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Executive Summary
Focus Groups, Community Survey, and
Pre-Meeting Surveys
Fall, 2016

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 the two rural counties have a population of just over 103,000 living in over 784 square miles. Granville's larger population (58,674 in 2015) is spread over 531 square miles, while Vance's 44,568 residents are spread over 231 square miles. Generally speaking, Vance is home to a larger number of health care providers.

As a first step, the GVHD conducted a needs assessment of parents of and providers supporting children and youth with special health care needs. In response to a request from Ms. La'Shanda Daniels, Granville Vance Health District (GVHD) Innovative Approaches (IA) Coordinator, Karen Dash Consulting LLC (KDC) provided the following services in fall, 2016:

- (1) Facilitation, Analysis, and Reporting of three IA Focus Groups of parents of and providers to children and youth with special health care needs (CYSHCN) in Granville and Vance counties
- (2) Analysis and Reporting of the Innovative Approaches Parent Community Survey Results
- (3) Analysis of IA Provider Community Survey Results
- (4) Analysis of Provider and Parent Focus Groups' Pre-Meeting Survey Results

Goals of Proposed Services

The Focus Groups and various survey opinion research 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)
- 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 for the IA initiative
- To develop a baseline for future opinion research analysis

II. METHODOLOGY

This report summarizes the results of seven 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 seven opinion research studies, along with recommended system change objectives.

The questions throughout the seven research efforts focus on themes of communication and partnership; awareness of resources; needed services/barriers to service; education and training opportunities; and childhood transitions – issues that can be effectively addressed through systemic change and which are at the heart of the Innovative Approaches initiative.

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 Center for Disease Control and Prevention's National Center for Health Care Statistics 2009-10 National Survey of Children with Special Health Care Needs and the 2007 National Survey of Children's Health (NSCH) Child Health and System Performance Profile.

The data collection instruments include:

Provider Community Survey: In late August, 2016, providers offering services to children and youth with special health care needs (CYSHCN) were invited to respond to an online survey regarding the needs of their patients and the challenges in serving them. In all, 59 providers offered their feedback and insights.

Parent Community Survey: This 26-question DHHS Survey was developed through the NC Division of Public Health (NC DPH) for the Innovative Approaches project. The Innovative Approaches Coordinator visited with different regional providers and with meetings related to special health care needs where she invited parents to complete a Community Survey regarding their experiencing in identifying, accessing, and paying for appropriate care for their children. Fifty seven parents completed this survey.

Three Focus Groups: Three focus groups were conducted on October 26, 2016 at the Vance County Health Department. The first focus group included 13 providers for a lunchtime meeting. During the evening, the IA Parents Steering Committee met as two focus groups, one of ten Granville County parents and one of eight 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. Eleven providers and 17 parents completed a brief Provider or Parent Pre-Meeting Survey.

NOTE REGARDING SURVEY SCALES

The NC DPH Parent Community Survey, Provider Community Survey, and two Pre-Meeting Surveys use Likert-Scaled questions, but measure opinion using different scales.

The NC DPH Parent Community Survey uses the following scale. "Always" is every time. "Usually" is regularly, most of the time. "Sometimes" is now and then. "Never" is not on any occasion.

Within the Provider Community Surveys and the Provider and Parent Pre-Meeting Surveys, questions asked for the respondent's level of agreement with the following statements on a scale of 1-5, with 1 being "Strongly Disagree," 2 being "Disagree," 3 being "Neutral," 4 being "Agree" and 5 being "Strongly Agree." Respondents could also answer Don't Know or Not Applicable.

For the Community and Pre-Meeting Surveys, the average level of agreement was measured as a weighted average on the 1-5 scale. The higher an average rating, the more strongly respondents as a group tended to agree with that statement.

III. PROFILE OF PARTICIPANTS

As previously stated, the focus group research and pre-meeting surveys were complemented by rigorous, in-depth surveys of the larger community’s families and providers. It is quite likely that several of the focus group participants also responded to one of the community surveys; we report highlights within the profiles of both sets of participants.

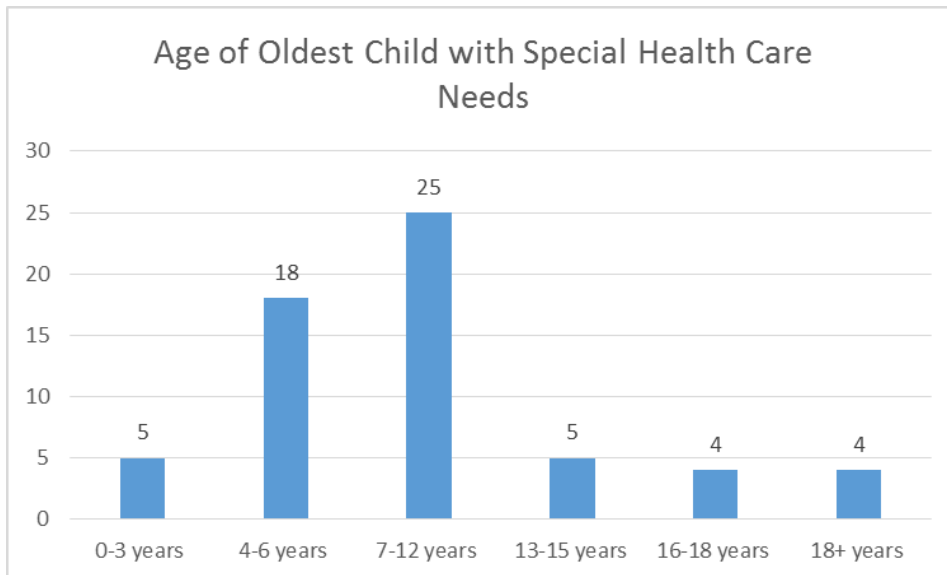
a. Community Survey Parents

PARENT COMMUNITY SURVEY

Fifty seven parents completed a survey at one of several meetings or events related to children and youth’s special health care needs in Granville or Vance counties. Of the 57 respondents, 28 resided in Granville County and 29 in Vance County. Fifty six preferred English, and 1 preferred Spanish.

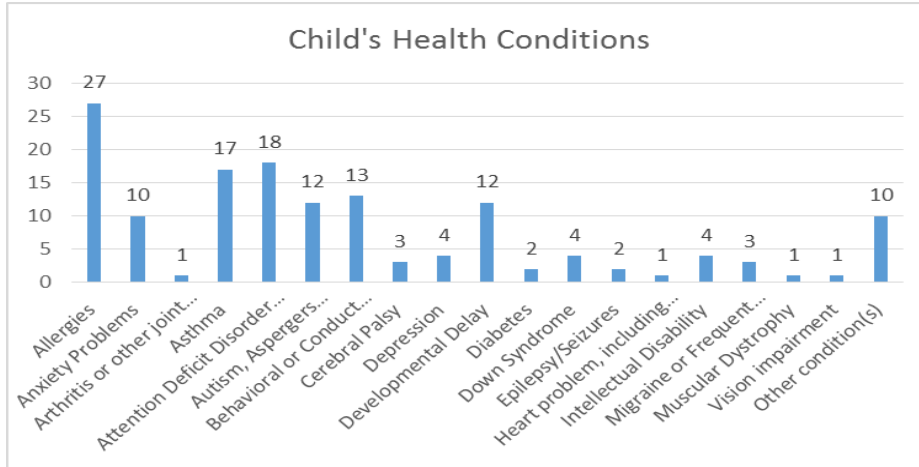
Age of Oldest Child – Community Survey

The largest age group, ages 7-12, represented 41% of the children with special health care needs whose families completed the survey. In all, children under 13 represented 79% of the children within the survey.



Child's Health Condition– Community Survey

The children represented had a wide variety of conditions, with the largest number having allergies, followed by Attention Deficit Disorder or Attention Deficit Hyperactive Disorder (ADD or ADHD) and asthma.



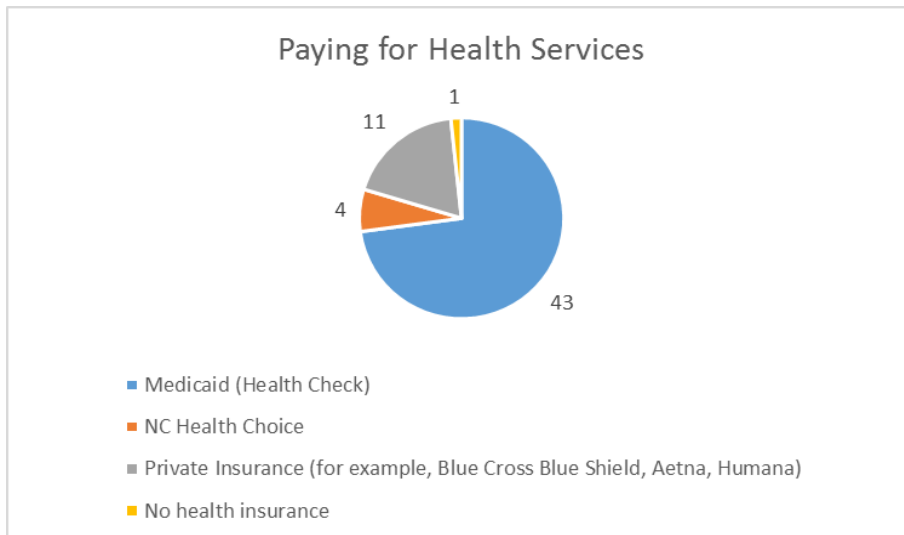
Please note: Responses in the “Other” category included two stating Eczema, two stating Speech Delay, and one each stating “Liver transplant small bowel and pancreas,” “Sensory integration disorder, mild atoxia,” “sickle cell,” “if he fall on ground he fights ground if he bumps anything he fight it,” “spinal bifida w/vp shunt,” and “she was born at 29 weeks and the muscles in her legs are tight causing her to walk on her tippy toes. she wear leg braces. she also has had surgery on her head when the bones connect too soon.”

Having a Doctor or Nurse – Community Survey

Forty two of fifty parents (84%) reported having a personal doctor or nurse for their CYSHCN child.

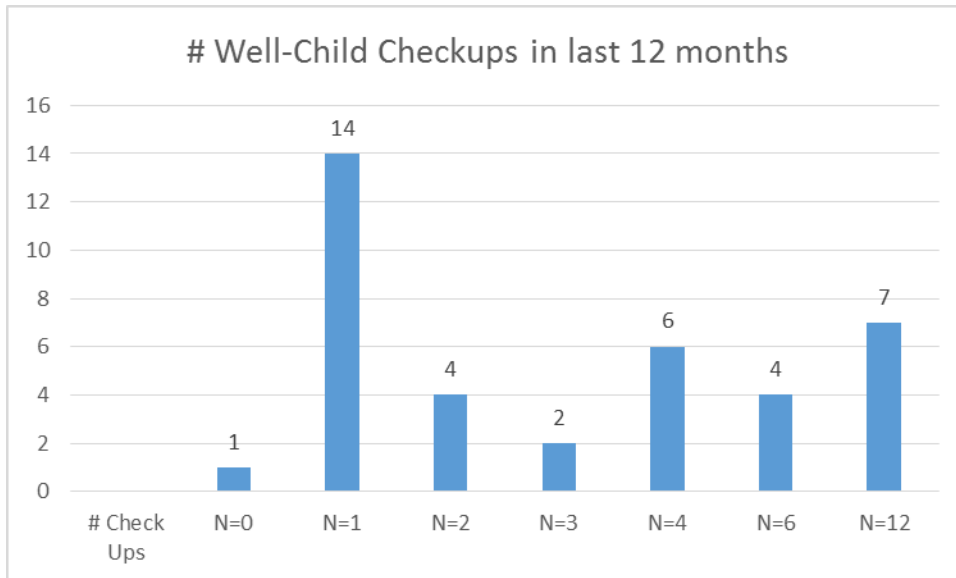
How to Pay for Services– Community Survey

Forty three of fifty nine respondents (73%) paid for their child’s health services through Medicaid.



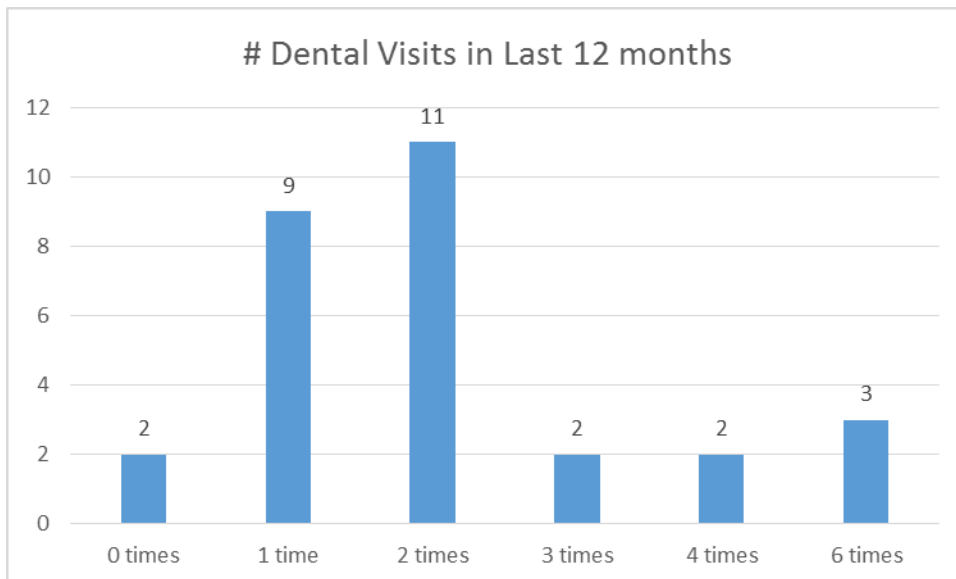
Well-Child Checkups – Community Survey

The largest number (14, or 37%) reported one Well-Child Checkup in the last year.



Dental Visits– Community Survey

The largest number of respondents (11, or 38%) had two dental visits in the last year. Two had no dental visits in the last year.



Other Comments about Being Screened Early and Continuously for Special Health Care Needs

Parents offered the following comments regarding being screened through Well-child or Dental visits.

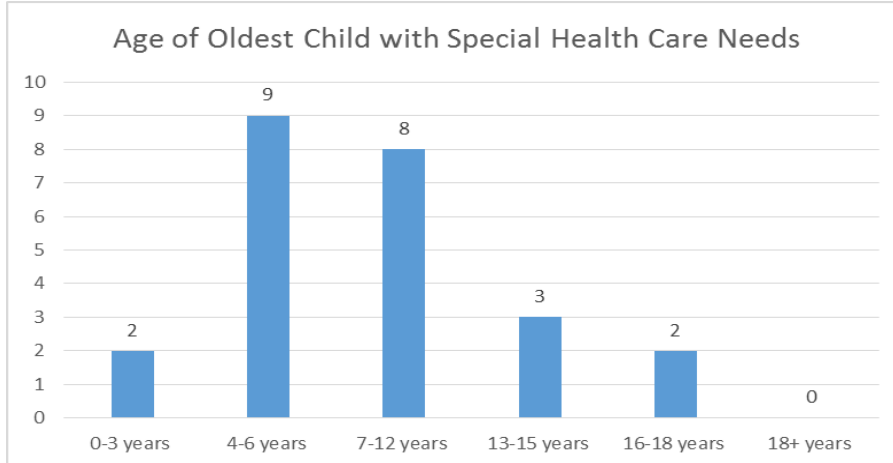
- Because we do not have medical insurance and self pay visits were limited
- He will see his cardiologist 10-28-16.

b. Focus Group Parents

Ten Granville and seven Vance parents attending focus groups completed Pre-Meeting Surveys. Of the children represented within those surveys, 12 were boys and 11 were girls.

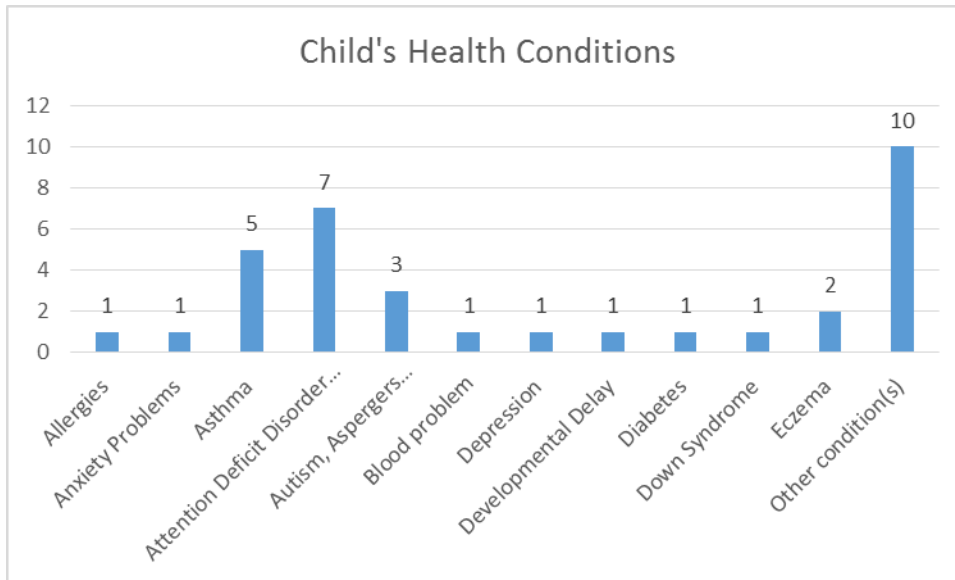
Age of Oldest Child with Special Health Care Needs – Parent Focus Group Pre-Meeting Survey

As with the Community Survey, 79% of the children represented were under 13 years old.



Child's Health Condition– Parent Focus Group Pre-Meeting Survey

The children represented within the Focus Group Pre-Meeting survey had a smaller range of diagnoses than those of the Community Survey, with the largest share having an ADD/ADHD diagnosis.



“Other” diagnoses included OSI; Ataxia; Defiant Disorder Detachment Disorder Hyper; Spina bifida with hydracephalus (upshunt), neurogenic bladder and bowel; PTSD, Failure to thrive, non-verbal, microcephaly, etc. FAS, microcephaly, speech apraxia; Allergic shots 3X week; Type 1; PDD-NOS; Auditory Processing D/O; Alcohol Syndrome, and ODD.

Family Care Providers– Parent Focus Group Pre-Meeting Survey

Granville and Vance families see a variety of local and Triangle-area service providers, including Raleigh Neurology and Duke.

**Providers to CYSHCN Families
(Focus Group Pre-Meeting Survey)**

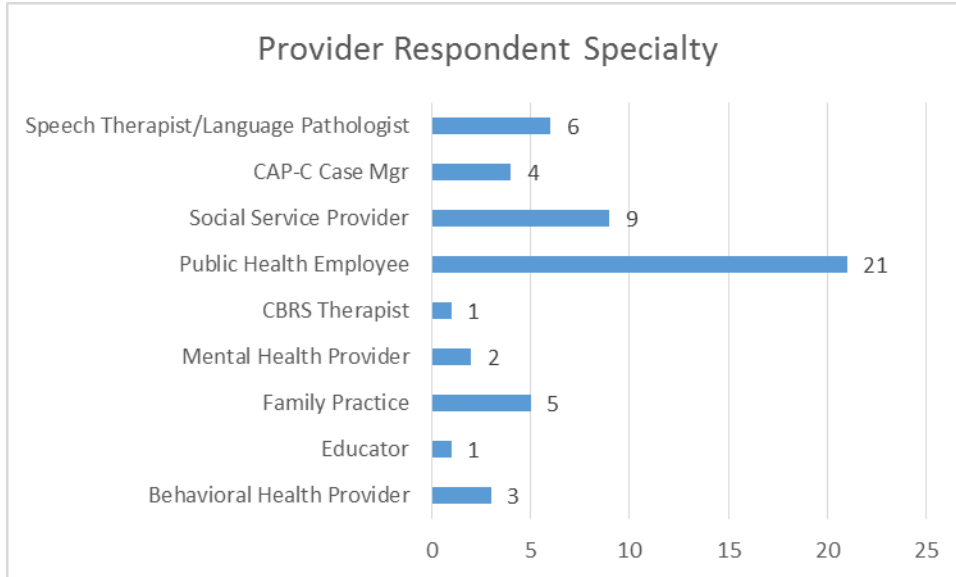
UNC Childrens, Duke Eye Center, AC on II
Henderson Pediatrics
Duke Primary Care (Creedmoor) Lennox Baker (Duke)
Rural Health
Raleigh Neurology & Pediatric Therapy Assoc (Wake County)
Henderson Pediatrics
Royal Health (Henderson)
Granville Pediatrics, Fast Brain
Raleigh Neurology
Daymark
N/A

c. Community Survey Providers

Fifty nine providers responded to the IA Provider Community Survey.

Provider Specialty – Provider Community Survey

The greatest share of respondents to the Provider Community Survey were Public Health employees.



Please note: In addition to the specialties cited above, one participant each identified their specialty as Lead Obstetrical Care Manager; Program provider for individuals with disabilities; early intervention, State employee in DHHS; Dietitian; and Environmental Health.

County of Work

Seventeen (29%) respondents reported working in Granville County, with 33 (56%) reporting working in Vance county. Additionally, six providers worked in both Granville and Vance counties, with another working in Vance, Franklin, and Wake counties, and one other working in Durham, Orange, Wake, Vance, Granville, Warren, and Franklinton.

d. Focus Group Providers

In their Pre-Meeting Surveys, providers listed a variety of specialties.

Provider Specialties

(Provider Pre-Meeting Survey)

CCNC Network NPCC
Both social and medical
CAP-C Case Management Agency
OBCM
ABCD Coordinator -- I work mostly with practices.
CC4C
Service Provider
Mental Health Provider
CDSA

IV. EXECUTIVE SUMMARY: HIGH LEVEL THEMES

The seven opinion research efforts highlighted important issues and concerns shared by parents and providers. At heart, many of these issues boil down to the challenges of strengthening the communication among different providers and with families and raising awareness of the importance of appropriate educational services for children and youth with special health care needs.

The commitment, engagement, and good will of parents and providers is evident; in fact, one of the participants in the provider focus group was later praised by name in the parents' focus group. Of particular interest within the Granville Vance region is the relative availability of services in the resource-rich Research Triangle area, within a few hours of home. While getting to these resources, especially for frequent appointments, can be a challenge for families, most other IA regions -- especially rural regions - do not have access to so many specialty providers within a reasonably close radius.

Therefore, while the Granville Vance needs assessment effort identified certain medical and social service needs similar to those in other IA counties, this opinion research identified a much greater dissatisfaction with the local school systems than any other region.

This Executive Summary provides a review of general themes that arose frequently throughout the Opinion Research process and can be summarized as Building Communication and Partnering Relationships; Awareness of Resources; School Services for Children & Youth with Special Health Care Needs; Needed Services/Barriers to Services; Education/Training Opportunities; and Transitions. These themes tend to be consistent with those found in other IA counties, but the Granville Vance Health District, in part due to its location, emphasizes different issues within those themes. Additionally, School Service issues was added as a separate issue.

Please note: Unless indicated as part of a survey, all discussion points are reflective of the Focus Group feedback.

A. Building Communication and Partnering Relationships

Summary: Providers and parents placed significant emphasis on the importance of respectful, cordial relationships and communication, including the use of appropriate language; the inclusion of parents' opinions in decision-making; recognizing cultural differences; and defining parents' roles and responsibilities in the process.

Creating Respectful Relationships

In focus groups, providers spoke of the importance of building a trusting relationship with patients and their families, and meeting families where they are, "not condescending" to the families, and not creating or suggesting a difference in social status. Providers suggested simple language like "How are you doing? How's so and so doing?" in order to connect with patients and families.

One provider, who does much of her work by phone, reported that she sometimes lets clients "vent" so that she can learn information about them. For example, she might learn that the father of the baby patient is in jail, or that some other individual is causing stress in the family's life.

From a home visiting context, building trusting relationships involves lots of visits to family residences. The home visiting professional providers spoke of not “jumping on or judging” families but letting them know that providers are there to see them through any challenges.

This emphasis on communication was echoed in the Provider Community Survey and in the Providers Pre-Meeting Survey, in which providers suggested that working closely with families was very important to them.

Provider Level of Agreement with Statement (1=Strongly Disagree, 5=Strongly Agree)	Community Survey	Pre-Meeting Survey
Parental input is an important part of our decisionmaking process.	4.45	4.36

The Parent Community Survey showed that parents generally had positive feelings about their relationships with their providers, although some of their comments expressed a need for more support. Over 80% were Always or Usually able to discuss treatment choices and ask questions of their children’s health care providers.

In response to the question, “A health care provider can be a family doctor, specialist, nurse, therapist, or other professional. How do your child's health care providers work with you to make decisions about his or her health care services and treatment?”

During the past 12 months...	ALWAYS	USUALLY	SOMETIMES	NEVER	DON'T KNOW
How often did your child's health care providers discuss with you the choices to consider for your child's health care or treatment?	26	19	7	3	1
How often did they make it easy for you to ask questions or raise concerns?	32	13	8	1	2

The following comments were provided by parents regarding their relationship with their doctors in terms of discussing choices, questions, and preferences.

- My family has reported having difficulty scheduling appointments and receiving return phone calls from their child's health care providers/specialists.
- NEW DIAGNOSIS
- Sometimes I feel that medical providers do not take parents concerns regarding treatment options into account. Providers need to remember that no one knows the patient better than their caregiver, as they are the ones whom care for the patients everyday.
- Usually I and health care providers work well together and on the same page with care.
- he is really uncomfortable. Just to type angry all the time. he needs help, i thing ADHD
- i always ask question until i'm satisfied with a solution
- i think she could use more therapy.
- i voice concern for her
- its very difficult to get a referral to see another doctor or specialist
- my child needs lots of help but it is hard to get the help i need for my child.

- need to explain more
- they wanted to make sure that it healed correctly and that it would not come back

Vance County focus group parents generally expressed few concerns about their doctors. By contrast, Some Granville parents suggested that doctors don't see parents as viable resource for information about their own child. For example, one parent brought her child for treatment for headaches that had lasted about six months, and the doctor did not think there was an issue. The parent felt frustrated that the doctor did not recognize that the headaches were a physical issue and that the doctor did not ask the parent what she thought was going on. "I'm not a babbling idiot," she said, noting that she does significant research on her own.

This Granville parent stated that she doesn't like going to doctors and only goes if there's an issue. She was upset that the doctors "try to blow (the headaches) off as depression or abuse." The parent said she "blew them out" and suggested a neuro-contrast MRI, but the doctor did not follow up.

Another Granville parent found that specialists could also be disrespectful of parents. When she went to get a second opinion, the second doctor asked, "Oh, who have you already seen, and what did s/he say?" The second doctor would generally just agree with the first diagnosis. She later found out that the second doctor plays golf regularly with the first, and she felt he probably wouldn't contradict his friend.

In their Provider Survey comments, providers suggested some of the following advice to parents:

- Communicate you needs to all who will listen, and ask for additional resources be your own best advocate for care and service linkage.
- Parents must advocate with their PCP to be the primary managers with all providers serving the child including the specialists, therapists, and support agencies such as the schools, and cap-c and innovation providers.

Using Appropriate Language

One provider stated that she felt it was important to minimize or reconsider language around "special needs," especially if there's a connotation that the child is disadvantaged. Recognizing that "your beautiful child has strengths" and that "there are long-term factors that the family will need to work with," is a much more effective approach, she felt, because parents view their child wholly and completely beyond their diagnosis. As another provider said, after a child has been through so many therapies, many parents simply see their child as "tough" and able to handle everything.

Another provider stated that many women feel intimidated by doctors, who, she felt, sometimes "destroy people's spirits" by speaking at a higher educational level than the patient and "using big words." Rather, she suggested, doctors should try to "break it down" for patients so that they understand and can relay that information to their care managers.

She felt it was important to keep in mind that many patients are of a different socio-economic status than doctors and don't have a relationship with their physician, other than knowing that they have to go visit the doctor. Doctors need to speak to patients so that they have the understanding and comprehension of their child's needs.

She noted one provider who kept stating that their mutual patient needed to breastfeed but wouldn't. The focus group participant asked the other colleague, "Did you ask (the patient) if she wanted to breastfeed?"

Utilizing Parental Input

One provider said that she lets families identify what help they need. Sometimes, the referring agency may be worked up about a particular issue, she stated, but the family is more concerned about a different issue. Providers should defer to families as much as possible in such circumstances.

The provider group discussed the importance of case managers recognizing that they must separate how they feel from how parents feel. One provider said she tells her clients, "This is a train, you are the conductor, I am here to help you change lanes or call the station attendant to tell them you are on your way."

Parent Community Survey

Forty six of 56 Community Survey parents (82%) felt that medical providers Always or Usually respected their opinions about treatment choices.

During the past 12 months...	ALWAYS	USUALLY	SOMETIMES	NEVER	DON'T KNOW
How often did (your medical providers) consider and respect what health care and treatment choices you thought would work best for your child?	28	18	6	2	2

The provider who likened the family-provider relationship to a conductor and a train worker suggested that "it's important not to give families the impression that we are there to fix things, *because some things can't be fixed*, but we are here to give resources and support."

Recognizing Cultural Differences

One provider spoke of her challenges with a Filipino client who is pregnant and whose baby will be born with special health care needs. The client does not speak English, and she is unwilling to talk about the baby's diagnosis through her male family interpreter, which limits the provider's ability to support her.

In their Community Survey, providers recognized generally some issues with language and translation affecting their ability to service families.

Provider Community Survey

Provider Level of Agreement with Statement (1=Strongly Disagree, 5=Strongly Agree)	AVG SCORE
Families have difficulty with language/translation issues.	3.14

Parents' Role in Partnership

Providers spoke of the lack of structure many parents had in their own homes as they were growing up, and how that may be replicated in their current home environments. Providers recognized that if families are worried about paying the rent or dealing with issues of domestic violence, they may occasionally end up as “no-shows” or be in “non-compliance” for not making their child’s provider appointment. Additionally, sometimes parents are so overwhelmed by medical advice and referrals that they don’t know what to do.

In the Community Survey, providers identified the challenges of transportation and child care for families trying to attend their child’s appointments.

Provider Community Survey

Provider Level of Agreement with Statement (1=Strongly Disagree, 5=Strongly Agree)	AVG SCORE
Families have difficulty attending appointments due to transportation issues.	4.26
Families have difficulty attending appointments due to their work schedules.	4.03
Families have difficulty attending appointments due to other child care issues.	3.54

At the same time, providers noted that they need families’ help in serving children and youth with special health care conditions, including for some families to take additional accountability for their child’s care. For example, one provider noted that patients can use online provider portals to schedule appointments, but that many parents do not. These same parents, she said, are able to access Facebook and Twitter online. Another said that if families can order and pay for pizza on their phones, they should be able to set their phones for appointment reminders.

Several providers spoke of the frustration of trying to reach their clients by phone, including clients who ignored 10-15 phone calls in a week and later admitted to providers that they just didn’t feel like answering the phone. One provider said that her agency tries very hard to be as informal as possible, and check in with families occasionally to ensure “things are working for them.”

Several suggested that families can just tell the provider that they don’t want a particular service, and the provider will stop calling them. Unfortunately, providers can’t control referrals, and so they must follow up again sometimes with that client if another provider refers that family to them for service. One provider said she had done this for one family for three years.

B. Awareness Of Resources

Summary: Generally speaking, while Granville and Vance parents and providers, like those in other counties, would like more information about resources available to them and their families, they didn't seem as frustrated about this issue as other IA counties.

Because of their relatively closer proximity to the Research Triangle area and its medical resources, most IA stakeholders were generally satisfied with the awareness of medical services and of service availability. This is reflected within the Provider (and Parent?) Community surveys. As Section C below shows, however, there is a strong need for more school-related resource information.

Provider Level of Agreement with Statement (1=Strongly Disagree, 5-Strongly Agree)	Community Survey AVG SCORE	Pre-Meeting Survey
Families are aware of the services we offer.	3.55	3.20
We have a formal process for ongoing communication with families.	3.73	4.00
We have a formal process for ongoing communication with doctors, schools, and other health care providers.	3.68	
We coordinate our care with that of children's doctors, schools, or other care providers.	3.95	
We work with our CYSHCN patients' care coordinators to coordinate services	3.74	

C. School Services for Children & Youth with Special Health Care Needs

Summary: Families in Granville and Vance counties expressed frustration with services available through their school systems. Nearly the entire discussion regarding Individualized Education Plans (IEPs) centered around Granville and Vance parents being unsure of what resources were available from schools to support their child.

Concerns centered around: a lack of partnership between schools and families; schools being unequipped to serve children with special needs; children not learning in school; the perception that special needs children are being pigeonholed; children's placement in school.

Lack of Partnership Between Schools and Families

One Vance County parent who also works with special needs families stated that it's been her professional observation that sometimes parents feel as if decisions related to the IEP process have already been made by the school before parents even meet. She asked parents if they would understand the IEP process steps, including how to make a formal IEP request. Many were unsure.

One Vance parent stated that a lack of communication is a county-wide issue in education. Her six-year old daughter is in a class with a teacher and two assistants, and she feels that the assistants are very knowledgeable about how to best care for her child. As a mental health professional, that parent had sat in IEP meetings and seen that the school personnel don't really talk to the parents or ask their

opinion, and thus the mental health professional would then ask, “Well, why don’t we see what mom thinks about this?”

Another Granville parent spoke of apparent miscommunications among school personnel at her child’s school, in which one Assistant Principal asked the parent why the Assistant Principal wasn’t included in a particular meeting. The parent felt that the conversation was not supposed to be “a power struggle” among school personnel but rather a meeting to help her child. She felt it was the school’s place to straighten out any internal communication issues.

A Granville parent noted that parents are afraid to complain too loudly for fear their child will be penalized somehow.

Schools Being Unequipped to Serve Children with Special Needs

Parents discussed a perceived lack of appropriate school services and a lack of knowledge among school personnel about how to serve special needs children. For example, one parent had her child in school speech therapy in Vance County, but he was in a class with 20 other kids and not learning anything. She hired a private speech therapist and wanted the private speech therapist to accompany him to school, but the school wouldn’t allow it.

When one family moved to Granville from Johnston County and enrolled at Stovall-Shaw Elementary School, the family told the school team that their child was autistic. To their disappointment, school personnel responded “Okay, what do we do?”

The Granville parent group urged the Stovall-Shaw parent and other parents to request an IEP in writing, to which the school has 90 days to respond. One parent recognized that small schools generally don’t have a lot of funding for services, and so “if you don’t ask for services, they won’t offer them.” She also recognized the importance of trying to “make friends” with schools in order to work together to support her child, but eventually feels she has to be forceful to get her child’s needs met.

Vance parents encouraged those parents whose child does not have an IEP to request one from the school. They stated their belief that the school will not pro-actively offer an IEP, and therefore it is important for the parent to request one in writing.

One Vance parent stated that the EC Center helped her child through the IEP process, and that her child had just been released from their IEP. The child will be entering a traditional high school next year, which the parent is somewhat anxious about.

Children Not Learning in School

One Vance parent expressed frustration that her child is behaving in class “and doing what he’s supposed to do and not learning anything.” A fourth grader, he now is reading at a 2nd grade level.

One Vance parent asked why, if her child has an IEP, is he still failing in one class and not learning anything. She shared an incident that occurred when she was visiting the school to request therapy services for her son. As she was leaving her son was running down the hall, and the therapist did not try to stop him.

Another Granville parent was frustrated that, at the end of the school year, school personnel told her that her son “won’t do anything.” She wondered why they waited until the end of the year, rather than tell her sooner so that they could work together to help her son.

Perception that Special Needs Children are Being Pigeonholed

Parents expressed frustration regarding their belief that schools tended to label their child or assume things about their student without getting to fully know the child. This tended to result, the parents felt, in lowered educational expectations for that student.

One Vance parent shared that her child had been suspended for 10 days. The child, who has an ODD diagnosis that makes him combative, had gone to get his report card, and a school official accused the child of skipping class. The child has no IEP but has a therapist and in-home counseling. One school official wanted to send the child to Western Vance High School, while another official felt that the child should be put in smaller groups.

One Granville parent stated that she was tired of “teachers and professionals pigeonholing my children.” One parent spoke of a professional educator/administrator who told her that her child would not succeed, and the parent found this devastating to be told this by a professional.

Another parent of a Granville 17-year old said that the school thought her child was “stupid” because he was very quiet. In middle school he was in a special class, where they gave him 3rd-grade level work. The son loves to draw and chose to do that instead, causing his teachers to say that he won’t do his work.

One Vance parent spoke about when her child was enrolled at a local charter school (Henderson Collegiate) and how much the faculty and staff cared about her son. “They cared, they cared,” she said. She spoke of how proud her son was to learn new things and to feel that he was performing as well as his classmates. He was using vocabulary like “facetious” she said. She fondly recalled how her son told her, “Mama, I’m smart.” When she’d observed class one time, she “nearly fell out of her chair” when she saw her son raise his hand to answer a question.

When it became too difficult to drop her son off for 7:30am school and be on time for her 8:00 job at Murdoch, she reluctantly returned him to the county school system. She now feels that his public school teachers “have given up on him.”

Children’s Placement in School

Parents felt that their school’s placement of their child in a traditional or special needs classroom does not always fit their child’s educational needs. A Vance parent asked about her options for her fourth grader with Asperger’s, whom the schools want to put in a traditional classroom. The mom feels that he should be in a smaller setting and knows he won’t progress in a traditional classroom. The other parents assured her that if her son has an IEP, he is entitled to be in the smaller classrooms.

The Vance parent whose child was previously in a local charter school stated that her child’s IEP doesn’t appear to be followed by public school staff, and that she feels the school has “given up on him.” She explained to the school that he needs a resource person to keep him focused, and that he needs to sit in the front of the class. When she visited him in school, however, she found that he sits in the back of the

class. He is now an 8th grader, and his teachers have told her “I have 20+ kids to take care of” in addition to her son.

One Vance parent said that, had she not been a strong advocate for her child, her child would have been placed in “a very inappropriate classroom” and her daughter would not have done well.

Special Education Classes in Vance County

One Vance county parent suggested that the public schools do not have classes for parents of Special Education students. While this researcher was able to find an Exceptional Children Process and Procedural Guidance Document (<http://www.vcs.k12.nc.us/Page/2437>), we were unable to find information on Family Special Education classes within Vance County schools.

Parents Pre-Meeting Survey

The Parent Pre-Meeting Survey suggests that families are more aware of services offered by the county school systems than those offered by medical and social service providers.

While seeming to contradict the focus group participants’ stated frustrations regarding the schools’ services, it may in fact indicate that while parents may be aware of those service, they may also find them inadequate.

Parent Level of Agreement with Statement (1=Strongly Disagree, 5=Strongly Agree)	
(Pre-Meeting Family Survey)	
My family is aware of the services offered by G and V counties' medical and social service providers.	3.00
My family is aware of the services of G and V counties' schools.	3.93
I understand how to advocate for my child's needs with our doctors.	3.82
I understand how to communicate with schools regarding my child's needs.	3.59
Our rural county makes it hard to communicate regularly with our child's doctors and teachers.	2.41
Transportation issues affect my ability to get care for my child.	2.13

Also of interest is that parents responding to their Pre-Meeting Survey did not find transportation issues to be as significant a hurdle as their discussions (and other surveys) indicate.

D. Needed Services/Barriers to Services

Summary: Unlike most IA counties, Granville and Vance County are located relatively close to many medical resources within the cities of Raleigh, Durham, and Chapel Hill, including Raleigh Neurology, Duke University Medical Center, and UNC-Chapel Hill Hospital. While families would prefer more local services, most services are within a few hours drive.

As occurs in most IA counties, participants found barriers related to transportation, insurance/Medicaid, coordination of care, medical homes, and shortages of extracurricular activities, opportunities to exchange used equipment and supplies. Most families tended to report few issues with getting referrals or with service availability.

Transportation

Nonetheless, transportation continues to be an issue for families.

The Provider focus group spoke of patients who could have four appointments on four different days at four different providers in different counties, or families who have to go to Duke 2-3 days a week for appointments, with little transportation money or options.

Several providers spoke of the frustration of working with the Medicaid KARTs system, which requires scheduling appointments 3-5 days ahead (depending on location) and requires users to be within the system all day long on their scheduled day. The latter requirement sometimes means parents, especially single parents with no one to watch their other children, may need to bring their other children with them on the KARTs trip. Additionally, scheduling sometimes precludes parents from utilizing the service at all, because someone needs to pick up their other school-aged kids from the bus stop at 3pm.

One provider has found that, whenever one of her clients has missed an appointment, it's usually due to the need to care for the client's other children after school. She has arranged for some of her clients to take early day appointments locally, which helps somewhat.

Parents noted long drives for services, such as Speech Therapy in Wake Forest. A Granville grandmother noted that her grandchild cannot get Speech Therapy and Physical Therapy at Maria Parham Medical Center because they don't offer services in her age group, and so the family travels outside the county.

In the Pre-Meeting Survey, Providers recognized the challenges of transportation and living in a rural community.

Provider Pre-Meeting Survey

Provider Level of Agreement (1=Strongly Disagree, 5=Strongly Agree)	
Our rural county makes it difficult to communicate regularly with our patients' families.	3.60
Transportation can be a barrier for some of our families to receive services.	4.60

Insurance, Medicaid, and Financial Issues

Families spoke of the challenges of eligibility for different services depending on their health insurance, and the significant financial struggles they face. Families expressed confusion or concern regarding their child's eligibility for Medicaid and about how to access other financial support/resources.

The Granville parents group discussed the difficulties of qualifying for public assistance, including Medicaid, which is based on a household income and not on the number of kids in the family or the health conditions they have.

A Vance parent sought better information about what services are available as a private insurance client or Medicaid client. Those with private insurance aren't sure what services are available and which are affordable. Another parent said her pediatrician advised her to call Social Services, but social services told her she was "not in our bracket."

Two Granville parents had large families that included adopted children and youth with special health care needs. They spoke of numerous challenges in affording care for their children. One Granville parent had to stop receiving services because her family couldn't afford them. She has a \$1,500 bill from Granville Health Systems because the insurer was trying to bill this as an out-of-state service. She said she owes Johns Hopkins \$20,000 and had paid \$9,000 for Ankle-foot orthosis (AFOs).

She pays \$200 a month for Medicaid for her daughter as a second insurance to her BCBSNC. In planning for her daughter's future, she expressed frustration that she could not save money for her daughter: to be eligible for Medicaid, the daughter cannot have a bank account.

The parent wonders how she can help her daughter with independence after the mom passes; she fears her daughter will be placed in a group home somewhere. "Without losing any coverage, how do you set her up for life? We want her to be who she can be." The mom has arranged for her 200-acre country property to be turned over to her oldest daughter, with provisions for her youngest daughter to live there, where she feels safe around animals.

The Granville parent stated "We are medically broke." While her husband makes a good salary, they cannot afford any more services and qualify for no governmental help. Without the generosity of others, she said, they would not have had Christmas last year, and will likely run into the same challenge this year.

One parent said that, while other parents worry about how they will pay for college, she is worried about how to pay for the \$20-30K in dental surgery her adopted son needs. She said that, because they can't afford the surgery, her dentist can only give her son Tylenol for the pain.

Parents also noted that insurance doesn't cover the gas costs of making long drives to providers out of the county.

One Granville parent suggested that she'd heard on the local 88.5 station WRTP about a Goodwill Foundation program that offers \$5,000 scholarships to cover medical needs.

In their Community Survey, providers recognized the financial difficulties medical care can pose for families.

Provider Community Survey

Provider Level of Agreement with Statement (1=Strongly Disagree, 5=Strongly Agree)	AVG SCORE
Families have difficulty paying for tests and medications we recommend.	3.53

Coordination of Care

Within the issue of Coordination of Care, issues regarding Coordinated Delivery of Services, and Coordinated Paperwork/Sharing of Information were most prevalent.

Please note that Medical Homes are discussed separately in the section below.

Coordinated Delivery of Services

Families expressed different concerns regarding the efficiency of being served by one centralized provider. One provider noted that in the past, a family could go to one building and get all the services needed for their child in a coordinated fashion, but that system no longer exists.

One Vance parent had concerns regarding the coordination of her child's services under one provider. She stated that she has different caregivers for her child for when she works, and all but one of them are from the same agency. She would like the last caregiver to be replaced by someone from the first agency so that the workers can substitute for each other if needed.

Unfortunately, a social worker whom she has spoken to about the situation won't "honor her contract" and allow the parent to work with the one agency. As a result, if that single caregiver from the second agency is unavailable, the parent must leave her night job and come home to care for the child.

A few providers also felt that coordination could be helped by mutual regard among providers, stating that "the lack of respect among all providers needs to be transformed." One provider stated that "if we can't coordinate locally, how can we work with Duke?"

Coordinated Paperwork/Sharing of Information

Both providers and parents spoke of the frustrations of trying to get paperwork completed by providers for sharing with another agency. In some cases, the parent or provider had to hand-deliver the paperwork to the provider to get it completed.

Vance parent participants stated that some local doctors try to reach out to other providers to share or receive information. Unfortunately, facilitating the transfer of information often entails an in-person visit by a parent or a provider. One parent stated that she was tired of hearing the excuse "that they didn't get a raise" from provider staff as a rationale for why the information-sharing process could be so difficult; she hasn't received a raise either, the parent said.

One provider shared her story of trying to get paperwork completed for a 20-year old young man with cerebral palsy and a trach whose mom was very ill and in and out of the hospital. Years earlier, the provider had suggested the mom get her guardianship papers in order before the child turned 18, but the mom hadn't gotten around to doing so.

When the provider had found a bed for the young man in a facility, she needed to get paperwork completed quickly before the bed was lost. When the youth’s doctor’s office didn’t return her calls, she walked her paperwork to them and spent a very frustrating time trying to get the paperwork completed. The doctor’s office tried to keep the paperwork she needed to file with the court. She felt no one listened, and she had to ask three times for her paperwork back.

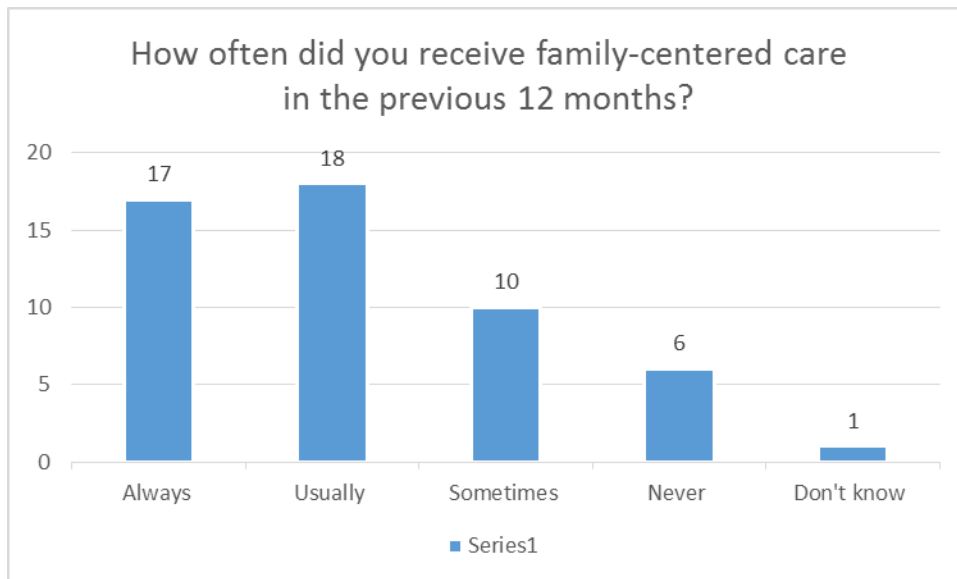
Another provider commented that, if that professional and knowledgeable colleague had so much difficulty getting through that process, how could anyone expect parents to be successful? She suggested that most parents would have been stuck at the first phase of the process. Another provider, who worked for CDSA for 10 years, said it took three years to really learn and understand the rules of eligibility.

Even with electronic health records, providers have challenges in obtaining information on their patients. One provider spoke of the difficulty of getting info or updates on mothers and babies once they are under doctors at Duke or other providers. She has difficulty finding updates in MAESTRO/EPIC because, as another provider said, “they all document in different places.”

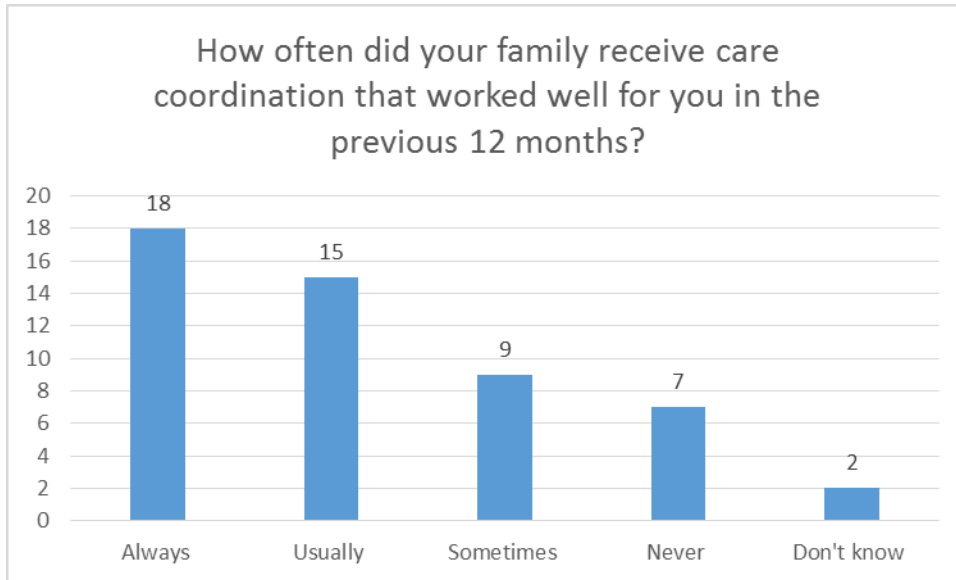
Care Coordination

In their surveys, families were generally satisfied with coordination of care, although one parent commented on a lack of services due to their child’s age. Thirty five of 51 Community Survey families (69%) reported Always or Usually receiving family-centered care in the previous year.

Community Survey Parents



Thirty three of 51 Community Survey families (65%) reported receiving care coordination that worked well in the previous year.



The following comments were provided by parents regarding coordinated, comprehensive care in a medical home:

- My ex-mother-in-law worked for Mental Health before it was dismantled. She was friends with the director and supervisors there. I am a social worker and also am friends with people who provide these services.
- it is hard to get the help my child need. when we go to the doctor they say she to young to medication. we will see you in 6 months.

In their Pre-Meeting Surveys, providers rated low agreement with the concept of coordination among providers. This is clearly an area for opportunity for Granville Vance.

Provider Pre-Meeting Survey

Provider Level of Agreement (1=Strongly Disagree, 5=Strongly Agree)	
Services for CYSHCN families are coordinated in a way that is easy for families to use (eg., Social Services, pediatricians, specialists, schools, etc.)	2.64
Many of our CYSHCN families have a central point of contact (besides the parents) with whom we work to coordinate their child(ren)'s services.	2.90
Our local medical and school providers working to support CYSHCN have established channels for communicating and collaborating.	2.78

In their Community Survey comments, Providers offered that centralized and electronic health records, a stronger emphasis on communication, and keeping “releases of information” waivers on hand can help strengthen communication and coordination. The following lists all suggestions offered by providers.

Provider Community Survey -- Comments

- a single portal of entry for documentation so that professionals can see what others are doing as are trying to meet a common need/goal
- Advertise your services through news, social media, etc... share success stories!!!
- Always carry blank releases of information with you when you meet with a family. If they mention a provider you are interested in speaking with, ask the family to sign the ROI and make sure to explain end date of ROI and why you are requesting ROI (to co
- Ask questions, and communicate opening with the parents about what they are doing well and what concerns exist. Communicate on the level of the parents, and communicate outside regular business hours as parents are sometimes working and not able to talk
- Be calm, understand that doctors are very time constrained and often spend several hours after work doing paperwork just so we can spend an adequate amount of time with patients. We are doing our best.
- contact lists with names, phone numbers and email addresses.
- Everyone has to be on the same page and willing to work toward the common goal of what's best for the child. Ensure that when meetings are held, that every team member is able to participate.
- for the providers and school to listen to the parents because they know their kids better than anyone
- Hold multi-disciplinary meetings with all agencies and vendors involved in the child's care.
- I suggest consistency in communication, follow-up, and honesty.
- less barriers to communicate with primary care providers. some way to share records electronically or a system each agency can access that has updated treatment information.
- Meetings, collaboration, and referral resources ... Make it al Plain
- more education on what CYSHCN is all about
- multi-disciplinary team meetings?
- Not Sure
- Open a clear dialogue. Create a person centered view point.
- PCPs offering brochures and addressing each issues at SICK visits , not just Well Checks
- The need to strictly adhere to confidentiality laws impacts our ability to communicate with all listed above.
- Use terms that parents understand as well as utilizing technology.
- Utilize coordination of care in existence more, multi team meetings for complicated special needs children
- would be helpful if we had easier access to medical and psychiatric records.

Medical Homes

Providers spoke a great deal about the concept of medical homes, with mixed feelings about how successful the counties' providers were in establishing medical homes for CYSHCN patients.

One provider stated that many primary care doctors do not understand their role as the child's medical home for coordinating services and for being aware of the child's specialist services and results.

Because many local children and youth with special health care needs see Duke specialists, primary care physicians associated with Duke are somewhat more aware of their patients' specialist services. Most local primary care doctors are not. For example, one provider stated that her office does not have access to patients' records for Wake or UNC Hospitals, and that NC Peds requires releases for information.

One provider works on the ABCD program, Assuring Better Child Development, through Smart Start. Her organization works with providers to help them become stronger Medical Homes for families, whether they use Medicaid or private insurance.

These doctors are taught how to validate Medicaid care, make referrals, follow up referrals, understand the Medical Home role, and recognize that not all issues can be resolved in 15-minute appointments but may require longer appointments. This representative noted that their agency is stretched very thinly and that she covers providers in three counties alone.

Through her agency, it is hoped that providers gain a better understanding of medical homes and what it means to be the "gatekeeper" for the family – e.g., that primary care provider may need to write prescriptions for the child.

One provider said that some doctors may not be willing to write a prescription for Synthroid, for example, even as it is running out because a specialist usually writes that prescription for the patient. Rather than force the family to go back to the specialist for the prescription, this provider felt that the primary care physician could do a simple blood test and write the Synthroid prescription.

Some providers suggested offering education to primary care doctors regarding medical homes, but another stated that she didn't feel that physicians would attend such trainings. Rather, she said, the doctors are more focused on reimbursement and following the rules of Medicaid or their other payers.

In lieu of training, one provider suggested identifying a central point of contact at each medical practice to get paperwork and information coordinated and communicated. They recognized that one person couldn't handle this job, and that having so many calls and inquiries and patients to manage would be very difficult.

Hiring more liaison people would help the network of providers to work more efficiently together for their patients. The provider also suggested that these coordinators be knowledgeable about specialties, such as ob-gyn, so that they could support a variety of patients.

One Vance parent spoke warmly of her "guardian angel," Ms. Kim Nesbitt, who "fights for" her and her child. For example, Kim was able to get her child, who has a trach, a new OT after the other transitioned out.

Extracurricular Activities

Parents seek more extracurricular activities for their children and teenagers, including playgrounds or social activities for their children. One Granville parent spoke of “arguing with the mayor” to get him to buy appropriate swings for her child. A private individual, upon learning that the local playground could not accommodate her child’s needs, purchased a swingset for the child, saying he couldn’t abide a child having to watch on the sidelines. The parent noted that another child, her daughter’s friend, also needs special accommodations to play.

One parent noted that in Vance County there are no sports activities for students with special needs. The IA Coordinator shared that Granville students can participate in the Vance Special Olympics if they would like.

Exchange of Used Equipment

Special needs families pass things along informally, but families talked of how helpful it would be if they could formally share used equipment with other families, or if there was a central place to do so. They recognized liability issues, but thought that if parents waived liability they could have access to walkers and other equipment that no longer fit another child.

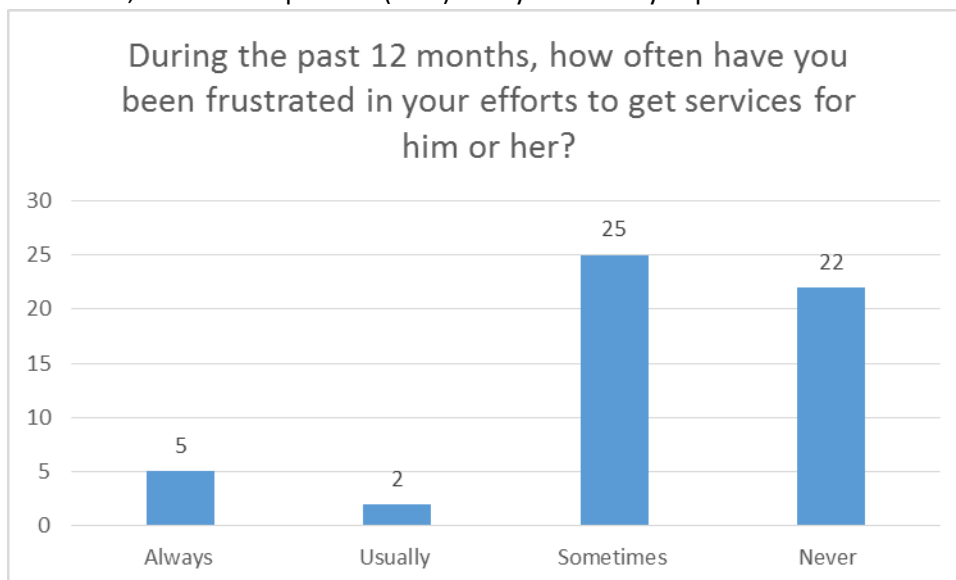
The arrangement could even be a temporary one, like a wheelchair needed for a few weeks. One parent spoke of getting a walker from a Duke staff member who dug one out of an old equipment room for her. Another spoke of being given a handtruck to use as a bike for her daughter.

Getting Referrals

Thirty eight of the forty five families who reported needing referrals reported not having any problems getting them (84%).

Parent Community Survey

In their Community Surveys, 22 of 54 parents (41%) never experienced frustration in getting services for their child; seven of 54 parents (13%) always or usually experienced frustration.



Difficulties or Delays in Accessing Services

During the past 12 months, 7 of 48 families (15%) reported having difficulties or delays in getting services for their child(ren). The most frequently-cited reasons for difficulty were waitlists or a lack of availability in the area.

The respondents included the following reasons.

- Balance not paid at the doctors office therefore could not schedule
- Dr. to fill out family illness paper
- getting the needed help for my child
- no services in this area
- school related
- with referral

During the past 12 months did you have any difficulties or delays getting services for your child(ren) because...

	YES	NO
...he or she was not eligible for the services?	8	42
...the services he or she needed were not available in your area	13	38
...there were waiting lists, backlogs, or other problems getting appointments?	15	38
...of issues related to cost?	9	45
...you had trouble getting the information you needed?	13	40

Parents included the following comments about accessing community-based services.

- Cardinal Innovations is terrible!!
- Health insurance is not affordable and family not eligible for NC Healthchoice
- I did experience problems when he was in school. He is 21 now so those barriers are no longer relevant. There are few services locally.
- It is difficult to find dental providers whom have experience caring for special needs children. Often times, referrals are sent to UNC School of Dentistry, which has a significant waitlist. When traveling that far, transportation and finances become an issue.
- To be able to find qualified and reliable nurses aides.
- he needs help just don't know how to do about it.
- services from public school have been questionable and requests for meetings with teacher have been put off or cancelled

Although one Granville focus group parent suggested that there were no OT services in Granville, another parent noted that her child gets OT and PT at Granville Medical once per week.

A Granville grandparent stated that there are not enough mental health providers in the area. Even though families may be told to go to the hospital for services, the local Parham Hospital does not offer mental health services.

One parent mentioned a four-month wait (until late January, 2017) for services at Raleigh Neurology; she as amazed that such a large practice could have so long a wait.

Provider Community Survey

Providers recognized the shortage of mental health and behavioral health care in the region.

Provider Level of Agreement with Statement (1=Strongly Disagree, 5=Strongly Agree)	AVG SCORE
Families have to go outside our county for specialist care (please indicate type of care in comments)	4.09
Our region has a shortage of mental health/behavioral health providers.	4.24
Accessing mental health/behavioral health care is a challenge (please explain why)	4.37

In their comments, Provider Community Survey respondents mainly noted obstacles and barriers around transportation, funding, and area resources for CYSHCN families. The following are a few other comments received:

- Medicaid issues with PCPs (having wrong PCP on the Medicaid card and being unable to get it resolved -even after 6 months of trying) lack of communication and follow through with DSS workers in regards to needed Medicaid changes driving time between clients in the rural areas of Vance County parents being hesitant to make early morning appointments parent "no shows" (we serve patients in their homes)
- Availability of specialists and therapists in our local community, transportation, limited cooperation from employers of the parents, education regarding the importance of consistent, and collaborative care.
- transportation, child care/jobs, parents understanding that they have to change in order for children to change.
- lack of providers; the providers that we do have stay booked and have waiting lists.
- Funding, Training to build clinical expertise, enough providers to cut down on waitlists
- Finding consistent in-home nursing staff and specialized therapists to work with children in rural areas.
- Lack of resources in the community. Money will get approved but community is not there yet with agencies able to handle intense behaviors.
- Time face to face in the office and rushed visits. Lack of care coordinators located in-house.
- Due to our providers providing services in the home, the obstacles that exists most are families not being home or families cancelling appointments due to family issues or other appointments.
- Finding a provider available to help them in their area at the frequency they need; communicating with parents the actual extent of their child's needs
- Medicaid issues with PCPs (having wrong PCP on the Medicaid card and being unable to get it resolved -even after 6 months of trying) lack of communication and follow through with DSS workers in regards to needed Medicaid changes driving time between clients in the rural areas of Vance County parents being hesitant to make early morning appointments parent "no shows" (we serve patients in their homes)

In their comments about barriers, Parent Community Survey respondents offered the following:

Parent Community Survey – Comments

- Local doctors have little understanding about how to communicate with special needs people. Our doctor was great, but he talked to us (parents) and we talked to him.
- THE SCHOOLS IS NOT MEETING HIS NEEDS

E. Education/Training Opportunities

Summary: Parents and Providers identified several different opportunities for additional training and education, including providing information regarding diagnoses in a parent-friendly manner; preparing for doctor visits/health notebooks; anti-bullying education for other students; support for foster care families; and other opportunities, including resource information and guides.

Information Regarding Diagnoses in Parent-Friendly Manner

One provider talked about how families may be overwhelmed with so much information and so many directives, particularly for newborns whom they hadn't known would be born with a health condition. She stated that it was important to communicate to families that they don't have to start every therapy now; rather, they can start off with a single therapy and add more over time.

A Vance parent mentioned receiving a survey and a Medicaid card from Cardinal Innovations, the local MCO. She was confused about who Cardinal was and why they had sent her this information; the Granville Vance IA Coordinator explained that Cardinal was the MCO and was likely asking for feedback about a particular provider. This lack of information suggests that the parent is not aware of the MCO/LME model for obtaining services, a crucial aspect of identifying and accessing services.

Some parents discussed the confusion of receiving a diagnosis and not knowing what to do next. A Granville parent noted that her 5-year old child, who does not speak clearly, was sent to a speech therapist, who diagnosed the child as autistic and provided medication, "but no one is calling me about services."

One Vance parent learned of her child's Asperger's diagnosis through her physical therapist. Another Vance parent stated that her child had carried an LDD label until he was age 7. Because the parent works with autistic kids at Murdoch, she feels fortunate that she can care for her child, who is now diagnosed autistic. She praised Dr. Cathcart.

In terms of receiving Advocacy training and support, one parent said she just wanted the names of someone or a group with whom she can talk about her child's health issues.

Preparing for Doctor Visits/Health Notebooks

The Provider group discussed supporting parents in advocating on behalf of their children, including maximizing the limited time that doctors sometimes have for appointments. Some families are reticent to ask lots of questions of doctors for fear of angering them, one provider suggested, adding that families also fear that their doctor will limit their time for questions still further on the next appointment.

Suggestions for most effectively utilizing appointment time included writing down questions beforehand, bringing in pictures of rashes or other conditions, or writing a timeline of the development of the particular illness or condition.

A CCNC representative stated that her organization created a Health Notebook that includes a medications tracker, a section to write questions for doctors, and a section to list your specialists and care managers. With parents so overwhelmed, she said, they will be able to have all their child's health information in one place.

Another provider felt that, in her work with the WIC program, she sees families having a hard time bringing basic documentation to their appointments. She felt that, unless parents felt the information was relevant to their needs, they wouldn't make the time to document all that information.

Anti-Bullying Education for Other Students

One Vance parent suggested that schools should work harder to identify children who bully other children, especially those with special needs. One parent spoke of her son's classmate continuously tapping his foot on her son's chair. The son asked the classmate twice to stop and eventually got into an altercation with the other boy. Other parents spoke of their children being teased or provoked by other kids.

A Granville parent whose five year old was recently diagnosed as autistic and given medication that, the parent said, "don't work and made her like a zombie." Now, the parent reported, kids are making fun of the child at school (Clark Hill Elementary).

Support for Foster Care Families

The Granville group digressed for a few minutes to the subject of foster care, debating how many North Carolina children were in foster care. (A December, 2015 report suggests 11,000 statewide.)¹ The group also felt that half the children in foster care were taken from good parents, but that schools or neighbors who didn't understand certain medical conditions were incorrectly calling DSS on those families.

A Granville grandmother stated her belief that perhaps 85% of children within Child Protective Services (CPS) were children with special health care needs. Further, she felt CPS staff have no knowledge or understanding of Fetal Alcohol Syndrome (FAS) or Reactive Attachment Disorder (RAD).

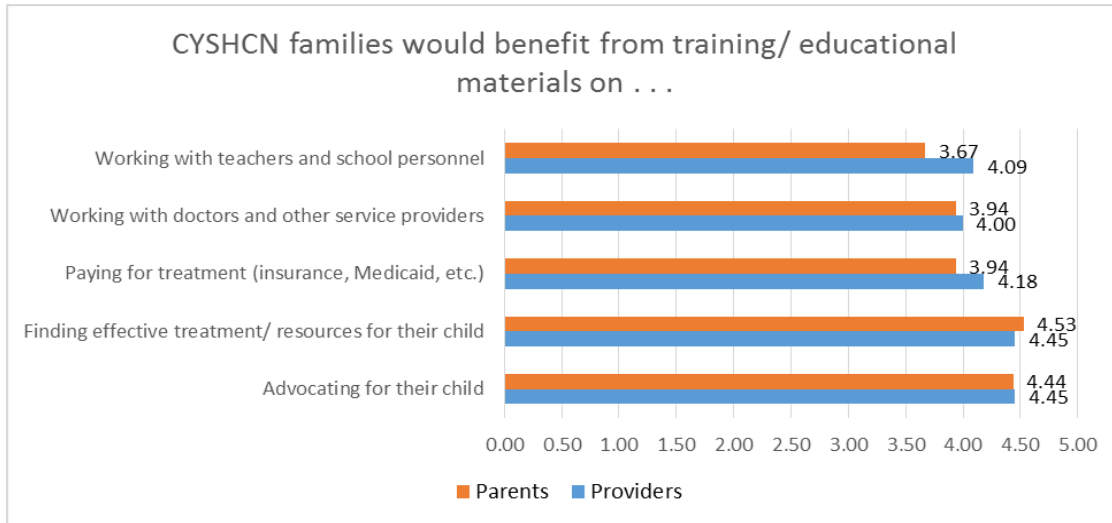
Within their Pre-Meeting Surveys, parents and providers generally agreed that families of children and youth with special health care needs would generally benefit the most from training or information on finding effective treatment and resources for their child, as well as in how to advocate for their child's needs. For the most part, providers and parents opinions were closely-aligned.

¹ <http://www.wral.com/11-000-children-in-nc-living-in-foster-care/15185900/>

Additional CYSHCN Family Training/Educational Opportunities

In their survey comments, providers and parents most strongly agreed that training and education for families on Advocating for their child’s needs; Finding effective treatment and resources; and Paying for treatment would be very helpful for families. They also agreed that information and training on working with school and medical/service providers would also benefit families.

(Parent and Provider Pre-Meeting Surveys)



Provider Community Survey – Comments

In their Provider Community Survey responses, providers suggested that they might benefit from training or education regarding available resources for their patients and contact information.

Additional comments regarding potential training or education for providers include:

- Education on diagnosis. Empathy training for the staff.
- How best to communicate issues that one of my families is having a problem directly with the PCP provider and to actually be able to have a direct conversation without going through a surrogate who may or may not communicate exactly what is needed with th
- information about caring for specific ailments
- Information regarding safety and location of families would be helpful due to our providers providing services in the home.

F. Transition Issues

Summary: Parents discussed the various work options available to their children after college. Several parents spoke of the challenges awaiting their children graduating high school and entering college or the workforce. In general, the families expressed concern about school support for transitions; potential programs for their teenagers and young adults; challenges for transitioning to family foster care; and transitions for younger children and youth with special health care needs.

School Support for Transitions

One provider, who has an adult son with autism, said that, as her child progressed through school, she kept asking, “What’s next? What’s next?” When he got to high school, no one came to her to explain his options, and therefore she did the research to find out about application processes and expectations.

She felt that, if a child has high development needs, providers don’t even try to transition the child; if a child is at the lower end of cognitive functioning but has “street smarts,” there’s some encouragement to transition the child to college or a career beyond high school.

One Vance parent with a 17-year old with OSI/ADHD stated that her son’s school was offering her child a certificate for graduation. She wanted a diploma for her son rather than a certificate, which she felt wouldn’t provide him with as many career or educational options. The parent also works at the school, and didn’t want any special treatment for her son, but she wanted him to have the same chance to graduate as anyone else. She encouraged other parents to educate themselves on graduation requirements and be sure their child meets those requirements.

One Vance parent said that she wants her child to be a “productive citizen, to go to college or the military.”

Potential Programs for Transitioning Teenagers and Young Adults

A provider mentioned that her developmentally delayed 17-year old nephew graduated high school and is now in a program where he is picked up by a bus and works at Creedmoor. Another mentioned a downtown Thrift Store that also employed developmentally delayed young adults (now called Community Workforce Solutions students).

One provider noted that there’s a long wait list for this program, and that many kids “just go home” upon graduating high school with nothing to do. When mental health programs were reorganized in the state, one provider noted, many work-related programs like this were cut.

Opportunities for teenagers may also depend on the type of insurance or coverage a family has. A provider noted that she has a young adult with Cerebral Palsy in her program who receives one-on-one care. His mom wants him out in the community interacting with other people, but “CAP-C policy limits community inclusion because we are a medical-based, needs-based program.” Another provider said that even for young people fortunate enough to get on waiver, there might not be services available to meet their needs.

On a positive note, one parent noted that her family moved to Granville from Johnston County because Granville has “phenomenal” Vocational Rehab services for her older children. “There are lots of jobs people can do at all levels.” She felt there are lots of job coaches and extensive testing to meet a young person at his or her level. Her 24-year old daughter is studying to be a CNA through an Alamance

County program for youth with special needs, and her son, who has a diagnosis of FAS/ADHD, is a gifted artist.

This parent said she fears most for her youngest son, who is non-verbal and severely delayed. “Where will he go?” she asked, fearing a group setting. “What will happen for him?”

Challenges for Transitioning to Family Foster Care

Upon being asked about the future for her children, a grandparent immediately said that she will move her grandchildren out of North Carolina. She stated that “grandparents have no rights in North Carolina” and that she’s had to get a lawyer to get any rights. She’d had to apply to become a foster parent to her grandchildren in order to raise them.

She spoke of the numerous drug tests and background checks and foster parent training she had to undergo, including training in caring for children with special needs. She also needed to spend significant amounts of money on car seats, clothing, beds, and a bigger house before the court would even consider giving her her grandchildren.

Transitions for Younger Children and Youth with Special Health Care Needs

While most of the discussion centered around teenagers transitioning after high school, one provider noted that, at CDSA, children age out at age 3, but that they can contact their former care managers for help or referrals on a one-off basis.

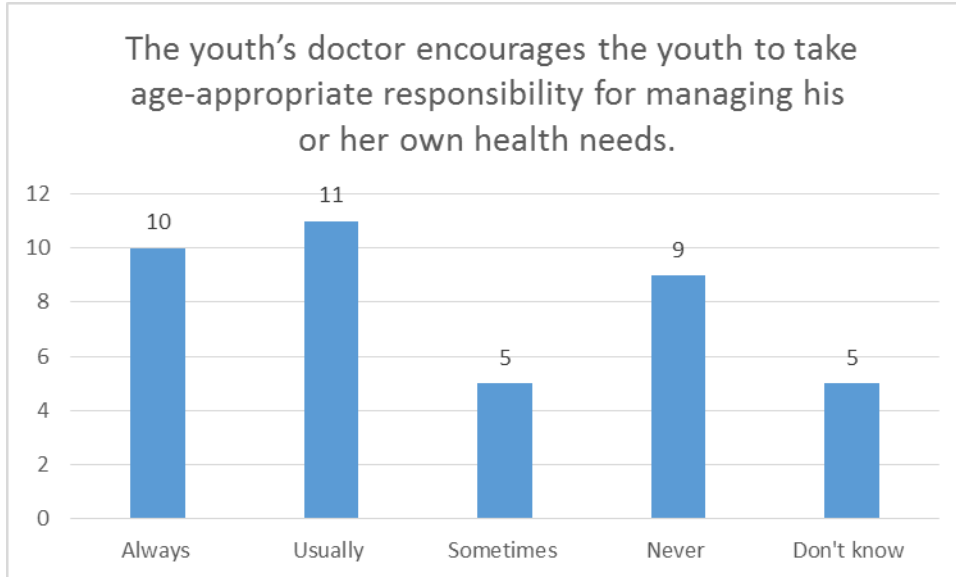
One provider noted that, once many children go through CCNC and CC4C, they do not have any additional support through transitions. She cited one family with 11-year old and 17-year old daughters with special needs, and she said they just go to their appointments and take their medications but do not have any care management.

Another provider noted that in the past, Mental Health/Developmental Disability Care Managers might get 12-15 people in their caseloads, “and we could do a lot.” In CDSA, this ratio was 18-22, for which they could still do a lot, but now it is 39-42 kids across four counties. She felt that more education was needed for newer care managers on how to help children and youth transition at different stages of their development.

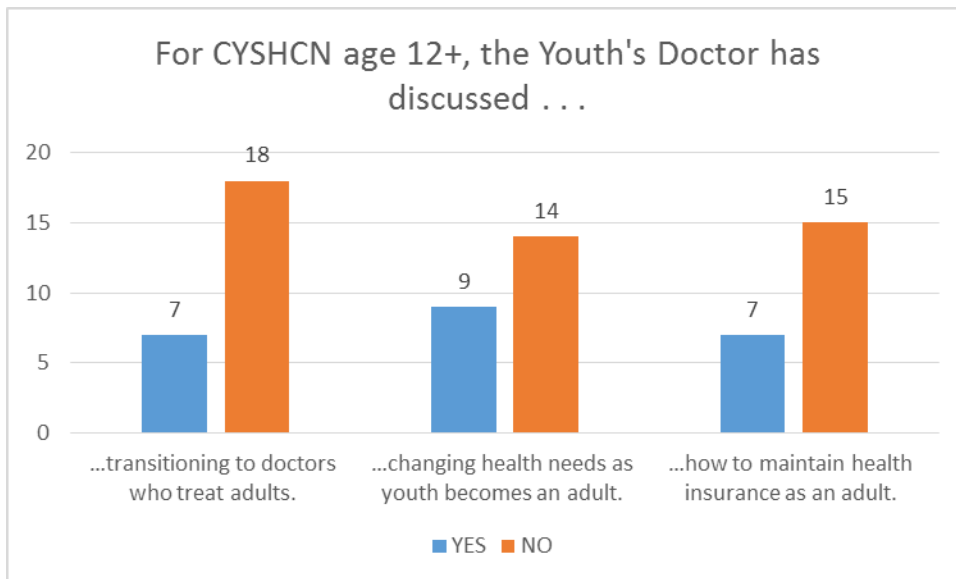
In terms of transitions, parents and providers felt that families of children and youth with special health care needs would benefit from training or educational materials on all school transitions, as well as teenagers transitioning to an adult care doctor.

Community Survey Parents

Twenty one of 40 parents, or slightly more than half, stated that their child's doctor Always or Usually encourages the child to take some responsibility for his or her health needs.



Nonetheless, Community Survey parents report that fewer doctors have generally discussed specific issues regarding transitions to adult health care with their teenagers.



Families provided the following comments about transitions:

- Our PCP did not really discuss these things with him. We did.
- To able to care for him or herself with personal assistant.
- taking care of himself

In their Community Survey, providers identified some potential supports for families going through transitions.

Provider Community Survey

Provider Level of Agreement with Statement (1=Strongly Disagree, 5=Strongly Agree)	AVG SCORE
Families would benefit from guides and checklists to help them through transitions.	4.13

V. RECOMMENDED SYSTEMS CHANGE OBJECTIVES

Increased Participation of Schools in IA Project: Increasing Participation of Granville and Vance school officials in the Innovative Approaches Initiative would offer significant support to families and students. Unfortunately, although invited to the Focus Groups and to other IA meetings, school officials have not participated in the Innovative Approaches Initiative. Based on the feedback of families, school participation could help further identify challenges to servicing students with special health care needs, including developing and following IEPs; ensuring a child is receiving the supports s/he needs; and ensuring teachers have the training and supports they need to support children.

Increased Participation of Cardinal Health Innovations in IA Project: As the state has evolved to an LME/MCO model of mental health and behavioral health care, the local LME/MCO, Cardinal Innovations, could offer significant expertise to the IA Project. Cardinal could provide information to IA colleagues and other providers and families on the process to identify eligibility, access, and pay for their care.

IEP Training for Families and School Personnel: Families, especially those in Vance County, expressed questions and concerns about the IEP process. Indeed, one provider who often sits in on IEP conferences felt that the school had already completed the IEP before even meeting with the parents. Parents would benefit from understanding:

- Their rights and obligations under the IEP process
- How to make a formal IEP request
- School services and opportunities available to their child
- Appropriate followup procedures and mechanisms to ensure the IEP is being followed
- Advocating for additional services after the IEP has been developed

Developing a Resource Guide for Parents and Providers: Many parents and providers alike are unsure of the resources available to children and youth with special health care needs. Perhaps partnering with Duke, UNC Hospitals, Raleigh Neurology and other local and Triangle providers, the IA Steering Committee could develop an online and/or paper-based directory of services and providers in the region. The directory might also include what types of payment are acceptable: Medicaid, private insurance, etc.

Additionally, because Cardinal Innovations, the local LME/MCO, plays such a significant role in the provision of health care, their participation and insights would be very helpful in the development of such a guide.

For example, please see the Cabarrus County Resource Café website for a Resource Guide.

<http://www.cabarrushealth.org/190/Resource-Cafe>

Develop Training/Educational Materials for Parents on Navigating the Health Care System: With the many changes in health care over the last five years nationally and statewide, particularly in the provision of mental health and behavioral health care, parents would benefit from understanding how to navigate the new landscape. For example, training or educational materials could cover:

- Cardinal Innovations, and its role in the family's search for mental health options
- What services Cardinal can connect families to
- How to contact Cardinal
- How to determine eligibility for different services
- How to provide feedback to Cardinal

Additionally, Granville Vance IA may also consider developing a Mental Health Flow Chart like that created by IA initiatives in Cabarrus and Robeson counties. Organized by age and diagnosis, the guide helps parents to determine their options for care.

Please see the Cabarrus County Resource Café for examples of this and other helpful tools for families. <http://www.cabarrushealth.org/190/Resource-Cafe>

Developing a Transition Resource Guide for Parents and Teenagers

As families consider options for their child after high school graduation, a resource guide with post-high school educational and career options, checklists, lists of organizations and contacts, information on transitioning to an adult care doctor, and examples of other students' transitional paths would be very helpful. This guide could be created as an online and paper-based resource.

Utilizing Social Media to Inform Families: Given the rural nature of the area, consider utilizing social media to bring information and opportunities to the special needs community. For example, a Facebook page or website could be developed to:

- Publicize extracurricular activities for CYSHCN, such as the Special Olympics opportunities for area families
- Introduce or highlight existing and new providers to families
- Offer families a venue for sharing old and used equipment (provided liability issues are taken into account)

Social media would be especially effective for communications to young people and teenagers, such as Transition Resource Guides.

Increasing the Availability of Case Managers or Care Coordinators: Parents and providers recognized a need for more care coordination among providers and families. One organization even trains medical offices in the establishment of Medical Homes for patients. While employing an in-house care coordinator may be prohibitively expensive for smaller practices, perhaps groups of practices can come together to fund a few dedicated positions to streamline coordination. Federal grant funding may even be available for such positions.

These Case Managers or Care Coordinators would need a strong background in various types of specialties so that they could make appropriate referrals for families and coordinate with those specialists.

Medical Home Training & Education for Providers: The ABCD program sponsored by Smart Start offers Medical Home Training for providers. While some provider participants suggested that medical providers might not be interested in this type of training, it is worth considering whether ABCD can expand its training or conduct "Train the Trainer" sessions for other regional providers.

In addition to the potential to inform and strengthen care coordination among providers, the training can also assist providers in strengthening their communication and partnership with patients.

Provider Training on Communication and Language

Many providers, while doing their utmost for their patients, may occasionally lapse into "jargon" or utilize language that may be inaccessible to their patients' families. They may also occasionally see a child as a "diagnosis" and not the beautiful, complete child they are. A brown bag lunch session about

“breaking down” diagnoses and treatments into terms that laypeople can understand would support parents and patients as well as reduce the need for repeated explanations. A better-informed parent is in the best place to partner with providers to obtain the best outcomes for their child.

Developing More Networking Opportunities for Providers: An additional benefit to focus group participation for many providers was the opportunity to meet other community service providers and exchange information about services and contact information. In addition to Steering Committee meetings, IA may provide different quarterly meeting opportunities centered around a particular service topic for professionals to continue to develop and strengthen those relationships. Alternatively, the IA team can partner with existing meetings to bring groups of providers together and introduce them to new resources. Where possible, simple refreshments always increase turnout!

Developing More Networking Opportunities for Parents: As with providers, focus group parents gained many insights from the sharing of experiences. Quarterly meetings built around a particular family’s story, or issues of concern to families (finances, advocacy, etc.) taught by other parents could be a powerful educational tool for families, as well as a source of strength and comfort. Again, if IA can “piggyback” on successful groups already in practice, families can find more opportunities for support within the community.

Developing More Extracurricular and Social Activities for Children and Youth

Area health, social, and sports organizations, including the Special Olympics, might work together to develop social events for young people, including dances, sporting events, or play days at the local playground. Publicizing the need for specialized play equipment for children with special health care conditions might invite donations.

New Hanover County has had some success in developing or spearheading movements to develop facilities accessible to all children and youth. Some have been funded by the local LME/MCO. Perhaps IA can communicate with Cardinal Health and any other potential funders to develop a similar facility. <http://miracleleaguelwilm.org/the-playground/>
<http://www.wwaytv3.com/2016/07/20/new-playground-accessible-to-all-kids-opens-at-hugh-macrae-park/>

Identifying Additional Opportunities and Funding to Expand Electronic Health Records: Many providers expressed frustration about having access to the medical records of their patients, either because their patient’s provider was not within their network; certain electronic networks didn’t talk to each other; or the patient hadn’t signed a release. Similarly, parents expressed frustration about having to hand-deliver requests for information to providers.

It may be more feasible on a local basis to convene a working group to consider:

- Technical solutions to allowing electronic record systems to communicate
- Facilitating the “release of medical records” among providers – as easily as providers carrying Record Release forms with them to offer to families

VI. CONCLUSIONS

It is clear that Granville and Vance area providers and parents seek stronger partnerships in supporting the region's young people with special health care needs. The level of dedication and commitment on the part of families and the professionals who serve the needs of children and youth with special health care needs is inspirational. The passion, resourcefulness, and willingness to support each other is an excellent foundation on which to build the strongest network of care possible in their region.

The Innovative Approaches project will help these important partners and other members of the community to identify and agree to their roles and responsibilities in strengthening the system of care for CYSHCN. The local schools will have an important role to play.

VII. APPENDIX

General Suggestions from Provider Community Survey Respondents to Support Parents

The Provider Community Survey respondents suggestions for families on how to best support their child or youth with special health care needs often centered on advocacy for their child's needs, either with their primary care doctor, specialists, or even the MCO. All of the concepts and some of these suggestions are incorporated into the Executive Summary, but all are included below in full for readers' review.

Provider Community Survey -- Comments

- advocate and be involved! ask questions when you don't understand, educate yourself about what your child is going through.
- Advocate for what you need with supporting data/details to back up what you are asking for or what your concern is.
- Advocate, advocate, advocate for your child!
- Ask questions and be fully informed of all available resources.
- Be able access services in wake and Durham counties that may be unavailable in Vance.
- Be persistent in finding appropriate resources for their child
- be willing to travel outside Granville/vance counties and be prepared to pay additional cost.
- Communicate you needs to all who will listen, and ask for additional resources be your own best advocate for care and service linkage.
- Do as much research as possible and utilize all of the resources that are out there.
- do your research
- Ensure that the providers or whomever will be working with your child has received training and education to serve your child.
- find an advocate to assist you in obtaining care and appropriate providers
- I tell parents to utilize all resources available to them and seek additional resources in other areas if applicable.
- I would consult with CC4C manager for resources/referrals
- Keep a planner; Write down and ask questions; Seek resources
- Keep appointments; seek help and advice when needed.
- Parents must advocate with their PCP to be the primary managers with all providers serving the child including the specialists, therapists, and support agencies such as the schools, and cap-c and innovation providers.
- Participate in all program meetings and meetings associated with other resources within the community; be an active participate in all care planing for the children; ask for assistance when needed versus going without services; maintain monthly contact wi
- seek help of PCP and schools
- Speak with MCO. Be a proper advocate. Speak with local politicians to affect change.

- Talk to your pediatrician first; impress upon him/her how important it is to you to get these needs checked out. Nag your doctor if needed. Follow-up on your pediatrician's recommendations and if you are comfortable with it, allow your EI agency to come
- Use all your resources possible, don't be afraid to suggest specialists or treatments to your doctors as they do not deal with this every day. Continue being an excellent advocate for your child.
- utilize your care manager if one is available because they can help you navigate resources.
- We recommend families to carry over strategies taught to them and their youth during sessions. Consistency in the area of communication is important for growth.