

2012

Children with Special Health Care  
Needs & Medicaid Managed Care  
in Michigan:

# Family Preferences, Concerns and Priorities

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**Children with Special Health Care Needs & Medicaid Managed Care in Michigan:  
Family Preferences, Concerns and Priorities**

**Final Report**

**July 15, 2012**

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# **Children with Special Health Care Needs & Medicaid Managed Care in Michigan: Family Preferences, Concerns and Priorities**

## **I. Background**

The Michigan Department of Community Health has a long, successful history of engaging in meaningful partnerships with consumers in the Children's Special Health Care Services (CSHCS) program. Previous experience in designing a managed care model for children and youth with special health care needs benefitted greatly from the integration of consumer input. Core components articulated by parents of children enrolled in CSHCS served as standards for the creation of a managed care construct for children and youth with special health care needs.

Because of the unique and intense health care needs of CSHCS enrollees, those members who were deemed eligible for both CSHCS and Medicaid have historically been excluded from enrollment in Medicaid Health Plans.

The Michigan legislature has mandated that CSHCS enrollees who are also enrolled in Medicaid will receive care by way of a Medicaid Health Plan. In recent years managed care networks have evolved and have a greater capacity to address the needs of the CSHCS population. Other managed care benefits such as transportation are generally found to be more accessible to health plan members and may be a better option for those enrolled in both Medicaid and CSHCS.

Specific contract provisions for managed care organizations that will enroll CSHCS members are under development with the benefit of input from those who bear responsibility for providing care, but input from those who will receive care, and thus live with the outcome of these deliberations is sparse. The primary mechanism for family input thus far has been staff representation and input from the CSHCS Advisory Council. While admirable, policymakers and families agree that DCH can and should create a more deliberate and integrated method to assure collaboration between all stakeholders.

## **II. Goal**

Integrate meaningful family input to the Department of Community Health regarding transitioning CSHCS enrollees into Medicaid Health Plans.

### **III. Method**

In April and May, 2012, focus groups were held across the state to explore family priorities regarding health care delivery for their child (ren) who are enrolled in both the Children's Special Health Care Services program and Medicaid. Meetings were held at or near the three pediatric hospitals in Michigan in Grand Rapids, Ann Arbor and Detroit.

Families from Kent, Jackson, Washtenaw, Oakland, Macomb and Wayne (in and out of Detroit City) counties participated. Mothers, fathers, grandmothers and foster parents were represented. All family members were fluent in English. The CSHCS enrolled children of the parents ranged in age from 2 – 20.

In all cases, dinner and child care were provided. All participants received a \$25 gift card at the end of the session. The Detroit and Grand Rapids participants were unaware of the gift cards prior to their involvement. A screening tool (Attachment 1) was developed to select appropriate and diverse participants.

In Kent County, an email which described screening criteria was sent to approximately 700 families (Attachment 2). Sixteen families self-screened and accepted the focus group invitation. Eleven parents (69%) attended.

In Ann Arbor, staff at C.S. Mott Children's Hospital identified thirteen potential focus group members. Two individuals did not meet screening criteria, one lives in Ohio and another does not have Medicaid coverage. Three preferred to participate in a conference call; five accepted the invitation, three attended. Two were not able to participate due to their child's health situation, but voiced their concern for access to existing providers and existing program benefits. One was not interested. Of the 5 who accepted the focus group invitation, 3 (60%) attended.

In Detroit, staff from Children's Hospital of Michigan identified 12 potential focus group participants. One did not meet screening criteria because the child did not have Medicaid coverage. Two opted to participate in a conference call. Two were unable or not interested in participating, and one provided written comments. Six family members accepted the focus group invitation, and all (100%) attended.

Statewide, 20 family members provided input, 7 expressed interest but did not attend. 6 preferred to participate in a conference call and one provided written comments (Attachment 3).

A screening tool for individuals whose children have a CSHCS eligible condition, but who declined CSHCS enrollment in favor of continued membership in a

Medicaid Health Plan was also developed (Attachment 4). A small group of families were identified by the Medical Services Administration. Thirteen names were provided. The caller was unable to contact 8 of the 13. Two were duplicate families, 2 were wrong phone numbers, 1 phone was out of service, 1 person hung up without speaking, 3 did not respond to multiple messages. Of the remaining 5, none were interested in attending a group meeting to discuss their Medicaid Health Plan experience. One family was out of town, 2 cited recent family tragedies, one had a child in the hospital and one was busy with recreational activities for her child. Two parents did agree to speak by phone.

Discussion guidance and standard open-ended questions were developed for both the CSHCS/Medicaid (Attachment 5) and the Medicaid only with CSHCS condition (Attachment 6) groups.

#### **IV. Selection**

Outreach was conducted through the Kent County Health Department and by Family-Centered Care leaders at Mott Children's Hospital and Children's Hospital of Michigan. (Attachments 7, 8, 9)

Families of children with a CSHCS eligible condition who are currently enrolled in a Medicaid Health Plan (MHP) were also queried. These families were identified by MSA. Attempts to convene a focus group were unsuccessful; however individual input was obtained via telephone interviews. Families who were interviewed by phone also received a \$25 Meijer gift card.

#### **V. Summary of family input across groups**

Several common themes emerged from the three CSHCS/Medicaid groups. The most frequently cited issues for all three groups are a) maintaining current specialty and subspecialty providers and b) maintaining current program benefits. These priorities appear in responses to each of the questions put forth to each group. Other issues include easy access to clear and simple information about program processes along with a designated person whose job is to help families navigate the health care system.

##### **1. Providers**

*"We have a big list of specialists and they all take her insurance"*

The greatest concern by far was the ability to maintain relationships with current providers of care. Some families felt that the relationships they had developed, and the providers' knowledge and understanding of their child's personal history was essential to maintain. This concern included the ability to maintain

relationships with specialists in different health care systems. Families want to maintain the ability to see specialists at Children's, Mott or Devos hospitals.

Regarding support services such as OT, PT, speech therapy, hearing aids and communication devices, or durable medical equipment suppliers, families are concerned about the availability of appropriate pediatric expertise within the health plan. Some have children enrolled in MHPs and they do not believe the networks have appropriate pediatric services. They are willing to travel outside of their immediate community to obtain appropriate pediatric services.

Out-of-state care was also mentioned. When no appropriate specialist is available in Michigan, families want to have the ability to seek specialty care where it is available when an appropriate pediatric specialist is not in network.

Recommendations regarding provider access:

- a. Members may maintain current providers.
- b. Health plans authorize current providers, in or out of network.
- c. Health plans contract with an adequate network of appropriate providers.
- d. When no appropriate pediatric provider is available in network, health plans facilitate access to the appropriate specialist in state when possible, or out of state.

**2. Benefits**

*"I get 90 (trach) noses when I only need 30 a month and 1 pulse ox probe when I really need 4 a month. I end up grabbing extra probes from the hospital when we're there."*

Families want to maintain current program benefits. The most frequently mentioned was incontinence supplies. Several parents mentioned appropriate, individualized authorization for supplies, standard amounts may be inadequate, or they may be wasteful. Families are fearful of calling to reduce the order for an authorized amount of necessary supplies for fear that the supply will be completely eliminated.

Recommendations regarding benefits:

- a. All currently available services and supplies are covered.
- b. Amount of authorized supplies meet the unique needs of the individual.
- c. Medical necessity definition includes habilitative and rehabilitative services.
- d. Specialized equipment for safety (car seats, etc) is covered.
- e. COBRA payments are covered.

### 3. Efficiency

*"They said it would take weeks to get my son's Dynavox fixed. Well, without that, he has no voice!"*

Efficiency is also a concern. Focus group participants spoke of burdensome delays in prior authorizations for mobility equipment, drugs and communication devices. They also expressed the need for a "loaner" device while their child's equipment is repaired.

Families have great concern about referrals, it is important that referral mechanisms do not delay urgent treatment or access to specialty care.

They reported that they frequently have difficulty obtaining timely authorizations. In terms of drug authorizations, it is important that appropriate drugs (rare, name brand or compounded) are covered and provided without delay when ordered by a pediatric specialist. Participants felt that their knowledge of their child's history, in partnership with the ordering physician recommendation should be taken into account. They feel that the requirement to demonstrate failure of less expensive drug options before the recommended drug is authorized is unsafe and ultimately, more costly.

Focus group participants wish to maintain financial supports currently available. The coverage for co-pays and deductibles is important as is coverage for COBRA payments. Focus group participants hope that travel assistance is available, reimbursement process is simple and reimbursements are timely, and that lodging (Ronald McDonald House) is covered.

#### Recommendations regarding efficiency:

- a. Prior authorizations are timely and referrals do not delay access to care.
- b. Loaners are available when necessary equipment is in for repairs.
- c. Travel assistance and reimbursement for mileage and lodging is simple and reimbursements are timely.
- d. Opinions of the pediatric specialist and the family who both know the child well are taken into consideration. Appropriate drugs (rare, name brand or compounded) are covered and provided without delay when ordered by a pediatric specialist.

#### 4. Information

*"I also have Blue Cross and they send me a simple chart showing what is covered and how much I have to pay."*

Participants frequently mentioned their frustration in finding clear, comprehensive information about CSHCS and Medicaid program benefits, processes and guidelines. Even very articulate families said that they would like to have information in plain language that is easy to obtain. They find the State of Michigan Website difficult to navigate and written in language that is difficult to understand. Charts that outline covered benefits similar to those published by commercial insurers are preferred. They would like to see a comprehensive list of participating providers. These materials would ideally be available on line and in writing.

Families expressed frustration with a lack of understanding and continuity across governmental agencies. They wish for example that the Human Services worker could provide accurate information about MDCH services.

Focus group participants are unsure now about where to find information on various issues. They would prefer one identified person who can help them find the answers they seek. They are also unsure about appeals processes and would like a clearly defined, timely appeals process.

In a health plan setting, it would be important to these families that the process to access services is straightforward, without administrative delays, and is clearly and simply articulated.

Families have a great deal of insight they wish to share. They want their knowledge and recommendations regarding the services their child receives to be sought out and acted upon. They also wish to have a mechanism for regular input to program operations. Families want to be listened to.

#### Recommendations regarding information:

- a. All member information is written in regular "living room" language.
- b. A chart or matrix showing program benefits is available in writing and on-line.
- c. Other human service agencies have current information about the program.
- d. The appeals process is defined, swift and simple.
- e. A current listing of participating providers is easily accessed.



- f. A process for accessing out of network providers is clear and easy to find.
- g. Family knowledge of the child is respected and integrated into health plan decisions.
- h. Family input is routinely sought by the health plan. Health plans have consumer advisory councils that include a majority of consumers.
- i. A listing of what is and is not covered is provided to families and available on line.

## **5. Care Coordination**

*"I asked the health plan if there was a nephrologist in Jackson we could go to. They told me that there is adult kidney doctor in Jackson, but that my son needed to see the specialist for kids in Ann Arbor."*

Not surprisingly, the families who choose to participate in a focus group were parents of children with more complex needs. Some have trouble finding pediatric primary care physicians who care for children with complex needs. Others expressed the need for a knowledgeable person to help coordinate multiple aspects of care. Families in all groups cited redundancies or inefficiencies in care provision that could be addressed by a dedicated care coordinator. They would like help transitioning from pediatric to adult care when necessary, and they would like that coordination to begin early.

Families also wish that they could coordinate covered services with their own resources, for example, they spoke of a limited number of eyeglass frames that are covered. They would like to be able to pay out of pocket to upgrade to a model they feel is better suited to their child's needs.

Participants would like help coordinating benefits between insurers when private coverage is in place.

### Recommendations regarding care coordination:

- a. Health plan staff is expert in the needs of children and youth with special health care needs and guide families in selecting appropriate services.
- b. Health plans reach out to assist families in accessing appropriate pediatric primary care.
- c. A health plan coordinator has regular (quarterly) discussions with each family to review status.
- d. Care coordinators are assigned and provide continuity.

- e. Health plans assist in coordinating benefits with other insurers and during transitions from one insurer to another.
- f. Services are authorized to be effective and efficient. Redundancies or duplications are eliminated.
- g. Health plans will assist with transition from pediatric to adult care.
- h. Ability to pay out of pocket for upgrades the child needs.

## **6. Communication**

The intended outcome of the focus groups was to obtain family-identified inputs to the transition of the 5/19 population into managed care. Families also identified ways that MDCH can support the transition through communication and collaboration.

Though participating families for the most part have good relationships with the local health departments or their pediatric provider network, an information gap still exists.

Families are eager for clear, concise information about CSHCS and Medicaid. They are uncertain about what is covered, when and how much it is covered, and who to go to when a barrier is encountered or information is needed.

In all cases including conversations with families of CSHCS eligible children who chose to remain in a MHP, families expressed a strong desire to connect with other families. They felt that peer support is an excellent source of information and guidance. They asked for more frequent family meetings to hear from one another and discuss resources and experiences.

CSHCS and Medicaid can assist families in maximizing appropriate benefits and services by enhancing existing communication. The Family Center for Children and Youth with Special Needs and or the Family-to-Family Health Information Center may be logical vehicles for enhanced communication.

### Recommendations for Communication:

#### **a. In writing.**

- Written information is clear and concise, and written no higher than 5<sup>th</sup> grade reading level in everyday “living room” language. The information is culturally competent and available in multiple languages.
- CSHCS information is disseminated in hospital-based labor and delivery units, through schools or other places where children typically go.

- A current and comprehensive list of all covered services and benefits is sent to the family home by regular mail and is available on the web. This information includes:
  - Step by step explanation of the process
  - Guidance on health plan selection
    - What are the decision points?
    - When to call for help?
    - How to change plans?
    - When can you change plans?
    - When is change required?
    - What happens if I don't make a choice?
    - What happens if I also have private insurance?
    - Can I drop CSHCS and keep straight Medicaid?
    - Frequently Asked Questions

**b. On the Web**

- CSHCS would create a family email list serve to facilitate communication of events, program changes, etc.
- A stand-alone website dedicated to CSHCS , not contained within the michigan.gov or other websites to include:
  - a. Doctors currently accepting patients
    - i. by specialty
    - ii. by region
    - iii. including primary care
    - iv. hard to find specialists i.e.; orthodontists
  - b. Equipment exchange
  - c. Links to other resources
    - i. Diagnosis specific
    - ii. Charitable organizations that assist CSHCN such as UCP
    - iii. Financial information, low interest loans for home modification
    - iv. Advocacy organizations
    - v. Local support groups
    - vi. Sibling supports
  - d. Covered benefits
  - e. Key Contacts within CSHCS, who to call for what
  - f. Message board: Interactive feature to post a question and others post replies
  - g. A "Craigslist" sort of directory of doctors for kids with special needs that are "parent recommended"

**c. By phone**

- Widely publicize the Family Phone line for parents. Provide timeframes to staff for communicating follow up or status updates.

**d. Peer support**

- Revitalize the Family Support Network of Michigan so peer support is more readily available
- Convene periodic community-based meetings to provide updates on advocacy efforts or changes to program components
- Create a video by and for families of children with special health care needs including a message of encouragement, and tips from parents to parents on where to go for help

**VI. Partnership**

Families who participated in the focus groups and the current MHP members who were contacted were eager to help the state make this transition by offering their perspectives as consumers of CSHCS and Medicaid services. They expressed a strong desire for ongoing opportunities for continued partnerships with the state.

Families are very interested in being part of the solution and collaborating to monitor the implementation of managed care arrangements for the CSHCS population and make continuous improvements.

Recommendations regarding partnership:

- a. Establish Patient and Family Advisory Councils in each CSHCS approved MHP.
- b. Continue to hold focus groups or similar mechanisms for ongoing input to CSHCS.
- c. Establish a stakeholder group comprised of families, providers, health plan representatives and others to monitor the transition process.

**Other**

Only two parents from the Medicaid Health Plans provided input, but these families stated that comprehensive coverage of their child's medical needs, information, and affordability were important factors contributing to their decision to decline CSHCS enrollment.

**Attachment 1**

**CSHCS and Medicaid Focus Group Screener**

**Please tell us how to reach you. Name:**

**Address:**

**Address 2:**

**City/Town:**

**State:**

**ZIP:**

**Country:**

**Email Address:**

**Phone Number:**

**2. What your child's age?**

**3. What is your child's main health concern?**

**4. Is your child enrolled in Children's Special Health Care Services?**

**5. Does your child have Medicaid coverage?**

**6. Do you or anyone in your family have experience with a Medicaid managed care plan?**

**7. Is your child also covered by a private insurance plan?**

## **Attachment 2**

The Children's Special Health Care Services (CSHCS) program is considering changes to the policy for children who are also enrolled in Medicaid.

CSHCS needs your help to move forward with this change. We want to hear how you think the change will affect your child's care. In the next few weeks, there will be meetings in three communities, including Grand Rapids. We want to talk with families about their CSHCS coverage and their experience with Medicaid managed care.

**If you have a child enrolled in CSHCS who also has Medicaid coverage**, we invite you to join us. We're hoping to meet on **Tuesday, April 24 from 6:00pm to 7:30pm** at the Health Department at 700 Fuller NE. Child care will be provided by the Kent CSHCS staff. Food will be provided for all!

**Please email or call me soon if you are interested!** Your ideas and suggestions are very important! Thanks! **Chris**

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### **Attachment 3**

Dear Ms. Crider,

I am writing you in regards to Children's Special Health Care Services and the positive impact that it has made on our family, especially in regards to our daughter, \_\_\_\_\_.

\_\_\_\_\_ has Myelomeningocele, shunted Hydrocephalus, and a neurogenic bladder and bowel. In order to address her variety of challenges, many aides, mobility devices, medications, therapists, and specialists are needed. \_\_\_\_\_ is flourishing and we know that it is due to the emphasis we, as her parents, take to ensure that she has all that she needs to continue to stay healthy, strong, and be as independent as she is able. Unfortunately, keeping abreast of all of \_\_\_\_\_'s needs does pose a financial stress at times, as it does with any parent having a child with special needs. Getting quality equipment and seeking the advice of many doctors is not free. We take it upon ourselves to make sure that both of our children have the necessary support needed to address their challenges. It should be noted that while our son is not covered under CSHCS, he has Asperger's Syndrome. The financial assistance CSHCS provides for \_\_\_\_\_, helps us to use our other income to pay for the therapy and needs of our son.

I felt the simplest way to show you what \_\_\_\_\_'s needs are, was to provide you with a list:

#### **Mobility Aides**

**Kaye Reverse Walker**

**Loftstrand Crutches**

**Invacare Jr MVP manual wheelchair for long distances/school/out in the community**

**Twister cable AFO's**

#### **Medications**

**Enemeez – Bladder and Bowel**

**Oxybutynin – Bladder**

**Bactrim – Bladder**

**Miralax – Bowel**

#### **Other Items**

**Bath chair**

**Commode**

**Catherization supplies- lubricant, catheters (covered by CSHCS)**

Catherization supplies – BZK wipes, gloves, pull-ups (not covered by CSHCS) We pay for these items out of pocket.

### Medical Staff

We attend the Myelomeningocele Care Center at Children’s Hospital of Michigan. The clinic has approximately 10 specialists and therapists that \_\_\_\_\_ sees. In addition, she sees an orthopaedic doctor (CHM) and a neurosurgeon (Beaumont Royal Oak).

Currently, Megan is not enrolled in therapy outside of school. In the past however, she has received physical therapy, occupational therapy, and speech/language therapy at CHM and through the Detroit Institute for Children. We were grateful for these services.

As you can see, there is a lot that goes into caring for \_\_\_\_\_ medically. This list does not include her general pediatrician, dentist, and eye doctor.

We are so thankful for the financial assistance we are offered by CSHCS. We also appreciate the diligence and concern our case worker, \_\_\_\_\_, has displayed over the years in regards to \_\_\_\_\_. If I ever encounter a problem or have a question, \_\_\_\_\_ is readily available to assist.

I am hoping that there will not be a massive modification in our coverage or change in the ease of seeking assistance through CSHCS. I certainly understand that some changes may be inevitable. I do expect that any changes that are made are made keeping the child as the focus. Cutting corners and unreasonable expectations will only hinder a child’s progress and cause more challenges for parents. When items are needed for a child, it should not take months and months to obtain. It should be attained in a reasonable amount of time. While change is never easy, I am confident that changes in the CSHCS will only choose to enhance the care for special needs children.

Thank you for your efforts. I look forward to learning about changes in the program. Please feel free to contact me via email or at home should you need more information. Please also keep us abreast of any changes to the program.

Warmest regards,



## **Attachment 4**

### **CSHCS eligible in Managed Care**

#### **Focus Group Screener**

Name

Age of child

Child diagnosis

Address

phone

County

Email

Medicaid enrolled

Past experience with CSHCS?

## **Attachment 5**

### **CSHCS and Medicaid Managed Care Focus Group Guide**

#### **Introduction:**

Thank you for joining us today. You were invited to join us because you have a child who is enrolled in both Children’s Special Health Care Services and Medicaid. This gives you a certain kind of expertise in receiving health care through these programs.

Michigan has a long commitment to family-centered care. That means working with patients and families to plan, implement, and evaluate care. We are asking for your input today to help plan how health care will be delivered.

Almost 20 years ago, Medicaid started providing health care to most people through managed care. Some managed care plans in this area are Molina, United Healthcare, Priority, Meridian, or Health Source. Children who are also enrolled in CSHCS have been excluded from these plans and receive primary care through a fee-for-service or straight Medicaid.

Plans are underway to move those children who are in CSHCS into Managed Care plans. The state is very interested in learning from you how that can best be accomplished.

I don’t have a lot of information today to share about what this will look like because this is still in the planning phase. When more information is available, we will be sure to let you know. For now though, I’m going to ask you a few questions about your child’s health care delivery. Your input will be shared with policymakers at CSHCS and Medicaid.

You may have some very good questions or ideas that are not necessarily related to the specific I will ask you so we will put those things in this “Parking Lot” so we can capture your ideas. Chris or I will follow up with you on these another time.

#### **Themes:**

1. What do you like best about CSHCS? Fill in this blank: “Whatever you do, don’t change\_\_\_\_\_”.
2. What could be done differently to make health care delivery better? If you had a magic wand and could make one thing come true about the way your child receives care, what would that be?
3. What kind of information would you like to have about CSHCS and Managed Care? What are important things for families to know and how should this be communicated?

#### **Wrap up:**

Thank you for your time and especially for the great information. I will prepare a report for CSHCS. We will let you know what is in the report, and how your information will be used to make a difference for children and families!

## **Attachment 6**

### **Medicaid Managed Care Focus Group Guide**

#### **Introduction:**

Thank you for joining us today. You were invited to join us because you have a child who is enrolled in a Medicaid Managed Care plan who is also eligible for CSHCS. This gives you a certain kind of expertise in receiving health care through managed care plans.

Michigan has a long commitment to family-centered care. That means working with patients and families to plan, implement, and evaluate care. We are asking for your input today to help plan how health care is delivered.

Almost 20 years ago, Medicaid started providing health care to most people through managed care. Children who are also enrolled in CSHCS have been excluded from these plans and receive primary care through a fee-for-service or straight Medicaid.

Plans are underway to move those children who are in CSHCS into Managed Care plans. The state is very interested in learning from you how that can best be accomplished.

I'm going to ask you a few questions about your child's health care delivery. Your input will be shared with policymakers at CSHCS and Medicaid.

You may have some very good questions or ideas that are not necessarily related to the specific I will ask you so we will put those things in this "Parking Lot" so we can capture your ideas. We will follow up with you on these at another time.

#### **Themes:**

1. What is the main reason that you decided NOT to join CSHCS?
2. What do you like best about your health plan?
3. What could be done differently to make health care delivery better? If you had a magic wand and could make one thing come true about the way your child receives care, what would that be?
4. What do families of children who will be newly enrolling into a Medicaid managed care plan need to know about the plan?

#### **Wrap up:**

Thank you for your time and especially for the great information. I will prepare a report for CSHCS. We will let you know what is in the report, and how your information will be used to make a difference for children and families!

## Attachment 7

### Summary

#### Focus group for families with a child enrolled in CSHCS and Medicaid

#### Grand Rapids, Michigan

April 24, 2012

Prepared by

Bev Crider, LLC

#### Consultant in Patient and Family-Centered Care

This focus group explored family priorities regarding health care delivery for their child(ren) who are enrolled in both the Children's Special Health Care Services program and Medicaid. The meeting was held at the Kent County Health Department. Sixteen parents of children who met the screening criteria were invited, eleven attended. The enrolled children ranged from age 2 to 19.

Dinner and child care were provided. At the end of the meeting, participants received a Meijer gift card in the amount of \$25. The families did not anticipate receiving a gift card prior to attending the focus group.

Discussion focused on three themes which are summarized below.

#### 1. **What do you like best about CSHCS? Fill in this blank: "Whatever you do, don't change\_\_\_\_\_".**

Family preferences centered on access, benefits and coordination of services.

##### Access:

- Ease in finding appropriate pediatric specialists
- Referrals to specialists
- All specialists accept FFS
- Free choice of physicians

##### Benefits:

- Diaper coverage and other incontinence supplies
- Equipment coverage
- I never have a problem with CSHCS, everything I need is covered
- Flexibility with non-standard supplies and medications

Coordination:

- Help navigating when my insurance changes
- COBRA payments are covered

One parent commented “The wheel is not broken, don’t fix it.

**2. What could be done differently to make health care delivery better? If you had a magic wand and could make one thing come true about the way your child receives care, what would that be?**

Again, there was a great deal of discussion about access to care, benefits and coordination. The group felt that access to specialists is much better in CSHCS, but access to primary care is very challenging. They reported that most pediatricians in their area do not accept fee for service Medicaid or are not accepting new patients with chronic, complex health conditions. Those who have other children enrolled in a Medicaid Health Plan found access to primary care pediatricians was easy, but access to appropriate pediatric specialists was difficult.

Choice, and easily available information to facilitate optimal decision making was also cited as important.

Access to appropriate medications was mentioned. Families expressed concern and frustration in obtaining specific medications that are found to be effective for their child. Delays in obtaining authorizations for certain medication or in being required to show the failure of one drug before another would be provided cause anxiety. They stated that they have already been through the trial period to discover a drug that does work. They want their child to be able to have the drug that is known to work for their child without delay. One parent noted that this is problematic for them in FFS as well. She stated that even though the Rx was “dispense as written” she could not get the specific drug ordered for her child and the child had a relapse and was subsequently re-admitted to a hospital for 3 days.

If these families had a magic wand:

- It would be easy to get primary care
- There would be an easy transition from pediatric to adult care
- A directory of doctors would be easy to find showing which doctors take which insurance

- Could easily find a pediatrician who could take patients with special needs (a list)
- A “Craigslist” sort of directory of doctors for kids with special needs that are “parent recommended”
- It would be easier to get equipment
  - Appointments would be available fast
  - Faster turnaround once equipment is ordered
  - Shorter timeframe to get equipment repaired and loaner equipment while the child's device is under repair (The father of a child who uses an augmentative communication device noted “without it, my son has no voice”.)
- Website where you can find non-covered equipment at discounted rates (A parent suggested [www.atxchange.org](http://www.atxchange.org) as an example)
- You could get the drug that works for your child right away if it's on the list or not
- Asthmatic medications would be covered
- Pamphlets on CSHCS is given to every child at birth
- HMOs will cover everything that CSHCS covers
- No paperwork for referrals, no delays
- Have it all- access to both primary and specialty care
- Non-mandatory enrollment
- Coverage for Pull-ups
- Coverage for anti-glare coating for bifocals
- Ability to pay out of pocket for upgrades, shouldn't be penalized for trying to purchase extras your child needs
- More, easier access to vision providers
- Follow through, coverage of both the eye exam, and the recommended glasses for correction
- A place to call for help when the HMO does not cover what you think your child needs
- Sensitivity to the unique needs of children with special needs. “My daughter is incontinent. When the treatment didn't work, the HMO would not cover pull ups because they said she should be better.”
- Equitable compensation for providers. “My doctor said he got paid less for CSHCS than in Medicaid managed care, I don't want him to drop off”.

### **3. What kind of information would you like to have about CSHCS and Managed Care? What are important things for families to know and how should this be communicated?**

Parents in this focus group placed a very high priority on the availability of easily available, current information regarding multiple aspects of health care for children with special health care needs. When asked what do families need to know, they responded “Everything”. One mother stated “I am petrified of what is to come”.

Recommended communication strategies are:

- Community meetings
  - Weeknights at 6 pm was best for this group
  - 2 weeks notice, more than that you forget, hard to plan with less time
- Flyers distributed through schools
- Email groups similar to the Kent County list serve
- Website for families to include:
  - Doctors currently accepting patients
    - by specialty
    - by region
    - including primary care
    - hard to find specialists i.e.; orthodontists
  - Equipment exchange
  - Links to other resources
    - Diagnosis specific
  - Benefits listing
  - Contacts within CSHCS, who to call for what
  - Message board
  - Interactive feature where parents could post a question and others post replies
  - Charitable organizations that assist CSHCN such as UCP
  - Financial information, low interest loans for home modification
  - Advocacy organizations
  - Local support groups
  - Sibling supports
- Phone line to call (parents were not aware of the CSHCS Family Phone Line)
- Who to call to report fraud or abuse
- Information about what advocacy efforts are underway

## **Attachment 8**

### **Summary**

#### **Focus Group for families of children enrolled in CSHCS and Medicaid**

**Detroit, Michigan**

**May 10, 2012**

**Prepared by**

**Bev Crider, LLC**

#### **Consultant in Patient and Family-Centered Care**

This focus group explored family priorities regarding health care delivery for their child(ren) who are enrolled in both the Children's Special Health Care Services program and Medicaid. The meeting was held at Children's Hospital of Michigan. Twelve parents were invited, 6 attended. One parent did not meet the screening criteria, 2 opted to participate in a telephone conference call at a later date and one submitted written comments. The participants' eligible children ranged from age 3 to 20.

Families in this group reside in Oakland, Macomb and Wayne counties. They are very active, interested families who successfully manage extremely complex medical needs. One participant has custody of her grandchildren, one of whom was diagnosed with a progressive, debilitating condition.

Dinner and child care were provided. At the end of the meeting, participants received a Meijer gift card in the amount of \$25. The families did not anticipate receiving a gift card prior to attending the focus group.

Discussion focused on access, benefits, medical necessity, accuracy of information, flexibility and respect for families.

**1. What do you like best about CSHCS? Fill in this blank: "Whatever you do, don't change \_\_\_\_".**

Access:

- Availability of in and out-of-state hospital care
- Easy to make doctor appointments. We have a big list of specialists and they all take her insurance
- I can go to any doctor my child needs



Benefits:

- Payments for medications
- Nursing care coverage
- No out-of-pocket expenses
- Ronald McDonald House is covered
- Coverage for specialized car seat, mobility seating and DME
- Incontinence supplies covered
- Coverage for all co-pays and deductibles

**2. What could be done differently to make health care delivery better? If you had a magic wand and could make one thing come true about the way your child receives care, what would that be?**

This group enjoys relatively easy access to a wide range of specialists, yet there was no mention of primary care.

Medical necessity determination was mentioned in relation to approval for durable medical equipment and supplies. One family noted that the supplies their child is approved for is not tailored to his needs. Their view is that these standard amounts are determined without regard to the child's individual need. Families stated that they are reluctant to notify the state of excess supplies out of a concern that the supplies will be halted altogether.

The group felt that the CSN Fund requirement to obtain 3 denials was inefficient and presents unnecessary barriers to timely access to funding.

Access to accurate and consistent information was cited as important. Prior to CSHCS enrollment, one family made a request for a second opinion in another state based on the recommendation from pediatric subspecialists at two of Michigan's major pediatric hospitals. This coverage was denied by Medicaid, the family did not know that out-of-state care is covered by CSHCS when appropriate care is not available in Michigan.

Families in this group were aware of the Family Phone Line; however they did not find it particularly useful. Though the Family Phone Line staff made appropriate transfers, they were dissatisfied with the follow up after their initial call.

If these families had a magic wand:

Access:

- I could get the appropriate pediatric specialty care for my child when there is no provider in Michigan who is qualified.
- My child could stay with the doctors she sees and others if she needs to.
- Keep it so I can take her where I want to.
- No waiting on a referral, my child needs to see the right doctor right now.
- Flexibility and quality of care. My daughter sees 20 specialists; they are really sub-sub-specialists. If you take that away it will cost my child's life.

#### Benefits:

- I would get the right size syringe. I need 10 cc but they send me 60cc. It is a waste of plastic and I don't think it is as accurate. I end up digging the 10 cc syringes out of the trash when I'm at the hospital and taking them home to wash them.
- Second opinions would be covered.
- I could get a special car seat for my daughter who was born at 25 weeks.
- Immediate access to specialized medications my child needs without referrals or approvals, etc. She has a very complicated condition, and I have to make adjustments all the time. She can't wait for Medicaid to review and approve a medicine that is not on their list. She needs it right now.

#### Medical Necessity:

- Medicaid staff second-guessing the experts who know her. She was denied an electric wheelchair because Medicaid said she was too low functioning. She is in regular high school making A's and B's. I fought it and she finally got her chair.
- Medical necessity determination decisions would take into account physician statement and not rely only on a "moment in time" test. "The doctor thinks she needs an apnea monitor but when they tested her she was breathing OK. They said she didn't need it but she stopped breathing again after that and she got sick."

#### Information:

- Trained DHS workers would have more knowledge about CSHCS
- More information about CSHCS

- There would be a trouble shooting line for parents to call. I called the Family Phone line with a question 2 weeks ago. I still don't have an answer about my coverage.
- Mi Health card would have the correct information

#### Flexibility:

- I would have more say over the goods and services my son receives so I could meet his individual needs – in other words get the right amount of the right things. He has a trach so they give us 90 trach noses and one pulse ox probe per month. I really need 30 trach noses and 4 pulse ox probes because he is developmentally delayed and he plays with the thing.
- CSN Fund would not require you to get 3 denials from community based organizations for ramps, lifts, etc. It's a waste of time and they know it.

#### RESPECT:

- No one would ever say “Crippled Children”
- I wish Governor Snyder and other decision makers could hear this group. We all “get” one another's issues and concerns.
- Everyone would listen to parents!

### **3. What kind of information would you like to have about CSHCS and Managed Care? What are important things for families to know and how should this be communicated?**

Family members expressed frustration with their inability to find clear, reliable information about services their children may benefit from and how different programs should work together. Health literacy concerns were noted with a request for simple explanations in clear, everyday language. “Families need to know what the benefits are. I was paying for nurses at school for 2 years.”

They also felt that their opinions and expertise regarding the needs of their children are not respected.

Recommended communication strategies are:

- Better information for families about CSHCS and moving between CSHCS and Medicaid

- Who gets the money? An itemized list of payments made on behalf of my child. I want to cross check the invoices; I could check this and maybe save the state some money.
- Want to know what I can ask for
- List of all services covered like Ronald McDonald House sent to my home.
- State website that is simplified and easier to navigate. Clear links for MDCH, Medicaid and CSHCS.
  - Explain that the MiHealth card is for Medicaid and CSHCS
  - Who does and does not qualify for what, written in “non-legalese mumbo-jumbo”, easy to understand, translated into regular language.
  - Who is the go-to person for which problem (including problems detailed on the pages)
  - Who to go to – what’s the bottom line? Respond to different learning styles
- Comply with the 5<sup>th</sup> grade reading level requirements
- Family forums at the different hospitals, monthly or quarterly meetings.
- Pay more attention to the parents who are interested.

## Attachment 9

### Summary

#### Focus Group for families of children enrolled in CSHCS and Medicaid

Ann Arbor, Michigan

May 23, 2012

Prepared by

Bev Crider, LLC

#### Consultant in Patient and Family-Centered Care

This focus group explored family priorities regarding health care delivery for their child(ren) who are enrolled in both the Children's Special Health Care Services program and Medicaid. The meeting was held at C.S. Mott Children's Hospital. Participants were identified by the Mott Family-Centered Care Manager. Thirteen prospective participants were identified. 2 did not meet the screening criteria. 3 preferred to participate in a conference call on the subject, 5 accepted the invitation, 3 attended. The children of the focus group participant ranged in age from 3 to 15. Two people have private insurance in addition to CSHCS and Medicaid. Dinner was provided and participants were given a \$25 Meijer gift card for their participation. Child care was offered, but all declined. Focus group participants reside in Jackson, Washtenaw and Oakland counties.

Discussion focused on access, benefits, coordination and information.

#### **1. What do you like best about CSHCS? Fill in this blank: "Whatever you do, don't change \_\_\_\_".**

The participants in this group wanted to emphasize that their top priority is to maintain current providers (physicians, hospital care, therapy, prescriptions, and incontinence supplies).

Access:

- No referrals are needed
- Ability to access current providers across multiple health systems
- I can maintain current services with current providers

Benefits:

- Incontinence supplies are covered
- Transportation reimbursements are easy
- Lodging reimbursement

Coordination:

- Coordination between primary insurance (BCBS), CSHCS and Medicaid.
  - It's seamless
  - No quibbling over portions of bills

**2. What could be done differently to make health care delivery better? If you had a magic wand and could make one thing come true about the way your child receives care, what would that be?**

All participants in this group have college degrees. Their children have extraordinarily complex health conditions. A very high priority for this group is access to information and supports they can use to best navigate health, education and community services.

They share the state's desire to appropriately and efficiently use state resources, but believe that providing the right services at the right time is the best way to achieve that goal. One mother said that her son's most frequent need is for chest x-rays because of aspiration risk. She notes "I wish I could just get a standing order for chest x-rays". Every time he aspirates, we have to go to the Emergency Department for a full evaluation. I know he just needs the chest x-ray, and of course that's where we end up. This emergency room visit cost thousands of dollars. The x-ray is about \$700."

This group also placed a high priority on coordination of all services, including parent to parent support. They felt that this would have helped them when their children were newly diagnosed. They spoke of the anxiety and confusion they felt at the time, and how difficult it was for them to find and engage necessary supports. One mother said that when her son was initially diagnosed, she was sent home with an Early On brochure but had no idea what Early On was or how it would help her son.

If these families had a magic wand:

Access:

- Parent Advisory board to each MCO
- Access to commonly used diagnostics without going to the ED
- Easy access to my child's specialty and subspecialty providers
- Stay with the doctors who know my son. If my providers are not currently in the network, grandfather them in for my child.

### Benefits:

- A team of professionals would meet together to plan for care and treatment. Social Worker, doctor, nurse, education rep, parent rep.
- Peer support referrals
- Supplies ordered and provided based on my child's unique needs. Model after "just in time" supply delivery methods used in manufacturing.

### Coordination:

- We would have a case manager, someone we know who knows us.
  - Meet quarterly to review DME, etc and help walk through the process
  - Explain services we are eligible for "We don't know what we don't know".
  - Continuity, just one point person
  - Reach out to me to check in
  - Knows everything we are entitled to
- Peer mentor- other families to talk to
- Better discharge information

### **3. What kind of information would you like to have about CSHCS and Managed Care? What are important things for families to know and how should this be communicated?**

Information was a very high priority for this group. Though they all felt that they can generally process information well, they felt that information related to their child's special needs was difficult to find and interpret. None of the group was clear about CSHCS or Medicaid benefits. A father who also has BCBS coverage said 'Blue Cross sends me this chart of what is covered, when it is covered and how much is covered. "Why can't I get that from the state?" They emphasized the importance of timely information, "when they were dropping coverage for diapers, I got a letter in the mail telling me it would end in 2 weeks. That's not enough time; I had already planned my budget for the month."

The group recommended looking at other states that provide care for children with special health needs through managed care arrangements to learn best practices.

The group also recommended multiple information pathways: through health care providers, from other families and electronically. The group would like better online access to information. They wondered if the current online material is purposefully confusing to discourage access.

Recommended communication strategies are:

- List of what my child is entitled to
- Initial package of information about the diagnosis when the diagnosis is made
- At diagnosis: a team of people to meet with to go over the diagnosis, resources available, what to expect (education, therapies, recreation, etc) and next steps
- Data base of parents with similar diagnosis
- Video of a parent “you’re not alone” and how to follow up with a support parent
- Peer support information
- Stand alone website for CSHCS and Medicaid blasted everywhere, not buried in michigan.gov
- Recommendations for reputable websites
- Information about the contract – easy to read
- Directions for what you have to do by when and why
- Guidance on how to choose a health plan:
  - What are the decision points?
  - When to call for help?
  - How to change plans?
  - When can you change plans?
  - When is change required?
  - What happens if I don’t make a choice?
  - Who and what is in and out of network for each plan?
- Decision making tool – a matrix to compare what is gained or lost with each plan
- What happens if I also have private insurance? Can I drop CSHCS and keep straight Medicaid?
- Frequently Asked Questions
- Who to call for different things, more than the local health department. The Family Phone Line may need more people.
- What other states have done this? What can we learn from them?
- List of providers in each plan
- Information in multiple languages and culturally competent



- EASY information about CSHCS
- Provide ongoing updates
- Video – when you go home, this is how you find us
- Comparison of all available health plans, a 2 page overview
- Access to detailed contract so I know what the health plan is supposed to do.
- How access to current providers will be affected
- Step by step explanation of the process
- Notice of CSHCS/managed care transition as soon as possible. Greater than 2 weeks.

## **Attachment 10**

### **Summary**

#### **Input from families with a CSHCS-eligible child enrolled in a Medicaid Health Plan**

**June, 2012**

Recognizing that some families have chosen to decline CSHCS enrollment in favor of maintaining health care coverage through their existing Medicaid Health Plan, CSHCS sought input from this perspective.

A screening tool and discussion guidance for this group was developed.

A small group of families were identified by MSA. Identified families reside in Jackson, Oakland, and Wayne counties. All families appear to have membership in the same MHP, Meridian.

Thirteen names were provided. The caller was unable to contact 8 of the 13. Two were duplicate families, 2 were wrong phone numbers, 1 phone was out of service, 1 person hung up without speaking, 3 did not respond to multiple messages. Of those remaining, none were interested in attending a group meeting to discuss their Medicaid health plan experience. One family was out of town, 2 cited recent family tragedies, one had a child in the hospital and one was busy with her child. Two parents did agree to a telephone interview.

While the input from these two families is helpful, input from families enrolled in a more varied set of health plans may have been more informative.

The two families who were interviewed are members of the same plan. Their children range in age from 18 months to 7 years. Conditions include asthma, apnea, epilepsy, hearing loss and kidney disease.

Both families are extremely satisfied with Meridian Health Plan. One mother said "My best friend is in another plan and lots of things she needs aren't covered. I told her to switch to my plan. They are excellent".

#### **Interview responses:**

1. What is the main reason that you decided NOT to join CSHCS?
  - Because I already had the doctors I needed in my plan. The plan has everything I need. I've never been denied for anything so I didn't see the need to switch.

- I didn't want to fill out 5 hours worth of paperwork and lose my plan when it has everything I need.
- Honestly, I forget exactly why but my insurance pays for everything and I would have had to drop my insurance.
- I didn't want my son to have a different insurance from my other kids. It's too hard to figure out.

2. What do you like best about your health plan?

- They cover everything.
- I like everything. They tell me what services I am entitled to.
- My son has to see a kidney specialist. I don't have transportation so getting to Ann Arbor is hard for us. I asked the health plan if there was a neurologist in Jackson we could go to. They told me that there is adult kidney doctor in Jackson, but that my son needed to see the specialist for kids in Ann Arbor. They also told me that I could qualify for transportation and they set that up. It works really great.
- I don't have to pay anything

3. What could be done differently to make health care delivery better? If you had a magic wand and could make one thing come true about the way your child receives care, what would that be?

- I think we're really blessed. I can't think of anything. I have no co-pays and no doctors have ever denied my insurance.
- Nothing really.

4. What do families of children who will be newly enrolling into a Medicaid managed care plan need to know about the plan?

- You don't have to worry about anything.
- Basically I didn't know anything. Meridian called me and told me what I am eligible for. I didn't know there were resources out there and they called me to tell me.
- They kind of take care of you.
- They don't cut corners because you have Medicaid.
- They won't deny your kid any help.
- Look at the plan, they will realize they are covered and they're not going to have to pay a bill.