



Needs Assessment for NH Project
Access State Implementation Grant:

FACETS of Epilepsy Care in
New Hampshire

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Background

Since 2004, the United States Department of Health and Human Services, Health Resources and Services Administration has offered competitively awarded “Awareness and Access to Care for Children and Youths with Epilepsy” grants for the development of statewide demonstration projects. In the first phase New Hampshire was not a grantee. However, in Phase 2 of this funding (2007-2010) New Hampshire was awarded a grant with the grantee being the Hood Center at Dartmouth College. Phase 3 of the funding was announced in May 2010 and Special Medical Services (SMS) submitted a proposal and was awarded one of the seven grants, to continue development of New Hampshire’s system of care for children and youth with epilepsy. SMS is the state’s Title V-Children with Special Health Care Needs agency and is a Section within the Bureau of Developmental Services. The grant was awarded for the period of September 1, 2010, through August 31, 2013.

The purpose of this proposed project is to continue to respond to the identified needs of children and youth with epilepsy utilizing innovative strategies and promising practices within the State of New Hampshire. This will be achieved by integrating into the current system of care a focus on creating an alliance between coordination of care efforts including family/youth involvement in health care design statewide.

The Project is expected to increase the capacity across the state for children and youth with epilepsy or seizure disorders. And, to insure that they receive quality health care and necessary family and community supports in a system that is easy to use. We will work to create a common point of coordination and expert consultation to all statewide providers.

The first step of the Project was a Needs Assessment process. Special Medical Services, New Hampshire Family Voices (NHFV) and Child Health Services (CHS) conducted the process, in the months of January – March 2011. The process and the findings of this process are outlined within this document.

Methods

All of the needs assessment tools provided by the Epilepsy Foundation were utilized. Seven (7) key informant interviews were conducted to include feedback from the Title V CSHCN Director; NH Family Voices, Epilepsy Foundation Affiliate, President of the NH AAP chapter, Key person (Epileptologist) at the tertiary medical center, Key person (RN Coordinator) at Epilepsy Clinic and the NH Director for the National Association of School Nurses. Additionally, fifty-eight (58) primary care providers, fifty (50) school nurses, three (3) pediatric neurologists, and two (2) providers in the Epilepsy Clinic completed surveys (via survey monkey). Family and youth were a major focus of the needs assessment process. Parents were surveyed (via paper surveys) with an associated incentive of a \$20 gift card for a grocery store of their choice. Ninety-three (93) parent surveys were completed. Focus groups were conducted to solicit feedback from parents. Two (2) focus groups for parents were held with twenty-four (24) participants. The focus group tool provided by the Epilepsy Foundation was modified for a Youth Focus Group and one (1) focus group for youth was held three (3) participants.

Findings

The findings presented are organized by interview subject and topic area, and are intended to portray the diversity of feedback and responses collected. The data reflects grantee analysis of both quantitative and qualitative data. The data analysis for the primary care provider surveys and the school nurse surveys was prepared by Mathematica Policy Research, Inc.

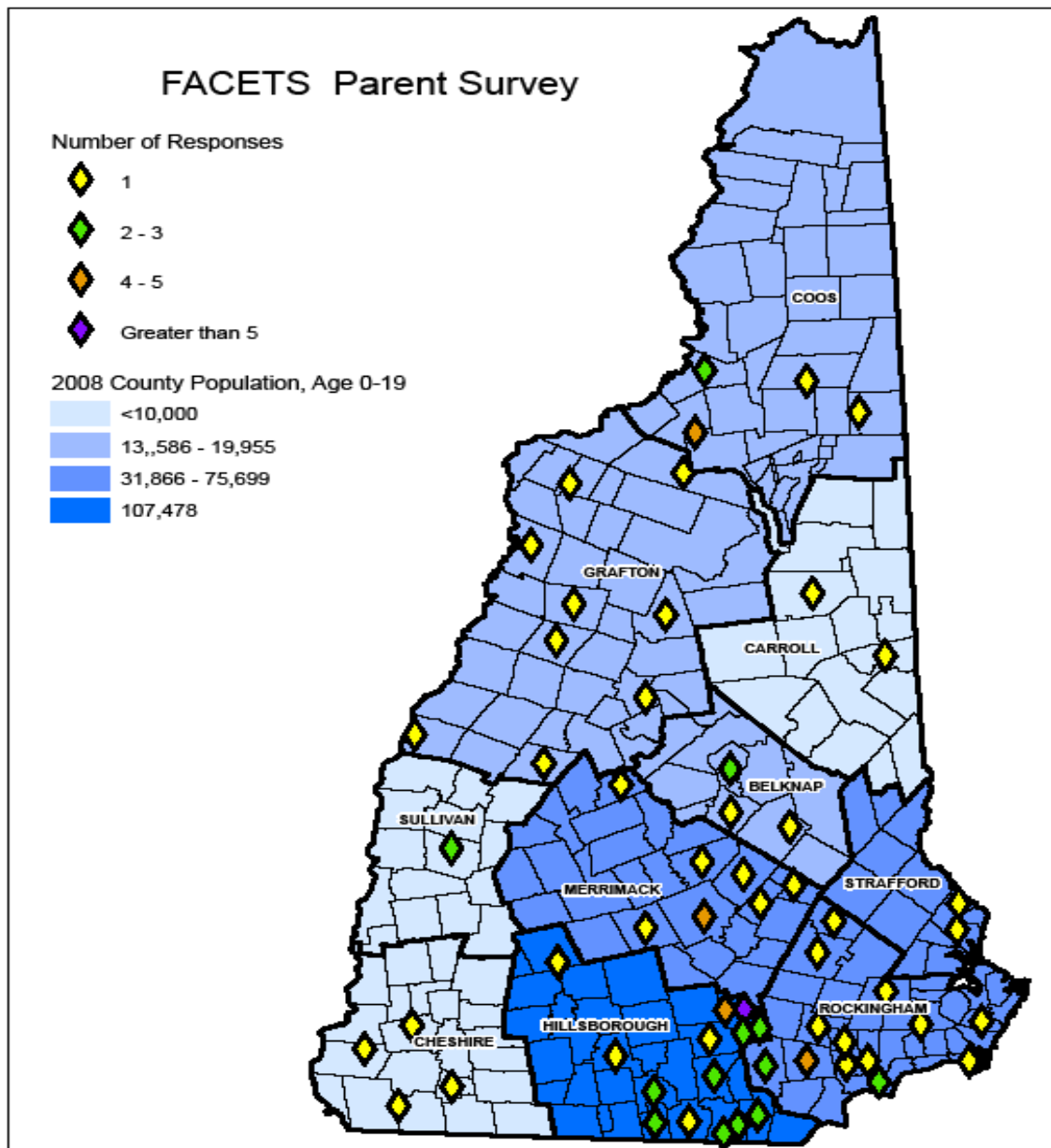


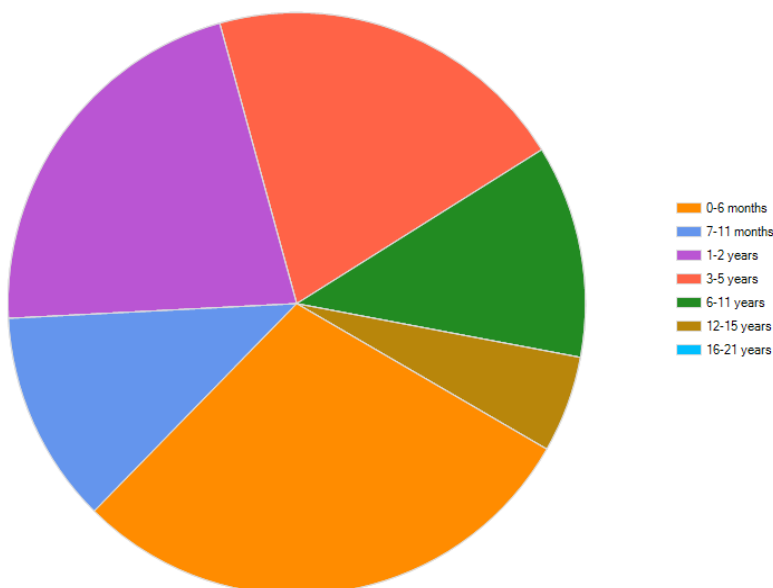
Figure 1. Map of Parent Survey Respondents

Family Respondents:

Every county in the state was represented by at least one parent responding to the survey. Focus groups were held in the northern part of the state (Berlin) and at CHS (Manchester). The Berlin focus group was held at the community Mental Health Center, and was facilitated by Michele

Santy, BS, with notes taken by the Project Coordinator and Susan Moore, RN, from SMS. The CHS focus group was facilitated by Sylvia Pelletier, Project Coordinator, with notes taken by Judy Coughlan, RN, from SMS.

At what age was your child first diagnosed with epilepsy?



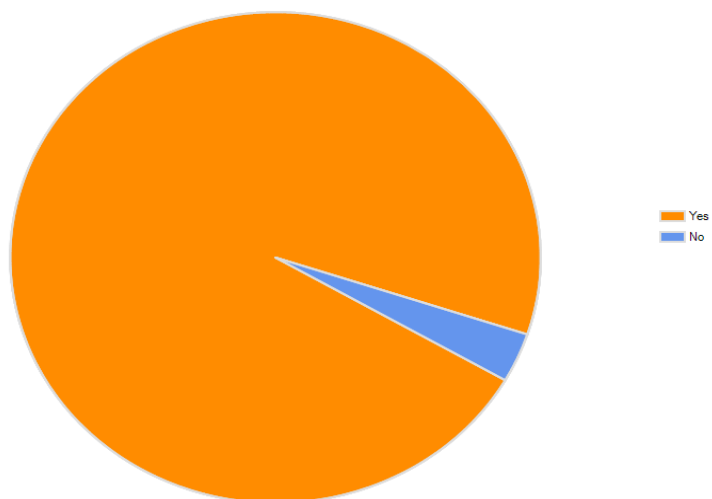
Barriers to access:

Transportation and distance were cited as barriers with the most frequency.

Few parents cited insurance as an issue (96.7% said they had adequate insurance.)

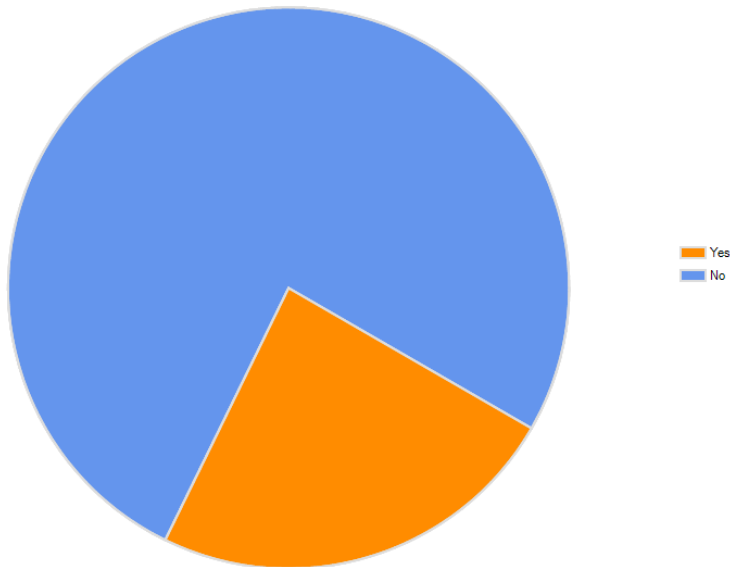
One family that had switched from Healthy Kids Gold (Medicaid) to Healthy Kids Silver (SCHIP) shared that the premium plus co-pays for medication was more than the amount they were over-

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



income for Healthy Kids Gold, resulting in net loss for family. One family cited co-pays for medications and frequent office visits as a concern for their family. *Of note, providers cite insurance and reimbursement as posing barriers with higher frequency than families.*

Does your child receive care within a medical home?



Access to primary care:

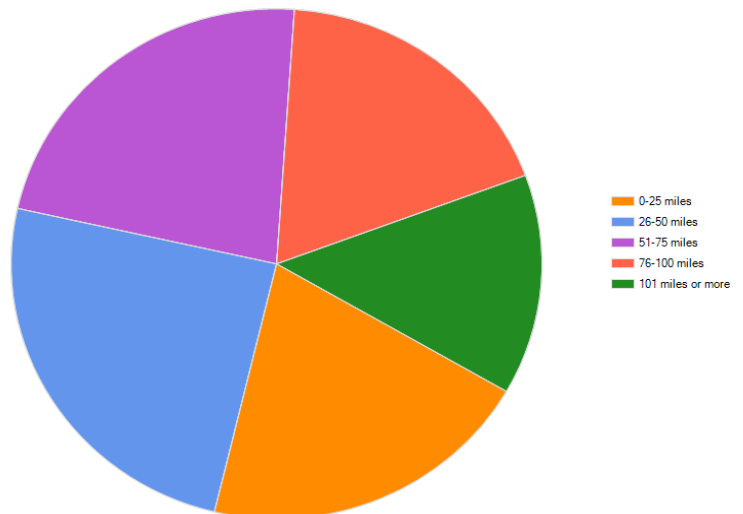
One hundred (100) percent of families reported that their child has a primary care provider. The majority of parents (76%) do not identify their child's primary care as a "medical home" when they were given the AAP definition. However, no barriers to access, or concerns regarding the provision of primary care were identified in either the focus groups or parent surveys. *Of note, Child Health Services provides translation services, social workers and*

transportation, all key in guaranteeing access for the families they serve.

Access to neurology care:

Almost all families (98.9%) reported that their child has a neurologist. Some parents cited concerns about a limited numbers of providers, the distance needed to travel to access them, and the challenge they had gone through to find a neurologist who would "hear" them and treat their "whole child". Several parents stated that they had no difficulty finding a neurologist, and reported they had been with the same neurologist since their child had been

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



diagnosed. Several expressed a concern about having to transition care from that provider when their child became an adult.

Parents in the north country reported the following concerns regarding neurology care:

No local pediatric neurology provider.

A limited capacity of local hospital to meet the care needs of their child.

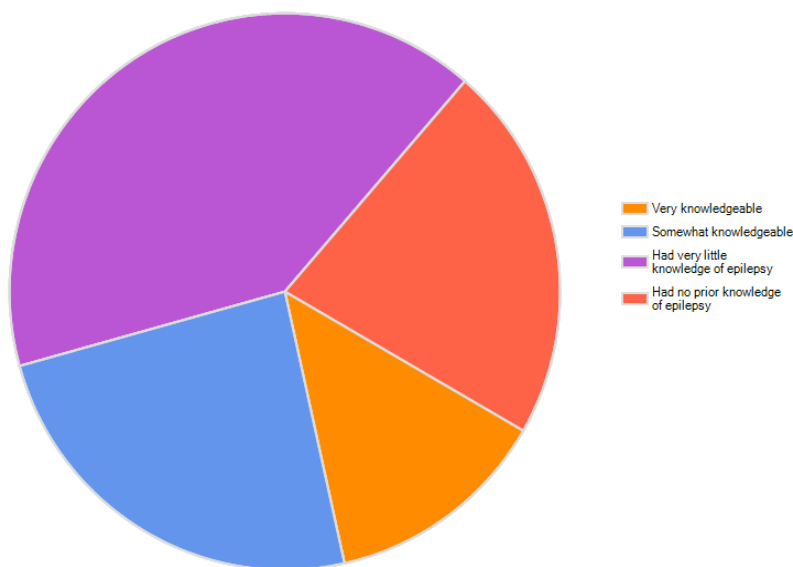
Parents in the southern part of the state reported the following concerns:

A limited choice of providers in the local community.

Longer wait for initial appointments. (Two new providers at Elliot Hospital in south central NH and the reported potential for new providers at Dartmouth will likely address these issues.)

None of the families at Child Health Services had a seizure action plan for their child. Two families had experienced communication / language barrier issues.

Circle your level of knowledge about epilepsy before your child was diagnosed.



Access to information:

Identified information needs FOR families:

Forty-one (41) percent of families were not directed to additional information about epilepsy. Those who were provided direction to additional information were more often directed by a specialist (83%), than by a primary care provider (44%). When this information was provided, seventy-eight (78) percent of the time it was in brochure/pamphlet format.

Sixty-one (61) percent of the time patients were directed to web resources. *This is significant because more than half (55.4 %) of the families reported that they do not use the Internet for information.*

Parents attending the focus group at Child Health Services expressed a need for basic information regarding epilepsy.

Information needs identified BY families:

Families reported that community providers (school, daycare) need additional training and information in order to safely and effectively provide care for their children.

Access to community services:

Families freely shared that they experienced an overwhelming sense of fear, anger, and devastation when their child was diagnosed, even when that diagnosis had happened many years before. Many families expressed that they still held fear and trepidation about what the future held for their child. Compounding this issue was the sense of isolation felt by families, many of whom had never connected with another family who has a child with epilepsy.

Families listed an array of services as being provided through their schools. However, several families cited difficulties with school as being an issue, such as refusal to allow a seizure dog to be at school, school nurse being the only one to hold and administer medication, intolerance, and 504 plan not being implemented.

Identified gaps:

- Respite Care
- Home Health Care
- Support Groups for parents (*Two groups are just starting in Concord & Manchester*)
- Recreational / Social Opportunities for children & youth with epilepsy
- Residential options for medically complex children *and adults* in the north country.
- Emergency Services – variability in terms of response times, availability of paramedics.

Youth Respondents:

The FACETS Youth Coordinator, Nicole Tucker, worked with the Project Coordinator, Sylvia Pelletier, to adapt the Family Focus Group guide for a youth audience.

The Project Coordinator facilitated the youth focus group, with notes taken by Kathy Cahill, RN, MSN, Program Manager, Special Medical Services. While small in size, the focus group of three 15-20 year old youth with epilepsy shared a wealth of information.

Access to Primary and Neurology Care:

All youth in attendance have access to primary and specialty care providers. One youth did identify that co-pays were sometimes a financial strain on his family.

Youth identified, however, that some providers could use some “youth-centered” training.

“He asks me questions I can’t answer, too technical. But then he talks to my mom, and I am like the little kid sitting in the corner.”

“Sometimes they talk to me. Sometimes I ask something and they just “blow it off”.

“Sometimes they think my questions aren’t important.”

Access to Information:

Youth identified that they want information by and for teens, available at primary and specialty care offices.

“I just want info to tell me “What’s normal?” Most stuff is written by adults. It’s too involved. Four paragraphs to answer a question is too much.”

Access to Community Services:

In terms of school, youth identified that peers and school personnel need additional training and education in order to understand and provide appropriate levels of support. Stories of varying levels of support, tolerance, understanding and assistance were openly shared. One student shared about his having been instructed to tell a peer about his newly diagnosed epilepsy, for his own safety. The peer he told then told everyone else, resulting in teasing. One student shared a success story about having an aide, another shared that his aide had been “attached at the hip”-preventing typical peer interaction. Youth shared that teachers do not understand the impact of epilepsy, and treatment, upon learning.

“Teachers don’t understand epilepsy – that I might need help in class.”

In terms of transportation, none of the youth in attendance expressed a desire to drive. In fact, two indicated they were afraid to do so. In regard to peer support, two of the youth present have connected with peers through NH’s Youth Advisory Council (YEAH – Youth Education Adults about Healthcare), and expressed a clear preference for face-to-face vs. “virtual” support.

Specialty Care Providers (Neurology)

Interviews / surveys were completed by 5 providers working in neurology (four pediatric neurologists and one nurse).

Access to care:

None of the providers identified any access issues. The wait times in practices, for initial appointments, varied greatly (3 days for provider in private practice, one week for providers new to the area and three months for an established provider in area).

Note: Providers stated that patients with an urgent need to be seen were able to be prioritized and seen more quickly.

Barriers to care:

Three of the providers identified insurance reimbursement as “often” or “sometimes” being a barrier, citing paperwork demands and a lack of reimbursement for care processes and activities that consume additional time. *Families did not identify this issue, suggesting that families may be unaware of the time required by providers to guarantee access and quality follow-up.*

Providers also identified that some of their time is spent on activities that do not require their level of expertise (e.g. prior approvals of medication, work leave forms, and medical statements). One provider identified that some phone calls would be more appropriately directed to a primary care provider. The same provider expressed that the pressure to see increased numbers of patients impacts the ability to provide comprehensive care and patient education.

“Many days I feel like all I do is put out fires and not really do teaching in overall epilepsy care.”

Interaction with Primary Care:

Two neurology providers filled out the Key Informant survey. In the survey, respondents rated the primary care provider knowledge of epilepsy diagnosis and treatment for children and youth. Both rated the level of knowledge as “most have some knowledge but need more”, which matches the rating that sixty-nine (69) percent of primary care providers gave themselves. Neurology provider rating of how well primary care was provided, in keeping with medical home characteristics (family- centered care, cultural competence), was high, with a notation that it is improving all the time. *Interestingly, this does not match family perception of whether their child receives care in a medical home.*

Three neurology providers completed the specialist survey, in which two indicated that communication via email, or assistance with medication compliance, were methods that could be used to improve coordination and communication between primary and specialty care.

Provider Survey Results

The Primary Care Provider Survey was sent out to the NH Listserv's for both the local chapter of the American Academy of Pediatrics and the Association of Family Practice providers. Fifty-eight (58) of these providers responded to the survey.

Provider Knowledge:

Table I.1. Provider Perception of Epilepsy Knowledge in Children and Youth

Type of Knowledge	Quite Knowledgeable (%)	Some Knowledge; More Needed (%)	Limited Knowledge (%)	No Opinion (%)
Basic epilepsy & seizure disorders	12	69	19	0
Early Detection & Treatment	17	50	33	0
Treatment Modalities	7	55	38	0

n=58

Table I.1 summarizes provider ratings of epilepsy knowledge. Providers then had an opportunity to explain their ratings. A summary of their explanations is provided below.

Knowledge. Among the providers (n=6) who offered an explanation, some providers identified a need for more information due to limited experience in treating a patient with seizures, difficulty in keeping up with changes in medications and treatment practices for children with epilepsy, and no longer practicing as a PCP.

Training. Providers had an opportunity to describe the type of training they've received regarding the care of children and youth with epilepsy, as well as to identify training needs. About 40% of providers stated that they had received no or minimal additional training regarding children and youth with epilepsy. About 28% of providers reported receiving CMEs, sometimes with epilepsy covered as part of broader topic on pediatrics. Other training areas mentioned included conferences as well as reading books and journal articles. A couple of providers mentioned consultations or interactions with specialists and a couple providers reported specific experience with epilepsy or seizure disorders. The most frequently cited training needs were around early detection of epilepsy, treatment options, and medication management. Providers recognized that available medications to treat epilepsy are rapidly evolving and a number of providers identified the

need to learn about newer medications, the risks and potential side effects of medications, and alternative treatments. Some providers also identified information/training needs around access to specialists and care coordination with specialists, resources for families and youth, and life planning and long term maintenance.

Medical Home Characteristics:

Table I.2. Provider Perception of the Provision of Medical Home Characteristics

Medical Home Characteristic	Always (%)	Usually (%)	Rarely (%)	Never (%)	No Response (%)
Overall Medical Home	19	45	9	2	26
Care Coordination	16	43	14	2	26
Self-management education	0	24	29	12	34
Culturally Effective Care	14	47	3	2	34
Family Centered Care	41	29	3	0	26

n=58

Table I.2 summarizes provider ratings of medical home characteristics. Providers were then given the opportunity to explain their ratings. A summary of the explanations is provided below.

Overall Medical Home. Less than 1/3 of providers offered an explanation for their response. Among those who offered an explanation, most said they have no or very few patients with epilepsy. Several providers said that providing a medical home is a priority for their office or built into their structure. Some said they did not always meet the stated medical home definition due to coordination issues with specialists. Many providers mentioned challenges with specialists, mainly coordination, communication, and care management. Some providers also mentioned challenges with access to specialists, stating that pediatric neurologists are far away and difficult for families to reach. Some providers said the small number of children affected means they or other parts of the medical system are less familiar with treatment or other issues, and one mentioned a support group would help children with epilepsy. A couple of providers mentioned lack of staff, resources, or information on where to find resources.

Care Coordination. The way in which practices handle care coordination varies. Some providers stated that it was their responsibility. Others stated that they refer patients to specialists, who then offer care coordination. Many providers said nurses or care managers handle care coordination. Some providers indicated that coordination occurred between staff in

their office and specialists. A few providers mentioned including families in the development of care coordination plans. One provider identified a need for clearly defining roles and responsibilities between PCPs and specialists.

Barriers to providing care coordination included issues coordinating with subspecialists; lack of a full-time care coordinator in the office and general staffing issues; and patients seeking other providers without notifying their primary care provider.

Self-management Education. A large majority of providers reported that they refer their patient to a specialist. There was an underlying assumption that patient education is handled by the specialists. Some providers stated they have handouts and provide other resources to families. Some providers reported talking with patients' families to address their questions.

Culturally Competent Care. Most providers said this was not a problem and/or their patient population was not culturally diverse. A number of providers stated they had interpreters available. In some cases the interpreter was an individual who was physically present for the appointment; in other cases services were provided via telephone. Some providers identified a need for written materials in languages other than English and a couple of providers stated that they have too few culturally diverse patients to be able to offer translation services or written material in alternate languages.

Family-Centered Care. Ninety-five percent of providers reported that their practice *usually* or *always* provides family-centered care; few providers provided an explanation for their rating. Some providers stated that it was a central part of their practice. One provider mentioned family issues (e.g., moving, divorce/separation) as a barrier to providing family-centered care.

Reimbursement

Table I.3. Provider Perception of Reimbursement as a Barrier to Providing Appropriate Care

Insurance Type	Often (%)	Sometimes (%)	Not Generally (%)	No Opinion (%)
Medicaid & SCHIP	14	27	29	31
Other Health Insurance	12	27	29	33

n=49

Table I.3 summarizes provider ratings of reimbursement as a barrier to care. Some providers then provided an explanation of their ratings. The most common issue mentioned was the lack of support for costs related to care coordination. A few providers mentioned that some patients lack insurance.

Specialists

Provider (n=49) perception of whether there are adequate numbers of specialists available to treat children and youth with epilepsy in his/her area varied. Thirty-six percent of providers stated that there were *generally* adequate numbers; 22% stated that there were *somewhat* adequate numbers, and 19% stated that there were *rarely* adequate numbers. Seven percent of providers had no opinion. Many providers stated that the specialists practice too far away for their patients. Providers also reported long wait times to see a specialist, especially for new patients. One provider reported that if he/she calls to schedule an appointment with a specialist on behalf of the family, the patient can get “squeezed in,” but if a parent calls, they are given a date months out.

School Nurse Survey Results

The Key Informant survey for the state Director of the National Association of School Nurses was created as a survey on survey monkey. This was done after the NH Director of NASN suggested that she would be interested to know how school nurses would answer the questions themselves. The survey was sent to all school nurses who subscribe to the NH Department of Education’s School Health Services Listserv. Please note that while seventy-four (74) school nurses started the survey and entered information about their profession and role, twenty-four (24) nurses did not complete any of the other questions in the survey.

Provider Knowledge:

Among the school nurses (n=50) who reported their perceptions of primary care providers’ knowledge about epilepsy diagnosis and treatment for children and youth in their area, 44% reported that providers are *quite knowledgeable*, 38% reported that providers have *some knowledge* but need more, and 2% reported that providers have *limited knowledge*. Sixteen percent of school nurses had no opinion. School nurses were given the opportunity to provide an explanation for their rating. Most nurses said the primary care providers’ knowledge was good. Some nurses framed their perception of provider knowledge within the context that providers fulfill their role in initially diagnosing a condition, helping with treatment, and referring the child to a specialist. One school nurse reported that most PCPs were more efficient at creating seizure management plans than at least one area specialist. Two school nurses reported that while providers had a good level of knowledge regarding epilepsy care, improvement is needed regarding psychological care of the child and family.

Medical Home Characteristics

Table II.1. School Nurse Perception of the Provision of Medical Home Characteristics, by Primary Care Providers, for Children & Youth with Epilepsy

Medical Home Characteristic	Most (%)	Some (%)	Few (%)	No Opinion (%)
Familiarity with & Practice Medical Home Model (n=39)	26	26	44	5
Provide culturally competent care (n=50)	26	24	6	44
Provide Family-Centered Care (n=39)	38	44	8	10

Table II.1 summarizes school nurse ratings of medical home characteristics. School nurses were then given the opportunity to provide an explanation for their ratings, which are summarized below.

Medical Home. Few nurses provided an explanation for their rating of the level of implementation of the medical home model in primary care practices. Some school nurses reported that the medical home model was generally implemented well, while others said it could be improved or that it was inconsistently used by providers.

Culturally Competent Care. Almost half of school nurses did not have an opinion regarding whether providers provide culturally competent care. Among the nurses who provided an explanation of their rating, many school nurses reported that care was generally provided in a culturally competent manner. A couple of nurses noted that it is getting better and a couple nurses noted that more work is needed. One school nurse who works with a diverse population commented that the Hispanic population is well served but that people speaking Arabic or African languages have had trouble getting culturally competent care.

Family-Centered Care. School nurses were generally positive about providers providing family-centered care. The main complaint was the need for more resources – either more provider time or better care/services coordination. There were a couple comments about not including the entire family in providing care. One respondent said pediatricians were providing family-centered care, but that family practitioners were not always providing it.

Reimbursement

Among the school nurses (n=38) who reported their perceptions of reimbursement for services as a barrier to providing primary care for children and youth, 34% reported that reimbursement for services is *often* a barrier, 11% reported that reimbursement for services is *sometimes* a barrier, and 39% reported that reimbursement for services is *rarely* a barrier. Sixteen percent of school nurses had no opinion. Few nurses provided an explanation of their ratings. Among the school nurses who did provide an explanation, three general themes were identified: access to insurance, problems with insurance coverage, and burden on physicians. Some school nurses reported that access to insurance is a problem, particularly for students over 19 years and for income-ineligible families. One nurse reported that families often don't know how to proceed or whom to contact with questions. Nurses also reported that insurance plans limit treatment options and create barriers to providing/receiving preventive and chronic care. Another nurse noted the burden that insurance companies/plans place on providers. This nurse stated that providers have to justify every benefit for their patients, which results in time-consuming paperwork. Two school nurses noted that children in the Healthy Kids Gold program receive very good care.

Adequacy of Services

Table II.2. School Nurse Perception of Adequacy of Care Coordination for Children & Youth with Epilepsy

	Generally (%)	Somewhat (%)	Rarely (%)	No Opinion (%)
Coordination of care between PCP and community services (n=35)	31	34	26	9
Coordination of care between PCP and specialists (n=36)	31	39	17	14

Table II.2 summarizes ratings of adequacy of care coordination for children and youth with epilepsy. School nurses had the opportunity to provide explanations for their ratings. Few school nurses provided an explanation; however, some nurses stated that unless providers have electronic records, care coordination can be difficult in rural areas because specialists are widespread. A couple of school nurses noted that coordination of services is difficult or lacking between schools, providers, and specialists. Other nurses reported that coordination and communication was good.

Community Services

Table II.3. School Nurse Perception of Availability of Services for Children & Youth with Epilepsy

Service	Generally (%)	Somewhat (%)	Rarely (%)	No Opinion (%)
Specialists (n=40)	20	48	20	13
School services (n=40)	58	35	5	3
Support groups for children (n=39)	15	36	18	31
Medical transitional services (n=39)	23	46	13	18
Other community services (n=38)	24	42	16	18

Table II.3 summarizes ratings of availability of specialists and community services for children and youth with epilepsy. School nurses had the opportunity to provide explanations for their ratings of the availability of services. While few nurses offered an explanation, some nurses reported that New Hampshire has an insufficient number of specialists to treat children with epilepsy. Availability of services and support outside of urban areas was identified as a problem, especially for low-income families who have difficulty traveling. Two nurses also noted the lack of availability of support groups. Some nurses reported a sense that the service system is fragmented. One nurse identified the importance of communication and collaboration between agencies so that agencies and families are aware of available resources. Another nurse reported that community services are often the first services to be cut from budgets. With respect to the availability of school services, nurses positively commented on their ability to provide care coordination.

Conclusions

The needs assessment process confirmed much of what had been suspected to be true about Epilepsy care in NH. As a result of the needs assessment, activities that are planned during the scope of the grant will address many of these needs. Additional activities will be planned to meet others newly identified.

Information for primary care providers and communication between primary & specialty care providers continue to be areas that need to be addressed. In Phase 2 of the Project Access SIGs: a number of podcasts and webinars were created to share information with primary care providers and large meetings were convened for the purpose of pediatric practice improvement

teams and specialty care improvement teams to meet and discuss opportunities for collaboration and to improve co-management with the Dartmouth-Hitchcock network. In the current phase, FACETS will create similar opportunities for providers to meet. In addition, efforts that will facilitate the sharing of treatment/care information will be undertaken. Another component that will address identified needs will be the opportunities for care coordinators to meet and communicate with one another. This will target all coordinators who practice across the system of care. The focus of these meetings will be to further encourage collaboration and effective use of resources to meet the needs of families and youth.

Training for school and community providers continues to be an area of need as well. This was identified by almost all groups targeted in the needs assessment process. The local Epilepsy Foundation affiliate has recently expanded services to NH. In this phase, the EF affiliate will be engaged in activities directed at meeting the training needs of community providers. Throughout the grant regional forums will be held, bringing together families, youth and community providers, to share resources and provide information to meet their training needs. Additionally, training to school and daycare personnel will be provided on site.

Information and support opportunities for families and youth are also needed. Some of these needs will be met through the regional forums. However, youth expressed a specific need for information to be available within their primary care and specialist practices. As an activity under this project, youth will be engaged to review existing materials, and to develop additional materials if the existing materials do not meet their needs. Originally development of a system of support via our youth coordinator via a social network was envisioned. During this needs assessment process, however, it became clear that web-based material/information is not the preferred format for support or information distribution, by many youth and families. As a result, feedback from youth will be gathered during our regional forums, and a method appropriate to meet their needs will be identified.

Table 1: Survey Methodology

Target Group	Method of finding individuals	Did you offer an incentive for participating? If so what was it?	Mechanism for Collecting Data (paper, online, mail, telephone, in-person)	# Surveys Sent Out	# of Surveys Received	Strengths of Information Source(s)	Limitations of Information Source(s)
School Nurses	School Nurse Listserv	No	Survey Monkey	592	74 (only 50 completed the survey)	Widespread representation of interested school nurses	School Nurses self-selected to respond to survey
Specialists	Title V coordinators	No	Paper – via fax	3	3	Experienced providers, representing care outside of Dartmouth Hitchcock system	Two neurology providers fairly new to NH, other provider is in solo practice with limited staff support
Primary Care Providers (Pediatricians, Family Practice)	Distributed to established Family Practice and Pediatric Provider listservs	No	Survey Monkey	260 Pediatric Providers 570 Family Practice Providers	58	Listservs are maintained and moderated through the state affiliates of National professional organizations	Providers choose involvement in Listservs so not all practicing providers were sent survey. Providers self selected to respond to survey
Parents	Child enrolled in either Special Medical Services or Partners in Health; Parents identified by NH Family Voices, Child Health Services	Yes; \$20 gift card to one of three grocery stores (parent choice) for completion of survey	Paper, telephone, in person	204 surveys mailed 9 surveys by phone, in person via translator	93	Respondents from every county in NH, children of variety of ages, years since diagnosis	There are children/parents not known to SMS, NHFV, PIH or CHS and these folks might have different needs as they are less connected to these resources
Nurse in Epilepsy Clinic	Involved in Project Access	No	Phone, Survey Monkey	1	1	Experienced Provider	Work within tertiary care center
Neurologist in Epilepsy Clinic	Involved in Project Access	No	Phone, Survey Monkey	1	1	Experienced Provider	Work within tertiary care center

Table 2. Methodology for Key Informant Interviews and Focus Groups

Target Group	Was this an interview or focus group	How many interviews /groups did you have?	Where did you have your interview/ groups (i.e., location & setting)?	How did you find your participants ?	How many people were asked/ invited?	How many participated?	Describe the interviewer/ focus group facilitator(s)	Strengths of Information Source	Limitations of Information Source
Families	Focus Group	2	Mental Health Center, Community Health Center	Providers, Partners in Health, Special Medical Services	2 groups #1 = 9 #2 = 6	2 groups #1 = 13 #2 = 9	We had 2 facilitators attend. One took notes, the other guided discussion. Employed by NH Family Voices , Child Health Svs	Families have received services for years, understand issues in their catchment area	Conducted one focus group in urban area, one in north country, not around whole state. Surveys were statewide.
Youth with epilepsy (ages 15-20)	Focus Group	1	Clinic	Partners in Health, YEAH council (youth advisory)	4	3	2 facilitators attended. One took notes, one guided discussion. Employed by NH Family Voices, Title V	Youth represented both newly diagnosed and long term chronic illness perspectives	Limited number of youth
Key Person at tertiary medical center (Epileptologist)	Interview (completed survey via survey monkey)	1	Phone	Involved in Project Access in NH in Phases 2 and 3	1	1	Project Coordinator, NH Family Voices	Experienced provider	Provides care within tertiary care center
NASN – NH	Interview (completed survey via survey monkey)	1	Phone	Via NH School Nurse Assoc.	1	1	Project Coordinator, NH Family Voices	Experienced provider, has participated in advisory focus groups in past	New to her role as NASN director
EF Affiliate	Interview	1	Phone	Familiar with organization	1	1	Title V Director	Local affiliate	Data limitations prevented answering many questions
CSHCN Director	Survey	1	State Office	Grantee	1	1	CSHCN Director	Collaborated with Phase 2 of PA	
NH Family Voices	Survey	1	State Office	Serves as Project Coordinator	1	1	Project Coordinator	Project Coordinator for Phase 2 of PA	
Key Person at Epilepsy Clinic (RN)	Interview (completed survey via survey monkey)	1	Phone	Involved in Project Access in NH in Phases 2 and 3	1	1	Project Coordinator, NH Family Voices	Experienced Provider Project Access Needs Assessment for NH	Provides care in tertiary care center

Table 3. Description of Other Data Sources Used

Needs Assessment Profile Question #	Data Source(s)	Name of Agency/Organization	Date	Comments
2-5		U.S. Census Bureau	2010	
6, 9	National Survey of Children and Youth with Special Health Care Needs	HRSA/MCHB	2005	
7	National Survey of Children and Youth with Special Health Care Needs	HRSA/MCHB	2005	Estimation based on %
8		U.S. Census Bureau	2010	
10-11	Penny Taylor, Administrator	NH Board of Medicine	2011	
12, 14-21, 26, 32, 39, 47-57, 59-62, 64-69	Project Coordinator Grantee	NH Family Voices Title V, CSHCN Director		
13	Pediatrician Participation in Medicaid / SCHIP, Survey	American Academy of Pediatrics	2000	based on 95.7% rate of participation identified in American Academy of Pediatrics. Pediatrician Participation in Medicaid/SCHIP, Survey of Fellows of the American Academy of Pediatrics, 2000
22-25, 29, 31, 33, 37, 38, 58	Family Focus Groups / Surveys		2011	
27-28	American Epilepsy Society, Provider Query, Hospital Provider List, Insurance Provider Directories		2011	Compilation of information from stated sources
30, 34, 35, 36, 39	Neurology Provider Survey		2011	
40-44	Susan Welby	Epilepsy Foundation of MA, RI, NH, ME	2011	
45-46	Family Focus Group Provider Survey		2011	
63	NH Department of Education	School Health Services	2011	The NH School Nurse Survey from 2010

Surveys

Key Informant Interview
Title V Survey
Specialists Survey
Primary Care Provider Survey
Pediatric Neurology Interview Guide
Parent Survey
Family Focus Group Facilitators Guide
Youth Focus Group Guide

Youth Focus Group Guide (modified from Parent Focus Group Guide provided by the Epilepsy Foundation)

Initial greeting – touch on the following:

Thank participants.

Provide overview of project: Special Medical Services and the Epilepsy Foundation are working to improve the care for children and youth with epilepsy as part of a federal grant. Your experiences and stories are very important to our work.

Give time frame: This meeting should take about an hour and a half.

Give overview of meeting: I will ask you questions about primary care, specialty care and community resources. Your experiences may be the same, or different, from others in the group. Everything you say in this group is confidential. We will not use your name in any report. We ask that you also respect the confidentiality of anything others say in the meeting.

Primary Health Care (*Youth coordinator recommends to prompt as “your every day doctor, where you go for a physical”*)

Where do you go for primary health care?

How far do you travel to see your doctor for primary health care?

Do you have insurance that pays for your doctor’s visit? (Medication?, Treatment?)
If you have to pay for care, is this difficult?

During your doctor’s visit, do you get your questions answered?

During your visit, does your doctor talk to you? Just to your parents? To both of you?

Is it easy to talk to your doctor? (Do you feel he or she listens to you? Understands what you want or need?)

Do you think your doctor refers you to a specialist when you need it? When you ask?
Yes? No? Not enough?

If you are still receiving primary care in a pediatric office, have you begun to discuss transition to an adult health care provider?

If you have transitioned, how did that process go?

Are you still in the process?

Do you need any help getting through the process?

Specialty Health Care

Where do you go for specialty care (neurology)?

How hard was it to find the neurologist?

How far do you travel to see your neurologist?

If you have a problem and have to call the neurologist, how long does it take for someone to call you back? For you to get an appointment?

How easy is it for you to talk to your doctor? (Do you feel like they listen to you? Hear your concerns?)

During your appointment, does the doctor talk to you? Just to your parents? To both of you?

If you are still receiving neurology care from a pediatric neurologist, have you begun to discuss transition to an adult neurology provider?

If you have transitioned, how did that process go?

Are you still in the process?

Do you need help?

Community Services

Did you / do you need help at school?

Yes? No? Sometimes?

What type of help? (Help with classes? Homework? Finding and scheduling classes? Social support?)

How do you connect with other youth with epilepsy?

If you don't, would you like to? If so, how would you like to? (at meetings, outings, online, anywhere else?)

Do you need other assistance or resources? (supports outside of school, home)

If so, for what?

What kinds of things do you need help with? (transportation?)

