APPENDIX M

UNIVERSITY OF THE WITWATERSRAND
DEPARTMENT OF PHYSIOTHERAPY

RESEARCH STUDY

CAREGIVER INFORMATION LEAFLET

(To be read to the caregiver of the disabled child in his or her own language)

TITLE OF THE STUDY

Parental perceptions and experience of rehabilitation services for children with cerebral palsy in poorly resourced areas.

INTRODUCTION

My name is _____________ and I am the mother of a disabled child. I am working together with Gillian Saloojee, the researcher for this study. Gillian is a full time student at the University of the Witwatersrand.

You are invited to participate, as a volunteer, in this study. This information leaflet is to help you to decide if you would like to participate.

By participation, we mean that we are asking you to agree to be interviewed. We will ask you some questions about yourself, the child you are caring for, the therapy the child has received and your feelings about yourself, the child and the therapy.

Before you agree to be interviewed, you should fully understand what is involved. If you have any questions which are not fully explained, do not hesitate to ask me or Gillian. You should not agree to be interviewed unless you are completely happy to do so.

WHAT IS THE PURPOSE OF THIS STUDY?

We are interested in learning more about the feelings and experiences of caregivers looking after children with cerebral palsy have about the therapy they have received. We want to know if the therapy has changed anything in the life of the child or the family. The information which we learn from this study will be used to improve the therapy that children with cerebral palsy receive in public hospitals.

WHY WAS I CHOSEN FOR THIS STUDY?

We chose certain hospitals which offer different services to children with cerebral palsy in Gauteng and Limpopo Provinces. All the caregivers who bring their children with cerebral palsy for therapy at these hospitals are invited to take part in the study.
**WHAT DOES IT INVOLVE AND HOW LONG WILL IT TAKE?**

I will be asking you some questions in a language which you understand and then I will fill in your answers on the form. The interview will take between approximately one hour complete. That is all the time that I need from you. We can do the interview here at the Clinic, or if you would prefer it, we can do the interview at your house.

We would also like to look in the child’s file to confirm the diagnosis of cerebral palsy and when he or she came for therapy.

If after the interview, you have more questions about your child or you would like to talk to somebody, then we will make arrangements for you to talk to a doctor or to one of the therapists at the hospital.

You are not obliged to take part in this study. Your participation is entirely voluntary. You can stop the interview at any time without giving any reason. If you decide not to take part, your therapy and treatment at the hospital will not be affected in any way.

There is no direct benefit to you for taking part in this study.

**WILL I BE PAID FOR TAKING PART IN THIS STUDY?**

Taking part in the survey by agreeing to be interviewed will not cost you anything. You will not be paid for participating in the survey.

**WHERE CAN I GET MORE INFORMATION ABOUT THIS STUDY?**

If you have any questions about the interview, please contact the researcher, Gillian Saloojee. Her telephone number is 072 483-5766. You can also contact the study supervisor, Dr. Aimee Stewart at the Physiotherapy Department at Wits University. Her telephone number is 717-3718.

**CONFIDENTIALITY**

We will not write down or record your name or the child’s name. The information which you give us is anonymous and all information obtained during the interview is strictly confidential.

Thank-you very much for your help.
UNIVERSITY OF THE WITWATERSRAND

DEPARTMENT OF PHYSIOTHERAPY

RESEARCH STUDY

Parental perceptions and experience of rehabilitation services for children with cerebral palsy in poorly resourced areas.

WRITTEN CAREGIVER INFORMED CONSENT FORM

I, ____________________________ confirm that I have been informed by the interviewer, __________________________, about the study in a language that I understood. I have also received, read and understood the above written information regarding the study.

I understand that I am not obliged to take part and that I can withdraw from the study at any time. I also understand that this will not affect my therapy or treatment in any way. I have been given the opportunity to ask questions and am satisfied that they have been answered satisfactorily.

I hereby volunteer to take part in this study. I agree that the interviewer, __________________________ and Gillian Saloojee can look in the child’s file to check the diagnosis and when the child came for therapy.

Parent’s / Caregiver’s name: ____________________________ (please print)
Parent’s / Caregiver’s signature: ____________________________ (Date) _______
Interviewer’s name: ____________________________ (please print)
Interviewer’s signature: ____________________________ Date _______

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VERBAL CAREGIVER INFORMED CONSENT FORM

(ONLY TO BE COMPLETED WHEN THE CAREGIVER IS UNABLE TO READ OR WRITE)

I, ____________________, have read and have explained fully to the caregiver, named _________________, the caregiver information leaflet, which explains what the study is about.

The caregiver indicated that he/she understands that he/she is not obliged to take part and that he/she can withdraw from the study at any time. He/she understands that this will not affect the treatment or therapy in any way. The caregiver has been given the opportunity to ask questions and is satisfied that they have been answered satisfactorily.

I certify that the caregiver has agreed to volunteer to take part in this study. I certify that the caregiver has agreed that the interviewer, _____________________ and Gillian Saloojee can look in the child’s file to check the diagnosis and when the child came for therapy.

Caregiver’s name : ____________________________ (please print)

Interviewer’s name : ____________________________ (please print)

Interviewer’s signature : ____________________________ Date __________

Witness’s name : ____________________________ (please print)

Witness’s signature : ____________________________ Date __________

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