APPENDIX 7

Focus Group and Interview Questions for Parents and Healthcare Providers
Parent Focus Group and Interview Questions

1. (show the Himelstein definition of children with life-threatening illnesses) Where do you see your child in relation to this definition? Does (s)he fit one or more of these 4 categories? How?

2. How would you describe the needs of your child and family?

3. What services have you received to address these needs?

4. What needs remain unmet?

5. What has been your experience in finding the services you need through the Military Health System (MHS), through both the military treatment facilities and services provided in the civilian community through TRICARE?

6. What has been your experience in finding services you need in the military community (not including the MHS)?

7. What has been your experience in finding services you need in the civilian community?

8. What education and information have you needed to find the health care and other services that your child and family need?

9. How has your child’s care been coordinated? Who has provided care coordination?

10. What has worked especially well in meeting the needs of your child and family?

11. How has your experience with your child been affected by the military? How has being in the military affected your experience with your child? How has the military career in your family been affected?

Specifics to explore if time:

Care coordination

Palliative care

Counseling/support

Respite care

Idea of physician/parent/care coordinator team, written plan of care, and a specific benefit for eligible children with life-threatening conditions
1. How would you describe the needs of the children with life-threatening conditions for whom you provide care?

2. How would you describe the needs of their families?

3. Please describe your experience and observations about meeting the needs of these children and families in military treatment facilities.

4. Please describe your experience and observations about meeting the needs of these children and their families through civilian care and services paid for by TRICARE.

5. How would you describe the concept of a medical home?

6. What education and information do you think is needed to help residents, staff physicians, nurses and others in the military health system provide comprehensive care in a medical home model for children with life-threatening illnesses and their families?

7. Have you ever had training in pain management or palliative care? Enough? Please describe it and what additional training you need?

8. What services do you see that families need beyond health care? Which of these services do you provide or actively link families with through the military treatment facility?