

Supplemental Information

STAKEHOLDER FOCUS GROUP GUIDE

Think about the time of discharge of a child with complex condition from the hospital.

1. What are your experiences with the discharge summary that you get from the hospital?

Probe: How often do you need the discharge summary?

Probe: How often do you receive the discharge summary?

Probe: what are some things that can be done to make the discharge summary better?

2. What should be communicated to the home health agency? To whom should it be communicated?

What should be communicated to the DME companies? To whom should it be communicated?

3. What are some problems that you face as children with complex chronic conditions are discharged from the hospital?

Probe: for those that work in the hospital, what are some problems that you face?

Probe: for those that work in the community, what are the problems that you face?

4. What are some things that you would like to change about our discharge process for children with complex chronic conditions?

5. What are some things that are going well about the discharge process at Brenner Children's Hospital?

6. How should we prepare new families for home care? By new families, I mean families of children who have not received home care services before. This could be a child from the NICU or a child who had

a trauma and now has complex condition.

Probe: how can we help guide them in choosing a home care company?

Probe: what should we educate and prepare them about working with home health providers?

7. Who do the families and home care companies need to contact soon after discharge from the hospital; in other words, whose contact information is most needed?

Probe: How is this best provided?

8. Tell me about your experiences with home health orders or DME orders that are sent from Brenner Children's Hospital?

Probe: what are some things that we can do to make the orders more effective and accurate?

Probe: what about orders related to medications?

9. Many times we order equipment for children when they are in the hospital for them to use at home. What are some things that we need to keep in mind when ordering "equipment" for home care when a child is in the hospital?

Probe: Let us use a chest physical therapy vest as an example. How do we order? What documentation is needed? Whose responsibility will it be to gather the needed information? Who will follow-up?

Probe: what about "specialty supplies" (ie, ostomy)? How do we order?

10. Specifically, let us talk about children who are on ventilators. What is your opinion about notifying emergency medical services and power company? What should we inform families about traveling with the child for the first time?

11. If we develop a "discharge checklist" to improve care from the hospital to the community, what are some items that you would like to see in it?

Now, let us focus a little bit on home care services once the child with complex chronic condition is at home.

12. Let's talk about ongoing home health orders. We see different formats of orders used by different companies. This makes it very difficult for the PCP. What are your thoughts on trying to develop standardized orders?

How do we develop standardized orders that can be used by all home care and equipment companies?

What state requirements will have to be met?

HOME HEALTH NURSE FOCUS GROUP GUIDE

1. How does your agency determine your assignments or cases?

Probe: Who decides?

Let's talk specifically about your experience caring for medically complex children.

2. What kind of special training is required by your agency for medically complex pediatric cases?

Probe: How does the training differ for licensed practical nurses and registered nurses?

Probe: How do training requirements differ between agencies?

3. What are some of the challenges you face in caring for children with complex chronic conditions at home?

- Probe: Equipment, demands, parents, training, working with other nurses, insurance and payment, home environment.
4. How do you handle these challenges?

Probe: How can they be resolved in the future?
 5. What help do you need from specialists or PCPs to be successful caring for these children at home?

Probe: What help from families?

Probe: What help from your agency?
 6. What kinds of cases are the most attractive cases? Why?

Probe: What makes you stay with a family for a long time? (home environment [space], child's responsiveness).
 7. Tell me what kind of assignment you might reject. Why?

Probe: What are the things that make you leave a case?
 8. Medically complex children can be hospitalized frequently. When the child is hospitalized, how that does that impact your job?

Probe: What are other consequences to you if a child you serve is hospitalized?
 9. What are some things you think can be done to prevent frequent hospitalizations?

Communication

10. Tell me the role that communication plays in providing home care for medically complex children.

Probe: Level of importance, level of difficulty.

Probe: At different levels: physician, parent, nurse, agency.
11. What are some challenges with communication that you have faced working directly with parents and caregivers?
12. How do you handle cases where the child is unable to interact or communicate?

Probe: Why are these types of cases more or less favored than other assignments?

Collaboration

13. Give me some examples of some ways that nurses need to collaborate with other health care providers such as doctors caring for medically complex children?
14. How does collaboration with other health care providers or the lack of collaboration affect your job?

Probe: What prevents collaboration from being effective?

15. Tell me how you think your collaboration with other health care providers (or vice versa) can be improved when caring for medically complex children?

Probe: Doctors, agencies, nurses, families.
16. How collaborative are home health care agencies? This includes collaboration with other agencies, doctors, and families.

Probe: What makes a relationship collaborative?

Probe: Please give examples of collaboration that you know about.
17. We've been talking about communication and collaboration. How do day nurses and night nurses differ in their needs for these things?
18. Tell me more about the differences between day nurses and night nurses.

Probe: Difficulty, skills, family interaction, help from other providers?

Future

19. In the future, how do you think home health nurses could be encouraged to accept medically complex pediatric cases?