Attached are Parent Questionnaire forms and other information to guide pediatric providers' conversations to engage parents in sharing information about social or family factors that may be impacting the family's ability to manage the child's chronic conditions or overall health. These tools and information were created based on valued conversations via a Parent Focus Group conducted by the Children's Health Foundation on behalf of our pediatric practice members. The objective was to offer language and scripts for pediatric providers to enable effective and compassion-informed conversations that engage families via non-threatening approaches. We value the perspective of the parents and caregivers who participated in this focus group as their feedback about how to hold these sensitive conversations was very transparent, honest and enlightening.

#### The following are enclosed in this packet:

#### 1. Parent Questionnaire (Standard)

 This standard questionnaire form has a condensed list of questions created for all patients. All "Yes" answers are considered action required responses.

#### 2. Parent Questionnaire (Extended)

This questionnaire form contains the same questions as the standard form but also has a list of questions for parents of children with special needs. Please note: on the combined questionnaire, the last question, #17, "No" is an action required response. During the pilot, we found this was the best way to word this question. Please feel free to customize or change for your practice.

#### 3. Menu List of Questions

This is a list of questions based on ideas from the CHF Parent Focus Group. Refer to this list for follow-up questions to help guide your discussions relating to positive answers on the questionnaire. These questions may also be helpful if you would like to add to or customize the questionnaire for your practice. Note: Questions listed in **bold** are questions currently used on the questionnaire forms.

#### 4. Tips for Providers from Parent Focus Group

 This is a list of tips to assist providers directly "from the mouths of moms". These tips were straight from our discussions with parents in the focus group.

Patient's Name:	

# Parent/Caregiver Questionnaire

We believe emotional needs, stress and limited resources impact a child and family's health. We would like to better understand these areas so we can work together to support your child and family's wellness.

Please know this information is confidential and will only be used to help your pediatrician better support you. To enhance our care for your child and family, please help us understand the following: 1) Yes □ No ☐ Maybe Would it be helpful for us to use a different language than English? 2) Yes No ☐ Maybe Do you worry about how you will get to appointments or pay for doctor's visits? 3) Yes No ☐ Mavbe If you were given a prescription today, would you have trouble filling it? 4) Tyes I No ☐ Maybe Do you have trouble giving your child medication when needed? 5) Yes No ☐ Maybe Would you find it hard to explain to others what your doctor talks about during your child's visits? 6) Yes No ☐ Maybe Have there been changes in your family that might be affecting your child? □ No ☐ Maybe 7) \[ \sum \text{Yes} \] Are daily demands or stresses keeping anyone in the household from getting enough sleep? 8) Yes No Maybe Is it hard to find family or friends to help you care for your child or babysit for you? 9) Yes No ☐ Mavbe Do you often feel overwhelmed by difficult decisions in parenting? 10) Yes No Maybe Does your child have behaviors that worry you or embarrass you? 11) Yes No Maybe Does your family have values, traditions or beliefs that affect how you want us to approach your child's medical care? Name of person completing this form: Relationship to patient: Would you like to discuss any of these topics confidentially with a member of your pediatric care team? ☐ No thanks Yes, by email at this address:

☐ Yes, by appointment

Yes, by phone at this number:

Patient Name:
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# **Parent/Caregiver Questionnaire**

We believe emotional needs, stress and limited resources impact a child and family's health. We would like to better understand these areas so we can work together to support your child and family's wellness.

Please kno	w this info	ormation is confid	dential and will only be used to help your pediatrician better support you.	
To enhance	e our care	for your child a	nd family, please help us understand the following:	
1) Tyes	□ No	☐ Maybe	Would it be helpful for us to use a different language than English?	
2) Tyes	□ No	☐ Maybe	Do you worry about how you will get to appointments or pay for doctor's visits?	
3) <b>1</b> Yes	□ No	☐ Maybe	If you were given a prescription today, would you have trouble filling it?	
4) Tyes	□ No	☐ Maybe	Do you have trouble giving your child medication when needed?	
5) Tyes	□No	☐ Maybe	Would you find it hard to explain to others what your doctor talks about during your child's visits?	
6) $\square$ Yes	☐ No	☐ Maybe	Have there been changes in your family that might be affecting your child?	
7)	□No	☐ Maybe	Are daily demands or stresses keeping anyone in the household from getting enough sleep?	
8) Tyes	☐ No	☐ Maybe	Is it hard to find family or friends to help you care for your child or babysit for you?	
9)	□No	☐ Maybe	Do you often feel overwhelmed by difficult decisions in parenting?	
10)☐Yes	□ No	☐ Maybe	Does your child have behaviors that worry you or embarrass you?	
11)☐Yes	□ No	☐ Maybe	Does your family have values, traditions or beliefs that affect how you want us to approach your child's medical care?	
If your child	has ongo	oing or special h	ealth concerns, please answer the following:	
12)☐Yes	☐ No	☐ Maybe	Would you like more information about your child's condition? Do you have any questions?	
13)☐Yes	☐ No	☐ Maybe	Is there anything you would like to share with us today about your child's treatment/health plan?	
14)☐Yes	□ No	☐ Maybe	Do you want us to connect you with another family who can answer questions and offer support?	
15) ☐ Yes	□ No	☐ Maybe	Do you find it difficult to schedule the appointments you need with other doctors of the school?	
16)☐Yes	□ No	☐ Maybe	Would you like our waiting room to be more sensitive to the needs of your child and family?	
17) <b>□</b> Yes	□ No	☐ Maybe	Do you feel comfortable that you understand what each doctor appointment is for?	
Name of person completing this form:				
Relationship to patient:				
Would you like to discuss any of these topics confidentially with a member of your pediatric care team?				
☐ No	thanks	·	Yes, by email at this address:	
$\prod \vee_{\alpha}$	hy nhon	a at this number.	Yes by appointment	



#### **Menu List of Questions**

(Based on ideas from a CHF Parent Focus Group)

#### Family Stressors (anxiety, depression, family disruption, foster care, chronically ill sibs or parents, substance abuse etc.)

#### Have there been any changes in your family that might be affecting your child?

How is everybody in the house?

How are the siblings doing?

Who lives in your household?

Does anyone in your household often feel down (sad) or low on energy?

How many people in your household have regular health problems?

Do you have concerns about anyone in your family that might be affecting your child?

#### Does your child have behaviors that worry you or embarrass you?

Do you have any concerns about your child's development, learning or behavior?

#### Do you often feel overwhelmed by difficult decisions in parenting?

Do you feel overwhelmed keeping your kids safe?

Do you feel overwhelmed keeping your kids healthy?

What seems to make things stressful?

How do you feel you are coping with the day-to-day demands of parenthood?

Can you give me an example of a typical day in your household?

What happens to let you will know it will be a good day, or a bad day?

#### Are daily demands or stresses keeping anyone in the household from getting enough sleep?

How is everyone in the house sleeping? Are you sleeping well?

Tell us what you would like more help with...

Are you getting time with all your children?

# Limitation of Resources (financial, transportation, medical insurance, lack of support network etc.)

# Do you worry about how you will get to appointments or pay for doctor's visits?

If you were given a prescription today, would you have trouble filing it?

Do you worry about how much money you have to pay for doctor's visits and medicine?

Do you have any questions about insurance or coverage?

Do you have reliable transportation to get where you need to go?

Do you have reliable housing?

In the past year, has it been hard to pay for basic family expenses?

There are some state programs that can help you with finances, are you aware of them?

Would you like any information on transportation or financial programs?

Are you currently using any state services (food insecurities, SSI, etc.)?

#### Is it hard to find family or friends that help you care for your child or babysit for you?

Is it hard to find a babysitter who can do the care your child needs?

Do you have family or friends you trust that can help with babysitting?

Do you have family or friends that are supportive of you to help you care for your child? Do you have help caring for your child?

#### \*Do you want us to connect you with another family who can answer questions and offer support?

Do you want to be connected with resources to help meet your family or child's needs?

Do you know anyone with similar condition(s)? Do you want us to connect you with someone who has a child with similar condition(s)?

Would you like to be connected to another parent, or other resources?

Do you need ideas on how to find support?

Would a referral be helpful to you?

#### Parental Health Literacy (understanding diagnoses and treatment plan or navigating health system, etc.)

#### Would you find it hard to explain to others what your doctor talks about during your child's visits?

Can you repeat to me the instructions given regarding treatment or medications?

Is it helpful for someone to help you read or understand handouts from our office, or instructions that come with your child's medicine?

Do you feel comfortable explaining this plan to a family member?

Do you think others will be on board with this plan?

Please call our office if you have questions when you get home.

#### \*Would you like more information about your child's condition?

#### \*Do you find it difficult to schedule the appointments you need with other doctors or the school?

## \*Do you feel comfortable that you understand what each doctor appointment is for?

Is it hard to understand what each doctor appointment is for? (if practice prefers Yes = action required)

Is there another specialist you would like me to talk to?

Does your child have a specialist?

Did you like the specialist – was your time well spent?

Have you had trouble getting an appointment with a specialist? Should we look for other options?

Did you learn more about your child after seeing the specialist?

If you have not heard from the specialist in a certain number of days, would you like us to call you?

Do you want help advocating for your child's needs?

Do you understand the "medical home" concept, your role, and my role?

#### Treatment Plan Follow Up (following through with appt's, treatment plan or medication regimen etc.)

#### Do you have trouble giving your child medication when needed?

Does your child resist taking medication?

Do you think it is sometimes hard to understand or manage your child's medications?

How many days a week does your child take this medicine? (celebrate success)

Is there something that would help your child take it more often? (look for improvement)

Do you need help with a schedule or a chart, or a different form of medicine?

Do you know what to do if the child is not taking/misses their medication?

Do you anticipate any problems with giving medication?

Do you think we should consider other forms of medicine?

#### \*Is there anything you would like to share with us today about your child's treatment/health plan?

Is there another person caring for your child that should be informed of treatment?

Do you have any concerns/reservations with this plan?

Are you feeling more confident now about your child's treatment plan than when you came in today?

#### Communication/Language/Cultural (English not 1st Language, difficulty w/ spoken or written communication)

#### Would it be helpful for us to use a different language than English?

At every visit or only at times?

Would you like the services of an interpreter other than a family member?

Would you like handouts/instructions in another language?

Does the information need to be released to someone else, or copied to someone else?

Would it be helpful to have another person at the appointments with you?

How does your family learn best?

How do you like to learn new information? Do you like having information explained or do you like reading it on paper or reading it on email?

How do you like to get new information? Having spoken instructions? Using email? Using internet?

How do you prefer to communicate – phone, email?

Does your family have values, traditions or beliefs that affect how you want us to approach your child's medical care?

### Patient Factors and Services (often can be observed or are associated with medical conditions and don't require questioning)

Does your child have behaviors that worry you or embarrass you? (also listed under Family Stressors)

Does your child need extra help with feeding, sleeping, hygiene, moving, or communicating?

Do you think your child may need help with behaviors including self-control, compliance, or anxiety?

Do you sometimes notice your child does not respond to you like you would expect?

Do you think your child may need extra help with school or learning?

Has your child been given a school assessment or IEP?

Do you think your child may need help with how he/she plays and socializes with other children?

Do you think your child may need help communicating or hearing or seeing?

Do you sometimes notice your child does not respond to your communication like you would expect (doesn't hear or doesn't understand)?

Bold = Questions currently used on the standard questionnaire forms.

<sup>\*</sup>Would you like our waiting room to be more sensitive to the needs of your child?

<sup>\*=</sup> Questions currently used on the combined questionnaire form.

# **Tips for Providers from Parent Focus Group**

What you can say to broach these topics and to help yourself be heard by the parent:

"This is really important, I want to make sure you hear this..."

"Of all the things we've talked about today, this one is the most important."

Talk about the difference between reality and a "perfect world". For parents, this is often the "death of a dream".

"Would you like this written down?"

"Let's share ideas for your child's treatment plan" (possibly lead into medical home explanation).

"Do you understand the "medical home" concept, your role, my role?"

"Do you think you will have any problems giving medication?"

"Do you think we should consider other forms of medication?"

"How does this plan sound to you? "

"Do you have any concerns/reservations?"

"This needs to work with your family – if it doesn't, then let's talk about it."

"How can I support you?"

"Have you had trouble getting an appointment with a specialist? Should we look for other options?"

Invite patient to call if they experience any problems.

Be sensitive to titles, avoid using mom or dad instead of actual name. An example of this is to model respect by starting out calling parents by Mr., Mrs., Ms. etc...then when invited by the parent to use their first name, feel free call them by their first name. Parents generally refer to providers as Dr. and would like to be acknowledged with the same respect.

#### Who is best to ask these questions?

Initially pediatrician, then engage MH or Care Manager, Nutritionist etc.

Be sure to have a face to face introduction with the care manager (if possible), not by phone.

It is nice to have the Care Manager get involved with doctor and family during last 10 minutes to discuss follow up and help coordinate.

It is very helpful if the families feel the providers take time to know them. One example is when an office had called ahead to make sure the NICU had extra large booties for a dad.



#### How to communicate or ask these questions:

Ask the parent or child what method is preferred.

Pre visit questionnaire or portals (like Well visit planner), many will not do paper ahead of time.

Appreciate/like a pre-visit engagement call, providers can ask some screening/goal questions. Anything you want me to tell the doctor ahead of time?

Ask child when appropriate, also ask parent.

iPad implies makes it easier for doctor but not for parent, most would rather fill out a form. Although might be better for teens and older kids, it feels statistical instead of personal.

Ask a question about how we like to do this – iPad or paper.

iPad with printout that is discussed can work well – key is review.

Be sensitive, explain and review. Parents do not want to feel the information is going into a "black hole".