DISABILITY & CULTURE

ANTH 306/Medical Anthropology
• Anthropology has contributed to knowledge about cultural relevance, cultural relativity, and defined meanings of culture.

• Concept of culture is important to anthropological study of disability because lens of culture may be applied to disability in a variety of ways:
  • Disability may be considered a culture.
  • Culture may be considered a disability.
  • Cultural norms & values influence conceptions of disability.

• Cultural anthropology has focused on perspective of outsider with respect to how different cultures perceive “otherness.”

• People with disabilities are often labeled “the Other,” somehow separate from people who are not considered to have disabilities.
But the “otherness” of disability is unique because anyone may become disabled at any time.

Anthropology’s “genuine fascination” with “the Other” can logically inform field of disability studies, but this connection has not fully been utilized.

Each subfield of anthropology overlaps with disability studies:
- Linguistic anthropologists have studied deaf sign languages and culture of language, but has not been a main focus of linguistic anthropology.
- Archaeology has contributed to the understanding of disability among prehistoric human ancestors, but contribution has been limited.

Many important contributions to the study of disability are rooted in anthropology.
Life History

• In anthropology the life history, or personal narrative of one’s life, has long been recognized as an important vehicle for learning about how culture is experienced and created by individuals.
• Life histories have a special significance in our highly technological, fast-paced, complex world.
• As we have become more isolated from one another, the life history offers a means of putting us back in touch with others, recognizing the intimacy results from listening to and telling stories.

http://www.unco.edu/anthropology/programs/life_history.html
• History
  • Ruth Benedict published *Anthropology and the Abnormal*, a groundbreaking study of cross-cultural conceptions of epilepsy (1934).
  • In 1950s Margaret Mead made public comments that included people with disabilities within the realm of “normal” Americans.
    • Argued that the study of American national character had to include all types of Americans (Mead, 1953).
    • First significant suggestion that people with disabilities need to be included in anthropological inquiry to fully understand human nature.
Robert Edgerton (1967) was 1st to explore mental retardation from an anthropological perspective.

Edgerton’s (1967, 1984, 1993) lifetime of work contributed significantly to anthropological interest in mental retardation and disability.

By the 1980s, Edgerton noted that “anthropology has begun to tiptoe its way toward involvement in the study of mental retardation” and he encouraged others to apply anthropological concepts to the field of disability studies.
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Sidney Mintz, Professor of Anthropology, Johns Hopkins University
Allison Ruby Reid-Cunningham: Anthropological Theories of Disability

- **Venus on Wheels** (2000) is life history of congenital amputee – woman born without arms or legs.
- Raised by parents as “normal” child but *differently abled*.
- Frank took used an emic approach to present research in a way close to the perspective of subject (Diane DeVries).
- **In the Eye of the Beholder – The Diane De Vries Story**

*Emic* – of, relating to, or involving analysis of cultural phenomena from the perspective of one who participates in the culture being studied. [http://www.merriam-com/dictionary/emic](http://www.merriam-com/dictionary/emic)

*Gelya Frank*, Professor of Occupational Therapy, University of Southern California.
Psychological adaptation

• M & T discuss individual coping mechanisms used to deal with chronic or progressive diseases or a disability.
• One example is Robert Murphy’s autobiographical account *The Body Silent*.
• A major component of adapting to physical impairment can involve redefinition of the meaning of that impairment.
• *'Fresh Air' at 20: Anthropologist Robert Murphy*
Psychological adaptation

- Gay Becker’s study of deaf community (M &T page 126).
- Long-term support networks of deaf are adaptive in old age.
  - Interdependence developed in adapting to hearing loss is “pre-adaptive” to old age.
- Adaptation to old age (from Growing Old in Silence)
- Aging in Today's World: Conversations Between an Anthropologist and a Physician
- Gay Becker Memorial Fund
Joan Ablon  Professor Emeritus, University of California San Francisco

Biographical History

• Research has focused on wide variety of topics including:
  • Stigmatized genetic health conditions
  • Therapeutic self-help groups & social support systems
  • Neurofibromatosis
  • Dwarfism
  • Alcoholism & the family
  • Disability & chronic illness

Written for patients with Osteogenesis Imperfecta (OI), their families and those who treat them including physicians, nurses, social workers, genetics counselors, and other persons with interests in differing kinds of physical disabilities. The book chronicles life experiences, coping patterns, and strategies for daily living of adults with OI, through personal accounts of medical experiences, education, economics, physical intimacy, dating, marriage, and general lifestyle issues. There are no other comparable books that deal with psychosocial issues of adults with OI.
Deviance involves straying from prevalent/valued norms in a way society perceives as negative.

Disabled bodies invoke stigma through their deviance.

Murphy – people with disabilities are “subverters of the American ideal”.

Perceived deviance of disabled bodies can lead to stigma & marginalization.
• Anthropologists have determined that disability is socially constructed: it depends very little on the degree of functional loss or impairment; rather it is defined by societal standards for normative bodies, behaviors, and role fulfillment.

• As a result, disability is viewed less as a limitation or dysfunction than as the “perceptions and prejudices of an able-bodied majority” that restrict the independence of people with disabilities.

• Some anthropologists even go so far as to claim that disability can be considered nothing more than a cultural fabrication, citing cross-cultural studies of disability and impairment to support their assertion.

• The significance of disability is culturally produced, and different cultures conceive of disability in diverse ways.
To summarize, I have presented a brief overview of anthropology’s thus-far limited engagement with disability studies and suggested several explanations for this. I have briefly explored the relationship between the study of disability and the disability rights movement and examined the role of people with disabilities in anthropology. I have presented a vision of an integrated approach to disability, which I believe offers a means of creating an important anthropological contribution to the study of disability in the past, with relevance to the present. Finally, I have argued that an integrated approach to the body is central to this process.

Anthropological engagement with disability does not only have the potential to enrich disability studies; it also contributes to the discipline of anthropology. The use of an integrated approach as suggested in this paper would help to open up lines of dialogue across disciplines and subdisciplines and to advance anthropological work on the body. Furthermore, how disability is produced and constructed in a particular time and place can illuminate much about that culture and society. Much like Gleeson (1990) declared geography impoverished by an absence of engagement with disability, Jakubowicz and Meekosha (2002) argue that social analysis is seriously constrained when research neglects to engage with disability theory and to take into account different bodies and how they are experienced. From this perspective, anthropology – in all its subfields – cannot afford to allow disability to remain at the margins.
Figure 1. Conceptual diagram of the triangulation of the subfields of anthropology towards a holistic approach to the anthropology of disability.
Disability & Poverty

- WHO Health Topics: Disabilities
- World Bank Disability

Disability disproportionately affects vulnerable populations.

- More common among women, older people and households that are poor.
- Lower income countries have a higher prevalence of disability than higher income countries.
WHO: What’s Disability to Me?

- **WHO: What's disability to me? Highlights from the video series**
- **WHO: What’s Disability to me? Series of Videos**
  - Feliza’s Story
  - Mia's story
  - Rachael's story
  - Faustina's story
  - Bernard's story
- **WHO: Professor Stephen Hawking supports launch of World Report on Disability**
End the Cycle of Poverty & Disability

• End the Cycle Explained
• The Cycle
• Healthcare, Disability and Poverty
• WOMEN and Disability, Double the Challenge