

## Talking and Reflecting Points for All Experiences

Below are questions that you may want to ask during your Special Health Care Needs experience. These may also serve as points of reflection for you as you write in your daily journal. This list of questions should not be approached as a "must ask" list. It is simply meant to be a tool for you to use as you prepare for each experience. These questions may help you to find out more about the members of the CYSHCN team, the impact of disease on family and the impact of family on disease. You may also have questions that are not included in this list. Please feel free to make suggestions to this list.

### ***Physical, Occupational and/or Speech Therapy Session Questions***

1. What is the difference between a pediatric and an adult PT (or SLP, OT)?
2. What education and training have you had, including continuing education opportunities, that helps you to work with CSHCN (children with special health care needs)?
3. What kinds of functional problems warrant a referral?  
When should I make that referral? Is there any benefit to the "Wait and see approach?"
4. Can you give me some examples of things that MDs have done that support you in your practice? Things that communicate the MDs respect for you and your level of expertise?
5. What could MDs do that would better support the work that you do both globally and with an individual child that they refer to you?
6. What could MDs do that would better support the family?
7. Do you like working with CSHCN? If so what do you like about working with CSHCN?  
What are some of the frustrations and barriers when working with CSHCN?
8. Do you have some advice for how I can work with families of CSHCN?
9. What is the difference between school (educational) therapies versus Medical therapy?  
Does every child that receives private therapy qualify for school therapy?  
Does every child receiving therapy in the school need and/or qualify for medical therapy?
10. Why provide therapy in a CSHCN who is not going to ever get better?
11. When talking to families in clinic please see Family Data Base on the shared drive (found in the Family Home Visit Experience preparation folder).

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### **Case Managers**

1. Are there different definitions for case manager? How do YOU define a case manager?
2. What type of education, specialized training and /or experiences did you have before becoming a pediatric case manager?
3. Do you participate in continuing education experiences related to CSHCN?
4. Who can I refer for case management services?
5. How can a family benefit from your services?
6. How can a physician benefit from your services?
7. Who exactly is paying for your services?
8. Do insurance companies see the benefit of your services?
9. Do you like being a case manager ? Why or why not?
10. Do you like working with CSHCN? If so what do you like about working with CSHCN?  
What are some of the frustrations and barriers when working with CSHCN?
11. What can MDs do to make discharge from the hospital happen more smoothly?
12. Do you make home visits? Tell me about that. Do you like that - why or why not?
13. Providing a medical home is the vision but is this realistic?
14. Do you have any advice for how I can set up my practice to best care for CSHCN?
15. Do you have some advice for how I can work with families of CSHCN?
16. Can you give me some examples of things that MDs have done that support you in your practice? Things that communicate the MDs respect for you and your level of expertise?
17. What could MDs do that would better support the work that you do both globally and with an individual child that they refer to you?
18. What could MDs do that would better support the family
19. When talking to families in clinic please see Family Data Base on the shared drive (found in the Family Home Visit Experience preparation folder).

### **Pediatric Extended Care**

1. Who works here?
2. What type of training/ education/experience does everyone have?
3. Does staff participate in continuing Ed opportunities? Like what?
4. Who (other disciplines) come and work with the kids here?
5. Who can I refer here?

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6. Why is there a need for PEC? What are the advantages of a child receiving nursing care here versus at home?
7. Do all communities have places like PEC?
8. How do you communicate with families? What about the kids that are transported to PEC on buses or by transport companies?
9. Can you give me some examples of things that MDs have done that support you in your practice? Things that communicate the MDs respect for you and your level of expertise?
10. What could MDs do that would better support the work that you do both globally and with an individual child that they refer to you?
11. What could MDs do that would better support the family?
12. Do you like working with CSHCN? If so what do you like about working with CSHCN?
13. What are some of the frustrations and barriers when working with CSHCN?
14. Do you have some advice for how I can work with families of CSHCN?
15. Do you have any advice for how I can set up my practice to best care for CSHCN?
16. Do you have some advice for how I can work with families of CSHCN?
17. What could the hospital/community do to better support PEC?
18. What are some things that the hospital/community does that supports PEC?
19. Who is paying for a child to go to PEC?
20. What are some ways that you involve families in the administration and organization of PEC?  
(For example policy development) If so how do you involve families?
21. How do you involve families in the care and plans for their child? Are families invited to care conferences?
22. How do you transition children from PEC when they either no longer need your services or get too old for PEC?
23. Are these transitions hard for families? If so how do you support family through these transitions?
24. Where DO kids go once they're too old to come to PEC?

### **Schools**

1. Who works with CSHCN in the schools?
2. How are all of these special services being funded? Any ideas for improving funding?
3. What are some ways that you include families in educational services?
4. Do you think that families are included too little? Enough? Not enough? Can you elaborate?

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5. Is it hard to include all CSHCN into the regular Ed classroom? What are some examples of how this is done successfully? Any examples of when this has failed?
6. Regular Ed Teachers: Who supports you in the classroom?
7. Regular Ed Teachers: Did your education prepare you for having CSHCN in the classroom?
8. Spec Ed Teachers: What education and training have you had to become a Special Ed teacher?
9. All: Do you participate in continuing Ed opportunities related to CSHCN?
10. Who gets an IEP and who gets a 504?
11. Can you give me some examples of things that MDs have done that support you as a teacher?  
Things that communicate the MDs respect for you and your level of expertise?
12. What could MDs do that would better support the work that you do when one of their patients is in your classroom?
13. What could MDs do that would better support the family?
14. Do you like working with CSHCN? If so what do you like about working with CSHCN?
15. What are some of the frustrations and barriers when working with CSHCN?
16. Do you have some advice for how I can work with families of CSHCN?
17. How do you transition these child from year to year? Teacher to teacher? School to school?  
Early intervention to kindergarten to grade school to high school and then out of HS?
18. Are these transitions hard for families and CSHCN/ Have you found anything that decreases the stress of transitions?
19. How could the community/ govt. better support CSHCN in schools?

### ***Durable Medical Equipment Provider: Home Care Medical***

1. Who works here?
2. What continuing Ed specific to CSHCN and or home care do you participate in?
3. Tell me how the perfect discharge would unfold from your perspective?
4. What could I do as the MD to better support that "perfect discharge".
5. What is the reality for you when the discharge papers get written and faxed to you? How many hours and people get involved in the average case?
6. How does a disorganized discharge affect the family and you?
7. Is it true that sometimes families are non compliant with prescribed therapy because the plan is unrealistic for home care? What do you do in those situations?
8. Do you make home visits? If so how is that helpful to you? To the family?

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9. Do you teach family members, patients, RNs to perform certain skills? Like what?
10. Is there a difference between home and hospital care? Tell me some of the differences – for example how is home care different for a patient who is TPN dependent? On a vent?
11. Does the TPN, antibiotics, formula arrive all prepared for the family to administer like in the hospital or does the family have something to do to make that happen? What do they have to do and how time consuming is that?
12. Can you give me some examples of things that MDs have done that support you in your practice? Things that communicate the MDs respect for you and your level of expertise?
13. What could MDs do that would better support the work that you?
14. What could MDs do that would better support the family?
15. Do you like working with CSHCN? If so what do you like about working with CSHCN?
16. What are some of the frustrations and barriers when working with CSHCN?
17. Do you have some advice for how I can work with families of CSHCN?
18. Do you have any advice for how I can set up my practice to best care for CSHCN?
19. How has home care changed in the last 10 years? What do you envision for the next 10 years?
20. How do you include families in home care?
21. What goes into deciding what is the appropriate feeding pump/ oxygen set up/ piece of seating equipment for a specific child?
22. Who is paying for all of these services?
23. Do you do any charity work?

### ***Clinics:***

1. What providers participate in this clinic? What is their education, training and continuing education related to this specialized area?
2. Who goes to the clinic?
3. How can patients benefit from this clinic?
4. When should the PCP make this referral? Is there any benefit to the “*Wait and see approach?*”
5. What are the basics I need to know about this specialized area as the PCP?
6. Do kids that can walk need wheelchairs? Why?
7. Who gets a handicapped card for their car?
8. How do you include the family in care and decision making?
9. How do you communicate with families?
10. What if someone needs equipment or a wheelchair and insurance will not pay for it?

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11. What do you need from the PCP?
12. Do you like working with CSHCN? If so what do you like about working with CSHCN?
13. What are some of the frustrations and barriers when working with CSHCN?
14. Do you have some advice for how I can work with families of CSHCN?
15. What about reimbursement for your services? Is it adequate?
16. How do you make a plan to transition the child to adult care? When do you do that? Are transitions hard for families?
17. What are some community organizations, agencies, government programs, etc. that you find helpful to CSHCN?
18. Do you refer families to support groups? Why or why not?
19. When talking to families in clinic please see Family Data Base on the shared drive (found in the Family Home Visit Experience preparation folder).

### ***Special Needs Family Center***

1. Do all states have services for CSHCN?
2. Do all states have equal services for CSHCN?
3. Do people move to get better services for CSHCN? Can you give me an example?
4. What services in the community, hospital and from the govt. are helpful to CSHCN? What type of services are lacking and need improvement?
5. Do parents use the Internet? What do you think about that?
6. Tell me about support groups –how can they make a positive difference for a family?
7. Where is the money for all these services coming from?
8. Who works here? What is everyone's education? Training? Experience?
9. What kinds of functional problems warrant a referral?
10. When should I make that referral? Is there any benefit to the "Wait and See" approach?
11. Can you give me some examples of things that MDs have done that support you in your practice? Things that communicate the MDs respect for you and your level of expertise?
12. What could MDs do that would better support the work that you do both globally and with an individual child that they refer to you?
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15. What are some of the frustrations and barriers when working with CSHCN?
16. Do you have some advice for how I can work with families of CSHCN?

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17. What is the point of paying for all of these services for a CSHCN who is not going to ever get better?
18. How do parents define case management?
19. How can a family benefit from your services?

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