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Executive Summary

Health Insurance for Children and Youth with
Special Health Care Needs

Focus Groups, Parent/Caretaker and Provider
Surveys

Fall, 2017

Granville Vance Health District

Innovative Approaches

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I. BACKGROUND

In June, 2016, the NC Division of Public Health's Children and Youth Branch awarded the Granville Vance Health District (GVHD) an Innovative Approaches grant to support improvements in the system of care for children and youth with special health care needs in Granville and Vance counties.

Funded by a federal Maternal and Child Services Block Grant, the five objectives of the North Carolina Innovative Approaches Initiative are:

1. Families of children and youth with special health care needs will partner in decision making at all levels and will be satisfied with the services they receive.
2. All children and youth with special health care needs will receive coordinated, ongoing, and comprehensive care within a medical home.
3. All children will be screened early and continuously for special health care needs.
4. Services for children and youth with special health care needs and their families will be organized in ways that families can use them easily.
5. All children and youth with special health care needs will receive the services necessary to make appropriate transitions.

Per the US Census, together Granville and Vance have a population of just over 103,000 living in over 784 square miles. Granville's larger population (59,031 in 2016) is spread over 531 square miles, while Vance's 44,244 residents are spread over 231 square miles. Since 2010, Granville's population has increased 2.6%, while Vance's has declined by the same percentage.

Generally speaking, Vance is home to a larger number of health care providers, but its population faces more challenges. Within Vance County, 13.7% of the under-65 population lacks health insurance, compared to 11% in Granville County and 12.2% in the state of North Carolina. The poverty rate for Vance is 24.2%, vs. Granville at 15.2% and an overall state average of 15.4%.¹

In fall 2016, under the direction of Ms. La'Shanda Daniels, Granville Vance Health District (GVHD) Innovative Approaches (IA) Coordinator, Karen Dash Consulting LLC (KDC) conducted a needs assessment based on extensive input from area families and providers of children and youth with special health care needs. Results showed that families were generally satisfied with their relationships with their health care providers but recognized an opportunity to partner more effectively with their county's schools. Over the last year, the Innovative Approaches Steering Committee has developed and implemented various systems change objectives to address identified issues.

For the 2017-2018 Innovative Approaches cycle, the GVHD conducted needs assessment research around the IA goal to "Increase the percent of CSHCN who have adequate health insurance and financing to pay for needed services," which only 58.4% of North Carolina CSHCN families reported having in 2009-10.²

Health insurance concerns affect numerous American families. A 2016 NPR / Robert Wood Johnson Foundation / Harvard T.H. Chan School of Public Health poll of 1,002 US adults found that one in four

¹ <https://www.census.gov/quickfacts/fact/table/NC,vancecountynorthcarolina,granvillecountynorthcarolina/PST120216>

² www.childhealthdata.org

respondents rated their health insurance as “fair” (20%) or “poor” (5%), and 29% characterize their family’s health care costs as “unreasonable.”³

Numerous national studies have identified the relationship between insurance coverage and the adequacy of services received by patients as well as their overall health. That research has shown that underinsured and uninsured people receive fewer preventive services such as vaccines; may be offered fewer treatment options; and are more likely to suffer adverse outcomes.⁴ A 2017 study by the American Academy of Pediatrics suggests that African-American and Hispanic children are much less likely to be identified for early intervention services than white children.⁵

In response to a request from Ms. Daniels, Karen Dash Consulting LLC (KDC) provided the following services in fall of 2017:

- (1) Facilitation, Analysis, and Reporting of two IA Focus Groups of parents of and providers to children and youth with special health care needs (CYSHCN) in Granville and Vance counties
- (2) Development of Parent/Caretaker Insurance Survey (online and hard copies)
- (3) Development of Provider Insurance Survey
- (4) Development of Pre-meeting Surveys for Parents/Caretakers and Providers
- (5) Analysis and Reporting of the Innovative Approaches Items 1-4 above

Goals of CYSHCN Health Insurance Needs Assessment Opinion Research

As with previous Needs Assessment Research, the Focus Groups and Family and Provider Surveys served the following goals:

- To capture the feedback of stakeholders in the Innovative Approaches community, especially families of children and youth with special health care needs (CYSHCN), regarding the challenges of financing their child’s medical, mental health/behavioral, and developmental health needs
- To provide GVHD IA with actionable, measurable feedback in order to identify community needs, as well as differences in perceptions of need
- To assist the IA team in prioritizing their goals and objectives in attempting to increase the percentage of families with adequate health insurance and financing
- To develop a baseline for future opinion research analysis
- To provide an understanding of differences in need or perceptions of need between providers and families in serving children and youth with special health care needs

³ <https://www.rwjf.org/en/library/articles-and-news/2016/02/patient-perceptions-vary-across-seven-states.html>

⁴ See, for examples, studies cited in <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1578641/>.

⁵ <http://pediatrics.aappublications.org/content/early/2017/10/12/peds.2017-2059>

II. METHODOLOGY

This report summarizes the results of six different data collection initiatives commissioned by the Granville Vance Health District Innovative Approaches Steering Committee. The report summarizes the overall results and themes that were prevalent throughout the six opinion research studies, along with recommended system change objectives.

The questions throughout the six research efforts focus on themes of insurance affordability and adequacy; knowledge of insurance options for children and youth with special health care needs and knowledge of covered services; insurance-related barriers to service; the implications of inadequate or unaffordable insurance; and education and training opportunities. While some of these issues are beyond the scope of the Innovative Approaches Initiative, others offer opportunities to provide information and to connect families and providers with resources, including potential financial support.

A variety of similar and complementary questions were asked to measure the breadth and depth of opinion among stakeholder groups and to identify gaps between stakeholder groups. In some cases, identical questions were asked in different opinion research instruments in order to cast the broadest net possible in gathering responses to that question.

Where possible, the questions were aligned to previous IA opinion research efforts, as well as concepts explored in national studies, such as the Biennial Health Insurance Survey and the Center for Disease Control and Prevention's National Center for Health Care Statistics 2009-10 National Survey of Children with Special Health Care.

The data collection instruments include:

Provider Community Survey: In October-November, 2017, providers offering services to children and youth with special health care needs (CYSHCN) were invited to respond to a 14-question online survey regarding the health insurance needs of their patients and the challenges associated with financing health care. In all, 15 providers offered their feedback and insights.

Parent/Caretaker Community Survey: During the same October-November timeframe, parents were invited to complete a 21-question survey regarding the challenges of financing of their child(ren)'s healthcare, as well as the strategies they pursued to afford healthcare. The Innovative Approaches Coordinator visited with various regional providers and healthcare-related events to invite parents to complete the survey. Thirty one parents completed this survey.

Two Focus Groups: Two focus groups were conducted on October 18, 2017 at the Vance County Health Department. The first focus group included 12 providers for a lunchtime meeting. During the evening, the IA Parents Steering Committee met as a group of 6 parents, 1 from Granville County parents and 5 Vance County Parents.

Two Pre-Meeting Surveys: A brief Pre-Meeting Survey was administered at the beginning of each focus group in order to acclimate participants to the focus group topics and collect additional information. Ten providers and six parents completed a brief Provider or Parent Pre-Meeting Survey.

Note: With the recognition that providers may not have discussed certain insurance issues with their clients, particularly financial issues, this study includes provider feedback to serve as another lens through which to measure insurance's impact on the larger community's families, i.e., those who have

not completed the Parent/Caretaker Survey. In order to measure the prevalence of insurance-related issues, parents/caretakers were asked to indicate if a particular issue had affected their families. Providers, on the other hand, were asked to indicate the frequency with which they observed a particular issue's effect on the clients they serve.

Note: Parent/Caretaker and Parent are used interchangeably in describing the family member survey respondents or focus group participants.

III. PROFILE OF PARTICIPANTS

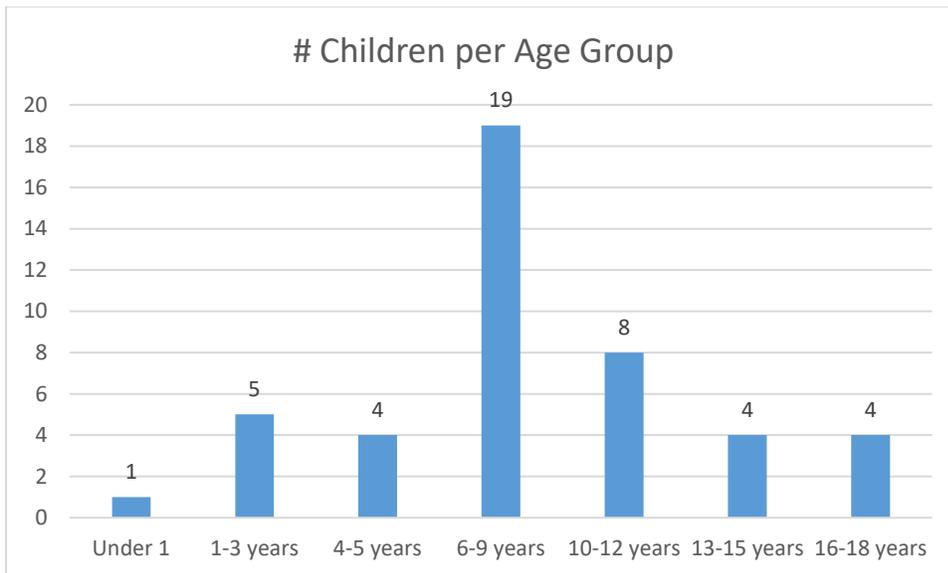
A. Profile of Participating Parents/Caretakers

Of the 31 families who responded to this question, 20 (64.5%) lived in Vance County. Five (16%) lived in Granville County, and two lived in Person County, with one each from Wake, Durham, Franklin, and Johnston counties.

Twenty eight parents reported having at least one child with special health care needs, with eight reporting having at least two children with special health care needs; four having at least three children with special health care needs; and four reporting at least four children with special health care needs.

Age of Children with Special Health Care Needs

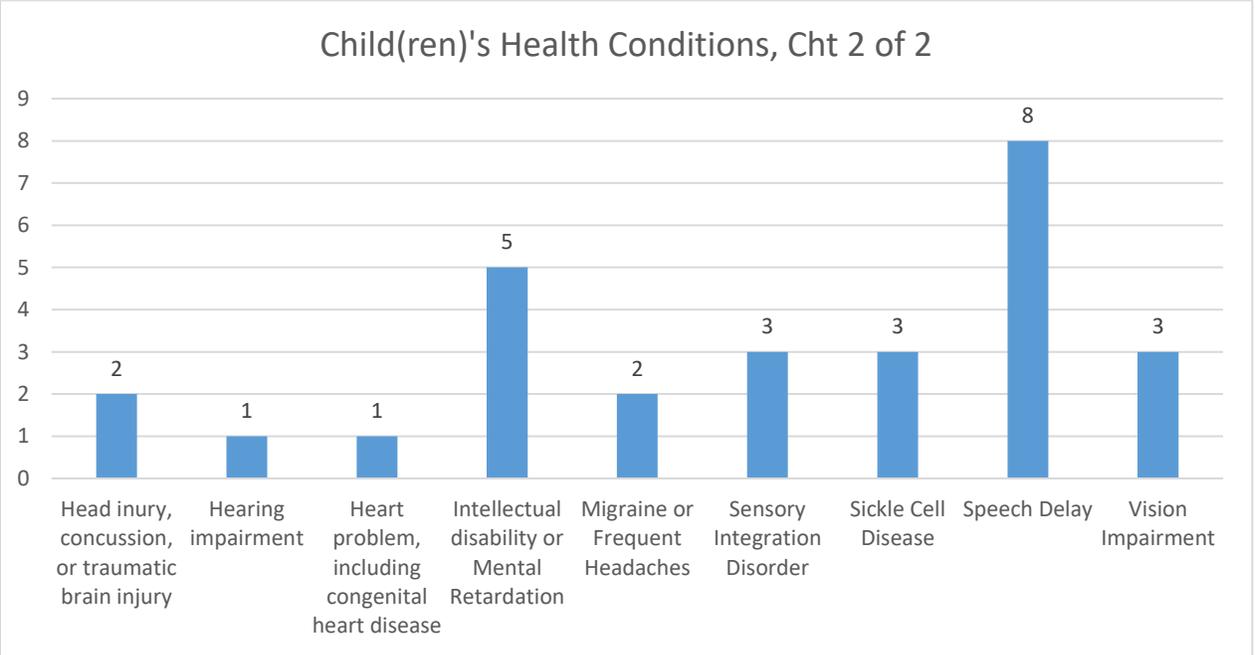
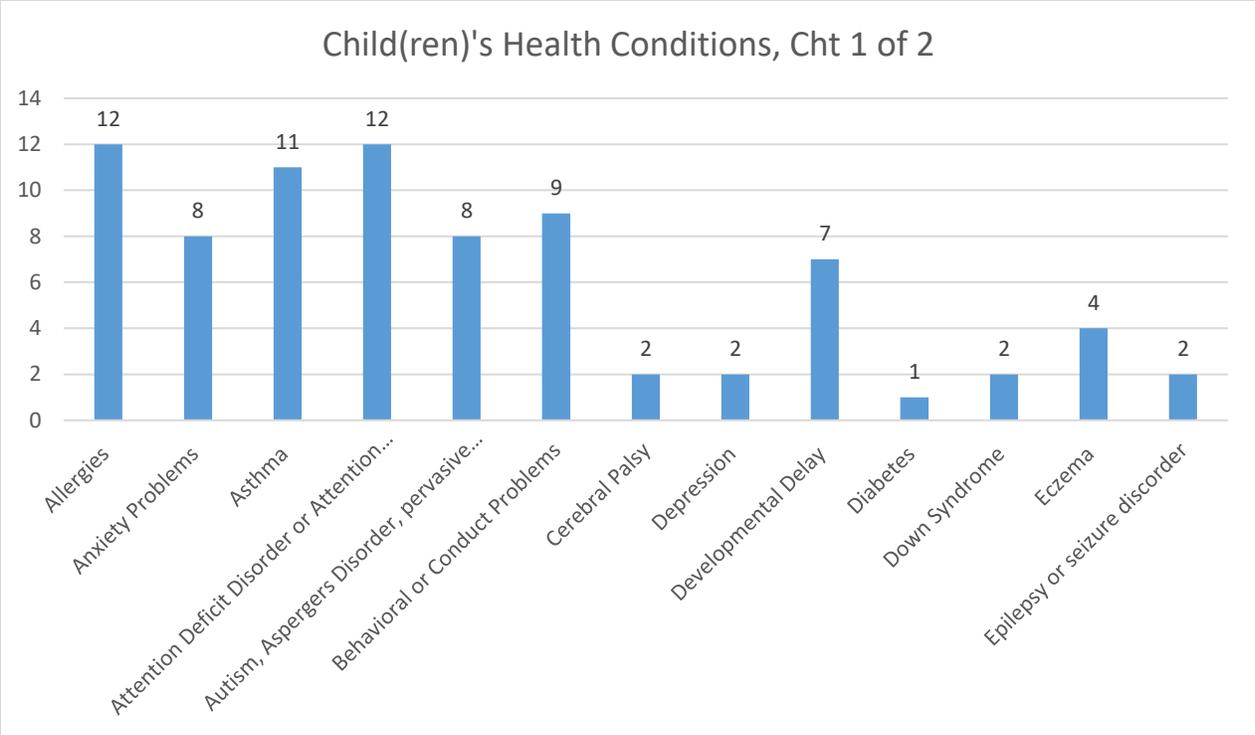
Among all children included within the study, the largest age group was children 6-9 years old, followed by 10-12 years old. No youth over 18 years of age were reported, although parental comments indicated that some have adult children with special health care needs.



Child(ren)'s Health Condition

The children included within this study had a wide variety of health conditions, as included within the charts on the next page.

Allergies or Attention Deficit Disorder or Attention Deficit Hyperactive Disorder accounted for the most frequent child's health condition, followed closely by Asthma. Other frequently-noted diagnoses include Behavioral or Conduct Problems; Anxiety Problems; Speech Delays; and Autism, Aspergers Disorder, pervasive developmental disorder, or other autism spectrum disorders.



In addition, in their comments, parents reported the following as “Other” health conditions:

- Separation, anxiety, sleep issues
- Child was born positive for cocaine at birth. Has upper respiratory infections, croup, and pneumonia frequently.
- Bowel syndrome irrital
- Hypothyroidism (2)
- Autistic tendencies have been noted but not yet confirmed.
- I have 13 children, though 5 are now over 18. But a few of those 5 do not have the mentality of adults yet. Truly, our lists are too long to write out. FAS, RAD, cyclothamia, microcephaly, colopolcephaly, c-ACC, failure to thrive, and many more besides the ones you have listed above.

Family Care Providers

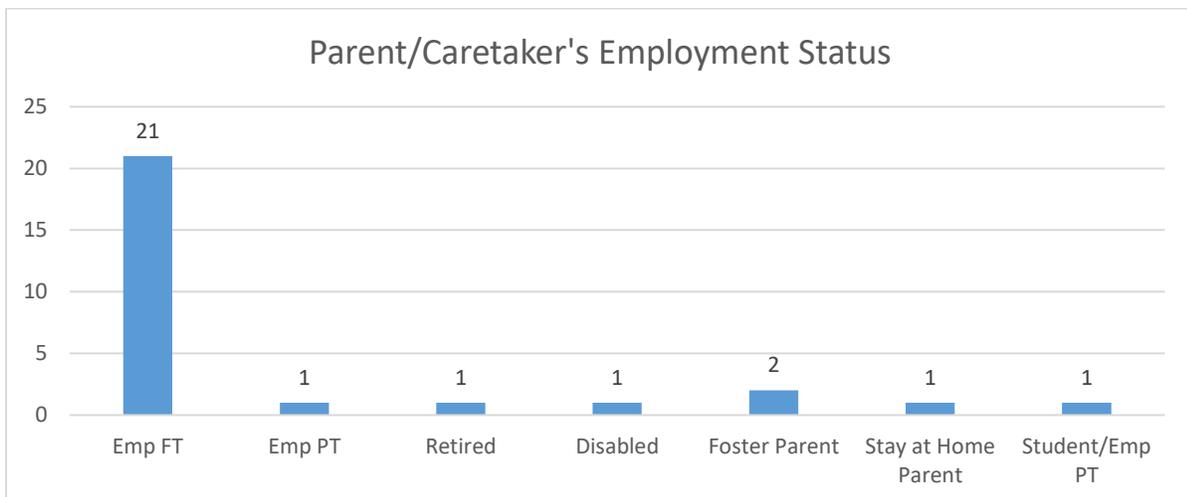
In their pre-meeting surveys, parents noted that their children received treatment at a variety of organizations, including Jeffers, Mann, and Artman Pediatrics; Duke Childrens Hospital; Durham County Health Department; and “Vance County home and school.”

Child(ren)’s Prescription Medication Use

Sixty six percent of parents reported their child(ren) taking prescription medications on a regular basis. The prescriptions noted include those for asthma such nebulizers, albuterol, and emergency inhalers; as well as ibuprofen, Benadryl, Tylenol, Miralax, and Levothyroxine.

Parent/Caretaker’s Employment Status

The vast majority of parent respondents were employed full-time.

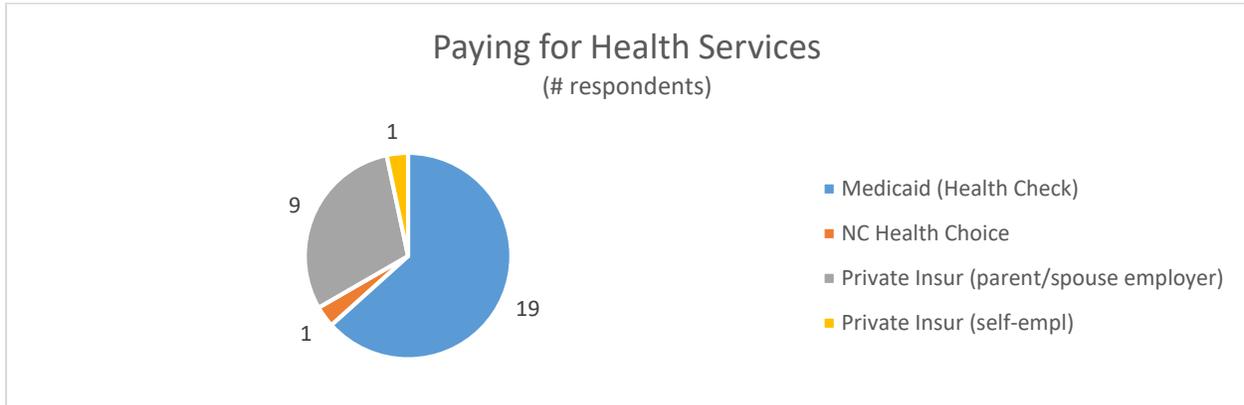


This corresponds with national rates of employment participation among Medicaid recipients, which some research estimates is as high as 8 in 10 nonelderly adults with Medicaid coverage.⁶

⁶ <https://www.kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work/>

Paying for Child(ren)'s Health Care

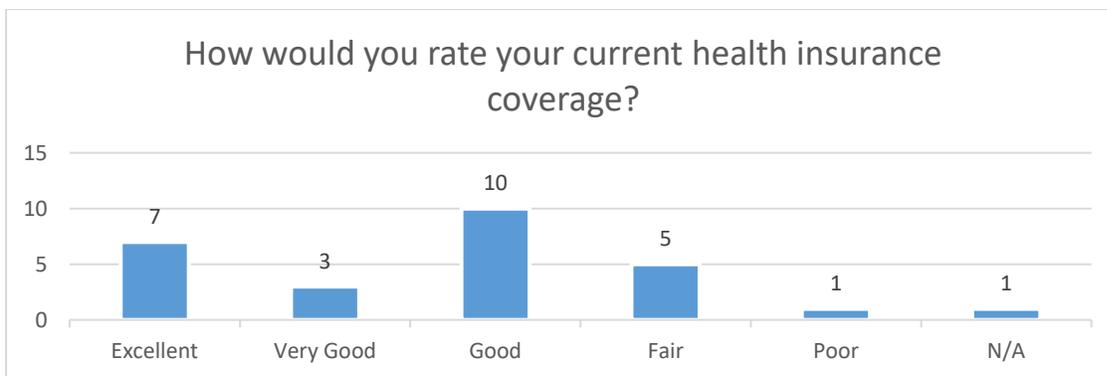
Nineteen of thirty parent respondents (63%) report utilizing Medicaid to pay for their child's insurance. No respondents reported obtaining health insurance through the Affordable Care Act exchanges ("Obamacare.") In a related question, one family reported not having insurance, from 4-11 months. One family reported not having any insurance for a short period of time but now had insurance.



Per research cited in a 2017 National Conference of State Legislatures report, approximately 1/3 of families of children and youth with special health care needs utilize Medicaid or the Children's Health Insurance Program (CHIP). However, that study found, 35.2% of minority children and youth with special health care needs experienced one or more periods without insurance in the previous year.⁷

Rating Current Health Insurance Coverage

Families were relatively satisfied with their health care insurance, with the largest number rating their coverage as "Good," or the middle of the rating scale. Seven parents, or 27%, rated their coverage as "Excellent." Clearly room for improvement exists. Section III provides additional detail regarding perceptions of quality, affordability, and adequacy of health insurance coverage.



As previously stated, 20% of American surveyed rated their insurance as "Fair" and 5% as "Poor;" additionally, 33% rated their insurance as excellent and 41% as "Good."⁸

⁷ National Conference of State Legislatures (NCSL), "Improving Systems of Care for Children with Special Needs," Sept 2017, p. 1, 3.

⁸ <https://www.rwjf.org/en/library/articles-and-news/2016/02/patient-perceptions-vary-across-seven-states.html>

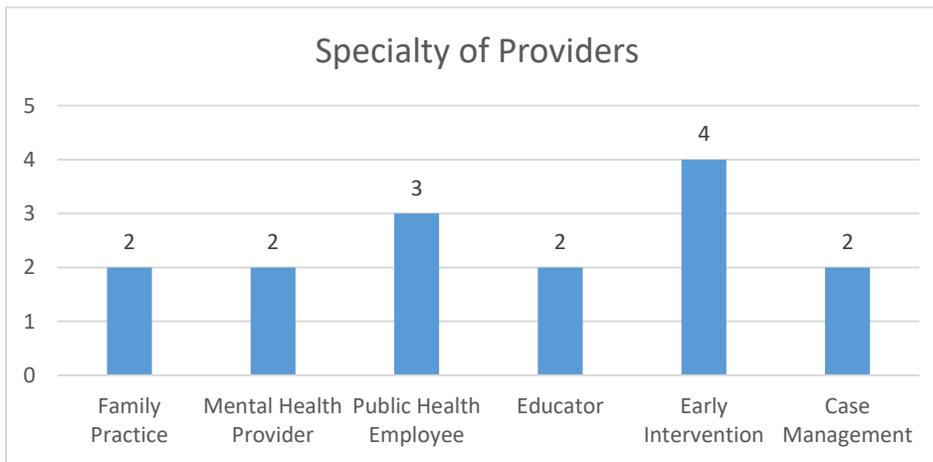
Profile of Participating Providers

Counties Served: Providers offered service in a variety of counties and in Virginia, with the greatest number serving Vance County.

County	Number of Providers Serving
Granville	10
Vance	12
Durham	3
Franklin	6
Wake	2
Warren	4
Halifax	1
Person	1
VIRGINIA	2

Provider Specialty

Providers represented a variety of specialties, with the largest number offering Early Intervention services. Within the pre-meeting surveys, one provider each identified their specialties as Family Practice, Pediatrician, or Obstetrics.



Paying for Children’s Health Care

Providers were asked to rank the form of payment for health care most used by their clients on a scale of 1-7, with 1=Least Used and 7=Most Used. Medicaid and NC Health Choice were the most commonly utilized by their patients as a group. By contrast, among the CYSHCN parents surveyed, Medicaid and Private Insurance are most used. Additionally, providers saw clients who had “Obamacare” insurance, while no parents reported using this. Finally, providers reported seeing clients with No Insurance Coverage on a relatively frequent basis.

Form of Health Insurance	Avg Score (1=Least Used; 7=Most Used)
Medicaid	6.5
NC Health Choice	5.9
Private Insurance through ACA (“Obamacare”)	3.29
Private Insurance through Employer	4.5
Private Insurance (self-employed)	2.57
Military/Veterans’ Insurance	1.29
No insurance coverage	4.7

IV. HIGH-LEVEL THEMES

The focus groups and survey responses fostered an informative and wide-ranging discussion of the various insurance issues affecting the care of children and youth with special health care needs. Several key themes emerged from the parent/caretaker and provider feedback:

- A. Challenges to Obtaining Health Insurance for Children and Youth with Special Health Care Needs
- B. Lack of Knowledge re Insurance Options and Alternative Sources of Financial Support
- C. Limitations of Current CYSHCN Families' Health Insurance
- D. Implications of Inadequate or Unaffordable Health Insurance
- E. Educational and Training Needs
- F. Other Challenges to Obtaining Health Care for Children and Youth with Special Health Care Needs

Each section and some subsections are organized to provider survey results followed by the focus group discussion.

A. Challenges to Obtaining Health Insurance for Children and Youth with Special Health Care Needs

Parents/caretakers and providers noted several obstacles to obtaining health insurance for children and youth with special health care needs, primarily within the areas of cost and eligibility.

As a baseline indicator, parents generally reported some difficulty in finding adequate and affordable coverage.

Difficulty in Finding Appropriate and Affordable Health Care Plan

On a scale of 1-4, parents/caretakers reported the following levels of difficulty in finding appropriate health care.

Aspect of Health Care Plan	Avg Score
Difficulty in finding a plan with type of coverage needed	3.15
Difficulty in finding affordable plan	3.25

Scale of 1-4, with 1=Not at All Difficult, 2=Not too Difficult; 3=Somewhat Difficult; and 4=Very Difficult

As previously stated, 29% of US adults consider their health care costs to be “unreasonable.”⁹

COST

The complexity of health care financing provides many opportunities for families to be priced out of the insurance market. Families reported challenges with costly premiums, deductibles, and co-pays. Some families reported that, as their costs increased, their benefits tended to decrease.

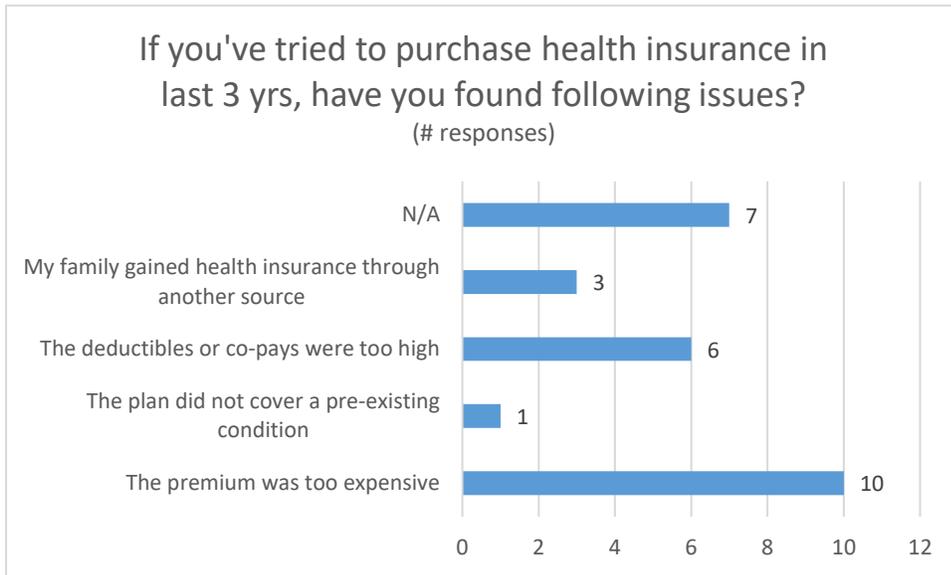
COST: Purchasing Family Insurance

Surveyed families were asked if they had tried to purchase health insurance on their own (rather than through an employer) over the last three years. Six families reported doing so through the private insurance market, with six others trying to purchase insurance through the Affordable Care Act (“Obamacare”) exchanges.

⁹ <https://www.rwjf.org/en/library/articles-and-news/2016/02/patient-perceptions-vary-across-seven-states.html>

Two parents who tried to purchase Obamacare reported on the high costs in their comments, “But I couldn’t afford the 11,000 deductible or monthly fee” and “Husband was unable to get something that was affordable through this program without having a high deductible.”

As the chart below shows, while six parents reported high deductibles or co-pays, 10 families who tried to purchase insurance reported that the premiums were too expensive.



COST: Providers’ Perceptions of Clients’ Challenges in Buying Private Insurance

Providers surveyed were asked how frequently they’ve heard of families of CYSHCN experiencing cost obstacles in attempting to obtain health insurance. On a scale of 1-5, with 1=Never and 5=Very Often, providers most frequently reported (“Sometimes”) hearing of high deductibles and co-pays, followed by expensive premiums.

As provider interactions with clients would mainly involve co-pays or deductibles in transacting payment for their services, more awareness of these issues seems reasonable.

How often have you heard of CYSHCN families having the following issues when trying to buy private health insurance?	Avg Score 1=Never; 5=Very Often
Premium was too expensive	2.89
Plan did not cover pre-existing condition	2.4
Deductibles and/or co-pays were too high	3.11
Plan didn’t cover the doctors they needed	2.25

Scale of 1-5, with 1=Never; 2=Infrequently; 3=Sometimes; 4=Often; and 5=Very Often

Note: Five providers were not sure re doctor coverage; four were unsure re clients’ premiums and deductibles, and 3 were unsure re coverage of pre-existing conditions.

COST: Providers: Clients’ Health Insurance: Adequate and Affordable Coverage

On a scale of 1-5, providers did not feel that their clients’ insurance policies offered adequate coverage. Asked whether they agreed with the statements below, providers generally disagreed that client

coverage was adequate for most of the features, with “a large network of providers” receiving the most positive feedback. The lowest scoring statement was “Offer affordable premiums.”

Feature of Coverage	Avg Score -- Providers
Offer adequate coverage for client needs	2.77
Offer affordable premiums	2.17
Offer affordable deductibles and co-pays	2.58
Offer sufficient prescription drug coverage	2.31
Offer a large enough network of providers	2.85

On a scale of 1-5, with 1=Strongly Disagree; 2=Disagree; 3=Neutral; 4=Agree; and 5=Strongly Agree

Providers offered the following comments.

- do not really know the in-depth of the insurance plan if other than medicaid.
- Most of my patients have Medicaid
- i do not have any idea if my patient's plan is obamacare, employer, or privately obtained. There is no way for the physiciain to know this.

Finally, in other survey comments, parents and providers emphasized the various scenarios in which cost was a major challenge to obtaining health insurance.

- PARENT: the biggest challenge for this family is the size of the family and having to maintain all coverage.
- PARENT: when both parents work and have private insurance some services are not affordable.
- PARENT: Payment of medical bills and inability to receive services for our daughter due to being employed and making too much to qualify for services she deserves
- PROVIDER: Affordable
- PROVIDER: A lot of families do not qualify, because the eligibility guidelines for family Medicaid are so low. A lot of families who have commercial insurance have limits to the benefits and if they purchase insurance through the exchanges the deductibles and copays are unaffordable.
- PROVIDER: Money. Either make too much or not enough.

FOCUS GROUP DISCUSSION: COST

Cost issues affect families at both ends of the income scale. In focus groups, parents/caretakers and providers noted that cost issues included families having too low or too high an income. One focus group provider noted that many of her patients tell her that they cannot afford Obamacare, even with its subsidies. At the other end of the scale, some of her patients “make too much to get Medicaid.”

The provider group discussed how some families might divorce so that one parent can qualify for Medicaid services for their child; sometimes families divest of assets, or move them out of their names, to try to qualify. The group felt that it wasn’t right to penalize families who had worked hard and perhaps obtained some land and a home.

Many of the parent focus group members noted that they had health insurance through their or their spouse’s employer. Some noted dissatisfaction with the high premiums and deductibles.

For families whose children’s care is very costly, meeting these expenses is a challenge no matter how high the income. One focus group parent who was unhappy with her private insurance policy wished

that Medicaid and other funding sources were Need-based rather than Income-based. “I feel like my child is getting punished because we work.”

Many parents expressed the sentiment that, even as their premiums increased, their covered services went down. Several parents had insurance from their employer, the State of North Carolina, and noted that the premiums were significantly increasing from 2016. For example, a single person paid \$15 per month in 2017, but will now pay \$50 per month in 2018, over 3x the cost.

In 2016, 45% of US adults surveyed stated that their health insurance premiums have increased over the last two years, and 35% say their co-pays and deductibles have increased.¹⁰

ELIGIBILITY

In their surveys, parents provided the following comments regarding eligibility challenges.

- PARENT: When you have intact families you can't qualify for medicad or nc health choice if you both have incomes.
- PARENT: THE SYSTEM IS BROKEN!!!! I can't get the coverage my children so desperately need b/c they are claiming we make too much money despite being broke at the end of each month. It's ridiculous. My childrens' quality of life is clearly hindered by this fact.

FOCUS GROUP DISCUSSION: ELIGIBILITY

In addition to the insurance challenges related to family income, parents and providers noted eligibility challenges related to receiving Medicaid, including maintaining eligibility for young people on Medicaid turning 21; renewing Medicaid coverage annually; and demonstrating need.

ELIGIBILITY: Medicaid Coverage at Age 21

As the provider focus group discussed, for young people turning 21, maintaining Medicaid becomes more challenging. Young people must go through a process to re-enroll for benefits, which requires a lot of intensive paperwork. People working with case coordinators at the LME/MCO can receive assistance there in applying for Medicaid as an adult.

The group discussed the fact that it is generally more challenging to receive Medicaid as an adult unless a person has a substantial enough disability, such as bipolar disorder or schizophrenia. Foster care residents with outpatient care and certain mental health issues may also receive services, but they still have difficulty reapplying for services at 21.

ELIGIBILITY: Renewing Medicaid Coverage Annually

One public health employee noted that families often don't renew their Medicaid each year on their anniversary date, with families sometimes stating they do not receive the paperwork. If families have moved frequently, they may not receive their updated paperwork.

If families do not file their renewal paperwork in a timely manner, they may need to initiate a time-consuming process of filing paperwork again, which can take an afternoon; if missing documentation, the process can necessitate multiple visits.

¹⁰ <https://www.rwjf.org/en/library/articles-and-news/2016/02/patient-perceptions-vary-across-seven-states.html>

This renewal process can place huge burdens on families. A public health employee suggested that some employers aren't willing to give employees time off to file such paperwork, and thus employees may have the choice of losing their insurance or losing their job.

The provider group discussed the potential for the state of North Carolina to privatize Medicaid, especially that for mental health and behavioral health services. The participants generally agreed that privatization would create challenges. On the other hand, privatization may also provide opportunities for more slots if private companies can find a way to finance Innovation Waivers more efficiently.

ELIGIBILITY: Demonstrating Need/Eligibility

Some families feel the need to go to great lengths to ensure their eligibility for services. One focus group grandparent shared the story of a child in her grandson's school who had unkempt hair and shoes that were too big for him, which the parent tied with laces. The grandmother donated some of her grandson's clothes to the family, while someone else fixed the boy's hair. To her surprise, the next day the boy returned to school with the unkempt hair and poorly-fitting shoes. The grandmother was told that the boy's parents keep him looking that way to underscore that he needs services and financial support.

While not referring to the costs of health insurance, the focus group grandparent noted that, because she is also a licensed foster parent, she might have been eligible for some foster care funding. However, the state did not offer her funding because of her relationship to her grandson. Her doctor was quite upset to hear this, and helped her to get in contact with Social Security in order to secure SSI benefits for her grandson.

B. Lack of Knowledge re Insurance Options and Alternative Sources of Financial Support

Parents/caretakers and providers reported a lack of knowledge regarding family eligibility for various insurance options; insurance coverage of specific services; and other alternative sources of medical financing.

Understanding Eligibility for Various Insurance Sources

On a scale of 1-4, with 1=Not at All Comfortable, 2=Somewhat Comfortable; 3=Comfortable; and 4=Very Comfortable, parents/caretakers report a lack of comfort in understanding their family’s eligibility for the different insurance sources. Providers, while slightly more optimistic, generally reported a lack of comfort among their clients.

An opportunity to educate families on the Affordable Care Act, especially as it evolves, and NC Health Choice could be helpful to families.

Comfort in Understanding Eligibility for . . .	Avg Score – Parents	Avg Score -- Providers
Medicaid	2.74	2.85
NC Health Choice	2.43	2.46
Affordable Care Act (Obamacare) coverage	1.83	2.08
Private Insurance	2.27	2.28

Scale: 1=Not at All Comfortable, 2=Somewhat Comfortable; 3=Comfortable; and 4=Very Comfortable

In their comments, one parent noted that they were a retired disabled veteran.

Another parent elaborated, “We do not qualify for Medicaid. And sadly, that is the ONLY way our kids can get help which I think is absurd in and of itself. Seems like you can get all the help you want for your kids if you are unemployed or don't make much money for whatever reason. However, if you are considered making too much by the state, you don't qualify for squat and your kids are not helped. I can't even get grants. I've tried it all. I shop consignment stores, do sales, coupons, etc. and for that, I'm still considered making too much! I just feel like my kids are being punished b/c our family has a decent job and budgets. How is this even remotely fair when it is supposed to be based on teh kids' needs? That's where I'm truly upset. We pay insurance every month and have some of the BEST insurance around yet still not enough in regards to special needs kids. They simply need more regular insurance companies can't provide.”

Understanding Services Covered by Various Insurances

Providers felt that their clients were most comfortable with understanding services covered by Medicaid, but the average score was still less than 3, or “Comfortable.”

Clients’ Comfort in Understanding What Services are Covered by:	Avg Score -- Providers
Medicaid	2.92
NC Health Choice	2.52
Affordable Care Act (Obamacare) coverage	2.08
Private Insurance	2.40

Scale: 1=Not at All Comfortable, 2=Somewhat Comfortable; 3=Comfortable; and 4=Very Comfortable

One provider stated in their comments: “Provide tutorial services with behavioral component to academically at-risk children. So most health questions are rarely discussed.”

A survey study by the University of Connecticut Health Disparities Institute found that “The survey shows that some (private insurance) enrollees struggle to understand basic health insurance terminology and how to use their benefits correctly. People with lower educational levels have lower HIL (health insurance literacy) skills; however, when we compared the HIL in people with the same educational level, we found significant differences by race, ethnicity and language preference with Black and Hispanic enrollees having more difficulty than Whites.”¹¹

Understanding Eligibility for Alternative Financing Sources

Limited sources of funding and support are available for families seeking services. These forms include:

- NC Innovations Waivers: Funding for children and youth with intellectual or developmental disabilities who are at risk of institutionalized care. Families can register their children on the Registry of Unmet Needs to apply for this funding.¹²
- NC Tracks (formerly Integrated Payment Reporting System Funding): Limited funding provided to organizations to serve clients without health insurance or Medicaid.
- Early Periodic Screening, Diagnostic, and Testing Funding (EPSDT): defined by the North Carolina Department of Health and Human Services as “. . . the federal law that says Medicaid must provide all medically necessary health care services to Medicaid-eligible children. Even if a service is not covered under the NC Medicaid State Plan, it can be covered for recipients under 21 years of age if the service is listed at 1905(a) of the Social Security Act and if all EPSDT criteria are met.”¹³
- NC START: North Carolina Systemic, Therapeutic, Assessment, Resources and Treatment (NC START) is a statewide community crisis prevention and intervention program for individuals age 6 and above with intellectual/developmental disability and co-occurring complex behavioral and/or mental health needs.¹⁴
- CAP/C (Community Alternatives Program for Children): Medicaid beneficiaries (or their representatives) can direct their personal care by employing service providers, including in-home and pediatric personal care.

Most of the focus group participants and survey respondents had little knowledge of these alternative funding sources. Please note: the survey did not ask about the last two sources, which were discussed in the focus groups.

Understanding Eligibility for Alternative Financing Sources

On a scale of 1-4, parents/caretakers report little understanding of their family’s eligibility for alternative funding sources. Providers are even less optimistic about their clients’ comfort with understanding eligibility requirements for these programs. (Please see chart on next page.)

While the alternative funding programs are all limited and have various eligibility requirements, and are likely particularly vulnerable in this governmental funding environment, increasing family and provider awareness of these alternative sources might be a good educational opportunity as well.

¹¹ <https://health.uconn.edu/health-disparities/health-insurance-literacy-survey-report/>

¹² <https://www.alliancebhc.org/consumers-families/idd-resources/nc-innovations-1915-c-waiver/>

¹³ <https://www.ncdhhs.gov/providers/provider-info/mental-health/early-periodic-screening-diagnostic-and-treatment-medicaid-services-for-children>

¹⁴ <https://www.ncdhhs.gov/divisions/mhddsas/nc-start>

Comfort in Understanding Eligibility for . . .	Avg Score -- Parents	Avg Score -- Providers
NC Innovations Waivers	2.13	1.45
Early & Periodic Screening, Diagnostic, and Treatment (EPSDT) funding	2.14	1.50
NC Tracks (formerly Integrated Payment and Reporting System (IPRS) funds)	1.77	1.55

Scale: 1=Not at All Comfortable, 2=Somewhat Comfortable; 3=Comfortable; and 4=Very Comfortable

In their survey comments, one parent said, “No problems exist.” Another stated, “Don’t know what these are.” A third parent stated, “Don't have any idea what NC Tracks is. Haven't had the opportunity to apply for innovations b/c was trying to get CAP-C as told it was better and more of what we needed. Yet, denied 3X despite pleas from doctors, therapists and the like.”

FOCUS GROUP DISCUSSION: Alternative Financing Sources

The focus group discussions on alternative financing sources demonstrated that families and providers lack knowledge on other ways to finance patient care.

Alternative Financing Sources: IPRS and EPSDT Funding

According to a focus group participant representing an LME/MCO, some providers receive certain funding, like (NC Tracks/) Integrated Payment Reporting System funding that includes the obligation to provide immediate assessments to patients regardless of their ability to pay. For example, a comprehensive community clinic receiving such funds must see all patients.

The LME/MCO representative explained that EPSDT Funding authorizes services over and above what Medicaid allows. For example, if a patient requires Trauma-focused Cognitive Behavior Therapy, s/he can receive this therapy in addition to in-home therapy through EPSDT funding. Additionally, young people living in residential treatment facilities may utilize these funds for specialized care.

Alternative Financing Sources: Innovations Waivers

Both focus groups discussed NC Innovations Waivers at length. One provider, who formerly worked with CDSA (Children’s Development Service Agency) stated that few of her former clients with children with developmental needs were unaware of Innovations Waivers unless CDSA helped them to apply for the waiver. She felt that families could get additional supports for medical needs “a lot quicker” than they could for developmental needs.

The LME/MCO representative suggested that families contact the main phone number 800-939-5911 to begin the process of applying for waivers. While the process is generally one of first-come, first-served, the process does try to prioritize high-needs individuals who have been waiting a long time for services.

The provider focus group discussed the limitations of Medicaid for families of children with developmental disabilities, who are constrained in the in-home and community-based services they may receive as well as in the frequency of services. Said a representative of the local LME/MCO, “Unless they are part of a waiver, it’s difficult to have adequate funding and services.”

In the fall, the LME/MCO representative explained, the Innovations Waiver slots are allocated to regions by the NC Division of Medical Assistance (NC DMA) to LME/MCOs, who thus lack direct control over the number of Innovations Waivers slots available for a particular area. Therefore, while many families in

Granville and Vance counties, and the surrounding area, have Innovation Waivers, there are 100+ families on the Registry of Unmet Needs, including some who've been on the list for years.

Within the parent focus group, one parent had been on the Waiver waitlist for about three years. Another had put her child on the Registry of Unmet Needs when the child was three months old; the child is now seven, and they still have not received services. When another parent said such stories were discouraging her from signing up on the register, the parent of the seven-year old said that, even if her child gets services at 16, those services will still be needed.

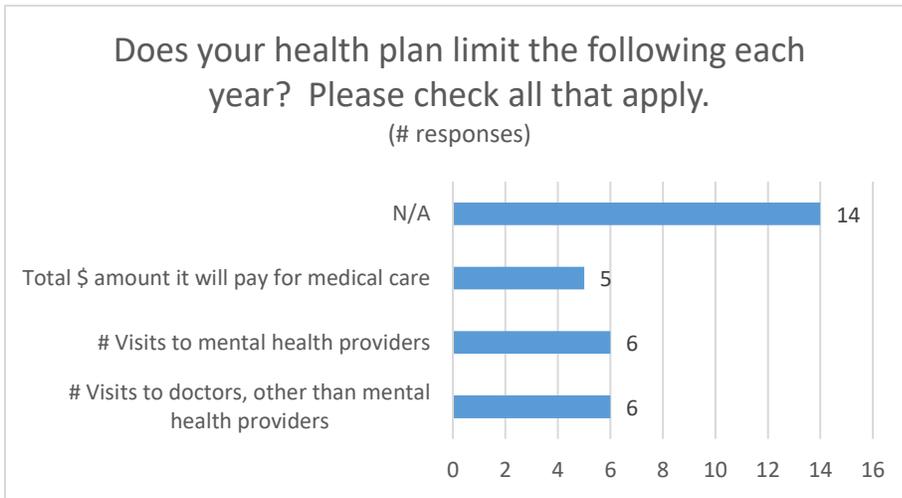
Many parents agreed that few parents know about CAP-C. Additionally, while the group did not discuss these in detail, one provider recalled seeing "children cycle through NC Start and NC Tracks without treatment."

C. Limitations of Current CYSHCN Families' Health Insurance

Most families did not experience significant treatment barriers due to their health insurance, but noted some plan limitations in terms of coverage issues, out of network providers, and high co-pays for specialty services. Providers discussed the challenge of low Medicaid reimbursement rates.

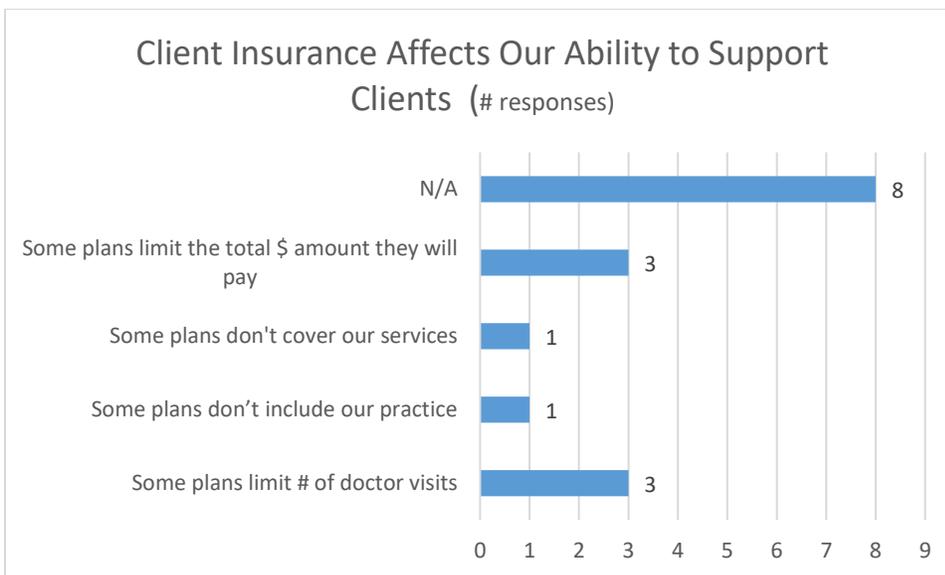
Health Insurance Plan Limitations

Generally speaking, most parent respondents did not report being limited by their insurers in terms of the number of doctor visits or dollar amounts of health care spending on an annual basis. However, about 20% of respondents reported limitations, either for mental health care or for other health care.



PROVIDERS SURVEY: Health Insurance Plan Limitations

About half of all providers responded that their clients' insurance plans do not affect their ability to support their clients. Nonetheless, three providers each noted limitations on the numbers of doctor visits or total dollar amounts for medical care.



In their Pre-Meeting Survey, providers stated that “sometimes” or “frequently” that “some of our organization’s services are not covered by some of my clients’ insurance networks.”

As previously stated, some national studies have shown that health care providers feel constricted in the treatment options they can offer their patients who have inadequate health insurance.¹⁵

Parent Survey: Other Problems with Health Insurance

Digging more deeply into the challenges of some limitations, the Parent/Caretaker survey found that about 10% of families reported problems with service coverage or charges not paid by insurance.

Problems with Current Health Insurance	# Respondents
I had expensive medical bills for services for my child not covered by insurance	3
My child's doctor charged a lot more than my insurance would pay and I had to pay the difference	2
My child's doctor's office told me they do not accept my insurance	2

One parent stated, “I cannot get the therapies my children need b/c insurance only pays for a certain # each year. I had to choose which therapy I wanted even though they need them all.”

In their surveys, parents and providers were given an opportunity to provide additional comments regarding how to make health insurance affordable and adequate for families of children and youth with special health care needs. Their comments included:

- PARENT: Making services available for working families
- PROVIDER: All children and youth with special health care needs should be eligible for Medicaid coverage in all states.

FOCUS GROUP DISCUSSION: Insurance-Related Challenges to Obtaining Services

Parents and provider focus groups discussed insurance issues that presented challenges for obtaining services, including being “out of network;” having limits to the number of visits or dollars spend on medical care; and high co-pays.

Out of Network

Focus group providers discussed the fact that, in some cases, patients newly-arrived to the area, or those from neighboring Virginia, may not have North Carolina-based health insurance, which will limit their ability to obtain specialty services in this state.

One focus group parent noted that her private insurance did not cover her daughter’s feeding therapy or speech therapy because they were out of network or the practices did not accept her insurance. While she has an HSA that is somewhat helpful, she still finds it difficult to get services. She recently looked into GiGi’s Playhouse (<https://gigisplayhouse.org/raleigh/>), a nonprofit located in Raleigh, and was able to get an appointment for her daughter to have a speech therapy evaluation in November. She reported that all of the services were free.

Another focus group parent drives her child weekly to Durham for OT (Occupational Therapy) and PT (Physical Therapy) services, noting that some practices don’t take her insurance. She is very satisfied

¹⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1578641/>.

with this provider, whom she feels communicates well with her. A previous speech therapist had tried to provide group therapy, which she found unhelpful, since she felt that every child had a different speech goal.

Employees who worked at the Department of Public Health stated that their clients' Medicaid insurance covers the services they receive at the health department. Because the Health Department receives Title V funds, they are required to serve anyone who comes to the Health Department. Referring patients out to other providers is more difficult, as this is done by primary care doctors. As one public health employee stated in their survey comments: "One problem is only the PCP can enter a referral so if they are seen at the health department we can't refer them somewhere else if we are not the PCP."

The LME/MCO representative noted that services within some counties may be contracting with some LME/MCOs but not with others. For patients who need a service not covered by the LME/MCOs contracts, a special "case agreement" can be developed between the provider and the one client.

Limits to Services

The parent group discussed the inclusion of various services, including autism services, within private insurance policies, but noted that the plan limits the number of provider visits.

One parent spoke of her own medications, and the fact that her provider "kicked out" some of the more expensive medications. That parent shrugged and noted that she had to pay the high costs: what else could she do if she needed the medicines? Said another parent, "It's scary when they won't pay for medications."

High Co-Pays

Additionally, co-pays were high, especially for specialty services. One parent noted that she is adding her 17-year old daughter, who has diabetes, to her private insurance during the upcoming enrollment period, and she is concerned about what her new premium will be. "We need to keep Cap-C, (community alternatives program)" she said.

Medicaid Reimbursement Issues

The group discussed the fact that, especially for very expensive, intensive services, providers would like to have higher rates of reimbursement. Providers must make decisions about the level of credentialed personnel they can offer to patients based on reimbursement rates.

The LME/MCO provider explained that his organization can "enhance" any Medicaid rate, but that the provider must formally request the rate and complete a burdensome paperwork process to document the need. While larger providers have personnel to navigate this complicated process, smaller providers generally do not. The LME/MCO tries to coach small providers through the process, but it's still a large administrative burden. Sometimes providers give up on getting an enhanced rate and instead end up letting go of staff.

The group discussed the fact that, as the state continues to cut back funding, some organizations have facilities, but because they can't afford to staff appropriately, they may end up closing their doors.

D. Implications of Inadequate or Unaffordable Health Insurance

Parents and providers noted various care-related, financial, and operational challenges of inadequate or unaffordable health insurance for children and youth with special health care needs.

SURVEY PARENTS: Care-Related Implications of Inadequate or Unaffordable Health Insurance

Most families stated that they did not have the following care-related issues in their management of their health care costs. However, about 10% of respondents did report some challenges that resulted in skipped appointments or tests; and insufficient dental care, prescriptions, or specialist care.

In last 12 months, was there ever a time when insurance or financial issues meant that you . . .	# Respondents
Did not fill a prescription for your child(ren)'s medicine	2
Skipped a medical test, treatment, or follow-up recommended by a doctor for your children	3
Did not get dental care for your child	3
You did not see a specialist for your child when you or your doctor thought you needed one	3
N/A	9

In their comments, one parent each stated, “Nothing medical wish would help educational,” “had to reschedule appointment,” and “Foster child placement. Medicaid eligible.”

Another parent stated, “My daughter needs a hearing aid. I cannot get it b/c I cannot afford it. We’ve been denied CAP-C for my son. He needs extensive dental care that our insurance will not cover. He’s in pain. The dentists are us are trying to find a way to get him the help he needs to no avail. My kids need therapy I cannot get. Being told we make too much money for the Medicaid and saying we don’t qualify for CAP-C despite my child needing 24/7 care!”

PROVIDERS: Care-Related Implications of Inadequate or Unaffordable Health Insurance

On a scale of 1-5, with 1=Never; 2=Infrequently; 3=Sometimes; 4=Often; and 5=Very Often, most providers stated that their clients generally did not experience the following challenges in managing their health care costs. Nonetheless, the providers’ clients “Sometimes” were unable to get dental care for their child or see a doctor when their child had a medical concern.

In last 12 months, was there ever a time when insurance or financial issues meant that your clients . . .	Avg Score 1=Never; 5=Very Often
Did not fill a prescription for child(ren)'s medicine	2.43
Skipped a medical test, treatment, or follow-up recommended by your (or another provider)	2.67
Did not get dental care for their child	3.33
Didn't go to doctor or clinic when child had a medical concern	2.90
Didn't see a specialist for your child when you or another doctor recommended one	3.27

Note: 6 providers stated they were not sure about the prescription concern.

In their comments, providers stated:

- Because we work with Medicaid recipients the biggest barrier is lack of transportation
- If they didn’t receive care, their Medicaid had lapsed and they needed to re-apply.

In their Pre-Meeting Survey, two providers stated that “frequently” “our clients did not get dental care for their child.”

FOCUS GROUP DISCUSSION – IMPLICATIONS OF INADQUATE OR UNAFFORDABLE HEALTH INSURANCE

The provider focus group discussed challenges for insuring young people of different ages. For children ages 3 and under, receiving mental health or behavioral health services, often in the form of play therapy, is a challenge. Very few counties offer mental health providers for children aged 3 or younger; one participant recalled such a provider in Johnston County, who apparently had a long waitlist.

The LME/MCO does not cover children under age 3, but those children may be covered if they are cared for within the course of covered family therapy.

Providers discussed the health insurance challenges of children over five years old, with one doctor suggesting that children between the ages of 10-17 most often lack health insurance, including Medicaid. One provider said that children up to age five “have an advantage,” in that they have the institutional support (e.g., CDSA) to obtain other referrals.

The 2016 national survey found that one in seven US adults indicated that, at least once in the last two years, they needed health care but could not get it due to insurance issues. Additionally, one third stated that they had received health care in a hospital emergency room at least once in that same time period, and 23% report going to the ER more often than they used to.¹⁶

Implications of Medical Debt

Survey Parents: Implications of Medical Debt

Managing the costs of medical care puts significant stressors on a family’s finances. In fact, health care costs are the leading cause of bankruptcy in the United States; in 2014, approximately 40% of American households had medical debt.¹⁷

In their surveys, several parents noted that medical debts had presented challenges in their families, while 10 families said it did not. In their comments, one parent stated, “Foster child placement – no medical debt incurred.”

In the last 12 months, has any of the following occurred within your family?	# Respondents
I had problems paying or was unable to pay for my child's medical bills	4
I was contacted by a collection agency about owing money for my child's medical bills	3
We had to change our family's way of life significantly in order to pay my child's medical bills	2
N/A	10

In a related question, five families each noted that because of medical debts over the last two years, their family has used up all their savings or taken on credit card debts.

Among US families of children and youth with special health care needs, 21% report dealing with financial problems due to their child’s health condition.¹⁸

¹⁶ <https://www.rwjf.org/en/library/articles-and-news/2016/02/patient-perceptions-vary-across-seven-states.html>

¹⁷ <https://www.theatlantic.com/business/archive/2017/02/medical-debt/516096/>

¹⁸ NCSL, “Improving Systems of Care for Children with Special Needs,” Sept 2017, p. 2.

In the last 2 years, has any of the following occurred within your family due to medical debt?	# Respondents
We've been unable to pay for basic necessities like food, heat, or rent	2
We've used up all our savings	5
We've taken on credit card debts	5
N/A	10

In their comments, one parent stated, “Foster child placement – no medical debt incurred” and another stated “I have to pay monthly on medical bill for myself.”

Survey Providers: Implications of Medical Debt

While providers are not necessarily aware of a family’s finances, they reported some knowledge of a family’s ability to pay for basic necessities being compromised by medical debts.

In last 2 years, was there ever a time when insurance or financial issues meant that your clients . . .	Avg Score 1=Never; 5=Very Often
Being unable to pay their child’s medical bills	2.57
Being contacted by a collection agency about their child’s medical bills	2.22
Being unable to pay for basic necessities like food, heat, or rent	2.70
Using up all of their savings	2.40
Taking out a mortgage against their home or took out a loan	1.50
Taking on credit card debts	1.83

On a scale of 1-5, with 1=Never; 2=Infrequently; 3=Sometimes; 4=Often; and 5=Very Often

Note: Six providers stated they were not sure about credit card debt concerns of their clients; five were unsure re parents being unable to pay their medical bills; and four were unsure about clients’ taking out extra mortgage or loans.

In their comments, one provider stated “Usually not an issue with the clients we serve.”

The 2016 national survey results show that 26% of adults indicated that, over the previous two years, their health care costs have caused serious financial problems for their family. Within that group, over 40% stated that they had spent all or most of their savings on health care bills.¹⁹

¹⁹ <https://www.rwjf.org/en/library/articles-and-news/2016/02/patient-perceptions-vary-across-seven-states.html>

E. Educational and Training Needs

Parents and providers expressed interest in education and information regarding general medical- and school-based resources; insurance options and eligibility; and navigating the insurance and health care systems.

In their pre-meeting surveys, parents generally expressed an understanding of how to advocate on their child's behalf with their doctors and with the school system. However, parents expressed less confidence in their knowledge of resources available within Granville and Vance counties for their children, including school-based resources.

Providers' pre-meeting surveys showed similar levels of need for more information about local medical and school providers. Providers also identified a need for more established channels among various providers for communicating and collaborating.

Parent and Provider Surveys: Educational Needs

In their survey comments, parents and providers noted the following educational and informational needs as the biggest challenges for CYSHCN families.

- PARENT: knowing resources and eligibility requirements
- PARENT: not understanding resources and options available
- PARENT: Knowledge to get services
- PARENT: Knowing the right insurance to apply for
- PARENT: The process for enrollment can be very challenging and difficult for families to understand.
- PROVIDER: Continuing education about the changing political environment and how it directly effects their health insurance coverage
- PROVIDER: Navigating the process.
- PROVIDER: Knowledge/navigation of the system.
- PROVIDER: Getting the information out to people who need it.
- PROVIDER: Understanding their eligibility.

Parents and providers survey respondents were offered an opportunity to include any additional suggestions for supporting families in obtaining affordable and adequate health insurance. Their suggestions included:

- PARENT: Quit the bureaucracy. They should have people come to the house and see what life is like on a daily basis for these families and then maybe they'd change their minds. Kids w/ special healthcare needs NEED more therapies and insurance companies should not limit that help.
- PROVIDER: Assess children with behavioral problems learning disabilities and attention deficits, work with Dr. Catacoot in "Fast Brain" resources

While not currently comfortable with providing information to clients on a variety of insurance related issues because of their own lack of knowledge, providers expressed willingness to pass on information they receive.

Provider Comfort in Providing Information to Clients

Comfort in Providing Information to Clients regarding . . .	Avg Score -- Providers
Medicaid	2.79
NC Health Choice	2.85
Affordable Care Act coverage (ObamaCare)	2.29
NC Innovations Waivers	1.93
Early & Periodic Screening, Diagnostic, and Treatment (EPSDT) funding	2.14
NC Tracks (formerly Integrated Payment and Reporting System (IPRS) funds)	1.92

In their comments, one provider stated, “Not aware of last program.”

F. Other Challenges to Obtaining Health Care for Children and Youth with Special Health Care Needs

In addition to insurance, parents/caretakers and providers noted other obstacles to CYSHCN families in obtaining health care services, including transportation and employment issues; a shortage of case management services; communication among providers; parent reticence to seek services; and attitudes toward children and youth with special health care needs.

Transportation and Employment Issues

As is the case in many Innovative Approaches counties, transportation continues to be a challenge for families seeking services.

In their survey comments, parents and providers noted the challenges of transportation, not only in getting to appointments, but even in applying for Medicaid benefits.

- PARENT: Having to travel for specialist
- PARENT: Having to drive far for services. Lack of providers in our area. Lack of the community knowing what's offered for special health care needs children.
- PROVIDER: Transportation to apply. Being eligible.
- PROVIDER: Transportation to DSS to apply for Medicaid and other needed Medicaid-related services.
- PARENT: The lack of certified health care professionals providing needed services in my area. The waiting list for needed services

In their pre-meeting surveys, providers strongly agreed that transportation was a barrier for some of their patients' families to use their services.

FOCUS GROUP DISCUSSIONS: OTHER CHALLENGES TO OBTAINING CARE

The Provider group discussed the KARTS (Kerr Area Transportation System) and Medicaid transportation options, which generally require a 2-5 day advanced notice to schedule. Such advanced notice presents challenges for families with urgent or emergency situations, such as an asthmatic child who needs services.

Additionally, these services require the family to wait all day at the provider until they are picked up again, and oftentimes siblings are not allowed to accompany the patient and parent. As a result, no one may be available to pick up the sibling from school or the bus stop. Parents may decide that it is simply easier to miss the appointment than to endanger the second child.

The group discussed the idea of utilizing Uber or a similar car service to provide flexibility in scheduling transportation to medical appointments. One provider suggested that Uber is trying to develop contracts within areas in which one or two large facilities serve a large number of patients (who then might become Uber customers.)

Unfortunately, working parents may have difficulty getting to appointments during the day if their employers isn't sympathetic to their family's needs. One parent noted that she had to take every Friday off from work initially to drive her child to his provider for services.

The group discussed the fact that many organizations let family members use FMLA time to go to appointments or take larger blocks of time off for family care. One provider noted that FMLA keeps your job available when you return, but that to get paid, you must use sick leave, vacation leave, short-term disability insurance, or leave donated by other employees.

One provider stated her concern with parents who are unable to make appointments due to transportation or work-related reasons, especially if they have a medically-fragile child. If the family misses three appointments and the child is failing to thrive, that provider felt that she needed to request the assistance of Child Protective Services (CPS) in order to get the child to a specialist at Duke, for example.

Managed Care

Care coordination is a challenge for many families and providers of children and youth with special health care needs. Nationally, 66.8% of Latino and 66.5% of black children and youth with special health care needs do not receive coordinated, ongoing, comprehensive care within a medical home.²⁰

Several providers expressed interest in more care coordination or case management services; one provider wished that kids over five could have care managers. The LME/MCO representative noted that his organization tried to pick up some of these duties after the state disbanded the case manager model several years ago. He offered to provide the group with a list of triggers to get care coordination through his agency; the list, he stated, included things like a history of hospitalization and failed levels of care. One provider stated that they would love to have a central coordinator to keep track of patients' various care and to answer questions about eligibility, obtaining and maintaining insurance, etc.

One provider, who is also a parent, noted that her child had an IEP at one school for two years, and then another IEP at another school, but that the school offered no follow-up to the family. She wished they could have had a navigator support them through the process and wondered how the families of children with more complex health conditions navigated the school system.

Communication Challenges Between Providers

One provider noted her concern with treatment requests from other providers for patient conditions about which she knows little. For example, she conducts many well-child checks in which the child's family is asked numerous questions and the child appears to be doing well.

The provider then sometimes receives a form from a therapist with the child's name and date of birth on it asking the provider to sign off on therapy services for the child. No other information is provided as to the child's condition or need for services. The provider stated that she needs additional documentation, either in the form of an evaluation or more information from the therapist requester, before she is comfortable signing off.

The LME/MCO suggested that the patient may be part of the enhanced benefit process, outside the regular outpatient therapy process. The child may receive an unauthorized assessment from a professional with the capacity to make such an assessment, such as a PA, MD, or Ph.D.

²⁰ NCSL, "Improving Systems of Care for Children with Special Needs," Sept 2017, p. 3.

The group discussed their preference to have a collaborative engagement with the other provider rather than just signing off on a paper with no information.

One provider referred to a discussion that took place at CCNC regarding their Integrated Health Approach. The organization has the internal capacity to make an assessment and make a detailed referral to a provider, who can use the information to create a good treatment plan.

Parent Reticence to Seek Services

The parent group discussed the fact that some families who have Medicaid don't necessarily seek services for their child. The group concluded that perhaps those families are frightened about what they may learn about their child's condition. A provider suggested that, in her experience, some families who see their child not meeting milestones and not thriving fear that DSS might take their child away. The parents may incorrectly feel that they are failing their child somehow, when the child's condition may have nothing to do with them.

Similarly, parents discussed, some Hispanic families may not seek services as frequently because one or more members of their family may be undocumented. They'd rather not engage with government agencies during a time of so much uncertainty about the implications of their immigration status.

As previously stated, a 2017 study by the American Academy of Pediatrics suggests that African-American and Hispanic children are much less likely to be identified for early intervention services than white children. In interviews with mothers of Black and Hispanic children, researchers found that mothers' beliefs about their child's development; mothers' perceptions and trust of doctors and the mothers' reliance on social networks for navigating care; competing social and financial pressures; and limited and conflicting information influenced parents' decisions to seek treatment for their child's developmental delays. The study suggests that unless these beliefs and perceptions are acknowledged and accommodated, identifying and providing treatment for all children with developmental delays will be hindered.²¹

In their pre-meeting surveys, only 1 of six parents strongly disagreed with the statement, "I feel that my input is an important part of my doctor's decisionmaking," while three parents strongly agreed and two parents agreed.

Attitudes Toward Children and Youth with Special Health Care Needs

It is apparent that additional education and support could help providers to support children and youth with special health care needs in a more effective manner. One grandparent spoke of her grandson being eligible for Occupational Therapy, but that, because he's the only "trach" student in the school, the teacher appears not to want to touch the boy. He is now mandated to wear a vest so that he doesn't accidentally "spit" on the teacher.

One provider recalled having a client who had "a thirst problem": he had to be watched by two people to ensure his and the providers' safety. The provider was by herself watching the young man, who would "grab" her and get away to get to his drink. She would have to call for help. As the young man grew stronger, this became a greater challenge.

²¹ <http://pediatrics.aappublications.org/content/early/2017/10/12/peds.2017-2059>

One provider noted that complications can ensue when a doctor needs to sign a form but a child doesn't have a primary care physician. In other cases, kids may be approved for a waiver but providers are uncomfortable working with a child who has difficult behavior. The physician may tell the family that they cannot help the child.

In an ideal world, said one parent, she would know up front what services are covered and which are not, so that she would have an idea of what a particular service would cost before she went to the doctor's. Another stated that she had been working since she was 13 years old, and was not 43, and felt that she had put enough into the system so that her child's services would be covered. In an ideal world, she said, anyone who works should qualify for insurance, and others who could not work should receive Medicaid.

V. SYSTEMS CHANGE OBJECTIVES RECOMMENDATIONS

By the nature of its strong network of members, the Innovative Approaches Steering Committee is well-positioned to share information among its parents, providers, educators, and other community members. Within a complicated and ever-changing federal and state health insurance system, the Innovative Approaches team can best serve the families and providers of Granville and Vance counties by facilitating the education of various stakeholders. Further, the Innovative Approaches team may leverage those opportunities to connect families and providers with (albeit limited) sources of health care financing.

Therefore, the following recommendations are offered within an overall framework of education and training opportunities for families, providers and educators, and the overall community. Links to federal or state sources of information are included. Additionally, helpful links for seminars and training offered by the NC Division of Medical Assistance can be found at <https://dma.ncdhhs.gov/providers/seminars-and-training>.

The Innovative Approaches team may take additional steps to ensure that minority community parents receive information and training as well, including culturally-competent training that recognizes different groups' experiences in obtaining insurance and health care. IA can partner with other organizations to develop or disseminate existing materials related to the following topics.

Health Insurance Basics

This introductory information/training can explain the various public and private options available to families of children and youth with special health care needs, as well as the various costs (premiums, co-pays, deductibles) and the tradeoffs in considering various plans.

Determining eligibility for Medicaid, NC Health Choice, and the federal Health Insurance Marketplace (ObamaCare).

This information may include income and resources requirements, or requirements related to age, disability status, and residency, etc..²² The Centers for Medicare and Medicaid Services offers outreach and education tools for navigators and partners to explain the Health Insurance Marketplace.²³

Applying for Medicaid, NC Health Choice, and ObamaCare. This education may include information about methods for applying, including on-line, in person, or paper applications.²⁴ ²⁵ Additionally, IA may also alert families and providers to the North Carolina ePASS, which allows families to apply for Medicaid, NC Health Choice or CHIP, and Food and Nutrition Services online.²⁶

Identifying Private Insurance Plans. For families who do not benefit from the ACA (Obamacare) Health Insurance Marketplace, finding a private plan to meet their needs can be challenging. Innovative

²² <https://dma.ncdhhs.gov/medicaid/get-started/eligibility-for-medicaid-or-health-choice>

²³ <https://marketplace.cms.gov/outreach-and-education/outreach-and-education.html>

²⁴ <https://dma.ncdhhs.gov/medicaid/get-started/apply-for-medicaid-or-health-choice>

²⁵ <https://www.healthcare.gov/>

²⁶ <https://epass.nc.gov/CitizenPortal/application.do>

Approaches might educate families on the Health Care Plan Finder operated by the federal government.²⁷

Maintaining Your Medicaid Health Insurance

Once families receive Medicaid benefits, they need to renew their Medicaid status on an annual basis or risk an interruption in benefits. The renewal process becomes more complicated when families move frequently, as they may not receive their notification in the mail at their new address and face a cumbersome renewal process if theirs lapses. Educating families on the importance of Annual Medicaid Applications/Renewals, as well as the importance of apprising Medicaid offices of any address changes, would likely save families the time and expense of renewal of lapsed benefits.

Alternative Financing Sources

The LME/MCO may assist Innovative Approaches in developing education or training regarding the various alternative forms of financing (EPSDT, NC Tracks, Innovations Waivers). The information could explain the limited nature of such funds, specific eligibility requirements, and how to apply for these funds. Such training would be helpful for families and providers.

Provider Training – EPSDT Funds, Medicaid Reimbursement Rates, Care Coordination Triggers

The LME/MCO might also provide periodic training sessions for providers about accessing EPSDT funding, as well as navigating the process of requesting a higher reimbursement rate. Information regarding triggers for Care Coordination Referral could assist providers and families in strengthening systems of care for families.

Educating Policymakers

While educating policymakers is outside the scope of Innovative Approaches work, individual members of the Steering Committee may choose to educate policymakers, especially at the state level. One of the providers suggested the importance of families understanding how the political environment directly affects their family's health care options so that they might become stronger advocates for the family. They in turn could educate policymakers. Some potential policymaker educational issues include:

- The importance of considering factors beyond household income, including family size and medical need, in determining eligibility for Medicaid or NC Choice
- Increasing Medicaid reimbursement rates
- The health care savings possible through a coordinated system of care,²⁸ especially for “high-need, high-cost” patients with multiple or complex conditions²⁹
- The advantages to updating KARTS’ policies in order to provide flexibility for families with multiple children or developing an Uber- or Lyft-based alternative transit option

²⁷ <https://finder.healthcare.gov/>

²⁸ See, for example, <https://www.communitycarenc.org/media/publications/health-care-savings-with-the-patient-centered-medi.pdf>

²⁹ <https://www.communitycarenc.org/media/publications/caring-for-high-need-high-cost-patients-what-makes.pdf>

Methods for Disseminating Information about Health Insurance

With its strong network of community members, Innovative Approaches has many different arenas in which to disseminate information about insurance eligibility. Working in partnership with DSS and the county health department, IA may consider sharing information at local gatherings, such as Family Nights at schools, school sporting events or performance events, PTSA meetings, Health Fairs, health-related support groups, faith communities, or community festivals.

Additionally, IA may partner with schools, day cares, libraries, and other public agencies to provide informational brochures and/or brief presentations to families. Hosting events or providing information to African-American and Hispanic families, potentially in Spanish, is critically important to reaching all communities.

Innovative Approaches might also consider popular family destinations, such as the local Walmart, Food Lion, or McDonald's. Setting up a table out front for an hour on a busy Saturday might reach a large segment of the community.

The Health Department and other community care providers might consider including a brief reminder about Medicaid renewals, or links to applications for various forms of insurance, within their current publications. Clients who come to the Health Department for some services might be asked if they'd like to sign up for a text reminder service.

According to the National Conference of State Legislatures, states have utilized home visits; the Women, Infants, and Children (WIC) program, and other methods to inform families about EPSDT funding.³⁰

Additionally, community partners might consider further utilizing technology to provide reminders to beneficiaries of government services. For example, DSS may consider sending out by email, text, phone, and mail multiple reminders of anniversary dates for renewal of Medicaid and other benefits. Perhaps these communications can also emphasize the importance of providing address changes to continue Medicaid coverage.

Finally, the IA team might continue its efforts to strengthen coordination and communication among providers, perhaps through networking events, such as brown bag lunch informational sessions.

³⁰ (NCSL), "Improving Systems of Care for Children with Special Needs," Sept 2017, p. 3.

VI. CONCLUSION

When the IA community comes together, the passion and depth of participants' commitment is evident. The Innovative Approaches Team has built upon its first year of success with a challenge to assess the need for health insurance among families of children and youth with special health care needs. The feedback of families and providers of services suggests that, while most families are relatively satisfied with their health insurance coverage, in certain families health insurance is a critical challenge. Whether due to eligibility, cost, or coverage limitations, some families struggle to manage their child's health care expenses, no matter what their incomes.

While many of the policymaking issues are beyond the scope of the team, and are particularly in flux on a national and state scale, IA is well-positioned to educate families and providers on the changing insurance landscape. Further, IA can utilize its wide network of members to deliver information in a variety of formats at a variety of venues throughout the community. Further, as the IA team members are trusted members of their deeply-rooted communities, families and providers will feel comfort in tackling such a complicated and frustrating process with the IA team's support.

By educating the CYSHCN community in understanding their options, potential resources for additional financial support, navigating the health insurance system, and maintaining their benefits, Innovative Approaches can help families to obtain and sustain benefits for their child's health care needs.