



WHY MEDICALIZING MADNESS HAS NOT WORKED

THE IMPACT OF INTRODUCING A DISABILITY STUDIES LENS TO MENTAL HEALTH SERVICE USERS AND PROVIDERS

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DISSERTATION RESEARCH FOR A PHD IN DISABILITY STUDIES

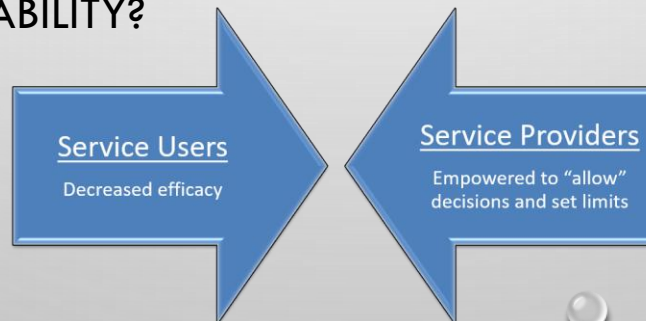
RESEARCH QUESTION

INTRODUCTION

MENTAL HEALTH SERVICE USERS AND PROVIDERS HAVE INCREASINGLY IDENTIFIED SELF-DETERMINATION AS A GOAL OF THE SERVICE RELATIONSHIP. DESPITE THAT GOAL, THE LITERATURE CONTINUES TO DESCRIBE A POWER RELATIONSHIP THAT FAVORS PROVIDERS AND PROVIDER SYSTEMS AND LIMITS ACCESS TO TRUE SELF-DETERMINATION.

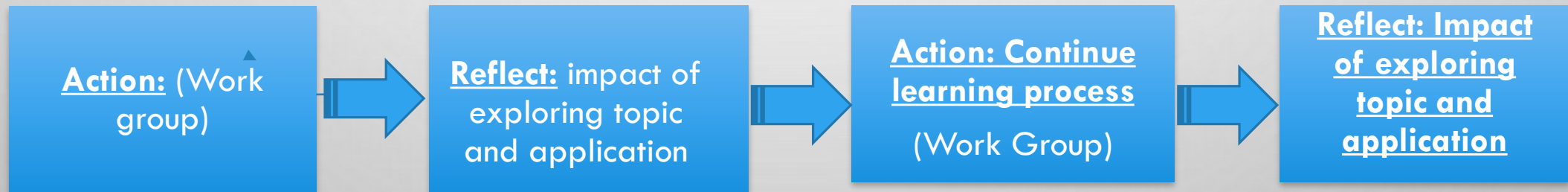
RESEARCH QUESTION

HOW DO SERVICE USERS AND SERVICE PROVIDERS CO-CREATE A SHARED UNDERSTANDING OF DISABILITY THROUGH A CIVIL AND HUMAN RIGHTS PERSPECTIVE, AS A WAY TO FOSTER SELF-DETERMINATION FOR PEOPLE WITH PSYCHOSOCIAL DISABILITY?



COLLABORATIVE INQUIRY

- **A MEANS FOR CONDUCTING PARTICIPATORY RESEARCH AS WELL AS FACILITATING ADULT LEARNING.**
- PARTICIPANTS ARE **CO-SUBJECTS** AND THE RESEARCH IS BASED IN PERSONAL EXPERIENCE. THE LINE BETWEEN THE RESEARCHER AND THE SUBJECT IS ELIMINATED.
- CONSISTS OF **REPEATED EPISODES OF ACTION AND REFLECTION** WITH THE RESEARCH GROUP, RESULTING IN ANSWERS TO QUESTIONS OF IMPORTANCE TO THEM. (BRAY, LEE, SMITH & YORKS, 2000)



DATA COLLECTION

INTERVIEWS WITH EACH PARTICIPANT, COLLECTED BASELINE INFORMATION ON THEIR UNDERSTANDING OF DISABILITY AND DISABILITY RIGHTS, THE RECOVERY MODEL, POWER RELATIONSHIPS AND SELF-DETERMINATION.

5 ROUNDS OF COLLABORATIVE INQUIRY – WITH ALL THE PARTICIPANTS.

ANALYTIC PROCESS: INDUCTIVE, THEMATIC ANALYSIS WITH THREE ROUNDS OF CODING USING NVIVO SOFTWARE. RIGOR WAS ESTABLISHED THROUGH MEMBER CHECKING, AND REVIEW OF THE THEMES AND QUOTES BY TWO PEOPLE UNFAMILIAR WITH THE STUDY.

RESULTS

ANALYSIS SUGGESTS THE PARTICIPANT'S THINKING EVOLVED OVER TIME.

THEME 1: BELIEF THAT DISABILITY IS IN THE PERSON

THEME 2: BARRIERS TO COMMUNITY PARTICIPATION

"WHEN I WAS IN THE NURSING HOME I APPLIED TWICE FOR (LOCAL APARTMENT COMPLEX) AND GOT IN, WAS ABLE TO GET IN BOTH TIMES. WHAT IT CAME DOWN TO THOUGH ON LEAVING WAS MY SPEND DOWN, THAT WHY I COULD NOT LEAVE. BECAUSE OF MY CHECK AND BECAUSE OF THE SPEND DOWN, IT WAS NOT FEASIBLE FOR ME TO LEAVE AT THAT TIME. AND THAT IS WHAT KEPT ME IN FOR SO LONG." (SU2)

THEME 3: POWER RELATIONSHIPS

"...IF SOMEONE IS TALKING – SAY I AM HAVING A PROBLEM WITH SLEEPING, UM, AND A STAFF OR SOMEBODY COMES UP "YOU KNOW IF YOU DO THIS.." THEY DON'T, THEY [STAFF] AUTOMATICALLY JUST FORCE YOU TO DO SOMETHING, OR TELL YOU TO DO, UM BECAUSE THEY GOT MORE KNOWLEDGE THAN YOU. AND THAT'S WHAT I STRUGGLE WITH....I LIKE TO BE ON THE SAME LEVEL, I DON'T WANT TO BE TALKED DOWN TO". (SU8)

THEME 4: STIGMA AROUND PSYCHIATRIC DISABILITY

THEME 5: RETHINKING DISABILITY

"AND THAT'S WHAT I WAS GETTING AT BECAUSE WHEN I WAS TALKING ABOUT THE DIFFERENT GROUPS AND HOW CERTAIN GROUPS QUALIFY AND OTHER GROUPS DON'T WHERE AS IF WE HAD A MORE, I DON'T LIKE TO SAY IMPAIRMENT IS MORE GENERAL, BUT IT JUST COVERS, IT'S NOT AS STIGMATIZING FOR ONE, WHICH IS IMPORTANT. THAT'S AN IMPORTANT THING. BUT IT'S INCLUSIVE. MORE INCLUSIVE I GUESS. "(PP10)

THEME 6: HUMANITY WITHIN DISABILITY

"DISABILITY IS A PART OF LIFE, SOME WILL HAVE THEM AND SOME WILL NOT. AND VERY FEW WILL NOT...IF WE ALL LIVE LONG ENOUGH WE WILL. THAT HAS REALLY STUCK WITH ME...BECAUSE, WE MAY ALL HAVE DISABILITIES NOW. BUT YOU KNOW WHAT? IT'S GOING TO CATCH UP TO THE OTHER ONES WHO DON'T"(SU2)

THEME 7: LOOKING TO THE FUTURE: "SO WHAT, NOW WHAT"

"AND IT'S LIKE THE OLD WAY WAS "OKAY YOU'RE DISABLED. THAT'S YOUR LABEL, THAT'S WHO YOU ARE. YOU ARE A DISABLED PERSON" NOW IT'S LIKE (SU6) "SO WHAT" (SU2) I HAVE, I HAVE A DISABILITY, SO WHAT. LET'S NOT LOOK AT THE LABEL, LET'S LOOK AT WHAT WE CAN DO TO AH, TO WORK WITH IT AND TO BE A MEMBER OF SOCIETY AND, AND STUFF LIKE THAT SO" (PP10)

DISCUSSION POINT #1

INTRODUCING DISABILITY STUDIES TO A GROUP CAN IMPACT SELF-DETERMINATION.

- **THE WORDS MATTER.** *DISABILITY* IS DEFINED IN DIFFERENT WAYS. *MENTAL ILLNESS* OR *IMPAIRMENT?* *PERSONAL RESPONSIBILITY* IS DEFINED DIFFERENTLY IN THE MEDICAL WORLD THAN IN THE PEER SUPPORT AND SURVIVOR WORLD.
- *RECOVERY* HAS SEVERAL MEANINGS - HAS BEEN USURPED BY THE MEDICAL MODEL. NONE OF THE INTERVENTIONS CONSIDER SOCIAL BARRIERS.

DISCUSSION POINT #2

POWER, PROFIT AND STIGMA ARE MAJOR CHALLENGES TO SELF-DETERMINATION

- PROVIDERS HAVE THE POWER TO LABEL EVERYDAY ACTIVITIES AS PATHOLOGICAL, TO REWARD PRIVILEGES FOR ACCEPTABLE ACTIONS.
- THE PARTICIPANTS WERE WELL AWARE OF THE MEDICAL INDUSTRIAL COMPLEX.
- STORIES OF GETTING BETTER – DESIGNED TO INSTILL HOPE AND CONNECTION – ARE MORE LIKELY FUNCTIONING LIKE OVERCOMING STORIES – AND ARE (LIKELY) PERPETUATING STIGMA.

DISCUSSION POINT #3

SERVICE USERS AND PROVIDERS, LEARNING ABOUT DISABILITY AND MAD STUDIES, TOGETHER, MAY SHIFT POWER IN THE HELPING RELATIONSHIP.

- REPURPOSE WORDS
- FOCUS STORYTELLING AND NARRATIVES TO ADDRESS ART, CULTURE AND THEORY, RATHER THAN ILLNESS AND RECOVERY.
- CREATE VIDEOS LIKE BILLY AND SCOPE THAT ARE FOCUSED ON OR AT LEAST INCLUDE PSYCHIATRIC AND INVISIBLE DISABILITY.

ACKNOWLEDGMENTS

- DR. YOLANDA SUAREZ-BALCAZAR
- DR. SUSAN MAGASI
- DR. SARAH PARKER HARRIS
- DR. TAMAR HELLER
- DR. LINDA OLSEN
- DR. GLEN FUJIURA
- JEANETTE TETREault AND ANGIE THINNES AND THE WONDERFUL MEMBERS OF MY GROUP