

FACETS of New Hampshire 2015 Parent Caregiver Survey

Prepared by:

Zachary S. Azem, M.A.

Andrew E. Smith, Ph.D.

The Survey Center

University of New Hampshire

July, 2015

The University of New Hampshire

Survey Center

The UNH Survey Center is an independent, non-partisan academic survey research organization and a division of the UNH College of Liberal Arts.

The Survey Center conducts telephone, mail, e-mail, Internet, and intercept surveys, as well as focus groups and other qualitative research for university researchers, government agencies, public non-profit organizations, private businesses, and media clients.

Our senior staff have over 50 years experience in designing and conducting custom research on a broad range of political, social, health care, and other public policy issues.

Dr. Andrew E. Smith, Director
UNH Survey Center
Huddleston Hall
Durham, New Hampshire 03824
603/862-2226 (voice)
603/862-1488 (FAX)
Andrew.Smith@unh.edu

Table of Contents

Executive Summary 1

Demographics..... **Error! Bookmark not defined.**

Sources of Health Care3

Main Source of Epilepsy Care5

Epilepsy Specialists6

Family Support.....9

Knowledge About Epilepsy10

Additional Services/Resources For Child12

Appendix A: Detailed Tabular Results A - 1

Appendix B: Open-Ended Responses.....B - 1

Appendix C: Survey InstrumentC - 1

Executive Summary

The University of New Hampshire Survey Center conducted a survey for the Facilitating Access to Care for Epilepsy and Transition Success (FACETS) project. The survey was designed to find out about the past experiences of parents and caregivers in New Hampshire who have children with epilepsy with some questions being replicated from a similar survey conducted in 2013. A mail survey was sent out to all two hundred sixty-three (263) families who have a child with epilepsy or a seizure disorder, who are either enrolled in Partners in Health or one of the programs with Special Medical Services. Eighty-four (84) completed the survey, resulting in a response rate of 32%. The following figures display survey results, detailed tabular results can be found in Appendix A and Appendix B contains the open-ended responses and Appendix C contains the survey instrument.

FACETS is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number H98MC262580202 for \$400,000. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

2015 FACETS SURVEY

2015 Survey Responses

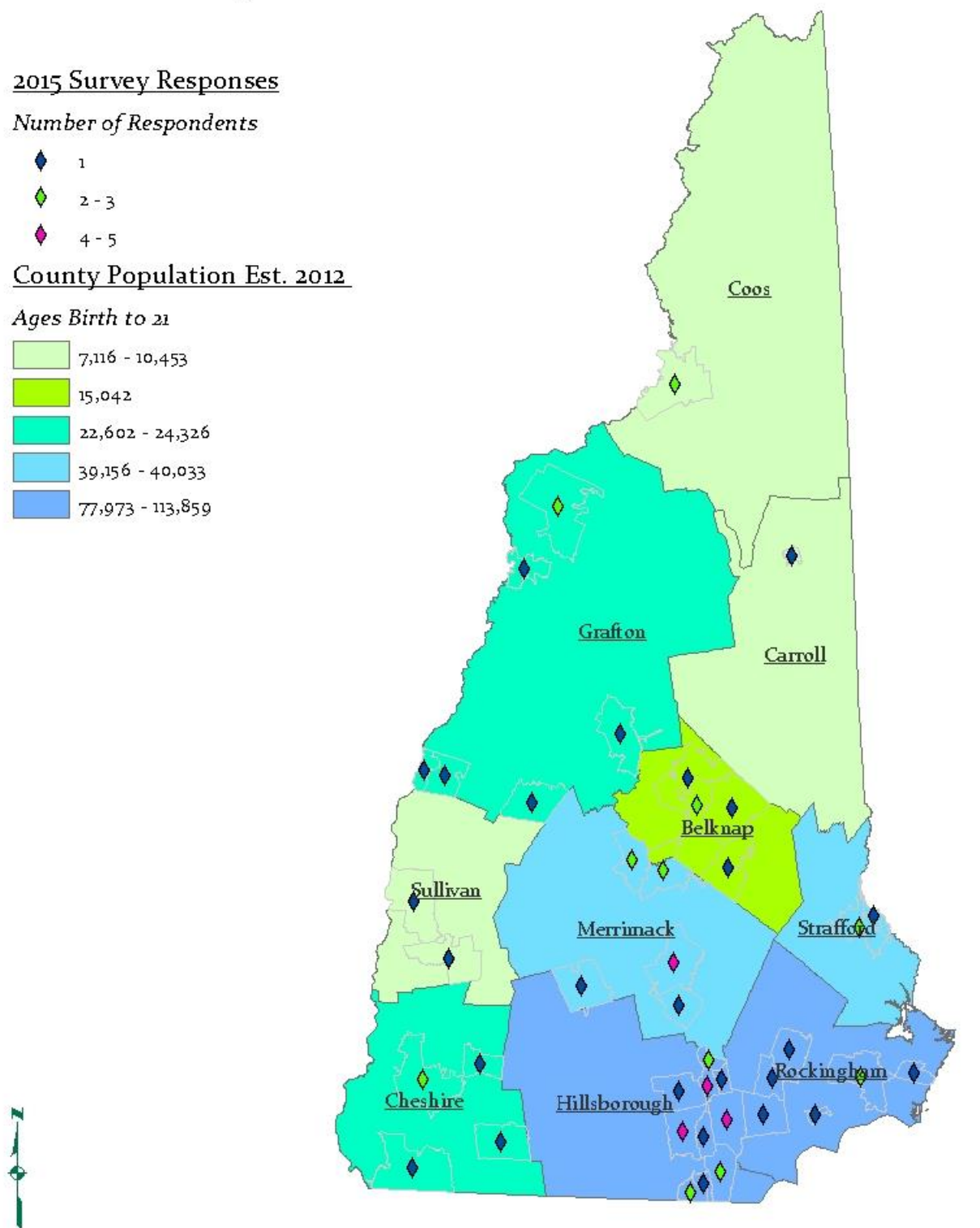
Number of Respondents

- ◆ 1
- ◆ 2 - 3
- ◆ 4 - 5

County Population Est. 2012

Ages Birth to 21

- 7,116 - 10,453
- 15,042
- 22,602 - 24,326
- 39,156 - 40,033
- 77,973 - 113,859



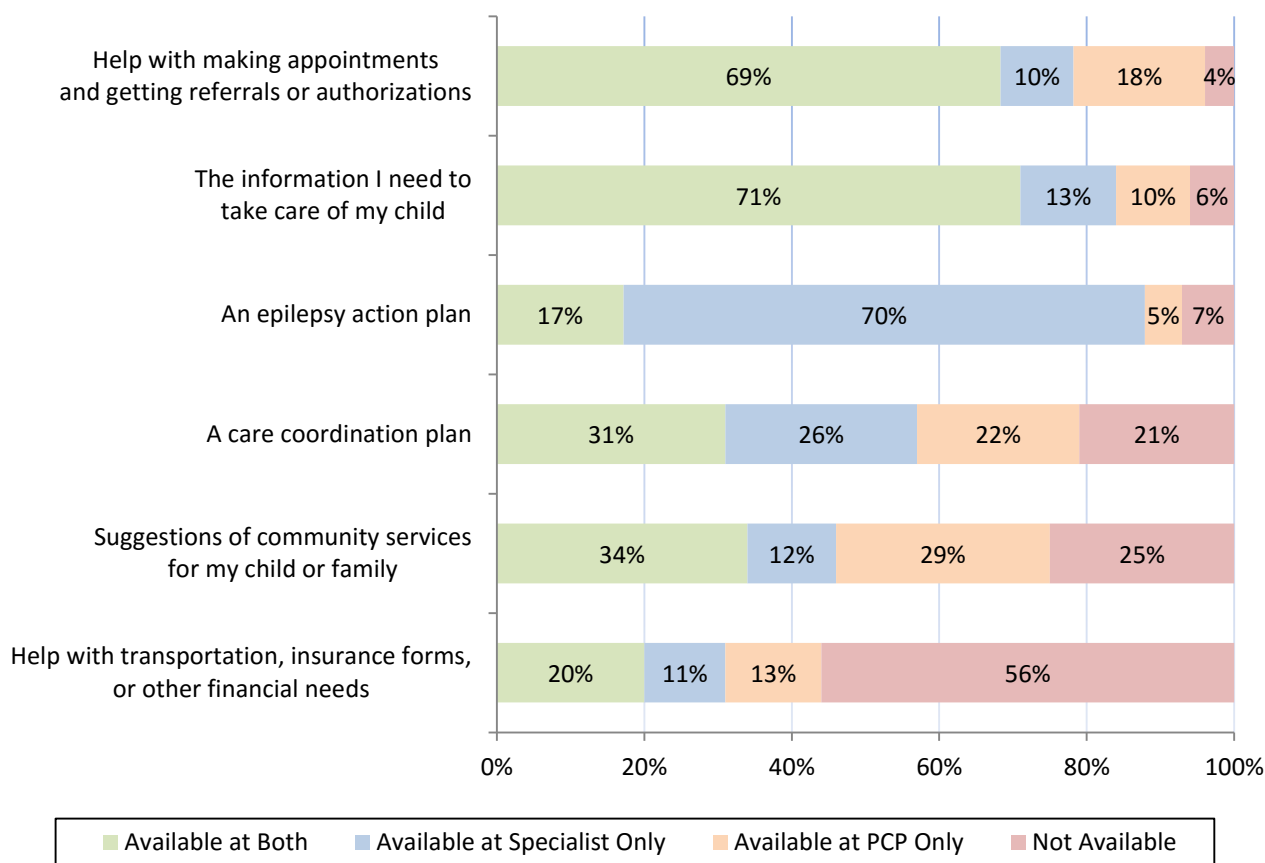
Source: U.S. Census Bureau, 2010-2012 American Community Survey

Sources of Health Care

Nearly all respondents say that help with making appointments (96%), the information needed to take care of their child (94%) and an epilepsy action plan (93%) are available to them at their child's specialist or primary care provider (PCP) or both. More than half (56%) of respondents say that help with transportation, insurance forms, or other financial needs is unavailable, 25% say suggestions for community services are unavailable and 21% say a care coordination plan is unavailable.

- An epilepsy action plan is much *more likely* to be available at a specialist (87%) than a PCP (22%).
- Respondents who are less knowledgeable about epilepsy and those with children who were diagnosed at an older age are *more likely* to say help with transportation, insurance forms and other financial needs are not available.

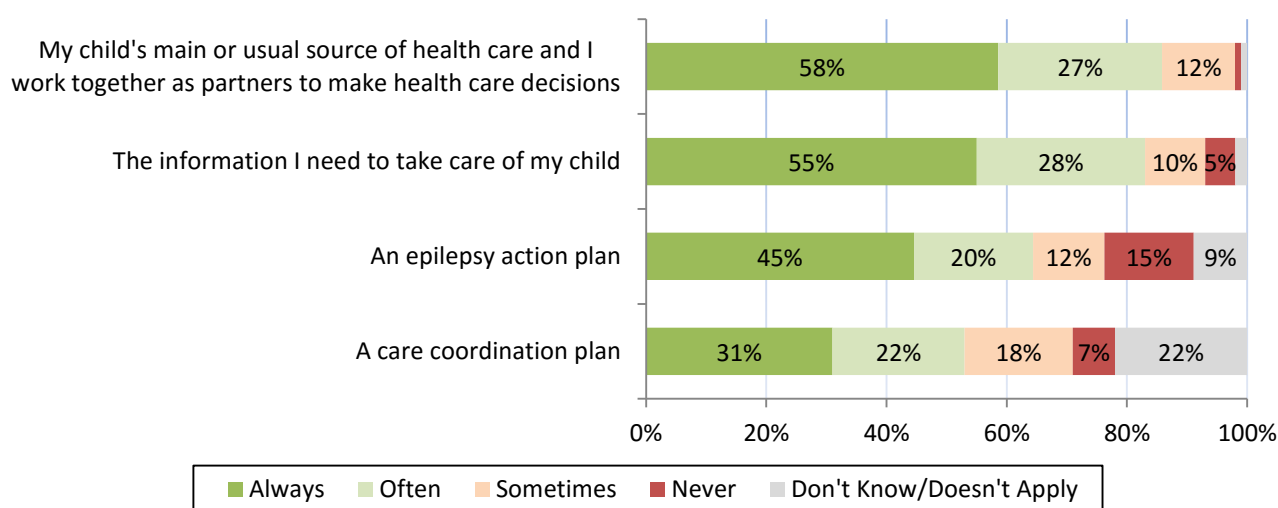
Figure 1: Availability of services at specialists and primary care providers



Fifty-eight percent (58%) of respondents say they and their child's main source of health care always work together as partners to make health care decisions, 55% always get the information they need to take care of their child, 45% always have an epilepsy action plan, and 31% always have a care coordination plan.

- Respondents who consider themselves very knowledgeable about epilepsy are *more likely* to always have a care coordination plan, epilepsy action plan and the information to take care of their child.
- Respondents whose children have an "other" usual source of health care are *more likely* to always have a care coordination plan.
- Respondents whose children have an epilepsy specialist or an "other" usual source of health care are *more likely* to always have an epilepsy action plan.

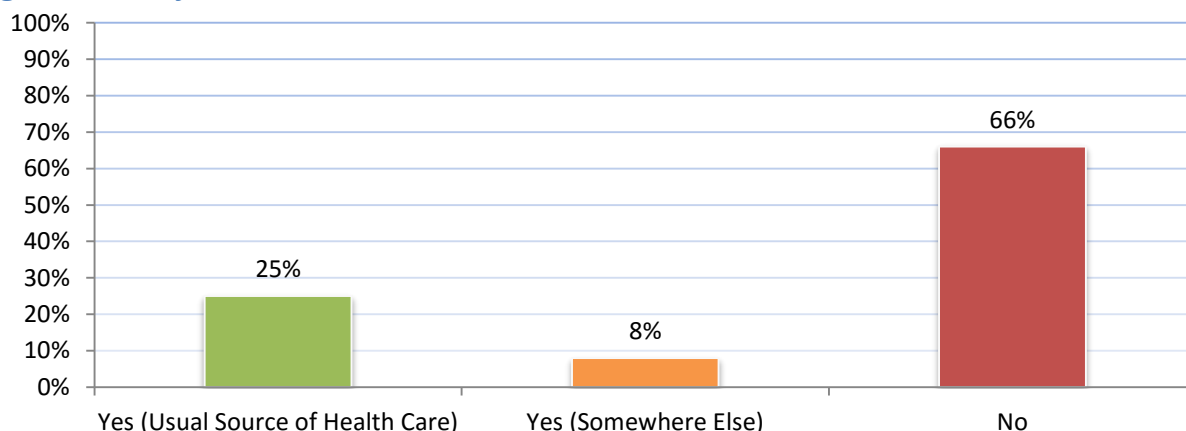
Figure 2: How often is true about child's main source of usual health care?



Two-thirds of respondents (66%) say their child does not have a medical home, 25% say their child's medical home is at their usual source of health care and 8% say their child's medical home is somewhere else.

- Children who are 6 years old or younger are *more likely* to have a medical home.
- In 2013, only 23% of respondents say their child had a medical home.

Figure 3: Does your child have a medical home?

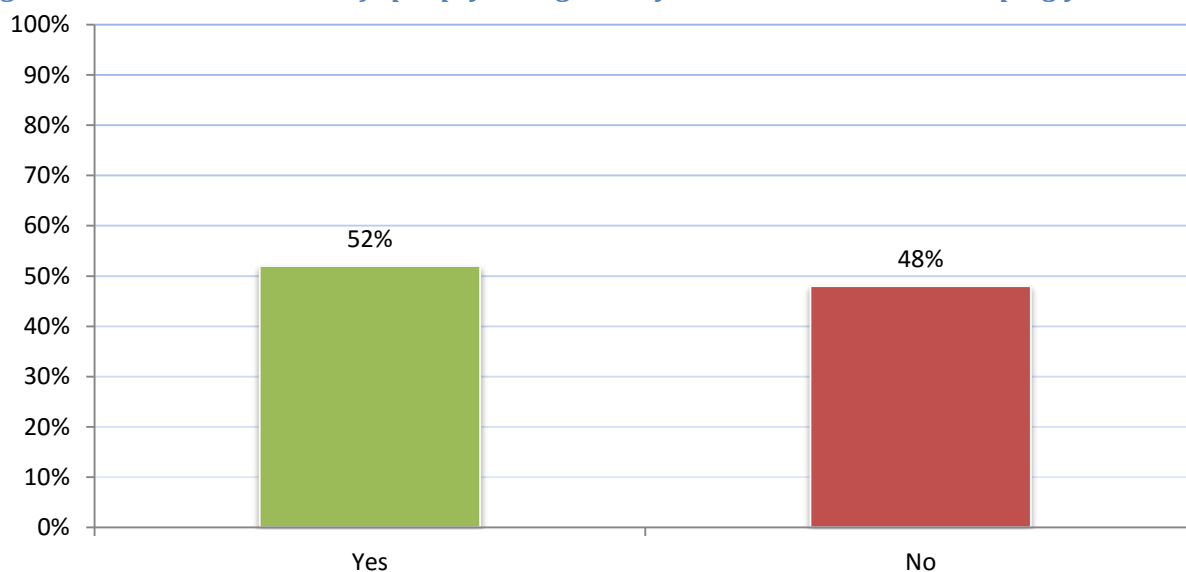


Main Source of Epilepsy Care

Just fifty-two percent (52%) of respondents say their child's main source of epilepsy care gives them ways to learn more about helping their child be healthy and grow.

- Respondents whose children have an "other" usual source of health care are *more likely* to give ways to learn more about helping their child.

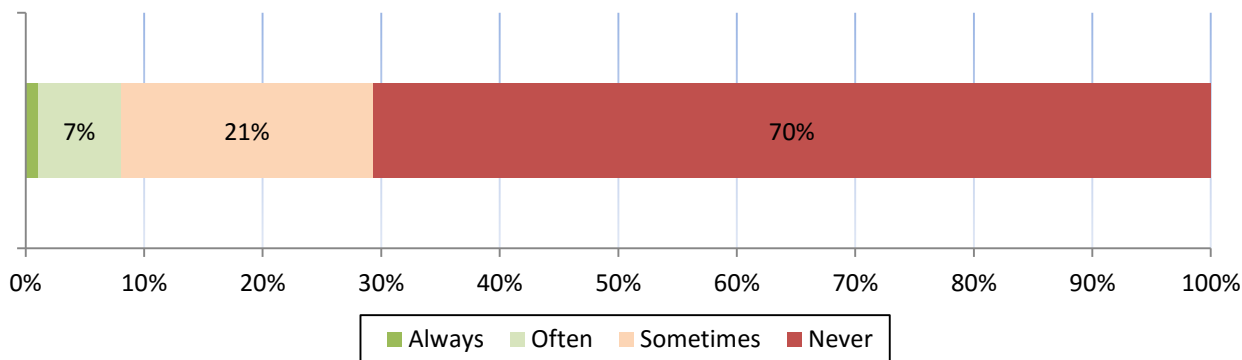
Figure 4: Does main source of epilepsy care give ways to learn more about helping your child



Respondents rarely get contacted by their child's main source of epilepsy care to see if they used a recommended service or program – just 1% said this always happens, 7% said it happens often, 21% say it happens sometimes and 70% say this never happens.

- Respondents whose children have an "other" usual source of health care are *more likely* to say this happens sometimes or often.

Figure 5: Contacted by main source of epilepsy care to see if a recommended program was used



Epilepsy Specialists

Nearly all respondents (94%) say their child sees an epilepsy specialist. Of these respondents, 69% say their child's specialist communicates with their PCP, 10% say they don't communicate and 21% are unsure.

- Respondents who are very knowledgeable about epilepsy and those who have children with an "other" usual source of health care are *more likely* to say their child's specialist communicates with their child's primary care provider.
- In 2013, 99% of respondents say their child saw an epilepsy specialist and 76% said their child's specialist communicated with their PCP.

Figure 6: Does your child see an epilepsy specialist?

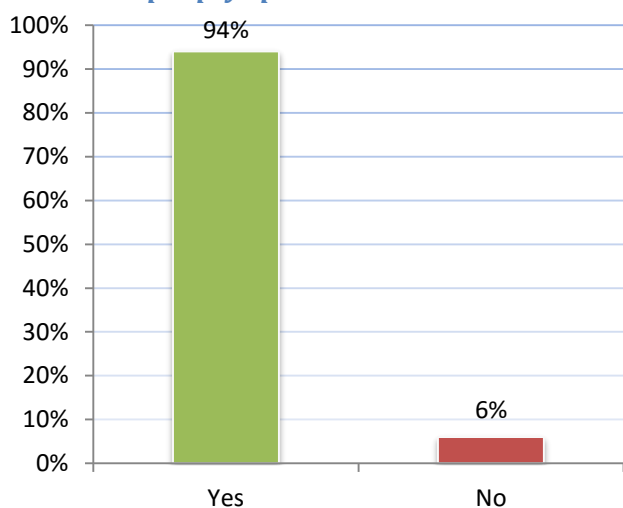
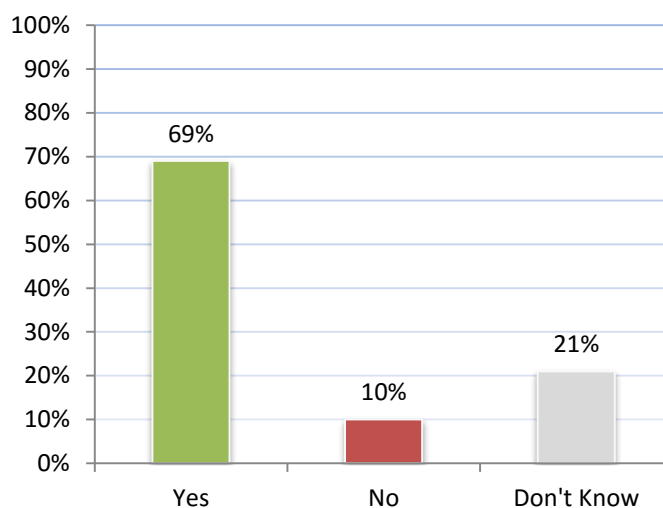
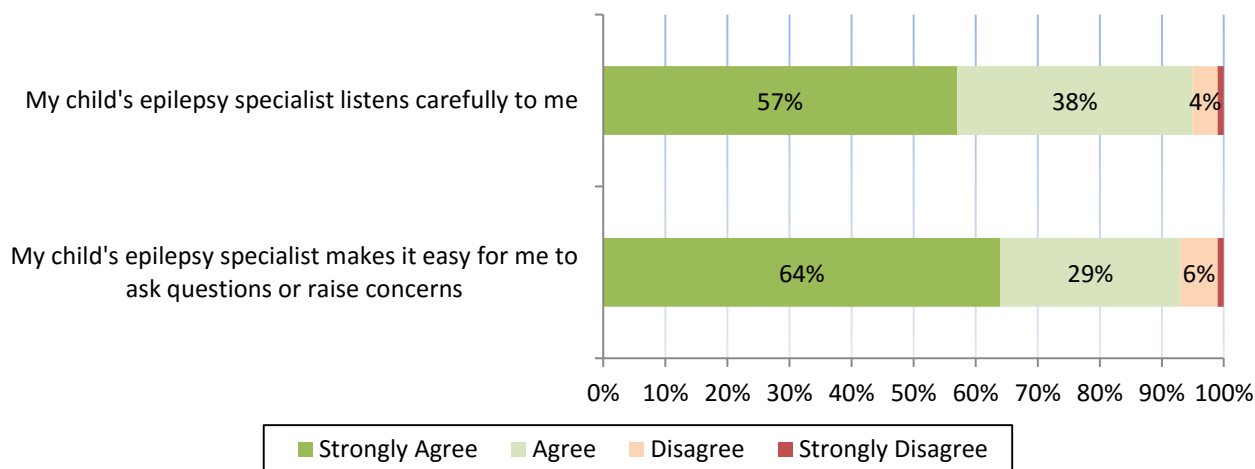


Figure 7: Does your child's specialist communicate with their PCP?



Nearly all respondents feel they communicate well with their child's epilepsy specialist – 95% agree (57% strongly agree) that their child's epilepsy specialist listens carefully to them and 93% agree (64% strongly agree) that the specialist makes it easy for them to ask questions or raise concerns.

Figure 8: Communication with your child's epilepsy specialist



Forty-three percent (43%) of respondents see their child's specialist once every 2-3 months, 35% see them less often, 6% see them more often, and 16% say it depends.

Thirty-one percent (31%) of respondents travel between 51 and 75 miles to see their child's specialist, 40% travel less of a distance and 29% travel farther.

Figure 9: How often do you see your child's specialist?

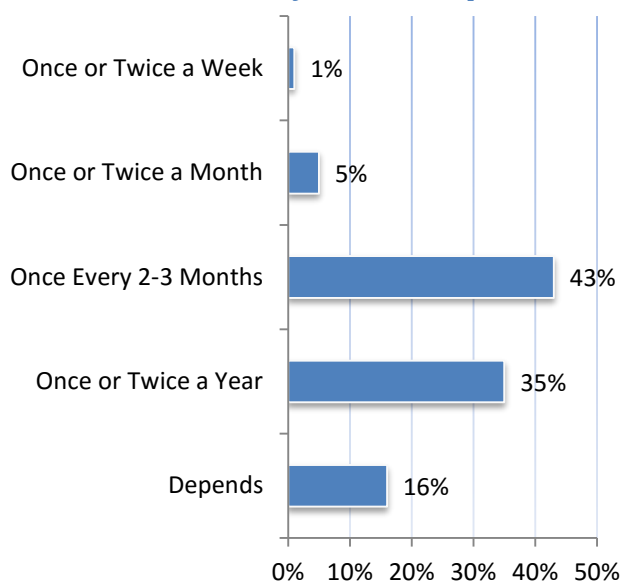
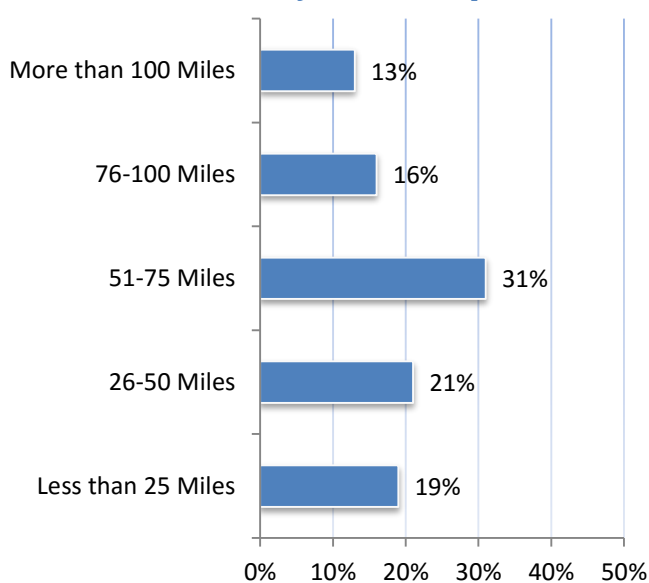


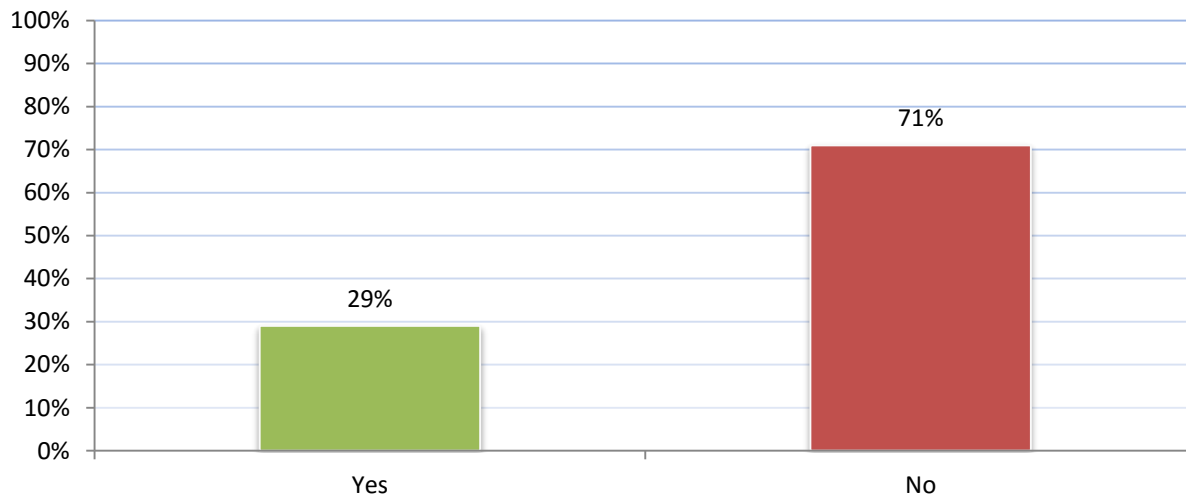
Figure 10: How far do you travel to see your child's specialist?



Just 29% of respondents say they limit appointments to the specialist because of the distance they have to travel.

- This is unchanged from 2013 when 28% of respondents said they limit appointments

Figure 11: Do you limit appointments to the specialist because of how far you have to travel?



Over half of respondents (54%) say they have had to schedule an urgent appointment with their specialist before. Of these respondents, only 15% got an appointment that day, 21% got an appointment the next day and 64% had to wait two days or longer.

- In 2013, there were also 54% of respondents who said they had needed to schedule an urgent appointment before.

Figure 12: Ever need to schedule an urgent appointment with your specialist?

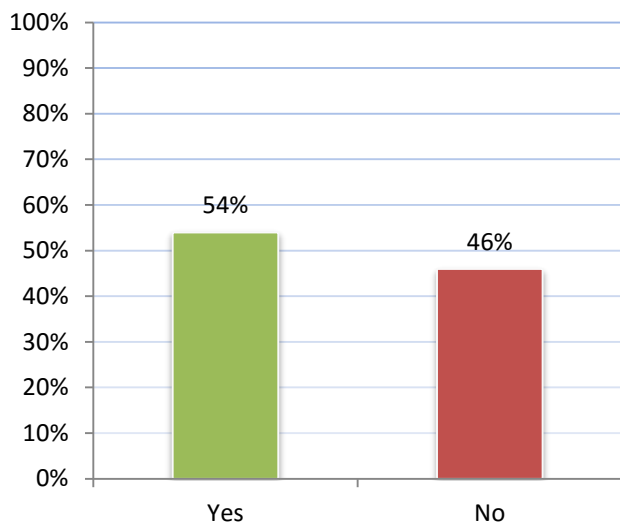
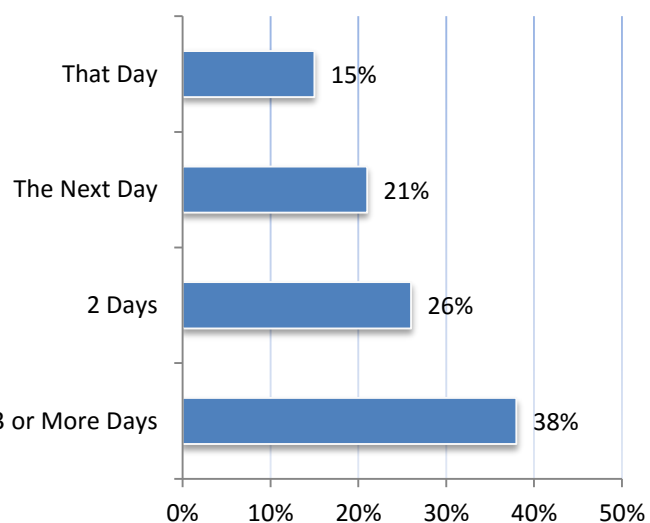


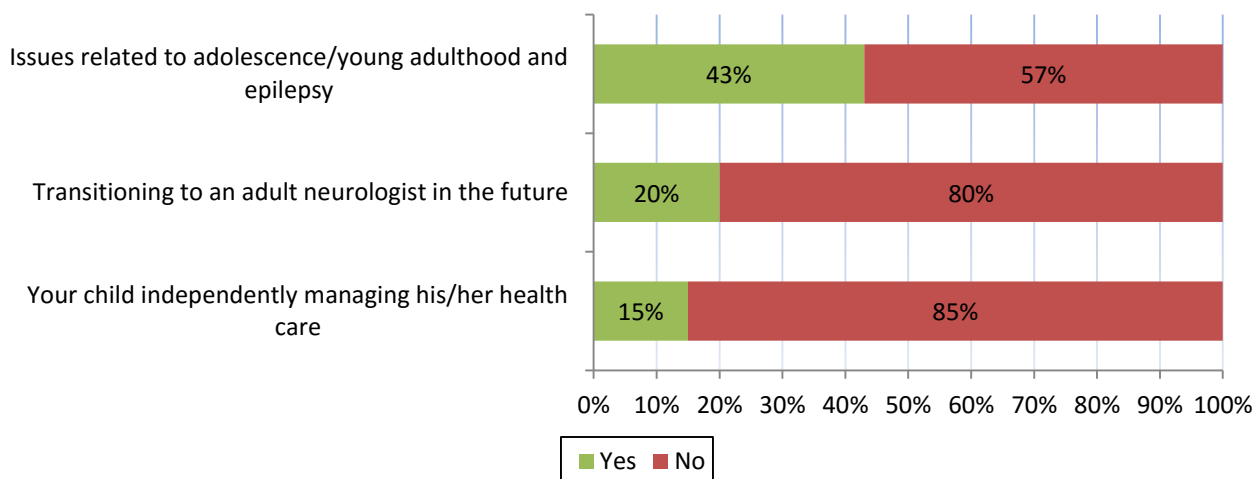
Figure 13: How long did you have to wait? (N=39)



Forty-three percent (43%) of respondents say their specialist has talked to them about issues related to adolescence/young adulthood and epilepsy, just 20% have discussed transitioning to an adult neurologist in the future, and 15% have discussed their child independently managing his/her health care.

- Respondents whose children have an epilepsy specialist as their usual source of health care are *more likely* to have talked to the specialist about all of these issues.

Figure 14: Has your specialist talked about:

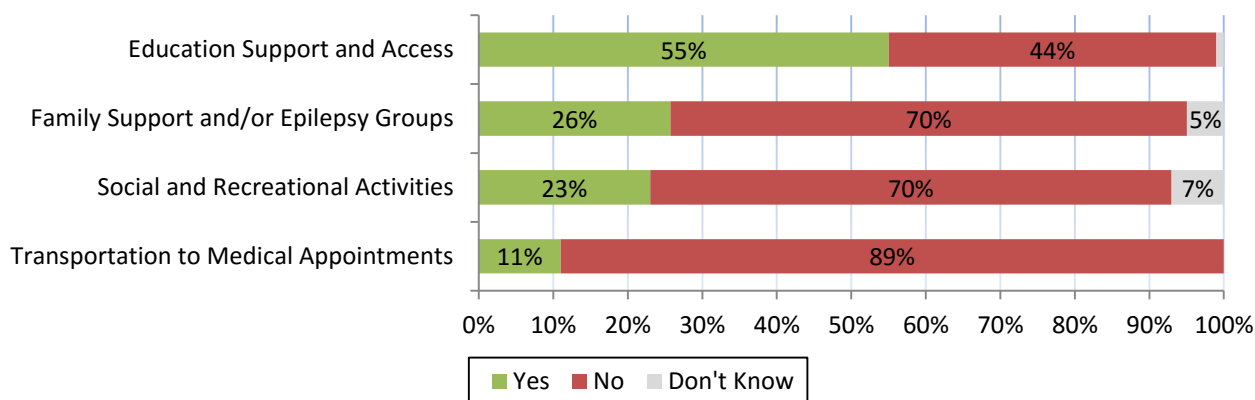


Family Support

Over the past 6 months, 55% of respondents say they needed education support and access, 26% needed family support and/or epilepsy groups, 23% needed social and recreational activities, and 11% needed transportation to medical appointments.

- Of those who needed education support and access (N=45), 73% were referred where to get this service, and 87% received the service.
- Of those who needed family support and/or epilepsy groups (N=21), 43% were referred where to get this service, and 65% received the service.
- Of those who needed social and recreational activities (N=19), 32% were referred where to get this service, and 32% received the service.
- Of those who needed transportation to medical appointments (N=11), 22% were referred where to get this service, and 22% received the service.

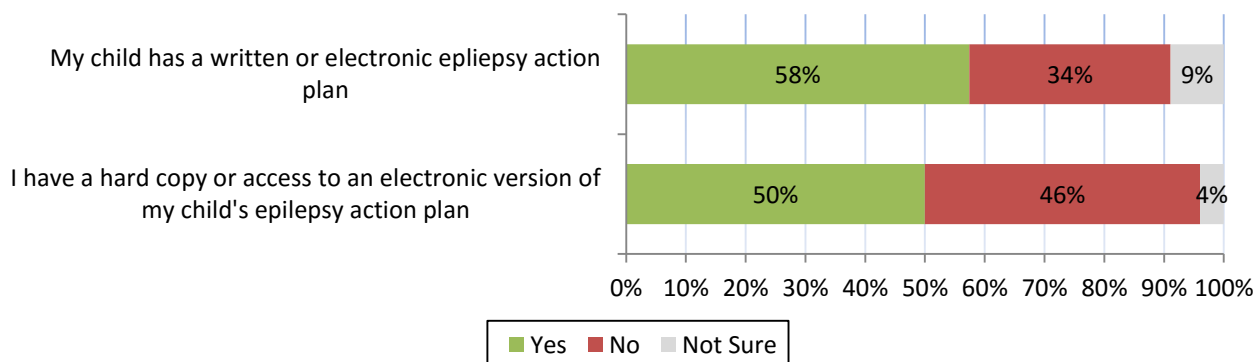
Figure 15: In the past 6 months, did you or your family need...



Over half (58%) of respondents say their child has a written or electronic epilepsy action plan, and 50% have a hard copy or access to an electronic version of their child's epilepsy action plan.

- Respondents who are very knowledgeable about epilepsy are *more likely* to say their child has a written or electronic epilepsy action plan and that they have access to it.

Figure 16: Your child's epilepsy action plan

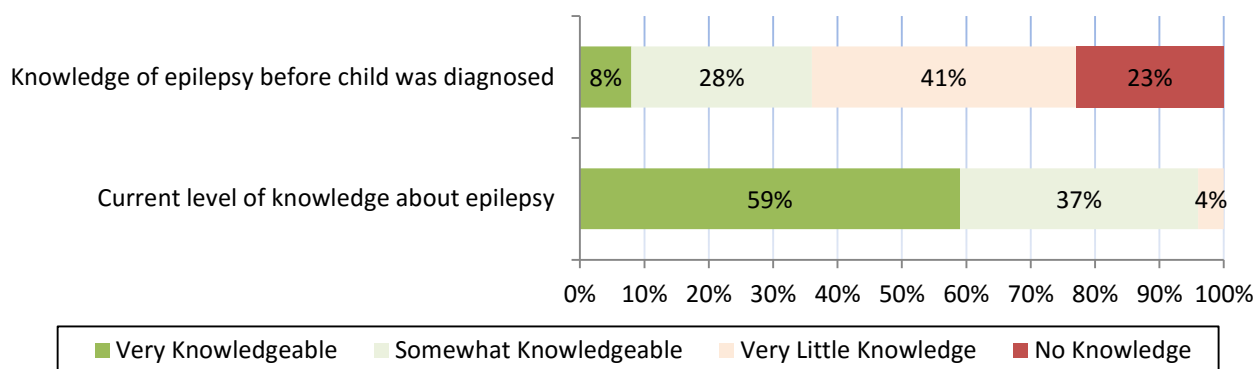


Knowledge About Epilepsy

Unsurprisingly, respondents' awareness about epilepsy has increased significantly since their child was diagnosed – before their child's diagnosis, just 8% were very knowledgeable about epilepsy and 28% were somewhat knowledgeable. Currently, a majority of respondents (59%) are very knowledgeable and 37% are somewhat knowledgeable.

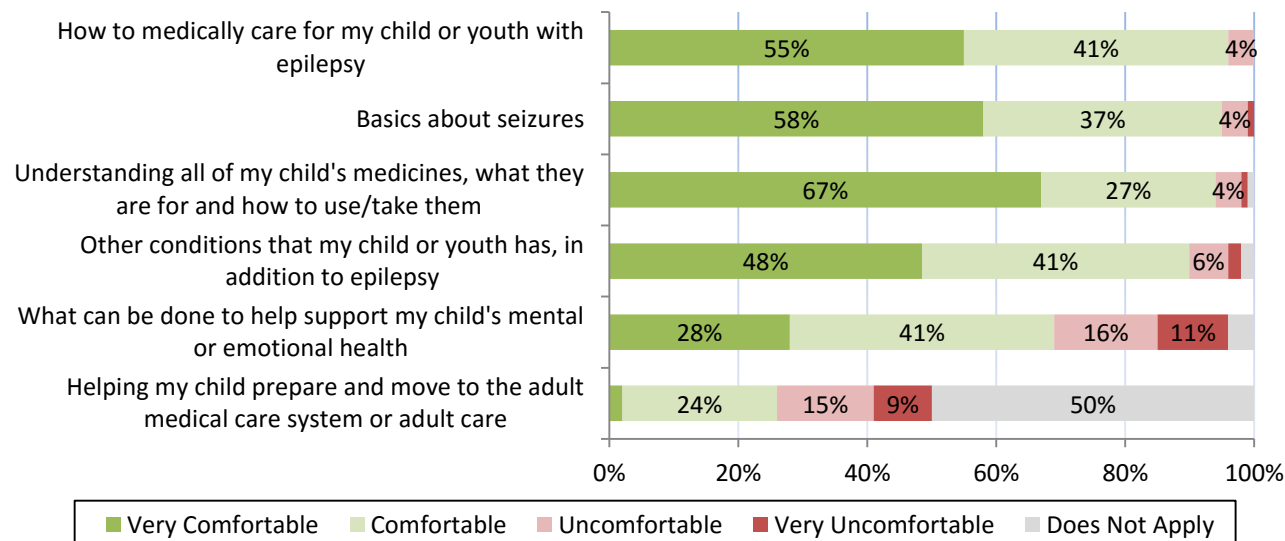
- These two measures are unchanged from 2013 when 10% were very knowledgeable and 28% were somewhat knowledgeable before their child's diagnosis and 59% were very knowledgeable and 38% were somewhat knowledgeable at the time.

Figure 17: Knowledge of epilepsy before and after child's diagnosis



Nearly all respondents are comfortable with how to medically care for their child with epilepsy (96%), the basics about seizures (95%), understanding their child's medicines (94%) and other conditions that their child has in addition to epilepsy (89%). Over two-thirds (69%) are comfortable with helping support their child's mental or emotional health. Just 26% are comfortable with helping their child prepare and move to the adult medical care system or adult care, but 50% said this was not applicable.

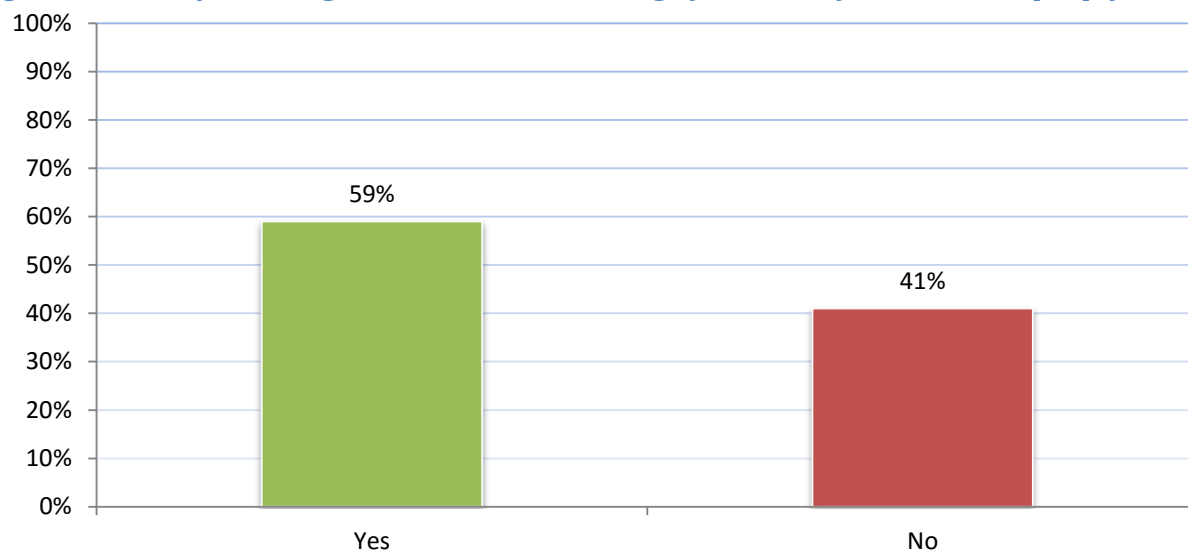
Figure 18: Comfort in various aspects of caring for child with epilepsy



Over half (59%) of respondents say they have been given more information on where to go for more information about epilepsy.

- This is unchanged from 2013 when 61% of respondents said they had been given advice on where to go for more information about epilepsy.

Figure 19: Have you been given advice on where to go for more information on epilepsy?



Forty-six percent (46%) received this advice from a specialist, 30% received it from a primary care physician, 18% from a care coordinator and 14% from a nurse. The types of information that are most likely to be given out are pamphlets/brochures (39%), website information (33%) and fact sheets (31%).

- There are no significant differences in these two measures since 2013.

Figure 21: Who gave you this advice?

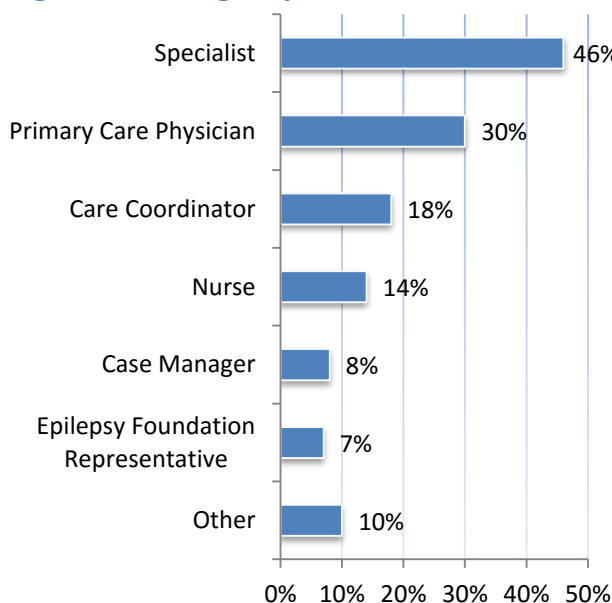
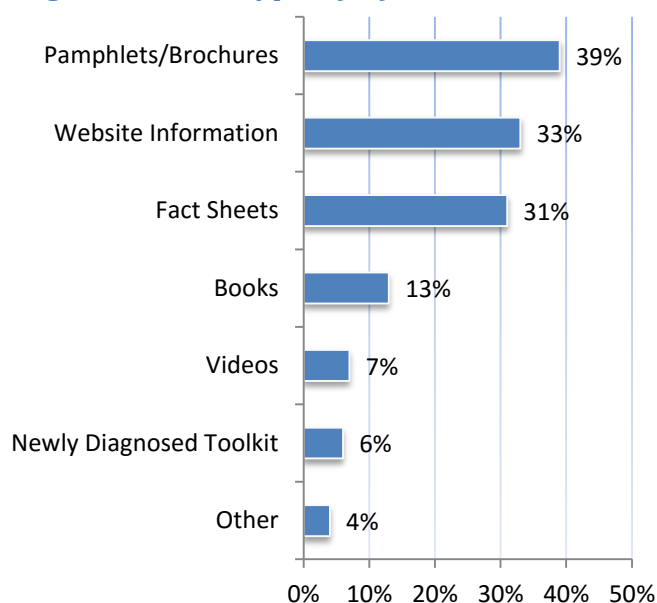


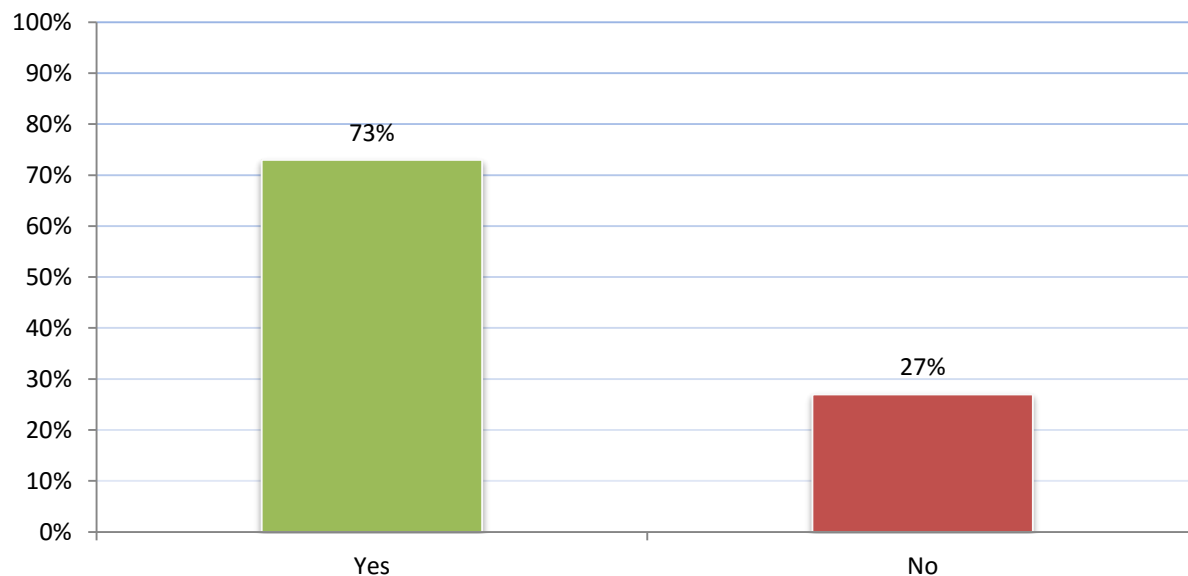
Figure 22: What types of information?



Seventy-three percent (73%) of respondents say they go online to get information on epilepsy. The most popular place for respondents to go is the Epilepsy Foundation webpage (See Appendix B for all webpages).

- This represents a significant change from 2013 when only 42% said they went online for epilepsy information.

Figure 23: Do you go online to get information on epilepsy?

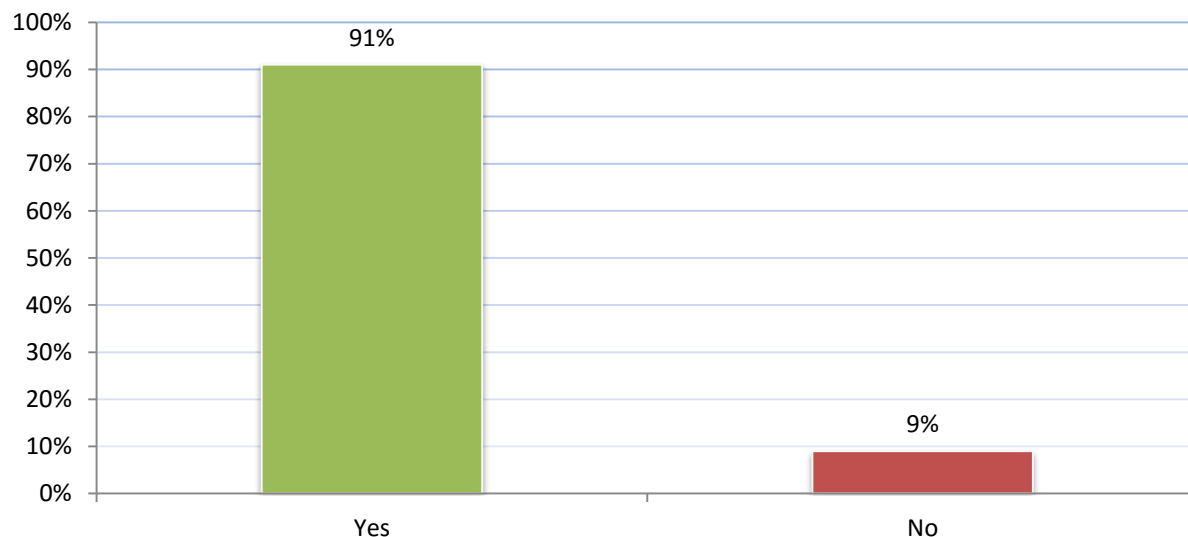


Additional Services/Resources For Child

Nearly all respondents (91%) say they have adequate insurance to pay for needed services.

- This is similar to 2013, when 89% of respondents say they have adequate insurance for needed services.

Figure 24: Do you have adequate insurance to pay for needed services?



Over half (52%) of respondents say they need respite care services for their child, and 81% of those respondents have received it. Of those who have received respite care 47% had used it often, 50% have used it sometimes and 3% have only used it once.

- This is similar to 2013, when 55% of respondents said they needed respite care, 72% of those respondents received it and 48% of those respondents used it often.

Figure 25: Do you need respite care services for your child?

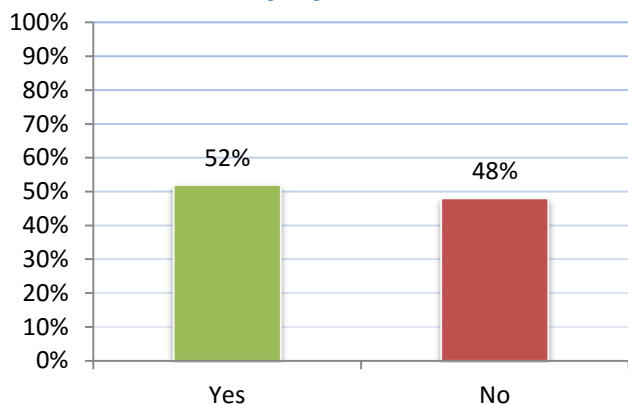


Figure 26: Have you received respite care services for your child? (N=43)

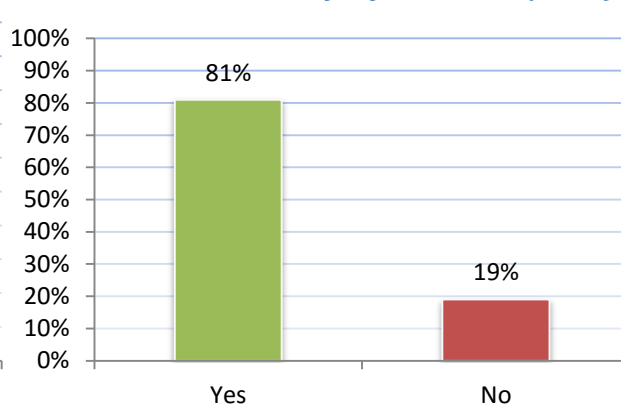
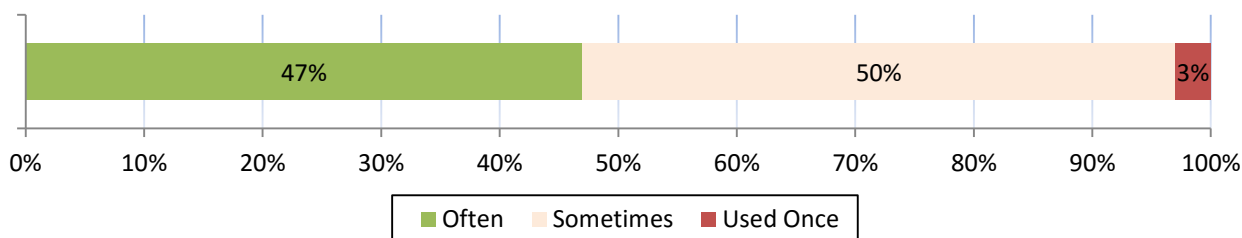


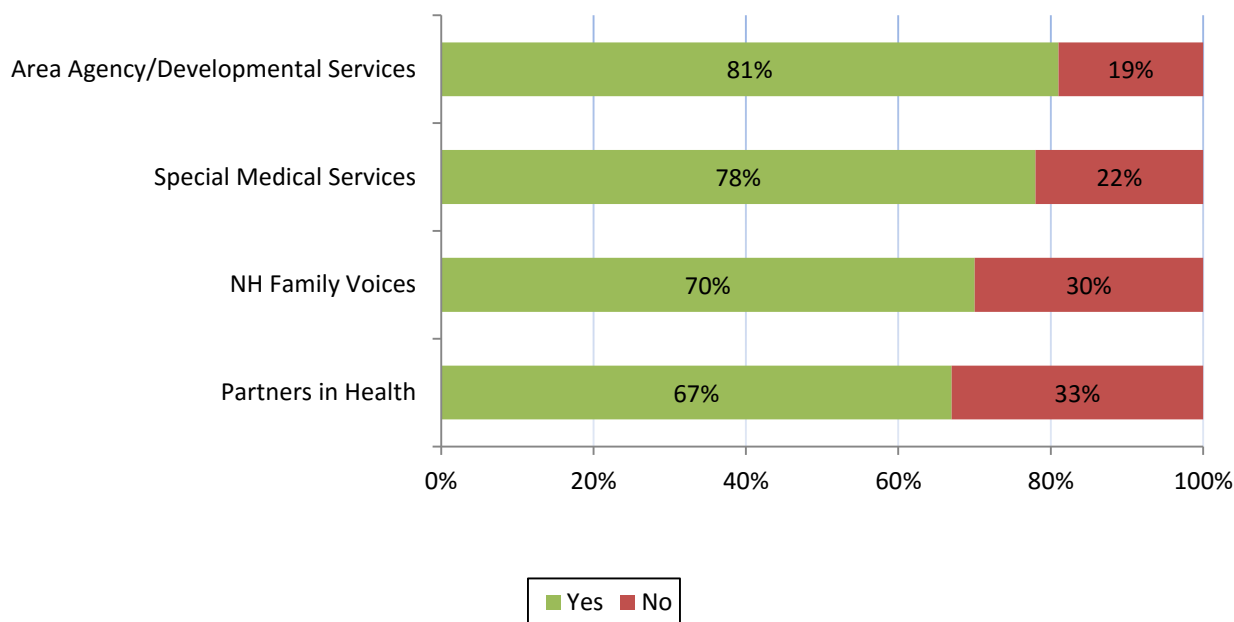
Figure 27: How often do you use respite care? (N=34)



Eighty-one percent (81%) of respondents are familiar with area agency/developmental services, 78% are familiar with Special Medical Services, 70% are familiar with NH Family Voices and 67% are familiar with Partners in Health.

- Respondents who are very knowledgeable about epilepsy are *more likely* to be familiar with all of these statewide resources.
- These results are similar to 2013 when 75% were familiar with Special Medical Services, 73% were familiar with Partners in Health, 72% were familiar with New Hampshire Family Voices, and 72% were familiar with area agency/developmental services.

Figure 28: Familiar with the following statewide resources



Appendix A: Detailed Tabular Results

Q1: Who is your child's main or usual source of health care?

	Primary Care Provider	Specialist in Epilepsy	Other (Specify)	Number Responding
PARENTS AND CAREGIVERS - 2015	56%	21%	23%	84
Child's Age				
6 Years Old Or Younger	55%	36%	9%	11
7 - 9 Years Old	67%	15%	19%	27
10 - 12 Years Old	29%	43%	29%	14
13 - 15 Years Old	72%	0%	28%	18
16 Years or Older	33%	33%	33%	12
Current Knowledge of Epilepsy				
Very Knowledgeable	51%	27%	22%	49
Some/Very Little Knowledge	62%	15%	24%	34
Age When Child Diagnosed With Epilepsy				
Less Than 1 Year Old	59%	18%	23%	22
1 - 3 Years Old	58%	23%	19%	26
4 - 6 Years Old	38%	38%	25%	16
7 - 9 Years Old	58%	17%	25%	12
10 Years or Older	67%	0%	33%	6

Q2A: What is available in each place - Help with making appointments and getting referrals or authorizations

	Available at Both	Available at Specialist Only	Available at PCP Only	Not Available	Number Responding
PARENTS AND CAREGIVERS - 2015	69%	10%	18%	4%	84
Child's Usual Source of Health Care					
Primary Care Provider	64%	4%	26%	6%	47
Epilepsy Specialist	61%	28%	11%	0%	18
Other	89%	5%	5%	0%	19
Child's Age					
6 Years Old Or Younger	82%	0%	18%	0%	11
7 - 9 Years Old	70%	11%	15%	4%	27
10 - 12 Years Old	57%	14%	29%	0%	14
13 - 15 Years Old	83%	0%	11%	6%	18
16 Years or Older	50%	25%	17%	8%	12
Current Knowledge of Epilepsy					
Very Knowledgeable	69%	12%	16%	2%	49
Some/Very Little Knowledge	68%	6%	21%	6%	34
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	86%	0%	14%	0%	22
1 - 3 Years Old	81%	4%	8%	8%	26
4 - 6 Years Old	44%	31%	25%	0%	16
7 - 9 Years Old	58%	17%	17%	8%	12
10 Years or Older	50%	0%	50%	0%	6

Q2B: What is available in each place - A care coordination plan

	Available at Both	Available at Specialist Only	Available at PCP Only	Not Available	Number Responding
PARENTS AND CAREGIVERS - 2015	31%	26%	22%	21%	81
Child's Usual Source of Health Care					
Primary Care Provider	31%	16%	20%	33%	45
Epilepsy Specialist	17%	50%	28%	6%	18
Other	44%	28%	22%	6%	18
Child's Age					
6 Years Old Or Younger	40%	20%	40%	0%	10
7 - 9 Years Old	35%	19%	19%	27%	26
10 - 12 Years Old	21%	36%	21%	21%	14
13 - 15 Years Old	41%	24%	12%	24%	17
16 Years or Older	17%	33%	25%	25%	12
Current Knowledge of Epilepsy					
Very Knowledgeable	32%	28%	26%	15%	47
Some/Very Little Knowledge	30%	21%	18%	30%	33
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	52%	14%	24%	10%	21
1 - 3 Years Old	32%	32%	20%	16%	25
4 - 6 Years Old	13%	31%	25%	31%	16
7 - 9 Years Old	25%	25%	25%	25%	12
10 Years or Older	20%	20%	0%	60%	5

Q2C: What is available in each place - An epilepsy action plan

	Available at Both	Available at Specialist Only	Available at PCP Only	Not Available	Number Responding
PARENTS AND CAREGIVERS - 2015	17%	70%	5%	7%	81
Child's Usual Source of Health Care					
Primary Care Provider	13%	72%	4%	11%	47
Epilepsy Specialist	17%	83%	0%	0%	18
Other	31%	50%	13%	6%	16
Child's Age					
6 Years Old Or Younger	27%	73%	0%	0%	11
7 - 9 Years Old	15%	70%	4%	11%	27
10 - 12 Years Old	7%	79%	14%	0%	14
13 - 15 Years Old	25%	63%	6%	6%	16
16 Years or Older	18%	73%	0%	9%	11
Current Knowledge of Epilepsy					
Very Knowledgeable	21%	74%	2%	2%	47
Some/Very Little Knowledge	12%	67%	9%	12%	33
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	23%	64%	9%	5%	22
1 - 3 Years Old	21%	71%	0%	8%	24
4 - 6 Years Old	13%	80%	0%	7%	15
7 - 9 Years Old	17%	67%	8%	8%	12
10 Years or Older	0%	83%	17%	0%	6

Q2D: What is available in each place - Suggestions of community service for my child or family

	Available at Both	Available at Specialist Only	Available at PCP Only	Not Available	Number Responding
PARENTS AND CAREGIVERS - 2015	34%	12%	29%	25%	76
Child's Usual Source of Health Care					
Primary Care Provider	35%	12%	33%	21%	43
Epilepsy Specialist	31%	25%	19%	25%	16
Other	35%	0%	29%	35%	17
Child's Age					
6 Years Old Or Younger	44%	0%	44%	11%	9
7 - 9 Years Old	32%	20%	24%	24%	25
10 - 12 Years Old	21%	21%	29%	29%	14
13 - 15 Years Old	38%	6%	31%	25%	16
16 Years or Older	40%	0%	20%	40%	10
Current Knowledge of Epilepsy					
Very Knowledgeable	29%	14%	33%	24%	42
Some/Very Little Knowledge	39%	9%	24%	27%	33
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	50%	5%	40%	5%	20
1 - 3 Years Old	41%	18%	27%	14%	22
4 - 6 Years Old	21%	14%	7%	57%	14
7 - 9 Years Old	8%	17%	33%	42%	12
10 Years or Older	33%	0%	33%	33%	6

Q2E: What is available in each place - Help with transportation, insurance forms, or other financial needs

	Available at Both	Available at Specialist Only	Available at PCP Only	Not Available	Number Responding
PARENTS AND CAREGIVERS - 2015	20%	11%	13%	56%	75
Child's Usual Source of Health Care					
Primary Care Provider	14%	12%	14%	60%	42
Epilepsy Specialist	29%	12%	6%	53%	17
Other	25%	6%	19%	50%	16
Child's Age					
6 Years Old Or Younger	50%	10%	10%	30%	10
7 - 9 Years Old	25%	13%	13%	50%	24
10 - 12 Years Old	0%	15%	15%	69%	13
13 - 15 Years Old	13%	13%	13%	63%	16
16 Years or Older	10%	0%	20%	70%	10
Current Knowledge of Epilepsy					
Very Knowledgeable	24%	14%	12%	50%	42
Some/Very Little Knowledge	13%	6%	16%	66%	32
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	16%	11%	32%	42%	19
1 - 3 Years Old	41%	9%	9%	41%	22
4 - 6 Years Old	14%	14%	0%	71%	14
7 - 9 Years Old	0%	17%	8%	75%	12
10 Years or Older	0%	0%	17%	83%	6

Q2F: What is available in each place - The information I need to take care of my child

	Available at Both	Available at Specialist Only	Available at PCP Only	Not Available	Number Responding
PARENTS AND CAREGIVERS	71%	13%	10%	6%	80
Child's Usual Source of Health Care					
Primary Care Provider	72%	9%	11%	9%	46
Epilepsy Specialist	53%	35%	6%	6%	17
Other	88%	0%	12%	0%	17
Child's Age					
6 Years Old Or Younger	82%	9%	9%	0%	11
7 - 9 Years Old	67%	15%	4%	15%	27
10 - 12 Years Old	54%	15%	23%	8%	13
13 - 15 Years Old	88%	6%	6%	0%	17
16 Years or Older	70%	20%	10%	0%	10
Current Knowledge of Epilepsy					
Very Knowledgeable	66%	17%	11%	6%	47
Some/Very Little Knowledge	78%	6%	9%	6%	32
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	90%	0%	5%	5%	21
1 - 3 Years Old	64%	16%	12%	8%	25
4 - 6 Years Old	60%	27%	7%	7%	15
7 - 9 Years Old	58%	17%	17%	8%	12
10 Years or Older	100%	0%	0%	0%	5

Q3A: How often is each of the following true about your child's main or usual source of health care? - My child's main or usual source of health care and I work together as partners to make health care decisions

	Never	Sometimes	Often	Always	Don't Know/ Doesn't Apply	Number Responding
PARENTS AND CAREGIVERS - 2015	1%	12%	27%	58%	1%	84
Child's Usual Source of Health Care						
Primary Care Provider	2%	11%	30%	57%	0%	47
Epilepsy Specialist	0%	11%	28%	61%	0%	18
Other	0%	16%	21%	58%	5%	19
Child's Age						
6 Years Old Or Younger	0%	0%	45%	55%	0%	11
7 - 9 Years Old	4%	15%	19%	63%	0%	27
10 - 12 Years Old	0%	7%	43%	50%	0%	14
13 - 15 Years Old	0%	11%	17%	72%	0%	18
16 Years or Older	0%	25%	33%	33%	8%	12
Current Knowledge of Epilepsy						
Very Knowledgeable	2%	8%	29%	59%	2%	49
Some/Very Little Knowledge	0%	18%	26%	56%	0%	34
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	5%	9%	23%	64%	0%	22
1 - 3 Years Old	0%	12%	35%	50%	4%	26
4 - 6 Years Old	0%	6%	31%	63%	0%	16
7 - 9 Years Old	0%	25%	25%	50%	0%	12
10 Years or Older	0%	17%	17%	67%	0%	6

Q3B: How often is each of the following true about your child's main or usual source of health care? - A care coordination plan

	Never	Sometimes	Often	Always	Don't Know/ Doesn't Apply	Number Responding
PARENTS AND CAREGIVERS - 2015	7%	18%	22%	31%	22%	83
Child's Usual Source of Health Care						
Primary Care Provider	13%	24%	15%	24%	24%	46
Epilepsy Specialist	0%	6%	44%	28%	22%	18
Other	0%	16%	16%	53%	16%	19
Child's Age						
6 Years Old Or Younger	0%	27%	9%	36%	27%	11
7 - 9 Years Old	19%	15%	11%	41%	15%	27
10 - 12 Years Old	0%	21%	43%	14%	21%	14
13 - 15 Years Old	0%	12%	24%	35%	29%	17
16 Years or Older	8%	25%	33%	8%	25%	12
Current Knowledge of Epilepsy						
Very Knowledgeable	6%	14%	20%	41%	18%	49
Some/Very Little Knowledge	9%	24%	24%	15%	27%	33
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	9%	27%	27%	27%	9%	22
1 - 3 Years Old	4%	12%	15%	42%	27%	26
4 - 6 Years Old	6%	6%	31%	25%	31%	16
7 - 9 Years Old	17%	33%	17%	17%	17%	12
10 Years or Older	0%	20%	20%	20%	40%	5

Q3C: How often is each of the following true about your child's main or usual source of health care? - An epilepsy action plan

	Never	Sometimes	Often	Always	Don't Know/ Doesn't Apply	Number Responding
PARENTS AND CAREGIVERS - 2015	15%	12%	20%	45%	9%	82
Child's Usual Source of Health Care						
Primary Care Provider	26%	20%	11%	35%	9%	46
Epilepsy Specialist	0%	0%	44%	56%	0%	18
Other	0%	6%	17%	61%	17%	18
Child's Age						
6 Years Old Or Younger	18%	9%	9%	55%	9%	11
7 - 9 Years Old	26%	15%	7%	52%	0%	27
10 - 12 Years Old	7%	0%	64%	21%	7%	14
13 - 15 Years Old	6%	6%	6%	65%	18%	17
16 Years or Older	9%	27%	27%	27%	9%	11
Current Knowledge of Epilepsy						
Very Knowledgeable	17%	10%	15%	54%	4%	48
Some/Very Little Knowledge	12%	15%	27%	33%	12%	33
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	18%	14%	14%	55%	0%	22
1 - 3 Years Old	12%	8%	16%	48%	16%	25
4 - 6 Years Old	13%	0%	31%	50%	6%	16
7 - 9 Years Old	25%	17%	25%	25%	8%	12
10 Years or Older	0%	40%	20%	40%	0%	5

Q3D: How often is each of the following true about your child's main or usual source of health care? - The information I need to take care of my child

	Never	Sometimes	Often	Always	Don't Know/ Doesn't Apply	Number Responding
PARENTS AND CAREGIVERS - 2015	5%	10%	28%	55%	2%	83
Child's Usual Source of Health Care						
Primary Care Provider	9%	9%	23%	55%	4%	47
Epilepsy Specialist	0%	12%	29%	59%	0%	17
Other	0%	11%	37%	53%	0%	19
Child's Age						
6 Years Old Or Younger	0%	18%	18%	64%	0%	11
7 - 9 Years Old	15%	4%	15%	63%	4%	27
10 - 12 Years Old	0%	15%	54%	31%	0%	13
13 - 15 Years Old	0%	0%	28%	67%	6%	18
16 Years or Older	0%	25%	42%	33%	0%	12
Current Knowledge of Epilepsy						
Very Knowledgeable	4%	8%	23%	63%	2%	48
Some/Very Little Knowledge	6%	12%	35%	44%	3%	34
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	10%	5%	33%	52%	0%	21
1 - 3 Years Old	0%	19%	19%	58%	4%	26
4 - 6 Years Old	6%	6%	31%	50%	6%	16
7 - 9 Years Old	8%	0%	42%	50%	0%	12
10 Years or Older	0%	17%	17%	67%	0%	6

Q4: We would like to know if your child has a medical home

	Yes And Is Usual Source of Health care	Yes But Not Usual Source of Health Care	No	Number Responding
PARENTS AND CAREGIVERS - 2013	23%		77%	113
PARENTS AND CAREGIVERS - 2015	25%	8%	66%	83
Child's Usual Source of Health Care				
Primary Care Provider	23%	6%	70%	47
Epilepsy Specialist	29%	0%	71%	17
Other	26%	21%	53%	19
Child's Age				
6 Years Old Or Younger	36%	18%	45%	11
7 - 9 Years Old	30%	4%	67%	27
10 - 12 Years Old	15%	8%	77%	13
13 - 15 Years Old	22%	11%	67%	18
16 Years or Older	17%	8%	75%	12
Current Knowledge of Epilepsy				
Very Knowledgeable	33%	6%	61%	49
Some/Very Little Knowledge	12%	12%	76%	33
Age When Child Diagnosed With Epilepsy				
Less Than 1 Year Old	27%	9%	64%	22
1 - 3 Years Old	31%	12%	58%	26
4 - 6 Years Old	25%	0%	75%	16
7 - 9 Years Old	9%	9%	82%	11
10 Years or Older	17%	17%	67%	6

Q5: My child's main source of epilepsy care gives me ways to learn more about helping my child be healthy and grow.

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2015	52%	48%	81
Child's Usual Source of Health Care			
Primary Care Provider	47%	53%	45
Epilepsy Specialist	44%	56%	18
Other	72%	28%	18
Child's Age			
6 Years Old Or Younger	45%	55%	11
7 - 9 Years Old	52%	48%	27
10 - 12 Years Old	62%	38%	13
13 - 15 Years Old	47%	53%	17
16 Years or Older	50%	50%	12
Current Knowledge of Epilepsy			
Very Knowledgeable	52%	48%	48
Some/Very Little Knowledge	52%	48%	33
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	59%	41%	22
1 - 3 Years Old	48%	52%	25
4 - 6 Years Old	31%	69%	16
7 - 9 Years Old	58%	42%	12
10 Years or Older	80%	20%	5

Q6: How often does your child's main source of epilepsy care call to see if you (your child) used a recommended service or program?

	Never	Sometimes	Often	Always	Number Responding
PARENTS AND CAREGIVERS - 2015	70%	21%	7%	1%	81
Child's Usual Source of Health Care					
Primary Care Provider	84%	7%	7%	2%	45
Epilepsy Specialist	67%	33%	0%	0%	18
Other	39%	44%	17%	0%	18
Child's Age					
6 Years Old Or Younger	64%	18%	18%	0%	11
7 - 9 Years Old	78%	11%	11%	0%	27
10 - 12 Years Old	64%	36%	0%	0%	14
13 - 15 Years Old	75%	13%	6%	6%	16
16 Years or Older	58%	42%	0%	0%	12
Current Knowledge of Epilepsy					
Very Knowledgeable	65%	22%	10%	2%	49
Some/Very Little Knowledge	78%	19%	3%	0%	32
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	71%	19%	5%	5%	21
1 - 3 Years Old	62%	23%	15%	0%	26
4 - 6 Years Old	81%	13%	6%	0%	16
7 - 9 Years Old	75%	25%	0%	0%	12
10 Years or Older	60%	40%	0%	0%	5

Q7: Does your child see an epilepsy specialist?

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	99%	1%	118
PARENTS AND CAREGIVERS - 2015	94%	6%	82
Child's Usual Source of Health Care			
Primary Care Provider	96%	4%	46
Epilepsy Specialist	94%	6%	18
Other	89%	11%	18
Child's Age			
6 Years Old Or Younger	91%	9%	11
7 - 9 Years Old	100%	0%	27
10 - 12 Years Old	86%	14%	14
13 - 15 Years Old	94%	6%	17
16 Years or Older	92%	8%	12
Current Knowledge of Epilepsy			
Very Knowledgeable	98%	2%	49
Some/Very Little Knowledge	88%	12%	33
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	95%	5%	22
1 - 3 Years Old	96%	4%	26
4 - 6 Years Old	88%	13%	16
7 - 9 Years Old	92%	8%	12
10 Years or Older	100%	0%	5

Q8: Does your child's specialist communicate with your child's primary care provider?

	Yes	No	Don't Know	Number Responding
PARENTS AND CAREGIVERS - 2013	76%	3%	22%	115
PARENTS AND CAREGIVERS - 2015	69%	10%	21%	77
Child's Usual Source of Health Care				
Primary Care Provider	59%	14%	27%	44
Epilepsy Specialist	76%	6%	18%	17
Other	88%	6%	6%	16
Child's Age				
6 Years Old Or Younger	80%	0%	20%	10
7 - 9 Years Old	59%	22%	19%	27
10 - 12 Years Old	75%	8%	17%	12
13 - 15 Years Old	75%	0%	25%	16
16 Years or Older	64%	9%	27%	11
Current Knowledge of Epilepsy				
Very Knowledgeable	79%	8%	13%	48
Some/Very Little Knowledge	52%	14%	34%	29
Age When Child Diagnosed With Epilepsy				
Less Than 1 Year Old	76%	5%	19%	21
1 - 3 Years Old	68%	12%	20%	25
4 - 6 Years Old	79%	14%	7%	14
7 - 9 Years Old	64%	18%	18%	11
10 Years or Older	20%	0%	80%	5

Q9A: Thinking about your child's epilepsy specialist, how much do you agree or disagree with the following statements? -My child's epilepsy specialist listens carefully to me

	Strongly Agree	Agree	Disagree	Strongly Disagree	Number Responding
PARENTS AND CAREGIVERS - 2015	57%	38%	4%	1%	77
Child's Usual Source of Health Care					
Primary Care Provider	48%	45%	5%	2%	44
Epilepsy Specialist	71%	29%	0%	0%	17
Other	69%	25%	6%	0%	16
Child's Age					
6 Years Old Or Younger	60%	40%	0%	0%	10
7 - 9 Years Old	56%	33%	7%	4%	27
10 - 12 Years Old	42%	50%	8%	0%	12
13 - 15 Years Old	63%	38%	0%	0%	16
16 Years or Older	64%	36%	0%	0%	11
Current Knowledge of Epilepsy					
Very Knowledgeable	69%	27%	2%	2%	48
Some/Very Little Knowledge	38%	55%	7%	0%	29
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	57%	43%	0%	0%	21
1 - 3 Years Old	52%	44%	4%	0%	25
4 - 6 Years Old	79%	14%	0%	7%	14
7 - 9 Years Old	55%	27%	18%	0%	11
10 Years or Older	20%	80%	0%	0%	5

Survey CenterJuly, 2015

Q9B: Thinking about your child's epilepsy specialist, how much do you agree or disagree with the following statements? -My child's epilepsy specialist makes it easy for me to ask questions or raise concerns

	Strongly Agree	Agree	Disagree	Strongly Disagree	Number Responding
PARENTS AND CAREGIVERS - 2015	64%	29%	6%	1%	77
Child's Usual Source of Health Care					
Primary Care Provider	61%	30%	7%	2%	44
Epilepsy Specialist	71%	29%	0%	0%	17
Other	63%	25%	13%	0%	16
Child's Age					
6 Years Old Or Younger	90%	10%	0%	0%	10
7 - 9 Years Old	63%	26%	7%	4%	27
10 - 12 Years Old	33%	50%	17%	0%	12
13 - 15 Years Old	69%	31%	0%	0%	16
16 Years or Older	64%	27%	9%	0%	11
Current Knowledge of Epilepsy					
Very Knowledgeable	75%	19%	4%	2%	48
Some/Very Little Knowledge	45%	45%	10%	0%	29
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	71%	29%	0%	0%	21
1 - 3 Years Old	64%	28%	8%	0%	25
4 - 6 Years Old	79%	14%	0%	7%	14
7 - 9 Years Old	45%	36%	18%	0%	11
10 Years or Older	20%	60%	20%	0%	5

Q11: How often do you travel to see your child's specialist?

	Once or Twice a Week	Once or Twice a Month	Once Every 2-3 Months	Once or Twice a Year	Depends	Number Responding
PARENTS AND CAREGIVERS - 2015	1%	5%	43%	35%	16%	75
Child's Usual Source of Health Care						
Primary Care Provider	2%	5%	28%	49%	16%	43
Epilepsy Specialist	0%	6%	59%	24%	12%	17
Other	0%	7%	67%	7%	20%	15
Child's Age						
6 Years Old Or Younger	0%	0%	50%	30%	20%	10
7 - 9 Years Old	0%	8%	35%	42%	15%	26
10 - 12 Years Old	0%	0%	50%	25%	25%	12
13 - 15 Years Old	6%	6%	38%	38%	13%	16
16 Years or Older	0%	9%	55%	27%	9%	11
Current Knowledge of Epilepsy						
Very Knowledgeable	2%	7%	50%	30%	11%	46
Some/Very Little Knowledge	0%	3%	31%	41%	24%	29
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	0%	5%	50%	35%	10%	20
1 - 3 Years Old	0%	4%	36%	48%	12%	25
4 - 6 Years Old	0%	7%	64%	14%	14%	14
7 - 9 Years Old	9%	0%	27%	27%	36%	11
10 Years or Older	0%	20%	20%	40%	20%	5

Q12: How far you travel to see your child's specialist?

	Less than 25 Miles	26-50 Miles	51-75 Miles	76-100 Miles	More than 100 Miles	Number Responding
PARENTS AND CAREGIVERS - 2015	19%	21%	31%	16%	13%	75
Child's Usual Source of Health Care						
Primary Care Provider	14%	30%	30%	12%	14%	43
Epilepsy Specialist	19%	6%	50%	19%	6%	16
Other	31%	13%	13%	25%	19%	16
Child's Age						
6 Years Old Or Younger	10%	20%	40%	20%	10%	10
7 - 9 Years Old	4%	26%	33%	26%	11%	27
10 - 12 Years Old	27%	9%	18%	18%	27%	11
13 - 15 Years Old	25%	38%	25%	6%	6%	16
16 Years or Older	45%	0%	36%	0%	18%	11
Current Knowledge of Epilepsy						
Very Knowledgeable	21%	19%	30%	23%	6%	47
Some/Very Little Knowledge	14%	25%	32%	4%	25%	28
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	19%	24%	33%	19%	5%	21
1 - 3 Years Old	24%	28%	24%	12%	12%	25
4 - 6 Years Old	15%	8%	54%	23%	0%	13
7 - 9 Years Old	18%	9%	18%	18%	36%	11
10 Years or Older	0%	40%	20%	0%	40%	5

Q13: Do you limit appointments to the specialist because of how far you have to travel?

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	28%	72%	115
PARENTS AND CAREGIVERS - 2015	29%	71%	76
Child's Usual Source of Health Care			
Primary Care Provider	37%	63%	43
Epilepsy Specialist	18%	82%	17
Other	19%	81%	16
Child's Age			
6 Years Old Or Younger	30%	70%	10
7 - 9 Years Old	37%	63%	27
10 - 12 Years Old	33%	67%	12
13 - 15 Years Old	19%	81%	16
16 Years or Older	18%	82%	11
Current Knowledge of Epilepsy			
Very Knowledgeable	23%	77%	47
Some/Very Little Knowledge	38%	62%	29
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	29%	71%	21
1 - 3 Years Old	16%	84%	25
4 - 6 Years Old	21%	79%	14
7 - 9 Years Old	45%	55%	11
10 Years or Older	80%	20%	5

Q14: Have you had a need to see the specialist quickly/schedule an urgent appointment?

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	54%	46%	115
PARENTS AND CAREGIVERS - 2015	54%	46%	76
Child's Usual Source of Health Care			
Primary Care Provider	44%	56%	43
Epilepsy Specialist	65%	35%	17
Other	69%	31%	16
Child's Age			
6 Years Old Or Younger	60%	40%	10
7 - 9 Years Old	48%	52%	27
10 - 12 Years Old	75%	25%	12
13 - 15 Years Old	38%	63%	16
16 Years or Older	64%	36%	11
Current Knowledge of Epilepsy			
Very Knowledgeable	57%	43%	47
Some/Very Little Knowledge	48%	52%	29
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	52%	48%	21
1 - 3 Years Old	64%	36%	25
4 - 6 Years Old	36%	64%	14
7 - 9 Years Old	64%	36%	11
10 Years or Older	40%	60%	5

Q15: The last time you needed an urgent appointment, how long did you have to wait?

	Got An Appointment That Day	The Next Day	2 Days	3 or More Days	Number Responding
PARENTS AND CAREGIVERS - 2015	15%	21%	26%	38%	39
Child's Usual Source of Health Care					
Primary Care Provider	11%	11%	28%	50%	18
Epilepsy Specialist	20%	20%	20%	40%	10
Other	18%	36%	27%	18%	11
Child's Age					
6 Years Old Or Younger	50%	17%	17%	17%	6
7 - 9 Years Old	0%	8%	38%	54%	13
10 - 12 Years Old	14%	29%	14%	43%	7
13 - 15 Years Old	17%	33%	33%	17%	6
16 Years or Older	14%	29%	14%	43%	7
Current Knowledge of Epilepsy					
Very Knowledgeable	19%	19%	33%	30%	27
Some/Very Little Knowledge	8%	25%	8%	58%	12
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	9%	27%	36%	27%	11
1 - 3 Years Old	25%	25%	31%	19%	16
4 - 6 Years Old	0%	0%	20%	80%	5
7 - 9 Years Old	20%	20%	0%	60%	5
10 Years or Older	0%	0%	0%	100%	2

Q19A: Has your specialist talked about: Your child independently managing his/her health care?

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2015	15%	85%	39
Child's Usual Source of Health Care			
Primary Care Provider	0%	100%	18
Epilepsy Specialist	50%	50%	10
Other	9%	91%	11
Child's Age			
6 Years Old Or Younger	50%	50%	2
7 - 9 Years Old	9%	91%	11
10 - 12 Years Old	0%	100%	8
13 - 15 Years Old	13%	88%	8
16 Years or Older	30%	70%	10
Current Knowledge of Epilepsy			
Very Knowledgeable	17%	83%	23
Some/Very Little Knowledge	13%	88%	16
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	9%	91%	11
1 - 3 Years Old	0%	100%	10
4 - 6 Years Old	44%	56%	9
7 - 9 Years Old	0%	100%	6
10 Years or Older	33%	67%	3

Q19B: Has your specialist talked about: Transitioning to an adult neurologist in the future?

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	24%	76%	21
PARENTS AND CAREGIVERS - 2015	20%	80%	40
Child's Usual Source of Health Care			
Primary Care Provider	5%	95%	19
Epilepsy Specialist	40%	60%	10
Other	27%	73%	11
Child's Age			
6 Years Old Or Younger	50%	50%	2
7 - 9 Years Old	0%	100%	11
10 - 12 Years Old	13%	88%	8
13 - 15 Years Old	11%	89%	9
16 Years or Older	50%	50%	10
Current Knowledge of Epilepsy			
Very Knowledgeable	22%	78%	23
Some/Very Little Knowledge	18%	82%	17
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	18%	82%	11
1 - 3 Years Old	0%	100%	10
4 - 6 Years Old	33%	67%	9
7 - 9 Years Old	17%	83%	6
10 Years or Older	50%	50%	4

Q19C: Has your specialist talked about: Issues related to adolescence/young adulthood and epilepsy?

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	40%	60%	20
PARENTS AND CAREGIVERS - 2015	43%	58%	40
Child's Usual Source of Health Care			
Primary Care Provider	11%	89%	19
Epilepsy Specialist	90%	10%	10
Other	55%	45%	11
Child's Age			
6 Years Old Or Younger	50%	50%	2
7 - 9 Years Old	9%	91%	11
10 - 12 Years Old	63%	38%	8
13 - 15 Years Old	44%	56%	9
16 Years or Older	60%	40%	10
Current Knowledge of Epilepsy			
Very Knowledgeable	39%	61%	23
Some/Very Little Knowledge	47%	53%	17
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	55%	45%	11
1 - 3 Years Old	10%	90%	10
4 - 6 Years Old	56%	44%	9
7 - 9 Years Old	50%	50%	6
10 Years or Older	50%	50%	4

Q20A: In the past 6 months, did you or your family need Family Support and/or Epilepsy Groups?

	Yes	No	Don't Know	Number Responding
PARENTS AND CAREGIVERS - 2013	26%	70%	5%	82
Child's Usual Source of Health Care				
Primary Care Provider	31%	64%	4%	45
Epilepsy Specialist	22%	78%	0%	18
Other	16%	74%	11%	19
Child's Age				
6 Years Old Or Younger	18%	82%	0%	11
7 - 9 Years Old	33%	63%	4%	27
10 - 12 Years Old	21%	71%	7%	14
13 - 15 Years Old	28%	61%	11%	18
16 Years or Older	17%	83%	0%	12
Current Knowledge of Epilepsy				
Very Knowledgeable	27%	71%	2%	48
Some/Very Little Knowledge	24%	68%	9%	34
Age When Child Diagnosed With Epilepsy				
Less Than 1 Year Old	27%	64%	9%	22
1 - 3 Years Old	15%	85%	0%	26
4 - 6 Years Old	38%	63%	0%	16
7 - 9 Years Old	25%	58%	17%	12
10 Years or Older	33%	67%	0%	6

Q20B: Were you referred to or told where to get this service?

	Yes	No	Don't Know	We Didn't Need This Service	Number Responding
PARENTS AND CAREGIVERS - 2013	21%	59%	3%	18%	80
Child's Usual Source of Health Care					
Primary Care Provider	23%	59%	2%	16%	44
Epilepsy Specialist	22%	61%	0%	17%	18
Other	17%	56%	6%	22%	18
Child's Age					
6 Years Old Or Younger	9%	55%	0%	36%	11
7 - 9 Years Old	19%	62%	4%	15%	26
10 - 12 Years Old	7%	64%	7%	21%	14
13 - 15 Years Old	41%	47%	0%	12%	17
16 Years or Older	25%	67%	0%	8%	12
Current Knowledge of Epilepsy					
Very Knowledgeable	22%	59%	2%	17%	46
Some/Very Little Knowledge	21%	59%	3%	18%	34
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	33%	48%	0%	19%	21
1 - 3 Years Old	12%	58%	4%	27%	26
4 - 6 Years Old	19%	69%	6%	6%	16
7 - 9 Years Old	18%	64%	0%	18%	11
10 Years or Older	33%	67%	0%	0%	6

Q20C: Were you able to get this service?

	Yes	No	Don't Know	We Didn't Need This Service	Not Available in My Community	Number Responding
PARENTS AND CAREGIVERS - 2015	25%	18%	6%	47%	4%	77
Child's Usual Source of Health Care						
Primary Care Provider	28%	16%	5%	49%	2%	43
Epilepsy Specialist	22%	28%	0%	50%	0%	18
Other	19%	13%	19%	38%	13%	16
Child's Age						
6 Years Old Or Younger	22%	11%	11%	56%	0%	9
7 - 9 Years Old	19%	12%	4%	58%	8%	26
10 - 12 Years Old	21%	43%	0%	29%	7%	14
13 - 15 Years Old	31%	19%	13%	38%	0%	16
16 Years or Older	33%	8%	8%	50%	0%	12
Current Knowledge of Epilepsy						
Very Knowledgeable	27%	22%	4%	44%	2%	45
Some/Very Little Knowledge	22%	13%	9%	50%	6%	32
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	24%	19%	5%	48%	5%	21
1 - 3 Years Old	21%	17%	8%	54%	0%	24
4 - 6 Years Old	33%	13%	7%	47%	0%	15
7 - 9 Years Old	27%	27%	0%	27%	18%	11
10 Years or Older	17%	17%	17%	50%	0%	6

Q21A: In the past 6 months, did you or your family need Transportation to Medical Appointments?

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2015	11%	89%	81
Child's Usual Source of Health Care			
Primary Care Provider	11%	89%	44
Epilepsy Specialist	11%	89%	18
Other	11%	89%	19
Child's Age			
6 Years Old Or Younger	9%	91%	11
7 - 9 Years Old	15%	85%	26
10 - 12 Years Old	7%	93%	14
13 - 15 Years Old	17%	83%	18
16 Years or Older	0%	100%	12
Current Knowledge of Epilepsy			
Very Knowledgeable	13%	88%	48
Some/Very Little Knowledge	9%	91%	33
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	14%	86%	21
1 - 3 Years Old	8%	92%	26
4 - 6 Years Old	0%	100%	16
7 - 9 Years Old	17%	83%	12
10 Years or Older	33%	67%	6

Q21B: Were you referred to or told where to get this service?

	Yes	No	Don't Know	We Didn't Need This Service	Number Responding
PARENTS AND CAREGIVERS - 2015	9%	39%	3%	50%	80
Child's Usual Source of Health Care					
Primary Care Provider	9%	20%	2%	68%	44
Epilepsy Specialist	6%	67%	0%	28%	18
Other	11%	56%	6%	28%	18
Child's Age					
6 Years Old Or Younger	9%	18%	0%	73%	11
7 - 9 Years Old	4%	41%	0%	56%	27
10 - 12 Years Old	7%	64%	7%	21%	14
13 - 15 Years Old	19%	19%	6%	56%	16
16 Years or Older	8%	50%	0%	42%	12
Current Knowledge of Epilepsy					
Very Knowledgeable	11%	34%	4%	51%	47
Some/Very Little Knowledge	6%	45%	0%	48%	33
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	14%	27%	0%	59%	22
1 - 3 Years Old	12%	35%	8%	46%	26
4 - 6 Years Old	0%	44%	0%	56%	16
7 - 9 Years Old	9%	55%	0%	36%	11
10 Years or Older	0%	60%	0%	40%	5

Q21C: Were you able to get this service?

	Yes	No	Don't Know	We Didn't Need This Service	Not Available in My Community	Number Responding
PARENTS AND CAREGIVERS - 2015	6%	19%	6%	68%	1%	80
Child's Usual Source of Health Care						
Primary Care Provider	2%	11%	7%	77%	2%	44
Epilepsy Specialist	6%	28%	0%	67%	0%	18
Other	17%	28%	11%	44%	0%	18
Child's Age						
6 Years Old Or Younger	9%	9%	0%	82%	0%	11
7 - 9 Years Old	0%	22%	7%	67%	4%	27
10 - 12 Years Old	7%	29%	0%	64%	0%	14
13 - 15 Years Old	13%	13%	6%	69%	0%	16
16 Years or Older	8%	17%	17%	58%	0%	12
Current Knowledge of Epilepsy						
Very Knowledgeable	9%	19%	6%	66%	0%	47
Some/Very Little Knowledge	3%	18%	6%	70%	3%	33
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	9%	5%	0%	86%	0%	22
1 - 3 Years Old	12%	23%	8%	58%	0%	26
4 - 6 Years Old	0%	19%	6%	75%	0%	16
7 - 9 Years Old	0%	27%	9%	55%	9%	11
10 Years or Older	0%	40%	20%	40%	0%	5

Q22A: In the past 6 months, did you or your family need Education Support and Access?

	Yes	No	Don't Know	Number Responding
PARENTS AND CAREGIVERS - 2015	55%	44%	1%	82
Child's Usual Source of Health Care				
Primary Care Provider	49%	51%	0%	45
Epilepsy Specialist	50%	44%	6%	18
Other	74%	26%	0%	19
Child's Age				
6 Years Old Or Younger	27%	73%	0%	11
7 - 9 Years Old	56%	41%	4%	27
10 - 12 Years Old	64%	36%	0%	14
13 - 15 Years Old	67%	33%	0%	18
16 Years or Older	50%	50%	0%	12
Current Knowledge of Epilepsy				
Very Knowledgeable	60%	38%	2%	48
Some/Very Little Knowledge	47%	53%	0%	34
Age When Child Diagnosed With Epilepsy				
Less Than 1 Year Old	50%	50%	0%	22
1 - 3 Years Old	46%	50%	4%	26
4 - 6 Years Old	56%	44%	0%	16
7 - 9 Years Old	75%	25%	0%	12
10 Years or Older	67%	33%	0%	6

Q22B: Were you referred to or told where to get this service?

	Yes	No	Don't Know	We Didn't Need This Service	Number Responding
PARENTS AND CAREGIVERS - 2015	46%	23%	2%	28%	81
Child's Usual Source of Health Care					
Primary Care Provider	43%	20%	0%	36%	44
Epilepsy Specialist	33%	28%	6%	33%	18
Other	63%	26%	5%	5%	19
Child's Age					
6 Years Old Or Younger	36%	9%	0%	55%	11
7 - 9 Years Old	44%	15%	4%	37%	27
10 - 12 Years Old	50%	29%	0%	21%	14
13 - 15 Years Old	59%	24%	6%	12%	17
16 Years or Older	33%	50%	0%	17%	12
Current Knowledge of Epilepsy					
Very Knowledgeable	54%	15%	4%	27%	48
Some/Very Little Knowledge	33%	36%	0%	30%	33
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	59%	9%	0%	32%	22
1 - 3 Years Old	42%	23%	4%	31%	26
4 - 6 Years Old	44%	19%	0%	38%	16
7 - 9 Years Old	42%	33%	8%	17%	12
10 Years or Older	20%	80%	0%	0%	5

Q22C: Were you able to get this service?

	Yes	No	Don't Know	We Didn't Need This Service	Number Responding
PARENTS AND CAREGIVERS - 2015	50%	11%	5%	34%	80
Child's Usual Source of Health Care					
Primary Care Provider	43%	7%	5%	45%	44
Epilepsy Specialist	41%	18%	6%	35%	17
Other	74%	16%	5%	5%	19
Child's Age					
6 Years Old Or Younger	20%	20%	0%	60%	10
7 - 9 Years Old	48%	11%	4%	37%	27
10 - 12 Years Old	57%	14%	0%	29%	14
13 - 15 Years Old	65%	6%	6%	24%	17
16 Years or Older	50%	8%	17%	25%	12
Current Knowledge of Epilepsy					
Very Knowledgeable	57%	9%	4%	30%	47
Some/Very Little Knowledge	39%	15%	6%	39%	33
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	50%	5%	0%	45%	22
1 - 3 Years Old	44%	16%	4%	36%	25
4 - 6 Years Old	50%	13%	0%	38%	16
7 - 9 Years Old	58%	8%	17%	17%	12
10 Years or Older	60%	20%	20%	0%	5

Q23A: In the past 6 months, did you or your family need Social and Recreational Activities?

	Yes	No	Don't Know	Number Responding
PARENTS AND CAREGIVERS - 2015	23%	70%	7%	82
Child's Usual Source of Health Care				
Primary Care Provider	29%	62%	9%	45
Epilepsy Specialist	11%	78%	11%	18
Other	21%	79%	0%	19
Child's Age				
6 Years Old Or Younger	20%	60%	20%	10
7 - 9 Years Old	26%	67%	7%	27
10 - 12 Years Old	21%	71%	7%	14
13 - 15 Years Old	33%	61%	6%	18
16 Years or Older	8%	92%	0%	12
Current Knowledge of Epilepsy				
Very Knowledgeable	22%	71%	6%	49
Some/Very Little Knowledge	24%	67%	9%	33
Age When Child Diagnosed With Epilepsy				
Less Than 1 Year Old	23%	64%	14%	22
1 - 3 Years Old	20%	76%	4%	25
4 - 6 Years Old	25%	75%	0%	16
7 - 9 Years Old	25%	67%	8%	12
10 Years or Older	33%	50%	17%	6

Q23B: Were you referred to or told where to get this service?

	Yes	No	Don't Know	We Didn't Need This Service	Number Responding
PARENTS AND CAREGIVERS - 2015	11%	56%	8%	25%	79
Child's Usual Source of Health Care					
Primary Care Provider	13%	51%	4%	31%	45
Epilepsy Specialist	6%	63%	13%	19%	16
Other	11%	61%	11%	17%	18
Child's Age					
6 Years Old Or Younger	0%	56%	22%	22%	9
7 - 9 Years Old	7%	48%	7%	37%	27
10 - 12 Years Old	0%	79%	7%	14%	14
13 - 15 Years Old	38%	44%	0%	19%	16
16 Years or Older	8%	67%	8%	17%	12
Current Knowledge of Epilepsy					
Very Knowledgeable	18%	44%	11%	27%	45
Some/Very Little Knowledge	3%	71%	3%	24%	34
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	14%	50%	9%	27%	22
1 - 3 Years Old	13%	48%	13%	26%	23
4 - 6 Years Old	6%	56%	0%	38%	16
7 - 9 Years Old	9%	91%	0%	0%	11
10 Years or Older	17%	50%	17%	17%	6

Q23C: Were you able to get this service?

	Yes	No	Don't Know	We Didn't Need This Service	Not Available in My Community	Number Responding
PARENTS AND CAREGIVERS - 2015	9%	38%	9%	41%	4%	79
Child's Usual Source of Health Care						
Primary Care Provider	9%	32%	7%	48%	5%	44
Epilepsy Specialist	0%	47%	12%	41%	0%	17
Other	17%	44%	11%	22%	6%	18
Child's Age						
6 Years Old Or Younger	0%	40%	30%	20%	10%	10
7 - 9 Years Old	4%	26%	11%	52%	7%	27
10 - 12 Years Old	7%	57%	7%	29%	0%	14
13 - 15 Years Old	33%	33%	0%	33%	0%	15
16 Years or Older	0%	50%	0%	50%	0%	12
Current Knowledge of Epilepsy						
Very Knowledgeable	11%	33%	11%	41%	4%	46
Some/Very Little Knowledge	6%	45%	6%	39%	3%	33
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	0%	36%	9%	50%	5%	22
1 - 3 Years Old	13%	33%	13%	38%	4%	24
4 - 6 Years Old	13%	31%	6%	50%	0%	16
7 - 9 Years Old	9%	55%	9%	18%	9%	11
10 Years or Older	20%	60%	0%	20%	0%	5

Q24A: My child has a written or electronic epilepsy action plan

	Yes	No	Not Sure	Number Responding
PARENTS AND CAREGIVERS - 2015	58%	34%	9%	80
Child's Usual Source of Health Care				
Primary Care Provider	58%	28%	14%	43
Epilepsy Specialist	56%	44%	0%	18
Other	58%	37%	5%	19
Child's Age				
6 Years Old Or Younger	55%	36%	9%	11
7 - 9 Years Old	62%	27%	12%	26
10 - 12 Years Old	64%	29%	7%	14
13 - 15 Years Old	72%	22%	6%	18
16 Years or Older	20%	70%	10%	10
Current Knowledge of Epilepsy				
Very Knowledgeable	67%	29%	4%	48
Some/Very Little Knowledge	44%	41%	16%	32
Age When Child Diagnosed With Epilepsy				
Less Than 1 Year Old	86%	14%	0%	22
1 - 3 Years Old	58%	33%	8%	24
4 - 6 Years Old	50%	38%	13%	16
7 - 9 Years Old	36%	55%	9%	11
10 Years or Older	17%	50%	33%	6

Q24B: I have a hard copy or access to an electronic version of my child's epilepsy action plan

	Yes	No	Not Sure	Number Responding
PARENTS AND CAREGIVERS - 2015	50%	46%	4%	82
Child's Usual Source of Health Care				
Primary Care Provider	51%	44%	4%	45
Epilepsy Specialist	50%	50%	0%	18
Other	47%	47%	5%	19
Child's Age				
6 Years Old Or Younger	60%	40%	0%	10
7 - 9 Years Old	48%	52%	0%	27
10 - 12 Years Old	57%	36%	7%	14
13 - 15 Years Old	56%	39%	6%	18
16 Years or Older	33%	58%	8%	12
Current Knowledge of Epilepsy				
Very Knowledgeable	60%	40%	0%	48
Some/Very Little Knowledge	35%	56%	9%	34
Age When Child Diagnosed With Epilepsy				
Less Than 1 Year Old	64%	36%	0%	22
1 - 3 Years Old	52%	48%	0%	25
4 - 6 Years Old	44%	56%	0%	16
7 - 9 Years Old	50%	42%	8%	12
10 Years or Older	17%	50%	33%	6

Q25: Describe your level of knowledge about epilepsy before your child was diagnosed

	Very Knowledgeable	Somewhat Knowledgeable	Very Little Knowledge	No Prior Knowledge	Number Responding
PARENTS AND CAREGIVERS - 2013	10%	28%	45%	17%	116
PARENTS AND CAREGIVERS - 2015	8%	28%	41%	23%	83
Child's Usual Source of Health Care					
Primary Care Provider	11%	28%	39%	22%	46
Epilepsy Specialist	6%	11%	56%	28%	18
Other	5%	42%	32%	21%	19
Child's Age					
6 Years Old Or Younger	9%	27%	45%	18%	11
7 - 9 Years Old	15%	30%	41%	15%	27
10 - 12 Years Old	0%	21%	57%	21%	14
13 - 15 Years Old	0%	39%	33%	28%	18
16 Years or Older	8%	17%	33%	42%	12
Current Knowledge of Epilepsy					
Very Knowledgeable	12%	27%	43%	18%	49
Some/Very Little Knowledge	3%	29%	38%	29%	34
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	5%	27%	50%	18%	22
1 - 3 Years Old	12%	31%	46%	12%	26
4 - 6 Years Old	13%	25%	31%	31%	16
7 - 9 Years Old	0%	25%	42%	33%	12
10 Years or Older	0%	33%	17%	50%	6

Q26: Describe your current level of knowledge about epilepsy

	Very Knowledgeable	Somewhat Knowledgeable	Very Little Knowledge	Number Responding
PARENTS AND CAREGIVERS - 2013	59%	38%	3%	116
PARENTS AND CAREGIVERS - 2015	59%	37%	4%	83
Child's Usual Source of Health Care				
Primary Care Provider	54%	41%	4%	46
Epilepsy Specialist	72%	28%	0%	18
Other	58%	37%	5%	19
Child's Age				
6 Years Old Or Younger	55%	36%	9%	11
7 - 9 Years Old	67%	30%	4%	27
10 - 12 Years Old	43%	57%	0%	14
13 - 15 Years Old	56%	39%	6%	18
16 Years or Older	67%	33%	0%	12
Age When Child Diagnosed With Epilepsy				
Less Than 1 Year Old	59%	41%	0%	22
1 - 3 Years Old	85%	12%	4%	26
4 - 6 Years Old	56%	38%	6%	16
7 - 9 Years Old	33%	58%	8%	12
10 Years or Older	0%	100%	0%	6

Q28A: How comfortable are you that you know what you need to about each of the following? - Basics about seizures

	Very Comfortable	Comfortable	Uncomfortable	Very Uncomfortable	Number Responding
PARENTS AND CAREGIVERS - 2015	58%	37%	4%	1%	83
Child's Usual Source of Health Care					
Primary Care Provider	50%	43%	4%	2%	46
Epilepsy Specialist	78%	22%	0%	0%	18
Other	58%	37%	5%	0%	19
Child's Age					
6 Years Old Or Younger	55%	36%	0%	9%	11
7 - 9 Years Old	52%	41%	7%	0%	27
10 - 12 Years Old	50%	50%	0%	0%	14
13 - 15 Years Old	61%	39%	0%	0%	18
16 Years or Older	75%	17%	8%	0%	12
Current Knowledge of Epilepsy					
Very Knowledgeable	80%	20%	0%	0%	49
Some/Very Little Knowledge	26%	62%	9%	3%	34
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	68%	27%	5%	0%	22
1 - 3 Years Old	69%	27%	0%	4%	26
4 - 6 Years Old	50%	50%	0%	0%	16
7 - 9 Years Old	33%	58%	8%	0%	12
10 Years or Older	33%	50%	17%	0%	6

Q28B: How comfortable are you that you know what you need to about each of the following? - How to medically care for my child or youth with epilepsy

	Very Comfortable	Comfortable	Uncomfortable	Very Uncomfortable	Number Responding
PARENTS AND CAREGIVERS - 2015	55%	41%	4%		83
Child's Usual Source of Health Care					
Primary Care Provider	54%	41%	4%		46
Epilepsy Specialist	61%	39%	0%		18
Other	53%	42%	5%		19
Child's Age					
6 Years Old Or Younger	55%	45%	0%		11
7 - 9 Years Old	63%	30%	7%		27
10 - 12 Years Old	36%	64%	0%		14
13 - 15 Years Old	56%	44%	0%		18
16 Years or Older	58%	33%	8%		12
Current Knowledge of Epilepsy					
Very Knowledgeable	73%	24%	2%		49
Some/Very Little Knowledge	29%	65%	6%		34
Age When Child Diagnosed With Epilepsy					
Less Than 1 Year Old	73%	27%	0%		22
1 - 3 Years Old	62%	38%	0%		26
4 - 6 Years Old	44%	50%	6%		16
7 - 9 Years Old	25%	67%	8%		12
10 Years or Older	50%	33%	17%		6

Q28C: How comfortable are you that you know what you need to about each of the following? - Other conditions that my child or youth has, in addition to epilepsy

	Very Comfortable	Comfortable	Uncomfortable	Very Uncomfortable	Does Not Apply	Number Responding
PARENTS AND CAREGIVERS - 2015	48%	41%	6%	2%	2%	82
Child's Usual Source of Health Care						
Primary Care Provider	57%	28%	7%	4%	4%	46
Epilepsy Specialist	29%	71%	0%	0%	0%	17
Other	42%	47%	11%	0%	0%	19
Child's Age						
6 Years Old Or Younger	60%	30%	0%	10%	0%	10
7 - 9 Years Old	48%	41%	7%	4%	0%	27
10 - 12 Years Old	36%	50%	7%	0%	7%	14
13 - 15 Years Old	50%	44%	0%	0%	6%	18
16 Years or Older	42%	42%	17%	0%	0%	12
Current Knowledge of Epilepsy						
Very Knowledgeable	53%	41%	2%	4%	0%	49
Some/Very Little Knowledge	39%	42%	12%	0%	6%	33
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	50%	50%	0%	0%	0%	22
1 - 3 Years Old	64%	28%	4%	4%	0%	25
4 - 6 Years Old	19%	75%	0%	6%	0%	16
7 - 9 Years Old	42%	33%	17%	0%	8%	12
10 Years or Older	50%	0%	33%	0%	17%	6

Survey CenterJuly, 2015

Q28D: How comfortable are you that you know what you need to about each of the following? - Helping my child prepare and move to the adult medical care system or adult care

	Very Comfortable	Comfortable	Uncomfortable	Very Uncomfortable	Does Not Apply	Number Responding
PARENTS AND CAREGIVERS - 2015	2%	24%	15%	9%	50%	66
Child's Usual Source of Health Care						
Primary Care Provider	3%	23%	8%	10%	58%	40
Epilepsy Specialist	0%	15%	38%	0%	46%	13
Other	0%	38%	15%	15%	31%	13
Child's Age						
6 Years Old Or Younger	0%	0%	0%	0%	100%	5
7 - 9 Years Old	5%	0%	5%	0%	90%	21
10 - 12 Years Old	0%	18%	27%	9%	45%	11
13 - 15 Years Old	0%	53%	18%	18%	12%	17
16 Years or Older	0%	45%	27%	18%	9%	11
Current Knowledge of Epilepsy						
Very Knowledgeable	3%	29%	21%	6%	41%	34
Some/Very Little Knowledge	0%	19%	9%	13%	59%	32
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	6%	39%	6%	6%	44%	18
1 - 3 Years Old	0%	24%	24%	0%	53%	17
4 - 6 Years Old	0%	8%	15%	8%	69%	13
7 - 9 Years Old	0%	18%	18%	18%	45%	11
10 Years or Older	0%	33%	17%	33%	17%	6

Q28E: How comfortable are you that you know what you need to about each of the following? – Understanding all of my child's medicines, what they are for and how to use/take them

	Very Comfortable	Comfortable	Uncomfortable	Very Uncomfortable	Does Not Apply	Number Responding
PARENTS AND CAREGIVERS - 2015	67%	27%	4%	1%	1%	83
Child's Usual Source of Health Care						
Primary Care Provider	67%	28%	4%	0%	0%	46
Epilepsy Specialist	72%	22%	0%	0%	6%	18
Other	63%	26%	5%	5%	0%	19
Child's Age						
6 Years Old Or Younger	64%	27%	0%	0%	9%	11
7 - 9 Years Old	78%	15%	7%	0%	0%	27
10 - 12 Years Old	71%	21%	0%	7%	0%	14
13 - 15 Years Old	56%	44%	0%	0%	0%	18
16 Years or Older	58%	33%	8%	0%	0%	12
Current Knowledge of Epilepsy						
Very Knowledgeable	80%	18%	2%	0%	0%	49
Some/Very Little Knowledge	50%	38%	6%	3%	3%	34
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	77%	23%	0%	0%	0%	22
1 - 3 Years Old	77%	15%	4%	0%	4%	26
4 - 6 Years Old	56%	44%	0%	0%	0%	16
7 - 9 Years Old	50%	33%	8%	8%	0%	12
10 Years or Older	50%	33%	17%	0%	0%	6

Q28F: How comfortable are you that you know what you need to about each of the following? - What can be done to help support my child's mental or emotional health

	Very Comfortable	Comfortable	Uncomfortable	Very Uncomfortable	Does Not Apply	Number Responding
PARENTS AND CAREGIVERS - 2015	28%	41%	16%	11%	4%	81
Child's Usual Source of Health Care						
Primary Care Provider	28%	41%	11%	15%	4%	46
Epilepsy Specialist	29%	35%	29%	0%	6%	17
Other	28%	44%	17%	11%	0%	18
Child's Age						
6 Years Old Or Younger	36%	36%	0%	18%	9%	11
7 - 9 Years Old	30%	44%	7%	15%	4%	27
10 - 12 Years Old	23%	31%	38%	8%	0%	13
13 - 15 Years Old	18%	59%	6%	12%	6%	17
16 Years or Older	33%	25%	42%	0%	0%	12
Current Knowledge of Epilepsy						
Very Knowledgeable	38%	40%	11%	9%	2%	47
Some/Very Little Knowledge	15%	41%	24%	15%	6%	34
Age When Child Diagnosed With Epilepsy						
Less Than 1 Year Old	27%	59%	5%	5%	5%	22
1 - 3 Years Old	40%	32%	8%	12%	8%	25
4 - 6 Years Old	25%	38%	25%	13%	0%	16
7 - 9 Years Old	9%	36%	36%	18%	0%	11
10 Years or Older	17%	33%	33%	17%	0%	6

Q29: Have you been given advice on where to go for more information about epilepsy?

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	61%	39%	110
PARENTS AND CAREGIVERS - 2015	59%	41%	82
Child's Usual Source of Health Care			
Primary Care Provider	64%	36%	47
Epilepsy Specialist	31%	69%	16
Other	68%	32%	19
Child's Age			
6 Years Old Or Younger	70%	30%	10
7 - 9 Years Old	63%	37%	27
10 - 12 Years Old	36%	64%	14
13 - 15 Years Old	72%	28%	18
16 Years or Older	45%	55%	11
Current Knowledge of Epilepsy			
Very Knowledgeable	72%	28%	47
Some/Very Little Knowledge	41%	59%	34
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	55%	45%	22
1 - 3 Years Old	76%	24%	25
4 - 6 Years Old	47%	53%	15
7 - 9 Years Old	50%	50%	12
10 Years or Older	50%	50%	6

Q30: Who gave you this advice?

	Primary Care Physician	Specialist	Nurse	Care Coordinator	Case Manager	Epilepsy Foundation Representative	Other	Number Responding
PARENTS AND CAREGIVERS - 2013	30%	50%	15%	14%	10%	12%	13%	119
PARENTS AND CAREGIVERS - 2015	30%	46%	14%	18%	8%	7%	10%	84
Child's Usual Source of Health Care								
Primary Care Provider	34%	49%	13%	13%	9%	9%	11%	47
Epilepsy Specialist	11%	22%	6%	6%	0%	0%	6%	18
Other	37%	63%	26%	42%	16%	11%	11%	19
Child's Age								
6 Years Old Or Younger	36%	55%	9%	9%	0%	9%	18%	11
7 - 9 Years Old	33%	48%	11%	15%	7%	4%	7%	27
10 - 12 Years Old	21%	21%	14%	21%	7%	7%	0%	14
13 - 15 Years Old	33%	61%	33%	28%	6%	11%	22%	18
16 Years or Older	17%	42%	0%	17%	17%	0%	0%	12
Current Knowledge of Epilepsy								
Very Knowledgeable	41%	57%	22%	29%	10%	10%	10%	49
Some/Very Little Knowledge	15%	32%	3%	3%	6%	3%	9%	34
Age When Child Diagnosed With Epilepsy								
Less Than 1 Year Old	27%	50%	18%	23%	9%	9%	9%	22
1 - 3 Years Old	38%	58%	19%	27%	4%	4%	19%	26
4 - 6 Years Old	25%	31%	6%	6%	6%	13%	6%	16
7 - 9 Years Old	25%	33%	17%	17%	8%	0%	0%	12
10 Years or Older	17%	50%	0%	0%	17%	0%	0%	6

Q31: If you have been given information, what types were given?

	Newly Diagnosed Toolkit	Website Information	Pamphlets/ Brochures	Fact Sheets	Videos	Books	Other	Number Responding
PARENTS AND CAREGIVERS - 2013	12%	45%	51%	39%	12%	20%	5%	119
PARENTS AND CAREGIVERS - 2015	6%	33%	39%	31%	7%	13%	4%	84
Child's Usual Source of Health Care								
Primary Care Provider	9%	38%	45%	34%	9%	15%	4%	47
Epilepsy Specialist	0%	17%	17%	11%	6%	6%	6%	18
Other	5%	37%	47%	42%	5%	16%	0%	19
Child's Age								
6 Years Old Or Younger	0%	36%	36%	36%	18%	18%	9%	11
7 - 9 Years Old	4%	26%	33%	30%	0%	11%	4%	27
10 - 12 Years Old	7%	21%	29%	14%	0%	0%	0%	14
13 - 15 Years Old	17%	61%	61%	50%	22%	28%	6%	18
16 Years or Older	0%	17%	33%	17%	0%	8%	0%	12
Current Knowledge of Epilepsy								
Very Knowledgeable	8%	39%	45%	43%	8%	14%	4%	49
Some/Very Little Knowledge	3%	26%	32%	15%	6%	12%	3%	34
Age When Child Diagnosed With Epilepsy								
Less Than 1 Year Old	9%	41%	36%	36%	14%	23%	5%	22
1 - 3 Years Old	0%	38%	46%	42%	8%	12%	8%	26
4 - 6 Years Old	13%	13%	25%	13%	0%	0%	0%	16
7 - 9 Years Old	0%	25%	42%	25%	8%	8%	0%	12
10 Years or Older	17%	50%	50%	17%	0%	33%	0%	6

Q32: Do you go online to get information on epilepsy?

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	42%	58%	116
PARENTS AND CAREGIVERS - 2015	73%	27%	84
Child's Usual Source of Health Care			
Primary Care Provider	66%	34%	47
Epilepsy Specialist	83%	17%	18
Other	79%	21%	19
Child's Age			
6 Years Old Or Younger	82%	18%	11
7 - 9 Years Old	67%	33%	27
10 - 12 Years Old	86%	14%	14
13 - 15 Years Old	72%	28%	18
16 Years or Older	67%	33%	12
Current Knowledge of Epilepsy			
Very Knowledgeable	82%	18%	49
Some/Very Little Knowledge	62%	38%	34
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	82%	18%	22
1 - 3 Years Old	69%	31%	26
4 - 6 Years Old	63%	38%	16
7 - 9 Years Old	75%	25%	12
10 Years or Older	83%	17%	6

Q36: Do you have adequate private and/or public insurance to pay for needed services?

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	89%	11%	114
PARENTS AND CAREGIVERS - 2015	91%	9%	81
Child's Usual Source of Health Care			
Primary Care Provider	93%	7%	46
Epilepsy Specialist	78%	22%	18
Other	100%	0%	17
Child's Age			
6 Years Old Or Younger	73%	27%	11
7 - 9 Years Old	89%	11%	27
10 - 12 Years Old	92%	8%	13
13 - 15 Years Old	100%	0%	17
16 Years or Older	100%	0%	11
Current Knowledge of Epilepsy			
Very Knowledgeable	91%	9%	47
Some/Very Little Knowledge	91%	9%	33
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	86%	14%	22
1 - 3 Years Old	88%	12%	25
4 - 6 Years Old	94%	6%	16
7 - 9 Years Old	100%	0%	10
10 Years or Older	100%	0%	6

Q38: Do you need respite care services for your child?

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	55%	45%	109
PARENTS AND CAREGIVERS - 2015	52%	48%	83
Child's Usual Source of Health Care			
Primary Care Provider	53%	47%	47
Epilepsy Specialist	44%	56%	18
Other	56%	44%	18
Child's Age			
6 Years Old Or Younger	64%	36%	11
7 - 9 Years Old	48%	52%	27
10 - 12 Years Old	38%	62%	13
13 - 15 Years Old	67%	33%	18
16 Years or Older	50%	50%	12
Current Knowledge of Epilepsy			
Very Knowledgeable	50%	50%	48
Some/Very Little Knowledge	56%	44%	34
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	68%	32%	22
1 - 3 Years Old	48%	52%	25
4 - 6 Years Old	44%	56%	16
7 - 9 Years Old	50%	50%	12
10 Years or Older	50%	50%	6

Q39: Have you received respite care services for your child?

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	72%	28%	68
PARENTS AND CAREGIVERS - 2015	81%	19%	43
Child's Usual Source of Health Care			
Primary Care Provider	84%	16%	25
Epilepsy Specialist	63%	38%	8
Other	90%	10%	10
Child's Age			
6 Years Old Or Younger	71%	29%	7
7 - 9 Years Old	100%	0%	13
10 - 12 Years Old	80%	20%	5
13 - 15 Years Old	67%	33%	12
16 Years or Older	83%	17%	6
Current Knowledge of Epilepsy			
Very Knowledgeable	83%	17%	24
Some/Very Little Knowledge	79%	21%	19
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	87%	13%	15
1 - 3 Years Old	83%	17%	12
4 - 6 Years Old	86%	14%	7
7 - 9 Years Old	83%	17%	6
10 Years or Older	33%	67%	3

Q40: How often do you use respite care?

	Often	Sometimes	Used Once	Number Responding
PARENTS AND CAREGIVERS - 2013	48%	42%	10%	48
PARENTS AND CAREGIVERS - 2015	47%	50%	3%	34
Child's Usual Source of Health Care				
Primary Care Provider	43%	57%	0%	21
Epilepsy Specialist	75%	25%	0%	4
Other	44%	44%	11%	9
Child's Age				
6 Years Old Or Younger	50%	50%	0%	4
7 - 9 Years Old	38%	54%	8%	13
10 - 12 Years Old	75%	25%	0%	4
13 - 15 Years Old	25%	75%	0%	8
16 Years or Older	80%	20%	0%	5
Current Knowledge of Epilepsy				
Very Knowledgeable	47%	47%	5%	19
Some/Very Little Knowledge	47%	53%	0%	15
Age When Child Diagnosed With Epilepsy				
Less Than 1 Year Old	33%	58%	8%	12
1 - 3 Years Old	60%	40%	0%	10
4 - 6 Years Old	33%	67%	0%	6
7 - 9 Years Old	80%	20%	0%	5
10 Years or Older	0%	100%	0%	1

Q41A: Are you familiar with the following statewide resources? -Special Medical Services

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	75%	25%	114
PARENTS AND CAREGIVERS - 2015	78%	22%	81
Child's Usual Source of Health Care			
Primary Care Provider	82%	18%	45
Epilepsy Specialist	72%	28%	18
Other	72%	28%	18
Child's Age			
6 Years Old Or Younger	73%	27%	11
7 - 9 Years Old	70%	30%	27
10 - 12 Years Old	77%	23%	13
13 - 15 Years Old	89%	11%	18
16 Years or Older	82%	18%	11
Current Knowledge of Epilepsy			
Very Knowledgeable	90%	10%	48
Some/Very Little Knowledge	61%	39%	33
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	95%	5%	22
1 - 3 Years Old	88%	12%	26
4 - 6 Years Old	53%	47%	15
7 - 9 Years Old	58%	42%	12
10 Years or Older	60%	40%	5

Q41B: Are you familiar with the following statewide resources? -Partners in Health

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	73%	27%	112
PARENTS AND CAREGIVERS - 2015	67%	33%	78
Child's Usual Source of Health Care			
Primary Care Provider	68%	32%	44
Epilepsy Specialist	76%	24%	17
Other	53%	47%	17
Child's Age			
6 Years Old Or Younger	44%	56%	9
7 - 9 Years Old	59%	41%	27
10 - 12 Years Old	57%	43%	14
13 - 15 Years Old	88%	12%	17
16 Years or Older	80%	20%	10
Current Knowledge of Epilepsy			
Very Knowledgeable	72%	28%	47
Some/Very Little Knowledge	58%	42%	31
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	75%	25%	20
1 - 3 Years Old	62%	38%	26
4 - 6 Years Old	69%	31%	16
7 - 9 Years Old	50%	50%	10
10 Years or Older	80%	20%	5

Q41C: Are you familiar with the following statewide resources? -NH Family Voices

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	72%	28%	108
PARENTS AND CAREGIVERS - 2015	70%	30%	80
Child's Usual Source of Health Care			
Primary Care Provider	80%	20%	45
Epilepsy Specialist	72%	28%	18
Other	41%	59%	17
Child's Age			
6 Years Old Or Younger	64%	36%	11
7 - 9 Years Old	74%	26%	27
10 - 12 Years Old	57%	43%	14
13 - 15 Years Old	75%	25%	16
16 Years or Older	70%	30%	10
Current Knowledge of Epilepsy			
Very Knowledgeable	81%	19%	48
Some/Very Little Knowledge	52%	48%	31
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	71%	29%	21
1 - 3 Years Old	77%	23%	26
4 - 6 Years Old	75%	25%	16
7 - 9 Years Old	40%	60%	10
10 Years or Older	60%	40%	5

Q41D: Are you familiar with the following statewide resources? -Area Agency/Developmental Services

	Yes	No	Number Responding
PARENTS AND CAREGIVERS - 2013	72%	28%	107
PARENTS AND CAREGIVERS - 2015	81%	19%	79
Child's Usual Source of Health Care			
Primary Care Provider	91%	9%	43
Epilepsy Specialist	78%	22%	18
Other	61%	39%	18
Child's Age			
6 Years Old Or Younger	82%	18%	11
7 - 9 Years Old	85%	15%	26
10 - 12 Years Old	54%	46%	13
13 - 15 Years Old	89%	11%	18
16 Years or Older	90%	10%	10
Current Knowledge of Epilepsy			
Very Knowledgeable	92%	8%	48
Some/Very Little Knowledge	65%	35%	31
Age When Child Diagnosed With Epilepsy			
Less Than 1 Year Old	95%	5%	21
1 - 3 Years Old	81%	19%	26
4 - 6 Years Old	87%	13%	15
7 - 9 Years Old	55%	45%	11
10 Years or Older	60%	40%	5

Appendix B: Open-Ended Responses

Q1: Who is your child's main or usual source of health care? (Other – specify)

- neurologist
- Neurologist of Neurosurgery
- PCP / Specialist
- PCP / Specialist
- PCP / Specialist
- PCP / Specialist
- PCP / Specialist in epilepsy / Other specialist
- PCP / We see a Dr. in Lebanon, NH
- PCP & Specialist
- PCP/ Neurologist
- PCP/ Specialist
- PCP/ Specialist
- PCP/ Specialist
- PCP/ Specialist (Neurologist)
- PCP/ Specialist/ Neurologist
- PCP/ Specialist/ Ortho/ Endro
- Specialist/ Gastroenterologist
- team in Boston

Q4: We would like to know if your child has medical home. (If other than main or usual source of care – where is it?)

- Community Bridges
- Community Bridges
- Complete care team. Boston Children's Hospital.
- Complex care services at Boston Children's? Not sure if that counts.
- Early Intervention
- MGH/ MEEI
- Neuromotor Clinic in Derry, NH. Monarch School in Rochester, NH helps too.

Q10: Describe any difficulty you may have experienced locating an epilepsy specialist for your child:

- Anna needs care at Boston Children's - Meo will have to continue. "illegible" a she will deteriorate.
- Boston too hard to get to with three little ones; husband can't get time off from work.
- Distance
- Distance
- Distance: 1 Hour
- Don't own a car/ transportation is difficult
- Haven't found one closer to home Nashua, NH
- Her doctors have been good about referring us to good neurologist and helping us get the appointments
- I haven't. I've had one since my son was 18 months old.

- [illegible]

Q18: What fears or concerns do you have now concerning your child's epilepsy?

- Academics

- After tons of meds and 2 surgeries it is still uncontrolled
- Behavioral issues, delayed developmentally and learning issues/social.
- Changes in seizures that occur as my child grows older and goes through puberty. Sudden death.
- Control, Damage done
- Developmental delays - communication needs
- Falling accidents due to dro seizures
- Fear that it will worsen as she grows. People don't monitor - unless its a "Hollywood Seizure"
- Fear that she will never have her seizures in control. Concerns on her learning and development
- Getting worse
- Hasn't had on in during day for 5 or 6 years but doctors say he has night ones
- He is more aware of it - challenges with pears, depression
- I don't have any because my son's epilepsy is under control.
- I don't see any problem
- I fear the drugs he'll be on for the rest of his life, as they can damage liver/ kidneys
- I want to start weaning him off meds but am scared seizures will start again after nothing for over 3 years.
- I worry for her safety and for her future.
- If he still really has it
- If she will outgrow it.
- Just if he has a seizure he will have it while sleep and then pass away
- Long term medication side effects
- Managing medication as he grows
- MCO
- Medication side effects
- Medication side effects
- Mostly controlled by medication
- My son has Lennox-Gastaut syndrome one of the rarest most debilitating forms of epilepsy, what "fears and concerns" don't I have.
- N/A
- No fear related to epilepsy - fear is state of NH won't let us continue to see our neurologist at Children's Boston!!
- none
- None
- None
- None
- None
- None
- None
- None
- None
- None
- None - well controlled
- None at the moment

- None currently
- Ongoing concerns about medication side effects
- Puberty
- Quality of life, death
- Recent EEG (4 weeks ago) is showing my son is seizing the whole time he sleeps. He may need an 8 week treatment with steroids. Possible ESES. Very scared he may have permanent damage
- Seizures
- Self-dependency, medication
- SUDEP, intractable epilepsy
- Swimming, standing, transportation
- Taking care herself
- That he may never grow out of them (seizures)
- That he will always have it.
- That it will worsen
- That it won't be well controlled. That it will have a negative impact on the child's quality of life.
- That she stays stable and not have seizures
- the medication and side effects
- The neuro putting Owen on new meds and not communicating when there's an issue.
- The side effects of the drugs
- Transition to adult services
- What are long term side effects to brain will she have.
- When will his next seizure be?
- Wonder if she will outgrow now that major growth spurt is over.
- Worsening? Seizures vs Dystonia?

Q27: If you have a better understanding now, how did you get the information you needed?

- Books, doctors, teachers
- Classes, books, internet, daily living with three children with epilepsy
- Courses, Parents, Doctors
- doctors
- Doctors and web search and other research/ reading on my own.
- Doctors office, internet
- Doctors, nurses, medical staff explained to me.
- Doing my own research and speaking with various doctors
- Dr. Filiano
- Epilepsy Specialist
- Experience. Reading and got info from my daughter's neurologist.
- Family
- First, learning to know my son. How he was acting when he was under a seizure. Then from the neurologist and final looking for it on internet.
- Friends with children with epilepsy and internet.

- From her new specialist in Leb. Internet
- Google and Facebook groups
- Had and Ex-boyfriend with epilepsy so I knew a little from him.
- Her neonatal neurologist spent an hour talking to us before he transferred her care to an epilepsy specialist. Her specialist is always available by email for any questions. I have also done a lot of research on my own.
- His neurologist gave me a website and links to some articles about his specific epilepsy and he gave me articles that could help with some problems resulting from it.
- Hospital
- I attended seminars put on by DHMC
- I found conferences to go to. I looked up information on the internet.
- I sought some of it out independently (Books) and was also educated by my son's neurologist.
- Information from neurologist, research myself, attended info session given by a neurologist.
- Internet
- Internet
- Internet and support groups, articles, medical websites.
- Internet research
- Internet- independent research on epilepsy.
- Learned myself
- Learned over the years
- Life experiences
- Living it with my daughter, years of experience, first hand.
- My brother, my son's uncle has epilepsy
- My own research
- My own research - appointment visits
- My own research - appointment visits
- N/A
- N/A
- New England Epilepsy Foundation, information after each Dr. visit.
- None
- On hands, books, doctors.
- Online or books, people here and there who have the same needs.
- Online, google and books
- Other patients or doctors
- Reading, research and education from doctors
- Research, doctors, videos, books, various websites
- Research, lived experience, reading rec. books from neuro team, talking and reading blogs of adults living with epilepsy.
- Research, questions, on the job training
- RN
- Self-research and working with specialists
- Self-taught research

- Support groups, School of hard knocks - living with it! My own research/ reading.
- Support/ computer/ doctor
- Through Dartmouth Hitchcock Lebanon, NH
- Through epileptic doctor and reading
- Through experience, support groups, research and talking to doctors
- Through research/ doctors
- Through research/ doctors
- Through the doctors, nurses, social workers, agencies and internet
- Took some classes, read a lot, and daily life of 3 children with epilepsy
- We have an even better understanding now that she has a specific diagnosis, only as of last year.
- workshops, literature, doctors
- Years of talking with doctors and learning on my own through research.
- Yes - Internet or books
- yes, web

Q30: Who gave this advice? (Other – Specify)

- Dravet.org
- Internet
- Mailings
- Online
- Parents
- Partners In Health Program NH Family Voice
- PCDH19 Alliance
- WDH Dover

Q31: If you have been given information, what types were given?

- Access to effective medication from other parents due to the nature of the epilepsy.
- Blogs, research articles.
- Seminar Info

Q33: What websites do you visit?

- all different
- any
- Any
- Any - support groups. Google search engine
- different medical sites from google
- Don't remember
- Dravet.org, Drugs.com, Charlotte's web
- Epilepsy Forums - medical websites
- Epilepsy forums, medical websites
- Epilepsy Foundation

- Epilepsy Foundation
- Epilepsy Foundation
- Epilepsy Foundation
- Epilepsy Foundation
- Epilepsy Foundation
- Epilepsy Foundation
- Epilepsy Foundation, Cerebral Folate deficiency sites
- Epilepsy Foundation, googled it
- Epilepsy foundation, groups on Facebook.
- Epilepsy Foundation, LGS website.
- epilepsy.com
- epilepsy.com
- Epilepsy.com
- Epilepsy.com
- Epilepsy.com, Epilepsynewengland.org
- Epilepsy.com, ninds.nih.gov, caring.com, mayoclinic.org
- epilepsy.org
- epilepsyfoundation.org
- google
- Google, Epilepsy Foundation
- Google, then to sites from Johns Hopkins on other med centers
- Googled different sites
- I google the information I'm looking for - usually medications
- I have looked at the Epilepsy Foundation
- Just I visited one, some time ago. It was epilepsy.com. Like I told you my son's seizures are under control, for that reason I did not check more pages of website.
- Lennox G
- Many - google
- Mayo Clinic, NINDS, Epilepsy Foundation and local support groups via Facebook.
- MD. com
- Medical journals, Ep. Foundation, the bump special needs board, special Facebook groups, treatment - related websites, services available locally - e.g. Swing For the Stars.
- PCDH19 Alliance, FB parent support group
- Special needs parents eparent.com
- Support groups, drug websites, WebMD, articles, emedicine.
- Too many to list
- too many to list/ remember
- unknown
- Up to Date
- Usually the epilepsy foundation site.
- various

- Web MD
- WebMD
- WebMD and other sites I am directed to.
- WebMD, Google.
- Q34: What school services are available for your child?
504 Care Plan
- 504 Plan
- all we need
- All. He'll be in school until 21 years of age. Speech, Physical.
- Basic - OT, PT, Speech, Vision
- BCBA, OT
- Case manager, IEP, transition and voc. aide.
- College level wrap around
- College level wrap around
- Don't know
- Don't know
- Epilepsy Foundation
- Has 1 on 1 aide/ nurse with him throughout the day.
- He gets special ed services. IEP
- He has an IEP, he gets speech, OT, teacher of the deaf, ABA, discrete trials.
- He has an IEP that includes speech and occupational therapy. He also gets extra help with math and reading.
- He is currently enrolled in a special preschool.
- Home based. All therapies
- Home placement; 10.5 hours of services a week; OT, PT, Speech, RT, music therapy, and tutoring.
- IED, wheelchair bus, nurse
- IEP - OT, Reading and math
- IEP is all we utilize
- IEP, 1 on 1, staff trained for my daughters E.A.P, OT, PT, Speech, diaper change.
- IEP, global delays, orthopedic impairment, blind visions services, PT, OT, SLP, orientation and mobility services
- IEP, nursing services, school aides (teacher helpers)
- IEP, OT, Speech, PT
- IEP, Paraprofessional, PT, OT, Speech, vocational program, sped classroom
- IEP, related services -> OT, Speech
- IEP, speech, PT, OT, 1:1 para
- Illegible, possibly "Nurses" of epilepsy? Ain RN
- IP, OT, Speech
- Liah sees a vision specialist and mobility specialist. Liah also has an ISP
- MMSC Service, SLP, OT, PT, Special education
- Music therapy and PT, OT, and speech therapy
- My son goes to his school every day full time and there he has OT PT vision speech and music therapies plus art and some rides on his wheelchair.

- My son has and IEP and his own "Para"
- N/A
- NA
- None, PT/ OT is home-based
- Not much and requires lots of follow-up.
- Not sure
- Not sure they have any.
- Nurse-emergency plan, OT and PT for cp, guidance counselor
- One on one support, nursing, speech, pt, ot, special educator.
- one on one, nurse
- OT, PT, SLP, BCBA
- OT, PT, SLP, BCBA, Vision
- OT, PT, Speech (no longer needed), Tvl, Orientation and mobility
- OT, PT, speech, special needs program, 1:1, IEP
- OT, PT, Speech, Vision, Hippo Therapy, Behavioral Specialist Therapy, nurse 24/7 at school
- OT/PT, Speech, 'Illegible'
- Physical Therapy, one on one aide, OT, speech
- Pre-school, OT, PT, Speech
- PT, OT and speech
- PT, OT, Para (LNA), SL, Reading Specialist
- PT, OT, Speech, 1:1 para educator
- PT, OT, Speech, Adaptive Sports Programs
- PT, OT, Speech, Vision Therapy, Nurse Therapy
- PT/OT/Speech/Vision/ Teacher/Nursing
- Public
- School nurse
- She has recently been relocated to a school for special needs children
- Spec Ed School
- Spec Ed, OT, Speech
- Special Aid, 1 on 1, hearing/ seeing, physical therapy, occupational therapy
- Special Ed through public school
- Speech path and to get info about what's available. School aide, communication supports, OT/PT.
- Speech services, the Laura Mahoney Autism and Epilepsy Foundation
- Speech, IEP
- Speech, OT, mini bus.
- Speech/OT/PT/1:1 aid
- TOD, ST, PT, OT, TUI
- too young; does have early intervention services though
- We homeschool - but our son is IEP eligible
- What he is receiving

Q35: Are there additional services you feel your child needs?

- "Sports" - that are not physically exerting (no running, no hyperventilating involved), she rides horses. Help with lessons would be nice.
- AAC training
- Academic help, behavior plan
- Always want more services to provide him with the best opportunity
- an education
- Don't know
- Emotional support - help processing emotions and feeling.
- Expanded day services
- General life skills
- He was getting one additional speech therapy outside of school, but his insurance denied that last summer.
- I feel she is very well covered.
- I wish she could qualify for hippo therapy (horseback riding for disabled)
- More help with academics
- More help with college academics
- N/A
- no
- no
- no
- No
- No
- No
- No
- No
- No
- No
- No
- No
- No
- No
- No
- No
- No
- No
- NO
- NO
- No - but the #!@\$ door with the auto open button need to actually work - broken for weeks - hard to actually get into school!!

- No for now
- No, not anymore
- No. But I want to say, I had to hire a lawyer and fight the school for 1 year just to get the services he's getting now.
- none
- not at this time
- Not at this time
- Not at this time
- Not at this time
- Not at this time
- Not currently
- Not really. College planning is a future concern.
- Not right now
- Nursing!!! Approved hours but no nurses available! Filling out paperwork for residential respite now. :(
- Outside of school P.T
- Planning for transition to independent living and supportive housing
- recreational activities
- Sometimes
- speech and swallow feeding
- Support for after school activities
- Therapeutic Therapies - aqua therapy, hippo therapy.
- Tutor, social structure with kids like him
- Tutor, Social structure with others like him.
- Yes - home PT and feeding and swallowing
- Yes but she might be getting soon SL
- Yes, SS disability and maybe Katie Beckett, but don't have time to do.
- Yes. Afterschool activities
- Yes. MNRI

Q37: Please share what services you need help paying for:

- Afterschool Activities, Summer programs
- Childcare since she needs specialized care when I'm at work.
- co-pays for therapy
- Cost of care
- Currently none
- Diapers, Pediasure, equipment to paid for by insurance
- Extra-curricular activities - that are "fun" not overly exerting - summer camps
- Extra nursing care sometimes
- Gas, Mileage, Tows
- gas/ mileage
- I am able to use flexible spending account for extra medical expenses

- I don't have any
- I often shy away from sending her to camp because she needs someone with her at all times.
- Medicaid well sense
- Medication
- Medication not covered by insurance
- medications, copays
- NA
- None
- None
- None
- None
- None at this time.
- Recreational activities and developmentally appropriate toys.
- Respite
- Swim therapy - although our place just closed - cited poor reimbursement
- Training my son's service dog
- Traveling back and forth to Lebanon, Medical - My insurance covers 60%. EEG/ overnight cost \$400.00 (out of pocket)
- Trips to Lebanon Hospital \$400. Out of pocket each time. Each visit day out of work. Refill scripts regularly.

Q42: What other services are available to help you and your child?

- ? I Don't know?
- ? LNA services through insurance.
- 'Illegible'
- ABA!
- Adaptive Sports Partners of the North Country
- All I know about is what community partners tells me and all that is is respite.
- Clinical social worker
- Community Bridges
- Community Bridges
- Community Bridges
- Connections made through support group
- Don't know
- Don't know
- Easter Seals - PT and speech services
- Gateways is working with us to help my son for the transitioning to an adult at home.
- good question
- Horse therapy
- I don't know
- I don't know
- Liah was set up with Partners in Health and has the Katy Becket Medicaid

- Money to help pay for a 24/7 caregiver if she was to go to after school care.
- NA
- NH DHHS Post-adoption services, Special Olympics
- none
- none
- None
- None
- None
- None
- None
- None that I know of
- None that I know of
- None; no family help; child too difficult
- Not sure
- Not sure
- Not sure what else is available in NH for us.
- P.I.C
- Parent information center
- Parent information center!
- Pathways
- Pediatric Advanced Care Team (PACT), palliative care from BCH
- River Center
- School and afterschool program
- Special medical services
- Special Olympics
- Unsure
- We are part of Medicaid's In-Home Support Waiver through Gateways
- We are using work opportunities to help with finding a job/ career path.
- We have an In-Home Support Waiver through Gateways/ Medicaid
- We have private duty nursing care.
- Who knows? Not enough time in a day to figure it out.
- Zebra Crossing, Dover NH

Q43: What other services are needed?

- A service dog, I bought a golden doodle to train as a service dog but I can't find the funding.
- ABA in the school
- ABA Therapy!
- Academic support
- Academic support
- An equipment company that doesn't completely suck. ATECH is seriously the worst company ever and negligent in what they do. They made a design that threatened the life of my child - hat everyone there.

- As a single parent I could use help finding services, filling out forms, and finding/ paying for appropriate childcare when I'm at work.
- Better transportation
- connections with other families
- Connections with other families
- Eventually in the near future Medicaid will not be paying for some of the prescriptions that my daughter uses. Last year they stopped paying for her Miralax and soon they will stop paying for her Pediasure which is her only source of nutrition. She is unable to chew food and uses Pediasure for nutritional value. I fear soon they will not pay for her diapers either. Both products are very expensive. Many families will need help.
- family - recreational activities
- Funding for DME
- Having a hard time looking for an LNA to come for morning home care. Went through one company last year but now they don't have anyone available.
- Help Meo coverage for Anna Rithie
- Home PT and feeding
- I don't think so that now we need something extra. We're ok now.
- I'm not sure
- Maybe support for how to help siblings deal with epilepsy
- Medical home.
- More nursing hours and available skilled nurses. There is a shortage of nurses to cover the hours we already have, so many go unused.
- More research into her specific epilepsy - ESES. There's not a lot of protocol and not many studies done.
- More respite or funds so someone else can be with my child 24/7 if she was to go to camp or other summer activity.
- More social/ support groups in this area
- NA
- none
- None
- None
- None
- None
- None
- None
- None
- None
- None
- none at this time
- None at this time
- None at this time
- None at this time.
- None, but consistent care and area agency would be helpful.
- None, really request now

- Not aware of any. We are in the process of changing Neurologist from Dr. Coulter at Children's to Dr. Filiano Dartmouth whom we had in the past.
- Not sure, EI does help but need more in-home care.
- Nursing!!! Home care nurses need to be paid more to draw more into the field.
- One on one LNA services that can be used outside the home, in the community, etc.
- Reflex Neuro Integration
- Respite - no services or respite for epilepsy when I could really use a night sleep. His seizures occur during the night - I haven't slept more than 4 hours in over 1 month. Exhausted and no help.
- Respite or day care for special needs child. No qualified for ABA services. Help us!
- Supportive housing
- We need more help with school IEP that doesn't cost a lot or you need to wait forever to get help.
- We will continue to need nursing services throughout his life

Appendix C: Survey Instrument

FACETS Parent Survey 2015

Q1. Who is your child's main or usual source of health care?

- ☐ A Primary care provider (ex. a pediatrician, general practitioner, family physician, nurse practitioner, physician's assistant)
- ☐ A Specialist in epilepsy
- ☐ My child does not have a main or usual source of health care
- ☐ Other (please specify) _____

Q2. When you think about the place where your child gets specialty care (with a neurologist or epilepsy specialist) and where your child gets primary care (such as check-ups of sick visits), what is available in each place? **(Check all that apply)**

	Available at specialist	Available at primary care provider	Not available
Help with making appointments and getting referrals or authorizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A care coordination plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
An epilepsy action plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Suggestions of community services for my child or family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with transportation, insurance forms, or other financial needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information I need to take care of my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q3. How often is each of the following true about your child's main or usual source of health care?

	Never	Sometimes	Often	Always	Don't Know/ Doesn't Apply
My child's main or usual source of health care and I work together as partners to make health care decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A care coordination plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
An epilepsy action plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information I need to take care of my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q4. We would like to know if your child has a medical home.

A medical home is a place where the health care team works as partners with a child and a child's family.

At a medical home, the medical and non-medical needs of the child are met.

- ☐ Yes, and it is my child's main or usual source of health care
- ☐ Yes, and it is someplace other than my child's main or usual source of health care (Where is it? _____)
- ☐ No, my child does not have a medical home

The next questions are about your child's main source of epilepsy care. This may or may not be the same as your child's main or usual source of health care. Answer the questions thinking about your child's main source of epilepsy care.

Q5. My child's main source of epilepsy care gives me ways to learn more about helping my child be healthy and grow. For example she/he gives me things to read, tells me about classes, or connects me with other opportunities in my community. ☐ Yes ☐ No

Q6. How often does your child's main source of epilepsy care call to see if you (your child) used a recommended service or program?
☐ Never ☐ Sometimes ☐ Often ☐ Always

Q7. Does your child see an epilepsy specialist? ☐ Yes ☐ No -> SKIP TO Q16

Q8. Does your child's specialist communicate with your child's primary care provider? ☐ Yes ☐ No ☐ Don't Know

Q9. Thinking about your child’s epilepsy specialist, how much do you agree or disagree with the following statements?

	Strongly Agree	Agree	Disagree	Strongly Disagree
My child’s epilepsy specialist listens carefully to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child’s epilepsy specialist makes it easy for me to ask questions or raise concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q10. Describe any difficulty you may have experienced locating an epilepsy specialist for your child:

Q11. How often do you travel to see your child’s specialist?

- ☐ Once or Twice a Week
 ☐ Once or Twice a Month
 ☐ Once Every 2-3 Months
- ☐ Once or Twice a Year
 ☐ Less Often
 ☐ Depends

Q12. How far do you travel to see your child’s specialist?

- ☐ Less than 25 Miles
 ☐ 26-50 Miles
 ☐ 51-75 Miles
- ☐ 76-100 Miles
 ☐ More than 100 Miles

Q13. Do you limit appointments to the specialist because of how far you have to travel? ☐ Yes ☐ No

Q14. Have you had a need to see the specialist quickly/schedule an urgent appointment? ☐ Yes ☐ No ->SKIP TO Q16

Q15. The last time you needed an urgent appointment, how long did you have to wait?

- ☐ Got An Appointment That Day
 ☐ The Next Day
 ☐ 2 Days
 ☐ 3 or More Days

Q16. At what age was your child first diagnosed with epilepsy? _____
 Q17. How old is your child now? _____

Q18. What fears or concerns do you have now concerning your child’s epilepsy?

Q19. Has your specialist talked about: (If your child is younger than 16, or has no specialist, SKIP TO Q20)

	Yes	No
Your child independently managing his/her health care?	<input type="checkbox"/>	<input type="checkbox"/>
Transitioning to an adult neurologist in the future?	<input type="checkbox"/>	<input type="checkbox"/>
Issues related to adolescence/young adulthood and epilepsy?	<input type="checkbox"/>	<input type="checkbox"/>

Q20.

Family Support and/or Epilepsy Groups	Yes	No	Don’t Know	We Didn’t Need This Service	Not Available in My Community
In the past 6 months, did you or your family need Family Support and/or Epilepsy Groups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Were you referred to or told where to get this service?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Were you able to get this service?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q21.

Transportation to Medical Appointments	Yes	No	Don't Know	We Didn't Need This Service	Not Available in My Community
In the past 6 months, did you or your family need Transportation to Medical Appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Were you referred to or told where to get this service?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Were you able to get this service?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q22.

Education Support and Access	Yes	No	Don't Know	We Didn't Need This Service	Not Available in My Community
In the past 6 months, did you or your family need Education Support and Access (such as assistance with an individualized education program [IEP] or an education aide)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Were you referred to or told where to get this service?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Were you able to get this service?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q23.

Social and Recreational Activities	Yes	No	Don't Know	We Didn't Need This Service	Not Available in My Community
In the past 6 months, did you or your family need Social and Recreational Activities (such as special programs for children and youth with epilepsy)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Were you referred to or told where to get this service?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Were you able to get this service?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Again, thinking about your child with epilepsy...

Q24.

	Yes	No	Not Sure
My child has a written or electronic epilepsy action plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a hard copy or access to an electronic version of my child's epilepsy action plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q25. Describe your level of knowledge about epilepsy before your child was diagnosed?

- ☐ Very Knowledgeable
- ☐ Somewhat Knowledgeable
- ☐ Had Very Little Knowledge of Epilepsy
- ☐ Had No Prior Knowledge of Epilepsy

Q26. Describe your current level of knowledge about epilepsy?

- ☐ Very Knowledgeable
- ☐ Somewhat Knowledgeable
- ☐ Very Little Knowledge

Q27. If you have a better understanding now, how did you get the information you needed?

Q28. How comfortable are you that you know what you need to about each of the following?

	Very Comfortable	Comfortable	Uncomfortable	Very Uncomfortable	Does Not Apply
Basics about seizures (ex. what a seizure is, types of seizures, what to do when a seizure occurs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How to medically care for my child or youth with epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other conditions that my child or youth has, in addition to epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(IF CHILD IS 12 or OLDER) Helping my child prepare and move to the adult medical care system or adult care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Understanding all of my child’s medicines, what they are for and how to use/take them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What can be done to help support my child’s mental or emotional health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q29. Have you been given advice on where to go for more information about epilepsy? ☐ Yes ☐ No ->SKIP TO Q32

Q30. Who gave you this advice?
(Check all that apply)
☐ Primary Care Physician
☐ Specialist
☐ Nurse
☐ Care Coordinator
☐ Case Manager
☐ Epilepsy Foundation Representative
☐ Other (Specify) _____

Q31. If you have been given information, what types were given?
(Check all that apply)
☐ Newly Diagnosed Toolkit
☐ Website Information
☐ Pamphlets/Brochures
☐ Fact Sheets
☐ Videos
☐ Books
☐ Other (Specify) _____

Q32. Do you go online to get information on epilepsy? ☐ Yes ☐ No ->SKIP TO Q34

Q33. What websites do you visit?

Q34. What school services are available for your child?

Q35. Are there additional services you feel your child needs?

Q36. Do you have adequate private and/or public insurance to pay for needed services? ☐ Yes ☐ No ->SKIP TO Q38

Q37. Please share what services you need help paying for:

Q38. Do you need respite care services for your child? ☐ Yes ☐ No ->SKIP TO Q41

Q39. Have you received respite care services for your child? ☐ Yes ☐ No ->SKIP TO Q41

Q40. How often do you use respite care? ☐ Often ☐ Sometimes ☐ Used Once

Q41. Are you familiar with the following statewide resources?

	Yes	No
Special Medical Services	<input type="checkbox"/>	<input type="checkbox"/>
Partners in Health	<input type="checkbox"/>	<input type="checkbox"/>
NH Family Voices	<input type="checkbox"/>	<input type="checkbox"/>
Area Agency/Developmental Services	<input type="checkbox"/>	<input type="checkbox"/>

Q42. What other services are available to help you and your child?

Q43. What other services are needed?

**Thank you very much for completing this survey.
Please fold it, insert it in the return envelope, and drop it in the mail TODAY!**

**Remember to include the form containing your contact information if you
would like to receive a gift card as a token of our appreciation.**