Please answer the following questions by circling yes or no:

Do you have any problems getting good health care for your child? **Yes** **No**

Do you feel comfortable with how well you can treat and control your child's pain at home? **Yes** **No**

Do you know how to take your child's temperature? **Yes** **No**
If your child is less than 5 years old, can you feel the belly for enlargement of the spleen? **Yes** **No**

Are you comfortable with your understanding of sickle cell disease? **Yes** **No**
Do you want more general information? **Yes** **No**
Do you need more information on how sickle cell disease is inherited? **Yes** **No**

Do you have problems with health insurance? **Yes** **No**
With parking? **Yes** **No**
With transportation? **Yes** **No**

Do you feel your child's pain problems are treated well when your child is in the hospital? **Yes** **No**

Which emergency room do you use? ____
Are you comfortable with the staff's knowledge of sickle cell disease and the way they treat your child's pain? **Yes** **No**

Do you feel that the people who work at our clinic understand and are sensitive to your cultural background and needs? **Yes** **No**

Do you feel that you have the opportunity to take part in making decisions about your child's health care? **Yes** **No**

Do you get the kind of help from others that you need? **Yes** **No**
If yes, from whom? (circle) Family Friends Church Other:
____

Would you like more contact with another family who has a child with sickle cell disease? **Yes** **No**

What is your child's grade in school? _________
Is your child enrolled in special education? **Yes** **No**
Do you feel there is a need for a better understanding of your child's special needs at school? **Yes** **No**
About how many days did your child miss from school last year? _________

If your child is more than 12 years old, are you receiving services to help your child prepare for an independent adult life? **Yes** **No**

Are your other children having any problems because of their brother or sister with sickle cell disease? **Yes** **No**
Are there any other worries in your life? **Yes** **No**

Would you be willing to work toward getting better care and more research on sickle cell disease? **Yes** **No**
Are you a member of the Sickle Cell Disease Association? **Yes** **No**

What are the hardest things about sickle cell disease that you have to deal with?

____

____

____

What else can we do for you?

____

____

____

Name of child: ________________________________ Age: _________

Date of Birth: ________________

Who completed this form? (Name, relationship to patient)

________________________________ Date___________