

**OHIO Medical Home Focus Group Project**  
***Summary Report***  
***The Foundation for Accountability***  
***September 2002***

**Introduction**

The Ohio Medical Home Focus Group Project represents a collaborative effort by The Child and Adolescent Health Measurement Initiative (CAHMI), the Department of Health (ODH), and the Ohio Department of Job and Family Services (ODJFS). ODH and ODJFS are both members of the FACCT/CAHMI state learning network. States participating in the learning network, in conjunction with CAHMI staff, work to implement projects that support the learning network's goal of creating sustainable models for measuring and improving child and adolescent health care quality.

The CAHMI state learning network offers two learning tracks: a) children with special health care needs; b) preventive health care services for young children and adolescents. The Ohio learning network participants choose to focus on quality of care for children with special health care needs (CSHCN). At the time, both ODH and FACCT/CAHMI were engaged in separate projects addressing “medical home” and children with special health care needs. The state learning network provided a natural opportunity for ODH, ODJFS, and CAHMI researchers to combine resources and expertise to study this topic in more depth. Specifically, ODH asked CAHMI to collaborate on and lead a focus group project with families of CSHCN. Funding for five of the six focus groups was provided by the MCHB State Systems Development Initiative (SSDI) Grant, administered by the Division of Family and Community Health Services, Ohio Department of Health.

The provision of regular ongoing comprehensive health care within a medical home is a key component of quality for CSHCN. The American Academy of Pediatrics (AAP) defines “medical home” as health care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, culturally effective – delivered by a physician who knows the child

or adolescent and works with the family to develop a partnership of mutual responsibility and trust (see Appendix A for the July 2002 AAP policy statement on medical home).

Increasing the numbers of CSHCN who receive health care in a “medical home” is a priority for child health care reform at the national and local levels. The US Department of Health and Human Services’ *Healthy People 2010* goals and objectives state that “all children with special health care needs will receive regular ongoing comprehensive care within a medical home. The proportion of CSHCN who have a medical home is also one of the performance measures reported by all states under the Title V Block Grant annual reporting requirements.

Despite this national focus, there is much that still needs to be learned about whether or not the health care children receive functions as a medical home. In response to this need, FACCT/CAHMI researchers are working to develop standardized national measures of medical home using parent-reported survey data. At the local level, ODH and its sister agencies in ODJFS are interested in learning how much the health care currently received by children enrolled in Medicaid or Title V programs reflects the characteristics of a medical home. Partnering together on a focus group project represents an unique opportunity for all involved to gain a better understanding of families’ experiences with their children’s care, as well as their attitudes and preferences regarding the concept of medical home.

## **Purpose**

The overarching goal for this study is to learn how ODH and ODJFS can improve services for CSHCN and increase access to health care that functions as medical home. Information and insights gained through focus group discussions with families of CSHCN would provide valuable guidance for quality improvement activities, programmatic planning, survey development, and other research. In addition, CAHMI researchers planned to use information about how families’ describe and prioritize different aspects of their CSHCN’s health care to develop and revise survey-based national assessments of medical home.

The four major research objectives guided the design of the study:

- To identify what, if any, barriers and challenges families of CSHCN experience in obtaining the medical care, services, and equipment needed by their children;
- To find out which health care providers, if any, families of CSHCN rely upon or trust for information, help with coordinating care, or other assistance related to their children's health needs;
- To examine families' attitudes and preferences regarding the overall concept of medical home and its subcomponents;
- To learn how families of CSHCN characterize the health care their children currently receive and to what extent this care reflects the concept of medical home.

## **Study Design**

Beginning in March 2002, staff from ODH, Ohio Bureau of Medicaid, and Ohio Bureau for Children with Medical Handicaps (BCMh) met with CAHMI researchers by telephone on a weekly basis to provide input on and review of the research questions, recruitment protocol, and focus group discussion guide.

### ***Discussion guide***

The selection of topics for the focus group discussion was guided by the American Academy of Pediatrics definition of the medical home. The areas selected for discussion included access to care and services, comprehensiveness of care, family-centered and compassionate care, coordination of care, culturally competent care, and the level of partnership, mutual trust and responsibility between the family and the child's health providers(s). Questions and follow up probes designed to address these components of medical home were organized into five topical areas for participant discussion and input:

1. Experiences getting needed health care and services for CSHCN during the past 12 months;
2. Experiences getting information and assistance when questions or concerns arise about the health or health care for CSHCN;
3. Experiences with assistance coordinating care or accessing special services for CSHCN;
4. Reactions to the concept of "medical home" and the extent to which CSHCN's current care reflects this concept;

5. Advice and suggestions to Medicaid and BCMH for improving care and services for CSHCN.

In addition to Ohio project staff, the discussion guide was reviewed by representatives from *Family Voices*, a national organization serving CSHCN and their families, and members of the federal Maternal and Child Health Bureau's medical home measurement advisory group. Suggestions from all reviewers were incorporated into the final version of the discussion guide included in Appendix B.

### ***Sampling and recruitment***

The parents or guardians of CSHCN living in one of three geographic areas (determined by zip code) were randomly selected from a combination of Medicaid and Title V enrollment records. The sample population was limited to children aged 0 – 17 years old currently enrolled in both Medicaid and Bureau for Children with Medical Handicaps (BCMh), with a telephone number and residing in the Lucas, Richland, or Franklin county areas. Participants were recruited by telephone using a standardized protocol and were paid a \$60 stipend in appreciation for attending.

The six focus groups planned were stratified according to age of the child with special health care needs, geographic location, and family ethnicity (see Table 1) – all factors hypothesized to influence the health care experiences of CSHCN. Specifically:

- CSHCN enrolled in Medicaid managed care are expected to report higher levels of care coordination or case management than those enrolled in fee-for-service Medicaid;
- Families living in rural versus urban areas are likely to face different types of access barriers and other challenges to getting services for their CHSCN;
- Families with CSHCN under the age of 5 years old are likely to get care coordination and other services through Early Intervention programs, in addition to those provided by Medicaid and/or BCMH;
- The issues and concerns that are the most important to families with CSHCN vary according to the age of the child;
- The experiences and concerns of Hispanic/Latino families with CSHCN are likely to differ from those of mainstream families because of language and cultural barriers.

**Table 1: Ohio Medical Home Focus Groups – sampling design**

	CSHCN (5 yrs old & under)	CSHCN (Over 5 yrs old)	CSHCN (All ages)
Medicaid managed care (Urban)	1 grp	1 grp	1 grp
Medicaid fee-for-service (Rural)	1 grp	1 grp	
Latino family ethnicity	1 grp		

Staff from BCMH specifically wanted to gain a better understanding of the cultural or language barriers that Hispanic/Latino families in the Title V program experience when getting care for their CSHCN. The original study design planned for two focus groups limited to only Hispanic/Latino families with CSHCN. Recruiting participants for these groups, however, was unexpectedly difficult. Multiple strategies were employed, including over sampling families with Hispanic surnames, outreach through Latino community centers, and the addition of questions to the recruitment protocol to screen for families with Hispanic/Latino cultural identity. Despite all efforts, only six Hispanic/Latino families with CSHCN were recruited; three of which attended a single Hispanic/Latino focus group held in the Toledo area.

The failure to recruit enough participants for a second Hispanic/Latino group became an opportunity to increase the diversity of focus group participants via another route. Participants for the sixth focus group were recruited from zip code areas in the city of Columbus representing communities with highly diverse demographics, especially Black/African American.

### ***Facilitation***

An independent consultant from Ohio with prior focus group moderation experience, familiarity with health care topics, and bilingual skills in English and Spanish facilitated all of the focus group discussions. A member of the senior research staff from FACCT/CAHMI served as co-facilitator and note taker. All of the focus group discussions were audio taped and later transcribed to aid in the content analysis of the discussions.

The study design and all focus group materials, including recruitment protocol, participant contact letters, discussion guide, consent form, and participant survey, received approval from

the Institutional Review Board of the Ohio Department of Health Human Subjects Review Committee. See Appendix B for copies of these materials.

## **Participants**

A total of 41 adults participated in the six focus groups, representing 39 families and approximately 47 CSHCN enrolled in Medicaid and BCMH (some families had more than one child enrolled in Medicaid and BCMH). Participants were predominately female—32 mothers; four grandmothers; four fathers; and one grandfather. All grandparents were the primary caretakers of their CSHCN grandchildren. Based on comments during the discussions, it is estimated that at least half of the participants had private insurance coverage for their CSHCN care and that Medicaid and BCMH functioned as secondary payers.

Three groups were conducted in Toledo, OH (14 participants); two groups in Mansfield, OH (17 participants); and one group in Columbus, OH (10 participants). Nearly two thirds of the participants were White/non-Hispanic, and about one third was Black/African American. One participant reported Hispanic/Latino ethnicity. The diversity of group composition varied from site to site; however, participants in the Columbus group were primarily African American. Additional participant demographics and a summary of focus group attendance are included in Appendix C.

The CSHCN represented ranged from less than a year old to 18 years of age. About one half were under the age of four years. Over a third of the children were enrolled in BCMH since birth; most of the remaining children had been enrolled for at least a half of their lives. All of the CHSCN represented in the focus groups experienced on-going medical conditions, many of which were severe and/or disabling. These included cerebral palsy, muscular dystrophy, health problems due to premature birth, hydrocephalus, seizure disorders, sickle cell anemia, rare metabolic disorders, developmental delay, and mental retardation. Several children had disabilities resulting from accidental injuries. Many of the CSHCN currently used medical equipment or devices such as wheelchairs, G-tubes, monitor, shunts, baclofen pumps, APO's and other orthopedic devices, and vision or hearing aides.

## **Focus Group Findings**

The findings from the focus group discussions are organized according to the five discussion topics included in the discussion guide. For each topic, convergent and divergent themes are summarized and illustrated with representative participant quotes. A more extensive compendium of participants' comments, organized by topic and theme, is included in Appendix D — providing a detailed account of the experiences of families with CSHCN served by Ohio Medicaid and BCMH.

### **Overarching themes**

Sharing of CSHCN-related information — tips, resources, and advice — took place constantly among participants before, after and during all the discussions. In every case, participants were reluctant to leave at the close of the discussion and many often lingered outside the meeting rooms to continue their conversations and exchange phone numbers. Interestingly, only two of the participants knew each other before coming to the focus groups — even though many participants saw the same pediatricians and specialists for their children. This was even true in the rural community of Mansfield, despite many these participants sharing the same BCMH nurses.

In addition to the above, several other strong themes — comprising a common denominator of experiences shared by all participants — were present in all the focus group discussions.

***Adjusting and coping — CSHCN less than 5 years old:*** Adjusting and coping to having a child with special health care needs is an on-going process. As expected, the issues and concerns that were the most salient for families changed as their children grew older. Participants whose CSHCN are less than five years old were unanimous in describing the stress and overload they experience, especially in the beginning. The majority of these participants' children had extended stays in Neonatal Intensive Care Units — and their families were simultaneously digging out of the unexpected morass of paperwork and financial burden while simultaneously trying to adapt to their children's health situations. In many cases, participants reported feeling so overwhelmed that they were not able to “take in” information they were given about services for their children or to keep up with the paperwork burden. Several participants described the



birth of child with special health care needs as feeling like a crisis with no end in sight. Or as one mother of a young CSHCN noted: "... abnormal becomes your normal."

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***Adjusting and coping — CSHCN less than 5 years old***

- **(Mom #1):** You're stressed because you are so nervous and scared about your child. When you do deal with these people, you're already at a heightened stress level. **(Mom #2):** I don't think they realize that. **(Mom #3):** We don't realize it either. We're already getting upset a lot quicker. We're tired, and the whole thing.
  - I actually didn't even continue to fill out the application just because I was so stressed in filling out forms and documents and paperwork. I basically just put it in the cabinet and said I can't go anymore.
  - You don't teach somebody something when they are in the middle of a life crisis, which is a problem because you can't turn it (the crisis) off.
  - Your lifestyle automatically changes—your mindset changes. You don't ever think you could do this.
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***Adjusting and coping — CSHCN over the age of 5 years old:*** Participants with CSHCN of school age had more or less adjusted to the daily demands of caring for their children. Many were caring for their children's medical complex needs in the home; making significant sacrifices to keep their children out of institutional care. As CSHCN grew older, having accessible bathroom layouts, equipment, and transportation that allowed them to move and care for children that were getting too big to carry was concern for many families. Nearly all participants mentioned the lack of support and understanding, and the vacuum of information they continually encountered — including the emotional drain of having to "tell your story" over and over again to an ever-changing stream of caseworkers and insurance representatives. Most of all, they wanted others to look past their child's disabilities to see the person underneath.

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***Adjusting and coping — CSHCN over 5 years old***

- Just because they are in a wheelchair, that doesn't mean anything—you have to see the person—see the child.
  - It's just not a comfortable conversation. It's been seven years since the day of my daughter's accident.....It's (still) hard to go in a room and talk to strangers that don't share the same things that we do and be able to talk about it without crying.
  - Nobody tells you when you have a special needs child—this and this are available to you. You find out later that you could have had it five years ago.....If you find out your own—it's like it's a secret.
  - Don't you wish some of these people (referring to caseworkers and insurance company representatives) that you talk to on the phone could come to your house for an hour?
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***Families as the first and foremost experts about their children:*** As daily caregivers of CSHCN, participants possessed detailed knowledge of their children's health and well-being. Many parents reported noticing problems, some serious, long before a formal diagnosis was made. A number of participants recalled instances when their observations and concerns about their children were discounted or unheeded by doctors and other health providers. It was not uncommon for parents to go to several doctors before finding one who took their concerns seriously. Several participants described times when they disagreed strongly with or refused to follow medical advice that later proved to be inaccurate or incomplete, saving their children from unnecessary procedures, medications, or symptoms.

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***Families as the first and foremost experts about their children***

- His doctor....he kept telling me it was normal, it was fine.....It took going to the evening clinic and getting another doctor and have her see what I saw. She's the one who gave me the referral
- By the time he was 11 months old, he wasn't sitting up or anything. They said he was still fine. He went through therapy for a year, and the day before his second birthday he was diagnosed with cerebral palsy spastic diplegia. I was on them the whole year that there was something wrong.
- .....not everybody knows all his little quirks and medications and stuff. I fought (my son's doctor) long and hard when he tried to take (my son's) medication away from him. Every time he took one certain medication away, (my son) seized more.....then finally he found another medication to substitute it. We weaned him off little by little.
- I said I wanted a second opinion because he (doctor) wanted to do surgery. Thank god, I went for a second opinion because she didn't need surgery....He (the first doctor) had prescribed the wrong lenses for her. She couldn't see through them at all.

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***Navigating the insurance payment arrangements:*** Confusion about the complex and often convoluted insurance arrangements paying for the medical care and services their CSHCN rely upon was nearly universal among participants. In particular, participants expressed a lack of clarity regarding the relationship between Medicaid and BCMH and the services covered by each — and some were concerned that their children might be missing eligible services as a result. More than half of the participants had private insurance in addition to Medicaid and BCMH, complicating the picture still further. Often, not even the billing staff in physicians' offices was able to keep things straight. For the most part, parents were resigned to the on-going hassles and continual need to untangle billing mistakes and unwarranted denials. Several parents mentioned having bills go to collection agents because they were not able to figure out what was going on

quickly enough. This situation was often connected with the birth of a premature infant because the overwhelming changes and stresses families experienced made it difficult to deal with insurance matters in a timely way.

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### ***Navigating the insurance payment arrangements***

- They just got back with me yesterday and I'm not sure what the lady meant. I have to call her back—something about my insurance that the doctor wouldn't take. I have three: private, Medicaid, and BCMH, so I'm not sure which one she meant.
  - How do we know that's being used? **Do you mean BCMH?** Yes. We're going to all this trouble to be on this program—how do we know how it's being used? We're on the medical card and that covers—supposed to cover one amount. How do we know what each of them cover?
  - There might be more potential out there that you are aware of because you don't get any information.
  - The paperwork—I just shoved in a cabinet because I couldn't do any more. I didn't have the quality time with him — just sit and hold him without your mind racing. (*mother of a preemie*)
  - (**Speaker A**): I knew I screwed up the minute I showed (the ophthalmology office staff ) that.....I should not have told them. (**Speaker B**): With (name of ophthalmologist), I did that. They asked if I was still on the medical card. If I say no, that's where I would have had to switch over from BCMH glasses (which) are a lot nicer and they're a lot lighter, prettier.
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## **Getting needed health care and services for CSHCN**

**Continuity of care:** Not unexpectedly, most of the participants had one or more health care providers they considered to be their children’s primary care providers. Most often these were pediatricians or family practice physicians. Nearly all the participants described long-standing relationships with the same doctor — who in many cases had been caring for the child since birth or shortly thereafter. Participants with CSHCN of all ages stressed the importance of having a doctor who is easily accessible, who knows their child well, and who is comfortable caring for special needs children. The trust and partnership that builds over time between a family and a specific provider was highly valued by participants. It is also not easily replaced or substituted. Two participants described having long standing relationships with their child’s doctors disrupted because of changes outside their control. In both cases, the parents had not yet found new doctors they felt comfortable with. As a result, they were regularly using the emergency room as the chief source of primary care for their CSHCN.

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### ***Continuity of care***

- My doctor—he knows my son. At first my son did go to a pediatrician—when he first came home from the hospital. She knew nothing. So I switched—he’s been my son’s doctor for seven years.
- I have a really good pediatrician at Mansfield Pediatrics. There’s two main doctors that see him. They are wonderful. Any questions I have that are medical, they know instantly because they know my son so well.
- I even called (my son’s pediatrician) at home—he said, “Call me at home, I’m in the book.” “Can you meet me at the doctor’s office tomorrow; my son’s tube came out?” My son trusts him. He said, “Sure.” The nurse tried to say that he wouldn’t do that, but the next day we went in.
- But once I was divorced everything changed.....Ever since she’s been born, she’s been with this one pediatrician. Well, that pediatrician doesn’t take BCMH or Healthy Start.....What I find myself doing, which is a cost to even them, is I always take her to the emergency room. When these issues come up, it’s call your doctor—but what doctor am I going to call?

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**“No holds barred” approach to seeking medical care:** Participants were active seekers when it came to getting medical care for their CSHCN — often switching doctors several times until finding one that met their standards. Participants place high priority on finding a doctor whose medical expertise they felt able to place their confidence in. But medical expertise alone was not sufficient. Participants also sought out health providers who treated CSHCN with respect,

sensitivity and understanding, and who were responsive to parents' concerns and questions. Participants went to great lengths to find this combination of attributes and did not hesitate to "fire" — as several participants termed it — doctors that did not meet these expectations. Some families traveled considerable distances, sometimes going out of state, to obtain medical care that met these criteria. Many participants made mention of the assertiveness skills they needed to develop in order to be effective advocates for their children when dealing with physicians and other health care providers. As one veteran parent whose special needs son is now 15 years old put it: "I pity the child with a shy mother!"

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***"No holds barred" approach to seeking medical care***

- A couple of doctors misdiagnosed my son. I tell them they are fired. I don't care whether I'm on Medicaid, or what I'm on. I don't let doctors, teachers, anybody treat me like a second-class citizen, or my son. I tell them they are fired. I've been through three doctors just to get him a bone doctor.
- (The new doctor) said, "Mom, I noticed you are a stay-at-home mom. What do you see?" I said, "Didn't you see the results of the tests?" He said, "I read them, but so what. You tell me." I looked at him, and I said, "I'd like to get up and hug you." This is what I wanted to hear. This is what I was looking for.
- This one particular doctor, he was a neurologist and made us wait three and a half hours in the waiting room before we could be seen.....he walked in the room (and) picks up my one son who is the worst. He has no head control. He has no muscle control. He's just limp. The doctor said, ..... "CP, extreme CP".....then he picked up my other son..... and kind of flopped him around, and he said, "I guess this one forgot to read the book." That was the extent of our visit. We never went back. We ended up going up to Ann Arbor. We saw a doctor up there who was extremely nice. She calls my children her second family, which is wonderful. You want to have that one-on-one.

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***Experiences with BCMH providers and services:*** Participants consistently reported positive experiences and high satisfaction with physicians and representatives affiliated with BCMH programs. Many participants expressed deep appreciation for the services provided by BCMH, especially the public health nurses. It does appear, however, that no consistency exists regarding when and how families learn about BCMH services. Some participants mentioned being enrolled by their children's physicians, others learned via community sources or by word of mouth. Only two focus group participants had negative experiences with a BCMH affiliated provider. These comments were made independently in different focus groups; however, both participants were from Lucas County. In both cases, the participants were very unhappy with the abrupt, impersonal care they and their children experienced from a pediatric nephrologist in the Toledo area. It is not known for certain if they were referring to the same physician, but the

likelihood is high. Both participants refused to take their children back to this provider and subsequently sought care from a pediatric nephrologist in Ann Arbor, MI.

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***Experiences with BCMH providers and services***

- So far, I've been very fortunate. I have had good experiences. One difference that it's been is my daughter's BCMH nurse has been the total forefront of the success of my daughter's health. She's the one who has found the doctors for me. (*Richland County focus group participant*)
  - I appreciate the BCMH doctor that comes up from Children's Hospital to Ohio Eye.....I could not ask for a better eye doctor. He is just excellent.
  - Actually I've been on BCMH for under a year. It wasn't until I went to see his oncologist and she told me about it. I had a problem with my son's prosthesis. It's a lot of money—it's like \$1,800.00 for it....He'll probably be needing a new one every two years until he is full-grown. So I'm happy that I did get BCMH.
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***Experiences with Medicaid and related programs:*** Participants universally described their encounters with the Medicaid system as problematic. The problems mentioned included inflexible processes, lack of adequate information, frequent misinformation, and the predictably unhelpful attitudes of Medicaid caseworkers. For the most part, participants' tone in reporting these experiences was one of resigned frustration combined with incredulous head shaking over the unresponsiveness and cumbersomeness of the system. Several participants even noted that the caseworkers they interacted with were basically well intentioned but beaten down by the system itself. Nonetheless, the rapid turn over of caseworkers and the accompanying lack of information and training led to frequent denial of services, many of which were later approved. In addition, participants frequently mentioned rude and unkind treatment from Medicaid caseworkers. Many participants noted the lack of information and misinformation they encountered when attempting to apply to the Medicaid Waiver program for their children — adding additional time to an already lengthy process. Overall, the cumbersome processes, poor information, high turnover of caseworker staff combined with high case loads resulted in frequent long delays in getting the equipment and benefits CSHCN were qualified to receive. After being denied the special chair that her child's doctor prescribed for her four year old son who lacks the motor control to hold up his head or feed himself, one participant stated: "I feel like taking my son into the Medicaid office and dropping him on somebody's desk and saying now look at my son and tell me that he is ineligible for this chair that we have asked (to get) for him."

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### ***Experiences with Medicaid and related programs***

- The caseworkers are the worst. It's just the pits. I understand—they are a huge agency and they serve all parts of life, but someone needs to give those workers some kind of a boost. They are negative but they started out wanting to help. They have the heart, but the system is knocking them down, along with us
  - To me Medicaid lacks information. They need to get their act together. You have to go down every year to get recertified. You feel like you are the scourge of the earth.
  - I think it was being passed from caseworker to caseworker. I understand they are overwhelmed, they are overworked, they don't have enough people, whatever—but it still doesn't make it easy on my end.
  - I guess one of my biggest things is—not so much with this organization (BCMh), but with Medicaid and initially applying for it. Everything was so much based on income. It just got so frustrating. We had to take down every document known to man—then was denied. Then we got a phone call back that they approved just (son's name) for Medicaid.
  - I got the home-based waiver, it's made an incredible difference in her life and mine. But getting there—even Medicaid Family Services didn't know what they were doing. They had the home-based waivers, but the worker didn't know what it was. It took me three years and crying down there in that public building in order to get somebody to listen to me enough to say, "Okay, here, you filled out the wrong form."
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*Specific barriers to getting care and services:* In the course of meeting the health care needs of their CSHCN, all participants interacted with multiple systems and health providers on a regular basis. These included primary care and specialist doctors, children's hospitals, educational services, physical, occupational, and speech therapists, home health care services, medical equipment suppliers, Early Intervention, BCMh, Medicaid, mental health and developmental services, etc. There was little evidence that the systems and providers serving the same child "talked" with each other in an organized fashion. Parents in general had low expectations of this happening, as well. Many of the specific barriers to getting care mentioned by participants were, to a greater or lesser extent, related to this lack of coordination and communication. Participants, however, were quick to differentiate medical care provided directly by physicians — with which they had few or no problems or complaints — from the difficulties and barriers they experienced getting the other types of services needed by their CSHCN such as medical equipment, transportation, home health care, and respite services. At the same time, participants expressed few or no expectations that their children's doctors had a role in helping access or coordinate these services.

In contrast to the active approach many parents took to getting medical care for their children, participants were often less sure about who to contact and where to go when it came to getting services that are not medical in nature. In fact, participants cited lack of information as the most frequent barrier to getting services and support for their CSHCN. Many participants, especially those with younger CSHCN, noted the absence of comprehensive, readily available sources of information about programs and services for which their children may be eligible. A consistent theme was that of finding out about services and programs through sheer coincidence or word of mouth. For example, one family continued to pay out of pocket for diapers for their nine year son even though BCMH covers this expense for children after the age of three years. A casual comment during an unrelated phone call with BCMH representative revealed this resource. Experiences of this type are not uncommon. In one participant's words: "Nobody tells you when you have a special needs child—this and this are available to you. You find out later that you could have had it five years ago.....if you find out your own—it's like it's a secret."

Participants also described denials of benefits and long delays in obtaining prescribed medical equipment as being frequent barriers to care. Often, the denials and delays mentioned by participants were related to lack of information — particularly when applying for and obtaining Medicaid Waivers for CSHCN. In other cases, participants cited the high turnover among Medicaid caseworkers combined with heavy caseloads as being the reason for long delays in obtaining approved equipment such as wheelchairs for their children. Participants noted that every time their children's caseworker changed, they had to educate the new caseworker about their child's specific medical conditions and related needs—an emotionally exhausting task. Two participants described the difficulties they experienced getting approvals for referrals to out of state or out of network specialists with expertise in treating the very rare metabolic or genetic disorders affecting their children.

Participants living in rural Richland County consistently cited the lack of local pediatric specialists and expertise as a major barrier in getting care for their CSHCN. Most of these families drove to either Cleveland or Columbus to obtain specialist care and other services for their children—trips that averaged about 2 hours each way and often required taking time off from work and children out of school. Several participants mentioned the cost of gas or unreliable transportation as being significant burdens. Interestingly, a few parents avoided these



trips by taking their children to pediatric sub-specialists who held office hours in Mansfield on a regular basis. It is not clear why more families did not take advantage of this opportunity. The lack of pediatric specialty care was especially problematic for families whose children had frequent emergent episodes. One parent described repeated trips to the local emergency room with his two year old child that always resulted in life-flight or ambulance trips to Columbus because local pediatricians did not have medical expertise to treat her condition. In contrast, none of the participants living in the urban areas of Toledo and Columbus mentioned problems related to the availability of pediatric specialty care.

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### ***Specific barriers to getting care and services***

#### ***Delays, denials and lack of information***

- Nobody tells you when you have a special needs child—this and this are available to you. You find out later that you could have had it five years ago.....If you find out your own—it's like it's a secret.
- *(Speaker A)*: It's such a big problem. You don't know unless you ask. You can't ask unless you already know. *(Speaker B)*: They're not going to volunteer any information to you.
- What I don't understand is the referrals. Like his therapies. He's doctor will send in that he needs to go and the insurance will kick back with he's denied because the reasons given are not good enough, or whatever—I don't understand.
- *(Responding to moderator's probe about obstacles in getting care)* The knowledge of knowing where to go. For a long time we didn't know about BCMH. We didn't know about the Medicaid Waiver. We just kept stumbling over things and not being connected with the right people.
- That Waiver Program—I found out through talking with *(speaker gestures to another group participant)*—his son and my son go to the same school. I had applied before him and they cut it out—he applied and got on it before I did. Nobody notified me—now there's a waiting list again. So my BCMH nurse and I apply once a month.
- They (referring to Medicaid) had the home-based waivers, but the worker didn't know what it was. It took me three years and crying down there in that public building in order to get somebody to listen to me enough to say, “okay, here, you filled out the wrong form.”
- I'm in Wood County and the caseworker I had there—it was like pulling teeth. I just try to ask about Social Security—would we qualify or what would allow us to qualify. (The caseworker) was like, “Don't ask, I'm not talking to you”..... as far as my experience with Wood County, it's just—I hate going in there.

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**Specific barriers to getting care and services (continued)**

Lack of local pediatric specialists

- There are nephrologists here in Mansfield, but due to the fact that he is a child, they refuse to see him.....so I said, “Forget it, I will go to Columbus.” I have to take a whole day off of work and he has to miss a whole day of school. But in the long run, I do believe that was the best choice because I don’t trust any doctors in this town except for my family physician. *(Richland County focus group participant)*
  - I wish, in hindsight, I would have listened to the nephrologist in Columbus, or he (her son) would have been diagnosed by now. But no, I chose to stay here for convenience so I wouldn’t have to drive. *(Richland County focus group participant)*
  - Now he (son) only goes once a month and the neurologist from Cleveland comes to Mansfield, which makes it a whole lot easier than me having to go to Cleveland. You have to consider taking time off from work and not everybody knows all his little quirks and medications and stuff. *(Richland County focus group participant)*
  - If I had the money to move—I’d move to one of the big cities, just so I could have better doctors for my son. *(Richland County focus group participant)*
  - But thank God for Columbus Medical and Children’s Hospital. Because I’ve met a lot of people that have come from Mansfield (Richland County)—all over the place—to bring their kids, because they don’t have those facilities. So at least we do have some things that work in our favor. *(Franklin County focus group participant)*
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**Unmet needs:** Other than long delays in obtaining equipment or benefits such a Medicaid waivers, participants did not report high levels of unmet needs. This finding may be related, in part, to the general lack of awareness and information reported by participants concerning services their children may potentially be eligible to receive. As one parent noted: “You don’t know unless you ask. You can’t ask unless you already know.” Dental care for CSHCN was the most frequent unmet need, however, it was only mentioned by Richland County participants. Specifically, the lack of local dentists with expertise in treating CSHCN who were willing to accept Medicaid payment created a barrier for many families in the Mansfield area. As a result, many participants traveled to Cleveland or Columbus or paid out of pocket. Other unmet needs included the out of pocket costs for uncovered medications, special diet food for a child with celiac disease, and travel expenses for weekly trips to Cleveland for therapy. Several participants noted that Early Intervention provides gas vouchers for trips of this type but this support disappears when a child with special needs turns three years old.

## **Getting information and help when questions or concerns arise**

Nearly all participants named their CSHCN's primary care doctor as the first point of contact when they had questions or concerns that were medical in nature. Participants also contacted their children's specialists when they needed medical help, sometimes bypassing the primary care doctor when the issues were more specific to the specialist's area of expertise.

The point of contact for families varied when the questions about care or services that were not specifically medical in nature. Several participants from the Richland County focus groups specifically named one or other of the local BCMH nurses from county health clinic as the first person they call with questions of this type. At the mention of the BCMH nurses' names, almost all the other participants in the Richland County groups indicated that they, too, knew of and used this resource. In contrast, not a single participant from the Lucas County focus groups who resided in Lucas County mentioned knowing or getting help from a BCMH nurse. However, participants attending the Lucas County focus groups from the surrounding counties of Sandusky or Henry made frequent mention of using their BCMH nurse for help with these types of questions. Participants in the Columbus group frequently mentioned calling staff at the Children's Hospital outpatient clinics when questions or concerns arose. Early Intervention nurses and hospital social workers were also mentioned as helpful resources by several participants with young CSHCN.

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### ***Getting information and help when questions or concerns arise***

- For me it would depend on what the issue is. She has about six different specialists. Our pediatrician is wonderful, but she's also has her limits and says, "That's just something I can't do, you need to go here."
  - My BCMH nurse. Like when he got diagnosed with asthma. I asked her who I should see, who did she recommend. I don't trust just what my doctor says. He doesn't have children. [inaudible] I trust my BCMH nurse to recommend me to other places. (*Richland County focus group participant*)
  - I call Ann Smith in Fremont, Ohio. She's a nurse that works for the health department. . . . All I have to do is call her and she does it for me. She's always said not to worry about it. I'll get off the phone and she calls me later. (*Lucas County focus group participant who resides in Sandusky County*)
  - I usually call Lois Hanna. She's in the Help Me Grow Program (Early Intervention program). She directs me where to go. (*Lucas County focus group participant who resides in Henry County*)
  - The nurse at the Children's Hospital. (*several Franklin County focus group participants*)
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## **Assistance coordinating care and accessing specialized services**

**No assistance:** When asked who — other than friends and family members — helps coordinate the care and services used by their CSHCN, at least half of the participants replied: “Nobody” or “You learn to do it by yourself.” A few parents indicated that they preferred to take the lead role in coordinating care. But the rest of the participants who received no assistance noted that they took on this role not by choice but by default—and would welcome more assistance and support to coordinate their children’s care among the multiple providers and services used. A striking example was the parent of two year old triplets with cerebral palsy whose coordination needs were significant yet she received no regular support in this area.

**Assistance of some type:** Participants who received help with care coordination got this help from one of two sources: 1) physician’s office; and 2) community-based services. When the physician’s office was cited as the source, the type of assistance reported by participants usually involved regular communication among their children’s primary care doctors and specialists. One or two participants in every group described how their children’s primary care provider and specialists regularly sent each other and the child’s family faxes and letters sharing the results of tests and recent visits. Other participants, upon hearing about these practices, frequently responded in amazement as nothing even close to this happened between their children’s doctors. The care coordination these physicians provided, however, was generally limited to sharing medical information among themselves—and did not extend to connecting the families with community services or other types of support. Only a small minority of participants received this type of assistance for their CSHCN within a clinic or office setting. Two parents in a Lucas County group reported a having a nurse practitioner in their pediatrician’s office who is specially designated provide assistance with coordination across the range of services their children needed. Unknown to each other prior to the focus group, it turned out that both families went to the same pediatrician. Two participants in the Columbus group received care coordination assistance through a multi-disciplinary team located in the sickle cell clinic at Children’s Hospital.

Richland County participants frequently identified the BCMH nurse as a regular source of care coordination assistance. Nearly every participant mentioned the Richland County BCMH nurses

by name and described in detail the ways they had helped to coordinate care and access services their children needed. In contrast, only a few participants in the Columbus group specifically associated help of this type with BCMH nurses from Franklin County. In the Lucas County groups, only participants who resided in counties other than Lucas (e.g., Sandusky, Wood, Henry) made any mention of receiving assistance from BCMH nurses.

A few participants also mentioned caseworkers from the county mental retardation and developmental disabilities (MRDD) services and the Medicaid Waiver program as sources of assistance with care coordination — but their experiences were not always positive. Several parents of young CSHCN had received care coordination help from Early Intervention nurses; however, they also noted that these services ended when their children turned three years old. Questions about case management or care coordination provided through the child’s health plan or managed care organization were specifically asked in the Lucas County groups. Only three participants had any knowledge or experience with this source of assistance. All three reported little to no help from this arena—a counter intuitive finding because the three CSHCN represented had medical needs complex and costly enough to make them prime candidates for intensive case management and care coordination.

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### ***Assistance coordinating care and accessing specialized services***

#### ***No assistance (at least half of all participants)***

- “Nobody.” “You learn to do it yourself.” (*frequent responses heard from participants in every focus group when asked who, outside of family members, helps them coordinate the care and services used by their children*)
- I will have to say that I use the doctor, but it’s mainly me (coordinating care and services). I want to make sure he gets what he needs. Any time there’s a question about whether he’s having a problem with feeding, or therapy, or whatever. I’m usually the one that...(coordinates things).
- (*Mother of triplet*) I have doctors for their lung disease and for their PPL, and for their cerebral palsy. I have all those doctors, but as far as all this goes, no, I don’t have just one person (who helps coordinate care among all the physicians and services used by her children).

#### ***Child’s primary care doctor and/or specialists***

- No matter when I go to any of (child’s doctors), they always fax whatever is happening that day, they fax to all the other ones. Whether it’s the allergist, the pulmonologist, the gastro doctor, they all get a copy within a week later....like if I go to the gastro doctor and the pulmonologist has put him on this medicine, you can’t put him on this medicine, because he’s on this medicine. He (son’s doctor) knows that before I even get there.
- Her seizure doctor and her surgeon—they all keep notes for each other. Even her pediatrician here (in Mansfield)—he has notes on her sent to the other doctors (in Columbus).

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### ***Assistance coordinating care and accessing specialized services (continued)***

- **(Parent #1)** She (the pediatrician) has a nurse practitioner with her. Mary Ann will coordinate all the care. A lot of times you don't have to bother the doctor. You just call Mary Ann and she serves as that go between. *(Lucas County focus group participant)*
- **(Parent #2)** I call Mary Ann unless it's an emergency and I know the doctor is going to see her. If I'm not sure what I should do, Mary Ann is the one that I call. *(Lucas County focus group participant who goes to the same pediatrician as Parent #1 above)*
- We're lucky—the Piedmont Clinic—for the sickle cell. We have a complete team. We have a case manager, a social worker, a doctor, nurses, and psychologist. So basically, whatever we need, they'll take care of it.

### **BCMH nurse**

- So far, I've been very fortunate. I have had good experiences. One difference that it's been is my daughter's BCMH nurse has been the total forefront of the success of my daughter's health. She's the one who has found the doctors for me. *(Richland County focus group participant)*
- My BCMH nurse—she might be the same one (referring to early comments made by a Mansfield group participant)—she's helped me from his education to finding suppliers for diapers and such things. *(Richland County focus group participant)*
- That's what I mean about my BCMH nurse. There's so many different little—like the respite care and Independent Living Center, New Hope—there's so many organizations out there working with themselves. My BCMH nurse can get all this in a group, it won't be so overwhelming. *(Richland County focus group participant)*
- BCMH helped me too. Like now I'm trying to get him counseling, being self-conscious about himself. He has to get plastic surgery..... have to battle him because he doesn't want to do it..... But when the (BCMH) nurse came to see me and she just gave me all kinds of lists of plastic surgeons, and anything I needed, and the behavior people and all that. She was very helpful. *(Franklin County focus group participant)*

### **Other**

- The Early Intervention nurse.....She's gone out of her way to help me. She's actually the one who got the therapy going for (son's name) finally. She writes letters and does different things for me.
- I have a case manager. **Who is the case manager with?** MRDD— Somehow she has those resources to hook me up. So she'll get the funding and she'll help me with the paperwork. She'll do the paperwork so all I have to do is sign my name. She's one of the major ones that has helped. *(Franklin County focus group participant)*
- My son, he just got on the Ohio Waiver Program a couple of years ago, so I have case manager through that. She doesn't really do anything, just like he has OTPT, and speech and all that. He has that at home. He has that in school also. She just coordinates to make sure that they get paid for that.
- I have a caseworker, but mine is Medical Mutual, a PPO. I saw the case manager and the only thing she tells me is the only thing she can help me with is my home health care. Even when I had a home health care issue, she couldn't help me. I don't know what good she was.....I called there several times trying to get someone involved. They would not have ever known that I needed a caseworker unless I called them. *(Lucas County focus group participant)*

## **The concept of medical home and the level of “medical home-ness”**

Participants were presented with the concept of medical home in three ways. First, they were asked what the term “medical home” meant to them. Next, the moderator read a brief definition of medical home and asked for their reactions. Finally, a diagram illustrating the continuum of “medical home-ness” was distributed and participants were asked to locate their children’s health care on the continuum

***Interpretations of the term “medical home:”*** None of the participants were familiar with the term “medical home.” The majority of their interpretations of its meaning fell into three categories: a) institutional care; b) care and services brought to the home; or c) support and services that made it possible to keep a medically fragile child at home. For many participants, the term “medical home” did not have positive connotations — “nursing home” and “county home” (meaning institutions for the mentally retarded) were the first thoughts that came to mind. This interpretation was, in fact, the most common among participants. Some participants, however, ascribed a more optimistic meaning to “medical home” — interpreting it as house calls with medical professionals coming to their homes to provide care for their children. The last category of interpretations stemmed from many families’ struggles to care for their children in their homes rather than putting them in institutional setting. This group interpreted “medical home” as having the resources, equipment, and skills to care for their children as long as possible in the family home.

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### ***Interpretations of the term “medical home”***

- “County home.” “Nursing home.” (*heard from at least 10 participants*)
  - Instead of us coming to them, having them come to us—the doctors, nurses...
  - House calls
  - A home you can keep a handicapped child in rather than placing him or her “outside.”
  - I just think about giving me all the medical needs I need to keep my child in my home for as long as possible.
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***Reactions to the definition of medical home:*** Participants reacted with both enthusiasm and skepticism to the definition of medical home read aloud by the moderator. Overall, parents were ready to “sign up” for health care with attributes described by the definition. The idea of having one health professional as the initial contact who shared responsibility with the family to coordinate care and make sure the child’s medical care and other needs were met was very appealing to participants. One mother noted that the health professional at the core of a medical home would: “..... need to be your cheerleader and the captain of the Quiz Bowl team.....because they have to be supportive and smart!” A few participants expressed a pragmatic skepticism about this concept sounding too good to be true. Their reservations, for the most part, stemmed from long experience with the systems that care for CSHCN. After hearing the definition of medical home, participants were also asked if they could think of a better name for the concept. Participants offered a number of suggestions — including “god on earth!” The comment of one parent, however, summarized participants’ reactions to the concept of medical home for their CSHCN: *“My question would be — what do we need to do to maybe start this? Is there somebody that we could write to? This is just on paper — as a group of mothers or parents what could we do to help get this into the state?”*

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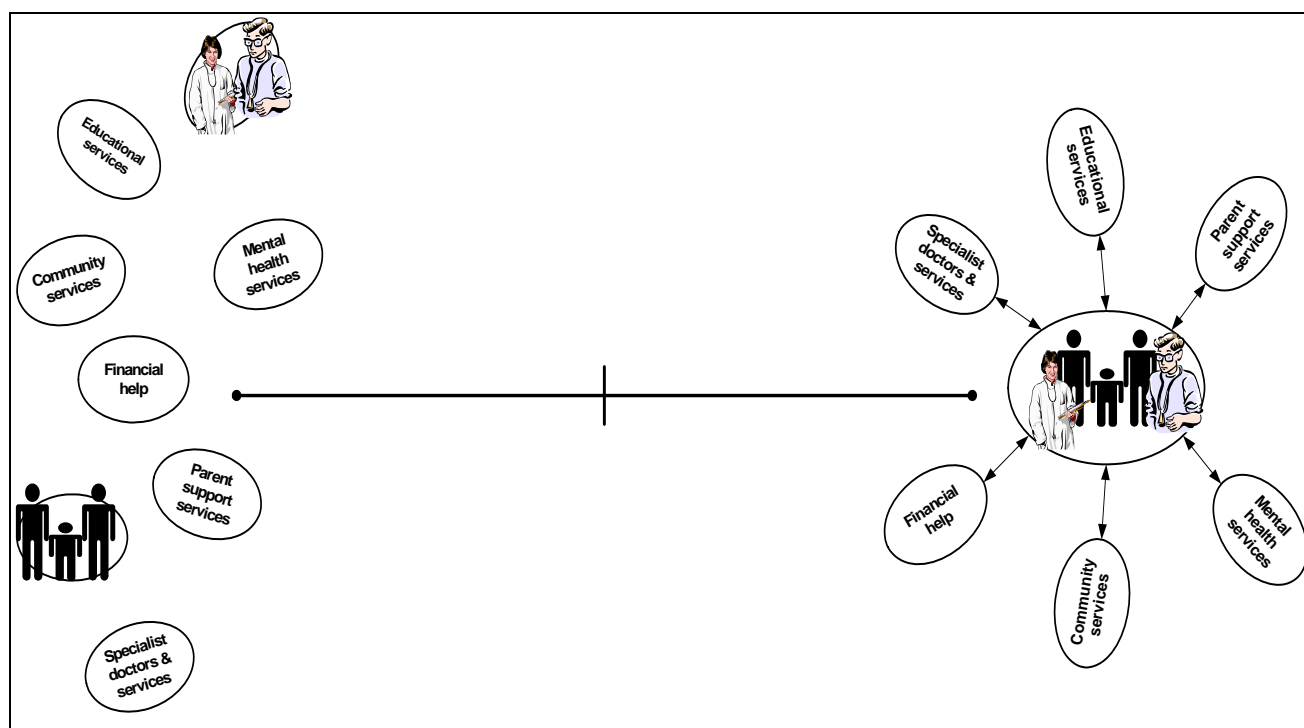
***Reactions to the definition of medical home***

- “Sign me up!” “I’ll take one of them!” (*heard from participants in every group*)
- It seems all organized.
- Everything is at your fingertips that way—easy access.
- Something like this would take the weight off.....you could relax a little....
- Knowing that you’re not the only one fighting to get something—that there’s somebody else there doing that for you—being your advocate, it’s very positive.
- With one, you wouldn’t have to repeat yourself 20 times—the same thing and you hope you tell them everything.
- I say skeptical. Because there’s always another side of it—what’s the catch? For one entity to have that much control, or that much over... I’m just skeptical about it.
- It sounds too good to be true.
- Would it really work? Would the caseload for that person be so much? Because that’s what happens. We start off with these new programs and the caseloads aren’t real heavy. Then more people start using it, but they don’t give us more caseworkers and then they’re overloaded.



**Level of medical home-ness:** After participants discussed the definition of medical home, they were given a sheet of paper with a diagram illustrating medical home as a continuum — ranging from one end showing the ideal of a united partnership between the family and health professionals as the core from which communication and coordination flows back and forth to all parts of the system — to other end showing a complete fragmentation of care and services. Participants were asked to think about their own children’s health care and to locate the position on the continuum they felt best reflected the level of “medical home-ness” they experienced (see Figure 1). The diagram was very successful method of communicating this concept — and not single participant left theirs behind when leaving. One mother even declared that she was going to take the diagram to her children’s pediatrician the next day and ask her if she knew she should be in the “core” with the family, working as a team to coordinate and connect with other services and systems.

**Figure 1: Continuum of medical home-ness**



Overall, about a third of participants reported low levels of medical home-ness (left side of the continuum), another third located their children's care in the mid point of the continuum, and the last third located their experience of medical home on the right side of the continuum (higher levels of medical home-ness). Families whose care reflected a low level of medical home-ness described receiving little or no assistance with coordinating care. Although the separate components of their children's care may be going well, they reported a general sense of no one knowing what the others were doing and concerns that they may be missing important services and support for their children. Families who located their experience in the middle of the continuum reported feeling as if the components of their children's health care were scattered and only occasionally did it happen that some of those involved knew about each other.

The families who reported a high level of medical home-ness fell into two groups: those who through their own hard work and long experience had learned how to function alone as the "core" of the medical home; and those having one or more health professionals who worked in close partnership with the family to coordinate and connect with other systems and services. Several participants in the latter group expressed amazement that their situation was not the case for all families with CSHCN. They were quick to recognize the fortuitous nature of their situation, including the fact that they had not sought it out. Rather, it was the luck of draw!

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### ***Levels of "medical home-ness"***

#### ***Left side of diagram—low level of medical home-ness***

- On the left side—definitely. Everything is here and there and no one knows what the other one is doing. I go in to a new doctor—tell the nurse that takes the information. He comes in and has never read the chart or anything. Reaches over and grabs him [inaudible]. Why didn't he read the chart?
- You just stay running around constantly—trying to pull things to you.
- I get wonderful care from the BCMH doctor, but really don't feel that I have that core (indicating the partnership shown in the medical home diagram)..... Somebody to tell me or show me that this is what I can get for them. (*mother of 2 yr old triplets*)

#### ***Middle of diagram—mid level of medical home-ness***

- .....that's just been recently (that she has moved to the center) —that I've had to make the decision that I have to be my child's advocate. Be the resource center myself—it's just been educating myself.
  - I feel like I'm the only one in the center of all the services. I feel like an island in the ocean and there are ships sailing around me. Some of them know the other ships are there and some don't.....
  - Probably in the middle—the scattered, because it just feels that way. It doesn't feel like it's all connected. Everything is separated.
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### ***Levels of” medical home-ness” (continued)***

#### ***Right side of diagram—high level of medical home-ness***

##### *Parents with assistance*

- I’m completely on the right. It’s just wonderful....Everything I need, all I do is call Ann Smith (BCMh nurse).....she is right there in the middle with the doctor and me. He knows her, she has called him. They go back and forth. It’s just so wonderful. It couldn’t get any better unless the doctor lived right there in my house.
- We’re over here (indicating right side of medical home diagram) All of them seem to work together..... All the doctors that he has, WIC people, everybody just seems to work together. I get calls all the time from different places.
- That’s about where we are with that sickle cell team at Children’s.

##### *Parents on their own*

- We get into this situation—our child has to suffer how many years before we’re educated enough to be on the right.
- I feel that I’m on the right, but it’s like she said, you have to put a lot of effort into it. I find it extremely difficult for me to try to get any kind of employment because of the effort I have to put forth to stay on the right.
- I can’t stress enough what I’ve gone through to get to this point. I still lose ground.....you go through a lot to get to that point where you feel, “Okay, I can talk now.” If we could help some of the younger parents not to have to go through all the tears and frustrations—then I think (more of us) could say we are on the right side. It’s an awful process!

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### **Advice and suggestions for improving care and services for CSHCN**

At the close of each discussion, participants were given the opportunity to offer advice or suggestions about how BCMH or Medicaid can improve care and services for CSHCN.

Participants’ input fell into three categories: a) increasing information; b) improving Medicaid processes; and c) support groups for parents and CSHCN.

***Increasing availability and usefulness of information:*** Participants’ suggestions in this area focused on having a centralized, “one-stop shopping source” or 800 number for getting information about the range of services and benefits for which their children may be eligible. A number of parents asked for pamphlets or directories of doctors and dentists that accept BCMH or Medicaid. Most importantly, parents wanted such information to be readily available, accurate, organized, and comprehensive.

***Improving Medicaid processes:*** Participants made several concrete suggestions on how Medicaid could improve the processes that all the families encountered on a regular basis. These included providing training to increase caseworkers understanding and sensitivity to the issues that families with CSHCN face daily caring for their children. Several families were willing to have caseworkers visit their home and children in order to provide this contact and context. If the high turnover of caseworkers and huge case loads could be reduced, participants felt the increased continuity would result in less problems with unwarranted denials because caseworkers would get know and understand the families and CSHCN they served. Finally, participants felt that a better system was needed for reviewing cases for eligibility — perhaps streamlining the processes or conducting the reviews at less frequent intervals or even coming to the homes of families whose children’s disabilities made it difficult to arrange child care. As one parent pointed out: “...these kids, it’s not like they are going to get well—that anything is going to change. They are always going to have the problems that they have.” Many parents took the perspective that their CSHCN were going to be in the Medicaid system for a long time and the review processes Medicaid employs should reflect that fact.

***Support groups for parents and CSHCN:*** Participants also made a plea for support groups for parents with CSHCN. As mentioned earlier in this report, only two of the participants knew each other prior to attending the focus groups — despite in many cases sharing the same pediatricians or BCMH nurses. During the discussions, as well as before and after, participants actively shared tips, resources, and advice. In every case, participants were reluctant to leave at the close of the discussion and many often lingered outside the meeting rooms to continue their conversations and exchange phone numbers. The experience of participating in a group discussion with other parents of CSHCN appeared to awaken a desire for more regular contact. Participants with older CSHCN noted the lack of support groups for CSHCN, especially adolescents, and suggested that BCMH consider this need as well.

Finally, parents of special needs children know a great deal about patience and realistic expectations. The underlying tone of all the suggestions and advice participants offered is summed up by this mother's words:

*“Even if these issues don’t get resolved tomorrow—we’re all adults and know they are not going to get resolved tomorrow.....If (Medicaid and BCMH) could just consider it and get the ball rolling. We’re not going to be the only five mothers sitting here. It happens every single day. These numbers are just going to accumulate. Even down the road if it can save the next mother—ten years down the road that doesn’t have to go through all this. It’s worth it. It’s a roller coaster.”*

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### ***Advice and suggestions from families for improving care and services for CSHCN***

#### ***Increasing availability and usefulness of information***

- I still think we need a pamphlet—a directory of information—all the doctors on BCMH and the services. Train the doctors that are on the list.
- Maybe like a 1-800 number to call to access a databank of doctors, or help, or resources. Just one-concentrated number.
- It would be nice if your pediatrician knows there’s something wrong with the child, if they had a pamphlet or a handout and said, “Here are the different services that are available to you. This is who you need to contact it. These are the addresses, and the telephone numbers.” Something that would streamline everything.

#### ***Improving Medicaid processes***

- They (Medicaid caseworkers) need to go into the hospitals, I think it should be part of their training, to see sick children, to see what we go through every day at home and then try to look at us and turn us down.
  - I think if the person doing the job (such case management or care coordination) wasn’t overwhelmed and they had 150 cases on their desk every day and you were just treated like a number. Then you are back to square one. Not that they are coming over for dinner and tea every night. But more personalized makes all the difference. Just somebody to make you smile and take the pressure off and actually cares, not just because they have to.
  - The things that I have concerns with is with us reapplying for these services—that they need to come up with a better system.
  - They need to understand that when we take a little time out to go and meet with them, we don’t have a lot of time.....(she describes the complicated childcare arrangements required for her to leave her child for even one hour).
  - **(Speaker A)** I think it would be nice if they would space it out, like you have to have an interview every year—maybe every two or three years. If you don’t need it, let them know, but just assume you need it unless you get in touch with them, I think that’s a little too regular. **(Speaker B)** These kids, it’s not like they are going to get well—that anything is going to change. They are always going to have the problems that they have.
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***Advice and suggestions (continued)***

***Support groups for parents and CSHCN***

- We need someplace for parents to meet. Look at all that we learned by being here today.
  - But we need something—parents need support groups. We need an organization for special needs children to get together and go have fun, and forget today that they are sick.
  - I would like to see BCMH to come up with some support for the parents—support groups—throughout the city and state—that are free to the parents. That we can go and talk. Also our kids have special medical needs, but why can't BCMH come up with some kind of a program to be able to get these kids together out doing something fun.....that's also part of their care.
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**Opportunities for improvement**

In the course of analyzing the focus group content, a number of opportunities for improvement or further exploration emerged. While main goal of this report is to explicate the experiences of families with CSHCN served the Medicaid and BCMH programs in Ohio, several areas for consideration and potential follow up are worth noting:

- The overwhelming stress and sense of unending crisis reported by families adjusting to the birth of a child with special needs creates substantial barriers to being able to take in new information and suggests that it may be worth revisiting the timing of information about services and the kinds of support offered, including facilitation of the transition when Early Intervention services end.
- The marked variation in the visibility and roles played by BCMH nurses in different counties suggests an opportunity to explore the different programs and identify best practices to serve as models.
- The lack of familiarity with the term “medical home’ and the nearly universal misinterpretation of its meanings indicates that the term should always be accompanied by additional explanation and context when used with families of CSHCN.

- The difficulties families experienced in finding reliable, comprehensive information about services and benefits for their CSHCN suggests a reassessment of current informational materials and dissemination strategies.
  
- Participants request for regular, organized support groups with other parents of CSHCN is a low resource intensive opportunity. If these services are, in fact, currently available, a reassessment of current information dissemination strategies may be needed.
  
- Finally, the consistent problems participants experienced with Medicaid processes and personnel represent an important opportunity for creative interagency problem solving. As parents pragmatically observed, many of these CSHCN will be part of the Medicaid system for a long time, maybe their whole lives. At a minimum, sensitivity training for caseworkers may be needed. Optimistically, it may even be possible to specially train a select group of caseworkers, maybe volunteers, to serve the needs of these children in order to create a continuity that would help streamline services over time.