

東吳大學社會工作學系研究所碩士論文

Department of Social Work College of Soochow University

Master Thesis

指導教授：葛書倫 博士

Advisor:Ko, Su Lun

助人與受助之間~

一位罕病致殘的社工人自我經驗實踐的反思

**Helping and Being Helped: The Reflection of Self-experience
and Self-practice by a Social Worker with Rare Disease and
Physical Disability**

研究生：蘇瑞臻 撰

Su, Jui Chen

中華民國九十九年七月

July, 2010

助人與受助之間~一位罕病致殘的社工人從自我經驗
故事對社會工作助人本質的反思歷程

東吳大學社會工作學系
碩士學位論文

研 究 生：蘇瑞臻

指導教授：

葛香倫

審核教授：

葛心蕊

謝文宜

社工系主任：

趙碧華

中華民國九十九年六月

感謝財團法人罕見疾病基金會提供獎助
學金，使此論文順利完成。



謝 誌

靠著許多人的協助和支持，我終於完成這本論文！

首先，感謝我的指導教授葛書倫老師，陪我走四年、接納我的衝撞！

感謝我的口委萬心蕊老師，啟發我看見自己的無知！

感謝我的口委謝文宜老師，協助我的就學困頓！

感謝李燕的盡心協同，陪伴我走過一段探索之路！

感謝大學同班同學，背我完成大學學業！

感謝碩班同班同學，相互鼓勵與學習！

感謝早療同事和主管們，守候我的身心健康！

感謝我的家人、家族親友和友人們，給予的愛和支持！

感謝每一個帶領我學習的社工實務工作者，無私的提攜！

感謝每一個身心障礙者、罕見疾病者、早療父母的生命經驗分享，特別是教

我生命可貴的 M 朋友一家人！

謝謝您們！

中文摘要

本論文是探究我朝向一位自主的罕病致殘社工人的行動歷程。

從回觀的敘說探究我個人兼具罕見疾病、身心障礙和社工專業等多種社會角色歷經殘疾烙印、死亡恐懼、社工專業與體制的多重層次複雜經驗，逐步揭露我個人在社工專業、特殊教育、身心障礙等教育體制和社會文化中，自我認同、受助經驗、社工專業學習和實務經驗等展現，這不僅是我個人尋找出路的歷程，也是呈現許多罕見疾病者、身心障礙者、基層社工人各在其體制文化壓迫中的集體生存處境。

因此，這篇論文的生產，除為自己、罕病者／身障者和社工人看見體制文化壓迫的摺痕，期自己再投身於身心障礙領域的行動實踐，凝聚更多罕病者、身障者、社工人共同推動利於身障／罕病族群的社會環境。

關鍵字：罕見疾病、身心障礙、社工專業、殘疾烙印、主體意識、行動研究

Abstract

This thesis explores my experience as an independent social worker with rare disease and physical disability.

With a retrospective narration, the study explores my several social roles as rare disease patient, physical disabled person and social worker, who has complexly experienced brand of disability, fear of death, study of social work and multiple levels of the system. Moreover, the thesis reveals my personal history of self-identity, aided experience, study of social work and practical experience under the educational system and social culture including social work education, special education, situation of physical and mental disability, etc.. The thesis presents not only my journey of pursuing a way out but also the general living conditions of a great number of rare disease patients, physical and mental disabled persons and the grassroots social workers under the oppression of system and culture.

Therefore, this paper is not only aiming to expose the rumples pressed by the system and culture to the rare disease patients, disabled people, social workers and to myself, but also to dedicate ourselves to the active practice in the field of physical and mental disability, as well as to unite with these people to promote a social environment in favor of the groups of disabled people and/or rare disease patients.

Keywords: rare disease, physical and mental disability, social work profession, stigma of disability, subject consciousness, action research