457	26%	1675
Child's Race and Ethnicity					
American Indian/Alaska Native	No	3%	31	2%	131
Asian	**Yes**	10%	115	13%	876
Black/African American	No	7%	82	7%	428
Native Hawaiian/Pacific Islander	No	1%	15	1%	70
White	**Yes**	45%	497	35%	2257
Other/Unknown	No	2%	18	1%	86
Mixed (Two or More Races)	**Yes**	15%	161	11%	730
Hispanic/Latino	**Yes**	36%	393	42%	2762
Child's Type of CA Qualifying Condition					
Autism Spectrum Disorder	**Yes**	32%	355	66%	4277
Cerebral Palsy	**Yes**	38%	419	7%	461
Intellectual Disability	**Yes**	66%	722	30%	1966
Epilepsy	N/A	N/A	N/A	N/A	N/A

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[1] The Sig. column indicates whether there was a significant difference between children with the focus diagnosis and those without. The specific test of significant group difference varied based on the type of question and response choices in the survey. See Appendix B for specific test used for each survey question.

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Child's Type of Disability					
Mental Illness/Psychiatric Diagnosis/Behavioral Disorder	**Yes**	17%	191	12%	757
Brain Injury	**Yes**	20%	221	2%	123
Chemical Dependency	**Yes**	3%	31	0.4%	13
Limited or No Vision/Legally Blind	**Yes**	23%	258	3%	218
Hearing Loss (Severe or Profound)	**Yes**	7%	78	2%	163
Down Syndrome	**Yes**	2%	27	10%	677
Prader-Willi Syndrome	No	0%	5	1%	34
Other Disabilities not listed	**Yes**	35%	389	13%	821
No Other Disabilities	No	2%	26	3%	166
Don't Know	**Yes**	2%	23	0%	0
Child's Primary Means of Expression					
Spoken	**Yes**	41%	452	68%	4412
Gestures/Body Language	**Yes**	38%	422	20%	1296
Sign Language/Finger Spelling	No	3%	37	3%	225
Communication Aid/Device	No	3%	38	3%	222
Other	**Yes**	12%	132	4%	253
Child's Preferred Language					
English	No	72%	793	72%	4731
Spanish	**Yes**	18%	199	23%	1487
Other	**Yes**	7%	75	4%	260
Frequency of Medical Care Needed for Child	**Yes**				
Less Than Once Per Month		53%	584	73%	4784
At Least Once Per Month But Less Than Once Per Week		24%	269	14%	905
At Least Once Per Week or More Frequently		19%	212	6%	420
Amount of Behavioral Support Needed for Child	**Yes**				
No Support Needed		26%	289	28%	1830
Some Support Needed		28%	311	36%	2370
Extensive Support Needed		22%	247	15%	963

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Amount of Help Needed for Child's Daily Activities	**Yes**				
None		3%	28	8%	527
Little		9%	95	23%	1480
Moderate		27%	295	41%	2649
Complete		62%	681	28%	1836
Family/Respondent's Demographic Information					
Respondent's Age	**Yes**				
Under 35		19%	213	21%	1386
35–54		65%	719	66%	4339
55–74		14%	158	11%	743
75 or Older		0%	4	0%	22
Respondent's Health	No				
Excellent		22%	238	22%	1412
Good		54%	591	55%	3585
Fair		20%	225	20%	1294
Poor		4%	39	3%	193
Respondent's Relationship to Child					
Parent	No	95%	1050	96%	6282
Sibling	No	1%	6	0%	26
Grandparent	No	3%	30	2%	145
Other	No	1%	12	1%	58
Respondent is Child's Primary Caregiver	No				
Yes		96%	1060	97%	6308
No		2%	23	2%	141
Number of Adults in Household	No				
One		18%	195	17%	1080
Two		60%	664	60%	3917
Three		12%	135	13%	852
Four or More		8%	91	9%	609

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Respondent's Highest Education Level					
No HS Diploma/GED	**Yes**	16%	180	19%	1257
HS Diploma/GED	**Yes**	13%	145	15%	998
Vocational School	No	5%	60	5%	339
Some College	No	21%	236	20%	1277
College Degree	**Yes**	41%	454	37%	2397
Total Taxable Family Income of Wage Earners in the Household in the Past Year	**Yes**				
Below $15,000		15%	163	20%	1311
$15,001–$25,000		17%	186	18%	1190
$25,001–$50,000		21%	234	21%	1351
$50,001–$75,000		13%	141	12%	794
Over $75,000		25%	279	22%	1436
Out-of-Pocket Expenses for Child in the Past Year	**Yes**				
Nothing		17%	185	24%	1580
$1–$100		9%	95	12%	762
$101–$1,000		29%	315	29%	1861
$1,001–$10,000		33%	363	25%	1636
Over $10,000		8%	84	6%	388
Services and Supports Received					
Services and Supports Received					
Financial Support	**Yes**	12%	134	9%	576
In-Home Support	**Yes**	64%	702	47%	3095
Out-of-Home Respite Care	No	28%	312	27%	1748
Early Intervention	**Yes**	10%	108	17%	1084
Transportation	No	22%	245	21%	1403
Other Services or Supports	No	44%	488	47%	3041
Social Security Benefits	No	43%	469	40%	2637

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Information and Planning					
Receives Information About Available Services and Supports	No				
Always		18%	200	19%	1241
Usually		21%	226	21%	1391
Sometimes		26%	291	26%	1690
Seldom		19%	214	18%	1173
Never		11%	125	12%	761
Information About Services and Supports Is Easy to Understand	No				
Always		24%	269	26%	1671
Usually		31%	345	31%	2027
Sometimes		21%	226	20%	1297
Seldom		6%	62	5%	358
Never		1%	13	1%	68
Information About Services and Supports Comes from Service Coordinator	No				
Always		28%	312	30%	1941
Usually		24%	265	25%	1602
Sometimes		17%	183	17%	1120
Seldom		10%	112	9%	558
Never		7%	76	7%	481
Service Coordinator Respects Family's Choices and Opinions	No				
Always		56%	617	56%	3624
Usually		21%	226	22%	1460
Sometimes		8%	89	7%	435
Seldom		3%	38	3%	218
Never		2%	22	3%	165

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Service Coordinator Tells Family About Other Eligible Public Services	No				
Always		27%	294	26%	1671
Usually		17%	189	18%	1168
Sometimes		15%	167	16%	1018
Seldom		15%	170	12%	776
Never		17%	188	19%	1228
Child Has an IPP	No				
Yes		67%	738	66%	4319
No		15%	170	17%	1092
Respondent Helped Develop Child's IPP	**Yes**				
Yes		89%	656	86%	3700
No		5%	40	7%	322
IPP Includes All the Services and Supports the Family Wants	**Yes**				
Yes		61%	448	58%	2500
No		23%	170	27%	1160
IPP Includes All the Services and Supports the Family Needs	No				
Yes		51%	374	52%	2228
No		31%	230	31%	1328
Family/Child Receives All Services Listed in Plan	No				
Yes		72%	529	70%	3044
No		13%	98	13%	559
Respondent Discussed How to Handle Emergencies Related to Child at Last IPP Meeting	**Yes**				
Yes		52%	387	42%	1829
No		33%	241	40%	1726
Respondents Received Information About Family's Rights	No				
Yes		67%	734	66%	4279
No		12%	135	14%	883

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Access and Delivery of Services and Supports					
Respondent Is Able to Contact Support Workers When Needed	No				
Always		40%	444	41%	2648
Usually		32%	355	30%	1958
Sometimes		14%	156	13%	857
Seldom		5%	53	5%	356
Never		2%	18	3%	182
Respondent Is Able to Contact Service Coordinator When Needed	No				
Always		42%	458	42%	2751
Usually		34%	375	29%	1922
Sometimes		14%	155	14%	900
Seldom		5%	54	7%	430
Never		2%	23	3%	206
Service and Supports Are Available at Times They Are Needed	No				
Always		26%	286	27%	1756
Usually		29%	321	29%	1869
Sometimes		25%	278	21%	1395
Seldom		8%	86	9%	560
Never		4%	39	6%	371
Services and Supports Are Available Reasonably Close to Home	No				
Always		27%	295	29%	1863
Usually		29%	321	29%	1906
Sometimes		17%	189	16%	1050
Seldom		6%	66	7%	429
Never		5%	51	5%	302

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Services and Supports Change When Child's Needs Change	No				
Always		25%	278	25%	1649
Usually		27%	294	26%	1695
Sometimes		13%	145	15%	978
Seldom		8%	87	7%	430
Never		5%	52	6%	369
Support Workers or Translators Are Available Who Can Speak to Respondent in Thier Preferred Language (If Not English)	No				
Always		12%	130	14%	922
Usually		5%	54	6%	373
Sometimes		2%	25	3%	173
Seldom		1%	8	1%	68
Never		1%	7	1%	46
Support Workers Communicate Effectively in Respondent's Primary Language (If English)	No				
Always		45%	499	43%	2806
Usually		15%	167	14%	886
Sometimes		3%	30	3%	190
Seldom		1%	8	1%	58
Never		1%	7	1%	63
Support Workers Can Communicate With the Child (If Non-Verbal)	**Yes**				
Always		8%	87	6%	385
Usually		9%	94	6%	419
Sometimes		8%	87	4%	282
Seldom		5%	51	3%	164
Never		8%	93	4%	278

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Services Are Delivered in a Manner That Is Respectful to Family's Culture	No				
Always		55%	607	53%	3483
Usually		22%	247	21%	1399
Sometimes		5%	51	5%	338
Seldom		1%	16	2%	106
Never		1%	11	2%	139
Child Has Access to Special Equipment or Accommodations Needed	**Yes**				
Always		27%	294	13%	820
Usually		18%	197	9%	578
Sometimes		10%	114	5%	328
Seldom		6%	63	2%	149
Never		8%	87	8%	528
Support Workers Have the Right Training to Meet the Child's Needs	No				
Always		34%	373	34%	2239
Usually		29%	316	26%	1725
Sometimes		12%	128	11%	719
Seldom		4%	43	4%	233
Never		2%	22	3%	191
Support Workers Who Come to the Home Arrive on Time and When Scheduled	No				
Always		45%	497	44%	2872
Usually		28%	308	23%	1531
Sometimes		5%	57	6%	417
Seldom		2%	20	2%	111
Never		2%	20	2%	148
Crisis or Emergency Services Were Provided When Needed (If Requested)	**Yes**				
Yes		19%	208	14%	896
No		8%	93	12%	773

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Respondent Has Access to Health Services for the Child	**Yes**				
Yes		87%	960	83%	5432
No		4%	40	5%	356
Respondent Is Satisfied With the Quality of the Child's Health Providers	**Yes**				
Yes		88%	843	83%	4518
No		6%	60	9%	467
Respondent Has Access to Dental Services for the Child	No				
Yes		82%	901	81%	5292
No		10%	109	9%	620
Respondent Is Satisfied With the Quality of the Child's Dental providers	No				
Yes		86%	773	83%	4385
No		7%	63	8%	405
Respondent Has Access to Necessary Medications for the Child	**Yes**				
Yes		90%	987	75%	4898
No		3%	31	4%	273
Respondent Is Satisfied With How the Child's Medication Needs Are Monitored	**Yes**				
Yes		87%	854	85%	4168
No		7%	67	4%	202
Respondent Has Access to Mental Health Services for the Child	No				
Yes		44%	482	45%	2915
No		12%	128	13%	844
Respondent Is Satisfied With the Quality of the Child's Mental Health Providers	No				
Yes		75%	361	75%	2192
No		7%	36	6%	173

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Respondent Has Access to Respite Services	No				
Yes		71%	787	63%	4109
No		11%	123	12%	767
Respondent Is Satisfied With the Quality of the Child's Respite Providers	No				
Yes		81%	639	79%	3262
No		9%	68	7%	305
Family Needs Other Services That Are Not Currently Offered/Available	No				
Yes		39%	434	36%	2366
No		21%	228	22%	1410
Choice and Control					
Respondent Chooses the Provider Agencies Who Work With the Family	No				
Always		25%	274	25%	1629
Usually		19%	208	19%	1266
Sometimes		14%	159	12%	800
Seldom		7%	79	6%	368
Never		16%	173	18%	1150
Respondent Can Choose a Different Provider Agency If Desired	No				
Always		20%	222	22%	1459
Usually		15%	162	14%	946
Sometimes		9%	101	8%	526
Seldom		4%	49	3%	218
Never		7%	73	7%	451

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Respondent Chooses Individual Support Workers Who Work With the Family	**Yes**				
Always		25%	277	22%	1437
Usually		15%	167	13%	822
Sometimes		9%	104	10%	660
Seldom		7%	82	6%	411
Never		19%	210	23%	1507
Respondent Can Choose Different Support Workers If Desired	No				
Always		24%	269	23%	1519
Usually		14%	150	13%	855
Sometimes		8%	92	8%	523
Seldom		4%	49	3%	218
Never		7%	72	8%	503
Respondent Chose Service Coordinator	No				
Yes		7%	81	8%	499
No		83%	909	82%	5341
Respondent Has Control or Input Over the Hiring and Management of Family's Support Workers	**Yes**				
Yes		27%	300	23%	1511
No		40%	437	44%	2866
Respondent Knows How Much Money Is Spent by the Regional Center or Behalf of Child	No				
Yes		30%	332	30%	1961
No/Don't Know/ Does Not Apply		66%	728	66%	4333
Respondent Has Say in How Regional Center Money Is Spent	**Yes**				
Yes		13%	145	10%	654
No		48%	524	52%	3413
Respondent Has All Information Needed to Decide How to Spend Regional Center Money	No				
Yes		52%	75	59%	385
No		21%	31	19%	121

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Community Connections					
Child Participates in Community Activities	**Yes**				
Yes		65%	720	71%	4664
No		30%	325	23%	1519
Reasons Child Does Not Participate in Community Activities					
Lack of Transportation	No	13%	42	15%	227
Cost	**Yes**	19%	62	28%	423
Lack of Support Staff	No	24%	77	24%	368
Negative Attitudes From Community Members	No	19%	62	17%	260
Other	**Yes**	47%	154	37%	564
Child Spends Time With Children Without DD	No				
Yes		77%	843	78%	5077
No		17%	182	15%	967
Satisfaction With Services and Supports					
Respondent Is Satisfied With Services and Supports Family Receives	No				
Always		27%	297	29%	1874
Usually		38%	414	34%	2193
Sometimes		19%	214	19%	1227
Seldom		7%	80	8%	498
Never		3%	36	4%	292
Respondent Knows How to File a Complaint or Grievance Against Provider Agencies or Staff	No				
Yes		38%	421	36%	2369
No/Don't Know/ Does Not Apply		58%	639	61%	3960

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Respondent Is Satisfied With the Way Complaints or Grievances Against Provider Agencies or Staff Are Handled and Resolved	No				
Yes		22%	240	21%	1363
No		11%	125	13%	850
Respondent Knows How to Report Abuse or Neglect	**Yes**				
Yes		61%	675	55%	3609
No/Don't Know/ Does Not Apply		35%	389	41%	2656
Respondent Reported Abuse or Neglect in the Past Year	**Yes**				
Yes		6%	70	5%	324
No		17%	187	19%	1213
Appropriate People Were Responsive to Report Abuse or Neglect (Past Year)	No				
Yes		43%	30	52%	169
No		16%	11	15%	48
Family Outcomes					
Family Supports have Made a Positive Difference in Family's Life	No				
Yes		74%	818	75%	4878
No		7%	76	8%	534
Services and Supports Have Reduced Out-of-Pocket Expenses	No				
Yes		66%	724	61%	3997
No		18%	196	19%	1211
Family Supports Have Improved Respondent's Ability to Care for the Child	No				
Yes		71%	778	71%	4621
No		12%	131	12%	776
Services or Supports Have Been Reduced, Suspended, or Terminated in the Past Year	No				
Yes		37%	403	34%	2242
No		47%	518	48%	3116

	Sig. [1]	Epilepsy (%)	Epilepsy (N)	No Epilepsy (%)	No Epilepsy (N)
Reduction, Suspension, or Termination of Services in the Past Year Affected the Family Negatively	No				
Yes		67%	271	65%	1448
No		17%	67	19%	426

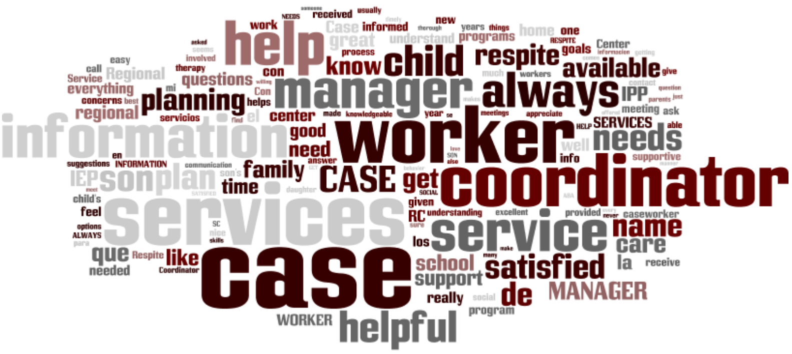
Appendix G: Analysis of Open-Ended Questions

Respondents were also provided the opportunity to comment on their satisfaction receiving services and suggested areas for improvement. The comments were systematically analyzed to identify common themes. Results are organized according to the open-ended questions *What are you most satisfied with regarding X?* and *What do you feel needs the most improvement regarding X?* Survey respondents were asked to provide their feedback to both of these questions in the areas of Information and Planning, Access and Delivery of Services and Supports, Choice and Control, Community Connections, and Satisfaction With Service and Supports in general. Approximately 24% (1,919) participants responded to the open-ended questions of what they were the most satisfied with and their suggestions for needed improvements pertaining to the process and provision of services[1].

Theme 1: Satisfaction with Process and Provision of Services

Among the questions asking about satisfaction with Information and Planning, Access and Delivery of Services and Supports, Choice and Control, Community Connections, and Satisfaction With Service and Supports, four themes emerged:

1. Personal characteristics of service providers
2. Family involvement in the process
3. Usefulness of information and services received when provided in partnership
4. Convenience of services



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[1] Responses to an individual open-ended question ranged from 14%–24% response rate.

Personal characteristics of service providers

The majority of respondents indicated that characteristics of service providers were important factors for feeling satisfied with the process and provision of services. Specific provider characteristics identified included wanting the child to succeed, being liked by the child, caring, easy to work with, helpful, organized, understanding, professional, personable, reliable, trustworthy, responsive and friendly. One parent[1] of a 12-year-old expressed appreciation for a service coordinator's level of concern for the child: *"The Coordinator is a great listener and I feel like she cares about my child and gets the services he needs."* Another parent of a 6-year-old expressed how helpful her service coordinator is in providing information: "*My case worker is very helpful and sends information often, and completely looks out for her best interest."* And a parent of an 18-year-old remarked how supportive their service coordinator at the regional center is: "*The regional case worker has given me and my family all the support and information, emotional and cultural, that we needed."*

Family involvement in the process

Some respondents identified that being involved in the process of planning made them feel satisfied. One parent of a 16-year-old commented that she felt respected in the process: "*We are heard and understood and our decisions are respected*." Another parent of a 6-year-old remarked that the information and planning feels collaborative and purposeful, "*It is collaborative and my opinion and needs are received and included."* A parent of a 5-year-old also relayed his satisfaction with feeling involved in the process: "*We are always part of the decision-making process and our case worker always tells us everything we could be eligible for, then allows us to decide*." Another parent of a 12-year-old expressed satisfaction with having the option to choose their respite worker: "*For respite, I do get to pick my own worker. I'm glad for my case manager*," while another parent commented her satisfaction with being able to choose

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[1] Due to the majority of survey respondents indicating that they were a parent, the term "parent" was used as being the person quoted.

who provided in-home support: “*Happy to be able to pick my own support for in-home support services.”*

Usefulness of information and services received when provided in partnership

Many respondents indicated satisfaction with services because their needs were met through a shared partnership. Parents felt that the needs of the child and family should be considered from their perspective and that they held the responsibility for making decisions about the services needed. Parents appreciated having a voice in the care of the child and being asked for their opinions. A parent of a 10-year-old remarked: “*The planning meetings have been very helpful. The committee has been very understanding and really listens to our case manager and listens to our concerns. They have been empathetic to our situation and helpful in suggestions*.” Some respondents identified that the information and planning process was helpful and purposeful. A parent of a 9-year-old stated: “*The plan we have in place helps my son learn and feel independent*.” And a parent of a 5-year-old states that the information and process of planning is useful in setting goals: “*The information and planning allows us to look to future goals as my child progresses.”* A parent of a 14-year-old commented how the teamwork involved in the process of planning provides useful information for goal setting: *“The IEP* [Individual Education Plan] *process is awesome the school and the regional center work well together. I don’t know what I would do without IEPs being in place, helps me a lot with setting goals and staying current with services available.”*

Convenience of services

Some respondents identified the convenience of location as an aspect of the process and provision of services they felt satisfied with. A few liked services in their home because of transportation challenges. One parent of a 3-year-old commented: *“Having the case manager come to my home for IPP* [Individual Program Plan] *meetings is very helpful.”* Similarly, a parent of an 8-year-old commented: “*The meetings are convenient, the case manager comes to our home.”*

Theme 2: Areas of Improvement for the Process and Provision of Services

Among the questions asking about satisfaction with information and planning, access and delivery of supports, choice and control, connections with community, and service and supports, five themes emerged:

1. Improved communication
2. The need for additional information about available services
3. The need for service providers to be more informed of services
4. The desire for additional support to navigate services
5. Assistance obtaining agreed-upon services

Improved communication

A topic frequently brought up was the desire for reliable contact and follow-through of service providers*.* One parent of a 13-year-old commented that the service coordinator is unresponsive: "*The case manager has poor follow-through and rarely responds to emails or voice messages.*" Another parent of a 5-year-old relayed how long the family waits to have contact with the service coordinator: "*Coordinators/case managers are overworked and meetings are at times past due*." Some respondents also commented that they would like communication in general to improve with their service coordinator. A parent of a 3-year-old commented: "*Communication from case workers in response to requests. Notifying of available resources and events are poor.*" Another parent of a 17-year-old relayed frustrations with her service coordinator: *"The case worker is not a good communicator. Frequently misunderstands what I am saying. Late to* *appointments. Long delay in returning phone calls."* A parent of a 5-year-old simply states wanting improvement in overall communication of services: "*Communication—honest and open communication*." Finally, some respondents expressed frustrations with having frequent changes in their service coordinators, as this parent of a 7-year-old commented: "*Communication needs improvement. I lack a common case worker. Changes all the time and cannot get worker on the phone. Trying to get respite but very confused by process."*

The need for additional information about available services

In the areas of improvement, respondents consistently described a need for information and guidance on services and supports available. A parent of a 10-year-old stated: "*As a parent, it is hard to know what to ask for. I get the feeling there should be more to offer our child to help her but I don't know what other assistance may be available."* Another parent of a 4-year-old expressed a desire for obtaining "*up-to-date information on services that would benefit our family.*" A parent of a 7-year-old remarked how obtaining information on access to services is difficult: "*I often don't know what's available and when I do ask for something, I'm told it's not available to my child because he's too 'high-functioning.' I quit asking for things because I'm always told 'no'*." Similarly, a parent of a 5-year-old also commented how the family wants information for accessing services: "*There is so much information out there but no easy way to access it. I needed to know what programs/funds were available for my son with autism diagnoses but was only offered ABA* [applied behavioral therapy]."

The need for service providers to be more informed of services

Some of the respondents indicated feeling that their service coordinators needed to be more informed of the available services that could be offered to their families. A parent of a 4-year-old stated: "*The case workers need better training on what is available to families; we shouldn't have to wait for a major emergency to find out what our child is eligible for*." A parent of a 12-year-old commented: *"Case workers need to be more informed about changes in law and how they affect accessing services*." Respondents also related that they would like other places or people to contact to obtain information.

As one parent of an 11-year-old commented: “*I would like to know what the available options are instead of relying on the case worker to tell me. The case worker does not always know what is available and I end up finding out information from other parents and having to go back to ask about it.*”

The desire for additional support to navigate services

Some parents indicated that navigating systems to obtain services was difficult, with organizational, communication, and access issues creating barriers. A parent of a 15-year-old relayed frustration over getting in contact with service providers in order to receive services: *“I feel that they [service coordinators] do not search enough, when I need support they give a phone number. We call that number and then they send us from one place to another, but the information and the services are not precise.”* Some of the challenges in navigating systems included a lack of information about what is available, variability in eligibility, availability of different services, locating services across different geographical areas and gaps between services. A parent of a 4-year-old indicates wanting to know what the family is eligible for: “*No one tells me what I qualify for and I need as much help as I can get!*” Another parent of an 18-year-old commented on the difficulty of obtaining services in more rural communities: “*We need services to be provided to remote areas of the state*,” while another parent of a 5-year-old remarked on the lack of available services in the area they live: “*I don't get much support. There is no preschool programs or special education programs in my area.”*

Assistance obtaining agreed-upon services

Some respondents expressed a desire to receive the agreed-upon services written in their child’s IPP/IEP. A common setback to receipt of services was that the approval process took too long. As one parent of an 8-year-old stated: “*When I need a service, the process to approve it is too long. It take 6 months to approve or deny the equipment—that is very exasperating.*” Another parent of a 12-year-old commented that accessing services takes longer than it should: “*I'm still waiting for respite care. In process of respite care from facility provider. Have not heard from them in over six months*.” A parent of a 13-year-old commented how the family started services but then had a long waiting process to reengage in services: “*Regarding my daughter needs, behavior therapy, they just give her 3 months, and after that there are 2 months of waiting.”* Some respondents also stated how they were not receiving the services put into their IPP’s. As a parent of a 5-year-old stated: *“I have not received the services in our IPP. Process needs to be faster.”* Finally, some respondents relayed that responsibility of payment was a barrier to receiving agreed-upon services. A parent of a 7-year-old conveyed the stress involved in trying to obtain services: “*We need to be told what we can actually get and what is offered. For different agencies to stop fight about who will pay the bill or should pay the bill, patient would get faster results. Way too many tricks and hoops for these kids to actually get things”*

Additional Services Requested

In addition to responding to the above open-ended questions, survey respondents were also asked to list additional services they would like to receive. Approximately 29% (2287) participants responded to the open-ended questions of what additional services they would like to receive. The responses were systematically analyzed to identify common themes as well as the frequency a service was requested. Requests for a form of therapy was the most frequently stated, (see Table VII-1). The most frequently stated type of therapy requested was behavior therapy, with 251 indicating it as a service need followed by speech therapy with 223 requests. The rest of the therapy requests were as follows: 110 requests for occupational therapy, 75 requests for counseling, 44 requests for physical therapy, 38 requests for group therapy, 34 requests for music therapy, 33 requests for equine therapy, 12 requests for sensory integration therapy, and 7 requests for aquatic therapy. See Figure 1 for list of all of the additional services requested.

Table VII-1: List of Additional Services Requested

What additional services would you like to receive?	# of responses
Respite Services	346
Behavior Therapy	251
Social Skills Training	223
Speech Therapy	223
In Home Care	174
Recreational Activities	166
Child care/Afterschool Care	145
Financial Support	137
Occupational Therapy	110
Parent Training/Education	83
Counseling	75
Dental Services	53
Medical Equipment	52
Summer Programs	47
Swimming Classes	40
Physical Therapy	44
Transportation Support	38
Group Therapy	38
Music Therapy	34
Equine Therapy	33
SSI Support	21
Diapers	17
Sensory Integration Therapy	12
Tutoring for Child	10
Sign Language Training	8
Aquatic Therapy	7