

APPENDIX I

FAMILY INTERVIEW

Please tell us a little about yourselves; where you are from originally, how long you've been married, what your own families of origin were like, what you do for a living etc.

Please tell us a little about your children; names, ages, what each child is like.

Talk a bit about your child's birth. What was that initial experience like? What were your reactions at the time? What kinds of thoughts and feelings did you have? Who did you turn to for support? What helped you the most at that time? What was the most difficult aspect for you?

How have your feelings toward your child changed since the birth? What feelings have gotten better? What feelings have become more difficult?

What kind of impact do you feel your child has had on your relationship with each other? What kinds of stresses has she introduced? In what ways, if any, has your marriage been strengthened as a result of your child's presence in the family?

How have your other children reacted to this child? What are the ways in which they have been affected by having a brother/sister with these problems?

What have been the reactions of extended family, grandparents and other relatives, both positive and negative? In what ways have they made your lives easier? In what ways have they made your situation more complicated?

What dreams and hopes do you feel you may have lost through this child's birth?

What meaning, if any, have you found in having a child with these kinds of problems?

What have your interactions been like with so-called experts and professionals? In what ways have they helped you care for and relate to your child? In what ways have they contributed to your problems?

What kinds of reactions and questions from well-meaning strangers are the most difficult for you to handle?

What aspects of your child's condition have caused you the most pain?

When you look toward the future, what do you hope for? What do you fear?

Besides the actual birth, what developmental milestones in your child's life thus far have been particularly difficult for you?

Looking back over the past 2 years, what are some of your happiest memories/some of your painful memories?

In what ways can professionals help you in dealing with your feelings regarding your child?

What are some of the more important things physicians need to understand about a family with a handicapped child?

What could physicians and other professionals do differently that might make you feel more supported and understood?

How has your life changed on a daily basis as a result of your child's having this condition?

What advice would you give to a family in a similar situation to your own, to help them deal with the stresses and challenges of having a developmentally delayed child?

What are some of the different ways that you've coped with the problems and challenges presented by this child?

With whom have you been able to share special joys connected with this child?

What do you think has helped you the most in dealing with the realities of your child's condition?

Many people in your situation are forced to think about WHY this has happened in their lives, to their child. How do you answer this question for yourself?

Do you feel that a severely handicapped child will have a better, worse, or essentially the same quality of life as most people? What makes you feel that?

How easily are you able to talk about your child's condition with each other? With other family members? Are any members of the extended family excluded from conversations about this child?

How has this child's presence influenced your relationship with friends, neighbors, strangers?

How have you changed as a person as a result of having this child as part of your family?

In what ways would you say your family is similar to or different from families of friends and neighbors with developmentally normal children?

Do you sometimes feel that your child's needs are more than you can meet?

When the two of you talk about this child, do you usually tend to agree or disagree? What kinds of things do you tend to disagree about?

Do you think you've developed any special skills (as a person, as a parent) as a result of having this child in your family?

How have you changed as a couple as a result of this child being in your family?