DISABILITY POWERPOINT PRESENTATION

1. THE EXPERIENCE OF DISABILITY AS EXPRESSED THROUGH LITERATURE

Johanna Shapiro, Ph.D. University of California, Irvine, College of Medicine April 21, 2001

- 2. WHY LITERATURE?
- 3. STUDENTS MUST LEARN TECHNICAL AND KNFORMATIONAL KNOWLEDGE
- 4. Where is the wisdom we have lost in knowledge?
 Where is the knowledge we have lost in information?
 T.S. Eliot
- 5. STUDENTS MUST ALSO LEARN DIFFERENT KINDS OF KNOWLEDGE:
 - Appreciation for other perspectives and points of view
 - Understanding of illness within the context of the lived life of the patient
 - Ability to listen as well as talk to the patient
 - The capacity for empathically imagining the patient's experience
- 6. LITERATURE CAN BE USEFUL IN CONVEYING "HARD-TO-TEACH" CLINICAL COMPETENCIES
- 7. WHY IS READING A POEM OR SHORT STORY DIFFERENT THAN READING A JOURNAL ARTICLE?
- 8. SCIENCE CAN TELL US THE WHAT, BUT NOT THE WHY
 Albert Einstein
- 9. TWO MODES OF THINKING: LOGICO-SCIENTIFIC AND NARRATIVE
- 10. PRESENTATION OF REALITY: LAWS AND PRINCIPLES VS. STORIES

Logico-scientific: goal is to explain reality through theories, laws, and rules

Narrative: emphasizes the primacy of storytelling in the way we construct and make sense of our lived experience

11. QUESTION: What is truer than the truth?

ANSWER: A good story

- Jewish proverb

12. WHAT IS IMPORTANT ABOUT EXPERIENCE: ABSTRACTION VS. PARTICULARITY

Logico-scientific: particulars of personal experience are eliminated in favor of abstractions, generalizations, systems of classification and diagnosis

Narrative: emphasis is on particulars of individual experience

13. We do not see things the way they are

We see things the way we are

- Anais Ninn

13. RELATIONAL POSITION: DISTANCE VS. ENGAGEMENT

Logico-scientific: emphasis is on objective stance, detachment, distance

Narrative: requires emotional engagement and participation in the event

14. NOT EVERYTHING THAT COUNTS CAN BE COUNTED - DENIS Burkit, M.D.

15. VOICE: PASSIVE VS. ACTIVE

Logico-scientic: voice, especially the patient's voice, disappears as a function of objectivity

Narrative: brings the patient's voice to the fore; acknowledges the multiplicity of voices present in any clinical encounter

16. WHATEVER IS REAL HAS A MEANING

- Michael Oakeshott

17. POINT OF VIEW: OMNISCIENT VS. PATIENT-CENTERED

Logico-scientific: patient's point of view is subjective, therefore suspect

Narrative: patient's point of view is subjective, therefore essential

18. INQUIRY: HYPOTHETICO-DEDUCTIVE INVESTIGATION VS. REFLECTION

Logico-scientific: testing of deductive hypotheses through replicable observation and experimentation

Narrative: examining the intersubjectivity and meaning of experience

- 18. WHY STUDY DISABILITY?
- 19. AN UNGLAMOROUS ASPECT OF MEDICAL PRACTICE?
- 20. DOCTORS...MAY HAVE TROUBLE DEALING WITH PATIENTS [WITH DISABILITY], WHOSE DIESEASE IN ITS INTRANSIGENCE DEFEATS THEIR AIMS AND MOCKS THEIR SKILLS
 - Nancy Mairs
- 21. DISABILITY STUDIES AS METYNOMY
- 22. WHAT ARE THE IMPORTANT HEALTH-PROVIDER PATIENT ISSUES?
- 23. OTHERNESS
 - * Psychological function of otherness
 - * Societal function of otherness
- 24. SHAME AND GUILT

Usual sequence of events: Socially deviant action → GUILT – discovery → punishment → SHAME

Sequence of events for person with disability: Societal stigma → SHAME – discrimination and bias → punishment → GUILT

- 25. WHAT IS NORMAL
- 26. Poem "Handicapped"
- 27. EMPTINESS AND FULLNESS
- 28. Poem "Fingers, Fists, Gabriel's Wings"
- 29. LOSS...
- 30. Poem: "The Stroke Patient"
- 31. ...Life Changed Forever

Generous people are waiting to give you everything on Earth but your main want, which is simply the person you used to be. But you're not that person now... Come back to life, whoever you'll be. Only you can do it.

- Reynolds Price

- 32. THAT TREACHEROUS LESS-THAN-HUMAN/MORE-THAN-HUMAN CONTINUUM
- 33. Poem "Spastics"
- 34. The ill person may not feel like acting good-humored and positive; much of the time it takes hard work to hold this appearance in place
 - Arthur Frank
- 35. I have come to realize how distorted and unrepresentative the success stories really are... if we fail, it is our problem, our personality defect, our weakness...To emphasize individual personal qualities as the reason for success in overcoming difficulties is self-serving for the individual and society

 Irving Kenneth Zola
- 35. Tugging at the fringes of my consciousness always is the terror that people are kind to me only because I'm a cripple
 - Nancy Mairs
- 36. THE HEALTH PROVIDER-PATIENT RELATIONSHIP
- 37. ISOLATION VS. COMMUNITY
- 38. STAGES OF SUFFERING
 - Chaos and isolation
 - Lamentation
 - Solidarity with others
- 39. quote from Ursula
- 40. SOLIDARITY IN THE PROFESSIONAL RELATIONSHIP
- 41. Poem: "Irene"
- 42. LEARNING TO SEE MORE CLEARLY
- 43. "WE ALL HAVE DISABILITIES, ONLY SOME OF US DON'T KNOW IT"
 - second year medical student

44. Poem: Fiser

45. CROSSING BETWEEN WORLDS

46. "Close your eyes now," the blind man said to me.

I did it. I closed them just like he said.

"Are they closed?" he said. "Don't fudge."

"They're closed, "I said.

"Keep them that way," he said. He said, "Don't stop now. Draw."

So we kept on with it. His fingers rode my fingers as my hand went over the paper. It was like nothing else in my life up to now.

Then he said, "I think that's it. I think you got it," he said. "Take a look. What do you think?"

But I had my eyes closed. I thought I'd keep them that way for a little longer. I thought it was something I ought to do.

"Well?" he said. "Are you still looking?"

My eyes were still closed. I was in my house. I knew that. But I didn't feel like I was inside anything.

"It's really something," I said.